Fairness First podcast Season 2, Episode 2: Guest Olivia Lindly, PhD

Speaker 1 [00:00:00] I think for me it's really made me kind of with each step we take in the project, forced me to pause, get input from our advisors, but also go slow, you know, so we have time to course adjust or correct and not just try and kind of plow ahead and get all the information, you know. So we're meeting the timelines.

Speaker 2 [00:00:25] You just heard the voice of Dr. Olivia Lindly, a health equity researcher at Northern Arizona University. She sat down to talk with us about her work in advancing health equity and improving health for children with developmental disabilities like autism and their families. Dr. Lindly shared her own experience working with the community, which involved a lot of slowing down relationship building, aligning goals and realities of the community with the research and lots of self-reflection. This is Fairness First, a podcast dedicated to exploring issues of health equity in Northern Arizona. This is a space for local community leaders and stakeholders to speak about how they understand health equity or health fairness in their own communities and build awareness of programs working to support the well-being of communities in the Southwest. Okay, everyone, thank you so much for listening. And let's go to our interview with Dr. Olivia Lindly. Thank you so much for doing this interview with us. Dr. Lindly I'm excited to talk to you and then learn more about the work that you do. Welcome.

Speaker 1 [00:01:47] Thank you so much for having me. It's an honor.

Speaker 2 [00:01:51] Thanks. To get us started in our conversation, can you explain to us what you do in the most grounded way possible and how it connects to health equity?

Speaker 1 [00:02:03] Sure. I am an assistant professor. And that means that part of my job is is research. And my research uses both quantitative methods that are more kind of around number crunching and looking at data and then also qualitative methods, which is more talking with people and trying to understand their lived experiences and factors that are shaping their communities health. And so that's kind of the research component of my job. And then there is a teaching component and then the other component of my job is service. And so some of that is service to my university, Northern Arizona University, and then some of it is to the state and my field more broadly. And so, for example, I am part of the Governor's Council for early childhood or early intervention, and we think about things like how we can bolster the early childhood workforce. I'm also part of the Navajo Nation Early Childhood Collaborative, which is focused in some similar ways, kind of on building the early childhood workforce, specifically Navajo Nation, but also on how we can optimize health for Navajo families.

Speaker 2 [00:03:39] Yeah, and thanks for that. A lot of what you shared sounds like it involves relationship building and feeling connected with the communities that you are trying to learn about, but also think collectively about solutions that advance health equity or health fairness. And with that, tell me more about that experience. But in connection to the ways in which you understand positionality, I'll give a little description of positionality as the set of values, views and location in time and space that influence how we understand the world and those around us and the people we're building relationships with. How would you describe your own positionality in regards to your research and all these other layers of your work and the way you build community relationships?

Speaker 1 [00:04:37] Sure. So I tend to be very pragmatically oriented to explain that a little bit more. I have the general belief that individuals interpret reality differently, and the best method for understanding those different interpretations of reality is one that solves. Problems are issues, of course, because my discipline is public health. So kind of in applying that position, I really in approaching kind of building relationships, I believe in showing up and putting in the time to try and really understand as much as I can. And so that also means recognizing kind of my own reflexivity or what I'm kind of bringing or superimposing on my understanding of a situation or a community or a culture within a community. And that also means treading lightly. So being more of an observer is, you know, trying to take the reins of something, but really giving myself the time and the individuals that I'm trying to learn from the time to develop a joint understanding and making sure that when I'm working with a community or a culture that is not my own necessarily or that I don't identify with myself checking my understanding as much as I can, and also making sure that I have partners who are part of the groups that I'm working with who can check me and and help me, you know, in collaboratively approaching the work we're doing.

Speaker 2 [00:06:35] So when you say reflexivity dedication to just have reflections on how is it that their relationship is going, do we have similar goals or different goals, how are community's perceiving my own person just trying to summarize a little bit, but you know, as you were talking, I, I then realized that I am curious if you could talk more about your most recent research projects in which you've had to build relationships in the community. And then from that, can you explain what is it that you have learned about yourself in that process, in in those particular research projects? How is it that you have learned to navigate these interactions based on positionally and reflexivity that you do, especially when you engage with community directly impacted by inequity?

Speaker 1 [00:07:36] One of the projects that our team has been working really hard on building relationships through is the SHERC Pilot Project that I have, which is to adapt a parent education and training program for Navajo or Dine parents and guardians of children with or at risk of autism. Part of developing that idea for that project was meeting with a lot of people in and around Flagstaff and trying to understand what was already being done to help support families of children with autism, including those who are Navajo. Part of just getting the project off the ground was really building these relationships. As part of that, I was able to better understand where the gaps were to do any kind of program adaptation. Well, you need some dedicated time and resources. And so we went through that process of getting funding and that involved getting letters of support and talking more with people in the community, making sure that our proposal was really aligned with what people saw a need for and thought could potentially be useful. We ended up kind of assembling an initial team of people in the community who were clinicians or they were involved in some other way, kind of in providing services to families of children with autism in northern Arizona. And then we went through the whole process of trying to get some funding to support our work because we knew that it would require resources just given that the Navajo Nation is such a vast geographic area, so is northern Arizona. One thing that I learned is that it doesn't work well in certain places like northern Arizona to use the model for parent education and training that involves highly trained. Trained health professionals because, A, we don't have a lot of them here. But B, they aren't always trusted by the community. And so one of the reasons we picked the program that we did to adapt for this project is because it uses community health workers. And we learned through kind of our partnership building process and the grant proposal process that that's a model that is used for health education on Navajo Nation.

Speaker 2 [00:10:35] And Dr. Lindly, could you explain what community health workers are?

Speaker 1 [00:10:41] Sure. There are lay individuals who are trained to provide health education, typically to individuals who identify as part of the same cultural or sometimes larger community group. And so in this case, there are other parents, Navajo parents or guardians of children with autism. So that was one thing that I learned kind of as part of our partnership building process for the project. And then as we've gotten grant funding, we've learned that there are a lot of different levels of approval that are necessary to work with indigenous populations. And so that's been a huge learning process for me and some of our partners is just kind of figuring out how to get the proper course of approvals for our project. So for example, in this past year we have we've gotten Institutional Review Board approval from NAU and then we've also gotten it from the Navajo Nation Human Research Review Board. But we've also had to get approved resolutions from the different agency councils that comprise the Navajo Nation. And so that's involved, you know, developing a presentation and giving a presentation and allowing individuals from the chapter houses that comprise the agency councils to give us feedback on our project, which has been great. But it was a new kind of process that I had to learn and it is really kind of relationship building. So it's been good, but it also is something that I didn't really account for as part of our project. And so I think that in combination with the pandemic happening, which has placed a huge burden on families of color, has really slow us down a bit with our project. But I think it's been really invaluable to get that input. And I do think that's very important.

Speaker 2 [00:13:18] Mm hmm. Yeah. I think that constant, open communication and I would agree that all of that process, it is it definitely takes time and a lot of relationship building. My next question and what I'm curious about, can you tell me a little bit of your own reflection about the ways in which you understand your positionality what it means for non-Indigenous people and specifically non-Indigenous researchers to want to carry on a project that directly involves the realities of Indigenous people.

Speaker 1 [00:14:01] Sure I think what I've realized is that it is very challenging to help lead a project as a non-Indigenous person myself. I've been really fortunate to have engaged and partnered with a number of Navajo faculty here at NAU and also other institutions, and then also Navajo parents of children with autism who are our parent advisors on the project and meet with at least monthly, if not more, to get input kind of on what we're doing and how we're doing it. Because what we thought at the beginning, although we haven't deviated dramatically from our what we proposed to do has changed to some extent. And again, part of that has been cultural. But part of that has been pandemic-driven. I think for me it's really made me kind of with each step we take in the project, forced me to pause and kind of get input from our advisors, but also go slow, you know. So we have time to course adjust or correct and not just try and kind of plow ahead and get all the information, you know. So we're meeting the timelines because my goal for this project is to create a sustainable program that can be used by the tribe that is free of cost. And so if we just plow ahead and try to get all of the information and meet our timelines, we're not going to reach that goal because we will have broken trust, we will have ruined relationships. And and so I have really been learning that you can't force this kind of work, like you have to let it kind of go on its own timeline. And unfortunately, that isn't always aligned with what the funders want.

Speaker 2 [00:16:13] Yeah, I love that you brought up time, but in this particular project you are involving community, a community advisory board who is representative of families with children without autism, which requires a lot of exchange of communication, which takes time. And I think you're bringing up such an important thing that often the way that research and funding works, sometimes it's not come comparative to the realities of communities and the way in which communities decide to build their own relationships with researchers. And I think being flexible, what I'm hearing from you makes me think about the requirement of health equity researchers to be flexible and just be guided on the timeline of the community. So thank you for sharing that. That's a big, big reflection for sure. My next question, it sounds like this project is mainly focused on thinking about what are the cultural components and overall day to day realities or knowledge that can inform the adaptation of a program that can support indigenous, in this case, Navajo families who have children with autism. What are the most pressing health inequities when it comes to accessing autism services among Navajo families?

Speaker 1 [00:17:58] There's really this kind of inequity around timely access to autism services. That's problematic because we know that children who get services later, their outcomes tend to be poorer generally. So, for example, they might not be able to transition to independence as easily when they become older and are finishing high school, for example. And so it's really critical that children are able to get those services either through the school or other providers. And that's another kind of issue, right, is that the Navajo Nation is a vast geographic area and there aren't a lot of providers. That's really why we think this program might be helpful is because it teaches parents skills that they can use at home with their child to promote things like social communication and positive behavior. And so it's not only kind of up to the school or other providers to provide those services that parents can be empowered to also provide certain skills and training to their children, working with their children.

Speaker 2 [00:19:31] So you've mentioned and identified health disparities that exist. So what you're saying is that, let's say compared to compared to white children who maybe might live in an urban setting, that timely access to autism services might not be that long compared to that. Say an indigenous kid who lives in reservation land. It may take longer for that particular kid to have access to autism services.

Speaker 1 [00:20:10] Yes. Or they might never really get them. We know that it can be very hard not only for the child, but also the family. The stress and some of the financial impacts that it can have on the family who is caregiving. And we can think about things, too, like, you know, children being expelled from school because they have challenging behaviors. Right. And then they have to be at home and who is kind of caregiving. And so, yeah, I think your way of describing the disparity is, is right or it's an accurate way of characterizing it.

Speaker 2 [00:20:57] So if we know that there is this health disparity and in the timeline of access to autism services, we know that there's a scarcity of providers, there's a scarcity of trained school staff to work with indigenous children with autism. So what do you think that are the social determinants of health involved in creating these unfavorable conditions for children with autism in in tribal communities to access services?

Speaker 1 [00:21:35] Sure. So I think, you know, some of it is ruralness. And then also the financing that goes along with that financing for schools and health care organizations tends to be less. And we see this in other rural areas that are not tribal. How that really does affect kind of the availability of high quality services that families of children with autism can access. I think how autism services are approved and financed by insurance companies needing to have a diagnosis, for example, before behavioral therapy can be approved to be paid for through an insurance plan. And so that's a policy that that is really problematic potentially, especially if you are living in a rural area that doesn't have many providers who can diagnose, which is northern Arizona. I think, you know, there is one diagnosing provider within like a 300 mile radius. So if we think about one in 54 kids having autism, that's not enough, right? Mm hmm.

Speaker 2 [00:22:58] Mm hmm.

Speaker 1 [00:22:59] There are awareness issues, too, and stigmatization of autism that affects maybe parents concerns about their child's development. I'm thinking about how there is not a word in Dine for autism, for example. And so part of that is related to cultural beliefs that autism isn't necessarily a problem. It's more of almost this view of it being part of neurodiversity or people, you know, just having different ways of processing the world, basically. But part of that is stigmatization and maybe viewing autism as a negative thing or something that might be the fault of a parent in some way. For example, those are some of the determinants, I think, that come into play when we're thinking about challenges families encounter with timely diagnosis and treatment.

Speaker 2 [00:24:01] So we're coming towards the end of the interview, I guess, to finalize our conversation and conclude everything, all your work. What would you say an autism services intervention guided by health equity looks like? What is it that is required to support Navajo families and their children from a justice and fairness perspective?

Speaker 1 [00:24:33] I think we're really trying to do it with our project as much as we can, where we are really tailoring it culturally to Dine families specifically. We're using a community health worker delivery model that we hope will be more sustainable. We're also using an open source program that people don't have to pay for. In those ways, we're trying to make the ability of the community to use it as easy as possible. It's also a program that can be tailored. It's not necessarily a one size fits all. And because autism, we know is on a spectrum. Right. And we know that families also are very diverse in how they operate and their dynamics. And so that's another reason why we chose the program that we chose is because it is more flexible. And so we can't not tailor interventions to specific groups, but within that tailoring, we have to maintain a certain level of flexibility that accounts for the diversity within groups. That's something that's pretty challenging to do, but it's something that we have to do as a field, and I think we're learning more and more about that as time marches on, but we still have a long ways to go.

Speaker 2 [00:26:11] The work never ends.

Speaker 1 [00:26:13] No.

Speaker 2 [00:26:14] Yes, reflection is a process. It doesn't have an end goal. Definitely. Well, is there anything, Dr. Lindly, that you would like to share with us to finalize our conversation?

Speaker 1 [00:26:28] I just really appreciate having the opportunity to talk with you. Thank you.

Speaker 2 [00:26:34] Thank you, Dr. Lindly, for this conversation. Dr. Lindly reminded us today of the importance of working collectively with communities in research, making it a priority to build those relationships with communities, and taking time to reflect on our own positionality and what we bring and take with us as we do health equity work. Thanks for listening. From the SHERC CEC. Bye. The Southwest Health Equity Research Collaborative Community Engagement Core and the Media Innovation Center at NAU produced this episode. It was edited by Dulce Jimenez. Music from filmmusic dot io song titled Fearless First by Kevin MacLeod licensed by Creative Commons. That org. Special thanks to the National Institute on Minority Health and Health Disparities. Grant number U54MD012388 and Northern Arizona University's Southwest Health Equity Research Collaborative for funding this podcast. Thanks to our Fairness First team, Carmenlita Chief, Dulce Jiménez, Alexandra Nicole Olin, Lisa Dahm and myself, your host Alexandra Samarron Longorio from the Community Engagement Core, and Brian Rackham, the director at the NAU Media Innovation Center. Thanks for making this podcast possible.