

EP 7 Disability Decolonized

Matthew Wappett

Welcome to the *Developmental Disabilities Network Journal* author insights Podcast. I am Dr. Matthew Wappett. I am the *DDNJ* Editor-in-Chief, the Executive Director of the Utah State University UCEDD, and it is also my privilege to host this podcast. This podcast is actually one of the favorite things that I get to do, because it gives me a chance to talk to so many different researchers and professionals who are out in the field making a difference. In fact, many of the people we have on this podcast are literally changing the world in their own quiet way. I think our interview today is a great example of that—people who are really flipping the script and thinking in different ways about how do we do diversity, equity, and inclusion better.

Before we jump in, and I give you more information on that, I do want to give you some background on this podcast. This podcast is actually part of our ongoing commitment to increase the accessibility of the *Developmental Disabilities Network Journal* for a wider readership. As most of you probably know, not everyone has the time to sit down and read an entire article these days, let alone an entire issue. More and more people are choosing to get their information through podcasts and audiobooks. In fact, I think I've said this on other podcasts, but this past year I've read, which I think is how you say it, more audiobooks than I have physical books, because I'm always moving, always walking, going somewhere, and I can listen to audiobooks while I do that, as opposed to having to sit at my desk or sit in a chair and read an article or a book. Anyway, that's the purpose of this podcast. The launch of the podcast means that you can access *DDNJs* content while you're on the go. You can listen to it while you're traveling, you can listen to it while you're doing chores around the house, you can listen to it in your car as you're driving. The whole idea is to make this more accessible, more easy for these ideas to get out there; but also make it easier to share on social media and other online platforms. Sometimes it's hard to share these articles and a podcast link can easily be put up on social media or shared via email. That's kind of the purpose for doing this. In the very basic sense, one of the big reasons is that this makes the information more accessible. Although, yes, we include plain language summaries, and we try to make sure that from a technical standpoint, the journal's information is as accessible as possible. But again, reading is not what everybody does. This podcast allows us to present this information in a more accessible format.

With that said, I'll say this upfront, I'm gonna say it at the end, please be sure to subscribe to our podcast feed on Apple podcast, Spotify, Stitcher, Overcast, Pod Bean, or wherever you get your podcasts, please subscribe. That helps us. Leave us a rating and a review if you can. Please share this podcast with your friends and colleagues. Your ratings, reviews, and shares, help us get this work out to a broader audience, which is going to help all of us in the long run.

Another reason that we decided to do this podcast is that academic research can sometimes be pretty dry, black and white on the page. And we like to acknowledge that authors and other contributors are more than just the name on the page. We want to help you get to know the people behind the publication. We want you to get a better understanding of the diverse voices who are working in the

field today. We want to provide some insights into what motivates these authors, where they get their ideas from, why do they do what they do? And how did these projects come to be. Behind every article there is a story and in many cases, years of work that has gone into making these articles come to light. That's part of the purpose too. We're providing a holistic view of the research process.

Today I'm excited because I have the opportunity to visit with Nathan Rabang and Dr. Vanessa Hiratsuka from the Center for Human Development at the University of Alaska Anchorage UCEDD. Both Nathan and Vanessa are two of the authors on an article in the most recent issue of *DDNJ* called "Disability Decolonized: Indigenous Peoples Enacting Self-Determination." This most recent issue of *DDNJ* is, I think, and I know I'm biased, but a huge deal. It just came out a couple days ago, but it's a special issue focused on diversity, equity, and inclusion. It was a partnership with the AUCD Multicultural Council. All of the contributions in this issue are coming from diverse voices, who are really trying to enact the basic principles of diversity, equity, and inclusion in their work. Nathan and Vanessa are no exception to that. Now, I do want to acknowledge also that Nathan and Vanessa, were only two of the authors on this article. Nathan and Vanessa at the University of Alaska Anchorage UCEDD, but Amy West from the University of Southern California was an author, and Eric Kurtz and Jim Warne at the University of South Dakota also contributed to this article. Again, this was a huge collective effort, but I think it's an article that makes a really important contribution to the way we think about working with indigenous populations in the disability field. Unfortunately, we don't have Amy Eric or Jim with us today. I have Nathan and Vanessa and it's my privilege to sit down and talk to them.

By way of introduction, Nathan Rabang is an indigenous researcher at the University of Alaska Anchorage. Nathan was born on Dena'ina land in Anchorage, Alaska, and he's enrolled in Shxwhá:y Village in southern British Columbia. In addition to his role as a researcher, he helped coordinate the Alaska LEND program. Nathan's work is largely focused on issues of disability, critical indigenous theory, and bioethics. Dr. Vanessa Hiratsuka also works at the University of Alaska Anchorage Center for Human Development. She's an indigenous researcher, Assistant Professor of Clinical and Translational Research, and Co-Director of Research and Evaluation at the UAA UCEDD. Dr. Hiratsuka is Diné from the Winnemem Wintu born for the Tangled clan. She is also an affiliate faculty member in the University of Washington's Department of Bioethics and Humanities. She received a bachelor's degree in Human Biology from Stanford University, a master's degree in public health from the University of Alaska Anchorage, and a doctoral degree in Public Health from Walden University. She is also currently the co-chair of AUCD's Council on Research and Evaluation. She has extensive experience coaching and mentoring community- and university- based researchers and practitioners in ethical, social, and legal implications of genomic research, and clinical and translational research, and developing culturally adapted chronic disease and behavioral health interventions in tribal health settings. Both Nathan and Vanessa were a joy to talk to, and it's really exciting that I've had a chance to get to meet them, but to better understand this important work that they're doing. This episode is a wide-ranging conversation. I think it provides some really important insight into how we work with indigenous populations in the disability field. It also includes some fun behind-the-scenes insights and innovative ideas that can be used to improve the work that you're doing in your respective teams and organizations. I would highly encourage you to check out this article, again that's "Disability Decolonized." We'll be sure to put a link to it in the show notes. Without further ado, here is my interview with Nathan and Vanessa.

Thank you, Nathan, and Vanessa, for joining us today. We're really excited to talk about your article on the latest issue of the Developmental Disabilities Network Journal. Before we jump in, could you tell us a little bit about your background with the UCEDD network in DD-related programs? How did you come to do this work? Why don't we start with you, Nathan?

Nathan Rabang

I started working at the Center for Human Development about a year ago. A little bit more actually. I started off as a research technician, so I was helping out with a lot of survey work across the State and then the research professional II position opened up, and I applied and was very happy to join the team full time.

Matthew Wappett

Awesome. What about you Vanessa?

Vanessa Hiratsuka

I am an indigenous researcher. For my work life, I've been largely working in tribal health. With the background, I'm Diné, I'm Navajo on my father's side, and Winnemem Wintu on my mother's side. I've had a calling to do support of indigenous communities as part of my work. For the past 20 some years, I've been working as a program manager in public health programs, an evaluator, and a researcher. Then I was a little bit burnt out from running research projects, biomedical and behavioral research projects in those indigenous communities across the State. I thought, I'd like to have a bit of a shift here. And that was happening just as COVID hit. I started interviewing for other jobs, thinking that I wanted to have a change of pace, different view on population health, and see what else was out there, how can I add tools to my toolbox and maybe support communities in a different way. I interviewed for a bunch of positions here in Anchorage because this is where we live. This is where I was raising my family, and the community that I wanted to continue supporting. On a whim, I took an interview for a temporary researcher position at the University of Alaska Anchorage, in the Center for Human Development, and I was offered the position and I thought, why not? That sounds like a nice thing to do—utilize some research skills but figure out my way in life next. I took a job where I wasn't quite sure if they were gonna keep me on or not and things like that. But I stepped out of my comfort zone and started with the Center and then over time realized that I really have a lot to learn about the disabilities community in Alaska, I realized that I wasn't thinking about diversity as well as I ought to as a public health professional, because I wasn't inclusive, in my mind, as to disabled communities. I really needed to, I think, enhance that aspect of my practice. The university was kind enough to offer me a faculty position and a co-directorship of the Research and Evaluation Group. And I thought, thank you very much. I accepted that position a couple years ago, and got involved with the UCEDD network around the same time and that's what I've been doing since. It's been a great expansion of the work that I had been doing. I'm really fortunate to be able to bring in some of the indigenous research, indigenous health research, and bioethics work that I was doing elsewhere, now, and intersecting that with our disability studies, and some of the training programs that we have too at the Center,

Matthew Wappett

That's awesome. It's amazing that you have that lived experience perspective, and then that you can marry that with your professional work as well, which I think is reflected very well in the article that you wrote here. We're excited to dig into that. You mentioned diversity, Vanessa, and how maybe when you came to this work, you weren't quite as familiar or maybe as competent in it as maybe you should have been. Why is it so important for disability-related programs to be more mindful of issues of diversity, equity, and inclusion? Why don't we start with you, Vanessa, this time, and then we'll go to Nathan?

Vanessa Hiratsuka

My background is in public health, and so we're looking at populations in that discipline—the full population. I've been a State health worker, an evaluator of a bunch of different types of health programs, education programs. When the people that I've worked with—those communities, those programs, school districts, cities, villages, tribes—have been looking at their population so frequently, they'll have targeted programming and activities for racial ethnic minorities, but not for individuals with disabilities—in particular, individuals who experience intellectual and developmental disabilities. When I work with our indigenous populations, when was it like 3 out of 10 individuals who are indigenous might also have a disability or one or more disabilities, I just was realizing that I was neglectful of an entire subgroup of our population and—a subgroup isn't the right word, but that's the language that tends to happen there in public health. When we aren't specifically thinking about people and inviting them to the table, then work isn't happening there. When it is happening, it's not happening the way it ought to with the considerations for the needs of that group of people and how they want it to be done, what their interests are. What does health look like? What does wellness look like? What should my life look like? That's really the stuff that I've been learning about, that I've been speaking to, and that I've been really blessed with having people in my life here at our UCEDD and across the nation, set me straight on. I really appreciate that. I appreciate the candor that self-advocates, in particular in families, have shown me and have given me so that way, I can be a better ally, a better supporter, and do better research and evaluation.

Matthew Wappett

Sometimes we're uncomfortable talking about these sort of things and the fact that it does take courage for people to speak up and say, "Hey, I'm here. Pay attention to me." It is incredible the people who take those risks and really do highlight the fact that we can do better. Nathan, let's go to you. What are your thoughts? Why is it so important for disability-related programs to be mindful of diversity?

Nathan Rabang

To begin, the disability community is super diverse. We touched on that in our paper. Indigenous populations all across North America are very diverse too. Just as an example, the Alaskan Native population is so culturally diverse within the state, but they're also so different from the indigenous populations from the lower 48 or from Canada, as well. As another example, my tribe is located in southern British Columbia enrolled in Shxwhá:y Village. The experiences that I've had there are so different from the experiences of growing up in Alaska, especially since I was born in Alaska, so I'm

American and the culture from, you know, just trying to get to my family and in Canada is difficult to get there sometimes, especially during COVID. Programs in Alaska need to focus on diversity, or cultural competencies with their programs, because the indigenous people and the disability community across Alaska, have different needs and different services that are different, that are unique than people in the lower 48.

Matthew Wappett

I think you're exactly right. This wasn't in the questions, I'm gonna editorialize for a second here. But one thing that I think that people overlook when it comes to indigenous populations and disability is that conceptions of disability can vary greatly between different indigenous groups, and that not every group views disability in the same way and that there is a whole culture, and in some cases a belief system around that, that is maybe very different from even what mainstream American culture today might view disability, or how it's conceptualized within the law. I think that's an important factor to keep in mind. I don't know if any of you want to say anything about that, but thought I'd editorialize.

Vanessa Hiratsuka

Absolutely there and I think it's important for folks to begin to develop an understanding that being American Indian Alaskan Native is both a racial ethnic category, but it's also a political category. Many of the tribes have federal and state recognition, and that recognition is something that also brings some federal and state law along with it. There are unique programs that are funded and required by federal law for tribal individuals. Having an understanding of the wide variety and diversity within tribal communities is important, but also the social political histories of those communities and what that then means for our practice in disabilities work.

Matthew Wappett

Well, I think that's a good segway to dive into your article. Your article is in the most recent issue of DDNJ and is called "Disability Decolonized: Indigenous Peoples Enacting Self-Determination." From what you've said before, I can kind of guess this, but I wanted to ask, and we'll start with you, Nathan, since you're the lead author here, how did you come to this topic and why is this specific issue so important?

Nathan Rabang

It's important because the disability community within indigenous peoples is super underrepresented. The intersection of tribal populations and the disability community have so many similarities that personally I didn't see until I started working at the at the Center for Human Development. I will actually pass the baton to Vanessa for how this article came to be because it's kind of actually a funny story.

Matthew Wappett

That's what we're all about. We want to hear it. Research just shows up on a page. People don't recognize that there's whole narratives behind how these projects come into being.

Vanessa Hiratsuka

Well, I'm trying to remember the fullness of the story here. This paper was a bit of a project that took on a life of its own. Over at AUCD there is a workgroup of individuals who had come together. I'm going to get the timeline incorrect, but over a year ago, so probably less than 2 years, more than 1 year, some folks were getting together, and it's the Indigenous Engagement Workgroup. This is a group of UCEDD faculty and staff and other UCEDD members who really wanted to get together and talk about programs and issues of indigenous peoples. With that, what are some exemplar programs? What are some areas of best practice? How are UCEDDs and LENDS, and IDPRCs really getting into the engagement of our indigenous populations and peoples? What are some of the areas of improvement on and on? This is what our workgroup had wanted to begin talking about. We're still finding our footing, frankly, right now. So if anybody's listening, we do have quarterly meetings. You can outreach to AUCD staff to get the links to those. In one of our quarterly meetings, we had talked about really wanting to get more information out into the literature about indigenous people's needs, and those programs that are currently occurring that are particularly developed by tribal communities and enacted for and with indigenous individuals with disabilities. With that, we thought, okay, that's something that we ought to do. We had some folks who were interested in the idea. At the same time, the call for abstracts of this special issue came out. I said, "Hey, I can write up a little something and pitch it around to the entire workgroup, and we'll see who would like to participate in this." We were really fortunate to get a nice group of individuals who represent a big swath, a nice crosscut of that indigenous engagement workgroup. We have co-authors on this paper who are indigenous disabilities, researchers, and also allies, and we were really fortunate to have those voices come across. As we were developing this paper, a lot of other things were happening in our lives. This was during the pandemic and several of us were getting swamped by those things, and the deadline was fast approaching for the full article. In a panic, I reached out to Nathan, one of my colleagues over at CHD, and I said, "You know, Nathan, I know, we've been talking about getting you involved in writing some publications. Would you like to hop on this workgroup with me? I know you have interest as well as an indigenous researcher in these topics. Nathan's a LEND coordinator, and heavily involved with our LEND program. He's been working with one of our indigenous LEND faculty, and also is doing some work in bioethics. And I thought this would be another aspect of development, maybe, you know, maybe, but it's all extra. And so I reached out to Nathan, and I said, "If you have some time, would you mind helping me out with this, and helping this work group out?" He really kindly said, "Sure," I wiped the sweat off my brow, and in my panic and went, okay. It was really, you know, a big blessing to be able to bring somebody in, with fresh eyes to these concepts that we were passing back and forth in our workgroup and having his viewpoint on it. And also really having a chance to have something that I think is really important, which is the intergenerational viewpoints on these things, because many of us who are on that byline are a little bit more seasoned. We've seen a little bit more of the earth passing the sun than Nathan has. With that, I think it's so important to really provide opportunities for people to be involved in these different ways of disseminating, to get different voices out into the literature, but also for us who are a little bit more seasoned to work with somebody who's going to have an energy and excitement, a different point of view on these matters. That's refreshing. That's something that also was there. So Nathan joined the team and really put in a lot of effort and he's first author on this paper. Nathan, I don't know if you're going to talk about how it feels to have your first published paper, but

that's something that is also a big joy of mine. I think I can speak on behalf of our co-authors, to also be able to support an indigenous researcher in reaching that achievement and milestone—that "achievement unlocked" type of idea. It was really lovely to be able to do that with, with Nathan.

Nathan Rabang

Yeah, it was a, it was a really great experience. I work with Vanessa all the time. Whenever we get a new project, I'm always excited, especially with something that's like this. There's something that kind of combines the two worlds that I work in. I remember when our conversation when we first talked about writing this paper, and you're like, "Okay, so we have this workgroup, we're all pretty busy. We have an abstract, but we need a paper, and it also needs to be done kind of soon." I was like, "You know what, let's, let's get to it. I'm excited." I think it was a great process. It was a lot of fun. It was a lot of fun writing, it was a little hard to write, too. There were parts that I had a little bit of an emotional response putting it on paper and putting my ideas down. It felt really good once it was done. And it was really exciting to be part of this team.

Matthew Wappett

Yeah, that's amazing. That mentorship is so incredibly important. I think we overlook just how important it is to be pulling in people with lived experience and new people, new researchers, and others, and teaching them that this is a process that you can do, but it can be very intimidating if you don't have a group of people helping you navigate that. So that's really exciting. Congratulations, Nathan, I didn't realize this was your first. We're honored to have published it.

Nathan Rabang

Thank you. Thank you, thank you so much.

Matthew Wappett

We don't want to give away everything in the article, because we do want people to go read it. But you do talk about this idea of "decolonization" within it. One of the things that I'm curious about is, how can researchers, educators, service providers really work to decolonize their programs? What are some practical examples of practices or policies that they could put in place that would help enhance self-determination?

Vanessa Hiratsuka

I think there's a couple of different things to bear in mind. Decolonization isn't a metaphor, it's an action. With that, there's, there's some education that we can all do. It's something that I feel like I'm constantly practicing. This is educating ourselves as to what are those histories of the people who we're working with—these communities that we're working with, and, as I mentioned earlier, the indigenous communities, indigenous nations, they are tribal nations, they have their own forms of government. There's government-to-government relationships with tribal nations. With that, there are policies and

procedures that we need to follow. Not just for moral obligation, but we legally need to follow these things. Upholding the sovereignty—the right of those tribal nations to enact their laws, and do what they need to do as nations is really important. And it's necessary. It's not just that it's nice, but it's necessary in our practices. Becoming aware of colonial history. What has happened to the groups of people, what laws and practices have affected individuals, and really change the norms, change the ways that people go about living their lives? Why people might feel stigma in certain ways, and what are these areas of systematic oppression, and concerns there where people have been treated, and policies have been in place that have deliberately forced or moved different people in different spaces in the world? Doing things a certain way? Prohibition? Stopping things like the sharing of using one's language, their native language? How that then can be internalized to the individual—what that looks and feels like for a person. I think it's important to have that recognition, but also come to a reckoning, right? Move into a space of "now that I know that, what ought I to do"? What are those practices and policies that we can put in place within our institutions to directly account for these historical disadvantages? With that, it's things like hiring. It's to think about "Where do we recruit for our staff?" "What types of training might we need to do?" "How might we need to work with different communities?" "What are the appropriate ways of doing that? What have they already been doing in their own self-determination?" Asking those questions of how can we change? How can we be of support? Those are some of the things that immediately come to my mind when I think about the process of engaging in decolonizing within the work that I've been fortunate enough to do in my life.

Matthew Wappett

Yeah. Nathan, what are your thoughts?

Nathan Rabang

I think Vanessa summarized it beautifully. One thing that I wanted to mention, though, is that there are already programs that are in place that are attempting to decolonize academic institutions like the Oyáte Circles that we talked about in the paper, and Sisa that exists up here in Alaska. There are programs and there are institutions that are actively decolonized. They are actively making culturally appropriate systems and services available for indigenous peoples, and specifically indigenous peoples with disability.

Matthew Wappett

You've kind of you've kind of talked about this earlier, but every research project, every writing project, is a process. There's a personal but also a political and also a social aspect to that. One of the things that we like to do here is kind of put a picture of what that process is like. Although you've talked about sort of mentoring Nathan into this, and kind of your thought process in coming up with the article, were there other memorable aspects of writing this article, funny events, exciting discoveries, new collaborations that came out of it that you're really excited about pursuing as you move forward?

Nathan Rabang

I think one of the funny events was when we first jumped on this project together. Like I mentioned, it was a, a quick turnaround for this paper, which is exciting and fun for this project. But one aspect of the paper actually was when we were writing it, and we were talking about some of the ideas that we wanted to mention and how deep we wanted to go with some of the history and some of the atrocities that have taken place over time. I mentioned earlier that I had kind of an emotional response writing some of this, and just being able to talk it out with Vanessa, not just as a mentor, but as just like this is how I'm feeling, this is how I am reacting to writing this. How would a reader react to this, especially if someone doesn't have the same experiences that I have. Just being able to talk that through with Vanessa was really powerful and important. There were definitely parts when we were writing that I really needed guidance on how much we wanted to put on the history side of this paper. It was really, it was really nice to talk that through and also just to talk through the emotions with Vanessa. That is so important to recognize. I think it's something that we overlook when we talk about participatory research. There is emotion. As researchers, when you're in academic programs, you're taught to be objective and to separate emotion from it and everything else. But when it's part of your lived experience, you can't avoid that. So that's an additional layer that you have to navigate. And I just appreciate you sharing that, Nathan. I think, something that we don't talk about enough. So, Vanessa, what about you?

Vanessa Hiratsuka

For me, this paper was one where we're building community. With that, I think I was just really excited and nervous to work with these scholars that I haven't met in person. When I look at the names of the people that we were working with, that were our co- authors that we were receiving feedback from, that we were engaging in, like a description of programs that they had developed through their life course, their histories, with their communities, it's really hard to have that intimacy—particularly when you're in these long-distance, academic relationships. With that, it was a bit of a, I felt like a tricky balance of trying to meet people where they're at, develop that community, develop that camaraderie to have an integration of the different thoughts and perspectives of our co-authors. I mean, that's true anytime, but particularly when the story that you're telling is a shared story. It was a toughie. Like Nathan said, for some of us, we're talking about our histories, we're talking about, you know, these things, and we don't want to get stuck only in the trauma of colonialism, but also to highlight the beauty, the impact of tribal self-determination of individual self-determination on how we move forward. Not only what good work is happening now, but what that can and ought to look like in the future. So that was also just really fun to have an opportunity to talk about aspirations, and to get that energy going within ourselves and across this team of folks who are in very different states in different fields, and different walks of life. So that that was energizing, as well as nerve racking.

Matthew Wappett

As all of the above. So we'll kind of go back to the question that we have. Again, we want people to go check out the article, we want people to read it. In two or three sentences, what's the main message that you want readers to take from this article?

Nathan Rabang

For me, self-determination is vital, and the application of it in the disability community is choice in education, choice in services, choice in every aspect of their life. And for tribal populations, tribal sovereignty is self-determination for them. Vanessa touched on this earlier about having that government-to-government relationship even between tribes and with the United States and between tribal nations. My last main point would probably be that there are programs out there that are actively decolonizing academic spaces. Finding them and implementing their practices and their policies is something that can be done for programs that already exist.

Matthew Wappett

Vanessa, what about you? Would you say the same? Or are there other aspects you'd like readers to take from it too?

Vanessa Hiratsuka

I think I'm very much in alignment with Nathan. I would say it just a little bit differently. Because we're different people and we think of things a little bit differently. With that, it's just that tribal communities are experts on how they want to live and how they ought to live. And individuals with disabilities, the same goes. They are the experts on how they ought to be treated and what ought to be done there. So back to self-determination, that self-determination should be honored. The journeys of individuals and the journeys of communities are important. Recognizing history and the effect on the Dow and the future, is integral in really doing work in a way that is collaborative, that is respectful. Absolutely, the way to go about this is to think about the colonial impacts of our lives and how we can really seek to dismantle those areas where we're thinking about the value of people by what they can do and what they can make and, and who they are in the power positions. We ought to go back to our relationship models.

Matthew Wappett

That is so important. I totally agree. That's why I love this article so much. Truly, I get to read all of them, and I like all of them. But this one particularly really resonated with me in the way that you approached it and the message that you were trying to get across there. A couple of last questions. These are questions that we ask to everybody because we like to know who are the researchers out there doing this work? So, what motivates you to do this work? Why do you do what you do? Because this is hard, and it can be depressing, and it can really drag you down. So why do you do this?

Vanessa Hiratsuka

I think we are when we're members of communities, we need to take care of one another. The way that I feel like the things that I have talents in are kind of unique and weird. Some people can do other amazing things. My brain works in such a way and my abilities are around inquiring about things and working with groups to get to our shared understandings. From there, what can we do to change this for what we think is better—not just for now, but for the future—our future generations. With that, it drew me to public health, it drew me to population health, it drew me to areas where I was working in policy. For me, I do that with the community that I'm most most attached to, and that's American Indian and

Alaska native communities, indigenous communities. It's also with health systems and by health systems. I mean, gosh, that's a really broad definition as well. So, that's what brought me to do the work that I do, and why I kind of keep coming back to it. I see myself as just being a supporter and amplifier, I guess of what the needs of communities are and trying to get that to work and provide evidence for programs and people, and hopefully, with that, see some growth and change.

Matthew Wappett

Thank you. Nathan, what about you,

Nathan Rabang

My motivations are my family and making sure that I have something that I can give back to my community and my family. As a researcher, I actually am newer to the field of disability research. Being able to be part of this work and being welcomed and being invited to participate in projects like this by Vanessa motivates me to just be the best researcher that I can and put forward the best work that I can. Giving something that can last and that can be used by other researchers that are starting off in their career just like me, and other researchers that have never examined the intersections of these two populations before and want to learn more and want to get involved.

Matthew Wappett

That is so incredibly important in that notion of intersectionality, which again, you know, 20 years ago, we never even heard that word. And yet, as we've become a little more articulate around these issues, that's something that's become increasingly more important. I think your article does a great job of really looking at those intersections between disability and indigenous cultures. It's really an outstanding example, I think of how to address that in an effective way. The last question here, this is one again we ask to everybody, but you know, most people who are in this field, they're always trying to improve and figure out ways to do things better. So the question is, "What is one thing that you've been doing to make your work, and that's broad, more inclusive and accessible"?

Nathan Rabang

One thing for me is reaching out to the platforms that we use and just asking their support to help me out. I'm involved with LEND, I'm the LEND training coordinator. The past 2years we've been on Zoom, which is a great platform—it keeps a lot of people together, but it's not very accessible. If you want to join a breakout room, you have to click it and not everybody has the ability to move the mouse to click to join a breakout room. And so reaching out to these companies and just being like, hey, here's my problem. I need some assistance; I need some help. Our solution for that was to make the main room, a breakout room and then breaking out people into separate breakout rooms just so we can make sure that everybody can participate in LEND and participate in the activities that we're doing. The same with captioning and just making sure that we have captions for LEND and making sure that we know how to turn them on and giving people the ability to know the services that we can provide.

Matthew Wappett

That's great. Vanessa, what about you?

Vanessa Hiratsuka

I'm really interested in developing community-based research and community-based researchers. This is something that I've been attempting to do throughout my career, really work with community members that are interested in doing research and evaluation and giving them the skills that are more of the academic side and honoring the skills that they have, and the reasons why we work with community members. Right. With that, I've been really seeking to develop partnerships within the community of individuals that experience intellectual and developmental disabilities, see who's interested in our local community and what questions they have, what methods might be most appropriate to answer those questions from their point of view—not from my point of view? And then working with them on, "Okay, well, how can we develop something that's fundable here, and how can we work together in a manner that is appropriate?" Also challenging some of the methodologies and practices that happen within a research and evaluation environment. Nathan was talking about how Zoom really privileges some of us that have certain areas of access—internet access, but also in a way of mobility. Certain types of research methodologies also privilege certain people and activities. I've been working with others, and a couple of UCEDDs to talk about and to start thinking about and challenge ourselves as researchers to talk about things like interview practice. The practice of doing interviews and how we often encourage masking, as trainers of individuals that are doing interviews, to keep them on. A neutral point of view, our bodies in a neutral manner, to hide a lot of the things that one might do or have as part of your being. Is that necessary? Is that helpful? What does that do to an individual as an interviewer to really question these things, and to think about how can we be respectful and ethical, when we're including our community members that have IDD as researchers. There are some ways that I think research practices are extremely harmful, like requiring somebody to mask.

Matthew Wappett

Yeah, it's kind of funny how we even have research coming out these days, showing that it's harmful, right, masking those emotions and pushing them down. It is not just a way to maintain objectivity, it actually is not healthy.

Vanessa Hiratsuka

Exactly. And that's one of the things I think is an area that's really important to me, as a researcher, is to develop a positive community of researchers, of our staff members. We spend a lot of hours at work. With that, I want those hours to be ones that are well spent in a person's life, where you're feeling good about that work, that you're in a collaborative environment and one where you're fully respected for all that you are. With that, that's the type of thing I'm trying to make myself aware of. Then also bring that awareness to my community, and my group of people that I get to work with, and hopefully get correction as well as to what ought to occur versus what is occurring.

Matthew Wappett

That is so important, right? As a researcher—listening and learning, not just telling. It's a different model, though, than what we've been taught. It's a more organic model. I would say even maybe even more indigenous model, right? To more interactive than the top down, sort of, "I'm the researcher, I'm going to tell you what needs to happen." So incredibly important. I want to thank you both for your time today. This has been just such an enlightening conversation and again, just grateful for your contribution and for the work that you've done here and just thank you.

Vanessa Hiratsuka

Thank you so much for having us. It's great.

Nathan Rabang

Yeah. Thank you.

Matthew Wappett

You are welcome. So that's it for our conversation today. I'd like to thank Vanessa and Nathan for their time and for the incredible work and insights they were able to provide today. I learned so much from this conversation, and it really was a privilege to visit with them. Again, I would like to encourage you to go check out their article. Please download it. Please go download all the others. There are 12 outstanding articles in this most recent issue of DDNJ, all focusing on different aspects of diversity. Again, I think it's incredibly important work and a huge contribution to the work that we're doing in the Developmental Disabilities Network.

Here at the end, I would like to thank DDNJ managing editor and author insights Podcast Producer Alex Schiwal for her hard work to get this podcast out. Alex has recently, within the last year, taken on the role of managing editor and she was integral to getting this most recent issue out, and we're excited to have her on board. If you have questions or concerns about the podcast or the journal or inquiries as to how you can contribute, please reach out to Alex. You can contact her at editor.ddnj@aggies.usu.edu. We'd also like to thank the Utah State University Institute for Disability Research, Policy & Practice for their financial and in-kind support for this podcast and the journal. The journal also receives support from the Utah State University Libraries and Digital Commons and we are grateful for all that they do to support our work.

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up the good work. You're making a difference. We want you to know that what you do matters. Stay tuned for our next episode, which will be another interview from this special edition on diversity, equity, and inclusion. It will be an interview with Elizabeth Morgan and Ida Ward on their article about working with Black families with children on the autism spectrum. It's also an exciting conversation. We're excited to share that with you. Thank you and tune in next time