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“THEY DON’T GET IT”: MARGINALIZED MOTHERS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES AND THEIR EXPERIENCES WITH SOCIAL SUPPORT

A Dissertation

submitted by

Zuleida Alemãn-Herba

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Division of Counseling and Psychology

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This dissertation, titled:

'They Don't Get It': Marginalized Mothers of Children with Developmental Disabilities and their Experiences with Social Support

as submitted for final approval by ZULEIDA ALEMÃN-HERBA under the direction of the chair of the committee listed below. It was submitted to the Counseling and Psychology Division and approved in partial fulfillment of the requirements for the degree of Doctor of Philosophy Degree at Lesley University.

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DEDICATION

To the participants and all mothers of children with developmental disabilities and their children past, present, and future.

ABSTRACT

Maternal caregivers of children with developmental disabilities (DD) experience a significant burden of care and increased parenting stress, making social support crucial to family well-being. This qualitative study used a feminist, intersectional framework to examine how marginalized mothers of children with DD, who have been less extensively studied than majority mothers (Stober & Franzese, 2018), perceive and experience social support from extended family, friends and community members. It also examined how social supports impact the mother’s quality of life, understanding that the caregiver's well-being is a determining factor for the child's well-being. The study investigated, from mothers’ perspectives, what kind of social support contributes to resiliency, is adaptive, and is helpful as well as barriers to social support that disrupt the family system. The research sought to examine barriers in mothers’ social-relational ecology that further burden caregivers advocating for their child and to provide possible solutions. Eleven mothers of children with DD participated in semi-structured interviews, which were analyzed through Interpretive Phenomenological Analysis (IPA) (Smith & Nizza, 2022). All the mothers interviewed identified as marginalized in ways beyond their gender and the disability stigma associated with their children. These compounding marginalized statuses were mainly the mothers’ racial or ethnic identity, role as single parents, being immigrants, or having lower SES. Caregivers with marginalized identities may encounter additional challenges with oppressive systemic barriers and discrimination, as well as a lack of social support. Caregivers overwhelmingly reported experiencing isolation and stigma, which negatively impacts well-being (Smith & Grzywacz, 2014). Findings included barriers to social support, geographic relocation for better access to services, discriminatory experiences, and helpful social supports contributing to resilience. Abandonment from members within the mother’s social support circle, and mother's distancing from key relationships as a protective factor, was a major finding. Clinical recommendations and a caregiver's bill of rights are offered.

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CHAPTER ONE: INTRODUCTION

Developmental disabilities (DD) occur in approximately 17% of children (CDC, 2024) and are a group of conditions present from birth or early childhood that involve severe, life-long mental and physical impairments affecting various life domains including self-care, language, learning and behavior. Parents of children with DD work to provide the moderate to extensive accommodations and supports needed for these children as they navigate developmental milestones (Safe et al., 2012). Mothers and fathers of children with developmental disabilities (DD) report significantly higher levels of parenting stress compared to parents of typically developing children, with 84% of mothers and 67% of fathers falling within a range of stress described as chronic and clinical (Boyd, 2016; Diallo et al., 2019; Findler et al., 2016; Oelofsen & Richardson, 2006). Wuffaert et al. (2010) found that parenting stress in families with a child with a developmental delay was associated with adverse outcomes for the parent, such as depression and poor physical health. They also found that stress levels tend to be chronic and that high levels of stress were correlated with the prevalence of the child's challenging behaviors.

Raising a child with DD is associated with high physical, financial, and emotional demands compared to raising typically developing children (Genereaux et al., 2015; Price & Oliverio, 2009). Within current systems of care, the responsibility of coordination, management, and care application is generally assigned to the child's primary caregiver, who is often the child's mother (Crossman et al., 2018; Diallo et al., 2019; Green, 2007). Providing care requires the caregiver to become an advocate and manager within multiple systems. For example, a caregiver may be involved with care management and application within medical, educational, therapeutic, and community support systems (Sousa, 2015a). With each formal system that is engaged, the demand on the caregiver is compounded with more tasks to manage (Brisini & Solomon, 2020; Safe et al., 2012).

Additionally, the developmental gap between typically developing children and children with DD can grow more comprehensive over time and not lessen, complicating care further for parents (Odom et al., 2007). For many parents whose children will require moderate to extensive support, the amount of work involved in securing adequate support may be unfathomable at the time of a diagnosis (Safe et al., 2012; Van Wyk & Leech, 2016). Compared to parents with typically developing children, parents engaged in caregiving work for children with DD report poorer subjective well-being and demonstrate an increased risk for mental health problems, depression, and physical health complications (Oelofsen & Richardson, 2006).

Research on caregiving and DD highlights how caregivers experience multiple barriers to finding emotional and instrumental support for the higher cost and intensive caregiving work of raising a child with DD (Genereaux et al., 2016; Price & Oliverio, 2009; Sousa, 2015a). Research has indicated that a primary barrier is often frustration with a lack of support in social, medical, and educational systems (Boyd, 2016; Brisini & Solomon, 2020; Findler et al., 2016; Pinquart & Sörensen, 2005; Price & Oliverio, 2009). In studies, mothers have described how challenging it is to find disability-affirming spaces for their children (Boyd, 2016; Brisini & Solomon, 2020). Caregivers noted the lack of funding, resources, and education needed that would enable them to integrate their children into community settings and access the expert support they need for the behavioral and/or medical complexity that can accompany a DD and co-occurring diagnosis (Woodman et al., 2015). To compound these issues, disability authors have described maternal caregivers' experiences of mother blame, where mothers are blamed by society for producing and raising behaviorally and physically inadequate children, contributing further to caregiver stress and isolation, which is described overwhelmingly in the literature by both researchers and mothers (Brock, 2014; Fisher & Goodley, 2007; Landsman, 2008; Marcenko & Meyers, 1991).

Caregivers report a high emotional cost, and researchers have explored grief, loss and identity challenges in addition to the impact of the more tangible costs of caregiving such as with finances and in the career/work arena as well as negative effects on parental physical and mental health (Genereaux et al., 2016; Price & Oliverio, 2009). Mothers, who are most often the primary caregivers of children with DD, report that their identity as a caregiver may become all-consuming and their well-being is at risk when they are spread too thin in caregiving roles (Brock, 2014; Diallo et al., 2019; Fairthorne et al., 2014; Findler et al., 2016; Flynn, 2021; Pinquart & Sörensen, 2005). Safe et al. (2012) explained that “Mothers reported coping using a process of grieving a loss of normality, lowering their expectations about their child’s future, and changing their perceptions of a meaningful life” (p. 297). According to one mother of a child with autism, “It’s impossible to maintain your role in other areas because there’s only one you and there are only 24 hours in a day and so everything else has to give a bit” (Safe et al., 2012, p. 299).

The quality and breadth of support that mothers receive can tremendously impact the family system. Family systems matter for the caregiver's well-being and, most importantly, the well-being of the child with DD (Boyd, 2016; Brisini & Solomon, 2020; Pinquart & Sörensen, 2005; Warfield, 2005). As the family system’s well-being is essential, the mother’s well-being is key for the well-being of her child (Benevides et al., 2019). Unfortunately, caregivers overwhelmingly report experiencing isolation, marginalization, and stigma, which can negatively impact well-being (Abdul-Chani et al., 2021; Fairthorne et al., 2014; Li et al., 2019; Tikkanen et al., 2019). While there is an increasing amount of research attention on the experiences of caregivers, there remains less research on mothers with marginalized identities as historically most of the research has focused on White, middle to upper-class, educated mothers (Flynn, 2021; Ha et al., 2011; Stober & Franzese, 2018).

This research focuses on mothers of children with DD working to support and secure their children's future. The study aimed to highlight the voices and experiences of marginalized mothers who identify as BIPOC, LGBTQ+, immigrant, single mothers, mothers with disabilities, or mothers from low SES. While not all these identities were ultimately represented within study participants, all mothers interviewed identified as marginalized in some way, in addition to their gender and their marginalization as parents of DD children. These compounding marginalized statuses were mainly through the mothers' racial or ethnic identity, role as single parents, being immigrants, or having lower SES. By focusing on maternal caregivers' experiences with social support, this study examines one aspect of well-being for the child with DD, understanding that the caregiver's well-being is a determining factor for the child's well-being.

Statement of Research Problem

This study explores how marginalized mothers of children with DD perceive the support of community members, which may include family members, friends, and professionals. Caregivers may struggle to communicate experiences in parenting children with DD that are inherently contradictory. When I have spoken to them in a professional or personal capacity, caregivers express that they feel misunderstood. While they often may find meaning in caregiving work and demonstrate resiliency, they also experience isolation, stigma, and feeling overwhelmed. Caregivers with marginalized identities may encounter additional challenges with harmful or oppressive systemic barriers that are associated with discrimination, as well as a lack of social support.

Past research on caregivers in the U.S. has highlighted the experiences of mothers with majority identities, such as White mothers with upper-middle class socio-economic status (Genereaux et al., 2016; Stober & Franzese, 2018; Warfield, 2005; Woodman et al., 2015). This group of mothers holds racial and economic privilege, although as women, they experience sexism and cisheteronormativity, but mothers of DD children also experience marginalization because of their proximity to disability. Research has more recently explored mothers' experiences with other marginalized identities, and an emerging body of literature examines mothers from racial or ethnic minorities, immigrants, and those who identify as LGBTQ+ (Coulter-Thompson et al., 2023; Flynn, 2021; Ha et al., 2011). This study highlights concerns about the lack of understanding and attention to caregiving mothers’ experiences, especially those with marginalized identities, and how this may impact the quality of care for the child. Additionally, this study uses a person-centered approach to acknowledge the impact of the mother’s social environment (Forber-Pratt et al., 2017; Stober & Franzese, 2018).

As a field, counseling psychology emphasizes cultural competence, person-centered practice, and trauma-informed care. It is well suited to support the uniqueness of the caregiver experience and inform new dimensions of understanding, including the adjustment to and integration of multiple facets of caregiving work (Adams et al., 2016). Counseling psychology has also conceptualized how identity and ecological/systemic frameworks are essential for understanding an individual or a family’s psycho-social health and well-being (Bronfenbrenner, 1994). Unfortunately, there has historically been minimal attention to the topic of disability in counseling psychology (Foley-Nicpon & Lee, 2012; Olkin & Pledger, 2003). This marginalization of disability topics within counseling psychology and the lack of adequate training in counselor education continues to contribute to an overall support deficit for families of children with disabilities, with minimal attention to the uniqueness of their experiences (Emir-Öksüz et al., 2024). This research contributes to deeper understanding of maternal caregivers so that counselors, clinicians, and medical or educational specialists working with them can become better informed. Families who have children with disabilities need access to support from counselors, psychologists, and advocates who understand the importance of a family's identity, the social-relational ecology, and the connection to well-being (Canary, 2008; Emir-Öksüz et al., 2024).

Seeking solutions, scholars in the field of disability have drawn heavily on disability culture and included social ecological frameworks to conceptualize the importance of the relationship between social support and well-being for families and their children with DD (Berry, 1995; Findler et al., 2016; Marcenko & Meyers, 1991). For example, Boyd (2016) differentiates between informal and formal forms of social support, defining the everyday social ecology of caregivers of children with DD consisting of extended family, friends, and the community in proximity to the child and their family system. Formal social ecology includes the professionals who support the child and the family. Both types of support are crucial (Boyd, 2016).

Similarly, I draw from Bronfenbrenner's (1994) social-ecological model to illustrate the importance of the connection between the child at the center, the caregiver, their broader social ecology, or systems of support within the community, and the narrower relational ecology, which are the caregiver's extended family and friends. Counseling psychology scholarship and professionals working with caregivers of children with DD have much to gain by more deeply investigating what is known and not yet known about caregivers’ relationships with extended families, friends, and the community, including the medical, educational, and therapeutic systems they use for support (Fenderson, 1984; Stober & Franzese, 2018). All these forms of support are especially significant for caregiving families (Seligman & Darling, 2007).

Knowing more about caregivers' experiences with children with disabilities and the family system they function within, as well as unpacking marginalized intersections of identities, informs understanding and may beneficially transform practice and policies toward this population. While there is increasing literature on mothers identifying as BIPOC, LGBTQ, immigrants, single mothers, mothers with disabilities, or mothers from low SES, it is a smaller body of work in comparison to the literature on caregivers more generally (Abdul-Chani et al., 2021; Baker & Burton, 2018; Ben-Moshe et al., 2014; Choe et al., 2023; Coulter-Thompson et al., 2023; Flynn, 2021; Ha et al., 2011; Lemus-Mogrovejo, 2019). Thoroughly accounting for marginalized identities could contribute depth to the field’s current understanding of caregivers and well-being. Even so, research on caregivers and their children with DD has found a strong connection between social support and well-being (Boyd, 2016; Brisini & Solomon, 2020; Findler et al., 2016; Smith & Grzywacz, 2014; Weeks et al., 2008; Zeedyk et al., 2013). The meaning and importance of family and friends as social support is deepened within the context of the lack of support caregivers report experiencing in their broader, systemic, and societal encounters (Brisini & Solomon, 2020; Landon et al., 2017; McIntyre & Brown, 2018). The remainder of Chapter One contains further context by offering a summary of the literature, my connection to the topic, the research questions, and an overview of the theoretical frameworks contextualizing the research, followed by a summary of the research design, the definition of critical terms, and social justice implications.

Summary of Literature

While the stress, burden, and isolation that caregivers experience are central discussions within the literature, research has called for further attention to the level or quality of support from extended family, friends, or community members (Brisini & Solomon, 2020). Additionally, challenges for caregivers include discrimination and stigma in response to marginalized identities, which further compounds the stigma already experienced in response to their children with DD (Abdul-Chani et al., 2021). Literature examining the impact of stress on caregivers emphasizes the significance of informal social support for maternal caregivers' well-being (Boyd, 2016; Findler et al., 2016; Hassanein et al., 2021). However, there are significant gaps within research about what kinds of social support are beneficial or detrimental to the caregiver's experience. For example, in a study of working-class mothers, Sousa (2015b) found that maternal well-being was associated with grandparents who are involved with caregiving routines for grandchildren with disabilities and frequently serve as significant emotional support for parents raising children with intellectual disabilities. Even though social support has been shown to enhance the quality of life, especially for women, both maternal and paternal caregivers reported significant impairments across all four domains of a quality-of-life survey that included social relationships (Malhotra et al., 2012).

In addition to examining essential information about caregivers more deeply, the literature review in Chapter Two explores what information is available on the lesser-examined topics of marginalized identity and formal and informal social support. I briefly touch on the topic of my researcher identity within this introduction. Then, later in Chapter Three, I re-introduce the topic of my identity with greater depth and reflexivity by examining the individual aspects of my identity that influence the research, inspire this study, and add a unique context to the research purpose.

Personal Connection

My work as a licensed mental health counselor began to shift toward disability populations when my son was born with disabilities. The presence of a developmental disability complicated his care and later limited his access to much that I took for granted he could have, including his education. The journey of diagnosis and then subsequent encounters with systemic barriers was an awakening to the realities of living with a disability in our society. These life-altering experiences have catalyzed my pursuit of a doctorate and my research on caregivers and children with DD.

I gained a broad interest in disability topics from lived experience, and accordingly, I have chosen to narrow my focus on mothers and their experiences with social support. Since research illustrates a picture of social support as pertinent to a caregiver’s well-being, I believe this topic to be of utmost importance for many parents and their children who receive a diagnosis that implies developmental differences or delays.

Research Purpose

The research purpose of this qualitative study is to examine what mothers with marginalized identities observe about their support systems’ impact on caregiver stress. It investigates, from mothers’ perspectives, what kind of social support contributes to resiliency, is adaptive, and is helpful. This study aims to contribute to the body of knowledge about the effects of social-relational ecology on caregivers and children with DD. It examines barriers that disrupt the immediate family system, including children with disabilities. This study shares insights from the mothers’ perspective about what is supportive or not, what kinds of social support are helpful, and how extended family, friends, community members, and professionals can beneficially intervene.

A qualitative study centering mothers' voices contributes to existing research and fills gaps within the literature on experiences of social support. Also, this study contributes to the smaller but growing body of literature on the experiences of marginalized mothers and how identity affects their experiences (Choe et al., 2023; Flynn, 2021; Ha et al., 2011; Stober & Franzese, 2018). Additionally, it further informs the field of counseling psychology by providing more information about maternal caregivers' experiences with social support for counseling psychologists, educators, and clinicians who work closely with disabled children and families. This research has implications for caregiving mothers, fathers, grandparents, extended family, and professionals who play an essential role in supporting the crucial early childhood to adolescent years that are foundational for every other stage of development into and through adulthood. This research provides an opportunity to inform stakeholders about the unique lived experiences of mothers providing care for developmentally disabled children. This way, the clinicians, professionals, and the social support network of family, friends, and community can become better educated about the caregiver's experiences and, in turn, offer improved and appropriate support.

Along with exploring mothers' experiences of friends and family as social support, this study aims to extend the current understanding of caregiver burden. By emphasizing the impacts of systemic complexity and barriers, the research seeks to counter disability stigma. This research does not imply that the child or their disabilities burden or cause hardship to their parents, families, or communities (Green, 2007). The more recent focus in research on caregiver resiliency highlights potential benefits to parents and siblings, including personal growth and a deepened sense of purpose (Hassanein, 2021; McConnell et al., 2015). Research also describes the benefits of including and integrating children with DD into community and family life (McConnell et al., 2013).

Previous research also examines how deeply systems impact caregivers (Diallo, 2019; Tebes, 2019). However, there is not enough research about marginalized mothers who may experience significant risk of stress, poverty, and disparity of resources (Baker & Burton, 2018; Sousa, 2015; Stober & Franzese, 2018), so this study highlights their perceptions and experiences. Investigating caregiver identity through an intersectional lens helps better examine the quality and level of social support for caregivers living within marginalized communities (Ben-Moshe et al., 2014). I examined caregiver perceptions and experiences of their social support to highlight what is problematic, what is helpful, and to explore possible solutions for the burden of care, which too often falls mainly on the primary caregiver, regardless of their identity, circumstances, or standing.

Research Questions

Gathering data on how mothers experience their friends and family may contribute to further insight and to minimizing stress experienced by parents of children with DD. This study's research questions are:

(RQ1) How do mothers of children with DD perceive and experience social support from extended family, friends, and community members?

(RQ2) How does this social support system impact a mother's quality of life and, by extension, that of a child with disabilities?

This work may be meaningful for caregiving families who struggle to convey to friends, family, and the community the burden of care work and their level of need for social support and respite opportunities.

Theoretical Framework

This research is grounded in a discussion of how counseling psychology has the potential to align with and contribute to centering the needs and the lived experiences of the disability community through the lens of critical disability studies. I introduce several theoretical frameworks that further ground this research, including (a) critical models of disability, (b) attachment theory, and (c) intersectional feminism. Each framework is helpful for a better understanding of caregiving mothers' experiences and highlights impacts on their children.

The theoretical portion of the literature review in Chapter Two utilizes several models that address the tension for caregivers who receive diagnoses and treatment plans for their children under the umbrella of the medical model of disability. The medical model is helpful for diagnosis and treatment planning; it also views developmental disability as inherently problematic and a problem to be solved (Landsman, 2005; Triano, 2000). In response to a diagnosis, maternal caregivers may internalize the stigma associated with a developmental disability. Research shows that most mothers will accept, become educated in, and embody the role of advocate, navigating multiple systems that historically stigmatize disability; it also finds that these mothers will experience bias (Barnes, 2015; Triano, 2000). This has significant implications for their caregiving experiences.

Critical models of disability theory, including the social model of disability, highlight systemic barriers and access issues for individuals with disabilities, reconceptualize support, and describe disability as a normative and inevitable outcome of human experience (Landsman, 2005; Rockhold et al., 2024). The critical model also addresses society's ableist tendencies toward overt and covert, institutional, interpersonal, and internalized discrimination, or stigma, that people with disabilities experience from non-disabled people who view disabled bodies as non-normative, flawed, and inferior (Davis, 2009; Mladenov, 2014; Neely-Barnes et al., 2010). For this research, a critical disability framework helps to explain how maternal caregivers experience ableism in proximity to their children, how they are triangulated within disability discourse, and how they may become increasingly isolated in their experiences over time.

Attachment theory is explored to contextualize the study of caregivers and how their stress may impact their children with DD, because it connects the well-being of the primary caregiver and their importance to the child with DD (Bretherton, 2004). Bowlby and Ainsworth's attachment theory explains how layers of influences combine to moderate safety, security, and comfort for the child and their primary caregiver (Bretherton, 2004). The caregiver and child form a dyad of comfort and security to help the child cope with challenges and threats, and these formative experiences cultivate a template for how individuals experience relationships and stress as adults (Becker-Weidman & Shell, 2011).

Intersectional feminism is credited to the work of Black feminists who named that individuals hold multiple identities and the importance of examining gender, along with the intersection of identities, and their relationship to power and oppression (Carastathis, 2014; Cho et al., 2013; Crenshaw, 1989). This lens highlights how mothers with marginalized identities face compounded barriers to access. For example, being a woman, a person of color, or a single mother with low socio-economic status informs and impacts mothering identity, caregiving, and advocacy work. In keeping with a feminist framework, I address societal expectations for mothers of children with disabilities through the feminist lens of Sousa's (2011) "Warrior

Mother," which examines the documented and detrimental impacts of hidden, unsupported work on maternal caregivers' careers and socioeconomic status.

This study aims to contribute to the current disability rights movement's focus on systemic and policy-based solutions that center the voices, experiences, and interests of people with disabilities over the perspectives and majority influence of non-disabled people (Davis, 2009; Piepzna-Samarasinha, 2018). This research has a social justice aim, so I highlight oppressive systems that affect the caregiving mother and her child.

Research Design

This research study, further described in Chapter Three, is qualitative, utilizing Interpretative Phenomenological Analysis (IPA) methods (Smith et al., 2009; Smith & Nizza, 2022), and is driven by a critical/ideological lens to contribute to social justice aims. I recruited eleven participants for the study. The criteria outlined for recruitment indicated that mothers have a child with a DD diagnosis between the ages of 6 and 14, and identify as marginalized with one or an intersection of the following identities: BIPOC, LGBTQ, immigrant, single mothers, mothers with disabilities, or low SES. To highlight complexity within caregiving work, it was a preference but not a requirement that children have a co-occurring diagnosis, such as a medical, physical, or another diagnosis that complicates care.

Data was collected through a participant demographic survey, a social map, and semi-structured interviews. Participants completed a social/relational map to concretize their experiences of family and friends in terms of social support (Josselson, 1992; Motulsky, 2010). Participant portraits were created, and themes were coded and then analyzed utilizing Interpretive Phenomenological Analysis methods. In the next section, I offer a list of specific terms and their definitions relevant to this study, describing the meaning behind the terms more precisely.

Definition of Terms

Complexity

While there is no consensus on what constitutes the combinations of diagnoses that amount to complexity, I have drawn from the available literature that defines complexity within a developmental disability diagnosis more broadly (Miller et al., 2012; Odom et al., 2007). For this research, complexity generally means a diagnosis in more than one category of developmental or medical disability that impacts the child's developmental pattern, the severity of their behaviors, and the intensity of the caregiver's experience as they work to access support.

Complexity is also used as an umbrella term in this study as a descriptor for three specific areas. Instead of emphasizing disability as inherently problematic, this dissertation primarily explores and highlights the formal and informal social ecology of the mother's burden of care because it is compounded by complex systems, stigma, and lack of access in key ways. Complexity may indicate an accessibility issue created by the multiple systems a caregiver must navigate as an advocate to access adequate support for their child within their community. Finally, complexity may indicate limited available resources, including the lack of accommodation for children with disabilities.

Caregiver, mother, parent, and advocate

The literature uses caregiver, mother, parent, and advocate interchangeably. The work of caregiving is relative to each parent's circumstances. However, scholars differentiate the job of parenting typically developing children from the hidden work of caregiving for children with disabilities (Freedman, 1995; Landsman, 2008; Safe et al., 2012). The latter involves advocacy and navigating bureaucratic systems to secure medical, educational, therapeutic, and community support so that access to experiences for the child with DD can reflect similarities with their typically developing peers.

Courtesy Stigma

Courtesy stigma is a type of stigmatization that mothers and family members experience because of their association with their child's disability (Ryan & Runswick-Cole, 2008; Goffman, 1963, as cited by Stober & Franzese, 2018; Tikkanen et al., 2019). Having a marginalized identity such as BIPOC, LGBTQ, low SES, etc. has been shown in research to compound the stress a caregiver experiences (Flynn, 2021; Rockhold et al., 2024).

Developmental Disabilities

For this research, the term "developmental disability" (DD) describes a difference in the learning and behavioral profile of children with disabilities compared to the trajectory of typically developing children. DD are not necessarily fixed, nor are they the final predictors of a child's intellectual or other capabilities, worth, potential, or future (Dalton, 2013).

Developmental disabilities (DD) is an umbrella category for a range of other disabilities and are categorized as "severe, life-long disabilities attributable to mental and physical impairments, manifested before age 22 that result in substantial limitations in three or more areas of major life activities including the capacity for independent living, economic self-sufficiency, learning, mobility, receptive and expressive language, self-care, and self-direction" (Odom et al., 2007, p. 8). These categories can but do not necessarily imply a syndrome and an intellectual disability. Odom et al. (2007) illuminate this population further by describing DD as falling along a continuum where there is not necessarily a clear differentiation between children with gifts and needs, except in extreme cases on either end of the continuum. According to Odom et al. (2007), DD is also categorized as points on a continuum of learning and behavior. In his book about gifted brains, David Sousa (2009) describes children who score with an uneven learning profile and become diagnosed with a developmental disability, including an educational diagnosis of PDD (pervasive developmental disorder), and then later mature past the bounds of their diagnosis. With positive intervention and support, sometimes, these children may narrow the gap and go on to live independent and fulfilling lives. Some children with DD are also incredibly gifted. They are 2E or ‘twice exceptional’ children (D. Sousa, 2009).

Family with Disabilities or Family System

A family with disabilities or family system consists of the immediate family members of the child with DD, commonly the siblings and the parents, who experience impacts when the primary caregiver’s role shifts to accommodate complexity. Each family member is impacted when the primary caregiver is chronically overly burdened. Roles may shift, the family dynamic is affected, and quality of life may become more difficult to achieve (Olkin, 2017; Seligman & Darling, 2007).

Hidden Work

Hidden work is the caregiving work of parents of children with a disability (Landsman, 2008; Safe et al., 2012). It includes but is not limited to tasks like monitoring the child’s condition, ensuring that others know how to deal with the child, advocating on behalf of the child with schools, government agencies, medical and other care providers, performing treatment or therapies for learning, emotional, or behavioral issues, giving physical or medical therapies, preparing special diets, and applying for, arranging, or supervising outside services. Hidden work also implies that because the work is not observed overtly or accounted for accurately, a caregiver’s access to regular and effective forms of respite is scarce (RAISE Family Caregivers Act, 2021; Safe et al., 2012).

Marginalized Mothers

This research focuses on the experiences of a marginalization by gender within a patriarchal society and by having a child with disabilities who experiences stigma in an ableist society. Marginalized mothers refer to mothers who identify as one or an intersection of marginalization such as BIPOC, LGBTQ, immigrants, having a disability, single mothers, or low SES. This focus is a response to the over-emphasis in research on maternal caregivers who identify as primarily heterosexual and cisgender, White, upper-middle-class, and well-resourced (Flynn, 2021; Stober & Franzese, 2018). Scholars have called for attention to mothers with intersectional identities who are further siloed and stigmatized; for example, when marginalized mothers are questioned as to whether they are as meaningfully invested or dedicated in their caregiving work as the caregivers who are overwhelmingly represented in literature (Sousa, 2015; Stober & Franzese, 2018).

Quality of Life Assessment

Quality of life refers to a 25-item scale that assesses ratings of importance and satisfaction with five important domains. These domains are family interaction, parenting, emotional well-being, physical/material well-being, and disability-related supports (Summers et al., 2005). In an earlier iteration of the scale, these domains included economic/future planning, daily care, health care, recreation, socialization, identity, affection, educational and vocational access, and spiritual identity (Seligman & Darling, 2007). For families with disabilities who experience a lack of social support, these essential tasks may be challenging to achieve (Olkin, 2017; Seligman & Darling, 2007).

Social Ecology

Social ecology references the work of social psychologist Bronfenbrenner (1994), who constructed a map of concentric circles to show the relationship between the individual and their social environment. Later versions demonstrate the relationship between the individual and the systems they function within. Josselson's (1992) and Motulsky's (2010) use of social-relational maps illustrates the caregiver's social ecology and relational world. In this research, social maps highlight the relationship to and the impact of social support within the caregiver's relational ecology.

Warrior Mother

Warrior Mother is a term coined by feminist scholar Amy Sousa (2011) to describe the cultural and societal expectations about mothers. Sousa (2011) implies that mothers seek to qualify, understand, and take on the many roles assigned by informal and formal systems that serve as support, including (a) caregiver, (b) case manager, (c) advocate, (d) negotiator, (e) specialist, and (f) therapist, and that they are expected to sacrifice their identity, career, and position in life to fulfill the role of warrior mother to their child with a disability (Brock, 2014; Sousa, 2011).

Social Justice Perspective

From a social justice perspective, intersectional feminism and critical disability theories guide this research, which is focused on the perceptions and experiences of a marginalized population within the U.S. Further, within the population of caregivers of children with DD, I am interested in hearing the voices of mothers with marginalized identities. More broadly, this study contributes to an ongoing conversation within an intersection of critical disability and feminist thought, which challenges the idea that parents, especially mothers, must become heroes to deserve the support that meets the variable and complex needs indicated by their child’s DD diagnosis (Landsman, 2008; Sousa, 2015). By exploring the experiences and perceptions of maternal caregivers with marginalized identities more thoroughly, readers might grapple with and come to a deeper acceptance of the realities of caregiving work. This way, collectively, society might also further the work of learning about, accepting, and integrating disabled bodies into our communities. Additionally, this research emphasizes how critical social support is for caregivers and their children with disabilities. I hope this research contributes to improving the disability practices and policies that are currently in place by explaining, from the caregiver’s perspective, how social and bureaucratic systems currently either help or contribute to harmful barriers for caregivers and their children with DD as well as how they may be improved. Ultimately, this research hopes to contribute to more adequate solutions to meet the needs of maternal caregivers, who seek support for their caregiving work while raising children with DD.

Finally, in addition to aspiring to change social attitudes by addressing counselors, clinicians, and the organizations and systems they work within, I am examining the meaning of social support for these mothers in the interest of helping mothers caring for children with DD cultivate more robust forms of support. In the next chapter, I explore literature that is relevant to the topic of caregivers of children with DD. In the literature review, I explore theoretical frameworks, definitions of disability in the United States, the Individuals with Disabilities Education Act, disability demographics, developmental disabilities, complexity, marginalized mothers, caregivers, the financial cost of care, navigating systems, meaning-making, and social support, including from spouses, siblings, extended family and community support systems.

CHAPTER TWO: LITERATURE REVIEW

While counseling psychology's knowledge of developmental and systemic impacts on typically developing children abounds, there remains a lack of counseling-based resources to support children with developmental differences and, by extension, the caregivers who support them (Foley-Nicpon & Lee, 2012). Because counseling psychology practices are typically client-centered, it is uniquely positioned to understand, support, and advocate for the caregiver's position. However, while information and training are available about caregiving and disability-affirming therapies directed to counseling clinicians, the profession still lacks knowledgeable clinicians to support this underserved population (Olkin & Pledger, 2003). When the family member of a child with disabilities seeks mental health support for themselves or their child, there is a high probability that the generally practicing clinician trained in counseling psychology or related fields will have limited (if any) exposure to disability-affirming training, education, therapeutic interventions, or where to find resources (Olkin & Pledger, 2003). Lack of resources increases the probability of the clinician unknowingly perpetuating stigma and complicating care, re-enacting the same oppressive structures that contextualize this phenomenon. Ignoring the felt needs of vulnerable and marginalized populations is counter to the ethics of counseling psychology and mental health practitioners to center and strengthen the well-being of the person, relationship, and, ultimately, their systems of support (Fenderson, 1984; Olkin & Pledger, 2003).

To contribute to closing the gap on disability, primarily within the profession of counseling psychology, and then more broadly, this review of literature focuses on children with developmental disabilities (DD), the experience of mothers of children with DD (who are most often the caregivers for children with DD), and the roles of extended family, friends, and community in the work of caregiving. The literature review reveals what researchers have established about challenges in the caregiver’s lived experience that impact their children, experiences which are likely hidden from the view of crucial formal and informal social support (Safe et al., 2012). This chapter encompasses what I view as essential for understanding the broader and more current discussions within disability while weaving in considerations for the positionality and identity of maternal caregivers before finally narrowing in on the literature directly related to the research subject of maternal caregivers and social support.

I first explore theoretical frameworks for the study, which is further framed within a discussion on the importance of disability topics in counseling psychology and related fields. Frameworks for the research on caregivers are grounded in models of disability, including the medical model (MDM), the social model of disability (SDM), and the social justice (or critical) model of disability. I ground the information in each section with concrete examples of how the model intersects with caregivers’ experiences. I further contextualize each of these models in a separate area that explores key components of the relationship between mothers, models of disability, and meaning. The section on models is followed by attachment and intersectional feminist theory, which I view as essential frameworks for understanding maternal identity within society. The review then transitions to familiarize the reader with definitions of disability within the U.S., demographics, and relevant statistics related to caregivers and their children with DD.

The foregrounding of the research through relevant frameworks is followed by a discussion of several subjects directly related to the research focus. It includes mothers and caregiving in the U.S., which provides pertinent information on caregiving work, emotional impact, financial cost, navigating systems, meaning-making, warrior mother identity, and marginalized mothers. Social support is then explored by reviewing the literature on fathers, grandparents, friends, and community social support. These sections are followed by a brief methodological review that leads to the conclusion of this chapter, and the methodology follows in Chapter Three.

Theoretical Framework

In this literature review, I address childhood disabilities and caregiving through the broader context of counseling psychology and disability. I then provide an overview of medical and social models of disability, attachment theory, and intersectional feminist theory. Issues of marginalization, accessibility, barriers, and civil rights for people with disabilities are best highlighted through critical disability theory, which I view as an evolution of the social model of disability.

Counseling Psychology and Disability

Several professional fields center on mental health counseling, including clinical mental health counseling, rehabilitation counseling, psychology, social work, and counseling psychology. Rehabilitation counseling and social work clinicians receive specific training to support adults with disabilities, for example, with vocational support. In contrast, counselors are trained to support individuals, families, and couples in their relationships with each other and the interpersonal systems that impact them (Ayoub et al., 2014; Barnhill, 1979; Fenderson, 1984; Olkin & Pledger, 2003). The field of counseling psychology has established strengths-based models, developed an understanding of child development and family systems, and has contributed to progress in funding research, training, assessment tools, and the development of multiple interventions for evidence-based clinical practice (Foley-Nicpon & Lee, 2012). Counseling psychologists have a foundation of knowledge that is well suited to support families caring for children with disabilities. Further, clinical practice has great potential to align with contemporary approaches to disability because of the inherently person-centered, systemic, and strengths-based approach; however, a lack of disability-affirming training and knowledge persists in the field (Olkin & Pledger, 2003). According to disability scholar, activist, and counseling clinician Rhoda Olkin, there are not enough clinicians who are trained to support the current population with disability-affirming practices, even as the need increases (Olkin & Pledger, 2003).

The reasons for the deficit of counseling professionals trained in disability or disability-affirming therapies are multifold. As counseling psychology has evolved to acknowledge that culture and identity are necessary considerations for practice, the field has developed a core emphasis on multicultural competency for clinicians and scholars. Multicultural studies are a standard requirement within graduate-level work and inform clinicians' training, understanding, and acceptance of how culture, identity, and ethnicity impact practice. However, this emphasis often does not include disability as a required competency (Olkin & Pledger, 2003). Further, multicultural competencies within psychology have historically excluded or minimized disability education, regarding the disabled population as the expertise of clinicians trained in rehabilitation services (Olkin & Pledger, 2003). Rehabilitative practices, in general, pre-date current views of disability, grounding rehabilitative social work within the deficit-based medical model, which views disability as non-normative (Fenderson, 1984; Olkin & Pledger, 2003). When held against recent calls for disability-affirming interventions, this deficit-based model is increasingly problematic.

Currently, of the 329.5 million people in the U.S., approximately 65% percent of the population, at some point in their lifespan, will live with a disability (ADA, 2024). In a critical analysis of five major counseling psychology journals between 1990 and 2010, only 1-2.7% of the published research articles addressed disability as a topic, highlighting a profound gap in the literature (Foley-Nicpon & Lee, 2012). The literature implies a significant misunderstanding of disability issues from a counseling psychology lens. Further, disability advocates view the lack of inclusion within counseling psychology as an extension of the marginalization that people with disabilities experience in a broader context and a missed opportunity to begin building comprehensive and disability-affirming knowledge, understanding, tools, and practice within the field across all intersections of marginalized identity and stages of human development (Fenderson, 1984; Olkin & Pledger, 2003).

For over sixty years, advocates have called for the inclusion of disability as a topic within multicultural counseling and as a prerequisite for licensure; however, momentum is lagging (Fenderson, 1984). Perhaps the importance of taking notice of the marginalization of disability within the field of counseling psychology is to notice the effect of multiple points of marginalization this population experiences more generally within society. This could change with attention from the relevant mental health professions, including counseling psychology. The practice of counseling psychology, with its emphasis on the person's health and social support, within a cultural and social context, has excellent potential to address, integrate, and enhance the quality of life of disabled people, who comprise a significant portion of the population. As this research suggests, I propose that addressing the needs of children with DD by focusing on the mother’s caregiver burden as well as a specific focus on the role of extended friends and family as support is an appropriate and relevant conversation to have within the field of counseling psychology. This study seeks to contribute to the dearth of disability topics in counseling psychology and address previous scholars’ calls to move from conceptualizing problems to highlighting potential solutions through a resilience lens (Fenderson, 1984; Foley-Nicpon & Lee, 2012; Olkin & Pledger, 2003).

Models of Disability

To contextualize the experiences of children with DD and their caregiving parents, one must grasp the systems they navigate and the potential for significant improvement in the lives of caregivers and children by clearly identifying and then addressing informal and formal systemic issues. Because caregivers, on behalf of their children, will navigate formal and informal systems for support, a foundational knowledge of the Medical Model of Disability, the Social Model of Disability, and the Social Justice or Critical Model of Disability is pertinent. Each of these models is a lens for understanding the caregiver's experiences of social support. Since social support and quality of life have been highly correlated with well-being for caregivers (Boyd, 2016; Findler et al., 2016; Hassanein et al., 2021), in this next section, I offer a broad overview of these models and then discuss how they connect to well-being for mothers and their children with DD.

The Medical Model of Disability. The Medical Model of Disability (MDM) is a positivistic model that is historically and culturally bound, positioning specialists as experts with power trained in processes that will frame a disability diagnosis as inherently deficit-based and, therefore, in need of fixing (Ong-Dean, 2005). The MDM, established and promoted within and by the medical-industrial complex, has and continues to permeate our society's ideas about disability (Mingus, 2016). Disability advocates find this model problematic because it is deficit-based, does not address barriers and stigma, and does not acknowledge strengths and potential (Mladenov, 2014). The MDM exists as the antithesis of current and more progressive models of disability, which are more contextual, accounting for the influence of the social ecology and the lived experiences of people with disabilities (Nusbaum & Lopez, 2019; Piepzna-Samarasinha, 2018).

Parents receive disenfranchising information about their child's diagnosis through systems embedded in the medical model (Ong-Dean, 2005; Pierce & Frank, 1992; Safe et al., 2012). The benefit of the model is the ability to understand and engage with a diagnosis. A diagnosis enables access to the medical, educational, specialist, and community supports that caregiving parents and children with disabilities will need. Medical, educational, and therapeutic specialists receive training in medicalized education models, utilizing examinations and assessments to gauge whether a child is meeting developmental milestones within a normative range. Support within a medical model may be crucial for a family engaging with specialists to better understand their child's diagnosis and support their child. Even so, it is essential to understand the implications of navigating systems that are disaffirming when considering a caregiver's lived experience (Fisher & Goodley, 2007; Landsman, 2005). While a diagnosis is helpful and even desired for expert medical care and treatment planning, the stigma associated with a diagnosis marks the relationship between the parent, the child, and any other disability diagnosis that will later emerge.

As disability studies evolve to affirm and center the voices of people with disabilities, the former views and definitions of disability embedded within the MDM become increasingly problematic because they perpetuate a capitalist, colonized system of power that perpetuates oppression for marginalized populations (Mladenov, 2014). While disability-affirming movements embrace the Social Model of Disability (SDM), which acknowledges impairment and barriers to accessibility, contemporary, socially justice-oriented iterations have since evolved. In applying each model as a framework for maternal caregivers' lived experiences, it is essential to remember that U.S. systems are culturally and legally bound to offer a diagnosis and treatment, in turn binding the caregiver to engage with a medical model of healthcare that historically perpetuates stigma (Landsman, 2005).

The Social Model of Disability. The Social Model of Disability (SDM) was created as a response to the deficit-based definitions and approaches of the Medical Model (Barnes, 2015). Like the MDM, the Social Model acknowledges the reality of medical and other health-related needs of people with disabilities, which can be a valuable framework for diagnosis and treatment planning. The social model differs from the MDM because it is based on an ecological framework that acknowledges barriers within systems and society as inherently more problematic than the disability itself (Landsman, 2005).

The SDM distinguishes between two specific terms: impairment and disability. Within the SDM, a disability is re-defined as any barrier to access, and the impairment describes a person's physical or other limitations (Barnes, 2015). Disability-affirming advocates and scholars propose that a shift toward the SDM could restore society's relationship with disability and minimize stigma. The SDM's view of impairment is that it is a normative and natural outcome of life, and it emphasizes that an environment of barriers and inaccessibility is problematic, not the impairment (Mladenov, 2014). There is a consensus in disability studies that highlights the benefits of the social model over the medical model to advance disability rights because disability-centered models integrate disability and address barriers in the environment while accepting and addressing the realities of living with impairments. From a social justice perspective, the SDM centers the environment, or the ecology, as holding barriers that prevent access to civil rights, including education, employment, and, ultimately, the person with a disability's full integration into society (Barnes, 2015; Landsman, 2005).

The SDM complements the holistic approach of counseling psychology (Olkin & Pledger, 2003). Both identify and acknowledge problems and move forward to emphasize strengths and ultimately highlight solutions. There are iterations of the social model that integrate bio-psycho-social-relational elements, centering people over policy and progress, better reflecting the work of counseling psychologists (Thomas, 2004). This lens could better reflect what is inherently problematic in current models of care, especially how the expectation that parents' caregiving for children with DD will navigate multiple systems as case managers and how the amount of time, attention, and energy this requires is problematic, impacting quality of life and well-being (Ayoub et al., 2014; Hassanein et al., 2021; Malhotra et al., 2012; Oelofsen & Richardson, 2006). A Social Model reflecting bio-psycho-social-relational elements, in combination with a counseling psychology framework, could provide further insight into what happens when the entire external ecology that has been designed to help but is often overly burdened, intersects over time with the caregiver's well-being, which is, in turn, impactful for the child. In this next section, I address the contemporary disability community, history, and scholarship, and foreground how they will connect to this research, with an overview of the social justice model, more commonly known as the critical disability model.

The Critical Model of Disability. Critical disability (CDM) is a contemporary disability model that emerged from the more established SDM and differentiated itself from previous models with a significant emphasis on social justice (Mladenov, 2014). The CDM is more strongly associated with current trends in activism and a social justice-oriented view of disability than others because of its emphasis on ableism. Ableism has been described as the overt and covert, institutional, interpersonal, and internalized discrimination, or stigma, that people with disabilities experience from non-disabled people who view disabled bodies as non-normative, flawed, and inferior (Neely-Barnes et al., 2010). A core theme of critical disability describes ableism as the chronic and systemic marginalization and discrimination, or oppression, of disabled people by non-disabled or able-bodied people. Disability scholars and activists assert that to address ableism fully, the voices of people with disability must become central to any conversation concerning disability rights.

More broadly, critical disability activism is represented in discourse through advocacy for identity and person-first language, petitions to create accessibility for people with disability across domains of life, embracing multiple marginalized identities, and ultimately seeking to minimize barriers and advance disability rights (Barnes, 2015). As technology advances, the community can advocate through podcasting, authoring, networking, and building platforms on social media (Joseph, 2013; Piepzna-Samarasinha, 2018). While there has not been a consensus within the disability community for a best practice or method to advance disability equality, meaningful conversations and dialogue continue to emerge as ableism is better defined and confronted. Similarly, as ableism is highlighted and discussions about critical models of disability evolve, disability rights are highlighted and, hopefully, will continue to advance (Human Rights, 2008). Above all, what has become resoundingly clear is that the identity and narrative of people within this community must belong to them, and that is as true for children with disabilities as it is for adults with disabilities (Nusbaum & Lopez, 2019).

Critical disability and ableism are central to discussing social justice and disability in this research because the literature reveals caregivers' concerns with societal stigma, barriers, and oppression significantly impacts the relationships among the caregiver, child, and their social supports. Additionally, caregivers are often the voice for children for whom developmental differences may create vulnerability. While self-advocacy is the goal for every person with DD from a critical disability perspective, a developmental disability may interfere with the potential for a child, with some exceptions, to participate in self-advocacy. Self-advocacy is a vital context for crucial development in early childhood through adolescence when communication may be challenging and identity is still being formed. With these points in mind, this research does not divorce itself from the critical fact that children with DD are dependent on and even vulnerable to the well-being of their caregivers, who are often mothers but can include fathers, grandparents, siblings, and legal guardians. In the next section, I further explore and connect models to the research by reviewing literature that focuses on the relationship between mothers, models of disability, and meaning-making.

Mothers, Models, and Meaning. Different models cause mothers to create various forms of meaning that affect how they understand disability and, potentially, how they feel about a disability diagnosis. Maternal caregivers who receive a child's diagnosis are immediately accountable and must weigh their standards for caregiving work against society's standards of care and neglect, which are typically viewed through a medical model of care. These standards and expectations are set by the social, educational, medical, and service professionals who have been trained, offer a diagnosis, and provide services under the umbrella of the medical model (Ong-Dean, 2005). Here lies the tension between the critical, social, and medical models of disability for caregivers. The societal stigma associated with parenting a child with disabilities, juxtaposed with critical disability's critique of parents who may be completely unaware of social justice issues when they receive a child's diagnosis, places parents in a bind somewhere between two polarized views of disability: the medical model and critical disability models.

To further explain this tension, critical disability theorists have suggested that parents engage in ableism when they reinforce the medical model by striving to minimize, fix, or integrate the appearance of their child's disability (Neely-Barnes et al., 2010). In some circles, critical disability activists conceptualize the parents of children with disabilities as antagonists or enablers of a system that is irreparably harmful to people with disability, without acknowledging the parent's position as an advocate within a society that is deeply embedded in a medical model (Runswick-Cole & Ryan, 2019; Ryan & Runswick-Cole, 2008). Critical disability advocates call for parents to become better informed and to help dismantle oppression within the medical model by becoming educated and supporting critical and social models of disability (Davis, 2009). In this way, parents may redirect their energy away from "fixing" or "normalizing" their children toward creating a society that fully accommodates differences and the spectrum of disabilities (Landsman, 2005, 2008). While this view is idealistic, it undermines the reality of a caregiver's legal responsibility and society's expectations to support their child's health, educational, and developmental needs. It also minimizes the power and influence of the medical model, which holds caregivers accountable to a specific standard of care.

While there is no immediate resolution for mothers caught in the tension between the medical model and socially justice-oriented critical models of disability, the issues highlighted are much more complex than just picking one side (one model) over another. In a qualitative study, Landsman (2005) explored how mothers of children with DD first encounter diagnosis within the MDM and then, eventually, intuitively reject stigma and adopt a social justice-oriented view of disability. Fisher and Goodley (2007) found that new mothers of children with disability diagnoses tend, by instinct, to resist counter-narratives to the medical model's view of their children's diagnosis. Multiple studies on mothers include their experiences at the intersection of marginalization and resiliency in countering stigma (Stober & Franzese, 2018).

In contrast to the idea that parents perpetuate ableism, scholars have noted that parents of children with disabilities also experience ableist forms of discrimination under the broad influence of the medical model in contemporary society (Neely-Barnes et al., 2010). In one example, health professionals were found to identify parents as some combination of neurotic, suffering, dysfunctional, or powerless (Neely-Barnes et al., 2010). If this is the ongoing conceptualization of health professionals, then any category a caregiver would fall into is a disempowering, maladaptive view of parenting that posits the primary supportive relationship in a child’s life as ultimately dysfunctional. Sousa (2011) further addresses dilemmas unique to the role of mothers of children with DD, many of whom respond to society’s pressure, grounded in the medical model, to identify as a kind of warrior-hero who can cure or overcome her child’s disability. Sousa (2011) also identifies mother blame as a significant contributor to parenting stigma, especially with children with intellectual disabilities. The idea of mother blame describes how excellent mothers raise well-adjusted, successful children, while mothers who are lacking in some way raise children who are not well-adjusted or successful at meeting developmental and societal milestones (Sousa, 2011). This concept of the “good mother” has complex implications across parenting responsibilities for the caregivers of children with DD (Brock, 2014).

Mothers experience complexity in navigating between two systems, the medical and critical models of disability, that exist in opposition to each other. While there is not yet a formal middle ground for caregivers of children with DD, the heavy-handed influence of the medical model that forms our society’s negative perceptions concerning disability remains the dominant force shaping culture; this is important to acknowledge because of the implications for caregivers and their children (Mladenov, 2014). Clinicians could help by becoming educated on these models, understanding their impact on the experiences of the mother and child, and then educating and offering exposure to disability-affirming resources. Engagement with social and critical models of disability may allow mothers to become exposed to disability culture and thought and thus renegotiate their perceptions of a meaningful life with a disability. Another implication of the influence of the MDM above social and critical models of disability is the expectation that mothers would be able to sincerely fulfill a child’s psychosocial and emotional needs while also juggling the demands of caregiving work. Attachment theory offers a construct for how the high levels of stress that are associated with caregiving affect the relationship between a mother and her child with DD. In this next section, I offer attachment theory as the framework through which this research explores how the primary relationship between a mother and her child affects parenting outcomes and is potentially affected by stress and caregiving work.

Attachment Theory

Attachment theory is credited to the work of John Bowlby and Mary Ainsworth in the mid-20th century, and it can inform an understanding of the impact of stress on the experience of bonding between a mother and her child with DD (Bretherton, 2004). Clinicians view the tenets of attachment as central to informing the processes and outcomes for bonding and connection of child and caregiver from the earliest stages of childhood development into adulthood. Attachment theory emphasizes the infant's use of the primary caretaker, usually the mother, as a secure base, which aids in forming their primary bond, creating an internal working model for relationships (Bretherton, 2004). This immediate bond is the template for future relationships, and the quality of a secure attachment with a primary caregiver has implications for how the child will experience their world and relationships as an adult.

Similarly, deprivation of secure attachment bonds in children, termed insecure attachment, increases the risk for adverse psycho-social-emotional outcomes in adulthood (Bretherton, 2004). Because secure attachment is associated with positive effects, and insecure attachment is attributable to high-risk factors for adverse consequences, these concepts are vital to understanding outcomes for social-emotional development. The healthy development that evolves from a child's secure attachment to a primary caregiver is the basis for many evidence-based therapeutic approaches and interventions within counseling psychology, including those that are person-centered and trauma-informed (Bloom, 2013).

The pressure of caregiving demands, including meeting the child's needs, understanding, and adapting to the child's disabilities, the demands of caregiving work within multiple formal systems, the stress associated with isolation, and the probable reduction in family income (which I address further in the section on financial cost), can contribute to difficulties in forming attachment bonds. Disrupted attachment between an infant and their primary caregiver may escalate the probability of abuse or neglect (Moore, 2009). Children with DD have the same needs as children without disabilities and even children with autism are as capable of attachment as children without disabilities; however, they are particularly vulnerable to a disrupted attachment and are more likely to be maltreated or neglected (Moore, 2009). Findler et al. (2014) reinforce this idea and describe mothers as particularly vulnerable to caregiving stressors because they are frequently primary caregivers, associating caregiving demands with potentially disrupted attachment.

Compared to what is known about attachment for typically developing children, there is less research about attachment between a caregiver and a child with DD (Durrani, 2014). Counseling psychology agrees that attachment is crucial for forming healthy bonds, first with the primary caregivers and throughout developmental stages and into adulthood. Utilizing attachment theory, I highlight how external expectations and caregiving demands may interfere with this essential and organic process. On the topic of caregiving mothers, I would suggest that there are limits or perhaps careful considerations to implementing attachment theory as a framework. Disrupted attachment, especially considering a developmental disability diagnosis, cannot be a catch-all for adverse outcomes. Otherwise, mothers might be blamed for negative results or severe behaviors that are better associated with a diagnosis.

I explore the concepts of mother blame, the good mother, and the warrior mother further in the literature review sections on meaning-making and warrior mother identity, where I review the studies, how they contribute to knowledge on the topic of caregivers, and what is not covered. However, they are being presented briefly in this section as essential counterpoints to understanding the benefits and limits of attachment theory as it relates to the research topic. Scholars in the field of disability are exploring society’s notion that mothers are responsible for poor outcomes better associated with a diagnosis through the concept of mother blame (Ryan & Runswick-Cole, 2008). Mother blame is society’s expectation that any perceived lack in the child reflects some deficiency in the mother (Landsman, 2008). While exploring the experiences of maternal caregivers, Landsman (2008) highlights mother blame as the guilt society imposes and that mothers feel about their perceived contribution to a child’s diagnosis. Compounding the issue of mother blame are the cultural expectations that mothers should fight for their children and fulfill every child's need, even if this is to their detriment. These ideas are embodied in the good mother and warrior mother ideologies, which are incredibly impactful for mothers of children with DD (Brock, 2014; Sousa, 2011). By explaining these concepts in the theoretical portion of the literature review, I hope to highlight where the attachment theory framework falls short in response to probable outcomes related to a DD diagnosis. Even if mothers have secure attachment with their children and provide every benefit, they and their children with DD may still fall far short of society's expectations of a more perfect, more normative child.

The influence of the attachment framework is pertinent to understanding this exploration of the caregiver's experience and potential impacts on the child. There are benefits and limits when exploring the maternal caregiver's experiences through attachment theory. As I seek to explore the relationship and the environment as it is connected to the caregiving experience in this research, attachment theory has significance for understanding the bond, backgrounds, positionalities, and identities of the caregiving mother and her child with DD. Further, understanding the benefits and limits of the attachment framework and cultural and societal implications for the positionality and identity of maternal caregivers is highly relevant for clinicians serving this population. Attachment is sociological and culturally embedded permeating society's view of mothering identity (Durrani, 2014). Thus, attachment is an essential consideration for this research, where mothers with marginalized identities experiences are explored through an intersectional feminist lens.

Intersectional Feminist Theory

Given the current understanding of the maternal caregiving experience and the lack of information on how intersectional identities impact this experience, research has only begun to describe the perceptions of caregivers with marginalized identities through an intersectional lens. Intersectionality emerged from the work of Black feminist and legal scholar Kimberlé Crenshaw (1989) in the late 1980s (Carastathis, 2014). The term has historical implications, addressing power dynamics and oppression from the perspective of Black feminists who were forerunners of the modern feminist and anti-racist movements (Smith, 2019). Informed by their experiences with discrimination and systemic racism, they first identified and asserted the importance of identifying and acknowledging discrimination at an intersection of race and gender and challenging the status quo. White feminists failed to discern how their oppressions differed from Black women due to the notion that oppression is the same for all people. Black feminism differentiated that there are various forms of oppression for other people. Inspired by this history, Crenshaw (1989 & 2019) initially named intersectionality a legal framework to address oppression at the intersection of race, gender, and class. However, intersectionality has evolved to include various identities and topics within scholarly discourse. Black feminist scholar Collins (2022) added the concept of organizing intersecting oppressions, and the intersections involved often include discussions on classism, ideologism, sexism, homophobia, ableism, ageism, and racism or ethnicism (Carastathis, 2014; Cho et al., 2013; Smith, 2019).

Intersectional feminist theory supports critical analysis of a gap in the research. The existing research has focused primarily on White, middle-class women as caregivers, while stories of marginalized women and their relationship to race, class, disability, and sexuality are too often excluded (Stober & Franzese, 2018). Intersectional feminist thought supports a conceptualization of a focus of this study, which includes a discussion of power dynamics inherent in issues of disability, gender and mothering, patriarchy, ableism, access, and social change (Stober & Franseze, . By exploring comprehensive views of behavior through the lens of intersectional feminism, Defalice and Diller (2019) emphasize the influence of interacting variables regarding research on human behavior, including race, gender, disability, and sexuality. Similarly, utilizing an intersectional feminist framework on caregiving mothers contributes to a deeper understanding of the multiple marginalized positions of mothers of children with DD, including race, gender, disability, and sexuality.

Further, intersectional feminism is appropriate to address marginalized identity among maternal caregivers, where research has typically highlighted the narrative of mothers who are White, heterosexual, and upper-middle-class. Currently, scholars have observed how this population dominates the landscape in research on caregiving for children with DD, further minimizing the experiences of those mothers who hold marginalized identities (Stober & Franzese, 2018). However, this tendency has begun to shift as more studies of marginalized caregivers emerge (Abdul-Chani et al, 2021; Barrio et al. 2018; Burkett et al. 2017; Choe et al., 2023; Coulter-Thompson et al., 2023; Flynn, 2021; Iljaba, 2015; Kew et al., 2023; Kim et al., 2023; Lahti-Anderson et al., 2024; Magaña & Vanegas., 2020; Maye et al., 2021; Onaiwu, 2020; Pearson & Meadan, 2018; Rains et al., 2010; Shorey et al., 2019), including this one. Research reveals that the mothers of children with special needs will forgo education, work, and career opportunities to meet caregiving needs for their child, as they are involved in meeting the requirements that medical, educational, and therapeutic specialists assign across developmental stages and into adulthood (Sousa, 2015). Within the research available, the positionality of mothers is complex (Fisher & Goodley, 2007; Landsman, 2005). While an ecological framework, such as the social model of disability, helps to frame position according to social ecology, an intersectional feminist framework draws upon important nuances of identity, power, and oppression that have otherwise been hidden within the discourse of motherhood and DD. Scholars have identified mothers of children with DD as a marginalized population, and their relationship to marginalization is complex and contradictory (Ryan & Runswick-Cole, 2008). While this information has helped move the needle in constructing a holistic understanding of the common experiences of mothers raising children with DD, scholars acknowledge that the literature on mothers marginalized by racism, sexism, disability, and heteronormativity remains sparse (Stober & Franzese, 2018). Thus, the experiences of marginalized caregivers are too often unseen, unexplored, and unknown, pointing to potentially cyclical forms of oppression that occur in the research, perpetuating stigma and contributing to harm within systems that remain uninformed about how race, class, and gender impact the caregiver and the child’s experience. Disability scholars have noted the gap and called for further use of intersectional analysis in the study of disability topics, especially for families of color, and within studies focused on the mothers of children with DD (Ben-Moshe et al., 2014).

To review and summarize this portion of the literature review exploring theoretical frameworks, I offered several relevant models as frameworks for research on caregivers of children with DD. The MDM is relevant because it is a model that disaffirms and medicalizes disability, is historically and culturally bound, and permeates the experiences of caregivers who receive a diagnosis (Landsman, 2005). The Social Model of Disability affirms disability as a normative outcome and emphasizes that barriers as accessibility issues in the environment are problematic. Caregivers and their children, who experience forms of stigma and navigate complicated, medicalized systems, could benefit from understanding and having their experiences heard through the lens of social and critical models (Brock, 2014; Ryan & Runswick-Cole, 2008). Critical models of disability name ableism, advocate for equality through accessibility, and center the voices and experiences of people with disabilities (Davis, 2009). Because they are navigating systems and relating most closely with the child with a diagnosis, a caregiver's experiences are triangulated, at any given moment, somewhere among these three models.

The stress of navigating within the MDM, which perpetuates stigma and views disability as non-normative, compounds and complicates caregiving (Landsman, 2008; Olkin, 2017). I assert that this phenomenon is disruptive, and in response to this disruption, I have included attachment theory as an essential framework for this research. Attachment theory highlights the impacts of caregiving work on attachment processes and how a stressful environment can negatively impact this process, which is essential for creating a sense of security between the caregiver and their child (Bretherton, 2004). Insecure attachment may increase the risk for adverse outcomes (Moore, 2009). This framework is beneficial for emphasizing the well-being of the maternal caregiver but is detrimental when used to blame a mother for adverse effects better associated with a DD diagnosis. Intersectionality offers a framework for unpacking issues of identity, power, and oppression inherent in the experience of caregiving mothers with marginalized identities (Crenshaw, 2019), primarily because literature has historically focused on women who are White, middle to upper-class, educated, heteronormative, and non-disabled, although this is beginning to change generally (Abdul-Chani et al., 2021; Baker & Burton, 2018; Ben-Moshe et al., 2014; Choe et al., 2023; Flynn, 2021; Ha et al., 2011; Lemus-Mogrovejo, 2019; Stober & Franzese, 2018). As disability culture advances, there is an increasing focus on naming and processing caregivers' experiences in a way that honors the reality of their experiences and highlights the strong current of ableism in society (Ryan & Runswick-Cole, 2008). I hypothesize that although many parents are unaware of these models and frameworks, they may be helped by psychoeducation and an understanding of the practical application of models of disability.

Further, I assert that the caregiver and child's support system would benefit from a deepening understanding of the realities of caregiving a child with moderate to severe DD. Perhaps through this and similar research, a counselor who understands these models, has insight into the lived experiences of caregivers and children, and has essential training in disability-affirming practice would advocate for stakeholders to cement the caregiver's support system. To further this understanding, I next contextualize the experience of the child's disability within the culture that mothers live within by providing a broad overview of information about disability from U.S. society's current understanding of what disability is and what the outcomes are for disabled populations.

Disability in the U.S.

In this section, I define disability through the lens of U.S. society, which acknowledges people with disability and their rights through the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA). By including these in the definitions, I hope to provide an overview of disability rights in the U.S. while contextualizing a mother's experience caring for her child within a medical system that sets the definitions of disability, the terms of care, and communicates the outcomes of her child's disability (Landsman, 2008). Parents who are caregivers receive a diagnosis initially through the medical model (MDM). At the start of their caregiving experience, they are likely to be involved in systems using this model's definition of disability (Landsman, 2005). Through the advocacy inherent in caregiving, parents become familiar with their child's diagnosis primarily through the medical model, then at some point by the definition of disability set by ADA (ADA, 2022) and IDEA (IDEA, 2022), though not necessarily in that order (Ayoub et al., 2014). I also contextualize this information later in the review by clarifying how disability law and disability demographics impact caregivers' future anxiety regarding their children's future.

Americans with Disabilities Act

An overarching view of the definition of disability in the U.S. can be found in the Americans with Disabilities Act (2022). The ADA, a civil rights law passed in 1990, prohibits discrimination against people with disabilities in everyday activities. The ADA guarantees that people with disabilities have the same opportunities as everyone else to enjoy employment, purchase goods and services, and participate in state and local government programs (Scotch, 2000). According to the ADA (2022), a person with a disability is someone who has a physical or mental impairment that substantially limits one or more major life activities. They have a history or record of such an impairment (such as cancer in remission) or are perceived by others as having such an impairment. If a person belongs to any of these categories, ADA law protects them. In 2022, 61 million adults in the U.S. will live with a disability, a significant percentage of the population who could benefit from intersectional analysis within the literature and attention within the helping professions (ADA, 2024).

Individuals with Disabilities Education Act

The Individuals with Disabilities Education Act (IDEA), passed in 1975, was initially called the Education for all Handicapped Children act (IDEA, 2022). This law makes free, appropriate public education (FAPE) available to eligible children with disabilities nationally and ensures special education and related services from preschool until graduation or, in some states, age 22 (IDEA, 2022). The demographic served includes infants and toddlers from birth to age 2, who are enrolled and then served in early intervention programs where they are typically referred by a medical specialist (Ayoub et al., 2014). Under IDEA (2022), children fall into thirteen different disability categories. These categories, as defined, are intellectual disability, hearing impairment, speech and language impairment, visual impairment, serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, specific learning disability, other health impairments, and developmental delay in physical and cognitive, communication, social, emotional, or adaptive development (IDEA, 2022).

In the U.S., children with DD will fall into one or more of these categories as defined in the ADA or IDEA. A physician or psychologist gives a medical diagnosis in either the medical or educational setting, indicating which category of disability is applicable (Fisher & Goodley, 2007). Often, children with DD have more than one diagnosis and fall into multiple categories, indicating increased complexity for the child's development and, thus, an increase in intensity for the caregiver's experience (RAISE Family Caregivers Act, 2021).

While many children are initially identified as having DD by a primary physician, categories in ADA or IDEA could potentially be determined once the child is in an educational setting in the preschool or early elementary years. Parents are often the primary observers of differences in a child's developmental trajectory, which can become the catalyst for medical or educational assessment (Forber-Pratt et al., 2017). A medical specialist, psychologist, or educational psychologist makes the identification and initial diagnosis at some point in early childhood, and this is often a mother's first encounter with the idea that their child's developmental path—as well as the entire life of the child—will be much different than what they envisioned (Landsman, 2008).

Disability Demographics

A recent survey on caregivers reported that of the 75 million children in the U.S., 3 million children under 18 have a disability (RAISE Family Caregivers Act, 2021). Of the children with disabilities in the U.S., approximately 818,000 have been diagnosed with more than one type of disability (RAISE Family Caregivers Act, 2021). The survey highlights the likelihood of children with disabilities having more than one diagnosis, indicating not only complexity in the diagnosis but also complexity in the experience for many children and their caregivers (RAISE Family Caregivers Act, 2021).

The most common type of developmental disability among children five years and older is cognitive (Odom et al., 2007). Mental disabilities are often understood to be synonymous with DD. They are inextricably linked, as cognitive impairment does not occur without impacting a child’s development. However, a developmental disability does not always indicate a mental disability. Many children with Autism Spectrum Disorder, for example, have high cognitive abilities in conjunction with developmental delays (Odom et al., 2007). The same phenomenon—high cognitive abilities combined with developmental delay—can be confirmed with language-based learning disabilities (Odom et al., 2007). These children may be very intellectually and specifically gifted while requiring specialist support for developmental delay in bio-psychosocial and emotional ways, which is another way of presenting a combination of diagnoses as complex (Odom et al., 2007).

Certain combinations of disabilities are prevalent; for example, many children with self-care difficulties also have independent living and cognitive challenges (RAISE Family Caregivers Act, 2021). These mental challenges affirm that most children with DD have multiple challenges, and the probability of multiple diagnoses also has implications for parent caregivers, who are responsible for supporting the child and securing appropriate resources (Canary, 2008).

Future Anxiety of Parents for Their Children with Developmental Disabilities

According to scholars, there is a lack of longitudinal information in the literature, specifically on correlations between children with DD and the risk of hardship in adulthood (Heyman, 2019). However, disability scholars cite that there are risk factors for children with disabilities and their outcomes as adults within the literature (de Ruiter et al., 2007; Riches et al., 2006; Yingling et al., 2019). This research builds an essential context for understanding the importance of a caregiver’s position as an advocate and potentially a mother’s motivation that necessitates her need for intensity, and even the perception or claims of professionals of neuroticism or aggression in her advocacy and caregiving work. For this reason, I have included what is known about outcomes for children with DD as they grow developmentally into adulthood.

Children with intellectual disabilities show a greater risk for psychopathology than typically developing children (de Ruiter et al., 2007; Riches et al., 2006). Significant numbers of adults with cognitive and psychosocial disabilities are represented in the incarcerated population in the U.S. (Baloch & Jennings, 2019; Ben-Moshe et al., 2014). Adults with disabilities are more likely to face hardships that are detrimental to their well-being, including unemployment, housing insecurity, incarceration, and homelessness (Ben-Moshe et al., 2014). Over one-quarter of the homeless population has a mental, physical, or intellectual disability (Stone et al., 2008; Thomas & Vercruysse, 2019). Overwhelmingly, the odds are that having an intellectual disability increases the chances of experiencing one or more of these risks. Through an intersectional feminist lens, having other marginalized identities further compounds stigma and increases the odds of risk for the person with a disability (Baloch & Jennings, 2019).

Society has created and continues to perpetuate stigma and oppression for disabled populations, and the critical model of disability further highlights these outcomes for adults with DD. The SDM highlights environmental challenges that require solutions, such as fostering accessibility to improve fatalistic outcomes for adults with DD. How caregivers navigate their work as they encounter barriers within multiple systems may be better understood by more deeply considering obstacles through the lens of models of disability and by considering what mothers have already shared about their experiences of caregiving, which I present in the next section.

Mothers and Caregiving

Mothers who are caregivers will eventually face concerns about what will happen when their child reaches adulthood, given historically poor outcomes. These concerns include caregiver and advocacy succession, required care management, and marginalization avoidance (RAISE Caregivers Act, 2021). This requirement for risk management could be a proxy for resilience that caregivers often demonstrate in preparation for (a) lifelong support systems and (b) lifelong navigation of multiple systems (Sousa, 2015a). To better understand the caregiver's perspective, the following section offers a broad view of caregivers in the U.S. and then explores the caregiver's work and the implications for mothers in both arenas.

Caregivers in the U.S.

The average research participant for studies centered on caregiving for a child with a developmental disability is a White, upper to middle-class heterosexual woman (Flynn, 2021; Ha et al., 2011; Stober & Franzese, 2018). The National Alliance for Caregiving (2020) reported on caregivers of children with disabilities in the U.S., which indicated that 72% of parent caregivers are female, they are on average 40.6 years old, and they are caregiving for a child that is on average 8.7 years of age. The survey contrasts data on the caregivers of children with caregivers of older people. While one might assume that caregiving for an elderly parent is more intensive and time-consuming than caring for a child with disabilities, the survey found that the opposite is true. Caregivers of children with disabilities have a more intensive experience and spend an average of eleven hours more in caregiving per week than caregivers of adults (RAISE Family Caregivers Act, 2021). On average, a caregiver of a child with disabilities spends 29.7 hours per week providing unpaid care. The survey further states that one in four will spend 41 hours per week caregiving for their child. It is striking that caregivers of children spend significantly more time in caregiving work than caregivers of older adults, especially given the lack of accessible care services for children with disabilities. Given these averages, the survey concludes that caregivers of children with disabilities are overextended in their work and proposes that future policies should shift to better support this population (RAISE Family Caregivers Act, 2021). A closer look at what caregivers' work entails daily aids in understanding what kinds of policies could benefit them and what professionals in the field may need to consider when supporting this population.

Caregivers' Work. Supportive caregiving activities for children with disabilities include monitoring the child's condition, ensuring that others know how to deal with the child, and advocating for the child with schools, government agencies, and care providers. Six out of ten caregivers perform treatments or therapies for learning, emotional, or behavioral issues (RAISE Family Caregivers Act, 2021). Caregivers are also be involved in giving physical or medical therapies, preparing special diets, and arranging or supervising outside services. In this survey, three out of four caregivers report changing their work to accommodate caregiving (RAISE Family Caregivers Act, 2021). Based on the study, the impacts on employment for caregivers of children were more severe than for caregivers of adults. Caregivers of children were more likely to cut hours, take a less demanding job, give up work entirely, and lose benefits. They were also more likely to take a leave of absence. Presently, no employment, legal, or governmental policies address the probability that finances will be significantly impacted when caregiving for a child with disabilities. The survey did not explore how intersectional identity affects the caregiving experience within the category of caring for a child with disabilities (RAISE Family Caregivers Act, 2021).

These recent caregiver demographics in the U.S. broadly illustrate some of the complexity inherent in the caregiving role. The information also highlights the caregiver burden and shows that most caregiving parents of children with disabilities are female (RAISE Family Caregivers Act, 2021). The survey names parents as caregivers but stops short of identifying that most primary caregivers for children with disabilities are mothers. However, qualitative and quantitative research on parenting children with disabilities has acknowledged that the primary caregivers of children with DD are most often their mothers and that they are most often the parents engaged in advocacy work on behalf of their children (Marcenko & Meyers, 1991). While the national survey highlights the prevalence of challenges with caregiving in contrast to society at large, it is only part of the story (RAISE Family Caregivers Act, 2021). A thorough review of literature reveals further details about a mother’s lived experience that would otherwise remain hidden (Safe et al., 2012). In national surveys and literature, scholars have suggested that caregivers of children with disabilities are under-supported and under-resourced for the day-to-day tasks involved in managing their well-being and themselves (Marcenko & Myers, 1991; Safe et al., 2012; RAISE Family Caregivers Act, 2021).

Emotional Impact. The themes that emerge from prior research contextualize maternal caregivers' lived experiences, including the emotional impact of caregiving on mothers. In a quantitative study, Oelofsen and Richardson (2006) surveyed 59 participants who identified as caregivers of children with DD and 45 families of typically developing children. Caregivers participated by completing a questionnaire designed to examine the relationship between parental stress, sense of coherence (SOC), social support, and health in parents of children both with and without DD. Sense of coherence was measured and analyzed using a two-step process that included having participants assess threat level as a potential stressor, followed by a reappraisal of the threat after identifying personal and social-ecological coping strategies. Individual caregivers from identical families' SOC scores were compared against each other. Results of the study indicated that the mothers of children with DD scored with significantly poorer health, higher parenting stress, and lower SOCs than their partners. Mothers and fathers of children with DD scored considerably lower than parents of children with typically developing children (Oelofsen & Richardson, 2006).

Parents of children with DD often suffer adverse impacts on their health. Smith & Grzywacz (2014) designed a quantitative, longitudinal study over ten years, utilizing a risk and resilience framework to delineate physical and mental outcomes for parents of children with special needs in the U.S. The study surveyed over 665 participants to identify parents’ protective factors, including parental control and social support. Parents were shown to have poorer mental health, more significant depressive symptoms, and greater declines in activities of daily living over time than parents of typically developing children (Smith & Grzywacz, 2014).

In the Netherlands, Wulffaert et al. (2010) facilitated a quantitative study utilizing surveys to engage 75 mothers of children with Angleman and Willis Pradar Syndrome. The study aimed to measure parent stress and child characteristics associated with anxiety and compare stress levels between diagnoses. In an assessment of the data, the descriptors “elevated” and “chronic” emerged in association with their measures of stress. These scholars acknowledge the impact of maternal stress on parenting, the implications of adverse effects on health, and the importance of support when stress is high (Wulffaert et al., 2010).

One study found that mothers’ experiences ultimately contributed to a new maternal identity, informed by caregiving experiences for a child with a developmental disability (Nicholas et al., 2016. The authors describe layers of culturally embedded challenges in which maternal love transforms into a resilient force that triumphs under extraordinary circumstances. Utilizing an ethnographic approach in a qualitative study examining caregiving experiences, Nicholas et al. (2016) surveyed 85 mothers of children with autism spectrum disorder (ASD) across three Canadian regions. Drawing upon feminist and caregiving theory, the study aimed to differentiate between maternal relational and caregiving work, the latter being invisible, taken for granted, and remaining unsupported within the current culture. In addition to surveys followed by semi-structured interviews, researchers participated in follow-up and observation sessions with ten mothers of autistic children (Nicholas et al., 2016).

Along with delineating the specific tasks associated with caregiving, Nicholas et al., (2016) described how mothers of children with autism reported fulfilling various roles related to care that varied based on the child’s developmental stage. Mothers shared their experiences with exhaustion, relational strain, and isolation. They described these experiences as compounding over time and occurring in response to navigating social expectations while supporting their children’s differences. They also reported experiencing a lack of empathy, understanding, and compassion from friends, family members, and strangers in public settings. They described feelings of isolation that compounded and did not lessen over time. Key themes included navigating through a diagnosis, seeking services, living and breathing the diagnosis, living with uncertainty, and redefining parenting success. Notably, the study concluded by observing the unfair burden on mothers to advance disability issues and then challenging readers to take on more responsibility for transforming society’s acceptance, understanding, and advancement of disability rights (Nicholas et al., 2016).

The outcomes illustrated in studies on caregivers' experiences overwhelmingly reinforce the notion that constructive social support is crucial for maternal health and well-being (Brisini

& Solomon, 2020; Landon et al., 2017; McIntyre & Brown, 2018). The meaning and importance of family and friends as social support is deepened within the context of the lack of support caregivers report experiencing and is striking in context with their broader, systemic, and societal encounters (Brisini & Solomon, 2020; Landon et al., 2017; McIntyre & Brown, 2018). While these and other studies examine the challenges of caregiving through the parents' social, cultural, or relational lens, many studies associate caregiver well-being with the severity of a child's behaviors. These studies provide insight into the relationship between therapeutic outcomes, severe behaviors, and caregiver well-being.

Behavior Severity and Caregiver Well-Being

Multiple studies correlate the severity of the child's behaviors with parental well-being. In Canada, McConnell et al. (2014) investigated resilience displayed by families caring for children with disabilities and behavioral challenges. Their study utilized a random sample of 538 families who completed the Family Life Survey, which measured child behavior problems, social-ecological resources, and family-level outcomes. Supported by relevant literature, the study asserts that behavior problems contribute to the risk of low-income family outcomes as family routines, relationships, and adaptive resources are disrupted. Their findings were consistent with the initial hypothesis that families of children with disabilities and behavior challenges fare better and demonstrate resilience with access to social and financial support. Scholars suggest that increasing access to social and economic aid may be more beneficial for the well-being of the caregiving family than support designed to address the child's behaviors (McConnell et al., 2014).

In a review of the literature, Zeekdyk et al. (2014) assert that the stress of the initial diagnosis and the specific characteristics and behaviors associated with the diagnosis of a syndrome negate parental well-being. Their study seeks to differentiate the parental adjustment of children with autism from Down Syndrome (DS), Fragile X Syndrome (FXS), Cerebral Palsy (CP), and Intellectual Disabilities (ID). These scholars also aimed to answer how parent well-being and coping strategies vary, identify similarities across disorders, and describe behavioral characteristics that impact families across conditions. Zeekdyk et al.'s (2014) methods included (a) a survey of existing literature on parental well-being and (b) sorting the results into three categories to differentiate them by diagnosis and intensity of behaviors. The study's data identifies which diagnosis is often associated with poor outcomes for parents.

Ultimately, this research associated more severe behaviors with autism than with other DD (Zeekdyk et al., 2014). The study's findings indicate that parents of children with autism, where the diagnosis indicates social and behavioral challenges, fare worse overall than parents of children with DS, where the diagnosis is more often associated with outgoing and loving demeanors. The suggestion of poor outcomes for mothers of children with autism (ASD) echoes multiple findings in a review of literature centered on the health of mothers of children with ASD and ID (Fairthorne et al., 2015). In addition, Zeedyk et al. (2014) found that maternal stress was higher when autism was present compared to the other syndromes included in the study. Researchers almost entirely associated problems with behavior and mental health with an autism diagnosis for parents' diminished well-being (Blacher & McIntyre, 2006, as cited by Zeedyk et al., 2014). They recommended further exploring the coping strategies utilized by parents to address behavioral challenges and then differentiating those strategies by diagnosis to broaden understanding of similarities and differences across the range of developmental disability diagnoses. Further, the study suggests future research should more deeply examine and analyze behaviors associated with a developmental syndrome, the impact on caregiver well-being, and overall outcomes. Like McConnell et al. (2014), Zeekdyk et al.'s (2014) study concluded that social and financial support might be more critical to caregivers than addressing the severity of behaviors.

Repeatedly, existing research highlights the importance of moving beyond problematizing the diagnosis to examining formal and informal community support surrounding caregivers and concrete solutions. Scholars call for further attention to social and financial support for caregivers to address well-being (Sousa, 2015). The request is striking in contrast to the lack of policies and programs focusing on family-caregiver risk and how those outcomes may impact the child with DD. Although research on well-being is not primarily focused on the financial cost of caregiving, there is literature on monetary cost. Financial cost frequently emerges as a concern when caring for a child with disabilities. A lack of resources should be considered a significant risk factor for this population. Prior research highlights that socioeconomic disparity further marginalizes legal guardians and parents of children with developmental disabilities to the detriment of the entire family (Genereaux et al., 2016; Maye et al., 2021). To further explore this dynamic, the next section reviews the financial cost of caregiving for a child with DD.

Financial Cost

Within the existing literature, researchers acknowledge the need for more information on how families fare with the financial cost of caregiving (Genereaux et al., 2016). In Canada, Genereaux et al. (2016) conducted a quantitative study utilizing an online survey to assess parents' cost of care for their children with Down Syndrome (DS). Using the "COPE: Costs of Caring Survey" (Studying the Costs of Parental Expenses), the survey focused on approximately fifteen categories of cost analysis. The cost categories include, for example, education, daycare, respite care, therapies, transportation, benefits, family support, employment, and additional expenses (Genereaux et al., 2016). Genereaux et al.'s (2016) cost analysis found that the annual median cost for parents raising a preschool-age child with DS in Canada is $35,409. The median yearly cost for parents raising a school-age child with DS in Canada is $43,349. Regarding societal costs, the survey found that the median cost for preschool-age children in Canada with DS is $8,559. Societal costs for school-age children in Canada with DS averaged $39,133. According to the study, the cost of raising a child with a disability, compared to a typically developing child, was nearly double (Genereaux et al., 2016).

In the discussion of results, researchers noted that the most common income loss is primarily a result of mothers being unable to return to work because of a lack of flexibility in the workplace to accommodate being available for their child's varying needs (Genereaux et al., 2016). The participant's reports about re-entry into the workforce are contrasted with what is known about the experiences of parents of typically developing children, who may re-enter the workforce as their children enter the school system. Approximately 20% of parents surveyed resigned from a job to care for their child with a disability, while 36% worked fewer hours to meet care needs. Additionally, an inconclusive number of parents reported that their child's needs were so irregular that holding a job would be impossible. Participants voluntarily shared that they incurred intangible expenses, such as the emotional and psychological cost of advocacy, networking, and being placed on years-long service waiting lists. The study concluded with recommendations for future studies to include the recreation fees, which this study did not cover. They also emphasized the utilization of the survey across regions and to measure costs for a differing disability diagnosis. Overall, the study recommendations include the need for more data on the costs of raising a child with disabilities and gathering a baseline of costs. Scholars viewed costs as the next imperative step in assessing the cost-benefit of support, programs, and policy in caregiving a child with disabilities (Genereaux et al., 2016).

In Wisconsin, Parish et al. (2004) addressed cost in a longitudinal, mixed-methods study by comparing 165 parent caregivers’ well-being and maternal employment to parents whose children did not have DD. The participant demographics primarily consisted of White, middle-class parents of children with and without DD. The study surveyed parent participants aged 18, 36, and 53, measuring economic outcomes as they cared for children with DD by measuring income, savings, home equity, and mortgage amounts at each age. According to the survey results, compared to parents with typically developing children, parents of children with DD had significantly less income and savings by midlife across each category measured. While fathers are more likely to maintain their careers, mothers’ careers are negatively impacted, with caregiving work interrupting or replacing work hours. Maternal parenting journeys that begin with relative financial equity at 18 show significantly less income and savings at midlife than the same-age mothers of children without disabilities (Parish & Cloud, 2004). Additionally, the severity of a child’s behaviors or impairment strongly predicts caregiving mothers' employment level. Overall, the study found that parents of children with DD, especially mothers, may not differ significantly in the early parenting or midlife stages, but overall, the mothers end up substantially disadvantaged financially in comparison to parents of typically developing children (Parish & Cloud, 2004).

A study examining the factors associated with life satisfaction among caregivers of children with DD in South Korea included the cost of care as a significant factor when synthesizing data from a national survey (Cho & Kahng, 2014). The study included 1,500 caregivers of individuals with DD and a subset sample of 390 caregivers of children under 18.

The study examined financial burden as a factor of life satisfaction. Cho & Kahng (2014) sought to determine parents' perceived financial responsibility and focused on assessing the extent of caregiver stress associated with health care, education, and transportation. In South Korea, having a child with disabilities is culturally regarded as an issue for the parent caregiver, who then likely lacks sufficient social or program support. This study's findings were like those in the Canada study (Genereaux et al., 2016) and the Wisconsin Study (Parish & Cloud, 2004). The expense of caregiving more significantly impacted mothers, and their perceived quality of life was lower because of the burden of added costs associated with caregiving (Cho & Kahng, 2014). Diminished quality of life for mothers was associated with reduced employment opportunities, leading to less income and poverty, in turn impacting stress levels. In short, mothers experienced financial, psychological, social, and physical stress. The study noted that caregivers with children whose behaviors were mild to moderate received less government support than those with severe disabilities, which contributed to a lesser quality of life and diminishing life satisfaction. The study described parents utilizing excessive amounts of time addressing children's behavioral problems, with lack of time for house chores, leisure, spending time with their other children, sleep deprivation, and frustration, all impacting the caregiver's perception of quality of life. Cho and Kahng (2014) recommended studies utilizing longitudinal data to examine more closely the relationship of variables, for example, how the degree and type of disability impact caregiving and quality of life. They also recommended contrasting caregivers' experiences of children with DD to those of parents of typically developing children.

Marital discourse and divorce are topics worth considering under the cost category, as the fracturing of a family system compounds the financial and psychological cost of caregiving. Namkung et al. (2015) compared 7,251 parents of children without disabilities to the risk of divorce in parents of children with DD in a longitudinal, quantitative study over 50 years. They found that while many marriages of parents caring for children with DD remain intact, parents raising a child with DD over the life course of a marriage are more likely to divorce than their peers with a typically developing child (Namkung et al., 2015). Interestingly, the number of children in the household was more strongly correlated with divorce than disability. Parents who had only one child with DD were significantly more likely to divorce. In contrast, parents who had a child with DD and typically developing siblings were less likely to divorce. The study authors conclude from the data that siblings contribute by fulfilling caregiving roles, thus contributing to the overall well-being of the family and, potentially, the outcome of the marriage. One limitation of the study may be the lack of clarification concerning how many of the participants might identify as marginalized and belonging to an ethnic, low SES, LGBTQ, or another minority group. The lack of clarification on marginalized identity obscures whether outcomes would differ if there were an emphasis on collecting data from marginalized populations (Namkung et al., 2015).

Significant observations on the cost of marital discourse for caregivers have been reflected in attorneys Price and Oliverio's (2009) experiences with divorce and caregivers of children with DD in family law. They advise that parents considering divorce should factor in direct and indirect costs of caregiving, the high cost of divorce when care needs are multiplied between households, and when the primary caregiver assumes the bulk of caregiving responsibility as a single parent. They address the primary caregiver’s vulnerability to poverty and the lifetime of services paid for out of pocket, often not covered or reimbursed by insurance. Within the most recent iteration of the RAISE Family Caregivers Act’s report to Congress are numerous insights on cost gathered from their listening guide project in August of 2021 and quantitative and qualitative studies supporting evidence on the financial cost of care. According to this report, in the U.S., the average cost of in-home care for caregivers of children with DD was estimated to be $35,000 a year annually. The survey demographics identify these caregivers as primarily middle to low socio-economic status (RAISE Family Caregivers Act, 2021).

While the cost of care emerges as a primary factor impacting the quality of life and well-being in multiple studies, cost also refers to other categories of lived experience. Cost can be measured in the challenges caregivers face across numerous domains of life, including the time and effort of navigating complex, fractured, and often overly bureaucratic systems for support. According to the RAISE report (2021), caregivers must conquer innumerable challenges as they advocate for their children across their lifespan. However, an ultimate concern arises when parents realize they will financially and physically age out of being able to care for their adult children with developmental and intellectual disabilities. The nature of caregiving is that it is perpetual work that occurs over the caregiver and child's entire life, and it centers on the accessibility of support within the systems that a caregiver navigates. The complexity of navigating systems to access necessary services across the child's lifespan and adulthood, and the lack of services, is another cost for caregivers that diminishes the quality of life and hinders well-being (Diallo et al., 2019). Navigating systems to find sufficient support, in contrast with the lack of accessibility to available services, is another relevant topic in a mother's experiences of caregiving and advocacy.

Navigating Systems

The literature on caregivers' experiences navigating systems implies that medical, educational, and therapeutic systems are not working cohesively to meet the child's or the caregiver's holistic needs (Jones & Passey, 2004; Safe et al., 2012; RAISE Caregiver's Act, 2021). The fractured nature of meeting a child’s needs between multiple systems misaligned in numerous ways contributes to the caregiver's burden. Instead of streamlining the process of accessing care to assist caregivers who support children with diagnoses, mothers are forced to adjust and cope for as long as they need to learn about and abide by therapeutic, medical, and educational protocols created for their children to address perceived deficiencies. This is an impossible task by all the caregivers' accounts within the literature (Safe et al., 2012; Seymour et al., 2020). Each system they navigate for care will create multiple points of accountability, including therapy plans, medical treatment plans, or educational plans designed to meet the child’s needs. Within the process of supporting a diagnosis, there is no plan for, nor do professionals formally assess, acknowledge, or consider the compounding burden of the caregiver across settings (Safe et al., 2012; Seymour et al., 2020). Even so, many caregivers of children with DD will still find a way to persevere as they navigate systems that (depending on the diagnosis) may create a burden of nearly impossible requirements, like waiting for years on waitlists to receive necessary services (Safe et al., 2004; Sousa, 2015).

In addition to examining cost of care, Nicholas et al. (2016) investigated the lived experiences of mothers of children with ASD, Asperger’s, or Pervasive Developmental Disorder and how they navigated systems. Among several themes that emerged within the study results was the journey of seeking services, which mothers would need to navigate formal systems to access (Nicholas et al., 2016). Mothers described the need to be organized, strategic, and strong advocates as they sought assistance. They shared what they described as the confusing and disjointed process of seeking services, with diagnosing professionals encouraging mothers to seek services early but with no offer of a roadmap to access those services. Mothers reported feeling pressure to access services to mitigate the long-term impacts of a diagnosis but then not knowing or understanding how to identify effective therapies or secure services for a particular diagnosis initially. Once services are identified, mothers report that the effort required to access services is undermined by the ineligibility of services due to age, cognitive ability, progress, or other criteria, resulting in tremendous frustration. Mothers explained their experiences of long waiting lists or inadequate funding resulting in limits to accessible services. For the mothers highlighted in this study, the complexity of navigating systems often prompted them to become strong researchers, advocates, and diagnostic specialists in a quest for support (Nicholas et al., 2016).

Hewitt et al. (2013) published an article summarizing the status of research regarding policy, funding, services, and experiences of families of individuals with ID and DD, echoing findings within the previously mentioned studies. Parent caregivers struggle with accessing formal services and support because of gaps and barriers in service availability. The obstacles include a lack of knowledge of services, not understanding enough about the process of obtaining services, long waiting lists, cost, and transportation issues. Families also reported that services were ineffective or of poor quality. Other matters discussed centered on barriers to accessing education, transition, employment, residential support, access to technology, and budget shortfalls that impact services.

Further compounding these issues is the general lack of training in disability-affirming practices for children (and adults) with disabilities among practitioners. Newton and McGillivray (2019) studied caregivers' perspectives of people with ID accessing services in Australia for care recipients ages 3 to 42. The qualitative study utilized semi-structured interviews to investigate the experiences of 25 mostly female caregivers of individuals with ID. Researchers sought to answer questions concerning the caregivers’ perceptions of barriers to accessing health care from general practitioners and what changes could result in more responsive care. According to Newton and McGillivray (2019), parents of children with intellectual disabilities struggle to secure relationships with healthcare providers (HCPs) who have adequate knowledge about working with disabilities or have been trained in disability-affirming practices. Themes that emerged as challenges include the general practitioners lacking knowledge or skills specific to disability, communication issues, establishing rapport, practitioner approach, substandard care, disempowerment, and complexity in navigating formal care systems. The study participants also highlighted the lack of accountability from the health system to the caregiver or the person with a disability and a “siloed approach,” which is the tendency for general practitioners to reduce presenting issues instead of taking time to hear holistically about concerns. Mothers reported that stigma was a significant barrier to accessing supportive HCP relationships within healthcare communities. The study recommends that communication is a significant challenge and that practitioners should seek to practice in flexible, open, and collaborative ways with caregivers, that practitioners can facilitate constructive experiences by offering space for the person or child with a disability to share and advocate collaboratively, and that the patient relationship could benefit from taking time to learn in-depth about the person with a disability. Further, the experience could be enhanced using an evidenced-based comprehensive health assessment to facilitate understanding and communication between the practitioner, caregiver, and patient (Newton & McGillivray, 2019).

In the UK, researchers Jones and Passey (2004) measured stress in parents of children with DD and behavior problems in a quantitative study, utilizing family stress and coping as a framework. The study surveyed 48 primary caregivers consisting of parents, grandparents, and foster parents of children who met the criteria for DD and may have had additional diagnoses of

Autism, Down Syndrome, ADHD, or Cerebral Palsy. Caregivers of children with DD reported their experiences with friends, family, and neighbors on a day-to-day basis as being extremely stressful. The caregivers cited social support stress as unhelpful as they experienced unwanted advice, stigma, staring, and social isolation. They identified interactions with health care providers (HCPs) as highly stressful because they did not feel listened to or understood by professionals and had difficulty obtaining a diagnosis. Caregivers reported needing to fight and persevere with HCPs to be heard and understood, contributing to perceived stress. Overall, the study found positive perceptions of informal and formal social support within systems are vital to lowering parental pressure (Jones & Passey, 2004).

In a review of the literature on special education teacher burnout (SET) from 1979 to 2013, twenty-three studies were selected (Brunsting et al., 2014). Each study offered quantitative measures of burnout combined with a focus on special education teachers as study participants to update the literature on special education teachers’ working conditions. While the study does not frame a specific question within its purpose, it implies the goals of synthesizing research on SET burnout, identifying gaps in the literature, and offering recommendations for practitioners. Bronfenbrenner’s Ecological Model was used as an organizational framework to order the variables associated with teacher burnout, and the article describes burnout through one or more of Maslach’s criteria (i.e., emotional exhaustion, depersonalization, and lack of personal accomplishment). Methods employed in the research included electronic, hand, and ancestral searches. Articles were coded first to meet the criteria for inclusion in the study and then for the number of agreements in the remaining studies. However, the instrument used for coding was not identified. The study results were charted into a table describing a range of variables correlated with SET burnout.

Further, the variables were categorized into individual (SET) level variables, classroom-level variables (including, for example, student behavioral challenges), and state or district-level factors associated with SET burnout (Brunsting et al., 2014). Student outcomes related to SET burnout were also identified and discussed. Among the many significant findings that the authors correlated to SET burnout, the study found that emotional regulation, efficacy for dealing with challenging behavior, and co-worker and administrative support played a significant role in SET teacher burnout. The study noted that it would be helpful to utilize the data gathered from this study to create further research addressing specific interventions that could contribute to the prevention of burnout among teachers. This information could support school administrators who might take a proactive approach to SET burnout prevention. The authors noted their alarm that SET burnout is related to adverse student outcomes, highlighting a detrimental cycle that could be attributable to SET's tendency to neglect self-care in the belief that they are helping and not harming student outcomes. This information is pertinent to this research on caregivers because it highlights caregivers' complexity in accessing support. The caregiver's relationship with the public school system's special educators is of primary importance, and they are heavily impacted by it, for better or worse.

Limited access to respite care is relevant to the discussion of caregivers navigating systems. Doig et al. (2008) identify in their study as having previous experience working in respite care for children with special needs. They utilize in-depth, open-ended interviews within a constructivist, grounded theory approach in a qualitative study seeking to describe parents' experiences securing respite care. The study addresses the need for respite care and how it has been shown to contribute to parental well-being and minimize family and marital tension. It also discusses the dilemma many parents face in seeking and securing respite care services because they encounter barriers with limited availability, quality, and accessibility. The study centered on the experiences of ten participants, seven mothers and two fathers from a primarily urban area, identified and selected through agencies dedicated to supporting caregiving families, with no specific inclusion or exclusion criteria. Data collection was qualitative, described as iterative, and employed audio recordings, transcriptions, and a line-by-line coding technique, followed by creating categories and subcategories with focused coding. Participants were offered a summary of findings by which they could verify, challenge, or offer feedback. The primary focus of the study centered on parents encountering difficulties with securing respite care, for which their frustration with access became central to the discussion. Parents identified problems communicating their need for respite care and being heard before hitting "the breaking point" and then having to "jump through hoops" to access care (Doig et al., 2008). Significant barriers to accessing respite care included having a medical diagnosis that meets the requirements, age restrictions, behavioral requirements, limits to the number of children, lack of consistency, unqualified providers, unique needs, negative experiences, transportation, and location.

Given that the study takes place in an urban setting and the participants currently access respite care, there were limitations to generalizing the data. Doig et al. (2008) conclude that further examination in different settings and populations would be critical for future research. The data collected in this study highlights another area of complexity for caregivers' experiences with accessing and navigating formal and informal social support within society's systems, which is important for setting context to the necessity for extended family and friends to position themselves proactively as support.

To summarize the literature, maternal caregivers of children with DD describe challenges in navigating multiple systems, including medical, educational, therapeutic, government, and community agencies, to access appropriate services and support (Nicholas et al., 2016). The lack of interaction or cohesion between systems compounds work for the caregiving mother. The mother must act as a case manager and an advocate, organizing and implementing treatment plans the child's diagnosis requires across many systems. Concerning navigating educational systems, there is a lack of literature on the experiences of parents of children with DD. Along with examining medical and specialist systems, the impact of caregiving on teachers may be worth noting in this discussion on caregivers, mainly because teachers who work in special education qualify in many aspects as paid caregivers, and parent caregivers interact with teachers as they advocate for services within school systems. In education systems, teachers and specialists experience high rates of burnout and lack of funding, even in general education settings. In special education settings, parents are required to advocate for appropriate support by participating fully in creating and implementing an individualized education plan (IEP) (Brunsting et al., 2014).

Even with these challenging systems to navigate, many caregivers of children with DD still find ways to persevere past a burden of requirements that feel impossible to fulfill. In the next section, I explore meaning-making as the caregiver seeks to navigate these systems and survive what feels impossible while staying motivated to sustain themselves and their loved ones who suffer from inadequate systemic support.

Meaning Making

Recently, there has been a shift from researching the negative aspects of parenting a child with disabilities. The trend in research is to portray caregivers' experiences through a lens of growth, meaning, and resiliency (Ryan & Runswick-Cole, 2008). I view this trend in literature from both non-critical and critical perspectives. From a non-critical perspective, how parent caregivers demonstrate resiliency in their experiences is meaningful and may allow for further understanding of the nature of parenting a child with a disability, as well as insight on how to replicate the process by which caregivers sustain themselves and their children in the face of numerous and varying social and systemic obstacles. From a more critical perspective, a drawback may be that highlighting the resilience of caregivers will de-prioritize the urgency to address systemic and social difficulties that are untenable and, while documented, are still without solutions. In an article addressing the tension of their lived experiences as academics and caregiving mothers, Ryan and Runswick-Cole (2008) share their lived experiences and highlight resiliency issues by explaining how mothers historically have been viewed by disability activists as either allies or oppressors. The authors identify as maternal caregivers and argue that they identify as neither allies nor oppressors but as academics, mothers, and advocates. The scholar-caregivers further state that caregiving mothers' skills and contributions are often overlooked, even though it is the experience of mothering children with disabilities that positions them to become more effective advocates on behalf of their children and the disability community at large. In a more recent article, Runswick-Cole and Ryan (2019) clarify their opinions about the benefit of mothers as advocates in contrast to critical feedback, while advocating that mothers join with the disability community and share their lived experiences as expertise to support the creation of concrete solutions for existing barriers. From either position, Ryan and Runswick-Cole, even as they address the tension of mothering disability, are clear examples of mothers making meaning and demonstrating resilience in their caregiving journeys.

Research on how caregivers make meaning and demonstrate resiliency continues to emerge. In a study named “Silver Linings,” Bultas and Pohlman (2014) utilize qualitative, interpretive phenomenological methods to understand the experiences of caregiving mothers of children with autism in St. Louis, MO. One of the four aims of the study includes discovering how mothers make meaning of themselves, motherhood, and their children and how this, in turn, shapes their mothering experiences. They interviewed 11 mothers of preschool children with Autism Spectrum Disorder (ASD) three times over six weeks and then analyzed the results. Data drawn from interviews showed that nine out of the 11 mothers could negotiate silver linings or an optimistic view of mothering experiences in the face of adversity. Mothers view these silver linings, for example, as becoming better versions of themselves through their mothering and advocacy experiences, reinforcing their faith, having the opportunity to mold their child into an adult, having a new sense of purpose, and re-prioritizing their life to focus on more meaningful things. The study acknowledged that positive associations, such as hope, strength, and self-empowerment, were often mixed with more complex feelings related to feeling overwhelmed, isolated, and despairing. In conclusion, Bultas and Pohlman (2014) recommended that instead of viewing positive associations of mothering a child with disabilities as delusional, healthcare practitioners should support and reinforce the caregiver’s variable experiences with caregiving. The study concludes with an observation drawing attention to the probability that caregivers of children with disability will experience stigma in their interactions with caregivers.

In a quantitative, survey-based study over three years, McConnell et al. (2015) investigated the positive impact of parenting a disabled child utilizing the family life survey. Participants included families of disabled children from birth through 18 years of age. The impairments indicated in the demographic analysis were most often ID, ASD, and CP. The survey measured activity limitations, behavior problems, financial hardship, social support, family cohesion, perceived stress, placement propensity, and parent-reported benefit. The study seeks to investigate how parents can report benefits against the odds. In other words, in the face of well-documented hardships, how do parents experience parenting children with disabilities as beneficial? The study hypothesizes more than one possible outcome. The first possibility is that parents utilize benefit-finding as a coping strategy. A secondary hypothesis suggests that parents who report benefits accurately represent their transformative parenting experiences. In response to the survey, parents report high financial hardship and difficulty paying bills. Parents also indicate low levels of social support, with people showing little or no interest in how their family is doing. Measurements of hardship are highly correlated with stress as McConnell et al. (2014) relate higher pressure and lower socio-economic status. However, there is no correlation with hardship when measuring benefits, indicating that parents experience benefits regardless of hardship. The study's conclusion defines benefits not as coping mechanisms for parent caregivers. Instead, the benefit reflects caregiving parents' experiences. The study concludes that when parents explain the benefits of parenting a child with disabilities, they should be believed (McConnell et al., 2014). Further, health care and human service professionals should resist "catastrophizing" disability. Instead, they may seek to highlight parent-reported benefits such as strengthening emotional bonds between family members, personal growth, enriched social relationships, and perspective transformation.

In "We're Tired, Not Sad," Green (2007) addresses mothers' perceptions of burden and benefits, exploring what she describes as the less-explored aspects of social context in a mixed-methods research approach. Green (2007) identifies as the mother of a child with Cerebral Palsy who requires assistance across activities of daily living and, with support, is actively involved in her community and academic life, with a photography career. Through a survey and follow-up interviews, the study sought to answer how mothers perceive and describe the benefits of having a child with a disability. The research participants were 81 mothers of children with disabilities living across three counties on Florida’s west coast. The ages of the children range from preschool to high school ages. The study included mothers of children with Cerebral Palsy, Autism, Down Syndrome, and non-specific developmental delay. In response to five benefit items on the survey, mothers agreed highly, meaning that mothers deeply resonate with the benefits of parenting their children with disability. Mothers expressed love, pride, and appreciation for the intrinsic worth of their children and a deepening appreciation for life. They also agreed that parenting a child with a disability allows them to see past superficialities and through to others’ inherent worth (Green, 2007).

Further, mothers became more comfortable with disability in general, and they generalize their caregiving experiences as character-building exercises that allow them to face other life challenges with strength (Green, 2007). According to the study findings, mothers’ knowledge and experience navigating healthcare systems make them a qualified resource when family and friends experience a health or other emergency because they can ask relevant questions and offer informed advice about accessing care. They also report a deepening awareness of experiences across cultures and social categories and a sense that they are more competent, stronger, and beneficial. To summarize, mothers perceive multiple benefits in having a child with disabilities, and they frame their perceptions of caregiving burden within the context of their socio-ecology and not their emotional distress (Green, 2007).

These studies share similarities in what parents convey about their experiences and contribute to an emerging theme. Challenges can help to highlight how caregivers experience meaning. However, without acknowledging difficulties and barriers, describing the meaning and benefits may unintentionally contribute to unrealistic, unsustainable, and unreachable standards for caregiving work. Viewing the meaning of caregiving again from a critical disability perspective highlights another dilemma central to the discussion on caregivers, disability, and meaning-making. According to these studies on resilience and meaning, mothers who are caregivers live at another intersection of tension. They demonstrate love and gratitude in their roles while simultaneously experiencing frustration and overwhelm through a lack of social and systemic support. Though the vast majority of mothers may initially struggle with absorbing a disability diagnosis and then an unexpected burden of care, they also can and do progress to find meaning and then ultimately perceive the duty of care to be primarily in the challenges they face to secure support (Landsman, 2008). Research recommends that healthcare providers and professionals working with caregivers position themselves supportively when parents express hope, resilience, and strength.

The resilience, strength, and tenacity of caregiving mothers and the tensions found within the identity of an advocate mother are best illustrated by Sousa’s (2011) work on warrior mothers. Warrior mother is a term used to describe mothers who identify or feel pressure to identify as vital advocates for their children and, potentially, an entire disability community. The following discussion explores warrior mothers because the term highlights the transformed identity of mothers for which their lived experiences of meaning-making and resiliency are catalysts.

Warrior Mother Identity

Mothers who find meaning as they become strong advocates for their children within systems that fall short of supporting their needs often experience a shift in their identity (Sousa, 2011). The topic of warrior mothers adds depth to mothers’ experiences of meaning-making and resilience and nods to elements of critical disability, attachment, and intersectional feminism theories, which may contribute to understanding the identity of caregivers.

Utilizing grounded theory methods to render a thematic analysis of thirty-three published memoirs of mothers, Sousa (2011) examines how American standards of intensive parenting impact the identities of mothers of children with intellectual disabilities. She frames this study solidly within a literature review, explaining the history of the warrior-hero mother identity. Sousa (2011) asserts that the warrior-hero mother is a socially constructed identity that places undue pressure on mothers to live up to unrealistic expectations and even includes notions of being responsible for curing their child with intellectual disabilities. Sousa (2011) also explores how literature written by experts within professions informed by the MDM reinforces ideas concerning the causal nature of the relationship between mother and child and contributes to mother blame. Society's message to mothers, framed by psychology, includes notions that bad mothers produce developmentally insufficient children, while good mothers, who work hard to invest fully and secure all necessary resources from experts, produce good children. In one striking example, she cites a psychoanalytic report from the 1970s suggesting that children with autism are the product of "refrigerator mothers" (Bettleheim, as cited by Sousa, 2011). Eventually, the more current narrative of the idealized good mother emerges as one who gives up her identity, career, and personhood to care for her child with a complex disability. Sousa (2011) notes the disparity between images of the good and bad mother and the unrealistic dilemma found in both identities when a diagnosis implies probable outcomes. Within this context of a historical view of mothering and identity, Sousa's (2011) study finds that mothers move through five iterative stages as their identity forms. These stages inform the caregiver's mothering identities and include (a) challenged expectations, (b) diagnosis, (c) quest, (d) battle with social systems, and (e) acceptance of a new conception of the parent-child relationship.

Utilizing a social constructionist approach, Brock (2014) conducted 20 in-depth interviews with Australian mothers of children with DD to explore mothering identity. The mothers were identified across the socio-economic spectrum and from rural, suburban, and urban locations. All identified as White, apart from one participant who identified as Asian. Like Sousa (2011), Brock (2014) posits the study with society's ideal of intensive parenting and good mothering. She finds that mothers fall into three distinct categories: mothers for whom their identities depend on their caregiving role, mothers whose identities are not reliant on their caregiving role, and mothers who acknowledge the complexity and fall between the two categories. According to her participants, mothers who identify more clearly with the warrior mother role express a loss of identity and then embrace a new identity. Mothers who maintained an identity other than a caregiver shared their experiences of maintaining a connection with other aspects of themselves, such as their career, private life, religious faith, and friendships. Some mothers who acknowledged complexity were found to be amid significant life adjustments, such as a transition from a primary caregiving role back into a career. Participants in the latter categories indicated that having identities outside of 'mother' provided a sense of well-being, respite, and the opportunity to separate themselves from their caregiving roles.

Brock (2014) expounds on the concept of the warrior mother and identifies five expectations for the "good mother of a child with a disability" (p. 20). These expectations are (a) for mothers to be primary caregivers for the rest of their lives, (b) to have qualities that allow them to embody their role as caregivers indefinitely, (c) to stay home and forgo paid employment, (d) to embody selflessly the skills required to nurture their children, and (e) to maintain a facade of normalcy as they fulfill these expectations. Further, she explores the unique identities that the participants hold in response to the expectations of society's good and warrior mothers.

Sousa (2011) and Brock (2014) acknowledge the profound impact of developmental disability on the mother's identity and the difficulty of the challenges she must face to navigate and embrace her sense of well-being and self. While these studies are pertinent to understanding society's expectations for caregiving mothers, the pressure they face in caregiving, and the impacts of all the above on their identity, there is still a dearth of literature centering the voices of mothers with marginalized identities. Researchers acknowledge that while there is much more to understand about caregivers' experiences in general, what we do know about caregivers of children with DD has been based on data from participants primarily who identify within the majority culture and the traditional nuclear family. Despite an emerging literature on mothers with marginalized identities, scholars and practitioners still know very little about mothers of children with DD who may identify as BIPOC, LGBTQ, single, disabled, immigrant, with low socioeconomic status, or another marginalized identity (Baker & Burton, 2018; Foley-Nicpon & Lee, 2012). Reviewing the extant literature on mothers with marginalized identities contributes to the central aim of this study, which is to provide meaningful insight into what it means to raise a child with DD within a society that stigmatizes disability and oppresses people with marginalized identities.

Society's Marginalization of Maternal Caregivers of DD

Mothers of children with DD experience marginalization within society, the disability community, and disability studies. Some scholars attribute the societal marginalization of mothers of children with DD to courtesy stigma, which occurs in response to the proximity of mothers to their children with disabilities (Ryan & Runswick-Cole, 2008). Additionally, scholars acknowledge that caregiving mothers with diverse identities are marginalized within research, as much of the focus on caregivers centers on the cultural majority and is overly represented by White, middle to upper-class, heteronormative women who are the mothers in a traditional nuclear family (Stober & Franzese, 2018). Historically, mothers have described the difficulty of accessing all forms of support, and some of this difficulty can be viewed as an outcome of stigma (Abdul-Chani et al., 2021; Li et al., 2019; Tikkanen et al., 2019). For example, mothers endure blame from society for having and raising disabled children; conversely, they have been blamed by disability communities for perpetuating disability stigma and are perceived as seeking to fix or integrate the child's disability or disability identity instead of accepting it (Landsman, 2008; Runswick-Cole & Ryan, 2019; Ryan & Runswick-Cole, 2008). Within disability studies, the complexity of mothers' identities as non-disabled people occupying disability space has subjected them to criticism from the disability community (Brock, 2014; Ryan & Runswick-Cole, 2008). Conversely, mothers with disabilities experience stigma, which they counter with specific strategies, contributing further to hidden work and unique challenges that compound parenting tasks (Farber, 2000; Frederick, 2017) There is a consensus in the literature on caregivers that mothers experience stress that contributes negatively to quality of life outcomes across domains (Fairthorne et al., 2014; Hassanein et al., 2021; Malhotra et al., 2012).

More recently, scholars' focus on caregivers has shifted to highlighting mothers' experiences at an intersection of identities, as marginalized mothers have been underrepresented in the literature (Maye et al., 2021; Onaiwu, 2020). They are also women, and they have been marginalized in a partriarchal society (Hunnicut, 2009). As researchers seek to highlight diverse experiences within the literature, discourse about professional cultural competence in practice concerning caregivers' experiences is emerging. A central aim of this study is to highlight the lived experiences of mothers of children with DD whose identities as caregivers intersect with identities that have been marginalized in the literature and American culture. This study is best contextualized by highlighting existing research on mothers at an intersection of identities. For this section, I will alternately refer to maternal caregivers of children with DD or mothers of children with DD simply as “mothers.”

Mothers and Marginalization

Stober and Franzese (2018) explored the marginalization of the family members of children with DD. At the time of this study, the authors noted a paucity of existing research on intersectional identities related to race, class, and sexuality for mothers of children with DD. The study included 21 total participants from the U.S. The majority identified as White, and smaller subset of mothers identified themselves with a marginalized identity. Four mothers identified as White and LGBTQ. One mother identified as Black and married. One mother identified as Black and single. More specifically, the subset participants identified as Black, trans, lesbian, and bisexual.

Within the subset of participants, mothers described how aspects of their identities compounded parenting challenges in contrast to singular experiences of discrimination (Stober & Franzese, 2018). Mothers experienced marginalization based on their relationship with their children, and researchers in the study identified this phenomenon as courtesy stigma. Participants correlated feelings of stigma with increased feelings of burden, observing that the caregiving burden can be exacerbated by the visibility of a child’s disability: “The more visible the disability, the more likely a parent and their child will experience discrimination” (Stober & Franzese, 2018, p. 74). Both the researchers and the participants in the study emphasize meaning and resiliency over the caregiving burden, again pointing to systemic issues and accessibility as the caregivers’ primary concern.

In more current research, scholars highlight the disparity within disability research on communities of color and are beginning to explore how intersectional frameworks might ameliorate deficits in knowledge. In a powerful editorial addressing the research community about the lack of representation in research, Onaiuw (2020), who identifies herself at an intersection of several marginalized identities, including a Black woman, an autistic adult, the mother of autistic children, and an advocate, argues that under-representation and ongoing disparity in research on people of color in the autistic community has contributed to violence. She highlights the deaths of Eyad Hallaq of Jerusalem and Elijah McCain of Colorado, young ethnic minority individuals, in recent years. Both displayed autistic traits and were killed by police violence. She further highlights the lack of knowledge about diagnostic access, outcomes, educational, psychosocial, economic, and other potential gaps for BIPOC autistic communities. She asks researchers to end disparity within the autism community by “doing what is right, not what is easy” (Onaiwu, 2020, p. 271). Her call to action is for clinicians, researchers, and scholars to (a) continuously increase knowledge on matters relevant to autism and race by engaging in activism and discourse, (b) plant seeds of change by creating inclusive practices and aligning with minority-serving institutions, (c) increase the number of BIPOC researchers and providers through mentorship, and (d) utilize privilege to increase disability representation.

Maye et al. (2021) echoed concerns similar to Onaiuw’s (2020) in a journal article highlighting research’s under-engagement with racially, ethnically, and socioeconomically diverse communities and autism. Logistical, practical, and systemic barriers limit the participation of people of color. These barriers may be related to low socioeconomic status, living in rural communities that are further away from research institutions, limited access to technology, unreliable transportation, language barriers, and inflexible work responsibilities. They recommend engaging underrepresented populations by creating community-academic partnerships that can utilize participatory action research (PAR) and then applying principles of cultural competency within these partnerships.

Mothers and Socio-Economic Status

Sousa's (2015) research on working-class mothers explores the relationship between income and parental involvement of children with DD, debunking the stigma that mothers with lower socio-economic status (SES) and fewer resources are lesser advocates or invest less of themselves in parenting compared to women with higher economic status. Sousa (2015) emphasized that specialists and educators perceive low-income mothers as either under-involved and under-invested in advocacy work or ineffectively strategizing within systems to support and cultivate their child's development. Specialists may view low-income mothers as defaulting to a neutral, less effortful position, passively accepting their child's natural development pattern and related outcomes. Therefore, children with disabilities who are low income are left at an academic and, later, a lifelong disadvantage. This study's findings contrasted with the available literature at the time, which suggested that low-income mothers are not as invested in their children as more-resourced mothers, and therefore, their children suffer adverse outcomes. Instead, participants in Sousa's study were found to be highly involved, primarily in educational decision-making. They demonstrated self-awareness and emotion management when navigating bureaucracies like medical services, social services, or the special education system. By highlighting the experiences of mothers with low SES, Sousa's (2015) study amplifies that working-class mothers can be fully invested in their advocacy efforts.

In a qualitative ethnographic study, Baker and Burton (2018) contributed to the discourse on marginalization by studying economic mobility among 31 mothers of children with DD living in Boston, Chicago, and San Antonio. According to their research, children with disabilities have a high prevalence of being from a household with a single mother. Additionally, children whose families are in poverty have a 40% greater chance of disability when compared to economically advantaged children. This study found that mothers of children with disabilities in poverty aspired to continue or complete their education, advance their careers, and desired to foster better education and economic outcomes for their children. However, they faced significant barriers that manifested as taxing or toxic social support, guilt when neglecting caregiving responsibilities to advance themselves, and dilemmas with securing adequate childcare. In addition, maternal health contributed to challenges with socioeconomic advancement. Mothers were found to work through mental and physical pain, neglect their health needs to care for their children, and make difficult choices between work and caregiving responsibilities. Baker and Burton (2018) urge researchers to invest further in highlighting the experiences of this population.

BIPOC Mothers

Rockhold et al. (2024) utilized a critical disability framework to examine solutions for disparities in the prevention, assessment, and diagnosis of fetal alcohol syndrome disorder (FASD) in racial and ethnic communities. In their review of the literature, they found that BIPOC women are less likely than White women to receive prenatal care. While BIPOC and low SES women are more likely to receive comprehensive health education, they will also experience disparity in healthcare settings that contributes to underutilization of services. Solutions reflect other scholars' conclusions about the benefits of increasing cultural competencies for mental health and prenatal care providers. Unique recommendations included identifying and utilizing cultural liaisons who could address cultural differences between providers and patients and who might assist with interventions. In addition, these researchers recommended that the professional workforce supporting ethnically diverse and low SES communities could benefit by elevating professionals who reflect the demographics of that population.

In a literature review between 2006 and 2010, Magaña, Parish, and Son (2015) analyzed results from the National Survey of Children with Special Health Care Needs. Magaña et al. (2015) explored whether racial and ethnic disparities have changed for children with DD who are ethnic minorities. Significant findings in the study included information gathered about the experiences of Black and Latino parents as caregivers and with their healthcare providers. Magaña et al.'s (2015) study acknowledged how the primary caregiver is most often the mother and used the term "parents" from the National Study interchangeably with caregiver. Black parents were less likely than White parents to report that their healthcare provider listened carefully to them. Latino parents were less likely than White parents to report that their provider offered essential information. Similarly to Black parents, Latino parents were less likely than White parents to report that their healthcare provider spent enough time with their child and was sensitive to family values and customs. The researchers concluded that racial and ethnic disparities persist and recommended the urgent need for policy intervention.

Magaña & Vanegas (2020) extended these findings by addressing the experiences of families of children with DD from various ethnic and immigrant groups, highlighting Asian, Black, and Latino families from information in the National Survey of Children's Health. Black Americans reported experiencing racial prejudice and discrimination due to race and disability status. Korean Americans feared cultural stigma and discrimination and hesitated to accept an autism diagnosis. In the Latino community, discrimination was higher when grandparents were from another country and non-English speaking. For all groups, levels of stigma were positively associated with unmet needs. Providers were less likely to recognize keywords or phrases when parents from these communities shared their concerns. They were also less likely to follow up with parents' concerns and provide a diagnosis evaluation or referrals (Magaña & Vanegas, 2020).

Conversely, Magaña & Vanegas (2020) found that specific disabilities are over-represented in educational settings among Black American, American Indian, and Latino children, resulting in a special education label and decreased opportunities for learning and socialization. Children's English language learning experiences were misrepresented, resulting in under- or over-referrals for special education evaluations. Magaña & Vanegas (2020) suggested that the higher prevalence of IDD within racial and ethnic minority children suggests underlying systemic, cultural, linguistic, and social factors that contribute to robust disparities in access to and utilization of services, identification, and diagnosis in these populations. The authors recommended cultural competence at the provider and educational levels and emphasized the importance of education, training, knowledge, and access to early identification and diagnoses, considering the needs of specific groups at the individual, family, and community levels.

Asian Mothers

A meta-synthesis of data examining Asian immigrants as primary caregivers of children with autism highlighted the different cultural influences of parenting a child with disabilities in Asian vs. Western contexts (Shorey et al., 2019). The researchers found that for Asians residing in their country of origin, parenting stress may be further exacerbated by their more conservative and collectivistic Asian culture, in contrast to parenting as an immigrant in the West. Key findings described how disability tends to be perceived as a social devaluation in Asian culture and can result in the child being isolated or shunned by extended family members. Asian parents, particularly mothers, tend to experience stigmatization within their communities. This is especially true in China, where family members may avoid shame by conformity to norms. In India, a disability may be perceived as an omen, resulting in individuals and their families being marginalized. Public stigma was observed in East Asian, Middle Eastern, and Western-based studies. Affiliate, or internalized stigma, was observed in East Asian and Middle Eastern studies. In the Middle East, gender inequalities hindered mothers' access to services. Poor resources and inadequate education motivated parents to move to bigger cities or other countries to seek help and treatment. Parents who sought treatment in different cities or countries received more nonmedical and biomedical therapy than those who remained. However, language and cultural barriers, racism, discrimination from the public and service providers, lack of community support, difficulty navigating systems, and a loss of cultural identity added greatly to Asian immigrant parents' stress.

In a study specific to the experiences of Korean immigrant mothers navigating special education in the United States, Choe et al. (2023) interviewed mothers and then analyzed their findings through community cultural wealth (CCW) and ecological theory frameworks. Korean mothers were found to embrace their roles as advocates. They were observed using various strategies, including seeking resources, attending training and support groups, connecting within the Korean community for information access, taking legal action, and accessing legal services. Korean mothers in this study drew on navigational capital by initiating information findings about federal and state special education law to become better informed about their rights. They also moved across districts or state lines to gain proximity and access to essential services.

Korean immigrant mothers described several challenges. These included the difficulty of navigating complex and specialized terminology and procedures, language barriers, and generic instead of specific information about services for their child's disabilities. Mothers expressed that intersectional identities and statuses compounded their challenges as racial and ethnic minorities and as first-generation immigrants with limited proficiency in English. Researchers' recommendations in response to the findings included cultural competencies for schools and educators to minimize racism, misogyny, and other forms of discrimination that Korean mothers reported experiencing. Additional recommendations included that school professionals provide individualized and detailed support for families, address language barriers, make processes and procedures explicit, and utilize school psychologists to offer personalized consultation to families and guide them through various complexities and communication barriers (Choe et al., 2023).

Black American Mothers

In a qualitative ethnonursing study, Burkett et al. (2017) examined the influence of respect and faith on parenting African American children with ASD. Themes of respect, faith, discipline, and family dynamics emerged in African American parenting of children with ASD to varying degrees. Parents emphasized teaching respectful ways at home, regardless of family structure. Traditional discipline practices, including verbal cues and stern tones, were valued by parents culturally but were not found to be effective for their children with ASD. Single- and two-parent families showed differences in feelings of isolation and dependence on support. All parents in the research were found to rely on family members for emotional support and coping with stress. However, single parents expressed feelings of isolation and more often relied on community support compared to two-parent families. Two-parent families were found to share responsibility and support within the nuclear family.

In a mixed methods study centering Black American mothers who are caregivers to children with DD, Lee et al. (2022) explored whether having adverse life experiences was more highly associated with having a child with DD across gender and ethnic minorities and highlighted in their study the experiences of Black mothers. The researchers hypothesized that having a child with DD compromises health more for women than men and that Black women experience more adverse effects than other race-gender groups. Key findings included that Black women have a higher caregiving burden and suffer more chronic illnesses than other groups. Black women were described as being “doubly marginalized” as they had higher exposure to discrimination, economic deprivation, and other life adversities. They had the worst health profiles across race-gender groups. However, it was striking to researchers that there were no significant differences found in the mental health of Black caregivers of children with or without children with DD, as parents in both categories were found to have access to fewer resources for caregiving and experienced more adverse childhood experiences (Lee et al., 2022). Black mothers were less likely to evaluate their caregiving role negatively than other racial minority groups. They reported better mental health, well-being, and higher self-esteem, which could be attributed to cultural values reinforcing social support's importance (Lee et al., 2022). Even so, researchers concluded that Black mothers experience a more significant burden, as they are more likely to be situated in multiple marginalized positions, experience considerable adversity, and have access to fewer resources throughout the life course.

In a study examining the disparity in early identification and diagnosis of ASD for African American communities from the parents' perspective, research revealed significant concern about the timing of diagnosis for African American children with ASD (Pearson & Meadan, 2018). On average, European American children received a diagnosis by age 5.5, in comparison to African American children, who were diagnosed on average by 7.9 years old. The disparity was attributed to a phenomenon defined as cultural divergence, which is a disconnect between parents of color and the medical professionals who treat them. Cultural divergence was highlighted as a barrier that contributes to culturally unresponsive care and untimely access to early intervention (Pearson & Meadan, 2018).

Across studies, respect from healthcare providers and the community was emphasized as crucial for parenting the urban African American child with ASD (Burkett et al., 2017; Lee et al., 2022; Pearson & Meadan, 2018). Faith in God influenced family care for children with ASD, leading to increased spiritual growth. Researchers recommended that healthcare practitioners can promote health and well-being by respecting the parenting lifeways and diverse care practices of urban African American parents and that educators and healthcare providers need more training and experience specific to ASD. They also shared parents' difficulties finding competent and trustworthy practitioners who showed them concern.

Native American Mothers

According to Lidell et al. (2021) understanding the historical context of Native American women's roles is crucial for informing social work or counseling practice with Native American communities. Historically, Native American mothers have played vital roles in their families and communities, with current gender roles influenced by historical oppression. Historians suggest that post-colonization led to negative impacts on women in Native American societies, which were traditionally matrilineal or egalitarian (Lidell et al., 2021). Egalitarian social norms were protective against violence, with labor divisions seen as mechanisms of survival rather than oppression. Gender roles were viewed as complementary and flexible, promoting resilience and harmony. Colonizers enforced patriarchal structures through violence, land ownership changes, and forced conversions. Christianity undermined traditional Native American gender roles and spiritual practices and promoted male dominance. Additionally, boarding schools targeted Native American girls to instill Western Christian values, which contributed to generational trauma that exists into the present. Historical oppression and patriarchal norms continue to be risk factors for violence against Native American women.

Liddel et al. (2021) recognized the resilience and power of Native American mothers in the face of intersecting forms of oppression. They emphasized the importance of acknowledging and valuing mother work within a specific socio-historical context. Motherwork was vital for resilience in tribal communities. Native American mothers were found to demonstrate resilience and transcend beyond the impacts of colonialism on their communities. In conclusion, social workers (and by extension, mental health clinicians) were urged to incorporate reproductive justice frameworks in research and practice. The findings informed a family-focused intervention lens to improve physical, mental, and social well-being in tribal communities.

In a qualitative study, Rains et al. (2010) discussed the systemic challenges Native American children face in predominantly White public schools through the narratives of Native American Mothers. Native mothers co-authored the work, a deliberate choice to empower and recognize their voice, allowing each woman to speak for herself, reclaiming Indigenous voice and empowerment. Mothers shared their hopes and dreams for their children and perspectives on what teachers should know about their children and their cultures to foster a more inclusive and supportive educational environment. They also provided specific examples of cultural insensitivity and disrespect in schools. Mothers stressed the need for teachers to engage with

Tribal Communities and learn about their cultures beyond textbooks. Mothers emphasized how engagement with the community can prevent misunderstandings and foster a respectful and inclusive environment for their Native American children. They urge teachers to get to know their Tribal Communities to build bridges and support the success of Native American children in public schools.

According to Kew et al. (2023), in addition to the challenges described previously, Native American communities in rural areas face challenges such as a lack of electricity, running water, health care, and qualified special education teachers. The pandemic disproportionately affected Native American students with disabilities in rural regions due to a lack of technology and face-to-face teaching. Issues raised in the case include Native American education, disability, school leadership challenges, access to the internet and technology, and family and community engagement.

Researchers emphasized culturally responsive leadership, equitable teaching practices, and the impact of COVID-19 on a school community (Kew, 2023; Liddel et al., 2021; Rains et al., 2010). They recommend how critical self-reflection is challenging during crises like the COVID-19 pandemic but necessary for effective leadership. According to Kew et al. (2023), transformative educational leadership involves self-reflection, analyzing schools, and addressing inequities related to race, class, gender, and more. Community values and knowledge are crucial in sustaining the heart of Native American culture and promoting cultural wealth. Finally, the authors emphasize the importance of engaging families from minoritized backgrounds using a Critical Disability lens.

Latin American Mothers

Iljaba (2015) shared significant, culturally relevant context about the Latin American immigrant community in the United States. The Hispanic population is the largest immigrant group in the U.S., representing 17% of the nation's total population. Approximately 70% are from Mexico, with groups from the Dominican Republic and Central America. Hispanics share foundational values that center families, such as “familismo” (family support), “confianza” (trust), and “respeto” (respect), for the nuclear and extended family. Each community's history and culture reflects distinct Indigenous roots, values, and traditions. There is a fusion of Caribbean, African, and Catholic cultural beliefs in Hispanic culture that contribute to traditional healing practices and their beliefs about disabilities.

In research, mothers shared their lived experiences of family separation, economic hardship, barriers to accessing services and education, limited employment opportunities, and a lack of social support (Iljaba, 2015; Magaña et al., 2015; Rios & Burke, 2020). Iljaba (2015) identified culture-bound disorders that are associated with depression, which influences mothers' engagement in their children's education. In this qualtitative study, Latina mothers ascribed their child’s disability to external forces explained by cultural beliefs and had an urgency to protect their children from further harm. They implemented various strategies that supported cultural values, such as engaging cultural healers, traveling home, and creating a calm environment for their child. Hispanic immigrant mothers in this study were less likely to view educational support as the best or primary source of interventions for their children’s disabilities.

Researchers in the study found that Latina mothers in IEP meetings experience high-stress levels before, during, and after meetings, with the lack of special education knowledge contributing to stress levels (Iljaba, 2015). Language barriers were reported as a significant issue in family-professional partnerships (Iljaba, 2015). Latino families were found to face more significant barriers in special education and caregiver health than their White counterparts (Rios & Burke, 2020). Literature identified cultural divergence, resource limitations, stigma, and lack of special education knowledge as significant barriers. Systemic barriers such as limited access to special education knowledge and poor parent-school communication were identified. The researchers identified facilitators, or factors, that contributed to improved support experiences for families. Facilitators for Latino families included understanding special education services, effective parent-school communication, and family support. Facilitators also included parent education on special education rights, culturally responsive resources, and improved communication with school personnel (Iljaba, 2015; Magaña et al., 2015; Rios & Burke, 2020).

The discussion on Latina mothers of children with DD emphasizes the need for more research on the relationship between special education experiences and parent health among Latino families (Iljaba, 2015; Magaña et al., 2015; Rios & Burke, 2020). It highlights that understanding special education services and having strong parent-school communication can improve experiences. Generally, the literature suggests developing peer support interventions to enhance health and well-being among Latino parents of children with IDD. It also emphasizes the importance of identifying barriers and facilitators to improve special education experiences and health outcomes for Latino families. Finally, it calls for targeted interventions and more inclusive research to address the unique challenges faced by this community (Iljaba, 2015; Magaña et al., 2015; Rios & Burke, 2020).

Mothers with Disabilities

Though it is even less explored in comparison to research on mothers as caregivers, research also addresses the personal experiences and perceptions of mothers with disabilities themselves engaged in the occupation of mothering, as well as the impact of their interpersonal environment on their mothering experience. Utilizing a grounded theory approach, Farber (2000) examined the experiences of mothers with disabilities or chronic illnesses in a qualitative study of eight mothers. In their study, two main themes emerged: participants' self-perception as mothers and their perceptions of their interpersonal environment. Drawing on her findings, Farber (2000) viewed mothers with disabilities as part of an adapting family system. She discussed the challenges and adaptations involved in parenting with a disability within the family system. She observed how mothers with disabilities consciously chose to have children despite health risks or uncertain disease courses, noting how the quest for maternal perfection can be particularly poignant for mothers with disabilities. Farber (2000) suggested that sociocultural factors, such as the women's movement and disability rights movement, influenced the experience of motherhood for parents with disabilities. She suggested that mothers with disabilities have both strengths and vulnerabilities, facing unique challenges in parenting. For example, the onset, timing, and progression of the parent's disability must be considered in family adaptation. Community resources may not be as accessible to families with a disabled parent, impacting their ability to cope with additional challenges. She advocated for more research and for the inclusion of the parent perspective in understanding mothering with a disability.

Fredrick’s (2017) qualitative study explored the everyday resistance of 42 mothers with disabilities against stigma and cultural beliefs surrounding motherhood and disability in the United States and Canada. Fedrick’s study revealed several strategies employed by disabled mothers to resist stigma, including visibility politics, respectability politics, and disengagement. Visibility politics involved assuming a more significant presence in the public to counteract stigma. Respectability politics involved presenting a carefully cultivated public image to defy negative stereotypes, with about half of the mothers interviewed discussing performing a highly disciplined version of motherhood. Disengagement offered a vehicle for resistance during moments of serious discrimination. Ultimately, the research revealed how hidden labor is performed by these mothers to negotiate barriers and navigate exclusionary institutional and community norms. Mothers were found to employ various strategies to resist stigma, each demanding different forms of hidden labor and negotiation of social contexts. In conclusion, Fredrick (2017) acknowledged the study over-represented mothers with some class privilege and politicized understanding of disability. She recommended future research on mothers with disabilities explore how intersecting identities and group identification impact everyday resistance strategies.

Single Mothers

Research on single mothers and children with DD generally defined single parents as individuals bringing up a child or children without a partner due to being separated, divorced, or widowed (Kim et al., 2023). Research addresses the additional burdens for single parents as challenges associated with the financial cost of care or detriments to their careers. In addition, much of the literature compares the experiences of single mothers to those of partnered or married mothers with DD or typically developing children (Abdul-Chani et al., 2021; Baker & Burton, 2018; Kim et al., 2023; Lee et al., 2004; Parish et al., 2012). As one example, researchers at The Institute for Women’s Policy Research inquired about the challenges faced by single mothers of children with autism spectrum disorders (ASD) compared to married mothers with ASD (Lee et al., 2004). Their study provided a review of literature that highlighted the importance of respite care in reducing stress and the relationship between respite care, daily uplifts, and depression in mothers of children with ASD. Mothers of children with ASD were found to have significantly higher levels of stress compared to mothers of typically developing children, with child-related stress factors falling in the 99th percentile for mothers of children with ASD. Caregiver burden and maternal depression were highlighted as common challenges faced by mothers of children with ASD, with over one-third of mothers at high risk for clinical depression. Respite care, which provides temporary relief to primary caregivers, was shown to reduce stress levels in parents of children with disabilities, although it was difficult to access.

Studies on mothers and socio-economic status (SES) revealed high rates of income and asset poverty among single mothers of children with DD (Parish et al., 2012). Single parents reported challenges such as sole parental responsibilities, social isolation, and difficulty accessing services. Single parents also faced barriers in accessing government support services, leading to reliance on the welfare system. They reported lower scores for family relationships regarding familial support and conflict than two-parent families (Kim et al., 2023). The exceptionally high poverty rates indicated a lack of resources to manage financial setbacks. Researchers concluded that single mothers of children with DD are financially worse off than both married mothers and single mothers without children with disabilities. Additionally, financial well-being for a significant portion of all three groups–single mothers of typically developing children, married mothers of children with DD, and single mothers of children with DD–was inadequate. Researchers in multiple studies recommended promoting maternal employment, providing accessible child care and respite, and raising asset limits for SSI recipients. In addition, they suggested that policymakers should consider targeted measures to improve single mothers' financial well-being (Abdul-Chani et al., 2021; Baker & Burton, 2018; Kim et al., 2023; Lee et al., 2004; Parish et al., 2012).

LGBTQ+ Mothers

One study focused on the experiences of lesbian, gay, transgender, and queer (LGBTQ) parents of children with disabilities in the U.S. from across nine states (Coulter-Thompson et al., 2023). Utilizing a survey in combination with semi-structured interviews, Coulter-Thompson et al. (2023) explored healthcare bias and discrimination from the perspective of LGBTQ parents. Most parents in this study identified as cisgender women, lesbian, White, English-speaking, and professionals with a graduate degree. One participant identified as a gay male, and one as a transgender man. Parents reported times when their status as parents was challenged, with professionals asking for the identity of the "real" parent. A parent in a rural, Southern area described experiencing anti-LGBTQ bias, with the physician sharing their own belief that gay couples should not raise children. Other parents shared their ambivalence about disclosing their LGBTQ identity for fear of discrimination. Parents felt that their LGBTQ identities impacted the level of care they received, with evaluators postponing, avoiding, or dismissing a diagnosis needed to secure services or specialist care. Parents offered feedback to improve services in healthcare settings that included bolstering social-emotional support, increasing training and education on family diversity, and improving forms and materials to include LGBTQ and diverse family constellations. Coulter-Thompson et al. (2023) noted limits within the study's conclusion, including the small sample size, the impact of caregiving in research participation, and the lack of intersex, asexual, and agender representation among participants. The study acknowledged that it did not seek to highlight an intersection of marginalized identities since the narratives highlighted were mainly White, highly educated professionals who identified as members of the LGBTQ community.

In a report from the National Center on Caregiving, Coon (2003) highlights the many barriers that the LGBTQ community faces in caregiving roles. With the heated debates surrounding sexual orientation and the specific needs of LGBT caregivers, Coon (2003) asserts that LGBT caregivers face unique challenges due to discrimination and social isolation. He also highlights the importance of understanding how individuals self-identify and the impact of heterosexism on service provision, further explaining how self-disclosure is complex, as it can lead to experiences of discrimination. Cultural attitudes about LGBTQ+ identities can lead to complexity for individuals who hold any intersection of ethnic or racial identities. Additionally, LGBTQ+ caregivers, especially those of color, may desire and benefit from religion and spirituality, but many such organizations are intolerant of LGBTQ individuals. Legal and financial challenges are common for LGBTQ caregivers who may be excluded from partner benefits and experience discrimination. Coon identifies a multitude of barriers impacting LGBTQ caregivers, including systemic and community barriers such as hatred, discrimination and intolerance, internalized homophobia, and a lack of inclusive policies.

Coon (2003) recommended several strategies to overcome barriers at differing systemic levels. At the individual and interpersonal levels, he encouraged providers to explore caregivers' sociocultural contexts, building on their strengths and respecting their levels of outness. At the organizational/systems level, he advocated for challenging discriminatory practices, providing inclusive materials, and training staff on LGBTQ issues. He recommended using media campaigns to raise awareness at community and policy levels, revising discriminatory policies, and advocating for legal protections. He suggested that professionals provide informational and referral sources for LGBT organizations and directories, as well as examples of support groups and workshops tailored to LGBT caregivers, including online support groups and collaborations with mainstream organizations. Finally, Coon (2003) emphasized the importance of providing ongoing education and training for service providers to enhance their competence in serving LGBT families.

Marginalized Mothers Summary

While the research on mothers at the intersection of marginalized identities continues to emerge, scholars also highlight the disparity of literature on minority caregivers compared to literature on the majority populations in the U.S. Contextually, this reinforces scholars' conclusions that further research is needed (Baker & Burton, 2016; Sousa, 2015; Stober & Franzese, 2018). In my view, this also highlights the cyclical forms of oppression that begin within research, which typically focuses narrowly on the experiences of nuclear, middle to upper-class families of children with disabilities. A lack of attention to marginalized identities perpetuates stigma and harm for caregivers and children within systems that remain uninformed about how gender, race, class, and identity impact their experience, echoing Teo's (2010) work on epistemological violence. For example, children with developmental disabilities are at a higher risk for abuse and violence than others (Flynn, 2021). Disability scholars have called for further application of intersectional analysis within the study of disability issues. Scholars continue to echo how broadening the research will contribute to the disparity gap, especially for families of color and within studies focused on the mothers of children with DD (Ben-Moshe et al., 2014).

Given the current understanding of the caregiving experience and the lack of focus on caregivers through an intersectional lens, research is now beginning to describe caregivers with marginalized identities and their experiences. Throughout this literature, I have highlighted the work of scholars who have explored marginalization in their studies of caregivers. These categories of research have highlighted the disparities of access to services and the discrimination evident within narratives from low socio-economic, ethnic and racial minority, and LGBTQ communities. While research about mothers predominates in the literature on caregiving for children with DD, understanding more about the experiences of other family members would be a helpful contribution to empirical knowledge and social support. In the next section, I briefly explore this literature, beginning with fathers as caregivers.

Family Members and Community as Support Systems

The idea of garnering support from family members, friends, or community connections outside the immediate family system caregiving for a child with DD is not new. Sandler's (1998) research on grandparents noted that scholars have called for the mobilization of informal support through a family-centered educational model (Dunst, Trivette & Deal, 1994, as cited by Sandler, 1998). Perhaps the notion that Sandler's work is now decades old is self-evident. Scholars have since continued to participate iteratively in conversations describing and documenting stress and well-being for caregivers (Weeks et al., 2008; Hartley et al., 2012; Smith & Grzywacz, 2014). An essential theme in the literature is that there are agreements within scholarly work about primary caregivers of children with DD: many are mothers who will statistically suffer detrimental impacts on their well-being, are already identified as marginalized, and are vulnerable to poverty or will become so over time. To explore mothers' experiences with informal support, this portion of the literature review briefly discusses the research on extended support systems of caregiving mothers, including fathers, grandparents, friends, and community social support.

Fathers

In a review of the literature on fathers of children with DD, Blacher et al. (2019) explored father involvement while acknowledging the emphasis in the research on mothers, generally the primary caregiver. In addition, there is insufficient information on fathers of children with DD. Blacher et al. (2019) note a lack of research on the impact of fathers in adolescence and across the lifespan. The authors further state that there “appears to be no overarching theoretical framework to capture the work done in the context of fathering and disability” (Blacher et al., 2019, p. 395). What is known about fathers within research indicates that they are significantly impacted by their parenting experiences with their children with disabilities. When fathers are present, they play an important role that affects the support structure surrounding children with disabilities. As with typically developing children, the absence of a father or father figure is also substantial, with adverse outcomes for the caregiving mother and child with disabilities.

In response to the gap in the literature on fathers, Blacher et al. (2019) utilized Bronfenbrenner’s (1994) ecology model as a framework for their literature review. They emphasize the gaps in the literature on this topic and the potential for future scholars to develop other frameworks for fathers’ impact on their children with DD. Through the lens of Bronfenbrenner’s (1994) ecological framework, they emphasize themes that are emerging in the literature, which include the negative impact of the “intrusive father” (Blacher et al., 2019, p. 396) on a child’s development, the impacts of career stress on the family system, and the impact of father involvement on a mother’s well-being. According to Blacher et al. (2019), the research available on fathers is benign, meaning there is a lack of in-depth analysis on this topic. For example, scholars found no significant improvement in fathers' parenting competence over time within a longitudinal study that sought to determine the influence of early intervention support on fathers’ parenting competence with children ages 3 to 15 (Crossman et al., 2018). Perhaps more significantly, scholars identified predictors of paternal parenting competence for fathers as perceived helpfulness of home visits, positive support, and the strength of family relationships.

A study on fathers of children with Sturge-Weber Syndrome (SWS) explored their experiences with courtesy stigma and social support (Tikkanen et al., 2019). For this study, researchers explain that fathers experience courtesy stigma related to SWS, which is characterized by a disfiguring purple facial birthmark, neurological complications, and internal abnormalities. SWS can include varying degrees of DD, ranging from intellectual disability to spectrum disorders. The study described fathers' experiences of courtesy stigma, perceptions of and responses to their children's experiences of discrimination, isolation, and criticism. To further frame the study, the authors discussed the relationship between courtesy stigma and the loss of power within interpersonal relationships and social support, which they view as undermining society's framework for traditional masculinity and father identity. In the literature, fathers described limited resources notwithstanding a desire for help about what is "good support" compared to what is available for mothers.

The study by Tikkanen et al. (2019) consists of interviews with 24 White, heterosexual, married professionals mainly from the U.S. Six participants were from other countries, including Italy, Holland, New Zealand, Australia, Canada, and Montenegro. Participants were recruited through snowball sampling, and interviews took place in person at a conference for SWS, during a focus group at the same meeting, through individual in-person interviews, and over consultations by phone. Data were analyzed using an interpretive thematic analysis. Fathers were found to use a buffering strategy of information to negate and defend against courtesy stigma, which manifested as hurtful and thoughtless comments from friends, family, and professionals regarding the visible parts of their child's disability. Fathers also described pre-emptively strategizing against stigma by sharing information to avoid adverse reactions, educating the public, and attempting to prepare employers for extenuating circumstances related to caregiving needs.

Fathers reported their efforts to educate the public by involving themselves in community events to create awareness and decrease the chances of a hurtful comment about or in front of their child (Tikkanen et al., 2019). Fathers were also involved in preparatory work, teaching children how to self-advocate. They reported accomplishing this by preparing their children for adverse reactions and taking them out in public to teach them coping skills. Finally, fathers utilized a strategy described by researchers as support blocking, which is characterized by declining social support to avoid or separate themselves and their children from courtesy stigma (Tikkanen et al., 2019). In these cases, fathers opted to handle things alone or within the nuclear family as a protective strategy to buffer against stigma. The study also described fathers utilizing support blocking in a threefold effort to (a) minimize perceptions of weakness and vulnerability, (b) avoid disingenuous offers of help from friends and family members, and (c) minimize the expectations of participating in social norms or social exchanges, which would be difficult for the family (Tikkanen et al., 2019). In keeping with what is known about mothers' identity within the literature, fathers' reported experiences offer a framework for understanding their identity as well as their experiences of caregiver burden. By identifying the fathers' coping strategies in response to courtesy sigma, the study also contributes to a framework for the construction and conceptualization of the father's masculine identity as it is significantly shaped by parenting a child with disabilities (Tikkanen et al., 2019).

Potter (2016) contributed to the current trend of disability research through the lens of resiliency and meaning by examining fathers' positive experiences parenting children with autism. The survey-based study recruited 306 fathers, primarily through online recruitment with contacts from autism organizations in the U.K. While an effort was made to recruit Black and ethnically diverse fathers, 95% of fathers who participated in the survey were White. They were also biological parents, aged 40 or older, married to the child's mother, and about 60% were employed.

In contrast to what Potter (2016) described as tragedy-model narratives that emphasize negative experiences, fathers more often framed their parenting experiences as positive and meaningful. They described accepting their children for who they are, identifying them first in connection with their personality and relationship, not the diagnoses. Fathers described the personal strengths and characteristics of the child with affection, sharing traits that included the child's sense of humor, perceptiveness, caring, honesty, and sensitivity. A few fathers commented on their children's intellectual skills, describing them as independent and abstract thinkers, witty, and charming. Fathers also emphasized the nature of their relationships with their children as loving, unconditional, and affectionate. They talked about the personal growth they experienced in parenting, which included becoming a better person, developing tolerance, and taking an educational journey. Fathers who spoke negatively about their parenting experiences also described a lack of social and systemic support and dealing with challenging behaviors, which Potter (2016) described as necessary for contextualizing their experiences. Potter (2016) discusses how further qualitative studies might shift the 70-year deficit-based narrative that comes with an autism diagnosis. He also stated that qualitative studies may offer a better understanding of the nuances of a father's parenting experiences and expand upon our understanding of children's capabilities.

Much of the research cited in this chapter has addressed parents' well-being. In a previous section, I shared how fathers fared better in their well-being than mothers and how fathers' well-being was detrimentally impacted compared to parents of typically developing children. Further, a study on psychological well-being of fathers of children with three different types of DD demonstrated that fathers of adolescents with Autism Spectrum Disorder were found to have elevated scores of depression and pessimism compared to those fathering other categories of DD (Hartley et al., 2012). The study predicted these elevated scores were linked to behavior severity (Hartley et al., 2012).

Researchers call for more attention to fathers of children with DD. Potter (2016) discussed the lack of focus on fathers and the absence of research on fathers with marginalized identities, how cultural perspectives influence the fathering role, and how socioeconomic status and education affect fathers' parenting. Like many other research areas on children with DD and mothers with marginalized identities, there is a strong call for researchers to respond to the gap in research and further develop what is known about fathers concerning their children with DD. I now transition to a brief overview of siblings who are part of the nuclear family. While siblings are not the focus of my research, they have a significant role and relationship with the child with disabilities as well as their parents and are crucially important, mainly because disability shapes their family role. Siblings also participate in, and are impacted by, the level and quality of social support surrounding the child with disabilities and the family unit.

Siblings

Siblings are not identified directly as caregivers in research. However, they often contribute to lifting the burden of caregiving work. They are directly impacted by the relationship with their sibling, their role within the family unit, and the parent's experiences of social support. Siblings are significant within the family constellation, and their experiences with disability shift the landscape of their identity as deeply and profoundly as any other immediate family member.

Giallo et al. (2003) studied the relationship between family and sibling functioning in families raising a child with a disability from the parental perspective, examining a crucial gap in the literature on the relationship between siblings and parent caregivers. A sample of 78 parents and school-aged children from Lake City, Utah, participated, half of whom were not raising a child with disabilities. Many of the families raising a child with disabilities had children with multiple disabilities, ranging from speech disorders to intellectual disability, Down’s syndrome, Autism/ASD, and Cerebral Palsy. Siblings' ages ranged in ages from 4 to 11 years. There were no significant differences between the family groups in the number of children or the parent demographics.

Giallo et al’s (2003) quantitative study measured parents' perception of siblings' social skills and problem behaviors by utilizing the Porter-O’Leary Scale and Bloom’s Family Functioning Measure. Teachers of school-aged siblings participated using a modified version of the Gresham and Elliot Social Skills rating system. In conjunction with a family resiliency model, the study measured the relationship between (a) meaning, (b) problem-solving and coping, (c) types and patterns of family functioning, and (d) adjustment and adaptation to stress. No family functioning correlations were observed between families with and without children with disabilities. However, sibling groups were correlated. Parents and teachers rated siblings of children with disabilities as having more self-control and cooperative/assertive behavior. Female siblings had more significant associations than male siblings. Both male and female sibling groups had greater correlations than children who did not have siblings with disabilities. Socioeconomic factors were associated with siblings’ experiences of externalizing and internalizing behaviors, perhaps implying the importance of resources and the connection to sibling well-being. The study further associated increased family cohesion and low scores in marital conflict with siblings' cooperative and assertive behaviors. In a discussion of findings, the study highlighted those older female siblings, who may take on greater responsibility in caregiving work, report difficulties adjusting to a younger child with disabilities, and may score differently than other siblings (Giallo et al., 2003).

Brigham Young University scholars Roper et al. (2014) designed a quantitative study measuring caregiver burden and sibling relationships in families with and without disabilities. One hundred seventy-two participants living in Utah were recruited, and data were collected from mothers and fathers through written questionnaires. The study observed significant differences in scores depending on the type of disability. Mothers of children with Down Syndrome and multiple disabilities reported more positive relationships with siblings than mothers of typically developing children (siblings of children without disabilities). However, mothers and fathers reported poorer relationships between siblings when challenging behaviors were present and the caregiver burden was high. The study asserted that problematic behaviors associated with a disability may require more attention from parents, resulting in less care and attention for typically developing siblings. This observation is important when considering the topic of social support. According to the data, siblings are not immune to the challenges of severe behaviors associated with a diagnosis. Social support could help them to navigate and buffer their experiences.

In a meta-analysis of the literature on siblings of children with disabilities, Dyke et al. (2009) offer a holistic view of their experiences through the lens of challenges and opportunities. The study found that contemporary perspectives suggest that overall family functioning is a more critical factor for siblings than disability. Secondary to family functioning, they affirm findings that financial hardship is a significant factor in the experience of siblings. Siblings have been found to benefit from positive personality characteristics, which emerge from increased tolerance for differences, caring and compassionate natures, maturity, and deep gratitude for their abilities and health. Conversely, siblings describe feeling embarrassed or ostracized by peer groups, consistent with findings related to courtesy stigma. Siblings also reported feelings of responsibility for the caregiver burden, but parents said these feelings were diffused in larger families, where the caregiving burden may be distributed. On an optimistic note, siblings of children with disabilities tended to seek careers in helping professions, such as education and medicine, as adults.

Within our society, the sibling, father, and mother are viewed as the most immediate support system for a child with a developmental disability. For better or for worse, these family members bear the weight of caregiving responsibility and any potential outcomes associated with a diagnosis. Although there are significant variations in their perceived experiences and roles within the family system, the literature reveals how critical these actors are in the life of a child with disabilities (Beneviedes et al., 2019; RAISE 2021). Mothers, fathers, and siblings find meaning in their roles and simultaneously experience courtesy stigma (Abdul-Chani, 2021; Li et al., 2019; Tikkanen et al., 2019). Adjustment, stress, and quality of life are connected to challenging behaviors associated with a DD diagnosis (Hassanien et al., 2021). Financial hardship compounds the burden of care (Genereaux et al., 2016; Maye et al., 2021). The breadth and quality of social support are essential to the well-being of the family of children with DD, both individually and collectively (Boyd, 2016; Findler et al., 2016; Ha et al., 2011; Hassanein et al., 2021; McIntyre et al., 2018; Seymour et al., 2019; Tikkanen et al., 2019). To better set the stage for exploring extended family members and friends as social support, the following sections explore and deepen the current understanding in the literature on the role of grandparents, friends, and community.

Grandparents

In some families, grandparents play a crucial role in abating the demands of caregiving and their impacts on the family system of the child with DD (Yang et al., 2018). Scholars have called for professionals to create interventions that include grandparents as support (Katz & Kessel, 2002). At the time of his literature review, Sandler (1998) noted the lack of information on grandparents as a source of support. He also pointed out that the research indicated that grandparents contributed to adjustment difficulty and stress more than providing supportive experiences. Grandparents' responses to diagnosis can mirror parents' experiences with shock, grief, denial, and anger that can culminate in a deterioration of the intergenerational relationship. Sandler also noted research that indicated the rarity of grandparents who can accept, love, and bond with their grandchild with disabilities. Paternal grandparents were suggested as having a challenging time adjusting and accepting the child's disabilities. Overall, grandparents who denied or minimized a diagnosis, harbored mixed feelings, were overbearing with their opinions, or were inflexible in their attitudes and approaches contributed significantly to distress for the parents of children with DD.

In Sandler's (1998) findings, supportive grandparents were identified as a rarity. Supportive grandparents were characterized as providing forms of support such as "babysitting (essential for respite), assistance with finances, gifts, and help with daily routines" (Sandler, 1998, p. 352). Parents also valued "expressive support" (Sandler, 1998, p. 351) in the form of hope for the child's future and gratitude for the child's existence, especially within the family.

The study explored the literature for why grandparents fall on one side or the other of the spectrum of support, including generational and cultural expectations of grandparents for their adult children to parent independently and to have the privileges of grandparenting without the responsibility of parenting.

Scholars have reiterated the importance of gathering more information on the grandparent dynamic and continue contributing to the discussion on grandparenting supportive roles for their grandchildren with DD (Trute et al., 2008; Yang et al., 2018). Yang et al. (2018) approached this work by understanding the roles of grandparents in the lives of grandchildren with DD from the parents' and grandparents' perspectives. They noted that non-custodial grandparents might have limited access to assessments and diagnosis information unless shared with them directly, so grandparents may have little information concerning the diagnosis or potential outcomes of a developmental disability. Within Yang et al.'s (2018) interpretive, qualitative study, grandparents shared their observation of the intensity of caregiving, their perceived roles in financial support, participation in the provision of care for the parents, and their identities as maintainers and adaptors of tradition modified according to their grandchild's needs.

Grandparents who intentionally navigated away from giving advice and instead asked questions to understand caregivers' unique or unfamiliar parenting approaches reported learning to navigate differences in parenting opinions more easily (Yang et al., 2018). Grandparents who observed boundaries in their supportive roles were found to differentiate themselves from the position of primary caregivers by maintaining support for the family system over any individual in the caregiving family. They also kept physical and emotional space when needed. One of the grandparents in the study communicated that some distance was necessary to maintain their sense of well-being as they aged. As grandchildren with DD aged into adolescent or adult services, grandparents described eventually needing to mend fences with adult siblings who felt neglected over time and attention spent with the caregiving family. This dynamic indicates how developmental disability impacts extended family members who may not be directly connected to the caregiving work. A significant observation of the study was the multigenerational impact on families for the cost of care.

In response to these and other significant findings, researchers recommended amending policies and services to consider the needs of families supporting children with severe conditions. Recommendations included policies supporting intergenerational familial involvement in respite care, financial assistance, and support for daily living (Yang et al., 2018). Researchers noted that a significant limitation of this study was the inclusion of primarily White, upper-middle-class families who lived near each other. In concluding the investigation, this team called for future research to include diversity from underrepresented populations and "geographically distant" families (Yang et al., 2018, p. 372). The topic of social support through friends and community is vital when considering families who live far away from extended family support or grandparents who live far away. In cases where an extended family is unavailable nearby to offer support, caregivers would benefit from informal support from friends and the community. However, even when a family is proximal and able to support caregivers and their children with DD, research supports the connection with caregiver well-being, family well-being, and strong social support.

Community

For caregiving parents, scholars have noted the importance of social support on quality of life (Hassanein et al., 2021), the positive impact on coping, and the reduction of stress and depression (McIntyre & Brown, 2018). While scholars have explored the broader research topic of social support and informal support as it relates to caregiving families, it is more challenging to uncover specific data on the role and function of friendship in the caregiving dynamic. McIntyre and Brown (2018) note that there is an absence of research on family utilization of informal and formal support. The topic of friendship was typically included in the study as a brief mention, often in a quote from a parent or the subsection of a broader study on social support. Studies then transition and emphasize social support more deeply related to stress and burden on the family dynamic (Hassanein et al., 2021; McIntyre & Brown, 2018; Weeks et al., 2008).

Some studies research the meaning or context of friendships for children with DD and their siblings as the primary topic (Dyson, 1999; Webster & Carter, 2007). While the information on peer relationships for children with DD and their siblings is important, there is significance in the paucity of information concerning the peer friendships of caregiving parents. In the absence of centering peer friendships of caregiving parents as a research topic, contributors could be missing elements of the caregiving experience that would indicate additional predictors for well-being. For example, in a recent study, women in mid-life who were not necessarily caregivers had greater overall life satisfaction with a more significant number of friends (Degges-White & Kepic, 2020). Does this observation generalize to caregiving mothers of children with DD, most of whom are also in the range of midlife?

For parents of children with autism spectrum disorder, social support is highly correlated with life satisfaction (Landon et al., 2017). However, parents were found to have significant impairments in a quality of life study surveying physical well-being, psychological well-being, social relationships, and environment (Malhotra et al., 2012). Particularly predominant were social relationships (Malhotra et al., 2012). Mothers reported masking or putting forward a more positive, well-adapted image to cover their authentic, more complex experiences and feelings to convince friends they are coping well (Nicholas et al., 2016). They also struggle with feelings of isolation among friends with typically developing children and are then overwhelmed with the work involved with a commitment to support groups (Safe et al., 2012).

Additionally, parents described avoiding social situations to minimize experiences of shame or stigma related to their child's behaviors in family and community settings (Malhotra et al., 2012). They also reported using specific coping strategies, with the types of coping indicating persistent challenges in social environments with friends and family members (Jones & Passey, 2004). Coping strategies included providing explanations of their child's disability and "avoiding certain places, not taking him with me, doing things yourself, acceptance, perseverance, expecting the worst, and legal action" (Jones & Passey, 2004, p. 39). From an inter-familial perspective, relational turbulence, connected to increased conflict over caregiving burdens, interferes with married partners' acceptance of social support (Brisini & Solomon, 2020). In linking this conflict to social support, relational turbulence between partners is understood to impact how well they can communicate the complexity of their needs to others in their formal and informal support systems (Brisni & Solomon, 2020). In any assessment, it is apparent that for families of children with DD, engaging socially with others is complex.

Another theme concerning social support seemingly non-existent in the research literature concerns children with DD and their experiences in community support settings (Freedman et al., 1995). Families of children without a DD diagnosis, in general, can expect to have available a variety of extracurricular activities and supports within their community that has been documented as contributing to the enhancement of social and other skills across the developmental stages (McCombs et al., 2017; Metsäpelto & Pulkkinen, 2012). Depending on the landscape of a family's locale, these activities are optional. However, they may include registration in daycare programs, private special interest clubs, a range of athletic endeavors or teams, afterschool curricular activities, K-12 childcare programs, faith-based programming within houses of worship, school vacation camps, or summer day and away camps (Metsäpelto & Pulkkinen, 2012). For the working parents of children who engage in out-of-school programming, these activities serve as a point of engagement for children with others in their community, hindering isolation and promoting connection (McCombs et al., 2017; Metsäpelto & Pulkkinen, 2012). Exposure to others in the community can allow children to form meaningful peer and mentor relationships outside the family system and contribute positively as an included and essential part of their community (McCombs et al., 2017).

Additionally, activities outside of school and home serve as an informal, regularly occurring form of engagement or respite for parents. Parents may participate with their children or step back from engaging directly with them. Either way, participation allows children experiences to foster peer and mentor relationships, independence, and social-emotional growth (Metsäpelto & Pulkkinen, 2012). How do caregivers of children with special needs experience or navigate with or without these specific and helpful kinds of social supports? What is known is that without the option of programs suitable for children with DD, mothers will assume the burden of care, reducing or eliminating income potential (Freedman et al., 1995; Genereaux et al., 2016; Warfield, 2005). Most of the literature on caregivers of children with DD generally refers to social support and sparingly references programming or structured activities outside school hours.

For families of children with DD, navigating social support is complex. Caregivers describe difficulty navigating social relationships attributable to stigma and complexity in caregiving work. Parents may have trouble accessing out-of-school activities readily available to typically developing children because there is a rarity of programming that can accommodate children with DD and because when there is, the financial cost is high. This lack of specialized programming contributes further to social-developmental gaps for children with DD. More research is needed to have a better understanding of the nature of burden and care for parents, to learn more about what is helpful, what is not, and what else needs to be considered regarding policy creation, community cultivation, and development of concrete forms of social support for caregiving mothers.

Conclusion

Parents, and overwhelmingly mothers, experience negative impacts on well-being attributable to the caregiving burden over the developmental lifespan of the child (Woodman et al., 2015). Research shows that parents caring for children with DD will experience negative impacts on their mental health, physical health, finances, and career, as well as stress and isolation compared to parents with typically developing children (Smith & Grzywacz, 2014). The research overwhelmingly focuses on mothers who endure the bulk of caregiving and absorb detrimental impacts on their well-being, career, and finances (Weeks et al., 2008). Systemic forms of intervention focus on the support for the child with a lack of support from the caregiving parent (Crossman et al., 2018). For example, early intervention, education, medical, and therapeutic organizations offer programs and support directly to the children without assessing the caregiver burden (Canary, 2008; Crossman et al., 2018). The caregiver burden increases when parents are expected to be full partners in an endless and progressively growing list of interventions created to meet the child’s developmental support needs from childhood through adolescence and adulthood (Safe et al., 2012). Managing DD care increases in complexity with adolescence, and the number of formal systems compounds the burden.

In most cases, the system itself is overwhelmed, with caregivers carrying the responsibility of seeking, demonstrating need, and applying for services, along with absorbing the additional financial costs of caregiving and managing complicated application processes and long waitlists to access services, if they are available (Brunsting et al., 2014). These systems inherently compound the burden of caregiving, multiplied by the number of systems the caregiver is navigating, and very often, the maternal caregiver is operating in the role of a case manager in addition to other pertinent functions (Sousa, 2015). Stable family functioning under these circumstances can be challenging. With each increase in complexity, the burden involved in caregiving or compensatory work adds additional stress to the family.

Even so, many parents can re-engineer their experiences, derive new meaning or purpose, demonstrate resilience, and may report personal development that emerges as a growing awareness and compassion for differences (Stober & Franzese, 2018). Mothers may gain expertise concerning disability issues and valuable insight into practice and policy. They may also become experts at navigating disability stigma in public places (Li et al., 2019). While historical and current research from the MDM offers breadth and detail on problems inherent with disability and caregiving, scholars increasingly embrace more progressive models of disability, pointing to a lack of emphasis on meaning and the potential for solutions (Olkin & Pledger, 2003). It has been four decades since Fenderson (1984) called for psychologists to attend to the gap in disability research. As this generation adapts to unique health challenges in the post-COVID-19 pandemic and takes on the care of an aging boomer generation, the reality is that even greater percentages of the population are qualifying as disabled. The time to address disability more broadly is now.

My research focuses on solutions to these issues. It addresses a gap in the literature on mothers as caregivers of children with DD, especially mothers with marginalized identities, and the role of extended family and friends in social support. Counseling psychology has the potential to contribute to this topic because of the emphasis on both individual and systemic well-being, along with person-centered, social justice, and solution-oriented approaches. As disability research moves away from the MDM and toward a more social and critical disability model, future research should focus not only on describing problems but also on offering solutions. The de-marginalization of disability within counseling psychology is one tangible step toward solutions, which can happen when counseling professionals (who are already being trained in compatibility with the social model) are required to learn about disability populations and have access to disability studies, and when disability-affirming practices are accessible within mental health and counseling psychology's general curriculum (Fenderson, 1984; Foley-Nicpon & Lee, 2012; Pledger & Olkin, 2003).

CHAPTER THREE: METHODOLOGY

My study explores how extended family and friends participate in support for caregivers and what caregivers observe about their support systems' impact on stress and the family system. I have two questions that are the core of this research. The first question is how mothers of children with developmental disabilities (DD) perceive and experience social support consisting of extended family, friends, and community members. The second question is how this social support system impacts a mother's quality of life and, by extension, that of the child with DD. In addition to these questions, I am also examining how formal support systems impact the maternal caregivers' experience of social support more generally. The data collected from this research is meaningful for caregiving parents who struggle to convey to friends, family, and the community their burden of care and the level of need for informal and formal social supports that are foundational for a family's well-being. It is also important to inform clinicians' and researchers' understanding of support practices and policies for family caregivers of children with DD.

This chapter covers the methodology and the qualitative research design grounded in Interpretative Phenomenological Analysis (Smith & Nizza, 2022). The sections presented in this chapter inform the study and include research assumptions, a review of the epistemological framework, reflexivity, the rationale for utilizing qualitative methods, and, in particular, phenomenology and IPA. This chapter also discusses participant criteria, data collection, data analysis, validity strategies, ethical issues, the pilot study, potential study limitations, and concludes with multicultural and social justice considerations.

Research Assumptions

Scholars are new to understanding families with disabilities, and in recent years, there has been a trend to focus on resilience (McConnell et al., 2014; Hassanein et al., 2021), which is an affirming position that I support. However, while caregivers find meaning and demonstrate resilience, I believe that helping professionals must not bypass a collective responsibility to offer solutions by first understanding and then tangibly meeting their challenges (Foley-Nicpon & Lee, 2012; Olkin & Pledger, 2003). Further, I believe that concrete solutions for overburdened caregivers are vital to resiliency for caregivers for children with DD complexity. I have outlined my epistemological stance throughout the introduction and within the literature review, although the epistemological portion of the methodology further clarifies my position in relation to this research topic.

Epistemological Stance

This study is positioned with a critical lens and draws from multiple epistemological and theoretical frameworks, each reflecting a dimension of caregivers' lived experiences of parenting children with DD while highlighting the impacts of social support on the family system. As described in Chapter Two, the research stems from a critical constructivist epistemology (Creswell & Creswell, 2018) and draws from relevant aspects of ecological systems theory, the medical model, the social model of disability, critical disability, intersectional feminism, and attachment theories to provide context and meaning for maternal caregivers' experiences. Because this study is critical and grounded in social justice, I emphasize the experiences of mothers with marginalized identities and minimize the traditional focus of this research, which has often featured the advocate mother who is White, cisgender, straight, and upper-middle-class (Baker & Burton, 2018; Lemus-Mogrovejo, 2019; Stober & Franzese, 2018). This research prioritizes the experiences of caregiving mothers who identify as marginalized, highlighting mothers who identify as BIPOC, LGBTQ, immigrants, single mothers or low SES. This research sought to reach populations in urban, ethnically and culturally diverse areas because mothers who are caregiving children with DD and who have marginalized identities are under-represented in current research. This project aims to help fill the void and contribute to greater understanding, practice, and policy for populations that have been historically marginalized.

Haverkamp and Young (2007) describe how a critical ideological paradigm challenges oppressive systems and empowers participants who are a part of historically marginalized populations. Viewing the population of mothers whose identities and experiences are marginalized through a critical ideological framework is paramount to this project. Further, Haverkamp and Young (2007) acknowledge the role of oppression and name the influence of historical, social, and political factors, which is an appropriate lens for conversations about disability. Disability spaces hold identities, cultures, and communities within them that have experienced oppression and have their own historical, social, and political narratives. Additionally, Haverkamp and Young (2007) describe the researcher who actively participates in dual goals of empowering participants while critiquing oppressive social constructs. In an informal pilot study for this research topic, these critically important dynamics emerged when a BIPOC mother affirmed the experience as empowering because it was the first time she could freely speak to challenges she encountered while having her voice and experiences as a caregiver remain at the forefront.

As a researcher subscribing to critical constructivist epistemologies, I have several aims. This research highlights the realities of the mother’s experience while emphasizing what is problematic in the environment that contributes to caregiving challenges. As a constructivist, I hope to contribute to a deepening understanding of how mothers make meaning and understand their experiences with social support. I believe that in exploring vulnerable populations, in this case mothers of children with disability, the research functions to name, address, and inform so that collectively, society can begin to solve persistent barriers to access that most significantly impact caregiving mothers and by extension, their children, their families, and potentially the community at large. To further develop these ideas, I offer reflexive insights on how my professional identity, my parenting identity, and my cultural identity intersect with the identities of caregiving mothers who have been marginalized and how these realities may have impacted the research.

Reflexivity and Positionality

In this section, I examine important aspects of my identity that are relevant to and inform my research topic. In so doing, I looked to experts in the field of applied research and counseling psychology as catalysts for how to best approach reflexivity and positionality. Josselson (2013) challenges her readers to consider how social location, including gender, race, class, age, sexual orientation, and nationality, informs how one thinks about one's research question. Marshall and Rossman (2016) extend this idea by referring to the researcher as an instrument, while Wertz et al. (2011) state that “research inevitably includes and expresses the orientation, methods, values, traditions, and personal qualities of the researcher” (p. 84). Considering these principles, I acknowledge holding dual roles as an insider and an outsider in several categories related to the topics I address in this section. To begin briefly, I am a counseling professional and a mother who advocates for children with visible and invisible disabilities. I am an able-bodied, bi-racial Latina, heterosexual, cisgender woman. As I summarize my identity into these concise phrases, it is clear on paper and in person that I have an intersection of experiences, culture, and identity that are variably relatable, unique, and impactful to this research project.

Professional Identity

To expound professionally, I am a licensed mental health clinician (LMHC), and currently, I have fifteen years of experience in private and clinical practice supporting individuals, families, and couples. My work is trauma-informed, threading together narrative, psychodynamic, family systems and roles, and mindfulness elements. Through the lens of my personal identity and my professional training, I have, for most of my practice, gravitated toward thinking about a client's psycho-social and emotional well-being, identity, and quality of life as connected by multiple levels of relational systems that include culture, family, community, and society at large. My work in counseling psychology shifted toward thinking about disability in similar ways when my son was born with disabilities, reinforcing my views of disability as a topic that needed further research that would inform the field of counseling psychology, supportive services, and disability policy.

Parenting Disability Identity

More personally, when my son was diagnosed with multiple disabilities and medical complications ten years ago, I was not intimately acquainted with the disability community or culture. As I experienced life through the lens of a parent caregiver and advocate for my children, I also went through a significant adjustment where I realized that much of what I assumed were his rights and what I believed could be accessible for us as a family would no longer be easily or automatically accessible to him, and by extension, us. After working hard to establish my life by what I understood to be academic and career achievement that would ensure a measure of access, security, and stability in a capitalist paradigm, I encountered multiple barriers and significant disruption as I worked to access my son's education, medical support, and therapeutic services. Our family suffered multiple losses and experienced stigma as well as overt discrimination. Counting the inflated costs, I wondered how parents with fewer resources cope. How do they navigate the complexity of systems when caring for a child with special needs? How do their children fare? Even as we continue to encounter barriers and stigma related to our son's disability, our family gains a deepening affinity and respect for any person who finds themselves struggling within power systems that predictably fail the needs of those who require the most support.

Cultural Identity

My most formative identity is that I am a biracial Latina. My upbringing in a multicultural home has given me points of connection for collaborating with clients from diverse backgrounds. For example, as our political landscape shifts and racial injustice is highlighted in important ways, I have experienced a significant increase in the number of clients of color who seek care from me because they identify with me as an ethnic minority. I did not attain licensure in my profession as an intentional act of representation; however, I believe that my presence and practice as a multicultural person who presents as visibly ethnic, with an overtly ethnic first and last name, has and will continue to have an impact on my experiences, how others experience me, and on this and future research projects. For example, I have direct access to organizations and contacts that care for people with marginalized identities who are also connected to disability culture. For some participants, I had credibility when they eencountered me as a caregiver with a marginalized identity who understands something of their experiences. Further, I benefit from insight gained from my own lived experiences. This insight was valuable as I created research questions, engaged in interviews, and drew on participants to expound upon their experiences. Finally, as I reflect on the multicultural part of my identity, I can identify internally how it has assisted me to feel at home working in disability and culturally diverse spaces. I believe this aspect of my identity contributed meaningfully to the interview process, especially as I was able to offer understanding and safety as I explored the topic of marginalization with participants.

Later in this chapter, I outline the specific methods that were used to incorporate ethical accountability to validity strategies as an essential component of this research project. In closing the reflexivity section, it seems relevant to mention that I drew from almost a decade and a half in clinical counseling experience, which included encountering and working through areas of transference with clients, and on the ethics of my profession to boundary my role as researcher and fully center on the participant's voice and experience. While I do relate in many ways to participants who are mothers with marginalized identities, I also carried an awareness that being too close to my topic could become problematic and interfere with validity. As the researcher with a similar lived experience, it was important to me to highlight and give voice to these mother's challenges. As a counterbalance, I committed to reflective practice along with several recommended validity strategies for researchers who are actively and accurately hearing and interpreting the participants' voices so that their lived experiences and insights are highlighted within research, practice, and policy (Blomberg & Volpe, 2019; Josselson, 2013; Marshall & Rossman, 2016). Next, I present my rationale for using qualitative inquiry and then Interpretative Phenomenological Analysis methods.

The Rationale for Qualitative Research

Qualitative research was appropriate for this project because it positions participants as experts and parents of children with disabilities often are experts on both their child and their child's diagnoses. The research topic of caregiving parents is suited for person-centered methods: it is narrative-based, it is in alignment with social justice, and with the methods within qualitative research that encourage creative expression (Wertz et al., 2011). As a person whose work within counseling psychology has been most effective and empowering when it is both person-centered and creative, I was drawn to qualitative research methods. Further, I view this research method as beneficial for the population I am centering in this research, which shares common themes and challenges that co-exist with unique identities, stories, and experiences (Marshall & Rossman, 2016). Qualitative research is flexible enough to allow for discovering both themes and exceptions, formal enough to be valid, and relational enough to directly benefit the participants while providing more in-depth insight into best practices supporting caregiving families (Creswell & Creswell, 2018).

The Rationale for Interpretative Phenomenological Analysis

Phenomenological approaches, in general, focus on the essence of a person's lived experience (Patton, 2014), and this aligns with my research with caregivers of children with DD, including the data collection method of interviews. In what I believe is in keeping with the ethics, art, and science of counseling psychology, Wertz et al. (2011) refer to eidetic analysis as a "general human capability that Husserl called the intuition of essences" (p. 126). This idea is based on a scientific method of analysis that is iterative, and so utilizing phenomenology for my research questions of maternal caregivers offered an opportunity to highlight the complexity and detailed descriptions that contribute to the meaning-making of lived experience rather than diminishing or narrowing it. This approach is a unique characteristic of phenomenological methods, and I believe it enhanced my exploration and interpretation of the caregiving experience for mothers of children with DD.

The research design is more narrowly grounded in Interpretative Phenomenological Analysis (IPA) methods. IPA is a specific phenomenological approach suited for understanding and interpreting participants' significant life experiences, exploring themes, and both similarities and uniqueness within those themes (Smith & Nizza, 2022). The method is helpful in exploring the experiences of marginalized populations and has been used effectively by scholars to study, for example, the motivation of students with DD in education (Emery & Anderman, 2020). Phenomenological methods are grounded in first-person accounts of lived experiences, primarily through interviews, which was the basis of the research. Journals, sketches, and drawings are common supplements, which I have incorporated into the research design using social maps to construct and understand participants' experiences. Social maps were used to illustrate, examine, and interpret each participant's understanding of friends and family as a social support system regarding caregiving for a child with DD (Josselson, 1992; Motulsky, 2010). Furthermore, I have incorporated tables to illustrate the participants' de-identified social and economic status and pertinent diagnostic information that highlights important aspects of identity for the maternal caregiving experience.

Another central element of IPA is hermeneutics, better defined as the understanding of how participants make sense of their experience in tandem with the iterative, analytic attempt of the researcher to understand and draw meaning from language and stories (Nakkula & Ravitch, 1998). IPA embodies idiographic methods because experiences are interpreted in several ways. Participants' experiences are interpreted within their greater context, on a case-by-case basis, and compared to one another for common and unique themes. When maternal caregivers' experiences are highlighted individually, thematically, and contextually, multidimensional insight into their experiences is facilitated. A multifaceted approach to research about maternal caregivers seems especially relevant as I consider the underpinnings of phenomenological research and IPA. I explore how IPA methods were utilized in this chapter's data collection and analysis sections. Since understanding and eliminating assumptions about DD is key to properly interpreting the data in this study, I have further defined DD as a part of qualifying the criteria for participants.

Participant Description/Criteria

While I provided an in-depth discussion of mothers and their children with disabilities in the literature review, I have further clarified the term DD within the introductory definition of terms section because it may be unfamiliar to the reader and may carry an assumption that this concept is only relevant to children with intellectual disabilities, which is not necessarily the case (Odom et al., 2007). Within the broader understanding of DD, the recruitment of caregivers with children with DD allowed for a wide range of both visible and invisible disability representation, including those with sensory or mobility impairments and invisible learning or other disabilities like spectrum disorders, to participate. The common denominator for these participants was not the type of diagnosis or the level of impairment but the complexity of care required.

The primary criteria for selection was focused on including maternal caregivers for a child with a complexity of care directly related to their disabilities. To reference the previous definition found in Chapter One, this might include potentially multiple medical or educational diagnoses that, even in the best possible circumstances, may compound the burden of care by involving the mother within multiple systems to access services or support. This meant recruiting mothers of children with more than one diagnosis, potentially a combination of medical and educational diagnoses, and those children who have qualified and secured an Individualized Education Program (IEP) in a public school setting or private special education placement. To highlight and make meaning of the systemic societal context that contribute to a mother’s hidden caregiving work, interviewing mothers of children with both a medical diagnosis (indicating interplay with the medical complex and the possibility of community or additional specialist support) and an IEP (indicating interplay with educational systems) was ideal. In recruiting participants, I assessed the level of complexity regarding their diagnoses and level of care before the interview process.

I recruited mothers with children with DD aged 6 to 14 because I wanted to interview mothers' experiences past the initial stages of diagnosis and acceptance, which often occur past the initial diagnosis between birth and early education (Fisher & Goodley, 2007). Mothers of children who receive diagnoses in the early developmental stages before school age may still be in the process of acceptance that can include stages of grief, including hope and denial, and fear of what is not known or understood about their child's diagnosis (Landsman, 2008; Seligman & Darling, 2007). In this stage, a caregiver may be working through a process of stabilizing and orienting themselves through the discovery and impacts of a diagnosis. While there are no hard and fast rules about how long it may take a caregiver to orient themselves and their lives to accept and accommodate a child's disability, for this study, the age of the child did not include infants, toddlers, or preschoolers, for whom the category of developmental disability, and therefore its challenges, may not be yet apparent or applicable. I now address the design of data collection methods as they relate to qualitative methods and IPA.

Participant Recruitment Process

IPA methods incorporate recruiting a homogenous group of participants to highlight better themes and differences in lived experiences (Smith & Nizza, 2022). After receiving Institutional Review Board (IRB) approval, I sought participants by emailing personal and professional contacts and posting flyers on several parent boards (Appendix A). The focus was on the recruitment of mothers of children with various developmental disabilities who were between the ages of 6-14 or approximately first through seventh grade. Because this study sought to highlight the experiences of participants who identified as single mothers, BIPOC, LGBTQIA+, disabled, immigrants, or low-income (SES), participants who identified in these ways were encouraged to apply. The recruitment effort included seeking connections with representatives from the Massachusetts Federation for Special Needs, the Cambridge and Boston Public School Districts, The Perkins School for the Blind, and The Guild, and posting flyers to various disability-related parenting boards and Facebook pages. Interested participants generally connected by email, where they were provided with both my email address and phone number and permitted to email or text me directly. Because caregivers are likely overburdened with caregiving work, I offered text as an easily accessible form of initiating and continuing communication about the study. Each potential participant who contacted me received an email response thanking them for the connection, summarizing the scope of the study, an attached copy of the participant packet, and the offer to schedule an initial follow-up phone call to explain the criteria, the informed consent process, and then determine eligibility for participation (see Appendices A and B).

Overall, participants were mostly self-referred to the study through the disability parenting boards. Recruiting enough women of color to represent their experiences became a concern at a mid-point in the study. Even though the recruitment flyers were given to a school with a history of serving a local Afro-Caribbean community and posted to boards dedicated to the interests of Black Mothers of children with Autism, there was no response from those. I previously contacted representatives of minority caregivers who I knew to be well-connected in the Greater Boston area about the study several times, but they did not return my communication. A crossroads in the recruiting process occurred when it became clear that the study successfully recruited enough women to fulfill study goals in terms of numbers of participants, but that they were not all women who identified as Black, Indigenous, or a person of color (BIPOC). Because of my commitment to the social justice focus of this research, I chose to hold the remaining open spaces and resorted to direct recruitment through personal connections to find eligible participants. This decision extended the data collection process by approximately three additional months. However, with this additional effort, I recruited four women of color who met the criteria and whom I had not previously known as caregivers. Similarly, there was a lack of participants from the LGBTQIA+ community. I had one potential participant who initially contacted me and identified as LGBTQ+. This person dropped communication after I responded and attempted a reasonable number of follow-ups so they were not further involved in the study. This felt like a lost opportunity.

In response to posters and recruitment emails highlighting the recruitment of participants with marginalized identities, mothers who were White, married, and from higher socio-economic and educational statuses also sought to participate in this study. These mothers identified so strongly with the feeling of marginalization within their experiences that they connected to the study's purpose and desired representation. Additionally, I recruited one adoptive single mother with two children who each had profound needs. I found each of these recruitment exceptions notable, so I included and highlighted their experience and feelings of marginalization as an important aspect of the caregiver's overall experience within this research. While my study was designed to represent as many marginalized identities as possible, it was not limited to only women of color or with a specific intersection of marginalized identities. In total, I recruited 11 marginalized mothers of children with various developmental disabilities who were in the specified age range.

Consent

Interested potential participants connected with me by email or text. Each participant who indicated interest received a follow-up phone call explaining the study and criteria further and was encouraged to ask any remaining questions. When participants indicated consent to participate, a time and day to meet were finalized, and they received another packet with informed consent to sign, a copy for their records, and support resources (see Appendix B for the informed consent). The informed consent communicated the participant's rights and protections, including opt-outs, confidentiality, potential risks, and contact information for questions. It also offered specifics about interview time and commitment. In the participant packet, participants received a demographic questionnaire and a social map (Appendix C & D), which were completed during or before the interview. Participants were given the option of meeting in person, but for ease of accessibility, the majority chose to schedule over Zoom. Caregivers were encouraged, if at all possible, to pick a time and day when there would be a minimal number of distractions. The participants' rights and confidentiality were reviewed and explained in the first few minutes of the interview meeting, the demographic questionnaire was completed, and the audio and video recorded interview over Zoom began with a discussion of the completed social support map.

Data Collection

Smith and Osborn (2015) highlight research as a dynamic process in which the researcher actively understands an insider’s perspective by engaging in a hermeneutical and iterative interpretation process. As stated previously, past the initial contact, I built rapport with my participants through an initial, more informal, short (not longer than 15-20 minutes) conversation over the phone to answer any questions, assess needs, and confirm the interview date, time, and location prior to the interview. I indicated to each participant that they could connect with me by phone or text with any research-related questions or concerns.

For each interview, I prepared an interview guide (see Appendix E) with the main and sub-questions that had been previously reviewed, edited iteratively, and approved in cooperation with my chair, other committee members, and the IRB. The interview questions were created mindfully in response to gaps in current research, the pilot study, and other related material. The interview guide contained twelve questions, and from these, probing questions to support the study's main research questions: How do mothers of children with DD experience their friends and family as support? How does this social support system impact a mother's quality of life and, by extension, the child with disabilities? Additionally, the demographic questionnaire and the social support map were completed and collected by the end of the interview session. Ten interviews were scheduled and held over Zoom. One interview was conducted in person in a reserved, confidential workspace in the participant's apartment complex and recorded over Zoom in the same space. I downloaded video files to my computer, where each audio file from each interview was then converted and transcribed through a confidential transcription service. Transcripts were downloaded into a password-protected file and then downloaded into MaxQDA software to prepare for the analysis portion of the project.

Social Map

Counseling professionals in therapeutic practice who work with family systems often use mapping to process concrete information relevant to the experiences of the individual, family, or couple they are supporting. It has been a useful tool in my practice. Two examples of effective uses of social maps, and what I based my work on, are Josselson's (1992) and Motulsky's (2010) use of a relational space map for their participants in qualitative research, in which they draw concentric circles, and ask the participants to position themselves in the center and then map out the people they feel closest and farthest from around a particular issue or question, accordingly.

As a part of the information-gathering process, participants in this research study were asked to complete and submit a worksheet outlining a ‘social support’ map (see Appendix D). This was completed at the beginning of each interview and served as an opening for dialogue for the interview. This map followed the example I gave above, with specific instructions on mapping themselves in the center and then positioning their family and friends as social support for caregiving. While I made every effort to ground the collection of information through the social support map, this was more challenging to do over Zoom than in person. There were clear instructions; the paperwork was sent at initial contact and then again just before the meeting with a text or email reminder. Many participants interrupted their overly busy schedules to meet, so even with reminders, they “forgot” to print out the social map that had been emailed to them ahead of the interview. In these cases, I shared a visual of the map on the screen, and the participants recreated the map with whatever memoing paper and writing utensils they had nearby.

One mother was prepared to fill out her social map prior to the interview, and she was readily available to scan her social map and demographic questionnaire to send shortly after the interview. Overall, asking to print out, find, and complete the map clearly burdened most participants. This was indicated through the participant’s common body language such as stressful uplift in voice, frantic movements, and exasperated breaths. In these cases, I worked to balance my request to complete the social map and participant needs by indicating the mother could use the map as a starting point and then move forward into the interview. Because mothers indicated some resistance to completing and returning more paperwork, the map served less as a means of recording information and more as a tool to warm up the participant for the interview and to help me to re-collect information that might not otherwise have been remembered or indicated clearly in the interview transcript. I observed after the interviews that collecting maps and demographic questionnaires required at least one or more follow-ups. Many of the social maps the mothers created were hurried and illegible, perhaps another indication of their feeling of the exercise being an added burden to their already heavy case and paper management work.

In any case, the information that was documented and, perhaps more importantly, the experience of walking mothers through the social map exercise served as another means of understanding more concretely the experiences of support for caregivers. They are overwhelmed with work and want less of it, yet they keep being asked to do more for the benefit of others, even by me as the researcher. Using interviews, gathering a demographic questionnaire, and completing a social support map allowed me to glean insight for the study into the caregiver's experience, further highlighting themes and triangulating the data, supporting validity (Creswell & Creswell, 2018). I now address data analysis methods related to the overall research design.

Data Analysis

I collected information from each participant to establish the context of caregiving, including their child’s disability and the complexity of the level of care. The primary source of information was the interview, which was recorded and then transcribed. The second source of information was the social map, which was intended to help interpret data about the participant’s support for caregiving work related to extended family members and friends but ended up being used more as a catalyst for discussion during the interview. The third source of information was the demographic questionnaire, which highlighted pertinent information about the caregiver and child identity.

According to Smith & Nizza (2022), IPA data analysis is a process that does not necessarily follow an exact formula; however, they outline an iterative process of analyzing data through the art of manual coding. In the first analysis stage for the interviews, each participant's case was reviewed and analyzed individually. This process was bolstered by referencing the interview recording and reading the transcriptions. Interpretive notes were taken within the margins of the transcript. These processes were repeated as necessary up to three times to capture descriptive, linguistic, and conceptual interpretations of the data. Descriptive interpretations describe what was happening at any certain moment in the interview. Linguistic interpretations emphasized what the participant communicated with words, and conceptual interpretations were taken to record any post-interview insights or observations.

Ponterotto states that "thick description" is "the lynchpin of qualitative writing" and that "thick description leads to thick interpretation, which in turn leads to thick meaning" (Ponterotto & Grieger, 2007, p. 415). These concepts underscored the analysis for the second stage of analysis. In the second analysis stage, I worked with each interview transcript to find and code experiential statements from the transcripts, utilizing MXQDA software. In keeping with IPA methods, the experiential statements varied in length but were selected to direct the analysis toward deeper meaning and depth (Smith & Nizza, 2022). As I coded transcripts, I looked for portions of the narrative that were especially rich and descriptive in nature, seeking to communicate both the spoken and unspoken meaning of the participant in the interview. The information collected from participants was categorized into major themes, and those themes were organized into a 373-page document of interview quotes. Major themes and relevant quotes were narrowed down to represent participant's experiences so that the data collected could be further viewed, analyzed, and interpreted.

Aligning the research with IPA methods and with Levitt et al.’s (2018) observation that "researchers tend to analyze data by identifying patterns tied to instances of a phenomenon and then develop a sense of the whole phenomenon as informed by those patterns" (p. 27), I entered the third stage of analysis. In this third stage, I collected the coded experiential statements and grouped them according to shared meanings, creating common themes among the participants (Smith & Nizza, 2022). These themes were then organized into tables, with major themes underscoring participant’s contributions to the interview. Even with clear instructions about how to use the map and a portion of the interview dedicated to completing the map with support from me, I found that participants’ use of the social support map varied. Some mothers thoroughly completed the map legibly, some mothers referenced the map and described their understanding of social support verbally, some mothers completed the map partially, and some mothers completed the map, but their handwriting was illegible. For these reasons, the social support map table was partially completed. However, it did not offer a holistic view of the mother’s social support as planned. The social support map served as a helpful opening to the interview and helped contextualize the research's focus for participants. All participants completed the demographic questionnaire, and a table was made from this, which has been integrated into the research findings.

Following the example of Motulsky (2010) and Josselson (1992), tables were interpreted and organized from the social maps as much as possible and the demographic questionnaire to completion. The social maps and demographic information were useful for supporting emerging themes, patterns, and exceptions as I began to interpret the data. All the data collected from each category contributed holistically to the findings and interpretation of the data. Next, I explore strategies that were implemented to adhere to academic standards of validity for this research.

Validity Strategies

My first commitment to validity was methodological integrity (Levitt et al., 2017). Qualitative research and IPA methods are enhanced by iteratively analyzing transcripts from each case study and then additionally analyzing the data for themes and exceptions in a cross-case analysis. Yeh & Inman (2007) state that "the goal of coding in qualitative analysis is not to produce a number or a count of things but to deconstruct or fracture the data and develop broad patterns, themes, or categories that are grounded in the data" (p. 390). Further, Smith and Nizza's (2022) recommendations include keeping records. This can include a checklist of the steps as they are completed and maintaining copies of the memoing at each stage of the process. This process was supported by the recording of interviews, the creation of transcripts, the review of these transcripts, the creation of notes, the coding of experiential statements, the organizing of these quotes, and the integration of quotes in the data analysis to support themes and conclusions or claims. To further clarify, the strategies I selected underscore the iterative nature of IPA methods to reinforce validity. Along with careful analysis and interpretation of the data, the research integrated reflexive journaling and memoing, including detailed descriptions, peer and committee debriefing, review of the interviewing, and the research process. Further, the research committee included a critical disability expert and a committee of qualitative research experts who offered feedback at critical points in the research process.

Finally, member checking has become standard, especially in qualitative research (Motulsky, 2021). While member checking is often incorporated as a contribution to validity, I considered Motulsky’s (2021) critique of benefits and drawbacks related to this study and concluded that member checking would not necessarily enhance the data’s validity or outcomes. In fact, I perceived that asking participants to offer critical feedback in hindsight about their part in the study design could unintentionally undermine the study’s outcome. In my view, this is directly attributable to the sensitive nature of the topic and how maternal caregivers have been found in research to mask, internalize, and champion their way through difficult circumstances. Further, it was clear during the interview process that participants' most precious resource was time. Requiring further time from this participant group could discourage them from participating. Therefore, my study did not incorporate a formal process for member checking within the design. However, I made myself available to participants and encouraged them to initiate a connection with me regarding their insights on their contribution and any feedback they may have after the interview. Finally, before the research study, I engaged in a pilot study to evaluate best practices and make relevant adjustments before conducting the research study, which I explore further in the next section.

Pilot Study

For the pilot study interview, I created a promotional flyer (Appendix A) and distributed it to friends and colleagues connected to the disability community. Although I followed up with each person, they could not secure any potential interview candidates. With the deadline in mind, I contacted my former workplace, where I served as a Director of Programs for children and families with disabilities. I recruited a single, Black, widowed mother of two children, one who is typically developing and the other who is 11 years old, with Autism and ADHD. To be clear, the pilot study mother did not participate in the research study, although I did have another widowed mother participate in the study. I sent the mother, who agreed to participate in the study, a consent form via Google Docs through a secure link for accessibility (Appendix A & B), and we agreed to meet at a convenient time for her over Zoom for approximately one hour.

The data I collected from the pilot interview gave insight into this maternal caregiver's lived experiences. However, my learning extended to include more concrete, logistical considerations relevant to the research methodology. One takeaway was that I needed to reconsider how long it might take to recruit mothers. While my connections may be enthusiastic about the idea of the study, there was often a lack of follow-through from mothers who understandably had full plates. Another takeaway was that I needed more preparation on my research questions to cover the topic adequately and to work on better phrasing for questions. Ideally, I would have liked to recruit an informal focus group ahead of the formal study, where I would have been able to practice interviews with a group of friends who are mothers of children with disabilities.

Finally, the most meaningful part of the pilot interview was hearing spontaneously from the mother that the experience had been cathartic for her. This was similar to comments off the record of mothers when we completed the interviews. The pilot study mother mentioned further that the interview was a catalyst for her to process thoughts, feelings, and experiences that she typically does not have the opportunity for and about which she does not feel heard. Her comments were a catalyst for thinking about how validating a hidden experience can be supportive and wondering what might be helpful for the participants' care post-interview.

Next, I explore ethical considerations in the research design and methodology.

Ethical Considerations

As with any qualitative study, there were several pertinent ethical considerations for this study (Bloomberg & Volpe, 2019). To begin, all participants in this project are adults. They were offered as much information about the commitment involved before they agreed to participate and how to opt out of the study. Participants recruited for the study received an informational flyer with an agreement outlining consent. This flyer outlined participant’s rights and boundaries within the study. Participants were informed verbally and in writing that they were not obligated to participate, could withdraw at any time, and that their information would be confidential (see Appendix B for informed consent). Participants were informed that pseudonyms would be used and that the names of extended family and friends, school and specific location information would be deidentified. Because diagnosis and burden of care were evident within the research, participants were made aware that some information would not be de-identified, such as mothers' marginalized identities, socio-economic status, and ages along with their children’s gender, age, diagnosis, medical, and care needs. However, all participant names and their children’s names remained confidential.

Participants were encouraged to utilize the researcher’s contact information at any point before, during, or after the study for feedback or if concerns arose. As required within informed consent documents, I included potential risks and benefits of participation. For example, I explained that talking about their experiences may catalyze participants to seek therapeutic support for themselves or a loved one. Participants had access to a resource sheet that included information for mental health resources and a local, accessible, and accredited counseling organization with access to licensed professionals, which they were encouraged to follow up with for support if needed (See Appendix G). To summarize, every effort was made to adhere to ethical standards for research in this study. The next section briefly summarizes this study’s cultural and social justice considerations as they pertain to the study’s design and methodology.

Cultural and Social Justice Considerations

There are a plethora of considerations that meet at the intersection of culture, social justice, and disability. In the literature review, I discussed calls from scholars to include disability as a multicultural competency within the field of counseling psychology. By focusing on the experience of social support as a part of a broader social ecology, I sought to understand challenges in the caregiver's experiences of social support and explore potential solutions for gaps in support. From a broader systemic context, I confronted the ongoing impact for caregivers and their children with disabilities, namely, the impact of a capitalist, colonialist culture that is steeped in the MDM's pervasive view that disability in and of itself, which is inherently problematic and perpetuates stigma. After conducting this research on caregivers, I more firmly believe that stigma is what ultimately pushes disability issues into the margins of overly bureaucratic systems and structures that hinder access to support.

Scholars who have studied related topics agree that there is more to gain by exploring the lived experiences of parents who are caregivers of special needs children (Brock, 2014; Safe et al., 2012; Stewart et al., 2016). As we create spaces for people with disabilities and those who love them to share their lived experiences, we integrate and destigmatize their experiences.

By focusing on the experience of social support as a part of a broader social ecology, I sought to understand both challenges and benefits of social support as well as explore potential solutions.

Methodology Conclusion

This chapter discussed the considerations in the design and methods of this research study, grounded in my positions as a licensed professional mental health counselor, a person with a multicultural identity, and as the mother of a child with disabilities. I explained how the study's focus on marginalized mothers, caregiving, and social support aligns with Interpretive Phenomenological Method's emphasis on meaning making. I designed the research to enhance validity and maintain ethical integrity so that the research can benefit the community of marginalized mothers and their children.

CHAPTER FOUR: PARTICPANT PORTRAITS

This chapter features a narrative portrait of each participant, interpreted through the responses to questions participants answered in semi structured interviews about mother's intersectional identities, their children's identity, and their experiences with social support. Each participant's narrative offers a broad overview of their perspectives and highlights the meaningful aspects of maternal caregivers' experiences. These narratives in turn underscore the key findings and the discussion of findings, which are presented in Chapters Five and Six. To protect participants' confidentiality as much as possible, all participants were given a pseudonym and identifying information has been changed, including children's names. I took care with each participant's story to highlight not only the mothers' challenges, but their strengths, the uniqueness of their stories, their concern and love for their children, and their resiliency.

Participants were recruited who identified as any intersection of marginalization by race or ethnicity, sexuality, disability, socio-economic or immigration status, or as single mothers. Out of 11 participants, all but one were in their 40s. Four mothers identified as immigrants who moved to the country seeking supportive services for their children, and one described herself as a dual citizen of the United States and a Middle Eastern country of origin. Three mothers identified as Black, two as Asian, three as White, one as Native American, one as Middle Eastern, and one as a Native Pacific Islander. Five mothers identified as single mothers, one widowed, and one mother is unmarried but with a long-term partner. Relative to socio-economic status, four mothers identified as having lower socio-economic status (SES), with the remaining mothers falling into middle or upper-class SES. Every mother had some form of higher education, with two mothers having some college, one had a bachelor's degree, one had a Ph.D., and the remaining eight mothers had Master's degrees. Three mothers identified as having or likely having a disability. None of the participants identified with a marginalized gender identity or as LGBTQ+.

Table 1

Participant Demographics

**See Diagnosis & Education Key Below*

Pseudonym	Age	Ethnicity /Race	Marital Status	Education	Child's Age	*Diagnosis	Siblings
Ruth	40s	White	Married	M	10	MI, CVI, DD	Yes - 1
Jenni	40s	Asian	Married	PhD	6	CVI, DD	Yes - 1
Julie	50s	Asian	Married	M	7	CVI, DD	Yes - 1
Christie	40s	White	Single	M	5	MI, CVI, DD	Yes - 1, also with disability
Lucille	40s	American Indian	Partner	M	12	MI, SI, ASD, DD	No
Tanvi	40s	Black	Widow	*SC	8	ASD, DD	Twins
Mandia	40s	Black	Married	M	8	MI, CVI, ASD, DD	Yes - 1
Sadie	40s	Pacific Islander	Single	*SC	14	ASD, DD	No
Melissa	40s	White	Single	M	7	MI, SI, ASD, DD	No
Marium	40s	Black	Married	M	10	ADHD	Yes - 1
Nadiah	40s	Middle Eastern	Married	M	6	ADHD, Autism	No

*ADHD - Attention Deficit Hyperactivity Disorder
*ASD - Autism
*CVI - Cortical/Cerebral Visual Impairment
*DD - Specific Developmental Disability
*M - Master's - MS or MA
*MI - Mobility Impairment
*SI - Sensory Impairment (Deaf and/or Blind)
*SC - Some College

Ruth

Ruth identifies as a 41-year-old White, cisgender, married heterosexual female with a high SES, as a parent of two and a caregiving mother to her son. Ruth lives in the northeastern United States and sought to participate because she identified with the feelings and experiences of caregiving and being marginalized. During the interview, she expressed great passion for her work as a caregiver advocate for her son, and other parents and children with similar diagnoses. Her parenting, diagnosis, and advocacy experiences with her son led to her current work with a disability advocacy group supporting parents and children with similarly complex diagnoses. She was enthusiastic about participating and sharing her story as an act of advocacy for children and their caregivers. Throughout the interview, she would answer a question thoroughly and on point, then follow her answer with "Is that right? Am I getting at what you need?" indicating her grounded commitment to sharing her story, not only for her, but also for other caregivers in the trenches with their children with disabilities. Ruth described her parenting journey as beginning with a difficult pregnancy, then complications soon after birth. She also clearly highlighted the contrast in her identity before learning about her son's diagnosis and then after: "I mean, already having a kid, it completely changes your life. But there was definitely the realization over and over again that our experience was not the usual experience. I had other friends who had babies around the same time and they didn't go through what we went through."

When asked about her son’s developmental diagnosis, she described how the initial diagnoses did not seem to explain her son’s challenges fully, and it was this discrepancy that sent her on an evolution from parent to parent advocate. It was on her advocacy journey that she learned that visual specialists repeatedly misdiagnosed her son’s visual issues for a mood disorder and behavioral challenges. Ruth described feelings of anger that emerged when, a few years later, she received an accurate diagnosis and realized how much medical specialists missed in the earlier years of her son’s life. The delay in diagnosis also delayed more immediate access to appropriate services. It also catalyzed her mistrust of healthcare providers and systems more generally. With her husband, Ruth moved across several states and engaged in what she described as a “battle” for accurate and extended information about her son’s needs and appropriate services. More recently, she participated in a conference at the National Institute of Health to raise awareness of her son’s rare diagnosis. Ruth’s interview included a poignant discussion about the suffering, grief, and stress of her advocacy journey and how she observes these experiences for other caregivers. She shared the following thoughts about the hidden grief that can accompany a child’s diagnosis and become exacerbated by well meaning, but unknowledgable professionals:

> The grief and trauma that's just so unseen in all of us as disability parents… I remember that hospital stay, one of the doctors who's never met him was like, "Just wait till he is three, he'll be fine." Why are you saying that to me? And you remember that. And he's still not getting better. He's not reaching those milestones, three has come and gone, he is still not talking. I wish people were much more upfront and truthful.

Ruth described her family and friend community as generally supportive. Still, when asked more specifically about how they are supportive, it became clear that in many ways, she experiences isolation and frequently a lack of care, understanding, and tangible support from her community concerning her experiences as a caregiver. She copes by participating regularly in gym classes, gaining friends, and receiving support for fitness goals. When asked to describe her son, she said he is a joy who makes everyone feel loved.

Jenni

Jenni identifies as a 40 year old Asian, cisgender, married heterosexual female with a high household income, and as a mother of two. She lives in the northeastern United States. Jenni initially observed her child with disabilities to have a motor and speech delay and then after pursuing what she observed as a visual difference, learned there was a more complex developmental disorder diagnosis affecting vision. She has a PhD but currently stays home and is primarily committed to her role of mother, caregiver and advocate. Jenni responded to a request for participants through a parent online support group for caregivers, and in her interview she emphasized that parent online support groups are her primary source of support. Jenni's interview was distinguished by responses to interview questions that mainly focused on her parent identity as a strong advocate. Jenni moved from the UK to Boston to secure services for her son after she realized that she would not have the support she needed within her community in the UK or in Asia, and she stated that she wanted to avoid the cultural stigma about disability she would have otherwise faced. In her interview, she contrasted the more helpful support she receives in online parent communities with the discomfort her parents have about her child's disabilities. Jenni discussed her parents' discomfort about their grandchild's disabilities, and their minimization or "denial of diagnosis" as a microaggression that can impose further distress on a caregiver. Jenni said about her parents:

> They're always trying to be encouraging. They always find what my children can do and share with us, but that is not a good thing all the time. When they keep saying, "Look, he can do that. He can do that," and that makes me think, "Do you accept their disability?" I mean, disability is not a dirty word. It's just who they are. Can you accept who they are as a whole person, not just his abilities? That's not always a good feeling.

Jenni described several important observations when asked about her thoughts on how a marginalized identity impacts her experiences as a caregiver. Jenni spoke about how the stereotype of the Asian mother with impossibly high standards impacted and undermined her sense of being heard or understood about her concerns. She believes having a Ph.D. compounded others' perceptions of her within this stereotype. Jenni described what it was like sharing her concerns about her children with peers:

> A mother told me "I don't think your child has a speech problem. I think he talks just fine. I think you guys just are too strict about your child…" And on the contrary, we do not like most Chinese families who request my children to be academic... No accidents. We let [kids] go with their interests.

Jenni also described feeling frustrated when parents of typically-developing children complain about their parenting work in response to her sharing about her caregiving experiences. She said:

> I was sharing my child's [diagnosis] and I was very emotional, and another mom… said, "Oh, I experienced it all and I'm still here…" [I was] hurt so I decided not to talk about that with her anymore. But eventually, she came back to me and apologized. She said she had no idea what she was talking about, and she had no idea what we were going through.

During the interview, Jenni focused intently on sharing her experiences as an advocate and her desire to support and educate other parents. Jenni's interview responses reflected a heavy emphasis on her advocacy for her children and on behalf of other parents. She described dissatisfaction with the level of competency of educational and therapeutic service providers. Even though Jenni already has a Ph.D., she shared that her experiences of incompetency within medical and educational systems led her to consider returning to school for additional training to become a special educator within the public school system. She also described being highly involved in supporting other parents in her church's parenting and disability ministry as a way to cope. She emphasized the need for services to support non-English-speaking caregiving parents, the significant barriers they face to access services, and what she viewed as her important work as a translator for Chinese-speaking caregiver parents.

Julie

Julie identified herself as being in her early 50's, Asian, and heterosexual with a high household income, and she lives in the northeastern United States. She identifies as an American citizen culturally and also being connected with her family, culture, and by birth to her home country. She has a Master's degree, works in academia, and with her husband, is raising her son and daughter, each with neurodiverse and specific learning or emotional disabilities. Julie began her interview by sharing her experiences about the confusion she felt when the earliest signs of her first child's diagnoses were caught by an early childhood center's screening; then they were minimized, dismissed, and unsupported by medical and educational professionals.

Julie shared poignantly about being an older mother and experiencing feelings of isolation, stating that she did not feel connected to younger mothers, and that she related to a generation who is less inclined to turn to online information as a resource or to online parent groups for support. When describing one of her more meaningful “inner circle” relationships, Julie described how it took another mother multiple attempts to connect to her when she ventured out to meet other parents through an in person special education parent group: “She just reached out to us… ‘You're [child’s name] mom? I think our kids are in the same class.’ She actually did this two or three times before I [realized] ‘This lady's trying to be my friend.’” Within her response, Julie emphasized the contrast between this supportive experience with a fellow mother and the unsupportive experiences she was having accessing professional or educational support.

Julie expressed frustration with the attitude she experienced from her children’s elementary school educational team in response to inquiries about her children’s diagnosis and needs. She described the difficulty of working to balance her intent to understand her children’s needs and access support with what educational team members may be thinking about her during IEP meetings: “I cried in the IEP meeting... I knew they were thinking, oh, look at this mom, she's crying because her kids have disabilities… I just couldn't believe that I was sitting at this table with people that I trusted my kid with for a year, and they weren't being straight with me and had not told me stuff.”

Julie described her caregiving work primarily in connection with educational advocacy and behavior management strategies; for example, taking extra trips in advance to familiarize her children with unfamiliar places. She works to prepare one child by carefully describing what to expect and counting down the weeks and days ahead of an event that is outside of the routine. She avoids spontaneous plans in order to minimize episodes of anxiety or behavioral challenges. She also described the challenges of living far from extended family members who do not have a real understanding of her day to day experiences. On the occasion they are able to spend time together with extended family members, she remains quiet because it is difficult to explain her kids' more specific needs, like navigating routines, sensory sensitivities, or narrow food preferences. For Julie's family, church provides some feeling of connection, but it is also a place where she has had to manage the disappointment of unsupportive experiences.There are times she must tread carefully regarding unwanted parenting advice or philosophies that would not be applicable to her children's needs.

Julie said that she copes by taking additional time to process and respond to any given stress and also by talking with her husband and friends who have children with disabilities. Julie takes and offers dance fitness classes as an outlet, stating (with humor) that she's the "coolest" suburban mother in her class. After a stress-related health scare, Julie began to recognize the importance of utilizing for herself the same regulation strategies she was learning about and teaching to her children: "So I would say about a year ago, I had a health scare and I am absolutely positive that it was stress related. And so now I'm just also, I'm trying to do the things that we're trying to teach our kids. I just realize these are just things I was never taught. So deep breathing and take a moment before you react in the moment and just try to also do things that you need." Julie stated that she desires three things for her son with disabilities: (1) She wants him to be able to access all the knowledge that he is able to, (2) She hopes that he will find someone to love him all of his life, and (3) She wants her son to find his purpose. As the interview closed, Julie expressed how important it is to her that she remembers she not view her son always through the lens of disability. She stated that she is: "raising a human being."

Christie

Christie identifies as a White, cisgender female, heterosexual, and as a single, adoptive mother of two children who both have developmental disabilities and medical complexities. She lives in the mid-central region of the United States. Both of her children are multi-racial. Christie is in her early 40s, attained a Master’s degree, and before seeking adoption for her children with disabilities, she worked as a special education teacher and cared for her pets and horses. Christie indicated that her income places her in a lower socioeconomic status. Early in the interview, she described her journey to become a single, adoptive mother to children with disabilities as a choice she made, but her family members, including her parents and siblings, struggle to understand and support her decision. She does not receive instrumental support from her parents who are elderly and unable to support caregiving work. Christie’s sister, who is a homeschooling mother, and is homebound due to mental health issues, serves as a paid caregiver when Christie is at work in her role as a special educator.

Christie differentiated her experiences as an adoptive mother of children with disabilities from those of biological mothers:

> I know that a lot of parents when they give birth to a child with a disability, there's a lot of grief and possibly even guilt. You kind of feel like you did that to your child. Some people do. I don't have that, but I have the grief and the guilt that when they needed me, I wasn't there. I don't want to say irrational, but it's kind of irrational because it was impossible. I didn't even know them at the time, but I feel like I should have been there.

Christie also shared how she came to a deeper realization of the life she imagined versus the life she has with her children. For example, getting frozen yogurt and swimming in the summer are the kinds of activities that are not possible for her children. She also discussed traditions she learned to forgo to accommodate dietary needs: “Holidays are always centered around food. Well, what do you do? Do you make the cookies and let them decorate and then eat them in front of them and say, ‘Sorry, you can't have any. Hope you enjoyed making them.’"

When asked about caregiving work, Christie discussed the difficulty of not knowing or having access to her children's birth histories and how this impacted her ability to anticipate their needs. Because her children were adopted as infants, she described a quick transition from single life to parenting, and the difficulty of feeling less knowledgeable about the full impact of their diagnoses than she may have experienced if adopting older children whose needs are already known. Caregiving work for Christie includes ongoing hospital care, supporting seizures and paralysis, engaging in specialty medical care, making blended food diets, and navigating accessibility issues for a wheelchair. She described physical aspects of caregiving that include lifting and moving the increasing weight of her child as he grows.

Another aspect of caregiving explored with Christie was the tension of coordinating education and care with her sister, who is available but does not have a caregiver personality. She shared how her sister's mental health needs created challenges for both of them, especially at the beginning of their arrangement. Christie described struggles to communicate to her sister how her children's complex needs differ from that of their cousins, who have diagnoses but need less support. Still, she finds this arrangement a healthier solution than her experience placing her children in the local elementary school where she works. In the experience of placement through the school system, she observed her son being yelled at all day and not receiving accommodations. COVID allowed her to pull back from the school system and create the current arrangement with her sister. Within a home environment, Christie believes her child has the benefit of integration with his more typically developing cousins and that he receives the maximum therapy, hospital, and necessary downtime. Christie advocates for and receives necessary services through her state's Department of Developmental Disabilities.

In response to questions about barriers to social support, Christie described feelings of isolation in her journey as a parent to two children with medical and developmental complexity: “So there is no true social life, like going out, seeing people, doing things, going to the pool by myself, going to lunch, going shopping, anything, unless they are at therapy or her house.” She also described feelings of guilt for wanting a break, and the difficulty of creating moments of respite with an ever-changing routine, working during the day, and supporting medical needs and routines overnight. She felt that support would look like an on-call babysitter who could effectively replicate her level of support so she could go to the grocery store or to dinner. In order to cope, she recognizes her feelings and then internalizes them, often not saying anything about her feelings in response to unsupportive experiences. She also attends a parent support group occasionally, but she can experience isolation there because her experiences and perceptions as an adoptive parent vary from the majority of parents who are sharing about their biological children. Christie says that as an adoptive parent, she understands that her experience and view of parenting are different from the biological parents she often encounters in parent groups. She hopes to help other families like hers and is pursuing additional certifications to become an IEP Coach and then open her own IEP coaching company. Christie’s passion for helping mothers navigate what she views as “complicated” systems was clear when she talked about her future plans.

Lucille

Lucille is in her early 40s, and she identifies as a cisgender female, heterosexual, and Native American living in the northeastern United States. She lives with her long-time partner (who has a mobility impairment) and her daughter, who is an only child. They live together near the special education school that supports her daughter’s educational needs. Lucille indicated that her income places her in the mid-range of socio-economic status. She works as a special educator and advocates for children and parents with disabilities at her daughter’s school and within the greater disability community. Lucille’s daughter’s disabilities required significant support, so she moved her immediate family away from her parents and extended family to be close to their school community, whose campus supports students with complex medical and multiple disabilities. Lucille’s daughter is non-verbal with multiple disabilities, and her needs include the use of a wheelchair. Additionally, she needs physical support to help transition, lift, bathe, and dress daily. Lucille describes her daughter as feisty, funny, and sweet, with the ability to take advantage of kind helpers who may unknowingly offer too much support, for example, when she can practice standing on her own. Lucille said that as her daughter is an only child, nearing the pre-teen years, she and her partner feel so much love for her. They both feel strongly for their child and can understand and support one another in the caregiving aspects of parenting. Lucille came across as more grounded than overwhelmed, which she said comes from the gratitude she feels that her daughter is alive, after experiencing uncertainty about her life in the beginning.

Lucille described a rough beginning, with her daughter undergoing a major surgery at one-month-old. At the time, she remembers asking extended family and friends to respect her need for space. Lucille wanted to avoid the additional pressure of invasive inquiries and comments from her more immediate community while they were still uncertain about her infant daughter’s viability. She suggested that instrumental help such as bringing meals, running laundry, and offering respite opportunities would have been helpful in the beginning, but that tangible lack of support stemmed from a lack of understanding from extended family at the time. Presently, she attributes the lack of tangible offers of support to the lack of knowledge of their need in combination with distance. She found a paid caregiver through her school community who is a source of intermittent support; however, the primary responsibility for managing her daughter’s physical and medical care remains with her.

Lucille copes by taking mini-breaks during errands to the store. She is also highly involved in her parent community, where she receives most of her social-emotional support. She described barriers to social support primarily in relation to her daughter’s limitations, which limits her ability to connect to parents whose children can participate in extracurricular activities. However, she does not feel that she has much in common or that these parents could relate to her. Her support circle consists primarily of parents of children with disabilities.

As her child has grown, physically lifting her child is becoming one of the more intensive aspects of caregiving work and the area where she receives the least help. Her partner’s recent medical events and subsequent diagnoses prevent him from helping physically, so Lucille is the only person who can lift, help with bathing, and other daily routines. This impacts her ability to be available to socialize, and she has not been able to find a caregiver who she described as young, strong, capable, and available enough to replace her. A new person would need to learn about her daughter’s care needs, and most people do not have the time to invest in that. She talked about plans to modify and equip their two-story home with a lift and the difficulty of affording necessary renovations, which insurance does not cover. She believes the solution is more empathy and understanding, so she continues to educate others about the reality of caregivers’ experiences.

Tanvi

Tanvi is in her late 40s and identifies as a Black, cisgender female and heterosexual, and she lives in the mid-central region of the United States. She indicated that she is widowed, has a college education, and her household income falls within a lower socioeconomic status. Tanvi is a talented musician who excelled in her craft from a young age and stated that she recognized she may have gone undiagnosed after learning of and understanding better her children’s diagnosis of Autism Spectrum Disorder. Tanvi's twins are non-verbal, and she describes them as great at communicating without words, calm, highly intelligent, and each with their unique special interests. Tanvi delivered her fraternal twins and then subsequently and unexpectedly lost her husband, who was a public personality and well-known in their circles. When Tanvi lost her spouse about ten years ago, the twins were two months old, and she was residing in the southeastern part of the United States, having recently made the move for her spouse’s career. Tanvi described how this unexpected loss, combined with the twin’s birth and then developmental delays, deeply impacted her experiences of motherhood, as well as her experiences of social support and relationships with extended family and friends. Tanvi’s interview was distinct from others because it contained specific and explicit examples of discrimination because of her race.

Tanvi emphasized how she was mindful of her family’s generational legacy of single mothering and acknowledged the stereotype of the Black single mother. Because she associated this experience with significant challenges, she sought to avoid becoming a single mother:

> This is exactly [why] I did not want to be a single mom, because my mom's a single mom, and there's just so many single moms in my family and the way they struggle, and I just didn't want that. I waited until I was older to have kids and stuff, just to make sure I was settled, and I didn't want to be like that but well. And then a few years later, find out that they're both autistic. I'm like, great. Wow. This is amazing.

She described the shock of becoming a single mother in the wake of what was going to be one of the happiest seasons of her life:

> I just became a single mom after thinking that this was about to be the happiest time of my life, but… I wanted twins. [My husband] was the love of my life. I was so happy with everything, and then just like that, it's the worst moment of my life. I think about it today, and I just can't believe it.

Tanvi described her initial experiences with medical professionals as a recently widowed and a newly single mother as daunting, unempathetic, and discriminatory. For example, when she arrived at the hospital behind her husband's ambulance, the medical team delivered the news of her husband's passing when she arrived, and then would not allow her to take his belongings home until she came back with a marriage license. Soon after the shock of learning her spouse passed, she began to wonder how she would cope as a single mother. Tanvi recounted how friends and family members stayed close by for about three weeks and then followed the daunting realization that she was left alone with her twin infants. She begged one of her best friends, who was one of her last remaining supporters, to stay longer:

> I was like, "Please don't leave me. I'm scared." And he's one of my best friends since high school, and I know that made him so sad that he had to go. He's like, "Tanvi, you're going to be fine." I'm like, "Okay." At some point I have to do this, because I knew there was just going to be this painful silence, but it had to happen. I had to eventually do that.

Tanvi also described herself as functioning poorly in those early weeks and months after the loss:

> I was a zombie. I was doing the stuff, but I didn't have any feelings. I was just doing it, and I never slept, and I didn't start sleeping until last year… I felt very vulnerable in a

> city where I don't know people anymore, and I was just scared. And I was like, "What if somebody breaks in this house? What am I going to do?" Just so many thoughts, and maybe some of them are irrational, but they're all things that could happen.

Tanvi's memory of the days after her loss was that friends and family members remained distant and offered minimal instrumental support, but on the occasions that they were in contact, they began to notice and comment on what they perceived as evidence of the twin's developmental delays. Because she was still grieving, Tanvi struggled to discern whether the symptoms were a consequence of grief and loss, or if the noted behaviors could be symptoms of a disorder. In response to concerns, she sought speech and occupational therapies for the twins at age two. Ultimately, her children were diagnosed at the age of four with non-verbal Autism Spectrum Disorder. She described the cognitive dissonance around whether her prolonged shock and grief contributed to the diagnosis and the shame and blame she felt from family members who would covertly suggest that she was deficient in her parenting of the twins:

> They seemed distant from people. To me, it all made sense. I'm like, well, their dad died. I mean, maybe they don't know that, but they live with me and I'm not raising them in the style or fashion of somebody who's not going through what I'm going through. I didn't see why people were shocked to see that they were behaving a little differently than other kids.

As Tanvi learned more about autism, she described having feelings of familiarity with her children's behaviors and even found them relatable:

> There's a lot of stuff about them that reminded me of myself when I was a kid.... I didn't talk. I did a lot of the same stuff… as my kids get older and I realize how much we have in common, it makes me realize that I might be autistic as well. So I'm neurodiverse.

> Yeah, it does open your eyes when you have that diagnosis and then you start to learn [about] your child and you start to look at yourself and your family tree. Yes. You start to see things, for sure.

Tanvi's caregiving work involves coordinating care and behavior management related to sensory sensitivities, eating, toileting, and sleep challenges. She locks the house from the inside and barricades potential exit points to prevent them from running away. Tanvi went through a process of accepting her children as they are, and giving up the expectation that they would be able to participate in frequent outings or within a school community. She homeschools her children and adapts her lifestyle according to their needs, such as not requiring them to wear clothes inside the house or avoiding battles over food preferences by adjusting their diet. It has been difficult for her to secure any kind of support. Paid caregivers have dropped out of her support circle without mention or warning. She described frustration in response to extended family members who judge her for unconventional parenting and offer advice, and check in on occasion or offer financial support from time to time but do not make themselves available to offer hands-on support:

> A lot of times… I try not to go out, and I wouldn't tell that to my family because they always put pressure on, "You got to take the kids places. They need to go somewhere," and then sometimes it'd be like, "They need to go somewhere every day." I'm like, "No, they don't. I didn't go somewhere every day." My mom was tired... I would [go out] just to shut my family up, and my kids would be upset. They don't want to go somewhere. They want to be at home. They love it here. I've made this place a place where they want to be, so they actually want to come home.

Tanvi stated that she copes by masking. She described how there are times when she gets to a breaking point and then she explodes on extended family members, acknowledging extreme responses backfire on her and distract from the greater dilemma of a significant lack of care support. She works to “be cool” with friends and family members but she struggles with resentment when her family wants to re-engage after long periods of no or minimal contact. She also copes by being in silence, making space for her own complicated feelings, zoning out on Netflix, and, when help is available, asking for time to take a long walk. She also affirmed that she knows she is a good mother who is doing her best given her circumstances and resources. She firmly believes that upon a child receiving a developmental diagnosis, there should be a way for parents to access a parent support group and that parents of children with behavioral or neurological complexities should also be able to access ongoing caregiving and respite support.

Mandia

Mandia is in her late 40s and identifies as a Black, cisgender female, heterosexual, a pastor’s wife, and a full-time nurse with a high household income, living in the northeast region of the United States. She is originally from Haiti, and she and her spouse speak English as a second language. She describes herself as having three full-time jobs: nursing, parenting, and caregiving. Mandia is the mother of two children, a son who is developing typically, and her younger daughter, who has been diagnosed with multiple disabilities, including visual impairment and non-verbal Autism Spectrum Disorder. She describes her daughter as sweet and funny, with the ability to make her laugh, and who loves to give kisses. Her daughter also loves music, especially Miley Cyrus, and picture books. Mandia describes that her daughter is able to walk but not for very long distances, and is dependent on others, requiring full support with activities of daily living. Her older brother is aware of and sensitive to his younger sister’s needs and participates with the family in her care. She describes her spouse as supportive and doing his best but believes that he does not always know or understand how to help the way a woman would. Her routine of caregiving work involves working full time and fulfilling her role as a parent, spouse, and community member, so Mandia often functions on three or four hours of sleep.

Mandia currently has her daughter enrolled in public school but would like to secure an out-of-district placement, which she believes would be more appropriate for meeting her treatment goals of becoming verbal and living a more independent life. Mandia’s parenting and experiences are defined by her belief that her non-verbal daughter can, and one day will, become verbal. She talked about facing significant challenges in securing specialized support, mainly that she has been discouraged by providers from believing that her daughter could gain language skills:

> But we are strong believers. We believe that she will not stay like this. She will improve. I don't see her like a disabled child. I see her like she learn different (sic)… That's how I see it… she will get there. The label is not her... She just need (sic) to be in a perfect environment.

She attributabes her challenges to access services more readily due to racial, language, and culture barriers. In addition to advocacy challenges, Mandia describes barriers as the outcome of a post-COVID world where specialists have long waiting lists, or are no longer working. This lack of availability has prompted her to consider returning to work to become a specialist in the areas where she perceives a shortage (for example, speech therapy). However, she acknowledges that with her current responsibilities, she is unlikely to make a challenging career change or go back to school.

Mandia’s faith and her faith community are an essential part of how she experiences social support. Mandia copes by staying involved with her faith community, singing, and praying. She receives prayer from a prayer partner within her community. To cope with her caregiving load, she likes to go out and shop and acknowledges that she rarely has the time to do this. Instead of going on a big trip, she will go into a store and purchase something small for herself. Mandia believes that mothers who live with the child are experts about what their child needs and should be listened to by medical experts. These mothers appreciate supportive listening, presence, hope for their child, and a break from caregiving work. She has asked specialists to recognize that mothers with burdens and responsibilities beyond caregiving work require support.

Sadie

Sadie is in her early 40s and identifies as Kama'aina, a person who was born and raised on a Polynesian island. Sadie identifies as a single mother who is a native Pacific Islander, she is cisgender, and heterosexual. She does not identify as having a disability herself but recognizes that she struggles with executive functioning and describes herself as scattered, all over the place, and as a spontaneous, artistic, creative personality. She recognizes in herself some traits similar to those of her daughter, such as resistance to last-minute changes to her routine. Sadie has some college experience, works as a public-school kitchen manager, and is a hairdresser six days a week. She alternates between these two positions, which are seasonal in nature. Her household income places her in a low socioeconomic status. Sadie’s adolescent daughter has a diagnosis of Autism Spectrum Disorder and attends a public school with an individual education plan (IEP). She describes her daughter as artistic and smart, with many remarkable talents and a desire to make others feel good. Sadie’s experiences as a caregiver are marked by intense feelings and frustration over a lack of support and experiences of stigma from family and community members in response to her daughter's behaviors and subsequent diagnosis.

Sadie was the first person to notice that her young daughter was initially developmentally advanced but then regressed, missed milestones, and demonstrated significant behavioral differences. Initially, she believed that her daughter would grow out of the regressions, but then changed her mind after observing her daughter's behaviors with peers. Family and friends distanced themselves. Medical professionals denied the diagnosis. Feelings of isolation in her experience eventually prompted her to move away from the place she knew from birth. Sadie moved to the northeast to seek specialist support when her daughter was younger. She expressed appreciation for the medical doctors in the northeast who finally validated her concerns and offered a diagnosis of Autism Spectrum Disorder. She expressed that while it was validating to have her instincts about her daughter confirmed, she was provided minimal support beyond a diagnosis and a long referral list. Sadie described feeling overwhelmed at the prospect of coordinating care beyond a diagnosis. When her daughter is not in school, she stays home alone for up to nine hours while Sadie works. Sadie describes how her daughter is able to independently alternate between preferred activities like video games and talking to a friend or drawing, but when she is not available, her daughter will simply not have the support she needs to follow through with essential self-care activities like bathing, eating, or going to the bathroom. She acknowledges that while her daughter is a teenager, she functions in many ways like a younger child. Behavior management is a large part of the caregiving work, as Sadie struggles to help her daughter adhere to self-care routines and work around sensory sensitivities and strong preferences. As her daughter ages into a young adult, Sadie continues to experience challenges around caregiving work related to managing changes in routine, limits around her daughter's social skills, menstrual hygiene, and strong preferences for specific pieces of clothing that feel better to her than others. She also described experiencing exhaustion as her daughter stays up later at night, leaving Sadie less time to recover from work and caregiving support. With no feasible options for caregiving support, and an inability to take on the high cost of specialized childcare, Sadie relies on her daughter's strong preference for staying home on the couch to manage concerns about safety while she works. Sadie's primary concern is whether her daughter will eat while she is away at work. Occasionally, a family member is willing to drop by and check in on Sadie's daughter, but that is disruptive to her regular routine, and prompts behavioral challenges. Sadie gets frustrated by family members who offer her advice to get more support and therapy for her daughter, but then do not offer the tangible support she would need to have the time and energy to coordinate additional, specialized support. Sadie stated that she struggles to advocate for herself and her daughter, as she has been used to handling life on her own.

Sadie feels judged about her parenting skills by family and friends, especially in moments when she is out in public with her daughter. She wishes that her family and community members would take the time to learn about her daughter's diagnosis so that they can accurately interpret challenging behaviors and offer support. She also wishes that they would recognize her as over-functioning instead of under-functioning as a parent, provide her daughter support, and provide her with the respite that she needs to cope with her daughter's challenging behaviors. Sadie recognizes that her daughter needs more help than she can offer her, and as a single mother, she feels her most significant barriers are energy, income, and time limitations. Sadie copes with the help of two close friends who also have children with disabilities. She regularly talks to one friend while they are making dinner together. If she could wave a magic wand for all caregiving mothers of children with disabilities, she would want them to have understanding and supportive experiences with family members. She would also make expert care and support for caregivers and their children more readily available and easily accessible.

Melissa

Melissa is a divorced single mother in her late 40s who identifies as a White, cisgender, heterosexual female. Melissa’s household income places her in a lower socio-economic status. She has a Master’s degree and works as a teacher in the public school system, while also being a mother to her son, who has a genetic syndrome with deafblindness. Her son is elementary-school-aged, and she describes him as affectionate, loving the playground, and preferring the outdoors. She describes her son as stubborn with the capacity to work hard and that when he wants to do something, he will “work and work and work.” Melissa learned that her son had a heart defect during her pregnancy. After delivery, she learned that he was born with a genetic syndrome. She recalls this as a shock, especially because she took all the genetic tests available to her at the time. The prognosis given by the medical community shortly after his birth was dire; they expected that he would be completely blind, never hear, never walk, and have difficulty developmentally. Melissa spent those earliest weeks and months with her son in the hospital, caring for her son through an open heart surgery at two months old and several more in the following year. Maternity leave covered Melissa’s absence for a portion of the time they needed, but eventually, her employer offered reduced pay for her to take an extended leave. The stress of their son’s medical events, her spouse’s inability to adjust, and financial stress contributed to their divorce a year later.

Today, Melissa describes her son's multiple diagnoses as complex and the caregiving routine involved as intense. Her son is medically fragile, and so a concern for her through the

COVID-19 pandemic was making sure that he avoided exposure. During the pandemic, her brother moved in to help care for her son while she worked. Caregiving involves managing her son’s non-verbal communication and interpreting behaviors, which she says can be especially difficult when he struggles to tell her what he needs or when he is in pain. Managing difficult behaviors can also be exacerbated by communication. Melissa manages a regimented medication and feeding schedule, a g-tube, a special pureed diet, medical care, and special equipment for chronic lung disease. The care routine is so involved that it keeps Melissa and her son up regularly until 10:30 or 11 every night. In addition, the symptoms of her son’s diagnosis indicate sleep issues. Melissa often feels chronically fatigued, from her son’s needs, combined with late nights, an early wake-up, and working with young children: “It's really difficult, especially when I'm working, it's just hard to [not get much] sleep. And it's hard because I've never had a nighttime nurse or my brother help with any of that.”

In addition to these more specialized kinds of caregiving, Melissa manages her son’s educational advocacy, medical and therapeutic appointments, and coordinates insurance and billing. She says she has spent hours on the phone with insurance and billing. Melissa often feels isolated when making medical decisions for her son, with no person in her social support sphere who is informed enough about her son’s needs to help her manage and make major decisions:

> I just feel like I'm fighting these fights all by myself. And even in the IEP, I write all the documents, and I fight all the fights. I hope I don't come off as a bitch, but I feel like sometimes when I wear that mama hat, mama tiger hat, I will fight for him and say I think he deserves more than this or he needs more hours of this therapy. . . And it doesn't feel good to always do it on your own, and it's exhausting. And it's also hard when you have no one, I can't really talk to his dad, really. And then I have no one else to talk to.

Melissa copes by going on short runs whenever help is available. She also keeps a gratitude journal and a photographic journal of her son that she updates, so she avoids repeating herself to anyone who asks. She works tiny breaks in to get coffee when her son has an appointment at the hospital. She also works to mentally compartmentalize her experiences of life with her son and her experiences of life outside of her caregiving. If Melissa could create any kind of support for other parents, she would make resources like meditation or yoga free for caregivers. She also would place an emphasis on increasing the availability of care workers who could take over care and offer respite services for exhausted parent caregivers.

Marium

Marium is in her mid-40's and is a Black, cisgender, heterosexual female, who is married with two children. Her household income places her in the middle of the socio-economic range for this study. The youngest was an infant at the time of the interview and her older son has a diagnosis of ADHD. He is also on a 504 and a behavioral plan at his local public school. She works as an educator at another public school in the northeast and is the founder and director of a non-profit serving underprivileged children. Marium identified traits of ADHD in herself but never received support or an official diagnosis. She described her son as a "mirror" to herself. Marium's faith plays a significant role in her worldview, life, parenting, and experiences of discrimination in parenting and advocacy for her son. She described her oldest son as an incredible young human being who is a visionary with many ideas, and that she wants to honor who he was created to be. She also acknowledges that he moves a lot on impulse without pausing to think about the impact of these impulsive behaviors on himself or others.

Caregiving work for Marium encompasses primarily behavior management and educational advocacy. For Marium, behavioral management includes consistently and continually re-engaging her son in conversation in an effort for him to have insight into what she views as problematic behaviors. Marium also spends a good amount of time communicating with her son’s teachers, so his needs and behaviors are addressed in the classroom as well as at home.

Marium is the heart of her home, and she works to create a structured routine with plenty of activities incorporating movement. Marium explained how she often works to find a solution or strategy to support her son with lagging executive functioning skills. While she views her son as capable and envisions a hopeful future for him, she also recognizes that she is prone to being triggered by his persistent maladaptive behaviors and what she calls his “big energy.” Marium shared how she observes her son’s responses as overreactions and then how she turns to recognize and deal with her overreactions, even as she works to help her son manage himself.

Marium copes by immersing herself in prayer, venting to God, and listening to uplifting music. She also seeks conversations with other parents who have similar experiences. She described how important it is for her to seek and to have deeper insight about how to better parent her son: “Honestly, when I have conversations with certain people, light bulbs go off…. I'm all set, and I don't need to prolong [worrying]... I don't have time to be in a rocking chair, honestly.”

If Marium could create the kind of support that parents need, she would eliminate all barriers to support at the onset of diagnosis. As an educator, she believes this change would also benefit educators who are often frustrated by the lack of resources available to help support children with social-emotional needs or disabilities:

> In an ideal world, everybody is seen for who they are. In an ideal world, there's no need to separate… anyone unless that's their need for education. Yeah, if there's a magic wand,

> we see each other, we have the time…we talk about everything…and actually have time to actually do the work that we actually need to do to actually know who the student is.

Nadiah

Nadiah identifies as a racially white, ethnically and culturally Middle Eastern, cisgender, heterosexual, married female in her mid-40s. Her household income is higher than average; she holds a Master's Degree from a university in the Northeast. Nadiah worked in international government and is currently a senior U.S. government official. Nadiah was born in a Middle Eastern country, and identifies herself as a dual citizen who spent her earliest years with her family in the United States, and a significant portion of her life living in the Middle East. She returned with her family to her home country as an adolescent and young adult, where she met and married her husband. Because she was acclimated to her country of origin and local community, Nadiah had no plans to return to the U.S. However, after having a son who was diagnosed with Autism Spectrum Disorder, Nadiah and her spouse had to reconsider. They decided to return to the U.S. so that their son could have access to more services, and minimize the stigma of ASD that is still prevalent in her home country. Nadiah describes her son as highly intelligent and intuitive, and as being very "with it." Caregiving work for Nadiah primarily consists of behavior management, coordination of care, and educational advocacy.

Nadiah described how different people in her life have been supportive at different times. In the earliest years, Nadiah's mother was supportive and available to help her by picking her son up from childcare, feeding him, and facilitating his bedtime routine. Her availability was limited due to additional responsibilities, including caregiving for extended family members with medical needs. The grandmother who was most willing to help was elderly and did not consistently have the stamina to meet her son's needs over longer periods. While they showed great affection for their grandson, the paternal grandparents are medically fragile with physical disabilities, and Nadiah found that she needed to limit the number of requests to take on further caregiving responsibilities. In the transition to seeking services in the United States, Nadiah and her husband have become their son's primary caregivers; outside of school services, she does not have support from extended family or friends.

Nadiah described several scenarios that prompted her decision to move internationally, some of which highlighted the difficulty navigating the stigma about disability in her country of origin: “I know my son. He's very smart. He knows who's treating [him] very normally, the same as a kid, and he knows that, ‘Ah, it's okay.’ No. So that's where I, in a sense, put up walls. That's a stigma.” Nadiah struggled to find accepting and inclusive spaces, whether in the community or daycare. In childcare settings, her son’s developmental differences were criticized by caregivers instead of supported: “When I used to take him to the daycares, when I used to take him to play areas and used to take him to playgrounds, and even to the mall, anywhere. . . . If he had his tantrums in daycares for example, he was way behind his peers.” She suspected one of these facilities of abusive behavior and subsequently moved her son to a different facility. Eventually, she found one teacher she could rely on, who had a background in psychology and understood enough about Autism Spectrum Disorder to become a more supportive caregiver in comparison to others. Nadiah found that while this was helpful, she still had to navigate the stigma of the administrators and other caregivers, who viewed her son as hopelessly delayed and challenged. After several consultations about placement, her son’s medical team strongly recommended that she leave her country of origin and integrate him into the U.S. school system. After an assessment with an American medical team, Nadiah’s husband also shared strong feelings about the necessity of leaving their country of origin. Nadiah recalled a significant moment after diagnosis in the U.S.: “I (will) always remember his face. He explained to me, "Baby, we can't go back...We're staying here."

Nadiah copes by engaging herself in her work, where she is involved daily in high-level government policy work. She has made friends with other parents from her country of origin, and they meet regularly to share their culture, food, and time. Nadiah and her husband have also coordinated so that they are both aware of and agree on managing their relationship with the school system, including which parent will attend school IEP meetings. They decide together what to negotiate with the school, so that neither parent is left with the full burden of advocacy: “So we agreed without them knowing, and then I put him on the phone because he knows how to fight. And then I ask the sneaky questions, and then he asks questions. We coordinate with each other.”

Nadiah believes that if others wanted to be more supportive of her, they could engage her son in playdates. She wishes she could have more friends but recognizes that the number of friends she can have is limited by her tendency to be careful and selective of her inner circle. If she could help all other caregiving mothers, she would increase the funding and budget for school districts and incentives for them to support children with disabilities. She would also create more social groups for people of the same culture and inclusive extra-curricular activities and sports for children. Nadiah believes that all teachers should have specialized training on the Americans with Disability Act (ADA). This could make a difference for families contending with barriers and access to services within the school system.

Conclusion of Participant Portraits

In this study, mother’s ethnic identities were varied, and their children represented a broad range of developmental disabilities from ADHD and Autism, to challenges with signficant developmental delay, sensory, and medical impairments. Overall, each mother who participated identified themselves as experiencing marginalization in their social support sphere by a lack of access to services, the minimization or denial of the severity or impact of a diagnosis, and a lack of more supportive experiences. Mothers with a BIPOC identity discussed challenges related to culture, language, and race. All mothers in this study identified strongly as advocates for their children, for whom they expressed affection, love, and hope. Mothers described challenges navigating community, medical, and educational systems for access to services. Mothers' experiences also highlighted how they worked to manage the significant adjustment to understand and support unfamiliar diagnoses.

Eight out of the 11 mothers in this study described making a significant life change when the diagnosis required a geographic relocation to access appropriate support and services. Multiple mothers expressed challenges communicating fully both the emotional labor and more tangible difficulties involved in their journeys as caregivers, to the friend and family members who they initially looked to for support. With every challenge, these mothers demonstrated incredible resilience, shared their expertise and insight in the hope of benefitting other parents, and were ready to share insight about how to improve the experience of social support for caregiving mothers more generally. In the next section, I summarize the key findings of the research, which fell into five main themes. These themes were: Marginalized Identity, Difficult Emotions, Caregiving Work, Barriers to Social Support, and Resilience.

CHAPTER FIVE: FINDINGS

This chapter discusses the key themes and findings from the research data drawn from semi-structured interviews with the 11 participants. The data analysis process was grounded in Interpretive Phenomenological Analysis (IPA) methods and produced five key themes. There were three primary sources of information that informed the data. These sources were the social support map, demographic questionnaire, and semi-structured interview. Data from the social support map and the demographic questionnaire were collected and organized into tables. Social support maps were utilized, but they were often illegible or incomplete so there was not consistent enough information to support a visual diagram, but the data contributed to the overall narrative about mothers' experiences with social support. Recordings from semi-structured interviews were transcribed and the data were downloaded into MAXQDA software, where descriptive elements of the interview were identified and then organized into over 20 categories. From these categories, ten main themes emerged. From each of these themes, three sub-themes were determined. Following the iterative design of IPA, the main themes were further reviewed and then narrowed into the most commonly addressed themes from participant interviews. The major themes identified, as shown in Table 2 below, were: Marginalized Identity, Racism, Difficult Emotions, Caregiving Work, Barriers to Social Support, and Resilience.

Table 2

Key Findings

Key Findings	Themes	Subthemes
	Marginalized Identity	Courtesy (Disability) Stigma Microaggressions
	Racism	Internalized Discrimination Language Barriers
	Difficult Emotions	Isolating Experiences: They Don’t Get It

	Adjustment to a Diagnosis
	Denial of a Diagnosis
Caregiving Work	Advocacy
	Behavior & Care Management
	Geographical Relocation
Barriers to Social Support	Parental Exhaustion
	Lack of Care Support
	Least Supportive Experiences
Resilience	Coping
	Most Supportive Experiences
	Ideal Scenarios: Magic Wand

Marginalized Identities

Mothers in this study were from a wide array of ethnic identities, social-economic statuses (SES), education levels, disability, and marital statuses. During the selection and interview process, it became apparent that the term “marginalization” had different meanings for different mothers, beyond the initial definition used for the study. During interviews, mothers shared how they more strongly associated marginalization with experiences of supporting their children with disabilities, rather than with the definitions of marginalization for race, ethnicity, sexuality, etc. Each mother who was selected for participation was explicitly asked how having a marginalized identity impacted their experiences, and all eleven mothers gave examples of experiencing discrimination, isolation, and microaggressions related to their child’s disability. These experiences were associated with family, friends, and the greater community, including specialists, educational staff, and medical professionals. Three mothers identified language and cultural barriers as a part of their experience of marginalization. Asian mothers described experiences of marginalization and discrimination based on their own and others’ internalized cultural expectations of the academically high-achieving Asian, which is one stereotypical portrait of a model minority. Black mothers in this study were able to clearly identify and describe experiences with racial discrimination.

Courtesy (Disability) Stigma

Courtesy stigma is defined as the stigma that caregivers experience in proximity to their children with disabilities disability (Ryan & Runswick-Cole, 2008; Goffman, 1963, as cited by Stober & Franzese, 2018; Tikkanen et al., 2019). Mothers in this study strongly associated feelings of marginalization with their experiences of stigma while parenting their children with disabilities. Courtesy stigma emerged more prominently as a theme when it recurringly underscored mothers' experiences within society, within medical, specialist, and educational communities, as well as with friends and family.

Nadiah, who immigrated from her home in the Middle East to the United States for educational services, described her experiences of stigma more generally as a societal issue within her country of origin. She said that if any family members "are mean or whatever, or stupid, you just block them. But you can't block people in the supermarket, playground, daycare, anywhere you go." More specifically, she described uncomfortable experiences with educators and childcare workers who described her child as "so behind" and "so weak," pointing out to her where her son was falling behind his peers. She felt these comments were an attack, and then asserted herself in an attempt to block the harmful conversations. Similarly, Sadie described her experiences of stigma in the U.S. when she is in public with her autistic teenage daughter:

> I know this shouldn't matter, but her whole entire life, I have felt a judgment on my parenting from strangers… I would get side eyes at the stores...and she wasn't naughty. She was just being herself... And I… felt inadequate as a parent. Like I'm doing it wrong. And this was well before her diagnosis.

Jenni cushioned her experiences of stigma by empathizing with ignorance about disability. Nevertheless, she indicated that she was still profoundly impacted by a lack of understanding about parenting children with disabilities:

> I mean, I don't blame them because there's so many different categories of disability… but some people do not have the patience to listen… And sometimes they think [it's the] parenting approach instead of the disability itself… if my child cannot sit still... It's just a parenting failure. That's not helpful.

Mothers described how experiences of stigma with educational and medical specialists or interventionists contributed to feelings of marginalization. Ruth felt the impact of discrimination when her son with multiple disabilities and low vision was denied vision therapy in the public school system, because he was competing for access to support with children who were fully blind. In another example of stigma impacting access to education, Julie recalled preparing diligently for an IEP meeting only to have her concerns be dismissed, and to be mocked by a lead administrator on the education team. Ruth shared her experience of stigma when speaking to medical professionals and specialists more generally about her child's prognosis, sensing their internalized stigma when they hesitated to discuss the reality of her child's significant disabilities:

> Nobody knows how to talk about when something's wrong with your kid and when your child has disabilities. And people just kept saying, "Oh, he'll catch up, he'll be fine." Over and over and over again. I mean, I remember that hospital stay, one of the doctors who's never met him was like, "Just wait till he is three, he'll be fine." Why are you saying that to me?

Sadie described similar experiences of professionals who were uncomfortable or unfamiliar with addressing the possibility of disabilities:

> They were like, "Oh, well, oh, well, she's just a hardheaded kid, or She's very difficult. She'll grow out of it. She'll grow out of it.” I'd be a millionaire if I got dollars every time they told me she'd grow out of it. I'm talking to teachers, parents, doctors, therapists, psychologists, psychiatrists. . . they all told me the same thing. We went to specialists [and when] I said, "I'm not sure, but I'm wondering if she's struggling with sensory processing disorder." And he looked at me and he said, "What's that?"

Experiences with friends and family members held significance for mothers who described how they experienced turning to the family for support, and then those family members creating distance. Sadie described how her father disengaged from the relationship with his granddaughter after realizing the disability diagnosis: “But after the diagnosis…he also stopped really interacting with her at all… My daughter could be sitting in the same room with him... She doesn't feel loved, or special, or anything. And she's got a ton of really awesome talents.”

Jenni navigated an international move from the U.K. to the U.S. She found that to have her parents’ emotional support, she needed to work around their discomfort with disabilities, which she identified as culturally bound:

> My mom sometimes got emotional. She'll cry a little bit in front of me and she says something like, "Why is it so hard for our family to raise our children?” ... “Disability is not a dirty word. It's just who they are.”

Melissa’s marriage ended in part under the strain of the multiple diagnoses her son received, and she described her ex-husband’s struggle with shame about their son’s disabilities and medical needs. She believes her ex, who considered himself an athlete from a sports-loving family, was struggling watching friends with their healthy children. She reported that he currently has minimal involvement with his son. Melissa, now a single mother, shared sentiments that were similar to other single mothers who had concerns and conflicting feelings about the prospect of finding a partner who would be willing to date the mother of a child with disabilities:

> Just in terms of being a single mom and dating, that's not something I need. But it's been challenging, like how much do you talk about? And then when you do talk about it, there's just way different reactions. And then also when you do get serious with someone, how much do you let on? And I don't even know what the trajectory of our life looks like, but I feel like, do you talk about that? My son might be living with me for my whole life. And at what point do you admit this stuff or talk about this stuff? And I don't know, when you just think about being a single mom and trying to enter that kind of realm of starting a new relationship, that adds a whole [other] element.

Overwhelmingly, mothers experienced stigma in proximity to their children’s experiences within every domain of social support. In response to stigma, mothers emotionally and mentally labored to understand and process their experiences. Courtesy stigma underscored significant experiences for mothers, impacting their ability to be heard about their child’s needs in professional settings, contributing to distance and feelings of isolation in their closest relationships, and for one mother, was a major factor in her divorce. Single mothers echoed how disability stigma is a barrier to dating and finding a partner. Ultimately, mothers had a profound awareness of courtesy stigma and the consequences for them, and for their children. In the next section, I share how mothers experienced microaggressions as a form of marginalization.

Microaggressions

In addition to experiences of marginalization through feeling courtesy stigma and shame, the theme of microaggressions emerged as mothers described navigating relationships within the context of family, friends, and community members. Microaggressions were identified in this study as exchanges in the context of family, friend, and community relationships that outsiders could perceive as harmless or even helpful (Sue, 2015). Still, they were described as hurtful to mothers who are parenting children with disabilities. Tanvi, who was widowed shortly after her twins were born and is now raising them as a single parent, described feeling hurt and further isolated when extended family members feign care by asking general questions while avoiding being more actively involved in her children's life. Tanvi stated: "They're just such generalized questions... they just don't try to understand anything. They're just going through the list of things they need to ask because they haven't talked to me in a long time." Additionally, Tanvi described how it felt when family members pressure her to take her kids out in public but are not willing to be available to support the enormous physical and emotional work involved when going on outings with her autistic twins:

> They always put pressure on [me]... I've tried to take my kids out. I would do that just to shut my family up, and my kids would be upset. They don't want to go somewhere.

Additionally, the microaggressions Tanvi experienced from family members are compounded by community members who shame her for how she manages outings with her twins, who tend to elope, or escape, which places them at risk for harm (Anderson et al., 2012):

> To this day, I push them around in this big wagon thing. It's expensive. Now they're big, so it's hard to push. When they're in there, I know where they are, and then there's people looking at me like, "Oh, they're too big to be in that." I'm like, "No, you don't know what you're talking about. Why don't you ask some questions first?" It's the judgments. That's

> why I don't like to go out, because I don't want to be judged and explain to people why I'm doing what I do with my kids.

In another example, Melissa’s caregiving consists of a heavy physical workload. She acknowledged that while she needs support, she experiences other people’s pity as a microaggression:

> People who express pity, like feel sorry for us, I don't like that. And because I'm like, we're very happy just because I'll say, "Oh, my son's deaf," and they're like, "Oh, I'm so sorry." It's like, "No, it's okay," or when they get embarrassed or stumble over [their words] and then want me to save them from that, it's just not my position to make you feel more comfortable... people just don't have the right words. [My landlord asked] "Is he ever going to be normal and will he ever be fully functioning?" And I was like, "Well, I feel like the hope is that he can function the best he can, and he is already normal. He just has some different abilities.”

Jenni experienced microaggression when she was hurt by a friend who compared and then minimized her experiences as a parent of a child with disabilities. As she shared the child’s diagnosis and her feelings about related challenges, her friend responded by comparing her experiences of divorce. Jenni experienced this as minimizing of the nature of her challenges, and she felt dismissed.

Marium described a similar scenario where her feelings were invalidated when she shared how she felt exhausted from the additional work parenting her son with ADHD required. She was hoping for support or encouragement, and instead her mother minimized her feelings about the additional work managing challenging behaviors:

> Sometimes you want to be able to just share how you're feeling and not be judged or criticized or not have it be demoted like, "Well, we're all tired. It's fine. You just have to deal with that." I think validating the feeling is incredibly important.

Mothers in this study shared multiple examples of microaggressions that contributed greatly to the emotional load of caregiving, and also to mother's feelings of exhaustion and burnout. For these mothers, microaggressions landed as unsolicited criticisms and unrealistic expectations from family, friend, and community members who were unfamiliar and uneducated about their child's disabilities and their more unique needs. Mothers generally indicated they understood that offenders were not familiar with disability or with their children more specifically. However, mothers still felt judged, criticized, and generally misunderstood, and this aspect of their experiences with social support contributed greatly to their caregiving burden beyond the tangible caregiving work. Mothers who identified as an ethnic minority described experiences of courtesy stigma and microaggressions, as well as discrimination directly connected to their race. Notably, mothers responses to microaggressions were either to confront directly or withdraw, and mothers primarily described withdrawing from or minimizing social exchanges as one way to cope. In the next two sections, I look further at examples of marginalization through themes of racism and racial discrimination that emerged in this study, including internalized discrimination especially regarding model minority stereotypes, and language barriers.

Racism

Black mothers in this study described experiencing racial discrimination more overtly than mothers of other ethnicities. They gave specific examples where racism impacted them and created further complexity in their experience of parenting a child with disabilities. Tanvi, the mother who was widowed shortly after her twins' birth, described one such experience that was the catalyst for a geographical relocation from the deep South to a Northern state, where she could access services and feel that she and her children were safe. Tanvi shared how she supplements her children's narrow diet, because of the strong preferences that are a common trait in children with an autism diagnosis. However, an agency prescribed a regime of drinking a nutritional supplement that her daughter refused. When Tanvi's efforts at communicating with the agency and adjusting to her daughter's preferences went unheard, the agency called Child and Protective Services (CPS). Despite her efforts to explain her situation, she was reported to CPS by a representative of the agency. They neglected to carefully review her history and recognize the incredible stress she was under as a dedicated, but recently widowed mother, with two young autistic children. Tanvi felt that she was perceived as the stereotype of the uneducated, single Black mother on welfare instead of an educated, concerned, and engaged mother who was recently widowed and facing significant life challenges:

> I think they were attacking me because, "This Black woman needs to come in here and shut up and just be grateful that we're doing this for her little kids. She thinks that she knows everything, and she's talking to us like this," because I didn't just say, "Oh, thank you, guys. Yeah, I'll just do what you're telling me to do." I opposed what they told me to do, and I told them why I wasn't going to. I told them why my thing was better, but I guess I wasn't supposed to say anything or know anything.

The incident was a significant event for Tania, and she described how she felt angry, minimized, and traumatized by the experience:

> Yeah, I'm supposed to be dumb. Just, "Thank you, guys. You know everything 'cause you just got out of school five years ago. You know more about my kids than I do. I should

> have just shut up." So then they called CPS on me. I'm traumatized to this day. Every time I hear a doorbell, it sends me into an anxiety attack because I think that somebody's coming to take my children from me. That really ruined my life for a while. I should go talk to somebody about it because that really destroyed me 'cause that was my worst nightmare, is for somebody to come and tell me they're taking my kids.

The event continues to impact her mental health and her feelings of trust about providers into the present: “I'm still having problems trusting anyone.”

While Tanvi’s experience in a community health program in the deep South was traumatizing for her, and overtly discriminatory, Marium described discriminatory experiences while navigating the educational system and her community in the North. Marium, who is a Black mother, married, and an educator, differentiated her experiences of parenting from others by describing her awareness of societal discrimination and the complexity of raising a young Black son with behavioral challenges. She describes herself as hypervigilant in her parenting, with concerns that her son could be more harshly or critically viewed in response to behaviors that are attributable to his educational diagnosis of ADHD. She especially fears what this means for him as he grows older, so Marium admittedly takes on a significant amount of mental and emotional labor to help her son better understand how he may be interpreted by community members who do not know about his diagnosis and challenges. She described a significant event where she felt her son was discriminated against because of his race:

> I felt, and I was told that there was discrimination essentially that was happening to my son because he's a child of color and so he was being accused of things that were not true. Social-emotionally, that social-emotional piece was already there, but it was heightened when there are two children doing the same thing and one is being picked out for doing

> something and being reprimanded for it when another child is not. Another family of color calls me on the phone and says, “I don't know if they're going to tell you this, but this happened.”

Marium shared how she works to adjust her expectations of others and how this baseline of expectation is tied to her experiences as a woman of color:

> I don't have very much, so I limit my expectations, and maybe this also, unfortunately, ties back to being a person of color. I honestly limit what my expectations are of other people to be able to understand what it is to walk in my shoes. Code switching is a really real thing and navigating different surroundings is essential to being able to sustain life.

Additionally, she feels used to advocating for herself and doesn’t wait for others to support her. Instead, when she needs support, she initiates conversations with people she trusts. She seemed to intuitively understand the need for her as a Black mother with a Black son to remain aware of and pre-empt challenges they would inevitably face. She manages by cultivating circles of trust where she will lean on a smaller cohort of people who are within her community for support:

> We collectively, or Black and brown people, I feel I have constantly had to navigate systems of oppression and systems of silencing for a very long time. For that reason, the majority of the time, the circles are incredibly small of trust, and so there's not that many people in the bigger circle because there's not a lot of trust outside of the people that are in your inner circle.

Marium went on to describe how the incident at her son’s school informs her thoughts, feelings, and parenting approach, which have been impacted by her understanding and experiences of racism:

> Now, if you're asking, has he suffered colorism? Yes, absolutely. Does he still suffer from colorism? Yes, he does. Is there an issue with him and understanding why people can be cruel? Yes, there is. He does not understand… It's very painful to hear, but basically he wants to be accepted… as a human being. When I've constantly said to him, "The content of your character is what is most important, and people need to remember the content of your character."

She further described the complexity of raising her Black son and supporting his disabilities in a society where he experiences racism:

> Well, that is a big concern… in a culture that basically, not demonizes fully, but discredits or makes children of color and most cartoons and most media to be either sidekicks or the best friend or the token, for different reasons, like Black or Brown is not necessarily powerful, but it's the lesser than. Trying to help him to feel empowered in his own skin is very challenging.

Internalized Discrimination

Asian mothers in this study acknowledged experiencing dissonance and feelings of loss regarding their children’s abilities and their own internalized cultural expectations of high academic achievement. Julie described how her Asian culture intersected with her advocacy experiences for her children. She discussed how coming from a hierarchical culture that teaches inherent respect for people in positions of authority, including educators, made it difficult for her to understand how to confront or challenge her children’s educational teams. She described hard feelings related to the process—embarrassment, distress, and anger coming in a “flood of feelings” at having to navigate a system that she didn’t know. She was upset with educators for not making the social rules and disability law clearer. “I don't know if it's the cultural thing or whether I myself have some sort of undiagnosed condition, but it becomes very emotional.” She was bewildered by the process of accessing services.

Julie further acknowledged how her culture, especially the regard for elders in the community and expectations of high educational achievement, helped explain her feelings of disconnection with the advocacy process. She spoke through a cultural lens about how she experienced grief when recognizing and letting go of the expectation for high academic achievement for her children, who may not be college-bound: “To realize… that what [you] assumed would be accomplished…that you don't even know if that's even possible for your own kids. It's just… something to really wrap your head around and to get past.” Julie also described feelings of grief and the need to shift her perspective about parenting away from her parents’ cultural paradigm of high academic achievement:

> You have to admit to yourself that there is a grieving process, which all parents do go through to a certain extent because there's the fantasy child that you think you're going to have, right? And then having to realize just, “Well, mom and dad are great, and 90% of what they taught me has been awesome, but they are limited in a certain way, I'm learning now.”

Additionally, when seeking support through advocacy efforts, Asian mothers in this study found it challenging to navigate the stereotype of the Asian mother who has very high expectations for their child. This stereotype interfered with their ability to be heard about their children’s needs. Jenni, who immigrated to the U.S., described one such scenario:

> I remember when my older child, when we first went to the new church and… a mother told me, "I don't think your child has [a] speech problem. I think he talks just fine. I think you guys just are too strict about your child. Just want it too much because both of you have PhDs." And I think she wanted to be complimentary, but that really hurt... [She thinks that] because we

have PhDs, we want our child to be perfect. And on the contrary… We let them go with their interests.

While the model minority is a framework that was not initially addressed in this research, it was integrated during the analysis because it emerged so clearly as a theme among Asian mothers in this study. Asian mothers were highly attuned to cultural and societal expectations that they raise childen who excel both physically and academically. Asian mothers contended with and expressed a dissonance between highly regarded cultural expectations, their own internalized expectations of themselves, and whether they or their children met those expectations. Relationships with close family members and friends were challenged as they navigated cultural bias within the community about disability. They also expressed an awareness of challenges in advocacy related to cultural differences, placing them and other Asian mothers at a disadvantage in the U.S. education system. One of the concerns mentioned was the lack of translation services within the education system for non-English speaking mothers, which was similar to the concerns shared by other mothers with English as a second language.

Language Barriers

Several mothers of various ethnicities (Asian, Middle Eastern, and Caribbean) who used English as a second language touched on language being a barrier to services for mothers who did not have access to translators in their communities. Jenni first mentioned her own challenges with advocacy with limited English: “When I attend meetings, sometimes I cannot find a word that's more powerful to express my thought and to make them understand.” She expressed empathy for mothers with even less fluency in her community: “The lack of information and knowledge and the English language is also a barrier…There's a booklet about your rights, but the parents wouldn't look at that because that's in English, but actually there's a Chinese version I found online. [The] school just does not provide it… .The resources are there, but parents don't know.” Jenni correlated the lack of language access for these parents with a lack of trust: “I'm in the parent group, Chinese-speaking family, and I find also most of the families do not understand how the public schools here work and they do not trust the school system.”

Mandia conveyed that English as a second language and a specialist’s perception of her as either uninformed or inappropriately hopeful about her daughter’s potential have impacted her ability to secure the educational and therapeutic support she wants for her daughter. English as a second language was potentially a barrier in a hurtful experience with a therapist that Mandia described as a “deception”: “The therapist told me, ‘We're going to stop because... She's not going to succeed, I'm going to stop.’ So [that] really, really, really hurt me that day.” Mandia didn’t say anything to the therapist after this event. Instead, she went out to the car alone and released her strong feelings by screaming.

Mandia shared similar feelings about accessibility and language regarding mothers in her Caribbean-American community:

> We wish we didn't have to struggle. It has to be a fight to get this. You have to fight. . . Me, I can read this paper, I can understand what it is. But if someone who doesn't know how to read English, it's harder. And then [at] the meeting, they just tell them, "Okay, she's doing good," blah, blah, blah. Done. You sign the paper and leave. You don't even know, oh this is not going [well].

Mandia believed her lack of fluency directly impacted the way professionals approached the importance of getting back to her: “I find people pretend they don't understand… and they never get back.”

Mothers in this study with English as a second language described how they believed a language barrier contributed to difficulties not only in communication but in their experiences of discrimination, as they described how efforts to advocate for their children's needs and access services were recurringly minimized or denied. While mothers in this study were proficient in English, they expressed concern for mothers who are navigating the system without sufficient English. In each mother's case, language barriers clearly contributed to a lack of trust and painful feelings about their experiences with medical and educational specialists.

While all mothers in this study resonated with the experience of marginalization, Black mothers in this study readily associated marginalization with experiences of racism while they navigated community and educational settings. Black mothers shared how they were highly aware of the stereotype of the uneducated single black mother and society's views of their children as poorly behaved vs. disabled, and they worked to mitigate racism in several ways. Tanvi worked to have clear communication about their circumstances through the intake process and throughout the treatment plan. Marium worked to educate her son about racism and built a community of support that she could rely upon for advice. Both mothers shared how their encounters with racism led to difficult feelings about the level of social support they were able to have within their communities. More generally, processing their difficult emotions in response to feeling marginalized was a common theme for every mother, and so it was also a major theme that emerged in the analysis of the data.

Difficult Emotions

Mothers in the study all shared the difficult emotions that they manage within their roles as caregivers. These experiences fell largely into three major subthemes: Isolating experiences or "they don't get it," adjustment to a diagnosis, and denial of a diagnosis. All mothers in the study shared feelings of isolation in scenarios where people within their social support circles misunderstood or minimized their experiences, and these experiences fell under the category of “they don’t get it.” Several mothers described challenging feelings that coincided with a significant process of adjustment upon receiving a diagnosis and/or realizing their child had a developmental disability diagnosis. Finally under denial of diagnosis, many of the mothers felt their difficulties as caregivers were compounded by social support members who denied, minimized, or underestimated the impact of the diagnosis on the caregiver’s experiences.

Isolating Experiences: “They Don’t Get It”

There was a wide spectrum of experiences under this subtheme. All mothers underscored how they work to share their feelings or experiences with others, but then feel further isolated and marginalized when they recognize that non-caregivers only have a limited understanding of what it means to be a mother and a caregiver to a child with disabilities. Jenni described how members of her church try to be supportive by offering prayer but fall short of an accurate understanding of her experiences as a caregiver: “Everybody has their load, and sometimes people want to support you in something; they want to be there for you, but they don't understand. . . . Even if you try to make them understand, they can't.” Julie described her disappointment when realizing that friends could not relate to her experience of parenting two children with disabilities: “I don't get into the details the way I would with one of the other moms or even with my best friend who has no kids just because I know they don't get it. So that was a bit of a surprise and sort of sad.”

Tanvi described her frustration with pediatric staff who must understand the technical definitions of a diagnosis but then miss the impact of the diagnosis and do not offer to help or take any extra measures to assist her as she manages behaviors and the required routine check ups for her autistic twins. Several mothers spoke about complicated feelings as they navigated friendships with parents of typically developing children. Sadie, who has a daughter on the autism spectrum, found that her feelings of isolation were amplified in her friendship with a mother who gave her parenting advice but had typically developing, well-behaved children: "Some parents think they're good parents, when in all actuality, they just have good kids… well behaved kids… I was just as strong of a parent as her. We just had two different kids."

Melissa, who is an educator, divorced, low SES, and caring for a child with multiple disabilities and medical issues, shared similar examples. She talked about difficult emotions emerging in response to a friend with typically developing children who complained about their parenting burden:

> "[She has financial and social support]. . .He's typically developing, he's advanced, but she complains all the time about how hard it is and how busy she is and how she's so tired. And I'm just like, "You want to hear what my schedule was like in the last hour, let alone today or the last week, how many doctors appointments, how many hospital stays?"

Sadie shared the frustration of family members focusing on superficial challenges that have less meaning for her daughter's developmental progress than others, like the type of clothes her daughter with sensory preferences wears. Sadie said:

> "I don't care. It looks ridiculous. But you know what? She's finding herself. She's figuring it out. So yeah, it's frustrating when my sister comes in and tries to help, but their idea of helping, it's not helping. Why don't you understand who she is or ask me what's going on?"

For these mothers, it felt important that community members who could offer support understand and delineate the difference between parenting a typically developing child and the work of caregiving for a child with developmental disabilities. Mothers felt particularly hurt when friends, family, and community members could not understand or acknowledge the importance of differentiating their experiences from the typical experience of parenting. Social support members who equated the experience of raising a typically developing child with that of a child with developmental disabilities served to minimize mother's efforts to support their children according to their more intensive needs. As mothers described their experiences, it became more clear that friends and family members missed opportunities to notice and encourage the caregiver, instead offering unwanted and unsolicited feedback or crticism. The culmination of misses by the social support community served as additional discouragment for mothers supporting a child with DD. Mothers expressed agreement that their social supports are generally unaware. Discussions about the lack of awareness from social supports opened up dialog where mothers shared insights about their own adjustment to the diagnosis. In the next section, I cover what mothers discussed concerning their learning about, and adjustment to, a developmental disability diagnosis.

Adjustment to a Diagnosis

Mothers experienced difficult emotions and shared about the significant adjustment they went through in response to a DD or related diagnoses. Most mothers in this study described an adjustment over time to accept, to understand, to process, and to adjust to what the diagnoses would mean for their child, for themselves, and their future. Nadiah shared her experience of adjusting to a diagnosis and how she blamed herself for not understanding or seeing it sooner.

> So it took me a while to just sink in, to observe the idea that he's on the spectrum, and understand "Okay, well, what's happening with the tantrums, with the rigidity, his flailing, his clapping." It's all kind of come in, like I now understand what's wrong with

> my child. And then, the blame started to come, blaming myself; I'm so stupid, I'm educated, I have two master's, what's wrong with me? How on earth didn't I research this? I thought it would pass. What's wrong with me?" All this blame.

For Nadiah, there was a significant adjustment involved with accepting the diagnosis of an Autism Spectrum Disorder, which ultimately ended with an international move. There was a significant transitory period where the family was traveling back and forth, coordinating care and logistics over several months between her home country and the U.S. When the family finally settled into student housing in the Northeast, they were faced with COVID shutdowns, which she described as a "brutal" experience, lasting three and a half years with no way to have access to family or friend support, no playground, no open play areas, no open schools, all while living in a small one-bedroom apartment. Nadiah felt the family's saving grace during this time was the in-home therapies provided for her son through public programs. Through the in-home therapists, Nadiah began to learn how to better support her son's needs, and by extension, navigate her inner world: "They really.. helped with his speech, behavior… And it kind of helped us understand… how to deal with his tantrums and understand ourself, how to deal with our emotions and frustration, because it starts with you."

For some mothers, the adjustment to the diagnosis happened more quickly, but for others, the process of adjustment and strong feelings spanned weeks, months, or years. The amount of time to adjust was variable, as mothers shared about an ongoing process of continual adjustments that change as the child grows and their needs shift. Jenni eventually learned more about her child's visual impairment and accommodations, which included a need for high contrast and visual simplicity. She talked about needing time to adjust to small but significant changes; for example, the idea that her stylistic preference in home decor would need to change to accommodate her child’s visual impairment. Ruth also shared candidly and more generally about how much their lives and priorities changed after the diagnosis:

> It’s changed our lives and of course we haven’t been able to travel as much…it’s changed where we live and our priorities for how we spend our resources…I found beauty and enjoy [everyday life], but when your child has a disability, you just cannot imagine what your life will become.

Mothers also shared the external and internal pressure to understand a diagnosis and quickly become an “expert automatically.” Family, friends, or professionals expected mothers to understand their child’s needs even as they grappled with the new reality after a diagnosis. Ruth shared about experiencing feelings of bewilderment and pressure to teach and support her son’s educators when he had really difficult behaviors: “It was the worst year, his behaviors were off the wall. He was tearing things up, throwing, screaming…And it’s like I was trying to teach everybody, but I didn’t know because I didn’t fully know his whole child needs.”

Christie, who was a special educator who participated in IEP meetings before becoming a parent, shared insight on how intensive the process of engaging in IEP meeting was for her once she was a caregiver: “But being on the other side of the table, I get why parents get really emotional and upset because I would cry at every meeting and I’m like, oh, this is, I get it now.” Internal pressure was often described by mothers primarily as feelings of guilt or grief related to a diagnosis. These feelings were connected to wondering what they could have done differently or how they might better advocate for their child’s needs. Julie described grieving the child she thought she would have, which was a theme that came up for most mothers in this study. She said, “You have to admit to yourself there is a grieving process, which all parents do go through to a certain extent because there’s the fantasy child that you think you’re going to have, right?”

As they shared about the significance of what receiving a diagnosis meant for them, mothers revealed helpful insights about the process of adjusting to the diagnosis. Mothers shared that they felt they were expected to almost automatically understand and adjust to their child's new diagnosis, and were not given time or support to process their own feelings when offered a diagnosis. For some mothers, a diagnosis brought clarity about their experiences with their children and a path forward. For others, it took a significant amount of time to accept, learn about, find the right support, and apply their new and growing knowledge base to support their children. However long the time to adjust, difficult feelings typically accompanied the period of adjustment. Generally, mothers found that they did not instinctually know about how to meet their own or their children's needs, and they required time to learn and adjust their parenting identity and their understanding of their child. As mothers adjusted, they also described attempting to share their experiences with members of their social support network. Unfortunately, sharing with others about challenges faced as the adjusted to the realities of diagnosis and advocacy was often met with minimizing their experiences and even outright denials of the diagnosis, which I discuss in the next section.

Denial of a Diagnosis

Mothers shared how challenging it was to interact with members of their social support system who minimized or denied a diagnosis, or the impact of the diagnosis. In many of these experiences, mothers were typically working to share about, explain, or advocate for their child's needs and ran into minimizing statements or even complete denial the child's diagnosis as a solid barrier to social-emotional support and/or access to essential services.

When Sadie attempted to share her thoughts about a spectrum diagnosis with family, friends, and community members, she felt they denied her observations: "Everyone was telling me I was crazy. Everybody said, ‘Everything's fine, nothing's wrong. You just have a very difficult child.’" This initial experience of denial extended to medical professionals and specialists.

> I got psychologists, psychiatrists, therapists, physical doctors, all the things making me think that I'm crazy. It was one of those, "Well, I can't diagnose her with that because she makes eye contact with me.” But my daughter's really also very good at faking it, too. So, I've gotten words like, “Do you think you're just being too hard on your kid? Maybe you're just not doing it right. Maybe you have too many high expectations.”

As Sadie experienced challenging behaviors from her daughter, she felt that the behaviors were interpreted by friends as a reflection of a lack in her parenting skills instead of an indication of a greater issue. Sadie recalled an attempt to gain understanding when she challenged a family member who was critical of her parenting to take over her parenting responsibility for two weeks. After this experience, the family member backed away from further interactions, resulting in feelings of isolation for Sadie and her daughter. Sadie recognized that the initial experiences of barriers within her community were related to the combination of the lack of education about children with disabilities, a lack of peer-parent support, and a lack of local resources for children on the autism spectrum.

Experiences of denial brought up strong emotions for mothers, and many examples involved professionals, family members, and friends who were uncomfortable with discussing a diagnosis and its impacts on the caregiver, child, or family system. Again, mothers discussed feelings of loss and grief as the impact of the DD diagnosis was denied or minimized:

> It’s just a moment when you just want somebody… to come over and be like, “Okay, this is hard.” Because it’s this ambiguous loss and grief that we’re going through… it’s like

> people can’t see it or understand it, so they don’t know how to help. I feel like across the board with disability parents, some people are afraid of disability because [there is] such a stigma.

Another mother in the study described similar thoughts that reflected her feelings of sadness and isolation:

> I think I would want [friends] to just come over and just be like, this is the hardest thing we’ve been through, but we just live in a culture where that’s just not a part of how we talk to each other. People are so afraid to talk about the hard things, and I wish people just stayed around a little more and were just with us.

Mothers who recieved a new diagnosis or who shared with community members about their child’s diagnosis, described contending with denials of the diagnosis and minimization of the impact of the diagnosis on the child and their life more generally. Denials and/or minimizations seemed to arrive at a particularly vulnerable times for mothers. They happened especially during the period of adjustment, and also when mothers were sharing more vulnerably about their experiences, when they hoped to experience more supportive words. This phonemenon contributed to feelings of pain and isolation for mothers. The minimization and denial of a diagnosis implies that characters in the mother’s circle of support are either unaware of the mother’s experience in her own adjustment process, or they are potentially challenged by their own uncomfortable feelings, and therefore unable to acknowledge or support mothers’ social emotional needs related to the diagnosis. Either way, the data reflects how mothers are isolated in the social emotional aspects of caring for their children. Similarly, instrumental caregiving work can be minimized and denied by the mother’s social support members. In the next section, mothers in this study discussed how the tangible labor of caregiving impacts their experiences of social support. They also shared how challenges with securing support for the more instrumental, tangible work of caregiving contributed to a lack of respite.

Caregiving Work

All 11 mothers in this study were actively involved in various caregiving work beyond that involved with parenting typically-developing children, and this work significantly impacted their experiences of social support. Mothers shared openly about the tasks involved with caregiving work. These tasks fell primarily into three major categories: advocacy work, behavior and care management, and geographical relocation. Geographical relocation to access services has received less attention in the broader discussion of the caregiver's experience. For this study, geographical relocation emerged and was highlighted as an essential experience for eight out of the 11 mothers, who described navigating a geographical relocation for access to services as a significant life transition that was both necessary and impacted their experiences of social support. Other studies have revealed the kinds of caregiving tasks that parents of children with disabilities participate in, including descriptions of the kinds of behavior and care management work that caregivers do, such as advocacy work (Parish et al., 2004).

Advocacy

Mothers described their advocacy work as the most important work of a caregiver. Many of the mothers spoke about their advocacy work as their primary social support experience. To move beyond advocacy in the interviews, mothers were asked to elaborate on their relationships with supportive or unsupportive people in their lives. However, the importance of advocacy and the connection to the mother's experiences of social support was further reinforced by participants' emphasis on the topic. Mothers described their advocacy work as more than a full-time job. In this study, mothers highlighted well over two dozen separate "jobs" they manage, and several specific advocacy-related challenges. Examples of advocacy included recognizing and attaining a diagnosis, learning about the diagnosis, educating family, friends, educators, and medical professionals on their child’s disability needs, navigating conflict and disagreement with family, friends, and educational or medical teams, coordinating private therapies and specialist care, navigating insurance systems, and helping other parents navigate systems. Mothers discussed time as one of their most significant barriers, as well as fighting with insurance, fighting with school teams for access to educational support and services, finding, applying, and waiting for services, a lack of understanding being detrimental to career and income, and the late night and early morning medical and/or caregiving routines as contributing significantly to exhaustion. Ruth described the work of advocacy as ongoing:

> It’s always evolving; can we talk about that? He’s in a new season with a really serious health condition, and it’s like…there’s always something next, and we have to figure it out. We have to find the right specialists, and a lot of times in trial and error and it’s time and it’s energy and we often times don’t get the answers that we need.

These acts of advocacy on behalf of the child occur across the mother’s various domains of life—home, career, school, personal, professional, etc. Therefore, the load in one area is likely invisible in others, and so remains unappreciated and unacknowledged by mothers’ social supports like family, friends, and professionals. In the next section, I explore behavior and medical management as another essential type of caregiving work that mothers explained often goes unacknowledged and unappreciated by their social support systems.

Behavior and Medical Management

Mothers were highly involved in behavior and medical management at home. They described behavior management as supporting their children's development by learning and practicing safety, life, and social skills so that the child can better integrate into their community. This kind of work typically involved the mother pursuing informal self-education and then teaching their child new skills, navigating, or adapting to disability-related behaviors. For example, mothers described supporting self-care skills like getting dressed, toilet training, bathing, and learning to brush their teeth, which is the work of an occupational therapist.

Elopement is a term that is acknowledged by the National Health Institute, and it is used to describe a behavior most associated with a diagnosis of autism. Elopement behaviors endanger children's safety when they compulsively and recurringly escape from their secure environment with caregivers (Anderson et al., 2012). Elopement was a significant source of stress for Tanvi, who found she had to work on safety in and outside of the home, while contending with family member's expectations about the children's level of exposure to developmentally appropriate experiences. Julie learned Orton-Gillingham to support her daughter's learning disabilities. Sadie talked about the difficulty of teaching her pre-teen daughter to manage her menstrual cycle and hygiene when sensory sensitivities and strong preferences are significant factors. Mothers discussed participating in speech, occupational, and other therapies at home. They also discussed the challenge of working with their children and their children's peers to support social skills development. This aspect of caregiving was incredibly challenging for mothers whose children are non-verbal. Both Julie and Sadie discussed the importance of pre-planning to minimize challenging behaviors. Julie said: "I prepare very well in advance, 48 hours in advance, three days in advance, whatever it takes. I have things set up in place."

Medical management compounded the work of behavior management for caregiving mothers. Lucille's daughter uses a wheelchair and requires assistance to transition. Transitions from the wheelchair to the bath or bed have become more challenging for Lucille as her daughter ages and her husband with disabilities is not able to assist with physical work. She spoke about the difficulty of navigating mobility barriers:

> I shared [on social media], me carrying her up the stairs just to show the reason we need more accessibility, the reason we need a wheelchair van, these sort of things. So people just have to think about, just sit down and think about day to day, what does that look like for (us)?

Lucille discussed several other factors as barriers to support, including the distance from family, the high cost of modifying the home with equipment, and the cost and unreliability of paid caregivers. Similarly to Lucille's early morning and evening medical care routine, Melissa described in detail an intensive care routine that requires two to three hours every evening to prepare her son (who is deaf, blind, and has mobility issues) for bed, and an early morning routine to prepare her son for special education before she heads out to work. Mothers who supported their children's medical needs reported that medical management also consisted of tracking oral medication and side effects, respiratory equipment, feeding tubes, specialized diets, and medical injections, as well as recognizing and responding to seizures and strokes.

Mothers shared extensively about the amount of caregiving work involved with supporting their children with DD. They shared details about their advocacy work across domains of life, which included advocacy for their children within personal and professional relationships. They also shared about the work of managing difficult behaviors, and supporting complex medical diagnosis. For mothers, the work involved was directly related to the complexity and intersection of differing diagnosis. Caregiving work for the child with DD was discussed alongside supporting other children and family members, career, and other responsibilities. In addition, several mothers explained how they needed to manage a move to access appropriate services for their children. This was a unique theme that emerged as caregiving work also entailed managing geographic relocations, sometimes internationally, or across the U.S., in order to access necessary education or medical services.

Geographic Relocation

An important finding in this study was that eight out of 11 mothers moved geographically to access educational and medical services for their children. Four of these mothers made an international move, two mothers moved within the continental United States, one mother moved from a Pacific island to the continental U.S., and one mother moved school districts to access appropriate services for her children. Most of these mothers commented upon the difficulty of moving away from what was familiar and away from friends and family support. In contrast, some mothers reasoned that the family and friend community they left behind would have been unable to realistically support their needs. Nadiah, who moved to the U.S. from a Middle Eastern country, described the tension of deciding to move:

> It’s a huge decision...It’s 50/50, you can stay for a couple of years and then try maybe he will get some care, start talking, get better, and you might consider coming back; and others say, you shouldn’t even bother, we don’t have the schools and even if you pay for the best private school, there’s no services. I left my job at the United Nations. I was a senior health practitioner… It was the hardest decision I ever [made] because I used to love my job. Really, really loved my job. And [my spouse] lost his job. We had a huge house . . .our family’s there, our friends, our culture, our language, everything. Chop, and literally, like a tree, you take that tree with the roots…and you have to find somewhere to root this tree.

The significance of caregivers choosing to move internationally, nationally, and even locally demonstrates the priority of the caregiver to secure solid support and further reflects the importance of strong social support in the experience of raising a child with disabilities. The majority of mothers who moved geographically felt that their children would not be able to access the level of education, medical services, or social support that they would need in their prior location, and many chose to move after already establishing the significant milestones of adulthood, such as an education, a home, a career, and a solid connection to family and friends.

As they spoke about moving, mothers in this study described their awareness of disability stigma and the importance of navigating away from it by moving to a location where their child's disability could be accepted and supported more fully. For mothers who moved locations, this meant a significant life change when they upended everything to secure a more supportive community, at a significant cost to their already established lives. Also, it is significant that mothers who did not move could find and describe their involvement with more supportive communities within their current locale. As mothers shared, it was evident that the lack of wider access to special education and medical services served as a significant barrier to social support. In addition to questions about the kinds of caregiving work they participated in, which led to discussions about geographic relocation, mothers were also asked to share more specifically about what they viewed as barriers to social support.

Barriers to Social Support

As a part of the interview process, mothers were asked to first to complete a social support map, and this was used as a tool for mothers to conceptualize their experiences, and then respond to specific questions about their experiences with barriers to social support. For this study, social support consisted of family members, friends, and educational, medical, or specialist support that mothers rely on as they provided caregiving for their children with DD. While mothers had a variety of responses to this question, three major themes emerged: exhaustion, a lack of care support, and unsupportive people in their social support circles.

Parental Exhaustion

Mothers described experiencing exhaustion as a barrier to social support and offered numerous reasons for this. A notable reason for exhaustion among mothers was simply a lack of sleep. This was most often attributable to prolonged morning and evening care routines for mothers. Mothers described their children as behaviorally or medically dependent on care routines that lasted as long as two to three hours and were physically taxing. For example, Lucille has a partner with a significant motor impairment that limits his ability to support the physical aspects of caregiving and to trade off with her as she manages her daughter's exhausting evening and morning routines. She said "I can't just say, 'Hey, I'm going out for dinner with a friend,' because then who's going to carry her upstairs, who's going to give her a bath? Who's going to put her in bed when he has physical limitations of what he should be doing on his feet or safely?"

Typically-developing children become more independent as they grow older, so parents transition out of the intensive caregiving work involved in the infant and early childhood years. For children with DD or medical complexity, the intensive caregiving routines can extend into adolescence or even adulthood. This was the case for many of the mothers in this study. The consistency, length, and involvement required for care become barriers to mothers' ability to take advantage of adequate rest on a consistent basis. Mothers also contended with the added complexity of a unique routine for the child going against the grain of other household members. Mandia said: "Her routine is different from everybody else who is in the house. You have to deal with that, you have to coordinate all this, so that's how I feel it's like a third job, so that's how I feel. So it's always a burden."

Mothers shared how these routines impacted their ability to involve themselves more generally with other forms of support, such as taking a break or a night away from the caregiving routine. In multiple cases, mothers described having "given up" the idea of being able to take a break from the routine because of a lack of consistent available support and the high level of care involved. One mother, Lucille, said "I can't just leave her with anyone and say, 'Here's what her seizure looks like, here's what she needs to eat. I'll be back in a few hours.' You just can't do that."

Lack of sleep and exhaustion extended to accommodating their child's unique sleeping patterns, as sensory issues contribute to intermittent sleep cycles, difficulties with napping, and sleeping through the night. Melissa stated, "He doesn't sleep through the night, he's like a baby, he wakes up…Normally, it starts anywhere between midnight and 3:00, and he is up every 30 minutes to an hour for the rest of the night, so I can't do that to somebody." Mothers described exhaustion due to their commitments to multiple forms of work, including managing the household, full-time employment, parenting other children, supporting other special needs parents, and handling advocacy. In some cases, dealing directly with their children's unique behavioral needs contributed to exhaustion. For example, Sadie said:

> And as soon as I sit on my bed, she's knocking at my door, "Mom, mom, mom, mom, mom, mom, mom." It's like…I could freak out, and then she gets mad, but also, two minutes later, it's like nothing happened. . .. We could have an all-out; she's my size now, so we have actual screaming matches. She'll go in her room, I'll go in my room, and not even five minutes later, "Hey mom, can you see this drawing?"

Exhaustion was a common theme among the mothers as they expressed their experiences managing invisible labor and intensive schedules to support multiple responsibilities. Mothers described how a lack of sleep was necessary to support these responsibilities, and how this interfered with coordinating opportunities for respite. Hiring sitters or finding paid caregivers was not an option for mothers whose caregiving routines were medically complex or whose children had difficult behaviors associated with the diagnosis. Very naturally, mothers segued from this discussion to offer their thoughts about the lack of availability of care support, respite care, and how this lack framed their experiences of social support.

Lack of Care Support

Another significant theme that emerged about barriers to social support was the mother's difficulty with finding and maintaining reliable and consistent forms of care support. Mothers described difficulty finding willing or adequate childcare options, which impacted not only their career and finances but also their experience of having the same social support as parents of typically developing children. Nadiah shared how she tried sending her son to several childcare facilities and was unable to find a placement for him:

> I changed to another daycare…they didn't say it to my face, but, (they said) "I think it's harder for other kids, we're not really trained for that.' I was like, 'You know what? They're going to throw me out.' And then I had to change to the third daycare. And bear in mind…I have to go to work.

Babysitters were not an option for mothers because of the need for specialized care. Ruth stated, "I just can't get any babysitter…I can't put him just anywhere. So the caregiver responsibility is even more, right? You can't get that respite." Mothers explained that it is challenging to secure care support even after obtaining government funding for respite.

Additionally, if a child was supported during the day by specialized educational services in school, mothers struggled with coordinating logistics and managing care during school holidays, extended breaks, or over weeks in the summer when their regular programming ceased. The difficulty in securing care support translated into an absence of social life, as Melissa stated: "So there is no true social life, like going out, seeing people, doing things, going to the pool by myself, going shopping, anything…[My time off] is all for doctors [appointments]."

Mothers described the challenge with finding suitable environments where care providers were willing to take on less desirable caregiving work. Sadie recalled a particularly difficult time when her teachers repeatedly ignored her daughter's hygiene needs:

> I explained to the teachers, "She has accidents." She always has a change of clothes and you can't tell me that's a sanitary thing in a classroom if she's sitting on it…But I'd pick her up at four o'clock and she'd been sitting [in] her feces all day and it was stuck to her body and kids would make fun of her…but no grown up ever took her by the hand and helped her. They just let it be, and it was a really big problem.

Mothers perceived that the lack of care was rooted in a lack of concern or education or even ignorance about their child and disabilities. Mandia encountered multiple challenges with medical professionals and specialists who either ignored or dismissed her concerns. She said that "You get a lot of ignorance…you have to keep going and going." Mandia felt that people would say that they'd do something that she requested, and she would have to follow up to make sure that it actually happened. Mandia continued on to describe the lack of care: "I don't think everybody is trained the way they're supposed to train to work with her…You [never] know what's going on behind the scene, so that's the biggest issue."

Mothers also spoke about the lack of availability of care providers as a barrier to social support. When asked about how family members and friends might contribute to care support, mothers felt that care from family members and friends fell short of what their actual care needs are. Sadie said, “My entire family. Love them all, but I’m doing it alone. I can call and complain. I can call and say what I need to say. It’s not like that. It’s a different type of support that I don’t feel I have.” In response to inquiring further about whether mothers could count on social support to provide respite opportunities, Mandia rather bluntly stated “Nobody wants to do it.”

A lack of care support extended to coordinating fun activities with others. Mothers described the difficulty of coordinating events or plans with other parents who have typically-developing children. Christie said: “I have friends, but they are really busy.” They also pointed out that the difference in the lifestyle of a caregiver is difficult for others to imagine. Melissa shared her challenges with coordinating events around her child’s needs with family members: “I just feel like it makes people feel really uncomfortable, mostly, even people who are my good friends”.

Sadie felt hurt when a senior family member with extensive career experience in childcare followed her long distance move to access services, then withdrew her support as a response to challenging behaviors. The family member then spent more time with typically-developing children in the family. Sadie’s daughter was aware of and grieved the distance: “So she'll disassociate herself, she'll walk away. . . . And she always had time for everybody else's kid. . . . She never had time for [my daughter]. That's a sore spot.” After many years of feeling misunderstood and isolated from friends and family support, Sadie decided to stop asking for help, stating that she would prefer to handle her daughter by herself than go through the heartache of disappointment that she feels when a family member or close friend lets her down.

Mothers met with resistance, distancing, and some rejection in response to their requests for support with caregiving work, which made even coordinating fun activities with friends and family members difficult. Even mothers who experienced these rejections still shared their desire to connect and have support from people in their circles. Ruth, for example, said she just wishes people were there for her, "even if they don't know what to do, just being there and knowing…It's like we don't have a show-up culture. Maybe we do…but that doesn't include disability parents for some reason." These honest conversations about the lack of care support provided a natural transition into discussions about who mothers perceived as the least supportive people in their lives.

Least Supportive Experiences

This study inquired about mothers' experiences with people they consider to be the least supportive. This topic was one of the most heavily discussed questions in the interviews, and the examples of least supportive experiences extended to every category of social support discussed by the participants. Mothers utilized the social support maps to begin the conversation about who the least supportive people in their lives were. The least supportive people they indicated included extended family members, grandparents (their parents), friends, the school system, therapists, and medical and school professionals. Additionally, mothers shared their interactions with insurance companies to describe least supportive experiences. This section combines the above categories and describes the mother's least supportive experiences with family members, friends, and professional support.

For some participants, the lack of involvement from their parents was attributed to advanced age, health, or geographic distance; however, these reasons did not necessarily mitigate the sense of loss they felt. Ruth, whose parents are aging and unable to participate with her actively in her parenting journey, stated, “I felt a big sense of my loss with my mom. . . . she’s aging really fast, and so she’s not there for me anymore the way that she was there for me 10 years ago.” She sought out therapy to cope with the loss she felt with her mother’s cognitive decline and understandable lack of involvement.

Mothers shared that grandparents cultivated distance to minimize involvement. Julie, who is Asian, shared “My parents are interesting because being a part of a culture where parents help a lot, I was expecting my parents to help. But…they had an opportunity to move closer to us, and they didn’t.” Additionally, mothers gave examples of grandparents who had some connection but struggled with internalized stigma about their grandchild’s disabilities. For example, Melissa moved in with her in laws for one year, and found that her in laws “didn’t want [their grandchild] practicing walking with his walker in the neighborhood because it was embarrassing. They didn’t want to learn sign language because they felt it wouldn't go anywhere. And they didn’t want to bring [him] to their [public] pool.” Tanvi shared that her children’s paternal grandparents “want their grandkids to be like everybody else’s grandkids. I understand, but at some point, it’s like, ‘You just got to accept that they’re not like everybody else’s grandkids, ok?’”

Mothers experienced a lack of grandparents’ understanding/supporting their caregiving experience. Christie explained, “So my mom even made a comment, ‘Do you ever get to stop? You haven’t sat down yet’ and I’m going, ‘Mom, I’m doing not even 50% of what I do on a daily basis.’” One caregiver, Marium, shared about her feelings of exhaustion and was met with an unempathetic response from her mother: “One time when I was just really tired and I said to my mom, ‘I’m just really tired. I’m just really tired.’ She’s like, ‘Well, we all are.’” Julie described how she began sharing less about her experiences when her parents responded critically: “I just needed them to be parents and to listen to me, but you just realize that people are still kind of judging you.”

Melissa described her family as supportive, but when asked to share more definitively about her experiences, it became clear that she has experienced a deficit of support from many extended family members. Melissa’s brother has been the most supportive in her caregiving role. He moved in and became actively involved in care during COVID-19, and she describes him as being patient and her son’s “bestie.” She also described him as still having a limited understanding of her son’s needs and the impact on her. At the time of the interview, her brother had recently moved out, and she was readjusting to living alone with her son again. Melissa describes her parents as supportive; however, they live far away and are too elderly to provide tangible support. She described a tricky relationship with her mother, who does not seem to understand or respect her grandson’s level of need and, for example, will skip a meal to do an art project. When Melissa tries to address the importance of routine to her parents, they label her as overly controlling.

These unsupportive experiences extended to Melissa’s ex-spouse, who is an athlete and has had difficulty connecting to his son due to his physical limitations. She described how she believes that the shame of having a son with disabilities caused him to become isolated from their mutual friend group, who might have supported him. She has deep concern about her ex-spouse’s mental health and whether, in a depression, he could take his own life. This deep sense of shame extended to experiences with the paternal family. She felt especially isolated from friends who are parents of typically developing children and involved in activities her son cannot participate in. The differences in her child’s medical routine and needs can also lead to feelings of disconnection from others’ experiences with their children. Melissa says that it was a culmination of these types of misses by family members and friends that eventually drove her back into therapy to seek support and understanding for herself as well as her disappointing and isolating experiences with her family.

Least supportive experiences with extended family members reflected similarly the feelings of isolation in the mothers' experiences with grandparents. Tanvi explained, "I feel like people have taken things personally in my family, and I find it shocking…I mean, you know that you can't imagine what I'm going through." Also, the distance was reflected in extended family relationships when Tanvi reflected further: "I feel like they feel guilty because they take too long to reach out and then they just don't do it at all." Even as mothers felt family members' distance, they expressed a desire for social-emotional and instrumental support. Lucille summed up the issue that most of the mothers expressed: "I know there are people that want to help, but they just don't know how, so then they just choose not to even offer… But physically I don't think we have enough support at all."

Tanvi described the dissonance of her experience as a widowed mother, where others have the freedom to interact with her children when it is convenient for them, but she does not have the same freedom to expect support or tangible help when she most needs it.

> I actually had to tell [extended family members] not to come last week, and I think they're mad at me or something. They didn't respond 'cause they just last minute, "Oh, we have some time next week. Can we come next week?" And I didn't want them to. I'm like, "I've got some stuff to do." They would've been here right now, and I didn't want them to be here while I was doing this. Now I feel like I messed up because I told them they can't come on their schedule; they have to come on my schedule.

Caregivers also described unsupportive and disappointing experiences. For example, Melissa described how a good friend terminated their friendship unexpectedly: “I had one friend who just told me it was all just too much for her…she was honest and we just totally drifted apart. And the funny part is she’s a therapist, but at least she could tell me.” In another scenario, Lucille lost a close friend when her child received a similar diagnosis: “I have no idea why… but she just stopped responding and her son had a seizure and this was around the same time my daughter was diagnosed with epilepsy. . . .Was it stuff with my daughter or is it you?”

Mothers described feeling their friends’ disapproval concerning behaviors related to a diagnosis. Sadie stated: “I would get judgment, even from one of my best friends. And she was like, ‘Oh, she’s so naughty, you need to discipline her.’ She’s known her since the day she was born.” There were also challenges navigating friendship with perceptions of need and offers to help, as Tanvi explained:

> After my husband died, everybody’s like, “Oh, let me know if you need anything” and a lot of times I would not take people up on that, but then there came times when I needed to…and it’s like, “Oh, I’m sorry, I can’t…” but I only have a few people and if I’m calling you, then I really need you.

Mothers described understanding and not wanting to place additional pressure on friendships. Christie explained: “Maybe I would call and say, 'we're having a really bad day because of this’ or ‘This is what happened today.’ But I don’t want to put more stress on them.” Mothers also described the tension for them in an ongoing process of balancing friendship by sharing, but not overly sharing. Lucille said, “But then there’s friends that I know that I can tell them some things, but I don’t want to tell them everything. So they’re not at the same level of trust but I still could get supported by them.”

Several mothers described the importance of a faith community's support. Still, those who engaged in such support also overwhelmingly described feeling undermined by a lack of understanding about the nature of disability and the intensity involved in caregiving work. Mandia, who is heavily involved in her church community, stated, "people might think, 'oh, where's your faith? You don't have your faith anymore.' But you're human. You are human."

Finally, all mothers in this study shared unsupportive experiences with professionals in therapeutic, medical, and educational roles. In these interactions, mothers described unsupportive experiences with professionals as being dismissed, minimized, or undersupported in their efforts to provide therapies, education, or necessary medical treatment for their children. For example, Ruth explained:

> I mean, I think of multiple medical providers who missed a lot about him. They were quick to label him and dismiss what I kept coming back to over and over again…To label him as a kid with behaviors versus really understanding why, he was trying to communicate with us…And it's gaslighting in a lot of ways. I think a lot of us moms feel that we are being dismissed.

Several mothers mentioned their battle with health departments or insurance to cover treatment or equipment. Lucille stated that it's not so much about "social or caregiving barriers, but there's constant barriers with insurance and that's what I think about…We've gotten so many denial letters. And then the next day, we'll have an approval letter, and then a denial letter all for the same thing. And I'm going, what's going on"? Christie similarly stated:

> Dealing with DHS, the Department of Human Services, is a nightmare. They lose your paperwork, even if you turn it in and get a receipt, they act like you've never turned it in. They cut your services off. It's just a nightmare. So dealing with that is really a pain.

Christie also shared a unique perspective that emerged in retrospect to parenting her adopted children; she believes she lacked essential training about children's needs as a special educator. She reflected on how much she feels she was never trained in how to support non-verbal children with medical complexity in wheelchairs. She described her experience post-adoption of being the first teacher in a school to interact directly with or touch a child who was using a wheelchair and non-verbal as a transformative example for teaching peers. She shared her anger about the lack of training for teachers and parents on supporting more complex disabilities. She believes teachers and parents must be taught how to help their children by utilizing various technologies, such as object communication devices. In fact, she described feeling so angry about the lack of training in her school district that "it comes out in tears." In hindsight, she has a greater awareness of what she might have done to support past students better:

> I did my best with my students, and I loved them, but I wasn't there to help them the way I would be now, because I've learned so much, having a child that is the kid that I would be teaching. And so, it hurts my heart that, knowing all those years, I could have done so much more.

Mothers described least supportive people within every category of support within the community. Mother's experiences with the least supportive people were striking in contrast to family support as a notion that is culturally found in almost all human societies. The U.S. has an embedded cultural expectation that an individual's social support will foremost consist of family members, including grandparents, siblings, partners, and others. Our medical and educational systems operate on the assumption that students, patients, and parents have access to a familial support system. Familial support is understood to be a foundational source of psycho-emotional support that is ideally available throughout a person’s life and can contribute enormously to overall well-being. Even so, overwhelmingly, mothers in this study described that having a child with DD has been a catalyst for further distance from familial and other important forms of support. In response to exchanges with those they indicated were the least supportive people, mothers in this study had strong and challenging feelings. They also demonstrated resilience by turning to more supportive people, by learning to cope, and by re-imagining how things could be different for them, and also for other caregivers.

Resilience

While much of the literature on caregivers in past decades has focused on burden of care and stress, research on caregivers has more recently trended toward descriptions of caregiver strength and resilience (Hassanein et al., 2021; McConnell et al., 2014). As caregivers, the mothers in this study demonstrated incredible resilience when navigating their more challenging experiences of social support. Examples of resilience were also highlighted in the mother’s responses to three questions that focused on their more supportive experiences with social support. Mothers were asked (a) to share their strategies for coping as caregivers, (b) to share their descriptions of the most supportive people within their social support spheres and (c) to respond to a magic wand question as a prompt: “If you had a magic wand, what would you change for all caregiving mothers?” The social support map helped mothers to begin to describe who the most supportive people and experiences were for them. Each of these questions and the incorporation of the social support map provided additional opportunities for mothers to share more about what already is, or could be, working better for them in their caregiving journeys. Their answers serve as considerations not only for working with this population of caregivers but also for a more comprehensive understanding of their experiences to support further caregiver research, practice, and policy.

Coping

In response to questions about coping, mothers tended to acknowledge limits on their ability to incorporate self-care or other strategies to help them recuperate or pursue active forms of respite. A lack of time, energy, support, and resources were offered as reasons why coping was not at the top of mothers' priorities. Further, this question was initially met with some explanation as to why caregivers are not coping well: “I don’t do very well,” said one mother. “I feel guilty about wanting a break,” said another. “I don’t think I do deal with it” was another example of an initial response to this question. Several caregivers also acknowledged the difficulty of asking for and receiving help. Some spoke about the process of realizing that they may need and benefit from specialized help for themselves; for example, Sadie reflected about how she might seek more support as she shared:

> I wouldn’t even know where to begin with that conversation, and that is probably something that I’m becoming more aware of [in] the last couple of years, definitely trying to seek help for me; not only for her, but help with somebody like a specialist for me. Tell me how to ask because I’ve never been a person to advocate for myself in general. I’ve always just handled things by myself on my own, even as a kid. Whatever happened, I processed it, coped with it, did my thing. Probably not the best way, but it’s how I did things. It’s how I survived in my life.

Ultimately, caregivers in this study were able to push past their initial resistance to the question about how they cope with unsupportive experiences, and they defined more specific strategies that they utilize to cope with the demands placed on them as caregivers. Strategies for coping with caregiver stress included various forms of dealing internally with stress. Mothers described coping internally by masking their true feelings with more positive ones, internalizing their feelings about their experiences as caregivers, or depersonalizing their experiences through detachment. Tanvi explained how she works to "mask" her true thoughts and feelings when extended family members engage with her unhelpfully: "Well, while they're here, I just put on a mask. But sometimes I get to a breaking point, and I explode on them, and then it's like, 'Oh, we're just walking on eggshells around Tanvi.'" Four mothers described coping with unsupportive experiences through detachment by imagining themselves and/or their children as being in a "bubble" in response to unsupportive experiences. Jenni explained,

> I would say detachment. I would just shut it down. I wouldn't go to that person again with the specific topic. You don't have to be my friend. I just put myself in a friendly bubble. I only need a small bubble. I don't need a whole world.

Mothers initially resisted the idea of taking time for themselves to cope. When pressed, they revealed that they utilize coping strategies such as resting when the children are resting, practicing the same regulation strategies that they are learning and teaching their children, and taking time for small luxuries such as watching TV, going to a store alone, eating food they enjoy, and finding joy in small moments. Though they struggled with finding time, mothers also talked about the importance of developing an outlet not connected to caregiving, and some activities that mothers mentioned were running, getting out for a walk, Zumba, and jewelry making. For a couple of mothers, their faith was central, and they described listening to worship music and prayer as their method of coping. Mothers coped and demonstrated resiliency by cultivating relationships with the most supportive people in their lives.

Most Supportive Experiences

To highlight what kinds of support are helpful for caregiving mothers, participants were asked about their experiences with the most supportive people in their social support spheres. Within their responses, mothers described what supportive care looked like for them. Mothers most frequently identified supportive experiences with friends, other parents of children with disabilities, and therapists. Mothers in this study were less able to locate supportive experiences with their child's grandparents and extended family members, school systems, medical professionals, and paid caregivers, so these categories were mentioned less frequently in response to mothers' experiences with supportive people. Three mothers were single and had no partner support for their caregiving work. One mother was a widow. Five mothers were married, and out of these, three named their spouse among the most supportive people. Although spouses and partners were mentioned, none of the participants overly focused on partner or spouse contributions to caregiving work in response to the interview questions.

As explained in the previous section, some caregivers limit their circle of social support by creating a "bubble" around themselves and their child. Most mothers described the importance of maintaining a small circle of friendship with specific friendships that feel supportive to them. Tanvi, the mother of two autistic twins, said:

> Oh, I have two friends, two or three specific friends, who are long time friends of mine who will drop everything and come and hang out with me...Especially a friend who has a baby now on her own, she can see some of the stuff I go through as a single mother, single Black mother too, but she'll also say like, "I have no idea…I only have one…I can only imagine what you've been going through this whole time."

Tanvi further described what is meaningful to her about the friendship:

> My friend never takes anything personally, and that's the type of person I need around because she's like, "No. No. Don't you dare apologize." She's like, "You are going through all of this. I have no idea. Yeah, forget it," and I wish I had more people like that in my life, but people, they truly don't understand.

The need for social support to recognize and provide moments of instrumental, tangible help was a theme that emerged for mothers. Mandia spoke of an incredibly supportive experience when a family member stepped in and offered to coordinate her daughter's birthday celebration in her absence due to work. Mandia was especially grateful that the family member executed it entirely without engaging Mandia in more work: "She dressed her… She [did] everything I was supposed to do, and then she [took my daughter] to church with my husband. And then she [took] nice pictures… [it] was really good for her."

Ruth described the importance of building and maintaining friendships outside of disability spaces:

> I think as a caregiver of a kid, you need to find something outside of this space to be yourself…being able to connect with women who are very like-minded in very similar spaces and are outside of that whole disability space but still get me deeply. I think just being able to have a chance to be yourself outside of this whole vortex of disability parenting has been life-saving for me.

Sadie, a single mother who manages to work full time and take care of her teen autistic daughter, described the importance of having friends nearby on speed dial:

> My friend who moved up on the third floor, she always says she's available if I need it, but she usually just catches me in those dramatic moments of me screaming and hollering. She's like, "Are you good? Are you okay?"

For caregiving mothers, there was an emphasis on the importance of non-judgemental close friendships. Marium stated:

> I have a few of my friends that…understand that's how I process, and without giving judgment. And then they say, "Do you want my opinion?" Or they know that I'm calling and asking for help. And I'm very, very grateful for those people in my life because those are the people in my circle that I trust with my family, I would trust them with my children, I would trust them with the world.

The most supportive experiences for Melissa included the community of parents affiliated with her son's genetic diagnosis. She appreciates the support from her son's special education school and its community, as well as the teaching community at her workplace. If she could, she would want to improve and expand her teaching community's understanding and application of disability inclusivity and accessibility. However, she understands that their intention to offer tangible support is there, which means a lot to her. Her most supportive experience was when a close friend who lost her brother to a childhood diagnosis sent bottles of wine or was willing to drive to and pick her up from appointments and errands. Melissa appreciates friends willing to ask hard questions and hear hard answers.

Caregivers recognized interaction with other parents in the disability community as some of their most supportive experiences. In these spaces, mothers described feeling connected to other parents and to the everyday experience of disability parenting and the ability to share resources and information on navigating systems, including access to educational and medical support. Julie shared a salient example of camaraderie within the disability parenting community when she reached out to a fellow mother after a sleepless night to help her process a stressful IEP meeting and her next steps in the early morning hours:

> I texted her at two in the morning and was just like, “I’m really sorry. You do not need to respond [now]. I’m just so stressed out about this. I need to get this out of my system and write to you and ask questions and we can talk later” She texted me in the middle of the night and said “Let’s have coffee in the morning” And we did.

Mothers also shared examples of interactions with parents that were not as helpful or supportive within these same communities; however, all mothers discussed the importance of finding support within communities of parents of children with disabilities.

Mothers said that therapists, both their own and their children’s, provided some of their most supportive experiences. Christie discussed the therapy clinic that is community based:

> It's more family centered. They take them out in the community if you want them to. They have groups at the clinic where kids are interacting, and they’re learning how to be around other kids and how to talk and accommodate for everything. It’s very loving. When I mentioned some behavioral issues we are having at home, the first thing they said is “Okay, let’s get together. Let’s meet. Let’s problem-solve.” That is what we can do at the clinic…So that was way more supportive than expected.

Christie further shared how the love her child received in therapy was more important to her than the level of skill:

> I wouldn’t say they were fabulous because the classroom staff was poorly trained. They had no clue, but I could tell he was loved. He wasn’t making progress, but he was loved, so I was okay. I could tell he was loved and taken care of, even though he wasn’t learning and developing.

Mothers also shared positive experiences in individual and couples therapy. Melissa said: “These days, my therapist has been really amazing. She’s a social worker, and I’ve been able to talk about everything under the sun with her. And she's been a critical social support." Ruth also described the importance of counseling to support her marriage. After one year of marriage counseling, she said "we're in the best season of our marriage now, and that was a lifesaver. . . . I still thank her every day for the support she gave us."

While mothers described examples of unsupportive experiences with their children's grandparents, some mothers shared more supportive experiences with grandparents. However, experiences with grandparents reflected a dissonance where supportive experiences were connected to unsupportive ones. For example, Jenni spoke about seeing her parents trying to be supportive. At the same time, she also works to educate them about the diagnosis and, in the process, encounters their sense of shame about the disability diagnosis:

> My parents, being in the States, often help us out. I'm trying to make them understand. I think they get a little bit of that. And also they are in my social media group as well so I'm constantly educating them. They understand that, but they wouldn't share with other family members back in [our home country].

Several mothers described grandparents who offered positive support but could not offer instrumental help due to geographical distance, age, and health-related issues. Melissa said that her dad tries to help, but "it's hard for him to be supportive because he lives really far away…He's had a stroke, he's had heart stuff, so he can't physically help too much. But he's been very supportive to me." Melissa described her mother as supportive but not attuned to her grandson's special needs:

> My mother, unfortunately, the things that are strengths for her are the opposite of what I need. So I would say she's really creative and she is very carefree and unscheduled and kind of self-absorbed. So all of those things do not work well with my child. She moved

> here when he was born and I had really hoped she was going to be a help and she's just not.

Nadiah's comments about her mother's support echoed similarly: "So the reasons why I didn't want him to stay [with] my mom, one, she's not young… physically, she can't cope with everyone, or anyone, so that's not very easy for her."

Some mothers had positive, supportive experiences and mentioned activities that helped to lift the burden of care. For example, Jenni's father remodeled a room to make it accessible for his visually impaired grandson:

> My dad made my child a little room. He used to be a carpenter, so he made a little room for him, although the size is too big actually, but that's the purpose with all the black room, the toys hanging, the lighting, and everything, that meant a lot to me.

One mother, Nadiah, appreciated that her mother was available for care while she worked:

> I chose a daycare that was relatively close to her place, so she can pick him up when I come. And he just loves mom, she's everything to him. And he sits next to her, he doesn't want me because she gives him chocolate and all that. So yeah, she really took care of him when I couldn't, for everything with work, and fed him, and put him to bed.

Another caregiver, Marium, also shared her mother's willingness to travel to help maintain contact and engagement during important medical or other events.

It was significant that mothers' most supportive experiences with social support were with people who they perceived as both understanding their children, understanding about mothers' caregiving load, and very often contributed in a tangible way to help offset the burden of care. At a minimum, the most supportive people in the mother's circle were a source of social emotional support. Mothers really appreciated when family members and friends not only interacted with them on a relational level, but also made an effort to learn about and integrate their child's needs into the fabric of relational experiences. Mothers seemed to select people to become close to in part on the basis of their ability to understand and interact well with their children. This is why sometimes therapists and educators, who were familiar with and supportive of the child's needs, were included as the most supportive people, while more familiar but less supportive people were shifted to the outer circles of mothers' maps.

Supportive relationships for mothers were clearly defined by the level of acceptance, understanding, and tangible support offered to their child. In the next section, I share mothers' responses to one of the final questions in the interview, which was based on a counseling intervention from solution focused therapy (Flynn, 2023) that served to inform me about what mothers wanted for themselves, and for other caregivers, going forward.

Ideal Scenarios: Magic Wand Question

The Magic Wand or the "Miracle" question is a solution-focused therapeutic exercise in counseling psychology that therapists typically use at the onset of therapy to help clarify goals (Flynn, 2023). This question aims to help clients envision and support their desired outcomes more clearly. The exercise begins with asking, "If you could wave a magic wand and solve all of your problems, what would change?" Historically, research on caregivers has focused primarily on describing challenges. In contrast, this research aimed not only to highlight caregivers' experiences with social support but also to begin to suggest possible solutions to the everyday challenges mothers of children with DD face. Each mother in this study was asked a version of the Magic Wand question to uncover ideal scenarios and possibilities for the caregiver's lived experiences: "If you could wave a magic wand and change things for other caregiving mothers, what changes would you make?"

In response to the magic wand question, mothers who participated in this study advocated for similar changes on behalf of all caregiving mothers of children with disabilities. They prioritized the need for respite care for all caregiving mothers, as demonstrated by Tanvi:

> I really feel like I need to get out and I just need to get away from my children, and I don't want to get away from them, actually. I feel like I always want to be around them, but I don't think that that's healthy either. I just need more time to go away from my children for extended periods. This little one- and two-hour stuff, I hate to be ungrateful, but that doesn't do it for me.

One mother, Lucille, suggested that respite care should be included in state services and accessible for all caregivers of children with disabilities. Mothers who did not have the option for more minor breaks during the week described their need for daily or weekly opportunities to engage in activities that are not caregiving related, such as taking a mental break, self-care, and managing non-caregiving related household and administrative tasks.

In various ways, mothers also addressed the need for greater access to care support through systemic changes and funding for multiple services through state and federal grants. Mothers suggested that funds could be used to employ automatic assignments to social workers, care coordinators and educational advocates, who could begin to help manage access to caregiving support as well as medical and educational services upon the child receiving a DD diagnosis. They suggested that a national healthcare system and an overhaul of insurance policies would be necessary for their children to access needed medical and mobility equipment. Funding to support programming and adaptive sports opportunities during school breaks and summers could help caregivers gain continuity and continue career growth. Ideally, caregivers would also have support as their children age out of care and into adult transition services, which, according to the mothers, is not readily available in many areas of the country. Mothers described the importance of funding and equipping organizations that already support awareness around specific diagnoses and toolkits that connect parents to resources and parent-to-parent support. They also discussed the importance of advanced training in the American Disabilities Act (ADA) and special education law in general. Specifically, they endorsed further training about disability for professionals working within educational and medical systems. The idea of training was explicitly extended to the notion that medical professionals and specialists could benefit from engaging in advanced training on supporting a disability diagnosis and the realities of caregiving work. Mothers expressed an interest in connecting with specialists or counselors with specific disability training, which could help support their well-being as they engaged in caregiving work. The idea of a robust social advocacy movement for mothers was mentioned in response to the magic question; as Tanvi stated, “It just seems obvious to me…if you want the children to do their best in this [life], then we need to be doing our best too.”

On a social-emotional level, mothers most commonly described the importance of active listening by the community of social support, including family, friends, and professionals. Mandia shared what she hopes friends and family will be willing to offer: “Be there and listen to what they want… Being there can give them a little breath. And then let the person know that…The person needs to know that you understand them, the moms.” Mandia explained:

> Listen to the mother because the mother knows what the child is going through. The provider is on the other side, but the mother is the one that lives with the child and knows exactly what the child needs…So pay attention.

There is an abundance of information in the literature, and now in this study, about the challenges and difficulties associated with caregiving work for mothers of children with developmental disabilities (VanWyk & Leech, 2016). Utilizing the magic wand question allowed mothers an opportunity to pivot from sharing about challenges, and to expound on what kinds of more positive, meaningful experiences within they wanted within their social support. It also gave them an opportunity to imagine about these experiences without limits. Answers to this question generally focused on access to respite, easier access to services, and more supportive experiences with friend and family members.

Through the use of a demographic questionnaire, social maps, and semi-structured interviews, eleven mothers of children with DD offered important considerations through their narratives. I present here just a few key points as a summary. One important consideration is that mothers of children with DD identify as a marginalized community in part because of their experiences with a lack of social support, which involved painful experiences of minimization, denial, discrimination, rejection, and distance in response to stigma associated with their child's disability. Mothers with marginalized racial or ethnic identities associated marginalization with their experiences of racism, and offered specific examples of this in their narratives. In spite of these experiences, all of the mothers in this study continued to care for and pursue the well-being of their children above their own, and while accumulating expert levels of knowledge about their child's diagnosis and care needs. The majority learned how to navigate medical and educational systems, and they used this knowledge to help advance other mothers' understanding of how to access support. Finally, mothers became adept at accepting distance, or distancing themselves, from less supportive relationships while cultivating more supportive ones. I further interpret all of the key findings by comparing and contrasting them with relevant literature in the Discussion and Conclusion in Chapter Six.

CHAPTER SIX: DISCUSSION

With this research, I sought to fill a gap in the research literature on maternal caregivers with children with DD by diversifying the participant pool and highlighting mothers' experiences at an intersection of identities. I also examined experiences with family members, friends, and community members within their social support system. Finally, I aimed to understand the role of more and less supportive people within mothers' social support system from the caregiver's perspective. This chapter discusses the study's key themes and how they align with the primary research objectives. The main research questions were: (RQ1) How do mothers with marginalized identities experience their social support? (RQ2) How does this social support system impact a mother's quality of life and, by extension, that of a child with disabilities? The research design utilized Interpretive Phenomenological Methods (Smith & Nizza, 2022) to highlight meaning from the lived experiences of maternal caregivers of children with developmental disabilities (DD).

The eleven participants shared their experiences with immediate and extended family members, friends, the community, and medical and educational professionals. They were also asked more specifically how any aspect of a marginalized identity impacted their caregiving experiences. Utilizing an iterative coding and data analysis process, five major themes emerged: Marginalized Identity, Difficult Emotions, Caregiving Work, Barriers to Social Support, and Resilience. In the following sections, I further synthesize the main themes that emerged in response to the main research question, which inquired about barriers to mothers' social support.

Barriers to Social Support

This study examined barriers that interfered with caregivers' experiences of social support. Barriers for caregivers have been explored regarding the intensity of caregiving work, emotional impact, economic factors, or behavior severity (RAISE Family Caregivers Act, 2021). Studies have explored key members of a child's support system; for example, the mother's and father's experiences of parenting a child with disabilities (Blacher et al., 2019) and grandparent and sibling relationships of the child with disabilities (Giallo et al., 2003; Roper et al., 2014; Yang et al., 2018). What has been less explored are the caregivers' barriers to social support from their own perspective. Similarly, there is minimal literature about how a marginalized identity may serve as a barrier to social support.

By highlighting the disconnect caregivers experience in relationships with family members, friends, and community members, this study extends the current understanding of "hidden work" as described by Landsman (2008) and Safe et al. (2012). In their study of mothers of children with autism, Safe et al. examined the nature of hidden work and mother's feelings of isolation in their experiences. Mothers shared experiences of discrimination, and they experienced this as a barrier to social support. Mothers of every ethnicity and race in this study identified feelings of marginalization, but this was more readily associated with experiences related to stigma and caregiving work than identity, and was also viewed as a barrier for mothers to social support. They shared their feelings of exhaustion, and how this was viewed by mothers as a barrier to social support. In these cases, the intensity of caregiving work was viewed as a barrier to social and other forms of support, such as having a social life, respite, and time alone. Mothers also shared their strategies for coping as a form of resilience. In contrast to Safe et al.'s (2012) study, mothers in this study described experiences of abandonment by key members of social support, or abandoning relationships in which they felt unseen, increasing feelings of isolation.

Abandonment

The core frameworks highlighting disrupted relationships and abandonment for this study were Attachment Theory and Bronfenbrenner’s (1994) Ecological Theory. Attachment theory was explored to contextualize the well-being of the primary caregiver and the importance of social ecology, consisting of family, friends, and community members, to the child with developmental disabilities (Bretherton, 2004). Bronfenbrenner’s Ecological Theory was utilized to organize the caregiver’s social support system, and it was the basis for the social support map that assisted caregivers to delineate the most and least supportive people in their social support sphere (Bronfenbrenner, 1994; Josselson, 1992; Motulsky, 2010). The integration of each theory supported my understanding of the experiences of the caregiver’s social support and how unsupportive experiences might contribute negatively to the welfare of the caregiver and the child.

Attachment theory proposes that a secure attachment with the primary caregiver sets the stage for more healthy, safe relationships across a person’s developmental lifespan (Bretherton, 2004). Anxious or avoidant attachment styles in adulthood are the result of an insecure attachment or abandonment by a primary caregiver and contribute to adverse outcomes. Attachment has been used as a framework in previous research on caregivers. For example, Findler et al’s (2016) study utilized attachment theory as one framework to examine the happiness of mothers of children with disabilities. They found that lower avoidance anxiety, stress levels, guilt, and solid social support contributed overall to happiness.

The attachment framework, which acknowledges the traumatic impact of disrupted relationships, further explains the stress associated with the caregiver’s experiences in the literature (Bretherton, 2004). By drawing directly from participants’ narratives, this study proposes that stress is not only directly related to caregiving and advocacy activities, as has been the focus of previous research, but it may also be compounded by the experience of isolation in the form of abandonment from multiple arenas of support within the social ecology. Initially, I proposed that a perceived disruption to social support could contribute to stress beyond the current definitions of caregiving work that research primarily highlights. Also, I posited that the enormous caregiving burden described in literature must have impact on the mother and, by extension, the child, but previous research has not investigated this directly (Nicholas et al., 2016; Oelofson & Richardson, 2006; Wulffaert et al., 2010). This study's findings support that caregivers experience abandonment that contributes to stress.

Participants in this study overwhelmingly shared examples of seeking support from their personal and professional relationships for disability-related challenges but then experiencing a breach, a distancing, or through an attachment lens, some form of abandonment initiated by individuals in crucial relationships. Critical relationships for mothers in this study at the various levels of social ecology included immediate family members, grandparents and extended family members, friends, and their educational, medical, and specialist supports. All of these relationships were explored in the study; however, the disruption of relationships with grandparents (i.e., the mothers' parents or in-laws) was a primary theme.

These findings provide nuance and extend the literature's emphasis on caregivers who experience stigma when they venture into public settings, shedding light on how caregivers can experience stigma in more personal relationships (Nicholas et al., 2016; Tikkanen et al., 2019). Similarly, mothers discussed distress that emerged in response to fractured relationships and disappointing interactions that led to disconnection and distance with friends, paid caregivers, and specialists (such as therapists, doctors, and teachers). They also shared experiences of abandonment from friends, both with and without explanation. Specialist support relationships were ended by the professional or the mother when mothers were offered insufficient or inaccurate explanations, treatment plans, or understanding of the nature and impact of the child's disability diagnosis.

The findings in this study further highlight the isolation reflected in the literature on mothers at an intersection of identities. Mothers from Asian communities shared experiences of internalized stigma in response to cultural and societal stigma about disabilities (Cho & Kahng, 2014; Shorey et al., 2019). Single Black mothers expressed feeling isolated from their community members, who primarily consist of friends and family (Burkett et al., 2017; Ha et al., 2011; Pearson & Meadan, 2018). Black and Latina mothers experience disparities such as lack of access to services, discrimination, and late diagnosis, which contribute to isolation in community support settings (Lahti-Anderson et al., 2024; Lopez et al., 2019; Magaña et al., 2015). English language learners experience stressors such as bias, navigating complexity in accessing services, and overcoming language barriers, which can contribute to disruption within professional relationships and isolation (Choe et al., 2023; Iljaba, 2015) Because isolation and stress were relevant both to previous literature and contributed as barriers to social support, I explore the emotional impact of isolation and stress further in the next section.

Emotional Impact: Isolation & Stress. Stress and caregiving are highly correlated in the literature. According to numerous studies, caregivers of children with disabilities experience clinical levels of stress, typically connected to an increased burden of care (Oelofsen & Richardson, 2006; Smith & Grzywacz, 2014, Wulffaert et al., 2010). The impact of the social support system on the caregiver and the child has been examined in research but not as thoroughly and not specifically from the lens of marginalized identity. Many of the findings in this study associated with isolation and stress echo Safe et al.'s (2012) findings in their study of mothers of children with autism, where mothers reported complicated feelings, sharing that their stress and isolation were a normative part of their experiences as caregivers. Mothers in my study described feeling stress when critical members of their support circles were unavailable for instrumental and emotional support. The lack of support contributed to complicated feelings. Mothers discussed their sense of grief over the loss of relationships, their sense of isolation, and their increased and ongoing level of responsibility, leading to ongoing distress that significantly impacted mother's sense of mental health and well-being. Single mothers in this study felt particularly isolated when members of their support system distanced themselves from their children with disabilities. While this research did not examine the impact of social support on the child specifically, these findings infer that there is an impact on the child through attachment processes and well-being across the lifespan.

During the interviews, mothers integrated the experience of being abandoned and the disappointment they felt. They integrated these feelings by placing themselves in others' shoes and remembering how they once did not know what it was like to raise a child with disabilities. The phenomenon of abandonment by members of the mother's social support circle was a novel finding. The fact that all mothers in this study experienced some form of abandonment from essential family, friends, and community members is striking.

Previous research has focused on siblings and grandparents who are described as supportive or engaged, provide respite, or help to manage the essential care of children with disabilities (Giallo et al., 2003; Yang et al., 2018). However, research has not investigated what happens when these key members who support the child with disabilities or the caregiver are absent. At the time of this study, no mothers had access to extended family members (such as parents or in-laws) who regularly engaged in caregiving support. Some mothers described reluctant or intermittent engagement and long disengagement from extended family members. In this study, grandparents willing to provide instrumental support with caregiving work could not because of various life circumstances. Participants described grandparents as aging, navigating health challenges, living a long distance away, financially burdened, prioritizing a social life after years of parenting, or having feelings of inadequacy to provide the specialized support needed. These factors were all mentioned as barriers to caregiver support. If a presupposition of access to family support is embedded in a sociocultural ideal, but unrealistic because caregivers are unlikely to be able to rely on support from extended family members, then perhaps an overfocus on the children's grandparents or extended family as caregivers' support reflects only a portion, and perhaps even the minority, of caregivers' experiences. In addition, discrimination emerged in this study as a relevant framework for mother's perception of barriers to social support, and I further highlight mothers' experiences with discrimination in the next section.

Discrimination

Scholars have noted the focus of research primarily on White mothers, who are middle to upper-class, and well-resourced (Ben-Moshe et al., 2014). Mothers' narratives have also been examined at the intersection of race and gender in the literature, and more studies are emerging in response to calls for research on mothers from minority communities from an intersectional lens (Lahti-Anderson et al., 2024; Burkett et al., 2017; Magaña & Vanegas, 2020; Onaiwu, 2020). Previous research has studied the marginalization of maternal caregivers through the lens of socioeconomic status and economic mobility (Baker & Burton, 2018; Sousa, 2015). Fewer studies examine LGBTQ+ caregivers of children with DD through an intersectional identity framework (Coulter-Thompson et al., 2023). The application of intersectional feminism was a helpful framework to support this study's social justice aims and expand on research about mothers at an intersection of identities. Specifically, I aimed to investigate whether having a marginalized identity further marginalizes mothers who, according to prior research, already demonstrate significant risk for stress, poverty, and lack of resources (Baker & Burton, 2018; Sousa, 2015; Stober & Franzese, 2018).

Maternal Caregivers Feel Marginalized. Participants identified themselves as mothers and caregivers, and they shared identities they described as marginalized. While all were female and experienced gender discrimination as women and mothers, not all shared a minority racial or ethnic identity, and education levels and socioeconomic status varied. Seven out of eleven mothers identified as BIPOC. Three identified as immigrants. Five participants were single mothers. Four out of the eleven reported having a low socioeconomic status (making less than $48,000 annually). Three participants explored the possibility that they might have an undiagnosed learning or other disability. Multiple unique identities intersected with the above common identities. When asked about experiences of marginalization as an open ended question, mothers shared more readily about experiences associated with discrimination related to disability than any of the other identities. This finding was a novel one, and it highlights how mothers can associate the experience of marginalization and discrimination more prominently with their experiences as caregivers than with their racial or ethnic identity. This was also notable when contrasted with findings in previous literature, which associates marginalization and discriminatory experiences as a factor mainly attributed to having an ethnic or racial minority identity over discriminatory experiences connected to mother’s proximity to disability (Maye et al., 2021; Onaiwu, 2020).

While all participants identified feelings of marginalization, the study found that having a marginalized racial or ethnic identity compounded experiences of discrimination for mothers, as mothers with racial or ethnic identities were able to share further about discriminatory experiences connected to racism. The types of discrimination that emerged most consistently and prominently were internalized stigma, explicit racism, language barriers, and microaggressions. The finding also supports my initial premise that while caregivers of children with DD experience marginalization, marginalized women with a minority ethnic or racial identity experience compounded marginalization through various forms of discrimination. The findings of this research on discrimination are a unique contribution to the intersection of gender, disability, and race identity, which often focuses on economics, access, and cultural competency as barriers (Kew et al., 2023; Lahti-Anderson et al., 2024; Magaña et al., 2015; Pearson & Meadan, 2018; Shorey et al., 2019).

Additionally, my findings were that discriminatory experiences were a catalyst for mothers to emotionally or physically distance themselves and withdraw from crucial relationships, which further isolated them from social support. Participants described having epiphanies that they could no longer shoulder the responsibility of caring for their children and the additional work of translating their needs to family, friends, and educational or medical professionals. Mothers recognized others' inability to relate and eventually stopped explaining themselves and sharing their feelings or needs. Mothers continued to actively participate in drawing in more supportive people and withdrawing from or excluding unsupportive social support members from their lives to minimize the emotional distress caused by various experiences of discrimination. In response to multiple experiences of discrimination (model minority stereotypes, racism, language barriers, and microaggressions) across their social ecology, mothers withdrew from relationships or reported restricting themselves to a smaller, more supportive circle of support, which sometimes consisted of no more than two or three people, and most often included other parents who could “get it.” However, this process of withdrawal contributed to increasing isolation. Isolation as a response to discrimination was integrated into the maternal caregivers’ experiences as though it was ordinary. Through this lens, the study findings extend previous research and suggest that such challenges with social support may also be an important factor to consider, as it likely contributes to the high probability of caregivers experiencing mental illness, physical decline, and economic disparity over their lifespan in comparison to parents of typically developing children.

In many cases, mothers attempts at advocacy fell short of the desired outcome, and after many attempts at advocacy, they either moved geographically to access better services or they indicated that they would eventually settle for good enough over best possible access to services. In the next section, I examine how mothers described barriers by contrasting this study’s findings with relevant literature regarding barriers. I begin with discussing the findings through the lens of ableism, which best describes mothers’ experiences with societal stigma about disability as a barrier to social support.

Courtesy Stigma & Ableism. Participant mothers in this study described the emotional and mental labor of navigating and living in an ableist society as a barrier. Utilizing the social support circle as a guide, mothers identified unsupportive experiences with individuals across every social support category, including family, friends, and professionals. They described recurring encounters with familiar and unfamiliar people who “don’t get” disability or disability parenting as a barrier to their social support.

Ableism is a term used to describe societal stigma about people with disabilities that is embedded in the culture and impacts individual’s conscious and unconscious views about disabled bodies (Neely-Barnes et al., 2010). Ableism is differentiated from Courtesy Stigma, which is better defined as the stigma that a family member or caregiver experiences by proximity to their loved one with disability (Stober and Franseze, 2019). The Social and Critical Disability Models emphasize the many barriers to disabled bodies living and existing in a highly ableist culture (Neely-Barnes et al., 2010). This is in keeping with literature that describes the challenges caregivers face with social and specialist engagement (Brisini & Solomon, 2020; Malhotra et al., 2012; Jones & Passey, 2004; Safe et al., 2012). While the medical model offers benefits to caregivers, such as diagnostic and treatment criteria for impairments, it views a disability diagnosis as a deficit and can perpetuate stigma (Ong-Dean, 2005; Pierce & Frank, 1992; Safe et al., 2012). This negative view of disability is understood through critical and social models to be culturally and historically bound within the medical system (Barnes, 2105; Neely-Barnes et al., 2010). Medical professionals often identified caregivers as some combination of neurotic, suffering, dysfunctional, or powerless (Neely Barnes et al., 2010). More recently, researchers highlight the lack of training in cultural competency as perpetuating stigma and a barrier to social support (Magaña & Vanegas, 2020).

The lack of support from specialists contributed to “Mother Blame,” described by Sousa (2011) as a significant contributor to parenting stigma for children with developmental and intellectual disabilities. The lack of support from educational or medical professionals who are culturally competent is also described in the literature about mothers who are ethnic or racial minorities (Burkett et al., 2017; Kew et al., 2023; Lahti-Anderson et al., 2024; Lopez et al., 2019; Magaña et al., 2015; Pearson & Meadan, 2018; Shorey et al., 2019) This study elucidates the complexity of minority caregivers at an intersection of identities, encountering a medical model of treatment and a culture with embedded disability stigma. According to study mothers, they experienced ableism as a lack of access to listening, knowledgeable, and caring providers. This was described as a barrier to their experience of social support. Some of the most disappointing encounters for mothers in this study were with professional organizations or specialists within educational or medical settings who seemed unable to grasp the nature of the disability, offer appropriate referrals, understand the impact of the disability on the family system, or comprehend the care burden that mothers of children with DD experience.

Similarly, mothers in this study conveyed a sense of being unable to be seen or understood by professionals and community members, especially family members, as the "good mother" who raises well-adjusted, successful children (Landsman, 2008; Sousa, 2011). When participant mothers in this study returned from disappointing experiences with professionals, and then turned to friends and family for support, they experienced family, friends, and community members who minimized the impact of a developmental disability diagnosis or denied its presence. In cases where the disability is invisible, and there were complex behaviors, mothers were blamed for their poor parenting skills. Mothers offered numerous examples of negative encounters with social support that illustrated significant barriers to their sense of belonging to a family, friendships, faith group, or a community group, such as the medical and educational professionals from whom they sought support. To further extend the analysis on ableist experiences on a societal level as barriers within the social support group, this study examined whether critical members of the caregiver's social support group contributed to mothers' experiences of courtesy stigma.

Courtesy Stigma. Courtesy stigma is described as the stigma that a caregiver experiences by proximity to a person with disabilities (Goffman, 1963 as cited by Stober & Franseze, 2018; Ryan & Runswick-Cole, 2008; Tikkanen et al., 2019). This research echoes studies that demonstrated how maternal caregivers experience courtesy stigma in proximity to their children with developmental disabilities (Brisini & Solomon, 2020; Landon et al., 2017; McIntyre & Brown, 2018; Nicholas et al., 2016). Like other studies, mothers in this study experienced judgment about their parenting and about their process of reconciling the impact of their child's disability, as they adjusted to understanding and supporting the diagnosis (Landsman, 2008; Seligman & Darling, 2007).

This study's findings about caregivers experiencing stigma when they are engaging socially or in public with their children are consistent with previous studies (Blacher et al., 2019; Ryan & Runswick Cole, 2008; Stober & Franzese, 2018). Mothers experienced courtesy stigma from the general public as they accommodated their child's behavioral or other challenges in public places.

In contrast, previous literature on grandparents typically highlights the caregiver grandparent who is to some degree invested and supportive of the child and the caregiver (Katz & Kessel, 2002; Trute et al., 2008; Yang et al., 2018). In multiple scenarios in this research, behavioral challenges related to the diagnosis were the reason for a beloved grandparent, aunt, or uncle to distance themselves from the caregiver and the child with disabilities. At this time, no known study expressly referred to the intentional distancing of family members in response to challenging behaviors. In some of the mothers' narratives, shame about the diagnosis or minimizing the impact of the diagnosis prompted distance from grandparents who internalized disability stigma that was culturally or socially bound. This was true for grandparents who identified within the cultural majority and minority.

For mothers who could not have help consistently from extended family members or friends, or access the right specialist help in their area, the need for the correct services from medical and educational professionals was pertinent. To secure support, mothers in this study made significant geographic relocations internationally and across state lines, or regionally to access services for their children, sometimes at a great personal or professional cost. In the next section, I explore geographic relocation and cost as another consistent pattern that emerged in mother's narratives.

Geographic Relocation & Cost

Research has pointed out that the cost of caregiving contributes to financial decline that emerges in the later stages of the caregiver's life (Parish et al., 2004). Research on immigrant mothers sheds light on how caregivers who stay in their country of origin have less access to services than those who move (Choe et al., 2023). In contrast to studies citing economic challenges for caregivers over time (Genereaux et al., 2016), the majority of the mothers in this study worked full-time, and a minority of them reported low SES. This contrast is likely attributable to the ages and life stages of caregivers in this study, none of who fit the criteria of caring for an adult child with DD. Even so, it was striking that eight out of eleven mothers made geographical relocations to access support and services to benefit their children, indicating their willingness to take on the significant stress and adjustment of geographical relocation to access services.

Four of the eleven mothers in this study transitioned internationally to gain better access to services. Three maternal caregivers navigated learning English as a second language as they engaged in advocacy work. Consequently, mothers in the study described a significant adjustment from relocation and exhaustion from chronic overworking to sustain themselves and their families economically. They explained that this was a barrier to accessing social and other forms of support. One mother, who navigated full-time professional work, parenting other children, and supporting her child with DD, described holding at least three full-time jobs to support herself and her child. Mothers described engaging in educational advocacy, managing challenging behaviors, navigating insurance and waitlists, and coordinating medical or therapeutic support services as barriers to social support, as each endeavor contributed to a lack of capacity to engage socially for necessity, recreation, or leisure.

As mothers shared stories of immigrating internationally, across state lines, or regionally, they showcased their tremendous resilience while experiencing a high relational and financial cost, each of which were viewed as barriers to accessing family and community members as social support. In the next section, I examine how mothers demonstrated resiliency.

Overcoming Barriers - Resilience

Historically, society and psychology blamed mothers for producing developmentally insufficient children (Sousa, 2011). Even so, mothers have historically demonstrated resilience in their experiences as caregivers. This study also reflected the concept of the Warrior-Hero Mother Identity, first described by Sousa (2011). It is a socially constructed identity that burdens mothers with unrealistic expectations to improve their child’s disabilities (Sousa, 2011). For example, mothers shared how they adjusted to the diagnosis and caregiving demands, overcame barriers, and eventually became experts in their children’s diagnoses. Several mothers shared how they used their experiences as motivation to help others, becoming professionals in disability advocacy or special education settings. Mothers also described fulfilling roles as volunteer advocates, from participating in online parent support groups to supporting other parents navigating similar challenges. Not all mothers in this study considered themselves experts, but many embodied advocate roles and readily shared specialized information about their children’s diagnoses.

Brock (2014) identified several societal expectations for good mothers of children with disabilities that are underscored by study mothers, which include that they are expected to be caregivers for the rest of their lives, to do so indefinitely, acquire skills, and maintain a normal facade. These findings also align with Green's (2007) research, in which mothers expressed love and pride for their children and experienced many benefits from parenting. Mothers in Green's study aligned with mothers in this study, who expressed that they are not sad about their children's disabilities, but tired from the caregiving work and the subsequent lack of support. Even as mothers in this study presented themselves as experts in advocacy and demonstrated resilience, they expressed difficulty responding to coping questions, indicating how deeply they internalized expectations to persist in the caregiving work and to prioritize caregiving over well-being. Mothers overwhelmingly cited a lack of time, energy, support, and resources as reasons for not prioritizing coping. When pressed further, mothers shared how they felt guilty for taking time for themselves and dealing internally with stress.

Echoing Brock's (2014) definitions of the societal expectation to maintain a normal facade, mothers in this study shared how they masked their feelings and experiences when interacting with individuals in their social circles. Instead of processing their experiences and feelings with others, they coped by disconnecting. Masking was a behavior that also aligned with Nicholas et al.'s (2016) findings, where mothers reported masking or putting forward a well-adjusted image to present themselves as coping well. Mothers also learned to limit their social support to only those they felt could understand their circumstances. These smaller circles of support consisted of only a few people (sometimes just one) they could rely on for emotional or other support. For Black participant mothers, community and faith was especially important as they navigated advocacy and racist expereinces. This echoed research on the importance of faith, culture and community (Burkett et al., 2017). How mothers avoid or minimize social interactions underscores Malhotra's (2012) findings that parent caregivers avoid social situations to minimize their exposure to societal stigma.

Coping as Resilience. Coping as a form of resiliency is widely reflected in the literature on caregivers to children with disabilities (Bultas & Pohlman, 2014; Green, 2007; McConnell et al., 2015). An important takeaway from this study, and one not readily reflected in research, was that a mother's coping often consisted of smaller moments that they described as "stealing time." Examples were going for a run or walk, going to a store alone, watching Netflix, or integrating a hobby such as jewelry making. Four out of the eleven mothers mentioned relying on their faith or a faith community as a form of coping. Many mothers in this study participated in online parent support groups. Even as mothers described how they cope, it was evident that mothers limited themselves in thinking about how they cope, or in their ability to engage in coping behaviors, mainly because they prioritized their children's well-being over their unmet needs to rest and rejuvenate. This was evidenced by the body language in response to the questions and their answers. It almost seemed that thinking about 'self' in some way disturbed their focus on the most important person (their child) by looking away, a facial grimace, wincing, withdrawing, and taking long pauses in response to my questions about coping. Mothers viewed the need for respite as a desire. The ability to persevere without adequate respite and with minimal outlets for coping demonstrated the resiliency of these mothers. The findings in this section and generally in this discussion chapter, invite a critique about why mothers of children with DD would need to or be expected to be resilient in this way.

Summary of Findings

Through an interpretative phenomenological framework, this research inquires about the participants' lived experience, including the potential impact of social-relational ecology on caregivers and their children with disabilities. From the mothers' perspectives, it also investigated what kinds of social support can be adapted or contribute to mothers' resilience. It examined the impacts of barriers in the social ecology that further burden caregivers advocating for their child. As the findings indicate, an overwhelming number of barriers disrupt key relationships, which negatively impact the caregiver. This stress must logically extend to the child with DD. This research explores the mother's experience regarding all support aspects, including what kinds of social support are helpful and how extended friends and family can be beneficial. The data collection also revealed that mothers have common experiences, including the hidden mental and emotional work of adjusting to and accepting a disability diagnosis for their child.

Critical disability theory asserts that eliminating barriers and creating accommodations for all people with disabilities improves life for everyone (Davis, 2009). This research embraces this critical perspective by highlighting and exploring how deeply familial and community support impacts caregivers (Diallo et al., 2019; Tebes et al., 2019). It also examines ways that a marginalized identity further isolates mothers who already demonstrate significant risks for stress, poverty, and a lack of resources (Baker & Burton, 2018; Sousa, 2015; Stober & Franzese, 2018). While literature on marginalized mothers is growing, there is currently insufficient qualitative data about intersectional identities that influence the quality and level of social support received by a caregiver (Magãna & Vanegas, 2020). Finally, this research explores ways support for the child and their caregiver works well. Mothers responded with resiliency through strategies such as distancing themselves from unsupportive experiences, cultivating smaller circles of unconditional support, becoming experts, supporting other parents, and stealing moments to make time for themselves. The mothers in this study discussed caregiver perceptions and experiences to highlight what is problematic, what is helpful, and possible solutions for the burden of care. It is essential to critically examine the limitations of the research, which may have influenced the interpretation of findings and the implications derived from them.

Limitations

While this study offers rich qualitative data on the experiences of marginalized mothers of children with DD, it is important to recognize the boundaries and constraints that may influence the interpretation and application of these findings. Despite efforts to capture diverse perspectives, the findings of this study did not fully represent the complexity and diversity of experiences among marginalized mothers of children with DD. While the study succeeded in finding participants who were racially or ethnically diverse, single mothers, and mothers who identified themselves as marginalized, they all identified as cisgender and heterosexual. Also, while some mothers questioned whether they had an undiagnosed or invisible disability, none of the mothers identified officially with a disability diagnosis. Additionally, mothers of low socio-economic status were under-represented in this study, with seven out of eleven mothers identifying themselves in an upper middle or higher level of socio-economic status. Mothers primarily had some form of higher education and all mothers had at least some college credit. Most mothers worked full-time within a profession. At the time of this study, most mothers lived in the Northeast U.S. or had relocated to another area in the U.S. to access specific services. The Northeast offers greater access to educational, medical, and specialized services than many other regions of the country. Mothers' experiences in this study may differ from those in other regions of the U.S. or internationally.

In any qualitative study, it is important to recognize the potential for researcher bias and subjectivity in data collection, analysis, and interpretation. I identify as an ethnic minority, as a maternal caregiver of a child with medical complexity and DD, and also as a counseling professional. In transparency, I disclosed these personal details to participants, as part of engaging with them in interviews. How my identity as an ethnic, maternal caregiver and licensed mental health professional helped or hindered the research process is not fully known, but it should be considered that my insider position, especially that of a fellow caregiver, impacted participants and how they shared their experiences. My impression was that in response to my sharing briefly about my caregiver identity, mothers were more willing to share their experiences. Mothers indicated that they felt they were speaking to someone who “already understood” something of their experiences. In some cases, this impacted the interview as participants gave brief answers because they assumed I understood their experiences, which I did not always. When this happened, I asked clarifying questions to draw the participant out. Or, I asked the participant to explain further as though I were a person who could not understand their experience. Identifying myself as a caregiver in the introduction contributed to several participants referencing how I must have experienced something similar in my journey as a caregiver. When this happened, I re-focused the participant on the interview questions and engaged the participant’s responses.

Similarly, my identity as a counselor was not lost on the participants. In the middle of one interview, one participant seemed to gain insight into her need for support. She then indicated that she wished that more counselors specialized in supporting maternal caregivers of children with DD, and she asked if I knew of anyone to whom I could refer her. Notably, every participant in this study was offered a list of mental health resources as a follow-up. Perhaps more notably, my search for providers who specialized in caregiver mental health revealed a significant lack of qualified care resources.

This research provided a critical perspective from the mother’s point of view. However, it did not include other points of view such as the father’s, siblings, extended family members, friends, or community members. Despite this limitation, mothers’ views are not often centralized in the literature. In the next section, I discuss the recommendations for future research.

Recommendations for Future Research

In future research, it could be beneficial to explore further how mothers learned these advocacy skills and more about the process of accepting the implications of a DD diagnosis. While the central aim of this study was to extend insight into marginalized caregivers and capture the experience of marginalization more broadly, it may enhance future studies to recruit a narrower and more specific intersection of caregiver identities so that literature may extend to mothers who are even further marginalized. Research would also benefit from even more focused individual and family phenomenological interviews or case studies that examine extended family and friend perceptions in the context of their experiences with caregivers and children with DD. These same research efforts could also focus on the community support experience consisting of educational and medical teams. Additionally, further narrowing down the list to specific types of social support could be helpful. For example, mothers described barriers to accessing childcare, afterschool, and extracurricular programs or activities that provide necessary respite for working parents and socialization opportunities for their children. Future research could also focus on maternal caregivers with specific marginalized identities and their experiences with the grandparents of their children. Additionally, research that accesses a narrower pool of participants could contribute to deeper insight and validity into the experiences of maternal caregivers with marginalized identities.

Implications for Clinical Practice and Policy

Understanding the clinical implications for maternal caregivers, particularly those at an intersection of identities, is paramount in bridging the gap between theory and practice and in informing interventions and strategies to improve the well-being of the family system that supports the child with disabilities. Researchers emphasize the need for cultural competency training for professionals who work with disability populations (Barrio et al., 2018; Magaña et al., 2015; Magaña & Vanegas, 2020). In this section, I delineate the practical significance of the study's results within clinical practice, highlighting implications for assessment, diagnosis, treatment, and support services. By translating this research into actionable insights, I aim to empower clinicians, practitioners, and policymakers to implement targeted interventions that address the diverse needs of individuals and families grappling with supporting children with complex medical and disability diagnoses. I hope to create positive change and enhance the quality of care and support available to all maternal caregivers of children with any diagnosis that complicates their care.

Mothers in this study were asked a Magic Wand question as an open-ended and depersonalized strategy to gain insight into mothers’ hopes for social support. This intervention, borrowed from solution-focused therapy, is designed to help clients further clarify their treatment goals (Flynn, 2023). Mothers were asked, “If you could wave a Magic Wand and change things for all caregiving mothers, what changes would you make?” Mothers' responses echoed and extended the findings from a recent RAISE Family Caregiver’s Listening Survey (2021), which reported the top concerns of caregivers under two main categories: caregiver services and support and financial well-being. Examples included references to respite, caregiver training, education, and direct pay support.

Similarly, mothers in this study shared that they would prioritize respite care access through state services funding. They suggested that every mother of a child with complex needs should be assigned a caseworker at the onset of a diagnosis. A couple of mothers indicated the need for specialized therapeutic services from a counselor who is proficient in disability and its impact on families. Mothers also stated that disability-specific and ADA legal training must be standardized across the medical and educational systems so that all professionals receive disability training. Further, they shared that disability education should not be limited or narrowed to disability-specific professions, such as special educators. Mothers advised that all professionals in medical and education systems should receive disability training. On a more personal level, mothers wanted to experience active listening from their social support network, including family and friends. Paying attention, learning about the child, learning about the disability diagnosis, listening, and being involved were emphasized by mothers as important to experience from their social support circles.

To conclude this implications section, I am offering a list of potential clinical applications for consideration based on mother’s feedback. To simplify the language in each application, I refer to social support as family members, friends, and professionals in this section as “professionals and community members.” In her seminal work on disability-affirming therapy, Olkin (1999) wrote a list of Rights for Children with Disabilities. I’ve referenced this list to inspire a “Caregivers Bill of Rights” that acknowledges caregivers’ experiences across the literature. I invite the professional community that supports caregivers to continue to engage with these points critically and to expand upon them. Drawing upon this study's findings and analysis, the following 11 clinical applications for maternal caregivers are recommended, and the Caregivers Bill of Rights follows.

Clinical Applications & Recommendations

- Professionals and community members might consider that mothers may identify more readily with marginalization in relationship to disability than cultural, ethnic, or racial identity. Therefore, along with training in cultural competencies, professionals and community members should be trained in and familiar with disability care frameworks and prepared to either provide the appropriate care and accommodations or supply an appropriate referral and follow-up.
- Professionals and community members should assess whether the maternal caregiver has or will continue to have positive social support in the form of family members, friends, or community members who will offer instrumental caregiving or emotional support. An informal or formal assessment should be used to determine the kinds of support and the level of access the maternal caregiver has to social support. The level of social support could be assessed on a regular basis, perhaps every six months, as mothers indicated in this study that the levels of social support were minimal and interest in their challenges decreased over time.
- Professionals and community members should recognize and emphasize the time it takes to adjust to the idea of a diagnosis, and that this adjustment may involve grief and complicated feelings that change over time. A caregiver’s adjustment to a child’s diagnosis may be a fluid and continual one, evolving over time as the implications of the diagnosis change and shift through the years as the child grows. For example, a caregiver may need to adjust the conscious and

subconscious expectations that emerge at each significant milestone for what she envisioned for her and her child's lives.

- Difficult emotions may be not the result of ongoing disappointment about the child or caregiver burden, but may also be in response to a caregiver's experience with insufficient support attributable to courtesy stigma and discrimination. Mothers with marginalized identities may encounter discrimination in multiple forms.
- Professionals and community members should learn to recognize the prevalence of difficult emotions or experiences of stigma for caregivers, assist by inquiring about these kinds of experiences, offer empathetic, active listening and validation for their experiences, and offer resources for culturally competent mental health support. Clinicians and community members can also solicit feedback from caregivers to shed light on and mitigate overt discrimination or microaggressions.
- Professionals should be careful to communicate directly with the mother about risks and unknowns, and not to offer false hope or platitudes, which mothers felt were patronizing, inauthentic, or minimized their experiences. Mothers in this study did not expect clinicians or community members to know everything about the child or the diagnosis, but they wanted to know that clinicians, specialists, and community members were willing to engage with them, to believe them, to support the mother's own process of deepening their understanding about the diagnosis, and to seek out the best possible care.
- Professionals should work to minimize transference and depersonalize the process of mothers evolving into experts on a child's diagnosis. Mothers as experts on

their child’s disability is common, and therefore, a predictable evolution in maternal identity. Mothers, as experts, will benefit from the support of the social system, and they will likely use their expertise to help other mothers. Clinicians can help support caregivers by becoming an ally, maintaining a state of non-defensiveness, and, in turn, engaging more fully with the mother’s questions, hopes, and challenges concerning a diagnosis.

- Professionals and community members may benefit from recognizing the level of expertise that mothers of children with can DD gain in their experiences of cargiving and advocacy. In turn, mothers' emotional and mental health may be better supported within groups of other parents with disabilities. Because well-being is strongly associated with more positive outcomes for caregivers in the literature, mothers will benefit from opportunities to become involved in group activities, including leadership, mentorship, and acting as advocates.
- Community members can offer support by making the necessary accommodations to continue including parents and their children in every day community interactions, for example, regular inclusion in extracurricular activities, family and friend gatherings, and home visits. If a caregiver opts out of participating, the withdrawal could indicate a lack of accommodation by the community. Community members should gather feedback about whether the caregiver feels their child is being included with the necessary accomodations and whether any additional accommodation could make it easier for caregivers to engage with support. Several mothers in this study spoke about the importance of presence, saying that they wanted friend and family members to “be there.”

- Professionals can advise and facilitate education about the need for respite to community members. Community members can then better understand the importance of offering caregiver respite to caregiving mothers who indicated that they are chronically overwhelmed and exhausted by an endless list of tasks. Community members may provide support and respite by learning the caregiver’s routine and stepping in to share the burden of care regularly. Community members could offer caregivers both shorter (1-2 hours) and longer (24 - 72 hours) breaks on a recurring basis. Mothers described helpful forms of respite, much like community members would offer during a short-term medical recovery; for example, they might help by picking up food from the store, bringing by a cooked meal, short visits or check-ins, or completing necessary chores. These actions would help alleviate the caregiving burden, benefit the family system, and support the child with disabilities. Community members should consider the long-term investment of caregivers in their child and the intensive and ongoing nature of caregiving work and communicate their ability to offer support so caregivers know what to expect. Community members need to communicate clearly and specifically about the type of help they can offer, how much they can do, and for how long.
- Professionals can learn, implement, and teach about Disability Affirming Therapy (DA-T) skills and techniques. As one example, DA-T promotes being flexible to cancel or reschedule when, for example, fatigue, pain, sensory sensitivities, or other disability-related complications prevent a planned activity (Olkin, 2017). Caregiving mothers in this study shared their appreciation for flexibility and

unconditional positive regard with the safer members of their social support in connection to scheduling events or meetings.

- Professionals and community members should actively support caregivers' efforts to foster an identity outside caregiving work. This means regularly engaging community members in the ongoing work of caregiving. Clinicians and community members should recognize the caregiver's work and how they continue to show up in the ways they can. Then, they can engage by working to mirror, match, and, at times, exceed the energy and efforts of caregivers while maintaining appropriate boundaries based on the relationship. Many mothers experience distancing and perhaps abandonment from those in their support networks. Still, they will also continue to find ways to support their children and perhaps others as well, despite stretched resources as well as a considerable lack of time and energy.

Caregiver's Bill of Rights

I. Caregivers have the right to integrate with supportive community members, including family, friends, and professionals, who seek to understand, support, and engage with them empathetically and constructively.

II. As per ADA law, caregivers have the right to expect community organizations to utilize their resources to make the necessary accommodations to include themselves and their children.

III. Caregivers have the right to expect community members to learn about, identify, and dismantle courtesy stigma and discrimination.

IV. Caregivers have the right to expect clinicians and key community members to participate with them to access and engage with specialized support.

V. Caregivers have the right to engage in regular respite.

VI. Caregivers have the right develop their identity and relationships outside of caregiving work.

VII. Caregivers have the right to engage in advocacy work with passion and as experts with lived experience, without being labeled as neurotic.

VIII. Caregivers have the right to pursue education and careers that are advantageous and foster economic security.

IX. Caregivers have the right to have complicated feelings about the difficult nature of caregiving work in an ableist society.

X. Caregivers have the right to utilize their lived experiences in transformative ways, to inform policy and practice, and to benefit other caregivers and their children with disabilities.

These recommendations and the Bill of Rights are offered to caregivers of children with DD and their community members or clinicians as a beginning point to address and apply practical solutions to the caregiver burden. I implore family members, friends, community members, future researchers, clinicians, and specialists to engage critically with these recommendations, expand upon them, and integrate them so that collectively, supportive care for this population is improved and enhanced.

Research Conclusion

This research makes a contribution by examining the essence of the maternal caregiver’s lived experience through an interpretative phenomenological framework, including potential impacts of their social-relational ecology. It also investigates, from mothers' perspectives, what kinds of social support contribute to resilience, are adaptive, and are helpful as well as issues contributing to a lack of social support. By examining themes and patterns in participants' responses, this research sought to examine barriers in the social ecology that further burden caregivers and provide possible solutions. The overwhelming number of barriers maternal caregivers face disrupt and negatively impact the immediate family system, including the child with disabilities. From the mother's perspective, this research demonstrates her experiences regarding support, including what kinds of social support are helpful, what is seen as supportive or not, and how extended friends, family, and community members can beneficially intervene. The experience of discrimination for caregivers is a more recent contribution to the literature on maternal caregivers because previous literature has focused on caregivers in the cultural and racial majority. Stober and Franzese's (2018) study highlighted mothers' awareness of discrimination due to a marginalized ethnic, racial, socio-economic status, or sexual identity. Similarly, this study underscored how visible and invisible disabilities contribute to the discrimination of children and their maternal caregivers, especially those who live with marginalized identities at the intersection of race and gender. Mothers in this study also spoke about cultural and internalized stigma, racism, English as a second language, and experiencing microaggressions as barriers to social support.

This research provides educators and counseling professionals who work with the disability population with multiple opportunities. As a professional community, we might better understand how caregivers experience interactions with extended family members and friends as support systems and how that enriches or hinders them. We can consider how stigma about disability may be impacting those interactions. We might learn where we can better apply disability-affirming practices within counseling psychology. We could offer insights to family members on the needs of their caregiving relatives. We could educate and thereby improve the support that specialists provide. We could better identify dynamics where systems provide support and then simultaneously undermine that support by assuming more than parents can carry in isolation. We might approach a remedy for the clinical levels of stress that caregivers experience. We could inform policy and end the current obligation of caregivers to over-function so as to experience an over-burden of care. Finally, we would have the opportunity to contribute effectively to an ongoing community of scholars who advocate for the disability community, advancing the cause of disability social justice to make the world more accessible for everybody.

Researcher Reflection

Beals et al. (2020) thoughtful descriptions of the tension in the dual roles as personal insider (emic) and researcher outsider (etic) resonate with my role as a researcher and the insider/outsider status I hold in relationship to caregiving, mothering, and marginalized identities. As I reflect on creating this research, I recognize that I approached the project with several relevant identities. I am an insider to the caregiver community, a parent advocate to a child with multiple disabilities, and a woman with a bi-racial identity. As the researcher, these insider identities permitted me to connect and build rapport with participant mothers quickly. In hindsight, my familiarity with mothers’ experiences supported safe interviews in which they opened up, sharing vulnerably and courageously about some of their most painful experiences of parenting.

Much of what I learned was familiar and as expected. I knew, for example, about parents' adjustment to the diagnosis and the frustrating experiences of feeling heard, seen, or understood by the family members, friends, and community professionals they hoped would support them.

Aspects of these kinds of experiences have been reflected in previous literature and also in the caregiver communities I am involved in. What I did not expect, and now want to amplify in this research and reflection, was the acuteness with which mothers described feelings of isolation and loss. In this study, mothers described compounded loss in relationships with their closest family members and friends alongside the challenges within professional relationships from which they sought support. Over and over again in this study, mothers shared how they worked to repair these close family and friend relationships with hopes of receiving understanding, connection, and support. When their attempts to explain and connect failed, many withdrew. Mothers coped with loss by defending themselves from further pain, self-isolating from community members who “don’t get it.”

As a counselor and counselor educator, I believe the pattern of isolation and the disconnect from critical members of the caregiver’s community is a crucial finding that must be recognized, emphasized, and addressed. Counselors, who are professionals trained to offer relationship-based, client-centered, and culturally competent support to caregivers, need to understand better how the discrimination caregivers experience resides not just at the macro level of community service providers. Discrimination, relationship rupture, and cut-offs are common and occur at the micro level of support, with caregivers' closest and most immediate family members. And yet, while compartmentalizing, coping, or grieving these unacknowledged losses, mothers soldier on, advocating and doing battle with systems on behalf of their children and the community. It is no wonder that literature has long established how the quality of life, well being, and economic standing of maternal caregivers diminishes greatly over time in contrast to their peers (Genereaux et al., 2016; Smith & Grzywacz, 2014). As the average maternal age increases and diagnostic assessments improve, an increasing number of families will support children with a developmental disability diagnosis. The work of counselor educators and counselor education programs should span and contribute to individual, family, and group psychoeducation and support, community and specialist trainings and workshops for professionals working with this population, and policy work. Each modality should include a depth of insight, including information about the multiple and complex barriers to social support that this population experiences.

As the researcher, I also sought to learn about what was unfamiliar. In studying the literature, I broadened my understanding of society's systems, which are largely driven by medical and educational institutions that serve the general population and reflect the strengths and weaknesses of the broader culture. Each has a long history of discrimination against disabled bodies, and discrimination occurs into the present. While disability laws and policies have been implemented, our society still lacks a true reform. In this context, mothers who are caregivers of their children with DD are bound to continue to experience a heavy caregiving load and also endure discrimination as they seek support for their children. As described in the literature, I found that the impacts on mothers navigating the system for access to services were detrimental. Caregivers of children with disabilities cannot be expected to navigate these challenges with the macro-view of systems often held by academics and legal experts. Without a better understanding that the discrimination that caregiving mothers face is pervasive and that they engaged in an ongoing power struggle at the center of gender, race, disability, and socio-economic status, these women are vulnerable to internalizing their experiences as personal ones instead of social and community issues, with more harmful outcomes.

I believe that one way harm might be mitigated is by improving counselor education and training so that counselors or clinicians can have a more accurate context of the family and caregiver experience, and counselors, in turn, could provide psychoeducation and appropriate interventions to address the relational impacts of disability on caregivers. Finally, I noted within the interpretation of findings how it was striking to me that all mothers in the study, regardless of their social identities, connected strongly with the experience of feeling marginalized. While I initially approached the topic of caregivers of children with DD as a counseling and policy concern, I now view it as a gender, race, disability, and socio-economic discrimination issue that is further compounded by having multiple marginalized identities.

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Appendix A

Recruitment Letter & Flyer

Greetings. My name is Zuleida Alemãn-Herba, and I am recruiting mothers of children with developmental disabilities (DD) who would be willing to participate in my research project by sharing their experiences of family, friends, and community as social support. This research is IRB approved and will use interviews to examine the types, quality, and breadth of support that maternal caregivers may experience from family members, friends, and the larger community. If you are the mother of a child or children with (DD), you know a mother, or you know a community of mothers who might want to participate in this study, please consider sharing this letter with them.

Why is this research important? This research is important because mothers of children with disabilities (DD) have been associated with poor outcomes for well-being over their lifespan, with the demands of caregiving impacting the quality of life. The depth, quality, and availability of social support can have a significant impact on the life experiences of both children with disabilities and their maternal caregivers.

What kind of participant am I seeking? Research shows that mothers with marginalized identities experience compounded challenges with their caregiving work. For this reason, this study seeks to highlight the experiences of mothers who identify as coming from any intersection of low socioeconomic status, single mothers, mothers who identify as Black, Indigenous, people of color, disabled, or from the LGBTQ community.

Who am I? I am a licensed mental health counselor who has worked in private and clinical practice with parents, families, and adolescents for almost fifteen years. I am a PhD Candidate in Counseling Psychology who identifies as bi-racial, and a first-generation Latina-American. I am also the mother of a child with multiple disabilities. By highlighting social support, I hope to illustrate through research what is working and what is not for maternal caregivers. Ultimately, I want this work to help improve the quality of life, especially formal and informal social support for caregiving mothers of children with DD whose experiences have been historically marginalized or hidden in research and policy.

What does this research involve? Primarily, this research involves completing a 1-2 hour interview in a safe, confidential location, either in person or over Zoom. Participants would share information about their caregiving experiences and how they experience support from family members, friends, and community members. The interview and information taken in the interview would remain confidential.

How do I show interest, ask questions, get more information? Please contact me at zherba@lesley.edu or call me at # here. **Please post, share, or email this letter so that I might reach eligible participants for this study.**

Spring 2023 Research Study:

Social Support and Marginalized Mothers of Children with Developmental Disabilities

Are you the mother of a child with developmental disabilities between the ages of 6-14?
This study seeks to share the stories of maternal caregivers of children with developmental disabilities who are marginalized within research, and identify as BIPOC, low SES, single, disabled, or LGBTQ+.
To Learn More, Share This Information, or Participate
Please Contact:
Zuleida A Herba, LMHC
PhD Student Division of Counseling and Psychology
Call or Text: 407.432.9428
zherba@lesley.edu

Lesley
UNIVERSITY

Appendix B

Informed Consent Agreement

Thank you for volunteering to participate in this IRB approved study about mothers of children with developmental disabilities and their experiences with social support. This informed consent contains pertinent information about the study's purpose, your involvement, and your rights as a participant. At the end of this consent, you may have additional questions about the study. Please do reach out to me with them.

Study Purpose: This research will use interviews to examine the types, quality, and breadth of support that maternal caregivers of children with developmental disabilities (DD) may experience from family members, friends, and the larger community. This study focuses on the experiences of mothers as caregivers and especially seeks to highlight the experiences of mothers who identify as coming from any intersection of low socioeconomic status, single mothers, mothers who identify as BIPOC – or any person who identifies as non-White. This can be people who identify as Black, Indigenous, or Brown. This study is inclusive of and seeks to highlight caregivers who identify as disabled, or from the LGBTQ community.

Participant Criteria: To participate in this study, you must be a parent of a child with a developmental disability diagnosis (DD) and between the ages of 6-14.

Participation Involvement: You may volunteer to offer a copy of your child's IEP, medical, or other record indicating a developmental disability. Your participation will entail (a) completion of a demographic questionnaire (b) completion of a social-relational map, where you will share who is most and least supportive in your caregiving work and (c) an audio or video recorded interview for approximately 1-2 hours. In the interview, you will be asked to share your experiences as a caregiver. This may include your experiences with initially receiving a diagnosis for your child, the kinds of caregiving work you participate in, and your experiences of friends, family, and community as forms of social support. You may choose to answer none, some, or all the survey questionnaires and interview questions. You may be asked to participate in follow-up questions by phone or email, to clarify findings. By signing the consent form, you give the researcher permission to use the statements you make during the interview in the study's findings.

Participant Rights: Your participation in this research is completely voluntary, and you may withdraw from the project at any time and for any reason. If you withdraw, your information will be eliminated from the study and destroyed. You may stop the interview at any point, or you may decline to answer any of the questions within the interview. Your information and any contribution you make to this study will be kept completely confidential. Interview data, including direct quotations, may be used for academic purposes, such as presentations, published research papers, or articles, but your name and any identifying information will not be associated with any part of the written portion of the research, Recordings, transcripts, and interview data will be stored in a locked file cabinet or on a password protected computer that only I will have access to.

Risks and benefits: By volunteering to be interviewed, you may develop greater insight into your own experiences and contribute to knowledge about this. As you discuss your experiences you may feel overwhelmed or experience hard feelings. You may always pause, take a break, or stop the interview if you feel distressed. Should you become distressed or find them helpful, I have provided a list of supportive resources.

Acknowledgement: Thank you for taking time to read this consent. Your contribution to this study matters greatly. If you have questions about this process or your involvement, please ask the researcher before signing this form. If you have questions or concerns about your rights as a research participant, contact me or Professor Sue Motulsky, EdD at smotulsk@lesley.edu.

An electronic copy of this informed consent form has been provided to you. Please sign below, indicating that you have read, understood, and agree to participate in this project. If you would like to, you may make or ask for, and then keep a copy of this document for your record.

Researcher: Zuleida Alemãn-Herba, LMHC
160 Cambridgepark Drive
Unit 341
Cambridge, MA 02140
zherba@lesley.edu
407-432-9428

There is a Standing Committee for Human Subjects in Research at Lesley University to which complaints or problems concerning any research project may, and should, be reported if they arise. Contact the committee chairperson at irb@lesley.edu

Signature Date: ___________________________________

Participant's Signature (You may type your name here to serve as your signature, indicating that you have read, understand your rights, and agree to participate in this research study)

Researcher's Signature: *Zuleida Alemãn-Herba*

Appendix C

Demographic Information

Name: ____

Address: ____
____

Contact information: Phone # ____
Email address: ____
Date of birth or age: ____

Identity:
Gender: ___ male ___female ___ transgender ___ gender neutral ___ non-binary
___ Other identity, please specify ______________________________________

Race and Ethnicity:
___ African American or Black ___ American Indian ___ Alaska Native ___ Asian
___ Hispanic or Latino ___ Native Hawaiian ___ Pacific islander ___ White
___ Multiracial, please specify ____
___Other, please specify ____

Sexual Identity/Sexual Orientation/Other:
____

Caregiver's Disability Diagnosis: Yes/No

Specify or describe disabilty:____

Education level: ___ Less than high school ___ High school or equivalent diploma
___ Some college, or associate's degree ___ Bachelor's degree ___ Master's, professional, or doctoral degree

Household annual income range: ___ $0 - $48,500 ___ $48,500 - $145, 000 ___ $145,000 and above

Marital Status: ___ Single ___ Separated ___ Divorced ___ Married ___ Partnered___ Widowed

Religious affiliation: ____

Occupation: _______________________

Child with developmental disability diagnosis: _________________________________

Approximate date or age of diagnosis: ____
Age: _________ Identity (please choose from options listed above or add an additional category)**:**
Gender: ______________ Race and Ethnicity: ____________ Sexual Orientation: ____________

Relationship to you: child, sibling, partner, other ______________________________________
Does the individual live with you: ___ Yes ___ No
If not, where does the individual live? ____
Other members of the family living in the same household with you: (partner, spouse, siblings, other relatives:____

Is there any other information that you think is important and that you would like me to know?____

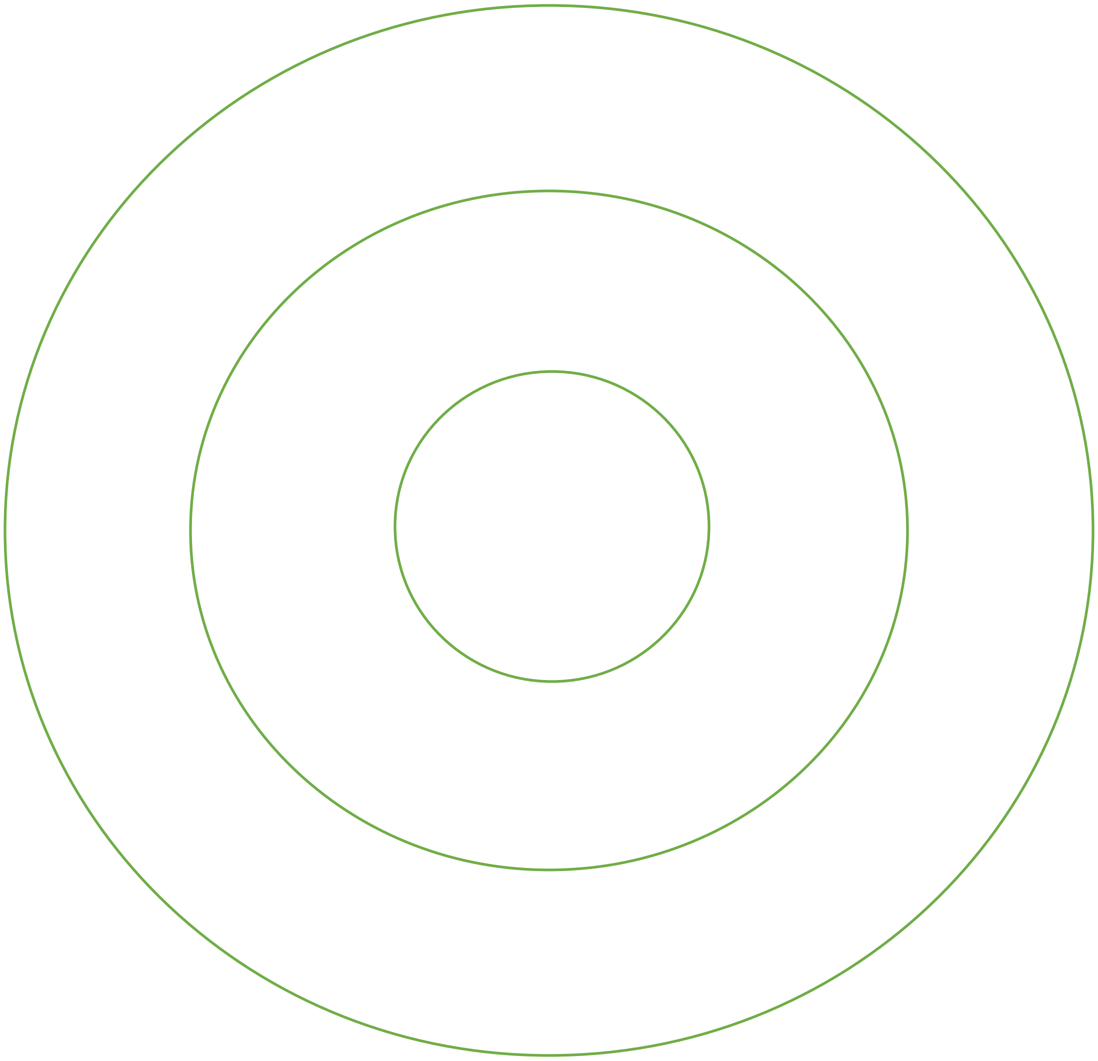
Appendix D

Social Support Map

Please write yours and your child's initials in the center of the social support map. Then, use the concentric circles to illustrate the family members, friends, and community members who are the most (closest to you) supportive and least (farthest from you) supportive in your caregiving experience.

Think of who 'gets' you, your child, your life, and who offers the most tangible kinds of support. Place those people closest to you in the circle and work out from there. Please include a range of people like significant others, other children, extended family members, friends, and community members such as clergy, doctor, therapists, teacher/child's teacher or practitioners, community support groups. Also include pets or deceased people that you felt were supportive and understood.

This information will be de-identified in the study results; names will not be used. Use the back of the sheet, and any additional space to make notes about why or how these individuals are more or less supportive in your experiences as the mother of a child with developmental disabilities.



Appendix E

Interview Protocol

Researcher Introduction: Acknowledge recording. Welcome and thanks for participation. Study overview. Brief personal and professional statement. Overview of consigned consent, agreement to record, confidentiality, ask for and address any questions or concerns before beginning. Facilitate: Collected IEP and or records? Clarified information on IEP? Completed demographic information? Clarified demographic info? Completed social support map?

Questions

As you know, this study is researching mothers of children with developmental disabilities and their experiences with social support. For this study, caregiving is used to describe work involved directly related to supporting your child's disabilities. This is the work that is different than raising a typically developing child – therapy, special diets, medication, doctors' visits, IEP meetings, specialists, behavior management, etc.

Social support focuses on your experiences with family members, extended family members, friends, and community members. Community members may be the people you will have significant interaction with in community settings on behalf of your child, for example day care workers, social workers, pastors/clergy, teachers, medical and therapeutic specialists.

Any questions? Ok great. Let's move on to learning about your experiences.

Diagnosis

1. When did you first initially learn about your child's DD?
2. Can you tell me how you understand your child's DD and what this means for your child?
3. Can you tell me how this diagnosis impacted you?
4. Can you share what caregiving work looks like for you?
5. Has anyone along the way asked how you are doing in a supportive or meaningful way?
6. Has your career trajectory changed and how?
7. Has your income shifted and how?
8. Have you adjusted expectations you previously had for the future? How?
9. How have you observed the diagnosis impacting your immediate family members – partner, siblings, household members

Social Support Map

1. In your caregiving journey, can you share with me who you find most supportive and for each person, share more about why?
2. In your caregiving journey, can you share with me who you find least supportive and for each person, share more about why?
3. Can you share one or two experiences with family, friends, or community members that you would describe as being most supportive?
4. Can you share one or two experiences that you would describe as being least supportive?
5. Generally, how has DD impacted your relationship with immediate family members?
6. Generally, how has DD impacted your relationship with extended family members?

7. Generally, how has DD impacted your relationship with friends?
8. How has DD impacted your relationship with community members?
9. What barriers do you experience to social support?
10. If there was a person in your circle who wanted to become more supportive in your caregiving work, how could they?
11. What strategies do you use to cope when you encounter unsupportive people?
12. If you could wave a magic wand, and put the right support in place for all caregiving mothers, what kinds of support would you wish for?
13. Is there anything else that you would like me to know?

Conclusion: Thank you so much for sharing your time today and also for sharing your experiences, which will be really helpful for this study. My work is centered on helping others to understand more about what mothers' experience when their child has a DD diagnosis, and what you have shared has been essential. I am all finished with questions at this time, but I would like to take a few moments to answer any questions you may have. (Space for questions, feedback, conclusion). What is the best way to follow up with you in case I have any questions, or need to clarify what you shared? If it's helpful, I've included a list of resources for support. Thank you again.

Appendix F

Protecting Human Research Participants Training

CERTIFICATE

OF COMPLETION

PHRP Online Training, Inc. certifies that

Zuleida Herba

has successfully completed the web-based course "Protecting Human Research Participants Online Training" (Program #[illegible]) and earned the following Continuing Education Contact Hours:

CHES®/MCHES® Contact Hours – 3

Date Completed: **2020-11-20** Certification Number: **[illegible]**

Appendix G

Resource List of Support Services

Hospital-Based Clinics Boston Medical Center (BMC) Psychiatry (617) 414-4238 → South End Newton Wellesley Hospital (617) 243-6006 → Newton/Wellesley area Tufts Psychiatry (617) 636-0219 → Downtown Boston MGH Psychiatry (617) 724-7792 → Downtown Boston McLean (617) 855-2300 → Belmont Hospital-Based Mood Disorder Clinics MGH Bipolar Clinic & Research Program (617) 726-5855 → Downtown Boston Tufts Mood Disorder Clinic (617) 636-0219 → Downtown Boston Autism AANE – Autism/Asperger's Network (617) 393-3824 → in Watertown *testing, meds, therapy, referrals* ADHD/Stimulants ADHD Boston (617) 326-8260 → Needham *testing, meds, therapy* Outpatient Psychiatry & Therapy: Rasi Associates (617) 266-2266 → Boston (Boylston St.) *therapy & meds Sameem Associates → Newton *therapy & meds. Substance use, takes Masshealth Massachusetts Mind Center (617) 977-6853 → Back Bay *BCBS, any other PPO* Ally Integrated Healthcare (351) 277-0501 → Back Bay *will take any PPO* Outpatient Psychiatry Newton Wellesley Psychiatry (617) 332-2047 → Newton/Wellesley area Dana Group Associates (781) 417-5178 → Needham Leggett Group (857) 273-2123 → Roslindale Arcara Personalized Psychiatry (617) 500-3856 → Back Bay *BCBS, OOP ONLY* Brookline Psychiatric Associates →Brookline *accepts most insurances Dr. Agrawal Hans (617) 234-4488 → Cambridge *takes Aetna & Medicare* One Medical →Boston *same/next day appts Outpatient Therapy Boston Evening Therapy Associates (617) 738-1480 → Brookline *evening and weekend appointments* Cambridge Health Alliance → Cambridge *Eating disorder specialties, takes MassHealth - Adult outpatient psychiatry: 617-591-6033 - Outpatient addictions program: 617-591-6051 Neuropsych Testing: Boston Neuropsychological Services (781) 559-8444 →Needham *forensic, disability evals Cornerstone Behavioral Health 508-791-3677 →Worcester/ Fitchburg *psych and neuropsych testing NESCA → Newton *C&A only Psych Testing: Psychological Care Associates → Woburn, Arlington, Stoneham, Chelmsford, Framingham *psych & neuropsych testing Dana Group Associates (781) 417-5178 → Needham Boston Counseling Services → Needham Cornerstone Behavioral Health→Worcester/ Fitchburg *psych and neuropsych testing Legal Issues Boston Forensic Associates (781) 326-0200 →Dedham *does neuropsych testing Schizophrenia CEDAR Clinic (617) 754-1223 → Boston ("Helping youth at risk for psychosis") DBT Cambridge Health Alliance DBT Program (617) 665-1000 → Cambridge Boston Child Study Center (857) 400-9211 → Back Bay Brighton Allston Mental Health Associates (617) 917-2782 → Brighton/Allston Tufts, Aetna Massachusetts Mind Center (617) 977-6853 → Back Bay - Asma Rashid, MD - Sadaf Hashmi, MD Ally Integrated Healthcare (351) 277-0501 → Back Bay Substance Use Column Health (339) 309-0347 → Arlington, Attleboro, Lawrence, Brighton, Somerville Massachusetts Mind Center (617) 977-6853 → Back Bay Ally Integrated Healthcare (351) 277-0501 → Back Bay *will take any PPO* Whitley Wellness (325) 515-5248 → Boston & South Boston Boston Psychiatric Care (617) 440-7211 → West Roxbury Psych Garden (857) 598-2808 → Belmont Eating Disorder Specialty Programs Cambridge Eating Disorders (617) 547-2255 → Cambridge *Services Include = Residential, Partial Hospital, Intensive Outpatient, Outpatient McLean Hospital- Klarman Eating Disorder Center (617) 855-3410 → Belmont *Services Include = Residential and Partial Hospitalization Program MEDA: Multi-Service Eating Disorders Association (617) 558-1881 → Newton *Services Include = Evaluation & Referral, Support Groups, Education Metrowest Nutrition (617) 332-2282 →

Newton The Renfrew Center (800) 736-3739 → Boston *Services Include = Residential, Day Treatment, Intensive Outpatient, & Outpatient Walden Behavioral Care (781) 647-6727 → Waltham *Services Include = Inpatient, Residential, Partial Hospitalization, Intensive Outpatient, Outpatient Services Cognitive Rehabilitative Therapy (CRT) Kelly Jones, PhD (413) 687-4708 → Boston & Woburn Whitney Havins, PhD (617) 297-8040 → Virtual Justin Centi, PhD (857) 336-1550 → Boston Community Health Centers Riverside Community Care (781) 329-0909 → Dedham, Newton, Upton, Somerville & Lynnfield *Services Include = Outpatient, Emergency Services, Day Programs Minor Psychiatry Outpatient Resources Boston Children's Hospital: Outpatient Psychiatry Services - 617-355-6680 Massachusetts General Hospital: MGHfC Psychiatry - Yawkey Center for Outpatient Care - 617-724-5600 CHA – Cambridge Health Alliance Outpatient Services: 617-665-2485