

## You First Podcast - Accessibility Outside the Box Episode 1: Travel and Vacationing

**Keith Casebonne:** Let's talk about travel and vacationing on the first episode of our new series, "Accessibility Outside of the Box," here on "You First," the Disability Rights Florida Podcast.

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**Keith:** Hi, there. I'm Keith Casebonne, host of You First. I should correct myself and now say co-host because I am very happy to introduce a new addition to the podcast, my co-host, Maddie.

**Madeline Crowley:** Thanks, Keith. Hi, everybody. I'm Maddie Crowley, and I'm excited to be a part of the podcast, especially with this new series.

**Keith:** Oh, me too. This is the first of six episodes where we'll discuss accessibility outside of the box. What do you think of when you think of accessibility, Maddie?

**Madeline:** Accessibility is such a huge subject. There's not just one or two things. However, most people would probably say something like making sure that the entrance to a building with stairs also has a ramp or having captions available on videos or TV. There's so much more to it than that.

**Keith:** I couldn't agree more. In this series, we'll talk about some of those aspects of accessibility that many people are simply not aware of, but they most definitely affect the daily lives of many people with disabilities. For example, without proper accessibility in place, lots of folks are left out of things like buying fashionable clothes, playing video games, going to concerts, taking a trip, or even participating in a research study.

In each episode, we'll chat with an expert that can help us understand these issues better.

**Madeline:** You don't want to miss an episode, so make sure to subscribe to our podcast. We're on all podcast platforms, including Apple Podcasts, Spotify, Google, Amazon, YouTube, and more. You can also find us on our website at [disabilityrightsflorida.org/podcast](http://disabilityrightsflorida.org/podcast).

**Keith:** Today, we're going to talk about travel and vacationing. There are so many aspects to taking a vacation. You've got to get where you're going. You've got to find a place to stay.

**Madeline:** Once you're there, you have to make sure you can get around and access whatever it is you traveled there to do.

**Keith:** Right. I spoke to Olivia Shivas and Rebecca Dubber to learn more about this topic. They host a great podcast called "What's Wrong With You?" where they recorded an episode during a trip they took, recounting the challenges they faced along the way. They shared with us what they learned about accessible travel and vacationing.

Hi, Olivia and Rebecca. Thanks so much for being our guest today. If you could each introduce yourself, tell our listeners a little bit about yourself. Olivia, we'll start with you.

**Olivia Shivas:** Sure thing. My name is Olivia Shivas. I am calling in from New Zealand, Aotearoa, in the Pacific. I am a journalist in New Zealand. My main coverage that I focus on is disability issues. I have a disability myself. I have muscular dystrophy. I'm a wheelchair user. I made this podcast, "What's Wrong With You?" with Rebecca.

**Rebecca Dubber:** Hi, everyone. I'm Rebecca Dubber. Like Olivia, I'm also calling in from Aotearoa, New Zealand. I also live with a disability called lumbar sacral agenesis. As a result, I use a wheelchair for mobility. I'm a Paralympian. I represented New Zealand in para swimming for quite a long time, went to two Paralympic Games, which was quite exciting and an honor for me to represent my country.

After I left swimming, I moved into the communications space. I work in public relations and met Olivia at University. That's how we became friends, I guess, because we work in similar industries, and we love telling stories about disability and connecting with our community.

We always talked about doing something like a podcast, so it's a little bit of a dream come true that we were able to make this podcast.

**Keith:** Let's talk a little about the podcast for a moment. The title is great, What's Wrong with You? I love that. That's a brilliant title. Tell us a little bit more about it.

**Olivia:** Yeah, we could say that the idea came from the stories that we tell. The stories that we often see in the media are not very well representative of our experience. We felt that the stories we see are very focused on tragedy or the opposite end, which is triumph and super-inspirational disabled people.

Yes, there are some stories that fit those stereotypes, but there's nothing in the middle that we could relate to. When we talked about during a podcast, we wanted to do something that was quite honest and confronting but also fun.

We came up with the title quite quickly because "What's wrong with you?" is a question that we often get asked on a regular basis from, what we say, random strangers in the street. That's why we called it that. Then we asked all of our guests that question, so you all had a various range of disabilities. That's how it came about. I don't know if Rebecca has something else to add.

**Rebecca:** We did, we brainstormed a few, didn't we? "What's wrong with you?" was the one that stood out as being probably the one that disabled people possibly get asked most often when you're in a new social setting. You may need someone near. They notice that you use a wheelchair or another type of mobility aid.

After they ask your name, the first thing out of their mouth is, "So, what happened to you?" or, "What's wrong with you?" On Olivia's point of being a little bit controversial, asking all of our guests what's wrong with you made for some interesting icebreaker discussions when we were doing our interviews.

**Keith:** That's brilliant. Second episode of your podcast was called, another great title, "Please Don't Break My Wheelchair," which is sadly a real risk when traveling nowadays, especially via air. A lot of stories about that.

Let's just open it up with what are some of the barriers you guys have faced? Some anecdotes you have, things like that.

**Rebecca:** In line with my swimming career, I spent probably a good decade traveling internationally and around New Zealand for swimming. Very lucky during that time that my horror stories are quite minimal in terms of my traveling experience.

Grateful that in the 10 years, my wheelchair was never damaged, I guess to the extent that we've seen in some articles that have come out recently.

**Keith:** That's good.

**Rebecca:** I don't know that it's a now-a-day problem. It's probably been happening for all time, but now we have more visibility of disabled people in the media. Those stories are coming through a lot more prominently and a lot more loudly, and with social media as well. We thank all those people for their advocacy and bringing light to those issues.

Most of my horror stories have come from domestic traveling where...I don't know if I told this story on the podcast. I was traveling for work once, and the airline carrier that I was traveling on put my wheelchair in the wrong space in the hold on the plane. When I flew back into Auckland, they couldn't find it.

They didn't know whether they had left it in the city that I'd been in previously. No one could find it in the city that I'd been in. They couldn't find it in Auckland either. Then I think through searching all of the different baskets that they have in the hold, they found out that it had accidentally been put in a basket that was on its way to Canada.

My wheelchair almost got a free trip to Canada, and I was not impressed. The thing that hurt the most throughout that experience was I guess the lack of empathy from the airline staff and the ground staff through dealing with that process.

How easy it was for them to suggest that I just sit in one of the airport wheelchairs and be rolled through the airport to then have to go and find out when I might be able to get my wheelchair back. Then through the process of them not being able to locate it, they're like, "Oh, if we can't find it tonight, is it all right if we just courier it to you?"

I'm like, "Well, how do you expect me to get to my car? I'm an independent wheelchair user. I don't travel with carer or supporters, so I'm on my own. What are you going to do, roll me out to my car? What do I do when I get home? How do I get around my house?" That lack of understanding and lack of empathy really upset me in that moment.

I was quite motivated after that to be like, OK, some change is needed. I started going through the process with the airlines asking them to do an investigation and if this happens a lot. Sending them through some of the articles I had read recently about airlines damaging and misplacing people's wheelchairs.

At the end of it, through all my troubles, all I got offered was some credit to their airline miles or a gift basket.

**Keith:** Because you're ready to fly with them again.

[laughter]

**Rebecca:** Yeah, and it did make my next couple of trips a little bit anxious wondering is it going to show up at the other end?

**Keith:** I imagine.

**Rebecca:** Then also seeing the influx of messages about people having their wheelchairs damaged by airports. That is also a source of anxiety as well. I don't know about you, Liv, but that was particularly front of mind when we did our trip to Dunedin for the podcast. Having all three of us and wondering, were we going to get three-for-three wheelchairs at the other end? Would they all be intact? Would they be damaged? How would that go?

With the travel podcast, we were hoping to...We're not hoping to, but looking to highlight some of those experiences in real-time so that people could understand and maybe gain a bit of insight into what it is like traveling as a disabled person.

**Olivia:** What's cool about the episode is the real-life recording we did right throughout the whole trip. For us, extra airtime that we go through is stuff that we're used to. In terms of double-checking that the vehicle is accessible, the hotel rooms are accessible, but outsiders or non-disabled people listening in are really surprised that we have to go through all those extra [inaudible 9:49] really realize how many barriers were in place.

I personally haven't had any major horror travel stories. I have had my wheelchair damaged. It was pretty minor in the scheme of things, but one of my middle push rims was dented.

I don't know if they had put my wheelchair on the side, which it shouldn't be done like that, but it was quite a big weight because those push rims are made out of metal.

Thankfully, it was at the end of my trip so it wasn't like I was on holiday with this dented push rim the whole time away. Yeah, same type of thing, it was just I don't think people working at airports or airlines realize how disruptive that is.

We went to complain or make a report about it. Sadly, it felt like it was just brushed off. There definitely needs to be more education and awareness in this area.

**Keith:** You all make great points about the lack of empathy, that they just don't seem to care. This isn't like they lost your socks. This is important. It's the fact that they just don't seem to see. Is it a lack of empathy, or training, or something there that's really missing that seems to be endemic of the airline industry especially, if not travel in general?

**Rebecca:** It's maybe we see our wheelchairs as an extension of ourselves. That is perhaps something that is unique to the disabled experience, that we do see our mobility aids that way. I

can't speak for the people on the airlines or the ground staff who have to deal with this on a daily basis, but perhaps they don't see our mobility aids that way.

They just see it as perhaps like an accessory, or something that's replaceable, something that's fixable, something that we can temporarily go without if they misplace it. Therefore, they haven't quite made the connection of how important these aids are to us, and that when they do lose them, or damage them, or misplace them, that it is actually very stressful.

Perhaps bringing awareness to the fact that...I've seen some articles recently of particularly power chairs that have been damaged beyond repair by airlines that have taken upwards of six months before that user has been able to go through all the necessary processes to get a new one back.

I guess our wheelchairs are custom-fitted to us as well. Like those other wheelchair users. It's not that we can just rock up to the wheelchair store and buy a new one that's fit for purpose. It is a lengthy process of visiting with occupational therapists, filling out funding forms. It can take that long to get a new wheelchair back.

Needing them to understand that's the consequences of breaking or misplacing someone's mobility aid. I don't think they grasp that.

**Keith:** No.

**Olivia:** Saying that, it's interesting when you go traveling. You have a lot of these two extreme experiences. [inaudible 12:55] highlights the negative ones, but also if you're [inaudible 12:59] traveling also can bring out the best in people. Some of these positive traveling stories did come up in the podcast.

A few months ago, we see the other side where you're like people actually do really care and make an effort when you are traveling with a disability.

I went away just to some beach towns with my flatmates. We stayed at this holiday home near the beach. Before every trip, I do as much research as I can in terms of finding places that are accessible, but there was this one step which I was not aware of before booking this holiday home. When we showed up, yeah, there was this step and it was going to be a bit tricky.

It was just too high for me to get up by myself with my wheelchair. Then the holiday homeowner was so lovely. She got her husband who had some big wooden workshop. He built a ramp and just made the whole thing so much easier, I could go around the house independently.

I think, Bec, you had a similar experience with someone building a ramp for you on holiday.

**Rebecca:** I think it comes across the podcasts. We love [inaudible 14:01]. People like that, it makes such a difference. Yes, there are some difficulties or extra challenges and barriers when you travel with a disability, but I really think it does bring out the best in people as well.

**Keith:** That's great. I'm glad you brought that up. That's an important side to see as well. That it's not always, don't break my wheelchair, but maybe, hey, thank you for looking out for me and understanding what I require.

Let's talk a little bit about some other things, hotels, or car rentals, things like that. Any other stories or issues you've come across or mentioned in your podcast related to some other aspects? I know, for example, some hotel rooms, if you request an accessible room, they got 1 out of 100. If they've given it to somebody else because they don't think anyone's going to want it, then what do you do? Anyway, any stories related to that.

**Rebecca:** My favorite one was the day you called me when you were trying to book the rental car, and you were like, "I'm sorry. I just have to tell you this story. I'm trying to figure out how we can get three wheelchairs into one vehicle, and I'm on the phone with the travel agent or the booking person, and they're suggesting that their rental car company give us a station wagon with a trailer as a solution for us carting our wheelchairs round Dunedin."

I was like, "That's brilliant and I think we should do it, but also, that's horrible that that's where their thought process went to."

**Olivia:** It's interesting because that situation was Grace, Rebecca, and I, we all use wheelchairs. We, obviously, need to take our wheelchairs. We had a lot of recording equipment, our luggage, and we also have various levels of ability in terms of transferring into a vehicle independently. We were trying to think of a solution. [laughs]

The biggest rental vehicle they had, I would have needed some help climbing into because the seats were high. I asked if there was a sedan car or something that was a lower level, but you wouldn't be able to fit all our stuff in. It would have looked hilarious if we did drive around Dunedin with a trailer and you could see all those wheelchairs piled in the back. [laughs]

Yeah, I guess we, by nature, do become a bit of a creative thinker. It's interesting hearing other people's solutions because they mean well, but you're like, yeah, no, that's not going to work. [laughs]

**Rebecca:** Then on the hotels, it was interesting because this was one of the questions that Olivia asked when we were checking into our hotel room. She did ask, "How many rooms do you have in the hotel?" It was like in the 20s, wasn't it Olivia? It was quite a small boutique hotel.

**Olivia:** Mm-hmm.

**Rebecca:** She was asking, "How many accessible rooms do you have?" He was a little bit taken aback and he goes, "Oh, these rooms. We have 2 out of 20 or something, but they're universally accessible, universally designed." We're like, "Thank you for letting us know. That's good."

Once we closed the door and Olivia turned off her recording equipment, we [inaudible 17:01] a little bit puzzled by his need to define them as universally accessible because when you would think about universal accessibility, you would think that all 20 rooms would be universally accessible.

**Keith:** Sure, yeah.

**Rebecca:** That's how that's meant to work when you talk about universal design and principles. That they were trying to move away from accessible and using universal instead, it's all 20 rooms

should be universally designed, not just 2. That is a very common thing that you come across with hotel rooms. Slight sidetrack, personal story.

My fiancé and I are planning our wedding at the moment. Our wedding is outside of the city that we live in, so most of our family and friends will be traveling to where we're getting married. Alongside myself, a few of my other family members have access needs and would require accessible rooms.

Everyone seemed to be looking at this one particular accommodation space that only had two accessible houses. One of the family members with access needs had already booked one of them, so then I had to get on to my mom to be like, "OK. You need to make sure that the other room is booked by you guys before someone else comes in and snaps it up."

There is a little bit of anxiety there. It's like, "Well, what if you call and an accessible room is not available?" I think I did have one instance on a trip, a swimming trip, where we got to the hotel...and because I competed in para swimming, quite often the competitions we would go to, there's a lot of disabled athletes, and they usually would only have three or four hotel options for everyone to stay in.

You can imagine you've got 300, 400 disabled athletes, all with varying disabilities, all probably requiring some level of an accessible room.

If you're booking into a hotel room that only has 6 out of 100, what are all these other disabled athletes doing? That was a unique challenge. It was the luck of the draw whether you were going to get an accessible room or not.

I'm fortunate that I'm quite mobile out of my wheelchair, so I can go either way. An accessible room meets all of my needs and makes my stay really comfortable, but if I need to, I can also adapt in a room that's not completely accessible and still be OK. There's a slightly more high risk of injury and bathrooms or stuff, but it's not manageable.

**Keith:** I'm just speechless thinking about the Paralympics not having enough accessible rooms. [laughs]

**Olivia:** It's so ironic. This whole movement is meant to be about celebrating and bringing into spotlight people with disabilities and their sporting achievements, but then the logistics of it is...

**Keith:** Yeah.

**Olivia:** Yeah.

**Rebecca:** The Paralympic Games is slightly different, to make a bit of a distinction. Where I talk about hotel rooms and para-athletes, that was more for World Championships and other types of IPC-sanctioned meets.

**Olivia:** Oh, all right.

**Keith:** Oh, I see.

**Rebecca:** The Paralympic Village, I always felt that my needs were met accessibility-wise.

**Keith:** Oh, good.

**Rebecca:** I'm sure there are other Paralympians that might have other stories. Rio was definitely a very interesting time for a lot of people, regardless of your level of disability, in the village.

**Keith:** True.

**Rebecca:** I imagine also the Olympians would have struggled with some of that as well. For the most part, the Paralympic Games is designed to be as accessible as possible, and always had very good experiences.

**Keith:** Looking forward, what hopes do you have for accessible traveling in the future? If you were to design what you would consider an accessible travel experience, what would that look like?

**Olivia:** [laughs] Where do we start?

**Keith:** It's a big...Yeah.

**Olivia:** I guess one of the reasons we wanted to make the podcast was, obviously, overnight not every hotel room is going to instantly magically have accessible rooms in every single room of the hotel, not everyone's going to build drapes overnight, and things like that.

I hope that through the podcast, and in the future [inaudible 20:53] and as other people had done recently in terms of raising the profile of these issues and talking about them and the visibility. People are more not just aware, but because of that, they care so much that they take some positive action.

An example of that is friends who go out with me to restaurants and they realize how inaccessible they are. In the future, they only book places that are actually accessible. That's a solid, tangible example of how people's attitudes can change over time in terms of being an advocate and ally for disability and accessibility.

Yeah, just that empathy and understanding like we were talking before that there needs to be systems set up where disabled people's needs are prioritized and taken seriously. Whether that is involving disabled people in the process of how do we safely put wheelchairs in the hold of an airplane, or involving disabled people in designing of new hotels, and things like that, so that disabled person's experience to speak to is there right from the beginning, not at the end when the hotel is already built.

They've got guests in wheelchairs and can accommodate them. That's too late, but...

**Rebecca:** Even going as far to say, could you involve disabled people in future airline design? I know that from a lot of the articles that I've read, a lot of wheelchair users, particularly across the United States, are requesting that their wheelchairs be stored onboard the airplane as is their right.

Do we need wheelchair cubbies on future built airplanes to give people who use mobility aids and wheelchairs more peace of mind when they're traveling that they're going to arrive at their destination in one piece and so as their wheelchair, and they're going to be able to go on and carry out their business.

**Keith:** Reading off of that, how can listeners advocate for accessible travel or just continue to push for that? Alternatively, if you're a person with disability and you're planning a trip, how can you plan better so that you can hopefully avoid as many issues as possible?

**Rebecca:** Maybe I need to take a bit of my own advice here, being a millennial who doesn't like talking on the phone. I have found throughout any instance where I have been planning my own travel or needing to get something done that actually pick up the phone and talking to another human to voice your concerns and talk about your needs is actually a really great way to get off on the right foot.

Always try and follow up with some written actions or get written confirmation, so that further down the line, when you are traveling, you can reference that this is something that's been talked about and this is something that's been agreed on by the airline, the hotel, the rental car company, whoever it is that you've spoken to.

Just being prepared that, by nature, things are going to take longer, so factoring in extra time into your planning and also your travel. Arriving at the airport just that little bit earlier so that check-in isn't a stressful time if they're asking lots of questions.

Because from the podcast, I don't know whether all of this was captured in the final episode, but Grace, Olivia, and I, even though we're all wheelchair users, we have varying levels of disability and our wheelchairs are all very different. For me, as a manual wheelchair user with no assists, it's very easy for me to check-in.

I just have to give my weight, make sure they put the green sticker on my chair. For those who aren't familiar with New Zealand air travel, the green sticker is what you need to have on your mobility aid or wheelchair if you want them to bring it back up to the aircraft when the flight lands.

[crosstalk]

**Rebecca:** Back to the door, so a door-to-door service as opposed to having to get it at luggage claim. Then Olivia and Grace who have power assists on the wheelchairs, that process is slightly more complicated for them because of the battery requirements and speaking all of that through with the person behind the desk.

Just being aware of what might trip you up, and what might take you longer, what questions might they ask. Leaving that extra time has always helped me and made me feel more comfortable when I'm traveling. Just trying to remain calm and stay polite.

Even though they sometimes make my life hard, I do try to empathize with the people that work in airports and imagine that their job probably isn't the easiest.

Never try to take their mannerisms personally. They might be having a bad day. Always trying to treat people with respect and kindness, and always approaching a situation in that way first, and then escalating if I feel like I'm being disrespected has always helped me.

**Olivia:** Exactly what Bec said, just planning. I love planning. I had a full-on itinerary when we went to record the podcast in Dunedin. Just doing what you need to do to give you a peace of mind, because traveling, even without a disability, it can be quite stressful. If I travel with my power assist, I always print out the international travel airline safety certificate.

I have that on me, so if there are any questions raised or anything, I've got this to be like, hey, this is safe for travel. Just keep documents like that. Because both of us have traveled quite a lot, we just know that there are things that won't go to plan.

I guess it's just knowing that sometimes the best thing you can do is just take a deep breath and just go with the flow with some things. [laughs] Yeah, just take your time if you need to. To be honest, I feel like some of the things that haven't gone to plan in my holidays have actually been the best experiences. Sometimes that can be beneficial.

Also knowing, there can be benefits to traveling with a disability. There are some discounts. There are things that you could research and look into, like maybe you have to pay for your ticket but your companion or your friend can go for free. Look out for things like that. Like I was saying with the people who randomly built us ramps, you'll come across really cool people as well.

There is [inaudible 26:53] . You want to still enjoy yourself on holiday, and even if things don't work out, see the things that you can enjoy and hold onto those.

**Rebecca:** It's also about remembering that, even when things don't go to plan, don't be afraid to ask for what you need.

If you get to your hotel or your destination and if something isn't as accessible as you thought it would be or it's not as advertised, just going up to the front desk or speaking to someone and just explaining your concerns, explaining what you need and seeing whether there is anything that they can do to make your trip more comfortable...

That's actually how our trip to Fiji where the beautiful staff from the hotel did actually build me a ramp into my burrow happened. If you are traveling and things aren't meeting your needs or meeting your standards, then don't be afraid to go and have conversation about it.

You've always got to keep it respectful, kind, and never expect too much from people, but if you do just calmly and politely explain what you need, people are usually more than willing to help find an accommodation for you in some way or another, whether that's upgrading you to a different room that might have some more space in it, or whether it is building you a ramp into your room or into your burrow.

**Olivia:** I guess overall why we made the podcast, was to share stories. When I go traveling to a certain location, or a part of the world, or wherever, I always ask locals or disabled people who have traveled there as well, what are some things we should visit that are accessible. Talking to

other disabled people about their experiences as well can also help you with your own, and make a picture.

**Rebecca:** Which disabled person gave you the recommendation for Larnach Castle? [laughs]

**Olivia:** That was my fault. We visited this castle in Dunedin, and it was not accessible. I just wanted to go into it.

**Rebecca:** Now we can recommend to all the other disabled people that it's not a very accessible place to go. [laughs]

**Olivia:** Our friend Umi, he lives there, recommended the farmers' markets. That was good.

**Rebecca:** That was good.

**Keith:** On that note, Olivia and Rebecca, thank you so much. I really appreciate your time and sharing your stories, and thanks for being our guests. We really appreciate it.

**Rebecca:** Thank you for having us.

**Olivia:** Thanks, Keith. Thanks for having us.

**Madeline:** Thanks so much to Olivia and Rebecca for being our guests on our first episode of Accessibility Outside the Box. We'll share a link to their podcast in the show notes.

**Keith:** Check back next week for our next episode. Thanks for listening to the You First Podcast or reading the transcript online. Please email any feedback, questions, or ideas about the show to [podcast@disabilityrightsflorida.org](mailto:podcast@disabilityrightsflorida.org).

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