

Understanding & Dismantling Privilege

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***Questioning Privilege from Within the Special Education Process**

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Abstract

This paper provides an analysis of how privilege functions in the negotiation of the rights and accommodations for children with disabilities. As white educated mothers, we examined how parents with race and class privilege are positioned in the interaction with schools, and how the structure of that interaction reinforces and reproduces inequity. The first process we consider is how parents with privilege are encouraged and expected to pursue the individualized strategy (i.e. 'save my son') over collective strategies (i.e. how do we equitably address the needs of all children with disabilities). The second process we consider is how parents are pushed to accept the rehabilitative approach over an approach which questions the construction of 'disability' and the range of possible institutional responses to it. Finally, from a Disability Studies theoretical framework, we question how our participation in these two processes helps reproduce the existing structures of inequality. Drawing on the work of Ong-Dean (2009) and Skrtic (2003, 2011) we examine how our privilege is implicated in the way we interact with schools and how schools co-opt that privilege.

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Introduction

The first author's son was presumed disabled shortly after birth based upon a blood test showing an extra twenty-first chromosome, while the second author's son was flagged for intervention at two years of age because he was not speaking. Both of these children were born into white American middle-class families to educated mothers and are currently provided with special education services based upon legislation focusing on their individually determined needs, but those services would likely look very different if these children had been born into different families. As another privileged parent acknowledged in an interview, the education system "is only fair for the people who are educated or who educate themselves and the other kids just suffer" (Ong-Dean, 2009, p. 41). This mother, a professional nurse who was married to a firefighter, voiced a common understanding among parents of children with disabilities that cultural and economic advantages are readily used in the education system to benefit certain individual children. In fact, the system was developed in response to calls from privileged parents for educational rights on behalf of their children. We do not blame these families, as we ourselves also advocate on behalf of our children, but we do have questions.

Janet: My questions about inequities within the educational structure emerged as a practicing elementary special education teacher who advocated for inclusive schooling for all students regardless of the impact of their impairment or category label of disability. Then I became a mother of a child born with an extra chromosome and the questions became personal.

I was now directly impacted by the system in which I worked, in ways I had previously only imagined. I questioned the

assumptions some of my colleagues, family, and friends made about my infant's future, when they presumed his diagnosis of Down syndrome predetermined restrictive educational placements and a life of dependence. Shortly thereafter I entered a doctoral program where I learned about disability studies and critical special education and began to revisit questions about the way children with disabilities were being labeled, sorted, and segregated systemically and the role I might have inadvertently played in the process. Reading and working with colleagues outside my educational discipline, such as Heather, provided me with the vocabulary and theoretical framework to analyze this structure from both a scholarly and personal perspective.

Heather: My research and teaching interests in both inequalities in education and the sociology of disability also predate the birth of my son. In particular, it was conversations with some of my undergraduate students with disabilities that initially sparked my interest in disability studies and my desire to address the glaring absence of any research on disability within the courses I taught. While there were indications of developmental issues prior to my son's second birthday (as he missed each pediatric speech milestone), it was after his second birthday that we were directed to early intervention services for a condition that was later diagnosed as ataxia (a neurological disorder of the cerebellum). It was in his transition into elementary school that I became increasingly aware and uncomfortable with the ways that schools structure the process for negotiating an Individualized Education Plan (IEP) in ways that I see as reproducing class and race privilege. In this ongoing process I find myself in conflict where, on one hand,

I experience at a personal and emotional level the stigma and shame afforded individuals with disabilities in our society—compelling me to fight for my child’s inclusion and acceptance, as hard as I can, using all of the resources that my privileged race and class status afford me—and on the other hand, unable to ignore questions raised as to the consequences of wielding this privilege.

The 2004 Individuals with Disabilities Education Act (P.L. 108–446), or IDEA, includes language requiring parental involvement in determining their children’s *individual* education plan. Why is there such an emphasis on individuals, and what are the consequences? How has the law impacted the subsequent policies and practices of school personnel and the families with whom they work? Can privileged parents simultaneously advocate for their children and work toward systems-level change? These are some of the questions we explore in this chapter, as parents with privileges who understand the inequitable educational system in which we play a part.

A Disability Studies Theoretical Framework

This paper examines the personal experiences of two children with disabilities from the perspective of their mothers using a disability studies (DS) theoretical framework. Disability studies offers a means by which to critically analyze social and political structures. For the purposes of this piece we will refer to the following definition of DS:

Disability Studies refers generally to the examination of disability as a social, cultural, and political phenomenon. In contrast to

clinical, medical, or therapeutic perspectives on disability, Disability Studies focuses on how disability is defined and represented in society. From this perspective, disability is not a characteristic that exists in the person so defined, but a construct that finds its meaning in social and cultural context (Taylor, 2003).

We are particularly interested in identifying the influences on the choices we are afforded and how we take advantage of our circumstances as self-identified parent advocates while recognizing the sociological and historical contexts in which decisions are made. In his sociological examination of disability and diversity, Sherry (2008) argues “disability is always a sexed, gendered, racialized, ethnicized, and classed experience . . . [that] operates within a framework of multilayered and complex patterns of inequity and identities” (p. 75). A disability studies theoretical framework offers an opportunity to examine the complexities involved in the daily (and sometimes moment-to-moment) decision-making processes we as parents are involved in. This critical self-examination is not something privileged parents are typically encouraged to participate in because it threatens to undermine the rights for educational access we seek for our children.

The authors acknowledge our privileged positions within the special education process and through this chapter grapple with the moral dilemma involved with advocating for our children while recognizing how we might implicitly contribute to systemic inequities based on our various forms of capital (economic, cultural, social, symbolic, etc.). We explore Ong-Dean’s (2009) claim that “our current expectations for parent advocacy may make it difficult for parents and others to see the

role privilege plays” (p. 7). As such, we uncover some of the privileges we have enjoyed, by offering some specific examples of our experiences, and analyze them with regard to the current related literature across various disciplines and through a disability studies lens.

Intersections in Special Education

Important questions about the negative influence of special education legislation were first raised in the late 1960s. Dunn (1968), for instance, asked the now oft-cited question, “Special education for the mildly retarded—is much of it justifiable?” He questioned why minority students were labeled mentally retarded because they were considered by teachers as “disruptive” or “slow learners.” The unnatural overrepresentation of poor and minority students in special education is well documented (Donovan & Cross, 2002; Ferri and Connor, 2005; Harry & Klingner, 2006; Skrtic & McCall, 2010; Sleeter, 1987). We know, for instance, that only about 1 percent of whites are labeled as having mental retardation, while 2.6 percent of black students carry this label (Donovan & Cross, 2002). Interestingly, this overrepresentation is not evident in the disability categories based in physical or biological etiologies, such as visual or hearing impairments. Furthermore, those students of color identified for special education are often served in more restrictive settings than their white counterparts. In this chapter we consider the various ways that parental involvement in the IEP process helps to reproduce these inequities.

Utilizing critical race theory, disability studies scholars have argued that rather than IDEA serving as civil rights legislation, it is used “to maintain the effects of the unacceptable and illegal segregation

by race” (Beratan, 2008, p. 337). Sleeter (2010) points out that “differential opportunities afforded to students in schools are not determined by the variety of children and youth who attend, but rather by how that variety is understood and responded to.” Sleeter’s comment points to the importance of the power of our social interactions and the underlying assumptions and biases in which we base those interactions, something she found when asking the question more than twenty years earlier: “Why are there learning disabilities?” Her answer: “Rather than being a product of progress, the category was essentially conservative in that it helped schools continue to serve best those whom schools have always served best: the White middle and upper-middle class” (Sleeter, 1987, p. 212). As Sleeter suggests, in addition to race, class is a social dynamic involved in the intersectionality of the special education process.

In her research about the role of class in schools, Brantlinger (2003) describes the way “affluent mothers narrate their own and other people’s children” (p. 35). She explains how advantages are secured through educational structures and policies, noting that even those in positions of power, such as principals and superintendents, “succumb to the demands of the powerful constituencies,” such as the interests of affluent families. She describes teachers she interviewed who, despite expressing frustration about the situations they observed, passively complied with inequitable practices. Instead of focusing on the problem of class-based educational stratification, Brantlinger’s study examines the people in power. She refers to Ball (1994), who “insists that to transform social hierarchies, it is necessary to understand groups that have the power to control them” (p. 189). This argument suggests the value

of self-examination as we try to figure out the rationale we make for our decisions.

Parental Involvement and the Individualized Strategy

The first process we consider is how parents with privilege are encouraged and expected to pursue the individualized strategy (e.g., “save my son”) over collective strategies (e.g., “how do we equitably address the needs of all children with disabilities?”). Considerable research contemplates the “home/school relation” as a primary locus for how the education system reproduces class inequality (Domina, 2005; Lareau, 2000). The individualized parent advocacy strategy can be located within broader trends in the educational system. One set of research in both the US and the UK looks at the level of discourse, pointing to the dominance within the K–12 educational system of the intertwined discourses of parental involvement and parent choice. The former discourse has strongly influenced school reform policy toward the goal of increasing parental involvement in the perhaps misguided hopes that this will redress class and race inequity (Domina, 2005).

Instead, researchers have generally found the parental involvement to privilege middle-class families in producing educational outcomes (Brantlinger, 2003; Kainz & Aikens, 2007). Studies looking at the ascendance of parent choice agendas (which David, 1993, connects to the ideology of “parentocracy”) have examined the consequences of this popular trend. In particular, researchers have suggested that despite the potential attraction of parents to this discourse, it creates a trade-off between freedom and equity (Reinoso, 2008). Kainz and Aikens (2007) similarly consider the bias of this discourse of involvement, in that

it articulates with a particular set of privileged parental resources:

Instead, we argue that selective access to the dominant discourse—selectivity due to strictly bounded cultural, gender, and family structure expectations—works to privilege certain groups of children and families at the expense of others, particularly because a dominant discourse on parent involvement obscures diversity in viewpoints, family structure, and resources for expected home/school relations (pp. 301–302).

This move toward a parent choice model is also connected to the creation of “quasi-markets” within the educational system that researchers argue reproduce and intensify existing inequalities (Cookson, 1994; Whitty, 1997). Mirroring the literature on discourse is research that looks at actual practices, in particular patterns of parental involvement/intervention. For example, a significant body of work within the sociology of education considers the effect of parental privilege on educational outcomes, including economic, cultural, social, symbolic, and emotional capital (Lareau, 2000; Reay, 1998).

Economic Capital

One of the most obvious ways privileged parents affect their children’s education is through the choice of where they live and the resulting quality and resources of the area’s local schools. While the quality of local schools affects all children, research finds higher SES (socioeconomic status) schools are more likely to offer inclusive (versus segregated) special education services, and children with learning disabilities who attend these

schools are more likely to attend college (LeRoy & Kulik, 2003). Local economic resources also affect the quality of teachers working with children with disabilities. Low SES children with disabilities are more likely to have uncertified or provisionally licensed teachers and to graduate with a certificate of attendance or completion rather than a high school diploma (Chamberlain, 2005).

Personal examples of economic capital.

Take, for instance, the privilege Janet's son has enjoyed because she and her husband have the funds to find a house in the neighborhood where she wants her son to be educated. She describes the time and resources her family used in their search for an inclusive school when they moved across the country (Sauer, in press). Similarly, Kluth, Biklen, English-Sand, and Smukler (2007) interviewed twelve families who sought out schools that they felt would offer their individual children the services they thought were best suited to support their children's education.

In a case study, Ryndak, Orlando, Storch, Denney, and Huffman (2011) describe a series of advocacy efforts by an advantaged mother named Sarah that secured support services including horseback-riding lessons, private speech therapy, respite care, and behavior interventions in the home, and she herself at times provided homeschooling and a supplemental reading program for her son. Some research also suggests that there is a "digital divide," where privileged families have increased access to assistive technologies (or just generic technologies, such as an iPad) (Clark & Gorski, 2001). Again, Janet and her husband used their economic advantage to purchase an iPad for their son to use in both the home and school

environments prior to the school-wide adoption of the technology. The effect of the boy's role as a "trend-setter" in his school is unclear, but ready access to the technology was shown to directly affect his academic achievement, as evidenced in his IEP.

Heather's family also was in the financial position (and had flexible work schedules) to pursue every type of medical testing and private speech therapy recommended by the pediatric neurologist. While some of this was covered by insurance, much of it was not. But the documented results of all of these tests went into her son's IEP file and clearly bolstered his case, serving as evidence and justification for particular IEP accommodations. Heather's perception was that the school's special education teachers were quite receptive to this type of data—that it was "speaking their language" (versus parents expressing a vague sense that "something is just not right" with their kid). How many poor families have the time or financial resources to provide these opportunities for their children? As we have seen here and will again describe later in greater detail, race and class play important roles in parent advocacy, whether for certain diagnostic labels, for services, and/or for placements where those services are provided.

Cultural Capital

Much of the work on transmitting class privilege via the home/school relation focuses on how cultural capital shapes parenting practices. Lareau (2003) characterizes middle-class parenting as following the logic of "concerted cultivation." She theorizes that concerted cultivation has three aspects: intensive language use, "over"-scheduling of children's free time, and intervening with

institutions such as schools on behalf of the child. In this chapter we focus on the last one: how parents negotiate with various institutions to maximize benefit and accommodation for the individual child.

Lareau (2003) suggests these practices have twofold results: the direct accommodation afforded middle-class children (the squeaky wheel) and the modeling of middle-class behavior to the next generation, that is, teaching the child to advocate for him/herself and the child feeling entitled to do so. In his book *Distinguishing Disability: Parents, Privilege, and Special Education*, Ong-Dean (2009) writes about the “burden of advocacy” the IDEA legislation has imposed upon families of disabled children. He argues for the “need to acknowledge that parents differ in how far they can shoulder this burden” (p. 2) based upon their cultural and economic resources.

Personal examples of cultural capital.

Both authors are keenly aware of the many opportunities within the IEP process to exercise cultural capital. While interacting/negotiating with special education teachers in a parental role, we are both armed with the specialized language, acronyms, and historical knowledge of, research on, and meaning of decisions such as those to determine the least restrictive environment (LRE) and how services might be provided (“pull out” or “push in” the child); scientific/medical language; and the ability to take on (or at least confidently convey) the role of “expert” with regard to the child’s “condition.” Janet’s master’s and doctoral degrees in special education certainly add credibility to her particular interpretations of assessment reports. Take, for example, the request from a school psychologist for an intelligence test to

determine a numeric quotient for Janet’s son upon arriving at a new school. She questioned the validity of the proposed assessment tool, arguing that she had used the tool herself and taught a college-level course on assessment illustrating the issues concerning so-called intelligence testing, so it was with ease that she quickly referenced related scholarly work (Borthwick, 1996; Kliewer & Biklen, 1996; Linneman, 2001). Janet also provided curriculum-based assessments she had secured from her son’s previous teachers as an alternative illustration of her son’s abilities. Few parents would have had this kind of skill set and the confidence needed to challenge the supposed power of the psychologist. Similarly, Janet’s specific training in special education sensitized her to the “hidden curriculum” of the IEP process so she might expend time and resources to prepare for IEP meetings. On occasion Janet found errors in the IEP document itself that she brought to the attention of the teachers or case managers, directly leading to changes in placement and services.

Race and Cultural Capital

While drawing important attention to the ways in which parenting styles help reproduce class privilege, Lareau’s work has been criticized for underestimating the effects of race (Bodovski, 2010; see also Lareau & Horvat, 1999). Bodovski (2010), using a large-scale representative survey, found that while socioeconomic status is related to cultural capital, race has an independent effect. Thus Bodovski (2010) found that black middle-class parents were less engaged in concerted cultivation than white middle-class parents. In addition, research suggests that factors such as race can affect institutional responses to similar displays of cultural capital.

So when black and white (both middle-class) parents actively negotiate for accommodations that are in their child's interest, educators perceive those interactions differently due to race. For example, Lareau and Horvat (1999) found that:

many black parents, given the historical legacy of racial discrimination in schools, cannot presume or trust that their children will be treated fairly in school. Yet, they encounter rules of the game in which educators define desirable family-school relationships as based on trust, partnership, cooperation, and deference. These rules are more difficult for black than white parents to comply with (p. 42).

The teachers repeatedly praised parents who had praised them. They liked parents who were deferential, expressed empathy with the difficulty of teachers' work, and had detailed information about their children's school experiences. In addition, the teachers often stressed the importance of parents "understanding" their children's educational situations, by which they meant that the parents should accept the teacher's definitions of their children's educational and social performance (p. 43).

McGrath and Kuriloff (1999) similarly find that African-American parents who express criticism of existing school policies and procedures were negatively evaluated by white elite mothers (seen as "always complaining"). This negative evaluation was used by white elite mothers to exclude black mothers from PTA (parent-teacher association) involvement.

Personal examples of racial privilege.

Racial privilege is perhaps more difficult than class to identify when one is white. But as whites in (vast) majority-white school systems, Janet and Heather are both aware that their ability to assertively negotiate for their sons is aided by their race. While the research discussed above finds that African-American parents display similar assertive behavior, it is often perceived by white educators (and other white parents) as aggressive and racially motivated.

Cultural Capital: "Individuality" and Middle-Class Parenting

Another element of cultural capital that researchers have identified is middle-class parents' tendency to emphasize their child's unique academic talents, preferred learning styles, competencies, and so on (Lareau, 2003). This tendency can be seen as within the larger picture of classed differences in interacting with the educational institution. Gillies (2005) found "parents' accounts demonstrated the extent to which the middle-class interviewees were invested in constructing their children as 'unique' and distinct from others" (p. 843). Similarly, Ong-Dean (2009) states:

While the creation of educational rights for disabled children follows in the footsteps of social reforms of the 1960s and 1970s, through which previously marginalized social groups gained access to new opportunities, this latest reform, unlike many of its predecessors, did not emphasize collective action or the goal of social justice. Instead individual families were to advocate for individual children's rights

toward the goal of meeting their “individualized” needs (p. 2).

Sleeter’s (1987) analysis of the development of the category of learning disabilities similarly highlights how “the ideology of individual difference” masks the political purpose of “protecting” white middle-class children from lower-class minority children. The idea is that parents can maintain their child’s inclusion among those considered of “normal intelligence” while arguing for variance in their child’s individualized learning support needs. This approach sees both the problem and solution as located within the individual child rather than examining broader societal systems.

Personal examples of individualizing processes.

This one is tricky because the “logic” of a child’s uniqueness is so central to the IEP process (starting with the title—“individualized” educational plan). There is also the obvious appeal to parents of a process that seems to acknowledge and appreciate their child’s uniqueness (although the various learning-disability, or LD, labels also constrain our understanding of the child as fitting into preconceived boxes). Unfortunately, another downside of this approach is that it creates a binary division (children with and without IEPs) where those without IEPs are seen as not unique (normative or slow learners, but not unique) and the kids with IEPs are separated for special accommodation.

In this chapter, we have examined how interactions with schools are structured to encourage an individual (“save my son”) approach over more collective approaches that might result in institutional change. While we are critical of the individual approach, we are aware that our perspective

may not represent those of other similarly privileged parents. Research on upper-middle-class parents suggests that this individual-advocate approach is actually consistent with and reflective of parental desire, not in opposition to it, particularly in the context of fighting for scarce resources. For example, McGrath and Kuriloff (1999) find “that elite parents’ advocacy for tracking is often driven by their desires to separate their children from those of lesser social status and to gain for their children access to the highest proportion of educational resources possible—often at the expense of other parents’ children (though we make no claim that upper-middle-class parents consciously recognize these distributive consequences)” (p. 606). Here, educators are seen as holding the more progressive and egalitarian position (i.e., detracking) while parents are the conservative force (McGrath & Kuriloff, 1999; Wells & Serna, 1996). McGrath and Kuriloff (1999) find this extends to special education, where elite parents also angle for a competitive advantage for their children:

Wealthier parents with children in the special education program often approached the school with similar intentions. For instance, some upper-middle-class parents sought to separate their special education children from other special education children, especially African American children. Often, they demanded that the district pay for private school placements (p. 619).

The authors continue, “Similarly, these (White elite) parents sought the most resources that they could get for their own children” (p. 621). In their study, Ong-Dean, Daly, and Park (2011) found evidence that parents with higher economic and cultural capital were more successful in securing

public school resources, such as reimbursement claims for private educational costs, than other parents. Brantlinger, Majd-Jabbari, and Guskin (1996) found that even middle-class, educated mothers who claim a liberal identity and commitment to integrated and inclusive education “often support segregated and stratified school structures that mainly benefit students of the middle class” (p. 590).

Cultural Capital, Preferential Labeling, and Placement

As discussed above, researchers have analyzed the crucial role of middleclass parents in creating the “learning disability” category (Blanchett, 2006; Ong-Dean, 2009; Sleeter, 1987), reflecting the desire for middle-class parents for preferential labels within the special education context, and rejection of negatively stigmatized labels (e.g., behavior, “mentally retarded,” etc.) (Blair & Scott, 2002). Even Dunn, back in 1968, warned that the special education categories risked labels and that related placements were being used to re-sort children based on disability, race, culture, language, and social class. The overrepresentation of minorities in certain less preferential categories continues today, which is why in Colorado we have Indicator 9, requiring schools to put into place protections against such problems (Smith, 2004). In fact, IDEA 2004 requires all states to collect demographic data regarding disability determination, but recent reports indicate only twenty-six states focused their monitoring and improvement efforts on the disproportionate representation of racial/ethnic groups in special education (US Commission on Civil Rights, USCCR, 2009). Those states reporting results from 2003 indicate “African American students are three times as likely to receive services

for mental retardation under IDEA Part B as are their age peers from the other racial/ethnic groups combined” (USCCR, p. 36). It is abundantly clear that cultural capital plays a role in preferential labeling of students who need educational supports.

Privilege has also been found to lead to different LRE (least restrictive environment) placements (Conway, 2005). In her discussion of the role race, class, and culture play in perpetuating segregation resulting from white middle-class families seeking privileged eligibility categories (such as learning disabilities rather than mental retardation), Blanchett (2010) outlines the inequitable treatment families of color receive in the special education process. Using large-scale national data sets from 2005 through 2009, she points out that despite four decades of research into addressing the overrepresentation of minorities in special education who end up in even more segregated settings than their white counterparts with the same labels, the problem persists. Interestingly, state-and district-level differences also suggest similar trends, but the intricacies of how labels and placements are determined is largely undocumented. What we do know is that there are large variances in the way the federal laws are interpreted and implemented at local levels. Blanchett (2010) explains,

When the privilege conferred by the LD label is compounded by the privilege of whiteness and social class privilege, it greatly advantages those students. However, when LD intersects with lower socio-economic status or class and with being African American or of color, the privileges . . . that are often associated with LD are denied these students (“Learning Disabilities: A

Category of Privilege” section, para. 6).

The 27th Annual Report to Congress (2005) illustrates the daily impact these differences have in educating students. It noted the concern of the finding that black students with disabilities were more likely than students with disabilities from other racial/ethnic groups to be educated outside the regular classroom more than 60 percent of the day. This is important because a relationship has been found between more restrictive placements and increased dropout rates, resulting in inequitable post-school opportunities. In an effort to explain why these discrepancies persist, Blanchett (2010) calls racism, white privilege, and white dominance and supremacy “the primary culprits.”

Some disability-studies scholars discuss how a “special” education, particularly when students are “pulled out” of the regular classroom, can be seen as segregation, where students with disabilities are socially isolated and stigmatized. (Barnes, Mercer, & Shakespeare, 1999; Irvin, 2004; Linton, 1998). Even when individualized “special” services are “pushed in” to the classroom, (e.g. a paraprofessional assigned to work with a single student), stigmatization from other students is an issue. As Conway (2005) points out, “Because special education often separates children with disabilities from their non-disabled peers, whether physically or nominally, it can also promote the very stereotypes of freakishness, pity, and lack of ability from which people with disabilities struggle to be free. Special education can be a subtle, or not-so subtle, form of discrimination that tracks children according to their ‘ability’ or other ‘distinctive’ characteristics” (Conway, 2005, p. 6). By contrast, many educators who tend not to

come from a disability studies perspective, view special education as the solution that represents every child’s right to an education (Council for Exceptional Children, 2012). Given the uneven adoption of inclusive (vs traditional “special education” approaches) considerable variation exists in the U.S. among educators as to which approach is in the best interest of a child with disabilities. It would likely follow that those parents with the least cultural capital would be most likely to capitulate to the strategies embraced by educators (Lareau, 2003).

Preferential Labeling and “Twice Exceptional”

Perhaps the gold ring for parents of children with disabilities, the additive label (and corresponding resource pool) of “gifted and talented” (making the child “twice exceptional”), has obvious appeal. On the one hand, it fits well with a diversity model open to the possibility of unique talents, learning differences, and strengths. But, as seen with the competition for preferential labeling within special education, it is subject to the same inequities in application. For example, in her discursive analysis of the justification of “highly gifted and talented” programs, Young (2010) argues these programs serve to reproduce class and racial stratification.

Personal examples of pre-referential labeling.

As previously mentioned, upon moving to Colorado, Janet refused IQ testing and the suggestion by some educational personnel to ascribe the state-based presumed label of SLIC, or significantly limited intellectual capacity for students with Down syndrome (see Sauer, in press). The family spent hours in discussion, email exchanges, and phone calls with the

schools, negotiating the label to be ascribed to Janet's son. Some professionals threatened a loss of future services if the parents were to refuse the recommended label. In the end it was agreed to adopt "physical disability" as the primary disabling condition and speech/language/communication as the secondary label. The family in this case was acutely aware of the social stigma related to labels such as SLIC or mental retardation, as well as its effect on teachers' expectations. At the same time, they were conscious of their right to refuse testing and knew if necessary they could recruit "experts" on their own behalf through parent advocacy groups and professional colleagues. In fact, each time an educator offered the family the parents' rights booklet that outlined these legal guidelines, Janet would give the teacher a knowing smile that seemed to communicate the shared understanding that these parents were very aware of their rights.

In the process of testing Heather's son, the neuropsychologist verbally expressed the opinion that (in addition to various other diagnoses) he had attention-deficit/hyperactivity disorder (ADHD). While accepting the other "more palatable" labels, Heather rejected the ADHD label and asked that it not be included (at least as a definitive diagnosis) in the report that would be shared with the school. The external (to the school) neuropsychological testing Heather's son received allowed for preferential labels (medical/neurological diagnosis of ataxia, "twice exceptional"). The parents rejected non-preferred labels (ADHD) that the testing had also generated.

Social Capital

Whereas cultural capital is understood as an individual's stock of high-status etiquette, tastes, preferences, and

behaviors, social capital is composed of the interpersonal networks or connections that individuals can draw on for support, information, and other favors (Coleman, 1988). A number of studies have indicated that middle-class parents are able to more successfully leverage their social capital in school interactions than less privileged parents (Horvat, Weininger, & Lareau, 2003; Pong, Hao, & Gardner, 2005). McGrath and Kuriloff (1999) summarize their finding: "The social networks that upper-middle-class parents form through schools help them to gain crucial knowledge about the workings of schools and to make influential social contact" (p. 606).

Personal examples of social capital.

Heather has had many conversations with other parents of children with IEPs. These conversations can be viewed as an example of social capital, including shared experiences of problematic negotiations and what kinds of accommodations other children are getting. In one conversation where parents were sharing their frustration with the consistent lack of follow-through on the written IEP, one parent mentioned that it was "obvious" and "expected" that parents would need to get a lawyer to force the school into compliance. While Heather has never felt compelled to hire a lawyer, just knowing that such recourse was out there (and having the financial resources to employ it) potentially shifts the balance of power in the IEP meeting. Throughout her son's fifteen years, Janet has employed her social capital in her advocacy efforts. She regularly provides her son's teachers and therapists with current literature and at times she has served as a volunteer parent and professional consultant, and educational researcher to schools. Through her work in pre-service education she has collaborated with teachers who have come to the

university as guest speakers and co-presented at conferences and workshops. As Janet occasionally chooses to point out, she was a teacher before becoming a mother and those identities do not have clearly delineated boundaries. Perhaps a less obvious but equally significant example of social (and economic) capital is that Janet typically brings food to the school meetings, recognizing that when she was a teacher she enjoyed meetings where food was shared.

Symbolic Capital

In addition to the actual knowledge accumulation (or human capital) assumed to be reflected in a professional degree, a doctoral degree confers symbolic capital based on prestige. Our case is interesting because whereas most parents enter school decision-making meetings (such as IEP meetings) with educators at a comparative disadvantage in terms of information and power (Fine, 1993), in our case that balance of power is questionable. While it is hard to demonstrate specific advantages gained because we have professional degrees, it would seem naive to assume they had no effect. As Ong-Dean et al. (2011) argue, “Whether they request a hearing or not, their words and actions are backed up by a material and symbolic power, which may be effective in the moment or may stand as a reminder of what could happen if they chose to fully exercise their rights” (p. 396). Another form of symbolic privilege worth noting is that of our married, heterosexual statuses. While mothers do the vast majority of interaction with their children’s schooling (Reay, 1998), research does suggest that, perhaps due in part to its relative scarcity, father involvement has a positive and mediating effect on educational outcomes (McBride, Schoppe-Sullivan, & Ho, 2005).

Personal examples of symbolic privilege.

In both Janet’s and Heather’s cases, their husbands typically attend every IEP meeting, if only to try to compensate for the large numbers of school professionals in an IEP meeting (usually five to eight). While it is difficult to point to a specific payoff for this effort, it would at a minimum seem to impress upon the IEP team the seriousness with which these parents take their children’s education (all taking off work) and willingness to fight for the desired accommodations. In Heather’s case, her husband has been the only man present at any of the IEP meetings (and any interaction with the elementary school). Janet has noticed subtle differences in the communication style in meetings when her husband is present.

Rehabilitative Approach Versus Disability Studies Approach

The second process we consider is how parents are pushed to accept the rehabilitative approach over an approach that questions the construction of “disability” and the range of possible institutional responses to it. Current orientations toward disability are based in a history of “otherness” that necessitates a rehabilitative approach to educating students who might experience impairments (Kliwer & Biklen, 2007). The systems that emerged from the deinstitutionalization movement of the 1960s and 1970s (Larsen, 1976) were framed as issues of access for people considered to experience significant disabilities (Jackson, 2005).

However, public discourse continues to rely upon a historical consciousness whereby impairment is pitied and viewed through a medical/deficit model. In the lives of American youth with disabilities, the

rehabilitative approach has meant segregated education. The thinking is, “You are broken, you cannot ‘fit’ among your nondisabled peers, and thus you need to go elsewhere to get some specialized education or related services and then you can return/reenter the general education learning environment.” Despite the unevenness in which different states and school districts determine placement of services, students considered to have more moderate or severe disabilities are typically removed (IDEA data). Even students with the most “mild” of disabilities are often removed from their general education classrooms for therapy sessions.

Jackson (2005) explains how arguments regarding segregation in disability parallel those used to justify slavery:

As an analogy, it has been said that slave traders justified their vocation by arguing that while slavery may be bad, the natives were better off because they were now in the new world and not in Africa. Likewise, many special educators acknowledge that restrictive placements can be problematic because of their enforced isolation from peers and typical experiences of life, but some then argue that the educational benefits of such placements outweigh the negative effects of segregation. In severe disabilities, neither the research data nor the day to day experiences of persons who know the field support the educational benefits argument for segregation. Only when such reasoning is set aside can significant access concerns be resolved, and only at this point can equity and quality concerns assume their rightful place as important

determinants of the critical issues in the discourse of our profession (p. 7).

Restrictive placement justifications are regularly made as part of the IEP process, but few families describe this intellectual negotiation as open, flexible, or clearly explained. Despite legislation guaranteeing active parent involvement and a process whereby the placement of services is to be determined only after assessment and goal-setting discussion, some families report that placement decisions were made before meetings. The link between labels and placement in practices across the United States is important because this has been a factor in families’ ability to advocate for particular labels based upon cultural capital.

Finally, from a disability studies theoretical framework, we question how our participation in these two processes helps reproduce the existing structures of inequality. Goodley, Mallet, Lawthom, Burke, and Bolt (2010) write:

Disability must be analyzed as a social and cultural phenomenon, which says as much about normalizing/non-disabled society as it does about the constitution of disability. Indeed, in the current economic climate, the need for analyses of disablism in everyday cultural life is arguably more necessary than ever (p. 3).

We write from a place of privilege, torn between two roads. The first follows our inclination to avail ourselves of the various form of capital (cultural, social, symbolic, economic) we can access with relative ease to benefit our own children in the immediate future (potentially at the expense of less privileged children). The second involves working toward systemic change that can

influence the lives of children less privileged that will take more time. While this problem and the possible solutions are not necessarily mutually exclusive, it seems worthwhile to reexamine the underlying reason for the tension. Who benefits from these structures and practices? Are we being duped into thinking it is okay to work toward our own children's "appropriate education" at the expense of other children and their teachers and families?

Personal examples of the rehabilitative approach.

The following quote from Heather's son's neuropsychology report illustrates the rehabilitative or medical model:

Robbie is fortunate to have parents who are highly invested in promoting his development and well-being. They have provided excellent advocacy for his needs and should be commended for their dedication to seeing that Robbie's potential is maximized. It was a pleasure working with Robbie and his family.

Heather found this statement somewhat bizarre and questioned its purpose and meaning. She interpreted it as a reward for pursuing the individual advocacy strategy and encouragement to continue to work within the current structure. This was one of a number of times that she felt embraced by the educational institution, reflecting a good "fit" between the "type" of parents we are and the institutional practices at play (see Doucet, 2011; Van Galen, 1987, for a discussion of how schools structure and constrain parental involvement).

On the other hand, rather than using a parent support group for parents of students with disabilities to bring disability

into equity discussions, Janet joined the PTA and its discussions of racism. Being keenly aware of her white race, Janet listened to a fellow parent chaperone at their children's middle-school dance talk about the recent use of racial epitaphs against her "mixed-race" daughter. This mother was one of a growing number of parents at their small, predominantly white school who felt the need to meet with the district leaders and discuss what seemed like a spike in prejudice against students of color. Janet and her husband joined what became known as the "angry parent meetings" and they tried to explain how the racial tension was part of a larger issue regarding a lack of respect for student diversity.

It's unclear how these discussions might have changed other families' or the school personnel's attitudes toward the idea expressed by Martin Luther King, Jr. (1963):

I am cognizant of the interrelatedness of all communities and states. I cannot sit idly by in Atlanta and not be concerned about what happens in Birmingham. Injustice anywhere is a threat to justice everywhere.

Janet used this quote in a complaint letter she wrote to the school upon learning that her son with disabilities was socially excluded from an activity celebrating King's birthday.

Discussion

This chapter provides personal experiences illustrating how privilege is implicated in the way certain parents interact with schools regarding their children served through special education. Skrtic and McCall (2011) consider how legislation enacted to support children with disabilities differentially benefited children of white,

middle-class (professional) families through access to decision-making and due process. They argue that antidemocratic practices resulted from IDEA because the practices are case-based, individualized, and “closed,” thus “muting” the broad systemic issues. They contend a reinterpretation of “needs politics” is needed from one based on a decontextualized rights-based struggle to one where the “medium of struggle [is] in an institutional context,” which provides a space of opposition that is more empowering and democratic. Their work highlights experiences of the “least privileged” where schools used delay tactics and questioned families’ credibility and thus their rights for access to due process. In this chapter, we reverse the focus to questioning ourselves as (unintentional) reproducers of inequity. As Sleeter (1987) turned her gaze to critical self-reflection in her early critique of special education, we, too, hope that our experiences and perspectives offer a “standpoint from which to view schools and society” (Sleeter, 2010). We believe that by sharing our personal experiences analyzed through a disability studies lens, we have contributed to a greater understanding of the effect our individual responses to disability seem to perpetuate problems in the field, particularly for families of children with disabilities who are already marginalized due to their class or race.

Ball (1994) “insists that to transform social hierarchies, it is necessary to understand groups that have the power to control them” (as cited in Brantlinger, 2003, p. 189). Indeed, we have implicated ourselves by bringing these personal stories forward. The process has been at times demoralizing and somewhat embarrassing, but it can also be viewed as a first step in moving forward in the process of change by seeking the critical feedback from our colleagues, both personal and professional,

in our attempt to unpack and make public the ways we ourselves have become oppressors. The sharing of our stories is not intended to be used by other parents as strategies for individual advocacy on behalf of children. Rather, we hope families might see themselves in these stories and share in recognizing how our role in navigating the educational system works to perpetuate historical inequalities. Once these are realized, we think we can more readily assent to (or take leadership in creating) changes on the systemic level.

Educational leaders, too, can take into account these personal examples and the related literature to more critically inform their practices. They might become more aware of the ways in which they ignore or even contribute to perpetuating practices that privilege certain families. At a time when public education is increasingly scrutinized and resources are limited, educational leaders could exercise their own agency to become change agents. Critical dispositions are necessary for inclusive school leaders to, in the words of Frattura, “choose to be emancipators” (Theoharis & Causton-Theoharis, 2008, p. 243). Initiatives that honor democratic principles for social justice in inclusive, culturally responsive classrooms have been developed (for example, see the *International Journal of Whole Schooling*), but they need leaders to enact them. Through critical self-examination, families and educators could find opportunities to collaborate on developing a broad shared vision for inclusive schooling that would focus energies on redirecting practices and creating policies away from reliance on individualism and move toward collective work that recognizes the value of our interconnectedness. It is important to include families whose children are not directly involved in the special education process to

become informed about these inequities so they might become allies. Just as Janet has pushed for inclusive education as a right and benefit for all children, she has found it important to infuse disability into PTA conversations about diversity.

As society has come to realize the need to address economic disparity, we need to address the ways in which social and cultural capital are used in the special education process. We suggest that expanding access to a disability studies theoretical framework in educational pre-service programs and parent advocacy will help facilitate a broader, interdisciplinary audience where we can build alliances toward changing educational inequities.

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