

President George H. W. Bush signs the Americans with Disabilities Act of 1990 into law on the South Lawn of the White House on July 26, 1990. Pictured (left to right): Evan Kemp, Rev. Harold Wilke, President Bush, Sandra Parrino and Justin Dart.

# The Impact of the ADA in American Communities

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July 23, 2015

Issued in celebration of the 25th Anniversary of the Americans with Disabilities Act





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#### PROLOGUE



Crowd of more than 3,000 gathering at the South Lawn of the White House on July 26, 1990.

There was a time, just 25 years ago, that is unimaginable to most people today. A time where individuals with disabilities were objects of unwanted pity and rejection—they were restricted to either their homes or beds in institutions because the outside world was inaccessible and not made with them in mind.

Imagine approaching but not being able to get into office buildings, schools, shopping centers, banks, pharmacies, theatres and restaurants. Imagine having no right to use public transportation or to enter the courthouse. Imagine a school denying you admission after you had met all the entrance qualifications and paid your tuition. Imagine a day when an employer could take one look at you and deny you employment without considering your qualifications.

Imagine the realities faced by more than 50 million Americans with disabilities before the ADA.

#### INTRODUCTION

On July 26, 2015, millions of people with disabilities, their family members and friends will celebrate the 25th anniversary of the signing of the Americans with Disabilities Act (ADA) of 1990. Americans with disabilities are joyful about their achievements and those of their communities during the past 25 years. They also are well aware of the opportunities yet to be realized and the challenges yet to be overcome.

When it was enacted, the ADA promised people with disabilities equal opportunity, nondiscrimination, and a "level playing field." President George H.W. Bush likened enactment of the law to the fall of the Berlin Wall. He said, "And now I sign legislation which takes a sledgehammer to another wall, one which has for too many generations separated Americans with disabilities from the freedom they could glimpse, but not grasp. Once again, we rejoice as this barrier falls proclaiming together we will not accept, we will not excuse, we will not tolerate discrimination in America."<sup>1</sup>

The report which follows indicates that – from the perspective of those for whom the law was intended to have the greatest impact – many expectations have been achieved; some would even say the impact of the ADA has exceeded their expectations. However, the report also indicates certain unevenness in implementation, and it highlights a number of areas where change for the better has been slow or even delayed. Perhaps most importantly, the report denotes areas where more work is needed to fully implement the ADA and to enable individuals with disabilities to reach their goals of independence, self-determination and full participation in society.

The original data referenced in this report was obtained through a nonscientific survey of 725 disability community leaders and advocates. The individuals who participated in the survey represent more than 600 communities across all 50 states and three of the five U.S. territories (no responses were received from Guam and Northern Mariana Islands territories). Those surveyed include men and women representing a broad range of disabilities, ages and occupations.

#### **SURVEY HIGHLIGHTS**

More than two-thirds of individuals with disabilities who were polled in the study believe the ADA has been the most significant social, cultural or legislative influence on their lives in the past 25 years. Survey respondents backed up their beliefs with the following personal observations:

"Public transportation is not allowed to charge more for the paratransit bus than it does for the regular bus. I became legally blind after 22 years of teaching in my district. I do not believe I would have been allowed to continue teaching without the ADA. Nor do I think I would have been given accommodations to help me." "As a parent who uses a wheelchair, and has two children (now eight and 10) who have mobility impairments, the ADA's impact on 'simple things' like accessible restrooms and accessible diaper changing stations has made all the difference in my family's successful inclusion in our community."

"I am able to work, volunteer at my son's school, and receive help from government agencies because of the ADA. Most importantly, I am able to be a vibrant part of the community because of the ADA, which has a big impact on people with and without disabilities."

"The ADA has helped people gain access to public accommodations with attention to things like curb ramps, accessible parking, buses with lifts and ramps, etc.—making media more accessible with closed captioning and relay services."

**The ADA's greatest impact has been improvements in access to public accommodations.** Of respondents, 57 percent agree access to public accommodations, retail and commercial establishments has shown the greatest improvement since passage of the ADA.



Beach wheelchairs at Grommet Island Park, an accessible oceanfront playground in Virginia Beach, Virginia.

For many, access to shops, stores, restaurants, theaters, hotels and other public places defines community integration, inclusion and full participation. Some respondents opined that having better access to retail establishments enables individuals with disabilities to be more fully engaged in commerce – thereby justifying expenses associated with required accessibility improvements – and generally improving the economy for everyone.

It also was suggested that by enabling individuals with disabilities to be more actively engaged in the ubiquitous retail economy, the ADA is helping to improve both the self-esteem of individuals with disabilities, and how they are perceived by others:

"Access to government buildings: before the ADA our county courthouse was not accessible."

"The ADA has resulted in more people with disabilities be visible in the community. Schools, travel, public access, restaurants, etc. More places than not provide accommodations now whether they like to do it or not."

"I am a guide dog user and the ADA has made it possible for me to enter most public spaces without encountering discriminatory behavior. When I do encounter discriminatory behavior, I feel comfortable in voicing my rights since I know that the ADA protects my access rights when I am working with my guide dog."

"[Because of the ADA] children with disabilities are now able to access their school and neighborhood playgrounds."

Other areas of significant agreement regarding improvement include access to transportation, access to independent and community living, and public awareness about the ADA and disability etiquette. More modest improvements are indicated in the areas of education, employment, education, access to government services, recreation, telecommunications and healthcare.

Many respondents described remarkable improvements in public transportation for people with mobility impairments since passage of the ADA:

"I am a C4-5 spinal cord injury, tetraplegia and the greatest change in my lifetime has been the provision of accessible transportation. Providing lifts on buses has made it possible for me to go to work and to travel by myself!"

"Accessible transportation in my small community has allowed people with disabilities to be independent, too!" "Local bus transportation is accessible and it has resulted in greater inclusion and visibility of people with disabilities in shopping malls, movie theaters, etc."

Eighty-four percent of respondents believe the quality of life for individuals with disabilities in U.S. communities has improved greatly since passage of the ADA.

The biggest disappointment among the disability leaders surveyed remains the lack of progress by individuals with disabilities toward reaching goals of economic independence vis-a-vis equal employment opportunities. There seems to be a sense that while general quality of life has been improved by the ADA, difficulties obtaining employment and ever increasing expenses have prevented most individuals with disabilities from raising their standard of living. Although there has been significant improvement in employment rates, retention and workplace accommodations for individuals with disabilities since 1990, there continues to be large disparities between Americans with disabilities and without, as evidenced by the employment rates of 17.6 percent and 64 percent, respectively.<sup>2</sup>

Respondents also were disappointed in the impact of the ADA on healthcare, housing and recreational facilities for individuals with disabilities:

"The ADA has made it possible for people with disabilities to maintain a job without discrimination. Still have a long way to go but it is better."

"I have been legally blind since 2007 after a long and continuous struggle with Glaucoma. I lost the job I held for 20 years. I went from being a very busy community activist to being afraid to leave my house. I became isolated and depressed. Because of the ADA, I was able to use the local paratransit system to attend school. That led to me graduating with honors, and then obtaining an internship and job at a non-profit that helps people with vision and hearing loss. I've been working here for five years and counting— paying forward what was offered to me."

"The ADA has changed lives in terms of employment and seeking accommodations. Before the ADA, if you became disabled while you were employed, there were very little options beyond being let go from your job. Thanks to the ADA, employers now need to engage in the process with employees to see if accommodations can be provided. This has helped tremendously also in terms of changing perceptions; people with disabilities *can* be gainfully employed and *can* contribute just like everyone else." "My son who has multiple disabilities is able to receive door to door transportation to enable him to go to post-secondary education and have a job."

"I'm able to do my job as an attorney because I can generally count on accessible parking, on accessible shuttles, busses and cabs when I travel."

"I don't have to 'fight' to obtain the equipment I need to keep my job."

The extraordinary importance of employment in the estimation of disability leaders is even more apparent when questions are asked about the areas in which the ADA is likely to have the most impact in the next 10 years, and areas where efforts need to be made in addition to the ADA. In both cases, employment is ranked highest.

Like employment, respondents indicated that access to healthcare and accessible housing are areas in which ADA implementation efforts going forward could be expected to have a greater impact, and where efforts above and beyond the ADA may be required to sufficiently address the issues (Figure 1).



Figure 1. Distribution of 2015 Survey Respondents' Perspective on Greatest Expected Impact from the ADA in the Next 10 Years, by Area of Impact Advocates are hopeful full implementation of the Affordable Care Act (ACA) of 2010, along with continued and enhanced implementation of the ADA, may help to improve access to and availability of needed healthcare services, long-term services and supports, medical equipment, and technical aids in the next decade. Community and independent living also ranked highly alongside healthcare and housing as areas where the ADA is expected to have the greatest impact in the next 10 years.

Some respondents contend the Supreme Court's *Olmstead* decision<sup>3</sup> is as important as the ADA as a vehicle for equality, justice and social change. The *Olmstead* decision affirmed the ADA's prohibition of the unnecessary institutionalization of individuals with disabilities and that states must provide services in the most integrated setting possible. States must provide community-based options for institutionalized individuals who wish to live in the community and who are capable of doing so.

Respondents offered many examples of ways *Olmstead* is being implemented. They also provided numerous examples suggesting increasing momentum for the deinstitutionalization of individuals with disabilities from both large state institutions and smaller private nursing homes.

Many respondents described specific efforts to **transition** people from institutions into the community, and to **prevent** those who are at risk of placement in such institutions from being moved out of the community into nursing facilities:

"Olmstead litigation helped to spur people to leave institutions."

"I believe the *Olmstead* decision is the most important thing to come out of the ADA, allowing for community integration and deinstitutionalization."

"[The] *Olmstead* case has improved [housing] choices, but unfortunately there is not a lot of affordable housing available."

Survey respondents were eager to enumerate ways that they and their organizations have worked to help implement the ADA. Chief amongst efforts by the disability community are:

- Educating employers and providing training for them about the ADA
- Conducting workshops and providing training about the ADA for school administrators, transportation providers and government agencies
- Serving as consultants to government agencies and employers
- Providing disability awareness training for businesses
- Informing individuals with disabilities about their rights under the ADA

#### **MULTIVARIATE ANALYSIS**

Considering other variables when looking at this survey data is important so as to gain a comprehensive perspective on what the data represent and also to reveal underlying trends. The variables under consideration for this analysis include the age of the survey respondents, the types of communities they reside in, their disability status and their role in the community.

When asked "How would you classify the community in which you live?," approximately 71 percent of survey respondents selected Urban and 29 percent selected Rural communities. The answer respondents gave to this question contextualized the answers that were given throughout the survey for these urban and rural sample population sets.

As expected, those who lived in rural communities had a greater tendency to say the ADA has had a modest or very limited impact on the way they live in their communities, compared to the respondents from urban areas due to the more conservative ideological and political values of rural community leaders.

Although there were complaints and suggestions for improvement of implementation from respondents in urban areas, they were outnumbered in both quantity and severity by respondents from rural areas, as depicted well by this respondent: "Living in a small town, changes are slow. We have public schools in rural areas of Oklahoma that outright refuse to accommodate students with certain disabilities, including autism and other cognitive disabilities." In the coming years, great improvements in terms of progress and impact are projected for rural communities, as increasing social and political pressure, particularly the aging population demographic, will encourage community leaders to seek and enact change.

The age variable becomes important when considering ADA impact because different age demographics have a higher demand for impact of different areas of the ADA. Figure 2 shows the majority of survey respondents are of middle age; this working-age demographic is reflective of why the ADA's impact on employment was the most consistently commented on with regard to noted improvements and also concerns in workplace discrimination, accommodations and retention of workers with disabilities.



#### Figure 2. Distribution of 2015 Survey Respondents, by Age Group (in Years)

Growing up in post-ADA America, individuals with disabilities in the Under 30 age group of respondents' comments was a testament to how the law has made education accessible for individuals with disabilities in terms of opportunities for government-subsidized scholarships, non-discrimination and reasonable accommodations.



Crowd gathering at Upper Senate Park, Washington, D.C. (July 23, 2014).

Of the survey respondents, 31 percent are at or above retirement age, hence why the proportion of people who tailored their responses with a focus on independent living services also was high—their strong desire to remain a part of the community and avoid institutionalization was apparent in their comments.

The number of respondents who selected Student as their role in the community was 10 percent, which is approximately twice the number of respondents who reported being under the age of 30. This suggests that many more mature, older adults with disabilities are wanting, willing and now able to access schools and build on their education; because for those who were growing up before the ADA, equal opportunities for obtaining education at secondary and post-secondary levels were unavailable at the time.

Another possible reason for more mature, older students – besides just being now able to – is because today's workforce demands skilled employees and individuals with disabilities, in particular, must have these skills and often a college degree in order to be considered for

employment, particularly for jobs that allow for upward mobility. Survey respondents' disability status is another variable worth considering. Of the 725 people who took the ADA impact survey, 194 (27 percent) had no disability themselves, but were perhaps commenting on their observations of how the ADA has impacted the lives of a child, family member, colleague or friend with a disability, or the disability community as a whole.

The response from disability advocates without a disability themselves mirrored the responses of individuals with disabilities, showing how their answers and comments were reflective of observations of the treatment of individuals with disabilities in different aspects of community life. For example, greatly improved accessibility of public transportation (compared to 25 years ago) has been witnessed by members of communities with and without a disability.

The only obvious difference in responses between these two disability status subsets was in response to the question, "In the last 25 years, has any cultural, social or legislative change affected your life more than the ADA?" Far more respondents with disabilities than without answered "yes," as the ADA directly applies to their everyday lives.

#### **NOW AND THEN**



Individuals participating in a march for disability inclusion.

The survey results highlighted in this report reflect the second collected data set part of a longitudinal study seeking to pin-point areas of society which have seen marked improvement in terms of ADA compliance and also, perhaps more importantly, areas that need further

improvement. The first set of data collected for the ADA impact study was in 2010 when this same nonscientific survey was conducted, and the results of that survey were released on the 20th anniversary of the ADA. A comparison of this year's survey results with the results of the same survey conducted five years ago in 2010 shows mostly negligible or modest differences.

Figure 3 shows the results of both data sets with regard to the most significant areas of contribution the ADA has made. It can be seen that Access to Healthcare is the only real improvement in terms of ADA impact on American communities between 2010 and 2015, according to the surveys. Specifically, it shows how access to healthcare has increased two-fold from 5 percent in 2010 to 10 percent in 2015; this observation likely can be accounted for by the ACA, which has taken a few years since 2010 for full implementation (largely occurring in 2014).

It is expected that access to healthcare will be an aspect of society that will continue to follow this upward trend and increase over the coming years for individuals with disabilities. The slight decreases in most other aspects of positive ADA impact on U.S. communities since 2010 are likely due to the different and slightly smaller sample population of survey respondents in 2015 as well as a number of other things, such as the changed economic and political climate.

Figure 3. Distribution of 2010 and 2015 Survey Respondents' Perspective on Greatest Impact from the ADA, by Area of Impact



Figure 4 (on the following page) represents areas respondents indicated as experiencing the least ADA impact in American society. As expected, this graph's results are reciprocal to those

represented in Figure 3; for example, Access to Public Accommodations has the largest bars represented for areas of greatest impact, but the smallest bars for areas of least impact. It also shows negligible or modest differences between 2010 and 2015 data. Of the three areas of major concern regarding limited impact (Equal Employment Opportunities, Access to Healthcare, and Access to Housing), an encouraging trend can be observed whereby a slightly smaller proportion of survey respondents in 2015 indicated these areas may not be as prominent as they were in 2010. It remains evident Americans believe there is a great need for improved ADA implementation within these areas for individuals with disabilities.

Figure 4. Distribution of 2010 and 2015 Survey Respondents' Perspective on Least Impact from the ADA, by Area of Impact



#### THE WAY FORWARD

The loudest message voiced by survey respondents is a call for action to implement those provisions of the ADA requiring equal opportunity in employment, access to healthcare, accessible housing and alternatives to institutionalization.

#### 1. Eliminate Work Disincentives for Individuals with Disabilities

In a nation where citizens are often defined by the work they do, and where we depend on employment to generate income to support our lifestyles and to pay our taxes, individuals with disabilities must have the opportunity to work. Figures vary, but most studies indicate that half or more of working age adults with disabilities seeking employment are unable to find work.

Economists argue about the reasons for such a high unemployment rate among individuals with disabilities, but everyone seems to agree that more aggressive action must be taken to provide employment opportunities for this population. One dynamic issue in particular requires further discussion, and that is the issue of disincentives.

For years, individuals with disabilities have asserted the challenge of attaining both work, particularly with entry-level wages, and needed benefits, such as health insurance, home care and housing assistance would be sacrificed. Various efforts have been made to minimize the impact of the so called benefit cliff, but none of them seem to have worked.<sup>4</sup> Perhaps it is time to enable individuals with disabilities to work while continuing to receive vital benefits.

Eliminating the fear of benefit loss among prospective workers with disabilities, while enabling them to raise their standard of living and begin paying taxes seems like a win-win solution.

#### 2. Fully Implement Healthcare Reform, Ensure Access to Preventive Care and Provide Needed Technical Aids and Durable Medical Equipment

The need for improved access to healthcare by individuals with disabilities is also one of long standing; however, the ACA offers the promise of solutions to some of the most critical issues facing individuals with disabilities who require healthcare.

Eliminating preexisting condition clauses from health insurance plans has enabled individuals with disabilities to purchase health insurance and to participate in employer-sponsored group health insurance plans. This may help resolve many health-related issues facing individuals with disabilities who are employed.

Better access to health insurance for people who are not employed will also benefit large numbers of individuals with disabilities whose healthcare options are now complicated by Medicaid waiver rules, which vary from state to state. By having insurance, people who before depended upon emergency rooms for routine healthcare can make appointments at clinics and doctors' offices, and otherwise access healthcare through more normal routes.

Community-based care significantly lowers costs for routine care by shifting that care from the emergency room to the community. It also is more likely to foster preventative measures and early intervention, thereby reducing the number of hospital admissions and the need for more costly acute care.

Timely provision of appropriate technical aids and durable medical equipment is also needed if individuals with disabilities are to function as independently as possible. Due to current Medicare, Medicaid and private insurance restrictions, assistive devices often are not covered benefits for people who need them in order to practice self-care.<sup>5</sup>

By restricting the provision of assistive devices and other technology which program administrators seem to consider too expensive, many individuals are forced to be entirely dependent upon relatively more costly and sometimes difficult-to-obtain human care. In addition, delays associated with extended review and approval processes for such equipment often result in expensive-to-resolve physical breakdowns and medical complications.

#### 3. Build Community-based Systems to Support Independent Living and Enable Older Adults and Individuals with Disabilities to Age in Their Communities

Independent living means making decisions which affect your own life. For most people, it also means living in the community and participating in family and community activities. For many with disabilities and older adults, independent living poses significant challenges related to housing and assistance with activities of daily living.

Housing options are limited for individuals with disabilities and older adults, particularly for those who are struggling to maintain their independence despite low incomes. When people are unemployed or seeking employment, or when they are retired, they face resource limitations which naturally limit their housing options. Even for people who own their own homes, property tax increases, inflation and retirement fund dynamics may threaten their ability to age in the community or setting of their choice.

For people who require assistance with activities of daily living or personal care assistance in their homes, finding qualified individuals to help can be very challenging, and having the resources to compensate them even more so. Because needed in-home assistance is either too hard to find or too expensive to pay for, because family members are not always available to help, and because housing is difficult to maintain, people with chronic, daily health-related needs often find themselves in intermediate care facilities or nursing homes.



Members of the National Advisory Board on Improving Health Care Services for Seniors and People with Disabilities meet in Washington, D.C. to discuss community-based systems for promoting independent living (2012).

Of course, most people do not wish to live in an institution or facility, but for individuals with disabilities, young or older, options for integrated, community living are few and far between. In a few communities, integrated housing and service demonstrations have proven to be quite successful. The On Loc program in San Francisco is a highly regarded example of a community-based program that provides assistance with housing and home care.<sup>6</sup> Program participants, even those on limited incomes and with limited resources, live in a fully integrated, community setting, outside of institutions and nursing homes, and they receive all the daily assistance and care they require in order to be independent.

Given the impending needs of approximately 79 million Baby Boomers whom eventually will face the same challenges with housing and home care that individuals with disabilities and older adults face today, it is imperative creative solutions are developed and instituted to support community-based independent living and to enable older adults to age in the community.

### CONCLUSION

While disability leaders passionately agree the ADA has had a significant impact on their lives and on the communities in which they live, they equally agree that work remains to be done if we are to reach our goals of equal opportunity, full participation, community integration and inclusion.

Improvements in access to public accommodations, transportation and public awareness are consistently acknowledged, but the need for further compliance is evident. Other areas where improvements are recognized, but where even more work remains to be done include education, telecommunications, recreation and government services.

Concerted efforts are required to address significant compliance gaps and unresolved barriers to full participation and equal opportunity for individuals with disabilities. Creative new solutions and aggressive action are required to address complex issues related to employment, healthcare, independent living, housing and deinstitutionalization.

The many ways in which individuals with disabilities themselves are working to improve their communities and to assist covered entities with ADA compliance provides manifest demonstration of both the practical and symbolic importance of the act. In his July 26, 1990 remarks, President Bush said: "This act is powerful in its simplicity. It will ensure that individuals with disabilities are given the basic guarantees for which they have worked so long and so hard: independence, freedom of choice, control of their lives, the opportunity to blend fully and equally into the rich mosaic of the American mainstream."

By embracing the law and investing themselves in its full implementation, individuals with disabilities are securing their own future and offering the promise of full participation, independent living and equal rights to future generations.

#### EPILOGUE



Pictured (left to right): Joy and Lex Frieden, South Lawn of the White House, viewing the signing of the ADA (July 26, 1990).

On the morning of July 26, 1990, I sat on the White House lawn with more than 3,000 other advocates. The air was fresh and the sun was bright and hot. As the Marine Band played and while we waited for the president to take his place onstage, I recall wondering if the patriots of the American Revolution and composers of the Bill of Rights, visionary as they were, could possibly have imagined it would take 194 years and three weeks for Americans with disabilities to have our rights confirmed.

I also remember thinking about all the provisions that people had made in the past to accommodate me, despite my disability and without the mandate which was soon to be enacted. I reflected on the many opportunities life already had afforded me, and I wondered how things might or might not be improved by this new law.

I recalled my first journey away from the hospital after my neck was broken. I remembered my mother pushing my wheelchair from one restaurant to the next, without being able to get over the curb or up the steps into any of them. I remembered the dismay I felt when my school-mates took me to the movies and there was no place for me to sit. And, I remembered my disbelief when the university's dean of admissions told me I would not be admitted because I had a disability.

And then my thoughts were interrupted by the melodious "Hail to the Chief," and shortly thereafter decades upon decades of citizenship without equality were ended. With a few well-conceived words and the stroke of a pen, years of efforts by countless advocates were rewarded by an act of law forbidding discrimination on the basis of disability and providing equal opportunity for millions of Americans with disabilities.

Now, 25 years later, my thoughts return to the question of how things might or might not be improved by this new law. Having had the opportunity to solicit and gain perspective on this question from more than 700 of my colleagues from cities and towns across America, I can say without question the ADA has had a powerful influence on our lives.



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Frieden convenes the National Advisory Board (NAB) on Improving Health Care Services for Seniors and People with Disabilities. The NAB partners with Anthem to provide guidance and policy recommendations – both to Anthem and the broader healthcare industry – for improving programs and services for older adults and individuals with disabilities.

A graduate of Tulsa University, Frieden has been honored as a Distinguished Alumnus. He holds a master's degree in social psychology from the University of Houston where he completed doctoral requirements in rehabilitation psychology. In 2004, he was awarded an honorary doctorate in law (LL.D.) by the National University of Ireland.



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Editorial and methodological contributions to the survey and to the report were made by Diego Demaya, Marj Elhardt, Edward H.J. Elms, Joy Hammel, Jean Herzog, Kathleen Murphy, Vinh Nguyen, Laurie Redd, Yasmin R. Tuchaai, Wendy Wilkinson and Claire Wulf Winiarek. The author also wishes to acknowledge the contributions and support of TIRR Memorial Hermann, the University of Texas Health Science Center at Houston, and Anthem Inc.

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