

Introduction to the Special Issue: ADA at 25 and People With Cognitive Disabilities: From Action to Inclusion

Peter Blanck

Abstract

The Americans with Disabilities Act (ADA) of 1990 has helped to define in the United States and globally the modern view of disability as a central element of the human experience. This second issue, of a two-part Special Issue of the journal *Inclusion*, examines the ADA at its 25th anniversary. From an array of disciplinary perspectives and lived experiences, the articles reflect on the past 25 years, examine present opportunities and challenges, and consider the future to ensure continued action toward the civil and human rights of individuals with cognitive and other disabilities for inclusion and active citizenship.

Key Words: *Americans with Disabilities Act; civil and human rights; cognitive disabilities*

The Americans with Disabilities Act (ADA) of 1990 has significantly defined in the United States and globally the modern view of disability as a central element of the human experience. This issue, the second of a two-part Special Issue of the journal *Inclusion*, examines the ADA at its 25th anniversary. From an array of disciplinary perspectives and lived experiences, the articles reflect on the past 25 years, examine present opportunities and challenges, and consider the future to ensure continued action toward the civil and human rights of individuals with cognitive and other disabilities for inclusion and active citizenship.

The articles in this Special Issue contribute to the knowledge base that individual and collective *action* remains a principal means to ensure the *inclusion* of people with cognitive and other disabilities. One predominant thread is that the principles enshrined in the ADA must be vigorously promoted and extended through rights- and evidence-based activities by people with cognitive and other disabilities (Blanck, 2015a, b).

Lived Experience of People With Cognitive Disabilities

Second to general mobility impairments, cognitive disabilities are among the most common category

of disability disclosed in the United States (Schur, Kruse, & Blanck, 2013, p. 240). Yet, unlike the physical-access barriers people with mobility impairments typically face, people with cognitive disabilities are particularly excluded from society on the basis of stigma and negative attitudes. The result is that among people with varying disabilities, people with cognitive disabilities are generally poorer, least likely to be competitively employed, and more likely to live in segregated settings and institutions (Schur et al., 2013).

Cognitive disability covers conditions such as autism, intellectual and developmental disabilities, cerebral palsy, traumatic brain injury, brain injury acquired from aging, physiological and environmental conditions, posttraumatic stress disorder, dyslexia and learning disorders, and print-related disabilities (Autistic Self-Advocacy Network, ASAN, 2015; Braddock, Rizzolo, Thompson, & Bell, 2004, pp. 49–50). These conditions coexist with other impairments and have a diversity of causes, levels of severity, and episodic presentations, often affected by individual characteristics, environmental demands, and social supports (Foley, Dyke, Girdler, Bourke, & Leonard, 2012; World Health Organization, 2015). Cognitive disabilities are not necessarily associated with lower levels of intelligence, and many individuals with cognitive disabilities have average and high

levels of daily life functioning and intellectual skills (Blanck, 2014; Foster & Pearson, 2012).

ADA at 25 and Evolving

The ADA is a comprehensive civil rights law that provides a mandate to end discrimination on the basis of disability. Its core goals include to assure “equality of opportunity, full participation, independent living, and economic self-sufficiency.” (ADA & ADAAG, 2008; Blanck, Hill, Siegal, & Waterstone, 2014, pp. 42–43). The ADA addresses discrimination in private employment (Title I), by state and local public entities (Title II and its integration mandate affirmed in the U.S. Supreme Court’s *Olmstead v. L.C.* decision [1999]), and by public accommodations that offer commercial services in the physical and online sectors (Title III).

The ADA is entering a third period of implementation. In the first phase of the law’s development (1990 to 2008), debate centered on who was covered by the law. Following U.S. Supreme Court decisions that narrowed the ADA’s definition of disability, the issue was resolved with passage of the ADA Amendments Act of 2008, and a second phase of ADA evolution was underway. Today, 7 years after the ADAAG, courts increasingly are conducting more individualized inquiries of disability (Blanck, 2014). The well-recognized definition of disability is expansive, using a three-prong functional analysis: Disability is a physical or mental impairment that substantially limits major life activities that may be a present actual condition, defined by a record of an impairment, and found where an individual is “regarded” as having an impairment. Individuals with cognitive conditions that limit daily life activities, such as intellectual and developmental disabilities, are individuals with ADA-covered disabilities.

Currently, ADA advocates are addressing issues concerning the operation and enforcement of the law. Many of the topics go to the heart of the ADA’s purpose; that is, to ensure full and equal inclusion in society for people with disabilities. The effects of the past 25 years, along with the evolution and development of other laws and policies, are accruing toward the recognition that people with cognitive and other disabilities have the right to be included in American society.

Yet, challenges and opportunities remain, and there is much to consider during the next 25 years.

To begin with, on the global front the ADA’s integration mandate has transcended U.S. borders, leading to increased international recognition of disability rights as set forth in the United Nations Convention on the Rights of Persons with Disabilities (United Nations, CRPD, 2008). Much has been written about the CRPD’s purpose to ensure the equal enjoyment of individual rights and freedoms by persons with disabilities. Though the U.S. community of disability advocates, courts, and policymakers are learning from the CRPD model, there is more to consider from the CRPD’s rights lens, and particularly from its enumerated liberties expressed as universal and interrelated conditions arising from the human experience that are fundamental to individual flourishing (Quinn, 2004). Thus: “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” (Blanck, 2015a, p. 51).

Second, within the United States, the ADA at age 25 is being applied to a growing and aging population, which is set to increase significantly. Estimates suggest that in the next 25 years the proportion of individuals over age 65 living in the United States will double (Blanck, 2014). A significantly larger share of older adults also will remain in the labor force (Bureau of Labor Statistics, 2013). At the other end of the age spectrum, a generation of young individuals with cognitive and other disabilities will come of age knowing a world guided by the ADA’s principles, as well as by the Individuals with Disabilities Education Act (IDEA) and similar civil rights laws. Their expectations are to participate in society as full and equal citizens (Blanck & Martinis, 2015).

But vigilance is warranted. In 2015, there were calls for return to the old “asylum” model as in the best interests of individuals with serious mental health and other cognitive conditions (Sisti, Segal, & Emanuel, 2015). Yet, calls for “reinstitutionalization” are not consistent with principles enshrined in the ADA and CRPD (Blanck, 2008). Indeed, they defy the mandate of *Olmstead*, which affirmed the ADA’s Title II integration directive that requires state and local governments to provide meaningful opportunities for community living and integrated services for people with cognitive and other disabilities.

Third, there are almost one million veterans of the Iraq and Afghanistan Wars, including hundreds of thousands of young men and women served by the U.S. Department of Veterans Affairs in health care and community inclusion programs. The present generation of war veterans, many with acquired cognitive disabilities (e.g., traumatic brain injury and posttraumatic stress disorder), seek to reengage with their communities. These U.S. veterans with disabilities are an average age of 25 years, and they have limited educational and employment experience. With history as an unfortunate guide, without intervention, their disabilities will negatively affect their future employment, health, social status, and life expectancy (Logue & Blanck, 2010).

Last, there has been remarkable progress in the disability rights agenda over the past 25 years and concordant growth in the political strength of the movement in United States and abroad. However, as experienced in the progression of other civil rights movements, there is ongoing retrenchment and backlash. Contrary to accounts that many disabled individuals and their lawyer advocates often pursue frivolous ADA legal actions, much of society remains physically, technologically, and programmatically inaccessible to people with cognitive and other disabilities. United States society has been on notice for the past 25 years regarding the ADA's equality principles. Yet, disability discrimination is encountered daily, and access barriers exist even when they do not make financial sense and are easily remedied (Blanck, 2014, in press).

Contributions to This Special Issue

The contributions to this two-part Special Issue of *Inclusion* examine each of the ADA's titles and leading edge developments in disability rights in the United States and globally. 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 fundamental rights of individuals with cognitive and other disabilities to live and participate in communities of their choosing.

In the first article, longtime disability community leader Lex Frieden and colleagues Joy Hammel and Katherine McDonald caution that

despite advances achieved with ADA passage and *Olmstead's* integration mandate, people with disabilities continue to face inequality and disparities in community living, and in work and economic participation. These authors describe their efforts in regard to the ADA Participatory Action Research Consortium (ADA-PARC), which is examining trends in community living and participation, and employment and economic participation. People with intellectual and developmental disabilities are playing important roles in the ADA-PARC, from inclusion in advisory boards to their presence among those affected by the *Olmstead* decision.

Next, Robert Dinerstein's article builds on the prior article and argues that, in the 25 years of the ADA's existence, *Olmstead* is without doubt the law's most significant legal decision for people with intellectual and developmental disabilities. Dinerstein examines the *Olmstead* decision and its implications in areas beyond the institutional context of the case itself.

Third, Michael Morris, Christopher Rodriguez, and Peter Blanck examine the Achieving a Better Life Experience Act (ABLE), which was signed into law in 2014 by President Obama. Perhaps one of the most important laws in the disability policy framework passed since the ADA was enacted, and emblematic of the *Olmstead* integration mandate, ABLE represents policy change designed to open pathways to independence and inclusion in living and economic self-sufficiency for individuals with significant disabilities. The authors discuss elements of ABLE implementation and the effect of the law on future disability policy.

Fourth, through a review of global trends and the contextualization of inclusion and accessibility milestones, such as those reflected in the ADA, Jutta Treviranus then proposes that a change of strategy is required to achieve the ADA's aspirations for full and equal inclusion in society. Treviranus argues that the disability community must continue to play a leadership role in shaping the transformation of society, but with consideration of three broad systemic areas—design and development, research and evidence, and education and learning—to avert widening disparity and address risks that affect the global disability community.

Fifth, Elyn Saks next describes her personal and professional experiences with mental health law and the ADA. Experiencing the pendulum of

mental health law as swinging between a focus on autonomy and well-being, Saks examines her experience in school and employment before and after the enactment of the ADA. Saks identifies important issues in mental health today, the effect of the ADA on people with mental health conditions, and her work at the Saks Institute for Mental Health Law, Policy, and Ethics.

Finally, in the closing article Peter Blanck underscores the first “A” in the Americans with Disabilities Act (ADA). That first “A” is to apply to *all* individuals with disabilities residing, working, recreating, using the web, and engaging in daily life activities with private and public organizations in the United States (and not necessarily only by U.S. citizens). Emphasis on the first “A” in the ADA is meant to emphasize the individual lived and social experience. Blanck uses the first “A” in the ADA as a starting point to consider 25 such other “A”s as helpful to understand the past and as useful for framing future action in disability rights.

Conclusion

In *only* 25 years, the ADA has given much to the United States and the world. As in other human rights struggles, equal and full inclusion in society is not attained at a certain time. Rather, the quest is ongoing and evolutionary; and it is affected by context, demography, economics, technology, and environmental shifts. In the dynamic world in which we live, the ongoing challenge is to marshal individual and collective *voice and action* toward the goal of human rights. The articles in this Special Issue promote this aspiration for people with cognitive and other disabilities. No doubt, the next 25 years will raise new and unforeseen challenges, but also unprecedented opportunities for continued evolution of the ADA.

References

Americans with Disabilities Act (ADA) of 1990, ADA Amendments Act of 2008, 42 U.S.C. § 12101(a)(8), 2008.

Autistic Self-Advocacy Network, ASAN. (2015). About autism. Retrieved from <http://autisticadvocacy.org/home/about-asan/about-autism/>

Blanck, P. (2008). “The right to live in the world”: Disability yesterday, today, and tomorrow.

Texas Journal on Civil Liberties & Civil Rights, 13(2), 367–401.

Blanck, P. (2014). *eQuality: The struggle for web accessibility by persons with cognitive disabilities*. Cambridge, UK: Cambridge University Press.

Blanck, P. (2015a). ADA at 25 and people with cognitive disabilities: From voice to action. *Inclusion*, 3(2), 46–54.

Blanck, P. (2015b). eQuality: Web accessibility and people with cognitive disabilities. *Inclusion*, 3(2), 75–91.

Blanck, P. (in press). eQuality: The right to the web. In *A research companion to disability law*. Oxford, UK: Ashgate Companion Series.

Blanck, P., Hill, E., Siegal, C., & Waterstone, M. (2014). *Disability, civil rights law, and policy: Cases and materials* (3rd ed.). London, UK: Thomson/West.

Blanck, P., & Martinis, J. (2015). “The right to make choices”: National Resource Center for Supported Decision-Making. *Inclusion*, 3(1), 24–33.

Braddock, D., Rizzolo, M., Thompson, M., & Bell, R. (2004). Emerging technologies and cognitive disability. *Journal of Special Education Technology*, 19(4), 49–56.

Bureau of Labor Statistics. (2013). Monthly Labor Review: Labor force projections to 2022: the labor force participation rate continues to fall (Dec.). Retrieved from <http://www.bls.gov/opub/mlr/2013/article/labor-force-projections-to-2022-the-labor-force-participation-rate-continues-to-fall.htm>.

Foley, K. R., Dyke, P., Girdler, S., Bourke, J., & Leonard, H. (2012). Young adults with intellectual disability transitioning from school to post-school: A literature review framed within the ICF. *Disability & Rehabilitation*, 34, 1747–1764.

Foster, E. M., & Pearson, E. (2012). Is inclusivity an indicator of quality of care for children with autism in special education? *Pediatrics*, 130, S179–S185.

Logue, L. M., & Blanck, P. D. (2010). *Race, ethnicity, and disability: Veterans and benefits in post-Civil War America*. Cambridge, UK: Cambridge University Press.

Olmstead v. L.C. 527 U.S. 581 (1999).

Quinn, G. (2004). *Disability rights: An American invention—A global challenge*. Paper presented at the Northeastern Law School 11th Annual Valerie Gordon Human Rights Lecture: Boston, Mass.

- Schur, L., Kruse, D., & Blanck, P. (2013). *People with disabilities: Sidelined or mainstreamed?* Cambridge, UK: Cambridge University Press.
- Sisti, D. A., Segal, A. G., & Emanuel, E. J. (2015). Improving long-term psychiatric care: Bring back the asylum. *Journal of the American Medical Association*, 313(3), 243–244.
- United Nations. (2008). Convention on the Rights of People with Disabilities (CRPD). United Nations Office of the High Commissioner for Human Rights. Retrieved from <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>
- World Health Organization. (2015, Oct.). Mental disorders. Retrieved from <http://www.who.int/mediacentre/factsheets/fs396/en/>.

This line of study was supported in part by grants from the Administration on Community Living (ACL) and the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), in

the U.S. Department of Health & Human Services, and the Office for Disability and Employment Policy (ODEP), in the U.S. Department of Labor. For additional information on this project, and funding, see <http://bbi.syr.edu>. For their helpful comments and suggestions, I thank Michael Wehmeyer and Karrie Shogren, editors of Inclusion.

Author:

Peter Blanck, University Professor & Chairman, Burton Blatt Institute, Syracuse University, Syracuse, New York.

Correspondence concerning this article should be addressed to Peter Blanck, Burton Blatt Institute, Syracuse University, 900 South Crouse Avenue, Suite 300, Syracuse NY 13244 USA (e-mail: pblanck@syr.edu).