

Testimony on the Occasion of the 20th Anniversary of the Signing of the Americans with
Disabilities Act

By

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Chairman Nadler, Ranking Member Sensenbrenner, and members of the Subcommittee:
Thank you for the opportunity to join you today to reflect on the first two decades of implementation and enforcement of the Americans with Disabilities Act (ADA). As you know, next Monday we will celebrate the 20th anniversary of the signing into law of the ADA, a landmark civil rights law and a declaration of independence for some 50 million Americans with physical, sensory, psychiatric and intellectual disabilities.

Today I want to share with you some of my experiences and views, both personal and professional, as a long-time advocate for disability rights. In particular, I will focus on the role played in my life by the ADA, the most important civil rights legislation passed into law since the 1960s.

I.

Let me begin with a story. As some of you may know, on July 1, 1960, fifty years ago, our son Peter, then an infant only four months old, was involved in a terrible automobile accident that took the life of his mother, my first wife. For a considerable period of time thereafter Peter's very survival was in doubt. He had suffered multiple skull fractures and extensive brain damage that were to result in severe intellectual disability.

After six months of intensive hospital care under the loving supervision of the Sisters of Mercy in our home town of Pittsburgh, during which time he was actually baptized with tubes running in and out of his tiny body, Peter returned home just before Christmas and we began life anew.

After spending three years as a single parent to Peter and his two older brothers, I was blessed to meet Ginny Judson, a 23-year old schoolteacher, and we were married forty-six years

ago. In 1966, Ginny and I added a fourth son to our marriage. She has been a model mom to our family and now a super “Granny” to six wonderful grandchildren as well.

Inspired by Peter, Ginny became an effective advocate for people with disabilities at the local, state and national level, serving as President of our local ARC (now ACHIEVA) and as a member of the President’s Committee on Mental Retardation (now the President’s Committee on People with Intellectual Disabilities). She is today the Director of the Interfaith Initiative at the American Association of People with Disabilities here in Washington, helping religious congregations of all faiths to identify and remove barriers to worship for persons with all types of disabilities. But her most important advocacy was and is on behalf of our son Peter.

Peter Thornburgh today, although still very limited, lives semi-independently in a supervised apartment near Harrisburg, Pennsylvania. He works as a volunteer in the local food bank where, in his words, he “help[s] poor people.” He has his own circle of friends and is welcomed by his church and in many other community activities.

Peter turned 30 the year the ADA was signed into law and this year he turned 50. In the last six years, Peter achieved two significant milestones that I would like to share with you. In 2004, Peter was confirmed as a member of the Chestnut Grove United Methodist Church. The Rev. David Miller met with Peter five times to explain what church membership means and to help him write, in Peter's own words, his Confession of Faith. Standing in front of his congregation, Peter enunciated the following Confession of Faith: "My name is Peter Thornburgh. I am an American. I am happy in my church and I am happy to have Jesus in my heart."

More recently, in April of last year, Peter received the "Essence of Humanity Award" from the United Way of the Capital Region - Pennsylvania. He was nominated by the Ronald

McDonald House of Hershey. Peter has collected thousands upon thousands of aluminum pop tabs from friends and relatives across the nation which he then gives to the Ronald McDonald House to recycle for cash. The beginning of his award statement reads:

"Peter Thornburgh exemplifies the basic qualities we all should possess if we are to be fully human. When life presents a difficult road to follow, the way in which you travel it mirrors your inner strength and beauty. Peter has overcome enormous difficulties with determination, caring and a good-natured attitude."

What an inspiration Peter has been for all of us who have shared his journey!

What lessons have Ginny and I learned from these experiences with our son?

1. To focus on the abilities, not the disabilities, of all individuals.
2. To seek to maximize the opportunities for inclusion of persons with disabilities in the mainstream of our communities.
3. To embrace all such persons within family and community. This is something that works both ways. Our family has gained as much, if not more, from Peter as he has gained from us.
4. To recognize that disability is part of the very fabric of life, simply one more of life's challenges to be met. And certainly nothing of which to be ashamed.
5. To celebrate the work of those who train, educate and advocate for people with disabilities and of parents, family members and friends who partner in such efforts.

II.

As good fortune would have it, I have also been blessed with opportunities to apply these lessons in public life as well.

In 1978, I ran successfully for governor of Pennsylvania and served two four-year terms in that office. Peter, it turned out, was a fine campaigner and a frequent participant in official activities when I was elected. Our feeling was one of pride in his accomplishments, not of reluctance to share his shortcomings. Everyone in Pennsylvania knew that the governor had a son with a serious disability and this helped to give heart to many in similar situations across the state.

During the 1980s, when I served as governor, we put an emphasis on providing community-based services for children and adults with disabilities as an alternative to large and isolated institutional settings. We emphasized “mainstreaming” for all persons with disabilities. We promoted independent living and supported employment opportunities to help provide the dignity and financial independence that can only come from a job. And we created a respite-care program to provide some “breathing room” for devoted parents and other caregivers.

Later, when I served in Washington, D.C. as Attorney General of the United States in the cabinets of Presidents Reagan and George H. W. Bush, once again good fortune smiled upon me. One of my principal tasks for President Bush was to spearhead the effort to obtain congressional passage of the ADA. As you know, the law was designed to end discrimination against persons with disabilities and to remove barriers to:

- employment
- public services
- public accommodations

- transportation, and
- communications facilities

The ADA developed bi-partisan support in the congress under pressure from the disability community in cooperation with parents, professionals and providers who saw the need to extend the protection of civil rights laws to those with disabilities. The bill was not a “quota” bill, one designed to give special preference or “set-asides” to persons with disabilities, but was fashioned to empower them to participate in the mainstream of American life.

As I noted when I testified on behalf of the Bush Administration before this Committee on October 12, 1989, the ADA:

“is fair, balanced legislation. It ... ensure[s] that persons with disabilities in this country enjoy access to the mainstream of American life. It builds on an extensive body of statutes, case law, and regulations to avoid unnecessary confusion; it allows maximum flexibility for compliance; and it does not place undue burdens on Americans who must comply.”

I concluded that testimony with an observation in which I continue to believe, and that two decades of enforcement and implementation of the ADA have borne out:

“[P]ersons with disabilities are all too often not allowed to participate because of stereotypical notions held by others in society – notions that have, in large measure, been created by ignorance and maintained by fear.

It is precisely these sorts of antiquated attitudes that have blocked people with disabilities from entering the mainstream of American life. Certainly attitudinal changes cannot be simply commanded or even legislated out of existence. No particular court order or single piece of legislation can alone change longstanding perception or misperceptions; regrettably, attitudes can only be reshaped gradually. One of the keys to this reshaping process, however, is to increase contact between and among people with disabilities and their more able-bodied peers. And an essential component of that effort is the enactment of a comprehensive law that promotes the integration of people with disabilities into our communities, schools and workplaces.”

On July 26, 1990, the Americans with Disabilities Act was signed into law by President Bush on a glorious summer day in a ceremony held on the South Lawn of the White House. Some 3,000 persons, with and without disability, and their family members looked on and cheered and cheered as President Bush called to let “the shameful wall of exclusion finally come tumbling down.”

What has been the effect of the Act? Before its passage, despite heroic efforts by advocates, the country’s existing laws and social benefit programs had proved inadequate. Vast numbers of individuals with disabilities lived in isolation and dependence. People with disabilities couldn’t get a job, ride a city bus or go to a restaurant or county library. We as a society had failed to eliminate attitudinal, architectural and communication barriers. All of which imposed staggering economic and social costs on our country.

After twenty years of the ADA, we see significant changes. New designated parking spaces at the local convenience store. A ramp at the neighborhood movie theater. A sign language interpreter at public gatherings. Braille on the ATM machine or in the elevator at the local hotel. And, most of all, persons with disabilities gaining more access to community living and to employment, although clearly not yet in the numbers we would like to see. Employment, in particular, is problematical as there has been no net increase in the percentage of employed Americans with disabilities in the past twenty years.

The ADA has been good for people with disabilities but, more important, it has been good for America, helping to fulfill the promise inherent in our democratic ideals. And, best of all, according to a nationwide NOD/Harris survey, nearly nine out of ten American adults aware of the ADA approve of the Act.

Many challenges remain, to be sure. Too many Americans still fail to appreciate the essence of the discrimination that people with disabilities face in their daily lives. Many Americans still don't see barriers to full inclusion— whether based on architecture, or attitudes. Many Americans still remain trapped by society's stereotypes about disability. Many Americans still think the barriers faced by people with disabilities stem primarily from their disabilities – not from what we as a society have erected.

It is essential too that we better educate people with disabilities about their rights and help them develop an expectation of equal treatment. Until recently, many people with disabilities had no choice but to internalize the exclusion and unfair treatment they experienced. Discrimination and unreasonable barriers were things that people with disabilities had to accept.

This was doubly harmful. Not only were people with disabilities excluded from important societal activities, but they were also sent a message that such exclusion was legitimate and natural. Well, it isn't. You know it. I know it. And now all America is learning to know it. Discrimination and exclusion are morally wrong and it is important that we make sure that people with disabilities know it is wrong and know there is something they can do about it.

III.

Yes, progress is being made, but this is no time to rest on our laurels or to savor our accomplishments.

Important issues remain unresolved as the ADA has moved from public debate in legislative halls all the way to the United States Supreme Court. Increasingly, the Supreme Court has been called upon to decide a number of issues arising from passage of the ADA.

Many of these cases are fact specific, not surprising in view of the broad language of the Act, but many have involved important policy questions.

While the results have been mixed, a major reaffirmation of the rights of persons with psychiatric or intellectual disabilities to live in the community was forthcoming from the Justices in the 1999 *Olmstead* case, in which I was privileged to file a friend of the court brief. Justice Ruth Bader Ginsberg wrote the majority opinion which found unnecessary institutionalization to constitute discrimination based on disability under the ADA. Her opinion stated:

“[U]nder Title II of the ADA, States are required to provide community-based treatment for persons with mental disabilities when the State’s treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.”

While falling short of the ringing endorsement of community-based services that many of us hoped for, the Court did strike down arguments made by forces arrayed to keep in place that “shameful wall of exclusion” about which President Bush spoke. Efforts to gut the ADA provisions designed to promote the integration of persons with disabilities into the mainstream community were rejected by a 6 to 3 margin. The Court specifically refused to overturn a lower court decision obliging states, pursuant to the ADA, to provide programs and services “in the most integrated setting appropriate to the needs of . . . individuals with disabilities,” pursuant to regulations which I issued while serving as Attorney General.

All friends of the disability movement were pleased with this positive result, even though it left many “nuts and bolts” questions still unanswered as to the specifics of the right to receive services in the community.

Thereafter, other serious challenges were raised to the constitutional reach of the ADA. In *Garrett v. University of Alabama*, for example, the Court decided that states cannot be sued by their citizens for damages in the federal courts for violating Title I of the ADA, the part of the

Act that precludes public entities such as states, cities and towns, from discriminating against people with disabilities in the area of public employment. While fatal to only a small proportion of remedial actions in the courts, the *Garrett* decision definitely represented a step backwards and, in the view of many observers, relied upon a cramped reading of the intent of Congress in passing the ADA.

Those of us interested in disability rights took heart, on the other hand, from the Supreme Court's decision in *Lane v. Tennessee*, also a case in which I filed a friend of the court brief. There the Court refused to extend the reasoning in the *Garrett* case to claims under Title II of the ADA addressing access to government services, at least insofar as access to court houses is concerned.

And remedial legislative action has been undertaken, most notably in the ADA Amendments Act of 2009, to cure some of the anomalies arising from adverse court decisions in the field of employment law. The Help America Vote Act also contained specific provisions designed to fully empower Americans with disabilities to exercise that most precious of all rights in a free society – the right to vote.

Needless to say, a raft of other issues await determination in our courts as the legal parameters of the ADA become more fully developed. And we still await the full effects of the recently-passed congressional reforms in our health care system. This legislation expanded Medicaid eligibility and, as a result, many states are already proposing draconian cuts to their state Medicaid expenditures. The fact that all Medicaid home and community-based services are optional makes them particularly vulnerable to being cut as states begin to further tighten their budgets. The effect of such action on *Olmstead* initiatives could be devastating.

Finally, I cannot help but note the need for our United States Senate to promptly ratify the United Nations Convention on the Rights of Persons with Disabilities which would help to extend the principles of the ADA to those estimated 650 million people with disabilities around the world who lack any such protection today

In closing, I must tell you that, when I look back upon all that has been accomplished through the passage of the ADA, IDEA and other laws dating all the way back to Section 504 of the Rehabilitation Act of 1973, I quickly come to realize that none of these statutes were on the books in 1960 when our beloved son Peter was so seriously injured. It is only during his lifetime that we have taken these giant steps forward.

On behalf of all the Peter Thornburghs of our nation and this world and their families and loved ones, I extend to you our heartfelt thanks for your willingness to fight for their dignity and respect. We wish you Godspeed in further endeavors as we pay tribute to this landmark effort to empower all people to live as they choose in their communities. What a magnificent way to celebrate the 20th anniversary of the ADA!