

UNDOING ABLEISM

TEACHING ABOUT DISABILITY IN K-12 CLASSROOMS

Susan Baglieri and Priya Lalvani



Undoing Ableism

Undoing Ableism is a sourcebook for teaching about disability and anti-ableism in K–12 classrooms. Conceptually grounded in disability studies, critical pedagogy, and social justice education, this book provides both a rationale as well as strategies for broad-based inquiries that allow students to examine social and cultural foundations of oppression, learn to disrupt ableism, and position themselves as agents of social change. Using an interactive style, the book provides tools teachers can use to facilitate authentic dialogues with students about constructed meanings of disability, the nature of belongingness, and the creation of inclusive communities.

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Typeset in Sabon by Taylor & Francis Books For the homeroom crew at RMHS who showed me why "sped pride" -S.B.

For Amiel and Minal –P.L.



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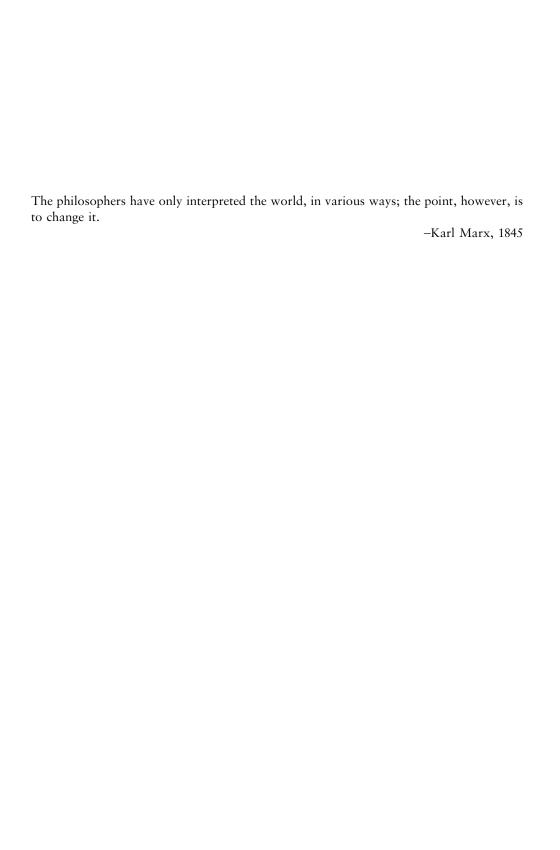
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1 Why Teach About Disability and Ableism in K-12 Education?

Disability is a form of human variation and an aspect of the human experience. People with disabilities are often described as the world's largest minority group. Yet, when the topic of ableism arises in our conversations with our teacher education students, friends, colleagues, and other education professionals, we frequently receive quizzical looks, followed by the question: "What's ableism?" Describing "ableism" as negative or prejudicial beliefs about disability that arise from, and result in, the systematic oppression of people with disabilities is often met with questions of concern: "Why introduce young children to sensitive topics like that?" "Might children be scared?" "Isn't thinking about disability depressing?" "Won't it make disabled kids feel uncomfortable?" "Isn't is better to focus on abilities, rather than disabilities?" "Do we really want teachers to spend time teaching another 'ism' in school?" And, the most frequently asked, "Why point out that some people are different if the children don't even notice?" Many educators believe that questions related to disability do not need to be answered if they are not openly asked, instead presuming that young children do not "see" disability. Consequently, in schools, there are few conversations aimed at addressing children's curiosity about disability and difference. In its place, there is a silence; like the proverbial elephant in the room, the topic of disability remains unmentioned, and the issue of ableism is unaddressed.

Ableism in Society

"The average American is not, nor should they have to be, prepared to fight every day of their life for basic civil rights. All too many incidences of discrimination have gone by undefended because of lack of protection under the law. In the past, disability has been a cause for shame. This forced acceptance of second-class citizenship has stripped us, as disabled people, of pride and dignity. This is not the way we, as Americans, should have to live our lives."

-Judith Heumann (1988, p. 74)

Disability oppression and the need to educate people, young and old, about disability and ableism seems far from public consciousness. There is little open dialogue about disability in society. Disability may be perceived as a private, personal, or medical matter, rather than a topic of social, cultural, and political importance. Thinking about disability and encountering disabled people may elicit existential anxiety, as it provokes confrontation of human fragility and raises fears about potential loss of control, frailty, and dependency (Hahn, 1988; Rauscher & McClintock, 1997). Avoidance of disability is also connected to the desire to conform to cultural expectations, ideals of normalcy, and the physical aesthetic. As Rauscher and McClintock (1997) state:

Deeply rooted beliefs about health, productivity, beauty, and the value of human life, perpetuated by the public and private media, combine to create an environment that is often hostile to those whose physical, emotional, cognitive, and sensory abilities fall outside the scope of what is currently defined as socially acceptable.

(p. 198)

Cultural discourses and sociocultural practices are rooted, then, in aversion to disability and a lack of understanding of what life with a disability is like from the perspectives of those who experience disability. Avoidance may have much to do with the discomfort many feel when thinking about disability. Lack of opportunities for nondisabled and disabled people to engage with each other is exacerbated by the historical exclusion of disabled people from school and work environments.

In the absence of robust public dialogue about disability and lack of opportunity to interact in mixed-ability groups, public understandings often reflect stereotypes and misconceptions that compose master narratives on disability. Master narratives are culturally derived, taken-for-granted "knowledge," or dominant assumptions about what is considered normal or desirable in society (Bamberg, 2004). Master narratives on disability characterize disability as something to be cured, eliminated, fixed, or overcome, and depict life with a disability as tragic, pitiable, and burdensome. People with and without disabilities encounter these narratives and come to understand disability as an undesirable and inferior state of being. For instance, the beliefs that people with disabilities lead lives that are burdensome or sad, that they deserve pity and compassion, or are courageous and sources of inspiration simply by being alive or engaging in everyday activities are largely unquestioned, yet are rooted in assumptions that disability must always be experienced as personal tragedy.

Ableism is a "pervasive system of discrimination and exclusion that oppresses people who have mental, emotional, and physical disabilities" (Rauscher & McClintock, 1997, p. 198). Ableism occurs because of the persistent devaluing of disability and the dominance of viewpoints in which disability is cast as an inherently flawed and undesirable state of being (Campbell, 2001, 2009). The proliferation and commonality of ableist assumptions about disability, over time, unfolds as a system of oppression. Similar to other systems of oppression, such as racism, sexism, classism, and heterosexism, ableism thrives on beliefs about the inherent superiority of some and the inferiority of others on the basis of group traits. Ableism operates in overt and subtle ways at individual, cultural, and institutional levels. At each of these three levels, advantages available to nondisabled people are perpetuated, and disadvantage is produced for people with disabilities. Like other kinds of structural oppression, prejudice is at ableism's core, and discrimination is an outcome. The following list describes examples of ways ableism is evident in society.

Institutional level:

- Many homes require the use of stairs; they are not built with ramps, and in many regions, wheelchair-accessible apartment buildings are not readily available.
- Many business facilities are not fully accessible to individuals with mobility, visual, or hearing impairments.
- Restaurants do not typically provide menus in Braille.
- In schools, instruction is often offered at a regimented pace in which students are
 expected to demonstrate their learning in specific activities—primarily reading and
 writing text. Those who need support to meet expectations must first receive a disability label—often stigmatizing—in order to receive help or accommodations.

- In many schools, there is often a lack of adaptive technology available for students with disabilities; similarly, there is often a lack of accessibility and adaptive technology such that people with disabilities can participate in local government meetings or committees.
- The continued existence of separate or "self-contained" classrooms for the education of students with disabilities results in the segregation of many students with disabilities from their peers.

Cultural level:

- Cultural narratives uphold restrictive definitions of normalcy by prescribing what people should be able to do and how they should do it, thus marginalizing those who do not fit the parameters of "normal" behavior.
- Independence and individuality are highly valued in many cultures; interdependence or needing care is thought of as a less desirable life.
- Cultural norms dictate the desired body and standards of beauty; these culturally constructed ideals are reproduced and reified through the media.
- People with disabilities are underrepresented in media, literature, pop culture, and so forth. When they are included, they are often represented in stereotypical ways.
- Our cultural lexicon is rife with negative terms for people with disabilities (e.g., slow, dumb, idiot, retarded), euphemisms that only serve to reify otherness (e.g., special, handicapable), and ableist metaphors (e.g., "a lame excuse," "blind to the truth").
- The widespread routinization of prenatal genetic testing reifies notions about normative children and upholds beliefs that it is undesirable or a "tragedy" to have a disabled child.

Individual level:

- People may believe that life with disability is "tragic" or characterized by profound loss, or that it is "better to be dead than disabled."
- Beliefs that people with disabilities are deserving of pity and compassion, or that they are sources of inspiration, are common.
- Beliefs that parents of children with disabilities are "saints," courageous, or "chosen" to have a disabled child are commonly held.
- Many people, including educators, believe that special education teachers must possess extraordinary amounts of compassion, endurance, and patience, compared with other teachers.

Sources: (Baglieri & Shapiro, 2017; Lalvani, 2011, 2013; Ostiguy, Peters, & Shlasko, 2016)

These examples are experienced by people with disabilities as prejudicial or discriminatory, even as many may not readily interpret them as such. Ableism is largely outside the public consciousness. There is little awareness that it exists and, as such, it is what Chodorow (1999) describes as a "permissible prejudice"—one that is unacknowledged and even accepted in society. That being disabled is abnormal and people with disabilities cannot expect to be "catered to" in every situation, or that the lives of people with disabilities are necessarily shaped by loss, tragedy, struggle, and the desire to be rid of impairment point to common misconceptions and assumptions that underlie the persistence of ableism.

We return to the frequent question, "Why point out that some people are different if children don't even notice?" It is likely that even young children have noticed disability or

markers of disability in the world. By the time they enter school, many have asked curious questions about neighbors in wheelchairs, service animals, or people they see who seem different from themselves in any number of ways. Contemporary media directed at children increasingly features people with disabilities. *Sesame Street*, for example, introduced Julia, a Muppet with autism in 2017. Picture books designed to educate children about disabilities are easy to find, and the (problematic) use of eye patches, dwarves, hooks, and humpbacks in children's stories has a long tradition. Most young people have probably observed the international symbol of access—the blue wheelchair symbol—hanging in many public areas. When disability is left unmentioned in the classroom it sends an implicit message that it is a topic with little relevance, yet the persistence of ableism suggests that it is relevant to all of us. In presuming that young people do not notice difference or that differences do not matter, we miss the opportunity to instill in children an appreciation for human differences in self, family members, and others, and to support futures in which they can participate in building more inclusive communities.

Ableism in Schools

Attitudes toward members of social, cultural, and identity groups different from one's own are formed through direct contact, implicit and explicit messages received from others, and through making meaning about depictions of others in cultural narratives. Children can gain an appreciation for diversity and develop knowledge about groups of people as a result of their own experiences within heterogeneous environments. In many schools, however, nondisabled children and those who have labels of disability may not have sufficient opportunities for sustained interaction and the development of meaningful relationships because some kinds of disabilities are quite rare among school-age populations. Another, more pressing reason that meaningful interaction is rare is that large numbers of students with disabilities continue to be educated in segregated and "selfcontained" learning environments in US schools. Students labeled with autism, intellectual disability, and multiple disabilities are overwhelmingly more likely to be educated in partially or entirely segregated learning environments (Morningstar, Kurth, & Johnson, 2017; US Department of Education, 2013). At the root of this arrangement is the existence of a bifurcated system of education within which general and special education function as parallel universes, each with its own sets of teachers, training programs, and teaching certifications, and with underlying implications about two distinct kinds of learners those with disabilities and those without; those deemed normal and those considered abnormal (Connor & Ferri, 2007; Linton, 1998).

In this bifurcated system, students are sorted by ability and many are assigned to physically segregated learning environments. Despite a decades-old struggle for inclusive education in which all children are educated together, in many schools being "included" in education remains characterized as a privilege only for those students who "keep up" academically and meet values-laden criterion for normative behavior (Lalvani, 2013; Valle & Connor, 2011). In this way, the bifurcated system of general and special education becomes an avenue through which the *otherness* of some students is constructed and the *normalcy* of others upheld. The very existence of separate classrooms reinforces the idea that some people are different enough that they cannot be educated in the same space as everybody else. Ableism plays a key role in decisions to exclude students from general education classrooms through educational discourses that support and sanction their segregation (Storey, 2007). These separations among children with and without disabilities allow ableism to proliferate by reinforcing disability stigma and preventing natural opportunities for interaction among ability-diverse children.

Stigma is a powerful phenomenon linked to the value placed on certain identities. Stigma involves recognition of a difference, and a consequent devaluing of the difference (Dovido, Major, & Crocker, 2000). Stigmatizing serves to establish a psychological and social hierarchy, and people who are stigmatized are almost always the target of prejudice and social rejection (Goffman, 1963). Goffman (1963), in his foundational work, discussed the ways in which stigma is produced by physical environments. In the context of special education, students with disabilities become marked as *other*, not just through the labels they are ascribed but also by virtue of the physical spaces to which they are assigned—or even via association with these spaces. As such, the existence of segregated physical spaces itself perpetuates the stigma attached to disability, and particularly to those with intellectual disabilities, in school culture and in society overall (Smith, 2010). Consequently, children with and without disabilities receive the message that they belong in different spaces and places, separated from each other.

Calls to end disability segregation in schools are clear and many schools and districts are inching toward more inclusivity, especially for students with learning disabilities and those deemed less "severely" disabled (McLeskey, Landers, Williamson, & Hoppey, 2010). The experience of education in a heterogeneous environment can provide an opportunity to develop understanding and acceptance of disability and diversity, however, merely "placing" children together is unlikely to achieve this outcome given the broader societal context of aversion to disability. Research literature suggests that peer acceptance for students with disabilities, even when they are physically present in general education classrooms, is a persistent concern. Students labeled as disabled continue to be marginalized in schools, remain on the social periphery of their classrooms, and, when compared with students without disabilities, are at greater risk for social isolation (Kasari, Locke, Gulsrud, & Rotheram-Fuller, 2011; Rossetti, 2014). Students with disabilities are also significantly more likely to experience harassment and bullying, and the bullying they experience is more frequent, more chronic in nature, and often directly related to their disability (Saylor & Leach, 2009; Wall, Wheaton & Zuver, 2009; Holzbauer, 2008). In his classic studies on intergroup prejudice, Allport (1979) explicated that physical proximity alone is not enough to reduce intergroup prejudice. Students do not receive enough information about disability, nor are they provided with the tools to question or disrupt the powerful messages imparted by the disability segregation that characterizes their everyday lives. Teaching about disability is essential to undoing the ableism that has structured much of human relations over time. The past century ushered in significant changes in orientations toward disability. Attention to ending discrimination, increasing accessibility, and committing to the realization of the civil rights of disabled people has been inscribed in public policy and mandated in the courts. It is cultural change, however, that is needed—one within which disabled perspectives and voices may rewrite the master narrative of disability, moving from one that centers on assumptions of tragedy toward one that is empowered, complex, and varied.

Why We Teach About Ableism

This book was built from a series of lessons that coauthor, Priya, conducted with young people and teachers in a mixed-ability, inclusive school. These lessons conducted in the school were based in an understanding that inclusivity in education is not about merely placing students with disabilities *into* general education and then hiding, pretending not to notice, or avoiding questions about difference. The inclusivity endeavored in this environment was one in which the group could engage with difference and develop understanding about ableism as being a destructive force in disabled people's lives.

Engendering niceness or even kindness toward others is not quite the same as working with teachers and young people to understand inequity and engage in work toward justice. Prejudice reduction is most likely to occur when members of different groups are positioned as having equal status and are institutionally supported to collaborate with each other in pursuit of common goals (Allport, 1979). Priya identifies as a nondisabled woman whose professional background includes working with people with labels of intellectual disability who had been previously institutionalized, and as a mother of a child with a disability. Coauthor, Susan, identifies as a nondisabled person who witnessed the importance of disability rights and culture while working as a high school teacher with young people labeled as disabled. For many of the students in her ninth grade selfcontained classroom, the first key to success did not come from striving to "overcome" disability or from specialized teaching techniques. Success was first able to be imagined through what one young man declared to be "Sped pride." Feeling belonging in a disability-segregated school began, for this group, with voicing the problem of being separated and claiming power using the label ascribed to them. It was this collective voice that enabled us to name exclusion and seek wider access and participation in the school. Self-efficacy and self-acceptance flowed, and so much more came with that.

We—the authors—teach about ableism because we have witnessed, through our personal experiences and work with those who have experienced seclusion from society or marginalization in schools, not only the damaging outcomes of society's failure to question the oppression of people with disabilities, but also the power of these ideas when people have an "a-ha" moment that changes understandings of disability for self and others. We work against all types of segregation in schools and society through our roles as teacher educators, researchers, and mothers. Writing a book for teachers about teaching ableism, specifically, responds to a gap among the many sourcebooks dedicated to practice in social justice education.

Why Might You Teach About Ableism?

Teachers are not impervious to the cultural narratives of disability that too often lead to aversion to or erasure of disability. Products of an ableist society, many of us—nondisabled and disabled people alike—avoid contact with those different from us, get embarrassed if caught staring, act a bit too nice, or imagine it is a kindness to emphasize similarities and muse that, "Everyone has difficulties with something." Once in the profession, educators are implicated in sustaining a parallel system that divides young people into two distinct groups—those with and without disabilities—who are often physically isolated from each other (Connor & Gabel, 2013). It is no surprise that teachers are infrequently equipped to provide students with tools to recognize or combat ableism. Even teachers who are genuinely committed to inclusivity often feel concerned, fearful, or ill-equipped to take on discussions about disability within their curricula, believing that someone else would know more about this topic (Ware, 2001). If you are wondering why you should or whether you can teach about ableism, consider the following discussion on some common questions and comments raised about including disability curriculum in schools.

1. "Isn't disability a special education concern?"

The education of students with disabilities in the US has traditionally occurred in special education classrooms or schools, which are separated from "general" education and overseen by teachers with disability-related licenses and preparation. This parallel system

creates a discourse in which professionals presume that disability is a matter and concern only for teachers of students with disabilities. It should not be assumed that special educators are teaching *about* disability and ableism simply because they are working with students with disabilities. There is surprising discomfort with and avoidance of having candid discussions about disability even within special education. Consider, for example, the common preference for describing students as having "special needs" or "learning differences." Schools respond to the stigma of disability by erasing the word, yet in doing so they actually reinforce the stigma that impairment or disability is shameful, as well as prevent learners from understanding their membership in a political group with ties to positive social identities, powerful histories, rights, and entitlements. Working against ableism does include understanding difference as natural and acceptable across a range of human variation, but as long as schools and society label people "disabled" it is a disservice to erase the term in working with young people. Learning about disability and ableism is important for all teachers and students.

2. "They don't even notice anything different!"

A persistent myth in schools today pertains to the notion that young children do not notice or react to differences between themselves in ways that we recognize as prejudicial. In conversations with preservice and in-service teachers about how the topic of disability is discussed in classrooms, or how one might address questions from students who are curious about the differences between them, it is not uncommon for teachers to state, "We don't need to say anything—our students don't even notice anything different about their classmates" or "Children don't ask any questions about disability—they are so accepting!" Similarly, it is not uncommon for a teacher to claim that they treat "each student the same," or that a visitor to their classroom would be "unable to tell which child has a disability." Although these statements are likely well intentioned, we problematize both the underlying assertion that children do not perceive difference—similar to a "color blind" orientation to race, and the belief that when children don't ask questions about human variations, it is indication that they do not have any. Children are likely to be curious about the differences they notice between their classmates and to have questions about the ways in which some of their peers communicate, learn, or move around (Lalvani, 2015). Their lack of questioning should not be taken to mean that they are not curious about differences, but rather, that perhaps they have learned to silence their curiosity about certain kinds of differences.

3. "But we already do disability awareness day!"

If schools endeavor to address the topic of disability at all, it is usually under the guise of the all-too-familiar "disability awareness day." This generally involves a series of watered-down and patronizing activities intended to inform children about disability—activities that end up, at best, presenting "feel good" moments for the nondisabled, and at worst, reinforcing ableist stereotypes. Special events tend to focus on messages of either compassion or inspiration and, thus, lack opportunities to teach children to think critically about issues related to identity, community membership, and civil rights. In these lessons, disability is located within individuals and discussed as an individual difference, rather than as inextricably linked with ableism, which operates at individual, cultural, and institutional levels. Consequently, these efforts usually fail to raise "awareness" about the systematic nature of disability oppression and one's personal complicity in the exclusion of some people.

4. "I am not an expert on disability."

Disability has always figured into the human experience. From infanticide in early cultures, to eugenics and euthanasia policies in the early nineteenth to twentieth century, to international disability rights movements occurring in the 1950s and '60s, disability has a perennial presence in history and culture. Despite the occurrence and significance of these events, the collective history of disabled people in America has generally remained outside of the public awareness, and, as Burch and Sutherland (2006) point out, the vast majority of high school graduates in the US are unlikely to have any knowledge of disability history and any awareness of the existence of the disability rights movement, for there is little or no mention of these in schools. Few educators have knowledge about disability history, and those who do lack resources for teaching it. Additionally, fear of mentioning the topic of disability in classrooms present further obstacles to addressing disability history in school curricula. You are not alone if you don't feel like an expert ready to teach about disability and ableism, yet there is no better time to learn. The Web is bursting with free and low-cost resources. Study of disability and disability history offers provocative insights into the experiences of Americans and of America; it provides a nuanced understanding of the ways in which power and privilege play out, and simultaneously allows us to explore complex issues around how American society has responded to human differences (Burch & Sutherland, 2006; Kudlick, 2003).

Anti-Ableist Education: Toward Inclusive Education

The story of disability is undoubtedly one of sustained and systematic oppression, but it is also a story about the power of radical action, the agency and empowerment of disabled people, and the evolution of disability culture and identity. At the same time as the civil rights and women's movements of the 1950s and '60s, those involved with the disability rights movement demanded public recognition of the mistreatment faced by people with disabilities (Connor & Gabel, 2013; Fleischer & Zames, 2011). Their efforts led to the passing of legislation to acknowledge and address the segregation and discrimination of disabled people, and to initiate drastic changes in the ways in which they are treated in the US (Rauscher & McClintock, 1997). Additionally, in recent decades, many people with disabilities who identify with the disability rights movement have reclaimed the term "disability" in a positive way. They reject the notion that being disabled is an inherently negative experience and that people with disabilities need to be fixed; instead, they view themselves as disabled by societal, environmental, and attitudinal barriers, rather than by their impairments (Rauscher & McClintock, 1997). From this perspective, the phenomenon of disability pride has taken root and is continuing to gain traction.

America has long reckoned with its histories of segregation, suppression, and abuse of young people in school. There is increasing awareness of the imperative to educate children inclusively, and shifts in practices surrounding curriculum and pedagogy are perceptible. Universal Design for Learning (Meyer, Rose, & Gordon, 2014) and Culturally Sustaining Pedagogy (Paris & Alim, 2017) are noted examples of practices and pedagogies that presume diversity among learners and approach difference not as "problems" for instructional design, but as integral to it. Attention to inequity and abuse in education with regard to race, sex, gender identity, social class, disability, and sexual identity is evident in teacher education. Many teacher education programs increasingly strive to prepare teachers to develop dispositions, curriculum, and pedagogy that recognize and respond to institutionalized racism. Conversations about race, diversity, and equity, for example, are positioned as an imperative as teachers explore complex issues related to the

social construction of human difference and injustice (Choi, 2008; King, 1991; Sleeter, 1996; Tatum, 1997; Ware, 2008). The call for critically multicultural, anti-racist, and social justice curricula has been at the forefront of remaking and reshaping K-12 school curriculum. Social justice educators critique "color blind ideology" and strive to end the silence around conversations about race and racism (Bonilla-Silva, 2003; Choi, 2008; Schofield, 2004). Open dialogue about inequity and justice and the expansion of voices and perspectives represented in the American curriculum in schools are increasingly called for by many (Banks & Banks, 2012; Gill, 2004; Nieto, 2000; Snyder & Broadway, 2004; Ware, 2001; Winans, 2006).

While school policies appear to require integration and equity in terms of sex, gender, race, class, disability, sexual orientation, and language, critical scholars point out that there is much work yet to be done on a system within which exclusion and the maintenance of social and economic hierarchy is entrenched (Annamma, Connor, & Ferri, 2013; Erevelles, 2000; O'Laughlin & Lindle, 2015; Oliver & Barnes, 2012; Waitoller & Thorius, 2015). The labor of reform is aptly directed by those with historically subjugated perspectives and voices calling for change. Yet, work toward integration and justice must be shared labor by all members of society. All must recognize and resist the pull of the past in which segregation seems to be natural, determined, and the way of the world. All must critically question discourses that blame victims of systemic injustice for their social or economic condition. Change in both what we teach and how we teach the next generation of leaders, thinkers, lawmakers, and laborers is a necessary and essential reform.

Reflection Points for Professional Learning

Why Teach About Disability in K-12 Curricula?

- Disability is a natural and enduring aspect of human diversity and a form of human variation; people with disabilities are one of the largest minority groups in the US.
- Disability relates to-and intertwines with-race, gender, and other aspects of social identity.
- People with disabilities have made many contributions to society.
- Ignorance about disabilities leads to stereotypes, prejudice, and discrimination.
- Literature, art, and media are filled with negative portrayals of disability. In order to eliminate stereotypes, it is necessary to first examine the assumptions and beliefs on which they are based.

Source: Ferguson (2001)

- 1 Table 1.1 is a list of five reasons to teach about disability in K-12 education. Why are you interested in teaching about disability?
- What was your own understanding, as a child, about disability? Reflect on your 2 earliest memories about disability. Make a list of experiences that have shaped your interest in, and ideas about, disability or ableism.
- 3 Make a record of questions that you hope this book will help you explore.

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