CLINICAL PERSPECTIVE

‘Start Paying Attention’ Leads the Message of Accessibility, Advocacy and Action

CEU ARTICLE REVIEW

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“Start paying attention.”

These are the words of Alexandra (Alex to those closest to her), whose lived experiences shaped her family’s passion for improving accessibility. It’s a simple phrase, but one that truly carries immense weight.

As a career-long wheelchair seating specialist, I considered myself to be especially tuned into the needs of people with impairments. But after meeting Alex and her brother, Sam, I quickly realized just how much I had been missing.

Alex and Sam have shared life’s big and small moments, including a diagnosis that greatly shaped their paths: Friedreich’s ataxia. It is a rare, inherited, progressive neurodegenerative disorder resulting in ataxic movement patterns, muscle weakness, fatigue, loss of reflexes, dysarthria, scoliosis and vision and hearing impairments.[1] The disorder affects approximately 1 in 50,000 people worldwide and is the most common of the hereditary ataxias.[2] Treatment focuses on symptom management and disease progression, as there is no cure for the disorder.

While their function has been significantly impacted, their cognition is not. Sam, the older sibling, was diagnosed at age 8. Alex’s diagnosis followed a mere two years later. They did not let Friedreich’s ataxia define or limit their ambitions. Both graduated high school and college. Sam earned a bachelor’s degree in video production and communications, and Alex earned both a bachelor’s and a master’s degree in social work.

Like many college graduates, they entered the workforce ready and eager to build their careers. Through Med Connect CT, a state-run program that assists disabled residents with employment, Sam secured a role in a local high school’s security department. Alex worked for a nonprofit organization serving homeless youth. There, she helped develop programs, coordinate speakers and connect individuals with community resources. She spent more than a year building meaningful initiatives before the organization underwent a leadership change. Despite her extensive contributions, she was not considered for advancement.

She continued searching for another role, but after several years without success, Alex had an epiphany. She and her brother had long been frustrated with the lack of access and “accessibility” for people with mobility impairments. She was determined to create her own nonprofit and pour her frustrations into action.

With her mother, Mary’s, assistance, Alex co-founded Peace, Love, ACCESSibility.

Their mission is “to empower individuals by advocating for universal access and promoting awareness about the importance of accessibility for all, especially people with mobility impairments. The organization is driven by a strong family commitment to making public spaces, services and opportunities available to everyone, regardless of their abilities. Through community outreach, education and partnerships with local stakeholders, we work to ensure that accessibility is not just a policy, but a reality that enhances the lives of Connecticut residents.”

Peace, Love, ACCESSibility’s primary focus area began with accessible parking—an issue that seems straightforward yet is frequently overlooked and misunderstood. Their outreach provides education on parking rules and regulations to area law enforcement while increasing awareness on consequences with lack of access. It would seem common sense dictates many of these laws — one should never use someone else’s placard; one should never park in an accessible spot without a placard; the striped spaces next to a spot are not for parking. Peach, Love, ACCESSibility has designed information cards to place on a vehicle should it be parked incorrectly or illegally, bringing awareness to those who may not know or choose to ignore others’ realities (see Figure 1).

Figure 1: One of Peace, Love, ACCESSibility’s information cards.

While accessible parking is at the forefront of the nonprofit’s agenda, there are still other areas where people with disabilities struggle on a day-to-day basis. While this article cannot address all these areas, it will highlight struggles with different modes of transportation and provide education on the Americans with Disabilities Act, its amended version and how to “start the conversation” within the community.

Disability Facts

According to the World Health Organization, one in six people lives with a disability. In the United States, that number increases to one in four adults, with mobility limitations being the most common.[5]

Disability can impact many aspects of life, including lower employment rates, lower earnings, higher instances of comorbidities and unequal access to healthcare and education.[4] These disparities are often exacerbated by barriers to accessing buildings or transportation services, lack of inclusion and societal stigma.

The Americans with Disabilities Act (ADA) "prohibits discrimination and guarantees equal opportunity in employment, public services and access to goods and services."[3] While this seems simple to uphold on paper, awareness and enforcement remain very inconsistent, leaving huge gaps between policy and practice for people with disabilities.

The Americans with Disabilities Act

The Americans with Disabilities Act piggybacked off of the Civil Rights Act of 1964, which made discrimination based on "race, religion, sex, national origin and other characteristics illegal."[6] What made the ADA different from the Civil Rights Act was that the ADA mandated employers with a certain number of employees to provide reasonable accommodations to employees with disabilities. The disability did not need to be severe or permanent. It also enforces "accessibility requirements on public accommodations."[6] This was supported by both sides of the aisle, with opposition mainly heard from business interests who felt that costs would be forced upon them by the legislation.

The "Capitol Crawl" may be considered the final step toward the support and signing of the ADA into law. Along with disability advocates, many physically disabled persons removed themselves from their assistive devices and wheelchairs and "crawled" up the 100 steps of the U.S. Capitol building.

The ADA was signed into law on July 26, 1990, by George H.W. Bush, who said, "Let the shameful wall of exclusion finally come tumbling down," and marked a decades-long effort to equalize civil rights protections for people with disabilities.

The ADA protects the rights of those with disabilities when it comes to employment, access to state and local government programs, places of public accommodation, telecommunications and miscellaneous provisions that encompass areas of everyday life. Also included in the original scope of the ADA was a provision making it unlawful to discriminate against one's association with a person with a disability.[3]

Stemming from U.S. Supreme Court decisions that were reversed due to text interpretation of the ADA came the passing of the ADA Amendments Act of 2008. The ADAAA expanded the definition of disability under the ADA, making it easier to seek protection against discrimination. It extended protections to include equal access, reasonable accommodations and effective communication. Despite ongoing education, 18 years later, significant disparity still exists.

The ADA: Title III – Public Accommodations

Title III of the ADA applies to public accommodations, including private businesses, nonprofit organizations and commercial facilities that are open to the public. It establishes accessibility requirements for both new construction and modifications to existing buildings. "It outlines requirements for equal access, communication and physical accessibility, including standards for new construction and alterations, and mandates barrier removal in existing facilities where readily achievable."[7] It ensures these spaces and services are equally and inclusively accessible to the disabled population. Many buildings were constructed without considering the needs of a mobility impaired person. Accessible design ensures that people with disabilities can use products or environments and is typically done to comply with ADA regulations. Universal design, on the other hand, ensures that all people can use a product or environment, regardless of age or disability, without the need for modification. Advocacy efforts play a crucial role in highlighting these challenges and insisting on retrofitting and redesign. This is further enforced through Title III of the ADA, should a violation be acknowledged. By documenting lived experiences and sharing personal stories, advocates bring attention to the real-world consequences of inaccessibility.

Not to be omitted, as physical access to buildings and spaces is the type of accessibility that

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first comes to mind, Title III also ensures that digital space requirements based on the "Web Content Accessibility Guidelines" are included. Web Content Accessibility Guidelines are international standards that guarantees digital content is "more accessible to a wider range of people with disabilities, including accommodations for blindness and low vision, deafness and hearing loss, limited movement, speech disabilities, photosensitivity, and combinations of these, and some accommodation for learning disabilities and cognitive limitations."[8] The POUR principles — perceivable, operable, understandable and robust — ensures web content is "usable via screen readers, keyboard navigation and supports varied needs."[8]

Physical compliance entails providing accessible entrances, including ramps, providing legible signage with text or braille and including accessible parking and ingress/egress. Examples of digital compliance can include color contrast, font size, alt text for images, keyboard-only navigation, and captions for video content. Should compliance be questioned and one feels there is a violation of public accommodation rules, Title III is enforced by civil legal action or through Department of Justice action with written complaints filed directly with the department. There are no routine checks to ensure compliance; therefore, the facility must exercise good faith to ensure specifications are met, as it is nearly impossible to monitor all facilities given the vast number that need to comply with ADA regulations. It is common for an entity to be required to modify accessibility constraints or provide reasonable accommodations if a lawsuit is filed and upheld.

Planes, Trains, and Automobiles

PLANES:

For individuals who rely on mobility devices, air travel can be daunting and present significant challenges. Rare is the air travel story that does not end with a wheelchair coming out the other end with some kind of damage or missing parts. It's a persistent issue that can quickly turn what should be a straightforward trip completely upside down; however, trends are moving in the right direction. Numbers from 2025 indicate a decrease in wheelchair and scooter mishandling claims from 1.26% in 2024 to 1.09% in 2025, although this data may be inaccurate due to a new reporting system.10 According to wheelchairtravel.org, Delta is the best performer when it comes to management of wheelchairs and scooters, with JetBlue falling to 10 place (from seventh) in 2025.[11]

Wheelchairs being physically lifted (and dropped) is the most common cause of damage to power wheelchairs. Components that are not meant to bear weight (armrests, footplates) suffer damage when they bear the brunt of the lifting, and the chair can weigh upwards of 400 pounds. Lightweight manual wheelchairs are also at risk, as crews can toss them into the cargo hold. Equipment not properly secured in the cargo hold results in wheelchairs being vulnerable to shifting during flight. Many domestic flights do not have a large enough door to load a chair, so it must be loaded on its side. Inclement weather exposure rounds out the top four causes of equipment damage, with chairs waiting on the tarmac prior to being brought to the jetway.

Poor equipment handling meant a wheelchair user had to travel around Ireland in a standard manual wheelchair instead of their custom ultra-lightweight manual chair, as it was damaged on the flight into the country. A more recent incident occurred where the Peace, Love, ACCESSibility executive director suffered a damaged joystick (see Figure 2), which rendered her power wheelchair inoperable. Fortunately, this occurred stateside, and a connection through her ATP "only" resulted in her being bedbound for an extra eight hours.

But this shouldn't be. The Air Carrier Access Act prohibits discrimination against passengers with disabilities and applies to all flights entering, leaving or within the United States. It requires airlines to provide assistance throughout the travel process, from security, travel to the gate, boarding, connecting flights and to the baggage claim. On the flight, it ensures appropriate seating accommodations to meet the passenger's needs. And it can include assistance with loading and storing one's assistive or mobility device.

But it is a hard pill to swallow when someone's mobility equipment is tossed around like a bowling pin, despite the myriad rules that are in place. Although protocols are

Figure 2: Broken joystick after an airline flight.

present to assist with damaged equipment, they are often of little help when the individual is rendered immobile until their equipment is repaired or replaced.

On domestic flights, full compensation for wheelchair loss or damage is required for U.S. carriers "without regard to rules limiting liability for lost or damaged baggage."[9] The Montreal Convention Provisions control payments for items, including assistive and mobility devices, on international flights. The complaints resolution official is the airline's expert on disability accommodation issues and should be contacted immediately after determining that damage has occurred to one's equipment.[9] The airlines are required to make a contact available in person or via telephone to address one's concerns and to assist in filing a claim.

Efforts are currently underway to allow passengers to remain in their own wheelchairs during flights, though widespread adoption is still years away.

TRAINS:

Trains generally provide greater accessibility than planes, allowing passengers to remain in their wheelchairs during travel should they choose. Under the ADA, train stations must meet accessibility requirements, including accessible parking, routes, restrooms and water fountains. With these accessibility regulations in place, one would think there cannot possibly be a barrier to entering/exiting a train... or is there?

A ramp or bridge plate is required to allow a user to gain access to the train car. However, a Peace, Love, ACCESSibility Board Advisor recently traveled via Amtrak, and there was insufficient space to access the bridge plate with mere inches available between its entrance and a concrete wall (see Figure 3).

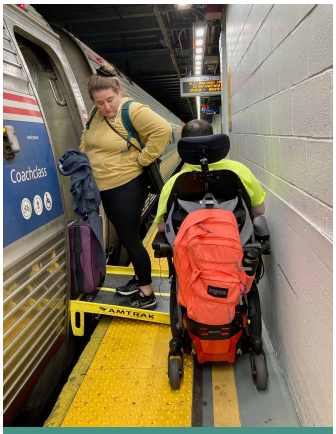

Figure 3: Poor bridge plate accessibility to enter an Amtrak train car.

Wheelchair users are entitled to specialized seating and access to bathrooms when using a train service such as Amtrak. People with disabilities, including wheelchair users, may also travel with service animals and may benefit from a 10% fare discount on Amtrak. Subways and local transit will ensure access to the train cars; however, they may not have accessible bathrooms. Again, this only works if they can gain access to the train cars.

Train travel is governed by the Federal Railroad Administration, which operates under the Department of Transportation. Unfortunately, like with air travel, there is no complaints resolution official. Recent events experienced by those with Peace, Love ACCESSibility has spearheaded another focus. Their reservation was not honored, and they had to share the space reserved for passengers with disabilities with luggage (see Figure 4). In addition, the direct caregivers had to accommodate available seating rather than being seated adjacent to the wheelchair users. The incident demonstrates a pattern of failure to provide effective, reasonable accommodations, maintain accessible space and ensure that passengers with disabilities and their assistants can travel safely, with dignity, and with the ability to provide necessary care.

The Federal Railroad Administration Office of Civil Rights is responsible for civil rights compliance and monitoring to ensure nondiscrimination in intercity rail services. Had a complaint resolution official been present, a complaint could have been filed immediately. Instead, the nonprofit will add to its focus of accessibility and advocacy and work to promote legislation that mandates such an official be present in person or via telecommunication to assist in claims resolution.

Figure 4: Luggage stored in a wheelchair-accessible space on an Amtrak train.

AUTOMOBILES:

Travel by car or bus offers great flexibility but is certainly not without its own pitfalls. Depending on where one lives (urban, rural or suburban), buses and transit vans are readily accessible; however, relying on public transportation or medical transportation services is not ideal. Being at the mercy of someone else can result in missed or late arrival to appointments. Often, when they are on time, there are concerning stories about how their equipment is secured, which could be catastrophic in the event of an accident.

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Privately owned wheelchair-accessible vans provide independence but are often cost-prohibitive. Even if one has the "luxury" of their own van, finding ample or appropriate parking can be difficult. According to the Accessible Parking Coalition, nearly 70% of people with disabilities have trouble locating accessible parking (see Figures 5 and 6).

The following are parking space rules and regulations surrounding accessible spaces:

LOCATION: A true accessible spot is one that provides the shortest accessible route to the accessible entrance. An accessible route is the "path the disabled person takes to enter and move through a building or facility."[3]

SPACES/VAN ACCESSIBLE SPACES: Depending on the type of vehicle (car vs. van), space and access aisle width is a formula that the facility can choose as long as they meet certain specifications. They have detailed features that make it easier to access the programs, goods or services that the given facility provides. Slope, surface and proper signage round out these requirements. The number of acceptable minimum accessible parking spaces depends on the total number of spaces in a lot or facility, ensuring that at least one of every six spaces is van accessible.

ACCESS AISLES: Access aisles are marked areas attached to either side of an accessible parking space that allow people using a wheelchair or mobility device to get in/out of their vehicle. As long as the width specifications are met, the access aisle can be shared. The aisles must be marked, be the same length as the actual parking space and be level with it.[3]

The U.S. Department of Justice Civil Rights Division relies on facilities to act in good faith to meet accessibility requirements, since it is not feasible to monitor every commercial property. If someone believes these standards for public accommodation have been violated, they may file a written complaint with the Department of Justice. In practical terms, the ADA (enforced by the Department of Justice) sets the requirements for accessible parking spaces, while the state Department of Motor Vehicles determines eligibility for parking placards, and local municipalities are responsible for day-to-day enforcement.

PARKING PLACARDS: Parking placards permit the use of a designated accessible parking spot. Obtained through the Department of Motor Vehicles, the individual requires sign-off by a licensed certified medical practitioner (doctor, physician assistant or advanced practice registered nurse) after meeting certain criteria. Federal law, via the ADA, regulates parking rules, including the number of spaces per lot. The number of parking spaces dictates the minimum number of accessible spaces. Medical facilities such as hospitals and rehabilitation facilities are required to have more accessible spaces and recognize placards as evidence of disability.

Inclusion criteria for accessible placards comprise of wheelchair users, those who are legally blind, people who utilize an assistive device or another person to ambulate, someone who uses portable oxygen or have a serious heart or lung condition that limits their ability to walk, people

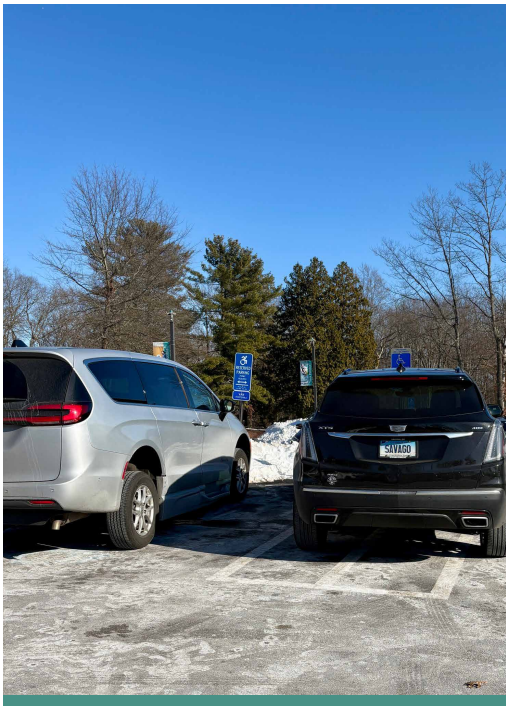

Figure 5: Parking in an access aisle with poor signage.

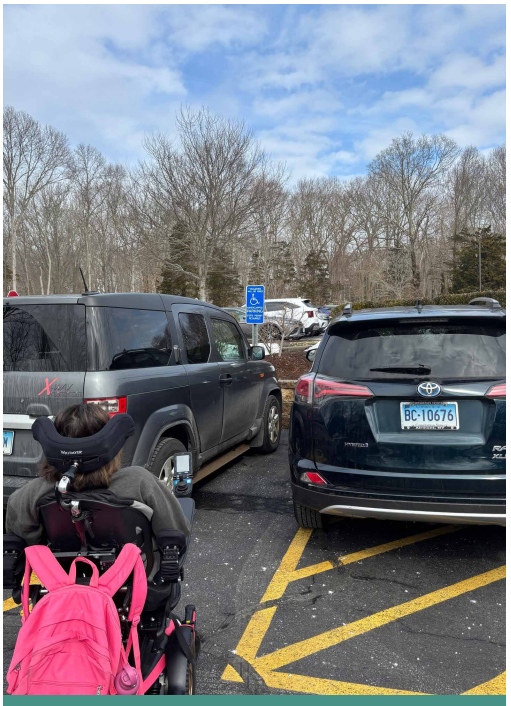

Figure 6: Parking in an access aisle.

who are unable to walk 200 feet without needing rest, and people with severe arthritic, neurological or orthopedic conditions that limit mobility.

The placard is issued to a person, not a vehicle, and allows them to use accessible spaces as long as they have it. The tag should only be displayed when the vehicle is stationary. In many states, it is illegal to hang anything from the rearview mirror. Finally, the placard is only valid when the holder is present. Failure to comply with these rules is considered fraudulent and can result in penalties, including fines and even cancellation of the permit.

Proper education of the medical professional community is integral to ensuring proper placard authorization and reducing fraud and abuse of this program. Their role is critical in maintaining the integrity of the accessible parking program.

Symptom manifestation may be a more equitable basis for issuing placards than a straight diagnosis. As a person with rheumatoid arthritis that is, fortunately, well-managed, I was offered an accessible parking placard by a physician. I immediately declined and offered education on the actual necessity. This is the prime example of symptom manifestation versus providing blanket approval for someone with a qualifying diagnosis.

Other Challenges

Many individuals face significant barriers in obtaining the equipment they need, often due to insurance limitations or denials stemming from misinterpretation of coverage rules. Even after securing equipment, a new challenge emerges: keeping it functional. While recent repair legislation has improved access to maintenance services, some policies lack meaningful accountability when providers fail to meet required timelines or standards. This leaves end users navigating a complicated and often delayed repair process. Additional legislation aimed at improving the speed and quality of repairs continues to be introduced, but its real-world impact on access for the disability community remains to be seen.

Moving Forward

One of the key messages from Peace, Love, ACCESSibility is that disability etiquette is rooted in respect and awareness, and in recognizing that a disability is integral to one's identity but not their defining feature. Interactions should be grounded in courtesy, patience, and respect — no different than how you should treat anyone else.

Figure 7: Peace, Love, ACCESSibility doing what they do best, advocating while promoting kindness.

Creating a more accessible world requires undoing long-standing barriers through inclusive design, equitable policy and a shift in cultural awareness. Progress depends on sustained collaboration across communities, governments, institutions and grassroots groups whose voices are increasingly shaping state- and local-level conversations. The goal is clear: ensure that all individuals, regardless of physical ability, can fully participate in society (see Figure 7).

Accessibility is not limited to buildings or infrastructure. It must also live in attitudes, policies and everyday practices. While awareness campaigns and legislative efforts are critical, lasting change depends on building a culture that values inclusion at its core. Education remains a major gap. National organizations like United Spinal Association, Disability Rights Education and Defense Fund, National Coalition for Assistive and Rehab Technology, Paralyzed Veterans of America and the Clinician Task Force play a vital role in advancing that education alongside local efforts such as Peace, Love, ACCESSibility, which help usher these conversations into communities.

Advocacy at the policy level is equally important. Lobbying and public testimony at both the state and federal levels can translate lived experience into actionable change. Events like the United Spinal Association's Roll on Capitol Hill provide meaningful opportunities for individuals, advocates and corporate partners to engage directly with lawmakers and champion policies that impact the independence and quality of life of more than 5.5 million wheelchair users nationwide. Without these efforts, momentum stalls and meaningful reform becomes far less attainable.

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Equally critical is ensuring that individuals with disabilities are not just represented but are actively included in decision-making. Too often, policies are developed without the voices of those most affected. True inclusion requires that stakeholders be part of the process from the very get-go. Without lived experience guiding outcomes, accessibility efforts risk falling short.

Since its inception, Peace, Love, ACCESSibility has reached 25 of Connecticut's 95 police departments, raising awareness of accessible parking regulations through education and real-world context. Their advocacy contributed to the designation of Accessible Parking Awareness Day in Connecticut on July 15, 2025. What began as a short-term initiative has evolved into ongoing training efforts designed to prevent complacency and reinforce accountability. Their work also extends to businesses, encouraging them to create environments that are welcoming and respectful of individuals of all mobility levels.

In recognition of these efforts, Peace, Love, ACCESSibility received the Human Spirit Award from the Denise D'Ascenzo Foundation in 2025.

Looking ahead, Peace, Love, ACCESSibility is focused on expanding education for healthcare providers who issue parking placards. By advocating for clearer training and better adherence to eligibility criteria, the nonprofit aims to preserve the integrity of the system and ensure access for those who truly need it. Recent testimony before the Connecticut Transportation Committee underscores a broader issue: accessibility must be understood, respected, and protected not only by those who need it, but also by the broader, able-bodied population.

This year, the nonprofit was front and center on Great Day Connecticut as a charitable partner in the Walk to Fight Rare Diseases. Taking place at Quinnipiac University, steps were walked, and wheels were rolled, to expand awareness of rare diseases. Peace, Love, ACCESSibility is not shy to these local universities, educating physical and occupational therapy students in accessibility trials and tribulations.

Additionally, 2026 is a big year for Peace, Love, ACCESSibility, as it expands on the annual Community Access Awareness Day and returns to its fundraising roots. It has been many years since the nonprofit focused on Friedreich's ataxia, but it has decided to hold a combined fundraising event with the Friedreich's Ataxia Research Alliance. Hope is the primary message and the feeling is contagious.

Despite meaningful progress, barriers persist. Accessibility and inclusion are still not universal, and many individuals with disabilities continue to face exclusion in everyday life. Accessibility does not begin and end at the street. It matters everywhere people live, work and move.

As Alex and Mary put it, "Start paying attention. Start the conversation. Get out and do something. And respect the true need for accessibility."

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