

Squeaky Wheels, Mothers from Hell, and CEOs of the IEP: Parents, Privilege, and the “Fight” for Inclusive Education

Priya Lalvani and Chris Hale

Montclair State University and College of Staten Island

Abstract

In this analytical essay, we examine parents’ engagement in advocacy for inclusive education as a site wherein the constructed meanings of disability and parenting a child with a disability are mutually negotiated within ableist discourses and practices in schools. Through a review of literature on parents’ historical role in special education as well as current literature on their perceptions of a continuing “struggle” to access inclusive learning environments for their children, we explore *why* parents continue to believe that they need to “fight” for inclusive education and we raise concerns about *which* parents would be most equipped to take on this “fight.” Highlighting the extent to which some parents of children with disabilities draw on their cultural and economic capital to negotiate their children’s educational rights, we problematize a special education system in which access to inclusive education for students with disabilities is linked with socioeconomic privilege.

Priya Lalvani is an Assistant Professor at Montclair State University within the Department of Early Childhood, Elementary, and Literacy Education. She has former work on the role of inclusive education and disability oppression.

Chris Hale is an Assistant Professor at College of Staten Island within Educational Studies who has spent much of his career as a literacy specialist working with students with learning disabilities.

A growing body of literature documents that decisions pertaining to the placement of children with disabilities in inclusive learning environments are often parent driven (e.g., Wang, Mannan, Poston, Turnbull, & Summers, 2004). Inclusive education, as it pertains to students with disabilities, refers to the practice of educating students with disabilities in general education classrooms with the provision of supports and supplementary services. There exists a body of research that highlights numerous benefits of inclusive education and indicates that the academic and social outcomes for students with disabilities who are educated in general education classrooms are better than for comparable students educated in non-inclusive classrooms (Cole, Waldron, & Majd, 2004; Downing, Spencer, & Cavallaro, 2004; Fisher & Meyer, 2002; Freeman & Alkin, 2000). Despite this, large numbers of students with disabilities in the United States continue to be educated in segregated or “self-contained” environments — i.e., classrooms or schools designated specifically for students with disabilities. Nationally, only 33% of all preschool children with disabilities and approximately 52% of all students with disabilities between ages 6 and 21 are educated predominantly (at least 80% of the school day) in general education classrooms (U.S. Department of Education, 2009).

In this analytical essay we examine parent advocacy for inclusive education in the contexts of dominant educational discourses and practices that continue to marginalize students with disabilities. Additionally, we explicate the ways in which the constructed meanings of disability, and of parenting a child with a disability, are negotiated through parents’

engagement in advocacy for a fair and equitable education for their children. The analysis we present is based on a stance that exploring the ways in which parents position themselves and become positioned as they navigate the special education system can provide insight into the fundamental inequities inherent in expectations of parental involvement in special education.

Since we aim to unravel the multiple contexts in which the education of students with disabilities is situated, we begin by locating ourselves and our own multiple roles and stakes in the politics of inclusive education. In addition to being scholars and teacher educators (one White and one South-Asian) whose work is invested in disability rights and advocacy on a broad level, we are also parents who relate to the experience of advocating for the support needs of their own children in schools.

I, Priya, have a child with a diagnosis of Trisomy 21 and have for many years collaborated with professionals at schools to craft a meaningful individualized educational program for my daughter in an inclusive environment. In order to make this happen, my husband and I have relied on the social and cultural capital available to us to effectively advocate for the education we envision for our daughter, to occasionally question or resist professionals’ recommendations for resource room programs or self-contained classrooms, to be highly involved in the IEP (Individualized Education Program) planning, and to work closely with professionals to support our daughter’s academic and social-emotional development.

I, Chris, have been engaged in advocating for my daughter at multiple

points in her school career. Several years ago, she was diagnosed with a mysterious autoimmune disease, which left her so fatigued and ill that we were forced to take her out of school for much of a semester. A few years later, she was diagnosed with type I diabetes. On a continuing basis, my wife and I have advocated for her. I have been required to apply my knowledge and experience as a teacher and a teacher educator, and we routinely tap our middle-class cultural capital in negotiating bureaucratic obstacles, dealing with resistant teachers and administrators, and cultivating helpful and compassionate ones. We sought and acquired protections under Section 504, and to this day we are regularly forced to invoke the statute to protect our daughter's rights.

Indeed, both of us represent parents who have benefitted from *dual privilege*; not only are we socioeconomically advantaged members of the middle class, but we also happen to be university professors with expertise in issues related to inclusive education. It may be fair to say that the latter is surely not an advantage shared by most parents who have children with disabilities. Drawing from critical theoretical frameworks and explicitly positioning ourselves and our own privilege in this discussion, in this essay we explore parents' engagement in the acts of advocacy for inclusive education, based on a stance that examining *which* parents advocate for inclusive education, *how* they do so, and *why*, has the potential to inform the ongoing discussion on the education of children with disabilities in sociopolitical contexts. Although some scholars have drawn critical attention to the cultural, ethnic, and socioeconomic background of parents as impacting the ways in which they participate in their children's education (Harry, 2008; Kalyanpur, Harry, & Skrtic, 2000), there is

little understanding that parents' navigations of the special education system are not only situated in power and privilege, but are also a site for the negotiating of identities, the reproduction of social class privilege, and the construction of the meaning of disability in an ableist society.

Parents and the Historical Struggle for Educational Rights of Children with Disabilities

Parent involvement in the education of children with disabilities is not a new phenomenon, rather, it is rooted in a tradition of activism and advocacy. Families were at the forefront and played a critical role in the historical struggle for access to the educational rights and resources of this group of children. Prior to the 1960s, educational services for children with disabilities were inadequate or nonexistent; in effect, the right to a public education was denied to this group. In the first half of the twentieth century, families had already begun to organize at the local level in efforts to gain access to educational services for their children with disabilities in schools or to provide the educational services themselves by establishing classes in their homes, community buildings, and the basements of churches (Turnbull & Turnbull, 1996). It was during the 1960s and 1970s, however, that these parents, working with other advocacy groups and taking their inspiration from the civil rights movement, spearheaded a new social movement. They formed grassroots organizations with the goal of establishing access to a public education for all children with disabilities (Turnbull & Turnbull, 1996; Winzer, 2009). Their efforts gained momentum and the impact cannot be overestimated: Parents united at the state and national levels, pressuring schools to change their practices, advocating for policy change, campaigning

to eliminate discriminatory laws, fighting for the right to be informed and to have a say in the treatment and education of children with disabilities, and often assisting in the writing of the legislation itself (Ong-Dean, 2009; Winzer 2009).

Their collective efforts culminated in an appeal to Congress and ultimately the passing of federal legislation, PL 94-142, which granted access to a public education previously denied to generations of children with disabilities and simultaneously granted their parents the right to “due process”—i.e., the system of checks and balances built into the laws that ensures fairness and accountability in the provision of special education. The landmark federal legislation, which today goes by the name of the Individuals with Disabilities Education Act (IDEA, 2004), and which governs the ways in which special education is delivered by states for all students with disabilities aged 3 to 21 in the United States, was thus in large part the outcome of a series of efforts by groups of advocates—not the least among them, parents of children with disabilities (Valle, 2011). As such, in the historical struggle for educational rights for children with disabilities, family advocacy has long provided the impetus and served as a driving force (Gallagher, 1984; Winzer, 2009), and the rest is history—and, as Valle (2011) states, “what a tangled history it is” (p. 183).

Still “Fighting” the System: How Far Have We Come in Four Decades?

Today, the importance and value of professional-family partnership in the education of students with disabilities is enshrined in educational law. IDEA grants parents the right to be involved in all aspects of special education planning and decision making and requires that schools make every effort to maintain a collaborative

relationship with them. Despite the existence of these laws and educational discourses focused on “equal partnerships,” the literature on parents’ experiences with the special education system tells a different story; a body of research underscores the tensions between professionals and parents, and reveals many parents’ perceptions of uncertainty, disenfranchisement, confusion, or frustration as a result of navigating the system (e.g., Sauer, 2007; Soodak & Erwin, 2000; Wang et al., 2004). Some parents’ narratives indicate that they believe they are merely “tolerated” rather than viewed by professionals as partners in the decision-making process (e.g., Erwin & Soodak, 1995; Fish, 2006; 2008). They also reveal the extent to which many feel alienated from the system, hold beliefs that they are in adversarial relationships with professionals, or find that their vision for the education of their children is at odds with the opinions of professionals (Erwin & Soodak, 1995; Lalvani, 2012; Wang et al., 2004). Additionally, studies that explored the experiences of culturally diverse and low-income families suggest that expectations of collaboration may be inconsistent with, or collide with, the cultural belief systems of some families (Harry, 2008; Kalyanpur & Harry, 1999; Kalyanpur, Harry, & Skrtic, 2000) and that the establishment of mutual respect, trust, and understanding between these parents and professionals remains an elusive goal (e.g., Cho & Ganotti, 2005).

Conflicts between parents and professionals arise around a host of issues concerning assessment, labeling, and the provision of services. However, few issues are as conflict-laden as those concerning educational placement, particularly when it involves parents’ vision that their children with disabilities be educated inclusively (e.g., Erwin, Soodak, Winton, & Turnbull, 2001; Sauer, 2007; Soodak & Erwin, 2000;

Wang et al., 2004). It is important to acknowledge here that not all parents are in favor of inclusive education as an educational option for their children; some view it as associated with social isolation and the possibility of peer rejection for children with disabilities, or have concerns that in general education classrooms teachers may be unwilling or unprepared to teach their children (Leyser & Kirk, 2004; Palmer, Fuller, Arora, & Nelson, 2001; Ryndak, Storch, & Hoppey, 2008). Among this group of parents, some view self-contained classrooms as “safe havens” where their children with disabilities are more likely to be welcomed by teachers and accepted by peers, and where they would have access to trained professionals and resources (Connor & Ferri, 2007; Lalvani, 2013a).

Another group of parents who resist the placement of their children in self-contained learning environments go to great lengths to gain access to inclusive learning environments for their children (Lalvani, 2012; Sauer & Albanesi, 2013; Soodak & Erwin, 2000). Studies on the experiences of this group of (mostly White) parents shed light on their perceptions that their vision for their children to be educated inclusively was met with institutional barriers, that professionals “steered” them toward choosing self-contained education for their children, or that they had to “fight” for inclusive education. In the context of dominant institutional discourses and practices that sanction segregated education for many students with disabilities, the parents in the aforementioned studies who sought inclusive education were placed in the difficult position of having to challenge professionals’ judgments and recommendations. Indeed, it was only through their resistance to professionals’ recommendations that they were able to

secure inclusive placement for their children. This is alarming because one might imagine that existing educational laws would have reduced the need for parents to advocate, and yet here we are, four decades later, with an understanding among parents that without their constant advocacy and vigilance, their children would *not* be educated inclusively. With regard to parents’ role in advocating for educational equity for children with disabilities, it appears that not much has changed in the past four decades.

The findings of these studies highlight the extent to which the practice of inclusive education is influenced by parent advocacy, and by extension, is embedded in middle-class privilege. The parents in these aforementioned studies relied on the cultural and economic capital available to them to become engaged in seeking information about inclusion, becoming educated about educational laws, and learning how to use the resources available to become effective advocates. Some went to litigation to force a school into compliance, or hired experts to advocate on their behalf, but more commonly, cultural capital manifested in parents “shopping” for diagnoses, requesting that certain labels *not* be used on their children’s documents, attending conferences on inclusion, networking with parent organizations, and so on (Fish, 2006; 2008; Sauer & Albanesi, 2013). Lalvani (2012) reveals that many middle-class parents accessed the resources needed to advocate for specific individualized services for their own children and that low-income families did not do so to the same extent. This raises concerns about the ways in which expectations of parental involvement contribute to discrepant outcomes among students from varying cultural, ethnic, and socioeconomic backgrounds.

We do not mean to dichotomize parents by implying that those who do not have cultural and economic capital do *not* advocate for their children's educational needs; indeed, the work of many scholars have focused on the experiences of low-income or minority parents who navigate the special education system and advocate on behalf of their children (e.g., Harry, 1992; 2008). However, we aim to problematize the ways in which the cultural and economic capital available to families aids them in their advocacy efforts and, more importantly, to draw attention to the ways in which this may contribute to discrepant outcomes for students with disabilities among these groups, as evidenced by the disproportionate placement of those from minority and lower socioeconomic backgrounds in self-contained environments (see, Fierros & Conroy, 2002).

Critical Theoretical Frameworks for Examining Parent Advocacy

Positioning Theory

In examining parents' participation in the special education system, positioning theory can be informative. Consistent with the idea that individual meaning-making emerges through discursive process (Foucault, 1965), *positioning* is a term understood as the ways in which individuals locate themselves and others in "jointly produced storylines" (Davies & Harré, 1999, p. 37). Positioning theory explicates the ways in which psychological and social realities are constructed and sustained: In discourse and activity, individuals "position" others and themselves, attribute characteristics to individuals or groups, and in doing so, collectively negotiate and uphold particular interpretations of the world (Harré & Moghaddam, 2003). Positioning theory is grounded in

sociocultural theory (Vygotsky, 1978), which posits that all human consciousness emerges from interpersonal and culturally situated activities; individual meaning-making cannot be separated from the social and cultural processes from which they derive (Wertsch & Tulviste, 1994). Thus, parents' engagement in negotiating inclusive learning environments for their children with disabilities is understood as embedded in historically and sociopolitically situated contexts. Through this lens we examine the ways in which parents position themselves, and in turn become positioned, in institutional discourses, and the ways in which constructed meanings of disability and institutional beliefs about the education of children with disabilities are enacted, upheld, or resisted.

Critical Disability Studies

Critical disability studies offer a sociopolitical orientation to disability, positing that the lived experience of disability is situated in the meanings that societies ascribe to human differences (Davis, 2002; Linton, 1998). Within this conceptual framework, disability is distinguished from impairment: Whereas impairment is understood as functional limitation, disability is characterized by the denial of life opportunities and experiences as a result of inaccessible contexts and ableist beliefs (Baglieri & Shapiro, 2012; Linton, 1998). The term *ableism* refers to negative or discriminatory attitudes towards people with disabilities (Hehir, 2002; Smith 2010), or a devaluing of people with disabilities in society based on "beliefs that some ways of being are superior to others" (Baglieri & Shapiro, 2012, pg. 222). The unpacking of ableist assumptions about disability is a central focus of disability studies.

Disability studies in education (DSE) scholarship are focused on illuminating fundamental inequalities for students with disabilities and on dominant practices in schools that lend support to the persistent practice of ability-based segregation of this group of students. DSE scholars view inclusive education as an issue related to educational equity and social justice, and argue that the practice of educating children with disabilities in separate learning environments is oppressive and fundamentally inconsistent with any agenda for education in a democracy (Beratan, 2006; Oliver, 1996; Slee, 1996). Using this framework, the experiences of the parents who negotiate access to inclusive learning environments can be understood as situated in institutionalized ableism and enacted within the constraints of power differentials in society.

The “Battle” For Inclusion as Site of Constructed Meanings and Negotiated Identities

Although there is a wealth of literature on parents’ experiences of negotiating access to inclusive education, there is little on the ways in which parents become positioned, and in turn position themselves, in relation to ableist discourses and practices in schools. Goodley (2007) highlights the importance of attending to the resistance of parents and exploring the constructed meanings that they bring to their experiences. Consistent with this notion, in this section we explore parents’ multiple interpretations of their experiences with professionals in schools, and elucidate the ways in which discursive practices are sites for meaning-making and the construction of identity among parents who advocate for their children’s educational rights. To this end, we explore a variety of themes found in parents’ counternarratives through a review

of existing literature. Taking heed of Goodley (2007), who cautioned against creating simplistic, mutually exclusive categories of parental responses, we would like to emphasize here that although we present our analysis through thematic categories of interpretations found in existing literature, we understand the roles and identities of parents to be fluid, overlapping, and contextualized.

Squeaky Wheels: Counternarratives of Resistance to Otherness

The narratives of parents of children with disabilities suggest that their support and advocacy for inclusive education is often embedded in their understanding of the social implications of being in particular environments and the cultural meanings ascribed to disability and normalcy (Lalvani, 2013a). Many parents’ opposition to the placement of their children with disabilities in segregated learning environments is underpinned by their broader resistance to institutional discourses and practices that position children with disabilities and their families as *other* (Goddard, Lehr, & Lapadat, 2000; Green, 2003; Lalvani, 2011). These parents hold beliefs that their children would be stigmatized by virtue of association with segregated educational environments. Thus, the practice of ability-based segregation of children with disabilities is interpreted by these parents as a tool for *othering*; self-contained classrooms are understood as spaces that mark the children in them as different and thus construct negative meanings of disability. Consistent with Brantlinger’s (2009) assertions that negative identities as a result of being stigmatized are imposed upon, and in turn resisted by individuals, these parents’ resistance to stigma and marginalization is enacted through their counternarratives in which they position

their children as more similar to, than different from, children without disabilities (Lalvani, 2008; 2011) and through their advocacy for inclusive education.

When discussing their navigation of access to inclusive learning environments for their children, many parents who seek access to inclusive education perceive themselves as “squeaky wheels”; they believe that if it were not for their frequently raising concerns and questioning professionals (squeaking), their children would *not* be educated inclusively (Lalvani, 2012). Although they characterize their relationships with professionals as *not* adversarial or contentious, they understand their role in their children’s education to be one of constant *vigilance*. These parents hold that it is important to maintain harmony and cordial working relationships with professionals (Soodak & Erwin, 2000), however, they also perceive that they must continually be involved, find ways to gently (and sometime not so gently) raise their concerns, and sometimes question professionals’ opinions and recommendations. Many report that taking on this role leaves them feeling “overwhelmed,” “exhausted,” or emotionally “drained” and believe that the “struggle” for inclusive education negatively impacts their entire family (Erwin et al., 2001; Soodak & Erwin, 2000). Yet they consider their engagement in advocacy to be a necessity or moral obligation. Additionally, cultural factors will undoubtedly add to the stress related to being a “squeaky wheel” because the idea of being assertive or questioning professionals’ opinions may be inconsistent with some families’ cultural expectations of their relationship with professionals and will thus leave them feeling further alienated from the system (e.g., Cho & Ganotti, 2005).

“Fighting the Fight”: Self as Engaged in Battle

In the accounts of parents who advocate for inclusive education, it is not uncommon to hear parents’ references to a “fight” (Lalvani, 2012) or to their “struggles” to access their children’s educational rights (Soodak & Erwin, 2000). In discussing their negotiations with educational professionals over issues of inclusion, parents often use combat-related metaphors, e.g., they view themselves as engaged in “battle,” “being armed,” having “ammunition,” or “pulling out the guns” (e.g., Wang et al., 2004); this group of parents come to understand themselves not as partners, but as adversaries who are actively avoided or disliked by school professionals. For instance, Lalvani (2012) quotes a mother who, in discussing her relationship with professionals at her child’s school, states: “They hate me. They totally hate me.”

It is worth noting that in the narratives of teachers (Lalvani, 2015) and of parents, it is the parents who are positioned as “fighting”; as such, educators and institutional practices become positioned as occupying the defensive role. This is remarkable in light of the vision of IDEA for equal partnerships and raises confounding questions about *why* parents would need to “fight” when, in fact, education in the general education classroom for students with disabilities is the default option as mandated by IDEA (Hale, 2013). Moreover, if a “battle” is required, one can expect that it will involve a considerable amount of economic and social resources; indeed, parents often utilize personal economic resources to engage in educating themselves about educational laws, or to pay for advocates or legal counsel (Sauer & Albanesi, 2013), and this raises questions

about the privilege upon which parents rely to access their children's educational rights.

“In Denial”: Master Narratives That Pathologize Parents

In dominant cultural narratives on parents of children with disabilities, a pervasive theme exists that centers around the notion that some parents may, at least for a period of time, be *in denial*—i.e., be unable or unwilling to “accept” their children's disabilities. In special education discourses, it is not uncommon for parents to be positioned as being *in denial*, particularly when they are in disagreement with the opinions of professionals (Gallagher, Fialka, Rhodes, & Arceneaux, 2001). Also in literature on professional-family partnerships in special education an unchallenged assumption exists that some parents' actions and reactions with regard to their children's education can be attributed to their unwillingness or inability to accept their differences or to recognize the extent of their challenges (e.g., Blacher & Hatton, 2007; Bove, 2007). In the context of cultural master narratives that position parents' behaviors as pathological, it is not difficult to imagine that parents who resist professionals' recommendations for self-contained placement and advocate strongly for access to inclusive learning environments for their children might sometimes be viewed as being *in denial* by educators; indeed, (Lalvani, 2015) found that some teachers believed that often parents' advocacy for inclusive education stemmed from “unrealistic expectations” founded in their denial of the extent of their children's disabilities.

To date little research explores the interpretations and meanings that parents themselves bring to cultural master narratives on parental denial; however,

explorations of this topic with parents may add much to the conversation. In a recent study (Lalvani, 2015) parents demonstrated an awareness of institutional discourses that framed parents as being *in denial*; a few ironically expressed that they would not be surprised if some of their own actions might be misinterpreted as denial by school professionals. These parents, all of whom had resisted professionals' recommendations for the placement of their children in self-contained classrooms, counterpositioned themselves in relation to dominant discourses and offered alternative interpretations for their own actions, which they believed might be viewed by professionals as indications of their being *in denial* of the extent of their children's educational challenges and needs for support. For instance, some parents interpreted their actions as motivated by a desire to avoid stigma for their children, others reframed denial as “hope.” One mother stated that she is in a “healthy denial,” which she explained as her deliberately maintaining beliefs in positive outcomes for her child and holding high expectations. All of these parents in this study had advocated for inclusive education for their children despite professionals' recommendations for self-contained placement. Their interpretations are informative in understanding the ways in which identities are imposed and resisted, and the ways in which institutional discourses become sites for reifying or resisting unchallenged assumptions about the education of children with disabilities.

“Mothers from Hell:” Counternarratives of Activism

Panitch (2008) notes that parents of children with disabilities, and mothers in particular, have always been at the forefront of disability activism. Historically, small

groups of women resisted pressure to institutionalize their children, and new sites of activism emerged in the homes, in the kitchens of these women. As noted earlier in this paper, parents became engaged in grassroots organizations, protested at their schools, and lobbied for change in legislation; thus, parent activism played a critical role in shaping policies and practices pertaining to people with disabilities (Turnbull & Turnbull, 1996).

A number of studies indicate that some parents who advocate for inclusive education come to view themselves as the “mother from hell” (Lalvani, 2012)—which they understand as a force of change or as someone with whom the special education system must contend despite their unwillingness to do so. Many among this group become engaged in activities aimed at broader educational and social change, taking the initiative to educate other parents about the rights of their children with disabilities, establishing local support groups, or becoming involved in efforts aimed at policy change at statewide or national level (Wickham-Searle, 1992). For example, a group of parents who created a website ironically named “Mothers from Hell,” which is aimed at providing information and resources to help all parents understand and advocate for their children’s rights in special education, describe themselves as “a grass roots parent advocacy group fighting for the appropriate education, community acceptance, desperately needed services, rights of and entitlements for people with disabilities...” The group’s stated mission is advocating for disability rights, and they articulate a vision for each individual with a disability to receive the services and inclusion to which they are entitled. As a disclaimer about the name of their website, they explain that: “Our name is not about our advocacy philosophy, but a

name bestowed on us for daring to stand up for our kids.” The use of the title “mothers from hell” by some parents is informative; not only does it shed light on the ways in which parents become malignantly positioned (Parrott, 2003) in dominant institutional discourses, but it also reveals parents’ resistance and counterpositioning of their own identities. Additionally, it is worth noting that the malignant positioning of these otherwise privileged parents may also be understood as highly gendered—that is, it is hard to imagine that *fathers* who advocate fiercely for their children would be labeled “fathers from hell” instead of “powerful, strong advocates.” It is indeed remarkable that these women claimed the negative descriptor, empowering themselves in their mission and simultaneously drawing attention to oppressive discourses on families (and particularly mothers) who challenge institutional practices.

The actions of these and other parents who organize to effect changes are often rooted in their understanding of disability oppression and of the ways in which individuals with disabilities are marginalized (Panitch, 2008). These parents are inclined to frame inclusive education as a civil rights issue; they view their advocacy for inclusive education less as an educational programming concern and more as a broader issue of social justice. They situate all educational practices in the context of equitable access to society’s resources, thus positioning inclusive education as a fundamentally democratic practice (Lalvani, 2013b). This explicates the ways in which parents who engage in negotiating for equitable education for their own children within the contexts of an ableist society and a medical model-based education system gain a heightened understanding of disability oppression; activities related to negotiating access to

inclusive learning environments for their children become sites for the construction of their own identities as activists.

“CEOs of the IEP”: Parents’ Perceptions of Driving Inclusive Education

Some parents’ narratives reveal their perceptions that they *lead* the process of educational planning for their children with disabilities or that the decision to place their children in inclusive learning environments was driven by themselves; they express that they are no longer invested in “equal partnerships” because, by their accounts, they have become disillusioned of this notion or have become mistrustful of the special education system in general (Erwin et al., 2001). These parents, who are generally White and middle class, express high levels of agency, i.e., they perceive that *they* make things happen and that their advocacy is critical in decisions pertaining to inclusive education for their children. For instance, as this mother stated: “I am the CEO of Max’s IEP.... I am the single most important person at that meeting. Bar none.” (Lalvani, 2012).

However, being the “CEO of the IEP” involves a significant toll on these parents who expend considerable time, energy, and economic resources in the process. Additionally, high levels of advocacy cause emotional distress and anxiety, which is detrimental for family functioning (Nachshen, 2000). Some parents discuss the stress involved in their self-appointed role of overseeing their children’s services; yet they do not perceive this to be a choice; they believe that their unrelenting oversight is critical to their children receiving an equitable education in an inclusive environment.

The Problem with Advocacy: Institutionalized Resistance, and Structural Inequities

Why Must They Still Fight? Advocacy as Situated in Institutionalized Ableism

The parents discussed above are clearly well resourced with high levels of cultural and social capital. They have succeeded in becoming dominant forces in the education of their children. They control (CEOs) and they demand their children’s rights (mothers from hell) yet, they articulate a view that they must perpetually “fight” for their children’s rights. With all their privilege and abilities and their knowledge and experience, why must they perpetually fight? One answer is that professional dominance is baked into the DNA of IDEA. The law contains two opposing discursive strains. On the one hand, it is deeply informed by the discourse of constitutionally guaranteed equality, and yet, on the other, it is infused with professional and medical discourses of deficit and differentiation. The law empowers parents to advocate for equal educational rights for their children, yet it authorizes professionals to apply medicalized schema to the “diagnosis” of those children’s deficits and to the prescription of differentiated “treatment” (Fulcher, 1989). The encoding of this discursive contradiction can be traced back to the inception of IDEA. The judicial and political victories that led to the establishment of the law were in many ways subverted by institutional and professional discourses. The demands made by parents—demands that would be difficult to satisfy without radical institutional reform—were translated by expert discourses in ways that allowed the application of established educational schema and structures. Thus, the politicized demands for radical change made

by parents were depoliticized and transformed into bureaucratically administrable needs that could be satisfied by the establishment of a parallel educational system structured as a continuum of segregated settings (Skrtic & Kent, 2013).

Thus, the pacification of the parental voice and the concomitant elevation of professional authority are embedded in IDEA. DSE informed analysis of IDEA and its interpretation through subsequent court rulings has long identified a hierarchy of expertise within the law; according to which professional expertise is valued over the knowledge of children with disabilities and their parents. From a DSE perspective, this oppressive hierarchy, among others, is maintained and reinforced by institutional ableism embedded in discriminatory structures and practices of special education (Beratan, 2006). Therefore, the answer to why parents, even parents with access to extensive resources, must unrelentingly fight the system to advocate for their children's needs is that, while the law provides access to adaptive and remedial education services, signaling compliance with legal guaranties, it is structured in ways that contain difference and maintain professional authority and is entrenched in institutional discourses which sanction ability-based segregation for students with disabilities, based on ideologies of *separate but equal*.

Who's Not Fighting? Parent Advocacy as Situated in Socioeconomic Privilege

To understand why many parents are *not* CEOs of their children's educational fate and do not engage in the "battle" to access their children's rights, it is important to recognize that both sociocultural forces and structural elements of IDEA contribute to limiting the ability of many parents to

"fight" for their children's educational rights. Individualizing structures within IDEA play an important role in determining which parents fight and who is relegated to the sidelines. Specifically, this phenomenon can be traced to the structure of the law's procedural guarantees. At the passage of the PL 94-142, Congress determined that enforcement of the law would occur on a case-by-case basis by individual parents advocating for their children's needs. Accordingly, parents were granted specific and extensive procedural guarantees by which they would be empowered to participate in all decisions relative to their children's education, and schools would be answerable to the quasi-contractual individualized educational program (Ramanathan, 2008). Consequently, this emphasis on individualized empowerment has undermined the broader purpose of enacting social change and protecting the rights of an entire class of individuals. Because much of the oversight of IDEA has been initiated by and limited to responding to legal claims of individuals, systemic issues that may improve services and eliminate barriers for all children with disabilities are less likely to be addressed. Addressing the needs of the many and continuing IDEA's original civil rights mission is discouraged in favor of deciding individual cases on the basis of their technical merits and issues of procedural compliance (Ong-Dean, 2009; Palley, 2006). Not only does this reliance on individual advocacy undermine the potential for broader systemic changes, it also acts to reinforce inequities and reproduce social class hierarchies. Contesting school authorities requires levels of cultural and economic capital that are often inaccessible to lower-income parents and those from marginalized groups (Ong-Dean, 2009). Additionally, entering into confrontations or conflict with educational professionals may

be inconsistent with the cultural beliefs and values of many families, and expectations of parent participation in their children's education and of equal partnerships with professionals are based on the ideals of dominant Western culture (Kalyanpur, Harry, & Skrtic, 2000).

Lareau (2000) asserts that the school system is set up to reproduce social class inequalities; this is achieved partly through residential choices of parents and the alignment of school culture and middle-class parenting practices. Additionally, the ability of some parents to use appropriate language and effective strategies to intervene and negotiate with schools contributes to a better education for their children and is thus instrumental in replicating the social class system (Lareau, 2003). As noted above, the parents highlighted in this paper are middle-upper class and White. Importantly, the vast majority of educators are White and middle class. Lower-class parents and those of minority status experience many more obstacles to successfully navigating school bureaucracies and contending with professional authority than their more privileged and culturally attuned counterparts. Low-income parents generally have less access to supportive and informative social networks (social capital) and are less able to develop expertise in technical knowledge, such as parental rights under IDEA (cultural capital). Therefore, they are often less successful advocates than more privileged parents (Horvat, Weininger, & Lareau, 2003; Trainor, 2010). Parents of cultural and linguistic minorities often encounter cultural bias (Alvarez-McHatton, 2005) and deficit-based judgments of their parenting from professionals (Alvarez-McHatton, 2005; Klingner & Harry, 2006). They are often excluded from the special education process, because professionals fail to address procedural barriers and/or provide

needed information (Angelov & Anderson, 2012; Klingner & Harry, 2006) or translation services (Alvarez-McHatton, 2005; Klingner & Harry, 2006). On the other hand, within an institutional system that works against them, privileged parents of children with disabilities are able to utilize the cultural and economic capital available to them to access the services, accommodations, and inclusive environments that they understand to be the fundamental rights of their children.

IDEA's individualization of parent participation and procedural due process provisions has another effect besides the disempowerment of poor and minority parents. It distracts from and even contributes to the perennial problem of disproportionality (the disproportionate placement and/or segregation of children of color) in special education. According to McCall and Skrtic (2009), "the parent participation and procedural due process provisions of the IDEA both mute broader social concern for the disproportionality problem and perpetuate the racial-ethnic and social class hierarchies that sustain it" (p. 15). By individualizing parent advocacy, collective action and egalitarian and democratic motivations are discouraged, as individual parents tend to their own children's needs. And, of course, when parents are left to advocate for their children alone, children of parents with the least access to forms of capital are more vulnerable to institutional and individual biases and professional dominance (McCall & Skrtic, 2009).

This paper is not intended to be a critique on parents who advocate; indeed, we concur with Ong-Dean's (2009) assertions that within a system where parents of children with disabilities are able to influence the services their children

receive, one cannot reasonably expect that parents who are able to advocate for their children will not. Parents, by virtue of being parents, are likely to understand one of their roles as protecting and advocating for their children. Additionally, let us not lose sight of the fact that historically the advocacy of privileged parents led to sweeping policy changes that benefited large groups of children, as in the passing of PL 94-142. Therefore, we do not locate the problem within parent advocacy per se, but rather, within a fundamentally flawed education system that reproduces social class inequalities and advantages. Having said that, although we do not fault individual parents, we do hope to raise critical questions among parents about the ways in which their advocacy for individual solutions for their own children may reify inequalities in education and to encourage them to consider advocating more for systemic change, the benefits of which can be accrued by all children. Additionally, it is a call for educators to view their own role as advocates in ensuring equitable outcomes for children with disabilities, thus removing this onus from parents.

Implications for Special Education Teacher Education

How should educators address systematic parental disempowerment in special education? The centrality and universality of parent-professional conflict in special education is made explicit by the parent narratives referenced above. The system (its structures and schema) mounts unrelenting resistance to even the most able parents. Of course, less affluent and less culturally attuned parents are likely to experience total domination and disenfranchisement. It is clear that special education must be reformed so as to fulfill IDEA's promises to children with

disabilities and their parents—but special education is a hegemonic system, fortified by institutional legitimacy, legal authority, and historical inertia. Reform is a long and arduous process requiring a critical mass of stakeholders (parents and professionals) who recognize the need for reform and are motivated to advocate for it. Reform will not happen overnight, however, teacher educators can contribute to the process of building consent for the need for change by fostering awareness of the oppressive nature and unfulfilled promises of special education law. Also, through the process of developing critical, compassionate, and aware special education teachers, teacher educators can contribute to changes in special education practices today, even without systemic reform. The provision of critically aware individual teachers will contribute to cultural change within special education. Teacher educators are in a key position to affect such change. No matter the rigidity and oppressive tendencies of the system, special education is enacted case by case at the point of individual interaction. Critically aware special education teachers can become advocates for parents and mediators of the system's effects at the point of application and enactment. Critically aware teachers influence other teachers and eventually become administrators; thus the culture of special education changes (Connor, Valle, & Hale, 2012).

If teacher educators are to develop critically aware special educators prepared to enact change from within, they must develop programs with focused missions and clear theoretical/philosophical orientations (Hale, 2013). Teacher education needs to be grounded in the perspectives offered in DSE, which provide teachers with the tools required to recognize and disrupt ableist discourses and practices in schools. Courses should encourage teacher

candidates to recognize how teachers' dispositions influence their interpretation of special education laws and regulations (Pearson, 2009). It is also important for candidates to hear the actual voices of parents of children with disabilities. Ultimately, as Slee (2001) noted, if we are to create truly inclusive schools and communities, all educators must learn to identify their own roles in perpetuating the status quo and confront their complicity in systematic exclusion. Therefore, teacher

candidates must be engaged in critical reflection on their own values and beliefs and how those inform their perceptions of children with disabilities and their relationships with parents (Trainor, 2010). Through multicultural perspectives and critical pedagogies, teacher educators must engage candidates in discussions of discrimination and prejudice in family-professional relationships, and the infusion of power and status in the practice of inclusive education.

References

- Alvarez-McHatton, P. (2005) Stigma and discrimination perspectives from Mexican and Puerto Rican mothers of children with special needs. *Topics in Early Childhood Special Education* 25(3), 131–142.
- Angelov, A. D. S., & Anderson, S. L. (2012). On the outside looking in: An African American family's experience in an individualized education plan meeting. *Mid-Western Educational Researcher*, 25(3), 1–20.
- Baglieri, S., & Shapiro, A. (2012). *Disability studies and the inclusive classroom: Critical practices for creating least restrictive attitudes*. New York: Routledge.
- Beratan, G. D. (2006). Institutionalizing inequity: Ableism, racism and IDEA 2004. *Disability Studies Quarterly*, 26(2). Retrieved from <http://dsq-sds.org/article/view/682/859>
- Blacher, J., & Hatton, C. (2007). Families in context: Influences on coping and adaptation. In S. L. Odom, R. H. Horner, M. E. Snell, & J. Blacher (Eds.), *Handbook on developmental disabilities* (pp. 531–551). New York: Guilford Press.
- Bowe, F. G. (2007). *Early childhood special education: Birth to eight* (4th ed.). Clifton Park, NY: Thomson.
- Brantlinger, A. E. (2009). Impediments to social justice hierarchy, science, faith, and imposed identity (disability classification). In W. Ayers, D. Stovall, & T. Quinn (Eds.), *Handbook of social justice in education* (pp. 400–416). New York: Taylor & Francis.
- Cho, S., & Gannotti, M. E. (2005). Korean-American mothers' perception of professional support in early intervention and special education programs. *Journal of Policy and Practice in Intellectual Disabilities*, 2(1), 1–9.
- Cole, M., Waldron, N., & Majd, M. (2004). Academic progress of students across inclusive and traditional settings. *Mental Retardation*, 42(2), 136–44.
- Connor, D. J., & Ferri, B. (2007). The conflict within: Resistance to inclusion and other paradoxes in special education. *Disability and Society*, 22(1), 63–77.
- Connor, D. J., Valle, J. W., & Hale, C. (2012). Forum guest editors' introduction: Using and infusing disability studies in education: Where and how? *Review of Disability Studies: An International Journal*, 8(3), 5–13.
- Davies, B., & Harré, R. (1999). Positioning and personhood. In R. Harré & L. van Lagenhove (Eds.), *Positioning theory: Moral contexts of intentional action* (pp. 32–51). Oxford, UK: Blackwell.
- Davis, L. J. (2002). *Bending over backwards: Disability, dismodernism & other difficult positions*. New York: New York University Press.
- Downing, J. E., Spencer, S., & Cavallaro, C. (2004). The development of an inclusive charter elementary school: Lessons learned. *Research and Practice for Persons with Severe Disabilities*, 29(1), 11–24.
- Erwin, E. J., & Soodak, L. C. (1995). I never knew I could stand up to the system: Families' perspectives on pursuing inclusive education. *The Journal of the Association for Severe Handicaps*, 20, 136–146.
- Erwin, E. J., Soodak, L. C., Winton, P., & Turnbull, A. (2001). "I wish it wouldn't all depend on me": Research on families and early childhood inclusion. In M. J. Guralnick (Ed.), *Early childhood inclusion: Focus on change* (pp. 127–158). Baltimore, MD: Brookes.

- Fierros, E. G., & Conroy, J. W. (2002). Double jeopardy: An exploration of restrictiveness and race in special education. In D. J. Losen & G. Orfield (Eds.), *Racial inequity in special education* (pp. 39–70). Cambridge, MA: Harvard Education Press.
- Fish, W. W. (2006). Perceptions of parents of students with autism towards the IEP meeting: A case study of one family support group chapter. *Education*, *127*, 56–58.
- Fish, W. W. (2008). The IEP meeting: Perceptions of parents of students who receive special education services. *Preventing School Failure*, *53*, 8–14.
- Fisher, M., & Meyer, L. (2002). Development and social competence after two years for students enrolled in inclusive and self-contained educational programs. *Research and Practice for Persons with Severe Disabilities*, *27*(3), 165–74.
- Foucault, M. (1965). *Madness and civilization*. New York: Pantheon.
- Freeman, F., & Alkin, M. (2000). Academic and social attainments of children with mental retardation in general education and special education settings. *Remedial and Special Education*, *21*(1), 3–18.
- Fulcher, G. (1989). *Disabling policies? A comparative approach to education policy and disability*. London: The Falmer Press.
- Gallagher, J. J. (1984). The evolution of special education concepts. In B. Blatt & R. J. Morris (Eds.), *Perspectives in special education: Personal orientations* (pp. 210–232). Glenview, IL: Scott Foresman.
- Gallagher, P. A., Fialka, J., Rhodes, C., & Arceneaux, C. (2001). Working with families: Rethinking denial. *Young Exceptional Children*, *5*(2), 11–17.
- Goddard, J., Lehr, R., & Lapadat, J. (2000). Parents of children with disabilities: Telling a different story. *Canadian Journal of Counseling*, *34*(4), 273–289.
- Goodley, D. (2007). Becoming rhizomatic parents: Deleuze, Guattari and disabled babies. *Disability & Society*, *22*(2), 145–160.
- Green, S. E. (2003). What do you mean “what's wrong with her?”: Stigma and the lives of families of children with disabilities. *Social Science & Medicine*, *57*(8), 1361–1374.
- Hale, C. (2013). Educating teachers to fulfill the promise of special education law. *PowerPlay, a Journal of Educational Justice*, *5*(1), 431–462.
- Harré, R., & Moghaddam, F. (2003). Introduction: The self and others in traditional psychology and in positioning theory. In R. Harré & F. Moghaddam (Eds.), *The self and others: Positioning individuals and groups in personal, political, and cultural contexts* (pp. 1 – 12). Westport, CT: Praeger Publishers.
- Harry, B. (1992). Making sense of disability: Low-income, Puerto-Rican parents' theories of the problem. *Exceptional Children*, *59*, 27–40.
- Harry, B. (2008). Collaboration with culturally and linguistically diverse families: Ideal versus reality. *Exceptional Children*, *74*(3), 372–388.
- Hehir, T. (2002). Eliminating ableism in education. *Harvard Educational Review*, *72*(1), 1–32.
- Horvat, E. M., Weininger, E. B., & Lareau, A. (2003). From social ties to social capital: Class differences in the relations between schools and parent networks. *American Educational Research*, *40*, 319–351.
- IDEA, (2004). Building the legacy: IDEA 2004. *U.S. Department of Education*. Retrieved May 1, 2013, from idea.ed.gov/
- Kalyanpur, M., & Harry, B. (1999). *Culture in special education: Building reciprocal family-professional relationships*. Baltimore, MD: Brookes.

- Kalyanpur, M., Harry, B., & Skrtic, T. (2000). Equity and advocacy expectations of culturally diverse families' participation in special education. *International Journal of Disability, Development and Education*, 47(2), 119–136.
- Klingner, J. K., & Harry, B. (2006). The special education referral and decision-making process for English language learners: Child study team meetings and placement conferences. *Teachers College Record*, 108(11), 2247–2281.
- Lalvani, P. (2008). Mothers of children with Down syndrome: Constructing the sociocultural meaning of disability. *Intellectual and Developmental Disabilities*, 46(6), 436–445.
- Lalvani, P. (2011). Constructing the (m)other: Dominant and contested narratives on mothering a child with Down syndrome. *Narrative Inquiry*, 21(2), 272–293.
- Lalvani, P. (2012). Parents' participation in special education in the context of implicit educational ideologies and socioeconomic status. *Education and Training in Autism and Developmental Disabilities*, 47(4), 474–486.
- Lalvani, P. (2013a). Land of misfit toys: Mothers' perceptions of educational environments for their children with Down syndrome. *International Journal of Inclusive Education*, 17(5), 435–448.
- Lalvani, P. (2013b). "Eye on the prize:" Parents, privilege, and the politics of inclusive education. *PowerPlay*, 5(2), 725–750.
- Lalvani, P. (2015). Disability, stigma, and otherness: Perspectives of parents and teachers. *International Journal of Disability, Development and Education*, DOI: <http://dx.doi.org/10.1080/1034912X.2015.1029877>
- Lareau, A. (2000). *Home advantage: Social class and parental intervention in elementary education*. Lanham, MD: Rowman & Littlefield.
- Lareau, A. (2003). *Unequal childhoods: Class, race and family life*. Berkeley: University of California Press.
- Leyser, Y., & Kirk, R. (2004). Evaluating inclusion: An examination of parent views and factors influencing their perspectives. *International Journal of Disability, Development & Education*, 51(3), 271–285.
- Linton, S. (1998). *Claiming disability: Knowledge and identity*. New York: NYU Press.
- McCall, Z., & Skrtic, T. M. (2009). Intersectional needs politics: A policy frame for the wicked problem of disproportionality. *Multiple Voices for Ethnically Diverse Exceptional Learners*, 11(2), 3–23.
- Nachshen, J. S. (2000). Advocacy, stress, and quality of life in parents of children with developmental disabilities. *Developmental Disabilities Bulletin*, 28(1), 39–55.
- Oliver, M. (1996). *Understanding disability: From theory to practice*. London: Macmillan.
- Ong-Dean, C. (2009). *Distinguishing disability: Parents, privilege, and special education*. Chicago: University of Chicago Press.
- Palley, E. (2006). Challenges of rights-based law: Implementing the least restrictive environment mandate. *Journal of Disability Policy Studies*, 16(4), 229–335.
- Palmer, D. S., Fuller, K., Arora, T., & Nelson, M. (2001). Taking sides: Parent views on inclusion for their children with severe disabilities. *Exceptional Children*, 67(4), 467–84.
- Panitch, M. (2008). *Disability, mothers, and organization: Accidental activists*. New York: Taylor & Francis.
- Parrott, W. G. (2003). Motivational styles and positioning theory. In R. Harré & F. Moghaddam (Eds.), *The self and others: Positioning individuals and groups in personal, political, and cultural contexts* (pp. 15–28). Westport, CT: Praeger.

- Pearson, S. (2009). Using activity theory to understand prospective teachers' attitudes to and construction of special educational needs and/or disabilities. *Teaching and Teacher Education*, 25(4), 559–568.
- Ramanathan, A. (2008). Paved with good intentions: The federal role in the oversight and enforcement of the Individuals with Disabilities Education Act (IDEA) and the No Child Left Behind Act (NCLB). *Teachers College Record*, 110(2), 278–321.
- Ryndak, D., Storch, J., & Hoppey, D. (2008). One family's perspective of their experiences with school and district personnel over time related to inclusive educational services for a family member with significant disabilities. *International Journal of Whole Schooling*, 4(2), 29–51.
- Sauer, J. S. (2007). No surprises, please: A mother's story of betrayal and the fragility of inclusion. *Intellectual and Developmental Disabilities*, 45(4), 273–277.
- Sauer, J., & Albanesi, H. (2013). Questioning privilege from within the special education process. *Understanding and Dismantling Privilege*, 1(3). Retrieved from <http://www.wpcjournal.com/article/view/11135>
- Skrtic, T. M., & Kent, J. R. (2013). Rights, needs, and capabilities: Institutional and political barriers to justice for disabled people. In A. S. Kanter & B. A. Ferri (Eds.), *Righting educational wrongs: Disability studies in Law and education* (pp. 58–101). Syracuse, NY: Syracuse University Press.
- Slee, R. (1996). Disabled people and poverty. In C. Christensen & F. Rizvi (Eds.), *Disability and dilemmas of education and justice*. Buckingham, UK: Open University Press.
- Slee, R. (2001). Driven to the margins: Disabled students, inclusive schooling and the politics of possibility. *Cambridge Journal of Education*, 31(3), 385–397.
- Soodak, L. C., & Erwin, E. J. (2000). Valued member or tolerated participant: Parents' experiences in inclusive early childhood settings. *The Journal of the Association for Persons with Severe Handicaps*, 25, 29–44.
- Trainor, A. A. (2010). Educators' expectations of parent participation: The role of cultural and social capital. *Multiple Voices for Ethnically Diverse Exceptional Learners*, 12(2), 33–50.
- Turnbull, A. P., & Turnbull, H. R. (1996). *Families, professionals, and exceptionality: A special partnership* (3d ed.). Upper Saddle River, NJ: Prentice Hall Professional.
- U.S. Department of Education. (2009). *Twenty-eighth annual report to Congress on the implementation of the Individuals with Disabilities Education Act*. Washington, DC: U.S. Department of Education.
- Valle, J. W. (2011). Down the rabbit hole: A commentary about research on parents and special education. *Learning Disability Quarterly*, 34(3), 183–190.
- Vygotsky, L. S. (1978). *Mind in society: The development of higher psychological processes*. Cambridge, MA: Harvard University Press.
- Wang, M., Mannan, H., Poston, D., Turnbull, A. P., & Summers, J. (2004). Parents' perceptions of advocacy activities and their impact on family quality of life. *Research & Practice for Persons with Severe Disabilities*, 29(2), 144–155.
- Wertsch, J. V., & Tulviste, P. (1994). Lev Semyenovich Vygotsky and contemporary developmental psychology. In R. Parke, P. Ornstein, J. Rieser, & C. Zahn-Waxler (Eds.), *A century of developmental psychology* (pp. 333–356). Washington, DC: American Psychological Association.

- Wickham-Searle, P. (1992). Mothers with a mission. In P. M. Ferguson & S. J. Taylor (Eds.), *Interpreting disability: A qualitative reader* (pp. 251–274). New York: Teachers College Press.
- Winzer, M. (2009). *From integration to inclusion: A history of special education in the 20th century*. Washington, DC: Gallaudet University Press.