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## Looking Back on the Americans with Disabilities Act 30 Years Later



President Bush signs the Americans with Disabilities Act at the White House, July 26, 1990. Sharing the dais are (standing left to right): Rev. Harold Wilkie; Sandra Parrino, National Council on Disability; (seated left to right): Evan Kemp, Chairman, Equal Opportunity Commission; and Justin Dart, Presidential Commission on Employment of People with Disabilities. Courtesy George Bush Presidential Library and Museum.

This past July marked the 30th anniversary of the passage of the Americans with Disabilities Act (ADA). This landmark piece of legislation followed years of pressure from disability rights activists, of which polio survivors were an integral part—people such as Justin Dart, Ed Roberts, Judith Heumann and others. The ADA allowed people with disabilities to challenge societal barriers that excluded them from their communities and would have a profound impact in making America a more inclusive society.

We asked a handful of polio survivors to reflect on the legacy of the ADA—its promise, its shortcomings and the work that still needs to be done.

### **We Should Celebrate. But There Is Still Work to Do.**

**Judith Heumann**

I was 18 months old when my parents learned I had polio. It was 1949, and things that were typical for children were not so typical for me. I was denied the right to go to school because the staff did not know how to accommodate a student who could not walk. Instead, I received just two-and-a-half hours of home instruction each week. People like me who did not fit into a neat little box had no laws to protect them. We were not advancing in our education and no one had expectations for our futures.

This discrimination continued when I pursued my teaching career. Though I passed all my exams, I was denied

a teaching license in 1970 because New York City's Board of Education thought I could not safely evacuate my students in case of a fire. There was no one who looked like me—who used a wheelchair—fighting for this right. I filed a lawsuit and I won.

I began to see other disabled people fighting for inclusion, and I found empowerment in our collaboration. On April 5, 1977, more than a hundred of us occupied a San Francisco federal building for what became known as the 504 Sit-in. We had fought with the Carter administration to sign regulations implementing Section 504 of the Rehabilitation Act of 1973, which prohibited programs that received federal

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Judith Heumann

funding from discriminating against disabled people, but after years of asking, 504 still had not been signed. We occupied the building for almost a month until our demands were met. Section 504 was key because it laid the foundation for the Americans with Disabilities Act.

The ADA helped open building doors, allowed us to earn an education and made it illegal to discriminate against a qualified person for employment.

We should celebrate the strides we have made. But there is still work to do. The way society thinks about disability needs to evolve, as too many people view disability as something to loathe

or fear. By changing this mentality, by recognizing how disabled people enrich our communities, we can all be empowered to make sure disabled people are included.

Judith Heumann, a former PHI board member, is an international disability rights activist who served in both the Clinton and Obama administrations. Her memoir, *Being Heumann: An Unrepentant Memoir of a Disability Rights Activist*, was released in February. This essay first appeared in the *New York Times*.

### **“The ADA is not good enough.”**

**William Stothers**

Wow!

As those of us who labored and lobbied and advocated for passage of the ADA 30 years ago, last month’s anniversary of the signing was a time to remember and celebrate the changes that the law has brought about. The landscape of the United States has definitely become more accessible. Life for disabled people—actually, for everyone—has improved.

But I must say that what heartens me most is the reaction among the first ADA Generation: “The ADA is not good enough.” Expectations have soared. They demand more. It’s just not good enough that all public facilities are not accessible; that accessible facilities are not matched with policies that make access functional; that programmatic access remains spotty at best.

The ADA Generation is pushing into leadership positions in activism as well as professions across the board. Its members are multicultural, confident and adept at new technologies.

I, for one, am delighted. And, to echo Justin Dart, the father of the ADA, “Lead on! Lead on!”

William Stothers is a past President of the PHI Board of Directors.

### **Uncovering Hidden Histories of the ADA**

**Karen Hagrup, PhD**

The future of the ADA depends on all of us. Right now, we need our collective voices to tell more of the truth about how far we’ve come and what still needs to be done. That means we have to be able to see what the ADA has actually meant for disabled people in their complicated everyday lives. Personally, I’m weary, and I’m hopeful. It makes sense that my feelings about the 30th anniversary of the ADA are mixed; for me, the ADA has been a mixed bag.

I’m weary because when the ADA first became law, I was one of the early people to test the strength of the law through legal action. In practice, this was a traumatizing experience for me. I’m still integrating and recovering from that period in my life. Suing the university where I worked in the early nineties meant not only that I needed the law because of discrimination I was facing, but also that I must go through an ugly legal battle that dovetailed with difficulties at home, some of which were based in cultural ableism that I had to withstand in my own marriage. I know in a very personal way that there can be a lot of pain, heartache, and even reproduction of oppressive systems even within anti-ableist legislative wins and wider political and social movements.

I’m also weary because my disabled friends, many of whom are white like I am, have often shared with me stories about their parents helping instill in them a sense of ownership of their lives and self-worth, against the backdrop of a wider culture that dehumanized them for being disabled. While I am grateful that my friends got this message, I can now see how it intersected with their whiteness and reinforced assumptions about how they mattered as white people above people of color.

It’s a complicated thing to be a white physically disabled person who both needs to feel whole in their humanity and simultaneously needs to interrogate their privilege and unlearn their learned superiority. Those intertwined parts of white disabled identity

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need to be worked with honesty and care. As Corbett O'Toole argues, white disabled people need to learn how to relinquish the disability rights mic to QTBIPOC disabled people.

I have long been able to see the importance of a cultural lens to social change work. I have known that legal campaigns would not be enough and that the ADA and the first 30 years of its implementation were not adequately capturing and attending to the social experience of disability.

And yet, I'm also hopeful. I'm hopeful because the ADA has provided us with ways to take legal action based on discrimination. It has contributed to a normalization of accessibility in the built environment, curb cuts and ramps, the addition of sign language interpreters at public speaking events, and the choice of adding captioning (some okay, some low quality) in television programs. Because of the ADA, there are many more wheelchair accessible restaurants and places that serve the general public. Information about accessibility is included in many marketing statements like brochures and web pages.

I am hopeful because the Paralympics show how people with all kinds of disabilities are using a variety of adaptive equipment in amazing ways. I am hopeful because, in addition to facing serious challenges to be more race and gender inclusive, Hollywood is being called out more for giving disabled roles to non-disabled people. I am hopeful because architects are designing accessible beautiful features in their public buildings, features that are preferred by a large variety of people. I am hopeful because computers and all kinds of devices include accessible technology for all kinds of disabilities.

I'm also hopeful because I am moving through and healing the ways that I was traumatized by my experience bringing legal action under the ADA. And I am getting in touch with the ways that I am proud of being one of the early people to test the legal limits of the ADA. I am proud of being part of the ADA's overlooked history of individual sacrifices to fight for the ADA in unglamorous ways, one institution at a time.

With this newfound pride, I am actively telling my story more publicly now, and I can see all the work that I have done to get to a place where I am ready and can tell my story widely. And I'm hopeful because telling my story means that more of the truth of the deeply complex experience of disability identity and disability history will be written down and shared. And when I look around now, I can see more and more disabled people telling their personal

stories, capturing more of the social history that I know to be so important for the ADA and disability liberation to keep going strong.

It's important to be able to see the good and the bad together. If I were only hopeful, I could miss the pain and struggle and possibly reproduce shame and silence. If I were only weary, I might give up and contribute to the surrender of others in a fight that still needs conviction.

Thirty years after becoming law, we need to keep studying the social history of the ADA to learn about its true legacy. Working with my daughter to write down my life story is one way that I'm making sure that one more disabled person is included in history and more of disability history is socially and culturally informed.

Karen Hagrup is an anti-Skinnerian educator and mother, a disabilities studies pioneer, and a staunch Obama supporter, who has spent her life fighting for people's rights and joy, her own included.

### **Polio Survivor Friends and the ADA**

**Richard Daggett**

Polio survivors were the first large disability group to attempt the transition from hospital to home, despite very severe functional limitations, often including ventilator dependence. We knew that this could be both safe and cost effective. We also knew that many obstacles remained.

Younger polio survivors were often excluded from public schools; there was no "mainstreaming" as we know it today. When I left the hospital, I was sixteen. I had a noticeable limp, but I walked well. Even so, my school district decided that it would not be "safe" for me to attend high school. I was assigned a home teacher. I benefited academically by having a home teacher, but my social life surely suffered. And I missed taking science lab courses and other in-person studies.

Many adult polio survivors faced architectural and social barriers to employment. Few commercial buildings were wheelchair accessible, and people with a noticeable disability were seldom seen in the front office.

Despite these barriers, or perhaps because of them, polio survivors were the driving force for disability rights, including the ADA. Justin Dart, Ed Roberts, Judy Heumann, Paul Longmore and numerous others were polio survivors. I am honored that these pioneers were my friends and colleagues.

Many others wrote letters, made telephone calls, and peacefully demonstrated. In 1675, Sir Isaac Newton wrote, “If I have seen further it is by standing on the shoulders of giants.” As we celebrate the 30th anniversary of the Americans with Disabilities Act, we must honor these “giants” who paved the way. We must also acknowledge that there is still work to be done.

Richard Lloyd Daggett is the author of *Not Just Polio: My Life Story* and is president of the Polio Survivors Association.

## The ADA and Accessibility

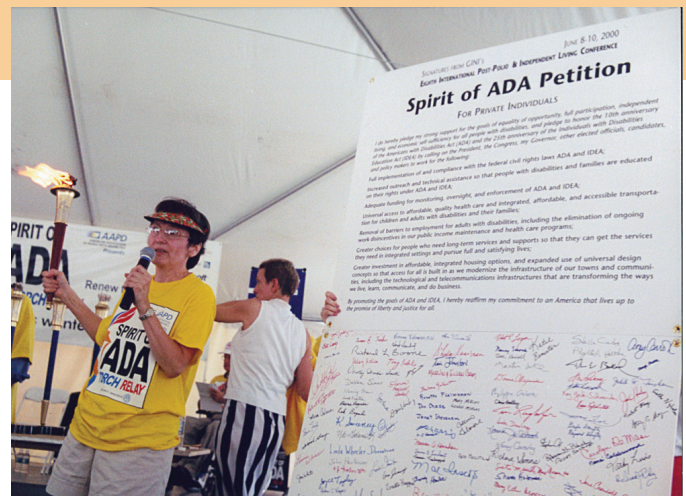
### Joan Swain

In 1950, when I returned home after five months in the rehab hospital, I was eager to try on my post-polio life as a senior in high school. That’s when I found out that the world was made up of stairs ... starting with my bedroom. That one was resolved by switching with a sibling. The others required more creative thought.

One of my first challenges was a trip to the dentist’s office, located at the head of a stairway that went straight up from street level in town. We came up with the idea of asking the local police department if they could loan us the help of one of their young officers. They agreed, and another problem was solved. I used crutches and braces and grew better at handling stairs over time, but they were always a challenge. I’ll never forget how those young officers helped me get around in those first days of dealing with polio, though.

Imagine the changes the ADA offered! There would be elevators to reach that dental office. Or more likely it would be in a one-floor building along with other medical offices. Ramps and curb-cuts would add to accessibility. Schools became accessible to children who earlier would have been isolated in special schools instead of with their friends and neighbors. And I could likely have attended class with my friends instead of studying with a tutor those last few months of high school.

In April of 1949, I had turned 17 and learned to drive in my family’s pre-WWII stick-shift Plymouth. Ready to drive again, I would need hand controls like those they were installing in cars used by homecoming veterans with serious leg problems. I had ridden in a black Buick convertible equipped with such hand controls the past summer. A family friend who used to build racing cars offered to build hand controls in the Oldsmobile my parents had recently bought.



Past PHI president Joan Headley in 2000 at the Spirit of ADA Torch Relay marking the 10th anniversary of the ADA and the 25th anniversary of the Individuals with Disabilities Education Act (IDEA).

And, happily, they let me drive it to the junior college I was attending nearby. Freedom!

Hand controls gave new independence to many drivers with disabilities, but they could not provide the parking places that would be needed. That was done by the ADA, which required businesses to allocate space and build a specific numbers of parking spaces. The ADA made public bathrooms, hotels, roadside inns, restaurants, parks, buses, trains and a vast inventory of additional features more accessible, and today makes travel by people with disabilities a welcoming opportunity.

With all that the ADA offers, do I still have needs that aren’t met? In a word, yes. I drive a ramp van, that is, a minivan with a ramp that folds away and then lowers from the side of the van so that I can drive in and out on it with my scooter. In New Jersey, there are often new smaller-sized accessible parking spaces and only one or two of the old standard-sized accessible spaces. The problem is that the smaller parking spaces do not allow room for the ramp to be lowered from the side of the minivan for the scooter to ascend or descend! If the two standard-sized handicap spaces are full, the only way to park is to take two standard parking spaces and park on an angle within the space created. However, that often earns you a parking violation!

Joan Swain is a founder of the Polio Network of New Jersey, where from 1991 to 2017 she edited both their quarterly *Newsletter* and *Newsline*, the monthly newsletter of the Raritan Valley Post-Polio Support Group. She is retired from Sanofi-Aventis US and lives at Fellowship Village Senior Living in Basking Ridge, New Jersey. ■