

# The ADA Project

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Prepared by:

LEGISLATION CLINIC

Kelvin Garcia, Student Attorney  
Marcy Karin & Laurie Morin,  
Faculty Supervisors

## ***EXPANDING ACCESS TO RIGHTS UNDER THE ADA: THE HISTORY AND IMPACT OF THE ADA A CONVERSATION WITH KEVIN BARRY***

The UDC Law Legislation Clinic interviewed [Kevin Barry](#), Professor of Law at Quinnipiac University School of Law, on November 9, 2018. Professor Barry teaches administrative law and disability law and is the co-director of the law school's Civil Justice Clinic. From 2006-2008, Barry was a teaching fellow in Georgetown University Law Center's [Federal Legislation and Administrative Law Clinic](#). Under the supervision of Professor [Chai Feldblum](#), he represented the [Epilepsy Foundation of America](#), working with a national coalition of disability rights organizations in support of their efforts to amend the [Americans with Disabilities Act \(ADA\)](#). These efforts culminated in passage of the [ADA Amendments Act of 2008 \(ADAAA\)](#), which clarifies and expands the definition of disability, resulting in broader coverage of individuals with disabilities.<sup>1</sup>

The goal of the interview was to get Professor Barry's insight on three main areas: (1) the events that led to passage of the ADAAA, (2) the impact of the ADA as amended on the rights of individuals with disabilities, and (3) the next frontier for the rights of individuals with disabilities under the ADA. This document presents an overview of the oral history that was captured during that conversation, offering a glimpse into the perspective of one of the people who has played a role in expanding the rights of individuals with disabilities.<sup>2</sup>

### **I. LEADING UP TO THE ADAAA**

#### **A. *Disability Rights as Civil Rights***

Professor Barry started the call by saying that his interest in disability rights began during his fellowship with Professor Chai Feldblum at Georgetown University Law Center's Federal Legislation and Administrative Law Clinic, where he was assigned to work with disability advocates on a campaign to amend the ADA.

<sup>1</sup> Chai Feldblum, Kevin Barry & Emily Benfer, *The ADA Amendments Act of 2008*, 13 TEX. J. CIV. LIB. & CIV. RTS. 187 (2008). See also THE PAST, PRESENT AND FUTURE OF THE ADA: A CONVERSATION WITH CHAI FELDBLUM, <http://adalawproject.org/s/Feldblum-Oral-History.pdf>.

<sup>2</sup> Professor Barry's responses to questions have been paraphrased unless quotation marks are used to indicate a direct quote.

Barry's fellowship involved helping Feldblum supervise the Legislation Clinic's work for the Epilepsy Foundation of America. As a legislative lawyer at the ACLU, Feldblum had played a crucial role in the creation and later enforcement of the ADA. When the disability community was ready to seek a legislative response to a series of Supreme Court cases that narrowed the scope of the ADA's coverage, Feldblum offered the Clinic's services. She assigned Barry to work on this project, along with a national coalition of disability rights activists, which ultimately resulted in the passage of the ADAAA.<sup>3</sup>

Working with Feldblum, Barry learned that the Supreme Court's narrowing of the definition of disability had a negative impact on the ability of individuals with disabilities to enforce their rights under the statute. More than that, he learned about the disability rights movement's major contribution to the progress of civil rights—the “social model of disability,” which holds that people are “disabled” not by the functional limitations imposed by their medical conditions, but rather by society's discriminatory reaction toward those conditions.<sup>4</sup> Until then, his understanding of disability was limited to the ways in which medical conditions restrict people's functioning. As a high school student enrolled in a Psychology/Sociology course, he worked with young people with significant cognitive and physical impairments who received special education services. He enjoyed the work greatly and thought society should be doing more for people with disabilities, but he viewed disability in terms of impairment rather than civil rights. His experience working on the ADAAA forever changed his assumptions. While impairment may be inevitable, societal discrimination based on impairment is not. Society can change, and law can guide those changes.

## B. *Courts Thwart Congressional Intent of the ADA*

In response to a question about the most important changes that were needed for the disability community at the time leading up to passage of the ADAAA, Barry responded: “The definition of disability definitely, definitely, definitely.”

He explained that decisions that were coming from the Supreme Court and lower federal courts had made it increasingly difficult for plaintiffs to establish that they had a covered disability under the ADA.<sup>5</sup> Before Barry started his Georgetown fellowship, much work had already been done to examine the ADA's impact after its passage in 1990. In 2004, [Robert L. Burgdorf Jr.](#) authored a report for the [National Council on Disability](#) (NCD) called [RIGHTING THE ADA](#)<sup>6</sup>, which set out a number of interpretive

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<sup>3</sup> THE PAST, PRESENT AND FUTURE OF THE ADA: A CONVERSATION WITH CHAI FELDBLUM, <http://adalawproject.org/s/Feldblum-Oral-History.pdf>.

<sup>4</sup> For a helpful discussion of the social model of disability and related issues, see SAMUEL R. BAGENSTOS, LAW AND THE CONTRADICTIONS OF THE DISABILITY RIGHTS MOVEMENT (Yale University Press, 2009). Available at: [http://works.bepress.com/samuel\\_bagenstos/29/](http://works.bepress.com/samuel_bagenstos/29/).

<sup>5</sup> Feldblum *et al.*, *supra* note 1, at 192-193. As a result of these decisions, it was difficult for people with a wide range of disabilities, including epilepsy, diabetes, psychiatric disabilities, and other disabilities to prevail in court.

<sup>6</sup> NATIONAL COUNCIL ON DISABILITY, RIGHTING THE ADA (December 1, 2004). Burgdorf, a former Staff

problems that courts had created. Key issues that the report highlighted included a narrow construction of reasonable accommodations, an overly broad construction of the provision that allowed employers to exclude persons with a disability who would pose a “direct threat” to health, and a narrowing of the definition of disability.

The disability community decided that the most important change needed was to restore a more expansive definition of disability to fulfill the original legislative intent of the ADA. Although they recognized other problems, the disability community believed that a “modest fix” to expand the definition and open the door wider for individuals with disabilities was the most important first step. Once that problem was fixed, other issues could be resolved in the future.

## II. LEGISLATIVE PATH OF THE ADA

The business community, the disability community, and Congressional stakeholders were all at the table during the crucial time leading up to passage of the ADA. This section focuses on the key issues and breakthroughs that stood out to Barry during the legislative process.

### A. *The Stakeholders and Key Relationships*

Barry was asked if it is normal for the business community to negotiate with people with disabilities on proposed legislation. If not, what was it about disability rights—or this legislation—that allowed various stakeholders to work together?

Barry noted that the business community had negotiated with the disability community in the past around the passage of the ADA. This is what made the legislative process so interesting. Many of the same people involved with the passage of the original ADA of 1990, including Feldblum, were all back at the table 16 years later. They had new positions, but they were back in the room negotiating with one another and continuously consulting with their respective communities and congressional staffers on the Hill.

When Barry thinks of the people who were really out in front on the ADA, he realizes that women played an especially significant role in getting the legislation drafted and passed. Around the table with Feldblum were advocates including [Heather Sawyer](#) (who directed Georgetown University Law Center’s Federal Legislation and Administrative Law Clinic in 2006 before becoming Minority Counsel for the House Judiciary Committee, Subcommittee on the Constitution in 2007), [Alexandra “Sandy” Finucane](#) (Epilepsy Foundation), Jennifer Mathis (Bazelon Center for Mental Health Law) and [Sharon Lewis](#) (Senior Disability Policy Advisor to U.S. House Committee on Education & Labor), among many others.

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Researcher with NCD, wrote the original version of the Americans with Disabilities Act (ADA) that was introduced in the 100th Congress. At the time he authored the 2004 report, Burgdorf was a Professor of Law at the University of the District of Columbia David A. Clarke School of Law.

Personal relationships played an important role in the process. For example, Feldblum had previously negotiated with the chief lobbyist for the Chamber of Commerce, Randy Johnson, when he was a staffer for the House Education and Labor Committee in the lead up to passage of the ADA. The original sponsor of a bill that would eventually become the ADAAA was [Representative Jim Sensenbrenner \(R-WI\)](#), whose wife, [Cheryl Sensenbrenner](#), served on the board of the [American Association of People with Disabilities](#) (AAPD)—one of the disability rights organizations involved in the effort to amend the ADA.

There were also moments of levity and humor in the process. For example, Feldblum affectionately referred to the disability rights community’s “drafting and analysis” working group as the “DA,” which is also the acronym for [“Dumbledore’s Army”](#)—a group of heroic witches and wizards in the Harry Potter series. Barry recognizes that a sense of camaraderie, humanity, and humor are all crucial ingredients of a successful advocacy effort.

### B. *The Spirit of Disability Rights Advocacy*

There was a point during the negotiations—“maybe just a few weeks but it felt like a month”—where Barry thought that the ADAAA was dead. The disability community did not want the words “substantially limits”<sup>7</sup> to remain in the definition of disability, but the business community needed it and this put the negotiations on hold.

The negotiators eventually agreed to keep the “substantially limits” language in the ADA’s definition of disability while proposing a “*per se*” list of specific disabilities that would be automatically included in the definition. The disability community rejected the *per se* list because they did not want to limit or exclude anyone from the law. For legal and ethical reasons, they did not want to create an “in” and “out” group within the community. Instead, advocates eventually negotiated rules of construction, findings, and purposes for the legislation that clarified the expansive scope of the definition.<sup>8</sup>

Asked whether it was normal for the disability community to stay united when offered a provision that helped some at the expense of others, Barry replied that, as far as the disability community is concerned, “absolutely yes.” During negotiations over the original ADA, the disability community resisted attempts by Congressmembers to exclude certain groups of people from the definition of disability, namely, people with HIV/AIDS and mental illness.<sup>9</sup> The disability rights community continued to stick together in this same spirit during negotiations over the ADAAA.

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<sup>7</sup> Under the ADA, the definition of disability applies to any person who has “a physical or mental impairment that **substantially limits** [emphasis added] one or more of the major life activities of such individual;” a record of such impairment; or is regarded as having such an impairment. 42 U.S.C. §12102.

<sup>8</sup> Kevin Barry, Brian East & Marcy Karin, *Pleading Disability After the ADAAA*, 31 HOFSTRA LAB. & EMP. L.J. 1, 5 (2013).

<sup>9</sup> See Arlene Mayerson, Disability Rights Educ. & Def. Fund, THE HISTORY OF THE ADA: A MOVEMENT PERSPECTIVE (1992), available at [http://www.dredf.org/publications/ada\\_history.shtml](http://www.dredf.org/publications/ada_history.shtml).

### C. *The Role of Bipartisanship*

Barry was asked if anything surprised him about the bipartisanship during the legislative process of the ADAAA. He replied that “the ADA was a bipartisan law, and the folks who were advocating for the ADAAA felt that it had to be bipartisan as well.” That type of bipartisanship is not necessarily normal; it distinguishes disability rights from other type of civil rights legislation, which tend to be more partisan.

In conclusion, Barry said: “When you look back at a successful legislative advocacy effort, it has a sense of inevitability. But it was not inevitable. It was a testament to the hard work of great advocates, great attorneys, and great staffers on both sides of the aisle. That’s what got the legislation through.”

## III. REFLECTIONS ON THE IMPACT OF THE ADAAA

The ADAAA passed Congress and was [signed into law](#) by President George W. Bush on September 25, 2008.<sup>10</sup> Barry was asked how he felt and what he was thinking at the time. He remembers that he was in the car when Feldblum called to tell him the news. He had left D.C. for a teaching position in Connecticut, and [Emily Benfer](#) had taken over for him at the Legislation Clinic. Feldblum, Benfer, and others were celebrating, and they called to include him. “I wasn’t there in person,” Barry reminisced, “but I was there in spirit. It’s not every day you get to see a major piece of bipartisan civil rights legislation get passed into law—and in just two years at that. I was so proud to have been a part of that effort.”

### A. *Impact of the ADAAA: Opening the Doors*

In response to a question about whether the ADA was successful in its goals, Barry responded that he shared Feldblum’s assessment that it absolutely was. The goal was to open the door to the protections of the ADA—to expand that class to the group that Congress had intended to protect. Barry believes the ADAAA has done that. “The door has been opened; how far we go when we get inside remains to be seen. That’s the future, and we may need more amendments to get there.”

Barry recalls how some advocates and attorneys were disappointed with the ADAAA, calling it needlessly complicated. Barry understands the concern, but he believes they missed the beauty of the ADAAA.

Although it is true that the language that caused all the problems of interpretation—“substantially limits a major life activity”—was not removed from the definition of disability, the ADAAA created rules of construction, findings, and purposes that force courts to interpret the statute in the way that Congress actually intended. There was intentional complexity to the ADAAA so that a textualist court would know

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<sup>10</sup> ADA Amendments Act of 2008, Publ. L. No. 110-325, 122 Stat. 3533.

exactly what the term “substantially limits a major life activity” means. It does not mean the narrow interpretation that the Supreme Court and EEOC gave to it.

Although it was not a simple fix, the ADAAA accomplished its purpose. It has made the ADA more expansive and inclusive. “This was the result that the disability community wanted, albeit not in the precise way that many wanted it.”

### B. *The Federal Courts and the ADAAA*

Barry was asked whether he thought the current composition of the U.S. Supreme Court and other federal courts would impact the future of disability law. If courts wanted to interpret the definition narrowly, he thinks that this law was tailor-made for strict constructionist/textualist judges. The ADAAA does not leave a lot to the imagination. It does not leave a lot of room for a judge who wants to construe the definition narrowly. It tells judges that they cannot do so through rules of construction.

Barry further explains this theory in an article he wrote, entitled “Exactly What Congress Intended?”<sup>11</sup> In this piece, he labels the ADAAA as a “micromanager statute” that very explicitly—in a granular fashion—tells a judge how it should be interpreted. The problem with the ADA, and the Rehabilitation Act before it, was that they were not micromanager statutes; they did not tell a judge what to do. They assumed that judges would interpret the language as Congress intended, but in practice they did not. When judges could look at the definition and say, “I don’t think a person with an amputated limb or a person with a mental impairment has a disability because they’re not limited *enough*, that was nonsense.” Judges who narrowly construed the ADA were not following the broad language of the definition of disability that Congress intended. While there are sure to be some close cases in the future, the ADAAA largely resolved that issue of interpretation.

### C. *The Next Frontier*

When Barry was asked what’s next on the disability rights agenda, he said that he is working on one of these frontiers right now: access to disability rights protections under the ADA for people with gender dysphoria. [Title V of the ADA](#)<sup>12</sup> excludes from protection three conditions that are associated with transgender people. Several district courts have held that these exclusions do not apply to people with gender dysphoria, a new and distinct diagnosis.

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<sup>11</sup> Kevin Barry, *Exactly What Congress Intended?* 17 EMP. RTS. & EMP. POL’Y J. 5 (2013). Available at SSRN: <https://ssrn.com/abstract=2240043>.

<sup>12</sup> 42 U.S.C. § 12211. Sub-section (a) excludes homosexuality and bisexuality from the definition because they are not impairments. Sub-section (b) excludes certain conditions, including “transvestism, transsexualism, pedophilia, exhibitionism, voyeurism, gender identity disorders not resulting from physical impairments, or other sexual behavior disorders” from the definition based on the moral opprobrium of several senior U.S. Senators. See Kevin M. Barry, Brian Farrell, Jennifer L. Levi, & Neelima Vanguri, *A Bare Desire to Harm: Transgender People and the Equal Protection Clause*, 57 B.C. LAW REV. 507 (2016), available at SSRN: <https://ssrn.com/abstract=2691846>.



According to Barry, protection for people with gender dysphoria is in keeping with the mandate of the ADA that the definition of disability be construed broadly. “If people have a medical condition that *would be* limiting absent treatment, if they once *had* a medical condition, or if they’re discriminated against based on a medical condition, real or perceived—they’re protected by the ADA, as amended.”

There are others who are working to expand employment opportunities for LGBT individuals with disabilities who are at the intersection of various marginalized groups. Barry explains:

Our civil rights laws understandably tend to divide us into discrete groups. We have racial justice laws, we have LGBT rights laws, we have disability rights laws, for example. But of course people are not so neatly divided; we can be black and gay and have a disability. We have intersecting identities. Part of the next frontier involves focusing on those at the intersections.

#### D. *Vision for the Future*

Asked about the future of the ADA, Barry pointed to the good work being done by the National Council on Disability in charting a course for the ADA in years to come.<sup>13</sup> He also shared some of his thoughts regarding future goals. In the employment arena, facilitating the ability for people with disabilities to work from home is a much-needed improvement. Affirmative action for individuals with disabilities, advocated by Feldblum, is another important goal.

With respect to government services, changes are needed in the education arena, including dismantling the school-to-prison pipeline for students with disabilities in elementary and secondary school, and making websites accessible at the university level. Changes are also needed to improve police interactions with people with disabilities. It is difficult enough for people of color in the criminal justice system—it is even worse for people of color with disabilities.

Public accommodations should improve integration of people with disabilities into the technology of now and of tomorrow. And the United States should join the international human rights community in ratifying the [International Convention on the Rights of Persons with Disabilities \(CRPD\)](#).

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The UDC Law Legislation Clinic thanks Professor Barry for taking part in this interview. The Clinic appreciates that he allowed us to create this document to share his unique perspective and stories about his work on behalf of people with disabilities.

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<sup>13</sup> NATIONAL COUNCIL ON DISABILITY, NATIONAL DISABILITY POLICY: A PROGRESS REPORT (2015), available at [https://ncd.gov/progress\\_reports/ncd-progress-report-celebrates-25-years-ada-envisions-next-25](https://ncd.gov/progress_reports/ncd-progress-report-celebrates-25-years-ada-envisions-next-25).