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Eclipsing Expectations: How a Third Grader Set His Own Goals (And Taught Us All How to Listen)

Diane Linder Berman & David J. Connor

In this paper we share a narrative about Benny, a third-grade student with multiple disabilities who comes to shape his own educational goals. The first part is written by Benny's mother, Diane. It describes her effort to seek an authentic, inclusive educational experience for her son. Her focus is upon particular ways in which children, parents, teachers, and the school community worked together toward providing greater access to both curriculum and social experiences for Benny. In the second part, David uses a disability studies in education framework to analyze and discuss key issues raised within Diane's narrative, emphasizing the influence of context—rather than disability—upon the success or failure of inclusion.

Using a Disabilities Studies in Education (DSE) Framework

A DSE perspective privileges the contextual understanding of disability and all of the complications that it brings. Bearing this in mind, the tenets of DSE include engaging in research, policy, and action that contextualizes disability within political and social spheres; privileges the interests, agendas, and voices of people labeled with disability; promotes social justice and equitable and inclusive educational opportunities; and assumes competence, while rejecting deficit models of disability (Connor, Gabel, Gallagher, & Morton, 2008, p. 448).

Using a DSE framework includes valuing disabled people—as well as, we argue, their family members—theorizing about disability. It also allows us to theorize about, among other things, contrasting disability as portrayed in medical, scientific, and psychological accounts with social and experiential understandings of disability; to focus on political, social, cultural, historical, and individual understandings of disability; to acknowledge the embodied experiences of people whose lives/selves are made meaningful as disabled; and to challenge the school and societal discourses that position such

All names are pseudonyms including Benny (the child), Boulder (the school), and all teachers except for Benny's mother, and co-author, Diane.

experiences as "othered" in relation to an assumed normate.

The Power of Narrative

The power of narrative is reflected in Lincoln and Denzin's (2000) description of it as "a minimal ethnography with political teeth" (p. 1052). In using personal narrative, we foreground experiences of a mother and her child, voices that are not sufficiently represented within educational research. Stories, which are among the most widely used ways of communicating, are ubiquitous. This has led Mishler (1986) to support "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). Richardson (2000) shares a similar sentiment, asserting that "Although life is not a narrative, people make sense of their lives and the lives of others through narrative constructions" (p. 10).

In many respects, a personal narrative is a form of self-representation and is potentially useful because it can lead to better understanding about various phenomena. 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 brief, a well-told story has both epistemological and ontological value, as it holds a form of "truth" deserving of study, along with methodological value, in that narratives provide access to how we better understand situations in which human differences come to be called disability.

Background Setting: City to Suburbs, Exclusion to Inclusion

At an early age, Benny had been given many disability labels, including pervasive developmental disorder not otherwise specified (PDD-NOS) along with various expressive and receptive language disorders. According to the local education authority (LEA), he had "failed to function" in two exclusionary/highly restrictive special education classrooms there, and was therefore recommended for placement in an even more restrictive environment. Exasperated and in deep disagreement with the LEA, Diane searched elsewhere in the state to find a school that she believed would be a potentially "good fit" for Benny, eventually finding one in a suburb and subsequently moving the family there.

This article provides a glimpse into the Boulder School, the place that successfully included Diane's son. We share this account to show how Boulder welcomed Benny, supporting him and his family in finding ways to ensure his inclusion in all aspects of schooling. Subsequently, Benny's presence and participation within the school grew over the years and significantly influenced its general culture in a

myriad of positive ways. In brief, we seek to share a successful story of inclusive education.

Diane: Setting Goals and Letting the Child Help Guide

The first few years at Boulder proved to be a time of adjustment for Benny and for his school. Boulder developed and implemented a behavior intervention plan for Benny that became part of his individualized education program (IEP). By second grade he had made wonderful strides in his ability to be part of the school community. Everyone was happy. Benny was already a success story. His academic progress was slow, but there was constant incremental growth. He was accomplishing his IEP goals with greater frequency.

Lucy, Benny's third-grade teacher, was a quiet woman with piercing eyes and a gift for maintaining a highly organized classroom that at the same time pulsed with creativity. She originally seemed to be a little nervous about having Benny in her class, confessing anxiety early in the year. This gave way to delight when she quickly found out that it was easy to "read" him most of the time as well as to find ways to support and challenge him.

Third grade progressed with remarkable smoothness. However, at home I began to see a sadness take root in Benny. He was moody and told me several times that he did not want to go to school. Instead of fighting with him, on a few occasions I took him to work with me, where I teach middle school math. Benny was bright and cheery there, surrounded by older students who were interested in him. He answered their questions. He told them knock-knock jokes. When the time came for my class to get to work, Benny wrote most of my notes on the board and then read them aloud. He spoke with an intensity that I had not heard from him, showing self-confidence and pride. I saw a part of him come alive: a voice that demanded to be taken seriously, a desire to connect and to entertain that had lain dormant for years. I began to realize that Benny craved the spotlight in ways I never ever thought possible.

Benny's IEP meeting came in early spring, and it was a celebratory event. His scores, while still far below average, had risen somewhat in every area, and his behavior had become exemplary. Both his therapists and teachers radiated delight as they reported their own stories of his progress. I knew that Benny needed something from us, but I held back, wanting his teachers to enjoy the success he demonstrated on paper. When I picked Benny up after school that day, I told him how happy his teachers were with his progress. He began to cry deeply and heavily. It had been a long time since I had

heard him cry like that, maybe not since he was a toddler struggling to imitate a sound. I recognized the sadness as similar to the sadness Benny felt when there was something he wanted to do but could not. At the moment, Benny was unable to tell me why he was so sad. I knew, though, that when I relayed the good reports to him, they did not bring him comfort; instead, they triggered a feeling that he was not doing all that he wanted to do or all that he felt he could do.

Successes, Continuing Challenges, and Collaborative Solutions

Teachers and therapists had been able to see Benny tackle more and more subjects with increasing ease. But he still was quiet in class. Although he continued to raise his hand as he had done in second grade, Benny was seldom able to answer the question when called on. Lucy was not quite sure how to handle this, and neither was I. She called on him anyway and gave him extended time to respond, but most often he was silent. Every few weeks, we would discuss this behavior, and neither of us understood it. It was clear that Benny desired to be called on, so Lucy continued to do that, even though he seldom gave an answer.

While I strained to find some clues from Benny, conversations over the following few days brought little illumination. One day when I walked into his room and sat beside him on his bed, he looked at me with an intensity that I had grown to see as a signal that a transformational event would follow. Benny's body was still droopy with sleep as he looked up with eyes that have the power to embrace and asked, "Mom . . . why do all my teachers tell me I am doing so well, when I never am able to answer any of the questions?" I did not have the words to respond, but my silence allowed him to continue. "Do you know why I never answer the questions?" he asked, with eyes wide with the purest insight, "I know the answers in my head . . . but I do not know the words to use." I knew then that this was at the heart of his sadness.

Benny's demeanor lightened instantaneously. While I had no ready answer, he relaxed as soon as he knew that I had heard and understood. When I took him to school the next day, he was already a happier child, as he knew we would find a way to help him. I found Dr. Ruby, the school psychologist—a wellspring of positive energy who brimmed with ideas about constructive and positive ways to help her students fit in and grow—and we made a plan to chat. I stopped by to speak with Kaitlyn, Benny's speech therapist, and over the next few days, the three of us came up with a few ideas. I remembered that earlier in the year, Lucy had assigned the students a project on sound for which they had to create and present a poster board. Benny loved the project, putting together an extra-large board and asking

to use both sides of it. Already an avid computer user, he found photos online of thunderstorms, trains, planes, musicians, and machines. When the day came to share the projects, Lucy was prepared to let him do only as much as he could, but Benny surprised her by standing in front of the class and presenting with ease and great pride.

We realized that with prompts in front of him, Benny was able to speak and to share. We also discovered that he craved these opportunities. Sitting quietly was no longer enough for him, and even though it was enough for us, we had to listen to his desires; his goals for himself had to be recognized and addressed. The IEP is a guide, but I saw that those static goals were insufficient for Benny. He desired something greater. He wanted to be heard, to contribute fully and reflectively to his class. Dr. Ruby, Kaitlyn, and I decided that he would prepare posters for several of the topics the class would be covering. Benny could use speech therapy time to prepare his presentation, and Lucy would give him a few minutes to share. It worked beautifully. Benny's sadness faded fast, his spark intensified, and he dove into these projects with great enthusiasm. His first poster presentation was on Kenya, and Benny got his first score of 100%.

Eclipsing Expectations

I had not looked too closely at the school clubs before, since getting through the school day had been enough for Benny to manage. However, I now reconsidered them, knowing that he was ready for more. One of them was the Junior Announcers Club. Each morning and afternoon, students made a series of announcements over the loudspeaker, informing the school community about the weather and the day's events, sending out birthday greetings, and giving reminders of upcoming deadlines. Because Benny had been mimicking the announcements at home for a while, I asked him if he wanted to join the club. He said it would be very hard and that he was unsure. But as he spoke, an irrepressible smile broke out on his face, and I knew that we had found another part of the solution.

Speaking to a large audience was not something anyone could have predicted would appeal to Benny—a child with serious expressive language delays (in the decimal percentiles on most official tests) who mumbled most statements and who appeared to be very shy—but it did. This was a challenge he was craving, that he delighted in. Benny wanted to be heard and seen. He was going to conquer his difficulties not only by speaking to his class but also be addressing his entire school community—more than 300 people—over the loudspeaker.

On the morning of Benny's first announcement, which happened to be on his ninth birthday, the area outside the office was crowded with teachers, therapists, school personnel, and one very nervous mother. Together we waited for the chimes that signaled the start of announcements. There was a hush upon the school. I was trembling. When I peered into the office, I saw Benny looking small and timid. His hands were wrapped tightly around the microphone. We heard soft chimes and then, suddenly, a voice, strong and clear—a mature voice, a voice never to be taken for granted, a voice that rang out from the microphone and filled the hallways and classrooms. The voice was in control, commanding, like a melody to my ears. "Good morning, Boulder School. Today is Monday, March 15th. The junior announcers this morning are Becky, Tom, and Benny . . ." The transition from silence to sound in the hallway transformed us. Something shifted for us all. We all learned about rising to a challenge, about eclipsing our expectations, and about pushing ourselves to our personal limits, as the principal so often suggested.

Benny returned to his class to a student-led standing ovation. Later that day, the teaching assistant, Lenore, overheard a few boys discussing their own desire to become a junior announcer. One of them had said to another, "I was going to try and do it, but now I don't know . . . I could never do it as well as Benny." At the end of the day, when I came to pick up Benny and Adam, his younger brother, my eyes fell first on Adam. He was radiant with pride. He had already decided he was going to join junior announcers the next year.

When Benny was in third grade, I finally understood that we construct deficits by the way we analyze and categorize. I saw that the labels we choose are subjective, that with freedom and support everyone can excel. In many situations, the IEP can appear somewhat meaningless to parents (and, I would argue, probably to teachers and students too). I learned that we must listen carefully to the child and use his or her dreams as the basis for the goals we strive to reach.

While the IEP is important and serves as a baseline for teachers, it is not an absolute. It is hard for a team to accurately predict how much children can grow or to anticipate the goals they may have for themselves. While many of us can find ways to achieve what we strive for, some students, like Benny and other with profound language impairments, may have difficulty taking advantage of opportunities within the school community. As teachers, we also have to be aware that we may unconsciously encourage some students to participate in optional activities while assuming that other students are not interested in engaging in them. None of us could have imagined that Benny would be interested in public speaking. Finding ways for him to grow entailed finding ways to listen to him.

David: The Context of Inclusion and Some Key Issues Raised

The theme of this article, letting the child be the guide, may sound idealistic to some educators. However, from a DSE perspective, privileging the voice of the disabled is central. Although Benny's journey was unpredictable, his behaviors, emotions, and actions informed Diane about his general state of mind. These revelations showed he experienced a great deal of frustration and pain before being given the opportunity to do more in school. Diane's recognition of these painful experiences, along with Benny's frustration, was the first step toward discussing possibilities with his speech therapist and the school psychologist both of whom was instrumental in developing new goals for him.

Although his school reports showed academic improvement, at home Diane had noted Benny's emotional shifts. She "began to see a sadness take root in Benny. He was moody and told me several times that he did not want to go to school." Here we can see an example of the emotional toll that school situations and commonplace practices have on some students who struggle to always understand what is going on—a struggle exacerbated by difficulties they have in expressing themselves.

Diane notices what could be a pattern in Benny's pain, observing, "It had been a long time since I had heard him cry like that, maybe not since he was a toddler struggling to imitate a sound. I recognized the sadness as similar to the sadness he felt when there was something he wanted to do but could not." Rather than pleasing Benny, his good school reports had the opposite effect because, Diane notes, "they triggered his feeling that he was not doing all that he wanted to do, all that he felt he could do." Then Benny himself found the words he needed, asking his mother a difficult—yet sensible—question: "Why do all my teachers tell me I am doing so well, when I never am able to answer any of the questions?" Benny goes on to tell Diane that although he knows the answers, he can't find the words to express what he knows.

At first this is a major conundrum for Benny and his teachers, yet addressing it became another example of problem solving by professionals and parents collaborating within a specific context. Contemplating the issue, the psychologist, teacher, and speech therapist agreed that Benny's desire to participate was not necessarily just about being able to answer questions when he was called on, but also about having the opportunity to share his knowledge with his peers. Previously, when Benny had been given the chance, like his fellow students, to present a project to his class, Lucy was "prepared to let him do only as much as he could." But when he had time to research, organize, and display his project, he had demonstrated his abilities, and his teacher was surprised when he stood in front of his

peers "presenting with ease and great pride."

What this situation revealed is that sharing knowledge in the moment was extremely difficult (perhaps, at that time, even impossible) for Benny, but that with preparation, he could manage it. The speech therapist then worked to help Benny further develop the abilities he already had by capitalizing on his strengths and using them to realize his desire for greater participation in class. Similarly, Lucy accepted and encouraged this arrangement, permitting Benny to share his knowledge with his peers in a way that worked for him and benefited them as well. The fact that Lucy "would give him a few minutes to share" reveals her flexibility in shifting pedagogy to match the needs and abilities of her students. Giving Benny these opportunities to engage in schoolwork in his own way is an example of an organic response to the conundrum originally presented.

The success of this arrangement can be measured by Diane's observation that Benny's "sadness faded fast, his spark intensified, and he dove into these projects with great enthusiasm." Providing an alternative method that permits students to share and contribute what they know and think allows them to be active—and equal—members of the community. Benny's situation showed us that not every student responds well to being called on in class to provide a response to teacher-directed questions on the spot. This is the type of learning that we, as educators, gain from students in the context of our classes.

Having confidence in speaking before others is a skill that many adults do not possess. For a child who struggles with expressive language, it seems like an impossible expectation. Yet it can be argued that when adults around him did not expect it of Benny, he expected it of himself. Diane and the professionals at Boulder came to realize that "Sitting quietly was no longer enough for him, and even though it was enough for us, we had to listen to his desires; his goals for himself had to be recognized and addressed."

It was at this moment that Diane put two and two together, noticing Benny's mimicking school announcements and subsequently feeling him out about the possibility of being a junior announcer. His first response was that it would be "very hard and that he was unsure." Yet his smile betrayed a desire to rise to the challenge, and as Diane realized, "we had found another part of the solution." This particular situation strikes me as a clear example of Vygotsky's (1934/1987) zone of proximal development. Among the many theories I have been exposed to, this is one that resonates with me the most because it is so simple that it seems like common sense. In sum, Vygotsky noted that in order

for students to grow in acquiring knowledge and/or learning how to perform a task, their current abilities have to be recognized. Then, with assistance and encouragement from the teacher, they can progress to their next level of growth. Such assistance and encouragement can take many forms, including modeling, giving examples and counterexamples, discussing specific dos and don'ts, and providing repeated exposure to a task, along with giving students multiple opportunities to experience new material—gradually transferring knowledge and skills before expecting students to "own" them. In the case of Benny possibly becoming a junior announcer, the timing was right for encouraging him to aspire to a higher level of public speaking than he had previously been able to reach.

At most schools, making announcements over the loudspeaker is an everyday act that most people take for granted. But for Benny, his family, and the team of professionals that have been working with him, making a school announcement is a watershed moment, a major accomplishment; when Benny did it, Diane observed, "Something shifted for all of us." Benny's success impacts his sense of who he is and what he can do and affects how his brother, peers, teachers, and parents perceive him. Indeed, Benny is demonstrating to the school community that he can do what some other children are not yet able to. As one of his fellow students himself said afterward, "I could never do it as well as Benny."

Among the many issues that this episode raises is the tendency of schools to conflate speech with participation and/or intelligence. A largely unquestioned universal classroom norm is having student raise their hands to be called on to speak, signaling their readiness and ability to participate in the learning experience. However, such expectations (or even requirements) neglect to consider a host of valid reasons why some students do not speak up in class (Schultz, 2003). Benny's narrative, therefore, highlights the need for teachers to consider how they can offer students multiple ways of communicating their learning on an ongoing basis.

Using a DSE framework, I see these episodes of Benny's presentations to his class and to the whole school as connected in ways that touch upon the importance of family and community and the "inclusion of disabled people in theorizing about disability" (Connor et al., 2008, p. 448). I believe in the importance of family members—in particular, parents, who come to know their disabled child in so many ways that others do not—theorizing about disability.

In Diane's representation of Benny, we see how he makes sense of the expectations in his class, his school, his community, and the world beyond. Diane has a sense of what Biklen and Burke (2006) have termed "presumed competence." This is a very important concept, as it invites us to begin our understanding of a person in terms of their abilities, many of which we largely able-bodied people—because of our own limitations—have not yet discovered. This goes beyond the value of having a "strength-based approach"; it is a deep disposition toward primarily viewing everyone in an openended way.

Beyond a Strength-Based Approach

Although using a strength-based approach with students is important, it is not enough. The technical framing of this approach in IEPs leads educators to mechanical understandings of a child's academic skills and social abilities. The point I wish to make here is that the IEP is only a guide required by law. It is not something etched in stone, akin to a religious text. However, educational systems tend toward rigidity over fluidity. Rigidity is far easier to manage, to predict, to control, to budget, to schedule, and to revert to when unsure of a situation (and then seek documented expertise).

Diane calls attention to the limitations of IEPs and the danger of clinging to them lest they—in their reductive nature—inadvertently preclude possibilities for the child. Benny's experiences led his own mother to understand and share what many educators may find shocking: "I saw [at last] that the labels we choose are subjective, that with freedom and support everyone can excel. In many situations, the IEP can appear somewhat meaningless to parents (and, I would argue, probably to teachers and students, too)." We are witness to Diane's epiphany that the context determines the disability. If teachers and administrators also understood disability in this manner, then classrooms and schools could become far more inclusive. For educators who ask, "What do you mean by a social model of disability?" Benny's case is a prime example: the contexts educators create (including the pros and cons of an accurate and thoughtful IEP) can serve to either enable or disable.

This paper calls to mind ideas found in the work of Thomas Skrtic (1991), who analyzed how educational bureaucracies—including special education programs—function, primarily viewing themselves as rational and efficient. He points out the limitations of technical approaches to measuring "success" within education, and argues against a technocracy in favor of an adhocracy. This is an admittedly highly abbreviated version of Skrtic's important idea, but I include it to highlight the difference between these approaches to education. What is needed for a child's growth is created as a response to knowing that a child within a particular context (making the supports adhoc) rather than to what has been prescribed as part of a formalized professional system (making the supports technical).

Much of what has come to be known as special education is a dense conglomeration of laws, rules, and regulations; an IEP often serves as a pro forma document, rather than an actual plan developed in part by students to help them grow. Boulder's approach to education is one of thoughtfulness, of making multiple connections with a view to people sharing what's best and therefore what's next for Benny. However, at the same time, I see that many practices employed at Boulder are still possible within his former LEA; indeed, they have been used there before and are currently employed in pockets here and there.

In order to better understand inclusive practices and encourage their growth, I believe it is useful for educators to become familiar with the adhocratic model of education as a way of thinking. For me, this model values teachers as reflective thinkers, collaborators, and allies with parents. It encourages teachers to study the children they are working with and be professionally invested in being proactive problem solvers. In contrast, the technocratic system appears to use educators as small cogs in a big machine, training them to unthinkingly generate pro forma and often decontextualized goals, set expectations for students with disabilities accordingly, and then (maybe) check the box if students approximate meeting them.

Conclusion

We believe the stories presented in this article can help in-service and preservice educators understand authentic inclusion, in part, as contextual, collaborative, and organic, and always as a work-in-progress. If teachers have no real voice in analyzing and contributing to solving the challenges of inclusive education, then there is even less likelihood that students can be heard. Diane writes, "We must listen carefully to the child and use his or her dreams as the basis for the goals we strive to reach." While some may argue that this is pure idealism, Diane's sentiment is actually very much in line with the intention of special education laws that seek to include children and their parents in the educational process. We believe that engagement with parents' knowledge of their own children can significantly help teachers understand how best to teach students with disabilities (Ginsberg, 2003; Valle, 2009). Learning what students think, know, and want—either directly from students or from their parents allows teachers to work in ways that are deeply satisfying to both themselves and to those they teach, as the possibilities for learning—and inclusive education—are endless.

Postscript

Now in eighth grade, Benny is an active member of the drama club, where he regularly appears in performances alongside his peers. His experiences in third grade seem, in retrospect, to be natural stepping-stones toward his participation in these activities. Had he stayed in our original LEA, he would have remained in classes with only children who were identified as severely language delayed, and most likely he would not be performing with his typical peers in full-length productions where he continues to develop his talents in acting, singing, and dancing.

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