National Indian Health Board

Submitted via e-mail: STDPlan@hhs.gov

June 3, 2019

U.S. Department of Health and Human Services Office of HIV/AIDS and Infectious Disease Policy Ms. Melissa Habel, MPH 330 C Street SW, Room L001 Washington, DC 20024 Attention: STD RFI

Re: Request for Information (RFI): Developing an STD Federal Action Plan

Dear Ms. Habel:

On behalf of the National Indian Health Board (NIHB),<sup>1</sup> I submit these written comments to the Office of HIV/AIDS and Infectious Disease Policy (OHAIDP or the Office) in response to the Request for Information (RFI) on the first federal Sexually Transmitted Disease (STD) [Sexually Transmitted Infection (STI)] action plan.

The United States has a unique legal and political relationship with American Indian and Alaska Native (AI/AN) Tribal governments. This relationship was established through treaties and affirmed by the United States Constitution, Supreme Court decisions, federal laws and regulations, and presidential executive orders. Central to this relationship is the federal government's trust responsibility to protect the interests of Indian Tribes and communities, including through the provision of health care and public health services to AI/ANs. Yet, Tribes remain behind other communities in their health care and public health infrastructure, capacity, and workforce capabilities.

Tribal communities face significant challenges as we seek to address rapidly rising rates of sexually transmitted infections among our Peoples. These challenges include lack of dedicated funding for prevention and treatment; pervasive stigma around sex and sexually transmitted

<sup>&</sup>lt;sup>1</sup> Established in 1972, the NIHB is an inter-Tribal organization that advocates on behalf of Tribal governments for the provision of quality health care to all American Indians and Alaska Natives (AI/ANs). The NIHB is governed by a Board of Directors consisting of a representative from each of the twelve Indian Health Service (IHS) Areas. Each Area Health Board elects a representative to sit on the NIHB Board of Directors. In areas where there is no Area Health Board, Tribal governments choose a representative who communicates policy information and concerns of the Tribes in that area with the NIHB. Whether Tribes operate their entire health care program through contracts or compacts with IHS under Public Law 93-638, the Indian Self-Determination and Education Assistance Act (ISDEAA), or continue to also rely on IHS for delivery of some, or even most, of their health care, the NIHB is their advocate.



infections; lack of health education resources that promote prevention; and lack of access to clinics offering routine and comprehensive screenings for sexually transmitted infections. Moreover, AI/AN communities face higher rates of preventable chronic health conditions including obesity, diabetes, substance use disorders, tobacco addiction, cancer, HIV and especially hepatitis C (HCV) than the national average. As the Office develops its national plan on sexually transmitted infections, it is imperative that the goals and indicators of the new plan are reflective of the many challenges unique to Tribal communities.

### **Background**

American Indians and Alaska Natives (AI/ANs) are disproportionately impacted by sexually transmitted infections, including gonorrhea, chlamydia, and syphilis. From 2015 to 2016, there was a 43 percent increase in rates of primary and secondary syphilis among AI/ANs, with a larger disparity among Native women versus men. In particular, there was an increase of congenital syphilis rates observed among Native women during the same time period, with rates 6 times that among Whites. In 2017, the Centers for Disease Control and Prevention (CDC) reported that gonorrhea rates among AI/ANs were 4.5 times higher than for Whites. In the same year, rates of chlamydia among AI/ANs were reported to be 3.7 times higher than for Whites while syphilis rates were reported to be 2.1 times higher. Nevertheless, *in Fiscal Year 2018, no Tribe or Tribal organization received funding from CDC for sexually transmitted infections*.

Systemic barriers, as well, leave many Tribes at a disadvantage in leveraging public health resources to improve health outcomes for their communities. For example, just under 30% of AI/ANs did not have health coverage in 2017—the highest rate of any group nationwide—in spite of the federal trust responsibility to deliver health services.<sup>2</sup> Federal appropriations for Indian health amounted to just \$4,078 per capita in FY2017, compared to a national average of \$9,726.<sup>3</sup> These budget pressures limit the range of health services available for AI/ANs to primarily the most immediate health needs, and constrain efforts to invest in upstream and preventative health services. Higher AI/AN uninsured rates also force greater reliance on emergency care and dramatically increase treatment expenditures for the IHS, Tribal, and third party entities.

#### **General Comments and Recommendations**

The new federal action plan is expected to address prevention, diagnosis, care and treatment, as well coordinate efforts, policies, and programs across the federal government. It will also address stigma, discrimination, co-infections (like HIV and viral hepatitis), and social determinants of health. NIHB's responses to the RFI will focus on Tribal communities and AI/AN individuals.

I. How should the federal government address the rising rates of STDs?

<sup>&</sup>lt;sup>2</sup> Georgetown University Health Policy Institute. Coverage Trends for American Indian and Alaska Native Children and Families (July 14, 2017), <a href="https://ccf.georgetown.edu/2017/07/14/coverage-trends-for-american-indian-and-alaska-native-children-and-families/">https://ccf.georgetown.edu/2017/07/14/coverage-trends-for-american-indian-and-alaska-native-children-and-families/</a>.

<sup>&</sup>lt;sup>3</sup> The National Tribal Budget Formulation Workgroup's Recommendations on the Indian Health Service Fiscal Year 2020 Budget, https://www.nihb.org/docs/03012018/TBFWG%20FY%202020%20Recommendations%20Brief.pdf.

### 1. Address the Rural Epidemic

Many Tribal communities are rural in nature, sometimes even located in frontier lands. For this reason, the Office must acknowledge that the approach for prevention and treatment for AI/ANs living in rural areas will differ from those that are urban or sub-urban. Issues that face rural Tribal communities include: remote locale, limited access to care and prevention services, lack of transportation, minimal work force to address a wide range of public health and medical issues, coupled with financial high need and incidence of health/medical concerns. The majority of initiatives launched to date to prevent or treat HIV [or viral hepatitis] have focused on urban areas, even when recent outbreaks in more rural areas clearly demonstrate the need to funnel resources to under-resourced rural and remote areas. To ensure that it is comprehensive, the STI plan should take specific steps to address the unique challenges faced by rural and remote AI/AN Tribal communities.

#### 2. Mitigate Stigma as a Key Driver of STI the Epidemic

STIs are largely social diseases that are driven by social conditions and behaviors. Unfortunately, in the United States (U.S.), many of those behaviors are frowned upon, and people engaging in those behaviors may face intense scrutiny and discrimination from their communities. This is especially so in Tribal communities, where estrangement from one's community due to shame or stigma can lead to deteriorated health outcomes. AI/AN individuals engaging in sexually-related behaviors may shy away from what could potentially be a larger support system or avoid engaging with services altogether due to shameful feelings and societal stigma. Individuals that shy away from help become more vulnerable to engaging in high risk or clandestine behavior and in practicing unhealthy coping mechanisms. This can lead many people to suffer more severe behavioral and mental health issues. Stigma is not a result of the HIV or STI epidemic, it is a key determinant of the epidemic, and should be addressed as such. To address stigma is to prevent infection and transmission.

### 3. Provide Direct Funding to Tribes and Tribal Organizations

No Tribe received funding from CDC in FY 2018 for STD prevention, despite having gonorrhea rates 4.2 times that of Whites; chlamydia rates 3.7 times that of Whites; and syphilis rates 2.2 times the rates for Whites. In order for Tribal communities to address the STI epidemic, they cannot be ignored in the halls of Congress or in agency policymaking.

II. What strategies can be implemented by federal agencies to improve the efficiency, effectiveness, coordination, accountability, and impact of our national response to increasing rates of STDs for all priority populations?

### 1. Address Social Determinants of health

Key social determinants of health in American Indian and Alaska Native communities include: poverty, education, access to healthcare services, and access to food. Corresponding risk factors include: alcohol use, drug use, and behavioral health. NIHB recommends that the STI plan create concrete strategies for addressing the social determinants of health in underserved and under-

resourced AI/AN communities, including, but not limited to: support for research, pilot projects, and the expenditure of funding on social determinant-related aspects of health.<sup>4</sup>

### 2. Address the Cross Cutting Elements of HIV, STIs and the Opioid Epidemic

Tribes would benefit from the federal government acknowledging and actively addressing the intersections of HIV, STIs, and the opioid epidemic concurrently ravaging the U.S. In a time of diminishing resources, the overlapping behaviors that place very distinct groups of people within geographic areas should be the object of targeted public health efforts. This is especially true in Indian Country. The federal action plan should develop a coordinated response that acknowledges opportunities to combine resources, expand reach, and work effectively with communities at risk. The plan could promote collaboration at the Tribal and local level. This includes the ability to cross pollinate projects to use funds to address related issues and concerns (for example, using funds from a drug use prevention project to provide STI testing services). This would help to drive partnerships, and reduce the siloed feeling and overwhelming sense of competition that public health practitioners are bound to experience.

# 3. Include Specific Strategies, Goals, and Objectives for Indian Country and American Indian and Alaska Native communities Toward Reducing STI Rates and Increasing Access to Treatment

In recent years, new and innovative models of prevention and treatment for STIs have led to improvements in access to care and health education. For instance, expedited partner therapy (EPT) is a best practice for delivering treatment for chlamydia and gonorrhea to sexual partners without the requirement of first being seen by a provider. Other innovative practices include mailin testing for sexually transmitted infections and mail-out prescriptions for treatment of infections. Even the Indian Health Service (IHS) HIV/STD Advocacy Kit and Policy Guide<sup>5</sup> discusses EPT as a best practice. However, Indian Country remains far behind other communities in the implementation of these innovative new models of care due to lack of dedicated funding and technical assistance.

As the federal action plan is designed, finalized and implemented, the Office should continue to meet with Tribal leaders and Tribal health experts and educators to learn more about the unique challenges and barriers restricting use of innovative care models for prevention and treatment of sexually transmitted infections in Indian Country. This could include creating a special position for rural health care outreach; hiring and training a Tribal liaison; and also working with existing Tribal health educators where they are present. Tribal health educators are a critical link between the rural AI/AN communities, federal hospital centers, and schools. Tribal health educators are on the front lines when an STI/STD epidemic arises in Indian Country. They provide harm reduction services and develop culturally relevant prevention messages; conduct HIV Rapid Screening/ HCV screening in Tribal jails, and collect health data. Working closely with Tribal leaders and Tribal

<sup>&</sup>lt;sup>4</sup> From NIHB's recommendation to HHS/OHAIDP on the National HIV/AIDS Strategy and National Viral Hepatitis Action Plan (Mar. 11, 2019), <a href="https://www.nihb.org/tribalhealthreform/wp-content/uploads/2019/03/NIHB-Comment-on-HIV-and-VH-Plans.pdf">https://www.nihb.org/tribalhealthreform/wp-content/uploads/2019/03/NIHB-Comment-on-HIV-and-VH-Plans.pdf</a>.

<sup>&</sup>lt;sup>5</sup> Tribal HIV/STD Advocacy Kit and Policy Guide (2017), <a href="https://www.ihs.gov/hivaids/includes/themes/responsive2017/display\_objects/documents/trainingkitinfo.pdf">https://www.ihs.gov/hivaids/includes/themes/responsive2017/display\_objects/documents/trainingkitinfo.pdf</a>.

health educators will allow OHAIDP to develop specific indicators in the national plan for Tribes to measure progress towards implementation and accurately reflect the picture of health care in Indian Country.

### III. What are the barriers to people getting the quality STD health services they deserve? What strategies can be implemented by federal agencies to overcome these barriers?

Barriers to AI/AN individuals receiving treatment include: lack of direct funding, stigmatization of STIs and STDs, limited options for screening, and limited options to utilize innovative strategies like expedited partner therapy, as described above. To fulfill the trust responsibility, the federal government can implement strategies to help AI/ANs overcome barriers. These include:

### 1. Provide Technical Assistance to Tribes That Have Launched Programs or Initiatives to Combat the STD/STI Epidemic on Reservations

While collecting comments and stories from Tribes and Tribal public health practitioners in response to the recent OHAIDP HIV/HCV request for public comment, NIHB repeatedly heard stories of inadequate access to training and technical assistance resources, and the reliance of Tribal staff upon county health departments—in some case located hours away—for basic resources. Geographic distance is an enduring challenge in Indian Country, as many Tribal communities are situated far away from the resource-rich, urban centers. Tribes should not have to drive so far to access basic prevention materials, such as condoms. Nor should Tribes be forced to turn to non-Native specific entities for training and technical assistance. Tribes and Tribal organizations, such as Area Indian Health Boards, know their communities. They have longstanding relationships and have developed trust within their communities that can serve to increase the reach and effectiveness of prevention and treatment programs. The Department of Health and Human Services (HHS) should, as an integral component of its STI federal action plan, direct funding to support Tribal-specific training, technical and capacity building assistance, and materials dissemination. This would help to ensure that AI/AN communities have access to the most current prevention and treatment technologies, and ensure that they keep pace with other communities.

#### 2. Encourage State and City Partnerships with Tribes to Build Sustainable Solutions

States and Tribes, although Tribes are sovereign nations, may choose to collaborate in their public health and clinical work to address the prevalence of HIV and STIs. However, Tribes should not be forced into such a relationship through outdated funding delivery streams. Tribes should receive funding directly from the federal government rather than indirectly through state channels. All funding opportunities originating with the federal government should feature Tribal set-asides for HIV and STD/STI prevention, care, and treatment. *NIHB cannot overstate the importance of direct funding to Tribes*. It is a more efficient model of resource delivery, it honors the federal trust responsibility, and it empowers Tribal communities to develop and *own* their prevention, care, and treatment programs. It is imperative that the STI plan discuss fair and equitable resource allocation, including direct provision of funding to Tribes.

IV. How can federal agencies influence, design and implement STD-related policies, services and programs in innovative and culturally-responsive ways for priority populations?

### 1. Provide Indian Country-Specific Topics and Objectives within the STI Plan

Tribal Nations are sovereign governments that share a unique government-to-government relationship with the federal government. Because of the distinct histories, health priorities, and legal status of AI/AN Tribal governments, NIHB strongly recommends that HHS develop separate and distinct objectives in the STI plan that apply specifically to AI/AN communities.

To honor Tribal sovereignty, HHS should make an effort to consult with Tribal leaders in each region, during each iteration of the plan: creation, adoption, and implementation. During the Listening Session that NIHB hosted with OHAIDP at the National Tribal Public Health Summit (May 15, 2019), Tribal leaders expressed disappointment with what they perceived to be a lack of recognition of the special leadership roles they hold within their communities. Each federally-recognized Indian Tribe is a unique entity, and a one-size-fits-all approach will therefore not benefit Tribal communities that are most in need of resources to combat the STI epidemic. We ask that OHAIDP—as it formulates the STI federal action plan and identifies the needs of Tribal communities—treat Tribes as separate and distinct governments, with overarching, general health concerns.

### 2. Direct Funding to Tribes and Tribal Organizations to Plan, Deliver, and Manage Their Own HIV and STI Prevention, Treatment, and Care Programs

Many Tribes have been forced to be creative in how they support efforts to prevent, treat and care for those afflicted by HIV or STIs. However, this is not a sustainable model for Tribes. These services, are essential primary prevention activities and cannot disappear for the spectrum of services provided. A Tribe's planning, delivering, and managing of its public health activities should be billable and reimbursable. The STI plan, then, should undertake a systems-level approach to expand access to coverage and billing for HIV and STI prevention and treatment services.

### V. How can the federal government help to reduce STD-associated stigma and discrimination?

## 1. Change the conversation by reflecting communities of color in advertisements, including marketing that is culturally appropriate and uniquely tailored to Tribal communities

During the phone call information session hosted by OHAIDP regarding the first STI federal action plan, participants commented on the "outdated" nature of campaigns promulgated by the federal government surrounding sexual health. NIHB agrees that HHS should revamp its outreach campaign with special attention to issues facing Tribal communities. In addition, the Office and federal government should create accessible informational brochures and a social media campaign that is reflective and inclusive of American Indians and Alaska Natives.

### 2. Promote regular testing, normalize STI screening, and promote disclosure

To promote STI screening, OHAIDP should develop screening and treatment guidelines to ensure that cases of STIs are diagnosed and treated appropriately. In addition, making information or resources widely available in Tribal communities would help to normalize the concept of regular testing, and reduce shame when an AI/AN individual decides to take this precaution.

### 3. Approach STIs with an attitude of primary prevention, as is done with other diseases

Prevention materials and campaigns rarely are inclusive of AI/AN communities, and are not reflective of the cultural and social realities of AI/AN communities. Funding allocated and directed by the federal and state governments rarely make it to Tribal programs. On the other hand, programs that do exist and are supported by the federal government are not adequate to meet the needs of AI/ANs. This leaves Tribes to rely upon their own limited resources to design, implement, and evaluate their own programs—further distancing AI/AN communities from any prevention plan in place for the rest of the country, and preventing them from reaping the benefits of the latest prevention science. The first STI federal action plan presents an opportunity to provide that segue to Tribal communities. By drawing attention to the unique needs of Tribal communities, OHAIDP, through the STI plan, has the opportunity to create a model strategy for other agencies to follow in the provision of health care to and prevention of disease in Tribal communities.

#### Conclusion

As the Office of HIV/AIDS and Infectious Disease Policy (OHAIDP) works to develop the first-ever national strategy to address sexually transmitted infections, it is imperative that the Office consult with Tribes and include meaningful and achievable goals and indicators specific to reducing disparities within American Indian and Alaska Native communities.

NIHB and the Tribes stand ready to work with HHS and OHAIDP, as well as other engaged federal partners, to build the public health capacity to combat sexually-transmitted infections, HIV, and viral hepatitis infections in Indian Country. Through this letter, we seek to promote prevention and advocate for the delivery of high quality treatment and care services to AI/AN peoples.

We thank you for this opportunity to provide our comments and recommendations on the first STI federal action plan, and look forward to further engagement with HHS on leveraging public health resources to raise the health status of all AI/ANs to the highest levels. Should you have any questions regarding NIHB's comments, or for more information, please contact NIHB's Director of Policy, Devin Delrow, at <a href="mailto:delrow@nihb.org">delrow@nihb.org</a>.

Sincerely,

Victoria Kitcheyan, Chair National Indian Health Board

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