

Town Halls and Focus Group Summary

Community Engagement Questions

- 1) From your observations and experiences, what are major obstacles as it relates to HIV prevention?
 - Stigma and ignorance
 - It's still the "gay disease"
 - People being told "you can't sit on my furniture"
 - PWH not seeking care because of fear and stigma
 - Misinformation
 - Everyone is "HIV possible- anyone can be vulnerable to HIV- mindset of "HIV can't happen to me"
 - Lack of community presence
 - Lack of training at the provider level, at most clinics and hospitals
 - Inability to maintain care when experiencing homelessness. There are barriers to processing disability and other support services when unhoused
 - Having been let down in the past by previous attempts at outreach
 - People not being aware of HIV transmission methods (e.g. thinking that HIV can be transmitted via sharing furniture)
 - Lack of HIV education is a barrier to prevention efforts. Infomercials, specifically on PrEP, on TV are only representing one population that is vulnerable to HIV (e.g. white gay men), when HIV affects everyone and PrEP is beneficial for all.
 - Access to providers who are educated about HIV is a barrier
 - Sex education not being in schools
 - Prevention/testing events are not effective/productive enough. Supervisors who are not certified to conduct HIV testing.
 - People with degrees talking down to clients
 - Larger numbers of younger people being diagnosed. No comfort level in being able to engage people, especially young folks, about their sexual health (e.g. condom use). Compared to other counties, there is a lack of
 - No community level access to preventative care like condoms and education and it causes disparities. Populations have the same access to HIV but not the same access to prevention and care.
 - No resources- only the health department
 - Can't go out to schools and can't even show condoms in schools
 - State is no longer funding to provide condoms (condoms are in the back- not accessible in the front if someone just walks in because they can't be displayed at certain providers)
 - No funding in general
 - In general people don't want to talk about sex.
- a. What do you think could be done to address the barriers to HIV prevention?
 - Making sure HIV education is linguistically and culturally appropriate
 - Populations that need to be educated about HIV:
 - Everyone
 - Grandparents who have influence on family education
 - Church groups

- Providers, especially PCPs and those who are unaware of what PrEP is, clinicians that do testing but don't offer PrEP
- People in jails/prisons
- Politicians
 - Being politically aware of what is happening in the political sphere, especially if it related to HIV
- Follow through for clients who are being tested
- Tapping into large employers (e.g. Disney, Universal) to create partnerships that will educate their workforce on HIV
- Permanent affordable housing. Addressing basic needs
- Using churches to educate and start conversations about HIV. Figuring out how to bring the faith-based community together to have plain language conversations, and in turn have more influence on politics (example of churches having influence on politicians being elected)
- New governor that will allow sex education in schools
- Strong leadership on prevention teams
- Going to middle schools to educate
 - Barriers to accessing the schools to provide that education
- Group homes, foster homes
- Provide materials in multiple languages (e.g. English, Spanish, Haitian Creole)

2) From your observations and experiences, what are major obstacles as it relates to (quality) HIV care?

- Not enough quality providers- hard to do research to find a provider that will fit an individual's specific needs
- Even with HOPWA funding, it is difficult to find low-income housing
- Mental health and substance use issues
 - Not enough education on how substance use can interact with HIV medications
 - Mental health complexities can impact medication adherence
- Accessibility
- Many people lack knowledge on how to advocate for themselves, what questions to ask, or how to navigate the system
- Cost
- Transportation
- Stigma
- Language barriers
- Some people's substance use dependence is valued more than their care
- Systems that are built without passion or urgency, people are treated as numbers and don't receive culturally rooted care. More providers need to set measurements for themselves that are connected to funding.
- Denial/being afraid of the diagnosis
- Fear of ICE. The solution is to make people feel comfortable enough to get tested and to do it in their jargon.
- Lack of access to pharmacies/ability to refill meds
- Clients being referred to providers that are not easily accessible via available transportation methods, e.g. the bus

- ADAP changes- reducing the FPL eligibility requirement, removing single-pill regimens from the ADAP formulary
 - Potential for medication resistance if medication regimens change
 - Dental services being inaccessible- dental services are one of the first services that are recommended to newly diagnosed PWH
 - No action or execution for addressing barriers to care (including the integrated plan being an ineffective tool)
 - The system of care itself is a barrier
 - The RWHAP system of care is not designed to empower clients or be innovative
 - The system needs to be revamped. Agencies need to be educated on how to improve the outcomes and measures that they have to meet to receive fundings. Innovative approaches are lacking, e.g. discussing and addressing chemsex
 - A large chunk of people do not know that PrEP exists
 - Property owners not allowing mobile buses on their land
 - Providers that are not familiar with RWHAP or how to monitor labs properly, but will give them the medications- clients end up not having a dedicated infectious disease doctor or proper case management
 - Providing medication without properly educating the client on HIV
 - Advent Health pharmacy don't have the doctors and nurses follow proper medication regimens when PWH are hospitalized (clients can't bring their own medications and have to follow the schedule outlined by the hospital). E.g. two pill regimens supposed to be taken at the same time are not being administered properly (i.e. nurses having to follow the pharmacy telling them to give only one pill at a time)
 - Education of hospital staff is necessary
- a. What do you think could be done to address the obstacles to HIV care?
- For the barrier on medical self-advocacy: peer counselors at medical providers to help them self-advocate for quality care
 - Medication delivery
 - Primary care providers should make screening for HIV part of their routine tests and include HIV testing in labs.
 - Educating providers
 - Routine testing
 - Education for providers on opting out of HIV testing in an effort to make testing more of a routine process
 - Accessible during non-traditional business hours
 - Contacting legislators
 - Agencies need to better collaborate and stop competing with each other
 - Using technology to educate younger people
 - Start with outreach and education at infectious disease providers
 - Look at how much funding the county gives to FDOH
- 3) How can the community be more involved in HIV prevention? What roles or actions would make the biggest impact?
- Providers to stop putting up barriers that prevent clients from accessing services (e.g. being territorial about clients seeing only them and no other HIV providers)
 - Have more mobile units (and have the existing ones be more effective)

- ACT Up
 - Need more advocates from people outside of the HIV sphere (Disney, Orlando Health)
 - Mobile units at lifestyle clubs, strip clubs
 - Groups that should be involved:
 - Religious leaders, educational institutions
 - Contacting the news to attend town halls
 - City council representatives
 - Parents, PTA parents
 - Directors of mental health programs (Circles of Care) so they can hear the impact of an HIV diagnosis to someone's mental health
 - Lifetime counseling services - Trauma-informed care
 - Meeting people where they are when it comes to mental health care
- 4) How can the community be more involved in HIV care? What roles or actions would make the biggest impact?
- Reinforcement of education is a way to overcome an obstacle
 - More testing
 - More access to be able to communicate with patients. E.g., using WhatsApp to expand the way providers can contact clients
 - Addressing stigma
 - Have a pharmacist come to a meeting/community meeting regularly to do a presentation on HIV medication (e.g. the generic equivalent of Biktarvy). Come on a quarterly basis to discuss advancements or new HIV medications in people-first and accessible language.
 - Accessibility – providing information in plain language that is understandable but not condescending
 - Ensure that people affected by addiction are at town halls/meetings to provide insight on how addiction and/or sobriety can affect their HIV care (e.g., abstaining from alcohol positively impacted someone's t-cell count)
- 5) What keeps people from starting HIV care after diagnosis?
- People don't want others to know (stigma)
 - Lack of follow through, education
 - Other health/life issues outside of HIV
 - Stigma, fear, no support, denial
 - A provider has heard clients say things like "If I don't feel sick, why do I need to take this medicine?"
 - Disbelief- not believing the results of the HIV test, overall medical mistrust
 - There are plenty of other non-HIV service providers that have routine contact with blood. We should be getting them on board with testing, providing PrEP, and teaching them how to link to HIV providers if someone tests positive
 - Teaching incoming providers and individuals who are entering the medical field early on about HIV prevention and care.
 - Didn't want people seeing medication bottles lying around
 - Not knowing who to reach out to
 - Visibility of getting HIV care (e.g., the possibility of being recognized while receiving care could prevent someone from going to the doctor)

- Lack of providers that accept certain insurance. Lack of providers in general (clients are sometimes told that they have to go out of the county that they live in to receive services, and then transportation becomes an additional barrier).
- Appropriate staffing at agencies
- Providers not being able to provide a service if it is not directly HIV-related due to certain conditions/concerns not being categorized as an allowable cost (not enough funding to cover all costs)

a. What can be done to make it easier for people to start HIV care?

- Direct hand off, linkage to care, follow-through
- Talk with the person to ask what their situation is outside of HIV (housing situation, other health issues)
- Normalize HIV so it can be talked about as easily as diabetes and hypertension (treat it as part of primary routine care and not specialty care)
- Education
- Have health care providers educated on HIV
- Have medication on hand as soon as an individual tests positive
 - Have an expert right there to give people their medication- have providers and physicians at outreach activities
- Engage patients to become liaisons to newly diagnosed folks/ ambassadors to young people
- Peer access
 - Peers/Sponsors
 - “Health Buddy” system- someone who is living with HIV and active in the community that can provide support to someone newly diagnosed. People can contact this individual via flyers in the community (something that was designed by a community member). Ensuring that people have someone that they can relate to (e.g., same age range, same gender, etc.). Health buddy can also help clients navigate some of the interpersonal and communication difficulties that can come with engaging with providers

6) What keeps people from staying in HIV care?

- Case managers that don’t know how to work with clients, that are new and need more experience
- People working in the field need more education
- Lack of follow-up
- Decisions from the state government

a. What can be done to make it easier for people to stay in HIV care?

- Serve the client at their level, meet them at their level
- More peers in more impactful roles
- More collaboration from case managers
- Innovative approaches to case management – telehealth
- Consolidation of consent forms
- Activism for HIV initiatives