# A Tapestry: The Story of Community Engagement to Decrease Syphilis in Two American Indian Communities

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NACCHO[SM]
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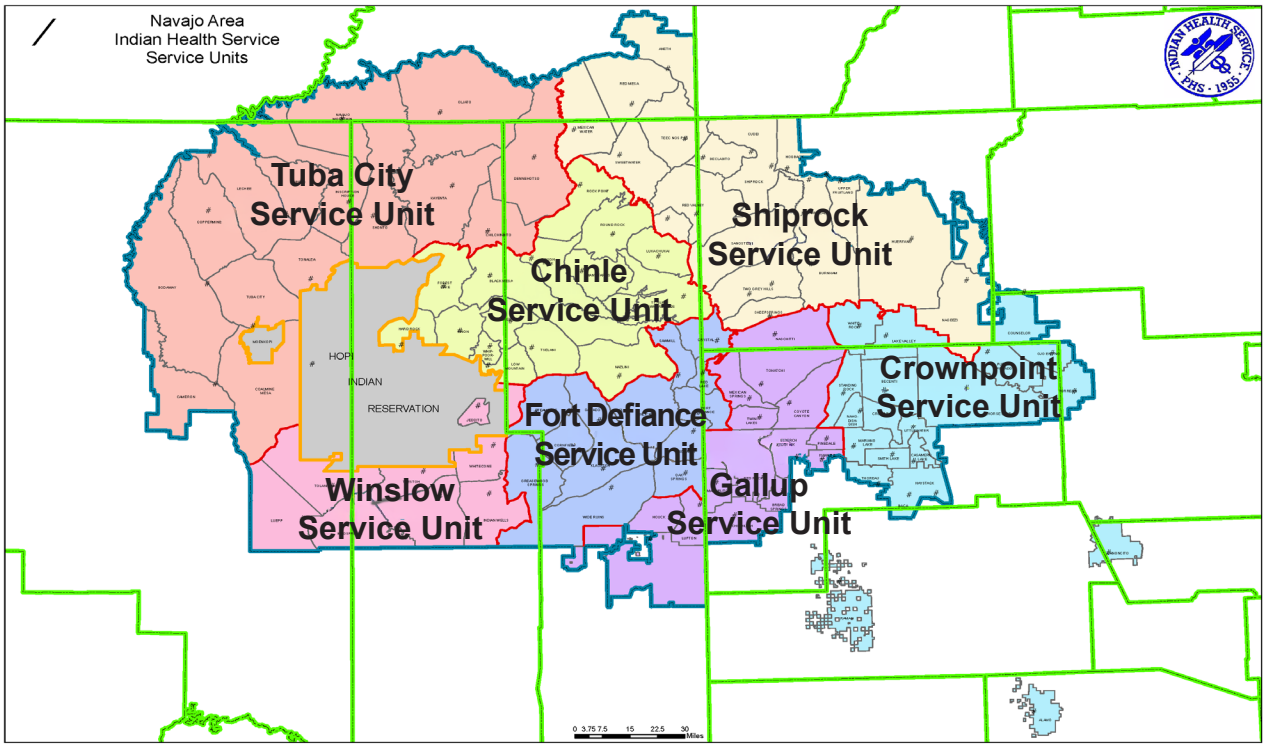
## Background

Addressing public health challenges in American Indian/Alaska Native (AI/AN) communities requires a grounding in historical and social context and a community engagement process that honors and respects the community's culture and traditions. This involves weaving together a tapestry of diverse voices from the community expressing their needs and priorities and is especially valuable in AI communities which are disproportionately affected by sexually transmitted infections (STIs), specifically syphilis and congenital syphilis.

Nationally, non-Hispanic AI/AN men and women report the highest rates of primary and secondary syphilis, with rates of 63.6 and 52.9 cases per 100,000, respectively[1]. From 2016-2022, the largest increases in maternal syphilis occurred for AI/AN mothers. In 2023, the rate of congenital syphilis was the highest among these communities, reaching 680.8 cases per 100,000 live births[2]. On the Navajo Nation reservation, the number of syphilis cases tripled from 2019 to 2021, increasing from 232 to 700 among Diné, or "The People."[3]

## Case Study Sites

The two sites featured in this case study are Indian Health Service (IHS) 638 facilities[4] that serve the Navajo Nation in Arizona. Their stories, which are based on interviews with their staff, highlight the intentional approach they took to community engagement. This community engagement was conducted to facilitate the development of community-informed plans to reduce syphilis.



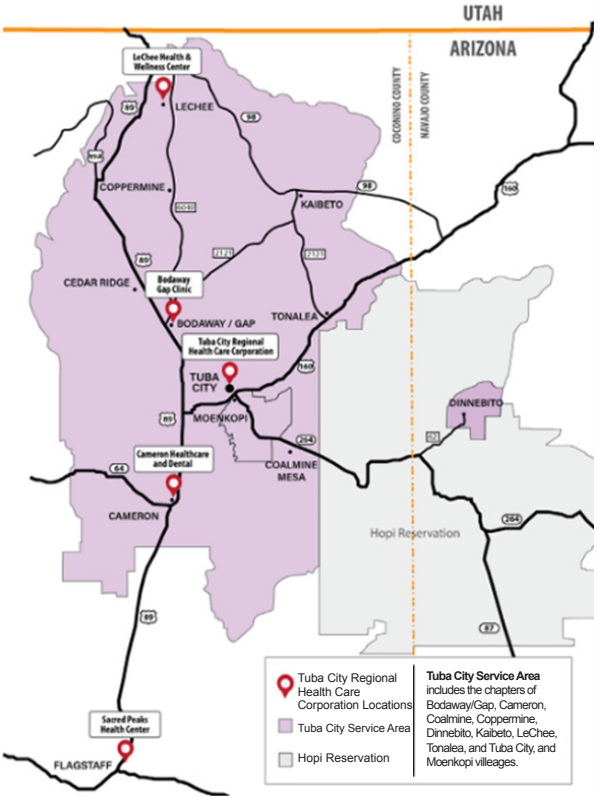

Navajo Nation covers more than 27,000 square miles that touch Arizona, New Mexico, and Utah and is larger than 10 US states.
Navajo Nation includes 5 IHS Service Units which provide health services to a population of over 250,000.
Source: Navajo Nation Addressing Authority website

**Tuba City Regional Health Care Corporation (TCRHCC)** is a community-based tribal health organization and provides services to over 7,000 square miles. The service area is very sparsely populated with an average of 3.2 people per square mile. Some individuals must travel significant distances on dirt roads to reach health care. The service area includes 36,000 individuals but the organization serves up to 100,000 individuals from surrounding Navajo and Hopi communities. TCRHCC's mission is to "provide safe, accessible, quality and culturally sensitive healthcare."

The Tuba City Service Area experienced a staggering 500% increase in new syphilis cases from 2019 to 2021, and the Navajo Nation overall had a 300% increase. In 2022, there was an additional 48% increase in syphilis cases. In that same year, women of childbearing age accounted for 54% of new syphilis cases which was a significant shift from before when it was largely found in men who have sex with men.[5] There were also 16 infants delivered or identified that were exposed to syphilis in the womb (congenital syphilis). And two resulting in fetal demise.[6]

TCRHCC is the only place for STI testing within a 75-mile radius. With their rising cases, TCRHCC increased their testing and treatment options to include home visits and field treatment, but they recognized that primary prevention efforts were needed. To ensure their efforts were culturally responsive and effective, they used three approaches to gain community voices in planning and implementing activities:

1. Established a Community Advisory Board (CAB)
2. Hosted Conversation Cafés, and
3. Offered key informant interviews




Source: Tuba City Regional Health Care Corporation website

To recruit for the CAB, TCRHCC reached out directly to community members via email asking them to participate. The CAB served as a critical part of the community engagement process by providing feedback on cultural appropriateness and reviewing interview questions to ensure that the community's voice was central to the engagement objectives. The consistent involvement of 6 to 8 CAB members demonstrated a strong local investment in this initiative, creating a more receptive environment for public health messaging.

Building on the CAB activities, TCRHCC launched "Conversation Cafés" to facilitate discussion with the community about sexual health. Each session was deliberately limited to 8-10 participants to create a platform for more intimate and focused conversations. To consistently engage community members, incentives and meals were provided to participants. Participants, predominantly women aged 30 to 50, discussed their knowledge of syphilis and STIs. These discussions revealed significant gaps in knowledge and underscored the urgent need for comprehensive sexual health education.

> ***All we see are condoms in jars, but not information.***
> - Community participant

Because of under-engagement in planned one-on-one conversations in person, TCRHCC pivoted to inviting interested individuals to arrange private phone conversations or complete anonymous questionnaires. This flexible approach allowed individuals to engage in discussions more comfortably, reducing the pressure that often accompanies group settings. Those conversations focused on individual's experiences with STI testing so there was no requirement that people identify as having had a prior STI. Conversations included questions about where individuals had been tested and what they liked or did not like about the experience, including even the process of making an appointment.

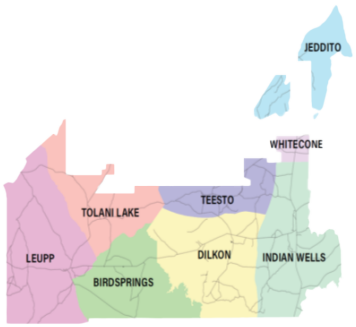
The engagement activities identified several community priorities for syphilis reduction moving forward. They included an effort to "normalize" sexual health and STI care, increased sexual health education, and a sexual health campaign to raise awareness about STIs in the community because as one participant said, "you see all the information about syphilis in the hospital, but nothing in the community." Highlights of the action steps identified in the syphilis reduction plan to address these priorities were:

- Providers, nurses and other health professionals, including community health professionals, talk about STIs and the connection to overall as part of regular routine health care services.
- Sexual health education taught in schools with an in-depth curriculum taught as is age and culturally appropriate and with more information "sprinkled throughout each year as children grow."
- Develop visually appealing and appropriate sexual health education material for the community and disperse them widely.

**The Winslow Indian Health Care Center (WIHCC)** serves about 18,000 individuals in the southwestern rural communities of the Navajo Nation reservation, covering 2,418 square miles including Birdsprings, Dilkon, Indian Wells, Leupp, Teesto, Tolani Lake, Jeddito, and White Cone., These communities face infrastructure challenges such as food instability and a lack of water access, electricity, and transportation. These factors hinder prioritization of STIs in the community.

Syphilis cases increased from 12 in 2020 to 26 in 2022. Additionally, the number of congenital syphilis (CS) cases increased from 0 in 2020 to 4 in 2021 though fortunately decreased to 2 in 2022. In 2022, the number of males and females testing positive for syphilis was equal.

The WIHCC focused their efforts on engaging Navajo adults on matters of sexual health and well-being. They recognized that it is taboo to discuss anything sexual, so they did not want to start with a focus on STIs and syphilis. To make a significant impact, they knew they needed to create activities that resonated with the community within their service unit, but they also recognized that there were community members that moved around the Navajo Nation, and even between Arizona and New Mexico. WIHCC's community engagement activities consisted of establishing a community core group (like a CAB), designing a questionnaire to assess community needs, and conducting focus groups to explore specific sexual health topics more deeply.




MAP OF WIHCC SERVICE AAREA DISTRICT 5&7
(EXCLUDES BORDERTOWNS)

Source: Winslow Indian Health Care Center website

Key to WIHCC's success was the use of incentives. Offering gift cards for groceries or gas acknowledge an understanding of the competing priorities of the community. Providing these items showed respect for the needs of the individuals that they wanted to engage. Despite initial challenges engaging individuals in the community core group to guide the development of the community engagement activities, attendance significantly increased over the course of WIHCC's activities and with the introduction of incentives to promote attendance. They also hosted two inaugural sexual health fairs —a new endeavor for their healthcare facility. Each sexual health fair attracted at least 75 community members and served as a central hub for education, with community partners actively participating.

Very similar to Tuba City, in Winslow there were many identified barriers to STI testing, treatment, and case management but especially community knowledge about STIs. As a result, many of the same steps were prioritized in the syphilis reduction plan.

The next steps for WIHCC and their communities are:

1. Increase the education level of community members on STIs including trends, transmission, testing, and treatment,
2. Address concerns for confidentiality surrounding accessing care at WIHCC, especially around STIs,
3. Ensure cultural sensitivity when offering STI services for effective communication of risks and stigma reduction,
4. Make services more patient-centered to ensure that patients feel positively about their experience.

## What Did the Sites Learn?

A deep well of Indigenous knowledge exists in these communities, which can serve as a valuable resource for educating and promoting community healing practices. This knowledge can help bridge generations from elders to youth. Through community engagement rooted in respect of Indigenous practices and the strengths and history of the community, the development of syphilis reduction plans can promote sexual health while respecting cultural beliefs and customs.

Training staff in community engagement principles, data collection methods, and trauma-informed care approaches was essential for effectively addressing participants' needs. To accomplish this, the sites participated in two training sessions offered by NACCHO and CDC staff. These sessions focused on community engagement principles, including indigenous elements that the AI community uses, and turning data into actionable information. For more, see *The Indigenous HIV/AIDS Syndemic Strategy: Weaving Together the National HIV, STI, and Viral Hepatitis Plans*.

### Observing and Preserving Confidentiality

Both sites initially experienced a lack of public engagement, which they attributed to participants' fear and discomfort related to the stigma around the traditional taboo of discussing topics of sexual health, which can be magnified by interacting with site staff who may also belong to their close-knit communities.
To overcome this, the sites relied on anonymous questionnaires and private one-on-one conversations to create a space of confidentiality and comfort.

### Community Customs and Approaches

Respecting and honoring indigenous cultural norms for the community engagement activities was essential. Participants stressed the significance of integrating traditional Indigenous values and practices into health education and approaching awareness campaigns with sensitivity and understanding, focusing on health from a community perspective rather than an individual one.

The sites aimed to eliminate barriers to participation. They used materials that aligned with the language needs of the community, providing materials, questionnaires, and radio ads or news reports, in the preferred languages of the tribes. Participants emphasized the need for sensitive, culturally informed approaches when discussing sexual health. Food was also provided at all events—both because it was something

that community members needed but also because it aligned with the community's cultural "norms" of welcoming, shared meals. Sites also considered that community members preferred gender-specific materials and responded more positively when the sexual health educator was of the same gender.

### Meeting People Where They Are

It was essential that the language used was appropriate to the community. Sites learned to make sure not to use "public health" language and instead framed activities around the concept: "Put yourself in a patient's shoes and tell us how you would want to receive services. Tell us what we can do better to serve you." Sites emphasized that it was important to remember that what works for some communities may not work for all settings. For example, if there is no wi-fi in a community, word of mouth, community health representatives, and the radio must be used to spread the word about events or focus groups.

They also expressed the need to provide education to all parts of the community on sexual health topics because culturally this was not a topic that had been discussed at home or in schools.

### Tailored Use of Incentives

Participants in all community engagement activities were offered popular promotional items, including Stanley drinking cups, insulated tumblers, and tickets to the Western Navajo Fair. The team learned the importance of understanding the participants' interests and motivations, recognizing that a one-size-fits-all approach is not effective.

## Conclusion

Throughout this journey, interactions between community members and health facilities deepened, creating a tapestry of voices where each participant's feedback was woven into the fabric of the syphilis reduction plan and for sexual health programming.

Addressing sexual health may not be the most pressing concern for many in the community, compared to fulfilling other needs. Factors such as poverty, transportation issues, and housing instability present significant challenges affecting health outcomes. Approximately thirty percent of the Navajo Nation lacks access to clean, running water,[7] which forces individuals to travel long distances to transport water , while housing instability and lack of employment opportunities mean that many frequently relocate between reservations and nearby cities like Phoenix. Addressing the rise of syphilis cannot be achieved solely by focusing on sexual health and instead must center awareness of these overall community needs. As a result, the syphilis reduction plans developed from the community engagement were expansive and looked through a syndemic[8] lens, to account for multiple factors surrounding and impacting STIs, specifically for syphilis. For more information see, *"Our Relatives Go Everywhere" Key Learnings and Recommendations from the American Indian (AI) and Alaska Native (AN) Sexual Health Convening.*

Despite their unique challenges, these sites demonstrated a deep desire to engage with their communities. In addition to providing a way forward for the community to address syphilis, investments in community engagement allowed the sites to normalize conversations about sexual health and reinforce the idea that seeking care is a pathway to collective healing, balance, and harmony rather than a source of shame. As relationships blossomed, barriers diminished, and a community emerged that was more educated, engaged, and empowered.

## References


1. Table 14. Primary and Secondary Syphilis — Reported Cases by Race/Hispanic Ethnicity, Age Group, and Sex, United States | STI Statistics | CDC
2. Table 6. Congenital Syphilis — Reported Cases and Rates of Reported Cases* by Year of Birth and Race/Hispanic Ethnicity of Birth Parent, United States | STI Statistics | CDC
3. Dine is translated as "the people" and is how Navajo refer to themselves. https://navajowotd.com/word/dineh/
4. Tribal health centers are outpatient health care programs and facilities that specialize in caring for American Indians and Alaska natives and are operated by Tribes or Tribal organizations under the Indian Self-Determination Act. https://www.ihs.gov/odsct/title1/
5. Tuba City Regional Health Care Corporation (2024). 2024 Community Health Assessment and Needs Survey.
6. *Id.*
7. https://nndwr.navajo-nsn.gov/
8. Syndemics and the biosocial conception of health - PubMed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