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# Disability Studies in Education: Storying Our Way to Inclusion

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# Disability Studies in Education: Storying Our Way to Inclusion

*Joseph Michael Valente and Scot Danforth*

This issue of the Occasional Papers Series aims to draw attention to the use of storytelling as a medium for provoking dialogue about inclusive classrooms and school communities. It offers readers stories of classroom life that provide insights into understanding the complexities that make up the lives of children with disabilities, their families, and teachers.

Scholarship on inclusion is often disconnected from the lived experiences of those it intends to describe. Far too often discussions about the education of children with disabilities is informed by deficit perspectives. And much of the scholarship on children with disabilities has revolved around debates about competing, one-size-fits-all inclusion paradigms. Both these perspectives ignore the many promising inclusive classroom pedagogies and practices being used in classrooms today. Stories from real classrooms are drowned out or undervalued by larger scholarly discussions. What seems to get lost are the multiple ways teachers and teacher-educators are already implementing innovative inclusion practices.

## **What is inclusion? Why the Urgency?**

The use of the term “inclusion” or “inclusion education” has become so commonplace that it is often conflated with what in years past we would have called “mainstream” or “integration” approaches to education. Two key features that distinguish inclusion from earlier and lesser approaches is the commitment to school/community transformations and to collectivist strategies of difference and schooling. Mainstreaming and integration, although frequently described as “inclusion,” involve merely individual placements of disabled students into general education classrooms. These timid, often contradictory approaches to inclusion prioritize the maintenance of the customary routines and structures of general education while placing primary responsibility for the success of the placement on the shoulders of the individual student. Significant reform of classroom procedures, pedagogy, or organizational structures are thus avoided (Danforth & Jones, 2015; Slee, 2011; Waitoller & King, 2015; Boldt & Valente, 2016).

By contrast, what Ferguson (1995) and Thompson (2015) describe as “genuine inclusion” involves serious reform of the curriculum and teaching in general classrooms as well as the organizational processes of the school. Inclusion isn’t a one-off, fragile arrangement that may return to a default segregation position at any moment. General educators, special educators, and administrators, support professionals, students, and parents unify in active commitments to developing and maintaining classrooms and schools that support all students and value the biological and cultural diversity of the school community. As the narratives in *Life in Inclusive Classrooms* will demonstrate, pursuing the fuller, more genuine version of inclusion is no easy task. Even making a lesser commitment to integration arrangements effective is challenging.

One reason that conversations about inclusion in the United States are complicated is because inclusion is not a requirement of the Individuals with Disabilities Education Act (IDEA). One could say that the federal law is quite ambivalent about the status of disabled students in American schools. At the heart of IDEA is the requirement that children with disabilities be placed in the least restrictive environment (LRE). It is the highly flexible LRE provision that gives rise to endless interpretations and misinterpretations of what, in fact, amounts to the LRE for each child and how to put it into practice (Waitoller & King, 2015).

More than ever, there is an urgent need for dialogue about inclusion and the implementation of inclusive classroom practices. Recent Office of Civil Rights reports (2012, 2014) show that young children with disabilities and minority students experience much higher rates of abuse, mechanical and physical restraints, seclusion, suspensions, expulsions, and in-school arrests than their white, able-bodied peers (Boldt & Valente, 2014). For teachers and teacher-educators, dialogue about more respectful and equitable practices is an integral part of the inclusion process.

## **What is Disability Studies in Education?**

To help promote this dialogue and to address shortcomings in inclusive scholarship, Disability Studies in Education (DSE) developed the tradition of using storytelling in research. Based on personal and collaborative narratives, the goal of DSE is to give life to stories of exclusion as well as to stories of successful inclusive classrooms. DSE is an interdisciplinary field of inquiry that includes scholars in the sciences, humanities, and arts. Early DSE scholars, led by Susan Gabel, Linda Ware (a contributor to this issue), Scot Danforth (co-editor of this issue), and colleagues

*asked questions such as: Why should a person with a disability, a teacher, or a parent care what academics say in their research and writings? Why should they care about the seemingly distant and esoteric writings in research journals and university textbooks? What is happening in these worlds that makes a difference? (Connor, 2014)*

The DSE tradition of research based on the personal and collaborative narratives of informants originated from criticisms that the mainstream education and special education research were de-emotionalized, depoliticized, and disconnected from the immediate realities and complexities of the lives of children, parents, and teachers. Scholarship that privileges storytelling offers counter-narratives that disrupt mainstream, ableist accounts of what disability means (e.g., Valente, 2011; Smith, 2013).

The storytelling tradition, in DSE as well as the DSE interdisciplinary lens, offer the larger fields of education and special education a unique take on contemporary schooling for children with disabilities. *Life in Inclusive Classrooms* brings together storytelling scholars to show how disability, inclusion, and exclusion feel inside inclusive classrooms in order to effect change in teaching beliefs and practices.

## **Nine (Classroom) Lives**

The nine contributions to this issue include lived narratives and analyses presented from a wide range of useful subject positions: parents, general and special education teachers, researchers, advocates, siblings, and persons who are themselves disabled.

The opening essay by Diane Linder Berman and David J. Connor, (Eclipsing Expectations: How A 3rd Grader Set His Own Goals (And Taught Us All How to Listen)), kicks off with a description of an illuminating journey through the eyes of a parent, Diane, who wanted a more inclusive experience for her son Benny. For Diane and Benny, this meant becoming meaningful participants not only in Benny's own classroom community but in the Individualized Education Program (IEP) meetings that determined his educational goals. David uses a DSE framework to analyze and highlight the importance of context, as opposed to focusing on the disability condition, in enacting inclusionary practices. The authors argue for an "adhocratic" model of education that views children, educators, and parents as allies.

In "Teaching Stories: Inclusion/exclusion and Disability Studies," Linda Ware and Natalie Wheeler-Hatz describe an exceptional collaboration between a university teacher-educator, Linda, and a public school teacher, Natalie. Together they develop a "Teaching Stories" in-service workshop for Natalie's

colleagues to learn about disability studies, as well as a curriculum for her fifth grade class. Teaching Stories participants engage in self-reflection to examine personal biases about disability, use media to critically review representations of disability, and learn how to harness the potential of young adult literature to provide illustrative, non-deficit perspectives on disabilities.

Louis Olander, an Iraqi war veteran and special education teacher in New York City, crafts a powerful story about his experiences coming to terms with a diagnosis of Post-Traumatic Stress Disorder and navigating the quandaries and everyday realities of what he terms “quasi-inclusion.” In “Rethinking Those Kids: Lessons Learned From a Novice Teacher’s Induction into In/Exclusion,” Louis argues for reframing inclusionary practices as pedagogies for equity that attend to the intersectional dynamics of race, class, and disability. He also encourages more local control over the implementation of inclusionary classroom practices.

Inspired by Vivian Paley’s storying scholarship, the essay “The Unfolding of Lucas’s Story in an Inclusive Classroom: Living, Playing, and Becoming in the Social World of Kindergarten,” tells stories about a vibrant kindergartner named Lucas through the viewpoints of his mother (Emma), teacher (Carmen), and teacher-educator (Haeny). In this multi-voiced story, the narrative centers on Lucas and shifts outward toward those orbiting Lucas’s wondrously playful universe. The magic of Lucas’s unfolding story is in the ways it disrupts conventional discourses about labels, interventions, and imposed meanings of Autism Spectrum Disorder (ASD).

Karen Watson’s ethnographic study, “Talking Tolerance Inside the ‘Inclusive’ Early Childhood Classroom” provides an inside look into what the Australian government calls “inclusive learning communities.” This term emerges from a national early-years learning framework that highlights ability and disability as diversity. Following the course of a six-month period in three “inclusive” early childhood classrooms, Karen offers an account of the transformative potential of inclusion in contrast to the harmful effects of teaching tolerance. Tolerance, as Karen’s study reveals, preserves the dualism of normal versus abnormal (or Other) and hinders critical reflection about ableist assumptions.

“Hitting the Switch: ¡Sí se puede!” takes us into the lifeworld of first-grader Jason at Castle Bridge Elementary School, a public, dual-language school in New York City. Written by Jason’s teachers Stephanie and Andrea in conjunction with his mother Sandra, this essay puts forward the ethos ¡Sí se puede! (Yes, you can!), which relies on children’s empathy and calls for a collective response to inclusion. “Hitting the Switch” concludes with practical suggestions for creating an inclusive space for

children who use assistive communicative devices so that they can become meaningful participants in the classroom community.

Emily Clark’s “I [Don’t] Belong Here: Narrating Inclusion at the Exclusion of Others,” privileges the voices of families in their quest for inclusive education. Borrowing from narrative research and Disability Studies in Education, Emily tells the story of her adoptive siblings Maria and Isaac, who were orphaned by AIDS. She explores the paradox of inclusion which is that it sometimes, if not oftentimes, fails and results in exclusion. A chief reason for the failure of inclusion, Emily argues, is that children with real and perceived differences challenge the “grammar” of schooling—that is, they stand out for their differences.

A beautifully crafted ethnographic description of a rural Midwestern middle school, “Lunch Detention: Our Little Barred Room,” by Lisa A. Johnson, pulls back the “facades of inclusion” to reveal emotional violence and deep-seated discriminatory practices against special education students. Lisa, herself blind, describes how she was approached by an administrator to take over the role of lunch detention supervisor for the “little barred room.” In a short time, the “little barred room” becomes a place of refuge for Lisa and the other students, who share stories of friendship and create an inclusive space that empowers them to challenge a culture of oppression.

Melissa Tsuei’s “A Circle With Edges: How Storytime Privileges the Abled Learner,” takes a critical look at one of the commonplace features of early childhood classrooms—story time. In her essay, Melissa considers the ways in which story time reinforces unequal power dynamics for diverse learners by privileging the able-bodied learner. In response, Melissa creates and presents the SPHERE model, which promotes active engagement and shared dialogue through collaborative storytelling and nurtures an inclusive literacy-learning environment.

Taken together, these essays are intended to offer readers an applied DSE approach to inclusive classroom pedagogy. These essays frame disability and the lives of young children with disabilities in ways that: privilege the self-understandings and experiential knowledge of the children and their families; illuminate oppressive systems, arrangements, and circumstances that deny them opportunities for access to participation and equality; and create opportunities for greater levels of access, participation, and equality for them. It is our hope that these essays will further amplify and provoke unending discussions about how to create and sustain genuinely inclusive classrooms and communities.

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