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Mothers of Children with Dyslexia Share the Protection, “In-Betweenness,” and the Battle of Living with a Reading Disability: A Feminist Autoethnography

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Abstract

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Keywords

Dyslexia, Critical Disability Studies, Reading Disability, Parenting a Child With Dyslexia, Feminist Methodology, Autoethnography

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Introduction

As a qualitative researcher with a background in feminist methodology, I often wonder why the voices of parents with children with learning disabilities are curiously absent from American educational research (e.g., Wong & Butler, 2012). More importantly, why are the voices of students with disabilities only slowly emerging now (e.g., Berger & Lorenz, 2015)? Except for some rare studies (e.g., Brock & Shute, 2001; Delany, 2017; Leitão et al., 2017) all of which are Australian, there exists very little empirical research on the voices of parents of children with dyslexia, and there is a specific, timely need in the United States. In the last five years, more than two thirds of all U.S. states have discussed or passed dyslexia-specific legislation, leaving schools to navigate and support a vaguely understood disability (Gabriel, 2018; see Dyslegia, 2018 for a list). With this study, I hope to provide new insight on the absence of understanding surrounding reading disabilities, as well as to provide a space to hear the voices of those affected by dyslexia, and to provide educational suggestions moving forward.

Gradually, qualitative researchers have brought people with disabilities from being the objects of research, to become more active participants in the research. In order to continue this forward momentum, there is a crucial requisite to evolve methodological discussions beyond being "about disability" and instead examine the real experiences of real people living their lives with a disability, both in and out of school, and in multidisciplinary ways (e.g., Berger & Lorenz, 2015). As qualitative researchers concerned about educational equity and justice for students with disabilities, we must ask ourselves the following research questions: What is the experience of parenting a child with dyslexia? How can educational contexts be more supportive of students with dyslexia, and their parents? How are students with reading disabilities (and their parents) positioned? Positional and identity based theories are situated in critical or emancipatory qualitative research, providing a lens to critique and explore social, political, cultural, economic, gender, and other structures that may exploit or constrain humans, especially in contexts of conflict (Dixson & Seriki, 2013).

Researchers' understanding of the impact of dyslexia on children and their parents is complicated by lack of consistent understanding of dyslexia in the first place. Experts have devoted several decades to debate what comprises dyslexia (Elliott & Grigorenko, 2014) without reaching consensus regarding specific criteria for research, diagnosis and the underlying processes (Bell, McCallum, & Cox, 2003; Delany, 2017). My nine-year-old daughter, Emily, has dyslexia. Although she has been formally diagnosed and supported in multiple therapies, her disabilities are mostly invisible and largely misunderstood. As a literacy specialist and feminist researcher, I was concerned about the lack of clarity surrounding dyslexia, and I have traditionally been accustomed to providing spaces to hear the voices of populations that had previously been silenced (e.g., Brown & Gilligan, 1992). How could I expect any less in my personal and professional circles?

In order to clarify some of the confusions surrounding dyslexia, this work draws upon critical disability studies to share the stories of mothers of children with dyslexia, myself included. This paper is organized as follows: first, the study will be situated theoretically, by defining dyslexia, then examining dyslexia within an overview of critical disability studies, while also honoring the role of parents' voices and literate identities. Second, the methodology, a feminist autoethnography, informed by the method of interpretive phenomenological analysis (IPA), will be explored. Data sources included interviews with 5 participants, plus myself, all mothers of children with dyslexia, who were in their 40s, and ethnically and socioeconomically diverse. Third, the results will be shared. Fourth, tangible educational implications will be provided.

Theoretical Framework

Defining Dyslexia

> Dyslexia is a specific learning disability that is neurobiological in origin. It is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities. These difficulties typically result from a deficit in the phonological component of language that is often unexpected in relation to other cognitive abilities and the provision of effective classroom instruction. Secondary consequences may include problems in reading comprehension and reduced reading experience that can impede growth of vocabulary and background knowledge.
> International Dyslexia Association (2017) https://dyslexiaida.org/definition-of-dyslexia/

Dyslexia is a multifaceted concept, demanding that educators and researchers take into account an individual's experience, and how best to educate him/her. The Diagnostic and Statistical Manual (DSM-V) places dyslexia within the broad category of "neurodevelopmental disorders" as a descriptive subset of reading within "specific learning disorders" (American Psychiatric Association, 2013). This further exemplifies how dyslexia is difficult to identify as a discrete diagnostic category (Snowling, 2013). Since literacy, and its acquisition, are such layered, complex concepts, any difficulty in acquiring literacy is also a complicated matter.

Some researchers contend that dyslexia is an unhelpful social construct, which does not explain the nuances of difficulties in becoming literate (e.g., Elliott & Grigorenko, 2014). Those who question the term, dyslexia, do not believe that it does not exist.

> However, the primary issue is not whether biologically based reading difficulties exist (the answer is an unequivocal "yes"), but rather how we should best understand and address literacy problems across clinical, educational, occupational and social policy contexts. Essentially, the dyslexia debate centers on the extent to which the dyslexia construct operates as a rigorous scientific construct that adds to our capacity to help those who struggle to learn to read. (Elliott & Grigorenko, 2014, p. 4)

Historically, many researchers have explained dyslexia using a discrepancy model (Shaywitz, Shaywitz, Fletcher, & Escobar, 1990). Under this model, when a student of average ability is still experiencing unexpected difficulty in acquiring reading skills, despite conventional classroom experiences (Bishop & Snowling, 2004), he or she may be identified as having dyslexia (International Dyslexia Association, 2013). Students who do exhibit average intelligence but continue to struggle with literacy skills, are frequently misunderstood, and sometimes even thought of as unintelligent and lazy (Thompson, Bacon, & Auburn, 2015). As educators, policy makers, experts, and researchers continue decades of confusion surrounding the existence and definition of dyslexia, along with the best methods to empower students with dyslexia, the parents and students affected by dyslexia are left feeling lost, disempowered (e.g., Delany, 2017) and caught in an in-between space.

Critical disability studies

With a foundation in several critically oriented literatures such as feminist, Marxist, queer, postcolonial, and critical cultural studies, critical disability theory covers hegemonic ideologies that portray people with disabilities as abnormal, inferior, and unequal (Charlton, 1998, 2006; Davis, 2006; Devlin & Pothier, 2006; Vaccaro, Kimball, Wells, & Ostiguy, 2015). As in other forms of critical scholarship, critical disability studies emphasize empowerment, agency, and social change. Moreover, the evolving field of disability studies distinguishes the vital roles that family members play in the lives of people with disabilities. One of the main intents of this paper is to provide further research into the views and experiences of family members.

Thanks to innovations in disability studies, researchers are more attentive listeners to what people with disabilities want, and how they want to participate. This provides new insights into ways we can support people with disabilities, to enhance their participation in a variety of contexts. "Inclusion and participation are essential to human dignity and to bring about a genuine equalization of opportunities" (De Schauwer & Davies, 2016, p. 84). Scholars in disability studies recast disability in social terms, so that the supposed "problem" of disability no longer resides in the bodies or minds of individuals, but in environments or social patterns that exclude or stigmatize particular ways of being in the world (Kafer, 2013). In this way, we are reminded that any social transformation we yearn for cannot be understood apart from the context in which it occurs (Kafer, 2013, p. 6).

> It is a living engagement; it applies to resources of our creative imagination in an attempt that is as much to disclose something about ourselves as it is to disclose something about the families. And in those encounters, disability studies seeks ways of being open to the not-yet-known, of learning from them—

> opening up new possibilities, crossing unanticipated thresholds, resisting normalization, and always being open to renewal. (De Schauwer & Davies, 2016, p. 84)

Parents' voices and literate identities

Dyslexia has proven to be both academically and emotionally demanding, not just for students, but can also be distressing for their parents (Delany, 2017; Elliott & Nicolson, 2016). Since reading is a central component of schooling, and ongoing independence throughout the lifespan (Snowling & Hulme, 2012), parents of students with dyslexia show higher levels of anxiety than parents of non-dyslexic students (Snowling & Melby-Lervag, 2016). Anxiety has been shown to increase when attempting to seek appropriate help for their child (Earey, 2013), especially when inflexible, administrative processes move too slowly to provide interventions early or timely enough to help students overcome dyslexic difficulties (Delany, 2017; Rose, 2009). Purely out of necessity, parents become advocates for their children (Poon-McBrayer & McBrayer, 2014), which creates further, intense, emotional and physical stress. Overall, the literature reports ongoing difficulties for parents as they struggle to support their child before, during and after the assessment of dyslexia (Delany, 2017; Earey, 2013).

This high level of stress in parents and in children makes sense when considering how literacy is an interwoven piece of our identities. Critical theorists argue that literacy is not only the ability to understand and construct textual meaning, but also a means through which individuals participate in constituting themselves and their worlds.

> Literacy is not a skill to be acquired, but instead is an interwoven piece of one's identity as an individual... literacy matters in different ways to different people, based on how writing and reading play a role in a given person's life. That particular role itself is based on theory that literacy is one of numerous sociocultural attributes which make up an entire continuum of interrelated attributes that affect one another. (Lassonde & Woodcock, 2001, p. 97)

When literacy development is slow, it can feel like an insurmountable challenge to students and their parents—affecting everyone in various ways, including emotionally, academically, physically, and financially.

"Sociocultural theories also acknowledge that reading disability is socially constructed, and once assigned, a reading disability becomes one part of an individual's identity along with the individual's history" (Randel, 2014, p. 53). Gee (2000) helps us to define identity as "being recognized as a certain type of person within a given context" (p. 1). Many parents, from numerous countries throughout the industrialized world, feel forced to seek help outside of their public school system (Delany, 2017; Rose, 2009). Diagnostic assessments and specialized education for dyslexia are expensive (Karande, Mehta, & Kulkarni, 2007) and often outside the financial means of students and their families (Harkin, Doyle, & McGuckin, 2015). What happens to children with dyslexia from working-class families and families with low socioeconomic backgrounds who are unable to pay for this support?

A key finding from the review of literature accentuates the high level of stress in parents of children with dyslexia. A feminist autoethnography was chosen to carry out this study because of the ways the method lends itself to forefronting the experience of parents of students with dyslexia, honoring their voices, to further support students with dyslexia and their families. As schools continue to contemplate the best methods to empower students with dyslexia, the parents and students affected by dyslexia are left feeling lost, while the critical stance in this feminist autoethnography provides a space to distinguish the vital roles that family members play in the lives of people with reading disability.

Methodology

In an effort to diminish some of the confusions surrounding living with dyslexia, this research synthesized theories from feminist and phenomenological qualitative methods to create a feminist autoethnography, informed by interpretative phenomenological analysis (IPA), as a means of seeking meaning and understanding from complex human dynamics (Pritchard & van Nieuwerburgh, 2016). In the following section, I review the elements of my method: participants, data sources, analysis, procedure/rigor, and the contributing elements of the feminist autoethnography.

Participants

In general, IPA dictates that researchers find a small, clearly defined group for whom the research question will be significant (Smith & Osborn, 2008). As a result, the method supports greater depth in understanding (Smith, Flower & Larkin, 2009) of the experience of the participants' individual perspectives (Smith & Rhodes, 2015) within their unique contexts (Delany, 2017; Pietkiewicz & Smith, 2014).

I had approval from my college's Institutional Review Board (IRB) for this study. For interviews, there were 5 participants, all mothers of children with dyslexia, who volunteered after an IRB-approved email was sent out at the college where I teach, and at the school that my daughter attends. Participants were in their 40s, and ethnically and socioeconomically diverse. All five participants were my personal acquaintances.

Data Sources

Semi-structured interviews (Smith, Flower & Larkin, 2009) were the major data source. With a small number of participants (Smith & Osborn, 2007) and language as an essential component of understanding in IPA (Brocki & Wearden, 2006), the interviews provided maximum opportunity for richer, authentic data to be obtained through dialogue (Smith & Osborn, 2008). With an ideographic focus on individual experience, and a flexible interview format and schedule with broadly constructed questions, the methodology allowed for unexpected themes to emerge (Callary, Rathwell, & Young, 2015). Once themes emerged, I then integrated some of my own experiences of parenting a child with dyslexia. In terms of analyzing and integrating my personal stories for the autoethnography, data sources consisted of my memoir journals, books, blog posts, and observational notes.

Analysis

Interpretative phenomenological analysis (IPA) was used in two fashions in this research. First, IPA informed the overall approach of the feminist autoethnography in the ways I identified data sources and conducted interviews. Second, IPA was utilized to discern themes in the research. First, I conducted interviews, and determined themes. Then, I interwove my own experiences of parenting a child with dyslexia into those pre-determined themes that emerged from the interviews.

IPA is a rigorous (Smith, Flower & Larkin, 2009) qualitative methodological framework (Pietkiewicz & Smith, 2014) that offers guidelines that are ideal for dynamic, contextual and subjective topics (Smith, Flower & Larkin, 2009) such as the experience of parenting a child with dyslexia. IPA also lends itself to explorations of identity, the self and sense making of that lived experience (Delany, 2017; Smith, 2004). A phenomenological attitude is a disciplined way of seeing with fresh, curious eyes (Finlay, 2014), and it is the central component differentiating phenomenology from other research methods (Rhodes & Smith, 2010). With the disciplined, phenomenological attitude, the researcher becomes wholly engaged in the exploration (Smith, 2011) and interpretation of the experience (Smith & Rhodes, 2015).

Procedure and Rigor

Data were collected using semi-structured interviews. Each mother participated in one in-person, audio-recorded interview. The central focus of the interview was to prompt the participants to tell their experience of parenting a child with dyslexia from the earliest suspicion of dyslexia to the present time. The main interview questions were inspired by a previous study performed in Australia by Delany (2017): What were some early indications you noticed that your child may have had difficulties with reading? How did you go about seeking help for your child? What has been the outcome to date for your child? What advice would you give to other parents who suspect their child may have dyslexia?

Since I am a professor, reading specialist, and the parent of a child with dyslexia, I was naturally acquainted with several parents known to have a child with dyslexia. Parents were able to register their willingness to participate in the study by responding via email, at which time they were sent by return email an informed consent sheet, which provided further details explaining the aims and requirements, as well as potential risks and benefits of the research.

After receiving twelve affirmative email responses, I carefully selected 5 participants, who were willing and able to meet on mutually-agreeable days, and who also suggested a range of cultural diversity. In addition to my contributions from my personal reflections on my experiences with my daughter, Emily, I share the stories of these five mothers and their children.

With IPA, I followed the analysis procedures as outlined by Smith and Osborn (2007), with some slight modification, which included color coding. I listened to audio recordings several times, and after I created my left-margin notes, I color-coded transcripts as I discovered themes in their transcripts. I found that layers of color coding helped me to organize the themes and then I brought the themes into the right margin. For me, the colors help with clustering themes and discerning any overlap. Once themes were solidified from the interviews, I color coded any overlap I found in my autoethnographic data, which included notes, memoirs, and journals. I interwove my own reflections from the color-coded, supporting evidence in my own memoirs and journals, which complemented and supported themes unearthed during IPA interview analysis.

With respect to rigor and trustworthiness, I continuously sought to check my claims in two fashions. First, I performed member checks. I asked the informants for follow-up interviews to clarify any thoughts, questions, or confusions. I also allowed the informants to see their transcripts, and allowed them to comment on them, and the themes I detected. Second, I am a member of an interpretive community (Tappan, 2001; Taylor, Gilligan, & Sullivan, 1995). This community is a collaboration of other qualitative researchers, all trained in IPA, and sensitive to the issues involved in my particular study. They were a willing and engaged audience, who regularly met to offer support and suggestions for interpretations of data. As a researcher, my involvement in this committed group provided me with the opportunity for new insights and enlightenments when our "different voices and perspectives are joined together in a common effort of understanding" (Tappan, 2001, p. 52).

Contributing elements of feminist autoethnography

While in research we must be intensely careful not to tell our stories through the voices of our informants, it is equally as important that we locate ourselves in the research, and allow our experiences to guide a suitable path (Coddington, 1997). As a result of this thinking, I carefully selected a feminist methodology that provided the freedom and the structure necessary to hear my voice, and the voices of other mothers, while locating personal experiences and reactions in a purposeful manner as well. "In a postmodern world of theory critique and multiple subjectivities, researchers must eschew innocent constructions of themselves… The personal, … is a starting point, and a valuable one" (Coddington, 1997, p. 22). Relations with others are central to knowing, composing, and acting (Bakhtin, 1981).

In addition, a feminist grounding in disability studies provides space for the roles and voices of students with disabilities, and their parents, to be evident in the research. "(A)s a researcher, I am no more, no different from the subjects of my research" (Walkerdine, 1997, p. 73). Feminist methodology allows a participant's involvement to have meaning and upholds the significance of reciprocity between researcher and researched (Lather, 1991). In essence, fellow mothers and I were active, co-producers of this work. "The potential for creating reciprocal, dialogic research designs is rooted in… people's self-understandings… Such designs lead to self-reflection and provide a forum for people to participate in the theory's construction and validation" (Lather, 1991, p. 65).

As a feminist, qualitative researcher, I realized that this study strove to become an autoethnography. After all, autoethnography celebrates the stories of a researcher, honors the roles of emotions, relationships, and creativity, as well as promoting social justice (Adams, Jones, & Ellis, 2015). We learn through story. We crave story. "Authoethnographic stories are artistic and analytic demonstrations of how we come to know, name, and interpret personal and cultural experience" (Adams et al., 2015, p. 1). Autoethnogpraphy is a research method that uses a researcher's personal experience to describe and critique cultural practices and experiences. The method acknowledges and values a researcher's relationship with others. Autoethnography is committed to social justice and making life better for its participants.

Perhaps what I found most appealing about autoethnography, after my history with feminist qualitative methods, is that autoethnography upholds the stance of no longer silencing the voice (Adams et al., 2015, p. 9). Autoethnography values the personal, and wants it featured it in its work. When researchers use autoethnography, at the level of analysis, it is sometimes referred to as writing as reverie and mining connections. Alongside of my own reflections as a mother of a child with dyslexia, I also interviewed five fellow mothers of children with dyslexia and detected overlapping themes in our stories, such as the misunderstood nature of our children's disability, the seemingly resistant nature the children exhibited, and the emotional battles we all faced. In the Results section, I share these themes, as they were detected in interviews, followed by analysis of autoethnographic information, which was often followed by areas of congruence and conflict.

Findings

Participants were all in their 40s, and ethnically and socioeconomically diverse. Pseudonyms have been used to protect confidentiality. Clara is mother to daughter, Maeve. Clarissa is mother to daughter, Holly. Anna is mother to son, Manny. Leena is mother to son, DJ. Sally is mother to son, Cash. And Sarah is mother to daughter, Renae. Thanks to their powerful contributions, by utilizing IPA, I was able to discern three, distinct themes in their stories—first, the blurriness, or "in-betweenness" of reading disability; second, the perceived resistant behavior of their children, which was later understood as a means of protection; and third, were the emotional battles waged by parents to fight for their children's educational rights.

"In-betweenness" of disability

Since there is still so much confusion surrounding the definition and diagnosis of dyslexia, it creates a lot of friction in families, for parents who realize something is slightly amiss in their child, yet it is difficult to distinguish or articulate. From the data, a strong theme of the blurriness of identifying dyslexia emerged. A mother named Clara shared:

> From the day Maeve was born, I sensed something was "off" about her, but I could not articulate it. From the perspective of others, including doctors and nurses, Maeve was fine. Visually, she was beautiful and there were no obvious markers of a disability. Yet, even as an infant, why was she looking all around, overly alert, when she should have been asleep? Why was she so difficult to put down to sleep? Why did she have trouble nursing and taking a bottle? As she grew through infancy, why did she roll over one way, but not the other? Why did she crawl in a unilateral fashion? Why did she seem to hit developmental milestones, but just a little bit late, or clumsily? Most importantly, why didn't anyone notice, or seem to care, except me? When I mentioned any concerns, they were quickly dismissed as overreacting. After all, Maeve did eventually sleep, eat, crawl, etc.

While many infants and toddlers with more discernable disabilities are identified and placed into early intervention services, another mother named Clarissa explained how instead, her daughter, Holly, was nearly four before she was diagnosed. And, it was still too early to identify a specific learning disability, such as dyslexia, so Holly was given other diagnoses instead, such as developmental coordination disorder and social communication disorder. Clarissa recounted how Holly's symptoms became more noticeable when she turned three.

Even in my own experience, my daughter, Emily, also had more pronounced, yet vague symptoms at age three. For her pre-school gymnastics class, the children had to line up and take turns running down a pathway to the instructor, who was waiting to help them bounce on a trampoline springboard, and up onto a large fluffy mat as a grand finale. In notes from my memoir book, I reflected,

> Looking back at me before she took off, (Emily) began to run with a tiny gait. Her eyes peered to the side, instead of at the instructor, or at the mat straight ahead. (Emily) lacked the coordination to jump on the trampoline, and therefore could not spring herself upon the mat. (Woodcock, 2015b, p. 82)

Some children, such as Emily, Holly, Maeve, and countless others, occupy in-betweenness in the ways they appear okay, yet they may be experiencing trouble processing information. For example, as I share from my blog,

> E(mily) might suddenly scream, pull her hair, or place an inappropriate object in her mouth. She may appear shy, yet she's really not introverted; she just can't sometimes retrieve language to respond, or to formulate a story. She's going to be okay, yet everyday feels like a battle to do the simplest actions, especially those that involve motor control, such as riding a bike. Eventually though,

> E(mily) did ride a bike, and I cried tears of joy when those tiny feet pedaled. (Woodcock, 2015a)

While these stories may feel unrelated to a reading disability, all of the children described above went on to be formally diagnosed with dyslexia. Their vague, in-between actions as young children were pre-cursers. Whether the students are younger, or older, there appears to be a pervasive misunderstanding in professional and educational contexts about the signs of dyslexia. When a mother named Anna was interviewed about her son, Manny, she shared,

> As the parent of a 13-year-old son with dyslexia, I see an urgent need to train teachers in interventions for students with dyslexia. Dyslexia is invisible and often misunderstood by teachers and administrators. Despite glaring symptoms of dyslexia since preschool, such as the inability to recite simple poems, a reading level not commensurate with Manny's expected ability, trouble writing his own name and memorizing our address, he was not identified as having a learning disability until I requested testing late during his 1st grade year.

In a similar vein, a mother named Sally shared the story of her son, Cash, and how he consistently showed signs throughout his childhood, which were difficult to interpret.

> When Cash was 8 years old and in the 3rd grade, we realized he was struggling to read and write. As we reflected back on it, we remembered how we tried to teach him to ride a bike at age 5, but it took him until age 11 to get it. However, once he learns something, it's learned for life, and he is now great at riding a bike! It also took him longer to count, tie his shoes, throw and catch a baseball. He just needs more time for everything and he will get it.

Clara explained the in-betweenness her daughter, Maeve, experienced by stating, "The struggle is real. Maeve struggled as a child. It is a hidden disability. If you had a broken leg, wouldn't you fix it?" Other parents have been noted as labeling dyslexia as a disability that is more difficult to accept than a physical disability because it is not as concrete in identification (Bell, et al., 2003; Delany, 2017) nor as obviously visible (Earey, 2013).

Bright youngsters are trapped in an in-betweenness because their intelligence and compensatory skills shield them from the truth, and from teachers. A mother named Leena shares,

> My son, DJ, is dyslexic. He is also a very bright 4th grader. His school denied testing, even though he was not able to write. Besides spelling his first name, DJ, he could not consistently spell any word, including our last name. His teachers and specialists at his school were not trained to detect his disability. DJ was able to compensate because he's so bright, but it eventually caught up with him.

With more robust, well-rounded definitions of dyslexia or reading disability, students could receive the structured interventions they need on an earlier and regular basis.

When we engage critically with disability, it creates a pathway for exploring the borders that define feminist theory, philosophy, and other fields of inquiry (Hall, 2015). Disability scholars have been forthright in acknowledging the "blurry categories" and "fluctuating abilities" that have confounded us (e.g., Price, 2011, p. 13). Just when certain disabilities may have gone unnoticed, seemingly invisible, suddenly some disabilities become vivid in the form of what is perceived as “odd behavior” that is difficult for some people to navigate. It has everything to do with the environment in which in which it dis/appears (Price, 2011, p. 18).

In a similar, landmark study by Lukia Sarroub in 2002, she articulated the term “in-betweenness” as a powerful heuristic to signify the hybrid adaptation of one’s practices or identity to one’s textual, social, cultural, and physical surroundings. This notion of in-betweenness is an effective concept when considering that people often occupy and practice nearly everything in in-between spaces. Some students, like Maeve, noted above (and their parents) struggle with multiple, less understood disabilities, which are difficult, both to see and to diagnose, and thus support.

I interpret Kafer (2013) as contributing to this conversation of in-betweenness by asking the question, “Is disability really a knowable fact of the body?” (p. 4). In truth, none of us can claim to know how a disability is shifting over time and context. None of us can claim to know how one’s experience of disability is affected by one’s culture and environment. Instead of trying to constantly re-negotiate one’s understanding of the disability, one must instead be in constant re-negotiation of the social processes that affect the lives of people with disabilities, and those who care for them. According to Kafer’s (2013) relational model of disability, disability studies is a site of questions rather than firm definitions. Proclaiming the in-betweenness of disability can be empowering in this stance, especially in the ways it contributes to deconstructing the traditional binaries of able/disabled, visible/invisible, etc. By making the in-betweenness more explicit, makes it real, and “normalizes” it, with the intention of evoking compassion and social change, to re-conceptualize a better future.

Protection

According to the parents interviewed, as children inhabited various levels of in-betweenness, they were reported to be joyful and willing with some tasks, and then the children would exhibit tremendous resistance with other tasks, especially if they were new or seemingly difficult situations. All of the parents told stories of how their children were not ones to take risks, and that made learning challenging. In my own experience, my daughter, Emily, was prone to avoidance, meltdowns, and tantrums that were not age or context appropriate. This resistance was problematic at home, school, etc. As Emily and I sought help from a variety of therapists for her resistant behavior, it was life changing when a practitioner finally suggested that Emily was not resisting—she was protecting herself. Amidst Emily’s consistent resistance, she was also revisioning who she was, and who she might become (Brown, 2001).

As Emily edged into first grade, her teacher had tremendous difficulty navigating Emily’s resistant nature. There were frequent conferences and email exchanges. At home, Emily would break down, saying,

> I won’t do the work. My work is different than what the other kids are doing. I even have a different folder and the other kids do hard work and my work is stupid and easy. I want to do work just like the other kids.

Shortly after all of those exchanges, Emily was formally diagnosed with phonological processing disorder and expressive language disorder.

Emily’s remarks and behavior, perceived by some practitioners as resistance, became her form of kairotic space, and her desire for more inclusive educational settings (Price, 2011). A classroom’s infrastructure may consist of tables, chairs, and participants, but it is arguably also comprised of beliefs, attitudes, and discourses. This multilayered infrastructure is what Price (2011) refers to as kairotic space. This theory is hugely helpful in more deeply understanding dyslexia for a number of reasons, namely the growing understanding of what constitutes dyslexia, as well as how to best support students with dyslexia, especially due to its linguistic basis. There are unfolding power relations and strong emotional elements in all of education, and right in Emily's elementary classroom as well.

As illustrated by Emily's experiences in first grade, there still exists an ableist desire to diagnose or fix the student before adjusting teaching practices. Instead of the deterministic model of disability, perceived as resistance, there needs to be a focus on transforming the disabling nature of some teaching (Price, 2011, p. 55). Rather than forcing Emily to fit into the model of the schooling context, her input could have been valued. If she had felt protected and understood, she might not have felt the need to resist.

Anna explained how her son Manny fell into what she referred to as a "downward spiral" at age 13. Manny would come home and tell his mother, "Teachers don't know how to help me. They take too long to change the laws and I have to go to school every day. I feel stupid." Heartbroken, Anna would watch Manny get off the bus each day, "with his head hanging in a totally defeated position." Manny would describe his teachers as saying things like, "You're not trying. You could do this yesterday. What's the matter with you? You need to put in more effort. Pay attention." As Anna put it, "Manny tries harder, until he becomes so discouraged that behavior problems emerge from frustration, and anger rises to the surface." In an effort to protect himself, Manny was sometimes perceived as being difficult.

Leena spoke of her fourth-grade son, DJ, sharing,

> Fourth grade has been the worst for him. His teachers didn't understand his disability and he would get in trouble for not finishing his work on time. When DJ tried to advocate for himself, he was seen as being rude. One of the (school personnel) even referred to DJ as being lazy.

These harsh words propel students and parents into a protective mode. Even prior to the harsh words, students are perceived as resistant, when in fact, they aim to protect themselves.

After her tumultuous experiences with her daughter, Holly, Clarissa explained,

> I don't want other parents and children to go through the years of strife that Holly and I did. It was a constant struggle to not let Holly become too depressed and insecure as many dyslexic children do when not given proper instruction and support.

Depending on how students with dyslexia are perceived, they could be celebrated for the unique gifts they bring to the classroom, or they may instead be perceived in a deficit-laden manner, which leaves students feeling defeated. Those defeated feelings often manifest as resistant behaviors, when in fact, the students feel insecure, and attempt to protect themselves. Nearly all of the parents interviewed indicated that at one point or another in their child's schooling, their child refused to go to school because of their perceived inadequacies.

Sally shared a compelling story about her son, Cash, and how he not only protects himself, but others as well.

> Cash was diagnosed with dyslexia in third grade. He was failing miserably and would always tell me he felt depressed and really stupid. He didn't want to go to school. Cash kept saying the teachers didn't know how to help him. No matter how many hours a week Cash went to see the special ed(ucation) [sic?] teachers, he was still falling behind on grade levels in reading. Then, I had Cash transferred to another school in fourth grade. Thank goodness, he had Mr. C as a teacher, and he was trained in the Wilson reading program. Mr. C made Cash

> work hard, but Cash gained reading levels. Cash would come home saying, "I feel smarter." Mr. C understood the dyslexic brain and would talk to Cash about how his brain worked. Sadly, at the end of the year, Mr. C left the district. The next year, Cash went back to school and there was a new special ed(ucation) teacher. She didn't understand Cash or dyslexia. She treated Cash like he couldn't do anything.
>
> It made him feel stupid again. He fell behind several reading levels. Cash would claim to feel hopeless and that he would never learn to read. Finally, I put Cash in private school specializing in reading disabilities. Cash has to work really hard, but it's worth it. It's amazing how small classes and the right kind of teaching can help you learn to read, write, and spell. In his first year at the new school, Cash made over two years of growth in reading. This year, Cash is still at that school and is reading on grade level. Cash now advocates for himself and others, saying, "I want other kids with dyslexia to learn how to read and to feel confident. They deserve it. No one should feel stupid."

As educators, we need to take cues from our colleagues in psychotherapy who demonstrate how resistance is a signal to a sensitive area in a person's life that he/she is trying to protect (e.g., Brems, 1999; Butler & Bird, 2000). When encountering resistance, it is our job to conceptualize or make sense of the resistance (Karon & Widener, 1995; Mahalik, 2002; Vernon, 2004). In fact, lack of attention to the resistance creates an impasse, and can even be viewed as a layer of protection around all involved parties (e.g., Erikson, 1980; Newman, 1994). In the case of every student noted above, their resistance was natural, and a sign that the heart of the issue had been hit, therefore those layers of protection are always worth exploring and supporting in any student. In parents' undying efforts to protect their children, stories of layers of protection turned into legacies of fierce battles.

Parents' emotional battles

Throughout this research, I sought insights to the questions: How are students with reading disabilities (and their parents) positioned? What is the experience of parenting a child with dyslexia, and how can educators help? Although the ideas of parental protection and the battles that parents face may feel universal, and not necessarily unique to the parents of children with disabilities, I share these stories to ensure that our collective voices are heard. Perhaps these stories say more about how education is carried out, than about children, with or without, disabilities. A mother named Leena explained the battle she experienced in her attempts to get proper support for her son, DJ. Whether a student has a disability or not, no one should have to endure the battle that DJ experienced. These stories say much about the experience of parenting a child with dyslexia, how parents of students with dyslexia are positioned, and what educators could do differently to help. Leena shared,

> Throughout the years, I asked DJ's teachers if he could have dyslexia. DJ's 1st grade teacher was silent. His special education teacher responded, "No, because DJ does not write his letters backwards." Since that time, DJ has been diagnosed with dyslexia and other learning disabilities. I cannot begin to express in enough words, the hurdles that my husband and I have had to jump over for our child. We have had to make countless calls and send numerous letters to the school asking for help, which often went ignored and unanswered. We have had to spend thousands of dollars of our own money to get him the help he needs. This includes hiring outside tutors, evaluators and transporting him for those

> appointments. Finally, we withdrew DJ from public school and placed him in a private special education school.

Sadly, it was not uncommon to hear stories of families that battled with school personnel, and who experienced silence on a variety of levels—silence from teachers, from students, and from schools. Rarely were parents silent, however. Parents continued to advocate in what they perceived to be pure battles. Clara, mother of Maeve, reported,

> I was so discouraged and infuriated by the school's lack of knowledge about disabilities that I privately arranged for a neuropsychological evaluation. The school just waited for Maeve to fail. As a parent, I refused to let Maeve suffer in silence. I had to do my own research to find the best neuropsychologist, the best specialists, tutors, and a private school specializing in empowering students with dyslexia. When will this ever end? I hate to consider the families, and especially all of the other kids, who suffer in silence.

Clarissa shared of her daughter Holly receiving a dyslexia diagnosis, "I felt SO relieved, as it is what my maternal instinct had told me was the reason for her struggles ever since she was a small learner." Much of this voice, authority, and battle is rooted in resources and socioeconomic background, though. What about the families with fewer resources for the battle?

Anna, mother to Manny, posed the questions, "I wonder how many other parents gave up and simply accepted that their child is a non-reader? What is the cost in having a citizen who cannot read?" Unless Anna had fought fiercely for Manny, he undeniably would have fallen through the cracks. Anna began fighting for other families as well. Anna explained how she came from a working-class background, and she did not want families of lower social and financial means to fall to the wayside.

> Finally, after years of struggling and fighting, Manny was given a one-to-one teacher who was trained in Orton-Gillingham (a multisensory, linguistic, systematic educational approach, requiring specialized training for teachers). This trained professional was hired from outside the district because they didn't have anyone trained to properly deliver this specialized instruction. He was also given an iPad and audio books. This wasn't easy to get for him; it took a complaint placed at the state level to get my son what he needed to be successful. This is all stuff I would have hoped, as a taxpayer, I could have relied on a public school system to provide my child. Thank God I had the time, patience, intelligence and resources to help Manny. I can only imagine the tragic results that other families endure who may not have the same resources I did. Some children and adults never know they have dyslexia and therefore go through life feeling stupid and have low self-esteem. This needs to stop! He could have been spared years of suffering and thinking that there was something terribly wrong with him, when he is actually very bright and insanely artistic. This has cost my family tens of thousands of unreimbursed dollars. Many dyslexic families sacrifice everything they have to support their child. We deferred building up our retirement accounts, limited our vacations, outings and activities, and picked up extra work to pay for our son's Orton-Gillingham tutoring. We were able to save my son, both academically and emotionally, with years of tutoring and therapy. This all could have been avoided if the right methods had been employed.

In her groundbreaking study on the experience of parenting a child with dyslexia, Delany (2017) articulated the grief that many parents experience as they mourn what they perceive to be the loss of normalcy in their children's lives. Seeing dyslexia through a lens of "hidden" disability suggests that participants identified a "wrongness" that interrupted the expected continuation of normal development (Cologon, 2016). The frequent challenges associated with accessing support services leave parents feeling defeated and stressed (Krauss, Wells, Gulley, & Anderson, 2001) and at significant risk of psychosocial distress and decreased quality of life (Feldman et al., 2007).

Consequently, the creation of supportive environments for parents is crucial for positive adjustment (Resch, Benz, & Elliott, 2012). Delany (2017) eloquently captured the increased confidence parents gained along their journey, illustrating a more-sophisticated theory of parental functioning (Hassall, Rose, & McDonald, 2005). "As parents armed themselves with information and understanding regarding dyslexia, their position changed from one of grief to one of assertiveness, like a warrior heading into battle for the betterment of their children" (Delany, 2017, p. 107). In an Australian study of mothers of children with dyslexia who participated in a support group, significant reductions were found for stress, isolation, self-blame, and greater emotional closeness attachment to the child was reported (Brock & Shute, 2001). There are only limited studies of parental strategies that illustrate parental agency, identity and knowledge in mothers of children with dyslexia (Griffiths, Norwich, & Burden, 2004). Fortunately, more parents are gradually sharing their stories, and current and future generations will benefit. In a special series from National Public Radio entitled, "Unlocking Dyslexia," Emanuel (2016) shared compelling stories from parents of children with dyslexia who described their experiences as "scary," "a nightmare," and "a crisis." Yet, they also offered suggestions of hope, happiness, and warnings to make financial plans to invest in educators who truly understand dyslexia.

Discussion

Through this research, I sought to answer the following questions: How are students with reading disabilities (and their parents) positioned? What is the experience of parenting a child with dyslexia, and how can educators help? In order to shed personalized light upon some of the confusions surrounding dyslexia, this study situated itself theoretically among feminist theory and critical disability studies to share the stories of parents of children with dyslexia. Using interpretative phenomenological analysis, results illustrated that the children inhabited an "in-betweenness" in their disability, in the ways dyslexia was less visual, and manifested itself with great variety and was therefore frequently misunderstood. Likewise, the children presented a great deal of resistance in their learning, which was later understood as a way of protecting themselves. Parents faced several emotional and financial battles. None of this matters, however, unless tangible, meaningful educational changes can be made. In this section, I share ways to notice and honor in-betweenness in students, enact practices to navigate the complexities of those students who protect, and suggest more ways to integrate the voices and experiences of parents into our work in schools.

Noticing in-betweenness

Whether practitioners are working in schools, higher education, or clinical/medical settings, it is imperative to honor the voices of people with disabilities, and the input of their parents, who arguably have tremendous insight on the nature of the disability. There are times when a disability is vague, less visible, and difficult to diagnose, and those cases require our utmost attention. We can no longer shrug off vague symptoms, or the distinguished instincts a parent often provides. As diagnostic tools are being updated, we need to think outside of the box, and document our hunches, as well as our suggestions for support.

In a stance toward disability justice, many disability studies scholars are reconceptualizing disability and the body as sites of becoming rather than of being (Hall 2014, 2015; Kafer 2013; McRuer 2006; Shildrick 2009). After all, disability is not a limited case—an extraordinary vulnerability or an extraordinary embodiment, although it is commonly represented that way (Kaul, 2013). Instead, this study is a reminder that disability is a concept that, in its specific mobilizations of bodies and subjectivities, the biological and the social, the real and the figural, makes extraordinary demands.

There is a specific type of agency experienced by students who feel empowered by identifying through the term dyslexic. The diagnosis can feel freeing in its strong, distinctive definition. Of course, no one should be made to feel stupid, yet when a student consistently struggles with reading and writing, it is understandably demoralizing. By embracing the positive nature of identifying as a dyslexic, it takes away the vagueness and in-betweenness of the reading disability, providing a sense of clarity and agency for these bright individuals. Moreover, a clear definition provides context for educators to more systematically address the academic needs of these students.

Teaching strategies for students who protect

The mothers in this study initially viewed their children's resistance as a stumbling block. Although educators may be inclined to view resistance as a nuisance and obstacle in teaching, children's resistance may be an opportunity for powerful teachable moments, with the possibility for more in-depth comprehension. Reconceptualizing expressions of resistance provides a window into how children are experiencing learning, and how they are experiencing life. "Through resistance, children give voice to their insecurities, anxieties, questions, and struggles" (Sipe & McGuire, 2006, p. 6). Children's resistance is one way they may be positioning themselves. Bruner (1990) describes position as how much control one feels he or she has in a situation. This idea of positioning is central to understanding a child's participation in learning activities. "Positioning helps to determine who can participate and who can be a knower in a particular domain" (Lassonde, 2006, p. 140).

All students are diversely situated learners, and classrooms can be set up with this assumption in mind (Price, 2011). Often, stubborn resistance is the direct result of a cognitive problem. Once the pedagogy embraces the cognitive challenges and works to strengthen them, the students are provided pathways to become more playful and flexible (Arrowsmith-Young, 2012). By taking the time to get to know students better, and by focusing on their strengths, teachers may focus on what is possible. As educators who embrace the idea of neurodiversity (e.g., Silberman, 2015), we may regard naturally occurring cognitive variations in our students, who each have distinctive strengths, rather than seen as merely dysfunctions. Price (2011) provides the suggestion of teachers explicitly describing the class's kairotic spaces, deepening and broadening channels of possible access for students. For example, what will discussions, presentations, deadlines, group work, etc. look like, with examples and/or clear expectations of each.

Early, clear, on-going, and consistent feedback is crucial to success. Obviously, communication is key, and the more multimodal the communication, the better. As teachers, the more input we receive from students and parents, the better equipped we are to meet the students' needs. "Accommodations are not charitable offerings; they are spaces we open to the best of our abilities, and revise, and revise again" (Price, 2011, p. 102). As teachers, when we brainstorm various methods of engagement, we avoid challenges, and we provide pathways of seeing how motivation, mindset, and self-regulation are inextricably linked (Kaufman, 2013).

Honoring the roles of parents and students with disabilities in the research

Since my background is in qualitative, feminist methodology, I was inspired to sculpt this study into a feminist autoethnography, informed by the method of IPA. Often, mothers find themselves having to trust their own instincts, and having to battle the silence. Gilligan's (1982) works have set a precedent for decades of devotion to the voices and silences of women. "By listening to their inner voices, women were discovering that they could challenge authority, shed their tendencies for obedience and self-sacrifice, and experience an increased sense of control" (Woodcock, 2010, p. 361).

Mothers were happy and grateful to share their stories about their experience of parenting a child with dyslexia. I believe that this substantiates the need to involve both students and their parents in more research concerning the experience of parenting a child with dyslexia, and what aspects of American infrastructure need to change to better assist families living with dyslexia. This study is somewhat novel in the ways it connects disability studies with the voices of mothers and their children. There are tremendous implications for schooling and larger societal supports for parents and the infrastructure necessary for people with a range of disabilities. "Within a participatory action research project, the experiential knowledge of oppressed groups is honored, prized, and sometimes privileged over the researcher's abstract academic knowledge" (Guishard, et al., 2005, p. 42). This makes sense when considering that collective self-inquiry and reflection are structured to provoke critical consciousness (Fals-Borda, 1979). "In participatory research, the conventional boundaries separating researchers from participants are intentionally blurred" (Guishard et al., 2005, p. 42). In traditional, positivist research, all facts must be observed and recorded from a distance, and people are treated as objects, incapable of investigating their own social reality (Maguire, 1987). Those old-fashioned treatments contributed to people's alienation from their own decision-making capabilities (Freire, 1970). In order to reclaim disability in critical qualitative research, we must take cues from feminist researchers in the ways they no longer tolerate their own dehumanization as researchers and participants (e.g., Kafer, 2013).

As parents, researchers, and educators, we must honor our instincts and voices in these stories and streams of research. Since I am a literacy specialist and the mother of a child with dyslexia, I am perplexed by researchers who say dyslexia does not exist (e.g., Elliott & Grigorenko, 2014; ILA 2016a; 2016b), or those who claim there is not one proven method to teach struggling children to read, when parents have seen huge gains in their children when they have been exposed to daily one-on-one instruction with a highly qualified individual who administers an evidence-based program, such as Orton-Gillingham (e.g., Lim & Oei, 2015). A primary goal in writing this paper was to tell the real stories of real people living with dyslexia. "The 'story' we should read in the lives of the individuals with dyslexia isn't a tragedy; it's an exciting story filled with hope, opportunity, and promise for the future" (Eide & Eide, 2011, p. 129).

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