

Katie Nieves Licwinko:

Welcome back to the Assembling Inclusion Podcast. Today, we are joined by Syren Nagakyrie. The founder of Disabled Hikers. So, Syren, thank you so much for being here with us today.

Syren Nagakyrie:

Yeah, thank you.

Katie Nieves Licwinko:

So, just to kick off, I was wondering if you could explain the inspiration for creating Disabled Hikers. I consider myself a hiker. When I heard about your organization, I immediately wanted to make sure that I talked to you. What unique perspective do you think this organization really brings to the world of outdoor experiences and advocacy?

Syren Nagakyrie:

I grew up with multiple disabilities and chronic illnesses myself, and I'm neurodivergent. So I, you know, growing up, we didn't do things like hiking trips or camping trips or, like, big national park vacations or things like that. But I spent a lot of time just hanging out in my yard and, you know, watching the birds and the bees and things like that. And that was really meaningful for me growing up. And as I got older and eventually learned that, like, hiking was a thing that people did and you know, I realized that it would provide a way for me to have more of those experiences and get to enjoy nature more. So I wanted to figure out what that meant for me and look like for me and my body. So. It was a lot of just trial and error and trying to figure out what I could do, what I couldn't do, how I could find information and resources, what was available out there. And, you know, I very quickly learned that there was not much available out there. And most people didn't know what I needed. And so, you know, I really had to figure it out for myself and I was probably in my mid twenties or so when I started really doing that. And then in my late thirties, I moved up to Washington state outside of Olympic National Park. And it's just an incredible place. It's so beautiful. There's old growth rainforest and rocky coastlines and it's just really stunning and I wanted to experience it, and started doing all of my trail research trying to figure out where I could go and, you know, still started out on a trail and encountered all of these obstacles and barriers that I didn't read about that weren't in any of the guides. Things like steep stairs or rocky drop offs, things like that non-disabled people tend to not really think about, but for me, it was really dangerous and I was, you know, just really frustrated and exhausted and in pain and in that moment kind of inspiration struck and I said, I'm going to do something about this and went home and wrote up a trail guide and put it up on the web and that was kind of how Disabled Hikers was born.

Katie Nieves Licwinko:

I mean, even the trail guides that I've looked at, they have this arbitrary, like easy, moderate, hard. And I'm like, "What does that even mean? What constitutes easy?" So, I can see how that would be problematic for somebody.

Syren Nagakyrie:

It was really tough, but the inspiration was kind of born out of that. So, I kind of have to be grateful in some ways, but even now, as much as we've grown-- this was in March of 2018 that I started it-- and, you know, even now we still encounter tons of obstacles and things like that out there

Katie Nieves Licwinko:

So, I noticed one of your key aspects of Disabled Hikers is writing those guidebooks, and I think on your website, it specifically says by disabled hikers for disabled hikers, which, you know, I think is great from the "own voices" perspective and knowing what people need to hear about in the guides. But how does this approach really ensure that outdoor experiences are more accessible and inclusive for different types of people?

Syren Nagakurie:

So, I really believe that access to information equals autonomy. So, you know, having all the information that someone needs to be able to make a decision for themselves is really important, especially for disabled folks who, you know, I think a lot of, like, non-disabled community tends to think that they have to make decisions for us--that they have to tell us what is accessible or not accessible. And, you know, I'm perfectly capable of making that decision for myself if I have that information available. So, providing it from that perspective is really important and also just centering disabled people in the outdoors. I think a lot of outdoor rec opportunities are often for disabled people, but not by disabled people. And, you know, that inclusion aspect is certainly important, but there's plenty of room for disabled folks to take the lead-- figure out for ourselves and for our communities and each other what being outdoors looks like and can mean. So, that's really kind of the process that we want to help support.

Katie Nieves Licwinko:

Empowering people to kind of talk about what something looks like from their perspective. I think that must be-- it must be more helpful in terms of accessing, you know, trails and different outdoor opportunities, especially because that's so important for people as a whole. I think everyone can benefit to some extent from being in the fresh air and being outdoors to whatever extent they're interested in. But that's great that you were kind of empowering people to take ownership of those experiences for themselves.

Syren Nagakurie:

I mean, there's all this talk about, you know, the mental health benefits of being outdoors and the physical health benefits of being outdoors, which is all true and valid. But, you know, I think the people who often need that support the most are disabled folks, but we have the least access to it. And we're also often excluded from those conversations about what does health and well-being in the outdoors look like when you are disabled and chronically ill? You know, it's not going to, like, cure me of my chronic illness. So, there's definitely that element to it, too.

Katie Nieves Licwinko:

That's definitely a good point. So, I know you're located in the Pacific Northwest. So, a lot of your guidebooks are currently based in that region, right? I think you have Washington, Oregon,

California...what criteria do you typically consider when selecting a location or a trail to be considered in those guidebooks?

Syren Nagakyrie:

It's a really long process for sure. Like when I was working on the Western Washington and Oregon guidebook, there's a total of like 60 trails in there, and I hiked probably 150 at least. So there's, you know-- a lot of research goes into it, but then it really just comes down to hiking it and figuring out what that trail is actually like, because the research is so limited. So, you know, I really try to find locations that are going to be accessible to a variety of folks and that includes like public transit when it's available-- seldom is-- but, you know, when it is, including that for sure. And then finding places that offer something for the experience. You know, a lot of, like, truly wheelchair accessible trails are often, like, really short and they don't really go anywhere. They're just like a few hundred feet to no real view or anything like that, which is super disappointing. So, you know, I try to find locations that are not like that, which is a challenge and then, offering both opportunities for people who want to or need to stay close to town or in their city, and also opportunities for folks who want to go out and have kind of that more like "off-the-grid" quote unquote wilderness experience and kind of get away from the city. So, I think disabled folks really want to have the same kinds of experiences as everyone else, so really trying to provide that as much as possible.

Katie Nieves Licwinko:

Yeah, it sounds like you have a lot of different options, then, for people based on what they're interested in. Because I think what I've looked, too, at wheelchair accessible trails or whatever is considered accessible on different hiking platforms I've used and seen-- it does tend to be, like, less than a mile, and paved and it kind of goes from the parking lot to an end point and then back again. And that's usually all I could find, which if somebody wants that, that's great. But, you know, if you want to have a little bit more of, like you said, an off-grid experience or something like that, then that's not going to satisfy your needs. So, I think it's great that you're kind of working to provide different options so that a variety of people can access what they want and what they need with being outdoors. So, you have a spoon rating system, right, for your trails? I wanted to know what that entailed and how could a hiker use that to figure out, like, the accessibility or understand the trail a little bit better.

Syren Nagakyrie:

So, like you mentioned earlier, you know, a lot of difficulty ratings are just kind of like easy, moderate, difficult, and they don't tell you what that means or "easy for who?" or anything like that. So, I wanted to offer some kind of, you know-- I think difficulty ratings need to be much more objective and be very clear about what they mean. You can define them in any way you want. Just be very clear about what that definition is. And then, I also wanted to offer something that was culturally relevant. So, you know, the spoon rating is based on the idea of Spoon Theory by Christine Miserandino, you know, and I know not everyone resonates with Spoon Theory and that's okay. But I think it is, you know, pretty commonly known within the community. So, it's this idea that, you know, many people with chronic illness and disability have to ration their energy levels every day. So, you start with, like, for example, 10 spoons, and then every

activity you do requires a certain number of spoons. And then at the end of the day, you have whatever's left, which may be zero or negative or one if you're lucky. So, I wanted to offer something that was, you know, relevant in that way. So, the spoon rating system is kind of on a 1 to 5 scale. So, it's not saying specifically, like, this trail will cost you one spoon. It's just on a 1 to 5 scale, right? And then, again, being very objective about what that means. For example, one spoon is going to be, like, under two miles, probably paved, you know, probably wheelchair accessible, no steep grades, things like that. And then, like, a five spoon could be up to five miles or have a lot of obstacles or, you know, be difficult to navigate something like that. And then kind of any one factor within that spoon rating can shift and may or may not change the overall spoon rating. So, for example, like a five mile long trail that's paved and flat and accessible may only be rated like a two spoon, whereas like a one mile trail that's super steep or super rocky may be five spoons. So, trying to really take into consideration how accessible that trail really is, being specific about what that means.

Katie Nieves Licwinko:

I like that you are specifically naming what the factors that you're considering in that rating system are because I've been on the trails where it's like, "Oh, it's moderate, but I'm scaling a wall vertically." And I'm like, "Well, that's not really moderate. I don't really know where that came from." Or ones that are moderate that are just a flat paved trail with, like, maybe a couple of rocks here and there. And I'm like, "this rating system is extremely inconsistent." So, I appreciate that yours has a little bit more of a concrete, "It's this length, but this, you know, type of experience." That has to make it a lot more accessible for people who want to get out there.

Syren Nagakyrie:

Yeah, I think it gives a much more at least specific starting point, you know, so I can kind of know like, "Oh, I'll probably be looking for something in like the two to four spoon range and then I can start there and start reading more of the trail descriptions to figure it out."

Katie Nieves Licwinko:

Yeah, it has to be a good starting off point, I would assume. And then, I think it eliminates that fear factor of like, "If I get out there, I know what I'm encountering." It's not the possibility that it's going to be an easy trail, but I'm still going to have to do some rock scrambling in there that I didn't know about. So, that has to be, I'm sure, very helpful for everybody. So, I know that beyond your work with the rails, you also offer, like, a broad range of different types of services. So, can you talk a little bit about how you work with different parks and organizations to continue your mission of, you know, building disability justice and accessibility within an outdoor space?

Syren Nagakyrie:

Yeah, we work with a lot of different parks and organizations. So, I worked with national parks around creating trail guides for their trails, doing assessments. I work with a lot of parks to do, like, trail and facility assessments to kind of determine, you know, how accessible things are. We do a lot of trainings with various organizations around disability and access and social justice, and we do a lot of consulting on things like, you know, park plans, trail plans, things like that to make sure that they're not just following the bare minimum accessibility guidelines, which

is all that a lot of parks have to go on. Unfortunately, you know, they have their set of guidelines. They figure they have to comply with those and they're good, but I think more and more, you know, parks are starting to realize that that's not everything and that you have to go beyond that and are trying to engage with the community more. So, that's where we kind of come in, offer that expertise, and also offer that connection with the community. You know, we'll often do things like organize community feedback sessions, where we bring in folks from our community to then offer their perspectives to the park, as well.

Katie Nieves Licwinko:

Oh, that's really great that there is that partnership between the work that you're doing with Disabled Hikers and the community and the parks themselves, because having the guides and everything is great, too, but then meeting people in the parks that they're already going to, like the national parks-- I think about how many people just in a year visit those spaces and making it more accessible to people that has to be pretty impactful. And it's great that they've been so receptive to the feedback, as well, and they have their own interest, I guess, in making things more accessible.

Syren Nagakyrie:

There's definitely still, you know, a lot of room for improvement, but we're slowly getting there.

Katie Nieves Licwinko:

Small steps is at least better than, you know-- going backwards is worse, so at least you're going forward. that's good. So, you also have a blog on Disabled Hikers, which is pretty cool. And I was reading those articles-- I'll be honest. There were things like, you know, community voices. I know we talked a lot about hearing from people within the community, but how do these articles specifically and initiatives like your storytelling project that you have-- how have that helped to build a sense of community for disabled hikers and outdoor enthusiasts?

Syren Nagakyrie:

Our approach to resources and storytelling kind of takes two angles, right? So, we have the resources that are geared more towards, you know, the non-disabled community and allies to kind of help educate them more on the outdoors and accessibility. So, that's where, you know, we provide things, like I have an article on accessible trail surfaces and how to find information and things like that. And then we also have our community voices project, which includes a storytelling project. And that's an opportunity for people, you know, within the community to be able to tell their stories. You know, there's so little representation of disability in the outdoors and what does exist out there tends to be like inspirational narratives of overcoming disability and, you know, there's so many other types of experiences that need to be shared. So, we really want to provide a platform for that. So, we pay people a stipend to write blog posts and just tell their story about what outdoors means to them, you know, how they engage with the outdoors, what it looks like for them, you know, both to provide that representation, and also help people feel less alone and have those opportunities for connection.

Katie Nieves Licwinko:

That was one of the things that stuck out as I was reading some of those community voices stories and experiences. I would imagine that somebody reading their experiences could make a connection and realize that they, too, could have that experience in the outdoors, as well, because I'm sure there's a lot of still, you know, people who might feel like they can't interact with the outdoors in that way. So, I'm sure hearing those stories is probably pretty powerful in helping to bring people into that type of experience. We talked a little bit about your collaboration that you do with parks and other organizations and brands, but so far, how have the experiences and initiatives within Disabled Hikers made a positive impact, do you think, on building more of a disabled hiker community or just getting people involved into those experiences more? What positive impact, I guess, have you seen overall?

Syren Nagakyrie:

I like to think we've had a really big positive impact. It's always kind of difficult to, like, quantitatively measure that kind of thing. But, you know, I hear from a lot of people from across the country and even around the world who follow our work and are inspired by it and excited by it. So, that feels good to me at least. We also, of course, do group hikes and community events, and that's another great way for people to come together with folks in their local community and build those connections. And I've heard from a lot of people who have attended those events who then said they went out hiking with some of the people that they met there afterwards and, you know, that's always great to hear. And, you know, I think that overall, even just in the last few years, there's been a huge uptick, I think, in the number of people who are sharing about their experiences as disabled folks in the outdoors and are really, you know, engaging with this work. And, you know, I think Disabled Hikers has had a part in that. It's, you know, really exciting to kind of see that movement.

Katie Nieves Licwinko:

It sounds like all of the work that you're doing has a positive impact. I know there's no, you know, quantifiable number to say, but just from, you know, hearing about the experiences that you've been providing and working on, it seems like there must be a positive impact. And I have to ask, and this is purely from my East Coast bias perspective, are you looking to expand for like trail guides to, I don't know, like midwest regions or east coast regions? I'm just curious. I mean, I would love to hike in the, you know, on the west coast a little bit more, and I actually have that on my list of things I'd love to do, but for right now, I'm stuck on the east coast-- so I was just curious.

Syren Nagakyrie:

Yeah. We get lots of requests from, you know, the midwest and east coast. And I actually-- I grew up on the east coast. I grew up in Florida and then lived in North Carolina for about 10 years. So, I still have connections over there and I get, you know, over on that side of the country, at least once a year and try to do, you know, at least some kind of event. So, we're definitely hoping to expand and do more. Of course, funding is always an issue as a non-profit. So, trying to get money to do that is a challenge. But yeah, we definitely have some plans in the works on how to expand.

Katie Nieves Licwinko:

That's just my biased question, because I always like to know if things are coming to my area. Even though you're doing such amazing work on the west coast, I was like, I need to know about this region. But that actually is a perfect lead into looking ahead right into the future. I always like to ask about the future. So, you have a lot of new initiatives that are going on. Like I saw that you have the Disabled Hikers Network Leadership Development Program. So, what are your goals with this new initiative, and is there anything else that you're working on that you're really excited about right now?

Syren Nagakyrie:

So, I've been planning this Disabled Hikers Network for a few years, and it's something that I really want to do. And it's to kind of help provide more opportunities for disabled folks to do this work in their communities, but also connect with each other. You know, I think there are, like, pockets of individuals who are interested in this kind of work or are doing something similar. So, providing an opportunity for those folks to come together and connect and network-- and also, we want to provide leadership development training for disabled folks to teach them how to do trail assessments and how to lead group hikes and how to write trail guides and how to work with the parks and how to do all of that while maintaining kind of a disability justice social justice lens. That's really important. So, you know, we're working on a few phases of that. So, starting with providing networking opportunities and then providing the training for individuals, piloting that on the west coast, because that's where we are, and then eventually expanding to doing that nationwide, which will then lead to chapters across the country and all of that. So, we're really excited about that growth.

Katie Nieves Licwinko:

Yeah, that seems like it'll give people who are interested some really great leadership opportunities and get the opportunity to get their voices heard, too, and do the work in that area. I'd have to imagine there are a lot of people who are probably interested in doing work in that space, so it's nice that you're providing a structured program to prepare them to take on that type of work. And I definitely could see that spreading just in general, having to, you know, be in a certain place at certain times to do the different events and things like that. So it'd be nice to have people who are, you know, on the ground to get things started.

Syren Nagakyrie:

And, you know, even just with my process of having to, like I said earlier, I had to really figure all of this out on my own. And it took a long time. And so, I want to provide a way for, you know, people to not have to do that on their own and just provide those opportunities to learn.

Katie Nieves Licwinko:

Yeah, give them the resources and the tools that they'll need. That's a great program. And I wanted to know for our listeners who wanted to learn more about Disabled Hikers or access your resources or engage in upcoming events or just overall support the organization, how would you recommend they go about doing that?

Syren Nagakyrie:

Yeah, so they can definitely check out our website at disabledhikers.com. We're on Instagram and Facebook. Of course, you know, actually, like, finding the information that you want on social media when you want it is always a challenge, so we also recommend that people sign up for our newsletter, which goes out twice a month and we share all of our upcoming events and opportunities and resources there. That's another great way. And then, if you're in an area where we're doing, you know, an event, come out to a group hike and meet others, it's another great way. And, you know, if you're in an area where you'd like us to come out and do an event or something like that, we're very open to that, especially if we can find someone or something to sponsor that.

Katie Nieves Licwinko:

Awesome. And I'll be honest, I spent a lot of time following and looking at your Instagram feed. There's a lot of great information out there. I mean, I spent a lot of time on the website, too, but, like, there's so much good content and information, I think for people just to take a look at, to learn a little bit more about the work that you're doing, and then just even information about disability inclusion and accessibility within outdoor experiences. It was, like, a wealth of information. There was a lot. So, I'll make sure to link all of those resources in our show notes. So, anybody listening can just check in the description or it will be at the bottom of the transcript on our website if you are a transcript reader for our episodes, as well.

Syren Nagakyrie:

So, I mentioned I have the Western Washington and Oregon guidebook out already. The Northern California book will be out in September. So, that's coming out, and then I'm working on a third book that I can't quite announce yet, but it'll be coming out in another year or so.

Katie Nieves Licwinko:

I'll be on the lookout for those. That'll be exciting. I'm really excited, too, in thinking about potential guests. I was like, how am I hiking and not thinking about hiking, like, in terms of accessibility. So, I'm really excited that I got to talk to you today. I've learned so much just from your website and from your social feeds. I just. I appreciate all of the work that you are doing, and I want to thank you so much, Syren, for being here with us today.

Syren Nagakyrie:

Yeah, thank you for having me.

SHOW NOTES

- [Disabled Hikers website](https://disabledhikers.com)
- [Disabled Hikers Facebook](#)
- [Disabled Hikers Instagram](#)