



# Presuming competence, belonging, and the promise of inclusion: The US experience

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**Abstract** This article examines the US experience with school inclusion, highlighting effective policies, practices, and school reform efforts. Specifically, it reveals how a case-by-case assessment of whether a child can be included works against the goal of full inclusion. Despite this policy limitation, inclusion is moving forward, especially when guided by the principles of presuming competence, belonging, and full citizenship, and informed by the experiences of students who have grown up within the change movement.

**Keywords** Inclusion · Presuming competence · Autobiographies · Disability · Inequality

Ironically, the concept of inclusive education exists because of segregation. In fact, my own interest in disability and inclusion began in the world of segregation. An early research project focused on the concentration-camp-like conditions of locked institutions, where people with disabilities endured malnutrition, disease infestations, isolation cells, absence of books or other educational materials, shabby clothing and nakedness, overcrowding, high death rates, verbal, as well as physical abuse, and widespread application of tranquilizers (Biklen 1973). At the Willowbrook State School, for example, hepatitis reached 100% of residents in the late 1960s and early 1970s.

It did not take long to realize that the only way to eradicate those conditions was to shut down the institutions (Biklen 2011; Blatt, Biklen, and Bogdan 1977). The reason that children could have been sent to these wastelands was that public schools and early childhood centers excluded many disabled children, leaving parents with few or no program options (Children’s Defense Fund 1974). During the early 1970s, my colleagues and I used our research as evidence in litigation and for community organizing, to win excluded students’ access to public schools (Biklen 1983) and then to effect full inclusion (Biklen 1992, 2005).

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In this article, I draw upon those experiences, as well as other resources, especially from Disability Studies research that analyzes disability and schooling through a cultural/social/political lens (Connor, Gabel, Gallagher, and Morton 2008). In the first section, I examine a problem inherent in federal US education policy. In the second section, I present three complementary accounts of inclusive schooling: a) one student's reflections on what makes for effective inclusion, based on his own experiences from preschool up to University, b) an examination of how Disability Studies researchers are recasting understandings of inclusion away from solely technical aspects to a more socio-cultural lens to formulate school change, and c) a student's firsthand account of how a person with a disability can play a central role, along with educators, in fashioning successful inclusion. Lastly, in the third section, I provide evidence on costs, briefly documenting the economic benefit of inclusion over separate classes and separate schools.

To conclude the article, I note the slight increase, yet persistent unevenness, of inclusion across the US and its disparities in relation to students' socio-economic and racial status. I also describe the growing influence of people with disabilities on policy and practice and the optimism this brings to the possibility that inclusion will proliferate—perhaps even to a moment when the terms *segregated/special* and *inclusion* give way to a discussion simply of education.

## Educational justification for inclusion

Schooling all children together requires that educators attend to student differences in a way that benefits all students, with the expectation that they will learn better (or at least as well) than if taught separately. This should not be controversial, inasmuch as research conclusively demonstrates the learning benefits of inclusion (Hehir et al. 2016). Based on a survey of 280 studies conducted in 25 countries, Hehir and his colleagues found that in inclusive classrooms, nearly all students with and without disabilities did better cognitively and socially compared to those in segregated classrooms. In the few instances without clear improvement, the students at least did no worse.

## Flaws in the case-by-case model and the promise of its alternative

Unfortunately, the weight of evidence favoring inclusion has not translated quickly or seamlessly into changed policies and practices. US education law (and by definition, State implementation of federal policy) still focuses on the individual child rather than systems (IDEA 2004) and asks whether he or she can benefit from education alongside nondisabled peers—in other words, is inclusion possible for this specific child? Clearly, that is the wrong question. Interrogating an individual child's eligibility for inclusion welcomes discrimination:

- The child with a disability is characterized as different from the norm, as someone to be feared or to be seen as a burden, non-contributing, and not belonging.
- Eligibility standards invite a kind of voyeurism from experts and lay people alike to judge a child's worthiness for inclusion.
- It presumes that educators can know about a student's possible learning even before schooling has begun.

- It imagines exclusion from general education as a proper, professionally endorsed, and government-approved action for at least a portion of the population.
- It ignores the long, well-documented history of discrimination and exclusion experienced by groups of individuals and treats present-day decisions about a child or youth's education as separable from the historical and cultural moment.
- It allows license to act as if the student is without voice, desire, and agency in regard to being schooled with non-disabled peers.

It is unlikely that the US will implement universal inclusive education until it changes its legal framework.

A commitment to universal access to general education would be consistent with Article 24 of the Convention on the Rights of Persons with Disabilities (CPRD): "Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live" (United Nations 2006). Although writing decades earlier than the CPRD, Burton Blatt, an international leader in education, called upon 1970s society to end the banishment of people with disabilities to state institutions such as mental hospitals and to ensure their participation as full citizens (Blatt 1969). He explained why the case-by-case judgment of who may be qualified to be educated, let alone to be included, undermines the promise of education.:

[W]hile the miracle of Anne Sullivan's triumph with Helen Keller was in the creation of a great and talented person, what caused the miracle to work was the unconditional nature of their partnership. If Anne Sullivan had required Helen to learn – that is, to change—as a condition for the continuation of their relationship, the miracle would in all likelihood never have occurred. Helen Keller would almost certainly have wound up as merely another cipher in the records of the Massachusetts School for the Feeble-minded. (Blatt 1979, pp. 15–16)

From the Keller example, Blatt derived several findings. First, "there is the lesson of human educability, the idea that people can change in remarkable, unpredictable ways" (Blatt 1979, p. 16). The key observation is that *how* students learn and especially *what* they accomplish is always often greatly unpredictable. As educators, we cannot know what someone else will achieve, especially not before we have engaged deeply with them. The important thing is that educators welcome all students, with the understanding that we will likely be surprised with the learning observed along the way; this is similar to Donnellan's (1984) concept of "the least dangerous assumption", where educators teach in a way that leaves open the greatest possibility/opportunity for development. Second, Blatt argued, students should not be required to prove they can change as a precondition for access to education and for being regarded as having "value as a human being" (p. 16). Students should be welcomed and appreciated simply because they are members of the community. Blatt's third lesson, which he described as a "seeming contradiction", is that "the likelihood of a human relationship (e.g., teacher and student) resulting in a miracle like Helen Keller's is inversely proportional to the importance which the prospect of such a miracle has to the relationship" (p. 16). Blatt worried that education had been so professionalized and medicalized that the importance of proving the student's progress dominated student/teacher relationships, eclipsing and perhaps even erasing the possibility of unconditional commitment to education-as-dialogue between instructor and learner. We might say that Blatt's words ominously predicted today's audit culture, in which testing and evidence of student progress seem to take precedence over the art of teaching.

## Making inclusion work

US inclusive education looks like a patchwork quilt, with inclusion occurring full-blown in some communities or in individual schools, yet surrounded by great expanses of separate special education classes and resource rooms—these are called pull-out programs—and even some special schools. Progressive educators, parents, and disability rights organizations argue forcefully that full, no-strings-attached, unconditional, purposeful inclusion should be the starting point for all education (Biklen 1985, 1992; Cutler 1981; Kliewer 1998; Kliewer, Biklen, and Petersen 2015), and indeed numerous schools *are* fully inclusive. Yet, national data confirm that inclusive education is unevenly distributed (US Department of Education 2014; Biklen 1988; White, Li, Ashby, Ferri, Wang, Bern, and Cosier 2019; White, Cosier, and Taub 2018). Whether a student with a particular disability attends school with non-disabled peers depends upon where he or she lives and whether and how hard parents or other advocates fight for inclusion (Biklen 1988). Further students of advantaged socio-economic class status and race are those most likely to have access to inclusion (Artiles, Harry, Reschly, and Chinn 2002; O'Connor and Fernandez 2006; White et al. 2019). The intensity of exclusion experienced by students of color is rooted in highly complex, racist cultural practices and systems, such that individual students cannot easily escape its forceful impact (Artiles, Kozleski, Waitoller, and Lukinbeal 2010).

Schools that fully embrace inclusion do so despite imperfect US policy. The underlying principle of these schools is that inclusion be unconditional and purposeful (Biklen 1992), with no requirement for case-by-case eligibility assessments. Within that framework, as in the CPRD policy, it becomes the responsibility of educators to construct schooling that responds to all. This philosophy has unleashed a broad array of practices designed to foster participation (e.g., Jorgensen, McSheehan, Schuh, and Sonnenmeier 2012; Sapon-Shevin 2007):

- School leadership committed to full inclusion: policies espouse inclusion, teachers are hired based in part on their support of the inclusion agenda, and staff are assigned heterogeneously (i.e., subject area instructors, curriculum design specialists, related service specialists) to classrooms and teams. Generalists and specialists collaborate.
- Teachers group students heterogeneously within classrooms and across age-level grades (i.e., no “tracking”) such that the proximity of students with different backgrounds, learning styles, experiences, and forms of performance enhances learning.
- Teachers see themselves as role models regarding interaction across difference; for example a teacher speaks to a student with complex, multiple disabilities and communication impairments in a matter-of-fact and respectful manner, using normal eye contact—rather than speaking in a patronizing fashion or with effusive praise (see Biklen 1992, p. 156).
- Educators incorporate accommodations for disability where necessary, but only as far as necessary, avoiding situations where extra support might isolate a student or interrupt participation in the class.
- Instruction uses universal design so that it is available in a variety of forms and all students can access the curriculum together.
- Teachers adopt a presuming-competence orientation where they define the student as someone who wants to learn and engage, thus putting themselves in the role of educational detectives, discovering ways to organize instruction that maximizes heterogeneous student-to-student interaction.

Such lists of ingredients appear in different forms in nearly every published inclusion guide, often with additional elements. Ashby's (2012) "key tenets" for preparing teachers to work in inclusive education, for example, include a "commitment to social justice... equality... democratic education; translation of philosophy into a guiding focus, by placing difference at the center of ... planning instructional practice, so that access to academic instruction as well as social participation in the life of the school are never ... afterthoughts" (Ashby 2012, p. 91).

One school reform model that typifies the inclusive education movement in the US—and conforms to the vision of a democratic educational relationship that Blatt saw as the essence of Anne Sullivan's work with Helen Keller—is *Schools of Promise* (Theoharis and Causton-Theoharis 2010). It posits that decisions about school organization, curricular design, and teacher/student interactions should ask: "Does this lead to the student feeling like he or she belongs?". The belonging framework resembles Kliever's idea that through inclusion students with disabilities, as well as all other students who may otherwise be treated as aliens or squatters (whether because of poverty, immigration status, sexual preference, gender, or ethnicity), will enjoy full citizenship.

As a whole-school reform model (Causton-Theoharis et al. 2011), *Schools of Promise* harnesses all of a school's teaching resources to make each classroom inclusive, distributes student diversity by race, gender, ability/disability, and socio-economic status across classrooms, and provides related services such as speech-physical-occupational therapies seamlessly in the classrooms. All staff, including administrators, general and special education teachers, special subject teachers (art, music, gym), and teaching assistants participate in extensive planning prior to implementation.

Drawing on their observations at one of the *Schools of Promise*, Theoharis, Causton, and Tracy-Bronson (2016) described the transformative moment of wonder for a student who thought he did not qualify in educators' minds to be a full citizen but who clearly desired to belong:

The teacher came over to Kenny and said, "Kenny come on, its time to get ready to go home. Let's get your backpack". Kenny looked at her and said, "I think the school has made a mistake. I've never been in a room like this [i.e., inclusive]. ... Do I get to come back *here* tomorrow...?" [The teacher responded] "Oh honey, you get to come back here every day. This is *your* classroom". (Theoharis, Causton, and Tracy-Bronson 2016, p. 3)

In the months that followed, that student came alive through a school-wide redesign that dismantled all separate, disability-only classrooms. He "performed so well behaviorally and academically that he no longer qualified for special education" (p. 4). Referring back to Kenny's question at the beginning of the school year, his teacher remarked, "For years we had left Kenny and the other students in the self-contained room – that was the mistake. A big one. He was right, the school had made a mistake...", but a systemic one not an error regarding one child (p. 4).

In the Theoharis, Causton, and Tracy-Bronson study, the researchers encountered some teachers and some parents who questioned inclusive education. Indeed, in my own experience advocating for inclusive education, it is not uncommon for some general education teachers and some parents of non-disabled students to believe that non-disabled children will not progress as well in inclusive classrooms as they might in "tracked" or "able-only" ones. The two schools in Theoharis, Causton, and Tracy-Bronson's study are diverse in terms of social class and racial composition as well as disability, yet contrary to the loss that some parents worried about, two years into the reform, overall student performance

(disabled and non-disabled students) improved in math by 20% on average and in literacy by 10% on average better than the performance levels in other schools within the same urban district (Theoharis, Causton, and Tracy-Bronson 2016, pp. 19–20). Inclusion made the schools better academically.

Of course, when a particular student (like Kenny) does especially well in an inclusive setting it is not uncommon for an observer to ask how many “labeled” students can do so well. That question mistakenly locates performance inside the child rather than seeing it as a function of both the student and school context. My response to this common question is what Kliewer, Peterson, and I wrote in our article “At the End of Mental Retardation”:

Our best answer is to ask what percent of labeled individuals has escaped stagnant contexts of isolation, has been included ... where the right to belong and to participate (and be appreciated) is realized without question, and has been provided tools and materials based on affirmation, actualization, and empowerment? What percent of individuals, we must ask, is immersed within communities of committed individuals who have realized and set aside deficit ideology, who are open to being surprised and learning something new, who do not seek immediate changes but who exhibit perseverance and deep self-critique, and who realize evidence of connectedness such that a new culture, a new discourse, a new paradigm of thought might guide all further and increasingly sophisticated engagement? (Kliewer, Biklen, and Petersen 2015, p. 22)

This reminds us of Blatt’s warning from the 1970s that it is incorrect to think about student performance as a function exclusively or primarily of disability and personal effort, rather than one deeply linked to the levels of acceptance and appreciation—or conversely, rejection and isolation—that the student encounters.

## The social justification for inclusion

### Which change to pursue? Rising voices

We are asking a lot of schools to create the conditions for transforming societal attitudes to end discrimination. Yet, that appears to be happening, if not in the manner or with the alacrity desired. When Blatt wrote about Anne Sullivan and Helen Keller, he explained that the field of education had a choice: embrace the educational relationship that Sullivan typified, emphasizing dialogue and respect; or, continue to treat the student as an object to be controlled and shaped. But even if education chooses such control and manipulation, Blatt wrote, “very likely society—through the movement of advocacy (and) the liberation of ... various excluded groups—will make us (educators) change whether we are ready or not” (Blatt 1979, p. 16).

Much as Blatt predicted, the rising voice of previously silenced individuals is now bending the narrative about human worth to include people with disabilities as full citizens. And it is in this emerging voice, crafted by the words and actions of people with disabilities, we can observe societal transformation: slow perhaps, but unrelentingly persistent. Early evidence of rights organizing came from physical disability groups such as Adapt Inc., the World Institute on Disability, and Disabled in Action, as well as allies such as the Disability Rights Education Defence Fund, The Children’s Defence Fund, and TASH, and then later expanded to include People First, the Autism National Committee, and other

organizations led by people formerly defined as intellectually and socially impaired (Shapiro 1994).

Yet, as dynamic as public disability-rights actions have been, most noticeably perhaps with sit-in demonstrations to force implementation of non-discrimination legislation/regulations and litigation to win access to freedom from total institutions (*Olmstead v L.C.* 1999) and to inclusive classrooms (*Board of Education v. Rowley* 1982; *Oberti v. Board of Education* 1993), nowhere is the emerging transformation more apparent (and perhaps less anticipated) than in autobiographical memoirs and essays by people with disabilities and in Disability Studies scholarship. Both the memoirs/essays and recent scholarship shift the focus and framework from a psychological study of the individual to an examination of schools, society-at-large, social policy, and culture.

### Jamie Burke's ideal school

The tension between a focus on the individual and attention to school culture appears in a conversation I had with Jamie Burke, which we shared in an article entitled "Presuming Competence" (Biklen and Burke 2006). When we collaborated on the article, we had known each other for more than 13 years. I first met Burke when he was just 4 years old. He attended the Jowonio School, a fully inclusive preschool in Syracuse, New York. There, I observed one of his teachers reading to him, showing him how to point at whole words, and introducing him to communication by pointing at letters to construct words. The classroom included a head teacher, a co-teacher, one or two assistants, and a heterogeneous (gender, socio-economic status, race) group of students, several with disabilities and most with no disabilities. Jamie Burke was identified as autistic. He could say some words, but usually as repetitive, spewed-out projectiles, not as phrases or sentences for conversation.

Burke's teacher spoke to him in a tone similar to how he spoke to other students, assuming that he would hear and understand what he said, even if it was not always easy to determine if he understood. When Jamie Burke and I began to work on "Presuming Competence", he was about to complete high school and attend university (a few years later he received a Bachelor of Arts degree at Syracuse University). He still did not speak conversationally, although he had learned to communicate by pointing or typing and could speak aloud the words and sentences that he typed or read. When I asked him to describe his ideal of what school should be like, he said it should be comfortable, filled with "wonderful books", and a place where fellow students would refrain from teasing or bullying each other. All students would be welcomed to join clubs (i.e., voluntary afterschool activities, for example language, chess, or theatre) (Biklen and Burke 2006, p. 168). Regarding teachers, he said they should be people who "desire to teach everyone", but who realize that "their dreams are not ours. Ask us what we will need to be an independent person later in our life. Teach good skills in a respectful way. Conversations with me will tell you if I am happy" (p. 169).

During his early school years, speaking was frustrating for Burke; he could not utter the words that were in his mind. He could not make his mouth "get those letters to come alive, they died as soon as they were born" (p. 169). He felt his "brain was retreating in defeat" (p. 169). Then, to add insult to injury, some teachers spoke patronizingly to him: "I felt so mad as teachers spoke in their childish voices to me, mothering me, but not educating me" (p. 169). Further, dialogue with students was difficult:



In conversations kids will ask questions and typing is again so much slower than quick use of an athletic tongue which spits out the words without so much as a jog around the jaw. By the time I can formulate a verbal answer, they have left to move onto another class. (p. 169)

Burke found he would get exhausted typing all day and sometimes lost focus: “It’s like a flea on a dog that’s getting wet, always moving to another area of escape” (p. 169). He explained that it helped having a teaching assistant or other individual nearby to remind or prompt him to stay focused. Also, teachers played an important role in structuring some conversations so that he could enter in—a strategy used in other schools as well (Biklen 1992). A consistent theme in Burke’s exposition about the ideal school is the importance of openness and commitment in the teacher’s approach to knowledge and relationship with his or her students. The teachers he admires are those who “accept all the variables as nothing that will alter the room ... (who) demonstrate their love of the knowledge they are teaching”, teach with passion, and inquire about how he experiences the class, “as if we dance in partnership on that floor of knowledge” (Biklen and Burke 2006, p. 169).

Burke also benefited from specialized supports brought into school. These included speech therapy/augmentative communication specialists, who helped him develop his ability to express himself by typing and then later in speech, sensory stimulation in the form of a barrel he rolled in and a beanbag chair that put soft pressure on his body, Listening Therapy, and occupational therapy. Over time, his “typing that was a VW Beetle ... [became] a Lamborghini”, mainly because he learned to “cross... midline”, moving his pointing finger and hand across his body from side to side and not simply forwards and backwards, giving him “greater ease visually... good, for example, for ... doing long calculus problems” (p. 170). He credited therapy with helping him manage anxiety that “comes as a regular visitor, just as breathing. ... When I was young, I walked in a constant pacing to help my body deal with it and I felt my nerves prickly as if a porcupine shot its quills into me” (p. 170). Sensory therapy acted “like a giant Band-Aid to my body. It wraps up the stingers as a ball of cotton and makes things more comfortable for me” (p. 170). Even different pitches of voices affected his stress level, as did test-taking, creating a feeling of sensory overload, of being “a man overboard awaiting ... rescue”; small print became a blur of black and white and lights troubled him, as did the rustle of papers, pencils scratching, coughing, and scraping chairs, all of which he learned to accommodate (p. 172). Sensory and other therapies helped him find his way academically.

In the end, the sine-qua-non for inclusive education is educators *wanting* to make it work, beginning by welcoming and valuing the student: “Teachers must be willing to not just give me a desk and then leave me to fill the chair. I need to be asked questions, and given time for my thoughtful answers. Teachers need to become as a conductor, and guide me through the many places I may get lost” (p. 172). More than just a desk, there must be a relationship, and an expectation that every student wants to learn and can learn.

## A socio-cultural framework

Jamie Burke’s description of his ideal form of education resembles the ethos advocated by many educators who have studied and written about inclusion more broadly (e.g., race, ethnicity, class) (Ashton-Warner 1963; Christensen 2019; Collins and Ferri 2016; Ladson-Billings 1993; Sapon-Shevin 2010). At its heart is not only the idea of recognizing the value of each individual student, but also of seeing the rewards that come when teachers regard their



relationship with students as one of “being with and working with each learner... beginning from the standpoint that everyone in the classroom community belongs” and where the central question for teachers is to figure out how to support “meaningful participation” (Collins and Ferri 2016, p.4). An important step in giving support is for the teacher to presume the student competent (Biklen and Burke 2006) and therefore *not* interpret difficulty in learning as residing within a student, but rather as a function of the relationship of student to context—for example, to the curriculum, the teacher’s ways of organizing materials (e.g., scaffolding, universal design, or multiple intelligences approaches) and groupings of students (Ashby 2012; Collins and Ferri 2016).

While many discussions of inclusive schooling treat it as a technical challenge, such as how to implement universal design or how to meld special and general education teachers and assistants into teams, effective inclusion seems always to return to the question of *belonging*. As Connor and Berman (2019) argued in their Disability Studies article about “authentic inclusion”, even though more and more students with disabilities have won a place physically in general education classes, “many feel marginalised within classes, believing they are unwelcome there” (p. 923). Berman described how she and her husband became so disappointed in their son Benny’s kindergarten placement in a local school that did not embrace inclusion that they moved 20 miles away, so he could enter an inclusive class in an inclusive school. At the time, Benny was diagnosed as having a Pervasive Developmental Disorder, though as with any disability category, knowing the diagnostic label did not tell teachers how to formulate an instructional plan for him. He had limited speech to the point of being described as “nonverbal”, and “his behaviour made it hard... to take him out...on buses and to local shops” (Connor and Berman 2019, p. 924). Berman wondered,

(Would) Benny ... ever really be able to have a conversation that flowed. He was able to use words to communicate but not in a spontaneous way. We saw humour and sensitivity in him, through his gestures, his play, and his drawings. We yearned to know him through his spoken words, but were beginning to accept that this might never be possible. (p. 929)

In the inclusive setting, educators began to connect with Benny. A speech therapist introduced “laminated cards that served as conversation starters” (p. 929); at first these were simple, but they slowly became more complex, spurring communication between Benny and his classmates. His classroom teacher then adopted this strategy as a twenty-minute conversation activity, through which all of the students developed their skills at listening, responding, and taking turns. As this and other ways of including Benny progressed, Berman reported being surprised at the importance the school placed on Benny’s “conversational and social growth” (p. 929). For example, Benny’s teachers observed that he had a deep interest in railway and subway maps and schedules—at his previous, segregated school, these were labelled obsessions. His new teachers asked him to bring in his maps and schedules to share with the class, whereupon they designed an activity in which groups of ten students each imitated four different subway trains moving across the school soccer field and baseball diamond, from stop to stop, including 42<sup>nd</sup> St and Penn Station. Thus, more than just having a seat in a classroom where he might be expected to stay quiet and well-behaved, Benny found himself appreciated by and involved with peers, as together they learned about urban transportation (p. 930). Connor and Berman concluded, “while defying categorisation, he is still a person within a community, and when the community bends toward him, he responds” (p. 934).

Not surprisingly, building classroom community is a mainstay in nearly every formula for effective schooling. Christensen (2019), for example, described it as an essential first step in moving any school classroom from a state of chaos to one of engagement in learning. In an account of co-teaching in a diverse (i.e., by race and social class) secondary class, she described using literature as a stepping-off place for students to connect their own often-difficult personal life experiences with academic skills. She and her co-teacher selected a book, Sherman Alexie's screenplay *Smoke Signals* (1998), which focuses on the relationships of children with their parents. Building on a theme from the play, the teachers asked the students to list people they might give or not give forgiveness to, lists that included an alcoholic parent, an abusive parent, and an absent parent. Next, the teachers gave the students an assignment to write "forgiveness" poems, with the option to write from the vantage point of a character in Alexie's screenplay or from their own lives. They wrote with passion, similar to what Ashton-Warner described in her classic book *Teacher* (1963) when she worked in New Zealand with Maori and European descendant children, that Freire describes in his now classic *Pedagogy of the Oppressed* (Freire 1970), that Kliever described in *Schooling Children with Down Syndrome* (1998)—where we find an inclusive preschool in which students compose and act out a play based on Sendak's *Where the Wild Things Are* (Sendak 1963), or in Haddix's "Writing Our Lives" curriculum (Haddix 2015) and Ladson-Billings' culturally relevant teaching (Ladson-Billings 1993).

Christensen found her classroom transformed when students' lives became part of the curriculum. She cited the poet Micere Mugo to explain her students' newfound energy and commitment: "Writing can be a lifeline, especially when your existence has been denied, especially when you have been left on the margins, especially when your life and process of growth have been subjected to attempts at strangulation" (Christensen 2019, p. 3). This seems perfectly to describe the situation of so many students who feel that they sit on the edge of school culture (Kasa-Hendrickson and Biklen 2004)—because of prejudice and discrimination based upon disability, poverty, immigration status, gender identity, ethnicity or other factors—but who want to come inside.

## D.J. Savarese's lessons for a future

Writing surely *is* a personal lifeline to identity and voice for students with disabilities, a tool for combating ableism, and also a lifeline to community. I first met D.J. Savarese more than 15 years ago. His parents had written to me to see if we could meet and talk about the path forward for D.J. and other students with disabilities. He has autism and, like Burke, is non-speaking, but he had learned to communicate by pointing. We met at a coffee shop and talked for a little over an hour, me with speech and he by typing. Toward the end of our conversation, he asked me what might seem an unusual question, but given the circumstance of his not being able to speak, it did not completely surprise me: "Do you fear for my future?"

I told him I did not, in part because he has parents who are positioned and absolutely committed to support his full inclusion in school and society but also because he was already imagining a future for himself in his own mind. No one could predict what D.J. might accomplish, yet I knew it was important to be open to many possibilities. I did not know that he would go on to earn excellent grades in high school and that he would be the first non-speaking person ever to attend Oberlin College, or that once there he would distinguish himself as a Phi Beta Kappa Scholar and earn a Bachelor of Arts degree in

Anthropology and Creative Writing, that he would lecture widely on issues related to his disability and inclusion, that he would publish in the *Seneca Review*, *Disability Studies Quarterly*, and other publications, and that he would author a Peabody Award-winning documentary film (Rooy and Savarese 2017).

In one of his essays, entitled “Coming to My Senses”, Savarese’s words achieve a thematic balance of the personal and political, revealing the ways he experiences the particularities of a disability and how he manages to get himself included in the wider society (Savarese 2019). Consider first his description of navigating a university campus environment when ensconced in a shower of sensory input that he associates with autism:

When I walk, I generally need to have a companion, but I do not exactly walk *with* that person. I tarry behind them – sometimes 50 yards behind them... Because I am in my senses most of the time... I am in danger of neglecting that most modern of predators: the automobile! I could notice the similar way that the light catches the windshield of a car and the skylight in my home in Iowa and end up crushed. The faint reminder of the person in front is enough to keep me from becoming entirely lost in patterned pulchritude. (p. 91)

In another passage, he describes himself “flapping arms, making duck-like noises, greeting each lamppost with my elbows, sometimes sauntering, sometimes doing a jig, as I cross campus” (p. 91). The person walking ahead of him is enough of a reminder of the task at hand, walking across campus, so that even with the flapping, noise making, elbow tapping, and a bit of dance, he proceeds. Of course, there are other aspects of autism with which he contends, including difficulty feeling his body in space, a phenomenon called proprioceptive awareness. He says carrying a backpack helps him with that, much as “someone with a mobility impairment uses a cane” (Savarese 2019, p. 91). He also has difficulty with speaking—he knows the words he would like to say but cannot get them out in the form of speech—and deals with both anxiety (a common companion for people with autism) and perseverance, as in the examples of flapping his arms or touching lampposts (Williams 1989, 1992, 1996; Grandin 2006; Blackman 2001). In his essays, Savarese described the personal qualities that are part of his autism, and, importantly, how schools/peers/society can learn to support him and his strategies for negotiating environments and interactions with others.

People who know him well come to realize that when greeting other people, he easily can “get over-stimulated, and ...feelings grow so strong that holding them inside is impossible. I desert reason, and my body repeatedly begins to flap or reach freshly toward them” (Savarese 2010, p. 1). He loves greeting others, but the act of greeting can cause him to “desert self-control temporarily” (p. 1). Once his breathing deepens and slows, he can then communicate by typing out his thoughts. When he gets nervous, it is as if he becomes deaf to what is being said to him. So, he explains, “ignore my involuntary gestures, including my signs for ‘done’ and ‘break’” (p. 2). Such utterances, he says, are part of “a cycle of autonomic impulses. Remember these gestures are not voluntary... just ... [the] body’s way of responding to stimuli” (p. 2). If people do respond to the autonomic gestures and words, his heart races even more. He says the best form of support is to “wait patiently and wordlessly”, giving him the space to respond intentionally (p. 2). Conversations are easier if the person engaging with him asks him a question and offers him a few choices, ideally writing them down. Then he can point independently on his own. He finds written conversations easier than spoken ones: “typing and writing your questions really lets me know that you hope to get a response. It also keeps the conversation going at an even rhythm, so I don’t fear that you’ll get bored and leave” (p. 2).

For some, learning to support inclusion will come naturally, but for many of us it must be learned. If we listen and read carefully, with an open mind, Savarese's descriptions serve as guides for educators. A person walking ahead of him, a backpack to help himself locate his body in space, a teacher asking him questions that include choices, a peer ignoring his automatic utterances and waiting patiently for his side of a dialogue, and impromptu dancing with him when he dances, arms flapping, become some of the modest accommodations that make inclusion work.

Savarese's personal account, as well as the narratives of so many other activists (Fries 1998; Heumann and Joiner 2020; Kuusisto 1998; Mairs 1997; Mukhopadhyay 2015; Rubin 2005; Savarese 2019; Titchkosky 2011; Van Der Klift and Kunc 2019), demand that mainstream culture see students with disabilities as peers, knowledgeable about what works for them educationally, and deserving that access to inclusion be automatic and not be a lottery. They insist on shifting their place from being silenced and always at the margins. They reject having to be explained by those who would presume the authority to decide their fate. The new firsthand narratives, such as those penned by Burke and Savarese, interrupt dominant segregationist imperatives and instead envision and exemplify the kind of education-as-dialogue that Blatt imagined. The proliferation of such accounts suggests that indeed inclusion changes attitudes, redefining normal to include disability.

## Common themes found in the social justification for inclusion

Whether in the Schools of Promise model, the autobiographical insights from Jamie Burke and D.J. Savarese, the analyses and reflections by Ashby (2012), Connor and Berman (2019), or Christensen (2019), several characteristic elements of successful inclusion surface repeatedly:

- Effective teachers know that students want to work and to be fully part of school life and that they appreciate educators who are interested in how they learn.
- Successful teachers are those who get to know their students, who believe they have much to contribute, and who look forward to learning from them.
- Students appreciate teachers who push them but also who defend them in the melee that often characterizes schooling and against ableist attitudes.
- Students profit from seeing role models who share some of the physical and emotional experiences of their own lives.
- The school culture, including the funding base and administrative structures and leadership, make inclusion central to the educational mission.

Of course, these are the same principles associated with successful schooling of all students who have traditionally been marginalized and, indeed, of all students.

## The economic justification: Abandoning dual systems, saving through inclusion

Nothing happens in a separate school or classroom that cannot be supported to occur in an inclusive school and classroom. If special expertise is needed to design and implement successful education, administrators can orchestrate that in typical schools and in general education classes. Not surprisingly then, the costs of inclusion are always either significantly

less or at least not more (Halvorsen, Neary, and Piuma 1996; Odden and Picus 2008; Odom et al. 2001) than special education, principally because inclusion avoids the need to duplicate administration, transportation, and other expenses. In the US, educating students in special schools typically costs 2–3 times as much as inclusive education. Separate residential schools and institutions can cost 2 times again the cost of separate day schools. No matter how one analyzes the data, inclusion costs substantially less than segregated schooling.

## Conclusion: Toward transformation

If the criterion for inclusion is full-time participation in the general education classroom, then it appears that the US is persistently, if slowly, progressing toward that standard. The national average for inclusion of students with disabilities in general education is 63%, up from just 41% 15 years earlier (US Department of Education 2003, 2018). Yet, some states do more inclusion than others. For disabled students in Hawaii and New Jersey, attendance in general education is 37% and 45% respectively, whereas more than 70% of disabled students in Vermont, Nebraska, and Colorado spend most of their school days in general education classes (US Department of Education 2018, pp. 148–149). But sadly, the extent of *segregation* intensifies when disability intersects with race and poverty (Artiles et al. 2002; Artiles et al. 2011; White et al. 2019). Thus, the likelihood and extent of a student being included depends greatly on the student's socio-economic and racial status and geo-location.

While national data show inclusion progressing sporadically and often unfairly as well as slowly, individual examples of transformation toward inclusion (Ashby 2012; Connor and Berman 2019; Kliever 1998) leave room for optimism. Clearly, quality inclusion is possible, yields positive educational and social benefits for students with and without disabilities, and at the same or less cost than segregated schooling. Perhaps most important, much as Blatt forecast in his 1977 essay, the way forward is now informed by disability activists who have themselves grown up through inclusive education.

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