Preventing Congenital Syphilis in Tribal Communities

Glenna Davis: Hello, everyone, and welcome to the Preventing Congenital Syphilis in Tribal Communities webcast. It is my pleasure to turn the floor over to our Head Start Deputy Director, Captain Tala Hooban. Captain Hooban, the floor is yours.

Captain Tala Hooban: Thank you, Glenna. Thank you, everyone, for coming and welcome. I know this was a short notice, but we're really glad you're here. My name is Tala Hooban. As Glenna mentioned, I'm the Deputy Director for the Office of Head Start. Today, we're talking about childhood as a whole. We're here to talk about a really important topic that is impacting many communities, but especially tribal communities. Today, we're talking about congenital syphilis in tribal communities.

I have invited some amazing colleagues to join in this webinar and share their expertise, and I'm hoping to hear from you about this topic as well. Just to talk about our speakers. It's me. You won't hear from me much, quite honestly, leaving it to the professionals. I hope you also have someone from the Centers for Disease Control and Prevention, Dr. Kevin O'Callaghan, Lieutenant Shawnell Damon from Indian Health Service, Maternal and Child Health, and Dr. Meg Sullivan with the Office of the Secretary.

Just to give a quick overview, we're going to talk about agenda again. We're talking early childhood programs as a whole, and I'll touch base about what I mean by that. Genital syphilis as, what it is, why we're talking about it, epidemiology, which is just how many cases are out there. Prevention and education and how we can use early childhood, our resources as early childhood professionals on to help with prevention, and then some resources at the end, just to quickly go over.

These are the three programs when we're talking early childhood education. These are the three I'm specifically talking about, the ones under the Administration for Children and Families. We're talking Head Start, Child Care and Development Funds, Office of Child Care, Tribal Maternal Infant and Early Childhood Home Visiting, Tribal, the Tribal Home Visiting Program, and we have individuals on the phone on the webinar that also, have that expertise and can answer questions if necessary. And with that, I am going to turn it over to Dr. O'Callaghan.

Dr. Kevin O'Callaghan: Thanks, Captain Hooban, and thank you for having me. I'm going to talk a little bit, about syphilis in general, and then some of the national and some more regional and local epidemiology across the United States of how syphilis is spread. This epidemic of syphilis and congenital syphilis sort of has occurred and how it's impacting, American Indian, Alaskan Native, and tribal communities, at rates that are concerningly worse, than the national average. First question, is what is syphilis and congenital syphilis? Syphilis is a bacterial sexually transmitted infection. That can cause serious health problems without treatment and infections with syphilis tend to be lifelong if they remain undiagnosed and untreated. However, syphilis is one of the more difficult sexually transmitted infections to diagnose.

It's often silent, and for large periods of infection, many persons with syphilis remain asymptomatic. Most persons with syphilis are symptomatic during their primary and secondary stage. Primary and secondary stages, which occur somewhere between about 10 days, and about six to nine months after their, after their first inoculation.

Congenital syphilis is when syphilis in a pregnant person. Is transmitted to the fetus or infant during the pregnancy or around the time of delivery. As Lieutenant Damon will detail later, there's some serious health consequences related to congenital syphilis. But the most important thing I think to know about congenital syphilis is that we consider it to be close to 100% preventable.

With timely testing and adequate treatment in pregnancy, most, if not all, pregnant persons with syphilis can be treated successfully, and we can prevent transmission of syphilis to their newborn and infant. We consider this to be what we call a fentanyl public health event when any single case happens, because every single case is preventable.

Next slide. Talking a little bit about the syphilis epidemic in this country. We actually came relatively close across the country to what we call syphilis elimination in the late 90s to early 2000s for a variety of different reasons. Concerted public health effort, federal, state, and local funding, high use of condoms, for example.

But over the last 24 years or so, we've seen some significant improvements. steadily increasing rates of syphilis in adults, and we're seeing the knock-on effects of that now in terms of rising rates of congenital syphilis in newborns born to pregnant persons with syphilis. This is an iniquitous disease. There are a number of inequities and disparities around the syphilis epidemic in this country, and it's disparately impactful on persons reporting American Indian and Alaska Native heritage and tribal communities.

We see here on the right the rates of those early stages, of syphilis that I mentioned, which are rising faster in persons of, American Indian and Alaska Native heritage compared to other communities. You see that rising rates, in the rates in white non-Hispanic and Asian non-Hispanic communities remain relatively flat, whereas they're steep rises in Black and African American non-Hispanic communities, and especially in American Indian Alaska Native communities.

In addition to rising rates of the sexually transmitted syphilis in adults, we're obviously seeing this follow-on effect of congenital syphilis in newborns. As rates have been rising over the last 20 to 25 years of syphilis, and particularly the highly infectious early stages of syphilis, what we call primary and secondary, we see this follow-on effect of rising rates of it in newborns.

Here in this graph, we see this black line, which is the primary and secondary syphilis rates in women aged 15 to 44, what we usually classify as what we call a reproductive age, or really an age at which you're likely to become pregnant. We see it basically a complete mirroring in the rise of case counts of congenital syphilis in the blue.

We've had a 1000% increase in cases of congenital syphilis in the United States in the last 10 years, rising from 335 cases in 2013 to 3, 755 cases in 2022. And that trend really sort of continuing unimpeded. Next slide. These rates really, as I mentioned, are disparately impacting minoritized communities and especially American Indian and Alaska Native communities. This shows sort of that disparate impact. The bulk of cases of congenital syphilis that we see here in the left-hand numbers, we see that most cases of congenital syphilis in 2022 occurred in persons who reported Black or African American heritage at 1,122 cases. Or Hispanic Latino at, 1,099 cases, and white at 1,034 cases.

But when we compared that to the size of these populations as a whole across the United States, the race in American Indian and Alaskan Native communities far outstrips those, of other race and ethnic communities. Even though there were, quote-unquote, only 171 cases of American Indian, Alaskan Native congenital syphilis.

The rate in AI and communities is far higher than it should be given their relative size. I think this was best laid out in the numbers on the right-hand side, which is how many cases we're seeing per live births. What this tells us is if we look all the way down at the bottom for every about nine and a half thousand, infants that are born to Asian non-Hispanic mothers, only one of them in 2022 had congenital syphilis.

Compare that to one out of 806 Hispanic or Latino infants, and then one in 155 American Indian or Alaska Native infants, which means that for every 155 pregnancies that resulted in a live birth in tribal communities and AIAN populations in 2022. One of them had congenital syphilis, which is a strikingly high rate, and a strikingly high case count, given the size of the community. And I think really bears underscoring and underlining. This is a highly iniquitous disease that is really desperately impacting, American Indian and Alaska Native communities. Next slide.

Why are we talking about CS? We're talking about CS because this is a national ongoing epidemic. There's a quote here on the right from, from Health and Human Services Secretary Xavier Becerra. The top line, I think, is really the most impactful. The syphilis crisis in our country is unacceptable. Each and every case of congenital syphilis is a federal public health event. It is entirely preventable, and this is a national crisis. And why are we talking about it in tribal communities? Well, as I hope I've underlined and underscored, CS case counts and case rates are on the rise across the country, but this is a disparately iniquitous disease.

This is affecting communities inequitably, and it is affecting AIAN communities and Black non-Hispanic communities at much higher and much worse rates than other communities. And again, I just want to re-underline this. For every 155 American Indian or Alaska Native births in 2022, there was one congenital syphilis case. I think this is probably the most striking and the most abhorrent statistic that we're able to offer and show on this crisis. I think it just underscores how much of a problem there is and how much we need to do and work on. At this point, I'll hand it over to Lieutenant Damon to talk about some of the health impacts of congenital syphilis.

Lieutenant Shawnell Damon: Thank you very much, Dr. O'Callaghan. Syphilis does profoundly affect our babies. And because when people are diagnosed with syphilis, when they are pregnant or when they give birth, it depends on whether they have access to prenatal care. We really encourage mothers to attain prenatal care. We definitely want to get the mothers in to be tested because we at the Indian Health Service test three times during pregnancy to prevent any of these impacts. If we do not treat for syphilis, the impacts are of course the loss of the baby. The baby could be stillborn or dead. born too soon or too early where the lungs are really tiny and the baby can barely breathe low birth weight, that means the organs have not fully developed and that's shortly after birth.

We really want to make sure that we are, encouraging mothers of all ages to come in. It's usually moms who are not really taking care of themselves. They may be living on the streets, or they may be taking drugs. Also, we've seen mothers who've had a lot of children. So, they're like we know how this works. We've had given birth to like three babies and now this is my four child and then they come and have the baby thinking that they're pretty much safe. And then we've had one, definitely still born to a person who just chose not to come in for prenatal care.

We're really encouraging, our people. We're really wanting to make sure we're testing more. We do test when they come into the clinic. Again, our high-risk mothers may not be coming in because they're afraid they might take away their babies. Or test positive for drugs or alcohol. These are the impacts that we have on the reservation and we have to actually go and find our moms and bring them back to our clinics or treat them out in the field. And we've been able to do that. We want to really make sure we're encouraging, prenatal care and, pre and testing throughout the pregnancy. Next slide, please.

Babies that are born with congenital syphilis they may have deformed bones, they might have low blood count of like certain vitamins that really keep our blood and our — are we're able to like clot. Those are some of the things that we might not have when you have a baby, they'll have severe anemia, they'll have an enlarged liver or spleen, their eyes may be yellow and they may have to be underneath these lights.

So that they can get their belly ribbon going and then brain and nerve problems. We do see blindness and deafness in babies who have not been treated during prenatal. And again, like Dr. O'Connell, Dr. O'Callaghan had said, this is all preventable. We definitely have the medication to treat these babies before they're born. We want to make sure that we're treating the moms and the babies. Babies who do not get, treatment for congenital syphilis are, can also develop symptoms later and then die from the infection. Definitely has a big impact. It can have a profound impact on a baby, especially if they are not accessing prenatal care again, or treatments for congenital syphilis.

We do have the medication to treat that's why it's really important to speak about congenital syphilis. It's really important that we get the word out there that this is in our communities. It's really important to test, and it's really important to talk about it. Next slide please.
As the Indian Health Service, we're really working hard to increase testing. We really want to find the people who may have syphilis, treat them, and their partners. You may see us in the

community, we do chem biotesting at tribal fairs, rodeos, jails. Street medicine. Like I said, we have a lot of people who are living on the streets, and we also have it on our Indian health service. If you feel like you might have been exposed, you can come straight to pharmacy or straight to clinic and get tested without having to go through all the special, intakes or without even having an appointment. We really wanted to make sure we have avenues for testing, to make sure that we make it across Indian country.

We also want to promote, I want the test, which you can get at home and also be tested at, and you can come back to an Indian health service or to clinic and receive treatment. Next slide, please. We definitely want to treat for syphilis. We want to find our moms who are out that are, haven't come in yet. We want to go to their homes and test them and treat them for syphilis. We also want to administer the treatment there in the community. We do direct observation therapy for people who are homelessness, substance abuse disorders, people who are incarcerated.

A lot of times we don't have transportation because where we live in the community is so far from a clinic, and we want to make sure we're out there in the clinic. We do have community health representatives and PHNs, working to get this medication out to our communities and really treating people and testing people right there. We have this chem bio where we can get tested right there in the community and then make sure they get their injections. We also have to make sure where we're at, that we have cell service. Just in case there's some kind of reaction, we want to make sure we're able to call in and get help if we need, but definitely these are some of the barriers that we have across, Indian country.

We are definitely reiterating the testing part and I can go back and go back over that. Another thing to really treat people, we're using incentive-based testing. We really want to make sure that people have — if they come in or they want to be tested, we should provide some kind of incentive.

A lot of times that's hard to work because people don't have money to get back to their house, or they might not have lunch to get back to where they're coming from. Incentives have been a really nice, work or work around for us. And we as a federal agency really can't give those out, but we've been working with our partners. We work with the Portland Indian Health Board and they're able to provide those to us and we provide them to our patients, courtesy of the health board, next slide, please. And then I can swing back to testing. Also, we want to make sure we're talking about this in the community.

We have culturally tailored public health messaging to where we are speaking to our. Tribal entities at their level. We want to make sure that grandmas, even though they might not be susceptible of getting syphilis, but they know that their grandchildren can. We don't want to just target just the lower or the younger people. We want to target everyone. We've been reaching out via radio, newspaper, social media. We're working and hopefully get some native influencers to help spread the word about being tested about protecting oneself. And then we've been working with community health workers in the community to make sure that they're helping us find patients and get treated right then and there.

We are also making the availability of condoms throughout our clinics. Restrooms and one of the best practices been at one of our trading posts, in between our clinics and like the community. And then also having them available at community events, having the testing available, having condoms available and constantly like communicating the need to prevent syphilis. If you can swing back to testing, Glenna, I think it's two slides before. The one way to really get a hold our epidemic is to increase testing. This will allow us to see and treat people who may not know that they have syphilis. We want to make sure that we're continuously testing.

You can come to an Indian health service and ask for an STI bundle without an appointment. You can get seen and leave the clinic right after that. You don't have to stay around. A lot of times we are. In the community with our community health representatives at tribal fairs and rodeos, making sure that we are testing people, at the jails, this was another one where we have a partnership with our tribal police, the detox centers.

A lot of times people are coming out to now know their status. We want to make sure that they know their status. And then street medicine. Like I mentioned a lot of times when we have congenital splice, it's because people are not coming into the clinic. These people don't want to see us at the Indian Health Service and they're not accessing care. We try to go out and find them. We have street medicine where we have, again, like the ChemBio where we have people Tested right then and there, and then we're able to treat right then and there. And then again, the home test kit is kind of like a joint partnership with Johns Hopkins University and Indian Health Service.

This allows you to get the STI kit that tests for chlamydia gonorrhea syphilis. And then there's also an HIV test. Depending on where the person lives and accesses this test, it will be sent back to a kind of like a corresponding Indian health service and to the person so that they can go back in and either get treatment. This is one of the biggest things that we do is fill treatment and, making sure that we're preventing by spreading public health messaging, the way to protect ourselves. Thank you for that. I think I covered all my slides.

Captain Hooban: Thank you Lieutenant Damon. Thank you. Dr. Sullivan.

Dr. Meg Sullivan: Great. Thank you so much. And, good afternoon, everyone. I am just going to cover a couple of things. First, I will say a big thank you to my colleagues, Dr. O'Callaghan, and Lieutenant Damon, who really hit the key messages. In these couple of slides, just going to focus on really the take-home points, definitely repeating a couple of those key messages, and then talking about what early childhood workers and staff can do.

I think key messages that we should be taking the take-home messages from today is that unfortunately, the rates of syphilis and congenital syphilis are way too high. And in particular, our American Indian and Alaskan Native communities are being particularly hard hit. Syphilis is treatable, especially, and it is really important to get tested.

If you're going to remember a message, if you're sexually active, getting tested is important. Anybody who is sexually active or even considering becoming sexually active should be having open and honest conversations with their healthcare provider to learn about testing,

to get access to testing, and to do it, on a regular basis. Specifically, when we talk about congenital syphilis, congenital syphilis is incredibly preventable and treatable if caught early. These are really messages that we want to make sure that everybody is aware of. The first is really reducing the risk of getting syphilis before and during pregnancy, by avoiding high-risk behaviors and using condoms.

As we've heard getting, over and over getting tested, regularly in accordance with guidelines. For individuals who are pregnant, early access to prenatal care is so incredibly important, and there are very specific guidelines around testing for syphilis, again, because congenital syphilis is preventable and treatable when caught early. It is important to access prenatal care early. Getting tested the first time that a pregnant person is seen at a health care provider during pregnancy and then there are specific guidelines about routine testing in the third trimester as well as at birth again to be able to catch these cases and prevent them.

In addition, management of partners, again, making sure that testing and treatment is happening, as applicable to prevent secondary infections during pregnancy is incredibly important as well. Next slide. And then, yep, specific. Just want to spend 1 slide talking about the role of early childhood programs and prevention. Thank you to all of you for joining. I think just having awareness. about the rates of syphilis and congenital syphilis. We're seeing the communities that are particularly hard hit and just these basic messages is so incredibly important.

An early childhood staff who work with pregnant people and families that already have young children and may become pregnant have such an important role here. I think just first and foremost, encouraging and supporting early access to prenatal care. This is so important for so many reasons. I think this webinar is just one example of why early access to prenatal care is important, but I know that early childhood staff can play such an important role there.

More specifically, when we are talking about congenital syphilis, I think just raising awareness, sharing information about it, just that it is out there, that how to prevent it, that it is treatable if caught early, and the importance of testing is so important to be able to talk with families that you are working with. As well as connecting families to screening and testing services. We heard directly from Lieutenant Damon about so many services that the Indian health service provides. We know that public health departments, other community health centers provide resources as well. And I think just making sure that families have access to those is so important.

And then again, for any individual that does test positive for syphilis or has a child that tests positive, really encouraging and, and facilitating access to early, treatment is so important here. And so really just want to thank everyone. I know that early childhood staff work with families in so many different ways. This is just the one example of where sharing information, facilitating access to healthcare, and facilitating access to treatment can be so important. And with that, I'll turn it back to you.

Captain Hooban: Thank you. Thank you to all of our speakers today. I wanted to highlight a couple of resources that came out of — out of some actually the speakers in their offices. There is this Northwest Portland area Indian Health Board. I think Lieutenant Damon mentioned actually, while she was speaking, but there's actual social media campaign materials that have a lot of information. They have posters, they have slides, stickers. They have postcards, flags, billboards. They really have the whole nine in there.

A lot of what you, the art that you saw in here was actually from there. That might be helpful resources. Some of the references we use for syphilis also and congenital syphilis and where, what about it. Those are clickable links too. And again, thank you for joining us. We have an email address. If you have any questions specific to this presentation, but otherwise per usual, if you're in The Office of Head Start, continue working with your regional office with any questions and raising anything up, and your TA providers.

For other early childhood programs, we do the same, but if you want something specific to this presentation, always feel free to email this address and you will talk to a real human. Thank you again for joining. Really appreciate the speakers. Thank you. I know this was short notice, but it's an important topic. Wanted to catch as many of you before break as possible. We'll post this later. Have a great day, everyone.