Embarrassing, Uncomfortable and Risky: What Flying Is Like for Passengers Who Use Wheelchairs

By Amanda Morris
Photographs by Scott McIntyre
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Charles Brown has always loved flying. He loves the steady roar of the engine beneath him as the plane rises high above a shrinking ground, turning houses into small blocks of color and cars into floating specks of light below.

Mr. Brown’s passion evolved from building model airplanes as a child to training in aviation ordnance when he joined the U.S. Marine Corps in 1985. His military career was cut short a year later, when he hit his head diving into a swimming pool and injured his spinal cord, resulting in incomplete paralysis of his arms and legs.

He now uses a wheelchair and, because of his disability, finds flying to be a risk.

“When I fly nowadays, it literally is a moment of, ‘OK, what do I have to do to get through this day without getting injured more?’” Mr. Brown explained.

On his first flight after his injury, Mr. Brown got a concussion during the landing; he couldn’t stay upright, and his head slammed into the seat in front of him. On another flight a few years ago, two airline employees dropped him — it was a hard fall — while lifting him into a special aisle wheelchair. He shattered his tailbone and spent four months in the hospital afterward, battling a life-threatening infection.

There’s also the worry of what will happen to his $41,000 wheelchair when it is loaded and unloaded from the plane. The wheelchair, custom designed to fit Mr. Brown’s body, prevents pressure sores. Without it, he could risk another potentially life-threatening infection.
It’s not uncommon for airlines to lose or damage wheelchairs. In 2021, at least 7,239 wheelchairs or scooters were lost, damaged, delayed or stolen on the country’s largest airlines, according to the Air Travel Consumer Report. That’s about 20 per day.

Because of these risks, many people who use wheelchairs say flying can be a nightmare.

Even on a flight that goes smoothly, Mr. Brown endures multiple indignities from the moment he arrives at the airport to the moment he leaves, he said, largely because of a lack of accessibility for people with disabilities.

Much of this could be avoided, he and other advocates argue, if airplanes and airports were designed to accommodate passengers who use wheelchairs. And while the Department of Transportation recently published a bill of rights for passengers with disabilities, the initiative was a summary of existing laws and did not expand the legal obligations of the airlines.

To get a firsthand glimpse of the difficulties faced by passengers who use wheelchairs, The New York Times documented Mr. Brown’s experience on two recent American Airlines flights from Palm Beach to San Antonio, with a connection in Charlotte, N.C. Here’s a step-by-step visual diary of what we saw.

Check-in and security

Mr. Brown arrives and meets his travel companion outside the Palm Beach International airport at 7:25 a.m., three hours before his first flight of the day. (He usually arrives early, he said, because every step of the process takes longer for him.) As he makes his way inside, he stops to fist-bump the airport employees who bring his luggage to the check-in counter. Mr. Brown, the president of the Paralyzed Veterans of America, flies frequently for his job and has befriended several Palm Beach airport employees, who are intimately familiar with his needs.
Most check-in counters tower above Mr. Brown, who must lean across the luggage scale to tell an employee that his custom wheelchair weighs 416 pounds — information that he already filled out on a form when he booked his ticket last week. Mr. Brown also checks a shower wheelchair, a medical bag and a second bag of luggage.

The security line, a snake of belt barriers that Mr. Brown bypasses because he cannot easily go through it, is quiet and completely empty this morning.

Mr. Brown gets personally screened by a Transportation Security Administration agent every time he flies. He stretches his arms out as an agent pats him down, running his hands along Mr. Brown’s back, collar, arms and thighs. The agent then swabs his hands, shoes, thighs, the back of his chair and the chair headrest for substance testing.
Today, Mr. Brown said, the agent did a good job. In the past, he has had agents who demanded he lift his legs or lift his body so that they could pat his butt — both actions that Mr. Brown cannot perform because of his disability. Once, after complying with two full-body pat-downs, Mr. Brown got an impossible request from an agent.

“They said, ‘Now I need you to stand up.’ I said, ‘That ain’t happening,’” Mr. Brown recalled. He had to call for a supervisor to resolve the situation.
Roughly 40 minutes after Mr. Brown arrived at the airport, he reaches his gate. He drinks some water and takes his medication.

Normally, Mr. Brown says, he would not drink water before a flight, because many airplane bathrooms are inaccessible to him. Planes with two aisles are required by the U.S. Department of Transportation to have at least one accessible bathroom on board, but planes with only one aisle — which have been used more frequently for long-haul flights in recent years — are not required to have an accessible bathroom.

Today is an exception to Mr. Brown’s no-water rule, though, because he recently had a kidney stone. Because he cannot use the bathroom on the plane, he is using a Foley catheter — which can increase his risk of getting hurt when he is carried and transferred by employees.

On previous flights, Mr. Brown has had to go to the bathroom into a bottle as he sat in his airplane seat, with blankets thrown on top of him, he said.

**Boarding the plane**
More and more passengers arrive at the gate, some of them consuming snacks or packaged breakfasts. Mr. Brown refrains from eating; he can’t risk needing to use a bathroom on the flight. He hasn’t eaten anything since 1 p.m. yesterday.

Forgoing food and water for hours before a flight is a common practice among travelers who use wheelchairs and cannot access the bathroom. When it's time to board, Mr. Brown must again tell airline crew members how heavy his chair is and how many people he needs to lift him onto an aisle chair — a special, small wheelchair that can fit into an airplane’s narrow aisles.
He repeatedly asks one crew member to put his wheelchair’s headrest into his suitcase and goes over instructions on how to fold up and stow his wheelchair safely. The crew member doesn’t seem to understand him, and eventually someone else steps in to help.

Mr. Brown enters the jet bridge before any other passengers. This gives him privacy during his transfer onto the plane — the part of traveling he worries about most. One drop or slip could mean serious injury.
Today, two managers are watching. This is unusual, he said. He tucks in his Foley catheter and raises his arms in anticipation. On the count of three, one airport employee grips his chest and the other lifts under his thighs to smoothly shift him into an aisle chair. In midair, Mr. Brown’s legs begin to spasm.

Mr. Brown is wheeled, backward, 13 rows to his seat, then positions himself for another transfer. His arms and legs dangle for a moment — during which he watches an armrest graze under his thighs and braces himself for any possible outcome — before he is safely put down again on a special cushion he uses to help prevent pressure sores when he flies.
In the air
During the two-hour flight, Mr. Brown jerks with movement every minute or two. His legs splay outward, spilling his right knee into the aisle and causing his hips to hurt. (He always gets assigned a seat by the aisle, not the window, because it’s easier for crew to lift him into those seats.) In his custom wheelchair, there are pads to hold his legs in place. On the airplane, the best substitute he has are his hands, which he constantly uses to readjust his legs and push them inward. By the end of the flight, he rates the pain level in his hips as a 2 or 3 out of 10, comparing it with a nagging headache.
Just before landing, Mr. Brown rams his right arm against the seat in front of him and presses with effort as the plane lands with a thud. He is trying to stop his head from lurching forward into the hard plastic seat.

It was a harsh landing — the kind a pilot in the Navy or Marine Corps would probably make, he says with a smile, but definitely not someone from the Air Force.
As other passengers leave the plane, suitcases and bags of all sizes and colors roll past Mr. Brown, some occasionally hitting his knee. He and his travel companion are the last to deplane; they’re waiting for airline crew to bring his custom chair to the jet bridge — something that airlines are required to do if passengers have requested it.

Mr. Brown doesn’t want to leave his seat and get into an aisle chair until he knows his custom wheelchair is ready for him at the jet bridge; if he spends more than 20 minutes in an aisle chair, he says, he’s likely to get pressure sores. Sometimes, though, he has been forced to sit in an aisle chair for nearly an hour while he waits for crew to find his wheelchair.

Exiting the plane

Cleaning crews have already come through — vacuuming, wiping down seats and picking up trash. Airline crew repeatedly ask Mr. Brown if he will get off the plane, even though his chair isn’t ready. The staff are under pressure to board the plane for the next flight. Eventually he relents, even though his custom chair still isn’t ready.

The two gentlemen lifting Mr. Brown for the transfer out of his airline seat seem hesitant, as if they’re afraid to hurt him. He tries to tell them to hold onto him tightly and reflexively takes a defensive position, tucking his shoulders and hands inward to protect himself.
The workers don’t quite lift him high enough, causing him to bump the raised armrest and be partially dragged into the aisle chair, landing with a dull thump. The straps on the chair to hold his feet in place don’t seem to be working properly, so a crew member refastens them three times.
Mr. Brown is pushed out of the jet bridge in front of a crowd of passengers waiting to board the plane for the next flight, which is now boarding later than expected. Some look exasperated, others tired; many are staring at him. As he wheels past, one stranger mutters, “Chaos.”

About 10 minutes later, employees bring Mr. Brown’s custom chair to the gate and start transferring him in front of a crowd of passengers.

“It’s frustrating,” he says. “I’m not going to say ‘embarrassing’ anymore because I’m just over that. But it is kind of embarrassing, especially if your pants are hanging off your bottom.” He’s had his pants fall down during public transfers before.

This time the men switch places, with the stronger man lifting Mr. Brown’s chest. They complete a better transfer. An airline worker at the check-in counter soon notices the commotion and comes over to apologize to Mr. Brown about the lack of privacy.
A layover and a connection
Mr. Brown has a two-hour layover in Charlotte and is supposed to board his 2:45 p.m. flight to San Antonio, which is scheduled to land at 4:42 p.m. As he waits, his stomach is starting to get “shaky,” he says.

Just before the flight is supposed to board, the gate agent announces that there is a delay. The flight will now depart at 4:30 p.m. and land at 6:30 p.m. But, with the time it takes to deplane and get to his hotel, Mr. Brown doesn’t think he can make it until after 8 p.m. to eat again.

At 2:16 p.m., he finally bites into a Snickers bar. It has been 25 hours since his last meal. Just before he boards his next flight, Mr. Brown also eats a cup of pretzel bites from Auntie Anne’s and strikes up a conversation with a fellow Marine who’s waiting at the gate. They trade stories and discuss where they were stationed.
As the flight prepares to board, airline crew wheel three elderly women on regular airport wheelchairs — the type of chair intended for use by those who can’t walk long distances — down the jet bridge to board the plane first. Then, regular passengers start to crowd around the check-in gate. A family with a baby stroller checks in and starts walking to the jet bridge. Amid the commotion, Mr. Brown seems to have been forgotten entirely.

Mr. Brown starts to get upset with the check-in agents. The Department of Transportation stipulates that disabled passengers who need additional time or assistance to board the airplane must be allowed to board first. Further guidance says that, if possible, airline crews should avoid transferring someone from an aisle seat to a plane seat in front of other people. Soon after he complains, Mr. Brown is quickly wheeled down the jet bridge, shaking his head in frustration and disbelief at a supervisor who insists she did nothing wrong.

In preparation for his second flight, two men strongly and swiftly transfer him to his aisle chair and then to his seat in a blur of motions that leaves Mr. Brown breathing heavily afterward.
Mr. Brown’s body becomes a physical hurdle of sorts for another passenger who tightly squeezes past him and steps over his legs to get to the window seat. (His travel companion was seated between them.) Mr. Brown looks uncomfortable, but, unable to move out of the way, he’s stuck.

He tries to nap on the second flight but has to rouse himself from his sleep to shove his legs back into a straight position and stop his knees from poking out.
The second landing is smoother, but the plane still rattles and shakes as it slows down. Mr. Brown’s arm is once again outstretched against the seat in front of him as he tries to hold himself steady, but there’s a shake of exhaustion in his elbow now. People start deplaning at 6:50 p.m., and one person thanks Mr. Brown for his service on the way out. Mr. Brown nods and pushes his knee in as people walk by, trying to avoid being bumped by suitcases. Soon after the plane empties, a crew in bright yellow vests starts to clean up around Mr. Brown.

At 7:10 p.m., his custom chair is ready for him in the jet bridge. Mr. Brown has another smooth transfer onto the aisle chair, but he is placed down a little crooked, so an airline crew member has to hold his knees to make sure they don’t bump every seat on the way out.
Amy Lawrence, a spokeswoman for American Airlines, said in an email that the company is focused on ensuring a positive experience for those with disabilities. In response to complaints of negative incidents while flying, she wrote: “In recent years, we’ve placed a particular focus on giving our team members the tools and resources they need to properly handle and track customers’ mobility aids, and we’ve seen improvement in handling as a result.” One such effort, she said, was the introduction of wheelchair-specific bag tags on all flights; the tags can improve the tracking of mobility devices and make it more clear what the features of each device are.

**Handling luggage**

Mr. Brown goes to pick up his luggage, then finds out from an airport worker that the San Antonio airport doesn’t have any porter service available to help him carry his shower wheelchair, carry-on suitcase and two large checked bags to the car. The U.S. Department of
Transportation requires airlines to assist disabled passengers with carrying their checked luggage if needed, but people with disabilities complain that, in practice, often either it isn’t provided or they can’t find someone to help them.

Erin Rodriguez, a spokeswoman with the San Antonio International Airport, said that all airlines provide assistance to people with wheelchairs, including helping with their luggage, at no charge. She added that the airport has phones throughout the terminal for travelers needing immediate or after-hours assistance.

The sun is setting, casting the sky pink beneath big, dark clouds as Mr. Brown maneuvers out of the cool airport into the humid Texas heat. (In the end, his travel companion helped him with his luggage; it would have posed a considerable challenge if he’d had to handle it on his own.)

At 7:38 p.m., he easily maneuvers up a ramp into a waiting car that, unlike the planes he just rode, is specially designed to accommodate his wheelchair.
In early July, Paralyzed Veterans of America filed a formal complaint against American Airlines on behalf of four members of its organization, including Charles Brown. Mr. Brown’s inclusion was based on his experience on the flights The Times documented in May. American Airlines did not immediately return request for comment regarding the complaint.

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The Oct. 31 death of longtime disability-rights activist Engracia Figueroa has amplified calls from the disability community to reform disabled air travel.

Last July, while Figueroa flew home to California from an advocacy rally in Washington, D.C., United Airlines severely damaged her wheelchair. While United eventually provided her with a loaner power wheelchair, Figueroa spent weeks fighting with the airline about whether they were obligated to repair or replace her wheelchair.

NPR reported that a previously-healing bedsore reopened in the weeks that she was forced to use the ill-fitting loaner wheelchair. According to Hand in Hand, the organization Figueroa was representing, “The sore became infected, and the infection eventually reached her hip bone, requiring emergency surgery to remove the infected bone and tissue.” She died Oct. 31, two weeks after being admitted to the ICU for complications from the infected pressure sore.

A Broken System

Frustratingly, the issues that led to Figueroa’s death are not new. Air travel was the only mode of modern mass transportation excluded from the Americans with Disabilities Act, and airlines’ disregard for the safety of disabled travelers has been a hot-button topic ever since. Air travel is covered under the Air Carrier Access Act of 1986. Figueroa died just days after the Department of Transportation celebrated the ACAA’s 35th anniversary. While they called it “one of America’s great civil rights achievements,” many disabled advocates see the ACAA as an outdated, toothless piece of legislation that has gone unenforced for years.

As Figueroa herself said in a quote that has been making the rounds in social media since her death: “Mobility devices are an extension of our bodies. When they are damaged or destroyed, we become re-disabled. Until the airlines learn how to treat our devices with the care and respect they deserve, flying remains inaccessible.” Her death highlights the true costs wheelchair users must weigh before booking a flight. Even the most minor damage to a custom wheelchair or seating system can impede the user’s mobility. More substantial damage can lead directly to sores and other injuries or prolonged stays in bed and the cascade of complications that come with that.
Due to successful advocacy from United Spinal Association, Paralyzed Veterans of America and many other disability groups, the 2018 passage of the Federal Aviation Administration Reauthorization Act included provisions from the Air Carrier Access Amendments Act, like tripling the previous maximum civil penalty of $28,500 per instance of mobility aid damage or injury and mandating that the Department of Transportation create a committee to recommend consumer protection improvements for disabled passengers. Still, it lacked true accountability measures that might adequately incentivize the industry to change its ways.

**Support the Air Carrier Access Amendment Act**

Congress needs to extend the Federal Aviation Administration’s programs in the next couple of years. As Congress examines the FAA’s programs and the air travel protections or lack of protections they should give to all Americans, now is the time to ask your members of Congress to cosponsor and support the Air Carrier Access Amendments Act (H.R. 1696/S. 642). This bill, championed by Senator Tammy Baldwin and Representative Jim Langevin, includes a number of new protections that will make air travel more accessible to people with disabilities:

- Increased penalties for damaged wheelchairs/mobility aids or bodily injuries, and allowing air travelers to sue in court to recover damages.
- An Airline Passengers With Disabilities Bill of Rights
- An Advisory Committee on Disability at the Department of Transportation
- Better stowage options for assistive devices
- Safe and effective boarding and deplaning process
- Higher standards for accessibility and safety, and airport and airline employee training

Please contact your members of Congress today and ask them to support and cosponsor the Air Carrier Access Amendments Act (H.R. 1696/S. 642). Take action here: [https://unitedspinal.org/roll-on-capitol-hill/](https://unitedspinal.org/roll-on-capitol-hill/)

For one, the ACAA needs to be amended to include a private right of action. Currently, disabled air travel passengers who are discriminated against or suffer serious harm due to their disability have no legal right to sue for damages. Without the ability to properly hold the industry’s feet to the fire, airlines and air service companies operate with relative impunity.

Enforcement of the ACAA falls entirely on the DOT, which can levy fines through enforcement orders against airlines for violations of the ACAA. Since the DOT began tracking the number of damaged and lost wheelchairs in December 2019, it has chronicled more than 15,000, or roughly 26 a day. That count doesn’t include the myriad other disability-related violations like when passengers are denied preboarding or refused seating accommodations, among others. Yet, according to the DOT’s website, it hasn’t filed a single enforcement order against an airline in that time frame. The last time it did fine an airline for a mobility-disability-related violation was in 2018, when it ordered Allegiant Airlines to pay $250,000 for failing to provide adequate assistance to passengers with disabilities moving within the airport terminal.

Even if the DOT were to do its job, it’s hard to imagine the occasional fine incentivizing change, especially on the heels of a massive industry bailout. As wheelchairtravel.org’s founder John Morris says, “What does a fine mean anyway when the treasury has just deposited $25 billion in your bank account?”

What’s Next

Hand in Hand’s statement detailing Figueroa’s death also served as a petition demanding that “United Airlines end the damage of wheelchairs and assistive devices on its flights and create an accessible process for people
with disabilities to travel safely, with dignity.” In a press release cosponsoring Hand in Hand’s petition, All Wheels Up plainly calls out the airlines’ lip service and record of inaction over the years when it comes to accessibility concerns, saying, “While the industry claims it is supportive of working toward a more accessible future, action and funding have been minimal.” AWU takes the call to action one step further by encouraging all stakeholders to partner with them in their goal of truly accessible air travel by providing a wheelchair spot on airplanes. The National Academies of Sciences recently said this is feasible, and functional prototypes for safe wheelchair securement are already being tested.

It Could Have Been Me

As a C3-4 quad myself, Figueroa’s story could easily have been my own. My skin was similarly damaged in 2016 on a United Airlines flight from Seattle to Newark. Multiple dehumanizing transfers in and out of the industry standard aisle chair and a six-hour flight on a regular airline seat caused such significant shearing injuries to my backside that I went straight to the emergency room after landing.

My recovery was hindered further because United had damaged my head-controlled wheelchair so badly that I spent 11 of 14 days on the East Coast without it. And when Alaska Airlines destroyed the same chair on my way home from Washington, D.C., less than a year later, it took a full six months to get it repaired.

It’s impossible to overstate how dangerous skin issues can be. I’ve lost friends to similar issues. I’ve lost years of my own normal life to skin breakdown like Figueroa’s.

Those experiences thrust me onto a platform I never chose, but since then I have fought alongside countless other tireless advocates to reform the system for all wheelchair-using travelers. While our efforts have been met with plenty of sympathetic and supportive rhetoric from industry executives and elected officials, we’ve seen little actual change. The most frustrating part is that wheelchair-accessible air travel is within reach.

London-based firm PriestmanGoode and Colorado-based Molon Labe Seating have produced workable designs that allow wheelchair users to fly safely in their own wheelchairs. I tested out the latter in a mockup design study just this last summer.

The system, featuring a sliding aisle seat that could collapse over the top of the middle seat, was originally designed to widen aisleways for faster boarding and deplaning. This would allow airlines to accommodate wheelchair users without losing a seat when the wheelchair space isn’t needed. I was able to drive through the cabin of a current configuration of a major airliner unimpeded and backed easily into a Q’STRAINT lock-in mounted on the floor.

The designer told me he could have it ready within a year. The obstacles to accessible airline travel are no longer technical — they’re in forcing an airline industry that prioritizes short-term profit above all else to finally start accommodating all passengers.

What remains to be seen is what, if anything, will come of this tragedy. In a Twitter thread last week, lifelong disability rights activist Judy Heumann laid the blame at the feet of the airlines’ leadership “for the frivolous manner by which they failed to address an issue that has been going on for decades.” Heumann implored Secretary of Transportation Pete Buttigieg, who said at the ACAA celebration there was a “moral and economic imperative” to improve airline accessibility, to convene a meeting of airline executives to demand accountability.

Given the recent news that the secretary just secured a $1.2 trillion infrastructure bill granting him unprecedented power, it sure seems like the right time to put his money where his mouth is. “He said some great things,” says Morris. “This is an opportunity for him to live up to it in assuring and guaranteeing that those rights will be honored and respected.”
The time for talk is over. Engracia Figueroa deserved better. And so do the rest of us. One can’t help but speculate that this isn’t even the first time this has happened. “I would honestly be surprised if she was the first person to have a downstream medical effect from a wheelchair being damaged,” says Morris. “She may not be the first person to have died in a circumstance like that — it is just the first one that we have heard about.”

We’ve crawled off planes. We’ve taken to social media. We’ve assembled and advocated on Capitol Hill. We’ve pleaded behind the scenes with industry executives. And now we’ve lost one of our own. The question we’d like airline executives and lawmakers to give us an honest answer to is this: What else is it going to take?
The Future of Air Travel for People with Disabilities

May 18, 2022, Vincenzo Piscopo, President & CEO, United Spinal Association

Today, the future of air travel stands at several crossroads. One set of paths, I’m sure you are well aware, concerns what direction airline industry will take to address its environmental footprint and sustainability. Another relates to the direction the airlines will take to solve the challenges the COVID-19 pandemic and ensuing labor shortages have posed to their just-in-time management systems. The general public may be less aware that people with disabilities are forging a new path for the airline industry: making air travel accessible for all once and for all, a concern that well precedes the former two crises.

If you think flying during the pandemic is a pain, try flying with a wheelchair on top of it all. Whenever people with disabilities take to the skies, we not only worry about broken wheelchairs, but also, tragically, broken skin and bones and other life threatening risks. For us, the whole air travel experience is fraught with potential dangers to our bodies and mobility devices, as well as personal indignities, from start to finish.

I have disembarked from flights only to see that my wheelchair was broken, ruining my trip plans and setting me on a completely different kind of journey as I seek out the correct service providers to perform urgent repairs. I know I am not alone. Thanks to the advocacy of organizations like United Spinal Association, we have access to highly revealing data about our experiences. According to the US Department of Transportation, just since December 2018, over 20,000 wheelchairs have been reported “lost, damaged or completely destroyed. In January of this year, the percentage of wheelchairs and scooters that were damaged in transit stood at twice that of baggage. Wheelchair users are 3.3 million strong in the United States, and we deserve better.

Let’s face it, coming home from a trip only to be stuck at home or in our beds until we complete the convoluted process of repairing—or even replacing—our wheelchairs is a truly a dark irony. It is not just a matter of time wasted or aggravation. Wheelchairs are not only close to being irreplaceable due to their cost, they also are custom fit to their users’ bodies and needs, preventing dangerous pressure sores (injuries) that are themselves incredibly costly to treat. A broken wheelchair can not only jeopardize our participation in our pastimes but also threaten our very livelihoods—what trip is worth that?

So, the moment we relinquish our wheelchairs as cargo to the airlines is an anxious one—what follows can often be no less reassuring. From the time when we are called to board to when we are finally seated, the standard processes and expectations to which people with mobility disabilities are subject range from suboptimal (having to transfer to a tiny aisle chair and be manhandled by poorly-trained personnel in order to board) to downright inhuman (not being able to go to the bathroom on board the aircraft).
Accessible bathrooms are not yet required on single-aisle aircraft—though a proposed rule released in March 2022 by the DOT may remedy that. Although they are mandated on double-aisle planes constructed after 1990, I have regularly experienced inadequate facilities on larger aircraft, as well. Our right to equal treatment with respect to restrooms is worth more than the corners that are cut to fit a few extra passengers on board.

Inadequate staffing levels and training plague the portion of the trip when we are transferred to an aisle chair, causing massive delays and injuries in the process. We put so much trust in the people transferring us, and if you have ever had that trust broken to the core by being mishandled or even dropped (as I have), you know how little immediate recourse you have. The aisle chairs themselves are often badly maintained to the point of causing further mistrust, and if they are missing straps, that presents yet another serious injury risk. Moreover, we are often abandoned on the plane waiting ages for transfer, with oblivious flight attendants admonishing us for remaining on board. What should be a simple, in-and-out process can end up being another minefield for people with mobility disabilities.

We ask ourselves how much longer will this continue. The Air Carriers Access Act (ACAA) of 1986 enacted into law policies of nondiscrimination, accessibility and assistance for people with disabilities, but clearly, it was not enough. Fortunately, there has been support for reform in Congress, which included some improvements in 2018, and the Biden administration is signaling they may be on board with some of these issues. At a public hearing held by the DOT on air travel wheelchair damages, Transportation Secretary Pete Buttigieg recently announced that they are working on a new rule “that would make damaging or delaying wheelchairs a violation subject to fines, improve training for airline employees that handle wheelchairs and do a lot more.” This month, DOT is also receiving comments on a rule making bathrooms accessible on single-aisle aircraft.

We can find even more hope in a bill now before Congress, the Air Carriers Access Amendments Act of 2021, introduced by two of our Congressional champions, Senator Tammy Baldwin (D-WI) and Representative Jim Langevin (D-RI 2nd). It will give our community much needed leverage to sue and receive potential monetary damages to remedy accessibility violations or damage to our equipment, bolster ACAA enforcement and the imposition of civil penalties on airlines that flout accessibility requirements, and create defined accessibility and improved safety standards for air travel. Support for the Air Carriers Access Amendments Act is a central pillar of our upcoming Roll on Capitol Hill, [https://unitedspinal.org/roll-on-capitol-hill-2022/](https://unitedspinal.org/roll-on-capitol-hill-2022/).

When we fall victim to the negligence of airlines that do not value people with disabilities, we pay far more than full price. Airlines have adopted diversity statements and policies around inclusion wholesale—let’s hold them to their word and let them know that we will not settle for anything else other than tangible, full-scale change. Progressive legislation and regulations are on the horizon, but as with all well-intentioned and emancipatory policies meant for people with disabilities, it will be up to us to make sure they are enforced. Speak up—and find your way to add your voice and your story to United Spinal’s efforts. [Visit this page to take action on the Air Carrier Access Amendments Act](https://unitedspinal.org/roll-on-capitol-hill/)
Dear Ms. Watchorn,

On behalf of United Spinal Association’s Access and Care Coalition¹, I am requesting that the Centers for Medicare and Medicaid Services support establishing new Healthcare Common Procedure Coding System (HCPCS) codes for intermittent urinary catheters. The hundreds of thousands of individuals living with neurogenic bladder whose medical conditions require long-term use of intermittent urinary catheters know too well the challenges they face and the key risk factors associated with urinary tract infections (UTIs).² ³

The mission of the Access and Care Coalition⁴ (ACC) is to support increased consumer access to medical supplies under Medicare, Medicaid and private insurance. The ACC consists of urological and ostomy medical technology suppliers and manufacturers, as well as clinician, physician, and consumer and disability advocates. Founded by paralyzed veterans in 1946, United Spinal Association has been dedicated to advancing the independence and quality of life of over three million wheelchair users across the country living with neurological and paralyzing conditions such as spinal cord injury, multiple sclerosis, amyotrophic lateral sclerosis (ALS), muscular dystrophy and spina bifida. United Spinal Association is also a VA-recognized veterans service organization (VSO) serving veterans with disabilities of all kinds.

We believe that coding distinctions between catheter differences, including surface material (e.g. hydrophilic technology) and features that aid with clean insertion of the catheter are necessary to ensure patients receive a catheter that fits their individual needs. Intermittent urinary catheters are currently grouped into one of three HCPCS codes; straight tip, coude (curved tip), or sterile kit with insertion supplies included. The current code set does not distinguish between hydrophilic coating, no touch functionality, protective features or any other advanced functions that are necessary for successful catheterization which, along with increased patient adherence, can lead to improved bladder health overall and the decrease of secondary complications.

Patients living with Neurogenic Lower Urinary Tract Dysfunction (impaired bladder function) are often dependent on managing their bladder with clean intermittent catheterization (CIC), done every 4-6 hours every day. Even with careful technique, CIC can lead to false passage, bladder infections and pain with catheterization especially with uncoated catheters. Advancements in hydrophilic (coated/lubricated) catheter technology can make catheterization easier, but more importantly, safer, by reducing trauma to the urethra and allowing patients to catheterize with less pain and discomfort increasing patient adherence to follow their catheterization schedule. Decreased friction leads to less damage to the urethra over time. Ready-to-use hydrophilic catheters

¹ https://unitedspinal.org/access-care-coalition/
³ https://my.clevelandclinic.org/health/diseases/15133-neurogenic-bladder
are often medically necessary for patients with limited functional capabilities, specifically for individuals with limited to no hand function and/or anatomical considerations.

In the recently published guideline on adult Neurogenic Lower Urinary Tract Dysfunction (NLUTD) the American Urological Association along with Society of Urodynamics, Female Pelvic Medicine & Urogenital Reconstruction stated the following:

“The clinician treating patients with NLUTD needs to balance a variety of factors when making treatment decisions. In addition to the patient’s urologic symptoms and urodynamic findings, other issues that may influence management options of the lower urinary tract include, cognition, hand function, type of neurologic disease, mobility, bowel function/management, and social and caregiver support”

An HCPCS code reform allows for a level of thorough decision-making when it comes to choosing a catheter that aligns with patient needs. We want to reduce the chances for life-threatening UTIs and other genitourinary complications, not increase them. We want to facilitate every effort to keep UTIs and other complications down to a minimum. The current coding system definitely costs Medicare more money with increased doctor visits, possible hospitalization and potential home health episodes, all because of unnecessary and possibly avoidable UTIs, resulting in an economic burden of at least $2.8 billion (2011 US dollars)\(^5\). A problematic UTI can hospitalize a beneficiary and if the infection becomes septic, can lead to death. UTIs are serious and can be dangerous to anyone – they are even more dangerous to individuals who are already immunocompromised and vulnerable to infections and secondary complications and comorbidities.

Any medical professional who understands permanent urinary retention in the thousands of individuals living with neurogenic dysfunction (bladder impairment) (including individuals with spinal cord injury, spina bifida, multiple sclerosis, muscular dystrophy) knows how important it is to avoid UTIs and any other infections and complications. Per the current local coverage determination (L33803):

*The beneficiary has had distinct, recurrent urinary tract infections, while on a program of sterile intermittent catheterization with A4351/A4352 and sterile lubricant A4332, twice within the 12-month prior to the initiation of sterile intermittent catheter kits.*\(^6\)

UTIs and other infections increase the chances of serious illness or death which equates to increased medical costs for Medicare. Infections increase antibiotic use which contributes to antimicrobial resistance (AMR), a WHO Top 10 global health threat.\(^7\) CMS should recognize the importance of decision-making in accordance with an individual’s functional capabilities and risk factors for complications such as urinary tract infections.\(^8\) \(^9\)

**Physicians should have a way to distinguish between catheter functionalities necessary for successful self-catheterization – which maintains bladder health and kidney function – and insurers need a way to process such orders.** More detailed code description will support shared decision-making between physician and patient and improve adherence to physician recommendations and patient needs. We therefore support CMS creating new codes in the LCD for A4351, A4352, A4353 to enable more equitable access across all populations living

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\(^6\) Medicare Local Coverage Determination, L33803, Urological Supplies


with neurogenic bladder. Please see ‘Coding Recommendations’ attachment. Thank you for your consideration. If you have any questions, please do not hesitate to contact me at abennewith@unitedspinal.org or 800.404.2898.

Sincerely,

Alexandra Bennewith

Alexandra Bennewith, MPA
Vice President, Government Relations

ACCESS AND CARE COALITION SIGNATORIES
Coloplast
Wellspect
Hollister
Muscular Dystrophy Association
Spina Bifida Association
United Spinal Association
Wound Ostomy Continence Nurses Society

UNITED SPINAL ASSOCIATION’S ACCESS AND CARE COALITION FULL MEMBERSHIP LIST:
https://unitedspinal.org/access-care-coalition/

CC: Meena Seshamani, M.D., PhD, Deputy Administrator and Director, Center for Medicare
    Liz Richter, Deputy Director, Center for Medicare

Encl.: Coding Reform Recommendations, UTI Burden of Illness
<table>
<thead>
<tr>
<th>State</th>
<th>Institution Name</th>
<th>City, State</th>
<th>Funded Dates</th>
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<tbody>
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<td>Alabama</td>
<td>University of Alabama at Birmingham (Birmingham, AL)</td>
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<td>TIRR Memorial Hermann (Houston, TX)</td>
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<td></td>
<td>VCU/Sheltering Arms Institute (Richmond, VA)</td>
<td>Richmond, VA</td>
<td>1995-2006, 2021-present</td>
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</tbody>
</table>
Former Spinal Cord Injury Model Systems

**Arizona**
Good Samaritan Medical Center (Phoenix, AZ)
Funded: 1970-1985

**California**
Northridge Hospital Medical Center (Northridge, CA)
Funded: 1982

**Kentucky**
Frazier Rehab Institute (Louisville, KY)
Funded: 2011-2016

**Louisiana**
Touro Rehab Center (New Orleans, LA)
Funded: 1982-1985

**Massachusetts**
Boston University (Boston, MA)

**Michigan**
Rehab Institute of Michigan (Detroit, MI)
Funded: 1983-2000

**Missouri**
University of Missouri (Columbia, MO)

**New York**
New York University (New York, NY)
Funded: 1972-1990

Rochester Regional Spinal Cord Injury Model System (Rochester, NY)
Funded: 1982-1990

**Ohio**
Wexner Medical Center (Columbus, OH)
Funded: 2016-2021

**Pennsylvania**
Magee Rehab Hospital (Philadelphia, PA)
Funded: 1979-2021

**Virginia**
Wilson Rehab Center (Fishersville, VA)
Funded: 1972-1990

**Washington**
University of Washington (Seattle, WA)

**Wisconsin**
Medical College of Wisconsin (Milwaukee, WI)
Funded: 1995-2000
SEATING AND WHEELED MOBILITY PRODUCTS

COVERED PRODUCTS (Medicare Part B)

General Use Cushion
available to everyone, provides comfort only

Aluminum Manual WC
available to everyone

Power Tilt and Recline
needed for pressure relief and catheterization

NOT COVERED PRODUCTS (Medicare Part B)

Skin Protection Cushion – NOT Available to All
diagnosis specific
- even if you have history of wounds

Titanium Chair
absorbs vibration when pushing outside
- lightweight to transfer into car

Power Seat Elevation
coverage under review by CMS
- public comments are SUPPOSED to open by August

Power Standing

NOT COVERED – Not Necessary for Mobility ‘In the Home’

5th Wheel for Manual Wheelchair

- lifts the front casters off the ground to prevent getting casters stuck

4 Wheel Drive Power Chair

- allows power chair users to ‘pop a wheelie’ to get over a curb, just like a manual chair