

June 1, 2022

The Honorable Maria Cantwell United States Senate 511 Hart Senate Office Building Washington, D.C. 20510 The Honorable Roger Wicker United States Senate 555 Dirksen Senate Office Building Washington, D.C. 20510

Dear Chairwoman Cantwell and Ranking Member Wicker:

In service of the neuromuscular disease (NMD) patient community, the Muscular Dystrophy Association (MDA) thanks the Senate Commerce Committee for the opportunity to provide information and suggested requirements to improve air travel for people with disabilities as the Committee begins to draft legislation to reauthorize the Federal Aviation Act in 2023. We are grateful for the Committee'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. 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.

Reliance on a wheelchair for mobility and the support of assistive devices often presents obstacles to comfortable and safe air travel by individuals with disabilities. In a recent survey on accessible air travel, 63 percent of respondents cited inaccessible lavatories as a reason not to fly. Many people with disabilities who have had to travel by air reported having to dehydrate themselves prior to travel so that they would not need to use the lavatory during their flight. In some cases, they also reported soiling themselves during flight, leading to unnecessary embarrassment and humiliation. No individual should have to engage in unhealthy practices like dehydration to travel by air. The inability to fly can lead many individuals with neuromuscular diseases to delay seeking healthcare or decline to participate in clinical trials that could lead to life-changing drugs and therapies for neuromuscular diseases. It can also lead individuals with neuromuscular diseases and other disabilities to avoid traveling to be present for family gatherings and milestones like graduations and weddings.

Additionally, an overwhelming majority of survey respondents cited a fear of their wheelchair being damaged during the flight as a reason for avoiding air travel all together. Lack of standardized, industry-wide training for airline baggage handlers on how to properly dissemble, load, and stow wheelchairs for flight in the cargo hold has led to some 15,000 reports of damaged or broken wheelchairs by airlines since the Department of Transportation started requiring airlines to report damaged or broken wheelchairs in 2018. In 2021, longtime disability rights advocate Engracia Figueroa died from sores she developed using a loaner wheelchair while waiting for repairs to be completed on her custom-fitted power wheelchair after it was damaged by the airline. This was a devastating tragedy, and efforts should be made to ensure such tragic events do not occur in the future.

MDA's Priorities for the FAA Reauthorization:

As the Commerce Committee begins to design legislation to reauthorize the Federal Aviation Act, we request that the following provisions be included to improve the accessibility of air travel for people with disabilities:

 Require DOT oversight of standardized, hands-on training of flight crew members, baggage handlers, and ramp agents: Many wheelchairs are damaged because baggage handlers and ramp agents have little to no training on how to properly dissemble, load, and stow wheelchairs in the cargo hold. Regular, routinized training will help minimize wheelchair damage during flight;

Passengers with mobility limitations often report that flight attendants and gate agents do not know how to safely assist wheelchair users with seat transfers. Legislation to reauthorize the FAA should require regular, hands-on training of gate agents and flight crew on how to properly assist passengers in transfers from the airport wheelchair to the onboard wheelchair (OBW), and from the OBW to the aircraft seat, and include people with disabilities as part of this training.

• Require regular maintenance and inspection of onboard wheelchairs: Onboard wheelchairs, which are used to transport passengers who use wheelchairs onboard the aircraft, down the aisle, and to their seat are often not in working order and can lead to injury. Requiring airlines to ensure that onboard wheelchairs are regularly inspected and maintained for proper, safe use can diminish the risk of injury and help ensure safe seat transfers.

In addition, MDA joins other disability rights organizations, including Paralyzed Veterans of America, in requesting that the following items be included in legislation reauthorizing the Federal Aviation Act:

• Amend the Air Carrier Access Act (ACAA) by including the Air Carrier Access Amendments Act (H.R. 1696/S. 642): The Air Carrier Access Amendments Act (ACAAA) would make the following improvements to the ACAA:

- Strengthen ACAA enforcement by requiring referral of certain passenger-filed complaints to the Department of Justice and establishing a private right of action:
- Ensure new airplanes are designed to accommodate the needs of people with disabilities by requiring airlines to meet defined accessibility standards. These standards will address safe and effective boarding and deplaning, visually accessible announcements, seating accommodations, and better stowage options for assistive devices;
- Require removal of access barriers on existing airplanes to the extent that it is readily achievable, easily accomplishable, and may be done without much difficulty or expense; and
- o Improve the overall safety of air travel for passengers with disabilities.
- Reauthorize the ACAA Advisory Committee: Section 439 of the FAA Reauthorization Act of 2018 required the Secretary of Transportation to establish an advisory committee on the air travel needs of passengers with disabilities. The Committee was appointed in 2019 and submitted a final report to the Secretary in 2022. The Committee is set to terminate on September 20, 2023. In light of the ongoing problems passengers with disabilities encounter in air travel, we strongly believe that this committee should be reauthorized in the 2023 FAA Reauthorization Act through the duration of that authorization.
- Require DOT to continue investigation into the feasibility of in-cabin wheelchair restraint systems: Section 432 of the 2018 FAA Reauthorization Act required the U.S. Access Board, in consultation with DOT, to conduct a study to determine the feasibility of in-cabin wheelchair restraint systems and if feasible, the ways in which individuals with significant disabilities, including those who use power chairs, could be accommodated in the cabin.

The U.S. Access Board worked with the Transportation Research Board (TRB) on this study. In September 2021, TRB released a report titled, "Technical Feasibility of a Wheelchair Securement Concept for Airline Travel." The TRB study was unable to "identify any issues ... that seem likely to present design and engineering challenges so formidable that they call into question the technical feasibility of an in-cabin wheelchair securement system and the value of exploring the concept further." The study acknowledged that further assessment was needed, however, "particularly to understand how secured personal wheelchairs are likely to perform relative to FAA's security criteria in restraining and protecting occupants during a survivable airplane crash or emergency landing," and called on DOT and FAA to undertake research on these issues. The TRB also called on the U.S. Access Board to assess demand from people with disabilities to fly while seated in their wheelchairs to inform the number of aircraft that would need to be modified to provide meaningful access, assuming remaining feasibility questions are satisfied.

We believe that the 2023 FAA Reauthorization Act should require DOT and FAA to follow through on the next steps as identified in the TRB report. If the remaining

issues are addressed in a way that does not call into question the technical feasibility of the concept, the 2023 FAA Reauthorization Act should also require DOT to promulgate regulations implementing requirements for in-cabin wheelchair securement.

• Allow DOT to assess up to three times allowable civil penalties for all ACAA violations: Section 436 of the FAA Reauthorization Act of 2018 allowed DOT to assess three times the allowable civil penalty damages for a violation of the ACAA involving damage to an individual's wheelchair or person. See 49 U.S. Code § 46301(a)(7)(A).

While we are well-aware that these improvements will take time to implement, 36 years after the enactment of the Air Carrier Access Act and 32 years after the enactment of the Americans with Disabilities Act, the time has come to make air travel accessible and safe for passengers with disabilities.

MDA is committed to ensuring that individuals with neuromuscular diseases and other disabilities can travel on aircraft safely, comfortably, and free from fear of persona injury or 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