Talking Circles Regarding HIV/AIDS in Native American Communities

A SUMMARY OF KEY THEMES

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Prepared by Wilder Research

MINNESOTA

Talking Circles Regarding HIV/AIDS in Native American Communities

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Minnesota HIV Strategy (www.health.state.mn.us/divs/idepc/diseases/hiv/strategy/index.html)

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Adults HIV/AIDS information (https://mn.gov/dhs/people-we-serve/adults/health-care/hiv-aids/)

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Introduction

In 2018, the Minnesota Departments of Health (MDH) and Human Services (DHS) released the Minnesota HIV Strategy report (www.health.state.mn.us/divs/idepc/diseases/hiv/strategy/reportfeb2018.pdf).

To assist with development of the Minnesota HIV Strategy, MDH conducted a number of focus groups to identify critical needs in each region of the state as well as within cultural communities that are at higher-risk for HIV. Unfortunately, MDH was not able to capture as much input from Native American community members or providers who serve Native Americans as was desired. In order to capture additional input from these individuals, Wilder Research and MDH co-facilitated a series of talking circles as part of a session at the White Earth Harm Reduction Summit on May 2, 2018, in Bemidji, Minnesota.

A total of 24 people participated in the talking circles and were broken out into smaller groups. Participants included individuals who identify as Native Americans, medical providers, and advocates for or members of high-risk populations. Participants also included at least one person identifying as each of the following: faith or spiritual leader, chemical dependency provider, youth worker, and city or county human services or public health official. Additionally, one elected tribal official participated. The talking circles included questions about participants' thoughts or concerns about HIV in their communities, needs and barriers related to ending HIV in their communities, efforts that are underway in their communities, and suggestions for how a state agency, such as MDH or DHS, could support any existing efforts or future efforts to end HIV in their communities. The following themes were identified through the notes taken during these four talking circles. An open coding process was used to identify these themes; however, due a small number of participants, findings include some comments made by one or two people.

The summary of themes is meant to increase our understanding of HIV/AIDS in Native American communities in Minnesota and to help guide future efforts of MDH and DHS as they develop tactics to end HIV/AIDS in all communities in Minnesota and to collaborate with Native American communities to do so.

Thoughts or concerns about HIV/AIDS in Native American communities

Major themes that arose regarding issues and concerns about HIV/AIDS in Native communities included stigma associated with having a positive HIV/AIDS status and lack of services and resources for those who are infected or are at risk of infection.

Stigma*.* Participants in the talking circles described many different types of stigma associated with an HIV/AIDS diagnosis. Stereotypes and stigma are common, particularly related to: injection drug use, opioid addiction; lesbian, gay, bisexual, transgender, and queer (LGBTQ) identities; and cultural beliefs (e.g., anti-Planned Parenthood sentiment in Fargo). The lack of anonymity in a small, closely-knit community, such as White Earth, makes it difficult for people to be tested or seek services for fear of stigmatization and isolation from their community. In addition to stigma, there is a misperception that HIV/AIDS is a "white man's disease" and is not seen as a disease that impacts Native populations. Lastly, the cultural taboo around discussing sex and sexuality make it difficult to address HIV/AIDS as an issue in Native communities.

Lack of services and resources*.* The lack of services and resources was described as a general lack of providers that provide HIV/AIDS services and treatment. Providers that are located in Native American communities often lack knowledge and information about pre-exposure prophylaxis (PrEP), and other treatments. There are limited HIV services, treatment options, and resources in general (e.g., access to PrEP, Narcan, 24-hour access to syringes) and, in particular, there is a lack of appropriate health care for transgender individuals or trans-friendly health care.

Additional concerns. Participants were also concerned about poor adherence to medication regimens and concerns that data collected on Native Americans is inaccurate or incomplete and does not reflect the reality of HIV/AIDS in Native American communities. Additionally, concern was expressed about how HIV/AIDS disproportionately affects transgender women of color and how there is no strategic outreach to inform this population about medications like PrEP. There was specific concern that transgender women are not being given the proper to care to prevent infection with HIV and to properly test for it. It was pointed out that there is nothing specific in the Minnesota HIV Strategy that addresses the issues specific to this disproportionately affected population.

Greatest needs related to addressing HIV/AIDS in Native American communities

Participants identified several needs in Native American communities related to HIV/AIDS. Major themes include: 1) education, 2) adequate health care services, 3) competent providers, 4) basic needs such as housing and transportation, and 5) outreach to increase HIV awareness and promote service utilization.

Education. Participants felt that there is a need in Native American communities for early sex education and general health education. Some specific strategies or platforms for sharing information that were suggested include risk reduction programs, counseling services, community forums, educational materials, including basic life skills or strategies throughout education, having drug use educators in schools, and providing effective trainings to address issues related to HIV/AIDS.

Adequate health care services. Health care services need to be offered in a comfortable setting for people living with HIV/AIDS and those at risk for HIV. One participant described this as settings "where providers and patients are equal." Convenient clinic hours are important to reduce barriers to accessing services (e.g., open on nights and weekends) and clinics should offer more information on services that are provided. In addition to decreasing these types of barriers, participants talked about the need for culturally appropriate services and for a structural change in the health care system to allow for more time between health care professionals and patients during a medical visit. Lastly, STD testing needs to be normalized and co-occurring issues, such as mental illness, substance abuse, and homelessness, need to be addressed in tandem with HIV prevention, diagnosis, and treatment.

Competent providers. There is a need for providers who are comfortable discussing HIV/AIDS and sexual health. Additionally, there needs to be trust-building between providers and people living with HIV/AIDS. People living with HIV/AIDS should not be afraid to visit a health care provider for fear of blame or criticism (e.g., for failing to adhere to medication). One group talked about how there needs to be better treatment of patients in general. A participant said, "Give help to those who need it. Treat people as people and not in relation to the availability of resources."

Basic needs. There is a need for housing, mentioned specifically was nurse-staffed apartments for people living with HIV/AIDS. Also needed in rural Native communities is transportation to services and, in particular, access to medical transportation.

Outreach. There is a need for culturally specific communication and media strategies to increase awareness, communicate information, and share positive stories from people living with HIV/AIDS. Strategies to promote health care services are also needed. Some strategies discussed include implementing universal screening, holding HIV/AIDS testing events, and using HIV rapid test kits. Participants also felt that people would benefit from less wait time between medical appointments and targeted outreach on reservations. Lastly, because of the associated stigma, it's important for HIV services to be marketed confidentially and not being targeted towards people in a way that would indicate that they have a positive status.

Additional needs*.* As mentioned previously, there is a need for accurate data. The fidelity with which the data is being collected and reported to the state is of concern. There is also a need for more funding options that are better publicized and available at the local level. One group said there is a need for funding for a teen clinic. Another group said there is a need for involving people with lived experience in coming up with solutions to ending HIV/AIDS in the Native American community and that there needs to be more work across systems in collaboration to address core issues that prevent people from seeking and staying in treatment.

Barriers to ending HIV/AIDS in Native American communities

Talking circle participants identified the key barriers Native American communities are facing to address HIV/AIDS as inadequate health care services and funding/resources.

Inadequate health care services*.* Participants shared that key barriers to addressing HIV/AIDS in their communities included frequent provider turnover and a lack of cultural competence among providers. There is also a lack of providers who belong to the LGBTQ community, which is a hindrance for some who would like to seek health care services, but do not feel comfortable because they don't have a provider they feel can relate to them.

Inadequate funding/resources*.* Participants said that there is a lack of funding due to low numbers of those infected with HIV/AIDS in Native American communities and that resources that do exist are largely for testing rather than treatment. Specifically, it was noted that Indian Health Services (IHS) is underfunded and that decisions about funding are made at the federal level, rather than the tribal level. In general there is not enough time nor resources allocated to the topic of HIV/AIDS in Native American communities.

Additional barriers*.* One group discussed that there may be issues of affordability for those without health insurance. Other barriers include transportation or distance to access HIV health care, and homelessness. Challenges also exist with treatment requirements (e.g., patients must be 'clean' to start anti-retroviral drugs). Other barriers include lack of trust in IHS, marginalization (people feeling like there's nowhere to turn), lack of knowledge among the general population about HIV/AIDs, and language barriers.

Ways state agencies can support existing or future efforts to end HIV/AIDS in the Native American community

When discussing how state agencies can support efforts to end HIV/AIDS in Native American communities, participants mentioned that, in general, there needs to be more dedication and commitment from state government on the topic of HIV/AIDS in Native American communities. Additionally, they commonly spoke about 1) changing available funding and resources, 2) collaboration with other state agencies and with smaller organizations, and 3) improving sex education.

Funding and resources. Participants indicated that the state should provide more funding in general and also work to maximize available resources. Specific funding needs included funding for a teen clinic, day care services for women with children, and disposable needle drop boxes (in public bathrooms, government centers, parks). There is also a need for support for newer and smaller organizations. Specifically, grant applications should be easier and more accessible to people without grant writing experience. Tribal nations could also use help leveraging national funds, such as from the Substance Abuse and Mental Health Services Administration (SAMHSA), for harm reduction and syringe exchange in addition to treatment and overdose prevention. One participant said, “MDH/DHS must support payment for treatment.”

Collaboration. Participants said that more collaboration between state agencies, and with tribes, in general would be beneficial to efforts in tribal nations around HIV/AIDS. It was specifically noted that the State could be instrumental in assisting tribes to identify how HIV testing data is being collected in clinics on reservations. Additionally, one group thought it would be supportive to have state agencies willing to partner and collaborate with smaller organizations.

Education. There is a need for support in improving sex education to be more comprehensive and to increase condom availability.

Next steps

In 2019, DHS and MDH will continue to gather input from individual Native American communities across Minnesota, including the metro area, to better understand the issues and needs they experience in relation to HIV/AIDS, as well as the barriers they face to ending HIV/AIDS. This process will also include gathering additional input on how state agencies can support efforts to address HIV/AIDS in Native American communities.