**Episode 231: Broken Promises for Native American Healthcare**

**Lisa**: I'm Lisa Hernandez,

**Lizzy**: I'm Lizzy Ghedi-Ehrlich.

**Lisa**: And we are your hosts for Scholars Strategy Network's No Jargon. Each month, we will discuss an American policy problem with one of the nation's top researchers without jargon. And this month we have decided to take on the disparities in healthcare for Native American populations.

**Lizzy**: And the, if you're listening to this show, it should be very early in December, which means we just passed American Thanksgiving. And also the month of November, I believe is supposed to be a, you know, native American heritage awareness month. So it's the time when just a lot of people start talking about the history of native Americans and it's not always done so well.

**Lisa**: Yeah. And, you know, thankfully we get to kind of go into December and keep having those discussions as well. We don't have to keep it within November since this episode's coming out in December and we can just keep talking about it all year long.

**Lizzy**: I mean, that's kind of the issue, right? It feels like everyone in one moment is like, oh right, this part of America. And then we ignore it the rest of the time. But meanwhile, there's some really important like political and structural issues around how all sorts of different native peoples in the United States kind of govern themselves and get access to resources or not. That's a little bit of what you talked about, right?

**Lisa**: Yeah, we talked a lot about, um, mainly with healthcare and even agricultural disparities within native populations. And it was honestly. I think just talking to Emily in general was kind of inspiring conversation for me because oftentimes when you're talking with folks, they kind of forget that there's always a reason why they're researching what they're researching and just like listen to her connection to community. And, um, her commitment to her own communities is, um, pretty inspiring. So I was really glad to get to listen in on some of that and learn a lot about all of these like issues with just literally accessing a hospital that's near you and things of that nature. So

**Lizzy**: Sometimes I think about from what we know as people who are working with researchers a lot, I hate that there's sort of a bias within the research community, against people who are studying populations that they're a part of...right? Cause it seems so natural to have that be part of your origin story about like why you do what you do. And it adds, you know, such an interesting layer to what you're finding out and how you can talk about it. But there's also this movement that says, you know, then you're too close to the center of what you're looking at.

We need to have sort of a remove about how we study, you know, if it's a certain demographic community or a geographic community. and I think challenging that a little bit and showing how it

can be done well and how, when a person does belong to a community, they study how rather than clouding their perspective, that just adds a strength to the way they're able to discuss it.

But I don't know. That's something I think about as an organizer of researchers, right.

**Lisa**: Absolutely. We talked a little bit about how people within their own communities, they know the solutions that they need to, their problems, like they know what is needed. And I think they also know the questions I need to be asked within their own communities as well. So I think that's a pretty interesting point, Lizzy.

**Lizzy**: Yeah. Well, that's the bigger problem, right? You can talk all day about the role of the researcher. Are they part of their community or not? But we see a lot more problems with people leaving the communities that they're studying. Out of the whole picture about like, all right, like what's actually going on here. What do you want to know? Not just, what do I want to know, or what does this journal think, you know, is the thing that everyone needs to know. Those are different questions. Um, and that really seems to be critically important and something that a lot of researchers are thinking.... Really looking forward to hearing this conversation once it's out.

**Lisa**: Yes, me too. Um, so I hope you all enjoy this conversation with Dr. Emily Haozous,, who is a research scientist for the Pacific Institute of research and evaluation. She studies the conditions that promote native American health equity with a special interest in urban Indian. Cancer and to end of life care, she draws on her background as a hospice nurse and her perspective as an indigenous woman to examine issues of policy and health equity here.

Here's our conversation

**Lisa**: Emily, thank you for coming on No jargon.

**Emily**: Thank you.

**Lisa**: You've done a lot of research on the health needs of native Americans and the inadequacies of the American government to meet those needs. Um, what guided your decision to focus on this topic?

**Emily**: Well, um, I, it's hard to say. Like there was one thing. I'm an American Indian woman. I'm a Cherokee all Fort sill, Apache. I grew up as a patient in the Indian health service. And so it's very personal to me. my kids actually are still patients within the IHS and so. I have a first, like a first person view of how things have gone.

And I see this as a system that has a lot of potential that is failing its patients on a daily basis with a lot of very dedicated people within the system who are working really hard to try and make it work. It's just really frustrating to know that there are solutions out there that can address the healthcare needs of American Indians and Alaska natives.

And, um, for some reason, those connections are being made.

**Lisa**: Um, I think it's amazing that you are taking this like personal connection with your community and going through these systems yourself and, um, all the questions that you had yourself and kind of answering them for yourself within your own work.

**Emily:** Sure. And doing this work and my own community has been really hard because it's about reading the words and talking to people who are directly impacted by the things that I see. and so there are these direct connections and it's heartbreaking to know that this is happening.

And I want to make a difference. I want to make a change so that, that doesn't happen in the first place. Um, my grandfather died from colorectal cancer and it was totally preventable. And then I'm doing research in cancer and I can see the data point. I can see his data point and know that that didn't need to be there.

And it's incredibly frustrating. Made worse, because I know that that happened because the system wasn't there to support him. The system wasn't there to prevent his cancer from happening. and so it just drives me crazy that this is happening still. My grandfather died in 1994 and there are still people who are going through the same thing that I went through when I was 20.

it just has to change. Ridiculous that we're still having the same problems that we had in 1994 in Indian country.

**Lisa**: Let's talk about the actual systems that are in place. Can you give us a little bit of background on what the Indian health service is and when and how it was creative and what a promise to do?

**Emily:** Sure. Well, the Indian health service is a, a formal health care system. It's not a health insurance, but as a healthcare system for American Indians and Alaska natives in the U S. We paid for, with our land, through our treaties. Um, so it's actually treaty guaranteed healthcare, and it was formalized through a series of different laws that happened over time.

Um, starting with the treaties that we signed at this point, it's, uh, divided across 12 areas in 25 states or 35 states actually. And the care is delivered through a range of clinics and hospitals and health centers and health stations. And then there are also a number of urban Indian health centers, in ma major cities, across the U S so it's, you know, a system of healthcare where if you are a member of a federally recognized tribe, you can go to an IHS facility and receive primary care. Um, so that's IHS in a very, very tidy, nutshell.

**Lisa**: And IHS or the Indian health service, um, has it fallen short of its promises and in what ways?

**Emily**: Oh boy. So if you think about how you would like to have your health care, or, you know, if you have health insurance, you think, well, I'm going to go to the doctor And, I'm going to have healthcare. And that means that I'll go to the doctor. And if I have a problem, I can trust that they're going to treat my problem, or they're going to refer me out.

If they can't take care of it. That is just an assumption that everybody makes about their healthcare. Well, the Indian health service doesn't function that way because they are terribly underfunded. And because of the kinds of decisions that they've had to make and policies that they've had to create over time to try and meet the needs of as many people as possible under these funding limitations. um, it means that. Those assumptions that we make about healthcare just aren't in place. So people who have serious health conditions can't trust that their health conditions will be treated.  if you don't live close to an IHS facility, you don't have your health care managed. so it's failed native people across the board and all sorts of really weird ways, which means that our health is compromised, uh, constantly.

**Lisa**: And have there been times in recent history when the health disparities have widened even more than usual?

**Emily**: There was a period between 2000 and 2008 when the budget for Indian health service was submitted every year For approval. I can't remember the technical word for it. It's not that technical even, but, it was submitted to be approved and it didn't get approved. It didn't,  it didn't go up. And so for that eight year period, the budget remained at the 1999 amount and it couldn't grow to meet the rising costs of healthcare, but medical costs during that time doubled.

So that means also that in 2009 and 2010, we were still operating on a budget. That was way behind what it should have been. And we're still trying to catch up within the Indian health service. and so this meant that all of those things that we'd had before, You know, the surgical suite, the maternal care, all of that, it all started to close and we saw, the fairly well-developed system of healthcare just crumble.

Um, right before our eyes. And I'll give you an example. That was very personal for me. so I had my first son in 2004 and he was born in a hospital away cause I was living in a place that didn't have healthcare, but I was really looking forward to having my second son in the same hospital where I was born in Santa Fe.

And, I was just assuming of course we would have labor and delivery at the hospital. I was pregnant. I was a grad student. I went to the hospital. I didn't have any health insurance and, I'm getting prenatal care and they said, oh yeah, no, you're not going to be able to have your baby here because we just closed our labor and delivery unit.

And this is in, um, 2007. And I was stunned. I mean, this is a hospital that for generations, since the early 1970s had been delivering babies. and it was devastating. It was personally devastating for me for a lot of reasons, but it was devastating for the entire community because

we, you know, people have a love, hate relationship with IHS, but we had loved having our babies there.

And that was the kind of stuff that happened because the budget didn't increase enough to sustain the services. Uh, and it meant that the health disparities that we experienced in 2000 became, well, we went from like a little, you know, a canyon to this huge goal.

Because the care that we would have received at IHS just disappeared.

**Lisa**: This is like I, so for context, I'm Puerto Rican. This is a very similar to some of the issues with funding that, um, the island is facing right now. So it is, um, I appreciate you sharing this story. It sounds like a lot of stories that I have heard of growing up as well. So, uh, it is unfortunate when, um, things just put on the back burner, when people's like whole health and lives are put on the back burner. And, uh, then some people have to deal with the realities of not even being able to be gave birth within their own communities, you know?

**Emily**: Yeah, absolutely. I mean, healthcare should not be a partisan issue.

**Lisa**: Agreed. So I assume that there have been times when that health inequality that we have been mentioning has been reduced to an extent, um, have there been any policies or changes over time that have contributed in a positive way that you can recall?

**Emily:** That's such a, you know, when I was a little kid, we would go to IHS. and we'd go to the hospital and it was a true hospital. Where there was a labor and delivery unit and there was a surgical suite and there were no beds. It was a hospital. So people, if they needed to stay in the hospital, they would stay there.

And most of your basic hospital needs could be addressed there at the Indian health service hospital in Santa Fe. And a lot of the IHS hospitals around the country were like that. so. People talk about kind of the good old days of IHS, where you could go. And most of the, conditions that you need for basic health care were met.

Um, and in fact, and I remember that we would talk about the other hospital here in town is kind of being the white hospital and you'd only go there. If there was something so serious, your life was threatened. So you'd go to the white hospital to die, basically. but that gives you a sense of how well they managed health care, um, back in the good old days.

So that was back when I just was relatively funded and the facilities were new. I should say that right now that same facility is there with the same, equipment. They've had very little updated since the seventies and early eighties.  it's really depressing.

And most of those units that were there, then the surgical suite and the labor and delivery, and even the hospital inpatient unit, it's mostly closed. I think they have a couple of beds available

just in case, but it's nothing like it was then. The other time that they've not the need is recently during the COVID pandemic.

They've done an amazing job with making sure that our populations are getting vaccinated. They were, well, I had COVID early in the pandemic and that was the one place I could go and get seen and get the care that I needed and have people listen to me. When everybody else was shut down and they just didn't know what was happening.

And so the Indian health service has done a really amazing job of responding to the communities and honoring tribal sovereignty, and working in collaboration as much as they could during this really terrible time.

**Lisa**: Yeah. I mean, we've definitely had our fair share of disasters. Some bloody brought up the pandemic, even though it's not something to be glad to be talking about really. But, um, as far as. How the health crises, um, how did it impact, uh, specifically like native people, throughout the country, you said you were able to access the care you needed, when you needed it, which is great to hear. But of course I remember hearing during the beginning of the pandemic. Back in March, April, all of these new stories about how it was specifically affecting native communities and, um, really concentrated way. Could you speak to that a little bit about how it impacted the committee?

**Emily:** Sure. And it's really complicated.  so we have these healthcare centers and hospitals and clinics where they were terribly underfunded. Most of their clinical staff or a good portion of their clinical staff are, members of the commission Corps. The commission Corps has this kind of branch of what a uniform services that are dedicated to being healthcare providers essentially. And that's deeper in the weeds than I even know enough to talk about. Except I know that the commission Corps, had to be ready at the start of the COVID pandemic to be deployed to places that were emergency locations, where they were considered hotspots.

And they were the only healthcare providers on the reservations and in these, these clinics. So, so there was nobody, uh, it's such a crazy story.  So you have a hospital out in the middle of nowhere. It's the only healthcare provider for, you know, miles, miles around. Um, you have reservations where the tribal leaders are being told that the only doctor that they have is going to be shipped out and then you have this pandemic coming around.

And they did the best that they could. They really did. They were so dedicated. And they managed as best they could. They didn't have things like ICU units. They didn't have respiratory care therapists. They didn't have any of that, that they needed. So when the pandemic happens and it comes into the community, the, um, community members.

They, a lot of them had preexisting conditions. Um, there were other factors that made it difficult to avoid the pandemic spreading and the communities and people got really, really sick and there was nowhere to go. And I think that's one of the reasons why, COVID-19 just decimated our communities the way it did and caused such terrible problems and tribal committee.

Because our healthcare system was underfunded, understaffed, and didn't have the resources that it needed at the time that it really, really needed it. and everybody was just worn out and tired already. Um, the Indian health service was totally understaffed before the pandemic even started.

**Lisa:** Yeah, it sounds like there were definitely systems that were sort of set up to fail because of a lack of action and sparse funding. Are there any policy suggestions that you think would have made a difference in having the equipment necessary for folks to have been ready for something of this size? As far as this COVID catastrophe goes.

**Emily**: Hm, policy suggestions. Well, this is a chronic problem, right? This is a problem of underfunding that goes back decades. So the first policy suggestion is to fund the Indian health service at a hundred percent of need. Um,and that's what they've needed to do. And that's what tribal leaders have been requesting for generations. And I mean, How do you say that that that's a policy suggestion, but it really is. You can't do anything if you don't have the money and you don't have the facilities. So prioritize, uh, the health of this nation's first peoples.

**Lisa**: Um, I wanted to ask a little bit about the affordable care act. and whether or not that policy decision impacted health opportunities within, native communities.

**Emily**: The affordable care act was, was really instrumental and starting to shift, the direction of native American health. Because it, helped to change the way that the budget was funded. And then it also allowed for,  for us to get a lot of native people on Medicaid. And it's those Medicaid dollars going into the Indian health service that have been this just huge infusion of dollars into the.

Where we didn't have those dollars before. So when I talk about funding, I mean, if you look at the budget, it's like,  I don't know I'm making this up, but it's somewhere around 70% of the budget now comes from Medicaid dollars. and so. There are a lot of other conditions of the affordable care act that have been really positive for the Indian health service, but it's Medicaid.

And the fact that so many American Indians don't make enough money to, not qualify for Medicaid that has made the biggest difference.

**Lisa**: Yes. Um, so let's switch gears a little bit. Uh, several years ago you created what I believe is called a health impact assessment in Santa Fe to determine the health needs of native peoples in that region. Can you share some detail about that project and what answers it provided?

**Emily**: Absolutely. So the, urban Indian community in Santa Fe is a little. Unique in that Santa Fe is a smallish city. We have about 75,000 people in the city limits, but then about 150,000 people in the county and Santa Fe is home to a tribal college that is focused on American Indian

art. And because of this, it brings in this really diverse community of American Indians and Alaska natives.

Many more than you would expect for a town of this size. And we're here and a lot of us go to the Indian health service hospital here. And so this gets in again into the weeds a little bit in terms of jargon, but  at the Indian health service, there are different pots of money for different services.

And I said earlier on, if you walk into the health service hospital, you can get primary care, you can get whatever's happening within those four walls.

But if you need some sort of specialty care like cancer treatment or a colonoscopy, or you need to see a podiatrist or something,  if you don't qualify for the pot of money that pays for specialty care, um, then you can't get it.

They won't pay for it. And that has really, major implications for the population of people who are, uh, members of tribes that aren't. And so that's, that's called purchase referred care.  So.

I went to our urban Indian community center, the Santa Fe indigenous center, and I said, we need to find out what the impact is on our community. when we have all these urban Indians and we have this hospital right here, um, and we don't, aren't getting our healthcare needs met.

And so we did this health impact assessment on that. And so the, what we found was, um, after doing a lot of surveys and interviews, that the, uh, we, we came up with four recommendations cause that's the goal of health impact assessment. The first is that we found that people wanted the Indian health service to be funded at a hundred percent. We found that, our urban Indian community was struggling with food and hunger. And, about 50% of the community had re or they were reporting that they weren't getting, or they were, um, rationing their food on a monthly basis. we found that people were very worried about mental health concerns and they needed more behavioral health services through the hospital. Uh, and the fourth one was that they wanted to eliminate this whole system of rationed care, according to where your tribals from

**Lisa**: Well, it sounds like you interviewed a lot of individuals. Could you share a little bit about what their experiences were?

**Emily**: Yes. Okay. So, The difficulties were really, um, significant.There were problems like, um, there was a woman that I talked to, who knew she had cancer and she couldn't get a diagnosis.

Like she knew in her soul that she had. And she was having all these health problems and she'd go to IHS and they would be like, yeah, you have cancer, but she couldn't get anybody to pay for her to get the diagnosis. And so what she ended up doing was she went to the doctor and she took the doctor a pot, you know, like a native American pot that she'd made.

And she traded that for the services that she needed so she could get the diagnosis of. And once she got the diagnosis, then she could start to get the services that she needed a paid for, but it's that kind of struggle. And, clearly just innovation and creativity that people were going through to try and get the healthcare they needed for basic service.

**Lisa**: That's definitely a very impactful story. And out of, collecting the stories, what would you say the was the biggest outcome from this project of figuring out the biggest problems and being able to use research to present this information?

**Emily**: I was really pleased that, immediately. The city and the community recognized that hunger was such a big issue and such an easy thing to address. And they right away jumped in and started to move resources around so that they could get food to the community. and make it available in a way that was culturally friendly because yes, we have a food bank here.

We have several, but for some reason or another people weren't going to the food bank and they weren't making use of the existing resources. So they made culturally friendly food. Uh, distribution systems available and that helped to address the problem right away. And we know that when you take care of food, you, you instantly impact other things like education and, you know, long-term health.

If you have healthy food, then you know that you're going to address all those other products.

**Lisa**: We have been talking about native people as a whole, but are there a particular groups within the native population who are especially vulnerable to the problems with healthcare?

**Emily**: I have been doing a lot of work recently with my colleagues, uh, the Pacific Institute for research and evaluation, really delving deep into the issues. Elderly native Americans and the, issues around how healthcare has impacted their lives and also how policy impacts them. And one of the things that it just blows my mind is even with the affordable care act, as wonderful as it is and everything else.

There's no line item for dedicated elder services or elder care in the. And so even though we really prioritize elders within our culture, we don't have any money to pay for their care. We actually only have one consulting geriatrician within the entire Indian health service system. We don't have any sort of long-term care  Uh, for our elders. And so they just ended up kind of falling through the cracks. And right now with COVID,  a lot of the senior centers are closed, so they don't have anywhere to go. They don't have any sort of social support. And, it's just. I I'm really devastated to see all of the, systems that they had in place before.

Just completely gone. They're sitting at home, they get meals on wheels. And so they don't have anybody to talk to because it just comes to their door and nobody, people don't want them to be sick, but then they're completely isolated. and so they're really vulnerable right now with health care, but then they're vulnerable in every other way as well. So. I, I wish that there was

something that we could do right now, but the, the thing that we definitely can do is to make sure that there's money in the budget for eldercare, going forward.

**Lisa**: Hmm. and I know that another part of your research does focus on end of life care. So I'd like us to talk a bit about that as well. Is there anything unique about the end of life care that native Americans request and are their needs and desires being respected within the healthcare system currently?

**Emily:** So end of life care, and indigenous communities is totally different. And I, you know, you have to be clear that we're talking about 574 different federally recognized tribes. And so that's 574. Tribal communities, different people. and you can't say that one thing is true for one and true for the other.

We're all completely unique. but the one thing that is definitely universal across the country is that we're not getting hospice care. We're not getting specialized care. and so. We don't really know what people want because nobody's asking the questions. Nobody is really meeting the needs of people at the end of life.

Uh, and so all of those resources that we know about that are available, like good symptom management, they're just not happening in Indian country.

**Lisa**: What are other things that you would tell a policymaker about the steps that they need to take to provide better healthcare and better health services to native populations? Especially since we're still in the midst of the pandemic.

**Emily**: So, uh, if I were sitting down with policymakers, And when I have sat down with policymakers, I really try and emphasize that there's no cookie cutter way of solving these problems. Every community is different. Every community has different priorities. And so we can't try. Um, just slap on some solution and call it good.

We really have to sit down and talk to the community. Tribal leaders recognize their sovereignty and work with them in collaboration and have them drive the bus because they know what's best for their communities and their priorities are going to be based on their values and beliefs as a indigenous people.

So you have to work in collaboration with the communities to solve the problems. If you try and answer the problems for them, I guarantee it's not gonna.

**Lisa**: Absolutely. I mean, who better to know their own communities and the people within their own communities. Right.

**Emily**: Right. Right. And I'll just add to that, that it may be that a tribal leader is saying to solve this problem. You have to fund a language program. And that might seem crazy. Like, why are

you going to solve cancer by answer, by teaching kids, how to speak their language. You just have to trust that that's going to be the solution.

And if you give it time and recognize that they know their community best, I promise you that that's going to be the solution.

**Lisa**: Well, thank you so much, Emily. It was really great to have you on this episode.

And thanks for listening for more on Dr. Haozous's work. Check out our show notes at scholar sot org. No jargon, no jargon is the podcast of the scholars strategy network, a nationwide organization that connects journalists, policymakers, and civic leaders with America's top researchers to improve policy and strengthen democracy.

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