

Preface to the Updated Edition

IN REVIEWING THE ACHIEVEMENTS, as well as the shortcomings, of the disability rights movement in the first decade of the twenty-first century for this updated edition (see Chapter 13), I have relied predominately on the leading voices that have emerged from the movement. Among those voices, the succinctly expressed insights of James Weisman, general counsel at United Spinal Association (USA) and board member of the American Association of People with Disabilities (AAPD), serve as an overview.¹ Most notably, Weisman observed, “The movement has continued to change sociologically as, rather than classified by diagnosis, the movement is increasingly cross-disability—that is, organized around issues, policy, lobbying, consumerism—and effectively responding to corporate America.”

Weisman pointed out the dramatic alteration of the built environment, for the question regarding newly constructed or renovated entities has ceased being whether they will be accessible. Instead, builders ask how functionally and aesthetically they can be constructed so they comply with the relevant regulations. “When they are not properly constructed, people notice,” Weisman added; consequently, failure to follow the required guidelines garners an appropriate response. The movement’s struggle for accessible transportation has been generally successful; as Weisman put it, “Everything that’s a bus in the United States is accessible, as are new rail starts and stations, and, on the occasional instances when accessibility is omitted in the construction, there is a timely public reaction and correction.” Accessibility is almost always incorporated in the original design, thus negating the need for costly and problematic retrofitting, Weisman noted, and “people are used to accessibility, whether they are wheelchair users, or have other mobility issues, or if they are pushing baby strollers.”

For most of the twentieth century, stadiums, arenas, theme parks, tourist sites, theaters, hotels, and transportation were “industries” that Weisman described as fighting against the legislation that protected people with disabilities, so he was among the attorneys who countered their obstructionism. “Now in the twenty-first century,” Weisman declared, “people like me are the paid consultants who representatives of these industries hire to make sure that they serve the needs of those with disabilities.” That shift has occurred not only because of what is currently deemed to be politically correct behavior but, as Weisman underscored, also because of the understanding that the expanding number of people with disabilities translates into a growing number of customers. Furthermore, the significant decrease in the instances of blatant mistreatment of people with disabilities by law enforcement, school personnel, hospitals, and businesses has heartened Weisman. “It’s not like it never happens anymore,” Weisman stated, “but the instances are far fewer than in

the prior century, and when they occur, there is a greater level of outrage.” Moreover, Weisman characterized disability rights organizations in this century as becoming more sophisticated in their ability to marshal legal and political support while, at the same time, the practice of disability law has evolved significantly around civil rights rather than just benefits.

Weisman acknowledged the inclusion of people with disabilities as political appointees in the Clinton administration, “which went out of its way to set a new standard for the administrations that followed.” By the Obama administration, however, Weisman emphasized that people with disabilities were no longer appointed primarily to disability-related positions, but according to their expertise. Also, he referred to how President Barack Obama introduced Supreme Court Justice Sonia Sotomayor—who self-identifies as a diabetic—as a person with this disability; yet nothing indicated that her condition, in the public mind, would interfere with her performance in her new capacity.² Moreover, Weisman continued, “Though the culture of disability studies [as an examination of another form of diversity] may have been initiated in the twentieth century, it has come of age in the twenty-first century.”

On the other hand, Weisman was acutely aware of the lack of adequate progress in pressing disability rights causes. It is abundantly clear that people with disabilities are far from receiving appropriate civil rights protection in health care, housing, education, and employment. Weisman would agree with Peter Orszag’s example of how public policy has failed to keep pace with changing realities: “When Congress created the disability insurance program in 1956, it required that recipients be unable to ‘engage in substantial gainful activity in the U.S. economy.’ . . . That was sensible at the time, when more jobs involved physical labor and technologies to assist people with disabilities were not widely available. Today, however, many people with disabilities are able to engage in some form of work—even if they can’t admit that and still keep their insurance benefits.”³ Such a policy is devastating to many people with disabilities, as well as to the economy.

Even the battles that have been won, such as transportation, are incomplete. For example, although some American cities, such as Boston, Minneapolis, and Las Vegas, have accessible taxis, the vast majority of cities still do not, including the city that has the most taxis, New York. The result is that many people with disabilities and older people have to depend on an inadequate, unreliable, expensive paratransit system that requires passengers to book well in advance without assurance that they will get the bookings they need. Because the technology for all taxis to be accessible has been available for many decades, and the savings to cities would undoubtedly be significant if this overused paratransit system were, for the most part, replaced by accessible taxis, Weisman predicted, “someday the word ‘taxi’ will mean accessible.” Yet, he added, “What will ultimately drive this change, which will serve not only the disability population but also the wider society, is not the fact that it is indisputably a civil rights issue, but the economics.”

It is the health care issue, however, that reveals most emphatically how, in truth, there is a spectrum regarding, rather than a distinct differentiation between, people with disabilities and the nondisabled population. The point is that the either/or categorization is as much a fiction regarding disability as it is with respect to racial identity.⁴ The difference between the two classifications is that an individual’s disability status is likely to change. Weisman deplored the omission of long-term care in the 2010 Patient Protection and Affordable Care Act that President Obama signed. This necessity for a long-term-care

provision in the legislation is unequivocally related to the disability community's to-date unsuccessful, although hard-fought, battle for the Community Choice Act. Weisman indicated that the impending dire situation could have been ameliorated had long-term care been included in the 2010 legislation. Thus, as a result of CCA's exclusion, he predicted that a great number of the baby boomers who are lucky enough to live long lives will exhaust all their resources on their final illnesses and die penniless.

Especially with an aging population, Weisman bemoaned the fact that "Medicare and technology do not mix" as short-term concerns about cost stifle scientific and technological research and development. To illustrate, he cited the invention of the IBOT, a stair-climbing wheelchair whose manufacture was halted when Medicare refused payment.⁵ Weisman also decried Medicaid's myopic procedures: "Medicaid has been willing to pay to amputate your foot because you have diabetes, but not for your weekly podiatry appointments to prevent that amputation." Ultimately that approach is very damaging to the individual and very costly to the program. Too often, policy lags behind current developments, as is revealed by the manner in which the Veterans Administration (VA) still categorizes disabled veterans (according to individual disabilities, such as psychiatric, amputations, and severe burns); as Weisman maintained, the VA should be set up to handle the "poly-trauma" that confronts most disabled veterans.

Still, disability activists have reasons for optimism: Cognizance of the necessity to include people with disabilities in visions of the future is auspicious, as is apparent in students emerging from schools in such fields as architecture, engineering, and biotechnology. And the level of expectation is promisingly high in the disability community, which is determined to settle for nothing less than the rights to which people with disabilities are entitled.