National Indian Health Board

September 5, 2024

Rachel Levine, M.D.
Assistant Secretary for Health
Office of the Assistant Secretary for Health
Washington, DC, 20201

RE: Tribal Consultation on the Syphilis and Congenital Syphilis Outbreak among Tribal citizens

Dear Assistant Secretary Levine,

On behalf of the National Indian Health Board (NIHB) and the 574 federally recognized American Indian and Alaska Native (AI/AN) Tribes we serve, we submit the following recommendations on the syphilis and congenital syphilis outbreak among Tribal citizens. We urge the U.S. Department of Health and Human Services (HHS) to swiftly respond to the syphilis and congenital syphilis outbreak by urging the Secretary to declare this crisis a public health emergency and investing federal resources within Tribal and IHS clinics.

NIHB is a 501(c)3, not-for-profit, national Tribal organization founded by the Tribes in 1972 to serve as the unified, national voice for AI/AN health. Our Board of Directors is comprised of distinguished and highly respected Tribal leaders whom the Tribes elect in each of the twelve Indian Health Service (IHS) regions. Since 1972, NIHB has advised the U.S. Congress, IHS, and other federal agencies under HHS about health disparities and service issues experienced in Indian Country. These disparities are exacerbated by pervasive inaccessibility of health services, chronic underfunding of the Indian health system, and high provider shortages within IHS, Tribal, and urban Indian (I/T/U) clinics and hospitals. As a result, AI/AN communities face higher disease morbidity and mortality rates and lower life expectancy and quality of life.

The syphilis and congenital syphilis outbreak within AI/AN populations demonstrates the limited federal resources invested in Tribal health facilities and public health infrastructures to respond to public health emergencies. According to the Great Plains Tribal Epidemiology Center, syphilis rates among AI/AN individuals in the Great Plains skyrocketed by 1,865% from 2020 to 2022, which is ten times greater than the national increase of 154%.[1] The same report found that one in every forty AI/AN babies born in 2022 were diagnosed with congenital syphilis, constituting 2.5% of all AI/AN births. HHS must release immediate and effective solutions to mitigate the effects of this outbreak.

Priorities for Addressing Syphilis and Congenital Syphilis

To combat the growing syphilis crisis, we request HHS prioritize deploying a capable workforce to Tribal

[1] Great Plains Tribal Health. (February 2024). Tribal Leaders Urge HHS Secretary to Declare Syphilis Emergency. Retrieved from: https://www.greatplainstribalhealth.org/news/tribal-leaders-urge-hhs-secretary-to-declare-syphilis-emergency-189.html.

and IHS clinics, immediately release HHS data to Tribal health programs and Tribal Epidemiology Centers (TECs), and allocate emergency resources and funding to Tribal and IHS clinics. These efforts were undertaken during the COVID-19 pandemic to prevent, prepare, and respond to the disproportionate rates of COVID-19 infection and related deaths within AI/AN populations and must *again* be taken to reduce the effects of syphilis and prevent any more infant deaths.

1. Workforce. During COVID-19 and the Mpox outbreak, U.S. Public Health Service Commission Corp (PHSC) members were increased within Tribal and IHS clinics to increase accessibility to screening, testing, and vaccines. As a previous successful model, it must be replicated to address the syphilis and congenital syphilis emergency. The Great Plains Area has requested 50 personnel for the PHSC to support syphilis and congenital syphilis outreach, diagnosis, and treatment, and increased prenatal/postnatal care support. HHS should review previous personnel placements during COVID-19 and consult with Tribes in every HHS Regional Area to determine the appropriate number of additional PHSC to be placed within Tribal and IHS clinics.

2. Data Access. HHS must prioritize Tribal health programs and TECs data access requests to the IHS Resource and Patient Management System (RPMS), Nationally Notifiable Disease Surveillance System (NNDSS), and the Centers for Disease Control and Prevention (CDC) STI Surveillance data. Immediate access to RPMS is necessary to monitor outbreaks in local communities, and the expertise of TECs can analyze the data on the number of tests and treatments administered. Streamlined access to RPMS was achieved during COVID-19 and was essential to monitoring outbreaks to deploy prevention and response efforts. In addition to more timely access to IHS data, improved access to CDC data is also necessary. While the *CDC's Public Health Datasets and Access Guide for Tribes and TECs* was a step forward, TECs continue to experience rejections and delays to data requests that hinder their ability to report out culturally appropriate data for AI/AN populations. This has stunted TECs' ability to report out updated syphilis and congenital syphilis rates in their regional area and efforts to release culturally appropriate public health campaigns. The Secretary should also make an announcement encouraging states to formalize data sharing agreements with Tribes and TECs related to the syphilis and congenital syphilis outbreak to ensure Tribes and TECs have access to saturated data to conduct meaningful evaluation and analysis. These data efforts during COVID-19 improved data reported on AI/AN populations, but it took intentional efforts by HHS and its divisions to enact this level of partnership with Tribes and TECs.

3. Resources. To increase resources available to Tribes and IHS clinics, we request Tribal access to the IHS National Supply Service Center (NSSC) for supplies and reemphasize the need for the Secretary to declare this outbreak a public health emergency that will grant Tribal access to the Strategic National Stockpile (SNS) for syphilis treatment. Additionally, HHS should determine which emergency supplies and funding are available to support syphilis response, treatment efforts, and monitoring of cases in adults and children. Tribal access to the NSSC and SNS was instrumental in responding to COVID-19 and will again be instrumental to respond to this outbreak disproportionately harming AI/AN populations.

HHS Implementation Efforts to Reduce the Cases of Syphilis and Congenital Syphilis
HHS's largest role must be to supply Tribal and IHS clinics with appropriate resources to respond to local outbreaks, including both workforce/contact tracing support and medical supply support. HHS's investments in deploying a robust PHSC workforce to Tribal and IHS clinics and ensuring Tribal and IHS

clinics access to Federal emergency resources will allow Tribal clinics to deliver continuity of care to screen, test, and treat individuals. As some individuals do not pick up their medications, it is necessary for clinics to have a robust workforce that can follow up and track down individuals in need of treatment. In addition, there is a need for increased rapid testing in IHS facilities, as recommended in recent guidance from IHS headquarters. Rapid testing is an essential tool for getting the epidemic under control but remains underutilized in many IHS facilities, particularly in the Great Plains Area. We urge IHS headquarters to take steps to ensure compliance at the facility level.

HHS must also communicate with their internal staff on the urgency of responding to Tribal and TEC data access requests related to syphilis. HHS should devise an internal procedure with staff who interact with Tribes and TECs to respond swiftly to data access requests and to provide technical support when a data access request is rejected. Internal staff should also receive training on Tribal data sovereignty and how to interact with Tribal health programs and TECs when providing additional support when a data access request is rejected.

HHS should also provide additional financial investment in TECs to monitor the long-term effects of congenital syphilis in each regional area. Unlike state and local health departments which receive substantial block grant funding from the Centers for Disease Control and Prevention for disease surveillance work, Tribal nations and TECs are chronically under-resourced. The small amount of base funding TECs receive is not enough to keep up with daily disease surveillance, let alone respond to a public health emergency of this nature.

As requested above, we urge HHS to declare this crisis a public health emergency and identify funding sources available to allocate to Tribes for responding to local outbreaks. Similar to COVID-19 supplemental funding, funding for this crisis should be made flexible allowing Tribes to spend the money as necessary to address the crisis in their communities. During the OASH Tribal Consultation, Tribes expressed various concerns including funding for equipment, public health campaigns, staffing, and public health infrastructure to create additional screening rooms or pop-up testing locations. As Tribes are aware of their unique needs, HHS must identify funding, resources, and programming available to Tribes, IHS, and TECs to implement their own action plans. If funding resources at HHS are not available, the Department should work with the Office of Management and Budget to request emergency supplemental funding from Congress. CDC recently requested supplemental funding for the FY 2025 Continuing Resolution to support respiratory disease intervention and surveillance. We encourage HHS to do the same with this crisis.

Successful Models and Innovations for Reducing Rates of Syphilis and Congenital Syphilis
Indian Country has responded to this crisis through outreach, clinical operations, and public health campaigns. However, this multi-pronged approach needs additional resources and investments to be expanded across Tribal and IHS clinics.

To ensure the public has been informed of local outbreaks, some clinics are tabling at events to share hand outs and information about syphilis and safe sex practices. Other clinics have been utilizing their trusted messengers like Public Health Nurses and Community Health Representatives (CHRs) to educate patients about the disease, symptoms, and treatment. CHRs are also critical for contract tracing and case investigation to contain an outbreak. Investments in existing Tribal infrastructures can enhance effective local community efforts for prevention, response, and treatment. However, it is critical that CHRs -which

are most often Tribally operated programs – be given the necessary clinical records by IHS-operated facilities so that they can do this necessary work and ensure continuity of care. It is also critical that IHS and HHS provide the necessary financial support to achieve this vital work.

Several Tribal and IHS Clinics have implemented policies and standing procedures for addressing the syphilis and congenital syphilis outbreak. Some IHS and Tribal clinics have implemented universal screening for pregnant patients, patients enrolled in behavioral health services, and other at-risk populations but they often lack the personnel and testing equipment to conduct these services. Other clinics have integrated an EHR flag system for testing patients and following up with patients for their diagnosis. Some clinics are training clinical staff and non-clinical staff on the process for syphilis diagnosis, staging, and treatment. For testing, clinics have developed standing orders for tests to be ordered by MAs, RNs, and Public Health Nurses to increase accessibility to testing. For pregnant persons, clinics have established the three-point syphilis testing strategy that tests for syphilis in their first prenatal visit, the beginning of their third trimester, and at the time of their delivery. While these efforts are achievable, many Tribal clinics struggle to implement them due to shortages in the workforce.

The Great Plains Area TEC has created culturally appropriate briefs with information, statistics, and symptoms on syphilis. This is part of their sexual health education which can help to de-stigmatize syphilis and ensure individuals are regularly tested and receive treatment as needed. However, access to NNDS and the CDC STI Surveillance data is critical to ensure each of the twelve TECs are able to report the most up to date information for their regional area.

Conclusion

HHS will need to replicate efforts made during COVID-19 to address the disproportionate rates AI/AN populations are affected by syphilis and congenital syphilis including declaring this crisis a public health emergency. It is urgent for HHS to deploy additional PHSC in Tribal and IHS clinics, ensure Tribes and TECs timely access to HHS datasets, and ensure Tribal access to the NSSC, SNS and other HHS emergency resources. These efforts can ameliorate this crisis and its effects within Indian Country. Critically, HHS and IHS must continue to explore long-term, sustainable systems that will enable disease response and surveillance to be dynamic and expedient. There must be investments made to establish a system – both in data access, personnel, and financial resources – to allow the Indian health system, in partnership with the TECs and local authorities (as appropriate), to be able to respond to public health threats quickly and nimbly to prevent future crises. This will improve health outcomes and save lives.

Sincerely,

Chief William Smith, Valdez Native Tribe
Chairman
National Indian Health Board

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