A Mother's Knowledge: The Value of Narrating Dis/Ability in Education

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Abstract

In this paper we answer the question: *In what ways does a mother's narrative of including her son with a disability in his local school inform inclusive practices in general?* Our research contains a theoretical framework informed by (1) Disability Studies in Education (DSE), (2) the importance of narrative knowing within research, and (3) the value of a mother's knowledge of her child. The data consists of the second author's written autobiographical accounts of her experiences with, and observations of, her child's school. We feature a series of four vignettes culled from second author's descriptions as a mother of a child who did not "fit the mold" in terms of academic, social, and emotional expectations. Using analysis informed by DSE, coupled with personal reflection, the first author discusses the value of ways in which a mother's knowledge about human diversity and desire for inclusion counters the deficit-based assumptions and expectations entrenched in much of special education's foundational thinking that, in turn, informs daily practices within schools that reinforces the exclusion of children with disabilities. Next, we link our findings to implications for the interrelated fields of education, special education, and inclusive education. Finally, we articulate some recommendations, based upon our work.

Keywords: Children with disabilities, mother`s knowledge

What does it mean to be human? How can we respond ethically to difference? What is the value of a human life? Who decides these questions, and what do these answers reveal?

Catherine Kudlick (2003, ¶1)

Introduction: Supporting Inclusive Education

This collaborative work reflects our mutual interest in inclusive education as citizens and teachers, and our disparate yet arguably connected roles as researcher and parent who are motivated by our belief in the civil rights of providing disabled children access to a quality educational experience. Our work grows out of Diane's desire to paint a portrait of a school in New York State that successfully included her son, Benny, who had previously "failed to function" in two exclusionary/highly restrictive special education classrooms in New York City. In contrast to the city schools, The Boulder School[4] welcomed Benny and supported him and his family in finding ways to ensure his inclusion within all aspects of schooling. In turn, Benny's presence and participation within the school grew over the years and significantly influenced its general culture in a myriad of positive ways. At the same time, the school also provided an oasis for Diane's younger son, Adam, who excels academically and socially. In contemplating the same school and the same teachers who met the needs of her two children with such dramatically different learning profiles, Diane felt compelled to chronicle how, and explore why, this school was successful whereas so many others in her experience had not been.

David's interest in creating this text lies in the fact that Diane had shared this school school's story with him. He became drawn to the challenge of "capturing" and analyzing a school that has attempted to develop an authentic inclusive educational experience for students—a process that is ongoing, admittedly imperfect, yet earnest. Despite major policy changes in regard to inclusive education over the past three decades, there have been very few clear examples of inclusive schools in scholarly works (Danforth, 2014; Hehir & Katzenberg, 2012) and documentary media (Habib, 2008; 2012) that can be shared in teacher preparation classes. In conversations with Diane, David could see how what was being done at the school to ensure authentic inclusion was, in fact, unsurprisingly, very much in tune with a Disability Studies in Education (DSE) framework. For this reason, he believed it would be worthwhile to document—and discuss—an example of where a "real life" example of inclusive education evolved with what he believes is a DSE-disposition that helps educators, parents, students, and community members best understand and approach how to "do" inclusion.

We begin my briefly sharing a few observations and anecdotes from our work as inclusive educators in the same teacher education program. David developed the required inclusion course for all general and special educators to have a DSE-framework through which to understand inclusion

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[4] All names of children and educators are pseudonyms.

as everyone's responsibility and a student's civil right (Valle & Connor, 2011). For the past four years Diane has integrated her personal story into the course and has brought Boulder staff to talk with her students. Each semester, 5-8 Boulder staff members, including the principal, visit her classes. When Diane spoke extensively with the Boulder staff, they often defer to "instinct" when explaining how they create their school culture. This response, and graduate students' questions about positive examples of inclusive settings became a primary motivation for her to write their story. While Boulder faculty present with a refreshing absence of technical jargon, we recognize that their general attitude and effective programs are in line with many elements that form the basis of DSE. We also recognize that in order to accurately document Boulder's approach to inclusive education, a deeper analysis is needed. In an effort to capture what is possible, we believe a formal analysis coupled with an open reflection upon a school that embodies a DSE-simpatico approach, will allow other teachers and administrators to become familiar with these ideas and see how they can apply within any educational or community setting. While our work is part of a larger project, in the interest of space limitations, the purpose of this paper is to address the research question: *In what ways does a mother's narrative of including her son with a disability in his local school inform inclusive practices in general?*

Our research contains a theoretical framework informed by (1) Disability Studies in Education, (2) the importance of narrative knowing within research, and (3) the value of a mother's knowledge of her child. The data consists of Diane's written autobiographical accounts of her experiences with, and observations of, The Boulder School. We feature a series of vignettes culled from Diane's descriptions as a mother of a child, Benny, who did not "fit the mold" in terms of academic, social, and emotional expectations. Woven throughout these vignettes David writes a mixture of analysis and reflection informed by DSE, emphasizing the value of ways in which a mother's knowledge about human diversity and desire for inclusion that counters the deficit-based assumptions and expectations entrenched in much of special education's foundational thinking that, in turn, informs daily practices within schools that reinforces the exclusion of children with disabilities. Next, in discussing our findings, we link them to implications for the interrelated fields of education, special education, and inclusive education. Finally, we articulate some recommendations, based upon our work.

Disability Studies and Sociocultural Perspectives of Human Differences
Although traditional special educators believe the hard sciences serve as the best model for special education theory, research, practice, and policy,

critical special educators working within Disability Studies in Education, are convinced that there is greater value in addressing the complexities of society, culture, and history—in relation to human differences. In brief, a DSE perspective believes the contextual understanding of education is crucial and, conversely, a simple objectivist disposition is impossible. Such ideological differences have given rise to scholarly exchanges in journals that have ranged from expansive and enlightening to acrimonious and rigid (see for example: Anastasiou & Kauffman, 2011; Danforth & Rhodes, 1997; Gallagher, 2006; Heshusius, 1989; Iano, 1996, 1990; Kavale & Mosert, 2003; Kauffman, 1999; Kauffman & Hallahan, 1995; Kauffman & Sasso, 2006a, 2006b; Skrtic, 1991).

Despite the dominance of positivism in special education, its devotion to medicalized understandings of dis/ability, and the subsequent impact that has upon practice and policy, critical special educators working within DSE have made progress in engaging with a field they recognize as inhospitable to their ideas, beliefs, dispositions, and research practices. In previous decades, critical special educators were understood to be individuals with an idea that caught the field's interest or troubled its conscience such as: Heshusius's (1989) urge to imagine viewing human differences from non-mechanistic paradigms; Gallagher's (1998) questioning of basic scientific assumptions; Skrtic's (1991) structural analysis of epic inequities; and Reid and Valle's (2004) groundbreaking reframing of learning dis/ability. The work of these scholars served as the basis of formalizing DSE into an alternative framework of conceptualizing dis/ability that we believe is worth featuring (Connor, Gabel, Gallagher & Morton, 2008). For example, the purpose of DSE is *to:*

Promote the understanding of disability from a social model perspective drawing on social,   cultural,   historical,   discursive, philosophical, literary, aesthetic, artistic, and other traditions   to challenge medical, scientific, and psychological models of disability as they relate to   education (Connor et al., 2008).

The tenets of DSE are to engage in research, policy, and action that: contextualizes dis/ability within political and social spheres; privileges the interest, agendas, and voices of people labeled with dis/ability; promotes social justice, equitable and inclusive educational opportunities, and full and meaningful access to all aspects of society for people labeled with dis/ability people; and, assume competence and reject deficit models of dis/ability (p. 448)

Examples of **theorizing DSE** include: contrast[ing] medical, scientific, psychological understandings with social and experiential understandings of dis/ability; focusing on political, social, cultural, historical, and individual understandings of dis/ability; supporting the education of

students labeled with disabilities in non-segregated settings from a civil rights stance; engaging with work that discerns the oppressive nature of essentialized/categorical/medicalized naming of disability in schools, policy, institutions, and the law, while simultaneously recognizing the political power that may be found in collective and individual activism and pride through group-specific claims to dis/abled identities and positions; recognizes the embodied/aesthetic experiences of people whose lives/selves are made meaningful as disabled, as well as troubles the school and societal discourses that position such experiences as "othered" to an assumed normate; includes disabled people in theorizing about dis/ability (p. 448).

We thought it was worthwhile to include tenets and examples of theorizing dis/ability as these have guided us in designing each aspect of our research, including the question asked, our theoretical framework, methodologies, data collection, analysis, interpretation, and findings. Our work recognizes and privileges knowledge derived from the lived experience of people with dis/abilities and their family members, and is purposefully located in this particular context. In addition, our work deliberately challenges research methodologies that objectify, marginalize, and oppresses people with dis/abilities. We openly acknowledge seeking participation in the construction of a new discourse of dis/ability in education that emphasizes dis/ability in its socio-political contexts and is respectful of dis/abled people. We also acknowledge our desire to recognize connections, overlaps, and dissonance between DSE and special education, including tensions, paradoxes, contradictions, and reticence within education at large toward conceptualizations of diversity that includes dis/ability.

Methodological Choices: Centering Narrative

The potential power of narratives can be seen in Lincoln and Denzin's description of them as "a minimal ethnography with political teeth" (2000, p. 1052). We believe this to be an apt description, as working with narratives, though arguably often undervalued methodologically, can serve to actively promote social change. Elbaz-Luwisch (1997) remarked

The conduct of narrative research gives rise to a range of political issues which include   the validation of narrative knowledge, the relationship between power and authority   among   research participants, and the distinction between the public and private domains
  (p. 75).
It is precisely for these reasons that we chose narrative as a methodology in this study.

Through the use of personal narrative, we foreground the experiences of a mother and through her, a child, voices that not sufficiently sought within much of educational research. As Clandinin and Connelly (2000)

point out, an important focus of this methodology lies in the lived experiences of individuals explaining, "In the grand narrative, *the universal* case is of prime interest. In narrative thinking, *the person* in context is of prime interest" (p. 32). Furthermore, as Fairbanks (1996) notes, "In narrative research accounts, the tendency is to explore or explain the significance of what previously have been considered ordinary events and to raise these events to the exceptional" (p. 236).

By focusing on what many may see as a relatively ordinary situation—the inclusion of a child into an inclusive classroom—we analyze "the stories individuals tell us or the events they experience together in light of theoretical concepts…[which is a] primary means of constructing knowledge through narrative" (p. 327). Narrative is keeping with a DSE stance, as Rossiter (1999) explains the importance of narrative, and its appropriateness for this research design:

Narrative knowing, in contrast to scientific knowing in the positivist tradition, is concerned   more with human intention and meaning than with discrete facts of events, more with   coherence than with logic, and more with understanding than with   predictability   and   control (p. 60)

It can be argued that stories are one of the most widely used ways of communicating. That they are ubiquitous, Mishler (1986) believes, "supports the view of some theorists that narratives are one of the natural cognitive and linguistic forms through which individuals attempt to order, organize, and express meaning..." (p. 106). Drawing from the influential work of Bruner (1990), Polkinghorne (1997) claims that, "narrative is the natural mode through which human beings make sense of lives in time" (p. 13, 1997). In keeping with this sentiment, Richardson (1990) believes that "Although life is not a narrative, people make sense of their lives and the lives of others through narrative constructions" (p. 10). As such, it is clear that all stories may be viewed as representations. Molloy (1991) asserts that a representation is "a re-telling, because the life to which it supposedly refers is already a kind of narrative construct. Life is always, necessarily, a tale" (cited in Clandinin & Connelly, 2000, p. 101). In many respects, a personal narrative is a form of self-representation, and useful as such as it can lead to better understanding among human beings about various phenomena. As Richardson (1990) writes, "It is the closest to the human experience, and it rejuvenates the sociological imagination in the service of liberatory civic discourses and transformative social projects" (p. 65). Of course, stories vary in quality. As Worth (2008) has noted, "it can be argued that there is a significant increase in epistemological value in a well-told story" (p. 52). In sum, well-told story not only has epistemological value, it has ontological value as it told as holds a form of 'truth' that deserves being studied, as well

as methodological value in that narratives provide access to understanding highly situated circumstances.

Our own work builds upon narrative knowing about dis/ability within DSE, including listening to the voices of: urban youth with learning dis/abilities (Connor, 2009); females identified as behavior disordered (Annamma, 2015); college students with learning dis/abilities and Attention Deficit Disorder (Connor, 2013); teachers with learning dis/abilities (Ferri, Connor, Solis, Valle, & Volpitta, 2005); a deaf scholar (Valente, 2011); adolescents with intellectual dis/abilities (Mutua & Swadener, 2015); and teacher of students with dis/abilities (Broderick, Hawkins, & Henze, 2012).

Narratives of Mothers with Dis/abled Children

Although parents are featured in the research literature on children with dis/abilities, the overwhelming majority of studies focus on parents as subjects, often casting dis/ability via a deficit-based lens and the impact is has upon marriage (Ristal & George, 2004), non-disabled siblings (Hannon, 2012), depression (Singer, 2006), and stress management (Singer, Etheridge, & Aldana, 2007). In many ways, such an approach to the topic of parenting children with disabilities is antithetical to DSE. There is, however, a small but growing number of memoirs by parents of students with dis/abilities that provide significant insights into how parents make sense of dis/ability, often conveying a markedly different understanding of dis/ability as portrayed in the professional literature, including Cutler (2004), Harry (2008), and Linder (2009). Likewise, there are several DSE-scholars who maintain an active interest in the area of being mothers and/or parenting children identified as dis/abled (Hale, 2011; Kalyanpur & Harry, 2012; Lalvani, 2011, 2014; Valle, 2002, 2009; Ware, 2006).

Vignette 1: Eavesdropping Behind a Tree

Often Benny sat alone, sometimes under the slides, studying the metal bolts that hold the equipment together. One morning however, a classmate from his new school called to Benny. They ran together for a while, Benny laughing hard and smiling long. David [my husband] and I delighted for a few moments in this until we heard the other child say to Benny, "Come on Benny. Let's sit down and chat for a bit." Upon hearing those words, that invitation to talk, I froze inside and filled with a panic that came on quickly. My legs wobbled and my stomach churned. Benny was still not to our knowledge conversational. He had many words; he could answer some basic questions but I had never heard him engage in a spontaneous give and take conversation. I called to David and we stood nervous together within earshot of the boys. I was delighted to hear them laughing; Benny was telling his new friend how his father broke a bowl in the sink the week before and how

several years ago his Daddy spilled tomato sauce on the CD player. The boy was laughing so hard he could barely catch his breath. Benny grinned with a mischievous twinkle and I was absolutely floored. David and I stood huddled together behind a tree, eavesdropping, mouths hanging open in surprise.

It was frightening to realize that I had no idea how well Benny could converse when in a natural setting. I realized that it had been a long time since I spoke to him expecting a full and spontaneous response. I quickly ran through the past few days' conversations with Benny. I had initiated the conversations, not in full voice, not freely. The questions I asked of him were not steeped in curiosity, did not reach out with true yearning for his response, but rather were often rhetorical, simple questions designed to open a dialogue but not to truly engage. They were mechanical exercises instead of invitations to relate. During the years when Benny was doused in years of therapy, unconsciously, I imitated the interactions I heard between Benny and his therapists. I had learned to speak to him in the same tone, asking questions that were staged and rarely spontaneous. I had lost hope in his abilities and this loss of hope colored every interaction between us. Benny seemed exquisitely attuned to this, and had no interest in more talk that went nowhere. His therapy was necessary, but this therapy was not enough. It enabled him to learn skills and vocabulary, but Benny desperately needed the music of the real world in order to involve himself in meaningful expression. This one small boy made me see what was possible and from that moment my own interactions with him grew. It was not long before my conversations with Benny sparkled with nuance and humor.

Reminiscent of a Shakespearian plot, Diane and David "accidentally" overheard social arrangements being made by their son and his friend that prompted them to hide behind a tree and eavesdrop. What comes to mind immediately is that this opportunity would not have occurred, because it could not have occurred, in Benny's previous school where all children considered to be autistic were placed together. Here, the everyday interaction of children—that many take for granted—talking together naturally and spontaneously, is highly appreciated and valued. Perhaps most importantly is Diane's realization that her own interactions with her son had remained largely in the discourse utilized by service professionals. In other words, Diane's interaction with her own son, despite a level of consciousness on her part, was still predominantly lodged within an "intervention" mentality that structured conversations as directions, didactic in nature, more akin to being a professional than a family member. In many ways, this realization illustrates a medicalized versus socio-cultural understanding of the purpose of language and its power to create and maintain authentic connections rather than be "more talk that went nowhere."

The other compelling aspect of this vignette is the ability of children to be with each other and develop their own communities without being overly supervised. Diane's epiphanic moment happened because of a small boy's reaching out to Benny with the expectations that they would communicate about a shared experience, having clumsy fathers (or, to give the benefit of the doubt, fathers who had clumsy moments). This invoked laughter on both of their parts, further encouraging a rapport that Diane and David did not think possible. From this experience, Diane changed her disposition toward conversing with her own son. She had to "unlearn" the limited ways she had seen professional specialists work with her child, in order to cease having him answer as expected, and to connect with him in ways he could identify and respond to, based upon his personality and interests.

Vignette 2: Response to a Kick
It is not easy to step into the world of the typical when you come with massive delays. It is not easy for the parent or the child. We must face our differences daily and in public. I wonder if it is fear of this reality that causes so many parents to choose segregated settings that do not place high demands on their children. Nevertheless, despite the principal's support, things were not going well for Benny in the classroom. There was already an assistant teacher in the room, before Benny joined the class—a lovely experienced woman who tried her hardest to keep Benny in check—but her efforts were not enough. Benny routinely ran from her and she seemed powerless to stop him. He had developed a habit in his first and second kindergarten self-contained classrooms of running clear out of the classroom. I imagine the habit began because he was truly trying to get away from the classroom, which offered little in terms of joy to him. Even though he was now in a school he loved, the habit stuck and when he wanted to avoid some task, out he went, fast as can be on his strong little legs.
The assistant teacher in his current room was assigned loosely to all the children with disabilities but began giving most of her attention to Benny. It was not enough. The inclusion specialist, Meryl, began spending extra time in the classroom, using her free time to chase after Benny. Lunchtime was especially problematic. Without the classroom structure, Benny was even harder to contain. Several teachers began giving up their lunchtime to take turns monitoring Benny.
One day, upon pick up, a young handsome man with a strong handshake came up to greet me. He walked beside a beaming Benny and told me he was now the Teaching Assistant assigned to the class and he would take responsibility especially for Benny. They had an immediate connection. Benny looked up to Gary with sincere respect and admiration. It wasn't until

years later, when the relationship between the principal and me had turned to friendship, that I learned what I had suspected; he had changed assistants to better accommodate Benny. This was the first time I saw the climate change for a child so dramatically. Benny who could learn to read and write had little control over his behavior. Instead of waiting for his behavior to improve, the school did what it could to find the best fit for him within the classroom.

Once again Benny's behavior improved for a few days and then he became comfortable. One day I came to pick up and could see from Benny's face that it had been a difficult day. Gary told me Benny had kicked him during a reading session. I was mortified, but Gary was calm and told me it was because Benny was frustrated by the task and that he would find a way to approach it with him another day, in a new way and that Benny would master the skill. I was perplexed. The emphasis was not on my son's act that might have led to suspension but on finding another way to teach Benny without extreme frustration. This moment broadened the trust that Benny had for Gary and that deepened the bond that I felt for the school.

This vignette raises many important issues, one of them being the notion of "delays." In special education language, delays are a paradoxical term as they assume that, like a late train arriving at the station, the journey will go on as originally anticipated, back to normal. However, "delays" are often a euphemism for being behind, with the fear of not being able to catch up. At the same time, in education we always want to keep an open mind about an individual's potential and actual growth, as otherwise there's an imposition of a ceiling of expectations. Even so, lived experience has informed all of us that everyone will never be able to do what's expected at school—if age and grade level standards are rigidly enforced, and also are constantly being raised over time. We are all very much restrained by the expectations always required and the language we use.

That said, Diane's recollection of this episode reveals ways in which schools can actually have a solid system of resources in place, yet still have to rethink them based upon the needs of a single child if need be. Of note in this situation is finding the right match of people. The teaching assistant who supported Benny, as Diane noted, understood the nature of the child. A kick is still a kick, and unpleasant to receive, but the assistant did not take it personally as he knew it came from a place of frustration that had not yet been tapped and channeled into a form of expression. The incident illuminates how punitive measures for children (think: "Zero Tolerance" policies) who respond violently as part of their struggle in school are rarely the answer, and can actually serve to exacerbate the problem. As the fit was a good one, the relationship between the supporter and the supported grew to work—allowing Benny to participate in the general education classroom.

Vignette 3: Showing vs. Telling

In Grade 2, Benny had a very experienced teacher, Barbara, with some 30 years of teaching when she met Benny. Admittedly she had never had a student quite like Benny and initially she felt that perhaps she did not have the right skills or training to help him. Barbara was in some ways a traditional teacher and felt the responsibility to do it all for all of her students. She wanted Benny involved and engaged in every activity and spent hours planning ways to accomplish that. Around the holiday time she brought in small looms for the children. They had been studying the 1800's and had visited a restored village. She wanted them each to create a woven potholder for their parents. Since Benny could not as of yet tie his shoes, or button a simple button, it seemed unlikely that he could create a potholder on a small plastic loom within an hour's time in the classroom. Barbara instead prepared a sorting activity for him. He was to sort the colored bands of fabric and then color in a bar graph relating to the numbers of each color.

Benny wanted nothing to do with that task and knocked the bands to the floor. Barbara tried to redirect him to the loom but he seemed to be all thumbs. She was frustrated and left for a while to assist some other students, many of whom were struggling. When she returned, barely ten minutes later, Benny was working away, weaving orange and white together, creating a potholder with the utmost of dexterity. Barbara looked right at Benny and asked him where he learned to do that. Benny just smiled and the girl next to him, a lovely red head, looked up and said, "Gee, Mrs. M, it was not that hard, I just showed him and he picked it right up." Barbara was floored. She took the potholder all around the school to show his other teachers and therapists and even the principal She called me that day to explain and then sent the magnificent square home in his book bag. She learned inadvertently that day that she did not have to be the only agent for Benny's growth. She had 26 students who might know even better how to get him to produce, and just might take him to a place no one expected he would get to. This experience enabled Barbara to relax a bit and let go of the tension that was interfering with relationship she was trying to build with Benny.

In this exchange we are reminded that all teachers cannot always reach all of the children in their classrooms in ways they wish to. The pressure, the responsibility, the very real limits of our knowledge (despite being an educator for three decades) can result in an impasse between teacher and struggling student. Although the phrase is somewhat clichéd, we see that teachers, by necessity, are life long learners. By stepping back when things were not quite working—instead of continuing to force the issue—the teacher inadvertently created a space for an observant student to step into and show Benny how to do what was being required. DSE encourages the cultivation of such classroom ecologies because it accepts that people are

actually interdependent, rather than independent. Help and support can be requested when and where it's needed, including exploring options related to space, time, amount, and complexity of work assigned. Each child in a class can potentially hold the answer to the question that the teacher cannot always have at her brain tips. In this case the opportunity for another "milestone" for Benny was created by his classmate; a situation that could not have occurred his original school.

Vignette 4: Drop Everything and Don't Read

The entire fourth grade had a 30-minute time period every day called DEAR time, which stood for "drop everything and read." His teacher, Rosalie, suggested to me that Benny be given this time to partner up with another classmate just to "hang out" instead of reading. She suggested that each week a different student would be Benny's DEAR time partner. They would go out into the hallway, take a game or two, a small whiteboard, some books and just play together for the time. My initial reaction was surprise. Playing instead of reading seemed contrary to what I had learned about education, especially in grade four, a high stakes testing year. Still, I had already learned to accept the wacky and wonderful ideas that germinated in the minds and hearts of these Boulderfolks. So I said, "sure," with a certain hesitation in my heart and mind. Once again I feared the resistance of other parents.

The idea was a hit from the start. Benny came out smiling every day, eager to tell me first about this time he was able to spend with a classmate. While I worried about how parents would feel, afraid that they would resent the time spent away from reading, parents told me their children looked forward to their time with Benny, and often prepared ahead. One boy taught him all about football, another girl taught him how to draw animals. Other teachers commented on how lively and happy Benny seemed out in the hall with his friends. Benny began to call his classmates on the phone, to continue conversations he began during DEAR time. Genuine friendships grew from this time together. Rosalie had told me this would last until March, with each student spending one week with Benny, after which she would find another activity for him. However, so many children had already requested extra time with Benny, recalling a missed day when they were absent or when there was a rehearsal, that accommodating all of these requests, Benny was booked through June.

DEAR time became a time when the Benny's classmates could see what really made him tick and they saw his humor and intelligence. Rosalie said she did it as much for Benny as she did for the other students. She knew Benny had a lot to share and wanted to give him an opportunity to do so. She also wanted the other students to know that it is worth the extra effort to get

to know a student who might seem more remote at first. She hoped this would carry over to middle school and enrich their lives as well. She wanted the other students to realize that inside his quiet demeanor was a creative, funny and passionate child. It was a lesson for everyone, a time to realize we all have parts of ourselves that can be hidden in certain situations.

Boulder believes that the social is as important as the academic. A child who is unhappy and unrelated to his peers is not a child who will learn well how to live and work in society. The emphasis we place on academics can only work if we conjoin it with an equal emphasis on community. This is magnified for students who may struggle socially but it is true for each and every one of them. This is perhaps where educational reform is heading most astray. The single-minded pursuit of academic excellence will not work because we need to work together in this world to create positive change and societal growth. I still marvel at how amidst the stress of Common Core and new state tests, grade 4 teachers across the country are cutting out all sorts of extra's from their classrooms, while Rosalie, here at Boulder, is taking away reading time and listening for laughter.

Of all the many reasons I wanted inclusion for Benny, the most compelling was for the chance to find friendship. I was not sure that simply moving him into a general education classroom would enable friendships to form, but that was my deepest wish for Benny. I could envision a life without the ability to read or write or even to speak, but I could not imagine a life devoid of companionship.

In this episode we see how a teacher can create an arrangement within a reading class that benefits all of the children. Although Benny does not yet read at this point in time, it is important for him to communicate with his peers. By allowing conversation time, he comes to know all of his classmates, their personalities, and their interests. The act of reading is about communication (albeit in a limited way), and in order to get there, Benny has to come to understand the value of communication in a larger sense, among his peers and about their interests. Then, reading makes more sense because people tend to read about what they are interested in. The opportunity to share likes, dislikes, skills, questions… makes for a rich experience for both students, and for Benny to understand the concept of peers/friends and for peers/friends to understand an atypical student like Benny.

It is precisely at junctures like this that teachers often feel stumped for the right thing to do—restrained by an unimaginative curriculum, and fearful of not always following the "official script" for all students, regardless of whether that script is within reach of a student's current capabilities. However, by opening up the format of the class (allowing 1 on 1 with a peer for Benny and the peer), and broadening the concept of independent reading to independent talking, the teacher actually provides

what students need. All students in that class come to see Benny as Benny, not primarily the student with a disability who is called Benny. The social, emotional, and academic are entwined in lessons like this, permitting all students to be who they are and contribute to the collective class knowledge. It also demystifies dis/ability as difference that is sometimes noticeable, and yet is natural. In reflecting upon Diane's desire to see that her son has friends, she knew that moving Benny to a general education class would not automatically result in friendships, but it was the first step in the right direction. Between the targeted attention of speech therapists and coming to understand all of his peers within the general education classroom, Benny eventually shifted from having little or no conversational skills to being fully conversational, thus averting "a life devoid of companionship."

Discussion

In this section we return to the question posed: *In what ways does a mother's narrative of including her son with a disability in his local school inform inclusive practices in general?* The vignettes featured are part of a larger narrative in which we study what Boulder and its staff did to ensure that Benny's experience with inclusion was successful. In some ways, Diane's constant interactions with members of the school, observations of the services and supports provided to her son, and her reflections on what was happening and why, create a deeply personal rendering of her own reality, and that of her family members. While highly personalized, her account provides numerous insights into ways an inclusive placement for a student who does not "fit the mold" can work.

As can be seen throughout the vignettes, Benny's inclusion is always very much a work in progress. No road map. No blue print for success. No quick and easy answers. The relationship between the school administration, teaching staff, teacher assistants, and Diane's family was calibrated with view to making Benny's school experiences as successful as that of all other students. The term "trial and error," is not an appropriate description of what occurred, but "Let's wait and see," appears apt, along with (to echo the sentiments of a kicked assistant teacher), "…and if things don't work out, we'll look for another way." What became apparent in Benny's classes and on the playground is the importance of peer relationships in working with an atypical child to satisfy social and emotional domains of schooling, while positively impacting the academic domain. Teachers sometimes do not sufficiently capitalize on these interpersonal types of pedagogy that can potentially give rise to 'win-win" situations involving all students participating and successfully contributing within classes.

Teachers themselves, even the most seasoned, sometimes were surprised at what did not work and equally surprised as what did. This raises

the point of how children with different needs *stretch* all teachers' pedagogy, expanding their repertoire, requiring them to pause, reflect, approach teaching from an alternative angle that had not been fully considered to date. Seeing oneself—as well as Benny's inclusion—as a constant work in progress is a healthy and realistic to integrate into one's teaching disposition.

Service providers in this story contribute to, but do not dominate, Benny's schooling experiences. The mechanical intervention approaches referred to by Diane eventually gave way to an integral experience in classrooms wherein the speech teacher "pushed in" to general education classes and helped all students with communication skills. All of the above characteristics of the school are cultivated by a principal who is committed to the idea that each student should feel welcome, grow, and be happy with who they are.

Above all, this narrative is testimony to Diane's unrelenting drive to have her son included into general education. The alternatives within New York City were simply not acceptable. It seems unbelievable that Diane and her husband David rejected what the school system offered to be the most "appropriate" placements, and were threatened with a lawsuit by the Department of Education who believed that the parent's desire to have their child included was borderline abusive. Instead, having followed her instinct, and rejected the knowledge, advice, and restrictive placements suggested by educational experts, Diane is secure in the knowledge that Benny's placement in a school that "does" inclusive education responsibly has immeasurably changed his life for the better.

Implications

This paper has verified the power of narrative knowing and the centrality of people with dis/abilities and/or their family members being at the center of the research. Narratives provide readers with accessible accounts of everyday events and commonplace dilemmas within schools and classrooms. As narratives describe actual happenings, even though they are filtered through the eyes of an observer/writer, they reflect a form of "reality" that is readily understood by the majority of teachers, parents, and people with disabilities. Within these shared vignettes, it is clear to see the actualities of a child, a family, a school, a community, and the ways in which they are linked. Such stories can be seen as counter-narratives to the dominant institutional discourses of exclusion and segregation (such as in New York City's Department of Education) for children with autism and their access to general education. Importantly, family perspectives of important issues within education such as inclusion can be less fettered by traditional special education groundings, and are not required to be quantitative and positivist in conception and design. Incidental, everyday,

"Let's try this and see" approaches have worked in this instance, and will likely work for many other children who are in highly particularized inclusive situations.

Conclusion

We have focused on a mother's narrative knowing about inclusive education for her son with a disability. This was accomplished through using the lens of DSE that privileges the voice of disabled people and their family members. Diane's story confirms and extends existing literature in the field, valuing the knowledge of mothers. The use of vignettes provides insights into different aspects of inclusive education—friendship, classroom support, pedagogy, and community—in a specific setting. Analysis and reflections upon ways in which episodes within vignettes inform the knowledge base of the interrelated fields of education, special education, and inclusive education. As a result of this work, our recommendations include an approach to inclusive education similar to the practices documented at Benny's school: a committed, visionary principal; flexible, open teachers; specially trained assistants; differentiated pedagogy and creative opportunities for students with and without dis/abilities to come together. Finally, it is crucial that we call attention to the exclusionary practices from which Benny escaped. If parents simply accepted what the school district advised them, Benny would not be the young man he is today and an active member of his community. As Lennard Davis notes, "The body is never a physical thing so much as a series of attitudes toward it" (2002, p. 22). We hope this paper has given renewed food for thought in terms of providing responsible inclusive options for students identified as dis/abled.

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