

## Enacting Literacy: Local Understanding, Significant Disability, And A New Frame For Educational Opportunity

by Christopher Kliewer & Douglas Biklen — 2007

*Background/Context:* Culturally authoritative texts such as *Text Revision of the Diagnostic & Statistical Manual-IV [DSM-IV-TR]* (American Psychiatric Association [APA], 2004) describe *literate impossibility* for individuals with disability labels associated with severe developmental disabilities. Our qualitative research challenges the assumptions of perpetual subliteracy authoritatively embedded within the DSM-IV-TR (APA, 2004). U. S. education policy also confronts, at least rhetorically, assumed hopelessness with reading and writing remediation in schools. Most recently, the federal government has directed national concern toward issues of literacy acquisition and child failure through the No Child Left Behind Act of 2001 (NCLB). One description of NCLB provided by the U.S. Department of Education (2004) suggested universal literacy was a primary objective. However, our research suggests that the NCLB statute appears to emphasize a restrictive standardization as the route to universal literacy that would in fact leave out many people with severe developmental disabilities.

*Purpose of Research:* In this analysis and synthesis of our recent qualitative and ethnographic studies, we specifically describe the dimensions of local understanding that foster citizenship in the literate community for individuals commonly acted upon as hopelessly aliterate, subliterate, or illiterate due to assumptions surrounding their degree of disability. We contrast these descriptions of local understanding with U.S. education policy that mandates what we believe to be a singular, narrow, and rigid approach to early or initial written language instruction.

*Participants:* This study is a synthesis of ideas developed in several previous qualitative and ethnographic research efforts. These previous studies have involved individuals labeled with significant developmental disabilities across the age span including preschool children, older students, and adults.

*Intervention/Practices:* Local understanding is an organizing dialogic built from the ideas underlying the theoretical construct local knowledge described in the work of anthropologist Clifford Geertz. Local understanding is the communal recognition that educational value and participation may be ascribed and enacted where history has primarily supported dehumanization and segregation.

*Research Design:* Local understanding developed out of previous qualitative studies.

*Conclusion:* Local understanding emerges from the literate netherworld of students at the educational margins. It requires providing the resources necessary to promote excellent educators in dialogue with one another and families, imaginatively crafting responsive contexts built on the full presumption that all children can be understood as competent and can grow in sophistication as literate citizens.

Nicholas had just turned three years old when we first met him as part of our ethnographic literacy research at the Shoshone School, an inclusive early childhood education center serving students with and without disabilities from birth through age six. Nicholas is one of dozens of people, ranging from preschool age to middle age, who have participated in qualitative studies we have conducted on literacy development, communication, and individuals with significant developmental disabilities (Biklen, 1990, 2005; Biklen & Kliewer, in press; Kliewer & Biklen, 2001; Kliewer et al, 2004). This research, including detailed observations of Nicholas's and other children's literate growth at Shoshone, provides the basis for what we term *local understanding*. Local understanding, as we have described it, is an educational dialogic in which the value, intelligence, and imagination (taken together, what we term *citizenship*) of all students, including those with significant developmental disabilities, are recognized and responsive contexts are crafted that foster increasingly sophisticated citizenship.

In this article, we specifically describe the dimensions of local understanding that foster citizenship in the literate community for individuals commonly acted upon as hopelessly aliterate, subliterate, or illiterate due to assumptions surrounding their degree of disability. We contrast these descriptions of local understanding with U.S. education policy that mandates what we believe to be a singular, narrow, and rigid approach to early or initial written language instruction. We contend that this policy not only excludes people with significant developmental disabilities, but is generally counter to the stated goal of an increasingly literate society. We conclude that sound education policy must consider dimensions of local understanding.

In our first encounter with Nicholas early in the school year, he approached a visiting researcher with a slight smile and his bright, brown eyes shining, though slightly averted. Nicholas brushed the newcomer with his hand, then slowly spun away, giggling euphorically. His teacher, Shayne Robbins, watched from across the busy room and called out in her assertive manner, "Nicholas, you're saying hi to our visitor. Maybe he can follow you and you can show him our room." "Can I?" shouted a nearby child. "Me too!" called out another student.

Unlike his peers in the inclusive Shoshone classroom made up of seventeen three- and four-year-old children, Nicholas did not speak. We were momentarily uncertain how to respond to his initial greeting; then Robbins stepped in and quickly modeled a valuing, engaging route to interpretation. *Read in his behavior meaning and purpose*, was the message conveyed in her seemingly organic translation of actions that might commonly be dismissed as nonsensical, aimless, and impaired. Her suggestion that he lead us on a classroom tour acknowledged him as capable and crafted a situation in which he had a coveted role of authority and value. In so doing, Robbins was *teaching us*, the visitors, by drawing us actively into the surrounding, immediate dialogic of expectation and possibility at the Shoshone School: a particular interpretive community in which purpose, capacity, competence, and potential are ascribed to members' actions and fostered across the various contexts of the school.

Local understanding emerged in our qualitative fieldnotes as an organizing dialogic, an active, educational variant of the ideas underlying the theoretical construct *local knowledge* described in the work of anthropologist Clifford Geertz (1983) and applied to myriad cultural contexts ranging from studies of weather prediction in rural villages (Rancoli, Ingram, & Kirshen, 2002) to determining effective crop rotations (Gray & Morant, 2003). According to Geertz, local knowledge has largely, and unfortunately, been discredited in the human and social sciences whose practitioners predominantly covet "grand textures of cause and effect" (p. 6) as deduced through "laws-and-causes social physics" (p. 5) to account ecumenically for cultural, social, and individual human phenomena. This effort at grand theory, Geertz is quick to assert, has "failed to produce the triumphs of prediction, control, and testability that had for so long been promised in its name" (p. 3).

As with the general drift of the human and social sciences, professional communities associated with disability predominantly seek a detached human cosmology of impairment. In contrast, those subversively organized around local understanding (i.e., the recognition of an individual's citizenship and the crafting of responsive contexts that foster this citizenship) understand that human behavior, communication, and intent do not have built-in, universal meanings awaiting an explanatory or regulatory law of deficit. Rather, it is understood that cultural meanings are built-up in the swirling, collective, interpretive and imaginative dialogues of a particular community, what Geertz has referred to as the dialogic of "local frames of awareness" (1983, p. 6) or as an "accent—vernacular characterizations of what happens connected with vernacular imaginings of what can" (p. 215). Local understanding is the communal recognition that educational value and participation may be ascribed and enacted where history has primarily supported dehumanization and segregation.

A nonspeaking child such as Nicholas who spins across a classroom may be considered within the disability profession's predominant efforts at explanatory and regulatory laws to be an objective representation of categorical impairment. Nicholas was born with Down syndrome. At the age of two years, eleven months, just prior to his official entry into Shoshone, Nicholas was also described as having autism spectrum disorder and intellectual impairment by a medical doctor at a clinic specializing in disability evaluations. Robbins of the Shoshone School, who had only met them a few weeks before, accompanied Nicholas and his mother, Dora Lancaster, to this appointment and three months later recalled in a research interview:

Right after he tells us Nicholas is autistic, he turns to Dora and says, "You know he's retarded. He's going to be very retarded. With Down syndrome and autism you get severe retardation." He just keeps going on like that, you know? He's got this reputation for being blunt and he's so proud of that and I'm saying to myself, "Stop it. Stop it. Shut the fuck up," and we get out the door and Dora is like white as a sheet. And I say to her, "We do not know what that means. We do not know what retardation means at all!"

The doctor was aligned with the expert community associated with disability, an interpretive network engaged in what are rhetorically described as *objective practices* (for a critical analysis, see Kliewer & Drake, 1998). These practices can reduce a child to various categories of impairment within 90 minutes of a first-ever meeting. This common notion of expertise embodies what Geertz described as "the machinery of distant ideas" (1983, p. 4). In the arena of disability, this machinery is built from the behavioral and psychometric branches of psychological science and the bureaucracy of human services. The distant frames commonly overwhelm other forms of understanding a child as they have generally come to dominate explanatory and regulatory discourses of disability available to professional interpretive communities. Seemingly ineluctable consequences of stratification often await those cast as severely impaired, including segregation into disability classrooms that commonly lack thoughtful or even recognizable academic opportunities such as gaining access literacy (Kliewer & Biklen, 2001; Mirenda, 2003). Segregated classrooms organized around the presumption of significant intellectual disability have consistently been shown to lower academic and social expectations for students in contrast to expectations for matched peers in inclusive classrooms (Baker, Wang, & Walberg, 1994; Freeman & Alkin, 2000).

In Shoshone School's vernacular, however, in its collective local understanding of Nicholas and other children with significant disabilities, the medical and psychological machinery of impairment, defect, segregation, and aliteracy were severely challenged by a community able to realize Nicholas's immediate competence as a literate citizen and imagine him growing in literate sophistication. Though he did not speak, his use of gesture, sound, some signed English, and eventually a visual symbol system supported Nicholas's growth in all areas of the preschool day. Of particular interest to our research was his literate development. Initial assessment numbers on the *Bracken Basic Concept Scale - Revised* and the *Test of Early Reading Ability - 2<sup>nd</sup> Edition* (TERA - 2<sup>nd</sup> Ed.), gathered out of bureaucratic necessity, indicated that Nicholas entered Shoshone performing at developmental levels associated with infancy.

To an outside observer, Nicholas's behavior in the first days of preschool might have confirmed those low developmental scores, but in his classroom, as Robbins explained, "We tend to see things otherwise." One afternoon early in the school year, we watched Nicholas enter the library corner of his class and immediately start stripping books from the shelf and tossing them like Frisbees. As children ducked, Robbins quickly moved in saying, "Nicholas, you're trying to find a book to read. I'll help you choose just one." During a story time that same week, Nicholas loudly and aggressively refused to sit with the group. A teaching assistant in the

classroom said to the students, "Nickie's listening to the book from the kitchen [area of the classroom]. That's where he listens best right now."

From the first days in the inclusive classroom, Nicholas's behavior, evaluated in bureaucratic fashion by the medical doctor as impaired, autistic, and retarded, was imbued with valued meaning within the Shoshone community. As the year progressed, his general classroom demeanor and specific performances in literacy-based activities developed in increasingly conventional, sophisticated, and valued directions. Eventually, he enjoyed the library corner and shared books with peers. In one observation in April, he and a friend had a large book of trucks opened across both their laps. Pointing with a finger, he enunciated strings of sound in a sing-song voice much like the voice of a teacher reading. In a group rendition of *The Little Old Lady Who Was Not Afraid of Anything* (Williams, 1986), Nicholas was one of the few children who was paying close enough attention to the picture book to stomp his shoes on cue with the text of the book as he sat in the lap of his favorite teacher's aide.

During the preschool summer program, a full year after entering Shoshone, Nicholas was reevaluated in a yearly ritual demanded by the state disability bureaucracy. This time on the *Bracken* and *TERA* his developmental scores ranged from 2.8 years to 3.3 years. We continued following Nicholas into the next school year as he began to use symbols, printed words, and letters to communicate more reliably. For instance, in one situation, a teacher's aide asked Nicholas if he wanted to go to the playground or join a small group of children in the kitchen to bake brownies. The laminated words *kitchen* and *playground* were stuck to a board using Velcro. Nicholas sat in the lap of the aide who held his left wrist which shot out and touched the word *kitchen*. He repeated the gesture and the two proceeded to the kitchen with the other children.

#### NATIONAL EDUCATION POLICY, UNIVERSAL LITERACY, & SIGNIFICANT DISABILITY

In several recent ethnographies, we have analyzed the experiences of individuals like Nicholas who are gaining access to literacy despite bureaucratic, distant prognoses of developmental-intellectual stagnation due to significant disability (Biklen, 2005; Biklen & Kliewer, in press; Kliewer, 1998; Kliewer & Biklen, 2001; Kliewer et al., 2004; Kliewer & Landis, 1999). These are individuals who have been medically cast into categories directly linked to lifelong aliteracy or subliteracy. In providing a culturally authoritative but profoundly flawed description of people labeled with severe intellectual disabilities, authors of the *Text Revision of the Diagnostic & Statistical Manual-IV [DSM-IV-TR]* (American Psychiatric Association [APA], 2004) make the claim: "They profit to only a limited extent from instruction in pre-academic subjects, such as familiarity with the alphabet ... [and] can master learning site reading of some 'survival' words" (p. 43-44).

Our research challenges the assumptions of perpetual subliteracy authoritatively embedded within the DSM-IV-TR (APA, 2004). U.S. education policy also confronts, at least rhetorically, assumed hopelessness with reading and writing remediation in schools. Most recently, the federal government has directed national concern toward issues of literacy acquisition and child failure through the *No Child Left Behind Act of 2001* (NCLB). One description of NCLB provided by the U.S. Department of Education (2004) suggested universal literacy was a primary objective: "The [Bush] administration has set the goal of making sure every child knows how to read at grade level by the third grade" (p. 2, emphasis added). Part B of the legislation entitled *Student Reading Skills Improvement Grants* is entirely focused on literacy development in the form of the *Reading First* program, its early childhood counterpart, the *Early Reading First* program, and the *William F. Goodling Even Start Family Literacy Programs*.

The NCLB statute appears to emphasize a restrictive standardization as the route to universal literacy. Descriptions of early literacy found in *NCLB* are dominated by a standardized emphasis on phonemic awareness and approved phonics programs as the singular beginning point of reading. In Subpart II of *NCLB*, Congress demanded that resources be restricted to "literacy activities based on scientifically based reading research that supports the age-appropriate development of: (A) recognition leading to automatic recognition of letters of the alphabet; (B) knowledge of letter sounds, [and] the blending of sounds...[and] (C) an understanding that written language is composed of phonemes and letters, each representing one or more speech sounds that in combination make up syllables, words, and sentences" (Part B, Subpart 2.a). Absent from this sequence, and distinctly removed from the coveted label of scientifically-based, is an interest in early or initial literacy efforts focused on making sense of the stories of others, finding and expressing meaning in one's own experiences, communicating thought through symbols, and deriving joy from critical, reflective engagement with printed language and other symbol systems, all of which are fundamental to literacy development in contexts of local understanding (Kliewer & Biklen, 2001; Kliewer et al., 2004; Kliewer & Landis, 1999).

While much criticism has been directed at *NCLB* specifically, the law is actually the culmination of a federal movement to control the meaning of, and approaches toward, literacy going back decades and across several administrations. In 1981, President Reagan's Education Secretary, T. H. Bell, convened what was called the *National Commission on Excellence in Education* (NCEE), made up of business leaders, college presidents, professors from various fields, school board members, and school administrators. Two years later, the commission published its widely read *open letter to the American people* entitled *A Nation at Risk* (NCEE, 1983) in which it decried the "rising tide of mediocrity" (p. A.1) in U.S. schools. The Commission linked school performance directly with commerce and economic expansion and recommended a curricular shift toward what it referred to as "the new basics" (p. B.1). Further, the Commission argued for the expanded use of "a nationwide system of State and local standardized tests" (p. B.3).

While *A Nation at Risk* was focused on high school and college instruction, it was quickly followed by the government-sponsored report of the Commission on Reading entitled *Becoming a Nation of Readers* (1985). As with its earlier counterpart, this Commission immediately linked education (specifically reading instruction) to economic vitality, both at individual and societal levels. The report emphasized reading as the result of "techniques, tools, and testing" (p. vi) and suggested that rigorous instruction could begin earlier in a child's life than was commonly practiced. The Commission challenged traditional early childhood curricula and suggested that "formal, structured, and intensive" (p. 29) literacy instruction could begin in preschool.

*Becoming a Nation of Readers* ostensibly supported a balanced approach to literacy; however, the report emphasized that phonics instruction should start in early childhood classrooms. This new emphasis was solidified as the singular beginning point to literacy with the 1990 publication of Adams's government-sponsored report to Congress entitled *Beginning to Read* (1990). Adams argued that the "cognitive energy and resources upon which skillful [reading] comprehension begins" requires prior word recognition skills that are "rapid, effortless, and automatic" (p. 5). As such, she firmly set instruction in phonics as the prelude to future comprehension. Adams later added, "In any complex endeavor, children must learn to walk [i.e., decipher phonemes] before they run [i.e., understand text]. Learning to read must start somewhere: if not with letters and phonemes, then where?" (2001, p. 68). It is an unfortunate metaphor, as our research demonstrates, in that some individuals will never "learn to walk" but with the correct supports they may still be extremely mobile and skilled at navigating multiple communities.

Nevertheless, Adams's influence has been deep and broad. Education legislation and Congressional reports throughout the Clinton years emphasized phonics as the singular *evidence-based* and *scientific-based* approach to promoting literacy in early childhood (e.g., Goals 2000: Educate America Act of 1994; Reading Excellence Act of 1997). The *National Reading Panel Report of 2000* (National Institute of Child Health and Human Development, 2000) was subtitled *An evidence-based assessment of the scientific research literature for reading instruction*.

Policy directed at phonemic awareness in early or initial literacy is not unreasonable. That it has become standardized as the sole focus of resources, however, is not in the best interest of a literate citizenry. What derives from the rules of phonics is that only research, assessment, teaching practices, and curricula standardized in support of these rules are sanctioned. Resources become directed only at those regimented programs that are claimed to derive from the newly minted "gold standard" of reading science: *randomized controlled trials* (U. S. Department of Education, 2003a) out of which initial literacy has now become synonymous with phonics and phonemic awareness. This gold standard is a calculated effort to model literacy research largely after pharmaceutical drug trials on the premise that "health in America has been profoundly improved over the past 50 years by the use of medical practices demonstrated effective in randomized controlled trials" (U.S. Department of Education, 2003a, p. iv). The claim is made that randomized controlled research "can help spark similar evidence-driven progress in the field of education" (p. iv). The medical model reduces literacy instruction to an *intervention* akin to ingesting a pill. The bizarre image emerges of masses of children moving from the a.m. Ritalin line to the literacy dosage line, a school nurse overseeing both.

We recognize that compelling criticisms of the literacy standardization embedded in U.S. education policy have been previously made (Allington, 2002; National Conference of State Legislatures, 2005). At least two important dynamics distinguish this current effort. First, our work grew out of the experiences of individuals with significant disabilities. We are unaware of any policy discussions that have begun with the literate lives of people so labeled. By ignoring these individuals, policymakers, researchers, and practitioners have missed opportunities to realize the responsiveness, resiliency, and complexity of thoughtfully inclusive schooling and the literacy development taking place at multiple levels therein. Second, our work brings together qualitative inquiry, autobiography, and disability studies to present evidence in support of a model of local understanding that directly challenges literacy standardization for any person as well as presumed literate hopelessness associated with particular disability labels. Here we offer three fundamental themes of local understanding as they emerged in the literate experiences of individuals labeled with significant disabilities and those without who shared inclusive environments.

#### THE COLLABORATIVE, DEMOCRATIC DIALOGIC

As Nicholas and his mother experienced at the medical clinic, the categorical label of significant mental retardation, mental disability, cognitive impairment, or some other such variation is doled out by an industry of experts often very early in a specific child's life. Children are then caught up in the implications of the classification. Most labeled with significant disabilities are steered into education tracts of strict segregation (U.S. Department of Education, 2003b). Under disability segregation for students classified as severely intellectually impaired, access to general education opportunities is highly restricted. Beginning in segregated preschool, literacy programs are commonly absent or are unrecognizable (Erickson & Koppenhaver, 1995; Mirenda, 2003). The resulting lack of literacy is then blamed on what are considered the children's intrinsic deficits.

The national policies described earlier generally support top down solutions to what is conceived as the nation's public school literacy crisis. For instance, the nonpartisan National Conference of State Legislatures (2005) contends that current policy "is a one-size-fits-all system that affects all students and brings the federal government into the day-to-day operations of public education" (p. 6). Goodman has noted that the *NCLB* "dictates how reading, writing, and math are taught and tested. Each state must have a proposal approved by bureaucrats in Washington, D.C. who may reject methods, materials, and curriculum not endorsed as 'evidence based' and who may order changes which are then imposed by the state on local schools" (2004, p. 3).

Our research documents that highly effective literacy practices are not imposed from above, but emanate from a local dialogic that emphasizes a deep, collaborative understanding of a child's right to full participation. Children at the Shoshone School, for instance, whether disabled or not, were presumed by surrounding adults to be citizens of the classroom's literate community. Certainly, the literate profiles of the students varied considerably based on interests, maturity, history of opportunity, and other factors. But no child, including Nicholas, was assumed to be intrinsically separated from making sense of the stories of others, finding and expressing meaning in his or her own experiences, communicating thought through symbols, or deriving joy from critical, reflective engagement with printed language and other symbol systems. In short, all children were considered literate. "I see them as all readers and writers," Nicholas's teacher told us. "Our job is to get [the children] to see themselves that way."

Robbins' use of the pronoun *our* was no accident. At Shoshone, promoting children's active community participation, the very heart of the curriculum, was itself a collaborative manifestation of active participation on the part of the entire Shoshone

community. During a research observation on a Wednesday afternoon, a time reserved for group meetings and faculty discussions, we noted Robbins asking one of the classroom's paraprofessionals, Stacie Hill, "Did you get a hold of Dora [Nicholas's mother] about the child-of-the-week?" Hill responded, "Yeah, I had left a message, but she caught me in the hall this morning and it's a 'go'." A language therapist who attended the meeting said, "Someone will need to take Nicholas down early so he can get rid of some of his energy."

The team of adults was discussing how best to support Nicholas as the focus during a show-and-tell time called child-of-the-week. A child's name was randomly chosen and that child brought in a favorite book to read, photos, and other mementos of choice that were displayed and discussed at a class meeting. This was still early in the school year and Nicholas remained extremely resistant to joining whole class meetings. Any effort at coercing him into such a context resulted in tantrums, screams, and a look of real terror on Nicholas's face. The question arose: How might Nicholas be supported such that he is the center of positive attention? The teaching team, in collaboration with Nicholas's parents, decided to have his child-of-the-week meeting in the hall near a display board of Shoshone student art that fascinated Nicholas. The team correctly assumed that this novel approach would excite Nicholas.

At his meeting in the hall, Nicholas held up his favorite book from home entitled *Grump* (Wong, 2001) about a very grumpy mother. His mother in attendance covered her face and said, "I cannot believe you chose that book. I tried to talk him out of it." Nicholas let out a laugh as did all the adults at the meeting. Later, when asked if she thought Nicholas's smile conveyed understanding of his mother's chagrin at the topic of his favorite book, Robbins shrugged and said, "It sure seemed like it." Robbins continued, "Did you see that when he held up the book he had it facing the kids the right side up so they all saw. He totally knows," meaning he was aware of certain early literacy ideas that are collectively termed *book skills*, including skills like holding the book correctly, differentiating text and illustrations, and following front-to-back, left-to-right, and top-to-bottom orientation.

If Nicholas's classroom team and mother had approached him from a conventional perspective on significant disability, his resistance to joining the group in the classroom may have eliminated his potential to be the child-of-the-week. Importantly, because organized literacy activities commonly occurred during circle time in the classroom, Nicholas's literate presence may have been severely obscured by his inability to join the group. Instead, a dialogic reflective of Freire's (1970), *conscientização*, occurred through which Nicholas was constructed as a literate child, but in need of different kinds of support than his classmates tended to require. According to Freire's literacy pedagogy, *conscientização*, born of and furthering a collective dialogue, is a deep awareness and enactment of the right to democratic participation on the part of individuals who have historically been silenced. Freire, with his colleague Macedo, noted that it is the process of active, valued participation that fosters literacy: "Reading the world always precedes reading the word" (Freire & Macedo, 1987, p. 29).

In Nicholas's classroom, the collaborative, democratic nature of the dialogic occurred on two levels. First, multiple voices belonging to adults who had direct, immediate, and deep roles in Nicholas's daily life converged to better understand and imagine Nicholas's literate participation in the classroom. Second, Nicholas's own communication contributed to the dialogic. While his actual voice may have been difficult to understand, his behaviors were read and interpreted from the perspective of supporting his participation in valued activities. Thus, his resistance to joining the group was not interpreted as Nicholas not belonging; rather, his behavior meant only that joining the group required new ways of imagining how Nicholas would be supported as a full citizen of his classroom community. The result was an enriched literate experience for all the children. This last point is extremely important because valued citizenship means contributing to the community-life of the group. Nicholas did just this in many ways, including bringing sets of skills to an activity that was enriched when it was modified in ways that caught the attention and excited the imagination of his peers.

The multileveled dialogic immediately surrounding and involving the person with significant disabilities is consistently evident in our studies of the experiences of individuals who defy categorical presumptions that they cannot become literate. Larry Bissonnette [actual name] provides a further example of this. Now in his forties, Bissonnette is a recognized Vermont artist and the focus of a recent documentary (Biklen & Rossetti, 2005), but spent his formative years in the Brandon State Training School, an institution for people labeled severely mentally retarded. At age 18 he was moved from Brandon to Waterbury State Hospital, another horrific site of filth, disease, and abject despair.

Bissonnette was born with autism. His spoken language is often nonsensical, repetitive, echolalic, and explosively impulsive. He was born in an age when institutionalization was the common response to the presumption of severe intellectual disabilities. He now types on a keyboard spelling out words to communicate in a more clear, reliable, and dramatically sophisticated fashion than his speech allows. He has noted, "I rely on typing for my personally important ideas" (Biklen & Rossetti, 2005). Initially, while learning to maneuver his hand across a keyboard, Bissonnette required physical support at the hand from a nondisabled partner, a controversial technique we have used and studied extensively referred to as *facilitated communication*. Those who have attended Bissonnette's frequent presentations before a professional audience know he now types with a mere touch on the shoulder or, at times, no support at all. As such he has joined what Mirenda described as a growing number of people "who once relied on facilitation (i.e., physical support of the hand or arm or emotional support) to type but are now independent typists" (2003, p. 273). Such independence has largely dispelled the controversy around this technique.

Like the collaborative dialogic that surrounded Nicholas's valued ascension to full citizen of his inclusive preschool classroom, Bissonnette's journey from institution inmate to artist and literate citizen emerged out of a dialogue that began when his sister, Sally Verway, went to see him at the Waterbury State Hospital where security guards had to escort her through the halls. In a documentary about Bissonnette, she recalled, "I saw Larry in awful condition—all medicated, sitting on the floor, legs crossed, banging his head on the wall" (Biklen & Rossetti, 2005). A distant, cultural interpretation of significant disability commonly

suggests this is simply a mirror of the category, an apt reflection of how things are and how we imagine they must be. Verway, however, brought local insight to the horrific scene. With the assistance of a small group of people who would eventually include among others an art teacher and an employee of a community-based disability-support organization, Bissonnette was freed from the institution and joined the wider community.

Given societal stereotypes of significant disability, it may seem startling that the efforts of this small group to support Bissonnette's valued citizenship focused any energy at all on literacy and artistic expression through paint, drawing, and photography. However, Bissonnette described the people who support him on a daily basis as "less worried about ... [my] peculiarities and more attuned to my potential" (Biklen & Rossetti, 2005). Sally Verway pointed out that her brother's communication, even when it was most difficult to decipher, was brought into the conversation in order to imagine in more complete fashion his full involvement in the community. She noted that in the institution,

[Larry] used to get up in the middle of the night, sneak into the kitchen, steal a butter knife, pick a lock, go into the sewing room, take all their brand new sheets at the Brandon Training School and make curtains. He sewed them by hand. (Biklen & Rossetti, 2005)

While at the institution this was considered rule-breaking, to Bissonnette's sister it was a sign of his creativity and ingenuity. Both Bissonnette and young Nicholas at the Shoshone School developed as valued citizens, but did so precisely because they found their way into an immediate, humanizing dialogic absent from U.S. policy efforts to improve language instruction.

#### LITERATE CITIZENSHIP ENVISIONED

The local dialogic supports in its originating community the capacity to *envision* literate citizenship where others caught in dominant perspectives cannot or will not. If Nicholas at Shoshone or Larry Bissonnette in Vermont had been solely judged based on disability conventions, the two certainly would have struggled to find their way into a valued literate community. Instead, immersed within local understanding, each was envisioned as capable of literacy: they were interpreted as individuals with stories and experiences of their own, with the imagination required to develop a connectedness with the stories and experiences of others, and with the capacity to contribute meaningfully to the community.

Nicholas, as described in the introduction to this article, was immediately revealed to our research team as a child with the determination and imagination required to connect symbolically with others. From that moment forward we observed hundreds of instances in which Nicholas was supported to build and express his story, whatever it might be, in connection with those around him. For instance, he was frequently found with other children pulling on various hats, helmets, and other forms of dress-up attire made available in the classroom. At one point he had on a fire fighter's helmet, a long dress, several necklaces, and was steered into a grocery store set up by a peer who announced to the child at the toy cash register, "We're robbing this place. Give us the money!" Rogow has noted that "sharing meaning through play, storytelling, and other life events is an important building block to literacy. By pretending, children learn to create and share meaning with other children" (1997, p. 10).

Larry Bissonnette has described how disability labels acted to obscure others' vision of his imaginative potential. He has typed, "Lore around autism uses situations of incompetence to predict what little potential people have to learn creative and artistic skills" (Biklen & Rossetti, 2005). Commenting on what followed his escape from the institution, Bissonnette noted, "I began painting," an endeavor of passion that had been shut off throughout his earlier life. His sister, Sally Verway, noted on his exit from the institution, "He wasn't an animal anymore. People could view him as a human being."

Alberto Frugone [actual name], also pointed to the importance of being envisioned as a literate citizen (Frugone, 2005). He was born in Italy in 1978 and was labeled autistic at age two-and-a-half. The label *mental retardation* quickly followed and Frugone was steered by professionals into segregated education with extremely restricted access to literacy. Years later, Frugone, who communicated via a keyboard rather than through speech, recalled of his segregated schooling, "I was sort of a piece of furniture in the classroom. I was engaged in senseless occupations all day long. I was unreachable. Nobody knew what to do with me" (2005, p. 183).

Frugone's mother, Patrizia Cadei, never wholly bought into the official interpretation of her son's near-complete incapacitation. She envisioned ability and imagination where others could not, and when he was a young teenager she contacted us based on research we were conducting into communication and literacy. According to conventional expertise, a cardinal feature of autism is a severe impairment in imaginative capacity (see American Psychiatric Association, 2004). Frugone, however, proved able to learn to read and type and has, over time, demonstrated an ability to imaginatively solve problems within contexts of local understanding. For instance, he struggled with auditory processing of information so decided, in effect, to "train," as he called it, his hearing (Frugone, 2005, p. 192). Frugone had his mother "tape at first some sounds from the environment including birds, water, bells, a passing car, a slammed door, and so on" (p. 192). Frugone then listened to the tapes and listed the source of sounds using his keyboard. In this self-initiated manner, he began to sort out the sounds of everyday life he experienced in such convoluted, overwhelming, and jarring ways.

#### ENACTING CITIZENSHIP

In following historical trends, current education policy simplifies and makes rigid the context of early or initial literacy: standardized assessment and standardized instruction in phonics serves as the rule. The New York City and Boston school districts were forced by the federal government to abandon their primary grade reading programs that incorporated actual children's literature for a programmed phonics approach. The federal threat to pull millions of dollars from the two districts occurred,

despite better test results associated with the former reading programs (Herszenhorn, 2004). In contrast, local understanding supports a complex approach to enacting a student's literate capacity. To do so, the responsive literate context must be individually meaningful, must recognize literacy as a social tool for connecting the students to one another and to larger cultural discourses, should weave a range of symbol systems into the person's expressive experience, and must recognize the human dignity that can only come from confronting reasonable intellectual risk in the classroom and beyond.

Shayne Robbins, Nicholas's Shoshone teacher, wove these elements into all of her students' early school experiences. For instance, one child in her class, Isaac, born with Down syndrome, entered Shoshone at age 4 a few months into the school year. Robbins had made two visits to Isaac's home to meet the family and ease Isaac's transition into the preschool. From those visits Robbins learned about Isaac's passion for books by the children's author, Maurice Sendak, including his classic *Where the Wild Things Are* (1963) about a boy, Max, who dreams of sailing to a land inhabited by monsters. On Isaac's first day of school, Robbins brought out the book. The children listened intently to the familiar story and Isaac sat, a stuffed Max character in his arms, gleefully awaiting each turn of the page. When Robbins got to the illustrations where the character Max engages in a dancing *rumpus* with the Wild Things, Isaac could no longer contain himself. He leapt to his feet and began dancing along with the book. Rather than demanding Isaac take his seat, Robbins had all the children start rumpusing! We observed the spinning, giggling children with a degree of wonder, having never considered the possibility of dancing to books at all.

Isaac had started the school year in a segregated early childhood special education setting for students with severe disabilities. His parents had pulled him out after becoming frustrated with the personnel's seeming inability to recognize Isaac's learning strengths. "He was just a defect to them," Isaac's mother said in a research interview. Amazingly, within one hour of starting school at Shoshone, Isaac had directly influenced the choice of literature, had shown his ability to be part of a group of fellow preschoolers, and had demonstrated dance and movement as a mode of symbolic communication that could augment and enhance text and illustrations. In doing so, Isaac took on the role of leader and experienced great joy. All this occurred because Robbins and her teaching team developed a context that was meaningful for Isaac, that recognized literacy as a social tool for connectedness, that supported multiple symbolic systems of expression, and that allowed for reasonable intellectual risk. Here, the risks taken included, among many, the demand by Isaac's parents that their child exit the segregated realm of severe disability and enter an inclusive setting.

These same themes related to a responsive literate context emerged time after time in our research on local understanding. They also appear in published, autobiographical accounts of the experience of significant disability. For instance, in the Academy Award-winning documentary, *King Gimp* (Whiteford & Hadary, 1999), Dan Keplinger, who wrote the script, described being placed as a young child in a segregated education facility for students with severe disabilities. Born with significant physical disabilities that affect his ability to communicate, Keplinger noted, "No one could understand I was an intelligent person inside of this body;" no one but Keplinger's mother, Linda Ritter, who began what Keplinger described as "the battle" to get her son in an inclusive setting when he was 14. Ritter explained, "The [segregated school] psychologist had said that Dan was not capable of handling a mainstreamed environment...They wanted to maintain and keep him in a special education setting. So I took it upon myself to start making phone calls to some local high schools." This is a seemingly strange task for a mother to be forced to take on, but Ritter found a public school that would accept her son. After his first day, she described him coming home in tears and she had lamented, "They told me he would fail and here he was failing."

The school experience, however, quickly improved primarily because Keplinger found art: "The best thing that ever happened to me," he explained. Like Bissonnette's experience, in the segregated facility Keplinger had never been exposed to the symbolic patterns of artistic expression. At his new school, he began to draw and paint by attaching charcoal or a brush to a pointing device strapped to his head. The high school art teacher noted in the documentary that his first response to Keplinger was, "How do we move Dan out? He doesn't really belong here." The teacher concluded, "Ultimately, we realized we could adapt," meaning the environment could be made more conducive to Keplinger's needs.

Keplinger's symbolic presence expanded in the inclusive high school art class. His art teacher explained in the documentary, "With the head stick, you know, it's his head writing. The same as calligraphy or handwriting like my own writing. And so he has his headwriting which are his marks...It's descriptive and for those who want to read it I believe there is a lot of communication on so many levels." Keplinger noted, "Art gave me a way to express myself without anyone interpreting for me." In effect, he found his way into a context previously denied precisely because it was individually meaningful, promoted his symbolic connection to the wider community, and supported his dignity in a manner never before experienced—all because he and his mother together took a risk in order that Dan's literate and broader citizenship be recognized.

#### CONCLUSION: TOWARD A LITERACY POLICY BASED ON SOCIAL JUSTICE

Recent policy proposals aimed at improved literacy in public schools have been linked by their advocates to civil rights. With the passage of *NCLB*, for instance, George W. Bush connected the mandate that "every child read at grade level by the end of third grade" to his contention that "reading is the new civil right" (Bush, 2004). Of course, the conjoining of literacy with full, democratic citizenship predates *NCLB* by centuries. The great abolitionist Frederick Douglass (1845/1987) described his revelation while still a slave that control over written language served as "the white man's power to enslave the black man" (p. 275). Douglass continued, "From that moment, I understood the pathway from slavery to freedom...Though conscious of the difficulty of learning without a teacher, I set out with high hope, and a fixed purpose, at whatever cost of trouble, to learn how to read" (p. 275). The cost, if discovered, was penalty of death (Kluger, 1975).

In describing the utter depths of degradation to which he had fallen prior to his conversion to Islam, Malcolm X said, "The streets had erased everything I had ever learned in school; I didn't know a verb from a house" (Haley & X, 1964, p. 151). His path out first

began in 1947 in prison as he learned to read and write: "After about a year, I guess, I could write a decent and legible letter" (pp. 154-155). He then began a correspondence course in Latin to better understand the origins of English. Malcolm X was initially inspired in his effort toward literacy by a fellow black prisoner named Bimbi who was able to orate on many topics with great depth and hold the attention of black and white inmates as well as the white guards. Malcolm X explained, "I wasn't the first inmate who had never heard of Thoreau until Bimbi expounded upon him. Bimbi was known as the [prison] library's best customer. What fascinated me with him most of all was that he was the first man I had ever seen command total respect...with his words" (p. 154, ellipse in original).

In her critical analysis of the 1954 *Brown v. Board of Education* school desegregation case, Prendergast stated, "Until the middle of the twentieth century, the dominant U.S. educational policy was to use whatever means possible, including the force of law, to restrict access to literacy for African Americans and to preserve it for Whites" (2002, p. 206). Into the 1950s it was estimated that more than one-in-four African Americans could not read or write (Kluger, 1975). The NAACP strategy in *Brown* focusing on integrating public schools was in part a recognition of the cultural links among education, literacy, and democratic citizenship. When the five lower court cases subsumed as *Brown* came before the U.S. Supreme Court, the lawyer defending South Carolina's segregated school system, John W. Davis, stated in his opening argument:

May it please the Court, I think if the appellants' construction of the Fourteenth Amendment should prevail here, there is no doubt in my mind that it would catch the Indian within its grasp just as much as the Negro. If it should prevail, I am unable to see why a state would have any further right to segregate its pupils on the ground of sex or on the ground of age or on the ground of mental capacity. (Quoted in Friedman, 1969, p. 51)

John W. Davis's hyperbole before the Court was the losing side's fearful recognition that indeed *Brown* had potentially far reaching consequences. The end to segregation of one disenfranchised category of children might well result in the equal protection of all America's children including African Americans, Native Americans, females, and, just maybe, children with presumed intellectual disabilities. Thus historically devalued students potentially would be guaranteed equal opportunity to access crucial cultural tools for community and societal participation, including—most prominently—literacy.

In an ironic twist, seventeen years later Davis's words were used to end the segregation of children with disabilities from public schooling. Attorney Thomas Gilhool, acting as counsel to the plaintiffs, included the Davis's words in the initial memorandum filed in the 1971 *Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania*. (Lippman & Goldberg, 1973). This was the original *equality of access to education* court case for students labeled with intellectual disabilities and would influence Congress in 1975 to pass the civil rights legislation known today as the Individuals with Disabilities Education Improvement Act which mandates that all children, including those with disabilities, receive an appropriate education at public expense.

Translating the hazy federal notion of *appropriate education* into its required complexity of local forms, however, has proved difficult not only for children with disabilities but for all children at the margins whose education is most reliant on, and most vulnerable to, national mandates. In large part we believe this reflects a lack of interest in educational complexity on the part of policy makers who substitute in its place ideological frames (Lakoff, 2004) that have nothing to do with actual children and how they individually learn. Thus a bill such as *No Child Left Behind*, focused as it is on "low-achieving students in our Nation's highest-poverty schools, limited English proficient children, migratory children, children with disabilities, Indian children, neglected or delinquent children, and young children in need of reading assistance" (p. 16), turns early or initial literacy for students from these categories into a mass exercise in back-to-basics phonics as the rhetorical panacea for a nation said to be at educational risk. This, in turn, is framed by its advocates as the new civil right.

Of course, civil rights is about valued societal access and full citizenship, not the mandating of a singular professional ideology for marginalized children. What we have learned in observing the literate development of individuals conventionally considered to be hopelessly illiterate is that the path to critical reading and writing skills involves a range of approaches grounded in a deep sense of the learner garnered through a dialogic on the part of the surrounding educators. In this sense, the complexity reflected in local understanding is in full agreement with Delpit's (1988) now classic, often misunderstood, contention that, when educating *other people's children* (p. 280), it is imperative that students be exposed to whatever is required for their success. Thus, if direct instruction in specific skills is necessary for the literate development of a particular student, he or she should be provided that forum. Delpit described this as "ensuring that each classroom incorporates strategies appropriate for all the children in its confines" (p. 287). She warned, however, "I do not advocate a simplistic 'basic skills' approach for children outside of the culture of power. It would be (and has been) tragic to operate as if these children were incapable of critical and higher order thinking and reasoning" (p. 287). Delpit concluded:

To summarize, I suggest that students must be *taught* the codes needed to participate fully in the mainstream of American life, not by being forced to attend to hollow, inane, decontextualized subskills, but rather within the context of meaningful communicative endeavors; that they must be allowed the resource of the teacher's expert knowledge, while being helped to acknowledge their own 'expertness' as well; and that even while students are assisted in learning the culture of power, they must also be helped to learn about the arbitrariness of those codes and about the power relationships they represent. (p. 297).

Delpit's work (1988) emerges from the literate netherworld of students at the educational margins, as does local understanding. Can social policy ever be made to reflect the complexity required to foster a truly literate citizenry? If so, it would require providing the resources necessary to promote the revolution that local understanding could create in classrooms and communities across the United States: Excellent educators in dialogue with one another and families, imaginatively crafting responsive contexts built on the full presumption that all children can be understood as competent and can grow in sophistication as literate citizens.



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