LABOR OF LAST RESORT: MOTHERS NAVIGATING SPECIAL EDUCATION IN A CONTEXT OF RESOURCE SCARCITY

By

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DISSERTATION ABSTRACT

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Prioritizing mothers' observations of their disabled children's lived experiences in special education offers us a crucial point of contact to check the pulse of a system upon which vulnerable children rely. Through my interviews with twenty-four mothers with children involved in special education across seven Oregon school districts, I sought to take that pulse and found it faltering. In my analysis, I put mothers' perceptions of special education and resource scarcity in conversation with student exclusion and institutional harm. My findings suggest that mothers confront and hold up an underfunded and poorly implemented special education system that does not meet their children's needs. Despite the rhetoric of inclusion, the current implementation of special education in these districts leads to student exclusion and other institutional harms, putting disabled children's personhood at risk. These mothers are laboring in schools alongside staff to minimize harm and ensure inclusion and educational access for their children. Their stories reveal how special education relies on the invisible, unpaid, and devalued labor that they invest. The absence of other options combines with the fact that their children's wellbeing is at stake, making maternal labor in special education compulsory. Compulsory labor is a reliably extractable resource that can offset resource scarcity in special education—

propping up the system just enough to keep it going. Mothers are the tourniquet on a system that is bleeding out. It is common knowledge that a tourniquet is not a long-term solution; nevertheless, these mothers' stories show how special education relies upon one as it struggles to serve and support students in the context of resource scarcity. Furthermore, this systemic reliance on unpaid maternal labor as their last resort reproduces the inequity, inadequacy, and inhumanity of a special education system where ableism is the starting point, and discrimination is rendered acceptable by the letter of the law.

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I dedicate this dissertation to Lyla, the once and future "Dr. L. B. Riley."

You are the mortar to their brick,
and I watched them try
to crush you.

They wanted hard,
-consistent-
They wanted testable,
-contained-
They wanted stillness
in your limbs.

They wanted you set in stone.
But you, my love, are not made
to be the mortar or the brick.

You are whirlwind.
You are fire.
You are as close to free
as anyone can be.

So, let your joy forever pull you
from your seat, and always hold fast
to your own humanity.

You are my wild child,
my whole world,
You are my
beginning,
middle,
and my
end.

The day you arrived,
is the day my life took shape.

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If You Will

We will start inside an Oregon elementary school, with a day in the life of a third-grader. Let us imagine for a moment this child, still relatively small, no more than nine years old, sitting alone at a single desk in a long, dimly lit hall. A soft grey light trickled in from the rain-speckled windows opposite the child. The light pushes weakly against the shadows on the floor at the child's feet. Behind this child is a row of coats still damp from the morning recess—another recess the child missed because they could not finish the morning lesson in time. The hall's air is chilly, and at each end of the corridor are two large doors leading outside. A draft attempts to dry the slowing tears on the child's face. The child is pushing a torn and crumpled piece of paper around next to an open lunch box. Behind the child's right shoulder, past the line of coats, there is a deep threshold and a dark brown closed door.

A rectangle of light trickles into the hall through the tiny window situated at eye level for the average adult. The child can hear the muffled sound of children's voices from behind the closed door. If the door had been open, a cacophony of voices and laughter would flood into the quiet hall. On the other side of the door, it is free choice seating, and the child's peers are talking and laughing with each other while eating their lunch. Free choice seating day is already stressful as the child struggles to build friendships with peers and is often bullied by them instead. The child's peers have learned how to push the right buttons and get a reaction. Disciplinary measures implemented by the staff often follow the child's response, and at that point, the child's peers usually find something else to do.

The child has a diagnosis of dysgraphia and attention deficit hyperactivity disorder (ADHD). Most of the staff, including the child's primary teacher, have suggested an autism spectrum disorder (ASD) evaluation. An Individual Education Plan (IEP) requires pre-instruction for all written assignments and the appropriate scaffolding and *supports to minimize all non-essential writing tasks. The special education teacher, the usual go-to person for help, is out sick that day, and the child has been worried for most of the morning because they do not have another safe, trusted adult to turn to when things are hard. However, to understand why the child is sitting alone in the hall, we will go back to the class period right before lunch.*

Imagine now a teacher. The teacher walks through the rows of desks, passing out writing worksheets. It is almost lunchtime. Maybe on a different day, the teacher would have had an educational assistant helping in the morning. Today the teacher is alone and trying to stay on schedule. She walks quickly through the classroom and approaches the child, not realizing that internally this child has been managing a whirlwind of anxiety all morning. The teacher sets down a blank piece of paper in front of the child without further instruction and quickly moves on. She has 30 students to get through. The child watches the teacher as she hands the student who shares the table a partially filled-out worksheet. The child looks at both papers and does not understand why they are different. The teacher intended to come back and explain, but of course, the child cannot know this. In this moment, the child stares down at the blank paper, and all the stress and anxiety that has been bubbling just below the surface all morning spills out. The teacher turns back and sees the child melting down for no apparent reason, tearing through the paper with the pencil and damaging the top of the desk.

Behind the child, other students have taken this opportunity to talk freely to each other, and the din of the room around the child is quickly getting louder. Through the noise, the child hears a peer loudly complaining that she "is starving." However, the child takes things literally and understands the word starving to mean something very different than hungry. Adamantly, the child turns and yells at the peer that she "is not starving. She is only "hungry." The child does not understand why other people miss this distinction. The girl keeps saying she is starving. The child keeps yelling back at her that she is hungry. The teacher realizes this situation will quickly eat away the limited time before lunch. She gives up on the worksheets and sends the child with their torn-up paper and lunch into the hall. The teacher instructs the child to sit out there and "think" and says that they can join their friends in the classroom for lunch after the child tells her what they did wrong. She closes the door and attempts to refocus the classroom to *transition to lunch. The child cannot realistically meet the teacher's expectations. The child sits in the hall and cries.*

The door at the far end of the hall to the child's right opens. A mother slips into the corridor. She has arrived on schedule to volunteer in the child's classroom like she does every Tuesday. The mother peers down the long hall and sees her child sitting there alone. She hurries towards her child. The child sees her and stops pushing the piece of paper across the desk, quickly stands up, and begins pleading, "Mom, tell Sarah that she is not starving. Tell her mom. Tell Sarah she is only hungry. She can't be starving; she can't be; she is only hungry. Tell her mom. Tell her." Out of breath, the child quickly crumples, like paper, into her arms as tears well up again. We will leave the two of them standing together in the dimly lit hall—the child crying and the mother pushing back her own tears as the soft grey light attempts, in vain, to drive away the shadows at their feet.

This is the story of a real child. Their story does not end there; this vignette captures the reality and complexity of just one of this child's school experiences. Other things captured here are less visible, less central—and certainly less visceral than the details of that specific section of that child's Tuesday morning. The scene provides a small glimpse of an unsupported and potentially overwhelmed elementary school teacher who has a strict schedule to keep. The vignette conveys the all-too-common absence of trained Special Education staff. It also conveys a mother supporting her child in the educational environment—a mother who walked into that moment with her child, unaware of all that transpired before she arrived. If we had followed her out of that moment and into the next few days, or even the next few weeks, we would have seen this mother carving out time to be on the phone and write emails and then finding even more time to meet in person with teachers and staff. Had we followed her, we would have seen the labor of a mother trying to make sense of that Tuesday and working to prevent it from happening again; this mother does not labor alone.

I am the mother in the opening vignette. Situations like the one I described were an everyday reality for my family—as they are for countless families navigating special education. My subjectivity as a parent of a child in special education led me to pursue research on the experiences of parents who are navigating special education with their children. While I initially sought to tell a story of parents, regardless of their gender, it became clear early on in the research process that it would become a story about how mothers live, understand, and describe their experiences with Special Education. I began this work by asking broad questions about the perceived effectiveness of their children's Special Education services. I wanted to get a sense of how those services built off or responded to their children's disabilities and their unique strengths and weaknesses. However, I came away with a rather distressing picture of families struggling to access public education in the context of resource scarcity. I found a picture of teachers, staff, and administrators working with limited funding and minimal resources—who may very well be doing their best to serve families yet were still consistently and unintentionally underserving, excluding, and even harming the children in their care. In the end, it also became a story of mothers who were striving to prevent or minimize the exclusion and harm an unequal educational system can and does inflict upon their children. Moreover, in their attempts to buffer and protect their children, these mothers invested significant amounts of invisible, unpaid, and compulsory labor into the Special Education system—a system that may be unknowingly reliant on their compulsory maternal labor.

My work draws on separate bodies of literature to bring seemingly separate facets of maternal experiences with special education together. I intentionally place mothers' perceptions of special education and resource scarcity alongside their stories of student exclusion and institutional harm. I then extend this conversation to include the different forms of compulsory labor mothers perform and the system's possible unacknowledged reliance on that labor in ensuring greater inclusion and educational access for their students. I ultimately argue that despite the rhetoric of inclusion, the current implementation of special education in these districts leads to student exclusion and other institutional harms that put children's rights and personhood at risk. Furthermore, I argue that maternal labor is simultaneously invested by mothers and extracted by special education in an attempt to prevent or minimize adverse student outcomes. I also offer that these facets of maternal experience are intricately connected in ways that may potentially uphold an unequal and harmful educational system for disabled children.

Literature Review

Inclusive Education in the Least Restrictive Educational Environment

A significant portion of the labor mothers invest in special education concerns their child's inclusion in the educational environment (Kalyanpur, Harry, and Skrtic 2000; Turnbull and Turnbull 2020). School districts must report data on where special education students “receive instruction” (Williamson et al. 2019). These reports should reflect that students are being included and supported in the least restrictive educational environment based on their disabilities. Some of the contention surrounding student inclusion and LRE stems from the phrasing in the IDEA itself, which states that disabled children must be educated and included with their nondisabled peers “to the maximum extent appropriate” (IDEA 2004a). Adding to this confusion is the variety of interpretations of the least restrictive environment (LRE) offered by Circuit Court different rulings and the fact that the U.S Supreme court has “not provided guidance” on this issue (Underwood 2018). Furthermore, varied interpretations of LRE mean that ultimately location could be a more significant determining factor in student placement than the actual “nature or severity” of their disability (Brock and Schaefer 2015).

Local educational agencies determine the least restrictive environment (LRE) for any given child based on their assessments of “the nature or severity of the disability” (IDEA 2004a). There are two different interpretations of the LRE requirement. One interpretation of LRE asks what environment is needed “to specifically address a particular disability and provide a free appropriate public education” (Carson 2015:1399). The other asks what the “least restrictive environment available to meet the students' needs” (ibid). Both approaches meet the legal requirement for meeting LRE. However, placement decisions “based primarily on a district's currently available and activated resources provides a standard that may fall short of the integrationist objectives of the IDEA” (ibid:1408). Because of the ambiguity and differences in interpretations of the law, overly restrictive placements for students with high support needs persist (McCabe et al. 2020; McLeskey et al. 2012; Smith 2006)—placements that remain legally justified as “appropriate” based on the “nature and severity” of their disabilities. The fact that “special education law favors the availability interpretation of LRE” (ibid) implicates resource scarcity in patterns of overly restrictive or inappropriate placements.

Furthermore, the context of resource scarcity implicates the state because the quality and "availability of educational resources is a matter that is within the scope of state action" (Bickenbach 2009:114).

The legal ambiguity alone provides more than enough fuel for the literature to disagree on what we mean by the word inclusion. Physical inclusion remains central to the efforts mandated by the Individuals with Disabilities Education Act (IDEA)—with school districts striving to physically place the majority of special education students in general education in general education at least 80% of the time. Consequently, special education's physicality and the importance of inclusion in general education cannot be discounted. Inclusion in the least restrictive environment (LRE), as an ideal, is often represented by a disabled student who has an ongoing physical presence alongside nondisabled students within the physical space of a general education classroom (Bakken 2016). In other words, "inclusion is an educational practice in which children with disabilities are educated in classrooms with children without disabilities" (Bakken 2016:3). This placement definition of inclusion is predominant (Nilholm and Göransson 2017). Alternately there is the assertion that special education is a context or a collection of services. This assertion suggests that the program's core is not about a student's physical placement but about how they are served in relation to their disabilities (Leach and Helf 2016). From this perspective, inclusion is "the coordination of services and supports to promote the learning of students with disabilities" (ibid:116). An "individualized definition" posits that inclusion is something that meets the social and academic needs of disabled students (Nilholm and Göransson 2017). Where inclusion occurs is secondary.

The artificial separation of inclusive education into a debate about "context" vs. "place" ignores the reality that real inclusion relies on a fundamental relationship between both concepts. Kozlelski provides an excellent example of the interdependence of context vs. place in special education when she asserts that "too often what passes for inclusive education is putting students in the same classroom absent designs for learning and growing" (2020:340). A specialized school for the blind or deaf may have "the designs for learning and growing" needed for disabled children to thrive. Nevertheless, the physicality of the place as something separate may sit too close to our understanding of segregation. Similarly, a general education environment that lacks the "designs for learning and growing" can include a student in a physical place while simultaneously excluding them from learning and growing. Either way, a general education classroom still represents the pinnacle of inclusion and a perceived move away from segregation.

The required reporting on placements and inclusion in general education is one way to track and ensure that schools are not excluding students based on their disabilities. However, the mothers' narratives suggest that inclusion data may not map onto any given child's lived experience of exclusion on any given day anywhere near as cleanly as it translates to a database or a progress report. The stories they tell capture the difficulty of avoiding exclusion when the only path to inclusion is a "continuum of segregated" placements across "parallel systems" of general vs. special education (Lalvani and Broderick 2015; Lalvani and Hale 2013). Even the ideas about "special" and "regular" education stem from an "established yet inaccurate and redundant binary evocative of oppressive notions of normality and abnormality (Slee 2008:111).

As we assess inclusive education, the challenge then should not be determining whether a special school, classroom or program is better or less restrictive than general education. The real problem confronting us is fundamentally about "the co-dependence of regular and special schools in the concealment of failure" (Slee 2008:111). We will not remedy this failure by continually contrasting inclusion against a backdrop of exclusion. All that analytical exercise offers us is an ongoing "false dichotomy" (ibid:102) that, as this study shows, absolutely cannot map onto the lived experiences of disabled students in the schools. We need to confront the lived experiences of disabled children because, ultimately, actual children exist in the middle of these debates about policy and practice. Inclusion and exclusion cannot continue to "occupy binary positions" (Merry 2020), especially when a binary understanding of inclusion vs. exclusion too often erases students' exclusion experiences when on paper, they represent the ideal of inclusive education.

What we understand as appropriate and inclusive education may be "faltering in a world of complex intersections of identity and difference" (Slee 2008:111). Slee's concern here is that "inclusive education is a casualty of a form of '*eduspeak'* characterized by reductionism and disconnection and devoid of its original political intent" (Slee 2008:104). Central to the idea of inclusive education for disabled students was a rejection of "traditional accounts of disability as defective or incomplete identities" (ibid:105)—a rejection of seeing and treating disabled people as nonpersons. Disability activists situated this rejection *alongside* the claim that disabled children had a right "to join their siblings and nondisabled peers" in their local neighborhood schools (ibid). Furthermore, the question of if we are genuinely situating disabled students as whole moral persons, who are not only worth including equally but also worth protecting from harm, remains missing in the forefront of most debates around inclusion. If student wellbeing remains secondary to special education implementation, can the original goal of acknowledging, honoring, and protecting disabled personhood be genuinely present in practice at all?

As we continue to reduce our idea of inclusive education down to the assumption that it "merely concerns the schooling of disabled children," we also reduce our "capacity to shape inclusive education as a comprehensive education and social reform" (Slee 2008:108). As we focus our attention on this reduction, we fail to see "schools as socio-political artifacts with differential impacts on a range of students" (ibid). This failure of our attention carries material consequences for students, resulting in the inclusion and protection of some students at the expense of others (Lalvani and Broderick 2015; Merry 2020; Slee 2008, 2011, 2019). The legal ambiguity in the IDEA allows schools to rely on the availability interpretation of LRE to manage resource scarcity. However, these placement decisions do not come without consequences for the mothers and their children. In many cases, the implementation of special education in a context of resource scarcity results in a denial of personhood and institutional harm. Furthermore, as a separate system from general education, special education in a context of resource scarcity perpetuates a dynamic where mothers must invest inordinate amounts of unpaid labor to increase their child's likelihood of being appropriately served and protected from harm.

Institutional Harms, Personhood, and the Rights of Disabled Children.

For those invested in a system of inclusion that relies upon a legal continuum of segregation and exclusion, restrictive special education placements “may be thought of as places of well-meaning confinement” (Richardson and W Powell 2011:30). However, the acceptance of exclusion as necessary and well-meaning allows us to settle for the idea that it is the only or best option. Furthermore, the focus on the good intentions of inclusion as justification for blatant inequality only serves to erase the impact of exclusion. Special education’s “failure to respond” appropriately “to the needs created by individual differences” is an institutional betrayal that reproduces “socially created inequalities” (Ikäheimo 2009b:111). In their discussion of institutional betrayal, Freyd and Smidt assert that an “examination of those settings in which traumatic events are more likely to transpire can help increase understanding of institutional-level policies, practices, and cultures that can serve to condone, hide, or normalize trauma” (2014:580).

Institutional betrayal is defined as “deliberate acts or acts of omission (e.g., negligence) perpetrated by institutions onto individuals that rely on these institutions for support, resources, protection, and in some cases survival” (Smidt and Freyd 2018: 491). Disabled children rely on special education for the proper support and services to access education, physical safety, and emotional well-being. The failure to protect disabled children is institutional betrayal. Smith and Freyd describe two kinds of institutional betrayal: one type of betrayal which comes from a “failure to protect,” while another form is mandated or sanctioned by the implementation of broad laws, policies, and procedures (Smidt and Freyd 2018). Most simply, institutional betrayal is finding harm where one should reasonably expect to find safety and protection (Smith and Freyd 2014). It is safe to assume that mothers bring their children into the educational environment and expect their children to be educated and included, cared for, and safe; this is not an unreasonable expectation. There is no viable reason to think that this expectation is different for mothers raising disabled children.

Perhaps more salient to mothers of disabled children than it should be is the knowledge that when schools betray their trust, it can cost them their children's lives (Kutz 2009; Zaami et al. 2020). Consider the 2018 death of Max Benson, a 13-year-old autistic boy who died face down while being restrained by school staff (Zaami et al.

2020). The wellbeing and safety of disabled students may very well be a secondary consideration in implementing special education. As Merry posits, "regular schools often are sites of victimization," and it is often disabled children who "are harmed by simply being in school, irrespective of whether the child is cognizant of the harm" (Merry 2020:17). It remains true that special education has done incredible work towards student inclusion (Bérubé 2003). However, the reality that special education implementation harms students remains, regardless of if teachers, staff, and school administrators are cognizant of it. It is also possible that this harm becomes visible when we use a lens of personhood and institutional betrayal to scrutinize the lived experiences of mothers and their children and the ongoing challenges confronting them in special education.

Congress continues to underfund Special Education, and schools continue to struggle to provide services (O'Laughlin and Lindle 2015)—this ultimately is a problem of redistribution. However, it is also a problem of personhood that translates into a statement on who is recognizable as worth teaching, or in this case, worth protecting. Those whom we recognize as whole persons gain access to a "moral community whose members have moral claims and status with regard to each other" (Ikäheimo and Laitinen 2007:9). A whole moral person has a claim to safety and protection. Ikäheimo's asserts that central one dimension "of having the standing of a person in the shared life-world of persons. . . is being someone whose happiness or wellbeing is taken as intrinsically important by others" (2009b:81). Personhood then is a matter of recognition (Ikäheimo 2007, 2009a)—and as Bérubé argues, "the politics of recognition are inseparable from the politics of redistribution" (2003:53). Ideas about personhood reflect "normative judgments about status and entitlement" (Robinson 2016:611). It is not until we consider disabled children as people—"as holders of full moral status"—that "an obligation to protect their rights is conferred" (Mithyantha and Bassi 2013).

Landsman argues that "personhood can be earned or reduced in increments" (Landsman 1999:135). Similarly, Luborsky argues that personhood is culturally constructed and is "not an automatic or intrinsic property of the individual" (Luborsky 1994:2). Furthermore, he states that personhood cannot be "gained by personal claim—it must be socially legitimated" (ibid). The boundaries between who is considered a whole person are rooted in racism, nationalism, and misogyny and have long been used to define who is and is not “deserving” of fundamental human rights (Robinson 2016). Like Landsman’s idea of incremental personhood, rights themselves are also things that “can be created, reinterpreted, extended and revoked” (Bérubé 2003:55). Bérubé argues that the recognition of “human dignity enshrined” within disabled people’s rights is “invented, and by the same token, those rights, and that recognition, can be taken away (ibid). Furthermore, Mithyantha and Bassi (2013) describe the way “moral status and protection by moral norms” are embedded within concepts of personhood, suggesting that those denied “full moral status” are not inherently “holders of human rights” (53). Disabled children occupy a particularly vulnerable position here, as their claims to full personhood remain up for debate on account of their status as children and their status as disabled.

Children have been defined as “proto or incomplete adults” who do not fully possess “the powers and capacities that characterize human beings” (Archard and Macleod 2002). In some cases, even the idea of childhood is complicit in diminishing the personhood of others (Hockey and James 2005:135). On the one hand, children are supposed to be protected as persons (Lopatka 2007:xxxvii). On the other hand, they are not yet granted the full personhood of adults socially or legally—and their diminished personhood complicates their full access to human rights (Archard and Macleod 2002; Lopatka 2007; Robinson 2016). Even the questions about the validity of children’s claim to full human rights, while persistent, are relatively new. The political and moral debate that “children as a group deserve to have extended to them all the rights possessed by adults” emerges in the 1970s (Archard and Macleod 2002:3), with the U.N. convention on the rights of the child following in 1989[1] (Lopatka 2007; UN General Assembly 1989). The United States remains the last country that has yet to ratify the convention, only signing it in 1995 (UNICEF n.d.). In addition to the contested nature of children as bearers of full rights are questions about their value. Ferguson (2004) asserts, that while children are valued in our society to such an extent that “avoidable harm and suffering to them is unacceptable,” society “quietly tolerates all manner of exploitation” and harms perpetrated against them (9).

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[1] While the UN declaration on the rights of the child was proposed in the 1959, it took 30 years for it to be adopted as a convention

The full extent of the philosophical, political, and legal debates around children's moral status as persons deserving of full human rights is much too large to take up in this paper. However, the ongoing debate illustrates the contention around granting children full personhood. A central argument in that debate is the idea that full personhood requires rational thought and that those who are found lacking "do not possess dignity and the moral status that we associate with persons" (Kittay 2015:2). The denial of personhood is not an unfamiliar concept in the disability community. Whereas children are viewed as "potential bearers of rights" or "creatures in the process of becoming" (Arneil 2002:77), this same idea of "potential" is not often extended to disabled people who are regularly denied the status of both. The discrimination and segregation experienced by disabled people continue to result in a further diminishing of their personhood and a denial of their fundamental rights, regardless of the laws in place to protect them. (Carpenter and Austin 2007; Landsman 2003; Luborsky 1994; McKeever and Miller 2004). De Schauwer et al. (2020) argue for a need to "expand the category of human in such a way that it does not exclude difference and, in particular, the form of difference currently categorized as 'disabled'" (2).

The philosopher and disability scholar Eva Kittay (2015) describes how those with cognitive disabilities are often "compared, in all seriousness and with philosophical authority, to a dog, pig, rat, and most flatteringly, a chimp" (397)—a comparison that carries material consequences in that community. She describes how her colleague, Jeff McMahan, argues that the moral status of personhood should be based on "intrinsic psychological capacities" (ibid 395). Kittay summarizes his argument that these capacities should "determine whether an individual is due justice" and if "it is as bad to kill that individual as it is to kill 'one of us'" (ibid). This train of thought moves beyond questioning a disabled individual's claims to justice to devaluing their very existence. The capacities that McMahan lists as fundamental to moral personhood are "a strong continuity of self," the "ability to project themselves into the future," and the "ability to appreciate the higher pleasures we associate with being human" (394). In making this claim, McMahan, like many others, holds the position that these things are inherently absent from the internal experiences of individuals with severe cognitive disabilities. This is a dangerous presumption that is "based on a totally inadequate familiarity with the population," who are the people who are at the most risk to be harmed by these claims (Kittay 2015:394).

Like children's experiences, the diminishment of personhood for disabled people is situated in a context of questioning their legal claim to the full range of human rights (Bérubé 2003). The U.N. Convention on the Rights of Persons with Disabilities does signify a move towards defining disabled individuals "as subjects capable of claiming their rights" rather than "objects of social protection" (Human Rights Watch). However, the convention itself was only adopted in 2006 and entered into force in 2008 (UN General Assembly 2008). Citing the ADA as "one of the most comprehensive civil rights laws," the United States still has yet to ratify the convention, only signing on as a party in 2009 (Human Rights Watch). However, in contrast to the idea that the existence of the ADA makes it unnecessary for the United States to ratify the Convention, as Bérubé (2003) points out, the rights of disabled people "are so rarely thought if in terms of civil rights" (55). Bérubé argues that viewing the ADA "as a broad civil rights law" and understanding it as "a law that potentially pertains to the entire population" would allow for disability law to "be understood not as a fringe addition to civil rights law, but as its very fulfillment" (ibid).

Unhindered access to fundamental human and civil rights for disabled children depends on their access to full moral personhood. In his work in political philosophy, Ikäheimo grapples with the concept of personhood as something that moves beyond psychological definitions to include an individual's status (Ikäheimo 2007, 2009a, 2009b; Ikäheimo and Laitinen 2007). While Ikäheimo recognizes the significance of the institutional personhood, he asserts that the interpersonal nature of personhood is significant because to be "seen as a person by relevant others" is what gives an individual the "standing or status of a person in one's encounters and interactions" (2009a:79). Since special education services are, fundamentally, a series of "encounters and interactions" between students and educational faculty, administration, and staff, I rely on the interpersonal definition of personhood throughout my analysis. Disabled students are academically "included" on paper, offered placements and accommodations, and their claims to institutional personhood take center stage as individuals whose rights are outlined and protected in the IDEA. Nevertheless, mother's narratives highlight how they labor in the education environment to ensure their children are included and protected. Their stories demand a genuine reflection on if special education includes their children as “full persons” or “liabilities.”

Maternal Involvement in Special Education

Despite our best efforts, the gendered division of labor is resilient. As a result, primarily mothers perform the bulk of unpaid and, often, invisible labor involved in raising and caring for children (Acker 1990; Williams 2000, 2003, 2010). This pattern is consistent across group differences like race, class, and nationality, ultimately impacting women in diverse and often unequal ways (Green 2007; Hill Collins 1994; Litt 2004). Mothers of school-aged children are primarily responsible for the labor involved in supporting and facilitating their children’s educations (Dudley-Marling 2001; Gillies 2006; Hutchison 2012; Reay 2005). Unsurprisingly, this pattern also persists among mothers raising children with disabilities (Blum 2007, 2011; Carpenter and Austin 2007; Clarke 2012; Maes et al. 2003; McKeever and Miller 2004; Scott 2010). The unequal responsibility for care work in the educational environment means it is often mothers navigating, witnessing, and responding to their disabled children’s lived experiences in special education (Lai and Vadeboncoeur 2013). This inequity raises the broad and thus far understudied question of how mothers raising disabled children understand and describe their experiences navigating special education in a context of resource scarcity with and for their children.

Parental involvement in education has long been recognized in policy as a valuable resource (Lai and Vadeboncoeur 2013). Increasing parental involvement in academic and non-academic spaces is one method for reducing the effects of limited budgets (ibid 869). However, parental involvement discourses suggest that parents must contribute in “ways that are recognized by school personnel” as proper parental involvement (ibid 868). The constraints around how schools expect parents to involve themselves limit their agency in the educational environment (ibid). This lack of agency occurs despite the overwhelming rhetoric of parental involvement as part of a reciprocal partnership between schools and the parents (Reay 1995). Furthermore, the policies and practices aiming to increase parent participation are presumably gender-neutral (Reay

1995; Shuffelton 2017). Nevertheless, scholars have found that parental involvement is overwhelmingly maternal involvement (Hutchison 2012; O'Brien 2007, 2008; Reay 1995, 2005; Shuffelton 2017).

Educational involvement is, as Hutchenson (2012) points out, "an 'implicit ought' of mothering" (196), that, in part, stems from "discourses requiring mothers to behave in particular ways in relation to their children" (198). However, most research on parental involvement "frames family support for education as an ungendered concept" (ibid,195). The bulk of the labor "involved in managing the interactions between home and school typically falls to mothers" (Hutchenson 2012, 195). Griffith and Smith assert that "the ideals of mothering in the context of schooling, and the mother's responsibility for realizing them, are absolute" (2005:33). The labor mothers invest in education "constitutes a normative and extensive expectation of parent-school co-operation" (Hutchenson 2012, 198). Furthermore, maternal labor "makes a significant difference to the level at which a school can operate" (Griffith and Smith 2005:67). Beyond the benefits to their children, maternal labor "contributes to the functioning of the school (ibid). Furthermore, social discourses around motherhood convey a particular "inalienability" of care work in education which suggests that "no one else can or will" do the work (O'Brien 2007).

Therefore, a "moral imperative to care" confronts mothers (O'Brien 2007), and investments of educational labor become constrained or socially coerced choices. The "inalienability" of care work may also be particularly powerful for mothers caring for disabled children (Blum 2007, 2011; Cole 2007; Lai and Vadeboncoeur 2013).

McKeever and Miller discuss how the actions and behaviors of mothers who are raising disabled children are "understandable and predictable responses to widespread societal discourses that devalue" disabled people (2004:1178). Ableist discourses these mothers respond to are continually colliding with the social expectations of motherhood, intensifying for them the "implicit ought of mothering that drives their educational involvement. These internalized discourses are especially powerful as mothers face the structural limitations of resource scarcity in special education. Many of the mothers in this study labored in one way or another because the safety and wellbeing of their children were at risk, and "when vulnerable children are at stake, mothers' ability to resist remains limited” (Malacrida 2001:141). When there is no one available “who can or will” take up the labor of protecting their children in the educational environment, mothers do it themselves. The lack of viable alternatives constrains maternal choices to invest labor into special education; therefore, their labor is compulsory and ultimately extractable.

Methods

I utilized qualitative research methods to examine, in-depth, mothers' experiences navigating special education with and for their children. This methodological decision gave me greater access to the meanings they attach to their interactions with schools and their observations of their children’s lived experiences. I chose to conduct semi-structured qualitative interviews as they allowed me to ask open-ended questions. This flexibility helped capture the depth and nuance of maternal perspectives, allowing me to offer new understandings of their experiences. I focus my study on a small group of mothers representing a handful of school districts in Oregon. I do not claim that my work represents how all districts implement their special education programs. However, there is enough consistency between my findings and the previous research to suggest strong parallels in how special education may be implemented outside this group of Oregon school districts.

Recruitment

I focused my recruitment on parents whose children were either currently involved in special education or previously involved in the system. I did not restrict the sample by disability category or type of student involvement in special education, as often students move through various levels of involvement during their school years. I did not actively recruit for specific demographics such as race, age of parent or child, or income. I also did not restrict recruitment to mothers specifically. I initially designed the study to assess parental perspectives in general; however, only one father expressed interest in participating. I was unsuccessful in my attempts to schedule an interview with him. Hence, the study became one of mothers’ experiences navigating special education with their children,

I used a mix of purposive sampling and snowball sampling for recruitment. I drew on my connections to community organizations that serve and support families in general and families involved in the special education system. I reached out to housing and self-sufficiency programs, the Division of Disability Services, local advocacy groups, and other support services. I contacted staff from those organizations via email and phone calls to ask for assistance. Two organizations required in-person meetings to discuss my research. I had one meeting with an organization director alone, and the other meeting at a different organization included the director and several staff members. In addition to direct community recruitment, I posted recruitment requests on Facebook, both in a general shareable public post and within private Facebook groups dedicated to families with disabled children. I also asked the mothers who participated in an interview to share my information with other parents who might be interested in participating. My positionality as a mother of an autistic child helped facilitate my access to these recruitment spaces while it also helped establish trust with my respondents.

Data Collection and Analysis

Data collection was “systematic, yet flexible” (Charmaz 2006; Emerson 2001) and consisted of 26 semi-structured interviews over four months beginning in July of 2019, with around half of the interviews occurring over summer break and the other half within the first few months of the new school year. Interviews took place in various locations, including respondents’ homes, places of employment, coffee shops, the library, and my office, depending on respondents’ personal preferences. The interviews averaged around 45 minutes, with the shortest interview lasting about 20 minutes and the most extended interview lasting about two hours. Out of respect for respondent’s confidentiality, their names and personal demographic information were discussed and written down before audio recording took place. After that point, I recorded all interviews with the Otter transcription app and took brief notes by hand during the interviews. Before the analysis, I gave respondents pseudonyms. I also listened to the recordings and edited the partial transcriptions produced by Otter for accuracy.

I had organized the interview schedule into two parts, pre-interview survey questions about a respondent’s demographic information followed by the main interview questions. The main interview questions targeted their involvement with special education, such as disability category and placements, and the perceived usefulness and accessibility of special education services and accommodations. To get a sense of who their child was as a person, I asked mothers about their children's social and academic strengths and weaknesses. The semi-structured nature of the interviews meant that I used the interview schedule as more of a guide for each interview. I did not always follow the same order with the questions, as I engaged a conversational interview style in which I allowed the interests and concerns of the parent to determine the structure of our discussion. When themes emerged in the first few interviews that were not specifically on the schedule, I incorporated those themes into subsequent interviews.

While my analysis for this study draws heavily from the iterative nature of grounded theory, I did not fully follow grounded theory procedures (Charmaz 2006). I began coding and analyzing data early in the data collection phase, listening to each interview in-depth and repeatedly, writing memos about emergent themes, and continued this process after completing interviews. These steps allowed me to develop a list of potential codes for my initial coding process. The potential codes included but were not limited to emotions, advocacy, participation, physical placements and removals, services, and relationships. The next step in data analysis involved listening again to the audio recordings alongside an initial focused coding of each transcript to assess the saliency of potential codes. I continued writing analytical memos during this step in coding, which helped assess which codes and analytical categories stood out (Charmaz 2006). When data collection was complete, I coded all transcripts a second and third time, thus developing the specific codes and sub-codes of three broad analytical categories that emerged as particularly salient: services, labor, and student exclusion.

Participant Demographics

The Mothers and Children

I interviewed 24 mothers whose children were involved in various stages of special education. The majority of the mothers lived in dual-parent households. Sixteen mothers were married, followed by three divorced mothers, three single mothers, one separated mother, and one cohabitating mother (Figure 1, see Appendix for all figures). Household income ranged from 11k to 170k, with five mothers reporting unknown (see (Figure 2). Twenty of the mothers self-reported as either White, White Non-Hispanic, or

Caucasian. One mother self-reported as Half-Jewish, another as Native American, one as Asian, and one mother identified as Italian-Mexican American (Figure 3). Nine mothers reported holding a 4-year degree, six held master's degrees, five mothers reported completing some college, one finished trade school, and three mothers finished high school (Figure 4). The average age of mothers was 41.5 years old, with one mother not disclosing her age (Figure 5).

I focused the interview on one focal child, though several mothers occasionally spoke about special education experiences with multiple children. The total number of focal children included eight girls and sixteen boys. However, the total number of children discussed overall, including the focal children, was 12 and 20, respectively. The average age of the focal children was 12 years old. The youngest child was 5 years old, and the oldest child was a 23-year-old adult dependent (Figures 6-7). Six focal children were in elementary school, five were in middle school, seven children were in high school, one child had just graduated, and a final child had left school (Figures 8-9).

Schools, Placements, and Districts Represented

Mothers reported seven different Oregon school districts, three out-of-state districts, and there were two mothers who reported their children as not currently affiliated with a school district. Twelve mothers had experiences across two districts, and four mothers talked about experiences across three different districts. The majority of current and previous placements that mothers described occurred in schools across one district (see Table 1 below).

Children were predominantly enrolled in public school. However, some students were either homeschooled or enrolled in a public charter hybrid or charter school. Of all the focal children, 19 of them had either a current or a recent individual education plan (IEP), four students had a 504, and one student was at the beginning of the process. Nine of the students with IEP’s had placements in the general education environment and had regular pulled-outs into a resource room for service delivery. Five IEP students’ placements were in contained classrooms or extended resource rooms, and they experienced various pull-outs for general education or mainstreaming. Three IEP students were in specialized life skills or behavioral classrooms; some of these students also had limited pull-outs for general education and mainstreaming. One IEP student was in a specialized program with zero access to general education or mainstream activities. All students with 504's are automatically in the general education environment and may or may not receive pull-out services into a resource room (see Table 2 and Figures 10-11 in appendix).

Table 1. Placements Across Districts

	Current District	Previous District	Additional District
All Districts	24	12	4
District 1	14	5	
District 2	2	2	1
District 3	3	3	
District 4	2		
District 5	1		
District 6		1	
District 7			1
No District	2		
Out of State		1	2

Disability Categories and Diagnoses

Mothers spoke about their children's eligibility categories and their children's actual disabilities. While there was some overlap, there were also notable differences. Of all children, including focal children, the primary eligibility category mentioned was Autism, with 12 children eligible in the category, followed by eight children eligible under other health impairments (Figure 12). Other health impairments is a catch-all category for various acute health conditions, including but not limited to conditions such as asthma, attention deficit hyperactivity disorder. In some situations, with 504's or their additional children, mothers did not clarify a specific eligibility category. The prominent disability diagnosis mentioned across all children was also autism. However, there were gender differences worth noting here. Six out of twelve girls had autism diagnoses, but only two were found eligible under Autism; this contrasts with ten out of twenty boys eligible under autism when only nine boys had autism diagnoses (Figure 13). Other diagnoses that mothers regularly mentioned included anxiety and attention deficit hyperactivity (see Figures 14-16 for all disabilities).

Summary

Regarding organization, chapter two will focus on maternal perceptions of the Special Education system itself, including thematic discussions of limited resources, inadequate funding, and mothers’ perceptions of staff. Chapter three describes mothers' narratives about their children’s exclusion experiences; it will cover both the structural and punitive nature of student exclusion and the different degrees of exclusion students experience regardless of their educational placements. Chapter four will begin with a discussion of the pedagogical and the social harms students experience. Using a lens of institutional betrayal, the final section of chapter four will illustrate the denial of personhood students experience. It will focus on the ways special education places some students in situations where basic social and bodily needs remain unmet or severely neglected, which ultimately violates their rights as children and as disabled persons.

Chapter five will then discuss the compulsory labor mothers invest into the Special Education system. This labor is invisible, unpaid, and invested at all points in the system, from their initial fight to get and keep services through the ongoing struggle to ensure their child’s educational, emotional, and physical needs are met. Chapter five will also offer a brief discussion of the unrewarded labor staff invest and close with a discussion of how labor invested by mothers and staff are attempts to buffer students from the exclusion and harm resulting from an underfunded and poorly implemented Special Education system. Chapter 6 will be the final chapter and will put the four chapters in conversation to discuss the cyclical nature of mothers' experiences and perspectives. I will close by imagining potential interventions that could begin to free mothers from the compulsory investment of unpaid labor while simultaneously moving us all away from the harms of legally sanctioned segregation.

CHAPTER II

MATERNAL PERCEPTIONS OF SERVICES AND STAFF IN A CONTEXT OF RESOURCE SCARCITY

The ones that have the hardest behavioral struggles are the ones who take the most resources, the ones who are the most marginalized to begin with. Those are the ones you drop.

~Gloria

This chapter highlights maternal perceptions and the material impacts of resource scarcity in special education as a starting point in a larger narrative about mothers' experiences navigating special education. To capture the complexity of maternal perceptions of services, I directly asked mothers what they found to be most helpful and what they felt was least helpful in supporting their children. We spoke about their child's strengths and weaknesses, socially and academically, and about the barriers in their child's ability to access services. I also asked mothers to choose three descriptive words they felt best captured their experiences with special education. Of the 69 words that mothers came up with, 47 had a negative tone, eight were relatively neutral, and 14 had a positive tone. The most repeated negative word was "frustrating," which four mothers chose, followed by heartbreaking, inconsistent, insufficient, and nightmare. Of the 14 positive words, mothers repeated helpful and hopeful twice (see Figures 17-18 in the appendix for all words).

Three mothers out of the twenty-four mothers expressed primarily positive experiences. While the other mothers did share positive perceptions, they spoke most often and at greater length about their negative experiences. Simultaneously, mothers often situated both their negative and positive perceptions alongside a nuanced understanding of the systemic structural limitations of resource scarcity. Consistent with previous work, the mothers' narratives paint a picture of an underfunded unsupported, and poorly implemented special education system that, in most cases, was failing to meet their children's needs. Mothers spoke candidly about funding and how resource scarcity has sustained an educational environment that cannot meet their children's needs, an environment that, in many cases, led to their students' exclusion and harm.

It is important to note that, while mothers described resource scarcity in terms of limited resources, I am not using these terms interchangeably, as they are not the same (Daoud 2010, 2015). Adel Daoud describes scarcity as a "quantitative relationship between means and ends," arguing that "when the means available to satisfy some ends are not enough, then a situation of scarcity arises" (1). At face value, this definition does look quite similar to limited resources. However, one aspect of resource scarcity is that it involves "a system of entitlements for access to resources" (Daoud 2015:1), which implies decisions are being made about who is entitled to what. My intentional use of resource scarcity in this way allows for a more nuanced analysis of the scarcity in special education.

In summary, I begin this chapter with maternal perceptions of resource scarcity regarding both the availability of funding and its redistribution on the ground. I then discuss how these funding decisions drive both the effectiveness of the special education services and the staff's abilities to implement those services. I close this chapter by engaging again with Bérubé 's argument that "the politics of recognition are inseparable from the politics of redistribution" (2003:53) to discuss how funding decisions at the federal, state, and local level are not value-neutral. These are distributive decisions that explicitly create and maintain the context of resource scarcity in special education while simultaneously making an implicit statement on the moral personhood of disabled children as valuable, as worth educating, as worth caring for and protecting.

Maternal Perceptions of Resource Scarcity

When Funds Are Limited or mismanaged

> *You can teach somebody to fish, but if you don't have the resources to provide a line and hook, it's not going to get anywhere.*
>
> *~Deanna*

Funding was a common theme in mothers' narratives about their challenges when navigating special education. Mothers often held contrasting opinions about the cause of limited funding. While they sometimes talked about resource scarcity as situational or outside the control of teachers and staff, they often described the intentionality behind funding decisions at the school or district level. Consider Bell, who is a 35-year-old mother of two children. Her eight-year-old son has a 504 under "other health impaired." Bell states that "the administration, the schools, the teachers, and the program itself are overwhelmed. They don't have what they need." With this statement, she communicates a "situation" that the school, its staff, and the special education program all face together—a situation that she admits creates tangible "roadblocks" in her son's ability to access the curriculum. However, Bell also expresses intentionality and choice in describing those roadblocks. Her son has attention deficit hyperactivity disorder and anxiety, and she states, "we have this whole list of things that we know will help him." However, they are "not willing to find a way to make it happen" because "oh, that might cost money. we can't do that."

Judith also uses the word "willing." Judith is a 42-year-old married mother of two children. Her 16-year-old daughter is autistic and suffers from anxiety and hallucinations. Judith's daughter qualifies for an IEP under the eligibility category of specific learning disability for dyslexia and dysgraphia. When I asked her what she thought the schools could do better, she responded with a few ideas about case management but quickly stated, "every idea in the world is great, but nobody's willing to fund the schooling to make it happen." Similarly, Cymone describes her son's experiences and the school's decisions behind the lack of support for her child. Cymone is a 32-year-old married mother of two children. Her 12-year-old son is autistic and, after several years in regular public school, is currently enrolled in online homeschool. Cymone talked about her son's support needs going unmet in public school, explaining, "there was just a lot going on, things weren't being followed, he really needed a one-on-one, and they weren't willing to give him that because it's expensive." Like Bell and Judith, Cymone frames things in terms of willingness. Cymone describes how the school consistently denied a needed communication device for her son because it was "looking out on money, more than they ever did for his best interest." She is upfront about her feelings that funding decisions interfere with the school's ability to provide adequate services for her son.

> *Honestly, I think it's absolutely all about budget, all about money, and what is better for the school district. I know, you wouldn't think that, but I feel like there's some kind of quota, somebody out there who's going, 'Well, we're not going to buy this because we don't have enough to go around,' or 'He's just borderline, so he probably doesn't need it.'*

Across the interviews, mothers consistently connected funding to the school or district's denial of one-on-one support for their children. Gloria is a 48-year-old married mother whose 17-year-old autistic son is in a life skills classroom. She shares that they initially had one-on-one support in place for her child, but the school "withdrew it, even though it was in the IEP." Gloria had to advocate for the school to reinstate her son's one-on-one aide. She states, "it seems to me that he should have a one-on-one, and the special education teacher at the time said that they were not legally obligated to provide him one because the IEP language said trial basis." However, she states that "the reality was there were budgetary constraints." Gloria describes what happened after she questioned them about the lack of support available for her son, and in doing so, touches on the situation teachers and staff face because of funding decisions made at other levels in the system:

> *Their response was that the district was not funding them. That the district had told them that because they had a comprehensive learning center on campus, they already had all the staffing resources that they needed to support the children by nature of being a CLC. So basically, I was told by them that they pushed it back on them to manage it. So how they managed it was they withdrew the support.*

Lyndsay also shared how funding interfered with her son's ability to access one-on-one support. Lyndsay is a 37-year-old divorced mother of three. Her son is 11 and has spent most of his school years in specialized behavioral placements. Professionals have suggested looking into an autism diagnosis, but he will no longer sit for testing. He is diagnosed with disruptive mood dysregulation disorder and oppositional defiance disorder. He is considered to have an emotional disturbance but qualifies for his IEP under other health impaired for his ADHD. Her son really needed a one-on-one aide. Her son's teachers really needed him to have that support. Nevertheless, Lyndsay tells me how funding prevented her from getting the school to provide one.

> *I was like, he needs a one-on-one aide. I was like, it doesn't have to be all the time, but it has to be for this time, whatever class it was, I don't know because it was every single day, he was, you know, leaving the class or injuring himself or yelling at someone there was an incident every single day in that class.*

She describes how she tried hard to get the one-on-one, "but the funding" determined the outcome over her son's needs. Lyndsay described feeling like the school is always asking for everyone to compromise but that it is always her who ends up compromising. She states.

> *In my head, I was like, 'I don't have to,' like, you know, but it still ended up me compromising, and I feel like they didn't at all, it's like 'oh, you're compromising with your funding. Okay, gotcha.'*

Bailee is a married mother of three children. She is 42 years old, and her oldest son is blind and autistic with high support needs. He has also spent his entire education in specialized classes or programs, and she describes how funding was often a point of contention in many of her IEP meetings.

> *They would literally tell me, there's other kids in the school, and we can't spend all the money on your son. I had to have an attorney have the special ed director stop talking to me about money because they're not supposed to, and like, they'd be like 'that will cost $10,000 to do that, and there's other students that need educated' and stuff like that, and I would feel guilty.*

Because of her son's unique needs, Bailee's perspective on funding diverges somewhat from other mothers. She does not describe a perceived absence of funding but rather the blatant misuse of available funding at both district and state levels. For context, Bailiee had tried for eight years to get her son placed at the school for the blind, but the school district kept saying they could teach her son and refusing that specific placement. When I asked her why she thinks they did this, Bailee responded:

> *I have a theory. I'm not sure. There's a fund that these districts can access for kids who have complex and rare disabilities, so there was extra funding that came with my son, though none of it was ever used on him. He was just segregated in a room. But I wondered if it was like he was a cash cow.*

After years of advocating, Bailee finally got her son into the school for the blind. This placement was not only the one placement where her son experienced any safety and success; it was also short-lived. Soon after she secured his spot at the school, the State shut down the school for the blind. Her son had to return to his home school district.

> *They decided that it was segregation and that the students should be in their districts, which all the parents protested. We went and spoke to the house representatives, we were like, that's where our kids came from, and it wasn't working, and that's why they're here, and you're saying that you're sending them back?! and they're like, 'we're closing down schools that are segregated.' So, they closed down the School for the Blind, and then they remodeled The School for the Deaf. So, it didn't make sense.*

Bailee also points out that it "doesn't seem like they took any sort of resources that were being used by the school from the blind and helped improve the public schools," even though "they were supposed to." She describes that after they closed down the school for the blind, "there was a lawsuit, and the families won $900,000 for their kids' is education." This money "was to go through to the districts, it was called the blind and visually impaired fund, so the districts could access it to get extra resources."

Bailee asserts that with this fund, "there was no reason why they shouldn't have been providing [her son] things." However, "the rule was that the district had to provide everything they were supposed to before they could access the funds, so they weren't doing that. So, they couldn't access the fund." Again, for Bailee, it is not an issue of resource scarcity but resource mismanagement. Finally, while mothers spoke directly to the lack of funding, they also continually highlighted how district-level decisions concentrated resources differently throughout the various schools, contained classrooms and special programs, and effectively eliminated mothers' agency and choice in team decisions.

The Lack of Agency and the Logistical Problems of Student Placements

The distribution of resources within and across school districts had tangible impacts on how mothers perceived their agency and their role on the IEP team; this was most salient in the mothers' accounts of their children's placements. There is a stipulation in the IDEA that states, "unless the child's IEP requires some other arrangement," the district must ensure that "the child is educated in the school that he or she would attend if not disabled" (IDEA 2004). This stipulation allows schools to an availability interpretation for placement decisions. These decisions often leave mothers feeling like they little to no say in the matter. These findings are consistent with Blum's assertion that "with funds for special education frequently embattled mothers were angered by the "team" rhetoric promising them a voice in their child's Individual Education Plan (IEP)." Mothers' lived experiences often contradict IEP team rhetoric. When it came to placements, mothers' stories most often suggest that while they are involved in the team process, they still have little control over the outcome. The lack of agency in the outcome is akin to Valle's (2011) "coercive persuasion." Furthermore, the district-enforced placement decisions created logistical burdens for mothers, and, in many cases, mothers did not feel like the placements met their child's specific support needs.

Regarding logistics, consider, Lysha, a 48-year-old married mother. Her 11-year-old son has an IEP for autism, and his placements have primarily been in contained classrooms with various pull-outs into the general education environment. Lysha and her husband "bought [their] house so that [her son] could go to [a certain school]," and when push came to shove, they ended up having to fight the district to get into that school.

> *It was made very clear to me that I don't get to choose what school he goes to; the district decides the placements because of the way they do things. . . this was a stressful thing for us because we didn't know for sure where he would go.*

Adelina describes similar logistical complications in placement decisions. Adelina is a married mother of two children. She describes her 10-year-old daughter as a sentimental child who "loves to read" and "loves life." Adelina's daughter is eligible for an IEP under other health impaired. Her daughter is currently in general education; however, she was in a contained classroom with pull-outs for general education and mainstreaming in her previous district. Adelina shares that in her experience, "when you are on an IEP, you don't get a choice in [the district], you don't. You go where they tell you to go." She recalls how their neighborhood school "didn't have room for her [daughter]" and points out that one school they wanted to place her at "was like an hour and a half bus ride which is ridiculous."

Louisa is a 44-year-old married mother of two children. Her 16-year-old son is autistic and is in a contained learning center. Louisa is one of the three mothers who described their overall experience as positive. Even still, Louisa states that "the IEP team, which includes the parents, and the teachers, didn't have a lot of say, of where [her son] was going." At one point, the district initially had her son "slated to go like way across town from where [they] live." She recalls that "this was the only time where we had some antagonism, and I actually had to threaten the lawsuit, which was huge for me because we haven't had any problems." She says the "whole idea of 'least restrictive or 'closest,' you know, to where they would be if they didn't have an IEP fell out the window." Their neighborhood CLC did not have room for her son at the time, so the district wanted to place him across town, which she ended up fighting.

> *I had to say, look, he'll be on the bus for over two hours. That's not acceptable, and this isn't going to happen, and the week before school started, we got into [our school], and it worked out. But it opened my eyes to how some people do struggle on how some decisions are made, and that was a district-level decision purely based on numbers.*

Louisa says that she has "since seen that happen with other kids and that they're just being placed based on where there's room in this program."

Mileena is a 40-year-old married mother of three children, all of whom are, or were, involved in special education. Her 12-year-old autistic son is currently in general education and is pulled out for IEP services. She also conveys a lack of agency in her son's placements, which again created a significant logistical burden: "we drove him for two or three years to [one] school, and then [the] school moved further, and the enrollment dropped, and that was all they needed." She points out that the resources to meet her child's IEP were no longer available,

> *at that point, the half-day IEP room they had went down to a quarter day due to enrollment. By dropping it to a quarter-day funded program that didn't facilitate my son's IEP requirement, so they forced us to go to [a different school]. We did not want to go to [that school], but they forced us to go.*

Mileena clarifies that they are now living "two blocks" from their neighborhood school, yet her son, even though he has a general education placement, is still placed at a different school almost five miles away.

Deanna is a married 40-year-old mother of two. Her daughter is a 7-year-old autistic child who is good at math, loves to read, and "really wants to help people." Her daughter has an IEP and, until very recently, has spent her time in contained classrooms with little access to general education. Deanna describes logistical problems resulting from her daughter's placement.

> *She’s actually not placed in our neighborhood school. They bus her to [a farther school] because that’s where they send the resource requests, and they said, we think these resources here will be a better fit for her. So we’re doing that.*

Logistically, her daughter’s placement outside of her neighborhood catchment also meant that Deanna had to apply to get her son into that same school so the siblings could stay together and had to get the district to allow him to ride his sisters’ bus. She points out that the bus ride to her daughters’ school is almost an hour-long, so she has “to drive her in, but she takes the bus home.” She is unsure what will happen to her son’s transportation when his sister graduates out of that school.

Gloria also expresses her frustrations with her son’s sixth-grade placement and describes how she had to fight the district for four months to get her son placed in a learning center specializing in autism.

> *They had placed him at another CLC Middle School, and I had requested that he go to [a specific middle school], because the teacher and staff there had a particular expertise in autism . . .the district told me that they have the ability authority to decide placement and that they wouldn’t place him there because all CLC’s can meet children’s needs . . . but this center over here specializes in autism. That’s my son’s eligibility. I want him to go there, and they would not do it.*

At this point in our conversation, Gloria recalls asking her district why it was so hard to find any information about the special education programs available in the district,

> *This is what the district told me. ‘Well, the reason we don’t do that is if we publicize it, and then parents will mistakenly think that they get to decide where their child goes to school, and the district decides placement. So, we don’t want parents to feel like they get to influence that.’”*

Gloria argues that their placement decisions are “driven” by a “lack of resources.” She asserts that they “manage those resources by creating the systems that say, we get to just put the kid where we think the kid should go because we have to balance out the numbers.” While some mothers pushed back and were eventually successful in getting children into their preferred placements, for mothers, who may not have the time, energy, and resources these mothers were able to deploy, the outcome would not have been the same. As mothers shared their perceptions of funding and placements, they spoke about these things as intricately connected to their experiences with the services themselves.

Maternal Perceptions of Services:

> *My frustration and disillusionment as a parent of a kid who's bright and charming and not the right-size peg for this little board game is that coming into this journey, I had expectations of her being a priority, and that just was completely shattered. It was like, I'm forced to speak their language, as far as this is what we do here, completely to the loss of the children that they serve.*
>
> *~Sarina~*

When mothers spoke about special education services, often, it was to express how the services were not meeting their child's needs. Mothers described situations where the services remained unavailable because individual education plans (IEP) were consistently denied or delayed, or the accommodations were thoughtlessly removed from the IEP. Additionally, when discussing the services their children did receive, mothers described them as driven by the system's needs rather than the child's needs. This perception of systems-focused motivation is similar and connected to mothers' perceptions about funding limitations driving placements rather than the student's actual need. Finally, mothers described a sense of ambiguity and lack of communication from administration, teachers, and special education staff. This ambiguity was especially problematic for mothers when it contributed to a lack of clarity around how to get services in place and how their child's needs were being met once services were in place.

The Unavailability of Services and Supports

A shared concern among mothers was how unavailable the services are. Mothers collectively describe situations where the special education services were unavailable to them for various reasons. In some cases, the school would regularly deny or delay evaluations and individual education plans (IEP). Additionally, mothers also shared that sometimes the school would remove the supports and services that they had struggled to get in the first place.

When Schools Deny Special Education Services

Denial through a refusal to evaluate:

Schools denied special education services by refusing or postponing an evaluation. Bailee shares how the district refused to evaluate her daughter for special education. The district justified their refusal by saying it is "because she doesn't spend enough time in the classroom because of her anxiety." When the district came in to discuss an evaluation, the woman representing the district told Bailee that her "daughter was excluded from being evaluated for special ed." She states,

> *I didn't like that she was using the word exclusion for the evaluation, and I investigated and talked to a bunch of people and found out that they have this evaluation team that would meet and decide whether a kid could be evaluated, which is against the law. So, I got a different person to do the evaluation.*

Bailee calls that group of district staff "the red tape team." She highlights the absurdity of their logic: "so you're excluding her from being evaluated because of the disability that's causing her to need to be evaluated."

Mileena describes how the district avoided evaluating her son for years, stating that she had "approached the school many times through kindergarten and first grade," asking them to evaluate her son. She recounts how even when she had put the requests in writing, the school kept dismissing them, saying things like "'Oh, well do it after Christmas break," or "oh we'll do it after spring break" and finally "'oh well it's the end of the year.'" It was not until much later in elementary school when the school finally took things seriously. Mileena relays how when they finally approached her saying, "'there is something wrong with your kid,'" please let us evaluate him,' she was like, "bring it on, please! I have been begging."

Judith described a similar dismissal and delay when she expressed concerns about her daughter having dyslexia:

> *I know it's a different curve, but it still felt wrong. It still felt like she shouldn't be doing this still, and [they would say] 'Oh, it's fine, it's fine if she's still doing it next year. We'll look at it, [repeating] If she's still doing it next year, we'll look at it.'*

However, as Judith points out, postponing an evaluation did not “help her in the meantime,” highlighting some of the material consequences of the delay by pointing out how her daughter’s “frustration made her hate school.”

Denial through a 504:

Another way that schools denied special education services under the IDEA was by offering students a 504 instead. While parents might believe that a 504 is just a less intensive version of an Individual Education Plan (IEP) or that it still falls under the IDEA umbrella, that is a misconception. While both documents relate to a child’s right to a Free and Appropriate Public Education (FAPE) and provide educators with information on how best to work with a child, a 504 is primarily about visibility and nondiscrimination. The 504 is, at its core, a document that says the school will not discriminate against students because of their disabilities. The Office of Civil Rights enforces a 504 under Section 504 of the Rehabilitation act of 1973. (DOE & OFCR 2016). The Individual Education Plan (IEP), on the other hand, is part of the Individuals with Disabilities Education Act (IDEA), which “focuses on special education services for children with disabilities and the related rights afforded to eligible students and their parents” (ibid 41). The Office of Special Education and Rehabilitative Services (OSERS) within the U.S. Department of Education administers the IDEA. The FAPE rights of a student with an IEP are protected under section 504. However, the right to FAPE for a student who has a 504 is not protected under the IDEA. Furthermore, a student with a 504 does not have access to the services and safeguards which are guaranteed through the IDEA (DOE & OFCR 2016).

There are situations where the 504 is all that is needed to ensure FAPE for a child, and sometimes the practice of offering 504 is entirely reasonable and appropriate. However, the mothers’ narratives in this study describe a different situation; for some mothers, when schools place their children on a 504, the school effectively denies necessary special education services. This denial is especially salient when transferring an individual family support plan (IFSP) to an IEP. An IFSP falls under part C of the IDEA and is in place to support the child by supporting the family. Once a child is school-aged, they are covered under part B of the IDEA, and the goals become about the individual student. However, some of the services offered and used in the IFSP, such as sensory tools and communication devices, are applicable and beneficial to the individual student in a school environment. Nevertheless, mothers discussed the challenges of getting services and continuing supports. They described learning that an IFSP does not always translate to approval for an IEP, nor does it imply that the services and supports will carry over.

Angelina is a 49-year-old mom of two. Her 17-year-old son enjoys making 3D sculptures out of paper, is "freaking brilliant," and "wickedly funny." He has a sensory processing disorder and spends a fair amount of his time in the general education environment. He is eligible for an IEP under the Autism category. Before entering public school, her son had an IFSP in his preschool program. However, after transferring, the school denied an IEP, giving him a 504 instead. The transition to a 504 resulted in the removal of functional supports from the IFSP. Instead of removing those supports, the school could have formally built upon them in an enforceable IEP. The schools' justification for the denial was that her son had met all the academic benchmarks, which meant her son did not "fit the criteria for an IEP." Angelina also describes how the 504 itself was not just "poorly written," but written without her input, "it wasn't a collaborative 504; it was the school making a presumption about who my kid was." Angelina describes going back to the district, saying, "look, you can't tell me that he's gotten help since day one, and then all of a sudden, now he's smart, and he can do a social situation like you're expecting."

Anais shares a similar situation. Anais is a separated mother of three who appears to be in her mid to late twenties. Her autistic daughter is seven years old and is very good at reading. She struggles with making friends but has social strengths, such as an awareness of personal space that lends itself to parallel play. Her daughter has additional diagnoses of ADHD, OCD, severe sensory processing disorder, and speech delay. She came to the public school with an IFSP, yet the school has consistently refused an IEP, stating they wanted to see how she adjusts in the general education environment with just the 504.

> *They were like, well, let's just see how she does without a 504 and without an IEP. Let's just see how she does, and I said 'she has an IFSP. I'm not willing to do that. We need to have something in place for her. Because I'm not going to set her up to fail.'*

In many cases, this initial denial of an IEP would lead to an unnecessary delay as mothers continued to advocate for their children. At the time of the interviews, Anais and several other mothers were still fighting to get their children's services through an IEP. In addition to these types of delays, mothers also had to grapple with the school or district's denial of specific supports their children needed once they got services in place.

When Schools Deny Specific Supports and Accommodations

The denial of supports was another way special education services were unavailable and inaccessible for their children. Mothers described two ways districts denied certain supports: a *direct denial* of the support itself and an *indirect denial* through eligibility categories that determine the kinds of supports available. The denial of supports is significant to consider here, as supports remain central to how schools determine the least restrictive environment for a student. Section 300.114(a)(2)(ii) of the IDEA states

> *special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily*

Furthermore, section 300.42 of the IDEA defines supplementary aids and services as

> *aids, services, and other supports that are provided in regular education classes, other education-related settings, and in extracurricular and nonacademic settings to enable children with disabilities to be educated with nondisabled children to the maximum extent appropriate*

However, many mothers had expressed that their child could have succeeded and even thrived in a general education placement if they had been able to access the appropriate "supplementary aids and services that the schools consistently denied.

Direct Denial of Needed Supports:

The denial of specific supports cuts across all my findings, so while I highlight it here, it will receive a much closer discussion in chapter four, and I will touch on it again in chapter five. One salient example of a denial of supports is when the school refuses one-on-one aides. A district may justify this decision with the claim that one-on-one aides are overly restrictive. There is research that supports this justification. Furthermore, thanks to the ambiguity of language in the IDEA, the justification itself is technically legal. Nevertheless, the stance is ultimately tone-deaf to what mothers are saying (Werts et al. 2004), which is a disconnect that exemplifies and reinforces an artificial hierarchy by placing district professionals, as the experts, above mothers who are not (Beratan 2006; Rossetti et al. 2020). Furthermore, it is a stance that ignores literature focusing on *how* districts train and deploy one-on-one aides, not *if* they use them, as a determining factor in their usefulness as an offered support (Freeman 2018; Malmgren, Causton-Theoharis, and Trezek 2005).

Lena is a 41-year-old married mother of three. Her 7-year-old daughter has cerebral palsy and is nonverbal. While her daughter's "determination is a huge strength for her," she and her teachers would benefit from consistent one-on-one support in the school environment. Lena shares that the school refuses to put a one-on-one aide in her daughter's IEP.

> *they refuse to use the word one on one, which is not uncommon, as you know, I'm sure. So, we asked them for documentation of their refusal, and of course, the term is I think what they [said they provide] is adult supervision or something like that, and we're like, she doesn't need supervision. She needs an aide.*

Lena is not alone in this experience. As discussed earlier, a one-on-one aide was one of the many compromises that Lyndsay describes making with the district because of inadequate funding. Lyndsay describes her son as a "social butterfly who can make friends with anyone," however, he also had intense support needs that went unmet in the school environment leading to safety issues for himself and others. The district ultimately placed her son in a series of highly restrictive placements, including one that consisted of a few hours a day in the district office. However, in Lyndsay's experience, the district consistently denied a one-on-one for her son.

A one-on-one aide is just a singular example of supports that districts denied. Mothers also spoke of the district denying adaptive technology. Cymone describes fighting to get a communication device. She states that the school "evaluated [her son], but they said there wasn't enough evidence to warrant" providing one. Cymone was trying to get the school to provide an updated Picture Exchange Communication System

(PECS) for her son. Not only did her son need it, but he was also previously using a PECS in the preschool environment under their Individual Family Support Plan (IFSP).

> *[He] didn't talk until he was four and a half, and so when he finally said his first words, they were things like Mama, and you know. When he went into school at five, he wasn't much better than he was at four and a half. So, it only made sense to carry over the pecs, which he had been consistently using all of preschool, [but they wouldn't carry it over.] Because it's expensive for them, and they have to provide it for him at home too. So, I had him reevaluated in fourth and fifth grade; they denied it both times then too.*

If we take seriously Kleinert's (2020) claim that "communicative competence represents the most fundamental of educational outcomes—for communication lies at the basis of all that we do (45), then it follows that a district's denial of communication devices is detrimental to a child's wellbeing. I discuss the denial of these fundamental supports further in chapter four, situating them as significant and common sources of the institutional harms special education can and does inflict.

Indirect Denial of Supports through Eligibility Categories:

Eligibility categories are not arbitrary. These categories can be a determining factor in providing or restricting available supports. Therefore, a school's use, or their avoidance, of specific eligibility categories can work as an indirect denial of supports. Bailee shares how the schools' use of eligibility categories was just one aspect of her struggle to get appropriate support for her son. Her son's IEP had him listed under an eligibility category of intellectual disability. Bailee clarifies that was only an option because a previous special education director falsified tests which led to the school mislabeling him as severely intellectually disabled

> *He's never been evaluated for an intellectual disability because every evaluator has said we can't. He's obviously very smart, and we don't know how to test a blind person for intellect because you have to do a different test for a blind person, and with his communication challenges, it just wouldn't be accurate. In fact, there's a psychologist who actually wrote a report saying don't test him unless you have somebody who really knows how. So, [the director] had in his IEP these test results that said that he didn't understand text if it's read to him, not true, basically [it] said that he was severely intellectually disabled.*

At that point, Bailee asked the school, “where did this come from? Can I please see the scaffolding of the testing? How did you test him?” and found out that “there was no teacher that tested him, there was no records of how he was tested.” She describes how this has presented ongoing challenges in getting the appropriate supports and services for her child.

> *Technically, he wasn’t tested; they couldn’t come up with a person who actually tested him. I think she just put it on there. It’s still following him. I’ve had it removed from his records, and then when I get his records, it’s back in there. So, I think that’s one of his biggest challenges is that he’s been misidentified as severely intellectually disabled.*

This is another example of how mothers are often token participants in the IEP team with little control over the IEP itself. More than that, though, this is an indirect denial of services because, as Bailee points out, it effectively eliminates the school’s obligation to provide specific supports.

> *It reduces the amount of things they would have to provide for a kid who can learn, like technology, like blind skills, you know, all the things that he wasn’t getting. They were like, well, ‘he can’t do them because he’s, you know, intellectually disabled.’ But he can! He’s very smart.*

While the school denied Bailee’s important technology through an eligibility category, mothers often described the alternative situation in which the school refused specific eligibility categories. Judith shares her experience with this, pointing out that even though her daughter is diagnosed with autism, the district will not consider her eligible under the autism category.

> *I don’t really understand if she’s been marked autistic by her psychiatrist, by her doctor, and they know she has autism; why can’t she qualify? Why isn’t autism a qualifier? But it seems like they are not treating autism as a spectrum. Like they only want to help these autistics and these autistics So, she’s over here, ‘well you’re not the autistic that we help.*

A student’s eligibility for services under an autism category allows for valuable supports, like student and teacher access to an autism specialist; it could also impact how teachers view and interact with a child.

Adelina shares her experiences and reasoning behind trying to get the school to consider autism eligibility. Adelina’s daughter is medically diagnosed with 18q syndrome; this is caused by “the deletion of the terminal long arm of chromosome 18” (Albuquerque et al. 2017). 18q leads to a variety of possible symptoms, including "developmental delay, hypotonia, facial and cranial deformities as well as visual, hearing and postural alterations" (Albuquerque et al. 2017). Adelina's daughter qualifies for an IEP under the categories of other health impaired and intellectual disabilities. Adelina had to push for the school to recognize that her daughter needed supports specific to Autism. She describes how trying to get supports added to the IEP is a long and extensive process, stating, "there's too many hoops that you have to jump [through] to get a student [support that] is obviously something they need. It's absurd the jumps that you have to do." She highlights the time and resources she has invested into getting her daughter the appropriate supports.

> *[It's]ridiculous. Like we asked for this IEP meeting at the beginning of the summer. It's [September]. It's very long, you know, and then I had to pay out of pocket for a psychologist to get the diagnosis, so I could get these supports that she clearly needed before the [ASD] diagnosis.*

Adelina's frustration is audible as she goes on to state, "this is what I mean by excessive like those hoops shouldn't have had to be there," pointing out that her daughter is "two months into a school year" and still waiting for supports.

> *They're still the same child after the diagnosis, as they were before. It's not like suddenly, 'Oh, maybe they need this now.' You know? I can't go back. No, you can't fix that damage. So, for me, I feel like it's excessive. I feel like if it's obvious that a child needs something, then get that support in place and give that child what they need to be successful.*

These direct and indirect denials of support and services are central to mothers' perceptions of special education services as unavailable. However, the removal of supports and services also played a role.

When Schools Remove Services and Supports

Mothers shared stories of finally getting services in place but having to continue advocating and fighting for the appropriate support to remain on the IEP; this was particularly apparent during elementary to middle school transitions. Many mothers talked about how the schools would remove individual supports from an IEP while keeping the rest of the IEP. They also talked about difficulties when the school would transition their child from an IEP to a 504. These are further examples of mothers feeling included in the IEP team on paper while remaining relatively powerless to impact the outcome. Furthermore, when mothers did discuss the schools transitioning them to a 504, they communicated an awareness of losing things like supports and accommodations and an understanding that the 504 did not carry as much weight as the original IEP. However, mothers did not often distinguish that the 504 no longer specifically protected their child's access to FAPE under the IDEA.

Mothers describe that when a district removes support, they must push and advocate to get the supports back. These efforts are salient in Gloria's situation discussed earlier. Budgetary concerns drove the school to remove her son's one-on-one aid, and she had to advocate to get the support reinstated. Lysha shares a similar situation when she mentions that at the next IEP meeting, she must advocate to get the "supports for classes music and PE" that the school removed put back into the IEP. Adelina also shares that her daughter's "adaptive PE has been taken away" despite being still needed. She describes how the school justified removing this support because they considered it "too restrictive."

> *She's had two feet surgeries. She has low muscle tone and abnormal gait, Just really clumsy. It's all part of the 18q, and why did they take it away? What did they tell us? Because it's more restrictive than they feel that she needs and won't allow her to play soccer the way she wants to.*

Adelina points out that removing the adaptive PE does not seem to about her daughter's needs. "What I heard is it was slowing the rest of the class down, and that's why they took it away. That's basically what I heard. Did they put it that way? No. But I'm a smart person." She also points out how the removal of support solidifies her feeling that the school always dismisses and discounts her and her husband's concerns.

> *It feels like we have been pushed a little bit and kind of treated like they know better than we do. The IEP has kind of already been done when we get there, and they just kind of go over what they think, and then they have us sign it. It has never been a lot of back and forth, and every time we ask about why something's been taken away or why this is like this, we just get told because that's how it has to be, according to the district.*

Mothers described how services were especially at risk for removal during specific school transitions, such as moving from preschool to kindergarten and transitioning to middle school. Cymone describes how her daughter lost the familiar supports from the IFSP when she enrolled her into kindergarten. Cymone's daughter is seven years old; she has an IEP for supports around ataxia, dyspraxia, and obsessive-compulsive disorder. Cymone talks about her transition and how "the public school lost all of her things, they had to resend it over several times, and even then, none of that was being followed." The lack of supports did not come without consequences for her daughter: "her sensory diet wasn't there, they weren't providing that for which was causing her to bolt." Furthermore, when it came to writing the IEP, Cymone goes on to state, "the school wasn't interested in what we had or what we wanted or what was best for [her daughter]. It was their system that they wanted to use." This situation meant that her daughter lost many of the functional supports she was used to in the preschool environment. The experience of losing supports and services was not isolated to her daughter; Cymone also describes how the school "cut her oldest son's [occupational therapy] services, saying he didn't need it anymore." She points out that "he clearly needed it," highlighting how the school removed this without thoroughly regarding his needs or her wishes.

Cecilia is a 33-year-old married mother whose son has attention deficit disorder and suffers from anxiety. She shares that her son has an incredible amount of empathy and "is very conscientious about how he engages" with other people. He quickly gets abstract concepts and "uses his empathy to be an ally" to the adults and other children around him. Cecilia's son currently has a 504, and she shares how her son lost services and supports. Her son had an "IEP in elementary school" that "included speech therapy." However, the school "decided in middle school that his speech was sufficient so "they were very quick to remove him from the IEP when he got into middle school" and give him a 504. Cecilia describes this as an "almost thoughtless level of removing him" pointing out that "they didn't even wait till he was in school for a couple of months to assess whether he needed [the IEP] still." Overall, Cecelia describes the transition from elementary to middle school as "awful."

> *They lost his diagnosis. They failed to communicate with the teachers. I had to completely redo his entire diagnosis with the doctors and resubmit it to the school when he went into sixth grade, and then they lost it again at the beginning of this year.*

This "meant that for two-thirds" of the previous school year, Cecilia's son "was not receiving any support" or services. Mothers' perspectives of special education services as unavailable, while discussed as analytically separate here, are linked to their perceptions of resource scarcity and their perceptions of special education as prioritizing the system's needs over the needs of students.

Special Education Services as Systems-Focused and Self-Referential

A prominent theme in the interviews was the perception of services as disconnected from children's needs. This disconnect between the system and their children was especially apparent in their descriptions of special education services as "inappropriate" for their children. More than that, though, mothers expressed concern that special education's primary focus is on what is best for the system; it follows that what is best for their children feels secondary. Gloria illustrates how services are inappropriate as she describes how her son has a range of academic, emotional, and social needs, as is the case for most children. However, her son's options are limited to how the district distributes its resources and staff. Here, Gloria highlights how the system's structuring and implementation limit the helpfulness of the services her son receives, stating that "what [she] find[s] the least useful is how siloed the services are." For example, she highlights how her son's needs don't fully fit in either general education with supports or in a life skills classroom, yet those are the only options available to him in this system.

> *I think the least helpful thing is that there isn't a responsive plan. So, anything that my son gets on the academic side at this point, I drive that, okay, and I have to look for ways to get him access to the curriculum without losing the functional support because, quite honestly, he could function in a gen ed classroom with supports, but his social life and his friends and where he feels comfortable socially, is in with the other children because they're all different.*

Gloria also points out that "the types of things that they're teaching in the life skills classroom are things that he can do," yet, "the children and this particular program have a range of skills when it comes to life skills, more so on the lower end." Gloria's example shows how the district's distribution of resources and staff limits her son's placements and services. Furthermore, his placement in a life-skills classroom limits the school's ability to meet his cognitive and developmental needs. Here, instead of responding to her son's needs as a whole person, the district utilized an availability interpretation of the least restrictive environment and provided the services that most easily fit the system's needs.

Lydia is a 45-year-old divorced mother of an 11-year-old who has an “engaging personality” that “people are drawn to.” Her daughter is both autistic and Black, an intersectional identity that complicates her experiences at school. She is a creative, intelligent, and resourceful child who has a strong vocabulary and loves to read harry potter books and graphic novels. Lydia shares that her daughter recently taught herself to sew to make a dragon costume based on one of her drawings. Lydia is currently homeschooling her daughter after too many challenging and traumatic experiences in public school. She shares her experiences with the distribution of resources determining what help was available for her child. Lydia described how the school was supposed to be supporting her daughter in the general education environment. Nevertheless, she was regularly getting pulled into the special education room for services rather than receiving the supports she needed in the general education environment—Lydia shares why the resource room was inappropriate for her daughter’s academic needs.

> *She needed the small group for sensory reasons, and she needed reading support, but she’s like, ‘Mom, they’re reading books about how to cross the street,’ because they are working with kids with cognitive issues she didn’t have, you know?*

Lena also expresses ways the services offered are inappropriate. She shares that her daughter is cognitively below her peers, resulting in staff making assumptions about her ability to learn. Lena describes how this results in them not knowing or not putting in the effort to meet her daughter’s unique academic needs.

> *I believe that the SPED program should be finding a curriculum for her cognitive ability, and they’re not. Instead of accommodating her, they’re making her accommodate their curriculum. I don’t care that she has the cognitive ability of an 18-month-old or a two-year-old, then go look at preschool material, and let me know what you find out. Like, I mean, she’s not the only child like this, and it is a struggle when they act like, we don’t know what to do, because she’s the only child who has ever, you know, lived, that has these needs, and it’s frustrating.*

Lena goes on to ask, “who’s to say that she couldn’t eventually learn colors?” Stating, “I think that they don’t want to try because they assume that she’s not going to understand . . . she understands far more than people think that she does.” One thing that stands out as she describes how offered services are inappropriate for her daughter is her comment that the school is making her daughter accommodate their curriculum instead of truly accommodating her. Lysha describes a similar situation of feeling like the school was asking her child to accommodate the system. Their focus was often on getting her son “to pass for neurotypical” through attempts to reduce or eliminate stimming as just one example. Stimming is one way her son self-regulates his sensory overwhelm. However, the school viewed his stimming as disruptive. Instead of providing the appropriate support for him to access his education, the school directed efforts towards eliminating the disruption without regard for the child.

While all of the above offer similar examples, which show some of the ways special education is systems-focused, some mothers were a bit more direct in pointing this out. Bell asserts that the schools use the system is used “to protect itself, rather than protect the child” stating, “this is beyond frustrating to me because they claim they want my child to succeed, but how can he succeed when [they are] putting up roadblocks everywhere, we go,” going on to wonder, “where would we have been, had we actually just sat down and said, what can we do for [my son]?” Bell’s last question stands out here because sitting down to ask what we can do for a child is what everyone believes is happening in IEP meetings.

Sarina is a 40-year-old married mother with two children. Her youngest daughter is eight years old and has an IEP for a joint and ligament issue impacting her hands and writing in earlier elementary school. She also struggles with ADHD. Sarina describes he daughter as a child with a strong sense of self who can advocate for what she wants. She loves to read, is good with numbers, and has “an absurd recognition of comedic timing.” Sarina expresses how her experiences with special education have left her feeling like it is “in service to make sense to itself, to make sure that funding is maintained.” Sarina suggests that the school is not asking what her daughter needs because they are more focused on tracking, so they can say, “look, oh my god, we’ve got 20 kids, and we’ve given them this stuff. So next year, we’re going to need this amount.” More than that, though, Sarina also argues that her daughter’s “accommodations do not accommodate her,” stating that instead, “they allow her to be visible to this system, that is this living, breathing, devouring beast.” She goes on to discuss her daughter’s accommodations, “it seems like they default to the categories that they are familiar with, not necessarily what’s going to serve the student.”

> *At each yearly meeting, I was like yeah, we probably don't need that, and they're like, 'you know, like, we're going to just put it in here. That way, like the teacher or the principal, has to honor this time.' It's a way of securing your spot. It's crazy, like, why don't we just write what she really needs, right? Because what she really needs does not fit into this particular category or that category like the resources that they have at special education, they have a lot of handwriting resources, but maybe they don't have a lot of resources about bullying or about self-esteem, or about social-emotional maturity.*

Sarina captures the disconnect between services and needs and describes special education as a "self-referential" system "that is not in service to help children learn at all." Furthermore, the experience she shares here illustrates how staff working within this system often silence mothers as uninformed and imply that, as experts, they know what is best for their children.

Special Education Services and Procedures as Unclear and Ambiguous

There so many people involved, and so many pieces and so many levels of approval, and you're not offered things you have to request them; you have to know to request them.

~ Judith

In addition to feeling like special education was systems-focused, mothers collectively shared a narrative that highlights a lack of clarity in the system as a whole. The two points most often mentioned as unclear were how the process works and how the services are delivered. Judith mentions how hard it was to find out the steps for getting services at all. She contrasts the inaccessibility of information with her feeling like the school expected her to know how the process worked, illustrating the impossible positions in which mothers find themselves. She states, "I had to get louder and louder. 'No, something is wrong. No, something is wrong," to which staff would ask if her child "was disabled or if she had documentation."

> *Like, 'no, I have nothing. I don't even know how to get tested,' and finally, somebody was like, 'you don't know this? you just get a referral from your physician,' and I was like, 'Why would I know this?' 'Why would I know to do that?'*

The lack of access to information can impact a child’s experience at school, potentially delaying their access to supports for years. Gabriella is a 46-year-old single mother with two children. Her daughter is 19 years old and just graduated. Her current goal is to go to school to become an esthetician. Gabriella describes her daughter as someone who is “very empathetic to people.” She is a “good listener” who “makes people feel good,” which helps her cultivate strong friendships. She struggles with depression, anxiety, and post-traumatic stress disorder, which created difficulties for her in public school. Gabriella shares that she and her daughter had to navigate those difficulties without support from the school. Gabriella could not get any official help for her daughter until her freshman year of high school, and even then, the school denied an IEP, giving her daughter a 504 instead. She describes how part of the delay in getting help was because she “didn’t know about the 504 or the IEP.”

> *I mean, and all the times I talked to the counselors, no one ever said anything. So, I just didn’t even know that was an option for somebody that wasn’t so severe that she needed the IEP, not that you have to be severe to need an IEP. In fact, she actually could have qualified for an IEP, I learned later. But I didn’t even know about the 504 before. So yeah, she should have had [help] much sooner.*

In this experience, Gabriella was also expected to inherently know how the special education process worked, as no one offered this information to her. Bell shares a parallel experience as she describes her current struggles accessing the information that she needs to get services for her child.

> *I’m not getting all the information that they should be giving me, and I’ve asked numerous times. What do I need to say? What do I need to ask for in order to get these things that he needs? Nothing. Like radio silence.*

As mothers described their frustrations with the ambiguity of the process, they shared that this ambiguity, this radio silence, did not just magically go away once special education services were officially in place. Several mothers shared that despite having an IEP, information about their children’s experiences in school remained inaccessible. They describe trying to piece together information and learning things from their children that the staff had an obligation to share.

Adelina describes how the lack of clarity experienced during the initial process remained once they successfully established services. She points out how they “were given a lot of misinformation" when they went into kindergarten and that she still struggles to get information about the services her child receives.

> *It's my understanding that there's an aid in the back of the classroom that decides when she thinks that my child's overwhelmed or anxious, and they pull out and take her into the other room. That's all I know. That's all I can get for them. I've asked for a daily schedule for a year now.*

Similarly, Nadia shares her experience with just trying to get access to her son's IEP. Nadia is a 45-year-old single mother raising an autistic child; her son was five years old at the time of the interview and spent his time in the general education classroom with pull-outs for service delivery. She states, "I felt like getting the IEP or copy of the IEP felt like I was requesting someone to give me their limb." Lysha also describes the inaccessibility of information as one of her "frustrations with sped services."

> *It was never clear to me, what was being done, how it was being done when it was being done, and what was on the paper didn't match up with what was happening in real life. Yeah, and so I can't tell you what percentage of the time he was in the classroom, third-grade year, or even fourth grade.*

She points out how there is not only "a lack of communication coming home," but her emails requesting information go unanswered—which is particularly frustrating for her as the IEP clearly outlines communication expectations.

> *I'm supposed to get an email every two weeks from the CFC teacher. I don't. She forgets. We hardly hear anything, and I have to go into the school and figure out what's going on. It's frustrating.*

Sarina shares a similar sentiment about a lack of information; however, she also connects that to a high staff turnover. This ambiguity was problematic because not only did Sarina not know what was going on, her daughter also did not know what to expect on any given day.

> *It has been such an enraging and disappointing process of like, I would be like, on Monday morning, I'd be like, 'okay. You might or might not be pulled out of your classroom today. Now, I want you to the first thing you say you're going to look to this man or woman; you're going to say my mommy says, I have to ask you what your name is.' I'm just trying to get names. That's it.*

Inconsistencies in available staff also impacted Lydia's daughter. Lydia describes how the school changed her daughter's one-on-one aide without sharing that information. The aide they removed worked well with her daughter by giving her space and independence while still providing effective supports. Nevertheless, the school had redeployed that aide and assigned her a new one. One part of Lydia's frustration was that the school had not shared this information with her beforehand, so she and her daughter learned this together when a staff member she did not recognize introduced herself.

> *She's like, 'my name is Patricia, I am your daughter's new aide,' and that's how we found out. So then [my daughter] is like 'what about Anya?' They tried to say they talked to her about it, but they didn't talk to me so I could help her, and it didn't seem like she heard them, so it was just a disaster from then on.*

While Lydia found out information with her child, Nadia shares an experience finding out information from her child. One of her child's strengths is memorizing things and "recounting them through dramatic play." She describes at least one instance where his strengths with dramatic play helped her get a sense of what was happening in the classroom.

> *My son has come home and put me on the behavior support plan, right? He is attempting to incentivize my good behavior and from his tone, etc. I know that that's being used with him. So, I have to ask more questions. If this is a general, we do it for everybody, and we just check in throughout the day about how they're feeling and give them a discreet stamp on a piece of paper, then I can live with it, and I'll sit with how uncomfortable it is to have someone implement a plan without your consent. . . If it's specific to him and not throughout the entire classroom, we're probably going to have some feedback.*

While she remains grateful that her child communicates with her in this way, she points out that if he "didn't do [that], there would be this huge void, no information, no access." This lack of communication, this "void," was a prominent point of tension for mothers as they struggled to get and maintain services for their children.

Maternal Perceptions of Staff

Mothers' reflections on staff most often centered on experiences with teachers. However, they also recounted interactions with special education professionals, school administration, and district staff. Maternal perceptions were not constrained as either positive or negative as they often described different experiences with different people across the entirety of their child's involvement with special education. While mothers tended to share their negative experiences, this does not mean they did not have positive interactions with individual staff. The mothers' negative perceptions were most salient when they expressed their frustration that staff rarely followed the individual education plan. Realizing the plan was not being followed was particularly frustrating for many mothers, as many of them had fought to get services and had trusted that the school, in turn, would support their children. Sometimes mothers shared their perceptions that not following the IEP was an individual choice for some teachers. However, more often, mothers shared their belief that inadequate information and support offered to teachers drove their lack of follow-through. Sometimes they held these opinions simultaneously. In the end, it did not matter to the mothers if the cause was personal or structural as both possibilities effectively constrained or eliminated the effectiveness of special education services for their children.

Uninformed about the IEP

Like the mothers' experiences with the ambiguity of services, a lack of clarity and communication also emerges as a central structural issue confronting teachers and impacting their ability to implement individual education plans. While Gabriella's daughter was not guaranteed services through an IEP, she describes how a teacher's lack of awareness of her 504 placed the burden on her daughter to advocate for her needs.

> *This is something that I saw as a parent, where she had a 504, but it was like, not all the staff was aware of her 504, or maybe they hadn't read it. So, when she would try to utilize it, like, 'Can I move my chair to the back wall,' she liked to have her chair in the back; it felt safest for her. They either would kind of like, question it, or make her feel awkward. So, she would have to explain the whole thing to them, and she's not really good at that, especially in the moments where she's starting to escalate.*

As Gabriella argues, "a 504 is supposed to be confidential and supposed to be something that can save a child from having to advocate so much for themselves, because they can't." Nevertheless, her daughter "was constantly having to advocate for her own 504 and what's in it." She also illustrates how educational staff members are often uninformed. "I don't think they're actually sufficiently communicating [the 504] to the teachers."

An uninformed staff created problems for Nadia's child as well; she states that "when [her] child went to school, the supports identified in the IEP were not available and there was no plan to implement them, because the teacher was unaware of the IEP." Feeling like the staff members were unaware of the IEP also led mothers to describe them as uncooperative.

Uncooperative about the IEP

Mothers shared a sense of feeling like staff members were uncooperative when implementing an IEP. In general, mothers described how the quality of services is, in many ways, the luck of the draw. For example, Gloria states that implementing an IEP "quite honestly all depends on the person who's got your kid in a classroom." She gives the example that her son "had teachers in a school who were exceptional, had some that were horrible, and some that were just okay." She describes it as a "hit or miss" situation that determines the effectiveness of the IEP.

> *So, the IEP gets done well when you got somebody who's got leadership, and who directs that leadership and inspires other staff and sees meaning in doing their best work and modeling that for others. And then it doesn't get implemented when you've got somebody who doesn't have the skills, doesn't really care, or actually feels burden by having this type of child in the classroom. Then it all unravels, and you always feel like you're kind of starting over.*

Lydia describes this hit or miss situation with staff as well "it's like the whole way there were these attempts, the things that could have worked and there were certain people that saw her and did well with her, certain aides, certain teachers, and just overall the system is broken."

While some mothers spoke in generalities, others shared specific examples of uncooperative staff. Sometimes they framed this as a personal choice on the teacher's part; however, they also understood the teachers faced structural issues. Mileena shares that the teachers "wouldn't abide" by her older son's "IEP at all." She states, "he's incredibly intelligent, and so teachers just basically said that you know, 'oh his IEP it's not needed.'" She also shares how her younger son's teacher "made the comment that she thinks 'IEP's are excuses, that they're just overused, and that kids get them for anything.'" Unfortunately, this teacher was her son's primary teacher, so to his detriment, his IEP was a wasted document for at least two periods a day.

> *His IEP clearly states that he gets 50% work. No homework, extra time to achieve things, you know, preferential seating, things like that. None of*

> *which were obeyed. Not a damn one in her class. She failed him all year—both classes all fucking year. An ‘F,’ not even an ‘I,’ A frickin ‘F’ all year without taking into consideration his IEP.*

I spoke with mothers about the specific accommodations they felt were the most and least useful in supporting their children. The question itself aimed to get at their perceptions of the specific accommodations. However, mothers often described that the whole IEP became the least useful when the teachers were uncooperative. Mileena frustration is evident as she states, “I think special education is so screwed up” and describes how basically anything on the IEP fits the description of least useful:

> *Anything because teachers choose whether they’re going to acknowledge them or not. So, yeah, it’s great if you get a teacher that abides by the IEP, but if you don’t, they’re useless. Because the teacher can pick and choose whether they like that accommodation or not.*

Mileena was not alone in this opinion. Cymone argues that “basically everything” in the IEP was ‘the least useful’ “because nothing was followed.” She shares that “maybe 50% of the time, some of them were followed, but I feel like there was a gross failure on the school district’s part.”

Kaleigh is a 40-year-old married mother of two. Her 14-year-old son has Autism and Hydrocephalus; he has an IEP with a general education placement. She describes him as a child who has a strong “interest in doing things and engaging himself in activities.” Her son is “happy as a cucumber, always.” He has a 4.0 GPA and enjoys school. She tells me that “he just loves to learn, he loves it all, he really does love school a lot.” Nonetheless, Kaleigh is in a similar position as Cymone in feeling like even “having an IEP” was the least useful because teachers and staff struggle to follow it. Kaleigh, however, touches on the structural issues. She offers a picture of teachers who are already overwhelmed and struggling and may not do what is right because they lack information, resources, and support.

> *[The IEP is] supposed to be beneficial, and they’re supposed to follow it. Yet, that does not even happen. It’s like a wasted document in some ways because we have teachers who are struggling to even do what they need to with non-IEP students. And yet, then they get an IEP student, and like, the document is in a foreign language to them, they can’t understand it, they can’t respect it, and they don’t accept it. And so, therefore, it’s not followed.*

While she recognizes the structural context, she also places the onus on teachers' choices and shares her experiences with teachers who "say, 'oh, this child has an IEP, they're so dumb, they don't need this, like, why even do that,' and that's upsetting in itself." Kaleigh's narratives get at the tension between the personal and the structural. On the one hand, she shares that in her experience, teachers "choose not to [follow] the IEP, which is a formal document that they are supposed to follow" and on the other hand, she offers that they do not follow it "because they don't feel like they're getting paid enough." Her latter observation once again implicates resource scarcity in teacher's individual choices by touching on how teachers are unsupported by their districts.

Unsupported by the District

Mothers collectively described their perception of a distinct lack of support for teachers and staff. They conveyed three interconnected ways districts left teachers and staff unsupported: the sheer number of students in a class overwhelming teachers, the noticeable absence of support and special education staff in the classrooms, and a lack of access to the appropriate training. For mothers, all the ways teachers were unsupported constrained their ability to engage with, teach, and support their children in school. Mothers' narratives illustrate the conflict between understanding the situation teachers are in and being concerned about their children.

Unrealistic Class Sizes

These mothers' narratives show how the demands on staff in terms of class size are ultimately unrealistic. Unrealistic class sizes were especially noticeable in mother's discussions of how it impacted their ability to communicate with their children's teachers; this connects back to the earlier discussion of how mothers struggled to access information about what was going for their children. Sarina acknowledges resource scarcity, stating, "teachers are profoundly disrespected in their pay and everything else." Nonetheless, she also grapples with the reality of unrealistic class sizes when approaching the teacher about punishing her daughter after spilling a water bottle. She shares how reaching out to the teacher feels pointless and intrusive when the teacher has too many students.

> *Should I have like, emailed her? I mean, they don't ever email back, honestly, and I just chalk it up to they have 30 kids and they have they have an assistant who's like, you know, 19, the poor thing, and I'm sorry, every time I even talked to them, I'm like, 'Hi, I'm sorry, that I'm talking to and taking your time.' That's honestly what I say because that's how I feel.*

Here, Sarina expresses guilt about burdening a teacher who is already overwhelmed with too many students and untrained support, making it difficult to follow up with the teacher.

Mileena also shares an experience she had following up with a teacher. She approached her son's teacher to clarify an assignment that her son did not understand. She recalls that the teacher's "response was, 'it should be written in his planner,'" and "something to the effect of 'if he paid attention, he would know, this is why I have my helpers.'" Mileena points out here how the teacher told her, "'I've got 43 kids in my class. You can't expect me to teach each kid individually.'" In this situation, the helpers in her son's class were other students, and Mileena explains having to remind the teacher that "they're not helping him. They're making fun of him."

Like other mothers, Adelina also describes how unrealistic class sizes limit her ability to communicate with teachers quickly and productively; however, she describes attempting to communicate with the special education teacher specifically.

> *I hear a lot from the CLC teacher, 'well, I've got like 25 kids on my caseload,' . . . and I'm just so tired of hearing that. I get it. You have other students, but this is your job, and I'm talking about my student.*

Lena echoes Adelina's conflict, stating,

> *I get that they worked hard, and I do appreciate the things that they do. The teachers, the aides, they are not paid well, you know. They work a lot. They have a lot of kids to think about, but at the end of the day, I'm worried about my kid. So, it's hard to reconcile those two things.*

Gloria shares that staff have "straight up told [her] like, 'we can't handle it. there are too many kids, too many needs.'" Again, mothers' perceptions circle back to resource scarcity constraining and ultimately disrespecting the teachers and staff responsible for educating and caring for their children.

An Absence of Qualified Teachers and Support Staff

In addition to unrealistic class sizes, mothers talked about a noticeable absence of staff, both in consistency and capability. The unavailability of staff had tangible consequences for mothers and their children. In addition to impacting mothers' abilities to communicate with their children's teachers, the absence of staff makes it almost impossible to meet disabled students' needs in general education. Because districts tend to rely on the "availability interpretation" of the least restrictive environment, the numbers and locations of staff throughout the district drive children's placements and impact their overall experience in special education. Deanna points out that her daughter "could have been partly mainstreamed in kindergarten, had there been staff to help her." However, "there were not staff, so they didn't even consider it."

How a district deploys its limited special education staff throughout its schools is not without consequences for mothers and their children. Sarina emphasizes the importance of longevity in relationships between students and staff, highlighting how staff need to be "able to recognize" what a student was "struggling with" and notice any progress. However, as she points out, "they are so understaffed, and there's such a rotation of professionals" that children cannot build those relationships. Sarina adds that relationships between students and staff are "really important, especially at these developmental milestones that are so crucial." However, staffing issues at the district meant that longevity in her daughters' relationships with staff, even with her special education teacher, were not feasible.

> *There was such a high turnover. I tell you that each year [the staff changes]. Beginning in kindergarten, so we're going on three years or four years, now. [every year]she had a different Special Education Coordinator. So like, every year, I was sitting down, and like 'who the fuck are you? Have you even met my kid? Like, what is this? And she's like, 'Oh, yeah, we know your kid, she's so darling, and she's really funny.' I'm like, okay, so I guess I need to be okay with the fact that she's having, I guess, one on one adult interaction, and that's, I guess really what it has boiled down to for me.*

Sarina critiques "the idea that this position is something that we can easily replace or take this person and ship them off to another school, or whatever the hell they do at the district."

Staffing issues impacted Gloria and her son as well. She described a situation at the very beginning of seventh grade, where the school tried to place the burden of staffing issues on her son. Her son was previously successful in this same school for all of the sixth grade and struggled to adjust in his first week of the school year. In this situation, the principal had expressed to Gloria that he "didn't think they were going to be able to meet [her son's] needs at the school." The school had decided that "because of his behaviors," he was a "safety risk." The behaviors he displayed were "primarily leaving campus and not being able to regulate." Gloria describes how the school "didn't have the staff support, and because of his "safety risk," the principal suggested he would be better served in a different program. Gloria is clear that "the issue was not [her] son."

> *The issue was they had gone from 14 children in that classroom to 19 children in that classroom in a year. The children who were in the classroom would come in and have significant behavioral challenges. They also had one or two children come in who had some medical management things too, and they had lost staff and resources.*

Gloria describes that when staff members confront these institutional level problems, sometimes the only obvious way they can see to try and solve it is to consider it an individual problem with a student.

> *When your staff and you are trying to do your best, and you're still asked to do more and more and more with less and less and less, the lever that you can pull is the safety lever, as an employee, and as someone represented by a labor union, that is the way to get attention to the fact that this is a working condition that is not appropriate.*

Gloria describes how it was ultimately an issue of her son "as taking resources at that time." Resources they did not have. She states that "instead of addressing it" as an issue of the unavailability of staff, the school took the approach of "we're not going to be able to meet your child's needs." In this way, the principal is "dealing with staff issues, under the guise of saying, I need to keep my staff safe." Her son then becomes the easiest piece on the board to move.

The District is Not Training Staff

In addition to class sizes and the limited availability of consistent staff, the lack of access to appropriate training was also a concern. Deanna points out that success with special education "depends very much on who's doing the supervising at that time and depends very much on the level of training that they have." She highlights the absence of training as one of the many things driving the "hit or miss" situation that mothers confront. Deanna states, "I think they could do with more training; I think they could do with more staff, and if they had those two things, I think our IEP would look different."

Adelina shares her concerns about the qualifications and the training available to educational support staff.

> *The people they hire for this program like you don't need any background in SPED to be an aide; I think that's gross. You're telling me an everyday individual who could have come off of like a construction site and needed a job is now a one-on-one aid for an elementary kid. It's not okay. There's no training. It's not okay.*

She adds to that how she feels that "if the district put more focus on that kind of stuff, then maybe the education would get better in there. Maybe the feelings would get better there."

These mothers are not alone in their concerns. Lysha has observed that teachers and staff are also aware that the lack of training is an issue.

> *That's one of the things that [the special education teacher] used to say to me when I would push her about getting [my son] more support. She was like, 'well, they're just going to hire somebody, and that person's not going to be trained.*

She also draws on her experience working in the schools, stating that "the district doesn't provide a lot of training." She feels like the training any educational assistants get is left "up to the sped teacher they work for, who supervises them directly." She recalls how when [she] got hired, [she] wasn't getting any training."

The lack of staff training had significant consequences for Bailee and her son because "the educators weren't competent in knowing how to manage his multiple disabilities." She describes the difficulty in finding staff equipped to support a student who is both autistic and blind.

> *It's like all the all of the regional program, people that teach the blind, none of them know what to do with an autistic person; and all of the people that help with autistic people don't know what to do with the blind person, and so they were always saying, 'well, you, it's your job. It's your job.' 'No, it's your job.' and no one ever did anything.*

In the end, she had to hire attorneys to get the school to "bring in somebody who was experienced with blind and autistic students." Even then, "it was just for one time to tell the teachers about it.’ The person with specific training in supporting her son “wasn’t allowed to work with him.”

Overall, mothers would describe how these examples of staff as unsupported by their districts would come together on the ground. Lysha highlights this, stating,

> *When you say you have to have an inclusive classroom, but we’re not going to teach you how to do that, we’re not going to give you the skills, we’re not going to give you the adults in the room that you need, the class sizes, you know, like, of course, it’s gonna fail.*

Similarly, Gabriela also recognizes the problem as a structural one. She argues that an “overall shift has to happen on probably the higher level, the administrative level about the way they’re even thinking about schools.” She goes on to share, “I think they’re overwhelming teachers, and they’re just expecting them to do like, these miracles that can’t happen by a human being.”

Summary

Taken as a whole, the narratives in this chapter offer an example of the many ways resource scarcity limits special education’s effectiveness overall. Mothers describe a situation in which they see special education and education existing in a context of resource scarcity. They describe it as underfunded, under-resourced, and unsupported. Mothers express a real need for clarity about the process and the services available. They also capture a definite need to dismantle the structural roadblocks preventing and limiting their access to services. Mothers share a desire for the staff to work in an environment where their labor conditions are reasonable. They want staff to teach smaller classes and receive fair wages, training, and support.

The implementation of special education in a context of resource scarcity consistently and systematically prevents disabled children from accessing necessary services and supports. However, it is crucial to recognize that scarcity is not a given; scarcity is a situation that develops in response to “human activity or social provisioning” (Daoud 2010). Individuals who “are excluded from accessing sufficient resources” can be said, “to be experiencing artificial scarcity” (Daoud 2015). Artificial scarcity is “a situation when scarcity is induced into a system when it potentially could have sufficiency or abundance” (ibid). While these mothers struggle to get services and supports for their children in this context of resource scarcity, the scarcity itself is ultimately constructed and maintained by people.

Consequently, it stands to reason that the resource scarcity these mothers and their children contend within special education is, in fact, artificial. When we situate this scarcity in Berude's argument that redistribution politics are fundamentally politics of recognition, the embedded value statements are more explicit. If we take up Berude's lens, it becomes possible to see that the redistributive choices impacting special education ultimately send a message about who is valued and recognized as whole people within these systems and who is not. However, the reality is that mothers confront these structural gaps and limitations of special education. As Griffith and Smith point out, "the mothering discourse makes no concessions to variations in the practical and material contexts of mothering work or to the realities of a mother's ability to control the school situation in which her child works during the day" (2005:39). Since their children's education and well-being are at stake, mothers continue to invest unpaid compulsory labor into special education, so at least someone is minding the gaps that their children are continually on the verge of slipping through.

CHAPTER III:
STUDENT EXCLUSION

Children with disabilities often receive little more than a warehousing experience, where schools – not unlike psychiatric wards – are but places of confinement and seclusion.

~Merry 2020

As I spoke to mothers about their perceptions of the services their children received, they described their challenges in accessing, understanding, and keeping appropriate services for their children. They also expressed their awareness and understanding of the difficulties confronting staff in providing special education services. However, it became apparent that another consequence of resource scarcity was student exclusion. As we saw in chapter two, resource scarcity was an essential factor in determining student placement and service delivery, with the district placing some students in overly restrictive classes. Mothers conveyed how schools could have successfully included their children in a general education environment had the staff, services, and supports been available to them in that environment. However, a district's distribution of resources drove placements more often than the child's specific needs.

Resource-driven placement decisions get at Slee's argument that "inclusion is conditional and subject to negotiation" (2019 914). However, it is worth asking ourselves what is truly happening as we negotiate between available resources and a student's placement needs? What happens if we shift away from the language of inclusion during these negotiations and ask direct questions using the language of exclusion? Would placements look different if IEP teams grappled with "what the maximum level of student exclusion is acceptable" for a child? What if they sat across from each other at the table and asked, "how much exclusion can we justify?" Furthermore, what happens if districts extended these questions beyond student placement decisions into students' lived experiences at school? When we take away the rhetoric of inclusion, these are the fundamental questions special education professionals and IEP teams are grappling with on the ground. Because underlying any negotiation of inclusion is the fundamental and unacknowledged question of how much exclusion a student can tolerate before it causes harm to their health and well-being.

I focus my analysis on the exclusion experiences mothers describe as salient in their children's educational placements and day-to-day lives. Exclusion experiences are happening across the continuum of alternative placements. I do not rely on a clear binary of inclusion vs. exclusion in my analysis, as mothers' narratives show that both are fundamental parts of their disabled children's lives. I draw on Ruth Cigman to move my analysis beyond the rhetoric of inclusion and offer a more nuanced picture of the student exclusion that mothers describe. Cigman proposes that student inclusion research needs to ask: what are disabled students included in, what are they excluded from, and who is excluding them? (Cigman 2007:xvii). I explore those questions; however, I also expand Cigman's inquiry to move beyond the "what" and "who" and ask about the mechanisms of exclusion embedded in the special education system.

In this chapter, I present mothers' narratives about their children's exclusion experiences in the school environment. I situate my work in the context of the long and heated debate about what is considered "inclusion." However, this chapter does not aim to continue or confirm either side of that debate—this chapter details mother's descriptions of their children's exclusion experiences from general and special education environments. I discuss how mothers described the marginalization of the program itself and the varying degrees of their children's exclusion, ranging from partial exclusion to complete exclusion. I describe two different but interconnected mechanisms of exclusion: structural and punitive. Structural exclusion occurs through student placement and program design, while punitive exclusion happens as part of discipline or attempts to contain or control students' behavior.

Spatial and Social Context of Exclusion

One aspect of the approval criteria for a district's special education program outlined in OAR 581-015-2005 (1)(b) is that "Special education must be established and conducted as an integral part of the district's regular school program" (OAR 2015). For the sake of perspective, I will define the adjective integral: "necessary to make a whole," "complete; essential, or fundamental," and "having or containing all parts that are necessary to be complete" (Oxford Languages). However, as mothers spoke about the exclusion of their children, they did not describe a program that was an "integral" part of general education. Instead, they described the marginalization of the special education program and staff. These observations suggest that social and spatial factors marginalize special education staff and students alike. Kaleigh highlights spatial factors when she describes the location of her son's special education room within the school building and her emotional response upon seeing it for the first time.

> *It was like, way over here, to the left, you know, and then to the right, or right here was the whole rest of the school. And like that just made me break down and cry. Like the first time I saw it, I was like, Are you serious? Like, I have never been this disrespected in any way, shape, or form my whole life. And I have been in the military, I've experienced so many things. And then you want to segregate my child because he has autism? Yeah, it was heartbreaking.*

She also recalls how her son's preschool special education program was housed within the elementary school, but they were never invited to attend any function within the school itself. She states that "they would be loud, or they would make a scene, or they would do something so none of them were invited to like, come down and participate ever." While there are other structural issues at play here in terms of preschool students housed but not officially a part of the elementary school, the sense of programmatic isolation remains.

Gloria also describes the physical structure and social arrangements of the special education program as "isolated."

> *Special education is either physically in a different place or in a different program. It's never located centrally, it's always off, and the teachers, the practitioners in those settings, have less engagement with other practitioners like you would in a grade level situation.*

She goes on to describes how you have "science teachers" or "second and third-grade teachers" all coming together to have discussions about their curriculum. Her question is, where do special education teachers "get to have those conversations? How can they raise issues? How can they be integrated? If they're structurally not?" Gloria goes on to describe how the isolation of special education extends beyond faculty arrangements.

> *If you go to school, any school, and you go to an open house, a curriculum night, you never hear about [special education] children? Forget accommodations? Unless they're talking about late work, right. When you*

> *go to PTA meetings, there's never intentional fundraisers for the [the learning centers]. There's, talk amongst parents around these kids with these behaviors, and you see things in the newspaper about, you know, all these behavioral issues. And what you're talking about is children whose needs are not being met, and yet, they're a liability. Therefore, if you're the practitioner who chooses to teach the child of special education, that's not a position of reverence in schools.*

Gloria touches on the ambiguity that mothers perceived around the special education process and services. She talks about how school staff members often do not even know what kinds of special education programs and services are available for students in their districts.

> *I went to our local high school before when we were looking at places for my son, and the staff didn't even know what I was talking about when I said, I'd like to know a bit more about this program.*

She describes how staff members at the district could not even offer her this information. "When I asked the district for descriptions of the different levels and types of services that are offered at the different high schools, I was told that didn't exist." She points out that the tangible and absence of an awareness of special education is still true three years later.

> *If you go to any high school's web page, you'll hear about their athletics, you'll hear about international programs, you'll hear about their drama club, you know, but where is the pride in providing exceptional service for students with disabilities?*

In their examples, Gloria and Kaleigh illustrate how special education itself is isolated and excluded in education's integral structural and social spaces. This context is important here because if there is an overall lack of awareness of special education as a program worth having pride in, there is a corresponding lack of awareness about what happens there.

Mechanisms of Exclusion:

Mothers' narratives collectively described the different ways schools structurally and punitively excluded their children from educational environments. I define these as the mechanisms of exclusion. Structural mechanisms connect to special education programming, policy, or practice. Structural mechanisms capture exclusionary situations resulting from placements, pullouts, and the varying supplementary aids and services offered to a particular student. Schools may consider behavioral support needs in their structural decisions regarding placements, pullouts, and services. However, as discussed earlier, resource availability is often the primary driver of those decisions rather than a child's needs. Furthermore, children's behaviors can tell us a lot about their unmet needs. Therefore, I do not define structural exclusion as a genuine or appropriate response to a child's behavior. I define structural exclusion as a situation where schools have embedded the mechanism of exclusion in their implementation of special education. Structural mechanisms of exclusion are particularly efficient in the context of resource scarcity.

Punitive mechanisms of exclusion connect to situations of exclusion resulting from disciplinary action. These exclusions happen when students are regularly sent to the hall or office, receiving in-school or out-of-school suspensions, and experiencing other forms of student isolation and restraint. It is true that schools punitively remove general education students from the educational environment. However, the different combinations and the relative consistency of student removals occurring between these two student groups result in special education students experiencing regular or reoccurring exclusion (Achilles, McLaughlin, and Croninger 2007; Bowman-Perrott et al. 2013; Duran et al. 2013). OAR section 581-015-2420 requires that schools determine if a child's conduct "was caused by, or had a direct and substantial relationship to, the child's disability; or if the conduct in question was the direct result of the school district's failure to implement the IEP" (OAR; ODE). Nevertheless, research shows that disabled students are "disproportionately represented in disciplinary exclusion statistics" even with protective measures to prevent it (Duran 2013). Punitive exclusion is directly correlated to a student's conduct, as it results from staff attempts to contain or respond to an immediate behavioral concern. However, student behaviors are children's attempts at communicating their needs. Unfortunately, staff are too often in the position of reacting to behaviors rather than responding to needs. Like structural exclusion, resource scarcity limits the viable options around classroom management, so it becomes a matter of staff attempting to managing the "problem" of the child because that is easier than managing a problem of resources. The child, again, becomes the easiest piece on the board to move.

The Role Hyper-Focus Has on Student Exclusion

Before moving into the broader discussion of exclusion, I must contextualize it in mothers' discussions of what they feel is a hyper-focus on their children specifically. As an analytical concept, hyper-focus is particularly relevant to the punitive means of exclusion. However, it is worth noting that general and special education teachers, school psychologists, and other professionals scrutinize disabled children at and between every IEP meeting to outline their "deficits" as students. These professionals measure, down to the minutes, how disabled students are making progress towards "goals." While the hyper-focus these mothers describe is indeed built into the structure of special education, mothers expressed the concept more directly when they spoke about teachers and staff's punitive actions when engaging with their children.

When highlighting what they felt was a hyper-focus on their child, some mothers described interactions between other students and their child, resulting in punitive actions they or their children perceived as unfair. While we cannot fully know what the school's actions are concerning other students, many mothers feel their children were disciplined unfairly. Angelina asserts that because her son has an IEP, "he's scrutinized." She mentions how "he was probably in some respects more well behaved than the typical kids, but the typical kids got away with frickin murder." Similarly, Angelina highlights the inequity she perceived, especially when her son's behaviors were a direct result of other students' intentional actions:

> *It was completely unfair on a regular basis how he would be patient, patient, and then somebody pissed him off, and then he blows up, and because his blow-up was so visible, they immediately crackdown on him. But did they ever go back in and get the regular kids for giving him crap? No, very rarely, very rarely. So, it was a constant battle.*

Suyin shares similar concerns. Suyin is a 47-year-old married mother. Her nine-year-old son has ADHD, and she is beginning the process of having him evaluated for special education. However, it has been difficult for her to gain traction with that. She describes her son as a child who "is not shy," stating, "he would go to everybody and try to make a friend." He has been reading chapter books since kindergarten and loves math and science. However, she shares her perception of the school's failure to respond when kids bully her son, and she contrasts that with feeling like the school gets him in trouble for almost anything. “Many, many times kids are bullying him, and the school don’t do anything, but if he’s the one, they focus on him for sure. So that makes him just get worse and worse.” Suyin shares how her son notices the hyper-focus on his negative behaviors, “he recognizes that he has been good all day . . . he says, ‘mom, I made one or two mistakes, and they wipe out my whole day.’”

Kristina is a 36-year-old mother of two who cohabitates with her partner. It is apparent by the toys and kids' books in her living room, the posters on the walls, and the collectibles on the higher shelves that her family shares a deep love of Star Wars. Her six-year-old is autistic and has an IEP. His placements have shifted recently between homeschool, specialized schools, and the general education environment. These transitions have been challenging for her, but she still holds positive perceptions of special education. Kristina gives me a sense of her son’s concern for others as she describes him rushing to bring a face wipe to a friend who had been crying. However, she also shares with me that she feels like the school is hyper-focused on his negative behaviors. She also points out how that her son notices and responds to what he sees and unfair through escalation and elopement: “he took off out of school because they, you know, they [told him] ‘no, you got to go back to the office;’ and he’s like, ‘no, I’m not going back to the office. You’re not punishing this kid. So why are you punishing me?’”

Lyndsay also describes hyper-focus when sharing how both her sons have gotten in trouble for self-regulation behaviors. Her sons, who have ADHD, would be tapping their pencils or wiggling their feet, and they would “get called out” by the teachers. Furthermore, Lyndsay shares that when one of her sons would advocate for access to the fidgets outlined in his IEP but banned in the school, he would get in trouble. Fidgets are a self-regulation tool students can use to meet some of the sensory needs behind the tapping and wiggling that Lyndsay describes. Lyndsay details how staff “got around” the fact that they were disciplining her son for asking for his accommodations “by saying that it wasn’t discipline for asking for the things in his IEP; it was discipline for talking back, or disrespect, or being argumentative.” In reflecting on the hyper-focus on her sons wiggling in their chairs or tapping their feet, she states, “it’s insane to me, and it’s like why?! What does it matter?!” Maybe it only matters because the classroom is an environment designed for one type of student. The students who cannot easily fit into the confines and expectations of that space are scrutinized, called out, categorized, and, as the concept of hyper-focus suggests, treated as problems. When we focus our attention on the student as the problem, the effort becomes about changing the student, not the environment—and if the student cannot easily change, the logical next step is their exclusion.

Degrees of Exclusion

Regardless of the means of exclusion as either structural or punitive, the physicality of exclusion was a salient theme, with mothers describing three degrees of physical exclusion: partial exclusion, isolated exclusion, and complete exclusion. Unsurprisingly, the different degrees of exclusion that mothers described line up with the "continuum of alternate placements" (Howard 2004) that educators draw on when determining the least restrictive environment (LRE) for each student. On paper, any student may appear to reside at some fixed point along the continuum of alternative placements. Furthermore, their point on the continuum of alternative placements implies that they are appropriately included and receiving proper support for their individual disability-related needs. However, the stories mothers shared showed their children experiencing different degrees of exclusion regardless of their special education placement. Therefore, rather than consistent inclusion levels easily tied to and tracked by a student's placement, students moved through different degrees of exclusion fluidly throughout their educational trajectory.

I ground this chapter's analysis in the following definitions of the different degrees of exclusion. I define partial exclusion as short-term experiences of exclusion. Structurally, this would be when a student is pulled out of general education to receive special education services. Punitively, this would be when a teacher sends a student to the hall or office due to behavioral problems, to which staff are ill-equipped to respond. Isolated exclusion is when a student is in the school building but isolated from peers. Structurally, this would be the student placed in a contained classroom and is effectively isolated from the general education environment. Punitively, this the physical removal of students from classrooms and their placement in solitary confinement situations, away from both their general and special education peers. I define complete exclusion as a situation where the student is entirely removed from the school environment either permanently or for an extended period. Complete exclusion could be when a student's placement happens in an environment outside of the public-school building or situations where mothers pursue temporary or permanent alternative schooling options. For complete exclusion, the line between punitive and structural is particularly blurry; complete exclusion of a student was often in response to behavioral needs, not academic ones. When we look at disabled children as whole people with unmet needs, it becomes easier to see how the "behaviors" schools view as problematic or disruptive and manage with exclusion are an outcome of children navigating an educational environment without the proper support.

Partial Exclusion

I just felt, like every time I was in the building,

I saw my son somewhere other than his class.

~Louisa

Partial exclusion often lines up with the normalized conception of the successful implementation of special education. Here the student is in the brick and mortar of a regular school, usually spending a set amount of time in the general education classes and receiving a certain amount of pull-out services that remove the student from the classroom. Situations that lend themselves to partial exclusion are those that educators and researchers alike hold up as exemplars of successful student inclusion. Schools correctly identify the students in need of support; students physically move in and out of general and special education environments. Students are appropriately placed, served, and included. However, as mothers illustrate, the schools are still excluding their children. Partial exclusion can be structural, punitive, or a complicated combination of both. The stories that mothers shared highlight how mechanisms of exclusion work together to create a regular and often predictable pattern of partial exclusion from the educational environment for many students. Furthermore, while I discuss the different degrees of exclusion separately, they can be cumulative for some students who may experience partial exclusion in addition to experiences of isolated and complete exclusion.

Partial Punitive Exclusion

Many mothers talked about partial exclusion, where the exclusion occurred because of punitive actions as teachers attempted to mitigate, control, or contain “disruptive” student behaviors. Consider the two following examples from Angelina and Kaleigh. Angelina talked about her son’s frustration with a storybook problem leading to his partial punitive exclusion. The premise of the problem was a student receiving money for graduation, and it was asking what percentage of the money the student would spend on different things. Her son takes things literally. Faced with a problem that seemed unrealistic to him, her son “melted down and he was like, ‘That’s stupid. Because nobody wants money for graduation,’ and he was like, ‘I’m not doing that. That’s stupid’” She describes how “he lost it for a good 40 minutes,” and the teacher contained that behavior by having “him out in the hallway.”

Kaleigh acknowledges her son’s “defiance” and shares with me how he had a habit of “only doing what he wanted to;” it is probably safe to say that this is a habit for most children in some form. However, her son’s defiance often resulted in punitive partial exclusion. She offers a particularly vivid example.

> *He was picked up out of his chair and put outside of the room and the door locked and the window screen like, you know, the curtain brought down so that he couldn’t be a part of it whatsoever . . .basically [they] just pushed him out.*

Furthermore, Kaleigh describes how instead of the “teachers handling it better, they would like put them in the hall and like, have them sit there for longer than should be because most of the time they forgot.” It is essential to point out that even as she describes her son’s partial exclusion, this mother also describes a situation in which the school just “forgot” about her child. I address how she is not alone in this experience in chapter four; because this “forgetting” on the school’s part, intentional or not, makes an implicit statement about disabled children’s value as whole people worth seeing and remembering.

The stories mothers shared also illustrated a situation where their children experienced regular patterns of partial punitive exclusion. Lyndsay describes how her son struggled with overstimulation and self-regulation, which would cause him to get in trouble every day in one class. Punitive and structural mechanisms of exclusion overlap here for her son. A one-on-one aide offering tangible supports to her son, specifically around emotional regulation, would have helped him, the teacher, and his peers. However, the district regularly denied access to this type of supplementary support. Lyndsay tells me that it eventually got to the point where he was only going "for the first 15 minutes [to] get the work assignment and then go to the sped classroom, to do it where there would be less kids." In this situation, the school is including Lyndsay's son in the general education classroom on paper; however, his physical presence in this general education class was regularly limited to 15 minutes a day. Furthermore, this was not the only class he struggled with, and this partial exclusion was in addition to her son's complete exclusion through an already shortened school day. Lyndsay's son experienced partial exclusion through the majority of his already limited general education time.

Bell describes her youngest son as someone "who can be positive about anything." He is a happy child "who loves to read." He "can devour books," and his happiness is "infectious." The fact that his "emotions are just out there" even when "they're big and painful emotions" can work against him in a school environment unequipped to respond. Bell captures the regularity of partial punitive exclusion for her son when she describes the differences between her son's experiences in kindergarten and first grade.

> *It was a big shock to the principal during his first-grade year that he was coming to the office every single day for behavior issues, and she was so confused because she hadn't seen him more than a handful of times in kindergarten, and it wasn't for behavior issues.*

I cannot confirm if teachers sent her son to the office "every single day." However, confirming that is not relevant. Bell's statement reflects her observation that the school partially excluded her son regularly. Additionally, she shared here that her son "was exhibiting signs very similar to what he was in first grade" and was able to remain in the classroom in kindergarten. Therefore, the statement also illustrates how situational factors rather than behavioral factors often drive student exclusion.

Angelina also grapples with a partial exclusion pattern when she describes how her son regularly spent time in the office.

> *He was always, you know, like, he was a regular visitor to the office. You know, like, that's not inclusion, that's exclusion; that's not appropriate. It's free appropriate public education. Equal means equal. It doesn't mean different. It means equal.*

The fact that Angelina describes her son "as a regular visitor to the office" makes it safe to assume the mechanism of partial exclusion was punitive since the office is not a regular location for the delivery of special education services.

Kristina's son was also "being pulled up to the office" a lot, and she describes that at one point, "he was literally sent to a timeout room with baby toys when everybody else was working on a computer." She describes how the school started suggesting that they shorten the school days, which would have changed her son's experience from partial exclusion to complete exclusion.

> *No, you're trying to fix your mistakes through, you know, making our child feel bad, and you've already made him look bad in front of the entire class because you're constantly pulling him out and putting him in the office or something. So it's just like no, he's already victimized before he's even started. You're already keeping in the office every day. Why am I sending him there just to sit in the office?*

She describes this as "the beginning of the end" at that school and how this was the point where she started pursuing different educational options. Her response to the school's request to shorten the school day highlights her son's ongoing physical removals from the classroom. However, as I will discuss more directly in the following chapters, her example also shows the social and emotional harm that regular partial exclusion can inflict on a student and the measures mothers may take to minimize those harms. The previous examples illustrated how punitive mechanisms lead to patterns of partial exclusion for students. What follows is a discussion of how structural mechanisms regularly facilitate partial exclusion.

Structural Partial Exclusion

Mothers captured the structural means of exclusion when they described ways in which regular aspects of special education service delivery or a teachers' attempts to modify and get through regular instruction demands resulted in their children's partial exclusion. Consider for a moment the opening quote from Louisa, whose son is an enthusiastic child who wants to meet and hang out with people. She states, “I just felt, like every time I was in the building, I saw my son somewhere other than his class.” It is worth repeating that Louisa’s perception of special education is positive for the most part. At several points in the interview, she described how lucky they were to have such support. However, even in the context of her positive trajectory through special education, she communicated several situations of partial exclusion similar to the one above. She describes being aware that her son “was in the hallway with his aide several times” instead of class. Louisa offers a structural example when she states how she got the feeling that his teacher “just couldn’t handle him being in the classroom.” Louisa describes how the teacher “just wanted to just kind of keep going, and the speed was just too fast for him at the time.” She states that “quite often he was off in a corner with a book, or he was in the hallway with an educational assistant.”

Gloria also illustrates partial structural exclusion as she talks about how a teacher would regularly deploy a graduate student assistant to manage her son in the classroom environment; this resulted in the partial exclusion of her son. However, she also highlights a lack of communication from the school about what was happening in the educational environment. The teacher “would regularly pull [her] son out of class and not tell [her]. She shares how she found out what was happening to her son from another teacher.

> *She would have the Graduate Student pull my son out into the hallway and do math with him in the hallway, one on one, and not in the classroom. Why? I have no idea. She never told me. I heard it from another teacher. Another teacher pulled me aside one day and said, ‘Do you know that your son is getting pulled out of the classroom?’ And I said, ‘No.’ She’s like, ‘yeah, your son’s getting his math in the hallway. The teachers using the student do that.’ . . . When I asked her about it, she said, ‘Well, [I} just thought it would be better for him.’ And I said, ‘well, it’s not better to be instructed in the hallway.’*

In this situation, the teacher is justifying excluding Gloria’s son with the reasoning that it would better meet his educational needs.

Adelina also offers an example that captures her daughter’s regular partial exclusion along with her daughter’s lack of agency in the educational environment.

> *They decide when [my daughter] has had enough, or they decide whether she understands something whether she does or not. . .So, they'll pull her out and stick her in this tiny little room when the rest of the class is doing a reading or a fun thing, and she's stuck over there.*

She states, "to me, this incredibly restrictive and ridiculous." Adelina is aware that this is a structural issue. She highlights how her daughter could have remained in the class and participated in the educational activity if the school provided proper support.

> *Give her an aide, put an aide next to her, help her with the science experiment with everybody else. They have a habit of pulling the CLC kids out when stuff like that is happening, and to me, that's just really restrictive and not okay.*

Kaleigh also captures partial exclusion as a structural problem that is ultimately harmful to children's well-being.

> *All children should go into a classroom, regardless, and maybe have like a reading table or a math table or, you know, something, they should all stay, it shouldn't be something like, oh, my God, Becky has to leave for five minutes, or, you know, more than five minutes, but you know, what I'm saying. And it's like that, in itself, causes a lot of trauma, a lot of harm.*

These mothers' experiences show the schools utilize structural and punitive mechanisms to exclude their children from the educational environment. They also highlight the regularity of this exclusion and some of the overlaps between partial, isolated, and complete exclusion. While most of the students experiencing partial removal may have an official placement percentage of 80% in the general education environment, some of these students already have more restrictive placements in contained classrooms or shortened school days. Several mothers highlighted how more supplemental aids and supports in the classrooms could have prevented their children's partial exclusion. Furthermore, the frequency and variety of partial student exclusion have tangible and often harmful impacts on a student's pedagogical and social experiences at school.

Isolated Exclusion

Like partial exclusion, isolated exclusion can be structural or punitive. Isolated exclusion has a student in the brick-and-mortar building but experiencing ongoing isolation from the general student population. Most commonly isolated exclusion is when the school places a student in a contained classroom or program with limited to no contact with the regular student body. This type of isolated exclusion is usually structural and lands near the “acceptable” range as districts have determined that this is the least restrictive environment for the student. However, as mothers express, it may be overly restrictive and inappropriate for their child, suggesting that it is the least restrictive placement for the school’s resources, not the child’s disability. Beyond a general form of isolated exclusion from “appropriate” placements, mothers also described situations of extremely isolated exclusion. Extremely isolated exclusion can be punitive or structural. Punitive mechanisms lead to exclusion when schools seclude and confine students as a punitive response to behavioral support needs. Extremely isolated exclusion is structural when the district places students in solitary spaces for service delivery. Students have an increased risk of harm and the denial of personhood in these situations and have minimal access to general education students and staff if any access at all.

General Isolated Exclusion

General isolated exclusion is often an example of an “appropriate placement” from an administrative standpoint. It technically meets the legal requirements for the least restrictive environment (LRE). In some cases, it is also a relatively fluid placement that satisfies some mothers. For example, Louisa, who reflects positively on their trajectory through special education, discusses her son’s placement in a contained classroom. She describes how her son has pull-outs for mainstreaming and inclusion in general education environments. In this situation, while her son is in the physical building, he has limited access to general education and mainstream spaces, even with his pull-outs. Louisa states that for them, “it’s always been a back and forth” but shares her experience that “some kids are there all day.” Louisa highlights the difficulty of serving kids with differentiated learning and support needs in a contained classroom. This difficulty feeds into mother’s perceptions of services as inappropriate for their children. Louisa describes how her son is “higher academically than some of his peers in that program, but he needs the social [instruction] and some of the other training” available in the learning center. She also shares that her son’s pull-outs into general education environments have not always been consistent. The previous school year “was probably the most restrictive. They didn’t put him in mainstream classes right away” because he was new to the program, “so they started the freshman [year] all-inclusive” in the learning center.

For perspective, Louisa’s son started his freshman year of high school in a contained classroom, isolated from his general education peers without first being given a chance to succeed in the general education environment. The school chose to isolate him in the contained classroom, excluding him from the general education environment because he was “new to the program.” However, her son had come to that program with demonstrated success in regular classes. Bailee describes a similar situation in which the schools chose isolated exclusion to determine how her child would adjust. In her case, this started as early as preschool. She describes how the school “decided that they would put him in a life skills program and then see how he did.” The agreement as she understood it was that “from there, they would decide what kind of placement [he needed], but he never left the life skills program for years.”

Lena shares a multi-layered example of isolated exclusion. Lena’s daughter has Cerebral Palsy and is primarily nonverbal. Her placement is in what “was historically an autism classroom. She recalls how she and her husband had wanted their daughter to go to their neighborhood elementary but ultimately agreed to this placement because it was a part of the teacher’s attempt to diversify the students in the contained classroom.

> *The teacher really emphasized that she wanted to diversify her classroom, and she wanted to, you know, to be more of an inclusive environment that wasn’t just, you know, kind of like, putting children with this label all in one place. And so, we wanted to be part of that, and we thought that she had really good ideas.*

Her daughter’s cerebral palsy means she is easily fatigued. Hence, she is already on a shortened schedule. She is in the school building for 4 hours each day and “spends 45 minutes in the morning in inclusion in her second grade [gen ed] class, and then she, she goes to the second-grade recesses, so she’s out there with her peers.” This is an example of an “appropriate placement” that meets the legal definition of the least restrictive environment; her daughter is included in a general education classroom and mainstreamed at recess. At 12:30 pm, Lena goes to her previous daycare facility to nap and spend the remainder of her day fully integrated with nondisabled peers. This transition shows that even though Lena’s daughter has a history of success in a non-segregated environment, the only “appropriate placement” available to her in public school is a contained classroom, with only a quarter of her already limited time spent around her general education peers. Furthermore, Lena’s daughter remains “the only girl and the only child with a diagnosis outside of autism in that classroom.” Her example also suggests that except for Lena’s daughter, and depending on their pull-out arrangements, the other students in this contained classroom spend a fair amount of time excluded from general education peers and their peers in special education who have a diverse range of disabilities.

These mothers' stories suggest that isolated exclusion is potentially a common occurrence for students with higher support needs. They also suggest that schools place students in overly restrictive environments as a first step rather than a last resort. Like Bailee’s son, this isolated exclusion could be a permanent placement for some children. Furthermore, regular isolated exclusion may overlap with extremely isolated exclusion, and both do not come without broader pedagogical and social consequences for students.

Extremely Isolated Exclusion

> *Parties shall take all appropriate measures to ensure*
> *that school discipline is administered in a manner*
> *consistent with the child’s human dignity*
>
> *United Nations Declaration on the Rights of the Child*
> *Article 28 2.*

The previous examples of what could be considered “common isolated student” removal focused on what would generally be considered an appropriate placement, and therefore an “acceptable” level of exclusion for an individual student. Common isolated exclusion offered some engagement with non-disabled peers in general education and mainstream environments, yet the students usually remain segregated from the general student body. However, several mothers also discussed the extremely isolated exclusion of their children through the school’s use of punitive and structural seclusion. Many mothers who spoke about their children’s seclusion described conditions akin to solitary confinement. While not openly discussed, the restrain and seclusion of disabled students is not uncommon in schools (Butler 2019; Kutz 2009; Shank et al. 2011; Mitchell, Kern, and Conroy 2019; ODE; Slee 2019; Turnbull and Turnbull 2020). Numerous attempts to legislate and reduce the use of restraint and seclusion have happened at the state and federal levels[2] (ODE; Shank et al. 2011; United States Congress 2020). However, schools still use seclusion and restraint, which disproportionately affects disabled children (Mitchell et al. 2019).

Punitive Mechanisms of Extremely Isolated Exclusion:

Mothers described extremely isolated exclusion that occurred when the schools secluded their children in what they called a "safe room" or "sensory closet." The seclusion was often an attempt to de-escalate a behavioral issue. Seclusion is not the same as when schools construct and provide these spaces in sensory-friendly ways for children to use for help with emotional regulation. A few mothers talked positively about the latter types as spaces or sensory rooms with open doors where students can take a break. Deanna describes her daughter having a positive experience in these spaces, "they have a sensory room now this year, I think she gets to go to sometimes. But I think that's more of a scheduled thing rather than you go to it when you need a break" and "she has benefited from" that. Deanna also describes how prior to an actual sensory room, the school "had what looked like it used to be a walk-in closet with the door removed" and that "kids who needed a little bit of quiet could go in there." This was also a positive experience for her child as she "would lie down in there" and her mother had "sent in a sleeping bag for her to have." She even "fell asleep sometimes" in these spaces. While Deanna's example is an indicator of the much-needed movement away from seclusion, other mothers spoke about a lack of clarity around what these spaces looked like and how the schools were using them. A few mothers described them as carpeted or padded rooms with closed or locked doors.

Deanna's daughter is a child with lower behavioral support needs, and she experienced both the sensory closet and the sensory room as a "place to quietly take a break." However, several mothers, particularly those whose children had higher behavioral support needs than Deanna's, recall them differently. Kaleigh notes that all her

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[2] for example, see H.2939; S.963 and H.3266, and most recently S.4924

children have experienced isolation in seclusion rooms at school. She considers it a misnomer to call them rooms at all "that's why I say the sensory closet. Because it wasn't really a sensory room, you can't shut a big heavy metal door in a room and have nothing besides carpet." Lyndsay describes her son's seclusion similarly: "there was a panic room . . .they call it the Batcave sometimes." She remembers how her son "got put in that room quite often" when "they were still allowed to close the door." Lydia also mentions the school's use of seclusion. She shared that when her daughter was escalating, "they would put her in the seclusion room, but couldn't shut the door." Curtailing the ability of schools to shut the door is the outcome of much of the legislation, which states that schools cannot physically prevent students from leaving seclusion rooms. However, it might not be curtailing their use of seclusion.

A significant problem with the schools' seclusion of their children was their failure to inform the mothers of this practice. Mileena highlights the lack of communication from the school regarding their use of seclusion:

> *[The school] has a safe room, except they don't tell parents that they use the saferoom, which I'm pretty frickin sure is illegal. It is a white padded room with nothing in it, and they lock your child in there for hours and don't tell you . . . when I found out about the quiet room, they said that basically, she was disruptive and that they put her in the quiet room to calm down.*

After finding out about her daughter's isolation, she "threw a giant fit and threatened to sue them." The aftermath of this event was the school transferring her daughter into a self-contained behavioral classroom, where she then spent 100% of her time. During the interview, Mileena questioned this placement as appropriate for her child's needs and pointed out that her son was in the general education classroom with higher support needs than his sister. The school had cited safety reasons to justify her daughter's overly restrictive placement because "they thought she was going to hurt other children." Mileena eventually removed her daughter from the public school system to enroll her in a private charter school. Her daughter demonstrated academic and social success with the proper support in place.

Mileena is not alone in feeling like there is a lack of information and communication about the seclusion practices and sensory rooms. Cymone also discusses the overall lack of clarity around the school's use of sensory rooms:

> *I don’t really know for sure what exactly went on, but they were, at one point towards the end, moving her to a “sensory room.” They said there were some sensory items available, but I was never shown the room. The guy who was in charge of it was this really big, burly, mean-looking dude; he didn’t seem like he cared at all, and I don’t know that he really had any training.*

Cymone reiterates her lack of knowledge about the room or her daughter’s removal from the contained classroom itself.

> *So, I have no idea what exactly was happening in those last couple of weeks. And I guess that really was what started the concern because I had no idea exactly where she was going every couple of hours, or I think it was like 20 minutes every 45 minutes, and it seemed like that was a lot and very restrictive.*

When pressed about the reasoning behind her daughter’s seclusion, the school informed her that her daughter had “needed time to calm down” and that “she was frustrated.” Cymone offers that boredom was a possible source for her daughter’s frustration in class. “I mean, if you stick her [in class] with, you know, with a sheet that tells her to write her name 50 times, yeah, she’s gonna be bored.” Cymone highlighted for a third time that she had “no idea what exactly went on” and going on to explain what she had envisioned about the space.

> *I mean, when they said sensory room, I assumed, you know, bolsters or swings or things like that, but do we ever really know? I mean, and especially because I just wasn’t shown anything that looked even like that.*

The ambiguity Cymone and other mothers describe included confusion around how and when schools used seclusion and confusion about the actual rooms themselves, suggesting that schools are not informing parents about their use of these spaces.

Structural Mechanisms of Extremely Isolated Exclusion

In addition to students placed in sensory closets temporarily, one mother describes a closet as her son’s permanent placement in the school environment. For Bailee, her son had “never left the life skills classroom” in elementary school. She states that he then experienced extended “solitary confinement from the sixth grade all the way through, except for when he went to the school for the blind” in his seventh-grade year. In this situation, Bailee’s son spent his entire school day inside what she describes as a “utility closet.” When asked to clarify if she was talking about a panic room or quiet room as both have been described in similar ways by different parents, Bailee responds that "they had a panic room attached to the closet" for her son. The room she described as a small "utility closet with a sink on one wall," which the school had modified for her son specifically. Before sixth grade, her son had been struggling with his placement in a life skills room.

> *He was blowing out all the time. And we had a meeting, and his teacher said what I had known for years, that he's intelligent, that he didn't belong in the life skills program, that he was frustrated that, you know, the other kids weren't giving him feedback to learn from socially. So, the school district was like, we'll just put him at home for now while we try to figure out what to do.*

The district's eventual solution was further isolation in the modified utility closet with two educational aids and a set of speakers so he could hear what was going on in some of the general education classes. The district considered her son's placement as "appropriate." Furthermore, her son had experienced similar isolation in a previous district as well, so it was not an isolated practice of one district vs. another. This extremely isolated exclusion impacted her child's ability to feel included and welcome in the academic environment. Bailee discusses how during her son's solitary confinement, "he was supposed to be integrated into the high school." Before that, "he had never been in a regular ed at all." A private program and the district arranged for this placement, housing it in the high school. The placement was supposed to allow for some level of inclusion with his peers. However, she states that the special education director prevented her son's inclusion in that environment, which furthered his ongoing isolation at school.

> *When he first started, [his aides] were taking him to choir and to the cafeteria for lunch, and he was successful. But when the special ed director found out that they were taking him out into the school, she made them stop. She said that he wasn't a student there, and he couldn't go out and to the school, even though he was being successful.*

At that point, Bailee had to work with the school and the program on alternative ways to include her son in general education. However, the alternative options agreed upon were not followed. Furthermore, the program and the school failed to inform her about what was happening,

> *We had meetings, and they agreed to put a speaker in the classroom and have it to where he could listen to class from the closet room. Then no one told me that apparently the speakers got stolen, and he never was given*

> *access to the regular ed. I didn't know this because nobody was telling me.*

While this is an extreme example of isolated exclusion as a structural problem in schools, I argue it is the most important one; looking at how a system treats its most vulnerable population shows us a lot about the values embedded in the system.

The isolated exclusion mothers result from specific placements and practices central to special education and due to accepted disciplinary measures. The structural and punitive nature of isolated exclusion meant that schools excluded students from both contained classrooms and general education classrooms. Additionally, resource scarcity leads to isolated exclusion because limited resources and support means staff have limited options to choose from when responding to challenging student behaviors. Furthermore, cases like Bailee's son's spending entire days for months on end in a utility closet, or Lyndsay's son's frequent isolation in the "bat cave," and Mileena's daughter's overly restrictive and inappropriate placement in the behavioral classroom reflect the gross neglect of their children's well-being as whole and valued people.

Complete Exclusion

What barriers do you see in your son's ability to access the curriculum?

'He doesn't get to go!'

~Lyndsay

The final degree of exclusion is the complete exclusion of a student from the school's physical environment. Complete exclusion can be punitive through temporary or permanent exclusions resulting from disciplinary actions, such as out-of-school suspensions. Complete exclusion can also be structural when the student receives educational instruction in the district office or home placement. Complete exclusion also includes the situations where students are removed from the district entirely and enrolled in homeschooling, online school, or private school or when a student transfers to a highly specialized program or institution. A form of complete exclusion can also happen when shortened school days are ongoing and excessive.

Suspensions

Several mothers shared how their children experienced complete punitive exclusion from the school environment through repeated suspensions. One school suspended Suyin's son was right after he transferred in, and while she was still fighting to get the appropriate services and supports in place for him. This suspension effectively ended her son's school year early.

> *It was pretty hard for him to transition to that new school. So, he did okay for the first week or two, but then he started to have issues. And then he started to do half-day, but it just didn't work anymore that he would be being physical. So, then school say, 'Well, this is almost the end of term, and school tends to be more loose, and we cannot just have him run out or disturb classes like this.' So, they just say 'no more school.' So that was two weeks suspension.*

Similarly, Angelina recalls how the school wanted to suspend her son "when he threw the shoe, that was kind of a deciding thing because they wanted to, like suspend him and I said, 'I don't think you need suspension. I think he needs more support.'" In this case, her advocacy dissuaded the school from relying on suspension to manage his behavior; however, she highlights how the absence of support drives complete exclusion.

In terms of a student's complete exclusion, frequent suspensions usually occur before other measures. Lyndsay describes the frequent suspension of her son and highlights how when the schools reached the upper limits; they utilized other forms of complete exclusion.

> *He was suspended a lot [in multiple schools] I think [one school]got to nine, because the ten is the max or whatever, and that's when it was going to be the tenth one, and that's when they're like, 'we can't have him here anymore. He's gonna go somewhere else; we'll do home instruction.' [In another school] I think they got like seven or eight suspensions.*

Lyndsay's son experienced multiple suspensions, a variety of placements, and eventually, the school had him on shortened school days.

Shortened School Days

Sometimes complete exclusion came in the form of shortened school days. Children would spend most of their time entirely out of the school environment. While they would have some time in general education, shortened days did not provide enough time to be considered a partial or isolated exclusion. Furthermore, in many cases, these children experienced partial and isolated exclusion during their shortened days at school. Lyndsay recalls how the school had initially removed her son “from the classroom altogether” and put him in a contained classroom before shortening his school days. Like many of his placements, that was a temporary arrangement. Lyndsay’s son spent half of the second grade on shortened school days. After that, he had a short-term but full-day placement in a contained classroom, and “then it was like a year and a half at the district office” for instruction. She adds that “for almost a year,” around the fourth and 5th grade, the school “didn’t want him around kids.” Therefore, they “had him doing one or two hours a day at the district office with a tutor.” When Lyndsay was like, “Hey, this is going on long enough. He deserves an education,” the school transferred him into a behavioral classroom but kept him at “two hours a day.”

At the time of the interview, Lyndsay’s son was beginning sixth grade and still had shortened school days. Unlike previous years, Lyndsay states that “they started him off this year, in just the regular classroom. So, he’s got the first three periods, and then he goes home.” However, “at the end of [5th grade], they hadn’t put him in general ed at all.” Therefore, most of his shortened days were happening in the context of already restrictive placements. Like many mothers, Lyndsay does not “understand what they’re waiting for [or] what their requirement for him having a full day will be.” She asks what that would “look like to them? Would he need to be perfect? Like, what do you need? To not be on an IEP?” Lyndsay’s questioning gets at how exclusion can be a consequence and a fundamental part of special education.

Several other mothers also described how their children had experienced long-term shortened school days. Kaleigh mentioned that her middle child had shortened days “for two years.” Bell states that for her son, “essentially, all of last year, the most amount of time he spent at school per day was two and a half hours.” Cymone describes how “they started her [daughter] right off the bat with half-day” and how they had told her that “it would be better for her [daughter] to adjust over time, to a full day.” In this case, like other students, her daughter was denied a chance to succeed with supports in a full day before moving to shorten her school day.

Sometimes mothers self-selected into shortened days. Anais argues that “what they’ve done is make sure that I’m shortening the days, and they will not put it in writing." The district has told her that they "don't recommend a shortened day," and it's her "choice." However, in the end, this is a false choice for Anais. She is still fighting for an IEP, and the lack of supports in the educational environment makes it impossible for her daughter to make it through the day. Lydia described a similar false choice when her daughter reached school age. "I refused to enroll her in [that] school without an IEP in place, so we started with them sending a tutor an hour day." One of her concerns was that the school was not a safe space for her Black and autistic daughter.

School Transfers

Shortened school days went hand in hand with complete exclusion through school transfers. Bailee recounts how in a life skills program that coordinated with the school, "they had him going 15 minutes a day" and that "it was supposed to build up." However, "they just weren't building up the program the way they were supposed to" so "after four years, [her son] was only going for two and a half hours a day." Bailee offers a grocery list of transfers:

> *He was in a life skills program, and then he went to the school for the blind, and then he was in an individualized program at home, and then they experimented and put in as an eighth grader in the high school in a life skills program there, and then, well, wait in between those two times. He went to a [specialized program]in [another state] and was placed on an IEP there for two and a half months, and then he came back and was in a program [here] that was on the site but was private, and it was at the high school, and then he transitioned over to another high school, and they had a private program created for him there, but it wasn't [the initial private program].*

She states that after all of this, her son eventually just "refused to go back to school." Bailee's recounting of this string of transfers reflects a larger pattern of special education students shifting through schools and programs based on how the district places their needs as a student as secondary to the needs of the district and the availability of resources.

Like shortened school days, sometimes school transfers are initiated by mothers. Bailee had to fight for many of the placements she listed, even as they continued to shift and ultimately harm her son. Kristina, whose perception of special education was positive, still described complete exclusion. Kristina talked about how she transferred her son to a different school outside of her catchment area when they started talking about shortening the school days. “They wanted to shorten the school days down so they could have more time to get a worker for him. It was my understanding [that] there was already supposed to be one in place where he went initially.” Kristina mentions how the school “basically told [her they] can’t deal with him,” going on to add that her resulting self-selection out of the school is “almost like expulsion.”

Similarly, Lydia describes how the school basically “pushed us out by telling her that she “had to change her [daughter’s] status from CLC to special school just to tour the school” that had the specialized program the district had suggested as a suitable placement. She recalls how she officially changed her daughter’s status; however, after touring the school, she decided against the transfer:

> *I was like, oh, no, because she would have no access to neurotypical peers. . . and all the behaviors stuff that they do does not work . . . and then the former director claimed FAPE and said, well, we’re offering you free and appropriate education. They wouldn’t change it! They wouldn’t change it back, and I had to pull her out and not put her back in until we had resolved all that.*

Her daughter remained completely structurally excluded from the school environment while Lydia struggled with the district to get an appropriate placement. These mothers’ stories illustrate the complicated ways in which a parent’s decision to remove their children from a school or district entirely is often a compulsory decision between equally undesirable options, not a free choice between equally viable placements. Redistributive choices at the district, state, and federal levels ultimately shape the constrained choices confronting mothers.

Summary

In all of the exclusion situations described in this chapter, the districts considered the placements and behavioral responses appropriate. However, critical scrutiny of these examples offers a different interpretation of “appropriate” and suggests that exclusion is just one consequence of special education implementation. According to Ball (2013), schools are a “collectivist vision mediated within the methodologies of division and differentiation;” therefore, exclusion is an “institutional feature” of education (48). Mother’s stories of student exclusion suggest that regardless of “the spirit” of the law, exclusion remains an “institutional feature” in special education as well—this might be most apparent as schools manage problems of resource scarcity with student exclusion.

In this chapter, I discussed the structural and punitive means of exclusion separately for purposes of clarity in my analysis. However, the separation of structural and punitive exclusion remains artificial, as both means of exclusion can implicate and reinforce one another in complicated ways. One example of this is how structural issues determine the viable options available to teachers and staff in meeting students’ differing support and educational needs appropriately. In the end, mothers describe situations where they are watching schools react to their children as problems rather than responding to their children as whole persons whose well-being is intrinsically important. I offer that if special education professionals are to understand the consequences of inclusion, they must genuinely start paying attention to the students most vulnerable to exclusion. Partial exclusion cannot continue to be held up as an example of inclusion’s success, as it is all too often. Special education professionals and practitioners must come to understand that partial exclusion cannot stand in the company of isolation, seclusion, and complete exclusion as the only legitimate “best practices” available to districts, regardless of what resource scarcity suggests. Anything less continues to devalue the lives of disabled children and continues to put their well-being at risk.

CHAPTER IV

INSTITUTIONAL HARMS

What does it mean to find danger in a place
where one instead expected to find safety?

~Smith and Freyd~

Here I leave the mechanisms of exclusion behind to illuminate the material consequences of student exclusion experiences. My findings suggest that both the implementation of special education in a context of resource scarcity and the exclusion resulting from that implementation leads to tangible institutional harms. The stories that mothers shared with me show that their children experienced harm across three main categories: Pedagogical Harms, Social Harms, and Harms to their Personhood. I define institutional harm as a negative impact resulting from a student's involvement with special education. I offer that a negative impact can be minimal and still fall under this definition of institutional harm. It is the normalization and acceptance of lesser harms that quietly sanction the more profound. I am not arguing that special education does not benefit children. Instead, I am offering that any discussion of special education's benefits must remain in critical conversation with how it simultaneously and systematically puts students' academic, emotional, and physical well-being at risk.

Institutional betrayal underlies my analysis of the harms that mothers describe; therefore, it is worth defining again. Smidt and Freyd define institutional betrayal as "deliberate acts or acts of omission (e.g., negligence) perpetrated by institutions onto individuals that rely on these institutions for support, resources, protection, and in some cases survival" (2018: 491). The stories that so many mothers shared with me convey how mothers trusted the special education system that their children relied on, yet it betrayed mothers and children alike. The consequences of that betrayal are the harms I discuss in this chapter. Furthermore, my findings suggest that the variety of harms students experience can result from both a school or district's "failure to protect" disabled children as well as their implementation of official policies and procedures. Therefore, it is both regular institutional betrayal as well as state-sanctioned betrayal.

At its most recognizable, institutional harm is academic—with students falling so far behind, it becomes unrealistic to expect them to catch up to their non-disabled peers. However, with limited chances for unstructured social time with their peers, students can also experience social harm. Pedagogical and social harms alone are enough to warrant a deeper reflection on what is considered best practice in special education. However, many situations these mothers describe also show that the implementation of special education denies or diminishes their very personhood as disabled children. One aspect of the denial of personhood is how often their basic needs as children, and whole people, are not systematically and structurally protected and prioritized, which can lead to a violation of their fundamental rights—rights outlined in the UN Declaration on the Rights of the Child for over 60 years (UN General Assembly 1989).

I have organized this chapter into three sections. The first section of the chapter will discuss pedagogical harms to a student, primarily tied to their exclusion. Pedagogical harm is probably the most visible consequence and the one most closely aligned with what the IDEA sets out to prevent. Pedagogical harms manifest when exclusion from the educational environment denies or limits disabled children's access to quality academic instruction that remains accessible to their nondisabled peers. The second section of the chapter centers on the social harms faced by students when their physical absence denies them opportunities for friendship building and social engagement with their peers. Social harms are often more opaque than pedagogical harms as they are not easily captured with student tracking, standardized testing, placement, or attendance records.

Social harms are subjective to an individual student's overall experience in school. While it is true that students may have social goals on their IEP's and receive services designed to improve their social skills, these services place the burden on students with disabilities to succeed in the social environment. They do not require the same effort from non-disabled staff and peers. The goals of social skills classes are, at their core, about teaching a child how to pass as developmentally typical. While efforts to ensure the environment is safe and welcoming to the disabled student and that staff and peers know how to engage and interact in a healthy, inclusive way are minimal to nonexistent (Lalvani 2013). In this way, "while special education remains uncritical of its pathological gaze, it continues to reduce social issues to personal troubles" (Slee 2013

171). Ultimately, the social harms experienced by students are “nonacademic” issues in a self-referential “academic” system—as such, they are not the priority of administration and staff.

The final section of the chapter will use a lens of institutional betrayal to discuss the final and most profound form of institutional harm, the denial of personhood. The implementation of special education in a context of resource scarcity leads to a denial of disabled children’s personhood. The denial of personhood can happen when districts place children in situations where their basic needs for health, safety, and protection are unmet or even woefully neglected. The denial of personhood can also occur when districts deny basic service and supports. These are the situations missed entirely in placement percentages and abstracted to the point of erasure in quantitative reports on school discipline. These are the dangerous situations, the neglectful situation, the abusive ones. They are the situations that need the most intervention yet receive the least attention. These are the realities that schools might not want to admit are an outcome of a system designed to support children, a system they invest themselves in and in which they are complicit.

Pedagogical Harms

> *“How can he be up to, you know, grade level academically if he’s not even getting the education time.”*
>
> *~Bell~*

Pedagogical harm often resulted from inappropriate placements, unavailability of appropriate services, and student exclusion. All of which occur as schools struggle to manage resource scarcity. Pedagogical inclusion is a central goal of a child’s right to a free and appropriate public education. Harm occurs when students are regularly denied equal access to general education classrooms and developmentally appropriate curriculum. Often pedagogical harm stems from “practices that appear on the surface to be supporting inclusion, but are actually undermining educational outcomes” (Brigham et al. 2016:33). A 2017 review of special education literature found that when special education students are “held to the same standards as their peers without disabilities,” they “are not performing at the same rate,” which results in “lower graduation rates for students with disabilities” (Kirby:181). Furthermore, this review found differences “in achievement in language arts, math, science, and social studies” (ibid:182). Pedagogical harms can follow students into their adult lives, ultimately showing that “special education is not fully educating or preparing students for post-secondary life” (ibid). The institutional harm mothers described fits with the literature that schools are failing to educate disabled children properly. Meanwhile, the special education system rolls on, managing its resources, and pushing more students through without ever looking back.

Pedagogical Harms Caused by Unavailability of Services and Supports

Cymone describes how the lack of appropriate supports within the classroom for her daughter led to pedagogical harm as her daughter was regularly missing large portions of her school day. While her daughter experiences a pattern of exclusion, her daughter’s regular absence from class is fundamentally a structural issue with denied and delayed services. In this situation, the school is not providing the needed support.

> *If she had all of those proper accommodations, then maybe we would be at a full day, and she wouldn’t be missing so much school; there wouldn’t be so many days that we are an hour and a half late because she’s literally dreading being there.*

In Cymone’s case, she was still working on getting the appropriate services in place. In other situations, mothers described how services were removed or misused. Gloria talks about how the result of the school withdrawing her son’s one-on-one aid was noticeable and made it difficult for him to remain in the general education environment.

> *They withdrew the support. He declined, both in behaviors and in academic performance, and they didn’t tell me they had withdrawn the support. So, then I got calls, six weeks later, eight weeks later, asking if something is going on in the household because his behaviors had regressed, and he was having difficulty being in the classroom. When I asked how they were using the one on one in that situation, that’s when I was told that he no longer had one.*

Her son’s academic decline is tangible evidence of pedagogical harm, harm that the school was pushing back onto the home environment as the cause. She shares her response to the school.

> *You are calling me and calling these meetings and asking for my input to help address this issue, where he’s not accessing the learning*

> *environment, and you've withdrawn a resource. So, it seems to me we should get this resource.*

Once again, Gloria had to rely on advocating for her son to ensure support was available in the educational environment, enabling him to access and benefit from the curriculum. Lydia describes a similar situation where the unavailability of services made the general education environment inaccessible to her daughter.

> *What I believe was happening was that they were redeploying her aide to other kids and bringing her into the small group activities where she didn't need her aide because the aide was supposed to be with her in the gen ed room. So, they kept pulling her more and more.*

For Lydia, however, her daughter's supports were not entirely removed from the IEP, just redeployed in the classroom resulting in her daughter's regular physical removal from general education.

The above examples show how the unavailability of services led to students' physical absence or removal from an educational environment. In this way, they cannot access and benefit from the curriculum because the absence of services limited their physical access to the classroom. However, the inability to remain in class was not always a prerequisite to pedagogical harm. Mothers also illustrate the pedagogical consequences for a child who remains in the educational environment without realistic and consistent access to appropriate services and supports. Anais describes how, without the proper supports in place, her daughter is so overstimulated that "she's not taking in anything."

Other mothers share similar experiences to Anais. Nadia's son is autistic, and she describes how her son "would spend more energy, fighting his anxiety and managing his body and wondering what's next, then actually absorbing the material." Angelina captures some of this when she states how starting her son "in kindergarten without an IEP and only with the 504 was not pretty." She recalls their conversations when he would come home.

> *He would get in trouble. [and say] 'Oh Mommy, I got in trouble today.' 'What did you do?' 'I got in trouble. I learned to watch the fish.' So, what [the teacher] would do is when he got in trouble, she would sit him in front of the fish tank that had a little neon. It was like a natural video game for him. He just sat there and watched the fish.*

In this case, her son would physically be in the classroom yet remain isolated from any pedagogical instruction. He was ultimately unengaged and disconnected from what was happening in the educational environment. There is pedagogical harm to her son because there is not much learning happening without the learner’s presence and engagement.

Other mothers share similar stories about disengagement and overstimulation resulting from the unavailability of services. Cecilia talked about times her son has “come home from school saying, ‘today was awful. My entire day was ruined.’” For him, the noise level could “completely disrupt his entire day.” She describes how once agitated and without the ability to access breaks and reminders, it “would mean that any classes he had after that he wouldn’t get the work done. He wouldn’t focus. He was just done. He would just draw or space out” because it all “just starts to compile” and “after a certain point, he’s just too anxious to actually do anything.” Anais also describes this situation when she argues that if the school would provide the proper support, her daughter “would be engaged in what’s actually going on instead of just going through the motions to get through the day.”

Pedagogical Harms Caused by Student Exclusion

Exclusion goes hand in hand with the unavailability of services, as some of the earlier examples show. However, there are also situations in which structural or punitive exclusion was the more prominent cause of pedagogical harm. Consider Cymone, the district has placed her daughter in a contained special education classroom, where she experiences varying degrees of structural isolated-exclusion. In this situation, the district has pedagogically excluded Cymone’s daughter from the general education environment. Furthermore, Cymone’s daughter is also regularly removed from her already restrictive placement and put into a “sensory room” where she experiences punitive isolated exclusion from the special education environment. Cymone states, “there is not a whole lot of learning going on if you are spending 20 minutes in a room every 40 minutes or so.” This statement illustrates how structural and punitive isolated exclusion leads to further pedagogical harm.

Adelina captures some of the pedagogical harms caused by inappropriate placements and isolated exclusion as she describes the noticeable difference in her daughter’s academic success once she was able to access pedagogical instruction in the general education environment. She had gone from a contained classroom in one district to general education with pull-outs into a resource room in another.

> *I hate the resource rooms over in [another district]. I hate them. I think that they’re just so seclusive and detrimental. Like we saw a big leap academically, in [her] once we moved her from there to here, like her fourth-grade year was just, she gained so much, it was amazing from just being more in the gen ed class.*

Before switching districts, Adelina’s daughter was structurally isolated from her non-disabled peers and had minimal access to a general education curriculum. Her academics suffered because of that exclusion.

These harms can also occur when districts are partially excluding children. Angelina described how structural partial exclusion limited her son’s access to pedagogical instruction in the general education environment. She recalls that they were always pulling him for social skills during science, which was a topic he enjoyed. In this case, the teacher went above and beyond to inform Angelina and find ways to incorporate social skills into science so they would stop pulling him from class. However, it is unrealistic for teachers to go above and beyond to ensure students’ inclusion. Not all staff have the skills, time, and energy to advocate for their students in that way. Nor are they structurally rewarded for doing so. If Angelina’s son had a different teacher in that situation, the pullouts during science and the pedagogical harm would have remained.

Partial exclusion and isolated exclusion are not alone in limiting access to pedagogical instruction. Complete exclusion has a significant pedagogical impact on students. This harm is salient in the mothers’ discussions of shortened school days. Bailee points out how “when you add in the fact that [her] son had shortened school days, he probably got maybe six years of an education” out of all his K-12 years. That is less than half of his free and appropriate education. Similarly, Bell, whose son went through a whole academic year on shortened days, asks, “how can he be up to, you know, grade level academically if he’s not even getting the education time.” I asked Bell how much she agrees with the statement “special education provides students with a full education in the least restrictive environment,” as this is one of its’ stated goals. As a final example of pedagogical harm, consider her reply: *“My son does not get an education!”*

Social Harms

Being permitted to attend an event where I soon discover no one will sit with me, or talk with me, or where no one exhibits the slightest interest in what I have to say renders inclusion farcical.

~Merry (2020)

While mothers described the various ways special education inflicts pedagogical harm on their children, they also shared stories of social harm. While it was not an either-or situation as sometimes children faced both simultaneously, I discuss them separately for clarity. Like pedagogical harms, social harms are intimately connected to resources, services, and exclusion. Mothers call attention to the many social harms experienced by their children in the educational environment as schools consistently deny them access to various social spaces. The ideal of inclusion, as Kozleski asserts, "speaks to the notion that every child deserves the opportunity to learn alongside peers, to benefit from the paths their peers take to explore knowledge, create friendships, and harness creativity" (Kozleski 2020:340). Nevertheless, these ideals often remain unmet as "the emphasis on the extrinsic goods" like school performance and student academic progress "legitimizes educating children with disabilities in more segregated special education classrooms" (Lim 2020:581). I argue that a district's over-reliance on limiting or denying services or using "restrictive placements" as a way to manage resource scarcity curtails "the personal initiatives and social interactions of children with disabilities" (ibid).

Schools should provide an environment that enables students to form friendships while building their social skills (Bakken 2016). Nevertheless, Shah's work on physically disabled students and their perceptions of their social lives showed that many students reported "feelings of isolation and loneliness" in the general education environment (Shah 2007:436). According to Shah, these feelings directly resulted from "the access limitations and attitudinal prejudice which prevented them from building positive social relationships with non-disabled students" (ibid 437). Similarly, Panacek and Dunlap argue that children with high emotional and behavioral support needs "have very restricted social networks in school, and very limited opportunities to establish supportive relationships with school friends" (Panacek and Dunlap 2003:344). The social networks of these children were often limited to staff and students within the special education program. Furthermore, they did not reflect their social networks at home, where they had meaningful friendships with non-disabled peers (ibid).

In discussing the lack of authentic conversations around disability in general education classrooms, Lalvani asserts that “physical proximity alone is not enough” to reduce prejudice effectively. She goes on to highlight the importance of how all members must “be institutionally supported to collaborate with each other” and be “positioned as having equal status” (Lalvani 2015:3). Merry (2020) argues that for social inclusion to be possible, “it must also be possible to enjoy a sense of belonging” (20). Genuine inclusion concerns much more than just “the legal entitlement or physical access necessary to becoming a member” (ibid:11). Because “merely being permitted to attend a school is not tantamount to inclusion” (Merry 2020:12). For example, if a student is physically isolated from general education peers, that child “has no realistic possibility of making friends” (ibid). Nevertheless, situations in which their children are isolated or not genuinely included in the social lives of their peers were more than abundant in the stories mothers shared.

Social Harm from Marginalization

> *Parties recognize the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child*
>
> *United Nations Convention on the Rights of the Child*
>
> *Article 31.1*

Mothers described how their children often struggle to form peer relationships. They shared stories about how their children’s behavioral and physical needs keep them on the margins of the social groups within the classroom. Sarina captures some of the social exclusion occurring within the classroom when she describes how her daughter “sort of exists on the margin of several peer groups, you know, but she doesn’t really have a peer group of her own. She’s not really a part of anything.” Here Sarina also grapples with self-selecting her daughter out of an upcoming field trip because of the unavailability of staff. She describes the field trip as “a really enriching experience, with friendship building" that also serves as a way "to begin their fifth-grade year" as "the oldest kids at the school." Sarina is clear that "not letting her go would exacerbate that marginalization, you know, because then they would have had these bonding experiences that she wouldn't have."

Lena paints a slightly different picture of her daughter's existence on the margins as she describes her inability to play with children at recess in any meaningful way. She describes her daughter sitting on her adaptive trike in the playground, watching other students swing on the swings. While she is physically at recess, she remains unable to play because there is not an adaptive swing.

> *It's great that she can use the trike at recess, but she also sees the kids on the play structures and on the swings, and she wants to swing. But they refuse to put an adaptive swing up in any school and elementary school because of the risk to other kids.*

She shares that outside of school, her daughter can enjoy adaptive playground equipment. "When we go to the park, we put her up on the structure. We put her on the swings." However, at school, she "can't do that because of the risk of injury." Her daughter shares the physical space of the playground with the other students. However, her limited access to any of the play structures functionally sets her apart from her peers in such a way that she is not "positioned as having equal status" (Lalvani 2015), ultimately curtailing her ability to share meaningful social interactions with other children.

Finally, consider Deanna's daughter. She is a child who has "the capability to be a great friend" yet remains structurally isolated from her non-disabled peers. Deanna expresses fear that "other kids are less likely to give her that chance, especially in mainstream[3] [spaces]." She states that "part of why [she] want[s] to get her into the mainstream [classes] is so she has a chance to socialize." Her daughter currently has minimal access to general education, and the resulting social harm is tangible. Deanna shares a story that captures this. In this story she is seated in the front of a school bus with

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[3] Her use of the term mainstream is referring to academic and nonacademic spaces. The terms general education and mainstream are often conflated, but do not mean the same thing. Mainstreaming is the intentional effort of including children in nonacademic environments and activities. General Education is about the educational environment of the classroom itself. However, her use of it generally encompasses both of these things.

her daughter watching her try, over and over, to engage other students as they board the bus.

> *I went, I always go with her on the field trips, because she needs one-on-one on the field trips . . . we were sitting near the front of the bus because of motion sickness issues for both of us, and there were other kids sitting in seats, and she was offering the space on our seat to other kids. It was like, 'No, thank you. No, thank you.' and she was trying to engage kids in conversation, but they were just so clearly not wanting to talk to her because she is different—because she's unknown—because she's in 'the different class.'*

Deanna describes how she got the sense that the kids were like, "'I don't know who or what you are, and that is slightly scary to me, so I'm not going to extend friendship to you.'" However, it was apparent that "at the same time [her daughter] was trying to make friends." Deanna states that "eventually [her daughter] gave up trying and decidedly turned around and looked out the front window."

In the example above, a lot is going on, especially when considering resource scarcity and Deanna's perspectives on the lack of staff and her daughter's overly restrictive placement limiting her social interaction with nondisabled peers. The lack of staff also contributes to Deanna's presence on that bus. While I discuss this further in the following chapter, I am calling attention to it here because it highlights how interconnected and inseparable my findings are. Deanna mentions to me again how she is "hoping to be able to get her [daughter] into mainstream with a positive experience around her peers." So that "she can start building these friendships." As she correctly argues, "you can't make friends with the mainstream peers if you never see them, except maybe at recess when you might be hyper-stimulated, and your meds have just worn off."

Deanna described a social environment where other students denied positive engagement with her daughter as a person worthy of friendship. She described how her daughter's relative isolation in a contained classroom contributed to her social ostracization. Recall Lalvani's argument about how a physical presence or proximity to other students will never be enough to dismantle prejudice (2015). Suppose Deanna can get her daughter's placement changed to general education, and the supports are available. In that case, this will help close the physical distance between her and her peers; however, it will not eliminate the social distance. Most likely, her daughter will continue to experience other forms of structural and punitive exclusions that noticeably set her apart from her peers as someone who does not hold “equal status” in that space.

Social Harm from Isolated Exclusion

Structural limitations socially marginalized Lena’s daughter on the playground by severely limiting her ability to play and engage in shared activities with her non-disabled peers. Other children socially ostracized Deanna’s daughter because she was “unfamiliar” or different.” Adding to these social harms, mothers also talked about situations when schools excluded their children from a social space or activity entirely. For example, Lydia’s daughter was structurally excluded from recess and other social activities.

> *Everything would be taken away from her like recess would be taken away, and in her gen-ed classroom, on Fridays, they did fun Friday, that was taken away to go to SPED. She just got pulled into the sped room more and more.*

Similarly, Angelina recalls how “they wouldn’t let [her son] have recess” and that she “fought tooth and nail” for that “because for him recess was *the* positive” part of his day (emphasis on the singular of positive is mine). Angelina also recounts how the school wouldn’t let him do lunch in the cafeteria “for a long time.”

Lyndsay shares that this was true for her son as well. The school regularly excluded her son from recess for almost half of the fourth grade.

> *They did not let him go to recess for four months. Four months! I was like, ‘are you kidding me?’ and they kept citing safety reasons, and I was like, ‘have an aide go with him.’ That was probably about the time where he kept getting in trouble at the same time, every day. I was livid. He would come home crying that he didn’t get to play or do anything.*

In addition to missing recess daily, she recalls how her son also “wasn’t even allowed to eat with the other kids. He would have to eat in the special ed room.” Lyndsay and Angelina are not alone in the school excluding their children from the lunchroom. Cymone describes a similar experience.

> *So, my oldest is a stuffer and he would aspirate, so they made him eat lunch every day in the resource room, versus to be able to be with his peers or anything. . . I didn’t realize how wrong it was. Initially, I was like, well, that’s weird. But you know, looking back on it. Now. It’s like, that was really, you know, secluding him from any possible social situation.*

It is hard to comprehend the full scope of emotional damage inflicted on children in socially isolating situations like these. Recall Merry’s argument that “simply being in school” harms disabled children “irrespective of whether the child is cognizant of the harm” (2020:17). I argue again that these harms occur whether teachers, staff, and school administrators are cognizant of them. Consider the possibility that staff cannot afford to think deeply about the consequences of refusing recess or sequestering students away at lunchtime. Resource scarcity may occupy too much of their attention. Special education policies and practices sanction this social harm and cause real and long-lasting damage to the children in their care. A school's failure to acknowledge and respond to this harm is institutional betrayal.

Social Harm from Partial Exclusion

Mothers shared ways in which partial structural exclusion limited their children’s ability to socialize with their peers and resulted in social harm. Sarina communicates that her daughter regularly missed out on class rewards like extra recess due to service delivery.

> *Sometimes the kids will earn with their behavior point chart system; the whole class will earn like a third recess. Going outside for, like, sometimes it’s only five minutes, but that could really make a difference in the afternoon between a pleasant afternoon and just kids bickering and just feeling cooped up. But those are typically the times where she’s pulled out of her classroom to go to her special education teacher in the afternoons. So, you know, I’ll hear about it when I pick her up, and she’s like ‘you know it’s not fair they got recess and I had to go with [a teacher] and practice my handwriting.’*

In this situation, not only is Sarina’s daughter aware that her peers get to enjoy the reward her efforts helped earn, but other students are also aware she does not. Again, we have a child structurally distanced from her peers in such a way that communicates that she does not have “equal status” with her peers (Lalvani 2015).

Lysha describes her son’s greatest strengths as his “desire to help others” and his ability to express himself. It is not surprising that, with these strengths, he would be interested in being on the student council. His strengths lend themselves to representing, organizing, and advocating for one’s peers. However, the structure of special education service delivery meant that her son could not join the student council regardless of his interests or his potential to thrive in that class. Lysha shares details on her son's experience when he found out his peers had the option while he did not.

> *He wanted to run for student council, but he couldn't be in that elective because they scheduled that elective is during the first elective period, which is when he has social skills. Because he's in social skills, he loses an elective slot. He didn't even find out about it until after the elections. He didn't even know it was an option. Nobody told him because it was that period, and he was so upset and unhappy and frustrated, with, you know, not being able to be included.*

The school missed an opportunity to teach to her son's strengths. The policies and procedures that prevent so many special education students from accessing electives deprive them of an integral part of education: the part where they have agency and choice and can come together with other peers who might share their interests. Her son missed out on a chance to build positive social connections with his peers, and it happened in the name of social skills.

Social Harm from Limited or Denied Access to Field Trips

Research shows that teachers "value the opportunities afforded by field trips for positive affective and social experiences" and that students are more likely to positively recall the social interactions they had on the trip (DeWitt and Storksdieck 2008:182). However, field trips remained a salient site of social exclusion for many special education students. School policies often place behavioral or attendance restrictions on field trips. These restrictions are not value neutral. Students involved in the special education system often require supports around behavioral and emotional regulation, which means that the policies around field trip permissions combine with a lack of available staff and supports to exclude many disabled children from critical social experiences.

Kaleigh recalls how in elementary school, both her children either missed chances to participate in field trips because they "didn't get enough points to go" or the "the worst one" was when they could attend but were unable to participate in the social activities freely.

> *I cannot even believe schools would do this, but they do, so you all must go to the field trip, but the ten [students] who are in trouble need to line against the wall and watch everyone else have fun*

She expressed her shock when she realized that this was happening and how at that point, she opted to keep him home from future trips: "um, my son will not be participating in school today because I'm taking him out for a personal day . . . and I was like, I can't believe that you guys go there." Similarly, Mileena contrasts her children's experiences with field trips. Her daughter was usually able to attend field trips because she was always able to "kind of talks her way into it" by saying things like, "'I'll be really good. I can do it. It's okay.'" This was not the case for her sons.

> *They were denied field trips. Every time. Every time! [the school would say] 'Oh, it's okay. You'll get to watch a movie in the library.' Or 'Oh, it's okay. You'll get to hang out in the office.' Yeah, no, fuck you. I let them stay home, and I took them to the movies. [For one son]they would say, 'Oh, well, we can't get an aid from the district to come with us. So, he can't come,' and then he'd get docked on his grade because the questions they had to fill out were about the field trip, and he wasn't there to get the info.*

There was both social and pedagogical harm resulting from her son's exclusion in this situation.

Similarly, Gabriella's daughter missed out on a field trip at her school because there were no supports in place. As the trip approached, her daughter's anxiety about the trip grew, and she opted to stay home. Gabriella pointed out that later they "got feedback that it was a required trip for credit, and therefore she didn't get credit." When asked if there would have been a way the school could have supported her daughter on that trip, she states that "there could have been, but nobody initiated that or said that that was a possibility, and this was like, a couple of years into high school, so they knew her really well."

In these situations, the school knew about the field trips, planned for them even. Nevertheless, schools do not always consider ways to ensure that special education students are appropriately supported and included as integral to their plans. The field trips these students missed are social and pedagogical experiences intentionally built into the educational environment because teachers and staff value them, and children benefit. However, a pattern of denying special education students access to those opportunities should cause us to question if the benefits of field trips may only be considered valuable for some children and not others.

Denial of Personhood as Institutional Betrayal.

Parties shall take all appropriate legislative, administrative, social, and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, [or] maltreatment.

United Nations Convention on the Rights of the Child

Article 19.1

Heikki Ikäheimo (2009a) states that "not being recognized by others, and therefore not having a full standing or status as a person in their eyes, is usually a harm – in the best case a limitation and in the worst case a catastrophe – to an individual" (40). Furthermore, he argues that these harms occur "wholly independently of its possible psychological effects" (ibid). Therefore, this section returns to his argument that "one of the dimensions of having the standing of a person" is being seen as "someone whose happiness or well-being is taken as intrinsically important by others" (2009b:81). As Merry argues inclusion, as a practice, "must contribute to the person's well-being" (2020:12). Truly centering a disabled student's well-being must include protection from harm. A child's ability to communicate, be understood, and feel cared for are all central to inclusion (Merry 2020:12). However, mothers described various ways their own children's needs to communicate, be understood, and feel cared for were not only overlooked or neglected but directly denied in the school environment. Mothers are confronted every day with the sense that their children are not valued or prioritized, yet they have and continue to place an enormous amount of trust in schools to protect and care for children in these spaces. The stories, fears, and frustrations they shared with me outlined a series of institutional betrayals, where staff repeatedly put their children in situations that denied them their moral status as persons and violated their fundamental rights.

All children have an inherent right to be kept safe, well-nourished, and free from physical, mental, or emotional harm. Schools must ensure that there are systems to guarantee that these rights are protected. Schools must provide students access to lunch with appropriate dietary options and do so for free or reduced prices for low-income families. Schools must have safety policies to account for student's whereabouts; there are lists of approved people who can pick the child up in each student's file. Schools must obtain copies of custody documents at registration, and even the transportation department requires permission for a kid to get off the bus at a stop other than their own. Schools are supposed to restrict corporal punishment and monitor and appropriately respond to bullying and other forms of physical or emotional harassment. The systems that are supposed to safeguard students and their rights as children are all followed imperfectly, but they are in place to ensure students' safety and well-being. However, these mothers' stories show that, in many cases, schools do not extend some of these basic safety measures to their disabled children. Within the mothers' narratives, there was a theme of the child's essential social needs to feel seen, heard, and respected going unmet. Neglect of their social needs paired with a pattern of denying children's bodily needs to be nourished, safe, and protected from harm.

Unmet Social Needs: Visibility, Communication, and Dignity

Mothers articulated situations in which their children's social needs were being neglected or obstructed in the school environment, resulting in a denial of their personhood in addition to other pedagogical or social harms. Mothers described how their children were looked over or even lost within academic and non-academic spaces, which hindered learning and created significant safety issues. Mothers also described situations in which their children's schools denied children their ability to communicate effectively with teachers, staff, and peers. While they may have been seen in the spaces, they were not heard. Finally, mothers described instances where the schools denied their children their dignity as people by placing them in embarrassing or humiliating circumstances, which hindered their ability to integrate into the classroom socially.

To Feel Seen: Visibility

Central to an interpersonal definition of personhood is recognition by others—"being seen" by others as a person. However, in many cases, mothers described how teachers and staff seemed not to see their children at all. Mothers shared that their children are just "not seen" in the classroom, in school buildings, on field trips, and even on the school bus. This sense of invisibility contrasts with mothers' perceptions that their children are hyper-visible to staff when they scrutinize their “deficits” and focus on their negative behaviors. At its mildest, their children’s invisibility in the classroom leads to diminishing personhood. In other situations, it is a denial of personhood as they are regularly lost and left behind in academic and social spaces. The invisibility of a child can and does lead to substantial safety risks. A student who is not seen is not a person protected from harm. Students’ invisibility was often paired with a lack of communication from the school about their children going missing or being left behind.

Tamara is one of the three moms with a positive perception of special education. Even so, she describes situations where her son was not being seen. Tamara is a 51-year-old single mother. Her 16-year-old son is partially deaf and has tourette's syndrome and ADHD. She tells me that her son is a “nice kid” who writes unbelievably well and likes to “make his own movies.” Tamara elaborates that he would write and direct movies “with his hamster” when he was younger. She also shares that sometimes teachers would not see him in the classroom. He “would basically just read books, under his desk and not do his schoolwork and never get caught.” She would ask him, “what did you do today in school” and he would say things like, “I read a whole Harry Potter book.” When asked directly about the academic subjects, he would respond with things like, “I dunno they didn’t tell me to do anything.” She brings this up as an example of how “they didn’t notice him, he was quiet he sat back, and he just daydreamed in his own little world.”

Tamara’s son’s invisibility represents minimal safety risk; however, it makes an implicit statement about his value as a person worth seeing and teaching in the classroom environment. It can also come with tangible pedagogical harms. Gloria also describes how her son was often marked absent while present in the classroom. She points out that her son is good at hiding and how she feels that staff and teachers who are less tuned in to those types of strategies, and, and in [her] opinion, little less confident in their skills will often miss him.” She describes a situation where he was marked absent while trying to regulate himself in a noisy environment. Her son was in the designated break area, as was outlined in his IEP.

> *I had a teacher report him absent when I personally brought him into the classroom. He was in the classroom and had been there for two hours. But she marked him absent because he was in the reading corner, not at his desk, you know. So, when she saw that he wasn’t in his desk, she was like,*

> *'Oh, he's absent' instead of looking for him . . . she told me that she 'had the aid look for him, and even the aid couldn't find him,' and that was what she used to support her claim that he was a good hider. I don't even know if she looked for him. To be honest.*

This invisibility suggests that Gloria's son, like Tamara's son, is not seen and therefore is not genuinely integrated into the classroom structure as a whole person worth teaching.

Anais describes a similar situation where her daughter "went missing for 20 minutes" in the school building and "was found curled up in a cubby somewhere." She recalls the school's assertion that her daughter was probably just "excited and wanted to go see the book fair" even though, as Anais mentions, "she was hiding on the opposite end of the school away from the book fair." She expresses frustration that the school "didn't notify [her] that she was missing." When she confronted the school about it at a safety meeting, they told her that it happened "after class had been dismissed, after school," and since "it wasn't on [their] time, it was "a support worker issue, not [their] issue." There are several layers of denial of personhood happening to Anais's daughter. They did not see her physically. She was missing in the school building for 20 minutes. When they finally did see her, they did not see what her emotional state was communicating about her needs as a sensitive and vulnerable person. Finally, they did not see her as someone whose safety and well-being are worth considering after school hours.

While the safety risk of a student not "being seen" in the classroom or school building remains low, this invisibility was not only limited to classrooms or campus. Adelina recounts how her child's "bus ended up downtown" with special education students still on it. Her daughter was "so late to school that attendance had already been taken." Adelina states that since she lives relatively close to the school, "there's no reason for her to be downtown." Their IEP states that school transportation "is not supposed to be more than 30 minutes." Situations like this are challenging as her daughter, while verbal enough to "have a conversation," is not "aware enough to say 'Hey, Mom, the bus went on a different way this morning, and I was late to school.'" She describes how her daughter "can't relay that to" her and how the school didn't tell her. Adelina "found out from another parent over the weekend that [she] happen to meet at a charity event." At the time of the interview, this incident was relatively recent, and she expressed feeling like "nobody cares" because, after a week, she still hasn't heard back from the school about her concerns. It worth repeating here that Adelina feels “like nobody cares” because this feeling speaks to the diminishment of her daughters’ value as a person worth caring about in the educational environment.

The school’s lack of communication about situations when they “lost” their children was a commonly shared experience. Gloria shares how the school left her son behind at their annual jog-a-thon. He was alone and without adult supervision, and the school failed to inform her that this happened.

> *Oh, he was left behind, and the parent called me and told me. The school did not tell me. It was a walking field trip, and they had gone from the elementary school to the neighboring middle school to have their jog-a-thon. So, the entire school is walking six blocks to the next school, and they did their running around the track thing, and then the entire school walked back; well, the teacher neglected to ensure that he knew where to meet afterward.*

Gloria went on to describe how when everyone was walking back, her son “waited until the last group initiated their walk, and then he started walking back.” At that point, his teachers and peers “were already back.” Gloria reiterates that other parents helped get her son back to his classroom and told her what happened.

> *Some parents had stayed to help clean up at the middle school, and they saw this kid, and they went up to him and said, you know, ‘who are you supposed to be with? Who’s your teacher?’ They said, ‘where is your teacher?’ He’s like, ‘I don’t know,’ and so, they walked back with him and the school, never called me. [the parent] called me to tell me what happened.*

The safety risk in this situation is obvious. Staff left him behind in an environment that is off school grounds and potentially unfamiliar. He quite possibly could have wandered away had other parents had not intervened. Gloria argues that the jogathon was “just another piece of evidence” that the teacher is failing to see her son.

> *I said, ‘she doesn’t want to teach my son. If she wanted to teach him, she would at least see him. She’s left him on a field trip. She’s lost him in her own classroom. She pulls him out into the hallways; she doesn’t see him. Either she is disciplined, or we transfer him, or we meet, and we have some very clear guidelines because she’s not seeing my son.’*

Her statement that if the teacher wanted to teach her son, then “she would at least see him” captures a sentiment conveyed by several mothers: that their children were not seen as people worth teaching.

To Feel Heard: Communication

The child shall have the right to freedom of expression; ***this right shall include freedom to seek, receive and impart information and ideas of all kinds****, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice.*

United Nations Convention on the Rights of the Child

Article 13.1

"It's traumatic to be so sensitive in this world. They're trauma kids. It's traumatic to have a communication disorder where you can't express yourself."

~Bailee~

Beyond visibility, mothers also described how schools denied their children the ability to communicate with teachers, staff, and peers. This failure is significant. Kleinert (2020) assesses the inequity of overly restrictive placements and their connection to the "limited access to augmentative/alternative communication" for many students. He states,

> *If we are not enabling students to acquire symbolic modes of communication to express a variety of intents across a variety of contexts with their teachers, families, and peers, we are denying them the benefits of more challenging educational environments.*

This denial often results in "further restricting both their opportunities and their placements" (ibid:36). This argument lines up with mothers' experiences of both the schools' failures to provide an appropriate mode of communication to their children and the use of overly restrictive placements.

Bailee's son was "supposed to get [assistive]technology," yet it was "one of the things they kept removing off of his IEP." She mentions how she "got all of his records" and "discovered that four different times without an IEP team meeting, they removed technology." This removal connects to their mislabeling him as severely intellectually disabled. Bailee had been trying to get the school to provide a "smart brailer." Her son struggles with regular brailers because his fingers are "very hypermobile." The smart brailer is easier to use, and it can vocalize what a student is typing in addition to brailing it and displaying it. The features facilitate communication and create a more interactive experience between students, staff, and peers in the educational environment. Bailee talked about how even though it is challenging for her son "to push down [the buttons] on the old school brailer, that's the only thing they've ever, you know, tried with him." When asked about progress towards getting him a smart brailer, she states, "I can never get one for him. Still haven't. Still trying."

The consistent removal of technology off his IEP represents a denial of personhood and a violation of her son's rights. This denial meant that her son had to navigate an already traumatizing environment without the ability to efficiently and effectively communicate his needs, interests, or desires to anyone. Denial of communication support also meant that the only viable way for her son to express his needs was through "behaviors." However, rather than considering these behaviors as communication attempts, the school defined them as "disruptive" and "unmanageable"—definitions that "justified" his ongoing isolation in overly restrictive placements and sanctioned the trauma they inflicted on him and his family. Furthermore, the denial of communication denied him the ability to form meaningful social relationships with other students and staff. Social relationships are fundamental aspects of personhood. By treating that as secondary to "managing" her son, the schools denied him full personhood as a disabled child worthy of communicating and belonging in the social environment.

Lena faced similar challenges and discussed her daughter's communication challenges at school. "She has certain behaviors that are not necessarily socially acceptable, you know, she gets excited, and she is too loud, or she gets frustrated, and she just screams, and it scares the living daylights out of people." Lena goes on to talk about how they are "really working on social behaviors and what's acceptable and what's not, teaching her, you know, to use a quieter voice and those kinds of things." However, these efforts at teaching her daughter socially acceptable behaviors are happening in the context of the school's denial of a communication device, because as Lena points out "they weren't ready for it." They had "started using partner-assisted communication with a pod book" over the summer and "the school's been hesitant to use that." Lena recounts trying to get staff to understand that often her daughter's behaviors were her way of trying to communicate.

> *I would say she's trying to tell you something like she's trying to grab your hands. She wants your help doing this. She wants to get out of her wheelchair. She wants to, you know; she's trying to communicate, and so when she gets frustrated and you don't understand why that's why!*

Lena is sure that access to a partner assisted communication device would help both her daughter and staff. "I think it'll be not only beneficial for her because it'll teach her that pictures have meanings, but also for the people who don't necessarily know her as well, just to give them a very straightforward form of communication."

> *What's difficult for people is when you try to engage with a child who doesn't, like, "engage," I'm using air quotes here, but speak back to you because you don't know what they're thinking, you don't know what they're trying to say. That has been a challenge for people unless you know her, and you know what she's trying to say.*

When Lena brought up the use of a communication device in school, the school placed their convenience and resources over her daughter's need to communicate with staff and peers. In exasperation, she shares, "the response I got when I told the teacher about it was 'that sounds time-consuming." She goes on to remark, "I almost took my daughter and walked out of the classroom. So yeah, it's been frustrating." In the end, her daughter, like Bailee's son, is forced to navigate an environment where she cannot communicate her needs to the people responsible for her care. Therefore, the school's continued denial of this support conveys that she is not seen or treated as a full person with the right to "receive and impart information and ideas of all kinds" (UN General Assembly 1989).

Kaleigh also struggled to get a communication device for her son. She shares that she and the speech pathologist worked together outside the district to get her son the device; she describes the district's role in getting the device as having nothing to do with "except the fact that they could have made it happen and didn't." At the time of the interview, the school was still not using the device. Similarly, Cymone shares how her son also struggles to communicate in the school environment. "He can make a basic request. But if he's upset, he can't talk at all." Since her son "was able to type more than he could speak, he was using text to speech when he was really upset." Cymone states that, every time she asked the school to provide her son with an iPad, "they said they would send him to the evaluation, which they did several times, and every time he didn't meet the requirements or qualification." At that point, she ended up purchasing an iPad for her son to bring to school with him. "I wasn't gonna let him sit there without it."

These mothers all describe the districts' denial of essential supports and services, resulting in barriers to basic communication in the educational environment. For these children, there are tangible social and academic consequences. Kaleigh highlights some of this when she states that "if he would have had [a communication device] at two or four or even eight-years-old we would be in a way different boat than we are right now." Communication facilitates connection in the social environment. These children want, need, and deserve to communicate. Lena might capture this best when she states, "You know, I think at the end of the day, she has a desire to communicate. She has a desire to be with people and wants to build relationships with children and adults alike"—this is key to full personhood.

To Feel Respected: Dignity

> *Parties recognize that a mentally or physically disabled child should enjoy a full and decent life in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community.*
>
> *United Nations Convention on the Rights of the Child*
>
> *Article 23.71*

In addition to not being seen or heard in the school environment, many mothers talked about ways their children were denied basic respect and dignity as people. This denial occurred when staff would minimize or discount their disabilities as legitimate. The denial of dignity as people was also apparent in situations where their child's embarrassment or humiliation was on display in front of their peers—often socially marginalizing them even further. In reviewing the historical trajectory of power and pedagogy in the formation of public education, Ball points out that there is a "whole set of micro-penalties, for lateness, absence, interruption" (Ball 2013:50). Historically, the "punishments in schools included both the spectacle of monarchical practices—the cane, the slipper, the taws—and increasingly over time reformatory and therapeutic practices" (ibid). As Ball states, schools developed over time; however, it was never about finding ways “to punish less but to punish better” (ibid). While today it may not be as overt as the cane or the dunce cap, the spectacle of punishment still had material consequences in these children’s lives.

Denial of Dignity and Diminished Personhood through Disability Erasure:

Staff would deny children their dignity and diminish their personhood by minimizing a child’s disability when staff would argue that a student’s challenges were not related to their disabilities. Minimization or erasure of disability was undoubtedly a factor in the difficulty mothers faced in getting appropriate services for their children. However, sometimes this minimization would translate to more than just a delay in services as mothers also described how teachers and staff would treat their child differently due to viewing the child’s challenges as character flaws instead of disabilities.

Lydia recalls how sometimes the teacher would shun her daughter and “physically turn her back to her if she was misbehaving.” Understanding that this teacher’s approach with her daughter is a typical behavioral training tactic used with dogs puts the denial of personhood in perspective. Furthermore, with her daughter’s heightened need for trauma-informed care, the teacher’s shunning would often trigger further fight-or-flight responses and ultimately escalate her behavior. Nevertheless, Lydia describes how teachers and staff told her, often, that her daughter was just “manipulative” and “in full control of what she was doing when she was escalating.” When her daughter needed safe relationships, connections, and supportive co-regulation the most, staff responded to her challenges as if they were not related to her disability. In doing so, they denied her access to all those things.

As Lydia argues, “if they were working with her in a real way, she wouldn’t be escalating.” However, staff often defined Lydia’s daughter’s fight or flight response in high-stress situations as intentional. Because her daughter “was so verbal and smart,” the school treated her as if “she wasn’t really escalated.” This erasure of her daughter’s disability diminished her personhood and placed her daughter in harmful and traumatic situations. In contrast, with the proper support for her whole identity as a black and autistic child, her daughter has experienced success in the general education environment. Lydia describes those interactions with a previous teacher.

> *She loved her gen ed teacher. They bonded over science, and the gen ed teacher was really good at doing things about race in an age-appropriate way and all that kind of stuff, and she actually did fairly okay in the first grade, and it happened faster than we expected for her to kind of move from the [contained classroom] into more gen ed.*

Like Lydia's daughter, Judith's daughter faced the diminishment of her personhood as a disabled child. Judith describes her daughter as a funny teenager who "has a really big heart," is "very patient," and warm and caring towards others. The ongoing dismissal and denial of her disabilities haa been traumatic for her daughter because "there's nothing like trying your heart out at, you know, eight or nine years old and being told, no you're just lazy." By minimizing or erasing children's disabilities, staff members diminished their personhood and, in doing so, functionally erased children's support needs along with their moral obligation as adults to meet them.

Denial of Dignity and Personhood through Embarrassment and Humiliation:

Beyond school staff minimizing a students' lived experiences as a disabled person with legitimate support needs, mothers also described their children in situations where they faced a diminishment or denial of personhood through social embarrassment or humiliation. A relatively minor example of the spectacle of punishment is the social embarrassment resulting from punitive classroom management. Sarina describes a situation where her daughter spilled her water bottle in her excitement about recess. As a child with ADHD who struggles with impulsivity, her daughter ran out to the playground instead of cleaning up, as many children might do. However, as a result, Sarina's daughter became the one student in class who was not allowed to have a water bottle at her desk. This specific punishment went on "for three months." In this situation, her daughter's punishment was not only unreasonable, but it was also visibly playing out in front of her peers.

The ongoing punishment marked her as somehow deserving of different treatment and, again, set her apart from her peers as someone who does not hold equal status. Beyond the visibility of the punishment, the complete removal of her water bottle was also not providing her with opportunities to learn and demonstrate more care within the classroom environment. Sarina describes how "in the last few weeks of school, [she] gave her a fucking water bottle and was like, 'tell [the teacher] mommy says that you get a water bottle.'" In this situation, the teacher's punitive measures also denied her daughter equally accessible access to water that her peers had.

Beyond minor social embarrassment, mothers also described situations where their children faced a grander spectacle of social humiliation, which led to health and safety issues. Cecelia recalls how when they removed her son's IEP and put him on a 504, he had a noticeable increase in "vomiting frequently." She mentions that "he was probably throwing up five to six times a week minimum." At the time of the interview, Cecelia had "been pushing to have an in-person meeting." She states,

> *If [my son] got anxiety to the point where he's throwing up again, then we're gonna have a problem. There's also a biohazard like there's an actual physical problem there, and then he gets sent home from school for throwing up.*

This example shows how the removal of services placed her son in potentially humiliating situations where he was regularly throwing up in front of his peers. However, the school was not responding to this situation as potentially embarrassing or harmful for the child. In their non-response, her son is not a whole person deserving of dignity. Furthermore, the school was not considering the impact of removing the IEP on her son's health and wellbeing in school, and there is nothing to suggest they would have without her bringing it up.

Adelina describes a pattern of similar embarrassment and humiliation. Her daughter's tethered spine impacts her awareness of her bathroom needs, and she highlights how that has played out for her daughter at school.

> *Oftentimes she has no idea she has to go to the bathroom until it's too late. She has accidents. We deal with it. I send extra clothes. Her IEP states this in there and to call us. You know, she's kind of behind. She doesn't really know how to change and be like, you know, hygienic about it and stuff.*

While the IEP outlines staff procedures for situations like these, Adelina expresses frustration and anger around how the staff handle it.

> *They don't call us. The last time I found out was the last week of school. She had an accident in her chair. They made her clean it up by herself in front of the whole class. I was about to rip somebody's face off. Oh my god, that is so demeaning.*

The spectacle does not begin with her unavoidable embarrassment from the accidents. The spectacle begins with the public humiliation and the degradation of being forced to clean it up by herself. The staff in this situation denied her daughter dignity as a child, as a person, worthy of help. That denial of dignity was on display to all of her peers. Furthermore, the accident is related to a documented disability. Forcing her to clean it up without help denies her dignity as a disabled person with legitimate and documented support needs.

Cymone's son also struggled with bathroom hygiene in the school, and he was consistently "coming home with [feces] dried to the back of his pants." He was also trying to engage with staff and peers in the social environment while potentially smelling like feces. Cymone asserts that "even when it was brought to the head of special education, even when it was brought to the principal, there was no change." She states that "you know, at some point, I was realizing this is a major health and safety concern." However, nothing changed in that environment for her child despite her efforts. Staff continued to ignore the problem and, in doing so, communicated to Cymone that her son's dignity as a person was not a priority. Shortly after this, she pulled him out of public school completely.

While these situations are bodily experiences, they are discussed as a social need here because these mothers describe situations where their children faced humiliation in front of their peers, humiliation that was either ignored or even facilitated by staff. There is a significant overlap between denying their children's dignity as whole people in the social environment and the school's failure to meet their children's basic bodily needs. For example, Mileena describes a less socially visible situation where staff did not take her son's bathroom needs seriously. In this situation, her son was not allowed "to use the bathroom at all." While this denial could have easily led to her son having accidents in front of his peers, it ultimately led to his hospitalization, where he "almost died from a major bowel blockage." Her son ended up on a stringent diet and daily medication for several years. After the hospitalization, she had it put in the IEP that her son was "able to use the bathroom whenever he said he had to go." For perspective, this mother had to stipulate in writing through an IEP that her child should have free and equal access to a bathroom because his physical needs were not being taken seriously in the school environment. Mileena’s example highlights here that beyond the basic social needs of children, to feel seen, heard, and respected going unmet at school, the theme of their bodily neglect also emerged.

Unmet Bodily Needs: Nourishment and Protection

> *I’ll go to a district meeting with all SPED, you know, like teachers and the parents, and there’s always someone worse off than you. Right? I mean, I don’t know that I’ve been to one of those meetings where I haven’t cried because someone else’s child. I think my child is in a bad place and then I hear the stories of someone else’s child, and I’m like, Oh, my gosh! I mean, it just breaks your heart.*
>
> *I don’t think a lot of people understand.*
>
> *~Lena*

As mothers described a pattern of bodily neglect, they talked about various ways in which the school consistently failed to make sure their children were nourished and protected from harm. Mothers described situations where their children went without appropriate food or experienced physical and emotional abuse. The school's neglect and its facilitation of abuse suggest a lack of care or concern for disabled children's well-being as whole people—this is institutional betrayal.

A Child’s Right to Nourishment

A few mothers talked about the school’s failure to meet their children’s bodily needs by limiting or denying them access to nutritious food. The barriers they described went beyond the physical and social exclusion from the lunchroom to the actual lack of food itself. Mileena’s son had long-term health impacts from the bowel obstruction, including a limited diet. However, the school was aware of his dietary needs yet did not consistently arrange to meet them. She describes a situation that occurred when she was hospitalized, where her friend was called to the school because her son “was screaming and wouldn’t come down.” When her friend arrived at the school, Mileena’s son told her that he was upset because “they gave [him] a piece of lettuce and told [him] that was [his] lunch.” Mileena describes how at that point, her friend was like, “What!? Let me see.” The staff attempted to tell her friend that it was not necessary to see the tray, to which her friend stated, “I wasn’t asking. Take me to your lunch tray.” His lunch was as he described it, except there was water and a few carrots in addition to the lettuce.

When asked if she knew the school’s reasoning behind providing such an inadequate lunch, she shares that they said it was “all they could accommodate that day.” This was not a one-time occurrence; Mileena talked about how it is a weekly “fight with them about food.” Furthermore, she highlights how this “constant” fight about food is occurring in the context of ongoing behavioral challenges for her son, “they are literally handing him some iceberg lettuce and some carrots and a cup of water and then wondering why [he] is such an asshole in the second half of the day,” sarcastically adding, “hmm. Gee, he’s hungry.”

By failing to arrange to meet her son’s nutrition needs, the school treats her son as if his health and well-being as a whole person do not matter. Furthermore, the lack of food interferes with his ability to cope with the stress of being in the school environment and further escalates “disruptive” behavior. The school, in turn, “manages” that behavior most often through structural and punitive exclusion. What Mileena describes then is how not only is the school neglecting her son’s bodily need for appropriate food, but also setting her son up for further exclusion and harm.

Lena also describes ongoing challenges around accessing food at school when she mentions that they provide food for their daughter. When asked if this was related to food allergies, she states,

> *No, they just don’t know; they get very stressed out about the texture. Like if it’s noodles, they’re afraid that they’re not going to cut them correctly or if it’s, you know, if it were up to them, they would feed her yogurt at every meal every single day because it’s smooth and it has nothing on it, right? No, she can eat lasagna. You just have to cut it up.*

Lena highlights how the school’s anxiety results in their neglect of her daughter’s bodily need for a balanced diet. To ensure her daughter’s nutrition needs are getting met, she and her husband “send food for snack and lunch every single day prepared, ready for her to eat.” Lena also describes how the school required her to “provide a choking protocol” to help alleviate their concerns around feeding her daughter. Even with Lena providing food each day, the school sometimes fails to ensure her daughter is getting fed. For example, near the end of the interview, she received a text from her daycare provider.

After reading the text, Lena looked up from her phone and let out a frustrated and sarcastic scoff; the provider had informed Lena that she was about to feed her daughter because she "didn't get lunch at school today." It was 3:00 pm. Her daughter's experiences speak to the unavailability of appropriate staff training. Furthermore, it illustrates how the school defines her daughter's needs as an individual problem her parents are obligated to solve for them. The school is responsible for her daughter's health and well-being in their care. Nevertheless, her bodily needs for food and her well-being as a person are ultimately secondary to managing the problems of resource scarcity.

A Child's Right to Protection

Beyond the school's neglect of their children's nutrition, mothers also talked about safety issues and tangible physical and emotional harm. At one end, there is a general lack of concern for a student's emotional wellbeing. On the other end, there are more dangerous and abusive situations resulting in extreme physical and emotional harm to the child.

When School Compromises a Child's Wellbeing and Safety:

Children are emotional people who are forced into self-regulation situations when they need co-regulation support from their adults. Coregulation is not something resource scarcity facilitates at school. Compassion and co-regulation are often not viable choices for teachers who are stretched between teaching and supervising students and managing unrealistic class sizes. This situation can take a toll on a child's well-being. Anais illustrates the school's general lack of concern for her daughter's well-being when she talks about showing up to a Jog-a-thon to find her daughter had been left alone under a table to cry without adult supervision or assistance.

> *She was taken to the jog-o-thon with the other kids, and she was so overwhelmed by the music they were playing on the track and the change in routine. I mean, she literally just curled up under a table and rocked back and forth and cried. When I got there, the teacher had left, she's walking off she and was like halfway down the track, and [the teacher is] like, 'I'm so glad you're coming in. She's having a really hard time. She's over there underneath the table.'*

Anais describes how she had to "remove her [daughter] from the setting and go color with her in the classroom." She shares that the teacher had "asked [her daughter] if she wanted to go, you know, go color or walk with [her], and she said no." However, Anais states, "at that point [the teacher] has an obligation to get her some help and not just leave her," conveying her frustration at the general lack of concern for her daughter's well-being. Anais wonders what might have happened if she had not shown up, "like would you have just left my kid under the table?"

Beyond concerns about wellbeing were mothers' safety concerns around student elopement. Elopement is when a child unexpectedly leaves school without permission. Sometimes these kids are known as "runners." Elopement is an issue that is particularly relevant for autistic children. Research on elopement often aims to develop appropriate "strategies" that facilitate "safe participation" and equal inclusion in a variety of social spaces, including schools (Lang et al. 2009; Olsen et al. 2021; Scheithauer et al. 2020). Mothers understood the structural challenges staff and teachers faced in situations like these; however, their concern for their children's wellbeing was paramount. Kristina described how in response to feeling like a punishment was unjust, her son "took off running"; however, "nobody went after him until he was out in the road." He was five years old. She recounts how the school told her that "by the time he was on the street [they] had somebody after him." She ended up removing him from the school because it "wasn't fenced in."

Kristina recounts her frustration that they could not "send someone after [her] five-year-old who was running away in tantrum until he is already out in the street in front of cars." At that point, she was "like, no! We're not taking this risk anymore." When the school suggested shorting the school days for a few weeks to find a solution, Kristina's response was, "no, in a couple of weeks, he could be dead." While the structural unavailability of staff is the more significant problem here, the school's offered solution of shortened days manages the child rather than the environment. While staff expressed a desire to find a solution that would keep her son safe at school, their options are limited. Funding and resource allocation in special education create and sustain an environment where staff cannot ensure disabled children's safety as people who have a right to protection from harm.

Cymone shared a similar experience of her five-year-old daughter running from the school, again pointing out that boredom might be connected. She states that her daughter is “prevented from reaching her full potential right now” because” they will not give her any harder work,” resulting in her getting bored at school. Cymone talks about how the school “can give her supplemental work, but they can’t give her anything that’s more appropriate for her, and she’s done in 20 minutes every single day,” which can result in behavioral issues such as eloping.

> *She was going to school, and they were having her write her name, which at that point she had been doing for several years and was very, very good at it. They were just making her do what every other child was doing, and she was running from the school. At one point, she ran without staff to [busy road], and she was only five at the time. When I mentioned my daughter being allowed to just run to the busy road, the principal said, ‘we’re not allowed to stop them.’ ‘Well, what are you gonna do, let her get hit by a car?’ I mean, like, I don’t know, like some things are just so questionable.*

Cymone mentions that situations like this “solidified her decision” to homeschool both her children. Mothers must trust schools to keep their children safe. That trust is almost as compulsory as education itself. Nevertheless, Cymone and Kristina faced situations where their five-year-old children ended up in the middle of busy roads. The schools violated that trust and did not keep their children safe. Resource scarcity does not soften the betrayal of trust mothers experience; redistributive choices are just that, choices that do not prioritize disabled children’s value as whole people worth protecting to the fullest possible extent.

Suppose schools could feasibly hire and appropriately train additional support staff. In that case, schools could respond appropriately to safety concerns such as these, and the trust that mothers must extend would be merited. Navigating the educational environment without appropriate services and supports is, in many ways, traumatizing. Just as mothers must trust the schools, their disabled children must rely on schools to support them and keep them safe—a school’s failure to do so is institutional betrayal. Elopement is part of a child’s fight or flight response. The very fact that children run should communicate to the adults around them that they are trying to keep themselves safe by fleeing an environment or situation where they feel unsafe. Elopement suggests that some disabled children do not feel safe, protected, and cared for in school. It is not misbehavior or defiance. It is communication.

When School is Traumatic for a Child:

> *My resources go to hurt children. I really hope that we can continue to change that because we've gotten better, but it's just not popular to point out that the things that we think are great today, 20 years from now, will be abuse.*
>
> *Nadia*

Mothers' narratives suggest that the school environment is ultimately traumatic for their children. Schools inflicted trauma in various ways. Sometimes trauma resulted from the unavailability of staff, the improper training of staff, and the administration's tolerance for cultural insensitivity and racism. The school's use of student seclusion or restraint was also a source of trauma and dehumanization.

Trauma from a Failure of Staff Training and Protocol:

Tamara shares how in middle school, because of unclear protocols, staff mistakenly put her son into a cab and sent him across town. She shares how her son "had gone to counseling every Wednesday forever," and every time, "she would come to the office and pick him up." She describes this routine as a "set thing."

> *Everyone knew he goes to counseling on Wednesdays, so in the office one day, the main secretary was out, and they have someone subbing for her. I did not have counseling that day, so I called, and I said, 'he does not have counseling; I will not be picking him up,' and the message just got lost. So, a taxi driver pulled up out front and said, 'I am here to take, you know, some kid, to counseling' and the receptionists who did not know what was going on vaguely recalled that my son had counseling on Wednesdays, so she stuck him in a cab a taxi and sent him to [a location] where he's never been in his entire life.*

She describes how when her son arrived at the location, "he had no idea what he was supposed to do as they dropped him off in the parking lot, so he walked inside," where a security guard noticed him.

> *The security guard said, 'why are you wandering around? Where you supposed to be?' and he's like, 'I don't know, they just dropped me off here. I want to go home,' And she said, 'Okay, well where do you live' and he says, 'I don't know.' So, they went into her office and pulled up google maps and found our address in there or something, and she stuck him in another taxi and sent him home.*

She came home to her son "crying on the couch." When she asked him what was wrong, he says to her, 'Well, someone picked me up at school and dropped me off someplace, and people talked to me, and then they stuck me in a cab and sent me home." At this point, she called the school and asked, "'Where did you send my child?! For what purpose?!'" Tamara talks about how the situation impacted her son and ultimately led to her pulling him from the school.

> *He was traumatized, you know, anxiety; he thinks he's being taken away. He was just horrified. . . I'm like, you stuck my kid in a cab and sent him out of the school by himself. What the heck, so we had like one more month of school, and so we finished it out, and I pulled them out after that. This is unacceptable.*

Not only was this situation traumatizing for her son, but it was also avoidable. While the school may have protocols for when children leave campus, either they were not followed, or the protocols were ineffective. Furthermore, additional protocols for keeping track of when and how disabled children, some of whom cannot advocate for themselves, need to leave campus may be missing. I cannot say what was happening in the office that allowed this to happen. However, once again, it is a situation facilitated by resource scarcity. How might it have looked different had this school had the resources to hire and train enough support staff?

Trauma from Racism and Ableism:

Lydia's daughter was regularly traumatized at school. She is black and autistic and already has a history of trauma. Therefore, she faces unique challenges at school that put her physical safety and emotional well-being at risk. The 1959 declaration on the rights of the child states, "the child shall be protected from practices which may foster racial, religious and any other form of discrimination." Nevertheless, Lydia describes how the principal dismissed racist bullying from her peers and made it impossible for her daughter to feel safe at school. Another child had told her that she "probably shouldn't sing in the President's Day singing performance because [she] was not really American." Comments like these are mechanisms of dehumanization and any institutional response besides protecting the victim is structural violence (Irwin 2020) and institutional betrayal (Smidt and Freyd 2018; Smith and Freyd 2014).

Lydia shares that when she took her daughter “to the principal’s office to try to re-establish a sense of safety, the first thing out of his mouth was ‘you both call each other names.’” Lydia and her daughter sat in the principal’s office while “he was equating her calling him a stupid head, or whatever she calls him, to him saying you should be excluded because of your race.” She describes that her daughter “escalated immediately” and tried to run out of the office upon hearing him say that. Her daughter was like, “Oh, you’re not gonna help me.” Lydia points out how that “set in place daily escalations, and she never felt safe there again.” The principal’s actions communicated that protecting her daughter from racism was not a priority—a message that was not lost on her daughter.

This example illustrates how ableism and racism compounded the denial of personhood that was a central part of her daughter’s educational trajectory. The school’s primary response to her daughter’s escalations after their failure to protect her from racism was to use seclusion and restraint. Her daughter has a trauma history already, and Lydia informed the school. She told them that they are not under any circumstance to use a specific hold with her daughter. She describes this hold as “they hold you from the back of your shirt and the back of your pants, so it’s basically like getting a brownie.” She told the school “you can’t do that. That is going to be incredibly triggering. You have to find a different way.” However, the school continued to use that hold with her daughter, despite her requests otherwise.

Staff at the school showed little regard for her daughter’s mental health and emotional wellbeing by using a hold they knew would trigger her historical trauma. The ability to fully empathize with another person is connected to perceptions of their humanity; in other words, “[some] do not care as deeply about the suffering of those [they] dehumanize” (Andrighetto et al. 2014). There is a tangible lack of empathy for her daughter as a human being in the examples she shares. The ableism in the school environment that Lydia describes cannot be separated from racism as they both contributed to her daughter’s dehumanization. Lydia highlights the denial of her daughter’s personhood, stating that if “you treat someone like a caged animal, they’re gonna act like one.”

Trauma from Forced Testing, Seclusion, and Restraint:

Other mothers also shared ways in which the school traumatized their children. Lyndsay described how the school forced her son through testing even though 'he won't sit for it." Her son "was screaming bloody murder, throwing things, putting holes in the wall for two hours." She emphasizes the point that "they still tried to make him do it, for two hours, before they called me. Like, Really?!" She also recalls how "one time they rolled [her son] in a blanket." When I asked if he had any sensory needs they might have been attempting to respond to, Lyndsay replied, "no, he doesn't have any sensory issues where you would need compression; I think like I use the word restraint. They're like, 'No, that's not what we're doing.' Staff placing the system's needs above her son's wellbeing as a whole person is particularly apparent in the example of how they forced him through testing against his will.

Like restraint, punitively excluding a child in a small space does not come without some level of trauma and harm. Mileena illustrates these consequences. The school had her daughter in a seclusion room for three hours. She says it was for being "disruptive." The only way she found out about it was because her daughter came home from school one day with "huge patches of hair missing," emphasizing that they were "big patches. Bigger than a quarter. Like, patches all over her head gone, and her scalp bleeding." She adds, "They didn't call me to tell me." Mileena had to call the school to find out what happened.

> *I was like, 'did anyone notice my daughter pulling her hair out today? 'Huh? No'. I said, 'Really? Because she came home with her scalp bleeding' 'Oh, well, I'll check with the staff and get back to you.' Nobody got back to me. I ended up going in the next morning, and that's when I found out about the quiet room.*

The incident leading up to the school's seclusion of her daughter was that she had been "standing up and sitting back in a seat." She clarifies that this happened while she had an IEP in place and that the school "knew she had ADHD." The school's use of seclusion in this circumstance was excessive and traumatizing to her daughter. Her daughter, a child, was left alone in a room for long enough to pull out chunks of her hair until her scalp bled and the adults around her did not notice.

When Child Abuse is Sanctioned Through Policy and Facilitated and Tolerated by Staff:

Mothers described situations where schools have denied their children access to their fundamental rights as whole people deserving of safety and protection in the school environment. However, Bailee's story is probably the most extreme and warrants an extended discussion. The denial of her son's personhood was ongoing, isolating, and at many points, it was physically and emotionally abusive. Bailee struggled against the schools' denial of the appropriate supports and placements for years and did so across multiple districts and states. She shares that after years of trauma, special education professionals from the local university came in and advised her about what they considered an appropriate placement for her child, a placement that the school initially did not agree with.

> *These people came in, and they were literally like, the only way you're going to save your son from an institution is to get him to this program [on the east coast], for kids that have, you know, explosive behavior. By this point, he's already traumatized so much, and I didn't know better at the time. So, I actually fought to get him in that placement.*

After years of struggling to get service for her son. After years of isolating placements in a literal utility closet. After continual denials of the smart brailer. After years of fighting just to get schools to see and treat her son as a human being worthy of dignity and safety, the idea of this specialized program gave her hope. So, she fought for it, and eventually, the state of Oregon and the school district facilitated his placement in the program.

The experts from the university had basically told her that her son was a lost cause without this program. She trusted them. Recalling this story, she shares, "I didn't know the dangers of ABA therapy." Applied Behavioral Analysis (ABA), at its core, is a behavioral modification program that informs many of the "evidenced-based" "best practices" used with disabled children in specialized classrooms and programs (Gruson-Wood 2016; Kirkham 2017; Mills and Marchant 2011.; Pyne 2020; Sandoval-Norton, Shkedy, and Shkedy 2021). ABA is a lucrative business built on the backs of autistics (Broderick and Roscigno 2021). It is a form of "psychological and physical abuse," and as Sandoval-Norton argues, ABA "violates the ethical obligation to do no harm" (2021). Bailee did not know this at the time, so she put her hope and her son in an RV and drove across the country.

> *When we got there, I was like, Okay, finally, yes, we're here. And so, for two and a half months, he went through abusive ABA therapy, where they would have like three people, two holding his arms, and one holding his head, and they would like force him to fold towels while he was trying to get away, and so the whole time he was there, I was advocating, like this is not right, you know.*

Bailee points out that "this place brings in the dough. It's an expensive placement." At one point, she had enough. She "called the school district's Special Ed director and said 'I'm bringing him home,'" recounting to her the things she has witnessed.

> *There's kids tied up here; there's kids being blindfolded and shoved in corners; there's kids being forced to, like they're having them on leashes, eating off the floor. The only food they gave them are cold mashed potatoes that I'm pretty sure leftovers from the day before, and they don't bathe them. It was horrific.*

She shares the response she got from the special education director in her home district, whose concern was funding, not the health and safety of Bailee's child.

> *She said, 'well, if you bring him home, you're gonna have to pay back for all of the time that he's been there,' and I was like, 'bring it on because I'm not keeping my son in an environment where he's being traumatized.' So, I brought him home. That was the second time I hired an attorney.*

Bailee's narrative illustrates the horrific abuse of her son and the other children in that program. While the abuse she described happened out of state, it is a direct outcome of how the local schools failed her son for years. Furthermore, it shows what can and does happen due to consistently denying the personhood of the most vulnerable children in our schools. Degradation and state-sanctioned child abuse is a slippery slope in the practice of "inclusion." In addition, the state-sanctioned "therapeutic" treatment her son experienced in that program underly the practices carried out by untrained staff in Baliee's home districts.

Lysha describes situations she has witnessed in working in a local specialized classroom. She shares that there was no schedule, no organization, nothing saying who the kids were or which staff was responsible for which child, and the "educational assistants were running the room."

> *It's really, really, really disorganized. So the staff, the EA's are just like scraping kids off the ceiling all day; and I saw a couple of EA's in there that are being too rough, physically rough with the kids. They're putting*

> *their hands on the kids in ways that they shouldn't be. They're grabbing too hard or pulling too hard. They're flinging kids around.*

In describing these things, she states that the educational assistants are “not doing anything that I could get away with reporting. But it's right on the line because they're mad because they're getting spit on, and they're getting hit.” What she describes is a situation in which resource scarcity leads to the school leaving untrained and unprepared staff without the structure or support necessary to handle a room full of vulnerable and volatile children.

> *Those kids need to not be treated that way. Like the reason [kids are] getting aggressive behaviors is because [staff are] acting aggressively towards these kids and not respecting their bodies and not respecting their space and not talking to them.*

In sharing how the educational assistants are not talking with the students, Lysha recalls one of the children in this classroom.

> *The girl that I worked with was minimally verbal, you know, some signs. But they didn't explain that to me. They use PECS*[4] *with her, but she didn't have access to her PECS cards. Like how is she supposed to communicate to you if you don't give her access to her communication system?*

Contextualizing the lack of access to a communication device within the chaos of this classroom highlights one of the many ways schools are not working with these children as full people who have social and bodily needs that deserve to be respected. Lysha goes on to describe the staff use ABA in this room.

> *So, the EA’S are in charge most of the time, and they don't know what they're doing, and they're doing it badly, being physically aggressive. They wanted me to use hand over hand with this girl. So, they're like using ABA, like hardcore ABA, in a way that I don't think it's okay. I don't like hand over hand at all.*

When I asked her to elaborate on hand over hand as an ABA technique, she shares that

> *Hand over hand is exactly what it sounds like, so the way it was explained to me is like you if you're doing a puzzle, like I would say, put this puzzle piece here, and if you didn't do it, then I would take your hand and do it for you. And then we would do it five times in a row. And then I would give you an opportunity to try and do it by yourself again. The reason hand over hand works is because it's immersive, right? We give you a chance to*

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[4] Picture Exchange Communication System

> *do it by yourself. If you don't do it, we physically make you do it three or four times in a row, then we give you a chance to do it again by yourself.*

Untrained and "angry" educational assistants use ABA with students who are already escalated in a classroom environment that is supposed to support them. She states, "it's just a nightmare." In our conversation, it is clear that she struggles with processing and responding to this information as a staff member and a mom whose kid is in a different contained classroom in the same district.

Lysha's narrative offers a glimpse of the range of ABA abuse and the harm it can cause. This is the educational context to which Bailee and her son returned. The abuse and trauma of the out-of-state program followed them both home, but it did not stop there. Her son experienced further physical harm and trauma at school. When they got home, Bailee fought to get him into a "transition program." She describes how once again, "the district didn't do what they said they were going to do, which was to have him in that program, and instead, they had him at the high school in the same closet where they had had him for several years." She also described how she had recently contacted the program to express her concerns about one of his aides "getting really burnt out" and remembers questioning if her son "should go to school."

To respect her son's agency, she ultimately "left the decision to him," and "he said he wanted to go." During a transition between buildings, her son "started to escalate and have anxiety because this aide was irritated." Furthermore, the school had been "doing ABA therapy" even though they know "he can't handle it because he'd been traumatized by it." She describes how they weren't supposed to be using those kinds of techniques with him, but they were ignoring that" and using them anyway. All of this just compiled and ultimately led to her son's head injury.

> *He's blind, so [when they were walking] he would be like, 'are you there? Are you there?' But you know, they were like if he doesn't respond with, you know, these things, then we ignore him. They'd already been told many times that they can't do that. So, they decided to walk him all the way back over to the High School. There were no other kids in the school because it was summer. But when they were in the breezeway, and he stopped walking because he does sometimes, and his aide grabbed him by the arm and pulled on him. he had a blowout. He just started bashing his head into the concrete, and they videotaped it. For twenty minutes, he bashed his head, and there was blood everywhere.*

Her son suffered a severe head injury that day despite the fact that a clear protocol was in place. The protocol outlined that staff "were to get him off of the concrete and get into a safe place if he was hitting his head." However, the staff had such little regard for her son's humanity or well-being that instead of following the protocol, "they videotaped him" and saw nothing wrong with that choice. Her son's experiences show the risks of continually denying someone their humanity. The more the district and staff denied his personhood, the further they distanced themselves from the moral obligation to care about her son as a whole human being deserving of safety, protection, and support. This absence of empathy was a daily part of his life in the educational environment. It was not until her son left this system that he was truly able to learn and develop the skills he will need for self-actualization because "once he was out of the traumatic environment, he started to learn."

Summary

It might be difficult for special education practitioners and professionals to cognitively connect the institutional harms these mothers describe to the "best practices" of a system in which they believe. However, it is necessary. At each step in their children's trajectories through the program, the pedagogical and social harms, the neglect, the trauma, the psychological and physical abuses these children experienced were either sanctioned, facilitated, or looked over by individuals working within and deeply connected to the system of special education. The ideal of special education is an admiral goal, but to hold the reality of it up as an example of genuine inclusion is inappropriate at best and harmful at worst. As Merry argues, "a policy of inclusion is not a proxy for justice" (2020:20). Inclusion requires "more than legal entitlement or formal access. It must have value for the person in question." Inclusion must provide "meaningful access" that not only allows room "for a sense of belonging" but also has the "utmost consideration for the child's well-being" (ibid). Unfortunately, this is not the type of inclusion these mothers describe. Instead, the stories these mothers shared all give voice to Merry's warning that "we mustn't forget that so-called inclusive education environments for many children exact a very high price" (2020:14). His warning is a dangerous one to ignore when the wellbeing of children is at stake. The failure to meaningfully include disabled students in the same level of care and protection as regular students comes with tangible pedagogical and social harms. More than that, though, is the fact that this failure denies disabled children their humanity during the formative years of their lives; and this is nothing less than institutional betrayal.

CHAPTER V

LABOR OF LAST RESORT

Beyond mothers' narratives of student exclusion and institutional harm in the context of an underfunded, unsupported, and poorly implemented special education system, a theme of unpaid and unrewarded labor also emerged. My focus will remain centered on maternal investments of invisible labor. However, I will also discuss the unrewarded labor of staff as this was also salient in the mother's narratives. The paid labor from teachers and staff that mothers highlighted as supportive, while visible to the system, was work that went beyond the minimum expectations and occurred without structural incentives, supports, or rewards. On the other hand, the unpaid labor invested into the system remained relatively invisible and was extracted from the mothers themselves. At all points in children's special education trajectory, mothers contributed their labor. However, sometimes, it manifested as a "labor of last resort" for mothers attempting to ensure educational accessibly, safety, and inclusion for their child. The potential reliance on invisible and unrewarded labor for the special education system to function highlights the structural limitations of the program. Furthermore, this systemic reliance suggests that unpaid maternal labor and the unrewarded labor of staff also represent "a labor of last resort" for the schools themselves as they try to serve and support students in the context of resource scarcity.

I have organized this chapter around the two broad categories of unpaid and unrewarded labor, which I discuss separately to show how both mothers and staff work to buffer students from exclusion and institutional harm. I start with the unpaid labor of mothers and describe the different forms of labor mothers' input into the system at any given point in their children's trajectories. The three primary forms of unpaid maternal labor were advocacy, direct support, and removal. I will then pivot to a shorter discussion of the unrewarded paid labor that staff invest to highlight mothers' reflections on staff members who went above and beyond to support their children. I close the chapter with a final discussion of how these labor investments are attempts to buffer children from the harms and exclusion that can stem from the resource scarcity and the problematic and programmatic inadequacies of special education that mothers described.

Unpaid Labor

> *Can you pick three words to describe your experience with special education?*
>
> ***Infuriating*** *is one of them. I'm trying to come up with a word that would be, like, I have to fight. I mean, so until this year, I've had to fight with the district over everything and so like it's a spirit of fight. So, I would say* ***battle****. Like it's been a battle. Recalcitrant. Recalcitrant just doesn't convey the intensity.*
>
> *Can you define Recalcitrant for me?*
>
> *Recalcitrant is like your toddlers. The official definition is having an obstinately uncooperative attitude toward authority or discipline. So, like that's the district towards parents.*
>
> *So like a toddler?*
>
> *Well, this is kind of the joke that I made with other parents, the district has ODD [oppositional defiance disorder] when it comes to when it comes to parents like that has been my experience until this year, that it doesn't matter what I say, because I'm a parent, they are oppositional to it. Yeah. Even when it makes sense, even when it's easy, even when it's, you know, scheduling a meeting, you know, so* ***oppositional*** *is, well, is the other word I would pick. They are not interested in doing what is best for the kids.*
>
> *Lysha*

The extended quote that opens this section paints a picture of the school district as a recalcitrant toddler with oppositional defiance disorder. Lysha flips the script by placing the diagnoses, and the deficit, on the district instead of the child. It is, of course, initially amusing to imagine the district as a defiant toddler; however, it is so much more than that. The quote is a painful illustration of what mothers face when advocating for their children: an infuriating battle with an oppositional district. This reality means that navigating special education requires that mothers invest a considerable amount of unacknowledged labor within the school environment. The primary purpose behind a mother's labor investment is to prevent or minimize student exclusion and institutional harm. This labor is compulsory. The initial form of labor I discuss is a labor of advocacy. Mothers invest this labor when advocating for appropriate inclusion in the school environment and educating school staff about their children's needs. The labor of advocacy is often ongoing throughout their entire experience navigating special education. The advocacy experience impacted mothers financially and emotionally. I will discuss this separately from specific examples of how mothers advocate for their children.

The following form of labor I discuss is the labor of direct support. Blum (2007) contrasts the "direct care of one's invisibly disabled child and the advocacy care required to obtain services" (212). Mothers are carrying out "direct care" in the schools through the labor of direct support. Mothers invest the labor of direct support when they enter the school environment to support their children. The motivation behind the labor of direct support is the well-being of their children. However, the mothers' labor benefits teachers and schools by filling in support gaps caused by the unavailability of staff—support gaps that make the inclusion of their children difficult or impossible for schools to facilitate. Sometimes the investment of the labor of direct support occurs after the labor of advocacy has produced less than ideal returns. The discussion of direct support will include the unpaid labor occurring inside the educational environment and that which happens in non-academic spaces. The labor of direct support in the educational environment was often a precursor to the final form of labor that I discuss, which is the labor of removal. The labor of removal is the unpaid labor that mothers input into the system when the school asks them to remove their children from the classroom, nonacademic activities, or in some cases the school itself. It also occurs when mothers self-select their children out of these spaces.

Labor of Advocacy

Experiences of the Labor of Advocacy

In their narratives of the labor of advocacy, the mothers shared patterns of taking on out-of-pocket expenses, feeling like their presence or input was not welcome or appreciated by the school administration, and having to bring in other people in order for their advocacy to be effective. Many of their experiences with advocacy line up with Carpenter and Austin's (2007) findings that when mothers are advocating for their disabled children are "silenced by not being heard" and are frequently "misunderstood and judged by medical and educational professionals and [are] told rather than listened to" (663).

Advocacy is Expensive:

Mothers described having to take on additional expenses for private evaluations. When they did take on these expenses, it was often because the district would not qualify their children under a particular educational category. However, sometimes they would pay for private evaluations as a preemptive or protective measure or because the district had lost their information entirely. Recall Adelina, whose daughter already had an IEP in place with a medical diagnosis of 18q. Her daughter needed additional support specific to her struggles with autism. Adelina shares, "I had to pay out of pocket for a psychologist to get [an autism] diagnosis, so I could get these supports that she clearly needed before the diagnosis."

On the other hand, Lydia took on the financial costs of a private evaluation because she was afraid of the school "dumbing" her daughter down. In addition to those expenses, Lydia shares that she had also "been paying a teacher to do like nine to 12 hours a week, just to make sure [her daughter] gets math." Finally, Cecilia shares how she had to get her son re-diagnosed because when he transferred to middle school, they lost his documentation. His transfer to middle school was also when the district removed the IEP and placed her son on a 504.

> *I have a high deductible insurance. So, I've paid for all of the appointments out of pocket. They basically said they had no record of the diagnosis, even though he'd had it since kindergarten. So, we had an IEP since kindergarten with an ADD diagnosis all the way through the same school district. He only moved about eight blocks.*

The salt in the wound is that mothers are taking on these expenses as a way to fight for their children's right to free and appropriate public educations. In addition to being expensive, seeking private evaluations or support can be another labor-intensive part of a demoralizing process.

Advocacy is Demoralizing:

Maternal advocacy is often a situation where mothers see very little progress from their continuous investment of time and energy. That alone is demoralizing, as the lack of real change chips away at their hope that their children will get the services they need and the educations they deserve. Lyndsay captures the process of losing hope.

> *The first couple of meetings, it was very hopeful, like, they can do this, and maybe he'll do this, and it'll be better, he'll be happier, they'll be happier, I'll be happier. And then it's frustrating because as it goes on, like, there's still a little bit of hope at the IEP meetings, but for the most part, you're just frustrated.*

In addition to losing hope, Mothers also do not feel heard or respected by school staff and special education administrators, which ultimately deepens their experiences of demoralization. Mothers shared feeling like the staff were annoyed, avoidant, or resentful of their advocacy.

Adelina describes her reception when she arrives at her 5th-grade daughters' school, "I go down and make my voice heard, and the principal usually runs when I pull up." Lyndsay acknowledges, "the school district does not necessarily like speaking with me. I'm very blunt. This is what he needs. I need you guys to step it up." What these mothers share illustrates how they are "being judged as mad if they challenge the silence imposed on them by raising issues that other people have no wish to discuss" (Carpenter and Austin 2007:664). The tension that sits in this space between maternal efforts and administrative response puts mothers in a position of having to take on the role of an adversarial mom. Lyndsay describes how it feels to be in that position: "You're like a nuisance, a nuisance. . . you know, when you call someone, and they're like, 'Oh . . .Hi'" recounting this response, Lyndsay mimics a tone of annoyance before settling into her voice again "yup, you got me again." A school's non-response is a way of silencing mothers, and a school's silencing of mothers was often a way of preventing them from taking action.

Carpenter and Austin found that in addition to "being silenced by professionals, many women became silent" (2007:664). They also argue that some mothers remained "silent to avoid confrontation, to avoid being judged, or to avoid being heard as 'not coping,'" offering that "for some mothers, being silent was a means of safety and sanity within the context of their experiences" (ibid). Some mothers felt like the schools were "shutting them down" and making judgments about their characters and mental stability. These judgments often served to delegitimize their claims as mothers and, therefore, justify the dismissal of their concerns as advocates. Sometimes the judgments prevented a mother's potential advocacy. In talking about how much more she knows now, Gabriella recalls feeling discouraged from advocating for her child, "you know, looking back, I think I could have advocated more, but I felt very shut down by the school. I felt like I was making them mad by asking for accommodations." Going on, she points out that after three years, she was still struggling to get the school to follow the 504.

> *Even by her senior year, we were still trying to advocate for her and her 504. I was still getting pushed back. Kind of [getting] like raised eyebrows, you know, like I'm somehow taking away from her education by trying to support her mental health.*

Similarly, Nadia mentions how the school kept "promising things that we're going to be delivered and then acting like [she] was over reactionary, problematic, and not a good fit." These types of experiences confirm McKeever and Miller (2004) assertion that medical and educational professionals "pathologize" mothers "as over-protective, difficult, unrealistic, or in denial of the extent and impact of their children's disabilities" (1177). Sometimes, this pathologization is a form of gaslighting and makes mothers question their own sanity. Anais describes regularly questioning her perceptions while advocating for her daughter. "I always feel like I am crazy. You know anything because I have a team of, you know, people that are supposed to be experts on the other side on the other side of the table saying no." These are just a few examples of the perception or feeling mothers had about the school's judgments of them.

Gloria, however, describes having that judgment confirmed for her when she was working with the school to schedule an IEP meeting. All the times that the special education teacher suggested were not feasible, either because they were on dates her family advocate was unavailable or only scheduled for half the time they would have needed. Gloria communicated the need to find different dates and recounts how a short while later, "the kindergarten teacher emailed [her] to tell [her] that the special education teacher was attempting to schedule an IEP meeting without [her]." Gloria describes how the special education teacher "had sent emails to all the team members" and was saying that Gloria "was being difficult, that [she] was repeatedly canceling meetings, and that if [she] continued [her] behavior, they would hold the IEP meeting without [her]." That was when the kindergarten teacher forwarded Gloria the string of emails, saying, 'you should see what's going on.' Gloria describes how she confronted the director of special education after she read the emails.

> *I just drove down the district office, and I met with the head of special education and said, I don't know who to talk to, but I need to talk to you about my file. His file was gone from the district office; they had given it to the school psychologist. And the reason was that the special education teacher had said that the parents were becoming hostile and that the psychologist had more experience with hostile parents and wanted her to review the file. So, when we had the IEP meeting, this woman would be involved, and I saw this woman's name appear on the IEP invitation like, why, you know, cause my son doesn't have her and what is this person's role, has she seen my son? Does she have an evaluation she wants to share? Her response to me was, 'well, she has a lot of experience dealing with children and families like yours.'*

In this situation, Gloria was asserting her rights. She asked for a reasonable and appropriate date for a meeting, but the staff and district treated her like this was problematic behavior. The special education teacher and district staff reduced her to a "hostile parent." In their correspondence and their treatment of her, she became "that mom." Many mothers are comfortable with being "that mom." This comfort illustrates an awareness that, without intervention, the needs of their children will remain unmet. Adelina states, "I am that parent, and I don't mind it." Nadia, whose son is now entering kindergarten, captures the line that many of these mothers walk, "currently they're really clear that my intention is to be a really wonderful supporting mom, and I might be Ms. Scorched Earth too."

Advocacy is the Only Option:

Taking on the role of "that mom" often connects to a mother's realization that she was the only one making sure her child gets the services and supports she needs. Blum uses the term "vigilante" to describe "the intensified monitoring" mothers must engage in and "the need to take the "law" into one's own hands when advocating on behalf of one's vulnerable child" (2007:212). Advocacy as a vigilante project is particularly salient in mothers' descriptions of feeling like they were the only ones who care about their children's well-being in the educational environment. Tamara understands the importance of her advocacy to the services her child receives, saying, "if I didn't advocate for things, I don't think it would happen." In discussing placement levels, Sarina states that her daughter’s expected time for receiving individualized instruction “was like 15 minutes, three days a week, pretty close.” However, she shares how even that “never fucking happened,” and she recalls realizing that “I have to get a handle on this. I am in charge of this now. Because no one else is, and this is my kid, and she’s not getting the service that she needs.” Lena echoes these mothers’ sentiments as she reflects on her experience navigating special education.

> *I think it has made us more of an advocate because we were naive going into it thinking we can trust everyone to have our daughters best interest and at the end of the day what we learned is we are her advocate, and we are the ones who are going to make sure she gets what she needs.*

These three examples highlight how, at some point in their trajectories, mothers realize that they the only ones left making sure their children are getting what they need. However, frequently this understanding is paired with realizing that they cannot do it on their own.

Mothers Need Advocates Too:

The feeling that they are alone in caring about their child’s wellbeing is often exasperated when mothers step into the IEP meeting. Anais recalls how at her first IEP, everybody else was there, and I was the only one on my side. It’s very intimidating.” While “they did not settle on an IEP” during that meeting, she “refused to leave the room” without a 504. Kaleigh shares going into an IEP meeting without informing the school that she was “bringing seven of [her] own people.” Her choice to bring in support directly responded to being outnumbered in IEP meetings by staff she felt did not know or understand her child. She states, “I brought my own seven and talk about intimidating and getting what you want.” Kaleigh describes how an action like this shows them “that you’re like serious and you’re about to like, take charge and show them what’s up.” She goes on to explain how she feels like the staff in the IEP meeting do not understand “what you’re going through” or “why you’re there.”

Mothers also pointed out that once they brought support people to the meetings, they started to see progress. Mileena describes how she brought her own mom, who is well known in the community and has a degree in early childhood development. It took Mileena’s mother going to every IEP meeting to get anything done in middle school. Her mother could leverage her “expertise,” while Mileena was viewed as just the mom. This is consistent with Carpenter and Austin's findings that special education professionals silence mothers and doubt "the authenticity of a mother's right to speak for her child" (2007:664). This silencing is gendered as well. Mothers' stories reflect that their voices are often "silenced in the effort to privilege" the voices of their husbands or male partners (ibid). Bell shares how the school has "a little giddy-up in their step right now." Her husband attended the last meeting in her place.

> *The last time. I was just so overwhelmed and upset and emotional about it that I was like, I wasn't going to do it alone. He was going to come with me. But I just decided you can do it. I want you to do this. Because I feel like they just don't listen to me, they don't take me seriously. My husband goes in there, and after one meeting, all of a sudden, things are moving. Oh, yeah, we do have this behavior support plan. Oh, maybe we can implement some things.*

At the time of the interview, Bell was "looking forward to bringing a [professional advocate] to the next meeting" and excited to "see what else gets done." However, she expresses frustration that it requires her bringing her husband or other professionals to get anything done.

> *The fact that we have a place here in town that is specifically to help parents navigate this tells me that it's broken. Because those teachers should, or you know, the principal should be saying, 'Oh, this is what we need to do in order to get him the supports that I agree he needs,' instead of like withholding it until I pull it out of them and say, 'Oh, I just found out you can do this,' 'Oh, you're right. I can, Okay; I'll do that now.'*

Bell asserts, "you need to have someone who speaks for you in there because everyone else is speaking for the district."

Mothers shared how the intensity of their emotions makes having an advocate or support person with them is essential. Audre is a 45-year-old married mom. Her 16-year-old son is autistic and spends his time at school in a life skills classroom. She shares that her son is really friendly and enjoys reaching out to people. Audre has had mostly positive experiences with special education. Nevertheless, she recognized the importance of having other people with you and the difficulty of her role as her son's advocate. She states, "it's helpful [to have support] because a lot of meetings can be emotional, and it's hard to have your advocate-head on when you're mom." Gloria also captures the difficulty of being both mom and advocate and the importance of having support.

> *I could not believe that I was entering an environment where someone who's supposed to provide special education services for a kindergartener would be deceitful, and I knew myself well enough that I was angry. I can quickly go into a line of conversation that will make people shut down, be very reactive and defensive. So, I also felt that that would be dangerous for my son. If they could now connect him to someone that made them feel threatened. So, I wanted to have someone there who could be a governor on what I thought was an atrocity.*

Gloria highlights how fine the line is that mothers have to walk when witnessing appalling behavior from the people they are supposed to trust to care for and educate their children. Her fear of how it would impact her son if she were to make them feel threatened—fear that the school will retaliate against their children if they are too emotional or too assertive—functions as silencing. Gloria captures how mothers "were constrained by fears that children would be deprived of necessary care or further devalued if they continued to be perceived negatively by professionals" (McKeever and Miller 2004:1183).

Furthermore, as mothers talk about the importance of a professional advocate, they illustrate how they "are silenced, by not being given voice and by not being heard when they do speak" (Carpenter and Austin 2007). When an advocate is present, they can intervene, often speaking the same things a mother might. The difference is that, in most cases, an advocate's voice is heard by the people on the others side of the table, but when a mother speaks, her voice is not. Gloria points out, "this is not something you do by yourself." A professional advocate can "be that person who could say, 'it sounds like you have a lot of administrative challenges. I'm not sure why that's being raised in this meeting, because quite frankly, that's not this family's responsibility.'" An outside party can "say it like that." However, as Gloria points out, "to say that as a parent is so much more emotionally complex. It's your kid, and even if you said the same words, the same things will be received differently." Their emotions as mothers are viewed and used by special education professionals to invalidate their claims about their children's needs. By positioning the mothers' knowledge as irrational or inferior, the staff reinforce their positions as the "experts."

Examples of the Labor of Advocacy

When Advocacy is the Labor of Escalation:

When their efforts to advocate are unwelcome by the district, or when the district is entirely unresponsive, this just requires more labor on their part as they are forced to escalate their advocacy. Lyndsay recounts, “I don’t know how many times I’ve called a number and not gotten a callback or have had to call like the superintendent.” Mileena describes her son as a “really, really smart” kid “who can do so many things.” She says that he “likes to cook,” “thinks he is hilarious,” and can “invent things, and they usually work.” When she would try to advocate for her son, Mileena experienced feeling ignored by staff. She got to the point where she “went in and sat in the superintendent’s office from open to close for about three days,” refusing to leave without a discussion of her son’s needs. Kristina describes the enormous amount of work involved in getting a school to understand her child’s needs, let alone meet them: “I’d already been to a meeting about it. Okay. And they’d already, you know, understood, I thought. I had talked to the principal. I talked to a counselor. Talked to everyone.”

Anais also shares her sense of exhaustion for having to advocate for the things her daughter clearly needs.

> *I feel like I put in so much energy, just trying to advocate for her. Like, basic stuff. My kid should get speech therapy. Adults have a hard time understanding her. This isn’t up for discussion. My kid needs sensory tools. It’s not up for discussion, just all of these things that I’m like, please don’t make me! Just do the right thing! Just give my daughter what she needs to succeed, and I will be out of your hair. I will help with your frickin PTO and your bake sales and, I’ll volunteer my time in a constructive way. Instead of being here in your office frustrating you and me.*

By that point, her daughter had already gone through multiple testings and gotten official diagnoses from private practices for eligibility for Developmental Disabilities Services. However, after the school’s continued refusals of an IEP, she took her daughter in for further testing to be sure she wasn’t pushing for something unneeded. The school is not even trying to diagnose, nor can it. It is just a matter of categorizing a child’s eligibility. The DDS diagnoses alone should qualify her daughter for an IEP with an autism category without further testing.

> *DD services is the one that originally diagnosed, they sent out their psychologist, and they don't mess around. So, they had sent out their psychologist to diagnose her and then her psychologist or psychiatrist, who had been working with her for three years, he diagnosed her, and then so when all this happened, I said okay, maybe I'm seeing something that's not there. Let's just go have evaluated by someone completely different, someone you know, who doesn't have any eggs in this basket, So we took her to [a private practice], and I just said, Okay, I just want a fresh look at this, and so without my input, without the schools implement without, you know, previous clinicians input, go ahead, do your evaluation and let me know what you come up with.*

The school's continued refusal not only meant that she had to go out of her way to arrange and pay for additional evaluations but that her autistic daughter had to once again sit for further testing only for her original diagnoses of autism to remained unchanged. Complete evaluations like these, take hours and children are in unfamiliar environments, sometimes away from their parents, with people they do not know while being confronted with a battery of various tests. The whole process is stressful, exhausting, and in some cases traumatizing for children as well as their mothers.

Lydia describes escalating her advocacy to involve upper administration as she shares her regular attempts to educate unresponsive staff about her daughter's needs as a black autistic trauma survivor. Lydia wanted them to use trauma-informed practices and protect her daughter from racial discrimination. "I sent them articles about trauma-informed and culturally appropriate [practices], like every week, [to the] entire IEP team, I sent it to SPED administration." Lydia's efforts, however, ultimately went unacknowledged by the school. The school was also unresponsive to Lydia's concerns about racism her child had experienced in school. Lydia recalls fighting with them to add "racial issues as a trigger" in the IEP. She "wanted [the IEP] to spell out how the adults should respond appropriately" to racist encounters rather than dismissing her daughter's experiences in the school environment as they had been doing. Lydia tried to get the school to understand how their previous responses to racial incidents had led to increasing and unmanageable escalations, which further traumatized her daughter. However, rather than taking her concerns seriously, she shares how the special education director told Lydia that the IEP meeting "isn't a place for talking about" racial discrimination and harassment.

> *She never told me where [that place] was, and my concern was that like, they didn't understand how [racism] fits, that her behavior is because of anxiety at school, she's gonna have more anxiety and therefore more behaviors.*

What Lydia was fighting to get the school to hear and take seriously is how "the conflation of institutional ableism and institutional racism serves to make both stronger than either would be on their own" (Beratan 2006). Beratan argues that "societies willingness to accept discrimination against disabled people as a result of individual deficiencies is used to make racism more palatable." The school's treatment of her daughter's understandable and justified reactions to racism as just "behaviors" related to her disability does not address her racialized experience in school—it is "the acceptance of the otherwise unacceptable" (Beratan 2004). It is dehumanization through a failure to empathize. It is a sanctioning of racial discrimination, and it is institutional betrayal.

Labor as "The Only Reason":

In addition to taking on the labor of advocacy and continually feeling unheard or dismissed by the district, Mothers also point out the significance of that labor to the school's minimal levels of inclusion and support for their children. The district had Lyndsay's son placed on a combination of shortened days, in-home instruction, and tutoring at the district office for an extended period. She states that "the only reason [her son] went to [a particular school] last year was because we were like, no, he needs to be in a classroom, he needs to be around other children." Similarly, Adelina connects her advocacy to her daughter's inclusion in an outdoor school experience.

> *They let her go to outdoor school last year, but I had to pull out that she has a right and you can't stop her, and you need to accommodate her. Like they were trying to get us to drive out there for the showers. No. That's your guys' job. You need an aide. I have other children at home.*

Lysha also mentioned having to advocate for her son's inclusion in the school's outdoor program. She described feeling like the teacher was hoping her son wouldn't want to go.

> *That was definitely something I had to push because, in fourth grade, they go to outdoor school. And you know, I just took the bull by the horns and was proactive about it. I said he's going to outdoor school. He wants to go [The teacher] was feeling me out like, 'does he want to go? Does he want to stay overnight? Maybe he could not go the whole time.' 'No. He's*

> *going. We're practicing sleeping . . . How are you going to support him? You need to do that.'*

Lysha points out feeling like he wouldn't have been included without her efforts, "I definitely feel like if I had given her room or signaled in any way that I was okay with him not going, she would have taken it as he did not want to go." Furthermore, her son's inclusion in outdoor school was not the only thing requiring the labor of advocacy. She also describes having to advocate for her son's inclusion in the school play.

> *Again, that's something that I've just pushed hard on because one of the things they do every quarter is a musical, and the kids try out, and every year there's a clause in the permission slip form about behavior. Like we cannot cast them. So, he didn't get a keynote. He was in the third grade. They don't get lines, and in fourth grade, he wanted a part, but he didn't get a part.*

A permission slip outlining who was eligible for casting, not unlike permission slips for field trips, is not value neutral. These types of requirements structurally excluded disabled children. By fifth grade, she had watched her son want, but not get, a role in the play for two years, so "when the permission slips came out," she approached the school.

> *I sat down with his sped teacher; I was like, 'Okay, do you know that this is what [the permission slip] says? Do you support him having a role? Are you gonna stand up for him?' She said she would. So, then I went to the assistant principal, and I sat down with her, and I said, 'Look, this is my concern. The person in charge of the play is his fourth or third-grade teacher, who doesn't like him and who's never supported him. I want to make sure you know that I understand you have these behavior concerns, and you need to understand that you can't use this disability against him.' So, he did get a part.*

Without Lysha's efforts, her child would most likely have not gotten a meaningful role in the play, nor would he have gone to the outdoor school program. Consider for a moment the material consequences to her son if she had not invested the labor of advocacy to push against her son's structural exclusion in these activities. Her son's exclusion would have meant he would not have been able to access and benefit from the pedagogical and social activities happening in those spaces.

The Labor is Relentless and All-Encompassing:

The stories mothers shared with me consistently conveyed the relentlessness of the labor of advocacy. Bailee's account of her advocacy efforts to get her son services best reflects how mothers continually invest the labor of advocacy into special education and are most often left feeling unheard.

> *They would just ignore me. For years, I would go to meetings, and I'd have like a list of things. I would say, 'he's a sponge. He wants to learn because he speaks in the third person.' And he would like, say these things, and they would be like, 'Oh, he's just spouting words. He doesn't know what he's saying,' you know, and it was just devastating.*

This is the devastation of knowing that no matter how many times she expresses that her child is a whole person who can understand and learn—who has an amazing sense of humor and is worth teaching—the school district dismisses her efforts, tells her she is wrong, implying that they, as experts, know what is best. The fact that it took her "three years to get a 504 plan" for her blind and autistic child—just a 504 plan, not even an IEP—amplifies that devastation.

Another example of the relentlessness of the labor of advocacy is Bailee's efforts to get her son a placement in the school for the blind. She shares, "I tried to get him in that school since kindergarten, and when I finally got the district to agree to place him there, they closed it down that year." Her son was in seventh grade. The labor she invested in the system to get her son into the school for the blind was relentless. Not only is it happening alongside just trying to get his basic needs met in his home district, but it is also going on for eight years. This labor was all-encompassing as it impacted all aspects of her life. When she first approached the district about a placement there, she was ready to move her family to another city so he could go to the blind school. However, after enough times of being told no, she shaped her life around that decision and bought a house in their home district, making it that much more difficult when the district finally agreed to place him in the school.

> *I was like, I will move, you know, and they were like we can't place him there because we can educate him ourselves. And I was like, but that's where he belongs. I've cried through a lot of meetings, begging people to, you know, listen, and I've hired an attorney three different times. But I think the school for the blind would have been, you know, a lot better, but it was a boarding school, so that was really hard too.*

Bailee's labor continued. After the school for the blind closed, when the university professionals recommended the private program out of state, she had to fight "to get him in that placement" as well. "I went to the House of Representatives, and they wrote a bill or law and all these things to get him there." As discussed earlier, the placement was ultimately abusive and traumatic. She brought him home, and her labor continued. At the suggestion of the special education director, she then invested even more labor in creating a program she could implement at home.

> *They told me to make my own IEP and that they would possibly pay for me to run a program from home. I was like, great. So, I actually wrote an IEP for him and wrote out a budget and wrote out what kind of teachers I would need everything, and then I took it to mediation, and they basically just threw it out.*

She describes how the amount of work she invested in that project was all-encompassing.

> *So instead of me focusing on what to do for, you know, a program through them, they made me believe, and I focused all of my energy on that, and then they didn't even look at it. They took some of the goals I had, but they didn't implement them the way that they should have been implemented.*

Bailee's story is especially heartbreaking because year after year, she invested the labor of advocacy, and year after year, not only did they fail to educate him, worse, they failed to protect him from abuse. The district's implementation of special education inflicted harm. It caused her son long-lasting trauma. While resource scarcity facilitated this failure, the administrators who orchestrated it and those who stood by and let it unfold are indeed culpable.

While the details of her story are unique, Bailee's experience of investing the labor of advocacy is not. This section sheds light on how maternal advocacy is labor-intensive, expensive, emotionally exhausting, and relentless for mothers. Judith conveys the tremendous energy and effort it takes to advocate for services and speaks to the cost of this all-encompassing work.

> *You have to become a special education expert, and there are books out there geared toward helping parents get there. But how do you read a book, take a class, understand all the things while you're working full time, maintaining the kid trying to get them to and from school and appointments, and I don't know, maybe have time to go to the bathroom, or take care of your own emotional wellbeing.*

Her statement illustrates how much these mothers are often juggling in addition to the labor of advocacy. She states, "caregiver burnout is real. When I asked her if she can find time to care for herself, Judith states that she does find that time but qualifies that by pointing she is not in the workforce. "I am [able to find time] now that I'm not working.

But I’m still on call in case [she] needs me to come rescue her from school, of course.” Here Judith captures how the labor of advocacy is happening alongside additional forms of unpaid labor. Mothers are also “on-call” to provide direct support within the educational environment.

Labor of Direct Support

Mothers’ investments of the labor of direct support into special education overlap in many ways with the other forms of compulsory labor. Nevertheless, it diverges enough from both labors of advocacy and removal to warrant a separate discussion. Direct Support as unpaid labor emerged in the interviews and went beyond just being “on-call” for direct requests to remove their children from the school. Mothers also reported a significant presence in the school environment. Just as the labor of advocacy helped prevent, on some level, their children’s’ exclusion, so too did maternal labor of direct support. However, sometimes the labor of direct support was directly related to partial and complete exclusion. Mothers described a pattern of teachers or staff directly asking or requiring mothers to enter educational spaces. Therefore, direct support often occurred after requests that the mothers pick up or supervise and otherwise support their children in the school environment. However, direct support also occurred when staff would politely suggest or “hint” to the moms that the labor of direct support would be beneficial and appreciated. Mothers also talked about entering the schools to perform the labor of direct support of their own accord, but the investment of labor is compulsory even then.

The mothers discussed the labor of direct support as something that occurred within the classroom environment and non-academic settings. In both cases, the labor of direct support ultimately benefited the staff who worked with their children. However, the labor mothers invested was primarily for their children; they shared a sense that their ability to provide direct support in the school had a positive impact on their child. Angelina describes how she thinks her son’s “school experience was better because [she] could be there often, and they knew how to get ahold of her.”

> *I was really lucky to always be in the school, and like all the teachers had my phone number. If they texted me, ‘hey, this is going on,’ I would just pop in the classroom. And my son never knew, like, he never knew that I was going to be there, which was good. I’m glad that I had the opportunity to do that. But it sucks that I had the opportunity to do that.*

The labor of direct support was most necessary in the lower grade levels and would taper off for some mothers as their children transitioned to middle school. For example, Louisa states, “at the elementary school, I was in there volunteering and, and helping out” and shares her relief that this has shifted a little now that her son is in middle school, “I kind of didn’t feel like I was needed as much because he didn’t need a touchstone . . . I appreciate it now. I don’t feel like I have to be there.”

Labor of Direct Support in Academic Settings

Mothers often entered the school environment after receiving a call from school staff. Kaleigh mentioned how the school would “physically take [her son] down to the office and have him sit there and wait for [her] to come and figure it out.” She recalls this happening so frequently that her “number was like, on a little post-it” at the front desk so “they could just call whenever they needed.” Kaleigh described the impact it had on her emotional wellbeing and the frustration she feels about taking on these forms of labor in the school. She states feeling “anxiety through the roof” when the school’s number came on the caller id. Kaleigh goes on to add, “like again, I am doing my part, and I wish they would do their part,” indicating an understanding of where her labor should end, and the school’s should begin.

Suyin describes a similar situation where the staff would often reach out to her for assistance with her son. Suyin shares that they would regularly call her to remove her son. Sometimes when she was there, she could sit with her son and be “able to calm him down.” She also recalls how “the principal [would] be emailing every day,” asking if she could facilitate talking to her son with him the following day before school. This communication from the principal would often occur after an incident the previous day. Suyin regularly tried to communicate that talking to her son in the morning before starting his day is ineffective. She describes how if forced to talk with the principal in the morning, her son “would shut down” or “just run away” and “that’s it for the day.” Here Suyin has offered another example of a mother providing vital information on how to best work with her child to have school staff ignore her. Her example also highlights how when schools ignore the mothers, damage control often demands a more significant investment of maternal labor.

While most times, on-call maternal labor responded to behavioral issues the school was ill-equipped to manage; however, this was not always the case. Sarina talks about the staff requiring regular in-person assistance with her daughter because the school felt unequipped to assist in a routine and minor medical issue. Sarina's daughter had loose ligaments, and her thumbs would regularly hyper-extend, so she would need help setting them back. The school would consistently call Sarina and ask her to drive to the school and assist. Sarina could not, so her mother would go and invest the labor on her behalf. Being on call to assist or remove their children was not the only way mothers provided direct support to school staff. Sometimes mothers would provide regular direct support in the classroom.

Angelina's child was denied an IEP in Kindergarten. She describes how when she went to the teacher to advocate for her son's needs, the teacher "wasn't very receptive." She shared her conversation with the teacher when she requested to support her son in the classroom.

> *I said, 'you know, I'm not a helicopter, mom, I'm not. But can I be here? Can I come and hang out in the classroom and help as needed?. . . I won't get in your business, but can I just help ease the transition,' and so she let me be in the classroom.*

Angelina talked about her ongoing presence in the school, recalling a situation in fifth grade when her child "was all spinning."

> *I came in, and I handed him the gum, and he put the gum in his mouth, and like three minutes later, that kid had totally chilled out, and he was like sitting there. He's like, 'Can I do my homework Now?' And [the teacher], she looked at me and goes, 'What did you just do to him?' Because it was that quick. It was like three minutes. I said, 'if you can get the principal to give the okay that he can have the gum, I'd be happy to supply you with gum.'*

Sarina also talked about spending time in the classroom or on the school property. Sometimes she would volunteer in the classroom to grade papers, and more recently, she described sitting in her car to see how her daughter was interacting with other children during recess. In this situation, she did not feel like she was getting accurate information from the staff or her daughter about what was happening, so she took it upon herself to check in on her daughter. She expressed some conflict about this, mainly as it related to her time in the classroom, "I don't know [if] that's my role as the parent, that I have to go and pretend I'm grading papers so that I can just watch her." Sarina mentions feeling like "there should be someone, [an] educational assistant" who fills this role, "I mean I'm sure they have a tough job because kids are nuts, but it seems like they could do more if they were more in tune with the needs of each kid."

The work of "socializing for acceptance" (Kittay 2015) underlies the labor of direct support that mothers invest in special education. This "otherwise invisible work" is the labor "that mothers of disabled children do when they work to socialize the world to meet their child" (ibid 398). When a mother's labor investment is specific to influencing the environment around their children and the people in it, this underlying labor of socializing for acceptance becomes more apparent. The labor of educating their children's peers on difference and disability is an excellent example of how mothers perform and invest the labor of "socializing" the environment to accept their child as a form of direct support for their child. Sarina describes going into the classroom at the teacher's request to talk about the visible medical devices her daughter had to wear.

> *I had to come into her fourth-grade classroom. I remember her teacher asked me to give a little explanation . . .because by this point, she had these [metal braces on both her hands], and kids are not about to let that go. It's like this is in fourth grade, and so I did a little dance, and [singing] I was like 'What's wrong with [kiddo] is she gonna turn into a robot?' . . . Approaching it in that way, the kids were a little more, you know, they're like, 'oh, maybe I'm gonna be a robot too.'*

Sarina was asked to come into her child's classroom to educate her nondisabled peers. Meanwhile, the school district should have trained staff and pre-prepared presentations on disability and difference. However, the responsibility for educating the other students fell to this mother. Her experience seems to be consistent with other mothers' experiences in her district. At a recent public meeting about SPED services in this district, several mothers asked the administration to provide prepared presentations for parents to take into the classroom, as the mothers in the room had been regularly doing these things on their own. One mother commented that the district should "provide trained professionals" to do these presentations. She pointed out that not all mothers can give presentations either because of a lack of knowledge or a schedule that does not permit that level of flexibility.

Sometimes the labor of direct support, while benefiting teachers and staff in these academic spaces, occurs outside of the school environment. Mothers talked about regularly spending time writing and updating summary sheets for the staff working with their children at school. Lena describes how "every year [she] write[s] a profile on her [daughter] for new EA's and new teachers and whoever else might come into her life." Similarly, Nadia provides summaries of her child. She is also fully aware that IEPs are often deficit-based, so she is intentional about putting positive content in the document. "I made a two-page sheet that summarizes my child and all the wonderful things about him." Nadia describes her child as someone with a "really generous spirit" who is "really observant" and "funny as hell." She states, "I love how he is, how he thinks and how he navigates the world and shares that with me." He is "a great builder, a great sequencer, and a problem solver." However, as Nadia points out, "none of that important information is in the IEP."

The documents these mothers create and provide overlap with the labor of advocacy as they are another attempt to secure support for their children in the school environment. It is important to note that all staff working with the child, including substitutes, should be familiar with the child and the IEP. This training is supposed to be handled by the school; however, resource scarcity places constraints on the availability of training. Several mothers reported that sometimes staff knew nothing of their children. Nadia shares, "like he has a substitute today. Is there any chance that she has any idea what's on [the IEP]?" Nadia is clear that "the information sheet is basically a request not to discriminate." Going on, she talks about getting feedback about these summaries from the special ed director in her district, "it's funny how [the director] experienced this two-page document as really helpful. The fact is, I'm doing the school's job."

The mothers, however, are doing more than "the school's job" when they provide these documents to staff; they are doing "the work of socializing for acceptance" (Kittay 2015). Kittay argues that "socialization for acceptance" involves not only helping a child "make [their] way in the world given [their] disabilities" but also helping to "shape a world that will accept" the child (398). The "requests not to discriminate" that mothers provide are physical manifestations of this labor. The summaries try to capture the whole child vis-à-vis the IEP's single-minded focus on deficits and behavioral interventions. In this way, the summaries function as another tool mothers draw on to manage the educational environment and increase the acceptance of their children. One could also argue that regardless of the type of labor mothers invest in the special education system, the invisible labor of "socializing for acceptance" may underly most of their efforts.

Labor of Direct Support in Non-Academic Settings

Maternal labor in nonacademic settings was another strong theme in the interviews. Mothers talked about their presence at extracurricular activities, field trips, and even transportation, which is often a crucial component of a child's inclusion. Kristina recalls the complication of using the public bus to get her children to school. She describes having to go "all the way to a different elementary" school and how it was "a really big fight to get him on the school bus over there." She talked about "running around on the bus, the public bus, just back and forth trying to get both kids to school then back." Kristina had to take on this labor because when she took the initiative to remove her son from her catchment school due to safety concerns, the school refused to assist with transportation.

> *They're not busing him because he wasn't expelled. He has to be expelled [for the] program to cover that [cost]. I'm just like, you guys basically told us you can't deal with him. That's almost like expulsion.*

In this situation and without a means of private transportation, bussing her children to separate schools was a significant burden on this mom, which the school dismissed as voluntary.

In another situation, Anais not only took on the labor of direct support in a non-academic school environment, but she also took the blame for her daughter's melt-down. Austin and Carpenter assert that "although [mothers] strive to manage their child's behavior and do everything right in their attempts to fulfill motherhood, they receive many messages telling them of their failure and few, or even none, telling them of their success" (Carpenter and Austin 2007: 666). Their assertion is consistent with Anais's experiences when she arrived at a jog-a-thon and found her daughter under a table. Anais pointed out to staff how her daughter was over-stimulated. She shares their response.

> *'Oh, well, you know, she thought you were coming, and you're late, so it's probably just because you know she was expecting you'. . .like it's*

> *completely my fault that my daughter had a meltdown at school because I should have been there on time.*

She describes how the school blaming her is their way of ignoring its role in the situation.

> *My five minutes late caused that? No, not anything going on with my daughter. Not that they don't have the right supports in place. Not that she wasn't properly prepped for the jog-a-thon. Even though this happened last year at the jog-a-thon as well.*

Investing the labor of direct support to attend field trips was also a common experience described by the mothers. It is, of course, common that parents can and do attend field trips with their children; however, it was often not a voluntary choice for these mothers. They talked about being asked directly to attend the field trips so their children could attend or receiving more subtle or indirect suggestions from their children's teachers that they needed help supporting their child on the trip. Furthermore, this required "volunteering" for field trips is happening in addition to the other forms of labor mothers were already performing in academic and non-academic spaces.

Tamara describes how for "anything in kindergarten and first grade [she] was pretty much required" to go.

> *The teachers told me, 'if your child wants to go on this field trip, you have to go with them to provide one-on-one because we can't do it. He is, you know, so hyperactive that, you know, he's a danger to himself and others, and we don't have the one-on-one. When we're in school, you know it's in a classroom. But we're out and about, and you know we fear for his safety, so please come along with us.'*

She also talks about "always be[ing] able to do that because of [her] work, which is very child friendly," and how "even now, even in high school, [she] still [goes] on all of his field trips or the big ones." She recalls a recent trip.

> *We did a three-day camping trip where they visited different archaeological things out there, geological parks and state parks, and things like that. And I went with them. They said, 'would you be willing to come along?' They know I like kids, high school kids and, you know, mine in particular . . .Yeah, so, good thing I like camping.*

Tamara also describes how staff would ask her to attend her son's field trips.

> *The kids had a field trip to go to the zoo, and [my kid] had it earned it. He really had. And then he had a little bubble, like, before they were going because she had talked about it. And she talked about it so often before it happened that it started to stress him out, and [he] melted down a little bit. And so [the teacher] was like, 'Okay, well, he can go to the zoo, but*

> *you need to come, and you need to be his personal chaperone.' And I'm like, 'I don't care. Fine.' I was a stay-at-home mom anyway; I'm going to go there for my kid.*

When asked about what might have happened if she had less availability, the mother replies that she did not think the teacher would have let him go, but at that point, she "would have pushed harder" for his inclusion in the trip. Tamara describes how in her case, the requests from the school usually fell somewhere between "oh my god, I'm not sure we can do it if you don't come, to please come, it would be really nice, and I really don't know how it's going to go and if you don't." For other mothers, it was the only way their children could attend. Bell talked about a "pumpkin patch field trip" she was required to attend.

> *I was told by the teacher that I had to come, or else he couldn't participate, which was fine because I was planning on going anyway. But the idea that he wouldn't have been able to go if I wasn't there was kind of hurtful.*

When asked if she thought they required other parents to volunteer, Tamara states, "there were other parents who volunteered, but not for the same reason. Not that I knew of anyway."

Lysha's advocacy for her son to attend a field trip also led to her direct support on the trip itself. As a staff member herself, she is very aware that the role she is taking on is that of an educational assistant.

> *There was some language [in the permission slip] for their third-grade field trip, and I made sure to ask [the teacher] about them. I was like, 'okay, is this applying to him? Because you know that he can't meet these.' I think it also made a difference that I was always willing to go, and in third grade and fourth grade, I was a sub, so I could say, 'look, I work for the district, you know, so I can be there. I can be there as his EA if you want it, you know, I can legally be there.' So, I feel like I that he got more support and less exclusion because I was pushing and because I was staff. I was faculty; I was, you know; they couldn't put me in a parent box.*

Similarly, Lyndsay shares how her presence was a requirement for her son to attend field trips. She shares that it wasn't even a matter of "we'll see how he does that day . . .if I wasn't able to attend the field trip with him," he couldn't go, or in some cases wasn't "even given the option to attend."

> *If I'm working eight to five, Monday through Friday, and I cannot take off just, you know, half a day to go on a field trip with him or an entire day. I*

> *know, it’s like, it’s not fair that he can’t do these things when all he needs is one-on-one.*

Lyndsay captures how the lack of staff support and the alternative of their child’s exclusion drives mothers to pick up that slack.

Anais says that she goes “on all those field trips,” stating that her daughter couldn’t go without her, “even when they just went to the firehouse, and it’s like an hour, I [had] to find a sitter and do all the things so that I can go.” Similarly, Lydia recalls that “the field trips [her daughter] did go on [she] went with her” and how she “drove her there because [she] thought the bus would be a nightmare for her.” In many of these examples, the mothers illustrate how their investments of the labor of direct support on field trips are glaringly compulsory. However, some mothers describe the investment more in terms of “the implicit ought” of motherhood. Louisa talks about how “when [her] son was little, [she] always just automatically volunteered to go with him.” She shares her thought process.

> *I just felt that it was kind of my job as a parent, and I and I never had them asked me to go. But I knew that he could be a handful, or you know, just not be following along because he just wasn’t processing fast enough. At the time, I was a stay-at-home mom, and I could do it.*

This example illustrates how mothers may not require direct requests to invest the labor of direct support. It also highlights how providing this support is not possible for all mothers.

The fact that some mothers cannot provide direct support during field trips hints at how the labor of direct support in academic and nonacademic spaces also overlaps with the labor of removal. If children cannot attend a field trip because their mother cannot go, the mother must often facilitate their removal. This connects to how mothers described being on-call to pick up their children and remove them from the school environment. Suyin offers a contrast between the reality of being on call for removal and how she wishes it was. Remaining on a call like this stood out to her as an avoidable burden. She shares that her son “would just run away,” and the school would call her “in the morning or whenever, and then I [would] have to go pick [him] up.” I asked her what her ideal would be in terms of the school supporting her son.

> *That they know how to calm him down, instead of trying to catch him and tell him you’re not allowed to run around in a building between classes. I*

> *don't know. I know it's hard. But maybe they're professional, and they know how to settle him down. Then at least he can be safe, and I don't have to go pick him up every morning. That would be ideal.*

Her ideal, however, is often not the case for these children—a reality that compels mothers to perform the labor of removal as their last resort.

Labor of Removal

The final theme of unpaid maternal labor is when mothers are given, or take on, the task of removing their children from the school environment, from non-academic activities, or from the school or district itself. The most visible form of the labor of removal is when the schools call the mothers to remove their child from school. Less visible is when mothers remove their children from school or activity without a specific request from the school. While removing a child from school without a request can be seen as a parental choice, the mothers do not describe situations where other options seem viable or available. Therefore, the labor of removal is a false or coerced choice mothers are forced to make, and it is usually their last resort. While the labor of removal inevitably results in their children's exclusion, the school or district's role in this outcome remains relatively indiscernible in the background of a mother's "choice."

Removal from the Classroom

The fact that mothers remained "on-call" to provide direct support in schools overlaps with mothers performing the labor of removal. While some mothers may enter the school environment to help calm their child and then leave, more often, the labor of removal is what they remain on-call to do. Kristina mentions this, "they were calling me every day to come get him out of the office." Tamara remembers how one of the first times she received a call, the school asked her to pick him up "because he climbed to the top of the bathroom stalls in the bathroom and wouldn't come down." She understands that her child's behavior is disruptive, but laughing, she states, "like you are calling me why?!" Bell describes one year when the school was regularly calling her to pick up her child.

> *I'm getting phone calls every almost every single day; you need to come pick him up, you need to come pick him up. Mind you, his behaviors are not violent toward other students or himself. His behaviors usually involve*

> *yelling, or hiding, or refusing to leave the classroom because transitions are hard. In my experience at the school, there are children who throw chairs, there are children who flipped desks, their children who hit other children. . . you know, and my child is not doing any of those things.*

Bell goes on to point out that from what she saw, her "child was not the only one that was being sent home consistently."

> *I mean, every time I was there, they were calling someone else's parents to get them down here. Okay, call that parent, get them down here, and that to me that's not doing their job. I mean, it is their job to deal with those situations and figure out how to educate through them. Not just call the parents when it gets tough.*

These examples illustrate how schools have to rely on mothers to remove their children from school because they lack proper resources and staff to respond any other way. This is yet another way schools manage the problem of the child, not the problem of the environment. When the school staff make those phone calls, they are reacting to the child's "behavior" instead of responding to the child's needs. Leading up to the phone calls mothers receive is a context where the schools have denied, delayed, or failed to provide proper services and supports—a context where staff have also remained unequipped or available to support disabled children. Furthermore, the regular escalations of behaviors in children are a direct outcome of navigating an educational environment that relies on dehumanizing behavioral modification practices such as ABA. Until those aspects of the educational environment change, mothers will remain on call for the labor of removal.

In addition to investing the labor of removal at the schools' requests, mothers also describe situations where they voluntarily keep their child home from school. Bell describes regularly picking her son up early from school to avoid an afternoon class with a long-term substitute teacher who openly questioned his diagnoses and said things like "if he continued on this path, he was not going to make it through high school" all within earshot of her son.

> *I pulled him. I started picking him up at lunch every day. I said, 'I don't want to get out of the morning routine, but I'm not going to force my son to sit in a classroom with a person who doesn't have faith in him, who doesn't think he's worth it, and who thinks he's just a bad kid.'*

Bell invests the labor of removal into special education to protect her son’s emotional well-being. She also shares that her son struggles with substitutes. Until the school “come[s] up with an accommodation when there is a substitute,” the labor of removal is Bell’s only option. It is her last resort. She is visibly frustrated with this situation, “there has to be a classroom that he can go to.” Because “we can’t keep him home every time there’s a substitute. Yeah. Like, he shouldn’t be truant because they can’t come up with a place for him to go when there’s a substitute.”

Sometimes mothers share that the school does not support their choice to remove their child. Anais mentions that the school is “already very snippy about like the number of mental health days I give her. If she’s waking up and she’s screaming for an hour and a half, I’m not sending her to school that way.” Other times, mothers express feeling like the school supports the mother’s removal of their child. Angelina shares how she “just kept [her son] home, just kind of as a mental health day” because, for her, “it was just smarter” than allowing him to go back the next day, “it was like it was a mutual agreement. Like he had a meltdown on a Thursday, maybe Friday, just don’t bring him to school.” The subtle request in this “mutual agreement” shows how blurry the line between a school’s request and a mother’s decision can be.

Removal from Non-academic Spaces

Mothers also describe taking on the work of exclusion by “self-selecting” their children out of activities. Lyndsay describes how they “went to every single, like, function because he had to go,” but because the environment itself was not sensory-friendly, her son rarely got to stay the entire time, “we would get there a little early. It would be a lot of people there. And then his first sign of agitation, I was like ‘okay, that was fun. Let’s go home. So proud of you. We’re doing so good. Let’s go.’” Without access to structured sensory-friendly spaces and activities, school functions remain inaccessible and difficult for Lyndsay and her son. She does what she can to facilitate his participation but usually removes him before reaching his threshold in the environment.

Field trips were another nonacademic activity that forced mothers to take on the labor of removal. Kaleigh described how her son’s school would use a point system for field trips and either make the children stay at the school or go and have limited participation in the activities. This mother responds to this by taking on the labor of removal, and like the other mothers, she "self-selects" her child out of school for the day: "I was just like, um my son will not be participating in school today, because I'm taking him out for a personal day." For this mom, excluding her son from school was the only viable option.

Sometimes the specific field trips can be pinnacle and formative experiences. Sarina is currently confronting this reality as she grapples with keeping her daughter home from a meaningful field trip. The trip takes place out of state and is a crucial multi-night experience for all fifth graders to begin their final year. This is a trip the school plans for almost a year in advance; however, the school had not approached the mother to discuss her child's individual needs at the time of the interview. The absence of this communication on the school's part suggests that the unique needs of special education students may not be an integral part of that planning process.

Sarina describes the significance of the trip. "It's to begin their fifth-grade year," when "they'll be the oldest kids at the school." She states, "my older daughter went and loved it." However, now that Sarina confronts the upcoming trip, she says she "might sort of self-select out of that. Just because there won't be resources there." She describes how there will be some staff from the school and how the camp itself does have full-time staff, yet "without her special education teacher," she is "just very apprehensive about that." In this situation, Sarina is confident that the present level of available staff will not be enough to meet her daughter's needs.

> *It's not going to be the level of structure that she needs. Like she's nine years old, and she still takes naps. So, especially in a situation like that where they're like sleeping in these very primitive camps like there's a cot on the floor, something like that, and then there's a hole in the ceiling so they're sort of outside but sort of, I just don't even know. I mean, she will just be a little monster.*

When asked about what it would look like if the school prepared for her child's inclusion in that trip, Sarina states: "I think they would have to send the educational assistant who she's known since kindergarten at this school." However, she immediately follows that by expressing how she understands the limitations of the school's resources: "it's a very expensive camp, and they sort of have the resources I guess to only accommodate I guess what they absolutely have to as far as staff to kid ratio." Sarina goes on to describe how advocating for her daughter's full inclusion "would be another huge intervention on [her] part." Unable to take on the labor of advocacy in this situation, she is left with the false choice of self-selecting her child's removal from this particular non-academic activity.

While Sarina's choice was between the labors of advocacy and exclusion, Suyin describes the internal tension when the choice is between the labor of direct support on a field trip and the labor of removal. "They didn't trust him yet, so that was really hard, so I didn't even tell him there was a field trip. I just said, 'well, you're gonna be in that room with this teacher doing something.'" In this situation, the mother took on the task of preparing her son for exclusion in the school setting. In tears, she recalls what happened when her son found out about the field trip.

> *He finally figured out what [was happening] he told me 'mommy, it's okay.' I said, 'because I did not take the day off, so you are gonna have to stay at school with Mrs. Nelson and do some work.' And I say, 'do you want me to take the day off so you can go to [the] field trip?' and he told me, 'Mom, mom. No, I don't want you to take a day off.' He said, 'I don't want you to do that," and I say, 'Okay. . .[but] I could take the day off, but he said, 'No, don't. I don't want you to do that. I'll just figure it out myself. I'll be in that room until you come pick me up.'*

Heartbreakingly the child in this situation also confronts a false choice between burdening his mother or accepting his exclusion. At the same time, the school's role in exclusion remains absent from this interaction between this mother and her child.

Removal from the School or District

Finally, the labor of removal confronting mothers can involve the choice to remove their child from the school entirely. Sometimes this involves transitioning to a different school or district, and other times it is a choice to pursue alternative options such as homeschooling. In some cases, mothers perform the labor of removal because of a physical safety concern. Kristina describes pulling her son out of the catchment school to homeschool her child until she could find a more appropriate setting for him.

> *We had some problems with the local school and their security level, and they weren't really up to dealing with emotional issues. So, we had to pull him out, and I did the homeschooling here while we were getting him an out-of-district transfer.*

Kristina eventually found a public school in a different catchment area and is currently bussing across town with her children while trying to get the new district to provide appropriate transportation.

The decision to remove their child from school is not always connected to a physical safety concern. This choice is also made from the mother's concern for her child's emotional wellbeing in the school environment. Anais talks about her current conflict with this choice.

> *I'm literally borderline like I'm just gonna pull her out. She does well at home. We really have a good routine. I enjoy her being at home, she enjoys being here, and it just removes all of that stress because she's so stressed about going to school now that she's having meltdowns. I'm stressed about having to force her to go to school. That's not where she needs to be. We'll do her work from home, and you know . . . I'm very much on the fence like, what's gonna be best for [my daughter].*

While Anais confronts the weight of this decision, other mothers have already made it because it was the only choice left.

Mileena did choose to pull her daughter from public school after an overly restrictive placement in a behavioral classroom. This placement occurred after Mileena confronted the school about putting her daughter in the seclusion room for 3 hours. It was the school's solution to being unable to meet her needs in the general education environment. She describes how "halfway through the second year, [her daughter] just begged not to have to be there," and at that point, she was like, "nope. We're done," and she removed her daughter from school. The fact that advocating for her daughter led to her removing her daughter from school entirely shows how the labor of removal is bound up in a mother's advocacy. As a mother advocates, often for years to get services for her child, sometimes it helps--sometimes mothers make progress. However, too many other times, the labor of advocacy and direct support are just a mother's repeated attempts at protecting their child from the harms of implementing special education in a context of resource scarcity and ultimately just a mother's excruciatingly slow progress towards the labor of last resort.

Unrewarded Labor

In addition to the various forms of labor that mothers invested in special education to prevent or mitigate a range of institutional harm it can inflict on their children, they also described the unrewarded labor of specific teachers and staff. They shared how certain staff members would often step in between the student and the system to buffer students from a dysfunctional special education system. Katherine Irwin's work on punitive exclusion in general education describes a similar tactic (2020). Irwin found that "teachers, counselors, and security guards were caught between punitive policies from above and more compassionate responses at the local level" (ibid 841). She also describes how many times staff in this structural bind between punitive measures and their compassion would try to find ways to minimize the risk of student harm. Sometimes these choices could put their jobs at risk (ibid).

Mothers described situations where specific teachers were exceptionally good at their job and situations when teachers and staff would go above and beyond to support their child despite the conditions of their labor. They described teachers and administration as having more agency and influence than interns and school counselors, making them potentially more successful in their ability to buffer students from the system's inadequacies. Therefore, sometimes when mothers did find staff who genuinely seemed to care about their children, these particular people were often not in a position to help them. Gabriella recalls how there were "a couple of teachers" who were supportive, "but they were like guest teachers or interns." She goes on to state that "they were the most understanding, but they couldn't help us because they weren't at that level. It was the higher-ups; the people were the most power that really would shut us down." Deanna shares that she has an "overall feeling that there are people strategically placed in [her district] who are really, really trying hard with the resources they have." However, she does not get this sense from the stories she hears from other parents. Nevertheless, when mothers did find these people, they made an impact in their lives.

When Staff Are Exceptionally Good at Their Jobs

Mothers described teachers and staff who truly understood their children and made an enormous effort to teach other staff members about their needs. One example of an exceptional teacher came from Gloria, who spoke of his successful efforts to support her son vis-à-vis untrained and unfamiliar staff. In this instance, her child had fled a conflict situation, the school called her, and upon arriving, she used GPS to locate her son hiding in the recycling bin outside. She recounts how this teacher, who "is no longer a teacher anymore, just gently put his hand" on her son's shoulder and said, "you know what I think this might be? I think this might be a big misunderstanding." Gloria points out that "misunderstanding" is "the word you need to use with him when he's lost it because he's got in his mind that he's been misunderstood and is being really punished."

> *So right there, right in front of my son, his main teacher said, 'you know, you've been doing so well, this whole year, with managing your behaviors and meeting expectations and staying on task, going to your classes, finishing your work. And we've had some new people here now, and we kind of forgot to remind people about, what to watch for, and how to make sure that we're not in a misunderstanding.' He's like, so on one hand, 'you're doing really great, and this is a good reminder that we should probably all go back and take a look at that plan because I think there's some people who don't know about that plan here. So, we're gonna do that,' and he immediately calmed down.*

This particular teacher deescalated the situation, which benefited her son and the less experienced staff members observing the situation.

Lysha also recalls a specific teacher who stood out regarding his support for her child. She describes him as an "amazing" teacher who made her son's fifth-grade year a really good year. . . He's a fantastic teacher because I did not have to fight with him for accommodations." She states, "I don't say that lightly" and recollects how "he sat, and he listened in [the] IEP meeting." In retelling this story, her emphasis on the word "listened" is audible. One of the main things her son needs is "written directions because he has a hard time attending to auditory directions in a group environment where there's a lot of stimulations." Lysha describes how this was "something that like nobody accommodated him" on. However, she "walked in the classroom" a few days after the IEP meeting to find that the teacher "had given warm-up directions on the projector screen and there was a countdown timer on the projection screen." Implementing even just a simple accommodation like this is significant because, as she describes, once this teacher "figured out" her son's needs, "he came up with accommodations on his own." She also adds that when her son brought his wobble stool from 4th grade, the teacher noted it and then "went and got the class wobble stools so that everybody could have them." Finishing her retelling, she states, "You know, the dream teacher." He is a dream teacher because he invested his labor in managing the educational environment as the problem that needed to be solved, not her child.

At the time of the interview, Bell acknowledged the strengths of the new teacher and expressed optimism about her son's school year.

> *I'm hopeful for change this year because the teacher seems much more proactive about making sure he's successful. Praising him when he's being successful, she has implemented three or four different things from the behavior support plan that last year, we were told they couldn't be done. Oh, wow. She has printed out a schedule for his desk, so he knows what's coming. He has a wiggle disk on his chair, which, again, he never got any of those like physical things before.*

Bell's is not just describing a teacher providing support and working to manage the educational environment, not the child. She also illustrates the difference between treating a child like a person, not a problem. Louisa's child had mostly positive experiences in the school environment, and she credits this to her IEP team members.

> *I would say the only year that we really didn't have much success, well, there are two years there was one year where there was just a teacher who didn't get special ed, and so a lot of the accommodations we worked for were not happening. That happens when you have a teacher that's not as comfortable with it. Another year, we had a case manager, but she was only there for one year, and she wasn't very effective. However, the other parts of the team were still there; the aides were effective, the therapists were effective, I still felt like my son was being cared for . . . we've been pretty lucky, and I recognize that.*

During the two years that did not go smoothly, Louisa points out that they "always had aides or his case managers who have picked up that slack."

When Staff Go Above and Beyond to Help Their Child

In addition to staff members who were doing their jobs exceptionally well, mothers also described staff members who went out of their way to support or include their children. Audre's own advocacy, combined with the principal's efforts, prevented her son's exclusion from a field trip. "In fifth grade, they had the outdoor field trip, and I kind of had to do little advocating to get him included in that because it's two nights away." She describes how her son "got to go for one night." Audre realized she would need to advocate for her son "when they first started talking about the trip and saying they wouldn't have staff that could go for two days from the classroom." It is important to note that general education students' supervision and supports are planned for and provided by default. She recalls that "what ended up happening was the principal actually said he would take responsibility for her son." While her child was still unable to attend the full trip because of a lack of available staff to properly support him, he experienced partial inclusion in that setting because the principal "had a soft spot" for her son.

Bell also describes a principal going out of their way to make sure her child was properly supported. She had "kept pushing for" supports "all through first grade" and getting nowhere. She recalls how it wasn't until the principal stepped in that any progress was made.

> *By the end of the year, the principal said, 'We have to do something. There is something obviously going on here.' She was great. She was always the one coming to help him. She even offered to drive me down to [a location] and set up the appointments to get him evaluated because she knew how stressed out I was. She was like, 'let's do this; whatever it takes, I'm here to help you.'*

Bell goes on, saying, "she was kind of my support line. She was the one saying, 'I know this is not his typical behavior. I know that this is something that he doesn't have control of. So, let's get this work done.'" When this principle intervened, Bell was finally able to "initiate the 504." However, as she mentions, "there was a definite issue going on" at the district level because when they got to second grade, "she was transferred" by the district to a different school.

Angelina shares an experience with a teacher who went above and beyond. Her son's science teacher, who had taught her daughter the year before, was intentional about meeting his social skills needs in the context of the science curriculum. She points out that at the time, "he was an elementary school, and they always pulled him out for social skills training when he was in science." However, "science was a strong suit."

> *It took a little bit, but it wasn't very long. It was probably about a month or so before she's like, hey, she pulls me aside. She says, 'They keep pulling [him] from science for social skills. and she's like, 'I realize that's the only time that they have, but he loves science, and he hears about us talking about science, and he's missing out.' She's like, 'I have to navigate things with the principal and some of the parents but, I'm wondering if I could do something in the classroom, where we teach science with social skills.' And I was like, 'I love you. Please do that. Let me know if I can help.' And she did.*

Rather than focusing on "deficits" outlined in the IEP, this teacher taught her son as a whole child by focusing on his interests and strengths; this benefited the whole class.

Angelina describes how “there was a little bit of pushback from a couple parents because they feel like ‘well, my child doesn’t need social skills.’” So, the teacher “phrased it for different parents in different ways” to promote the benefits of teaching social skills with science.

Kaleigh offers another example of staff going above and beyond to help their child. She struggled for years across multiple districts to get a communication device for her child, and it was not until a speech pathologist within one of those districts stepped up and went out of her way that it finally happened. Kaleigh reflects on that, stating, “I think it’s important to know that this lady went outside of work, and made phone calls, took care of her paperwork, made sure I was taking care of my paperwork, and we filed together.” Without this woman going outside her assigned duties, Kaleigh’s son would still lack access to a communication device. To reiterate, a staff member in special education had to go outside of the special education system to meet a child’s fundamental need to communicate, which is one of his rights as a person; this alone points to an incredibly dysfunctional system.

The narratives mothers share about staff who care about and support their children highlight, once again, how special education remains a hit-or-miss situation for many families. Furthermore, it is rare when the people who visibly care are also the people who can impact fundamental changes. When asked if she felt that the special education system mitigates the effect of disabilities and allows students to access and benefit from the school’s general curriculum, Angelina laughs. She replies, “that’s a joke,” going on to point out again that the success of special education depends on “the quality of the people you are working with.” She argues that “staff get so pushed and pulled from the district, especially [this district]: you can do this, you can’t do this, you can’t do this, you can’t do this.” However, she states,

> *You do have those staff members that do go above and beyond, and I’ve been blessed to have some staff members that really went back and helped. But the majority of it, that party line from the district is different than what it looks like in real life.*

Angelina was not the only parent to discuss the role of administration in facilitating or limiting what staff are able to accomplish. A descriptive word that came to mind for Gloria when thinking about special education was “underperforming.” Her reasoning behind choosing that word highlights the structural reasons certain staff efforts stand out to mothers.

> *Underperforming came to me because they have some gems in terms of practitioners, but their district leaders are too far removed from what's happening in the classroom. As a result, the capacity for the practitioners to do really good work is diminished.*

Gloria has "experienced more helpful people than not," and she shares her sense that they want her to know they wish things were different.

> *For whatever reason, they disclose their work environment challenges to me. I think that's because they want me to know that they care and if they could have it be different, they absolutely would. They work within a system that lacks vision and leadership, and until that changes, I don't think the performance will change. I think with the right vision, and the right leadership, the right culture building, that special education could perform next year markedly better than it does now.*

Gloria articulates how administrative decisions and challenges drive special education outcomes in the classrooms on the ground. Even when teachers want to do good, when they work exceptionally hard, when they go above and beyond, at best, it makes a small positive impact for a few families, but the system itself and the harm that comes from it remains unchanged.

Summary

The findings discussed in this chapter suggest that mothers invest significant amounts of unpaid compulsory labor into the special education system in their efforts to buffer students from exclusion and institutional harms. The mothers' narratives highlight the adversarial and demoralizing positions they are in by contrasting their efforts to push schools to educate and protect their children against the administrative responses they receive. This chapter also shows how staff members struggle to balance the structural demands of implementing special education in a context of resource scarcity with the knowledge that children deserve an education, safety, and care. In these situations, teachers and staff leverage their compassion and what little power they have to prevent or minimize institutional harm. These findings also suggest that this investment of labor functions as a scaffolding of sorts—propping up a system that would ultimately exclude and harm disabled students in the absence of unpaid and unrewarded labor. In this way, the unpaid labor of mothers and unrewarded labor of staff is the special education system's labor of last resort. Furthermore, the unexamined systemic reliance on this labor potentially works as a mechanism that slows programmatic progress and ultimately allows an unequal education system to persist.

CHAPTER VI

DISCUSSION AND CONCLUSION

Mothers occupy a vital and often devalued position in the special education system. They are not the recipients of services, nor are they the providers. They are the contested space between the two. They are the witnesses, the observers, and their positionality in this middle space of special education offers a valuable perspective on the quality and functionality of the system as a whole. Listening to mothers' stories, valuing and amplifying their voices is central to measuring the distance between the ideals of inclusion and the reality on the ground. Prioritizing mothers' observations of their children's lived experiences in the educational environment offers us a crucial point of contact to check the pulse of a system upon which vulnerable children rely.

Through my interviews with twenty-four mothers whose children are in special education, I sought to take that pulse and found it faltering. In my analysis, I put mothers' perceptions of special education and resource scarcity in conversation with student exclusion and institutional harm. My findings suggest that mothers confront and hold up an underfunded and poorly implemented special education system that does not meet their children's needs. Mothers are laboring in schools alongside staff to ensure the most minimal inclusion and educational access for their children. Special education relies on the invisible, unpaid, and devalued labor these mothers invest. The absence of other options means that the unpaid labor that mothers invest into special education is compulsory. Compulsory labor is a reliably extractable resource that can offset the resource scarcity in special education—propping up the system just enough to keep it going. Mothers are the tourniquet on a system that is bleeding out.

It is common knowledge that a tourniquet is not a long-term solution; nevertheless, these mothers' stories show how special education relies upon one to function in a context of resource scarcity. Furthermore, this systemic reliance on unpaid labor from mothers and the unrewarded labor from staff reproduces the inequity, inadequacy, and inhumanity of special education. Mothers shared the perspective of looking up from the ground into a special education system where funding fails to trickle down. When the staff, services, and supports promised in special education are not there, "mothers learn that entitlements are not fulfilled for their 'budget-buster children'" (Blum

2007). Mothers witnessed schools failing to meet their children's pedagogical and social needs. The schools also failed to meet or severely neglected children's emotional and bodily needs. The only viable option left for mothers in this situation is to pick up the slack of resource scarcity by investing significant amounts of their labor into special education. Their narratives highlight how, all too often, their children's inclusion, education, well-being, and sometimes their very humanity depended on unpaid maternal labor in special education.

A notable limitation of this study is the small sample size of both mothers and districts. Another methodological limitation is my reliance on convenience sampling through community organizations that help parents navigate special education. While it is true that this might introduce bias into the findings, I attempted to offset sampling limitations by reaching out to non-advocacy-related organizations. Furthermore, I argue that my sampling is a strength in my work for two reasons. There were mothers in my sample who did not seek out advocacy, and some of them held positive perceptions of special education. However, their stories often overlapped with the narrative of mothers who had more difficulty in special education. This overlap highlights, as Merry suggests, the ways harm may occur regardless of if we are fully cognizant of it (2020). Moreover, I argue that any negative bias in the sample is essential, as these are the experiences we need to illuminate. Calling attention to the harrowing stories, the experiences that people want to believe are outliers, gives us a greater insight into a system that considers the degradation of the most vulnerable of our children an "acceptable" cost of inclusion.

As mothers shared pieces of their lives with me, they shared a story of what special education in the context of resource scarcity looks like—what it feels like—on the ground. What they describe is not inclusive education. Mothers describe a self-referential system where the "caveats to mitigate risk, suppress cost escalation, maintain school structures, and preserve professional interest" not only lead to their children's exclusion but "attenuate the human rights agenda" (Slee 2019: 913). Despite the rhetoric of inclusion, special education implementation in these districts facilitated student exclusion, institutional harm, and institutional betrayal. Special education policies centered on managing resources and meeting the letter of the law at the children's expense. When these policies come together with the personal investment and belief that practitioners have in special education practices, children's rights and personhood are at risk. Often, the students who are excluded and harmed the most are those with the highest support needs.

Mothers conveyed how behavior and classroom management practices exacerbate the deficits of the educational environment and have repeatedly traumatized their children. They described situations where schools, using untrained staff, regularly deployed structural interventions and punitive responses grounded in ABA and behaviorism to manage the child. Mothers described how thin the line is between these interventions and abuse and how sometimes there is absolutely no line at all. Furthermore, the “behaviors” that teachers and staff are struggling to manage are not symptoms of a disability. They are “our best evidence” (Swenson 2020) that something is missing in the educational environment for that child. In their advocacy work, mothers repeatedly tell special education professionals and practitioners precisely what is missing for their child, but their voices and expertise as mothers are silenced and ignored.

Mothers painfully illustrated a glaring absence of appropriate services and support for their children. They shared how the schools regularly denied or delayed essential accessibility accommodations like communication devices and brailers. These denials are akin to denying wheelchair ramps. In some cases, it is like denying the wheelchair itself. In every case, it is structural discrimination. Damage control in these situations demands maternal labor. The enormous amount of unpaid labor mothers collectively invest in special education suggests a critical point of intervention in the system: the point where people are making redistributive decisions about resources. Suppose that somewhere up the line that funding had been distributed differently at the district, state, and federal levels. How might that change the situation for mothers on the ground? Suppose the federal government followed through with its funding commitment. Suppose it had not failed to do so for decades. Appropriate federal funding allocation would mean states would have more resources for their districts, and in turn, districts would have more resources for their schools, teachers, and students.

An appropriately funded special education system is not the one mothers are navigating. Instead, mothers, along with teachers and staff, navigate a context of resource scarcity. However, there is “sociocultural causality” behind the scarcity in special education (Daoud 2010). Daoud argues, “if scarcity is possible, then abundance and sufficiency are also, by definition, possible” (2010:1221). He points to the role of “institutions and habits” in determining “the availability of resources” (Daoud 2010:1222). Furthermore, he acknowledges that the core values held by people and societies are bound to “have a causal effect” on resource scarcity and its alternatives, resource sufficiency or abundance (ibid). Resource scarcity, as a problem of redistribution, is bound up in social understandings of full and moral personhood. As Bérubé asserts, “recognition politics have consequences for the redistribution of social goods” (2003:53). A group’s position on the hierarchy of resource distribution can tell us a fair amount about their social “value” overall.

Looking at special education through the lens of personhood illuminates decades of redistributive decisions that have continually underfunded and debilitated a system designed to protect disabled children from the harms of discrimination. These distributive choices suggest that disabled children are not worth investing in and, therefore, not seen as worth protecting. The painful and, at times, heartbreaking stories that mothers shared paint a picture of what it is like when the redistributive choices that devalue their children trickle down. It is the obligation of anyone invested in special education not to look away. An interpersonal definition of personhood offers that one facet of being a whole person is “being seen” by those around you as “someone whose happiness or well-being is taken as intrinsically important” (Ikäheimo 2009b:81). Therefore, the adults responsible for protecting children must grapple with questions of personhood.

The concept of interpersonal personhood forces an interrogation of the assumption that special education, and the funding decisions for and in that system, recognize disabled children as people whose well-being and happiness are “intrinsically important.” These mothers’ narratives suggest that the special education system does not treat their children as whole people who deserve full access to their human rights. The point of intervention in a special education system that is bleeding out must go beyond funding decisions that would allow us to take the tourniquet off. Intervention must include a genuine interrogation of our collective desire and willingness to believe that special education is anything other than exclusion “camouflaged in the language of good intentions” (Beratan 2006). As Fine reminds us, “partial inclusion” will “almost always result in the downward drift of exclusion to those whose bodies can't be packaged as 'equal' or 'same'" (Fine 2015:180).

Special education has a powerful gravity. It is always easier to succumb to the weight of gravity than push against it. It is easier to let students, like Bailee's son, slip down through the cracks of a dysfunctional system, far easier to call them "outliers" on the bell curve of inclusion's success, easier to call them "the costs" than it is to include them. The students that special education leaves to the gravity of exclusion are often the most vulnerable—dropped because their needs are the most expensive to meet. However, protecting the most vulnerable should always be the starting point, not the afterthought. Still, our most vulnerable students are left behind in the name of inclusion. For those invested and implicated, in special education, calling the students special education fails 'the best we can do with an imperfect system' might be a comforting lie that allows them to keep looking away. However, that comforting lie is a harmful collective fiction.

A continued belief in the collective fiction of inclusion continuously puts disabled children at risk. For every "act of inclusion, there is a drip-fed degradation of those left behind" (Fine 2015:180). Professionals and practitioners might not believe that the current structure of the special education system is the best way to serve students. However, they accept the structure as a given and remain invested in it as the only way. Decades of effort have gone into improving the special education system as it is currently structured. These efforts are couched in ending discrimination against disabled children, but the system itself is slow to change. Slow change is dangerous when ableism is the starting point, and discrimination is rendered acceptable by the law (Beratan 2006; Lalvani 2020). Slow change is problematic when "the word appropriate serves as a qualifier" —a caveat that "overshadows" the spirit of the law and renders discrimination and exclusion palatable (Beratan 2006).

The special education system continues to function "as a mechanism of exclusion," and general education remains "complicit by providing the permission to *look away* (Lalvani 2020 172 emphasis original). Ball argues that the "task of the intellectual" is not only to show other people "how intolerable taken-for-granted exercises of power" function but also to "show them that things could be different" (2013:145). He posits that this work "involves analysis of and experimentation on the limits within which we are set" (Ball 2013: 145). Central to the "ethics of intellectual work" is a "concern" for both truth and existence (ibid); concerns that turn our attention towards "the 'costs of the limits of possibility—what is lost, obscured, sacrificed in the present" (ibid:146). Truth-telling in the face of collective fiction is "the disturbance of conventional ways of thinking" (ibid). It opens space for other possibilities, other solutions. It allows us to see that special education, as it is today, and as these mothers describe it, "does not exhaust the possibilities" of what inclusion could be (Ball 2013:146).

Too often, the debate oscillates between the physical placement and the individual context definitions of what constitutes inclusion (Nilholm and Göransson 2017). However, there is a "community definition" of inclusion (ibid). Inclusion, in this sense, is about creating educational communities that enable belonging. Community inclusion facilitates students feeling socially incorporated, physically safe, and able to participate in and achieve their academic goals (ibid). Here inclusion "is not simply a service placement for learning" but an intentional educational community built around the idea that each and every student is valuable and belongs (Bakken 2016:4). Student belonging would be "a conceptual and practical precondition" of community inclusion (Slee 2019:910).

Inclusive education is a "transformational project" that requires community (Kozleski 2020:340). Any arrival at genuinely inclusive education requires practitioners and professionals to reckon with the legal segregation embedded in the system they invest and believe in. True inclusion requires moving beyond "parallel systems of education, and the implicit ideology of *separate but equal* upon which they rely" (Lalvani 2015:159 emphasis original). As Kozleski posits, inclusion "requires fundamental shifts in our beliefs in human potential and the capacity of public education to achieve success for each and every student" (2020:352). Kozleski states that "activity binds people, including children, together as they make sense of the world around them" She calls this activity "culture in action." Educational communities can "build new activity cultures that can release practices that prevent the full participation of everyone" (ibid:350).

The current limits of possibility have us stuck in special education as we know it to be. These limits in our ability to envision other potentialities and possibilities outside a continuum of segregation come at a tremendous cost. Despite the overwhelming rhetoric of best practices, progress, and programmatic improvement, too many disabled children pay the price of inclusion with their personhood. Those are the children we lose, the children that mothers labor to protect, the costs that should be intolerable. Slee argues that "educational policy embraces and advances beliefs and values as the tools with which to construct the future" (2011:189). Our responsibility is to ensure that the beliefs and values we are advancing include disabled children as whole people who are an integral part of the future we want to build.

APPENDIX

Table 2: Respondent Involvement Information Chart[a.]

Mother	Child's Gender	Involvement	Previous	Current School	Current District	Previous District	Additional Districts	Placement Level
Sarina	Female	IEP	IFSP	Public	District 1			GenEd w/ Pull Out
Suyin	Male	Starting		Public	District 2	District 1		GenEd w/ Pull Out
Kaleigh	Male	IEP	IFSP	Public	District 3	District 1		GenEd w/ Pull Out
Louisa	Male	IEP	IFSP	Public	District 1			Contained Class (CLC) w/ Pull Out
Mileena	Male	IEP		Public	District 1			GenEd w/ Pull Out
Angelina	Male	IEP	504	Public	District 1			GenEd w/ Pull Out
Lyndsay	Male	IEP		Public	District 1	District 3		Specialized Class (BH)
Adelina	Female	IEP	IFSP	Public	District 1	District 3		GenEd w/ Pull Out
Cecilia	Male	504	IEP	Public	District 1			GenEd w/ Pull Out
Cymone	Male	IEP		Online Homeschool	District 4	District 2		Home
Bailee	Male	IEP	504	Left	District 1	District 3	Out of State	Specialized Program (LS)
Gloria	Male	IEP		Public	District 1			Specialized Class (LS)
Bell	Male	504		Public	District 1			GenEd w/ Pull Out
Judith	Female	IEP	504	Charter	No District	District 1	District 2	GenEd w/ Pull Out
Gabriella	Female	504		Public	District 1			GenEd w/ Pull Out
Lysha	Male	IEP		Public	District 1	Out of State		Contained Class (CLC) w/ Pull Out
Nadia	Male	IEP	IFSP	Public	District 3			GenEd w/ Pull Out
Anais	Female	504	IFSP	Public	District 5			GenEd w/ Pull Out
Lydia	Female	IEP		Homeschool	No District	District 1	District 7	Contained Class (CLC) w/ Pull Out
Lena	Female	IEP		Public	District 1			Contained Class (CLC) w/ Pull Out
Tamara	Male	IEP		Public Charter	District 1	District 6	Out of State	GenEd w/ Pull Out
Deanna	Female	IEP		Public	District 3			Contained Class (CLC) w/ Pull Out
Audre	Male	IEP	IFSP	Public	District 2	District 1		Specialized Class (LS)

a: IEP is an individual education plan under the IDEA; IFSP is an individual family support plan under the IDEA; 504 is a nondiscrimination document enforced by the Office of Civil Rights under Section 504 of the Rehabilitation act of 1973. Note on Placement Levels: BH is a Behavioral classroom; LS is a life skills classroom. CLC's included extended resource rooms

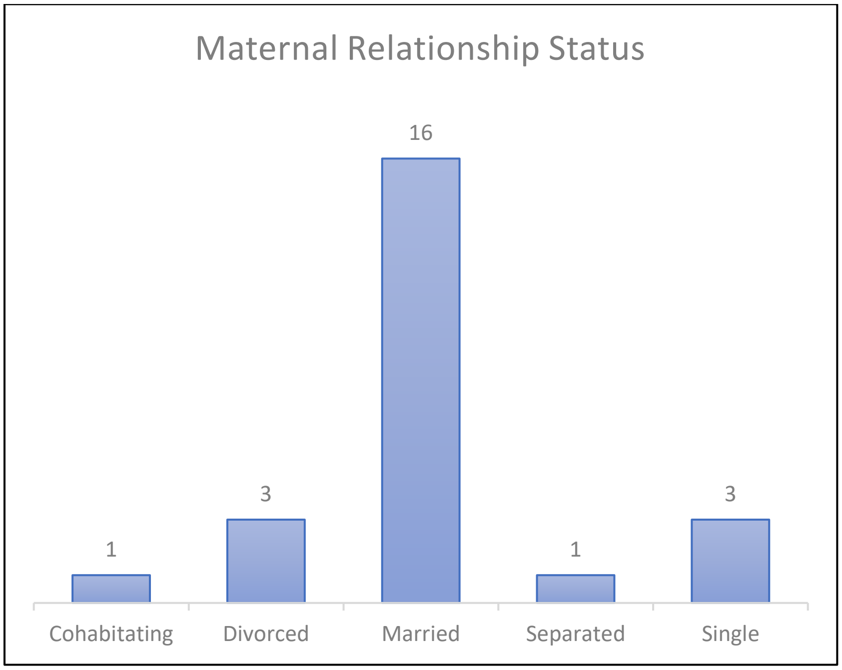

Figure 1: Mother's Relationship Status

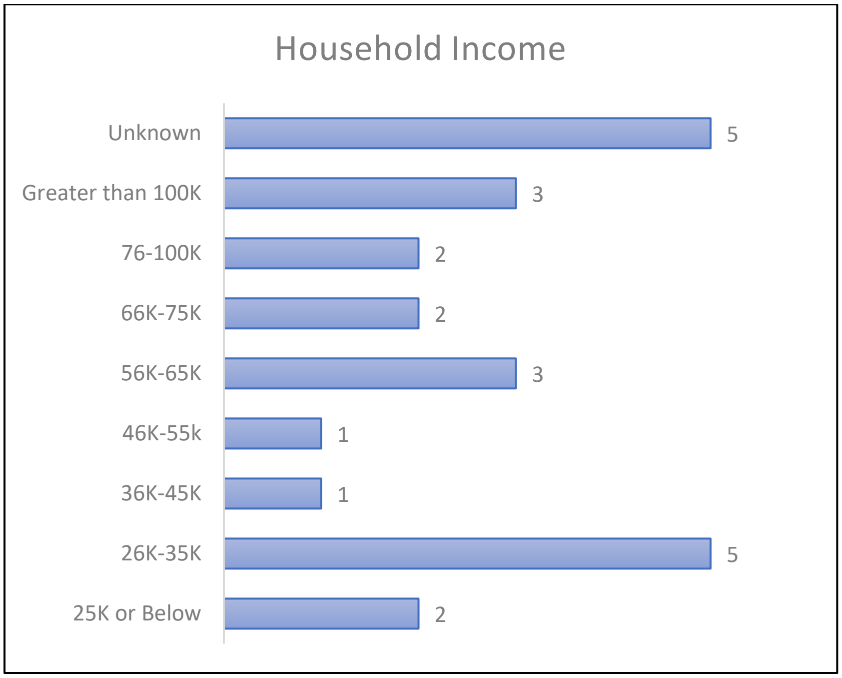

Figure 2: Mother's Estimated Annual Income

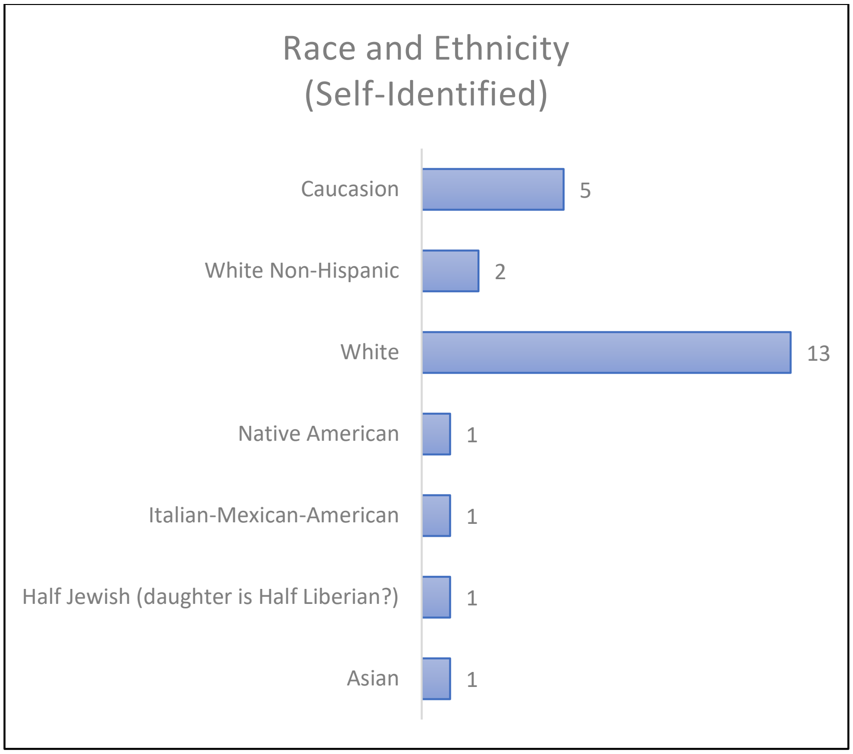

Figure 3: Mother's Self-Identified Race and Ethnicity

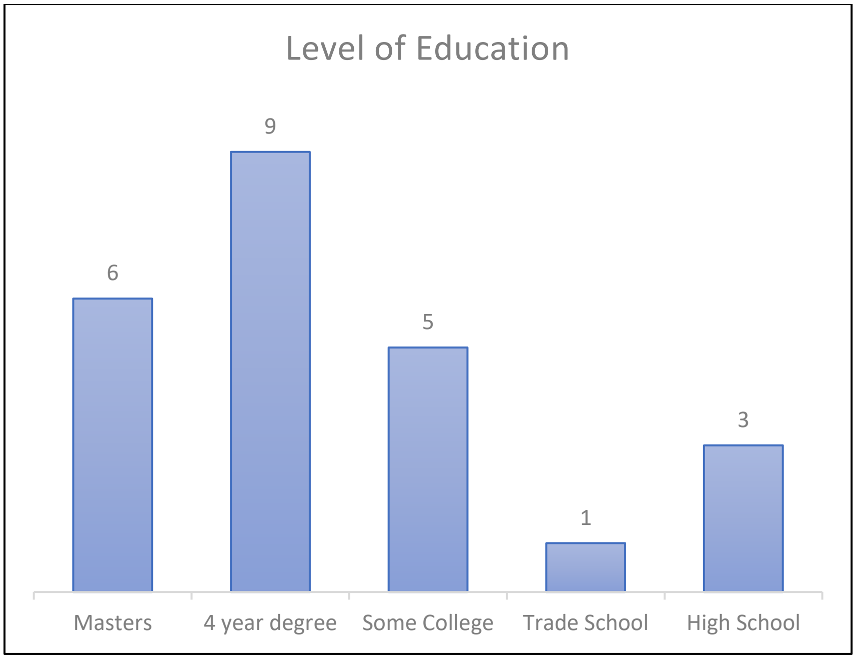

Figure 4: Mother's Level of Education

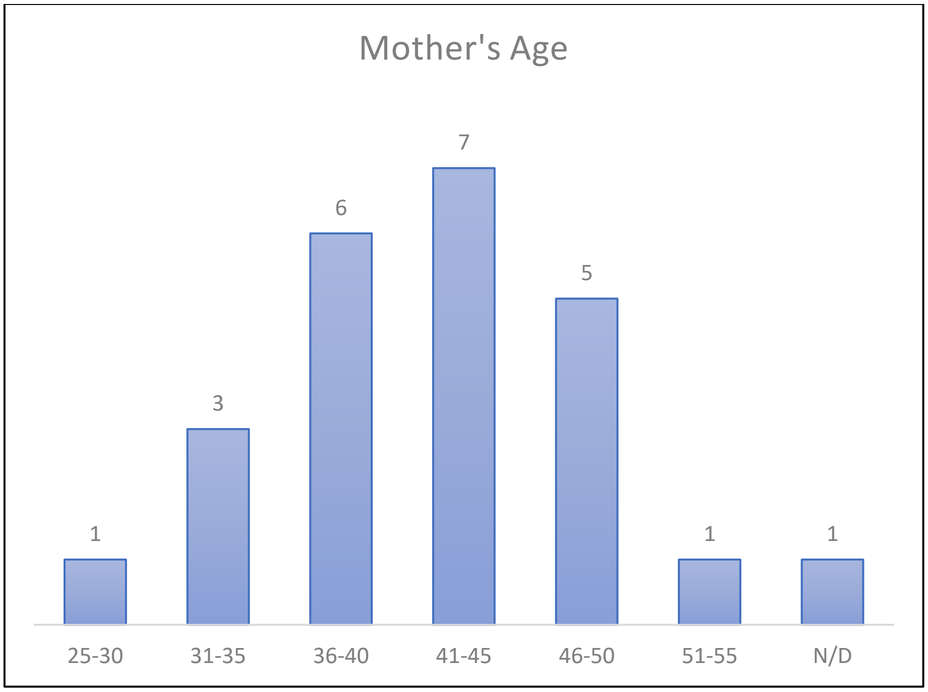

Figure 5: Mother’s Age—Grouped

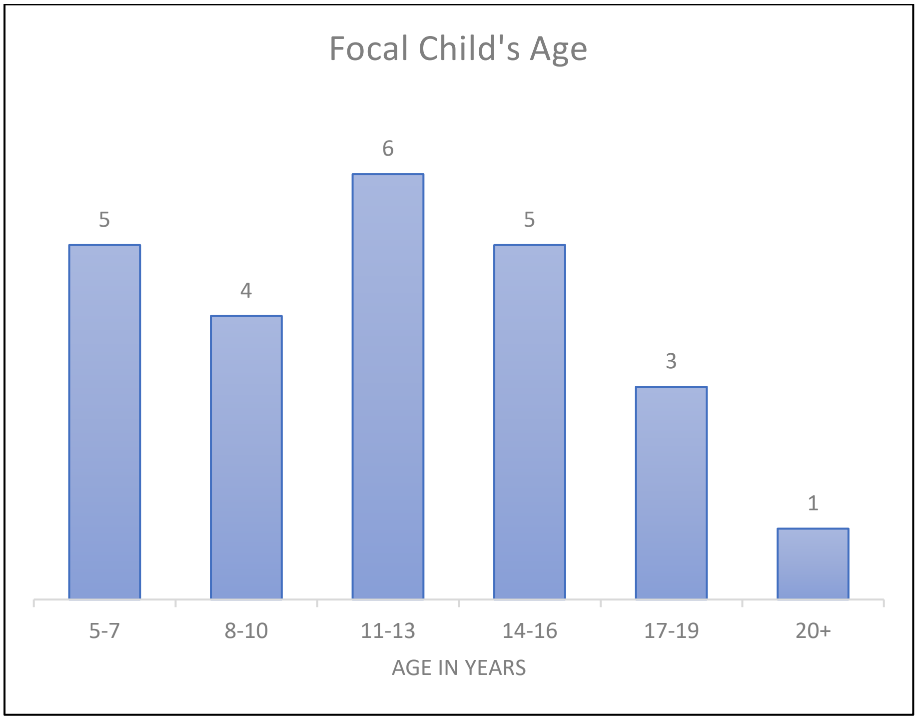

Figure 6: Focal Child’s Age—Grouped

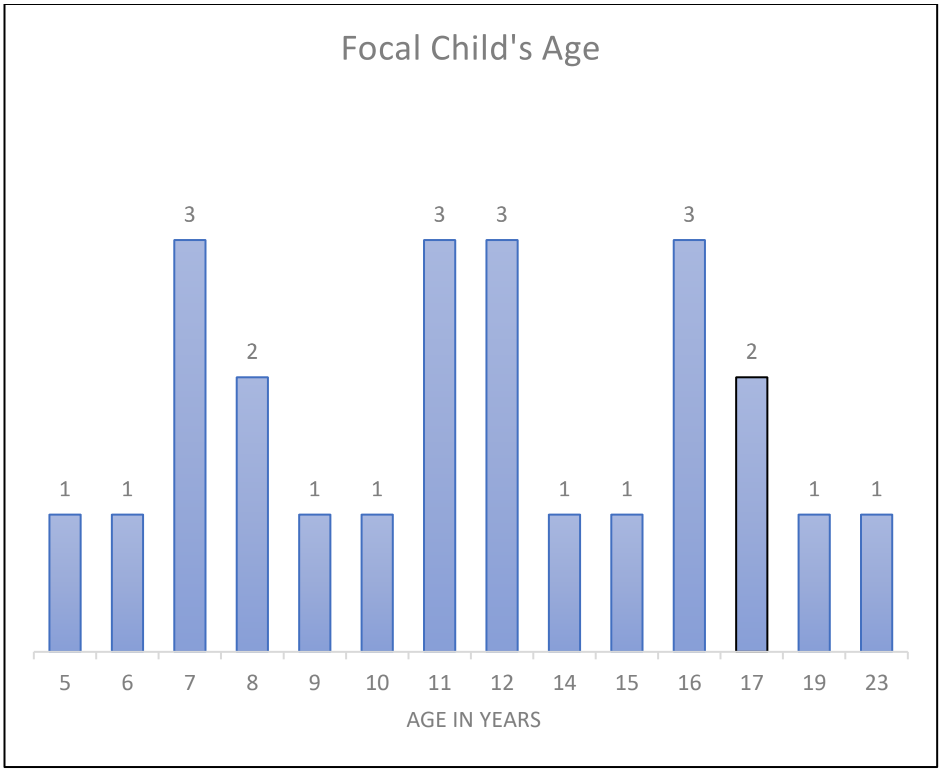

Figure 7: Focal Child's Age—Ungrouped

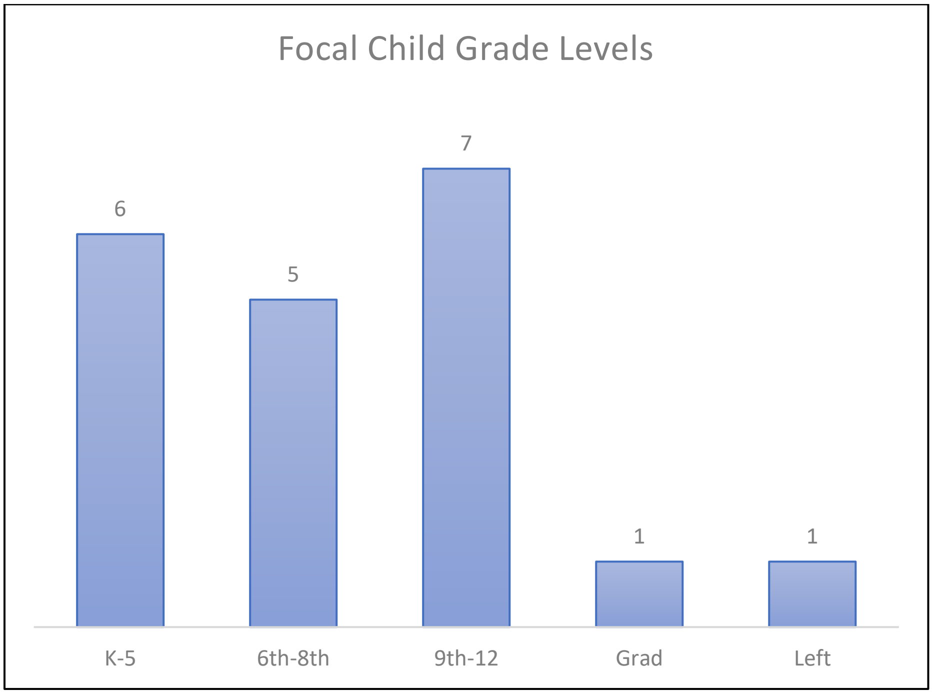

Figure 8: Focal Child's Current Grade Level—Grouped

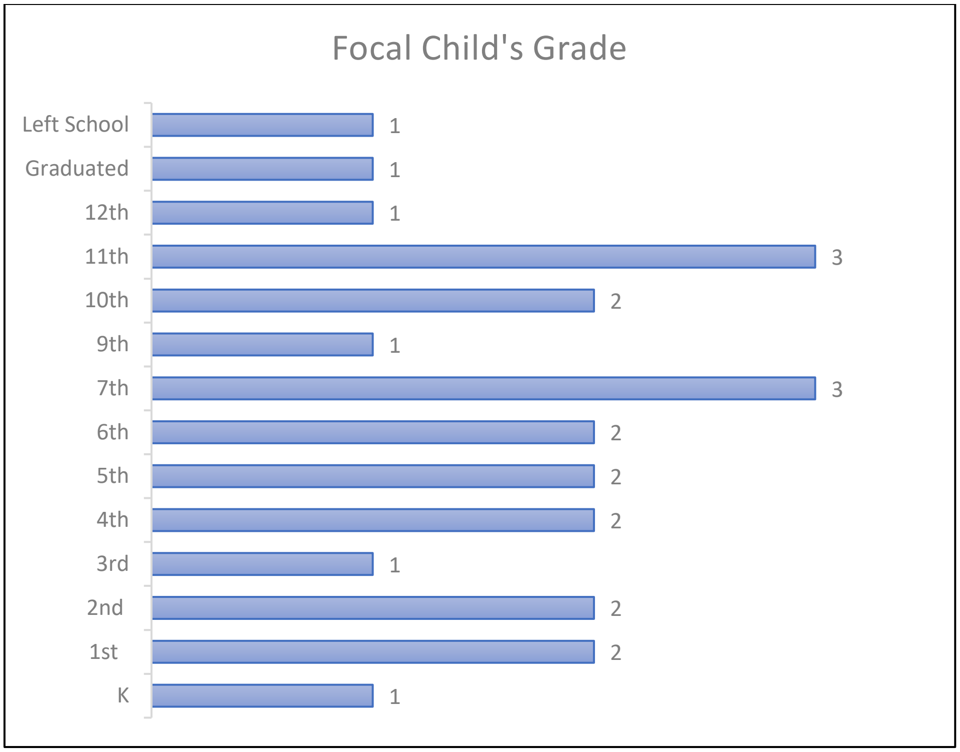

Figure 9: Focal Child’s Current Grade Level—Ungrouped

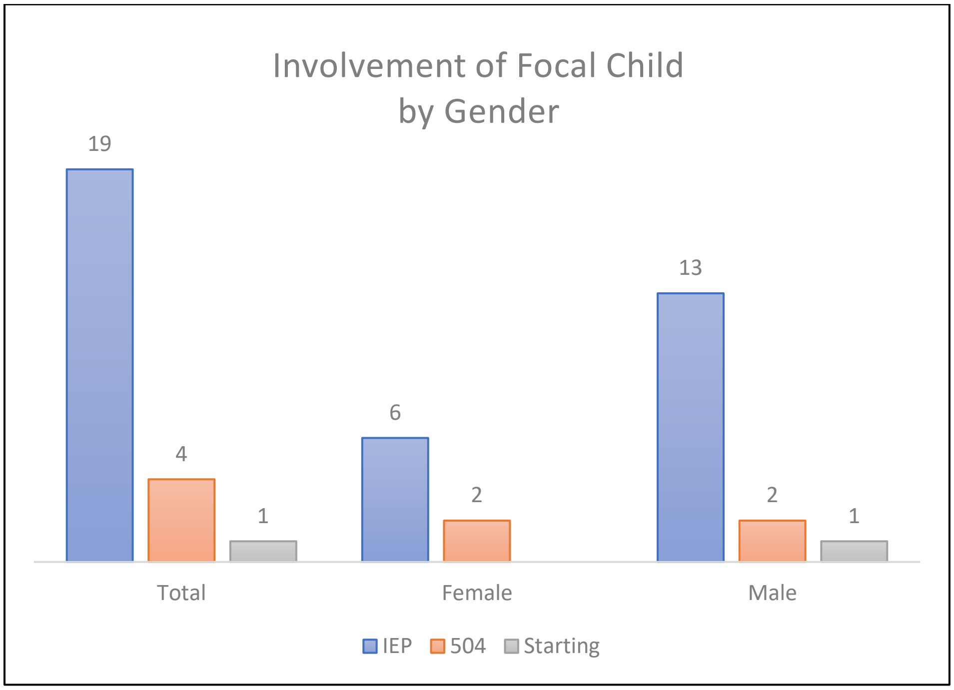

Figure 10: Focal Child Involvement by Gender

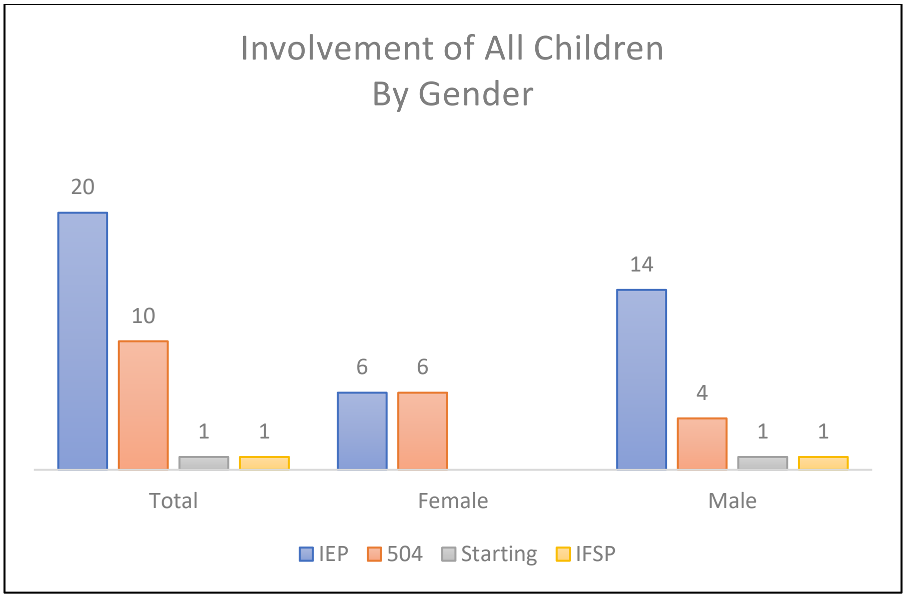

Figure 11: All Children’s Involvement by Gender

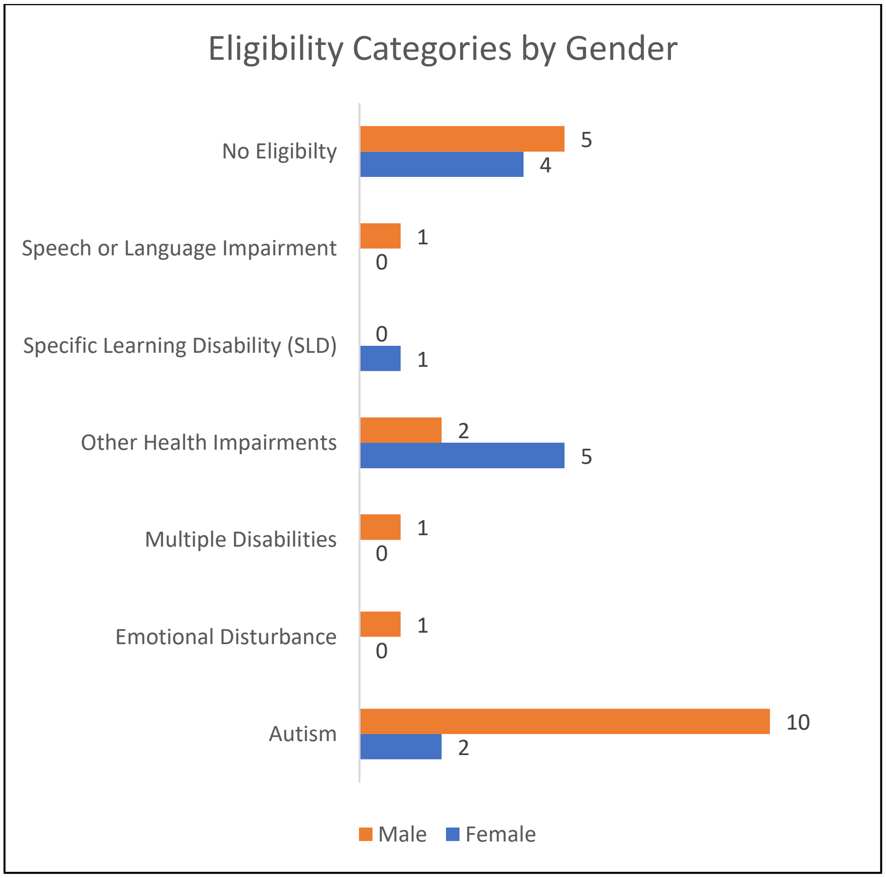

Figure 12: Eligibility Categories Represented by Gender

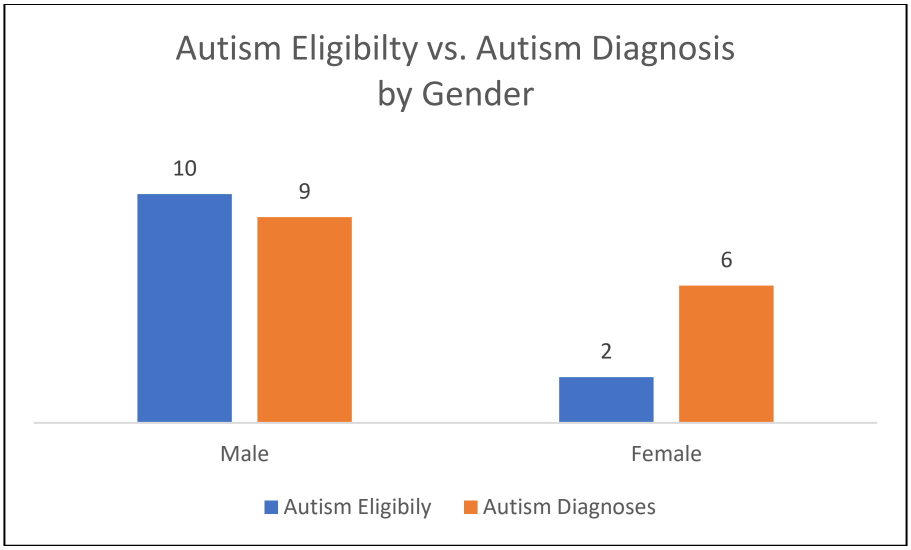

Figure 13: Autism Eligibility and Diagnoses by Gender

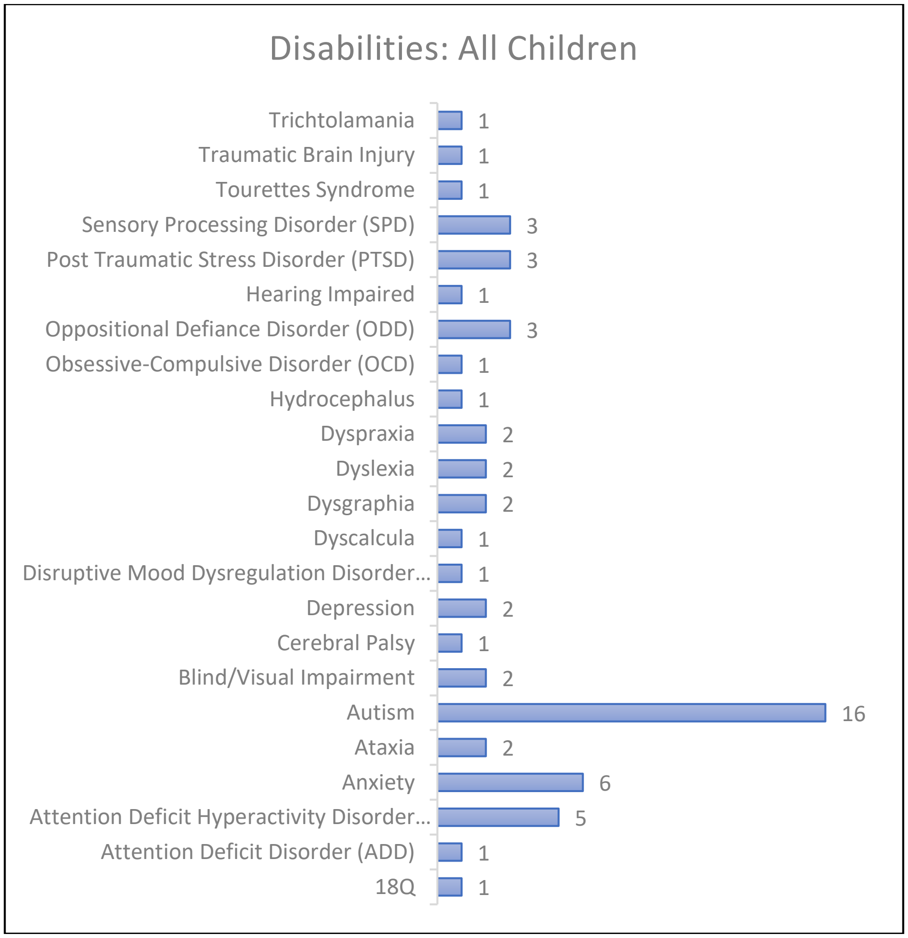

Figure 14: All Disabilities Represented

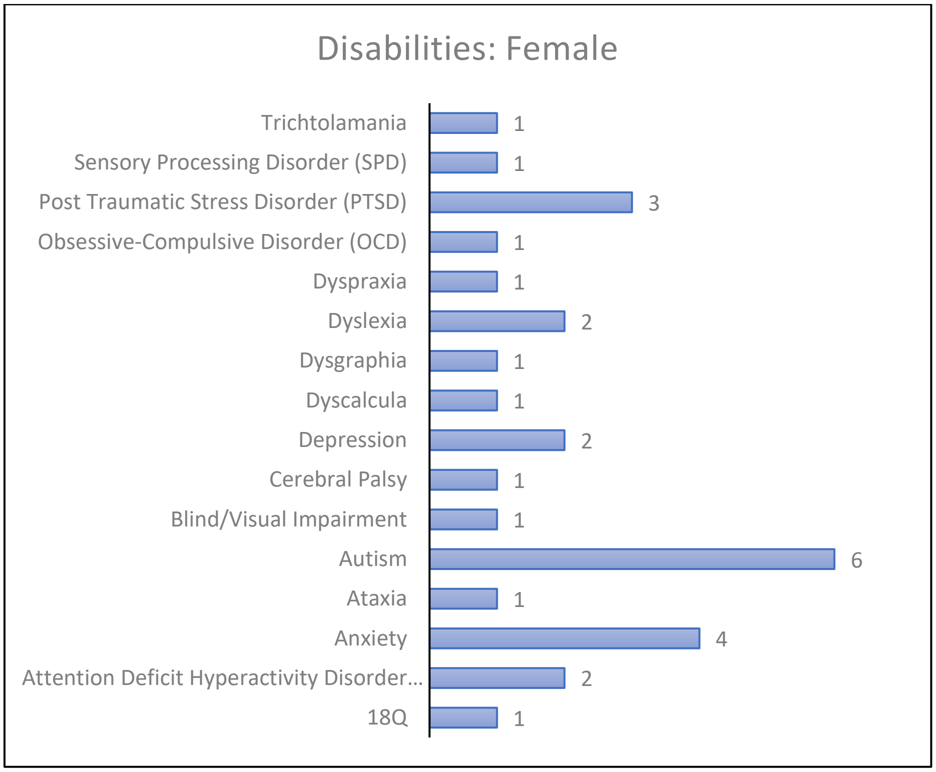

Figure 15: Disabilities Represented by Gender—Female

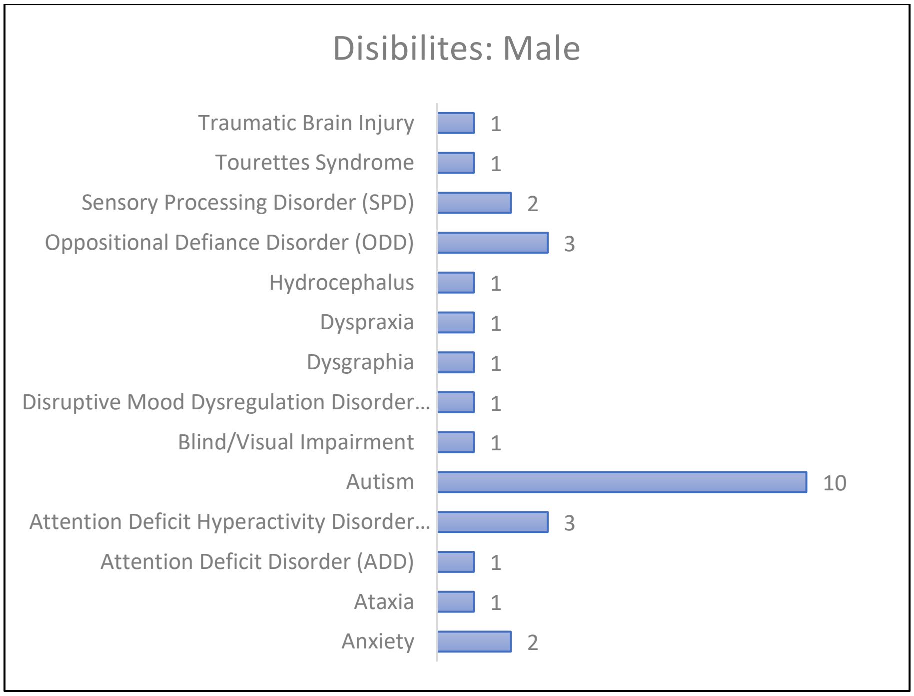

Figure 16: Disabilities Represented by Gender—Male

Figure 17 Word Cloud—All Negative Words Chosen

Dark bold words indicate word was repeated four times. The second to largest font indicates word was repeated twice. Some mothers expanded on their original descriptive words

Figure 18: Word Cloud—All Positive and Neutral Words Chosen

Bold indicates words repeated twice. Some mothers expanded on their original descriptive words

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