A MISFITS PERSPECTIVE: THE LIVED EXPERIENCES OF MOTHERS OF DISABLED CHILDREN

by

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DISSERTATION ABSTRACT

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This dissertation explores the lived experiences of mothers of disabled children. Through qualitative methods, including 39 in-depth interviews and two years of participant observation, this project examines Latinx and white mothers' perspectives on disability and lived experiences navigating spaces on behalf of and alongside their disabled children. The project employs a misfits framework, based on the theorizing of Rosemarie Garland-Thomson. Within a misfits perspective, disability arises when the environment does not support or sustain an individual's embodiment. A social relational model of disability, misfits locates disability in the interaction between atypical bodies and inaccessible environments. The primary research questions developed through thematic analysis of the interview data, field notes, as well as the existing literature.

This manuscript analyzes themes in mothers' disability definitions and influences on the development of those definitions. Mothers understand disability as a natural manifestation of human biodiversity. Mothers perceive their disabled children as capable, valuable, and inherently the same as other, non-disabled children. According to these mothers, the problems of disability primarily arise because the world does not accept or support their children. Mothers develop these critical perspectives on disability through experiences of misfitting and fitting. A second research aim examines mothers' advocacy experiences in the special education system. Mothers' advocacy results from their children's experiences of educational misfit. Mothers' advocacy focuses on creating fit for their children. When mothers' challenge educational norms, they experience misfit, themselves. This project also explores unique aspects of the misfit experienced by Latinx-immigrant mothers who advocate on behalf of their children in education, medical, and public disability systems. Characteristics of Latinx-immigrant mothers' own non-majority embodiment may lead to misfit when environments are inaccessible or unsupportive.

By applying a misfits analysis, this dissertation seeks to contextualize mothers' lived experiences and disability perspectives within a largely, inaccessible world. Mothers feel their children's disability-based misfit and sometimes misfit themselves as they navigate hostile spaces. Findings demonstrate that mothers experience types of disablement, like misfit, similar to their disabled children. The manuscript concludes with scholarly and policy-based recommendations.

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To my parents.

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CHAPTER I

INTRODUCTION

> "I think it [Matthew's disability] was like a curse, at first -- the cross you need to bear, you know, as a good Catholic -- I wanted to fix Matthew… And now, I actually feel that [it] is an attribute -- that I don't want Matthew to be discriminated [against] or abused or exploited, but I feel that I don't want Matthew to be any different than who he is today because I have grown with his disability." -- *Isabel, 62, Latinx-immigrant, middle-class, mother to an adult son diagnosed with autism*

Perspective changes like Isabel's, and the experiences which motivate them, are at the heart of this dissertation. Isabel moved to San Francisco from Mexico City as a young woman to pursue her career as a ballerina. She fell in love with and married an American man. Soon after his birth, Isabel's second son, Matthew, was diagnosed with developmental delay, and later, autism. Isabel, her husband, and three sons moved from the Bay Area to a suburban city, in the state where this dissertation research occurred, when Matthew started high school. Quickly, Isabel realized that the inclusive education Matthew received in California would not move with them; Matthew's new teachers and principal balked at Isabel's requests that Matthew attend classes with non-disabled peers. Isabel missed the community of parents of kids with disabilities that surrounded her in California. She began attending disability rights trainings and classes, learning about the law and available disability services. One day, when Matthew was a high school junior, he pushed an educational assistant. Matthew was handcuffed by the school's liaison officer, arrested, and later charged with eight offenses. At Matthew's court hearing, the judge addressed Matthew and asked him to state his name. Matthew hid behind Isabel. He held an Ernie, a Sesame Street character, stuffed animal. Isabel and Matthew had practiced going to court multiple times before the court appearance; one day driving by the courthouse, another day, parking outside and walking up the steps, next, going into the court building. But Matthew was still afraid and confused that day. The judge later dismissed all charges against Matthew.

After Matthew's encounter with the criminal justice system, Isabel founded a self-advocacy group for parents of children with disabilities, Alianza de Padres/Parent's Alliance (ADP). For the past 20 years, Isabel and ADP have led trainings around the state where she resides for Latinx, Spanish-speaking parents. Through these trainings, Isabel teaches Latinx-immigrant parents practical advocacy skills, informs parents of their rights, and spreads the social model of disability. ADP also promotes disability inclusion at the collective level through media campaigns, presentations, and collaborations with state councils. ADP professes an allegiance to the social model of disability; Isabel and other ADP volunteers were not interested in fixing, changing or curing their children in any way.

I met Isabel six years ago. She gave a guest presentation in a Disability Law course I enrolled in, hoping to meet like-minded disabled scholars and lawyers. Isabel began her presentation by showing a video, a spoken-word rendition of "A Credo for Support," a disability rights guide for how to be an ally to people with disabilities. Listening to Isabel, I knew that she got it. She wasn't like the other non-disabled lawyers or advocates who had spoken in class, and she wasn't like my colleagues, mostly non-disabled law students who hoped to work in disability law after graduation. In Isabel, I saw an ally, and I felt that she understood that disability isn't a tragedy, and it isn't a cause for inspiration, either. It just is.

It was the first time I heard a non-disabled person talk about people with disabilities as rights holders and equal citizens. It was also the first time I heard a parent of a person with a disability speak with anger directed not towards the mere fact of her son’s disability, but towards the social institutions which had discriminated against him on that basis. I needed to know how she developed that perspective, and if we could figure out a way to teach it to not just other parents of people with disabilities, but to everyone. I needed to know how to develop this perspective because I think, on some level, the primary work of disability rights and disability studies continues to be arguing for the continuing presence of people with disabilities in the world; in other words, the fight is still simply a fight for existence, a fight to convince others that people with disabilities deserve to live in the world.

I contacted Isabel, told her of my interest in her work, and desire to become involved with ADP (at the time I was looking for pro-bono legal opportunities). After a few months of meeting with Isabel, helping her with the nuts and bolts of formalizing a non-profit, writing brochures, and organizational statements, setting up a Facebook presence, she invited me to attend one of ADP’s meetings. It was the last meeting of the year, and the parents were deciding on topics to discuss in the future. I was immediately struck by the positive disability thinking which arose in the meeting, and the dynamics through which this thinking was developed. More than one parent suggested sexual education as a potential topic. Parents wanted to know how to talk to their children with disability about sex. I remember thinking, ‘Wow, these are quite progressive parents, wanting to learn about the sexuality of their kids with disabilities!’ One mom, who shared that it was her first meeting, suggested that the group learn about the cause of autism and any potential cures. Isabel addressed the mom and explained that this topic did not fit with ADP's agenda. She explained that ADP's focus was not on the causes or treatment of disability because disabled children do not need to be fixed. As a group, ADP was concerned with the reality of disability, rights, and community inclusion. I was astonished; most of the parents I had encountered in my own disabled childhood desperately sought a cure. Another mother spoke up, gently reinforcing Isabel's message. This mother, who I would later learn acted as a leader in the group, shared that her son had Down syndrome and is perfect just as he is. She elaborated that her job was simply to advocate for him, not change him. I was speechless. How did these women come to develop these understandings of disability? To say, and for me to see it written on her face, that her son with Down syndrome was perfect, just as he is. How did she get there?

This dissertation examines how mothers develop positive perspectives on disability. How do mothers make sense of their, and their children's, experiences with disability? How does advocacy influence mothers' critical perspectives on disability? What are mothers' lived experiences of disability advocacy? How does race shape these experiences? Rosemarie Garland-Thomson argues that experiences of "misfitting," or encounters with an inaccessible and hostile environment, may lead to an "oppositional disability consciousness" (Garland-Thomson 2011). Isabel's story, and the stories of other mothers I met in ADP, reflected Garland-Thomson's theory. Mothers shared similar stories, in which disability professionals held negative expectations for their children, excluded their children, and disregarded mothers' knowledge of their children. Mothers sought help and found community in parent-led organizations. In these spaces, mothers reaffirmed their love for and belief in their children (which they felt disability professionals dismissed). These mothers' accounts inspired this dissertation.

Overview of the Study

Much of the social scientific literature on parenting children with disabilities paints the experience as “a terrible unending tragedy” (Kafer 2013: 2). Historically, this literature has not always approached disability from a social model perspective. Studies have tended to list the “unfortunate consequences” of an “unquestionable tragedy” (Ferguson 2001: 386). Often, research expects mothers of children with disabilities to be grief-stricken "victims of individual tragic circumstances … mired in emotional distress" (Green 2007: 161). The extant research emphasizes the added burdens associated with parenting a disabled child. For example, numerous studies document greater levels of stress, anxiety, depression, and exhaustion among parents of children with disabilities than among parents of non-disabled children (Baker et al. 2002; Baker et al. 2003; Dyson 1996; Eisenhower, Baker, and Blacher 2005; Gupta 2007; Lopez et al. 2008; Hoffman et al. 2009; Gerstein et al. 2009; Zablotsky, Bradshaw, and Stuart 2013). Research has also focused on parents' reported economic burdens, such as income loss, absence from the labor force, and difficulty finding childcare, as well as high levels of marital strife (Ferguson 2001; Green 2007; Brandon 2007; Hogan 2012; Scott 2010).

Some of this research has focused specifically on mothers' experiences with disabled children (Green 2007; Scott 2010; Blum 2007, 2015). Mothers of disabled children expend considerable energy navigating courtesy stigma, mother blame, and obtaining services for their children (Green 2007; Blum 2007, 2015). Mothers' experiences with courtesy stigma, stigma based on an association with a spoiled identity, add to their feelings of subjective burden (Green 2003; Blum 2007, 2015). Mothers must also deal with mother blame, a cultural norm in which mothers are held responsible for their children's disabilities and for "normalizing" their children as much as possible (Green 2003; Panitch 2008; Blum 2007, 2015; Colker 2013, 2015). Mothers internalize this sense of personal responsibility for their children's disability and report feeling that others blamed them for their children's problems (Blum 2015). Because of their extensive advocacy efforts, efforts to obtain services for their children, mothers of disabled children have been characterized as "warrior-heroes" (Sousa 2011) and "vigilantes" (Blum 2007) fighting within complicated bureaucracies.

Within this body of literature, research on the experience of Latinx-immigrant mothers is limited. However, the existing scholarship largely "depicts the general situation of Latina mothers as one of increased need and decreased access" (Iland, Weiner, and Murawski 2012). Studies focus on identifying barriers to Latinx-immigrant mothers' access to services and participation in disability advocacy. Barriers include language usage (Lo 2008; Cobb 2014; Burke and Goldman 2018), a lack of information about services (Sanchez 2006), and discrimination (McHatton and Correa 2005; McHatton 2007; Angell and Solomon 2017). Research also examines the mental health and coping skills of Latinx-immigrant mothers of disabled children (Reyes-Blanes, Correa, and Bailey, Jr. 1999; Torres and Rollock 2004; Magaña and Smith 2006; Blacher and McIntyre 2006).

The extant research tends to focus on mothers' emotional distress and extensive care-giving burdens without contextualizing mothers' experiences within widespread disability oppression. The literature presents a one-sided view of mothering disabled children that reaffirms common sense views that disability is an unending tragedy. This project attempts to present a more complex understanding of mothers' relationship to their children's disability, an understanding that aligns with the social model of disability. This dissertation adopts the social model of disability by emphasizing the ways that social interaction, social norms, and social institutions hurt disabled people and their families. Put simply, the analysis does not focus on the very real limitations caused by the impaired bodies and minds of these children or the burdens that their mothers face in navigating a largely inaccessible world. Instead, the analysis contextualizes mothers' experiences and perspectives within social environments that exclude and devalue disabled people and their allies.

This dissertation includes the experiences and perspectives of an often-overlooked group of mothers, Latinx-immigrant mothers. Disability studies has largely failed to analyze the influence of race in the lives of people with disabilities (Bell 2011, 2013; Erevelles 2011; Annamma, Ferri, and Connor 2018). Traditional disability studies scholarship has centered the experiences of white disabled people, assumed those experiences to be universal, and then ignored the experiences of disabled people of color or their parents (Bell 2011, 2013; Erevelles 2011; Annamma, Ferri, and Connor 2018). By analyzing the lived experiences and disability understandings of Latinx-immigrant mothers, through a social model perspective, this project addresses this critical gap in disability studies.

Literature Review

From the Social Model of Disability to Misfits

Both historically and currently, the dominant social understanding of disability is that of a personal tragedy and a medical misfortune (Davis 2013; Oliver 1990). Disability studies seeks to shift away from this understanding and toward a conceptualization of disability as a social construction whose meaning is determined primarily through discourse, power, and knowledge (Linton 1998; Garland-Thomson 2011). An early step in this movement was the development of the social model of disability, first appearing in the writing of UPIAS (the Union of the Physically Impaired Against Segregation) and later outlined by U.K. sociologist Michael Oliver. The social model of disability separates impairment and disability, in the same way feminist scholars distinguish sex and gender (Rubin 1975 [2011]). Impairment refers to bodily difference, the abnormal body, whereas disability arises from a social organization that excludes and devalues impaired people (Oliver 1990). As Vic Finkelstein wrote in 1975, "it is society which disables physically impaired people. Disability is something imposed on top of our impairments" (UPIAS 1976). Based on this perspective, activists argued for improved access to buildings, educational services, and employment. Scholars, then, sought to reform assumptions of pathology within the rehabilitation fields, theorize the creation of disability as a social category, and develop "emancipatory research" (Oliver 1990; Linton 1998).

However, the distinction between impairment and disability has recently been criticized by scholars who argue that both impairment and disability are socially constructed and that the social model discounts the embodied experience of impairment or disability (Siebers 2008; Shakespeare 2013). For instance, research indicates the centrality of the body (pain, difference) within the experience of disability for many disabled people; similarly, research identifies a diverse array of experiences among people with different impairments (Shakespeare and Watson 2002). Additionally, some scholars argue that a ‘false’ binary between body and society underlies the social model (Hughes and Paterson 1997). Others fear that a rigid social model discourages the use of medical technologies or treatments to alleviate impairment (Shakespeare 1996).

Rosemarie Garland-Thomson’s concept of *misfits* addresses this academic debate. *Misfits* focuses analysis on the interaction between the material environment and the “particularities of embodiment” (2011: 592) to explain the lived experience of disablement. *Misfits* maintains the social model’s focus on the disabling impact of the environment while requiring attention be paid to the unique body. Most societies are built for and sustain “majority-bodies”; this typically produces *fits* for non-disabled people. A *fit* occurs when the environment supports an individual, meets the needs of the individual, and allows an individual anonymity. *Fitting* provides a sense of belonging, well-being, and acceptance. Like other unmarked and privileged statuses, *fit* is often invisible and results in physical and symbolic inclusion.

In contrast, *misfit* occurs when the environment does not sustain the body, captured by the image of “a square peg in a round hole” (2011: 593). People with disabilities often experience *misfit* when navigating the environment, which does not meet their needs. Garland-Thomson provides multiple examples of misfitting to illustrate the concept: misfit occurs between the wheelchair user and the flight of stairs, between the deaf, sign language user and the boardroom of still speakers, between the blind woman and the voiceless ATM machine. Misfit primarily results in the exclusion of disabled people. Exclusion may be literal, or physical, as when the wheelchair user cannot enter the building, or interactional, as when the deaf signer cannot participate in boardroom discussions.

Although typical analyses might consider a person as either disabled or non-disabled, or an environment as either inaccessible or accessible, the concept of *misfit* suggests, instead, that each human embodiment may *fit* or *misfit* in any given moment, in a specific environment. In this view, both disability and access are contextual and ever-changing. For example, in the above scenarios, when stairs turn to ramps, when boardrooms include interpretation services, and ATMs provide oral cues, *misfit* may turn to *fit*. *Misfits*, thus, recognizes the inherent, universal, vulnerability of human beings (Zola 2005). Without a supportive environment, any embodiment can *misfit*. This focus on context and change limits the tendency to create hierarchies of disability, i.e. differentiating between those with severe or mild impairments; instead, the level of disablement reflects a social reality in which some embodiments experience greater fit because of the material environment (not the degree to which a body deviates from a biological norm).

Figure 1 maps out my interpretation of Garland-Thomson's "critical concept *misfit*." If, when the body meets the environment, the interaction is harmonious, a fit occurs. In contrast, jarring encounters between body and environment produce misfit. In other words, the encounter between body and environment either leads to fit or misfit. Although Garland-Thomson's explanations focus on bodily characteristics typically associated with physical impairments, the body also refers to traits commonly understood to arise from the mind (Lewiecki-Wilson 2003) and other socially meaningful characteristics, such as race, class, and gender. The body includes embodied differences associated with mental disabilities, such as "madness" and "cognitive and intellectual disabilities of various kinds” (Price 2011: 31). For example, embodiment includes traits such as brain-processing speeds, sensory needs, emotional expressions, and other manifestations of neurodiversity.

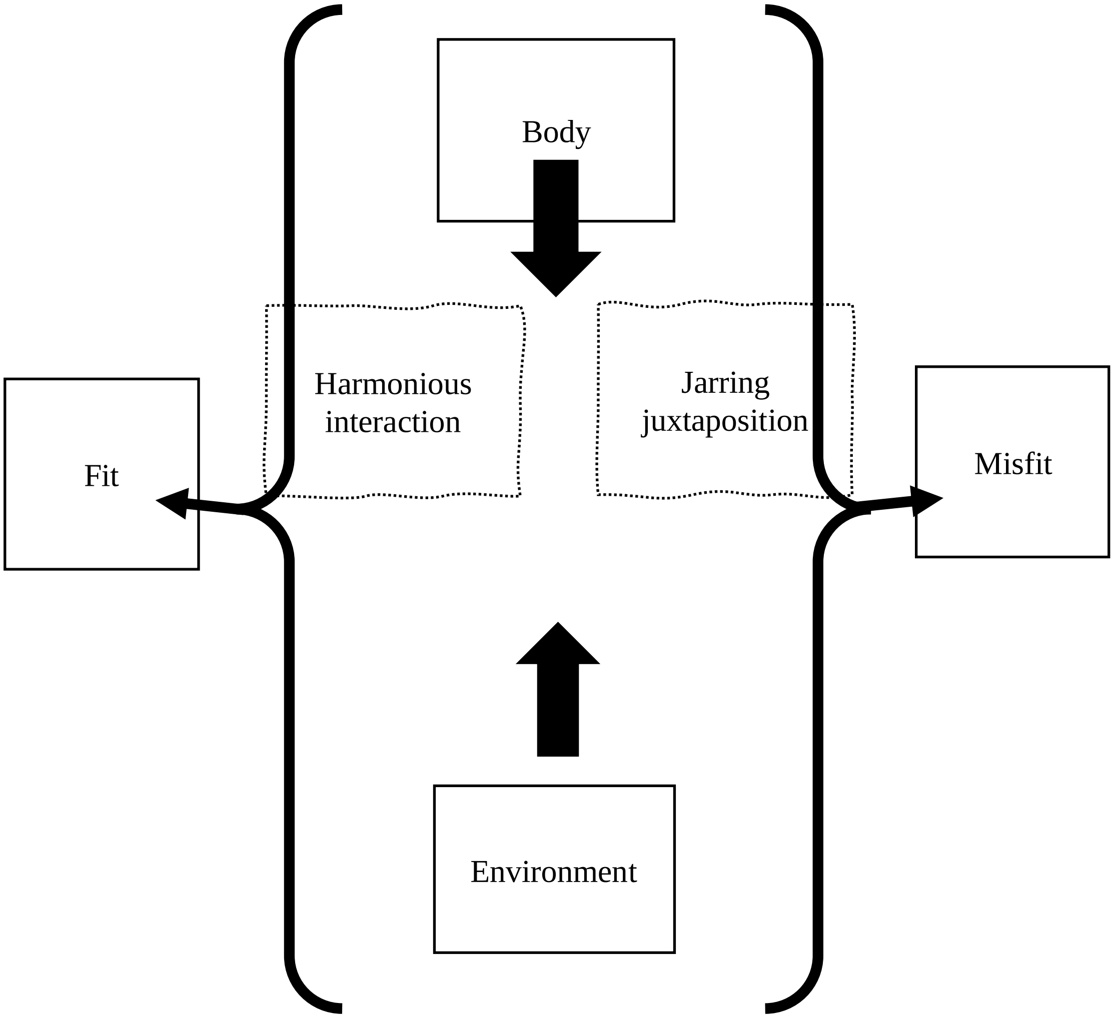

Figure 1. Conceptual Map of Misfit

Garland-Thomson also defines the environment broadly. Within Garland-Thomson’s definition, the environment includes the macro structures of the world, such as capitalism, racism, sexism, as well as social institutions like the family, workplace, schools. The environment also encompasses architectural features, i.e. curb cuts, ramps, steps, and technology, both accessible and inaccessible. Social actors, interaction expectations, and cultural forces (the way "modernity presses us relentlessly toward corporeal and other forms of standardization" (2011: 603)) are included in the environment, as well. Most succinctly, the environment refers to "the ways the world is built for certain kinds of bodies" (2011: 602).

The Experience of Disablement

In this section of the literature review, I discuss broad patterns or themes among peoples' lived experience of disability. These patterns shape the context within which mothers and disabled children navigate the world and make sense of their experiences. Key aspects of the environment which facilitate misfit for disabled people include (1) expectations of uniform and independent bodies, minds, behaviors, (2) the dominance of disability professionals, and (3) the association of disability and inability (connected to the assumption that rationality equates with personhood). In practice, these assumptions manifest in policies and interactions and lead to the exclusion of disabled people from mainstream social institutions, like the workplace, schools, and the public sphere (politics). Scholars trace this exclusion to the transition from a localized feudal economy to industrial capitalism, when disability became a master status signifying the total inability to participate in the labor market (Gleeson 1997; Finkelstein 1981; Oliver 1990). The rise of industrial factories and the standardization of pace and mode of production left no room for people with physical and mental impairments. Institutions, such as the poor house and workhouse, arose to house individuals who could not work (Stone 1984; O'Brien 2001). Disabled people were viewed as incapable of work and therefore deserving of support. Impaired people's identity thus transformed from workers into dependents incapable of meaningful participation in the labor market (Russell and Malhotra 2002; Gleeson 1997; Oliver 1990; Finkelstein 1981).

As disabled people were subjected to institutionalization throughout the eighteenth and nineteenth centuries, they were transformed from human beings into human subjects (Hughes 2005). As Bill Hughes noted, “Disabled people became (were inscribed as) people who could not do things for themselves, who were a burden group in need of intensive and instructive systems of surveillance” (2005: 83). Lennard Davis related this subjectification to the development of statistics and the concept of the bell curve (Davis 2002). Alongside the rise of institutionalization, driven by factory labor and its need for interchangeable workers, this period also witnessed the development of the concept of normal; the word normal, itself, arrived in the English language only around the 1840s (Davis 2002). The concept of the norm implied that most people “must or should” fall under the arch of the bell curve; those who fall on the margins represent statistical deviations and social deviants (Davis 2002). Statisticians then divided and ranked the bell curve into quartiles (Davis 2002). People with physical and mental deviations fell in the lowest quartile; they *misfit.*

Disability came to be a proxy for distinguishing the deserving and undeserving poor, those who could not and those who would not work (Stone 1984; O’Brien 2001). Professionals played an important role in this process. Historically, and currently, medical professionals serve as the proper authorities to differentiate between real and “feigned” disability (Stone 1984; Schweik 2009; Davis 2000; O’Brien 2001). Disability professionals often expect disabled people to accept and follow their recommendations, without argument (Beratan 2012; Bilken 1992; Linton 1998). The medicalization of disability legitimizes this professional dominance (Oliver 1990; Lewis 2010). Rehabilitation experts viewed disabled people as narcissistic, unable to form meaningful bonds with others, and in need of rehabilitation (Davis 2000; O'Brien 2001). Within popular culture, disabled people are often portrayed as deserving of pity, as monstrous freaks, or as "super crips" capable of overcoming any obstacle through hard work (Garland-Thomson 2005; Haller 2010; Longmore 2005).

For people with mental impairments, including traits labelled madness and intellectual impairment, disability came to represent more than just the inability to work, or meaningfully contribute to society. Disability stripped these individuals of personhood (Parmenter 2001). For enlightenment era philosophers, personhood was based on rationality and consciousness (Stainton 1994). As John Locke wrote, "where the 'lunatic' has lost his mind, the 'idiot' never had one" (quoted in Radford 1994; 12). Similar assumptions underlie the arguments of modern-day philosophers like Peter Singer (Taylor 2017). Singer proposes that some individuals with mental impairments should not be considered humans (Johnson 2003). Personhood, in this framework, rests on one's capacity for self-consciousness (Singer 1995). Scholars connect these assumptions to late 19th century and early 20th century eugenics programs and institutions; institutions segregated individuals with mental impairments in order to prevent their procreation (Parmenter 2001). Statistical measures of intelligence, such as the Stanford-Binet and the various IQ tests which it spawned, helped identify individuals who should be removed from the population. At the time, eugenicists believed that segregating, and eventually eliminating, these "defectives" would reduce crime rates and poverty (Parmenter 2001).

The association of disability with inability, or biological inferiority connects disability and race oppression (Erevelles 2011). Eugenics grouped disabled people and people of color under the category of "defect" (Mitchell and Snyder 2003; Jarman 2011). In early twentieth century debates regarding the citizenship status of immigrants, women, and African Americans, these groups were associated with disability traits in order to support their unequal treatment (Baynton 2001). Disability was often used to justify discrimination against oppressed groups: a "common strategy for attaining equal rights …seeks to distance one's own group from imputations of disability and therefore tacitly accepts the idea that disability is a legitimate reason for inequality" (Baynton 2001: 51).

Currently, disabled people experience lower employment rates, lower educational attainment, and higher rates of poverty (Erickson and von Schrader 2018; Erickson and von Schrader 2020). In 2016, the employment rate among working age people with disabilities was 36.2 percent compared to 78.9% percent of people without disabilities (Erickson and von Schrader 2020). Additionally, federal law still allows disabled employees to receive subminimum wages in segregated workplaces, or sheltered workshops (U.S. Department of Labor 2019). People with disabilities still live "institutional" lives; disabled people reside in nursing homes, group homes (often described as mini-institutions), and prisons (Ben-Moshe 2013). Some studies estimate that 55 to 70 percent of incarcerated youth qualify for special education services (Russell and Stewart 2001). Incarcerated adults are three times as likely to have a disability than the non-incarcerated population (Bronson, Maruschak, and Berzofsky 2015). The ACLU estimates that 40% of prisoners have disabilities (ACLU 2017).

These institutional lives (exclusion) begin in childhood as students with disabilities continue to be segregated into separate classrooms and experience high rates of both bullying and suspensions (Weber 2002; Reid and Knight 2006; Valenzuela et. al. 2006). Brown and Black disabled students are more likely than white disabled students to be placed in "self-contained" classrooms (Parrish 2002). An education system marked by "the collusive normalizing processes" of "racism and ableism" requires uniformity in development and performance (Annamma, Ferri, and Connor 2018: 47; see also, O'Connor and Fernandez 2006; Reid and Knight 2006). Students who misfit, whose embodiment is not supported by mainstream education environments, are labelled with disabilities and removed to "special" settings. A growing body of scholarship suggests that this process serves to maintain racial segregation after *Brown v. Board of Education*; by diagnosing brown and Black students with educational disabilities at higher rates than white students and placing them in segregated classrooms, the education system perpetuates de facto racial segregation (Annamma, Connor, and Ferri 2013; Beratan 2012; Reid and Knight 2006).

Thus, the environment in which individuals come to fit or misfit is one characterized by the exclusion and oppression of disabled people; an environment structured around the assumption that disabled people do not act, but are acted upon; an environment which requires uniformity, normality, and the exchange-ability of workers; an environment that premises equal treatment on equal biology; and an environment that classifies, categorizes to create hierarchy. The environment or "the material status quo" includes the widespread exclusion and oppression of disabled people.

Developing a Political Disability Identity

Developing a positive disability identity, for disabled people and their parents, is a process (Zola 1991; Shakespeare 1996; Watson 2002). This process entails rejecting deficit models of disability and embracing a social model viewpoint (Shakespeare 1996; Linton 1998). Many disabled people internalize the dominant deficit model of disability (Murphy 1990; Zola 1991; Shakespeare 1996; Watson 2002). Individuals with and without disabilities are socialized to view disability as a "personal deficit" (Morris 1991; Shakespeare 1996). Developing a social model perspective or identity requires disabled people to see exclusion and oppression as arising from structural forces, not the impaired body (Shakespeare 1996). Scholars often analogize the shift from the deficit to social model as a "coming out" process (Shakespeare 1996; Garland-Thomson 1996[2017]). Shakespeare describes this "coming out" as "the process of positive self-identification, rejecting the categorization of subjection, and affirming subjectivity and collective power. It is about developing new definitions and new political forms" (1996: 101). Simi Linton terms this process "claiming disability" (1998), while Garland-Thomson uses the phrase "becoming disabled" (2014). This process often occurs in community; the disability rights movement provides this "positive disability" space (Shakespeare 1996; Linton 1998; Garland-Thomson 2014). Garland-Thomson suggests that the experience of misfitting may spur this process: "The experience of misfitting can produce subjugated knowledge from which an oppositional consciousness and politicized identity might arise" (2011: 597). Prior research also suggests that disability pride may develop in connection to intersectional experiences of discrimination (Nishida 2016). Through other statuses, i.e. race, gender, and sexuality, more commonly understood as political categories, disabled people may achieve a critical consciousness that they then apply to their experiences of disability (Nishida 2016).

Less is known about how parents of disabled children develop social model perspectives on disability. Prior sociological research into parent perspectives on disability suggests that parents rely on both social and medical (deficit) models of disability to help make sense of their and their child's experiences in the world (Landsman 2005; Runswick-Cole 2008; Cologon 2016; Manago, Davis and Goar 2017). In other words, parents sometimes locate the root cause of their child's suffering in social practices and other times in their embodiments. For example, Landsman found that mothers of recently diagnosed disabled children combined medical and social models in complicated ways; although mothers often rejected the medical model when applied to their own children (i.e., mothers argued that medical professionals mislabeled their children or failed to accurately see their children's capabilities), they continued to view disability, in general, as a medical phenomenon (Landsman 2005). However, at the same time, these new mothers identified future discrimination as their biggest concern. Thus, these mothers understood disability as both a medical defect and the result of social discrimination. Additionally, parents may switch between social and medical models in different social contexts and for different purposes. In practice, parents may rely on the medical model to deflect stigma; parents may describe their children's atypical behavior as biologically based to challenge the association of disability and moral failure (Blum 2015; Manago, Davis and Goar 2017).

Parent Experiences Navigating Special Education

Much prior scholarship focuses on parental involvement in the educational realm. Parents played a key role in the development of the Education for All Handicapped Children Act, later renamed and reauthorized as the Individuals with Disabilities Education Act (IDEA 2004; Krainz 2013). Passed in 1975, the statute guaranteed disabled students’ access to a public education. Previously, many states had laws excluding certain groups of students, such as children with hearing and vision impairments, as well as children with Down syndrome and other developmental disabilities, from attending public schools (Individuals with Disabilities Education Act 2019). Although IDEA succeeded in increasing the number of disabled children receiving public education, the statute was less clear as to what specific services and supports these children should receive in school. IDEA required that parents and schools meet to determine how to accommodate the needs of individual students. The law treats parents as the safe guarders of their disabled children’s right to an education and assumes parents will challenge inappropriate educational placements and methods (Colker 2013).

A large body of scholarship examines the experiences of parents navigating the special education system. Parents describe their interactions with special education personnel as fraught, inequitable, and stressful; parents feel unheard, silenced, or disparaged (McHatton and Correa 2005; Trainor 2010a, 2010b; Colker 2013; Bacon and Causton-Theoharis 2013; Wright and Taylor 2014; Burke and Hodapp 2014; Colker 2015; Stanley 2015; Wilson 2015; Angell and Solomon 2017; Burke and Goldman 2018). Parents and educators often hold conflicting views on disability; parents feel that educators view their children through a deficit model lens and fail to see their children’s full humanity (potential) (Lalvani 2015; Shakespeare and Watson 2002). Parents rely on cultural capital and extend enormous amounts of time and energy attempting to secure better educational services and inclusive placements for their disabled children (Ong-Dean 2009; Trainor 2010a, 2010b; Blum 2007, 2015; Colker 2013, 2015); this work often falls most heavily on mothers (Colker 2013, 2015; Blum). White parents with access to attorneys and financially able to hire expert witnesses can challenge school decisions more successfully than non-white parents, poor parents, and parents with less cultural capital (Ong-Dean 2009; Colker 2013).

Linda Blum's study of primarily white, upper-middle class mothers' experiences with invisibly disabled children highlights the intense pressure these mothers face to "normalize" their children. Blum examined mothers' advocacy within the education and medical spheres. She contextualizes these mothers' "relentless action" (2007: 222) to secure diagnoses and services for their invisibly disabled children within a neoliberal culture of public "stinginess" (2007: 203). Blum views mothers as "vigilantes" responsible for monitoring their children's education and medical treatment and who must invoke the law in order to protect their children.

Ruth Colker examines mother's experiences challenging public school decisions regarding their disabled children's education; Colker identifies "mother blame" as a significant influence on mothers' ability to enforce children's educational rights (2015). In an examination of due process suits (special education lawsuits), Colker identifies how judges and school districts blame mothers' for children's disability-related needs and behaviors (2015). When mothers' actions are seen as too emotional, irrational, and demanding, judges dismiss their claims and affirm school district decisions to place students in segregated classrooms or deny services. Blum's and Colker's studies, as well as most work within this line of scholarship, analyze mothers' experiences using feminist or cultural capital frameworks; this dissertation contributes to this body of literature by employing a disability studies lens.

Latinx-Immigrant Parents

Culturally and linguistically diverse (CLD) parents face added barriers navigating the disability business, i.e. special education, medical institutions, and public developmental disability services (McHatton and Correa 2005; Harry and Klinger 2014; Cobb 2014; Stanley 2015; Angell and Solomon 2017). Such barriers include the lack of interpretation, limited outreach, and perceived discrimination (Harry 2008; Lo 2008; Cobb 2014; Burke and Goldman 2018). For immigrant parents, cultural discourses around deservingness and immigration pose additional barriers (Kibria and Becerra 2020). In a study based on interviews and participant observation with a diverse group of immigrant mothers, Kibria and Becerra examined how these mothers faced competing cultural narratives while advocating for their disabled children. Cultural expectations suggest that "good" mothers advocate to obtain more and better public services for disabled children and that "good" immigrants are self-sufficient, hard workers who do not use public benefits (Kibria and Becerra 2020). Immigrant mothers are often caught between these two contradictory expectations.

Angell and Solomon found, based on an ethnographic study of bilingual Latinx-parents, that parents' experiences differed from cultural stories which suggest that Latinx-parents do not advocate effectively or aggressively to obtain disability services for their children with autism. Media reports connect Latinx children's lower rates of autism diagnosis and treatment access to their parents' lack of cultural capital, "passivity" or cultural differences (Angell and Solomon 2017). Angell and Solomon's research offers a different explanation. In their study, some Latinx-parents reported that discrimination, on the part of school district administrators and other professionals, halted their advocacy efforts. Other parents chose not to challenge professionals out of fear of retaliation; parents worried that professionals would mistreat their children if parents did not agree to their recommendations (Angell and Solomon 2017). Similarly, in a study of Mexican and Puerto Rican-immigrant mothers, McHatton and Correa identified perceived discrimination as a frequent experience in mothers' interactions with education, medical, and disability service professionals (2005).

This Project's Disability Perspective

Garland-Thomson's *misfit* and materialist disability studies scholarship inform the disability perspective in this dissertation. I use both the terms disabled people and people with disabilities interchangeably; this reflects the dominant practice in disability studies (DS) research. Typically, in DS scholarship, disabled people connotes a more critical, often Marxist, perspective on disability. In contrast, people with disabilities suggests a liberal perspective and is the term used in disability rights legislation and promoted by most disability rights organizations. It is important to note that these choices are political and controversial within disability scholarship and activism. Similarly, there is no consensus on whether to refer to people without disabilities as non-disabled or able-bodied. The language of *misfit* allows for a consideration of unique characteristics, without needing to connect them to diagnostic categories. However, here, I describe students' embodiments, as best as I can, and use their disability labels, because those labels carry meaning and consequence.

Although Garland-Thomson's misfits has been widely cited and incorporated into relational theories of disability, its application to empirical studies is limited. Important exceptions include research examining feelings of fitting and misfitting as connected to disabled or majority-spaces for people with a variety of impairments (Morrisson et. al. 2020), feelings of fit among disabled sailors on an adapted ship (Lamont-Robinson, Williams, and Thompson 2018) and blind and visually impaired fencers (Koncul and Slatman 2019), as well as shared feelings of misfit among disabled academics (Merchant et. al. 2019). Other research has explored the misfit between assumptions of normative sexuality and recognizing disabled women's sexuality (Santos and Santos 2017), the ways software algorithms misfit computer users (Eatmen 2020), and how traditional qualitative research strategies can result in misfit for people with dementia (Williams et. al. 2020). This body of work demonstrates that the misfit concept captures feelings associated with disablement, around exclusion and belonging for a variety of disabled people, sailors, fencers, and academics. Additionally, this research shows how misfit occurs with respect to physical environments and cultural assumptions. Finally, perhaps most importantly, this literature evidences the possibility of creating fit for disabled people; adapting sailboats, sexual norms, research strategies, and computer software can turn misfit to fit.

The current study builds on this work by using misfit to analyze mothers' perspectives and experiences in relation to the material environments within which they occur. This dissertation seriously engages Garland-Thomson's assertion that misfitting applies to both disabled and non-disabled people. Furthermore, this research identifies symbolic and material misfit at the micro and macro levels among mothers of disabled children. Finally, this dissertation identifies pathways to creating fit, and thus, responds to Garland-Thomson's call to reconstruct "narratives that revalue the particularities we think of as impairment and deviance to bring forward 'information or strategies that disabled people need to survive and flourish'" (2011: 603).

By engaging a misfits' perspective, this dissertation addresses a gap in the literature. Although a substantial body of work examines parental experiences of disability, few studies employ a disability studies perspective. This dissertation begins with the social model of disability, the proposition that disability is a socially constructed category, and that disabled people's oppression arises primarily from an inaccessible, hostile, social world. I sought to describe mothers' perspectives and experiences from this viewpoint, to give a sense of how it feels to misfit, and to identify the many ways that mothers and disabled children misfit. This dissertation also centers the experiences of Latinx-immigrant mothers. This study examines common experiences among Latinx-immigrant and white mothers while also analyzing experiences unique to Latinx-immigrant mothers. Mothers of children with disabilities occupy a "complex, contradictory and marginal position" (Ryan and Runswick-Cole 2008: 199). I hope this dissertation captures some of that complexity.

Relationship to Disability

Disabled scholar and activist Corbett O'Toole urged those writing in the field of disability studies to disclose their own "relationship to disability" (2013). I share a status with the children of the parents I interviewed: I am an adult disabled child. Thus, my relationship to disability and to parents of children with disabilities is both personal and political, both emotional and academic. Like the parents and children in this study, I have memories of diagnosis, educational exclusion, and accessing positive disability spaces. Unlike the research participants, however, I did not experience the special education system. My lived experience informed my disability perspective.

In writing this dissertation, I faced this quandary: How could I report the very negative disability experiences I witnessed or learned about from mothers in a way that did not simply add yet another tragedy narrative to the scholarship on disability? Artist and activist Sunny Taylor eloquently described this dilemma:

> Disabled scholars and activists have had to invest a lot of energy in dispelling certain stereotypes about tragedy and suffering, as these oversimplified tropes have played an essential role in naturalizing disabled people's inequality. […] Striking a balance between admitting hardship and denying disability can be extremely challenging, as the supposed tragedy and undesirability of disability leads directly to discrimination. Disabled people are too often left in a quandary: they can compromise themselves by denying their own struggles or risk fanning the flames of ableism. (Taylor 2017: 142)

Given current and widespread ableism, I feel that the stories we tell about disability must support a social model perspective, emphasizing the role of social oppression and downplaying the limitations of the body. How could I examine the grief experienced by these parents without hurting their children, without bolstering the assumption that people are better off not being disabled? I sought to address this dilemma by focusing on mothers' activism, agency, and resilience rather than parental grief. Garland-Thomson's concept of misfit aided in shifting analytic focus from individual mothers' knowledge and ability to inaccessible social environments.

Methods

Research Design

This work investigates the complex lives of mothers of disabled children. A qualitative research design allowed me to access depth and nuance regarding mothers' perspectives on and lived experiences with their children's disability. This study relies on semi-structured, in-depth interviews with mothers of disabled children and participant observation of parental-advocacy organizations. The research design began with my connection to a disability advocacy non-profit, Alianza de Padres/Parent's Alliance/ADP, and expanded to include new populations and research sites as I became more familiar with the world of these mothers and children.

This dissertation also incorporates aspects of ethnography, "a systematic and immersive study of human cultures" (Harrison 2012: 157). Ethnography may include both participant observation, based on a researcher's time in the field, as well as ethnographic interviews, or in-depth, repeated interviewing (Becker 2001; Emerson 2001; Heyl 2001; Harrison 2012). Although I only interviewed mothers once, I spent time with interviewees during two years of participant observation. In order to understand their experiences and perspectives, in-depth, sustained contact and observation seemed an appropriate method. This exploratory study does not aim for generalizability. Instead, the small sample size, which is not nationally representative, allows for an in-depth examination of mothers' lived experiences.

Target Population and Recruitment

I sought to interview mothers of children with disabilities who had advocated on behalf of their children. To be considered an advocate for purposes of this project, a mother must have participated in a disability advocacy organization, sought information about disability rights or services, or worked with a disability rights advocate or attorney. I chose to interview mothers with advocacy experiences because these mothers possess knowledge and familiarity with the disability business, i.e. the settings which disabled people must enter in order to access needed services, education, and medical treatment. Mothers' advocacy experiences also evidence a critical perspective on disability. I did not restrict the sample based on a child's specific impairment or diagnosis. In order to provide an "in-depth" focus into how race influences mothers' experiences with and perspectives on disability, the study focused on only one racial comparison, between Latinx-immigrant and white, U.S. born mothers. Although I sought to include both men and women in the sample, the final group was predominantly women; only three Latinx fathers participated in interviews. I did not include these men in the sample. Although men were sometimes present at conferences and presentations (larger gatherings), they rarely attended the trainings or monthly meetings of either organization I examined.

To draw a sample of self-identified advocate mothers, I used purposive sampling, recruiting interviewees through parent-advocacy organizations, disability rights advocates and attorneys, and disability service providers. I first identified potential interviewees through a Latinx disability advocacy non-profit, Alianza de Padres/Parent's Alliance/ADP. ADP offers training opportunities to Latinx, Spanish-speaking parents on a variety of disability issues (services, legal rights, behavior supports) and engages in collective advocacy, such as presenting at universities, government offices, and community events. Importantly, (in contrast to other disability advocacy groups in this state) all ADP trainings are conducted in Spanish, participants are Latinx people, and the organization acknowledges the role of race-based discrimination (and anti-immigrant sentiment) within disability experiences. As a volunteer with ADP, I showed up to meetings, introduced myself as a disabled student studying disability discrimination, and listened. I helped with paperwork, organizing, and served as the Treasurer when the organization became an official 503(c) non-profit.

In order to access a more diverse sample of parents, I started to make contacts at another parent organization, CFED, Connecting Families Experiencing Disability. Like ADP, CFED provides a variety of parent training opportunities, community building, and outreach activities. However, unlike ADP, CFED is a white-led organization, and English is the organization's primary language, although Spanish language interpretation is offered at some events. Finally, I also recruited participants through a special education attorney and disability service providers.

My positionality as a disabled student likely facilitated access to interviews. Mothers treated me as an insider, someone who understands the social model of disability and shares mothers' views on disability. Access to Latinx-immigrant mothers was likely facilitated by my bilingual abilities, quiet demeanor, and regular presence at ADP meetings. Isabel's (ADP's president) approval and assistance was critical to my access and the high level of rapport and familiarity I found with the Latinx-immigrant mothers.

Data Collection

My formal participant observation of ADP occurred over two years and entailed several activities: attending monthly meetings (three hours each) in three different locations; helping parents prepare documents before special education meetings; driving parents to meetings; organizing community outreach events; and presenting with parents at conferences and training sessions. While in the field, I did not take extensive field notes in order to not disrupt the flow of meetings and events. Instead, I wrote quick "jottings" in the field. After leaving the field, I either recorded verbal field notes while driving or wrote notes once home.

My first interview was with ADP's leader, Isabel, at her home, and served as a trial-run to obtain both her approval for requesting interviews with ADP members and her insight as to which questions would most resonate with parents. I first interviewed ADP members, then CFED members, and finally, participants who did not belong to either group. I continued to recruit interviewees until I reached data saturation and no new information related to the analytical themes emerged in interviews (Charmaz 2006; Small 2009).

Interviews were conducted between May 2016 and April 2018. The interviews typically followed a chronological history, beginning with their child's birth/diagnosis, and then covering the receipt of early education or county disability services, transition to kindergarten, and special education experiences. Later in the interview, I asked specific questions about disability conceptualization and identity, the importance of rights, and the likelihood of engaging legal services. Prior studies of disability identity and lived experiences have employed similar interview strategies, gathering data on respondent's life histories by asking broad, autobiographical questions as well as specific interview questions about disability (Engel and Munger 2003; Evans 2017). The interview protocol is included as an Appendix B.

Interviews lasted forty-five minutes to three hours, with the average interview lasting approximately one and a half hours. 13 interviews were conducted in Spanish, 1 was in both Spanish and English, and the remaining 25 were in English. Interview language reflected mothers' preference. Interviews with mothers who spoke no English or very little English were conducted in Spanish. One interview began in Spanish and switched to English after 15 minutes; this mother found she could discuss her experiences better in English, which she speaks fluently, because that is the language in which her advocacy occurred. Interviews were conducted in person at a variety of locations: respondent's homes, the CFED office, restaurants, coffee shops, and my apartment.

Because my interviews and participant observation coincided with the election of President Trump and a rising sense of fear among parents regarding deportation, I did not ask white or Latinx mothers about their immigration status. At an ADP meeting in November 2016, parents discussed the rumored deportation of the father of a girl with cerebral palsy living in the state capital; the harassment of a disabled Latinx girl whose peers had chanted, "Our parents are voting for Trump so your parents will be deported"; and one mother's fears of retaliation when her autistic son's inability to perceive social cues led him to repeatedly criticize Trump at school. However, although I did not specifically ask about legal status, mothers shared their immigration status during interviews or participant observation. Latinx-immigrant mothers' legal immigration status varied. Almost half of mothers were undocumented. A small number of mothers were permanent residents or naturalized U.S. citizens. Isabel, ADP's leader, had become a U.S. citizen a few years before we met. She carries the copy of the constitution she received at her citizenship hearing in her purse. Thus, the sample is over-representative of undocumented Latinx-immigrants; the vast majority of Latinx-immigrants residing in the United States are documented (Budiman et al. 2020).

After each interview, I wrote notes to record additional details about the interview setting, the respondent's physical appearance, our rapport, and my initial impressions. Throughout the data collection process, I wrote memos to flesh out emergent themes.

Interviews were recorded. I transcribed two interviews, and the rest were transcribed verbatim by a professional transcriptionist. Interviews conducted in Spanish were transcribed in Spanish. Interviewees were assigned pseudonyms, and all identifying information was removed from transcripts. Interviews were then uploaded to Dedoose, a qualitative data analysis software program.

Data Analysis

My qualitative analysis incorporates an inductive, modified grounded theory approach (Glaser and Strauss 1967; Strauss 1987). Grounded theory provides researchers with an open and flexible method of analysis in which unanticipated themes emerge from the data (Charmaz 2006). My analysis includes many of the distinguishing characteristics of grounded theory, such as simultaneous data collection and analysis, open coding, analytic memo writing, and theoretical sampling (sampling to check theoretical patterns) (Charmaz 2006).

I utilized Dedoose, a qualitative data analysis software program, to code sections of interview material based on keywords and themes. Working with the data inductively, I analyzed the transcripts and coded emergent themes. After coding two interviews, I developed a coding framework, which was refined and updated as I coded more interviews. Spanish-language interviews were coded in Spanish; I translated interview quotes when writing first drafts of the empirical chapters. In addition to this open coding, I also coded for themes identified in the extant literature, such as the importance of diagnosis experiences and the interaction between parents and disability professionals (e.g., physicians, therapists, and educators). I combed through the data for patterns between mothers' disability definitions and lived experiences, paying particular attention to similarities and differences across race and class categories. This modified grounded theory approach to coding (using both open codes and codes informed by the literature) produced major themes. Core themes included parent advocacy, the school setting, parents' lived experience, and traditional disability perspectives. Each of these themes encompassed several specific subthemes, which form the basis of the three empirical chapters.

Study Participants

Study participants included 39 mothers: 21 white mothers and 18 Latinx-immigrant mothers. The majority of mothers participated in a parental disability organization; these mothers worked at, volunteered with, or attended CFED or ADP activities. 12 Latinx women were connected to ADP, and 16 white women and 4 Latinx women were connected to CFED. 2 Latinx mothers and 5 white mothers did not participate in any disability advocacy groups.

Mothers had children with a wide variety of disability labels. Almost half of the children had Autism diagnoses. The next most common disability labels were Down syndrome and Attention deficit hyperactivity disorder (ADHD). Multiple children also had mental health diagnoses, Cerebral Palsy, Epilepsy, Fetal alcohol spectrum disorder, and Intellectual disability labels. Individual children had Prader-Willi syndrome, Reactive attachment disorder, Cowden syndrome, Wolf-Hirschhorn syndrome, Kidney disease, Neurofibromatosis, Traumatic brain injury as well as unspecified learning disabilities.

More mothers were middle-class than working-class: of the 23 middle-class mothers, 19 were white, while 14 of the 16 working-class mothers were Latinx. This pattern reflects the class background of the two organizations. Most of the Latinx mothers who participated in ADP meetings were working class, based on education and occupation. In contrast, most of CFED's primarily white participants were middle class. Almost all mothers were married or partnered. 25 mothers worked outside the home, and 14 were stay at home moms. Mothers' ages ranged from 26 to 62. Most mothers lived in an urban metropolis or suburban cities; three lived in rural areas. More detailed respondent characteristics are included in Appendix A (See Tables 1 and 2).

All Latinx-immigrant mothers spoke Spanish as their dominant or primary language. The majority of these mothers did not communicate in English. Almost all of the Latinx-immigrant mothers moved to the U.S. as adults; 15 mothers were born in Mexico, 2 in Chile, and 1 in Colombia. Almost half of the Latinx-immigrant mothers were undocumented. A small number of mothers were permanent residents or naturalized U.S. citizens. All of the Latinx-immigrant mothers were racialized as non-white, meaning that others regularly identified them as Latinas. Mothers' skin color varied from very light to tan.

Chapter Outlines

In this dissertation, I analyze the lived experiences of mothers of children with disabilities. This introductory chapter explains the theoretical frameworks and research methods employed in this dissertation. Chapter two examines mothers' critical perspectives on disability. Mothers reject a deficit model of disability and reimagine disability as normal and valuable diversity. Mothers' definitions align with the social model or social relational perspectives on disability, by identifying the ways disability may arise from inaccessible environments and discriminatory social interactions and norms (Oliver 1990; Linton 1998; Thomas 2004; Garland-Thomson 2011). However, mothers' models also describe impairment as a key part of the disability experience. Chapter two also explores common influences on the development of mothers' new disability definitions. Findings revealed three important influences on mothers' understanding of disability: interactions with professionals, exposure to positive disability spaces, and learning from their children. Findings indicate that each of these influences, individually or in combination, spur mothers to develop new disability models.

Chapter three focuses on mothers' lived experiences navigating the special education system. Disabled children's educational misfit was central to mothers' advocacy. Misfit arises when an environment does not support children's "particularities of embodiment." Children's misfit both spurred mothers' advocacy and shaped mothers' advocacy outcomes. Using a misfit perspective, this chapter shifts analytic focus from mothers' actions and resources to understanding how aspects of the educational environment fail to support children's needs and mothers' advocacy. Mothers across race and class categories employed similar advocacy strategies and shared similar hopes for their children; advocacy succeeded when the educational environment sustained the needs of disabled students. Perhaps, most importantly, misfit centers the experiences of disabled children within mothers' advocacy and contextualizes mothers' advocacy within a hostile environment.

In chapter four, I examine the lived experiences of Latinx-immigrant mothers engaging in advocacy for their disabled children. Advocating for a disabled child, as a Latinx-immigrant mother, is filled with moments of misfitting. Like their disabled children, Latinx-immigrant mothers misfit in spaces built for non-disabled, English-speaking, U.S. born people. Latinx-immigrant mothers experienced misfit connected to Spanish-language usage, immigrant background, and racialized embodiment. Misfit experiences range from exclusion, feelings of unease, being forced to make a scene or stand out, and a sense of not being welcomed. Latinx-immigrant mothers experienced these types of misfit in various environments, including a disability rights parental advocacy organization. However, when Latinx-immigrant mothers created their own advocacy group, an environment structured to meet their needs, they experienced fit.

Finally, I conclude the dissertation by returning to the central research questions and discussing the theoretical and practical implications of this project for the field of sociology as well as for disability advocates.

CHAPTER II

REIMAGINING DISABILITY: MISFIT MODELS

> "We might see disability not as anomalous but as a significant universal human experience that occurs in every society, every family, and most every life…we might accept that fact." (Garland-Thomson 2011: 603)

> Emily: You know how when people are pregnant, and they ask, is it a boy or girl? And the common response is, oh, I don't care, as long as it's healthy. We have this cultural thing - as long as it's healthy, because God forbid, it's not healthy. And what does that mean, that we don't value an unhealthy… [pauses] or what, you know?
>
> Katie: You can't have a good life, if you're not healthy.
>
> Emily: Right. When people find out [you have a child with a disability] and you say, yeah, my daughter has whatever [diagnosis], "I'm sorry," [whispered] that's what you get…that just needs to be turned on its head, completely, it's not bad news.
>
> Katie: Right.
>
> Emily: It's just news.
>
> -- *Emily, 31, white, middle-class mother to a 12-year old daughter with a rare genetic disorder*

This chapter examines how mothers *reimagine* disability as "just news." As Emily's interaction highlights, and as disability scholarship demonstrates, commonsense suggests that disability is not only "bad news," but an all-encompassing negative human characteristic. Here, I untangle what it means for disability to be "just news," according to mothers. How do they make sense of their, and their children's, experiences with disability? How did they develop these critical perspectives on disability? In essence, I seek to understand common themes among mothers' new disability definitions as well as common influences on the development of these definitions. Mothers reject dominant understandings of disability, in which disabled people are understood as people "for whom something has gone terribly wrong" (Garland-Thomson 2014), and craft new narratives of disability, in which disabled people are understood as "just" people.

Traditionally, disability is understood as bodily lack, excess, or flaw, a personal tragedy, and a medical problem (Davis 2013; Oliver 1990). Deficit models of disability, which view impairment as "an inherent inferiority, a pathology to cure, or an undesirable trait to eliminate" (Garland-Thomson 2005: 1558), permeate current U.S. cultural values. This dominant perspective on disability assumes that embodied differences are the primary source of disabled people's struggle. This viewpoint encourages an almost exclusive focus on changing the "deficits" within individual embodiments so that people with disabilities can exist within the majority world (without needing to change the built environment). For people with mental impairments, the deficit model is even harsher; both common sense and philosophical theorizing suggests that individuals with mental impairments who lack the capacity for self-consciousness should not be considered human (Stainton 1994; Singer 1995; Parmenter 2001; Johnson 2003; Taylor 2017).

Shifting these dominant perspectives continues to be a primary goal of the disability rights movement (Linton 1998). The social model of disability reframes impairment (bodily difference) as a normal part of the human experience; disability only arises in specific social contexts in which people with impairments are excluded or devalued (Oliver 1990). This perspective suggests that efforts at improving the life chances of people with disabilities should primarily focus on changing the material world. Rosemarie Garland-Thomson uses the concept of "misfit" to further elucidate how disability is located in the relationship between an individual and the social context (not just in the individual). She argues that disability arises from misfitting, or when one's embodiment does not fit in the majority world. Garland-Thomson elaborates, "A misfit…describes an incongruent relationship between two things, a square peg in a round hole. The problem with a misfit, then, inheres not in either of the two things but rather in their juxtaposition, the awkward attempt to fit them together" (2011: 593). Garland-Thomson's concept addresses a debate within the disability studies literature regarding the role of impairment in disablement; some scholars interpret the social model of disability's focus on the environment as ignoring the body (Hughes and Paterson 1997; Siebers 2008; Shakespeare 2013). Misfit brings the body back into theorizing while maintaining a focus on the inaccessible built environment. Although most disability studies theorizing arose from the experiences of people with physical impairments, the social model, itself, and the models it inspired, like misfit, do not distinguish between physical and mental disability. However, the experiences of people with mental impairments did not directly inform the development of these critical disability models, and people with mental impairments continue to be overlooked within the literature (Price 2011).

Prior sociological research into parent perspectives on disability suggests that parents rely on both social and medical (deficit) models of disability to help make sense of their and their child's experiences in the world (Landsman 2005; Runswick-Cole 2008; Cologon 2016; Manago, Davis and Goar 2017). In other words, parents sometimes locate the root cause of their child's suffering in social practices and other times in their embodiments. For example, Landsman found that mothers of recently diagnosed disabled children combined medical and social models in complicated ways; although mothers often rejected the medical model when applied to their own children (i.e., mothers argued that medical professionals mislabeled their children or failed to accurately see their children's capabilities), they continued to view disability, in general, as a medical phenomenon (2005). However, at the same time, these new mothers identified future discrimination as their biggest concern. Thus, these mothers understood disability as medical defect and the result of social discrimination. Additionally, parents may switch between social and medical models in different social contexts and for different purposes. In practice, parents may rely on the medical model to deflect stigma; parents may describe their children's atypical behavior as biologically based to challenge the association of disability and moral failure (Blum 2015; Manago, Davis and Goar 2017).

Developing a social model perspective is not straightforward or simple. In fact, many disabled people internalize the dominant deficit model of disability (Murphy 1990; Zola 1991; Shakespeare 1996; Watson 2002). Individuals with disabilities, as well as non-disabled people, are socialized to view disability as a "personal deficit" (Morris 1991; Shakespeare 1996). Scholars often analogize the shift from the deficit to social model as a "coming out" process (Shakespeare 1996; Garland-Thomson 1996 [2017]). Shakespeare describes this "coming out" as "the process of positive self-identification, rejecting the categorization of subjection, and affirming subjectivity and collective power. It is about developing new definitions and new political forms" (1996). Simi Linton terms this process "claiming disability" (1998), while Garland-Thomson uses the phrase "becoming disabled" (2014). This process often occurs in community; the disability rights movement typically provides this "positive disability" space (Shakespeare 1996; Linton 1998; Garland-Thomson 2014). Prior research suggests that disability pride may develop in connection to intersectional experiences of discrimination (Nishida 2016). Through other statuses, i.e. race, gender, and sexuality, more commonly understood as political categories, disabled people may achieve a critical consciousness that they then apply to their experiences of disability (Nishida 2016).

Garland-Thomson suggests that the experience of misfitting may lead disabled people to adopt a social model perspective. “The experience of misfitting can produce subjugated knowledge from which an oppositional consciousness and politicized identity might arise” (2011: 596). Here, I argue that mothers’ disability redefinitions are examples of this “oppositional consciousness.” Mothers’ definitions reject dominant, negative conceptualizations of disability, and instead paint disability as valuable human diversity. Like Garland-Thomson’s critical concept of misfit, mothers’ disability definitions recognize the role of society in creating disability without ignoring the embodied dimensions of impairment. A misfit framework, which implicitly underlies mothers’ definitions, sheds light on both the embodied and social aspects of disability. Often, mothers craft these critical definitions after experiencing their children’s misfit. Mothers’ intimate knowledge of their children misfits with, or contradicts, dominant disability narratives, which they encounter in social interactions with disability professionals, out in the community, and even internally. The oppositional consciousness of mothers, as children’s guardians, legally and in practice, may shape their children’s own disability identity.

Investigating the ways mothers make sense of disability is a necessary and timely subject for inquiry; the family remains a critical site of disability activism (Leiter 2004; Panitch 2008; Earl 2011; Walmsley et al. 2017; Carey, Block, and Scotch 2019). Parent advocates played key roles in both the passing of the Individuals with Disabilities Education Act and the Americans with Disabilities Act (as well as in other avenues of activism, such as the Independent Living Movement and deinstitutionalization). Analyzing the personal perspectives of mothers is important for understanding the role of families in disability identity formation and disability activism. Families shape other aspects of social identity, such as race and gender, and mold educational aspirations (thus influencing upward mobility) (Kao and Tienda 1998; Vazquez 2010b; MacLeod 2018). These definitions matter; as the people most closely involved in their children's embodied experience of the world, these mothers possess a unique and tight relationship to the nature of disability. By redefining disability as a normal part of the human condition, mothers engage in re-labeling work that counters mainstream labels and associated low expectations. Mothers have important information about disability; although not disabled people themselves, the understandings of disability they shared with me differed starkly from the understandings they perceived from disability professionals and the wider community.

In this chapter, I first describe common themes among mothers' disability models. These themes include universal vulnerability, expanding sameness, disabling environments, the need for accommodations, and valuable diversity. Next, I examine common influences on the development of mothers' oppositional consciousness or critical disability perspectives. Three key influences arose in data analysis: interaction with professionals, exposure to disability activism, and learning from disabled children. Finally, I conclude with a discussion of core findings, relationship to prior research, and broader implications.

Mothers’ Disability Models

Mothers, across race and class groups, shared surprisingly similar disability definitions. Similarly, mothers of children with a variety of mental and physical impairments, both visible and invisible, conceptualized disability in analogous ways. Through these redefinitions, mothers humanize their children. Mothers' definitions focused on capabilities, on how all human beings have strengths and weaknesses, and on the essential “sameness” of their children. Additionally, mothers recognized the role of the environment in creating disability; disability arises when others label and devalue an individual’s difference, and when an individual needs accommodation to fit into the world. All definitions claimed humanity for children with disabilities, an effort particularly important for children with mental impairments. Some conceptualizations reject dualistic thinking, while others recognize the social construction of disability. These understandings revalue the typically unvalued. Mothers’ definitions shared common themes: universal vulnerability, expanding sameness, disabling environments, the need for accommodations and valuable diversity. Themes are not mutually exclusive; some mothers drew on multiple themes to conceptualize disability. I refer to mothers’ models of disability as critical perspectives because they reject dominant, common-sense views that equate disability with “a deficit model of existence” (Garland-Thomson 2014).

Universal vulnerability

Appearing in almost half of mothers’ redefinitions of disability, the theme of universal vulnerability focuses on mothers’ rejection of binaries. Here, mothers’ definitions blur the line between disabled and non-disabled people. Mothers conceptualize disability as a universal human characteristic. For these mothers, disability refers to an individuals' "particularities of embodiment" (Garland-Thomson 2011), or unique abilities and deficits. If all humans possess limitations and capabilities, all humans experience disability. In support of this proposition, disability studies scholarship often points to the reality that as people age, they develop impairments, limitations, and illness (Shakespeare and Watson 2002; Zola 2005).

Susan, a white, middle-class mother, describes disability as universal: "I think we all have disabilities, really, in general. It's just something where you might need a little bit more accommodation or support. Basically, we're just different. We're all just a little bit different." Julia, a Latinx, working-class mother, also describes disability as a general human characteristic: "I think that everyone has disability… the other day I saw a man on TV, and he didn't have arms, and he played the guitar with his feet, and well, you know, I have hands and I don't know how to play the guitar. And with my feet, no way. In general, I think that we all have disabilities, it's just that for children with disabilities, we call them disabled, and we make them disabled, right? When, really we all have it." By claiming all humans experience disability, mothers shift disability's meaning from total inability (all-encompassing master status) to human individuality. Each human individual has needs, abilities and limitations; some humans need more help, sometimes that need is stigmatized and categorized as disability.

Lisa, a white, middle-class mother, also recognizes the role of labelling in creating disability, in distinguishing between what are seen as normal human limitations and what become deviance and defect:

> "I think we've got to get away from seeing everything as either/or - we all have our strengths and weaknesses. This is how I taught Aaron about disabilities, so I

> thought, okay, Aaron doesn't understand differences, period… So, I started pointing out differences… because he didn't notice, he didn't notice things like that. I'd point out the curb cuts, and I pointed out how the bus door drops down. I'd just point out that people get around in different ways, and I started pointing out, 'I'm terrible with names, but you, Aaron are great with names. So, I'm going to ask you what those people's names are, because I'm supposed to know them, and you're really good with that and I'm bad at it.' And I started presenting this idea that we all have these deficits and strengths, and we're a mixture. And your particular set of deficits and strengths is called autism. But I think we all have this continuum of stuff, that either puts us in a range of needing more help or not. But anyway, that's what I think about it. Just like with gender, going away from just people are either male or female, heterosexual or not, it's just open up the boundaries a little bit and don't get on people's cases."

Here, Lisa conceptualizes disability as socially constructed; all humans have strengths and weaknesses, but only certain sets of strengths and weaknesses become disabilities. Aaron's difficulty recognizing differences and ability remembering names becomes autism, while Lisa's ability to recognize differences and difficulty remembering names remains normal, or unmarked. At the same time, Lisa doesn't deny that some combinations of deficits and strength mean people need "more help." Lisa recognizes both that these unique human traits have material consequences in the world and that much of the consequence is unnecessary, tied to labelling, which categorizes and then hierarchizes human groups.

Expanding Sameness

Expanding sameness, a theme which emerged in approximately one-third of mother's redefinitions of disability, refers to mothers' attempts to reframe the concept of normal to include disabled children. In essence, mothers described disability as both difference and similarity; mothers held seemingly contradictory beliefs, emphasizing the inherent sameness of human beings while recognizing significant differences, e.g. below, Elena describes Andy's differences, such as drooling, stumbling, talking atypically, as normal. Importantly, mothers did not deny children's difference, or attempt to downplay difference, but reframed difference as normal, as typical, as human. In changing the meaning of normal, mothers remake a concept which scholars connect to the formation of disability as a social category (Linton 1998; Davis 2002).

Elena, a Latinx, working-class mother, defines disability quite simply as difference: '…for me, disability is acting differently, learning differently." A story she tells gives more background to her perspective and explains the meaning she attaches to this difference. Elena describes a chance encounter between her oldest son Andy, now 14 years old, and a neurologist.

> "Okay, for me, even then, Andy was *normal*, Andy drooled a lot, he spoke, he didn't speak well, he was very clumsy… he stumbled a lot… but he was *normal* because he walked and talked, I mean you couldn't understand him very well, but he talked … and one day we had an appointment with the neurologist, Juan (her son diagnosed with autism) had an appointment every 6 months, and that day I didn't have anyone to take care of Andy. So I brought him with me, and I thought he was being *normal*, playing with his toys, and the doctor said to me, 'Have you

> noticed that your son isn't *normal*, like other kids?' And I said, "No.' And I asked, 'Why?' because I saw him as *pretty normal*, I never paid attention to those things because for me it was *normal*, he did all the things other kids did, maybe it took him longer, but *normal*. She said, 'Why don't you get an evaluation?" And I said, 'No, the boy is fine, but okay, we'll get one.' And yeah, it came out that he had a delay, he had cerebral palsy, not too bad, but he had it, because you could see how he drooled all the time, but I just thought it was *normal*. He was about three then, maybe three and a half. And so we started with Andy, with all the therapies, but for me Andy is *normal*. They told us, 'He's delayed about two years,' but I never focused on that…"

Here, Elena describes Andy as both normal and different. However, in the doctor's view, Andy's difference means he isn't normal, and he isn't like other kids. But Elena views Andy as similar to other children and different. For Elena, Andy's difference does not negate his essential sameness to other children (his inclusion in the category of children).

Similarly, in defining disability Jimena, a Latinx, working-class mother, emphasized her son's essential sameness, while recognizing his difference: "He's the same as you and me. It's only that he learns a different way. But he's the same. He has the same feelings. If you say something hurtful to him, he will get sad. And if you say something he likes, he will be happy. The same." Alejandra, a Latinx, working-class mother, describes her daughter as the same as and different from other children: "My daughter is the same as them, it's just that she's different. She needs more help, but she is the same." For Sharon, a white, middle-class mother, disability means "just having more obstacles, I think it's just the same path, but just having more obstacles in the way. Still a lot more same than different, really." In the above examples, mothers emphasize their children's sameness, associate disability with difference (not defect), and reframe normal to include difference.

Disabling environment

Another theme emerging in over half of mothers' definitions centered on the role of the social environment in creating disability out of difference. Here, mothers associate disability primarily with barriers in the material world, not their children's embodiments. Disability exists in the relationship between a child and an unsustaining social context. This theme most closely aligns with a strong social model of disability, in which social organization turns simple human difference into defect and disability (Finkelstein 1981; Oliver 1990). Mothers' definitions identify a variety of aspects of the disabling environment: cultural norms, social actors, and social institutions.

For example, Allison, a white, middle-class mother, describes disability as "a natural part of life." Allison then recognizes the universality of human ability and limitation and points to the environment as the cause of disability: "I think everybody has areas of strength and areas where they need more support. And I think that the environment is what can disable you the most." Similarly, Angela, a white, working-class mother, connects disability to the overall environment: "I think disability is not real. I think the way we construct our environment makes it inaccessible to people." Adriana, a Latinx, middle-class mother, points to social actors as key parts of a disabling environment: "I feel like having a disability is hard. I see my daughter, and I know she has the capacity, but I don't know if people are able to see that or give her the opportunity to explore things, to have a job that she deserves."

Isabel, a Latinx, middle-class mother, views disability as situational; disability reflects both her son's embodiment and his community:

> "I now see that society in this democracy, the U.S., has labels and programs and funding and it comes with that, but I feel that we all have abilities and disabilities. And so I feel that disability as the DD Act [Developmental Disabilities Act] says, is part of the human experience. I feel that if you put me in a place where I'm not going to be able to think or I don't understand the language or I don't know where I am, I'm going to be a very disabled person. *I feel that it's situational.* You have disability situationally, and it's for everybody. When people would say, 'Well, how disabled is your child?' I would say, 'Well, it depends on the community. If we are in a very progressive and supportive community, you know, he'll do okay. But if we are in a community of stigma and bias and discrimination, he has the extreme disability.''

In describing aspects of the environment that produce disability, Isabel notes the role of social programs, language, geography, discrimination, culture, and individual's actions. Isabel's understanding of disability connects broad social structure and individual actors; importantly, Isabel illustrates how her son Matthew's disability changes according to the community, not his embodiment. In either a progressive or discriminatory community, Matthew's embodiment remains the same; his experience of disability changes as his embodiment encounters new environments.

Need for accommodations

About one-third of mothers' redefinitions noted their children's need for extra help, supports, or adjustments. Here, mothers connected disability to their children's need for accommodations, or help fitting into an unsustaining environment. Accommodations, such as a personal support worker or adaptive technology, may mitigate children's misfit in a world not built for them (Garland-Thomson 2011). Mothers sometimes, but not always, connected the need for accommodations to the misfit between their children's bodies and the environment (explicitly acknowledging that accommodations are necessary because the world is built for some, but not all, bodies); other times the environment went unmentioned. For example, within her redefinition, Lucia, a Latinx, working-class mother, reframes normal, blurs the line between disability and ability, and highlights the need for accommodation, or help: "Yes, we are all normal, or people with disabilities, and people who don't have disabilities, we are all human beings, we are all equal, or with help, everyone can [do the same things]... For me, he is a normal child, he can work, but with help and supports." To fit within a world not built for people with disabilities, Lucia's son, Matias, needs extra help; with accommodations, Matias can work and can fit.

Similarly, Deborah, a white, middle-class mother, defines disability as a need for accommodations (because the world was not built for difference). "I think it's when accommodation or adaptation is necessary to help a person be as independent as possible, so, whatever the need that facilitates challenges. I guess using my definition we all have disabilities, one way or another. But I don't think of it much. I don't give it a whole lot of credence I guess other than to say somebody who because of how their body presents itself requires adaptation or accommodation to, you know, live life in its fullest. Ultimately, the person with a shorter arm might need an adaptive steering wheel. But the adaptive steering wheel doesn't tell her where she has to go. It just enables her to go.” In connecting disability to accommodation, Deborah highlights how the world was not built with all bodies in mind. Cars were not designed for drivers with atypical arms. Deborah places no negative judgment on non-majority embodiment; the need for accommodation doesn’t reflect an inherent lack or inability, but a misfit between body and world. Accommodation simply helps the atypical body fit in a world not built for it.

Laura, a white, middle-class mother, shares a similar focus on fit within the community. Laura’s definition also reflects her working experience; Laura attended law school and uses the ADA’s language in her definition (the ADA defines disability as a substantial limitation in a major life activity):

> “I think -- it's anything that affects a major life activity… not being able to go to school, not being able to have a relationship with friends, it's a major life activity -- If you cannot do the things that make life liveable, enjoyable -- actually, you can't feed yourself and stuff, clearly those are disabilities, but it's also, really a comparison with the general population. We need to look at, like what does the community think? I think using a community as a model, makes a lot more sense than having, "Well, I can't take 12 steps," but saying, "What is it within this community that makes life liveable, and makes me be able to have a job, be able to have a partner, be able to have friends, be able to really fulfill what I want to do?"

Laura’s definition focuses on the interaction between individual and community; disability arises not just from the inability to “take 12 steps,” but from the interaction between that embodied reality and the community. Accommodations bridge the gap between embodiment and the ability to live an enjoyable life (within a community not built for all embodiments). Accommodations make community life accessible for people with disabilities. Disability arises when individuals who can’t “take 12 steps” lack the accommodations necessary to engage in typical, meaningful human experiences within their community.

Valuable Diversity

A final theme emerging from a little less than half of mothers’ definitions recognized that children with disabilities, because of their impairments, may develop new or unusual or valuable skills. Indeed, mothers also reframe traits, typically seen as negative, as valuable. Here, mothers discussed the positive capabilities and unique characteristics of their children. Disability studies scholarship often reframes disability as valuable human diversity (Garland-Thomson 2011). Additionally, the struggles associated with navigating a disabling environment may produce new knowledge, strengths, and resources (Linton 1998; Garland-Thomson 2011).

While noting her two sons’ essential sameness, Daniela, a Latinx, working-class mother, highlights their unique capabilities: “We all have disabilities because we all have limitations, there are things that are difficult to do, we all have limitations… They’re whole, they can do anything, they can even do things better than us. Gabriel can put Legos together without even reading the directions, when you or I would have to look at the directions, he just looks at the picture, looks at the pieces, and puts it together. They can do so many things, maybe there are certain limitations, but it's like, we all have trouble learning some things, they are the same." Daniela reframes the association between disability and limitation by claiming limitation as a universal human trait; she then asserts that both her sons' wholeness is not negated by their limitations. Limitation is only part of disability, only part of her sons. Finally, Daniela connects her sons' limitations to capabilities. A typical child might need to follow instructions in order to put together Legos, yet her son merely looks at the picture. Daniela turns dominant notions of disability upside-down; she associates disability not with inability, but with the possibility to "do things better." Similarly, Kate, a white, middle-class mother, defines disability broadly, as difference, and then immediately notes how her son's difference leads to potential and ability. "Having a brain and a body that isn't like everyone else's.…He looks just like any other kid. His brain works in very different ways than other kiddos. His memory is phenomenal…He'll talk about something he did, and it was when he was like three years old, and he clearly remembers it."

Amanda, a white, middle-class mother, reframes Logan's cognitive difference as a desirable, sought after trait: "I always tell everybody that we all go to yoga and meditation. We're all trying to get on this Zen path and Logan is there. Logan is in the moment. He rarely can remember what happened five minutes ago. He has a really hard time understanding the future to the point where we had to give him a big calendar and put it on there so that he can start to visualize things, because it's not up here. He lives like right here. We're all trying to get there. If we could all see that and appreciate that -- I wouldn't change anything." Although Logan's non-majority thinking might misfit within current social structures, Amanda recognizes the value in that atypicality. A difference which may pose difficulties, may be valuable at the same time. In fact, Amanda suggests that her friends might learn valuable ways of being in the world from Logan.

Paula, a Latinx, working-class mother, recognizes how her son's impairments spur resourcefulness and perseverance: "He is very capable. Maybe he does things differently, but something I've admired about him, since he was very young, is that he doesn't give up. He doesn't stop at 'I want…' or 'I'm going to try…,' he looks for the way to do something. When he couldn't speak very well, I would say, 'I'm sorry, I don't understand you,' because there were words I really couldn't understand. Then, he'd wait, as if thinking, 'How do I say it, so she understands?' And then he would try to find the words. He, on his own, he gave me clues to help him find the word. I think I have learned a lot from him about not giving up." Paula describes how not being able to do something in the typical way may lead to creative ways of being, new knowledge, something precious and human.

Finally, Amy, a white, middle-class mother, describes disability as a combination of positive and negative characteristics, that may inspire new ways of seeing the world, and even lead to social change. In describing the positives of disability, Amy values many of her daughter's impairment characteristics: "A lot of the stuff I actually wouldn't wish away because it is turning into positives. Some of it's making lemonade out of lemons, but some of it just showed up as lemonade." While highlighting the positive, Amy doesn't deny the difficulties associated with disability; sometimes it requires "making lemonade out of lemons." Amy values her daughter's different way of thinking; for Amy, atypical can be powerful, change producing, resourcefulness creating: "I want her to get past the experience that she had in school that basically taught her, ‘If you don't learn like everybody, you can't do it.’ I want her to [know] …differently is okay and nothing in this world ever got done by doing the same thing that everybody else did. I want her to know that her different way of thinking and different way of doing things means she can create different results and the results can be anything. I want her to be able to think out of that same box and not just take other people's words for what she is. She's not typical. She doesn't have to listen to typical people and what their typical plans are for her.”

Across race and class categories, mothers of children with a variety of mental and physical impairments defined disability in strikingly similar ways. Some mothers conceptualized disability as simple human diversity; all humans, not just their disabled children, possess a wide range of abilities and limitations. Other mothers’ definitions more closely evidenced a social model perspective on disability. Here, mothers connected disability to the social world, discrimination, and an inaccessible built environment. Finally, mothers reframed disability as valuable and positive. Through their reimagining of disability, all mothers claimed humanity and equality for their disabled children. In the following section, I describe key moments or influences which spurred mothers to reject dominant, negative disability models and craft these new, critical perspectives.

Influences on Mothers’ Critical Disability Perspectives

In this section, I examine patterns in how mothers developed the critical disability perspectives discussed previously. Prior to meeting their children, these mothers, like most non-disabled people, had little to no experience interacting with disabled people, neither those with physical nor mental impairments. Relatedly, these mothers formerly held dominant, deficit-based views on disability. Mothers readily acknowledged that their understanding of disability had changed. Like disabled people themselves, mothers sometimes struggled to shed dominant, negative perspectives on disability; developing a positive disability identity is a process (Zola 1991; Shakespeare 1996; Watson 2002). This process entails rejecting deficit models of disability and embracing a social model viewpoint (Shakespeare 1996; Linton 1998). Prior scholarship identifies disability communities as critical to this change (Shakespeare 1996; Linton 1998). Additional influences include witnessing or experiencing injustice and participation in race, gender or sexuality-based activism (Nishida 2016). Here, I examine key influences, or themes, which emerged from the interviews, that spur mothers' critical disability perspectives. These influences include (1) negative interactions with professionals, (2) exposure to positive disability spaces and (3) learning from their child. Sometimes these influences stand alone, and in other cases, interact to shape mothers' development as critical disability thinkers.

Interactions with professionals

In discussing their changing perspectives, a majority of mothers noted the influence of negative interactions with professionals, such as doctors and educators. Within mothers' narratives, negative encounters with professionals appeared often. When confronted with experts' dire prognosis, low expectations, and entirely negative predictions, mothers' hope, love, and knowledge of their children misfit; mothers experienced a "jarring juxtaposition" between their knowledge of their children and professionals' diagnoses. Mothers, then, felt anger, pride, or defiance. Professionals' deficit views on disability, when applied to mothers' children, inspired an oppositional consciousness, a rebellion, and change; mothers knew, instinctively and based on intimate knowledge of their children as well as exposure to disability activism, that experts' entirely negative perspectives on disability could not be true.

For example, Amanda, a white, middle-class mother, dismissed the doctor's negative predictions regarding her son's future. "That will remain a dark mark on our existence - our doctor and how she unveiled this news to us. As though she was sad and she told us, 'Well, you guys are really outdoorsy with the kayak shop. I don't know what you'll expect from your son.' She was sorry… I heard and remember, 'Don't expect much.' That was my green light for go. That was my permission to expect everything. I was like -- 'Thank you.' Because that's what hit the hot button -- But it just seared me forever." Amanda wasn't just angry; she acted. "Well, of course, I'm the person that went, 'Get him in a kayak. Can he hold his head up? Then he can paddle.' [laughs] Put him between my legs, so he's been on surfboards, he's got his wetsuit, he's had lessons with friends, peers in Kauai." Throughout our interview Amanda described this encounter with her son's pediatrician four times. The interaction still matters. She describes how it continues to spur advocacy (putting positive disability images into the world): "Every year we make calendars with the family, of our trips and everything and give them to everybody for Christmas. At the end of one year, about four years ago, my mom mailed one to the doctor, and said, 'Just wanted you to know, he's doing fine.' Trips to Hawaii, trips to South Dakota, trips to California, he's doing it, doing it, yes."

Olivia, a Latinx, working-class mother, describes the similar, long-lasting effects of the interactions surrounding her son's diagnosis: "It's something that I'm just now getting over, it used to hurt so much, it was always in my mind… the cruelty of the doctors, the pediatricians, even now.” Olivia’s son Isaac was diagnosed with Down syndrome after spending three weeks in the hospital. On the day of the diagnosis, Olivia recalled walking into the hospital and seeing her son alone in a crib surrounded by a group of medical professionals. Looking back, she presumes they were medical students shadowing an instructor. The doctors told Olivia and her husband that Isaac had Down syndrome. They told her he would never walk or talk, and he would have multiple heart attacks. She remembered their dire prognosis (through an interpreter), “Your son is basically going to be a sack of potatoes; there’s no hope for him. Children with Down syndrome are useless.” Like Amanda, Olivia defied the doctor’s negative predictions. Once home, she told Isaac, “You won’t be what they told me, I know that you will be more, and it doesn’t matter, even if no one supports us, I will help you.”

For Clara, a Latinx, middle-class mother, interactions with special educators spurred her advocacy, and development of a critical perspective. After Clara’s son David was diagnosed with ADHD in elementary school he was sent to segregated classrooms and segregated schools. “So whatever the school said, it was all wrong in my experience. Whatever the school said and did, 99% of the time was wrong. They were wrong about him. He had a different way of learning. It's not that he couldn't learn.” Clara rejected the educators’ recommendations, hired two attorneys, and eventually moved out of state. Later, Clara began working as a translator at a disability advocacy organization.

Lisa, a white, middle-class mother, experienced similar interactions with her sons’ educators; Lisa felt that Aaron’s teachers believed he couldn’t learn. “I really felt…I had hope that he could learn... My attitude towards it is not that he's not able to learn, instead it’s just going to take a lot more effort and time -- and I so much felt like the attitude was incapable, coming from the public-school system, from special ed teachers. So that's the attitude I felt. I could feel the attitude of, you think he could do that? You’re so deluded, you know, you know? And in a certain way they’re right, but they’re also not right. They could see him more objectively than I could, because I’m his mother and I love him. And I had a lot of hope. But I had hope that drove me to teach him to tie his shoes for every day for a year. So, that hope is useful even if it's a little off, you know?” Through interactions with Aaron’s educators, Lisa perceived their low expectations. She withdrew Aaron from the public school and homeschooled him; she drew on her hope in his ability to learn.

Positive disability spaces

Exposure to positive disability spaces emerged as another theme, or pattern, in almost all mothers’ development of critical disability perspectives. Positive disability spaces refers to mothers’ introduction to settings in which disability is discussed in a positive light or as a rights-granting, minority group status. For example, within this theme, mothers described listening to a disability rights speaker as life changing. Access to new ways of understanding disability helped mothers move past or reject deficit perspectives; these critical views, based on the social model, provided an alternative to dominant models and aligned with mothers’ lived experience with their disabled children. In essence, mothers experienced fit or a “harmonious interaction” in these spaces; within positive disability spaces, mothers’ lived experiences (and belief in their children’s potential) were validated and supported.

For Latinx mothers, exposure to social model perspectives was often connected to their individual advocacy; mothers learned about positive disability thinking through interaction with Isabel, a professional advocate who also held Spanish-language special education trainings in the state. On the other hand, white mothers often accessed social model thinking at parent-led conferences or through motivational speakers. Most mothers also cited online communities as valuable resources (that supported their new views on disability and provided key information about public services, legal rights, and private therapy).

At a national Down syndrome conference, Deborah, a white, middle-class mother, heard Andrea Friedman, an actress with Down syndrome, speak: “She gave a keynote... she spoke to a room, a large national conference room, [there] easily could have been 500 to a thousand people in there and she commanded the room. She told the story about how it was her parents' commitment, her parents' drive that set her on the path to where she made her dreams come true. I left believing that I now had a battle cry. I have to dream big dreams; I have to put you on the path so that one day you're dreaming the big dreams and making the dreams you have for your life come true.” Deborah connects what she heard at the conference to a new disability understanding; she develops new beliefs that children with disabilities, like her son Brian, can and deserve to dream.

One day, on her lunch break, Linda, a white, middle-class mother, attended a local disability conference. Kathie Snow was the speaker, and she spurred Linda’s drive for Oliver to attend a regular education (not segregated) kindergarten classroom (and her view that disabled children can and should be included). “Have you looked into Kathie Snow? That woman put words to my feelings. She was able to share exactly what was going on in my brain and say the words that I didn’t even know I was thinking. She said them - just the thought that disability is a natural part of the human experience, that the green apple is more like the red apple than it is different, right? I mean, just this audacity of being typical, just being a person… just this radical thought of just living a life, of just being a person and going to school and not being in therapy… all of these different things... And hearing her and listening to her, I realized, nope, we're not going to do a specialized classroom. And nope, we're not going to do specialized therapies and we're not going to do those things. It's not going to happen... I knew that that wasn't the right route for Oliver... I was like, oh, no, guns are blazing." Here, Linda's exposure to positive disability thinking confirms her own beliefs, based on her experiences with her son, that disability is a natural part of the human experience. Disability community bolsters Linda's rejection of segregated, or special, services and supports her efforts towards integration.

Through attendance at a local parent education group and work with a professional advocate, Jimena, a Latinx, working-class mother, learned about the principle of inclusion. "Well, there's been so many things that I've learned from Isabel… [she lists practical advocacy lessons] ... I've changed as a person, in how I think about people with disabilities. Before, I felt like it was another world, that I was in another world with my son, a world just for people with disabilities. And now I say no. It's the same world, it's just how we treat people with disabilities. Before, I felt like my son and I belonged to that other world, that's what I used to think. But not anymore, now, I say that my son and I belong in this same world, where everyone belongs… there are different lessons, life gives you different lessons when you live with a person with a disability." Before meeting Isabel, and other Latinx mothers of disabled children, Jimena accepted the segregation she experienced with her son; yet, through disability community, Jimena changes her perspective and views segregation as part of an unsustaining environment. Segregation is no longer natural or acceptable, but socially constructed, built, and harmful to children with disabilities.

Like Jimena, Julia, a Latinx, working-class mother, worked with Isabel individually and attended Spanish-language trainings. "I learned a lot from her. She taught me that when people stare, as they do, to ignore it… I've asked her all kinds of things, and she said, 'When they [anyone] ask you why your daughter is sick...you tell them that she isn't sick. They're going to look at you like you're crazy, but you say, she isn't sick, she has a disability.' You know, sickness is when a kid has a cold, or the flu, any typical kid might be sick…Oh, and she taught me that too [to say 'typical']... not to differentiate Fabiana from a 'normal' kid… because normal makes it sound like kids with disabilities are from the moon…so you say a typical kid." Here, Julia describes aspects of her changing disability perspective. Julia comes to perceive the stares and questions of others as inappropriate, unacceptable, discriminatory (not just hurtful or shameful). Fabiana's difference doesn't remove her from the category of normal; she isn't from the moon. Through community, Julia's new beliefs are supported, she isn't the only "crazy" mom.

Learning from children

A final theme, apparent in all interviews, centers around mothers' lived experience learning from their children. Learning from children includes both mothers' learning about their individual children's ability and learning about the prevalence of disability discrimination. Children surprised, amazed, and taught mothers; children consistently demonstrated their capabilities, intelligence, and perseverance. Mothers also learned, through their connection to their children, about the role of discrimination in creating disability (a social model perspective). Mothers' daily life with their children spurred new perspectives on disability. Simply as a result of having a child with a disability, mothers learn about the lived experience of disability; everyday life provides mothers with new knowledge and beliefs about disability.

Emily, a white, middle-class mother, underestimated her daughter Charlotte's ability to grasp concepts in her middle-school science class. Charlotte attends a regular (general education) science class; her teacher modifies classroom work and Emily modifies homework (adjusts the assignments and activities to meet Charlotte's abilities). One homework assignment required students to differentiate between two kinds of cells, and Emily assumed Charlotte would not be able to complete it. Emily's husband, Jeremy, helped with the homework (and disagreed with Emily's low expectations):

> "I was like, okay, Jeremy, your turn to do the homework, like modify it somehow, I don't know, just look at videos about it, talk to her about it. Put the words in her communication device and like see how that goes… and he ended up rightfully thinking that I was probably being too low in my expectations... so he just explained to her, the cell is called this, and it means it doesn't have a nucleus, this is a nucleus, remember? And then he asked her, so what's this one? And the words don't come out, so then he was like, just point to it… and she got it right. And then he did it again and she got it right, and then he did it again and she got it right… and I was like, oh, so, you know this stuff and you've actually been learning this - it is six grade level science… and I told her teacher what we did, she's like, oh, that's perfect, that's exactly what she showed me yesterday. I was

> like, oh, so... she was actually demonstrating the same knowledge in front of her science teacher consistently. That’s amazing to me.”

As Emily’s quote highlights, she learns to question dominant, and internalized, deficit models of disability through daily life with her daughter; Charlotte teaches Emily that she doesn’t need to speak in order to learn. **“**I am constantly having to remind myself, even though I would tell other parents to have high expectations for their children and to not limit their opportunities, I'm still guilty of having too little expectations for Charlotte on a regular basis.”

While recovering from surgery Olivia, a Latinx, working-class mother, was unable to help Isaac as much as usual. “I had always helped him with personal hygiene, you know… but I was stuck lying on the couch… Isaac was so good, he saw that I was sick, tired, and he started changing his diapers on his own. I told him, ‘Please, son, I need you to help, I can’t do it.’ He was so conscientious, aware of what I was going through, and he started taking care of his own personal hygiene, he got in the bath by himself. He learned to be indispensable. Sometimes his little sister was hungry, and would say, ‘Mommy, I’m hungry.’ And you know, my husband had to work… so Isaac was a good brother, he would grab the pack of sausages, use a fork to open the bag and heat them up in the microwave for his sister. He grabbed them and brought them running, put them here on her little table. And he’d bring her milk too. I saw how my son started to change… you know, people always tell you that a child with a disability is stupid, that he doesn’t know how to do anything… And in those moments, I saw how strong my son can be.”

Mariana, a Latinx, working-class mother, describes learning from her son about growth, challenging typical expectations of linear and steady growth. Mariana recalls how Nicolas learned to swim and how his growth comes in jumps: “I really like how, all of a sudden, he has like jumps - did I tell you that already? I think of them as jumps in time, jumps from one moment to another where you say, ‘How did he learn that? How did he learn to do that?’ But looking back… it’s the process, that you’ve helped with, day to day, so that one day he can begin to do it on his own. When he started to swim, he didn’t even like the water to touch his face, and now a lot of time has gone by, years even, but now he jumps off the high dive, it’s 12 feet high… so when you see him suddenly swimming and floating and jumping off the diving board - I remember him crying whenever the water splashed him - so you say, ‘Wow!’ - they’re jumps like that, where suddenly he makes you say, ‘Look, he could do it.’” Through daily life with their children, Emily, Olivia and Mariana (like all mothers in this study) learned to question their assumptions that people with disabilities are incapable of learning, growth, or independence. Instead, mothers learn that children who don’t speak can display knowledge in other ways. Similarly, when given the independence to take care of themselves, and others, children with disabilities rise to the occasion.

Through everyday life, and proximity to their disabled children, mothers also learned about the role of discrimination in disability. Deborah, a white, middle-class mother, found a community college program specifically for people with disabilities; however, when she went to enroll her son, she realized that the program excluded students like Brian. “So I took Brian and he had to do an assessment test. It was like pulling teeth to get any information. It became very clear that disability… did not include intellectual disability. And I sat next to Brian -- they let me sit next to him... I watched my son work his ass off. I saw him concentrating. I saw his little broken penmanship. And he was supposed to draw a picture or something and he worked so hard -- they never had any intention of entertaining that he'd be able to go into their program. And so the segregation, the stereotyping, the bigotry... [she sighs].” Here, Deborah learns about a common aspect of disablement; disabled people report that the attitudes of others are a primary barrier (Hahn 1983; Wilson-Kovacs et. al 2008; Shier, Graham, and Jones 2009).

Mothers also learned about another key disability experience: navigating the world with a stigmatized, i.e., marked or discredited, identity (Goffman 1963 [1986]). As mothers accompanied their disabled children throughout the social world, they experienced stares, microaggressions, and a sense of misfitting. Susan, a white, middle-class mother, recalls the first time she took her son Mason, and his walker, to the grocery store. “That part was just hard -- I remember when Mason started using a little walker, and we went to...the grocery store for the first time and I was so excited, almost like showing him off, like, ‘You're walking!’ People were looking at us, staring -- and my head's down and I'm just bawling, tears dropping to the floor -- Just because it's just too much. All of it's just like, ‘I don't know if I feel happy about this. I don't know if I'm sad. Everyone is staring. I don't know how to handle all of this.’ That type of thing.”

For Paula, a Latinx, working-class mother, the stares of others occur alongside unwanted advice and comments. “Sometimes, people say things like, ‘Well, give him to me for a week and see how different he’ll be when I return him,’ as if they think that in a week everything will change, or that he doesn’t really have autism… At first, I felt sad or embarrassed, I don’t know, and I would say, ‘Okay, his excuse is that he has autism,’ and now I say, ‘No’ -- I don’t have to explain anything to people. If they want to stare, they can stare. As long as I know what’s going on, I don’t need to explain things to anybody, or excuse his behavior.” For children with largely invisible mental impairments, like Paula’s son Martin, disability becomes visible through non-normative behavior. In Martin’s case, he often became very enthusiastic and loud when visiting restaurants; his non-normative behavior revealed his stigmatized identity.

As these examples demonstrate, mothers’ perspectives on disability change as they confront the negative views of professionals, learn about disability rights and the social model, and experience everyday life with their children. Together, these moments shape mothers’ understanding of disability, helping mothers to reject dominant and negative viewpoints and craft new and more positive disability models. Mothers move past the medicalized, deficit understanding of disability, which they face when interacting with professionals, and draw on knowledge gained through positive disability community and daily life with their disabled children to reimagine disability as a natural aspect of human diversity.

Discussion

In the following section, I discuss both research questions addressed in this chapter. First, how do mothers make sense of their, and their children’s, experiences with disability? Second, how did they develop these critical perspectives on disability? For each research question, I examine core findings, relationship to the literature, and implications. The first half of the discussion focuses on research question one, and the second half, on research question two.

This chapter first explores mothers' critical perspectives on disability. How do mothers of children with mental and physical impairments understand disability? Mothers reject the traditional, deficit model of disability and reimagine disability as "just news" or normal or valuable. Mothers across race, ethnicity and class categories crafted similar disability definitions. Additionally, mothers of children with a diverse array of diagnoses and disability labels understood disability in almost identical ways. Mothers did not differentiate between mental and physical disability; instead, mothers spoke of disability, in general, to describe children with both mental and physical differences (non-majority embodiments). Similarly, mothers of children with both visible and invisible impairments shared analogous conceptualizations of disability.

Mothers' disability models centered around the themes of universal vulnerability, expanding sameness, disabling environments, the need for accommodations and valuable diversity. The theme of universal vulnerability focused on mothers' understanding of disability as a universal, human experience. Here, mothers first defined disability as the collection of abilities and limitations, and then asserted that all humans possess such varied traits. Expanding sameness refers to mothers' redefinition of the category normal; mothers expanded the boundary of normal human characteristics and experiences to include disability. Mothers rejected assumptions that disability and normality are opposites. The theme of disabling environments appeared when mothers tied disability to the environment, such as the built world and social norms. Mothers asserted that the discriminatory environment creates disability by turning difference into deviance. Similarly, mothers also understood disability as the need for accommodations, extra help or assistive technology. Finally, a key theme reflects mothers' reimagining of disability as diversity. Disability leads to resourcefulness, unique capabilities, and potential for social change.

Mothers' reimagining of disability reflects the theorizing of disability studies scholars. Mothers' definitions align with the social model or social relational perspectives on disability, by identifying the ways disability may arise from social interactions, values or discrimination (Oliver 1990; Linton 1998; Thomas 2004; Garland-Thomson 2011). However, mothers' models also validate the importance of impairment (embodiment) within the disability experience. Thus, mothers' models heed the calls of disability studies scholars to bring the body back into disability theorizing (i.e., validate the lived experiences connected to impairment and the body as well as social discrimination) (Hughes and Paterson 1997; Siebers 2008; Shakespeare 2013). Additionally, mothers' definitions, which are based on lived experience with children who have mental and physical impairments, demonstrate the applicability of social relational disability models not just to physically disabled people, but to all people with disabilities (including children).

These findings both align with and complicate prior research. Previous studies document parents' familiarity with both medical and social models (Landsman 2005; Runswick-Cole 2008; Blum 2015; Cologon 2016; Manago, Davis and Goar 2017). Here, mothers evidenced knowledge of the dominant medical or deficit model of disability; however, no mothers defined disability according to a deficit view. While mothers acknowledged difficulties associated with both their children's non-majority embodiment and disability-based discrimination, mothers contextualized these difficulties within an ableist society and against their children's full humanity. Pain, difference, struggle may be part of impairment. Yet, mothers also associated children’s disability with positive experiences, growth, learning, and diversity. In essence, mothers rejected a key implication of the deficit model, that disability leads to “a deficit model of existence” (Garland-Thomson 2014). By interviewing older mothers (in terms of time since children’s diagnosis), I expand previous analyses which focused on the meaning-making of mothers new to disability. Young mothers may not possess the same level of intimacy and comfort with disability. Additionally, these findings build on prior work by examining the perspectives of Latinx-immigrant mothers as well as white middle-class mothers (whose viewpoints are overrepresented in previous research).

These findings have important implications for developing more nuanced disability models. As the people most closely involved in their children’s experiences of disability, mothers possess valuable information about disablement. Mothers of children with mental and physical impairments understand disability as simple human diversity. Mothers largely connect the negative aspects of disability to a hostile environment, while also recognizing the messy difficulties which may arise from non-majority embodiments or impairment. Mirroring Garland-Thomson’s critical concept of misfits, mothers’ definitions combine a social model perspective with a focus on embodiment; these definitions bridge early social model theorizing and newer calls to theorize embodiment and impairment. Importantly, these findings center disability definitions based on often overlooked experiences connected to mental impairment and demonstrate the relevance of social model perspectives for a diverse group of mothers and disabled children.

This chapter also explored a second research question; how do mothers develop these critical perspectives on disability? Findings revealed three important influences on mothers' understanding of disability: interactions with professionals, exposure to positive disability spaces, and learning from their children. Findings indicate that each of these influences, individually or in combination, spur mothers to develop new disability models. Negative interactions with professionals represent a moment of misfit for mothers; mothers' personal knowledge of their children jarred against professionals' deficit views of disability. Faced with experts' entirely negative predictions, mothers rebel and reject a view of their children as generally incapable or unvaluable. When mothers access positive disability spaces, such as disability rights conferences or motivational speakers, mothers learn about new disability models, which better fit their daily lives. Mothers, then experience a harmonious interaction between their views and social, cultural values. Finally, through lived experiences with their children, mothers gain knowledge about the reality of disability. Mothers see their disabled children both exceed expectations and face discrimination.

Previous research examines the development of positive disability identities among disabled people themselves, especially adults with physical impairments. My findings regarding mothers align with past work. Here, mothers' development of critical disability perspectives mirrors the development of positive identities among disabled people in important ways. For both mothers and disabled people, access to positive disability spaces and social model thinking spur "oppositional consciousness" (Shakespeare 1996; Linton 1998; Garland-Thomas 2011). Similarly, both disability studies theorizing and the individual accounts of disabled activists suggest intimacy with other disabled people may lead to more positive views on disability (Taylor 2017; Heumann 2020). Mothers, too, learn from their close relationship with their disabled children. These findings suggest that both disabled people and close allies, like mothers, may develop positive disability identities and perspectives in response to similar stimuli.

These findings have important practical implications. Mothers regularly experience interactions with professionals, such as physicians and educators, as harmful. Perhaps surprisingly, professionals continue to view disability as a deficit mode of existence. Professionals would benefit from accessing positive disability spaces, just as these mothers did. Additionally, professionals' perspectives might change, for the better, if they spent more time with and were open to learning from disabled people. Mothers' development of critical disability perspectives demonstrates the important role of community integration in spurring critical disability views. Intimately knowing people with disabilities is key to transforming dominant deficit models of disability.

As discussed in the next chapter, children with mental and physical impairments continue to experience segregated educational environments. These segregated lives often continue into adulthood. Through connection with their children, mothers develop new and critical perspectives on disability. Community integration, combined with positive disability education for professionals and support for disability rights organizations, may help more people develop nuanced, useful, and positive perspectives on disability.

CHAPTER III

MISFITS AT SCHOOL

> “The discrepancy between body and world, between that which is expected and that which is, produces fits and misfits.” (Garland-Thomson 2011: 593)

> “And the more I learned - I realized that they have no idea what they're doing. The schools, the teachers, special education has no idea how to help these children. So then it became the advocacy part. I was the crazy lady. I'm expecting too much and I'm requesting too much… This is what we do in CFED, right? But I was the crazy lady. And all those women in CFED they were the crazy ladies too, you know? You're asking for what? You're going to put a child with Down syndrome in regular ed? You're going to put a child with ADHD, when he's being disruptive, [in regular ed]?" -- *Clara, 46, Latinx-immigrant, middle-class, mother to David, diagnosed with ADHD*

In trying to understand mothers’ perspectives on and experiences with disability (more specifically, why and how mothers’ advocate on behalf of their disabled children), I struggled to reconcile the stories I heard and the existing literature on disability and parental advocacy. Take Clara, for example. Well-spoken, intelligent, hard-working, clever, she never succeeded in obtaining an appropriate education for her son David. She learned everything she could about David’s diagnosis of ADHD. She hired an attorney to fight the school district’s decision that David must attend a “special” school. She moved to another city, looking for a better educational fit. But David dropped out in 10th grade, and Clara remained “the crazy lady” fighting for the inclusion of disabled students. While scholarship suggests that cultural capital enables privileged parents to gain the necessary educational accommodations for their disabled children, this relationship didn’t hold true for Clara and the other mothers I met. Instead, I was struck by the similarities between the lived experiences of working-class, Latinx-immigrant and middle-class, white mothers as they navigated a disabling educational institution. Using a framework based on Rosemarie Garland-Thomson’s concept of *misfit*, this chapter examines the lived experiences of mothers advocating within the special education system. I identify commonalities across mothers' experiences and attempt to untangle the relationship between mothers' advocacy and their children's misfit at school. Why and how do mothers' best efforts to defend their disabled children's educational rights fail?

Garland-Thomson's concept of *misfit* helps make sense of mothers' experiences. Misfits presents a new way of conceptualizing disability; in this framework, disability, or misfit, arises when an individual encounters an unsupportive or unsustaining environment. Misfit may occur in the interaction of architecture and embodiment, or cultural expectations and embodiment. A "jarring juxtaposition" between embodiment and environment leads to misfit. If the interaction between embodiment and environment is harmonious, fit happens. Both physical and cultural misfit may lead to deviation from social norms or literal exclusion. Similar to the social model of disability, misfit shifts analytic focus away from embodiment onto the way environments may or may not sustain or support certain embodiments. Children's educational misfit was central to mothers' advocacy. Children's misfit both spurred mothers' advocacy and shaped mothers' outcomes. In understanding mothers' advocacy, then, misfit requires an examination of how mothers and children's embodiment meet the educational environment. Focus shifts from analyzing mothers' actions and resources to understanding how aspects of the educational environment fail to support children's needs and mothers' advocacy.

Prior scholarship on parental advocacy in disabled children's education has focused on parents' varying cultural capital. Working-class families, and families of color, may not possess the communication styles, social networks, or leisure time necessary to engage with schools. Working-class parents tend to participate less in their children's formal public education; scholars debate whether this trend is due to working-class parents' different child rearing styles and lack of comfort in professional spaces (Lareau and Weinginger 2003) or to a conscious decision that refraining from engaging with the school may actually benefit their children (Sousa 2015). Scholarship also documents lower participation rates among families of color (Finders and Lewis 1994). Within IEP meetings (special education meetings in which an education team decides a students' placement), working-class parents and parents of color are less involved in team decisions; specifically, they ask fewer questions and provide fewer private evaluations (Wilson 2015; Defur, Todd-Allen and Getzel 2001; Geenen, Powers and Lopez-Vasquez 2005; Kim and Morningstar 2005; Trainor 2010a). However, even when parents advocate actively (as defined by white, middle-class norms) schools may still disregard their efforts (Harry and Klingner 2014).

In this study, I focus less on parents' cultural capital (although I acknowledge its importance, especially as it relates to social networks, access to professional assistance, and comfort negotiating with school personnel) and more on mothers' reports of school practices which misfit their children. Importantly, this perspective brings the body back into disability studies and centers the experiences of disabled children. Mothers advocate because their disabled children misfit at school. In interviewing mothers, meeting their children, sitting with their pain, I felt the centrality of disabled children's misfit in these women's lives. When educational environments promote the segregation, exclusion, and mistreatment of disabled children, mothers advocate. Mothers misfit, then, in deviating from socially proscribed norms. Whether mothers and children experience fit at school reflects not their individual actions, but instead how the educational environment supports their embodiments.

In this chapter, I first identify key aspects of children's non-majority embodiments which tended to misfit in school settings. I then examine common unsustaining (unsupportive or inaccessible) features of the educational environment. Next, I discuss mothers' own experiences of misfit. Finally, I conclude with a discussion of core findings, relationship to prior research, and broader implications.

Body

Here, I describe some aspects of children's "particularities of embodiment" (2011: 593), as recounted by their mothers. When these characteristics come up against an inaccessible environment, children often misfit in school. In attempting to explain these children's experiences of misfit, I focus on their "particularities of embodiment" which were not supported by the school environment. In a different environment, these characteristics might fit. These traits are, of course, only part of these children's identities, abilities, and personalities. However, once viewed through the lens of their disability label, these traits often outshone the full humanity of a child.

The sample included children ranging in age from 4 to 37, more boys (71%) than girls, slightly more white children (53%) than Latinx children, and more middle-class children (57%) than working class children. In the following paragraphs, focused on children's embodiment, I don't discuss children's race, ethnicity, class or gender. However, I recognize that these social categories influence children's embodiment in important ways. For example, research documents that Latinx children receive Autism diagnoses at later ages than their white peers (Angell and Solomon 2017; Colker 2013;

Mandell et. al. 2009). An official diagnosis makes treatment, such as speech therapy or behavior therapy, possible; the lack of such treatment may hamper children's development and therefore shape the particularities of their embodiment.

Children's disability labels included a broad range of diagnoses. About half of the children had Autism diagnoses. The next most common disability labels were Down syndrome and Attention deficit hyperactivity disorder (ADHD). Multiple children also had mental health diagnoses, Cerebral Palsy, Epilepsy, Fetal alcohol spectrum disorder, and Intellectual disability labels. Individual children had Prader-Willi syndrome, Reactive attachment disorder, Cowden syndrome, Wolf-Hirschhorn syndrome, Kidney disease, Neurofibromatosis, Traumatic brain injury as well as unspecified learning disabilities. Some children had more than one diagnosis; for example, Laura has autism and Cowden syndrome, William has Down syndrome and autism, and Ann has ADHD and a mental health diagnosis.

Children's embodiments varied widely, within and across diagnostic labels. For example, both Andy and Mason have Cerebral Palsy diagnoses. Mason uses a walker, does not speak, and needs assistance toileting and eating. Andy sometimes wears hearing aids (when his mom reminds him), walks with a limp, and is on his high school football team; he usually gets to participate in one play each game and loves it. Similarly, Nicolas and Liam have autism diagnoses. Nicolas, 13 years old, needs specific reminders to brush his teeth, take a shower, and get dressed in the morning; before the last presidential election, Nicolas demanded his teachers tell him whether they planned to vote for Trump or Clinton, and then suggested that only racists would vote for Trump. Liam, 7 years old, does not speak and is learning to communicate with an iPad. Sometimes, he hits or kicks to express his frustration. For example, Beth describes Liam's reaction to being forced to play duck-duck-goose (a game which involves sitting in a circle, tagging, chasing, and running) by his teacher, "he was just like, 'This is not how I operate. You are overwhelming me but I cannot speak. So, I'm going to hit you, I'm going to bite you, I'm going to throw myself on the ground and scream.' It was his way of saying you need to stop."

Children possessed a wide range of both majority and non-majority traits. For purposes of this analysis, I identified four broad themes among children's non-majority characteristics: bodily needs, communication, behavior, and conceptual thinking. These themes are not mutually exclusive or strict categories. For instance, in the example of duck-duck-goose above, Liam's non-majority bodily needs, communication, behavior, and thinking become salient when forced to play. Liam doesn't speak, his non-majority communication occurs through actions (and assistive technology, which, unfortunately isn't often readily available in the classroom). Liam's actions of biting, hitting, throwing himself to the ground, and screaming are not majority behaviors in a classroom. Perhaps, what Liam's mom Beth describes as his "sensory stuff" was also involved in the encounter; maybe he didn't want to be touched. Finally, Liam may not have understood the rules of the game or may simply have not enjoyed the game like majority children.

Almost half of the children needed help with toileting, bathing, eating, and/or getting dressed; I characterize these traits as non-majority bodily needs because majority individuals tend to toilet and bathe without assistance from others. For instance, Emily washes her 13-year-old daughter Charlotte's hair (although Charlotte is starting to desire more independence). Lucia reminds 21-year-old Matias to brush his teeth, change his clothes, and take showers. She says, “It just doesn’t seem to matter to him.” Michelle’s 4-year-old son Henry drinks bottles and won’t eat solid food. If Linda doesn’t remind Oliver to eat, she half-jokes that he would “not eat all day and all night.” Isaac wears diapers to school, everyday; Juan’s diaper use varies year to year, and his mom Elena suspects this might reflect his changing anxiety levels. One of Lisa’s proudest memories is the year she spent teaching Aaron to tie his shoes.

More than half of the children also possessed non-majority communication. Here, non-majority communication refers to non-verbal communication, such as formal or informal sign language and communication supported by assistive technology devices. Non-majority communication also includes atypical speech, such as the combination of signs and words or verbal language that others find difficult to understand. For example, when Deborah’s son Brian presented with his class, he memorized and spoke his part, like everyone else. Deborah also wrote out his lines on a poster board that he held in front of him because Brian’s pronunciation then, and now, is “difficult.” Beth’s son Liam is learning to use an iPad to communicate; recently, he broke his arm. When the doctor asked Beth which color cast Liam would like, she turned to Liam, showed him colors on his iPad, and he responded “Boo.” His cast was blue. Olivia developed her own form of sign language to communicate with Isaac. They also use made-up words to refer to milk, Isaac’s sister, and his favorite stuffed animal. Lisa describes some conversations with her son Aaron as “monologues” and repetitive; he sometimes is “totally clueless that he and I have had the same conversation at least 50 times.”

Almost two-thirds of the children displayed non-majority behaviors. I use the term non-majority behaviors to refer to children’s intense emotional outbursts, physical movements, or sensitivity to sounds, lights or textures. In some ways, these behaviors overlap with communication traits, as in the example of Liam playing duck-duck-goose above. Other times, the behaviors seem more connected to physical needs or ways of being. For example, Clara describes her son David as a “busy body” who was always “tapping a pen” or “shaking his leg” or “doing something.” Mariana’s son Nicolas likes to take his shoes off and lie down to read. Laura, Adriana’s daughter, often covers her ears during loud noises; Elena’s son Juan hates the sound of his younger brothers crying. In other cases, non-majority behaviors refer to atypical reactions. For instance, one time, in 5th grade, Nicolas threw a fit when Mariana picked him up from school. According to Nicolas, his teacher took away his drawing because he wasn’t focused on class work. She said he could have it back at the end of the day. Perhaps she forgot. Mariana describes Nicolas’ reaction: “So, he was anxious, angry, and crying, saying that he wouldn’t leave without his drawing… he even started kicking some things.” Mariana held Nicolas, fearful that his teachers would call the police. Eventually Nicolas’ drawing was returned. As Mariana summarizes, Nicolas sometimes “makes some little thing into something big, as if it was the end of the world.”

Finally, the vast majority of children shared non-majority ways of conceptual thinking. Here, non-majority thinking refers to atypical learning styles, perhaps slower or faster than average processing speeds, or the inability to read, write, add or subtract. Non-majority thinking also includes one’s understanding of abstract concepts or interpretation of social cues. For example, when John’s teacher said she was starving, John argued that she was hungry, not starving. The school called Angela to come pick him up, and she found John crying in the hallway. Angela describes John as having “a very strict sense of justice….even if it doesn't make sense, things have to be fair to him.” Jimena worries that her son Alejandro doesn’t understand when other children are bullying him; sometimes, according to her nephew who attends the same school as Alejandro, other children teach him to say bad words or stick his tongue out. Clara’s son David needs to listen to music in order to focus and pay attention. Linda’s son Oliver wants to be treated like an adult and wants her to still do his laundry: “He’s wanting to have the independence of being almost 16, but there’s a lot of things that he doesn’t understand -- because it’s a concept that is too big or too abstract for him. He’ll get there. He will understand it. Most 16-year old’s do understand it. He hasn’t gotten there yet. I know he will. But it’s taking him longer.”

In sum, children’s embodiments included a wide range of unique abilities. Although typically framed as disability symptoms, these non-majority characteristics might be reframed as aspects of human diversity. However, in the context of school, when these traits confront an inaccessible, unsustaining environment, children and mothers misfit.

Environment

Within the misfit framework, the environment refers to social structures, such as capitalism or racism, social institutions, i.e. the education system or workplace, architectural features, social norms, and social actors. In essence, the environment encompasses the material world, a world that “is built for certain kinds of bodies” (Garland-Thomson 2011: 602). Key features of the educational environment include neighborhood or school-district level policies which shape school architecture, programs, and funding, as well as classroom level norms and school actors. In the following section, I describe salient aspects of the educational environment which shaped children's fit, based on patterns among mothers' perceptions. First, the educational environment varied dramatically between neighborhoods or school districts; within some schools inclusion was the norm, however, in most schools, inclusion was an anomaly. Second, classroom norms and expectations shaped children's fit or misfit; when classroom norms required uniformity among behaviors, communication or learning styles, non-majority children experienced greater misfit. Finally, the actions of school individuals, such as teachers, aides or administrators, produced fits or misfits. At both the neighborhood and classroom levels, I discuss the role of school actors. These three themes, neighborhood level policies, classroom norms, and school actors are not exclusive categories; teachers may maintain or disrupt classroom norms, just as neighborhood level policies may shape teacher actions.

Neighborhood Level

At the neighborhood level, school cultures may promote inclusion or segregation. This happens through school district level decisions or policies, such as whether to sponsor special schools (only for children with disabilities), create disability-specific programs (i.e., self-contained or life skills classrooms) or develop inclusive classrooms (such as co-taught classrooms). Additionally, the overall level of funding varies dramatically among school districts, sourced from state income taxes, property taxes, a lottery fund, and federal funds (Oregon Secretary of State 2020). Thus, more wealthy neighborhoods had better funded schools, which might, depending on the disability culture, provide "fit" for students through aides and technology.

Mothers were aware that segregated spaces within the built environment normalized their children's' exclusion and promoted their misfit within regular classrooms (by allowing regular classrooms to stay the same and not change to accommodate the particularities of their children's embodiments). Similarly, many mothers knew that this process varied across school districts. Beth knew, from talking to other moms at her children's school, that Liam, white, middle-class, would likely be forced into a "special classroom" because "he doesn't speak with words and he has behaviors."

> "So we realized that our home school district would most likely enroll him in a Gen Ed [regular] classroom, but then, based on just their history, would say, "Ooh, he needs an awful lot of support. (she emphasizes awful, draws it out) And so we have this special place for him (emphasizes "special," fake enthusiasm)." So we knew that was going to happen and so we chose to lottery out of our district, both of our kids, out of the district to a fully inclusive school…"

As Beth's quote suggests, the existence of a "special place" allows for the maintenance of the inaccessible, unsustaining classroom, a classroom that doesn't provide support for Liam's particularities. A regular classroom might include support such as a one-on-one aide to assist with bodily needs, toileting and eating, and learning style, by giving reminders or encouragement. Such a sustaining environment would also include acceptance of and familiarity with Liam's assistive technology-supported communication. When a classroom does not include aides, recognition of diverse learning styles, and assistive technology, the environment does not sustain Liam; the interaction between Liam's embodiment and the environment is jarring. A built environment that includes segregated placements does not allow for students with non-majority bodies to fit in regular classrooms.

Isabel, who worked as a professional advocate after her experience fighting for her son Matthew's, Latinx, middle-class, inclusion, describes how the built environment of a school district forces students with disabilities to be uprooted and moved about, as if they were plants:

> "Why is it that only kids with disabilities, they get transplanted, like, 'Are they trees?' Like, they went to this school or this program up to this grade, and even though their typically developing peers would continue there, [school districts say] 'Oh, no, because we have this other program and this other middle school,' and then, 'he has high needs so maybe it's going to be this other one.' And, it became almost like a categorical, 'Go there!' and so Matthew moved schools like no other child."

Isabel's quote highlights an important consequence of segregated school district environments; the existence of "special" or disability-specific programs excludes disabled students from the typical education trajectory, in which a student attends a school with neighborhood peers. In part, Matthew's misfit resulted from the interaction between his particularities of embodiment, what the school terms "high needs," and a built environment that provides supports, such as toileting assistance and one-on-one aides, only in segregated spaces (not in the regular education classroom). Regular education classrooms typically do not provide for continual, individual support, such as reminders to pick up a pencil, open a laptop, move to the reading circle, or line-up for lunchtime.

For Susan’s son Mason, white, middle-class, a built environment that does not include such individualized support creates a misfit. Recognizing Mason’s need for one-on-one support, his teacher urged Susan to ask the district to provide funding for a personal assistant. However, the district refused to allocate the funds, and Mason’s teacher feared she would lose her job if she pushed the district. An environment without personal assistants, or personal support workers, does not sustain Mason, who requires assistance to move many parts of his body. For students who need toileting assistance, the lack of personnel within a classroom also creates misfit. Julia’s daughter Fabiana, Latinx, working-class, uses a diaper and requires assistance changing the diaper and cleaning herself. The school district’s summer school program did not include teacher’s assistants, and therefore, according to the program director, Fabiana could not attend. The lack of personnel created an unsustaining environment which would have led to Fabiana’s exclusion; however, after the involvement of a public advocate, the district was forced to hire an assistant, and, thus, allow the possibility of fit for Fabiana.

Segregated spaces within the built environment allow for the segregation of disabled students; social actors maintain (or contest) this segregation, as exemplified above in Mason’s case. In order for Mason to participate in regular education spaces, both classrooms and the lunchroom, he requires individual support. While Mason’s teacher pushes for the school environment to change in order to provide Mason a better fit, school district administrators maintain the environmental status quo (no personal assistants) and thus, Mason, continues to misfit (experience exclusion).

School district representatives, as well as some teachers, pressured many mothers to accept segregated, disability-specific placements, typically not at their child’s neighborhood school. At a meeting to determine where Emma, white, middle-class, would attend kindergarten, Nancy recalls how, “they were really pushing me to put her in a Special Ed room.” Valentina describes a similar experience at a meeting to decide Alex’s, Latinx, working-class, kindergarten placement, “I said, I just don’t like that class [a classroom exclusively for non-verbal children], please, I don’t want my son there, but they pressured me so much.” Paula remembers arriving at Martin’s neighborhood school for the meeting to decide which kindergarten class Martin, Latinx, working-class, would attend, and seeing “a mountain of people,” including the principal of another school, located about 40 minutes away. Paula says, “I don’t know if they invited her, I don’t know why she was there, but she was, maybe whenever there is a kid with a disability in the district, they invite her? To tell you the truth, I don’t know why she was there, but at the end of the meeting, she said, “Okay, I’m here because I want to tell you about this program that we have at Wilson [elementary school].” Paula soon realized that in her school district most children with disabilities, like Martin, were sent to Wilson.

In Emily’s case, the school district representatives never presented the option of Charlotte, white, middle-class, attending a regular preschool. When Emily realized students like Charlotte [children with disabilities] can attend regular schools, she was angry: “… [it was like] oh my god, wait a minute, why is she even in this preschool? What the hell is going on? Then I was mad -- because I was never offered anything else, like there was no discussion about should she go to a community preschool and what would that look like?... it was just assumed, natural, and I was complicit in that decision because I didn’t fight it at all - for her to be in a specialized school.” Once Clara’s son David, Latinx, middle-class, was diagnosed with ADHD, at 7, the school district recommended he attend a special school. Clara viewed the recommendation as a sales pitch: “This is what they sell you. They say, oh, we’re going to put him in a special ed class, this is completely set up for special kids, you know, that have a disability -- and they’ll get the support one-on-one, you know, that kind of thing. It's not true.” When school administrators “sell” mothers on “magic classrooms” or segregated placements, they, in effect, maintain disabled students’ misfit within the education system. For David, neither the regular education classroom nor the special education classroom sustained his particularities of embodiment. Clara describes how David felt his misfit: “So he started feeling like, "Mom, I don't belong with this group. I want to be in regular Gen Ed.” Clara eventually moved to another neighborhood, hoping to find a more sustaining school environment. However, after many years in a segregated classroom David struggled to “find his place,” and dropped out in 10th grade.

Classroom Level

Just as children’s experiences of fit and misfit varied across school neighborhoods, children’s experiences varied within any given school. While the analysis at the district level focused on the existence of segregated spaces, the analysis at the school level focuses on aspects of children’s lived experience at school. Within the school setting, regardless of whether that environment includes segregated spaces, classroom norms and teacher actions may produce fits or misfits for students with disabilities. Classroom norms and teacher actions overlap; teachers create and maintain classroom norms, which then shape teachers’ perceptions and actions. These norms include requirements of uniformity, such as all students must sit still, all students must engage the same learning material, and all students must follow the same schedule.

Classroom norms also include expectations of independence, that students begin and continue work without prompts or assistance. These norms, which materialize in classroom practices and teacher actions, may misfit students with non-majority bodies.

Classroom norms that required students to be still and silent did not support students with a wide range of non-majority traits. Nicolas, Latinx, working-class, became frustrated when forced to keep his shoes on and sit at his desk while reading; after an outburst, Nicolas was often removed from his classes. However, in one particular class, the teacher allowed Nicolas to remove his shoes, and Mariana describes how Nicolas then felt, “more relaxed, more comfortable, less irritated.” Mariana credits that one teacher for helping Nicolas get through 5th grade; a classroom norm that allows students to remove shoes helped Nicolas fit. According to Clara, in elementary school, a teacher placed a cubicle around David’s, Latinx, middle-class, desk so that the “busy body” wouldn’t distract other students by tapping his pencil; later David was moved to a special school. Clara describes how classroom norms did not support David’s embodiment: “He’s busy, like he – will be tapping on something or shaking his leg or, you know, doing something, you know, trying to occupy his mind… But that was not acceptable. You just need to sit there and look at the teacher, you know, so it was a problem.” John, white, middle-class, who spends most of his day in the regular classroom, frequently gets in trouble for “getting up and talking to people.” He describes feeling that his energy level is “130%” when he’s at school. Although his individual education plan mandates that John have breaks to release that energy, he found the breaks too short to be effective: "I get two-minute breaks after every 45-minute period. Two minutes - That's like getting rid of 10% of my energy when I am at 130%.”

The expectation that all students engage with the same learning material while in class may not support non-majority students. Here, I refer to a classroom norm that all students read the same novel in high school English or that all kindergarten students work on reading skills. Although seemingly common sense (that all students in a class learn the same thing), this norm is not the only way to structure a classroom. For instance, when Brian's, white, middle-class, high school English class read the *Strange Case of Dr. Jekyll and Mr. Hyde*, Brian read a comic book version. Brian experienced fit in that case; Brian experienced a harmonious interaction between his embodiment (reading level) and the environment (a classroom accepting of diverse student levels). However, in middle school, Brian's teachers argued he could not be in a regular English classroom; he needed to be in a life skills class [a class made up only of students with intellectual disabilities]. Deborah recalls how the school's argument focused on how he would not be doing the same activities as his peers in a regular classroom: "Well, everyone else was just, you know, [there's] too big of an educational gap, and I'd have to respond, IDEA [the Individuals with Disabilities Education Act] doesn't say he has to catch up in order to be included. Then they said, the modification would be too difficult, and I said, IDEA doesn't say that you, you know, whatever, so it was this back and forth, back and forth."

Similarly, when Elena pressed the school representatives to allow her son Juan, Latinx, working-class, to attend a regular classroom, they argued that he "wouldn't be able to do it." Elena recalls, crying, how "I saw American [Anglo/white] children that had more needs than Juan, and they were in a regular class with an assistant." When Isabel requested inclusion for Matthew, Latinx, middle-class, the high school principal said, "Your child is the most impaired child in this school, how do you expect him to go to a regular Ed class?" Yet, the classroom norm that all children must do the same work when in a room together is not necessary. When classrooms have multiple teachers or teachers' assistants, students can engage with varied academic work. One student might read a biology textbook, another might watch a biology-based YouTube video. One student might write an essay, a classmate might illustrate a story.

These norms, around forced uniformity, appeared both in regular education and special education classrooms. For example, Deborah lost her cool during a mediation with the school (she was fighting for Brian's, white, middle-class, inclusion in regular education classrooms), and said to the special education teacher, "it's become clear to us that the curriculum in the life skills classroom is pretty much like a frozen dinner and that every kid gets the same meal." Nicolas, Latinx, working-class, attended a self-contained kindergarten classroom; he learned to read at home. Mariana "realized that he was higher intellectually than his classmates, and so he would get bored and he wasn't interested in anything that was going on in the classroom." When Mariana asked the teacher if he could learn "something he doesn't know" while in her class, the teacher responded, "We can't slow down or speed up for one child." The classroom norm of uniformity failed to support Nicolas' particularities of embodiment.

School Actors

Within schools, the actions of individuals, such as teachers, assistants, and peers, form part of the unsustaining environment. A key pattern of non-sustaining teacher actions centered around attempts to remove students with disabilities from their classrooms. These actions reflect teacher beliefs that disabled students don't fit. Research confirms that many teachers share a belief that special education placements, i.e.

segregated placements, are where disabled students ‘fit’ (Lalvani 2015; Davis and Watson 2001; Beratan 2012). Critical scholars suggest that the devaluation of disabled students is built into special education law; first, the Individuals with Disabilities Act (IDEA) defines disability using a deficit model perspective (which does not consider the way environments creates or shapes disability), and second, the IDEA permits the exclusion of some disabled students from regular education classrooms, if students cannot fit (Beratan 2012; Colker 2013). In the following examples, teachers’ individual actions create misfits for students with disabilities by excluding or devaluing disabled students.

Sometimes teachers directly informed mothers that their children did not belong, other times teachers removed children from their classroom without mothers’ consent or used a students’ non-majority behavior to shorten a students’ school day. For example, Alex, Latinx, working-class, misfit in his first kindergarten classroom. At a meeting to decide whether Alex could continue at his neighborhood school, his classroom teacher listed out the reasons he did not fit in her classroom:

> “running out of the classroom, climbing on tables and chairs, laying on the floor, doesn’t participate with whole group activities, resists transitions out of the classroom, yells out, and doesn’t clean up after himself, short attention span, unable to share group materials, plays by himself during free time. When he speaks or vocalizes, it isn’t directed toward anybody or the activity. When adults or peers ask him questions there is no response. Academically, reading and writing time, doesn’t complete tasks, often doesn’t begin tasks. Leaves group or isn’t with group to begin with.” (Field Notes, January 25th)

Alex's teacher framed these examples as "safety issues." However, while at school, a paraprofessional, or teacher's assistant, accompanied Alex; an assistant should mitigate any dangers posed by Alex's climbing on tables or chairs. Alex's teacher recommended, and the school's principal and a district representative agreed, that Alex must attend a program for non-verbal students. Here, Alex's teacher enforced non-sustaining classroom norms: all students must sit still during circle time, all students must engage in the same activities at the same time, all students must play with others, all students must speak clearly and direct their communication to others, all students must begin tasks and complete tasks with minimal adult instruction. Alex's embodiment "jarred" against such classroom norms.

Oliver's, white, middle-class third-grade teacher, Mr. Brent, requested multiple IEP meetings [special education meetings in which an education team decides a students' placement] to argue that Oliver be removed from his regular education classroom. Linda connects Mr. Brent's actions to his failure to believe in Oliver: "Oh, man, I wanted Mr. Brent to be the one. He was so cool. He's got long hair, plays the guitar in class and… he was awful and horrible and didn't believe in Oliver, and just [said] that he was a detriment to his class and how can we get him out of here?" I asked Linda to elaborate on Mr. Brent's reasoning, and she replied: "Oliver did not fit in his classroom. He was a square peg in a round hole. He didn't fit. At our IEP meetings, he [Mr. Brent] would call them frequently to say, you need to get him into a specialized program. That's the only place for him. He needs to go over there. He needs to not be here in my class." Throughout his elementary school career, Oliver worked with a one-on-one assistant, who provided help with toileting, staying on task, and classroom work. Mr. Brent's actions, and underlying negative perspective on Oliver, are part of a non-sustaining educational environment.

In contrast, Mariana accidentally found out Nicolas, Latinx, working-class, was removed from his general education classroom. One day, Mariana went to eat lunch with Nicolas at school. When Mariana walked Nicolas to his regular education classroom after lunch, she realized his desk was gone:

> “I saw that Nicolas went to the back of the classroom, and I thought, “Okay, where is this guy going?’ I looked for his desk, and there wasn’t a desk with his name on it, not a chair or anything. He went to sit in the back of the class where they had all of their supplies, boxes, extra chairs, computers, all that stuff, and he went and sat in a metal chair that’s nothing like the little desk where we put his supplies, and I said to him, ‘Is this where you sit?’ and he said, ‘Yes,’ and I said, ‘Okay,’ and I sat beside him.”

The teacher had stepped out, while an assistant passed out a worksheet. When the teacher returned, she told Mariana, “You know Nicolas doesn’t belong here, it’s best if he goes back to the special education room.” In the moment, Mariana was too confused to be angry or upset; she questioned whether she had misunderstood the teacher’s English. Mariana later learned that Nicolas had not attended that class in months, per the teacher’s request. The school had not consulted Mariana about this change, even though special education law requires them to do so. Although Mariana never learned why the teacher felt that Nicolas didn’t belong, she surmised that Nicolas was removed because of his non-majority behavior, such as removing his shoes to work, asking too many socially awkward questions, or throwing tantrums when upset.

By chance, Deborah also learned that Brian, white, middle-class had been removed from his math class. One day, Brian’s new teacher went to the student store and said, “Ladies, I have a teacher's conundrum - because Brian’s family doesn't believe in life skills, I've been saddled with teaching that little Down's boy Math. Do you mind if I send him in here and let him play with money?" Unbeknownst to the teacher, Deborah’s best friend was volunteering at the school store that day, and she relayed his sentiments to Deborah. Shocked and devastated upon learning of the teacher’s feelings towards Brian, as well as the teacher’s violation of special education law, Deborah filed a lawsuit against the school. Brian’s teacher subsequently resigned. These teachers’ actions are part of a built environment that often does not support the embodiments of students with disabilities. Just as ramps support the inclusion of students who use wheelchairs and classrooms with teachers’ aides support the needs of students with intellectual impairments, so do teacher actions.

Teachers also attempted to remove students with non-majority bodies in more indirect ways. For example, many mothers received daily, negative complaints about their children’s classroom behavior; oftentimes these complaints were accompanied by requests to take students home for the day. Olivia recalls how by second grade, Isaac, Latinx, working-class, barely went to school: “It was just complaint after complaint after complaint… too many complaints and so many letters saying that Isaac behaved badly, he hit someone, he pushed someone. The third year was worse… Isaac didn’t really go to school. They would call me, ‘Olivia, Isaac did this or that. Come get him, please.’ So, I would go, get him, and bring him home - it was almost every day.” Olivia eventually wrote the teacher a letter, asking, “Why don’t you understand? Why do you send me so many complaints, if you are the teacher? You have to have a way to calm Isaac down, to help him be in the school, to motivate him." In effect, Olivia identified how the school environment did not sustain Isaac's embodiment; somehow the teaching methodologies, classroom schedule, or course material did not motivate or calm Isaac.

The school environment, ranging from district policies, classroom norms, and school actors, fails to sustain non-majority students. District-level decisions to create segregated programs and classrooms and limit funding for personal aides lead to children's misfits. Similarly, classroom norms that require uniformity and teacher actions to remove children from their classes fail to sustain non-majority embodiments. Mothers intercede in these interactions between their children's bodies and the education environment; mothers attempt to mitigate these moments of misfit. However, in doing so, mothers' own embodiments may also confront a non-sustaining environment. Mothers, themselves, may then experience misfit.

Misfit Mothers

At school, mothers represented their children's interests, and often, seemingly, functioned as extensions of their children. When mothers advocated for inclusion, within a segregated educational environment, they became misfits. By challenging disability professionals' expertise (i.e., that disability-based segregation is appropriate or necessary), mothers deviate from "that which is expected" (Garland-Thomson 2011: 593). Social norms suggest that disabled people accept and follow professional recommendations, without argument (Biklen 1992; Linton 1998; Beratan 2012). In confronting school authorities, a misfit arises between mothers' actions and cultural expectations of appropriate deference to disability professionals. For example, when

Clara, Latinx, middle-class, advocated for her son David's inclusion in general education, she felt as if the school viewed her like "the crazy lady." David attended both segregated classrooms and special schools for students with disabilities. Within this educational environment, Clara's advocacy failed. She elaborates, "[They thought] I'm expecting too much and I'm requesting too much. Now - this is what we do in CFED, right? [Advocacy organization where she works] But I was the crazy lady. And all those women in CFED they were the crazy ladies too, you know? You're asking, for what? You're going to put a child with Down syndrome in regular ed? You're going to put a child with ADHD, when he's being disruptive, in regular ed?" Clara never succeeded in convincing David's school district that changes could be made to the regular classroom so that David fit; Clara both felt David's misfit and misfit herself. As the crazy lady, her desires for and beliefs in inclusion marked Clara as deviant, transgressing social norms within the educational environment.

Similarly, Lisa, white, middle-class, felt like she "just stood out sideways" at Aaron's school. Lisa experienced a misfit, a "jarring juxtaposition," between her embodied knowledge and Aaron's educational environment. Lisa complained to her son's principal that disabled students should be given more independence. "Why are the teachers carrying the kids' lunches down to the cafeteria, down to the lunchroom? The kids should be doing that. Why? You get people who want to be helpful, and they help too much with the wrong things." Lisa's belief that disabled students can or should carry their own lunches, mirrors Clara's belief that David, kids with ADHD and kids with Down syndrome can or should be in regular classes. Lisa, like Clara, felt that the special education teachers viewed her as "delusional" for believing that Aaron was capable: "My attitude towards it is not that he's not able to learn, instead it's just going to take a lot more effort and time -- and I so much felt like the attitude was incapable, coming from the public school system, from special ed teachers. So that's the attitude I felt. I could feel the attitude of, you think he could do that? You're so deluded, you know, you know?" An education environment, shaped by a cultural belief that disabled students are incapable, did not sustain Lisa or Aaron. Lisa moved Aaron to various private schools, searching for a sustaining environment.

For Deborah, white, middle-class, the simple act of challenging disability professionals produced misfit. Deborah describes feeling "demeaned" by educational professionals. She recalls being asked to call an occupational therapist "Dr." W: "You know, parents are demeaned that way often from the time their kids [are born] -- when you're talked to like that… if I feel demeaned, puny, if the idea is that I can't master this, if it's inferred that as a parent, I will always be lesser than you because you have a degree, to me, that's disabling." Here, Deborah illustrates how the dominance of professionals can produce misfit or disablement; norms in which professionals know best, and disabled people must agree, devalue disabled people's knowledge. Social norms dictate that mothers, like their disabled children, are the "passive helped" while professionals are "active helpers" (Finklestein 1981).

For Latinx-immigrant mothers, racist, controlling images intersect with expectations of disabled peoples' passivity. Isabel questioned the school's hostile response to her desire for Matthew to be included in general education classes:

> "I have a thick accent as well. And I just felt like it was not acceptable for me to be an empowered parent... But I could tell through my cases years later that those

> parents are the ones that are most affected by the system… And certainly I just felt that -- I had a target on my back always. And I think it was very much about power. They didn't want me to have any power -- and I think they were really heavy-handed. I think that they didn't appreciate my knowledge. They were angry about it."

Isabel's embodiment, her voice, her knowledge, her desire for her son, as well as Matthew's embodiment encountered an unsustaining environment. As a Mexican-immigrant, woman, mother to the "most impaired child" at school, Isabel deviates from a racist stereotype assuming Latinx parents to be uninformed, a social norm that the "most impaired" disabled people must be segregated, and an expectation that she, as Matthew's representative, should accept professional recommendations. Isabel elaborates on how she perceived that school personnel assumed that Latinx parents would be ignorant. She didn't fit their expectations: "I was very shocked at the principal, how she wanted to control everything, and I kept thinking -- maybe they are used to Latino parents not knowing their rights and they are comfortable with that sort of box, and I almost feel like I shattered their stereotype and they didn't like it." Isabel's particularities of embodiment didn't fit cultural expectations in the environment; she misfit.

Within this sample, one mother regularly experienced fit. Kate's, white, middle-class, fit reflects her embodiment, her son Jacob's embodiment, and the school environment. Through her family's personal network, Kate learned which school district was most likely to offer Jacob the opportunity to attend kindergarten in an integrated setting [with non-disabled peers]. Kate and her husband bought a house there. Jacob attends regular education classes, sometimes with an aide. He receives decompression breaks throughout the day, to relax and destress, and his teachers readily accommodate his non-majority needs. Teachers' also respond to Kate's concerns and value her input. Kate's embodiment conforms to traditional femininity: she brings baked goods to school meetings and tries to be "the really, really nice mom." Because the school environment supports Kate and Jacob, through "wonderful teachers" and inclusive classrooms, Kate does not need to confront disability professionals. Kate's fit occurs in the meeting of Kate and the school setting. Kate's embodiment is not enough; it is the interaction between her and the social structure, a school district which does not have segregated classrooms, employs teachers who both respect and listen to Kate, and accept and support her son's embodiment.

Discussion

This chapter explores the lived experiences of mothers navigating the special education environment. These experiences center around disabled children's misfit at school. Misfit arises when an environment does not support children's "particularities of embodiment." Key aspects of disabled children's embodiment include non-majority bodily needs, communication, behavior and thinking. These traits, shared by children across various disability labels, lead to students' misfit when unsustained by an educational environment. In this study, most disabled children misfit in the school setting. Notable aspects of this unsustaining environment are physical and architectural segregation, discriminatory (ableist) classroom norms, and individual teacher and administrator actions.

When school districts build segregated spaces for disabled students, mainstream spaces, such as the regular classroom, do not need to change to provide fit for students with disabilities. Within an education system premised on normalization [perhaps best seen through reliance on standardized testing], special education often serves as a "safety valve" to remove misfit students (Barton 1986; Beratan 2006). Thus, the simple existence of segregated spaces allows for the removal of children with non-majority embodiments and the maintenance of non-sustaining regular classrooms. This process normalizes the exclusion of disabled students. Segregated spaces function similarly to other architectural barriers; steps may exclude wheelchair users from entering a school building, while self-contained classrooms exclude children with intellectual impairments from participating in the regular classroom.

Within classrooms, norms which require uniformity among students also lead to misfit for disabled children. Expectations that students sit still and listen quietly misfit students who need to tap their feet, flap their arms, mutter under their breaths, wear headphones or pace in the back of class. Garland-Thomson provides a similar example; a misfit occurs between "the extravagant full-body gesturing of the deaf signer" in "a boardroom full of executives seated in contained comportment with moving mouths and stilled bodies conferring on important decisions" (2011; 595). Some teachers enforce these norms by requesting that disabled students who deviate from these expectations leave their classrooms.

Mothers intercede in their children's misfit. Mothers' advocacy is an attempt to create fit for their disabled children, to change the school environment to sustain their children's embodiments. However, mothers' advocacy occurs within the unsustaining educational environment: an environment characterized by disability-based segregation, expectations of uniformity, and beliefs that disabled students don't belong. Mothers who deviate from these socially prescribed norms misfit; mothers argue that disabled children belong, that difference can exist within a single classroom, and segregation is wrong. Additionally, mothers challenge the social norm that disabled people accept expert recommendations about their impairments. In sum, mothers' advocacy leads to misfit, or the "discrepancy between…that which is expected and that which is." (Garland-Thomson 2011: 593)

Although I began the project with a social model understanding of disability, I was surprised to find how well *misfits* explained mothers' experiences of advocacy. In particular, *misfit* helps explain both the similarities and differences within these mothers' lived experiences with disability professionals in the education sphere. Mothers across race and class categories employed similar advocacy strategies and shared similar hopes for their children; advocacy succeeded when the educational environment sustained the needs of disabled students. Perhaps, most importantly, misfits centers the experiences of disabled children within mothers' advocacy and contextualizes mothers' advocacy within a hostile environment.

In many ways, this study aligns with prior research on special education and parental advocacy. Parents experience their interactions with special education personnel as fraught, inequitable, and stressful; parents feel unheard, silenced, or disparaged (McHatton and Correa 2005; Trainor 2010b; Colker 2013; Bacon and Causton-Theoharis 2013; Wright and Taylor 2014; Burke and Hodapp 2014; Colker 2015; Stanley 2015; Wilson 2015; Angell and Solomon 2017; Burke and Goldman 2018). Parents and teachers use contrasting conceptualizations of disability. Teachers tend to define disability according to the deficit model, while parents employ a social model perspective

(Davis and Watson 2001; Beratan 2012; Lalvani 2015). This study also supports research on students' experiences within special education. Disabled students experience microaggressions within self-contained classrooms, understand that they are labelled as different and lesser within the school system (Davis and Watson 2001; Beratan 2012; Dávila 2015; Banks 2017). Even within inclusive schools, classroom norms and teacher expectations may stigmatize disabled students as other (Davis and Watson 2001; Beratan 2012).

Prior research identifies parents' cultural capital as influencing advocacy experiences and outcomes. For example, more privileged parents ask more questions within IEP meetings, hire attorneys to challenge school district decisions, and achieve more inclusive placements for their children (Trainor 2010a; Colker 2013; Wilson 2015). Differential rates of segregation among disabled students might support this conclusion. Research documents that children of color spend more of their school day in segregated classrooms and receive less services than their white peers (Beratan 2006; Valenzuela et al. 2006; O'Connor and Fernandez 2006; Reid and Knight 2006). However, misfits suggests an alternative explanation. Perhaps, parents' individual advocacy matters less than the particular education environment in which they advocate. As seen in this chapter, school environments vary among neighborhoods and districts. Some neighborhoods develop inclusive educational environments, with teachers' assistants, integrated classrooms, and assistive technology. Others maintain segregated schools or classrooms and limit funding that would provide necessary accommodations, i.e. changes to the environment so that disabled children might fit.

Additionally, prior research on parental advocacy often leaves undiscussed children's impairments and un-critiqued the widespread segregation of disabled students. Children's fit or misfit within schools is key to understanding the motivation for mothers' advocacy and the outcomes. When children's misfit can be more easily changed to fit, mothers' advocacy may be more successful; similarly, when a child's teacher believes disabled children can and should fit (i.e., the environment is more sustaining), advocacy has a better chance. A parent's access to resources, sense of entitlement or comfort within an educational space, and knowledge of the law is only part of the explanation. Misfit focuses attention on the interaction between parents and the educational environment. Mothers' advocacy cannot be judged successful or unsuccessful without consideration of both their embodiment and the environment, or the level of fit they experience within a social institution.

Using misfit to analyze the experiences of mothers of children with disabilities has broad implications. First, as Garland-Thomson urges, policy interventions must focus on creating more fit for mothers and their children within the education system. Currently, interventions focus on teaching mothers to more effectively advocate. Misfitting suggests that interventions must, instead, change the environment to sustain children and mothers' diverse embodiments. Second, and perhaps more importantly, this perspective centers disabled children's experiences. Mothers advocate because their disabled children face a segregated world. Almost 50 years after the passage of the Individuals with Disabilities Education Act, the federal law which grants disabled students' right to education, children with disabilities continue to learn in segregated classrooms and schools. A misfits perspective suggests that this segregation is not natural or necessary, but a result of an educational environment which does not support the needs and abilities of disabled student's non-majority bodies. Finally, this research pushes disability studies to examine the experiences of disabled people's closest non-disabled allies, mothers. Within disability studies and disability activism mothers occupy a "complex, contradictory and marginal position" (Ryan and Runswick-Cole 2008: 199). Although the mothers in this study are not themselves impaired, they experience the disablism directed towards their children viscerally and physically.

CHAPTER IV

MISFIT FOR LATINX MOTHERS

> "It's another thing, the language, we don't speak English – how are we going to speak for him if we can't speak for ourselves? That's where the problem is.*"* -- *Lucia, 51, Latinx-immigrant, working-class, mother to Matias, diagnosed with an intellectual disability*

> "Since I'm Latina, I don't know the system, because I didn't study here, I don't know it, I'm learning… but… I think 'If I had studied here, I would have had a better understanding of how things go.'" -- *Renata, 38, Latinx-immigrant, working-class, mother to Luis, diagnosed with a learning disability, and Andrea, diagnosed with autism*

> "Maybe they are used to Latino parents not knowing their rights and they sort of are comfortable with that sort of box, and I almost feel like -- I shattered their stereotype and they didn't like it." -- *Isabel, 62, Latinx-immigrant, middle-class, mother to Matthew, diagnosed with autism*

What are the lived experiences of Latinx-immigrant mothers engaging in advocacy for their disabled children? A description from Rosemarie Garland-Thomson's essay on misfits captures a key aspect of mothers' shared experience of disability advocacy: "slamming against an unsustaining environment" (2011: 597). Although Garland-Thomson developed the concept of misfit to describe disablement, the concept also helps make sense of Latinx-immigrant mothers' advocacy experiences. Misfit arises when an individual encounters an unsupportive environment; for Latinx-immigrant mothers, engaged in disability advocacy, misfit emerges when their "particularities of embodiment" encounter inaccessible environments. The purpose of this chapter is to examine Latinx-immigrant mothers' disability advocacy experiences through a misfits perspective; in what ways do their non-majority particularities of embodiment interact with an unsupportive environment to create misfit?

Like the social model of disability, misfit locates disability in the relationship between individuals and the social environment. Disability, or misfit, results when society excludes or oppresses individuals with non-majority embodiments (individuals with traits considered impairments). A misfit analysis requires an examination of both an individual's relevant particularities of embodiment and the unsustaining features of the material world. Within this framework, particularities of embodiment refers to the body's "particular shapes and capabilities" (2011: 594), including, "the way we look and how we function" (2011: 597). An inaccessible environment does not "sustain the shape and function" (2011: 594) of an individual's embodiment; an inaccessible environment may exclude an individual or force the individual to "stand out, make a scene, or disrupt through countering expectations" (2011: 596).

Advocating for a disabled child, as a Latinx-immigrant mother, is filled with moments of misfitting. Like their disabled children, Latinx-immigrant mothers misfit in spaces built for non-disabled, English-speaking, U.S. born people. The concept of *misfit* suggests that each human embodiment may *fit* or *misfit* in any given moment, in a specific environment. Thus, misfitting describes not just disablement, but other forms of institutional oppression. Misfitting may occur between unsupportive environments and gendered, racialized, or classed bodies. Without a supportive environment, any embodiment can *misfit*.

Latinx-immigrant mothers advocate, and then misfit, because their disabled children misfit. Their disabled children misfit in a variety of unsustaining environments: schools, doctor's offices, public disability services, and, even, disability rights spaces. Mothers witness their children's misfit. Mothers see children arrive home from school with bruises and dirty diapers. Mothers hear doctors dismiss children's pain. Mothers sense the low expectations of social workers. Mothers feel, vividly, their children's misfit.

After seeing their children misfit, Latinx-immigrant mothers seek to create fit for their disabled children. In the context of this study, advocacy means any action mothers undertake to support and accommodate their disabled children, any action designed to increase their children's access to medical care, education, and community inclusion. Previous studies support this broad perspective on advocacy; mothers of disabled children engage in multiple forms of advocacy "as they mediate and negotiate the world on behalf of their children" (Ryan and Runswick-Cole 2008: 204). Mother's advocacy work includes formal organizational advocacy efforts, such as advocating for independent living and deinstitutionalization at the national level (Panitch 2008; Krainz 2013; Carey, Block, and Scotch 2019), and the informal efforts of mothers negotiating everyday interactions, stigma, and access to treatment (Landsman 1998; Green 2003; Blum 2007; Ryan and Runswick-Cole 2009).

Within this study, Latinx-immigrant mothers engage in three types of advocacy: information gathering, pressuring, and sharing information. Information gathering refers to mothers' attempts to learn about their children's diagnoses and available services. Here, Latinx-immigrant mothers ask questions, of old acquaintances abroad, of strangers on Facebook, of people met at church, in grocery stores, and support groups. Mothers also attend trainings about legal rights, children's diagnoses, special education services. Pressuring refers to mothers' constant (practically) interaction with disability professionals; mothers make phone calls, send emails, show up at school, at doctor's offices, at therapy appointments. Mothers employ attorneys, write complaints, and file lawsuits. Sharing information refers to mothers' public outreach. Mothers' present at universities, churches, state-sponsored conferences, and disability rights events. Thus, advocacy involves continuous learning, interacting with professionals, and public speaking; mothers advocate to obtain better services for their children and increase community awareness around disability issues. Communication is key in these practices.

Latinx-immigrant mothers' experience of disability advocacy entails witnessing children's misfit and feeling that harm, as if done to themselves. Mothers then enter spaces that do not support their or their children's needs, as they attempt to improve their children's experiences. The environment which excludes and misfits their disabled children, then excludes and misfits Latinx-immigrant mothers, according to similar logics. When mothers enter schools, doctors' offices, disability services, their embodiments misfit. These environments are inaccessible for Latinx-immigrant mothers because these spaces do not support mothers' modes of communication, needs for information and explanation, and general well-being. Mothers' narratives revealed three types of misfit: misfit occurred when environments did not support Latinx mothers' Spanish language usage, immigrant background, and Latinx ethnicity.

Prior research confirms that culturally and linguistically diverse (CLD) parents encounter multiple barriers when advocating on behalf of disabled children (McHatton and Correa 2005; Harry and Klinger 2014; Cobb 2014; Gainey Stanley 2015; Angell and Solomon 2017). Identified barriers include the failure of schools and hospitals to provide outreach services (to inform families about available programs and resources) or qualified translators (Lo 2008; Cobb 2014; Burke and Goldman 2018). Discrimination, or

CLD parents' perceptions that professionals viewed them as ignorant or uneducated, is another barrier to advocacy (Harry 2008; Cobb 2014; Burke and Goldman 2018).

Latinx-immigrant mothers also experience misfit within the disability rights movement. Historically and currently the disability rights movement, including parent-led organizations, has been dominated by white people and shaped by their concerns and issues (Bell 2013; Miles, Nishida and Forber-Pratt 2017). Alianza de Padres/Parent's Alliance (ADP) and Connecting Families Experiencing Disability (CFED) are two parent advocacy organizations. CFED is white founded and led, while ADP is helmed by Latinx-immigrant mothers. In CFED spaces, Latinx-immigrant mothers experience misfit, similar to the misfit they experience during other forms of advocacy.

In this chapter, I first describe relevant aspects of Latinx-immigrant mothers' embodiment. Next, I examine types of misfit arising during advocacy. Then, I contrast Latinx-immigrant mothers' misfit within a mainstream disability rights organization with their fit in ADP, a Latinx-immigrant led counter organization. I conclude with a discussion of core findings, relationship to prior research, and broader implications.

Mothers' Particularities of Embodiment

A *misfits* analysis focuses on the interaction between inaccessible aspects of the material environment and an individual's "particularities of embodiment" or unique body (2011: 592). Particularities of embodiment refers to mothers' physical characteristics, capabilities, limitations, and perspectives, and also includes the way mothers communicate, understand social norms, and feel within social spaces. In this section, I describe Latinx-immigrant mothers' unique traits or characteristics of embodiment connected to misfit. These characteristics only lead to misfit within an inaccessible or unsupportive environment (an environment which does not facilitate smooth or easy interaction); characteristics' relevance depends on the contours of the material environment. For purposes of this study, I identify three key aspects of mothers' embodiment: language usage, immigrant background, and racialized embodiment/Latinx ethnicity.

First, in this study, all the Latinx-immigrant mothers spoke Spanish as their dominant or primary language. The majority of mothers did not communicate in English. By this I mean that mothers did not speak English, read or write English, or understand spoken English. These mothers lived among other Spanish-speaking people; they communicated in Spanish at home, at work, and at church. I interviewed these mothers (12) in Spanish. Three mothers understood and could speak some basic English language sentences; however, these mothers could not express or defend a point of view in English or understand complicated syntax or vocabulary. With these mothers, I conducted the interviews in Spanish, as well. Four mothers communicated fluently in Spanish and English; these interviews were done in English. Like people who communicate through assistive technology or sign language, mothers who do not speak English use non-majority communication (within the U.S. context).

Second, almost all of these Latinx mothers moved to the U.S. as adults. Two arrived as teenagers. Mothers' legal immigration status varied. A little under half of mothers were undocumented. A small number of mothers became naturalized U.S. citizens. Mothers' immigrant status is part of their embodiments. Mothers' perspectives, likes, tastes and culture exist in the mind and in the body. Garland-Thomson's phrase, "particularities of embodiment," refers broadly to the "particular form, function, and needs of one’s body” (2011: 600). In this analysis, the body includes the mind. Immigrant status shapes mothers’ cultural expectations, common sense and experiential knowledge base. Within the U.S. context, this immigrant background is a form of non-majority thinking or behavior; immigrant background shapes mothers’ basic or core notions about the way things should be, how society functions, and the way one moves through the world.

Third, all of the Latinx mothers, in this study, were non-white, meaning that others regularly identified them as Latinas. Mothers’ skin color varied from very light to tan. Again, this trait connects to misfit because of the material environment. Being non-white leads to misfit within spaces in which people of color are “typically absent, not expected, or marginalized when present” (Anderson 2015: 10).

Class status also shapes mothers’ particularities of embodiment, such as language use and level of comfort in majority (non-immigrant) environments. The majority of mothers were working-class; no women were full-time homemakers before the birth of their disabled children. The majority of mothers worked in factories, canneries, agriculture, and cleaning services. A little under half of the mothers quit their jobs to take care of their disabled children. Almost all mothers were married or partnered.

A final, important shared trait includes being a mother to a disabled child. Children’s impairments formed part of mothers’ embodiments; mothers experienced pain when their children misfit at school, and mothers felt joy when children learned new skills. Mothers encountered courtesy stigma (stigma based on association with a person with a spoiled identity) while advocating on behalf of their children (Green 2003; Blum 2015). Mothers also experienced emotional effects of disablement, such as internalizing oppression (Ryan and Runswick-Cole 2008). Of course, mothers possessed many more traits. However, for purposes of this analysis, an examination of mothers' misfit during disability advocacy, the previously described characteristics appeared salient. Mothers' communication traits, comfort navigating U.S. society, and racialized bodies were not supported or sustained by the environments in which they advocated.

Spanish-Language Misfit

As described previously, the majority of Latinx mothers, in this study, did not communicate in English. When mothers communicate in Spanish, an environment designed for and inhabited by English speakers limits their ability to advocate for their disabled children. The environments in which mothers advocate include spaces such as schools, doctor's offices, and public disability services. These environments, built for English speakers, do not sustain or support Latinx-immigrant mothers' particularities of embodiment. Spaces typically lack interpretation services or translations. Advocating within an environment which does not receive, process, or understand mothers' communication leads to misfit, exclusion, and a sense of not belonging. This failure of the environment, to not support or facilitate Spanish-language use, functions like an architectural barrier. When Spanish-speaking mothers encounter a building without interpreters, without translations, mothers cannot participate, meaningfully. A monolingual environment prevents these mothers from accessing information and expressing concerns. The lack of interpreters, the lack of translation, acts as a material barrier that produces misfit.

When spaces include interpreters and translation services, mothers' fit increases. However, the quality of these services matters. Mothers paint a dismal picture of the interpretation and translation services encountered during disability advocacy; sometimes the quality of services was so poor as to increase mothers' feelings of misfit and exclusion. Other times, the ineffective nature of translation services allowed mothers to only minimally participate in decision-making regarding their children's disability concerns.

Even when mothers adequately communicated through interpreters or spoke English, misfit sometimes remained. Mothers felt like misfits; mothers perceived social actors in the environment to negatively respond to their need for interpretation, Spanish-language accents, or Spanish surnames. Mothers felt that physicians and educators perceived them as less intelligent and as not belonging because of their Spanish language usage. Although mothers' communication needs are supported (through translation), misfit remains when mothers encounter an unwelcoming culture and disrupt expectations of who belongs.

In the following analysis, I discuss mothers' differing experiences of misfit, connected to Spanish-language usage. These experiences of misfit include total exclusion (lack of interpretation), unequal participation (poor quality interpretation), and perceived devaluation/sense of belonging (stigmatization of Spanish-language usage).

Total Exclusion

For the vast majority of mothers, who did not communicate in English, language-based misfit functioned as total exclusion. Here, total exclusion refers to mothers' inability to access information, participate in decisions regarding their children's treatment, or express concerns and opinions. In an environment without interpretation, without translation, these women misfit, and were excluded from services, knowledge, and personal expression. Communication, the core of advocacy, was stifled by monolingual environments.

Lucia did not speak English; she spoke Spanish at home and work. Her son Matias, 21-years-old, had been denied developmental disability benefits and disability social security. In describing her frustration at her thwarted advocacy, her attempts to obtain disability accommodations and supports for Matias, Lucia pointed to the role of language: “It’s another thing, the language, we don’t speak English – how are we going to speak for him if we can’t speak for ourselves? That’s where the problem is.”

Similarly, Elena did not communicate in English, and she lived and worked in environments inhabited by other Spanish-language speakers. Elena recalls not knowing she could request more early intervention services for her sons; she connects her exclusion from information (and her sons’ exclusion from therapy) to a monolingual English environment. “I just didn’t know…. They gave them [her sons] therapy once a week, and I didn’t know that I could tell them that the boys needed more help, that once a week wasn’t enough for them, but I didn’t know that I had the right to ask… that’s one example… there’s so many things that you don’t know about and sometimes I think, I always wonder, is it because of the language, if you don’t speak English you miss so many things.”

Renata does not speak English; when she first moved to the U.S. she worked in canneries, and she now works as a Latinx community organizer (where she communicates in Spanish). She did not know she could request an interpreter, when advocating at her children’s school. No one offered the service. Renata describes how the lack of interpretation excluded her from communicating with her children’s teachers.

> “... I also think that the district had a responsibility, or at least a teacher had it, if she saw that I had trouble communicating, to say – ‘You can ask for an interpreter, if you want, if you can’t tell me something, there’s an interpreter.’ That would have been so much help for me, and that’s something I said, at the meeting we had with the superintendent… I told him, ‘I needed [that help] when my children started first grade, [I needed] you all to guide me, and if you had only told me that I had a right to an interpreter, with that, you would have helped me, and opened things up for me, because I would have been able to express more, like what I’m telling you now.’”

Unequal Participation

Even when interpretation services are provided, misfit often remains. Unequal participation describes a type of mothers’ language-based misfit; although interpretation allows some access to knowledge and services, poor quality interpretation limits mothers’ participation in disability advocacy. Latinx-immigrant mothers could not participate equally or similarly to English-speaking mothers because of an inaccessible environment. Misfit remains when interpretation or translation isn’t adequate, supportive or effective. In these moments, misfit doesn’t entail total exclusion. Instead, misfit occurs because the environment forces mothers to stand out, make a scene, and struggle. Mothers can access the space, but mothers do not fit smoothly, seamlessly, comfortably in the environment. This type of misfit involves feelings of unease and the inability to participate on an equal footing.

Although Jimena speaks and understands some simple English phrases and vocabulary, she needs an interpreter to effectively communicate in advocacy spaces.

Before working with a professional advocate, Jimena attempted to communicate with school actors, without a qualified interpreter. The school relied on an interpreter, who Jimena describes as “not really an interpreter.” Poor interpretation resulted in misfit for Jimena; in essence, the low quality of interpretation excluded Jimena from participating in decisions regarding Alejandro’s educational needs. Here, Jimena’s advocacy stemmed from the daily complaints she received about Alejandro’s behavior in class: “And the school kept sending notes home that Alejandro behaved badly today. That Alejandro said a bad word. That Alejandro scratched a classmate. That Alejandro pulled on the teacher. (Jimena pounds her fist on the table.) Well, what on earth am I going to do? They just kept sending them, and I didn’t know what to do.”

Jimena spoke with Alejandro’s teacher and the principal, and then requested a formal IEP meeting. In the following quote, Jimena describes the experience of poor interpretation when advocating at school.

> “...well, they had an interpreter, but it wasn’t really an interpreter… Thank God I understand English… Once they had a lady there, who works at the school and speaks Spanish, but she isn’t an interpreter… So, one time the teacher was saying a lot of things to me, and she [the interpreter] was saying something else, not what I understood the teacher to say. So that’s why I say, she’s not an interpreter… everybody is talking and she’s talking to me at the same time and the truth is that I can’t understand everything they tell me – sometimes I wonder if it’s bad to understand both [English and Spanish] a little because I’m listening to what everybody is saying and then the interpreter is talking to me, too. It’s not good. Before, they just used anybody who was around [to interpret].”

Poor quality interpretation involves providing incorrect information and failing to pace the conversation; if “everyone is talking” while the interpreter works, the interpreter cannot effectively communicate all information to Jimena. In this case, Jimena misses key information, for example, the communication between teachers and the principal that occurs while the interpreter focuses on Jimena.

The quality of document translation created a similar misfit for Mariana. Sometimes Mariana received documents in English, sometimes in Spanish. She describes how a poor Spanish translation actually creates greater misfit (exclusion and confusion) and a need for more advocacy.

> “That was another thing, they would give me a paper and I would say, ‘Ah, okay one more paper to store,’ but when you really read it, even when they’re giving you the papers in Spanish - it’s just a bunch of nonsense that they put, I mean, the translations aren’t correct… So you think, ‘Well, and this, what does it mean? And here, what’s that say?’ – they’re things that make you say, ‘I’ve got to talk to them about this’ because I want to know what they’re talking about… one time I said to a teacher, ‘I want to know what it is that I signed, because this here, it doesn’t tell me anything, the translation is terrible’.”

Julia describes how poor interpretation creates a sense of unease; mothers don’t know or trust interpreter’s abilities. Past, negative experiences lead mothers to doubt the quality of interpretation. Additionally, low quality interpretation does not capture or convey the nuance of mothers’ concerns. “It’s also not knowing English, because you don’t know if they’re interpreting well, you know, if you want to express yourself one way, you can’t, because an interpreter doesn’t give it the same feeling that you would.”

Perceived Devaluation

Even when mothers speak English or interpretation adequately conveys mothers' intentions, misfit may remain. Perceived devaluation refers to mothers' sense that the need for interpretation or their Spanish language usage spurs stereotypical reactions in others. Mothers perceive professionals, such as educators and physicians, to associate mothers' Spanish language-usage with a lack of education or intelligence. Misfit continues when social actors view the need for interpretation as lesser, weakness, as a sign of deviance and unbelonging. Misfit arises when mothers feel judged, devalued, demeaned for using interpretation services. Although the physical environment allows access, social actors create an unwelcoming culture.

Isabel, who speaks Spanish and English fluently, works as a professional advocate (helping parents navigate various aspects of disability advocacy). Isabel speaks English with a Spanish accent. In discussing her personal advocacy, on behalf of her son Matthew, Isabel notes the role of her accent. She felt that Matthew's educators perceived her accent to mean that she would be uninformed, docile, and accommodating. "I think that it was. Because I have a thick accent as well. And I just felt that they didn't want to -- it felt like an empowered parent was not acceptable for me to be. And I happened to be married to an Anglo-Saxon individual, American. And that sort of helped. But I could tell through my cases years later that those parents are the ones that are most affected by the system."

Clara speaks English and Spanish; she works as a professional interpreter. She felt that educators perceived her as uneducated because of her Spanish surname. "They stereotyped me because of my last name. They assumed that because you're Latino, you have a Latino name -- that you don't speak English as a parent, you know. Or -- because they assume you don't speak English, because they assume you're not educated, they assume that they can just do whatever they want without asking you. And that happened with David, but, you know, then I stepped in and then, ‘Hey, I speak English’ …. So, yeah, based on our name, it was just by the last name, there was an assumption that you don't know.”

Adriana now speaks English and Spanish fluently, and she works at a disability advocacy organization. When she first moved to the U.S., she spoke and understood some basic English phrases, but continued to use interpreters when advocating for her daughter. She describes feeling that her daughter’s physicians assumed that her need for interpretation correlated with a lack of education. Adriana suspected that her daughter had Autism, as well as Cowden syndrome, and shared her concerns with a variety of medical professionals.

> “Well... I feel there's this misconception that if you don't speak the language, you're not educated. That's the way I feel. I don't know if they really thought something or it was in their mind -- Because I also suspected, my husband too, that my daughter had autism or was on the autism spectrum because of some typical [Autism] things she used to do. We went to therapists and doctors and I would say things like, ‘Do you think that she could have autism?’ It was like, ‘Uh.’ The look was like, ‘What are you talking about?’ So, I feel ashamed sometimes that I was like, ‘Oh, okay. Maybe I don't know what I'm talking about.’ - I feel like they thought I was crazy. My husband felt the same. The

> doctors would be pretty much like, ‘What are you talking about? You have no clue.’ That's the way we felt. Then, she ended up having a diagnosis for autism.”

Immigrant Background Misfit

Within this study, the majority of Latinx-immigrant mothers arrived in the U.S. as adults; mothers, thus, attended school, worked, lived, grew up outside the U.S. (16 in Mexico, two in Chile, and one in Colombia). Once in the U.S., most mothers settled in “immigrant enclaves,” in which they lived, worked, and socialized with other Latinx-immigrants (Alba et. al. 2014). Mothers remained embedded in “dense ethnic networks” (Waters et. al. 2010). Prior to their advocacy experiences, these Latinx-immigrant mothers had limited exposure to the environments in which they advocated, such as U.S. public schools, doctor’s offices, and public disability services. In a sense, mothers misfit when they were not familiar with the processes and norms of these social institutions. Mothers’ expectations, perspectives, ways of being, communicating, and beliefs about how society works were shaped outside the U.S. context. These expectations, perspectives, ways of being, these “particularities of embodiment,” shaped or developed outside the U.S., misfit within U.S. environments which did not provide immigrant mothers with guidance, explanation or orientation. Environments, or spaces, built on the assumption that social actors understand the social norms, expectations, and processes which regulate the environment, misfit mothers who did not know the social norms and expectations.

Mothers described a sense of disorientation, confusion, and isolation, that arose when advocating. Working-class mothers and mothers who did not speak English were more likely to express these sentiments than middle-class, bilingual mothers (who worked outside immigrant enclaves). For example, Renata describes how she felt advocating at her children's school: "completely lost… it's like being disoriented, lost." Renata moved to the U.S. as an adult and remained embedded in her immigrant community (living and working alongside other Latinx immigrants). Neither Renata nor her husband spoke English. "I was really isolated because I didn't have many friends. When I arrived in this country, I worked in canneries and packing houses. I didn't have much contact with other people. I didn't know any other parents." Throughout elementary school, Renata's son Luis tested below grade level. Although Luis understood and spoke English well (Renata knew this from a bilingual cousin), Luis received ELL classes (English-Language Learner). At annual conferences, in which the school provided an interpreter, Renata requested that Luis be removed from ELL and evaluated for a learning disability. She also requested that Luis be held back when he did not meet grade-level benchmarks. Each year, her requests were denied. In requesting Luis repeat a grade, Renata drew on her experience of schooling in Mexico. She describes her reasoning: "I told the principal, 'Well, I don't know why, here, when he's not at grade level, you keep moving him along. But, in my country, I'm used to - that if you don't pass, if you're not on level, you stay back a grade.' They said that is not good for his self-esteem, and I said, 'Well maybe not, but I think sometimes we need to repeat a grade to get it.'" Luis was evaluated for and diagnosed with a learning disability in middle school.

Now, Renata connected her advocacy struggles to her background, unfamiliarity with the U.S. education system, and an unsupportive environment: "Since I'm Latina, I don't know the system, because I didn't study here, I don't know it, I'm learning… but…

I think ‘If I had studied here, I would have had a better understanding of how things go.’” Renata attends trainings, sponsored by a non-profit organization, not the public-school system, to better understand the structure of U.S. education. The school system did not sustain Renata, did not support her needs as an immigrant, by providing an orientation to public education, broadly, and special education, in particular.

Mariana moved to the U.S. in her early thirties, after meeting her husband in Mexico. Before the birth of her twin sons, Mariana worked in the kitchen at a fast-food restaurant. Now, she is a stay-at-home mom, and her husband works in an auto-repair shop. Mariana’s life is embedded in her ethnic community. Mariana speaks some basic English phrases, and she uses an interpreter to advocate for her son at school and with physicians. In the excerpt below, Mariana recalls part of her advocacy journey, (focused on pressuring her son Nicolas’ teachers to change his diapers more frequently) and explains a Spanish phrase to me:

> Mariana: I don’t remember exactly when he stopped using diapers for good, but it was at Central Elementary, and he was at Central for first and second grade, I think it was probably at the end of second grade… [sigh] But, yes, I was fighting a long time at Central, and it was at Central where I realized that I was on the street of bitterness, do you know that saying?
>
> Katie: No.
>
> Mariana: It’s a phrase Latinos say a lot, “you’re on the street of bitterness,” and it means that you’re totally lost, you don’t even know where you’re walking…well, that’s when I realized that I was lost.

Mariana realized that by focusing her advocacy on Nicolas' hygiene, she had missed the larger picture (fighting for his inclusion with non-disabled peers in regular education spaces). Nicolas attended a segregated classroom for children with intellectual disabilities; Mariana didn't know Nicolas could attend a regular classroom, with accommodations. Perhaps more critically, Mariana was not familiar with the norms and processes of the U.S. education system. Mariana didn't know that her role on the IEP team (the special education entity responsible for determining Nicolas' specialized education services) is to safeguard Nicolas' right to an education. In other words, through contact with the education system, Mariana learned that she must advocate; without her advocacy, the school did not keep Nicolas clean and did not follow special education law.

As an immigrant, with limited contact to mainstream social institutions, Mariana was not familiar with the inequalities and adversarial relationships within U.S. education. The environment, the school setting, did not include general information about the structure and workings of education or specific information, such as an explanation of critical special education procedures. In describing this lack of information, connected to her experience of misfit, Mariana elaborates on the meaning of the street of bitterness: "Even though I was completely unaware of so many things… how it [special education] worked… or what an IEP was all about… I wanted to get involved, to know more. But I didn't even know where to get help or who I could talk to or where I could go or who could guide me through it all." Additionally, Mariana notes how the school district never provided information: "... the school district has never, to this date, volunteered information, they've never said, 'Look, you can go to this place or talk to this person or look, we have this help available.' Never, to this date, never."

Accessible information, guidance, and orientation are part of the material environment; people with atypical embodiments (such as blind people, neurodiverse people, or immigrants with limited acculturation) may need accommodations to navigate spaces designed for majority bodies. Latinx-immigrant mothers also experienced this type of misfit outside the educational space. For example, Jimena learned about Developmental Disability Services, or DD services, during a chance encounter at the grocery store (not from Alejandro's social worker). Developmental Disability Services provide mothers with funds for respite care, assistive technology, disability related goods like diapers, and wages for time spent taking care of children's disability related needs; DD services provide the community support necessary to keep disabled people out of institutionalized settings. Jimena moved to the U.S. as a teenager; she has worked in a variety of agricultural positions alongside other immigrants. As discussed in the previous section, Jimena understands and speaks some basic English. She uses an interpreter to communicate with Alejandro's teachers and physicians. Although Alejandro was born with an impairment (Prader-Willi syndrome), and was assigned a social worker, Jimena did not learn about available DD services through any of Alejandro's service providers (medical professionals, educators, or the social worker).

> "I learned about the program from a lady I met one day at the store. She also had a child with a disability, and her son is 13 years old now. And so, I ran into her, I was shopping, and Alejandro didn't want to leave, and this woman… said, 'Can I ask you a question? Does your son have a disability?' And I thought, do I tell her yes or no? Why is she asking? But then I thought, okay, and I said, 'Yes, why?' And she said, 'Don't worry… I'm just asking because I have a child with a

> disability too.’ And when she said that, I thought, okay, she gets it… And we started to talk, and she said, ‘Excuse me for asking, but does your son receive help from the county? Like diapers and things like that?’ And I said, ‘No, nothing like that.’ And she said, ‘How’s that possible?’ I said, ‘Look, no one, not his therapists or anyone like that, said that he could get diapers, that the county would give me diapers.’ I bought all of his diapers, until she told me about that. So then, I asked his doctor, and she said, ‘Yes [he can receive diapers].’ I thought, Wow, [she’d been his doctor for] so much time, and she’d never mentioned that…”

Through a stranger, Jimena learned about a variety of public disability services. The developmental disability services environment produced misfit for Jimena; the environment did not include outreach to Latinx parents, like Jimena. As in the school context, public disability services did not provide sufficient information. The environment did not support or sustain Jimena’s unfamiliarity with U.S. public services.

Similarly, Olivia learned about developmental disability services for her son Isaac through an out of state acquaintance on Facebook. Olivia does not speak English. Before Isaac’s birth Olivia worked with other immigrants in a factory and on a gardening crew. Isaac was born with Down syndrome, and was assigned a social worker, who did not adequately orient Olivia to the U.S. disability system. “I found someone that has two sons with Down syndrome, and she said, ‘Your son should receive speech therapy, occupational therapy, and physical therapy.’ And I said, ‘No, my son doesn’t receive any of that.’ And I asked, ‘I don’t know about that, tell me, you have a son like mine, how are you handling this? How does this work in California?’” Although Isaac’s social worker had come to the house once, Olivia describes her assistance as unhelpful: ‘She was a little like a tyrant, or rude, you know, like ‘This is what you get, fill this out, that’s all the information that I have.’ She wasn’t friendly.”

Middle-class Latinx-immigrant mothers, like Adriana and Isabel, experienced greater fit in these spaces; social networks oriented them within the U.S. disability system. For example, Adriana moved to the U.S. as an adult, after graduating from university in Chile and meeting her husband, who grew up in Oregon and Chile. Adriana taught Spanish at a language school for adults; during her first years in the U.S., she required an interpreter to communicate with medical and education professionals. Currently, she works at a disability rights organization, where she leads Latinx outreach programs. Adriana attended her first IEP meeting with a friend who worked in early intervention. This friend alerted Adriana to the possibility that the school may not follow the legal contract (IEP) to which all parties had just agreed:

> “I’ll always remember, after the meeting she was like, "You have to be on top of this. You have to do this. You have to make sure they do what they say." I was like, "What?" Kinda surprised. You don't expect something like that. For me it was more like, "Okay, I'm going to the IEP meeting. They're going to do what they have to do, what they're supposed to do, and I will just need to give the input.”

Friends also helped Isabel navigate the U.S. disability system. After attending college in Mexico City, Isabel moved to California to pursue a career as an artist. She fell in love with and married an American piano teacher. Although she maintained close ties to her family in Mexico and Latinx communities, Isabel worked and lived in mainstream spaces as a professional disability rights advocate (not in ethnic environments). Isabel recalls learning “the magic words” from other moms, who she knew through a local Co-op. “...I learned, I learned key words and the key word was -- development at risk. So this other mom said, ‘Just say that, that's all you need.’ And so I said, "Okay, he's at risk for development," and then developmental disabilities made him eligible.” Isabel moved frequently and drew on her personal network to learn the ropes of the local disability business: “I always was very lucky that there was always a mom who was an advocate who knew everything in the area and would talk to me. And then I became that mom.”

Racialized Embodiment Misfit

In this section, I examine mothers’ perceptions that their racialized embodiment, or categorization as Latinx, produced misfit in their disability-based advocacy. Racialized embodiment refers to how others perceived and treated mothers as nonwhite (Vasquez-Tokos 2020). Within the U.S., Latinx people may be racialized (perceived and defined) as non-Hispanic white, Hispanic/Latino, or non-Hispanic black (Golash-Boza and Darity 2008; Vasquez 2010a). Phenotype and skin color are key in Latinx people’s differential racialization (Ortiz and Telles 2012; Vasquez 2010a; Vasquez-Tokos 2020). Darker skin leads to more racialization, while lighter skin may allow Latinx people more flexibility in their racial identification (Vasquez 2010a). In this study, mothers were defined and treated by others as nonwhite, Latinx.

Misfit occurred when environments, which mothers entered in order to advocate, did not support mothers’ racialized embodiment; misfit centered around the mismatch between cultural expectations of belonging and deservingness (connected to whiteness) and mothers’ racialized embodiments. Mothers’ perceived and experienced environments, such as schools, doctor’s offices, and public disability services, to be “white spaces” (Anderson 2015). In defining “white space”, Anderson highlights demographics: “white spaces vary in kind, but their most visible and distinctive feature is their overwhelming presence of white people” (2015: 13). Within such spaces, stereotypes may “rule perceptions” (Anderson 2015: 13). When advocating, mothers routinely encountered spaces inhabited, overwhelmingly, by white people. For example, during the 2018-2019 school year, 89.6% of teachers, in this state, were white (OR Statewide Report Card 2019).

Additionally, these environments (practices, processes, social actors) are shaped by discourses around deservingness and immigration (Kibria and Becerra 2020). These cultural sentiments denigrate “immigrants who represent public costs” (Kibria and Becerra 2020: 2). When immigrant mothers of color advocate on behalf of their disabled children, they confront these notions, and the assumption that immigrants should not access public entitlements (Kibria and Becerra 2020). Similarly, public discourse often portrays disability rights as “special rights,” “privileges” or “preferential treatment” (Dorfman 2019). Survey research indicates widespread suspicion of people’s disability claims and various types of rights for people with disabilities (Dorfman 2019). Thus, Latinx-immigrant mothers (of disabled children) experienced misfit within environments shaped by anti-immigrant sentiment and disability suspicion.

Within the misfit framework, the environment includes social actors. The presence or absence of social actors, such as interpreters, as well as such individuals’ actions, may shape experiences of fit or misfit. An environment which produces misfit for Latinx mothers includes social actors that act on racial prejudice (intentionally or in colorblind ways) as well as policies and practices (that have a racist effect), and an overwhelming proportion of white people. Mothers' perceived discrimination ranged from denial of services, differential treatment, microaggressions, and racist stereotypes. Misfit, in this context, may result in exclusion (denial of or limited access to services) and feelings of unease and unbelonging. Within advocacy environments, mothers felt themselves (and their children) to be discriminated against because of their Latinx embodiment. Patterns emerged around two themes: mothers described perceived differential treatment and encounters with stereotypes.

Differential Treatment

Latinx mothers in this study perceived differential treatment in their interactions with professionals and in their children's access to services. All of the Latinx mothers reported that they often felt demeaned or ignored by professionals and that their children received less and poorer quality services than white children. They described both a general feeling of differential treatment and recalled specific instances of unfair treatment. These experiences made them feel unwelcome, uncomfortable, and not suited to the environment. For example, Julia worries that her daughter, Fabiana, will be excluded or ignored because she is Latina. In fact, Fabiana was not allowed entrance to summer school, purportedly because of her need for toileting assistance. Once Julia's advocate informed the school director that this action violated special education law, Fabiana returned to summer school. Julia describes the feeling of differential treatment, "It's only sometimes, that, yes, you feel discriminated against for being Latina… it's like… sometimes… with adults that are from here [USA] there's some kind of rejection towards us… or because you're Latina they push you to the side, well, I guess, it's racism…"

Similarly, Renata's children struggled in school and did not receive educational disability accommodations until middle school. Renata viewed that experience as an example of differential treatment, in which her children were not treated equally in comparison to their white peers: "Of course, there's discrimination… my color, even though people don't talk about it much, but I see the difference, they won't treat my children equally, because they aren't white…" Lucia, who dreaded attending her son's IEP meetings at school, because of hurtful interactions with his teacher, described her perception of differential treatment: "Being Latino, they discriminate against you, too much, just seeing your skin color, they think you're bad, they treat you badly. The language and your color… they discriminate against you a lot."

Latinx mothers also recalled specific examples of perceived differential treatment. Lucia's son Matias recently graduated (with a modified diploma) from high school. Matias is a quiet, respectful young man. He learns, moves, and talks slowly. He gets tired easily. Although Matias received special education services, throughout his school career, he was denied both adult developmental disability services and disability social security. Frustrated, fearful, anguished, Lucia worries that her son will not be able to support himself if she or her husband dies; at the time we met, Lucia, with the help of an advocate, was appealing the decisions that Matias did not qualify for public disability support. Lucia perceived her son's lack of access to educational resources and public disability services to be a form of race-based discrimination: "I feel like they've discriminated against him a lot because he's Latino… I feel that - that they haven't given him the services that he needs simply because he's the son of Latinos. For me, I feel like that's what happened to him, because if he had been the son of someone from here, they would have given him all the services, and even more, but because he's the son of Mexicans or Latinos, common people, we're not worth anything here, that's the truth."

Similarly, Mariana wondered if an instance of perceived differential treatment was due to her Latinx embodiment. Mariana has twin sons who go to the same school. One son attends a regular education classroom, and the other, Nicolas, goes to a special education classroom. Every morning, Mariana drives to her sons' school and parks a few blocks away, so she can walk them to the building. Typically, Mariana would enter the school and walk with Nicolas to his special education classroom door. However, one day, when Nicolas was in fourth grade, and a few months after Mariana had engaged in a mediation with the school, the principal sent Mariana an email. The email informed Mariana that the school had implemented a new rule and that parents could no longer walk their children to the special education classroom. Instead, these students would need to be dropped off at the front of the school with their non-disabled peers. So, Mariana began to drop both her sons off at the school entrance. After a few days, Mariana noticed that other parents continued to walk their children to the special education classroom. "I thought, 'How come they can drop their kids off there, and not me?' and so my mind started spinning, that's one of my problems, I start to worry…and I kept thinking about what was going on and I thought, 'Are they doing this….are they discriminating against me?' Because I was the only Latina and Nicolas was also the only Latino student in special education…" Mariana contacted the advocate, Isabel, who had represented her in the earlier mediation with the school; Isabel informed the principal that a rule prohibiting only Mariana from walking to the classroom door was discriminatory. Mariana, then, received another email, one addressed to all special education parents, and the rule was applied to all parents. Mariana, and her advocate Isabel, perceived the principal's actions to be race-based discrimination and retaliation for Mariana's previous mediation. Mariana had challenged the school after learning that Nicolas had been removed from his general education classroom, without her permission, and Nicolas was awarded compensatory education (legal damages) in the mediation. Restricting Mariana's access to the classroom limited her ability to uncover other legal violations.

Stereotypes

Mothers also perceived that racial stereotypes, or assumptions about members of a racial category, negatively influenced their interactions with disability professionals. Prior research identifies a variety of racialized and gendered stereotypes that Latinx people encounter in the U.S. context; such stereotypes paint Latinx people as "docile menial laborers, unauthorized immigrants, criminal, gang members, rapists, seductresses, and athletes" (Vasquez-Tokos and Norton-Smith 2016: 913), "lazy Mexican[s]... not inclined towards education" (Vasquez 2010a: 56), and "poor, uneducated, unclean, illegal aliens, and prone to teenage pregnancy" (Golash-Boza 2006: 28). In the context of this study, Latinx mothers felt that disability professionals perceived mothers, and their children, to be uneducated, docile/passive, and emotional/angry. Latinx-immigrant mothers experienced misfit when confronted with these stereotypes.

As Latinx-immigrant mothers navigated public services on behalf of their disabled children, they perceived social actors to rely on stereotypes. For example, Julia describes feeling that educators viewed her as uneducated and docile: "...sometimes being Latino, it's like Isabel says, they see you like, 'Ah, they'll agree to anything.'" Isabel, now a professional advocate, encountered a related stereotype, that shaped her interactions with her son Matthew's principal: "And I was very shocked at the principal how she wanted to control everything and I didn't think that she liked me -- maybe they are used to Latino parents not knowing their rights and they sort of are comfortable with that sort of box, and I almost feel like -- I shattered their stereotype and they didn't like it." At the time, Matthew attended a predominantly white school; after living in California, for almost fifteen years, Isabel moved to Oregon and connected Matthew's educational segregation to the lack of racial diversity at his school. Within such a "white space," Isabel perceived stereotypes, holding Latinx people to be uneducated and docile, to have influenced school actors.

A few months before our interview, Paula started working as a receptionist at another school in her son's district; she immediately perceived a change in how school actors viewed and treated her: "Now, they don't see me like the crazy, angry mom. And I've realized that they really do catalog you, like 'Oh, here comes this mom...' You know? I had this history too, that I was divorced. I mean, I didn't tell them, but they knew. The father's not here, he doesn't come [to the school]. This woman doesn't even work… They look at you like, 'Oh, poor dear, she's coming to take it out on us, because things aren't going well.' They don't pay the same attention to you."

Adriana, who challenged the recommendations of her daughter Laura's medical providers, describes facing a similar stereotype, associating Latinos with a lack of education and misplaced anger: "I think, just being Latino, it's like you're in the same packet. You're uneducated, or you may be educated, but you're still this angry Latino parent who's always talking about racism — There is still that misconception." Tumors are one symptom of Laura's condition, Cowden syndrome. After Laura began walking with a limp, Adriana consulted a number of physicians, who dismissed Adriana’s worries, and an orthopedic surgeon, who suggested that Laura’s limping was simply “a bad habit.” Later, a trip to the emergency room revealed a large tumor in Laura’s leg (not a bad habit); multiple medical professionals had dismissed Adriana’s concerns. Adriana felt that both her, and Laura’s, status as Latinx influenced these professionals’ reactions.

Olivia feared that stereotypes influenced her son Isaac’s treatment at school; she worried that Isaac’s teachers viewed him as dirty and unclean. Isaac used diapers throughout elementary school and regularly arrived home in dirty diapers. “Because sometimes he came home totally dirty, and I thought, ‘No, if I sent you with extra clothes, diapers, wipes, and gloves for the teachers.’ I would buy the teachers hand-sanitizer, even scented and name-brand, spending more than I really could, and I told her, ‘This is for you,’ because the teacher looked at Isaac like, ‘He’s dirty, why doesn’t he know how to go to the bathroom?’”

Misfit and Fit in the Disability Rights Movement

In this section, I examine Latinx-immigrant mothers experiences of misfit within a mainstream disability rights organization, CFED, Connecting Families Experiencing Disability. I then discuss their experiences of fit in a Latinx-immigrant run group, ADP, Alianza de Padres. As outlined in the previous sections, in this study, Latinx-immigrant mothers experienced misfit when environments were monolingual, lacked effective interpretation, failed to provide adequate guidance, or felt like ‘white spaces.’ Latinx-immigrant mothers experienced similar types of misfit in the ostensibly inclusive setting of a parental support and training group. In other words, Latinx-immigrant mothers experiences within CFED were “jarring juxtapositions,” in which the organizational environment did not support their embodied knowledge and needs.

Special education law mandates the formation of parental training centers to support parents of children with disabilities; such associations provide parents with information about their rights, legal procedures, special education services and advocacy strategies (Trainor 2010a; Rossetti et. al. 2018). In the state where this dissertation research occurred, CFED, Connecting Families Experiencing Disability, is the association charged with providing such parent training opportunities. CFED provides individual parents with advice and support through a hotline and runs parent training classes on a variety of topics, such as special education and disability support services. The organization also promotes the social model of disability and educational inclusion at the collective level through media campaigns, presentations, and collaborations with state councils.

CFED is primarily led by white mothers of disabled children. At the time of my data collection, the organization had two Latinx-immigrant staff members, interviewees Clara and Adriana (out of a staff of 21). The spaces in which CFED meetings were held, office parties attended, and trainings performed were largely inhabited by white, middle-class, U.S. born, English-speaking women. CFED did offer Spanish-language interpretation at trainings and Spanish-language assistance over the hotline. CFED’s environment, composed of social actors, policies, institutional values, training events, advocacy advice, and office space, often produced misfit for Latinx-immigrant mothers. These experiences of misfit mirrored Latinx-immigrant mothers’ misfit within medical, educational, and public disability services environments.

Although CFED provides translation services during trainings, Latinx-immigrant mothers still experienced Spanish language usage-based misfit. For example, in one parent training course, Clara skillfully interpreted for two Spanish-speaking mothers, Elena and Juana, all interviewees. The three women sat in a corner, physically separated from the rest of the group (of about 10 parents) and often engaged in private conversation. The need for simultaneous translation, without microphones and headphones (accommodations or assistive technology), led to this visible misfit or separation.

During this same CFED training course, a charged moment of misfit occurred; Elena's Spanish-language usage, immigrant background, and racialized embodiment "jarred" against the inaccessible environments of both CFED and her son's school. Earlier in the training, parents had learned about an advocacy strategy, known as a one-page profile. A common advocacy tool among parents in the special education arena, the one-page profile is a document describing a disabled child. Parents typically bring this document to school meetings or other interactions with adults who may exercise authority over their children. The document is both practical and symbolic. It may help facilitate interactions between a child and unfamiliar adults and also help others see the unique characteristics of the child and not just the disability.

At the beginning of one meeting, Elena described her recent experience using the one-page profile to advocate for her son at school. Through Clara, the interpreter, Elena recalled, "I sent the one-page profile about a week before our meeting and when I got to the meeting…they were barely translating it and they were just barely looking at it." Elena does not speak or write English, and she had sent the school a Spanish-language one-page profile a week prior to a special education meeting. Her tone suggested doubt about the utility of the one-page profile as well as a plea for assistance. Deborah, a white, middle-class CFED staff member, who was leading the training session, responded, “That’s more of an advocacy point, more than anything else, and you could say, ‘This information is gonna be really important, and in that I submitted it a week ago, I was really planning on it being included in the IEP. Shall we reschedule this meeting?’ That’s what I would recommend.” Deborah’s advice misfits Elena’s experience; Deborah’s recommendation that Elena demand the school timely translate her documents fails to account for the largely inaccessible, monolingual educational environment. The educational environment, in which Elena advocated, lacked readily accessible interpreters. The school’s failure to translate Elena’s document also evidences differential treatment. Elena misfits within an educational environment that includes racial stereotypes and anti-immigrant sentiments. However, Deborah’s response ignores these aspects of an inaccessible environment. Deborah’s advice (which reflects CFED trainings and resources) forms part of another inaccessible environment, in which Elena misfits. In Deborah’s exchange, Elena’s embodied actions became the reason for misfit, not the inaccessible environment.

Adriana, one of CFED’s two Latinx-immigrant employees, elaborates on her view that Latinx-immigrant families misfit within CFED’s organization as well as in the public spaces in which they advocate. Adriana argues that these environments fail to meet the needs of Latinx-immigrant families:

> “Well, they [Latinx-immigrant parents] need more support first. It's not just one phone call, and that's that, it's done - you can't really tell them, ‘Oh, write a letter,

> and put...' and that's it. They need more support. They need someone to meet in person... what I did with the families I was working with before, I would meet with them, I would check their letters, I would translate their letters, kind of write them... but it [CFED's response] was always like, 'Why are you doing this? Why are you supporting this family this much?' I'm like, because if you really want to support families, that's what you need to do. It's not like you can tell them like people here, because you speak English, and I can tell you, 'Write this, this, this,' and you would be like, 'Oh, okay. Got it.' You know the education system here - we don't. So, I can say, 'Oh, your son is going for a modified diploma' and they'd be like 'What? A what? What is that?' In my country, there is only one diploma. So, there's a lot of things that you need to do differently, and in order for them to be comfortable with you, they need to talk to you a couple of times. You need to follow up...."

Adriana recognizes that Latinx-immigrant mothers experience misfit while advocating because of their Spanish-language usage and immigrant background. Tools or support, which might assist white, U.S. born mothers, do not create fit for Latinx-immigrant mothers.

Alianza de Padres/Parent's Alliance (ADP) is another parent advocacy organization. ADP was founded by Isabel, a Latinx-immigrant mother, after her son was arrested at school for behavior connected to autism. Like CFED, ADP provides parents with individual help through parent trainings, phone calls, and in-person assistance. ADP also engages in collective advocacy, such as presenting at universities, government offices, and community events. However, unlike CFED, ADP conducts all trainings in

Spanish, almost all participants are Latinx people, and the organization acknowledges the role of race-based discrimination (and anti-immigrant sentiment) within disability advocacy. In essence, these aspects of the organizational environment provide fit for Latinx-immigrant mothers, in a collective disability advocacy space. In ADP, Latinx-immigrant mothers' embodiments interact harmoniously with the environment.

ADP's environment creates fit for Latinx-immigrant mothers by centering Spanish-language usage; information and advice is provided in native and complete Spanish (not translations). Similarly, ADP's environment fosters fit by assuming that mothers did not grow up in the United States; ADP's trainings include information on the overall structure of the public education system and advice about interaction expectations and social norms in U.S. institutions. Additionally, ADP readily acknowledges that racism and anti-immigrant sentiment shape both children's and mother's experiences. For example, in group meetings, mothers frequently discussed their fears about their disabled children's safety at school and in the community; mothers shared strategies they use to protect their children. Such strategies included ensuring children are well-dressed in public as well as obtaining legal protection for their children. For example, in one meeting, Mariana described how she requested the school create a Behavior Intervention Plan or BIP (a document, required by law, to support students whose behavior may interrupt the classroom). A BIP provides educators with specific steps to take to help a student avoid or to deescalate a crisis. Although Mariana doubted that the school would follow the steps, she wanted the BIP, and recommended other parents obtain one as well, to protect her son Nicolás from a potential arrest. "Really, I only wanted it [the BIP] to protect my son, because … if they allege that Nicolás had a problem, whether it's physical or verbal, and they want to expel him or remove him [from school] somehow, and [they say] that it wasn't part of his condition, his autism, that he just did it because he wanted to - that he just wanted to be rude – well, then that paper [the BIP] shows that they knew that Nicolás has behavior problems because of his autism… so even though it isn't really helping him [the BIP], it's protecting him." Mariana went on to explain that a BIP can protect a child from being sent to jail. "You know how it is, a lot of the things they [children with autism] do, they can't control… but you know, there can be retaliation for that… they can be expelled, or they [the school] can tell you that your son isn't going to be admitted in this school anymore… so this is one of the things you can do to protect children with a disability… they'll [the school] know that it's part of their condition, that type of behavior, and they can't send them to jail, because a lot of times they call the police…" As a leader in ADP, Mariana shared her knowledge of the U.S. education system (that students are arrested at school for disability-related behavior) with younger mothers. Mariana's advice fits Latinx-immigrant mothers' embodied experiences; Latinx-immigrant mothers, and their disabled children, may misfit in schools, and Mariana's advice recognizes that reality. Within ADP, Latinx-immigrant mothers experienced fit, as the organizational environment, including social actors like Mariana and institutional messages, such as her advice, support mothers' embodiments.

Discussion

This chapter explores the lived experiences of Latinx-immigrant mothers as they navigate public spaces on behalf of their disabled children. These mothers experience multiple types of misfit when their embodiments enter inaccessible environments, including spaces within the mainstream disability rights movement. Misfit experiences range from exclusion, feelings of unease, being forced to make a scene or stand out, and a sense of not being welcomed. Latinx-immigrant mothers experienced misfit connected to Spanish-language usage, immigrant background, and racialized embodiment.

Within monolingual environments, Latinx-immigrant mothers' Spanish-language use produced different degrees or levels of misfit: total exclusion, unequal participation, and perceived devaluation. Total exclusion occurred when environments lacked any interpretation services, and Latinx-immigrant mothers could not access information or participate in decisions regarding their children's disability services. Unequal participation refers to misfit that arose from poor, inadequate and ineffective interpretation and translation. Finally, perceived devaluation describes mothers' perceptions that disability professionals associated their need for interpretation, Spanish-language accent, or Spanish surname with a lack of education or intelligence. Within inaccessible environments, mothers' Spanish-language use led to misfit.

Immigrant background misfit refers to how mothers' status as immigrants produced exclusion and unease in environments which assumed actor's familiarity with U.S. public institutions and did not offer information, guidance or support. In the context of this study, most Latinx-immigrant mothers worked and lived in ethnic enclaves; these mothers were not familiar with the norms and processes of the U.S. public education system, medical institutions, and public disability services. Misfit arose because these environments did not provide an orientation or guide to Latinx-immigrant mothers.

Mothers' racialization, or categorization by others, as Latinx produced misfit in 'white spaces' (Anderson 2015). Mothers perceived social actors to treat them, and their children, differently than white mothers and children. Mothers recalled instances of perceived differential treatment, as well as a general sense of not belonging and unfair treatment. Stereotypes emerged as a significant pattern in mothers' narratives. Latinx-immigrant mothers perceived stereotypes to influence their interactions with disability professionals.

Latinx-immigrant mothers experienced these types of misfit within multiple environments, ranging from medical facilities, schools, developmental disability services, and even a disability rights organization, CFED. However, Latinx-immigrant mothers fit when environments facilitate Spanish-language communication, do not assume familiarity with U.S. cultural and social norms, and recognize the influence of race on disability experiences. The environment of a Latinx founded and led organization, ADP, provided such a fit.

In many ways, these findings align with prior research. Past studies have identified a variety of difficulties that culturally and linguistically diverse parents face when advocating (McHatton and Correa 2005; Harry and Klinger 2014; Cobb 2014; Stanley 2015; Angell and Solomon 2017). Such barriers include the lack of interpretation, limited outreach, and perceived discrimination (Harry 2008; Lo 2008; Cobb 2014; Burke and Goldman 2018). For immigrant parents, cultural discourses around deservingness and immigration pose additional barriers (Kibria and Becerra 2020). Parents also encounter courtesy stigma, based on their association with a child with a spoiled identity (Green 2003; Blum 2015). Similarly, parents must navigate public perceptions that disability rights are unearned, unfair "special privileges" (Dorfman 2019).

A misfits perspective provides a new way of understanding these patterns; Latinx-immigrant mothers experience misfit because the environment fails to support their embodiments, to meet their needs, to facilitate their communication, to instill a sense of belonging. In other words, Latinx-immigrant mothers encounter barriers when advocating because the environment is inaccessible, not universally designed, and does not encourage their advocacy. Embedded in misfits (and other social relational models of disability) is a neutral stance towards non-majority embodiments, both those socially constructed as impairment as well as Latinx-immigrant mothers' Spanish language usage, immigrant background and non-white racialization. Like the social model of disability, misfits suggests that interventions focus on changing the environment to provide fit for more embodiments (as opposed to focusing change on the individual). Thus, public environments, like schools, physician's offices, and disability services, must include effective interpretation services. Adequate interpretation will create greater fit for Latinx-immigrant mothers, as well as for Deaf people and individuals with non-majority communication needs. These environments must also provide orientation services and accessible information. Finally, disability rights organizations must seek to create racially inclusive spaces, within the movement and in the environments where disabled people receive services.

CHAPTER V

CONCLUSION

> “And I just hope that all of this information gets to the teachers. I ask God, please, let them be aware of what’s happening, and that the new generation of social workers, the new generation of special education teachers, or any teachers, anyone that’s going to work with children, that they’re aware.” -- *Olivia, 40, Latinx-immigrant, working-class, mother to an 11-year-old son diagnosed with Down syndrome*

> “I think the biggest thing is learning about people's voice... parents shut up -- shut up when the person who has a disability decides to talk or share and say, ‘This is how it is for me.’ People need to listen. I don't care if you're a mom or not… my friends and I -- we have clashed on that… it's hard to raise a kid, period. It's hard to raise a kid who needs more support or has this or [needs] different accommodations, all of that is hard, but that voice shouldn't take over or affect the kid who has a disability... we're so tired of hearing all the parents say how hard it is and how awful autism is and blah blah blah. Don't say that to your kids. Don't say it around them. The world needs to accommodate and support autism, period.” -- *Susan, 35, white, middle-class, mother to a 9-year-old son diagnosed with Cerebral Palsy and autism*

In the preceding chapters I explored mothers’ perspectives on and lived experiences with disability. I sought to answer the following research questions: How do mothers make sense of their, and their children’s, experiences with disability? How did they develop these critical perspectives on disability? What is the relationship between mothers’ advocacy and their children’s misfit at school? Why and how do mothers’ best efforts to defend their disabled children’s educational rights fail? What are the lived experiences of Latinx-immigrant mothers engaging in advocacy for their disabled children? This analysis employed a misfits framework to understand how mothers’ develop critical understandings of disability and navigate social institutions, like education and medicine, on behalf of their disabled children. Rosemarie Garland-Thomson uses the critical concept of misfit to describe the lived experiences of disablement; disability, or misfit, occurs when the environment does not support an individual's embodiment. Although inspired by the experience of physical impairment, misfit proved a useful framework to explore experiences related to mental impairment and other aspects of embodiment. The dissertation extends Garland-Thomson's concept to develop a framework for examining mothers' perspectives on and experiences of disability. The dissertation findings contribute to sociological understandings of disability, mothers' advocacy, and disablement practices. In this chapter, I discuss core findings, scholarly contribution, study limitations, future research, and recommendations. I conclude with a brief reflection on the motivation for this dissertation and my key takeaways.

Findings

In chapter two, I examine how mothers redefine disability as a natural part of the human experience. Mothers reject the mainstream, deficit model of disability and reimagine disability as a valuable form of human diversity. Mothers' understandings of disability shared common themes: universal vulnerability, expanding sameness, disabling environments, the need for accommodations, and valuable diversity. In conceptualizing disability, mothers emphasize their children's strengths and cite their belief that all humans have strengths and limitations. Mothers describe their disabled children as essentially the same as other children. Mothers also recognize how the environment creates disability through labelling practices, stereotypes, and inaccessible spaces.

Chapter two also explored how mothers developed these critical disability perspectives. Prior to meeting their children, these mothers, like most non-disabled people, held dominant, deficit-based views on disability. Mothers' understanding of disability had changed over time. I identified three key influences that spurred mothers' new perspectives on disability. These influences include negative interactions with professionals, exposure to positive disability spaces, and learning from their child. Mothers found the negative predictions of medical and educational professionals to misfit their knowledge and love of their disabled children. Mothers dismissed professional’s deficit views of disability as false. In accessing positive disability spaces, such as conferences or parent support groups, mothers learn about the social model of disability and the disability rights movement. The new disability models that mothers learn in these positive spaces better fit mothers’ lived experiences with and personal knowledge of disability. Through their daily lives with their children, mothers gain insight into the lived experience of disability. Mothers see, firsthand, how stereotypes limit their children. Mothers develop critical perspectives based on their lived experience with their children’s disability. This chapter explored both the development and complexity of mothers’ disability definitions, which reflect Garland-Thomson’s misfit concept by combining social model principles and centering the embodied reality of impairment.

Chapter three focuses on mothers’ lived experiences navigating the special education system. The analysis focuses on disabled children’s misfit at school because children’s misfit spurs and shapes mothers’ advocacy experiences. For disabled children, misfit arises when educational environments do not support children’s “particularities of embodiment” or non-majority traits. Key features of inaccessible or misfit-producing education environments include physical segregation, discriminatory (ableist) classroom norms, and teacher and administrator actions. When school environments include self-contained or segregated classrooms, disabled children misfit in regular spaces; social actors assume separate classrooms are the appropriate place for disabled students. When classroom norms require uniformity, students with non-majority behavior, communication, and bodily needs misfit. Teachers and school administrators enforce policies that remove disabled students from regular classrooms.

Mothers witness their children's misfit and intervene; their advocacy efforts seek to create fit for their disabled children, to modify the school environment to support their children's embodiments. Mothers' advocacy occurs in an environment shaped by disability-based segregation, norms of uniformity, beliefs that disabled students don't belong, and the assumption that professionals know more than mothers or disabled students about disability. When mothers challenge these norms, by arguing that their disabled children should be in regular classrooms or that they know more than the experts, they misfit. By using a misfits perspective, this chapter shifts analytic focus from mothers' actions and resources to understanding how aspects of the educational environment fail to support children's needs and mothers' advocacy.

In chapter four, I center the lived experiences of Latinx-immigrant mothers as they navigate public spaces on behalf of their disabled children. Latinx-immigrant mothers experience misfit when their embodiments encounter unsupportive environments, spaces they must navigate to secure services for their disabled children. Misfit sometimes resulted in exclusion, or inability to participate in decisions regarding their children's services, as well as feelings of unease and a sense of not being welcomed. In spaces built for non-disabled, English-speaking, U.S. born people, Latinx-immigrant mothers experienced misfit connected to Spanish-language usage, immigrant background, and racialized embodiment. Within English-language environments, Latinx-immigrant mothers' Spanish-language use produced different degrees of misfit: total exclusion, unequal participation, and perceived devaluation. Total exclusion occurred when environments lacked any interpretation services, while unequal participation arose in connection to poor, inadequate and ineffective interpretation. Perceived devaluation describes mothers' sense that the need for interpretation or Spanish-language usage led to stigmatization. Latinx-immigrant mothers also experienced misfit when environments assumed their familiarity with the norms and processes of U.S. public institutions. When Latinx-immigrant mothers lacked this knowledge, misfit arose because these environments did not provide an orientation or guide. Mothers' racialization, or categorization by others, as Latinx produced misfit in 'white spaces' or environments populated by white people. Mothers perceived social actors to treat them, and their children, differently than white mothers and children. Latinx-immigrant mothers felt that stereotypes influenced these discriminatory interactions. Through a misfits analysis, this chapter highlights how institutional structures and practices do not support Latinx-immigrant mothers' advocacy. Latinx-immigrant mothers' experiences of misfit occurred in medical and educational environments, as well as in a disability rights parental advocacy organization.

Contribution

A Misfits Framework

The primary contribution of this dissertation is the development of a sociological misfits framework, based on Garland-Thomson's "critical concept" of misfits. Garland-Thomson's concept addresses an important theoretical debate within disability studies, regarding the role or relative importance of embodiment in the experience of disability. Garland-Thomson suggests that disablement experiences reflect moments of misfit, which arise when an environment does not support an individual's embodiment. The concept of misfit locates disability in the interaction between body and space. When such interactions are "jarring," misfit occurs. In contrast, an individual experiences fit when the interaction between their embodiment and the environment is harmonious. Thus, disability, or misfit, is contextual, becoming and unbecoming as environments and bodies change.

This dissertation builds on or extends Garland-Thomson' concept to develop a broader, sociologically-minded framework. Garland-Thomson's theorizing primarily focused on physical non-majority embodiments (impairment) and physical, material environments. In this dissertation, I expand embodiment to include characteristics typically understood to be based in the mind as well as traits not associated with impairment, such as Spanish-language usage or immigrant background. Additionally, I theorize mothers' embodiment to encompass their children's embodiment; a child's non-majority or atypical embodiment shapes mothers' lived experiences, knowledge, and worldview. The child's embodiment becomes part of a mother's embodiment, as they navigate inaccessible spaces, together. I also add to Garland-Thomson's conceptualization of environment. Within the concept of environment, my analysis includes social norms, such as classroom requirements that children sit still or silently, and institutional practices, i.e., developing segregated classrooms and programs for disabled children. The environment also refers to the racial or ethnic make-up of social actors in a given space.

By delineating this misfits framework, based on Garland-Thomson's concept, this dissertation provides a new way of thinking about parental experiences and advocacy.

Most prior studies of mothering children with disabilities have utilized a feminist or cultural capital theoretical framework (see, e.g., Green 2003, 2007; Blum 2007, 2015; Trainor 2010a, 2010b; Colker 2013, 2015; Sousa 2015). This body of work examines mothers' access to private attorneys and expert witnesses, familiarity with medical and legal jargon, and free time to dedicate to advocacy. These studies indicate that mothers with more access, more resources, and more time achieve better outcomes for disabled children. Additionally, this literature analyzes how mothers, not fathers, do the majority of this advocacy labor. However, a misfits framework shifts analytic focus away from parents' cultural capital to focus on inaccessible aspects of the educational environment. The misfits framework, thus, centers disabled children's experiences within mothers' advocacy and contextualizes mothers' advocacy in an ableist society. When the environment does not support children's embodiments, mothers' advocacy cannot succeed, regardless of their access to cultural capital or financial resources. Like the wheelchair user outside the rampless building, mothers' individual efforts, alone, cannot restructure the architecture of school buildings and classroom norms. Fit can occur, however, when the environment, which includes social actors like teachers and administrators, changes to support the needs of disabled students.

A misfit lens identifies features of the systemic ableism, racism, and xenophobia, which mothers encounter, in the institutions of medicine and education. Prior studies have examined the way discriminatory actions of individuals, such as teachers and medical professionals, hamper culturally and linguistically diverse parents' advocacy (see, e.g., McHatton and Correa 2005; Angell and Solomon 2017). This dissertation, by using a misfits framework, adds to this knowledge by highlighting how institutional practices and policies, as well as discriminatory actions, shape both white and Latinx-immigrant mothers' disability-related experiences. Exclusion, based on any non-majority embodiment, whether typically understood as impairment or not, results when environments do not sustain or support the variety of human forms. The misfit analyses in this study aid the scholarly understanding of the similarities among different types of institutional discrimination.

An Intersectional Approach to Disablement

Experiences of disablement, and misfit, vary across social identities and categories. However, disability studies scholarship and theorizing has largely focused on the experiences of white disabled people and assumed them to be universal experiences of disability (Bell 2013; Miles, Nishida and Forber-Pratt 2017). In other words, disability studies has failed to "to engage issues of race and ethnicity in a substantive capacity, thereby entrenching whiteness as its constitutive underpinning" (Bell 2013: 275). By examining the lived experiences of both Latinx-immigrant and white U.S. born mothers of disabled children, this dissertation seeks to critically engage with race and ethnicity.

This dissertation identified similar experiences and perspectives among Latinx-immigrant and white mothers. For example, all mothers shared similar understandings of disability, which reflect the theorizing of disability studies scholars and the social model of disability. For both Latinx-immigrant and white mothers, negative interactions with medical professionals, access to a positive disability community and lived experience with their disabled children shape their critical disability definitions. Latinx-immigrant and white mothers also share common experiences navigating the special education system. Their disabled children misfit in educational environments that don't support the needs of children's non-majority embodiments. Mothers, then, misfit when they challenge expert recommendations. In essence, mothers deviate from social norms that expect disabled people (and their mothers) to accept, without argument, the decisions of experts.

However, this dissertation also examined how race, class, and immigration status shaped mothers' experiences. For instance, Latinx-immigrant mothers experienced unique forms of misfit when navigating education, medical, and public disability institutions on behalf of their disabled children. In such social institutions, environments perceived as "white spaces," Latinx-immigrant mothers' often misfit. Additionally, Latinx-immigrant mothers experienced misfit within the mainstream disability rights movement, an environment typically assumed to be inclusive. Within a parent advocacy organization, CFED, founded and run by white, middle-class mothers, Latinx-immigrant mothers misfit. CFED's environment, policies and actors did not support or sustain Latinx-immigrant mothers' embodied knowledge, needs, and experiences.

Latinx-immigrant mothers found fit in ADP, a Latinx-led parent advocacy group. ADP's environment centered Spanish-language usage and recognized mothers' racialized and immigrant embodiment. Thus, the interaction between Latinx-immigrant mothers' embodiment and ADP's environment was harmonious. This dissertation's analysis of Latinx-immigrant mother's misfit experiences within mainstream disability spaces provides empirical evidence to support the theorizing of disabled scholars of color and the activism of the disability justice movement (Bell 2013; Miles, Nishida and Forber-Pratt 2017). A misfits framework highlights similarities among different identity-based oppressions; for both Latinx-immigrant and white U.S. born mothers, as well as disabled people, misfit may occur when an environment doesn't support an individual's embodied needs.

A Revaluing of Disability

This study's examination of mothers' disability definitions suggests that some mothers have "revalued" their children's impairments in complicated ways. Earlier studies of parent perspectives on disability suggest that parents hold both social model and deficit model understandings of disability (see, e.g., Landsman 2005; Runswick-Cole 2008; Cologon 2016; Manago, Davis and Goar 2017). Prior scholarship interpreted parent's use of medical terminology or attempts to secure medical treatment for their children, as evidence of a deficit model perspective (Landsman 2005; Manago, Davis and Goar 2017). However, in this study, mothers shared more complex disability definitions that drew on the social model and recognized the embodied aspects of disability, which may necessitate medical intervention. In this dissertation, no mothers described disability through a deficit lens. Instead, mothers' new disability definitions contradict common sense and traditional understandings of disability. Mothers' disability definitions reflect a misfits framework, conceptualizing disability as the result of embodied difference and inaccessible social structures. These views on disability, that disability is simply human diversity, valuable, even, are key to helping disabled people "survive and flourish." Critical perspectives on disability claim space for disabled people to live and participate in society; they challenge cultural values that suggest disability should be eliminated through genetic testing, abortion, and sterilization. This study also identifies influences on that "revaluing" process, such as learning from disabled children and positive disability spaces. These influences may also help other non-disabled people develop social model perspectives.

The dissertation findings suggest that institutional actors and policies perpetuate the deficit model of disability. Professionals espouse deficit perspectives when interacting with parents, while educational policies maintain disabled students' segregation. This dissertation's in-depth examination of mothers' disability definitions treats disabled people, and their mothers, as knowledge holders whose views on disability should influence policy and scholarship. Typically, disabled people, especially individuals with mental impairments, are not seen as experts on their experiences (Biklen 1992; Linton 1998; Beratan 2012). Likewise, mothers of disabled children, who reject deficit views, are alternatively viewed as self-sacrificing or delusional (Landsman 2005; Blum 2007). By treating mothers' disability definitions as a proper focus of academic study, this dissertation values and bolsters mothers' subjugated knowledge.

In sum, this dissertation contributes to scholarly understanding of how mothers of children with disabilities experience disablement, adopt a disability rights perspective, and challenge traditional notions of disability as an individual familial tragedy. This study also examines mothers' disability advocacy experiences and the influence of race on these experiences. The dissertation develops a misfit framework, based on Garland-Thomson's critical concept, to contextualize mothers' experiences within institutional ableism. This research has practical implications, as discussed in the section on recommendations.

Limitations and Future Research

In this section, I point to some of the limitations of this project and avenues for future inquiry. A key limitation includes the small sample size, formed of mothers from only two racial groups living in a single state. Although I conducted interviews until I reached theoretical saturation, and no new themes emerged, this sample of 39 mothers does not allow for generalizability. Additionally, disability cultures and school practices vary widely between states; thus, these findings may not reflect the experiences of mothers in areas more closely connected to the disability rights movement, such as northern California and upstate New York. The racial demographics of the state where interviews and participant observation occurred are unique in the high percentage of white inhabitants. The state also has a history of anti-immigrant sentiment and exclusionary laws and policies. Latinx people constitute the largest non-white group in the state. Findings may, therefore, not reflect mothers' experiences in more racially diverse communities.

Future research should examine mothers' experiences in other geographic contexts, among a larger sample, and across more demographic categories, perhaps using a mixed-methods approach, in order to retain the nuance which in-depth interviews and participant observation allow. A natural progression of this work is to analyze whether mothers of disabled children develop more critical perspectives in other arenas of their lives, based on their experiences of misfit. A further study could assess how and if mothers of disabled children advance critical disability perspectives among their social networks. Future research might also use a misfits framework to analyze other experiences of disablement, outside the education and medical contexts and among other groups of people. In what other arenas does misfit help make sense of disabled people's experience? How might fathers, siblings, or friends of disabled people misfit? More research is needed to understand the dominance of segregated education for disabled students within the public education system. Why has special education law, intended to integrate disabled students, been relatively unsuccessful in changing this pattern of exclusion? What types of professional development or training might aid educators, medical providers, and others working in the disability field adopt social model perspectives? Finally, future research should explore the applicability of the misfit framework to other aspects of human difference and embodiment. How might other embodied characteristics lead to misfit in inaccessible social and material environments?

Recommendations

In this section, I discuss practical recommendations based on my research findings. Recommendations include additional training for disability professionals, fostering the development of more positive disability spaces, creating more accessible environments (for parents and their disabled children), and supporting inclusive education. These recommendations may help revalue particularities of embodiment considered disabilities and support the survival and flourishing of disabled people.

Train disability professionals

The first recommendation is that disability professionals, such as physicians, educators and social workers, receive more training on the social model of disability. As the dissertation findings confirm, the deficit model of disability colors diagnosis experiences. Mothers report that professionals describe disability in negative terms, either as an unalterable tragedy or something to be fixed, cured, or removed. For parents of disabled children, the diagnosis may be their first encounter with disability. The deficit views, expressed by trusted professionals, negatively shape parents' emotions and actions long after the actual diagnosis. Instead, the professionals charged with delivering diagnoses should be accompanied by disabled advocates, individuals living with the diagnosis or their parents or friends. Professionals' diagnosis scripts should also be reviewed and approved by disabled activists. Professionals' should be exposed to the social model of disability during their training, and certification should require professionals to spend time with and learn from disabled experts, themselves. Disabled people should help determine medical school curriculum, as well as teacher training programs and social worker preparation.

Foster positive disability spaces

A second recommendation involves the development of more positive disability spaces, such as disability rights trainings and conferences, where people learn about the social model of disability. Disabled people, and their mothers and allies, need spaces in which to discuss and make sense of their collective experiences. In this study, positive disability spaces were key in mothers' development of critical disability perspective; in positive disability spaces, mothers learn about the social model and find strength in community. Schools, hospitals, and social services should sponsor positive disability spaces, in which disabled people and their advocates lead meetings, determine topics, and guide the organization. While professionals should create and support these opportunities, disabled people and allies should lead them.

Create accessible environments

The environments in which mothers advocate and disabled children receive medical care, education, and other public services must be made more accessible. Access requires more than just ramps. An accessible environment includes readily available and understandable information, individualized supports, and interpreters and support workers. An accessible environment also calls for an inclusive, welcoming culture. When parents receive their child's diagnosis, in a hospital or school setting, professionals should provide easy to understand and complete information. This information should be approved or monitored by a committee of disabled advocates. If a parent needs assistance understanding the information, filling out forms, or locating services, an individual support worker should be provided. The burden should not be on parents to learn about public services. In part, this reflects a cultural assumption that disability benefits are unearned privileges or perks. Instead, disability benefits should be understood as necessary accommodations to allow disabled people to access institutions not designed with their needs in mind. Institutional cultures should welcome and value the participation of disabled people and their families.

Support inclusive education

Disabled students should receive their education in non-segregated classrooms and schools. When disabled students attend segregated classrooms, they do not gain the preparation necessary to live as adults in the community. The Individuals with Disabilities Education Act (IDEA) requires that disabled children attend class with non-disabled peers to "the maximum extent appropriate" (IDEA 1412(a)(5)(A) 2004). Disabled children may only be segregated when "the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily" (IDEA 1412(a)(5)(A) 2004). Unfortunately, courts and school districts have interpreted this provision to permit the widespread educational segregation of disabled students. In the future, the IDEA should be re-written to require the inclusion of disabled students in all cases, with exceptions only for safety. Currently, experts in the legal community fear that conservative justices would use any attempts to alter the IDEA to further limit the statute's effect. Thus, legal challenges should wait for a less hostile judicial environment.

Final Thoughts

This dissertation began after I met a courageous group of women, the mothers involved in ADP, Alianza de Padres. I was struck by their critical perspectives on disability, their anger at disability discrimination, and their drive to share their knowledge, help other mothers, and spread disability awareness. In listening to their stories, I realized that disability studies had largely ignored their, and their children's, experiences. The stories of people with impairments labelled intellectual, developmental, emotional or learning disabilities are missing from the literature. Within disability studies, most disabled scholars have physical impairments, themselves, and their lived experiences have come to represent all disability experiences. This makes sense, in a way, as most people come to disability studies or disability activism through a personal connection. Social structures, such as inaccessible education, standardized testing requirements, and lack of social accommodations, limit the possibilities for people with mental impairments to access higher education. Disability scholarship and activism must focus on creating fit for these individuals, the most marginalized disabled people - disabled people who, like these mothers' children, are excluded from mainstream educational spaces and from cultural constructions of personhood, deservingness, and belonging.

APPENDIX A

SAMPLE DEMOGRAPHIC CHARACTERISTICS

Table 1. Latinx Participants Demographic Characteristics

Name	**Country of Origin**	**Age**	**Marital Status**	**Class**	**Location**	**Child's Gender**	**Child's Age**	**Child's Disability Label**	**Group**
Isabel	Mexico	62	Divorced	Middle	Suburban	M	37	Autism	ADP
Olivia	Mexico	40	Partnered	Working	Rural	M	11	Down syndrome	ADP
Sofia	Mexico	38	Married	Working	Urban	M, M	14, 8	Autism, Autism	ADP
Jimena	Mexico	44	Married	Working	Rural	M	6	Prader-Willi syndrome	ADP
Mariana	Mexico	47	Married	Working	Suburban	M	13	Autism	ADP
Paula	Mexico	26	Divorced	Working	Suburban	M	6	Autism	ADP
Alejandra	Mexico	37	Married	Working	Urban	F	6	Epilepsy	ADP
Julia	Mexico	40	Separated	Working	Suburban	F	5	Down syndrome	ADP
Daniela	Mexico	29	Married	Working	Suburban	M, M	10, 5	Autism, Autism & Kidney Disease	ADP
Renata	Mexico	38	Divorced, Remarried	Working	Urban	M, F	19, 17	Learning Disability, Autism & Mental Illness	ADP
Camila	Mexico	26	Married	Working	Suburban	F	10	ADHD	ADP
Lucia	Mexico	51	Married	Working	Suburban	M	21	Developmental Delay	ADP
Clara	Chile	46	Divorced, Remarried	Middle	Urban	M	27	ADHD	CFED
Adriana	Chile	39	Married	Middle	Urban	F	13	Cowden syndrome & Autism	CFED

Table 1. (continued).

Name	**Country of Origin**	**Age**	**Marital Status**	**Class**	**Location**	**Child's Gender**	**Child's Age**	**Child's Disability Label**	**Group**
Elena	Mexico	37	Divorced, Remarried	Working	Urban	M, M	14, 11	Cerebral Palsy, Autism	CFED
Juana	Mexico	46	Divorced	Working	Urban	M	17	Autism	CFED
Valentina	Colombia	44	Married	Working	Suburban	M	5	Autism	None
Sara	Mexico	54	Divorced	Middle	Suburban	M, F	16, 16	ADHD, ADHD & Mental Illness	None

Table 2. White Participant Demographic Characteristics

Name	**Ethnicity**	**Age**	**Marital Status**	**Class**	**Location**	**Child's Gender**	**Child's Age**	**Child's Disability Label**	**Group**
Emily	White	31	Married	Middle	Urban	F	13	Wolf-Hirschhorn syndrome	CFED
Beth	White	40	Married	Middle	Urban	M	7	Autism	CFED
Deborah	White	50	Married	Middle	Urban	M	25	Down syndrome	CFED
Patricia	White	58	Married	Middle	Urban	M	26	TBI & Epilepsy	CFED
Linda	White	35	Married	Middle	Urban	M	16	Down syndrome	CFED
Susan	White	35	Married	Middle	Urban	M	9	Cerebral Palsy & Autism	CFED
Amanda	White	49	Married	Middle	Rural	M	13	Down syndrome	CFED
Allison	White	48	Married	Middle	Urban	M	14	Down syndrome	CFED
Sharon	White	49	Married	Middle	Urban	M	16	Down syndrome & Autism	CFED
Carolyn	White	38	Engaged	Middle	Suburban	M, F	13, 8	Autism, Autism	CFED
Lisa	White	48	Married	Middle	Urban	M	17	Autism	CFED
Nancy	White	60	Divorced	Middle	Urban	F	18	Down syndrome	CFED
Kate	White	36	Married	Middle	Suburban	M	9	Autism	CFED
Michelle	White	44	Partnered	Middle	Suburban	M	4	Down syndrome	CFED
Helen	White	42	Separated	Working	Urban	M	19	Autism	CFED
Sandra	White	51	Married	Middle	Urban	F	21	Intellectual Disability	CFED
Amy	White	42	Married	Middle	Suburban	F	6	PTSD	None
Rebecca	White	60	Partnered	Working	Suburban	F, M, M, M	43, 37, 9, 8	ADHD, LD, ADHD, RAD	None
Ashley	White	40	Married	Middle	Suburban	F	7	ADHD & Neurofibromatosis	None

Table 2. (continued).

Name	**Ethnicity**	**Age**	**Marital Status**	**Class**	**Location**	**Child's Gender**	**Child's Age**	**Child's Disability Label**	**Group**
Laura	White	53	Married	Middle	Suburban	F, M, M, F	22, 20, 17, 15	Autism, Autism, Autism, OCD	None
Angela	White	38	Never Married	Middle	Suburban	M	11	ADHD & Autism & ED	None

APPENDIX B

INTERVIEW PROTOCOL

In each section, English-language questions are followed by Spanish-language questions.

Background

- Tell me a little about yourself. Where did you grow up?
- How old are you?
- How long have you lived here?
- Tell me who lives in the household. [get details on household composition, marital status, number of children, ages of children]
- What is your educational level?
- Are you currently employed? If employed currently–tell me about your current job. Is it full time? Are you your child's primary caregiver? Who helps you with their care?

Fondo/Datos Personales

- Cuéntame un poco de ti. ¿De donde eres? ¿Cuantos años tienes? ¿Como te describes?
- ¿Como llegaste a Oregón? ¿Por cuanto tiempo has estado aquí?
- ¿Con quien vives en tu casa? (Detalles sobre la composición del hogar, el estado civil, el número de hijos y las edades de los niños)
- ¿Cuál es su nivel de estudios?
- ¿Tienes trabajo? ¿Trabajas fuera de la casa? ¿Tu trabajo es de jornada completa?
- ¿Quien se encarga principalmente del cuidado de tus hijos? ¿De tu hijo con una discapacidad? ¿Quien te ayuda con su cuidado?

Children

- Tell me about your children. What grades are they in? What are their interests? How are they each doing now? [this is intended to be a warmup question] Do any of your children besides [name of child with illness/disability] have any problems you would consider serious? If so, tell me about that.
- When did you first become aware of [child's name] illness/disability? How did that happen?
- Tell me about your child's condition. (e.g. problems and strengths)

Niños

- Cuéntame de tus hijos. ¿En cual grado escolar están? ¿Cuales son sus intereses/hobbies? ¿Como están? ¿Además de tu hijo con una discapacidad, otro de tus hijos tiene algún problema que te parece serio? (¿Puedes contar me sobre ese problema?)
- ¿Cuándo te diste cuenta de que tu hijo tenia problemas/una discapacidad? ¿Como pasó?
- Cuéntame de la discapacidad de tu hijo. (Problemas y fuerzas)

Diagnosis

- When was your child diagnosed?
    - How old were they? What events led up to the diagnosis?
    - Can you recall what the doctor told you?
- What was your initial reaction?
- What did you do right afterward?
- What was the experience like?
- How did family/friends/you/siblings react?
- Did you have experience with disability before?

Diagnóstico

- ¿Cuándo le diagnostico a su hijo?
    - ¿Cuantos años tenía? ¿Cuales eventos condujeron al diagnostico?
    - ¿Recuerdas lo que te dijo el medico?
- ¿Cual fue tu primera reacción?
- ¿Que hiciste justo después del diagnostico?
- ¿En tus palabras, como fue esa experiencia?
- ¿Como reaccionaron tu familia/amigos/los hermanos de tu hijo?
- ¿Conocía a personas con discapacidades antes?

Services

- What did you do when you first became aware of your child’s condition? Where did you seek help?
- What support services do they receive?
- Is your child receiving, or has he/she received in the past, any of the following services? If so, where and when?

Services	Place of Treatment (home or center-based)
_____Occupational Therapy	______________________________
_____Physical Therapy	______________________________
_____Speech Therapy	______________________________
_____Social Worker	_____________________________
_____Early Head Start	______________________________
_____Head Start	______________________________
_____PreK Handicapped	______________________________
_____Hospital Specialist	______________________________
_____Neurologist	______________________________
_____Psychologist	______________________________
_____Ophthalmologist	______________________________
_____UCP (United Cerebral Palsy)	______________________________
_____Other	______________________________

- Have you had any problems getting services? Can you give me examples?
- How often does your child have appointments?

- How do you keep track of everything?

Servicios

- ¿Que hiciste después de saber que tu hijo tenia una discapacidad? ¿En donde buscaste ayuda o apoyo?
- ¿Que servicios de apoyo recibe tu hijo?
- ¿Recibe tu hijo alguno de los siguientes servicios?
- Si recibe servicios, ¿en que lugar y cuando?

Servicios	Lugar (En casa o hospital/oficina)
_____Terapia ocupacional	______________________________
_____Fisioterapia	______________________________
_____Terapia del lenguaje	______________________________
_____Asistente social	_____________________________
_____Early Head Start	______________________________
_____Head Start	______________________________
_____Educación Especial	______________________________
_____Especialistas medicos	______________________________
_____Neurólogo	______________________________
_____Psicólogo	______________________________
_____Oftalmólogo	______________________________
_____Otro	______________________________

- ¿Ha habido problemas en cuanto a obtener estos servicios? Puedes dar ejemplos?
- ¿Con que frecuencia tiene tu hijo citas medicas o otras citas para su discapacidad?
- ¿Como te organizas en cuanto a las citas, los servicios, la educación de tu hijo?

Education

- Can you tell me about your child’s experiences in school? (favorites classes, friends, teachers, problems)
- What grade are they in? When did they start special education? What services do they receive at school?
- Let’s dive into some of the challenges you’ve faced when dealing with schools. What conflicts have you experienced with regards to your child’s education? or What are your concerns regarding your child’s education?

Educación

- Puedes contarme de las experiencias de tu hijo en la escuela? (Clases favoritos, amigos, maestros, problemas)
- ¿En que grado esta? ¿Cuándo empezaron con la educación especial? ¿Que servicios recibe en la escuela?
- ¿Cuales conflictos has tenido con respeto a la educación de tu hijo? ¿Cuales son tus preocupaciones en cuanto a su educación?

IEP/IFSP Meetings

- What was your first experience at an IEP meeting like?
- Did you know what an IEP was before your child entered special education?
- How did you learn what it was?
- Can you tell me about the most recent IEP meeting?
- Are you happy with the current IEP?
- How do you prepare for IEP meetings? Do you?

Reuniones de IEP/IFSP

- Puedes describir su primera reunión de IEP (o IFSP)? ¿Como fue?
- ¿Sabias lo que fue un IEP antes de que su hijo empezaste con la educación especial? ¿Como aprendiste sobre lo que significaba?
- ¿Puedes contarme de la reunión mas reciente?
- ¿Estas contento con la IEP actual de tu hijo?
- ¿Como te preparas para las reuniones?

Language

- Do you use a translator to interact with the school?
- Have you had translators present at all IEP meetings? Do you feel like the translator adequately represents your words?
- Are there Spanish versions of the forms/paperwork from the school? Have you ever had difficulty obtaining paperwork in Spanish?

Idioma

- ¿Trabajas con un interprete en las reuniones con la escuela?
- ¿Han estado interpretes en todas las reuniones? ¿Crees que la interprete te representa de modo adecuado?
- ¿Los papeles/documentos que recibes de la escuela están traducidos al español? ¿Has tenido algún problema en obtener documentos en español?

Group Advocacy

- How and when did you learn about ADP/CFED?
- How often do you attend meetings? Why do you go to the meetings?
- Why did you first go to a meeting?
- What have you learned from ADP/CFED?
- Has your experience with special education changed after being part of ADP/CFED (advocacy group)? How?
- Who do you go to meetings with? (Alone, friends, partner, advocate) Do you see other parents outside the meetings?

Abogacía

- ¿Como y cuando aprendiste sobre ADP/CFED?
- ¿Con que frecuencias asistes a las reuniones?
- ¿Por que participas en el grupo?
- ¿Por que fuiste a su primera reunión?

- ¿Que has aprendido del grupo?
- ¿Han cambiado sus experiencias con la educación de su hijo después de hacerte parte del grupo? ¿Como?
- ¿Con quien vas a las reuniones? ¿Ves a otros miembros fuera de las reuniones?

Legal Consciousness

- Do you know what law makes schools create IEPs?
- Can you tell me some of the rights that the law gives you with respect to your child's education? How did you learn about these rights?
- Have you been represented by a lawyer or advocate other than Susana in these meetings?
- If you couldn't reach an agreement with the school about your child's education, would you bring a lawsuit/what would you do? Why or why not?
- Have you worked with a lawyer in another aspect of your life? (Other encounters with the legal system)

Conocimiento Legal

- Sabes cual ley regula la educación de tu hijo?
- ¿En tus propias palabras, cuales derechos tiene tu hijo en cuanto a la educación? ¿Como aprendiste de estos derechos?
- ¿Has trabajo con un abogado en las reuniones de tu hijo?
- ¿Si no podías llegar a un acuerdo con la escuela, presentarías una demanda?
- ¿Has trabajo con un abogado en otro aspecto de tu vida? ¿Has tenido encuentros con el sistema legal antes?

Disability Identity

- How does your child's disability influence daily life? Can you describe a typical day for me?
- Has having a child with a disability changed you? How has having a child with a disability changed your life? Can you give me some examples?
- What does having a disability mean to you?

Discapacidad

- ¿Como afecta a la vida cotidiana la discapacidad de tu hijo? ¿Puedes describir a un día típico?
- ¿Como te has cambiado al tener a un hijo con una discapacidad? ¿Como ha cambiado su vida? ¿Puedes dar ejemplos?
- En tus palabras, ¿que significa tener una discapacidad?

Ethnicity

- Do you think that being Latino has changed your interactions with special education providers?
- Do you think that being Latino has changed your child's educational experiences?
- Can you give me some examples?

Etnia/Ser Latinx

- ¿Creas que ser latino ha cambiado sus interacciones con la escuela?
- ¿Creas que ser latino ha cambiado las experiencias educacionales de tu hijo?
- ¿Puedes dar ejemplos?

Future/Recommendations

- Do you have any suggestions for improving your experiences with the special education system?
- What would an ideal educational plan look like for your child?
- What are your hopes for your child's future?
- Has having a child with a disability brought any benefits to your life?
- What advice would you give to new parents of kids with disabilities? To special education teachers? To school administrators?

Futuro/Recomendaciones

- ¿Que sugerencias tienes para mejorar el sistema de educación especial?
- ¿Como será el ideal plan educacional para tu hijo?
- ¿Cuales son tus esperanzas para el futuro de tu hijo?
- Normalmente, hablamos de los problemas y dificultades en cuanto a tener a un hijo con una discapacidad. ¿Cuales beneficios ha llegado a tu vida por tener a un hijo con una discapacidad?
- ¿Que consejos darás a nuevos padres de niños con discapacidades, a maestros, a administradores educacionales?

REFERENCES CITED

Alba, Richard, Glenn Deane, Nancy Denton, Ilir Disha, Brian McKenzie, and Jeffrey Napierala. 2014. "The Role of Immigrant Enclaves for Latino Residential Inequalities." *Journal of Ethnic and Migration Studies* 40(1): 1-20.

American Civil Liberties Union. 2017. *Caged In: Solitary Confinement's Devastating Harm*. 1–85.

“An Annual Report to the Legislature on Oregon Public Schools.” Oregon Department of Education. 2019. Retrieved June 2020. (https://www.oregon.gov/ode/schools-and-districts/reportcards/Documents/rptcard2019.pdf).

Anderson, Elijah. 2015. "The White Space." *Sociology of race and ethnicity* 1(1): 10-21.

Angell, Amber M., and Olga Solomon. 2017. "'If I was a different ethnicity, would she treat me the same?': Latino parents' experiences obtaining autism services." *Disability & Society* 32(8): 1142-1164.

Annamma, Subini Ancy, David Connor, and Beth Ferri. 2013. "Dis/ability critical race studies (DisCrit): theorizing at the intersections of race and dis/ability." *Race Ethnicity and Education* 16(1): 1-31.

Annamma, Subini Ancy, Beth A. Ferri, and David J. Connor. 2018. "Disability Critical Race Theory: Exploring the Intersectional Lineage, Emergence, and Potential Futures of DisCrit in Education." *Review of research in education* 42(1): 46-71.

Bacon, Jessica K., and Julie Causton-Theoharis. 2013. "'It should be teamwork': a critical investigation of school practices and parent advocacy in special education." *International Journal of Inclusive Education* 17(7): 682-699.

Baker, Bruce L., Jan Blacher, Keith A. Crnic, and Craig Edelbrock. 2002. "Behavior problems and parenting stress in families of three-year-old children with and without developmental delays." *American Journal on Mental Retardation* 107 (6): 433-444.

Baker, Bruce L., L. L. McIntyre, Jan Blacher, Keith Crnic, Craig Edelbrock, and C. Low. 2003. "Pre-school children with and without developmental delay: behaviour problems and parenting stress over time." *Journal of intellectual disability research* 47(4-5): 217-230.

Banks, Joy. 2017. ""These People Are Never Going to Stop Labeling Me": Educational Experiences of African American Male Students Labeled with Learning Disabilities." *Equity & Excellence in Education* 50(1): 96-107.

Barton, Len. 1986. "The politics of special educational needs." *Disability, Handicap & Society* 1 (3): 273-290.

Baynton, Douglas. 2001. “Disability and the Justification of Inequality in American History.” *The New Disability History: American Perspectives*. Ed. Paul K. Longmore and Lauri Umansky. New York UP.

Becker, Howard. 2001. The Epistemology of Qualitative Research. In *Contemporary Field Research: Perspectives and Formulations*, ed. Robert Emerson, 317-330. Wavleand Press, Inc.

Bell, Christopher. 2011. ed. *Blackness and Disability: Critical Examinations and Cultural Interventions*. Michigan State University Press.

Bell, Christopher. 2013. “Is Disability Studies Actually White Disability Studies?” In *The Disability Studies Reader*, edited by Davis Lennard. Routledge.

Ben-Moshe, Liat. 2013. "Disabling Incarceration: Connecting Disability to Divergent Confinements in the USA." *Critical Sociology* 39(3): 385-403.

Beratan, Gregg D. 2006. "Institutionalizing Inequity: Ableism, Racism and IDEA 2004." *Disability studies quarterly* 26(2).

Beratan, Gregg. 2012. "Institutional Ableism & the Politics of Inclusive Education: an Ethnographic Study of an Inclusive High School." Doctor of Philosophy, Institute of Education, University of London.

Biklen, Douglas. 1992. *Schooling without labels: parents, educators, and inclusive education*. Temple University Press.

Blacher, Jan, and Laura Lee McIntyre. 2006. "Syndrome specificity and behavioural disorders in young adults with intellectual disability: Cultural differences in family impact." *Journal of Intellectual Disability Research* 50 (3): 184-198.

Blum, Linda M. 2007. "Mother-blame in the Prozac nation: rising kids with invisible disabilities." *Gender & society* 21(2): 202.

Blum, Linda M. 2015. *Raising generation Rx: Mothering kids with invisible disabilities in an age of inequality*. New York University Press.

Brandon, Peter. 2007. "Time away from “smelling the roses”: Where do mothers raising children with disabilities find the time to work?." *Social Science & Medicine* 65 (4): 667-679.

Bronson, Jennifer, Laura M. Maruschak, and Marcus Berzofsky. 2015. “Disabilities Among Prison And Jail Inmates, 2011-12.” *Bureau of Justice Statistics*.

Budiman, Abby, Christine Tamir, Lauren Mora, and Luis Noe-Bustamente. 2020. “Facts on U.S. immigrants, 2018: Statistical portrait of the foreign-born population in the United States.” *Pew Research Center*.

Burke, Meghan M., and Samantha E. Goldman. 2018. "Special education advocacy among culturally and linguistically diverse families." *Journal of Research in Special Educational Needs* 18: 3-14.

Burke, Meghan M., and Robert M. Hodapp. 2014. "Relating Stress of Mothers of Children With Developmental Disabilities to Family–School Partnerships." *Intellectual and developmental disabilities* 52(1): 13-23.

Carey, Allison C., Pamela Block, and Richard K. Scotch. 2019. "Sometimes Allies: Parent-Led Disability Organizations and Social Movements." *Disability studies quarterly* 39(1).

Charmaz, Kathy. 2006. *Constructing grounded theory: a practical guide through qualitative analysis*. Sage Publications.

Cobb, Cam. 2014. "Critical Entanglement: Research on Culturally and Linguistically Diverse Parental Involvement in Special Education 2000-2010." *Exceptionality Education International* 23(1): 40.

Colker, Ruth. 2015. "Blaming Mothers: A Disability Perspective.” *Boston University Law Review* 95(3): 1205-1224.

Colker, Ruth. 2013. *Disabled education: A critical analysis of the Individuals with Disabilities Education Act*. New York University Press.

Cologon, Kathy. 2016. ""What is disability? It depends whose shoes you are wearing": Parent understandings of the concept of disability." *Disability studies quarterly* 36(1).

Dávila, Brianne. 2015. "Critical race theory, disability microaggressions and Latina/o student experiences in special education." *Race Ethnicity and Education* 18(4): 443-468.

Davis, John M., and Nick Watson. 2001. "Where Are the Children's Experiences? Analysing Social and Cultural Exclusion in 'Special' and 'Mainstream' Schools." *Disability & Society* 16(5): 671-687.

Davis, Lennard J. 2000. “Bending Over Backwards: Disability, Narcissism, and the Law.” *Berkeley Journal of Employment & Labor Law*, 21-193.

Davis, Lennard J. 2002. *Bending over backwards: disability, dismodernism, and other difficult positions*. New York University Press.

Davis, Lennard J. 2013. *The Disability Studies Reader*. Routledge.

Defur, Sharon H., Mary Todd-Allen, and Elizabeth E. Getzel. 2016. "Parent Participation in the Transition Planning Process." *Career development for exceptional individuals* 24(1): 19-36.

Dorfman, Doron. 2019. "Fear of the Disability Con: Perceptions of Fraud and Special Rights Discourse." *Law & Society Review* 53(4): 1051-1091.

Dyson, Lily L. 1996. "The Experiences of Families of Children with Learning Disabilities: Parental Stress, Family Functioning, and Sibling Self-Concept." *Journal of Learning Disabilities* 29(3): 280-286.

Earl, Dave. 2011. "'A Group of Parents Came Together': Parent Advocacy Groups for Children with Intellectual Disabilities in Post—World War II Australia." *Health and history* 13(2): 84-103.

Eatman, Megan E. 2020. "Unsettling Vision: Seeing and Feeling With Machines." *Computers and composition* 57: 102580.

Eisenhower, Abbey S., Bruce. L. Baker, and Jan Blacher. 2005. "Preschool children with intellectual disability: syndrome specificity, behaviour problems, and maternal well-being." *Journal of intellectual disability research* 49(9): 657-671.

Emerson, Robert, ed. 2001. *Contemporary Field Research: Perspectives and Formulations*. Wavleand Press, Inc.

Engel, David M., and Frank W. Munger. 2003. *Rights of inclusion: law and identity in the life stories of Americans with disabilities*. University of Chicago Press.

Erevelles, Nirmala. 2011. *Disability and difference in global contexts: enabling a transformative body politic*. Palgrave Macmillan.

Erickson, W., Lee, C., & von Schrader, S. 2018. *2016 Disability Status Report: United States*. Ithaca, NY: Cornell University Yang-Tan Institute on Employment and Disability(YTI).

Erickson, W., Lee, C., & von Schrader, S. 2020. *2018 Disability Status Report: United States*. Ithaca, NY: Cornell University Yang-Tan Institute on Employment and Disability(YTI).

Evans, Heather Dawn. 2017. "Un/covering: Making Disability Identity Legible." *Disability studies quarterly* 37(1).

Ferguson, Philip M. 2001. "Mapping the family: Disability Studies and the Exploration of Parental Response to Disability." In *Handbook of disability studies* edited by Gary L. Albrecht, Katherine D. Seelman, and Michael Bury, 373-395.

Finders, Margaret, and Cynthia Lewis. 1994. "Why Some Parents Don't Come to School." *Kaleidoscope: Contemporary and Classic Readings in Education* 106: 50-54.

Finkelstein, Vic. 1981. "Disability and the helper/helped relationship. An historical view." In *Handicap in a social world: A reader*, edited by Ann Brechin, Penny Liddiard and John Swain. Hodder and Stoughton.

Garland-Thomson, Rosemarie. 2005. "Feminist Disability Studies." *Signs: Journal of Women in Culture and Society* 30(2): 1557-1587.

Garland-Thomson, Rosemarie. 2009. *Staring: how we look*. Oxford University Press.

Garland-Thomson, Rosemarie. 2011. "Misfits: A Feminist Materialist Disability Concept." *Hypatia* 26(3): 591-609.

Garland-Thomson, Rosemarie. 2014. "The Story of My Work: How I Became Disabled." *Disability studies quarterly* 34(2).

Garland-Thomson, Rosemarie. 2017. *Extraordinary bodies: figuring physical disability in American culture and literature*. Twentieth anniversary ed. Columbia University Press.

Geenen, Sarah, Laurie E. Powers, and Alfonso Lopez-Vasquez. 2005. "Barriers Against and Strategies for Promoting the Involvement of Culturally Diverse Parents in School-Based Transition Planning." *The Journal for Vocational Special Needs Education* 27(3): 4-14.

Gerstein, E. D., K. A. Crnic, J. Blacher, and B. L. Baker. 2009. "Resilience and the course of daily parenting stress in families of young children with intellectual disabilities." *Journal of intellectual disability research* 53(12): 981-997.

Glaser, Barney G. and Anselm L. Strauss. 1967. *The Discovery of Grounded Theory: Strategies for Qualitative Research.* Hawthorne, NY: Aldine de Gruyter.

Gleeson, Brendan. 1998. *Geographies of Disability*. Routledge.

Goffman, Erving. 1986. *Stigma: notes on the management of spoiled identity*. First Touchstone edition. Simon & Schuster Inc.

Golash-Boza, Tanya. 2006. "Dropping the Hyphen? Becoming Latino(a)-American through Racialized Assimilation." *Social forces* 85(1): 27-55.

Golash-Boza, Tanya, and William Darity. 2008. "Latino racial choices: the effects of skin colour and discrimination on Latinos' and Latinas' racial self-identifications." *Ethnic and racial studies* 31(5): 899-934.

Green, Sara E. 2003. "“What do you mean ‘what's wrong with her?’”: stigma and the lives of families of children with disabilities." *Social science & medicine* 57(8): 1361-1374.

Green, Sara Eleanor. 2007. "“We're tired, not sad”: Benefits and burdens of mothering a child with a disability." *Social science & medicine* 64(1): 150-163.

Gupta, Vidya Bhushan. 2007. "Comparison of Parenting Stress in Different Developmental Disabilities." *Journal of developmental and physical disabilities* 19(4): 417-425.

Hahn, Harlan. 1983. "Paternalism and public policy." *Society* 20(3): 36-46.

Haller, Beth A. 2010. *Representing disability in an ableist world: essays on mass media*. The Avocado Press.

Harrison, Jill Ann. 2012. *Buoyancy on the bayou: shrimpers face the rising tide of globalization*. Cornell University Press.

Harry, Beth. 2008. "Collaboration with Culturally and Linguistically Diverse Families: Ideal versus Reality." *Exceptional children* 74(3): 372-388.

Harry, Beth, and Janette Klinger. 2014. *Why Are so Many Minority Students in Special Education? Understanding Race & Disability in Schools. Second Edition*. Teachers College Press.

Heumann, Judith. 2020. Being Heumann: An Unrepentant Memoir of a Disability Rights Activist. Beacon Press.

Heyl, Barbara Sherman. 2001. Ethnographic Interviewing, In *Handbook of Ethnography,* ed. Atkinson, Paul, 369-383. London: Sage Publications Ltd.

Hoffman, Charles D., Dwight P. Sweeney, Danelle Hodge, Muriel C. Lopez-Wagner, and Lisa Looney. 2009. "Parenting Stress and Closeness: Mothers of Typically Developing Children and Mothers of Children With Autism." *Focus on Autism and Other Developmental Disabilities* 24(3): 178-187.

Hogan, Denis P. 2012. *Family consequences of children's disabilities*. Russell Sage Foundation.

Hughes, Bill. 2005. "What can a Foucauldian analysis contribute to disability theory." In *Foucault and the Government of Disability*, edited by Shelley Tremain, 78-92. University of Michigan Press.

Hughes, Bill, and Kevin Paterson. 1997. "The Social Model of Disability and the Disappearing Body: Towards a sociology of impairment." *Disability & society* 12(3): 325-340.

Iland, Emily D., Ivor Weiner, and Wendy W. Murawski. 2012. "Obstacles faced by Latina mothers of children with autism." *Californian Journal of Health Promotion* 10.SI-Latino: 25-36.

Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004).

Individuals with Disabilities Education Act. "About IDEA." Retrieved April 20, 2019 (Resites.ed.gov/idea/about-idea/).

Jarman, Michelle. 2011. "Coming Up from Underground: Uneasy Dialogues at the Intersections of Race, Mental Illness, and Disability Studies." In *Blackness and Disability*, edited by Christopher M. Bell. Michigan State University Press.

Johnson, Harriet McBryde. 2003. "Unspeakable conversations or how I spent one day as a token cripple at Princeton University." *New York Times* 16: 50-5.

Kafer, Alison. 2013. *Feminist, Queer, Crip*. Indiana University Press.

Kao, Grace, and Marta Tienda. 1998. "Educational Aspirations of Minority Youth." *American journal of education* 106 (3):349-384.

Kibria, Nazli, and Walter Suarez Becerra. 2020. "Deserving Immigrants and Good Advocate Mothers: Immigrant Mothers' Negotiations of Special Education Systems for Children with Disabilities." *Social problems*.

Kim, Kyeong-Hwa, and Mary E. Morningstar. 2005. "Transition Planning Involving Culturally and Linguistically Diverse Families." *Career development for exceptional individuals* 28(2): 92-103.

Koncul, Ana, and Jenny Slatman. 2019. "Rehab/ituation from a Phenomenological Perspective: The Case of Fencing for the Blind and Visually Impaired." *Scandinavian journal of disability research* 21(1): 67-77.

Krainz, Thomas. 2013. "Becoming Educated: The Fight for Free and Appropriate Education by Parents of Children with Mental Retardation during the Post–World War II Decades." *Disability studies quarterly* 33(3).

Lalvani, Priya. 2015. "Disability, Stigma and Otherness: Perspectives of Parents and Teachers." *International journal of disability, development, and education* 62(4): 379-393.

Lamont-Robinson, Catherine, Val Williams, and Trevor Thompson. 2018. "Pitching Perspectives on Disability: Voyage Experiences of Disabled Sailors on Tall Ships." *Scandinavian journal of disability research* 20(1): 102-110.

Landsman, Gail H. 1998. "Reconstructing Motherhood in the Age of "Perfect" Babies: Mothers of Infants and Toddlers with Disabilities." *Signs: Journal of Women in Culture and Society* 24(1): 69-99.

Landsman, Gail. 2005. "Mothers and Models of Disability." *Journal of Medical Humanities* 26(2): 121-139.

Lareau, Annette, and Elliot B. Weininger. 2003. "Cultural capital in educational research: A critical assessment." *Theory and society* 32(5/6): 567-606.

Leiter, Valerie. 2004. "Parental Activism, Professional Dominance, and Early Childhood Disability." *Disability studies quarterly* 24(2).

Lewiecki-Wilson, Cynthia. 2003. “Rethinking Rhetoric through Mental Disabilities.” *Rhetoric Review* 22 (2): 156–167.

Lewis, Bradley. 2010. *Moving beyond Prozac, DSM, and the new psychiatry: The birth of postpsychiatry*. University of Michigan Press.

Linton, Simi. 1998. *Claiming disability: knowledge and identity*. New York University Press.

Lo, Lusa. 2008. "Chinese Families' Level of Participation and Experiences in IEP Meetings." *Preventing school failure* 53(1): 21-27.

Longmore, Paul, K. 2005. "The Cultural Framing of Disability: Telethons as a Case Study." *PMLA: Publications of the Modern Language Association of America* 120(2): 502-508.

Lopez, Vicki, Tessen Clifford, Patricia Minnes, and Hélène Ouellette-Kuntz. 2008. "Parental stress and coping in families of children with and without developmental delays." *Journal on Developmental Disabilities* 14 (2): 99.

MacLeod, Jay. 2018. *Ain't No Makin' It: Aspirations and Attainment in a Low-Income Neighborhood, Third Edition*: Taylor and Francis.

Magaña, Sandra, and Matthew J. Smith. 2006. "Psychological distress and well–being of Latina and non–Latina white mothers of youth and adults with an autism spectrum disorder: Cultural attitudes towards coresidence status." *American Journal of Orthopsychiatry* 76 (3): 346-357.

Manago, Bianca, Jenny L. Davis, and Carla Goar. 2017. "Discourse in Action: Parents' use of medical and social models to resist disability stigma." *Social science & medicine* 184: 169-177.

Mandell, David S., Lisa D. Wiggins, Laura Arnstein Carpenter, Julie Daniels, Carolyn DiGuiseppi, Maureen S. Durkin, Ellen Giarelli, Michael J. Morrier, Joyce S. Nicholas, Jennifer A. Pinto-Martin, Paul T. Shattuck, Kathleen C. Thomas, Marshalyn Yeargin-Allsopp, and Russell S. Kirby. 2009. "Racial/Ethnic Disparities in the Identification of Children With Autism Spectrum Disorders." *American journal of public health* 99(3): 493-498.

McHatton, Patricia Alvarez, and Vivian Correa. 2005. "Stigma and Discrimination: Perspectives From Mexican and Puerto Rican Mothers of Children With Special Needs." *Topics in Early Childhood Special Education* 25(3): 131-142.

McHatton, Patricia Alvarez. 2007. "Listening and learning from Mexican and Puerto Rican single mothers of children with disabilities." *Teacher Education and Special Education* 30.4: 237-248.

Merchant, Wendy, Stuart Read, Stephen D'Evelyn, Caroline Miles, and Val Williams. 2020. "The insider view: tackling disabling practices in higher education institutions." *Higher education* 80(2): 273-287.

Mitchell, David, and Sharon Snyder. 2003. "The Eugenic Atlantic: race, disability, and the making of an international Eugenic Science, 1800-1945." *Disability & Society* 18(7): 843-864.

Miles, Angel L., Akemi Nishida, and Anjali J. Forber-Pratt. 2017. "An open letter to White disability studies and ableist institutions of higher education." *Disability Studies Quarterly* 37 (3).

Morris, Jenny. 1991. *Pride against prejudice: a personal politics of disability*. London: Women's Press.

Morrison, Carey-Ann, Esther Woodbury, Lynda Johnston, and Robyn Longhurst. 2020. "Disabled people's embodied and emotional geographies of (not)belonging in Aotearoa New Zealand." *Health & Place* 62: 102283.

Murphy, Robert F. 2001. *The body silent*. WW Norton & Company.

Nishida, Akemi. 2016. "Understanding political development through an intersectionality framework: Life stories of disability activists." *Disability studies quarterly* 36(2).

O'Brien, Ruth. 2001. *Crippled justice: the history of modern disability policy in the workplace*. The University of Chicago Press.

O'Connor, Carla, and Fernandez Sonia DeLuca. 2006. "Race, Class, and Disproportionality: Reevaluating the Relationship between Poverty and Special Education Placement." *Educational researcher* 35(6): 6-11.

Oliver, Michael. 1990. *The politics of disablement: a sociological approach*. St. Martin's Press.

Ong-Dean, Colin. 2009. *Distinguishing disability: Parents, privilege, and special education*. University of Chicago Press.

"Oregon Secretary of State." *State of Oregon: Blue Book - Public Education*. Retrieved June 20, 2020 (sos.oregon.gov/blue-book/Pages/education-public.aspx.)

Ortiz, Vilma, and Edward Telles. 2012. "Racial Identity and Racial Treatment of Mexican Americans." *Race and Social Problems* 4(1): 41-56.

OToole, Corbett. 2013. "Disclosing Our Relationships to Disabilities: An Invitation for Disability Studies Scholars." *Disability studies quarterly* 33(2).

Panitch, Melanie. 2008. *Disability, mothers, and organization: Accidental activists*. Routledge.

Parmenter, Trevor R. 2001. "Intellectual Disabilities - Quo Vadis?" In *Handbook of Disability Studies*, edited by Gary L. Albrecht, Katherine D. Seelman and Michael Bury, 267-296. Sage Publications.

Parrish, Thomas. 2002. "Racial disparities in the identification, funding, and provision of special education." In *Racial inequity in special education*, edited by Daniel J. Losen & Gary Orfield, 15-37. Harvard Education Press.

Price, Margaret. 2011. *Mad at school: Rhetorics of mental disability and academic life*. University of Michigan Press.

Radford, John P. "Intellectual Disability and the Heritage of Modernity." In *Disability Is Not Measles: New research paradigms in disability*, edited by Marcia Rioux and Michael Bach, 9-27. Roeher Institute.

Reid, D. Kim, and Michelle G. Knight. 2006. "Disability Justifies Exclusion of Minority Students: A Critical History Grounded in Disability Studies." *Educational researcher* 35(6): 18-23.

Reyes-Blanes, Maria E., Vivian I. Correa, and Donald B. Bailey Jr. 1999. "Perceived needs of and support for Puerto Rican mothers of young children with disabilities." *Topics in Early Childhood Special Education* 19 (1): 54-63.

Rossetti, Zach, Amanda Redash, Janet S. Sauer, Oanh Bui, Yuewu Wen and Debra Regensburger. 2018. “Access, Accountability, and Advocacy: Culturally and Linguistically Diverse Families’ Participation in IEP Meetings.” *Exceptionality.*

Rubin, Gayle. 2011. *Deviations: a Gayle Rubin reader*. Duke University Press.

Runswick-Cole, Katherine. 2008. "Between a rock and a hard place: parents' attitudes to the inclusion of children with special educational needs in mainstream and special schools." *British Journal of Special Education* 35(3): 173-180.

Russell, Marta, and Jean Stewart. 2001. "Disablement, prison, and historical segregation." *Monthly Review – An Independent Socialist Magazine* 53(3): 61-75.

Russell, Marta, and Ravi Malhotra. 2002. "Capitalism and Disability." *Socialist Register* 38.

Ryan, Sara, and Katherine Runswick-Cole. 2009. "From Advocate to Activist? Mapping the Experiences of Mothers of Children on the Autism Spectrum." *Journal of Applied Research in Intellectual Disabilities* 22(1): 43-53.

Ryan, Sara, and Katherine Runswick-Cole. 2008. "Repositioning mothers: mothers, disabled children and disability studies." *Disability & Society* 23(3): 199-210.

Sanchez, Lorna Luz. 2006. Barriers to diagnosis and treatment services faced by Latino parents of children with autism: Understanding the needs of Latino families. Unpublished doctoral dissertation. The Chicago School of Professional Psychology.

Santos, Ana Cristina, and Ana Lúcia Santos. 2017. "Yes, we fuck! Challenging the misfit sexual body through disabled women’s narratives." *Sexualities* 21(3): 303-318.

Schweik, Susan. 2009. *The Ugly Laws: Disability in Public*. NYU Press.

Scott, Ellen K. 2010. “‘I Feel as If I Am the One Who Is Disabled’: The Emotional Impact of Changed Employment Trajectories of Mothers Caring for Children with Disabilities*.” Gender & Society* 24 (5): 672–96.

Shakespeare, Tom. 1996. "Disability, Identity and Difference." In *Exploring the Divide*, edited by Colin Barnes and Geof Mercer, 94-113. Leeds: The Disability Press.

Shakespeare, Tom. 2013. "The Social Model of Disability." In *The Disability Studies Reader,* edited by Lennard J. Davis, 214-221. Routledge.

Shakespeare, Tom, and Nick Watson. 2002. "The social model of disability: an outdated ideology?" *Research in Social Science and Disability* 2: 9-28.

Shier, Michael, John R. Graham, and Marion E. Jones. 2009. "Barriers to employment as experienced by disabled people: a qualitative analysis in Calgary and Regina, Canada." *Disability & Society* 24(1): 63-75.

Siebers, Tobin. 2008. *Disability theory*. University of Michigan Press.

Singer, Peter. 1995. "Is the sanctity of life ethic terminally ill?" *Bioethics* 9(3-4): 327.

Small, Mario Luis. 2009. "'How many cases do I need?' On science and the logic of case selection in field-based research." *Ethnography* 10(1): 5-38.

Sousa, Amy C. 2011. "From Refrigerator Mothers to Warrior-Heroes: The Cultural Identity Transformation of Mothers Raising Children with Intellectual Disabilities." *Symbolic interaction* 34(2): 220-243.

Sousa, Amy Christine. 2015. "“Crying Doesn’t Work”: Emotion and Parental Involvement of Working Class Mothers Raising Children with Developmental Disabilities." *Disability studies quarterly* 35(1).

Stainton, Timothy. 1994. *Autonomy and social policy: rights, mental handicap, and community care*. Avebury.

Stanley, Summer Lynn Gainey. 2015. "The Advocacy Efforts of African American Mothers of Children with Disabilities in Rural Special Education: Considerations for School Professionals." *Rural Special Education Quarterly* 34(4): 3-17.

Statistics., Bureau of Labor. 2018. "Persons with a Disability: Labor Force Characteristics News Release". https://www.bls.gov/news.release/disabl.htm.

Strauss, Anselm L. 1987. *Qualitative Analysis for Social Scientists*. Cambridge, UK: Cambridge University Press.

Stone, Deborah A. 1984. *The disabled state*. Temple University Press.

Taylor, Sunaura. 2017. *Beasts of burden: animal and disability liberation*. The New Press.

Thomas, Carol. 2004. "How is disability understood? An examination of sociological approaches." *Disability & society* 19(6): 569-583.

Torres, Lucas, and David Rollock. 2004. "Acculturative distress among Hispanics: The role of acculturation, coping, and intercultural competence." *Journal of Multicultural Counseling and Development* 32 (3): 155-167.

Trainor, Audrey A. 2010a. "Diverse Approaches to Parent Advocacy During Special Education Home—School Interactions: Identification and Use of Cultural and Social Capital." *Remedial and Special Education* 31(1): 34-47.

Trainor, Audrey A. 2010b. "Reexamining the Promise of Parent Participation in Special Education: An Analysis of Cultural and Social Capital." *Anthropology & education quarterly* 41(3): 245-263.

Upias. 1976. *Fundamental principles of disability*. London: Upias.

U.S. Department of Labor. "Subminimum Wage Employment for Workers with Disabilities." Retrieved April 20, 2019 (https://www.dol.gov/agencies/whd/workers-with-disabilities/overview)

Valenzuela, J.S. de, Susan R. Copeland, Cathy Huaqing Qi, and Miwha Park. 2006. "Examining Educational Equity Revisiting the Disproportionate Representation of Minority Students in Special Education." *Exceptional Children* 72 (4): 425–41.

Vasquez, Jessica M. 2010a. "Blurred Borders for Some but Not "Others": Racialization, "Flexible Ethnicity," Gender, and Third-Generation Mexican American Identity." *Sociological perspectives* 53(1): 45-71.

Vasquez, Jessica M. 2010b. "Chicana Mothering in the Twenty-first Century." In *Twenty-first Century Motherhood: Experience, Identity, Policy, Agency*, edited by Andrea O'Reilly, 23-39. Columbia University Press.

Vasquez-Tokos, Jessica, and Kathryn Norton-Smith. 2017. "Talking back to controlling images: Latinos' changing responses to racism over the life course." *Ethnic and racial studies* 40 (6): 912-930.

Vasquez-Tokos, Jessica. 2020. "Do Latinos Consider Themselves Mainstream? The Influence of Region." *Sociological perspectives* 63(4): 571-588.

Walmsley, Jan, Liz Tilley, Sue Dumbleton, and Janet Bardsley. 2017. "The changing face of parent advocacy: a long view." *Disability & Society* 32(9): 1366-1386.

Waters, Mary C., Van C. Tran, Philip Kasinitz, and John H. Mollenkopf. 2010. "Segmented assimilation revisited: types of acculturation and socioeconomic mobility in young adulthood." *Ethnic and racial studies* 33(7): 1168-1193.

Watson, Nick. 2002. "Well, I Know this is Going to Sound Very Strange to You, but I Don't See Myself as a Disabled Person: Identity and disability." *Disability & Society* 17(5): 509-527.

Weber, Mark C. 2002. "Disability harassment in the public schools." *William and Mary law review* 43(3): 1079.

Williams, Val, Joe Webb, Sandy Read, Roy James, and Harry Davis. 2020. "Future lived experience: inclusive research with people living with dementia." *Qualitative research* 20 (5): 721-740.

Wilson, Natasha M. 2015. "Question-Asking and Advocacy by African American Parents at Individualized Education Program Meetings: A Social and Cultural Capital Perspective." *Multiple voices for ethnically diverse exceptional learners* 15(2): 36.

Wilson-Kovacs, Dana, Michelle K. Ryan, S. Alexander Haslam, and Anna Rabinovich. 2008. "'Just because you can get a wheelchair in the building doesn't necessarily mean that you can still participate': barriers to the career advancement of disabled professionals." *Disability & Society* 23(7): 705-717.

Wright, Amy Conley, and Sarah Taylor. 2014. "Advocacy by Parents of Young Children With Special Needs: Activities, Processes, and Perceived Effectiveness." *Journal of Social Service Research* 40(5): 591-605.

Zablotsky, Benjamin, Catherine P. Bradshaw, and Elizabeth A. Stuart. 2013. "The Association Between Mental Health, Stress, and Coping Supports in Mothers of Children with Autism Spectrum Disorders." *Journal of autism and developmental disorders* 43(6): 1380-1393.

Zola, Irving Kenneth. 1991. "Bringing Our Bodies and Ourselves Back In: Reflections on a Past, Present, and Future "Medical Sociology"." *Journal of health and social behavior* 32(1): 1-16.

Zola, Irving Kenneth. 2005. "Toward the Necessary Universalizing of a Disability Policy." *The Milbank Quarterly* 83(4).