



Episode 32: Accessible Air Travel and Advocacy Updates

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Mindy Henderson: Welcome to the Quest Podcast, proudly presented by the Muscular Dystrophy Association as part of the Quest Family of Content. I'm your host, Mindy Henderson. Together, we are here to bring thoughtful conversation to the neuromuscular disease community and beyond about issues affecting those with neuromuscular disease and other disabilities and those who love them. We are here for you, to educate and inform, to demystify, to inspire and to entertain. We are here shining a light on all that makes you, you. Whether you are one of us, love someone who is or are on another journey altogether, thanks for joining. Now, let's get started.

Today, I have two guests with me who are here from the MDA advocacy team to discuss the latest in accessible air travel. First, I have Michael Lewis. Michael has spent over a decade working in disability rights for various organizations. His passion for disability policy advocacy stems from his experience as an individual with cerebral palsy. As director of disability policy at MDA, Michael leads MDA's advocacy efforts on Capitol Hill and with federal agencies to defend and expand access to civil rights, education, economic independence and employment and accessible recreation and travel for people with neuromuscular diseases and other disabilities.

Joining us next is Mark Fisher, who is the Director of Advocacy Engagement at the Muscular Dystrophy Association. In his role, Mark leads MDA's grassroots program and advocacy volunteer efforts. He works to empower advocates and connect them with key decision makers in order to advance public policies that improve the lives of neuromuscular disease community. He previously served as the digital grassroots manager at the American Heart Association and was also a field organizer on a US Senate campaign.

Great. Mark and Michael, thank you so much for joining me today to talk about this topic that I know everyone in our community cares deeply about. Appreciate you being here.

Michael Lewis: Glad to be here.

Mark Fisher: Yes, thank you for having me. I'm happy to be here.

Mindy Henderson: Absolutely. So I did of course just read a bit of information about both of you, but would each of you like to just share briefly about the role that you personally do with the MDA and what that means?

Michael Lewis: Yeah, sure. I am Michael Lewis I do disability politics through MDA. And so, I lead all the legislative and regulatory efforts on behalf of the MDA community pertaining to most recently and most importantly, lately acceptable air travel. That's been the big this entire calendar year and before, but this year certainly because the Federal Aviation needs to be reauthorized by the end of September.

But in addition to that, I also lead efforts related to disability civil rights, voting education, access to employment, financial security, SSI and SSDI, which I know a lot of our community members rely on for financial security. So that's a lot of what I do on a day-to-day basis and lobbying members of congress and fundable agencies on those [inaudible 00:04:37].

Mindy Henderson: That's amazing. Those are a lot of really hot topics. Thanks for that, Michael. Mark, what about you?

Mark Fisher: So again, my name is Mark Fisher, Director of Advocacy Engagement here at MDA and I run our grassroots advocacy program. I work hand in hand with Michael and our other lobbyists to really push through key legislation, key agencies. And I do that through the power of the grassroots network. I like to say that I am not a lobbyist because I'm not, but I make our many volunteers across the country into their own lobbyists. And I help connect them to their decision makers or their lawmakers to make sure that they hear their voice when they're making key decisions about policy. So I connect them to their lawmakers. A good example is with air travel. We definitely have had many people write to members of Congress, come to DC to meet with their members of Congress, film videos of what this issue means to them.

So, my role at MDA is really to allow people to raise their voices and make sure that their members of Congress hear them loud and clear. And we do that through grassroots advocacy. So, the ideal is when Michael goes to Capitol Hill and talks to lawmakers and then we follow up with the voice of the constituents. That's a really powerful one, two combination.

Mindy Henderson: That's amazing. And I've worked closely with both of you personally. For anyone who is listening and may not be aware, I live with spinal muscular atrophy myself and so this is a topic that's very important to me. And the work that Mark and Michael and their whole team does is incredible. And I worked with both of you on the recent Hill Day in Washington, which was a really great experience.

So, I'm going to dive in. There's so much to talk about and there's actually been some very timely activity on this topic. So for anyone who is tuning in that may not be following this topic, maybe hasn't traveled as a wheelchair user or as someone with a disability or someone that they know who may travel under those circumstances, let's go ahead and just break down real quickly why it's so important that we change the current experience and barriers for safe air travel for people with disabilities. What are the current problems that exist?

Michael Lewis: Okay. One, I think the bottom line is that air travel is currently not very adaptable, and some people would say not acceptable at all for people with wheelchairs, other mobility devices or even their crutches, the walkers, the what have you. A lot of it is everything from arriving at the airport and going through a security and waiting for the airport personnel to put through security and need be's and then getting to the gate. And waiting for the airport and airline personnel to put you on the aisle chair and get you to your seat onboard the aircraft. The auto wheelchairs were broken and damaged wheelchairs, rolling on wheelchairs today are broken and damaged by airline and the airlines are required to repair or replace them. But a lot of times that can take a very long time, weeks and months, during work time you can be in the wheelchair that is not configured to your body or your needs or what have you.

And that can be very dangerous for people with disabilities and especially, people with neuromuscular diseases who can get [inaudible 00:09:16] sores and whatnot from being in a wheelchair that is not customized to their needs. We also have this through onboard the aircraft, the seating with the amount of space between it where we sit, that seemed to be gotten smaller and smaller as the years go by. And that makes it very difficult to do the seat transfer from the passenger's own wheelchair to the aisle chair. And then from the aisle to the seat on the aircraft increasing the risk of injury of and being dragged over an armrest. They all very, very dangerous propositions that a lot of people decide, "You what, it's not worth the aggravation. It's not worth the risk, bodily harm or injury to get in my seat, with basically my leg broken and not usable while I work the repairs."

The Congress passed a law in the mid aining called the Interior Access Act that was intended to make air travel acceptable. And that act which is known as the ACAA [inaudible 00:11:03], what it did was direct the Department of Transportation, if you regulate them that would attempt blame/make air travel more accessible for people would disabilities. Unfortunately, the regulatory process is open to public comment. The airline industry gets this seat at the table, they fought over the last 37 years to make air travel more acceptable. And so, because the ACAA only directs the Department of Transportation to its irregulation without the work can come and go with residential administration. The agency regulations are not permanent. If you go through the rule making process, they can be trained.

Mindy Henderson: You actually didn't know that.

Michael Lewis: Yes, indeed. And that is why FAA reauthorization represents such a tremendous opportunity for the disability community to get accessibility providence included and that reauthorization legislation. Because that means that their susceptibility providence [inaudible 00:12:56]. And they can only be modified through congress act again. It's not like an agency regulation where they can implement a regulation and then 10 years later or three years later a new administration can come and say, "Oh, well, we've heard only complaints from the airlines that this regulation is a heavy burden to them and so on and so forth. So, we're going to make it a little easier for the airline."

Mindy Henderson: Right. And I thought that I was informed about air travel and accessibility in air travel and I learned a number of things from everything that you just said. One thing that I think people don't necessarily always know is that the ADA doesn't actually apply to air travel. And I think that's a common misnomer. Would you agree?

Michael Lewis: Absolutely. So especially when we meet with congressional staff members, a lot of them do not know that, well, the ADA was there or enacted 32 years ago in 1990, as a matter of fact the 33rdanniversary was yesterday, two days ago. A lot of them do not know that air travel was one of the only industries that ADA did not apply to. And the reason for that is that the time the ADA was being written, the airline said, "Well, we just passed the air carrier after that, three years ago. So, we've already taken care of that. We don't really need to be included in this new legislation."

And then there was a lot of push back, one, the ADA was being debated from a lot of industries, thinking that this was going to be an enormous cause to property managers and business, public transportation systems and taxis, the list goes on. And 30, 20 years later nobody thinks about it. It's the cost to doing business. It's harder to build a new door, they're going to make sure that the parking lot had the required numbers of acceptable parking spaces. When the city or the state or the town builds a new street, they're going to make sure that the sidewalk that this contract by the building, effectively a public building. Obviously, you're not talking about a privately owned, but a publicly acceptable

building. They're going to put in the elevators and 33 years later it's just built in the cost of doing business.

Mindy Henderson: It's all just normalized at this point and it's just how it is now. And I think that's sort of, we have to make this initial change with air travel and there will be some expense that goes into it and some effort, but then it's just going to be become the new normal.

Michael Lewis: Exactly.

Mindy Henderson: So there's a lot to unpack I think, in the legislation that just passed the house, was it this week or last week?

Michael Lewis: Almost two weeks ago at this point.

Mindy Henderson: Almost two weeks. Okay. So again, the FAA has to get reauthorized every five years or airplanes don't fly. And like you said, this was a really good opportunity to get some of the language written into law now that would improve accessibility. Actually Mark, let's turn to you, the language in the bill that was passed recently that's now waiting for senate approval, what ended up being included and what didn't end up being included?

Mark Fisher: I'll definitely take a stab at that. But Michael being the policy expert, he can fill in some of the gaps.

Mindy Henderson: Trying to share the love.

Mark Fisher: I appreciate that, for sure. So a couple of big things. One of the big things we hear from people is when they interact with airline or airport personnel, whether it's assisting passengers from their wheelchair to the aisle chair, from the aisle chair to the seat or vice versa, the training isn't there. And it's a luck of the draw if you get someone who knows how to properly transfer a passenger from an aisle chair to the airline chair or vice versa. Mindy, I know you've experienced where you have arrived and the people who are supposed to be there were not.

Mindy Henderson: I recently had to be transferred by the pilots because there was no one else there that was supposed to be, that is typically responsible for that particular thing.

Mark Fisher: Exactly. So the training piece is missing. And so the house bill would mandate that sort of training for both airline and airport personnel. Which is important because depending on the airport, sometimes you are interacting with airlines, sometimes you're with airport or a mixed bag. So it would mandate training for that. It also would mandate training for folks who handle wheelchairs because right now the training's just not either there or not sufficient. So it would mandate training for people to know how to handle wheelchairs as they load them into the cargo hold, where to place them, how to take them out. A lot of times that sort of knowledge is set on the shoulders of the passenger. So the

passenger will have to tell the crew, this is how you handle my wheelchair or my power chair. That is now going to switch to the responsibility of the airline and airport personnel, where they need to be trained on that. Because a lot of times if someone has a connecting flight, they can't even talk to the loading crew on that second flight because they're too busy connecting. So better training overall.

Mindy Henderson: And can I stop you there for a second? I apologize because I know that there's a bunch of things that are included that we want to get to. So on the training piece, is that training going to be standardized or will there be certifications or a certain number of hours of training that people will need? Do we know yet what that's going to look like?

Mark Fisher: I might toss that back to Michael if he knows. I know there was written, there were some parameters in the law, but a lot of times those gaps get filled in later by DOT. But Michael, I don't know if you have anything on that.

Michael Lewis: The language actually directs the secretary of transportation, excuse me, to if you were not the public rulemaking, requiring across the board training both for airline personnel and the public contractor that it's passing with disabilities and transfers or even its wheeling them through the airport while as baggage and loading down a wheelchair to flight. And the language specified that this training could happen every six months and that airline personnel should have to demonstrate competency in order to be wheel-chaired in a place like that.

Mindy Henderson: Okay.

Michael Lewis: So, they seem pretty robust. The language also encourages the secretary of transportation to include people with disabilities in the training, it doesn't require that. But it encourages the secretary to consider including people with disabilities in the training.

Mindy Henderson: That would make sense.

Michael Lewis: Which I think would go a long way rather than just watching a 20-minute video, actually meeting with 3, 4, 5 passengers that rely on a wheelchair.

Mindy Henderson: Right, right. Okay. Okay, fair enough. So training is a great start. We're going to ping pong back and forth between you and Michael for the details and things. What's the next thing that was included in the bill recently?

Michael Lewis: Mark, do you want to talk about wheelchair parks on the inside.

Mark Fisher: I would say, and then he can back me up on this. Because I know the general and then Michael can fill in the details. So we know that the holy grail's for allowing people to stay on their wheelchairs in planes, like drive up and lock in. That is everyone's ultimate goal and this legislation furthers that goal. Previously for this to happen a lot of folks will say, "Why can't I just roll into a plane, lock and ready to go?" And there's a few reasons why it's taken a bit of time. One is

there had to be some studies to be done to prove that a restraint system could probably secure a wheelchair in case of a crash or crash testing. Make sure that a wheelchair can get around the cabin easily, make sure that it doesn't break the floor of the cabin. I promise you that was one thing they tested.

Mindy Henderson: I believe it.

Mark Fisher: And how many seats would an average airline have to remove to allow wheelchair to drive on the plane? So there's a lot of testing and studying they have to be done. Some of that has already been done previously. We still have a bit more to go. There needs to be a secondary study on crash testing for these restraint systems and then there needs to be an economic study so airlines know what the demand will be. So there's a lot more to do. But for that to continue, congress had to ensure that that research continues. We had to make sure that the progress we made doesn't stop because if not, then all that research would stop and we would be doing nothing. So the house bill that was passed continues that momentum and not only that, it sets up a concrete timeline that those studies have to be done.

Those original studies have to be done. Before it was like, "Please get these done." Now it's, "No, these must be done by this time and this time and this time." To keep the momentum going because we need to keep it going to make sure folks eventually can wheel onto a plane. So, this is the first time they'd set a concrete timeline to get the necessary steps for this to happen because this is the ultimate goal. Now I'm sure Michael knows what that timeline is, but it's an important step as Michael said, to get that in statute that these studies have to be done by that time is a pretty significant development.

Mindy Henderson: And that was going to be my next question because I think probably everyone who's listening, ultimately what we all want to know is "When am I going to be able to take my wheelchair on an airplane?" And so Michael, to Mark's point, do we know what that timeline actually is now? I love that there's some accountability finally in place, but what is that accountability actually?

Michael Lewis: For one, believe that feasibility and economic studies have to be done within the next five years.

Mindy Henderson: Within the next five years?

Michael Lewis: Yeah.

Mindy Henderson: Okay.

Michael Lewis: What is the duration of the reauthorization? After the studies the done the secretary of transportation have to convene a working group to go on with those studies, make recommendation and put down a report of those recommendations to Congress. And I believe that either a year or two years after that report was submitted to Congress, there has to be a notice to proposed rulemaking that would require a wheelchair park on the airplane. One

thing that we at MDA, and the lobbyist and half of MDA have been lobbying for, especially as the Senate continued to prepare their version of the bill is trying to make sure that the feasibility and economic study runs simultaneously. Instead of waiting for one study to be done and then taking however many months or years after that to do the other study, we want them to run concurrently in the timeline, so to speak.

Hopefully, by the end of the five years we can be at the point where they're doing the negotiated rule making instead of having to punt that to the next reauthorization. Unfortunately, even when they do come out with a regulation requiring wheelchair parks on airplanes, there is going to be a rather long implementation timeline, probably five to 10 years, I would guess. If I had to have to guess, then we could get a fantastic administration in five years. But to the point I was making a lot earlier where the DOT released their long-awaited final rule requiring acceptable lavatories on single aisle aircraft.

And that rule making process started at the tail end of the Obama administration, and then the intervening administration between Obama. But now they mop off that whole thing and sort of when they current Biden administration came in, they picked the ball back up, sort of to speak, in early 2021. And the original negotiated rule making with the airlines and the ability community they envisaged, again seven years ago. The timeline was going to be that an accessible lavatory would be required on single aisle aircraft that either ordered 18 years from the date of the final rule be in public or delivered 20 years. But the date has been from the date of the final will be in public until-

Mindy Henderson: Okay, nobody else can see my face, but my jaw just hit the floor.

Michael Lewis: Understandably. And so, when the proposed rule came out late last spring of 2022, the disability community was allowed to have a lot of concern about that timeline. And with medical comment, we have many, many members of the neuromuscular disease community, the MDA community submit comments on the proposal. And just back in May, Paul Melmeyer, who is the vice president of public policy and advocacy here at MDA, we met with the Office of Management and Budget. And they're the agency that had the final review of all federal regulations that go out the door. And we met with them and said, "We really feel because this whole rule making process started seven years ago, the airlines have known this was coming for seven years. And we feel those intervening years did count towards that timeline."

And we were very pleased when the rule came out on Tuesday to see that they had shortened the timeline from 18 to 20 years to 10 to 12. And that it's mandatory. And as a matter of fact, for new type certified aircraft, let's say Boeing in the path of getting a brand-new Boeing 837 certified by the FAA. Obviously, it's not on the market yet, but they're building it. For any new aircraft like that, brand new model, everything, they are required to have an accessible lavatory within one year. That's the rule.

Mindy Henderson: Oh, that's great. Okay, so let me ask you this. So you said the new timeline is 10 to 12 years, but that initial seven years that it's already been in progress, is that factored in? So it's really like three to five years from now or is it still 10 to 12?

Michael Lewis: It's factored in and that it was short and familiar with 15 to 20 to the 10 to 12.

Mindy Henderson: Okay. I tried

Michael Lewis: Kind of, but now really.

Mindy Henderson: Okay, so this is great. So we've got actual legislation that's passed the house, going to any day, we're sure of it, well maybe not any day, but in the very near future we anticipate that it will be passed by the Senate. We're going to talk more about that at the end. But everybody needs to do their part to raise their voices and make sure that that happens. We'll give you some more information at the end of the call, but we've got legislation now that puts a timeline to certain things to enforce some accountability and move us closer to wheelchair spots on planes. So if and when, mostly when the FAA reauthorization passes the house, what can we expect to see change immediately, if anything in terms of the experience that passengers with disabilities on aircraft have? I mean, will we even see improvements to how knowledgeable staff are that are handling us or our chairs or when can we expect to see anything change?

Michael Lewis: It's not going to be immediate. A lot of these accessibility provisions require notice to public rulemaking by the Department of Transportation. And not to get too legal in Milwaukee, but there is a plan time for federal regulatory rule making, called the Administrative Procedure Act. So that is the very set process that they have to convene all the stakeholders. They have to do the research. They have to put out the proposed rule and then they have to have 60 days to public comment. And then they go back and based on the public comment, we write the rule. And then they put out a proposed final rule and there's another public comment period before the final rule gets released. So, it's not going to be overnight but it's not going to be 10 years either. A lot of these people didn't have timeframe, the 12 to 24 months. Obviously, now the wheelchair parks on airplane's is one that's going to take a little bit longer. But a lot of the rule making regarding training requirements and making towards the information boards and departure and arrival are visible systems, they're accessible, those have much shorter time frames.

Mark Fisher: I would just say by the next time we do this in five years from now, all the things we talked about the training piece, those should be in place is what we're thinking.

Mindy Henderson: Okay.

Mark Fisher: So the idea is those will be in place. So next time FA reauthorization comes around, either Congress doesn't have to deal with it, we already solved it this year or they do tweaks to it. Another thing that people should hopefully see soon is the size of cargo hold doors is going to be more public than it is now for

folks who need to know how big the door is, so if the wheelchair can fit through it. It's very hard to find that information now that should be more accessible by the next time we come around to this FA reauthorization. And also with the accessible lavatories rule, that's a little different reauthorization, but it's all lumped into the same thing.

For existing bathrooms, they should be made more accessible than they are now within three years. So, more grab bars, just more accessible information. Now for many folks, it doesn't matter, they're still too small to begin with. So, it doesn't matter how many grab bars you put in there, it's not workable. But for folks who maybe just need more assistance that will be in there in three years. But Michael does bring up so many things about the process. Every step of the way we have to make sure that folks are, and this will get to the last part, raising their voice at every step of the way. Because I guarantee you every step of the way, whether there's possibility for feedback or possibility for comments, the airlines are going to come full blazing with reasons why they don't need to do it. I mean, they'll come full blaze like, "Oh, we can't do this because of X, we can't do this because of y."

And the reason we've made the progress we've made in the last couple of years is because we stood up to them and said, "No, but you can do this." And the outpouring of honestly, anger to what's going on has been so high that we've seen results. So that as much as you can hear from this conversation, we've made great steps. We can't stop because we have to continue it because of the way the process is set up with how these ir regulations are done. There's a lot of opportunities for a wrench to be thrown in there. And you better believe that the airlines are going to try to throw wrenches in the system. And we have to make sure that that's not successful.

Mindy Henderson: And I mean as someone who is not a lobbyist, I don't work in the airline industry, but even I know how big a change this is and how costly frankly a change it will be for that industry. Those are poor reasons I think not to do something because like we said before, it's going to be a big change at first and then it normalizes, but-

Mark Fisher: And every other industry's had to do it.

Mindy Henderson: Exactly.

Mark Fisher: The airlines are the last ones to do it. And I think most folks understand how awful air travel is. Most people get on that plane and go, "Oh, my goodness, I don't want to be here. It's so tight, it's so cramped." And then when you say, "Well, think about it, if you're a wheelchair user, how would you even do this?" And they're like, "I never thought that before." So the more that's shown, I think the public understands that say, "Hey, come on airlines, it's about time," because so many folks in their lives will experience being in a wheelchair in their life. And they might not realize it now, but 10 years from now you have no idea what could happen.

This is one of the only groups that anyone can use a wheelchair or crutches or who knows what, any time of their life. And so just to say that something that once people learn about it, even though the airlines might hem and haw about it, I just think the general public once you realize, "Oh wait, this would be awful if I had a loved one in a wheelchair or myself or my elderly parents." You're like, "Oh yeah, this needs to be done."

Mindy Henderson: It's true. And I heard somebody and I wish I could remember who said it, I'd love to be able to give them credit. But I saw something I think on LinkedIn the other day, and it was very simply stated, typically if something doesn't exist for you, it doesn't exist. And so unfortunately it takes a ton of awareness, just like you just said, Mark, under the best of circumstances, air travel is tricky and uncomfortable and all of that. But if you lump a wheelchair or crutches or other mobility aids on top of that, an injury, anything, it gets exponentially more complicated. And it's going to take all of us speaking up and standing up to this very powerful industry to require them to make change.

And I'd love to ask a follow-up question because I think the other thing that we're going to have to see more of in order to force their hand is for there to be more in the way of fines and things imposed when the airlines do injure a person, break a wheelchair, those sorts of things. Is that part of the language that was included in the FAA reauth this time around is to put some rigor around those fines that the DOT imposes?

Michael Lewis: There was an amendment offer by Dean Atided in the markup. And Dean Atided is a representative from Nevada. The amendment requires one, the Department of Transportation get a complaint of an APAA who within 120 days notify in writing both the person that lodged the complaint and the airline as to what the outcome of the investigation was. Whether or not a violation occurred and whether or not a fine was being imposed. And it was an enforcement act. And then it also requires the secretary of transportation to submit a report to Congress each year on how many complaints they received regarding ACAA violations and what the outcome of those complaints were. Whether they were found to be reactive with the violation, whether they imposed penalties on the airline. We believe that imposing penalties will change behavior on the part of the airline. They will be more careful when they accept and feed transport.

Mindy Henderson: Absolutely.

Michael Lewis: Bear mind that the department of transportation have the power to impose financial penalties for many, many years, they just haven't used it like that. And so, we're hoping to put, we got language in the health bill, now the big hurdle is the standards, making sure that they pivot and get into whatever final words in this pack.

Mindy Henderson: Thank you for that, Michael. And I think that again, this is another area where it's really important. It's already such a hassle for this community to travel this way anyway. And then if there's an incident to file the appropriate paperwork to

go to the DOT website, all of that. It's an imposition. It absolutely is. But I would say that it's even more important than ever that you go to the trouble and report any incidents that you experience because it's a numbers game. And the more volume of reports the DOT is seeing, the quicker I think that we'll see change because it compounds. The more people speak up and say, "No, this happened and this happened," I think that's when we'll start to see even more results of the financial flavor that Michael was talking about.

I am so sad; we are almost out of time. And I want to ask just one or two more quick questions. The Delta seating solution has been in the news a lot lately. And I know it's not the Delta seating solution per se, but it's Delta and another company that worked together. And they recently announced a possible seating solution that would make room for wheelchair spaces on aircraft. And it got a lot of attention, and it generated a lot of excitement, understandably so, myself included. And so, I think a lot of people are wondering if this is a seating solution that's going to have an actual impact on the timeline or speed along the process to get wheelchairs on planes. And I know that we've talked about how much work there is still to do, but what about this recent announcement and that seating solution in terms of impact on change or the timeline?

Mark Fisher: So I'll go first. First, I would say there's a lot of angst against the airlines and I get that. Totally get that. And I would say though, it's a division of Delta, but the first time I think, Michael, you can correct me, that we've seen an airline come out forward and say, "Hey, this is what we're working on."

Mindy Henderson: That is so encouraging.

Mark Fisher: That's pretty remarkable. And a lot of times we always say airlines won't do it until they're forced. They won't do it until they're forced. I still believe that. But I still think this was the first time we have seen an airline say, "Hey, we're putting a solution forward," so let's give that credit. Because-

Mindy Henderson: Absolutely.

Mark Fisher: ... the first time we've seen it and hopefully I don't really care what the motivation was for it, but I'm glad that they did it. So that's a really big positive, I think. And hopefully they continue the effort to refine it. Hopefully other airlines either jump on board with their own or join. I don't know how that all works, but that's the first time that we've seen an airline do that proactively. And I think we have to look at it as a positive and give credit where credits due, because it's about time.

Mindy Henderson: 100%.

Mark Fisher: I will say, Michael, I'll ask you this, but that solution would still have to go through quite a bit of testing though to make sure that it is safe and make sure it works. So let's say Delta says "We're done, we've finished it, this is what we want to do." It still has to go through some testing and studying, right, Michael, before it would be on a Delta flight?

Michael Lewis: It has to be craft tested for airworthiness and has to be type certificated by the FAA. There's a lot of stuff that need to happen, but the encouraging thing is that we're seeing the movement toward that.

Mark Fisher: I think that's right, Michael. What I'm hoping for is they don't quit developing and maybe we see another airline say, "This is our idea." I have to think that the writing's on the wall because this couple of years has just seen such a big groundswell momentum where people are just tired of it. They're tired of their wheelchairs being broken, they are tired of all the things that go into flying and it's the most groundswell I've seen in a very long time. And we also have to recognize that the population's aging. And if airlines want to continue to fly folks around the world with an aging population that they want to fly, they're going to have to do something to-

Michael Lewis: They're-

Mark Fisher: ... going to have to do something to make, because you can't just say, they're going to cut off quite a bit of potential revenue. So I'm hopeful. As I said, I don't care what the motivation is in the end, I just think it was positive it came from an airline for once.

Mindy Henderson: Totally agree. And so I want to wind us down just a little bit by saying, first of all, thank you to both of you for being here again and for sharing your knowledge. And honestly, as both a person living with neuromuscular disease and an employee of the Muscular Dystrophy Association, I am so proud to work for an organization that has a team of people who care about and actively come to work every day working on creating progress on things like air travel.

And so, I just want to ask this almost final question. So, with so many issues in the world that we could be working on, unfortunately it's not a perfect world and there's a lot that we could be working on fixing. Why has the MDA advocacy team chosen to make accessible air travel a priority?

Michael Lewis: A big part of that is because for a lot of people with neuromuscular diseases, they're living in the adulthood. They are getting married, they're going to college, stuff that nobody thought was possible 20, 30 years ago. Even still there's still no cure, there's a lot of things, but there's no cure and so clinical trials are vitally important. And unfortunately, not everyone can just go to the local hospital and get the treatment in it because there's not a [inaudible 00:52:54] every county hospital. That matter at that [inaudible 00:52:58] delay at every hospital. And sort of to both find a diagnosis and get treatment and even participate in clinical trials, trying to find new treatment and cures for neuromuscular diseases, a lot of times air travel is required. And to get to study sites, the hospitals or what have you.

And so, because air travel is not accessible, a lot of people with neuromuscular diseases will say, "Hey, I'd love to participate." And then they go to trials, but-

Mindy Henderson: I can't get there.

Michael Lewis: Yeah, can't get there. Or I could get there, but they might not have a wheelchair when I got there or I couldn't get there, but I might be injured when I got there. A lot of people declined to do them, or they forgo medical treatment or treatment that might be significantly better than what they can receive at their local hospital.

That is why we make such a tremendous push for accessible air travel because especially within the neuromuscular disease community, air travel, the neck and all the other injuries, being able to get there for the diagnosis or the treatment or the study, it's all connected.

Mark Fisher: I think from my perspectives too, it's luckily that we all agree that it's number one issue. It's the one issue that we at MDA serves a lot of different people with a lot of different neuromuscular conditions or ALS or so many different conditions under our umbrella. Air travel was probably one of the number one issues that connects them all. We do work on issues that might be more specific to a certain condition over another or certain age group over another. Air travel touches everybody and it's the one that gets our grassroots advocates the most route up. It's the one that people will have the most connection with. And it's been the number one this year, just because FAs off every five years, this is the time to do it. This is the year that we need to put everything we have because we might not have another chance for another five years to make any gains.

And then another reason is this is another organization that a lot of our partner organizations work on. That we work with veterans' groups, that this is very important to them, as you can imagine. This is important to groups who represent senior citizens. This is very important to groups for people with visual impairment. I mean the more you think about it, the more you're like, "Oh, I didn't think about this group. I didn't think about this group." So many of us are affected by this issue that it's an easy one to rally the troops, so to speak. It's an easy one to bring in our other partners in for one voice. So, I mean, we could do a whole hour why this is the number one issue, but it's the one in my mind that anyone that we serve in MDA can relate to.

Mindy Henderson: Very well said. Very well said. And to that point, Mark, I would love to give you the last word-

Mark Fisher: Oh, boy, that's exciting.

Mindy Henderson: ... and just talk a little bit about how people can get involved. And what people can do to make their voice heard and join the ranks of people who are rallying so hard on this issue.

Mark Fisher: I'd love to. So the easiest way is for folks to go to mda.org/airtravel. You can go to mda.org/airtravel and you can simply enter your information in and we pre-populate a letter you can send to your members of Congress, urging them to make huge strides in this FAA reauthorization. If you've never contacted your member before or don't even know who your member is, it's totally fine. Our system will match you to your lawmaker, so you don't have to worry about that.

We'll give you a pre-populated letter that you can edit if you'd like or just send it in as it is. And then you can make your voice heard that way. So the easiest way is mda.org/airtravel and that's the best way to take action on this issue.

And I want to say that living in 2023, there's understandably a lot of skepticism whether your voice matters or not, and I understand that, but I would say this issue is very bipartisan. We have champions on both sides of the aisle. I like to say that people being upset about air travel is a bipartisan issue and this one surely is. So, we have very surprising champions on both sides, and this is one that we've heard lawmakers listening to our advocates pointedly. This is one that they want to hear from us. They want to hear your voice. I know people say they don't listen to me, trust me, they do. They do. This issue hits home for so many people. When they read a letter that says, "Hey, my mother can't travel because of how awful it is," that Senator totally understands that. They can feel that they can relate to it. So, I encourage people to make their voices heard, throw away the cynicism, throw away the skepticism. Your voice matters in this issue, and it will continue to matter.

As we talked about before, we are making significant progress, but there is a long way to go. And we can't stop at any step along the way, we got to keep the voices heard. We're up to this point now because we've had so many advocates and so many volunteers say, "Enough is enough." We're not stopping. We have to make changes. We got to keep that momentum up. And I believe we will. I think we're at a point where we push the ball down the hill and it's going to keep going. I don't think people can stop us. I think we have the momentum on our side, so we've got to make sure of that. So please go to mda.org/airtravel and you can sign up with us, take action and we'll keep you updated along every step of the way.

Michael Lewis:

The legislation have passed the house, we still waiting on the senate to take action. And it is worth noting that Congress is getting ready to land for the entire month of August. Traditionally they have August recess where they go home to the district, and they meet with constituent, and they kiss all the babies. And they do all that kind of politics and stuff. They're not in Washington marketing that bill. They're taking votes, but they are having kind hall meetings and that sort of thing. They will come back to DC after Labor Day. And at that point Congress will have about two and a half, three weeks to get this thing out the door. Of course, the possibility that either the majority leader or the speaker of the house could call everyone back to DC before Labor Day or even in the middle of August. But like Mark said, we will keep you updated every step of the way.

Mindy Henderson:

Perfect. And so well said by both of you. When they get back to Washington after being in their local offices, let's make sure that they come back to a big giant stack of letters and phone messages from their constituents who all want to see air travel made more accessible. I think that this is truly an issue where it's taken the collective voices of all of us to get it to this point. And just as you

said, Mark, we can't take our foot off the gas at this point because we're really close and the progress has been really, really exciting.

So again, thank you both for being here. I really appreciate both of you and all of your hard work and appreciate all of you for listening in. If you've learned something from this podcast today, do us a favor and share with a friend, someone who you think may not know about the accessible air travel issue and let's grow the circle.

Michael Lewis: Absolutely. And again, thank you for having us, Mindy.

Mark Fisher: Thank you for having me, Mindy.

Mindy Henderson: Thanks so much.

Thank you for listening. For more information about the guests, you heard from today, go check them out at mda.org/podcast. And to learn more about the Muscular Dystrophy Association, the services we provide, how you can get involved and to subscribe to Quest magazine or to Quest newsletter, please go to mda.org/quest. If you enjoyed this episode, we'd be grateful if you'd leave a review. Go ahead and hit that subscribe button so we can keep bringing you great content and maybe share it with a friend or two. Thanks everyone. Until next time, go be the light we all need in this world.