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The Honorable Peter Buttigieg  
Secretary  
U.S. Department of Transportation  
1200 New Jersey Avenue, SE  
Washington, DC 20590

**Re: Ensuring Safe Accommodations for Air Travelers with Disabilities Using Wheelchairs Proposed Rule**

Dear Secretary Buttigieg:

The ALS Association appreciates the opportunity to comment on the Department of Transportation (DOT or Department) Proposed Rule, *Ensuring Safe Accommodations for Air Travelers with Disabilities Using Wheelchairs*, Docket ID: DOT-OST-2022-0144, RIN 2105-AF14.

The U.S. Department of Transportation needs to strengthen its enforcement of the *Air Carrier Access Act* (ACAA) to address the significant barriers that individuals with disabilities experience using wheelchairs and scooters when flying by air. Flying by air is not a safe or comfortable option for people with disabilities, who often face harm to their dignity and safety. They frequently encounter broken wheelchairs and scooters and improper transfers between on-board aisle chairs and their own wheelchairs. The Proposed Rule is a much-needed revision to the Air Carrier Access Act (ACAA) and in line with the *FAA Reauthorization Act of 2024* to improve safeguards for people flying with disabilities.

The ALS Association agrees with the Department's Proposed Rule that aims to safeguard and respect disabled airline passengers who need their wheelchairs for their mobility and want the airlines to manage their equipment with care. We urge DOT to uphold strict criteria and track progress to address the needs of passengers with disabilities and keep collaborating with the airline industry to improve air travel for people with disabilities.

Our comments focus on how the Department's Proposed Rule impacts people with Amyotrophic Lateral Sclerosis (ALS) who need mobility devices such as power wheelchair systems, wheelchairs, scooters, and other medical devices and specialized equipment when they travel for both enjoyment and for medical reasons. We fully support and endorse these standards for airlines to provide quick, safe, and respectful assistance, backed by improved training for staff and contractors who assist passengers with disabilities and handle their wheelchairs.

Regulatory change is necessary to make air travel better for people who have ALS. They face many risks and challenges when flying, such as injury, indignities, and loss and damage of their equipment. Many

carriers refuse to transport their mobility devices. Many in our community avoid air travel because of these concerns. This is discrimination based on disability, as it prevents them from accessing the benefits and opportunities of air travel. We collected and will share stories from people who live with ALS and their caregivers, hoping that by telling their experiences, we can show the importance of flying with security and respect and being treated fairly is of the utmost importance:

**I was heading to Tampa Bay, eager to soak in the warm Florida sun. But as I was wheeled off the plane, a sinking feeling crept into my chest. My wheelchair was nowhere to be seen. Panic washed over me as I realized I was stranded, alone and vulnerable. The airport staff assured me they were looking into the situation, but minutes turned into hours. My anxiety soared as I imagined all the scenarios playing out. What if my wheelchair was damaged? What if it was lost? Tears welled up in my eyes as I felt the crushing weight of my disability. I felt isolated and abandoned. Eventually, a replacement wheelchair was located, but the damage had been done. The experience left its mark on me, a reminder of the constant challenges I faced as someone living with ALS.**

The ALS Association is dedicated to addressing these unfair situations and collaborating with the federal government to find solutions. We provide these comments and endorse the letters from other organizations that focus on disability in favor of these new regulations. We hope that by highlighting the stories of those who have faced these challenges firsthand motivates the change that is long overdue.

Our goal is to raise awareness of the experiences of people with ALS and their caregivers, and to urge air carriers to accommodate and respect the needs of people with ALS, so that they can travel with dignity. These powerful stories from the lives of people who have ALS show how important it is for airlines to address these problems as soon as possible.

#### **Delays and Rough Handling:**

Molly Veydovec's mother was given less than a year to live, so her family made it a priority for her to see them before she was no longer able to travel. Airline employees did their best, but her mother was "treated like baggage," she said. Her mother waited over half an hour after everyone else had left the plane for assistance. The airline crew member who moved her was rough and she felt "pushed and prodded" during transport. "In a situation where people with ALS have already lost so much dignity, air travel is one place they could be made to feel human," Veydovec said.

#### **Inaccessible Restrooms:**

Paul Klotz had difficulty securing seats next to a restroom on all his flights to Italy. His scooter and portable wheelchair were in the baggage compartment and walkers are not ideal for navigating narrow airplane aisles. "The location of the restroom from my assigned seat made it difficult to use the bathroom," he said. "Assigning an aisle seat next to a bathroom would make it more accessible for people with disabilities," Klotz said, "and grab bars would be an added safety measure for disabled travelers to access the bathroom."

**Damage to Mobility Lifelines:**

John Roselle's wife was diagnosed with ALS in 2021 and got her power wheelchair in May of 2022. She took her first trip to Philadelphia the following month. Her chair was significantly mishandled on both legs of the trip and required an immediate replacement, which was not available. Roselle took photos of the ground crew loading his wife's 400-pound power chair onto the ramp to the baggage compartment. They put it on its side, which damaged one of the arms and the communication links. "It was obvious they had no idea how to handle the chair or get it on the plane," Roselle said. He and his wife decided after that experience never to fly again and instead rely on their mobility van for long drives.

**An Invisible Disability:**

When Kelly Stonebrook's father, a man living with ALS, was flying to Florida, his family informed the airline that he had a disability and needed assistance getting on and off the plane. Since he was not yet using a wheelchair full-time, the airline was not supportive. "He didn't look like someone with a disability," Stonebrook said. The airline denied him preboarding because his disability was not visible, and the crew failed to assist him during the flight despite his requests. "He never flew again," Stonebrook said. She recommends better education for airline crews about ALS. "Even if the person looks OK, they might be having invisible disabilities, pain, or discomfort."

These are just a few of the stories and first-hand experiences that emphasize the importance of:

- Prioritizing timely assistance for passengers with ALS.
- Ensuring accessibility features, such as nearby restroom seats and grab bars.
- Proper training for airline staff on handling mobility equipment and understanding ALS.
- Recognizing and accommodating invisible disabilities to provide appropriate support.
- Ensuring accountability and responsiveness from airport staff to address immediate needs and concerns.

**Safety and Dignity:**

The ACAAs were passed by Congress with the purpose of ensuring safe travel for passengers with disabilities without discrimination. The new *FAA Reauthorization Act of 2024* (P.L. 118-63) reaffirms Congress's intention to further safeguard the safety and dignity of passengers with disabilities, especially those who use mobility devices, in air travel.

The *FAA Reauthorization Act of 2024* included measures that require the Department to improve the training standards for air carrier personnel who help passengers with disabilities or handle wheelchairs and scooters; mandates detailed yearly reports to Congress on the number of complaints related to disability issues; instructs the Department to make rules on additional accommodations for passengers with disabilities; and addresses the accessibility of the aircraft and aircraft services. We agree that these requirements are necessary to ensure the safe and dignified air travel experience for passengers with disabilities.

We also encourage the Department to work with the airlines and the disability community to improve their policies and procedures, enhance passenger transfers and the handling of personal mobility aids, expand accessibility services training for frontline workers and raise awareness about passengers with

disabilities, and support the continuous research and development of safe and feasible aircraft accessibility features that increase air travel opportunities for passengers with disabilities. We also ask for the Department's help to bring together public forums for air carriers, air carrier associations, airplane manufacturers, and patient advocacy organizations to work together and offer feedback on how to make air travel better for people with disabilities and their caregivers. The ACAA's core principle is the passenger's safety and dignity. The passenger's safety should always be the priority. Their safety and wellbeing should always be paramount.

**Training for Airline Personnel:**

Passengers with disabilities may face emotional and physical harm when they travel by air. The wheelchair attendants who assist passengers with mobility impairments often lack the skills to help them safely. In addition, passengers who use wheelchairs often worry, sometimes rightly, that their power wheelchair will be damaged. Poor and insufficient training leads to more incidents of damaged mobility devices and harmed passengers. Training standards, including refresher courses, need to be enhanced to protect the passenger's dignity and safety.

*The FAA Reauthorization Act* reinforces Congress's mandate to make air travel safer for mobility device users by requiring better training for employees and contractors. Anyone who works for airlines or their contractors must know the carrier's rules and the rights of passengers with disabilities under the ACAA. The training must include the skills needed to assist passengers, handle wheelchairs or scooters, or help passengers with disabilities. Sadly, inadequate training in assisting passengers and handling mobility devices can result in harm to the passenger and damage or loss of their devices, causing physical injuries, medical expenses, loss of autonomy, reduced quality of life, and loss of dignity.

The training of all personnel who assist passengers with disabilities or handle mobility devices should be improved to ensure that passengers are transported safely on commercial aircraft and receive the same level of service as passengers without disabilities. Moreover, all personnel who assist passengers with disabilities or handle mobility devices must show a qualified instructor that they can provide safe physical assistance and how to properly load, secure, and unload wheelchairs and any specialized equipment. We also support both initial training and recertification to remain qualified for providing mobility assistance. By providing effective training, including skill evaluations, passengers and their mobility devices will have enhanced safety and receive assistance in a respectful way.

The ALS Association and its community are eager to work with the Department on developing training criteria and guidelines that can inform both the government and the airlines industry about the needs of those living with ALS to ensure secure and dignified air travel. We are eager to have representation on the ACAA's Advisory Committee at the Department and or work with the Department on enhancing training standards for passengers who use wheelchairs. We also strongly recommend the Department and air carriers collaborate with national disability organizations and patient advocacy organizations, such as the ALS Association, in creating auditing and training to improve assistance standards for people living with ALS and their caregivers.

**Enforcement Recommendations:**

We firmly endorse enhancing the ACAA's regulations and proposal *Ensuring Safe Accommodations for Air Travelers with Disabilities Using Wheelchairs*, but we also recognize that new regulations without

effective enforcement will probably not make much difference in the quality of air travel for people with disabilities. These improvements are necessary to make air travel more secure, more accessible, and more respectful for people with ALS, who deserve to travel with dignity and care.

The Department must investigate and enforce the ACAA rigorously. The Department should pursue more frequent and severe enforcement actions to enhance the safety of passengers with disabilities promptly. The Department must work vigorously with the airlines not only provide remedies to violations but also to prevent violations like not preboarding passengers with disabilities, not training airline personnel properly or on time, not providing deplaning and transfer help, or breaking complex wheelchairs or other equipment. The Department should enforce air accessibility requirements and take actions to prevent carriers from refusing to transport passengers who rely on wheelchairs or scooters as a way of reducing or evading ACAA obligations.

The Department acknowledged that a strong enforcement program is essential to safeguard the rights of airline passengers. The Department issued previous notices to clarify its investigatory and enforcement policies and practices and reassert its determination to forcefully enforce the law to protect aviation consumers, hold carriers accountable, and prevent future violations. However, this commitment to enforcement has not been yet implemented to systemic or egregious ACAA violations. We urge the Department to gather and analyze data on the kinds and number of cases of wheelchairs being mishandled and to publish the data on its website for public access. Enforcement should cover all parts of passenger rights to accommodations and services related to disability and hold air carriers responsible not only with civil penalties but also with other measures to ensure compliance. Airlines should be held responsible to fully reimburse passengers for personal injury and or wheelchairs being mishandled and address discrimination concerns.

Air carriers must cover the costs of mishandling a passenger's wheelchair or mobility device and additional expenses. Just as passengers can claim provable direct or consequential damages for mishandled baggage, they can also claim provable direct or consequential costs for the damage or loss of their wheelchair or mobility device. These costs could include additional medical services needed due to using a substitute wheelchair that is not as tailored as their personal device, medical supplies or services required when the passenger has limited function and safety without their personal wheelchair, lost income due to functional limitations, additional personal care services such as hiring a caregiver or a family member taking time off work to assist with activities of daily living, more expensive transportation if the passenger cannot use their usual mode of transport without their personal mobility device, and any other direct and consequential incurred costs. Enforcement should serve to uphold the quality of fair treatment for people with disabilities and motivate air carriers to check themselves and make improvements to enhance the air travel experience for people with ALS and other disabilities.

We support the appointment of an Assistant Secretary to lead the Department's Office of Aviation Consumer Protection to oversee the enforcement of aviation consumer protection and civil rights authorities granted to the Department by federal statute. We support the authorities of Office of Aviation Consumer Protection to assist, educate, and protect passengers' rights, monitor compliance, conduct investigations, and take appropriate action to address violations of the ACAA. We propose the Department inform disabled consumers about their civil rights, provide resources on how to report air

carrier accessibility issues, and receive additional support from the Department. We also recommend the Department collaborate the Department of Homeland Security to improve the experience of disabled passengers with the Transportation Security Administration, and with the Department of Justice on matters elevated for enforcement under Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act of 1990, or any other relevant legal provision.

**The ALS Association:**

Founded in 1985, The ALS Association is the only national nonprofit organization that works on every aspect of the fight against ALS. We strive to find new treatments and a cure for ALS by conducting worldwide research, offering comprehensive care in certified clinical care centers, and collaborating with government agencies. We also create hope and enhance the well-being of people affected by ALS. The ALS Association is dedicated to ensuring that all people with ALS have fair access to health care services that enhance their health and wellbeing and improve their quality of life. Until ALS is cured, our goal is to make ALS a livable disease for everyone.

We need everyone and our government partners at the federal and state level to act quickly and cooperate with each other across different locations, backgrounds, beliefs, and values, to find a cure and effective treatments for people who have ALS. The ALS Association strives to be inclusive and respectful of the needs and opinions of patients and caregivers as we support, involve, advocate for, and enable people with ALS to live fully and actively. We are committed to overcoming any obstacles that prevent advancement in the fight against ALS and ensuring that our work for the mission is guided by diverse views and experiences.

**What is ALS?**

ALS stands for Amyotrophic Lateral Sclerosis, a disease that damages the nerves in the brain and spinal cord, leading to loss of muscle control throughout the body. People with ALS become trapped in their own bodies, unable to eat, breathe, or move by themselves. However, their minds usually stay alert and aware of what is happening to them. There is no cure for ALS, and most people with the disease die within 2 – 5 years of diagnosis.

ALS often begins with muscle twitches and weakness. The weakness gradually affects both arms and both legs as the motor neurons slowly die and stop signaling the muscles, causing loss of function in a limb or speech problems. Eventually, ALS affects major muscles that are needed to move, speak, eat, and breathe. As the disease gets worse, a person with ALS needs more help with daily activities. They need specialized care from doctors and other health professionals, as well as skilled (nursing and other professional) and non-skilled (daily living) care services from paid providers and family caregivers. A person with ALS often needs access to medical equipment to help them manage their condition, such as advanced power wheelchairs, ventilators, speech generating devices, and other technologies that help people with ALS live a quality life and communicate with their family member or caregiver.

**Conclusion:**

We appreciate the leadership of the Secretary of the Department of Transportation for issuing the *Ensuring Safe Accommodations for Air Travelers with Disabilities Using Wheelchairs Proposed Rule* and

express our willingness to work with the Department and all relevant parties to significantly improve air travel for individuals with disabilities and especially for those living with ALS.

Please contact Rich Brennan, Vice President, Federal Affairs at [rich.brennan@als.org](mailto:rich.brennan@als.org) with any questions.

Thank you,

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