Parents’ Participation in Special Education in the Context of Implicit Educational Ideologies and Socioeconomic Status

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Abstract: This qualitative study situates parents’ perceptions of their participation and role in special education planning in multiple contexts. Semi-structured interviews were conducted with 33 diverse parents of children with disabilities. The findings reveal the existence of special education discourses and practices that are entrenched in a deficit-based model and in implicit educational ideologies that sanction segregated education for many children with disabilities. Parents’ perception of themselves as advocates was a key theme. Decisions about the placement of children with disabilities in inclusive classrooms appeared to be parent-driven. The findings shed light on the socioeconomic contexts in which family-professional partnerships and educational decision-making for children with disabilities are embedded.

Parents’ engagement in seeking meaningful education for their children with disabilities is not a new phenomenon in the landscape of special education in the USA. Indeed, in the historical struggle for educational rights for children with disabilities, family advocacy and grassroots family movements emerged as a driving force and provided impetus for sweeping changes in educational laws pertaining to this group of children (Gallagher, 1984; Winzer, 2009). During the 1950’s and 1960’s parents banded together, establishing networks and organizations, the impact of which cannot be overstated. Parents organized to raise awareness in their local communities, lobbied for changes in legislation, brought litigation, called for school boards to provide programs, and created their own programs to educate their children (Winzer, 2009). The national groups that emerged during this time, such as the National Association for Retarded Citizens (now the ARC) and the United Cerebral Palsy Association (UCP), became powerful lobbying bodies that were instrumental in the formation of federal legislation pertaining to students with disabilities (Kirk, 1984; Winzer, 2009).

Today, parent participation in all aspects of decision making for students receiving special education is not only acknowledged, but also mandated in educational laws. The Individuals with Disabilities Education Improvement Act of 2004 (IDEIA) validates the role of parents and requires that schools make every effort to maintain a collaborative relationship with them throughout the IEP development and implementation process. Given that the legislation explicitly calls for parent involvement in special education planning, it is imperative to examine the ways in which families perceive their experiences of this process. Moreover, if educational laws position parents as equal partners or as collaborators, it is relevant to ask questions about how families position themselves and about whether collaboration with all families is equally valued, encouraged, and validated through institutional practices.

Research literature suggests that there is wide variability in families’ perceptions of the special education process. Some studies (e.g., Fish, 2008) indicate that parents of children receiving special education services are, for the most part, satisfied with their level of involvement, generally report positive percep-
tions of the IEP process, and perceive that their input is valued. Other findings shed light on parents’ dissatisfactions with their communications with professionals, negative perceptions, and feelings of alienation with the special education system (Fish, 2006; Garriot, Wandry, & Snyder, 2000; Stoner et al., 2005). Studies have highlighted parents’ perceptions that professionals dominated the decision-making process (Kalyanpur, Harry, & Skrtic, 2000), or that their relationships with professionals were adversarial relationships in nature (Bennet, Deluca, & Bruns, 1997; Erwin & Soodak, 1995; Fish, 2006; Yssel, Engelbrecht, Oswald, Eloff & Swart, 2007). Furthermore, it is documented that collaboration and mutual trust with special education professionals may not characterize the experiences of low income and minority families (Cho & Gannotti, 2005; Harry, Allen, & McLaughlin, 1995; Salas, 2004). Drawing critical attention to sociocultural contexts of families, some researchers argue that expectations of collaboration may be inconsistent with, or collide with, the cultural belief systems of some families (Harry, 2008; Kalyanpur & Harry, 1999; Kalyanpur et al., 2000).

The study reported in this article is based on a stance that parents’ participation in the special education process does not occur in a sociopolitical vacuum and should be situated in the multiple contexts in which they exist. Although there is considerable research on parents’ perceptions about their experiences with the special education process, there is less that examines these in the contexts of institutional discourses and practice. An emerging body of critical scholarship argues that dominant educational practices are deeply rooted in hegemonic discourses that broadly identify two categories of learners—those with disabilities and those without—and conceptualize special education as a place rather than as the delivery of educational services (Connor & Ferri, 2007). Complicating the issue further, another key element in IDEIA pertains to the concept of least restrictive environment (LRE) or the educational mandate that all students with disabilities be educated, to the maximum extent possible, alongside their typically developing peers, with the provision of supports needed. In its identification of a continuum of placement options to achieve this goal, this educational mandate may be deceptively innocuous. Although the LRE principle purports to safeguard children’s right to be educated among their non-disabled peers, some argue that it is a loophole, or a tool that lends institutional support to the practice of educating students with disabilities separately (Linton, 1998; Taylor, 1988). A related body of scholarship highlights parents’ resistance to dominant educational discourses and documents their efforts to access inclusive education for their children (Erwin & Soodak, 1995; Lalvani, 2012; Swick & Hooks, 2005).

The purpose of this study was to examine parents’ participation in special education in multiple contexts. To this end, it sought to explore the perceptions of diverse parents with regard to their experiences of the special education planning process for their children and their understanding of their role in it.

Method

Qualitative methods were used because they lend themselves to this study’s aim to examine parents’ perspectives based on their multiple frames of reference. The study did not seek to verify existing hypotheses, but rather, to gather rich and descriptive data in the form of narratives (Bogdan & Biklen, 1992). Semi-structured interviews were selected as the method for collecting data because this is consistent with the study’s emphasis on understanding the contexts within which individuals interpret their experiences and meaning is derived.

Participants

The participants were 33 parents of children with disabilities who were receiving special education services. They resided in New York City (2) and Northern New Jersey (31) in urban and suburban areas, and hailed from a range of ethnic, cultural, linguistic, and socioeconomic backgrounds. With regard to ethnicity, the families identified themselves as: Caucasian (18); Black (8); Hispanic (4); and South Asian (3). With regard to socioeconomic status, many would appear to fall within the middle–upper-middle class range. Nine families were considered to be in a low socio-
economic category and were identified as such if they were either receiving public assistance or their children qualified for the National School Lunch Program (NSLP), which provides free or reduced school lunches to children from low income families. Beyond this, I did not ask participants to reveal information about family income because, in efforts to establish rapport, it was necessary to minimize questions that may be considered intrusive. Seven parents were single mothers; all others were married. In terms of gender, there were two fathers who participated in the study; the rest were mothers. Parents in the study had children with IEPs whose ages ranged from 4–14 years, and were enrolled in preschool or elementary schools (preschool–eighth grade) in environments that ranged from full time placement (80% or more of the day) in general education classrooms to self-contained classrooms or separate schools. They had diagnoses or educational classifications that included: Down syndrome, Cognitive Impairment, Autism, Asperger’s syndrome, Speech Impairment, Learning Disability, ADHD, Fragile X syndrome, and Hearing Impairment. Some children who were in preschool had the general classification of “Preschool Disabled.”

In order to recruit participants, initially I circulated information about the study through local parent groups and email groups to which parents of children with disabilities belonged. This represents a technique known as homogeneous purposive sampling (Patton, 1990; Punch, 2005) in which a relatively homogeneous group of individuals provide rich and intensive information pertaining to an area of interest. I also employed a sampling strategy known as snowballing (Patton, 1990), whereby parents who participated in the study were asked to provide information about the study to another parent of a child with a disability whom they may know. Many additional participants were recruited in this way.

Data Collection and Analysis

Data was collected through individual semi-structured interviews. Most of the interviews took place at participants’ homes, though some chose to meet at the author’s home or office. The interviews were guided by open-ended questions about specific aspects of parents’ experiences with special education such as: the IEP planning process, their perceptions of their children’s present educational programs, and the process through which educational placement for their children was determined. Parents were also asked to reflect on their relationships with educational professionals, their beliefs about their role in their children’s education, and their perceptions of themselves as parents. The average length of the interviews was approximately two hours. All interviews were audio-recorded and later transcribed. Data collection continued until no new data emerged.

During data analysis I reviewed the transcripts exhaustively and recorded commonalities in the experiences, perspectives and interpretations of parents. This is consistent with the Emergent Themes Approach (ETA), which is described by Glaser and Strauss (1967) as a method for analyzing data in which conceptual themes emerge from the evidence rather than the other way around. In the next stage, patterns were noted in a non-discriminate manner and codes were identified based upon frequency and consistency of shared experiences, perspectives or interpretations reported by parents. Following this, more abstract stratifications or broad categories of codes were identified, each consisting of a cluster of codes containing salient and discrete accounts or perceptions that pertained to a broader conceptual phenomenon. Once these core categories of shared experiences were identified, the data was coded based on identified codes. All of the data analysis and coding was done by the author.

Results

There was wide variability as well as remarkable commonalities in parents’ perceptions of their experiences negotiating the special education system and of their roles in it. The results of this study are presented below, organized under thematic clusters of findings that emerged.

Beliefs about Special Education

Parents expressed strong opinions about educational programming for their children with
disabilities. Parents who were socioeconomically in the middle–upper-middle class range (whom I henceforth in this article refer to as parents in the higher SES group) had greater understanding of special education laws and the range of learning environments that can be considered for the education of students with disabilities. Most parents in this group articulated an understanding of the concept of LRE; however, for many, placement in inclusive environments was understood as determined by children’s abilities and developmental levels, or by the physical existence of these classrooms. For example, several parents expressed that although they would have liked inclusive placement for their children, their district “did not have inclusive classrooms” in particular grades. Furthermore, many parents believed that placement decisions were based on children’s performance on assessments or their abilities to “keep up” in a general education classroom. All parents in the higher SES group were aware of inclusive education and most discussed this educational practice in terms of its potential social-emotional benefits for children with disabilities. Some discussed their beliefs about its long term benefits such as preparing children with disabilities to function as adults in “the real world.” Additionally, a few raised the potential advantages of inclusive education for nondisabled children, such as an appreciation for diversity and articulated their understanding of it as a practice that pertains to children’s rights and to fairness in education. Although, inclusive education was regarded positively by most parents, their understanding of the reasons that their own children were being educated in non-inclusive settings, or had been in the past, included that their children (either presently or in the past) needed smaller, less distracting learning environments, that they were “not ready” for inclusion but would be at a later time, or that the school “did not have inclusion classrooms.”

Parents from the low SES group were less familiar with educational laws than the higher SES parents, and many were not aware of the full range of educational environments that could be considered for children with disabilities. There was also less variation among this group in terms of the present educational placements of their children with IEP’s, all of who were being educated in self-contained classrooms or schools. The majority of parents in the low SES group were unfamiliar with the LRE concept. Although most were familiar with the idea of inclusive education, they did not believe that that this kind of education could be considered for their own children. Remarkably, some expressed that prior to being asked questions about inclusive education by the author during the interview, they had not been aware that the topic bore any relevance to the education of their own children. In their understanding, their children were being educated in self-contained classrooms or schools because of the nature of their disability or because of their cognitive, social, or communication difficulties. It is worth noting that the children with IEPs of the low SES parents were reportedly being educated in more restrictive settings, compared to the children with similarly described needs for support of the higher SES parents. This appeared to be the case even when these socioeconomically diverse groups of children attended the same schools.

Institutional Discourses and Implicit Educational Ideology

The overwhelming majority of parents in this study reported that professionals had identified self-contained classrooms as the most appropriate learning environment for their children, based on disability labels or the outcomes of educational or psychological evaluations. The findings indicate that professionals had recommended placement in general education classrooms for children with mild disabilities, or soft labels such as Asperger’s syndrome and Learning Disability. Parents whose children had severe disabilities or educational classifications of cognitive impairment, Autism, or ADHD, reported that their children were being educated in self-contained classrooms, or had been until the parents had advocated for a transition to a less restrictive setting. Parents recalled that in particular, there was little or no consideration given by professionals to inclusive education for preschool, and by some accounts, professionals had informed parents that their school district did not have the option of inclusive preschool. Consequently, many parents had
initially believed that self-contained settings were the only option available to their preschoolers. Additionally, many parents were informed that professional judgment deemed separate, smaller learning environments to be critical for their children’s learning and development. Some parents recalled that they had concurred with these recommendations, because they believed that their children needed specialized services and individualized instruction which they understood as accessible only in self-contained classes. The following quotes from parents elucidate the ways in which self-contained and general education classrooms were presented to parents:

They said: “We have a small classroom where Drew won’t be overwhelmed. We don’t want him to be overwhelmed in a bigger class setting, you know, ... the kids do great there in this class.” I’m trying to remember how exactly she phrased it, but more or less it was a very positive–presented in a very positive way ... So how could I say no to that? Especially because I didn’t understand least-restrictive, I didn’t understand inclusion, I didn’t understand any of that stuff ... So that’s why, you know, I took the advice.

They were very, very adamant that he stay in the self-contained classroom–that he needed that. . . . They likened his moving on to inclusion as if the rug were to be swept from under his feet . . . . They made some good arguments for him staying in the place where he was. . . . That he needs a calm, consistent environment. One that he’s used to, one where he won’t feel threatened.

Some parents were informed by professionals that a transition to a general education classroom would be considered when their child was “ready.” These parents said that they had made concessions to self-contained placement in preschool, believing it would be temporary. However, during the transition to Kindergarten, many of these parents found that self-contained classrooms were again presented by professionals as the most appropriate learning environments for their children. For children entering elementary schools, the most commonly stated reasons provided by professionals for placement in restrictive settings included: their children’s performance on evaluations or “functioning levels;” the need for small learning environments (often as small as three students in a classroom); and the unavailability of inclusive classrooms at the schools. Additionally, many perceived that professionals had attempted to steer them towards self-contained learning environments by emphasizing its many attractions and benefits, as seen in the following quote:

The picture was painted beautifully–that Sara would get so much more extra help . . . The picture they painted was that it’s a small class, they have many staff members in there that can concentrate really on every single child in this classroom . . . And then they were saying me the other picture of a (general education) classroom with twenty-something kids in there. And they said, in a classroom situation like this, Sara would get lost–she won’t be able to follow the instruction there.

The majority of parents reported that inclusive education was not seriously considered by professionals, or that the topic did not enter the discussion unless they initiated it themselves. However, not all parents were aware that it was a topic that could be raised. Although the initial experiences with professionals who recommended self-contained environments were similar for the majority of parents across the study, subsequent experiences were very different for parents from different SES groups. In the higher SES group, many parents reported that they had educated themselves about inclusive education, challenged professionals’ recommendations for self-contained classrooms and sought placement for their children in general education classrooms. Some in this group reported that their advocacy on behalf of their children’s rights to access general education had resulted in inclusive placement for their children in preschool or elementary school. Others reported that they had encountered resistance from professionals, and that their pursuit of inclusive education for their children was ongoing and unresolved at the time of the interviews.

Accounts of negotiating access to inclusive education for their children were largely absent from the narratives of the parents from the lower SES group. As noted earlier, many in this group of parents expressed that they were unaware that their own children could
be educated inclusively. Some expressed that they had initially hoped that their children would be “mainstreamed” but they had been informed by professionals that their children would be educated in self-contained classrooms; none recalled any discussion, consideration, or mention of inclusive education during IEP meetings. Four parents in this group reported that they had been highly dissatisfied with the education their children were receiving in the self-contained classroom in their school districts and had requested out-of-district placement in schools for children with disabilities. It is remarkable that by their accounts, low income parents were able to engage professionals in discussions about more restrictive placements—the four parents who advocated for this were successful in having their children placed in private, segregated schools at the cost of the district—yet, parents who attempted to have their children moved to a less restrictive setting were strongly resisted. As an example, Carla, a mother living in New York City had advocated for her son to be moved from a highly restrictive setting (a self-contained classroom of six students within a public school for students with Autism) to an only slightly less restrictive setting (a self-contained classroom with 12 students situated within a public school for nondisabled children). Carla’s efforts had been entirely unsuccessful—she was informed that the less restrictive setting she wishes for her son cannot be considered until her son demonstrates an improvement in his social, verbal and communication skills. Carla’s reasoning that her son does not have adequate opportunities to model, learn, or practice these skills in a classroom of only six students, four of whom are non-verbal, and all of whom have similar difficulties, have, in her belief, been dismissed by professionals.

Parent as Student

Parents expressed that they had felt an urgent need to educate themselves about special education and narrated their journey to “learn everything they possibly could.” To this end, many reported that they had done a great deal of reading or searched the web for information about their children’s disabilities, available resources, special education laws, and so on. Additionally, some parents in the higher SES group also reported joining national or local organizations which, among other things, provide information and support to families of children with disabilities. Among this group, it was not uncommon that parents had attended workshops or sessions at conferences on topics such as special education laws, applied behavioral analysis (ABA), inclusive education, and so on. Additionally, parents in this group identified other parents as their most valuable resource; many were well connected to parent groups, which served as avenues for the exchange of ideas, resources, and emotional support. Some of these groups also provided direct opportunities to access information through guest speakers, such as special education advocates or service providers, and were a forum for dialogue with school district professionals who attended. Many parents expressed that they had become more aware of inclusive education as an option for their own children and had learned ways to advocate for inclusive placement through their connections with these parent groups.

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Engagement in Seeking Appropriate Education

This section presents findings pertaining to parent’s engagement in seeking a meaningful education for their children with disabilities. Many parents from the higher SES group expended inordinate amounts of time, effort, and resources in order to effectively negotiate the special education system. Parents from the lower SES group also engaged in these efforts; however, they were limited by their work schedules, lack of financial resources, language barriers, and a full understanding of their children’s educational rights. Overall, the range of activities related to parents’ negotiating special education is discussed below under three thematic categories.
sources, information, and support as their higher SES counterparts.

**Parent as Advocate**

Parents’ perceptions of themselves as advocates emerged as a consistent theme in this study. The majority of parents in the study, regardless of SES, reported that they had questioned some of the recommendations made by professionals and advocated for what they believed was a better education for their children. However, there were differences in perceptions of the efficacy of their advocacy. Most parents in the higher SES group expressed beliefs that their advocacy had been critical in the decision-making process and that their efforts had eventually led to some changes in educational programming for their children. Parents in the low SES group did not usually experience their advocacy efforts to be as effective; some reported that they had been entirely unsuccessful in engaging professionals in a serious dialogue about their concerns; others said that they had not been persistent in their efforts, believing that ultimately “professionals know best.” Despite this discrepancy, accounts of advocacy were present in most parents’ stories regardless of SES, and related to the following three areas: (1) negotiating services (2) negotiating placement and (3) negotiating labels.

**Negotiating services.** Many parents reported that they had “done the research” and had made an argument for the providing of particular delivery models (e.g. “team-teaching”), additional support services, or classroom aides for their children. Some parents had advocated for the use of technology in the classroom such as FM devices or iPads; others requested more systematic communication between professionals or between their children’s teachers and themselves. Many parents believed that professionals had been appreciative of the ideas suggested by them and had implemented them or added the services to their children’s IEP’s. Advocacy for services was more common among the higher SES group, although noted in both groups.

**Negotiating placement.** Most commonly, parent advocacy was related to educational placement. Among the higher SES group, the majority of parents said that they had questioned professional judgment about self-contained environments as most appropriate for their children. Although two parents in this group had advocated for a move from a self-contained classroom to placement in an out-of-district private school for children with disabilities, for most, the “struggle” or “fight” was over access to inclusive education. In their efforts to advocate for inclusive placement for their children, many talked about a “rocky journey” often involving the expenditure of a great deal of time, energy or financial resources. Some parents had hired advocates to advise them or to accompany them to IEP meetings, some had spent months visiting schools or “researching” school districts in search of model inclusive settings, and a few reported that they had pursued litigation against their school district or had considered it. In almost all instances in which children were being educated inclusively, parents believed that they had either initiated the discussion with professionals or needed to strongly advocate for it. It is worth noting that all parents who had advocated for inclusion were in the higher SES group. As noted earlier, parents from lower the SES groups expressed that they were not aware of inclusive education as an option for their own children. Therefore, although many among them engaged in advocating for what they believed was the best education for their children, they did not, nor did they know they legitimately could, advocate for inclusion.

**Negotiating labels.** Many parents in the study held strong beliefs, both positive and negative, about the implications of having certain educational classifications. For some, certain labels were more desirable than others because of the services with which these were associated; these parents engaged in extensive efforts to obtain particular diagnoses or classifications for their children which they believed would result in their receiving more help in schools. For instance, one mother recounts that in seeking and obtaining the diagnosis of Autism for her son, she was able to successfully advocate for him to receive additional hours of speech and ABA therapies at school. On the other end, many parents strongly resisted particular labels and negotiated for these to be removed from their children’s educational documents; their concerns
pertained to the stigmatization of their children or the impact of the labels on teachers’ expectations of them. Among the labels most associated with negative implications for parents were those of Autism and cognitive impairment, the latter being the most strongly contested and resisted by the parents. It is important to note that parents who resisted particular labels did not dispute that their children required special education services, nor did they disagree with professionals about their children’s learning difficulties, delays in development, or behaviors; the dispute pertained largely to the naming of the “problem.” Although there were parents in both SES groups who disputed their children’s classifications, only parents in the higher SES group were influential in having them changed. This quote from a father is informative:

The school psychologist wanted to change his classification to cognitively impaired, which is mildly retarded and I was taken aback by that . . . She says these are true scores, your son is mildly retarded. And I said: “I know what cognitively impaired is.” And then I said, I am not going to go with that label even if it was true. You’re gonna call it something different because I don’t want to put a ceiling on him . . . and when you sense someone is mildly retarded you’re assuming there’s a ceiling, you know. So we had a bit of a battle with that. I quick sent an email off to (the director) and (the superintendent) . . . saying I want to have a meeting to talk about a proper classification for my son. We had a meeting very quickly . . . I said the same thing—we’ll never accept that (label). Even if that’s what it is, it’s simply not going to be on his paperwork. So we agreed upon ‘multiply disabled’—ADHD with some underlying learning disabilities.

Parent as Educator

Many parents reported that they took on a leadership role in educating professionals about their children’s disabilities, learning styles, and educational needs. Some parents compiled information packets or created photo essays intended to familiarize professionals with their children’s strengths, difficulties, and unique personalities. There were also accounts of parents providing information to professionals about available resources, local workshops, conferences or events pertaining to special education. These were viewed by parents as ways of collaborating with professionals in efforts to improve educational programming for their children. In most cases, parents believed that professionals were appreciative and responsive to their input, and this generally contributed to positive perceptions of the family-professional partnership.

Parents also discussed their efforts at educating others about special education practices and laws. To this end, some were involved in the organizing of parent support groups or took on leadership roles in these. A few also discussed their engagement in activities to educate general education students or their local communities about their children’s disability or issues related to disability in general. These activities included: developing curricula, leading a lesson during a classroom visit, creating a classroom library, or taking part in organizing community events aimed at raising awareness about disability. This theme of parents as educator was found predominantly in the accounts of parents in the higher SES group.

Relationships with Professionals

The findings pertaining to parents’ perceptions of their interactions with educational professionals and the ways in which they positioned themselves in the family-professional relationship are organized under the following four themes that emerged.

“Experts Know Best:” Decision-making Dominated by Professionals

Some parents in the sample perceived themselves as following the lead of professionals. Parents in the lower SES group were more likely to hold this view of the parent-professional relationship than parents in the higher SES group. This is not to say that parents in the lower SES group agreed with all of the decisions that had been made. Some had reportedly questioned professional judgment (mostly about educational placement); however, few among them had taken it any further than voicing their concerns. They expressed that they felt disempowered to make any real changes, were unsure about their role in spe-
cial educational planning, or held beliefs that "professionals know best." Additionally, there were parents in both SES groups who believed professionals had positioned their own "expert" knowledge as the "truth," or cautioned parents about going against the "objective" judgment of professionals. For example:

"They told me that I am disregarding the professional’s, you know, judgment, and that inclusion is a buzzword that I’m hearing and bringing to the table. So I did tell them that it’s not that I heard inclusion on CNN yesterday . . . I mean they actually implied that they are right and I am wrong because I am just a parent, I cannot see the whole thing objectively and they are the professionals, they know what’s right and they think it’s not right for Tara to be in the general ed. setting right now."

"We’re a Team:” Partners in Decision Making

There were parents in both SES groups who discussed relationships of mutual trust and partnerships with professionals. They believed that they participated in decision-making and that they were regarded by professionals as equals. These parents believed that their role was to reinforce learning at home, to support and provide information to professionals about their children or to problem-solve collaboratively with professionals. Parents who believed that their input and participation in the decision-making process was encouraged and truly valued by schools generally also expressed greater levels of satisfaction with their children’s educational programming. In particular, parents’ levels of satisfaction with the special education process were higher when they perceived that they had established relationships of mutual trust with a particular teacher or other professionals.

"CEO of the IEP:” Parents Leading the Process

This theme pertained to parents’ beliefs that they had needed to “monitor” or oversee professionals. In one account, a parent had called the school on numerous occasions to inquire why occupational therapy had not begun to be provided several weeks into the school year. In another, a parent reported that she brought to professionals’ attention that her child was supposed to have an aide, as specified on the IEP. Some reported that they had researched information about particular instructional strategies themselves and shared the information with educators. Many parents believed that their vigilance was necessary, and used terms like “watchdog” to describe their role in the special education process. Others believed that they were much more than vigilant; they were the driving forces in the creation of meaningful educational programming for their children. In discussing their relationship with professionals, these parents positioned themselves in the dominant role.

"My relationship is very professional. And I’m the CEO . . . I am the single most important person in Jack’s education. Bar none. I am currently the CEO of Jack. I am working towards succession where Jack will become the CEO of Jack. Everybody else—they’re in a supporting role."

Parents’ perceptions of themselves in a leading role existed particularly in the context of educational placement and most commonly among parents whose children were being educated inclusively. Almost all parents whose children were being educated inclusively believed that without their advocacy, their children would not be receiving this kind of education. Moreover, some expected that the need to advocate for inclusive placement would be continual; they reported that each time their children began in a new grade or school they had to “convince” professionals over again, even though their children had thrived in inclusive classrooms the preceding year. This high level of involvement and vigilance was experienced as stressful by many parents, or as a strain on their time, resources and familial relationships. This mother expressed the impact and toll taken by the constant need to advocate, on her experience of motherhood: “This journey becomes so wrapped up in getting your kid the services and classroom setting that they need, that I forget that sometimes I just need to be his mother, not his therapist, not his advocate, just Mommy.”

"Mother from Hell:” Adversarial Relationships

Many parents in the study understood their relationships with professionals to be highly
contentious in nature and marked by persistent conflict. They described their role in special education as one in which they engage in “battle” or are “fighting the fight.” Additionally, some parents anticipated that conflict would continue to be an aspect of their experiences with special education, or as one mother articulated: “You’re only as good as your last fight.” Parents generally found these adversarial relationships to be emotionally draining, but they believed that if they stopped “fighting” there would be a decrease in the quality of their children’s education, or a change in their children’s educational placement. Also stressful for parents was the belief that they were viewed negatively by professionals at their children’s schools; in describing their beliefs about how they are viewed by professionals, many used terms such as: “an annoyance,” “a squeaky wheel,” “a nuisance,” and one mother said: “I’m the mother from hell. They hate me. They totally hate me.” As with the previous theme discussed, accounts of adversarial relationships were mostly around the issue of educational placement. For instance, Carla, whose experience of trying to engage professionals in a conversation about moving her son to a less restrictive setting was discussed in an earlier section, described her perception of her role as: “Fighting for my kid. Just have to be positive, be strong . . . Don’t give up. Just keep fighting to get the rights for my son.”

It should be noted that in general, negative or adversarial relationships did not appear to characterize parents’ perceptions of their relationships with teachers; rather, when they were described, they were usually in the context of relationships with administrative professionals. Indeed, most parents shared stories about particular teachers whom they believed had gone out of their way to advocate on their children’s behalf, or had otherwise provided exceptional levels of support to their children and their families.

Discussion

The findings shed light on special education practices that are entrenched in a deficit-based model and in implicit educational ideologies that position children with disabilities as other. This was most evident in parents’ accounts of the ways in which educational placement was determined for their children; the majority of parents in the study reported that professionals had recommended self-contained learning environments for their children, based on their children’s educational classifications, performance on assessments, developmental “functioning levels,” or “readiness” for inclusive education. Similar to previous findings (Lalvani, 2012), this study highlighted parents’ beliefs that they were steered toward self-contained classrooms by professionals who presented these in highly appealing ways, describing them as access to special educators and to individualized instruction. These findings also lend support to the work of scholars who argue that educational discourses are based in conceptual notions of special education as place (Connor & Ferri, 2007) and of inclusive education as a privilege for a select group of students with disabilities or as compromising individualized instruction (Lalvani, 2012; Sapon-Shevin, 2007).

Parents’ perceptions of their own advocacy and vigilance as critical to the development of meaningful educational programming for their children with disabilities emerged as a key finding in this study. This supports the findings of other studies in which advocacy was viewed by parents of children with disabilities as an avenue for improving educational services, and the extent to which advocacy is required was understood as distinctive to the experiences of parenting children with disabilities (e.g. Lalvani, 2011; Wang, Mannan, Poston, Turnbull, & Summers, 2004). Additionally, consistent with other studies (Bennett, Deluca, & Bruns, 1997; Yssel et al., 2007), many parents perceived themselves to be in adversarial relationships with schools and became engaged in conflicts which sometimes involved mediation, professional advocates, or litigation, which led to perceptions of stress and frustration among many, particularly those whose individual or cultural frames of reference were inconsistent with the assuming of this role. This resonates with the assertions made by Wang et al. (2004) that although educational laws should have reduced the need for parents to advocate, there is today, an implicit and explicit expectation of involvement based on European-American middle class value systems, as well as an understand-
ing among parents that they will need to advocate.

In this study, stories about advocacy or conflict were generally related to services, labels, or placement, and of these, the issue of educational placement appeared to be the most contentious. A small number of parents in the study sought out-of-district placement for their children in private schools for students with disabilities because they believed that their children were not receiving a meaningful education in their school districts. For the majority of the parents however, conflicts arose over the issue of inclusive education. Similar to other studies (Erwin & Soodak, 1995; Swick & Hooks, 2005), many parents believed that they had to “struggle” or “fight” for their children to be in inclusive classrooms. Highlighting the existence of institutional resistance to inclusive education, this study reveals a serious disparity between educational law and educational practice. Additionally, the finding pertaining to parents’ beliefs that professionals, using evaluations that are clinically and scientifically sound, can effectively identify students who need to be educated separately lends support to Brantlinger’s (2004) assertion that much of educational practice is based in positivist beliefs about the neutrality of science, when in fact, what is taken to be scientific knowledge is situated in hegemonic discourses that privilege certain “knowledge” over others. Thus, parents in this study found themselves negotiating a special education system that legitimized the segregated education of some children, based on the clinical judgments of those in positions of power or control (Kliwer, 1998; Skrtic, 1995).

The study’s findings pertaining to the perceptions of parents from higher SES groups that they had been influential in securing particular educational placements, and those that highlight differences among parents from different socioeconomic groups in their understanding about inclusive education reveal the extent to which placement decisions may be situated in socioeconomic contexts. When considered together with parents’ descriptions of the kinds of educational environments in which their children were being educated, these findings shed light on the intersections of inclusive education practices and socioeconomic class. In this study, the children with disabilities of the parents from the lower SES group were all reportedly being educated in self-contained environments, whereas many of the children with similarly described needs for support of the parents in the higher SES group were being educated inclusively. Many parents in the higher SES group related that they had educated themselves about inclusive education and had learned how to advocate effectively for it; among this group decisions to educate children with severe disabilities or with certain classifications were largely parent-driven. Parents in the lower SES group did not articulate the same level of comfort in challenging professionals’ decisions. Additionally, unlike parents from higher SES groups, these parents had a less sophisticated understanding of educational laws, lesser access to resources that would help them to advocate for the kinds of education that they had originally envisioned for their children, and generally felt less empowered to make changes in their children’s educational programming. None among them had ever initiated a dialogue with professionals about inclusive education, and more remarkably, they had reportedly not done so because they had not known that this kind of education could be considered for their children. These findings contribute to the growing body of scholarship that addresses the issue of overrepresentation of children from racial, linguistic, and socioeconomic minorities in segregated special education environments (Ferri & Connor, 2005; Fierros & Conroy, 2002). Ferri and Connor (2005) discussed that in the years following Brown v. Board of Education, the practices of ability tracking and educating students with disabilities in separate classrooms served as institutionally sanctioned avenues of racial and social class segregation, situated in ideologies that maintained privilege. In this study, self-contained classrooms were recommended for the children with disabilities of almost all parents in this study, regardless of SES or ethnicity. The only exceptions involved children with labels like Learning Disability or Asperger’s syndrome. For children with labels of Autism, cognitive impairment or ADHD, or those with more severe disabilities, self-contained learning environments had been
considered appropriate, at the very least, for some portion of their schooling, which is consistent with Smith’s (2010) finding that the overwhelming majority of students with severe or intellectual disability in the US are educated predominantly outside general education classrooms. However, many of the higher SES parents had successfully advocated for a transition to a less restrictive setting or for the creating of fully inclusive programming for their children. Adding a new dimension to the discussion on overrepresentation, this study reveals another way in which socioeconomic factors intersected with special education. In this study, SES was not as much of a factor in which children were placed in self-contained classrooms, as it was in which children got out of them. Thus, when the principle of LRE intersected with SES, it served as a sorting tool, separating children not only by their abilities, but also by the socioeconomic positions of their parents.

Finally, the findings shed light on the range of ways in which parents perceive their roles in special education and on their relationships with educational professionals. Remarkably, few parents used the language of equal partnerships. In their descriptions, their experiences with special education were often characterized by imbalances in power and influence; some parents believed they were “following” professionals, others, that they were “leading” the process. Overall, parents’ accounts of conflict, frustration, stress, and institutional resistance to their vision for their children’s education suggest that true partnerships between professionals and parents of children with disabilities continue to be an elusive goal.

The findings have implications for educational practice and policy. First, they suggest a need to scrutinize the practices of individual school districts with regard to the extent to which they are in accordance with special educational laws. This study also supports the need for policies aimed at raising awareness about the benefits of inclusive preschool education and their interpretations of their children’s disabilities. Lastly, the study calls for educators to scrutinize the ways in which professional “knowledge” is privileged over parents’ vision for their children’s education, and to work toward establishing genuine family-professional partnerships with the goal of optimal outcomes for all students with disabilities.

References


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