

# National Indian Health Board



Submitted via email to: [HepHIVStrategies@hhs.gov](mailto:HepHIVStrategies@hhs.gov)

March 11, 2019

Alex M. Azar II  
Office of the Secretary  
U.S. Department of Health and Human Services Attention:  
200 Independence Ave S.W.  
Washington D.C. 20201

## **RE: Public Comment on Next Versions of the National HIV AIDS Strategy and the National Viral Hepatitis Action Plan**

Dear Secretary Azar:

On behalf of the National Indian Health Board (NIHB), and the 573 federally recognized American Indian and Alaska Native (AI/AN) Tribes we serve, I write to submit comments on the U.S. Department of Health and Human Services (HHS) Office of HIV/AIDS and Infectious Disease Policy (OHAIDP) request for comments regarding the next iterations of the *National HIV/AIDS Strategy (NHAS)* and the *National Viral Hepatitis Action Plan (NVHAP)*.

Established in 1972, NIHB is an inter-Tribal organization that advocates on behalf of Tribal governments for the provision of quality health care and public health services to all AI/ANs. 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. Whether Tribes operate their entire healthcare 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.

NIHB appreciates the opportunity to provide feedback to help ensure the next iterations of these two separate and distinct national strategies are inclusive of Tribal public health and healthcare priorities. NIHB issued a call for comments to all 573 federally recognized American Indian and Alaska Native Tribes. Comments were received via an online portal as well as through a virtual forum to discuss issues, concerns and comments. Additional comments were solicited through NIHB's Medicare, Medicaid, and Health Reform Policy Committee (MMPC), which consists of Indian health policy experts. All of the input and feedback that was received is incorporated into this body of comments. Tribes and NIHB are committed to working with HHS and OHAIDP to promote objectives that will work to reduce the HIV and hepatitis-related health disparities AI/AN communities currently experience.



## ***Background***

The United States has a unique legal and political relationship with 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 healthcare and public health services to AI/ANs.

Tribes remain behind other communities in their healthcare and public health infrastructure, capacity, and workforce capabilities, as a result of being largely left behind during the nation's development of its public health infrastructure. These systemic barriers leave many Tribes at a disadvantage in leveraging public health resources to improve health outcomes for our Peoples. Just under 30% of AI/ANs continued to lack health coverage in 2017 – the highest rate of any group nationwide –in spite of the federal trust responsibility to deliver health services.<sup>1</sup> Federal appropriations for Indian health amounted to just \$3,332 per capita in FY2017, compared to a national average of \$9,207.<sup>2</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 IHS, Tribal, and third party entities. Indeed, 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.

AI/AN communities have been disproportionately impacted by the HIV epidemic since its inception. The rate of HIV infection among AI/ANs in 2016 was 10.2 per 100,000 – the fourth highest among other racial/ethnic groups.<sup>3</sup> Furthermore, the number of diagnoses of HIV infection among AI/AN persons continues to rise. There was an overall increase of 70% in the rate HIV infection among all reported AI/AN (from 143 in 2011 to 243 in 2016),<sup>4</sup> and a 54% increase in HIV diagnoses among gay and bisexual AI/AN men from 2011 to 2015 – the highest such increase in the country.<sup>5</sup> AI/ANs have one of the lowest survival rates after an AIDS diagnosis among all

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<sup>1</sup> Georgetown University Health Policy Institute. Coverage Trends for American Indian and Alaska Native Children and Families. Retrieved from <https://ccf.georgetown.edu/wp-content/uploads/2017/07/Amer-Indian-Alaska-NativeCoverage-final-rev.pdf>

<sup>2</sup> National Tribal Budget Formulation Workgroup. (2018). Recommendations on the Indian Health Service Fiscal Year 2020

Budget. Retrieved from

<https://www.nihb.org/docs/03012018/TBFWG%20FY%202020%20Recommendations%20Brief.pdf>

<sup>3</sup> Baugher, A.R., Beer, L., Bradley, H.M., Evans, M.E., Luo, Q., & Shouse, R.L. (January 4, 2019). Behavioral and clinical characteristics of American Indian/Alaska Native adults in HIV Care – medical monitoring project, United States, 2011–2015. *Morbidity and Mortality Weekly Report* 2019; 67:1405–1409. DOI: <http://dx.doi.org/10.15585/mmwr.mm675152a1>

<sup>4</sup> Ibid.

<sup>5</sup> Centers for Disease Control and Prevention. (2018). HIV among American Indians and Alaska Natives in the United States. Retrieved from <https://www.cdc.gov/hiv/group/raciaethnic/aian/index.html>



groups, and one of the lowest rates of viral suppression in the country.<sup>6</sup> While Tribes and other AI/AN communities experience poorer health outcomes after an diagnosis, and exhibit higher rates of new infections, there have been little to no targeted prevention efforts for AI/AN communities, and funding is not provided directly to Tribes.

AI/ANs are disproportionately impacted by HCV morbidity and mortality. In recent years, rates of cirrhosis deaths due to a Hepatitis C (HCV) infection have increased as a result of the ongoing national opioid epidemic. In 2014, American Indians/Alaska Natives had the highest hepatitis A-related mortality rate (0.1 deaths per 1000,000), and the highest hepatitis-C relative mortality rate (11.2 deaths per 100,000).<sup>7</sup> From 2015 to 2016, incidence rates of acute HCV among AI/ANs rose from 1.8 to 3.1 cases per 100,000.<sup>8</sup> In addition, rates of chronic liver disease and cirrhosis deaths are 2.3 times higher among AI/ANs than Whites.<sup>9</sup> American Indian/Alaska Native women are 50 percent more likely to die from viral hepatitis, as compared to non-Hispanic, white women.<sup>10</sup> In 2016, American Indians/Alaska Natives were 2.7 times more likely to die from hepatitis C than non-Hispanic whites, and 2.3 times as likely to die from hepatitis B.<sup>11</sup>

There are many intersecting public health and clinical aspects of HIV and viral hepatitis, and many more so when examining the system in which these issues are funded, prevented, and addressed. Therefore, it is prudent to address these issues that cut across both epidemics rather than parcel them out. The following recommendations have the opportunity to significantly impact the manner in which the federal government interacts and engages with federally recognized American Indian and Alaska Native Tribes when addressing either HIV or viral hepatitis, as well as concrete recommendations to improve the delivery of services in Indian Country.

### **Direct Funding to Tribes and Tribal Organizations to Plan, Deliver, and Manage Their Own HIV and Viral Hepatitis Prevention, Treatment and Care Programs**

There has been hundreds of billions of dollars spent in this country to try to prevent and treat HIV and viral hepatitis. Regrettably, very few of these efforts and even fewer amount of dollars have been focused on one of the most vulnerable populations in our country – American Indians and Alaska Natives. The AI/AN population is one of the few communities that has seen a rise in the rate of new diagnoses in HIV over recent years and continues to see an increase in viral hepatitis mortality, however there is very little funding that is directed to Tribally-based prevention, treatment, care or capacity building efforts. Prevention materials and campaigns rarely are

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<sup>6</sup> Ibid.

<sup>7</sup> CDC. (2016). Viral hepatitis – statistics & surveillance. *Surveillance for Viral Hepatitis – United States 2014*. Retrieved from <https://www.cdc.gov/hepatitis/statistics/2014surveillance/commentary.htm#bkgrndC>

<sup>8</sup> Swaim, R.C., & Stanley, L.R. (2018). Substance use among American Indian youths on reservations compared with a national sample of US adolescents. *JAMA network open*, 1(1), e180382-e180382.

<sup>9</sup> Stanley, L.R., & Swaim, R.C. (2015). Initiation of alcohol, marijuana, and inhalant use by American-Indian and white youth living on or near reservations. *Drug and alcohol dependence*, 155, 90-96.

<sup>10</sup> CDC. (2017). Deaths: Final data for 2015. *National Vital Statistics Reports*, 66, no. 10. Table 10 and Table I-17.

Retrieved from [http://www.cdc.gov/nchs/data/nvsr/nvsr66/nvsr66\\_06.pdf](http://www.cdc.gov/nchs/data/nvsr/nvsr66/nvsr66_06.pdf)

<sup>11</sup> CDC. (2017). Summary of notifiable diseases - United States, 2015. *MMWR*, 65, no. 53. Table 5. Retrieved from <https://www.cdc.gov/mmwr/volumes/64/wr/pdfs/mm6453.pdf>



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, and programs that do exist and are supported by the federal government have not been enough. This leaves Tribes to rely upon their own limited resources to design, implement, and evaluate their own programs – further distancing AI/AN communities from the prevention plan of the rest of the country, and preventing them from reaping the benefits of the latest prevention science.

When communicating with Tribes on HIV and viral hepatitis concerns, it became clear that there were not enough Tribally-specific efforts. Stories were told of inadequate access to training and technical assistance resources, and the reliance of Tribal staff upon county health departments, located hours away, for resources. Geographic distance is a real challenge in Indian Country, as many Tribal communities are situated far away from resource rich, urban centers. Tribes should not have to drive so far to access such basic prevention materials 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 and have long-standing relationships within their communities that can serve to increase the reach and effectiveness of prevention and treatment programs. HHS should, as integral components of its national HIV and viral hepatitis response, 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.

States and Tribes may choose to collaborate in their public health and clinical work to address HIV and viral hepatitis. 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 coming from the federal government should feature Tribal set-asides for HIV and viral hepatitis prevention, care and treatment. NIHB cannot stress enough the importance of direct funding to Tribes. It is a more efficient model of resource delivery, it honors the trust responsibility of the federal government, and it empowers Tribal communities to develop and own their prevention, care and treatment programs. It is vital that the plans being developed discuss fair and equitable resource allocation, including direct provision of funding to Tribes.

### **Need for Indian Country-Specific Topics and Objectives within the Plans**

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 consider developing separate and distinct objectives that apply specifically to AI/AN communities.

The current national plans do not address the unique prevention and care realities of Indian Country. There must be specific language to discuss American Indians and Alaska Natives as a population that is statistically at higher risk for acquiring or passing away from HIV or viral



hepatitis. Often times, AI/AN health inequities are overlooked when combined with broader national health issues, which can translate to less prioritization and access to funding. It can also lead to misrepresentation of AI/AN health needs which can exacerbate health disparities in the long-run. It is imperative that HHS examine how to best design a framework, topic areas, and objectives that meet the health needs of Tribes and advance the federal government's trust responsibility for health.

### **Need for Tribal Consultation during Development of HIV and Viral Hepatitis Funding Streams and Initiatives**

Executive Order 13175 requires all federal agencies to engage in meaningful, robust consultation with Tribes and Tribal organizations prior to enacting policies that may have implications for Indian Country. Although we applaud HHS's request for comments on this issue, we believe that the most important and needed recommendations will come from open dialogue with Tribes directly. Therefore, NIHB encourages HHS to engage with Tribal Nations directly and gain their input on how best to meet the needs AI/ANs as it develops the new NHAS and NVHAP, as well as their implementation plans and other initiatives that will seek to achieve the goals with the respective plans.

### **Address the Cross Cutting Elements of the HIV, Viral Hepatitis and the Opioid Epidemics**

The federal government should not shy away from acknowledging and actively addressing the intersections HIV, viral hepatitis, and the opioid epidemics 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 provide a beacon for effective, targeted public health efforts. This is especially true in Indian Country. A national coordinated response should be developed that acknowledges these opportunities to combine resources, expand reach, and most effectively work with communities exhibiting risk; and promote this level of 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 HIV testing services). This would help to drive partnerships, and reduce the siloed feeling and overwhelming sense of competition that people in the field are experiencing.

### **Need for Tribally Inclusive Evaluation and Surveillance Systems**

Data-driven decision making has been the rallying cry of the federal government for over a decade, and a reliance upon epidemiological and program evaluation data has crafted the current state of prevention and treatment efforts – with certain geographies and populations receiving increased resources and support.

Racial misclassification and undercounting of AI/ANs in state and national disease surveillance systems and registries is a chronic, pervasive issue that disproportionately impacts AI/ANs. There has been well-documented cases of widespread and commonplace misclassification of racial identities of American Indian and Alaska Native people across large periods of time and in all



realms of health care.<sup>12 13 14 15</sup> Because many disease registries rely upon mortality data, misclassification of AI/ANs on death certificates can have the net effect of underestimating population-based disease rates. This in turn can severely impede Tribal, federal, and state efforts towards identifying areas of need for public health education, programming, and delivery of health services. For example, the CDC noted that the actual number of drug overdoses for AI/ANs from 1999 to 2015 might be underestimated by as much as 35% due to racial misclassification.<sup>16</sup> Going even further, CDC reported that the proportion of racial misclassification of AI/ANs across multiple causes of death in the National Longitudinal Mortality Study from 1999-2011 was as high as 40%.<sup>17</sup>

In a time of data-driven decision-making, it is vital that the data is reliable and respectful. Both the NHAS and NVHAP should address the need to evaluate program implementation in a culturally respectful and inclusive manner. This is especially true when prevention programs address risk and protective factors that are AI/AN culturally distinct. Current evaluation protocols do little to capture the effectiveness of such culturally-based and grounded approaches, even when positive outcomes seem to warrant further investigation, investment and implementation. HHS should invest in evaluation frameworks that works with AI/AN communities to capture and report this data (including permitting more qualitative approaches that can appropriately depict critical topics regarding HIV and viral hepatitis) so that such programs can be recognized, bolstered, and potentially replicated. Furthermore, HHS should look within the existing systems to address under sampling in the state surveillance systems. American Indian and Alaska Natives are often represented at such low levels that their data is unreportable. This should not happen in communities and states with sizeable AI/AN populations, yet it still does. In order to more accurately account for impact and capture data on Indian country, HHS should create strategies to represent AI/AN data alongside all other communities.

Tribal Epidemiology Centers (TECs) serve an important role in the public health framework of Indian Country. As many Tribes do not have the resources to operate their own surveillance

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<sup>12</sup> Jim, M.A., Arias, E., Seneca, D.S., Hoopes, M.J., Jim, C.C., Johnson, N.J., & Wiggins, C.L. (2014). Racial misclassification of American Indians and Alaska Natives by Indian Health Service contract health service delivery area. *American Journal of Public Health, 104*(S3), S295-S302.

<sup>13</sup> Lieb, L.E., Conway, G. A., Hedderman, M., Yao, J., & Kerndt, P. R. (1992). Racial misclassification of American Indians with AIDS in Los Angeles County. *Journal of Acquired Immune Deficiency Syndromes, 5*(11), 1137-1141.

<sup>13</sup> Stehr-Green, P., Bettles, J., & Robertson, L. D. (2002). Effect of racial/ethnic misclassification of American Indians and Alaskan Natives on Washington State death certificates, 1989–1997. *American Journal of Public Health, 92*(3), 443-444.

<sup>14</sup> Sugarman, J. R., & Lawson, L. (1993). The effect of racial misclassification on estimates of end-stage renal disease among American Indians and Alaska Natives in the Pacific Northwest, 1988 through 1990. *American journal of kidney diseases, 21*(4), 383-386.

<sup>15</sup> Lieb, L.E., Conway, G.A., Hedderman, M., Yao, J., & Kerndt, P.R. (1992). Racial misclassification of American Indians with AIDS in Los Angeles County. *Journal of Acquired Immune Deficiency Syndromes, 5*(11), 1137-1141.

<sup>16</sup> Mack, K.A., Jones, C.M., Ballesteros, M.F. (2017). Illicit drug use, illicit drug use disorders, and drug overdose deaths in metropolitan and nonmetropolitan areas – United States. *MMWR Surveillance Summary 66*, no. SS-19, 1-12.

DOI: <http://dx.doi.org/10.15585/mmwr.ss6619a1>

<sup>17</sup> CDC. (2016). *The validity of race and Hispanic-origin reporting on death certificates in the United States: An update*. Hyattsville, MD: US Department of Health and Human Services, CDC, National Center for Health Statistics. Retrieved from [https://www.cdc.gov/nchs/data/series/sr\\_02/sr02\\_172.pdf](https://www.cdc.gov/nchs/data/series/sr_02/sr02_172.pdf)



systems, many rely upon the TECs to process their data and produce reports on the state of health for their communities. However, confusion over how the TECs operate under a legal public health authority, and bureaucratic barriers to accessing state and national level data have all created significant barriers to the TECs serving the Tribes in the most effective and efficient manner. TECs require access to all health data, as permitted by their constituent Tribes, on American Indian and Alaska Native communities within their catchment areas – and have legal authority to this data. HHS should work with TECs to incorporate them into the U.S. surveillance system for HIV and viral hepatitis, and remove the existing barriers they face when seeking to access such data.

### **Primary Prevention is Essential**

Primary prevention is the bedrock of HIV and viral hepatitis prevention. It addresses primary risk behaviors and engages with communities and individuals to create realistic approaches to changing behaviors, shifting norms, and addressing triggers. In a time where biomedical technologies have increased the number and effectiveness of additional and innovative prevention strategies, the focus on risk reduction, partner communication, behavioral interventions and condom use is disappearing. These are key strategies in Indian Country because they may not have ready access to new strategies or may not exhibit a readiness to implement such strategies. Furthermore, behavioral interventions have proven an efficacious vehicle for reinforcing culturally-based worldviews that serve as powerful backbones for prevention messaging. The indicators listed in the National Strategy do not include mention of any intent to provide or measure primary prevention strategies through the delivery of effective, behavioral interventions. HHS must support the ongoing use of basic and core prevention strategies in Indian Country to maintain and expand the delivery of culturally-relevant health interventions.

### **Bolster HIV and Viral Hepatitis Testing Efforts**

There is little doubt that testing will continue to be promoted and supported in future plans and efforts. However, there is a distinct need to increase the resources that permit Tribes to conduct HIV and viral hepatitis testing, as well as sustain existing testing approaches, such as anonymous testing. Anonymous testing permits community members to receive a test for HIV or viral hepatitis without providing their name. This helps to protect the confidentiality of the individual (which is an immense concern in AI/AN communities) and creates an easier on-ramp for people to access such needed prevention services. Now, it is understood that anonymity cannot be maintained if tests are reactive or if a person wishes to engage in more clinical services, however anonymous testing has proven successfully in AI/AN communities, and the new plans should continue this support.

Additionally, the new plans should include metrics for rolling out and supporting HCV rapid tests. HCV rapid testing is readily available, however many communities are not utilizing the rapid tests as they are not funded to do so. The new plans should focus on how to get rapid HCV tests directly to those communities exhibiting higher need for a rapid response – such as AI/AN communities.

### **Address the Rural Epidemic**

Many Tribal communities are rural in nature, sometimes even located in frontier lands. As such,



it is necessary to acknowledge that the approach for prevention and treatment may differ from those that are sub-urban or 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 a 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. The plans should take specific steps to address the unique challenges faced by rural and remote AI/AN Tribal communities.

### **Mitigate Stigma as a Key Driver of the Epidemics**

Both HIV and viral hepatitis are largely social diseases that are driven by social conditions and behaviors. Unfortunately, in the U.S., many of those behaviors are looked down upon, and people engaging in those behaviors may face intense scrutiny and discrimination from their communities. This forces people to shy away from what could potentially be a larger support system, to avoid engaging with services, to engage in high risk behavior clandestinely, to engage in unhealthy coping mechanisms, and can lead many people to more severe behavioral and mental health issues. Stigma is not a result of the HIV or viral hepatitis epidemic, is a key determinant of the epidemic, and should be addressed as such; to address stigma is to prevent infection and transmission.

Some AI/AN communities experience stigma around lesbian, gay, bisexual, transgender, questioning and two-spirit (LGTBQ2S) identities and orientation. Men who have sex with men are the population that makes up the majority of current and new cases of HIV among American Indians and Alaska Natives. Additionally, in smaller AI/AN communities, the LBTQ2S community generally do not self-divide along identity lines – instead they comprise a tighter-knit component of the community together. Addressing the stigma and the discrimination that LGBTQ2S people in Indian Country experience will impact the transmission and health of the men who have sex with men in those communities as well. HHS should dedicate resources to shift the attitudes that people have about LGBTQ2S people, and their role in the community's health.

There is additional stigma around behaviors that may be seen as taboo that are not related to LGBTQ2S identities. Sex, in general, may be seen as taboo, in many AI/AN communities, as well as talking about sex, talking about disease or dying, engaging in Western medicine or treatment, or bringing disease into a community. HIV and viral hepatitis thrives in settings where open and honest communication is difficult. AI/AN people may lie to health care providers about the level of risk in which they engage, thus preventing them from accessing testing or preventative services. Community level interventions, community-based outreach and education, and social marketing are key strategies to address widespread stigma, and should be openly promoted as potential strategies against community-based stigma.

Previous iterations of the National HIV/AIDS Strategy have created objectives specifically seeking to address stigma in risk populations. These must be included in both the HIV/AIDS strategy and the viral hepatitis action plan. However, these objectives must be expanded beyond just LGBT identities and include questioning and two spirit people – who oftentimes struggle in AI/AN communities to access resources.





## **Expanding the Support for and Use of Harm Reduction Strategies and Syringe Service Programs**

The science has repeatedly held firm that harm reduction strategies are effective in reducing new infections and prolonging life of people living with HIV or viral hepatitis. Harm reduction can work on primary prevention activities, while also helping to build community awareness. Initiating HIV and viral hepatitis prevention programs in Tribal communities with a foundation of harm reduction can allow communities that are reticent about sensitive topics to build community buy-in and increase awareness of such issues. Once the harm reduction groundwork is in place, work can begin with more intense and focused trainings and interventions on HIV and viral hepatitis. Harm reduction strategies, like syringe service programs (SSPs), are currently embraced and finding success by some Tribal communities. Federal restrictions are placing limitations on the full potential of these programs, as well as the partnerships and benefits that could result from them. The plans should openly advocate for harm reduction approaches and strategies – especially for those that use drugs as a primary risk behavior for HIV and HCV transmission or acquisition – and embrace these approaches alongside other veteran prevention strategies. This includes, but is not limited to eliminating the ban on the use of federal funds for purchase of needles for syringe exchange programs. Such language in the plans would help to facilitate Tribes to further define SSP requirements and allowances in Indian Country where federal or state guidance is ambiguous or subjective in terms of program activities and funding. Furthermore, as sovereign nations, Tribes can truly innovate and create new approaches and strategies based upon their own community culture. The plans should include language that encourages Tribes to explore and adapt federal and state requirements on syringe service programs especially for Tribes.

Medication assisted treatment (MAT) is a key harm reduction approach that has also shown to be very effective. Both plans should promote its use and seek to expand its application. In Indian Country, many people are receiving care from clinicians other than doctors. Physician assistants, nurse practitioners, and pharmacists have all shown to excellent sources of care, and the plans and HHS should work to minimize the existing barriers for non-physicians to be certified to provide MAT.

### **Social Determinants of Health in Indian Country**

A recent publication by the CDC stressed the disparities in the social determinants of health experienced by AI/ANs currently in HIV care.<sup>18</sup> The article clearly states that AI/AN in HIV care have higher levels of poverty; that viral suppression is suboptimal, and rates of exposure to other significant risk factors are higher. "... 51% of AI/AN patients with HIV infection had incomes at or below the U.S. Department of Health and Human Services' annual poverty limit, 27% had symptoms of depression, 78% reported internalized HIV-related stigma, and 20% reported binge drinking in the past 30 days."<sup>19</sup> Further research should be conducted on interventions to address

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<sup>18</sup> Baugher, A.R., Beer, L., Bradley, H.M., Evans, M.E., Luo, Q., & Shouse, R.L. (January 4, 2019). Behavioral and clinical characteristics of American Indian/Alaska Native adults in HIV Care – medical monitoring project, United States, 2011–2015. *Morbidity and Mortality Weekly Report* 2019; 67:1405–1409. DOI: <http://dx.doi.org/10.15585/mmwr.mm675152a1>

<sup>19</sup> Ibid.



disparities within key social determinants of health (e.g. poverty, education, access to healthcare services, and access to food) and corresponding risk factors (e.g., alcohol use, drug use, behavioral health) in order to mitigate the impact on HIV outcomes.

The National HIV/AIDS Strategy and the National Viral Hepatitis Action Plan should create concrete strategies for addressing the social determinants of health in underserved and under-resourced American Indian and Alaska Native communities, including supporting research, pilot projects, and the expenditure of funding on social determinant-related aspects of health.

### **Access Quality of Care**

Access to consistent, high quality care is probably the most important component across the spectrum of HIV and viral hepatitis services. This care provides and supports access to life saving treatments, medication adherence, referrals to other needed services, and a pathway for general health and wellness for people who may otherwise be removed from the normal cycle of care. However, in Indian Country, access to care can be more complex.

Linkage to care has been proven to be one of the most effective and simple interventions that can be undertaken with a person newly diagnosed with HIV or a person that has fallen out of care. The concept is simple, but the execution can be more complicated – especially in Indian Country with fundamental infrastructure challenges that create barriers to linkage to care. There are only a handful of providers that are trained to provide HIV specialty care across the entire IHS/Tribal/Urban healthcare system for American Indians and Alaska Natives. These providers are geographically scattered across the country. Therefore, Many AI/ANs are required to rely upon referral care to providers outside the Indian health system, and outside of their own communities – often traveling hours to make appointments. These providers, while technically knowledgeable, may not have experience or the cultural knowledge to be able to provide comprehensive, competent care to AI/AN people living with HIV. The lack of local providers, distance to HIV specialists, and lack of culturally competent serve as deterrents for many AI/AN to seek ongoing care and monitoring

Competent care refers to both clinical competency, but also cultural competency. People receiving care should be able to move forward with confidence that their providers have the knowledge, humility, and respect to provide them care and guidance that aligns with their worldview. The plans should emphasize the importance of culturally competent care for American Indian and Alaska Native peoples living with or at risk of acquiring HIV or viral hepatitis.

As geography and the recruitment of specialist physicians both provide unique challenges to AI/AN communities, Tribes have led the way in generating innovative methods of providing high-quality, uninterrupted care to people in need. One such method is the provision of telehealth and telebehavioral health for people living with or at high risk of acquiring HIV or viral hepatitis. The plans should recognize the need to expand telehealth models for care coordination and provision, and enable billing the time needed to access, utilize and deliver telehealth (especially for primary care physicians).



## **Inclusion of Pharmacists as Key Clinicians**

Pharmacists have become a reliable and consistent source of guidance and support for people receiving services from their Tribal or IHS-operated clinic. They are qualified to provide medication advice, support medication adherence, monitor basic indicators of health, and provide referrals to other services. However, they have been largely omitted from the framework of care coordination for HIV and viral hepatitis. There is a great opportunity to tap into the expertise and consistent presence that pharmacists have in Indian Country and bring them into the treatment plans for people living with HIV or viral hepatitis (especially those with HCV). The plans should include pharmacists in the language for treatment management and coordination, and continue to include them as key providers of service and maintainers of continual care in Indian Country.

There are some comments below that are specific to the HIV or viral hepatitis epidemic in this country. So while the above comments reflect opportunities to address cross-cutting issues or aspects, the following are specific to either viral hepatitis or HIV.

### **VIRAL HEPATITIS**

Hepatitis C is a curable disease. This important fact has shaken the infectious disease world, and forced providers to re-examine how to treat and work with people living with HCV. The goal now is to get people living with HCV onto one of several new treatment regimens that effectively cure the infection, and ensure that they complete the regimen. The issues with access to consistent, high quality care is noted above and does not bear repeating here. However, it must be stated that the cure regimen is very expensive. And regardless of the fact that the American Indian and Alaska Native communities in the U.S. are the most impacted by the HCV epidemic, there has been no set aside or targeted allocated funding – either through the CDC (for prevention) or the Indian Health Service (for treatment) – for HCV. More than a billion dollars was allocated for treatment of patients within the Veteran’s Administration, and this singular act has significantly reduced the number of people living with HCV within that healthcare system. HHS must provide adequate funding for the I/T/U system to treat all patients with chronic HCV, thus reducing the viral load in the community, reducing the burden on the healthcare system, eliminating the costs of longer term treatment, and prolong the life of members of the community.

More and more American Indian and Alaska Native people are accessing the benefits of private insurance to access care and improve their health. And even more so are accessing Medicaid and other public forms of coverage to supplement the services they receive from the IHS. However, eligibility guidelines for people living with HCV can restrict access to the treatment regimens that can cure the infection. The plans must reiterate that that public and private insurers' HCV treatment eligibility should be aligned with clinical guidelines from the American Association for the Study of Liver Diseases and Infectious Diseases Society of America.

### **HIV**

HIV prevention is not a new activity to Indian Country. Tribes have been disseminating condoms, educating community members on how to prevent transmission, and getting people into care for



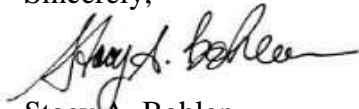
decades. However, these services are largely not funded or supported. They are conducted out of necessity, regardless of the support. Many Tribes have been forced to be creative on how they support these efforts. However, this is not a sustainable model for Tribes. These services, are essential primary prevention activities and cannot disappear for the spectrum of services provided. These activities are core public health activities and should be billable and reimbursable. The plans must look at a systems level approach to expand access to coverage and billing for HIV prevention and treatment services.

### ***Conclusion***

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 HIV and viral hepatitis infection, promote prevention, and deliver high quality treatment and care services within of Indian Country. We thank you for this opportunity to provide our comments and recommendations on the next iterations of the National HIV/AIDS Strategy and the National Viral Hepatitis 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 level.

Should you have any questions regarding NIHB's comments, or for more information, please contact NIHB Chief Program Officer, Robert Foley, at [rfoley@nihb.org](mailto:rfoley@nihb.org).

Sincerely,



Stacy A. Bohlen  
Chief Executive Officer

