

Re-envisioning Community Engagement

**A Practical  
Toolkit to  
Empower HIV  
Prevention  
Efforts with  
Marginalized  
Communities**



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# Moment of Reflection

NASTAD recognizes the myriad people who contributed to the development of this toolkit. This project was created and implemented by many amazing people representing the communities highlighted in the toolkit. As the HIV field continues to further integrate meaningful community engagement into programming and practices, it is imperative to recognize the emotional labor this task places on the many staff of color and individuals who identify as Lesbian, Gay, Bisexual, Transgender, Queer, Questioning, Intersex, and Asexual (LGBTQIA+), and many other identities. People of color and those in the LGBTQIA+ community engage in a disproportionate amount of emotional labor in the workplace due to navigating the

daily macro and microaggressions that historical and cultural norms have indoctrinated over time. The more public health communities realize and address the emotional labor experienced by many of these individuals, the more we can truly support our colleagues, partners, and the communities we serve.

*Note: Recommendations in this toolkit and the videos are meant to inform public health efforts; this is not a step-by-step guide to doing the work. As you will see in this toolkit, the community is not a monolithic concept, and the public health response should maintain these distinctions as we respond.*

# Navigating the Toolkit

This toolkit walks through the foundational concepts and principles that shape community engagement within HIV prevention and care. With the identified goals of the Ending the HIV Epidemic in the U.S. (EHE), it is crucial for EHE jurisdictions, health departments, and community organizations to effectively engage communities within the process. Community engagement applies to different communities and regions. When executed with authenticity and humility, community engagement is an effective empowerment tool.

Structured around the community engagement principles, the toolkit content explores definitions, concepts, theories, and practices that integrate community engagement into the fabric of HIV prevention programming and activities. Community engagement is a cumulative process that takes time, patience, and perseverance. The community's needs, how they want to engage, and how they choose to partner

will change over time. However, if HIV prevention continues to center its internal processes and structure around community engagement, it will ensure successful outcomes.

The final section of the toolkit provides practical examples to strengthen community engagement within the health department and community organizations. Below each recommendation, the corresponding principle is noted to bridge where and how the recommendation fits into community engagement overall.

Lastly, there is a section entitled, Culturally Responsive Outreach and Engagement with Diverse Communities and Across Different Strategies. This section is a compilation of videos providing insight into the lived experiences of different community members with health departments and HIV prevention support.

# Introduction

In February 2019, the U.S. Department of Health and Human Services announced the initiative, [Ending the HIV Epidemic: A Plan for America \(EHE\)](#). This initiative seeks to reduce the number of new HIV cases by 75% by 2025 and 90% by 2030 in the communities most impacted by HIV and influenced by social risk factors.<sup>1</sup>

Ending the HIV Epidemic is not a new goal, but it is the first time we have dedicated resources and a solid endorsement of the need for buy-in from all partners and stakeholders. Much of what is discussed in this toolkit can be applied to both HIV prevention and treatment. Activities related to the initiative will be accomplished by health departments and community stakeholders collaborating to create and implement EHE plans that focus on four key pillars (or strategies):

- **Diagnose** all people with HIV as early as possible.
- **Treat** people with HIV rapidly and effectively to reach sustained viral suppression.
- **Prevent** new HIV transmissions using proven interventions, including pre-exposure prophylaxis (PrEP) and syringe services programs (SSPs).
- **Respond** quickly to potential HIV outbreaks to get needed prevention and treatment services to people who need them.

EHE encourages new and innovative approaches that build on non-traditional partnerships and collaborative coordination between community stakeholders and public health providers by framing the work within these pillars.

EHE focuses efforts on 57 jurisdictions where more than 50% of new HIV diagnoses occurred between 2016 and 2017. Within those [57 jurisdictions](#), there are 48 counties, seven states, and two United States (U.S.) territories.<sup>1</sup> Most of the identified jurisdictions are geographically located in the South. Southern states account for 38% of the U.S. population but bear the highest HIV incidence and prevalence, with 51% of annual HIV infections, 46% of people with HIV (PWH), and 51% of undiagnosed HIV cases

(CDC, September 2019). The Centers for Disease Control and Prevention's (CDC) "HIV in the Southern United States" Factsheet shows:<sup>2</sup>

- Eight of the ten states with the highest rates of new HIV diagnoses are in the South, as are nine of the ten metropolitan statistical areas with the highest rates.
- Black people are disproportionately impacted in every risk group, accounting for 53% of new HIV diagnoses in the region in 2017.
- Black gay, bisexual, and other men who have sex with men (GBM) account for six out of every ten new HIV diagnoses among Black people in the South. Among GBM, the number of new diagnoses in Black GBM is nearly twice that of white and Latinx GBM.
- New diagnoses among Latinx GBM in the South have increased by 27% since 2012.
- Among women, Black women are also disproportionately impacted, accounting for 67% of new HIV diagnoses among all women in the South.
- 24% of new HIV diagnoses in the South are in suburban and rural areas – more than any other region of the country.
- The national opioid crisis is placing people at risk for HIV and hepatitis C virus (HCV), predominantly in non-urban areas. 68% of counties vulnerable to an HIV or HCV outbreak are among people who inject drugs are in the South.

It's imperative that ending the HIV epidemic includes strengthening resources and support to communities and people in the South. ■

## SECTION 1

# What is Community Engagement?

Community engagement is defined as “the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people.”<sup>3</sup> Community engagement is an ongoing and cumulative process that centers on trust-building. It takes time to engage community effectively; there are a set of principles that should be followed.<sup>4</sup>

The field of HIV prevention and care services began with community advocacy in 1981 when advocates demanded treatment, research, funding, governmental support, public education, and community resources, including the first community-based AIDS service center in 1982: The Gay Men’s Health Crisis.<sup>5</sup> Every advancement in HIV prevention or care can be traced back to advocates’ resilience and tenacity in the early 1980s. Advocacy is the backbone of HIV work. The strength of EHE is its collaboration between public health professionals, HIV advocates, and the community. For the goals of EHE to be accomplished, the community must be more equitably integrated into current programming.

Although it may be overlooked as an effective tool, community engagement has been a cornerstone of the movement to eradicate HIV from the earliest days of the global pandemic. With the aid of medical advice, activist influence, and public health intervention, the collective field developed a framework. The keystones of engaging the community are built on accountability, respect, multi-sector communication, and a shared desire for an idealized future. Thinking critically about community engagement ensures



that we do not take the community’s involvement for granted and ultimately value their lived experiences and expertise.

## Community Engagement in Public Health

Community engagement continues to be a necessary public health strategy that strengthens programming. The EHE initiative created opportunities to examine how community engagement is employed and reinforced its importance in HIV prevention and care. Each EHE plan is a roadmap created collaboratively between health departments and the local community to promote public health practices and community advocacy. It is a living document readily available to the public and allows for continuous community feedback.

Public health uses community engagement first and foremost to address needs in the community. Engaging communities can also improve people’s health, empower those who lack power to gain control over their health, and connect people to services and programming. Ultimately, community engagement for EHE planning and implementation will build trust and relationships between communities and external parties to form a genuine and equitable partnership to achieve a common goal.

As you explore this toolkit, consider the jurisdiction's EHE plan development and implementation process. Ask yourself these critical questions that challenge how your agency engages with local communities and how these activities can better support the EHE initiative:

- Have you reached out to and included the community authentically?
- What challenges are you still experiencing with specific communities?
- Are those challenges related to internal processes?
- Where has the agency succeeded, where can it improve?
- Are you providing the proper support to staff to effectively collaborate with community?
- How can you integrate community engagement into the programming moving forward?

## Community Health

According to the American Public Health Association (APHA), “public health promotes and protects people’s health and the communities where they live, learn, work and play.”<sup>6</sup> The public health professional’s role is to prevent people from getting sick or injured, promote wellness, and encourage healthy behaviors. The public health worker’s goal in community-focused care is to enhance healthcare services and patient outcomes in prioritized populations. By applying public health theory on a local, personalized level, community health providers can cater to a specific demographic and bring a sense of wellness to communities that otherwise lack proper care access.

Community health is an integral component of public health that focuses on people’s role in enhancing their own health. The work of community health professionals, according to the CDC, “helps to reduce health gaps caused by differences in race and ethnicity, location, social status, income, and other factors that can affect health.”<sup>7</sup> Community health workers design health education programs to reach communities and encourage healthy behaviors. Community health programs address health disparities (i.e., inherent differences experienced by marginalized communities – like race, gender, socioeconomic status – that impact quality of health) by striving for equitable access to health resources.

Disparities often lead to accessibility issues for communities like limited healthcare providers in rural settings, the inability to afford health insurance or receive adequate coverage. Remember, community health centers often serve in place of primary care providers in communities where public health is trying to minimize inequalities and inequities. Given this, they can be a strong partner and source of support for particular communities within EHE planning and implementation.

## Community Engagement in HIV prevention

Traditionally, community engagement efforts focused on addressing gaps and barriers, and gathering feedback from the community. However, typical actions used to engage the community do not always meet the needs of those most impacted. Community members have consistently conveyed that they provide feedback, complete surveys, and participate in focus groups, but that is usually where the engagement ends. The decision-making process is not always open to the community, and the process’s outcomes are not always shared or transparent. This can escalate frustrations in the community. Some health departments have successfully partnered with the community by bringing them to the table and providing space to share their voices (to learn more about what other health departments have done, please reach out to NASTAD [here](#)). Partnering with non-traditional partners is one way health departments have expanded community engagement. This can include barbershops, salons, restaurants, entrepreneurs, or agencies that provide services other than HIV (e.g., local businesses, universities, historically Black colleges and universities (HBCUs), homeless shelters, youth-serving organizations and institutions, or a local American Civil Liberties Union (ACLU) chapter). For example, one county in Florida partnered with a local NFL player to speak with youth in the area. Another example, a county in North Carolina formed a faith-based advisory board. The board discusses appropriate services and information health departments and community-based organizations (CBOs) can provide during church services. The health department invites the advisory board to local and internal meetings and makes a point to ask what they would like to see in the future. These examples may be strategies your jurisdiction has tried and perhaps were not as successful as hoped. Do not be discouraged; remember that community engagement is a long-term, cyclical process. ■



## SECTION 2

# Community Engagement Principles

The health department or CBO should become familiar with key principles to understand community engagement better and use it as a strategy.

As the word implies, these principles provide the foundation for developing partnership and understanding between the agency and the community. The following are the principles of community engagement, and each will be described in more detail:<sup>8</sup>

1. [Set clear goals](#)
  - a. Priority setting
2. [Learn about the community](#)
  - a. Personal autonomy
  - b. Medical mistrust and generational trauma
3. [Develop cultural humility](#)
  - a. Person-centered language
  - b. Recognizing implicit bias and cognitive dissonance
4. [Foster transparency](#)
  - a. Addressing power, privilege, and stigma
5. [Ensure diversity and representation](#)
  - a. Parity, Inclusion, and Representation (PIR)
6. [Provide and promote capacity building](#)
  - a. Asset-based approaches
  - b. Community empowerment, resilience, and healing
7. [Build trust and partnership](#)
  - a. Building rapport through mutual understanding and respect
8. [Maintain long-term commitment](#)
  - a. Establishing institutional consistency

## > The first principle is to set clear goals.

It is essential to be clear about the purpose and goals of the communities in which the health department or CBO is engaging. The goals can be narrow and focused on specific topics (e.g., increasing the number of people who learn about PrEP, engaging three new community partners not traditionally engaged). They can also be broad and focused on general objectives (e.g., increasing HIV awareness in a community, sharing resources and information with the community). Agencies and organizations need to be clear about several different factors as they are setting goals and developing activities toward achieving EHE goals:

- What is the staff/program seeking from the community? Is it information, advice, or feedback to help design/inform programs? To complete data requirements? Mutual collaboration?
- What is the level of partnership? Is the agency able and willing to share power and control with the community? What are their limitations as an agency or organization?
- Who will be engaged or involved? Individuals living in a specific zip code? Individuals who identify as part of a certain race/ethnicity, gender, age group, sub-population (e.g., sex workers, faith-based, people with a disability, etc.), or income level?

### a. Priority setting

Decision-making on how to best allocate resources depends on health department priorities. However, the priority setting process for services and support with appropriate community involvement is also an excellent way to identify mutual goals within EHE or any other programming. Many different factors influence the priorities and vary according to the group, agency, data, social norms, etc. The health department should expect priorities to differ from what the community wants to prioritize. Although people may not always agree on the priorities and perspectives, the variances can provide valuable information about the community's concerns and their identified opportunities.

As stated, priority setting helps pinpoint goals for the program or activities. To achieve desired goals, identify, prioritize, and assess the next steps. Once

goals have been set, establish a process to maintain consistency, accountability, and success in the planning and implementation processes. Such necessary steps to develop a plan include a timeline, budgeting, health communication, monitoring, evaluation, and learning. The health department and the community will want to consistently revisit this process to ensure they are holding to the agreed-upon plan and prioritizing the community's needs. Incorporating a mechanism for receiving feedback from the community is also essential. Lastly, let the community know that the health department is open to receiving input through a formal and/or informal system.

### › **The second principle of community engagement is to learn about the community.**

Become knowledgeable about the community's cultures, economic conditions, social networks, political and power structures, norms and values, demographic trends, history, and experience with previous engagement efforts by outside groups or the health department.<sup>8</sup> Part of learning about and understanding the community's history and experience with prior engagement efforts includes learning about their perception of those trying to engage them – e.g., how the community perceives health department structure. It is also essential to understand how the community will perceive any benefits and drawbacks to participating in engagement efforts and assess their readiness to adopt new strategies. Learning and having a thorough understanding of the community will allow engagers (and potentially the community) to map community assets, understand how the community conducts business, and identify community members whose support is essential for successful engagement.

#### **a. Personal autonomy**

People should be able to decide a course of action in their life regardless of any moral content or perspective and have those decisions respected, honored, and heeded within a social and political context; this is known as personal autonomy. Essentially, it is an individual's capacity for self-determination or self-governance. Working with different communities requires respect for the people's choices with whom the health department is working. It's essential to be aware of and respect that another's personal choices may be different from our own. Most people are making the best decisions they can with the tools and resources available. Part of community engagement includes advocating for clients' patient autonomy, especially those who may have diminished

autonomy. That advocacy may be one of the few sources of support the community or patients have. When faced with differences, open communication and respect allow for compromise, mutual understanding, and progress.

#### **b. Medical mistrust and generational trauma**

As public and community health workers, building a working relationship with community members is essential. A great way to initiate this is to understand and acknowledge medical mistrust throughout history and how it presently influences the community showing up and participating. A long history of medical experimentation and abuses led to feelings of vulnerability, suspicion, and distrust toward medical institutions.<sup>9</sup> Growing research evidence shows that systems-level medical mistrust is a barrier to health care participation and adherence to recommended health behaviors.<sup>13</sup> Medical mistrust continues to be a current and ongoing barrier prevalent within Black, Indigenous, and other People of Color (BIPOC) and other marginalized communities. Reestablishing trust within these communities is essential to reducing health disparities.

In the United States, African-Americans, Indigenous tribes, and other communities of color have endured a history of multiple traumas. When Europeans came ashore to North America, Indigenous people were subjected to colonization, forced marches and displacement from their lands, coercion, false peace treaties, widespread sexual and physical abuse of children, and genocide. African-Americans have endured the legacy of being stolen from their native lands, systematically abused, dehumanized, sexually assaulted and raped, Jim Crow laws, mass lynching, and mass incarceration. Many people carry the burden of historical trauma and navigate a disproportionate number of daily stressors from this legacy. The documented impact of this trauma was even shared by Dr. Michele Andrasik, who wrote an article explaining how generational trauma has scarred the health and well-being of communities of color.<sup>10</sup> To improve our collective community's health, we must strive to make every effort to understand how human beings take in and hold onto trauma and stress so that we can avoid traumatizing and re-traumatizing one another.<sup>10</sup> While outreaching and working with community members, health departments could trigger the generational trauma continuously experienced by people of color.

An example of how this could present in community engagement is where health departments and CBOs are engaging people. When deciding to host activities or where to establish clinics, it is important to have knowledge of the historical context of the locations (e.g., past site of an atrocity or traumatizing site, if a place has cultural or spiritual importance, etc.), particularly in marginalized communities. Although the health department's location may not be able to move, it is important to recognize factors, like the historical context of buildings or sites where participants meet, that lead to re-traumatizing individuals. Recognition can happen from conversations and listening sessions with the community, assessing what (and why) has succeeded or failed in past engagement activities, learning about the region's history, or honoring the past or those involved. Recognizing trauma would be to understand the historical or current events in the communities served by the health departments that are creating opportunities and challenges. After acknowledgement, develop a plan of action to address how the organization will strengthen community engagement strategies. Ultimately, this will be a long-term process and may shift over time, but always push forward by centering the community.

### › The third principle of community engagement is to develop cultural humility.

Public health practitioners are often seen as experts. However, it is impossible for public health workers to thoroughly understand communities' lived experiences and challenges with whom they may not identify. This is where cultural humility can provide space to foster mutual respect and understanding. Cultural humility is the "ability to maintain an interpersonal stance that is other-oriented (or open to the other) in relation to aspects of cultural identity that are most important" to the community.<sup>11</sup> Through cultural humility, providers can welcome the community into the process, creating space for them to problem-solve challenges, voice their needs, identify partners, and direct what support could be prioritized.

#### a. Person-centered language

Language is powerful; it can empower people or oppress people. This section of this toolkit has described the role language can play in societal inequities, injustices, and distrust; it can be a key factor that separates or unites different groups. How the community, our patients, or stakeholders identify should center their humanity, which is why we use person-centered language. Person-centered language is a linguistic prescription to avoid

marginalization and dehumanization regarding a health issue or disability.<sup>12</sup> This practice may seem unimportant, but it is a subtle rebuke of oppressive and stigmatizing language. Identities, preferences, and other factors are consistently used to devalue groups making it easier for dominant people, groups, and systems to perpetuate repressive policies, procedures, and beliefs.

Standard practices of person-centered language include not describing people by their illness, disability, stigmatized behavior or situation (e.g., retarded, crazy or psycho, epileptic, drug (ab)user or addict, hobo), and not using morally loaded descriptions (e.g., infected, fairy, junkie, dirty or clean, bad blood, hooker or prostitute). Here are some other examples of person-centered language:

- people who live with HIV
- people of trans (or non-binary or non-conforming) experience
- people who use drugs
- a person experiencing homelessness.

The use of stigmatizing and hurtful language may further isolate the community that the health department or CBO is trying to engage. Providers can always ask individuals the language they prefer to be used to reference identity or status. Using person-centered language prioritizes community power. Additional resources for person-centered language can be found through the University of Minnesota's [Center for Practice Transformation](#).

#### b. Recognizing implicit bias and cognitive dissonance

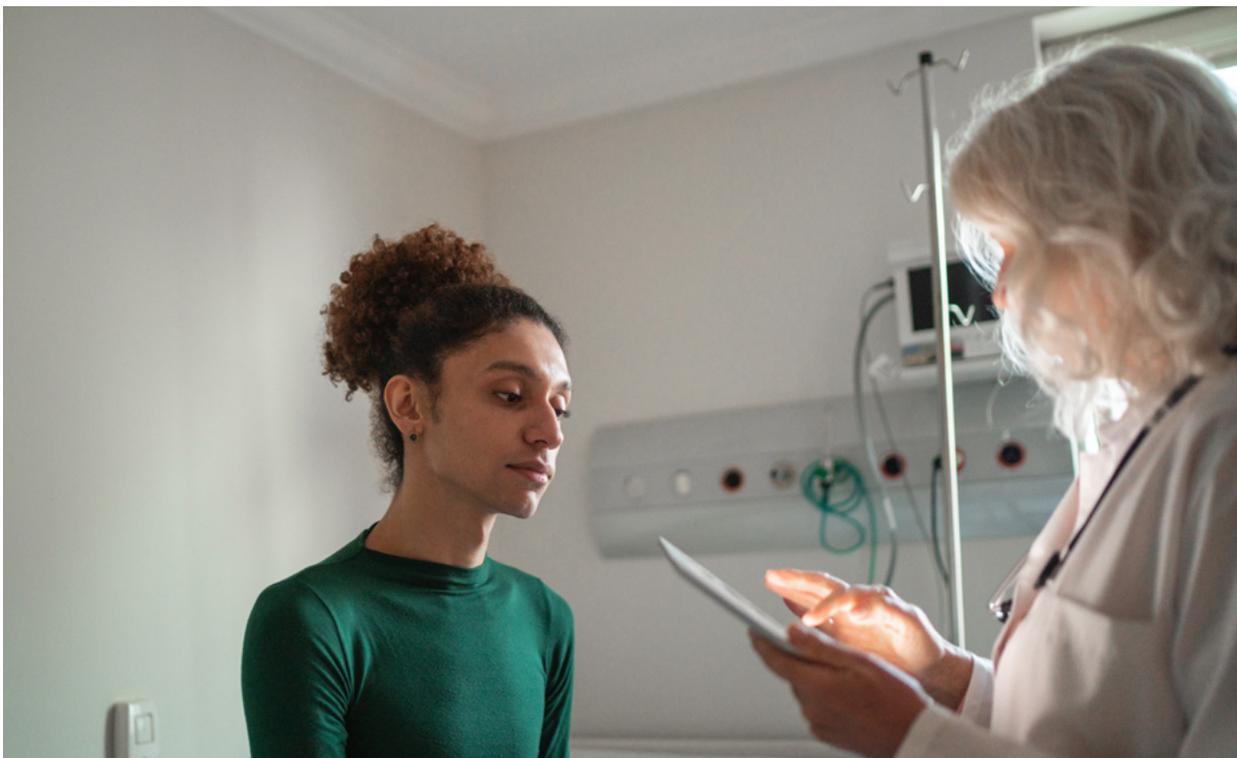
Two of the most significant issues that exist in addressing the HIV epidemic, especially when engaging with the community, are implicit bias and cognitive dissonance. Implicit bias describes an attitude or stereotype that unconsciously affects understanding, actions, and/or decisions.<sup>13</sup> Implicit biases are subtle, unintentional, and unconscious forms of discrimination activated unknowingly by situational cues (e.g., a person's skin color or gender expression). These forms of biases most often reinforce prejudices and stereotypes, which can perpetuate stigma or inadvertently influence conscious evaluations of others. This can seriously impact health behaviors and outcomes (e.g., patient-provider interactions and clinical decision-making). Implicit bias is widespread, meaning everyone possesses them, even those committed to fairness. Explicit biases are related but a very different

mental construct from implicit biases; they are not mutually exclusive and could even reinforce each other. People's implicit associations do not always match up with declared beliefs or even reflect stances explicitly endorsed. People generally tend to have biases that favor their ingroup – a group of individuals connected through shared identity or characteristics that produce feelings of solidarity (e.g., white queer nonbinary person or light-skinned biracial cisgender immigrant). However, research shows implicit biases can still be held against a person's ingroup. Lastly, implicit biases are malleable, meaning they can change. Implicit associations formed in the brain can be gradually unlearned or undone through various debiasing techniques to transform how one thinks about things.

Cognitive dissonance is a state of internal conflict that arises when an individual holds beliefs, attitudes, or behaviors incompatible with one another.<sup>14,15</sup> The conflict often causes a state of confusion, anxiety, or discomfort that motivates individuals to move out of dissonance. It is common to accept something as true more readily when it aligns with an individual's pre-existent beliefs; however, life experience or new information can challenge preconceived notions.

Examples of implicit bias and/or cognitive dissonance in a healthcare setting:<sup>16-18</sup>

- A health provider who does not offer or selectively offers sexual health vaccinations (e.g., HPV, hepatitis A and B, etc.). This action can be pervasive by only offering certain vaccinations to young girls but not boys, through hyper-sexualizing girls vs. "saving" young boys, etc. This reinforces distrust and is unethical medical practice.
- A health department assigning a young queer man to work on a gay nightlife outreach program, based on the assumption he knows the scene (e.g., clubs, parties, etc.) and the people who participate in it. This stereotypes the staff person because of one characteristic, disregarding their experience, comfort, or if they are the best person.
- A health provider perceives a patient who is a sex worker as too promiscuous, financially irresponsible to adhere to a drug regimen (e.g., PrEP), or is scared they will sell the pills, so they refuse to prescribe it. This reinforces stigma and distrust within the community.
- A bachelor's or master's education level requirement on job openings without substitution of lived experience (e.g., drug



use, sex work, homelessness, etc.) or existing community connections. This can alienate good candidates and community members' trust in your staff and program.

- A health provider improperly treating a Black patient for pain management because of implicit associations (e.g., Black patients exaggerate, they are just trying to get pain medication, etc.), despite research disproving these beliefs. Again, this reinforces stigma and distrust within the community.

Let us use this case study to demonstrate how this may present. Note that this example has the potential to reinforce the existing stigma that members of the community feel: John Doe comes in for an appointment with their new Infectious Disease (ID) provider. During their appointment, John discloses that they have five partners and don't use condoms with any of them. However, John and their partners get regularly tested and have committed to only each other. Although John's viral load is undetectable (aka suppressed) and several of their partners are on PrEP, the provider lectures John about how they are irresponsible and endangering their partners. Since John is undetectable, the provider knows that they cannot transmit HIV to their partners, but the provider has assessed that John's lifestyle means they are negligent. After leaving the appointment, John is angry, ashamed, hurt, and confused; they don't return for a follow-up appointment six months later. Unknown to John, the ID provider has been in a long-term relationship with one partner but has never been tested nor had a conversation with their partner about monogamy because they aren't engaged in what they believe to be risky behaviors.

There are a couple of facets of cognitive dissonance present in the case study:

- The provider knows that people living with HIV and undetectable cannot transmit HIV to sexual partners. However, his implicit bias against an HIV-positive status results in conflict, making him believe the patient's protection strategies are ineffective.
- The provider used a coping strategy (e.g., rationalization, denial, minimization, etc.) while lecturing the patient to justify their approach.
- Power dynamics are coming into play where the provider used their status to shame the patient.

- The provider, while well-educated, has not applied any of their knowledge to their own relationship. Although the provider does not have HIV, they have not taken the necessary steps to get tested because they don't think they are at risk.

One may look at this example and think, "The provider was being honest about the client's risky behavior." However, the perceived honesty may come off as judgmental to some clients. If John feels judged by the provider, this can further stigmatize them and create a significant barrier to engagement and care. To achieve transformational learning ("the process of deep, constructive, and meaningful learning that goes beyond simple knowledge acquisition and supports critical ways in which learners consciously make meaning of their lives")<sup>19</sup>, the provider should take accountability for how their behavior reinforced distrust and reflect on where there could be changes in the engagement. Introspection and self-accountability are crucial parts of community engagement work. Transformational learning happens when people open their hearts and minds to this work, not just the knowledge of the work.

A situation like the one in the case study can significantly impact community engagement because it can intensify distrust and persist prejudices. Perhaps the provider does not work for the health department but has a close working relationship and is present at various stakeholder meetings. The provider's proximity to the health department may reinforce negative perceptions the community could have about the health department. Additionally, it is anticipated that the community would have acquaintances and networks that promote negative beliefs about the health departments and their programming.

Within the context of EHE planning and implementation, it is crucial to recognize the role of cultural humility within HIV prevention and care programming. Offending and disrespecting groups and individuals, even if unintentional, will impact the community's perception of your program, your colleagues, and your effectiveness in reaching the goals. Also, note that offenses may come from affiliated community partners and health systems and can impact your perception just as seriously. As you identify needs and activities within your plans, take the time to ensure that you properly address implicit bias and cognitive dissonance, reinforce person-centered language, and create an accountability response should any mistakes or conflicts occur.



### › The fourth principle is to foster transparency.

Transparency is key when engaging with the community, particularly when discussing power and partnership. It is a term that often gets tossed into conversations with the community because it is an essential component of a partnership. It is also often misunderstood and perceived differently between groups, which can cause tension and problems. Learn about and understand the internal hierarchies and power dynamics that direct the agency or organization's work. This information will help guide the next step, having open and honest conversations with colleagues, partners, and the community. Meaningful community engagement is about building camaraderie, which may mean sharing power dynamics and/or deferring to the community's guidance.

This could look like allowing community members to lead a task force group or allowing community members to co-direct the implementation of a new initiative. Given agency structures, this can be challenging but can support achieving equity.

Public health tends to do this already (e.g., community-based [teach-backs](#)) in a clinical setting with how providers engage and communicate with patients. For example, using plain, comprehensible language that is comfortable for the community.<sup>20</sup> To see this in practice, look at data and surveillance. Standard language in reports includes how the community is identified (e.g., MSM). Often, this does not align with how the community wants to

be identified in reports. The misalignment is for various reasons, but if this is the case for your health department, then this is a place to have transparent conversations with plain, accessible language. Ask the community how they would like to be identified, brainstorm how the health department can ensure they respect the community's wishes, and be honest about places you may not be able to meet the requests. Again, this may come up within funder reports, but perhaps there are opportunities to include in the report where language differs or the community's feelings about problematic language.

It is also important for the program, organization, or agency to identify and admit any existing limitations in transparency. Limitations may derive from funding requirements, confidentiality, programmatic capacity, time constraints, or organizational policies. Be straightforward and sincere about the limitations and if any cannot be addressed (e.g., legislation, external policies). However, continue the conversation to determine which can be addressed through internal policy changes, communication with funders about issues, or additional resource allocation. Overall, ownership of limitations sets a standard for both the community and partners connecting. The community will respectfully challenge transparency and any limitations, but that is okay.

#### a. Addressing power, privilege, and stigma

Community engagement is a key component in the success of the Ending the HIV Epidemic (EHE) plans and is crucial to addressing power dynamics, privilege, and stigma. Health departments in the Southern United States have a unique history influenced by racism, economic and normalized discrimination, and stigma when engaging with priority populations. As a result, historical and current medical mistrust can greatly impact effective community engagement. Therefore, it is beneficial to health departments to successfully acknowledge the medical mistrust to engage priority populations. "Stigma refers to the social devaluation of people who are different due to conditions that do not affect the majority of a population (e.g., HIV, mental illness), or more ordinary conditions that affect many or all in a population (e.g., demographic features tied to age, race/ethnicity, gender)."<sup>21</sup> Power reflects how groups are included in the society in which they live, work, play, and worship, which is vital to the physical, psychosocial, and political empowerment underpinning social well-being and health equity. Simultaneously, power structures create the conditions necessary to implement effective community

engagement efforts or limit the engaged subjects' action, voice, and autonomy. Inequitable power dynamics are an ongoing dilemma of public health since interactions are sometimes rooted in the agency or organization's interest (e.g., superficially joining in the community to gather data). A power dynamic often exists in community engagement efforts because individuals outside of the community who provide their skills and resources may not truly understand or connect with the community but feel they can speak for or act on behalf of the community.

An example of how this manifests in HIV programming is in partnering with a local organization: a health department released a Request for Proposal (RFP) to partner with a new CBO to educate and encourage HIV testing in the Latinx community. They are deciding between two applicant organizations. The first CBO has been around for 30 years, is well known in the health department, and provides many health services, including HIV prevention. They have locations in certain areas of the region, but none in the area where many Latinx communities reside. The second CBO has been around for five years, is not as well known in the health department or regionally, and provides health services, including HIV prevention, where there is a sizeable Latinx population. After the health department examines the RFP applications, they decide to proceed with the first CBO because they can provide many more services, are well known to the health department, and feel the application was well written and delivered.

Although the first CBO is a good organization, they may not be the proper organization for this particular RFP. The application is well written because they can hire grant writers, but they don't have a presence in the community or the proper services (e.g., language access) to support the community. Simply, they may be considered the safer option for the health department because their work is known. However, here is an opportunity for health department staff to invite a new partner into the work, learn more about this organization, and learn from them about connecting with the Latinx community.

Health departments can engage individuals who access services and gather input on recommendations for what to include in the RFP/RFAs. Lastly, health departments should continually cultivate relationships with emerging providers or potential emerging providers and build this into the planning efforts. This is an opportunity to use the health department's position, power, and privilege – by re-examining their policies, procedures, resource allocation, and funding structures – to invest in the community.

Typically, the skills and resources are intertwined in their positions of economic, social, and political privilege. Privilege operates on personal, interpersonal, cultural, and institutional levels. It is crucial to acknowledge the power and privilege that health department staff possess based on race, education level, social status, sexual orientation, gender, etc. when planning community engagement efforts in EHE implementation. Please refer to the [Social Determinants of Health](#) section of the toolkit for more tips on addressing stigma in EHE community engagement.

Practical concepts for addressing power dynamics, privilege, and stigma in community engagement:

- Implicit bias training aims to identify unconscious judgments within the health department staff based on ingrained stereotypes. This is crucial when engaging with priority populations because it will affect HIV testing, prevention, and treatment efforts supporting the EHE plan.
- Structural competency recognizes systemic, institutional, and policy-related barriers that cause social and health inequities. It is important to understand the difference between cultural responsiveness and structural competency. Whereas cultural competency focuses on identifying provider bias and improving provider-client understanding and communication, structural competency emphasizes diagnostic recognition of the economic and political conditions that produce and racialize inequities in health in the first place. There needs to be a meaningful shift from cultural competency to structural competency within health departments, focusing on cultural humility and responsiveness.
- Positionality is awareness of, and an ongoing internal dialogue by health department staff that examines their role in producing knowledge, research, and programming based on a position of social status conferred on them by heritage training, institution, gender, and/or race.
- Acknowledge the privilege that health department staff possesses and how that will impact the way priority populations receive community engagement efforts. Accept and understand that if you identify as white, cisgender, male, heterosexual, American, or

educated (Bachelor's, Master's, or Doctoral degree), you possess some privilege compared to priority populations.

- Community engagement must consider incorporating principles from Community-based Participatory Research (CBPR) that acknowledge power dynamics.<sup>22</sup> This is especially necessary when health department staff and researchers representing centers of power, privilege, and status engage with communities that have been shaped by a history of structural, socioeconomic, and racial/ethnic inequities.

#### Additional Resources:

*Addressing Stigma: A Blueprint for Improving HIV/STD Prevention and Care Outcomes for Black and Latino Gay Men:* <https://nastad.org/resources/addressing-stigma-blueprint-improving-hivstd-prevention-and-care-outcomes-black-latino>

*Talking Points: The Resource Guide for Facilitating Stigma Conversations* <https://www.nastad.org/talking-points-resource-guide-facilitating-stigma-conversations/vignettes>

### › The fifth principle is diversity and representation.

Elements of diversity and representation can affect a community's access to healthcare, health status, and response to engagement efforts. A diverse representation of community members creates buy-in and encourages the community to participate. The program will also more readily identify which identities or communities are missing in the process.

#### a. Parity, Inclusion, and Representation (PIR)

An existing and effective tool used by public health professionals is the process of parity, inclusion, and representation (PIR). As one of the fundamentals of HIV community planning, it can be very beneficial to center this process on community engagement. Parity is a state of maintaining equity regardless of inequalities.<sup>23</sup> Identifying goals, expectations, and where disparities exist in the HIV planning group or community engagement activities are great places to ensure equity. Connected to parity is inclusion. Inclusion is "the practice or policy of providing equal access to opportunities and resources for people who might otherwise be excluded or marginalized, such

as those who have physical or mental disabilities and members of other minority groups."<sup>23,24</sup> Health departments can practice inclusion by involving the community earlier in the decision-making process, inviting nontraditional partners or new voices, or providing skill-building opportunities to expand community awareness. Inclusion ensures that the nontraditional and local partners' views and perspectives are included in a meaningful manner in the EHE planning process.

Representation outside of public health is typically defined as how media portrays things about society, including individuals, populations, and communities.<sup>25</sup> Representation in public health is essential because we all like to feel that we can relate to something or someone. It can also help embrace an identified culture, create space for often missing stories, or ground reality for many people. For this toolkit, media signifies how health departments, CBOs, national organizations, and federal partners portray communities.

Representation can challenge believed "norms" and allow for acceptance. Let us explore how this may play out in the health department. More people feel comfortable living authentic and open lives as LGBTQIA+ and many other identities at younger ages. Because of this, there is an increased request for LGBTQIA+ representation in the media. Unfortunately, the media portrayal may perpetuate stereotypes and stigma. The limited LGBTQIA+ identified folks in media are often hypersexualized, non-dimensional side characters from a heteronormative perspective. In many instances, the media continues to treat queer romantic relationships as synonymous with sexuality and sex, leading larger society to view these relationships as taboo or non-substantive.

Additionally, many LGBTQIA+ identified characters or figures in the media are white, able-bodied, fit, cisgender men, which is not representative of the greater queer community (people of color (POC), women, gender non-conformity, youth, etc.). This singular portrayal can create a negative self-image, reinforce stereotypes and/or stigmas, and isolate people. As previously stated, societal representation has been limited. This should not extend to your programs and engagements. As health departments and CBOs look to engage many different communities, always ensure that portrayals, images, marketing materials, and promotions reflect all identities.

As important as PIR is, part of this process recognizes that the communities engaged with are not monoliths, and neither are the entities doing the work. PIR at all levels is essential (coalitions, leadership roles, etc.). However, it cannot just happen to check a box; it must be authentic to serve its purpose. Communities have intersectional identities that influence their experiences and how they choose to show up in environments. Intersectionality is an analytical framework to understand how people's social, cultural, and political identities influence oppression and privilege. Because of varying intersectional identities, what works for one group may need to be modified for another.<sup>26</sup> The community can feel empowered through intersectional and realistic portrayals; they will feel visible, connected, and heard. This can translate to people seeking guidance or support from professional and knowledgeable sources, like the health department, and improving their health quality (e.g., learning safer sexual practices, harm reduction, consistent HIV/STI testing, etc.).

### › Providing and promoting capacity building is the sixth principle of community engagement.

Engagement is more likely to continue when health departments and CBOs incorporate learning, training, and skill-building. Potential trainings to offer the community includes leadership development, securing resources, partnership and coalition building, resolving conflict, or organizational development for grass-roots initiatives. During the COVID-19 pandemic, health departments moved towards virtual means of engagement and capacity building. NASTAD hosted a [webinar](#) that shared more community engagement information through digital technology. Community members can bring about change and act if empowered with proper support and resources.

#### a. Asset-based approaches

HIV prevention strategies traditionally use assessments, surveys, and counseling to address the community's needs, challenges, and behaviors. While these can be valuable tools, they focus too much on the community's deficits and perceived weaknesses, reinforcing stigma for those community members. Instead, asset-based approaches (also known as strength-based approaches) in community engagement emphasize the community's skills, knowledge, and experience. It values their competence and vulnerability to be open while building on a combination of diverse and differing human, social, and physical capital existing in local communities.<sup>27</sup>

This approach can empower the community to work with

health departments and CBOs to promote partnership, autonomy, and confidence. However, when incorporating asset-based approaches into the work, be sure that it is authentic and lacks condescension; the community will sense insincerity. To get started, here are five key questions the health department may want to ask:<sup>27</sup>

- What can the community do best by themselves?
- Where can partner organizations provide support and skills?
- What do community organizations do best (as opposed to health departments)?
- What can the agency stop doing because people in the community can do it themselves?
- What can the agency offer to the community to support its actions?
- How can I enlist some of these human assets to help advance public health goals?

#### b. Community empowerment, resilience, and healing

Once acknowledgment of mistrust occurs, the community and health department can move toward healing. Marginalized communities are not limited by their challenges; they hold a lot of power and resilience. Community empowerment and resilience will dismantle the community's lack of trust and build great relationships over time. Progress in this area would depend upon the community member's efforts and willingness to work with the health departments in community engagement efforts. The World Health Organization (WHO) defines community empowerment as "the process of enabling communities to increase control over their lives."<sup>28</sup> Community empowerment is viewed as the model for affecting social, economic, and political changes that improve whole communities' quality of life by sharing existing power (i.e., some gain power and others lose some power).<sup>29</sup> However, at any level, the community empowerment process should start with practical community issues that are achievable in that they can produce small visible successes in the short term. This helps sustain interest and promote the progression onto more complex initiatives.

When organizations engage in community empowerment, they are uplifting community resilience among the individuals. Communities are resilient because of their survival, but empowerment means they can use that resiliency to inform better strategies or solutions because

of their lived experiences and expertise. According to the National Health Security Strategy, resilient communities are composed of “healthy individuals, families, and communities with access to health care and the knowledge and resources to know what to do and care for others in routine and emergency situations.”<sup>30</sup> Resilient communities have the power to sustain, the ability to withstand, adapt to, and recover from adversity. Uplifting a resilient and robust community could bring forth better community engagement. There are resilience domains that could contribute to the community’s overall strength, such as physical resilience or resilience in the built environment. However, the community’s power is heavily dictated by the level of involvement given to community members. Health departments cannot expect to make a healthier community if they fail to involve community members in their community engagement efforts. Repeating the cycle of creating programs without the community’s input will only add fuel to the emotion of distrust.

For centuries, communities of color, sex workers, and people who use drugs have experienced medical mistrust and lacked support from their community leaders and organizations. Even with increased protections, laws, and ethical considerations, marginalized communities may still feel invisible. Trust will always be weak or nonexistent until the field appropriately recognizes the communities’ diversity and honors their importance. Public health practitioners can take active steps to start building trust by “using community workers, working with faith-based organizations, hiring health care staff which reflects the population, and respecting people’s time and effort by providing participant compensation.”<sup>31</sup> Another method is to “include facilitating opportunities for communities with lived experiences to be heard, acknowledging power dynamics, competently and sensitively addressing historical and ongoing injustices, incorporating trauma-informed approaches, having open and honest dialogs about risk, and obtaining federal certificates of confidentiality.”<sup>31</sup> It is in the organization’s best interest to create a line item in the budget to allocate funds towards the community members who facilitate their personal insights and expertise. As you continue to read the toolkit, we provide examples of capacity building and leadership development for communities.

› **Central to effective community engagement is the seventh principle, trust-building and partnership.**

All partners need to be actively respected from the start. Treat community members with compassion and care, listen to their views, and consider their perspectives. Community members are more likely to stay involved if they can see a real change and feel valued.<sup>8</sup> As referenced above, engagers need to be willing to share power and responsibility to build trust among the community to show equitable partnership. The community will hold engagers accountable, and engagers need to honor their commitments and keep promises. Trust is tied to empowerment, and equitable partnership can lead to desired outcomes.<sup>3</sup> Every partner involved in the community engagement process is responsible for the outcomes of the engagement efforts.

Here are some reasonable action steps to build trust, collaboration, and partnership within community engagement efforts.

- Recognize one’s privilege, and how that may influence the work and the community served.
- Acknowledge the historical trauma encountered by community members.
- Construct a plan of action to address how the organization will implement better community engagement strategies.
- Collaborate with the community to identify strengths and skills.
- Connect with community gatekeepers/key informants.
- Create opportunities for community members to have an equal seat at the planning table.
- Clearly define roles in partnerships and develop shared visions, mission, goals, and objectives.
- Invite grassroots organizations that have built or are building significant relationships within the community to work alongside the health departments.
- Keep the community members aware of the efforts the health department is taking.
- Produce agendas based on the wants and needs of the community members.
- Celebrate milestones and successes with the community, not just the health department or CBO successes, but also the important achievements to the community.

### a. Building rapport through mutual understanding and respect

Community engagement is a mutualistic relationship where goals are achieved by working together to benefit all. However, that relationship is not always immediate and can take time. Remember, community engagement is cumulative, ongoing, and about building rapport. Rapport is an earned, existing, and lasting relationship realized by continuous and open communication, respect, accountability, and willingness to negotiate amongst multiple stakeholders.<sup>32</sup> To build rapport, maintain respect regardless of moral values or perspectives. As health departments, this can include acknowledging the community's experience and identities, listening to their concerns and needs, and creating institutional accountability. Several great ways to start are reflecting on the program's language, how the communities are represented within the work, if the program focuses on community strengths, what the health department reflects in its structure, and what the health department is communicating to partners.

An example is Medication-Assisted Treatment (MAT). People who use drugs that want to seek treatment can access MAT, an approach where medications are prescribed to assist with opioid dependence and can be combined with counseling and behavioral therapies. Ideally, the approach is meant to address patients holistically and to be tailored to each person. Yet, the process often involves punitive measures such as urine screenings or ongoing surveillance, resulting in client termination or creating unnecessary barriers to care. Clients engaged in drug use or sex work must often overcome service provider stigma to access basic medical care, which is often cited as one of the largest barriers to care. Recognition of this issue provides workforce and workplace improvement opportunities for stigma reduction efforts, including ongoing education, training, program evaluation, and ultimately building trust with the community.

Three ways to expand on mutual understanding and rapport building are through person-centered language, recognizing personal autonomy, and the presence of parity, inclusion, and representation.

### › The eighth and final principle of community engagement involves maintaining a long-term commitment that will contribute to sustainability.

Although public health may rely on community engagement for time-limited initiatives, it is imperative to reframe this approach. Like any partnership, the community needs to build comfort and understanding of the relationship. Long-

term partnerships have the greatest capacity for making a difference in the health of a community. Much of what was addressed in these principles takes time but will be worth it, so engagement planning should go beyond the allotted timeframe within the EHE plan.

### a. Establishing institutional consistency

Institutional consistency is a framework for internal and community-facing action established to support the community's needs, regardless of organizational capacity. Specifically, it is the ability to maintain service provision despite internal and external changes, developments, or expectations. Communities feel valued when institutions (e.g., health departments, agencies, community organizations, etc.) align policies and program structures with community input. This involves being accountable for the work, having a basic agreement on transparency, and learning about the community. Organizations should implement and uphold the policies they advocate and "practice what is preached."

Elements that support institutional consistency include:

- Having individuals who identify with priority populations in positions of leadership without tokenization (holding a person in a marginalized group as the sole representation of that group but not actually valuing their contributions to the work),
- Collecting identity-related data to ensure better health outcomes are achieved for specific populations/communities. Surveillance can be extremely triggering for certain communities – like undocumented people or people of trans experience. Be sure to have frequent, in-depth, and open conversations to gauge the community's comfort with how it is conducted. This includes sharing the requirements from grants, what is/is not working, and who is overseeing it. Refer to the toolkit's [Data, Evaluation, and Learning section](#) to learn some strategies to integrate surveillance into community engagement appropriately.
- Engaging with the community in collaboration or with latitude instead of a hierarchy or with dominance,
- Having flexibility when engaging with the community (e.g., times, locations, activities, timelines, etc.), and
- Explicitly stating whether clients are expected to "code-switch" (altering language, way of

speaking, behavior, appearance to optimize comfort for fair treatment) to appease health department structures. Be upfront about those expectations and work to find ways to revise the structures and expectations.

### Stakeholder Engagement

The community engagement process works across various organizations, communities, and systems to help shape the decisions or actions of the health department or a specific program. The organizations, communities, and systems that come together, also known as stakeholders, typically have an invested interest in the community or the outcomes of a program or activities. A stakeholder is defined as “a group or individuals who can affect or are affected by an issue.”<sup>33</sup> In community engagement, the community should be viewed as one of the most vital stakeholders and partner with the health department. Generally, standard stakeholders in public health include three groups:

- Those involved in program operations (e.g., management, program staff, funding agencies),
- Those served or affected by programs (e.g., patients, clients, consumers, advocacy groups, community members, community businesses), and
- Those who use evaluation results (e.g., decision-makers, funding agencies, coalition members).

There are a series of steps to go through when engaging stakeholders:

- Identify and list who the stakeholders are,
- Note key individuals within the list who may improve credibility, support implementation, encourage advocacy, or inform funding decisions,
- Engage those stakeholders and representatives of stakeholder organizations

From there, create a plan for stakeholder involvement and identify areas for stakeholders to provide their input. Stakeholders should be informed and included for regular participation in crucial steps. Potential steps could include stakeholders in writing program descriptions, suggesting and choosing evaluation questions, disseminating the evaluation results, education of services, outreach, etc. Overall, you want to ensure that stakeholders agree on the program’s goals or activities and prioritize the needs of the community.

### Community Engagement Spectrum <sup>27</sup>

	PUBLIC PARTICIPATION GOAL	PROMISE TO THE PUBLIC	
INCREASING IMPACT ON THE DECISION ↓	<b>INFORM</b>	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	We will keep you informed
	<b>CONSULT</b>	To obtain public feedback on analysis, alternatives	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision. We will seek your feedback on drafts and proposals.
	<b>INVOLVE</b>	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.
	<b>COLLABORATE</b>	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	We will work together with you to formulate solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.
	<b>EMPOWER</b>	To place final decision making in the hands of the public.	We will implement what you decide.

When informing the community, organizations often mobilize people to support or provide limited feedback but are not genuinely facilitating community empowerment. Community is considered empowered when they have decision-making power, become advocates and leaders, and feel valued by the agency or organization. It is essential to strive toward a positive, effective, and collaborative relationship with stakeholders. However, not every system, program, or activity can allow empowerment. That’s why it is important to understand how you can engage stakeholders and their role within the partnership. An easy way to decide how you can engage stakeholders is to use the community engagement spectrum. The spectrum graphic was created by the Collective Impact Forum and Leading Inside Out and adapted from the International Association for Public Participation (IAP2). The community engagement spectrum shifts power to and from the community along the range.<sup>27</sup> When organizations are willing to relinquish some of their power by trusting the community, optimum results are achieved.

Understanding and using the community engagement spectrum within EHE planning and implementation allows for better communication with partners and engagement across EHE pillars. Community and partner involvement will vary across the spectrum. It is important to clearly understand the expectations of roles and responsibilities from community to colleagues. ■



## SECTION 3

# Engaging Communities for EHE Planning and Implementation

The HIV epidemic affects different communities in different ways. To achieve the goals of EHE, state and local health departments will need to understand how HIV affects their local communities and partner with individuals who have this knowledge. This partnering is a form of community engagement and can allow for collaboration in developing and implementing state or county EHE plans.

### Outreach and Recruitment of Community Partners

A key component of the EHE plan is the culmination of knowledge, skill, and resources to invite the community and partners into the process. This process includes an assessment of what is available, who is involved, partner strengths, and safeguarding sustainable long-term efforts. However, it is just as important to assess for gaps and what has interrupted sustainability. This is why within the EHE

process, the CDC challenged EHE Phase 1 jurisdictions to identify and engage new and/or non-traditional partners, facilitate their understanding and participation in EHE, and examine ways to leverage existing partnerships in new and innovative ways.

To support EHE phase 1 jurisdictions with TA, NASTAD facilitated conversations with health department staff and community members about past community engagement efforts and opportunities for future efforts. NASTAD also employed different activities and methods to engage the community and partners (both new and remaining partners). From NASTAD's conversation with health departments, they shared that they used traditional community engagement events to gather information on EHE plans and to promote HIV prevention, like education sessions, focus groups, community-based planning meetings, and social/public events promotions.

### New and innovative examples of community engagement include:

- Outreach with local entrepreneurs, especially people of color and local business districts.
- Focus groups in a brunch setting with the

community but not solely HIV prevention focused.

- Local artists to work on promotional projects, like community murals
- Outreach and collaboration with student-led organizations on college campuses to bypass school administrators
- Faith-based advisory group

#### Some of the activities and methods NASTAD used include:

- Contracting with community engagement experts across various populations and social determinants of health (SDOH).
- Facebook Live events – via consultants – for facilitated discussions about trust-building and partnering with health departments.
- Zoom focus groups discussing community engagement opportunities within EHE
- Monthly peer calls around specific community engagement topics to share questions, successes, and challenges
- TA requests, calls, and emails. This ranged from trainings to information dissemination
- Outreach to community organizations and CBO focused blog/digital magazine
  - [CommuniTEA Volume I](#) and [CommuniTEA Volume II](#)
- Community involved and focused EHE promotional videos
- Facilitated townhall event

In an instant, the attention and purpose of community engagement can change. Why is that? To put it bluntly: attention spans are short, interests can wane, internal capacity and community involvement ebbs and flows, messaging changes, and external circumstances force change. Despite the challenges, health departments are presented with new outreach opportunities for groups and individuals; to reimagine the process, use innovation, and exercise creativity.

Nevertheless, how can effective community engagement be maintained and respond to the ever-changing environment? The answer may seem simple, but it requires a lot of work, understanding, and dedication, as we have learned throughout this toolkit. Sustainability isn't just about making certain programmatic aspects of the plan, program, or funding continue, it is also about guaranteeing the people who shape the plan and programs are seen, heard, respected, and appreciated. Community engagement is first and foremost about the people, the communities. They will be the force that promotes and provides sustainability. Align efforts around community engagement principles and then apply the existing continuous quality improvement skills within the agency or organization. Lastly, remember that sustainability, like the EHE plans, should be constant throughout the initiative and beyond; it is not a one-time survey or one-time listening session. Because the EHE plans are living documents, opportunities to update and adjust practices and maintenance of those practices is unlimited. ■

## Maintenance of Engagement Activities

As discussed, foundational work around the community engagement principles is crucial to success within the EHE plans. However, success is only strengthened by sustainability. In the current environment with COVID-19, executing and shaping community engagement is more complicated. Many of the communities served feel the brunt of the challenges, meaning that continued support and advocacy from health departments is more essential than ever.

## SECTION 4

# Practical Examples of Things To Do

## Within the EHE Work

Successful integration of community engagement into the EHE work will depend on the health department's ability to bridge many of the concepts covered in this toolkit into practical strategies. However, translating concepts to practice is often tricky given how different some communities are, program requirements or limitations, and changing priorities. Part of this work requires connecting with the community(ies) and responding appropriately.

Connecting with communities means recognizing, accepting, and adapting the work to the community's intersectional identities. Below are some actions health departments and CBOs can take to ensure that the response and efforts throughout the EHE process are appropriate. If done effectively and appropriately, they can achieve sustainable community engagement.

### Addressing Problematic or Missing Processes and Policies

Unique challenges facing many marginalized communities require specific programmatic and policy responses. These responses may vary depending on the overseeing institution (e.g., federal, state, local, private). These institutions' policies and requested procedures may not align with personal beliefs or the community's wants or needs, leading to conflict and misunderstanding. There also may be some restrictions to approaches or missing policies that could protect or support the communities engaged. As hard as the agency may work to avoid this, this will likely occur. When this happens, it's essential to identify those policies and procedures that are problematic or missing and problem-solve with the community to change or address them. When

doing so, remember to refer back to how the community receives communication, what transparency expectations exist, and where partnerships can collaborate to advocate for changes.

Let's examine an example of the potentially problematic policy of drug testing or sobriety requirements for specific positions. Traditionally, these restrictions are expected in the workplace, but for particular roles, it helps have individuals who are part of the community and may not be sober do the work. Knowing that the worker engaging people has lived experience can increase community buy-in and trust. When developing a job position, think if drug testing or sobriety is necessary (to learn more about what other health departments have done, please reach out to NASTAD [here](#)). Perhaps it's other aspects like the educational requirements, the years of professional experience, or certain professional characteristics (e.g., dress standards), etc. These typical job requirements reinforce privileged systems that continue to marginalize oppressed communities. Lastly, these policies or programs are often directly related to individuals' perceived beliefs (e.g., that people can't be functional drug users or only highly educated people are credible). These beliefs emphasize aspects of problematic policies or procedures, where staff know certain positions require individuals with lived experience who may not fit all of the job requirements, but then don't work to change the process to create space for them.



COMMUNITY ENGAGEMENT PRINCIPLE(S):  
[Develop cultural humility](#), [Foster transparency](#), [Maintain long-term commitment](#)

### Enhanced Communication and Collaboration with Human Resource Departments

One of the best ways to connect with the community is to hire them in positions within the health department. However, some challenges make this difficult to do (see

the previous section). Although the health department may want to hire individuals from the community, the educational and professional requirements may not align with the individual's experience. When this happens, the community may feel discouraged from engaging with the health department because the intention to partner with them will feel inauthentic and patronizing. If this is the case, the health department should work with the human resource (HR) department to discuss these challenges. This will be a time-consuming process, but it is very important.

### Good Community Engagement Practice Tips:

- Invite HR into conversations with the community to discuss what is necessary for the job positions and which things can be revised (e.g., education level, training, experience requirements) to allow for more diverse candidates.
- Introduce and educate the HR team on the work and what is valued by the community. The HR team is situated in the health department, but they generally are isolated from the work, the community, and the training available to program staff. They may not understand why these changes need to occur, but it is your responsibility to teach them as public health practitioners.
- Make sure these conversations are happening consistently. Quarterly, biannual, or yearly meetings where HR and program staff can review existing conflicts, like problematic policies or gaps in hiring practices, needed internal training, etc., are efficient ways to maintain open communication and accountability.



COMMUNITY ENGAGEMENT PRINCIPLE(S):  
[Learn about the community](#), [Foster transparency](#), [Representation](#), [Build trust and partnership](#)

## Establishing Accountability Measures

Setting up a process to collect, analyze, and report information is necessary when implementing activities or efforts. This is known as performance measurement and is very useful in guiding progress, setbacks, and successes. However, do not stop at analyzing and reporting the information; move a step beyond and establish accountability measures.

Accountability measures can be informal agreements between the agency and the community that create ownership of and consequences for performance or actions (negative and positive). It is essential to establish equitable dynamics and clarify expectations between the community and the agency. It also demonstrates accountability by sharing data or information back to the community from where it was collected. Lastly, it allows new staff coming into EHE work to understand what is currently being done and what still needs to be done.

### Good Practice Example:

Let's look at HIV Planning Groups (HPG) or Community Advisory Boards (CAB) for examples of accountability measures. These groups create conditions and a forum for the community to voice their concerns and interests, and collaborate with the health department and CBOs.

- When assembling or reorganizing these groups, **assess the structure and if it effectively and equitably functions**. If not, then there is a good chance that accountability standards are not present. Think back to the previously presented concepts of transparency, limitations, parity, inclusion, and representation.
- **Set standards for the work and roles within the groups**. This can include what program information and data will be shared and how often. Listen to how the community wants to be represented in data reports (especially the GBM and Trans communities). Establish measures for ensuring representation and equity across various identities (i.e., race/ethnicity, gender identity, age, ability, etc.) in the groups. This should be clear across HPG or CAB role responsibilities, expectations, and guidelines.
- After identifying the criteria, it is essential to **form requirements for how the group members and health departments will ensure the standards are upheld**. Some simple ways to do this are to create timelines and check-in points, set micro-goals that tie into larger goals, seek feedback, and institute review periods.



COMMUNITY ENGAGEMENT PRINCIPLE(S):  
[Foster transparency](#), [Build trust and partnership](#)

## Capacity Building and Leadership Development for Community

Health departments have the means to provide development opportunities to the community, which is where capacity building and leadership development play a role. Capacity building is a process where organizations, groups, or individuals enhance their knowledge, competence, and tools to execute the work. Within health department roles, staff seeks capacity building from other sources, but staff also serve as a source to provide capacity building to the community. Examples of capacity building include: skill training (e.g., grant writing education, financial and program planning, communication methods), mentorship, fundraising, compensation for contributions (e.g., hiring people in the community as consultants or staff), alliance or partner building, or networking (e.g., sponsoring participation in national conferences). Providing these opportunities can start to repair some of the mistrust between the community and health departments.

The community has expressed that they only feel involved if the health department needs them to complete surveys. Afterward, they don't see the surveys' outcomes and feel used, discouraging their participation. The more the community feels meaningfully involved, valued, and respected, the more buy-in increases from existing community leaders and potential leaders. There is not solely one definition or notion of a leader because a leader is not one thing. Leaders look different in varying environments and connect differently to diverse communities. As individuals, we should continue learning and sharing. Individuals the health departments are engaging may be interested in stepping up their involvement, connecting with others, and advocating. Again, the health department can help achieve this through leadership development. A word of caution: capacity building and leadership development should not be conflated with management. The health department manages the programs, not the community. Distinguishing between management and leadership is vital to sustaining community buy-in.

### Overarching Questions to Address Internal Capacity<sup>34</sup> for Engaging Community:

- Does this aspect of our organization actively work to erase inequity?
- Does it seek to create justice?

- Is this aspect of our work part of the greater building movement to create and support social change?
- What are the power dynamics at play?
- Is there a single cultural lens through which things get interpreted for the group?
- Whose voices are at the table? Whose are not?
- Who benefits from the way things are currently done?
- Who is hurt by the way things are currently done?
- Are differences celebrated or tolerated?
- What other questions do we need to ask?



COMMUNITY ENGAGEMENT PRINCIPLE(S):  
[Learn about the community](#), [Provide and promote capacity building](#), [Build trust and partnership](#), [Maintain long-term commitment](#)

## Creative Use of Funding to Engage Community

One of the strongest ways health departments can support the community is through funding. Getting funding and resources out to the community allows real change. Still, restrictions often exist on how the money can be used, or systems may become complacent in its distribution. Despite these potential challenges, there are inventive ways the agency can reassess how they spend funds and support the community. One strategy is to utilize microgrants, a small amount of funding distributed to individuals or organizations. Microgrants can encourage meaningful collaborations between stakeholders, support leadership development among those organizations and community members, or distribute practical resources to communities.

Also, review the health department's or CBO's funding requirements and structures. Specific funding requirements may be bypassed, welcoming new partners and organizations into the work through smaller grant amounts. Health departments that have used this strategy have seen great results with CBOs who do not have 501c3 designation (to learn more about what other health departments have done, please reach out to NASTAD [here](#)). It is encouraged

to work with both procurement and licensing to discuss what regulations or protocols must be observed to provide funding through microgrants. Does an agency or provider have to be 'licensed' through the health department to apply? Is there anything in the procurement process that would act as an obstacle to new or smaller organizations? The grants' purpose can be specific to their goals or have a more general focus to address various aspects of the program.

Another innovative approach is re-examining funding processes, like the Request for Proposal (RFP) process. Health departments that have changed their RFP process to make it user-friendly and less intimidating for newer and smaller organizations to apply have welcomed new and diverse partnerships, voices, and perspectives in the work. This is especially good for organizations with established trust and relationships with different communities but may not have the capacity or resources to expand their work.

Lastly, health departments and CBOs should prioritize paying people for their contributions, expertise, and time commitments. The community often provides insight and shares their lived experiences so that health departments can achieve their goals. Now is the time to think beyond (or in addition to) providing travel reimbursements, food/drinks at meetings, minimal gift cards, honorariums, or exposure opportunities. Many community members are tired of these approaches to compensation, and with growing economic disparities, they should be paid. This is a significant sign that they are being valued.



COMMUNITY ENGAGEMENT PRINCIPLE(S):  
[Provide and promote capacity building](#),  
[Build trust and partnership](#), [Maintain long-term commitment](#)

## Data, Evaluation, and Learning

Community Engagement is an essential public health tool that supports improved health outcomes, helps local government promote sustainable decisions, and ensures community empowerment. Good data collection, monitoring, and evaluation are crucial elements to ensuring that we achieve our goal of EHE in the U.S. by 2030. Data collection and analysis could ensure that public health

practitioners identify a particular need or problem in a specific community so that health departments can address and track the process and outcomes of specific programs in addressing public health needs. It is important to learn from existing projects, the impact of projects that may have ended, and community stakeholders' engagement when collecting data to inform EHE efforts.

Before deciding to collect new data, review what data is currently available. Brainstorm any topics of interest, concern, and importance among the health department staff, CBO staff, and the community. Then, document what is identified and prioritized in a matrix structure: social determinants of health (social-ecological model) by HIV continuum of care. Lastly, ask if the existing data are:

- Available and sufficient (or appropriate)
- Available and insufficient (or inappropriate)
- Not available

If the data are available and sufficient, or available and insufficient, develop summary measures and record them on a community indicators table.

If the data are insufficient or not available, then identify methods to collect data for monitoring, evaluation, and learning on community engagement activities, outputs, and outcomes. This is a crucial step in the development of an EHE implementation plan for the planning process. Here are some key questions that need to be raised during this step:

- What kind of data are needed?
- Where and how will data be collected?
- How will community stakeholders be meaningfully engaged in this process?
- When will data be collected (baseline, routine, mid-term, and final evaluation)?
- How are topics and questions developed for the data collection tool?
- Who analyzes the data and reports the outcomes in a culturally responsive manner?
- Who has the responsibility of collecting the data and have they been trained?
- Is there consistency with how data are collected if multiple people are responsible?
- How will the information collected be utilized?
- How will health department staff be accountable to community stakeholders in the process?

**Good Practice Tips:**

- Develop a plan to conduct an internal assessment of the organization's readiness to engage the community. Many traditionally marginalized communities have a complicated relationship with the government due to traumatizing and stigmatizing (historic or recent) events. Consider offering training opportunities to educate staff members on implicit bias, historical trauma, anti-racist principles, and supporting internal conversations on strategies for engaging community members.
- Consider engaging local community partners actively and intentionally in the data collection, analysis, and reporting process. Local community partners include peer workers, the staff at community-based organizations, clients, and consumers. Including partners in data collection enriches the process by providing insight into findings. Those locally engaged are the only ones with intimate knowledge of factors that can both positively and negatively impact EHE implementation efforts.

**Here are some resources on Data Collection, Evaluation, and Learning:**

- [Program Evaluation and Evaluating Community Engagement](#)
- [Community Engagement Resource Guide](#)

Please refer to the [Data, Evaluation, and Learning](#) section of the toolkit for more insight.



COMMUNITY ENGAGEMENT PRINCIPLE(S):  
[Set clear goals](#), [Foster transparency](#),  
[Representation](#), [Maintain long-term commitment](#)

**Connect with Other Professional Agencies**

Social determinants of health (SDOH) or social factors significantly impact the community's quality of life. With

EHE, there are more opportunities to address SDOH in innovative ways. Although this is an excellent step in the right direction, and there are many ways HIV prevention and care can support this work, remember that we do not always have to be experts in those associated fields. Work with other agencies or CBOs and develop strategies to make HIV prevention and care services more appealing, which could be done by providing additional services in conjunction. Trust that individuals in their respective fields know their community and are willing to educate and collaborate with the health department. The use of Memoranda of Understanding (MOU) or Memorandums Memoranda of Agreement (MOA), non-traditional funding prospects, and advisory groups are mechanisms to foster partnerships and expand the range of care to all people impacted by HIV. The more health departments expand their reach, knowledge, and support, the better the health outcomes will be for people at-risk or living with HIV.



COMMUNITY ENGAGEMENT PRINCIPLE(S):  
[Learn about the community](#), [Build trust and partnership](#), [Maintain long-term commitment](#)

**Support Non-HIV Specific Focus from the Community**

As discussed in previous sections of the toolkit, individuals have a myriad of things that impact what and how they prioritize their health. Often, folks can't focus on HIV and sexual health because they are more concerned about heart disease, obesity, diabetes, mental health, etc. Additionally, specific cultures and societies stigmatize discussion of HIV and sexual health. Although professionals know the direct impact HIV may have on particular communities, it may not be prioritized the way it should be. How can the field circumvent these barriers? Build a trusting and respectful relationship by supporting a non-HIV-specific focus. Once this happens, many communities are then open to discussions and programming support. Not only does this mean partnering with other agencies, organizations, and stakeholders, it also includes reexamining where this may need to occur within HIV programming. For example, while outreaching and engaging the community to inform their EHE plan development, one health department brought

folks together for a brunch focus group. During this event, folks who don't usually participate in outreach events were invited, and topics focused on all aspects of health and lifestyle, never directly bringing up HIV and sexual health. Health department staff purposely did this to see if and how HIV came up in the responses and conversations. This provided a different perspective about where HIV is prioritized and insight into how the health department could potentially support community needs to increase attention to HIV prevention. While this approach may not apply to all programming and events, this can have a substantial impact on building HIV awareness, education, and intervention.



COMMUNITY ENGAGEMENT PRINCIPLE(S):

[Set clear goals](#), [Learn about the community](#), [Build trust and partnership](#), [Maintain long-term commitment](#)

## Conclusion

We now have the evidence to support that HIV treatment is prevention, and Undetectable = Untransmittable (U=U). However, to truly end the HIV epidemic, other programs, like hepatitis, sexually transmitted diseases (STD), drug user health, Medicaid/Medicare, Housing Opportunities for Persons with AIDS (HOPWA), Substance Abuse and Mental Health Services Administration (SAMHSA), the U.S. Department of Justice, Supplemental Nutrition Assistance Program (SNAP), and other social services and health programs must be involved.

Involvement is imperative in programming, community planning groups, advocacy, contracts, and anywhere else where decisions are made with the community. This may seem daunting, but like any other process, allow yourselves the time to proceed efficiently and space to regroup if the health department falls short, as long as the consequences don't fall back on the community.

There are many considerations that health departments and community stakeholders have when collaborating in support of successful EHE planning and implementation.

Execution and management may not go as intended, but health departments are learning the best approach for their community. They are reaching out to peers to understand more and address any challenges. History shows that we cannot separate the person from the disease, nor should we; HIV is one aspect of their lives. Therefore, HIV is not just a health issue or a social justice issue but also a human issue. There will always be challenges and frustrations, but if we continue to center our communities (i.e., ensure their needs and lived experiences are prioritized and met), the successes will always outweigh the failures. ■



# Culturally Responsive Outreach and Engagement with Diverse Communities and Across Different Strategies

The following sections and videos were created by NASTAD consultants who are experts in the field and identify with the following communities. They have direct experience and knowledge about community engagement with health systems. The different video sections are:

- Womxn of Color (WOC)
- Gay, Bisexual, and Other Men who have Sex with Men (GBM) – Black and Brown Men
- People Who Identify as Transgender, Gender Non-conforming, or Non-binary (TGNCNB)
- People Who Use Drugs (PWUD)
- Rural Communities
- Youth and Young Adults
- Immigrant and Migrant Health
- Tribal/Indigenous Communities
- Social Determinants of Health (SDOH)
- Data Collection, Evaluation, and Learning (DEL)

The purpose of this section is to provide realistic insights into the experiences clients have had with health departments and community organizations. It also provides recommendations for how to best outreach and engage these different communities across HIV prevention and care. Each of the videos touch on several different community engagement principles; the community engagement principle is noted at the top of each section. The videos should be used to help guide health systems with trust building and rapport through a culturally humble lens as they navigate community engagement and outreach. By listening and learning from the video participants, health departments can strengthen their EHE plans to achieve the identified goals. Lastly, each of the videos touches on one or several of the [community engagement principles](#).

Informed by the consultants' experiences and of those they are interviewing in the community, what is written and shared in the videos is from their voices, their opinions, and shared graciously.

## Womxn of Color (WOC)



**Developed by: Jennifer Lee, PhD**

Jennifer Lee is a passionate public health professional who values the principles of health equity in her leadership and management, especially as a woman of color to ensure that all communities of women are heard, uplifted, and prioritized in the work. Her expertise and experience in providing capacity building and technical assistance has taken her from community organizing, to the Deputy Executive Director of the HEAT Program, to various consulting opportunities, to the New York State Department of Health (NYSDOH)/AIDS Institute (AI) Bureau of Special Populations, and the Center for Quality Improvement and Innovation (CQII).

The term womxn is the most recent alternative political spelling of the word woman to avoid perceived sexism<sup>1</sup> in the standard spelling and to explicitly include all woman-identified individuals regardless of assigned sex at birth,<sup>2</sup> ensuring that our language is reflective and recognizes transgender women and nonbinary people.<sup>3,4,5</sup> Dating back to 1977, it has become a term that stands for solidarity and a commitment to work in collaboration with other oppressed women of color who have been minoritized. To learn more about its history read [here](#)<sup>6</sup> and watch a video of Loretta Ross [here](#).<sup>7</sup>

The terms Womxn of Color or WOC is intended to transcend and embrace diverse shades of color and to welcome and unite those of us who identify as women and gender expansive people of Asian/Pacific Islander, Arab/Middle Eastern, Black/African American/Caribbean/West Indies, Native/Indigenous, and Hispanic/Latin descent.<sup>8</sup>

***Enhancing Community Engagement with Womxn of Color (WOC): Cecilia Gentili***



Why don't we place greater value on the voices of those we seek to serve? Why don't we routinely listen to our most important WOC community members?

The views and experiences of people who benefit, in this case WOC, are often overlooked and underappreciated, even though they are an invaluable source of insight into a program's effectiveness. Listening to those who matter most and centering their voices in our work is essential. We must change the narrative from "hard-to-reach" WOC communities to "engaged and involved" WOC communities for our work to move forward effectively. There may be barriers and challenges, but one small step can lead to larger dreams of sustainable and active engagement and involvement of WOC communities. When we bypass WOC as a source of experience, information, and expertise, we deprive ourselves of insights into how we might do better and improve our services – insights that are uniquely grounded in the everyday experiences of the very people the programs, initiatives, and interventions are created for. Centering WOC embodied knowledge, experiences, and expertise means we hold ourselves accountable to the value that WOC bring to the table.<sup>9</sup> This work must be grounded in collaborative relationships with WOC where trust-building and acknowledgement of historically unjust relationships between WOC communities and HD's exist.<sup>10</sup> Direct action health departments (HD) can take to do this include work from community-based participatory research methods including building meaningful relationships, acknowledging and sharing power, encouraging participating, privileging the community's knowledge, and making equity-oriented change.<sup>11</sup>

The next video will highlight the stories of health departments and how WOC themselves who work within these health departments engaged and centered the voices of WOC – meeting them where they are to build sustainable and impactful programming.

ChyChy Smith is a certified health education specialist, and currently works at the Arkansas Health Department in the Office of Health Equity. As a health equity manager, she is dedicated to promoting positive social change and advancing health equity through education, advocacy, and policy. She is also a Doctor of Public Health candidate, the 2018 recipient of the Arkansas Public Health Association's Emerging Leader Award, and an inducted member of the Sigma Alpha Pi Leadership Society.

Shakia Jackson is the maternal and child health coordinator for the Arkansas Department of Health Office of Health Equity and states that “public health is a selfless but rewarding job with endless opportunities. It allows me to identify my true passion. My lived experiences allow me to form genuine connections with women from all backgrounds, and my life’s work is dedicated to helping women and children, reducing disparities, and creating equitable environments.”

**Enhancing Community Engagement with Womxn of Color (WOC): ChyChy & Shakia**



Disrupting the status quo is about self-reflexivity and taking direct action toward health equity. Reflexivity requires us to analyze our everyday actions and participation in the structural production of social and health inequities. This can include how we are either advantaged or disadvantaged within various institutions by status quo power relations. Reflexivity also calls on us to take account of the values, morals, and beliefs that underpin and inform our worldviews, as well as how our intersecting social positions may impact our decisions throughout the community engagement process.<sup>12,13</sup> Disrupting the status quo is especially important when conducting community engaged work, where power dynamics, hierarchies and marginalization can be reproduced in the process of engaging community members and may cause more harms or mistrust if not addressed.<sup>14</sup>

This last section shares a bit about how to address disrupting the status quo and will reference a [set of questions](#) HDs should utilize when developing internal capacity regarding WOC community engagement. These questions were outlined in Section 4 of the toolkit. It is important to remember they are not an exhaustive list of questions but meant to spark thought and conversation regarding how HD’s can be both self-reflexive and take direct action toward disrupting the status quo.

Lastly, budgeting and funding can have an important role

in disrupting the status quo. On a day-to-day basis, HDs fulfill their WOC HIV-related objectives and goals through developing and implementing well-thought-out policies, plans, institutions, and budgets – ones that hold the promise of being effective – and then assessing them to determine whether they have been successful in realizing WOC positive health outcomes. The budget is one of the HDs most important economic policy document. A carefully developed, implemented, and evaluated budget is central to the realization of WOC health outcomes and wellness. Similarly, WOC communities should be able to hold HDs accountable for realizing their health and wellness needs, they too need to know about the budget, as the budget has a disproportionate impact on their health. Gender-responsive budgeting (GRB) is government planning, programming, and budgeting that contributes to the advancement of gender equality, equity, and the fulfillment of women’s rights. This entails identifying and reflecting needed interventions and community engagement to address gender gaps and services, work plans and budgets.<sup>15</sup> Participatory budgeting compared to status quo normal budget processes have a significant voice in setting priorities for budget expenditure. Such a process is obviously an important step in realizing people’s right to participate with their local HDs and enhances HDs accountability to the population. Simultaneously, it is likely that expenditure of funds through this engagement is more effective in realizing WOC needs because investment choices have been informed by people’s needs.<sup>16</sup> HDs should establish proper mechanisms and inclusive processes through which WOC communities can have a meaningful say in all stages of the budget process and these documents should be made publicly available in a timely fashion so that WOC communities have the necessary information to be engaged and to make a useful contribution to the process. Lastly, key budget information should be produced in a format and using plain language that makes the budget accessible to ordinary people and communities.<sup>17</sup>

The last video highlights the ways in which a community-based organization and WOC disrupt the status quo to ensure WOC lives matter and are valued in their work, leading to meaningful and impactful community engagement and health outcomes.

Dr. Charlene Sinclair is a grassroots organizer steeped in advancing the intersection of race, gender, and economic justice. She is the Principal of InSinc Consulting Collective, a consulting firm that provides strategic and organizational development assistance to social justice organizations and progressive grantmakers.

**Enhancing Community Engagement with Womxn of Color (WOC): Dr. Charlene Sinclair**



**Gay, Bisexual, and Other Men who Sex with Men (GBM) – Black and Brown Men**



Developed individually by: Torrian Baskerville and Oscar Lopez, [Poderosos](#)

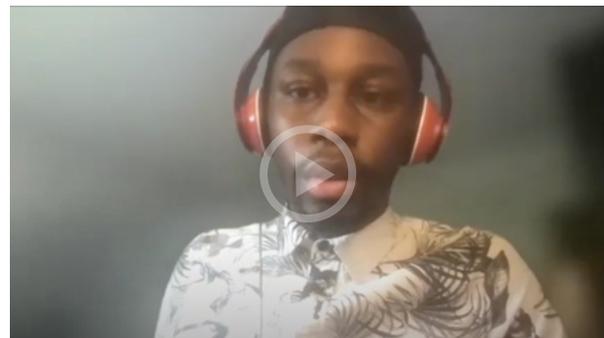
Oscar Lopez is the CEO and National Director of Policy for Poderosos. Poderosos prioritizes improving the health of immigrants, queer youth, MSM, cis- and trans-women, and other minority groups with a focus on Latinx people. He has dedicated over 25 years of his life addressing the intersecting epidemics of HIV, viral hepatitis, substance use disorders and other related conditions.

There is growing recognition that a singular focus on biomedical treatments is insufficient to address the HIV prevention and healthcare needs of Black and Latino men who have sex with men (MSM). Ending the HIV epidemic requires a multifactorial approach accounting for the social, cultural, economic, and environmental factors that drive transmission of HIV and STIs. Emphasis will need to be placed on the development and financial support of culturally appropriate HIV prevention interventions for MSM of Color that explicitly acknowledge the social determinants of health – particularly stigma, homophobia, poverty, and discrimination (both racial and sexual) – and new aggressive interventions (e.g., PrEP and HIV viral suppression), while

focused on the realities lived by MSM of Color. If done effectively, then we will see the reduction new HIV infections and people living with HIV thriving. Culturally appropriate, locally developed and HIV specific prevention interventions provide a model for HIV health-care providers, public health officials, and community leaders to address the unique needs of Black and Latino MSM.<sup>1</sup>

**Black and Brown GBM:** Richard A. Hutchinson, Jr. co-founded [He Is Valuable, Inc. \(HIV, Inc.\)](#) in 2015. Using the hashtag #HeIsValuable, the campaign addressed sexual health, mental health, relationship development, community building, and a host of other issues faced by the Black Queer Male community. Quickly, the social media campaign grew into a social movement. HIV, inc. programming seeks to encourage the community to create a social movement in four targeted ways: Social Justice, Social Marketing, Social Opportunities, and Social Capitol.

**Enhancing Community Engagement with Black GBM (Gay, Bisexual, MSM): Richard Hutchinson**



**Latino GBM:** Oscar Lopez, the CEO and National Director of Policy for Poderosos. Poderosos prioritizes improving the health of immigrants, queer youth, MSM, cis- and trans-women, and other minority groups with a focus on Latinx people.

**Enhancing Community Engagement with Latino Gay, Bisexual, MSM (GBM): Oscar Lopez**



## People Who Identify as Transgender, Gender Non-conforming, or Non-binary (TGNCNB)



**Developed by: Cecilia Gentili,**  
**[Transgender Equity Consulting](#)**

Cecilia Gentili started Transgender Equity Consulting in the beginning of 2019 after serving as the Director of Policy at GMHC, the world's first and leading provider of HIV/AIDS prevention, care and advocacy from 2016 to 2019. She has collaborated extensively with organizations including the AIDS Institute, the New York City Department of Health and Mental Hygiene, Funders for LGBTQ Issues, Borealis Foundation, and Cicatelli Associates Inc. Her reputation amongst these organizations, and many more, is reflective of the deep personal commitment she brings to the work, and her unique insight which enables a deeper connection with queer and trans communities

The transgender, non-binary, and gender non-conforming communities are such a vibrant, generous, and fun community. We go through so much, including family rejection, discrimination in education and employment, bullying, poor access to healthcare, lack of housing, police harassment and incarceration due to engagement in alternative economies that are criminalized (e.g., sex work or drug use). But we cannot be reduced to a community that is only about problems. We are creators, great friends, smart employees, inventive people, and great entertainers! Often, health systems develop programs based off what they think we are as a community instead of learning how to respect our needs and wants. One of the things you can do first to be able to offer well-informed services is learn more about us, starting with terminology. Respectfully using the terms and concepts that create a welcoming environment for the TGNCNB communities is an established way of building trust. It is also an effective way to discredit the misunderstandings around gender and address discriminatory behavior experienced by the communities. The following video is a tool that introduces many of the terms and concepts used within the TGNCNB communities. It is fairly comprehensive, but it is important to remember that language is ever evolving and may vary from region, age group, community, etc. As always, we encourage you to always maintain open communication with folks in the community. You can also refer to the glossary in the appendix of this toolkit for additional support.

## Enhancing Community Engagement through Trans Health: Terminology



As mentioned before, there are many problems that transgender, gender non-conforming, and non-binary people face in their daily lives. If we are unaware of those realities and don't understand what they go through navigating a world that is most of times hostile, then we can't really connect with them.

Here are just some of the biggest issues trans people face:

**Identity and Documentation:** the ability for a transgender person to legally change their name and gender marker in documents, like driver license, identification card (ID), social security number, or birth certificate can make a great and positive difference in their lives.

**Family Rejection:** many TGNCNB folks face family rejection when they come out as trans, non-binary, or gender non-conforming.

**Housing and Homelessness:** often because of family rejection, TGNCNB people face homelessness due to being kicked out of their homes by their families; these folks are often youth.

**Employment:** more than one in four transgender people have lost a job due to bias, and more than three-fourths have experienced some form of workplace discrimination. Refusal to hire, privacy violations, harassment, and even physical and sexual violence on the job are common occurrences and experienced at even higher rates by TGNGNB people of color.

**Police Harassment:** law enforcement has a history of targeting and further traumatizing TGNCNB folks just because they are trans, often citing drug use and sex work

as justification for the harassment. For trans immigrants that are undocumented, who came to this country to escape violence from their home country, they may face deportation and horrendous treatment in immigration detention.

**Healthcare Discrimination:** despite the protections of the Affordable Care Act and other laws that prohibit discrimination, transgender people continue to encounter denial of medically necessary care regardless of insurance coverage. Even when transgender people have access to comprehensive coverage, discrimination is still prevalent in many health care settings, and contributes to health disparities when compared to the general US population, including higher levels of HIV infection and suicidality.

**Violence:** according to the Trevor Project, in 2020 40% of transgender and gender non confirming youth reported being physically threatened or harmed in their lifetime due to their gender.<sup>1</sup> The world is not a safe place for trans people, especially black trans women. Eradicating the world of anti-trans based violence happens by listening to and providing trans communities with resources that fill the gaps that put them at risk, not by focusing on the perpetrators.

**Enhancing Community Engagement through Trans Health: Narratives**



**Enhancing Community Engagement through Trans Health: Life as a Trans Person**



It is common to hear providers in CBOs or health departments say, “It is difficult to reach this community” or “These folks don’t want to be engaged” or “Trans people are always late or miss their appointments.” To a certain extent this can be true because we are like everyone else with challenges and barriers, but we cannot put all the blame on the trans community. We should think for a minute: “Why does it seem as if they are so difficult to engage?” Are they or are the systems hard to engage? I have a couple of ideas about that! If we really want to engage trans folks, we should think about what they need and what we can provide from those needs. It is much easier to engage a trans person into HIV care if we truly think about their immediate needs outside of HIV care. If a trans person comes in and they are hungry, then offer them lunch or a gift card to the coffee shop to grab breakfast or snacks. If trans people are homeless, we can offer them hygiene packages or connect them with places that offer a warm shower or a place to do laundry. If we know these folks are being rejected by their families, connect them to mental health providers. While or after addressing those needs, then you can offer them the services that you have available.

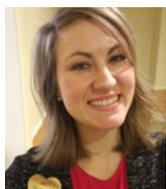
We cannot continue going to trans people expecting that they are going to be happy to hear from us when we don’t even know their needs or address what they are going through. If you invest in offering the help they NEED, then you will be able to engage them in the services.

Let’s listen to providers who were successful in engaging TGNCNB folks!

**Enhancing Community Engagement through Trans Health: TGNCNB & Medical Care**



## People Who Use Drugs (PWUD)



### Developed by: Tricia Christensen

Tricia Christensen has more than a decade of experience working in non-profit and government settings – a combination of academic, research, and professional practice – exposing her to various opportunities to engage local partners for the development and implementation of programs to reduce transmission of infectious disease, prevent overdose, and reduce costs to the healthcare system. She has spent her career engaging people with behavioral and somatic health needs, researching and supporting legislative reform efforts, and providing health education and services.

While people who use drugs are often recognized as important peer supporters and participants in recovery and treatment programs, they are regularly overlooked as partners or collaborators in the design and implementation of supportive programs that serve people at risk for, impacted by, and living with HIV. This blind spot can be attributed, in part, to underlying biases about the nature of addiction, and stigma directed toward people who use substances which has been largely normalized in our society. Additionally, the criminalization of drugs in the US has historically been led by the belief that drug use is morally and legally wrong, and that abstinence is the primary goal. These attitudes and legal retributions not only prevent health departments from reaching out to this community - they also prevent people who use drugs from welcoming many invitations. As you are creating or revisiting your Ending the HIV Epidemic plans to include people who use drugs, you must begin by thinking through what internal work your team may need to do in order to address internal biases and stigmatizing behaviors.

### Enhancing Community Engagement with People Who Use Drugs (PWUD): Tricia Christensen



Once your team is ready to reach out to people who use drugs, it is important to think through proper representation and compensation of individuals and partnering organizations to help you do the work. This might mean working with less familiar partners and being flexible with funding and timelines in order to be more inclusive.

### Enhancing Community Engagement with People Who Use Drugs (PWUD): Zach Kosinski



Zach Kosinski works in public health in a local jurisdiction in Maryland doing harm reduction work, and is also a person living in long term recovery.

Continued trust building and sustainability of relationships with people who use drugs will be instrumental in successful implementation of your Ending the HIV Epidemic plan. Not only is it important to show up for this community in the context of prevention and service delivery, but it is also necessary to demonstrate your commitment to increasing quality services as well as actively working to end stigma and discrimination against people who use drugs.

### Enhancing Community Engagement with People Who Use Drugs (PWUD): Kirsten Forseth



**Additional Resources:**

- Prevention Solutions at EDC: [Words Matter - How Language Choice Can Reduce Stigma](#)
- Prevention Solutions at EDC: [Engaging People Who Use Drugs in Prevention Efforts: Strategies for Reducing Stigma](#)
- [NASTAD's Drug User Health team](#) and Harm Reduction TA Center
- Prevention Solutions at EDC: [Engaging People Who Use Drugs in Prevention Efforts: Benefits & Considerations](#)
- NASTAD: [Innovative Financing for Drug User Health and Syringe Services Programs: Using Ryan White Resources](#)
- NYS Office of Alcoholism and Substance Abuse Services: [New York State Peer Integration and Stages of Change toolkit](#)
- National Harm Reduction Coalition: [Principles of Harm Reduction](#)
- CDC: [Effectiveness of Syringe Services Programs](#)
- CDC: [Syringe Services Programs - A Technical Package of Effective Strategies and Approaches for Planning, Design, and Implementation](#)
- NASTAD: [COVID-19: Suggested Health Department Actions to Support Syringe Services Programs](#)

**Rural Communities****Developed by: Tricia Christensen**

Working with rural communities can present challenges related simply to the logistical complications of covering a large geographical span, but it's also essential to recognize that these communities often hold different cultural values compared to their urban and suburban counterparts. Additionally, rural communities face their own hardships relating to declining and aging populations and concentrated poverty. Understanding these values and concerns is important in your efforts to build trusting relationships and engage individuals and organizations from rural areas for your Ending the HIV Epidemic plans.

**Enhancing Community Engagement with Rural Communities: Tricia Christensen****Enhancing Community Engagement with Rural Communities: Melissa Clark**

Melissa Clark is the Associate Director at [AHEC West](#), which focuses on improving health access and services through education and quality care. AHEC West works primarily in the mountains of Western Maryland in Allegany, Frederick Allegany, and Garrett counties.

Additional preparation may be needed if the rural area you are looking to engage includes migrant communities. While immigrants tend to be concentrated in big metropolitan areas, they have been responsible for a larger share of overall growth in rural areas, and in recent years have been instrumental in offsetting the effects of population decline in those areas. These communities also sometimes live in terrible conditions that exacerbate health issues and make engagement efforts particularly difficult.

Gabriela Zavala is the president and the CEO of the Asylum Seeker Network of Support, which branches out into creating different grassroots efforts that help provide direct aid to asylum seekers, in undocumented and migrant populations within the Texas/Mexico border region, more specifically the Rio Grande Valley. Much of the work entails working within the rural and underserved communities and places where the economy is scattered. She was born and raised

in Brownsville, Texas, which is a border community with Mexico and has been a community organizer for the entire portion of her adult career. Since the age of 19, she's worked with community across various avenues including, door to door outreach, education, and community health initiatives.

**Enhancing Community Engagement with Rural Communities: Gaby Zavala**



In the Youth and Young Adult section, I will take you through a plethora of activities and action steps that health departments and community-based organizations are encouraged to take before engaging young people, and as they are engaging young people. Lastly, I will describe what follow-up looks like for continued trust-building and sustainability with young people.

*Note: the terms youth, young adults, and young people will be used throughout the videos interchangeably.*

Health departments and community-based organizations may be at different places within their internal processes when it comes to engaging young people in their EHE planning strategies. Some organizations may already be engaging young adults and not necessarily youth (individuals under 18 years of ages) and vice versa. The goal of this section is to provide realistic actions steps and activities that both health departments and organizations can conduct internally with the current workforce. This list will not be exhaustive or will not be in chronological order but will provide a solid foundation for the ongoing work needed to be done to engage all young people.

Developing and creating consistency within internal processes is continuous and activities and efforts should continue as health departments and community-based organizations start to engage youth and young adults. Action steps and tasks may have to be re-evaluated as new information becomes available, and organizations must be willing to be flexible and pivot as necessary. Flexibility will be important in all phases of engagement process with all young people.

Health departments and community-based organizations should recognize youth as experts in their own needs. Acknowledge their feelings and try to listen to understand and not to respond from a superior mindset. Working with health departments can be intimidating for young people mainly because of the traditional imbalance of power between young people and adults who ultimately get to make final decisions. Provide affirmation. Young people are the future, remind them of that through positive affirmation. In this section, I will provide both strategies and activities that health departments and community-based organization are encouraged to implement once they start to engage young people in their EHE planning process.

**Additional Resources:**

- United States Census Bureau: [Rural America Interactive Story Map](#)
- Pew Research Center: [What Unites and Divides Urban, Suburban and Rural Communities](#)
- NRHA: [National Rural Health Association Community Health Worker Training Network](#)
- NRHA: [Advocacy Priorities for Rural Health](#)
- NRHA: [List of State Rural Health Associations](#)
- Center for American Progress: [Revival and Opportunity: Immigrants in Rural America](#)

## Youth and Young Adults



**Developed by: Sabrina Xavier**

Sabrina Xavier has served in HIV public health both internationally and nationally implementing community health programs and providing direct service to underserved populations, particularly youth and young adults. She is committed to strengthening governmental public health through advocacy, capacity building, and social justice.

### **Enhancing Community Engagement with Youth and Young Adults While Engaging: Sabrina Xavier**



Trust-building and sustainability is crucial in any community-engagement effort aimed towards uplifting the many voices of a particular community. In this module, we will explore what follow-up and investment looks like as it relates to continued trust-building and sustainability with young people.

Investing in community engagement with young people can help to:

- Inform service models and produce relevant program needs.
- To improve how, where and when services are delivered
- To get real-time knowledge about conditions and needs of young people
- To help maximize resources and reduce saturating the same services in the same communities
- To advance health equity and justice, especially for those disproportionately impacted by the HIV epidemic.
- Develop and sustain relationships with current and new partners
- Lastly, investing in community engagement with young people will help to honor the lived experiences of youth people impacted by the epidemic

### **Enhancing Community Engagement with Youth and Young Adults After Engaging: Sabrina Xavier**



#### **Additional Resources:**

- JSI: <https://www.jsi.com/project/what-works-in-youth-hiv/>
- UNAIDS: [https://www.unaids.org/sites/default/files/media\\_asset/youth-and-hiv\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/youth-and-hiv_en.pdf) (ACT!2020)
- Grassroots Soccer: <https://www.grassrootsoccer.org/>
- One Man Can Campaign: <https://genderjustice.org.za/project/community-education-mobilisation/one-man-can/>
- AMCHP.org: [http://www.amchp.org/programsandtopics/AdolescentHealth/Documents/FINAL\\_JuneAYAHCenterNewsletter.pdf](http://www.amchp.org/programsandtopics/AdolescentHealth/Documents/FINAL_JuneAYAHCenterNewsletter.pdf)
- InnerCity Struggle: <https://www.healthaffairs.org/doi/10.1377/hblog20190709.680185/full/>
- AjA: <http://ajaproject.org/work/>

## **Tribal/Indigenous Communities**



**Developed by:** [Alicyn Heinrich](#), NASTAD

Ronny Bell is the director of the office of Cancer Health Equity at the Wake Forest Baptist Comprehensive Cancer Center, and the chair of the North Carolina American Indian Health Board. In both of those roles, he

works with community to try to address issues around health equity and health disparities. Much of his work is focused on the eight recognized tribes and four urban Indian centers in the state of North Carolina. This work is important to him, both personally, as an enrolled member of the Lumbee tribe, and professionally in his passion for working with native communities, to try to develop strategies to understand what health disparities exist, and how to address those disparities.

### ***Enhancing Community Engagement with Tribal/ Indigenous Communities***



## **Social Determinants of Health (SDOH)**



**Developed by: John Meade Jr., MPH with assistance by Jennifer Lee, PhD**

For the last decade, John Meade Jr has gained extensive expertise in combatting the broad disparities that stall the advancement of communities of color, immigrants, and other marginalized populations by coordinating and managing international and national initiatives, providing technical assistance, and executing community engagement activities with clinical and non-clinical providers, government officials and other key community stakeholders. His lived experience and experiential learning being part of the community while also being closely connected with communities disproportionately impacted by systems of oppression (e.g. intersectional identities of persons of color, sexual orientation, gender identity and health status) lend to a deeper understanding of equity and addressing disparities that impact community.

Health starts in the home, school, work, places of worship, and in communities. Social determinants of health, as defined by the Centers for Disease Control and Prevention, are conditions in the environment in which people are born, live, learn, work, play, worship, and age that affect a wide range of health functioning, and quality-of-life outcomes and risks. Healthy People 2020 emphasizes addressing the social determinants of health by naming it as one of the four overarching goals for the next decade.<sup>1</sup>

When working to End the HIV Epidemic in the Southern United States, it is crucial to acknowledge and address the social determinants of health in community engagement and implementation of any evidence-based interventions. There is a plethora of Social Determinants of Health but some that affect HIV prevention include:

- Social norms and attitudes (e.g., discrimination, racism, and distrust of government)
- Availability of resources to meet daily needs (e.g., safe housing and local food markets)
- Access to educational, economic, and job opportunities
- Access to health care services
- Transportation options
- Social support
- Exposure to crime, violence, and social disorder (e.g., presence of trash and lack of cooperation in a community)
- Socioeconomic conditions (e.g., concentrated poverty and the stressful conditions that accompany it)
- Residential segregation
- Language/Literacy
- Access to mass media and emerging technologies (e.g., cell phones, the Internet, and social media)
- Culture

This section of the Social Determinants of Health component of the toolkit will highlight videos from community leaders and stakeholders across various communities and identities within some of the identified SDOHs working to end the HIV epidemic. They work to ensure health departments are aware of the factors that are affecting HIV prevention efforts. It is crucial that health departments take time and collaborate with partners to address these factors as part of the Ending the HIV

Epidemic plan and not separately. The following videos welcome some of the leading professionals and community advocates within HIV prevention and care to share their experiences and knowledge about the relationship between health departments and community.

**HIV and Health Equity:** Dr. Oni Blackstock is the former assistant commissioner for the Bureau of HIV for the [New York City Department of Health and Mental Hygiene](#). Her research considers the experiences of women and people of color in healthcare.

**Enhancing Community Engagement through Social Determinants of Health (SDOH): Dr. Oni Blackstock**



**HIV and people with disabilities:** Christina Curry is the Executive Director for the Harlem Independent Living Center (HILC). Ms. Curry began her career in rehabilitation as an advocate for minority Deaf, Hard of Hearing communities (Lexington Center for the Deaf).

**Enhancing Community Engagement through Social Determinants of Health (SDOH): Christina Curry**



**HIV and the faith-based communities:** Michael Roberson is a public health practitioner, advocate, activist, artist, curator and leader within the LGBTQ community. He is the co-creator of the nation's only Black Gay Research group and National Black Gay Men's Advocacy Coalition, as well as an Adjunct Professor at The New School University/Lang College NYC, and Union Theological Seminary NYC.

**Enhancing Community Engagement through Social Determinants of Health (SDOH): Michael Roberson**



Bishop Stacey S. Latimer, Founder and Spiritual Leader of Love Alive International Sanctuary of Praise-Worship Center of New York City, a non-denominational ministry of believers. Bishop Latimer has been instrumental in the national mobilization of the Black church around issues of HIV/AIDS, and sexuality. He possesses over 17 years' experience working in the field of HIV and AIDS, in various capacities.

**Enhancing Community Engagement through Social Determinants of Health (SDOH): Bishop Latimer**



**Additional Resources:**

- MAP-IT: A Guide to Using Healthy People 2020 in Your Community: <https://www.healthypeople.gov/2020/tools-and-resources/Program-Planning>
- Analyzing Community Problems and Solutions: <https://ctb.ku.edu/en/table-of-contents/analyze/analyze-community-problems-and-solutions>
- A guide to community engagement frameworks for action on the social determinants of health and health equity: <https://nccdh.ca/resources/entry/a-guide-to-community-engagement-frameworks>
- CDC Programs addressing Social Determinants of Health: <https://www.cdc.gov/socialdeterminants/cdcprograms/index.htm>

## Data Collection, Evaluation, and Learning



**Developed by: John Meade Jr., MPH**

This section of the Data, Evaluation and Learning component of the toolkit will highlight videos from community leaders working to end the HIV epidemic in the Southern jurisdictions to ensure community members are included in the process of collecting and evaluating data.

**Community partnership development:** Justin Smith, Director of the Campaign to End AIDS at Positive Impact Health Centers, where he works with community partners to develop and implement strategies to bring about an end to the HIV epidemic in Metro Atlanta. He also currently serves as a member of the Presidential Advisory Council on HIV/AIDS (PACHA).

**Enhancing Community Engagement through Data, Evaluation, and Learning (DEL): Justin Smith**



**Community-based research:** Dr. Robin Lennon-Dearing, PhD, MSW, associate professor at the University of Memphis School of Social Work. She is engaged in community-based research in the Memphis area on the effect of embedding community health workers into HIV care teams to accomplish the goals of the ending the HIV epidemic.

**Enhancing Community Engagement through Data, Evaluation, and Learning (DEL): Robin Lennon Dearing**



**Community outreach support:** Kevin Holmes, LGBT Outreach Coordinator for the Infectious Disease Branch at the Arkansas Department of Health for the last two years. In his role Kevin serves as the liaison to the Community Connector’s Program, a program that funds individuals across the state to do outreach in their respected communities. ■

**Enhancing Community Engagement through Data, Evaluation, and Learning (DEL): Kevin Holmes**



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toolkit and the design. One of One Productions edited the community videos.

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## APPENDIX A:

# Glossary of Terms and Acronyms

## A

- AIDS – Acquired Immunodeficiency Syndrome
- ASO – AIDS Service Organization
- Autonomy – The quality or state of being self-governing or self-directing; existing or acting independently.

## B

- BIPOC – Black, Indigenous, People of Color

## C

- CBO – Community-based organization
- CDC – Centers for Disease Control and Prevention (Division of HHS)
- CE – Community engagement
- Cisgender – Relating to a person whose sense of personal identity and gender corresponds with their birth sex.
- Cognitive dissonance – A state of internal conflict that arises when an individual holds beliefs, attitudes, or behaviors that are incompatible with one another.
- Community empowerment – The process of enabling communities to increase control over their lives.
- Community health – Helps to reduce health gaps caused by differences in race and ethnicity, location, social status, income, and other factors that can affect health.

## D

- DUH – Drug user health

## E

- EHE – Ending the HIV Epidemic
  - Four Pillars: Diagnose, Treat, Prevent, and Respond

## F

- FQHC – Federally Qualified Health Center
- FSW – Female sex worker

## G

- GBM – Gay, Bisexual, and Other MSM
- Gender – A person's deeply felt, inherent sense of being that may or may not correspond to a person's sex assigned at birth.
- Gender expression (GE) – The external manifestations of gender, expressed through such things as names, pronouns, clothing, haircuts, behavior, voice, body characteristics, and more.
- Gender identity – An individual's personal sense of having a particular gender.
- Gender non-binary (GNB) – To refer to people who identify with a gender outside of the gender binary. The word non-binary describes a wide array of different identities which fall outside of the gender binary and can be related to or separate from male and female gender identities.
- Gender non-conforming (GNC) – To refer to someone whose gender expression does not conform to the cultural or social expectations of gender, particularly in relation to male or female.

## H

- Harm reduction – A set of practical strategies and ideas aimed at reducing negative consequences associated with drug use and a movement for social justice built on a belief in and respect for the rights of people who use drugs.
- HHS – U.S. Department of Health and Human Services
- HIV – Human Immunodeficiency Virus
- HOPWA – Housing Opportunities for Persons with AIDS
- HRSA – Health Resources and Service Administration (Division of HHS)
  - HAB – HIV/AIDS Bureau
- HUD – U.S. Department of Housing and Urban Development

## I

- IDU – Injection drug use(r)

- Implicit bias – An attitude or stereotype that affects understanding, actions, and/or decisions unconsciously.
- Ingroup – A group of individuals connected through shared identity or characteristics that produce feelings of solidarity.
- Institutional consistency – A framework (characterized by the ability to maintain service provision despite internal changes/developments and external stimuli) for internal and community-facing action established to support the needs of the community, despite the status or presence of organizational personnel.
- Intersectional/Intersectionality – A concept to describe how oppressive institutions (racism, sexism, homophobia, transphobia, ableism, xenophobia, classism, etc.) are interconnected and cannot be examined separately from one another. The term was first used in the context of feminism by civil rights scholar and advocate Kimberlé Crenshaw.
- Intersex – Someone who, due to a variety of factors, has reproductive or sexual anatomy that do not seem to fit the typical definitions for the female or male sex. Some people who are intersex may identify with the gender assigned to them at birth, while many others do not.

## M

- Medical mistrust – A suspicion or lack of trust in medical organizations.
- MEL – Monitoring, Evaluation, and Learning
- MER – Monitoring, Evaluation, and Reporting
- MSM – Men who engage in sexual intercourse with men/men who have sex with men
- M&E – Monitoring and Evaluation

## N

- NIH – National Institutes of Health
- NOFO – Notice of Funding Opportunity

## O

- OUD – Opioid use disorder

## P

- PEP – Post-exposure Prophylaxis
  - nPEP – Non-occupational post-exposure prophylaxis
- Person-centered language – A linguistic prescription to avoid marginalization and dehumanization regarding a health issue or disability
- PLHIV – People living w/ HIV
- PLWH – People living w/ HIV
- PrEP – Pre-exposure Prophylaxis
- Public health – Promotes and protects people's health and the communities where they live, learn, work and play
- PWID – People who inject drugs
- PWUD – People who use drugs

## R

- Rapport – An earned, existing, and ongoing relationship characterized by continuous and open communication, respect, accountability, and willingness to negotiate amongst multiple stakeholders
- Representation – How media portrays and shows us things about society
- Rural – HUD defines rural areas in 3 ways:
  - A place having fewer than 2,500 inhabitants
  - A county or parish with an urban population of 20,000 inhabitants or less
  - Any place with a population not in excess of 20,000 inhabitants and not located in a Metropolitan Statistical Area (MSA)
- RWHAP – Ryan White HIV/AIDS Program

## S

- SAMHSA – Substance Abuse and Mental Health Services Administration (Division of HHS)
- SDH/SDoH – Social Determinants of Health
- Sex – Assigned at birth and is usually based on the appearance of the external anatomy. Often confused with gender.
- Sexual orientation (SO) – The desire one has for emotional, romantic, and/or sexual relationships with others based on their gender expression, gender identity, and/or sex. Many people choose to label their sexual orientation, while others do not.

- SME – Subject matter expert
- SSP – Syringe Services Program
- Stakeholder – People or organizations impacted by or invested in the program, interested in the results of evaluation, and/or with a stake in what will be done in the results of the evaluation
- Stigma – The social devaluation of people who are different due to conditions that do not affect the majority of a population (e.g., homosexuality, HIV/AIDS, mental illness), or more ordinary conditions that affect many or all in a population (e.g., demographic features tied to age, race/ethnicity, gender)
- STDs – Sexually Transmitted Diseases
- SUD – Substance Use Disorder

## T

- TA – Technical assistance
- TG – Transgender
- TIA – Trauma-informed Approaches
- Transgender – Relating to a person whose sense of personal identity and gender does not correspond with their birth sex.

- Transition – The process through which some transgender people change their gender expression to more closely resemble how they view their gender identity. This can include personal, medical, and legal steps, such as, using a different name and pronouns, dressing differently, changing one's name and/or sex on legal documents, hormone therapy, or gender affirmation surgery. Some transgender people may not choose to make these changes or may only make a few. The experience is an individualistic one; there is no right or wrong way to transition.
- Trans-man – To refer to a person who was assigned female at birth and lives and/or identifies as a man.
- Trans-woman – To refer to a person who was assigned male at birth and lives and/or identifies as a woman.

## U

- U=U – Undetectable Equals Untransmittable

## W

- WHO – World Health Organization

## APPENDIX B:

# NASTAD Resources

## i. NASTAD Community Engagement TA and Support

NASTAD is the current Capacity Building Assistance (CBA) provider under the five-year project funded by CDC PS19-1904 to provide CBA services regionally to all CDC-funded HDs and CBOs in the South on integrated HIV activities and structural interventions (including community engagement). NASTAD is also engaged with supporting Southern jurisdictions in developing and implementing annual jurisdictional CBA plans which includes strengthening community engagement within programming activities.

NASTAD is also the lead organization for two national EHE initiatives for CDC and HRSA. NASTAD is in Year 3 of its cooperative agreement with CDC's Division of HIV/AIDS Prevention (DHAP) Office of the Director (OD) for Strategic Partnerships and Planning to Support EHE in the United States (PS19-1906 Component A). NASTAD supports HIV prevention programs in EHE Phase 1 jurisdictions through strategic communication and policy activities, partnerships, and data analyses related to EHE. Through this scope of work, NASTAD, along with national partners, provides TA in the development of EHE plans, and establishes, builds, and maintains collaborative relationships with organizations to support the implementation of the EHE plans through CDC PS20-2010.

Use this [link](#) to reach out to NASTAD for further support on community engagement EHE implementation activities or to address any related challenges.

You can also contact NASTAD by:

- Engaging your project officer to submit a CTS request which will be assigned to NASTAD.
- Emailing any NASTAD person to submit a CTS request on your behalf.
- Emailing any NASTAD person to discuss needs and determine which TA support and approach may be best.

NASTAD related community engagement TA activities include:

- CBA trainings and presentations
- Information gathering and dissemination
- Facilitated collaboratives across various communities and programs (e.g., housing learning collaborative, PrEP learning collaborative)
- Facilitate communication and connection with peers and/or community stakeholders
- Resource development
- The EHE listserv
- EHE related policy TA support (e.g., data privacy, HIV criminalization)

## ii. Interview Guide

NASTAD used the following interview guide throughout our conversations with EHE jurisdictions in the South, community partners, and community representatives. We've included it in this toolkit as a source of guidance and reference.

EHE Community Engagement Interview Guide

1. How do you define community?
  - 1a. How do you see yourself as a part of the community (if at all) that you have defined?
2. What are your current EHE community engagement plans or how are you currently engaging the community in your EHE work?
  - 2a. What steps have you already taken to engage the community in your EHE planning?
3. What barriers or challenges has your health department has encountered relating to achieving your EHE CE goals?
  - 3a. How has COVID-19 impacted community engagement efforts (e.g., access to services, in-person engagement, etc.)?
  - 3b. Are there any areas you've already identified as areas you'll need support?

4. There are multiple EHE funding opportunities presented (sometimes simultaneously). How has this impacted the way you approach your community engagement strategy?
  - 4a. What are your plans to create a sustainable community engagement model with this funding?
  - 4b. How has this impacted how you are able to keep up or prioritize your EHE work?
5. Who would you consider your underrepresented populations within your EHE CE plans?
  - 5a. What populations have you worked with in the past?
  - 5b. What populations would you like to reach out to more?
  - 5c. What organizations or groups do you currently partner with within your jurisdiction to reach the underrepresented communities you've identified?
6. Being a small, rural county, what are some challenges you face related to community engagement?
  - 6a. What are some ways you believe your county could overcome these challenges?
7. How has medical mistrust (historical and recent) impacted the way you approach community engagement?
8. What's the main feedback you have received from the community about why they may choose not to engage with your health department?
9. What are some new approaches your health department intends to take with understanding the people within your county?
10. What are the current gaps in the continuum of HIV care (awareness of services, testing, diagnosis, linkage, treatment, viral suppression) within your jurisdiction?
11. What strategies/practices/policies have been implemented to reduce HIV-related disparities in prevention, testing, and treatment services for populations disproportionately affected by HIV?
  - 11a. How are you aligning your EHE activities back into the HIV cases in your jurisdiction to show impact?
  - 11b. What initial assessment and/or screening tools did you utilize to measure the implemented activities' effectiveness on reducing new HIV cases?
  - 11c. How do you know this strategy is working?
12. In your jurisdiction, what tools (digital, social media, traditional, etc.) or processes (planning bodies, etc.) do you currently have in place to encourage and uplift community engagement?
13. How are you receiving feedback from the community and incorporating community voices in policy changes?
  - 13a. How are you publicly sharing your EHE plan for their review/comment? (i.e., townhalls, public-facing website, asking community leaders to disseminate the plan, creating EHE workshops, etc.)
14. Are there any new or unique ideas – especially those that don't require many resources or funds – you would like to share with us. This could also be ideas you've seen from other HDs or even other organizations outside of HDs.
15. What does your health department hope to achieve through community engagement?
  - 15a. How can NASTAD assist you, whether individually or broadly, in accomplishing your community engagement goals? ■