

same time she cautions those involved not to make the mistake of becoming so exclusive that other's views are shut out. Soto ends her essay with the same Chinese proverb that began the volume:

Ants can move a mighty mountain.

Water can drip through stone.

If you do not climb the mountain, you will not see the plain. (p. 208)

And climbing the mountain means attention to love—the understanding of the whole process of life—technique with understanding—the dream-space of social justice and equity—and I will teach/live differently beginning now.

### References

- Delpit, L. D. 1996. *Other people's children*. New York: New Press.
- Krishnamurti, J. 1953. *Education and the significance of life*. New York: HarperCollins.

## Schooling Children With Down Syndrome: Toward an Understanding Of Possibility

by Chris Kliever

Published by Teachers College Press, 1998

Reviewed by Celia Oyler

It continues to startle me how backwards most progressive people are when it comes to understandings related to our fellow citizens with cognitive or intellectual disabilities. In contrast, well-meaning white folks know these days to be cautious in their assessments and judgments about African Americans, Asian Americans, Latinos, and Native Americans. Straight folks are learned enough to take their cues about gay/lesbian/transgendered issues from the insiders. Holistic educators heartily reject standardized test scores as valid measures of children's learning or progress. Advocates for social justice unilaterally defend the rights of the marginalized and the oppressed.

How is it then that in the year 2000 we find that people who are labeled as "mentally retarded" are reduced to their IQ scores and other reductionist fallacies of human error? What is the history of our soci-

ety's response to disability that has so isolated individuals whom we have labeled retarded? How did it come to pass that we have conflated presumed cognitive incapacity with limited morality? Why is it that so few of us have contact with persons labeled mentally retarded? Where are such people as we express our commitments to social justice and diversity?

*Schooling Children with Down Syndrome* is a powerful call to begin to ask questions about citizenship, democracy, capacity, and community values, not only for people with Down Syndrome, but for all of us. In this elegantly written and persuasively argued volume, Christopher Kliever fully articulates an alternative version of schooling and community citizenship and offers a scathing indictment of our dual system of education. As a professor of education and a former special education teacher, Kliever steps quite bravely forward to render a careful, but pointed, argument against the very existence of special education. Further, and even more provocatively, the author forces us to reconsider our notions of human capacity.

Ostensibly, this book is an ethnographic account of "the cultural meanings of Down Syndrome in the school lives of children" (p. xv). In actuality, the volume is much more than that; the book is a call to build educational communities in which human diversities are viewed as strengths, where teachers see themselves not as technocrats transferring knowledge but as creative problem solvers and community builders, and where every student is an active learner of democracy, literacy, and human valuing.

Although much rhetoric surrounds the calls for viewing human diversity as a strength, there is usually little attention paid to people who are seen as cognitively impaired. Kliever shows how students with Down Syndrome are often viewed and indeed act as non-conformists who present challenges to school systems designed to reward compliance. In the social institution known as school, students' worth is typically measured "by the degree of their conformity to established patterns of behavior" (p. xv). Those who follow the rules, answer the

CELIA OYLER is an assistant professor in the Department of Curriculum and Teaching at Teachers College.

teacher's questions, do well on the tests, and keep their hands and feet to themselves are promoted, if not praised. Special education is the place for the rest.

By drawing sustained attention to the ways that schools act not only as sorting machines, but also as a mechanisms of self-surveillance and social control, Kliewer joins past scholars, activists, and educators who use critical theory to critique the institution of public schooling in the United States. By focusing specifically on students with Down Syndrome, he offers a unique perspective, bringing to bear a rich literature base on democratic schooling and integrated curricula as a counterpoint to the reductionist skills orientation that has been central to special education.

For readers not familiar with the history of special education, Kliewer analyzes our current dual system from both historical and philosophical contexts. In this way, *Schooling Children with Down Syndrome* would be an excellent choice for an introductory education course as it compels the reader to ask fundamental questions about the purpose of schooling, the hidden curriculum of compliance and conformity, and the essential values that are reflected in school as a sorting machine. Kliewer does not soft pedal issues, and names Chapter two, "Down Syndrome and the History of Community Banishment." Here he traces the idea of moral inadequacy that has been conflated with mental retardation to the rise of scientificism and eugenics. It is also in this chapter that he clearly names the racism that was inherent in Dr. Down's race-based categories of human development, that led eventually to the name "Mongoloid" for the phenotype associated with trisomy of the 21st chromosome. By citing primary research, Kliewer succinctly illustrates how this classification system remained an integral part of understanding Down Syndrome well into the 1980s. Even as late as the 1970s, he demonstrates, schools did not try to educate students with Down Syndrome.

This excavation Kliewer does recalled for me my own preparation in special education during the 1970s. Public Law 94-142 had just been passed, mandating free education for all students, regardless of disability. We were told that students with Down's Syndrome (as it was then called) were always found in classes for the Trainable Mentally Retarded. This was, "of course," because they would not be able to

be successful with the more academic curriculum found in classes for the Educable Mentally Retarded. I was disturbed by the images of animal training that were conjured up for me with the label "trainable" and I did everything I could to avoid being placed in such a room for student teaching.

The true extent of our society's misreading of people with trisomy 21 comes near the end of the book as Kliewer presents current research on literacy acquisition for students with Down Syndrome. He foreshadows what were for me startling findings with older investigations from research of the 1950s. Almost 40 year ago, researchers were speculating that people with Down Syndrome were not necessarily mentally retarded. Kliewer, quite brilliantly, I believe, places these findings in the historical context he calls, "The Birth of Advocacy," and thus signals his book's membership in the rapidly expanding field of disability studies. In this way, Kliewer's volume is one of the very first to take disability studies/disability rights directly into the classroom.

My admiration for this author (whom I never met, although we both were at Syracuse University during some of the same years) simply skyrocketed as he dropped his main bombshell: Mental retardation exists only as a metaphor. Mental retardation is not some material reality that exists within individuals, but is built by doctors and scientists (with the collusion of educators) to explain incompetence. Quoting from the book:

When one consistently performs as if he or she is incompetent, whether it be on tests or on the playground, the result is a scientific label of cognitive deficiency referred to as mental retardation.... The label symbolizes a *chasm between a student's manner of performance and that which is valued by schools.* (p. 63; emphasis added)

However, research from the last two decades, Kliewer shows us, indicates that people with Down Syndrome have significant difficulties with motor planning, including the motor planning involved with speech production, and with impulse control. When taken together, it is easy to see how difficult it would be for a typical person with Down Syndrome to be able to even *signal* their capacities and intentions. There is a poignant moment Kliewer relates about a second grader in one of his observations that

vividly illustrates the research on motor planning that the author reviews.

Lee ... was completing a workbook page for a language arts lesson. He squeezed his glue bottle but applied too much pressure, resulting in a glob of glue spread across this desk. He looked surprised, then apprehensive, as he glanced toward an assistant teacher helping a classmate nearby. Lee attempted to scoop the puddle of glue back toward the middle of the desk, drenching his fingers as he did. He promptly stuck his hand into his mouth, resulting in an audible expression of distaste that caught the assistant teacher's attention. Looking over she cried out, "That is not to eat!" Several classmates laughed. One wrinkled her nose and said, "Oh, gross!" Lee, who did not speak was unable to explain the situation. Though he had been working diligently on the assignment, his effort resulted only in a drenched worksheet, an angry adult, a bunch of disgusted classmates, and glue dribbling down his chin. (p. 67)

Kliewer intersperses such powerful classroom vignettes throughout the book, helping give particularity to the rich bodies of research he weaves together to tell the story of how people with Down Syndrome have been systematically excluded from much of community life. Indeed, the exclusion of these students into segregated education is one of Kliewer's main axes of critique. He minces no words here and tells us, "Segregation ... diverts tremendous amounts of resources toward structuring an existential location of hopelessness entrapping people whose very humanness is in question" (p. 4). He illustrates such hopelessness with curricular examples, such as the student whose "functional" curriculum consisted of putting together plumbing fixtures that were kept in a bucket in the corner of the room. Once the student had put the pieces together, the teacher took them apart and the student was to start over.

What gets highlighted in such stories is not just the limits of special education, but also the serious flaws of so-called regular education. How much of students' time do we waste with such make-work tasks that are mere imitations of productive labor? How often do we ask children to comply with tasks we

have created seemingly designed to keep them busy or to teach isolated skills designed by someone, somewhere as stepping stones to the real learning that will supposedly come later? In this way, Kliewer's indictment of special education shows us a caricature of schooling itself: an elaborate machine built upon utilitarian assumptions of human worth and capacity.

Regarding the central findings of *Schooling Children with Down Syndrome*, Kliewer found three broad school representations that he termed the squatter, the alien, and the citizen. Students who were treated as aliens were denied community membership, banished to segregated environments and presumed to be intellectually and developmentally defective. Such marginalization is one of the organizing principles of special education, which is of course, predicated on diagnosing individuals' defects and prescribing treatments to remediate the deficiency. To this way of thinking, certain human differences are seen as abnormalities that can be objectively identified, scientifically measured, and educationally treated. Indeed, many of the general educators with whom I have worked over the years believe special education is a place where the abnormal can be housed together with particularly "special" teachers fully prepared to either fix them and send them back, or at least work with them to reach their "fullest potential."

Such marginalization, Kliewer demonstrates over and over, works against the very preparation for democratic living and full participation in civic life that is the right of all citizens. Rather than learning literacy skills in the contexts of print rich environments, too many segregated classrooms for students with moderate and severe disabilities do not even teach reading, focusing instead on "life skills." and condemning students to illiteracy. When my own preservice students express doubt about putting students with severe disabilities into general education classrooms, asking, "What does a child who doesn't speak and can't move get out of the regular classroom?" I always counterpose, "As a teacher of six such students all in a room together all day long, what would you do for curriculum and instruction?" They, of course, have no viable answer. Kliewer sums up this issue succinctly. He says: "Students with dis-

abilities thrived in the midst of the energy of these regular classrooms. Period" (p. 14).

The second location for students with Down Syndrome in Kliewer's study was that of squatter. The squatter is given space on the periphery of the community but is viewed as a community burden: "the squatter represents the struggle for citizenship stalled at the margins" (p. 12). Kliewer does not say this, but this is a position created in large part by our liberal humanist orientation toward those with disabilities: It is unfortunate that some people are disabled, and so we must be benevolent, kind and protective toward them. This sort of orientation toward disability produces a charity discourse (Oliver 1990) that circulates through such vehicles as the Jerry Lewis Telethon and the Special Olympics. Children who grow up seeing *disabled squatters* kept within sight, but just out of reach of real friendship and community membership, learn early that certain human differences are, as Kliewer puts it, "differences that matter." Such differences, in the case of people with Down Syndrome, are believed to convey limits of mental capacity and human worth.

The third location for students with Down Syndrome that Kliewer found was that of the citizen. In vividly drawn vignettes, the author portrays classrooms in which curriculum is designed around *all* of the community members. Literacy is assumed as a centerpiece of such citizenship, and even non-speaking class members are taught to read. Participation structures are created to build upon the students' capacities, thus helping students reveal all that they know, can do, and believe. In such classrooms, "One's human development does not set the conditions for community acceptance; rather, acceptance is the terrain on which development occurs" (p. 12). Rather than attempting to "shape disabled children to look more normal" (p. 13), such community spaces are built on the premise that the web of community life is enriched by all members because of their differences. From this perspective, then, disability is a point of identity, not of shame. The school's mission, from this vantage point, is to bring all young citizens into full community participation. In Kliewer's vision of participatory democracy, schools serve as central organizing sites for collective agency and creative, community-based problem solving.

As I sat down to read *Schooling Children with Down Syndrome* for the second time in order to collect my thoughts and write this review, Johnny-Paul Penry was scheduled to be executed. Mr. Penry is on death row, sentenced to be killed by the state of Texas for his dual crimes of rape and murder. After eating his final meal, Mr. Penry was granted a last minute reprieve, due to his label of mental retardation. This case, unlike most of hundreds of other executions in Texas, has received much publicity. Journalists are fairly univocal in their portrait of this particular inmate on death row: "He has no sense of morals and no sense of propriety; although he is approaching his mid-40s, Penry still believes in Santa Claus" (Selinger 2000).

I remain haunted by this case, as the appeal for justice for Mr. Penry is predicated upon an assumption of his basic lack of humanness. Indeed, it is against international law to execute a person with mental retardation as people with this label are presumed to have "no sense of morals" and "no sense of propriety." Christopher Kliewer, in his deeply moving book forces us to reconsider such taken-for-granted ideas of mental retardation. Indeed, this book demands that we abandon all attachment to science's claim to measure human capacity. Instead, we are called to assume capacity and ask, "What do we wish our community to look like" (p. 139)?

### References

- Oliver, M. 1990. *The politics of disablement*. New York: St. Martin's Press.
- Selinger, H. 2000, November 21. Death penalty, Inequity for all. *Columbia Daily Spectator*, p. 5.