April 29, 2024

The Honorable Pete 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

Dear Secretary Buttigieg:

As the leading national organization that advocates for individuals with a neuromuscular disease known as spinal muscular atrophy (SMA), Cure SMA is pleased to comment on the U.S. Department of Transportation’s (DOT) proposed rule related to ensuring safe accommodations for air passengers who use wheelchairs.

While the SMA community’s top air travel priority remains allowing passengers to use their personal wheelchairs as their airplane seats, the requirements recommended in this notice of proposed rulemaking (NPRM) will greatly improve air travel for people with SMA and other disabilities. Cure SMA and the SMA community that we represent applaud DOT for working to improve the safety and dignity of passengers with SMA and other disabilities who utilize wheelchairs. We are pleased to provide the following feedback related to questions and themes raised in the NPRM. In addition, we support the comments of the working group of other national disability organization focused on accessible air travel.

CURE SMA RESPONDS TO THE FOLLOWING NPRM QUESTION ON SAFE AND DIGNIFIED ASSISTANCE

- Are the terms “safe” and “dignified” easily understood by carriers and by the public?

Air travel for passengers with SMA and other disabilities is not currently safe or dignified. While air travel may represent the most obvious travel option due to distance, many adults with SMA and children with SMA avoid or only reluctantly travel by airplane due to lost or damaged wheelchairs, injuries during aircraft seat transfers, inaccessible lavatories, and other negative experiences. “Flying does not feel like a means of transportation as much as it feels like a horrible and unfair gamble,” said one person with SMA.

Many individuals with SMA use power wheelchairs that are tailored to their individualized SMA needs such as customized seating with extra back and side supports or repositioning and positioning features to improve function and breathing. Damage to wheelchairs and other mobility devices is detrimental to the health, safety, and independence of a person with SMA. “Wheelchairs are our legs. Wheelchairs are our independence,” shared a woman with SMA from Florida. Many individuals with SMA also suffer significant injuries while transferring from their wheelchair to the aircraft seat. “The transfer folks were jamming the armrest into my back. I ended up with a huge bruise on my back,” said an adult with SMA.

In addition, the air travel experience for many individuals with SMA can be stressful, humiliating, and dehumanizing. On his way home from a family trip, a California man with SMA experienced
the following: “The pilot announced over the intercom that the flight was delayed due to having to load my chair into the cargo bay. So not only was I embarrassed and blamed in front of a plane full of strangers, but I was made to feel bad for being disabled on top of mishandling my chair and the fallout related to that misstep.” While “safe” and “dignified” should be easily understood by carriers and the public, the reality is that this minimum standard for assisting all passengers throughout the air travel process is not currently being met by carriers. Cure SMA recommends that DOT define safe and dignified assistance and strengthen penalties for failing to meet these commonsense and baseline customer service thresholds.

CURE SMA RESPONDS TO THE FOLLOWING NPRM QUESTIONS ON PROMPT ENPLANING, DEPLANING, AND CONNECTING ASSISTANCE

- With respect to deplaning assistance that requires the use of aisle chairs, should “promptly” continue to mean that personnel and boarding chairs must be available to deplane the passenger no later than as soon as other passengers have left the aircraft?
- Should the fact that the individual is able to deplane the aircraft on his or her own factor into when the assistance is available?
- Is there another standard that the Department should use to define “prompt?”

Passengers with SMA consistently face long wait times for aisle and personal wheelchairs after their flight lands if they come at all. A parent of a child with SMA from Colorado shared “On one bad travel day, it took 45 minutes to get my daughter’s chair unloaded from cargo so we could deboard the plane. There was no aisle chair available to get on or off the plane during the delay. Had to piggyback during deplaning.” A passenger with SMA from Illinois had a similar experience. “Upon arrival on one trip, there was no wheelchair attendant to provide a chair and help me off the airplane. The flight crew became increasingly annoyed that I was waiting inside the aircraft for a chair to arrive. They ultimately asked that I get on an aisle chair to be transported up to the top of the jet bridge so they could leave the plane. Unfortunately, no one ever arrived and so we ended up having to use the aisle chair ourselves to get through the airport to baggage claim.”

Cure SMA recommends that personal wheelchairs as well as the aisle chair arrive at the plane promptly, as the last passenger who does not need assistance deplanes. This will ensure the health and safety of passengers with disabilities by limiting their time in aisle wheelchairs that do not have proper support. Wheelchair assistance should also be available once the plane lands for ambulatory passengers with SMA and other disabilities who can exit the plane without assistance but need a wheelchair once they exit. Prompt wheelchair assistance should be a standardized practice for all passengers who utilize a wheelchair.

CURE SMA RESPONDS TO THE FOLLOWING NPRM QUESTIONS ON MISHANDLING OF WHEELCHAIRS AND ASSISTIVE DEVICES AS PER SE VIOLATION

- Is it reasonable to consider any mishandling of a wheelchair or other assistive device a per se violation of the ACAA? Why or why not?
- Is the proposed definition for “mishandled” appropriate?
• What, if anything, do airlines currently tell passengers when checked wheelchairs and scooters are mishandled?
• Should the proposal to notify passengers of their rights and options be limited to wheelchairs and scooters or extended to include other checked assistive devices?

For passengers that rely on wheelchairs for their health, mobility, and independence, the safety of these devices is critical and requires the same priority standard as passenger safety. Unfortunately, many individuals with SMA continue to experience wheelchair damage during air travel. An adult with SMA shared “While we were sitting at the gate, I watched the crew throw my wheelchair seat on the ground while it was raining and then 4 men flung my chair on its side on the conveyor belt. When we landed, they brought my wheelchair to the gate only to discover that it was non-functional. The chair had no power, and the joystick had an error code on it. The chair would not move at all. The repairs to my chair were over $3000. It was the most humiliating and frustrating experience of my entire life.”

Cure SMA supports making any mishandling of a wheelchair or other assistive device a per se violation of the ACAA. In addition, we believe the NPRM definition of mishandled (“Wheelchair or other assistive devices that is lost, delayed, damaged, or pilfered”) is appropriate. However, Cure SMA believes the definition of damaged should include a device being returned in the same condition it was surrendered in. Finally, we believe the process for reporting wheelchair damage should be streamlined. Currently, the burden is placed solely on the passenger, who must journey to the baggage claim office, wait in line, and report the damage. In rare cases, staff inform passengers about their mishandled or damaged wheelchairs or devices and even assist with making the report. For passengers who do not see damage at the airport, as it is difficult to examine the chair you are sitting in, they are required to return to the airport to make a claim for repair. Most airlines require the damage claim to be made in person rather than over the phone or video call. While airlines have a complaint resolution officer (CRO) that can assist with reporting wheelchair damage and other issues, where or how to receive this assistance is not commonly known. Some airlines inform passengers of accessibility services and the Airline Passengers with Disabilities Bill of Rights through an email before their flight. This same information would be useful to share with individuals traveling with assistive devices beyond just wheelchairs and scooters.

CURE SMA RESPONDS TO THE FOLLOWING NPRM QUESTIONS ON PASSENGER NOTIFICATIONS AND RETURN OF DELAYED WHEELCHAIRS OR SCOOTERS

• What are airlines’ current practices regarding tracking wheelchairs and scooters and providing updates and notifications to passengers on the status of their wheelchairs and scooters?
• Should the Department consider requiring airlines to provide other status updates to passengers about their checked wheelchairs and scooters?
• Should carriers be required to provide the dimensions of their cargo compartments prior to travel to any passenger who shares that he or she will be traveling with a personal wheelchair or scooter?
• If an individual with a disability incurs additional, associated costs because a wheelchair or scooter is delayed, should the airline be responsible for reimbursing the individual for those costs?
• How do airlines deliver delayed wheelchairs and scooters to passengers?
Wheelchair damage often occurs during the loading and off-loading process. When a wheelchair or mobility device is too large to fit through the cargo door of the airplane, staff often turn them on their side and use force to make them fit. Some airlines offer flight finders where passengers with wheelchairs can enter their wheelchair dimensions to find which planes can accommodate their chairs. This can provide customers with valuable information when booking. “Damage to mobility devices during air travel is avoidable with proper procedure and oversight,” said a Wisconsin man with SMA who researches cargo hold dimensions and tapes signs to his chair with clear lifting and storage instructions. It is common practice in Australia for airline staff to measure wheelchair heights at the check-in counter using a stick that represents the size of the cargo opening. This practice allows customers to recline, fold, or remove a backrest before surrendering their wheelchair to ensure it fits through the cargo door. Cure SMA recommends that airlines be required to provide their cargo compartment dimensions and provide tools, such as flight finders and measuring sticks, to mitigate wheelchair storage issues. In addition, Cure SMA recommends that airlines make it possible for passengers to track or receive updates on the location of their wheelchair or other mobility devices. Many airlines already allow passengers to track their luggage through their app systems. Airlines should adopt similar best practices to allow passengers, crew, and wheelchair attendants to know where the passenger’s wheelchair is at all times. “We have traveled 4 times in the last 3 years and the experience for my son and us as parents and caregivers was horrible. Waiting for his power chair takes too long especially when they say they don’t know where it is,” shared a mother of a son with SMA from California.

Hearing that an airline is unaware of the location of a wheelchair or scooter can be devastating and unsafe to a passenger with a disability who depends on that device. While airlines do their best to try and find the wheelchair, once located, it can still take days to arrive back to the owner, and the communication between the airline and passenger is severely lacking. A woman with SMA from Illinois shared “My most recent flight included an emergency landing in Orlando that resulted in having no access to my wheelchair, food or water for almost 12 hours. I was stuck in an oversized transport chair that had no head or body support that my custom chair provides. Making matters worse, the airline didn’t put my chair on our return flight. It remained in Orlando for over 2 days. Throughout this situation I was separated from my wheelchair (aka "my legs") for a total of 54 hours where I was stuck at the airport and then in bed. This whole experience was awful and the way I was treated and the amount of misinformation I received from the airline was unbelievable.”

A delayed wheelchair or scooter can cause significant financial and other costs. Financial costs include medical expenses, lost wages of the passenger and a backup caregiver, caregiving costs, cost of cancelled trip, expenses to transport and repair a backup wheelchair, and additional airport parking fees. Non-financial burdens include emotional distress, loss of opportunities, and loss of enjoyment of daily life. Carriers should be required to promptly return and reunite delayed wheelchairs with their owner. Cure SMA recommends that airlines be required to return a misplaced wheelchair on the next available flight, and no later than 24 hours, even if it requires the use of a different carrier. In addition, airlines should deliver the delayed wheelchair to the passenger’s location rather than require the passenger to return to the airport given the passenger may live hours away from the airport.

Cure SMA responds to the following NPRM questions on prompt repair or replacement of damaged wheelchairs or scooters.
• Should the Department consider stricter and detailed timelines rather than using a reasonableness standard to which airlines must adhere when handling wheelchair and scooter repairs and replacement?
• Are certain types of wheelchairs and scooters no longer repairable or replaceable?
• Should the passenger be given an opportunity to independently review their determination and carry out their own assessment?
• Should the NPRM’s first option include a “testing period” for wheelchair repairs?
• Does it seem reasonable to provide “temporary wheelchair repairs”?

When a wheelchair, scooter, or other device is returned to the passenger in a damaged condition following a flight, it is critical that it is fixed or replaced promptly, according to the passenger’s reasonableness standard, not the airlines. Cure SMA recommends that in cases where a wheelchair is damaged beyond repair, it should be replaced with a wheelchair that provides the individual with equivalent or greater function and safety. In cases where a passenger is dissatisfied with the decision to repair or replace their wheelchair, they should have the opportunity to review and appeal the decision.

Cure SMA recommends that passengers be given 14 days to file any claims after their flight lands. For example, electrical damage caused by a pinched wire or water damage that occurred while in-flight may not set in for days. A passenger with SMA from Ohio shared, “Twice, I have seen no damage coming off a flight, but then a few days later my chair completely stopped working. I had to fight the airline for hours to finally convince them my wheelchair needed repaired even though it was a few days after a flight.” Cure SMA recommends a 30-day period from when the last repair was completed to carry out and determine if additional repairs are needed. Individuals with SMA and their families reported making temporary repairs to their wheelchairs to proceed with their trip. Airport personnel with tools, zip ties, etc. could assist passengers with mishandled wheelchairs for these much-needed repairs. However, when reasonable, airlines should have on-call durable medical equipment vendors to provide emergency repairs at the airport.

CURE SMA RESPONDS TO THE FOLLOWING NPRM QUESTIONS ON LOANER WHEELCHAIR ACCOMMODATIONS

• What types of customizations should be required under this proposal, how much such customizations generally cost, and how quickly such customizations can be completed?
• If an individual with a disability incurs additional, associated costs because the loaner wheelchair provided by the airline restricts his or her mobility or independence, should the airline be responsible for reimbursing the individual for those costs?

Although prompt repair or replacement of a wheelchair or scooter should always be the main priority, it is likely that loaner wheelchairs will be needed by passengers with mishandled wheelchairs. “I do not travel by air as much as I would like. My wheelchair was damaged, and I was in bed for days because I did not have a second power wheelchair,” shared a woman with SMA from Florida. For individuals with SMA who utilize complex power wheelchairs, Group 3 power wheelchairs with all four functionalities (seat elevator, tilt, recline, foot elevator) should be the base models for power wheelchairs. Adjustments such as seat pan, back rest, seat cushion and arm and leg rests should be made by the vendor at delivery. In cases where an individual does have a
backup wheelchair, airlines must prioritize basic adjustments, such as battery replacement, to get the backup chair into working shape while their primary chair is replaced or repaired. Some power wheelchairs are fitted to every curve of an individual’s body, and they may not be able to use standard joysticks or driving methods. In cases where a loner wheelchair limits an individual with a disability’s independence and restricts their mobility, they may incur additional costs, including additional caregiving hours, additional needed equipment, and forgone wages. These incurred additional costs need to be covered by the airline and reimbursed for the period while they do not have their wheelchair or scooter.

CURE SMA RESPONDS TO THE FOLLOWING NPRM QUESTIONS ON ENHANCED TRAINING FOR CERTAIN AIRLINE PERSONNEL AND CONTRACTORS

- Are the proposed amendments to the training requirements in Part 382 sufficient to address concerns and inadequacies with current training practices?
- Should other types of airline employees and contractors be subject to the enhanced training requirements set forth in this proposal?

Individuals with SMA and their families report a significant lack of knowledge, training, proper equipment, and consideration by airport and airline staff during all aspects of the air travel experience. One adult with SMA said, “Many problems I encounter arise from airport and airline staff not knowing process or rights that I have a person with a disability.” The proposed amendments to the training requirements in the NPRM should be expanded to include those who handle assistive devices as well as supervisors and managers. Training for emergency situations, including when a passenger is dropped, should be covered in this hands-on training. Cure SMA recommends that the DOT require a certification or some other competency test to ensure that training goals are met rather than recording attendance. Cure SMA recommends that in all cases where an aisle wheelchair is used, two attendants should be present to assist with the chair and transfers. In addition, DOT should require that specialized lift equipment be available and used when storing power wheelchairs into the cargo hold of the plane. We support the proposal to requires hands-on training and certification annually for relevant staff.

CURE SMA RESPONDS TO THE FOLLOWING NPRM QUESTION ON NEW IMPROVED STANDARDS FOR ON-BOARD WHEELCHAIRS (OBW)

- Should airlines be required to expand the existing on-board wheelchair stowage space of the aircraft, or modify the interior arrangement of the lavatory or the aircraft to enable the OBW to fit?

Cure SMA recommends that airlines be required to expand the existing stowage space to accommodate an OBW as soon as possible. The most frequent use of an OBW is often to access the lavatory. In extreme cases, passengers with disabilities may elect to scoot or crawl on the aisle floor to access the lavatory when an OBW is not available. This practice shows that even before the installation of accessible lavatories, an OBW needs to be on every airplane.

CURE SMA RESPONDS TO THE FOLLOWING NPRM QUESTION ON SIZE STANDARD FOR LAVATORIES ON TWIN- AISLE AIRCRAFT

- Is the 95/95 standard, which has been adopted for future new single-aisle aircraft lavatories, appropriate for twin-aisle aircraft lavatories?


The lack of accessible restrooms deters many passengers with SMA and other disabilities from air travel. Individuals with SMA who do travel by air report taking several precautions before boarding an airplane. “I am forced to eat and drink as little as possible before and during the flight because I am unable to get to the bathroom during the flight,” said an adult with SMA. A travel blogger with SMA recently shared a video on how he purchases diapers before every flight, because that is his only option to use the restroom on board a plane. Flights as long as 7 hours can take place on single aisle aircrafts throughout the United States. It is undignified for any passenger to not have access to a restroom for that length of time.

The SMA community also reports challenges with existing accessible aircraft bathrooms. “It was almost impossible to fit two people in an airplane bathroom without getting hurt,” said an individual with SMA. The 95/95 standard that is used for twin-aisle aircrafts should be increased to accommodate a standard of a large male passenger and two large male attendants. For most passengers with SMA, lifts cannot be performed by just one attendant. Accessible restrooms on current double aisle aircraft are not large enough for attendants to assist. A man with SMA shared, “There was one time I needed to use the bathroom on a flight and getting into and out of the bathroom was a nightmare. My parents struggled to figure out how to get me off the toilet, and I kept worrying I would be accidentally injured in the process. Those bathrooms are way too small for a person with physical disabilities to use, and it caused anxiety for my entire family.”

Double aisle aircraft still often do not fit the 95/95 standard, or they may require the use of curtains or doors to remain open, providing passengers with a lack of dignity and privacy. “The last time we flew overseas, the flight attendant allowed us to use the first-class bathroom and we had to leave the door open while using it, as it was too small. That is beyond embarrassing and would not fall within any health safety measures,” shared an Alabama mother of a daughter with SMA. Cure SMA recommends that all aircraft be equipped with an accessible bathroom large enough for people with disabilities who may need the assistance of two aides.

CURE SMA RESPONDS TO THE FOLLOWING NPRM QUESTIONS ON REFUND OF FARE DIFFERENCE WHEN PASSENGERS’ WHEELCHAIRS CANNOT FIT ON PREFERRED FLIGHT

- Do any airlines currently offer individuals with disabilities rebooking on another flight on the same airline at no additional cost when their wheelchairs or scooters cannot be carried on their originally booked flights and if the subsequent flights have higher fares?

- Should the Department require airlines to refund the fare difference when passengers must book more expensive flights because their personal wheelchairs and scooters cannot be carried on cheaper flights?

Individuals with SMA regularly face uncertainty and complications related to wheelchair storage, especially at smaller airports that utilize regional jets with small cargo hold doors. A mother of a child with SMA shared “My son can’t get on an airplane because his specialized wheelchair does not fit on most planes.” Some power chairs can be tilted back and reclined to fit through the cargo door of these smaller jets, but they will still often take more time to load and unload due to tight quarters. In this case, a larger power wheelchair may be denied due to the lack of knowledge or training of the baggage handlers. In cases where power wheelchairs are denied at the airport, the airline typically rebooks the passenger on another flight with a larger aircraft through the same airline. Depending on the destination, however, this may add additional layovers and time to the trip, which can be disruptive and unworkable for many individuals and families with SMA. Even when
their wheelchair fits on smaller regional jets, many adults with SMA struggle to reach their assigned seats due to very narrow economy aisles. While the aisle chair may fit down the plane’s narrow aisles, an adult that is sitting on the aisle chair often will not. A woman with SMA from Pennsylvania shared “On one flight, my seat was further back in the plane and the aisle chair didn’t fit with me on it to get to my seat. They tried to just carry me, but my legs were being dragged causing a knee injury. Eventually after being made to feel like a complete burden, they put me back in the aisle chair. My elbows and shoulders kept hitting every seat and causing me a lot of pain.”

Injuries when traveling back to a passenger’s seat are common. An adult with SMA from Ohio shared “After repeatedly trying to jam me into the economy row of the aircraft, bruising my hips and causing me to erupt into tears, the crew finally decided to give up and allow me to sit in one of the first-class seats. I am not a large human, so I have no idea which wheelchair users are possibly fitting through the economy aisle of that airplane.” In this situation, the airline allowed the passenger to sit in the upgraded seat at no additional cost. However, on the return flight on the same aircraft, the passenger was unable to request this larger seat ahead of time at no additional cost and instead was required to prove once again that they could not fit, facing additional injuries before receiving the upgraded seat. At the gate, a passenger with a disability may request a seat closer to the aircraft door at no additional cost, however it is up to the gate agent’s discretion if that request can be made. The request for a higher seat classification can only be granted by the flight attendants onboard and cannot be requested ahead of time even when the problem will remain on the return flight on the same aircraft.

Another significant seating barrier occurs with static armrests. “On a flight to the Dominican Republic, getting into the plane was fine until I had to be transferred to a seat without an adjustable armrest. This made the transfer very difficult and unsafe,” shared a man with SMA from New York. A woman with SMA shared “When traveling on a solo international flight I discovered there were no seats that had moveable armrests. This is the only way I can safely transfer onto the seat, but also it is required in case I need to use the onboard wheelchair to go to the restroom during the flight. They gave me a business class seat with still no movable armrest, but with a bit more room to transfer. However, I was still unable to safely transfer and was forced to go 11 hours without using the restroom. It took 5 adults to transfer me out of this seat once at my destination.”

To ensure safe travel to their destination, passengers with disabilities frequently pay for more expensive flights on larger aircrafts that will accommodate their large power wheelchairs with less layovers, reserved seating, and an upgraded class of seats to guarantee they can fit on the aisle chair going to their seat. This makes it very costly for individuals with disabilities to fly, not factoring in damage to wheelchairs and equipment. Cure SMA recommends a reimbursement or request process for individuals with disabilities to request the basic accommodations needed for them to fly safely without financially penalizing them.

CURE SMA FINAL COMMENTS
Cure SMA and the SMA community appreciate DOT’s efforts to improve air travel for passengers with SMA and other disabilities who use wheelchairs. The requirements proposed in this NPRM would make air travel safer and more accessible. In addition to implementing this important rule, Cure SMA respectfully asks that you prioritize working toward accomplishing the SMA community’s top air travel priority of allowing passengers to stay in their wheelchair during the flight. A woman with SMA shared “I travel about three times per year; nationally and internationally. Always with my family, never alone. It is very hard for my dad to lift me up by himself. My mom or brother must be
around to help. I don’t think it is safe for anybody. Me, my father, or anybody involved. It would be incredible to be able to be in my own chair in the airplane. The chair I am in 24/7. The chair that helps me position my neck, hips, and legs. The chair that knows all my curves and was made exactly for me to be comfortable. It would be a dream come true.” For passengers with SMA, staying in their wheelchair would be the safest and most dignified way to travel by air, like other modes of transportation. “When the pilot says, ‘sit back, relax and enjoy the flight’, that ought to refer to everyone!” said a mother of an adult child with SMA.

Truly accessible air travel—being able to sit in your own wheelchair on the airplane—would open air travel for all individuals with SMA and other disabilities. “Allowing wheelchairs on the airplane must become a reality because it will unlock the world for all folks with disabilities,” said an adult with SMA. Another person with SMA shared a similar view: “Being able to roll or drive onto the aircraft would allow me to finally access everything this beautiful country has to offer.” The first-person experiences and recommendations included in this letter are aimed at achieving the goal of equal access to and experience with air travel for all passengers, with and without disabilities.

Thank you for the opportunity to comment on the air travel challenges of wheelchair users with SMA. We welcome the opportunity to work with DOT and other stakeholders to improve air travel for all wheelchair and scooter users. For more information, please contact Sarah Bellish, Manager of Policy and Advocacy at Cure SMA, at sarah.bellish@curesma.org or 202-871-8005, or Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at maynard.friesz@curesma.org or 202-871-8004.

Sincerely,

Maynard Friesz
Vice President of Policy & Advocacy
Cure SMA

Sarah Bellish
Manager of Policy & Advocacy
Cure SMA

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