

End The Syndemic Tennessee 2022 Needs Assessment

Consumer Report September 2023

Acknowledgements

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Stigma & Discrimination
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Youth & Young Adult Engagement
Consistency in Services
Integration of Services
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Glossary of Abbreviations

ART	Antiretroviral therapy
BIPOC	Black, Indigenous, and People Of Color
CHASCo	Coalition For Healthy & Safe Campus Community. This coalition addresses alcohol, drug, and violence prevention issues on Tennessee's campuses by providing high- quality consultation and training, technical assistance, research support, and policy development to member institutions.
Cis / Cisgender	a term used to describe a person whose gender identity corresponds to their sex assigned at birth
COVID / COVID-19	Coronavirus Disease 2019
DOH	Department of Health
EBT	Electronic Benefit Transfer: a system for delivering benefits, such as the Supplemental Nutrition Assistance Program (SNAP or food stamps) and cash assistance, to eligible Americans
EIS	Early Intervention Specialist
ESL	English as a Second Language
ETS	End The Syndemic
FGD	Focus Group Discussion
GNC	Gender nonconforming
HAV	Hepatitis A Virus
HBV	Hepatitis B Virus
HCV	Hepatitis C Virus
HIPAA	The Health Insurance Portability and Accountability Act of 1996 (HIPAA) is a federal law that required the creation of national standards to protect sensitive patient health information from being disclosed without the patient's consent or knowledge.

HIV	Human Immunodeficiency Virus
HOPWA	Housing Opportunities for Persons with AIDS
IRB	Institutional Review Board
КІІ	Key Informant Interviews
LGBQ+	Lesbian, Gay, Bi, Queer
LGBTQ+	Lesbian, Gay, Bi, Trans, Queer
LTS	Long-Term Survivors
MAT	Medication-Assisted Treatment
MDHA	Metropolitan Development and Housing Agency
MOUD	Medications for Opioid Use Disorder
MPHD	Metro Public Health Department
MSM	Men who have sex with men (includes gay, bisexual, same gender-loving men, and other men who have sex with men)
NASTAD	National Alliance of State and Territorial AIDS Directors
PEH	Persons/people experiencing homelessness
PEP	Post-exposure prophylaxis
PLWH	People living with HIV
PrEP	Pre-exposure prophylaxis
PTSD	Post-Traumatic Stress Disorder
PWUD	People who use drugs
SDOH	Social Determinants of Health
SNAP	Supplemental Nutrition Assistance Program
SSI	Supplemental Security Income
SSP	Syringe Service Program
STI	Sexually Transmitted Infection
SUD	Substance Use Disorder
TDH	Tennessee Department of Health
TDMHSAS	Tennessee Department of Mental Health and Substance Abuse Services
TGA	Transitional Grant Area

Introduction

End The Syndemic Tennessee

In Tennessee, many people that are impacted by HIV are also disproportionately impacted by sexually transmitted infections (STI), substance use disorder (SUD), and viral hepatitis. Interconnected epidemics that worsen each other are called a **syndemic**.

To be defined as a syndemic, the included health conditions must be connected through:

- Data demonstrating separate epidemics are occurring within the same community
- **Biological interactions** between conditions that result in enhanced disease acquisition, transmission, progression, or other negative health outcomes
- Behavioral links that increase vulnerability to and/or transmission of the included conditions
- Common social drivers of health that fuel and sustain vulnerability

End The Syndemic Tennessee, also known as ETS, is a movement and integrated strategic plan to address the prevention and treatment of HIV, sexually transmitted infections, substance use disorder, and viral hepatitis in Tennessee.

End The Syndemic Tennessee was developed by Amber Coyne, MPH, in partnership with people with lived and living experience, community-based organizations, and State and local health department staff. ETS was largely inspired by Merrill Singer's syndemic theory, local Ending the HIV Epidemic planning, the HIV and HCV outbreak in Scott County, Indiana, and the resulting Tennessee Department of Health (TDH) <u>HIV/HCV outbreak vulnerability assessment</u>.

The ETS strategic plan was informed by internal workgroup meetings between TDH and TDMHSAS, regional community planning meetings, federal and local strategic plans, federal planning guidance, secondary research of emerging and evidence-based practices, syndemic oriented pilot projects across the state, and the 2022 TN Syndemic Needs Assessment. To learn more about End The Syndemic Tennessee, please visit <u>https://endthesyndemictn.org/</u>

End The Syndemic Tennessee 2022 Needs Assessment

The End The Syndemic Tennessee 2022 Needs Assessment was an effort to better understand needs, gaps, barriers, and facilitators related to HIV, STIs, SUD, and viral hepatitis prevention and care services in Tennessee (TN) from consumer and provider perspectives. A mixed method approach was implemented where a statewide syndemic needs assessment survey was administered as well as focus group discussions (FGD) and key informant interviews (KII) were conducted to provide more nuanced insights from priority populations that were underrepresented in the survey and ETS planning process.

The ETS statewide survey had the largest reach compared to previous HIV needs assessments. There was a total of 1,014 survey respondents with 848 consumer respondents and 183 provider respondents. To note, providers are also consumer of services with lived and living experience and these respondents had the opportunity to take the consumer, provider, or both surveys.

End The Syndemic Tennessee 2022 Needs Assessment: Consumer Report

The End The Syndemic Tennessee (ETS) 2022 Needs Assessment Consumer Report outlines the key findings from the statewide syndemic needs assessment efforts and reflects **consumer responses** from an online statewide needs assessment survey administered in 2022 to capture perspectives on syndemic and support service needs and barriers.

Additionally, ETS priority population-specific (i.e., people who use drugs [PWUD], people in rural TN, Latinx men who have sex with men [MSM], and people who are experiencing homelessness [PEH]) focus group discussions (FGD) and key informant interviews (KII) were conducted in 2022 to provide more nuanced insights to complement information gleaned from the survey from priority populations underrepresented in the survey.

Furthermore, in partnership with United Way of Greater Nashville, the TDH Ryan White Part B Program conducted FGDs and KIIs for people living with HIV (PLWH) in five regions across TN in 2022. Ryan White Part A Nashville also conducted FGDs with PLWH in their transitional grant area (TGA) in 2022. The additional qualitative efforts from the TN Ryan White Programs provide in-depth insights to the experiences of PLWH across TN.

All activities are described below in more detail along with a summary of findings from consumer responses for each needs assessment activity. The information learned from the needs assessment directly informed the ETS integrated strategic plan to better address the needs and barriers expressed by those living with or vulnerable to the syndemic throughout Tennessee.

The ETS Needs Assessment Consumer Report is designed with sections and subsections. Please use the table of contents to locate specific needs assessment content. The report starts with the syndemic statewide survey methods with subsections for consumer key findings which include: Consumers Statewide; Regional and Rural Consumers; Consumers living with HIV; and Consumers who use drugs. After the survey findings, there are qualitative findings which includes ETS priority populations, Ryan White Part B statewide consumers living with HIV, and Ryan Part A Nashville TGA consumers living with HIV. The report ends with syndemic needs assessment conclusions and appendices with additional needs assessment data and details.



End The Syndemic Tennessee Needs Assessment Survey 2022

Introduction

The purpose of the ETS TN Needs Assessment Survey was to better understand needs and barriers related to HIV, STIs, SUD, and viral hepatitis (i.e., syndemic) prevention and care services in TN. The ETS Needs Assessment Survey included respondents who were consumers or providers of syndemic prevention and care services in TN.

Methods & Data Collection

The survey was developed by the ETS team in collaboration with the ETS Internal Workgroup, TDH Ryan White Part B Program, Ryan White Part A Nashville and Memphis TGAs, United Way of Greater Nashville, and Statewide HIV Needs Assessment Committee, all of whom reviewed and provided feedback on the survey design. Additionally, a pilot of the survey was conducted with PLWH prior to data collection. This pilot was in collaboration with Nashville CARES HealthyU program and included PLWH who reviewed and provided feedback on the survey design.

Survey Design

The survey was designed for consumers and providers and included branching logic to help streamline the survey process and provide respondents with questions relevant to their individual experiences. Respondents could identify as a consumer, a provider, or both. The consumer portion of the survey asked about syndemic and support service needs and barriers, as well as questions related to telehealth and mail-order services. The provider portion of the survey asked about their clients top unmet syndemic and support service needs and barriers, as well as the syndemic and support services they provide to their clients and barriers experienced in providing these services. If a respondent identified as both a consumer and a provider, they had the choice to take the consumer, provider, or both portions of the survey.

Data Collection

The survey was created as an online survey via Alchemer, with English and Spanish options. Although the online survey design helped to increase distribution and reach of the survey, the survey design could have impacted participation from those unable to access the survey due to device or internet limitations. To address this challenge, there was a phone survey option for those with limited internet access who preferred to take the survey over the phone. Additionally, in-person surveys were conducted in Knoxville and Memphis due to agencies requesting in-person surveys for those who were less likely to have access to internet (e.g., people experiencing homelessness); which resulted in an additional 100 surveys completed. Furthermore, some partner agencies assisted their clients who may not have had internet access at home in taking the survey at their sites. Data collection opened in June 2022 and closed in August 2022. Data collection period was based on the findings of previous iterations of the needs assessment and consensus of the needs assessment committee.

Marketing materials were created for recruitment purposes and included materials for social media and flyer distribution. Recurring recruitment emails were sent out to various internal and external ETS partners to further distribute recruitment materials among their networks. These partners included, but were not limited to, CHASCo (TN Coalition for Healthy and Safe Campus Communities), ETS planning members and networking platform, HIV Needs Assessment Committee, HIV planning bodies, Ryan White Part A Programs in Nashville and Memphis, TDH Ryan White Part B Program partners, TDH Health Equity newsletter, TDH HIV, STI, and viral hepatitis programs, TDMHSAS leadership, United Way of Greater Nashville leadership and HIV regional coordinators, and other various providers and organizations across TN.

Incentives

Each person who completed the survey had the option to receive one \$15 dollar gift card; however, due to an early influx of responses to the survey, we hit our incentive budget early in the data collection period. In discussion with the Statewide HIV Needs Assessment Committee, it was decided to continue data collection without an incentive with clear messaging about this change on the first survey page and updates made to marketing materials.

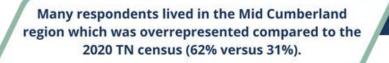
Limitations

Although there was active survey engagement, due to the nature of needs assessment data collection and sample size, generalizability of the results is unknown. People not engaged in services were underrepresented in varying aspects of the survey. For example, many respondents living with HIV were individuals receiving regular HIV care and consistently taking HIV medication, and many of the respondents who identified as someone who uses drugs were surveyed while accessing care at a syringe service agency. Additionally, people residing in the Mid-Cumberland region were overrepresented in the survey due to agencies in that area actively promoting the survey. There was also underrepresentation within the Southwest region (Shelby, Tipton, and Fayette counties) due to concerns around survey burden in that region. A separate 2021 Needs Assessment was conducted by the Ryan White Part A Memphis TGA team (https://hivmemphis.org/about-hcap/resources). Limitations should be kept in mind when reviewing the data presented throughout the Needs Assessment Report.

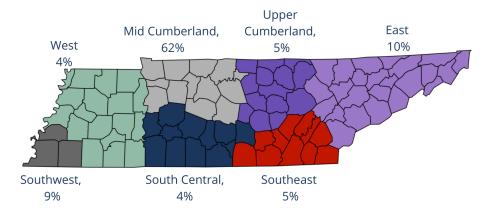
Consumers Survey Findings

Overview & Demographics

A total of 1,014 unique people completed the needs assessment survey. Of these, 848 respondents completed the consumer portion of the survey, and 183 respondents completed the provider portion of the survey. Of note, these numbers do not equal the total 1,014 survey responses; 27 respondents indicated being both a provider and a consumer and completed either the consumer (n=9), provider (n=1), or both (n=17) portions of the survey. Outlined below are varying demographics of consumer survey respondents (n=848) including residency, age range, race and ethnicity, gender identity, and sexual orientation.



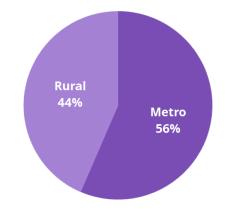
ETS Region Of Residence Among Consumer Respondents (n=848)



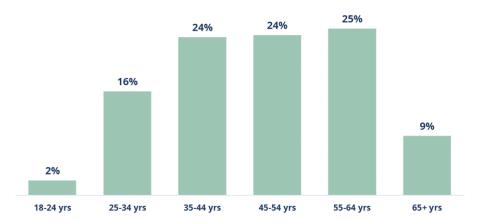
rural region of Tennessee.

Over 40% of respondents resided in a

Rural-Metro Residence Among Consumer Respondents (n=848)

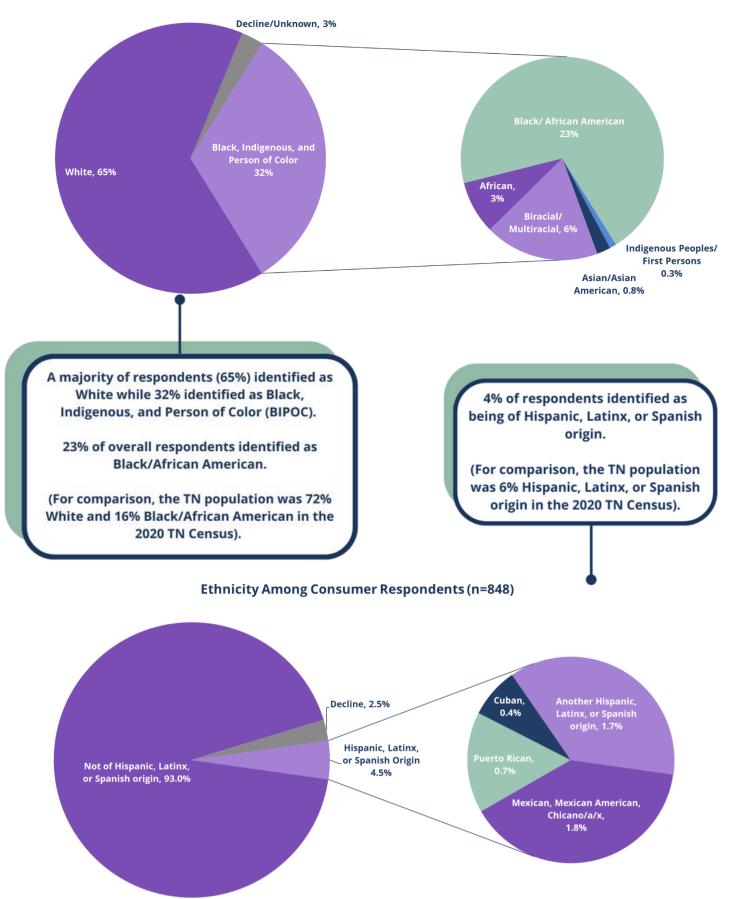


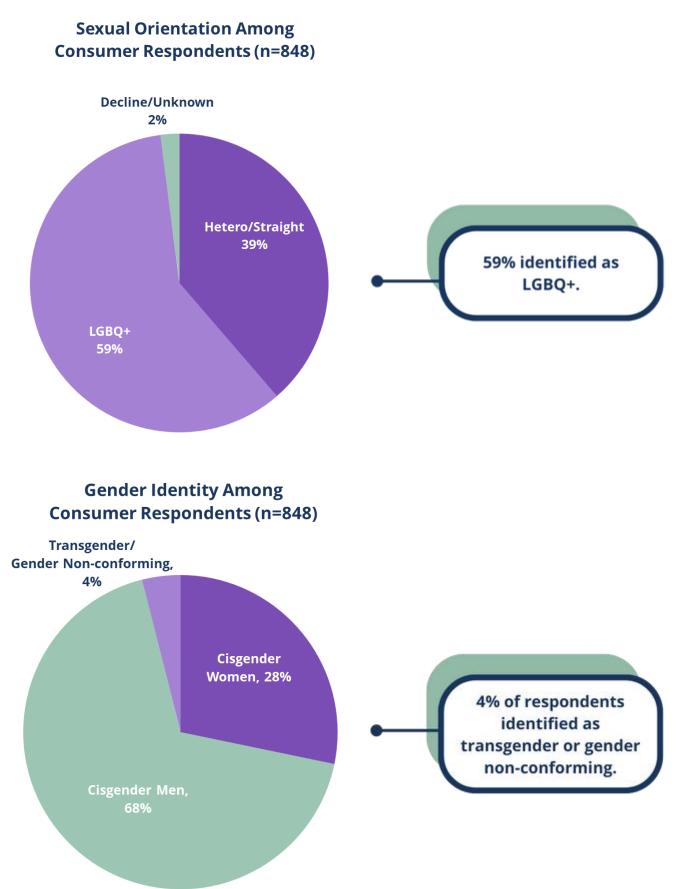
Age Range Among Consumer Respondents (n=848)



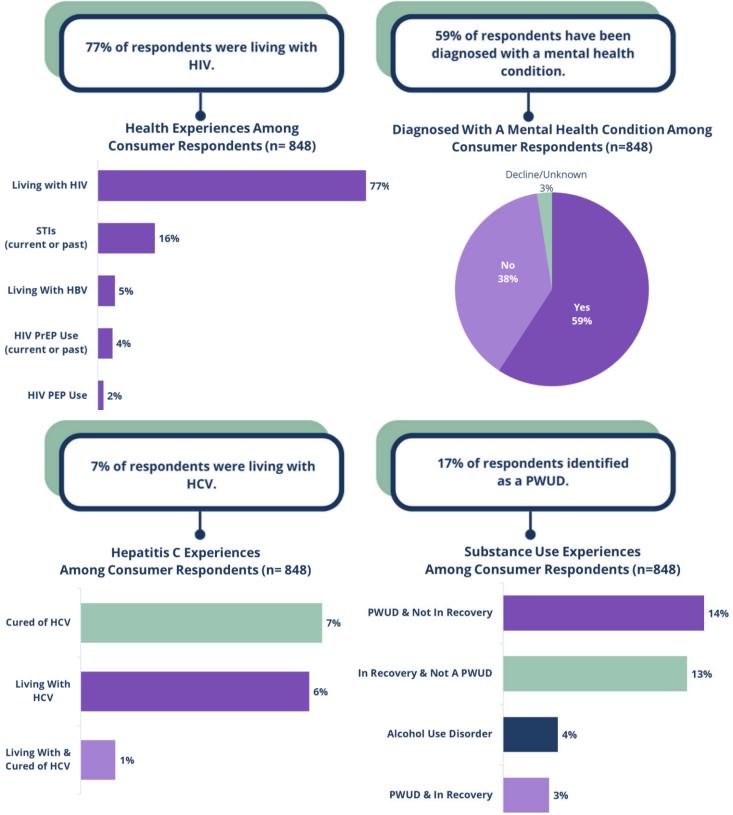
Most respondents were 35-64 years old with low participation among young adults who were 18-24 years old.

Racial Identity Among Consumer Respondents (n=848)





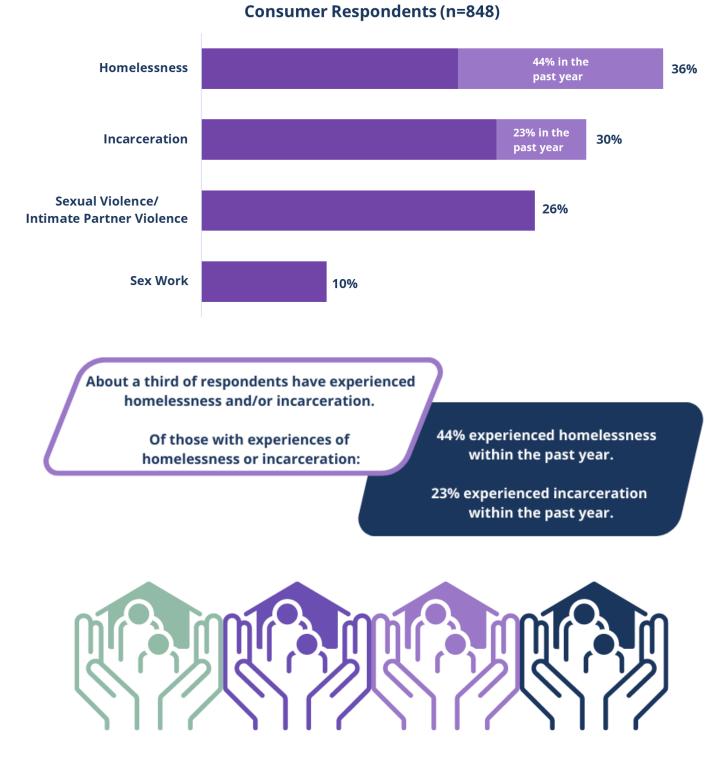
Cisgender Women: indicated sex assigned at birth as Female and gender identity as Woman **Cisgender Men**: indicated sex assigned at birth as Male and gender identity as Man **Transgender/Gender Non-conforming persons** represent respondents who indicated: (1) sex assigned at birth Female and gender identity as Man, (2) sex assigned at birth Male and gender identity as Woman, or (3) or identified as Genderqueer or identified as Non-binary or Third Gender Survey respondents were asked about varying health experiences that included HIV, HIV PrEP (preexposure prophylaxis) or PEP (post-exposure prophylaxis) use, hepatitis B virus (HBV), hepatitis C virus (HCV), STIs, substance use, and mental health diagnosis. Respondents could select all that applied.



In the survey, respondents could choose either alcohol use disorder (AUD), PWUD, or both. PWUD is defined as those who choose the indicator "I am a person who uses drugs."

Survey respondents were asked about their experiences with homelessness, incarceration, sexual/intimate partner violence, and sex work, and could select all that applied. There were follow-up questions about recent experiences of homelessness and incarceration within the past year. Survey questions regarding carceral experience did not distinguish between prisons and jails.

Lived Experiences Among



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Syndemic Service Needs & Barriers

All consumer respondents (n=848) were asked about syndemic prevention and care service needs in the past five years. Any respondent who indicated an unmet need (needing and not receiving a service) were asked about barriers to receiving care for each unmet service need indicated and could select all barriers that applied.

The figure below demonstrates the gap in access for needed syndemic services. The **green** bars represent the number of respondents who needed each service. The **purple** line represents the disparity in service access demonstrated as the percentage of unmet need for each service (i.e., the number of people who were unable to receive the service among those who indicated needing the service).



Syndemic Service Need & Unmet Need Among Consumer Respondents (n=848)

Top 3 Unmet Syndemic Service Needs

- HIV PrEP (34% unable to access)
- Inpatient/residential SUD treatment (29% unable to access)
- SUD counseling services (27% unable to access)

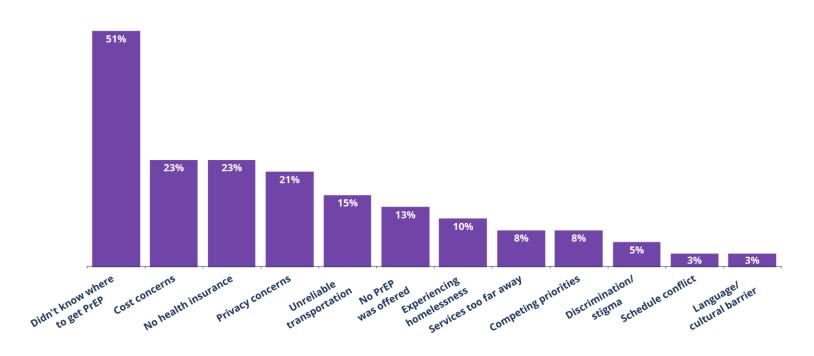
Among all syndemic services, the most needed services were infectious disease testing, and most respondents who needed these services were able to receive them.

- HIV testing (51% needed and 97% received)
- STI testing (45% needed and 95% received)
- HCV testing (37% needed and 95% received)

The figures below outline barriers to the top three unmet syndemic services (HIV PrEP, SUD treatment, and SUD counseling). Respondents could select all barriers that applied and there was an "other" open response option. For barriers related to the additional unmet syndemic services, *see Appendix I*.

Top Unmet Syndemic Service Barriers: HIV PrEP

HIV PrEP was indicated as a needed service among 14% of respondents (n=116) with 34% of those respondents (n=39) who were unable to receive these services.



Barriers to HIV PrEP Among Respondents Who Indicated an Unmet Need (n=39)

Among those who indicated HIV PrEP as an unmet service need, top barriers included:

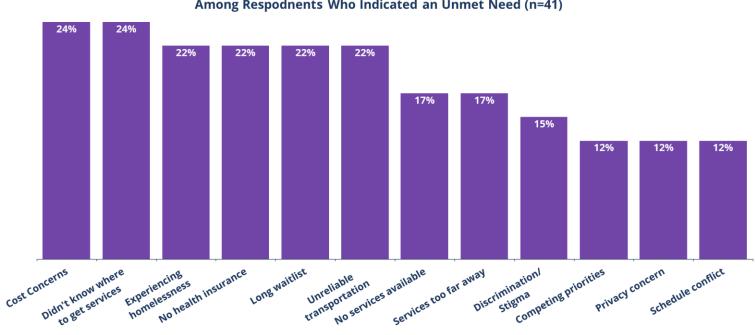
- Not knowing where to get PrEP
- Concerns about cost
- · Having no health insurance

Additional barriers cited:

- Didn't know what PrEP was
- Unsure about using PrEP
- Providers uncomfortable prescribing PrEP

Top Unmet Syndemic Service Barriers: In-patient or residential SUD treatment

SUD treatment was indicated as a needed service among 17% of respondents (n=143) with 29% of those respondents (n=41) who were unable to receive these services.



Barriers to In-patient or Residential SUD Treatment Services Among Respondents Who Indicated an Unmet Need (n=41)

Among respondents who indicated in-patient/residential SUD treatment as an unmet service need, top barriers included:

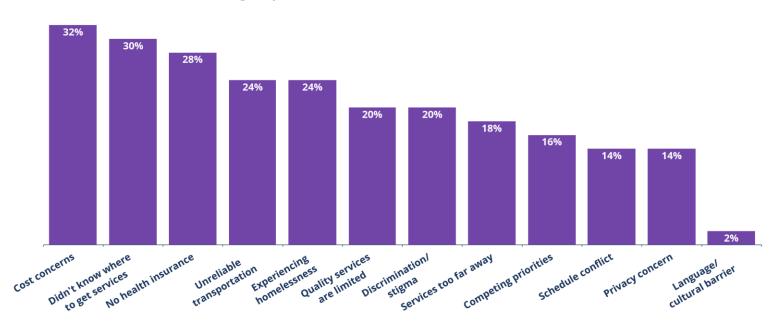
- Not knowing where to get services
- Concerns about cost
- Experiencing homelessness, no health insurance, long waitlist, and unreliable transportation

Additional barriers cited:

- Incarceration
- Substance use
- Treatment centers unwilling to permit service dogs
- Undecided about engaging in services

Top Unmet Syndemic Service Need Barriers: SUD Counseling

SUD counseling was indicated as a needed service among 22% of respondents (n=185) with 27% of those respondents (n=50) who were unable to receive these services.



Barriers to SUD Counseling Services Among Respondents Who Indicated an Unmet Need (n=50)

Among respondents who indicated SUD counseling as an unmet need, top barriers included:

- Concerns about cost
- Unaware where to get services
- · No health insurance

Additional barriers cited:

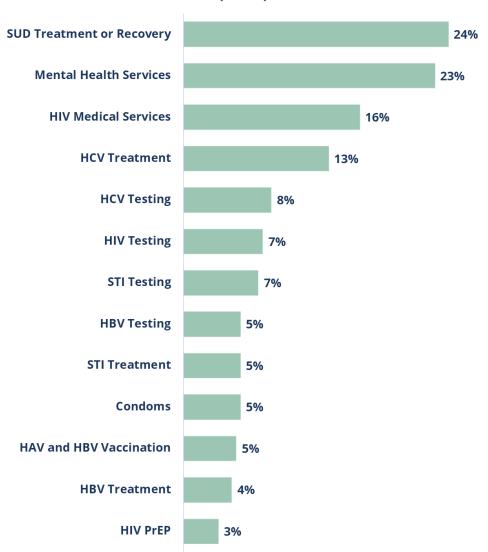
- "Kicked out"
- Insurance did not cover services
- Post-traumatic stress disorder (PTSD)
- Denial
- Incarceration
- No phone to schedule appointments
- Counseling not available for longer need
- Substance use abstinence requirement

Barriers to Received Syndemic Services

Respondents who indicated a syndemic service need and received it (n= 717) were asked if there were difficulties accessing those services and if so, what the barriers were. The majority (90%, n=632) of consumer respondents who were able to receive needed syndemic services did not experience barriers to accessing services. For those who did experience difficulties (10%, n=75), the top barriers included lack of transportation, quality services being limited, concerns related to cost or having no insurance, services were too far away, and experiencing discrimination/stigma (e.g., based on substance use, a health condition, sexual orientation).

Syndemic Service Unmet Need While Incarcerated

Respondents who indicated carceral experience (n=253, 30%) were asked about services they needed but were unable to receive while incarcerated, and respondents could select all that applied.



Unmet Service Need While Incarcerated (n=253)

Some indicated they did not need services (30%) or were able to receive all services (23%) while incarcerated. The top unmet syndemic services while incarcerated were:

- SUD treatment or recovery services
- Mental health services
- HIV medical services
- HCV treatment

Support Service Needs & Barriers

All consumer respondents (n=848) were asked about supportive service needs in the past five years, whether they needed services and if those needed services were received or not. Respondents who indicated an unmet need for any supportive service were asked about barriers experienced and could select all barriers that applied.

In the figure below, the **green** bars represent the number of respondents who needed each service. The **purple** line represents percentage of unmet need for each service (i.e., the number of people who were unable to receive the service among those who indicated needing the service).



Support Service Need & Unmet Need Among All Consumer Respondents (n=848)

Top 3 Unmet Support Service Needs

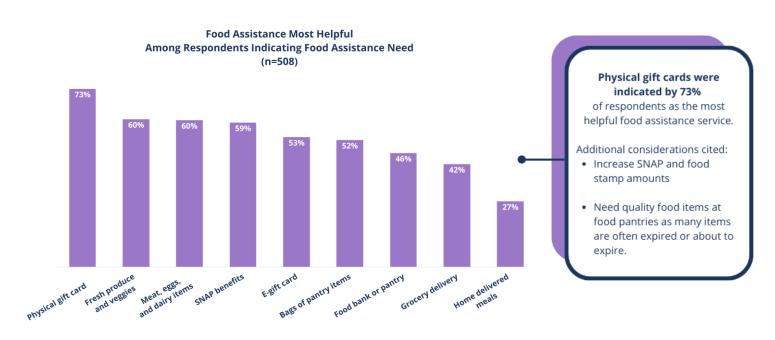
- Job-related services
- · Financial literacy and budgeting support
- Legal services

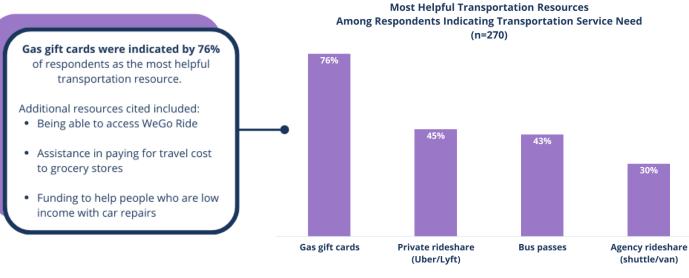
Over 60% of respondents indicated unmet need for each of these services. Overall, there was a relatively high indication of need across a majority of supportive services.

Although case management and medication assistance were among the top needed supportive services, these services had the lowest unmet need, whereas over 40% of respondents indicated they were unable to receive services for dental or eye care.

Food & Transportation Resources

Respondents who indicated a need for food assistance (n=508, 60%) or transportation assistance (n=270, 32%) in the past five years were asked about which resources would be helpful, and respondents could select all that applied.





Housing Assistance Need & Unmet Need

All consumer respondents (n=848) were asked about housing assistance needs in the past five years, whether they needed services and if those needed services were received or not.

In the figure below, the **green** bars represent the number of respondents who needed each service. The **purple** line represents percentage of unmet need for each service (i.e., the number of people who were unable to receive the service among those who indicated needing the service).



Housing Assistance Service Need & Unmet Need Among All Consumers (n=848)

Barriers To Supportive Services

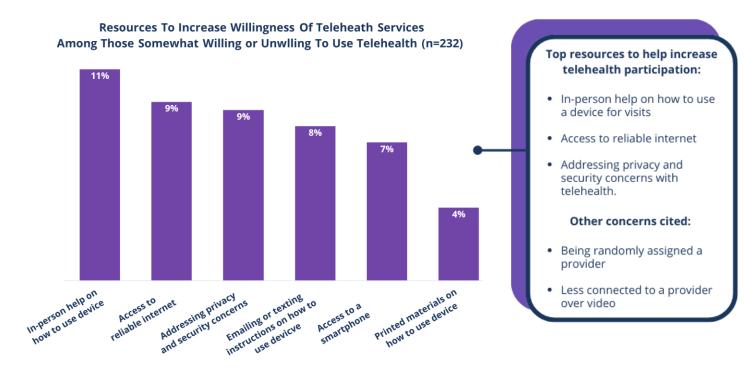
Respondents who indicated not receiving needed supportive services were asked about barriers to accessing these services. The top barriers were that quality services were limited, followed by concerns about cost, services being too far away, experiencing homelessness, and not having transportation.

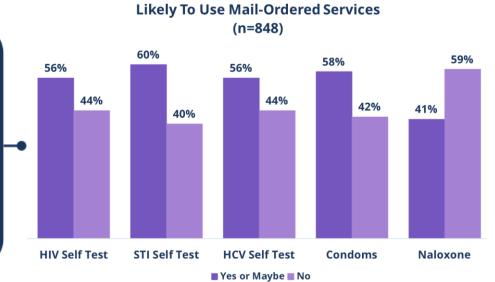
Telehealth & Mail-Ordered Services

Consumer respondents (n=848) were asked questions related to telehealth services such as being able to access services and willingness to participate in such services.

A majority (94%, n=799) of consumer respondents indicated having consistent access to a smartphone, tablet, or computer with 81% of respondents (n=692) indicating no difficulty in accessing reliable Wi-Fi or internet.

73% of consumer respondents (n=616) were willing to participate in telehealth. Those who were somewhat willing or unwilling to participate in telehealth services (27%, n=232) had a high preference to see a provider in person (53%, n=122) or were not interested in telehealth services (32%, n=74).





Consumer respondents were asked if they would be likely to use mail-ordered services for HIV self-testing, STI selftesting, HCV self-testing, condoms, and naloxone.

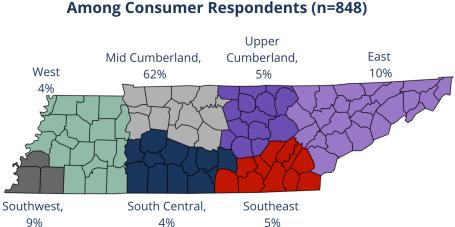
Overall, there was interest in mail-ordered syndemic services with the highest interest for mail ordered STI self-tests (60%).

Tennessee Regional Findings

Region

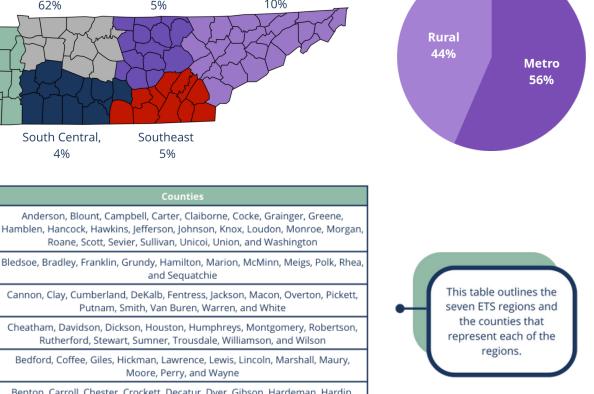
East

This section provides a comparison of syndemic and support service needs and barriers, telehealth, and mail-order services for consumer respondents across the ETS regions as well as a focus on rural consumer respondents.



ETS Region Of Residence

Rural-Metro Residence Among Consumer Respondents (n=848)



Roane, Scott, Sevier, Sullivan, Unicoi, Union, and Washington Bledsoe, Bradley, Franklin, Grundy, Hamilton, Marion, McMinn, Meigs, Polk, Rhea, Southeast and Sequatchie Upper Cannon, Clay, Cumberland, DeKalb, Fentress, Jackson, Macon, Overton, Pickett, Cumberland Putnam, Smith, Van Buren, Warren, and White Cheatham, Davidson, Dickson, Houston, Humphreys, Montgomery, Robertson, Mid Cumberland Rutherford, Stewart, Sumner, Trousdale, Williamson, and Wilson Bedford, Coffee, Giles, Hickman, Lawrence, Lewis, Lincoln, Marshall, Maury, South Central Moore, Perry, and Wayne Benton, Carroll, Chester, Crockett, Decatur, Dyer, Gibson, Hardeman, Hardin, West Haywood, Henderson, Henry, Lake, Lauderdale, Madison, McNairy, Obion, and Weakley Southwest Fayette, Shelby, and Tipton

Anderson, Blount, Campbell, Carter, Claiborne, Cocke, Grainger, Greene,

Regional: Syndemic Service Needs & Barriers

ETS Regions: Syndemic Need, Unmet Need, & Barriers

A majority of regions indicated HIV and STI testing within their top 3 needed syndemic services (East: 44% and 37%, Southeast: 62% and 40%, Upper Cumberland: 56% and 37%, Mid Cumberland: 54% and 50%, South Central: 56% and 47%, and West: 51% and 35%, respectively). Overall, HIV and STI testing seem to be relatively accessible with most respondents being able to receive these services. Also, HCV testing was indicated as a top needed syndemic service in the East, Southeast, and West (55%, 38%, and 30%, respectively) and was relatively accessible with a majority of respondents able to receive these services.

While STI treatment was indicated as a top needed service in Upper Cumberland, Mid Cumberland, and South Central (29%, 40%, and 33%, respectively), it was also relatively accessible with a majority of respondents being able to receive these services.

However, in the Southwest region, top syndemic service needs were mostly related to substance use services with syringe service programs (71%), substance use counseling (59%), and medication-assisted treatments (MAT) (47%) being the most in-demand services. Substance use counseling and MAT services were relatively inaccessible with 41% and 35%, respectively, unable to receive these services in the Southeast. It is important to note that 72% of Southwest respondents identified as a PWUD and this may have been influenced by in-person data collection at SSPs in the region.

Across the ETS regions, the highest unmet service needs were for substance use services, HCV treatment, and HIV PrEP and PEP. See Appendix II for regional syndemic service need and unmet need figures. The table below outlines each region's top 3 unmet syndemic service needs and their associated top barriers.

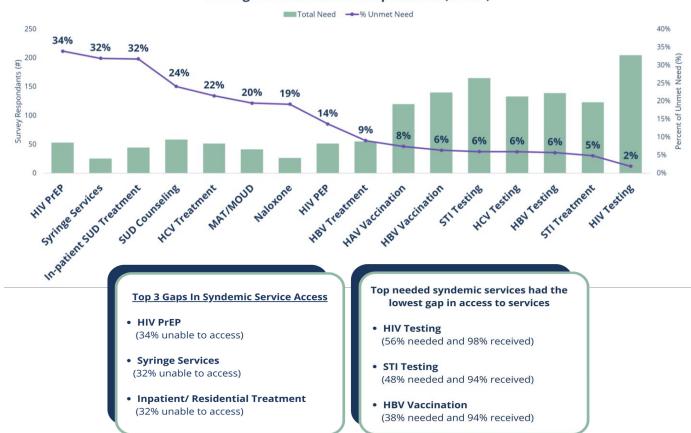
Region (n= total region respondents)	Top Unmet Need	Top Barriers
	In-Patient/Residential Substance Use Treatment	 Concerns about cost Unaware where to get services
	(total need n=22, 36% unmet)	3. No services available
		1. Unaware where to get PrEP
East	HIV PrEP	2. No health insurance
(n=86)	(total need n=14, 36% unmet)	3. No or unreliable transportation
		4. Privacy concerns
	Hepatitis C Treatment	1. Unaware where to get services
	(total need n=25, 32% unmet)	2. Experiencing unstable housing
	(3. No or unreliable transportation
	Additional barrier cited in open responses include not	t knowing that PrEP existed.
	Naloxone (total need n=1, 100% unmet)	1. Concerns about cost
	Substance Use Counseling (total need n=7, 57% unmet)	1. Unaware where to get services
Southeast		2. No or unreliable transportation
(n=45)		3. Quality services are limited
	In-Patient/Residential Substance Use Treatment (total need n=7, 57% unmet)	1. Unaware where to get services
		2. No treatment services available
		3. No or unreliable transportation
Upper Cumberland (n=41)	HIV PrEP	1. Unaware where to get PrEP
	(total need n=3, 67% unmet)	2. Language or cultural barrier
	Hepatitis C Treatment (total need n=6, 50% unmet)	1. Concerns about cost
		2. Unaware where to get services
		3. Experiencing unstable housing
	HIV PEP	1. Unaware where to get PEP
	(total need n=4, 50% unmet)	2. Concerns about cost

	Syringe Service	 Services are too far away Discrimination/stigma
	(total need n=29, 45% unmet)	3. Privacy concern
Mid		1. Unaware where to get PrEP
Cumberland	HIV PrEP (total need n=78, 35% unmet)	2. Concerns about cost
(n=525)		3. No health insurance
	In-Patient/Residential Substance Use Treatment	1. Long waitlist to get into services
	(total need n=58, 26% unmet)	2. Concerns about cost
		3. No or unreliable transportation
	Syringe Service	1. Services are too far away
	(total need n=5, 40% unmet)	2. Discrimination/stigma
		3. Privacy concern
South Central	Naloxone	1. No or unreliable transportation
(n=36)	(total need n=3, 33% unmet)	2. Concerns about law enforcement
		3. Unaware where to get naloxone
	Substance Use Counseling	1. Discrimination/stigma
	(total need n=5, 20% unmet)	2. Unaware where to get services
		3. Privacy concern
	Syringe Service	
	(total need n=1, 100% unmet)	1. Services are too far away
		1. Unaware where to get PrEP
West	HIV PrEP (total need n=6, 50% unmet)	2. Privacy concerns
(n=37)		3. Unable to take due to kidney
		function
	Hepatitis C Treatment (total need n=5, 20% unmet)	1. Sobriety restrictions
	Henetitie C Treatment	1. Unaware where to get services
	Hepatitis C Treatment (total need n=24, 54% unmet)	2. Fear of hepatitis C diagnosis
		3. Concerns about cost
Southwest (n=78)		1. No health insurance
	Substance Use Counseling (total need n=46, 41% unmet)	2. Experiencing unstable housing
		3. Unaware where to get services
	Medication-assisted Treatment (total need n=37, 35% unmet)	1. Concerns about cost
		2. No health insurance
		3. No or unreliable transportation
Additional barriers cited in open responses include being unsure if they were eligible f hepatitis C treatment while using drugs, not having someone to watch their service an while they would be in substance use counseling or treatment, substance use counsel treatment services not being available in the area		meone to watch their service animal

Rural: Syndemic Need, Unmet Need, & Barriers

In the survey, 44% of consumer respondents resided in a rural county (n=369). Respondents residing in a county without a metro health department were categorized as Rural.

The figure below demonstrates the gap in access for needed services. The **green** bars represent the number of rural respondents who needed each service. The **purple** line represents the disparity in service access demonstrated as the percentage of unmet need for each service.



Syndemic Service Need & Unmet Need Among Rural Consumer Respondents (n=369)

The table below outlines rural respondents' top 3 unmet syndemic service needs and their top barriers.

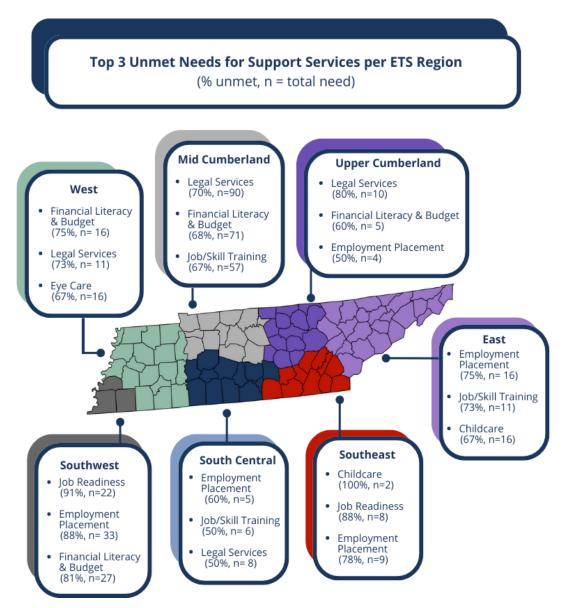
Top Unmet Services	Top Barriers Among Unmet Need
HIV PrEP (total need n=53, 34% unmet)	 Don't know where to get PrEP Concerns about cost No health insurance Privacy concerns
Syringe Services (total need n=25, 32% unmet)	 Don't know where to get services Concerns about law enforcement
Substance Use Treatment (total need n=44, 32% unmet)	 Unaware where to get services Concerns about cost Long waitlist for services Discrimination/ Stigma

Regional: Support Service Needs & Barriers

ETS Regions: Support Need, Unmet Need, & Barriers

All ETS regions reported prescription assistance, food assistance, dental care, and eye care as top needed supportive services. Additionally, case management was indicated as a top needed support service in six of the seven regions. The Southwest region indicated help obtaining health insurance as a top support service need. Case management and prescription assistance were well met across a majority of the ETS regions. There was relatively high unmet need for dental and eye care across all the ETS regions. Of note, the Southwest region had high unmet need across almost all of the supportive services except case management (0% unmet need). Unmet need for support services in Southwest region ranged from 91% (job readiness) to 44% (prescription assistance).

See Appendix II for regional support service need and unmet need figures. The figure below outlines each region's top 3 unmet support services including the percent unmet and the number of participants who indicated the need for the support service.



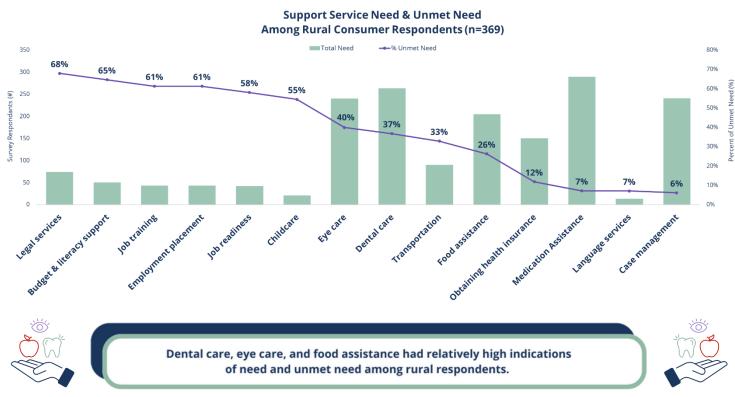
With slight variations, all ETS regions reported concerns about cost, access to reliable transportation, and limited quality services as top barriers to receiving support services. The East and Southeast regions were unique in that unstable housing and homelessness were indicated as top barriers to receiving support services. The table below highlights the top barriers to support services in each region.

Region	Top Barriers for Support Services
East (n=86)	 Concerns about cost No or unreliable transportation Quality services are limited Unstable housing/ experiencing homelessness Additional barriers cited in open response include having personal items stolen (e.g., ID, social security card, backpack), prior criminal record, services being unavailable or working on a first come first served basis, housing is too expensive causing people to lose their housing and being unable to find different housing
Southeast (n=45)	 Services are too far away Concerns about cost Quality services are limited Privacy concerns Experiencing homelessness/unstable housing Additional barriers cited in open response include unaware of services, pharmacy issues, depined apprivate (concerns)
	denied services (especially rent assistance)
Upper Cumberland (n=41)	 Services are too far away Concerns about cost Quality services are limited Additional barriers cited in open response include having a criminal record, no affordable housing, no funds to assist with housing
Mid Cumberland (n=525)	 Quality services are limited Concerns about cost No or unreliable transportation Additional barriers cited in open response include unaware of services, no services available, denied benefits
South Central (n=36)	 Services are too far away Quality services are limited Concerns about cost Discrimination/ stigma Privacy concerns

West (n=37)	 Services are too far away Quality services are limited Concerns about cost No or unreliable transportation Additional barriers cited in open response include unaware of services, no follow up when reaching out for services
Southwest (n=78)	 Quality services are limited Experiencing homelessness/unstable housing No or unreliable transportation Concerns about cost Additional barriers cited in open response include unaware of services, process is challenging or confusing, long waitlist, not having needed documentation (e.g., identification or birth certificate), denied services, no phone, no follow up from service personnel/staff, food assistance not enough to cover

Rural: Support Need, Unmet Need, & Barriers

This section represents rural respondents' supportive service needs and unmet needs in the past five years. The figure below demonstrates the gap in access for needed services. The **green** bars represent the number of rural respondents who needed each service. The **purple** line represents the disparity in service access demonstrated as the percentage of unmet need for each service.



Rural respondents top barriers to accessing support services included services being too far away, concerns about cost, limited quality services, privacy concerns, and experiencing homelessness or unstable housing.

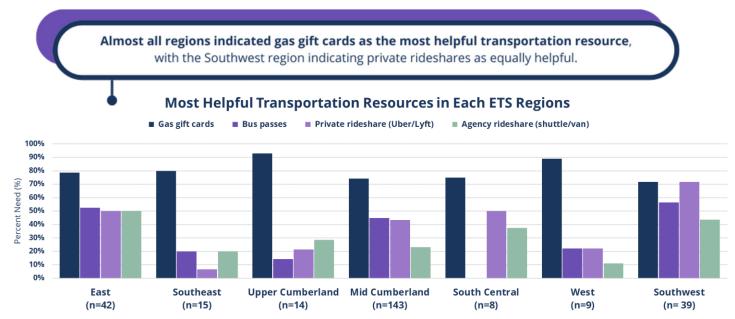
Regional: Food & Transportation Assistance

Food Assistance

Overall, there were no major differences across ETS regions regarding the most helpful resource for food assistance. Gift cards were indicated as the most helpful across all regions. In the Southeast region, e-gift cards and fresh grocery items were indicated as equally important as physical gift cards.

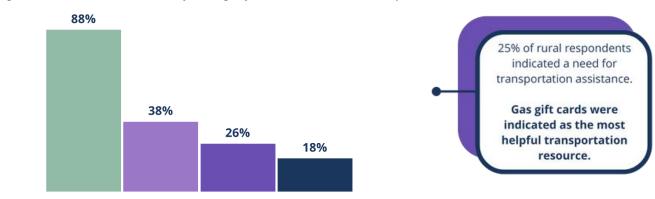
About 56% of rural respondents indicated a need for food assistance (n=205). Top food assistance resources included physical gift cards, fresh grocery items, and SNAP benefits.

Transportation Assistance



Most Helpful Transportation Resources Among Rural Consumers Indicating Service Need (n=91, 25%)





Regional: Housing Service Need & Unmet Need

ETS Regions: Housing Need & Unmet Need

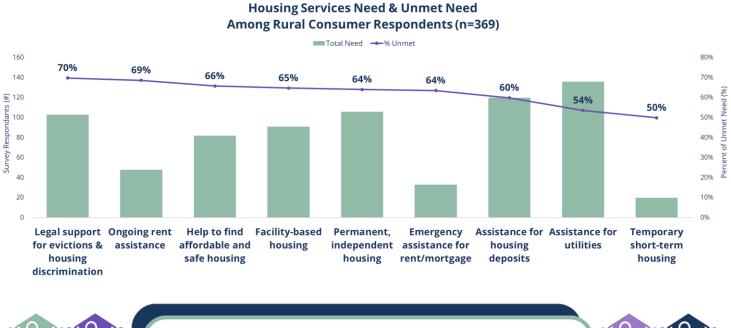
Across all ETS regions, there was a high reported need for almost all housing services except legal services and facility-based housing. Overall, there was a high percentage of respondents across each region who were unable to receive needed housing services. In a majority of ETS regions (6 out of the 7 regions), assistance for utilities was the top indicated housing need, except in the Southwest region. In the Southwest region, temporary short-term housing was the top needed housing service (65% needed and 63% unable to receive). The Southwest and East regions had overall higher percentages of need and unmet need across all housing services compared to other regions. The table below outlines top 3 needed housing services in each region.

Region	Top 3 Needed Housing Services (% needed and % unmet)
	1.Assistance for utilities (58% needed, 54% unmet)
East (n=86)	2. Assistance housing deposits (55% needed, 62% unmet)
(11-00)	3.Help find safe and affordable housing (55% needed, 62% unmet)
	1. Assistance for utilities (49% needed, 41% unmet)
Southeast	2. Emergency assistance for rent/mortgage (44% needed, 35% unmet)
(n=45)	3. Assistance housing deposits and ongoing assistance for rent
	(both 38% needed, 53% unmet)
Upper	1.Emergency assistance for rent/mortgage (41% needed, 47% unmet)
Cumberland	2. Ongoing assistance for rent (41% needed, 47% unmet)
(n=41)	3.Assistance for utilities (41% needed, 41% unmet)
Mid	1.Emergency assistance for rent/mortgage (34% needed, 62% unmet)
Cumberland	2. Assistance for utilities (34% needed, 57% unmet)
(n=525)	3. Assistance housing deposits (31% needed, 55% unmet)
South Central	1.Assistance for utilities (33% needed, 58% unmet)
(n=36)	2.Help find safe and affordable housing (31% needed, 64% unmet)
	3.Assistance housing deposits (31% needed, 55% unmet)
West (n=37)	1. Assistance for utilities (41% needed, 58% unmet)
	2. Ongoing assistance for rent (38% needed, 47% unmet)
	3. Help find safe and affordable housing, Assistance housing deposits, and Emergency
	assistance for rent/mortgage (all: 30% needed, 45-55% unmet)
	1.Temporary short-term housing (65% needed, 63% unmet)
Southwest (n=78)	2.Assistance for utilities (62% needed, 71% unmet)
(n=/8)	3.Permanent, independent housing (60% needed, 83% unmet)

Rural: Housing Need & Unmet Need

This section represents rural respondents' housing service needs and unmet needs in the past five years. Among rural respondents (n=369), 26% identified as experiencing homelessness, 31% experienced it within the past year.

The figure below demonstrates the gap in access for needed services among rural consumer respondents (n=369). The **green** bars represent the number of rural respondents who needed each service. The **purple** line represents the disparity in service access demonstrated as the percentage of unmet need for each service.

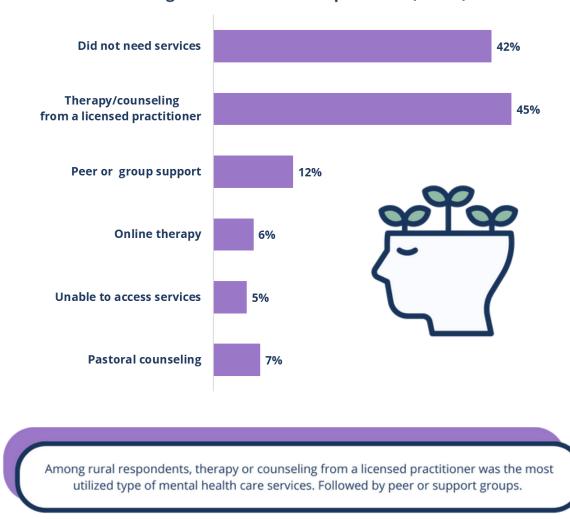


Over 50% of rural consumer respondents indicated an unmet need for each of the housing services listed.



Regional: Mental Health

When mental health services were needed, therapy or counseling from a licensed practitioner was the most utilized type of care across all ETS regions. The East, Mid Cumberland, South Central, and Southwest regions respondents reported peer group support as the next popular form of care accessed (16%, 14%, 17%, and 22%, respectively). In the Southeast region, respondents indicated pastoral counseling (7%) as the next most popular form of mental healthcare, while those in Upper Cumberland preferred online therapy (10%). In the West region, pastoral counseling and online therapy (11% each) were the next most utilized types of mental healthcare. Regions with the highest percentage of consumers who were unable to access mental health services included the East (13%), Southwest (12%), and Southeast (11%) regions.



Mental Health Services Utilization Among Rural Consumer Respondents (n=369)

Regional: Telehealth & Mail-Ordered Services

Device & Internet Access

Access to a smartphone, tablet, or computer was high across all ETS regions. In most regions, at least 90% of respondents were able to access a device. The East region had the lowest reported access (76%) and reported the most difficulty with access to reliable internet (42%).

Overall, most rural respondents indicated they had consistent access to a device (98%), as well as no difficulty in accessing internet (84%).

It is important to note the predominately online survey design and the potential bias of those with telehealth capabilities who took the survey.

Telehealth Willingness

The regions with the lowest willingness to utilize telehealth services were Upper Cumberland (49% willing) and West (59% willing).

Across all regions, respondents less willing to use telehealth had a preference to see a provider in person and were not interested in telehealth services. When asked how to increase willingness, across most regions, respondents reported a desire for emailed, texted, or in-person help with using their device, as well as the need for access to reliable internet. The Mid Cumberland region uniquely reported a higher need to address privacy and security concerns with telehealth services.

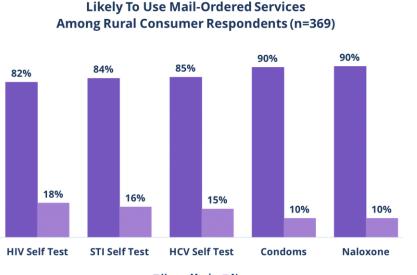
About 70% of rural respondents indicated a willingness to utilize telehealth services. For rural respondents who were somewhat or unwilling to use telehealth (n=111, 30%), there was a preference to see a provider in person (n=59, 53%) and not being interested in telehealth services (n=27, 34%). When asked how to increase willingness, the top reported resources included in-person help for using their device (n=16, 14%), access to reliable internet (n=10, 9%), and emailed instructions on how to use their device (n=9, 8%).

Mail-Order Services

Across all ETS regions, respondents were interested in using mail-ordered syndemic services. All regions report a high interest in using mail-order naloxone (ranging from 80% in Upper Cumberland to 98% in Southeast) and condoms (ranging from 86% in South Central to 97% in Southwest).

There was relatively high interest in mail-ordered HIV, STI, and HCV self-tests as well; however, there was slightly lower interest in the Upper Cumberland (66%, 68%, and 68%), South Central (75%, 72%, and 75%), and West (78% each) regions compared to other regions ranging from 82–96% interest in self-test kits.

A majority of rural respondents indicated interest in using mail-order services for HIV, STI, and HCV tests, condoms, and naloxone (82%, 84%, 85%, 90%, and 90%, respectively).



That would be great to be able to get one [mail-ordered test], that way they could do it in their home privately.

66 -

Like we were able to go online and order those COVID tests to have them at home. Nobody knew that but who we ordered them from.

> - Rural FGD Participant Cisgender Woman, PLWH

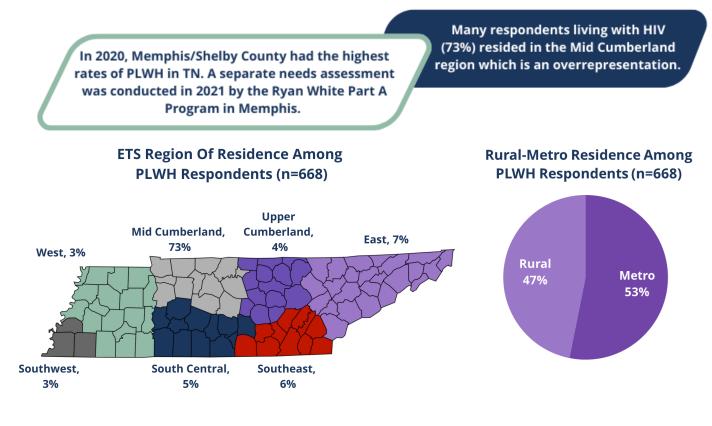
> > - 99

📕 Yes or Maybe 🔳 No

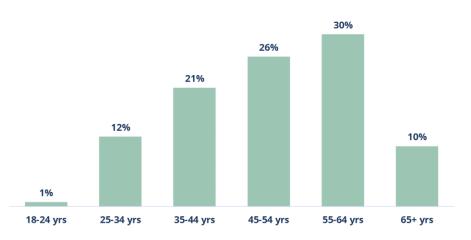
Persons Living With HIV

Overview/Demographic

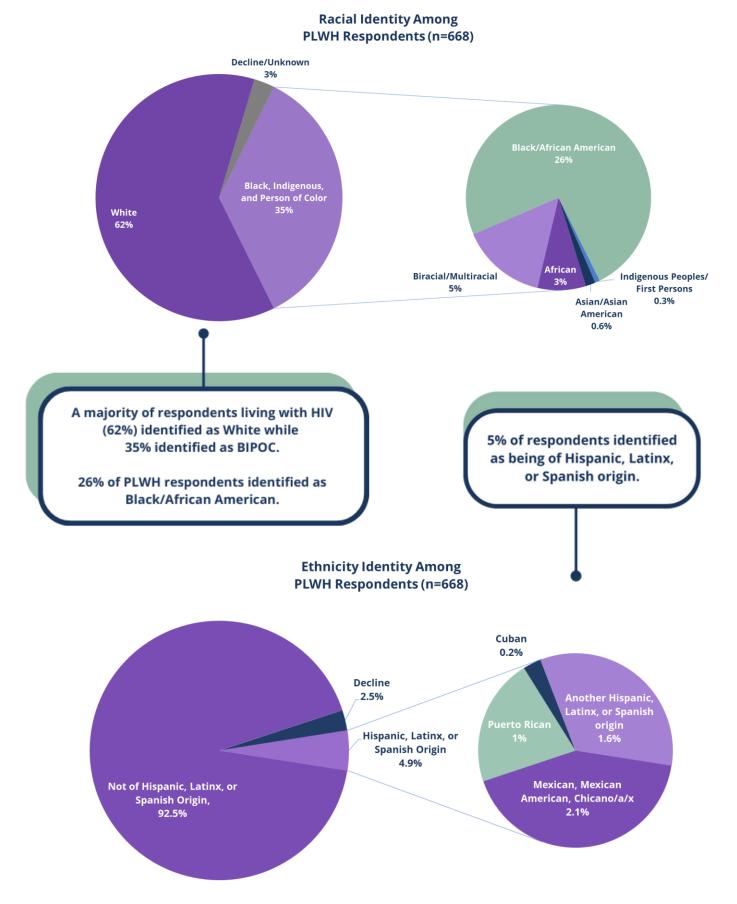
This next section outlines HIV care needs and barriers, as well as syndemic and support service needs and barriers, for respondents who indicated living with HIV. All respondents (n= 1,014) were asked if they are a person living with HIV. A total of 668 participants responded they are living with HIV (66% of total respondents). This total includes respondents who were identified as a consumer, provider, or both. Outlined below are varying demographics of respondents living with HIV including residency, age range, race and ethnicity, gender identity, and sexual orientation.

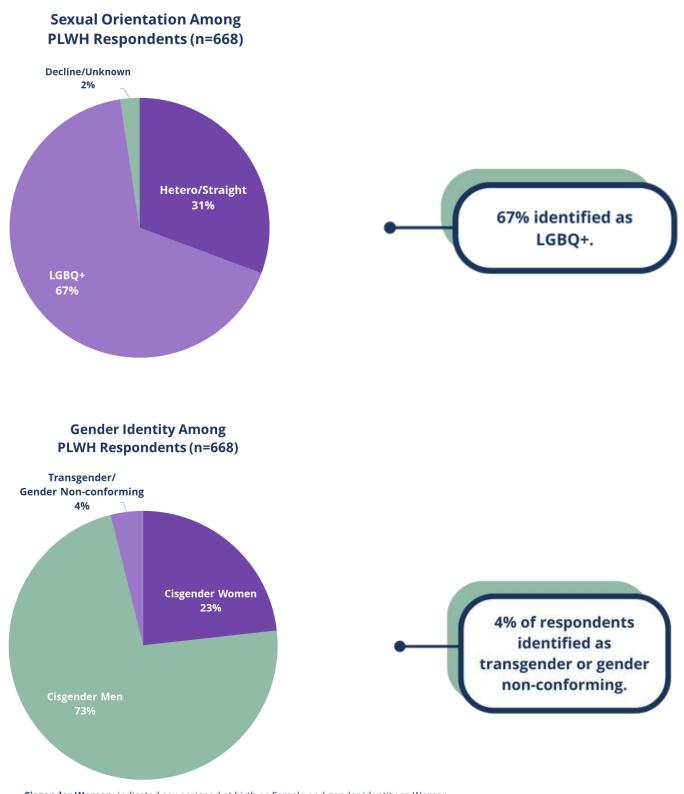


Age Range Among PLWH Respondents(n=668)



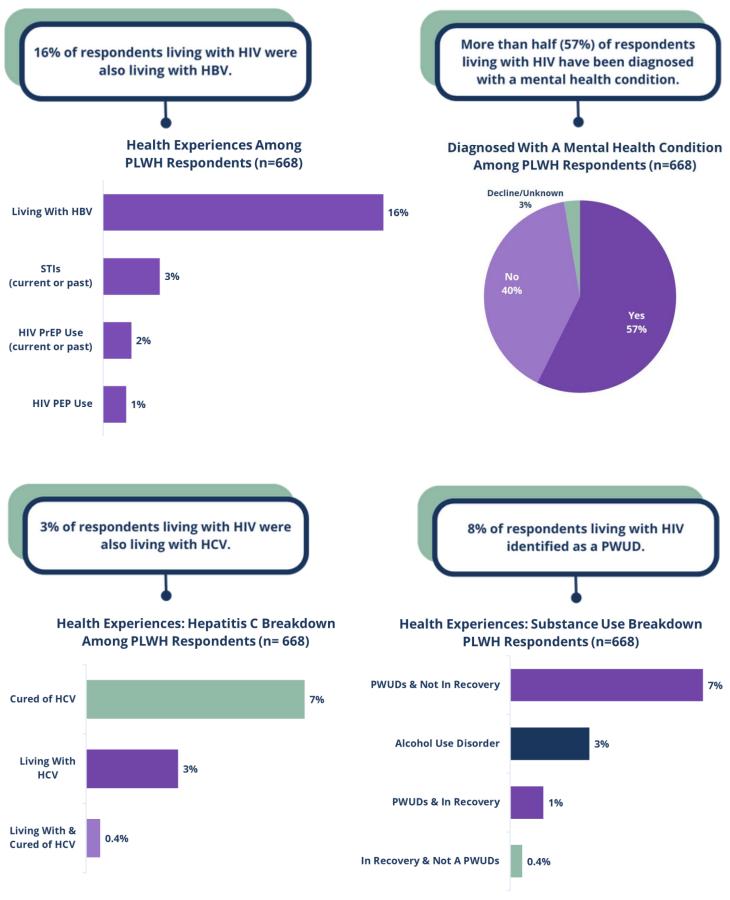
There was low participation among young adults who were 18-24 years old (1%). The highest participation (30%) was among respondents 55-64 years.



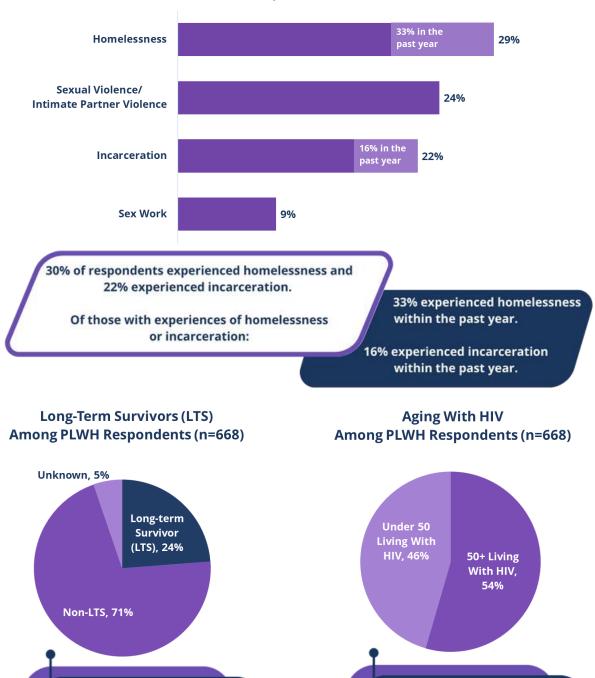


Cisgender Women: indicated sex assigned at birth as Female and gender identity as Woman
 Cisgender Men: indicated sex assigned at birth as Male and gender identity as Man
 Transgender/Gender Non-conforming persons represent respondents who indicated:
 (1) sex assigned at birth Female and gender identity as Man, (2) sex assigned at birth Male and gender identity as Woman, or (3) or identified as Genderqueer or identified as Non-binary or Third Gender

ETS TN 2022 Needs Assessment Consumer Report



In the survey, respondents could choose either alcohol use disorder (AUD), PWUD, or both. PWUD is defined as those who choose the indicator "I am a person who uses drugs." Survey respondents were asked about their experiences with homelessness, incarceration, sexual/intimate partner violence, and sex work and could select all that applied. There were follow-up questions about recent experiences of homelessness and incarceration within the past year. Survey questions regarding carceral experience did not distinguish between prisons and jails.



Lived Experiences Among PLWH Respondents (n=668)

Long-Term Survivors are defined as having a HIV/AIDS diagnosis before 1996 (before HAARTs). Defined by National Resource Center on HIV & Aging at GMHC, 2022.

24% of respondents living with

HIV were Long-term Survivors.

Aging with HIV is defined being a PLWH who is 50 years old or older. Defined by DHHS, 2019.

54% of respondents living with

HIV were aging with HIV.

All respondents (consumers and providers) who identified as a PLWH (n=688, 66%) were asked about HIV care needs and barriers.

Stage 3 HIV Diagnosis (also known as AIDS)

A quarter (25%) of respondents living with HIV reported they received a Stage 3 HIV diagnosis at some point. Of those who received a Stage 3 HIV diagnosis, most (95%) received it within one year of their initial HIV diagnosis.

Early Intervention Specialist

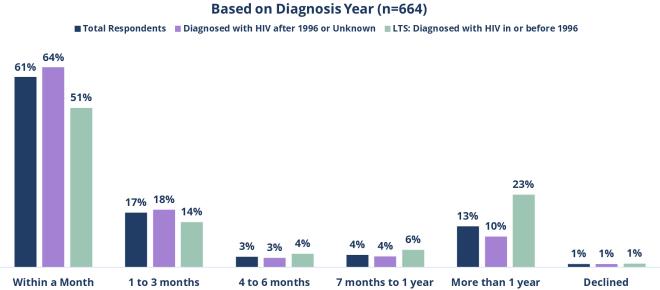
Early Intervention Specialists (EIS) provide services to support people who were recently diagnosed with HIV access HIV treatment and supportive services. Over half (58%) of respondents living with HIV indicated not being contacted by EIS services and 27% were unsure. It is possible that respondents may have been contacted by EIS personnel; however, were unfamiliar with the term Early Intervention Specialist, or EIS.

A majority (90%) of those who reported being contacted by EIS felt that this service was helpful.

For those who felt EIS services were somewhat or unhelpful, aspects that impacted their EIS experience were related to privacy issues such as a note being left on the door, as well as their mental health during time of diagnosis and not being in a place to receive the information.

Rapid Start & Barriers

Over 60% of respondents had received HIV care within a month of their initial diagnosis. The national HIV/AIDS goal is 95% linked to care within 1 month of HIV diagnosis.



Start of HIV Medical Care After Initial Diagnosis

Some (13%) respondents indicated receiving care more than a year after their initial diagnosis. When considering year of diagnosis, there is a higher percentage of long-term survivor respondents who indicated starting HIV care after one month of diagnosis, particularly more than one year after diagnosis. This aligns with HIV medical care being limited during this time period, which was prior to the development of HAART around 1996.

Top barriers to HIV rapid care included no appointments available within 30 days, worried someone might find out their HIV status, not having symptoms, and not knowing where to get HIV medical care. Additional reasons cited include being in SUD treatment at the time, being pregnant at the time, denial/mental health issues, and provider wanting to wait.

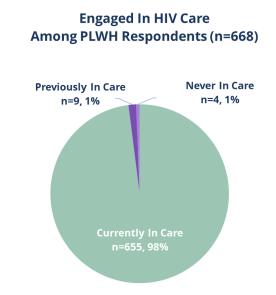
HIV Care

<u>Currently In HIV Care</u>

A majority (98%) of respondents living with HIV were currently receiving HIV care (n=655). In 2019, 65% of PLWH in TN were engaged in HIV care. Therefore, individuals not engaged in HIV care services were underrepresented in the survey.

Most respondents indicated receiving care every two to five months (39%) or twice a year (54%), with less receiving care once a month (3%), once a year (3%), or less than once a year (n= 1).

A little over half indicated having no challenges to receiving HIV care. The top barriers to receiving care include:



• Concerns that someone may find out about their HIV status (14%); concerns about cost (11%); unreliable or no transportation (11%)

Previously in HIV Care

Respondents who were previously in HIV care (n= 9), the top reasons for no longer receiving HIV care were:

• Concerns about cost (44%); scheduling conflicts, specifically being unable to attend during health service hours (33%); not having health insurance (33%)

Never in HIV Care

Respondents who reported never being engaged in HIV care (n= 4), the reasons for not receiving care were:

• Not knowing where to get HIV care; scheduling conflict, specifically being unable to attend during health service hours; recently diagnosed and planning to get into care

Regular Place To Receive HIV Care

Respondents who indicated receiving HIV care at one point (n= 662), almost all (99%) indicated that they have a regular place they went to for HIV care. People who did not have a regular place for HIV care (n=4), indicated experiences of homelessness (n=3), incarceration (n=2), and identified as PWUDs. (n=3).

Impact On HIV Care Engagement

For those who are currently not involved in HIV care (n= 13), 38% reported experiences with homelessness, 23% reported carceral experience, and 31% identified as being a PWUDs. Respondents who identified they were not receiving HIV care and had experienced incarceration in the last year (n=3), also identified experiencing homelessness in the last year and being a PWIUDs that is not in recovery.

Discrimination/ Stigma Barriers To HIV Care

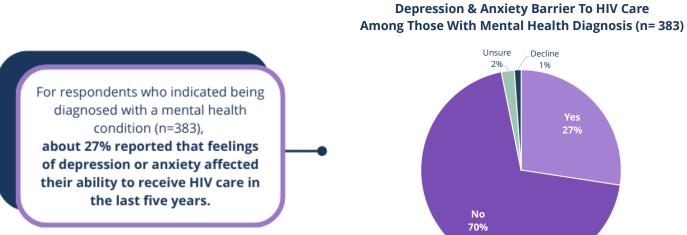
Some respondents living with HIV (7%) reported discrimination/stigma as a barrier to HIV care. The top types of discrimination/stigma experienced were based on sexual orientation (47%), income level or poverty (37%), or health condition such as HIV or HCV (31%).

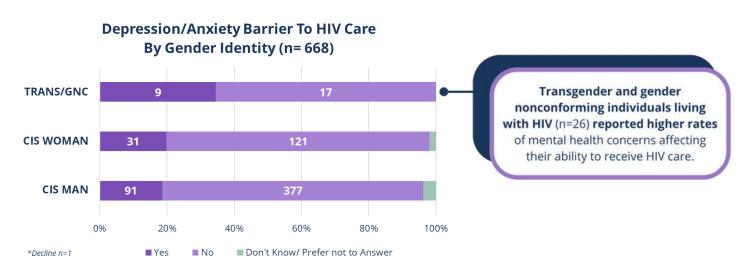
Some people can be really, I don't want to just say they're jerks, but I've grown to know that what people don't understand, they fear. Even in the medical field, or even in case management, you know, they hire people and I think they just in it for the job because once they get around clients or consumers, they you know, they guit, or they make people feel offended.

FGD participant: Indigenous Cisgender Woman, PLWH

HIV Care and Mental Health

- 66 -





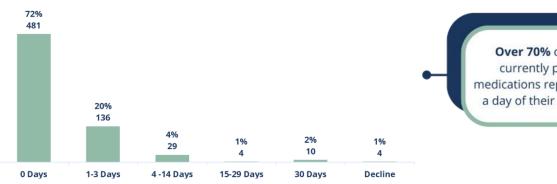
HIV Care & Ryan White Services

Of respondents who indicated having Ryan White coverage (n=440), a majority (91%) were satisfied to very satisfied with the service quality. Respondents who indicated being somewhat satisfied to very unsatisfied (n= 40) reported suggestions and considerations to increase satisfaction, including:

- Better coverage and increase access to dental and eye care services
- Increased coverage and assistance for supportive services (e.g., housing, food, and transportation)
- Increased medication coverage as some clients are still paying high out-of-pocket expenses
- Better pay and benefits for peer navigators as well as hiring PLWH for Ryan White positions
- Reimbursement process is confusing and often leads to their providers not being paid or not paid in a timely manner
- Consideration for the needs of an aging population such as coverage to include nursing homes and long-term care

HIV Medication

Most respondents living with HIV (99%) were currently prescribed HIV medications. Of those who reported not currently prescribed medication, all three were ages 35–44 and had experiences of homelessness, and two had experienced homelessness and incarceration within the last year.



Days of Missed HIV Medication (n=664)

Over 70% of respondents currently prescribed HIV medications reported not missing a day of their HIV medications. For respondents who reported missing one or more days of their HIV medication (n=179), the most common reason was forgetting to take medication (71%). Additional reasons include:

• Errors in mail-order/pharmacy (9%); not having enough food to take with HIV medication (5%); concerns about side effects (5%); difficulties with insurance; pharmacies not keeping medication in stock; losing all belongings (including HIV medications) in a city-wide encampment sweep

Of respondents who reported missing one or more days of their HIV medication, 40% reported experience with homelessness, 31% reported experience with incarceration, 19% identified as a person who uses drugs, and 13% reported experience with sex work.

<u>U=U Prevention Strategy</u>

A majority (91%) of respondents living with HIV indicated knowing what U=U means. Of respondents who knew about U=U, 80% had a medical provider who discussed U=U with them and 58% felt comfortable talking about it with their partners, family, or friends.

For those who indicated being somewhat comfortable (24%) or uncomfortable (18%), top resources to help them feel more comfortable talking about U=U included the need for more U=U messaging in the media, printed resources with scientific evidence, and more medical providers supportively talking about U=U. Additional comments cited were issues relating to HIV stigma and the need for anti-stigma campaigns to be able to talk to others about HIV and U=U.



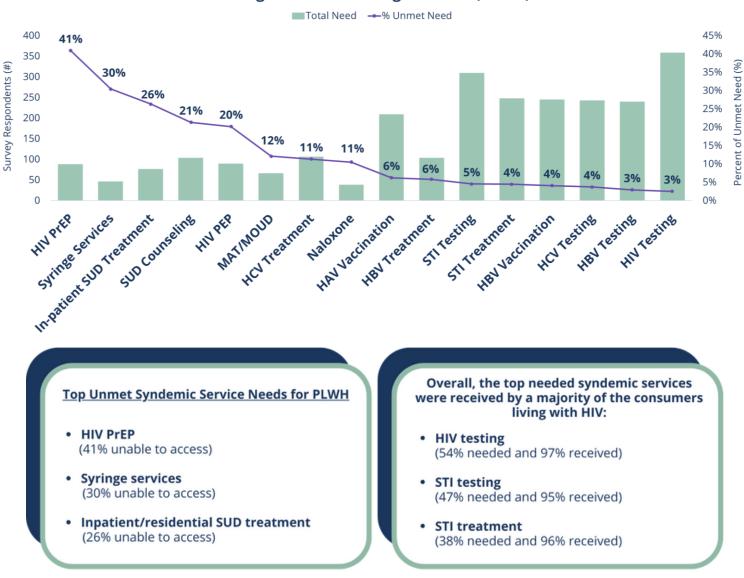
ART (antiretroviral therapy) is medication that stops the HIV virus from multiplying in the body. ART can decrease the amount of HIV in the blood until it is too low to measure. When the viral load cannot be measured, **this is called an "undetectable viral load."**

When a person's viral load is undetectable, they cannot transmit HIV to partner(s). Achieving lower viral loads can also provide important health benefits to people living with HIV.

Persons Living With HIV: Syndemic Service Needs & Barriers

The next few sections provide a breakdown of service needs and barriers for consumer respondents who identified as a PLWH (n= 657). Due to the survey design, respondents living with HIV who opted to only take the provider portion of the survey (n= 11) were not included in the findings below.

The figure below demonstrates the gap in access for needed services among consumers living with HIV. The **green** bars represent the number of respondents who needed each service. The **purple** line represents the disparity in service access demonstrated as the percentage of unmet need for each service (i.e., the number of people who were unable to receive the service among those who indicated needing the service).



Syndemic Service Need & Unmet Need Among Consumers Living With HIV (n=657)

Additional analysis was done for subpopulation of long-term survivors and people aging with HIV; however, these populations show similar needs and barriers to overall needs of people living with HIV.

Barriers To Top Needed Services

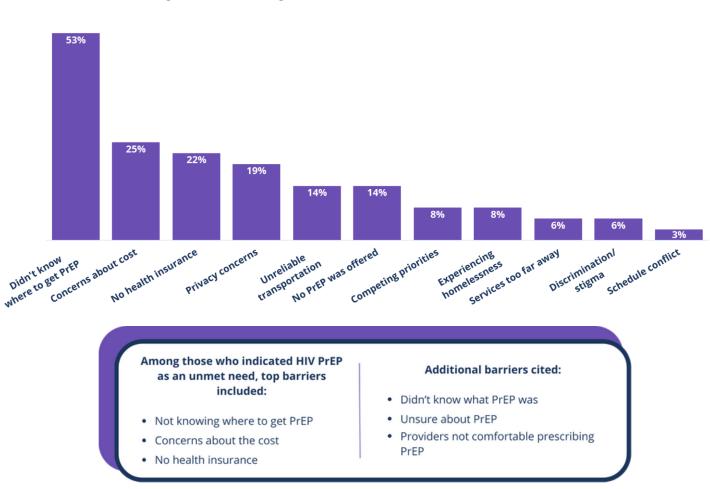
Although top needed services were indicated as accessible to most, for those unable to receive HIV testing, the top barriers were privacy concerns, schedule conflicts, and experiences of discrimination or stigma.

For those unable to receive STI testing, the top barriers included not having reliable transportation, not knowing where to receive testing, and concerns about cost.

Regarding STI treatments, the top barriers were concerns about cost, no health insurance, and not knowing where to receive treatment.

Top Unmet Syndemic Service Barriers: HIV PrEP

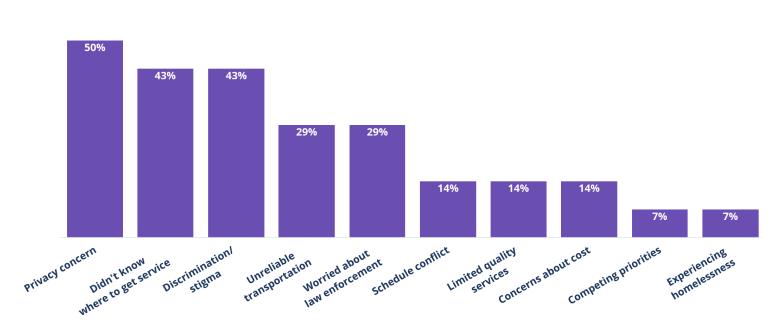
HIV PrEP was indicated as a needed service among 13% of respondents (n=88) with 41% of those respondents (n=36) who were unable to receive these services. Respondents were asked about their syndemic service needs in <u>the past five years</u>, therefore, consumers living with HIV could have needed HIV PrEP prior to their HIV diagnosis. Some respondents in the open responses explained how prior to their HIV diagnosis they asked their provider for HIV PrEP, but their provider refused to prescribe it.





Top Unmet Syndemic Service Barriers: Syringe Services

Syringe services was indicated as a needed service among 7% of respondents (n=46) with 30% of those respondents (n=14) who were unable to receive these services



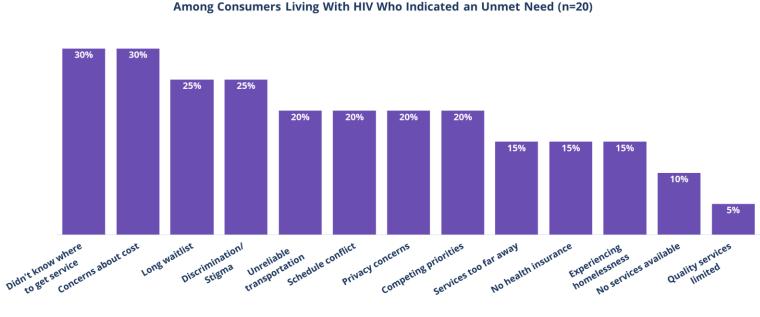
Barriers to Syringe Services Among Consumers Living With HIV Who Indicated an Unmet Need (n=14)

Among those who indicated syringe services as an unmet need, top barriers included:

- Privacy concerns
- Did not know where to get services
- Experiences of discrimination/stigma

Top Unmet Syndemic Service Barriers: In-patient/Residential Substance Use Treatment

SUD treatment was indicated as a needed service among 12% of respondents (n=76) with 26% of those respondents (n=20) who were unable to receive these services.



Barriers to Inpatient or Residential SUD Treatment Among Consumers Living With HIV Who Indicated an Unmet Need (n=20)

Among those who indicated inpatient/residential SUD treatment as an unmet need, top barriers included:

- Did not know where to get services
- Concerns about cost
- · Long waitlist to get into treatment services
- Discrimination/stigma

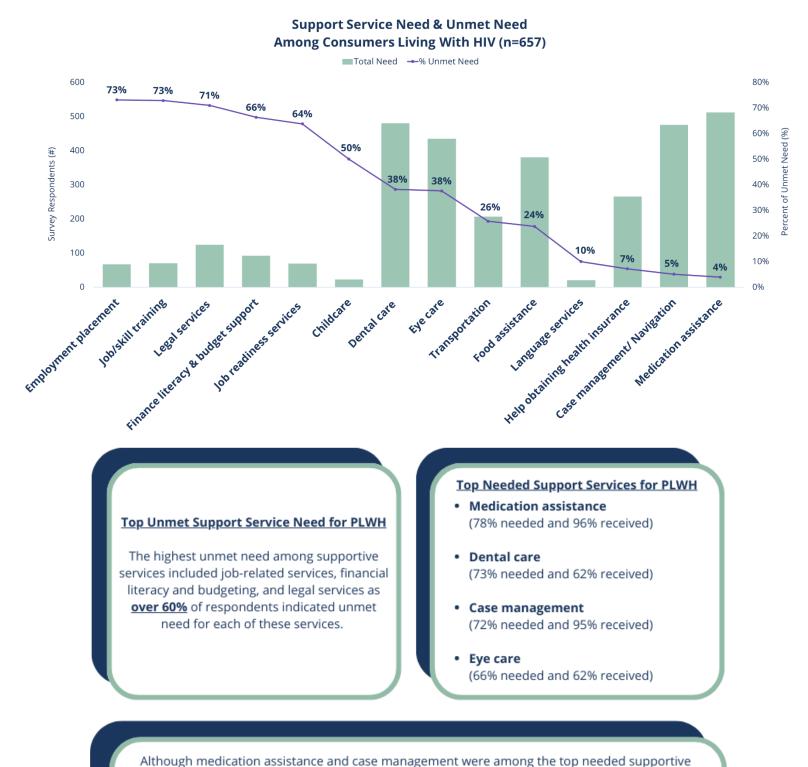
Barriers to Received Syndemic Services For PLWH

Consumers who are living with HIV, indicated a syndemic service need, and received it (n= 554) were asked if there were difficulties accessing those services and if so, what the barriers were. Most respondents (91%) indicated no barriers to accessing services. The top barriers were related to limited quality services, concerns about cost, services being too far away, and unreliable or no transportation.

Additional barriers mentioned include issues related to Case Manager negligence, provider not offering services or stating services were not needed, insurance or pharmacy issues disrupting health services/medication needs, and overall difficulty getting into services.

Consumers Living With HIV: Support Service Needs & Barriers

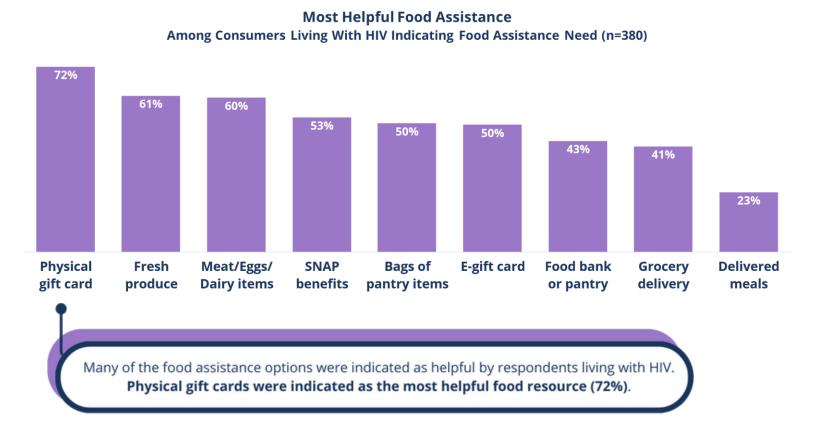
In the figure below, the **green** bars represent the number of respondents who needed each support service. The **purple** line represents percentage of unmet need for each service (i.e., the number who were unable to receive the service among those who indicated needing the service).



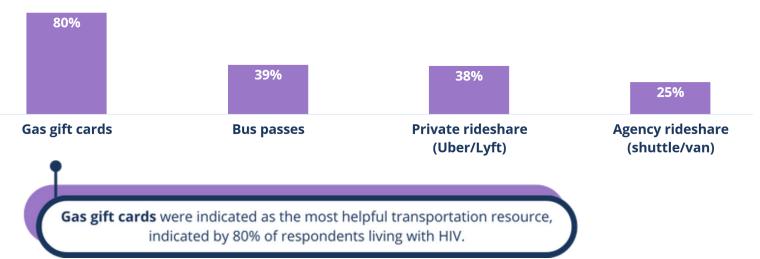
services, these services had the lowest unmet need whereas 38% of respondents indicated they were unable to receive services for dental or eye care.

Food and Transportation Assistance

Respondents who indicated needing food assistance (n= 380, 58%) or transportation assistance (n=206, 26%) in the past five years were asked about which resources would be helpful, and respondents could select all that applied.

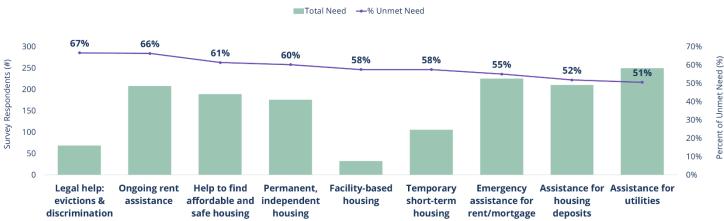


Most Helpful Transportation Resources Among Consumers Living With HIV Indicating Transportation Need (n=206)

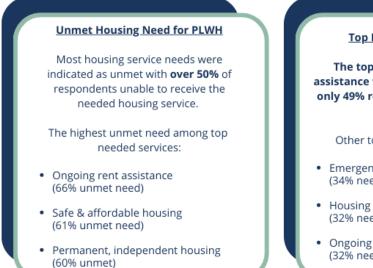


Housing Assistance Need & Unmet Need

In the figure below, the **green** bars represent the number of respondents who needed each housing service. The **purple** line represents percentage of unmet need for each service (i.e., the number who were unable to receive the service among those who indicated needing the service).



Housing Assistance Service Need & Unmet Need Among Consumers Living With HIV (n=657)



Top Housing Need for PLWH The top housing service need was assistance for utilities (38% needed) with only 49% respondents who were able to receive it.

Other top housing needs included:

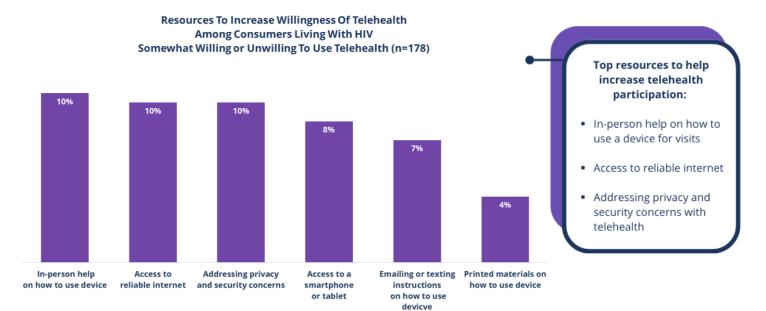
- Emergency assistance for rent/mortgage (34% needed)
- Housing deposit assistance (32% needed)
- Ongoing rent assistance (32% needed)

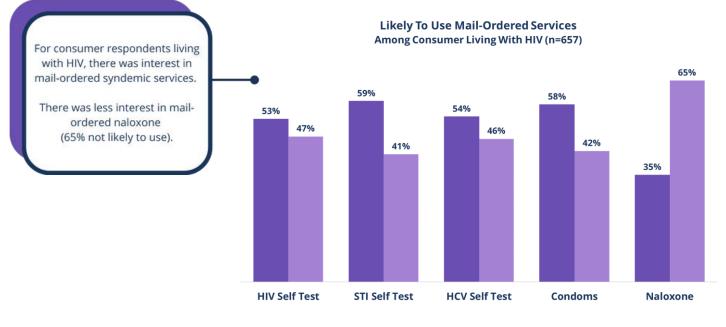
Barriers To Supportive Services

Respondents who indicated not receiving needed supportive services were asked about barriers to accessing these services. The top barriers were limited quality services, cost concerns, and services being too far away.

Consumers Living With HIV: Telehealth & Mail-Ordered Services

Overall, most consumer respondents living with HIV indicated having the necessary equipment to participate in telehealth services. Most respondents (97%, n=635) reported having consistent access to a smartphone, tablet, or computer, with 86% (n=562) reporting no difficulty accessing reliable Wi-Fi or internet. When asked about willingness to participate in nonemergency telehealth visits, 73% (n=479) were willing to participate in telehealth. Those who were somewhat willing or unwilling to participate in telehealth. Those who were somewhat willing or unwilling to participate in telehealth a higher preference to see a provider in person (54%, n=96) or were not interested in telehealth services (34%, n=61).





🔳 Yes & Maybe 🛛 🔳 No

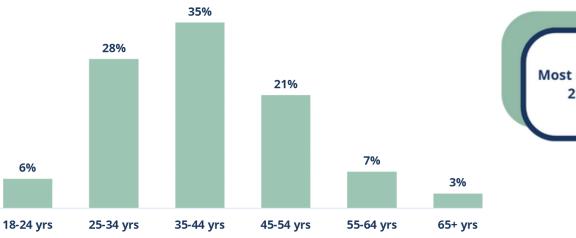
Persons Who Use Drugs Consumers: Service Needs & Barriers

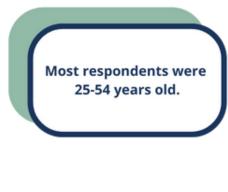
This section provides a breakdown of syndemic and support service needs and barriers, telehealth, and mail-order services for consumer respondents who identified as a person who used drugs (PWUD, n= 145). In-person surveying was conducted at SSP location to better capture voices unlikely to take the survey online. The data below more likely captures PWUDs who are engaged in services which should be considered when reviewing the data presented.

PWUD Consumers: Demographics

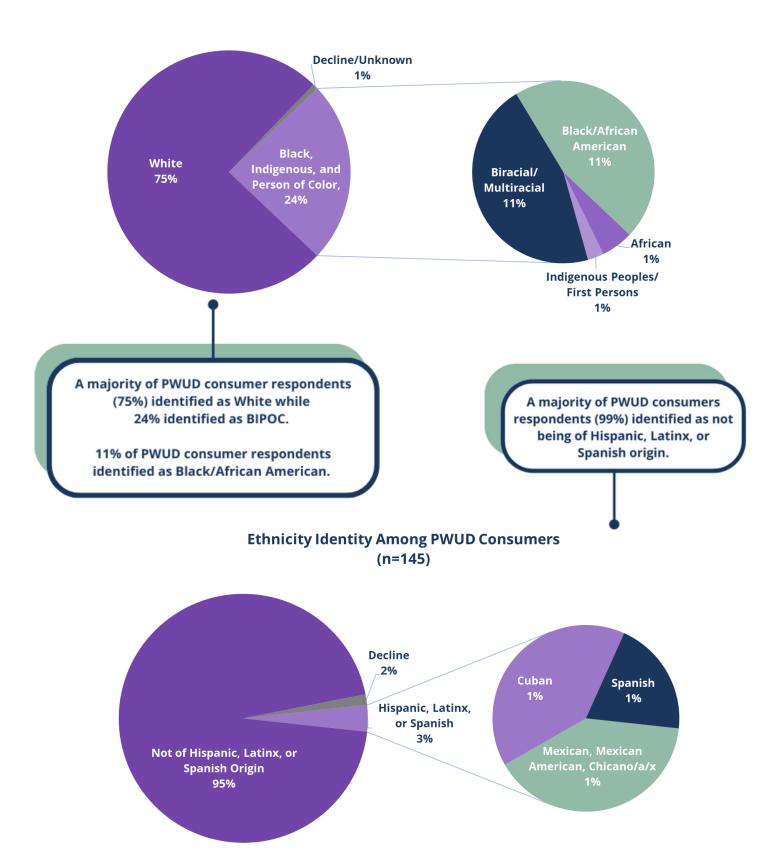
Higher responses from Southwest and East regions may be due to A majority of PWUD consumers resided in a in-person surveying at SSP locations metro region of Tennessee. Additionally, in those regions. majority of respondents lived in the Southwest, East, and Mid Cumberland regions. **Rural-Metro Residence ETS Region Of Residence** Among PWUD Consumers (n=145) Among PWUD Consumers (n=145) Upper Mid Cumberland, Cumberland, Rural East, 29% 26% 0.7% West. 3% 17% Metro 83% Southwest. South Central, Southeast, 39% 1% 1%

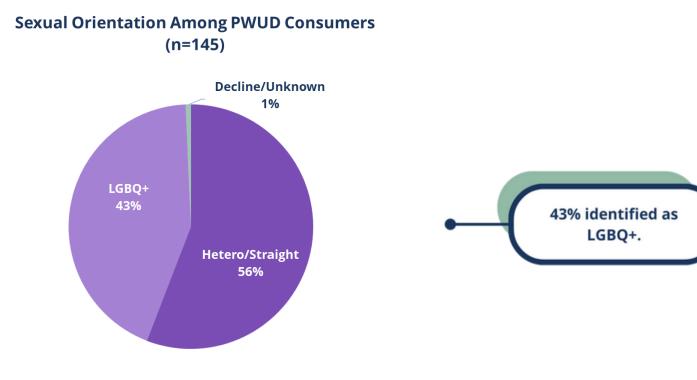
Age Range Among PWUD Consumers (n=145)



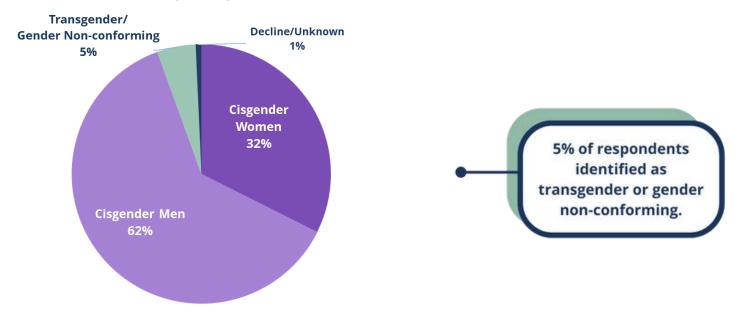




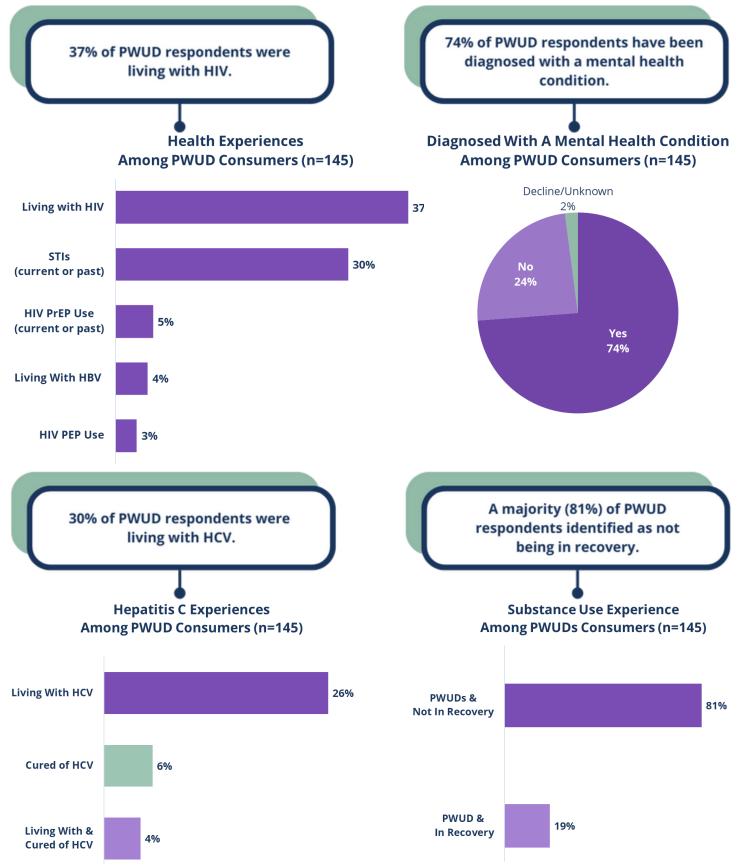




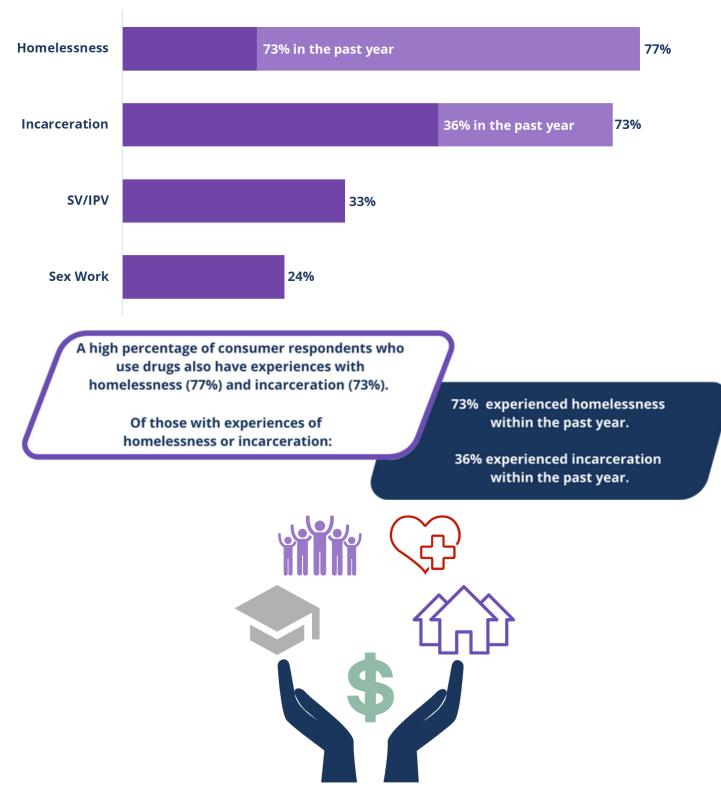
Gender Identity Among PWUD Consumers (n=145)



Cisgender Women: indicated sex assigned at birth as Female and gender identity as Woman **Cisgender Men**: indicated sex assigned at birth as Male and gender identity as Man **Transgender/Gender Non-conforming persons** represent respondents who indicated: (1) sex assigned at birth Female and gender identity as Man, (2) sex assigned at birth Male and gender identity as Woman, or (3) or identified as Genderqueer or identified as Non-binary or Third Gender Survey respondents were asked about varying health experiences that included HIV, HIV PrEP or PEP use, HBV, HCV, STIs, and mental health diagnosis. Respondents could select all that applied.



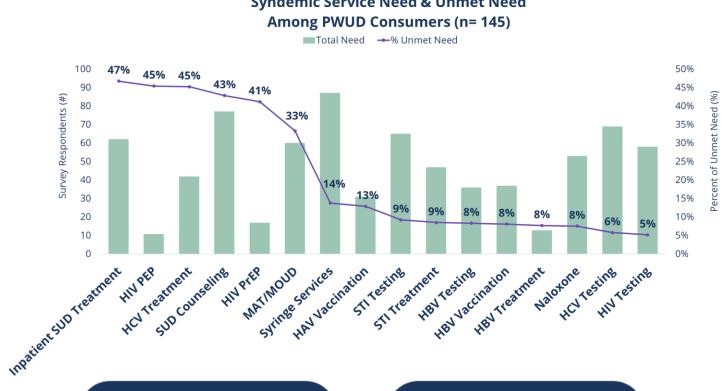
Survey respondents were asked about their experiences with homelessness, incarceration, sexual/intimate partner violence, and sex work, and could select all that applied. There were follow-up questions about recent experiences of homelessness and incarceration within the past year. Survey questions regarding carceral experience did not distinguish between prisons and jails.



Lived Experiences Among PWUD Consumers (n=145)

PWUD Consumers: Syndemic Service Needs & Barriers

The figure below demonstrates the gap in access for needed services among PWUD consumers (n=145). The green bars represent the number of respondents who needed each service. The purple line represents the disparity in service access demonstrated as the percentage of unmet need for each service (i.e., the number of people who were unable to receive the service among those who indicated needing the service).



Syndemic Service Need & Unmet Need

The highest unmet need included SUD services, HIV PEP and PrEP, and **HCV treatment**.

- In-patient SUD treatment (47% unable to access)
- HIV PEP (45% unable to access)
- Hepatitis C treatment (45% unable to access)
- Substance use counseling (43% unable to access)
- HIV PrEP (41% unable to access)
- MAT/MOUD (33% unable to access)

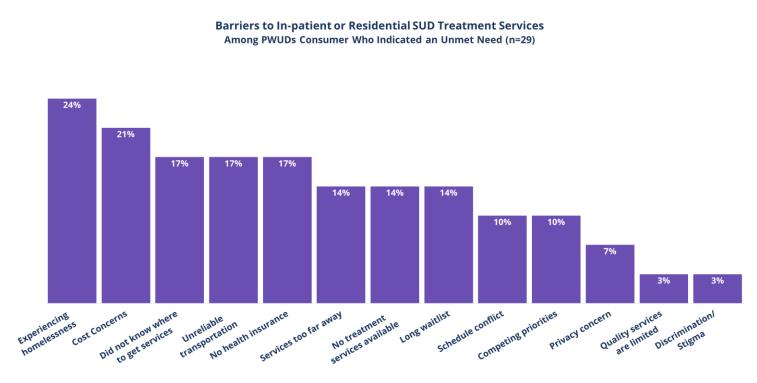
Syringe service was the top needed service (60%, n=87), and 86% were able to receive it. Additional top syndemic service needs included:

- Substance use counseling (53% needed)
- Hepatitis C testing (48% needed)
- STI testing (45% needed)

The top needed testing services (e.g., HCV and STIs) were received by most of the respondents who needed them.

Top Unmet Syndemic Need Barriers: Inpatient or Residential Substance Use Treatment

Inpatient/residential SUD treatment was a top needed service indicated by 43% of PWUD consumer respondents (n=62) with 47% of those respondents (n=29) who were unable to receive these services.

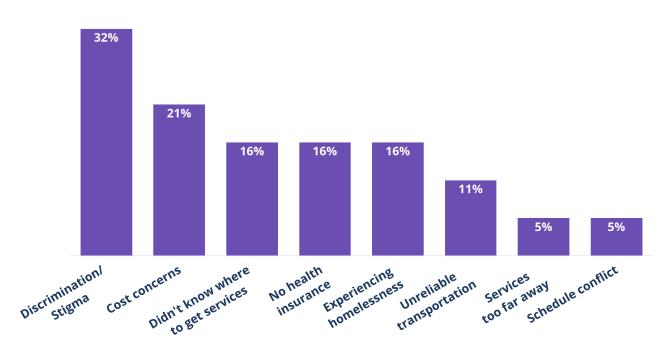


Among those who indicated inpatient/residential SUD treatment as an unmet need, top barriers included:

- Experiencing homelessness
- Concerns about cost
- Did not know where to get services, unreliable transportation, no health insurance

Top Unmet Syndemic Need Barriers: HCV Treatment

HCV treatment was indicated as a needed service among 29% of respondents (n=42) with 45% of those respondents (n=19) who were unable to receive these services.



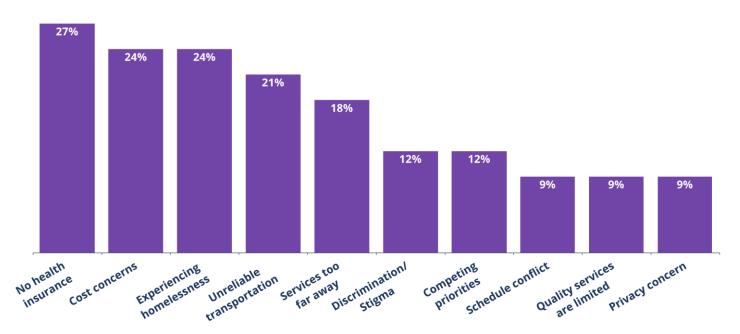


Among those who indicated HCV treatment as an unmet need, top barriers included:

- Discrimination/Stigma
- Concerns about cost
- Did not know where to get services, no health insurance, homelessness

Top Unmet Syndemic Need Barriers: Substance Use Counseling

SUD counseling was indicated as a needed service among 53% of respondents (n=77) with 43% of those respondents (n=33) who were unable to receive these services.



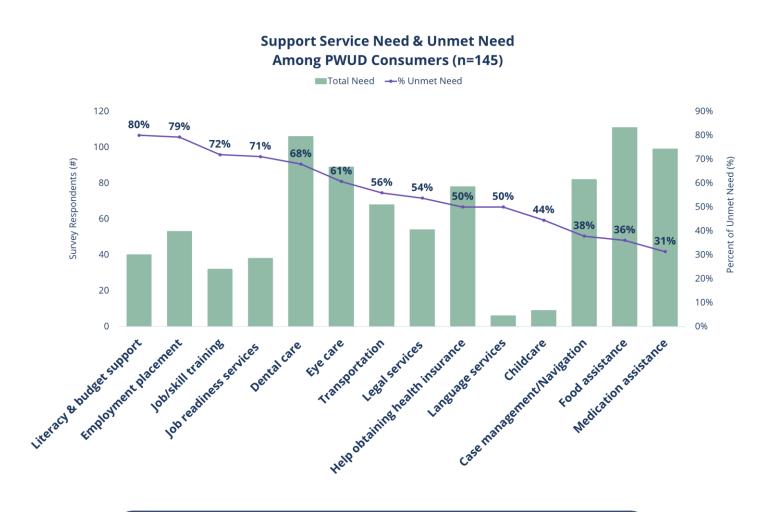
Barriers to SUD Counseling Services Among PWUD Consumers Respondents Who Indicated an Unmet Need (n=33)

Among those who indicated substance use counseling as an unmet need, top barriers included:

- No health insurance
- Concerns about cost
- Experiencing homelessness

PWUD Consumers: Support Service Needs & Barriers

The figure below demonstrates the gap in access for needed support services among PWUD consumers (n=145). The **green** bars represent the number of respondents who needed each service. The **purple** line represents percentage of unmet need for each service (i.e., the number of people who were unable to receive the service among those who indicated needing the service).

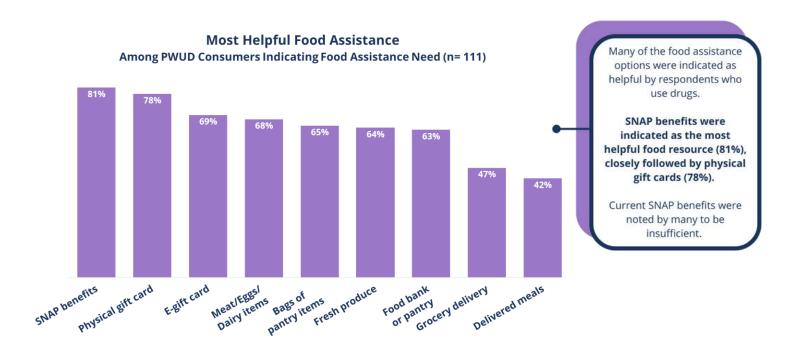


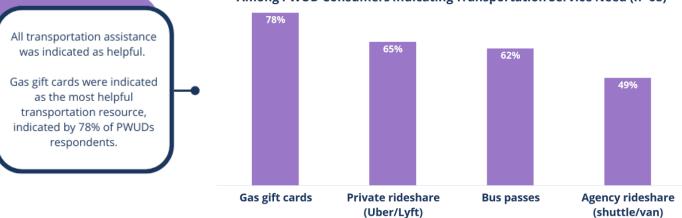
Overall, there was a high indication of need and unmet need across many of the supportive services. Support services that are underlined highlight services with a high need and unmet need.

 Food assistance 	77% needed	36% unable to access
<u>Dental care</u>	<u>73% needed</u>	68% unable to access
 Medication assistance 	68% needed	31% unable to access
• <u>Eye care</u>	<u>61% needed</u>	61% unable to access
 Case management 	54% needed	38% unable to access
 Obtaining health insurance 	50% needed	54% unable to access
<u>Transportation</u>	<u>47% needed</u>	56% unable to access

Food and Transportation Assistance

Respondents who indicated needing food assistance (n= 111, 77%) or transportation assistance (n=68, 61%) in the past five years were asked about which resources would be helpful, and respondents could select all that applied.

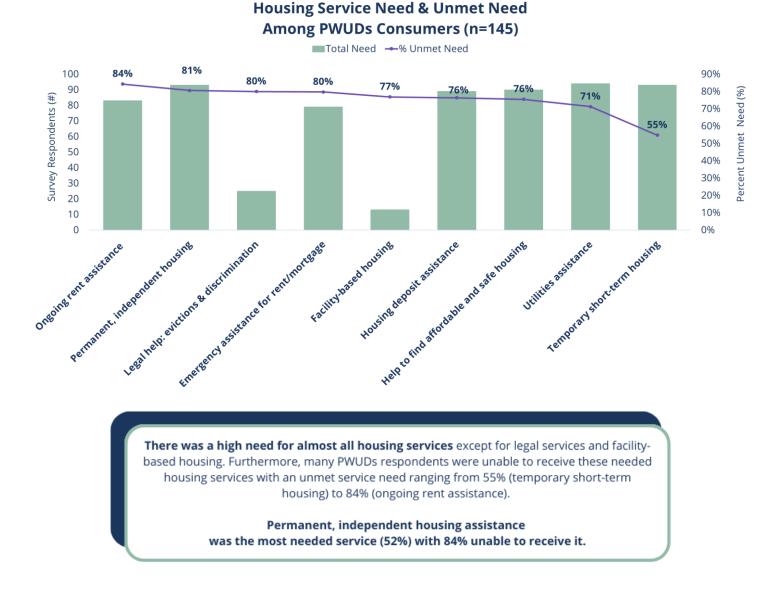




Most Helpful Transportation Resources Among PWUD Consumers Indicating Transportation Service Need (n=68)

Housing Assistance Need & Unmet Need

The figure below demonstrates the gap in access for needed housing services among PWUD consumers (n=145). The **green** bars represent the number of respondents who needed each service. The **purple** line represents percentage of unmet need for each service (i.e., the number of people who were unable to receive the service among those who indicated needing the service).

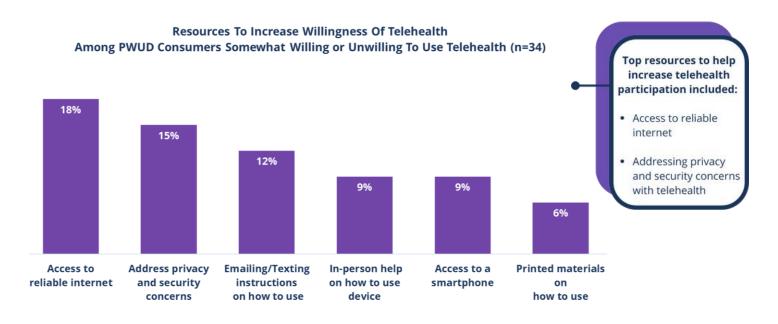


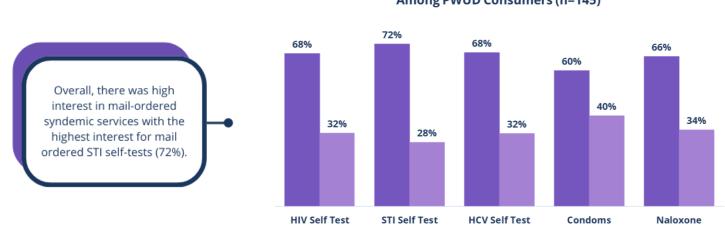
Barriers To Supportive Services

Respondents who indicated not receiving needed supportive services were asked about barriers to accessing these services. The top barriers included limited quality services, experiences with homelessness, concerns about costs, and unreliable or no transportation. Additional barriers cited included lack of awareness of services and how to access them, the confusing and challenging process, not qualifying or being denied assistance, not having a phone or a charged phone, and no follow up from provider when applying.

PWUD Consumers: Telehealth & Mail-Ordered Services

Many respondents who use drugs (81%, n=117) reported having consistent access to a smartphone, tablet, or computer, with 59% (n=86) reporting no difficulty accessing reliable Wi-Fi or internet. When asked about willingness to participate in nonemergency telehealth visits, 77% (n=111) were willing to participate in telehealth. For those who were somewhat willing or unwilling to participate in telehealth services (23%, n= 34), there was a higher preference for seeing their provider in-person (56%, n=19) or were not interested in telehealth (21%, n=7).





Likely To Use Mail-Ordered Services Among PWUD Consumers (n=145)

🛾 Yes or Maybe 🔳 No

End The Syndemic Tennessee Qualitative Report

Introduction

In 2022, focus group discussions (FGDs) and key informant interviews (KIIs) were conducted with priority populations who were identified as underrepresented in the ETS regional planning meetings. The purpose of this qualitative effort was to compliment the needs assessment survey data with a deeper understanding of the unique health priorities, needs, and barriers for five priority population groups in TN: transgender individuals, those living in rural areas, PWUDs, Latinx MSM, and PEH. These FGDs and KIIs utilized a status-neutral approach and included participants vulnerable to or living with HIV, STI, SUD, and viral hepatitis.

Methods

The ETS team hosted virtual and in-person qualitative FGDs and KIIs. Virtual FGDs and KIIs were conducted through Webex for the transgender FGD, rural FGD and KIIs, PWUDs FGD and KIIs, and Latinx MSM KII. A virtual approach was utilized to increase participation and incorporate voices across the state of Tennessee. In-person KIIs were conducted for PEH to increase participation from those who may have had limited to no access to a smart device or internet.

Facilitation Guides

Semi-structured facilitation guides were created for each of the five priority population groups. Each group had similar open-ended questions, but also had tailored questions for specific priority populations based on information gathered through ETS regional planning meetings and preliminary findings from the ETS statewide needs assessment survey. The facilitation guides were created by the ETS team (three ETS interns, the ETS lead needs assessment associate, and the ETS project coordinator). Questions were related to health priorities, needs, barriers, and facilitators for HIV, STI, SUD, and viral hepatitis prevention and care services. See Appendix III for each facilitation guide.

Recruitment

Virtual recruitment for PWUDs, Latinx MSM, and those living in rural TN was conducted by creating and sharing population-specific marketing materials with various internal and external partners to distribute within in their networks and communities as well as shared on the ETS networking platform. Screener surveys were created to outline the purpose of the FGD/KII. These included demographic questions to determine eligibility and were used as recruitment forms to help determine best time and day for FGDs and KIIs. Eligible participants were sent invitation and confirmation emails to participate.

Recruitment for in-person PEH interviews included collaborating with the Knox County Health Department and two local community organizations. The two local organizations conducted in-person recruitment with eligible clients. Specific interviews dates and times were determined ahead of time to meet the needs of the staff and participants.

The Trans Taskforce was leveraged for recruitment for the Transgender FGD.

Data collection

The ETS team collaborated with external facilitators for the PWUDs and Latinx MSM FGDs and KIIs. Specifically, for the PWUDs qualitative sessions, the ETS team collaborated with NASTAD's Drug User Health team to facilitate the FGDs and KIIs to provide space for open and honest conversations. The NASTAD Drug User team also reviewed and provided feedback on the facilitation guides. Additionally, the ETS team collaborated with a bilingual facilitator for the Latinx MSM KII. Similarly, the Latinx facilitation guide was reviewed by the facilitator and feedback was incorporated. The Latinx guide was first developed in English then translated by two staff members fluent in Spanish with a final review by the bilingual facilitator. The Spanish guide was not used during the Latinx MSM KII because the participant preferred the interview in English.

The ETS lead needs assessment associate and the ETS project coordinator facilitated rural FGD and KIIs as well as the in-person interviews with PEH.

The ETS team collaborated with the Knox County Health Department for the in-person KIIs for PEH. The PEH interviews were conducted at two different locations in Knoxville, TN, and in partnership with two community organizations who work closely with PEH.

All participants were required to be 18 years or older to be eligible to participate in FGD or KII. All FGDs and KIIs were scheduled for 1-hour session and each session ranged from 30–60 minutes. All FGDs and KIIs were audio-only recorded. Facilitators first explained the purpose of the discussion, provided an opportunity for any questions, and then obtained verbal consent to proceed with the recording and discussion. All participants were eligible for a \$35 gift card at the end of the discussion/interview. Virtual participants had the option of an e-gift card, or a physical gift card mailed to them. In-person participants were provided a physical gift card at the end of the interview.

Priority Population	Qualitative Type and Participant Numbers
Transgender	1 FGD (n=7)
PWUDs	1 FGD (n=4) and 1 KII
Latinx	1 KII
Rural	1 FGD (n=4) and 2 KIIs
PEH	9 KIIs

Analysis

Most of the audio recordings were auto-transcribed with the exception of one interview which was manually transcribed. All transcripts were thoroughly reviewed and edited for accuracy.

Data analyses were conducted using the qualitative data analysis software Dedoose Version 9.0.17 and consisted of deductive and inductive coding approaches. Thematic analysis was conducted to closely examine the data and identify key themes within each priority population group and across all groups. The themes are reported in the next section of this report.

Limitations

Efforts were made to host FGDs with young adults (aged 18–24) and Latinx MSM. Due to participation challenges, there were no FGDs with young adults, but we did conduct a KII with a Latinx MSM participant. The data are self-reported and subject to social desirability bias where participants may have answered questions in a way that they believed would be viewed more favorably. To address this limitation, facilitators reiterated confidentiality and privacy of the participant's data throughout the interview especially in moments were the facilitator felt hesitation or potential concern from the participant. Although virtual efforts were able to reach participants across the state of TN, the in-person PEH interviews were focused in one location of TN (Knoxville) and represented those who were engaged in health or social services (e.g., SSP services or housing services). These limitations should be considered when reviewing the data presented throughout this Needs Assessment Qualitative Report.

Transgender Summary

Within the Transgender FGD (1 group, n=7), key themes were related to barriers to healthcare for trans individuals as well as needs and strategies to improve trans health and wellbeing.

Limited Availability

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A major obstacle to accessing syndemic services (including trans-health services) was limited availability of providers and health supplies. It was specifically mentioned that there is limited availability of health services for low-resource populations (such as those under- or uninsured, residing in rural TN, and people with carceral experience).

Participants emphasized a lack of providers who specialize in trans health and when there are transhealth providers available there are long wait lists to see those providers. It was also noted by participants that many providers believe they cannot provide healthcare services to trans clients, even for primary care related health concerns, unless they specialize in trans healthcare.

Access to competent care. Get so many people that are like, "well, you're trans so, I can't treat this because you are trans," and I'm like, okay, if my legs broken, it's broken, me being trans doesn't mean that you can't treat me.

When referring to limited product availability, this included medications such as PrEP options for transgender individuals or gender-affirming supplies such as needles and syringes that are often only prescribed through trans-specific healthcare providers or have limited availability in pharmacies. Participants explained that due to barriers in accessing health supplies especially related to their gender-affirming care, trans people often access these supplies through the "grey market" from the internet or other trans people.

Inconsistent Care

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Inconsistent care, including interruptions in services, was a source of frustration and negatively impacted the health and wellbeing of trans individuals. Trans participants explained that providers often fail to follow up or provide referrals when they are faced with an unfamiliar or complex case.

So, there's not the amount of data that doctors like to refer back to. So, when they can't refer back to that data, they're just, kind of throw their hands up and they're like, "I don't know what to do for you." So, you're on your own and so, they kind of try to exit you out of their care quickly because, like, "I don't know how to serve you."

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Another issue highlighted was the "one size fits all" healthcare approach in which current healthcare practices fail to recognize the diversity of need, and that providers believe there is only one way to provide trans healthcare. Furthermore, participants discussed the burdensome work that trans clients often experience with their providers by either having to explain their "transness" to their providers or educate providers on trans healthcare or research.

Limited Trans Healthcare Research

The lack of trans healthcare research available, as well as trans individuals often being excluded from health and medical research, was highlighted as a key barrier.

Low Barrier Care

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Participants emphasized the need for healthcare that is easy to access (e.g., low-cost, timely appointments, etc.) and transparent about the services providers offer and how to access them. Further highlighted was the need to increase the standards for what is considered a "trans-friendly" provider.

Participants specified the need to release funding opportunities dedicated to trans-specific care as a way to make trans healthcare more affordable and accessible.

Telehealth was indicated as a beneficial strategy to access services especially for those who live in rural areas or are less open about their trans identity. Some participants did mention concerns and considerations about telehealth specifically, related to ensuring the quality of telehealth services so they're not rushed, impersonal, or used as a "check off."

I started hormones through an informed consent provider who gave me a prescription immediately. That gave me a lot of sense of dignity. It was amazing to just be able to get it that easily through a provider I felt like really respected me.

Trauma-Informed Approach

A harm reduction and a trauma-informed approach to health services for transgender individuals was a salient need. It was emphasized that many trans individuals experience discrimination, stigma, and trauma from their peers, family, broader community, and providers. Additionally, many participants described experiencing this stigma and trauma impacts the health, wellbeing, and safety of trans individuals.

Training & Education

Participants described the need for increased provider training as well as training within the trans community. Specifically, there is a need for training to help reduce stigma, increase knowledge of syndemic health conditions and services, and increase access to care.

Integrated Care

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Participants emphasized the need for holistic care through the integration of services to address not only healthcare, but also SDOH needs such as job placement, food insecurity, and housing. Also, there's a need to increase collaboration and communication systems between healthcare providers to better meet the needs of their trans clients. One participant suggested implementing a "Trans Navigator" program to help link and navigate trans clients to various healthcare and social services in alignment with their healthcare goals.

A great need that's not being met is being seen as a priority as the rest of the population is because we are all priority. We all are individuals, we all have individual needs, and all of those needs are important. And when those needs are seen as important equally, I believe, is when things start to smoothly sail. So, we are waiting for that day.

People Who Use Drugs Summary

Among the PWUDs FGD (1 group, n=4) and KII (n=1), key themes were related to stigma, representation, impact of SDOH, and barriers and facilitators to syndemic services.

Stigma

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Stigma and discrimination were discussed as pervasive issues impacting the health, wellbeing, and safety of PLWH, PWUDs, and transgender individuals. Participants experienced stigma and discrimination from their peers, the broader community, service providers, and law enforcement. Participants living with HIV, and specifically those who use drugs, noted the need to constantly advocate for themselves among service providers, acknowledging that not everyone has the ability to advocate for themselves and this may prevent many people from accessing services.

A lot of people judge you for it [HIV] or whatever or think you're a horrible person or this and that about you because you caught something.

Participants highlighted several strategies to help reduce stigma. One strategy was for providers and community to use more inclusive language especially regarding substance use (e.g., using "person who uses drugs" instead of "addict"). Participants who also are living with HIV felt that there needs to be more U=U advertising to help reduce HIV stigma in the broader community. Another highlighted strategy included implementing training among service providers (especially Case Managers) and law enforcement regarding trauma-informed approaches and language inclusivity.

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Limited Providers & Services

Participants highlighted that the limited availability of providers and services was a key barrier to engaging in syndemic services. Specifically, there are very few MAT providers and limited services in rural areas of TN. Participants emphasized the importance of "meeting people where they are" to reduce barriers by increasing the span of services into other neighborhoods and communities.

Social Determinants of Health (SDOH)

SDOH acted as key barriers to accessing services to maintain health and well-being. Lack of affordable housing was indicated as a prime challenge impacting participants' physical health, mental health, and safety. Additional factors impacting health and well-being included lack of employment opportunities, health insurance, nutritious and affordable foods, reliable and efficient transportation, mental health services, and health literacy.

Comprehension, I think that language that most of the medical providers use is kind of hard for us to comprehend what they're saying, and I see that being a big problem. Because if you can't comprehend what's being said to you, it really just goes over your

Representation

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Participants emphasized the importance of representation in the syndemic workforce and within in health education and marketing. Participants highlighted the importance of women and women of color represented in syndemic marketing particularly for HIV services such as testing, PrEP, and HIV care. Also, noted was the need to hire people with living experiences in harm reduction programming. Participants discussed how they function as peer champions in their communities by delivering health education and resources (e.g., naloxone), and connecting peers to health services.

Just include us. You know, actually include us in the house [in health programming and paid positions].

HIV, HCV, & STI Testing

Participants highlighted major barriers, facilitators, and possible strategies to infectious disease testing. Top barriers to testing included fear of diagnosis, outdated beliefs about the health conditions (i.e., "HIV is a death sentence"), or the treatment regimens, concerns about treatment cost, and HIV criminalization laws. Participants highlighted the need for a safe and private testing space to help with confidentiality and nervousness people may experience. Self-test kits and increasing point-of-care testing were seen as important to increase accessibility of testing among PWUDs.

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PrEP

Overall, participants felt that PWUDs are generally unaware of HIV PrEP or do not know where to access it. Participants also thought that HIV PrEP use was uncommon and there was low interest among PWUDs. Other barriers to PrEP use include lack of transportation and the potential for medication being stolen. Participants identified that HIV PrEP available at SSPs would increase PrEP knowledge and use.

Some participants discussed the gap in HIV PrEP for women. They highlighted a lack of women in PrEP advertising and providers often not prescribing HIV PrEP to female client.

But I think for women, I see so many commercials around PrEP, and it's basically targeted for men. And what I don't see is that information being put out there for women, especially women of color.

Harm Reduction

Syringe services programs are important to increasing access to syndemic services, and therefore improving the health and wellbeing for PWUDs. Participants highlighted the absence of SSPs in rural areas.

In West Tennessee, there's not really many SSPs. So, I would like to see maybe health departments offer syringe access. I think we should have mobile SSPs.

Participants expressed limits on syringe distribution as a major barrier and highlighted the need for peer distribution to help distribute supplies to those most in need. Another salient barrier to accessing SSPs was law enforcement. Participants reported that law enforcement is unaware of the immunity law protecting clients of SSPs. Participants felt that the law provided limited protection, and that people are still being arrested for accessing SSPs. Hosting SSPs within health departments and implementing more mobile SSPs were strategies suggested to increase accessibility and utilization of SSPs.

There were inconsistencies in the availability of naloxone noted by participants. Some participants felt naloxone was accessible in metro areas, while others felt naloxone was limited in more rural areas. Required training and the lack of training sites were seen as major barriers to accessing naloxone. One strategy to increase naloxone awareness and reduce stigma was to create advertisements about naloxone. Participants also wanted to have access to an accurate list of SSPs with their location and hours, as well as where to access naloxone.

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Rural Tennessee Summary

Key themes from the rural FGD (1 group, n=4) and KIIs (n=2) were related to the syndemic and social service barriers and needs in rural TN.

Stigma

Stigma and discrimination were seen as a pervasive issue impacting individuals' health, wellbeing, and safety in rural TN. The type of stigma discussed was often related to HIV, substance use, sexual orientation, and gender identity. It was noted that providers of color experience discrimination that can drive them away from practicing in rural areas.

A key strategy to help reduce stigma included normalizing syndemic services and continually communicating with community about these services. One participant highlighted that there has been an overall loss of trust in healthcare especially in rural TN, and it is essential to partner with trusted community members and leaders to increase engagement in prevention and treatment services.

So, the stigma, normalize what we do. Normalize the disease of HIV, but that's very hard to do in the Bible Belt because the reality is a lot of people associate their morality with their health care, and it's going to be hard to break that statement, but it can be done in due time.

Participants discussed the importance of collaborating with churches and schools in syndemic efforts but also acknowledged challenges within these institutions that often promote stigmatizing views.

Limited Services Available

A key barrier to engagement in syndemic and support services was the limited availability in rural TN. Providers who are knowledgeable about HIV and syringe services are especially lacking. One participant described having to travel up to 175 miles to access quality HIV services but emphasized that many rural people do not have that kind of time or transportation to access services far away.

Unaware of Services

Rural participants voiced that many are unaware of syndemic and supportive services available or do not know how to access these services, especially for HCV prevention and treatment services, HIV PEP or PrEP, SDOH assistance such as housing assistance, and harm reduction services such as syringe services.

Overall, there needs to be increased advertising of services available in the area through TDH website, social media, dating apps, and outreach events collaborating with churches, drug coalitions, services providers, health departments, and organizations that serve people experiencing homelessness. A few participants mentioned how stigma from the broader community impacts service providers' ability to advertise services they offer.

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Transportation Barriers

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Transportation was a significant barrier to accessing services in rural TN. Participants noted that public transportation options are limited and although rideshares are available they are time-consuming, often an all-day process, and sometimes have a service fee which prevents many from accessing these services. Overall, participants would like to see more options for transportation in rural areas of TN.

I have heard people talk about the fact that transportation can be a big issue, because I know a lot of people in East Tennessee that are very low income. If they own a car, is it reliable enough to get to town at the price of gas, can they afford to drive to town to see a doctor? So, transportation can also become a big issue.

Integration of Services

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Integration of services in rural TN was seen as key to increase accessibility by reducing barriers related to limited transportation, privacy concerns, stigma, and time constraints.

I honestly feel like the biggest barrier is general access to health care, especially for someone who finds out that they're positive. You want to get on some meds and nobody wants to wait, they want to be able to get in and get in fairly quickly to get the health care that they need.

So, providing access to someone that's willing to do the blood work and that's willing to prescribe the medications, even if it's not someone that all they treat is HIV, but someone who is well versed enough in medicine that they feel comfortable, writing and managing those individuals in those health conditions.

Integrating syndemic navigation services within the carceral system (i.e., jails or prisons) or immediately upon release was highlighted as an important strategy to increase engagement in syndemic and social services.

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You know, maybe if, instead of just being locked up for however many years, if there was like an education or a help there. Most of the time, when you've been locked up, you just feel like your option is going back to the street. Whereas if y'all, if there was a way to intervene there and be like, "yeah, you could go back to the street, but we also have these options that would be available to you." That's whenever people need their options, instead of just going back to the street.

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Housing & Basic Necessities

Affordable and safe housing was a prevalent need in rural TN. Participants felt that housing resources are available in some rural areas, but most people are unaware of these services or how to access them. Additionally, participants described the process to access housing services as very confusing and challenging. One particular issue mentioned was related to having to find housing on your own and that many housing units that are available and affordable are deemed unsafe and do not meet the housing assistance standards.

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I don't think a lot of people are aware of some of the resources available to them as well. That was really my challenge in starting the process of getting off the street. I didn't know where to start. It was somewhere I'd never been, something I'd never gone through. I didn't feel safe. My basic needs were broken down. So, I couldn't even feel a sense of security, it was very traumatic for me. I didn't know where to start.

Case Managers

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Case Managers were seen as vital to directly linking clients to syndemic and social services (such as housing). Participants felt that Ryan White Case Managers were very knowledgeable and helpful with Ryan White-specific services but noted the need for additional training for other health and social services in the area. There were inconsistencies noted in the quality of Case Managers. Some were seen as unreachable especially for urgent matters such as when a client is unable to receive their HIV medications.

It's very imperative you don't miss taking your meds. But if you have a hiccup with medicine delivery, and you're going to be out of meds next Tuesday, and you need to do something about it, I can't wait to hear from a Case Manager for two weeks, this is something that has to be responded to now.

Peer Champions & Educators

Participants emphasized that peer educators are important in syndemic work and many PLWH, PWUDs, PEH provide education and resources to their communities.

Whenever I would be at a [recovery] meeting or with somebody who could possibly have it [HIV], I would direct them towards the health department because we all have no insurance, you know.

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Mental Health Support

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Mental health support was indicated as a vital service need in rural TN. Access to mental health services was especially important for participants living with HIV, experiencing homelessness, or SUD.

I will tell you that the thing that has been paramount to me is access to an excellent therapist. She's helped me process quite a bit of trauma, seen my journey and early recovery in substance abuse, and kind of guided my path from a therapy perspective. In that regard, helped me to process the trauma of being homeless and process some of the traumas that were causing the substance abuse to being with, which ultimately led to that situation. So, access to a therapist was the thing that was really the life changer for me.

SUD & Harm Reduction

Overall, participants noted that SUD services are very limited in rural TN and syringe services are essentially nonexistent. Stigma against PWUDs is pervasive in rural TN and some community members are adamantly against SUD and harm reduction services in their community. Participants emphasized the importance of harm reduction services and the need for them as SUD was highlighted as a health priority in rural TN. Participants felt that naloxone was accessible and available in their communities.

Long-Term HIV Survivors (LTS)

A particular need within HIV care was to consider the needs of LTS. One participant indicated that LTS have unique needs related to aging with HIV and the impact of being on HIV medications for many years. Also, it is challenging to find providers knowledgeable to the needs of those aging with HIV and LTS.

Initially, my biggest need was finding a local doctor that knew something about HIV care and for somebody that has been positive for over 30 years... For long-term survivors' issues of all the complications of having taken HIV meds for 30 years and all the side effects which can be not only cognitive issues, but kidney, liver issues, neuropathy, osteoporosis, and on and on and on down the line.

Mail-Ordered Testing Services & Telehealth

Mail-ordered testing services were indicated as convenient and useful to address privacy concerns. Overall, telehealth was seen as beneficial in helping to increase service access, however, interest and acceptance among rural residents was mixed. There were conflicting views on the availability of smart devices and reliable internet for people living in rural TN. A participant suggested that health departments should collaborate with local rural libraries to provide private spaces with computers and reliable internet to access telehealth services.

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Latinx MSM KII Summary

Key themes from the Latinx MSM interview (n=1) related to engagement and representation of the Latinx community, stigma impacting access to services, barriers to services, and the need for affirming care.

Representation Matters

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A crucial need emphasized throughout the interview was the need to increase and improve services and messaging to reach the Latinx community, specifically the need to invest in Latinx programs. Not only do educational and marketing health materials need to be in Spanish but they need to be culturally relevant by including translations into various Spanish dialects and addressing and understanding *"machismo."* Other considerations included a resource directory and social media messaging in Spanish.

I think creating messaging in Spanish would be a great start. I think having some consistency with Latinx values, machismo and how to fight that. Understanding that better on a cultural level.

Language was indicated as a key barrier to healthcare. The participant underscored the need to hire more Spanish speaking providers and staff, often Latinx adults rely on their children to translate, and information gets lost in translation. Additionally noted, translation services are not always ideal because there is a need to not only be fluent in the language but also knowledgeable in the subject matter for accurate translation and understanding.

Engagement: Youth & Broader Latinx Community

An essential strategy noted to improve syndemic awareness and prevention services was the need to better engage Latinx youth. Youth engagement was specifically emphasized regarding HIV prevention efforts and could help decrease stigma as well.

The participant noted how schools and churches would be the best avenue to reach youth and young adults but also acknowledged the challenges and stigma within these institutions. The participant felt it might be best to work with community organizations already working with these populations instead.

There's gotta be a way to tap into youth to get the education and the awareness to start fighting the stigma earlier. I don't think that's something that's been done. Well, I think it could be improved and there's a lot of stigma around teaching children that. So, about safe sex so there's a battle in itself already. But my answer would be starting younger with youth.

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Privacy and fear of being reported impacts access and utilization of services. Affirming care was identified as a key approach to increase awareness and access to prevention and care syndemic services within the Latinx community. Affirming care included "meeting people where they are at," a status neutral approach, and a welcoming and safe environment with clear communication and signage about safety and privacy.

Collaboration with trusted local programs working within the Latinx community was highlighted as an important strategy. Engaging and collaborating with community leaders and champions would help build trust and reduce stigma within the Latinx community. Other strategies to increase engagement included the need to conduct outreach events outside of clinic spaces which can provide a more comfortable environment as well as mobile units that go into Latinx communities to provide education and health services.

I don't know if there are, there's like a mobile unit for Latinx outreach for different communities. I think getting somebody that's in the community that knows the people that people trust is important too. I think those would probably be my two big things, meeting the community where they're at and then having somebody that the community trusts.

The participant felt that there was low HCV awareness, spurring a need for more messaging and education within Latinx communities and neighborhoods specifically emphasizing that HCV is curable and the ease of the newer treatment process.

Stigma

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The participant noted stigma is a pervasive issue in general and within the Latinx community, specifically around HIV. Stigma was identified as a key barrier that prevents Latinx individuals especially youth and young adults from accessing testing and prevention (e.g., PrEP use) services. Supportive and positive messaging about HIV and promotion of syndemic services by Latinx community champions were seen as effective methods to combat stigma.

Telehealth

Telehealth was noted as a beneficial option to increase access to healthcare specifically in the Latinx community. Telehealth was specifically noted as a way to reduce transportation barriers by saving money on gas, public transit fees, or parking fees as well as reduce travel time. It was also seen as beneficial to help with privacy and confidentiality concerns.

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People Experiencing Homelessness Summary

Among the PEH in Knoxville, TN KIIs (n=9), key themes were related to stigma, impact of SDOH, and barriers and facilitators to HIV and SSP services. A majority of PEH KII participants were people living with HIV and indicated substance use (n=6, 67%).

Stigma & Discrimination

All participants described experiencing stigma and discrimination related to being unhoused, their HIV status, and their substance use.

Participants specifically mentioned being treated poorly by shelter staff, hospital staff, and law enforcement. Regarding shelter staff, one participant expressed that they would rather "sleep on the streets" than stay in the shelter. Stigma and discrimination were key barriers to utilizing services and impacts PEH health and wellbeing. All participants deeply expressed that they wished their community understood that "we are human too" and that human connection and compassion can go a long way.

We've had to make adjustments and living out there does change you in certain ways. You have to change to survive. You have to be tough to survive out there. But that most people, if they took the time to speak to, they're just as nice as your neighbor next door. They may have a drug issue and a lot of people do, they're still human. They still need human contact, they need kindness, they need just a little support or just a kind word makes all the difference.

Just don't judge. Don't judge.

Lack of Housing Impacts Health

Participants noted being housed is helpful to accessing and staying engaged in SUD treatment. Lack of housing creates an unstable environment impacting one's physical and mental health, making it impossible to prioritize anything else outside of obtaining basic necessities.

Participants explained there are limited quality housing and shelter options in Knoxville. For PEH and living with HIV, HOWPA was seen as very helpful. However, accessing support services such as housing is often very challenging due to the cumbersome application process, multiple applications, long wait times, no follow-up from service providers, and no phone to contact service providers. Ryan White Case Managers and other service navigators were vital to navigating challenges.

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Housing stability. I would say I need help again, like to be back in recovery, which I know like if I just ask, that they'll help me but, and I need to get my mental health under control too, cuz it ties into me and my addiction.

Top Need: Mental Health Support

Mental health support was indicated as a vital service need. The intersection between housing instability and mental health issues and its impact on substance use was also emphasized.

Transportation

Transportation is a major barrier to accessing services and accessing them on time. Participants indicated they access health and social services usually by bus, bicycle, or on foot. Having services located along the bus routes was helpful, but the bus system is not always reliable, often runs late, and causes participants to miss their appointments. Additionally, for PLWH, the Ryan White Medical Transportation program helps participants get to appointments, but not all participants were aware of this service. Non-traditional clinic hours or flexibility for late arrivals were also indicated as helpful to accessing services.

Mobile Services & Telehealth

Participants felt that mobile health services would be well-received by PEH and would help to "meet people where they are." Participants indicated two major considerations to mobile services: location of services (i.e., where most people congregate) and service hours (i.e., non-traditional service hours). Strategies to increase engagement in services mobile units and outreach efforts included attentiongrabbing (e.g., music), provide food, and phone chargers available to use.

There were mixed feelings about utilizing telehealth. Some prefer to see their provider in-person but acknowledged that telehealth services would be beneficial in circumstances such as feeling too sick to move or lacking access to transportation. Concerns were raised regarding PEH having access to devices, internet, and, most importantly, a charged device as this is a major barrier for PEH who have devices.

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I was helping people like that had abscesses and sores and stuff, you know, trying to keep 'em clean and cover 'em and, you know, and, and stuff. And he [service provider] was great to give bandages and different things to help with that.

Peer Champions & Educators

Most participants explained the varying ways in which they take care of their community. Participants described acting as informal peer educators by delivering health education (e.g., discussing HIV, PrEP, and harm reduction) and resources (e.g., administering naloxone), and connecting peers to health services.

HIV Prevention & Care

HIV Knowledge

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Participants became more knowledgeable about HIV and HIV transmission after their diagnosis. Many participants were tested due to being very sick or in the hospital, and one participant found out their HIV status while incarcerated.

In jail. So, it sucked. Just in jail when they tell you got it [HIV diagnosis], they just give you a pill and take you to the health department. [While in jail] they gave me no medicine.

HIV Diagnosis & Care

Participants who were contacted by their local health department reported positive experiences where staff were supportive and explained that "HIV is not a death sentence," helping to reduce fear and stigma. Participants expressed HIV care is very accessible especially through the help of the SSP and having clinic staff and Case Managers onsite.

Openly Discuss Status

Most participants openly discuss their HIV status but acknowledge the challenge of stigma from the community. One female participant experienced partner violence when disclosing their HIV status.

HIV Medication

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For participants receiving HIV medication, major barriers to regularly taking their medication included lack of insurance, feeling sick when taking medications, sometimes forgetting, medication storage difficulties, and medication being stolen. Losing HIV medication during city sweep of the encampments was emphasized as a common barrier.

That's a big thing. I've lost my medicine several times and the city come in and used that big picker and took my tent one time, you know, my medicine was in it. That's... that's hard.

Service providers, especially Ryan White Case Managers, were indicated as a top facilitator for easy HIV medication access, especially when medication had been stolen or lost. Having a set routine (e.g., taking in the morning after waking up) or having an alarm helped participants regularly take their HIV medication. However, setting a phone alarm requires the phone to be consistently charged.

<u>U=U</u>

Most participants were unfamiliar with the term U=U or Undetectable=Untransmittable, but instead understood it as "undetectable." Overall, there was hesitancy to fully believe in U=U and respondents still worried about the possibility of transmitting HIV to others.

<u>PrEP</u>

Some of the participants knew what PrEP was before their diagnosis but many found out about it after. Overall, there seems to be limited knowledge about PrEP among PEH and PWUDs. Participants expressed some PEH/PWUDs are interested in PrEP or interested to learn about PrEP but are too scared to ask about it due to the stigma around HIV.

SSP Access

Participants who access an SSP expressed that the program helps them to better take care of their health and other social and support needs. They find the SSP is very accessible and that the staff creates a safe environment which is beneficial to engaging with PEH and PWUDs. Some participants described law enforcement arresting people accessing the SSP and presenting challenges for staff who work at the SSP.

Overall, participants indicated that the SSP does its best to provide enough supplies but sometimes there was a need for more. Some participants provide their peers with unused supplies who are unable to reach the SSP indicating a needs-based and peer distribution approach. They also indicated the need for more SSPs and in different locations to better reach people unable to travel.

Conclusion Summary

Challenge: Stigma/Discrimination

Stigma and discrimination were salient barriers to accessing syndemic and supportive services across all groups. Participants experienced stigma and discrimination from their peers, the broader community, and service providers. Additionally, it was noted that providers of color also experience discrimination, particularly within rural TN, causing providers to leave resource-limited areas.

Challenge: Lack of Basic Necessities

Social determinants of health (SDOH) were indicated as a particular barrier to accessing services and maintaining their well-being. Lack of affordable housing was indicated as a major challenge impacting participants' physical health, mental health, and safety. Additional factors impacting health and well-being included lack of employment opportunities, health insurance, nutritious and affordable foods, and reliable and efficient transportation especially in rural areas. For PEH, the need to have a phone and a way to charge it was highlighted as key to accessing necessary services.

Need & Facilitator: Representation Matters

Participants underscored the importance of hiring people with lived and living experiences. Participants feel a lack of representation in the workforce negatively impacts engagement in syndemic services. Representation in health marketing was noted as an important strategy to engage priority populations such as including health marketing in Spanish. Participants discussed how trans/GNC persons, PLWH, PWUDs, and PEH function as peer champions in their communities by delivering health education and resources (e.g., naloxone), and connecting peers to health services.

Need: Mental Health Support

Mental health support was indicated as a vital service need and was particularly noted among PLWH, PWUD, and PEH. The intersection between housing instability, mental health issues, and the impact on substance use was also emphasized.

Need: Low Barrier Services

Low barrier services were noted as a priority to improve accessibility. Integrating services was highlighted as a mechanism to increase accessibility, especially for those with limited transportation or those with inflexible work schedules. Furthermore, participants emphasized the need for services to "meet people where they are", referring to availability of services at convenient location(s), offering non-traditional service hours, or in alignment with their healthcare goals. Telehealth and mobile clinic services were also seen as beneficial to increasing access to services.

Facilitator: Case Managers & Navigators

Case Managers and Navigators were seen as valuable resources to connect clients to needed syndemic and support services. Being non-judgmental and knowledgeable about various services was emphasized as critical qualities. Case Managers/Navigators were seen as helpful when navigating complicated processes that require a lot of paperwork and follow up to receive services, such as housing services and health insurance. There were inconsistencies noted in the quality of Case Managers/Navigators, as some described them as being "fabulous," while others noted that they were "hard to get a hold of", not as knowledgeable about services in the area, or frequently replaced due to high staff turnover.

TDH Ryan White Part B Program Qualitative Report

Introduction

This report summarizes qualitative data and key findings as a component of the ETS Needs Assessment to assess the service needs and barriers of PLWH in TN. This component involved conducting FGDs and KIIs across the state to gain more in-depth insight into the experiences of PLWH. This report includes an outline of the methodology, analytic approach, common/overarching themes, and key findings per location. This report was prepared by Lindsay Menard-Freeman for TDH via United Way of Greater Nashville.

Methodology

Participants were asked open-ended questions related to the following areas:

- their individual relationship with existing services and unmet needs
- perceptions of others' needs
- their personal satisfaction with current services

The FGD guide can be found in Appendix IV.

Procedures

After reading the opening script and explaining the purpose of the discussion, the process for reportwriting, and the commitment to confidentiality, the facilitator asked the participants to respond to a series of open-ended questions related to their experience with living with HIV in Tennessee. After all questions were asked and participants were given all opportunities to share their perspectives, the facilitator thanked the participants and distributed the incentives.

Setting

FGDs and KIIs were scheduled at times convenient to participants at neutral, non-agency locations. An effort was made to ensure that participants represented both urban and non-urban regions. A breakdown of each discussion setting is detailed in Appendix V.

Analytic Approach

During each discussion, descriptive notes were taken by the facilitator, as well as audio recordings and transcripts. The responses were themed and organized around the questions that were presented. Often respondents would provide information not strictly on the question, and the responses were connected to the theme of the appropriate question. The results are provided first as a summary of themes that emerged across all regions, then as summaries of each region.

Limitations

While this method allowed us to capture responses from numerous clients, there are some weaknesses associated with this method. Most importantly, the opinions of the individuals in the group may or may not be representative of the entire population, especially in those settings with only one participant, and insights recorded in this report must be reviewed with this in mind. Importantly, the results do provide additional understanding of the circumstances and experiences of those group members — and while not universal to all PLWH, are important to our overall understanding of how individuals experience their relationship with services. Participants were identified based on region and geography, rather than any other demographic characteristics.

Additionally, turnout was low, with concerns about confidentiality cited to United Way coordinators, who were charged with securing participants and locations for the FGDs. Three of the five FGDs had one participant, with one group having no confirmed participants by the date of the session.

Common Themes

Several themes emerged repeatedly in the majority of the discussions, and in some cases all discussions. Though the groups were made up of different populations from across the state, many of the participants echoed one another when discussing certain topics and themes. The following themes are further described by their impact specifically on each of the regions when appropriate.

Stigma & Discrimination

The clearest finding was the impact of stigma, discrimination, judgment, and bias from their community and, at times, from providers. The assumptions and perceptions of PLWH have a discernible impact on their access to care, services, and safety in their lives. All participants in all regions indicate that the level of knowledge among the general public about what it means to live with HIV, including basic information such as modes of transmission, treatment options, etc. is unacceptably low.

As a layer on top of general stigma and discrimination against PLWH, participants referenced the general conservative religious and political environment of Tennessee. All participants mention that they have been treated as "less than" because of assumptions about their identity or circumstance, whether referencing attitudes towards the LGBTQ+ community, criminalization of drug use, or a general lack of a social safety net when they found themselves homeless, financially insecure, etc. Participants referenced that Tennessee is in the heart of the Bible Belt, and that has meant that they cannot always assume that they are speaking to someone, especially service providers and medical staff, who will not discriminate against them based on their HIV status, their sexuality/gender identity, or other aspects of their identity.

Role of Case Manager

Nearly all participants shared insights that indicate that their Case Manager's involvement is crucial to their care and quality of life. Given that nearly all participants come to their diagnosis with compounding lack of access (housing insecure, food insecure, etc.) that necessitates access to assistance or services, their Case Managers are positioned to support their needs in a comprehensive manner if they have skills and capacity. However, Case Manager workload, overall level of information, and staff turnover seemed to be barriers to individual levels of access to care. There is also the perception that, with the exception of some well-informed Case Managers, most Case Managers are unaware of the continuum of services within their community.

Geography & Compounding Lack of Access

For the majority of participants, their HIV status comes with, and is often compounded by, other forms of insecurity. This includes, but is not limited to, housing insecurity, food insecurity, rural/remote living situation that requires transportation support, financial literacy, etc. There is often a great need to integrate services and access in order to ensure that participants have the full range of support they require, and that integration (especially in a streamlined and consistent manner) is often lacking. Location plays a significant role on service access, the array of available services, and the time required to access or receive services. In general, the farther someone lived away from a central city, the fewer comprehensive service offerings available to the individual, and there was increased difficulty in accessing available services. Individuals in rural areas often only had medical service options and very few accessible support services or access to informal social support from other PLWH. The farther individuals lived beyond these areas, the more difficult the service access and the more isolated participants became.

Need for Informal Social Spaces & Communication Channels

While it may be typically assumed that individuals become aware of services through their interactions with their service providers, it was quite clear in all regions that individuals typically found out about service offerings informally through their interactions with other PLWH. In all regions, there is the perception that services are not evenly distributed and that an individual is required to connect with specific gatekeepers at an organization to access certain services or request explicitly a specific need or specific service. It was also consistent that individuals perceived that they may need to access more than one service provider to gain access to all services for which they are eligible.

These informal interactions included information about types of services, who to speak to, what to say, and where to go. While the importance of connecting with others to increase service access was discussed in all regions, in some regions it was also emphasized as a survival skill. During all of the FGDs, the participants often shared information and intel with each other about specific services they received with some focus group members who became aware of services and how they could access them for the first time during the groups.

Integration of Services

While many of the participants had lived their entire lives or experienced their entire disease in a single geographic location, several participants had lived in other states and experienced other HIV service systems. Some participants had moved to Tennessee from other areas and had perspective on what is *possible* when it comes to a holistic approach to HIV care and services. These individuals were less positive in their comparisons with services in Tennessee to other service delivery systems and often suggested improvements based on those experiences. Many of the suggestions for specific services were based on what they considered to be a standard level of services that was available in other states.

Most participants were complimentary of the service providers they had engaged with, but they also expressed frustrations related to a limited menu of service options, fewer ancillary services, a smaller and fragmented HIV community, slower response time, and experiences with HIV stigma from providers and the community. One site that was given as an exemplary approach was in Chicago, where food security and nutrition services were put first and foremost as a programmatic offering; there was a partnership between a grocery store and a food stamp program, that meant that the participant could access fresh fruit and vegetables, lean meat, and other groceries as a part of their stipend. In contrast, Tennessee offers a \$25/month food card and food bank access, which often offers expired food.

ETS TN 2022 Needs Assessment Consumer Report

Site Specific Analysis

This section outlines the specific feedback given per site, with analysis per area of inquiry.

East: Johnson City

This section highlights major themes that emerged during the Johnson City key informant interview (n=1).

Barriers to Care/Services

<u>Lack of care team integration</u>. The participant spoke about how difficult it is if one member of his care team has to shift, given the matrixed nature of his care.

Everyone works together as a care team, so it's hard to just find someone new if you can't pay and need to switch to a new person.

<u>Stigma and Discrimination.</u> The participant spoke at length about stigma from medical providers, and the uncertainty about how a new provider will treat them if they must change providers.

<u>Lack of information flow.</u> The participant indicated misinformation and miscommunication are barriers to accessing services.

There's not enough transparency about what's available or why it's not available. Sometimes people will tell you that a certain service is not available, but then you find out from somebody else that it is. There's a lot of misinformation and miscommunication.

<u>Low-income status.</u> The participant gave an overview of how his financial situation caused the most stress in his life. Additionally, he mentioned the variation in the willingness of providers to work with him on copays and payment options. He mentioned benefitting from financial literacy support.

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Three years ago, I lost everything, and I'm still recovering from payday loans – paying \$300/month to pay that off. I have a kidney doctor who I was seeing who calls me every day to collect payment, which adds to my stress. I had trouble even making the \$30 copay amount. 99

Services/Support Needed

<u>Mental Health.</u> The participant mentioned that there have been several barriers to finding a therapist who could help.

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My therapist was gone for four months for surgery, plus providers aren't always empathetic to what it means to live with HIV, so just "finding someone new" wasn't really an option. I have a lot of stress from my financial situation, and the barriers that exist to finding the right mental health provider add to that stress.

Lack of social options for meeting new people. The participant mentioned that it is very isolating living with HIV in this area, and not knowing if people are safe to disclose their status to when you first meet them.

I would really like some kind of situation where it's possible to meet like-minded people [who "get it"] that's not therapy or treatment-related. Some sort of way to meet people that's not at a bar. Something like a cooking class, or something.

The participant did not speak further about any programs or services that are lacking but highlighted the importance of a caring community.

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All of these things (food, transportation, case management, oral health, housing) are available and at a good level. This is a very caring community, and everyone involved [in my care] are super people, which is what keeps me here. I'm at a point in my life where I can move to wherever I want to go, and I want to stay here.

<u>Options for integrative medicine</u>. The participant mentioned that it could be helpful to have more holistic health options to support living with HIV, such as kinesiology, acupuncture, Chinese herbs, chiropractic care, etc.

I want to put my body in the best position it could to be aligned and accept medication.

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East: Knoxville

This section highlights major themes that emerged during the Knoxville key informant interview.

Barriers to Care/Service

Location. Living in non-urban TN, access to HIV-specific healthcare is cumbersome due to travel.

A few years ago, there was a local expert who left the area (she was a religious minority and children were not accepted) and it was a great loss to anyone living with HIV in this area. Traveling to get HIV care is cumbersome, and there are people who live much further than I do from a provider.

<u>Bureaucracy</u>. The participant gave insights into all the different services he has tried to access over the years, with varying degrees of success.

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When I transferred my health to the local Health Department for HIV care, there was a competent doctor, but bureaucracy was unacceptable. Nobody answered the phone, and the answering machine said they would respond within 48 hours. I stopped going there for my healthcare. Went to an HIV clinic here and got more personal responses to needs. At my age, missing a dose of meds is unacceptable. If something happened with my prescription, I could miss days of my meds. Not quick or responsive service.

<u>Stigma.</u> The participant outlined how community perceptions about PLWH have had an impact on his and others' access to care.

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In the Bible Belt, there is a lot of stigma and homophobia and Christian norms about having HIV (sinful, promiscuity). Hidden or overt, there is a lot of judgment regarding HIV

<u>General population knowledge levels about HIV.</u> The participant spoke about how different groups have greater difficulty accessing services.

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I have done community outreach to try to talk to faith groups, community groups, anyone who will listen about how HIV is preventable and treatable. The general knowledge is very poor, especially among communities in need. I live in white community, and the largest needs are among young African American men, which is outside my social group.

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<u>Confidentiality in a small community.</u> The participant spoke about how many people either do not know their status or are afraid to find out their status because others would find out.

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Treatment can become a public thing. If you're getting mail delivered from pharma [about treatment], and if your cousin delivers your mail, it can be difficult to be private.

<u>Services for unhoused</u>. The participant specifically mentioned that there are barriers for members of the LGBTQ+ community seeking housing services.

Some nonprofits that cater to homelessness have homophobic problems of their own. Can you stay in a shelter as gay man, if your trans? They lose access to services.

Services/Support Needed

<u>A well-organized support group.</u> The participant gave insights into other examples of support groups that exist elsewhere (such as at the University of Denver and through Vanderbilt clinical trials).

There's a group in K

There's a group in Knoxville that has a monthly meeting with a meal and people who come in and discuss issues. I've gone a few times and find that the education level of attendees is a disgrace, in comparison to where I used to live. I was on the board of a group that has a monthly support group, where doctors come in and give presentations on healthcare trials, recruiting participants, things like that. The room was filled with 80–100 people, who are members of the community asking in-depth questions about how it might affect them and how they can get involved in the future. Not sure that it even exists in Nashville, but I wish it existed here.

<u>Comprehensive communication channel.</u> The participant mentioned that there is not one central place to get information out to the whole community of PLWH.

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There are issues getting information to people. You can't send mail that identifies someone as PLWH, and you can't do bulk email. For some people, the only time they get information from their Case Manager, who they see two times a year. If something new comes up, like a change in dental program, you might not know about it until your case visit in June. The DOH [department of health] has weekly newsletters, but not sure how many people would be getting that.

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<u>Education on healthy eating.</u> The participant mentioned that they live in a food desert and reflected that there is not demand for information on nutrition even though there is a need.

85% of restaurants are fast food in Oak Ridge. While I know the Knoxville Health Department has a healthy cooking class every month, no one signs up.

<u>Physical activity/movement support.</u> While the participant indicated that they already prioritize physical exercise, he reflected on how it would be great to learn more about how to move as his body ages.

I'm not a member of a gym but would like to know more about how to move my body as I age in a way that's healthy. Things in addition to riding my bike.

<u>Dental.</u> The participant gave a critical review of the dental program.

The dental program is not working within Ryan White. Every year there's a new director. Every year they say we'll get it sorted, but never gets fixed. Seems to be working better now, as you can find a dentist who can do the work and payment is made and worked smoothly. Until this year, I have not known anyone who has done this successfully.

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Southeast: Chattanooga

This section highlights major themes that emerged during the Chattanooga FGD (n=6).

Barriers to Care/Services

<u>Stigma/Lack of HIV Knowledge.</u> All participants shared stories about how members of their community lacked accurate information.

People don't have information about living with HIV. This includes misconceptions and myths about transmission. There's a lot of stigma because people don't ask questions and don't understand.

In the Black community, there's still a lot of ignorance and backwards thinking. My family knows but they still make me drink from a plastic cup.

<u>Case worker/service provider attitudes.</u> A few participants indicated that their Case Manager and their ability to make connections or follow through was lacking. While some mentioned that their Case Manager was really supportive, others mentioned that they had to do a lot of advocacy for themselves to get what they needed.

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When you are sick and in need of services, you don't want to jump through hoops to get the care I need. If I wasn't sick, [my Case Manager] wouldn't have a job. Stop acting like you have the money, because it's allocated to my needs.

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Participants also mentioned high turnover and a difficult work environment for the Case Managers.

I'm on my third Case Manager. I've been labeled as "difficult" because I'm informed and advocate for myself. It doesn't seem like there's a lot of scrutiny in hiring people, as many are not open-minded. The default assumption is that people are trying to take advantage of the system. There is judgment (racism, homophobia, etc.) sometimes, and I have to get into fight mode and advocate for myself and struggle to get services.

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<u>Transportation</u>. This barrier was particularly severe for individuals who live outside of the central city. Participants discussed informal ride share agreements that some individuals in the community have developed to help others access services and stay connected to each other.

<u>Mental health support</u>. Participants reported that finding the right mental health provider, particularly someone who could help with depression and substance use disorder, affected their ability to stay engaged in services.

It's been hard to find a therapist who understands all of my various experiences and identities, as a black man, as a person with HIV, etc.

Another participant reflected on how the services were not adequate when he was in crisis.

I kept getting passed on to someone else when I needed immediate support [around drug use] while I was in crisis. I kept getting referred because I didn't fit a specific profile. I sort of had to pull myself out of it, because no one really turned up in time to help. Some people aren't able to pull out of it.

<u>Dental.</u> Participants identified that if they have more severe dental issues, they may have to stop their care mid-service depending on the availability of funding for the dental program. So, sometimes they have to wait until the next year to get dental work completed.

I needed a root canal, so I had to contact an oral surgeon. That procedure alone took up half the funds, so I had to supplement with other insurance. The dentist is great but if you don't call early enough in the year, too, the funds run out. I think we all need more information about the best way to use those funds and support as we navigate that care.

Services/Support Needed

<u>Affordable housing</u>. Participants indicated that in addition to a lack of affordable housing, some organization staff can make the housing process more difficult.

The income-based program is backed up for years. I couldn't find options for affordable housing, and the rep had a really bad attitude, which was a barrier. Plus, my income needs to be three times the rent, which was not feasible.

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<u>Healthy food/spending flexibility.</u> There was a discussion among participants about the food desert in this area, and how buses do not go to grocery stores. Recommendations for mobile markets or a more robust Meals on Wheels type program. Additionally, food stamps were reported to be inadequate by all participants, and participants emphasized that a small monthly stipend to use on gas, clothes, utilities, and phone services (mostly for making doctor appointments) would go a long way.

The food banks don't accommodate different dietary needs, plus, the food isn't fresh and is often moldy.

One participant reflected on an exemplary program he was able to access in Chicago called Vital Bridges.

<u>Exercise/movement.</u> Participants indicated the need for exercise programs that would improve their overall health and well-being. They specifically highlighted the need for programs that were rehabilitative and inclusive (i.e., for all body types and abilities) and accessible (i.e., convenient operational hours, accessible location, and free). Participants referenced specific exercise programs (e.g., yoga, Silver Sneakers program, and other low-impact programs) that are offered but emphasized the inaccessibility of these options.

<u>Home support</u>. A participant highlighted how assistance with household management would positively impact their ability to better care for their health and wellbeing.

I don't need someone to take care of me, but I could use help cleaning my apartment and keeping my home in good health. It can be really hard to stay on top of everything, especially when you're sick, when you're grieving.

<u>Communications/information-sharing</u>. Participants identified that Case Managers are well-positioned to share information and connect people but are not always doing it. This was framed as a major gap in participants being able to meet others, know what services are available, and know how to support one another.

West: Covington

This section highlights major themes that emerged during the Covington key informant interview.

Barriers to Care/Services

<u>Homelessness.</u> The participant explained that he is currently unhoused due to an administrative error after an eviction that he was trying to dispute (that would have required him to pay for an entire year of rent up front). He was unable to secure housing while the claim was pending. Additionally, all housing options require three times the rent as income, and he could not show that. His housing insecurity is both a service need and a barrier to care.

<u>Issues with insurance.</u> The participant was denied Supplemental Security Income (SSI) benefits and was caught in an appellate process. Due to this situation, he was not eligible for many services or assistance programs, such as SNAP and EBT. Additionally, his health insurance changed and that impacted his access to needed services.

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Insurance changed because of Covid and funding. I had Blue Cross Blue Shield and changed to Cigna Connect. There aren't a lot of doctors who accept Cigna, and those who do aren't good quality. I've been in search of a different primary care provider, which has been a huge headache. The one I have now doesn't take Cigna, so it's a \$150 office visit.

<u>Confidentiality</u>. The participant shared a story about how his HIV status was shared throughout his whole community, and that his partner received threatening calls at work once people found out. Additionally, healthcare providers in the community also shared information about his status, violating ethics agreements and HIPAA. The breach of confidentiality made it extremely difficult for him to live in the community and lead a normal life, and there was no way to get accountability for those who violated his privacy.

<u>Provider discrimination and refusal of care.</u> The participant outlined a time when he went to the hospital with multiple issues and was sent away for what he can only assume to be related to his HIV status.

Last month I had pneumonia and COVID, and I went to the hospital. I was treated like a "stepchild." Because I also had HIV, they kicked me out and didn't share any information with me about why I wasn't getting treatment. I had vertigo. They sent me away twice, and I was living in my car. They offered to "walk me to my car."

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Services/Support Needed

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<u>Comprehensive legal services.</u> Due to the multiple legal issues the participant is facing, he mentioned that he is at the discretion of a private lawyer. His disability status has been denied several times, and he has experienced extreme difficultly securing an advocate for his legal needs, including for any rights that were violated because of his HIV status.

<u>Mental health support.</u> The participant reflected on how difficult it was to find a therapist or counselor who could understand him.

I was not getting the help I truly needed. It has been hard to find someone who understands me as a Black man, as a veteran, as a homeless man, and on top of that, my HIV status. I had a therapist who would give me homework, but never really seemed to understand where I was coming from.

<u>Basic public services.</u> This participant was not accessing most services. While his HIV treatment and care seemed to be a crucial part of his life, as he did not make any negative assessments of any of his medical care specific to his HIV status, the other insecurities (housing, food, financial, legal, etc.) detracted from an enabling environment for him to be healthy and well.

West: Jackson

This section highlights major themes that emerged during the Jackson FGD. Approximately 15 participants attended this focus group, some arriving late and others leaving early.

Barriers to Care/Service Access

<u>HIV status disclosure.</u> Several participants mentioned that they are not open with their status, and in many cases, their family does not know. While this makes participants feel safer, it often means they are isolated and cannot ask family or friends to drive them to their HIV treatment appointments if they have not shared their status.

<u>Stigma from doctors.</u> Participants mentioned that it is a gamble when starting to work with a new provider due to potential of being stigmatized or judged. This was a particular issue in the area, especially when one doctor (who was very beloved in the community) left to go to another clinic.

When the stigma comes from regular people in your life, it's more excusable because you don't know how they were raised or where they've gotten their information. Sometimes it's just about educating them, even though that's exhausting. But for a doctor, who is a trained medical professional and <u>should</u> know better, judges you, it's the worst.

Services/Support needed

<u>Peer support services.</u> The group had mixed feelings about offering support groups. On one hand, many indicated that there is a need, and one member of the group mentioned that there is a group that is poorly attended. Overall, the group emphasized the importance of peer support.

Peer support is really crucial.

Just being able to talk to someone who has navigated this disease, these systems, in this city.

<u>Information-sharing</u>. Participants mentioned that it would be helpful for them to have clear channels of communication to get all of the information they need in one place. This includes information about services, support groups, nutrition, latest research, events, updates in the Ryan White Part B program (like the dental program), and more.

<u>Dental.</u> Participants mentioned that there are now only two dentists that work with the dental program. Participants indicated they would be more likely to access routine checkups if there were enough providers.

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I don't know why, but dentists pulled out of the Ryan White program. It's now really limited and hard to find providers. It means a lot of clients lost service.

<u>Recertification</u>. While the majority of participants indicated that the recertification process was fairly straightforward for them, one mentioned that the paperwork was not filed properly for him, and he went to a pharmacy to find that he could not get his medications.

There is a lot of turnover at the department of health, and it would be great if we were able to do it over the phone or could mail in the paperwork. We know about it ahead of time, so wish there was just a different way to plan for it.

Another participant said that they wish there was an online portal or app where clients could take pictures of appointment cards or share receipts, or where they could find critical paperwork like a Food Stamp approval letter.

<u>Navigating benefits.</u> Several participants agreed that they wish there was someone to help break down the benefits that are available to them and help them navigate the system.

Additional Findings

The following insights were highlighted by various participant but did not fit into any of the categories above.

<u>Telehealth.</u> Most participants found that there were some benefits to telehealth, especially during COVID and especially for appointments like reading test results. Most participants indicated a preference for inperson care with their trusted providers at a frequency that is convenient for them and in locations that are near to them.

<u>Injectable treatment.</u> Overall, there were mixed reviews from participants about the possibility for injectable antiretroviral therapy (ART). Some had seen commercials for it and generally had some interest. Others seemed to prefer staying with their current treatment, given that they have invested so much time getting their HIV treatment right.

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Nashville Transitional Grant Area HIV Qualitative Report

Introduction & Methods

During August and September 2022, five focus groups were conducted in the Nashville Transitional Grant Area (TGA) by Ryan White Part A staff. These focus groups were held to gain a better understanding of the service needs, gaps, and barriers to care experienced by persons living with HIV (PLWH). The focus group study was internally reviewed by the Metro Public Health Department (MPHD) Institutional Review Board (IRB) to ensure activities followed ethical guidelines that have been established to protect human research subjects. Ryan White Part A staff coordinated with regional agencies and community members to recruit participants for each of the focus groups. Focus groups included between 4–12 participants. Participants were informed of the scope of the study, provided their consent to participate, and received \$40 gift cards for their contributions. All groups were asked the same set of questions covering topics including stigma, service needs, and barriers to care.

Each of the five focus groups were designed to explore the perspective of specific subpopulations, based on either higher burden of disease or a history of having their voices underrepresented. Although there was not a separate group for transgender PLWH, transgender PLWH participated in the PLWH over 45 and Black MSM groups.

- 1. PLWH over 45 Between 2016-2020, 60% of PLWH were 45 years old and older.
- 2. Hispanic PLWH The number of Hispanic PLWH in the Nashville TGA increased 23% between 2016-2020.
- 3. Black men who have sex with men (MSM) ages 18–35 In 2020, 60% of new diagnoses occurred among PLWH ages 15–34. Of PLWH ages 15–34, 86% were cisgender male, and 61% were non-Hispanic Black. Focus group age minimum was 18 years.
- 4. Women In 2020, 20% of PLWH were cisgender female.
- 5. Rutherford County Rutherford County has the highest rate of PLWH after Davidson County in the Nashville TGA and it is important to get the perspective of PLWH living outside Nashville. The number of new diagnoses and overall number of PLWH in Rutherford County increased over 50% between 2016–2020.

Group-Specific Themes

PLWH Over 45 Years Old

<u>Stigma</u>

When asked about experiences of living with HIV in communities, many participants described ongoing stigma, false perceptions on HIV transmission, and a lack of community knowledge. Some participants felt public messaging could be improved to highlight the diversity of people affected by HIV, as well as the ability to live a normal life while living with HIV. Transgender participants also described feeling uncomfortable and unacknowledged when not addressed by their preferred names in medical offices.

Peer groups are helpful, but the narrative needs to be changed. Anyone can be affected by and infected with HIV.

Service Needs

Although participants were appreciative of the services offered by the Ryan White program, they also identified several ways in which the services were not meeting their needs. Although gas cards are provided, several participants mentioned monthly limits that do not adequately address their need, particularly for clients living in rural areas given the number of appointments and services they require. The limitations with the gas cards have also been exacerbated by rising inflation and cost of living.

Dental services also reflected an unmet need for many participants. Some participants were able to receive basic cleaning and X-rays but had insufficient funds to cover the cost of more complicated dental care, causing them to put off these additional services.

Housing services were also described as in need of expansion, particularly for older PLWH. Housing options in the Nashville TGA were described as very limited, often located in unsafe areas, and sometimes occupied by people who inject drugs, presenting problematic living situations for individuals in addiction recovery.

Access to Services

Transportation remains a barrier to care for many PLWH. Although ride share options exist, availability may be limited, and some clients have reported difficulty in scheduling and maintaining rides. Bus routes in rural areas are also limited.

Telehealth services had mixed reactions from participants. While some appreciated the flexibility, other participants preferred in-person visits as designated time to focus on their health needs without distraction. Overall, participants preferred in-person medical visits but were more comfortable with telehealth mental health visits.

66 -

Improving Access and Care Quality

Some participants described the need for improved training with customer service at agencies and medical providers. Participants described feeling unseen and unheard, treated like just another number rather than a unique individual. Clients want to feel like a person, not just another number while receiving care. Time with the provider should be quality, not rushed!

99

Hispanic PLWH

A Spanish translator was utilized to help facilitate discussion for the Hispanic focus group.

<u>Stigma</u>

Participants expressed ongoing stigma in Hispanic communities, stating that they do not feel particularly comfortable sharing their HIV status with others, particularly with individuals not living with HIV. Some participants also mentioned that they have to lie about why they are going to doctor appointments. Additionally, some participants felt that it was difficult to participate in HIV-related events due to work, community perceptions, and associated stigma.

Service Needs

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Language continues to be a barrier for Hispanic PLWH. Participants also mentioned seeing Hispanic staff at agencies could help make clients feel more comfortable seeking care. Even though linguistics services exist, not being able to fully communicate with providers remains a challenge.

Less than 10% of the clients were Hispanics and the reality is that even more of the population in the future will be Latino, so, it is important to make sure the people coming to this country are educated and that all HIV information is easily translated into Spanish.

Dental services also represented a major concern, and several participants wondered why there have been changes to their dental benefits.

Housing/rent assistance and nutrition services were described as very important support services to clients.

Access to Services

Telehealth services had mixed reactions from participants. Some participants appreciated the additional flexibility with telehealth, as it allows them to engage in care even after a long workday. However, other participants felt that in-person visits allowed them to express their current state of well-being more fully. Overall, participants preferred in-person medical visits but were more comfortable with telehealth mental health visits.

Improving Access and Care Quality

Participants suggested that agencies should be more present on Instagram and other social media platforms for clients to know they exist. Social media outreach tailored to Hispanic PLWH could be used to increase awareness of care options and organizations. Outside of medical services, participants also suggested that more English as a second language (ESL) classes are needed to help Spanish-speaking clients understand the diagnosis and their health management.

Black MSM, Ages 18–35

<u>Stigma</u>

Participants expressed that they still experience stigma related to HIV status. Coming out in their community and to their family was intimidating for some and depended on what kind of household they came from. Many described the need to have a strong peer network for support with the diagnosis and to speak more openly with others. Some participants described an aversion to mental health therapy, viewing it as against their culture and that they felt it more appropriate to face their challenges independently or with guidance from members of their own community. Other participants viewed therapy in a more positive lens, as support that has empowered them to take control of their own situations and lives.

Service Needs

Participants described a need for dental services. Participants also described needing expanded options for housing, mental health, and transportation services. Additionally, there is a need for more assistance in finding employment and community engagement resources.

Access to Services

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Telehealth services had mixed reactions from participants. While some participants appreciated the flexibility, others felt that they did not feel private enough, especially when conducted via telephone.

Improving Access and Care Quality

Turnover at agencies, particularly in case management, is an obstacle for participants, as it makes it more difficult to maintain consistent quality of care. Additionally, representation of PLWH in agency staff was important to participants, as they felt that they were not always understood. A few participants also described negative and judgmental experiences with front desk staff (at a non-agency medical office) based on their HIV status, gender, and sexual orientation.

Providers could do a better job in making the clients feel more comfortable by not making assumptions that they are "ghetto" because of their race or how they present themselves or by their looks. It shouldn't matter what you look like or "whatever" you are, no one should just assume they know you. Everybody goes through things and the way staff interacts with the client can be the best interaction they have for the day. Everyone wants to feel respected.

Women Living With HIV

<u>Stigma</u>

Participants described a different experience with stigma as HIV is often primarily thought of as affecting men who have sex with men. Women often feel left out because the majority of them were infected through their partners with living HIV or intravenous drug use. They also felt PrEP is primarily marketed towards MSM, not women.

Service Needs

Participants described an urgent need for dental services. If participants were able to access dental care, the care often only covered the bare minimum of their needs. Some participants wondered what happened to the more comprehensive dental care they used to receive. When programs do not offer enough services or funding, some participants do not feel it is worth trying to go through the process only to get only part of the work they need.

Overall, participants expressed satisfaction with gas card and food delivery services.

Service Access

Participants recommended expanding transportation services, as options may be limited especially if a client has several medical appointments scheduled on the same day. Although buses are affordable options, the routes and stops do not always align with the client's needs.

Improvements to Access and Care Quality

Participants expressed the need for expanded housing services, including more directions on how to obtain housing. Metropolitan Development and Housing Agency (MDHA) options were limited, and some participants expressed that favoritism seems to occur within the housing agencies.

Staff turnover at agencies was also described as an obstacle for some participants, as it hindered continuity. It also made participants feel like interactions were less personalized.

Participants also described the need to expand transportation and dental services. Some participants felt that Medical Case Management services were not as helpful to them as they should be.

Additionally, participants expressed need for more HIV services and groups targeted for older PLWH, as older PLWH often have more medical needs and require more financial assistance.

There should be more HIV services and groups for the 50 and up, with age comes more medical needs and financial support. Social Security is not enough to pay for everything needed as people grow older.

Rutherford County

<u>Stigma</u>

Participants expressed that being open about their HIV status is challenging, and that it is only shared on a need-to-know basis. While experiences varied between participants, a few described receiving strong support from their family.

Service Needs

Staying healthy for some is very difficult and you can easily get lost if you don't have a strong voice and advocate for yourself.

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Transportation is a prominent challenge in rural areas. Although buses are available, limited stops, routes, and times make it difficult to meet the needs of participants. Some participants did not feel comfortable using rideshare services as they forget to call ahead or run the risk of missing their appointments. One participant mentioned an occasion when they scheduled rideshare, but the driver did not show up to take them to their appointment. Participants were reminded to work with their Case Managers for assistance setting up rides.

Participants described the need for expanded affordable housing options, as choices and financial support are limited. Some housing options require at least three months of rent to move in, even though verification of income shows that they make enough to pay consistently.

Affordable housing in safer areas is needed with inflation, there needs to be more choices and more financial support.

Participants appreciated peer support groups as a venue to learn more from other people going through similar situations that may be more knowledgeable of how to navigate the system and available services.

Service Access

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More medical services and agencies are needed in rural counties, as most appointments took at least 30 to 45 minutes travel time to get to the agencies in Davidson County. Participants noted that it takes a lot of consideration to determine how they will make their appointments before committing. Clinics that are open in the evening in rural areas were suggested as a way to accommodate the needs of rural clients. Participants were open to more telehealth/virtual appointments for counseling to reduce the need for travel. Some participants thought using telehealth services was relatively easy while others struggled with the technology and user experience of the online portals.

Improvements to Access and Care Quality

Participants described additional concerns regarding aging while living with HIV. With income limited by Social Security, the client may not be able to pay for all services, especially as needs change or costs increase.

Focus Group Summary For Ryan White Part A Nashville TGA

Across all subpopulations included in these focus groups, HIV-related stigma remains a challenge. While experiences vary person to person, mental health services and peer support groups were regarded as important services to deal with some of the challenges of living with HIV.

Regarding unmet needs, comprehensive dental care was one of the most commonly cited concerns across each focus group subpopulation. Dental service coverage has varied significantly for several years in the Nashville TGA, leaving growing numbers of PLWH without adequate resources to fully maintain their oral health.

Housing services were described as needing expansion, as options were limited and not always in safe locations for PLWH. Older PLWH may be in particular need of more housing options as their income may be more limited.

Transportation services appear to be partially meeting clients' needs as there are options for gas cards, rideshare, and bus passes. However, expanding these services may allow them to meet clients' needs more thoroughly. Increased funds for gas cards and increased consistency and assistance with scheduling rideshare programs can improve client utilization and make it easier to attend appointments. It is also necessary to ensure that there are sufficient transportation options in areas outside of Davidson County.

Focus group participants also expressed the importance of PLWH working at agencies that provide services for PLWH. This representation may address some of the challenges participants expressed when they receive care, such as feeling unheard or unseen as an individual. Additionally, it is imperative that agency staff treat all clients with dignity and respect and address them by their preferred name. Reducing staff turnover at agencies could also help to improve and maintain the quality of care and experiences of PLWH attending their appointments. Increasing the number of Spanish-speaking staff could also improve the quality of care for Hispanic PLWH. Telehealth services remain a valuable tool, but older PLWH may benefit from increased support in using these options.

Agencies should also consider developing their online and social media presence in order to increase awareness in the community of the services they provide. Resources should be made available in English and Spanish at a minimum and should highlight that HIV does not only affect one subpopulation.

End The Syndemic Needs Assessment Conclusion

Syndemic & Support Service Needs

In TN, those living with or vulnerable to one or more syndemic conditions are heavily impacted by varying social determinants of health such as experiences of unstable housing/unaffordable housing, incarceration, financial constraints, lack of transportation, and stigma and discrimination.

Overall, HIV, STI, and HCV testing services were top needed syndemic services that were generally received by most. In contrast, people who needed HIV PrEP or varying substance use services were more often unable to receive these services due to financial concerns (from cost to no health insurance), not knowing where to get services or were unaware of services, providers refusing to provide PrEP services, and sobriety restrictions and long wait lists especially for SUD services.

There was overall high need and unmet need for supportive services such as housing services, dental and eye care, job-related assistance, transportation, and food assistance. Barriers included limited quality services, cost concerns, distance, lack of stable housing, and lack of transportation.

Specifically, PWUDs, PEH, and people with carceral experiences were faced with unique barriers to receiving HIV care as well as other prevention and care syndemic services. These barriers included limited availability and accessibility of support resources as well as experiences of stigma/discrimination when trying to access these services. This situation creates an unsafe environment, and when one does not feel safe, it impacts the capability to take care of more complex issues including their health.

Telehealth was indicated as an accessible and important option to varying health services but with important considerations specifically around privacy, quality of services and consistency of provider. In addition, mail-ordered syndemic services were seen as helpful options by many specifically for HIV, STI, and HCV testing.

Stigma & Discrimination

Stigma and discrimination are pervasive and major barriers to accessing syndemic and supportive services especially for people living with certain health conditions, PWUDs, PEH, transgender individuals, and sex workers. Not only does stigma and discrimination impact service utilization but also impacts the safety and wellbeing of these individuals.

Mental Health Support

Mental health support was indicated as a top priority for those living with or vulnerable to syndemic conditions. It was particularly noted as a resource needed for those PLWH, PWUD, and those who experience incarceration, and/or homelessness. Mental health support was often indicated as important to help with experiences of stigma and discrimination.

Representation Matters

Overall, representation of those with living experiences is needed in syndemic efforts in TN. People with living experiences are already champions in their communities and help to connect people to services and provide social support, usually indicated as a survival mechanism. There was robust discussion around the need to hire people with living experience not only as peer navigators but in leadership positions. Particularly offering paid positions for, but not limited to, PLWH, PWUD, women, transgender/GNC individuals, and BIPOC.

Youth & Young Adult Engagement

Meaningful youth and young adult engagement was noted as a challenge throughout the various aspects of the needs assessment. In recognition of the political climate, policies, and laws that often impact the ability to effectively reach youth and young adults, it will be important to collaborate with current organizations that have built trust with this population.

Consistency in Services

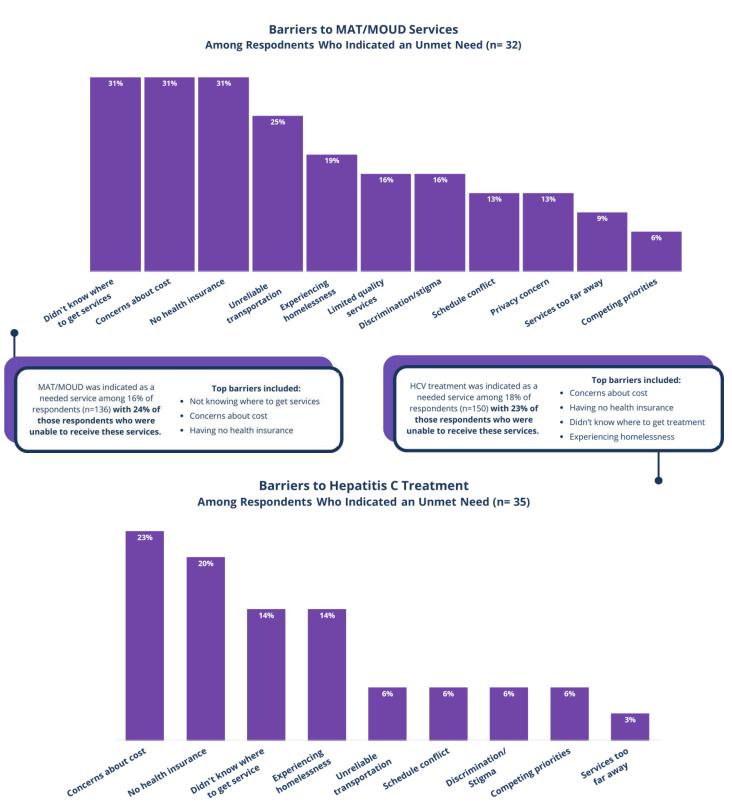
Case Managers and Navigators are important to help clients access varying syndemic and supportive care services. There seems to be inconsistency in the quality of services and provider knowledge of available services in the community, especially for supportive services. Trainings are needed for provider and staff regarding trauma-informed care and cultural humility, as well as a need to retain staff and reduce staff turnover.

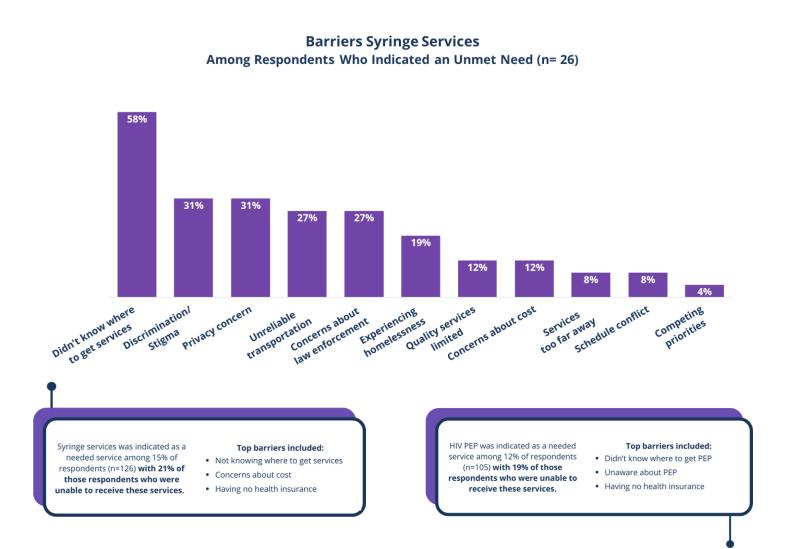
Integration of Services

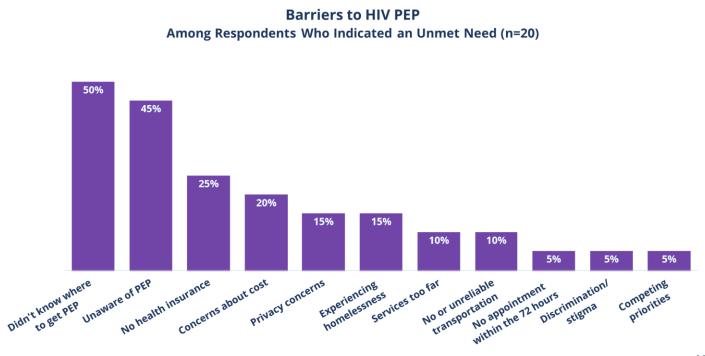
Integration of services was indicated as particularly important especially for those who live in more rural areas to help minimize travel burden and increase accessibility of services. In addition, there is a need for better transportation assistance to access services with physical gas gift cards as a top preferred resource. Currently, using public transit or rideshares is an all-day process for just one service appointment.

APPENDIX I

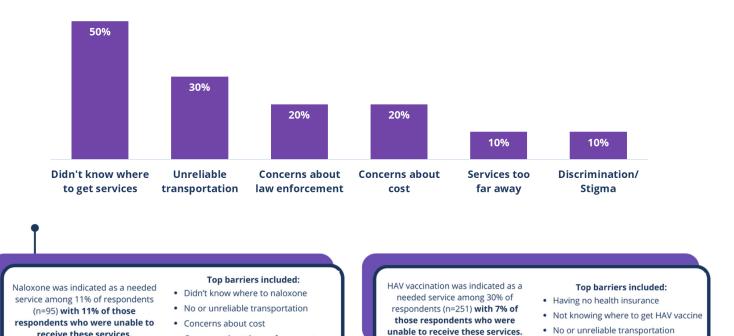
Appendix I includes additional figures for barriers to services for consumer respondents (n= 848) who indicated an unmet service need. These figures continue in order from highest to lowest percent of unmet need indicated by consumer respondents.







receive these services.

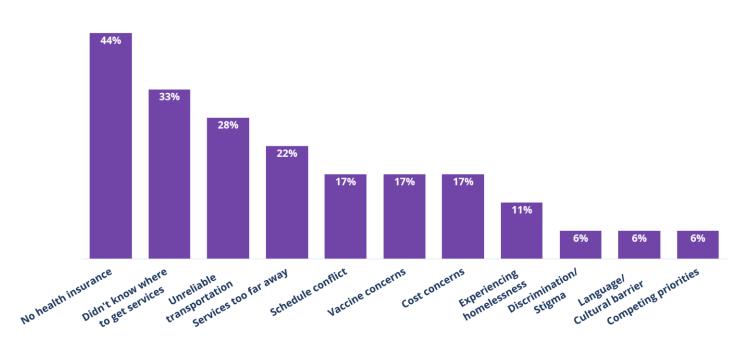


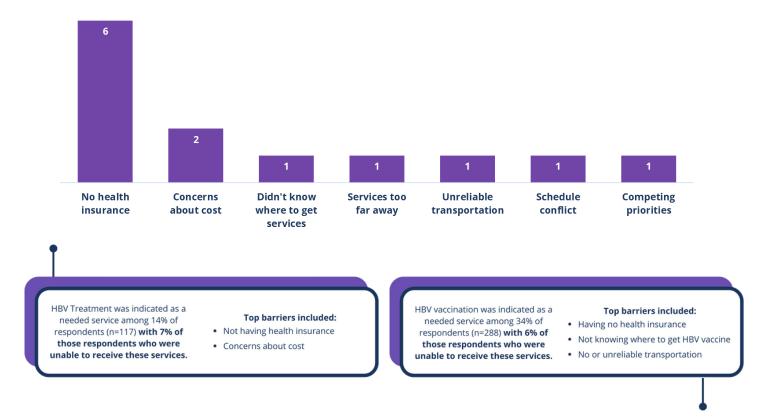
Barriers to Naloxone Among Respondents Who Indicated an Unmet Need (n=10)

Barriers to HAV Vaccination

· Concerns about law enforcement

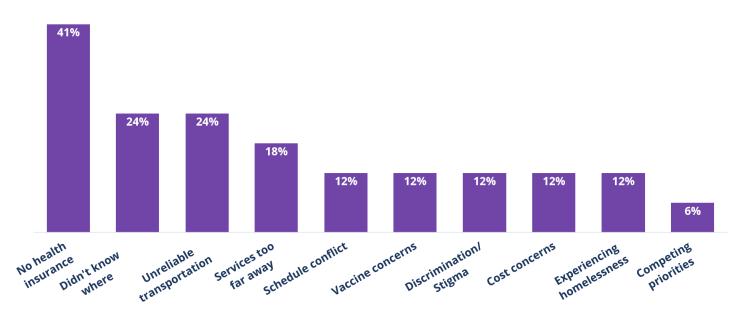
Among Respondents Who Indicated Unmet Need (n=18)





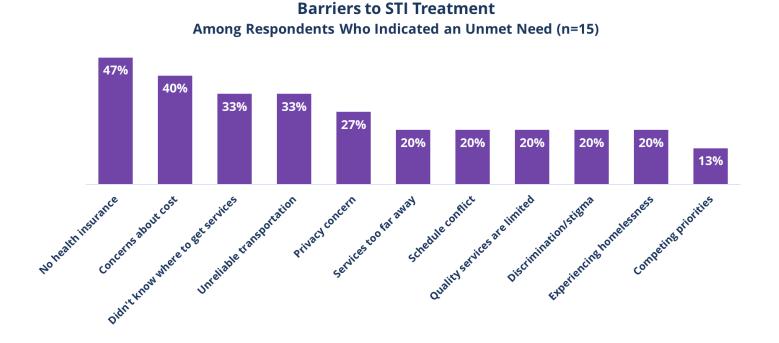
Barriers to HBV Treatment Among Respondents Who Indicated an Unmet Need (n=8)

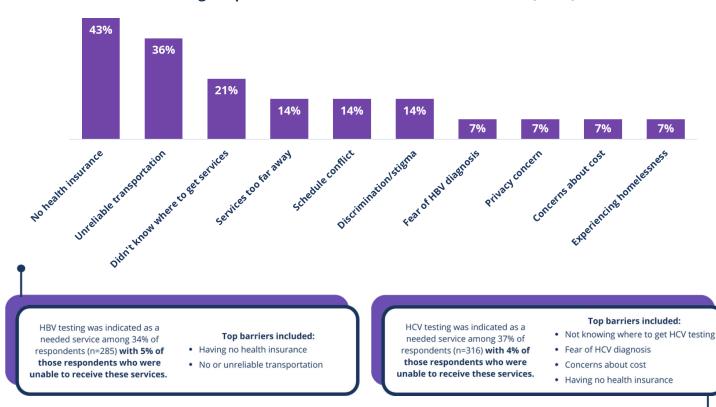
Barriers to HBV Vaccination Among Respondents Who Indicated an Unmet Need (n=17)





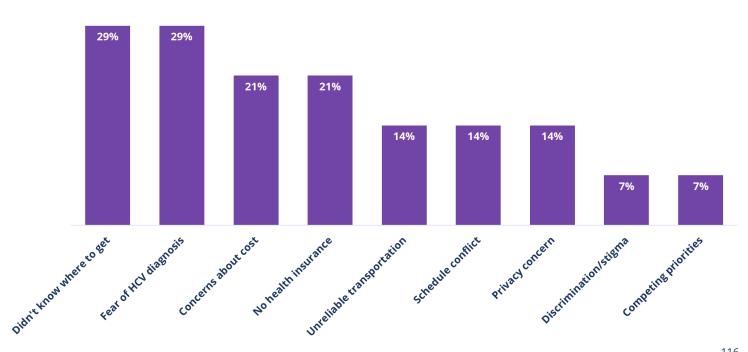
Barriers to STI Testing Among Respondents Who Indicated an Unmet Need (n=21)

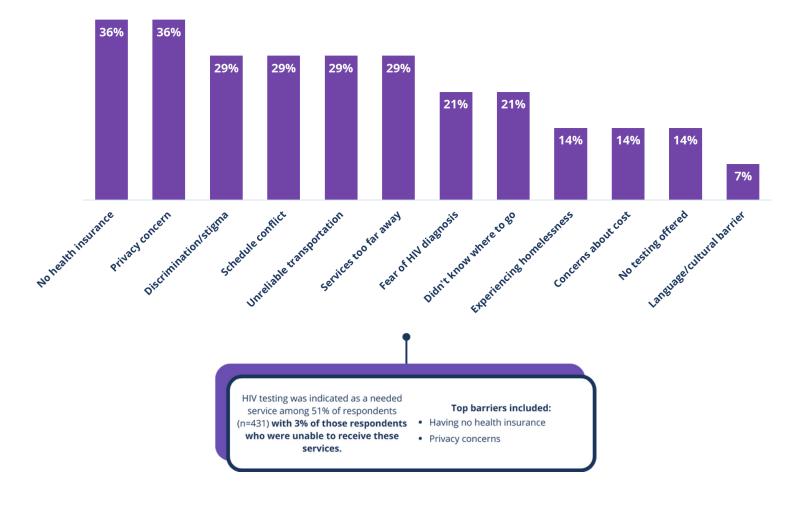




Barriers to HBV Testing Among Respondents Who Indicated an Unmet Need (n=14)

Barriers to HCV Testing Among Respondents Who Indicated an Unmet Need (n=14)



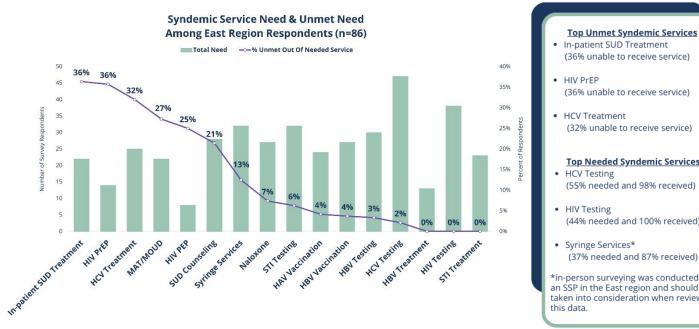


Barriers to HIV Testing Among Respondents Who Indicated an Unmet Need (n=14)

APPENDIX II

Appendix II includes regional figures for syndemic and support service need and unmet need.

All figures in Appendix II, the **green** bars represent the number of respondents who needed each service. The **purple** line represents the percentage of those who needed the service but were unable to get it.



East Region

(36% unable to receive service) HCV Treatment (32% unable to receive service) **Top Needed Syndemic Services** HCV Testing (55% needed and 98% received)

- · HIV Testing (44% needed and 100% received)
- Syringe Services* (37% needed and 87% received)

*in-person surveying was conducted at an SSP in the East region and should be taken into consideration when reviewing

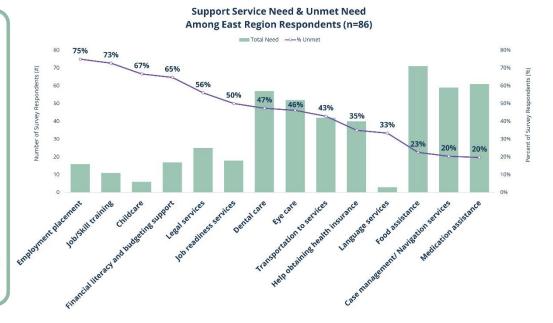


- **Employment Placement** (75% unable to receive service)
- Job/ Skill Training (73% unable to receive service)
- Childcare (67% unable to receive service)

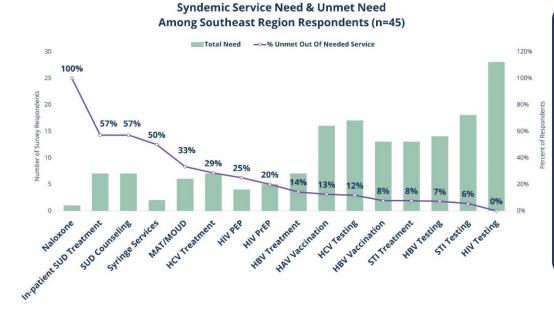
Top Needed Support Services Food Assistance

- (83% needed and 77% received)
- Medication/Prescription Assistance (71% needed and 80% received)
- Case management/Navigation (69% needed and 80% received)

There is also relatively high need and unmet need for dental and eye care in the East region.



Southeast Region



Top Unmet Syndemic Services Naloxone

- (100% unable to receive service)
- In-patient SUD Treatment (57%% unable to receive service)
- SUD Counseling (57% unable to receive service)

Top Needed Syndemic Services

- HIV Testing (62% needed and 100% received)
- STI Testing (40% needed and 94% received)
- HCV Testing (38% needed and 88% received)

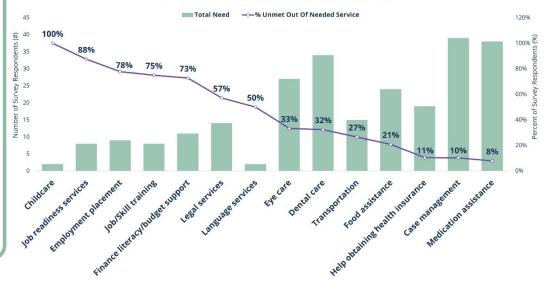
Top Unmet Support Services Childcare

- (100% unable to receive service)
- Job Readiness Services (88% unable to receive service)
- Employment placement (78% unable to receive service)

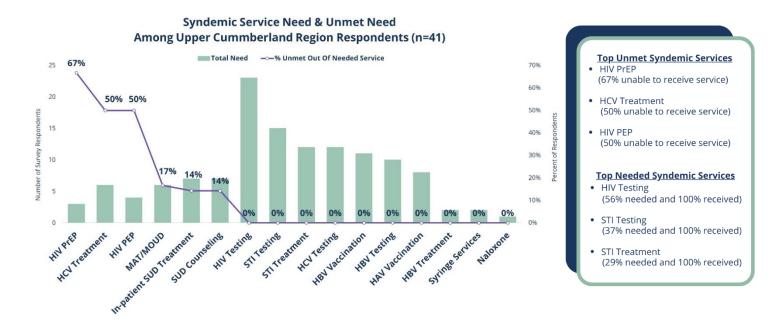
Top Needed Support Services

- Case Management/ Navigation (87% needed and 90% received)
- Medication Assitance (84% needed and 92% received)
- Dental Care
 (76% needed and 68% received)

Support Service Need & Unmet Need Among Southeast Region Respondents (n=45)



Upper Cumberland Region



Top Unmet Support Services

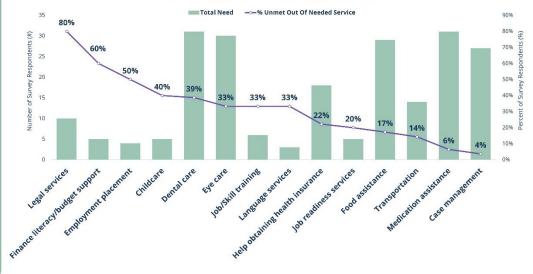
- Legal Services (80% unable to receive service)
- Financial Literacy/ Budget Support (60% unable to receive service)
- Employment Placement (50% unable to receive service)

Top Needed Support Services Dental Care

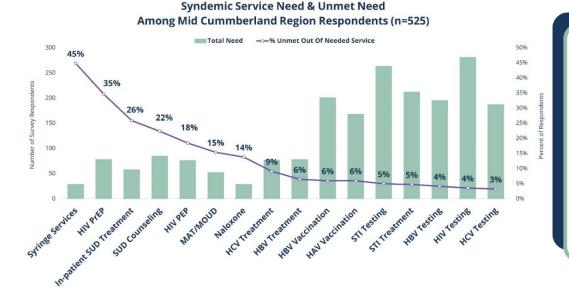
- (76% needed and 61% received)Medication Assistance
- (76% needed and 94% received)
- Eye Care (73% needed and 67% received)

Dental and eye care were among top needed support services with a higher unmet need compared to other top needed support services.

Support Service Need & Unmet Need Among Upper Cumberland Region Respondents (n=41)



Mid Cumberland Region



 Top Unmet Syndemic Services
 Syringe Services (45% unable to receive service)
 HIV PrEP

- (35% unable to receive service)
- In-patient SUD Treatment (26% unable to receive service)

Top Needed Syndemic Services

- HIV Testing (54% needed and 96% received)
- (34% needed and 56% received)
- STI Testing (50% needed and 95% received)
- STI Treatment (40% needed and 95% received)

Top Unmet Support Services Legal Services

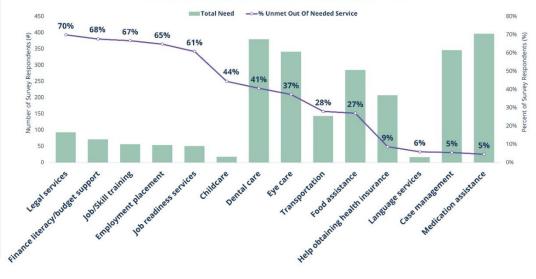
- (70% unable to receive service)
- Financial Literacy/ Budget Support (68% unable to receive service)
- Job/ Skill Training (67% unable to receive service)

Top Needed Support Services

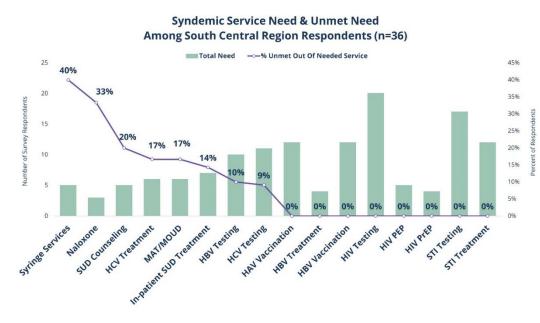
- Medication Assistance (75% needed and 95% received)
- Dental Care (72% needed and 59% received)
- Case Management (66% needed and 95% received)

Dental and eye care were among top needed support services with a higher unmet need compared to other top needed support services.

Support Service Need & Unmet Need Among Mid Cumberland Region Respondents (n=525)



South Central Region



Top Unmet Syndemic Services• Syringe Services(40% unable to receive service)• Naloxone(33% unable to receive service)• SUD Counseling(20% unable to receive service)• Develop Needed Syndemic Services• HIV Testing(56% needed and 100% received)

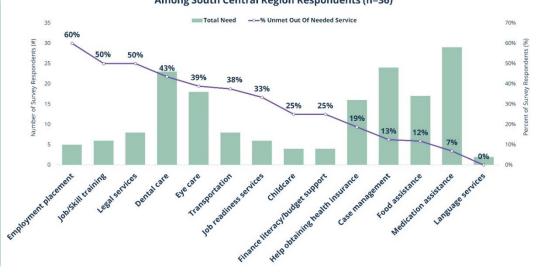
• STI Testing (47% needed and 100% received)

Infectious disease prevention and treatment services were among top needed services were relatively accessible for South Central respondents. Whereas SUD services and HCV treatment had a higher unmet need.

Top Unmet Support Services Employment Placement

- (60% unable to receive service)
- Job/ Skill Training (50% unable to receive service)
- Legal Services (50% unable to receive service)
- Top Needed Support Services
 Medication Assistance (81% needed and 93% received)
- Case Management (67% needed and 88% received)
- Dental Care (64% needed and 57% received)

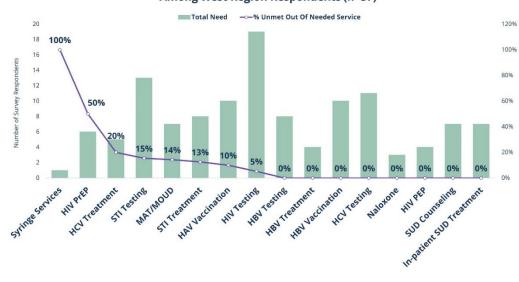
Dental and eye care were among top needed support services with a higher unmet need compared to other top needed support services.



Support Service Need & Unmet Need Among South Central Region Respondents (n=36)

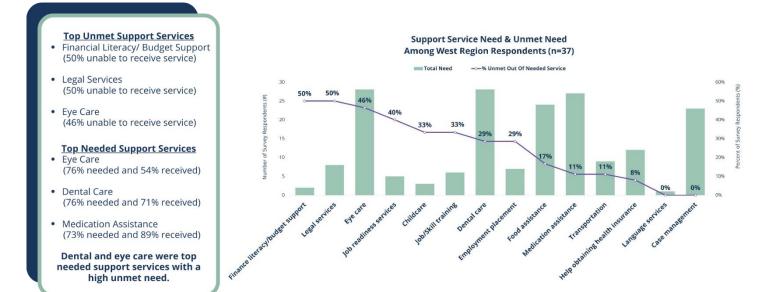
West Region



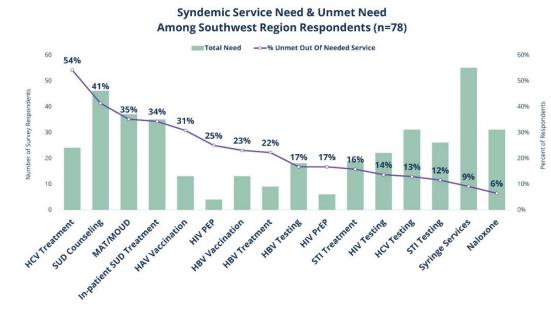


Top Unmet Syndemic Services Syringe Services (100% unable to receive, n=1) HIV PrEP (50% unable to receive service) HCV Treatment (20% unable to receive service) Top Needed Syndemic Services

- HIV Testing
 (51% needed and 95% received)
- STI Testing (35% needed and 85% received)
- HCV Testing (30% needed and 100% received)



Southwest Region

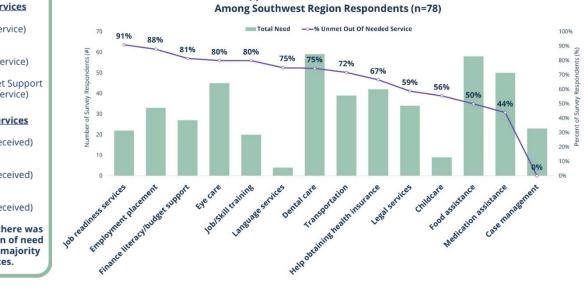


Top Unmet Syndemic ServicesHCV Treatment
(54% unable to receive service)SUD Counseling
(41% unable to receive service)MAT/MOUD
(35% unable to receive service)

Top Needed Syndemic Services

- Syringe Services (71% needed and 91% received)
- SUD Counseling (59% needed and 59% received)
- MAT/MOUD (47% needed and 65% received)

SUD Counseling and MAT/MOUD were top needed services with higher unmet need. *in-person surveying was conducted at an SSP in the Southwest region and should be taken into consideration when reviewing this data.



Support Service Need & Unmet Need

- Top Unmet Support Services Job Readiness Services (91% unable to receive service)
- Employment Placement (88% unable to receive service)
- Financial Literacy/ Budget Support (81% unable to receive service)
- Top Needed Support Services
 Dental Care
- (76% needed and 25% received)

 Food Assistance
- (74% needed and 50% received)
- Medication Assistance (64% needed and 56% received)

In the Southwest Region, there was an overall higher indication of need and unmet need across a majority of the support services.

APPENDIX III

Appendix III includes ETS Qualitative Facilitation Guides for each priority population.

Trans ETS Focus Group Guide

Facilitator Introductions

Greetings Everyone my name is Amber Coyne. I use she/her as pronouns, and I am the End the Syndemic Coordinator at the Tennessee Department of Health. I am joined today by my colleague.

Hi, my name is Rebecca Amantia. My pronouns are she/her and I am the End the Syndemic Project Associate

We would like to encourage everyone to turn on their cameras for this discussion.

Discussion Framing

<u>Purpose:</u> The purpose of this discussion is to better understand health priorities, needs, and barriers of transgender people in Tennessee. We know that transgender people are disproportionately impacted by HIV, sexually transmitted infections, substance use disorders, and viral hepatitis. Transgender persons also have unique needs and face unique challenges in getting those needs met. We would like to understand these in the context of Tennessee and the aforementioned health topics.

The information learned during this discussion will be used to inform strategies and next steps for the End the Syndemic Tennessee initiative including objectives, action items, and survey development.

<u>Procedure:</u> Over the next hour we will ask you all several questions and facilitate discussion. We will be audiorecording this session and as well as taking notes. We will not be recording video and will not begin recording until after introductions. Your responses will remain confidential, and no names will be shared, although we may share some of the themes that arise out these discussions with those involved in End the Syndemic Tennessee. You can choose whether or not to participate, and you may leave at any time during the course of the discussion.

Please note that there are no right or wrong answers to the questions we ask today. We want to hear the varying viewpoints and would like for everyone to contribute their thoughts. Out of respect, please refrain from interrupting others. However, feel free to be honest even when your responses counter those of other group members.

We also ask that you respect the privacy of each other by not disclosing any content discussed today without gaining consent from that individual.

Participant Introductions:

We will now ask each of you to introduce yourselves with your name, pronouns, and region of the state you represent for the Trans Task Force. If you feel comfortable sharing your relationship to various gender descriptors you are welcome to do so in as many or as few descriptors as feels comfortable.

For example, my name is Amber. I use she and her as my pronouns. I use both cisgender woman and femme to describe my gender identity and expression.

Start Recording

Now that we have finished introductions, we are going to start the recording. As a reminder we are not recording video just audio content.

Discussion

- 1. What do you think most impacts your health, or your ability to achieve health?
 - **Probe:** What has had a positive impact on your health?
 - i. **Probe:** what people, programs, or resources have positively impacted your health?
 - ii. Probe: what has helped get you connected to the care you need?
 - **Probe:** What has negatively impacted your health?
 - i. **Probe:** What has hindered or stopped you from getting the care you need?
 - ii. Probe: how could those barriers be removed or reduced?
- 2. What are your greatest needs related to your health?
 - **Probe:** Reminder. Health can be whatever you define it to be. So, this could include things related to your mental, emotional, and physical health such as housing, nutrition, social support and more.
 - **Probe:** What needs do you or other trans people have related to HIV, sexually transmitted infections, substance use disorder, and viral hepatitis?
 - i. **Probe:** Do you feel you have access to meet these needs?
 - ii. **Probe:** If not, what needs to happen to increase access
 - **Probe:** Have you heard about programs or resources in other places that you think would increase the health of transgender people in Tennessee
- 3. What is the number one thing we can do to address the HIV, sexually transmitted infection, substance use disorder, and viral hepatitis syndemic among transgender people in Tennessee?
 - **Probe:** How can End the Syndemic Tennessee ensure the input of transgender people is well represented in the plan?
 - **Probe:** For those of you involved in End the Syndemic already how can we improve the planning process?
 - **Probe:** For those if you not involved how do you think strategic planning can be improved generally to ensure community input is centered?

ETS PWUD Focus Group Guide

Facilitator Introductions

Greetings everyone, my name is [*TDH staff name*]. I use [*pronouns*] pronouns, and I am [*state position/affiliation*]. I am joined by [*insert NASTAD staff name*] who will be facilitating the discussion today. First, I am going to review the purpose and process of this discussion and then hand it over to [*insert NASTAD staff name*] to start the discussion at which time TDH staff will leave.

Discussion Framing

[TDH staff will read discussion framing and then hand it over to NASTAD staff to facilitate]

The purpose of this discussion is to better understand the health priorities, needs, and barriers related to prevention and care of HIV, sexually transmitted infections, viral hepatitis, and substance use disorder for persons who use drugs living in Tennessee.

The information that we learn during this discussion will be used to inform strategies and activities to address these health conditions over the next several years in Tennessee.

<u>Procedure:</u> Over the next hour and a half the NASTAD team will ask you all several questions. There are no right or wrong answers. Your opinions mean a lot to us, so we want everyone to share their thoughts. Feel free to be honest even when your responses may be different from other group members. The facilitator may jump into the discussion every once in a while, to make sure that everyone has an equal chance to share their thoughts.

We will be recording the audio of this session; we will <u>not</u> be recording any video. The recording will begin after introductions, and we will let you know when the recording has started. Notes will be taken to help summarize thoughts and suggestions from the discussion. Your responses are confidential, and no names will be shared. If names are mentioned during this discussion, they will be removed from the transcription and notes. You can choose whether or not to participate, and you may leave at any time during the discussion.

We ask that you respect privacy of each person in this group by not sharing anything discussed today without asking first.

We would like to encourage everyone to turn on their cameras for this discussion. Lastly, after we finish talking today, you will receive a short survey to complete. After you complete this survey, you will receive a \$35 VISA gift card for your time.

Does anyone have any questions before we begin? [TDH staff answer any questions]

[Check to make sure everyone's camera/audio is working before starting]

At this time, the Tennessee Department of Health staff will be leaving the discussion to provide space for open and honest conversation. Now, I am going to hand it over to [insert NASTAD staff] to start with introductions.

Participant Introductions:

Thank you all for being here today. We will now ask each of you to introduce yourselves with your name, pronouns, and as an icebreaker, feel free to share with the group what your favorite meal is.

For example, my name is ____, and I use ____ as my pronouns. My favorite meal is ____.

Now I will go down the list of names and ask each of you to introduce yourselves.

Start Recording

Now that we have finished introductions, we are going to start the recording. As a reminder we are not recording video just audio content. If everyone is ready, we will now start with our first question.

Discussion:

- 1. What needs do you or other people who use drugs have related to health?
 - *Reminder:* Health can be whatever you define it to be. So, this could include things related to your mental, emotional, and physical health such as housing, nutrition, social support and more.
 - [note to facilitator: be sure to transition to the next question after a few minutes to help keep the discussion moving and on topic]

2. Now we are going to ask about services specific to HIV, sexually transmitted infections, and viral hepatitis.

- 2.A The recommendation for all persons is to get tested for HIV and hepatitis C virus at least once in their life. And for some people with ongoing vulnerability, testing is recommended more often. Part of the role at the health department is to help increase access to testing for these conditions in different settings like health department clinics, health centers, community-based organizations, health fairs, and more. Getting tested for these health conditions is the first step to be linked to other services, regardless of the result. So, we would love your input on how to make testing more routine, comfortable, and normal for people who use drugs in Tennessee. Thinking back to a time when you most recently tested for HIV, sexually transmitted infections, or viral hepatitis (like hepatitis B or C), what was that experience like for you?
 - Probe: How often do you get tested for HIV, Hepatitis C, and/or STIs?
 - *Probe*: What are reasons that prevent you or other people who use drugs from getting tested for HIV, Hepatitis C and/or sexually transmitted infections?
 - *Probe*: Do these reasons differ based on type of test (for example, are there different reasons that people hesitate to get tested for HIV vs. sexually transmitted infections vs. hepatitis C?)
 - *Probe*: How can we make testing easier or more desirable to people who use drugs?
 - *Probe:* What would help motivate people who use drugs to access testing services?
 - *Probe:* Where could we put testing services that would make it easier for people who use drugs to access?
- **2.B** What have you heard about PrEP for HIV prevention?

- [facilitator note: You may need to explain what PrEP is -especially if there is no to minimal response. Not everyone may know what PrEP is. Wait a moment for response and then explain...
 - *"PrEP is a medication that can be taken to prevent HIV. It's more than 99% effective in preventing HIV from sex and 74% effective in preventing HIV among persons who inject drugs."*]
- *Probe: [if HIV PrEP is known, ask]:* What are your experiences with accessing or using PrEP?
 - *Probe*: Do you have a hard time taking your medication every day? If so, why?
 - Probe: What would help you take your medication daily?
- *Probe:* What do you think are some reasons that people who use drugs in Tennessee may not seek out PrEP?
- *Probe:* What are ways to increase PrEP awareness among people who use drugs?
- Probe: What are ways to increase PrEP use among people who use drugs?

3. Now we are going to ask you about care and treatment for HIV, sexually transmitted infections, and viral hepatitis.

- **3.A** What sort of things have helped you access HIV, sexually transmitted infections, or viral hepatitis care or treatment? (This can be people, programs, or resources that helped you get services).
- **3.B** What sort of things have made it difficult to get the care you need for HIV, sexually transmitted infections, viral hepatitis? (This can be people, programs, or resources that act as barriers or are difficult to access services).
- 4. Now we are going to ask about experiences with services specific to substance use. What are your or other people who use drugs experiences with accessing harm reduction services in Tennessee? Some examples of harm reduction services include syringe service programs, naloxone for temporary overdose reversal, fentanyl testing strips, or safer drug use resources.
 - **4.A** What sort of things have <u>helped</u> you access harm reduction services? (This can be people, programs, or resources that helped you access services).
 - **4.B** What concerns do you or other people who use drugs have regarding <u>laws and policies and/or law</u> <u>enforcement</u> when accessing or using harm reduction services?
 - *Probe*: Please tell us about any experiences you or others you know have had with laws and policies and/or law enforcement when trying to access harm reduction services.
 - **4.C** How accessible is naloxone (temporary overdose reversal, aka Narcan) to you or other people who use drugs in Tennessee?
 - *Probe:* What are reasons you are not able to get naloxone?
 - *Probe*: What has been your experience accessing the type of naloxone that you prefer?

- [facilitator note: make sure to clarify which naloxone they are referring to. Nasal- Narcan or Klaxxado, or intramuscular].
- *Probe:* What would make it easier for you or other people who use drugs to get naloxone?
- *Probe:* What are ways we can increase getting naloxone to those who need it?
- **4.D** What are your or other people who use drugs experiences with substance use treatment or care services? Some examples of services include but are not limited to in-patient or residential services, medication assisted therapy (such as buprenorphine or Suboxone), or counseling services (such as one-on-one, peerto-peer, or group sessions).
 - *Probe:* What has prevented you or other people who use drugs from being able to access substance use treatment and care services?
 - *Probe:* What sorts of things have helped you or others you know access other substance use treatment and care services?
- 5. We will now move on to our final question... What is the number one thing we can do to better address HIV, sexually transmitted infection, substance use, and viral hepatitis for people who use drugs in Tennessee?
 - *Probe:* Have you heard about programs or resources in other places that you think would increase the health of people who use drugs in Tennessee? Please tell us more about these programs.

End Discussion:

That is all the questions we have for you today. I'd like to thank you so much for your time and participation today. Your input is incredibly valuable. I will now place the link to the gift card survey in the chat. Once you complete the survey you are free to leave the call. Your gift card survey response will be processed within 1 week. If you have difficulty accessing the survey, please let me know.

Also, if you want to learn more about HIV, STIs, viral hepatitis, and substance use disorder & TN's plan to address these health conditions, you can visit endthesyndemictn.org or contact TDH at <u>endthesyndemic.tn@tn.gov</u> (provide webpage and link in the chat).

Rural ETS Focus Group Guide

Facilitator Introductions

Greetings Everyone my name is [*facilitators name*]. I use [*pronouns*] as pronouns, and I am [*state position/affiliation*] and I will be facilitating the discussion today. First, I am going to review the purpose and process of today's discussion.

Discussion Framing

The purpose of this discussion is to better understand the health priorities, needs, and barriers related to prevention and care of HIV, sexually transmitted infections, viral hepatitis, and substance use for those living in rural Tennessee.

The information that we learn during this discussion will be used to inform strategies and activities to address these health conditions over the next several years in Tennessee.

<u>Procedure:</u> Over the next hour we/I will ask you all several questions. There are no right or wrong answers. Your opinions mean a lot to us, so we want everyone to share their thoughts. Feel free to be honest even when your responses may be different from other group members. The facilitator may jump into the discussion every once in a while, to make sure that everyone has an equal chance to share their thoughts.

We will be recording the audio of this session; we will <u>not</u> be recording any video. The recording will begin after introductions, and we will let you know when the recording has started. Notes will be taken to help summarize thoughts and suggestions from the discussion. Your responses are confidential, and no names will be shared. If names are mentioned during this discussion, they will be removed from the transcription and notes. You can choose whether or not to participate, and you may leave at any time during the discussion.

We ask that you respect privacy of each person in this group by not sharing anything discussed today without asking first.

We would like to encourage everyone to turn on their cameras for this discussion. Lastly, after we finish talking today, you will receive a short survey to complete. After you complete this survey, you will receive a \$35 VISA gift card for your time.

Does anyone have any questions before we begin?

[Check to make sure everyone's camera/audio is working before starting]

Participant Introductions:

Thank you all for being here today. We will now ask each of you to introduce yourselves with your name, pronouns, and as an icebreaker, feel free to share with the group what your favorite meal is.

For example, my name is ____, and I use ____ as my pronouns. My favorite meal is ____.

Start Recording

Now that we have finished introductions, we are going to start the recording. As a reminder we are not recording video just audio content. If everyone is ready, we will now start with our first question.

Discussion

- 1. What are your greatest needs related to your health?
 - *Reminder:* Health can be whatever you define it to be. So, this could include things related to your mental, emotional, and physical health such as housing, nutrition, social support and more.
- 1.A What needs do you or others in your community have related to HIV, sexually transmitted infections, substance use disorder, and viral hepatitis?
 - *Probe:* Do you feel you have access to meet these needs? If not, what needs to happen to increase access?
- 2. What sort of things have made it difficult to get the services you need for HIV, sexually transmitted infections, viral hepatitis? (This can be people, programs, or resources that act as barriers or are difficult to access services).
- **2.A** What sort of things have helped you access HIV, sexually transmitted infections, or viral hepatitis services? (This can be people, programs, or resources that helped you get services).
 - *Probe:* What needs to be considered going forward to make these programs accessible to people living in rural areas?

[If transportation is not addressed, read question 2B]

- 2.B What are your experiences with transportation to accessing healthcare?
 - Probe: What would you like to see changed in transportation access?
 - Probe: What are some possible solutions to these issues?

[If privacy is not brought up read question 2C]

- 2.C What concerns do you or people in your community have about privacy when accessing HIV, sexually transmitted infection, viral hepatitis, or substance use services?
 - *Probe:* What would help ease these concerns?
- **3.** Currently, there are programs in place which will mail you a discreet package containing a self-administered test for HIV, sexually transmitted infections, or Hepatitis C. Additionally, there are programs that provide mail-ordered naloxone and condoms in the same way. **What are your feelings about the mail-ordered services mentioned?**

- *Probe:* Would you or others in your community be interested in having a self-test kit mailed to you for HIV and sexually transmitted infections
 - i. Probe: How about mail-ordered naloxone or condoms?
- *Probe:* What concerns do you have with mail-ordered self-test kits?
 - *i.* What about mail-ordered naloxone or condoms?
- 4. What are your experiences using virtual or telehealth services, for any type of health care or prevention services?
 - Probe: Have you ever used telehealth services? Can you tell me more about that experience?
 - *Probe:* Is telehealth a feasible resource your community can use for non-emergency care? Why or why not?
 - *Probe:* What would make you or others in your community be more likely to use this service?
- 5. If you wanted to seek out health information about HIV, sexually transmitted infections, substance use disorder, and/or viral hepatitis where would you go?
 - Probe: Who do you trust to give you that information?
 - *Probe:* What are your experiences with programs that you think are doing a good job with providing health information about HIV, sexually transmitted infections, substance use disorder, and/or viral hepatitis?
 - *i. Probe:* Can you explain more, tell me about that experience, what was good about it?
 - *Probe:* What types of outreach services and programs would you like to see?
 - *i. Probe:* Are there any non-health groups you would like to have this information [*If needed, example include* a church, a school, local 12-step program, etc.]

6. We will now move on to our final question... What is the number one thing we can do to address the HIV, sexually transmitted infection, substance use disorder, and viral hepatitis for people living in rural Tennessee?

• *Probe:* Have you heard about programs or resources in other places that you think would increase the health of people in rural Tennessee? Please tell us more about these programs.

End Discussion:

That is all the questions we have for you today. I'd like to thank you so much for your time and participation today. Your input is incredibly valuable. I will now place the link to the gift card survey in the chat. Once you complete the survey you are free to leave the call. Your gift card survey response will be processed within 1 week. If you have difficulty accessing the survey, please let me know.

Also, if you want to learn more about HIV, STIs, viral hepatitis, and substance use disorder & TN's plan to address these health conditions, you can visit endthesyndemictn.org or contact TDH at <u>endthesyndemic.tn@tn.gov</u> [provide webpage and link in the chat].

Latinx ETS Focus Group Guide English V.6

Introduction & Discussion Framing

Greetings everyone, my name is [*facilitators name*]. I use [*pronouns*] pronouns, and I am the facilitator for today's discussion.

The purpose of today's discussion is for the Tennessee Department of Health to better understand health priorities, needs, and barriers related to prevention and care of HIV, sexually transmitted infections, viral hepatitis, and substance use for Latino, Latinx, or Latine men who identify as gay, bisexual, or men who have sex with other men living in Tennessee. So, we are talking with you today to get a better understanding of your experiences to help inform strategies and activities to address these health conditions in Tennessee.

I would also like to note before we begin that I will use the term "Latinx" to describe Hispanic, Latinx, Latino, or Latine communities in Tennessee. We recognize that this is not the perfect term for everyone. Please feel free to let me know if there is another term you all prefer, and I can use that for the remainder of the discussion.

<u>Procedure:</u> Over the next hour and a half I will ask you all several questions. Please note that there are no right or wrong answers to the questions we ask today. We want to hear the varying viewpoints and would like for everyone to contribute their thoughts. I may jump into the discussion every once in a while, to make sure that everyone has an equal chance to share their thoughts. Feel free to be honest even when your responses may differ from other group members.

We will be recording the audio of this session; we will <u>not</u> be recording any video. The recording will begin after introductions, and I will let you know when the recording has started. Notes will be taken to help summarize thoughts and suggestions from the discussion. Your responses are confidential, and no names will be shared. If names are mentioned during this discussion, they will be removed from the transcription and notes. You can choose whether to participate, and you may leave at any time during the discussion.

I also ask that you respect privacy of each person in this group by not disclosing anything discussed today without gaining consent from that individual.

I would like to encourage everyone to turn on their cameras for this discussion. Lastly, you will receive the incentive of a \$35 VISA gift card after we have concluded the discussion. There will be a short survey to complete to receive your gift card.

Does anyone have any questions before we begin?

[Check to make sure everyone's camera/audio is working before starting]

Participant Introductions:

I will now ask each of you to introduce yourselves with your name, pronouns, and as an icebreaker, feel free to share with the group what your favorite meal is.

For example, my name is ____, and I use ____ as my pronouns. My favorite meal is ____.

Now I will go down the list of names and ask each of you to introduce yourselves.

Start Recording

Now that we have finished introductions, we are going to start the recording. As a reminder we are not recording video, just audio content. Your responses will remain confidential.

Discussion

1. What are your greatest needs related to your health?

- *Reminder*: health can be whatever you define it to be. So, this could include things related to your mental, emotional, and physical health such as housing, nutrition, social support, and more.
- [note to facilitator: be sure to transition to the next question after a few minutes to help keep the discussion moving and on topic]
- **1.A** What needs do you (or other Latinx gay & bisexual men or Latinx MSM) living in Tennessee have related to HIV, sexually transmitted infections, substance use, and viral hepatitis?
 - Probe: Do you feel you and/or others in your community have access to meet these needs?
 - *Probe:* If not, what needs to happen to increase access for Latinx gay & bisexual men or Latinx MSM in Tennessee?

2. Now I am going to ask about services specific to HIV, sexually transmitted infections, substance use, and viral hepatitis.

- 2.A The recommendation for all persons is to get tested for HIV and hepatitis C at least once in their life. And for some people with ongoing vulnerability, testing is recommended more often. Part of the role of the health department is to help increase access to testing for these conditions in different settings like health department clinics, health centers, community-based organizations, health fairs, and more. Getting tested for these health conditions is the first step to be linked to other services, regardless of the result. So, we would love your input on how to make testing more routine, comfortable, and normal for Hispanic and Latinx communities in Tennessee. Thinking back to a time when you most recently tested for HIV, sexually transmitted infections, or viral hepatitis (like hepatitis B or C), what was that experience like for you?
 - Probe: Was it a good/bad experience? Why?
 - Probe: How often do you get tested for HIV and sexually transmitted infections?
 - *Probe:* Where do you typically get tested?
 - Probe: What would make a testing experience more comfortable for you?
 - Probe: What are some reasons that Latinx gay men or Latinx MSM hesitate to get tested?
 - *Probe:* Do these reasons differ based on the type of test (i.e., are there different reasons that people hesitate to get tested for HIV vs. sexually transmitted infections vs. hepatitis C?)
 - Probe: For people in Latinx communities who do get tested, what motivates or influences them to do so?
 - *Probe:* Would you be interested in having a self-test kit mailed to you for HIV and sexually transmitted infections?

- **2.B** What have you heard about PrEP for HIV prevention?
 - [Facilitator note: You may need to explain what PrEP is -especially if there is no to minimal response. Not everyone may know what PrEP is. What a moment for response and then explain...
 - *"PrEP is a medication that can be taken to prevent HIV. It's more than 99% effective in preventing HIV from sex and 74% effective in preventing HIV among persons who inject drugs."*]
 - *Probe:* What are some reasons that Latinx gay men or Latinx MSM may not seek out PrEP?
 - *Probe:* What are ways to increase PrEP awareness among Latinx gay men or Latinx MSM in Tennessee?
 - *Probe:* What are challenges to accessing PrEP for you and/or other Latinx gay men or Latinx MSM in Tennessee?
 - *Probe:* What are ways to increase PrEP use among Latinx gay men or Latinx MSM?
- **2.C** How does substance use or addiction impact Latinx communities?
 - *Probe:* In your opinion, do you feel substance use or addiction is an issue in your community? [*if yes*]: Could you explain further?
 - *Probe:* Have you seen or heard about substance use or addiction impacting Latinx individuals or families?
 - o *[if yes]:* Can you tell me more about how substance use or addiction has impacted your community?
 - *Probe:* What resources are needed to help address substance use or addiction in your community?
 [facilitator: make sure to clarify which type of substance(s) they are referring to]
- 2.D Is hepatitis C a concern in the Latinx gay or MSM community? Why or why not?
 - Probe [for those who answer yes]: What are your experiences with accessing treatment for hepatitis C?
 - *Probe:* Tell us what you know about hepatitis C treatment? (i.e., how long it takes, potential side effects, how to access it, cost, etc.)
 - *Probe:* Are people in the Latinx gay or MSM community aware that hepatitis C can be cured in 8 to 12 weeks with one pill per day?
 - *Probe:* How could access to treatment for hepatitis C be improved?
- **2.E** What are your experiences using virtual or telehealth services, for any type of health care or prevention services?
 - Probe: What would make you or other Latinx gay men or Latinx MSM be more likely to use this service?
- 3. Now, I'd like to know more about your experiences accessing receiving care or treatment for HIV, sexually transmitted infections, viral hepatitis, or substance use.

- **3.A** What sort of things have <u>helped</u> you access HIV, sexually transmitted infections, viral hepatitis, or substance use care or treatment? (This can be people, programs, or resources that helped you access services)
- **3.B** What sort of things have <u>made it difficult</u> to get the care you need for HIV, sexually transmitted infections, viral hepatitis, or substance use? (This can be people, programs, or resources that act as barriers or are difficult to access services).
- **3.C** What concerns do you or others in Latinx communities living in Tennessee have surrounding <u>documentation</u> <u>or immigration status</u> when accessing healthcare services?
 - *Probe:* [for people who have concerns]: What could help ease these concerns?
- **3.D** What concerns or issues do you or others have related to <u>language as a barrier</u> to accessing services?
 - *Probe:* What resources would help reduce language as a barrier for you or others in your community?
 - Probe: Do you know of providers in your area that are fluent in Spanish?
 - *Probe:* Would having a provider fluent in Spanish make it easier for you or others in your community to access the care you need?
 - *Probe:* If a Spanish speaking provider was not available to you when accessing care, have you been offered translation services?
 - *Probe [for anyone who answers that they were able to access translation services*]: What was your experience with the translation services provided?
 - For example, was the service helpful? Did you have a good or bad experience? Did you feel comfortable using the service? Do you feel like you were accurately represented when you used the service?
 - *Probe:* Is there anything that would make your experience better with translation services?
 - *Additional probes if time:* Have you felt like you've been judged or treated differently when trying to get the care you need? Can you describe more about those experiences?
 - Probe: How has this impacted your ability to receive care?
 - Do you feel this is a concern for other Latinx gay men or Latinx MSM as a barrier to receiving care services?
 - *Additional probes if time:* Has <u>cost or ability to pay</u> ever been a barrier to accessing services for you or others in your community?
 - *Probe:* Have you been able to access programs that help assist in paying for medical care (such as payment assistance programs)?
 - Probe [for people who answer yes]: What was your experience with these programs?
 - *Probe* [for people who answer yes]: How could your experience have been improved when accessing these programs?
- 4. What is the number one thing we can do to address HIV, sexually transmitted infection, substance use, and viral hepatitis among Latinx gay men or Latinx MSM in Tennessee?

• *Probe:* Have you heard about programs or resources in other places that you think, if implemented here, would improve the health of Latinx gay men or Latinx MSM in Tennessee?

End Discussion:

That is all the questions we have for you today. I'd like to thank you so much for your time and participation today. Your input is incredibly valuable. I will now place the link to the gift card survey in the chat. Once you complete the survey you are free to leave the call. Your gift card survey response will be processed within 1 week. If you have difficulty accessing the survey, please let me know.

Also, if you want to learn more about HIV, STIs, viral hepatitis, and substance use disorder & TN's plan to address these health conditions, you can visit endthesyndemictn.org or contact TDH at <u>endthesyndemic.tn@tn.gov</u> [provide webpage and link in the chat].

Guía para el grupo de sondeo Latinx de ETS Español V.2

La Introducción y el Marco de la Discusión

Saludos todos, mi nombre es [*nombre de facilitador*]. Uso [*pronombres*] pronombres, y soy el moderador para la discusión de hoy.

El propósito de la discusión de hoy es para el Departamento de Salud de Tennessee para entender mejor las prioridades de salud, las necesidades, y las barreras relacionadas a la prevención y cuidado del VIH, las infecciones de transmisión sexual, la hepatitis viral, y el uso de sustancias para hombres latinos/latinx/latine que identifican como homosexual, bisexual, o hombres que tienen relaciones sexuales con otros hombres viviendo en Tennessee. Entonces, estamos hablando con ustedes hoy para obtener un mejor conocimiento de sus experiencias para ayudar a informar estrategias y actividades para abordar estas condiciones de salud en Tennessee.

También, antes de empezamos, gustaría notar que usaré el término "Latinx" para describir comunidades hispanas, latinx, latinas, o latines en Tennessee. Reconocemos que no es el término perfecto para todos. Por favor díganme si hay otro término que prefieren, y puedo usarlo por el resto de la discusión.

<u>Procedimiento</u>: Durante la próxima hora y media preguntaré varias preguntas. Por favor nótense que no hay respuestas correctas ni incorrectas a las preguntas que preguntaremos hoy. Queremos oír sus puntos de vista y nos gustaría que todos contribuyeran con sus opiniones. Puede que me meta en la discusión de vez en cuando para asegurar que todos tienen la misma oportunidad de compartir sus opiniones. Sientan libre de ser honestos incluso cuando sus respuestas puede que difieran que otros miembros del grupo.

Grabaremos el audio de esta sesión; no guardaremos el video. La grabación comenzará después de las introducciones, y les diré cuando la grabación ha empezado. Los apuntes serán tomados para ayudar a resumir sus opiniones y sugerencias de la discusión. Sus respuestas están confidenciales, y no serán compartidos ningunos nombres. Si los nombres están mencionados durante esta discusión, serán quitados de la transcripción y los apuntes. Puede escoger si quiere participar, y puede salir a cualquier tiempo durante la discusión.

También, les pregunto que respetan la privacidad de cada persona en este grupo por no revelando cualquiera cosa discutida hoy sin obtener el consentimiento de ese individuo.

Me gustaría pedirles encender sus cámaras para la discusión. Finalmente, recibirán como agradecimiento por participar una tarjeta de regalo de \$35 de VISA después de que hayamos concluido la discusión. Habrá una encuesta corta a completar para recibir su tarjeta de regalo.

¿Alguién tiene algunas preguntas antes de empezamos?

[Verifique que las cámaras y los audios de todos están funcionando antes de empezar]

Introducciones de los participantes:

Ahora, preguntaré cada uno a presentarse con su nombre, pronombres, y como una charla para romper el hielo, sientan libre de compartir con el grupo su comida favorita.

Por ejemplo, mi nombre es ___, y uso ____ como mis pronombres. Mi comida favorita es ____.

Ahora, recorreré la lista de nombres y preguntaré a cada uno a presentarse.

Empezar la Grabación

Ahora que hemos completado las introducciones, empezaremos la grabación. Como un recordatorio, no estamos grabando el video, solo el audio. Sus respuestas serán confidenciales.

Discusión

- 7. ¿Cuáles son sus mayores necesidades relacionadas a su salud?
 - *Recordatorio*: salud puede ser cualquier cosa que define. Así que, puede incluir cosas relacionadas con su salud mental, emocional y física como la vivienda, la nutrición, el apoyo social, y más.
 - [nota al facilitador: está seguro de avanzar a las siguientes preguntas para ayudar a mantenerse en movimiento y en tema la discusión]
- **1.A** Para los que viven en Tennessee, ¿cuáles necesidades tienen usted u otros hombres Latinx homosexuales y bisexuales o hombres Latinx que tienen relaciones sexuales con hombres relacionadas con el VIH, las infecciones de transmisión sexual, el uso de sustancias, y la hepatitis viral?
 - *Sondeo:* ¿Se siente que usted y/u otros en su comunidad tienen acceso para satisfacer estas necesidades?
 - *Sondeo:* Si no, para los que viven en Tennessee, ¿qué necesita ocurrir para aumentar acceso para hombres Latinx homosexuales o bisexuales o hombres Latinx que tienen relaciones sexuales con hombres?

8. Ahora les preguntaré sobre los servicios específico al VIH, las infecciones de transmisión sexual, el uso de sustancias, y la hepatitis viral.

- 2.A Las recomendaciones para todas las personas son hacer un chequeo para el VIH y la hepatitis C por lo menos una vez en su vida. Y para unas personas con vulnerabilidad en curso, las pruebas están recomendadas más a menudo. Parte del rol del departamento de salud es ayudar a aumentar acceso a las pruebas para estas condiciones en diferentes ambientes, como clínicas del departamento de salud, centros de salud, organizaciones basadas en la comunidad, ferias de salud, y más. Hacer chequeos para estas condiciones de salud es el primer paso en ser unido con otros servicios, a pesar del resultado. Entonces, nos gustaría escuchar sus contribuciones en cómo hacer de rutina, mas accesibles, y normales las pruebas para las comunidades hispanas y latinas en Tennessee. ¿Hagan memoria del momento más reciente que se hicieron un chequeo para el VIH, las infecciones de transmisión sexual, y la hepatitis viral (como hepatitis B o C), cómo fue su experiencia?
 - *Sondeo:* ¿Fue una buena/mala experiencia? ¿Porque?
 - Sondeo: ¿Con qué frecuencia hicieron un chequeo para el VIH y las infecciones de transmisión sexual?
 - Sondeo: ¿Dónde típicamente hicieron un chequeo?
 - Sondeo: ¿Qué haría que una experiencia de prueba sea más cómoda para ustedes?

- *Sondeo:* ¿Cuáles son algunas razones que los hombres latinx homosexuales o los hombres latinx que tienen relaciones sexuales con otros hombres dudan a hacer un chequeo?
 - Sondeo: ¿Difieren estas razones basado en el tipo de prueba (i.e. hay diferentes razones que personas dudan a hacer un chequeo para el VIH frente para las infecciones de transmisión sexual frente para la hepatitis C)?
- *Sondeo:* Para personas en las comunidades Latinx que hacen chequeos, ¿qué les motivan a o influyen en hacerlo?
- *Sondeo:* ¿Estarían interesado en recibir en su buzón un equipo para autocomprobarse para el VIH e infecciones de transmisión sexual?
- 2.B ¿Qué han oido de la PrEP para la prevención de VIH?
 - [Nota al facilitador: Quizás que necesita explicar lo que PrEP es especialmente si no hay respuesta o hay respuesta mínima. Puede que todos no saben lo que PrEP es. Espera un momento por respuestas y luego explica...]
 - "PrEP es un medicamento que se puede tomar para prevenir el VIH. Es más de noventa y nueve por ciento eficaz en prevenir el VIH del acto sexual y setenta y cuatro por ciento eficaz en prevenir el VIH entre personas que inyectan drogas."
 - Sondeo: ¿Cuáles son algunas razones que los hombres Latinx homosexuales quizás no buscan la PrEP?
 - *Sondeo:* Para los que viven en Tennessee, ¿cuáles son algunas maneras de aumentar el conocimiento de PrEP entre hombres Latinx homosexuales o hombres Latinx que tienen relaciones sexuales con otros hombres?
 - *Sondeo:* Para los que viven en Tennessee, ¿cuáles son algunos desafíos para acceder a la PrEP para usted y/u otros hombres Latinx homosexuales o hombres Latinx que tienen relaciones sexuales con otros hombres?
 - *Sondeo*: ¿Cuáles son maneras de aumentar el uso de PrEP entre hombres Latinx homosexuales o hombres Latinx que tienen relaciones sexuales con otros hombres?
- 2.C ¿Cómo afecta las comunidades Latinx el uso de sustancias o las adicciones?
 - Sondeo: ¿En su opinión, siente que el uso de sustancia o la adicción es un problema en su comunidad? *[si sí]:* ¿Puede explicar más?
 - Sondeo: ¿Han visto u oído el uso de sustancia o la adicción afectando individuos o familias Latinx?
 [si sí]: ¿Puede dígame más sobre cómo el uso de sustancia o la adición ha impactado su comunidad?
 - *Sondeo:* ¿Cuáles recursos se necesitan para ayudar a atender el uso de sustancia o la adicción en su comunidad?
 - [facilitador: asegúrese de clarificar qué tipos de sustancia se están haciendo referencia a]
- **2.D** ¿Es una preocupación la hepatitis C en la comunidad de hombres Latinx homosexuales o hombres Latinx que tienen relaciones sexuales con hombres? ¿Por qué si o no?
 - Sondeo [para la persona que responda sí]: ¿Cuáles son sus experiencias con acceder al tratamiento para hepatitis C?

- *Sondeo:* Díganos lo que sabe sobre el tratamiento para la hepatitis C (cuánto tiempo dura, efectos secundarios potenciales, cómo accederlo, el costo, etc.)
 - Probe: ¿Están conscientes personas en la comunidad de hombres Latinx homosexuales o hombres Latinx que tienen relaciones sexuales con hombres que hepatitis C puede ser curada en ocho a doce semanas con una píldora por día?
- Sondeo: ¿Cómo puede mejorar el acceso al tratamiento para la hepatitis C?
- 2.E ¿Cuáles son sus experiencias usando servicios virtuales o de telesalud, para cualquier tipo de asistencia médica o servicios de prevención?
 - *Sondeo:* ¿Qué les harían más propensos a usar este servicio usted u otros hombres Latinx homosexuales o hombres Latinx que tienen relaciones sexuales con otros hombres?

3. Ahora, gustaría saber más sobre sus experiencias accediendo cuidado o tratamiento para el VIH, las infecciones de transmisión sexual, la hepatitis viral, o el uso de sustancias.

- **3.A** ¿Qué tipos de cosas les han <u>ayudado</u> a acceder cuidado o tratamiento para el VIH, las infecciones de transmisión sexual, la hepatitis viral, o el uso de sustancia? (Esto puede ser personas, programas, o recursos que les han ayudado a acceder servicios)
- **3.B** ¿Qué tipos de cosas les han complicado a obtener el cuidado que necesitan para el VIH, las infecciones de transmisión sexual, la hepatitis viral o el uso de sustancias? (Esto puede ser personas, programas, o recursos que sirven de barreras o están difíciles a acceder servicios)
- **3.C** ¿Cuáles preocupaciones tienen usted u otros en comunidades Latinx viviendo en Tennessee circundante documentación o estado de inmigración cuando acceden servicios de asistencia médica?
 - Sondeo: [para personas que tienen preocupaciones]: ¿Qué puede ayudar a aliviar estas preocupaciones?
- **3.D** ¿Cuáles preocupaciones o problemas tienen usted u otros relacionado con el idioma como una barrera a acceder servicios?
 - Sondeo: ¿Qué recursos ayudaría bajar el idioma como una barrera para usted u otros en su comunidad?
 - o Sondeo: ¿Sepan de proveedores en su área que habla con fluidez el español?
 - *Sondeo:* ¿Tener un proveedor que habla con fluidez el español simplificaría acceder el cuidado que necesitan usted u otros en su comunidad?
 - *Sondeo:* ¿Si un proveedor que habla español no estaba disponible a usted cuando acede servicios, ha sido ofrecido servicios de traducción?
 - Sondeo [para todos que respondan que estaban capaz de acceder servicios de traducción]: ¿Cuál fue su experiencia con los servicios de traducción que proveyeron?
 - ¿Por ejemplo el servicio fue bueno? ¿Tuvo una experiencia buena o mal? ¿Se sentía cómodo usando el servicio? ¿Se sentía como le representaron exactamente cuándo usó el servicio?
 - Probe: ¿Hay cualquier cosa que mejoraría su experiencia con servicios de traducción?

- *Sondeos adicionales si tiene tiempo:* ¿Ha sentido que alguien <u>le juzgó o le trató diferente</u> cuando intentaba obtener el cuidado que necesitaba? ¿Puede describir más sobre esas experiencias?
 - o Sondeo: ¿Cómo esto ha afectado su capacidad de recibir cuidado?
 - ¿Siente que esto es una preocupación por otros hombres Latinx homosexuales o hombres Latinx que tienen relaciones sexuales con hombres como una barrera a recibir servicios de cuidado?
- Sondeos adicionales si tiene tiempo: ¿Alguna vez, han sido una barrera <u>el costo o la habilidad de pagar</u> por acceder servicios para usted u otros en su comunidad?
 - *Sondeo*: ¿Han sido capaz de acceder programas que les ayudan a pagar por cuidado médico (como programas de asistencia de pago)?
 - Sondeo [para personas que respondan sí]: ¿Cuáles fueron sus experiencias con estos programas?
 - Sondeo [para personas que responden sí]: ¿Cómo se podían haber mejorado su experiencia cuando accedieron estos programas?
- 5. Para los que viven en Tennessee, ¿cuál es la cosa más importante que podemos hacer para abordar el VIH, las infecciones de transmisión sexual, el uso de sustancia, y la hepatitis viral entre hombres Latinx homosexuales o hombres Latinx que tienen relaciones sexuales con hombres?
 - *Sondeo*: ¿Han oído de programas o recursos en otros lugares que piensan que, si estaban implementado aquí en Tennessee, mejorarían la salud de los hombres Latinx homosexuales o los hombres Latinx que tienen relaciones sexuales con hombres?

Terminar la Discusión:

Esas son todas las preguntas que tenemos para ustedes hoy. Gustaría agradecerlos muchísimo por su tiempo y participación. Sus contribuciones son increíblemente valiosas. Ahora, pondré el enlace a la encuesta para la tarjeta de regalo en el chateo. Cuando completen la encuesta, puedan salir la llamada. Sus respuestas de la encuesta para la tarjeta de regalo serán procesadas dentro de una semana. Si tienen dificultades para acceder a la encuesta, por favor díganme.

También, si quieran aprender más sobre la VIH, las infecciones de transmisión sexual, la hepatitis viral, el uso de sustancias, y el plan de Tennessee para abordar estas condiciones de salud, pueden visitar endthesyndemic.org o contactar el Departamento de Salud de Tennessee a <u>endthesyndemic.tn@tn.gov</u> [provea la página web y el enlace en el chateo].

ETS Interview Guide- Knoxville

Unhoused PLWH

Introduction

Hello! My name is [interviewer's name], I use [interviewer's pronouns] pronouns. I work for [state position/affiliation].

The Tennessee Department of Health would like to better understand your experiences with living with HIV as part of our larger statewide needs assessment. The information that we learn today will be used to inform activities to address HIV over the next several years in Tennessee.

Over the next hour I will ask you several questions. There are no right or wrong answers. Your experiences and opinions mean a lot to us, and I want you to feel comfortable sharing.

I will be recording our discussion today. The recording will begin after introductions, and I will let you know when I start the recording. The purpose for recoding is so I can make sure that I have accurately captured what was said today. Your responses are confidential meaning we will not share any identifiable information such as not sharing any names. If names are mentioned during this discussion, they will be removed from our notes. You can choose whether or not to answer a question, and you may stop the discussion at any time.

Lastly, I do have a \$30 VISA gift card for your time today that I will give you at the end of our discussion.

Do you have any questions before we begin? [TDH staff answer any questions]

Participant Introductions:

Thank you for agreeing to chat with me today. Now, I am going to ask some questions to get to know you a little better. I have not started the recording and I will be sure to let you know when the recording has started.

[Read Demographic questions if participant did not fill out the form].

Start Recording

Now that we have finished introductions, I am going to start the recording and start with our first question.

Interview Questions:

1. What needs do you have related to health?

• *Reminder:* Health can be whatever you define it to be. So, this could include things related to your mental, emotional, and physical health such as housing, nutrition, social support and more.

Now I am going to ask you questions related to HIV.

2. Can you describe the testing experience you had when you received a HIV diagnosis?

• Probe: Why did you decide to get tested that day?

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• *Probe:* When you found out about your HIV test results, did you feel like you received the information and support you needed? What information or support would have helped in that moment?

3. Can you tell me about your understanding of how HIV is spread?

- *Probe:* Was this the same or different knowledge you had before your HIV diagnosis?
- Probe: Do you feel able to talk to others in your community about how HIV is spread?

4. What have you heard about PrEP for HIV prevention?

[May need to explain what PrEP is -especially if there is no to minimal response. Not everyone may know what PrEP is. Wait a moment for response and then explain...

- "PrEP is a medication that can be taken to prevent HIV. It's more than 99% effective in preventing HIV from sex and 74% effective in preventing HIV among persons who inject drugs."]
- *Probe: [if HIV PrEP is known, ask]:* How did you hear or learn about PrEP for HIV prevention?
- Probe: What are ways to increase PrEP awareness in your community/among your peers?
 - *Probe [if identified as a PWUDs, ask]:* Do you think people know that PrEP also works for people who use drugs?
 - *Probe [if identified as a PWUDs, ask]:* What kind of messaging would help people who use drugs learn about the protection PrEP can provide?
- 5. How have you been treated by your peers or others in your community since you received a HIV diagnosis?
 - *Probe:* Do you feel you are treated differently by your peers/community? Please tell me more about that.
 - *Probe:* What are your experiences talking about your HIV diagnosis with your peers or others in your community?

6. What has your healthcare experience been like since you received a HIV diagnosis?

- *Probe:* Do you feel like you are treated differently since receiving a HIV diagnosis?
 - *[if yes]:* Please tell me more about these experiences, how have you been treated differently by healthcare staff?

Now I am going to ask you about your experiences with care and treatment services for HIV.

- 7. What sort of things have made it difficult to get the care you need for HIV? (This can be people, programs, or resources that act as barriers or are difficult to access services).
 - *Probe:* How do you think being unhoused has impacted your HIV care?

- *Probe:* How has being unhoused (homeless) impacted your ability to attend your HIV medical appointments?
 - Probe (as needed):
 - Do you have a provider you see for HIV medical care?
 - Are you able to make your HIV medical appointments?
 - How often do you miss your HIV medical appointment?
 - *Probe:* What sort of things would help you to access HIV medical care appointments?
 - [if needed, some examples: appointment times, transportation, etc...]
- *Probe:* Can you tell me about your experience with getting and/or taking your HIV medication?
 - *Probe (as needed):* What challenges, if any, do you experience trying to fill/get your HIV medication?
 - *Probe (as needed):* What challenges, if any, do you experience taking your HIV medication every day?
- *Probe:* Can you tell me about your experience with storing your HIV medication?
 - *Probe:* Do you experience challenges with storing/keeping your HIV medication?
 - [*if a barrier, ask*]: Can you tell me more about these challenges?
 - *Probe [if experiencing storage barriers]:* What sort of things would help you to better store your HIV medication?
- 8. What sort of things have helped you access care you need for HIV? (This can be people, programs, or resources that helped you get services).
- 9. Do you know what U=U (undetectable equals untransmittable) means?
 - *Probe:* Where did you learn about U=U?
 - *Probe:* What is your experience talking with others about U=U?
 - *Probe:* Do you feel comfortable talking with others about it?
 - *Probe: [if not comfortable, ask]:* What would make you feel more comfortable talking about it?

Now I am going to ask questions about different types of healthcare services and your experiences using varying services.

10. What are (main/top) factors that would motivate you and/or your peers to access health services?

11. What are your experiences with using mobile health services?

- *Probe:* What are your thoughts about using mobile health services (such as a health clinic out of a van)?
- *Probe:* How would your peers or your community feel about mobile health services being offered in the area?
 - *Probe:* Would mobile health services and staff be welcomed by the community? Why or why not?
- *Probe:* What services would you like to see offered at a mobile health clinic?

- *Probe:* What sort of things would make it easier to access mobile health services?
 - *Examples:* timing of services (days of the week or timing of the day), location, awareness of services, appointments (longer window for running late) vs. walk-ins, etc...
- *Probe:* What are your thoughts about seeing a doctor virtually (so, through a video call) on a mobile health van?
- 12. What are your experiences with accessing housing services such as shelters, temporary housing, ongoing assistance?
 - **a.** *Probe:* What sort of things have made it difficult to access housing resources?
 - b. Probe: What sort of things have been helpful or easier to access housing resources?

[If they identified as a PWUDs, ask following substance use questions. Otherwise skip to Q#-15Law Enforcement] Now we are going to ask about experiences with services specific to substance use.

- 13. What are your experiences with accessing syringe services or needle exchange in Tennessee?
 - *Probe:* Do you feel that you get the amount of supplies such as needles, cookers, and cotton that you need to not share or reuse supplies until the next time you can make it to the SSP?
 - *Probe:* How do you get to the needle exchange program? And how long does it take you to get there?
 - *Probe:* How did you first hear about the needle exchange program?
 - *Probe:* What sort of things have <u>helped</u> you to access or use the need exchange program? (This can be people, programs, or resources that helped you access services).
- 14. What are your or other people who use drugs experiences with substance use treatment or care services? Some examples of services include but are not limited to in-patient or residential services, medication assisted therapy (such as buprenorphine, Suboxone or methadone), or counseling services (such as one-on-one, peer-to-peer, or group sessions).
 - a. *Probe:* What has prevented you or other people who use drugs from being able to access substance use treatment and care services?
 - b. *Probe:* What sorts of things have helped you or others you know access other substance use treatment and care services?

[if not PWUDs then start with Q15- Law enforcement]:

15. What has your experience with local law enforcement been like?

- a. Probe: How has this impacted your health?
- 16. Last question, what is one thing that you wished those in the Knoxville community understood about you or other folks who are unhoused?

End Interview:

[STOP RECORDING]

That is all the questions we have for you today. I'd like to thank you for your time and willingness to chat with me today. Your input is incredibly valuable. Now, I will give you the \$30 Visa gift card for your time. [Be sure to mark gift card information and then give participant the incentive].

ETS Interview Guide- Knoxville

Unhoused- People not living with HIV

Introduction

Hello! My name is [interviewer's name], I use [interviewer's pronouns] pronouns. I work for [state position/affiliation].

The Tennessee Department of Health would like to better understand your health priorities, needs and barriers. The information that we learn today will be used to inform activities to address prevention and care services for HIV, sexually transmitted infection, viral hepatitis, and substance use disorder over the next several years in Tennessee.

Over the next hour I will ask you several questions. There are no right or wrong answers. Your experiences and opinions mean a lot to us. I will be recording our discussion today. The recording will begin after introductions, and I will let you know when I start the recording. The purpose for recoding is so I can make sure that I have accurately captured what was said today. Your responses are confidential meaning your individual responses will not contain any identifiable information such as no names will be shared. If names are mentioned during this discussion, they will be removed from our notes. You can choose whether or not to answer a question, and you may stop the discussion at any time.

Lastly, I do have a \$30 VISA gift card for your time today that I will give you at the end of our discussion.

Do you have any questions before we begin? [TDH staff answer any questions]

Participant Introductions:

Thank you for chatting with me today. Now, I am going to ask some questions to get to know you a little better. I have not started the recording and I will be sure to let you know when the recording has started.

[Read Demographic questions if participant did not fill out the form].

Start Recording

Now that we have finished introductions, I am going to start the recording and start with our first question.

Interview Questions:

1. What needs do you have related to health?

- *Reminder:* Health can be whatever you define it to be. So, this could include things related to your mental, emotional, and physical health such as housing, nutrition, social support and more.
- 2. The recommendation for all persons is to get tested for HIV and hepatitis C virus at least once in their life. And for some people with ongoing vulnerability, testing is recommended more often. Part of the role at the health department is to help increase access to testing for these conditions in different settings like health department clinics, health centers, community-based organizations, health fairs, and more. Getting tested for these health conditions is the first step to be linked to other services, regardless of the result. So, we would love your input

on how to make testing more routine, comfortable, and normal for people who use drugs in Tennessee. Thinking back to a time when you most recently tested for HIV, sexually transmitted infections, or viral hepatitis (like hepatitis B or C), what was that experience like for you?

- Probe: How often do you get tested for HIV, Hepatitis C, and/or STIs?
- *Probe*: What are reasons that prevent you or other people who use drugs from getting tested for HIV, Hepatitis C and/or sexually transmitted infections?
 - *Probe*: Do these reasons differ based on type of test (for example, are there different reasons that people hesitate to get tested for HIV vs. sexually transmitted infections vs. hepatitis C?)
- *Probe: [if indicated substance use]:* How can we make testing easier or more desirable to people who use drugs?
 - *Probe:* What would help motivate people who use drugs to access testing services?
 - *Probe:* Where could we put testing services that would make it easier for people who use drugs to access?

3. What have you heard about PrEP for HIV prevention?

[May need to explain what PrEP is -especially if there is no to minimal response. Not everyone may know what PrEP is. Wait a moment for response and then explain...

- "PrEP is a medication that can be taken to prevent HIV. It's more than 99% effective in preventing HIV from sex and 74% effective in preventing HIV among persons who inject drugs."]
- *Probe: [if HIV PrEP is known, ask]:* What are your experiences with accessing or using PrEP?
 - *Probe*: Do you have a hard time taking your medication every day? If so, why?
 - *Probe*: What would help you take your medication daily?
 - *Probe:* Do you experience challenges with storing/keeping your PrEP medication?
 - *[if a barrier, ask*]: Can you tell me more about these challenges?
 - *Probe [if experiencing storage barriers]:* What sort of things would help you to (better) store or access your PrEP medication?
- *Probe:* What are some reasons that you or others in your community/your peers may not seek out PrEP?
- Probe: What are ways to increase PrEP awareness in your community/among your peers?
 - *Probe [if indicated substance use]:* Do you think people know that PrEP also works for people who use drugs?
- Probe: What are ways to increase PrEP use among in your community/among your peers?
- *Probe:* There is now an injectable option for HIV PrEP medication which is longer acting and does not need to be given every day. What are your thoughts about using the injectable option for PrEP?

4. What have you heard about PEP for HIV prevention?

[May need to explain what PEP is -especially if there is no to minimal response. Not everyone may know what PEP is. Wait a moment for response and then explain...

- *"PEP, or or <u>post</u>-exposure prophylaxis, means taking medicine to prevent HIV <u>after</u> a possible exposure. PEP can reduce the chance of getting HIV after a possible exposure"]*
- *Probe: [if HIV PEP is known, ask]:* What are your experiences with accessing or using PEP?
- Probe: What are some reasons that you or others in your community/your peers may not seek out PEP?
- Probe: What are ways to increase PEP awareness in your community/among your peers?
- Probe: What are ways to increase PEP use among in your community/among your peers?

Now I am going to ask questions about different types of healthcare services and your experiences using varying services.

5. What are (main/top) factors that would motivate you and/or your peers to access health services?

6. What are your experiences with using mobile health services?

- *Probe:* What are your thoughts about using mobile health services (such as a health clinic out of a van)?
- *Probe:* How would your peers or your community feel about mobile health services being offered in the area?
 - *Probe:* Would mobile health services and staff be welcomed by the community? Why or why not?
- Probe: What services would you like to see offered at a mobile health clinic?
- *Probe:* What sort of things would make it easier to access mobile health services?
 - *Examples:* timing of services (days of the week or timing of the day), location, awareness of services, appointments (longer window for running late) vs. walk-ins, etc...
- *Probe:* What are your thoughts about seeing a doctor virtually (so, through a video call) on a mobile health van?
- 7. What are your experiences with accessing housing services such as shelters, temporary housing, ongoing assistance?
 - a. Probe: What sort of things have made it difficult to access housing resources?
 - b. Probe: What sort of things have been helpful or easier to access housing resources?

[If they identified as a PWUDs, ask following substance use questions. Otherwise skip to Q#10-Law Enforcement] **Now we are going to ask about experiences with services specific to substance use.**

- 8. What are your experiences with accessing syringe services in Tennessee?
 - *Probe:* Do you feel that you get the amount of supplies such as needles, cookers, and cotton that you need to not share or reuse supplies until the next time you can make it to the SSP?

- Probe: how do you get to the needle exchange program? And how long does it take you to get there?
- *Probe:* how did you first hear about the needle exchange program?
- *Probe:* What sort of things have <u>helped</u> you to access or use SSP (syringe service program) services? (This can be people, programs, or resources that helped you access services).
- 9. What are your or other people who use drugs experiences with substance use treatment or care services? Some examples of services include but are not limited to in-patient or residential services, medication assisted therapy (such as buprenorphine, Suboxone, or methadone), or counseling services (such as one-on-one, peer-to-peer, or group sessions).
 - *Probe:* What has prevented you or other people who use drugs from being able to access substance use treatment and care services?
 - *Probe:* What sorts of things have helped you or others you know access other substance use treatment and care services?

[if not PWUDs then start with Q10- Law enforcement]:

10. What has your experience with local law enforcement been like?

- Probe: How has this impacted your health?
- 11. Last question, what is one thing that you wished those in the Knoxville community understood about you or other folks who are unhoused?

End Interview:

[STOP RECORDING]

That is all the questions we have for you today. I'd like to thank you for your time and willingness to chat with me today. Your input is incredibly valuable. Now, I will give you the \$30 Visa gift card for your time. *[Be sure to mark gift card information and then give participant the incentive].*

APPENDIX IV

Appendix IV includes TDH Ryan White Part B Program Qualitative FGD Guides

Greetings everyone. My name is XXX, I use YYY pronouns.

- Why are we here today? I am here because I have been contracted by the Ryan White Part B program to collect your insights about living with HIV in Tennessee. This assessment is essential to developing policies and strategies to better meet the needs, and improve the health outcomes of people living with HIV in Tennessee. We have about 90 minutes together to answer 9 questions.
- **Confidentiality**: The responses from today's discussion are being recorded, and will be used as part of the statewide assessment of need. All of your responses today will be confidential. While I am recording this session for purposes of transcribing it later, your individual responses will not contain any identifiable information. The responses that end up in my final report will say something like, "A person in Jackson TN shared the following experience about getting linked to HIV services..."
- **Housekeeping:** A couple other housekeeping notes before we begin; I am an independent consultant contracted by United Way for the sole purpose of collecting information about people's lived experience with HIV in Tennessee. I do not work for United Way or the Tennessee Department of Health, and I do not work for the Ryan White Part B program. I cannot answer any questions you may have about Ryan White services, or your individual healthcare.
- **Incentives:** Finally, I do have \$40 gas cards that I will be distributing after our discussion, which should last approximately one hour. Are there any questions about anything I just said before we begin?

QUESTION	PROBES	NOTES
When you think about your experience of living with HIV in your community, is there anything about your community that makes living with HIV more complicated (such as people's thoughts or attitudes about HIV, access to other social networks with people that understand and accept you, etc.)?		
What services do you think that you need to be healthy, but are unavailable or difficult to access in your community?		
What HIV services are you receiving, or have received in the past few years, that you like (for example food, transportation, case management, oral health, housing, etc.)?	What is it about those services that you like?	
What HIV services are you receiving, or have received in the past in the past few years, that you have not been satisfied with?	What is it about those services that you did not like?	
	(Oral Health): Is there anything specific about oral health that you think has changed in the last few years that has made it better or worse? Even if you had oral healthcare through Ryan White, how likely would you go to the dentist for a routine check-up?	

If you are a Ryan White client, do you think the process to enroll and/or recertify into Ryan White is easy or difficult?	What about the process, if anything, delays your ability to recertify?	
	Is there anything that you would change to make the process easier to enroll or recertify in Ryan White?	
With regards to ART medication, are you aware of new long-term injectable ART medication (which is shot you can take once every month instead of ART medication pills)? Would you be interested in a monthly shot instead of your current ART medication regiment? Why or Why not?		
What are your opinions of telehealth services for HIV care?	Have they changed in the last few years? If so, how?	
	If you could access telehealth services, would you prefer telehealth or in-person medical visits? Why?	
How has your mental health affected your ability to live a healthy life?	What effect, if any, do you think COVID-19 has had on your mental health?	
Aside from medical care from your doctor, what are one or two services that you really need to live a healthy life?		

APPENDIX V

Appendix V includes the dates and settings for the five focus groups detailed in the TDH Ryan White Part B Program Qualitative Report.

Five focus groups were conducted across the state. An effort was made to ensure that participants represented both urban areas (Knoxville, Nashville, Jackson, and Chattanooga) in each of the areas, as well as other less urban areas in the three larger regions.

Region	City	Interview Site	Date	
East	Johnson City	East Tennessee State University Center of Excellence 615 North State of Franklin Road, Johnson City, TN 37604	29 August, 2022	
East	Knoxville	United Way of Greater Knoxville 1301 Hannah Avenue, Knoxville, TN 37921	30 August, 2022	
Southeast	Chattanooga	Council for Alcohol & Drug Abuse Services (CADAS) 207 Spears Avenue, Chattanooga, TN 37405	31 August, 2022	
West	Covington *	Children and Family Services (CFS) 412 Alston Street, Covington TN 38019	28 September, 2022	
West	Jackson	Tennessee Homeless Solutions (THS) 100 Federal Drive, Jackson, TN 38305	2 September, 2022	
*No informants signed up to participate in this focus group, which was scheduled for Thursday, 1 September 2022. The consultant conducted a phone interview on Wednesday, 28 September 2022 in lieu of a discussion.				