

Introduction

I can still recall the smell, a pungent mix of ammonia and human waste. I can still recall the rows of metal beds, the children and adults who were forced to lie in them, day and night. I can still recall the racket in the ward, the bedridden residents' crying, moaning, yelling, and pleading. The year was 1971, and I was an undergraduate taking my first course in special education, called Nature and Needs of the Mentally Retarded. I encountered this scene on a field trip to a state school for the mentally retarded. I kept wondering where the school was.

It was not only the images that stayed in my mind, but also the attitudes expressed by staff. "This is all you can expect of these people. They're severely brain damaged, vegetables." When we returned to the college, we discussed our feelings about what we had seen. Our professor assured us that these children and adults were capable of far more than was apparent during our visit, and that we would visit other sites where we would see that these students could learn and have full lives. These other sites included special schools and classes in which more fortunate students were learning to read, write, and laugh. However, though some children were getting a chance at a better life, children with significant disabilities were not guaranteed a right to an education. They could be denied entrance to school.

My professor predicted that the time would come when all disabled students would be entitled to a public education. He told us about lawsuits and legislative initiatives that were seeking to ex-

tend public education to all disabled students. He also showed us a book, *Christmas in Purgatory* by Burton Blatt, a professor of special education at Syracuse University, which exposed the inhumane treatment of people with mental retardation in state schools that was creating a stir in public policy circles. The lesson was clear from my early classes in special education: The conditions evident in the state schools were not the result of mental retardation alone but, rather, the way society responded to mental retardation. That is, society viewed people with disabilities as inherently incapable of learning and responded by institutionalizing them in substandard conditions where they were deprived of the most basic opportunities. Talking to us as special educators in training, our professor made it clear that our job would be to expand educational opportunity to children with mental retardation and to prove society's negative assumptions wrong.

When I finished my undergraduate work, I decided to pursue a master's degree and had the great fortune to study under Burt Blatt. It was a heady time for special education, as lawsuits were proceeding through the courts challenging exclusion from school and exposing the miseries of institutionalization. Syracuse University was in the middle of it all, with Burt serving as an expert witness in several cases. One course I took, taught by Doug Biklen and Bob Bogdan, was entitled Law and Human Abuse. The course focused on how the law at that time was being used to deny people with disabilities basic human rights. These professors argued that this needed to be turned around, that law should promote, not deny, rights. I left Syracuse energized and pleased that I had chosen a career of such importance: teaching students with disabilities.

I returned to Massachusetts and began teaching at a vocational high school, Keefe Tech in Framingham. The school was brand new, and from its inception it included a broad range of students with disabilities. The state had just passed a comprehensive special education law, Chapter 766, which required that all students with disabilities receive publicly funded education in the least restrictive environment. A number of my students at Keefe Tech

had started their lives in the state institutions I had visited three years before. Most of the students with disabilities thrived in this new environment, achieving at levels few would have predicted and going on to real, competitive jobs.

Perhaps no group of disabled students has suffered more historically from negative societal attitudes than students with mental retardation. The change in status of this group over the past 30 years demonstrates clearly that attitudes and policy matter a great deal to the real lives of disabled people. The educational status of mentally retarded children and adults, as well as their integration into communities, has improved greatly over the past three decades. The practice of widespread institutionalization that existed prior to the law has been largely relegated to the past. In the early 1970s, the number of children with mental retardation in state institutions was over 100,000, with many living in filth and getting little education (Blatt, 1970; D'Antonio, 2004). By 1990, an approximately 90 percent reduction in institutionalization had occurred (Scheerenberger, 1990). These students are increasingly placed in integrated schools and classrooms. By the 2000–01 school year, fewer than 6 percent of children with mental retardation were educated in separate facilities (U.S. Department of Education, 2003). New approaches have been developed that demonstrate that even students with significant retardation can move from school to supportive, competitive work environments (Mank, 2001). Other innovative educators are demonstrating how even students with significant mental retardation can have access to literacy instruction (Kliewer et al., 2004).

Although there is significant room for improvement, the educational status of these children is in sharp contrast to what it was before the passage of PL 94-142 and Section 504 of the Rehabilitation Act of 1973.¹ Prior to these laws, it was legal to exclude

1. Section 504 of the Rehabilitation Act of 1973 was the first federal law that guaranteed education to all disabled children by prohibiting discrimination against the disabled by any institution that received federal funds. Therefore, given the fact that

students with mental retardation from school entirely, and most states did. Some states even required local school districts to exclude students with mental retardation (Hehir & Gamm, 1999). In response to the eugenics movement, policies in the first half of the 20th century had actively sought to separate the “feeble-minded” from the rest of society through the development of a vast array of state institutions. Mental retardation was thought to be a hereditarily determined, fixed trait that could be diagnosed based on performance on a standardized intelligence test. These policies created the institutions I visited as a young man. People were literally incarcerated without recognition of fundamental constitutional rights simply by scoring poorly on these tests. The result was that even children without mental retardation, often wards of the state, were placed in these institutions (D’Antonio, 2004).

Blatt’s (1970) description of the conditions of “back wards” captures the horrors endured by many people with mental retardation incarcerated in state institutions:

In each of the dormitories for severely retarded residents, there is what is called, euphemistically, the day room or recreation room. The odor in each of these rooms is overpowering, to the degree that after a visit to a day room I had to send my clothes to the dry cleaners to have the stench removed. The physical facilities often contributed to the visual horror as well as to the odor. . . . Most day rooms have series of bleacher-like benches on which sit denuded residents jammed together without purposeful activity or communication or any kind of interaction. In each room is an attendant or two, whose main function seems to be to “stand around.” . . . I was invited into the female as well as male day room, in spite of the supervisor’s knowledge that I, a male, would be observing denuded

public schools accepted federal money, they were covered under the act. The Individuals with Disabilities Act (IDEA), originally PL 94-142, the Education for All Handicapped Children Act, passed shortly after Section 504 in 1975. PL 94-142 provided funds to states to assist in the education of the disabled, along with significant regulatory requirements. All states eventually chose to accept this money and therefore are subject to the IDEA’s regulatory requirements.

females. I noticed feces on wooden ceilings, and on the patients as well as the floors. (p. 16)

Blatt (1970) goes on to describe the abusive conditions encountered by children:

The children's dormitories depressed me the most. Here, cribs were placed—as in other dormitories—side by side and head to head. Very young children, one and two years of age, were lying in cribs without contact with any adult, without playthings, without apparent stimulation. In one dormitory that had over 100 infants . . . I experienced my deepest sadness. As I entered, I heard the muffled sound emanating from the “blind” side of the doorway calling, “Come, come, play with me. Touch me.” I walked to the door. On the other side were 40 or more unkempt infants crawling around a bare floor in a bare room, crying for attention. One of the children had managed to squeeze his hand under the doorway and push his face through the side of the latched door, crying for attention. His moan begged me for some kind of human interaction. (p. 18)

D'Antonio (2004) captures the horrors endured by boys with questionable mental retardation who were placed at the Fernald School in Massachusetts, and their interminable desire for freedom, in *The State Boys Rebellion*. He recounts the actions of one of the more abusive attendants:

Unlike other violent attendants who were unpredictable and might suddenly become enraged, McGinn was methodical. For example, during almost every meal in the crowded first floor dining room, he walked silently around the tables with a large metal spoon in his hand. A boy who talked too loudly, or at all when McGinn had commanded silence, would get a whack on the head with a spoon. At other times, McGinn declared that he was searching for “hollow heads” and walked his way around the tables thinking as many skulls as he pleased.

Up in the wards, where he was often alone with the boys, McGinn allowed himself to practice sadism with a sexual component. Instead of red cherries, he would have the boys line up, pull down their pants, and stand still while he went down the line yanking on each one's testicles. The pain was almost equaled by

the shame the boys felt as they trembled with fearful anticipation. Many began crying as McGinn approached, well before he even touched them. (p. 45)

In addition to such atrocities, these boys were subjected to medical experiments under the auspices of the U.S. government, Harvard University, and the Massachusetts Institute of Technology, in which they were fed irradiated cereal. Most lived to see the day when President Clinton offered a formal apology to the victims of these experiments (D'Antonio, 2004).

The conditions at Fernald, depicted by Blatt and D'Antonio, were not confined to Massachusetts and were sometimes worse in other states. Geraldo Rivera's historic 1972 exposé of the Willowbrook State School in New York City asserted that 100 percent of the residents contracted hepatitis B within a year of admittance. In 1966, many states were spending less than \$6 a day on inmates in state schools for the mentally retarded (Blatt, 1970, p. 186).

The horrors described by Blatt, Rivera, and D'Antonio are largely a thing of the past, due to changes in societal attitudes and the power of more benevolent and progressive public policies reflected in PL 94-142. These changes began when a coalition of parents of children with mental retardation and progressive educators challenged the dominant view of mental retardation as tragic, hopeless, and potentially menacing. This was replaced by an optimistic view that children with mental retardation could benefit from education and supportive families and communities, and that people with mental retardation had rights just like all Americans under the Constitution. They further asserted that institutionalization harmed these children and exacerbated the impact of their disability. Again, Blatt (1970) summed up this view presciently:

Our true mission is to guarantee to every human being the right to be treated as a human being. . . . [O]ur true mission is to eradicate forever the evils of the back wards and the philosophies that breed them, and the conception that those evils resulted from a condition called "mental retardation" rather than a condition called civilization. (p. 253)

We are reinforced again and again in our conviction that intelligence, that all human development, is plastic and a function of practice and training, motivation and stimulation, as well as it is a function of neurology, chromosomes, and genes. (p. 254)

We must develop more optimistic convictions concerning the abilities and potentials of those we call mentally retarded, however severe that mental retardation may be. The prophecy of incompetency and vegetation associated with mental retardation is self-fulfilling. Equally self-fulfilling can be the prophecy of competency and achievement. (p. 258)

Looking back from a vantage point 30 years distant, visionaries like Blatt were clearly correct in their conception of the malleability of mental retardation and wise in their use of rights-based strategies. Their rights-based arguments successfully ended the practice of exclusion, initially through the courts (Hehir & Gamm, 1999) and ultimately with the passage of PL 94-142. The new special education law enshrined rights-based concepts of due process concerning the identification and placement processes of disabled children, significantly curbing the states' power to place children unilaterally in inappropriate placements and giving parents a powerful implementation tool (Hehir, 1990). A new generation of parents has used these tools to promote more inclusive education for their children, continuing a long march toward a brighter future for children with mental retardation (Hehir & Gamm, 1999).

Evidence of a much-improved world for children with mental retardation is everywhere. Most children with mental retardation learn to read. Many play on athletic teams, belong to Scout troops, and participate actively in their houses of worship. Parents write poignant accounts about the gift of their child with mental retardation (Bérubé, 1996). The Special Olympics is a major sports event in its own right. One recent news segment described a new program opening this fall at the University of Southern Maine for young people with developmental disabilities. An incoming freshman with Down's syndrome was interviewed about his future plans, while his mother expressed her long-held desire that her

son continue his education after high school. This is a far cry from the institution of the 1970s.

It is important to note that this optimistic picture of the status of education for students with mental retardation is by no means universal. Too many children with mental retardation continue to be inordinately segregated and insufficiently challenged, reflecting continuing low expectations. Some students, particularly racial minorities, continue to be placed inappropriately in special classes (Losen & Orfield, 2002). However, the trends for students with mental retardation are generally positive. Widespread exclusion and institutionalization have been eliminated and major strides toward integration have occurred.

The progress we have made over the last 30 years in the education of children with mental retardation supports the underlying thesis of this book: *Attitudes toward disability have a major impact on the education these children receive.* Changed attitudes toward mental retardation were necessary to challenge the dominant dysfunctional and abusive practices that characterized society's responses to children with this disability for most of the 20th century. Policies and practices have changed radically in a relatively short time. However, it would be a mistake to assume that merely changing attitudes is sufficient. This change was also dependent on the development of new approaches in education and early intervention for these children and their families. Progress has occurred through innovation within a values-based context of optimism propelled by strong law based on constitutional principles of equal rights and procedural due process. I believe that the progress that has occurred for children and adults with mental retardation is the result of the conversion of three forces. First, attitudes toward mental retardation became more benevolent and optimistic. Second, significant changes in care supported more progressive approaches and guaranteed important rights. And third, new approaches and innovations were developed that allowed children with mental retardation to learn at higher levels.

I wrote this book because, as a career special educator, I want both to celebrate the successes of the field over much of the last 30 years and to articulate a future that can build on those successes. However, as one who has a rather unique vantage point due to the various positions I have held, including director of the Office of Special Education Programs (OSEP) for the U.S. Department of Education, I am deeply concerned with the lack of direction of the field. I am further concerned with the fact that large numbers of students with disabilities are not able to benefit from the innovative, research-based practices that have been developed. Thus as we move into a new century in which special education has become a major component of American education, I feel we need to reevaluate the role of special education.

Is our role simply to comply with law or to comply with the spirit of law? Are we simply providers of service, or do we produce results? In an age of standards-based reform and inclusion, what is the proper role for general education, and to what degree are regular educators accountable for students with disabilities? Are the only important results of our efforts performance on standards-based tests, or do we have a more robust agenda? Do we accept dominant negative societal attitudes toward disability, or do we seek to change the world through education?

As I have reflected on these questions, particularly when I became head of OSEP and since that time, I have benefited greatly from the insights of adults with disabilities and of parents of children with disabilities, with whom I have worked and developed friendships. These friends and colleagues brought me to the realization that many of the problems that disabled students experience have discrimination at their core.

I recall a discussion I had with my former boss, then assistant secretary of education and longtime disability activist Judy Heumann, about the exclusion of disabled students from state testing accountability systems. "Why are you surprised Tom? Don't you see it's discrimination? It's ableism. Most disabled people experi-

ence that their whole lives because others don't believe they are capable." I was viewing the problem as a policy issue while Judy saw it through a much clearer lens. Though this exclusionary practice is ending due to changes brought about in federal law by disability activists like Judy, discrimination continues. Judy's use of the term "ableism"—deeply held negative attitudes toward disability that are analogous to racism—took me aback. It seemed such a strong word with serious implications. However, as I kept working with Judy and other disability activists, I began to see more clearly how deeply some educational practices reflect this prejudice. Requiring deaf students to lip-read rather than sign, preferring to have children with minimal vision read print rather than learn Braille, expecting dyslexic students to read a textbook far beyond their reading level in order to access a physics class are common examples of practices that I began to see as ableist at their core.

The lens of ableism began to take on great power for me as a special educator and provided a critical way to both evaluate practices and provide direction. It was clear to me that educational practices at times reinforced ableism, while at other times they served as important vehicles to overcome this form of discrimination. However, as I have spoken around the country on this issue, I have become aware of how few of my colleagues have even heard the term.

This book is an attempt to apply the lens of ableism to the field of special education in order to provide direction to a field that seems a bit out of focus. I would love to rekindle among educators and parents the clarity of purpose instilled in me as a young special education teacher, the determination that special education should define itself explicitly as a field that seeks to change negative views of disability while providing students with disabilities access to a quality education.

This book goes beyond the important discussion of attitudes of ableism and how ableism may negatively affect the education of children with disabilities. It focuses also on making the right decisions about the education of children with disabilities: the deci-

sions we make about individual children, the way we provide for their education, and the policies that support progress. It will provide detailed treatment of how we might greatly improve the education of children with disabilities through changing attitudes, innovative practices, and supportive public policy.

The book is organized as follows: Chapter 1 defines ableism in education and gives examples of how these negative attitudes have influenced the education of various groups of disabled students. Chapter 2 addresses the role of special education in promoting educational equity for students with disabilities and proposes a framework on which educational decisions for students with disabilities can be based. Chapter 3 focuses on the issue of placement in general education classrooms or inclusion. This issue has had a major impact on special education and remains controversial among many educators and advocates. Chapter 4 discusses the promise of universal design—the concept originating in architecture that calls for designing buildings, technologies, and services in ways that assume the need to provide access for people with disabilities. This chapter addresses the appropriate design of early reading programs, school discipline and behavior programs, curriculum access, and school structures. Chapter 5 addresses the most pressing policy issues facing students with disabilities today: standards-based reform and high-stakes testing. The chapter concludes with a set of recommendations on how to improve the likelihood that students with disabilities will benefit from these reforms. The book ends with a chapter that recognizes the central role policy has had in expanding educational opportunities for students with disabilities. It includes an in-depth discussion of special education policy.

This book is based on my optimistic view that education holds great promise as a vehicle by which individual children with disabilities can gain access to greater opportunity while at the same time promoting a society that values the equality of all its disabled citizens. In this way, education can continue to change society while opening up educational opportunities to all children.