

## ADA at 25 and People With Cognitive Disabilities: From Voice to Action

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### Abstract

The Americans With Disabilities Act (ADA) of 1990, and the ADA Amendments Act (ADAAA) of 2008, are effecting dramatic changes in the perception of cognitive and other disabilities, from primarily viewing disability as a medical state to be cured and pitied toward acceptance of disability as an element of human experience and self-identity. The ADA's modern understanding of disability is as much shaped by diversity in biology, local culture, and self-identity over the life course, as it is by the barriers to inclusion we build and maintain in society. This view reflects the paradigm shift from the prior and dominating medical model to a social and environmental approach to disability civil and human rights. This two-part special issue of the journal *Inclusion* examines the ADA at its 25<sup>th</sup> anniversary. The articles reflect on the past 25 years, examine the present, and anticipate the future to ensure continued progress towards the civil and human rights of individuals with cognitive and other disabilities.

**Key Words:** ADA; cognitive disabilities; civil and human rights

The Americans With Disabilities Act (ADA) of 1990 and the ADA Amendments Act (ADAAA) of 2008 are effecting dramatic changes in the perception of cognitive and other disabilities, from primarily viewing disability as a medical state to be cured and pitied towards acceptance of disability as an element of human experience and self-identity. The ADA's modern understanding of disability is as much shaped by diversity in biology, local culture, and self-identity over the life course, as it is by the barriers to inclusion we build and maintain in society (Blanck, this issue; 2014a, 2014b). This view reflects the paradigm shift from the prior and dominating medical model to a social and environmental approach to disability civil and human rights.

This two-part special issue of the journal *Inclusion* examines the ADA at its twenty-fifth anniversary. The articles reflect on the past 25 years, examine the present, and anticipate the future to ensure continued progress towards the civil and human rights of individuals with cognitive and other disabilities. They examine an

array of groundbreaking substantive issues as well as legal cases on the interpretation of the ADA, including *Bragdon v. Abbott*, *Sutton v. United Airlines*, *PGA v. Martin*, *Olmstead v. L.C.*, *National Federation of the Blind (NFB) v. Target*, and others.

Nonetheless, in significant part, the articles in this issue are not about litigation strategy; rather, they contribute to the knowledge base that individual and collective action remains a principal means to foster the civil rights of people with cognitive and other disabilities. One predominant thread is that the principles enshrined in the ADA must be promoted through rights- and evidence-based advocacy involving people with cognitive and other disabilities. Although there have been unparalleled developments in disability rights during the past twenty-five years, work remains to ensure self-determination and full and equal opportunity in global society for people with cognitive and other disabilities (Blanck & Martinis, 2015).

## People With Cognitive Disabilities

In *People With Disabilities: Sidelined or Mainstreamed?* Lisa Schur, Douglas Kruse, and I chronicle engagement in society by people with cognitive and other disabilities using as measures the U.S. Census and other national data sources (Schur, Blanck, & Kruse, 2013, p. 288). Review of the 2010 U.S. Census shows that, second to general mobility impairments, cognitive disabilities were the most common category of disability disclosed (Schur et al., 2013, p. 240 and fig. 2-4). When we examine the barriers reported by people with disabilities in economic, political, and social spheres, we found that they resulted largely from how society has been organized and constructed.

Our findings highlight the ways in which people with cognitive disabilities are particularly excluded from society. In the United States, people with cognitive disabilities have the highest poverty rates (28%), as compared to those with visual (23%), mobility (22%), and hearing (14%) impairments (Schur et al., 2013). They have the lowest employment rates as compared to other disability types and the lowest rates of self-employment (Schur et al., 2013, fig. 3-3). People with cognitive disabilities are more likely than other disability groups to live in separate congregate settings and institutions, and not in the community (Schur et al., 2013, fig. 4-1). People without disabilities report feeling more uncomfortable being around people with cognitive disabilities than around people with other disabilities.

Who are people with cognitive disabilities (Blanck, this issue)? People with cognitive disabilities have “a substantial limitation in one’s capacity to think, including conceptualizing, planning, and sequencing thoughts and actions, remembering, interpreting subtle social cues, and understanding numbers and symbols” (Braddock, Rizzolo, Thompson, & Bell, 2004, pp. 49–50). Cognitive disability covers conditions that may be based on the interaction of biology and environment over the life course—autism, intellectual and developmental disabilities, cerebral palsy, traumatic brain injury, brain injury acquired from aging, physiological and environmental conditions, post-traumatic stress disorder, dyslexia and learning disorders, and other conditions called print-related disabilities (Autistic Self-Advocacy Network, ASAN, 2015).

Often, cognitive disabilities coexist with sensory and physical impairments, with mental

health conditions (e.g., depression and bipolar disorder), and have a diversity of causes, severity, and episodic presentations. Cognitive disability is affected separately and in combination by individual characteristics, environmental demands, and social supports (Foley, K. R., Dyke, Girdler, Bourke, & Leonard, 2012; World Health Organization, 2015). Cognitive disabilities are not necessarily associated with lower levels of intelligence as defined by standard tests and measures of daily functioning. Many individuals with cognitive disabilities have average and high levels of daily life functioning and intellectual skills. These individuals, whether with dyslexia or autism, may experience limitations in social and communication abilities due to a range of factors (Foster & Pearson, 2012). Cognitive disabilities thus include an array of conditions and behaviors, which may be present at birth, acquired by a life event, or result from the aging process. These conditions coexist with others (Blanck, 2014a; Hu, Feng, Lazar, & Kumin, 2011; Jinjuan, Lazar, Kumin, & Ozok, 2010). For these reasons, generalizations across individuals are made with caution.

## Overview of the ADA

The ADA contains a preamble followed by main titles or subchapters, as amended by the ADAAA (Blanck, Goldstein, & Myhill, 2013; Blanck, Hill, Siegal, & Waterstone, 2014). In the preamble, Congress sets out the law’s “Findings and Purposes” as to assure “equality of opportunity, full participation, independent living, and economic self-sufficiency.” (ADA & ADAAA, 2008; Blanck et al., 2014, pp. 42–43). The ADAAA added that people with disabilities have a “right to fully participate in all aspects of society,” to the law’s original purpose to “provide a clear and comprehensive national mandate for the elimination of discrimination against people with disabilities.”

Following a definitional section focused on who is covered by the law as a person with a disability, ADA Title I addresses nondiscrimination in private employment in all its aspects—job application procedures, hiring, reasonable accommodation, career advancement, workplace benefits, and training.

ADA Title II prohibits discrimination by public entities (state or local governments) in areas of public employment, transportation, and physical and online services and programs. Title II

provides the basis for the law’s integration mandate, which was reaffirmed in the U.S. Supreme Court’s *Olmstead v. L.C.* decision (1999). *Olmstead*, discussed later in this article, held that governmental services and programs must not perpetuate unnecessary discrimination and segregation on the grounds of cognitive or other disabilities.

Title III prohibits discrimination by “public accommodations,” which are private entities that offer commercial services to the public. Private retailers, hotels, and entertainment services are considered Title III entities. To prevent discrimination against people with disabilities, commercial enterprises must make “reasonable modifications” to their policies and operations, unless these adaptations change the way the entity does business or prove to be unduly burdensome. Under Title III, individuals with disabilities are entitled to the “*full and equal enjoyment*” of the activities of public accommodations, meaning the enjoyment of all rights and privileges offered. The U.S. Supreme Court has interpreted this ADA directive broadly (*PGA v. Martin*, 2001, pp. 674, 683 n.38). For people with cognitive and other disabilities, this requires more than segregated access and signifies the right to participate in all aspects of commercial services.

In *National Federation of the Blind v. Target Stores* (2006), for example, the federal court read Title III to cover Target.com, and not just those services provided in Target’s physical retail stores. The distinction was important to the *Target* court, which declined to narrow the law simply to cover “services occurring *on the premises* . . . [which the Court said] would contradict the plain language of the statute” (*Target*, 2006, p. 953, citations omitted, emphasis added). Thus, Target.com was to be enjoyed equally, as was access to its brick-and-mortar stores. Moreover, Title III’s reasonable modification principle necessitates that commercial entities “take affirmative steps” to prevent discrimination (*Target*, 2006, p. 951, citations omitted; Foley, A., & Ferri, 2012). In *U.S. Airways v. Barnett* (2002, pp. 397–398), the U.S. Supreme Court recognized that accommodations must provide disabled individuals “the same . . . opportunities that those without disabilities automatically enjoy.” Yet, Title III does not, and in reality cannot, guarantee that individuals with disabilities will have an identical experience and achieve the same benefits from the services offered to all individuals,

only that there is a reasonably equivalent opportunity to participate in a given circumstance.

The determination of what is reasonable is made on a case-by-case basis, with consideration of the extent to which the services as modified for a user with a disability are sensibly related to the range of possible uses in that situation. For instance, in the well-publicized case of professional golfer Casey Martin (*PGA v. Martin*, 2001), the U.S. Supreme Court found that Title III permitted the use of a golf cart to reasonably accommodate Martin’s walking disability in a PGA tournament that otherwise prohibited carts. The Court reasoned that this modification did not provide an unfair advantage that would change the golf competition, and the PGA did not claim that the requested modification posed an undue burden.

### ADA at 25 and Evolving

The principles for full and equal, and active membership in society are set out in the ADA—the right to equal opportunity, full economic, social, and civic participation, independence in living, and economic self-sufficiency (Blanck, 2008). These values are promoted by the ADA, although many issues of equality for people with cognitive and other disabilities remain to be addressed in education, transportation, and employment, among other areas of daily life.

The United States is perhaps in a third period of ADA implementation. During the first phase of the law’s development, from its passage in 1990 until 2008, debate centered on who was covered by the law. That is, who is a person with an ADA disability? The straying from Congress’ intent in answering this question had resulted from U.S. Supreme Court decisions that narrowed the ADA’s definition of disability, which had been drawn from the earlier Rehabilitation Act of 1973 and its Section 504 antidiscrimination and reasonable accommodation provisions.

Interpretation of the ADA’s definition of disability began well enough in 1998 with the U.S. Supreme Court’s first ADA decision in *Bragdon v. Abbott*, which found that an individualized and functional inquiry of disability was required by the law, and that underlying and episodic conditions, such as asymptomatic HIV disease, were covered by the law’s protections (*Bragdon*, pp. 641–642). *Bragdon* was brought under ADA Title III as a “full and equal” access

case. The Supreme Court considered whether a dentist who was a private health care provider was required to accommodate, within reasonable and medically appropriate bounds, his office practice to provide for the dental needs of an individual with asymptomatic HIV disease. The Court answered in the affirmative.

Congress had intended the ADA's definition of disability to be expansive, using a three-prong functional analysis. For purposes of the ADA, disability is a physical or mental (e.g., cognitive, neurological, mental health) impairment that substantially limits major life activities (e.g., learning, reading, concentrating, thinking, communicating) of an individual. Disability may be a present actual condition, defined by a record of an impairment, and found in circumstances where an individual is "regarded" as having an impairment. A similar conceptualization of disability is used in the World Health Organization's (WHO's) International Classification of Functioning (ICF), in which the relationship of impairment, environment, and activity are understood in the context of full and equal participation (WHO, 2015).

The year after *Bragdon* was decided, in *Sutton v. United Airlines* (1999), the U.S. Supreme Court ruled that physical and mental impairments that are mitigated, or reduced in functional severity, by medications, assistive technologies, and personal adaptations, were not necessarily covered as ADA disabilities. The Court reasoned that a person may not have a disabling condition for the purposes of the ADA (e.g., individuals with severe myopia and vision corrected with eyeglasses) if the functional limitations and symptoms may be alleviated or are not significant in every aspect of daily life. An ADA disability, therefore, was to be considered in its mitigated state. The result was that many conditions, while otherwise requiring reasonable accommodation to ensure participation, did not meet the threshold definition of disability under the ADA because they did not functionally limit an individual's major life activities.

The definition became more restricted when in *Toyota v. Williams* (2002) the U.S. Supreme Court reasoned that only those conditions that "substantially" limit an individual's major life activities were to be considered ADA disabilities. For a condition to rise to the ADA definitional threshold, it was not enough to be substantially limited from a back injury or an intellectual disability in a major life activity such as employ-

ment, when one still may drive a car, garden, or read a book.

The definitional debate culminated with *Littleton v. Wal-Mart Stores, Inc.* (2007), where a federal court found that the plaintiff, who had intellectual disability (then described as mental retardation), was unable to prove that he was substantially limited in the major life activity of learning because he had graduated from high school with a certificate in special education, attended a technical college for mechanical maintenance, was able to read and drive, and did not need a job coach at work. The court determined the plaintiff was not covered by the ADA.

Under the *Littleton* formulation, individuals with serious cognitive conditions may not be covered by the ADA. Indeed, few people were able to overcome the high definitional threshold, and their cases were dismissed summarily, as a matter of law, without the opportunity to address the merits of their complaints. Because these cases were terminated at an early stage in the proceedings, evidence of individual qualifications and the benefits of accommodations and modifications were not considered, even though they were foundational aspects of the ADA.

In 2008, a second phase of the ADA was initiated with passage of the ADA Amendments Act (ADAAA), which returned coverage of the law to individuals with disabilities as was originally intended by Congress (Long, 2015). The ADAAA, which was not to be applied retroactively, is beginning to have an impact. ADA cases are being decided on their merits, such as to whether an individual with a cognitive disability is qualified for the job and the requested accommodations are reasonable, rather than on the threshold definition of "disability" status (Befort, 2013). Accordingly, in ADA Title I employment disputes, courts are closely analysing essential job requirements and whether the requested accommodations and modifications are reasonable. For instance, whether the provision of job coaches and assistive technologies in a particular circumstance may be within reason or unduly burden the employer by fundamentally changing the nature of the job.

At the time that disability advocates were working to correct the law's definitional problems, before passage of the ADAAA and beginning in the late 1990s, efforts increased to use the ADA to enhance full and equal inclusion in society. The capstone of this effort came in 1999. The U.S. Supreme Court's ruling in *Olmstead v. L.C.*, as

mentioned, affirmed the ADA's Title II integration mandate, requiring state and local governments to provide opportunities for community living and integrated services for persons with cognitive and other disabilities, rather than only in restricted segregated settings, such as in institutions, nursing homes, and sheltered workshops. The effects of *Olmstead* resonated with other principles in the ADA and those embedded in laws such as the Individuals with Disabilities Education Act (IDEA, 2004), reaffirming the rights of persons with cognitive disabilities to be included in society and to ensure opportunities for participation in all aspects of daily life.

### Global Context

The ADA has been in effect for 25 years, and with it, there has been a concordant growth in the political strength of the disability rights movement worldwide. When the ADA was signed into law in 1990, millions of Americans with disabilities and their family members hoped to be included equally in society and at all stages of life. Over time, the ADA's integration mandate transcended U.S. borders, leading to increased international and comparative interpretation and to a third conceptual phase of implementation (Giannoumis, this issue; in press; 2014; Halvorsen, 2010).

There are more than 1 billion individuals with disabilities around the globe with expectations for self-determination, and for full and equal involvement in their communities. These individuals are living longer, yet most still live in poverty. The majority of people with disabilities live in developing nations. These individuals experience low levels of literacy, education and employment, and disparities in access to basic resources in social services, healthcare, rehabilitation, and technology. Despite recognition of and exponential increases in age-related disabilities, women and men with disabilities across the globe continue to experience dire conditions for economic and social advancement.

In 2008, the human rights of disabled people were formally recognized in the United Nations Convention on the Rights of Persons with Disabilities (United Nations, CRPD, 2008) and today more than 150 nations have ratified the treaty. The CRPD reflects a commitment by member states to value active citizenship by persons with disabilities in the global community

(DISCIT, 2013). Article 1 of the CRPD states its purpose as "To promote, protect and ensure the *full and equal enjoyment* of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity." Persons with disabilities are those with long-term physical and cognitive impairments who face societal barriers that "hinder their *full and effective participation in society* on an equal basis with others" without such conditions (emphasis added).

The CRPD's human rights lens is similar to, but different from, that of the ADA's civil rights approach. The CRPD's enumerated fundamental liberties are expressed as universal and interrelated conditions arising from the human experience. These liberties are not granted by governments or laws. Rather, they are fundamental to human dignity and fulfillment, autonomy and capacity, and individual development regardless of disability (United Nations, 1998).

Among its obligations, the CRPD (Article 9, Accessibility) aims to ensure comparable access to communications technology and to the web. Johan Borg and colleagues, for example, believe that the CRPD declares the right to technology equality for people with disabilities "to ensure their *full and equal enjoyment* of all human rights and fundamental freedoms" (Borg, Larsson, & Östergren, 2011, emphasis added). Likewise, in comments on Article 9 of the CRPD, Professor Anna Lawson (2014) notes that "accessibility is a precondition for independent living and for full and equal participation in society." Lawson's view is supported in the CRPD (2014) in which "accessibility is also given the status of a 'general principle' . . . which highlights its cross-cutting relevance to the entire Convention." In accord with the CRPD's presumption for full and equal individual participation in society, CRPD Article 12 affirms that "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life." States must therefore "take appropriate measures" to support the opportunity for individuals with disabilities to participate fully in society.

To date, the U.S. Senate has declined to ratify the CRPD. Yet, Americans with disabilities continue to advocate for the rights enshrined in the ADA by pointing to the example of the CRPD. Former Pennsylvania Governor and U.S. Attorney General Dick Thornburgh, who testified before the U.S. Senate in favour of ratification of the CRPD, argues that ratification is not just about

U.S. citizens who already have protections under laws such as the ADA. This is because, Governor Thornburgh (2013) said, the CRPD creates “a permanent place for disability within the human rights framework.” It places “disability issues on the radar screen of governments and societies as a legitimate human rights concern to which they must pay heed.” And it provides “guidance and standards and create[s] legal obligations for governments to respect the rights of this sizable population. It can serve as a powerful advocacy tool for the global disability movement to promote inclusion and equality of opportunity.”

Twenty-five years after its passage, people in the United States and around the world acknowledge the positive effect of the ADA and the CRPD. Citizens of other countries have built on and extended the ADA’s principles in domestic and supranational disability antidiscrimination laws (Quinn, 2004). If the ADA was one source of inspiration in developing disability rights, then the CRPD is the substantive glue that holds together the global commitment to that paradigm.

### Contributions to This Special Issue

The contributions to this two-part special issue of *Inclusion* examine each of the ADA’s titles—employment, state and local governmental services and programs, and the services offered by public accommodations—as well as leading edge developments in disability rights in the U.S. and globally. Thus, with a foundation of rich and varied lived experiences, and from multiple disciplinary viewpoints, the authors reflect on the past 25 years of the ADA, and they foretell the possibilities for future advancement in the United States and globally to ensure the rights of individuals with cognitive and other disabilities.

In the first article, Julie White describes a national demonstration project, one of two funded by the U.S. Department of Labor’s Office of Disability Employment Policy, called Onondaga Pathways to Careers (“OPC”). The project is designed to implement a model program to improve transition planning for youth and young adults with disabilities through secondary education, into and through supportive community college pathways. Community colleges enroll nearly half of all U.S. undergraduates, with 12% of enrollees indicating they are students with disabilities. In accord with the objectives of ADA

Title I, the OPC project is geared toward supporting individuals with cognitive and other disabilities into skilled employment for which they have trained, and that offers living wages, benefits, and opportunities for advancement.

Margaret “Jenny” Hatch, Samantha Alexandra Crane, and Jonathan G. Martinis then expand on the importance of community inclusion by persons with cognitive disabilities when they examine the use of overbroad and undue guardianship as a violation of the ADA Title II. They put the case of Margaret “Jenny” Hatch, a young woman with Down syndrome who, even though she lived and worked in the community and wished to continue doing so, was placed under plenary guardianship and forced to live in a segregated group home and work in a sheltered workshop. Recounting Ms. Hatch’s case in her own words, the authors illustrate the harm that results from overbroad and undue guardianship. They foreshadow a “next wave” of advocacy, in the United States and under the CRPD (Article 12) focused on ensuring that people with cognitive and other disabilities, and older adults who may acquire disabilities, have access to decision-making supports to help them to live and work in integrated community settings in accord with the principles of the *Olmstead* integration mandate.

Peter Blanck’s contribution to this special issue builds on the recent book—*eQuality: The Struggle for Web Accessibility by Persons with Cognitive Disabilities* (Blanck, 2014a)—examining the right under the ADA Title III (public accommodations) and Title II (governmental services) to web access for people with cognitive disabilities. This article continues a line of study on the full and equal enjoyment (accessibility and usability) of web content by people with cognitive disabilities. It considers definitions, legal challenges, and rights discussed more fully in *eQuality*, and it reflects on new disability law and policy developments in the United States (e.g., Section 508 refresh and web equality case law) and internationally (e.g., developments in CRPD Articles 9 and 12, and European standardization efforts) since *eQuality* was published.

Anthony Giannoumis explores the 25-year influence of the ADA on European Union (EU) disability policy. Giannoumis examines the EU’s disability policy learning experience, which has been a process of integrating domestic and international ideas for policy advancement, as applied to ensuring web and communications

technology accessibility for persons with cognitive disabilities. Giannoumis argues that the ADA's core principles have influenced disability law and policy in the EU by inspiring regulatory reforms at the national and supranational level. However, he contends that despite drawing inspiration from the United States, the EU's approach that combines a universal human rights perspective with networks of varying policy actors provides useful insights for related U.S. policy reforms for persons with cognitive disabilities.

### Conclusion

Over the past 25 years, what has the ADA given to America and the world? How may we—as researchers and teachers, policymakers, advocates, and persons with cognitive disabilities—use the power of the ADA to continue to achieve meaningful and positive social change? We hope the articles in this special issue of *Inclusion* help contribute answers to such far-reaching questions.

Nonetheless, despite lingering challenges, for persons with cognitive disabilities, 25 years of ADA has enshrined the full and equal right to live in one's community, as opposed to being placed in segregated institutions and nursing homes. Twenty-five years of ADA has established the full and equal right to learn and work in integrated classrooms and workplaces, as opposed to separate special classes and segregated sheltered workplaces. And 25 years of ADA has promoted active citizenship in the physical and cyber worlds, as opposed to relegation to “disabled-only” public accommodations, governmental services, and websites.

In these and other ways, the ADA, along with the CRPD and other laws, continue to promote the liberties of citizenship, independence, and human dignity, not only for persons with cognitive and other disabilities, but for us all. In the coming 25 years and beyond, we must continue to build on the ADA's principles and bring new voice to individuals with cognitive and other disabilities in the United States and globally.

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