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Episode 4: Access to the World: Air Travel September 8, 2021

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Mindy H:

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. Our mission with this podcast is 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'd also like to acknowledge CMT Awareness, Duchenne World [00:00:30] Awareness Day, Myotonic Dystrophy Day, Periodic Paralysis Day, and LGMD Day, which we join you in celebrating this September. 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. Today [00:01:00] our conversation is a continuation of our access to the world series. With more discussion on accessible travel. Now let's get started.

I am thrilled to welcome the two guests I have with me now who are here to chat with me about accessibility in air travel. First up I have Dr. Chris Rosa. Dr. Rosa is a member of MDA's Board of Directors, and also serves [00:01:30] as Assistant Vice Chancellor for Student Inclusion Initiatives at City University of New York or CUNY, the nation's largest urban public university system. A published disability studies scholar. He served as a faculty member for the university's master's program in disability studies and has served as the co-executive officer of the Society for Disability Studies, the international professional association for disability studies [00:02:00] scholars. Chris has served as the Chair of the Executive Committee of the US President's Committee on Employment of People with Disabilities. And for his leadership and expanding employment opportunities for New Yorkers with disabilities, Chris was awarded a Liberty Medal by the New York post in 2012.

And second, I have Michelle Erwin, President and Founder of All Wheels Up. Michelle created All Wheels Up in 2011 [00:02:30] and has led the charge to prove that existing wheelchair restraints like those used in inaccessible cars and buses can exceed the FAA Requirements and are now working with regulators such as the FAA, airlines, airplane manufacturers, and Congress to see how we can make airplanes accessible. All Wheels Up is currently the only organization in the world crash testing wheelchair tie-downs and wheelchairs for commercial flights. [00:03:00] I am so excited to have you both with me today. You're so impressive. And I feel like I need a nap after getting through all of your credentials, but air travel is such a huge topic for this community of individuals with disabilities. And you're both doing such great things to bring about awareness and to bring about change. So welcome to both of you.

Chris Rosa: Thank you, Mindy.

Michelle Erwin: Thank you for having us.

Mindy H: Absolutely. So, Chris, I'm going to start with you, if you don't mind. [00:03:30] Would you tell us just a little bit about your condition and how it manifests?

Michelle Erwin: Sure. And it's really an honor to be here and it's such a thrill to meet Michelle. She's one of our movement's true heroes and really has set a standard for grassroots organizing and mobilizing and grassroots advocacy. It's the very best work that our movement does. So it's an honor to be here with her today. And so, I have limb-girdle muscular dystrophy. [00:04:00] I'm 54 years old, and I was first diagnosed in 1976 at age 9 at an MDA Care Center at New York University Medical Center. I've been using a wheelchair since I'm 12 years old. So I have a lot of time in the saddle and it really empowers me to be very mobile in most context. And it's why air travel is such a high-stakes opportunity and concern for me. So [00:04:30] it's really an honor to be here and participate in this important dialogue.

Mindy H: Well, thank you so much. And you're here to represent the people as you say, who are on the front lines, traveling and using airplanes and all of that. And so, I think you're going to be able to really speak to that first-hand experience that you've had in addition to some of the advocacy work and experience with legislation that you've done. And we'll get to all of that in just [00:05:00] a second. But first, Michelle, would you mind telling us a little bit about yourself and why accessible air travel is important to you?

Michelle Erwin: Absolutely. So I started All Wheels Up about 10 years ago when I learned that there was no organization out there, even having the discussion about a wheelchair spot on air airplanes. And I just saw the white space and decided to create All Wheels Up, so we can start [00:05:30] funding crash tests. So we can really have the smart dialogue with the regulators and Congress who will need to make these decisions. And the reason I got into this space is I have a child who uses a wheelchair. He has spinal muscular atrophy, and I learned really quickly how difficult it was to travel as a wheelchair user. And I was just the caregiver. And I did not see down the road in the future, [00:06:00] how my son was going to be able to travel for college or for employment one day. And then it

hit me, I'm like, well, how are people traveling today? And so, that's why I started All Wheels Up, so we can have a better future.

Mindy H: Well, I know there are a lot of us who are really glad that you did, and you've done some exciting things. But Chris, let's jump right in with you first and talk a little bit about your experiences while traveling. I know that you travel quite regularly, [00:06:30] at least when we don't have a pandemic in the world. Tell me about your experiences with air travel over the years.

Chris Rosa: So I've flown much of my whole life. I have the privilege of growing up in an airline family. My dad worked for an airline. And so, over the arc of my life, I've had a lot of experience with air travel. And since I've worked, I've been fortunate enough in a pre-pandemic life. [00:07:00] And hopefully, we can return to it post-pandemic, where I fly at least once a month for work, whether that be for my work at the university or my volunteer work for MDA and other nonprofit boards. And my experiences have been very typical of the experiences of individuals with neuromuscular disabilities served by MDA.

Over the arc of that, I've had really painful experiences brought with [00:07:30] physical injury at times. I have a travel chair that's been destroyed and replaced at least three times. And my current chair has very few of its original parts because it's been sort of the sacrificial independence fostering device that allows me to travel without compromising my everyday power chair. And in the worst-case scenario that the experiences that I found most troubling and most painful [00:08:00] is that in a few instances, I've been denied access to a flight by the crew because I don't meet the DOT standards of independent travel, meaning that I'm unable to demonstrate that I can evacuate independently.

Mindy H: Oh my goodness.

Chris Rosa: So we've had some really difficult experiences with air travel and it's why reform is so urgently needed.

Mindy H: Right. Right. I feel like I heard somewhere that you prefer to travel on [00:08:30] your own without a PCA or anyone accompanying you. First of all, did I get that right? Is that correct?

Chris Rosa: That's correct. That's correct.

Mindy H: Okay. I know, for me, I've also... I've got spinal muscular atrophy and use a wheelchair. And for me, I know that one of the most uncomfortable parts of air travel is having to be transferred by strangers, basically. But I typically travel with either my husband or a personal care assistant. [00:09:00] Can you describe what your experience is like traveling on your own and having to navigate things like transferring to an aisle chair without the familiarity of having someone who knows you and knows your limitations?

Chris Rosa: So thank you for asking. On the one hand, it's strangely exhilarating because once I leave my power chair, the one that's customized for me, I am completely vulnerable with the exception [00:09:30] of self-advocacy skills and my ability to

speak up for myself. So under those circumstances, it's really like working without the proverbial net. So it's exhilarating, it's mildly terrifying, but every time I'm able to successfully navigate a flight under those circumstances, fraught with barriers, it feels like a remarkable achievement and a remarkable affirmation of my independence. That being said, it also is fraught with tremendous [00:10:00] risk, mostly brought on by barriers and the lack of quality professional development of the third-party contractors that airlines engage in order to provide the assistance that travelers with disabilities need in order to travel. I found that as the best practice, the better you're able to articulate your help, the help that you need in very specific terms. And the more assertive that you can be in demanding that the people with whom [00:10:30] you partner execute it the way you describe it, the better you'll be.

Mindy H: Very true. And it is a double-edged sword, just like you said. And I love the kind of positive spin that you put on it and trying to look at it as sort of an empowering thing when and where you can, as difficult as it may be. I think that's great.

Chris Rosa: Thank you.

Mindy H: Does anything come to mind? I would be remiss if I didn't ask if there were good experiences that come to mind that you've had [00:11:00] when traveling by plane and if so, what do you attribute the good experiences to?

Chris Rosa: It's a very good question. I don't think that I've encountered a particular carrier that is better than others, but my best travel experiences are ones where the flight crew and the ground crew seem not only to be very prepared but have seemed to espouse inclusion as a core value. [00:11:30] And my best experiences are not when somebody has done anything extraordinary to save the day, but where I feel they've embedded these practices in their standard operating procedures and the way that they do business and when it's smooth and virtually imperceptible, I feel as though that's the gold standard and those are my very best experiences.

Mindy H: That's great. This next question may be a little bit tricky to answer given the travel constraints [00:12:00] that we've had for the last 12 or 16 months, but do you see the experience with air travel for wheelchair users getting better or worse? Do you see any changes happening in the trends in the last couple of years?

Chris Rosa: Personally, I haven't seen any dramatic improvement over the arc of the last 10 to 15 years. I think that the cause of the great work of advocates like Michelle, [00:12:30] who have insisted that the Department of Transportation be more transparent and accountable about the magnitude of the problem. I think we understand that better, but I think there are some sources of optimism on the horizon. One is the grassroots movement that Michelle is led through All Wheels Up. And the other is something that I know we'll get to chat about is some legislative resolutions that we hope [00:13:00] are on the horizon.

Mindy H: Great. So one more thing that I want to talk about you just from your personal experience, Chris. And Michelle, I know that this is something that you and All Wheels Up has had the opportunity to influence when an individual has a bad experience or their chair is damaged. Like we've already heard in this conversation. Can you share Chris, what a person should do to get the appropriate attention and resolution? And does it vary [00:13:30] from airline to airline?

Chris Rosa: Very good question. And it's something that I've learned through hard experiences. My instinct and all individuals' instinct is very often you don't find out that your chair has been damaged until you come off the plane and your chair is presented to you in some sense of disorder. And then, you proceed to the baggage area and you fill out a complaint. So I thought I was doing [00:14:00] due diligence and that was important, but I was only registering my report and my claim with the airline itself. I've now been very conscious of also filling out the Department of Transportation Form to record it as the data, as an incident where both I experienced a travel barrier and damage of the wheelchair because that's where the US Department of Transportation, that's how they count.

So I saw in a recent article where Michelle was cited, [00:14:30] she's always brilliant in articulating the dimensions of it. That on average, that there are 29 wheelchairs damaged a day by airlines. And that data point is derived from US Department of Transportation Data and not from self-reports by the airline itself. So it's important not only to register your complaint and your claim with the airline but then to register it with the department of transportation so that we can get our [00:15:00] arms around the true magnitude of the problem. And that data will empower us when we leverage it as advocates for legislative remedy.

Mindy H: Right. And Michelle, I have so many questions that I want to ask you as well, but like Chris said, you and your colleagues were instrumental in sort of regulating this piece of things so that airlines are required to report how much damage is being done [00:15:30] to wheelchairs, is that accurate?

Michelle Erwin: There's a coalition. The MDA is part of it. There's a small coalition of organizations that take accessible air travel on as a platform. But we definitely advocated it for that particular amendment in the FAA Reauthorization Act. I believe this was in 2018, for that to be dictated that all airlines had to report damages back to the DOT. And the reason that is so important [00:16:00] is not just for the visibility for the wheelchair community or the DOT in general, but it helps organizations like mine then use these numbers as powerful numbers to leverage for change.

Mindy H: Absolutely. Because I know that one of the sort of arguments or objections for lack of a better term that we need to overcome is that should airlines modify their airplanes with [00:16:30] spaces for wheelchairs. There's the concern about losing a seat or two on the airplane, but in truth, they're spending so much money having to repair wheelchairs and replace wheelchairs that are being damaged in this process, correct?

Michelle Erwin: That is correct. Back in 2016, just one airline alone spent \$2.6 million on wheelchair repairs and replacements. But the numbers actually [00:17:00] go deeper than just that. We're talking about [tarmac turned time efficiency 00:17:04]. We're talking about the legal issues and the legal payouts to maybe individuals who have been dropped or for any other reasons that may have an airline going into a lawsuit over a damaged wheelchair, then you have vouchers that are provided for missed flights, or just trying to compensate the wheelchair user. So paying for their current flight and then paying for a future flight. So the [00:17:30] numbers just keep accumulating and that's what we're trying to show the industry is that not to look at it as maybe one or two lost seats for this current flight, but to look at the overall value and that it's not a detriment, but actually a cost-saving.

Mindy H: Right. Which is why it's so important as Chris says, to fill out the forms if you do experience something like that, so that we can get really good solid data to work from. [00:18:00] So Michelle, let me take a step back. Tell me about the work that All Wheels Up has done to date. You've been at this since 2011. So for about 10 years, can you kind of take us through the journey of what you've accomplished and how you've helped us get closer to our goals of being able to do something like drive a wheelchair onto a plane?

Michelle Erwin: Absolutely. You know, I'll be honest. The first five years was pretty slow. There's not much to [00:18:30] report, but we were laughed at, we were told to close down, we didn't have any funding in the beginning. I mean, none at all. It was all personal funding at that point to just keep us sort of moving forward. And once we started really having the conversations and put an animation out there and showed Congress what we thought was possible. And we provided the real data that the wheelchair securement systems that we currently have in our minivans [00:19:00] pass the 20G test and where a airplane seat only goes through a 16G crash test.

We could really have real conversations. And then, we were able to secure funding and we did the very first crash test of wheelchair securement systems in 2016. We were able to bring all of those crash test videos back to Congress in 2017. And they asked what we needed. And at that time, the FAA Reauthorization [00:19:30] Act was still on the table. It didn't get passed back in 2016, which sometimes, everything happens for a reason. And it allowed us to add in the feasibility study for a wheelchair spot on airplanes. And that's where we are today with the NAS, the National Association of Sciences, reviewing our crash test data with experts from all areas, whether it be aviation, wheelchair manufacturers, universities that do crash testing, [00:20:00] they come from every stakeholder holder group. And so, they're reviewing our data and we are now to the point where hopefully in September, they will be publishing their findings to move forward with larger R and D dollars for this project.

Mindy H: So good. And this may be a silly question, but what is it that's so complicated about making an airplane accessible to the point of driving a wheelchair onto it? It makes such sense [00:20:30] to me in my mind, I'm not an engineer, but we have restraint systems for wheelchairs and cars. We've already talked about the

financial objective that some airlines and people have, but why can't the same simply be done on airplanes? What's so complicated about it.

Michelle Erwin:

The project is very complex and multifaceted and while it seems to say the wheelchair user in our community, that it's simple. We've actually [00:21:00] had really great, robust dialogue with airlines and plane manufacturers and the wheelchair manufacturers and everybody and it's really great getting everybody in the room to share what are the questions and concerns? One of the questions we realized is education, right. The airlines and plane manufacturers of the world didn't even know that wheelchairs had standards. So they thought wheelchairs were just being driven around with no real sense of standard so that they were already crash tested, say [from other 00:21:29] vehicles. So [00:21:30] we have working groups and we've actually brought in the universities that crash test wheelchairs [from other 00:21:35] vehicles and even just educated them of where we are today. And we're actually using today as a springboard for tomorrow. And we're not starting from ground zero.

And because I think we started off with education, we are having these next step conversations that are really robust, where we're talking about, okay, what is the turn radius of a wheelchair? And does it actually... Can that happen on an airplane? And we're talking about [00:22:00] the weight of a wheelchair and the weight of the individual in the wheelchair and can the floor hold those Gs. So while the restrains themselves can hold the Gs is what can happen on an airplane floor, which is very thin. So now we're talking with engineers at these stakeholder groups and it's a whole different level conversation. And we're not saying that it's not possible. Now we're just trying to figure out how to make it happen.

Mindy H:

Amazing. I mean, this is not a small effort that you've gone to Michelle. You are [00:22:30] truly out there on the front lines, breaking boundaries, going to huge financial expense to prove what's possible and changing minds. You were a mom with no engineering and no airline background. You have, I believe another full-time job, how have you managed this over the year to keep going, despite being laughed at, despite the objections, the financial expense, and the walls that you've had to plow through?

Michelle Erwin:

So, [00:23:00] first and foremost, I have a really supportive husband and family. I think it's great that my kids are actually excited when I tell them that I'm traveling to have a meeting, whether it be with an airline or a stakeholder, they're equally excited that their mom is an advocate for such an important topic. And I don't do this all by myself. All Wheels Up is a non for profit. We have other volunteers, Alan Chaulet, for example, he's our VP. And we have an incredible [00:23:30] board and we have a lot of projects, and not one person can do it alone. And so, I lean into them. I lean into my board and our volunteers.

Mindy H:

That's great. So, Chris, let me come back to you. You mentioned legislation a few minutes ago, and I'm wondering what's being done now from a legislative perspective to improve the landscape. Is it just the air carrier access

amendments [00:24:00] act, or is there other legislation that's being considered?

Chris Rosa: In terms of our advocacy through MDA's advocacy network? We focused our efforts around the Air Carriers Access Amendments Act, the ACAA. The act was introduced in March of this year. The sponsor on the Senate side was Senator Tammy Baldwin from Wisconsin. And on the house side, it's representative Jim Langevin [00:24:30] from Rhode Island and the ACAA would dramatically transform access and opportunity and air travel for individuals with disabilities. Among other things, it would establish a right of private action and increase administrative enforcement of the act, which would be critical in making sure that the rights of people with disabilities and air travel are preserved. It would establish a set of physical standards of access that all new aircraft would [00:25:00] have to meet. And therein lies some of the opportunity that Michelle was referring to. And it would also require airlines to remove access barriers on existing aircraft. If the barrier removal is readily achievable. So it would really transform access and opportunity for air travelers with disabilities. And so, MDA through its advocacy network has really focused on that piece of legislation.

Mindy H: That's fantastic. Do you know what the timing is [00:25:30] on voting on that or I'm not sure what the next step in the process would be for that piece of legislation?

Chris Rosa: At this point, we've been urging our network to contact their congressional representatives and urge them to sign on as co-sponsors. If it's okay, Mindy, this may be a time for a gratuitous plug of MDA's advocacy network [crosstalk 00:25:57] to urge everybody to join us by visiting [00:26:00] advocacy hub at www.mda.org/advocacy or to text MDAUSA to 50457 in order to join the effort.

Mindy H: Fantastic. And I'm going to put all of that information into the show notes as well, so that everyone can participate in that who would like to.

Chris Rosa: Thank you.

Mindy H: So, Michelle, what's the next step in the process for All Wheels Up for making planes accessible?

Michelle Erwin: [00:26:30] Advocacy is still a huge part of what we do. We are out there. We're currently boots on the ground in Washington, DC with our volunteers promoting the ACAA. And we're also working with Congress on a new bill that would specifically fund the R and D for the original equipment manufacturers, the wheelchair manufacturers, the plane manufacturers to give them the funding to specifically [00:27:00] go into R and D that's specif for enhancements for people with disabilities. Funding is always critical. Especially, if they're looking at something while we may say, we feel this is important, there also needs to be an ROI.

So we're looking to fund that, and that's what we're working with Congress right there. And then in regards to next steps, in regards to say the engineering and that aspect, we're actively having meetings with manufacturers, with plane

manufacturers, and we're really talking about [00:27:30] the technical side of things. We now actually really need to move forward with, what is that standard look like? So the crash testing that we did was airplane seat standards, but the manufacturers of wheelchair securement systems and wheelchairs need to know what are the standards for a wheelchair and for wheelchair securement system. So they can specifically go into R and D for a device that would be specifically purchased for aviation purposes.

Mindy H: I see. Well, it's certainly [00:28:00] a complicated issue. To my mind coming into this conversation, it feels like such an easy problem to solve, but when you really dig into it, there's so much to consider. And Michelle, I think the work that you and your organization are doing is great. Chris, you've been such an advocate with MDA and to the legislation that's being considered right now. And I'm just so honored to talk to both of you. And I know that I [00:28:30] am feeling incredibly optimistic, just hearing about all of the work and the efforts that are going on. I'm hoping that there are a lot of people out there who are feeling the same way that I am after hearing both of you speak about this. I want to ask you both the same couple of questions to kind of round things out. Chris, let's start with you apart from maybe joining MDA's advocacy group. How can individuals who are listening best get [00:29:00] involved and help advocate for improvement in air travel?

Chris Rosa: Well, first of all, if I may give an endorsement, I think we should all do whatever we can to support All Wheels Up through their grassroots fundraising and advocacy campaign. It's a true grassroots movement. It's the very best that we do in the disability rights community. So we should all get behind All Wheels Up. And again, I just wanted to reinforce the importance of joining [00:29:30] for people with neuromuscular disabilities, to joining MDA's advocacy effort through our advocacy hub.

Because the stakes are very high for the families that we serve just as a data point, we know from MDA's most recent survey of the individuals that we serve that prior to the pandemic, 80% of people with neuromuscular disabilities served by MDA participated in air travel and a sobering 70% of [00:30:00] those respondents reported experiences with significant barriers to air travel that limited their access and travel opportunities. And these difficulties were particularly prominent for power wheelchair and scooter users. A whopping 40% of people with neuromuscular diseases surveyed indicated that they experienced damage to power chairs during flights. And when you consider this figure, Mindy, this is really a staggering amount of damage and disruption to the lives of people who are [00:30:30] served by MDA. So there's a really big stake in all of us getting this right for the people that we all represent.

Mindy H: So true, our wheelchairs are in essence, our legs. And if anyone can imagine getting to your destination on an airplane and having both of your legs broken, that's a serious problem and really puts you at a disadvantage and if nothing else can really wreck a trip.

Chris Rosa: You're here.

Mindy H: So Michelle [00:31:00] is there anything else that, well, first of all, let me say, I agree with Chris and supporting all of your efforts. It's amazing the work that you do. And I'm assuming that if we post your website and the show notes and things, there's information there about how people can support you, is that right?

Michelle Erwin: Correct. Our website has a lot of data. You'll see, even videos that we posted about what we think accessible air travel could look like in the future. We are having a virtual run in August in [00:31:30] recognition of National Aviation Day. National Aviation Day recognizes all of the progress that the aviation industry has made to date. And we want to just be part of that future.

Mindy H: That's fantastic. So, Michelle, I'm going to ask you this question, and then Chris, I'd like to give you the final word. But Michelle, is there anything else that you would like to share either about the current state of the union or about how we can all work together to make this better?

Michelle Erwin: [00:32:00] Absolutely. I think if accessible air travel is important to you, like Dr. Rosa was saying, get out there and support the ACAA, let your legislators know why this is important to you. We are seeing a drastic uptick, maybe not drastic, but we're seeing a lot of momentum on this bill. And I think your viewers can definitely help promote that. And I want to let everyone know, I know air travel and accessible air travel rather can be discouraging, but with all of the [00:32:30] stakeholders coming to our meetings and having these robust dialogues, I believe change is on the future. And I want everybody to feel really positive about what the future could look like for accessible air travel. We know it's slow, we've been at it for 10 years. It certainly couldn't happen fast enough, but we also have to consider the safety of every single passenger on the airplane and make sure that we have the proper certifications before we move forward.

Mindy H: Very well said. And Chris, is there anything [00:33:00] else that you would like to share, or just some words that you would like to leave us with on this issue?

Chris Rosa: Sure. And I learn a lot from Michelle and All Wheels Up all the time. But during this podcast, I was particularly taken by All Wheels Up approach to conducting a cost-benefit analysis and how much of a financial impact on the airline and tourism industry, greater accessibility for travelers with disabilities [00:33:30] can have. Prior to the pandemic, the tourism industry reported that travelers with disabilities spent some \$58 billion annually on travel. And while this is a really big number, it's only a fraction of what Americans with disabilities would spend if our opportunities weren't limited by the inaccessibility of air travel. So this is not only about human rights and about values of inclusion. It's in airlines business interest [00:34:00] to be able to make air travel more accessible to all of us. And so, I appreciate Michelle bringing that to light. And I think that aside from the right space approach to this, it's also in all of our financial interests for us to have equal access to air travel.

Mindy H: Absolutely. I can't tell you both how much I've enjoyed this conversation. It's such an important issue, but I think that we are seeing the momentum and the [00:34:30] progress that we're making and for everyone listening like Chris said

who this is an important issue to, I think that so much of that momentum comes from not only the work that people like Michelle and All Wheels Up are doing, but the way that people are using their voices today to be heard and to tell our legislators what is important to them and why it's so important to put focus [00:35:00] on this issue. So again, Michelle and Chris, thank you for being with me and for sharing your time and your expertise.

Chris Rosa: Thank you, Mindy. And thank you, Michelle.

Michelle Erwin: Thank you.

Mindy H: 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 [00:35:30] 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.