

Excerpted from *"A Land We Can Share": Teaching Literacy to Students with Autism*
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LITERACY FOR STUDENTS WITH SIGNIFICANT DISABILITIES: ADDRESSING COMMON QUESTIONS

In these times of inclusive schooling, NCLB, and high standards, it should be obvious that all learners deserve an appropriately challenging literacy education. But we find that questions still arise continually when it comes to students with significant disabilities. After fielding so many of these queries, we thought that some of our readers might need more information to help them think and talk about how to design literacy experiences for these learners. For this reason, we have constructed responses to some of the most common questions we hear related to students with significant disabilities and literacy.

How Can We Teach Him to Read? He Can't Even Hold a Pencil.

Many students with autism are seen as incapable of learning either because they cannot use materials in typical ways (e.g., a student may be unable to hold a pencil or turn the pages of a book) or because they cannot communicate reliably. As a group, individuals on the spectrum are not alone in being doubted as competent (or dismissed). As Crossley pointed out, there is a long history of making conclusions about intellect based on assessments of speech, communication, and the normative perspective:

In the eighteenth century society discovered it had been making a mistake about one group of people who behaved like idiots. These people weren't intellectually impaired at all, they had a sensory problem; they were deaf. The true nature of their impairment was discovered and an educational system developed to capitalize on the language of sign. (1997, p. 274)

Other groups who have been negatively affected by low expectations include those with physical disabilities and/or sensory impairments, and those with the label of mental retardation. When people cannot communicate reliably, when they move in unusual ways, and when they exhibit unexplained behaviors (e.g., screaming that seems unprovoked), we often assume they are not competent, and in many ways "less than" (Donnellan & Leary, 1995) other people.

Julia Tavalaro, a woman who awoke from a coma to find herself paralyzed and unable to communicate, experienced this bias firsthand. When she tried to use her eyes to communicate, none of her caregivers noticed her attempts for several

years. Tavalaro describes the experience of being both cut off from typical experiences and being seen as incompetent as unbearable. She shared, for instance, the horrible and degrading experience of having her personal care issues discussed in front of her, with her body treated like an object. Many of her care providers appeared to dismiss her humanity altogether:

A white dress comes close to me, lifts me, laughs to another white dress who makes a sucking sound between her teeth and says, "The vegetable needs changing." I realize with sudden terrible knowledge that I am a grown woman about to experience what it's like to be a baby. (Tavalaro & Tayson, 1997, p. 22)

During this episode, the workers exchanged insulting remarks about Tavalaro and even shared opinions on how long she would live.

Only years later did a therapist notice Tavalaro's communication abilities and restore dignity, control, and intimacy to her life. This story, however moving and shocking, is hardly rare. Many people with significant disabilities gain access to augmentative and alternative communication and demonstrate their complexity and ability in ways never dreamed by those in their lives. Helen Keller may be the most famous example of this, but there are countless other similar tales throughout history and around the world (Biklen, 2005; Blackman, 1999; Brown, 1989; Crossley, 1997; Donnellan & Leary, 1995; Sellin, 1995).

So what does this mean for literacy instruction and people with significant disabilities? It means, in part, that when people with autism have severe problems with movement, communication, and learning, it can be extremely challenging for them to show what they know. This means that if students do not appear to have any literacy skills at all we do not wait for them to demonstrate such skills before providing instruction. Instead, we must teach "as if" students are capable of understanding us (a topic we will discuss later in this chapter) and continue to explore ways to connect with, communicate with, and support them.

But His IQ Is 16. Why Would We Focus on Literacy Instruction for Him?

Only a dozen years ago or so, many textbooks claimed (and some still do) that most students with autism are "mentally retarded." Over time (and as technology and teaching methods improved), that percentage dropped, leaving researchers, practitioners, and families alike to question the supposed link between autism and low cognition (Biklen, 2005; Donnellan & Leary, 1995; Edelson, 2006; Wallis, 2006). Many researchers now see those symptoms that brought on a diagnosis of mental retardation (e.g., hand flapping, failure to respond to cues, pacing, vocalizing) as symptoms of *autism*, not as indicators of cognitive disability. As Claudia Wallis reported in a recent issue of *Time*, much of our thinking about autistic behavior has changed:

Many classic symptoms of autism—spinning, head banging, endlessly repeating phrases—appear to be coping mechanisms rather than hard-wired behaviors. Other classic symptoms—a lack of emotion, an inability to love—can now be largely dismissed as artifacts of impaired communication. The same may be true of the supposedly high incidence of mental retardation. (2006, p. 44)

We have seen this theory of low IQ scores being a result of unreliable communication tested when students get access to their voices for the first time. In these instances, we often see that the better our supports and the better the match between the learner and his or her new system or device, the higher a student's IQ score jumps! Perhaps no person is more suitable to illustrate how cognition "suddenly" improves with communication than Sue Rubin. Rubin, subject and writer of the Oscar-nominated documentary *Autism Is a World* (Wurtzburg, 2004), was believed to have mental retardation until age 13, when she began communicating via facilitated communication (supported typing). After gaining access to communication, Rubin was tested to have an IQ score of 131, well above average. She reinforced the notion that her early "problems" were related to expression, not intellect:

As a person with autism I have very limited speech and lack motor control governing my body movements. When I was in school autistic people like me were usually placed in separate schools or special day classes with other disabled students [and] were not allowed to learn academic subjects. Because of the way we move and our lack of speech we were assumed to be retarded. But all this changed when I could type without support. . . . (Rubin et al., 2001, p. 419)

Rubin has every classic symptom of autism. She rocks. She flips her fingers in front of her face. At times, she vocalizes incoherently. She shares that her body is often hard to control and, in fact, it took her several *years* to get her movement under control to the point where she could type on her device without physical support. For these reasons, people who do not know her or have access to her communication often believe that she IS her body. In other words, they understand all of those markers of autism as markers of low cognition. But as Rubin herself points out, her "very existence" challenges these beliefs: "When people see me they are forced to admit that their assumptions about mental retardation are wrong" (2001, p. 419).

Clearly, for many students like Rubin, a test does not exist that can measure what they know and what they can do; most of the instruments that are used in evaluations measure autism symptoms as much as or more than these students' abilities. In addition to the instruments used in these assessments being inadequate, many aspects of the evaluation process itself make accurate assessment challenging if not impossible. As we shared in Chapter 4, there are many barriers to accurate testing for students with autism, including problems with language. Tests that are highly dependent on language comprehension, for example, are biased against students with autism because lengthy verbal directions are almost always challenging for these learners. Even tasks that require performance and not verbal responses often depend on receptive language skills to understand the directions.

In addition, many children and adults with autism cannot participate as they are asked to due to movement problems, sensory differences, or related difficulties. It is not terribly uncommon for a student with significant disabilities to get a low score on an instrument because he or she did not have a reliable pointing response (but was able to point). In other words, students may be asked to point to a monkey and actually know which image represents the monkey but point to a giraffe instead. This type of problem with motor planning is widely reported by people with autism (Donnellan & Leary, 1995; Leary & Hill, 1996; Marcus & Shevin, 1997; Rubin et al., 2001).

What does all of this IQ critique have to do with literacy learning? Seeing how intelligence has been understood and measured is crucial to understanding how so many students, to this point, have been left out of academic learning and literacy experiences. IQ scores often determine where a child receives his or her education, how rigorous that education is, what materials are used, and whether or not an academic curriculum is pursued. So we implore our readers to question the construct of IQ, not only for students with autism but also for all learners (Gould, 1981), and to teach to student strengths and abilities versus perceived limits.

He Seems So Low, I Don't Know Where to Begin.

When we do not have a way to assess what students know, we have to make some guesses. Too often the guesses or assumptions we make about learners lack generosity, creativity, and introspection. Instead of assuming, for instance, that a student who is nonverbal is expressing everything he or she knows, we should assume the individual knows more than he or she can show us. That is, we should be making decisions for students with significant disabilities based on what Anne Donnellan, a prominent scholar in both autism and special education, calls the "least dangerous assumption." According to Donnellan, experiences should be designed with the belief that the "individual with a disability is a 'person first,' deserving the same considerations and concern as would be given a person without a disability" (Donnellan & Leary, 1995, p. 98). The Least Dangerous Assumption principle asks us to consider, "What if we later learn that the person is more competent than we ever imagined . . . what curriculum and instruction will we wish we had provided?" This principle is critical during this time when we know so little about autism and significant disability. Therefore, even in cases in which we do not know what a student understands or how or if he or she is communicating, we have a moral obligation to provide him or her with literacy experiences that are varied, interesting, challenging, and connected to peers and general education curriculum.

A teacher operating from the Least Dangerous Assumption should always be asking, "What would an education for this student look like if I viewed him as a literacy learner?" and "What does it mean to give this student the benefit of the doubt educationally?" All students, regardless of label, must be provided with opportunities to communicate through drama, art, and movement; to explore a range of augmentative communication strategies and techniques; to socially interact with peers; and to see, hear, and examine a range of books and other materials. And in the case of literacy instruction, this means that every student with significant disabilities should have IEP objectives related to literacy and learn alongside their peers without disabilities in general education classrooms.

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