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Who May Be Literate? Disability and Resistance to the Cultural Denial of Competence

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Through a critical interpretivist frame, the authors use ethnography and archives to examine themes associated with society's ongoing denial of literate citizenship for people with perceived intellectual disabilities. They link this denial to the experiences of other devalued and marginalized groups to challenge the common perception that citizenship in the literate community is an organic impossibility for people defined as intellectually disabled. The authors present four themes of literate disconnection and, in the conclusion, ponder the moral shift necessary to craft a science of literacy for all.

KEYWORDS: advocacy, disability, disability rights, disability studies, literacy, special education

“Until the middle of the twentieth century,” Prendergast (2002) wrote in reference to *Brown v. Board of Education*, “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” (p. 206). Among children segregated from the cultural locations of educational privilege, opportunities to develop as literate citizens have historically been curtailed, circumscribed, suppressed, or wholly outlawed by those in control of the formal institutions of education.

When in 1954 the five lower court cases subsumed as *Brown v. Board of Education* came before the U.S. Supreme Court, the lawyer defending South Carolina's segregated schools, John W. Davis, opened his oral arguments by linking the end of segregation for African American children to the possibility that other marginalized groups of children might also find equal protection before the law. In a statement meant to frighten, Davis opined, “May it please the Court, I think if the appellants' construction of the

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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” (cited in Friedman, 1969, p. 51). Refusing to stop there, Davis continued: “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” (p. 51).

Over the five decades since the *Brown* decision, the dismantling of racial segregation has been a rancorous, incomplete project. However, of the linked “grounds” for segregation in John W. Davis’s statement, that of presumed intellectual disability¹ has remained most closely associated with pre-1954 justifications for continued *legal* segregation and its consequential separation of labeled children from valued access to the citizenship tools of literacy.²

Racial segregation, with its manifest restrictions on literacy, was ultimately realized in the *Brown* decision to represent an arbitrary and thus unconstitutional denial of equal protection. In contrast, the presumption of intellectual disabilities continues to provide what is commonly considered to be an objective, intrinsic rationale for the educational separation of labeled from nonlabeled individuals. Restricted literacy among people with disabilities has become institutionalized as a presumably natural manifestation of organic defects thought to objectively exist well beyond the reach of social, cultural, or historical consideration. As an example, in providing a culturally authoritative description of people labeled with significant intellectual disabilities, the authors of the text revision of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*; fourth edition; American Psychiatric Association, 2004) made the following unqualified claim: “They profit to only a

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limited extent from instruction in pre-academic subjects, such as familiarity with the alphabet [and] can master learning site reading of some 'survival' words" (pp. 43–44).

Our explorations into literacy and disability, however, suggest that the *DSM* characterization of literate (im)possibility and the dominant worldview it represents may be less a biologically based actuality and much more akin to social impositions historically ascribed to children outside the circles of educational privilege (Biklen, 2005; Kliewer & Biklen, 2001, in press; Kliewer et al., 2004). In this article, we merge our ethnographic literacy and facilitated communication³ research with first-person, action, and autobiographical disability research to deeply examine themes associated with the ongoing denial of literate citizenship for people with perceived intellectual disabilities. Furthermore, we explore how this denial is socially linked to historic practices of general human devaluation. In so doing, we also describe social practices of resistance that support a more inclusionary literate citizenry while further challenging and dismantling the presumed logic underlying varied institutions of segregation that remain educationally prominent and viciously stratifying.

We begin by going back in time to two different eras and two different young women, one of African heritage and the other with severe disabilities, whose juxtaposed stories of struggles to be recognized as literate citizens present an intersectionality of themes related to perceptions of human competence, value, and citizenship. We follow this introduction with a discussion of our theoretical orientation and research methods through which we originally uncovered the complexities of literate disconnection, its resistance on the part of certain individuals construed as intellectually disabled, and the links with other marginalized groups struggling to access the citizenship tools of literacy. We then examine in ethnographic and archival fashion how themes of literate disconnection have continued over the decades to reverberate in the lives of people with disabilities and how certain labeled individuals and their advocates have resisted the cultural imposition of subliteracy.

Struggling for Literate Citizenship: The Parallel Tales of Phillis Wheatley and Helen Keller

In October 1772, in the city of Boston, 17-year-old Phillis Wheatley, kidnapped 11 years earlier from the Senegambian coast of western Africa and brought to the colonies on the tightly packed slave ship *The Phillis*, stood alone before a tribunal made up of 18 White men, all extraordinarily prominent in government and commerce (see Robinson, 1982). These 18 judges included the governor and lieutenant governor of Massachusetts as well as John Hancock, then a successful Boston-area merchant. They were charged with determining amid tremendous skepticism whether Wheatley, a slave from Africa, could possibly be the author of a series of English-language poems attributed to her by her owners, who sought to publish them as an anthology.

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Some 120 years later, again in the city of Boston, 11-year-old Helen Keller, blind and deaf, was brought before a similar tribunal (see Keller, 1954). Her court of investigation was composed of nine high-level administrators at the Perkins Institution for the Blind. This panel was established after accusations of plagiarism directed at portions of Keller's writing, and it was charged with determining whether the child, as a person with significant disabilities, was capable of crafting original fiction.

Wheatley and Keller, separated in time by 12 decades, shared across the temporal expanse a common struggle. Circumstances suggested both were in profoundly subjugated, seemingly voiceless positions. Wheatley was an adolescent female slave owned by an elite Boston family headed by John and Susanna Wheatley. She spoke no English when brought ashore in chains at 7 years of age. No one knew her name. It was Susanna who christened the child after the slave ship that carried her from her home. Phillis 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" (cited in Renfro, 1916, p. 80).

Keller was a female child with profound disabilities. When she lost her sight and hearing in the midst of a severe fever after her first birthday, most of the extended Keller family as well as friends assumed she also lost her potential to reason. 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" (cited in Lash, 1980, p. 69).

Primarily as a result of to their facility with the written word, however, Wheatley and Keller ultimately generated powerful voices that could not be ignored. For Wheatley, poetry served as her primary mode of written expression. Within 16 months of being purchased and with only minimal instruction, she had mastered spoken English and was learning to read (H. L. Gates, 2003). In 1765, 4 years after being bought, Phillis wrote her first poem and was instructing herself in Latin. By the age of 17, Wheatley had written hundreds of poems, 28 of which her owners sought to publish as a collected anthology. In one she powerfully revisited her initial enslavement: "What sorrows labor in my parent's breasts/ Steel'd was that soul and by no misery mov'd/ That from a father seiz'd his babe belov'd/ Such, such my case. And can I then but pray/ Others may never feel tyrannic sway" (cited in Renfro, 1916, p. 80).

For Helen Keller, her language, gestured into the hand of another, flowered after the fabled moment at the water well with teacher Anne Sullivan. Keller was just 6. Only 2 months later, Keller wrote her first letter, a note to her mother. It was written in pencil with a script referred to as "square hand" developed at the Perkins Institution for the Blind. By the age of 8, already known internationally, Keller was studying French and, like Wheatley, was just beginning to engage in the self-study of Latin. At age 10, Keller ventured into writing fiction, penning a short story titled *The Frost King* as a birthday gift for Michael Anagnos, director of the Perkins Institution. In turn, Anagnos published the story in a professional newsletter (Einhorn, 1998).

Themes of Literate Disconnection

Their written forays into the world of fiction, imagination, and poetry were precisely what forced Wheatley and Keller to eventually stand solitarily before their respective courts of inquisition. Each had done what was deemed impossible for individuals ascribed to the status of slave or profoundly disabled: They had used written language as a powerful tool to transcend the here-and-now, to imagine what might be, or to imagine at all instead of to communicate the mere day-to-day mundane. In so doing, Wheatley and Keller wandered dangerously close to that ideological border that historically has separated valued citizenry, intellectual and moral, from those whose very humanness is in doubt.

Rendering Literate Possibility Invisible

Phillis Wheatley and Helen Keller struggled against the prominent theme of literate invisibility as a product of their cultural dehumanization. In 1772, when Wheatley's owners sought to publish an anthology of her poetry, they in effect requested that underwriters and a publishing house make visible the literate possibility that a slave from Africa could produce written works of high art. At the time, in Europe and the 13 colonies, it was widely considered that most peoples of Africa and their descendents had no human intellect at all. The renowned Scottish philosopher and historian David Hume, a contemporary of Wheatley's, concluded in his mid-18th-century essay *Of National Characters* (Hume, 1963) that Africans "are naturally inferior to the whites," incapable "of either action or speculation. No ingenious manufacturers amongst them, no arts, no sciences" (p. 213). Immanuel Kant, the Prussian philosopher and also a contemporary of Wheatley's, responded with agreement to his Scottish counterpart, claiming that Africans "have by nature no feelings that rise above a trifling" (Kant, 1763/1960, p. 111).

The visibility of full humanness hinged, in Wheatley's time, on literacy. "The question," H. L. Gates (2003) explained, "turned on whether or not Africans could write" (p. 26):

Could [Africans] create imaginative literature? If they could, this line of reasoning went, then they stood as members of the human family on the Great Chain of Being. If they could not, then the Africans were a species sub-human, more related to the apes than to Europeans. (p. 26)

Like Wheatley, Helen Keller experienced an intense undercurrent of incredulity directed at her literate accomplishments. Indeed, most faculty at Perkins felt Sullivan was deceiving the public and the profession by misrepresenting Helen's abilities (Lash, 1980). During Keller's life, disability, including blindness and deafness, was inextricably linked with ideas of intellectual *idiocy* and spiritual vacuity (Johnson, 1903). As had been Wheatley's

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experience, the possibility of citizenship, including literate citizenship, was rendered largely invisible by the predominant beliefs of the time. Anne Sullivan was convinced that the instructional methods she had learned as a teacher-in-training at Perkins, reflecting state-of-the-art approaches, actually imposed further restrictions and needless limitations on Helen's and other children's potential to learn. Sullivan wrote, "I am beginning to suspect all elaborate and special [i.e., disability] systems of education. They seem to be built up on the supposition that each child is a kind of idiot. Whereas if the child is left to himself, he will think more and better" (from an 1887 letter cited in Keller, 1954, p. 260).

Disability as a Static Construct

Maintaining the invisibility of literate potential was supported by deeply ensconced beliefs that Phillis Wheatley and Helen Keller represented static categories of personhood and so were themselves spiritually and intellectually enfolded, unable to grow toward citizenship, literate or otherwise. In his fundamental legal treatise justifying U.S. slavery, the antebellum lawyer Thomas Cobb (1858/1968) opined, "This inquiry into the physical, mental, and moral development of the Negro race seems to point them clearly, as peculiarly fitted for a laborious class. Their mental capacity renders them incapable of successful self-development" (p. 47). The complexity of any given individual was completely obscured as Cobb (1858/1968) shaped the abstract category to be one dimensional and wholly static. Referencing her directly, Cobb dismissed Phillis Wheatley's poetry, describing it as "amusing in its meagerness" (p. 45).

Helen Keller was often cast as a *representative* of the static category deaf-blind. Explained Alexander Johnson (1903), general secretary of the National Conference of Charities and Correction and a pioneer in the development of institutions:

The chronic insane, the epileptic, the paralytic, the imbecile and idiot of various grades, the moral imbecile, the sexual pervert . . . *the blind, deaf-mutes*. All these classes in varying degrees with others not mentioned, are related as being degenerates. (p. 246, italics added)

According to definition and convention, the degenerate and the defective could not function as full and literate citizens of society. Psychologist Thomas D. Cutsforth wrote, in *The Blind in School and Society* (1933), that Keller's writings reflected "implied chicanery" (p. 48). A *New York Nation* review of Keller's autobiography described her writing as "lacking in literary veracity" and rife with "literary insincerity" (cited in Braddy, 1933, p. 201). Such accusations occurred precisely because Keller dared express in letters what was popularly determined to be beyond the intellectual capacity of a person who was both deaf and blind.

Literate Accomplishment Censured and Dismissed

When the philosopher David Hume was confronted with evidence that a Jamaican named Francis Williams was an accomplished writer, he simply dismissed the report, noting that “likely he is admired for very slender accomplishment, like a parrot who speaks a few words plainly” (p. 213). The accusation of “parrot” was one commonly hurled at Wheatley to dismiss and explain away her poetry (H. L. 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. In this way, 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 also the accusation used to dismiss the literate accomplishments of 10-year-old Helen Keller. An anonymous reader saw *The Frost King* and reported similarities between it and a previously published story titled *The Frost Fairies*. Suddenly, and very publicly, Helen Keller was censured as a plagiarist, a fraud, and a dupe of her teacher, Anne Sullivan. Ozick (2003) noted that throughout her life, Keller battled accusations that hers were “parroted words” (p. 188) and that Anne Sullivan was little more than a “ventriloquist” (p. 190). Helen Keller’s accomplishments under the tutelage of Sullivan clearly subverted deeply ensconced professional and cultural responses to significant disability. Through dismissing her as nothing more than a parrot, the status quo could be maintained, the need for professional change averted, and the cost would be but a single child and her devoted teacher.

Proving Literate Competence

Both Wheatley and Keller were forced into trials that demanded they meet criteria of validity as to their literate capacity. Of course, the criteria of proof and manner in which they were met were determined by those who held authority without consulting the needs or interests of the person whose capacities were suspect.

To ensure that no parroting took place during their trials set 120 years apart, both Phillis Wheatley and Helen Keller were led alone into their respective Boston chambers. For Wheatley, it was her prominent owner, hoping to capitalize on Phillis’s abilities, who convened the panel of 18 (Renfro, 1916). John Wheatley felt that once his slave’s literate abilities were validated by highly powerful White men, he would have a better chance of finding a publisher or underwriters for her book of poems. Wheatley must have performed admirably before her judges. The panel of 18 subsequently crafted a statement of authenticity that all signed. It read, in part, “She has been examined by some of the best Judges, and is thought qualified to write them [the attributed poems]” (cited in Renfro, 1916, p. 17). John and Susanna Wheatley still had to travel to England to find a publisher willing to risk releasing the first

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book of poetry written in English by a person of African descent, *Poems on Various Subjects, Religious and Moral* (first published in 1773).

Wheatley must have emerged from her inquisition feeling somewhat triumphant. Helen Keller, on the other hand, did not. The night before she was to be judged as either able to write fiction or not, Keller (1954) recalled, "I felt so cold. I imagined I should die before morning, and the thought comforted me" (p. 65). She later recalled the intensity of her interrogation, which went poorly: "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" (Keller, 1954, p. 65).

Four judges concluded that Keller was competent of creating the fiction attributed to her and had not been a mere parrot of Sullivan's, and four judges voted that indeed Keller was nothing more than a parrot. Michael Anagnos broke the tie, siding temporarily with those who felt Helen had validated her abilities (Keller, 1954). Within a year of the inquisition, however, Anagnos was publicly stating that "Helen Keller is a living lie" (cited in Lash, 1980, p. 168). Replacing claims to a literate presence with the construct of a "living lie" is an act that wrenches the substantive humanity from the accused and in its place leaves a specter of fraud and vacuity.

The themes of literate disconnection experienced by Phillis Wheatley and Helen Keller have retained a vicious credibility still directed against individuals who represent devalued categories. Through the construct of intellectual disability, we explore the continued reverberations of literate disconnection and the manner in which these themes are contested by actual people demanding recognition of their complex humanity and full citizenship.

On Methods

The themes presented herein were framed by a disability studies and critical interpretivist orientation.⁴ In contrast to a traditional form of interpretivism, with a focus on exposing a deeper understanding of the social constructions under scrutiny, a critical framework actively seeks out and further promotes contexts and stories in which people together are resisting traditional institutions and social practices that marginalize and dehumanize particular groups.⁵ Our general interest is in the active cultural construction of individuals with significant disabilities as competent and full citizens of the valued community. Specifically, we have studied processes of presuming competence and rightful citizenship in areas such as literacy development and facilitated communication that may promote understanding between people labeled with significant disabilities and those who are considered to be nondisabled (e.g., Biklen, 2000, 2005; Kliewer & Biklen, 2001, in press).

By studying situations and locations (e.g., classrooms, families, friendships, job sites) where the individuals who make up these contexts are actively resisting traditional frames that disconnect people with disabilities from the valued literate community, we discovered that our data actually exposed institutions and practices of disconnection as much as they illuminated processes

of connectedness. For instance, one teenaged participant involved in our literacy ethnographies was labeled with autism and intellectual disabilities and attended a segregated school for students with severe disabilities (see Kliewer & Biklen, 2001). At home, his family and friends recognized him as a fluent reader who had consumed nearly every book in the local library on butterflies. At his segregated school, however, he was provided with no recognizable literacy program and was considered to be illiterate. When asked about this jarring discrepancy in persona, his mother calmly responded, "School's not really a place for reading" (see Kliewer & Biklen, 2001, p. 1).

Our work retains the traditional interpretivist emphasis that people in interaction construct the meanings that matter in daily lives. As we spent time with people actively presuming competence and potential in individuals often considered to be hopelessly incompetent, we began to also explore a marginalized but extremely exciting archival history of similar efforts involving people with significant disabilities (e.g., Buck, 1955; Hunt, 1966; Schmidt, 1945; Seago, 1964). We treated these published studies, essays, journals, and diaries as further data to be analyzed and that ultimately helped clarify and deepen emergent themes in our field research.

Here we combine our previous research, ongoing fieldwork, and archival sources to explore how themes of literate disconnection are educationally experienced and contested by people with significant disabilities and their allies. The stories may appear to be from disparate sources, but each exposes particular dimensions of the collective effort toward a recognition of human competence and literate citizenship.

Rendering Literate Possibility Invisible

In their struggle to access the tools of literate citizenship, people with presumed intellectual disabilities have continued to encounter the literate invisibility at times experienced by Wheatley and Keller. This obscuration frequently occurs in the customs of special education practitioners who exert tremendous influence over the day-to-day opportunities of their students with significant disabilities (Katims, 2000; Mirenda, 2003). An example was detailed in a research interview we conducted with a teacher in a segregated school for students with significant disabilities. The teacher explained that 2 years earlier she had chosen her segregated special education job over a regular first-grade position in the same small city precisely because, as she explained:

In first grade here [in the city's school system] there is so much pressure to teach reading. It's make or break. You have so many people watching, and the pressure is intense. Here [at the segregated special education school] there's no teaching reading. I don't have to worry about it. My kids aren't readers and they never will be.

In rather straightforward fashion, any possibility or visibility of a literate presence on the part of this teacher's students was disavowed. This invisibility

translates into an absence of opportunities to encounter activities that foster literacy. In addition, the segregated school did not have a student library, and the classrooms commonly did not have normal child-oriented reading materials such as storybooks. It would be difficult to be anything but sub-literate surrounded by such disconnection from written opportunities.

The day-to-day literate invisibility experienced directly by each student in this segregated school was shaped by, and also affirmed, an abstract invisibility. By this we mean the establishment of categorical rules by professional expert authorities. These categorical rules set the contours of what is then presumed to be innately or naturally possible (and impossible) regarding literacy development for individuals within a defined category. Abstract invisibility often requires the manipulation or ignoring of data such that a literate presence must never be fully acknowledged for those who compose culturally devalued categories: The abstract category is used as the frame to set the contours of possibility for the actual individual, and the actual individual, who is interpreted as wholly incompetent, is then used to affirm the category. Thus, the limitations of the abstract are presumed to be the limitations of the actual, and the actual is known only through a categorical lens of utter hopelessness that obscures or makes invisible literate possibility.

Categorical obscuration of an individual's literate possibilities can be seen in the example of Isaac Johanson, born with Down syndrome, who became part of our research on early literacy as a 4-year-old entering an inclusive early childhood preschool program, the Shoshone School, for children with and without disabilities.⁶ At the urging of medical doctors and several early intervention disability professionals, Isaac's parents had initially sent him to a segregated program aimed exclusively at preschool children considered to be severely disabled. In a research interview Isaac's mother explained, "We were doing exactly what we were told would be best for him. When you have no clue, I guess you listen to experts."

Isaac's parents described the segregated program as devoid of recognizable preschool opportunities, including a dearth of literacy activities. According to Isaac's mother, "[There were] no picture books, no children's books at all, no paint, no pretend kitchen, no dolls." Isaac's father interrupted, "Nothing that you think of when you think of nursery school. Nothing like what his brothers had."

Isaac's parents reported that about 6 weeks into the school year, when they raised the issue of reading, writing, painting, and other recognized aspects of a quality general early childhood program, their queries were immediately shut down. Isaac's mother recalled, "We were told that other functional skills were a priority as if reading is somehow unfunctional." Isaac remained in the segregated program for approximately 6 more weeks when his parents pulled him. "He was nothing but a defect to them," Isaac's mother said. "I was set to home school, but then we heard about Shoshone."

An opening occurred in a combined-age, 4–5-inclusive classroom at Shoshone taught by Shayne Robbins, a teacher involved in our literacy ethnographies. Prior to Isaac entering her classroom, Robbins made two visits to

his home to meet the family and ease Isaac's transition into the new preschool. From those visits, Robbins learned about Isaac's passion for books by children's author Maurice Sendak, including his classic *Where the Wild Things Are* (Sendak, 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 while 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, Shayne Robbins had all of 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.

In his previous, segregated program, Isaac's literate possibility was rendered invisible. Amazingly, within 1 hour of starting school at Shoshone, Isaac had directly influenced the choice of literature, had been part of a peer group focused intently on a book, 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 literate joy.

For Isaac, the path toward literate visibility occurred when his parents challenged tradition and pulled him from his segregated preschool program. Sue Rubin, labeled with severe autism, has similarly encountered and resisted the imposition of literate invisibility. A student at Whittier College (Whittier, California), Rubin has in recent years become recognized as an eloquent, literate spokesperson for disability rights (Rubin, 1997, 1998, 1999; Rubin et al., 2001) and was recently the focus of an Academy Award-nominated documentary that she herself wrote. In relation to her label of autism, Rubin's ability to speak is highly disordered and is primarily limited to bursts of sounds strung together without discernible meaning, echoed phrases that she utters out of context and at unusual moments, and, on occasion, rudimentary sentences that are difficult to decipher.

Rubin's intellectual eloquence is captured not in speech but in her communicative typing, which originally required facilitated support (see Footnote 3). However, Rubin, now in her 20s, did not learn to communicate understandably until she was 13. Up until then, she was considered to be profoundly mentally retarded with only a rudimentary capacity for literacy. She writes:

When I was in eighth grade, the school psychologist and speech therapist introduced me to facilitated communication [an augmentative-alternative communication approach]. I was a terrible subject because of my behaviors, but my mom insisted I practice everyday. . . . After a few months, I progressed from getting a few letters right, to words, then phrases, then sentences and paragraphs. By the spring I was typing well enough to go into a [middle school] science class. (cited in Rubin et al., 2001, pp. 419–420)

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Rubin's literate emergence resulted less in celebration and more in an extreme professional incredulity. Debates over facilitated communication are often misapprehended as simply about the nature and degree of the physical support provided the person typing. However, such confusion is analogous to suggesting that the skepticism initially directed at the literacy of Phillis Wheatley or Helen Keller was over the depth of Wheatley's skill with rhyme and meter or Keller's ability to hand-in-hand finger spell or to manipulate a Braille machine. Instead, the initial outcries challenged the very idea, central to literate citizenship, that an individual of African origin or an individual with multiple sensory disabilities might have complex, imaginative, profound visions to express at all.

Similarly, at the root of the facilitated communication controversies is the refusal to conceive that people professionally diagnosed as intellectually impaired might make use of written language, when speech has failed them, to establish an original, complex, and heretofore unexpectedly sophisticated intellectual presence. Mirenda (2003) captured just this point when she noted that early professional refutations of facilitated communication were less about technique; rather, "the controversy emerged largely because of the unexpected quantity and quality of the messages produced by many facilitated typists who had not received [traditional school-based] literacy instruction and were presumed to be unable to read and write" (p. 272). Individuals making use of facilitated communication broke the established abstract rules of severe disability and literacy.

In response, prominent voices from the disability sciences dismissed literate-based communication as nothing more than parroted behavior, the result of cues and prompts from facilitators (e.g., Green & Shane, 1994). The technical aspects involved in the physical support became an easy target, but the skepticism was invariably ideological in terms of who should and who should not be visible as literate citizens. In one early critique, Cummins and Prior (1992, p. 232) compared people using facilitated communication with "Clever Hans," a horse that in late-19th- and early-20th-century Berlin infamously responded with hoof tapping to human cues in such a way that it appeared as though the animal could multiply, divide, read, and spell. The unfortunate reference equating marginalized people to an animal, thereby rendering invisible any literate possibility, is a practice grounded in a long history of utter human devaluation exemplified, as we earlier described, in the comparisons of Wheatley and Keller with parrots.

Ironically, sustained efforts with facilitated communication that served to advance particular technical dimensions have further exposed the controversy as less about technique and more about ideology over who might be visibly recognized as literate. An international group has emerged made up of individuals with significant developmental disabilities who have gained increasing control over gestures and hand movements so that the necessity of physical support for typing is dramatically reduced or eliminated altogether (Biklen, 2005; Mirenda, 2003). For Rubin, 5 years of effort were necessary before she gained independent movement in her typing. Mirenda (2003) reported:

Today, there is a growing number of individuals in North America and elsewhere who once relied on facilitation (i.e., physical support of the hand or arm and emotional support) to type but are now independent typists (e.g., Blackman, 1999) or even functional speakers (e.g., Broderick & Kasa-Hendrickson, 2001). In 1998, Sue Rubin, a young woman with autism who used [facilitated communication] for many years before she began to type independently, wrote that, "Before I began to type, I did not think." (p. 273)

Were the controversies primarily over empirical techniques and not about who may be literate, theoretical investigations and descriptions of presumed intellectual disability would necessarily need to account for challenges to convention found in the empirical and documented experiences of Sue Rubin and others. However, the lack of a vibrant conversation among researchers, educators, and policymakers suggests that the path away from categorical invisibility associated with the literate presence of individuals with disabilities has less to do with incremental technical advances and more with established beliefs about competence or incompetence and specifically with a narrative of pessimism that accompanies the construct of disability.

Disability as a Static Construct

Literate invisibility emerges out of a sense of the culturally devalued category (and, thus, the categorized individual) as *static*: simple, one dimensional, dormant, stalled, and fossilized. People with significant disabilities are culturally constructed in a calcifying vein: as "something static, something beheld from afar, not complex, not shifting in meaning" (Biklen, 2000, p. 339). Disability becomes an idea that precludes the possibility of human development, including, importantly, the development of a literate presence.

Thomas Naber's mother, Kara Naber, has struggled for years with this enfossilizing perception cast on her son by disability professionals. Thomas Naber, born in 1989, has been an ongoing participant in our ethnographies of literacy development. He was identified within his first year of life as having Prader-Willi syndrome, a relatively rare genetic anomaly at the 15th chromosome. The meaning of such a diagnosis in terms of intellectual development is contested, but Kara recalled the definitiveness of the messages immediately sent by professionals regarding Thomas's future. While he was still in his infancy, Kara recalled being told by the consulting physicians, "He'll never really function at a level even approximating a 6-year-old." Participating in a research interview, Kara Naber leaned forward and whispered to us, "Then the one [doctor] suggested I be real cautious about having any more [children] because, he said, 'We don't need any more little Thomases running around.' I was just sick."

While Kara, then a young, single mother, had no reason to doubt the professionals' static prognosis for her son, she also intuitively, and antithetically, believed he would benefit from sound schooling. She enrolled Thomas in a university laboratory preschool program where he remained for 2 years.

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There, said Kara, “He just really picked up on books.” Her son’s literate development in a regular preschool program seemed to challenge professional assertions that his intellectual growth would quickly stall, but, according to Kara, disability professionals were completely uninterested in Thomas’s accomplishments.

When Thomas turned 5, he was transferred to a segregated school for children with severe disabilities. At the segregated school, Kara explained, “They just really weren’t equipped to develop a reading or writing program for Tommy. . . . They never really knew about his love for poetry . . . about Emily Dickinson being his favorite poet.” When asked what he would like to see changed about the segregated school, Thomas responded, “I like music about America and I like poetry and we never—we never do music and we never do poetry.”

In 2003, Kara and Thomas decided together that he would be better off in a special education program located in their town’s only high school. For Kara, a primary reason for the change was to emphasize access to a more rigorously academic program than the one offered in the segregated school. She insisted Thomas be provided a program that allowed for the development of “expressive written language skills.” In the summer before shifting to the high school, Kara took Thomas to his annual checkup at the university hospital clinic where the diagnosis of Prader-Willi was first made. Kara was excited to tell Thomas’s doctor, described in hospital literature as a nationally recognized “leading expert” on Prader-Willi, about the changes she had fought for in Thomas’s schooling. In a research interview after the clinic visit, Kara told us, “She [the doctor] looks at me, and I swear she sighs and she says, ‘Now, Mom, is this a [written language] goal for Tom or is it a goal for Mom?’ I just about died. But then you start asking yourself, ‘Well, maybe this is about me?’ ” The professionals surrounding Thomas appeared unable to see him as someone who could grow and develop as a literate citizen.

The disability category of Down syndrome provides further evidence of literate disconnection based on presumptions of inherent stasis. Oelwein (1995) described a mother bringing her 18-year-old daughter with Down syndrome to the University of Washington Reading Clinic. The daughter was a nonreader, having never been taught literacy in school. After one short lesson, however, she was reading sentences. The mother was furious at the years lost to illiteracy. She demanded, “What is wrong with those teachers, anyway? Why didn’t they do this?” (p. 4). Oelwein (1995) responded:

I advised the mother to forgive the teachers for not having the information they needed, or the wrong information; for not attending the right conferences; for not reading the right books and journals; [or] for not having the right professors. (p. 4)

Oelwein’s powerful point is that a systemic ideology of stasis permeates the professional culture of Down syndrome and disability generally, such that individuals assigned to particular labels are consistently and broadly

interpreted to be mired in a sort of static subcitizenship. Professionals widely subscribe to the notion of the individual with disabilities as organically unable to grow as a citizen and so divert the labeled person into programs absent expectations of literacy as a critical tool of community participation. Individuals with disabilities commonly live down to the expectations that surround them. Their lack of literate development is then a tautological reification of disability stasis. Oelwein's (1995) career as a reading specialist has been focused on smashing the static notions of literate capacity surrounding students commonly viewed as intellectually disabled. She wrote that if a child with Down syndrome "has been unsuccessful in a reading program, it does not mean that he is an unsuccessful reader" (p. iii). The problem exists not in the student but in what is offered the student.

Oelwein (1995) noted that, when she first began teaching in the 1960s, she had access to only a very few references suggesting literate possibilities among students with significant developmental disabilities. One of these references was a journal published in 1965 by Nigel Hunt, a young man with Down syndrome. At the time, Hunt was receiving widespread acclaim and even a hint of celebrity (see Kliewer, 1998) but was also being dismissed as an exception to the rule (of static development) attached to Down syndrome. Oelwein (1995) recalled, "I did not believe Nigel Hunt was the exceptional one: his parents were the exception. They gave him the opportunity to learn to read and type" (p. 1). It is in the opportunity of literate citizenship, so often overtly denied, that we find literate accomplishment among people with disabilities.

Literate Accomplishment Censured and Dismissed

Over the decades, the literate accomplishments of certain people considered to have intellectual disabilities have been documented. All too commonly, the response from professional authorities has been to censure and dismiss these documented accomplishments. For instance, in the 1920s and 1930s, Grace Fernald, a professor at the University of California, Los Angeles (UCLA), and her teaching colleague Helen Bass Keller of the UCLA training school (not the more famous Helen Keller of whom we have been writing) devised methods for teaching reading to children considered to be intractable reading failures (Fernald, 1943; Fernald & Keller, 1936). Children from around the world were brought to UCLA to work directly with Helen Bass Keller (see Fernald, 1943).

Among the dynamics involved in the Fernald-Keller literacy approaches were an emphasis on the children's own experiences as the basis for literacy and, in the tradition of Maria Montessori, a belief that human movement (i.e., kinesthetics) was integral to learning (Fernald, 1943). Fernald and Keller published in-depth case studies of their methods (Fernald, 1943; Fernald & Keller, 1921, 1936; Keller, 1931) and in turn were resoundingly attacked in journals by other education professionals who questioned the credibility and veracity of the reported successes (e.g., Burt & Lewis, 1946; A. I. Gates, 1935; Witty & Koppel, 1936). In response to the criticism, Lewis Terman (1943), a

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friend of Fernald's, publicly stated, "Dr. Fernald has gone quietly on with her work and left the controversy to others" (p. ix). In fact, Fernald and Keller maintained an extreme silence in relation to the literacy development of their student, Paul Scott, born with Down syndrome (see Seagoe, 1964).

In 1923, when Paul was 6 years old, he and his father appeared at Helen Bass Keller's reading clinic at the UCLA training school. On first meeting Paul Scott, Keller is reported to have immediately dismissed the child because of her widely shared assumption that a child with Down syndrome could not be taught:

She thought Paul was mongoloid because of his appearance and manner. He spoke no intelligible words or sentences and asked no questions. He made incoherent sounds as he played, pulling out drawers of her desk, taking the chalk and erasers from the blackboard and laughing with joy as he threw them at the ceiling. (Seagoe, 1964, p. 12)

Keller immediately told the father that she did not teach children *like Paul*. The father reportedly responded, "What do you mean, 'Children like Paul?' Paul can learn. He does not belong with mentally retarded children; he is not mentally retarded" (Seagoe, 1964, p. 12). Keller acquiesced and accepted the 6-year-old child into the UCLA reading clinic, where she began to teach him using the same principles she held for all of her students:

Appeal to his sense of touch and movement rather than teaching through visual cues alone. Give him concrete experiences as background for everything you try to teach. Base reading and writing and play and travel on events that interest him. . . . Teach him to write words as a key to reading them. . . . Follow his interests and build on them. Improvise material; take advantage of every situation for learning. Do not try to force new patterns, but demonstrate; let him explore and discover for himself. Above all, treat him as a person, with feeling and abilities and rights. Include him in everything, welcome him, enjoy him as he is. (cited in Seagoe, 1964, p. 31)

At the age of 6 years, with only 2 months of instruction, Paul Scott started reading and writing. After 7 months of instruction:

Paul was able to work from thirty to forty minutes at a time, and lessons stretched to an hour or more. He read from a primer, recognized the words out of context, made drawings of a head with arms coming out of it [indicative of a developmental milestone], and wrote his name after, "I love you. Will see you soon." (cited in Seagoe, 1964, p. 16)

Paul's successes come to us through a journal he began at age 12 and maintained through the late 1950s. In it he dutifully recounted the events that made up his daily life, including numerous trips and voyages taken with his wealthy father across the United States and throughout Europe and Asia. He

also used the journal to comment on theology, politics, and friendships. In 1961, a friend and UCLA colleague of Grace Fernald (who had died in 1950), psychologist May V. Seagoe, was given Paul Scott's journal. She immediately understood its importance in terms of recasting the intellectual hopelessness then associated with Down syndrome (see Blatt, 1987). Given Seagoe's immediate realization of the important nature of the journal, it is strange that Fernald and Keller maintained such a profound silence on Paul Scott's literate development. In all of their publications, only once is Paul referenced, and then not by name and with no mention that he had Down syndrome (see Fernald, 1943, pp. 265–266). Rather, a few sentences from his journal are used to suggest that students with extremely low IQ scores may learn to read for enjoyment. In a somewhat defensive tone, Fernald (1943) noted, "If there were no other argument in favor of teaching reading to mentally retarded individuals, the happiness that they derived from the experience would seem to justify the experience" (p. 266).

We can speculate that Grace Fernald's silence surrounding her literate success with a student with Down syndrome (considered at the time to be basically impossible; see Kliewer, 1998), in combination with her defensive justification for allowing a few students labeled mentally retarded into the UCLA reading clinic at all, meant that the controversy surrounding her work with Helen Bass Keller had indeed influenced how she reported, or failed to report, particular fundamentally important data. In fact, on receiving Paul Scott's journal, May Seagoe struggled to find a publisher for the important document precisely because disability experts dismissed and censured the idea that a person with Down syndrome could learn to read or write at the level suggested by the journal entries (Blatt, 1987).

At times, the censure of literate accomplishment in the lives of people described as intellectually disabled takes on a formidable, organized appearance that overwhelms claims to developing competence. Bernardine G. Schmidt, a Chicago special education teacher who completed her doctorate in education at Northwestern University in 1945, experienced this situation when she asserted, in *Psychological Monographs*:

True democracy draws no lines of discrimination between nationalities, religions, or races; nor between economic, social, or intellectual levels; and, consequently, group interaction must depend for its effective success upon the mentally feeble as well as the mentally gifted. . . . The needs of feebleminded children are the same as the needs of all children; and, therefore, the aims of education of the feebleminded are the same as the aims of general education. (Schmidt, 1946, pp. 1–2)

Schmidt (1945, 1946) offered her students a strong, dynamic curriculum that included rich, innovative opportunities for critical literacy development. One child, Helen, labeled mentally retarded, who initially hid under her desk and refused to take part in any type of reading lesson developed literacy skills when she was assigned the purposeful task of cataloging

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the class library: “Soon” it was reported, “she was learning to read the titles on the library cards” (Stern, 1947, p. 35). Access to a school-based library for children with significant disabilities was a radical departure from other prominent curriculum descriptions (see, for example, Kirk & Johnson, 1951) and continues to this day to be unusual for many children identified as severely disabled (Erickson & Koppenhaver, 1995; Kliewer & Biklen, 2001). In another set of lessons, Schmidt had small groups of children, all labeled *feeble-minded*, work together to map the neighborhoods surrounding the school. The students included keys and detailed labels on their maps. The unit ultimately led to independent use of public transportation over wider sections of the city (Clark, 1947; Schmidt, 1946, 1947; Stern, 1947).

In 1935, Schmidt began to systematically study her instructional efforts with children reportedly labeled feeble-minded at five education sites in Chicago. Her central finding was that a dynamic curriculum guided by a vision of all children’s full and valued citizenship in a democratic society fostered social, literacy, academic, and intellectual growth among children considered by others to be hopelessly uneducable. Noted Schmidt (1945):

Quite in contrast to their originally predicted roles as necessarily potential social liabilities, these youth . . . have made for themselves a role as social assets and have repudiated that of incompetence and dependence to which they were first doomed by a fatalistic educational psychology. (p. 412)

A brutally acerbic response to Schmidt’s findings was quick, fierce, and organized by certain of the most prominent professional voices associated with issues of disability. Samuel Kirk, a principal shaper of modern special education, penned a letter to John F. Dashiell, editor of *Psychological Monographs*, requesting that Schmidt’s study not be published. In response, Dashiell inserted a “prefatory statement” (1946, p. iii) into the monograph that referred to it in part as “a piece of research [that has] produced results which appear to be in sharp contrast to conventional professional opinion” (p. iii). Kirk (1948a) responded by publishing a harsh critique of Schmidt and her study in the popular *Psychological Bulletin*. He then republished it nearly verbatim in the journal *Exceptional Children* (Kirk, 1948b).

Kirk’s efforts to discredit Schmidt, widely embraced by colleagues, ignored the main thesis of Schmidt’s study: that thoughtful instruction within a framework of democratic participation allowed for the development of human competence where most others presumed only defect. Indeed, so apparent was this absence of reasoned or reflective criticism, even at the time of the controversy, that it caused F. C. Rosecrance, a professor at Northwestern who was a member of Schmidt’s thesis committee, to lament, “It is unfortunate that the present controversy has indicated so little interest in verifying the feasibility of her [instructional] methods which seemed to me to be the most important point in the issue” (cited in Nolan, 1949, p. 225).

Kirk (1948a) sidestepped Schmidt's innovative methods by absurdly claiming that her efforts were "standard practice for the mentally handicapped" (p. 323). This very claim would then be repeated with no analysis by others whose voices joined with Kirk's in discrediting Schmidt. Freed, as such, from the actual substance of Schmidt's thesis, Kirk (1948a) proceeded to publicly denigrate it primarily on points of detail he felt were suspect. For instance, Kirk claimed that the reported IQs of Schmidt's subjects did not match the range or numbers supposedly identified in Chicago Board of Education records for the years of the study. In her response, Schmidt (1948) pointed out that Kirk was in fact misrepresenting the available data as well as the actual years of her study. In fact, well over a thousand children per year were not accounted for in the tables Kirk (1948a) produced.

Further public denigrations of Schmidt followed, all of which appeared to be based entirely on Kirk's critiques, with no clear effort to understand or comment on Schmidt's original study or her reply to the initial censure. For instance, Lewis Terman (1949) opined, "I have read Dr. Kirk's evaluation and Dr. Schmidt's inadequate and evasive reply" (p. 228). He continued:

Most readers will either accept or reject [Schmidt's findings] according to their degree of scientific naivete or gullibility. To me the claims are fantastically absurd, and the discrepancies which Dr. Kirk found between the facts he dug up and certain facts reported by Dr. Schmidt appear to justify my skepticism. (p. 228)

Florence Goodenough, a psychologist who, a decade earlier, had attempted to discredit Skeels's famous Iowa studies in which it was demonstrated that IQs may increase with environmental factors (see Goodenough, 1939; Skeels & Dye, 1939), expressed "grave doubts as to the trustworthiness of any of the facts reported" in Schmidt's research (Goodenough, 1949, p. 230). Another critique referred to Schmidt as "psychologically incompetent and educationally reckless" (Newland, 1949, p. 232).

In the midst of these severe rebukes, we found only one positive defense authored by C. E. Stothers (1949), the director of special education for the Ontario, Canada, Department of Education. His was also the lone description of any effort to implement instructional methods described by Schmidt. Stothers (1949) reported that, on the basis of Schmidt's work, an experimental school unit for *ineducable children* was opened in Toronto. He noted that the students in attendance included

children classified as idiots and imbeciles who have the following defects: one mongolian, two spastics, two hard-of-hearing, two retarded sexual development, three speech defective, and one visual defective. Two pupils had been previously enrolled in special classes but after attending for four years failed to learn to read. (Stothers, 1949, p. 227)

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It was reported that, with the implementation of Schmidt's methods, students' performance had dramatically increased:

Two [students] are reading at grade three level and all but two are reading beyond expectations. . . . All except one have been introduced successfully to group activities. At the beginning of instruction not one child could copy a four-letter word correctly or make a simple mark. After eighteen months three write short original letters and six others write their names and addresses. . . . Visiting psychiatrists have commented very favorably. The experiment will probably be extended to see if similar results can be secured with a larger group. (p. 227)

Despite this dramatic replication, the organized denigration of Schmidt silenced the fledgling researcher. After 1948, Schmidt never again published in the field of education or the human sciences (see Kliewer, 1998).

Subsequent controversies surrounding literacy and disability have brought about similar well-organized public condemnations of particular methods and individuals using or researching these methods. Reuven Feuerstein, an Israeli educator, has published extensive empirical accounts of his successful work developing literacy and academic competencies among students labeled with moderate to severe intellectual disabilities (e.g., Feuerstein & Rand, 1974; Feuerstein, Rand, Hoffman, & Miller, 1980; Feuerstein, Rand, & Rynders, 1988). However, in the United States his efforts have largely been denigrated and dismissed (Bradley, 1983; Frisby & Braden, 1992; Gresham, 1987; Shayer & Beasley, 1987).

Demonstrations and documentations of literate advancement on the part of people with severe disabilities whose typing or writing is physically facilitated have been widely condemned in an extremely virulent nature. Mostert (2002) linked Nazi-era pseudoscience and the consequential atrocities and genocidal murder of people with disabilities from 1936 to 1945 to what was termed "the unfortunate history of facilitated communication" (p. 166). He explained this Nazi-facilitated communication link as follows:

FC's [facilitated communication'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[s] of many members of the public and media, who embraced FC based on the flimsiest of evidence, were hardly less astonishing. (Mostert, 2002, p. 166)

Such censure and dismissal actively denigrate explorations of the possibility that people presumed to be hopelessly subliterate might find through literacy a profound way into community connectedness. Rather, the question "Who may be literate?" is answered via professional tradition. In 1993, Eugene Marcus, labeled with autism, watched a scathing hour-long indict-

ment and censure of facilitated communication broadcast nationally on PBS (Palfreman, 1993). Several minutes of the show described an experiment conducted at the O. D. Heck mental retardation institution in New York (see Wheeler, Jacobson, Paglieri, & Schwartz, 1992, 1993). It was reported that 12 residents of the institution failed in their typing to correctly label a single picture over hundreds of trials. Furthermore, manipulation of the typing by the person providing physical support was demonstrated.

Marcus, whose speech was highly disordered, decided that he would take and pass the test used in the O. D. Heck study (Marcus & Shevin, 1997). In his initial efforts to type picture labels under the published protocols, however, Marcus recalled, "I was amazed—truly amazed—at how hard it was for me [to meet the criterion of validity]" (Marcus & Shevin, 1997, p. 118). What then ensued was a fascinating action study of the factors involved in passing the O. D. Heck test for a person with autism. The test had established a criterion for *proving* one's literate presence based on a nondisabled person's perspective without anyone considered to have severe disabilities being consulted. But Marcus had a variety of behavioral, emotional, and sensory idiosyncrasies that required consideration (and that had resulted in labels of intellectual impairment earlier in his life). For instance, because of Marcus's visual distractibility, the photos used had to be simplified and moved closer to him. He required an increased amount of time to initiate his typing, at times sitting silently for several minutes before movement ensued. He also needed to simply practice the act of naming sets of pictures under the test conditions to reduce his ever-present anxiety.

Marcus eventually passed the test and has since become less reliant on physical support in his typing. The combination of Marcus's success under experimental conditions, increasingly independent typing, authorship of chapters on the experience of being autistic, and adjunct instruction at a university might infiltrate and affect the organized censure of facilitated communication and general perceptions of literate (im)possibility associated with severe autism. However, the entrenched categorical contours of significant disability, grounded in a static literate hopelessness, appear to remain largely in place. Thus, the work bridging literacy and significant disability is still at the professional margins; however, unlike the sad story of Bernardine Schmidt, it has not been silenced but is indeed, as this article attests, increasing in volume.

Proving Literate Competence

Phillis Wheatley's and Helen Keller's skeptics demanded that each prove her literate veracity under test conditions created by those in positions of power or authority. Both essentially succeeded in the moment (Wheatley, as we reported earlier, more so than Keller), but they continued to be hounded by doubters and critics. Wheatley was unable to publish a second anthology and died in obscurity. Accusations of literate fraud followed Keller throughout her life. She responded that those who raised doubts about her capacity bore the burden of proof; it was not, Keller argued, her obligation to continuously

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validate her competence (Einhorn, 1998). Keller stated, "Some brave doubters have even gone so far even as to deny my existence. In order, therefore, that I may know that I exist, I resort to Descartes' method: 'I think therefore I am.' Thus I am metaphysically established, and I throw upon the doubters the burden of proving my nonexistence" (Keller, 1920, p. 40). In a 1908 magazine article, Keller wrote:

Has anything arisen to disprove the adequacy of my correspondence? Has any chamber of the blind man's brain been opened and found empty? Has any psychologist explored the mind of the sightless and been able to say, "There is no sensation here"? When we consider how little has been found out about the mind, is it not amazing that anyone should presume to define what one can know or cannot know? (p. 782)

Censure of claims to literate competence (or potential competence) among individuals ascribed to categories of literate hopelessness continues to occur in conjunction with demands that such individuals prove their literate worth according to protocol and criteria set by those positioned to pass judgment. The burden of proof regarding the right to literate citizenship generally rests squarely on the shoulders of those at the cultural margins. H. L. Gates (2003) explained that "the politics of [literate] authenticity . . . and the rituals of validation scarcely died with Phillis Wheatley" (p. 69). They remain, in fact, ferociously evident in the arena of disability. Oelwein (1995) wrote of a young woman with Down syndrome whose parents knew her to be literate. Their skeptical physician handed her a medical text and asked her to read a section. She did so. He then asked her to explain what she had read. She hesitated. The physician dismissed her literacy. Oelwein (1995) noted, "I personally feel very fortunate that no one has made a judgment as to the value of my reading ability, based on how I handled a medical book. I fear that I would have flunked the reading as well as the comprehension test" (p. 3).

Consider Eugene Marcus, the young man with autism who was inspired to take a validity test of facilitated communication that he saw featured on a nationally aired PBS show denigrating the literacy-based communication method (see Marcus & Shevin, 1997; Palfreman, 1993). In the television documentary, as mentioned, a psychologist at the O. D. Heck mental retardation institution where the original study was conducted reported that among the 12 residents of the institution put to a total of 180 picture-labeling trials, "We literally did not get one correct response. Unbelievable really." The voice-over stated, "Life at O. D. Heck returned to the way it was before facilitated communication," meaning that critical literacy was eliminated from the experiences of the institutionalized residents. "The clients," the audience was told, "returned to learning the life skills they would need to survive outside."

In discussing the elimination of literate possibilities from the institution on the basis of the test, an O. D. Heck staff psychologist said he felt the "impact on the facilitators [support people] was going to be traumatic." No considera-

tion was expressed for the people with disabilities. They had apparently reverted to literate invisibility. A staff person who had acted as a facilitator before the testing told the show's interviewer, "It's like taking your best friend and going out and their getting hit by a car. They're just dead." But of course the people with disabilities were not dead; rather, they were simply, but profoundly, redefined from competent to wholly incompetent, from alive to, in the staff person's language, fundamentally "dead."

A similar situation ended with the failure of Douglas Hahn, labeled with autism and mental retardation, to pass a literacy test imposed by a federal trial judge. In the *Hahn v. Linn County* (2002) case, Hahn's family had demanded that the agency responsible for Hahn's residence and employment provide access to facilitated communication training. The agency, stating concern over the controversial nature of the method, demanded in turn that Hahn pass a literacy test to be conducted without facilitated support demonstrating Hahn's capacity to engage in literacy at a conversational level. The catch-22 was obvious to the family, and, when mediation failed, Hahn ended up in federal district court.

Sue Rubin, who, as described earlier, was labeled with autism and now communicates through independent typing, served as an expert witness for the plaintiffs. Rubin's typed testimony from the witness stand described a childhood spent under the presumption of severe mental retardation because she could not communicate. She recounted her introduction to facilitated communication at age 13 and her incremental development of typing skills that occurred with the physical support of a facilitator. Finally, she explained the years of struggle she undertook to become an independent typist (see Rubin et al., 2001).

Incredibly, the decision handed down by the presiding judge of the district court, Mark W. Bennett, never mentioned Rubin's testimony at all (see *Hahn v. Linn County*, 2002). Her name does not appear even once in the decision. Other experts, all professionals, are discussed at length, but Rubin's participation in the trial was entirely eliminated. She was made wholly invisible, thus obliterating the message of her testimony.

Ignoring Rubin's description of the lengthy, arduous process required to become a communicating citizen, Bennett ruled that Hahn failed during a closed session in chambers to meet a particular, albeit unstated, criterion of literate competence imposed by the judge himself. Thus furthering rather than challenging the original catch-22, it was determined that Hahn should not have access to training in literacy-based facilitated communication because he was unable to pass the judge's test of competence with facilitated communication. Bennett wrote:

In light of the court's finding that Mr. Hahn is not communicating through the use of FC, FC is not an effective means of communication for Mr. Hahn in particular; therefore, neither federal nor state law requires the [defendants] to provide it. (*Hahn v. Linn County*, 2002, p. 23)

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Having eviscerated Rubin, the only witness able to give a first-hand account of the struggle for literate citizenship faced by individuals with significant disabilities, the judge instituted a test with no stated criteria of success on which Douglas Hahn's fate hung. Like the 12 residents at the O. D. Heck institution, Hahn failed the test, and in so doing he apparently abrogated any presumption of a right to literate citizenship.

Conclusion: A Moral Stance on Resistance to Literate Disenfranchisement

Themes of literate control and disconnection continue to reverberate in the lives of individuals with significant disabilities. However, we also are witness to a resistance to these social impositions, as evidenced in the numerous stories offered of individuals with significant disabilities who have demonstrated a literate presence where imposed invisibility has been the general rule, who have demonstrated a capacity to grow in their literacy despite predominant assumptions of disability stasis, and whose literate voices have not been silenced by organized censure or hopeless demands for authentication.

We wish, however, to caution against the seductive logic that what is required to counteract literate disconnection is the accumulation of opposing evidence, scientifically collected, such that at some point a critical mass is reached. The logic would follow that this mass might bring down the house of cards on which the denial of literacy in the context of disability is constructed. While we clearly see value in building evidence of literate possibility, were it simply a case of critical mass or scientific accumulation, the literate disconnection would have been smashed years, or even decades, ago.

Rather, denial of literacy is insidious, as is racism, and is nearly impervious to conflicting evidence. It is hegemonic: a part of an ideology of control imposed on the marginalized by those who lay claim to the center. As such, we recognize that an overarching science of literacy is distinctly possible but extremely unlikely until a seismic shift takes place in the *moral fabric* of how people with disabilities are understood. Only after we establish a democratic morality that assumes citizenship and challenges marginalization will the science of literacy follow that supports the general acceptance of literate individuals who are also significantly disabled.

In December 1952, Robert Carter, a young NAACP attorney arguing for the plaintiffs before the Supreme Court in *Brown v. Board of Education*, brought up a lower court finding of fact in which the court had unequivocally accepted the testimony of a psychologist who claimed he had scientifically verified that school segregation resulted in a sense of inferiority on the part of African American children (Kluger, 1975). In effect, Carter was suggesting to the Supreme Court that science demanded the overturning of *Plessy v. Ferguson*. Justice Hugo Black, enormously sympathetic to Carter's position in the case, realized the precarious path Carter was following: Where one psychological study may point to detrimental effects of segregation, another may highlight psychologically healthy children who experienced years of

segregated schooling. Interrupting Carter, Justice Black asked, “What would the lawyer say if the court below had made a contrary finding? Are you implying that segregation might be legal in some places and not in others, depending on varying finding of facts?” (Kluger, 1975, p. 569). Carter, recognizing the justice’s concern, quickly returned to the NAACP theory of *Brown* in suggesting that science need not determine what was ultimately a moral affront violating both the 5th and 14th Amendments.

Our contention that morality must first change before science itself changes contrasts with professional disability convention. Predominant ideology suggests that science leads rather than follows one into citizenship. Science, so the tale goes, establishes methods that allow people to acquire valued skills of citizenship (e.g., critical literacy) prior to their being defined as a citizen. It is rare, however, that people assumed to be innately disconnected from the valued community (as is the case among those with significant disabilities) are able, through the use of evidence-based practices, to prove their way into membership. Rather, valued citizenship, literate or otherwise, appears to be reserved for those whose valued citizenship is fundamentally presumed. Thus, Sue Rubin, as an example we have previously cited, can publicly shift from the label of severe mental retardation to literate citizen (Rubin, 1995), can be the focus of an Academy Award-nominated documentary that she herself wrote (Wurzburg, 2004), can publish articles describing her experience (Rubin et al, 2001), can present at international conferences (Rubin, 1998), can be examined in others’ scientific publications (Mirenda, 2003), can major in history at Whittier College, and can generally build up a body of evidence that challenges all conventions of literacy development and severe disability—all of this while having absolutely no visible impact on the core of the field of special education or disability science.

Sue Rubin and others we have described acting in resistance to the dominant ideology of literate disconnection are doing so precisely because they have found valued membership and the presumption of citizenship in certain contexts of their lives. For many individuals with significant disabilities, this begins with their families, who presume (and consequently see) human value where society and the professions associated with disability commonly do not. On the basis of this presumption of connection, families push for its manifestation through moral terrains such as school inclusion and community access. It is on these particular terrains of connectedness, then, that the skills of citizenship, including literacy, are constructed. Hence, the seismic moral shift that will precede the science of universal access to literacy is, ultimately, an end to human devaluation and consequential segregation in schools and the wider community. This is the moral path to literacy for all.

Notes

¹Traditional deficit models of disability assume an objective reality to the labeled conditions. Thus, “intellectual disability” (i.e., mental retardation) is considered an objective manifestation of impaired capacity to know and think that can be measured and grouped according to severity. In contrast, we view labels as metaphors. Briefly, at some point the

nature of what it means to be smart was determined (e.g., responding in particular ways to particular questions on IQ tests). People who did not conform to such expectations were said to be other than smart (e.g., feeble-minded, retarded, stupid). Instead, they were performing in ways *as if* they were other than smart as determined by certain authorities. One can never know the full mind or motivations of another. However, the *as if* aspect of the performance, its metaphoric quality, was quickly forgotten and the label reified as an actual condition. We do not believe a person *has* an intellectual disability; rather, the person is *defined* by others as *having* the condition. Our language throughout the present article reflects this belief.

²An act of Congress in 1975 was required simply to guarantee that children with disabilities be allowed in school at all. While the Education for All Handicapped Children Act of 1975 (since reauthorized as the Individuals with Disabilities Education Act of 2004) favored full integration of children with disabilities, it provided an escape clause, referred to as the principle of the least restrictive environment, that allowed for the continued segregation of children into traditional locations far removed from the social, curricular, and literate mainstream (see Biklen, 1992). According to the most recent data available from the U.S. Department of Education (2003), legalized segregation is in fact the predominant educational approach directed at children who in today's lexicon are considered to have moderate to severe developmental disabilities.

³*Facilitated communication* is a controversial way of thinking about and enacting communicative expressiveness among people defined as having severe communication (spoken language) impairments and voluntary motor movement disturbances (meaning, among other things, difficulty gesturing on demand). These conditions are commonly associated with, but are not exclusive to, the label of severe autism. In the context of facilitated communication, rather than relying on ineffective speech or nonsymbolic means for communication, people with disabilities learn to gesture toward signs and symbols, including alphabetic print, in a typing motion to express thoughts previously deemed beyond their capacity. This process of learning to gesture or type requires initial physical support at the hand or arm (i.e., facilitation) from a communication partner.

⁴Disability studies emerged in the 1990s as a scholarly, academic, and activist convergence of autobiography, political advocacy, social critique, the humanities, arts, theater and film, phenomenology, critical sociology, anthropology, cultural studies, economics, and modes of qualitative inquiry. These studies represent a complex effort toward holistic realizations of disability experience that displace traditional, reductionistic psychological and medical orientations with their emphases on defect, impairment, and abnormality. Traditional interpretivism proceeds on the assumption that reality is created and social (Ferguson, Ferguson, & Taylor, 1992). This does not deny human difference but, rather, suggests that what is important is the meaning we make of human difference in specific locations at specific times. Traditional interpretivism also suggests that the goal of research is to describe, interpret, and understand.

⁵Our critical interpretivism extends from a sociological tradition initially articulated by Bogdan and Taylor (1990). They pointed out that substantial portions of their careers in qualitative research had been focused on examining and challenging institutions of dehumanization in the professional disability fields, but they had become increasingly interested in using qualitative research methods to explore and further promote practices and moral attitudes of participation, citizenship, and humanization.

⁶When data from field notes are presented, all proper names, unless otherwise noted, have been altered to protect confidentiality.

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