Ending HIV/AIDS in African-Born Communities in Minnesota

SUMMARY OF COMMUNITY STAKEHOLDER INPUT

July 2018
Prepared by Wilder Research

MINNESOTA

Ending HIV/AIDS in African-Born Communities in Minnesota

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Introduction

The Minnesota Departments of Health (MDH) and Human Services (DHS) convened 15 facilitated workshops around Minnesota to develop tactics for implementing the Minnesota HIV Strategy. The Minnesota HIV Strategy is a comprehensive plan to end HIV/AIDS. It includes five goals supported by 22 total sub-strategies (strategies) focused on how the goal will be achieved. The Minnesota HIV Strategy is available here: Minnesota HIV Strategy report (www.health.state.mn.us/divs/idepc/diseases/hiv/strategy/reportfeb2018.pdf).

Each facilitated workshop focused on a specific region of the state or high-risk community. Workshop participants included stakeholders and community members with knowledge, connections, and insights about challenges and opportunities to support the success of this strategy. Wilder Research facilitated each workshop.

A workshop specifically focused on the African-born community was held because they experience high HIV rates in Minnesota. The rate of HIV/AIDS among African-born people is more than 13 times greater than the rate among white, non-Hispanic people. This workshop was held on April 26, 2018, at the Minneapolis Urban League in Minneapolis, Minnesota. Nineteen individuals participated. During the beginning of the workshop, several participants expressed major concerns about the workshop's format and structure. These concerns are summarized below:

- Previous community engagement efforts from MDH and DHS were not inclusive of African populations. In particular, participants noted that the Liberian community, one of the largest African populations in Minnesota, was not engaged in the process. In addition, participants pointed out that there is no such thing as one "African-born" community, as each community has its own leadership and communication structures.
- This lack of engagement made it feel as though the Minnesota HIV Strategy was being *done to* the African community, rather than being *done in collaboration with* the community.
- Participants expressed discomfort with repeated requests for information from the community without seeing tangible outcomes or benefits for the community. In particular, participants noted that their communities have had negative experiences with MDH and DHS in this regard.
- Traditional methods of communication from MDH and DHS were ineffective for African-born refugees who cannot read or write, further excluding these portions of the population.
- The HIV Care Continuum data for African-born residents was outdated.

After hearing these concerns, the facilitators decided to deviate from the planned process and capture feedback from participants in a way that was comfortable for them. Ultimately, workshop participants agreed to break into smaller groups to comment on the current Minnesota HIV Strategy and make suggestions to help the Minnesota HIV Strategy better conform to the needs of the African communities that participants represented. In addition, MDH, DHS, and Wilder Research held a follow-up meeting with participants on June 27, 2018 to review what was heard during the initial workshop and invite feedback to ensure their input was accurately captured and described. What follows is a summary of the small group discussions and follow-up meeting.

Small group discussion

During small group conversations, participants provided input about how MDH and DHS could better connect with African populations. Additionally, participants offered comments about the goals and the strategies that are part of the Minnesota HIV Strategy.

Suggestions regarding connecting with African populations

- Create opportunities for authentic engagement with African communities. This begins by acknowledging that these communities are not "one size fits all," and that engagement looks different for different tribes. Suggestions for engagement focused primarily on face-to-face dialogue–rather than email and phone—such as focus groups, making connections through community leaders (tribal leadership, religious leaders, etc.), and attending existing meetings or celebrations. Create and grow true relationships and partnerships with the community.
- Acknowledge that African communities have existing infrastructure (for example, tribal groups, women's groups, youth groups) that can and should be used to do this work, rather than developing new groups or using intermediaries.
- Keep the engagement and momentum going by providing sustainable and ongoing resources (funding and staff time). There had been funding, training, and momentum in the past, but policies and funding shifted away from that, disrupting momentum and awareness of HIV.
- Strategies and tactics should be determined by the African community, as they are one of the populations most heavily impacted by HIV/AIDS. The community should be able to drive the process.
- All strategies and tactics should address social determinants of health, which operate differently in African communities than in American or majority communities. African communities have specific social and cultural contexts that need to be addressed throughout the process. It is important to remember that these contexts vary by tribe, geographic community, etc.
- Create conditions for mutual accountability between the state and communities. Acknowledge that this effort is happening in part because the solutions presented to date have not been effective. Work with communities to establish what accountability looks like for the state and for the community.

Feedback on Minnesota HIV Strategy

Feedback from participants on specific goals and strategies included in the Minnesota HIV Strategy is summarized below. This summary only includes the goals and strategies that were brought up by participants during the workshop.

Goal 1: Prevent new HIV infections

Strategy 1.1: *Increase HIV education and awareness for all Minnesotans, especially health professionals, students, and high-risk populations.*

- The focus should be on high-risk populations—list this group first in the wording of strategy 1.1.
- Simplify data for people to understand and communicate easily, particularly if they are not as highly educated or don't know the specialized vocabulary/jargon. For example, instead of saying "50 percent," say "1 of every 2 people in this population are affected." Visualize the data with infographics.
- Employ Africans, both within state agencies and in outside capacities, to do the work as instructors; they can blend these educational activities into existing community events.
- Educate community leaders (including faith leaders) on HIV and HIV resources, and then utilize them and existing structures to deliver educational messages to the community. Support this work with funding.
- Diversify educational strategies like combining community leader engagement with social media and community-specific media outlets to deliver messages.
- Provide training for culturally responsive education. For example, for African women, ask them what culturally specific sex/HIV education should look like.
- Education will look different for different African communities.

Strategy 1.4: *Increase availability, access and use of evidence-based interventions that prevent HIV infections, such as PrEP, PEP, syringe services programs, and partner services.*

- Provide incentives for interventions. For example, provide incentives for every individual tested or provide incentives in more creative ways to save money (raffling, etc.).
- Give resources (particularly funding) to sustain the strategy and the work done in communities.
- Purposefully involve different African communities to lead and do the work for themselves, rather than collecting them into one centralized African organization or entity.
    - Encourage money for implementation within existing initiatives and programming. For example, do not give money for new staff or new rent for a new initiative.
    - Understand that networks already exist within and among African communities—use these networks to do work collaboratively.

Goal 2: Reduce HIV-related health disparities and promote health equity

Strategy 2.2: *Engage community leaders, non-profit agencies, people living with HIV, and other community members to identify and to address barriers that prevent testing and person-centered care.*

- Include and involve faith-based leaders (imams, pastors, etc.), as these leaders are trusted within African communities.
- Support existing structures of leadership and community engagement to find champions within African communities. In addition to faith-based leaders, this includes tribal leaders, women's group leaders, youth group leaders, etc.
- Use grassroots and informal networks to deliver messages as well.

Strategy 2.3: *Dedicate adequate resources to populations of color hardest hit by HIV to eliminate health inequities.*

- Clarify that the primary resource needed is funding: African communities in Minnesota have networks and infrastructure with willing staff to carry out the work, but they need adequate funding to do so.
- Focus on sustainability of these resources; provide ongoing support to sustain momentum, not just build it.
- Dedicate these resources directly to community and organizations within the community, not to intermediary organizations who may then subcontract with community organizations. Acknowledge that there is inherited mistrust of mainstream/intermediary organizations due to the disruption of work that was already being done within African communities.
- Provide capacity building and technical assistance for smaller organizations to grow and better qualify for state funding. Allow smaller organizations to focus on the community-based work while, for example, partnering with a larger organization that can handle tasks such as accounting or administrative work.
- Move away from competitive grant-making processes as these are too complex and prohibitive for smaller organizations. Grant-funding models also pose other challenges in their selection and implementation (e.g., needing to have "evidence-based" approaches that may not work in African communities, proposals for funding graded on writing, grant funding runs out). Consider a cohort model of organizations to create a common agenda with MDH/DHS and have mutual accountability.

Strategy 2.4: *Reduce HIV-related stigma, systemic racism, and other forms of structural discrimination that prevent people from accessing HIV care and prevention services.*

- Stigma is a major factor/barrier to accessing HIV education, care, and prevention. Addressing stigma is the most important factor in the ongoing work. Create urgency in and by the community to bring the issue into focus and reduce stigma.
- Any tactics to address stigma and structural discrimination/systemic racism need to be culturally responsive and community driven—people will listen to those whom they trust.
- Reduce stigma by integrating HIV services with other health services. For example, by providing HIV testing at a "health fair event" with multiple types of testing (blood pressure, blood sugar, etc.), or by providing access to PrEP at the community pharmacy. In both instances, people are able to avoid outing themselves for "going to the [HIV] clinic" or specifically getting HIV testing.
- African-born residents need different strategies than Africans born in the U.S.; strategies need to address continual influx and learning of new people coming from movement back and forth between the U.S./Minnesota and Africa.
- Address care and prevention for undocumented citizens.
- Address the generational nature of the disparities that exist; this includes educational restrictions on who can do the work (for example, requiring a master's degree for certain positions).

Goal 4: Ensure stable housing for people living with HIV and those at high risk for HIV infection

- Provide subsidies for existing housing (e.g., rent vouchers and transportation supports) so that people can live near their existing communities and where they work; make it a priority to keep families and communities together.

Priorities identified during June 27 follow-up meeting

During the follow-up meeting, MDH, DHS, and Wilder sought recommendations about high-priority next steps as well as guidance on the best way to communicate with African-born community leaders and members about next steps and progress on the Minnesota HIV Strategy. Those recommendations are listed below.

High-priority next steps

- Prioritize providing funding and other support to African communities that have the highest incidence and prevalence of HIV here in Minnesota.
- Prioritize reaching out to the "gatekeepers" or champions within the community, such as faith-based leaders and formal and informal group leaders who are committed to their communities and the work of ending HIV/AIDS.
- Prioritize community education with simplified data, working with and providing training and funding support to the community to do this.
- Prioritize providing organizations and leaders within the community with ongoing support and capacity building in order to promote sustainability. Organizations and leaders within the community should be charged with leading the work of ending HIV/AIDS within their community.
- Prioritize working with community to build an idea of what success in this work looks like within the community. Do this instead of imposing benchmarks or guidelines of what success looks like from the state/institutional perspective.

How to communicate with African communities, and vice versa

- Participants expressed a specific desire for this communication to be bi-directional. MDH and DHS should not just communicate with communities, but communities should be able to initiate contact and communication with the state as well. Ensure that there is mutual accountability.
- Begin by bringing leaders from the most impacted African communities and state staff together for face-to-face dialogue.
- Ensure continuity across contact and engagement; in the words of one participant, "It needs to be a continued, ongoing relationship. We can't just jump in and jump out."

Web survey input

In addition to the facilitated workshop, a web-based survey was offered so that individuals who were unable to participate in the workshop were able to contribute their input. The survey asked respondents to identify the three strategies that they feel are most important for the African-born population, to recommend a tactic that addresses each strategy, and to identify barriers to implementing the tactic as well as resources that could support it.

Eleven people provided input via the survey. Table 1 shows survey participants' roles or areas of work. Participants could select multiple roles or areas of work.

Table 1. Roles of survey participants

	Survey participants (N=11)	
Role or area of work	N	%
Advocate for, or member of, high-risk population[a]	2	18%
Chemical dependency provider	0	0%
City or county public health or human services professional	1	9%
Faith leader	1	9%
HIV services provider	1	9%
Housing provider	1	9%
Medical provider	2	18%
Mental health provider	0	0%
Social service provider	0	0%
Youth advocate/youth worker	0	0%
Other	2	18%
Prefer not to answer	1	9%
Missing	1	9%

Note. The numbers above may not sum to the total number of participants because each participant was able to select multiple roles.

[a] High-risk populations include men who have sex with men, people who inject drugs, people experiencing homelessness, African-born men and women, African American women, Latina women, and transgender people.

Strategies prioritized by survey respondents

Web survey respondents were also asked to identify strategies that they thought were most important for ending HIV/AIDS in the African-born population. Each survey respondent could identify up to three strategies they thought were most important. The most commonly selected strategies are shown in Table 2.

Table 2. Prioritized strategies from survey participants

Strategy	N (out of 11)	%
Strategy 2.2: Engage community leaders, non-profit agencies, people living with HIV (PLWH), and other community members to identify and to address barriers that prevent testing and person-centered care.	6	55%
Strategy 3.3: Provide culturally and linguistically appropriate services, as well as gender appropriate and sexual orientation appropriate services in clinical and/or community support settings.	6	55%
Strategy 2.4: Reduce HIV-related stigma, systemic racism, and other forms of structural discrimination that prevent people from accessing HIV care and prevention services.	4	27%

Note. The strategy numbers (e.g., 2.2) correspond to the numbering system used in the Minnesota HIV Strategy. Only strategies that were selected by at least four people are included in the table; some strategies were prioritized by a smaller number of respondents.

Tactics identified by survey respondents

Each survey respondent was invited to recommend a tactic that should be used to implement each of the strategies they selected as most important. Table 3 lists the tactics that they recommended.

Table 3. Recommended tactics from survey participants

Prioritized strategies	Recommended tactics
Strategy 2.2: Engage community leaders, non-profit agencies, PLWH, and other community members to identify and to address barriers that prevent testing and person-centered care.	▪ [Engage] community health workers (CHW) and Minnesota Local Public Health Association (MLPHA) [in] conversations with leaders. ▪ [Provide] training on basic HIV/AIDS issues and stigma to community leaders, religious leaders, and other leaders. They should know how to respond to an HIV/AIDS problem when it arises in their community and be able to counsel, refer, and connect [community members] with service providing organizations. ▪ Give them the skills to advocate and ask for [what they] want [and] need; listen. ▪ [Engage community-based individuals.] Just as one person cannot run another person's home effectively, so outside-of-the-community experts cannot address local community and individual needs effectively.
Strategy 2.4: Reduce HIV-related stigma, systemic racism, and other forms of structural discrimination that prevent people from accessing HIV care and prevention services.	▪ [Engage] individuals who know the African-born cultures. ▪ [Produce] more media about the changes in HIV. People are still stuck in the 1980s about transmission. [There are] patients [who] refuse to set up local primary care because they believe they will experience discrimination. [Provide] education on professional confidential laws. Educate the population about the importance of primary care. ▪ Education.
Strategy 3.3: Provide culturally and linguistically appropriate services, as well as gender appropriate and sexual orientation appropriate services in clinical and/or community support settings.	▪ [Provide] more community resources for those with Anuak language for meeting basic needs such as county services. Anuak interpreters are difficult to find, and language is very important for medical care. ▪ [Make] health navigators available to newly diagnosed patients. ▪ Speak to functional African-born HIV/AIDS related agencies in Minnesota. ▪ Provide cultural sensitivity training to staff (including front desk folks, janitorial staff, and even executive directors).

Note. The strategy numbers (e.g., 2.2) correspond to the numbering system used in the Minnesota HIV Strategy. Only strategies that were selected by at least four people are included in the table; some strategies were prioritized by a smaller number of respondents. Some respondents did not provide a tactic for their chosen strategies. Some responses that were provided to the question about tactics were non-responsive and thus not included above.

Next steps

Using the information from this summary, as well as other regional and community summaries and a statewide report of synthesized results, the Minnesota HIV Strategy Advisory Board will prioritize a set of tactics to be implemented. In fall 2018, MDH, DHS, and Wilder Research will prepare an implementation plan (including a fiscal analysis which describes the anticipated cost) and an evaluation plan to guide and monitor these efforts.

An updated Minnesota HIV Strategy will be submitted to the Minnesota Legislature by January 1, 2019. The update will include the most current data about the status of HIV/AIDS in Minnesota, information related to the outcomes of the facilitated workshops and web-based survey, the prioritized tactics, and the implementation and evaluation plans.

DHS is creating a new position to coordinate and report on the progress of the implementation and evaluation plans as well as progress in reaching the outcomes and indicators included in the Strategy. As tactics are successfully implemented in coming years, additional tactics will be prioritized and added to the implementation and evaluation plan.

For additional information about developments in the Minnesota HIV Strategy, please visit Minnesota HIV Strategy (www.health.state.mn.us/divs/idepc/diseases/hiv/strategy/index.html) or email Health.HIV.Strategy@state.mn.us.