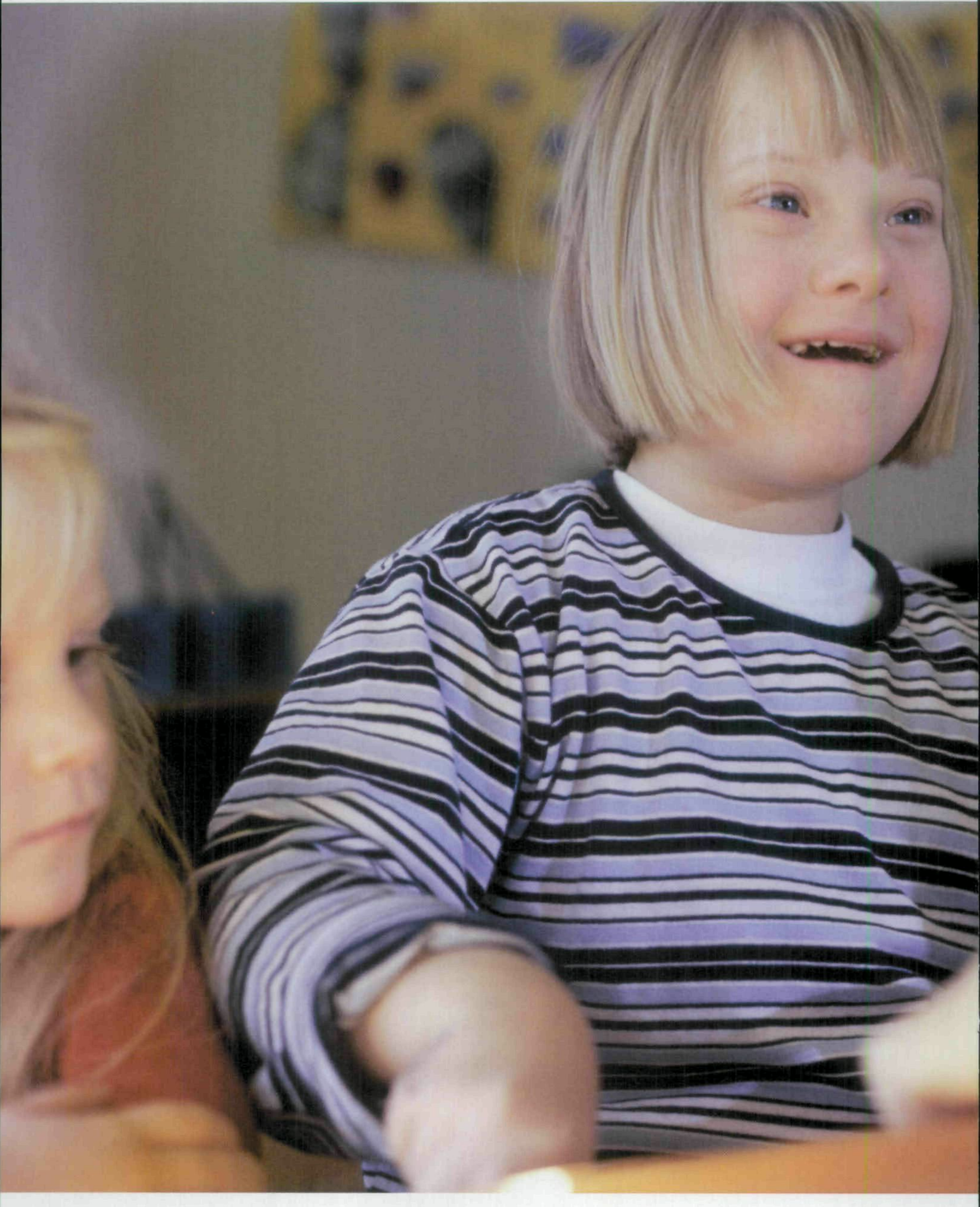

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Confronting Ableism

Negative cultural attitudes toward disability can undermine opportunities for all students to participate fully in school and society.

Thomas Hehir

When Ricky was born deaf, his parents were determined to raise him to function in the "normal" world. Ricky learned to read lips and was not taught American Sign Language. He felt comfortable within the secure world of his family, but when he entered his neighborhood school, he grew less confident as he struggled to understand what his classmates seemed to grasp so easily.

Susan, a child with dyslexia, entered kindergarten with curiosity about the world around her, a lively imagination, and a love of picture books. Although her school provided her with individual tutoring and other special education services, it also expected her to read grade-level texts at the same speed as her nondisabled peers. Susan fell further and further behind. By 6th grade, she hated school and avoided reading.

These two examples illustrate how society's pervasive negative attitude about disability—which I term *ableism*—often makes the world unwelcoming and inaccessible for people with disabilities. An ableist perspective asserts that it is preferable for a child to read print rather than Braille, walk rather than use a wheelchair, spell independently rather than use a spell-checker, read written text rather than listen to a book on tape, and hang out with nondisabled kids rather than with other disabled kids.

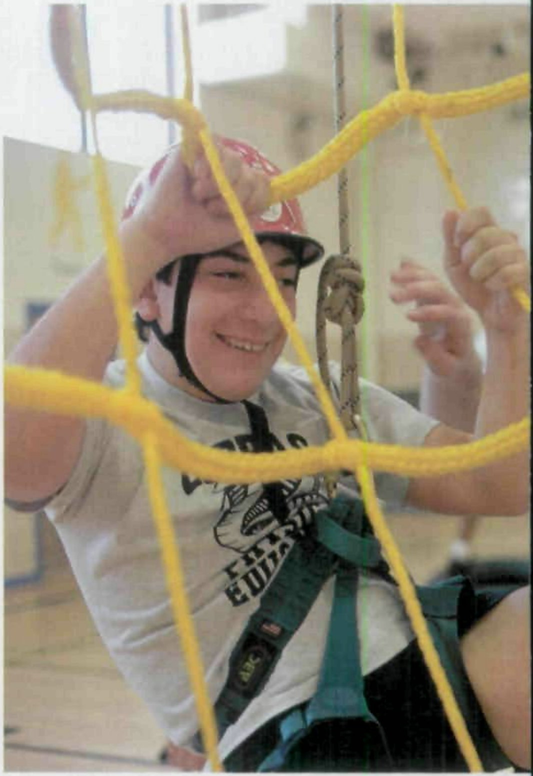
Certainly, given a human-made world designed with the nondisabled in mind, children with disabilities gain an advantage if they can perform like their nondisabled peers. A physically disabled child who receives the help he or she needs to walk can move more easily in a barrier-filled environment. A child with a mild hearing loss who has been given the amplification and speech therapy he or she needs may function well in a regular classroom.

But ableist assumptions become dysfunctional when the education and development services provided to disabled children focus on their disability to the exclusion of all else. From an early age, many people with disabilities encounter the view that disability is negative and tragic and that "overcoming" disability is the only valued result (Ferguson & Asch, 1989; Rousso, 1984).

In education, considerable evidence shows that unquestioned ableist assumptions are harming disabled students and contributing to unequal outcomes (see Allington & McGill-Franzen, 1989; Lyon et al., 2001). School time devoted to activities that focus on changing disability may take away from the time needed to learn academic material. In addition, academic deficits may be exacerbated by the ingrained prejudice against performing activities in "different" ways that might be more efficient for disabled people—such as reading Braille, using sign language, or using text-to-speech software to read.

The Purpose of Special Education

What should the purpose of special education be? In struggling with this issue, we can find guidance in the rich and varied narratives of people with disabilities and their families. Noteworthy among these narratives is the work of Adrienne Asch, a professor of bioethics at Yeshiva University in New York who is blind.



In her analysis of stories that adults with disabilities told about their childhood experiences (Ferguson & Asch, 1989), Asch identified common themes in their parents' and educators' responses to their disability. Some of the adults responded with excessive concern and sheltering. Others conveyed to children, through silence or denial, that nothing was "wrong." For example, one young woman with significant vision loss related that she was given no alternative but to use her limited vision even though this restriction caused her significant academic problems. Another common reaction was to make ill-conceived attempts to fix the disability. For example, Harilyn Rousso, an accomplished psychotherapist with cerebral palsy, recounts,

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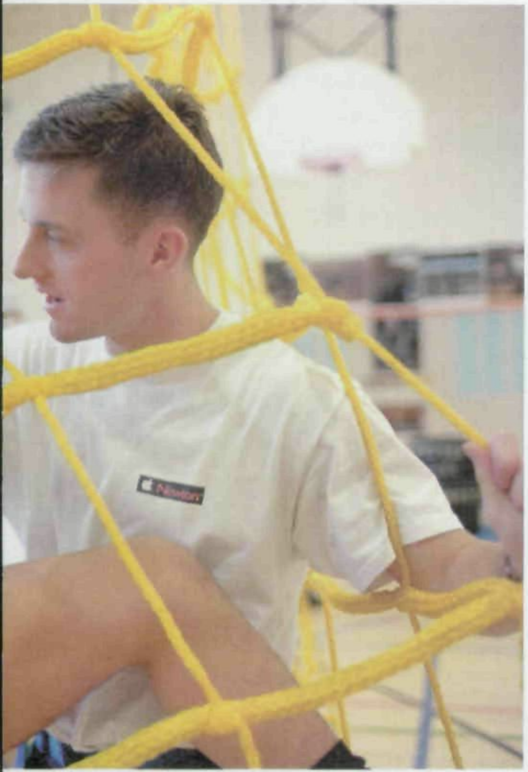
> My mother was quite concerned with the awkwardness of my walk. Not only did it periodically cause me to fall but it made me stand out, appear conspicuously different—which she feared would subject me to endless teasing and rejection. To some extent it did. She made numerous attempts over the years of my childhood to have me go to physical therapy and to practice walking "normally" at home. I vehemently refused her efforts. She could not understand why I would not walk straight. (1984, p. 9)

In recalling her own upbringing and education, Asch describes a more positive response to disability:

> I give my parents high marks. They did not deny that I was blind, and did not ask me to pretend that everything about my life was fine. They rarely sheltered. They



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> worked to help me behave and look the way others did without giving me a sense that to be blind—"different"—was shameful. They fought for me to ensure that I lived as full and rich a life as I could. For them, and consequently for me, my blindness was a fact, not a tragedy. It affected them but did not dominate their lives. Nor did it dominate mine. (Ferguson & Asch, 1989, p. 118)

Asch's narrative and others (Biklen, 1992) suggest that we can best frame the purpose of special education as *minimizing the impact of disability and maximizing the opportunities for students with disabilities to participate in schooling and the community.* This framework assumes that most students with disabilities will be integrated into general education and educated within their natural community. It is consistent with the 1997 and 2004 reauthorizations of the Individuals with Disabilities Education Act (IDEA), which requires that individualized education program (IEP) teams address how the student will gain access to the curriculum and how the school will meet the unique needs that arise out of the student's disability. Finally, this framework embraces the diverse needs of students with various disabilities as well as the individual diversity found among students within each disability group.

Falling Short of the Goal

Minimizing the impact of disability does not mean making misguided attempts to "cure" disability but rather giving students the supports, skills, and opportunities needed to live as full a life as possible *with* their disability. Maximizing access requires that school practices recognize the right of students with disabilities to participate fully in the school community—not only in academic programs, but also in sports teams, choruses, clubs, and field trips. A look at common problems encountered by students with low-incidence disabilities, specific learning disabilities, and emotional disturbances illustrates that schools still have a long way to go in fulfilling the purpose of special education.

Students with Low-Incidence Disabilities

In Adrienne Asch's case, minimizing the impact of her blindness meant learning Braille, developing orientation and mobility skills, and having appropriate accommodations available that gave her access to education. Asch also points out that because of New Jersey's enlightened policies at the time, she could live at home and attend her local school, so she and her family were not required to disrupt their lives to receive the specialized services she needed.

Unfortunately, many students today with low-incidence disabilities like blindness and deafness are not afforded the opportunities that Asch had in the early 1950s. Parents sometimes face the choice of sending their children to a local school that is ill equipped to meet their needs or to a residential school with specialized services, thus disrupting normal family life. Parents should not be forced to make this Hobson's choice. Services can be brought to blind and deaf students in typical community settings, and most students can thrive in that environment (Wagner, Blackorby, Cameto, & Newman, 1993; Wagner & Cameto, 2004). It is up to policymakers to ensure that such services are available.

We must give students the supports and skills they need to participate fully at school.

Students with Specific Learning Disabilities

Because students identified as having learning disabilities are such a large and growing portion of the school population, we might expect that these students would be less likely to be subjected to ableist practices. The available evidence, however, contradicts this assumption. Many students with dyslexia and other specific learning disabilities receive inappropriate instruction that exacerbates their disabilities. For example, instead of making taped books available to these students, many schools require those taught in regular classrooms to handle grade-level or higher text. Other schools do not allow students to use computers when taking exams, thus greatly diminishing some students' ability to produce acceptable written work.

The late disabilities advocate Ed Roberts had polio as a child, which left him dependent on an iron lung. He attended school from home in the 1960s with the assistance of a telephone link. When it was time for graduation, however, the school board planned to deny him a diploma because he had failed to meet the physical education requirement. His parents protested, and Ed eventually graduated (Shapiro, 1994).

We can hardly imagine this scenario happening today, given disability law and improved societal attitudes. Yet similar ableist assumptions are at work when schools routinely require students with learning disabilities to read print at grade level to gain access to the curriculum or to meet proficiency levels on high-stakes assessments. Assuming that there is only one "right" way to learn—or to walk, talk, paint, read, and write—is the root of fundamental inequities.

Seriously Emotionally Disturbed Students

Perhaps no group suffers from negative attitudes more than students who have been identified as having serious emotional disturbance (SED)—and no other subpopulation experiences poorer outcomes. Students with SED drop out of school at more than double the rate of nondisabled students. Only 15 percent pursue higher education, and approximately 50 percent are taught in segregated settings (U.S. Department of Education, 2003; Wagner & Cameto, 2004).

For large numbers of students with serious emotional disturbance, their IEPs are more likely to include inappropriate responses to control the most common symptom of their disability—acting-out behavior—than to provide the accommodations and support the students need to be successful in education. Only 50 percent of students with SED receive mental health services, only 30 percent receive social work services, and only 50 percent have behavior management appropriately addressed in their IEPs (Wagner & Cameto, 2004).

What *do* these students typically receive through special education? They are commonly placed in a special classroom or school with other students with similar disabilities (U.S. Department of Education, 2003)—often with an uncertified teacher.

From an early age, many people with disabilities encounter the view that disability is negative and tragic.

Placing such students in separate classes without specific behavioral supports, counseling, or an expert teacher is unlikely to work. Substantial evidence, indicates, however, that providing these students with appropriate supports and mental health services can significantly reduce disruptive behavior and improve their learning (Sugai, Sprague, Horner, & Walker, 2000). Such supports are most effective when provided within the context of effective schoolwide discipline approaches, such as the U.S. Department of Education's Positive Behavioral Interventions and Supports program (www.pbis.org). Schoolwide approaches also produce safer and better-run schools for all students.

Guidelines for Special Education Decision Making

The goal of minimizing the impact of disability and maximizing opportunities to participate suggests several guidelines for serving students with disabilities.

Recognize that diagnosis is important. To minimize the impact of disability, parents and educators need a clear understanding of the nature of the student's disability. Clearly, to make good decisions for a 3rd grader who does not read well, we need to know whether the problem is related to mental retardation, dyslexia, attention difficulties, or some other source. The student with mental retardation may be performing up to his or her capacity, indicating that the current instructional approach is working well, whereas the student with attention problems may need targeted accommodations or carefully prescribed medication. The student with dyslexia may need a highly structured reading program provided by a teacher with specialized training.

Another example of the importance of careful diagnosis is the case of two vision-impaired students who are learning to read and have the same visual acuity level. Although both are functioning well at present with the support of large-print texts, one student's vision impairment is progressive. Detailed knowledge of the disability would guide the school in deciding that this student also needs to learn Braille to ensure his or her success in the future.

Consider family capacity and desires. Good instructional decisions should take into account family capacity and desires. For example, the mother of an adolescent with Down syndrome, discussing her son's high school program, told me,

> I don't want the school wasting his time teaching him to cook or do laundry. I can teach him that! As a matter of fact, he is already a pretty good cook. I want him in band class.

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Although learning independent living skills is important for many students, particularly those with mental retardation, learning to cook would be a waste of precious instructional time for this high schooler. His family was already doing a great job of minimizing the impact of his disability in this area.

Involve students with disabilities in education decisions when appropriate. Students themselves play a crucial role in achieving better results. By involving students in decisions about their own education, we can gain important insights about the way they learn best, encourage them to take responsibility for their own education, and teach them to advocate for themselves as they move into higher education and employment. A focus on self-determination also helps students integrate their disability into their self-image in a natural, positive way (Ruosso, 1984). Self-determination is the opposite of the paternalism that has plagued the lives of so many people with disabilities.

Jorgenson (1997) provides practical suggestions about how to build self-determination, including involving students in important decisions regarding their education; transitioning students ages 18–21, particularly those not going on to postsecondary education, out of school settings to work and other typical adult settings; and integrating transition planning for students with disabilities into an inclusive process that helps students plan for their futures.

Encourage students to develop and use skills and modes of expression that are most effective for them. Parents and educators naturally want children to have the ability to perform in a typical manner. But if instructional programs focus too much on this preference, many students with disabilities will miss education opportunities as schools disregard their more effective, disability-specific modes of learning and expression. Of course, deaf students who can read lips have a competitive advantage in a hearing world. However, research has long shown that most deaf children do not develop elaborate language through oral methods alone (Stuckless & Birch, 1966). Paradoxically, a deaf child who has developed language skills through learning American Sign Language from birth (or, more recently, through cochlear implants) may actually read lips better because he or she has developed a larger vocabulary.

Keep integration into the general education environment the priority. IDEA's requirement that all students be educated in the least restrictive environment has resulted in significant positive change for students with disabilities. Research has shown that including students with disabilities in the general education environment improves academic achievement (Wagner et al., 1993). Inclusion also plays a central role in the integration of disabled people into all aspects of society, both by giving students the education they need to compete and by demonstrating to nondisabled students that disability is a natural aspect of life. For most students with disabilities, integration into regular classes with appropriate accommodations and support should be the norm.

Promote high standards. The most damaging ableist assumption is the belief that people with disabilities are not intellectually capable. Therefore, although performance on a high-stakes test should not be the only means through which students with disabilities can demonstrate what they know and are able to do, the requirement to include students with disabilities in standards-based reform holds promise. Many in the disability community hope that this requirement will counter the low expectations that have plagued students with disabilities in the past.

To improve the likelihood that students with disabilities will be successful on high-stakes tests, schools should provide early intervention for those experiencing academic or behavioral difficulties, give all students access to the regular curriculum whenever possible, and carefully choose accommodations in both instruction and assessment so that these accommodations minimize the effects of the disability.

Employ concepts of universal design. The principle of universal design first pertained to architecture; it called for public buildings to be designed so that people with disabilities would be able to use them. Buildings designed with this principle in mind, for example, would include ramps, automatic door opening devices, and fire alarm systems with lights activated for the deaf. Universal design allows for access without extraordinary means and is based on the assumption that disabled people are numerous and should be able to lead regular lives.

This principle has recently been applied to schooling and shows tremendous promise in minimizing the impact of disability and transforming the curriculum for all students. For example, Rose and Meyer (2002) have developed new multimedia curriculum materials that enable all kinds of students to gain access to information: students with physical disabilities can turn pages with the touch of a key; students with visual disabilities can expand the size of the print; students with learning disabilities can have words that they cannot decode read aloud to them.

Getting Past Ableism

The U.S. education system has made major strides in improving education opportunities for students with disabilities. More of these students are finishing high school than ever, and record numbers are moving on to employment and higher education (Wagner & Cameto, 2004). Much of this improvement has taken place because of the work of school leaders throughout the United States.

The requirement to include students with disabilities in standards-based reform holds promise.

To continue and expand this progress, however, educators must recognize and challenge the ableist assumptions that still permeate the culture and guide much special education practice. Students with disabilities need carefully constructed, individual instructional programs that recognize the effects of their disability while creating opportunities for them to learn and fully participate in school and society.

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