National Disability Forum

"Removing Barriers to Accessing Services in Tribal Communities"

Part One

August 29, 2024

James Edrington: Hello, everyone. And welcome to Social Security's National Disability Forum in Removing Barriers to Accessing Services in Tribal Communities, Part One. I would like to now turn it over to Kilolo Kijakazi, Principal Senior Advisor to the Commissioner at the Social Security Administration.

Kilolo Kijakazi: Hello, everyone. And thank you for joining us today. I am Kilolo Kijakazi, Principal Senior Advisor to the Commissioner of the Social Security Administration, and I have the pleasure of welcoming you to our 28th National Disability Forum, Removing Barriers to Accessing Services in Tribal Communities. These forums are a cornerstone of our approach to better understanding and addressing the needs of the communities we serve. First, let me review a few housekeeping items. The National Disability Forum is a public forum and may include representatives of the press so any statements or comments made during the forum may be considered on the record. This virtual forum is being recorded and will be available on the National Disability Forum's website within four weeks after today's forum. Second, we have disabled the chat, microphone, and video feature for our attendees. If you dialed into this Microsoft Teams Meeting, please use your phone's mute feature. And third, we are offering two accessibility features today. We have an American Sign Language interpreter and closed captioning. If you would like to use closed captions, please go to your MS Teams toolbar, select three dots titled "more," then select the "language and speech" menu and select the "turn on live

captions" option. And now I'll outline our focus areas for today. First, identifying health equities and barriers in tribal communities. Second, strategies to support housing programs. And third, strategies to support vocational programs. More inclusive, and accessible, and equitable Social Security programs and services, require ongoing commitment and collaboration. I'm proud of the progress we've made to remove barriers to access for all tribal communities, but I know there is more we can learn from our panelists and from everyone joining today. Commissioner O'Malley is unable to join us live, but he has recorded brief remarks. In July of 2023, Martin O'Malley was nominated by President Biden to serve as Commissioner of SSA. Following confirmation by the U.S. Senate, he was sworn into office on December 20th, 2023. Prior to this, he served as Governor of Maryland from 2007 to 2015, following two terms as Mayor of Baltimore. Commissioner O'Malley is a lifelong public servant and a pioneer of using performance management and customer service technologies in government. He has written extensively on how to govern for better results in the information age by measuring the outputs of government on a real-time basis. Now let's hear from Commissioner O'Malley.

Commissioner Martin O'Malley: Hello, Commissioner Martin O'Malley here. And I want to thank you for joining today's important discussion. Although I am unable to join you in real-time today, I wanted to recognize our Office of Native American Partnerships, which was established by Dr. Kilolo Kijakazi in 2022 and is now led by Renee Ferguson. In May, I had the privilege of traveling to South Dakota and co-hosting a tribal consultation with the Oglala Sioux Tribe, co-hosted with Tribal President Frank Star Comes Out. We had a chance to listen directly to tribal members about improving customer service in South Dakota which is hours away from any Social Security office. To ensure tribal voices continue to be heard we're establishing the Commissioner's Tribal Advisory Committee to serve as a direct channel for tribal leaders to

provide recommendations on policies and programs affecting their communities. And this benefits the Agency as well because we'll have firsthand knowledge to help us address the specific needs of tribal communities and overcome barriers. But in addition to sustained dialogue and in-person consultations, we're using technology to better connect SSA's programs and services with your communities. So, we're reducing wait times on our 1-800 number and working with partner agencies to improve Internet connectivity and remove other barriers to accessing services online. And we know language is also often a barrier, so we're incorporating native languages into our materials and services and honoring the rich cultural heritage of tribal communities. But to help us carryout this work, we're also aiming to actively recruit native students through internships, scholarships, mentorship programs, and invest in their retention within SSA. The Office of Native American Partnerships is also offering specialized training sessions to ensure that tribal government employees can effectively assist community members in navigating Social Security benefits and services. In closing, many thanks to our esteemed panel members for sharing your expertise, including strategies for vocational programs like SSA's Ticket to Work which supports career development for people ages 18 through 64 who receive Social Security disability benefits and want to work. Renee Ferguson and other Agency leaders are listening closely for potential solutions we can deploy to assist tribal members who are disabled get back into the workplace. And so, I encourage tribal members and leaders to reach out to Renee if you're interested in partnering. Thanks very, very much.

Renee Ferguson: We appreciate Commissioner's -- that you all joined us today for this focus on tribal communities. As stated in the email instructions, there will be no chat features so that we ask that you please email your questions or comments. You can do so during the forum. For those that we can get to the panelists right away, we will. You can email at the

nationaldisabilityforum@ssa.gov. And please do not include a Social Security number, or address, or other personally identifiable information. Your name will be sufficient with your email. In September we will post today's recording and it will be found on ssa.gov/ndf, and then you will search under the previous NDF section, and then the date for today, August 29th, there will be a tab there and there will be the recording. It's going to take us a few weeks to get that posted. Today we are providing our stakeholders an opportunity to share your unique insights directly with SSA leadership who have joined us, and the policymakers for SSA to gain insight by listening to the panelists. You will help us shape the future of Social Security by strengthening our disability policy development and contributing to our effort to address equity within our disability policy and practices. This is a two-part series. With Part 2 that will be offered in November, it's going to be on Wednesday, November 13th, so, please, save that date on your calendar. After today's panel discussion, there will be a virtual Q&A session so we would like for you to please submit your questions for the panelists via the email box nationaldisabilityforum@ssa.gov. Now I would like to introduce you to the moderator for today, Dr. Stephanie Fryberg. Dr. Fryberg is the James E. Johnson Professor of Psychology and the founding director of the Research for Indigenous Social Action and Equity Center at Northwestern University. Dr. Fryberg's primary research focuses on how social representations of race, culture, and social class influence the development of self-psychological well-being and educational attainment with expertise on indigenous representation, biases, and inequalities indigenous people face. Dr. Fryberg received numerous honors and awards including: An introduction in the Multicultural Alumni Hall of Fame at Stanford University; an election into the American Academy of Arts and Sciences; Dr. Fryberg provided testimony to the U.S. Senate Committee on Indian Affairs regarding the impact of racist stereotypes on indigenous people. To

learn more about Dr. Fryberg and all of our expert panelists you can visit the National Disability Forum Homepage previous NDF tab, and over to that August 29th tab. And that is on ssa.gov/ndf. We would like to extend our sincere appreciation to you, Dr. Fryberg, and all of our great panelists that join us today. We appreciate your participation. Dr. Fryberg, we welcome you, and the floor is yours.

Dr. Stephanie Fryberg: Thank you, Renee, for the warm welcome. I join SSA today in welcoming our panelists and attendees to the National Disability Forum on Removing Barriers to Accessing Services in Tribal Communities, Part 1. Today, as mentioned, we will have a closed discussion with five panelists, experts in their field. After the discussion we will accept questions via email. As time permits, I will share your questions with the panelists. If you wish to ask a question or provide a comment by email, please include your name and location in your email question. The appropriate email address is nationaldisabilityforum, all one word, @ssa.gov. The chat line will not be open during the discussion segments. All questions must be received via email. Before we begin this afternoon's discussion, I would like to take a few minutes to set the context for the panel discussion today. The Social Security Administration plays an important role in fulfilling the Federal Trust responsibility to Native people. The inequities for Indian country, in health, housing, and vocational opportunities, were starkly visible during the pandemic and continue to be major concerns in the everyday lives in our people. I have witnessed firsthand the significant barriers people in my community experienced during the pandemic, from the loss of lives due to health inequities, to the loss of jobs due to pandemic economic downturn that led to increased disparities on an already exhaustive housing crisis. It is imperative that we seek solutions that create a safety net to support our most vulnerable in times of crisis and build sustainable systems with partners like SSA to meet the needs of our

communities. This is why we have brought together these distinguished panelists to discuss removing barriers to accessing services in tribal communities. Allow me to now introduce our distinguished panelists. We have James Lovell, the Chief Community Development Officer at Chief Seattle Club. Dr. Jolie Crowder, a National Eldercare Consultant with the Division of Clinical and Community Services with the Indian Health Service. Joshua Drywater, the Director of Native Initiatives with the Virginia Commonwealth University Rehabilitation Research and Training Center. Irma Goodwine, the Vocational Rehabilitation Program Manager with the Association of Village Council Presidents. And Richard Peterson, the President of the Central Council Tlingit and Haida Indian Tribes of Alaska. Extensive bios of the SSA executives and these distinguished panelists are provided on the National Disability Forum website again at nationaldisabilityforum@ssa.gov/ndf, and it's under today's forum tab, and is August 29th, 2024. Okay. So, to begin today's conversation, I would like to start with a focus on health equities and barriers in tribal communities. So, what does health equity mean from a tribal perspective? Can we start -- James, would you like to jump in on that?

James Lovell: Sure, thank you. I'm actually going to take a couple of minutes at the beginning to describe the community that we're working in at the Chief Seattle Club, if that's okay. So, Chief Seattle Club is a Seattle rate-based non-profit organization founded in 1970. We provide a number of social and human services in the region. Our core focus is on single adult, chronically homeless Native people. Many folks refer to the people we serve as clients or patients. I mean, those are fine terms in their context, but we use the term members when we talk about the people we serve. To define the scope a little bit, I would like to take a look at the native community we are centered in because it's very relevant for the health work, health equity work we do. We work with what is called Urban Indians. And the Urban Indians Health Institute defines that as tribal

people currently living off federally defined tribal lands in urban areas, and that is about 71% of all American Indian-Alaskan Native people. So, we are not a tribe or an Alaskan native corporation, we are not a reservation; we're a non-profit. Our work is focused on single adult chronic homelessness. Single adults doesn't mean that we don't work with couples or people that have intimate partners. It means that we work with adults and not family homelessness or with minors. There is a great definition of chronically homeless folks that you can find on the HUD website. It basically is folks with a disability who are living in a place not meant for human habitation and have been homeless for at least 12 months or on at least four separate occasions in the last three years. We do not require that everyone served by or housed by Chief Seattle Club is a member of a federally-recognized -- an enrolled member of a federally recognized tribe. However, the vast majority of people we serve are enrolled members of federally recognized tribes, or Canadian First Nations Inuit or Mis groups. As I said, we serve Urban Indians, and this represents over 70% of native people in the U.S. per the census. In Seattle, the vast majority of Urban Indians are not from local tribes, and this is due to a number of federal policies and programs, especially the Indian Relocation Act of 1956 which relocated native people from rural reservations to cities across the country, including Seattle. This is the time period when my family left our reservation, the Turtle Mountain Band Chippewa Indian Reservation in North Central, North Dakota, and relocated to Tacoma, Washington, and then Seattle. If you research the American Indian Urban relocation in the National Archives, you will find that the National Archives describes how native people, and I quote, struggled to adjust to life in a metropolis and faced unemployment, low-end jobs, discrimination, homesickness, and the loss of traditional cultural supports, end quote. This led to the rise of Urban Native homelessness, and today native people make up between 1 to 2% of the people in the Seattle, King County area. However, per

the 2020 Point in Time Count, which is a federal count, we make up 32% of the chronically homeless population in the region, so, we estimate that there are over a thousand native people on the streets on any given night in Seattle, King County. All of the work Chiefs Seattle Club does is focused on this community of chronically homeless Urban Native people. Each of these individuals qualifies as having a disability. If not self-reported -- if not diagnosed, then at least self-reported. So, we are dealing with pretty much 100% disability qualification. 100% of our members have been rejected by the health system at some point in time due to their status as a chronically homeless person. So, our work is really centered on understanding what is an Urban Indian chronically homeless Native person's life experience and how can we make them feel like we are a safe place for them to go. So, we do a day center which is where they come from 7 to 2 and get meals, and that is where we have a nurse, for example. If you are chronically homeless you don't always feel welcome in standard hospital or clinical settings. However, if you come to a day center where you have two hot meals and other native people who can identify with your Urban Indian identity, and there is a nurse there who will help you take care of your wound, it can help prevent infection. We have transitional shelters, again, with the same mentality there of feeling like it's a comfortable place to come and be Native, especially as a chronically homeless person, and ask for help from other Native people or people who are culturally responsive to Native people, including nursing and mental healthcare. We also have permanent supportive housing. We have 339 units open today and more units opening over the coming years, again, with that same focus. All of this background and context is to make sure that the folks understand we are not tribal -- or not a tribal organization, but a non-profit organization working with a specific federally -- a community of people whose lived experience is based on federal policy, as it is for any native person, I would argue. And that the way we approach health is

always through their identity as a Native person and as a chronically homeless person first because that's the only way that many of our members will actually accept even lifesaving healthcare. That was a lot. I am really appreciative of the ASL interpreter powering through all that! Thank you.

Dr. Stephanie Fryberg: Yes. Just to be clear, James, did you feel like you got the opportunity to really dig into how your organization thinks about health equity?

James Lovell: I think so. If there is a part I missed, I can certainly add more. What do you think?

Dr. Stephanie Fryberg: No, it's good.

James Lovell: Okay.

Dr. Stephanie Fryberg: I just want to make sure it was part of your introduction there.

James Lovell: Sure.

Dr. Stephanie Fryberg: Can I turn to Richard now.

Richard Peterson: Good morning. Can you hear me?

Dr. Stephanie Fryberg: Yes.

Richard Peterson: Great. Well, as we delve into this conversation, it's essential to recognize the unique challenges our communities face. I'm located in Southeast Alaska. Tlingit and Haida is the largest of the tribes in Alaska. There is 229. We have about 38,000 tribal citizens worldwide. In fact, we have about 8500 in the Seattle area, so the Seattle, Chief Seattle Club and the Seattle Health, Urban Health serves many of our people. And that shows some of the disparities we have from villages of a couple hundred people to urban centers with thousands of people that need to be served. And I think some of these challenges we face are really rooted in a history of colonization and systemic marginalization of indigenous people. You know, health equity from a

tribal perspective means that the tribe works to fill the gaps that the state, federal or IHS entities do not meet the needs of so many of our people, such as small rural and remote communities that do not have-- that we just don't have access to the highest quality of care. Oftentimes we're at the mercy of weather, and medevacs, limited resources. So, to fully understand those health disparities in our communities, we must acknowledge the lasting impacts of colonization. The systemic suppression of our cultures and our ways of life has not only disrupted our connection to our traditions, but it has also led to profound health inequities. Colonization didn't just change our environment; it changed our bodies, our health, and our access to the resources that we need to thrive. Generations of trauma have been passed down from one to the next, have left our people with heightened levels of stress. This isn't just a psychological burden; it's a physiological one as well. High cortisol levels, a direct result of chronic stress, have devastating effects on our health. This trauma deeply ingrained in our DNA manifests in ways that are too often overlooked by mainstream healthcare systems. For example, the introduction of commodity foods and the resulting dependency on highly processed items have led to a nutritional crisis in our communities. These foods lack the nutrients our bodies need and have replaced the traditional diets that kept our ancestors healthy. So, addressing food poverty and restoring access to traditional foods are critical steps in reclaiming our health. And our traditional ways of life which sustained our ancestors for thousands of years were criminalized and our access to nutrient-rich foods were systemically stripped away. This loss has been compounded by the forced dependence on government-issued commodities, foods that are highly processed, and contribute to the epidemic of chronic diseases in our community. And finally, there is a critical need for trauma-informed training and care among native health providers. Our healthcare professionals must be equipped with the knowledge and sensitivity to understand the deep-seated trauma that

many of our people carry. Trauma-informed care isn't just the best practice; it's a necessity if we are to provide meaningful and effective healthcare in our communities. And first it is so important to meet us where we are at. There is a significant lack of staff to support those in our rural communities to help with complex processes of SSI or SSDI application services. Many of our people are being forced to move from their home communities to get the services and support that they need. So, in addressing these barriers we must approach with a mindset of healing and reclamation. Healing the wounds of colonization, reclaiming our traditional foods, and ensuring our healthcare systems are responsive to our unique needs are all vital steps towards equity. By recognizing these challenges and actively working to overcome them we can create a future where our communities not only survive but thrive. And we need our federal and state partners to help us provide quality care to our people. For example, access to behavioral health services without the barriers of Medicaid regulations has been a serious issue in the State of Alaska for decades. Tlingit Haida stood up our own community behavioral services department to fill a significant need for services in our community and it's been an uphill battle trying to work with the state to be able to bill Medicaid to serve our citizens. We shouldn't have to fight so hard to bring healing to our people. Building trust comes with acknowledgment by providers. Only acting as tools to help create space for indigenous people to heal through culturally responsive modalities that could be paired properly with evidence-based practice secondarily. I'm going to cheeshawa and take you to our ASL interpreter.

Dr. Stephanie Fryberg: Great. Thank you, Richard. So, as I want to turn to Jolie, but I also want to add to the larger discussion because I hear it coming up as well that in addition to sort of what does health equity mean from a tribal's perspective, what are significant barriers that you see in the work that you do to healthcare access?

Dr. Jolie Crowder: Thank you so much. This is Jolie Crowder. Can you hear me okay?

Dr. Stephanie Fryberg: Yes. Thank you.

Dr. Jolie Crowder: Thank you**,** guys, so much for having me here. And like my former counterparts, I think, just a little bit of introduction for context setting. My background is **in** nursing and I spent 25 years in the non-profit sector in healthcare and other non-profit organizations, and came to the Indian Health Service two years ago when the agency received first-time funding to do work on Alzheimer's. And, so, most of my experience is not in the Indian Health System versus sort of as on the outside of the community sector looking in. So, a little bit about Indian Health Service, because I think it almost speaks to the question about barriers potentially also, I think in the great work we're doing, but IHS provides healthcare services and supports to just over 2.8 million people at 574 tribes, and there is a network of 600 plus hospitals, clinics, and health stations. And then there are also Urban Indian health organizations that are funded by the Indian Health Service. In total, the agency alone employs 15,000 people and that doesn't include the Tribal and Urban Indian staff. Thankfully, as part of ISDEA, the Indian Self-Determination and Education Assistance Act, tribes have the option of exercising their right to self-determination and take control of their healthcare programs. And starting in the early '90's, the IHS started to enter into agreements with tribes, and at this point, more than 60% of IHS appropriations, what we receive by Congress, is administered by tribes. And then I think one of the speakers already talked about the fact that 70% of American Indian and Alaska Native people live in urban areas. Some funding also goes to 41 healthcare organizations. And, so, collectively, you'll see the acronym ITU sort of in our inner circles here and that stands for the services Indian health services provides, the care and services provided by tribes, and then the populations served by Urban Indian health organizations. So, you know, kind of in that space I

think getting to a little bit dipping into the barriers question, I think it's a complex system, like our own. And then I think we heard the previous speaker who talked about the challenges with Medicaid eligibility. And then also sort of in the population I focus on, which is older adults, we have the Medicare payment system. And, so, at the local level, like in the healthcare service provider perspective, it's a really complicated billing system, you know, payer management, and it's not, like, as much time as I feel like is spent on the administrative management billing of healthcare as we are spending in healthcare, unfortunately, because of the complexity of that system. So, you know, I think our program, we were seeking Congressional appropriations in '21 for the Alzheimer's work. Our staff was brought on in '22, and I think kind of getting at the question of health equity, I believe that we have a really great team. And I think you know as I answered and thought about the question, I'd reflect on what is health equity from the tribal perspective, and how we have purposefully started to build in our program. And there are some key principles that are the core of our work, and also the agency's approach. And that includes recognizing tribal self-determination, recognizing tribes as sovereign nations, and respecting that tribal sovereignty. We prioritize relationship-building with our tribal and urban partners. Even in our grant funding, where we are you know giving them money, we don't take on a monitoring and compliance role. Rather as a partner to help support their work in capacity building. We are continually looking for seeking timely and meaningful feedback from the communities that we work with to help shape our work. Like constantly talking with folks in the community. The four major priorities for our program are the direct result of far more tribal consultation and urban confer that happened right after we got the money. So, you know everything that we do is guided by the people that we serve to the best of our ability with sort of the constraints we have. So specifically, to your barriers question, you know, I was jotting down some notes on this. I'd say

you know at the, at the agency level and at the local level, I'd say funding, the funding is always an issue for folks. Unlike Medicare, IHS is not an entitlement program, and we're subject to appropriations. You know, a year or so ago, Congress for the first time ever allowed for advanced appropriations, which means we go a year in advance. That's really nice because whenever there was a government shutdown or threat of a government shutdown, our services and care were at risk of being shuttered, so, you know, so we have about a year, you know, a year out, of funding about a year out. But consistently, the budget request doesn't match the funding. And that means that we have to -- that means we have to be smart about how and what we choose to fund, and how and the funding that goes to tribes. So, I think other barriers to access, again, the gentleman before me did a really nice job, but in a lot of the rural communities they struggle with really basic health needs like clean water, unpaved roads, reliable electricity, sewer, and septic. This is water week. It is my first water week here at the agency, and it is a big deal. Because access to clean safe water has been historically a major issue. So, in addition, you know, geography reality. I think what is really great about our Alzheimer's grants is they recognize the importance of social determinants of health and health-related social needs, like transportation. And so, they're like, you know, coming up with innovative ideas to address issues like that. They physically can't get into their clinics, and so these poor folks are providing the transportation as transportation vouchers. You know, I think the first gentleman spoke to the urbanization and the relocation efforts that were underway a few decades back and sort of what that left us with. And I know we know that even though they might not face these same geographic issues, there are still food deserts and many of the same issues that impact folks in tribal communities, continue to impact folks in native communities, like poverty and socioeconomic issues. The other barrier I think from our perspective too as a health care system

is the health care workforce shortage. COVID did no one any favors unfortunately, but it has been a longstanding struggle to attract and maintain health care staff. Not many folks want to move to very rural isolated communities. And if they do, there often isn't housing or the infrastructure to support that. So, I think I will pause there. Because I do feel like I talked a lot and see what other barriers folks have to offer. So, thank you.

Dr. Stephanie Fryberg: Great. Thank you so much, Jolie. I wanted -- I want to bring Irma and Joshua into this discussion, and really as we've -- so far, we have really identified health equities, barriers, we have heard a lot of discussion both in community and urban settings. But, you know, you two are coming from very different perspectives as well. And so, I think it makes sense. Irma, I would love to give you the opportunity to jump in here and share some thoughts about barriers, and you know different causes of these inequities. And then we'll turn to Joshua, so that you get the opportunity to talk a bit more from that research perspective, researcher perspective. I cannot hear Irma. Is it just me? No, others cannot hear you either.

Irma Goodwine: Can you hear me now?

Dr. Stephanie Fryberg: Yes. Yes.

Irma Goodwine: You can hear me now.

Dr. Stephanie Fryberg: Yes.

Irma Goodwine: Okay. Great. Thank you very much for having me. I'm kind of representing all of the Tribal Voc Rehab managers across Alaska. There is 11 of us. But I think Richard pretty much described everything that our region is experiencing. We deal, our program deals with the health system, the Yukon-Kuskokwim Health Corporation offers all the health care services, and whereas associates of Navarre's council president offers TANF, general assistance, energy assistance, tribal workforce realty, natural resources, construction. I'm under the Tribal

Workforce Development under the Vocational Rehabilitation Program. There is 56 tribes. And out of those 56 tribes, there is 50 villages, and we are not on the road system. There is, the only means to get to those villages is by a small plane. And each program, villages can be compacted. If they are compacted with AVCP, we serve all 56 tribes. If they are not compacted, then some of the programs offer certain services. So, with that said, just imagine how if someone needs medical assistance they have to get on a plane, either a six-seater or a nine-seater, and it costs about five to $700 round trip just to Bethel. And Bethel is the hub where the hospital, where the hospital is. So, each community has a clinic, YKHC clinic, and they have community health aids. They don't have physicians. So, they have some subregional clinics that serve several villages around that community like Saint Mary's is one of them. [inaudible] is one of them, Toksook is one of them. So, what the village community clinics cannot do, they attempt to do it at the subregional clinic. So subregional clinics do not perform any serious procedures, so they have to be referred to Bethel. So, they have to be flown in here. They do not do surgeries here; they do not do MRI's here or CAT scans. So, they have to fly into Anchorage. So, you are looking at people with disabilities who are expected to travel from Tununak, to Bethel, to Anchorage. Some are sent to Seattle. One of the most serious ones are sent to Seattle. But those are one of the barriers that we encounter with vocational rehabilitation programs. Thank goodness for our program. We are able to assist some individuals who are qualified for our services to travel here, either to get their hearing aids or to get a psychological evaluation. Because not all telemedicine is reliable. I mean, the Internet is, even in Bethel I'll probably freeze and disappear. A lot of times when I am in a meeting virtually, I will get cut-off. So those are some of the barriers that we have. A lot of our individuals with disabilities do not have a phone or do not know how to use a phone, or do not have access to computers. We do have some tribal workforce navigators

out in the villages, but not every individual goes to these job centers. So many of them are not qualified for Medicaid. So, and they can**n**ot afford to pay five, $700 round trip to be seen for something serious. So, what do they do? They make that decision to stay home and just deal with it. And many of the documents require a medical doctor's signature. So AVCP Region is about 25,000 or more people including Bethel, and it is just difficult especially with the weather as well. We were supposed to be traveling toward 25 villages, so a lot of people, their appointments get canceled. So, when they reschedule, it gets pushed back one month or two months. So, like I said, YKHC has only three doctors for a whole region. So, some of the documents that require the doctor's signature, we have had to work and be creative by meeting with the hospital and having created a form, a medical clearance form that maybe a physician will see the patient, and then the doctor will over, go through the medical records and then sign a document. It does not happen like that all the time. So, I'll give you a little example of our consumer, we call them the consumer, who had been waiting for services because he couldn't get to his appointment because of the weather. Because they had to reschedule six months later, he finally received his services, because we were just waiting for that doctor's signature. I have more to say on other general questions, but those are some of the things that I wanted to bring up.

Dr. Stephanie Fryberg: Well, Irma, you brought up so many important issues with respect to geography, transportation, socioeconomic conditions. Thank you so much for sharing. So, Joshua, can I turn to you now?

Joshua "Josh" Drywater: Sure. [speaking in native language] Hello, everyone. My name is Josh Drywater, and I am a citizen of the Cherokee Nation. I'm the Director of Native Initiatives at Virginia Commonwealth University's Rehabilitation Research and Training Center. I come today with I would say a lot more input and insight into the world of vocational programs. But I

think that my input here kind of fits into the holistic viewpoint of a lot of native communities. And you know several of the speakers have brought up the disparities with geography and socioeconomic conditions. But I think that it's key to also point out even with, you know, the Public Law 638 and self-determination and even further with a lot of the tribes moving towards self-governance of their health care system, that the systems are still often underfunded to, to a great extent. Furthermore, you know, I come as insight, my viewpoint as a native citizen, and not representative of any of the tribal governments throughout the United States. However, I think that it is important to just understand to not have the homogenous mindset when it comes to a lot of these issues and questions that we're discussing, because every tribal government, tribal community for that matter, has varying differences on cultural values and traditions and how they view their sovereignty and to what extent. I will say you know as I mentioned with the holistic approach that tribal citizens generally have with health, it involves that inter-connectiveness with physical, mental, emotional and spiritual well-being. So, you know, often we may see federal programs having these, these policies or set standards of how they would like to see a program operate which can often be contradictive to the way that a tribal government sees that holistic health and inter-connectiveness of its people. So, you know a lot of the inequities and disparities have been brought up by the speakers. I definitely think that there needs to be like the conversation in line with you know that community focus and exactly what the particular tribal community is, is looking for in terms of health and being able to take those best practices that the tribal governments and tribal communities are doing at the lower level and help facilitate them to build. So, they are getting the proper input, and you know formation of the services that they are wanting.

Dr. Stephanie Fryberg: All right. Thank you so much. I wanted to -- I want to shift a little bit at this point to talk about housing programs. And really so we can get at all three of the topics today, and then we'll get to looking at more generally how federal agencies can help to mitigate these concerns and barriers. So, I would like to turn to Richard, and the question on the table is, what are the housing concerns in your communities? And how are your -- like, what are your concerns surrounding these housing programs?

Richard Peterson: That is a big question. You know, we operate under NAHASDA, right, and so here in rural Alaska, we barely generate enough funds for new housing, let alone for housing maintenance. So, we are seeing an out-migration of our communities based on the inequities in housing. It is so expensive. And I, I live in Juneau, but I'm from a very small village in southeast Alaska. And a lot of people are leaving the communities because of the lack of housing. But the problem is, once you get to Juneau, we are also in a housing crisis here, so they can't afford to even get into housing. You know, when I talk to friends and family who say they want to leave our communities, because of how expensive or the lack of housing, I tell them it takes almost $6,000 just to get into a rental. And you know that, that just prices most of our people out of even being able to obtain housing. So, there is a severe inequity in housing. Here in Juneau, we just saw the city subsidize a new housing project that was supposed to be for low income, and the first thing the developers realized is they couldn't build it for low income. And so, what was a hope for new low-income housing turned into extremely expensive condominiums that minimum were $500,000. Our people cannot survive at that. So, we're seeing a huge uptick in homelessness or unhoused population. And it is becoming a real crisis point. I grew up in a very traditional village. The first languages I heard were Xaad Kil, the Haida language, Of my father's people. And now we are just seeing the out-migration. Nobody can afford to live there. Elders

have to move into urban centers, into subsidized senior housing. So, it is an incredible crisis here in rural Alaska.

Dr. Stephanie Fryberg: Wow, thank you so much for sharing. James, can we turn to you to -- excuse me **--** to speak from the urban perspective? Because the housing crisis is very similar, yet different. We cannot hear you, James.

James Lovell: How about now?

Dr. Stephanie Fryberg: Yes, thank you.

James Lovell: Thank you. Again, this is James Lovell. I'm with the Chief Seattle Club of an Urban Indian Organization in Seattle, Washington. I forgot to mention I'm enrolled in the Turtle Mountain Band of Chippewa from Belcourt, North Dakota, but was born and raised here in Seattle. As a result of that 1956 federal policy, the urban, the Indian Relocation Act. So, when I spoke earlier, I described how there are so many chronically homeless native people in urban centers, and I tried to couch that within federal policy context and datasets that came from sources. For housing specifically, there is broad conversations around housing for urban Indians, which include folks who are currently homeless or not. Our work as an organization is centered on chronically homeless folks. However, we know that not everyone was born or hardly anyone is born chronically homeless. One of the key places I look when I'm trying to talk about this work is a place like the National Institute of Health, right, a federally supported organization. And they, when we are looking at housing for native people in urban settings, we really do have to start the conversation around discrimination, and a study by the National Institutes of Health identified, and I quote, widespread high levels of discrimination personally experienced by Native Americans today across many areas of life, regardless of geographic or neighborhood context, end quote. So that study tried to document the prevalence of racial discrimination

against Native Americans across institutional domains such as health care, education, employment, housing, and the criminal justice system, as well as interpersonal experiences that effect health outcomes, including slurs, micro-aggressions, harassment, and violence. So, since we know that there are challenges around discrimination in the housing world and in the health world, for an organization like Chief Seattle Club it is essential that the people we serve, who are chronically homeless urban Indians, don't face that discrimination based on racial or political categories. So, our work is very much centered in, I will also say National Institute of Health also has documented the feelings of discrimination that chronically homeless people have in very similar institutional settings. So, folks are not going to hospitals or traditional housing organizations to get those services. They are finding other social service, such as the Chief Seattle Club and we have only offered housing since January of 2022, that we have been around since 1970. They have come to organizations that can understand their identity, as a native person, as an urban native person, as a chronically homeless urban native person. And for us, we add that other feature of being an adult. We do not do family homelessness, which is a different kind of work. Some of the major concerns we have are that the tools for housing people are, were fairly limited. And a big part of that is there are not, there is not enough funding for the -- to get the total number of units that are needed to get chronically homeless native people off the streets. It takes millions of dollars to open a single building. And so while a building can house 80 people or a 120 people, it takes a lot of time to generate the -- what we call a funding stack of different jurisdictions that will provide the funding to build a building, and then to have culturally responsive services in the building ongoing, because we know that folks who are chronically homeless, it is not just about getting folks off the street into housing, is that they have to, we have to keep folks there. We have to create an environment full of love and full of respect

for their identity, where they want to stay housed. And so, there are major barriers in housing that the whole community faces, but when you compound that with the experience of chronically homeless folks, you end up with a very limited number of providers who can actually address the housing concerns that chronically homeless native people have.

Dr. Stephanie Fryberg: Thank you. Joshua, can we bring you in here on this issue as well?

Josh Drywater: Sure. Again, this is Joshua Drywater with the VCU-RRTC. I think the housing issue much like the health inequity questions, goes back to that holistic mindset that you know often there is several determinants when it comes to issues with housing. One, being, you know, having good employment, having good training for good employment to get into some of the housing. But even the housing that is provided as was mentioned, you know, there is a lot of different things that go into that, including the cultural component as far as the individual being comfortable being in that environment. But you know also having a place where they can openly you know, display their culture, their traditions, have that community. You know, Native American communities in general are often very collective -- have a collective ontology to where their nucleus, their close family, or even the community is very important to the overall decisions that they make and the satisfaction that they see in their lives. So, community definitely is a big component into that. So, you know, with the different determinants that we mentioned with health, inequity, the housing, vocational training, and so it is really that holistic thought that, that there needs to be a focus on a lot of different determinants to really see an improvement in the overall situation or where natives see happiness in life and really what are those measures. You know, often with a lot of federal programming there are the datasets, and I understand the evidence-based practice and the needs for data. But you know a lot of the performance measures aren't necessarily the measures that native communities use to kind of judge or view their

happiness in life from. So, I think that it is, you know, it is important to increase the funding and the access, but there is, it really needs to be approached from many different points of view and many different categories, you know, including the health, including the housing. So a lot of what we are talking about today really all wraps into one overall bundle that needs to be improved and built upon for that success.

Dr. Stephanie Fryberg: Thank you, Joshua. So, let's, let's combine this issue of housing, like strategies to support housing programs with strategies to support vocational programs. So here I'd really like to bring in Irma to talk more about what are those strategies. Like what vocational supports currently exist in tribal communities? And then what are the most significant barriers to vocational programs that you are aware of?

Irma P. Goodwine: Can you hear me?

Dr. Stephanie Fryberg: Yes.

Irma P. Goodwine: So, in Bethel we have what is called Yuut Elitnaurviat. It is a learning, People's Learning Center, where people can come into Bethel for vocational training. That is the only vocational program we have here. But our tribal workforce development recruits individuals from each village to go to college or to go to vocational training either in Seward, Alaska, here, or in --

Dr. Stephanie Fryberg: Okay. I think Irma has froze.

Irma P. Goodwine: -- have limited --

Dr. Stephanie Fryberg: Okay, she is back. Sorry, you froze for a moment, Irma. So we lost probably the last sentence you were saying.

Irma P. Goodwine: Well, the village level, there are almost none -- no resources for vocational training, unless there is online training. But like I said the Internet services are not reliable, so a

lot of people move away to go to college or to go to vocational programs. And the only travel college we have in Alaska is in Iḷisaġvik that was Barrow, Alaska. Not very many people, it is at the top of the world, at the top, the top of Alaska. So, we have limited funds. So, a lot of people cannot afford to go to school. And there is limited places to go to. And a lot of our individuals with disabilities are afraid to leave their communities, so it, in order for them to find employment to vocational programs, they have to leave their communities. And because the unemployment rate out in the villages is so high, some is 90%, the only employment out there is the tribe, the clinic, the school, and maybe the corporation. So, they have to make that choice of leaving home and not returning home because there's no jobs at whatever they are studying in, so they have to make that choice of leaving their home or staying at home. So, there are several programs that assist individuals. There's our tribal workforce development. If they qualify for a vocational rehabilitation program, they qualify for that. They always have that because of the limited funding they have $10,000 left to pay. So, because of the internet connection, they are unable to apply for all these programs because they have deadlines. I don't know if I addressed --

Dr. Stephanie Fryberg: You did. That was very helpful. Thank you. Jolie, I want to bring you in here as well, and the issues when we think about older populations, I think really tie into both housing and vocational concerns. So I want to give you the opportunity to speak to both.

Dr. Jolie Crowder: I lost one EarPod, so hopefully you can hear me. This is Jolie speaking. Yeah, I really appreciate your, you know, pivot to discussions about the needs of older adults in this space. You know, notably, the Alzheimer's funding that I just got in 2021 was the first time Congress had ever allocated funds for the Indian Health Service to do work for older adults. And so, we're trying to do our best to leverage those funds as best we can for all older adults. And I think the same issues that I think people living with dementia faced we know are the similar

issues faced by others, like, you know, increased frailty, falls, the complexity of managing multiple chronic diseases, and the like. I can say what we're seeing in our grants, I think, which is probably the best way to talk about the housing situation is, you know, we know generally that older adults in Tribal communities and everywhere want to age in place, they want to live and die in their own homes. And to the best of our ability, you know, folks who work in aging services, that's really our goal, is to keep people in their homes when we can. In certain populations and certain health status folks aren't able to stay in their homes, and at times there's a spectrum of long-term services and support. Like day care, respite care, you know, assisted living, all the way up through, like, a full-fledged long-term care facility, or what we often think of as nursing homes. And so, there's a lot of gaps in that space of aging in place all the way through long-term care facilities. There are a lot of Tribes who, of their own accord, pay for programs to update seniors' houses that they're living in. So, they might have a program, for instance, that would install grab bars or install ramps. Those are unique to each Tribe, and unless it's, you know, official durable medical equipment and required by the prescription of a doctor, not something necessarily that would be covered by IHS or Medicare funds. But at a certain point, you know, an individual is going to potentially lose the capacity to manage themselves and their care needs at home, or, you know, they have an increase in falls, or they have a lot of meds, and it becomes very hard to manage all of that. So your next options in most places are, you know, assisted living, or some type of facility or communal living. And there is a huge scarcity of those types of facilities in American Indian and Alaskan Native communities. At present, IHS is not authorized to pay for long-term care facilities or many services and supports that would fall in that space. So it would fall to other programs, you know, housing programs, for instance, or, you know, Medicaid funding for certain types of facilities which are really complicated to set

up. And so, if there are, there are some nursing homes and I think we're seeing a small but growing number of other types of home care, communal care-type facilities. There's one grantee who has a foster care program and has built accessible housing on Tribal lands. But I think those are the -- not the norm, and if folks need -- if they really do need the intensity of long-term care or even rehabilitation, they many times are sent many miles and sometimes hours away from their own homes to receive care. So there is a scarcity of facilities, and, you know, this is underpinned, I think, by the issue I brought up earlier -- if you want to bring in a facility, a licensed facility, you also need the staff. So, we go back to those earlier issues that we talked about where if you want to bring in staff or grow your own staff, like, they need -- that's really hard to do. There's a shortage, there is lack of housing for those people and so, you know, I think there are just a myriad of issues. So we're doing, you know, our best work here that we can, with limitations, you know, on the congressional side about what we can and can't do when it comes to aging in place and long-term services and supports. I think a lot of Tribes are doing a lot of great work in this space, and probably are the best ones to hold up as examples because they're choosing to use their funds in that way. There are other programs funded by the federal agency through the Administration for Community Living, Title VI programs or elder services, and those folks also are kind of direct care and services programs with that mission. And so, right now, it's a bit of a patchwork and I think we're not really well-positioned to take care of our existing older adults or the rapid growth that we're going to see in the future.

Dr. Stephanie Fryberg: Thank you, Jolie. I was just thinking as you were speaking, my mom's on Elder Council for our Tribe and so I hear a lot about the issues and, you know, the way you brought up the different access issues, like one that's harder with older populations is that you may be perfectly fine one day and not the next. And yet, accessing many of these resources take

time. And so, you know, we often find that there's a period in our community where an Elder's in serious need of ramps and this, and trying -- you know, but there are others who have been waiting, and so it really gets into a difficult issue of, how do you figure out how to take care of everyone's needs with a limited number of funds? And, I mean, for many of these individuals, it's life or death. Like, this access and having these different bars in place can really mean preventing falls, preventing injury, a longer life, and that independent living that they require. So thank you so much for those comments. Before we move on to talking about the role that federal agencies can play, I just want to circle back to Richard and James to give you the opportunity to also talk about vocational supports. I think, you know, in your communities, these are big issues, and it's important that we not move on without also hearing from your respective communities. Why don't we start with James this time?

James Lovell: Sure. Thank you, Stephanie. This is James Lovell with the Chief Seattle Club and I'd like to remind folks I'm working with chronically homeless Native people in Urban centers or in the Seattle King County area. So, the vast majority of chronically homeless people are not employed, it's almost -- it's nearing 100%. It is one of the major challenges that folks can find short-term employment in doing, like, security at sports events or at concerts, but as a general rule, holding down long-term employment is difficult. What we have found one of the most effective places for chronically homeless Native people to find employment is, is at their -- the providers, even, that are housers, such as Chief Seattle Club, explicitly, with us. There's a skill set that chronically homeless Native people have to identify the conditions that another chronically homeless Native person is living in and therefore some of the -- they are more skilled in identifying strategies to help someone stay housed or to determine whether or not someone is in a healthy state because they've been in the same place. That skill set is very, very, difficult to

teach. And so while many chronically homeless Native people who are now employed with Chief Seattle Club don't have a lot of the concrete skills, such as Microsoft Excel, or Outlook, or -- they may not be challenging Mavis Beacon for the typing title any day soon. They do have a skill set that makes them ideal providers of services when they're fully supported in their employment. For folks who are formally chronically homeless who are now -- who have rejoined the workforce in some way, shape, or form, it is important to have scaffold that supports for them so that the skills that they have are able to be used and displayed to help the community members that they're serving and that the expectations of other skills aren't overloaded in job descriptions or in qualification -- you know, resume qualifications that you have. So, one of the strategies that we have found is helpful for chronically homeless Native people during employment is to eliminate education requirements because even something like a high school diploma, which has those layers of historical trauma and discrimination built into the racial and political group that we work with, we find that even that as a minimum qualification would keep us from employing, honestly, the most skilled and highest-quality potential applicants for the positions that we have. I'll go ahead and stop there.

Dr. Stephanie Fryberg: Thank you, James. Richard?

Richard Peterson: Thank you. You know, as we discuss removing barriers, it's crucial to also focus on the strategies that empower our people, especially those living with disabilities to achieve that self-sufficiency and independence that we all want. At Tlingit & Haida, our Tribal Vocational Rehabilitation program, there's a key component in this effort working in partnership with the State of Alaska, Division of Vocational Rehabilitation, to serve eligible applicants across Southeast Alaska. But one of the most significant barriers to employment for individuals with disabilities is navigating the complex vocational rehabilitation process. So our TVR

counselors are dedicated to guiding clients every step of the way, whether it's identifying the right training programs or helping them overcome challenges. We ensure that they have the support they need to succeed. Because employment's not a one-size-fits-all journey, especially for those with disabilities. So our TVR program is committed to making sure that our clients are referred to employment opportunities that align with their skills, abilities, and strength. And I think this personalized approach increases the likelihood of long-term success and job satisfaction, which are crucial for maintaining the employment. And we recognize that the journey to employment is not just about finding a job, it's about addressing the whole person, and that's why our counselors provide holistic support, including moral guidance and referrals to address, you know, basic needs and education and issues related to alcohol and drugs. And by addressing these factors, we help our clients overcome obstacles that might otherwise derail their paths to independence. Tlingit & Haida maximizes collaboration and interdepartmental partnerships, helping to ensure Tribal citizens have timely access to culturally responsive wrap-around services meeting multiple needs, such as out-patient mental health and substance use services, vocational rehabilitation, education and training, and housing for individuals seeking sober, safe living, for those that were formerly incarcerated. So our partnership with the State of Alaska's Division of Vocational Rehabilitation exemplifies the power of collaboration, and by working together, we are able to pool our resources and expertise through comprehensive services that truly meet the needs of our community members. And this collaborative model is one that can be replicated to enhance vocational programs across other Tribal communities. And I think one of the most beautiful things about our culture is that we make space for everyone. Every person has a role within our community and is important to our community. Differences are not bad, but rather, they're our strength. So in supporting vocational programs like TVR,

we're not just helping individuals with disabilities find jobs, we're helping them reclaim their independence and build a future where they can thrive, helping them find their role in their community. And these strategies are crucial in breaking down the barriers that have historically kept our people from achieving their full potential. It's really about empowerment, self-sufficiency, and ensuring that everyone in our community has the opportunity to succeed.

Dr. Stephanie Fryberg: Thank you, Richard. So, I want -- you know, I had planned to go straight to talking about the role that federal agencies play, but I think I'm going to segue a bit and then come back to it because you really brought up an important issue, Richard, and that's really the role of culture and culturally responsiveness. So when we think about, for example, disability as a construct, that idea differs greatly across cultures. And so, I want to put out to the panel, like, can you help us understand ways to frame disability that we can communicate to our grantees to improve their cultural sensitivity working with Indigenous people with disabilities? And so I'll go ahead -- I know, Richard, you brought this up, but I'm going to actually segue and bring Irma in for a second and let her speak to this issue first.

Irma Goodwine: Can you repeat the question? You were -- you froze.

Dr. Stephanie Fryberg: Oh, I did? Okay, yes.

Irma Goodwine: Yeah.

Dr. Stephanie Fryberg: So when we think about disability as a construct, it differs greatly across cultures, and I'm wondering if you could help us understand ways to frame disability that we can communicate to our grantees to improve their cultural sensitivity working with Indigenous people with disabilities?

Irma Goodwine: So a vocational rehabilitation program like Richard's program, we're exactly alike, and I did not say as much as I should have, like Richard, but I ditto him. So a disability -- hold on -- when it states that -- I took my notes. I'm kind of nervous, but --

Dr. Stephanie Fryberg: You're doing great.

Irma Goodwine: For an individual, you cannot frame a disability. Two people who have the same disability have totally different difference. So there's not enough advocates or representatives for our people. Out in the villages, there are hardly any resources. Like, the lady was talking about the independent living services. The nearest service -- independent living service we have is in Anchorage. I'm part of the Statewide Independent Living Council and we're always dealing with the housing issue. But being culturally sensitive, I think the biggest barrier that we see is actually having SSA provide an advocate or a representative for each of our regions, because language comes up too. There's different languages for each region, and even in my region, I speak Yup'ik, but my neighboring village speaks the same language, but we have totally different dialects and different words, different meanings. So, I think it's critical that SSA employees are trained in that area or at least have their own people in their own region that speak their language, rather than hiring an interpreter, just because they're not necessarily going to understand me. But having the knowledge of our culture, our traditional ways, a lot of people don't perceive an individual with a disability, an individual with a disability. They deal with it in their own way in the community. So, I really do believe that if SSA was to have a representative in each region, that would really help. In Anchorage, they used to have 50 employees at SSA. Now, they're down to 10. So it's really difficult for me. We wear 10 different hats because Bethel, I have to be a job developer, I have to do work with SSA, I have to be a counselor -- I wear so many different hats. I think if SSA would have their own hat -- because I'm having to

train myself to know the ins and outs of SSA and I have people coming in, even though we don't do SSA, we do SSA. So we call in and we have people come in -- even if we have to wait 30 minutes to get their SSI squared away. A lot of people are falling through the cracks because they don't have advocates to call in for them. Even if they have family to call in for them, they don't know the SSA language. So, a lot of them end up falling through the cracks. So those are the barriers that we are really hoping that SSA would help us with. SSA reaches out to the hospitals for an applicant, for example, and I just learned this. So they don't get that medical records from the hospital and there's a limited time, an unrealistic limited time, or a deadline to get those medical records in, and then the SSA counselor does not get that information. So when the time comes for the adjudication, they don't have any information, so therefore they're denied. So, the mailing system in rural Alaska is really slow. I had a check mailed from my village to Bethel, it's like 115 miles away, one plane ride away, I did not get that check until one month later. So, in Metlakatla they just had -- the postal service just made an announcement that it's even going to get more delayed. So the mailing system is just horrible. Making the letters to the individuals simple and not confusing, un-well-educated. So when they do read that letter, it's a little confusing for recommendations on one part and then another recommendation on one part. I'll stop at that.

Dr. Stephanie Fryberg: Okay, thank you so much, Irma. I think we've really reached a point where -- I mean, we have heard so much geography, we've heard poverty, we've heard transportation issues, unemployment, health concerns. And so, I think it is important to ask the question, what role can federal agencies play in mitigating concerns and barriers? And I want to acknowledge here that in many ways, Irma helped us transition there already because she really talked specifically about federal -- I mean, the postal service, you know, just the inability for

them to -- for her communities to meet unrealistic deadlines, right? So really taking into consideration social and cultural barriers to health and well-being. And so, let's really circle back to this idea of what role can federal agencies play in mitigating concerns and barriers? And let's start here with James.

James Lovell: Yeah, thank you very much. This is James Lovell with the Chief Seattle Club. We're a nonprofit serving chronically homeless Native people in the Seattle area. So, one of the things that -- as you listen to the responses from my other panelists, I think what is crystalizing, hopefully, for our audience, is that -- I think Richard even said it earlier, it's about meeting us where we are. And that's going to be very different for Alaska Native villages, or for rural reservations, like my reservation in North Central North Dakota, 10 miles south of the Canadian border and hundreds of miles from anything that would be considered a major metropolitan area. So, for chronically homeless Native people, what federal agencies can -- the role that federal agencies can play in mitigating concerns and barriers is to -- I think it really comes down to identifying people who can serve as the culturally responsive service provider. What we've said earlier, Native people experience discrimination in a wide range of settings at very disparate rates, and this has all been documented by the National Institute of Health, among other very reputable research organizations. We also know that chronically homeless people experience these same issues. So with chronic homelessness, one of the things that we have found -- actually, I was thinking about this with the disability conversation before -- is that, since 100%, or nearly 100% of the chronically homeless people we serve that are -- have a disability. It is not the disability that they think of first when they're looking for a provider; it's that, is this provider going to treat me in a way where they respect my identity as a Native person, enrolled or not enrolled? So they come to social service providers who are Native before they go to health

service providers who can meet the needs of their physical or mental disability. So, it's not just the location that matters, it's the case that Native people will exclusively work with providers who are Native or who are culturally responsive, and this means that many chronically homeless Native people will forego lifesaving medical care or essential services because of the discrimination they report they've experienced from non-Native providers. So how does a federal agency, which can often be seen as the center of this distrust and of the policies that have created the disparities in chronically homeless Urban Indians, how can they address that, is by partnering responsibly with Urban Indian organizations that can become that trusted proxy who -- we can help filter some of the responses. We can help people walk in two worlds, which is one of the phrases I know we've -- I grew up with in our community, is you're a part of the dominant American society, which is often framed as the white world. My Dad's white, and then I'm also part of my mom's world, which is this Native world. And so it can also be framed as code switching. These organizations can help code switch so that the federal organizations are actually meeting the needs of the people because again, it's not just that you have high-quality medical providers or high-quality housing resources. If it's not a Native person or someone who can offer the service in a culturally responsive way, Native people will often -- like I said, forego even lifesaving care because it's not. So, partner with those folks, I think is one of the main roles that a federal agency can play when mitigating the concerns and barriers around really any of the topics we've talked about today.

Dr. Stephanie Fryberg: Thank you. And this is such an important issue that I want to give each of the panelists an opportunity to speak from your perspective. So next, Jolie.

Dr. Jolie Crowder: [no audio]

Dr. Stephanie Fryberg: Jolie, we cannot hear you.

Dr. Jolie Crowder: [no audio]

Dr. Stephanie Fryberg: Jolie, we cannot hear you.

Dr. Jolie Crowder: [no audio]

Dr. Stephanie Fryberg: Okay, Jolie, while we figure that out, let me turn to someone else and then we'll come back to you. Joshua?

Josh Drywater: All right, awesome. And I really think that this is kind of the bread and butter of this whole panel discussion. Again, my name's Josh Drywater with VCU's RRTC. I come today as a Tribal citizen but also someone who has worked in many Tribal communities and lived as part of a Tribal community throughout the Nation. You know, I just first want to say, you know, with Richard and Irma working with the Tribal VR programs that the Tribal VOC rehabilitation programs really can be seen as these best practice models of what works for Tribal communities, specifically their ability to utilize funding for holistic approaches and traditional healing methods. You know, what I will say and I kind of touched on before, was the funding piece. So, with over 500 federally recognized Tribes, there's less than 100 Tribal VR programs throughout the country. So a lot of our Tribal citizens, including those in the urban setting, are getting their vocational rehabilitation services from the state government, which does not allow for funding for those traditional healing and cultural practices or that overall holistic approach. We've also talked about the bureaucracy, a lot of times, with receiving this funding. For example, with the Tribal VR programs, there's limited funding that's offered for all of the Tribes. It's a competitive grant that Tribal VR programs have to reapply for every five years. If a new Tribe wants to bring in their own Tribal VR program, they're essentially creating against other Tribal entities who already have established VR programs. So I think increased funding there. Particularly, I do want to also mention, you know, I think that James kind of hit it right on the head where he says,

"meet the individuals where they're at." You know, as working throughout the Nation with different Tribal communities, they are doing amazing things at small grassroots levels that target the needs of their citizens. The issues tend to be financial sustainability and capacity to operate these programs. And I also wanted to backtrack a little bit to the elder care situation, because one of the best practice models that I have seen work in Tribal communities is, as was mentioned by Irma, I believe, the Tribal citizens don't want to leave their home. They don't want to have to go somewhere else for a job. So what I have seen that works is -- you know, and Irma mentioned it, too -- wearing multiple hats. Your average Tribal vocational rehabilitation program specialist is doing way more than what a standard, let's stay, state VR person is doing. A lot of times, they're doing the job coach, employment specialist role as well. So I've seen where Tribal youth, and with vocational training programs, are starting to, you know, the Tribes are starting to build programs that can lead their citizens into these career pathways where they're the ones who are providing the services to their other Tribal citizens. And James mentioned that too. You know, Natives want to be -- to receive service from other Natives. So I think that one thing that we should take into consideration would be, you know, as far as the outreach and the work with SSI and SSDI, is having those individuals who live within the community trained to take on those roles and responsibilities to help their Tribal citizens get access to those services. You know, I've traveled and worked with a lot of different Tribal communities, and I've still yet to really find a traditional Native word for disability. It's often seen as, this individual needs more assistance here, just as I need more assistance in another way. So that understanding and that collective ontology approach is really what differs in the Tribal communities as far as coming together to accomplish a mission, even if that means extending the reach of what would be traditionally your job description. And then, you know, further, I just wanted to mention, too, with the employment

networks and the Ticket to Work program with SSA, you know, it's a close to 90-page application process for a Tribe, which becomes very cumbersome, especially with a lot of the bureaucratic asks of the federal government of these Tribes to really explain how they want to provide services to their individuals, needs to fit into this model of what the agency is looking for. So I think that's just kind of me circling back a little bit on some other topics, but really, you know, introducing the idea, really, is that the Tribal communities know what's best for their citizens, and they are doing these grassroot programs.

Dr. Jolie Crowder: Testing.

Josh Drywater: So being able to really center funding and strategic help in those directions to help them build the long-term sustainability of those programs, to me, is the solution in all this. So I'll leave it at that.

Dr. Stephanie Fryberg: Great. Thank you. Thank you, Joshua. Okay, let's try Jolie again.

Dr. Jolie Crowder: Can you hear me now?

Dr. Stephanie Fryberg: Yes, we can.

Dr. Jolie Crowder: Yay! So apparently, it's not --

Dr. Stephanie Fryberg: Yay!

Dr. Jolie Crowder: -- only Alaska that has connection issues. So, so sorry about that. Everything froze and then exploded. So -- and I'm sorry, I didn't get to hear the others because I got kicked off, but I think I kind of have a checklist. I was like, bam bam bam, like -- this is Jolie from IHS. I am not myself American Indian or Alaska Native but have worked with the community for 12 years. So I would frame, sort of, my comments based on my perspective as someone who's been an advocate and ally and spent years trying to connect with and work with communities. So maybe sitting in the shoes of many folks who work at this agency. You know,

our Alzheimer's program mission focuses on -- and I think this reflects the last speaker -- supporting and strengthening the communities that we're working with. And that means the long haul, not a drop-in once a year sort of approach, but creating those relationships. And instead of doing it ourselves. So our job is to help build capacity so they can take on the work. You know, we've had a couple great comments about centering and recognizing culture in the community. I really appreciated the comment earlier about first looking for strengths and assets. Who are the connectors? Who are the people in the community, either in organizations or, I think, Elder Councils, I think you brought that up, that there are lay folks in the community who could be very powerful in these situations. If -- you know, I don't know how in the SSA world, how -- like, sort of approaches, but what we find on the health care side is there are a lot of mainstream models, or interventions, or approaches, and we have consistently found those don't work in Tribal communities. And so, you have to start from scratch, and you have to build those approaches with the communities as well. So if there's a program that works great in Washington, D.C., I think you need to consider whether you can adapt, but possibly go back to the drawing board. Just sort of a chop list of bullets. Go to the communities and be present and available and consistent. I always try to work hard to be humble and open. I try to listen more than talk, but I'm obviously not very successful. I think it's really important to recognize if you've worked with one Tribal community and program, you've only worked with that one community. You can't assume that they're a monolith and it crosses communities. We place a heavy emphasis in, I would say, in my work as well, is prioritizing relationship building and exploring new and different ways of supporting Tribal capacity building. This goes back to the meet them where they are. And in our work, that includes supporting folks both pre-award and post-award for, like, our funding and grant opportunities. So I think the types of technical assistance that we

provide here need to be more open and supportive in addition to, like, the pre-award piece. You know, kind of systematically, I'm not sure if you all offer grants in this space, but I would say Tribal and Urban communities do best when the field of competition for grants are their own counterparts, and we're not trying to pick Tribes and compete against other, you know, universities or larger communities. So, set aside funding specific to Tribes, Tribal organizations, or Urban Indians is our practice here. I'd say in Indian health settings in particular, keep in mind the serious workforce shortages, and there's a lot of competing crises. And so, I think that health systems can be a great resource. They touch a lot of people and a lot of patients through their community health programs and in the clinics. But there's a lot of people who want their help reaching folks, so. I think when you're talking about the resources and putting hands and consumers of people are in the community, there's an overwhelming amount of information that exists. There's so many websites. There's so many fact sheets and so many toolkits. So if you're thinking about creating something, make sure it doesn't already exist. Make sure what you package is really simple, digestible, and easy to read. I mean, that really speaks to, I think, sort of plain language and literacy levels. And then for consumer outreach materials, I would say field test everything. Don't create it in a vacuum. Have some folks look at it. Go into the communities, paying specific attention to both health literacy, and, you know, kind of from our perspective, like, what you're reading but also the reading level. So, I think that's my little chop list there. Thank you.

Dr. Stephanie Fryberg: Great. Thank you so much, Jolie. Irma.

Irma Goodwine: Like Jolie said, I think permanent funding for vocational rehabilitation programs is one. We have 93 vocational rehabilitation programs throughout the Nation, and when our fifth year comes up, those who are up for refunding, we do compete with other

programs, whereas the State of Alaska Division of Voc Rehab does not have to compete. They get permanent funding. So having that permanency would really help. We have a nationwide consortium of American Native Administration Rehabilitation that may be a liaison to SSA, but when you want to become a little bit more remote, State of Alaska has 11 programs, 11 vocational rehabilitation programs, and we do have a consortium that meets yearly. So if we could be a point of contact or something, or a Tribal liaison to SSA, you would cover pretty much the whole Alaska -- all the regions. Because we all have our own way of providing services, culturally. So I really do believe having a liaison and having permanency. Because if we do not get this program, I'm up for refunding in 2026. I mean, our program's been running for about 25 years. So if I don't get this -- if I don't get refunded, then that's it. So those services are cut, and then our people with disabilities are left with State of Alaska Division of Voc Rehab, which their offices are in Anchorage. So, geographically, it -- a lot of people have trauma history with State of Alaska as well as federal. So a lot of people don't want to deal with someone in Anchorage. Whereas they would rather work with us, where we speak their language and we know how it is to live in the community where there's no running water, no road system. So I think those are pretty much important. The housing system, as well. I was going to talk a little bit about our housing situation. We do have another agency under Association of Village Council Presidents Regional Housing Authority that deals with 29 villages, I believe. And their resources are limited as well, so not -- there's people applying for housing, but then only a few would get for each, like for Tununak, there's going to be six houses built within the next year. So under our agency, we do have a housing improvement program. And I just learned this last week, that over 700 individuals have applied for a housing improvement program to build a house, to build the house. Only two will be -- they will only help two households in our whole region. And it has

something to do with the federal regulations. We do have assisted living homes here, a nursing home, but the wait list is so long. AVCP Regional Housing Authority runs two apartment complexes for seniors and people with disabilities that are SSI recipients, but that list is so long that they send people to Seward, Alaska, or to Anchorage, Alaska. We do so much independent living services. But like I said, the Access Alaska, in Anchorage, Alaska, that's our independent living services, which is 400 miles away. And we were talking 50 villages who need ramps, home mods to keep them at home. But the services mainly do not get there. So they end up living with their relatives, who are tired. There's no personal care assistance. We used to have, through the health care system here, home care services. But that ran out of funding. So they looked to outside home care services, direct services in the Mat-Su, or in Anchorage. They now have Safe Care -- I believe they're called Safe Care. But they have employees that are out of region, which means that they have no understanding of our cultural values. I'll leave it at that.

Dr. Stephanie Fryberg: Okay, thank you so much, Irma. I want to note here, we want to open it for discussion, but I really want to give Richard the opportunity to say anything that has not been mentioned. You know, we've kind of run over on this part, but this is just such an important topic to hear everyone's responses.

Richard Peterson: Yeah. Gunalchéesh hó hó for that. I agree. I think it has been said, but if I could encapsulate it, you know, our motto here at Tlingit & Haida is, meet our citizens where they're at. And I think that's true of, like, our federal partners and grantors. Sometimes they need to come and see. They need to touch, feel, hear, and experience, right?

Dr. Stephanie Fryberg: Yes.

Richard Peterson: And I can say, not trying to be political, but under this administration, we've seen more secretaries or undersecretaries here for the first time ever, and it's paid huge dividends.

And we do that with our grantors and philanthropic partners as well. Once they see kind of the burden of what it is -- you know, in our villages, we're asked to fill out forms, and they don't understand that we usually, in a lot of our villages, only get mail once a week, and that's weather-dependent. And in the wintertime, like, my home village, you could go three weeks without mail. And they don't -- they can't even comprehend that. And then they'll say, fax it. Well, most people don't have fax machines. And they have to go -- and then they're asked to pay, you know, for the mail, certified, this and that. Some of our citizens can't even afford that.

Dr. Stephanie Fryberg: Yes.

Richard Peterson: So those kind of barriers, you really have to see firsthand to really truly understand. I grew up in a village you could only get to by boat or floatplane. And you explain that to somebody who's sitting in Maryland or Virginia or D.C., you know, they don't get it. To them, rural is a very different concept. And so, I think it's important when they touch down here to see that. And lastly, I just want to say something that I was thinking about earlier. We started our own behavioral health department to really work, because of the inequities in that area. And our motto is "culture heals." And the reason why -- we had an esteemed Elder, Dr. Walter Soboleff, who lived to 104. And he always started his speeches, "When we know who we are, we don't harm ourselves." And that's really that touch to our cultural identity, knowing who we are, who we come from, and, you know, you have to address the traumas to do that. So I wanted to put that out there with something earlier that I think is just imperative to who we are and the work we're doing, and getting our partners to understand why our culture is so important. We're a living, thriving culture. We're evolving. You know, oftentimes people talk about our culture in some past tense, where it's, you know, talking about, you know, the Trail of Tears, or

romanticizing what our culture is. And, you know, we're still here. We're still thriving. And we still are trying to live our way of life. So, gunalchéesh hó hó.

Dr. Stephanie Fryberg: Thank you, Richard. Thank you to all the panelists today for your time and this great discussion. I'm sure we could continue this discussion all afternoon. We -- the plan at this point was to open up the conversation for questions. I want to side note here that this is a two-part panel. So we won't get to many questions today. The time is limited. I'm going to put up -- pull up one question to get us started, but we do have a hard stop. And so, we promise to make sure that we go through all of the questions and that we work hard to address them in Part Two of this series. So the question that I will bring up here is, do you have strategies for connecting members of Tribal communities with individuals who can help with filling Social Security or SSI applications? And I think I will start here with, um, -- one second, one second -- with Jolie.

Dr. Jolie Crowder: Thank you so much. I think, you know, as I was thinking about this response, a couple of approaches came to mind. The Affordable Care Act, they did a really nice job in funding, like, creating a model where they funded Tribal and Urban Indian health centers, and others, lots of CBOs out there, to train up their staff and then offer, like, benefits enrollment. I think they may still do that. But I think the other that comes to mind is the Administration for Community Living also funds Medicare benefits enrollment centers. Again, they're giving money to the community to build the capacity to be able to do this work, and I think as an approach, that may be the best strategy. Like, to find the local people in the community and recognize their time and pay them and fund them to help provide these services. Practically speaking, I think either of those, the people who serve in those roles for the ACA or benefits enrollment centers in the clinics, could potentially also serve as a mechanism. And I think they do. A lot of folks need SSDI to be able to get on Medicaid. So there's a lot of stuff that's already

happening in that space. But I really think it's more about the approach of providing funding for CBOs and Tribes and people in the community. And then I'd say, you know, bottom line -- and I feel like if there's nothing that folks take away, I feel like I've heard this a lot -- but, like, you've got it get out there into the communities to serve the people where they're at. Like, the whole fax machine -- I don't even have a fax machine, right? But, like, this belief that we can sit behind four walls and really impact the people and get at the equity issues of people in greatest need just doesn't work. Like, we have to get into communities. We are trying to do the same thing. And so that would be, I'd say, you know, a suggestion and challenge. Thank you.

Dr. Stephanie Fryberg: Great. Another question: What efforts are made, and through which organizations, to advise Native people of services? And so, here to get two different perspectives, James, if you are open to it, I'd love to segue to you, and then to Irma.

James Lovell: Yeah. One of the approaches we use as -- again, this is James Lovell. I'm with the Chief Seattle Club. We're an Urban Indian, chronically homeless -- well, providing services for Urban Indian chronically homeless folks. We have a day center, which is open from 7:00 to 2:00 every day. And this is -- I'm not advertising it as much as using it as a demonstration of one of the ways we meet the needs of folks who are still on the streets, since there are not enough shelter beds and there are not enough housing units, is we have a day center open every day. The vast majority of the staff at the day center are Chief Seattle Club Staff who provide culturally responsive care, and as an organization, we have 156 employees, and 85% of the employees are American Indian, Alaska Native. One of the folks we have here is a contracted partner with DSHS, Department of Social and Health Services, who comes to our day center a few times a week and is in the basement in our day center -- so right where the members, the folks who are currently homeless, can come, and actually get DSHS benefits signed up. And so, it's an example

of a best practice, when I was talking earlier about going where the people are, for chronically homeless people, this means going into places that are tip -- either you're in places that are not fit for human habilitation, or you're going to transitional shelters and day centers. So finding partners in Urban centers who -- actually, many Tribal communities have day shelters and overnight shelters, as well. Those are optimal places to build partnerships -- not to force one's way in, but to begin building a partnership so that Social Security signup is available where the people are likely to come. Because individuals who are experiencing homelessness can be hard to find on the street if you don't know what you're doing. And I think a lot of times, the government is not well-suited in locating the people who have highest need for SSA signups. So go to the places where they're already congregating, sometimes, which is going to be day centers, transitional shelters.

Dr. Stephanie Fryberg: Great. Irma, do you have anything you'd like to add?

Irma Goodwine: I would recommend working with the already existing departments or programs. To start with our program -- or it could be under the benefits division. They're already working on processing applications for social services, for TANF, for general assistance, energy assistance, LIHEAP, and then there's the other State Division of Public Assistance, who refer a lot of their individuals to the medical social worker at the hospital. So there's three different agencies that SSA can likely work with that already exist. I know the medical social worker has already worked with some of our consumers to try to get that application done. I do believe Division of Public Assistance should step up as well, because they know all of these people who have disabilities, and our agency would be a good fit as well. Because we already work with our people out in the 56 Tribes.

Dr. Stephanie Fryberg: Great. Thank you, Irma. So, thank you to James, Jolie, Joshua, Irma, and Richard for your valuable time and the feedback you provided to assist Social Security in strengthening their disability program. I trust everyone joining us today found it both beneficial and informative. I want to thank Social Security for the invitation and for allowing me to moderate this important panel. I will also be moderating Part Two on November 13th, and I look forward to continuing this conversation. Now let me turn it over to Renee Ferguson, Director for the Office of Native American Partnerships.

Renee Ferguson: Thanks, Dr. Fryberg. We do apologize. We had some audio technical difficulties early on with the Commissioner's video, so those who joined by phone were not able to hear the Commissioner. The recording will be available in a few weeks so you can hear directly from the Commissioner. Thank you, Dr. Fryberg. It was amazing. And all the expert panelists today. This was truly an excellent discussion. In closing, our panelists leave guidance for SSA to please recognize that in our business processes, that there are so many barriers and a lack of Tribal Nations staff and resources, geographic, numerous barriers, too many to name, compounded with the fact that SSA has a lack of staff resources and have been unable to fill some of our losses in our own staffing losses. These barriers only make the situation worse for Tribal Nations and the complexity of our processes for SSDI and SSI applications. Their desire to help their people, in addition to the difficulty of grant processes, becoming a successful grantee, there could be opportunities that SSA could look for under the Executive Order 14112 to try to find some flexibilities. We learned more challenges for Tribal workforce development, vocational resources, lack of employment opportunities, compounded by the housing barriers. Our panelists shared who they may be collaborating with. This is something we can take back, whether they're collaborating with state or local community. But now, where can we encourage

collaboration with SSA, with our offices who administer the Ticket to Work program, building that partnerships, for example, recruiting Tribal entities to become employment networks, and position to reengage with Tribal vocational rehabilitation programs. There are a number of strategies we can help Tribal Nations with increased access to Social Security's employment and self-sufficiency initiatives. So save the date. Register when registration is open for the November 13th Part Two. We are going to dig into solutions. Think about what opportunities SSA can provide that may address any of these significant barriers. So join us for Part Two. SSA leadership will be considering what approaches and solutions could be designed to address the barriers that were discussed today, whether that's funding or access, and those are only parts of the solution. So as I close, a special thanks to all of you who participated, for our participants for taking the time to listen to the guidance and advice so you can bring those forward for consideration in your own offices or components. And with that, we gave some instructions at the beginning of today's session. If you have questions following today's meeting, you can reach us at NationalDisabilityForum@SSA.gov. Thanks again for joining and we hope to see you next time. Please stay safe and enjoy the rest of your day.

James Edrington: This concludes the Social Security Administration's National Disability Forum on Removing Barriers to Accessing Services in Tribal Communities, Part One. Thank you for joining us today. Stay safe and have a wonderful day. We ask all our panelists and Renee to stay on and -- as we remove everyone else from the meeting.

Dr. Jolie Crowder: While you guys are wrapping up, unfortunately I have to jump for a call with one of our grantees. So, thank you so much for the opportunity, and if there's any feedback, which I always welcome, please shoot it my way. You guys have a great day. I appreciate you.

Speaker: Thank you so much for everything.

Dr. Stephanie Fryberg: Nice to meet you, Jolie.

Renee Ferguson: We appreciate the collaboration, Jolie. Thank you.

Dr. Jolie Crowder: You guys have a great day.

James Edrington: Thank you so much, Jolie. We really appreciate it.

Dr. Jolie Crowder: Yeah.