International Journal of Inclusive Education

Publication details, including instructions for authors and subscription information:
http://www.tandfonline.com/loi/tieg20

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To cite this article: Douglas Biklen & Christopher Kliewer (2006): Constructing competence: autism, voice and the ‘disordered’ body, International Journal of Inclusive Education, 10:02-03, 169-188

To link to this article: http://dx.doi.org/10.1080/13603110600578208

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Constructing competence: autism, voice and the ‘disordered’ body

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Definitions of intelligence have traditionally been rooted in literacy competence. In this article, the authors examine two historical examples where societal prejudices and institutional forces worked to limit and regulate access to literacy. The first example illustrates how racism and denial of competence were so profoundly linked and established in 18\textsuperscript{th} century America that author and poet Phillis Wheatley was forced to go before a tribunal to demonstrate her faculties. The second example concerns Helen Keller. She too was, on more than one occasion, presumed a fraud and had her literacy interrogated. The authors then identify contemporary instances of societal monitoring of who may be literate, drawing especially on experiences of individuals classified as autistic. Based upon these examples, the authors examine the connection between perceptions of communicative competence and understandings of intelligence and mental retardation.

In October 1772, in Boston, Massachusetts, 17-year-old Phillis Wheatley went before a tribunal comprised of 18 white men. Her judges included the Governor, the Lieutenant Governor, as well as a prominent, quite successful businessman by the name of John Hancock, and James Bowdoin, founder of Bowdoin College.\textsuperscript{1} Wheatley was a slave, having been wrenched from the coast of West Africa, what is now Senegal and Gambia, and transported across the Atlantic on the tightly packed slave ship the \textit{Phillis} (Robinson, 1982). Wheatley, purchased by elite Bostonians John and Susanna Wheatley, spoke no English when brought ashore in chains at age 7. No one knew her name; Susanna apparently thought it appropriate to name her after the brutal ship on which she had been captive. Wheatley would years later write in verse: ‘I, young in life, by seeming cruel fate! Was snatch’d from Afric’s fancy’d happy seat’ (repr. in Renfro, 1916, p. 80).

Within 16 months of being bought, and with only minimal instruction from the Wheatley's teenage daughter, Phillis had mastered spoken English and was learning to read (Gates, 2003). As early as 1765, merely 4 years after being enslaved, she wrote

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ISSN 1360 3116 (print) ISSN 1464 5173 (online) 06 02 30169 20
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DOI: 10.1080/13603110600578208
her first poem and was instructing herself in Latin. Her owner, John Wheatley, remarked that it was her 'curiosity' that led her to literacy 'in so short a time' (written in 1773; repr. Renfro, 1916, p. 16). By age 17, Wheatley had written hundreds of poems, 28 of which her owners desired to publish as an anthology. But how could they? Debates throughout Europe and the American Colonies questioned Africans' competence. In the mid-18th century, the famed Scottish philosopher and historian David Hume, for example, declared 'Negroes naturally inferior to the whites' and incapable 'of either action or speculation. No ingenious manufacturers amongst them, no arts, no sciences' (Hume; repr. 1963, p. 213). Similarly Immanuel Kant, the Prussian philosopher, wrote: 'So fundamental is the difference between [Africans and Europeans] and it appears to be as great in regard to mental capacities as in color' (1763/1960, p. 111). The presumption of intellectual incompetence was at the time, as it often is today, linked to perceptions of communication. As Gates (2003) writes, the question of humanity 'turned on whether or not Africans could write' (p. 26). If Phillis Wheatley would be recognized, even adjudicated as a person of letters, Gates argues, what would this say about prevailing categories of humans and subhumans on which slavery was justified? Wheatley was, in Gates's words, 'auditioning for the humanity of the entire African people' (p. 27) when put before the tribunal of 1772.

One hundred and twenty years later, also in the city of Boston, 11-year-old Helen Keller, blind and deaf, was brought before a similar tribunal (Keller, 1954). Her court of investigation was composed of nine high-level administrators at the Perkins Institution for the Blind, including its nationally known Director, Michael Anagnos. Keller had lost her sight and hearing, presumably as the result of a severe fever just after her first birthday. So disabled was she that most of the extended Keller family as well as friends assumed she had lost her potential to reason. Less widely realized today is that even before Anne Sullivan arrived on the scene, Keller in fact had invented a host of signs with which she communicated to those family members who were willing to grant her some competence. She had fashioned at least 60 gestures and pantomimes to communicate with her parents particular needs and wants. She would hold her hand out and the brush across it with her other hand, indicating the action of spreading butter over bread; and she would shake her body and then mimic cranking a lever or wheel, to indicate the actions required for making ice cream (Lash, 1980). Apart from her mother and a daughter of the family's maid, however, Keller's intelligence and social drive were largely ignored based on the presumption of stalled development, obliterated ability and global defect. Keller's uncle demanded of her mother: 'You must put that child away [in an institution]. She is mentally defective and it is not very pleasant to see her about' (quoted in Lash, 1980, p. 69).

The story that followed is well known. She was just 6 when she learned to communicate. She would later recall:

As the cool stream gushed over one hand, [Anne Sullivan] spelled into the other the word water, first slowly then rapidly. I stood still, my whole attention fixed upon the motions of her fingers. Suddenly I felt the misty consciousness as of something forgotten... a thrill of thought; and somehow the mystery of language was revealed to me.

(Keller, 1954, p. 36)
Keller's biographer, Lash, describes her emergence into the world of spoken and recorded words as rapid:

> The speed of Helen's progress in the acquisition and use of words does seem remarkable. It was as if Annie's turning of the key to her mind had released the word-hunger that is characteristic of children Helen's age in whom impressions outrun vocabulary. For years the process of matching impressions to words had been dammed up, and now she was furiously fitting labels to experiences that were stored up somewhere in her memory.

(Lash, 1980, p. 75)

Sullivan suggested the flood of language was Helen 'awakening from a dream' (quoted in Lash, 1980, p. 75). By age 8, already known internationally, Keller was studying French and, like Wheatley, was just beginning to learn Latin.

At age 10, Keller ventured into writing fiction, penning a short story entitled *The Frost King* as a birthday gift for Michael Anagnos, Director of Boston's Perkins Institution for the Blind. As it turned out, the similarity of this story to an already published one, by another author, precipitated her being before a tribunal. The rapidity of Keller's learning was apparently unbelievable to some, and the similarity of Keller's story to another seemed to give license for a public airing of such scepticism.

Here it is instructive to note that the accusation of 'parrot' was one commonly hurled at Wheatley and her poetry (Gates, 2003). If she indeed scribbled the words on paper attributed to her and was able to recite those words when called upon, so the allegation went, it was not an act of creation but one of rote response to the cues and signals of others. She was *nothing but a parrot*. Through this frame, the status quo of the slave as subhuman, incapable of real literacy including imagination, transcendence, and critical reasoning, could be maintained.

The charge of parroting was similarly directed at 10-year-old Keller. Suddenly, she was labelled a plagiarist, a fraud, and a dupe of her teacher, Anne Sullivan. In a *New Yorker* article, Ozick (2003) notes that throughout her life Keller battled accusations that she merely 'parroted words' (p. 188) and that her teacher, Sullivan, was little more than a 'ventriloquist' (p. 190). Even a sizeable group of faculty at Perkins felt Sullivan deceived the public and the profession, by misrepresenting Helen's abilities (Lash, 1980). Perhaps it is because of the undercurrents of incredulity that surrounded both Wheatley's and Keller's explosive emergence into communicating, or indeed that they could be literate at all, that they could be so easily transformed from youthful writers, and published authors, to suspected plagiarists, parrots, and frauds.

And so the respective tribunals went forward, with Wheatley and Keller each led alone before their inquisitors, lest there be any chance of signalling or other influence in their communication — in a later part of this article we will show how this practice of isolating and testing the individual before a tribunal is still with us today, e.g. in the case of one Anne McDonald (Crossley & McDonald, 1980). In Wheatley's case, her owner thought that if she could have her literacy validated then she could find a reputable publisher for her writing. Would that it were so.

The panel of 18 subsequently crafted a statement of authenticity, so to speak, which all signed. It read in part:
We whose Names are under-written, do assure the World, that the Poems specified in the following Page, were (as we verily believe) written by Phillis, a young Negro Girl, who was but a few Years since, brought an uncultivated Barbarian from Africa. ... She has been examined by some of the best Judges, and is thought qualified to write them.

(Renfro, 1916, p. 17)

Perhaps not surprisingly, given the dominant ideological stance of a society in which slavery had its prominent apologists, Wheatley did not experience any 'ol'ly ol' income-free' (Vonnegut, 1979). Even with the statement and signatures of the best Judges in hand, John Wheatley could not convince Bostonians or the Boston publishing houses that Phillis was in fact other than a barbarian and that she could be capable of poetic literacy. He and his wife Susanna subsequently found a publisher in England willing to risk releasing the first book of poetry in English by a person of African descent, *Poems on Various Subjects, Religious and Moral* (1773). The statement of authenticity by her 18 inquisitors prefaced the volume and was considered by its publisher to be essential if the book was to sell at all (Gates, 2003).

Keller’s victory would be more narrowly drawn. As Hermann interprets, she was, in effect, put on trial ‘by ... the very people who purported to help her communicate with the outside world, but who fought to possess her as if she were an exotic specimen’ (Hermann, 1998, p. 85). The night before the inquest, with her teacher having been consigned the status of an accused perpetrator of fraud, Keller (1954) recalled, ‘I felt so cold. I imagined I should die before morning, and the thought comforted me’ (p. 65). And apparently even the dire consequences that might accrue to being seen as a pawn or parrot did not render Keller silent about the importance of allies. Far from declaring herself an independent, autonomous self, she honoured her close, productive relationship with Sullivan and all that she had learned through her assistance:

My teacher is so near to me that I scarcely think of myself apart from her. How much of my delight in all beautiful things is innate, and how much is due to her influence, I can never tell. I feel that her being is inseparable from my own, and that the footsteps of my life are in hers. All the best of me belongs to her — there is not a talent, or an aspiration or a joy in me that has not been awakened by her loving touch.

(Keller, 1954, p. 47)

Thus, ironically, although quite predictably, the tribunal was set to judge Keller’s independence even as she acknowledged her connectedness to those around her, especially to her teacher. By her own accounting, this was no moment of triumph:

I felt in every question the doubt and suspicion that was in their minds, and I felt too that a loved friend [Michael Anagnos] was looking at me reproachfully. ... The blood pressed about my thumping heart, and I could scarcely speak except in monosyllables. ... (W)hen at last I was allowed to leave the room, I was dazed and did not notice my teachers caresses, or the tender words of my friends who said I was a brave little girl.

(Keller, 1954, p. 65)

Eventually, four judges concluded that Keller was competent of creating the story attributed to her and had not been a mere parrot of Sullivan’s, while four other judges voted her a fraud. Anagnos broke the tie, siding temporarily with those who felt Helen
had validated her abilities (Keller, 1954). Within a year of the inquisition, however, he was publicly decrying her as 'a living lie' (quoted in Lash, 1980, p. 168). Other accusations of fraud would follow, naming her 'a dupe of words' whose writing was 'a matter of auto-suggestion' (Desmeserets; quoted in Lash, 1980, p. 571). No matter that Keller would later graduate from Radcliffe and proceed to influence the course of suffrage, civil rights, workers' rights, to say nothing of disability rights was no living lie or dupe.

Disability, literacy, and questions about competence/incompetence: two centuries after Wheatley

At this point we want to explore the implications of Wheatley and Keller's experiences to recent Disability history, and to do so somewhat autobiographically. Sadly, Wheatley and Keller's experiences of 100 and 200 years past have strong parallels in events and ideologies of today.

As a young graduate student in 1969, the first author of the present paper happened on an announcement of a lecture entitled 'Human Abuse in Institutions' to be given by Burton Blatt. The topic of that lecture was new to him, and probably to the rest of Blatt's audience as well, for it concerned institutional abuse of people labelled mentally retarded. Two and a half years earlier, Blatt had begun a national awakening about the horrific conditions in US mental retardation institutions through his publication of Christmas in Purgatory (Blatt & Kaplan, 1966). In a lecture given recently at the Pennsylvania State University's Rock Ethics Institute, the first author recalled his lack of awareness about the politics of disability at the time of hearing Blatt speak:

I had not yet read the official definitions of mental retardation. I did not know there was more than one definition or that definitions of mental retardation had changed over the decades during the 20th century.

I thought of mental retardation as something physical, basically immutable, and more or less tragic or, at least, reason for discouragement.

I had never linked Helen Keller or race to debates about or definitions of intelligence — I had not yet heard of Phillis Wheatley.

I was woefully ignorant about the existence of institutions for people labeled mentally retarded.

I did not think of mental retardation as a site for struggle over human rights.

The point is that 'mental retardation' is not a topic that most people have thought a lot about, unless they have a family member or close acquaintance that has been so classified. Psychology and social science courses often cover the testing movement history during the 20th century, but its far less common for such courses to examine the relationship of this to forced segregation in education or of sterilization and incarceration of thousands of people labelled mentally retarded, all of which are predicated on estimations of intellectual incapacity.
Blatt got the audience's attention. He showed pictures of mental retardation institutions. His slides included barren, but overcrowded sleeping quarters, stark day rooms devoid of any reading materials or other evidence of literacy, physical restraints and other forms of dehumanizing treatment. Blatt's analysis was at once both shocking and exciting. He spoke in a narrative that echoed the civil rights movement. There was nothing in his rhetoric that suggested people should have to prove themselves before winning opportunity. His was an altogether democratic message: 'If there is hope', he wrote, 'it is not in any improvement in institutional life — imprisonment and segregation can be made more comfortable, but they can never be made into freedom or participation'.

Looking back at Blatt's writing during that period, some of it now seems almost romantic, though it was refreshingly political for a field that often acted as if political ideology did not exist: 'What we must learn from the nightmare of institutions', he wrote, 'is that ... to have a decent society we must behave as decent individuals'. His was an earnest call to side with the incarcerated and to challenge the professional community, those who kept quiet about or apologized for what went on inside them. In contradiction to the field of mental retardation that then, as now, seemed to mete out opportunity or lack of it through crude labels of perceived impairment levels — in Blatt's day it was 'profound', 'trainable', 'educable'. Blatt broke with the cultural rules of his time when he abandoned the individualizing, psychological for a socio-political frame. His remedy for legally sanctioned abuse was not for science to sort out who should and should not be incarcerated, but to free everyone from assault and battery and forcible detention that institutions perpetrated in the name of treatment.

The most profound lesson from Blatt was his warning that mental retardation is but a metaphor. It would be years later that we came to see how terribly dangerous and disenfranchising this particular metaphor is. Neither of us has yet met a person who chooses to be called mentally retarded, though sadly, we have met people quite willing to place that appellation on others.

Following Blatt's lead, both of us began to work on issues of educational rights; it was obvious that children ended up in institutions shortly after they had been forcibly excluded from public education. For the first author — keep in mind that this was before passage of the Right to Education for All Handicapped Children's Act, later renamed the Individuals with Disabilities Education Act — this work was involved getting children into school, closing down disability-only, segregated schools, and creating classrooms occupied by students with and without disabilities, what is today often called inclusion. As our colleague, the sociologist Robert Bogdan remarked and then wrote, asking whether mainstreaming is a good idea is a silly question (Bogdan, 1983). Asking that question is like asking whether Tuesday is a good idea. Rather the question we asked was how to foster integration. What form would it take? Along this line of reasoning, as with his analysis of institutions, Blatt liked to say that mainstreaming or integration were not for science to anoint. Whether or not to support integration was a matter of morality, not of science. Blatt's was a distinctly different position than most of the rest of the field adopted. Even lawsuits, in that era and since, have been predicated on the notion that professionals, albeit with parents' input,
would determine how much inclusion was possible. Blatt also understood that looking for others to change their ways was not sufficient — for instance it would be disingenuous to expect schools to change society's ablest attitudes about intelligence; it would be a kind of artful dodge from personal responsibility.

Beginning in the late 1980s, we awoke to the importance of communication. This resulted from observing classrooms in which teachers were doing what was at the time called 'mainstreaming' (later termed 'inclusion') and also from reading books about communication breakthroughs, especially Rosemary Crossley and Anne McDonald's classic Annie's Coming Out. This book led one of us to go to Australia to conduct an observational study of something called facilitated communication, reported by Biklen (1990).

Facilitated communication is a form of augmentative and alternative communication that involves using physical support to overcome unreliable pointing skills and problems with speech and thus to aid individuals with autism and other developmental disabilities to communicate by pointing (Crossley, 1994). The method has been controversial. A familiar charge is that those said to use it are merely parrots or worse-yet dupes of a clever-Hans-style prompting. Thus, many school districts, human service agencies and the like have demanded evidence that a person was independent of influence before they would be supported to use the method. That there is a 'Catch-22' involved here should be obvious: be independent before being allowed to try the method. At the same time, a number of recent studies do offer support for the method's validity.

Having just reviewed the Keller and Wheatley ordeals, criticisms of facilitated communication will sound familiar, if now couched in present-day objectivist vocabulary of scientism. Recently, Mostert (2002) compared Nazi-era pseudoscience and the consequential atrocities and genocidal murder of people with disabilities from 1936 to 1945 to what he calls 'the unfortunate history of facilitated communication' (p. 166). Mostert explains this astonishing comparison of a form of augmentative communication to Nazism as such:

(Facilitated Communication's) FC's proponents have attempted to legitimize their claims with 'research,' which on closer examination is shot through with serious problems of validity and logic (Mostert, 2001). The results of these actions were extremely damaging, both practically and ethically, to many of the people FC was supposed to assist. The reaction of many members of the public and media, who embraced FC based on the flimsiest of evidence, were hardly less astonishing.

(p. 166)
communicate with facilitation is plainly observable. Mostert positions himself as unaccountable when he assumes the authority of professionalism, embellished with references to science—of course, without acknowledging that this is an ideological position—never for a moment even hinting at the existence of a disability rights narrative.

Much as Wheatley and Keller found after their tribunals, even those who have proven their communication in court, as McDonald’s did in a habeas corpus action in Melbourne Australia in the late 1970s, or in research studies, have continued to live under a cloud of suspicion about their communicative competence. Thus, it is not in a state of unconsciousness or out of any belief in the autonomous individual that even in our own work invariably we feel compelled to somehow ‘authenticate’ the writing of any user of facilitation whom we quote, much as Wheatley’s publishers felt it necessary to include a preface to her book from her tribunal. Simply, to get much of our work published, we must acquiesce to the demand to authenticate the words of those we write about and with. So, for example, in *Autism and the Myth of the Person Alone,* it may have seemed necessary to announce that with but one exception the contributing authors are people who can type without physical support or who can speak the words they type, before and as they type them and after they have typed them. Further, in that text and here as well, it is reported, if knowingly in self-defence, that Beukelman & Mirenda (1998; also Mirenda, 2003) state:

> In regard to a small group of people around the world who began communicating through FC (facilitated communication) and are now able to type either independently or with minimal, hand-on-shoulder support ... there can be no doubt that, for them, (facilitated communication) ‘worked,’ in that it opened the door to communication for the first time. ... For them, the controversy has ended.

(p. 327)

No doubt it is a submission to prevailing, deficit ideology that we declare that three of the individuals with autism who we will introduce later in this article have already published prior accounts of their emergence into independent typing (Blackman, 1999; Mukhopadhyay, 2000; Rubin *et al*., 2001; Frugone, 2005) that one is featured in a research paper on learning to speak after first learning to type (Broderick & Kasa-Hendrickson, 2001) and that three of the four we will cite have appeared in documentary films (Kasa-Hendrickson *et al*., 2002; Wurzburg, 2004; Biklen & Rossetti, 2005). Admittedly and perhaps rhetorically, we must ask, is each of our talks and articles or books on this topic a tribunal on competence, held in absentia? And in showing video footage or references to studies on authorship, do we not produce a facsimile of the Wheatley book’s preface from the 1772 crowd of 18? Is this the practical reality imposed by the prejudices of our time?

**The person inside the body**

Over the past 10 years, we have corresponded with and worked with people labelled autistic who type to communicate. In their writing can be found fundamental questions about the relationship of communication to intelligence, about disability to
participation and self-definition, and about mental retardation as a social construct. It is perhaps worth highlighting that at this point our analysis becomes radical, for it directly questions not simply degrees of intelligence or degrees of literacy, but the very definition of intelligence and mental retardation. Here we enter into an area about which the Disability Studies field has not been very vocal — we suspect that critical academics' relative silence on matters of mental retardation relates to concerns about their own claims to smartness. How else to explain the persistence of the metaphor of mental retardation and its toxic effects? More about this shortly.

For this part of our analysis we will draw on the writing of four contributing authors to *Autism and the Myth of the Person Alone* (Biklen, 2005). Each is an activist in the tradition of Wheatley and Keller. Each has had his or her body linked to incompetence; each has a sharp awareness of how disability intersects with issues of social justice; and each sees him or herself engaged in a campaign to transform dominant ways of constructing intelligence.

*Alberto Frugone: competence in a world where nothing is easy*

Alberto Frugone lives with his mother and stepfather in a house far above the town of Zoalli in northern Italy on the coast of the Mediterranean. Until 2003, when he was 23 years old, he attended secondary school. He has since taken Italy's post-secondary qualifying exams and so is about to become the first non-speaking Italian classified as autistic to attend a university.

The first author met Alberto several years ago when he had just begun learning to communicate by typing. He still communicates in this way, typing slowly, letter by letter. Alberto is blind in one eye. He squints with his left eye as he types with the index finger of his right hand. Initially, when he began this way of expressing himself, he needed someone to stabilize his arm as he typed, prompting him to pull back after each letter selection. Now, however, he can type without any physical support, though he requires his mother or a teacher to sit beside him as he types; he says the presence of his mother or teacher helps him maintain attention. The words come slowly but clearly.

On a late June day when we met it was exceptionally hot. Frugone is small in stature, has deep brown, shortly cropped hair, and a square chin. On this summer day he had a brilliant tan, and was wearing a white T-shirt, blue shorts and sandals. The first author and Frugone had met many times before over the preceding 8 years and so knew that he was not a person who could walk up and shake hands. Instead, it is left to the person meeting him to say hello and hold out a hand, palm up, for Frugone to come and put his hand on top, and for the person with the hand out to do the shaking for both. The interview took place at a table on Frugone's veranda, overlooking the sea, on Ezra Pound Place; the hillside street is named for the writer who at one time lived in a villa about a half-mile away, within view of where we sat. As his mother, Patrizia Cadei, got out his electronic typewriter and placed it in front of him, propped up on its case so that it tilted toward him, Alberto put his thumb in his mouth and began sucking it. His mother told him to take his thumb from his mouth and then reached over and
flicked at his hands, as if to make sure it happened quickly. (If we say this about him, shouldn't we admit to you that one of us chews his fingernails to the quick when anxious?) With the typewriter in front of him, Alberto began to press the keys, slowly but at a regular pace. His mother translated into English as he typed in Italian.

'I am happy to reason things out with you', he wrote. He shook his head as in a tremor, squinted his eye, and typed with his right index finger, slowly. 'Do we examine only the script mistakes or do we examine the actions I have described?' The first author smiled as his mother translated these words from the Italian, for it was exciting to see him produce the words. As disabled as Alberto appears in body, the content of the text he produced was perfectly conversational. He is thin and his movements are halting in everything from typing to walking, yet in this conversation that afternoon, it was hard not to recognize that Alberto was in charge of the direction it was taking.

He had written a dozen pages earlier in the year and was now being asked to comment on them, to provide clarifications and additional examples to illustrate some of his points. We wanted him to elaborate further and especially to concretize his remarks by grounding them in the everyday. The process is reminiscent of work with university students, for here one of us was pleading with Alberto to provide more details to explain his thoughts. He writes at a high level of abstraction often leaving out or neglecting examples to illustrate his meaning. 'Give ... specifics', we 'need to be able to visualize what you are' saying. Alberto is not one of our students, but that day he might as well have been, for we wanted to say to him: 'specifics, specifics, specifics'. For us, 'you cannot be too specific'. A standard we often use to convey the level of detail needed is to imagine the reader as a film director who has to have enough concrete description in the script to be able to create scenes that the scriptwriter intended. The hope was to have Alberto let readers see what autism means to him.

By Alberto's own description, and according to our observations, physical movements, particularly sequenced actions such as getting a glass of water, eating food, or taking out his typewriter are difficult for him. It is not that Alberto has any palsy. He does not. It is just that he moves slowly and appears awkward. When grasping a spoon, Alberto uses his fingers to press it against his palm. He does not handle it with his index finger and thumb. If there is meat on the table, a dinner partner must cut it for him. He has not been able to do complex things such as cooking a meal, although he could stir a spoon in a pot. Nearly any action that requires sequencing leaves him stymied. When he walks, Alberto does so slowly — 'I take mechanical steps (short steps) if I walk alone, but if taken by the hand or the arm, I walk regularly'. On his own, he makes no quick moves. He resembles somewhat a person walking in the dark, feeling out the terrain as he goes. He sometimes flicks his fingers next to his left eye, and he often breathes shallowly. He does this when he feels anxious. It is, in his words, 'hyperventilation'.

Alberto is a person whom most autism experts and perhaps the public as well would describe as among the most disabled of all people labelled autistic. Anyone can see his extreme difficulty with movement. Anyone can observe that he does not speak. And anyone who has spent even a bit of time with him can see that without a typewriter in front of him he has quite limited ways to communicate other than to pull his
mother or other person to something he might want or with a simple gesture: 'at the
tender age of 24 I have learnt to nod and say no with my head. I have difficulties to
remember how to do it when requested and I make a big effort to do it'. But what
does halting, awkward, dissembled movement and difficulties in making gestures
connote? Many people might look at Alberto and presume that somehow there is a
correlation between physical awkwardness and impaired intellect. But they would be
wrong. If one person could embody the contradictions that seem ordinary with
autism, Alberto might be that person.

Alberto explains that his difficulties are not with thinking and knowing but with doing
or acting. Looking at his typed sentences, it is hard not to recognize that his many
physical difficulties, with speech, movement, and any other actions cannot be taken
as evidence of his intellectual abilities. His struggle seems to be in performance. When
asked to give examples of things that are hard to do and things that he finds easier, he
responded, in Italian, 'Elementare Watson'. He typed and his mother translated into
English, with him explaining that literally 'everything is hard'. With but a few exceptions,
he cannot do anything that involves more than one action, one step. Yes, he has
learned to brush his teeth, but only because of repeated practice and with much prompt­
ing, step by step, 'Open the toothpaste. Put the paste on the brush. Pick up the brush'.

Alberto's struggles with performance often leave him feeling and looking not only
tongue-tied but also body-tied — yet the implications of this are complex. How
should people who meet Alberto interpret him? Are his physical actions never indic­
ative of his thinking abilities? If they do sometimes reflect his intentions, how can the
observer know when they do and when they do not? And these practical questions
lead to larger more theoretical ones. For example, if action does not necessarily reflect
thought, what does this say about how scholars have constructed the idea of intelli­
gence? What constitutes competence? Is physically independent action a component
of intellectual ability? For that matter, is being articulate what shall be taken as smart­
ness? And, what constitutes fairness or justice for people who seek to participate in
society in ways that differ from the so-called 'normal'?

Sue Rubin: the body and the label: Rubin unpacks mental retardation

We first met Sue Rubin in the mid-1990s when, as a teenager, she was just emerging
into communication and had just moved from segregated special education into
inclusive academic classes. She is short in stature and thus appears younger than her
years. At that time, her mother held her arm as she pointed to letters on a letter board.
Several years later she developed the ability to independently point to letters on a
letter board or on a computer or hand-held communication device.

Before her teen years, Sue had been defined as autistic and retarded. She was tested
throughout her early schooling. At the age of 7, psychologists declared her to have a
'Mental Age' of 2 years 11 months on the Stanford Binet, 2 years 10 months on
the Merrill Palmer Scale of Mental Tests, and 1 year 1 month on the socialization
domain of the Vineland Adaptive Behavior Scale. She was retested at the age of 12
years 10 months, just before she began to learn how to communicate by typing. The
ISO D. Bledm and G. Kliewer psychological report stated that she was operating at the level of '2 years 6 months on the Arthur Adaptation of the Leiter International Performance Scale, 1 year 4 months on the Developmental Test of Visual Motor Integration, 2 years 3 months on the Normative Adaptive Behavior Checklist, and 2 years 1 month on the broad independence rating of the Inventory for Client and Agency Planning' (Rubin et al., 2001, p. 428).

After she had a way to communicate, Rubin took a full load of academic classes in high school, published two opinion Editorials in the Los Angeles Times and was featured in documentary segments developed by a local public broadcasting station. She has since become a leading disability rights advocate and keynote speaker at many disability conferences. She is now a history major at Whittier College and is the subject of a forthcoming CNN documentary Autism Is A World (Wurzburg, 2004). In that documentary she explains:

I certainly understand why I was assumed to be retarded. All of my very awkward movements and all my nonsense sounds made me appear retarded. Perhaps I was. Voices floated over me. I heard sounds but not words. It wasn't until I had a communication system that I was able to make sense out of the sounds.

In a recent essay, she extends this thought when she writes:

It was not until I became an active communicator that I wanted to be around people. And as I have matured, people's lives now impact me. Everyone I meet has shown me what it is to be 'socially normal'. As daunting a task as it may sound, at the age of 23, I now want to surround myself with people that I can relate to. I enjoy listening to problems and gossip and the most rewarding of all is how all the people in my life relate to each other. I am the silent fly on the wall that listens and watches everything. I may not initiate conversation, but I am fascinated by the conversations going on around me. Many of the times I am included in these exchanges and always have an ear open on those that I am not.

In Rubin's words can be seen the absolute importance of exposure to literacy broadly defined, in other words to multiple forms of communication.

Jamie Burke: the shoe tying affair

Jamie Burke, a high-school student, illustrates Rubin's implicit critique of mental retardation through a poignant story about a familiar developmental marker. We first met Burke when he was 4 years old. He now can type independently and he can speak the words he is typing as he is typing them, as well as read anything aloud, although for the first 12 years of his life, he could do none of these things. Burke tells us that learning to tie his shoes was for him a perpetual reminder that intelligence and worth have been culturally scripted into particular acts — literally, intelligence is performed, even physically performed. If you do not or cannot do particular acts, you must be impaired. Performance stands in for intellect. 'So many things were hard', he writes. 'I now think it was so foolish to ask me to learn to tie my shoes'. The school 'believe(s) it important mostly as a way to tell you that you are now just greatly smart'. He speaks for everyone who along with him found it hard to tie their shoes, when he writes, 'if a kid can't tie shoes, you know they get frustrated with you'. Even words meant to
Constructing competence: autism, voice and the 'disordered' body

console, words such as 'it doesn't matter' and 'we will use Velcro' don't really assuage the 'heart (that) feels defeated'. To Burke the shoe tying agenda was trivial when compared to the far more essential problem of 'tying ... speech to my mouth from my brain'. Having a way to be heard was so much 'more critical to life than making a piece of cotton secure'. So, when at the age of 15 he did succeed in tying his shoes, he found praise and excitement about it 'still foolish', even 'ridiculous' (Burke, 2005).

During his growing up years, while he was hoping to be able to speak, some people around him smiled and said 'I know you will speak someday', but in their faces he could see that they did not really believe their own words. He says that in their expressions he saw 'sympathy ... not belief'.

In recent years, the fact that he has learned to speak words before and as he types has removed him from severe questioning about his intelligence and the authenticity of authorship for the words he types, but we cannot help but wonder what would have been his fate had he not been able to conform to the 'normalist' demand for physically independent typing and speaking. Would he have been counted among the incompetent that Mackay (2003) says are created by imperious professional ideas about communication that somehow is independent of active listening and even of interaction? Would he have been told that he must endure tribunal-like testing of the sort imposed on Keller and on Wheatley?

Larry Bissonnette: outsider artist

We first met Larry Bissonnette in 1993. He had come to Syracuse to participate in an interview with an NBC reporter on a show on autism and communication. Since then we have gotten to know Bissonnette through his writing and his art. He is an accomplished painter whose work has appeared in a number of galleries and is referenced in outsider art compendia (Sellen, 2000).

When we met in 1993, Bissonnette was 36 years old. He had spent 10 years, from the age of 8, in the Brandon Training School, a mental retardation institution in Vermont that has since closed. For a time he was also incarcerated at the Vermont Psychiatric Hospital at Waterbury. He currently lives with his sister in Winooski, Vermont. He has autism, but over the years he was also variously classified as mentally retarded schizophrenic, and clinically insane (Bissonnette, n.d). During his youth, psychologists tested and judged him as moderately retarded. It was not until he was in his mid-30s when he learned to communicate by typing that he began to escape Mental Retardation status. His own account of his life as an artist appears in the documentary he has written, entitled My Classic Life as an Artist (Biklen & Rossetti, 2005).

Like Wheatley and Keller, for Bissonnette, expression has provided an avenue to acceptance, even appreciation. And this now is an existence he would not want to give up. Recalling life in the Brandon institution, Bissonnette writes, 'Going back in desolation where it's only me and letterless walls is not pleasant to think about. Nothing 'apartheids' you like the insensitive world of institutional existence'. In the documentary about his life he describes the role of art as a form of expression (i.e. literacy):
Not allowing people with disabilities their patterns of inspiring art through total freedom of expression is like limiting creativity with censorship. Without art, waiting smell of earth's pleasures would kite away to land of inanimate objects.

**Bodies labelled retarded**

Three of the four people whose narratives we have cited and quoted above were at one time or other labelled or presumed mentally retarded — Jamie Burke escaped official classification, although he too has met his share of people who have dismissed him as retarded. Even a brief perusal of the formal definitions of mental retardation and professional accounts of it in levels suggest how cruelly inadequate and debilitating the concept is, and how grossly unfair it would be to attach it to any of these people, and judging by these examples, to anyone. Consider just one of the official 'levels' of retardation. The official diagnostic manual of the American Psychiatric Association, the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition Text Revision DSM-IV-TR, defines retardation authoritatively. Apparently, its readers are expected to believe that mental retardation is real and that the American Psychiatric Association can tell us just what it is.

The definition of severe retardation sets strict, pessimistic parameters of agency:

> 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.

(American Psychiatric Association, 2000, pp. 43 44)

Within such constructs, an individual possesses qualities that define life opportunities, as if there are natural, predetermined consequences for perceived biology, for example educational success limited to a second grade level or to pre-academics. These definitions are imperious in the authority they grant professional diagnosticians and, by extension, the public, to speak for the person labelled. As Blatt once observed, the label itself invokes pessimism.

*A social constructionist way of thinking about competence*

Neither autism nor mental retardation, and not any perceived combination of the two — they are often conflated — is natural or real. They are, rather, socially constructed. This is by way of saying that disability categories are not 'given' or 'real' on their own. Rather, autism, mental retardation and competence are what any of us make them.

To explain and justify this assertion, we want to present three principles. The first concerns the importance of recognizing the metaphors disability professions have
made real. Disability has been increasingly framed as medical abnormality, catalogued into new or available taxonomies. In the context of utilitarian politics, where individual economic worth depends on a person’s perceived productivity, any condition that might be thought to violate prevailing norms is subject for analysis, with difference being treated as pathology, to be reformed, isolated, or blotted out. Autism, like other disabilities was initially described as a deviation from an ideal norm of behavior or performance and is increasingly studied as an example of deviation in neural structure. As you can probably tell by now, we do not take the position that autism is pathogenic and certainly not that autism demands a cure — these are not our judgements to make.

Autism as an identity, like gender and race, has been linked to particular, externally imposed, interpretations of the body. Frugone, Rubin, Burke and Bissonnette have a history of being interpreted, often pejoratively, based on what they looked like and how well they perform in particular situations, according to particular normative standards. This is not unlike cultural treatment of race (Appiah & Gates, 1995, p. 4), even though unlike with race or gender, the person labelled autistic has been known to complain about an unruly body that will not always comply with intention. As the examples we have provided make clear, difference in the body does not equate with incompetence unless people decide to say that it does. Unfortunately, the press to regard certain bodies as prima facie evidence of incompetence; ‘that person really looks retarded’, ‘she's a severe case’, ‘is there any hope for that one?’

Autobiographical narratives afford a window on the specific nature of people’s experiences. To the extent they are different from other people’s experiences, such accounts suggest how these differences can be negotiated in social and cultural contexts and how others can make performance easier. In other words, context matters. This leads to a second principle: In order to begin to understand the person labelled autistic, as to understand any person, it is necessary to examine social context. What is the world that the person inhabits? And then how does the person negotiate different environments?

We are often asked, ‘What percentage of people with autism can be expected to achieve the communication abilities that Alberto Frugone or Sue Rubin or Jamie Burke or Larry Bissonnette have achieved?’ Clearly, such a question grows out of the pathology perspective. It imagines people and their neurology inhabit a continuum of ability, ranging from extreme pathology to less pathology, verging on normalcy — we answer by talking about privilege or opportunity. It has always seemed to us that representations of autism and achievement are only partly related to individuals’ neurological makeup; and really the same point must be made about anyone and about any educational regime. For example, the likelihood that a particular student will be included in a regular class or sent off to a special school will likely have more to do with local educational policy toward students with autism than with any neurological assessments — for a more elaborate discussion of this point in relation to all disabilities, see Biklen (1988). Similarly the educational performance of any non-disabled student is invariably related to family wealth, geographic location and other social factors. So, in response to the question about how many people with autism
might develop excellent, alternative communication abilities, we suggest that the percentage is likely to be a reflection of context. How many have parents — in the main this has been mothers — who can contribute huge amounts of time and energy to their education? How many have access to academic school curricula? How many enjoy access to communication training and hundreds of hours of practice? It is not insignificant that Frugone, Rubin, and Burke all had mothers who devoted themselves to providing intense instruction and who interceded with schools to see that they received academic content even when social policy and prevailing professional and social doctrine and attitudes discouraged it. Presumably, autobiographical accounts may illuminate how and why some contexts allow for more successful performance than others.

The third and last principle is the importance of presuming competence. Our use of the term ‘presuming competence’ is similar to Goode’s anthropological, emic perspective, where intimate contact with the person and openness to the person allows you to dispense with the fault-finding, deficit-seeking framework of the professional diagnostician and to learn about the person through engagement (Goode, 1992). It is what Linneman (2001) calls mindedness. Speaking of the denial of mindedness or presumed incompetence, Linneman explains that once a mind has been obliterated in the observer’s imagination through a declaration that the person is mentally retarded, ‘mind can only persist’ or re-emerge ‘to the extent that it is experientially preserved’ (p. 65). In the circumstance where one person has accepted that the other person has been authoritatively declared intellectually incompetent, interacting with the person in a way that requires the person to have understanding is something that demands ‘some kind of intimate contact’ (p. 103). Linneman argues, ‘The specter of mental retardation creates an altered set of expectations’ (p. 183). Thus if a person is deemed to have ‘autism but not mental retardation, it is likely that his or her interpretative community will consider ‘mind’ as present but hidden. If mental retardation is detected (i.e. believed to exist and treated as real), then mind will become contested territory’ (p. 183). In adopting a presuming competence stance, the outsider regards the other as a peer, as someone with whom to interact and communicate and from whom one can learn, if only a means of interaction can be discovered. More simply stated, if you are interested in seeing another’s competence, it helps to look for it. As the work of Frugone, Rubin, Burke, and Bissonnette attest, this optimistic stance holds substantial rewards. It is a necessary condition of meaningful inclusion.

Notes

1. The first author graduated from Bowdoin College in 1967. The first section was written by the second author for a longer historical analysis of the Wheatley and Keller experiences. Subsequent sections are based in part on material that appeared in Biklen (2005). Portions of this paper were given in the form of an address given at The International Colloquium on Inclusive Education, McGill University, July 2004, and a subsequent address at Pennsylvania State University’s Rock Ethics Institute, November 2004.

2. Others with disabilities, in recent autobiographical narratives, have recalled their own emergence into literacy, e.g. the Irish authors Christopher Nolan (1987) and Christy Brown (1955,
3. Controversy has swirled around the method of facilitated communication because it has been shown that a facilitator’s physical touch of the typist’s hand or arm could influence the person’s pointing, and because in a number of studies failed to validate authorship (Bebko et al., 1996; Bomba et al., 1996; Cabuy, 1994; Crews et al., 1995; Eberlin et al., 1993; Klewe, 1993; Monte¢ et al., 1995; Moore et al., 1993; Regal et al., 1994; Shane & Kearns, 1994; Smith & Belcher, 1993; Szempruch & Jacobson, 1993; Wheeler et al., 1993).

4. These studies use a range of test situations as well as linguistic analysis and documentation of physical, independent-of-facilitator typing to confirmed authorship (Broderick & Kasa-Hendrickson, 2001; Calculator & Singer, 1992; Cardinal et al., 1996; Emerson et al., 2001; Janzen-Wilde et al., 1995; Niumi & Karna-Lin, 2002; Rubin et al., 2001; Sheehan & Mattiuzzi, 1996; Tuzza et al., 2004; Weiss et al., 1996; Zanobini & Scopesi, 2001). The studies by Cardinal et al. (1996), Sheehan & Mattiuzzi (1996) and Weiss et al. (1996) all involved message passing experiments, but unlike many of the assessments in which individuals failed to demonstrate authorship, these included extensive testing sessions, with the possible effect of desensitizing the subjects to test anxiety. The non-experimental studies noted above in which individuals successfully demonstrated authorship involved unobtrusive assessments, such as linguistic analysis, statistical analysis of word selection and independent typing after a period of facilitated typing.

5. The American Psychological Association, for example, passed a resolution that ‘adopts the position that facilitated communication is a controversial and unproved communicative procedure with no scientifically demonstrated support for its efficacy’. (American Psychological Association, adopted in council, August 14, Los Angeles, CA, p. 1).

6. The term ‘mental retardation’ is still used widely in the USA, while other jurisdictions have long since abandoned it in favour of ‘intellectual disability’ (Australia) and ‘learning difficulties’ or ‘learning disabilities’ (UK). It is used here because the term is the label that was applied to Rubin by educational authorities. The term ‘mental retardation’, like ‘intellectual disability’, is, of course, socially constructed, and its meaning has often shifted over the years. Colleagues in the UK tell us that the terms ‘learning disabilities’ and ‘learning difficulties’ are still routinely debated and are constantly shifting in meaning.

7. The second author was one of his teachers in an inclusive preschool.

8. We do not want to imply that children who do not seem to flourish arc somehow the victims of poor or inadequate mothering. After all, fathers can also play important roles in child-rearing as can schools and others social settings. We mean only to draw attention to the very gendered nature of current societal practices with regard to disability. Others have written about the gendered quality of this work and the fact that accomplishing it depends on a measure of middle-class privilege as well as a willingness to resist dominant professional discourses of disability that are so often pessimistic (Harris, 2003; Morris, 1991; Traustadottir, 1991a, b); the role of parents, and particularly of mothers, comes up in many of the autobiographies of people with so-called high-functioning autism and so it is not surprising that it arises in the context of those who had been defined as ‘low functioning’. At the same time, there are examples in the literature of individuals who have found other people and opportunities for support (e.g. Williams, 1989, 1994).

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