At the End of Intellectual Disability

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In this essay, Christopher Kliewer, Douglas Biklen, and Amy J. Petersen unravel the construct of intellectual disability that has dominated both policy and practice in schools and communities. The authors synthesize data from first-person narratives, family accounts, and participatory inquiry to propose a theory of human connectedness in which intellectual competence is constructed through social action and interaction. The authors trace the isolating, brutalizing, and dehumanizing consequences of the presumed "nothingness" associated with those labeled as having an intellectual disability and, by way of contrast, integrate written and video data that offer counterpoints to the notion of intellect as immutable and individual. The authors discuss the development of supports in valued arenas where the right to belong and to participate is realized without question; the provision of resources and materials based on affirmation, actualization, and empowerment; and the fostering of surrounding communities comprised of committed individuals who have stepped apart from deficit ideology and who are open to self-critique, surprise, and learning. The authors propose that in these contexts is found the end of intellectual disability.

Beginning in infancy, Sue Rubin's developmental trajectory dramatically strayed from conventional age-based standards and expectations. In the Oscar-nominated documentary *Autism Is a World* (Wurzburg, 2004), written by Rubin, her mother, Rita, recalls that as a young child "Sue didn't really give us a lot of hope. She did a lot of self-abusive behaviors," including biting and banging her head against windows, concrete surfaces, and walls. When Sue turned four, her family took her to a university psychologist for evaluation of "autistic tendencies." In the documentary, Rita relays memories of the doctors describing her daughter's behaviors as permanent: "Forget the tendencies. She's really autistic."

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Among the developmental domains, Rubin's limited speech emerged in sporadic, echolalic, and dialogically nonsensical forms. Her fine motor movements appeared impulsive, awkward, and often random. She did not approach relationships and interactions in a manner understood by others. As Rubin got older, repeated psychological assessments documented her cognition as stalled at the stage of a toddler, suggesting a profound social and intellectual disconnectedness with the surrounding world. When she was thirteen, Rubin's tested intelligence quotient (IQ) stood at 24 (see also Rubin et al., 2001). Rubin's extremely low IQ scores in combination with adaptive functioning deficits, described by the American Psychiatric Association (2013) as a "failure to meet . . . sociocultural standards for personal independence and social responsibility" (p. 33), resulted in Rubin being categorized as severely mentally retarded.

Once an individual is cast into a developmental disability category, sources on this subject often express a singular discourse of educational, sociocultural, and intellectual incompetence and perpetual disconnectedness (Gallagher, Connor, & Ferri, 2014; Smith, 1999). The most recent incarnation of the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (*DSM-5*) supplants *mental retardation* with the current preferred label *intellectual disability* (APA, 2013; Rosa's Law, 2010). However, any corresponding revisions to performance expectations or potentials remain mired in the prevailing discourses of hopeless disconnection. For instance, for those categorized as profoundly intellectually disabled, the *DSM-5* (APA, 2013) reduces human interaction to "nonsymbolic communication" (p. 36), and community participation to examples of the person "carrying dishes to the table . . . [finding] enjoyment in listening to music . . . or participating in water activities" (p. 36).

The grand narrative of severe disconnectedness mapped out the educational opportunities and expectations thought possible for Rubin. In the documentary (Wurzburg, 2004), Rubin's mother explains, "We knew that she would be retarded . . . and we knew that she would be educated in special day classes with other people with severe handicaps." During a key-by-key typing scene, this perception is challenged when Rubin ponders, "Was I retarded?" With the voice of actress Julianna Margulies narrating, Rubin continues, "I certainly understand why I was assumed to be retarded. Perhaps I was." Ironically, Rubin's acceptance of the reality of her own cognitive vacuity exposes at the immediate level the unreality of intellectual disability in her own life. Pondering one's lack of capacity to ponder contradicts more than a century's worth of accumulated scientific and educational dispositions regarding the innate and immutable reality of the grand narrative of intellectual deficit (Danforth, 2014).

In this article, we link the experiences of Rubin with other data — such as first-person accounts, family narratives, and participatory research, including our own field work —to expose and deconstruct the pessimistic fable of intellectual disability.[1] The meta-tale no longer holds. In its place, we pro-

pose a theory of human variation associated with intellect premised on human connectedness, inclusion, and the presumption of competence (Artiles, 2003; Biklen, 2005; Danforth, 2014; Gallagher et al., 2014; Ginsberg, 2002; Hehir & Katzman, 2012; Kingsley & Levitz, 1994; Mooney, 2007; Petersen, 2009b, 2011; Sellin, 1995; Williams, 1992).

Intellectual Disability, Nothingness, and Connectedness

In *Autism Is a World* (Wurzburg, 2004), Rubin makes a reference to her existence as "a nonperson." This sentiment is echoed by modern-day blogger Amy Sequenzia, a disability rights activist who, in her youth, was labeled profoundly mentally retarded. Sequenzia (2012) blogs about surviving within a spectral existence: "There were no expectations for me to fulfill because I was *nothing*." Jamie Burke, a fellow activist who was also labeled on the autism spectrum, similarly notes, "Do you know that vintage movie, *The Invisible Man*? That's how I've felt. The clothes were there but the body and soul felt like *nothing*. How can you live a life getting treated like that?" Burke's description of his perceived nothingness appeared in the documentary *Inside the Edge* (Kasa-Hendrickson, Broderick, Biklen, & Gambell, 2002) depicting his struggle to develop understandable communication and, beginning in his teenage years, useful speech.

The Origins of Nothing and Disconnectedness

Like Rubin, both Sequenzia and Burke have led lifelong struggles against the perception of significant intellectual disabilities foisted on them in daily experience and by the formal testing and diagnostic tools of psychology and education. The initial scientific legitimacy accorded to psychology was largely derived from early-twentieth-century efforts by those in the discipline to identify and attribute mental defects through supposedly objective and quantifiable means (Danforth, 2014; Slee, 2004). For example, in 1905 Alfred Binet and his student Théodore Simon, under the charge of the French ministry of education, developed a rather innocuous screening in order to identify children who might struggle at school (Pollack & Brenner, 1969). The test was efficient to administer, scored numerically, and correlated closely with teachers' opinions of children's educational levels (Gould, 1981). Gardner (2004) suggests a particular intention of this effort, noting that "Binet devised the first tests of intelligence to sift out retarded children" (p. 15).

Binet (1909) believed that his test did, in fact, assess children's intelligence; however, he understood this to be neither a fixed nor innate construct. Intelligence, according to Binet, was complex and largely a concern of environment and opportunity (Gould, 1981). Portending debates to come, within a short time after the test's introduction, Belgian researchers working from a model of intellect as innate and hard-wired proclaimed that Binet's test proved that their nation's children were inherently smarter on average than French chil-

dren (Binet, 1909; Lewontin, Rose, & Kamin, 1984). In response, Binet (1909) warned,

> Some recent thinkers . . . have given their moral support to . . . deplorable verdicts . . . affirming that an individual's intelligence is a fixed quantity, a quantity that cannot be increased. We must protest and react against this brutal pessimism; we must try to demonstrate that it is founded upon *nothing* [emphasis added]. (p. 101)

Binet realized that *nothing* is always something; intellectual disconnectedness is a form of connection, just a highly devalued and nonconformist one. The emergent field of psychology, Binet feared, was in danger of losing what he perceived to be its modernist optimism and promise as it veered away from the empirical into merely reifying the preexisting pessimism directed at those deemed unruly or disordered. For much of history, human defect had largely been left to the definitions and explanatory dogma of myth or religion, often resulting in isolation of or brutality toward individuals deemed intellectually disabled (Trent, 1994). Binet recognized the "empirical nothingness" out of which ecclesiastical and cultural prejudices were used to form "natural" hierarchies of human worth. Binet's Pollyannaish hope was that his fellow modernists in psychology might share a sense of human possibility born of an actual science to replace the existing myths that he characterized as empirical nothingness. However, he realized that this hope was quickly slipping away, and his sudden death in 1911 effectively silenced what might have been an influential and progressive psychological discourse on intellectual fluidity, malleability, and resilience (Trent, 1994).

In 1908 Binet's intelligence test reached America's shores and arrived in the hands of Henry H. Goddard, a psychologist and head of research at the Vineland Training School for Feeble-Minded Boys and Girls, located in New Jersey (Trent, 1994). Goddard, an avowed eugenicist, had been struggling to develop a reliable social Darwinian scale for sorting individuals cast as mentally defective. In his revision of Binet's test, Goddard (1911) believed he had formulated an apt tool to identify—and thus control—those deemed to be defective. His revision introduced the attribution of a numeric mental age to an individual. This construct suggested that one's total intellectual performance could be expressed as the chronological age at which an average person was said to reach the same abilities. Following this adjustment to Binet's measure, Lewis Terman (1916) developed an iteration now known as the Stanford-Binet Intelligence Scale. IQ tests, most often divided into subsections, were said to assess a subject's capacity to reason using novel information, referred to as *fluid intellect,* and to effectively make use of existing knowledge to solve problems. Terman (1916), in authoritative terms, expounded on Goddard's eugenics philosophy by suggesting, "[Through the IQ test] there will be discovered enormously significant racial differences in general intelligence, differences which cannot be wiped out by any scheme of mental culture" (p.

91). Terman included Stern's ratio between mental and chronological age and thus appeared to dissolve the dilemma of Binet's "nothingness" by identifying intelligence as an incarnate and measurable objective quantity. Subsequently, the Stanford-Binet IQ was accepted by scholars and the general public alike as a predictive statistic that falls along a bell-shaped curve (Lewontin et al., 1984). Those who scored poorly or who were deemed to have *less* intelligence were thus perceived by psychologists and educators as possessing an objective and measurable disconnectedness from valued citizenship and full humanness (Smith, 1999).

Challenging Nothing and Disconnection

Over subsequent decades, the fields associated with defining and controlling disability reified notions of an objective, innate intelligence measured as a singular, individualized quotient. Thus, it was business-as-usual when, in the late 1990s, psychologists assigned thirteen-year-old Rubin an IQ score in the low twenties and described her as possessing the mental capacity of a two-year-old (Rubin, 2005; Rubin et al., 2001). However, renegade researchers from within the field of psychology had begun theorizing models of social and multiple cognitions that ran counter to the grand discourse of a nativist and individually autonomous intellect. These efforts suggested that intelligence was not a discrete construct locked within an individual; rather, it was fluid and multidimensional and flowed across relationships among surrounding people, materials, tools, opportunities, and expectations (Resnick, Levine, & Teasley, 1996).

Models of social cognitions range from the more progressively modernist to those that are increasingly radical in their interactional, constructivist, and contextualized orientations (Cole & Engestrom, 1993). For example, Gardner (2004), who is generally grouped with the progressive modernists, promulgated a theory of intelligence that expanded the construct into what he now identifies as 8.5 autonomous multiple intelligences within each human being (the .5 being his somewhat facetious reference to an Existential Intelligence he has only preliminarily suggested). Gardner posits that the described intelligences, and others yet to be identified, do not function in isolation but exist in a transcursive fashion across an individual's mind and between the mind and the social realm. Those capacities that have so far been named in his theory are identifiable today because the historical, cultural, and physical worlds have brought them forth and made them necessary and valued.

Though he recognizes the interactional nature of the multiple intelligences, Gardner (1991, 2004) insists that the 8.5 intelligences are not the relativistic whim of differing cultures and historic ages, manifesting here but not there; rather, they exist as biological truths across time and place (albeit varying in degree of value and visibility). Thus, Gardner's work has firmly expanded the locations and ways in which one might have sought to understand Rubin's

mind when she was a child, and this might have been extraordinarily useful. But we are also left with a theory that might simply have resulted in Rubin failing in 8.5 ways rather than one. Indeed, Gardner (1991) hints at the latter possibility when, in describing the preschool years as the "age of symbols," he qualifies the title as "true for *normal* [emphasis added] children the world over" (p. 56).

Appearing counterintuitive to the ensconced belief of intellect as an innate, wired possession of an individual, more radical conceptualizations of socially emerging cognitions heighten the roles of environment, history, and context (Groff, 2013). Herein, cognitive processes are considered to be distributed across members of a social group and the cultural tools that are crafted or are made available (Resnick et al., 1996). Salomon (1993) notes, "What characterizes thinking is that the social and artifactual surrounds, outside the head, not only are sources of stimulation and guidance but are actual vehicles of thought" (p. xiii).

Intellect as socially shared has been illustrated, for instance, as "transactive cognitive partnerships" (King, 1998, p. 14), in the context of peer-tutor relationships, through which children in interaction mutually appropriate whole new cognitive avenues. Lebeau (1998) combines sociocultural and ecological psychology to describe the distribution of medical expertise across communities of professionals and materials available resulting in qualitatively altered diagnostics and approaches to treatment. Others have focused on whole classrooms as knowledge-building communities (Groff, 2013; Hatch & Gardner, 1993; Hewitt & Scardanalia, 1998) and suggest that individual competence is indivisible from group processing. Thus, the science of traditional psychology, which foregrounds individual intellect as objectively knowledgeable and measurable apart from the social context, requires a radical transformation. Within this revolutionized paradigm, "*mind* cannot be studied independently of the culturally organized settings within which people function" (Moore & Rocklin, 1998, p. 107).

The idea of cognition as situational and social has been applied to the complexities of school-based struggles in individual children and marginalized groups (Kincheloe & Steinberg, 1996; McDermott, 1999). However, students with presumed severe intellectual disabilities, such as Rubin, remain excluded—"examples where culture seems beside the point; where physiology has gone so far awry that it threatens to overwhelm the social context" (Ferguson, 1987, p. 56). The apparent absence of any reference to minds labeled as severely intellectually disabled within the psychological literature on social cognitions is disturbing. The omission is rationally interpreted to mean the models can only stretch so far. However, such a caveat invalidates the models as aptly descriptive of the breadth of human intellectual engagement. Consequently, for these theories of thought to hold, the minds, and thus the humanity, of people labeled as severely impaired must be dismissed as irrelevant. We are left wondering if this is the operating presumption.

From Nothing Toward Connection

In day-to-day life, apart from the formalities of psychological science, a competent intellect has vernacularly been ascribed to those who perform in expected ways in the classroom, home, community, workplace, and other valued daily environments (Linneman, 2001). As such, colloquial judgments of another's intellect are based on that individual's conformity to the cultural mores of particular social situations and contexts. In essence, the better one knows and follows the rules, the more intellect one is said to possess.

In its effort to operationalize and scientize intelligence as an objective attribute subject to precise measurement and quantification, the field of psychology sought to disentangle the construct from the messiness of cultural and social contexts (Danforth, 2014). Intelligence was to be a detached, quantifiable entity of mind that remained stable as an individual moved from situation to situation; it was to be an abstract cognitive aptitude that could both explain and predict an individual's capacity to perform in any form of social environment. However, in this endeavor to prove a detached global cognition, the architects of IQ merely reified the colloquial tradition requiring conformity to dominant norms. The test-taking structures themselves create a social context that demands conformity relative to the version provided. As important, the content presented in the tests forces the test taker to rely on what he or she has been taught, exposed to, or allowed to experience. In his classic analysis of the mismeasure of intellect, Gould (1981) provided multiple examples of context-bound, culturally idiosyncratic questions from the Stanford-Binet IQ tests, noting, "Terman's tests stressed conformity with expectation and downgraded original response. When the expectations are society's norms, then do the tests measure some abstract property of reasoning, or familiarity with conventional behavior?" (pp. 175–176). As such, judgments of one's intellect remain wholly entangled with one's behavioral and interactional conformity to established norms.

As was Rubin's experience in childhood, Peter Gwazdauskas's nonconformist performances across context after context were consistently judged as failed, and significantly so. Born with trisomy 21, Gwazdauskas is featured in the Academy Award–winning documentary *Educating Peter* (Wurzburg, 1992), which focuses on Gwazdauskas's third-grade year, when he transitioned from segregated special education for children with judged cognitive deficits into a regular education classroom. Trisomy 21, or Down syndrome, is an interesting genetic anomaly in that, despite a generally ignored body of evidence to the contrary, it is inextricably linked both professionally and colloquially to innate intellectual deficits (Kliewer, 1998).

In *Autism Is a World* (Wurzburg, 2004), Rubin describes her intellectual disengagement by saying, "I was lost in some way . . . Voices floated over me." While with *Educating Peter* (Wurzburg, 1992) the audience is not privy to the same level of insider perspective, Gwazdauskas certainly does appear "lost in some way" as he shifts from segregated schooling into the hectic reality of a

third-grade classroom. The documentary portrays Gwazdauskas as a stranger in a strange land, writhing on the floor in lone combat with a chair, prone to aggression, and demonstrating a general lack of competence within the patterns and mores of the elementary school. In one interview in the documentary, Gwazdauskas's teacher, Martha Ann Stallings, explains, "I think Peter felt a little lost . . . He knew he was out of place." Gwazdauskas's peers appeared to feel the same way. This sentiment is illustrated in interviews early in the documentary when classmates disclose such things as, "I stare at him 'cause he looks different," and "I was really scared of him kind of 'cause he was making these really loud noises." One peer asks directly, "Why do we have him in this class? He's not going to learn anything."

As depicted in both documentaries, Rubin and Gwazdauskas eventually experienced a profound inversion of their social and intellectual disconnectedness. In Rubin's case, up to age thirteen she had been exposed to only minimal, highly rigid, and rudimentary efforts with alternative systems of communication apart from speech to indicate immediate physical needs. In an odd yet not uncommon conundrum, her spoken language was deemed to be so severely disordered that offering communicative alternatives was deemed hopeless (Rubin et al., 2001; Rubin, 2005). Rubin's teachers believed that her speech reflected the ossified, unalterable rudiments of her intellectual capacity. When Rubin turned thirteen, however, these same teachers encountered an augmentative and alternative communication (AAC) approach for people with severe communication struggles. Referred to as *facilitated communication training* (Crossley, 1997), the method appeared to address various motor movement and anxiety struggles that Rubin experienced. Employing the system, personnel at her school introduced Rubin to a simple alphabet board and a small keyboard from which she could select letters by pointing. A teacher provided her with initial physical support to stabilize, calm, and slow her arm and hand gestures as she reached toward the board. That human touch, provided at her hand, seemed to allow Rubin increased control over the initiation and direction of pointing. Within the realm of facilitated communication training, this stabilization through touch counteracts profound anxiety, sensory-perceptual, and physical movement struggles associated with autism and other developmental disabilities (Donnellan, Hill, & Leary, 2013; Kanner, 1943; Oppenheim, 1977; Torres et al., 2013). Following a trajectory documented for many people engaged in facilitated communication training, Rubin required less physical support as her pointing skills developed (Biklen, 2005; Mirenda, 2003; Rubin et al., 2001; Wilson et al., 2014). She now types to communicate without any human touch at all.

Wurzburg's documentary reveals that, at first, Rubin's physically facilitated pointing toward a keyboard was haphazard and only marginally decipherable. Just as Gwazdauskas did not immediately appear to fit into his newly inclusive third-grade class, Rubin did not immediately appear to benefit from her AAC method. However, in both situations, surrounding educators persevered.

Rubin admits, "Progress was slow at first. I was a terrible subject." Her mother pointed out that after four months of focus, much of Rubin's typing remained as "gibberish." At times, however, contextually meaningful letters and even whole words began to emerge. "My mom insisted that I practice every day," Rubin recounts. "My mind began to wake up." Regarding her daughter's slow but ultimately dramatic progress, Rubin's mother notes, "When it came time to go to high school, we knew that [Sue] had to be in regular classes in an academic curriculum" (Wurzburg, 2004).

Rubin—surrounded by a committed team, in interaction with a tool for communication *other than speech*, provided opportunities in new environments, and presented heightened expectations—was realizing an inversion of the nothingness out of which her presumed intellectual disability had been crafted. Similarly, in *Educating Peter* (Wurzburg, 1992), the audience is witness to an almost pure example of Vygotskian scaffolding (Daniels, 1996) as Gwazdauskas internalizes the literate, academic, and social culture of the classroom. Six months into the school year, a peer tells an interviewer, "He started reading; he started pasting; he started running and catching things; and he just changed it all." One is left wondering what precisely occurred in his previous segregated special education placements that left him so unprepared for a regular classroom setting. In one scene, Gwazdaskas participates in a science lesson in which he defines the term *environment*. A few minutes later he calls to the teacher and quietly announces, "I stupid." He repeats this several times as if talking to himself. Rubin's contemplation of her own intellectual incapacity was done retrospectively; and here, again, we are confronted by a person labeled cognitively deficient pondering his own intellect *in the moment*, a trait not found in the *DSM-5* description of intellectual disability.

Realizing Connectedness and Competence

For Rubin and Gwazdauskas to experience an inversion of their defined intellectual disconnectedness, parents and teachers of the two young people suspended deeply held ideologies of deficit while engaging them in new contexts, thus fostering an ever-increasing social *connectedness*. This connectedness was based on radically altered expectations of social and intellectual competence (e.g., Collins, 2013). In both situations, immediate success was not expected; nor, in fact, did it occur. Human development is not a crash of cymbals but rather an elaborate symphony that plays out in movements (albeit with crescendos and moments of raging percussion). Suspension of a deficit ideology within contexts of heightened expectations requires recognition of the individual's right to participate and an acknowledgment that she legitimately belongs in the newly crafted situations (e.g., Gwazdauskas in a third-grade classroom; Rubin within a communicative system responsive to her needs). The process toward ultimately and genuinely presuming competence requires perseverance on the part of team members, an openness to the possibility of

learning something new and of being surprised by and about the individual and one's self, and continuous effort at critical self-reflection and problem solving across multiple support personnel (Kliewer & Biklen, 2007).

Regarding Rubin's case, belief in her intellectual incompetence was not immediately displaced but, rather, it was set aside while incremental success begat increasingly sophisticated success. As her capacity to communicate expanded with a certain few trusted individuals, she continued to experience high levels of anxiety in other situations, thus making her look highly incompetent in some contexts but not in others (Rubin, 2005).

Gwazdauskas benefited from his educational team's perseverance and commitment to his successful inclusion as a rightful member of the third grade. As with Rubin, the teachers' communal efforts appeared to foster increased academic and social successes though struggles remained evident. His classroom teacher, Stallings, noted that in the seventh month of school, "Peter was still having *a few* outbursts [involving aggression], but they all occurred at the end of the day when it was time to get on the bus and leave his friends." Peter was no longer an outcast at school. Stallings and her colleagues had changed their expectations: "I went from, 'Peter, I'm not sure you can do some of the things I'm wanting you to do,' to 'Peter, I'm expecting you to do these things.'" One of his school friends explained, "He changed because we changed. He changed because we changed our minds about him." In the documentary, Gwazdauskas is observed reading, writing, and engaging as a full citizen of the class in a variety of situations.

For both Gwazdauskas and Rubin, initial connectedness led to *increasingly complex connections* between the two and their surrounding worlds, further dissolving perceptions of intellectual deficiency. For Rubin, connectedness that led to beliefs of intellectual competence opened and expanded her world; she graduated with a history degree from Whittier College and walked the Oscars' red carpet. While he did not engage in grade-level schoolwork, Gwazdauskas's academic participation expanded exponentially alongside his developing relationships. One friend, who earlier in the documentary recounted being physically attacked by Gwazdauskas, noted in an interview toward the end of the year, "It doesn't really matter who your friends are. Peter's one of my best friends, and some normal people in my class aren't my friends at all." In this friend's eyes, Gwazdauskas had not achieved the status of "normal," but that particular label lost its exclusionary meaning as Gwazdauskas, his peers, and his teachers redefined connectedness and belonging.

The Fragility of Connectedness and Competence

Educating Peter was awarded an Oscar more than two decades ago. While some professional terminology has subsequently changed, the underlying story of a child labeled as mentally retarded and struggling for acceptance in a general education setting remains uncomfortably relevant. For Gwazdauskas, this

vacillating struggle continued throughout his public schooling, as recounted in the follow-up documentary *Graduating Peter* (Wurzburg, 2001). In this second film, focusing on his high school experience, Gwazdauskas encounters numerous social and academic obstacles that distance him from his peers. The fragile shift toward a discourse of connectedness is a transition in which those around the individual come to understand him as a valued, able learner and a full participant across the breadth of social and cultural opportunities presented in nurturing contexts. This path, however, is persistently tenuous.

Certain of these complexities emerged for two of us, Petersen and Kliewer, during a multiyear statewide research initiative supporting literacy for students with significant disabilities. The funded project developed in part out of our mutual career-long interest in supporting all children's curricular and social involvement in general education. The initiative brought together multiple teams of educators, forming a cohort that first met over an intense weeklong summer course taught by the two of us. The teams were voluntary and self-selected, and members appeared motivated; thus, within the area of ongoing professional development for teachers, the summer course might be considered enough to disrupt ideologies of school-based literate and communicative disconnection often experienced by students with significant disabilities. Indeed, the teams took away from the course action plans and a palpable air of excitement about opening new avenues to writing, reading, and communicating for their students with significant disabilities. This optimism on the part of many participants, however, appeared to quickly revert to entrenched belief patterns of student deficiency. Yet, our research suggests that with ongoing support, team members could regain the traction of possibility as they challenge their own deficit ideologies through group perseverance, openness to new practices, willingness to be surprised, and continuous critical self-reflection.

Following the summer course, the project protocol required the researchers to conduct monthly classroom visits. These monthly visits continued throughout the first year of the initiative. In the second year, the first-year teams remained in the project as mentors to a new cohort and continued to have in-class visits by the researchers. We designed the visits to provide direct, situation-specific support involving the introduction and implementation of curricula, methods, principles of inclusive education, and technology.

Despite the summer professional development, our initial fall visits suggested that the teachers' dispositions and practices toward students with disabilities often reverted to tradition and deficit ideologies. This reversion demonstrated to us the importance of our sustained, consistent schedule of visits. For instance, on our first visit to the classroom of Jean Zubak,[2] we encountered a sensitive situation. Zubak had been teaching for twenty years in self-contained special education classrooms. During the summer course, she expressed a great deal of excitement about the possibility of introducing emergent literacy practices she had previously considered far too complex for her kindergarten and primary-grade students with significant disabilities. During

that initial visit, however, Zubak pointed out one of her five-year-old students, Rosa, and told us, "This one knows *nothing*. She just has *nothing* going on. No language." At that moment, Zubak insinuated that the literacy project would prove to be irrelevant to certain or even most of her children. Fortunately, Zubak remained a committed participant of the project, and she eventually experienced a profound shift away from stifling deficit ideologies and toward a discourse of connectedness for many, though not all, of her young students.

We founded the summer course in which Zubak had so passionately participated on the assertion that "no child is too anything [i.e., too disabled] to read and write" (Yoder, 2000). Underlying this premise is the understanding that human variation associated with disability need not be conjoined with morally based judgments of deficiency cloaked in the language of objective science. Human differences, of course, are tangible, observable, and real: one person speaks while another may not; one person walks while another rolls. Cultural contexts and institutions have been largely crafted to effectively accommodate those whose performance patterns most closely align with the majority; however, operating outside the parameter of the majority does not necessitate being defined as innately defective and in need of confinement (Gallagher et al., 2014; Petersen, 2009a, 2009b). Rather, cultural contexts and environments—associated with communication, literacy, academics, schooling in general, mobility, human relations, and so on—can be transformed and transformative (Danforth, 2014; Groff, 2013).

Policy and Practice Toward Transformation

The message of contextual transformation—in this case, specific to literacy and communication opportunities in school—undergirded the summer course of which Zubak was an active participant. She and her colleagues were exposed to methods and rationales for comprehensive literacy instruction in which all children are provided daily, increasingly complex opportunities to read, write, communicate, and reflectively listen (Pebly & Koppenhaver, 2001). Throughout the weeklong class, we focused on AAC and technology. The content was supported by both legislative policy and certain transformative movements within the fields of education and community access. At the policy level, the Americans with Disabilities Act of 2008 and the Individuals with Disabilities Education [Improvement] Act (IDEA, 2004) are civil rights laws enacted to counter entrenched and institutionalized discrimination by mandating access to valued communities through reasonable accommodations. Gwazdauskas's shift from segregated schooling into the regular third-grade classroom was the direct result of his school district's efforts at transformation in response to the IDEA's Least Restrictive Environment (LRE) mandate, which states, "To the maximum extent appropriate, children with disabilities . . . are educated with children who are nondisabled." In the fall of 2011, in response to the LRE, half of U.S. students labeled as having intellectual disabilities from

preschool through high school spent at least 60 percent of their school day in general education environments. In 1990, that figure was only 25 percent (U.S. Department of Education, 2013).

In addition to the IDEA, the No Child Left Behind Act of 2001 in part responded to a growing chorus from families and educators demanding "access to academics" on the part of students receiving special education services. Thus, efforts have galvanized along the lines of the state-supported literacy project that Zubak and her team adopted to promote the language development of students who are considered to have significant disabilities.

In response to policy, attention has been focused on pedagogical models that disrupt entrenched belief patterns that emphasize the presumed defectiveness of students with disabilities such that they are denied social and academic opportunities. An example of one such conceptual approach is Universal Design for Learning (UDL) (Center for Applied Special Technology, 2014). The model is premised on the recognition that any classroom, inclusive of students with disabilities or not, is inherently a diverse cultural context (Glass, Meyer, & Rose, 2013). Rather than condemning diverse ranges of abilities as hindrances to learning, UDL offers a framework for facilitating action and problem solving that supports the structuring of environments, which are increasingly responsive to the needs and strengths exhibited by students (Vanderlinde, Aesaert, & van Braak, 2014). For instance, UDL challenges educators to replace monolithic teaching approaches by considering multiple means of representation, action and expression, and engagement when planning instructional opportunities (Center for Applied Special Technology, 2014). As an example, many teachers rely on whole-class lectures followed by assignments done individually by students (Udvari-Solner & Kluth, 2007). This reliance is based on tradition rather than evidence of teaching effectiveness. In a classroom premised on the principles of UDL, a teacher might instead create student learning teams focused on students' interests on a specific topic. The teacher would embed a range of options and supports to guide students' inquiry and provide the students with the autonomy to choose the most effective means from a broad array of options for expressing new conceptual understanding. The UDL framework provides ample space for the inclusion of approaches often directed specifically at the participation of students with disabilities. These include differentiated instruction, implementation of assistive technology, and development of AAC systems (Glass et al., 2013).

The Vestiges of Deficit Ideology

At the beginning of the school year, Zubak also viewed Stacy, one of Rosa's classmates, as too intellectually impaired to benefit from emergent literacy opportunities introduced in the summer course. In a subsection of Stacy's Individual Education Plan (IEP) titled "Present Level of Academic Achievement & Functional Performance," Zubak, the primary author of the docu-

ment, begins, "Stacy has Down syndrome," leaving the IEP reader to garner the relevance of this proclamation as it relates to Stacy's current achievement. Zubak then describes Stacy as having "significant cognitive delays" and notes that her "progress is significantly below her peers in general education." The IEP asserts that Stacy does "not independently acquire functional life skills" and that she has "a short attention span" for which instruction "must be provided in a one-to-one special education setting." Finally, the IEP notes that Stacy "gains attention by destroying materials, hitting others, running from adults, and throwing toys and materials." Omitted from the IEP is any discussion related to Zubak's still-early participation in the statewide literacy project. Nor is anything akin to emergent literacy levels or goals presented in the document. Zubak's IEP for Stacy adopts a negative framing of the child by focusing on what she can't do and how she is behaviorally deficient in comparison to others. The document does not summarize Stacy's present level of academic achievement.

In close collaboration with the literacy project researchers, Zubak and her team, including general educators, therapists, and paraprofessionals, began to incrementally introduce literacy and communication opportunities within the classroom. For instance, following our initial visit, Zubak instituted a daily guided reading period in which she or another adult read to a group of children and asked multiple questions as the reading proceeded (Pebly & Koppenhaver, 2001). Children were expected to respond. For those students who struggled to speak, the reader introduced AAC systems. Zubak also instituted a daily emergent writing period for all of her students, a time during which she encouraged them to draw or write stories. As did many of her colleagues from the cohort, early on in this effort Zubak approached new activities with skepticism. "I don't know if this'll work," she often said.

Like teachers and family surrounding Rubin who had to confront their own deeply held deficit ideologies, Zubak, in collaboration with a team of support, was challenged to see past her existing pedagogical frame to experience a shift from certitude (in this case, around beliefs in her students' deficits) into a moment of transition that opened the possibility for exploration. In so doing, her perception of the children's performance began to change as hints of connectedness emerged. For instance, when she decided to implement daily writing, Zubak told one of the researchers, "I can't see Rosa doing this. I've never even seen her hold a marker." Nonetheless, Zubak sat with Rosa drawing and labeling Rosa's pictures to serve as a model and to offer emotional support. Within weeks, Rosa was writing her own name in legible fashion and could identify the letters in it. In one writing session, Rosa drew a picture consisting of intertwined shapes and then wrote beneath it two clear Ms and an approximation of the letter A. She tapped her writing and loudly announced, "Momma." Zubak, who was roaming nearby, put her arm around Rosa and said, "That is a beautiful picture of Momma." Such demonstrations of increased literacy sophistication altered Zubak's perception of her role as

a teacher, which fostered an increasingly responsive educational context. In a research interview late in the school year, Zubak explained, "I never really had given kids much of a chance to be readers or writers. This is all different now."

Identities in Flux

As seasoned action researchers, we were not overly surprised by the initial dearth of comprehensive emergent literacy curricula in Zubak's classroom and in many of the other programs participating in the literacy project. Nor were we shocked by Zubak's deficit-driven characterizations of Rosa and Stacy. Curricula with little relevance to general academics predicated on the ideology that intellectual disability is an innate and objective deficiency in conceptual capacity remain pervasive in special education programs across the United States (Smith, 2010). What we were most interested in, however, was the fragile emergence of understanding, reflection, and action on the part of Zubak and others in the project reflecting a counterdiscourse premised on human possibility and connectedness to valued social and cultural contexts, including literacy and general education classrooms.

We use *fragile* here because, in Zubak's situation, the emergence of this discourse of possibility and connectedness required the convergence of several tenuous dimensions that, if absent, could easily have left her students disconnected from the possibility of literate citizenship. For instance, no policy required Zubak and her team to join the project. Most teachers who were invited chose not to participate. The project itself might have been designed without monthly follow-up support. Professional development in education often does not provide direct, in-classroom assistance on a monthly basis. Zubak might have overtly rejected the supports provided her or simply quit the project at a point of discouragement.

In the shadow of the dominant deficit model of disability, the fragility of connectedness is ever present. This fragility is further informed by Dan Keplinger's Oscar-winning, self-authored video documentary *King Gimp* (Hannah & Whiteford, 2004). Keplinger is a recognized artist with significant physical disabilities. At his birth, Keplinger's mother was counseled by professionals to institutionalize her son. She refused. Later, Keplinger's school district policy forced his enrollment into a segregated special education school (Keplinger, 2001). The struggles presented by Keplinger's physical disability, such as his indecipherable speech, inability to use his hands, and inability to walk, led professionals to presume that he had significant intellectual deficits as well. In his film Keplinger (Hannah & Whiteford, 2004) explains that "no one could understand I was an intelligent person inside of this body." He eventually found his path into art, but not without struggle. He reports that by age fourteen he desperately wanted out of the confines of his segregated school. His mother recalls, "The psychologist said Dan was not capable of handling a mainstream environment, nor was he ready for that level." However, perhaps

in part buoyed by the mandates of the IDEA (2004), she presumed her son's legal right to the possibilities offered in a general education setting and initiated what Keplinger describes as the "battle" to exit his previous school and find a regular high school that would accept him.

The documentary reveals that Keplinger's battle for desegregation is eventually won. In his new educational environment, Keplinger explains, "The best thing that happened to me had to be art." Keplinger, unable to effectively use his hands, discovered charcoal, pencils, and paintbrushes that could be connected to a pointer attached with a strap to his head. These media became his primary tools for engaging with the world—"Art gave me a way to express myself without anybody interpreting for me . . . The brush became my force."

However, Keplinger's entry into the studio was initially tenuous and fragile. The high school art teacher recalled in an extremely honest interview that when Keplinger initially motored into the classroom his "first reaction was how do we get around *this* or even possibly how do we move Dan out?" Keplinger, on sight, was immediately a *this* to be gotten around or *moved out*. At that moment, Keplinger's future balanced precariously on the decisions made outside of his control. How might this narrative have proceeded had the art teacher acted on his discomfort and feelings of pessimism toward Keplinger, rejecting the IDEA mandates? "Ultimately," the teacher explains, "we realized we could adapt." Those in authority around Keplinger recognized that barriers to his participation were not innate but socially, attitudinally, and environmentally imposed. Again, while Keplinger's inclusion and access to adaptations and supports are his by right, according to the IDEA, deficit ideologies commonly result in the denial of social justice for labeled people (Hehir & Katzman, 2012).

The teacher's realization that "we could adapt"—and thus remove socially created barriers to participation—resulted in Keplinger no longer fulfilling the role of an abstract and defective *this* existing as an obstacle to be gotten around. As the art teacher explains in an interview in the documentary, he had come to understand Keplinger's human complexity:

> Every piece he makes is somewhat a self-portrait in that they have a very specific reference to who he is and his physical conditions [no longer presumed *intellectual* conditions]. It's descriptive, and for those who want to *read* it, I think there's a lot of communication there on so many levels.

Continuing with the metaphor of literacy and language, the instructor shares, "With the head stick, you know, it's his head-writing—the same as calligraphy or handwriting. And so he has his head-writing, which is his marks, which are very personal to him." The presumption of Keplinger as a rolling embodiment of disconnectedness was replaced—in that specific context of the high school art room—by a presumption of artistic competence.

While still in high school, Keplinger accumulated a growing portfolio of paintings that were displayed in galleries and shows. And while it seemed that

his profound talents could not be denied, he continued to encounter deep skepticism about his intellectual and artistic capacities. In his documentary, he recounts that in college "one teacher told me to my face that I would never be an artist," and how "two professors wouldn't even speak to me," evoking the specter of nothingness. Keplinger says that for a time he actually quit painting. For people with presumed intellectual deficits, identities aligned with connectedness and competence and those associated with hopelessness and dehumanization are in constant tension (Collins, 2013; Danforth, 2014; Gallagher et al., 2014; Petersen, 2009a). Was Keplinger an artist with a verifiable body of work, or was he an ethereal nothing unworthy of being spoken to? Similarly, Rubin suggests that she continues to experience ambivalence and even hostility directed at her intellect despite scripting an Oscar-nominated documentary and graduating from college. In an e-mail exchange, she notes that in this presentation of her narrative, we captured how professionals "saw and still see my behaviors" (personal correspondence, December 2013), adding, "I am really sick of how they see me, but it is something that I cannot control—it is something that has to change within them."

As further stark illustration, Collins (2013) presents the case study of "Jay, an eleven-year-old child whose school identity is one of profound failure. Since preschool, school psychologists have labeled Jay with a multitude of educational disorders associated with behavior, attention, and intelligence. As with Keplinger, these officially sanctioned ascriptions of deficit tended to overwhelm other possible ways of understanding Jay and served as a master status. In contrast, Collins (2013) provides extensive descriptions of Jay in contexts other than school in which he demonstrates sophisticated intellectual capacities. For instance, Jay expresses a deep interest in insects and bugs, and with Collins's encouragement he embarks on a months-long arthropodological study that includes meeting with an entomologist who is decidedly unversed in the ideology and professional language of human deficit. Together, Jay and the scientist spend hours examining specimens. Jay labels and describes many of them from his own research. They discuss Jay's collection techniques, and the scientist advises Jay on ways to better capture and record his findings. Among a variety of other competencies, Jay also composes (as well as teaches) twelve-bar blues poetry and is an active, valued, devout member of his family's church. But come Mondays, on entering his classroom, he steps back into his identity of defectiveness, into a place where his teacher says, "I'm not sure he's capable of being encultured . . . It will be very, very difficult for him to learn how to function in this class" (Collins, 2003, p. 77).

As was the case with previous illustrations involving Rubin, classmates Rosa and Stacy, and Keplinger, professionals who perceived in Jay human and intellectual deficiencies did so from the dominant objectivist perspective. In this frame, the deficiencies are considered to be a natural manifestation of innate defect as measured on psychological and classroom-based assessments and in the individual's performance in school or the wider community. The assess-

ments and performance expectations are considered, in this objectivist frame, to be natural, self-evident, wholly rational, and above question. Thus, those who are judged or measured as failures within the assessments or performance expectations are reduced to irrational or disordered elements that naturally belong elsewhere. However, as our examples further illustrate, social contexts can be altered meaningfully to promote valued participation and connectedness. For Jay, this meant having to leave school for the university science lab and other locations in which he was recognized as capable and as a learner. The fragility of connectedness, however, remains starkly apparent in that his access to the university setting hinged on a researcher taking a particular interest in Jay. Further, his identity as "scientist" did not infiltrate the school, a location where he failed seven hours a day.

The objectivist deficit ideology certainly permeates much of schooling; however, the examples of Rubin, Gwazdauskas, Rosa, and Stacy suggest that a student need not escape school to assert an identity of a learner. Clarifying this is the example of Meredith, a classmate of Rosa's and Stacy's. Meredith was born with significant physical disabilities. She does not walk, she has very limited control over limb and hand movements, and her speech is difficult to understand beyond a certain few one-word utterances within highly structured activities. Following her birth, early intervention services and special education preschool programs offered her intensive physical therapies and a curriculum that, as apparent from her file, was highly structured, task oriented, and deficit focused. As such, Meredith, like her classmates, missed out on the emergent literacy experiences shared by many nondisabled children who, in preschool, begin to interactively craft narratives through dramatic play, imaginative drawings, and self-initiated experimentation with letter-like symbols to convey meaning (Kliewer, 2008).

Meredith's IEP, also authored by Zubak, mirrored her classmate Stacy's, often line for line (see Hehir & Katzman, 2012). It noted that Meredith was "significantly below her peers in general education," that she "does not independently acquire functional life skills," and that she has a "short attention span and difficulty attending to tasks." Meredith's earlier preschool IEPs also had noted a short attention span: "Meredith," one version read, "is motivated by stickers. She will not attend to academic activities unless multiple opportunities are provided for her to earn stickers." Into her kindergarten year, Meredith's personhood was defined within an objectivist, deficit framework.

As part of the literacy project, Zubak, her team, and the researchers introduced Meredith to emergent literacy opportunities that allowed her to self-explore written language (Koppenhaver & Erickson, 2003). For instance, they gave Meredith the opportunity to eye-scan a flip-chart alphabet and select letters of her choice through head movements. This presented her with her first-ever opportunity to control text on her own terms. We filmed for an hour as Meredith filled six pages with letters of her own choosing. There were no stickers for reinforcement, and no short attention span was apparent. The activity

ended only because it ran into Meredith's scheduled physical therapy session. As she pushed Meredith's wheelchair away from the flip chart, Zubak said to her student, "I had no idea you loved letters so much." Later in the day, at a team meeting, Zubak asked, "Do you think Meredith's therapy could maybe happen in the class? I don't know really what goes on, but maybe letters could be part of it?" The question suggests that Zubak was critically examining the structure and rationality of Meredith's school program and considering the possibility that the program might be reorganized or recreated.

Zubak's efforts with Meredith's literacy did not end with consistent emergent literacy opportunities apart from adult evaluation. Rather, increased sophistication allowed balanced participation in adult-directed activities and centers as well. Meredith was fitted with a computer mouse that she could control with head movements, an adaptation that allowed her to access software, including on-screen keyboards. In both her general education kindergarten and in the segregated primary class, Meredith engaged with her peers in daily literacy lessons. As her literate complexity and connectedness increased, teachers began to realize that Meredith was a competent learner. Zubak mentioned in a team meeting midway through the school year, "I'm going to have to rewrite Meredith's IEP. Nothing [in the document] makes any sense anymore. Nothing." Meredith had, at age five, shifted from a person potentially in need of perpetual custodial care to a literate citizen in control of a computer and with access to general education curricula (Koppenhaver & Erickson, 2003; Musselwhite, 2009).

While Zubak and her team introduced dramatic changes to the classroom, certain deficit identities remained apparent. For instance, they continued to primarily identify Stacy, who had Down syndrome, as a behavior problem. At the same time, given the comprehensive literacy curricula, AAC, and technology, Stacy was demonstrating unexpected literacy development. In one observation conducted midway through the year, Stacy joined her peers on the floor as Zubak read a story. She no longer was thought to require a second adult beside her whose sole purpose was to physically control her behavior. During the story reading, Stacy shared a communication-symbol book with a friend seated beside her. The two pointed together to relevant commentary, taking turns flipping the pages. When later discussing the activity, Zubak focused less on Stacy's appropriate participation and more on what she felt were distractions she caused: "I felt like the flow was disrupted too much. I kept having to stop Stacy bugging everyone around her." We, as the observing researchers, did not notice this same level of distraction. In another activity, we observed Stacy, with a digital camera, join her friends on a tour of the school. When Stacy's photos were printed, she sat for fifteen minutes at her desk writing about the pictures using strings of letter approximations and actual letters (Glass et al., 2013).

The contrast between Stacy's current engagement and her original IEP was dramatic. Stacy, like her classmate Rosa, as well as Gwazdauskas in *Educating*

Peter, was not necessarily performing at "average" curricular levels, but she had never before been provided with contextually responsive language instruction and opportunities. Who could presume to know her possibilities? However, into the second year of the literacy project, Zubak continued to express general concerns over the appropriateness of efforts to integrate certain of her students into general education classes, with specific skepticism related directly to Stacy's behavior. In a research interview, we mentioned how dramatically different Stacy was in terms of her connectedness to the classroom's literate community. "I know," Zubak responded, her voice trailing off. "Sometimes I just don't know."

Zubak's ambivalence toward Stacy's development persisted even as Stacy demonstrated unforetold growth throughout day-to-day routines and on sanctioned evaluations. Eventually, as Stacy aged, surrounding school personnel, including Zubak, determined that Stacy would be schooled best in a segregated classroom set aside for students whose behavior was thought to preclude sustained academic involvement with nondisabled children. Referred to as the Behavioral Intervention class, students placed there engaged in comparatively low-level academic work, but none was defined as cognitively disabled. Stacy's educational identity had shifted from intellectual impairment to behavioral disorder.

Though fraught with ambiguities resulting in a fragile connectedness for her students, Zubak was incrementally challenging herself in her efforts to create a context of connectedness for her young charges. On reflection she said, "We never did literacy before." In stating this, she was not suggesting that books and writing tools had been entirely absent from her students' experiences; rather, she was recognizing that she had held few expectations regarding the children's capacity to construct symbolic meaning in a language-rich environment (Heydon, 2008). Recalling her earlier belief patterns, which reflected her previous presumptions closely aligned with the *DSM-5* prognosis for the "intellectually disabled," Zubak said:

> Okay, these kids are going to [ultimately] be in a [sheltered] workshop, and so you've got to teach them skills that they can do to work in a workshop. I mean, we had books that told how to do all this stuff for work jobs, for working in a sheltered workshop. So that's where we were coming from: "Okay, let's stuff envelopes. Let's put rubber bands around things and twist ties and put things in Baggies," and that kind of stuff. Well, I haven't done that. I did at the beginning of the year, but we've kind of faded out trying to make more things more purposeful.

By "more purposeful," Zubak was pointing to the teaching team's elimination of vocational training for her five-year-olds while exponentially expanding opportunities and experiences to construct meaning through multiple symbolic and sign-based language systems. For an experienced teacher such as Zubak, this is a radical transformation. The industry of special education

imposes menial and repetitive labor training at the expense of literacy precisely because the ideology of deficit decrees it to be purposeful while critical literacy is dismissed as superfluous (Danforth, 2014).

In a research interview, we asked Zubak about concerns she had regarding her students' increasingly complex connectedness with valued contexts. She immediately responded, "That they'll leave our program and won't get anything." Even while vacillating on Stacy's place in school, Zubak was coming to realize the depths of the deficit ideology that would likely continue to surround her students in future environments—just as it surrounds Rubin, Gwazdauskas, and Keplinger. The fragility of newly presumed competence and an identity of the individual as a learner is glaringly evident.

At the End: Realizing Metaphors

Referring to psychologists at the time—who he felt misused his work to reify a priori beliefs in an innate, static intellect—Binet (1909) writes, "They operate as the graphologists did, who, when Dreyfus was believed to be guilty, discovered in his handwriting signs of a traitor or a spy" (p. 199). Alfred Dreyfus was eventually exonerated of treason, but the science underlying his incarceration went unchallenged for decades. A century later, Rubin, Gwazdauskas, the students in Zubak's charge, Keplinger, and countless others experience the ongoing repercussions of the early psychologists' fledgling efforts to create a detached empiricism of defect and disconnectedness, one antithetical to Binet's profound sense of the *scientific* nothingness on which such activity was based.

In our brief illustrations on how intellectual deficit has become inscribed in scientific, positivist terms, professionals stood apart from and looked back in to measure presumed innate incapacities. Central to science is that models reflect and account for *all* relevant data and provide for accurate predictions (Kuhn, 1996). Did the authoritative detachment of human deficiency account for and predict Rubin's presence on the red carpet at the Oscars as she entered the Kodak Theater just feet away from Gwyneth Paltrow? In the scramble for a universal objectivity at the expense of local realizations, could those who authoritatively define intellect in nativistic terms understand that Rubin's odd need to clutch a spoon for security might be just that—an odd need and not a further indictment of her intellectual personhood? As earlier noted, the *DSM*-5's scientifically based model of intellectual disability includes "participating in water activities" as an example of limited social possibilities (APA, 2013, p. 36). In *Autism Is a World* (Wurzburg, 2004) Rubin is depicted holding her spoons under a faucet stream. For Rubin, this interest in water flowing across spoons is just that—an interest. Any judgment or implication of intellect attached to this action, whether heightening our sense of Rubin's capacity to think or detracting from that sense, is an inference entirely grounded on culturally based, historically situated patterns of judg-

ment. The cultural inference ends only when we actually ask the individual to tell us about the action. Rubin is now able to explain that the spoons and water are a self-created adaptation to a hectic, often overwhelming sensory world; they calm her anxieties that otherwise emerge in fits of aggression. So much for the evidence reifying profound retardation.

Intellectual disability (and its immediate categorical antecedent, *mental retardation*) is no more objectively real than was the label *witch* imposed by male authorities onto some unfortunate women to explain and control supposedly disturbing and troublesome behavior. With perhaps a degree of smugness, we now dismiss the intrigue and brutality of seventeenth-century Salem as endemic of "mass hysteria" or "moral panic," a collective delusional action surrounding a now-discredited threat to community. Like witchcraft, intellectual disability is also a metaphor (Blatt, 1987; Blatt, Biklen, & Bogdan, 1977; Bogdan & Taylor, 1982; Braginsky & Braginsky, 1971). We do not literally see mental retardation; we infer its existence. It is *as if* the performance (social, communicative, etc.) of the person so labeled derives from defective intellect. It is *as if* certain responses on the Wechsler scales must be products of globally retarded thought patterns. Intellectual disability does not exist independent of the observer but is, in fact, always an inference made by those in positions of power and control over those accused. Here and there we may actually see a chromosomal anomaly or a neurological disconnect between brain and movement, but the abstract quality of defective and disordered thought that is so commonly conjoined with even these forms of human variation is always inferred.

Culturally entrenched metaphors disguised as science, even when based on an increasingly exposed nothingness, do not exit language easily. When we present narratives illustrating the end of intellectual disability, someone invariably asks us, "But what percent of intellectually disabled people are we talking about and what percent are really retarded?" Our best answer is to ask what percent of labeled individuals has escaped stagnant contexts of isolation, has been included in valued arenas where the right to belong and to participate is realized without question, and has been provided tools and materials based on affirmation, actualization, and empowerment? What percent of individuals, we must ask, is immersed within communities of committed individuals who have realized and set aside deficit ideology, who are open to being surprised and learning something new, who do not seek immediate changes but who exhibit perseverance and deep self-critique, and who realize evidence of connectedness such that a new culture, a new discourse, a new paradigm of thought might guide all further and increasingly sophisticated engagement?

We have reached a point where the empirical evidence can no longer be ignored or dismissed. School leadership and education policy must now acknowledge, encompass, and extend the realization of the end of intellectual disability. Doing so will require a vanguard of visionary risk takers who are able to step outside the confines of existing traditions to imagine student

and teacher possibilities. Educational leaders, for instance, must dismantle dual systems of schooling that emerged from and further the premise that some students are objectively normal and others are innately deficient. Separate physical locations, sovereign bureaucracies, and split faculties arose not in response to empirically deduced necessities but as a means of controlling the defective, and they serve only to perpetuate the myths of intellectual disability (Ferri & Connor, 2006; Smith, 2010). Leaders must also promote space and time for teams of committed personnel to actively engage in planning. Effective teaching requires collaboration among focused professionals (Moolenaar, 2012). This requires the expectation of consistent opportunities for teachers to join together intellectually in order to problem solve as a group. Leadership must also support and value teachers' and students' efforts, even though outcomes may not be immediate or easily quantified (Connor, 2008; Smith, 2010). Fostering connectedness with an individual who has previously been treated as innately defective is an ongoing process that requires a complex reorganization of the relationships surrounding that person. Teachers must be provided the time and space to accomplish this. Finally, leaders must themselves remain in direct relationships with students who struggle to form valued social and academic connections. Only through such relationships can those who oversee school systems recognize and deeply listen to the meaningful intent of individuals with disabilities no matter how obscure or indecipherable the students' voices may seem (Henderson, 2011; Pace, 2011).

As with intellectual disability and mental retardation, fostering valued connectedness and presuming competence is itself a metaphor and is antithetical to the metaphor of intellectual disability/mental retardation. Presuming connectedness and competence suggests that we involve ourselves with others *as if* we all make meaning of the world, *as if* we all have a rightful place in valued communities, *as if* we all think, and *as if* we all can continue to deepen and expand in our connectedness with the surrounding world. As such, the metaphor of presuming competence is not a veiled effort demanding that labeled individuals conform to specific, culturally sanctioned, and valued performance patterns (e.g., traditional literacy), thus proving the presumption worth the effort. It is, instead, a charge crafted on the premise and expectation that teachers and others can fashion responsive contexts in diverse forms that support an ever-increasing connectedness for all individuals. Certainly some or many of the points of connectedness may reflect traditionally valued performance patterns (e.g., literacy, oil painting, etc.). However, the social context of even these traditional points of connection will take on infinite appearances as they are localized in relation to the individual; in this process, performance patterns previously defined within an ideology of deficit will be newly imbued with affirmational meaning.

Connectedness and competence directly challenge us to leave behind ideologies of deficit and their derivative contexts of pessimism and human control. Instead, we build valued connectedness within local understandings of

the individual, further promoting that connectedness in whatever directions it might lead. Rather than blaming an individual's intellect for difficulties with performance, the presumption of competence directs attention to the educator who must find ways that allow for the demonstration of competence; in the absence of success, the presumption of competence impels the educator to keep searching for new ways of engaging and connecting. Thus, replacing the label *mental retardation* with *intellectual disability* is ultimately a superficial change, as it leaves fully in place the dogma of defectiveness. Instead, connectedness and the presumption of competence contests all that mental retardation has represented and brings us to the end of intellectual disability.

Notes

1. In using previously produced narratives to illustrate the end of intellectual disability, including certain documentaries, we open up this essay to particular criticisms. First, some may raise concerns related to the "crisis in representation" (Eisner, 1991, p. 123). How do we ensure that the stories presented are accurate? We make no claim to truth in its objective incarnation but understand validity as a pragmatic concern (Kvale, 1995). Second, do the narratives lead us toward useful understanding? In terms of narrative accuracy, Collins (2003) points out that people with disabilities live multiple storied lives and are positioned by others or position themselves within a range of identities, each with a variety of shifting narratives. Sources we include are first-person presentations of disability; as such, the individuals make choices and decisions about the stories or identities ultimately expressed. Further, autobiographical expressions are not without accountability to the contexts described, though the contexts may be viewed quite differently across individuals. For instance, a child labeled as emotionally disturbed may have a radically different story to present than does his teacher, though both stories ostensibly involve the same environment (Collins, 2003). Finally, in our selection, we might be accused of purposeful ignoring or cherry-picking. The question may arise, "But what about the person who really is intellectually disabled?" Every person described here has existed, or continues to exist, within official narratives of "real" retardation, narratives that have emerged with fierceness from within constructs of absolute and objective truth such that the complexity and possibility of the individual was overwhelmed by scientific certitude.
2. All names have been changed to protect the identities of participants.

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