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## Disability, Stigma and Otherness: Perspectives of Parents and Teachers

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## **Disability, Stigma and Otherness: Perspectives of Parents and Teachers**

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This qualitative study explored the perspectives of parents and teachers in the US with regard to the meaning and implications of disability in the context of schooling, and of raising a child with a disability. The findings revealed broad conceptual differences in the perspectives of these two groups. Teachers' beliefs were generally consistent with medical model perspectives on disability as biologically defined. Parents' interpretations, more aligned with a sociocultural paradigm, were situated in the cultural meanings ascribed to disability and linked with issues of stigma, marginalisation and access. The findings also revealed the existence of master narratives on families of children with disabilities, entrenched in assumptions of pathological functioning and negative outcomes among these families. Implications for professional–family partnerships in the education of students with disabilities are discussed.

**Keywords:** disability studies; dominant discourses; families of children with disabilities; parents' perceptions; professional–family partnerships; social model of disability; sociocultural contexts of disability; teachers' beliefs about disability

### **Introduction**

Family–professional collaboration is considered to be a cornerstone in educational practices for children with disabilities; special education laws in the USA (IDEA, 2004) explicitly identify the role of family members as partners in all aspects of educational planning and decision-making. Existing literature in the area of family–professional partnership suggest that there is wide variability in parents' perceptions of their experiences with special education professionals. Some studies indicate largely positive perceptions among parents of children receiving special education services (Childre & Chambers, 2005; Fish, 2008), while others highlight parents' feelings of frustration or alienation, or their perceptions of adversarial relationships with education professionals (Fish, 2006; Kalyanpur, Harry, & Skrtic, 2000). Additionally, some studies highlight the tensions between special education professionals and families from low-income or ethnic minority backgrounds (Cho & Gannotti, 2005; Salas, 2004), and reveal that Western expectations of collaboration may be inconsistent with, or collide with, the cultural belief systems of some families (Harry, 2008; Kalyanpur et al., 2000).

A related body of research is concerned with understanding parents' experiences of raising a child with a disability. Master narratives on the experience of parenting a child with a disability centre on notions of profound loss, grief and burden, and these are

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upheld in institutional discourses and practices (Lalvani, 2011). A substantial body of research literature lends support to these notions; however, in traditional research the interpretations of professionals are privileged over those of parents (Lalvani & Polvere, 2013). More recently, in an emerging body of narrative research which seeks to understand the experiences of families of children with disabilities from their own perspectives, it is indicated that parents do not experience the presence of a child with a disability in a homogeneous or universally negative manner, and that there is a wide range of outcomes for these families (Ferguson, 2002; Lalvani, 2011; Van Riper, 2007). Beyond this, parents' interpretations of having a child with a disability are often situated in the sociocultural meanings ascribed to the constructs of disability, normalcy and parenthood (Fisher & Goodley, 2007; Goddard, Lehr, & Lapadat, 2000; Lalvani, 2011). Narrative research on parents' perspectives is potentially informative in the context of the education of children with disabilities; it could be argued that parents' socio-culturally situated interpretations of disability and of their familial experiences may be connected to their participation in educational planning, and are likely to influence both the decisions they make for their children's schooling as well as their interactions with professionals.

Similarly, it could be argued that teachers' perspectives on disability and their beliefs about families of children with disabilities can also inform a discussion on professional–family partnerships. However, there is little research concerning teachers' conceptualisations of disability or their understanding of the experiences of families of children with disabilities. This study aims to fill this gap, and is based on a stance that professional–family partnerships are situated in the beliefs, perceptions, and interpretations of both groups with regard to the fundamental goals and issues involved in the education of students with disabilities.

This study is grounded in the perspectives offered in critical disability studies which frames disability as a socially constructed phenomenon, its meaning embedded in sociopolitical contexts, rather than as a biological or universal reality (Baglieri & Shapiro, 2012; Davis, 2002). Disability studies scholarship is fundamentally derived from socio-cultural theory (Vygotsky, 1978) which emphasises the situated nature of all individual experiences and understands these as inseparable from the contexts within which they exist. Drawing from a social constructivist epistemological paradigm, critical disability studies focuses on the political, economic, social, and cultural oppression that people with impairments experience, and contends that the concepts of normalcy and disability are strongly influenced by those in positions of power and control (Kliewer, 1998).

Furthermore, this study is based in a view of narrative as a tool for constructivist inquiry (Sparkes & Smith, 2008). Narratives are a pervasive and crucial activity through which the human experience is simultaneously projected and shaped (Phoenix & Smith, 2011). Although the term narrative has been interpreted in different ways by scholars, this study takes an approach that is informed by the premises offered in social constructionism (Gergen, 1985) and discourse analysis (Bruner, 1991); rejecting the notion of narratives as storied accounts that transmit a set of existing realities, narratives are instead understood as social products and devices through which meaning unfolds (Bamberg, 2004) and particular perspectives are privileged. Of course, the privileging of particular perspectives in narrative research is itself embedded in multiple contexts and does not exist in a socio-cultural vacuum. As Ferguson, Ferguson, and Taylor (1992) point out, whenever we, as researchers, tell other people's stories we inevitably become involved in telling *our* stories of *their* stories. Thus, using an interpretivist

approach, the narratives of parents and teachers in this study are examined through the lens of critical disability studies and understood as their engagement in meaning-making regarding the education of students with disabilities, and indeed disability itself.

Keen (2007) asserts that meaningful and productive partnerships between families and professionals rely, in part, on true collaboration toward shared visions and goals. However, drawing from CDT perspectives, it can be further argued that neither professionals' nor parents' visions and goals for children with disabilities exist in a sociopolitical vacuum; rather, they are linked with the constructed and contextualised meanings ascribed by individuals and societies to the phenomenon of disability. Therefore, professional–family partnerships toward the end of improving educational outcomes for students with disabilities may be strengthened by understanding the ways in which situated interpretations of disability influence the educational decision-making process for this group of students. To this end, this study aims to unravel the complexities, nuances, similarities and conflicts in the interpretations of parents and teachers, regarding the salient issues and concerns in educating or raising children with disabilities.

### **Methodology**

Qualitative methods were used for this study. Semi-structured interviews were used in order to elicit narratives from parents and teachers. This strategy is consistent with the study's aim to gather rich and descriptive information as well as with its emphasis on understanding the contexts in which individuals interpret their experiences and in which meaning is derived (Bogdan & Biklen, 2007). In the tradition of narrative inquiry, the study was based conceptually and methodologically on a stance that there are multiple frames of reference rather than objective realities (Denzin & Lincoln, 2000).

### ***Participants***

#### *Parents*

Thirty-two parents of children receiving special education services in New Jersey participated. They were from a wide range of ethnic, cultural, linguistic, and socioeconomic backgrounds. The majority was married and seven were single parents. There were two fathers who participated in the study; the rest were mothers. The ages of their children receiving special education services ranged from 4 to 14 years. They identified their children's disabilities as: Down syndrome, autism, Asperger's syndrome, speech impairment, learning disability, ADHD, fragile X syndrome, and hearing impairment.

#### *Teachers*

Thirty teachers (20 general education teachers and 10 special education teachers) currently teaching in New Jersey public elementary schools participated in this study. In terms of gender, 4 were male and 26 were female. Their teaching experience ranged from 4 to 30 years.

### ***Recruitment and Data Collection***

#### *Parents*

Written information about the study was circulated among the members of several parent groups and organisations. This represents a technique known as purposeful sampling

(Bogdan & Biklen, 1998). I also employed a sampling strategy known as snowballing (Patton, 1990); parents who participated were asked to provide information about the study to other parents of children with disabilities whom they knew. Data were collected through individual, semi-structured interviews. The interviews were guided by open-ended questions about parents' experiences navigating the special education system, their experiences with education professionals and their interpretations of having a child with a disability. Examples of questions include: "Are you satisfied with your child's educational programme?" and "What does a typical weekend look like in your home?" The average length of the interviews was approximately two hours.

### *Teachers*

Flyers which described the study were posted at elementary schools in New Jersey. Teachers who were interested in participating contacted the author. Additionally, the snowballing technique (Patton, 1990), described above, was utilised. Semi-structured interviews were conducted with teachers who sought to participate in this study. The interviews were guided by open-ended questions that encouraged teachers to reflect on their beliefs about disability and the education of children with disabilities. Teachers were also asked to reflect on their beliefs about the quality of life, functioning, and concerns among families of children with disabilities. Examples of questions were: "In your opinion what is the best learning environment for children with disabilities?" and "What do you imagine a typical weekend might be like for families that have children with disabilities?" Interviews lasted between one and three hours. All interviews were audio-recorded and later transcribed.

### *Data Analysis*

This study used the methods of inductive analysis which is a commonly used technique derived from grounded theory (Patton, 1990). In inductive analysis, patterns, themes, and categories of analyses emerge from the data rather than being predetermined prior to the analysis (Patton, 1990). Using this method, transcripts were reviewed for any and all patterns and commonalities in perspectives. Initially all issues and concerns raised by parents and teachers were noted in a non-discriminate manner, and initial codes were identified based upon frequency and consistency of particular concerns or issues raised in either group of participants. Following this, categories of codes were clustered together under more abstract stratifications or themes; each theme consisted of a cluster of codes containing salient and discrete accounts or perceptions that pertained to a broader conceptual idea. Once the final codes were identified, the data from both groups of participants were coded under the same coding system. All coding and data analysis was done by the author.

### **Findings**

The narratives yielded a wide range of findings which are presented as follows, organised under two broad sections entitled: (a) The meaning of disability, and (b) Beliefs about families of children with disabilities. Each section discusses clusters of findings which emerged, organised by the codes which were used. Although the findings highlight conceptual differences in the perspectives of parents and teachers, it should be noted that there were also commonalities in their perspectives, just as there was also

variability in perspectives *within* each of these groups, and these are discussed throughout.

### ***The Meaning of Disability***

#### *Interpretations of Labels*

A consistent theme in the parents' narratives pertained to the issue of *labelling*, or the classification of students under disability categories for the purpose of receiving special education services in schools. Some parents had negative views about labelling *per se*, articulating beliefs that the identification of a child with a disability alters perceptions of the child. More commonly, parents had strong reactions to *specific* disability labels which they viewed as less acceptable than others, and many went to great lengths to advocate for the classification of their children under labels they believed were less stigmatising than those ascribed to their children by professionals. The least desirable label was cognitive impairment or intellectual disability (which some parents referred to by the formerly used term "mental retardation"); parents whose children were assigned these labels reacted in strongly negative ways.

Parents who resisted the labelling of their children were not necessarily in disagreement with professionals about their children's difficulties in school or about their children's developmental delays. Rather, for some, interpretations of "normal" versus "impaired" cognitive functioning differed from those of professionals. The mother quoted below explained her reasoning for her resistance to the label of "mental retardation" for her son:

That is the one I argued. Autism—I can accept that one. But the mental retardation—I don't see it—because there's no danger. He ride his bicycle, he ride his scooter, all those things he's doing. He go out, he plays very well. He don't go wild or run into children, I don't think. He's not really talking, but he knows everything that's going on ... Mentally retarded children, they don't know what they are doing, like they could run into the street. When he's riding his bicycle to go to the park ... he knows to stop. To cross the street, he has to wait for me. He has common sense.

Other parents articulated beliefs that being labelled as "cognitively impaired" would lower teachers' expectations of their children and would stigmatise them, as seen in this quote from one father:

(The psychologist) kept saying, "cognitively impaired ... this means mildly retarded." And I said, "I know what cognitively impaired, means." Then they said, "Why are you so afraid of that label?" I said: "If God whispered in my ear and said your son is mildly retarded I still wouldn't allow you to put it in the paperwork because I know the next teacher is going to put a ceiling on it ... Those are strong words. I am not going to go with that label even if you convinced me it's true. You're gonna call it something different because when you sense someone is mildly retarded you're assuming there's a ceiling ..." So we had a bit of a battle with that.

Whether they sought to obtain a specific classification or to avoid it, many parents were acutely aware of the implications of labelling children. Although the issue of labelling was reportedly a source of conflict between some parents and professionals, disagreements were typically *not* over the identification of the child as needing special education. Parents resisted the negative implications of *specific* labels, as seen

in this mother's explanation of her resistance to professionals' labelling of her son as "autistic":

I really don't want to use the label right now because of the preconceived notions of autism ... Right now, I want to say David has developmental delay, or a developmental disability, or he needs help with his speech, he needs help with his motor skills ... And it's not that I'm in denial about the label, but I'm fearful of the way other children and other adults react ... Right now I think it's more harmful to give it a label than it is helpful.

In contrast, for most teachers, regardless of their number of years of teaching experience, disability categories and labels were viewed as helpful in determining educational placement, programming, or learning goals. Some expressed beliefs about access to inclusive learning environments as based on specific disabilities that children may have. Many teachers considered placement in a general education classroom to be unrealistic for students with labels of intellectual disabilities or autism, believing that children with autism require a separate programme that focuses on Applied Behavioural Analysis (ABA), and that those with intellectual disabilities would benefit from a "life skills curriculum" rather than one that is focused on literacy and academics. For example one teacher said:

A child who is autistic—they have to be in the autistic room because their needs are so unique that they do have to be there. But, like ADHD, maybe Asperger's, things like that, they can be mainstreamed.

### *Stigma*

Many parents expressed beliefs that negative reactions to their children were elicited by their being identified as having a disability or as receiving special education. In articulating these concerns, they understood the stigma to be greater when children were removed from general education classrooms for services or when children were being educated predominantly in a self-contained classroom. One mother related this story:

My other daughter's friend was over and she was looking at Chloe's homework because it was spread out on the table, and there was a math worksheet from this particular special ed. teacher—Mrs. L. Everybody knows Mrs. L is with the kids from the self-contained class. And this girl said: "Oh, Mrs. L? She has Mrs. L?" And she said it in the tone like this is a bad thing. So the stigma is definitely there. I know that the kids are talking about it—"Oh, she's in Mrs. L's class."

Most teachers did not consider stigma to be associated with disability. Some expressed perceptions that disability is no longer stigmatised in society or that, although they were aware that parents may have concerns about stigma, they believed their concerns to be unnecessary. However, five teachers in the sample did raise the issue of segregated learning environments as contributing to the problem of the marginalisation and stigmatisation of students with disabilities. This is seen in this teacher's comments:

There's a young man in my homeroom who has autism, and when he has to go out for services, his whole physical demeanour changes—the head down, the shoulder slump. He knows something is different about him than everyone else. In an ideal world, I would never let him leave my room. Because what I'm doing is, I'm sending a signal, a message

to him or her as well as those that don't have needs that there's something inherently different about this individual.

These teachers (who varied in terms of their years of teaching experience) reflected on the negative impact of separate education for students with disabilities. Their views were closely aligned with the beliefs of most parents, with regard to the experience of disability as linked with socio-cultural attitudes.

### *Otherness*

Many teachers attributed positive as well as negative learning outcomes to students' inherent or innate characteristics. As such, some children were viewed as having the capability to successfully learn school curricula or as having "gifts", while children who had difficulties in school were viewed by many teachers as "being wired differently". In discussing their beliefs about the education of students with developmental disabilities, many teachers (general and special education teachers alike) adhered to beliefs about this group of students as requiring significantly different methods of education, usually in separate environments. As such, they focused on the differences of students with developmental disabilities, rather than on characteristics that rendered them largely similar to those without disabilities. However, five teachers (whose views were discussed in the earlier section) rejected the notion that "some children are smarter than others" and instead expressed beliefs that learning outcomes are situated in multiple contexts. This small group of teachers also expressed the strongest personal commitment to inclusive teaching practices.

Most parents on the other hand, positioned their children as more similar to, than different from, children without disabilities. For them, the meaning of disability was linked with the ways in which their children were perceived in schools and in society. Some resisted the placement of their children in self-contained classrooms because this was understood as reifying notions of the *otherness* of their children, and alternatively sought access to inclusive classrooms because of beliefs that their children "belong" with their peers. Others explained their preferences for self-contained environments as motivated by a desire to protect their children from peer-rejection and social isolation in general education environments. Regardless of whether they sought inclusive or self-contained settings, parents' advocacy for access to particular learning environments for their children was often rooted in issues of belongingness.

### *Locating Disability*

Among teachers, the difficulties experienced by students with disabilities were more commonly understood as stemming from their impairments or from limitations in functioning. Successful and unsuccessful outcomes for students with disabilities educated inclusively were attributed to individual students' attention spans, behaviours, or abilities to function independently or semi-independently. The accessibility of general education curricula, teaching practices, and institutional ableism were not typically examined. Similarly, in discussing the topic of peer rejection, bullying, or the social isolation of students with disabilities in general education classrooms, the problem was more often understood as stemming from the inherent differences of students with disabilities, rather than attributed to lack of understanding, awareness, or acceptance among the nondisabled population. With regard to this, many teachers believed the solution to be the placement of students with



disabilities in “safe” environments, which were identified as self-contained classrooms. That the removal of rejected students from general education settings might serve to further stigmatise and marginalise them, and that this solution would do little to address the attitudes of nondisabled students, was not considered by teachers.

Parents’ narratives suggest that many of them understood the “problems” faced by their children in school as a complex interplay of their children’s impairments with the kinds of instruction they received, and with the school environment overall. Many parents believed that successful educational outcomes for their children depended on whether they received accommodations such that they could access curricula and on the strategies used to teach their children. Additionally, many parents discussed their beliefs about negative societal attitudes toward disability and about general education teachers as unwilling to teach children with disabilities, outlining these as potential issues in the education of their children. Many raised concerns about the potential social isolation of their children with disabilities in general education classrooms. Although for some, these concerns fuelled a support for self-contained learning environments, most parents believed that interventions should involve addressing the attitudes of nondisabled peers in general education classrooms. Overall, parents tended to locate the source of the “problems” for children with disabilities in educational and social environments. In contrast, teachers were more apt to locate the “problems” for students with disabilities within individual minds and bodies, leaving individual, cultural, and institutional practices unexamined.

### ***Beliefs about Families of Children with Disabilities***

#### *Assumptions of Stress, Grief, and Burden*

Although teachers articulated positive perceptions about individual parents of children with disabilities whom they knew, in general, most held beliefs that were consistent with dominant cultural narratives about the lives of this group of parents as characterised by burden, grief, and inordinate levels of stress. In their discussions about this group of families, notions about grieving over the loss of a “normal child” or of “a dream” were prevalent. One teacher said:

I would have to believe that when you have a child you have a dream of a certain thing happening. Them growing up a certain way, or taking them to a park and having them play, or you have a dream of them growing up and having children. You know, you have a dream and when the disability takes away that dream, I’d imagine you’d feel a lot of loss.

Many teachers articulated beliefs that feelings of grief and loss are likely to be manifested throughout these parents’ lives. In discussing what they believed it might be like to raise a child with a disability, teachers used terms like: “a struggle”, “drains their emotions”, and “wears them out”. As such, being a parent of a child with a disability was understood by many teachers as a predominantly negative life experience, and as the teacher quoted below articulated, one that she is “lucky” not to have:

I could never imagine being in their shoes and I’m glad I’m not in their shoes ... I’m really lucky ... ‘Cause I think it’s a lot of hard work. And they would just like to wake up and have a normal day.

Additionally, many teachers located the source of parents’ grief or stress in their children’s impairments. The everyday difficulties which many teachers believed

characterised the lives of this group of families were understood as resulting directly from physical, cognitive, or sensory limitations embodied in children, which prevented families from having “a normal life”. This is seen, for example, in one teacher’s expressed views that parents of children with disabilities have “a real fear that their child cannot live a successful, happy life as a result of their disability”. Another teacher articulated it in this way:

They don’t have the life you wanted for them. I think it’s a great deal of grief for many parents ... and then many times it stays because if the child isn’t able to improve much, you know you’re just always seeing them struggle and I, I think it’s a great loss.

Conspicuously absent in teachers’ reflections about this group of families were any acknowledgements of the socio-cultural nature of the experience of raising a child with a disability, and the contexts in which the experiences of families are situated. Teachers in this study did not raise issues related to marginalisation or negative societal attitudes toward disability as potential stressors among these families; no differences were noted in the views of general and special education teachers. Also largely absent in their descriptions of the familial experience of disability were consideration of the extent to which supports or services available to children with disabilities and their families may influence their lived experiences. Ironically, in discussing stressors, the difficulties that parents may experience in negotiating the special education system or in communicating with educational professionals were not considered by teachers.

It is important to note however, that there was some variability in the perspectives of teachers with regard to their views on families of children with disabilities. There were eight teachers in the sample who expressed beliefs that families of children with disabilities were no different from families in general, and articulated beliefs about a range of outcomes for families of children with disabilities. However, even among this group, through well-intentioned remarks about this group of families, such as “I think they are really special people” and “God doesn’t deal out more than you can take”, their discourse implicitly positioned families as *other*, and reified that being the parent of a child with a disability is a largely undesirable experience.

Some explicitly voiced their sympathy for this group of parents. One teacher described what she imagined to be a typical weekend in the life of a parent of a child with a disability in this way:

I think it’s a lot of hard work and they would just like to wake up and have a normal day .... You know, wanting to sit on the porch and have a cup of coffee without worry. Without having to know where your child is and what your child is doing. You know, and engaging in true dialogue. Not having to change a feeding tube, not having to change the diaper of a grown child.

In contrast, parents emphatically rejected notions of grief, burden, and suffering as characterising their families’ lived experiences. Most parents positioned themselves as having “normal” families and lives, describing their daily lives in much the same ways as one might expect from parents of children without disabilities. Many of the stressors they identified for themselves were not related to their children’s disability, and, in addition to stressors, they also highlighted the joys or simply the “ordinary” moments of being parents. The following quote from a mother of a child diagnosed with multiple disabilities describing what a typical weekend may look like in her family is remarkable

only because it stands in stark contrast with the gloomy scenario imagined by the teacher quoted above:

You know, we make very concerted effort to do things together with the family. We don't plop in front of the TV ... I make a list in the beginning of the summer of all the things—you know—county fairs, and we go to arts and crafts in the park, we go to the balloon festival ... sometimes we go into the city, so the kids can go listen to the orchestra in the park ... We try to do all the stuff that I sort of grew up doing.

Although many parents did identify stressors related to their children's disability, most did not attribute these solely to their children's impairment but rather, viewed these as resulting from a combination of their children's impairments and environmental factors. For instance, stress was perceived as resulting not only from attending to their children's needs, but also from having to educate others about their children's disability, from efforts to protect their children from rejection, and from cultural stereotypes that position their family as non-normative. Some parents expressed that negative experiences for their family were a result of feeling stigmatised. Stress was also perceived by parents as resulting from their high levels of involvement in the special education process, from their "constant vigilance" over their children's educational programming, or from their having to advocate for access to inclusive learning environments for their children. Advocacy on behalf of their children with disabilities, particularly over issues of access to inclusive learning environments, emerged as a strong theme in the narratives of parents; many parents believed that it was necessary for them to be fierce advocates in the special education arena, and that in this one regard, their experiences as parents could be distinguished from those of parents of nondisabled children.

### ***Disabling Discourses on "Denial"***

Many teachers expressed beliefs that parents of children with disabilities are likely to experience, at the very least, an initial stage of denial, and that some parents remain "in denial" about their child's disability indefinitely. Additionally, many said that they personally knew a parent whom they could identify as being "in denial" and in explaining their reasons for believing this to be the case, they made references to instances of parents' "unrealistic expectations" about their children's abilities, their opposition to their children being evaluated for special education purposes, or their dispute of a diagnosis or of their children's placement in self-contained environments.

Parents too, had strong opinions about this topic; most were aware of a cultural narrative on denial as it pertains to parents of children with disabilities. Although some found the existence of the notion itself to be absurd, others expressed beliefs that "being in denial" could explain the behaviours and actions of other parents whom they knew. In discussing their own reactions to their children's disabilities however, every parent emphatically asserted that they were not, nor ever had been, in denial. Indeed, their narratives did not seem consistent with clinical or cultural definitions of "denial"; many had pushed to get their children evaluated despite assurances from their pediatricians that "everything was fine" or had themselves initiated the referrals. Once their children had received a diagnosis, most had quickly mobilised themselves to secure services and interventions for their children. Some said that they sought second opinions because they were in disagreement with the specific diagnoses (or lack thereof) that were made. Many parents offered alternative perspectives and interpretations of their

own behaviours, stating for instance that as new parents, their initial lack of knowledge about children's development, or their "missing certain cues" that would have pointed to delays in their children's development, could certainly be construed as "denial". One mother explained that what some people perceived as "denial", others could construe as holding high expectations or a belief in positive outcomes for a child. Her description of what she referred to as her own "healthy denial" is informative:

I have a healthy denial in that I think my son's gonna go to college. If I didn't think that, then I would never push as hard as I've pushed, or try to teach my son as hard as I teach him. I think he is capable of learning as much as I can teach him. Now, if I didn't have that healthy denial, and you know what, when he becomes 21, he may not be able to go to college but for right now—he's going to college ... You might call it expectations. It depends on whose perspective ... I think the ABA people think we're in denial.

For others, acceptance of their children's differences was understood as a separate issue from acceptance of a diagnosis or an educational classification. These parents explained that their resistance to having their children labelled was not indicative of their denial of their children's disabilities, but rather, based in concerns that their children would be perceived in negative ways. This is seen in the words of the mother who was quoted in an earlier section, in which she explains her resistance to having her child labelled as autistic in this way: "It's not that I'm in denial about the label, but I'm fearful of the way other children and other adults react". It is worth noting that despite having alternative explanations for their own behaviours, many parents paradoxically held beliefs that the behaviours of other parents of children with disabilities may be attributed to their being "in denial". Indeed, three parents held that their own spouse's reactions to their children's disabilities could be explained as "denial".

## Discussion

This study reveals broad conceptual differences in parents' and teachers' interpretations of the meaning of disability. For most teachers, disability was equated with impairment and understood as defined by physical, neurological or cognitive limitations. Their conceptualisations of disability as biologically determined were aligned with medical model perspectives on disability as fixed, universal, and residing in individual minds and bodies (Linton, 1998). In contrast, parents' conceptualisations of disability were more aligned with sociocultural paradigms which posit that the meanings individuals ascribe to their experiences are embedded in the sociopolitical contexts in which they exist; as such, parents' perspectives on the education of their children with disabilities were situated in their understanding of the cultural meanings ascribed to disability and linked with issues of stigma, otherness, marginalisation, and access. Broadly, the findings suggest that teachers tended to locate disability within individual students, whereas parents were more apt to locate disability not solely in their children, but also in the contexts of cultural and educational discourses and practices.

The narratives suggest that differences in interpretations of disability labels may well underlie many conflicts between parents and professionals during educational planning. Many parents viewed disability labels as restrictive and problematic, whereas most teachers viewed labels as guides to educational planning and necessary in understanding the needs of individual students. Parents' strong reactions to specific labels and their understanding of these as linked with stigma or with lowered expectations of their children shed light on their motivation to secure particular educational classifications for

their children, or to resist them altogether. Resonant of Goffman's (1963) notion of the *spoiling of identities*, many parents viewed labels as leading to a devaluing of their children. Consistent with existing research (Gray, 1993; Green, 2003), concerns about the stigmatisation of their children in schools and society was a key theme in parents' narratives. The findings suggest that for parents, support or advocacy for particular educational environments (whether self-contained or inclusive) may be motivated by their concerns about belongingness, membership, and social acceptance. Additionally, some parents' perceptions of feeling stigmatised as a family are resonant of Goffman's (1963) notion of *courtesy stigma*, which refers to the ways in which stigma impacts not only individuals, but also those associated with them.

Notably, there was little resemblance between the ways in which teachers perceived families of children with disabilities and the ways in which parents discussed their familial experiences. These findings can be examined using the lens of master narratives and counter-narratives. Master narratives refer to the dominant constructions or the storylines that are assumed to be the normative experience and are culturally reproduced (Andrews, 2004). Many teachers' views were consistent with master narratives about negative outcomes among families of children with disabilities, and in their descriptions of this group of parents as special, courageous, or deserving of admiration, hegemonic beliefs about the otherness of these families were upheld. In discussing stressors among this group, teachers failed to consider that for parents, stress may also result from their efforts at resisting negative assumptions or from their advocacy for educational equality for their children.

In stark contrast, parents emphatically rejected notions of grief, distress, and difficulties as characterising their families' experiences. Consistent with Bamberg's (2004) assertion that when positioned in master narratives, individuals are agentic in producing counter-narratives which assign new meaning to interpersonal and psychic phenomena, the findings of this study reveal parents' engagement in meaning-making with regard to their experiences of having a child with a disability. These parents' resistance to discourses of otherness and their positioning of their families as "normal" are resonant of Lalvani and Polvere's (2013) assertion that through counter-narratives, individuals offer perspectives which challenge social expectations and problematise dominant viewpoints on human experiences.

This study's findings pertaining to beliefs about *denial* among parents of children with disabilities are informative in the context of schooling. Most teachers in this study did not problematise the labelling of particular responses as "denial", suggesting that they understood the disabilities as absolute and parents' alternative perspectives as an additional problem. This is resonant of Lalvani and Polvere's (2013) assertions about the existence of hegemonic discourses which pathologise parents of children with disabilities. Additionally, consistent with scholarship which aimed to unpack the notion of *denial* among families of children with disabilities (Gallagher, Fialka, Rhodes, & Arceneaux, 2001; Hartshorne, 2002), the findings from parents suggest that their reactions to their children's disabilities can alternatively be understood as their advocacy, their holding high expectations for their children, or their rejection of stigmatising labels. However, despite their emphatic rejection of the idea that their own behaviours could be categorised as denial, many did not challenge the master narrative on denial itself when discussing other parents of children with disabilities. This highlights the existence of master narratives on families of children with disabilities so deeply entrenched in assumptions of pathological functioning and negative outcomes that they

were upheld even among those parents whose personal experiences were reportedly inconsistent with them.

This study has implications for the ways in which we prepare teachers to collaborate with families in the education of children with disabilities. First, it suggests that there is a need for a conceptual shift in the ways in which educators, and indeed *all* professionals, conceptualise disability. Moving away from deficit-based models, professionals need to examine the socio-culturally constructed and contextualised nature of disability, and to consider the alternative perspectives of individuals with disabilities and their family members. Second, teachers should be encouraged to explore and understand the broader implications of inclusive education for children with disabilities. Finally, it is imperative that teachers learn to challenge dominant discourses about families of children with disabilities and to problematise medical-model based assumptions of negative outcomes and pathological functioning among this group. If there is an expectation of partnership between professionals and parents, it is imperative that we question whether true partnerships can exist if one group holds paternalistic beliefs about another. Positioning families of children with disabilities as suffering, grieving, or “in denial” privileges the perspectives of professionals and negates the possibility of mutual respect; feelings of pity are incongruous with relationships of equal status and not conducive to an atmosphere of collaboration. Professionals should be encouraged to reflect deeply on their own beliefs and assumptions about this familial experience. The findings of these studies are a call for all education professionals to rethink the source of the “problems” for individuals with disabilities and their families and to rethink institutional discourses and practices that contribute to their marginalisation in schools and communities.

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