

ARTICLE

REFLECTIONS ON THE AMERICANS WITH DISABILITIES ACT: A TRIBUTE TO MY FATHER

*Jessica L. Roberts**

In honor of the twenty-fifth anniversary of the Americans with Disabilities Act (ADA), this personal narrative explores how the Author's experiences as the child of a parent with a disability shaped her interest in disability rights and her commitment to achieving social justice through the law.

I am delighted to host this online symposium honoring the twenty-fifth anniversary of the Americans with Disabilities Act (ADA).¹ I have devoted a significant portion of my academic life to analyzing the ADA and both its failures and its triumphs. However, I have never before had the opportunity to explain why I find this particular area of the law so compelling and how I came to specialize in disability rights.

All too frequently lawyers and law students are encouraged to ignore the emotion inherent in the law. Aristotle's famous adage comes to mind: "Law is reason[] free from passion."² Yet, the law can be immensely personal. It has an undeniably human side. These truths are particularly salient with respect to the ADA. Over the coming weeks, authors will share their stories of how this exceptional statute has touched their lives. These stories will not be uncritical—the ADA is by no means perfect nor is the project of equality, integration, and access for people with disabilities complete—but they will demonstrate how a law can affect our

* Associate Professor of Law, University of Houston Law Center. The Author dedicates this Article to her father, Dr. Thomm Kevin Roberts. Many thanks to the editors of the *HLRe*, particularly Benjamin A. Cohen-Kurzrock, for the opportunity to share my personal experiences about disability, exclusion, and the power of the law to affect change.

1. Americans with Disabilities Act (ADA), 42 U.S.C. §§ 12101–12213 (2014).
2. ARISTOTLE, *THE POLITICS OF ARISTOTLE* 146 (Ernest Baker trans., 1946).

daily experiences and, in so doing, can move us ever closer toward justice. This Symposium seeks to be a rare glimpse into the law's human side. It is an honor to start this series with my reflections on the powerful role the ADA has played in my own life.

I have chosen to write my contribution about my father, Kevin Roberts. Yet, this Article is not the first time I have written a personal reflection about my dad. When I was sixteen years old and applying to colleges, one application prompted me to write about a personal hero, someone whom I admired and sought to emulate. While the topic seemed to envision applicants writing about their favorite movie star or baseball player, the choice was obvious to me: I decided to write it about my dad. I had always looked up to my father as a model of intelligence, strength, and perseverance. He instilled in me that, no matter the outcome, effort was the most important thing and, if I wanted to succeed, I needed to work and work hard. These life lessons seemed well suited to a college application so I wrote the essay and sent it in. After that, I frankly forgot about the whole thing. That is until I discovered almost a decade later that my dad had kept a copy, folded neatly into fours, in his wallet. My little essay had gone everywhere with him, nestled safely between crisp dollar bills and crumpled receipts. And, it definitely showed its age. The paper was soft and almost disintegrating in the creases from where it had been folded and refolded. The ink was faded and smeared. Not only had my father kept the essay, but he had also read it seemingly countless times. When he showed it to me, it was one of those rare moments when a child fully understands just how deeply and enduringly her parents truly love her. So, that is the perspective from which I write this piece, not as a dispassionate legal academic but, rather, as a daughter.

My father was an exceptional person. He was many things: thoughtful, intelligent, kind, funny, and charming. He was also a person with a disability. He lost both of his legs when he was hit by a car in 1965, fifteen years before I was born and four years before he married my mom. Apparently, in the time immediately following his accident and rehabilitation, my dad took a run (pun intended) at using prosthetic limbs, but, by the time I came into the world, he had settled on a wheelchair as his preferred means of mobility. Because I didn't know my father before he acquired his disability, it never occurred to me that he had ever "lost" anything. He was just my daddy, and we did what any family with disabilities does. We adapted. I went on wheelchair rides instead of piggyback rides. My father tobogganed instead of skied. For show-and-tell, I brought my first grade classmates into the school parking lot to show them how a person with no legs could drive. We figured it out and largely on our own.

My father's disability certainly did not define him, but it did shape our lives when I was growing up. I was born in 1980, ten years before Congress passed the ADA. That meant that, while we were adapting and thinking creatively about access and accommodation, most of the world around us was not. I have clear memories of my mother, with her petite 5'2" frame, hauling my dad's bulky wheelchair in and out of our trunk or over curbs and doorframes. Once, when I was a bit older, I noticed that anytime we went to a new place, like a restaurant or theater, her eyes would flicker around the room for the first couple of minutes that we were there. Finally, I asked her what she was looking for. She replied, "Jessica, I'm trying to figure out how I'll get your father out of here if there is an emergency." My mom knew that in a largely inaccessible world, getting in—and out—fell on the individuals with disabilities and their loved ones. And, of course, there were some places my dad just could not go or things he could not do. I remember my immense disappointment when he couldn't see how my classmates and I had decorated our classroom for open house because the third graders were on the second floor of a building with no elevator. My mother assured me she would tell him all about it.

Years later, I read that the thing that unites people with different types of disabilities—visual impairments, hearing impairments, mobility impairments, cognitive impairments, etc.—is a shared experience of social exclusion.³ While varying types and degrees of impairment inevitably affect individuals differently, people with disabilities have historically found themselves shut out in one way or another.⁴ This statement definitely rang true for me as I thought back to all those childhood experiences and of all of those places we could not go or where we went at our own peril.

But, it wasn't just structural barriers that my family encountered. Although I didn't understand my father as different or exceptional, I learned very quickly that others did. Children in particular would stare at us. On more than one occasion, I caught someone near my age looking fearfully at my dad while we were at the mall or the park. I remember being overcome with anger, staring right back, and bellowing, "DON'T LOOK AT MY DADDY!" My mother would literally have to hold me back. She would scoop me up with all my little limbs wriggling to break free.

3. See, e.g., RHODA OLKIN, WHAT PSYCHOTHERAPISTS SHOULD KNOW ABOUT DISABILITY 2–3, 41 (1999) (describing the common experience of disability as involving exclusion and discrimination and noting that "[b]eing shut out is a way of life for persons with disabilities").

4. See *id.*

Less often, a kid would actually approach us and ask my father why he didn't have legs. Even though I would have gladly run him or her off, my dad would patiently explain that he had been in an accident and warn the little boy or girl to be safe around cars. Adults were sometimes no better. My first grade teacher once pulled me aside to ask "what had happened" to my dad. At first, I didn't know what she meant. I remember feeling awkward and ashamed, but I could not figure out why. There was just something about her hushed and hurried tone that caused me to think her question was embarrassing. These were my first lessons in stigma. I can't help but think that all of those early altercations solidified my commitment to social justice and my desire to see people as full human beings without reducing them to their outward characteristics.

As a ten year old, I was not immediately aware when the ADA passed. I had of course heard my father talk about it, hinting that it would make our lives easier. And, slowly but surely, we did notice things starting to change. Wheelchair sections appeared in theaters, we had more parking spots to choose from, and my dad could get from the sidewalk to the street without assistance thanks to curb cuts. These changes were so subtle and cumulative that I barely noticed them at the time.

My thinking about disability crystallized while I was in college at the University of Southern California, majoring in Political Science. As a junior, I was looking to fill my fall schedule, and I saw a class mysteriously titled "Stigma in Society." I was already interested in antidiscrimination and civil rights issues, so I enrolled. I didn't realize until the first day that it was a class devoted entirely to disability, taught by the world-renowned scholar and activist Harlan Hahn.⁵ Harlan was a wheelchair user like my dad, so when he rolled into class the first day, I didn't share my peers' reaction of surprise or discomfort. I felt like I had miraculously ended up in exactly the right place. I had never thought of disability from an academic or theoretical perspective before, so Harlan's class helped me understand that my family was not alone. Countless other people with disabilities encountered structural barriers and inappropriate questions or stares. Through Harlan's class, I came to understand people with disabilities as a social minority and, by consequence, the ADA as civil rights legislation. It was not my father's or my mother's responsibility to ensure that we could safely get from place to place but, rather, society's responsibility to construct inclusive and accessible environments. That class helped me connect with my

5. See Pamela J. Johnson, *In Memoriam: Harlan Hahn*, 68, UNIV. S. CAL, (May 5, 2008), <http://news.usc.edu/16105/In-Memoriam-Harlan-Hahn-68/>.

dad on a whole other level, as I told him about all the things I was learning and shared my course readings and assignments with him.

Harlan Hahn's class also led me to my current career as a legal academic specializing in discrimination on the basis of health-related information.⁶ Part of our grade was a group project that explored how the issues and problems we studied in our class played out in the real world. It just so happened that the semester when I was studying disability rights was also when terrorists flew planes into the World Trade Center. 9/11 was such a shock to the American conscience that it permeated all my classes that fall, and Harlan's class was no exception. Stories emerged of people with disabilities who had been trapped in the towers while their able-bodied counterparts evacuated or had been carried down the stairs by their co-workers.⁷ Of course, I thought of my dad. My father housed his psychology practice in an impressive Houston skyscraper. Should something happen there, would he be able to get out or would he be trapped or dependent on "heroes" to help him while those who could walk flowed down the stairs? I remembered the ADA and its promise of access. I knew it applied to places of employment⁸ and to public accommodations.⁹ Surely the law would not legislate people into buildings without providing them a way to get out? Egress seemed to be access's twin. Wouldn't they go hand in hand? I proposed this topic to my group: What if we made our project about emergency evacuation for people with disabilities? My group members agreed, and I began to research.

What did the ADA have to say about evacuation? It turned out very little. The Access Board had promulgated regulations that stated accessible routes "shall also serve as a means of egress for emergencies or connect to an area of rescue assistance"¹⁰ and that "[i]n buildings or facilities, or portions of buildings or facilities, required to be accessible, accessible means of egress shall be

6. My commitment to disability rights grew into an interest in discrimination on the basis of other sorts of things, such as genetic information and health-related behaviors. See, e.g., Jessica L. Roberts, *Healthism & The Law of Employment Discrimination*, 99 IOWA L. REV. 571 (2014); Jessica L. Roberts, *The Genetic Information Nondiscrimination Act as an Antidiscrimination Law*, 86 NOTRE DAME L. REV. 597 (2011); Jessica L. Roberts, *Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act*, 63 VAND. L. REV. 439 (2010).

7. See, e.g., Samuel Miller, A Day to Remember, MY DISABILITY STUDIES BLACKBOARD (May 1, 2011), <http://mydisabilitystudiesblackboard.blogspot.com/2011/05/day-to-remember.html>.

8. See 42 U.S.C. §§ 12111–12117 (2012).

9. See *id.* §§ 12181–12189.

10. Nondiscrimination on the Basis of Disability by Public Accommodations and in Commercial Facilities: ADA Standards for Accessible Design, 28 C.F.R. § 4.3.10 (1994), available at <http://www.ada.gov/1991standards/adastd94-archive.pdf>.

provided in the same number as required for exits by local building/life safety regulations.”¹¹ So, I went to California state law and then Los Angeles municipal code. Each source deferred to a more specific entity. Eventually, I got to the Los Angeles Fire Department and its manual for evacuating people with disabilities. The manual likewise deferred responsibility for developing specific evacuation plans to individual building captains and floor managers, but it revealed one thing. At the time, the major “evacuation” strategy for people with mobility impairments was to move them to a structurally sound place in the building, sometimes called “an area of refuge” or “an area of rescue assistance,” and leave them there in the hopes that emergency personnel would find and save them.¹² I thought of what that would be like—to be trapped in a building while everyone else left—and it stirred those old feelings of anger and injustice I felt in my childhood. It was this project about the ADA and its shortfalls that inspired me to go to law school.

When I arrived at the Yale Law School in 2003, there was no disability law course, and no one on the faculty specialized in disability legal theory. I was determined to learn disability law nonetheless. I decided, if there was no class, I would create one as an independent study. Thanks to a thoughtful and supportive mentor,¹³ I expanded my undergraduate project into a student note. It was my first piece of legal scholarship, and I published the following year.¹⁴

Ten years later, I am a full-blown legal academic and a recognized expert in disability rights. Here, at the University of Houston Law Center, I teach a class that I, ironically, never took: Disabilities and the Law. In addition to educating my students about the ADA and its accompanying regulations, I urge them to understand how society, and not impairment, is often what creates exclusion and to recognize human fragility and that able-bodiedness is merely a temporary state.¹⁵

As I have evolved over the years, so has the ADA. Congress amended it in 2008,¹⁶ and new changes are continuing to be made.

11. *Id.* § 4.1.3(9).

12. See CITY OF LOS ANGELES: DEPARTMENT OF LABOR & SAFETY, ELEVATORS, EGRESS AND AREAS OF REFUGE, PLATFORM LIFTS 3–5 (2011), available at http://ladbs.org/LADBSWeb/LADBS_Forms/PlanCheck/PC-DAD-CorrLst05.pdf (showing the Department of Labor’s codification of a similar standard several years later).

13. I will forever be in debt to Kenji Yoshino for encouraging me to pursue both that project and a career in the legal academy.

14. See Jessica L. Roberts, Comment, *An Area of Refuge: Due Process Analysis & Emergency Evacuation for People with Disabilities*, 13 VA. J. SOC. POL’Y & L. 127 (2005).

15. One thing that Harlan taught me was that, assuming we live long enough, we will all become people with disabilities just by virtue of the aging process.

16. See Americans with Disabilities Act Amendments Act, Pub. L. No. 110-325, 122

For example, I smile whenever I see a lift next to a pool.¹⁷ While my family never benefited from these innovations, I think of all the people that will. To be sure, it is now a vastly different world for people with disabilities than the one in which I grew up. Just this last semester, one of my law students made an off-hand comment during the class that she was born a year after the ADA passed. Up until that moment, it had not occurred to me that there was no such thing as a “pre-ADA world” for a substantial number of my students. While this development is nothing but positive, it means that, if I truly want to educate them about disability rights, I must also educate them about disability history.

All of this is to say that, while it sometimes disappoints or frustrates me, I believe in the transformative power of the law. If I didn’t, I wouldn’t have chosen the career I did. I would not have decided to teach and to write about social justice. I feel blessed to have had Kevin Roberts as a father. He died on October 4, 2013. While he is gone, I think about him and his effect on my life every day. Not just because I keep a picture of him and his graduate students taped to my computer at work but because he is present in almost everything I do: in how I see the world, in what I write and teach, and in my faith in humanity. Beyond strength and resilience, my father taught me about empathy and patience. He taught me that the best way to change people’s minds or alleviate their fears is to educate them. He taught me how to be a good listener, as well as a thoughtful speaker, and not to fear difference but, rather, to seek to understand it.

I also believe that our best, most admirable laws seek justice, even though they may not always achieve it. As the ADA turns a quarter century old, it is my hope that the statute will do what people with disabilities have themselves done for ages. I hope it will continue to adapt. This is my story, and I look forward to reading others.

Stat. 3553 (codified at 42 U.S.C. § 12101 (2012)).

17. See U.S. DEPT OF JUSTICE, ACCESSIBLE POOLS: MEANS OF ENTRY AND EXIT 3 (2012), available at http://www.ada.gov/pools_2010.pdf.