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# Proem

# According to the CDC

A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).

Clearly, it's not a legal definition. I would add *self-image*, *societal perceptions*, *and environment* as components of that definition. Some days, I feel more disabled than other days, and some situations enhance or reduce my abilities. Ability/Disability is a continuum that changes over time and situation. Travel accentuates my abilities - puts them in high relief - for me. Travel requires close examination of my abilities so I can figure out how to manage minute-to-minute - constant decision-making. Travel allows me to stretch my capabilities. It's exhilarating and eventually exhausting. Periodically, I share my travel experiences. Remember the two <u>Camino de Santiago pilgrimages</u>, one in 2019 and the other 2022? In 2023 we explored <u>Costa Rica</u>. We're planning a music trip to Cuba in four months. Today, I describe our trip to Cloudland Canyon State Park in northwest Georgia.





Figure 1: Image from the Aimee Copeland Foundation

After a zip-lining accident in 2012, when she was 24, Aimee Copeland was hospitalized and diagnosed with a flesh-eating, bacterial infection. They had to amputate both of her hands, right foot, and entire left leg. Before the infection, she was extremely active, rock climbing, backpacking, and trail running. In response to her frustration with wheelchair life, she created the Aimee Copeland Foundation, which raises funds to create opportunities for connecting with the self, the community, and the earth through the provision of a fleet of all-terrain wheelchairs for free use by people with disabilities within select Georgia state parks. In this podcast episode, we

interview Philip Shadle, CEO of the Aimee Copeland Foundation. You can find videos of me motoring in an all-terrain wheelchair on my YouTube channel—links in the show notes.

### Podcast intro

Welcome to Health Hats, the Podcast. I'm Danny van Leeuwen, a two-legged cisgender old white man of privilege who knows a little bit about a lot of healthcare and a lot about very little. We will listen and learn about what it takes to adjust to life's realities in the awesome circus of healthcare. Let's make some sense of all of this.

## Off-road wheelchair travel

Health Hats: Philip, thank you for taking a few minutes to tell me about yourself and the Aimee Copeland Foundation. I am a person with disabilities. I've got all my limbs and use two-forearm crutches and an electric wheelchair. I can walk. My balance pretty much sucks. I like to travel. My wife and I have friends we travel with. When one of our fellow travelers looked up disability travel, they found the Aimee Copeland Foundation. We went to the Cloudland Canyon State Park and used their all-terrain wheelchair. It was awesome, just awesome. I have a foldable electric wheelchair that does maybe a 12% grade and, at top speed, might go four miles an hour. And I do some pretty rough stuff with it, but I can tip over.



Figure 2: Image by Ann Boland

Anyway, I just want to tell you the thrill I experienced with the all-terrain wheelchair. The process was easy: take the online safety training, get a certification, and reserve the all-terrain wheelchair. Everybody was so lovely in the park, and I did two miles in two hours, which was enough. I'm glad I was strapped in.

**Philip Shadle:** Yes, you must get used to the chair's operation. The ride can be a little bit rough for first-time users. Like anything, the more experienced, the better you get at handling the trails.



Health Hats: I'm comfortable on trails because I've done it with my chair, and I'm very comfortable with a joystick. I had scouts to help me., I went to the website and looked at Ms. Copeland's biography and story, and it's awe-inspiring. Tell us a little bit about yourself.

## Introducing Philip Shadle

Philip Shadle: I became a dealer for Action Track Chair in 2011. When I started, I realized this is something unique, allowing people who might not otherwise have an avenue to get outside and do things to get off the boardwalks and the pavement and get in touch with the earth. As a dealer, I saw how they helped people physically and mentally be outdoors and go places other people go. Just to be included, one of the things that stuck out in my mind in the early years was when I sold a track chair to the parents of a little boy who was 11 at the time. The most significant thing he wanted to do was play in the creek with the other kids, and he wanted to know if the track chair could go in the water. And I said, it absolutely can go in that water. It was only maybe six inches in a little creek. So, on the first day, I brought a demo chair down to him. He put it in the creek with the other kids, which changed his life. There was no other way, no other wheelchair. He could go down the embankment and into the creek with the kids. I realized then it was something special.

## Travel in Costa Rica

Health Hats: We found a travel agent in Costa Rica that specializes in people with disabilities and offered the services of a guide. We went for a week. He drove and set up everything. He was the grandfather of disability travel in Costa Rica. What an enjoyable experience, especially since he took me on some capability-stretching experiences. He took me in my chair on a 10th-of-a-mile-long suspension bridge six inches wider than my chair on each side and 20 stories over the canopy, swaying 18 inches when you hit the middle. I'm scared of heights. I was ready to pee my pants the whole time, but once I got over it, it was like, oh man, I did that. I did that. See my travel videos here.

## Foundation Business Model

Health Hats: How do you fund your work? Those chairs, maintenance, and services can't be cheap.

Philip Shadle: Fortunately, the maintenance is next to nothing. They're very easy to maintain. There's not a lot of parts that go bad on the chairs. So, we launched the program a little over two years ago, and we've only had to repair some of the attendant controls. A cable that allows an attendant to drive the chair can get pinched in the track, and we must replace them. But other than that, the chairs, the maintenance, and the function is easy. We are 100% funded by donations and grants. We reach out to the public. We asked for corporate grants for individual donations and everything in between to help do that.

Health Hats: Good. I just sent a hundred bucks and subscribed to the blog.

Philip Shadle: Thank you.



**Health Hats:** Oh, it's worth it. I would've paid to use the all-terrain wheelchair. I couldn't believe the Park didn't charge me.

Philip Shadle: In today's world, everything costs.

### All-Terrain Wheelchair Models



Figure 3: Image from the Aimee Copeland Foundation

Health Hats: Did the 11-year-old kid get the same wheelchair I used, or was it smaller because he was a kid?

Philip Shadle: It was smaller. We have different sizes. It was the exact model you sat in, but the one you rode was 24 inches wide between the arms, and his was only 16 inches. The chair his parents got for him was a little too big. But they went with it because of the longevity of the chair. They wanted him to be able to grow and adapt and not grow out of it. So that's one. And now we have different models that have expanding arms. I've retired from Action Track Chair, but they have models that expand. So, it has the same base, but the arms go in and out to accommodate growth.

**Health Hats:** I saw the new model on Instagram or TikTok. Aimee was in a new pink one, and she was thrilled. It was so much lighter.

**Philip Shadle:** Yes. They have a new model called The Axis, which is an adjustable model. To use that can go with growth or change the arm widths in and out.

### Call to action

I now have one URL for all things Health Hats. <a href="https://linktr.ee/healthhats">https://linktr.ee/healthhats</a>. You can subscribe for free or make a contribution through Patreon. You can access show notes, search the 600-plus episode archive, and link to my social media channels. Your engagement by listening, sharing, liking, and commenting makes quite an impact. Thank you.

# Training for Off-Road Travel

Health Hats: My wife's a hiker. She would hike the Grand Canyon or another National Park with our friends every year, and I'd stay home. Okay, whatever, I can't do the Grand Canyon. Those days are over for me. Then, when they wanted to go to Spain and hike the Camino de Santiago, I said, forget it. I'm going. We're figuring this out. I developed a training plan for myself: what do I need to do to be able to do 14 days of travel? What about when I can't do all those things? How am I going to travel on a train or a bus? It made me up my game in terms of figuring out how to be accessible or how to have access. See



my travel videos <u>here</u>. Oh my God, my mental health. I can't tell you how much it helps my mental health. I can do shit,

Philip Shadle: That's right, realizing you're no longer restricted.

Health Hats: Everybody has restrictions. That's just the way it is. For some, it's fear, like I would've never gone on that bridge. I wouldn't have walked across it able-bodied, but here it was. This guy set it up. He was there. And I am like, Hey, I'm here. And once I go forward, there's no going back. Because you can't back up because there are people behind you, and you had, I had to do it. And, so then that's, yeah. So, then it's, oh man, so I'm 71 years old, and I have these disabilities. I'm an old fart, plus I'm gimpy, but still. So anyway, I want to thank you guys.

# Birthing the Foundation

Health Hats: What a great business.

Philip Shadle: We would like to think that it's Aimee's creation in her mind after her accident and discovering that she was limited to what she could do versus what she used to do. Her first idea was to create a park accessible to all people and put in specialty items. And then the more she thought about that, the more it's no. We don't need a specialty park. We want to go where everyone else goes. That's when she came up with the idea and contacted me in 2019. She had researched and seen the Action Track Chair, and we took one to her. She mapped some trails in a state park and was thrilled, laughing and driving through the creeks. She said we need to put this out there so that people can enjoy the same state parks that the general public enjoys. The idea



Figure 4: Image from the Aimee Copeland Foundation

of an adaptive park got pushed aside because it made no sense. We don't want to go someplace special. We want to go where everybody else goes.

## **Expanding the Foundation Offerings**

Health Hats: Are you thinking about other states doing it? Are other states interested?

**Philip Shadle:** Very many other states are looking to us. Look at our model. They call and advise. We are welcome to help other states, but we focus on Georgia. We're just doing our phase two that we're calling, putting nine more chairs out this year. They're all out except for two. We will have 20 chairs in the Georgia State Park historic sites. We have three additional tiers in national parks in Georgia, including two in Cumberland. If you haven't been there, that's a fantastic place.



Health Hats: So, are the new ones smaller and lighter?

Philip Shadle: We have several different models. Some of the same models in the parks have a narrow version, and then there are newer ones. Aimee's, which you saw, is 30 inches wide. It goes up the ramp into her van. She can drive up there just like she would in her everyday power chair and then transfer her swivel into the driver's seat.

If you have some of the bigger models like what you enjoyed at Cloudland Canyon, people will haul those usually on a trailer or in the back of the truck if they do. Many of my independent users have a trailer, and the attendant control you saw allows someone to guide the chair and load or unload the all-terrain chair while you're in your everyday chair next to the trailer. So that's one way of doing it by yourself.

Health Hats: I like renting an all-terrain chair instead of owning and storing one.

Philip Shadle: This year, we introduced a new program. We purchased a big empty cargo van that can move the track chairs. We're going to have 20 parks that host the chairs. They'll live in the park, but if you decide to visit another park, we're mapping ten new parks that are not hosting a chair, and we will put them online. Maybe you decide you want to have an event, you and your buddies all want to get together, and there are four of you. You'll give us advanced notice. We'll go around and pick up four chairs and get them all in one location for you to use for your event. We want people to be able to use the state parks. The state parks are amazing. They have so much to offer; we want people to enjoy it.

## Grateful

Health Hats: Thank you. What a gift. You must have a team. Thank them for all the excellent work they do. Here's one person who appreciated it. I had the time of my life. I'm still buzzing. It was a thrill, a total thrill.

### Contest

Philip Shadle: There's one other thing I could lead with you that you might want to fit in there somehow. On June 1, we're going to launch a sweepstake, and we are going to be giving away a brandnew action track chair. You get an entry for a donation, and there are different levels of donations and entries, so the sweet takes work. And it's going to run through September. People will have a reasonable time to see, share, and participate. And then we will give away a brand-new action track share, just a time for our beautiful fall weather to get out and watch the leaves change. Anyone In the 48 contiguous states can apply. So, it's going to be exciting. They're going to get to choose the size. It will be the model you rode in, but they choose their size and color, and the manufacturer will custom-build it. We get to deliver it and make somebody very happy.

Health Hats: Alright. Thank you so much, sir.



Philip Shadle: Thank you.

## Reflection

I'm still high off my two-hour, two-mile all-terrain wheelchair experience. I did it, I did it, I did it! I had plenty of help: a team – the Aimee Copeland Foundation, Action Track Chair, Georgia State Park rangers, the airlines, and my travel friends and family. Any of us can benefit from warm and sensitive workflow, device, and personal assistance to expand our abilities. It's humbling and exhilarating. Onward.

## **Podcast Outro**

I host, write, and produce Health Hats the Podcast with assistance from Kayla Nelson and Leon and Oscar van Leeuwen. Music from Joey van Leeuwen. I play Bari Sax on some episodes alone or with the Lechuga Fresca Latin Band.

I'm grateful to you who have the critical roles as listeners, readers, and watchers. Subscribe and contribute. If you like it, share it. See you around the block.

