# It's your community, too



# People with disabilities encounter obstacles and opportunities in the cities where they live.

# by Matt Alderton

Boston is the birthplace of American independence. Established nearly 400 years ago, it's where angry colonists revolted against British tea taxes, where the Revolutionary War commenced and where a judicial decree made Massachusetts the first U.S. state to abolish slavery.

For residents with disabilities, however, Boston hasn't always lived up to its promise of liberty. To them, Boston won't be a truly free city until it's a truly accessible one.

"The city of Boston is an old city," says Boston native Christos Koutrobis, whose father John Koutrobis has lived with multiple sclerosis for about 36 years—the last 18 of which he's spent in a wheelchair. "Because of that, there are many different areas of the city that are considered historic. And for reasons I'll never understand, that trumps people's accessibility. For example, there's Beacon Hill, where the Massachusetts State House is. All the sidewalks there are made of bricks that are sticking up. There's no way that someone in a wheelchair could maneuver that part of the city by themselves."

But there are bright spots, too. "My dad can't drive anymore, so for the last two years of his work as a teacher with the Boston Public Schools, he took the RIDE, which is [an on-demand paratransit service] offered by the city's train system, the 'T,'" Koutrobis says. "They'll pick you up and take you to whatever your destination is. It's an unbelievable program."

In that way, Boston is typical of many cities: There are both assets to love and deficits to

lament. By becoming accessibility advocates, however, residents with disabilities and allies can help perpetuate what's working in their communities and help fix what isn't.

# Accessibility: a civil right

According to the federal Americans with Disabilities Act (ADA), accessibility is a civil right.

Enacted in 1990, the ADA prohibits discrimination against individuals with disabilities and guarantees them equal opportunity in all areas of public life, including employment, education, transportation, state and local government services, commerce and telecommunications.

"There are a lot of technical details in the ADA, but the overarching theme is that business and government have an obligation to make programs and services accessible," explains Carol Fulkerson of Bend, Oregon, who was diagnosed with MS in 1993 and became an accessibility advocate when she witnessed the obstacles faced by members of her MS support group. "It was through helping my friends that it became very apparent to me: It is really hard to get around in one's community using mobility equipment."

Nobody knows that better than Scott Crawford, PhD, who returned to his native Jackson, Mississippi, after being diagnosed with primary progressive MS.

"When I returned to Jackson in late 2006, I tried getting around on my own utilizing the public transit system," Crawford recalls. "Many of our buses were decades old with nonfunctioning wheelchair lifts, so I was frequently being left on the side of the road. Moreover, I discovered that Jackson had few sidewalks, and almost none of those were accessible to people with disabilities."

More than 15 years after passage of the ADA, Crawford discovered that the local government hadn't yet taken any steps to comply with it.

"That's when accessibility ... became a prime focus of my life," Crawford says. "Without it, people with disabilities will never achieve the community integration called for by the ADA."

Like Crawford, New York-based filmmaker Jason DaSilva felt the opposite of integration—isolation—when he realized how inaccessible his community was. "There were [times] going all the way back to 2008, when I went into a wheelchair, that I could just not go outside," says DaSilva, whose Emmy Award-winning documentary, "When I Walk," chronicles his life after being diagnosed with MS in 2006. "I couldn't go outside because I couldn't go in the nearest coffee shop or restaurant; I could only go to a handful of places that I knew were accessible."

Accessibility is not just about buses and bathroom stalls; rather, it's about the quality of life they afford.

#### What makes cities accessible?

Although no city is completely accessible, best-in-class communities include Chicago; Philadelphia; Portland, Oregon; and Washington, D.C. These and other highly accessible cities share a few common traits:

# **Transportation**

Crawford's experiences illustrate the importance of accessible public transit: Without it, many people end up stuck, literally and figuratively.



Like Boston—whose public transit

authority recently announced plans to develop a next-generation subway car that's 100 percent accessible—many cities boast accessible transit. In Washington, D.C., for instance, 100 percent of the city's Metro trains and train stations are accessible. In Philadelphia, meanwhile, all buses have wheelchair ramps, and the city is working with ridesharing companies like Uber and Lyft to create accessible transportation alternatives.

"We now have more than 70 wheelchair-accessible [rideshare] vehicles in Philadelphia," says Charles Horton Jr., executive director and accessibility compliance specialist for the Philadelphia Mayor's Commission on People with Disabilities.

Chicago requires ridesharing companies to offer accessible vehicles, and has more than 300 wheelchair-accessible taxis, plus 24/7 paratransit service.

Farther west, Portland, Oregon, is a leader. "Our public transportation system is consistently rated one of the best in the country," says Joanne Johnson, Portland's Disability Program coordinator. "All of the buses, all of the streetcars and all of the light rail have ramps, as they should. That's not true in every city."

The city even has adaptive bikes available as part of its BIKETOWN bike share system.

### **Sidewalks**

Accessible transit is only effective if people with disabilities can get to and from a transit stop. That requires "complete streets" that are designed to be safe for everyone, regardless of ability.

"That inherently means well-maintained ADA-compliant sidewalks, crosswalks, accessible pedestrian signals, etc.," Crawford says.

The ADA requires cities to install curb ramps when they build new roads or modify old ones. But some cities are moving at an accelerated pace. Chicago, for instance, has installed nearly 95,000 ADA-compliant curb ramps since 2007. Philadelphia, meanwhile, has an ADA Curb Ramp Partnership Program through which the city assesses curb ramp needs. And in Portland, the city recently pledged to create 1,500 curb cuts per year—more than double its current rate.

#### Government

Title II of the ADA requires state and local governments to make public facilities, services and programs accessible. Under the law, all governments must appoint an ADA coordinator to oversee Title II compliance. The most accessible cities, however, go above and beyond the role of ADA coordinator. Portland, for example, also has the Portland Commission on Disability, which advises the mayor on issues of import to disability communities.

"The Portland Commission on Disability is not a substitute for the ADA coordinator; it's a complement," Johnson explains. "Whereas the ADA coordinator is one person making sure the city is compliant, the commission is about giving disability communities a voice in the way the government shows up for them."

Similar bodies exist in Philadelphia, Chicago and Washington, D.C.

"There is a difference between just being an ADA coordinator and being an office in the mayor's cabinet," says Karen Tamley, commissioner of the Chicago Mayor's Office for People with Disabilities. "The fact that we have the Mayor's Office for People with Disabilities to keep watch on the day-to-day issues that come across not just our desk, but the city as a whole, is unique and something other cities often aspire to."

# Housing

Affordable and accessible housing is critical, according to Crawford. "Without affordable rental units with roll-in showers and fully accessible kitchens, sinks and toilets, people won't be able to live in the communities of their choice," he says. "The Fair Housing Act's Accessibility Guidelines are insufficient for many wheelchair users. Also, some developers use loopholes to evade even these meager standards. Rent-controlled apartments are necessary for individuals like myself, whose income never rises."

To help disabled residents with housing concerns, cities like Chicago, Philadelphia and Washington, D.C., offer financial assistance to homeowners whose homes need adaptive modifications.

"We provide home accessibility modification up to around \$10,000," Tamley says of Chicago's program, which also is available to apartment renters and condo owners. "It's a

really critical program, given that the stock of accessible housing in the Chicago area is very, very limited."

In Philadelphia, the fire department recently purchased 4,000 adaptive smoke alarms for citizens who are deaf, hard of hearing, blind or have low vision. And in Portland, the city is considering a policy that would allow construction of new, compact residences—called infill housing—in between existing homes; if approved, the policy would likely require a portion of infill homes to be accessible, thereby increasing housing options for people with disabilities.

#### **Businesses**

Title III of the ADA requires private businesses to remove physical barriers for disabled customers when doing so is "readily achievable."

"That leaves wide latitude to leave barriers in restaurants, stores and other privately-owned buildings," Crawford says.



With that in mind, the most accessible

cities educate and engage local businesses in ways that inspire and incentivize voluntary ADA compliance. In Philadelphia, for example, the Mayor's Commission on People with Disabilities hosts an annual "Access Achievement Awards" ceremony during which it recognizes private businesses, public agencies, nonprofit organizations and individuals that have made outstanding efforts to improve and increase access for people with disabilities.

"We've given out well over 100 awards to businesses that have supported the disabilities community," Horton says. "Those awards go to some of the largest companies in Philadelphia and to some of the smallest corner stores, restaurants and gas stations to thank them for their hard work and support."

#### Recreation

People with disabilities need places to not only live, work and shop, but also to play. Cities like Washington, D.C., are therefore committed to accessible recreation.

"Going forward, we're going to focus a lot on parks," says Mathew McCollough, director of the Washington D.C. Office of Disability Rights. "In my mind, trying to access parks and

recreation centers is the last frontier of accessibility; we need to make sure that grandparents and parents with disabilities are able to have fun with their children and grandchildren, and that children with disabilities are able to play with other kids. So over the next few years we're going to assess each and every park, playground and recreation center in the District to address barriers to accessibility."

# **Activating Accessibility**

If you live in an inaccessible community, there are many things you can do to affect positive change:

**Contact your ADA coordinator:** Step one is finding and contacting your city's ADA coordinator, according to Fulkerson, who says citizens should turn to that person first when they notice problems with sidewalks, curb ramps or traffic signals.

"Contact somebody in the local government and ask, 'Who is your ADA staff person?'"
Fulkerson advises. "If they don't have somebody, your next question is, 'Why don't you have someone, and when are you going to hire them?'"

If the ADA coordinator is nonresponsive, escalate. "Contact the mayor or commissioner or city council member," says Fulkerson, who has successfully escalated issues all the way up to state legislators.

**Speak at public meetings:** When she began using a wheelchair seven years ago, Terri O'Hare wanted to participate in the same outdoor activities enjoyed by the rest of her neighbors in Albuquerque, New Mexico. Unfortunately, there were no accessible trails along the Rio Grande River, local hikers' and cyclists' most popular destination. So, she joined a citywide effort to create one. The advocacy effort was already underway, but her simple contribution—sharing her story in front of policymakers—helped it cross the finish line.

"This trail was on the verge of not getting built, so I went to the city council and spoke, which scared me a lot," says O'Hare, who was diagnosed with MS two years ago. "I said, 'I've lived here for eight years and I've never seen the river up close; I've only seen it in my car driving over it.'"

Ultimately, the city council decided in favor of the four-mile long ADA-accessible trail, which was completed in 2017.

**Organize:** If your community doesn't offer forums where you can speak, consider creating your own.

"It is incumbent upon us to make ourselves available, to get involved, reach out and offer our perspective," says Crawford, whose mantra is "nothing about us without us." "Often that means joining or forming an 'ADA Advisory Council' in your jurisdiction and inviting community leaders to visit."

Even informal efforts—letters to lawmakers, for instance—are more effective when they have multiple signatories. "More voices in the choir makes the song a little louder," Fulkerson says.

**Show, don't tell:** Showing your story can be even more effective than telling it, according to Crawford, who helps organize awareness-raising public transit "ride-alongs" on behalf of Working Together Jackson, a coalition of nonprofits and faith-based organizations working to rebuild metro Jackson.

Even Jackson Mayor Chokwe Antar Lumumba has participated.

"He was there to see me left on the side of the road by an inaccessible bus," Crawford says. "He looked at me and said, 'I get it.'"

Fulkerson has likewise succeeded by organizing "Disability for a Day" events, wherein architects, engineers, construction managers and policymakers experience navigating their communities in wheelchairs. "It made a huge difference in our interactions with the commercial construction industry in central Oregon because we got the general managers and CEOs from five major construction companies to participate," she says. "The experience amazed them."

"Showing" also helped Judy Pollock Hallam of Meriden, New Hampshire, who was diagnosed with MS in 1995 and uses a power wheelchair.

Frustrated at the frequency with which it happened, she began taking photographs of accessible parking spots where people had blocked the access aisle (the white or yellow striped area between accessible parking spaces) next to her vehicle.

"I decided to make up five small booklets with a cover letter explaining my dilemma and the photographs showing the problem," says Hallam, who sent the booklets to lawmakers and advocates, one of whom—the advocacy manager of the National Multiple Sclerosis Society's Greater New England area—arranged for her to testify before state legislators in hopes of passing a law. "As a number of people with disabilities testified, the legislators nodded their heads in agreement. I spoke last and handed out my booklet. Their faces lit up and they said in unison, 'Oh, that's what you're talking about!' A law was passed in 2004 making it punishable by a fine for anyone to park in the access aisle." The law included a provision allowing photographs of the aisles to be sent to police with an affidavit as evidence.

A campaign called "A Picture Is Worth A Thousand Words" was launched to raise awareness about the importance of the space.

**Engage businesses:** In private businesses, there is no ADA coordinator. There are, however, managers and owners, many of whom are receptive to accessibility concerns when they're made aware of them. Often, all you have to do is ask.

"I was finding myself not shopping in certain stores because of heavy doors and feeling

angry. My father taught me that if you don't speak up no one will know that there is a problem; I was being unfair to them by not giving them a chance to correct the situation," says Hallam, who politely asked the managers of several stores and a bank if they would consider automatic door openers. "I told them something that became my mantra: If you can't get in, you can't spend money. Initially I was met with some resistance, but I continued to be polite, pointing out that door openers make [businesses] accessible for everyone. Advocacy became a little easier after my initial successes. It literally 'opened doors' for me."

Tools like AXS Map—a mapping application that harnesses crowdsourcing to rate and review businesses across the country based on their accessibility—can help you further plead your case. "It's helped our users, but the real target is business owners," explains DaSilva, who created AXS Map. "We want to help them see that making places more accessible is going to increase not just quality of life for people with disabilities, but also business."

Finally, tax incentives also can be persuasive. "There is a tax credit and a tax deduction available from the IRS for specific ADA improvements," Fulkerson points out. "If you're asking a business to spend money on improvements, it's always good to say, 'And did you know you may be eligible for a tax benefit, too?'"

At first blush, it may feel embarrassing or selfish to ask for accommodations. But consider this: Making a single sidewalk, bus or park accessible won't just help you; it will help thousands of your neighbors, too.

"The bottom line is this: If you find a barrier you want to have fixed, go for it," Fulkerson says. "It's not self-serving. It helps everyone."

## Matt Alderton is a Chicago-based writer and editor.

Find more information about the Society's **Government Relations Advisory Committees**.

Learn more about <u>becoming an MS activist</u>.