

TESTIMONY OF CHERYL SENSENBRENNER
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BEFORE THE UNITED STATES
HOUSE OF REPRESENTATIVES
COMMITTEE ON THE JUDICIARY

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Chairman Conyers, Ranking Member Smith, and Members of the Committee:

Thank you for the invitation to testify on the occasion of the 20th anniversary of the landmark Americans with Disabilities Act (ADA). I am honored to have this opportunity to join my friends Leader Hoyer and Governor Thornburgh to reflect on two decades of progress and some of the ongoing challenges facing people with disabilities in the United States and globally. My name is Cheryl Sensenbrenner, and I am pleased to offer my testimony today as the Immediate Past Board Chair of the American Association of People with Disabilities (AAPD), a national non-profit, non-partisan membership organization promoting the political and economic power of the more than 50 million children and adults with disabilities throughout the U.S. With more than 100,000 members, AAPD is the largest national cross-disability membership organization in the country. In addition to my affiliation with AAPD, I offer my testimony today as a disabled woman who remembers what it was like before the ADA; as the big sister of Tara, who has Down syndrome; and as the mother of Frank, who has attention deficit hyperactivity disorder.

I last appeared before this Committee's Constitution Subcommittee in October 2007 to testify in support of what became known as the ADA Amendments Act, an important bipartisan bill that helped to restore the broad scope of protections in the original ADA and undue much of the damage that had been created by a series of harmful court decisions interpreting the definition of disability in the ADA. That 2007 hearing helped lay the foundation for a successful bipartisan bicameral effort that bore fruit in 2008. I remember fondly the floor vote in June of 2008 when the House voted 405-17 in support of this critical legislation that restored civil rights protections for millions of Americans with epilepsy, diabetes, depression, cancer, and a range of other conditions. I want to start my testimony today by offering my heartfelt thanks to all of the members of this Committee who worked with my husband Jim, Leader Hoyer, and our broad coalition to bring a well-designed bill to President Bush for signature. Watching President Bush sign that legislation in September of 2008 was one of the proudest moments of my time in Washington, and it could not have happened without the bipartisan leadership and support of the members of this Committee.

I.

We are here today for a broader purpose than when I last appeared, to celebrate two decades of implementation of the ADA and to reflect on the work that lies ahead of us as a nation to fully realize the vision of that powerful law. In 1990, with tremendous bipartisan support, Congress passed the ADA, and President George H.W. Bush signed it into law. During its passage, Congress acknowledged that people with disabilities were extremely disadvantaged socially, economically, vocationally, and educationally—this “political powerlessness” on account of pervasive discrimination, segregation, and exclusion “resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society . . .”

Congress’s intention was clear. This great law, the ADA, was meant to stand as the “emancipation proclamation for people with disabilities” against the unfair discrimination that had permeated all aspects of life for people with disabilities for far too long. The law’s broad directive to employers, public transportation systems, public accommodations, as well as other program and service providers (including the private sector) was to stop the unfair treatment of people on the basis of their current, past, or perceived disabilities. Once implemented, the ADA was intended to give all people with disabilities the opportunity for independence and full participation and inclusion in society.

And to be sure, in the last 20 years since its passage, we have witnessed an undeniable transformation in our society. Access to public transportation has improved considerably on account of the ADA requirement that all new buses, trains, and accompanying stations be accessible for people with mobility, sensory and other disabilities—there is no question we live in a more accessible society than in 1990 on account of the ADA. Closed-captioning, curb cuts, power-assisted doors, and large print signage—all of these are hallmarks of society post-ADA—of a society more welcoming of and accessible to people with disabilities than in a time past. As we experience the aging of my generation of baby boomers, I am delighted that the ADA has prepared America for our growing population of people with mobility and sensory impairments related to age. We can all get around easier and stay active in our

communities longer thanks to the accessibility improvements spurred by the implementation of the ADA.

As someone who travels frequently with Jim, I have also observed that the ADA has inspired countries around the world to pass their own legislation to improve accessibility and recast disability issues in terms of civil rights, human rights and equality of opportunity. I was excited to see our government sign the U.N. Convention on the Rights of Persons with Disabilities last year, and I remain hopeful that our Senate will ratify that important treaty when it is delivered for their consideration later this year.

II.

As we reflect on the progress of the last two decades, I think it is important that we remind ourselves about the pervasive discrimination that existed in this country and around the world before we ever had an ADA. I can remember cold, snide remarks, and demeaning looks and stares that my sister, Tara, who has Down syndrome, endured nearly every day growing up. And for myself, I vividly recall numerous occasions in which I was subjected to the ignorant comments and low expectations of others after acquiring my spinal cord injury at age 22 in 1972. I remember once waiting for my father, then Attorney General of Wisconsin, in the lobby of a bank while he conducted some business, and I remember a bank executive staring at me and stating coldly, “People like that belong on park benches out front and not in our lobby.” I remember it so clearly—“People like that,” he said. “People like that” are I, my sister, my son, many of my dearest friends, and countless Americans. “People like that” are your loved ones, your friends, or even you—now, or in the future.

I can also remember going to the Mayo Clinic after my accident, and I remember the specialists there telling my father that because of my disability, I would never get a job, never get married and never have children. I remember my father telling me that I should not worry, that I could live at home with my parents for the rest of my life, that he would take care of me. That was in 1972. I am happy to tell you that I did not accept the circumscribed life that the specialists envisioned for me. In fact, after my accident, I became the first woman to run for State Assembly in Door County, Wisconsin, and I

remember receiving a financial contribution from one of my father's political opponents, a young handsome Republican named F. James Sensenbrenner. As you all know, Jim and I got married in 1977, and, with my strong encouragement and hard work, Jim was elected to the House in 1978. We have two remarkable sons and we have never let my disability keep us from travelling the world and enjoying the ups and downs of a long career in politics.

Our oldest son Frank was diagnosed with attention deficit hyperactivity disorder as a young child, and we had our share of challenges finding the right school environment for a brilliant boy who needed a school that could provide the right combination of structure, mentoring, and challenging academic work. Frank did not take a traditional path, completing high school in Canada and earning a college degree in the U.K. Jim and I are so proud of what he has achieved personally and professionally, and I am delighted to tell you that Frank is on the verge of earning a Ph.D. in Finance from the University of Sydney. With the encouragement of Frank, I eventually got myself tested and learned that I too have attention deficit disorder. Our experience with Frank reminds us that the ADA provides protections and encouragement to millions of Americans who are charting their own course through the world of education and employment with their own unique learning style, often having to innovate a path that very few professional educators can help them figure out.

In sum, I can tell you that our country is a more welcoming place for people like me, my little sister Tara, and my son Frank thanks to the ADA. You see, the ADA starts with the recognition that disability is a natural part of the human experience. Any person at any time can encounter or acquire a disability. Some people are born with their disabilities, like Tara, Frank and me, in the case of the ADHD. Some acquire their disabilities through accident or injury, like I did when I acquired my physical disability after the car accident. Others encounter invisible disabilities through a bout with an illness. Some manifest their disabilities during their school years. Others acquire a disability as they age. And still others acquire disability while putting their lives on the line for our country, as we are reminded daily with each wave of returning soldiers from Iraq and Afghanistan.

Given that all kinds of disability can enter any person's life at any time, often without warning, the more accessible the society we create, and the more intact our system of legal protections, the greater benefit we all reap as a result. The ADA, then, is a law for all people. It was meant to ensure that whatever the circumstances may be that surround a person's encounter with disability, Americans are never to be treated unfairly, excluded unnecessarily, or relegated to second-class citizenship on the basis of disability without recourse.

III.

Despite all the progress since the passage of the ADA, sadly, we still have a long way to go before the ADA's inclusive vision becomes a reality in America. For instance, I am amazed at how routinely kind and well-educated individuals with whom I interact assume that I acquired my disability after marrying my husband Jim, by remarking how good it was of him to "stick by me" through that. The fact of the matter is Jim and I fell in love and got married during a time in which I was already disabled. You see, he "got me" in a wheelchair, or at best on Canadian crutches. As for my sister Tara, through the support of family, she graduated from high school, pursued college coursework, and has gone on to support herself through various jobs, which she has used to finance and insure her car and participate in numerous hobbies. And yet despite all her immediately apparent independence, Tara too still routinely runs up against paternalistic words and actions. She also continues to run up against a Supplemental Security Income program that creates perverse incentives for her to limit her work hours and not save too much money for fear of losing benefits.

In my travels with Jim on numerous Congressional delegations over the years, I have learned that it is very difficult to predict the reception that we will receive from foreign dignitaries when they learn that a member of the delegation has a mobility impairment and is using a wheelchair. To this day, we run into people who are disgusted and mortified when they learn of my disability. I remember on one trip our hosts were so concerned for my well being that they seemed tempted to follow me into the bathroom! And yet, for every bad experience, I can recount a positive one. I was pleasantly surprised by the extraordinary accessibility of Svalbard, a remote island off the coast of

Norway; and charmed by the ability of Japanese dignitaries to make it possible for me to visit ancient temples in my wheelchair while in Japan.

Although there are many obstacles yet to be removed for people with disabilities in the U.S. and globally, I believe the largest and most pervasive one to remain is that of attitude. The fears, myths, and stereotypes about people with disabilities from my youth are the same fears, myths, and stereotypes that I still hear of and encounter today, and they are the same fears, myths, and stereotypes that all too routinely result in people being shut out of employment and educational opportunities. There are still cultures around the world that see a disability as a curse on the family, and we still have millions of disabled people in the U.S. and globally whose lives are artificially limited by the confines and rules of life in a nursing home or other institutional setting. I believe that we all need to bear witness to the injustice and immorality of these ongoing human rights violations, and I commend you for having this hearing today to help remind us all that our country's work in implementing the letter and spirit of the ADA is not complete.

I have thoroughly enjoyed the work I have done as a volunteer with the American Association of People with Disabilities, and I especially enjoy each summer when I have an opportunity to get to know the college students who participate in AAPD's two summer internship programs. I want to share a story from the 2009 summer program to help illustrate some of the attitudinal challenges that are still with us today, notwithstanding almost two decades since the enactment of the ADA. During the Spring of 2009, AAPD's CEO and my good friend Andy Imparato was going from office to office working on securing placements for AAPD's eight Congressional interns. Andy has learned from experience that it is helpful to actually meet the intern coordinators in the offices to which our interns have a geographic connection, and to take the opportunity of the in-person meeting to try to answer any questions the intern coordinators might have about a potential candidate. One of our interns last summer was a stellar Gallaudet undergraduate who was deaf and required qualified sign language interpreters in order to have access to the full range of opportunities that would be available to typical summer Congressional interns. When Andy explained our candidate's need for interpreters to the intern coordinator of the House member who

represented the intern's permanent address, the intern coordinator said to Andy, "Excuse my ignorance, but what would a deaf person do in a Congressional office?"

This happened last year, not 25 years ago. As you all know, deaf people, when provided reasonable accommodations like interpreters, video relay, and real time captioning, are able to do what anyone else does in a Congressional office. The deaf woman I mentioned ended up having a life-altering positive experience working for Leader Hoyer, and he can certainly tell you what a deaf person can do in a Congressional office. So can Speaker Pelosi, whose counsel Mike Tecklenberg has a hearing disability. I tell this story not to pick on the intern coordinator who asked Andy the question, but to remind all of us that there is still a lot of ignorance about disabilities in the workplace, even in workplaces with well educated and public service oriented employees. How many people fail to make an offer of employment because they are afraid to ask questions that would help them learn about how to accommodate a worker with a disability?

IV.

While it is obvious that the ADA has acted as a great equalizer in a variety of contexts, it is equally apparent to me that the law's full potential has yet to be realized. The ADA, as Congress intended in its passage, creates an incentive, arising from a legal obligation, for all citizens to forge a better understanding and more proper perspective for accepting and integrating people with disabilities into all aspects of society, including the workforce. In order for that to occur and for the greatest barrier to all people with disabilities—fears, myths, and stereotypes—to be removed, we must continue down the path that we have begun with two decades of implementation of the ADA, and develop new methods to start to improve education and employment outcomes for this population.

The employment rate of people with disabilities has not improved during the two decades since the passage of the ADA. Two-thirds of individuals with disabilities who do not have a job say they want to have one but cannot find employment. Many of those who do find employment often experience discrimination along the way—in hiring,

requesting accommodations, or in unlawful terminations—on account of the same pervasive fears, myths, and stereotypes which characterized the past.

In my role with AAPD, I often think of our organization's summer Congressional and information technology interns with disabilities. I think of how gifted, capable, and sometimes eccentric they are—all so unique and all with such varied disabilities—and I wonder what kinds of artificial barriers lie ahead of them as they make their way into the working world.

My hope and expectation is that this Committee and your colleagues in federal, state and local government will take the opportunity afforded by the 20th anniversary of the ADA to begin a conversation with your own constituents—with the disabled people and their families who live in your districts. Ask them what barriers still exist that inhibit or prevent their full participation in society. Ask them what we can do to open wider the doors to employment, home ownership, and participation in the middle class. Ask them to get involved in your election campaigns and the day-to-day work of governing. And perhaps most importantly, when you find a person with a disability who has good ideas and a vision for how to continue down the course that we charted when we passed the ADA, take the next step and hire that person to work in your Congressional office. When the staff of this Committee and when your personal office staff truly reflects the diversity of your home districts, including representation from your citizens with disabilities, then you will have led by example and all of us will benefit from the insights that these staff will bring to the work of government.

Thank you for giving me the opportunity to provide my testimony this afternoon.