

April 25, 2022

U.S. Department of Transportation 1200 New Jersey Avenue, SE Washington, DC 20590

Re: Department of Transportation Public Meeting on Air Travel by Persons Who Use Wheelchairs (DOT 2022-05422)

Dear Secretary Buttigieg,

In service of the neuromuscular disease (NMD) patient community, the Muscular Dystrophy Association (MDA) thanks the Department of Transportation (DOT or "Department") for the opportunity to comment on the issues raised at the Department's meeting entitled, "Air Travel by Persons who Use Wheelchairs" on March 24, 2022. We are grateful to have had the opportunity to testify twice during the meeting, in addition to the written comments we submitted prior to the meeting. We appreciate the Department's efforts to improve air travel for individuals with disabilities.

MDA is the nation's leading nonprofit organization dedicated to transforming the lives of individuals living with neuromuscular diseases through innovations in science and innovations in care. MDA fulfills its mission by funding biomedical research, providing access to expert clinical care and support through its national MDA Care Center Network, and by championing public policies and programs that benefit those we serve, including removing barriers to improve access to education, employment, travel, and leisure. Since inception, MDA has invested more than \$1 billion in research grants to accelerate treatments and cures for neuromuscular disorders, making MDA the largest source of neuromuscular disease research funding in the U.S. outside of the federal government.

Neuromuscular diseases are diseases that affect individuals' muscles, limbs, and mobility, and often leads to reliance on a wheelchair. This often presents obstacles to comfortable and safe air travel by individuals who use wheelchairs. A recent survey done by MDA in conjunction with Paralyzed Veterans of America and other disability advocacy groups found that lack of accessible aircraft lavatories, fear of injury during transfer from wheelchair to aisle seat and aisle seat to plane seat, lack of knowledge and training by airline personnel, and wheelchair damage leads many in the neuromuscular community to avoid air travel at all costs. This can lead many in the neuromuscular community to delay seeking care and decline to participate in clinical trials because of the inability to travel safely and comfortably by air.

Wheelchairs are Customized for the Individual

One of the solutions put forward during the public meeting by the airline industry was for people with disabilities to simply purchase wheelchairs that cannot be broken or damaged by airline personnel. This proposal reveals a lack of awareness about how wheelchairs are designed and

about the disabilities of the individuals who use them. For people with neuromuscular diseases, wheelchairs are custom fitted to meet the unique needs and shape of the user's body, and as a result, these wheelchairs costs tens of thousands of dollars. As a case in point, MDA advocate Donovan Decker testified at the meeting that he often sleeps in his wheelchair while traveling because hotel rooms are often not designed so he can get into bed. Donovan's wheelchair is specifically tailored to his body, which makes the wheelchair a literal lifeline.

For people with neuromuscular diseases, their wheelchairs often provide vital trunk and spine support, curvature support, and can accommodate assistive technology that helps the individual speak or breathe. As such, for people with neuromuscular diseases and other disabilities, their wheelchairs do not simply provide a means of transportation, but also allow for the mobility of assistive devices and equipment that is essential to their well-being.

It is not possible to simply design a wheelchair airline personnel cannot damage or break. Wheelchairs can often weigh hundreds of pounds and typically have a strong, durable frame. Yet, airlines have damaged over 15,000 wheelchairs since the Department required airlines to report these damages beginning in 2018. Often, airline personnel do not know how to put wheelchairs into manual mode and disengage the motorized component before disassembly, loading, and stowage.

However, regular training of airline personnel on the safe disassembly, loading, and stowing of wheelchairs and other mobility devices can go a long way in eliminating damage to wheelchairs and other mobility devices during flight.

There is currently a bill in Congress entitled the "Air Carrier Access Amendments Act of 2021." This legislation would mandate training for airline personnel on how to properly handle wheelchairs. During the public meeting, there were proposals that airline personnel receive hands-on training with actual wheelchairs to learn how to disengage drivetrains, dissemble, and load wheelchairs. All these measures, including regulatory action by the Department, would go a long way in ensuring that individuals who use wheelchairs can fly without fear of their life sustaining medical devices being damaged or broken.

ACCESS Board Finds Aircraft Can Accommodate Wheelchairs

In response to the claim by the airline industry that aircraft are not designed to accommodate motorized or manual wheelchairs onboard, the FAA Reauthorization Act of 2018 (Public Law 115-254) tasked the U.S. Access Board with conducting a study to assess the feasibility of incabin wheelchair restraint systems, which would allow passengers to board the aircraft and fly in their wheelchairs. In 2021, the study found that in-cabin wheelchair restraint systems could be installed on aircraft with some minor modifications.

Currently, public transit systems such as city buses and subway systems, as well as taxis and ride-sharing services must provide access for passengers who use wheelchairs via wheelchair restraint systems and accessible vehicles. The study by the U.S. Access Board shows that it is feasible for passengers with disabilities to fly safely, comfortably, and securely in their wheelchairs, just as they do on our nation's public transportation systems. For passengers who

use wheelchairs, remaining in their wheelchair for the duration of their travel is the safest and most comfortable way for them to travel. Not only is it feasible, but 36 years after the enactment of the Air Carrier Access Act and 32 years after the enactment of the Americans with Disabilities Act, it is a concept whose time has come.

MDA is committed to ensuring that individuals with neuromuscular diseases and other disabilities can travel on aircraft safely, comfortably, and free from fear of their expensive wheelchairs being damaged and rendered unusable while repairs are performed.

We appreciate this opportunity to provide comment on the air travel experience of persons who use wheelchairs. For questions regarding MDA or the above comments, please contact me at 202-519-2963 or mlewis@mdausa.org

Sincerely,

Michael Lewis

Michael Lewis

Director, Disability Policy

Muscular Dystrophy Association