

## OCALI Podcast Episode 28

### **Making Change In The World. And Out of It. Dr. Sheri Wells-Jensen on Disability in Space**

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**SIMON BUEHRER:** Welcome to *Rewind the Inspiring Change* podcast series featuring conversations and connections from OCALICON, the premier Autism and Disabilities Conference. Each year, OCALICON brings together a cross section of internationally recognized leaders, educators, service providers, advocates, and many others for a multifaceted approach to improving the lives of people with disabilities across the lifespan. Rewind is the audio showcase of some of OCALICON's best moments, the speakers, sessions, and stories that make it all happen. I'm Simon Buehrer.

**DR. SHERI WELLS-JENSEN:** As disabled people, it's easy for us to feel isolated and it's sometimes easy for us to feel like we don't have any power. But as disabled people, the more we come together, the more change we can effect in the world.

[MUSIC]

**SIMON BUEHRER:** We're going to start with Earth. That's a pretty good place to start, right? Because everything we know, think, believe, do, fight over, create, love -- the sum cum total of our existence as a species starts and, for now, ends on Earth. So, Earth. Let's start there.

And let's start with a picture. Early on in this episode, you'll hear Dr. Sheri Wells-Jensen refer to a photo of Earth. And sometimes that's a challenge when we take a video recording, and we turn it into an audio podcast. Because of course you can't see the photo she's talking about. But I don't think it matters here. It doesn't matter for one because Dr. Wells-Jensen is skilled in the art of audio description. When she shows you a photo of Earth -- and she shows other pictures as well throughout the video -- she tells you what's in it using descriptive language to highlight the key elements and features. Audio description is important for creating access. Even if you can't see the photo, her words can help you build or conjure an image in your mind.

But it also doesn't matter because it's not the *photo* that's important, as Dr. Wells-Jensen says. It's the notion of *wonder* that the photo inspires. And wonder is not intrinsic to the photo. That comes from you. It's part of you. It's a gift. So, wondering, wonderful being -- keep that gift close at hand. Let's step into this bold audio adventure with Dr. Sheri Wells-Jensen.

**DR. SHERI WELLS-JENSEN:** I'm not here to tell you that what you ought to do is follow your dreams and steadfastly do that and just ignore all the criticisms and do it do it do it. And break your hearts and shatter your endurance trying to do the impossible. That's not what I'm here to tell you to do. Because that, honestly, that whole single-handed running-at-barriers thing, is a way to break your heart and it is a way to wear yourself out.

But there is a way to make change in the world. And I have something much more important and much more urgent to say to you than try your doggone hardest all by yourself. Remember that one out of five human beings on this planet is disabled. That's a lot of people and that's a lot of potential power. We don't need to do things individually.

I want to start with something inspirational, something amazing, something like Earth. Here's a picture of Earth. It is the most mundane and yet the most miraculous thing we know. Astronaut Chris Hadfield, who spent many days in space, both aboard the shuttle and aboard the International Space Station, he talks about looking down at Earth. He talks about it like this. You're holding on for dear life to the shuttle or to the station with one hand, and it's just a pouring glory of the world roaring silently next to you. Just a kaleidoscope of it. It takes up your whole mind. It's like the most beautiful thing you've ever seen just screaming at you.

It's not only just beautiful, it's more than that. Carl Sagan reminds us of this. That's here, that's home, That's us. On it, everyone you love, everyone you know, everyone you've ever heard of, every human being that ever was, lived out their lives...there. The aggregate of our joy and our suffering, every saint and sinner in the history of our species lived there on a mote of dust, suspended in a sunbeam. Looking at Earth from space, they say changes people.

It's called the overview effect. You see the little globe out there. When you look down at it, it's all green and blue with little fluffy clouds and maybe some storms gracefully moving across the face of the Earth. You see it without political boundaries. It looks so beautiful; it looks so vulnerable that you are profoundly moved. One of the reasons to go to space, or so they tell me, is this exact picture.

But I need to say one other thing to you about this picture. They talk about bringing that sense of wonder, that sense that sweeps through you that tells you that you're not alone and that the universe is big and beautiful, and maybe, just maybe, you're sort of beautiful yourself because you're part of it. We need that understanding on Earth today. We desperately do given all the crises that are going on all around us all the time. So many problems, so much fear. We desperately need this overview effect. Of course, we do.

But I want to clarify a thing, and it's this. That sense of wonder, that sense of awe doesn't come from looking at things. Looking at things is good. I'm a fully blind person, but I acknowledge that looking at things is pretty great. I can celebrate the beauty of a thing. But the beauty of a thing is not wonder. That's not the source. The source of wonder is you. The source of wonder is that feeling that comes up from inside you. It does not come from a picture; it does not come from stars up in the sky. You can get that sense of wonder in a whole lot of different ways. You can get that sense of wonder if you're a hearing person by listening to music. You can get that sense of

wonder by feeling your body moving through the world. You can get that sense of wonder, honestly, by sitting very still and getting very quiet and tuning into the wonder that is your mind and the wonder that is being alive and having a body and having a mind and living on this planet.

So...overview effect. Good. Have that. It's not a problem to have that. It's only a problem if you ignore the fact that the sense of wonder is a wellspring inside of you. Not a thing that gets pumped in from the outside, not a thing that you have to travel and struggle for. That sense of wonder belongs to you. It's your birthright.

We're still thinking about Earth, right? We're still thinking about how beautiful and how marvelous earth is. It's majestic to look at, but it's also a great and perfect place to live. Earth, I'm a fan. It's great.

But my friends, you stick your nose just above the atmosphere, just a little, tiny bit, just put your nose up above the atmosphere, and you get a very rude awakening. Outer space is ready to play Whac-A-Mole with any creature that pops its little mammalian nose out of the atmosphere.

Once you get into space, if you do get into space, if you don't just fall back down and go splat on the ground. If you do get yourself into space, sorry, but there are a thousand ways to die and all of them are nasty.

Early space science didn't know what would happen if you got into space. We knew it was going to be difficult, but we didn't have a lot of facts. We honestly didn't know what would happen to the human circulatory system and the human heart. Would your heart just race, race, race, race, race? Or would it stop abruptly as soon as gravity went away? What is the effect of gravity on the circulatory system and on the heart? We just had no idea. What about sleep? We didn't know if you could sleep in space. We know people need to sleep but in space, how would that work? We just really, honestly, didn't know.

Would people hit zero gravity and go instantly into dreamland? Or would they suffer from debilitating insomnia and be unable to work effectively? We didn't know if people would slip into useless euphoric states. Kinda fun but not a good way to get work done. Or whether you would get into orbit, you'd experience Zero-G and something about that -- we didn't know what -- would cause you to slip into debilitating depression. We didn't know if you would be unable to eat or drink in space. What about swallowing? Does it require gravity?

We know these things now, but we didn't know them then. And even so -- even though we didn't know them even though we had all these questions and all these fears and all these justifiable, scary potentialities, we still decided we're going to go. And we have gone.

This is the beginning of the human space adventure. We're not ready to boldly go very far from Earth yet. I'm not so sure what skills we will need along the way, but I know that there's going to be a variety of things that we need. We have begun to accept different kinds of people as astronauts, especially now with the commercial space companies coming online. People with

other backgrounds. People with different professions. We have people of color. We have women now in space. We have members of the LGBT community. But we don't have any disabled people yet in space. We don't even have disabled people in our astronaut corps.

If we need all kinds of people, what is stopping us from allowing ourselves to accept disabled astronauts along with all the other astronauts? I think there are a couple of reasons.

The first, I don't have to tell you about this, the first reason, I mean, you're all thinking it right now. When I ask people, "why aren't there disabled people in space?" -- all the disabled people I know have the same immediate, reflexive, and correct answer. I don't need to tell you what it is, but I will. It's that attitude. Disabled people, we still put up with quite a bit of discrimination. We are underemployed, we are underpaid, we are under challenged, we are underappreciated, and we are underestimated. I know that if I sat down with any of you disabled people and our allies, we could fill an afternoon, heck, we could fill a week with the stories that make it quite clear to us what attitudes disabled people face, "in the wild."

We work around the fact that the world is not made for us, and the effect is, my friends, that we become stronger and cleverer than they imagine that we are. The playwright Neil Marcus talks about disability as an art. He says it's an ingenious way to live. We have years of practice creating plan B because we figure plan A isn't going to work. We create plan C and plan D, and we create the Hail Mary last resort plan zillion. We do this all the time. We're always forming contingencies. We're always working around the fact that the world is not designed for us. All the while getting everything else done that we are expected to do. We sharpen our problem-solving skills every day. The world is our whetstone. We get sharper, we get keener, we get more fit every day that we live with our disabilities. You want flexibility, my friends, you need a disabled person.

So, although we have the societal attitudes, we know and our allies know, and anyone who is paying attention knows that that stuff is ridiculous. The other reason that I often hear for why disabled people don't go to space is that space is really super dangerous. It's really dangerous out there. You might get hurt. To which I say, you know what? You are right. Space is really dangerous. In fact, space is always trying to kill you, and if space can't kill you, it will be perfectly happy to disable you.

Disability will occur in space. Whether we send disabled people or not, disability will be there. With the current state of our technology, it might be complicated to send a disabled person into space tomorrow. But it would be absolutely devastating to have an astronaut become disabled in space a million miles from home with no hope of assistance. Maybe unable to read the control screens that he needs to pilot the ship. Maybe unable to hear communications that she longs to hear and needs to hear from Earth. Maybe without a space suit that fits anymore.

We haven't gathered the data yet for how disabled people are going to do their thing in space. For example, if you are deaf and you use ASL and your hands are gracefully moving through space, sometimes vigorously moving in the space around you. If you're inside gravity is that going to sort of knock you around the room? As you gesture will you push yourself around? If

you are a wheelchair user and you have lower limb paralysis, what do you do with your legs in zero gravity? Does it make sense to sort of...I mean what are you going to do? Is it -- is that okay? Is it going to be all right? Are they just going to trail along, or should you maybe tether them together? You need some kind of brace? What's the best practice there? If you're a blind person, what do you do about that dropped cup? Where did that go anyway if it just floated away from me?

We need data and we need to have access to zero gravity so that we can figure things out. We do that with parabolic flights. This is a way of creating short bouts of zero gravity that NASA has been using for decades now. I'll tell you more about what it feels like inside the plane in a minute, but this is what the plane does.

Here we go. Here's our little plane. He's flying along at about 10 or 15,000 feet. Then he puts his nose upward and he goes sharply, 45 degrees up. Accelerate high into the air. Fast, fast, fast to about 30,000 feet. Everyone in the plane is experiencing 1.8 gravities. They're all pushed back into their seats or on the floor wherever they're at. Then the airplane tips up and over and he points his nose down scarily, I think, looking at it like this at about 45 degrees and it just sort of dives downwards. [WHOOSH] And while the plane is falling through the air everyone on board experiences about 15 or 20 seconds of zero gravity floating around inside the plane. When it gets back down to about 10,000 feet so, you know, it doesn't splat into the water. It pulls up -- the pilots pull the plane, pull the nose up and it levels out.

On board the coaches are yelling, "Feet down, coming out!" And you all know that gravity is about to return. Then it levels out and then it immediately starts going up the other side of the next hill, the next parabola. It goes up to the top, and it crosses over the top, and it dives down the other side with the people all screaming and laughing and doing their experiments and it gets to the bottom, and it pulls up again, and it just continues to fly in these parabolic arcs.

So, this on your screen now is a picture of the Zero-G plane from the Zero-G Corporation that we all flew in. Let me tell you a little bit about what that is like. It is a perfectly ordinary 727 except for the fact that the first two thirds of the cabin have no seats. The seats are removed. The back third has regular airplane seats in it with actually regular tray tables and the whole works and you get on the airplane. And it's run just like a regular flight. You see the same flight attendant comes on and says the same [MIMICS MUFFLED AUDIO] that you can't really understand. Telling you to buckle your seat belts and put up your tray tables and take off and off you go. Same thing. And you're thinking, this is prosaic and weird. This feels so completely normal.

When you get out to the place over the ocean where you're going to do your parabolas, you get about 15 parabolas. They tell me that that's about the point at which people start to feel a little bit sick if they're going to feel a bit sick.

Everybody unbuckles their seat belts, and they start moving into the front two thirds of the airplane, which have been changed from a couple rows of seats with an aisle in the middle to this great big giant padded area. They feel kind of like and look kind of like white wrestling mats.

They're just very thickly padded on the floor. They're very thickly padded also on the walls. They're also very thickly padded on the ceiling because remember we're about to do zero gravity here, so who knows where your body is going to end up.

And here this was me going out there from my seat into this area where we practiced doing this before we had the plane, the day before, we'd run through it. Everyone around me was bouncing up and down and they were so excited to be doing this thing. And I'm thinking, please God, don't let me cry. Please God, don't let me just burst into tears and call for my mama. Let me at least have a little bit of dignity about this because I was scared. But I was super curious about what was happening. It was the curiosity that had brought me, not the thrill of the hunt or the excitement of the dive. It was just, what is this going to be like?

We all went out to our places, and we laid down on our backs and we heard the flight attendant, the coach actually call, "On the pole!" Which meant the airplane was starting to do its rise up the first hill of the first parabola. It felt like kind of a not very wild roller coaster. I remember thinking to myself, jeepers, this isn't so bad. I'm not pasted onto the floor. I can move my arms and legs around. I'm doing okay. It's really loud. It's also quite cold because that's one of the reasons they do that is to keep everybody from getting sick because heat causes nausea, right?

It's cold, it's loud. Two of my least favorite things. It's shaky, and we're about to do something dangerous. Without any real warning, the noise of the airplane shifts slightly. I think that I feel the nose of the airplane tipping down. Anyway, it feels like my feet are getting lower than my head, and I had just this white, hot streak of panic go through me thinking, this is it. It's going to feel like falling, and I am going to cry. [LAUGHTER] I'm going to scream. I'm going to yell, "please get me off this plane."

As I'm thinking that I'm getting ready to grab for something to hold onto, and then the weirdest thing happened that I've ever experienced in my life. I reached behind me, and instead of the floor being behind me -- that I was supposed to be laying on, there's a couple inches of air. I thought to myself, what kind of weird air do they have here that can slip between you and the floor like that? I didn't feel myself lift up; I just wasn't laying on the floor anymore. Then my friends, things got really weird, and it was the most fun I have ever had. It was a delight. It was not scary at all.

It felt like you were being held, but that you weren't being touched. It felt like you had arms. Well, actually you didn't have arms because you think of arms as being on the top of your body. I had four limbs, but I didn't know if they were arms and legs because I couldn't stand up, but I couldn't fall down. Every movement I had, every movement that I made, trained as I was in gravity, every movement I made did some unpredictable thing. I didn't know how to stand up, I didn't know how to fall down. It didn't feel like floating because at least in floating, there is some sense of up and down. It didn't feel like falling and it didn't feel like swimming because, again, swimming, you always know which way's up and which way's down. It was incredibly funny, and it was incredibly gentle, and it was fun, and it was glorious, and it was liberating, and it was wild.

But the point was not to show that disabled people can take a shaking. If that's all we wanted to show is that we're kind of tough and we're kind of brave...I mean most of us are brave, then there's me. We're tough and we're brave, most of us. But the point was, the tasks that we were able to perform in zero gravity, and the things that we learned.

So, we did learn between that flight and a couple subsequent flights, we did learn that probably the best thing to do with your paralyzed legs is in fact tether them together, and to tether them together pretty tightly. We did learn that not only does ASL not knock you around the cabin, but if one of you is standing up floating this way feet down, and the other one is floating upside down with reference to that person feet up toward the ceiling and you're signing to one another. We learned that you can in fact, understand one another.

We learned some things about orientation for a blind person in zero gravity. We learned that you can use some tactile markers on the walls to get a quick and accurate sense of which way is up, and which way is down, and which way is the exit. On later flights, we took up some of the questions that the industry has been asking. For example, can a disabled person, a blind person, or a person in a wheelchair in particular, can those people find and get themselves into a seat in zero gravity and fasten a five-point harness in the allotted time? Which I think is 15 seconds. The answer is yes. Yes, we can.

So those are some of the things that we learned. It was great and it was amazing, and it was new, and I really do think that we have moved the needle a little bit. We are changing what the space industry thinks astronauts should be like. I think slowly we are making that change. But space is only part of this goal. Honestly, lack of access to space is not something, well, not something yet anyway, that bothers most disabled people on a daily basis.

I told you that there was something better than follow your dreams that was going to come out of this, and this is that thing. I think that I have learned that it takes two things to make real change in the world. The first is a loving and supportive community. We did not go to zero gravity. We didn't do these things. Nobody did this by themselves. It was not one person's audacious and ceaseless fight, all by themselves, breaking their hearts alone to make this thing happen. This thing happened because of a determined, and dedicated, and loving community of disabled people and our allies making this work together. It's this abiding sense of community. Abiding sense of community is the first thing you need.

The second thing you need is an abiding sense of dissatisfaction with the way things are. We can change just about anything that we put our minds to, and we can have this. I love this picture. This to me is the best result pictorially and maybe the best experience of all of our Zero-G flights. This is a picture of Zero-G 727 called G-FORCE ONE. Instead of just the sleek airplane sitting there, it is the sleek airplane sitting there with the side cargo door open, and this marvelous, beautiful, graceful wheelchair ramp moving from that cargo door down to the tarmac so that anybody can walk aboard the airplane.

Honestly, this is the picture of the airplane that I love most of all. It's the picture with the ramp, and if we do that, we can have this. This is the picture of all of us, the disabled folk and our allies standing outside in front of the plane. We can create this.

This can be the next class of NASA astronauts. They can look like us. In this picture, we have several folks in wheelchairs, we have people with prosthetic legs, we have a couple blind people standing there with our white canes, we have deaf folk, and we have our allies and we're all gathered there together. If we can hang on to our community and we could hang on to our abiding sense of dissatisfaction long enough to do the things that we've already done, we could do just about anything that we want to do.

SIMON BUEHRER: Dr. Sheri Wells-Jensen is an Associate Professor at Bowling Green State University in Bowling Green, Ohio, and the 2023 Baruch S. Bloomberg NASA Library of Congress Chair in Astrobiology, Exploration and Scientific Innovation. She's also on the leadership team of AstroAccess, a project which, among other things, is dedicated to promoting disability inclusion in space exploration. This podcast was produced from her OCALICON keynote, "Disability and Space: A Necessary Partnership." You can find more great presentations by Dr. Sheri Wells-Jensen on YouTube and other streaming platforms. While you're at it, check out her band GRUBS, the Grand Royal Ukulelists of the Black Swamp.

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You're listening to *Rewind*, our podcast series featuring conversations and connections from OCALICON, the premier autism and disabilities conference. Learn more about OCALICON at [ocalicon.org](http://ocalicon.org). Thanks for listening. I'm Simon Buehrer. We'll see you soon.

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