The Americans with Disabilities Act at 25: The Highest Expression of American Values

Lawrence O. Gostin
Georgetown University Law Center, gostin@law.georgetown.edu

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The Americans With Disabilities Act at 25
The Highest Expression of American Values

Lawrence O. Gostin, JD

Twenty-five years ago, on July 26, 1990, President George H. W. Bush signed the Americans with Disabilities Act (ADA), a historic moment when the polity gave voice to the nation’s highest ideals. The ADA enshrined in law a social promise of equality and inclusion into all facets of life, while offering an inspiring model that much of the world would come to embrace. As a civil rights law coming in the wake of racial and gender equality legislation, the ADA has had profound symbolic meaning and real-world effects. Its promise of full participation in life stood in marked contrast to the often-impenetrable social and physical barriers that individuals with disabilities faced regarding inclusion in the workplace and public spaces. In sponsoring the ADA, Senator Edward Kennedy described life for persons with disabilities as an “American apartheid.” The ADA embodies the highest values of the United States—a compassionate nation with the vision to unleash the vast potential of persons with disabilities and to inspire global social change.

Why should a medical journal like JAMA highlight the 25th anniversary of the passage of the ADA? Physicians care for many patients who have disabilities that are either preexisting or directly caused by injuries or disease processes. The ADA, moreover, directly affects health professionals and institutions by requiring nondiscriminatory treatment and reasonable accommodations for disabled patients. At the same time, physicians may develop disabilities and the statute affords them the same protection in the workplace as other workers. Importantly, medicine’s highest values are its compassion, a deep empathy for patients, and an abiding commitment to respect and protect human dignity. It is natural, then, that a leading medical journal like JAMA would champion a social project as important as the ADA. Accordingly, this theme issue of JAMA includes 3 Original Investigations2-4 that report novel research findings directly relevant to the ADA. The issue also features 6 scholarly Viewpoints5-10 that address multiple aspects of the ADA, ranging from landmark Supreme Court rulings, to aspects related to employment and genetics, to considerations for health professionals with disabilities.

The marginalization of persons with disabilities is in one sense remarkable because so many individuals have been, or will become, disabled. At any given moment, one-fifth of all individuals in the United States live with 1 or more disability, and many, perhaps most, will experience some form of disability during the life course. Although disability can occur at all ages, it is 8 times more likely in old age; one-fourth of Americans in their mid to late 60s have a severe disability, such as major impairments in mobility, vision, hearing, or the ability to care for themselves. More than half of those 80 years or older have a severe disability and more than 70% experience multiple disabilities.11 As the population ages, the prevalence of disabilities will continue to increase with enormous personal consequences as well as health and social costs.12

The ADA was bipartisan in ways that few pieces of social legislation are today, demonstrating that affording opportunities for flourishing lives of dignity should be beyond political contestation. Yet the ADA’s aim—a truly inclusive and just society—is still to be fully realized. What began as a social movement and then a landmark legislative accomplishment has become, unfortunately, an object of political discord, with critiques of its costs to local government and businesses.13 Yet completing the ADA’s goal of full integration will unleash the creativity and entrepreneurship that persons with disability bring to their communities and to the nation.

The High Aspirations of the Disability Rights Movement
Like all major pieces of civil rights legislation, the ADA did not emerge in a vacuum. Rather, it was the culmination of decades of groundwork laid by disability rights advocates—an exceptionally diverse and innovative group of individuals and organizations.

Advocacy groups representing a wide spectrum of individuals with disabilities campaigned for civil rights legislation. Prior to the ADA, the movement’s most important success was the passage of the 1973 Rehabilitation Act (and, after additional struggle, the implementing regulations issued in 1977). Section 504 of that act proscribed discrimination and required affirmative accommodations to enable persons with disabilities to participate in employment and other life activities.14 The act’s major limitation, however, was that it applied only to recipients of federal funding.15 With this new legal tool, activists began targeting institutions that impeded their full access, especially public transportation. They achieved remarkable success, convincing major cities such as San Francisco and New York to make their transit systems accessible.16

By the 1980s, the disability rights movement had matured, bringing together an array of groups working toward a single goal—comprehensive antidiscrimination legislation. Relying around slogans such as “Nothing About Us Without Us,” disability rights organizations came together to advocate for the ADA.

Certainly, the movement had diverse, sometimes conflicting, aims. For example, individuals using wheelchairs wanted
Review the concepts of “substantial limitation” and “major life activities” at various points in the article. The ADA prohibits discrimination against persons on the basis of disability in employment, state and local government, public accommodations, commercial facilities, transportation, and telecommunications. Understanding the ADA helps in interpreting these concepts narrowly, reducing the scope and reach of the ADA over time. The Supreme Court redefined “substantial limitation” to mean one that “prevents or severely restricts” a major life activity. The high court also narrowly construed the concept of “major life activity” to encompass only activities of “central importance to most people’s daily lives.” This resulted in a high and unreasonable threshold for gaining the protection of the ADA, even excluding a man diagnosed with mental retardation. As Bagenstos details in this issue of JAMA, overall the Supreme Court’s record on the ADA has been mixed, sometimes expanding coverage for persons with disabilities but at other times restricting coverage.

In 2008, Congress passed the Americans with Disabilities Act Amendments Act (ADAAA), specifically replacing the Court’s narrow interpretation of the law, making clear that courts and employers should apply a broad standard when determining whether an individual is “disabled.” The ADAAA instructs courts to provide protection “to the maximum extent permitted” and provides a nonexhaustive list of “major life activities,” which include caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working. The ADAAA sought to shift legal discourse away from semantics, refocusing on the ADA’s original intent—eliminating discriminatory conduct. The breadth of the definition of disability, as discussed by Clayton in this issue of JAMA, even enables the ADA to serve as a tool to protect against the misuse of genetic information. This protection is particularly important with increased use of genetic testing and the evolving science of genomics in health care.

The ADAAA also clarified that the ameliorative effects of mitigating measures, such as prosthetic devices or medication for epilepsy, are irrelevant in determining whether the statute protects an individual. Before the ADAAA, several Supreme Court decisions had stated that in establishing whether an individual has a disability, courts must consider the effects of any “mitigating” or “corrective treatment.” Now, with the exception of eyeglasses and contact lenses, any medications or devices such as hearing aids or mobility devices that may compensate for disability are not relevant in determining whether a person is protected by the ADA.
when medical examinations can be required, based on the stage of employment. For example, at a job interview an employer cannot inquire about the existence or nature of an individual’s disability. Furthermore, the ADA restricts the types of medical examinations or inquiries the employer can make once the individual is employed and requires that all medical information be kept confidential.

Public Services
Title II of the ADA prohibits disability discrimination across all activities of state and local government and requires public entities to provide persons with disabilities equal opportunity to benefit from government programs and services. The scope of protection is broad, including ensuring nondiscriminatory policies, practices, and procedures. Narrow exceptions apply when accommodations would fundamentally alter the nature of the service, program, or activity being provided or would result in undue financial and administrative burdens. The act also sets accessibility standards for new construction and alterations to existing buildings.

Furthermore, Title II requires public transportation authorities to ensure accessibility of buses and rail cars, as well as stations, unless it would result in an undue burden. In places where public transportation is not accessible, other types of transportation must be provided.

Public Accommodations
Title III prohibits disability discrimination by “public accommodations,” private entities that offer certain types of public services (eg, hospitals, physicians’ offices, restaurants, retail stores, pharmacies, schools). Public accommodations must ensure that any new or altered construction is accessible; that, wherever reasonably possible, barriers are removed from existing buildings; and that policies and practices are nondiscriminatory.

Importantly, Title III focuses on the effects, not the intentions. In other words, what matters is not the purpose of practices or policies, but whether they are, in fact, discriminatory.

Telecommunications and Other Provisions
Title IV requires all US telecommunications companies to make available interstate and intrastate telecommunications relay services to hearing-impaired and speech-impaired individuals.

Influence on Health, Health Care, and Insurability
By addressing discrimination and enabling access for individuals with disabilities in a broad range of private and public services, the ADA has had a major influence on the ways in which persons with disabilities interact with the health care system.

Along with the provisions most commonly associated with health care, such as access to health care facilities or the availability of auxiliary aids for individuals with vision and hearing impairments, the ADA has expanded access to health care through Title I. Nearly half of all individuals in the United States receive health insurance coverage through their employer. By removing many of the barriers that kept disabled individuals from working, the ADA gave many previously uninsured (or underinsured) persons with disabilities access to health insurance coverage.

In a Viewpoint in this issue, Rothstein provides a cogent reminder that the ADA also protects physicians and other health care workers, who may not be discriminated against due to a disability. Health workers are entitled to accommodations to enable them to perform their jobs effectively and safely. A key issue is patient safety, such as a physician with a history of substance abuse.

Integration Into All Facets of Society
A key purpose of the ADA is to allow individuals with disabilities to have the same access to all facets of society, to the extent possible, as those without disabilities. In Bragdon v Abbott, the Supreme Court gave clear expression to this “integration mandate.” Psychiatrists cleared 2 women in a psychiatric ward for discharge to the community. However, due to a lack of available community placements, they remained institutionalized. The Court found that such involuntary institutionalization was unlawful under the ADA as it “perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life” and diminishes opportunities for meaningful engagement in society.

Burnim explains in his JAMA Viewpoint that the mental health system should further expand community services, with many proven, cost-effective approaches.

Olmstead also involved a Medicaid placement program, thus recognizing that even public insurance schemes were subject to ADA scrutiny. The decision had a major influence on Medicaid and marked a significant trend toward community integration of individuals with physical and mental disabilities. In the period 1999-2010, the Health and Human Services Office for Civil Rights conducted 81 “Olmstead investigations,” of which 61% led to corrective action.

Discrimination in Accessing Health Care
The ADA includes nondiscriminatory access to health care as an explicit purpose of the statute. Many individuals with disabilities have ongoing and extensive health care needs, and their ability to access health services and manage their care is critically important. By defining “public accommodation” to include health services, the ADA significantly expanded legal protection. Previously, disabled individuals were protected only if they went to a hospital or other health center, program, or clinician receiving federal funding.

The Supreme Court in Bragdon v Abbott significantly expanded access to health care for individuals living with HIV/AIDS. Sidney Abbott was refused care in a private dental office. In a landmark ruling, the Court held that asymptomatic HIV infection could be a disability under the ADA because it could “substantially limit” the “major life activity” of reproduction. The Court also clarified that the dentist could not claim that there was a “direct threat” of contracting HIV infection because risk assessments had to be based on “objective, scientific information.”

Health care offices and institutions can claim that treating an individual with a disability poses an “undue burden,” but the courts have rarely allowed such a defense. For example,
ample, the courts required a pediatric practice to provide an American Sign Language interpreter during a consultation. In another case, however, a court determined that requiring an older hospital to make its bathroom facilities wheelchair accessible would impose an undue burden, whereas the hospital did provide other accommodations such as bed baths and bedside commodes. The ADA has also improved accessibility to medical equipment. Two lawsuits in particular, one against Kaiser Permanente in California and the other against the Washington Hospital Center in Washington, DC, have resulted in an increase in the manufacture and use of accessible equipment throughout the country.

Even as access to medical equipment improves, researchers continue to examine how to improve the effectiveness of medical supports. In their innovative report in this issue of JAMA, Hargrove and colleagues studied 7 patients with lower limb amputation and demonstrated that electromyographic signals from leg muscles during ambulation along with historical information from prior gait studies could be used to improve real-time control of powered lower limb prostheses. As scientists seek to enable people with disabilities to regain lost functions, new forms of medical supports for other disabilities, such as acute spinal cord injury, are anticipated. In this issue, Jain and colleagues report on the epidemiology of acute spinal cord injury in the United States. Overall the rate of spinal cord injury has remained unchanged from 1993 through 2012, although the prevalence among older adults has increased, and overall mortality from these injuries remains substantial.

Much work remains to be done to fully realize the goals of the ADA. Major disparities continue to pervade employment, access to health care, and health outcomes. Only about half as many disabled as nondisabled persons are employed, and poverty rates among the disabled remain significantly higher. People with disabilities experience poorer health outcomes and higher rates of risk factors for noncommunicable diseases. As poignantly discussed by Rosland in her Piece of My Mind article in this issue of JAMA, some health care professionals may harbor misconceptions about persons with disabilities, which can lead to unequal access to screening, health advice, and treatments. The evidence from the study by Searcy and colleagues that students with disabilities who had been granted extra time for MCAT examinations took longer to graduate from medical school and performed less well on the United States Medical Licensing Examinations raises many important issues, including the education needed throughout the medical school system and financial preparation for what may be a longer period of time in medical school.

The ADA's International Influence

“As the Declaration of Independence has been a beacon for people all over the world seeking freedom, it is my hope that the Americans with Disabilities Act will likewise come to be a model for the choices and opportunities of future generations around the world.” President George H. W. Bush's aspiration upon signing the ADA has come to pass, from national legislation modeled after the US law to the disability rights movement’s crowning legal achievement, the Convention on the Rights of Persons with Disabilities (CRPD).

An international movement for the rights of individuals with disabilities predated the ADA, including the 1981 formation of the first international disability rights coalition, Disabled People's International, with its membership spanning 69 countries by the end of the decade. The 1975 UN Declaration on the Rights of Disabled Persons foreshadowed the ADA's "reasonable accommodations" principle, asserting that "disabled persons are entitled to the measures designed to enable them to become as self-reliant as possible" and that "their special needs [should be] taken into consideration at all stages of economic and social planning," while calling for social integration "as far as possible."

The ADA turned these principles into specific, legally binding requirements, while entering new normative territory with individuals’ right to participate in all aspects of public life. The ADA catalyzed a wave of national legislation protecting the rights of persons with disabilities. More than 40 countries enacted domestic disability rights legislation in the 1990s, with some laws protecting against discrimination in only certain areas (eg, education) and others embracing the ADA's breadth. The laws also varied considerably in their remedies—most offered none—and in the definition of disability.

The ADA's influence is also apparent in the UN's 1993 Standard Rules on Equalization of People with Disabilities, with one rule (Rule 7) encouraging "employers to make reasonable adjustments to accommodate persons with disabilities." The Standard Rules aim at the "equalization of opportunities," enabling persons with disabilities to fully participate in society. The ADA also served as a model for the 1999 Inter-American Convention on the Elimination of All Forms of Discrimination Against People with Disabilities.

The United Nations adopted the landmark CRPD in 2006, which 154 countries have now ratified. President Obama signed the CRPD in 2009, but the US Senate fell 5 votes shy of ratifying the treaty in 2012—even though the CRPD was modeled on the ADA. Disability rights organizations have lobbied for US ratification to advance disability rights globally, as well as to expand rights domestically. For example, the CRPD includes directives to combat stereotypes and prevent exploitation, violence, and abuse, while ensuring social protection and an adequate standard of living.

Ensuring a Future of Equality and Integration

The ADA embodies the US ideals of equality and integration, affirming that each person is a valued member of society. Yet as the racial tensions that have flared recently in Baltimore and beyond highlight, deep inequities persist, not least in health. On the 25th anniversary of the ADA, the task of ensuring the full rights for persons with disabilities is substantially advanced yet far from complete. There could be no better way to mark this anniversary than to ratify the CRPD, thus furthering the law’s mission at home and globally. Even beyond the rights of persons with disabilities, the law’s ideals are ones that we should all coalesce around and honor, continuing to transform the richly diverse face of America—the engine of creativity and a reflection of shared humanity.
ARTICLE INFORMATION

Author Affiliation: O'Neill Institute for National and Global Health Law, Georgetown University, Washington, DC.

Corresponding Author: Lawrence O. Gostin, JD, O'Neill Institute for National and Global Health Law, Georgetown University Law Center, 600 New Jersey Ave, NW, Washington, DC 20001 (gostin@law.georgetown.edu).

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