"Listen to the Parents, Just Listen to Them": Exploring the Beliefs and Actions of Mothers Advocating for their Children with Disabilities

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Abstract

Through the analysis of 13 interviews of mothers who self-identify as advocates or activists, the author describes how mothers' experiences with and understandings of disability impact the narratives they tell and the actions they take when advocating for their children. While participants identified positive results of advocacy, many mothers recognize the limits of their advocacy. This work is significant because parental narratives and counter-narratives are powerful in that they may challenge existing notions of disability.

Keywords: disability studies, parenting, counter-narratives

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Listen to the parents, just listen to them. Know that they know who their child is. They have been doing this for a long time, struggling for a long time. You need to listen to them, to understand them, to understand their child- not in the way that you view them, but in the way that the parents view them. ~ Mariela[1]

While 14% of elementary and high school students in the United States have disabilities (National Center for Education Statistics, 2019), many schools have failed to create inclusive spaces to serve all children (Danforth & Gabel, 2006). Within this context, parents have a unique role in advocating for their children. This article explores caregivers' perspectives of children with disabilities as they advocate for their children. I have centered caregivers' experiences because they are often the first to frame disability for their children and advocate for their children within medical and educational systems (see Valle, 2009). I have specifically focused on the stories of mothers because only mothers responded to my research call, which is consistent with the literature that describes mothers' central role in caring for and advocating for their children with disabilities (Fisher & Goodley, 2007; Valle, 2009). However, many of the lessons learned from interviewing mothers would also extend to other caretakers (Rogers 2007a).

Mothers' understandings, frameworks, and advocacy efforts can impact their children's early experiences in school and society. As such, I assert the need to heed Mariela's call to "listen to parents," listening to mothers and caregivers' experiences can provide a perspective from those simultaneously navigating and critiquing education systems.

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[1] The names of all mothers in the study are pseudonyms.

In this context, listening can also offer insights about places where parents, including those who self-identify as advocates or activists, could benefit from connections to larger disability rights and disability justice movements.

In this article, I explore what disability means to mothers and how understandings of disability impact actions. While many of the parents in my study do not identify as having disabilities, "[e]veryone, disabled or not, who interacts with disability is engaged in producing its meaning and its social identity" (Titchkowsky, 2003, p. 4; see also Rogers, 2007b). As such, caretakers have experiences and knowledge that have value in discussions about school-based practices for children with disabilities. Specifically, I explore the following questions through both parent narratives and a review of the literature:

- How do mothers understand disability?

- How do mothers advocate for their children, other specific children, and children with disabilities in general? How do they understand the use of cultural, economic, and social capital to influence advocacy efforts?

- What do mothers hope for their children and children with disabilities in general?

Theoretical Frameworks

This article utilizes Critical Disability Studies (CDS) and Disability Studies in Education (DSE) frameworks to explore mothers' understandings of their own beliefs and actions.

Critical Disability Studies

Disability Studies (DS) is an interdisciplinary field that, according to Dan Goodley (2011), provides a *counter-view* to medical (or deficit) models of disability and focuses on "cultural, historical, and socioeconomic conditions" that impact individuals with disabilities (p. 9). Many DS scholars have illustrated ways that our school policies operate within the

medical/deficit model that seeks to "diagnose" and "treat" students with disabilities to help them become more like their nondisabled peers (Valle, 2009). There are many alternatives to the medical model, including the social model, popularized by Oliver in the 1980s, which positions "disability as a political category and provide[s] a vocabulary for contesting the processes of disablement: social, economic and cultural barriers that prevent people with impairments from living a life like their non-impaired brothers and sisters" (Goodley, 2014, p. 7).

Within the larger field of Disability Studies, I specifically draw upon the ideas of Critical Disability Studies (CDS) scholars. While CDS does not ignore experiences of the body (Goodly, 2014, p. 84) or physical or physiological differences that have meaning in people's lives, it provides a framework to examine "the interaction between ideas, the body, and society" (Robinson, 2017, par. 2). This informs my work in two ways. First, in this work I seek to explore the impacts of ableism, a system of beliefs that centers and normalizes the experience of nondisabled people, and disableism, which includes active "oppressive practices" that discriminate against individuals with disabilities (Goodley, 2014, xi). Second, critical disability studies, according to Goodley 2013, "starts with a disability but never ends with it" (Goodley, 2013, p. 632). As Annamma et al. (2016) document, there are "qualitatively different experiences of students of color labeled with the same dis/ability in comparison to White peers" (p. 15; also see Voulgarides et al., 2021). Further, racism and differing conceptualizations of independence can create barriers for families of culturally and linguistically diverse students (Harry and Ocasio-Stoutenburg, 2020, p. 116). The mothers interviewed are engaging in larger systems, and such engagement is influenced not just by disability but also by race, class, gender, and other identities.

Disability Studies in Education

Disability Studies in Education (DSE) scholars use similar theoretical frameworks as DS scholars; however, DSE emerged in the late 1990s when "scholars and educators began to move away from positivist inquiry and problematized conceptualizations of disability as deficit" within education systems (Buffington-Adams & Vaughan, 2019, p. 4). Focused on the ways that disability is understood and acted on within schooling, I embrace DSE's focus "on *what disability means*; how it is interpreted, enacted, and resisted in the social practices of individuals, organizations, and cultures" (Danforth & Gabel, 2006, p. 5). In addition, DSE provides a framework to explore parents' understanding of disabilities and even parents' hopes for their children.

Literature Review

I seek to contribute to an ongoing conversation about parent advocacy and disability. Multiple scholars have documented how parents of children with disabilities navigate school and social systems (Valle & Gabel, 2010; Ware, 2002), retheorize experiences through counternarrative (Ferguson & Ferguson, 1995; Kitty, 1999; Ryan & Runswick-Cole, 2008; and Vaughan & Super, 2019), critique existing curricular, pedagogical practices in schools (Gabel, 2002), and advocate for children in schools (Lalvani & Hale, 2015; Leitner, 2004; Kliewer, 2006; and Rogers, 2007a). I am influenced by scholars who have documented how varying degrees of social, economic and cultural capital affect the efficacy of advocacy work (Harry, 2008; Harry & Ocasio-Stoutenburg, 2020; Ong-Dean, 2009; Ryan & Runswick-Cole, 2008; Sauer & Lalvani, 2017). Finally, I am influenced by typologies of narratives, including a study by Fisher and Goodley (2007) that describes three types of narratives that parents of young children with dis/abilities tell about their experience of motherhood, including a

narrative of "challenge," which aligns with a social model of dis/ability. Within this narrative, mothers are more critical of professional or expert opinions and more likely to engage in "resistance against oppressive and normative values" (p. 73). In the "narrative of challenge," which is similar to the narrative of resistance (Valle & Gable, 2010) or the "quest narrative" (Frank, 2013), parents resist unjust structures within schools and society.

In crafting my call for parents who self-identified as advocates or activists, I anticipated having multiple parents engaged in "narratives of challenge." In my work, I seek to expand upon these bodies of literature by discussing parental understanding of disability, advocacy efforts, recognition of privilege within such advocacy efforts, and hopes and desires. In so doing, I hope to offer counternarratives of disability and schooling.

Methods and Positionality

I utilized an interpretive framework in this small qualitative study, designed as an exploratory project (Glesne, 2011). As an interpretivist, I seek to understand how mothers' lived experiences influence their understandings of disability. I also seek to understand how mothers interpret their actions. I am also influenced by critical frameworks in that I am centering the knowledge and agency of those being interviewed with a focus on impacting future practices. As Ferguson and Ferguson (1995) explain, counternarratives can transform the field of disability and special education research by providing a forum for those impacted by disability to share their own stories and expose conditions that need to be changed (pp. 118-119).

Focus on narratives

I asked mothers to share their own stories of mothering and advocating with me in this work. I did not verify the stories they were sharing, nor did I ask their children or educators for their own stories of the same events. As such, my article seeks to amplify the

experiences and stories of mothers, focusing on sharing stories so that mothers could learn from each other, and educators and researchers could consider the experiences and wisdom of parents. Because the act of mothering is often private and because I was asking parents to share stories about mothering (which is, of course, relational), I made sure that participants were aware of the purpose and process of the interview, as well as their rights to skip questions and/or withdraw consent at any time.

Author's Positionality

While this work is not auto-ethnographical, I acknowledge that this work is a standpoint project in that my own experiences as a member of the community I am studying (Harding, 2009, p. 149-150) inform the questions I ask and my understanding of the context of schooling. As a researcher, I also disclosed my experience as a mother of a child with disabilities to research participants, which may have provided a level of familiarity with the experiences mothers shared. However, I sought to ask questions clearly and interpret parents' experiences without bias. Within these tensions, I sought to "work the hyphen" to make transparent my relationship with those researched (Fine, 1994, p. 72).

Qualitative interviews

In designing this research project, I worked with representatives from three organizations that work with families of children with disabilities to distribute information about the study to potential participants. In determining eligibility, I focused on mothers who met three criteria: each has a child or children with a disability eligible for school-based services; the child had experience in public or private schools; the mother self-identifies as an advocate or activist. In formulating my research questions, I looked at academic research and publicly documented parental narratives, including newspaper and media articles. My central

questions focused on participants' early experiences with and understandings of disability; knowledge of and actions taken regarding their child's schooling and community activities; experiences with schooling and special education services; and advocacy or activism related to dis/ability. Inspired by Eve Tuck's (2009) calls for researchers to move toward "desire-based" research in which participants share not only pain but also "wisdom and hope" (p. 416), I also asked parents about their hopes or desires.

Interviews were semi-structured. I recorded each interview using a digital audio recorder and transcribed and coded each interview. Many of the codes were "in vivo" codes, coming directly from participants' words (Glesne, 2011, p. 195). Codes evolved and changed through analysis (Glesne, 2011, p. 197). I analyzed transcripts using AtlasTI qualitative data analysis software for common themes. After the analysis was concluded, I shared my findings with colleagues and conference audiences. I also sought to identify connections between what I had observed and themes presented in the existing literature.

Table 1

Name	Advocacy/ Activism Efforts (not a complete list)
Adeline	- School-based advocacy for her child, including providing education for teachers and community members - Community and state advocacy through organizations or nonprofit organizations focused on both special education and disability-specific initiatives - Leadership roles in a community organization or nonprofit organization
Betty	- School-based advocacy for her child - Advocacy through professional activities in her role as an educator
Carmen	- School and community-based advocacy for her child and children of friends or community members - School and organizational volunteer and leadership activities - Advocacy at the community level for special education
Helena	- School, community, and church-based advocacy for her children - Advocacy for children of friends or community members
Isabel	- School-based advocacy for her child, including providing education for teachers - Advocacy for children of friends or community members - Participation in an informal group for mothers of children with disabilities
Elaine	- School-based advocacy for her children, including providing education for teachers and community members - Advocacy through professional activities as an educator - Advocacy for other individuals with disabilities

Frida	- School-based advocacy for her child, including providing education for teachers and community members - Advocacy for other individuals with disabilities, - Volunteer work with a disability-specific organization, including meeting with other families
Julia	- School-based advocacy for her child - School-based advocacy for children throughout the community and city - Community advocacy through a community organization or nonprofit
Katrina	- School-based advocacy for her child, including providing education for teachers and community members - School, community, and statewide advocacy for children with a specific disability
Mariela	- School-based advocacy for her child - Advocacy with community organizations or nonprofits, including speaking with the press and attending district meetings
Nancy	- School-based advocacy for her child - District-wide advocacy for children with the same disability as her child - Volunteer activity and leadership within organizations for children with same disabilities as her child
Olivia	-School-based advocacy for her child, including providing education for teachers and community members - Advocacy for children of community members - Advocacy through professional activities as an educator - Work with community organizations or nonprofits, including legislative advocacy and media advocacy
Reina	- School-based advocacy for her child, including education for teachers/ schools/community - Online education and advocacy about a specific disability

Mothers interviewed

I interviewed 13 participants, including nine White women, one African American woman, and three Latina women. Three mothers either discussed having a disability/ chronic health condition or recounted their personal experiences in special education classrooms. Three additional mothers grew up with family members with disabilities. All participants lived in the Midwest region of the United States, with participants from large urban areas, suburbs, and towns. Four participants discussed professional experience working with people with disabilities in schools or health care settings.

Multiple disabilities/disability labels represented

Each mother interviewed had at least one child who had received special education services, and four mothers had more than one child with a disability label. Participants shared

that their children had a wide range of disabilities/ disability labels, including epilepsy, Tourette's syndrome, Attention Deficit Hyperactivity Disorder, autism, speech apraxia, hearing impairment, anxiety, cerebral palsy, learning disabilities, and cognitive impairments. Children were in various school-based placements, including public and private schools. Within those schools, children were educated in general education classrooms for children with and without disabilities, co-taught classrooms with general education and special education teachers, special education classrooms that included only children with disabilities, and special education schools for only children with disabilities. Because I only interviewed 13 mothers, additional research that included a more diverse representation of parents would be beneficial to see if the themes identified below were more widespread.

Findings and Themes

Instead of presenting results, I offer four themes gleaned from in-depth interviews. Within these themes, I assert that mothers' understanding of and experiences with disability and their social, economic, and cultural capital influenced their advocacy efforts. While most participants found that individual advocacy efforts were successful, many mothers acknowledged the limitations of individual advocacy

Theme one: Mothers had a wide range of understandings about disability informed by various information-gathering processes

I always said God doesn't make abnormal people; people make abnormal people, . . .

their ability might not be like the majority, but they have ability. ~ Helena

Language of disability

The women in the study described their children's disabilities in various ways. Some used the term disability, while others preferred "differences" or "special needs." About half of the mothers in the study talked about disability as needing *extra* help to accomplish tasks

(academic, professional, independent living). While this can be understood as a conservative or "deficit" perspective in that it compares a person with disabilities to a peer without disabilities, many participants mentioned that all people have strengths and challenges (Broderick & Lalvani, 2017). In addition, a few mothers interviewed expressly rejected words like "typical" or "normal." For example, in the quote above, Helena rejects the labels of normal/abnormal and asserts that it is not her children's impairments but how society interacts with her children, creating the concept of "abnormal." Thus, even though parents did not reference Disability Studies literature, many parents shared a rejection of definitions that reified deficit perspectives. This is important because some participants critiqued schools for focusing too heavily on deficit perspectives.

Sources of information

Many participants identified their personal experiences with disability as essential to their understanding and advocacy. For example, one mother explained that she knew:

> exactly what kinds of things, like situations, I want for my daughter because I know that growing up with an IEP [Individualized Education Program], I would get taken out for periods at a time, and I would miss out on that education, and I actually thought the people [educators] for the IEP, they didn't know what they were doing.

Another mother recounted: "I don't think I ever really thought of anyone as having a disability, because I grew up with my mother who had severe seizures and um, you know, I don't think I really viewed it as anything because it was something I was born into." For mothers who had personal experience navigating medical and education systems, advocacy often focused on removing barriers or challenging systems that harmed their children. However, the concept of disability was "not on [their] radar" for many of the other mothers. Even though most participants attended public schools as children, many mothers did not remember children with disabilities included in their classrooms, and most did not

have significant relationships with peers with disabilities in school. Multiple caregivers shared that they only began to learn about disability after the birth of their children. As such, some participants "c[ame] to the experience as 'others'" and initially viewed disability as "unexpected," "undesirable," or something to be feared (Ryan & Runswick-Cole, 2008, p. 203).

Many participants expressed frustration about the lack of information about their children's disabilities and education processes and practices. Mothers gathered information about their children's disabilities through their doctors, therapists, educators, community organizations, books, Internet sources, and formal and informal networks of families of children with disabilities. Nine mothers identified friends as an essential source of information. Others reported that they researched their children's disabilities directly or to find disability-specific support groups. Many parents, even those who independently found resources, expressed a desire for more information about their children's disabilities and education services.

Information gathering and advocacy

The process by which mothers came to understand disability is crucial as it also has implications for advocacy efforts. In 1975, the Education for All Handicapped Children Act was passed, now known as the Individuals with Disabilities Education Act (IDEA). This legislation guaranteed free and appropriate education for all children and increased parents' rights to participate in their children's education. However, as Ong-Dean (2009) documents, while this legislative victory emerged from the civil rights struggles, parents were often left advocating for individual children instead of a collective good (p. 2). In this context, those parents who had access to the most information through their networks, experiences, and research skills were often better able to navigate medical and educational systems.

The mothers in this study generally researched their children's particular disabilities – not disability in general. As such, understandings of disability culture were secondary to insights into their children's specific impairments. Also, while many mothers sought out other parents, the only mothers who explicitly mentioned drawing upon the experience of adults with similar disabilities were those who shared a disability/chronic health diagnosis with their children or those with close family members with disabilities. Finally, while some parents sought out disability-specific organizations, many of these organizations appeared to be led by parents and not people with disabilities (see Carey, Block, & Scotch, 2019).

Theme 2: Mothers used varying degrees of social, cultural, and economic capital to advocate for their children and other children with disabilities.

One of the things that I think is depressing about the special education piece is that ... what you get for your child really depends on what parents advocate for. I don't feel that the system is set up necessary well to work in terms of equality of service delivery and for equity. ~ Elaine

In my interviews, mothers attended IEP (Individual Education Program) meetings for their children and other children, volunteered at extracurricular events so that children with disabilities could participate, encouraged pedagogical and curricular changes in their children's districts, worked with community groups to advocate for legislation changes, organized parents around specific issues impacting children with disabilities, spoke to the press, attended and spoke at Board of Education meetings, filed legal challenges to their children's placements or services, and served as parent representatives on medical and educational boards and committees. Many mothers expressed their desire to support their children and others in their schools and communities. Yet, as Ong-Dean (2009) argued that parents "who have the most cultural and economic resources at their disposal" are often able to "make the strongest claim to distinguish their children's particular disabilities and needs in

an objective, scientifically and legally justified way," which can equate to more services (p. 3).

Some participants utilized their cultural and professional knowledge, as well as what Lareau and Weininger (2003) describe as "interactional strategies" and "cultural resources" to intervene in education settings (pp. 589-590). Many mothers recounted how personal connections with education, social work, or legal experts helped their families with school selection, placement, extracurricular activities, and legal advice. For example, Carmen shared when she sought out a knowledgeable friend's advice because she was overwhelmed when reading the specialized language ("jargon") in IEPs and 504 plans. Olivia, a teacher, described a moment in an IEP meeting when there was a disagreement. She stated:

> Ahhh, I said this is, I am going to change my role a little bit. I said, if I were an advocate for families with children who have special needs, this is where I would say that you don't have the data, that this child did not get a free and appropriate public education, and that this would lead, could lead the family to go due process.

The parent challenged the school on their lack of data, and "in the end, [the woman running the meeting] said, you sold me. She said, I see your point and I will go with the IEP." This parent had to step into the role of a teacher and advocate to get her child's needs met.

In addition to cultural capital and networking, many parents used their economic capital to secure additional tutoring, services, and expert opinions. Others recognized the differing levels of service provided in school districts. Of the 13 mothers interviewed, five mothers reported that they moved at least in part to find a school that they thought would better serve their children. Finally, mothers credited time spent in schools as helpful in their advocacy. For example, Julia noticed problems with the staff-to-student ratio because she was often at the school. Elaine began preparing for the IEP re-evaluation meeting months before it

occurred through incremental conversations with teachers and service providers while in her children's school. A few mothers also noted that parents had facilitated inclusion at extracurricular events, like school dances and sports. For example, Isabel shared the following experience:

> [my child] is an excellent athlete. . . My agreement with them, with the coaches, was that I would be available to pick him up when he goes down [because of his disability]. So I get the phone call, 'Runner down.' We are at this location. The coach would call, I would go there.

Racism

Within the Midwest of the United States, there is significant racial diversity. There has been considerable research about the intertwined "legacy of historical beliefs about race and ability" (Annamma et al., 2016, p. 10), impacting parents' experiences and advocacy efforts. In my study, some parents identified discrimination within special education services. For example, Helena, an African American mother, explained that despite her advocacy, "I felt like I was being discriminated against or they had never seen a child in their school with [a particular medical condition]. I just didn't understand what was going on." Helena thought that she and her daughter experienced discrimination based on her race and her daughter's disability.

Another parent explained that she had witnessed discrimination in schools where she had done advocacy work. She recounted that "there is a pattern of obfuscation, of misrepresentation of the law, of emotional manipulation, perpetrated by case managers and some service providers are in collusion with this." For example, she commented that she had observed service providers trying to talk mothers of African American boys out of services by convincing them that they don't want to have the child "labeled with a disability." Thus, while there is a powerful critique of the overrepresentation of African American and Latino

children in special education (see, for example, Annamma et al., 2016, p. 10), This narrative also illustrates how children's access to services is limited.

Benefits and limitations to individual advocacy

My study adds to scholars' growing documentation about how parents use their privileges to get services for their children. In their narratives about advocacy, many participants simultaneously discussed successes in their advocacy and offered a critique of a system that relied on parents' advocacy to support students. Many mothers, including Helen, Frida, and Nancy, discussed providing information and support to other mothers navigating school and medical systems. Julia recounts a story about her daughter, who used assistive technology in the classroom. When the technology was lost, a service provider told her that the school district had prohibited purchasing additional technological devices. Knowing her rights, Julia said she would give them a week before filing a formal complaint. The provider "found" the device by taking it from a child refusing to use it. She reflected:

> So, instead of trying to find a way to make sure the kid would comply through counseling or other systems, she took it and gave it to my kid. And it's horrible, right, it's horrible, but I'm not going to fight other's battles. I took the thing. I took it for my kid because it is my kid. . . That's what it is [in] Special Ed. It is clawing and scratching.

Yet, many mothers (including Julia) tried to use their knowledge and capital to change education practices and systems and not just change their children.

Theme three: While most mothers in the study were able to advocate for their children successfully, many critiqued special education and education in general

> [The IEP team] still needs to fit within the school district culture, and it wasn't always in the best interest of my child. The metrics are somewhat arbitrary. Um, the goals still have to fit within the classroom and the goals of the particular class in that

particular year. And sometimes, it is just silly, and it doesn't make a lot of sense.

~Isabel

Many mothers described their children's schools as places of learning and community. For these mothers, advocacy efforts can help improve particular problems or instances when the system was not working as it should. Carmen discusses how the teachers helped her learn to embrace social and academic goals for her child. She worked with other parents to create more accessible extracurricular activities and support parents in advocating for their children. Helena, unhappy with her children's first school experience, found her children's new schools to be places of inclusion, belonging, and learning. Julia offers multiple critiques of the school system and IEP process; however, she stated: "it is not a perfect structure, but if they [the school systems] followed the mandates and the statutes in the way they're intended to be used, yes it could totally help the situation." However, for some mothers, their advocacy efforts were designed to change systems.

Each mother I interviewed could describe specific ways in which her advocacy benefited her child/children; however, many participants reflected on the limitations of individual advocacy. For example, some mentioned that accommodations were too narrowly defined. Others lamented that some educators and service providers working within the special education department focused on offering services instead of helping children succeed. These critiques extended far beyond concerns about the lack of services for children. Mothers critiqued the process of identifying children with disabilities and the process of labeling. Isabel, for example, stated:

the labeling requirements give us services. You get a label; you get a service. Why do you need a label to get a service? How is that any longer helpful? The model is now outdated because we are finding that there are so many labeled and unlabeled unmet needs.

Multiple mothers also noted that our current model of special education focuses too heavily on student failures. Mariela argued against:

> the mentality where a child has to fail to get services. Your child should be able to thrive and succeed, and if something is working, then it is working, let's keep it going for a little while longer and then slowly remove things and when they are able to do it, instead of just taking everything away.

Katrina provides an explicit example of this. She recounts that because her child entered school at grade level, she was ineligible for placement in the class "for kids who were struggling," even though she was not learning. She recounts:

> What I had to do, which the teacher and I came up with this together, was to let her fail- and she had to fail miserably. I had to stop working with her at home. So, against my nature. It only took two months . . . and [the administrator] took her reading and word test and she did so poorly that he . . . had to put her in the class.

Some mothers in the study critiqued the rigidity of services for children with disabilities. Betty called for increased "flexibility" for all students, and Adeline called for "creativity" to find things that work for the individual students. Betty, speaking as both a special education teacher and a mother of a child with a disability, noted that teachers "try to make our goals tied to the [general] curriculum as best we can, because in my school we don't even have a resource period with the kids." Betty acknowledged that "it is the best-case scenario for what we are given, but it is not the best-case scenario for the kids." Betty also noted that increased flexibility "either with the age range in the classroom or the curriculum you could access" would benefit all children.

Adeline noted that her daughter previously attended a public school that had a "pity model." While the school was less restrictive because it had children with and without disabilities, Adeline did not find the school a place of learning for her child. She believed that

the teachers saw their roles as caretakers instead of educators and did not provide meaningful experiences. Describing her experience at her child's special education school, she explains that the teachers now "think that she is capable of learning." She further states that the teachers realize that her daughter "is a person with interests and ideas and is a fully-fledged human being. She's not her deficits."

Many mothers discussed the over-emphasis on assessments, especially standardized assessments, to determine instruction. Others said that the skills and knowledge tested by standardized exams were not aligned with mothers' ideas of success for their children. Some mothers emphasized different goals for their children – including engagement with interesting work, development as productive members of society, and opportunities to grow academically and socially.

Theme four: Mothers in the study expressed hopes for their children and changes in how schools and social institutions understood and responded to disability

I thought, you know what, why do we assume that because you cannot move your body in a [typical] way, [that] you cannot verbalize in a typical way, that you do not have an interior life? That you do not crave beautiful words and beautiful music and interesting problems and that thing that we love, stories, [which are] at the root of so many of our interests. . .. And people are like, OK lady, you think [your child] is smart, whatever. It is not that I think she is smart or not smart; I am not using those words. She is a human being, and she has an interior life. We don't get access to it, which is our great loss, but that is not her fault. We shouldn't assume that because her expression isn't on our wavelength that it is not happening, you know? ~ Adeline

Participants expressed many hopes for their children, schools, and society. While some mothers wanted a "cure" (medically or educationally), many also said they desired for more systemic changes. Many articulated a desire for enriching, holistic education for their

children and more acceptance from educators, students, and society. Others wanted schools to provide their children with multiple opportunities to learn information and express understanding. Still, others wanted appropriate academic and social systems for their children and better supports for young adults. Some discussed their desires for their children to learn to be self-advocates. Many mothers spoke about their desire for teachers to reframe what it meant to be successful and embrace their children's multiple dimensions. Another recurring desire was for more significant partnerships between educators and families and for educating all children about inclusion with and without disabilities. For example, Reina expressed a wish that schools would work to expand understanding of disability:

> Most schools, um, they don't hear about disability, and they might think they are doing everything they can, but there is always more that can be done. For instance, if there is a kid with disabilities in the classroom, talk about it. Get the other kids involved. Explain to them what is going on with this child.

For many mothers, their desires for their children share many similarities with the work of educators advocating a move beyond inclusion and toward "inclusive education," which includes a focus on "quality opportunities to learn" and "valuing of all student differences as reflected in content, pedagogy, and assessment tools" (Waitoller & Artiles, 2013, p. 322).

Discussion

In this study, many mothers discussed ways that they both participated in and critiqued systems of special education. While some participants talked about ways they were making changes in a system that they thought mainly was working effectively, other participants discussed examples of societal and school-based practices that harmed their children, including lack of accessible spaces, a failure to allow multiple expressions of

knowledge, an absence of awareness about specific disabilities, a deficit view of children, and curricular decisions made to meet school or district policies, instead of addressing the needs of the child. In addition, some mothers identified when schools were creating initiatives/policies to support students with disabilities, they often reinforced ableist and disablist practices.

Despite the many valid critiques of schooling and education practices, many mothers described the importance of schools as academic and social spaces of learning. Many mothers in the study would likely agree with the comments of critical educators, such as Pedro Noguera (2003), who argued that while there are many pervasive problems in systems of public education, public schools are "indispensable to those they serve" (p. 4). Noguera (2003) wrote that "[w]ithout any viable alternative available, urban public schools cannot be written off as rotten structures in need of demolition" (p. 4). This idea was echoed by Adeline, who stated that schools "are the only resource for so many people, and so if you do not do the school well, then these families are just whacked on the head and then of course what happens when the school is gone?"

Many mothers found that their critiques of special education also applied to larger systems. For example, Adeline argued that increased accountability efforts in schools have created "less enriching academic experiences" for all students; however, she noted:

> in special ed[ucation], there is a horrible siren song which is, oh, we are doing right by kids with disabilities because we are going to measure them, we are going to include them in assessments, and you are one of us. Do we really want to be included in that club? I am not sure we do.

In this case, Adeline discusses how the impact of testing and narrowing the curriculum can be the "siren song" for all parents. Multiple mothers in the study addressed the need to change our education system while creating inclusive spaces for their children. The "offering of

disability," as described by Goodley (2014), invites us to rethink neoliberal education reforms, to "deman[d] humility on the part of educators in terms of what they are trying to achieve in educational settings," and to disrupt "[e]ducation's obsessive academic standards and school performativity" (p.104). Goodley (2014) further argues that "[d]isabled children offer an olive branch to educators: to embrace a 'dialogic ethic' of collaboratively working together to develop ideas in local contextual environments" (p. 103). I would argue that mothers, too, could offer a proverbial olive branch to schools by challenging commonly accepted notions of disability and opposing structural barriers for those with disabilities and all students.

While many mothers critiqued ableist societal norms, very few connected with networks or resources offering alternative frameworks to deficit-based perspectives. As mentioned in the finding above, most mothers relied on personal or familial experiences with disability or sought out information from doctors, parents, disability-specific (and often parent-led) organizations, or independent research. Few of the parents identified disability justice organizations – this deserves further study about why parents are not turning to disability justice organizations and how access to such information could impact parental perspectives. As mothers both mediate the "cultural assumptions regarding disability" (Valle, 2009, p. 219) and help their children make meaning of such assumptions, it becomes increasingly essential for mothers of children with dis/abilities to share stories that reject narratives that pathologize children with dis/abilities and to call into questions policies and systems of oppression that disable students (see Vaughan & Super, 2019).

The themes in this article are not new; however, listening to parents who are actively navigating systems continue to be necessary. When narratives of disability in schools are often focused on technical provisions of services, personal stories can empower the storyteller and be transformative for the reader. Narratives of parental advocacy are needed

because they can challenge commonly accepted notions of disability and emphasize structural

barriers and the need for more just policies and schools. The narratives in this study also

suggest that, as parents seek out sources of information and critique existing ways to

participate in advocacy, there may be opportunities for Disability Studies scholars to provide

information and connections to parents.

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