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## Presuming Competence

Douglas Biklen and Jamie Burke

At least since the early 1990s, educators in inclusive schooling as well as scholars in Disability Studies have critiqued prevailing notions of intellectual ability and have suggested the importance of interpretive communities for constructing student competence (Biklen, 1990; Goode, 1992, 1994; Kliewer, 1998; Kluth, 2003; Linneman, 2001). This work follows in the tradition of education-as-dialogue, which some have argued is a sine qua non for conceptualizing education with individuals who have been traditionally marginalized (see for example, Ashton-Warner, 1963, Freire, 1970). The core of this article is a conversation between a university educator and a high school student with autism who types to communicate. Out of this essay, the authors find a series of principles for inclusive schooling, the most central of which is the idea of presuming competence of students.

The authors of this article have known each other for a long time, though when they first met, they could not have imagined that they would be writing together at this juncture, 13 years hence. We, the authors, first met in Syracuse, New York, at the Jowonio School, a preschool that includes students with and without disabilities. One of us was four years old, the other a university professor in his forties. The latter followed the former around a preschool classroom, recording his every move. The professor watched the four-year-old student look at pictures on the page of a children's book and then point to letters on an electronic typing device, making words in response to his teacher's questions; the teacher, a young man, alternately held the boy in his lap or sat behind him on a stool, with his hand under the boy's arm as he typed. A few moments later, the professor scurried with the video camera to record a scene of the boy, with both hands held by his teacher, jumping on a mini trampoline.

That video recording did not provide enough data to predict the future for this boy. Would he become an active participant in school life as a teenager? How would his peers receive him? Would teachers in his future grades have ways of involving him in the academic curricula? None of this could be known when he was four years old. Indeed, observers of the video might even wonder how much could really be known about his abilities then, at the age of four. After all, the method of communication that the boy used, facilitated communication, was controversial (Beukelman & Mirenda, 1998).<sup>1</sup> Not every-

one who saw the boy pointing to letters was convinced that he was indeed communicating. It could have been his teacher, they argued, who did the pointing for him. How could you tell? How could you be certain? Was it not wishful thinking to believe that this boy who had very little speech, limited to a few words at a time, could be as smart as the typing suggested? Yet his family and many of his teachers and several key school administrators *did* give him the benefit of the doubt; they supported his communication training so that today he can type without physical support and also can speak words as he types them as well as read aloud novel text as well as anything he himself has written (Broderick & Kasa-Hendrickson, 2001; Kasa-Hendrickson, Broderick, & Biklen, 2002). In this article we talk about the importance of *presuming competence* of students with disabilities, as for all students, and the link between this concept (presuming competence) and inclusive education. It may be commonplace for parents and early childhood educators to approach non-disabled children as competent—for example, adults routinely gesture, sing, and talk to infants, presuming such children will at some point connect spoken words and visual enactments to things and concepts. Teaching literacy is carried out within the expectation that most, if not all, children are capable of developing literacy skills. Yet with children classified as autistic, it is not uncommon to link early expressive difficulties to a presumption of incompetence. Leading authorities declare 75% of persons classified autistic as retarded, linking severity of symptoms with cognitive level (Carpentieri & Morgan, 1996; Rapin, 1997). Delays or perceived deficits in language are taken as evidence of intellectual impairment (see for example,

Address correspondence to Douglas Biklen, 376 Huntington Hall, Syracuse University, Syracuse, NY 13244. E-mail: dpbiklen@syr.edu

Jacobson, Mulick, & Schwartz [1995] and Volkmar & Cohen [1985]). "There is little doubt," Carpentieri and Morgan declare, "most children with autism suffer from substantial cognitive impairment (p. 611). Their use of the term "suffer" implies that autism is a kind of wound. Further, Carpentieri and Morgan argue that compared with individuals who test at the same level of cognitive ability/disability, people classified as autistic are more impaired in verbal reasoning abilities (p. 611). In light of the pessimism that surrounds autism and the intellectual abilities of persons so classified, to presume competence is to step outside of conventional theory and practice.

### WHY THE THEME OF PRESUMING COMPETENCE?

The tradition in American education to assume incompetence of students who have severe communication impairments extends beyond autism, and includes those with other developmental disabilities, such as Down syndrome, Rett syndrome, Cri-Du-Chat, and others. This happens through the process of classification. Students "become" mentally retarded on the basis of their performance on intelligence tests and adaptive behavior scales. As an illustration, consider how the American Psychiatric Association's (APA, 2000) definition of severe retardation declares a person retarded *because* of difficulties in performance:

The group with Severe Mental Retardation constitutes 3%–4% of individuals with Mental Retardation. During the early childhood years, they acquire little or no communicative speech. During the school-age period, they may learn to talk and can be trained in elementary self-care skills. They profit to only a limited extent from instruction in pre-academic subjects, such as familiarity with the alphabet and simple counting, but can master skills such as learning sight reading of some "survival" words. In their adult years, they may be able to perform simple tasks in closely supervised settings. Most adapt well to life in the community, in group homes or with their families, unless they have an associated handicap that requires specialized nursing or other care. (pp. 43–44)

Schools are the site where labeling most often occurs. Then, once labeled, students are routinely expected to prove that they can benefit from inclusive, academic instruction in order to be maintained in the regular class, often with supportive and specialized services. Specifically, federal regulations read:

- (1) That to the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are nondisabled; and
- (2) That special classes, separate schooling or other removal of children with disabilities from the regular edu-

cational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily. (Office of Special Education and Rehabilitative Services, 1997)

Federal courts have found that if a student is determined not to be benefiting from inclusion in the regular class then exclusion is permissible (*Hartmann v. Loudoun County Board of Education*, 1997). Of course, the problem with this reasoning is that the criterion for inclusion, as for diagnosis of intellectual disability, is a circular one. The very student who has difficulties with performance, including speech, will often be caught in the diagnostic category of severely retarded, not because of any proof about thinking ability, but because of an absence of evidence about his or her thinking ability. Hence the student may be defined as unable to benefit from inclusion. Whereas at one time (i.e., before the passage of federal right-to-education legislation [Education for All Handicapped Children, 1975]) students had to prove their educability, now they must prove their ability to be included. Once diagnosed, the student may be shunted aside into special classes or special schools on the assumption, not proof, that he or she cannot benefit from the same academic instruction enjoyed by nondisabled peers.

This theme, demonstrating-competence-in-order-to-be-granted-it, arises in popular culture as well, for example in the classic *Flowers for Algernon* (Keyes, 1966) or its cinematic derivation, *Charly* (Nelson, 1968), where the lead character's intelligence is portrayed as linked to a body that is quick, agile, and immediately responsive or, conversely, plodding, awkward, and only slowly and intermittently able to imagine what the world around him expects. In Levinson's *Rainman* (1988), the main character, Raymond, gets returned to the closed, segregated, disabled-only institution when he disassembles as his toast in a toaster burns and smokes—the implication is that Raymond cannot manage the requisites of daily living and so cannot be part of the everyday world of "normal people." His fate is sealed when he is inarticulate and seemingly unable to speak for himself in response to questions from a psychiatrist who is deciding on where he should be placed.<sup>2</sup>

In short, the outside observer (e.g., teacher, parent, diagnostician, associate) has a choice, to determine either that the person is incompetent (i.e., severely retarded by the APA definition) or to admit that one cannot know another's thinking unless the other can reveal it. The latter is actually the more conservative choice. It refuses to limit opportunity; by presuming competence, it casts the teachers, parents, and others in the role of finding ways to support the person to demonstrate his or her agency.

The notion of presuming competence is not a new one in the field of severe disabilities. Blatt (1999) was one of the first scholars to illustrate this when he pointed out the metaphorical nature of retardation; People labeled

mentally retarded, he argued, were about as real as a photograph of a person *is* a person. To drive home his argument, Blatt notes that prior to Helen Keller becoming an internationally famous writer, speaker, and humanitarian, she was herself believed to be retarded. Only with the help of Anne Sullivan, and the means of communication that Sullivan taught, did Keller escape "being" retarded. It is a special, ethical responsibility, Blatt writes, for the teacher to presume the student's educability. While Anne Sullivan had no way of knowing at the outset of her work that she would enable Keller to become world famous, or even that Keller would learn to read and write, Sullivan was nevertheless obligated to think such accomplishments were possible.

Recently, other scholars have used a similar lens through which to construct educational approaches to students with disabilities (e.g., Biklen, 1990; Goode, 1992; Kliewer, 1998; Linneman, 2002), indeed as many have done for conceptualizing education for others who have been traditionally marginalized (see for example, Ashton-Warner, 1963, Freire, 1970). For example, the notion of presuming competence implies that educators must assume students can and will change and, that through engagement with the world, will demonstrate complexities of thought and action that could not necessarily be anticipated. Within this frame, difficulties with performance are not presumed to be evidence of intellectual incapacity (Biklen, 2000). Similarly, in a book detailing his work with children whom schools had classified as autistic and severely retarded, Linneman (2001) demonstrates their abilities to work with him on a variety of computer programs where they reveal their interests. Linneman refers to granting a person "mindedness;" his "mindedness" appears to be analogous to presuming competence. He credits the idea of being open to individuals' competence as crucial to his work. Conversely, "the specter of mental retardation creates an altered set of expectations" (p. 183), he writes, such that the person's mind is thought to be absent or at least "contested territory" (p. 183). Yet if classified as autistic but *not* mentally retarded, "it is likely that" the mind will be thought to be "present but hidden" (p. 183).

Whether from the perspective that Linneman (2001) refers to as belief in a person's "mindedness," that Blatt (1999) calls "educability," that Goode (1992) describes as the "emic" perspective, or that we refer to as "presuming competence" (Biklen, 1990), the observer's obligation is not to project an ableist interpretation on something another person does, but rather to presume there must be a rationale or sympathetic explanation for what someone does and then to try to discover it, always from the other person's own perspective. Thus the presumption of competence does not require the teacher's ability to prove its existence or validity in advance; rather it is a stance, an outlook, a framework for educational engagement. As readers will see, this presuming compe-

tence lens provides the foundation for the interview that follows.

## A CONVERSATION ABOUT INCLUSIVE SCHOOLING

The text in this section is a dialogue between the professor and the now high school (soon to be college) student. As will become apparent, the conversation covers not only questions of school organization, the ideology behind everyday educational practice, but also specific descriptions of how the second author experiences school culture as well as particular personal qualities associated with his disability and what he suggests might be changed to create more inclusive schools. Taken as a whole, the discussion itself evidences the possibilities that accrue from presuming competence.

### Initial Thoughts on What Makes for an Ideal School

*Biklen:* Let me begin straightforwardly. If you could design the ideal school, what would it be like?

*Burke:* What would a school of my dreams look like? Good soft seats and desks that held wonderful books that told of love and kindness. Kids would need to behave in the most kind manner and teasing would be a detention time. Everyone would be asked to join all clubs . . . and pleasing music would play everywhere.

*Biklen:* Okay, so you want physical comfort but also rich learning. Does your call for no teasing mean that you've encountered teasing?

*Burke:* Well, I can think of many times, but places where I was teased seemed to be where the others experienced it as well. The lack of speech was an enormous handicap. It made me not sad, but furious. I could not shout at them or harangue them. One terrible time was when I got seated in the back of the school bus. Two bullies told me to jump out the window. Did they think I was stupid? I was vindicated through my typing because the principal listened to me and they were chastised. That example was one, but I was given the opportunity to tell teachers if I was not being called on for sufficient answers. When I had a tough experience in chorus in fourth grade, I was able to talk to my school psychologist who became excellent in facilitating my typing. We shared much in emotional freeing of angry looks at how life dealt me a lousy hand. In the ideal school I would be able to tell my thoughts and troubles when I chose, not when others desire.

*Biklen:* Are there ways that a school can help you feel confident about your place in it?

*Burke:* My school is very good and people try both teaching and loving me and my autism. So I think I am fearing less now than younger times of my life. Joy in life as a boy in a journey to a happy life is even a dream now seen. Respect comes with love and understanding each kid's abilities and the desire to teach so therefore teachers must have

a desire to teach everyone. They must 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.

*Biklen:* That seems like such an important principle: Give students a chance to be heard and listen to them! I wonder how we address this issue when some children have trouble speaking or communicating.

*Burke:* When I was growing up, speaking was so frustrating. I could see the words in my brain but then I realized that making my mouth move would get those letters to come alive, they died as soon as they were born. What made me feel angry was to know that I knew exactly what I was to say and my brain was retreating in defeat. I felt so mad as teachers spoke in their childish voices to me, mothering me, but not educating me.

### A Matter of Timing

*Biklen:* So how do you think these experiences compare to what other students may encounter?

*Burke:* Perhaps the question should reflect how we differ in the speed of conveying our thoughts. Vocalized thoughts slip quickly and with little prior planning. On my part, I must first have a way to indicate I desire to comment. Then, a facilitator must be available to promptly cue my body to get my communication device (e.g., by gesturing to the computer keyboard). Then I need physical support to type [with certain facilitators such as his mother, Burke types without physical support]. All of this takes too long for typical kids. I have lost many comments that may have engaged friendships because of the complications of this way of communicating. Yet, I am forever pleased to use it to involve my self in the world of my peers.

Teachers can give students a chance to know me. Friends are so hard to keep interested as it takes very much desirous time to type. Kids are mostly good at talking but listening is not an asset they use. If I am able to talk, it still is not very good, as time is fleeting and so are they.

*Biklen:* So your teachers and fellow students strongly influence how much participation is possible.

*Burke:* Greatly. The issue is that even though my speed of typing is much faster now, it still is an enormous amount of time in order to type a response to a question. In English class we were studying Shakespeare, I believe it was Hamlet. My teacher asked if I could respond to a query about the plot. I was hopeful that she called on me because my knowledge of Shakespeare is fully evident. While typing, the kids were restless and pencils were tapping and the loud sounds of talking distracted me. I needed full concentration, and it's so distracting with the background noises to concentrate on the long English names of the play. I did all right, but could have done better work in a quiet environment. That meant it took me longer to respond. 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. This leaves me with my response and no one to respond to. It may pop out of the brain even after someone else asks a new question, and I begin it all once more. It's so frustrating to me.

*Biklen:* A few years ago you wrote, "if homework was told to be done, time more than one day would be given." Is this another aspect of how time to complete a task can inhibit you from achieving what you desire?

*Burke:* Perhaps it's the enemy of those who cannot execute directly from their initiation direction. I mean that I must read and use both auditory and visual connection. Stimuli are needed in both areas. (Then there is the complication of stamina, or lack of it.) Typing at the end of day exhausts me and my focus. It's like a flea on a dog that's getting wet, always moving to another area of escape. Again, my old participating partner of motor planning inability makes having an adult to keep me on task necessary. I feel it's reasonable and fair to give me an extra day for reports of projects. I must say I rarely, if ever, ask for that accommodation, as it screams of disabled.

*Biklen:* it seems unfair that a useful accommodation is treated as evidence of inadequacy.

### Ideal Teachers

*Biklen:* How about the teachers in your school? What should they be like?

*Burke:* The teachers, good and many of them, would only be as we choose, not assigned by computers. Courses would be chosen by teachers' love of subject and teachers must be excellent in that class (the one chosen).

*Biklen:* I'm sure most teachers would share your view: Allow them to teach what they care most about. But I sense there is some other reasoning behind your statement.

*Burke:* It's always curious to me as to why some have chosen this profession. After all, I assume the desire is to impart what they've gone to great monetary debt and great time to learn. Some seem annoyed I am asking to have an additional adult in the room. It is necessary for me to have a facilitator so that I may communicate. Others seem very interested in the curiosities of autism. The best teachers just seem to accept all the variables as nothing that will alter the room, and they demonstrate their love of the knowledge they are teaching. It's a passionate feeling in their delivery and how they seek me out to answer the questions. It's as if we dance in partnership on that floor of knowledge.

*Biklen:* I know that your mother has been very involved in making sure that teachers know how to support you. Is that part of the ideal teaching equation?

*Burke:* Well certainly I think politics seem to require people to initiate the uninitiated. I mean, I think that those who know us best and also in our worst state of being can represent us in the way parents want their children to be seen. I think in fairness, [a parent's input] may put the teachers more at ease than a special education teacher. My understanding has been [that] the special education teacher places her or his educational worth on the percentages

of acceptance of a kid into regular education classes. The special education teacher very often must try to sell us as worthwhile [for regular class teachers] to take up their effort.

### School as a Sensory Field

*Biklen:* When you first wrote about your ideas for an ideal school, you touched on how you experience your sensory sensitivities. This has often been discussed in other first-hand narratives (Rubin, in Biklen, 2005; Jackson, 2002) You said, "Lunch would be served in a room far from cooking so smells are not sickening. The lunch would be a time for peaceful eating and not loud talking and annoying bells and whistles which split my ears as a sword in use of killing monsters—my ears hear colossally well so noise can be difficult." I am especially interested in this, because it is something that other people with autism have mentioned. But it also may suggest that the busy school could play havoc with your sensory sensitivities. Some might argue that this could justify creating special classrooms and schools less prone to creating sensory overload.

*Burke:* Total bullshit. Please excuse the term, but I feel it's the end result of ideas ingested that produce a crappy result. What purpose would being exposed to another who hand stims or who has vocal out-thoughts (echolalia)? For me, that would only make my sensory sensitivities higher. It's like a domino, but in reverse order. Setting it off doesn't make it fall lower, but escalates that energy higher. Perhaps the most productive idea is to assist us in lessening the sensitivity. This can be done before classes or exams. It can be done after school. The effects, while taking a certain amount of building up in the brain, will certainly carry over. Treat the difficulties now in order to have a fully functional life after school is done. I am not planning a segregated life for myself. As a young child I often looked to other students' ways of being in order to be a living example of how autism is not fully diving into a shallow pool.

*Biklen:* Okay. So what are the kinds of strategies that have helped you deal with sensory differences?

*Burke:* It seems very long ago when this sensory wall was erected. So many perfect therapies that secured through marvelous people have effectively torn down that wall of protection. [My occupational therapist (O.T.)] is serving up the sensory diet of Flow, Infinity Walk, platform swinging while spelling and sequencing. Willbarger Brushing, EFT [emotion freeing therapy], and the love of talking to me as we learn about the brain's ability to redirect and dissipate neurological pathways. [The O.T.] also introduced to me the Listening Therapy music. Listening therapy is a joy. It gives your ears the feeling of reaching the bridge over the missing meaning of sounds. Listening therapy is a grouping of music that has certain frequencies changed. This helped me to integrate my system of midline crossing<sup>3</sup> and helped me to tie my shoes at 15. She has me blow darts through a small tube from a distance to a target on the window. This seems to help my lips form better with more accuracy. At times my ears listen with no difficulty.

Other times, I must really focus to hear and make a bridge of sound to cross into the continuation. That seems to help me hear whole words. Before, I would lose certain sounds and the words seemed as garbage to be thrown out with no use to them. You might say I felt I am training my brain to hear better. It helps me to begin to speak better. Also it sends needed rhythm to my speech. I find the classical music best for me. My brain follows the very thorough and detailed patterns.

As for hearing what was said around me, I believe my ears only could hear the strong sounding words, I mean the words that made my ears stretch to listen.

*Biklen:* Please tell me more about what you just said. Are you now speaking of a sensory and/or processing difficulty with making sense of spoken conversation?

*Burke:* Yes, the spoken word was so difficult to make clear sense of its purpose. When I was in my tender years, the words were as waves in an ocean, washing over and around me. Soothing, but not making any useful sense.

*Biklen:* I know you have also tried what people call "sensory integration."

*Burke:* To me and my brain and body, this is the magnificent therapy that just must never be overlooked. [With that therapy] my body and brain felt more as one unit and not two separate ones. When I would be stressed from demands of staying in the class or the stimulation of too much color in the classroom walls, I could go to the Physical Therapy room and roll in the rainbow barrel or sit on a soft beanbag chair where its firm but soft pressure on my body from all sides would bring control back to me. The desire to scratch or scream to get away was greatly sublimated to just a pesky controllable feeling. It is absolutely paramount that people know that now in my older teenage years my O.T. has assisted me as an angel of mercy in giving me the Listening Therapy and others that have helped me to type much faster and hear better. My typing that was a VW Beetle is now a Lamborghini. It's the grace of faster access to crossing midline. Accessing midline gives me greater ease visually and [that's good, for example, for] doing long calculus problems. It's easier keeping track of the numerical order of problem solving. The readers may not know this, but another vastly helpful therapy has taken the fears that are like a paying customer which ride the autism, and it has left them at the exit gate. This [is] NET [neuro emotional therapy] and kinesiology. Many terrifying fears from those days of frustration and confusion are gone. People must acknowledge that this autism loves to confuse and frighten. Only the person that truly desires to help and not cure [are the ones I require]; they must creatively search all this jumble of wires so inordinately mixed and seek a clear road out from that jumbled mess.

*Biklen:* Jamie, I know that some people will read what you said earlier about sometimes needing a quiet environment, without the other students' restless tapping of pencils, or away from the busy, sensory overloaded school as an argument in favor of creating and maintaining, separate, disabled-only classes. But if I understand you correctly, your answer to sensory differences is not segregation but access to helpful services such as those of the O.T.

## Learning to Speak, a More Valuable Task than Learning to tie One's Shoes

*Biklen:* It must have been hard to be aware of what you wanted to say and yet not able to make your speech work, even as nearly everyone else around you was chattering away.

*Burke:* I understand why kids [with impaired speech] scream. It's frustrating not being able to speak and feeling as a mostly invisible being. Do you know the vintage movie, *The Invisible Man* (Whale, 1933)? That's how I felt. My clothes were there, but the body and the soul felt like nothing. How can you live a life getting treated as that?

*Biklen:* How did you begin to emerge from that invisibility?

*Burke:* Understanding that the only way to make this hell a heaven was with speech, I decided to take a risk and began to try just one word. I know my voice sounded foolish, but it felt okay to try. As my bold new hope grew as a fine new true reality, I tried more and felt that heaven moved closer.

*Biklen:* So this was something you deliberately decided to pursue, even if it was excruciatingly difficult.

*Burke:* So many things were hard for me to learn. I now think it was so foolish to ask me to learn to tie my shoes. My brain moved into hiding the reason for not being able to do it, but yet my school believed it important mostly as a way to tell you that you are now just greatly smart. Why is shoe tying important compared to the fact that you can't speak? Like saying the letters, mostly there was no pattern to follow in my brain for tying my shoelaces. After much practice, as with my words, it seemed a pattern moved into my brain, giving direction to my hands. I think my music therapy gave help with this. Doesn't tying your shoes mean you are now enclaved in the world of pigtailed and basketballs? When a kid can't tie shoes, you know they get frustrated with you, and even though those words of "it doesn't matter" and "we will use Velcro" are heard, your heart feels defeated. I screamed silently, "make my mouth work as my hands; can you idiots not see my struggle to tell you I have so many answers to the questions you place before my face? Isn't tying the speech to my mouth from my brain more critical to life than making a piece of cotton secure? When I was 15 I tied my shoes and people rejoiced as if I had won an enormous prize in some battle. I laughed at them in my brain. If they knew how ridiculous they seemed. Adults deemed it worthy of such excitement. Mom was happy and dad proud, but my mind believed this excited reaction to tying shoes still foolish.

*Biklen:* Jamie, I'm embarrassed to tell you how many times I've seen teachers working with students on shoe tying, and yet I never thought much about it, except that it might not be the best use of anyone's time. I wish that I had thought more about what the children must have been thinking. But then there's the problem of how any of us can know what another is thinking if the person cannot speak or otherwise make a choice clear to others. This must have been so hard to you.

*Burke:* I now think it was a big effort for those who smiled . . . and said, "I know you will speak some day." They did not really believe what they said to my face. I knew their smile hid what they really believed and that sympathy and not belief filled them. Why do all those who have said they are educated in the ways of teaching not know that hope and desire must be moved into place as the pillars of strength first before the floors can be built?

*Biklen:* Yes, who needs charity if it signals pessimism? So confidence and maybe even security were more what you wanted, to feel secure that you would have chances to grow?

*Burke:* Security comes from making *your* choices heard. Choices, even something like selecting a cereal, could be hard. In the morning I was given many silly choices. But as my voice was not a true one, I had to pick the choice I heard. Many times it was not my true choice and both my mom and me were mad if I did not finish the cereal. I mean when you are little and have speech that is only just a few small babyish words, you cannot get yourself unstuck to make a new selection. Like a car that keeps slipping into reverse gear because the track isn't strong enough to move forward. It was impossible to move to a joyful and delicious choice. After I was served, I was furious with myself and mad at mom. Even saying, "do you want something else" didn't help. The gears refused to move. I think many times it felt better to scream and run, than to feel like gagging on the bitter food. Even as the selections were viewed, my brain made only the same choice every day. Many times I desired pancakes but my lousy hand pointed to the bitter choice.

*Biklen:* Is there anything that a teacher or anyone else could have done to help with this?

*Burke:* I believe if I had a moveable brain image as a child it would have been easy.

*Biklen:* What's a "moveable brain image"?

*Burke:* The moveable brain image came as I learned to watch videos in moving order. Moving order means to me the ability to make things move along in order and not get stuck on an image or phrase that captured my attention.

*Biklen:* What's an example of this?

*Burke:* Perhaps getting stuck is the same as getting trapped in a pattern that makes you feel comfortable. In the realm of autistic brains, it's the perfect way to not move forward from the fear of being challenged with a new thought or task that you have no reference for. Being stuck in that pattern is certainly safer than venturing into fear and uncertainty.

Anxiety comes as a regular visitor, just as breathing. I believe my cells have a nucleus filled with it. I think when I was young I walked in a constant pacing to help my body deal with it and I felt my nerves prickle as if a porcupine shot its quills into me. I think that sensory integration . . . has been 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.

I am now able to handle many situations that would have sent me into man-overboard feeling. One thing that sent me overboard was being asked a question when I felt

stressed over the voices asking it. Women have a pitch to their vocal chords that are like vibrato. Sadly, you are expected to respond, but you truly feel as a bird trapped. Fluttering away seems lovely, but the expectation (of others) is a wire cage. Fighting to be appreciated, but longing to escape, I feel I made myself struggle, as this was the way to become competent.

Another time the overboard feeling comes is in tests. I need to focus on the question, work with the difficulty of small print which is black and blurs my eyes. The rustle of papers, pencils, scratching, coughing and scraping chairs, and lights drive me crazy. I do well for the beginning, then it adds up as a bank balance ready to be withdrawn. I am a man overboard awaiting my rescue. But you can't leave, can you, or I will fail. Failing is fundamental, but only for those who aren't in special education designation.

*Biklen:* Here again, readers might interpret your statements as justification for segregated schooling.

*Burke:* Segregation equals a distinction of lesser ability. Am I lesser because I get nervous about an exam? Am I deemed less intelligent because my feelings only make passing a higher stakes? I again ask you to think of who is it that has placed this way of evaluating worthiness? Have they placed their feet in my shoes? I would enjoin them to try, and to allow me to view the straightness of their path. Every sensory therapy has bonded my movement pattern stronger to my brain. . . . [This explains how] I have managed to do independent typing. Not every person has received my many therapies that have lessened anxiety. I believe that allows the learning and calming to step forward. It's just like looking to make the brain place the gear in forward, not in reverse.

The idea of school inclusion can be as a lousy or lovely happening. It's really all in the hands of the teachers along with the permission from the big boss, the superintendent. 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.

## CONCLUSION

We began this article by suggesting that when students and teachers participate in inclusive schooling, they cannot possibly predict what directions it will take them. In particular, when a student has difficulties with speech, as the second author did when he first entered school, teachers cannot know what the student is thinking. This is a situation that demands a kind of compact between teacher and student to choose the most optimistic stance possible, what we have called "presuming competence," within which to effect inclusive education. As it turns out, during his earliest years of being included, Burke understood far more than he was able to express. Fortunately, his mother and a group of teachers and external consultants kept looking for ways that he might

communicate. Clearly, his experience stands out as worthy of telling, mainly because it contrasts so vividly with the more common practice of regarding performance difficulties as evidence of incompetence and then expecting little. Pessimistic assessments trigger circumspection about students' potential for learning and lead to diminished expectations—recall for example Burke's account of a curriculum on shoe tying—with little enthusiasm for exploring how students might participate and achieve academically.

The principle of presuming competence leads to consideration of a series of corollaries, each of which can be found in the interview above. These corollaries follow:

- There needs to be a strong commitment to inclusive education that expects student agency, where the participation of the student in the heart of the classroom is a given, not an experiment, and not conditional, and where participation amounts to more than mere physical presence; the student must be seen as someone more than a body to fill the chair. Only then is the stage set for an attitude of problem solving where, when difficulties arise, teachers, teaching consultants, parents, and administrators can work with the child to figure out solutions. Good teaching involves dialogue with the student, for teachers cannot assume they know what students are thinking or aspiring to; as Burke explains above, teachers' "dreams are not ours."
- Disability may cause some students to experience the world in ways that may be dramatically different in degree and even nature from other students. As the above conversation suggests, much of a school administrator's or teacher's work is to find ways of learning about how a student experiences his or her environment. This may involve seeking advice from specialists such as occupational therapists, physical therapists, consultants on anxiety, and people knowledgeable in sensory integration strategies; Burke warns against defining such services as the privilege of middle- and upper-middle-class students. If seen as rightful, schools will aggressively seek out specialized expertise to support students who may benefit from them. It is critically important to remember that difference does not equate with deficit. Unless educators attempt to adapt the school environment, for instance by providing support services that are in response to how students experience social interaction and other environmental characteristics, a student with a disability can indeed be physically present but not really part of the school. Adapting to styles of receiving information effectively, for example by providing visual as well as auditory input, was important for Burke's early education.
- Educators and, especially, specialists are often cast in the role of explaining students to other professionals, to parents, and to themselves. And they are often expected to do so authoritatively. Yet speaking for the other is always problematic. Instead, it would seem best always to seek ways for the other person to explain himself or herself. Schools can provide students with opportunities to be



informants about themselves in relation to school culture. Above, Burke notes how the time it takes for him to type his side of conversations affects most of his interactions in school. Particular ways of organizing an environment (rules, standard operating procedures) may privilege some students and disadvantage others, hence the need to analyze how disability may be related to the implicit and explicit rules of a setting. All students could be enlisted to share their thoughts on how the school culture and school practices, including peer-to-peer styles of interaction, can be adapted to enable more democratic participation.

- The idea of “normal” is itself a social construct and can be altered, shifted, and transformed. Hopefully, this article will encourage educators to question the very idea of normal. Clearly, ideas of what is possible in regard to human relationships and education do shift within particular historical/cultural moments; and individual teachers, students, researchers, parents, and others can have a part in the reshaping. Although the idea of presuming competence may seem reasonable and advantageous, if introduced to a school where large groups of students are categorized as mentally retarded, this will represent a radical shift in educational ideology. Burke’s comments above reveal that even in a school officially committed to inclusion, assumptions of incompetence can still surface—he describes a situation where he was taunted by two students on the school bus. Such events reaffirm the importance of putting disability and ideas of normalcy/difference at the center of conversations concerning school reform; dealing with them is essential to the creation of democratic schooling.

## NOTES

1. All of the text written by the second author of this article was produced after he learned to speak as he typed (he can say the words before and as he types them). In the year prior to our writing this article, the student developed the ability to type without any physical support. For all of his writing, the second author had a facilitator sit next to him as he typed. Parts of the discussion were first drafted by the second author for speeches and for an essay that appears in the book, *Autism and the Myth of the Person Alone* (Biklen, 2005), adapted here with permission.

Controversy about the method of facilitated communication centers on the question of authorship. It has been shown that a facilitator’s physical touch of the typist’s hand or arm may influence the person’s pointing. A number of studies have demonstrated this fact and/or have failed to validate authorship (Bebko, Perry, & Bryson, 1996; Bomba, O’Donnell, Markowitz, & Holmes, 1996; Cabay, 1994; Crews et al., 1995; Eberlin, McConnachie, Ibel, & Volpe, 1993; Klewe, 1993; Montee, Miltenberger, & Wittrock, 1995; Moore, Donovan, Hudson, Dykstra, & Lawrence, 1993; Regal, Rooney, & Wandas, 1994; Shane & Kearns, 1994; Smith & Belcher, 1993; Szempruch & Jacobson, 1993; and Wheeler, Jacobson, Paglieri, & Schwartz, 1993). These studies use one basic type of assessment, namely message passing; that is, the person being assessed was re-

quired to convey information that could not be known to the facilitator. Other studies, using a wider range of test situations as well as linguistic analysis and documentation of physical, independent-of-facilitator typing have successfully demonstrated authorship (Broderick & Kasa-Hendrickson, 2001; Calculator & Singer, 1992; Cardinal, Hanson, & Wakeham, 1996; Emerson, Grayson, & Griffiths, 2001; Janzen-Wilde, Duchan, & Higginbotham, 1995; Niemi & Kärnä-Lin, 2002; Rubin, Biklen, Kasa-Hendrickson, Kluth, Cardinal, & Broderick, 2001; Sheehan & Matuozi, 1996; Tuzzi, Cemin, & Castagna, (2004); Weiss, Wagner, & Bauman, 1996; and Zanobini & Scopesi, 2001). The studies by Cardinal and his colleagues (1996), Sheehan and Matuozi (1996), and Weiss, Wagner, and Bauman (1996) all involved message passing experiments, but unlike many of the assessments in which individuals failed to demonstrate authorship, these involved extensive testing sessions, with the possible effect of desensitizing the subjects to test anxiety.

2. It is perhaps fitting that the psychiatrist is played by the film’s director, Barry Levinson, for the film itself, *his* film, conveys the message that a person who is different belongs in an institution and has no place in the everyday world inhabited by the undiagnosed.

3. Crossing midline refers to a person’s ability to move an arm from one side of the body to the other, a skill one needs for playing most games and for many other tasks.

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**Douglas Biklen** is Dean of the School of Education at Syracuse University, Professor of Cultural Foundations of Education and of Teaching and Leadership, and is a senior faculty member in the Center on Human Policy, Law and Disability Studies.

**Jamie Burke** lives in Syracuse, New York where he attends high school. He was the subject of a research report published in 2001 and has written and narrated a video documentary, *Inside the Edge*, about how, as a teenager, he emerged from typing to speaking.