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## The Enforcement of Normalcy in Schools and the Disablement of Families: Unpacking Master Narratives On Parental Denial

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## **The enforcement of normalcy in schools and the disablement of families: unpacking master narratives on parental denial**

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The notion that some parents may be ‘in denial’ is a pervasive theme in dominant discourses on families of children with disabilities. In this analytic essay, I deconstruct cultural and institutional master narratives on parental denial and discuss their role in the marginalization of students with disabilities in schools. I argue that discourses on parental denial privilege the perspectives of those in positions of power and control, leave the practice of ability-based segregation in schools unexamined, and discredit agency among families. Additionally, drawing from existing narrative-based research, I explore alternative interpretations of parents’ responses to their children’s differences, situating these in the framework of critical disability studies.

**Keywords:** master narratives; inclusive education; families of children with disabilities; parents’ perspectives; professional–family partnerships; critical disability studies

### **Points of interest**

- A pervasive theme in dominant cultural narratives on families of children with disabilities pertains to the notion that some parents may be ‘in denial’ about their children’s disabilities.
- This analytic essay deconstructs cultural and institutional master narratives on parental denial and discusses their role in the marginalization of students with disabilities in schools.
- Alternative interpretations of parental denial are explored, based on a review of existing narrative-based research.
- That which is unquestioningly understood as parents’ denial may be reframed as parents’ engagement in meaning-making about the implications of disability labels and their resistance to the positioning of their children as other.

### **Introduction**

The notion that some parents of children with disabilities may be ‘in denial’ – that is, they are either temporarily or for an extended period of time unable to accept their children’s disabilities – is a pervasive theme in master narratives on these

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families in the United States (for example, Bowe 2007; Gorman 2004; Naseef 2001; Ray, Prewitt-Kinder, and George 2009; Seligman 2000; Whiteman and Roan-Yager 2007). This widespread belief about some parents' initial reactions to their children's disabilities, rooted in Kubler-Ross' (1969) stage theory of grief, is institutionally upheld in mental health practice and is explicitly communicated through literature targeted to pre-service professionals (for example, Gorman 2004; Healey 1997; Kroth and Edge 1997; Seligman 2000) and to families themselves (for example, Dowling, Nicoll, and Thomas 2004; Naseef 2001; Whiteman and Roan-Yager 2007). Despite many changes during the past century with regard to professionals' understandings of the familial experience of having a child with a disability, and despite a growing body of scholarship that offers perspectives on the phenomenon of disability as a sociopolitical construct (Davis 2006; Goodley 2013), interpretations of parental reactions in response to a child's disability through a clinical lens of psychopathology has remained largely unchanged both in research and practice concerning these families (Ferguson 2002).

In their institutional support for hegemonic notions about parental denial, mental health professionals find unlikely allies among educators; in the context of schooling, there exist many assumptions about parents who resist the evaluation of their children for the purpose of delivering special education services, as well as about those who advocate for inclusive education for their children, one of these being that they are 'in denial' about the existence or extent of their children's disabilities (Lalvani *forthcoming*; Gallagher et al. 2002). In special education texts, the language of denial is omnipresent (for example, Blacher and Hatton 2007; Bowe 2007; Kirk et al. 2009; Ray, Prewitt-Kinder, and George 2009). Entrenched in the medical model paradigm that equates disability with impairment and attributes school 'failures' to deficits in individual minds and bodies (Baglieri and Shapiro 2012; Connor and Ferri 2007), traditional special education discourses represent parents as responding to their children's disabilities in a sociocultural vacuum, and often fail to take into account the contexts within which families exist.

In contrast to traditional special education, a body of critical disability studies scholarship rejects notions of disability as embodied deficits, framing disability instead as a sociopolitical construct and emphasizing society's *disablement* of individuals with impairments (Baglieri and Shapiro 2012; Connor and Gabel 2013; Davis 2002; Goodley and Roets 2008, 2013). Critical disability studies invites us to question disability oppression (Goodley 2013) and locates school 'failures' in institutional structures and practices that present disabling barriers to students with disabilities (Slee 2011; Thomas and Loxley 2001). Within this framework, the experiences of families of children with disabilities are understood as situated in sociopolitical contexts (Lalvani 2011).

In this analytic essay I deconstruct cultural and institutional master narratives that position parents' resistance to professionals' opinions as a pathological reaction, arguing that the theorizing of parents' disagreement with professionals as denial is a form of oppression of these families. My argument is presented systematically in four sections. In the first, I situate discourses on denial in the broader context of a historical pathologizing of families of children with disabilities. In the next two sections, I unpack master narratives on denial and discuss specifically the ways in which these are upheld in cultural products and institutional discourses. Here I argue that by privileging the perspectives of those in positions of power and control, dominant institutional narratives on denial reify restrictive meanings of normalcy,

leave the practice of ability-based segregation in schools unexamined, and discredit agency among families. In the last section, drawing from existing narrative-based studies that situated families' adjustment to their children's disabilities in sociocultural contexts, I explore alternative ways of understanding parents' actions and reactions in relation to their children's differences, using a critical disability studies lens. Goodley (2013) argues that disability cannot be separated from the 'politics of life' and that disability oppression must be confronted at all levels. It is this facet of the experiences of families of children with disabilities that I explore and aim to explicate in this paper.

### **Pathologizing as a means of social control: families of children with disabilities in historical context**

Perspectives on the familial experience of disability are entrenched in a long history of ascribing blame for children's disabilities to their parents, dating back to early western civilizations when children born with congenital malformation were taken as indications that their parents had displeased the gods (Braddock and Parrish 2001). During the eighteenth and nineteenth centuries, the causal blame for children's disabilities was placed explicitly on parents, and more specifically on the poor, whose immoral or ignorant behaviors were viewed as having obvious connections to the problem of disability in society (Ferguson 2001). The burgeoning of residential facilities and asylums for the feebleminded in the nineteenth century was informed by, and in turn informed, cultural beliefs that parents could not execute sound judgment, and that therefore decision-making about the care of 'vulnerable' children was best entrusted to professionals (Ferguson 2001). Children with known disabilities were systematically institutionalized; this practice was sanctioned by the medical and mental health establishments, and parents were advised by professionals that this was in the best interest of all concerned (Ferguson 2001; Trent 1994). Countless parents heeded this council from trusted experts, believing them to be based in scientific knowledge (Bérubé 1996; Rapp and Ginsberg 2001). Although few parents questioned their physicians' advice, and one cannot reasonably expect otherwise, there were some who swam upstream; in acts of resistance, they challenged professionals' judgment and brought their children home (Bérubé 1996).

During the mid-twentieth century, a new form of parental blame gained popularity. Theoretically based in a post-Freudian psychoanalytic framework, Kanner (1943) posited a connection between autism and an absence of maternal warmth. The notion of the 'refrigerator mother' as the causal factor in autism took hold, championed by psychoanalyst Bruno Bettelheim (1967), and it became widely accepted that autism was the result of having a cold, rejecting, mother who had failed to establish an attachment to her child. As in the case of parents who resisted recommendations to institutionalize their children, parents who resisted notions about refrigerator mothers were dismissed as unwilling to get help or to accept the 'expert' opinions of professionals (Simpson, Hanley, and Quinn 2002).

Although the contexts for raising a child with a disability are drastically different today than in the past, the legacy of a historical positioning of families of children with disabilities as the source of the problem remains. Today, these parents are no longer routinely advised to institutionalize their children, nor are they considered to be 'refrigerator mothers'; however, the belief that they may not always act in their children's best interests because their decisions are often complicated by their

feelings of guilt, shame, anger, grief, or by their denial of their children's disabilities is a pervasive theme in cultural and institutional discourses. As such, parents who resist professionals' opinions continue to be considered a 'problem.' This is not to imply that all parents respond in similar ways to children with differences or act in unison; indeed, there is a wide range of parental responses and outcomes among families of children with disabilities (Ferguson 2002). In discussing parents' adjustment to their children with disabilities, Soloman (2013) concludes that although myriad families come to accept and even celebrate the 'profound differences' between themselves and their children, some families do not; that is, not all parents have a positive impact on their children's identities, nor are all parents' actions necessarily in the best interests of their children. Acknowledging that there are a wide range of parental responses to a child's disability and multiple pathways to families' adjustment, it is nonetheless imperative that professionals begin to problematize the clinical lens through which we view them, and to question the positioning of their responses to their children's disability labels as denial *per se*.

In the following sections, I unpack master narratives on parents of children with disabilities and discuss their implications. My arguments are grounded in a stance that the familial experience of having a child with a disability is situated in sociopolitical contexts. Additionally, my reasons for beginning this paper by calling attention to the historical pathologizing of families of children with disabilities is intentional; I frame my discussion of dominant discourses on parental resistance to 'expert' knowledge in the context of the historical events described earlier, in which there were profoundly negative outcomes for those who did not resist. Therefore I argue that, rather than problematizing parents' resistance to professionals' judgment, it is the institutionalized master narratives, cloaked in the myth of the neutrality of scientific knowledge, which need to be problematized.

### **'In denial': master narratives on parents of children with disabilities**

A dominant theme in master narratives on parenting a child with a disability pertains to the idea that some parents may initially be 'in denial' about their children's differences. For instance, Dowling, Nicoll, and Thomas state that 'when a special-needs child is born, denial is one of the first emotions experienced by many families' (2004, 30). In cultural products on the topic of parenting a child with a disability, the language of denial is ubiquitous. Take, for example, this following blog post entitled 'Autism Awareness: When Denial Gets in the Way,' in which Thomas states:

What happens when we or another family member denies there is anything \*wrong\* with their child? None of us want something to be the matter with our child. But denial can stand in the way of treatment. ... Let's say, for example, that you know your child is autistic, or mentally retarded, or any other \*unseen\* disability. The child is diagnosed by a doctor. Yet your spouse, or close family member, refuses to believe or admit that their child could be anything less than perfect. They cannot \*see\* anything wrong with the child, although they know the child acts differently. Having someone living in denial is hard on you, but harder for the child. (2006, paras 1–2)

The use of the term denial in the context of psychological functioning is rooted in Freudian psychodynamic theory, where it is understood as a self-protecting, unconscious defense mechanism 'used to resolve emotional conflict and allay anxiety by disavowing thoughts, feelings, wishes, needs, or external reality factors that are

consciously intolerable' (Stone 1988, 47). More recently, the use of the term denial in mental health practice has been informed by Kubler-Ross' (1969) extensive work on death and dying, in which she identified the stage theory of grief, with denial being one stage along the path to acceptance. Although Kubler-Ross' stage theory focused more specifically on the psychological processing of death or terminal illness, over time mental health professionals have applied this theory, by extension, to individuals' reactions to other forms of loss – which is to say, situations that are socioculturally interpreted as a loss.

Grounded in grief theory, the framing of the birth of a child with a disability as a profound loss has become a mainstay among professionals (Ferguson and Ferguson 2006). As Gallagher et al. (2002) point out, through their coursework and training in nursing, social work, or counseling, future professionals are indoctrinated to expect that parents of children with disabilities may mourn the loss of the 'perfect child' and that they may initially be 'in denial' before they are able to accept their children's disabilities. In an extensive body of literature aimed at preparing professionals to work with families of children with disabilities (for example, Blacher and Hatton 2007; Bove 2007; Gorman 2004; Healey 1997; Kirk et al. 2009; Kroth and Edge 1997; Ray, Prewitt-Kinder, and George 2009; Seligman 2000) as well as in literature targeted to the families themselves (for example, Dowling, Nicoll, and Thomas 2004; Naseef 2001; Whiteman and Roan-Yager 2007), the notion that parents are likely to undergo a stage of denial after the birth or diagnosis of their children with disabilities is explicitly identified as an expected and often even a 'necessary' parental response because it may have the function of making the 'pain bearable' (Naseef 2001, 28). So deeply ingrained into the collective consciousness are these beliefs about denial that many parents of children with disabilities may have internalized them (Lalvani *forthcoming*). Indeed, some professionals who uphold the discourse of denial are themselves parents of children with disabilities who hold that they too were, at one time, 'in denial' (for example, Naseef 2001; Whiteman and Roan-Yager 2007).

Informed by, and in turn informing, master narratives on pathological responses among parents of children with disabilities, there also exists a body of research which supports the idea that many of these parents tend to remain 'in denial' for a period of time or are unable to 'adjust' to their children's disabilities (for example, Luterman 2004; Murray and Cornell 1981). Although there is support for the idea of parental denial in the research literature, few researchers have attempted to unpack the notion itself. In this body of medical model-based research there is little exploration of parents' interpretations of their own reactions labeled as denial, and little acknowledgement of the sociopolitical contexts within which individuals act. In failing to problematize the positioning of particular parental responses as pathological, this body of research lends institutional support to cultural and institutional discourses on parents of children with disabilities as the 'problem' (Lalvani and Polvere 2013).

Interpretations of particular acts as indications of parents' inability or refusal to accept their children's disability is problematic on many levels. First, they reify assumptions of negative or pathological functioning among this group of parents, and perpetuate the view that parents' emotions may stand in the way of their children's best interests. Further, they validate the notion that professionals need to tell parents what is right for their children, thus privileging the 'knowledge' of professionals over parents' insights, perspectives, and concerns. Disguised in the



language of ‘acceptance of disability,’ the real expectation seems to be that parents should accept professionals’ opinions and worldviews. Thus, parents who refuse to acquiesce – that is, those who oppose the classification of their children or those who contest the specific labels ascribed to their children – are positioned as unwilling to accept their children’s differences and are therefore ‘in denial.’

Discourses on parental denial do not leave room for sociocultural variations in interpretations of disability, and nor do they consider alternative pathways in familial adjustment to a child with a disability; in these discourses, grief and trauma are assumed to be universal response to a child’s disability. For instance, Seligman acknowledges the birth of a child with a disability as a ‘traumatic and life-altering event’ (2000, 79). Here, there is an unquestioned expectation of trauma, with little discussion that perceptions of the birth of a child with a disability are embedded in cultural attitudes, values, and beliefs about disability (Lalvani 2011), and little exploration of the source of the ‘trauma.’ Similarly in Naseef’s assertion about denial as making the ‘amount of pain bearable’ (2001, 28), the source of psychological distress is located in the impairment; parental distress resulting from negative socio-cultural attitudes towards disability is left unexamined.

Finally, narratives on parental denial are problematic because they reify that the child’s disability itself is ‘real’ and absolute, and that parents’ resistance to the labeling of their children’s behaviors as a ‘problem’ is itself a problem (Lalvani and Polvere 2013). For instance, Seligman states that the parental defense mechanism (of denial) interferes with an ‘objective appraisal of a situation or an event’ (2000, 51). Here, the ‘objective appraisal’ is understood as that of the professionals; parents’ alternative interpretations are positioned as a refusal to accept an ‘objective’ and universal reality. Consistently in discourses on denial, disability is positioned as ‘fact’ or ‘truth’ (for example, Gorman 2004; Healey 1997), with little acknowledgement that the phenomenon of disability is itself a sociopolitical construct (Davis 2006; Goodley 2013). Entrenched in medical model interpretations of normalcy and in a history of the medicalization of disability as a means of social control (Conrad 2004), discourses on denial lend institutional support to the oppression of families.

### **Disabling discourses on denial in the context of schooling**

The positioning of parents as being ‘in denial’ is a pervasive theme in special education discourses; in pre-service literature, teachers are explicitly educated about parents’ denial (for example, Blacher and Hatton 2007; Bowe 2007). For instance, Bowe states that: ‘[F]amilies will cope ... first by denying reality. Any [educator] who has worked with parents of newly diagnosed children knows that denial is a powerful impulse in these parents’ (2007, 11). In the context of special education, some teachers believe that parents who hold ‘unrealistic expectations’ about their children’s abilities, those who refuse to consent to their children’s evaluation for special education services or dispute particular special education classifications, or those who resist the placement of their children in self-contained classrooms may be ‘in denial’ (Lalvani *forthcoming*). Although notions of parental denial appear to be widely endorsed by educators, the connections between discourses of parental denial and the marginalization of children with disabilities in schools have hitherto been largely unexplored. Discourses on denial in the context of schooling are linked with implicit educational ideologies that sanction segregated education for many students with disabilities; in positioning parents’ resistance to the labeling of their children or



to their placement in self-contained classrooms as denial, the practice of ability-based segregation and the marginalization of students with disabilities in schools remains unchallenged (Lalvani *forthcoming*). To illustrate this point further, consider the following comments posted on the blog 'Autism-tips.com' entitled 'Parents in Denial.' The post begins 'Please don't live in denial! It's a waste of time.' The blogger, a special education professional, goes on to describe her experiences working with a child described as having 'severe autism' in an inclusive learning environment:

The level of this classroom was way above his. Given the fact that his condition wouldn't let him join the class and the teacher to learn in a formal way, he missed out on all learning opportunities from his instructors, and was not able to participate in the simplest group activities ... The reason why he was in this classroom in the first place was his parents' choice. They believed that exposing Johnny to a higher level classroom environment would fix his problems. ... Had his parents fully accepted his condition and the professionals' suggestions ... he would have been in an environment tailored to his condition with other children like him ... In the end, the parents' denial defeated the purpose of their intention: putting Johnny in a class of a higher level separated him from the class activities and classmates ... We understand the parents' feeling when they are first hit with the diagnosis and we know that it takes time to grieve that their child is not 'normal' ... Be patient, it's a long journey, take it one day at a time. And don't forget: don't be in denial. (Shanab 2010, 2–6 and 7)

The assumptions and conclusions made in this blog post are problematic on a number of levels and need to be unpacked. First, in the writer's understanding, the only reason for the child's being educated inclusively was that it had been the 'parents' choice.' Although this may very well have been the case, the fact that federal laws in the United States mandate that children with disabilities be educated alongside their non-disabled peers in general education classrooms to the extent possible (IDEA 2004) is not mentioned. Indeed, in light of existing educational laws, that the parents in question should have needed to advocate for inclusive schooling for this child is remarkable. This, however, is not under scrutiny in the blogger's commentary; instead, the parents' advocacy for inclusive education is pathologized and labeled as their denial of their child's disability. Second, the reportedly unsuccessful outcomes of inclusion discussed in this blog post (i.e. that the child was 'not able to participate in the simplest group activity') are attributed solely to limitations in the child as a result of his disability; limitations in instructional strategies, programmatic design, and teachers' abilities or willingness to create adaptations to the lessons and activities are not implicated. Entrenched in medical model paradigm, the 'failure' of inclusion is attributed to embodied deficits rather than to unfair institutional practices. Locating the source of problem in the parents' denial of their child's impairment, teaching practices are left unquestioned, thereby absolving educators from any role in the reportedly unsuccessful outcomes for the child.

Finally, and perhaps the most problematic of the assumptions implicit in this blog post, is that parents should unquestioningly 'accept' professional opinion and judgment. In the context of the historical oppression and segregation of individuals with disabilities, and in light of the fact that many grassroots family protest movements provided impetus for sweeping changes in educational laws pertaining to children with disabilities in the United States (Winzer 2009), it is remarkable that even today in educational discourses, professionals' judgments are understood as objective realities, and parents' questioning of it as pathological defense.

### **Alternative perspectives on parental denial in the context of schools**

In this section, I explore alternative interpretations of parents' responses to their children's differences or disabilities, often unquestioningly understood by educators as their being 'in denial.' Supporting my argument with findings from existing narrative-based studies that sought to examine the experiences of families of children with disabilities as embedded in the sociocultural meanings of disability and normalcy, I argue that the reactions of parents which are interpreted as their being 'in denial' are better understood as their engagement in meaning-making as they navigate the education system for their children. In my analysis of existing literature, I use a critical disability studies lens to discuss parents' interpretations of their children's differences, and a contextualized understanding of the issues involved in the education of children with disabilities (Florian and Mclaughlin 2008).

#### ***Reframing denial as resistance to stigmatizing labels***

A body of scholarship sheds light on parents' reactions to stigmatizing labels (for example, Gallagher et al. 2002; Green 2002, 2003; Hartshorne 2002). Issues pertaining to labeling, or the classification of students under particular disability categories for the purpose of providing special education services in schools, have been found to underlie many conflicts between parents and professionals during special education planning (Lalvani forthcoming; Fisher and Goodley 2007; Harry 1992; Kalyanpur, Harry and Skritic 2000). More specifically, Lalvani (forthcoming) indicates that some parents may have strong reactions to particular disability labels (e.g. autism or intellectual disability), which they view as more stigmatizing than others. Resonant of Goffman's (1963) notion of 'stigma as spoiled identity,' many parents may understand certain labels as positioning their children in profoundly negative ways. In the context of education, Harry (Harry 1992; Kalyanpur, Harry and Skritic 2000) points out that parents whose perspectives differ from those held by professionals, or those parents who contest the specific labels ascribed to their children, are often viewed as being resistant or unwilling to accept their children's conditions. It is then likely that some of these parents might be viewed by professionals, unjustifiably, as being 'in denial.' However, as Harry (2000, 1992) argues, although the issue of labeling is occasionally a source of contention between parents and professionals, the conflicts are often not over the identification of the child as needing additional help in school; rather, they are usually over the naming of the problem. This is consistent with other studies that similarly highlighted parents' resistance to notions of the *otherness* of their children with disabilities (for example, Goddard, Lehr, and Lapadat 2000; Green 2002, 2003; Lalvani 2011) and revealed that parents may locate disability not solely in their children, but also in sociocultural environments. Thus, some of the actions of parents, which are unquestioningly understood as their being 'in denial,' might be reframed as their resistance to negative attitudes toward disability in society and their shielding their children from stigma.

#### ***Reframing denial as rejection of dominant interpretations of disability and normalcy***

It is necessary to acknowledge that parents' responses to their children's disabilities are situated in culturally constructed meanings ascribed to disability and normalcy. For instance, Harry's (1992) extensive ethnographic research with a group of

low-income Puerto Rican families reveals that these parents' understandings of 'normal' versus 'impaired' cognitive functioning differed from those of school professionals; as such, they understood normalcy within wider parameters than would be expected in a western context. Additionally, issues pertaining to language and terminology may also be at the root of some misunderstandings about parents' unwillingness to 'accept' a particular disability. For instance, Harry's (1992) work indicates that some parents reacted strongly to their children's classification of 'mental retardation' because of a cultural interpretation of this term as indistinguishable from mental illness and its association with the vernacular term *loco* (crazy). Furthermore, in some cultural contexts, parents' interpretations of their children's disability labels may be embedded in their understandings of family identity; for some families, labels of intellectual disability and mental illness may take on greater significance because of cultural perceptions that these reflect poorly on their families' functioning and dynamics (Harry 1992; Taylor 2000). The work of these scholars elucidates that the actions and reactions of parents from socioeconomically and culturally diverse families, casually attributed to their being 'in denial,' is not only unjustified, but also serves to further alienate ethnic minority or low-socioeconomic-status families as they attempt to navigate the schooling system.

### ***Reframing denial as challenging societal expectations for children with disabilities***

Some responses of parents that may be positioned by professionals as denial may be alternatively interpreted by parents as their holding high expectations or maintaining hope for their children (Gallagher et al. 2002). Parents' beliefs about the power of labels to alter perceptions and expectations of their children emerge as a theme in many of their counter-narratives. For instance, Lalvani (forthcoming) discusses a father's conflict with school professionals over the issue of his son's classification under the category of 'cognitive impairment' and asked that it be changed because he believed the label would lead to lowered expectations of his son among teachers. From this perspective, the father's resistance to the label of cognitive impairment had little to do with his acceptance of his son's disability; rather, it had to do with his beliefs about altered perceptions of his child as a result of a specific disability label. Other scholars have similarly argued that that parents' denial could also be construed as their push back against a pervasive attitude of expecting little from children with disabilities and as their resolve to maintain high expectations as a parent and their belief in positive outcomes for their children (Gallagher et al. 2002; Hartshorne 2002). Resonant of scholarship that deconstructs the notion of denial among families of children with disabilities (for example, Allred and Hancock 2012), parents' counter-narratives in these studies reveal that what some teachers may refer to as parents' 'unrealistic expectations,' and by extension their denial of their children's disabilities (Lalvani forthcoming), can alternatively be understood as their remaining optimistic about their children's future, or perceiving their children as capable of achieving academically.

### ***Reframing denial as advocacy for inclusive education***

Parents' efforts to advocate for inclusive education and their 'struggles' to secure access to inclusive learning environments for their children with disabilities are well

documented in the research literature (for example, Lalvani 2012, 2013; Ryndak, Storch, and Hoppey 2008; Swick and Hooks 2005). These studies suggest that despite federal regulations (IDEA 2004) which mandate that schools make every effort to educate children with disabilities alongside their non-disabled peers to the maximum extent possible before considering more restrictive options, decisions pertaining to the placement of children with disabilities in inclusive learning environments continue to be, to a great extent, parent driven. In their efforts to advocate for inclusive education, many parents encounter institutional obstacles and perceive themselves as having to ‘stand up to the system’ or to ‘fight for’ inclusive education (Erwin and Soodak 1995; Lalvani 2012). As such, these parents often find themselves negotiating a special education system that legitimizes the segregated education of some children based on the clinical judgments of those in positions of power or control (Kliwer 1998; Skrtic 1995). In light of this, it is not difficult to imagine that some parents, particularly those whose children have severe disabilities and who advocate strongly for access to inclusive learning environments for their children, might be viewed as being ‘in denial’ by educators. Indeed, Lalvani (forthcoming) found that some teachers held beliefs that some parents’ advocacy for their children to be educated inclusively may stem from their denial of the extent of their children’s disabilities. A similar reasoning was articulated in the blog post discussed in the preceding section (Shanab 2010, 2–6 and 7), in which a special education professional interpreted the efforts of parents who advocated for inclusive education for their child with autism as indications of their denial of their child’s disability.

Brantlinger (2004) asserts that much of educational practice is based in positivist beliefs about the neutrality of science, when in fact what is taken to be scientific knowledge is situated in hegemonic discourses that privilege certain ‘knowledge’ over others. Institutional and cultural discourses on parental denial play a supporting role in exclusionary schooling practices. In privileging the perspectives of professionals who uphold the need for parallel systems of education (Linton 1998) and pathologizing those of parents who oppose segregated education for their children, notions of the otherness of children with disabilities are reified and the practice of ability-based segregation of children in schools remains unchallenged.

## **Conclusion**

Professionals’ interpretations of parents’ responses to their children’s disabilities through a clinical lens is the legacy of a historical oppression and social control of individuals with disabilities and their families. Institutional discourses on parental denial of their children’s disabilities are entrenched in a medical model paradigm that equates disability with impairment and fail to acknowledge the ways in which the lives of individuals with disabilities and their families are influenced by socio-cultural and attitudinal factors. In the context of education, master narratives on parental denial lend institutional support to the practice of ability-based labeling, sorting, and separating of children in schools.

Narrative-based research that elicits parents’ counter-narratives sheds light on their understanding of the contextualized nature of the meaning of disability and of the familial experience of having a child with a disability. Parents’ counter-narratives are consistent with the perspectives offered in critical disability theory, which conceives of disability as a sociopolitical construct, distinguishes disability from

disablement, and understands disabled people as ‘a collective defined by common experiences of oppression’ (Baglieri and Shapiro 2012, 27; Davis 2006; Goodley 2013). Consistent with Goodley’s (2013) assertion that the experience of disability cannot be separated from the ‘politics of life,’ families’ responses to their children’s differences are better understood as situated in a sociopolitical system that marginalizes children labeled with disabilities and positions them as other.

This paper makes a case for a conceptual shift in professionals’ understanding of families of children with disabilities; moving away from universal interpretations of these parents’ responses as psychological defenses and towards an understanding of them as agentic or purposeful. Furthermore, it is imperative that professionals interrogate their own complicity in perpetuating oppressive discourses on of this group of families, and question positivist interpretations of disability as reality and of professionals’ opinions as knowledge. As such, this paper is a call for educators to consider the sociopolitical and individual meaning-making contexts that frame parents’ role in the education of children with disabilities, and to allow for educational decision-making to be informed by parents’ unique perspectives of the lived experiences of parenting a child with a disability.

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