

# Literate Lungs: One Autist's Journey as a Reader

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*This article underscores the importance of coupling a practical orientation to the many challenges of autism with a philosophical and political orientation that refuses merely to make room for disability in the classroom or to accommodate its specific needs. It uses a case study approach to illustrate the ways in which subject matter and narrative convention were problematic for a nonspeaking, autistic boy who had been abused in foster care. The article focuses on his elementary and middle school years to illustrate the way in which an understanding of disability studies must inform our reading pedagogy if marginalized children are to find a safe place in our classrooms and our communities.*

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## What's in a Name?

My first breathing easy day was the day my kindergarten teacher changed my name on the attendance chart from Swanson to Savarese. I knew then that I was a lot safer than I had ever been. I had spent time fearfully living in foster care. When my name changed to Savarese, time stood still. Years of hurt were over, and years of humanity had begun.

The name Savarese refers to people who came from Southern Italy. My dad's grandfather came to America from Sicily, but that's not what my last name means to me. To me the name Savarese means freedom and safe passage. It means that I belong with my mom and dad and reasonable people, greeting the world as dear. I hear my name with great pride.

My middle name was also changed from Joseph to James. My dad thought I was named David James while I was in foster care—my caseworker had incorrectly listed it as James on my file. When he

freed me, he decided to hear my real self. When he adopted me, he wanted us to share middle names, so he gave me his middle name James. To me James feels dear and reassesses autism as a fresh way of seeing the world rather than a disability.

My formal first name is David, which means friend or beloved. I love those meanings, but I prefer to be called Deej. Mom calls me Deej, and I really love when kids or adults call me that because then I know they know my kind-hearted parents.

DJ Savarese. I hope one day to see that name on the cover of my book. Frees are people who talk a lot and who don't have autism. They don't understand why I hold feelings inside, but years of breaking the barriers between frees and autistics rests on my shoulders. If you're sitting in front of your computer some time, Google DJ Savarese. You will greet all the work I have done so far to free my people. *Reasonable People*, the book my dad and I wrote, is just the beginning.

I have freed myself, and now I hope to free other kids who want a chance to read and write. When I think of dear Mrs. Johnson, my kindergarten teacher, I easy breathe. And I wonder if she realizes that the day she changed my name on the attendance chart was the beginning of my reassessed as smart self's walk down freedom's trail.

So our son, DJ, wrote in an assignment for speech class in the spring of his junior year of high school. Delivered on his text-to-voice synthesizer, his "name speech" touches on the central theme of this essay: the importance of a disability studies approach to the project of inclusion. By disability studies approach, we mean a number of things: (a) an awareness of the socially constructed nature of any impairment or physiological distinction—DJ compares the act of changing his middle name through adoption to the act of "reassessing autism as a fresh way of seeing the world rather than a disability"; (b) an understanding of identity politics and the role of activism in the fight for civil rights—DJ speaks of "all the work I have done so far to free my people"; and (c) a commitment to

self-representation and empowerment through literacy—DJ “hope[s] one day to see [his] name on the cover of [a] book.” *Reasonable People* (2007), Ralph’s memoir of our family’s early years, which concludes with a chapter written by DJ, is “just the beginning.”

For DJ, a new name symbolized a new life. A boy who was once labeled “profoundly retarded” and who was abandoned by his birth family and severely abused in foster care looks back on the first moments of his inclusion journey and links his kindergarten teacher’s acceptance of him to his later academic and social success—what he calls, referencing his hero Harriet Tubman, “my smart self’s walk down freedom’s trail.” Recently admitted to Oberlin College, which enjoys the distinction of having accepted the country’s first female and African American college students, DJ will be only one of a handful of nonspeaking autistics in higher education, and he will be the first to try to live in the dorm.

As we look back on his journey, we want to underscore the importance of coupling a practical orientation to the challenges of autism with a philosophical and political orientation that refuses merely to “make room” for disability in the classroom or to accommodate its specific needs. As we argued in our recent co-edited special issue of *Disability Studies Quarterly* (Savarese & Savarese, 2010), the concept of neurodiversity, which can help, on the one hand, to foster the kind of self-esteem that any young autistic needs and, on the other hand, to remind neurotypicals of the danger of naturalizing one form of cognitive functioning while demonizing all others, emerged from a disability studies approach to physiological distinction. Neurodiversity, as the progressive autistic community has come to define it, conceives of neurological variation as a subset of biological diversity and—as such—something to be embraced rather than cured. It calls people whose neurology closely resembles that of most people “neurotypicals” and people whose neurology operates differently—in particular, autistics—“neuroatypical.” The latter group’s differences need to be understood and appreciated, not vilified and eliminated. With an understanding of neurodiversity, strengths can be accentuated, and the world can be altered to naturally support a full range of neurologies.<sup>1</sup>

And yet, autism does, at least in some respects, constitute an impairment. To many, including many autistics themselves, autism can be exasperating. How far are we

willing to go in explaining a different neurology with a social constructionist lens? What happens to the exasperation in such a framework? Can the experience of fine motor impairment and profound anxiety be written off as simply the effects of stigma? There is no doubt that the presumption of universal incompetence at the so-called low-functioning end of the spectrum has been socially fabricated.<sup>2</sup> We would not be surprised by the “miraculous” breakthroughs of autistics like DJ or Sue Rubin or Tito Mukhopadhyay if we did not equate an inability to speak and odd behavior with mental retardation. But what a culture makes of physiological difference is distinct from the difference itself.

Snyder and Mitchell (2001) offer a narrative of the field’s development in which social constructionism, while providing the strategic advantage of “disassociating disability from its mooring in medical cultures and institutions” (p. 2), came at the expense of the lived experience of disability. In this narrative, a focus on embodiment emerged as a corrective to too much social constructionism, and it did so at exactly the right moment: when the work that social constructionist arguments needed to do had been done—at least in the academy. Siebers (2001) notes a similar trajectory. Here, lived experience trumps whatever one might ideologically say about it. Indeed, the unacknowledged difficulty of disability seems to stand in for a kind of essential difference. And so, the question becomes, how to capture that particular experience, which is often painful or taxing or simply different, without othering disability? How to insist on social construction while attending to the very real implications of an alternative embodiment?

In the case of autism, some aspects of this alternative embodiment are not as disadvantageous as they might

<sup>2</sup> Meredith Goldberg Edelson published an important study in 2006, showing just how flimsy and unsupported have been the claims of mental retardation in published articles from 1937 to 2003. Of the 215 articles reviewed, three quarters of the claims derived from nonempirical sources and half of these never originated in empirical data. Moreover, the data that did exist had been gathered 25–45 years ago and often from problematic testing vehicles. A study the following year addressed this problem by using a different vehicle. Michelle Dawson, Isabelle Soulières, Morton Gernsbacher, and Laurent Mottron—Dawson is herself autistic and an important member of Mottron’s research team at the University of Montreal—substituted the Ravens Progressive Matrices test of fluid intelligence for the standard Weschler Intelligence Scale for Children, and the incidence of mental retardation in the autistic sample dropped significantly. Following up on this study, Thomas Zeffiro and Isabelle Soulières compared the speed at which autistic and nonautistic groups completed the Ravens test, and they found that the former were up to 40% faster than the latter and with the same error rate. This study prompted our son, DJ, to quip, “Who’s retarded now? Maybe one day Frees [his word for neurotypicals—they have freedom, he contends] will have to ask for accommodations.”

<sup>1</sup> Michalko (2002) remarks, “As often as I have celebrated the day of my birth, I have never celebrated the birthday of my blindness. No societal convention exists that provides for the celebration...of a disability” (p. 113). Michalko invites us to imagine holding a party for autism, a party that pushes back against a barbaric history of prejudice and exclusion. Refusing to give one inch to the pathologization of neurological difference, the Canadian blogger Estée Klar (2010) actually proclaims “the joy of autism.”

first appear; others, such as superior perceptual and mnemonic abilities, can only be called boons. As Grandin and Scariano (1986) and Prince (2005) have repeatedly pointed out, autism is *both* an impairment and a gift. Once, when Ralph asked DJ why he dipped his head in the water and then pensively watched each drip hit the pool deck, while flapping his arms and making a loud humming noise, he replied on the computer, "Light makes the water beautiful."

The act of celebrating autism must appear, if not realistic exactly, then plausible, alert to complication and ambiguity. It must be able to accommodate ostensibly irreconcilable declarations, such as these from our son: "Autism sucks" and "I have a great mind. I see things you don't see." It must acknowledge the prospect of a difference only hinted at by the sister-from-another-planet trope of Grandin (1995), who claims that she is like an anthropologist from Mars, but one somehow able to communicate with us Earthlings.<sup>3</sup> And it must do so while insisting, in the words of Kitay (2001), on "a more capacious concept of personhood" (p. 5), which is to say a more capacious concept of the human. One night when he was in the fifth grade, DJ declared on his talking computer, "Freak is ready for bed." Such a comment reflects the deleterious internalization of our culture's prejudice, an internalization made possible, paradoxically, by his evolving literacy. We have worked tirelessly to combat this prejudice; we have worked just as hard to help our son manage his anxiety and perseverance.

Thankfully, DJ's "name speech" and so many of the speeches, essays, and poems he writes now show how literacy can eventually facilitate empowerment through self-representation.<sup>4</sup> In the short term, however, learning to read and write created unforeseen problems for him. We had envisioned literacy simply as a means of communication, one that would allow DJ to maintain his position in a regular education classroom, but we had not anticipated the problems that would emerge when he gained access to our culture's literature and history. Nor had we realized how the act of reading and discussing prose with a group of neurotypical, White peers would highlight his difference and provoke his resentment and anger, sometimes threatening the very inclusion we thought it would promote. Finally, we had not considered how his early trauma and a different neurology might impact literacy, compelling an overidentification with characters or historical subjects and producing monu-

mental anxiety.<sup>5</sup> For this reason, we have chosen to focus the paper on DJ's elementary and middle school years both to foreground the aforementioned issues of literacy and to illustrate the way in which an understanding of disability studies must inform our reading pedagogy if all children are to find a safe place in our classrooms and our communities.

### A Lot of People Like to Catch Them in Cages

At the time we adopted DJ, one month shy of his sixth birthday, we were determined to empower him. What that meant seemed daunting but clear: (a) we wanted him to feel unconditionally loved and understood; (b) we wanted him to allow others to earn his trust; (c) we wanted him to envision himself as able and worthy; (d) we wanted him to be acknowledged as a full participant in his regular education classroom at our neighborhood school and in our social community; and (e) we wanted him to learn to communicate so that he might be able to ask for help, to defend himself against undesirable actions, and eventually to pose and answer questions about his past and present experience. We felt confident that a literacy-based, inclusive classroom would give him the best shot at attaining these goals. Emily, who was working as an educational consultant for the Center for Autism and Related Disabilities, knew most nonspeaking students with autism were attending special education classes, classes in which literacy instruction was usually limited to functional sight words or discrete skill training. If we truly wanted DJ to attain (d) and (e), then he needed to be in a literacy-based classroom, in which reading and writing are studied and practiced as powerful, meaning-making tools.

Truth be told, we had no idea what DJ's intellectual potential was. His individualized education programs (IEPs) from the center school indicated that he had not attained a single goal in 3 years. The school's teachers and administrators seemed to presume that this reflected his potential; we presumed that the segregated environment had not been conducive to his learning. We

<sup>3</sup> See "Toward A Postcolonial Neurology: Autism, Tito Mukhopadhyay, and a New Geo-poetics of the Body" (Savarese, 2010) for a discussion of what Ralph calls "neurocosmopolitanism," a term denoting the need for *both* neurological types to meet in a space of well-traveled and sympathetic familiarity. This essay appeared in the *Journal of Literary and Cultural Disability Studies* (Vol. 4, No. 3, 2010) and can also be found at <http://www.ralphsavarese.com> <<http://www.ralphsavarese.com>>.

<sup>4</sup> Google "DJ Savarese" to find other writings by our son.

<sup>5</sup> See "River of Words, Raft of Our Conjoined Neurologies" (Savarese, 2012) for a discussion of how the alternative neurology of classical autism might affect the reading process. See also *The Master and His Emissary: The Divided Brain and the Making of the Western World* (McGilchrist, 2009) for an elaborate treatment of the issue of cerebral lateralization and its relation to human empathy. While McGilchrist simply rehashes received wisdom about autism—it's not the focus of his book—he shows that left-hemispheric inhibition of right-hemispheric processing in neurotypicals results in a diminution of actual felt empathy, among other things. If classical Autists remain right-hemispheric dominant or exhibit significant right-hemispheric activity—and there are studies that suggest they do—then these Autists might indeed have a more intense reading experience than their neurotypical peers. See as well *The Soul in the Brain: The Cerebral Basis of Language, Art, and Belief* (Trimble, 2007).

knew, as scholars and activists in the field of disability studies, that an impairment can become especially disabling when a society fails to provide the necessary accommodations for performing competence. Because nonspeaking autistics were thought to be universally incompetent and because they lacked communication systems to counter this presumption, that failure seemed to many a reasonable—indeed, scientifically justified—response to profound disability. However, we had heard accounts of nonspeaking autistics who had been taught to read and to type, and we recognized that the field of autism was changing.

Consider, for example, the response of Sacks (1995) to Grandin and Scariano's (1986) groundbreaking memoir, *Emergence: Labeled Autistic*,

When I first read [Grandin's] book, I could not help being suspicious of it: the autistic mind, it was supposed at the time, was incapable of self-understanding and understanding others and therefore of authentic introspection and retrospection. How *could* an autistic person write an autobiography? It seemed a contradiction in terms. (p. 253)

Distinguishing between Asperger's syndrome and what he calls "classical autism," Sacks thus revises his understanding of neurological impairment in accordance with new evidence and implicitly points to the need for future revision,

The ultimate difference...is [that] people with Asperger's syndrome can tell us of their experiences, their inner feelings and states, whereas those with classical autism cannot. With classical autism, there is no window, and we can only infer. With Asperger's syndrome there is self-consciousness and at least some power to introspect and report. (p. 247)

Eight years after publishing his famous portrait of Grandin, Sacks would blurb Mukhopadhyay's (2003) memoir, reviving what Ralph refers to as the "syntax of surprise."<sup>6</sup> Here the shock of "authentic introspection and retrospection" greets the work of someone labeled "deeply autistic,"

The book is indeed amazing, shocking too, for it has usually been assumed that deeply autistic people are scarcely capable of introspection or deep thought, let alone of poetic or metaphoric leaps of imagination—or if they are, that they are incapable of communi-

cating these thoughts to us. Tito gives the lie to all these assumptions, and forces us to reconsider the condition of the deeply autistic. (p. xix)

What did the experts really know that was definitive about nonspeaking autistics? Not much, we concluded. Practicing what Anne Donnellan has called "the least dangerous assumption," we postulated that the failure of collective knowledge and imagination to create a "window" could produce the diagnosis and, hence, the appearance of low functionality. (When asked what he had been doing all of those years prior to learning how to communicate, Mukhopadhyay (2003) responded mischievously, "Listening," thus underscoring the problem of "inference" that plagues any purportedly objective assessment of cognitive ability.)

What DJ could achieve thus seemed entirely up for grabs. Envisioning ourselves as his sponsors, we sought to help him knock down or circumnavigate any of the socially constructed barriers that blocked his way. With the help of a devoted guardian angel, we advocated for him, urging a bevy of judges and the Department of Children and Family Services to allow us to become his parents "despite our unrealistic expectations of/for him." The use of "of/for" does not reflect grammatical uncertainty; rather, it reflects the fact that DJ's future depended upon our ability to bring a range of officials across that line. Their "of" represented an essentialist view of DJ; our "for," a social constructionist one. They believed that the extensive collection of 3" binders and manila folders that accompanied this 5-year-old, nonspeaking, autistic child accurately captured who he was and what he would be able to do; we believed that they spoke volumes about the institutions and discourses that had constructed his identity as fixed and his development as stagnant.

Fluent in the dominant educational discourse, we understood the importance of context and expectations in the process of learning—how they help to construct a lens through which students come to view themselves and be viewed as learners (or not). In the sixth grade, DJ would write his kindergarten teacher, telling her "you taught me to just feel I was really studious and deserved to yearn to be treated respectfully." We understood the privileging of literacy skills in regular education classrooms and the cultural capital that educated, supportive parents bring to the IEP table, and we knew how to mobilize this capital so that DJ could enter a space he had never been allowed to enter before: a regular education classroom. Understanding the way in which words and assumptions can construct a reality, we strategically deployed the very laws and school records used to justify DJ's placement in the most restrictive environment, a segregated school for children with disabilities, to persuade people to move him to the least restrictive one, a regular kindergarten at our neighborhood school, without him first having to prove himself worthy or "ready."

<sup>6</sup> In *Reasonable People*, Savarese (2007) writes, "Although the Tito blurb indicates a desire to move beyond the present understanding [of profound social, intellectual and emotional incompetence], it almost seems stuck in the syntax of surprise" (xx).

Having secured for DJ a new placement—he was the first child ever to leave the center school for a regular education classroom—we then set about developing the tools we thought would enable him to keep himself there: the ability to read and write. However, instead of constructing ourselves as teachers and DJ as the student, together we created and learned a new, shared language of signs and photographs, which we later supplemented with picture symbols, printed words, and, eventually, whole sentences, thus putting everyone on a more equal footing.

Arguing against prognostication, we encouraged a language of possibility that left his ultimate potential unknown. As Bissonnette, one of the stars of the recent documentary *Wretches & Jabberers*, has famously remarked, “Fastening labels on people is like leasing cars with destinations determined beforehand” (Biklen & Rossetti, 2005). Over the next 5 or 6 years, DJ learned more than even we had allowed ourselves—at the outset—to imagine. Within the first 6 weeks of kindergarten, he had been invited to his first birthday party. By spring of that year, DJ’s presence was visibly transforming how some of his peers—and subsequently how the teachers and parents—were thinking. Emily still remembers the morning one of his friends excitedly reported, “We have a kid on our t-ball team who’s just like DJ.” “What do you mean?” Emily asked, assuming she was about to hear his particular take on autism. “He speaks two languages, too. English and Spanish,” the boy replied. “Oh,” Emily said, trying to mask her surprise. “What two languages does DJ speak?” she asked. “Pictures and sign,” he replied, rather annoyed by her thick-headedness. DJ’s complete acceptance by his peers played a huge part in ensuring that he “belonged,” and his cognitive gains worked to dispel whatever residual doubt remained.

It seemed there would be no looking back. By first grade, DJ had acquired a limited but growing sight word vocabulary and was regularly accused by his peers of “blurting out the answers” (with his augmentative communication device). By second grade, he could point independently to the correct word to fill in a blank when given three distinct choices. By third grade, he began to read and answer questions about brief stories in *Reading Milestones*, a series designed for deaf children. By fourth grade, he had begun using two to three sentences to articulate original thoughts and ideas. By fifth grade, he was reading at a fourth grade level, was deemed eligible to take the Iowa Test of Basic Skills, and was writing poetry that exhibited both a command of figurative language and an ability to relate what he was reading to his own experience in ways that surpassed his peers.

And yet, these achievements brought with them signs of trouble. What had previously been unambiguously pleasurable and a source of pride—learning—was becoming fraught with the kind of relational understanding that only past traumatic events can compel. DJ could not help but connect what he was reading and writing to what had happened to him as a young child, as the following

acrostic makes clear. Part of the science curriculum, the assignment asked students to share what they had learned in a unit about prairie dogs.

“Prairie Dogs”

Prairie dogs live in burrows,

Race out of their holes.

A lot of people like to catch them

In cages,

Rolling the little ones in paint,

Identifying them in the wild.

Everyone is trying to catch one.

Dogs fight in springtime.

Other females in need of meat

Get their babies from others’ nests.

Some get eaten.

Teacher: “DJ, tell me about this poem.”

DJ: “It’s personal.”

Teacher: “I’d really like to know.”

DJ: “About foster care.”

Could the last line of the poem be any more brutal, what with its succinct and utterly matter-of-fact recognition of the fate of some foster kids, to say nothing of most nonspeaking autistics? Later that year in language arts, in a unit on the Titanic, DJ typed, “There were rich people on the boat. There were poor people down below. I was a poor person once.” His teacher was astonished. Not only had DJ latched on to the socioeconomic status of the passengers, something that none of the other students had seemed to notice, but he had tied these circumstances directly to his own life.

### Very, Very Easy Breathing

When DJ was in fifth and sixth grades, we began to realize how shortsighted were our efforts to empower him through literacy. Although he had been fully engaged in the regular education curricula for social studies and the language portion of language arts since kindergarten, in fifth grade his antagonism toward these two disciplines emerged. Rather than giving him the strong sense of empowerment that we had imagined,

literacy now afforded him access to some troubling subject matter. Through fourth grade, the reading curriculum had focused more on vocabulary embedded in simple stories devoid of any real conflict or characterizations, and the social studies curricula had focused on geography and cursory descriptions of various cultures around the world. It was not until fifth grade that the curriculum turned its full attention to realistic fiction and to history.

At first, DJ's fear seemed directed at a difficult subject matter that struck close to home. For example, in the first 2 weeks of fifth grade language arts, the class read "The Orphan Train" and a novel about a dog that is badly abused by its owner. DJ lasted only 2 weeks, retreating to the resource room where he could dissolve in private. At the end of the course, he told his teacher, "Hurt...that you got really, really frightening books." That year he refused to do the free reading program or literally to open his social studies textbook. Generating original prose was still time-consuming, and he had plenty to keep him busy. And so, we allowed him to skip the free reading program, but we pushed on with social studies, photocopying the entire text. It was as if the heavy covers of the original allowed DJ to believe that the past and its innumerable travesties could be conveniently entombed. No one objected to the small, nervous tears he made on the edges of the photocopied pages.

During this same period, DJ began to report the abuse that he had suffered in foster care—horrific, terrifying stuff, some of which we knew about and had been documented by the police. In *Reasonable People*, Savarese (2007) reflects on the belated acquisition of expressive language and its effect on the phenomenon of abuse:

Rather than imagining a process of arduous recall, it might be more fruitful to think of DJ finding words for the abuse and thereby producing, creating, the trauma that plagued him. His own narration of trauma propelled him into selfhood, such that the articulation of injury and the crystallization of the self in language were essentially one and the same.... In a sense, he organized a self around the enormously disorganizing event of traumatic injury, and you could see this tension...between organization and disorganization in his accounts of that injury. His syntax and vocabulary would falter; his command of idiom would disappear. His utterances would be fragmentary, cryptically poetic. At times, this struggle took the form of a contest between language of any kind and the less specifically communicative act of aggression and self-injurious behavior. (p. 255)<sup>7</sup>

<sup>7</sup> See *Reasonable People* for an extensive account of belated language acquisition—in particular, how language paradoxically allowed DJ's trauma to crystallize.

Our son seemed to be moving in two directions simultaneously: toward and away from meaning; toward and away from a usable, which is to say narrativized, past. The coincidence of reported abuse with a new focus in school on realistic history and literature was anything but, we soon recognized. DJ was discovering the story of himself in the larger, trauma-filled story of America. Like the country's many marginalized groups, he, too, had been the victim of unspeakable violence and oppression. We could not help wondering about other so-called "behaviorally or learning-disabled" students in the school: How many of them might be struggling, not with the decoding of language, but with their own personal experiences depicted in the literature?

The fifth grade social studies curriculum, which began with Iowa history and spent the rest of the year on U.S. history, offered its own challenges. Although the first unit concerned the various Native American tribes that had roamed our region before the arrival of European settlers and included such fun facts as the invention of the ice cream cone, what DJ recalled when asked to write an historical "I-poem" about an Iowan from the mid-to-late 1800s and early 1900s was the hypocrisy of his own townspeople who had offered slaves their freedom and yet denied them the right to attend school. Having lived with a proud African American foster family—his only good foster home—DJ naturally analogized his plight to that of African Americans, but learning about the educational discrimination to which this group had been subjected cemented the analogy.

In his submission that year to the Elks Club's contest "Our Flag: What It Means to You," DJ had internalized the idea of systemic oppression:

The great United States of America is breathtakingly not free. Equality is not sacred because not everyone has access to it. Freedom is not as available as many people think. First of all, free people want to treat my people as mindless. Second, they underestimate us as bad instead of reaching out to us. The creators of everyone's very important Declaration of Independence wasted their breath.

Notice the repetition of "breath"—the way that the paragraph begins and ends with this word. It's as if DJ had condensed the primary physical symptom of his anxiety-heavy breathing—into a political modifier. Critiquing the proponents of the Autist-in-his-own-world paradigm, Manning (2012) notes, "There is no mindblindness here. Mindblindness dwells in the neurotypical world. It lurks on the edges of a notion of politics that speaks of democracy as though we had all acceded to the level of easy breathing." An autistic boy was demanding his place in America. We remember taking note of the signature trope, which rediscovers the body as a way of reviving the cliché and picturing democracy itself in respiratory distress.

The concern with breathing shows up repeatedly in DJ's writings, particularly in the sixth grade when he composed the final chapter of *Reasonable People*. This concern points to the problem of presuming some sort of universal student, unmarked by race, class, gender, or neurological type—to say nothing of trauma. The habit of exposing children to the suffering of others is noble enough, but there needs to be more awareness of those kids for whom the story is not just a story. DJ's chapter includes a letter that he wrote to his middle school principal after a meltdown threatened to have him expelled. Meltdowns were occurring regularly, and some were quite violent. "It's very important to me to be at Grinnell Middle School" (Savarese, 2007, p. 434), he writes. "I very much value teachers who give nice instructions breathing easily" (p. 434). "You ignored the resentment in my young breath" (p. 434), he continues, grateful for another chance to prove himself. "As long as I treat people resentfully, I will miss out on telling people that kids who don't talk deserve to be in a real school" (p. 434). As the letter comes to an end, he engages the topic of respect, noting, "Respect for others is important. Respect for underestimated kids is important, too, because they read and resent testing that mistakenly identifies them as retarded. Testing kids is scary" (p. 434). Then, in an explicit analogy to the civil rights movement, he compares himself to Martin Luther King: "I imagine these words resembling dead Martin Luther King's respectful vision" (p. 434).

Elsewhere in the chapter, underscoring the anxiety that constantly plagues him and punning off of the book's title, he remarks, "Reasonable people promote very, very easy breathing" (p. 435). "Respectful people love my real self. They know that my real self hears loving sounds" (p. 436), he explains. "Great breathing frees the creatures [DJ's metaphor for the nightmares and visions that haunted him], so just very much need someone breathing easily" (p. 436). Toward the end of the chapter, he says of Emily, his adopted mother, "I hear sweetness in your very, very kind love and respect. Breathing feels great now. Breathing feels kind of like joy.... Creating a kind, sensitive, loving, reasonable human being feels fresh. I'm ready to treat others like in a beautiful dream" (p. 437).

Lest we imply that DJ managed at this point to conquer his anxiety or to achieve the kind of distance that reading about conflict usually enables, we must report that his darkest days still lay ahead. The middle school language arts curriculum was similarly one long source of agitation; at times it was not clear that he would survive literacy, so profound was its destabilizing effect. Whether reading about Shirley Temple Wong's loneliness in *The Year of the Boor and Jackie Robinson* (Lord, 1997), or about the blind boy in *The Cay* (Taylor, 1969), which he resented for its sentimental restoration of the hero's sight, or about the homeless boy in *Maniac Magee* (Spinelli, 1990), DJ struggled not to think of himself

and his own predicament. Of the McNab family in this latter novel, he wrote,

The McNabs dreadfully remind me of my sinful, biological mom taking care of me, hurting my future. They don't respect Black people. When segregation took place, they never questioned it. They were ready to live in separate fear. This means that they never played together. My biological mom was the same way. She never cared if my sister and I were ok. That's why they remind me of each other.

And yet, even as we despaired, we saw signs—flickers really—of a productive resolution to this literacy paradox. DJ had apprehended one of the hallmarks of disability studies: namely, an activist sensibility. And he intuitively grasped the idea of identity politics, or the re-coding of difference through organized contestation. In his flag paragraph, he speaks of autistics as "my people," and in his letter to the middle school principal he alludes to Martin Luther King's "respectful vision." By this point, we had begun attending as a family progressive autism conferences, where DJ got to meet other nonspeaking autistics who could read and type and who had been fully included in their schools or colleges—people like Sue Rubin and Jamie Burke. He listened to scholars who deployed a word—neurodiversity—that we had been deploying at home to create a "posautive" space of affirmative autism. And he listened to activists with autism who were fighting for autistic civil rights. Such activism, we hoped, might successfully transform the pain and violence of his past, the injury of having been unwanted because autistic, and make them productive in the present and future. Little did we know that three years later he would be sitting with CNN's Dr. Sanjay Gupta in a New York hotel room proposing a summit for autistic people so that they might "define themselves." DJ and Amanda Baggs, who is famous for her YouTube sensation "In My Language," would be communicating online as a way of showing the importance of the Internet to autistics. When Gupta (2007) would ask DJ if he thought that autism should be treated, DJ would impishly type, "Yes, treated with respect."<sup>8</sup>

### Keep the Reader Going

The seventh and eighth grade language arts curriculum focused almost exclusively on issues of social justice. We thought the activist in DJ might find comfort and hope in these narratives; instead, his fear and resentment grew. The very act of reading and discussing

<sup>8</sup>See interview: <http://www.ralphsavarese.com/category/reasonable-people/media-reasonable-people/>.

stories—any story—now isolated him from his peers who seemed blithely to process whatever was placed in front of them. In seventh grade, he complained, “Resent how authors use fear to keep the reader going.” A similar sense of difference pervades the letter he wrote to introduce himself to his eighth grade teacher:

Dear Mrs. Buter,

There are lots of things about me you might love. Really. I realize that you’re one of the best teachers of the year. Plotting to really get to know about you. One of my greatest dreams is to be just like my dad. He reads his poems and books to respectful people. Yes. I’ve already given two respected readings: one poetry reading at the college and one speech in New York. Poetry really might be my fears in verse. You’re much freer to say things. Yearn to just open my mouth and, yes, feel the courage to let my voice out. You might hear heartfelt dreams. Stress created by this looks like bad behavior but it’s not. Young people look freely at books, very much enjoying the suspense, but I don’t.

Quite heartfelt, DJ Savarese

Fear and freedom very much concern DJ, but here it is not the subject matter that he fears per se; rather, it is the very trope of conflict/resolution that tends to structure Western narrative. The four stages of a narrative plot are (a) exposition, (b) rising action/conflict, (c) climax, and (d) resolution. In his letter to Mrs. Buter, DJ seems to be objecting to stages (b) and (c), the period in a story when the main character struggles to make his way, confronting obstacles and bullies at every turn until he’s faced with a decision: fight or flee. In effect, knowledge of the very arc that neurotypicals use to calm themselves, and from which they derive pleasure, scared—and angered—DJ.

Having actually experienced the unrelenting fear of neglect and abuse, he could not imagine inviting such fear into his life—certainly not as entertainment. He vehemently disliked the sister and brother in *From The Mixed-up Files of Mrs. Basil E. Frankweiler* (who voluntarily leave the safety of a loving home) (Konigsburg, 1967), and he expressed similar disdain for us when Ralph needed a hip replacement. In preparation for the procedure, we had borrowed a hospital bed from the local medical center and put it in the front room of our first floor. We had a narrow, spiral staircase at the time, and our bedroom was on the second floor. When DJ saw the bed, he was outraged. He had just completed a research project on arthritis for school, which carefully enumerated the various steps one can take to avoid surgery, things he reported to Ralph as if they were new when, in fact, he had been trying them all for years but to no avail. “Mom and dad have invited injury into the

home!” DJ anxiously typed to his therapist. Now *we* were behaving like privileged neurotypicals who casually seek out pain and suffering.

A closer investigation of narrative convention produced even more fear and anxiety in DJ. He learned that conflicts can be divided into two categories: external and internal. External conflict pits the self against an Other, Society, or Nature; internal conflict pits the self against itself. There is no such thing as “no conflict.” And so time and time again, the protagonist stands alone, a single self, struggling against someone else, against some prejudice, against some unforeseen act of God or natural disaster. And if no such external force exists, one wars with oneself. Now, both in and out of the classroom, DJ rarely—if ever—seemed at peace, pacing relentlessly, banging his head, and waking screaming in the middle of the night.

But what about the salutary effects of the resolution, or stage (d), when the character makes the right choice, receives the help he needs, or finds a way out? Why didn’t this give DJ the reassurance he required? He knew, his comments suggested, that every conflict in life does not get resolved and every victim does not prevail. In his writing, DJ acknowledged there were “thousands of kids yearning to get free” just as there were thousands of other foster kids who longed to have loving families. Were they invisible? Unworthy of having their stories told? Not considered people or selves? Once, in conversation with a young student teacher who worked with autistics, DJ had pleaded, “Trust that they are human.” It seemed to us that DJ’s identification with characters had become so strong and so automatic that his body literally responded to rising conflict by activating his own fight-or-flight response. When, in his words, “his feelings assaulted him,” he seemed incapable of making it to the resolution, of “hearing” it over the pounding of his heart, or of believing that it compensated him for the pain and fear that he had had to endure to get there. Yes, he made it through some difficult literature but not without insisting he “take breathing easy mom to class to create more security,” something he never requested for science or math.

Instead of gazing at, DJ so overidentified with every protagonist that he found himself constantly gazing within. In his journal entry to *The Giver* (Lowry, 1993), having been asked to write a letter to Jonas, the main character, advising him on whether he should leave his parents and his community of sameness to search for a world of difference and feeling, he wrote,

Dear Treated as Different [Jonas had identified himself as “Troubled in Utopia”],

You’re very just breathing hard. You experience emotions kind of estimated as autistic because you get assaulted by your feelings. Seriously, you feel emotions testing you. When these feelings try to irritate you, treat them very, very responsibly. Say



that fresh start is dear and that looking out for others sweetly washes away the fear and pain.

#### Yearning to get free, DJ Savarese

While reading seemed to position DJ inside the character, it also seemed to position his classmates and teachers as spectators, gawking at, enjoying, and even seeking out the characters' misfortunes to say nothing of their own elevated heart rates as they neared the climax. In class discussions, their comments on, and critiques of, the characters' choices always irked him. Not only did he find these responses reprehensible, but the experience served to isolate him from the rest of the group. In his answer to the question, "If you were Harriet Tubman, would you have had the courage to travel the Underground Railroad 19 times?" DJ seemed to reprimand—and distinguish himself from—the entire Western or free world:

#### "Estimating Harriet Tubman As Respected"

If we're breaking the barriers, great freedom fearfully awaits. Harriet realized, until freedom treated her people with respect, her intestines seemed unsettled, her heart beat resentfully, and her fear never disappeared. The challenges she faced each day were far greater than anything you and your people have ever endured; breathing resentful air, great very hard breaths, undermines heartfelt feelings and deeply effects the western world. Pedestals rest on hurt, great, estimated dressed not great human beings deserted by frees. I heartily entreat you to help my unfree, treated responsibly, great, hip, jumping self to walk the trail. You kind, responded breathing easy frees don't understand how terrifying seemingly fresh freedom is.

We wondered, had our attempt to promote identity politics backfired? Was it possible that, in teaching our son to read and write, we had somehow confined him to the position of perpetual victim? If so, how had this happened? Hadn't we understood and loved him unconditionally? Hadn't we worked assiduously to earn his trust by creating a predictable and stable home, refusing to break our word to him, and ensuring that nothing threatened his sense of permanence with us? Hadn't he been acknowledged as a full participant in his regular education class at our neighborhood school and in our community for seven straight years? Hadn't he learned to communicate—not just to ask for help or insist someone stop but also to pose and answer questions about his past and present worlds? Hadn't he tested out of remedial reading, and wasn't he writing poems and responses that wowed even the most demanding of his teachers? Why, then, did he characterize himself so persistently and fervently as "unfree"?

At least part of the answer has to do with DJ's physical response to the act of reading. Listen to his description of Harriet Tubman: "her intestines seemed unsettled, her heart beat resentfully...great very hard breaths." These were not details DJ and his classmates had read; rather, they were physiological descriptors he frequently used to talk about himself, which he now attributed to Harriet Tubman. When it came to reading, DJ's internal conflicts manifested themselves quite literally inside his body. His fight-or-flight reflex brought with it a physiological response that overwhelmed him sensorially and eventually manifested itself as some sort of external conflict. He seemed to be held hostage by this involuntary, cyclical response. That the assault came from within his own body seemed to undermine DJ's trust in everyone, including himself.<sup>9</sup>

A week after the unit on Harriet Tubman, DJ and his classmates listened to a recording of Paulsen's (1993) *Nightjohn*, a novella that portrays with stark efficiency the brutal consequences for slaves who had learned to read and write. For once, DJ was not alone in his discomfort. Even his neurotypical classmates chewed on pen caps, covered their mouths in horror, and turned hot, their faces flushed as DJ sat, looking down, his eyes brimming, his mouth in a quivering frown, deliberately trying to swallow the saliva that warns of vomit. When asked, "What did you learn about slavery that you never knew before?" DJ replied, "I didn't know that people were ever killed for learning to read and write."

If the reading curriculum in seventh and eighth grade depicted life as a lone journey, the social studies curriculum depicted it as a group endeavor. At school, DJ became intimately familiar with the gross inequities wrought upon Native Americans and Blacks throughout our country's history, but he also began to learn more about the Civil Rights Movement of the 1950s and 1960s. He read about Gandhi's concept of nonviolent civil disobedience and saw that the NAACP consisted of well-educated African Americans who used their knowledge to argue for change. In the winter of eighth grade, despite never having engaged independently in unrequired reading, DJ picked up and read *Access to Academics for All Students: Critical Approaches to Inclusive Curriculum, Instruction, and Policy* (Kluth, Straut, & Biklen, 2003), a book that sought to broaden the inclusion movement beyond students with disabilities to those from other marginalized ethnic, racial, and socioeconomic populations. The following February, when students were asked to honor Martin Luther King, Jr., by writing their own I-Have-A-Dream speeches, DJ

<sup>9</sup> Lest the reader think that only DJ's trauma was behind his fully embodied identification with Tubman, consider that a range of people with autism have commented on their intense reaction to human suffering. Steven Shore, for example, speaks of "fusing" with another's pain, becoming so overwhelmed as to lose track of himself.

composed one that ended up being printed in our local paper. Part of it reads:

Most people still perceive of kids with autism as bad and retarded. Instead of helping us, they hurt us. Instead of treating us with respect, they get us locked up in institutions. Instead of teaching us to read and write, they keep us in segregated classrooms of easy lessons. I have been justly treated, but there are thousands of kids yearning to be free.

DJ was finally experiencing firsthand the power of words and positive political activism. He still struggled with the internal, physiological responses that anxiety provoked, but high school would allow him to balance his own schedule. Initially, this meant taking the mandatory courses in Social Studies and English with electives in Science, a subject that still offered him a break from the emotional and provocative content of life. In biology, DJ would learn about the fight-or-flight response that all humans have. He also would learn about homeostasis, the body's natural instinct to regulate itself internally when external factors cause it to temporarily become imbalanced. This knowledge would give DJ a foundation upon which to build his own self-regulatory power. By sophomore year, he would write the script for and assistant direct a dramatic presentation of his life story, which would reach the finals of the state theatre competition. The drama teacher's invitation to serve as playwright and director would go a long way toward making him believe that he had neurotypical comrades, fellow "political freedom fighters." By senior year, he would create a collage of performed writings by a number of autistic self-advocates and begin embracing what he calls "artful advocacy," utilizing art's appeal to both the mind and the heart as the most effective means of bringing about lasting change in neurotypicals. The piece, entitled "Finding Our Voices," would end with a hopeful appeal to the younger generation and an acknowledgment that giving neurotypicals knowledge about autism was—and is—the autists' power.

### A Journey Well Worth Taking

The road to empowerment through literacy is not an easy climb to happiness, but it is certainly a journey well worth taking. In this essay, we shed light on the problematic aspects of literacy not to dissuade teachers and parents from meaningfully engaging nonspeaking autistics in literacy-based, inclusive classrooms; rather, we hope to unearth socially constructed barriers that may not be visible to those of us born and raised in the dominant culture, barriers that may unnecessarily obstruct the literacy learning not only of autistics but of other students who are labeled "learning-, behaviorally-, or emotionally disordered" or "at risk for school failure" as well.

Some might perceive DJ's journey as one based solely on self-awareness, discovery through learning, or family

support, and not on inclusion, but we would disagree. Certainly those elements were necessary, but it was DJ's meaningful participation in inclusive, literacy-based classrooms that allowed him to uncover some of the assumptions that unknowingly exclude children—and later, adults—from becoming full and meaningful participants in their schools and communities. Without inclusion, DJ might have learned to read and write, but he would never have been exposed to the troubling, but ultimately important, dialogues that pushed him past resentment to a place of empowerment where he strives to partner with his peers to create a different world.

We could not have helped DJ without the support of myriad teachers, aides, principals, and peers: people who opened themselves up to—and embraced—DJ's difference, who appreciated the ways in which—as the ethic of neurodiversity suggests—their interactions with him had begun to change the way they perceived of their roles as educators and people. It was often the most skeptical or notoriously "demanding" teachers who ended up championing his cause the loudest. When, after a semester of Economics, his teacher acknowledged that having DJ in his class had awakened him to the emotional needs of *all* of his students, we experienced, firsthand, the advantages of acknowledging and understanding difference instead of working to cure it.

As parents, we used our knowledge of disability studies not only to find tools that could help DJ work through his self-image as a victim but also to buoy ourselves in periods of hopelessness and disequilibrium. However progressive and liberal, we found ourselves panicking when DJ began to position us as "other" during his middle school years. Knowledge of identity politics and social constructionism helped us to realize and accept that even—or, rather, especially—his sponsors would need one day to step aside, thus removing themselves as obstacles on DJ's freedom trail. This could be achieved, we learned, while making sure that our son's very real needs as a person with a disability get met. Schwarz (2007), one of the leaders of the Autism National Committee, perhaps the country's most progressive and integrated autism organization, speaks of the role of "allies" in the fight for autistic rights.<sup>10</sup> This is the service to which we now aspire-aside, of course, from continuing to be the most exuberant and joyful of DJ's cheerleaders.

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<sup>10</sup> See this YouTube entitled "16 Ways Neurotypical People Can Empower Autistics": <http://www.autismstreet.org/weblog/?p=127>.

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