

On-screen: *Data Equity = Health Equity* by Sarah Wondmeneh, MD, MPH, Katie Labgold, PhD, MPH, Jessica Penney, MD, MS, MPHTM EIS 2022. April 23, 2024 Sarah Luna Memorial Ted-Style Talk Session 2024 Epidemic Intelligence Service Conference. CDC logo on bottom right.

SARAH WONDMEHNEH: Who has the right to access public health data?

JESSICA PENNEY: How does the CDC uphold structural barriers to data equity for tribes and tribal public health authorities?

KATIE LABGOLD: And what can we do as CDC to be better allies and working toward data equity?

SARAH WONDMEHNEH: These are questions that we wrestled with as officers were investigating a syphilis outbreak among tribal communities in the Great Plains region.

JESSICA PENNEY: So back in July of 2023, ten CDC staff, including ourselves, deployed to South Dakota to assist the Great Plains Tribal Leaders Health Board.

South Dakota had seen a dramatic increase in syphilis cases since 2020, with over 80% of these cases occurring among those identifying as American Indian or Alaskan natives.

KATIE LABGOLD: The mission of the Health board, including the tribal epicenter is to protect the health of the 18 federally recognized tribes and their tribal communities in four of the Great Plains states: North Dakota, South Dakota, Nebraska and Iowa. They have been doing community screening events and building these mass media campaigns to build awareness around this issue, and they wanted to do more.

SARAH WONDMEHEH: And though they had the institutional will and they had buy-in from tribal leadership, they were running into one major issue. They had to respond to an outbreak without the data that would best inform that work.

KATIE LABGOLD: Although those negotiations were in progress, at the time of our deployment, the Health

Board did not have data sharing agreements in place with other public health authorities in the region, for example, the state health departments and the Indian Health Service.

JESSICA PENNEY: But meanwhile, staff at the Health Board were acutely aware of the profound effect this epidemic was having on members of their community. They had heard about the man who presented with neurologic changes from a syphilitic infection who had presented to the emergency department multiple times but had been overlooked.

KATIE LABGOLD: Or the young woman whose infant died from congenital syphilis, in part because the prenatal testing and treatment facility was too far away.

JESSICA PENNEY: Yeah, over 100 miles away.

SARAH WONDMEHEH: So when we started to work on this investigation, the anger and fear and frustration from the Health board was palpable. Syphilis is

preventable, syphilis is curable, something needs to change.

KATIE LABGOLD: So our team on the Health Board started planning. But we needed the right data to guide our investigation.

JESSICA PENNE: But what is the right data? So to understand that, we have to think through how data is used to respond to a syphilis outbreak.

KATIE LABGOLD: In a syphilis outbreak, there are three key steps to stopping transmission. First, testing to identify persons with syphilis, second, treating those persons, and third, because syphilis is a sexually transmitted infection, we also need to identify those sexual partners that are in need of testing and treatment.

JESSICA PENNEY: But as many of us know, our healthcare system is often fragmented. So tracking this comprehensive person-level testing and treatment data across facilities is complicated.

SARAH WONDMENEH: Yeah. For example, a tribal member may seek care at an Indian Health Service facility, a tribally run clinic, a private hospital, or a public health clinic.

JESSICA PENNEY: And to further complicate this picture, these facilities might not have a shared electronic health record. So tracking this information between facilities feels next to impossible.

KATIE LABGOLD: But there's hope. Laboratories are mandated to report positive syphilis lab results to either the local or state health department, so this data does eventually become centralized.

SARAH WONDMENEH: And that's important because that data are then used by case investigators at state or local health departments to ensure that people with syphilis and their partners are appropriately tested and treated.

JESSICA PENNEY: And the data is also used on a population level to inform programmatic decision makings and address any potential gaps in prevention and control methods exactly.

KATIE LABGOLD: Exactly. A data-driven approach to public health action. In fact, in our investigation, we needed that person-level data to both guide those on the ground activities and understand the outbreak from a population level.

SARAH WONDMENEH: So, on July 9th of 2023, our team deployed to South Dakota to assist the Health Board in their investigation of the syphilis outbreak, knowing that they did not yet have all of the data that they needed for the response.

KATIE LABGOLD: And four days later, we had an epiphany about our responsibility as CDC responders in these conversations of data access that ultimately changed the course of this investigation.

SARAH WONDMENEH: So let's get back into that moment.

SARAH WONDMENEH: All right, team, time to check in. Katie, Jess, it sounded like there's something we need to talk about.

JESSICA PENNEY: Yeah, so, I was chatting with the Health Board leadership today and they shared that some of our state partners are expressing concerns about sharing the person level data with the tribal epicenter and are instead proposing to share that data only with the CDC staff for analysis.

KATIE LABGOLD: Sounds like that would still allow us to accomplish our EPI-AID [phonetic] objectives.

JESSICA PENNEY: Yeah, but the tribal epicenter isn't OK with us having access to the data unless they have equal access as well.

SARAH WONDMENEH: Can they have access to that level of data?

JESSICA PENNEY: Yes, tribes and tribal public health authorities have legal public health authority, so they have the implied power to exchange data with state, local, or federal jurisdictions for the purpose of the public health.

KATIE LABGOLD: On the flip side, I could understand why the states would still be cautious about sharing identifiable data because they do have a responsibility to protect the data they collect.

JESSICA PENNEY: Yeah, but protecting the data doesn't have to interfere with public health authority. If a data use agreement is needed to share data across jurisdictions, then we should be partnering with tribes and tribal public health authorities to ensure they have access to all the data, identifiable or not.

SARAH WONDMEHEH: I mean, don't they also need access to that data to inform their control activity?

KATIE LABGOLD: I agree with that moving forward, but right now the Health Board does not have the staff to perform case investigation services. That's all being done by the states. Maybe de-identified person-level or even aggregated data is still enough to accomplish the EPI-AID objectives.

JESSICA PENNEY: Yeah, but the tribal epicenter hasn't built that workforce capacity in part because they haven't had access to the data, they're in this vicious cycle where they want to try to identify workforce needs, but they can't without access to all of the data needed to do so. So that access needs to start now, not later.

SARAH WONDMEHEH: I mean, it does sound like we're bringing in some of our own biases because we're just more used to working with state and local and federal partners.

KATIE LABGOLD: I mean, yeah, now that we're talking about it, it does seem like this could be a more widespread issue.

SARAH WONDMEHEH: Actually, do you remember at the beginning of the, when we were planning this, there was some questions about the authority of the Health Board from a couple CDC offices for example, like, could they even request an EPI-AID?

JESSICA PENNEY: Yeah, and that's just one example. I'm sure there's all these other potential biases or maybe just misunderstandings that we haven't touched on or maybe even recognized.

KATIE LABGOLD: OK, but what about for this specific issue about this EPI-AID? Sure, the Tribal Health Board does have the authority to be sharing data with the states, so, maybe we should just let them work out this data sharing issue directly with the states.

JESSICA PENNEY: Yeah, but doesn't taking a passive approach implicitly uphold the status quo? We're

equal partners in this investigation, so as such,
it's our responsibility to advocate for tribal data
equity.

KATIE LABGOLD: What would that look like?

JESSICA PENNEY: That's a good question.

SARAH WONDMEHEH: OK. How about if we communicate to all of
our partners that we recognize their public health
authority equally and that we're going to work hand-
in-hand with the tribal epicenter and health board as
we would in any other investigation?

KATIE LABGOLD: Yeah.

JESSICA PENNEY: Sounds good to me.

SARAH WONDMEHEH: All right, let's go talk to the rest of
the team.

JESSICA PENNEY: Alright, so what happened after this late
night discussion in South Dakota?

KATIE LABGOLD: Well, we assisted in negotiating data sharing between the Tribal Health Board, state partners and CDC, which ultimately allowed us to accomplish all the goals of our EPI-AID.

JESSICA PENNEY: And this EPI-AID and also provided the unique opportunities to see firsthand the challenges faced by tribal public health authorities, as well as the profound effect this epidemic was having on members of their community.

SARAH WONDMENEH: And it also served as a reminder that tribes and other tribal public health authorities are often excluded from our public health systems.

KATIE LABGOLD: This talk focused on data sharing, but data equity goes way beyond data access alone.

SARAH WONDMENEH: So how can we, as CDC, be better allies to our tribal partners?

KATIE LABGOLD: Well, first we can build our institutional knowledge. Throughout this EPI-AID, CDC staff, including ourselves and those in multiple offices, were unaware of the Health Board's public health authority. Education is needed at all levels. That could take the form of structured trainings. For example, an EIS [phonetic] summer course or unique standalone talks, like this TED Talk.

SARAH WONDMEHEH: The second thing that we can do is to be active in our support of capacity building among tribes and other tribal public health authorities. For example, during our EPI-AID, we identified a need and the Health Board expressed a desire to build tribal case investigation capacity. CDC has supported capacity building among other jurisdictions such as local and state health departments for years. And now we have an opportunity to uplift our tribal partners as they now work to strengthen and build their public health infrastructure.

JESSICA PENNEY: And third, we can improve CDC data sharing. So this EPI-AID prompted several

conversations about how we often exclude tribes in our own data sharing practices. So, tribes and tribal public health authorities need to be key partners in the CDC data modernization efforts if we're going to be able to effectively respond to public health threats.

KATIE LABGOLD: These are only a few examples. The reality is, is that these health inequities are continuing to worsen and more work is needed if we are going to meaningfully support tribes and other tribal public health authorities.

JESSICA PENNEY: After all, without data equity, there is no health equity.

(Applause)

On-screen text: CDC Logo (in the center). 2024 Epidemic Intelligence Service Conference