

End The Syndemic Tennessee 2022 Needs Assessment

Consumer Report: People Who Use Drugs September 2023

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<u>Authors:</u>

The ETS 2022 Needs Assessment Consumer Report was created by Rebecca Amantia, PhD, MPH (Director of Harm Reduction Initiatives), Abigail Anderson, MPH (former Syndemic Epidemiology Intern), and Anastasia Cajigal, MPH, CPH (Syndemic Special Projects Coordinator).

Contributors:

Syndemic Coordination Director:	Amber Coyne, MPH	
Viral Hepatitis Program Director:	Lindsey Sizemore, MPH, CPH	
Ryan White Part A Director, Metro Public Health Department:	Beverly Glaze-Johnson MSP, LBSW, BSW	
Ryan White Part B Quality Management Director:	Garett Switzer, MPA	
HIV Program Director:	Robertson Nash, PhD, ACNP-BC	
HIV Prevention Program Director:	Kimberly Truss, MPH	
Ryan White Part B Program Director:	Phadre Johnson, MAOL, BSB	
Sexually Transmitted Infections Program Director:	Steffany Cavallo, MPH	
Former HIV Program Director:	Meredith Brantley, PhD, MPH	
Former HIV/STI/Viral Hepatitis Medical Director:	Pamela Talley, MD, MPH	
Former End The Syndemic Intern:	Grace Schepens	
Former End The Syndemic Intern:	Sarah Matthews	

For any questions regarding this report, please contact: Endthesyndemic.TN@tn.gov

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Glossary of Abbreviations

ART	Antiretroviral therapy	ΗΙν	Human Immunodeficiency Virus
BIPOC	Black, Indigenous, and People Of Color	HOPWA	Housing Opportunities for Persons with AIDS
CHASCo	Coalition For Healthy & Safe Campus Community. This coalition addresses alcohol, drug, and violence prevention issues on	IRB	Institutional Review Board
		KII	Key Informant Interviews
	Tennessee's campuses by providing high-	LGBQ+	Lesbian, Gay, Bi, Queer
	quality consultation and training, technical assistance, research support, and policy	LGBTQ+	Lesbian, Gay, Bi, Trans, Queer
	development to member institutions.	LTS	Long-Term Survivors
Cis /	term used to describe a person whose	MAT	Medication-Assisted Treatment
Cisgender	gender identity corresponds to their sex assigned at birth	MDHA	Metropolitan Development and Housing Agency
COVID / COVID-19	Coronavirus Disease 2019	MOUD	Medications for Opioid Use Disorder
DOH	Department of Health	MPHD	Metro Public Health Department
EBT		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
EIS	Early Intervention Specialist	PEH	Persons/people experiencing homelessness
ESL	English as a Second Language	PEP	Post-exposure prophylaxis
ETS	End The Syndemic	PLWH	People living with HIV
FGD	Focus Group Discussion	PrEP	Pre-exposure prophylaxis
GNC	Gender nonconforming	PTSD	Post-Traumatic Stress Disorder
HAV	Hepatitis A Virus	PWUD	People who use drugs
HBV	Hepatitis B Virus	SDOH	Social Determinants of Health
HCV	Hepatitis C Virus	SNAP	Supplemental Nutrition Assistance Program
HIPAA	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.	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.

The *People Who Use Drugs Subreport* includes quantitative and qualitative findings from this priority population. To access the full Consumer Report, visit <u>EndTheSyndemicTN.org</u>.



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 (<u>https://hivmemphis.org/about-hcap/resources</u>). Limitations should be kept in mind when reviewing the data presented throughout the Needs Assessment Report.

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)





Racial Identity 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).



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.



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

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

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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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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.

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 select 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.





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

APPENDIX II

Appendix II includes a ETS Qualitative Facilitation Guide for the People Who Use Drugs priority population.

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.

ETS TN 2022 Needs Assessment Consumer Report

<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 when accessing or using harm reduction services?</u>
 - *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).