

# The Disability Rights Movement —The ADA Today



Karen Knabel  
Jackson navigates  
Washington  
DC's Metro.

by Katherine Shaw

If you're over 30, you probably remember a time in the not-too-distant past when a curb cut was unusual, there were no beeping sounds at crosswalks on busy city street corners, no Braille at ATM machines, no handicapped-accessible bathroom stalls at the airport, few if any ramps anywhere, and automatic doors were common only in grocery stores.

Today, thanks in large part to the Americans with Disabilities Act (ADA), which was signed into law in 1990, these things are part of our architectural

ADA legislation brought amazing changes to the nation, but more needs to be done to level the playing fields for citizens with disabilities.

landscape—expected, understood, and fostering independence, access and self-sufficiency for people with a wide range of disabilities.

Yet, with all of these advances, court decisions and inconsistent policies have eroded the intention of the ADA, lessening protections for people with disabilities. As a result, the ADA Restoration Act of 2007 (H.R. 3195/S. 1881) was introduced last year to restore and clarify the original intent of the legislation. Hearings have been held in both the House and Senate and the bill is expected to pass in 2008.

Here's how the ADA works or doesn't work for some people with MS today.

### A no-win situation

Pat had a successful career as a nursing home administrator in the Chicago area. She was diagnosed with relapsing-remitting MS 15 years ago, but until very recently had no visible symptoms. Now, however, looking for a job has become a nightmarish and very predictable cycle. "I've had literally dozens of terrific phone interviews," she explained, "but once I meet face-to-face and it's noted that my gait is impaired, the interview is over in a matter of minutes."

The first time Pat was asked, "Why do you walk that way?" she sought legal counsel. She was told that, by law, she was not required to respond. The ADA provides protections against these kinds of questions. In practice this puts a job candidate in a difficult position.

"If I don't answer the question, it's an immediate red flag," Pat related. "If I explain that the ADA doesn't allow that kind of question, it's clear I'm hiding something. There are no good options."

Pat has tried being completely open about her MS during interviews. The results were concerns about the potential for extended absences and/or her running up the employer's insurance costs. Now 18 months without employment, Pat is applying for SSDI benefits. She may not get them because she is, in fact, able to work.

### A little resistance, a little persuasion

For John Bromell, pushing for ADA compliance had a positive outcome. He petitioned the Missouri Bar Association for additional time to take his bar exam. He was initially rejected, but "the ADA provided me with the leverage I needed," he said. John sent the committee letters from his physician documenting his condition. He also sent excerpts from medical journals explaining how the bar exam environment

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# Creating a Movement:

## The First 18 Years of the ADA

by Richard Meneghella and Helen Russon

"Let the shameful wall of exclusion finally come tumbling down!" That's what former President George H.W. Bush proclaimed on July 26, 1990, when he signed the **Americans with Disabilities Act (ADA)** into law. This triumphant moment, shared with over 3,000 supporters on the South Lawn of the White House, had been a long time coming. It was the result of people with disabilities organizing, lobbying, demonstrating and even occasionally getting arrested.

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How our disability rights heroes did it.



President George H.W. Bush (center) signs the Americans with Disabilities Act. Seated: Justin Dart, chairman of the President's Committee on Employment of People with Disabilities (right) and Evan Kemp, chairman, Equal Employment Opportunity Commission (left). Standing: the Reverend Harold Wilke (left) and Sandra Swift Parrino, chairperson, National Council on Disability (right).

GEORGE BUSH PRESIDENTIAL LIBRARY AND MUSEUM

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could impact his condition. As a result, accommodations were made and John passed the exam.

### A win-win situation

A few years later, John ran into another compliance issue. He and a friend decided to go to the movies, but as it turned out, the movie they wanted to see was on the second level of the multiplex and there was no ramp and no elevator. John noticed that certain movie titles were tagged **Not Wheelchair Accessible** on the lobby bulletin boards. “This isn’t possible! It’s like not allowing African Americans,” he told the box office employee. The manager was called, who eventually connected John to the chain’s corporate vice president.

“I didn’t want to be overly litigious, or have the theatre incur a lot of expense for retrofits. I just wanted to be sure everyone could see every film,” John recalled. The result was a win-win. The chain instituted a policy where all films shown on the second level would be rotated and shown on the first level as well.

### A nudge towards compliance

Certainly ADA compliance is linked to training and education—and to persuasion and protest. This was the case for Sharon, who visited the Smithsonian Institute in Washington, DC, from her home in Pennsylvania. As she entered the museum on her Segway she was told that she would not be allowed to bring it inside. “Because the Segway is relatively new, I’m careful to attach my handicap placard so it’s not confused with a recreational vehicle,” Sharon said.

Nevertheless, the Smithsonian staff wouldn’t budge. She was offered a manual wheelchair. Because her MS has compromised her arm strength, she was not able to operate it. Her husband, who had accompanied her, pushed it, saving the day from total loss even though Sharon much prefers the eye-level view provided by her Segway. But fundamentally, the compromise felt all wrong.

“When I got home, I decided to make a few phone calls,” Sharon recalled. She contacted the Department of Justice. Results came in time: a letter of apology from the Smithsonian. The letter explained that the Segway is allowed—and has been since 2005. It also explained that the museum was in the process of reiterating this policy to staff, and would add it to the training for all new employees.

### Walking a mile in someone else’s ... wheelchair

The Dallas Chapter of the American Institute of Architects has held three accessibility awareness workshops, providing their members with the opportunity to spend a day in a wheelchair. The brainchild of Walter

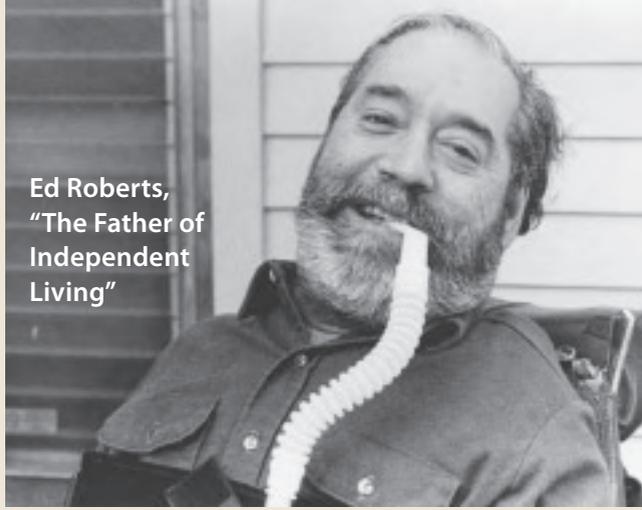
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More adaptations that keep Karen on the move include automatic push-button doors and extra-wide turnstiles.

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Ed Roberts,  
"The Father of  
Independent  
Living"



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In his book, **No Pity: People with Disabilities Forging a New Civil Rights Movement**, Joseph P. Shapiro describes a scene the National MS Society faced in 1988: The recipient of our "Man of the Year" award was essentially marooned. He could not travel in his wheelchair across the street to the hotel where he was to receive the award because there were no curb cuts. Ultimately, the Society had to rent a van with a hydraulic lift to help the honoree simply get to the other side of the street.

Unlike other minority groups, anyone can enter the ranks of the disabled in an instant. And the longer we live, the more likely we are to do so. The latest estimates put the number of Americans with disabilities at approximately 54 million, or some 20% of our population. But unlike many other minorities, members of this group are often hard to see. Disabilities may be invisible or may keep people out of public view.

People with disabilities had to create a civil rights movement in order to achieve visibility and legal standing. As in all other such movements, certain individuals blazed the trail.

### **Ed Roberts, the Rolling Quads and the Independent Living Movement**

Ed Roberts contracted polio when he was 14 and needed 18 hours every day in an iron lung. When he was refused admission to the University of California, Berkeley, in 1962, he took his case to the newspapers. The university reluctantly reversed itself.

Since the traditional college dormitory couldn't house his iron lung, a supportive counselor made

arrangements for him to live in a wing of the university hospital. Other students with disabilities soon joined him and they formed a tight-knit group known as "the Rolling Quads." Soon the group evolved into a support network for many other students with disabilities. When Roberts graduated, he expanded the effort and organized the nation's first Center for Independent Living. Today there are over 400 Independent Living Centers in the United States, run by and for people with disabilities.

### **Section 504: The 25-day sit-in**

The Bay area was the site of other noteworthy events in the movement. One of the most dramatic was a 25-day sit-in at the San Francisco Office of HEW (the now-defunct Department of Health, Education and Welfare).

In 1973, Congress passed Sec. 504 of the Rehabilitation Act. This law, a progenitor of the ADA, prohibits entities that receive federal funds from discriminating based on disability. But after the law was passed, the Carter administration delayed and attempted to weaken the regulations necessary for the legal protections to take effect.

The disability community resorted to a common tool of the time: they organized sit-ins at HEW offices throughout the country. Most demonstrators left after a few hours or days, but those occupying the San Francisco office stayed for an astonishing 25 days. It was astonishing because some of the participants were putting their health at risk by going for that long without their usual medical regimens. Finally, HEW Secretary Joseph Califano signed the regulations, and Sec. 504 became law.

### **On to the ADA**

Energized by the victory, the disability rights community took their message to Washington, DC. What they said was simple: As people with disabilities, we have been considered sick, pitiful and in need of protection. The fact is that many of us

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Kilroy, AIA, this innovative project fits wheelchairs to participants, who then go through their daily routines. They discover firsthand the challenges of going through glass doors, navigating a cross slope and accomplishing “simple” tasks such as making coffee.

“Our goal wasn’t to verify the requirements that we all know, but rather to discover what small adjustments in our designs might make a big difference in accessibility,” Kilroy explained. He chairs the Dallas Legacy Committee, which sponsors these events.

Following their day in a wheelchair, participants write up their observations and send them to Kilroy. He then uses these observations to create displays for the Texas Society of Architects’ annual convention. The idea seems to be taking off. The “day in a wheelchair” event is now being offered at other AIA chapters.

## The ADA in a nutshell

The Americans with Disabilities Act of 1990, or ADA, has four major components: **Title I**, which applies to employment; **Title II**, applying to state and local government facilities, including government-run transportation such as Amtrak; **Title III**, applying to public accommodations, including privately run transportation services and private facilities open to the public such as stores, theaters, medical and law offices; and **Title IV**, applying to telecommunications.

The full law can be found at [dol.gov/esa/regs/statutes/ofccp/ada.htm](http://dol.gov/esa/regs/statutes/ofccp/ada.htm). A detailed overview is in the Society’s booklet “ADA and People with MS,” which can be read online or downloaded—or obtained in print form from the nearest Society office (1-800-344-4867).

## Stepping up a push for compliance

For Jim Lawson of San Antonio, Texas, the biggest problem with the ADA is enforcement. “Without enforcement, no law is effective,” he said. Lawson was diagnosed with MS in 1984 and today, at age 62, is pushing for ADA compliance through private lawsuits with help from Access Now, a national nonprofit disability rights association. “What’s wrong with the ADA is that there are no consequences to ignoring it.”

Lawson also points out that the ADA is fraught with misunderstandings. People who lease buildings often assume the law only applies to the building

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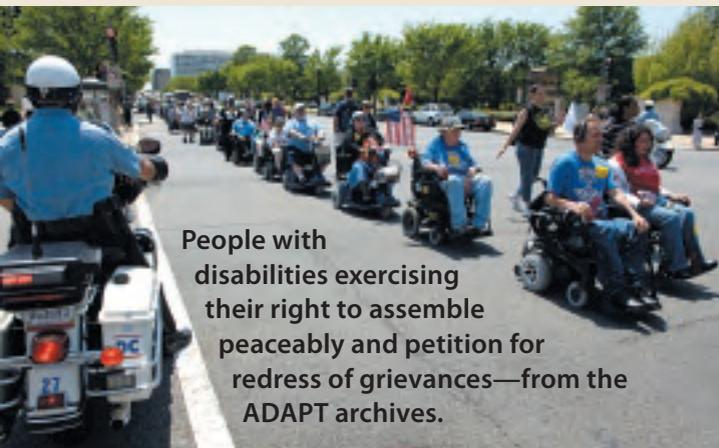


Karen exercising her right to move easily around her city.

To learn more visit:

- The Equal Employment Opportunity Commission ([eeoc.gov](http://eeoc.gov)) and the Job Accommodation Network ([jan.wvu.edu](http://jan.wvu.edu)) for employment issues
- The Department of Justice ([usdoj.gov](http://usdoj.gov)) and the ADA Center ([adaproject.org](http://adaproject.org)) for information about access
- The Federal Communications Commission ([fcc.gov](http://fcc.gov)) and the Disability and Business Technical Assistance Center ([adata.org](http://adata.org)) regarding telecommunications.

—Richard Meneghello and Helen Russon



People with disabilities exercising their right to assemble peaceably and petition for redress of grievances—from the ADAPT archives.

efforts, was released in 2007 and is now available on DVD. (See our review on page 34.)

Many others collectively chipped away at that stubborn wall to which the first President Bush referred. Evan J. Kemp, Jr., Patrisha A. Wright, Robert Burgdorf, Jr., and Judith E. Heumann, currently the director of the Department on Disability Services in Washington, DC, are only a few of them.

### Mixed results

With the benefit of years of perspective, it is easy to see that the ADA has resulted in widespread changes in the way we all live—and that it has fallen short of some intended goals. Employment remains a major frontier. Of the tens of thousands of employment discrimination charges filed with the Equal Employment Opportunity Commission over the past 18 years, 57% to 61% are dismissed every year because the agency cannot find “reasonable cause” to rule in the employee’s favor. Plaintiffs have fared even worse in court. In the first ten years of the ADA, 83% of ADA plaintiffs lost their cases in federal appeals courts across the country. Many of these decisions were the result of narrow interpretations of ADA that the recent ADA Restoration Act of 2007 (passage pending) attempts to address.

The reality is that the ADA is an imperfect tool. The good news is that the ADA brought change and opened the door to creating new public attitudes. The not-so-good news is that we still have a long way to go. ■

Richard Meneghello is a partner at the Portland office of Fisher & Phillips, LLP, one of the oldest and largest employment law firms in the country dedicated to representing the interests of management. He is the former Chair of the Oregon State Bar’s Disability Law Section, and often advises and represents employers in disability law matters.

Helen Russon is an attorney who teaches disability law at Willamette University College of Law in Salem, Oregon. She conducts seminars, provides telephone assistance, and writes newspaper columns about employment issues for the Oregon Bureau of Labor & Industries. Helen was diagnosed with MS in 1997.

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are able and eager to hold down jobs and contribute meaningfully to society. Yes, we have limitations, but one of our biggest limitations is the limited thinking of the public. That’s why we need a national law to prohibit discrimination against us and to require that employers, governments, public facilities, and businesses make accommodations for our limitations without unreasonable difficulty.

For the next 13 years, the disability community built coalitions, lobbied, demonstrated, and educated the nation about their legitimate status as a minority group and their need for legal protection. Along the way, several important laws were amended. For example, the Fair Housing Amendments Act of 1988 included “disability” as a protected category.

In 1988, Senator Lowell P. Weicker, Jr., and Representative Tony Coelho introduced the first draft of the ADA. Rewrites and debates filled the next two years. Perhaps the most profound contributions were made by the late Justin Dart, Jr., chair of the Congressional Task Force on the Rights and Empowerment of Americans with Disabilities. Dart, often called the “Father of the ADA,” did not let his wheelchair stop him. He traveled the country, holding public hearings and gathering documentation about discrimination faced by people with disabilities. Fragile but tireless, his zeal and determination inspired people both with and without disabilities.

Richard Pimentel, who became an activist after losing most of his hearing in Vietnam, also worked avidly to garner support for the ADA. **Music Within**, an award-winning movie that chronicles his



**Karen uses an adapted ATM (top), hands-free sink (right), and a lowered parking meter.**



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owners. Others think  
ADA requirements  
apply only to new  
construction. Still  
others know that  
there's no enforce-  
ment, so there's little  
incentive to comply,  
short of a lawsuit  
being filed.

When Jim began his  
involvement with  
ADA compliance, he talked with store managers  
and wrote letters to corporate offices. Then he filed  
complaints. He has made over 100 official complaints to the Department of Justice, the Federal Highway Department, the Federal Transit Agency and the Department of Education. Often, these complaints have resulted in limited increases in compliance. However, he found many organizations take a “wait until we're sued” approach.

So Jim sues. To date, he's filed 44 lawsuits in federal court and, in each case, the defendant has been required to comply fully with the ADA. Some of Jim's most notable suits include the Oklahoma

State University Football Stadium and several McDonald's franchises.

### **It may be the law, but ...**

When civil rights legislation was passed in the 1960s it didn't mean an immediate end to segregation, let alone racism. Nor was there an immediate shift in public opinion. Even now with some 40 years of positive changes, the struggle for racial equality continues.

Similarly, the ADA called for broad change in terms of access to public facilities, transportation and employment. But that was only the beginning. Continued advancement in access for people with disabilities requires a strong legal footing and a shift in public attitudes.

“Understanding of and compliance with the ADA is an ongoing process,” said Shawn O'Neil, associate vice president for Federal Government Relations at the National MS Society. “We've come a long way, but we still have a long way to go. Passage of the ADA Restoration Act of 2007 will be welcome and much needed, renewing awareness and advancing the cause of equal access.”

Jim put it this way: “Noncompliance must stop, and the only way that will happen is for each of us to stand up for our rights. As people with disabilities, we each must stop accepting discrimination. There are many things we can do, but doing nothing should not be an option.” ■

Katherine Shaw is a freelance writer based in Portland, Oregon. She was diagnosed with MS 10 years ago and most recently wrote about MS and relationships in the Winter 07-08 issue of **Momentum**.

# Beyond the ADA:

## Eleanor Smith Is Fighting for Access at Home

by Patricia Wadsley

**S**ometimes people just have an epiphany,” said Eleanor Smith. “Even though I had been using a wheelchair since I was three years old, the light bulb didn’t go on until I was well into my forties. I was driving past homes and thought, why can’t these be accessible to everyone?”

Smith—who lives and works as an activist in Atlanta, Georgia—had polio as a child and has used a wheelchair ever since. As an adult she worked for 25 years as a teacher and professor in the public and private school systems before her disability forced her to change careers.

In 1987, Smith joined the American Disabled for Accessible Public Transit, or ADAPT, where she and other activists mounted national media campaigns and lobbied for accessibility on public transportation. Their efforts, both at a grassroots and a policy level, led to an inclusion in the ADA of 1990 of the provision for wheelchair lifts on every new public bus in the country.

“We drew attention to the issue by blocking buses with wheelchairs,” Smith said.

### Houses anyone can visit

With this win Smith’s fight for access had just begun. One day, while driving through a new housing development, she noticed as if for the first time the steps at every entrance to the homes.

“I had paid the price of lack of access over and over again,” she explained. “I could not go to friends’ parties, crawled to get into bathrooms, and had great difficulty finding suitable apartments. I had also seen wheelchair users looking out from behind screen doors with no ramps and no way to come down.”

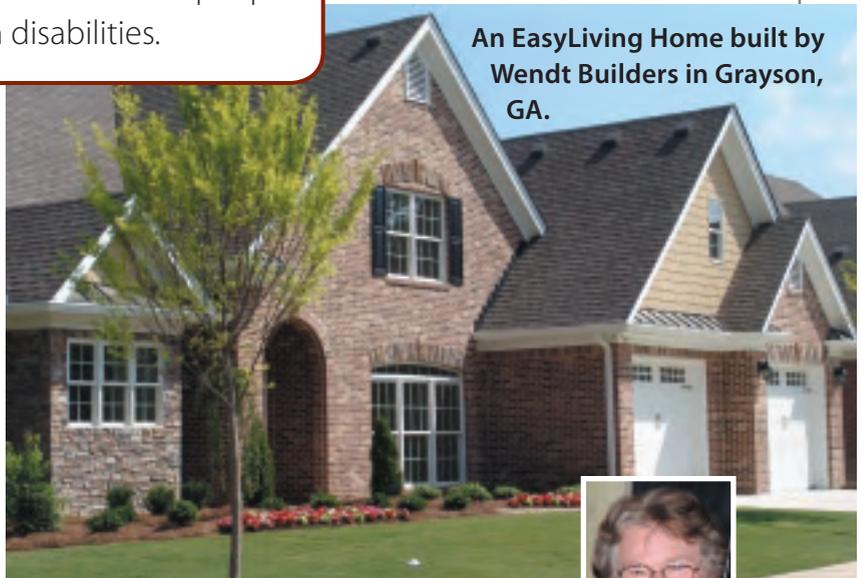
Smith wanted life to be different.

### Establishing the basics

In 1987, Smith brought her ideas to a local disabilities group and together they founded Concrete Change, an organization committed to basic access in the construction of new houses. Focused on impacting legislation,

“Visitability” makes people think about every house, not just about special houses for people with disabilities.

An EasyLiving Home built by Wendt Builders in Grayson, GA.



“The next step is legislation that would make basic access a reality for private homes,” Eleanor Smith (inset) said.

EASYLIVING HOME

they sent flyers and contacted government officials, housing groups, disabilities advocates, and builders.

Smith drew the attention of a young Japanese architect who also used a wheelchair and was exploring the accessibility movement in America.

“Yoshi Kawauchi told me that what I was calling ‘basic access’ or ‘accessibility’ is called ‘visitability’ in Europe,” Smith said. “I was immediately excited by the term, since it makes people think about **every** house, not just about special houses for people with disabilities.”

Smith developed three principles that define a home’s visitability:

- one exterior door with a step-free entry
- all interior doors at least 32 inches wide to allow for wheelchair entry
- a bathroom on the first floor

To learn more about Easy Living Homes, visit [easylivinghome.org](http://easylivinghome.org); for more on Concrete Change, [concretechange.org](http://concretechange.org); for **Universal Design and Accessible Homes** check out [design.ncsu.edu/cud](http://design.ncsu.edu/cud).

“People can manage as visitors if they have at least these three things,” she explained. “All we are asking for are the basics.”

### Making changes

In 1989 Smith persuaded Habitat for Humanity in Atlanta to adopt these three principles in all new homes, a policy that remains in place today. But when she pushed to expand the movement outside of Habitat for Humanity, she found some builders resistant.

“They balked at what they thought would be higher building costs for a relatively small market,” Smith said, “but we persuaded them that the market was growing—reminding them that the baby boomers are coming of age.” As boomers enter their sixties, nearly half will develop one or another kind of disability.

As Smith was promoting visitability, the Universal Design movement was gaining steam. Universal Design, accessibility and visitability combined have

helped make builders see the viability of basic access housing. Although still opposed to legislation, many builders embraced the idea of a voluntary program.

### Coalition building

In 2001, Smith led a small number of accessibility advocates to form a coalition of builders, health-care facility administrators, the Georgia chapter of the American Association of Retired Persons (AARP), and Concrete Change. The coalition created Easy Living Home, a voluntary certification program for home builders. The program invites builders to pay a fee to register, based on how many homes they intend to build. The homes are inspected and certified upon

completion if they meet visitability standards. In Georgia alone, some 800 homes have been built that meet these standards. The program has been picked up in New Hampshire, Texas and Virginia.

“You can create basic access housing for the same cost as any other housing,” current Easy Living Home program director Bonnie Bonham explained. “This movement may have grown from the needs of people with disabilities, but it makes sense for everyone. It is the wave of the future.”

Easy Living Home is now developing a remodeling certification program—to include standards beyond adding ramps to preexisting structures.

Stephen Thomas, one of the first Easy Living Home builders in Virginia, is positive: “I just hope more builders and home owners realize the benefits of this type of housing and what it means to their lives and livelihood,” he said.

That will come, Smith believes, with legislation. “The ADA affected public buildings,” she said. “The next step is legislation that makes basic access a reality for private homes, too.” ■

Patricia Wadsley is an associate editor of **Momentum**.