

Destination: Accessibility



For people with MS, accessible transportation is vital — and often elusive.

by Matt Alderton

New Yorker Yulia Steshenko lives steps from North America's largest public transportation system. Operated by New York's Metropolitan Transportation Authority (MTA), it includes 472 subway stations and 418 bus routes, all of which operate 24/7. No matter where in New York City's five boroughs she wants to go, or at what time, public transit will get her there ... in theory, at least.

In practice, Steshenko spends most of her time isolated in her apartment. Because she uses a wheelchair, and public transportation isn't as accessible as it should be, she has trouble reaching destinations that are located down the street, let alone across town. Although she lives in a city of more than 8 million people, there have been long stretches when it felt like she lived in a city of one.



Yulia Steshenko, who lives with MS, finds a lot of the New York public transportation inaccessible.

“For many years, I couldn’t get out on my own because of the inaccessibility,” says Steshenko, 40, who has multiple sclerosis. “It just goes to show you: society puts up so many barriers that exclude people like me and that’s impacted me deeply. Accessibility is often an afterthought, if addressed at all, and it’s even resisted.”

Scott Crawford, PhD, knows the feeling. A retired clinical neuropsychologist who was diagnosed with MS in 2002, he’s been a wheelchair user and public transit passenger for more than 20 years.

“Mobility is freedom itself. Period,” says Crawford, 56, of Jackson, Mississippi, who won a lawsuit in 2010 against the City of Jackson over its lack of accessible public buses. “Accessible transit gives people with disabilities the opportunity to work, engage and contribute to their communities. The alternative is tantamount to ‘house arrest.’ That’s exactly how it feels to people who can no longer drive and have no access to accessible, affordable transportation.”

When they’re confined to their homes, people with disabilities suffer mentally, socially and even physically. Social isolation, for example, has been linked to early mortality, depression and dementia, whereas physical isolation makes it difficult to access food, employment, social services and healthcare. In fact, 3.6 million people per year do not obtain medical care due to transportation issues alone, according to the American Hospital Association.



Virginia Dize, co-director of the National Aging and Disability Transportation Center (NADTC).

“If you can’t get to the grocery store, if you can’t get to the doctor and if you can’t travel in your community — to connect with neighbors and friends, for example, or to access an exercise program or go out for a meal — then your life is really blighted by that,” explains Virginia Dize, co-director of the National Aging and Disability Transportation Center (NADTC), which promotes the availability and accessibility of transportation options for older adults and people with disabilities. “Not only can that have a very detrimental effect on your quality of life, but it also can impact your mental and physical health.”

Although they have varying degrees of mobility, people with multiple sclerosis are among those who can be hurt by a lack of accessible transportation. Therefore, they’re also among those who can most effectively advocate for it.

Troublesome train stations

Some 25.5 million Americans aged 5 and older have a travel-limiting disability, according to the Bureau of Transportation Statistics, which says 3.6 million of them — approximately 1% of all Americans — are homebound because of their disability.

It is with those people in mind that President George H.W. Bush signed the Americans with Disabilities Act (ADA) in 1990. Ever since, Title II of the ADA has protected people with disabilities from discrimination in public transportation by guaranteeing them equal access to public transit systems.

There’s just one problem: the ADA is self-regulated. So, while governments deploy inspectors to ensure food safety at restaurants, safe working conditions at factories, and the structural integrity of highways and bridges, they take no such measures to enforce the ADA. Instead,

they rely on people with disabilities to take action in the event of noncompliance.

Sometimes, that means filing complaints that go unanswered. Other times, it means filing lawsuits that take years for courts to resolve. In both cases, the net result is an inconsistent transit experience for passengers with disabilities.

That inconsistency is further exacerbated by the fact that facilities are exempt from the ADA if they predate it. Because it dates back to 1904, for example, the New York City subway remains largely — and lawfully — inaccessible.

“Only about a quarter of all subway stations in New York are wheelchair-accessible,” says New Yorker Jessica Murray, 42, who has relapsing-remitting MS. Although she doesn’t use a wheelchair, she has become a transportation advocate out of concern that she might one day need one.

“If you do the math — both your starting destination and your ending destination have to be accessible — that means you can make only about 4% to 5% of all possible subway trips in a wheelchair, which isn’t great.”

The number of available trips can be reduced further by maintenance problems.

“One trip could involve five different elevators, all of which have to be working for you to get where you’re going,” Murray continues. “If you get somewhere and the elevator is out of service, that causes a huge problem.”

Burdens for bus riders

Buses also have issues. In New York, for example, 100% of buses are wheelchair accessible. But drivers don’t always announce all stops, which can make rides precarious for passengers with visual impairments, including people with MS who experience ocular symptoms.

Routes and schedules can also be limiting, says Steshenko, who says buses in some underserved neighborhoods have less coverage, leading to longer wait times.

Problems aren’t limited to New York. Stephanie Barnes, for example, routinely rides the bus in Cleveland, Ohio. Although all the buses are accessible, she says, there are only two spaces for wheelchairs on each of them.

“There have been a few times where the bus stopped and there already were two people on board in wheelchairs, so I had to wait for the next bus,” says Barnes, 59, who has primary-progressive MS. “Luckily, I wasn’t in a hurry.”



**Scott Crawford, PhD,
diagnosed with MS in
2002, has been a public
transport passenger for
20 years.**

Like elevators at train stations, lifts on buses can break. And so can the sidewalks around bus stops, which may be impassable for wheelchair users, if they exist at all.

“It does little good to have a transit system if, once you leave the bus, you’re relegated to risking your life riding in the street because the sidewalk is broken, inaccessible or missing,” stresses Crawford, who says errant bus drivers also can be an issue. “I was recently visiting an urban area with beautiful streets, sidewalks and brand-new accessible street cars and buses, but found the system unwelcoming. Bus operators were rude and intolerant of visitors that were unfamiliar with the system, or wheelchair users who they regarded as taking too much time to board. That system left me on the side of the road twice in one day by passing me up in my wheelchair.”

Whether it’s due to broken equipment, inaccessible stations or insufficient routes, passengers with disabilities who can’t take the train or bus have another option: ADA-mandated paratransit.

Although it’s convenient in some respects — it provides door-to-door service, for example — it unfortunately is inconvenient in many others. Passengers typically have to make reservations 24 to 48 hours before their ride, for example, and receive large and imprecise pickup windows during which they have to be ready to go. They also have to make multiple stops for other riders, which can extend the length of their trip, and can receive service only if they’re located near a train or bus that they could take if they were able-bodied.

“The only time I use paratransit is to go to the airport,” Barnes says. “You have to wait too long, and they pick you up too early. It’s just not very convenient.”

What about ride-hailing?

To make paratransit services more efficient for riders, some cities are providing “on-demand” paratransit in partnership with transportation network companies (TNCs) like Uber and Lyft. In Denver, for example, the Regional Transportation District (RTD) allows paratransit customers to schedule up to four trips per day or 60 trips per month using Uber’s ride-hailing app. Designated vehicles are available for wheelchair users, who pay the first \$2 of their fare and thereafter receive up to \$20 in subsidized fares for each trip.

In Boston, Massachusetts, the Massachusetts Bay Transportation Authority (MBTA) has been piloting a similar program since 2016. Riders get a certain number of rides per month based on past paratransit usage, pay a \$3 co-pay per ride, as well as receive up to \$40 in subsidized fares for each trip.

It’s a creative solution that makes paratransit more useful for more riders. But TNCs aren’t perfect, either. For one, only select cities have forged paratransit partnerships with them. In cities that haven’t, TNCs may or may not be a viable transportation option for people with disabilities. And without subsidies like the ones offered in Denver and Boston, they often aren’t.

“Depending on where you live and the places you need to go, it may be cost-prohibitive for you to take more than a couple rides per month,” Dize says.

And even if you can afford to use TNCs often, you still might not be able to. “TNCs don’t exist everywhere. They’re spreading, but they’re mostly urban,” continues Dize, who says rural and exurban passengers are less likely to have TNCs in their area. “Also, you have to have a smartphone to use them, and not everyone does.”

Depending on where you live, TNCs may or may not offer wheelchair-accessible vehicles (WAVs), which are typically modified vans.

Through their Uber WAV and Lyft Access services, respectively, both Uber and Lyft offer WAVs in some markets, but not all. Where they do offer them, it’s often because state and local lawmakers require it. In 2016, for instance, lawmakers in Chicago passed reforms requiring TNCs to expand wheelchair-accessible services in the city. And last year, Uber and Lyft expanded their wheelchair-accessible services in New York in response to city pressure, agreeing to respond to at least 80% and 90% of requests for WAVs in under 10 and 15 minutes, respectively.



Stephanie Barnes routinely takes the bus to get around but finds their accessibility options limiting.

In cities where TNCs don't offer wheelchair-accessible services, passengers suffer. Barnes, for example, can't take the bus in the wintertime because the sidewalks to and from the bus stop are impassable in her wheelchair. So, she has to rely on TNCs. But because vehicles can't accommodate her wheelchair, she has to leave it at home and use a cane instead.

"I usually take Uber or Lyft to the hospital, and the hospital is very big. A lot of times, I have to walk far, and I have to find a place to stop and rest because I get so tired," Barnes says. "In fact, I recently was at the hospital for an appointment and had to stop and ask an employee to call for someone to transport me to where I was going. I really wished I'd had my wheelchair."

TNCs are able to offer WAVs in some places and not others because they identify as technology companies instead of transportation companies, which exempts them from the ADA.

Crawford disagrees with their logic. In 2017, he and fellow plaintiff Jarvis Jernigan filed a lawsuit against Uber for failing to provide accessible rides in Jackson, Mississippi. Plaintiffs Stephen Namisnak and Francis Falls have filed a similar suit in New Orleans, Louisiana.

"Uber WAV is a service in other cities, such as Chicago and Washington, D.C., but that service is not available in New Orleans or Jackson," says civil rights attorney Garret DeReus, a partner at Bizer & DeReus, which is representing the plaintiffs in both cases. "Our clients are arguing that it would be a reasonable modification for Uber to provide Uber WAV in New Orleans and in Jackson, just as it provides it in other cities. They aren't seeking any special treatment. They're just seeking the same service that folks in other cities enjoy."

The cases rest on two questions: Is Uber a transportation company? And is it, in fact,

“reasonable” for Uber to provide WAVs in New Orleans and Jackson? Although an answer to the second question was still pending at press time, a judge already answered the first, according to DeReus, who says the court ruled that Uber is “essentially no different than a taxi company or the operator of a bus system.”

Neither Uber nor Lyft responded to interview requests. In court, however, Uber has indicated that implementing Uber WAV in cities like New Orleans and Jackson would be too costly.

Advocating for accessibility

To be sure, wheelchair-accessible services do have a price tag. When people with disabilities are robbed of independence, however, the price can be even higher. “If people can’t live freely in the community — if they develop a disability and can no longer take care of their grocery needs or their medical needs, for example — then they may end up going into an assisted-living facility or a nursing home, where the costs to taxpayers are much greater,” Dize says.

But what gets measured in cents also should be measured in sense.

“I can say that one of the biggest gaps is education and knowledge,” says Karen Mariner, executive vice president of MS Navigator Experience at the National MS Society. Mariner previously served as chair of the Paratransit Appeals Board at the Southeastern Pennsylvania Transportation Authority (SEPTA), which oversees public transit in Philadelphia. “If you’re an individual with a disability, understanding what your rights are is essential so that you can be an advocate for yourself within the system. At the same time, transportation providers need to understand what the ADA actually is, and what the expectations are for them to be able to meet its requirements. They need to realize how their systems are set up to work against individuals with disabilities, and what things they can do to engage people with disabilities and make their systems better for them.”

The courts are one vehicle through which people with disabilities can exercise their rights and educate transportation providers. But they aren’t the only vehicle.

“Transportation issues are often very local, so I encourage people to become advocates at the local level,” Mariner continues. “For example, does your local transit provider have a public council or committee — some mechanism that they use to gather input from the community around paratransit or ADA-related transportation? Joining those councils and committees and being at those meetings is a powerful way to influence policy positively.”



Barnes is one of millions of Americans with a travel-limiting disability.

Social media also can be effective. “If Uber and Lyft don’t have an accessible van in your area, Tweet them. Ask them why,” Mariner advises. “Keeping constant pressure on companies is what eventually will get them to change.”

It’s hard work, but you don’t have to do it alone, stresses Steshenko, who serves on the board of the Center for Independence of the Disabled, NY (CIDNY), a community-based organization that advocates for people with disabilities in New York.

“Getting involved with advocacy groups is the most effective way to make change,” she says. “First of all, it’s really helpful and inspiring to find a community of people like you, to know that you’re not alone. But also, it gives you a loudspeaker. You’re not just emailing a complaint to someone. You’re participating in a group that will engage elected officials and companies and the press to make it known that these are systemic issues that deserve attention.”

Mariner agrees. By giving local, state and national advocacy organizations their time, money and support, she says, people with disabilities can turn small contributions into big impacts. When they support the National MS Society, for example, members and donors enable services like the MS Navigator program, which connects people to local transportation resources and, in some cases, can even arrange rides to MS-related medical appointments. They also are equipping the Society to lobby policymakers and private companies on their behalf—which it did in 2018, when it was part of a coalition that secured federal reforms making it easier for passengers with disabilities to fly on commercial airlines.

Progress is slow, but also significant. In New York, for example, the MTA hired its first-ever accessibility chief in 2018, and in 2019, established a new Advisory Committee for Transit Accessibility (ACTA) through which community members can work with the city to identify

and address accessibility issues.

“They’re listening to people with different access needs and getting our input when they’re thinking about things like future rail car designs, future bus designs and new payment systems,” says Murray, who chairs that ACTA. “They’re having conversations with us, which seems small but is important because, for a long time, they weren’t even doing that.”

At the end of the day, those conversations benefit everyone, regardless of physical ability or health status. Elevators at train stations don’t just help wheelchair users, for example. They also help older adults who have trouble with stairs, travelers with luggage, parents pushing strollers, delivery personnel and individuals with mild mobility impairments, like a bad hip or knee.

“There’s this ‘othering’ of people with disabilities,” Steshenko concludes, “but accessibility benefits everyone.”

Matt Alderton is a Chicago-based writer and editor.