



What Matters to YOU?

Needs Assessment for People Living with HIV in Indiana

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Indiana State
Department of Health



TABLE OF CONTENTS

ACKNOWLEDGEMENTS.....	i
EXECUTIVE SUMMARY.....	ii
BACKGROUND AND INTRODUCTION.....	1
HIV in Indiana.....	1
Resources for the Health and Well-being of PLWH.....	2
Purpose of this Study.....	2
METHODS.....	4
Study Design.....	4
Data Entry and Cleaning.....	9
Data Analysis.....	9
Limitations.....	10
RESULTS AND DISCUSSION.....	11
Sample Characteristics.....	11
Housing Status.....	18
Education and Employment.....	21
Health Challenges.....	23
Substance Use.....	26
HIV Medical Care and Adherence.....	29
Perceived Discrimination and Disclosure.....	34
Aging while Living with HIV.....	38
Positive Prevention.....	41
Service Needs, Access, and Barriers.....	48
CONCLUSIONS AND RECOMMENDATIONS.....	63
Enhancing Access to and Quality of HIV Services.....	63
Future Assessment.....	64
Appendix A: Abbreviations	
Appendix B: Glossary	
Appendix C: Data on Discussing Sensitive Topics	
Appendix D: Data on HIV Testing and Diagnosis	
Appendix E: Level of Need and Level of Access by Service Tables	
Appendix F: Data Supplement	

Tables and Figures

List of Tables

Table 1:	Classification of non-medical case management cases	8
Table 2:	Study participation	11
Table 3:	Respondents by current living situation	19
Table 4:	Respondents who have experienced unstable housing situations in the past six months	19
Table 5:	Respondents who have experienced problems getting housing in the past six months	20
Table 6:	Respondents who have experienced problems maintaining housing in the past six months	20
Table 7:	Respondents by highest level of education completed	21
Table 8:	Reasons respondents are not currently working	22
Table 9	Share of all respondents who are employed who have experienced each challenge while working as PLWH	23
Table 10:	How respondents rate their overall health	24
Table 11:	Health conditions and challenges reported by respondents	25
Table 12:	Respondents' substance use behaviors	27
Table 13:	Respondents' substance use experiences in the past three months	28
Table 14:	Respondents' use of drug and alcohol services	28
Table 15:	Needle or syringe use among respondents	29
Table 16:	Last time survey respondents saw an HIV medical provider	31
Table 17:	Where respondents usually go for HIV medical care	31
Table 18:	Reported results of respondents' most recent HIV blood tests	32
Table 19:	Reason for missing HIV medication dose in the past two weeks	33
Table 20:	Reasons respondents feel they have been treated poorly by medical providers	34
Table 21:	People (other than HIV medical providers) who know respondents are living with HIV	37
Table 22:	Respondents' concerns about telling someone their HIV status	37
Table 23:	Respondents' concerns as they age	38
Table 24:	Respondents' concerns about ongoing HIV care as they age	39
Table 25:	Respondents' concerns about their overall health as they age	39
Table 26:	Respondents' concerns about relationships and social networks as they age	40
Table 27:	Respondents' concerns about end of life care	40
Table 28:	Respondents concerns about other factors as they age	41
Table 29:	Share of respondents who correctly answered HIV-related questions	47
Table 30:	Distribution of number of services needed	48
Table 31:	Top three services identified, by level of need	49
Table 32:	Most commonly reported services by level of need (essential and not needed) for all respondents	50
Table 33:	Most commonly reported services by level of need (essential and not needed) for respondents in TGA	52
Table 34:	Most commonly reported services by level of access (met needs and unmet needs) for all respondents	54
Table 35:	Most commonly reported services by level of access (met needs and unmet needs) for respondents in TGA	55
Table 36:	Top three services reported as met needs and unmet needs	56
Table 37:	Summary of significant variations in level of access among all respondents by population	57
Table 38:	Summary of significant variations in level of access among respondents in TGA by population	57

Table 39:	Summary of significant variations in unmet service needs among all respondents by population	58
Table 40:	Share of respondents who reported barriers in accessing each service	60
Table 41:	Share of participants who reported each barrier	61
Table 42:	Respondents' prioritization of funding for services	62

List of Figures

Figure 1:	Map of Indianapolis TGA counties	3
Figure 2:	Survey administration approach	7
Figure 3:	Survey respondents and PLWH in IN by gender	12
Figure 4:	Survey respondents by sexual attraction	12
Figure 5:	Survey respondents attracted to men by gender	12
Figure 6:	Survey respondents and PLWH in IN by race/ethnicity	13
Figure 7:	Survey respondents and PLWH in IN by age	13
Figure 8:	Geographic distribution of survey respondents and PLWH in IN by HIV Care Coordination Region	14
Figure 9:	Survey respondents and PLWH in IN by primary language	15
Figure 10:	Survey respondents living in poverty	15
Figure 11:	Survey respondents by household size	16
Figure 12:	Survey respondents by health insurance coverage	16
Figure 13:	Survey respondents by years living with HIV	17
Figure 14:	Survey respondents and PLWH in IN whose HIV viral load is suppressed by race and sex	17
Figure 15:	Respondents who have experienced challenges related to housing	18
Figure 16:	When respondents received mental health treatment or counseling	26
Figure 17:	Respondents who have talked with someone about substance use in the past six months	27
Figure 18:	How often respondents have missed a dose of HIV medication in the past two weeks	32
Figure 19:	Respondents who have discussed HIV medication adherence with someone in the past three months	33
Figure 20:	Respondents who agree with statements on perceived discrimination	36
Figure 21:	Number of unmet needs for services among respondents reporting higher levels of HIV-related stigma	36
Figure 22:	Respondent agreement with statements about discussing sexual health and substance use with their primary HIV medical provider	43
Figure 23:	Respondent agreement with statements about discussing sexual health and substance use with their HIV case manager	44
Figure 24:	Respondents who have discussed their sexual health with someone in the past six months	45
Figure 25:	Need for and use of help in positive prevention activities among all respondents	45
Figure 26:	Need for and use of help in positive prevention activities among respondents in TGA	46
Figure 27:	Respondents who feel each prevention strategy is effective	46
Figure 28:	Service priority, need, access, and use among all respondents	51
Figure 29:	Service priority, need, access, and use among respondents in TGA	53
Figure 30:	Geographic regions used for analysis	59
Figure 31:	Average number of unmet service needs by region	59

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Prepared by:



10 South New Jersey Street, Suite 300
Indianapolis, Indiana 46204
www.communitysolutionsinc.net

EXECUTIVE SUMMARY

In 2018, Indiana was home to just over 12,700 people living with HIV (PLWH), with 522 newly diagnosed or their cases to health officials. With early diagnosis and treatment adherence, they may have unique service needs or experience unique barriers to accessing services, PLWH can expect long-term quality and duration of life. Available and accessible support services, including HIV medical care, case management, and social supports, are important resources in maintaining adherence to care.

The purpose of the What Matters to YOU? Needs Assessment for PLWH in Indiana was to learn from PLWH in Indiana about the care system barriers they face and the priorities they have for their own health and wellness. This information will be used by the Indiana State Department of Health (ISDH) and partners for planning and decision making for HIV programs and services. The study, which utilized a two-phase survey approach, was led by the ISDH Division of HIV/STD/Viral Hepatitis, with technical support from a research team at Community Solutions, Inc. The Institutional Review Board of Indiana University School of Medicine provided study oversight and Matthew Holley, PhD, Assistant Professor of Family Medicine at the Indiana University School of Medicine, served as the principle investigator. The ISDH HIV Advisory Committee provided input and guidance.

The needs assessment measures and assesses the self-reported needs and barriers related to services and resources of PLWH in Indiana by gathering information about the kinds of services they need, the kinds of services they use, issues related to service access, and their experiences as a person living with HIV in Indiana. Just over 7,000 PLWH in Indiana met the study inclusion criteria, which included being at least 18 years of age, having a mailing address on file with the ISDH, and having consented to receiving mail from the ISDH. Of those 7,000 people, about 3,500 were included in the study sample, about 3,100 received survey materials, and 289 participated in the study. The study participants represent about 2% of all PLWH in Indiana, with similar demographic distributions related to sex, race, geography, and primary language. Due to the low participation rate, among other factors, there are limitations to how well the data represents all PLWH in Indiana. However, the information collected is still valuable for program and service planning and decision making.

Recommendations for Enhancing Access to and Quality of HIV Services

The needs assessment yielded a great deal of information from PLWH in Indiana about the care system barriers they face and the priorities they have for their own health and wellness. The data collected were used to identify the following recommendations for the ISDH and partners to consider for planning and decision making for HIV programs and services in Indiana.

Funding and programming decisions should be made to:

- Create resources and campaigns to promote the types of HIV services that exist in Indiana, who is eligible for them, and how to access them.

- Expand access and reduce barriers to services for non-majority populations, specifically: young people, women, people of color, and people who are non-MSM.
- Prioritize primary medical care services for PLWH that incorporates regular medical care and monitoring of HIV and other chronic conditions.
- Prioritize services that help PLWH pay for their medications and services, with specific programs or outreach for the population of people aging with HIV.
- Prioritize HIV case management services that help PLWH coordinate their care, connect with essential HIV and non-HIV services, and overcome barriers to access.
- Increase the number and/or capacity of services that provide regular dental care, food bank vouchers, peer-to-peer support, and legal support for PLWH.
- Increase outreach to and resources for people who do not have stable housing. Resources include financial support for mortgage/rent and utilities and helping place PLWH in housing.
- Support PLWH who are not working or are working but facing challenges related to the effects of or side effects of medications to control their HIV, e.g., their energy levels or fear of disclosing their HIV status at work.
- Increase awareness and accessibility of resources for mental health counseling or treatment.
- Educate medical providers, especially those in private practice, at hospitals, or in community health clinics, to increase their comfort level and expertise around treating PLWH and discussing sensitive topics, such as substance use, mental health, and sexual health.
- Provide resources for individuals struggling with perceived discrimination and fear of disclosure.
- Incorporate long-term life planning for PLWH, especially around long-term health and end of life planning.
- Educate PLWH about HIV, HIV transmission, and modes of positive prevention.

Recommendations for Future Assessment

The What Matters to YOU? Needs Assessment for PLWH in Indiana was an important step in understanding the needs, experiences, and barriers to service faced by PLWH in Indiana, but it was not designed to be the sole instrument for future assessment. As the population of PLWH in Indiana change and their service needs, resources, and issues accessing services change, regular assessment must be done for use in program and service planning.

Listed below are recommendations for future assessment. Future needs assessments should be done every one-to-three years and utilize a mixed methods approach, including survey and qualitative data collection through focus groups or interviews, to gather contextual information.

The survey method should:

- Utilize a single-phase survey approach. The vast majority of Part I respondents completed Part II.
- Oversample for non-English speakers, people under the age of 40, and people of color.
- Blend random sample methodology with other approaches to collect information from hard-to-reach populations, including individuals who are not stably housed, immigrants, and those with lower reading levels than the survey may accommodate. Examples include INMMP, working through grassroots organizations, and administering surveys at care sites serving large shares of clients in the oversample categories.

Areas to explore in future study include:

- Specific barriers in access to services for non-majority populations, specifically people of color, female, individuals who are non-MSM, or ages 18-39.
- Variations the levels and types of needs and barriers experienced, by urbanity.

BACKGROUND AND INTRODUCTION

HIV in Indiana

Human Immunodeficiency Virus (HIV) is a virus that attacks the CD4 (T-cells) of the body's immune system, damaging the immune system and making it more difficult for people living with HIV (PLWH) to fight off infection and disease.¹ HIV has three phases: acute HIV infection, the first two-to-four weeks after transmission; clinical latency, asymptomatic HIV or dormancy; and Acquired Immunodeficiency Syndrome (AIDS), the final and most severe stage.²

Approximately 1.1 million people in the United States are living with HIV, with 30,000-40,000 new diagnoses each year.³ With early diagnosis and proper medical care, progression to AIDS is almost completely preventable, and the life expectancy among PLWH is comparable to that of the rest of the population.⁴

In 2018, just over 12,700 PLWH were living in Indiana, 522 of whom were people newly diagnosed or newly reported to health officials. The majority of PLWH in Indiana are male, with the greatest share of cases being males ages 40 years or older. African Americans people are the most disproportionately impacted demographic group and account for almost one-half of those newly diagnosed. Almost one-half of PLWH in Indiana and new diagnoses live in the central region of the state, specifically Boone, Hamilton, Hancock, Hendricks, Johnson, Marion, Morgan, and Shelby counties, with the greatest share living in Marion County. More than two-in-five PLWH in Indiana live in Marion County.⁵

Living with HIV can affect many aspects of a person's life, resulting in unique service needs. These service needs may be related to housing, employment, accessing and paying for HIV care, adhering to HIV-related care and medications, side effects from HIV or medications, other health problems, mental health issues, substance use, stigma and discrimination. For these reasons, effective primary prevention strategies are critical as they can prevent new cases of HIV infection. Available and accessible support services for PLWH, including HIV medical care, case management, and social supports, are important in the long-term quality and duration of life of PLWH in Indiana.

¹ Centers for Disease Control and Prevention. (2019). About HIV/AIDS. Retrieved from <https://www.cdc.gov/hiv/basics/whatishiv.html>

² Ibid.

³ HIV.gov. (2019). U.S. Statistics. Retrieved from <https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics>

⁴ Deeks, S. G., Lewin, S. R., & Havlir, D. V. (2013). The end of AIDS: HIV infection as a chronic disease. *Lancet (London, England)*, 382(9903), 1525–1533. doi:10.1016/S0140-6736(13)61809-7

⁵ See "Transitional Grant Area" section, beginning on page 3, for additional information about this region of the state

Resources for the Health and Well-being of PLWH

The current HIV care system includes services that help PLWH meet their medical and support needs. This system aims to help individuals maintain continued care services by minimizing the barriers that inhibit access and supporting resources to increase access to HIV-related services. The U.S. Health Resources and Services Administration (HRSA) has identified nine core services for PLWH: outpatient and ambulatory health services, AIDS Drug Assistance Program Treatments, substance abuse outpatient care, oral health care, medical case management, mental health services, emergency financial assistance, housing assistance, and medical transportation. Funding for these services comes from HRSA through the Ryan White Program.

The Indiana State Department of Health (ISDH) receives funding through Ryan White Part B Grants to fund core medical and supportive services that aim to improve HIV-related health outcomes. PLWH who meet eligibility requirements may enroll in the HIV Services Program (HSP) to access these services at state-funded, community-based clinics and sites. There are three eligibility requirements for HSP: one must be living with HIV, be an Indiana resident, and have a household income no greater than 300% of the federal poverty level.

PLWH who are enrolled in HSP and are not eligible for Medicare, Medicaid, or an employer-provided health insurance program may also enroll in comprehensive health insurance coverage through Health Insurance Premiums and Cost Sharing Assistance (HIAP) during open enrollment. For those needing coverage starting outside of the open enrollment window, they may enroll in the AIDS Drug Assistance Program (ADAP), a temporary insurance program that covers HIV-related medical care.

Any PLWH in Indiana, regardless of income level, may access non-medical case management services funded through ISDH. Non-medical case management is the delivery of a range of client-centered activities that focus on improving access and adherence to core medical and supportive services. These services include the coordination, guidance, and assistance in accessing medical, social, community, legal, financial, employment, vocational, or other needed services. As of fall 2019, 4,289 PLWH were engaged in non-medical case management services, with 3,539 engaging with a non-medical case manager at least once per month.

Services funded through the Ryan White Part B grants managed by the ISDH are not the only services available to PLWH in Indiana. Regional or local institutions may provide additional services for PLWH in their communities with funding support from Ryan White Parts A and C Grants, as well as a multitude of other publicly-funded grants, community and private foundations, and individual donors.

Purpose of this Study

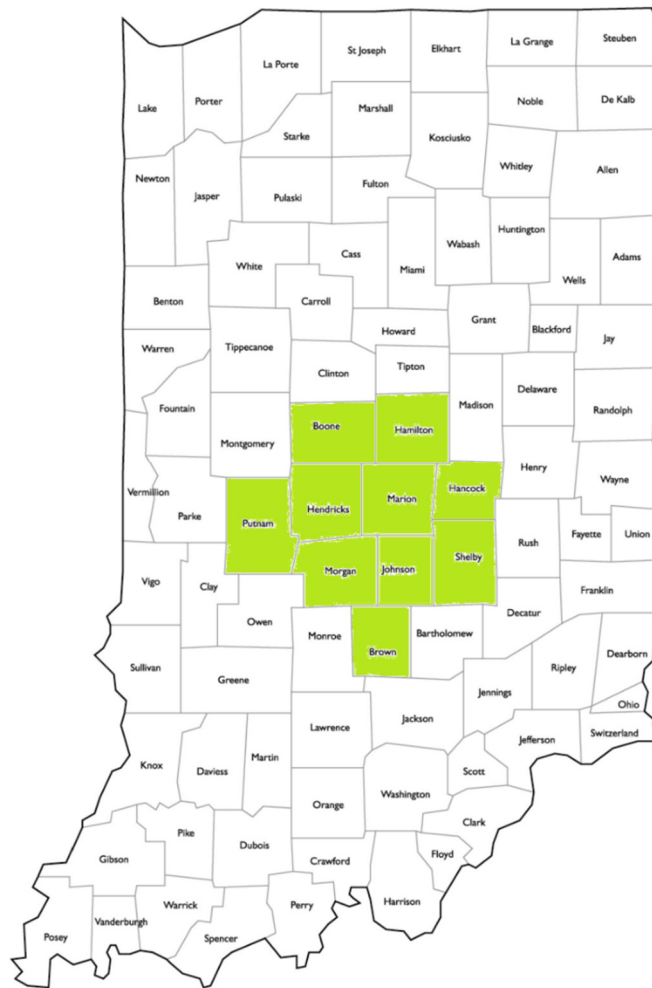
The purpose of this study is to learn from PLWH in Indiana about the care system barriers they face and the priorities they have for their own health and wellness. This information will be used by the ISDH and partners for planning and decision making for HIV programs and services. The study measures and assesses the self-reported needs and barriers related to

services and resources of PLWH in Indiana by gathering information about the kinds of services they need, the kinds of services they use, issues related to service access, and their experiences as a PLWH in Indiana related to housing status, education, employment, health challenges, substance use, HIV diagnosis, HIV care and adherence, perceived discrimination and disclosure, issues related to aging with HIV, and positive prevention.

This report presents survey data at two geographic levels: statewide and the Indianapolis Transitional Grant Area (TGA). Part A of the Ryan White HIV/AIDS Treatment Extension Act of 2009 provides assistance to Eligible Metropolitan Areas (EMAs) and TGAs, which are the counties and cities most severely impacted by the HIV epidemic. Indianapolis is one of 28 TGAs across the country. The 5,890 PLWH in the TGA in Indiana represent 46% of all PLWH in Indiana. The Indianapolis TGA includes Marion and the surrounding counties: Boone, Brown, Hamilton, Hancock, Hendricks, Johnson, Morgan, Putnam, and Shelby (Figure 1).

Data from study participants in the TGA will be useful for the Ending the HIV Epidemic work taking place in Marion County. *Ending the HIV Epidemic: A Plan for America* is a national initiative that began in 2019 to reduce the number of new HIV infections in the United States by 75% within five years and by 90% within ten years – averting an estimated 250,000 new infections. In 2016-17, more than one-half of new HIV diagnoses occurred in 48 counties, Washington, D.C., and San Juan Puerto Rico; and seven states have a disproportionate occurrence of HIV in rural areas. This initiative targets these geographic hotspots, which includes Marion County, Indiana as one of the highest-burden counties. In addition, using the information collected through this needs assessment for state-level planning and decision making for HIV programs and services, the data for participants within the TGA will be useful in developing strategies to End the HIV Epidemic in Marion County.

Figure 1: Map of Indianapolis TGA counties



METHODS

The What Matters to YOU? Needs Assessment for PLWH in Indiana study utilized a two-phase, random sample survey approach to collect information about services needed and used, access and barriers to services, and various aspects about the experiences of PLWH. The study was designed to be representative of PLWH in Indiana and to protect the confidentiality of study participants and anonymity of their responses. The study was led by the ISDH Division of HIV/STD/Viral Hepatitis, with technical support from a research team at Community Solutions, Inc. The Institutional Review Board of Indiana University School of Medicine provided study oversight and Matthew Holley, PhD, Assistant Professor of Family Medicine at the Indiana University School of Medicine, served as the principle investigator. The ISDH HIV Advisory Committee provided input and guidance.

Study Design

The needs assessment study was designed to collect information from PLWH in Indiana through a two-phase survey: Part I and Part II. Part I included a short-form survey that was widely distributed to a random sample of nearly one-half of the 7,035 adults living with HIV in Indiana who had granted permission to ISDH to contact them. Part II consisted of a long-form, follow-up survey administered to participants who completed Part I and elected to complete Part II (either electronically or paper form). Participants who completed both Part I and Part II were offered a \$20 Walmart gift card as a token of appreciation for their time and effort.

The study design period launched in January 2019. The design and survey instruments were developed, tested, and finalized in the first quarter of 2019. In the second quarter, the sample frame was developed, and participants within the sample were identified. Administration of the Part I survey began in June 2019, and data collection for both Parts I and II closed on August 31, 2019.

The research team utilized several resources in the development of the survey instrument and administration process. These include the review of written materials from New York Patient Satisfaction Survey for HIV Ambulatory Care (PSS-HIV) (March 2002); 2002-2003 Atlanta EMA HIV Consumer Survey (November 2004); Massachusetts and Southern New Hampshire HIV/AIDS Consumer Study (June 2011); Needs Assessment for HIV Services New York Eligible Metropolitan Area Ryan White Part A (2014); New York State/New York City/Long Island 2017-2021 Integrated HIV Prevention and Care Plan (2017); HIV/AIDS Epidemiology Report King County & Washington State (2017); and Washington State Statewide Coordinated Statement of Need 2017-2021 (October 2018). Community Solutions spoke with representatives from the New York City Health Department, who provided additional materials; Midwest AIDS Training & Education Center – Indiana (MATEC), and a consultant with experience working with ISDH and the Massachusetts and Southern New Hampshire HIV/AIDS Consumer Study.

Due to the nature of the study topic and some of the questions asked on the survey, the research team sought additional resources for best practices to use when discussing living with HIV, stigma, sexual orientation, gender identity, race, and disabilities. These resources include University of California San Francisco HIVE, LGBT Campus, the CDC, and other literature. In addition, the research team sought guidance throughout the design process from the ISDH HIV Advisory Committee and Quality Group for HIV. Research team members presented and gathered feedback at three HIV Advisory Committee meetings throughout the study design and administration period, and the Quality Group was involved in the drafting and testing of the survey instruments.

Survey Development and Administration

The Part I and Part II survey instruments were designed in the first quarter of 2019. The instruments were translated into Spanish by a member of the research team who is a native Spanish speaker. The draft Part II survey was also built in Survey Monkey to allow for both hard copy and electronic testing. The Part I and Part II survey instruments were reviewed and tested by the volunteers from the ISDH Quality Group for HIV and colleagues who they engaged to test the survey, as well. The feedback was used to edit and finalize the instruments in April 2019.

The shorter Part I survey included demographic questions as well as questions about the services PLWH in Indiana want and use. The longer Part II survey included demographic questions and more detailed questions about different parts of the experiences of PLWH, including housing, education, employment, their HIV diagnosis, health status, primary care, substance use, mental health, access to services, HIV medication and adherence, stigma and disclosure, aging, positive prevention, and their HIV knowledge and literacy.

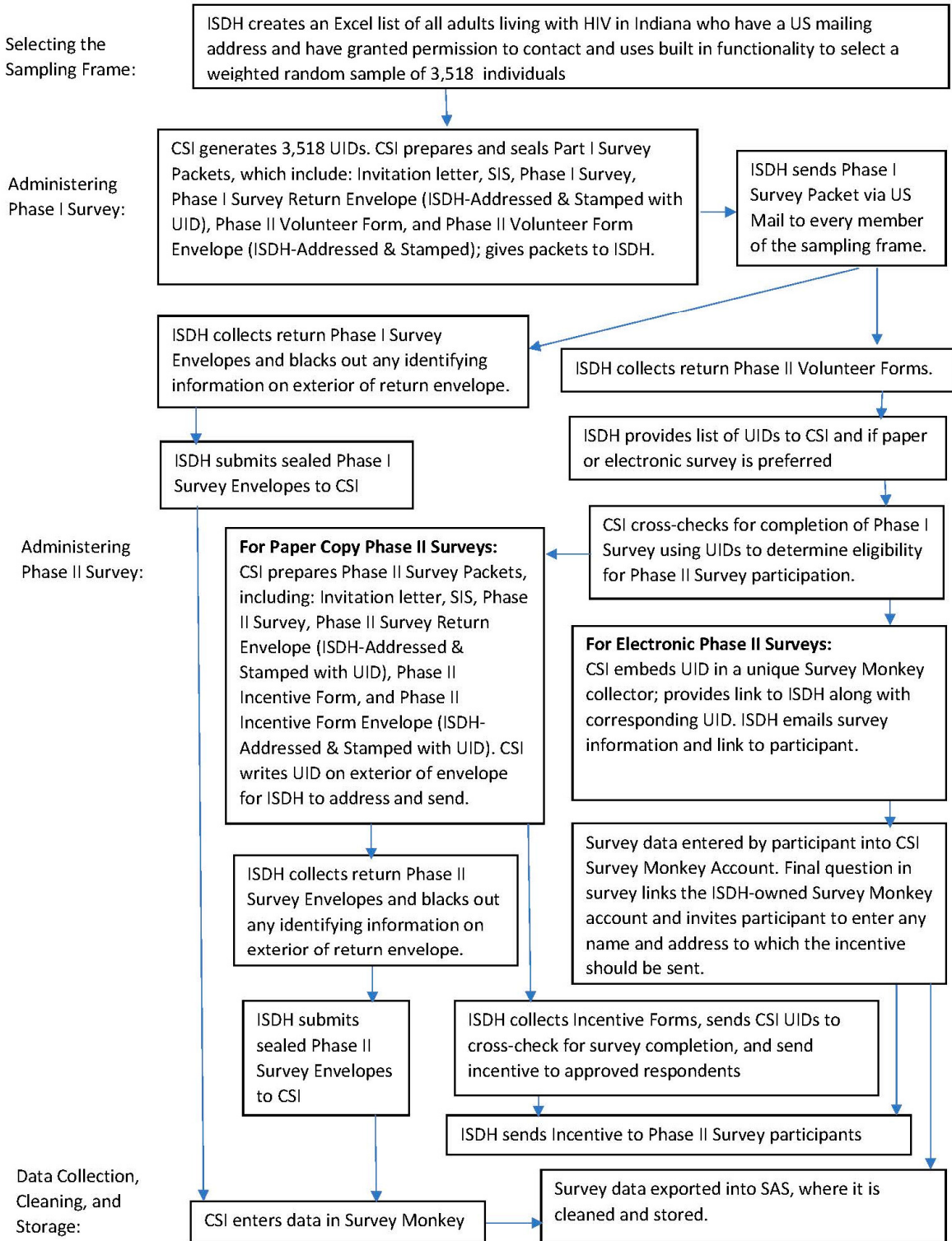
The research team developed several materials to accompany the survey instrument to facilitate the administration process and encourage participation among PLWH invited to participate in the study. Materials included a Study Information Sheet (SIS) and invitation letters with instructions for both parts of the survey. Additionally, they created marketing materials for HIV service providers to post in their offices or share with their clients announcing the needs assessment and informing them that they may be invited to participate. Marketing materials were completed and shared with service providers in April 2019. All study-related materials were available in English and Spanish.

PLWH in Indiana who were included in the sample were mailed an initial packet of study information that included an invitation letter, the SIS, the Part I Survey form, a Part II Survey volunteer form, and two return envelopes. Those who chose to participate in the study were instructed to mail the completed survey form and their Part II volunteer form in separate envelopes, ensuring that any contact information would not be tied to their survey responses. Those who completed the Part I survey and elected to participate in Part II were sent a packet of materials – via mail or email as per their request – that included a Part II invitation letter, the SIS, the Part II Survey form, information on how to claim their incentive, and, for mailed

packets, two return envelopes. Again, survey participants were instructed to mail their completed Part II survey forms and incentive form in separate envelopes.

Great efforts were made to ensure the confidentiality of study participants and the anonymity of their responses. Only ISDH staff had access to any identifying information of PLWH in Indiana or those in the study sample, including names, addresses, or dates of birth. To achieve this, ISDH provided aggregate descriptive statistics on PLWH in Indiana who met the inclusion criteria to the research team, who then used this information to determine the number of individuals who should be included in the sample and which populations should be over- or under-sampled to increase the likelihood of representative response rates. The research team provided instructions to ISDH staff on how to select a random sample using the sampling frame. ISDH staff used the random number generator function in Microsoft Excel to select study participants and assign the unique participant ID numbers. The research team prepared Part 1 survey mailing packets, which included the participant ID on the exterior of the outgoing envelope, the Part 1 survey and other study instructional materials, and two postage-paid return envelopes, directing all responses to ISDH. Participants were instructed to return the completed survey form in one return envelope and the Part II Survey Volunteer form or Survey Incentive form in the other return envelope. The return envelopes that contained the survey responses were provided to the research team unopened, and envelopes containing the Part II volunteer form or incentive form, which included the name and contact information for where to send the Part II survey or incentive, respectively, were only opened by ISDH. The process is outlined in Figure 2 below.

Figure 2: Survey administration approach



Participant Incentives

Study participants who completed and returned both Part I and Part II of the survey were eligible to receive a \$20 Walmart gift card. They could receive the card via mail or electronically. Contact information about where to send the gift card was sent to ISDH in an envelope or survey form that was separate from the Part II survey form. ISDH then used the participant ID numbers to confirm with the research team that both parts of the survey had been completed by that participant. The research team supplied the gift cards, which were then distributed by ISDH.

Eligibility and Participation

To be eligible to participate in the study, individuals had to be Indiana residents who are living with HIV, at least 18 years of age, have a valid mailing address, and have given permission for ISDH to contact them. Participation in the study was voluntary and anonymous. The invitation letters and SIS clearly stated that those invited to participate in the study could choose to ignore the invitation and not participate without facing any penalty or loss of benefits or services. If individuals chose to participate in Part I of the survey, they still had to volunteer to participate in Part II. However, because the survey responses were anonymous, participants could not withdraw their data from the study once submitted. The SIS informed study participants about the study, potential risks, benefits, how their information would be protected, incentive information, and who to contact with questions or problems. Consent to participate in the study was given through the submission of survey instruments.

Among PLWH in Indiana, 7,035 individuals met the inclusion criteria. This included individuals who had engaged in non-medical case management at some point, though their cases may be active, in maintenance, or closed (see Table 1 for definitions). The sample size, 3,518, represents 50% of eligible individuals. Several small-but-critical subpopulations were over-sampled at 100%. These include young adults ages 18-24, older adults ages 65 and older, people who reported their race as 'Hispanic' or 'Other', and people who reported Spanish as their primary language. Some subpopulations were under-sampled, specifically individuals ages 25-64 whose primary language is English and who are African American or White. Among this group, black women were sampled at 80%; white women were sampled at 80%; black males were sampled at 40%, and white males were sampled at 29%.

Table 1: Classification of non-medical case management cases

Active	Level of Intensity of Active Services High – more than 6 hours documented services per month Medium – 1 to 6 hours of documented services per month Low – less than 1 hours of documented services per month
Maintenance	Client has been assessed as self-sufficient by a non-medical case manager, requiring limited services
Closed	Client no longer wishes to engage in case management services

INMMP Outreach

In an effort to reach PLWH in Indiana for whom ISDH may not have contact information or who may have never engaged in non-medical case management, additional survey outreach was done through the Indiana Medical Monitoring Project (INMMP). INMMP is a special HIV disease surveillance project funded by the CDC in collaboration with the ISDH. The MMP includes a personal interview and medical record abstraction with randomly selected patients from a representative sample of HIV care providers within the state. After completing the script for consent for MMP participation, INMMP staff informed patients about the needs assessment study and invited them to participate, sharing all the SIS information, including the fact that participation is voluntary, and their information would be kept confidential. If patients agreed to participation, INMMP staff then went through the Part I survey with them. Once Part I was completed, INMMP provided the materials for the patient to volunteer to participate in Part II, specifically, the volunteer form and envelope. INMMP staff then checked with ISDH staff to determine if that individual was already included in the sample. If yes, the INMMP staff person sealed the survey in the Part I return envelope, wrote their corresponding participant ID number on the outside, and gave it to ISDH staff. If the patient was not included in the sample, the INMMP staff person contacted ISDH staff to generate an ID number. The INMMP staff person then sealed the survey form in the Part I envelope and wrote the new ID number on the outside before giving it to ISDH staff. After completing the Part I survey and receiving the Part II volunteer form, the administration process continued as usual.

Data Entry and Cleaning

Data entry for Part I of the survey began when the research team received survey responses from ISDH. Each response was checked for its unique ID number and entered into Microsoft Excel (2018). Part II survey data submitted via paper survey and returned via US mail were entered into Survey Monkey® by the research team. The rest of the Part II surveys were completed by respondents electronically via Survey Monkey®. All Part II survey data were exported from Survey Monkey to Microsoft Excel. Following the closing of the survey data collection period for both Part I and Part II, survey responses stored in excel were imported into SAS® 9.4 for data cleaning procedures. Each survey was reviewed for completeness and to ensure all appropriate responses were included in data analysis, including individuals who wrote-in an 'other' response. Data were reviewed for missing values, duplicate entries, and any observed errors. Additionally, surveys completed in Spanish were translated to English prior to analysis.

Data Analysis

The research team created a data dictionary and data were formatted in SAS® 9.4 using the coding scheme provided in the data dictionary associated with the Microsoft Excel (2018) data entry files. Variables of interest were grouped as numeric categories for further analysis. Part I and Part II survey data were stored as separate data sets, and a third dataset was created containing the combined data for individuals who completed both parts. Descriptive tables

were generated for all continuous and categorical variables. The generated frequencies had varying n's due to some respondents not answering certain questions. SPSS version 25 was used to generate additional descriptive tables. Stratified analyses by gender, age, race, Hispanic ethnicity, and income were conducted. To determine relationships between variables of interest and access to needs, Pearson Chi-square statistics were conducted.

The level of need was assessed using Part I survey data about respondents need for services. The combined met need and unmet need of individuals was compared with those who did not need or use any of the listed services. Statistically significant differences in level of need by geographic region were analyzed using the Kruskal-Wallis test. Access/utilization of services was determined by comparing individuals who had met needs to those with unmet needs. The mean and standard deviations from the mean number of services selected was used to distribute respondents into categories of low, medium, and high met need and unmet need.

For all statistical analyses, a p-value < 0.05 was considered significant.

Limitations

The methodology for the needs assessment posed several limitations, primarily due to the population from which the sample was drawn. As Part I of the needs assessment survey was sent via US mail, the sampling frame was limited to PLWH who have a valid mailing address in the ISDH system and have agreed to be contact by ISDH. Only PLWH in Indiana who had engaged in non-medical case management through an ISDH-funded site at some point prior May 2019 would have their contact information in the ISDH system. PLWH in Indiana who have never engaged in non-medical case management would not have had the opportunity to be included in the sample. These are individuals for whom information about need for and access to services would have been particularly valuable.

Among those who had engaged in non-medical case management and were included in the ISDH system, only those with a mailing addresses were eligible for participation. Excluding people without mailing addresses limited the information that could be collected from people without stable housing. Additionally, by only including individuals who had to have given ISDH permission to contact them, the study does not incorporate information about needs, access to resources, and experiences of people who have not granted such permission.

Efforts were made to gather some input from individuals who may not have engaged in non-medical case management, may not have had a mailing address, and may not have granted ISDH permission to contact them. This was one of the primary reasons the MMP outreach was incorporated into the methodology. However, there is no way to ensure that members of these populations were reached through MMPs. There may be additional bias among respondents due to the use of incentives. Those most interested in the gift card would have been more likely to participate.

Other limitations are due to language and literacy of the needs assessment survey. Because it was a written survey, participants had to be able to read and comprehend the survey

background, instructions, and questions. Efforts were made to lower the reading level of all survey materials, but this is particularly difficult with medical-related topics. Similarly, the survey materials were offered in English and Spanish but no other languages. Individuals who were not able to read the survey materials in English or Spanish would have been precluded from participation.

Finally, a relatively low response rate limited opportunities for statistical analysis and the ability to generalize responses to all PLWH in Indiana. While the information collected is still valuable for program and service planning and decision making, some information for smaller subsets of respondents that would have provided additional detail or insight could not be reported, as it would not have accurately reflected the larger population of PLWH in Indiana.

RESULTS AND DISCUSSION

This section of the report presents the data collected through Parts I and II of the needs assessment survey.

Sample Characteristics

Of the 3,518 individuals in the original sample, 442 were not sent because the individual no longer lives in Indiana, returned to sender, or returned because the individual is deceased. With the mailing of materials to the sample and the MMP outreach, 3,089 individuals received the Part I survey materials. Table 2 below shows the number and percentage of PLWH in Indiana who completed Part I and Part II of the survey and the mode of completion.

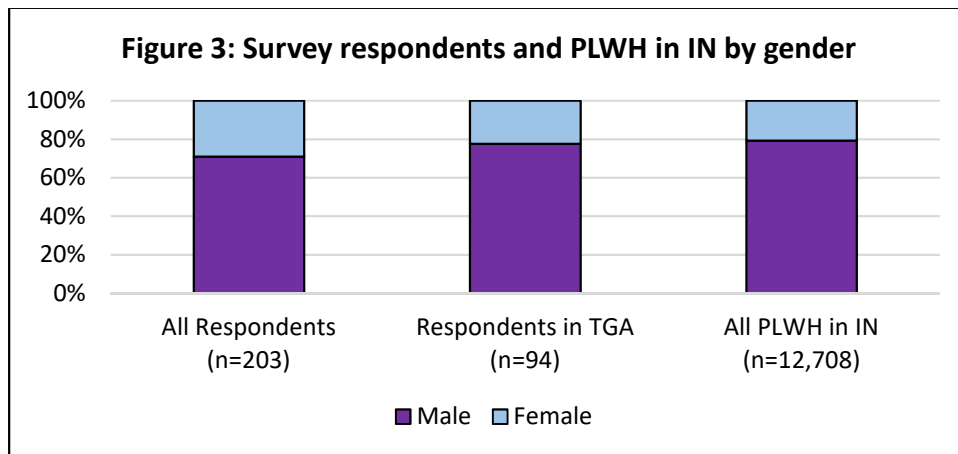
Table 2: Study participation

Study Participants	Number	Percent
In the sample	3,518	100%
Received PI materials	3,089	87.8%
Completed PI	289	9.4%
Completed PI via MMP	19	6.6%
Completed PII	178	67.2%
Completed PII via mail	135	75.8%
Completed PII online	43	24.2%
Completed PI and PII	178	5.8%

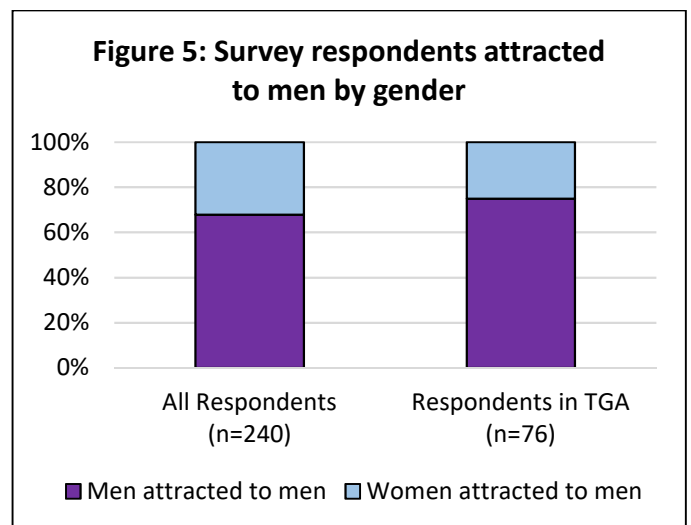
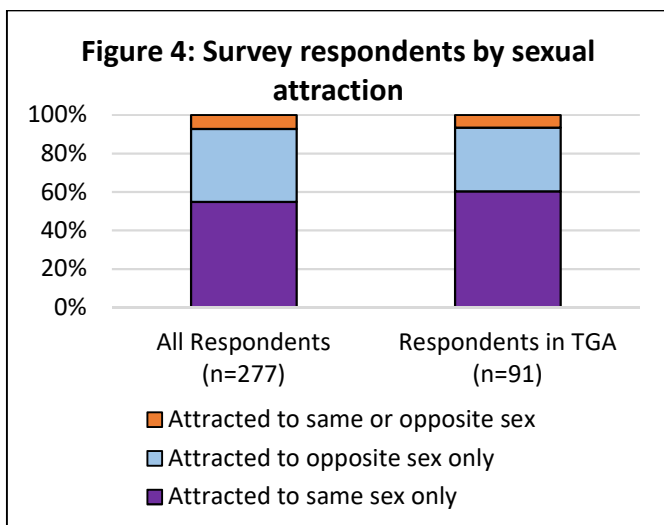
This section describes the demographic distribution of all survey respondents and survey respondents within the TGA. When possible, those distributions are compared with all 12,708 PLWH in Indiana (2018).

Figure 3 shows the distribution of survey respondents and PLWH in Indiana by gender. For the purposes of this report, individuals who report being transgender were classified as the gender to which they transitioned and not the gender to which they were assigned at birth. Among survey respondents, there was a slightly more even gender distribution (71% male, 29% female) than among all PLWH across the state (79% male, 21% female). Survey respondents within the

TGA aligned closely to the statewide distribution (78% male, 22% female). The share of individuals who reported being gender non-conforming or gender-queer in the survey was suppressed due to $n < 5$.



HIV disproportionately affects men who have sex with men (MSM).⁶ Figure 4 shows the reported sexual attraction of survey respondents, based on their reported gender and who they are attracted to. More than one-half of all respondents and respondents in the TGA reported being attracted to members of the same sex (55% and 60%, respectively), about one-third reported being attracted to members of the opposite sex (38% and 33%), and 7% of each group reported being attracted to members of the same or opposite sex. Figure 5 shows the share of survey respondents who reported being attracted to men by gender. About two-thirds of all survey respondents who reported being attracted to men are male, as are three-quarters of respondents in the TGA.



⁶ Beyrer, C., Baral, S. D., van Griensven, F., Goodreau, S. M., Chariyalertsak, S., Wirtz, A. L., & Brookmeyer, R. (2012). Global epidemiology of HIV infection in men who have sex with men. *Lancet (London, England)*, 380(9839), 367-377. doi:10.1016/S0140-6736(12)60821-6

Figure 6 shows the distribution of survey respondents and all PLWH in Indiana by race and Hispanic ethnicity. While the distributions were similar overall, a larger share of survey respondents identify as White Non-Hispanic (60%) and a smaller share who identify as Black Non-Hispanic (27%) than among all PLWH in Indiana (48% and 38%, respectively). The demographic distribution among respondents in the TGA aligned very closely with the distribution among PLWH in the state.

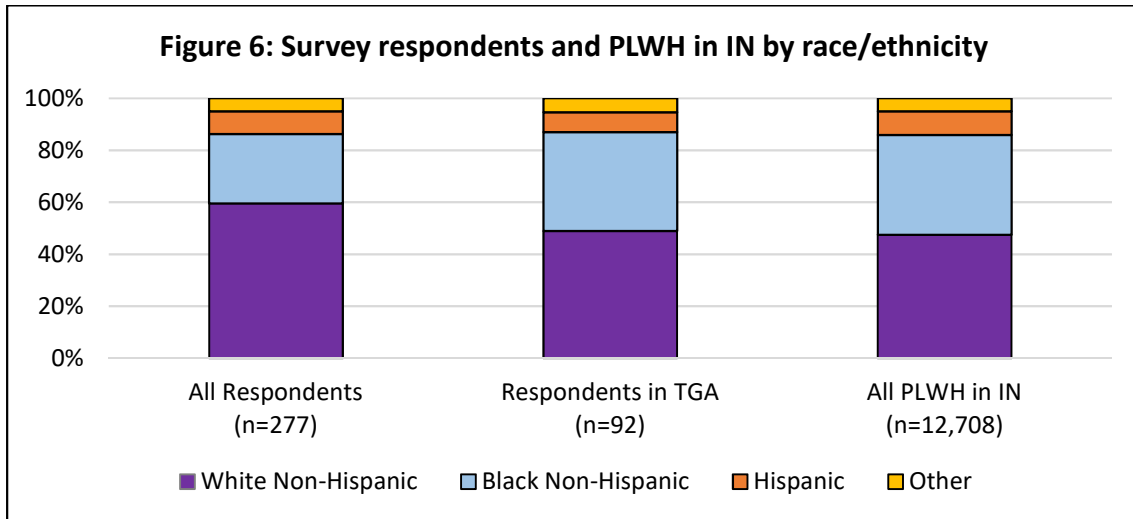
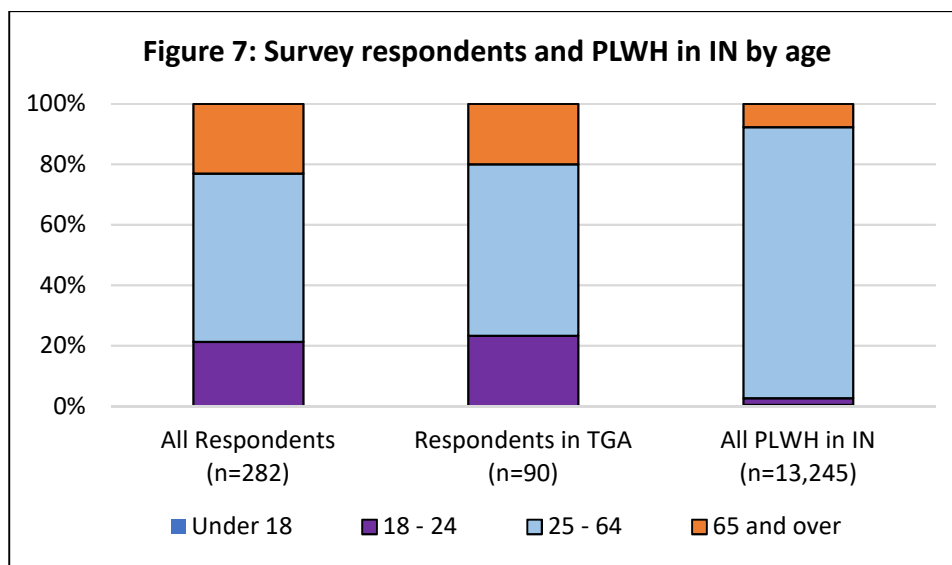


Figure 7 shows the distribution of survey respondents and PLWH in Indiana by age. There was greater variability in the ages of survey respondents than in the state as a whole. Slightly more than one-half of survey respondents (56%) are ages 25-64, compared with nine-in-ten PLWH in Indiana. About one-in-five survey respondents are ages 18-24 or ages 65 or older, compared with 2% and 8%, respectively, of PLWH in the state. Fewer than 1% of all PLWH in Indiana are under the age of 18, but those individuals were not eligible to participate in the survey. Among respondents in the TGA, 23% are 18-24, 57% are 25-64, and 20% are 65 or older.



Indiana has 12 HIV Care Coordination Regions, as shown in Figure 8 below. The geographic distribution of survey respondents is very similar to that of all PLWH in Indiana. Among both groups, the greatest share of people live in Region 7, which includes Marion County. Respondents in the TGA live primarily in Region 7, with a small share in Region 6.

Figure 8: Geographic distribution of survey respondents and PLWH in IN by HIV Care Coordination Region

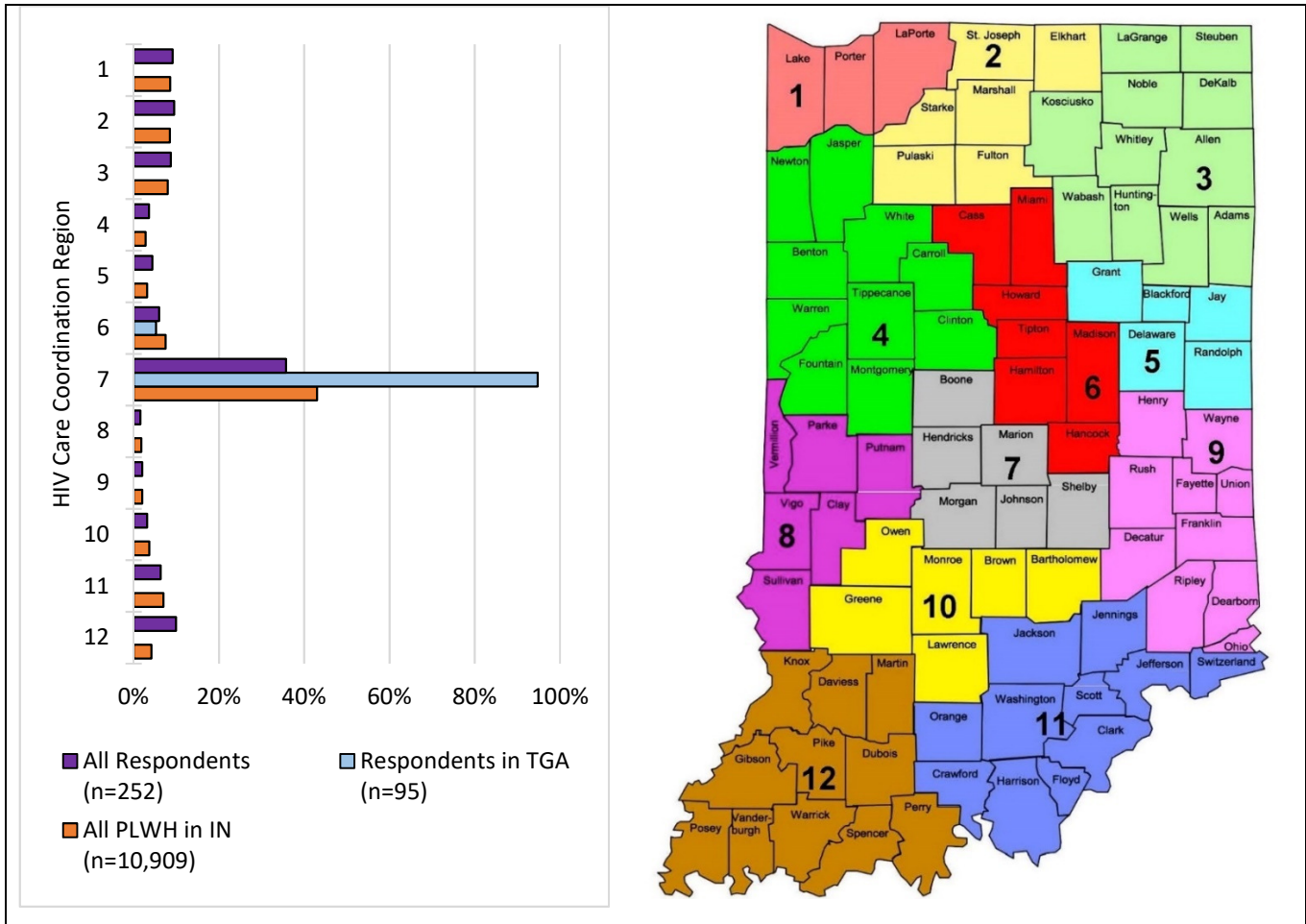


Figure 9 shows the distribution of respondents and all PLWH in Indiana by language spoken in the home. The share of all survey respondents who speak English at home is comparable to all PLWH in Indiana (95% and 92%, respectively), and 5% of both groups speak Spanish at home (97% of respondents in the TGA speak English at home, and 3% speak Spanish). Only 3% of all PLWH in Indiana speak a language other than English or Spanish, compared with less than 1% of survey respondents. All respondents in the TGA speak English at home. Almost all survey respondents were born in the United States (91% of all respondents, 98% of respondents in the TGA).

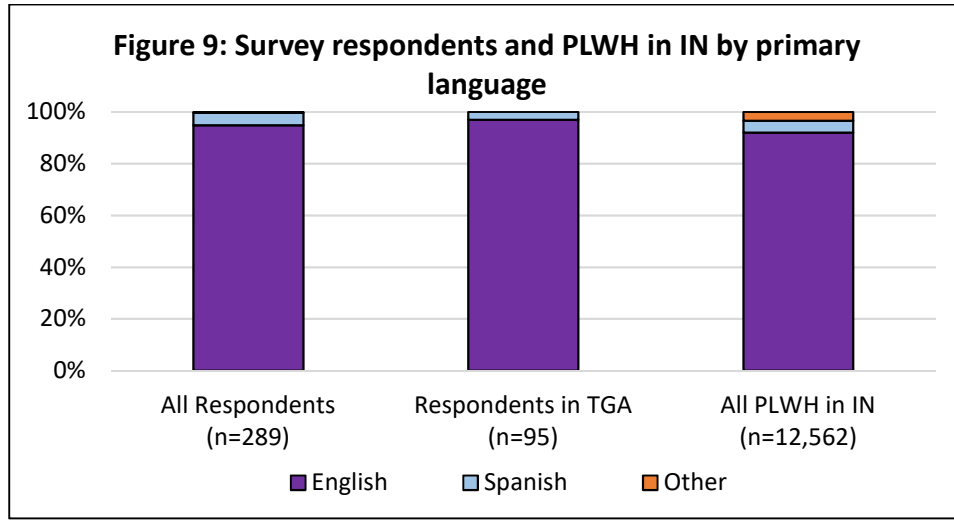


Figure 10 shows the poverty status of survey participants. Living in poverty is defined as living at or below 300% of the federal poverty level. Almost all survey respondents are living in poverty (98%). The same is true for survey respondents in the TGA (98%).

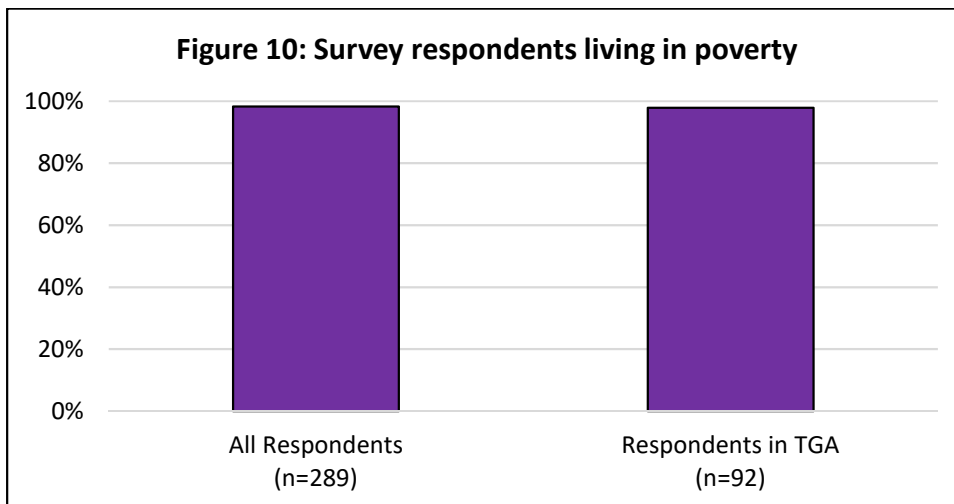


Figure 11 shows the distribution of household size among survey respondents. About one-half of all survey respondents and survey respondents in the TGA live alone (50% and 49%, respectively), with fairly even distribution of all survey respondents and respondents in TGA who live with one other person and with two or more people.

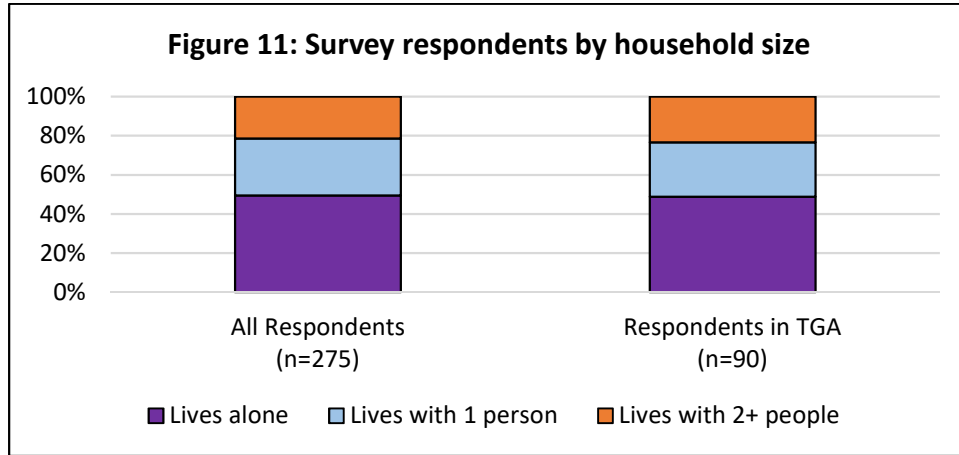


Figure 12 shows the distribution of health insurance coverage for survey respondents. Among all respondents, the largest shares have Medicaid A, B, C, or D or coverage funded through HSP at ISDH (43% and 42%, respectively). Only 2% of all survey respondents are uninsured. Among survey respondents in the TGA, the largest shares have Medicaid A, B, C, or D or Insurance Marketplace coverage (61% and 39%, respectively). Fewer than five individuals are uninsured. Note that insurance through the HSP is purchased through the Marketplace, so some share of individuals who selected Marketplace may have state-funded coverage.

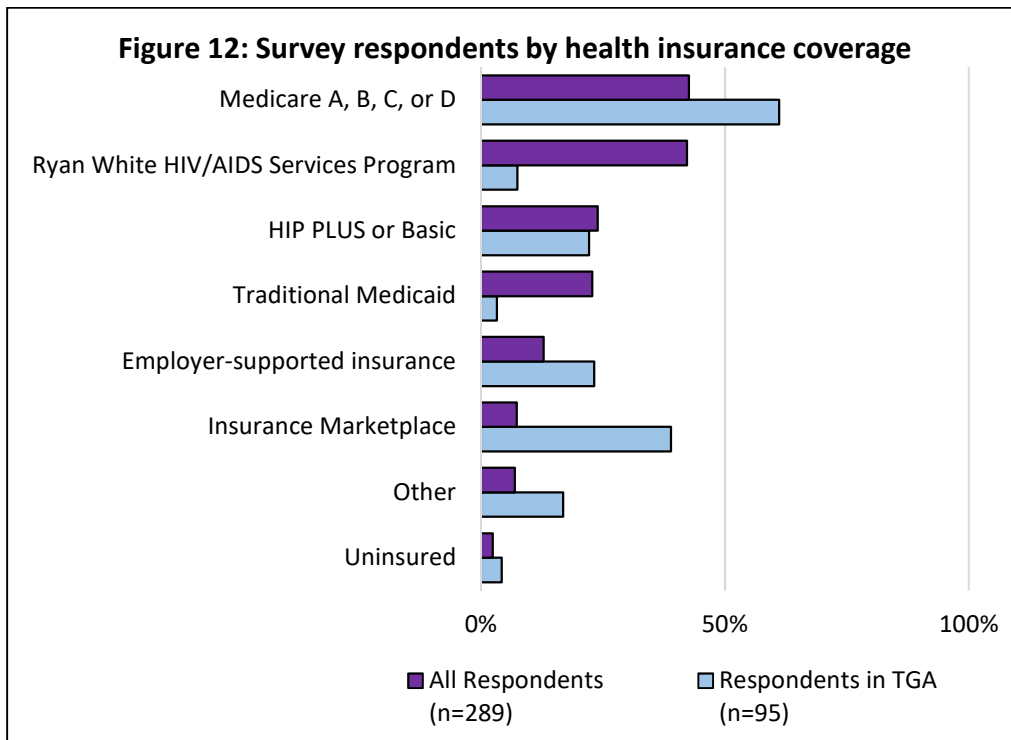
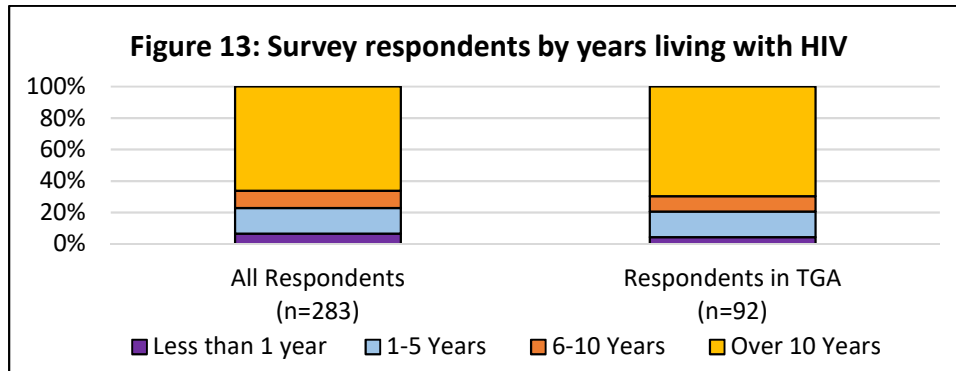
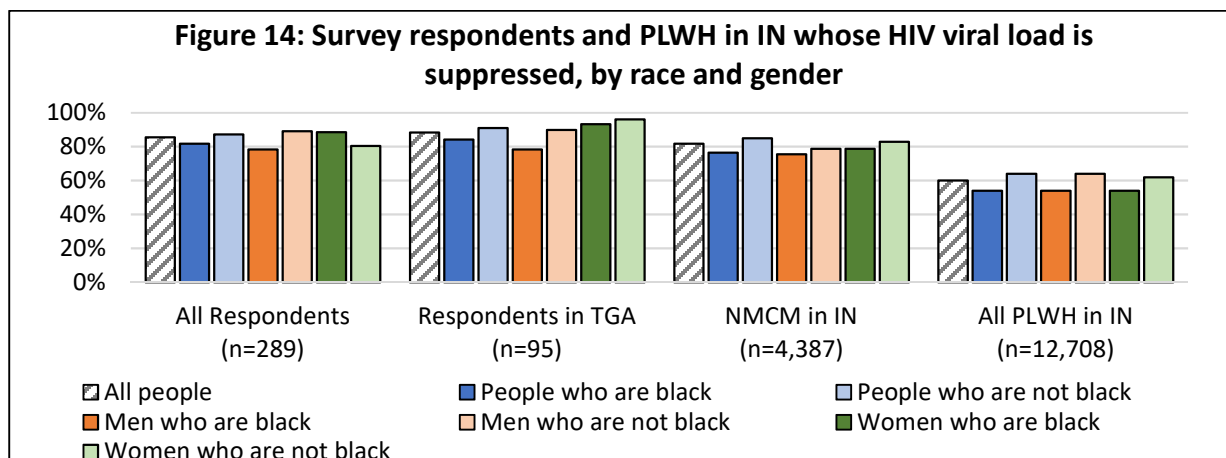


Figure 13 shows how long survey participants have been living with HIV. About two-thirds of all survey respondents and survey respondents in the TGA have been living with HIV for more than ten years. Only 7% of all respondents and fewer than five respondents in the TGA have been living with HIV for less than one year.



A PLWH has a suppressed viral load if they have fewer than 200 copies of HIV per milliliter of blood.⁷ While this does not mean they are cured of HIV, it does mean that their HIV is currently being managed, reducing their risk of HIV-related health complications and HIV transmission.⁸ While viral suppression rates among the study population are similar to all people in non-medical case management, both are much higher than all PLWH in Indiana. Figure 14 shows the shares of survey respondents, all PLWH in non-medical case management (listed in the chart as NMCM) in Indiana, and all PLWH in Indiana with suppressed viral loads – for everyone and by race and sex. The shares of survey respondents with suppressed viral loads were slightly larger than all people in non-medical case management and notably larger than all PLWH in Indiana. Viral suppression is lowest among black men across all populations; however, among all PLWH in Indiana, the share of black men with suppressed viral loads is the same as black women and all black people.



⁷ UNAIDS. (2016). The Need for Routine Viral Load Testing. Retrieved from https://www.unaids.org/sites/default/files/media_asset/JC2845_en.pdf

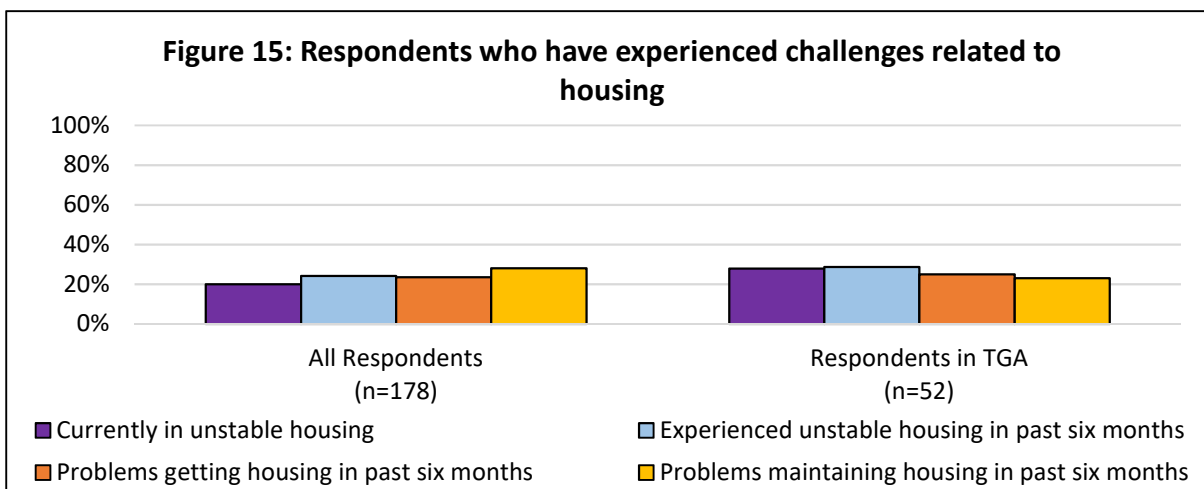
⁸ Ibid.

Housing Status

Stable and secure housing is important for all people, especially PLWH. Homelessness and unstable housing are conditions strongly associated with inadequate HIV health care, including failure to connect with a primary care provider.⁹ For the purposes of this report, unstable housing includes living with a friend or family member, in a temporary shelter, in a car, in jail or correctional facility, in a live-in substance program, or on the street. Stable housing includes living in a house or apartment of one’s own, whether that home is subsidized or unsubsidized. Lack of stable housing can affect a person’s ability to access and regularly take antiretroviral drugs creating an inability to suppress viral loads necessary to maintain health.¹⁰ PLWH who experience improvements in their housing situations have seen improvement in their overall health status.¹¹

Data in this section show information about respondents’ housing status, stability, and related issues. Though in the minority, finding and maintaining stable housing is an issue for a significant portion of survey respondents. The greatest challenges with getting and maintaining stable housing are financial.

Many survey participants have faced recent challenges related to finding and maintaining stable housing. Figure 15 shows the share of survey participants who are currently living in unstable housing, have experienced unstable housing in the past six months, have had problems getting housing in the past six months, and have had problems maintaining housing in the past six months. One-in-five respondents currently live in an unstable housing situation. About one-in-four respondents have lived in at least one unstable housing situation, had problems getting housing, or had problems maintaining housing in the past four months.



⁹ Kidder, D., et al. (2007). Health status, health care use, medication use, and medication adherence in homeless and housed people living with HIV/AIDS. *Am J Public Health* 97(12): 2238- 2245

¹⁰ Aidala, A., et al. (2016). Housing Status, Medical Care, and Health Outcomes Among People Living with HIV/AIDS: A Systematic Review. *Am J Public Health* 106(95): e1-e23.

¹¹ Ibid.

Table 3 shows where respondents are currently housed. The most common unstable housing situation is living with a friend or family member.

Table 3: Respondents by current living situation

	All Respondents (n=178)	Respondents in TGA (n=52)
In a non-subsidized home or apartment of my own	57.9%	55.8%
In a friend or family member's home, which I do not consider my home	16.9%	25.0%
In a subsidized home or apartment of my own (e.g., Section 8 or other government-assisted housing)	15.7%	13.5%
On the street, in a shelter, in a car, or some other temporary place	1.7%	1.9%
In jail, prison, or correctional facility	0.0%	0.0%
In a live-in alcohol or substance use program	0.0%	0.0%
Other	7.9%	3.8%

Table 4 shows the share of respondents who have experienced each unstable housing situation in the past six months. The most common experience participants report is living with a friend or family member.

Table 4: Respondents who have experienced unstable housing situations in the past six months

	All Respondents (n=178)	Respondents in TGA (n=52)
Lived with a friend or family member in a home you did not consider your home	18.5%	25.0%
Lived in a hotel	2.2%	3.8%
Lived on the street	2.2%	1.9%
Lived in a car	1.7%	3.8%
Lived in any public or private shelter for a short time	1.7%	1.9%
Lived in any other unstable or non-permanent housing situation	1.7%	1.9%
Lived in a public place, such as a park, bus station, airport, or camping ground	1.1%	1.9%
Lived in transitional housing	1.1%	0.0%
Lived in an abandoned building	0.0%	0.0%
Lived in a jail, prison, or correctional facility	0.0%	0.0%
Didn't have a fixed, regular, adequate place to sleep at night	0.0%	0.0%

Table 5 shows the share of respondents who have experienced each issue in getting housing in the past six months. The most common issues faced by respondents are waiting lists and meeting eligibility requirements.

Table 5: Respondents who have experienced problems getting housing in the past six months

	All Respondents (n=178)	Respondents in TGA (n=52)
Waiting lists	9.0%	11.5%
Meeting eligibility requirements for subsidies (government support) or other public housing programs	9.0%	7.7%
Credit problems	6.2%	5.8%
Finding a place to live that will take my rental subsidy	4.5%	3.8%
Criminal Record	2.2%	1.9%
History of drug or alcohol use	1.1%	0.0%
Issues with my immigration status	0.6%	0.0%
Other	4.5%	5.8%

Table 6 shows the share of respondents who have experienced each issue in maintaining housing in the past six months. The most common issue faced by respondents is paying rent, mortgage, or utilities.

Table 6: Respondents who have experienced problems maintaining housing in the past six months

	All Respondents (n=178)	Respondents in TGA (n=52)
Hard to pay rent, mortgage, or utilities	19.7%	17.3%
Eviction	4.5%	3.8%
Credit problems	5.1%	5.8%
Drug or alcohol use	1.7%	0.0%
Legal/criminal justice system involved	1.7%	1.9%
Issues with my immigration status	1.1%	0.0%
Other	5.1%	3.8%

Education and Employment

Educational attainment and employment status are key social determinants of health. Various aspects of education and employment can affect overall health. Education and health are intrinsically linked as the basic skills learned through education – problem solving, reasoning, fundamental knowledge, self-control, and interactional abilities – are critical to long-term health.¹² Education also leads to better employment opportunities, and employment and job security are associated with better quality of life for PLWH.¹³ Individuals who are employed often have higher incomes and access to health insurance, which can result in better health outcomes.¹⁴

This section discusses data on survey participants’ educational attainment, current employment status, reasons for not working, and challenges of working. Although the vast majority of respondents report having at least a high school diploma, most are not currently working due to a variety of reasons including disability, not having energy to work, or being retired. Many of the respondents who are currently working report challenges related to their HIV, most commonly including lack of energy and lack of comfort disclosing their HIV status at work.

Table 7 shows the highest level of education completed by survey participants. High school diploma completion rates are relatively high among all respondents and those who live in the TGA (91% and 96.1%, respectively) as compared with the estimated rate for all adults in Indiana (87.3%). However, the share of respondents who have obtained a Bachelor’s degree or beyond is lower than the comparable rate for the state as a whole (30.9%).¹⁵

Table 7: Respondents by highest level of education completed

	All Respondents (n=177)	Respondents in TGA (n=52)
Bachelor's degree or higher	25.4%	19.2%
Vocational/technical school or Associate's degree	14.1%	17.3%
Some college or university, no degree	34.5%	44.2%
High school diploma or GED	17.0%	15.4%
No high school diploma	9.0%	3.9%

¹² Hahn RA, Truman BI. (2019). Education Improves Public Health and Promotes Health Equity. *Int J Health Serv* 2015;45(4):657–78.

¹³ Rueda S, Raboud J, Rourke SB, Bekele T, Bayoumi A, Lavis J, Cairney J, Mustard C. (2012). Influence of employment and job security on physical and mental health in adults living with HIV: cross-sectional analysis. *Open Med* 6(4):e118–26. PMID: 23687526; PMCID: PMC3654507.

¹⁴ Office of Disease Prevention and Health Promotion. (2019). Employment. Retrieved from <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/employment>

¹⁵ US Census Bureau, American FactFinder 2017 American Community Survey. Retrieved from <https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=CF>

About two-thirds of survey participants are not currently working (65% of all respondents, 69% of respondents in the TGA). The primary reasons respondents give for not working are disabilities both related and unrelated to HIV, retirement, and lack of energy. Table 8 shows the reasons survey participants reported for not working. Many respondents reported more than one reason. Two-fifths of respondents reported having a disability as a result of their HIV status, and more than one-third reported having a disability related to some other health condition. More than one-quarter of respondents are either retired or do not have the energy to work.

Table 8: Reasons respondents are not currently working

	All Respondents (n=112)	Respondents in TGA (n=35)
I'm disabled as a result of having HIV.	39.29%	37.14%
I'm disabled as a result of some other condition	34.82%	37.14%
I'm retired	29.46%	31.43%
I don't have the energy	27.68%	25.71%
I'm afraid I will earn too much and lose government benefits (such as SSI/SSDI, Section 8, food stamps, health insurance)	16.07%	17.14%
I'm worried about getting sick on the job	13.39%	11.43%
I'm afraid I will lose access to HIV services	11.61%	11.43%
I can't find a job	8.93%	8.57%
I'm worried about medication side effects at my job	8.04%	5.71%
I don't have enough training or skills	4.46%	5.71%
I'm worried people will find out I have HIV	4.46%	5.71%
I got fired or laid off	3.6%	2.9%
I don't need to work or am not interested in working	2.7%	2.9%
I have immigration or visa issues	2.7%	0.0%
I don't know how to apply or interview for a job	1.8%	0.0%
I don't have someone to take care of my kids or family	1.8%	0.0%
I have issues with drug or alcohol use	1.8%	0.0%
I'm now getting training or education, so I can get a job	0.9%	2.9%
Other	20.5%	8.6%

Respondents who are working reported facing several challenges related to living with HIV, most commonly related to their energy levels and feeling uncomfortable about disclosing their HIV status at work. More than three-quarters (77%) of all survey respondents who are currently working have experienced some challenges that are related to living with HIV. Data for respondents in the TGA are not available due to low n. Table 9 shows common challenges of respondents who are working. More than one-half of respondents faced challenges related to their energy levels and disclosure of HIV status in the workplace.

Table 9: Share of all respondents who are employed who have experienced each challenge while working as PLWH

	% (n=61)
My energy level sometimes makes it hard to get through the day.	59.0%
I do not feel I can be open about my HIV status in the workplace.	55.7%
I worry about getting sick or have gotten sick on the job.	31.1%
I worry about getting or have gotten medication side effects on the job.	16.4%
It is difficult to get away during the workday to go to HIV medical and service appointments.	13.1%
I cannot find or pay for someone to take care of my kids or family.	3.3%
Other	4.9%

Health Challenges

PLWH can experience a range of health issues. Often, PLWH may suffer from multiple co-occurring conditions such as Hepatitis B and C, Tuberculosis, or opportunistic infections.¹⁶ Even if HIV is well controlled, the disease causes chronic inflammation which may put PLWH at risk for other chronic conditions such as cardiovascular disease, kidney disease, bone disease, liver disease, cognitive disorders, and some types of cancer.¹⁷ PLWH are also at greater risk for mental health issues.¹⁸ Common experiences for PLWH – major life changes, negative life experiences, and opportunistic infections that impact the brain and nervous system – are risk factors for mental health problems.¹⁹ PLWH who experience symptoms of mental health conditions such as persistent feelings of sadness or anxiety, irritability, frustration, difficulty sleeping, eating more or less than typical or changes in appetite, feeling tired (even after

¹⁶ HIV.gov. (2019). Do People Living with HIV have Other Health Conditions? Retrieved from <https://www.hiv.gov/hiv-basics/staying-in-hiv-care/other-related-health-issues/other-health-issues-of-special-concern-for-people-living-with-hiv>

¹⁷ Ibid.

¹⁸ US Department of Health and Human Services. (2019). HIV and Mental Health. Retrieved from <https://aidsinfo.nih.gov/understanding-hiv-aids/fact-sheets/27/92/hiv-and-mental-health>

¹⁹ Ibid.

sleeping well, feeling guilty, worthless or helpless, or thinking about suicide or hurting oneself should seek mental health counseling through providers or support groups.²⁰

This section discusses survey participants’ physical and mental health challenges, aside from living with HIV. Though most study participants are living with health conditions other than HIV, they generally feel that they are in good physical health. A small but notable share of respondents report having issues related to their mental health, and fewer than one-half have discussed mental health topics with someone or received mental health treatment.

Respondents generally feel that they are in good physical health. Table 10 shows how survey participants rated their overall physical health. More than one-half of survey respondents rated their physical health as good or excellent, while fewer than one-in-ten rated their health as poor or very poor.

Table 10: How respondents rate their overall physical health

	All Respondents (n=173)	Respondents in TGA (n=51)
Excellent	12.7%	13.7%
Good	43.9%	47.1%
Fair	35.8%	35.3%
Poor	6.4%	3.9%
Very Poor	1.2%	0.0%

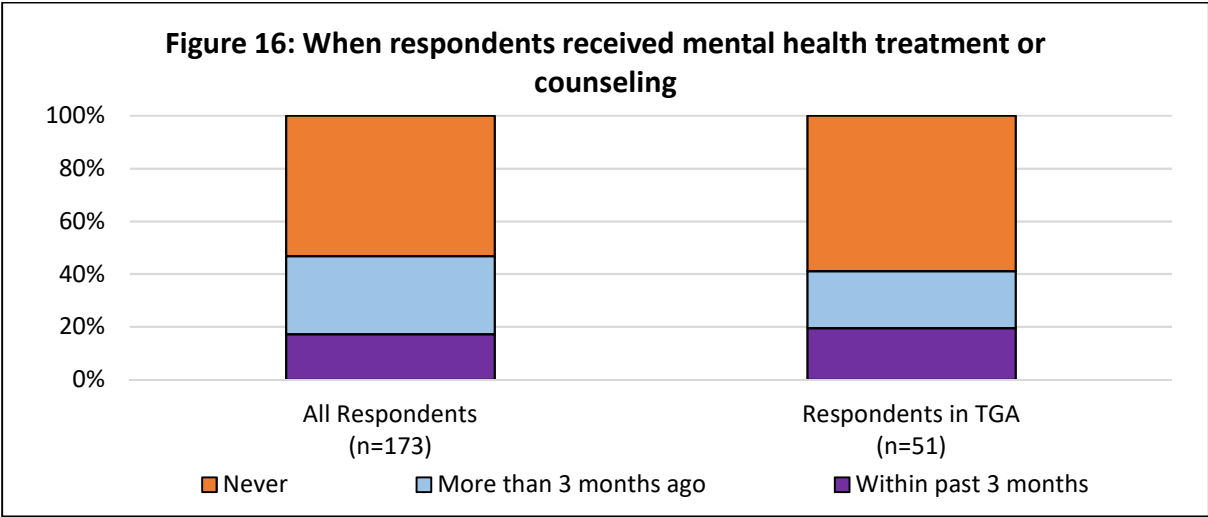
²⁰ HIV.gov. (2018). Mental Health and HIV. Retrieved from <https://www.hiv.gov/hiv-basics/staying-in-hiv-care/other-related-health-issues/mental-health>

Despite reporting generally good health, six-in-seven respondents are living with health conditions or issues in addition to their HIV (85% of all respondents, 92% of respondents in the TGA). When asked to select which health conditions, issues, or disabilities they experience, other than living with HIV, respondents most commonly reported living with high blood pressure, arthritis, high cholesterol, neuropathy and diabetes. Most respondents who answered that they have one or more of these health conditions are age 40 and over. A full list of respondents' other health conditions and disabilities is included in Table 11.

Table 11: Health conditions and challenges reported by respondents

	All Respondents (n=178)	Respondents in TGA (n=52)
High blood pressure	41.6%	44.2%
Arthritis	31.5%	38.5%
High cholesterol	27.0%	26.9%
Neuropathy	23.6%	26.9%
Diabetes	18.5%	23.1%
Asthma	16.3%	17.3%
Chronic obstructive pulmonary disease (COPD)	13.5%	9.6%
Heart disease	13.5%	23.1%
Brain or mental health issues	11.8%	13.5%
Sexually transmitted infection (such as, Chlamydia, gonorrhea, syphilis, herpes)	7.9%	7.7%
Lung condition that affects my ability to move around	7.3%	5.8%
Disabilities: Loss of hearing	6.7%	5.8%
Physical disability that requires me to use a walker, crutches, or leg braces to move around	6.7%	9.6%
Osteoporosis	6.2%	7.7%
Loss of vision not fixable with glasses	6.2%	1.9%
Hepatitis C	5.1%	3.8%
Cancer	4.5%	1.9%
Heart condition that affects my ability to move around	4.5%	7.7%
Hepatitis B	3.4%	1.9%
Lung disease (not tuberculosis or COPD)	2.2%	1.9%
Liver disease	1.1%	0.0%
Hemophilia/blood disorder	0.6%	1.9%
Physical disability that requires me to use a wheelchair to move around	0.0%	0.0%
Other health conditions	11.8%	11.5%

When it comes to mental health care, Figure 16 shows that three-fifths of survey participants have spoken to someone about mental health topics in the past six months – 60% of all respondents, 62% of those in the TGA (for additional details on who respondents discussed mental health topics with, see Appendix C). While a slight majority of respondents said they have never received mental health treatment or counseling, almost one-in-five reporting receiving it within the past three months and an another two- or three-in-ten respondents said they have received this type of service more than three months ago.



Substance Use

Substance use disorders are closely associated with increased risk of HIV transmission and negative treatment and maintenance outcomes. Substance use disorders are the problematic pattern of using alcohol or recreational drugs.²¹ Use of alcohol or drugs can lead to risky behavior, such as sex without a condom or intravenous drug use, that increases the risk for HIV transmission.²² High-risk practices are especially common among persons who inject drugs.²³ Sharing needles, syringes, and other drug equipment is a common method of transmitting HIV.²⁴ Prolonged substance use also weakens the already weakened immune systems of PLWH and can reduce the effectiveness of antiretrovirals, leading to increased viral loads and poor long-term health outcomes.²⁵ People who use alcohol or recreational drugs may avoid accessing

²¹ Centers for Disease Control and Prevention. (2019). HIV and Substance Use in the United States. Retrieved from <https://www.cdc.gov/hiv/risk/substanceuse.html>

²² Ibid.

²³ Centers for Disease Control and Prevention. (2019). HIV and People Who Inject Drugs. Retrieved from <https://www.cdc.gov/hiv/group/hiv-idu.html>

²⁴ Ibid.

²⁵ American Addiction Centers. (2019). Substance Abuse & HIV/AIDS. Retrieved from <https://americanaddictioncenters.org/health-complications-addiction/substance-abuse-hiv-aids>

services or treatment due to stigma and discrimination about participating in illicit activities; this is especially true for persons who inject drugs.²⁶

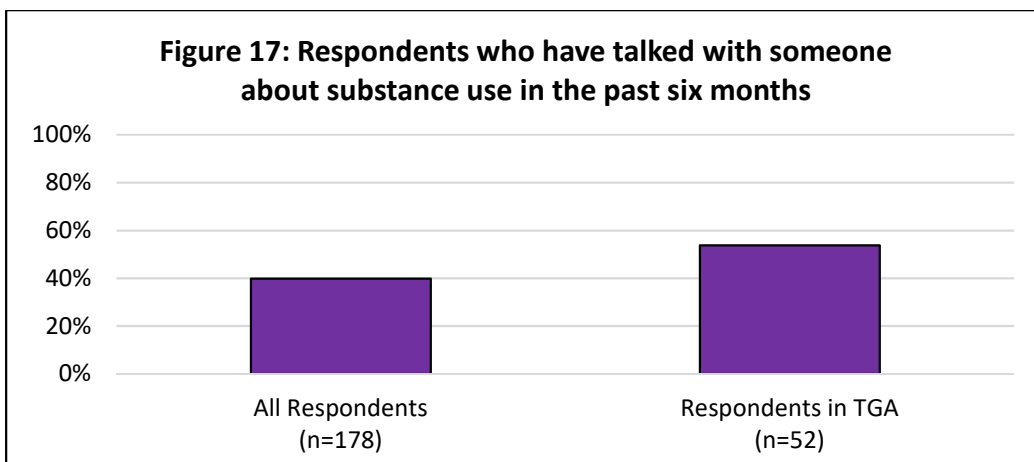
This section discusses the reported alcohol and non-prescribed drug use among study participants. Fewer than one-half of respondents reported substance use, and they are twice as likely to drink alcohol as use recreational drugs. Injection drug use is not common behavior among survey respondents, and sharing needles is very rare.

While many of the respondents do not use substances, those who do are more likely to drink alcohol than use recreational drugs. Table 12 displays reported substance use behaviors among survey respondents. More than one-third of all respondents drink alcohol, while almost one-in-six use recreational drugs. More than two-thirds of respondents in the TGA reported using at least one substance, with more than one-half of respondents in the TGA reporting drinking alcohol and almost one-quarter using recreational drugs.

Table 12: Respondents' substance use behaviors

	All Respondents (n=178)	Respondents in TGA (n=52)
Drinking alcohol	36.5%	55.8%
Using recreational drugs	15.7%	23.1%
None of these	54.5%	32.7%

About one-half of respondents have talked to someone about their substance use in the past six months, as seen in Figure 17. For additional details about who respondents spoke with about substance use, see Appendix C.



²⁶ Centers for Disease Control and Prevention. (2019). HIV and People who Inject Drugs. Retrieved from <https://www.cdc.gov/hiv/group/hiv-idu.html>

Among respondents who reported drinking or using recreational drugs, more than three-in-five have never experienced potential warning signs that they have a substance use issue. Table 13 shows things that respondents who drink alcohol or use recreational drugs have experienced in the past three months. The most common warning sign experienced by participants is the feeling that they should cut down or stop drinking or using drugs in the past three months.

Table 13: Respondents' substance use experiences in the past three months

	All Respondents (n=93)	Respondents in TGA (n=41)
Felt you should cut down or stop drinking or using drugs	16.1%	9.8%
Felt guilty or bad about how much you drink or use drugs	5.4%	2.4%
Woken up wanting to have an alcoholic drink or use drugs	5.4%	0.0%
Been annoyed by someone telling you to cut down or stop drinking or using drugs	3.2%	2.4%
None of these	63.4%	73.2%

Three-in-ten respondents have engaged in at least one drug or alcohol service. Table 14 shows the drug or alcohol services that have been used by survey participants. Almost one-quarter of all respondents have used 12-step meetings. More than one-third of respondents in the TGA have used at least one drug or alcohol service, with the largest share participating in 12-step meetings.

Table 14: Respondents' use of drug and alcohol services

	All Respondents (n=178)	Respondents in TGA (n=52)
12 step meetings (such as Alcoholics Anonymous or Narcotics Anonymous)	22.5%	30.8%
Inpatient services (services provided in a treatment facility or hospital setting and require patients to live at the facility)	11.8%	11.5%
Outpatient services (services that allow the patient to return home)	11.2%	19.2%
Detox or rehab programs	11.2%	9.6%
Residential or halfway house (services provided in non-hospital setting and require patients to live at the facility)	3.9%	7.7%
Needle exchange	2.8%	3.8%
Services or treatment in a shelter	1.1%	1.9%
Medications to treat drug or alcohol addiction other than Methadone or Buprenorphine	1.1%	0.0%
Methadone	0.6%	0.0%
Suboxone or Subutex (Buprenorphine)	0.6%	0.0%
Other	2.8%	3.8%
I have never used drug or alcohol services	69.1%	63.5%

Use of injection drugs is not common behavior among survey respondents, and sharing needles is very rare. Table 15 shows survey participants' reported needle or syringe use. While about one-in-eight survey participants have a history of injection drug use, only four respondents report still using injection drugs. Only one person reported sharing needles in the past 30 days. Among survey respondents who reported a history of injection drug use and that they are still able to get clean needles or works when needed, they reported getting supplies through a needle/syringe exchange or pharmacy.

Table 15: Needle or syringe use among respondents

	All Respondents (n=175)	Respondents in TGA (n=52)
Ever used a needle or syringe to inject any drugs into your body that were not prescribed to you.	13.1%	15.4%
No longer use needle or syringe to inject drugs	10.9%	11.5%
Used needle or syringe to inject any drugs that were not prescribed to you in the last 30 days	2.0%	1.9%
Shared needles in the past 30 days	0.6%	0.0%

HIV Medical Care and Adherence

HIV is a treatable condition that can be managed with early diagnosis, adherence to medication therapy, and regular visits to an HIV care provider, allowing PLWH to live long, healthy lives.²⁷ For PLWH, consistent HIV medical care leads to improved health outcomes, greater suppression of HIV viral loads, and reduced chances of HIV transmission.²⁸ The Health Resources and Services Administration (HRSA) introduced the HIV Care Continuum model to describe engagement in HIV care for PLWH, across the spectrum from people unaware of their HIV status to those fully engaged in care. HIV medical care retention involves appointment adherence, visit constancy, and lack of gaps in care.²⁹

ISDH recommends that PLWH should see their HIV care provider every three-to-four months for T-cell (CD4) and viral load testing.³⁰ T-cell testing measures the number of CD4 cells in the blood to fight disease, and viral load testing tracks the amount of HIV in the blood.³¹ Optimum testing shows a high T-cell count and low viral load.³² Normal T-cell counts are between 500

²⁷ HIV.gov (2017). Seeing Your Health Care Provider. Retrieved from <https://www.hiv.gov/hiv-basics/staying-in-hiv-care/provider-visits-and-lab-test/seeing-your-health-care-provider>

²⁸ Roscoe, C. and D. Hachey. (2019). Retention in HIV Care. *National HIV Curriculum*. Retrieved from <https://www.hiv.uw.edu/>

²⁹ Ibid.

³⁰ Indiana State Department of Health Division of HIV/STD/Viral Hepatitis. (2019). HIV Disease. Retrieved from <https://www.in.gov/isdh/23722.htm>

³¹ HIV.gov. (2017). Lab Tests and Results. Retrieved from <https://www.hiv.gov/hiv-basics/staying-in-hiv-care/provider-visits-and-lab-test/lab-tests-and-results>

³²Ibid.

and 1,500; if a person's T-cell count drops below 200, they are considered to have AIDS.³³ Viral load testing is considered the best way to tell if someone's HIV is being managed.³⁴ HIV is considered to be suppressed when a person's viral load is less than 200 copies of the virus per milliliter of blood.³⁵ This is accomplished through antiretroviral therapy that prevents the virus from making copies of itself.³⁶ Almost every PLWH who adheres to daily antiretroviral medication will see their viral load drop to suppressed levels, or even undetectable levels (less than 50) within six months.³⁷

Adhering to HIV medications is important for reaching the desired T-cell and viral load counts.³⁸ Lack of proper medication adherence can lead to high viral load numbers, drug resistance, treatment failure, and damage to the immune system.³⁹

PLWH may not retain HIV medical care for a variety of reasons. Some of the risk factors for decreased retention in care are related to race/ethnicity (increased risk for people of color), gender (transgender women), sexual orientation (heterosexual), geographic location (non-metropolitan area), age (ages 24 and younger), insurance status (un/underinsured), mental illness, substance use, and stigma and fear. Increased engagement and retention in HIV medical care is a key priority of the *Ending the HIV Epidemic: A Plan for America*.⁴⁰

This section discusses data on survey participants' current HIV health status, engagement in HIV medical care, and medication adherence. Most respondents are adhering to recommendations about engaging in and adhering to HIV medical care and medication adherence and are managing their HIV, according to T-cell and viral load testing. Generally, respondents who did not adhere to their HIV medication regimen as prescribed did not do so intentionally. A small but notable share of respondents feel they have been treated poorly by medical providers due to sexual orientation, race, age, gender identity, sex, or religion.

Most respondents have seen their HIV medical provider within the recommended timeframe – the last 6 months. Table 16 displays the last time survey respondents saw an HIV medical provider. About one-in-seven survey participants are out of compliance, having seen their HIV

³³ The Well Project. (2019). Understanding CD4 Cells and CD4 Cell Tests. Retrieved from <https://www.thewellproject.org/hiv-information/understanding-cd4-cells-and-cd4-cell-tests>

³⁴ UNAIDS. (2016). The Need for Routine Viral Load Testing. Retrieved from https://www.unaids.org/sites/default/files/media_asset/JC2845_en.pdf

³⁵ Centers for Disease Control and Prevention. (2019). HIV Treatment as Prevention. Retrieved from <https://www.cdc.gov/hiv/risk/art/index.html>

³⁶ National Institute of Allergy and Infectious Diseases (2017). 10 Things to Know about HIV Suppression. Retrieved from <https://www.niaid.nih.gov/news-events/10-things-know-about-hiv-suppression>

³⁷ Ibid.

³⁸ US Department of Health and Human Services (2019). HIV Treatment Adherence. Retrieved from <https://aidsinfo.nih.gov/understanding-hiv-aids/fact-sheets/21/54/hiv-treatment-adherence>

³⁹ Ibid.

⁴⁰ Ibid.

medical provider more than six months ago. Fewer than five of all survey respondents have never seen an HIV medical provider.

Table 16: Last time survey respondents saw an HIV medical provider

	All Respondents (n=281)	Respondents in TGA (n=93)
Less than 6 months ago	85.1%	89.3%
6 months to 1 year ago	11.0%	9.7%
More than 1 year ago	3.6%	1.1%
Never	0.4%	0.0%

Almost all respondents get HIV medical care, most commonly at a private doctor’s office. Table 17 shows the share of survey respondents who access HIV medical care at different settings. More than one-half of all respondents usually go to a private doctor’s office for HIV medical care, while about one-fifth go to a hospital or community clinic (two-fifths and one-third, respectively, among respondents in the TGA). Where respondents access ongoing HIV medical care corresponds to where most respondents were tested when they were diagnosed with HIV. For additional information about where and why participants were tested, see Appendix D.

Table 17: Where respondents usually go for HIV medical care

	All Respondents (n=175)	Respondents in TGA (n=52)
Private doctor's office	57.1%	42.3%
Hospital clinic	21.1%	36.5%
Community health center or clinic	10.9%	9.6%
Veterans Affairs (VA) hospital or clinic	2.3%	1.9%
Emergency room	0.0%	0.0%
Other	7.4%	9.6%
I don't get medical care	1.1%	0.0%

Almost all respondents are keeping their HIV medical appointments (96% of all respondents and respondents in the TGA). Only seven participants reported that they did not keep their last appointment, providing the following reasons:

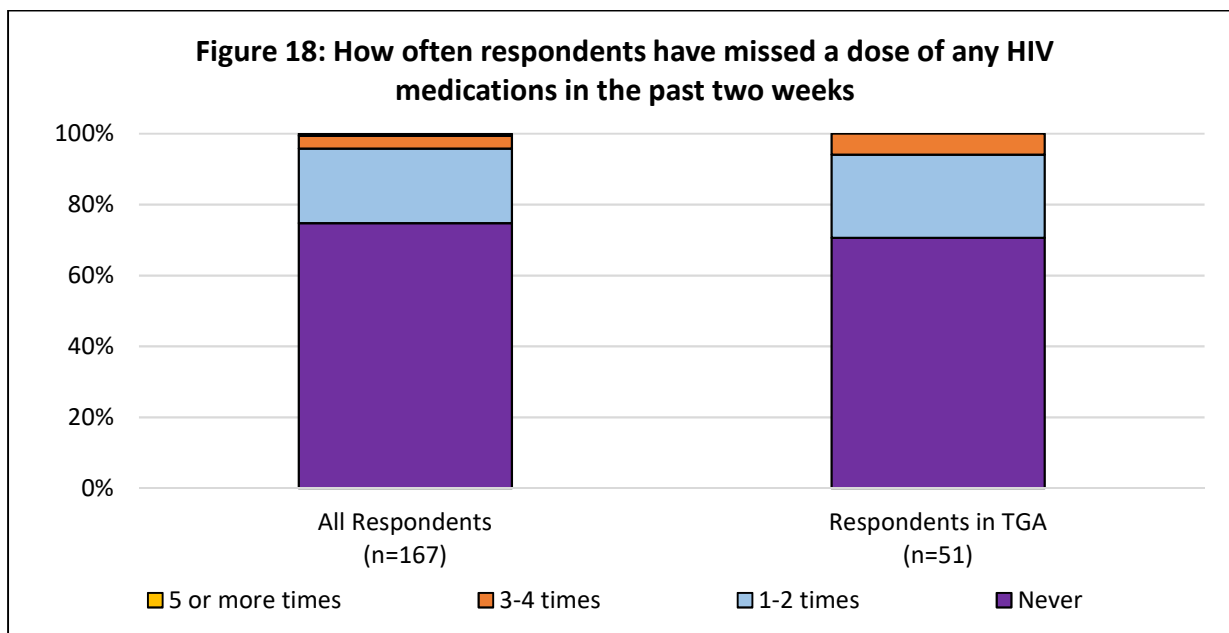
- Lack of transportation to/from their appointment
- Unable to leave work
- Lack of child care
- Too sick to go
- Family emergency

Most respondents are managing their HIV, based on their T-cell and viral load tests. Table 18 shows the reported most recent T-cell and viral load numbers for survey participants. Two-thirds of respondents have a desired T-cell count of 200 or more, and almost six-in-seven have the desired viral load of less than 200, meaning their HIV is suppressed.

Table 18: Reported results of respondents' most recent HIV blood tests

	T-Cell (CD4) Test		Viral Load Test	
	All Respondents (n=172)	Respondents in TGA (n=51)	All Respondents (n=171)	Respondents in TGA (n=49)
Less than 200	16.3%	11.8%	86.5%	89.8%
200 or more	67.4%	76.5%	5.3%	2.0%
I can't remember my test results	14.0%	11.8%	7.0%	8.2%
I've only had one test and am still waiting for the results	0.6%	0.0%	0.6%	0.0%
I don't know if I've ever had a test or don't know what it is	1.7%	0.0%	0.6%	0.0%
I've never had a test	0.0%	0.0%	0.0%	0.0%

Almost all survey respondents (97%) are on antiretroviral medications, and most are adhering to their medication as prescribed. Figure 18 shows the number of times respondents taking HIV medications reported missing a dose in the past two weeks. Only one-quarter of respondents reported missing any doses in the past two weeks, with about one-in-five respondents only missing one or two doses. The number of people who reported that they do not take antiretrovirals was too low to analyze why they are not taking them.

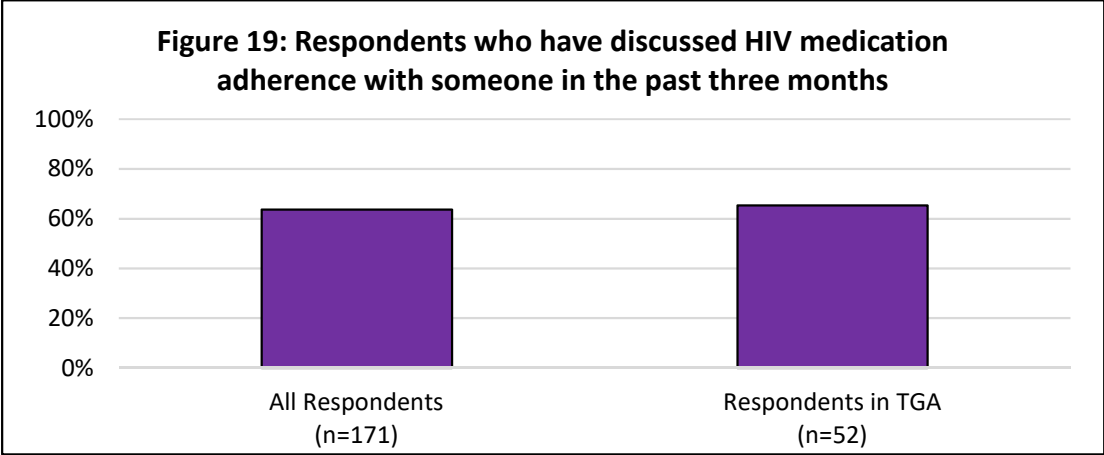


Generally, respondents who did not adhere to their HIV medication regimen as prescribed did not do so intentionally. Table 19 shows the reasons respondents reported for missing a dose of any HIV medication in the past two weeks. While some respondents reported multiple reasons, a vast majority of all respondents said they missed doses of their medication because they forgot to take them. However, it is notable that one-in-ten respondents chose not to take their medication. Analysis could not be reported for respondents in the TGA because the number of respondents was too low.

Table 19: Reason for missing HIV medication dose in the past two weeks

	% (n=40)
Forgot to take them	87.5%
Felt depressed or overwhelmed	15.0%
I chose not to take them.	10.0%
Wanted to avoid side effects	7.5%
Had problems taking medication at a certain time	5.0%
Had too many medications to take	5.0%
Felt too sick	5.0%
Could not get to a pharmacy	5.0%
Could not afford medication	2.5%
Could not get to a doctor or clinic	0.0%
Was living on the street or homeless	0.0%
My medical provider told me to stop taking them.	0.0%
Other	5.0%

Most respondents discussed HIV medication adherence with someone in the past three months, as seen in Figure 19. For additional details on with whom respondents discussed medication adherence, see Appendix C.



About one-in-ten survey participants feel they have been treated poorly by medical providers due to discrimination. Table 20 shows the share of survey respondents who felt they have been treated poorly by medical providers based on age, race, sex, gender identity, sexual orientation, or religion. The most common reasons respondents have felt they were treated poorly by medical providers are sexual orientation and race.

Table 20: Reasons respondents feel they have been treated poorly by medical providers

	All Respondents (n=178)	Respondents in TGA (n=52)
Sexual orientation	3.9%	5.8%
Race	2.8%	3.8%
Age	1.1%	1.9%
Gender identity	1.1%	1.9%
Sex	0.6%	1.9%
Religion	0.6%	0.0%
Immigration status	0.0%	0.0%
None of these	89.9%	88.5%

Perceived Discrimination and Disclosure

HIV-related stigma and discrimination are detrimental to PLWH and the public at large. HIV stigma is about prejudice or negative attitudes and beliefs about PLWH, while the behaviors that result from those negative attitudes or beliefs are discrimination.⁴¹ Stigma and discrimination are often rooted in fear driven by misinformation and misperceptions about the transmission of HIV and who can get it. HIV is still commonly perceived as dangerous, contagious, and associated with certain behaviors or groups.⁴² This leads to negative value judgments about PLWH and their lifestyles.⁴³ Individuals living with HIV may internalize stigma in a way that results in negative self-image and feelings of shame, fear of disclosure, isolation, and despair.⁴⁴ It also serves as a major barrier in the prevention of new HIV transmissions and engaging PLWH in treatment, care, and support services and their adherence to treatment and care regimens.⁴⁵ Fear of stigma and discrimination can prevent PLWH from

⁴¹ Centers for Disease Control and Prevention. (2019). Facts about HIV Stigma. Retrieved from <https://www.cdc.gov/hiv/basics/hiv-stigma/index.html>

⁴² Thapa et. al. (2018). Theorizing the Complexity of HIV Disclosure in Vulnerable Populations: A Grounded Theory Study. *BMC Public Health*. 18:162. DOI 10.1186/s12889-018-5073-x.

⁴³ Centers for Disease Control and Prevention. (2019). Facts about HIV Stigma. Retrieved from <https://www.cdc.gov/hiv/basics/hiv-stigma/index.html>

⁴⁴ Ibid.

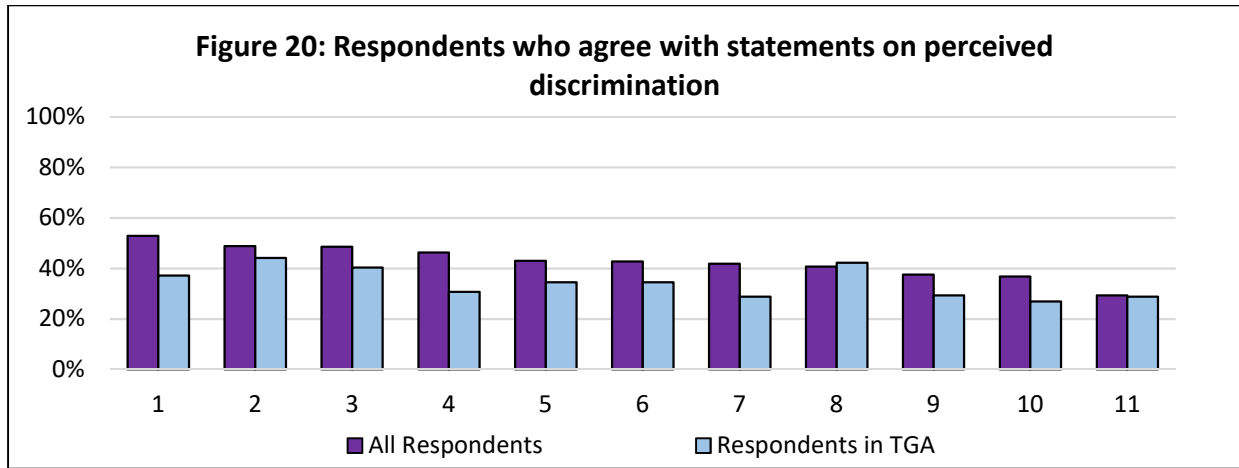
⁴⁵ Stangl AL et al. (2013). A Systematic Review of Interventions to Reduce HIV-related Stigma and Discrimination from 2002 to 2013: How Far Have We Come? *Journal of the International AIDS Society*. 16(Suppl2): 18734. <http://dx.doi.org/10.7448/IAS.16.3.18734>.

disclosing their HIV status to others. PLWH are more likely to access HIV treatment, utilize strategies to prevent HIV transmission, and live healthier lives after disclosure.⁴⁶

This section discusses the perceived discrimination survey participants feel because they are living with HIV, disclosure of their HIV status, and concerns they have felt when considering disclosure. While specific feelings of perceived discrimination vary among survey respondents, every respondent agreed they have at least some fear of stigma associated with living with HIV. People who experience high levels of perceived discrimination have unmet needs related to their HIV. While most participants experience concerns when considering telling someone they are living with HIV, almost all respondents have disclosed their HIV status to at least one person other than their HIV medical provider.

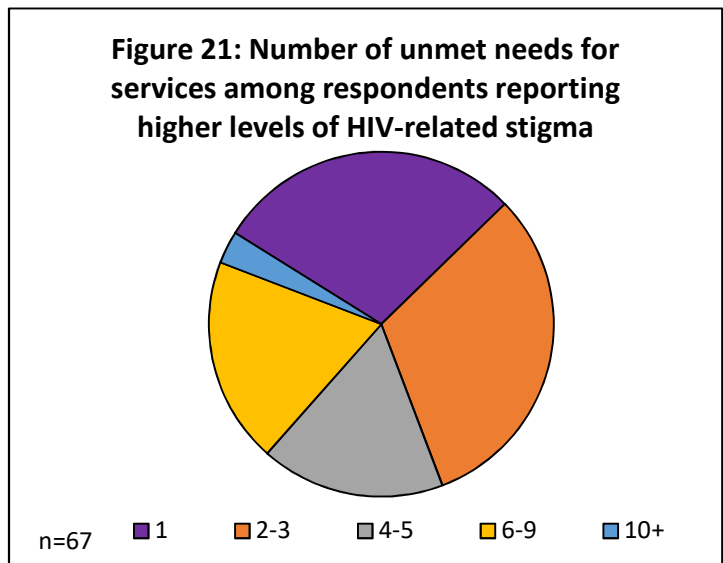
Perceived discrimination is a concern among survey participants. They were asked to share their level of agreement with a series of statements about perceived discrimination based on HIV status. All respondents agreed with at least one of the statements and about two-in-five agreed with three or more statements. Figure 20 on shows the shares of all respondents and shares of respondents in the TGA, respectively, who agree with statements on perceived discrimination due to their HIV status. The statement with the highest level of agreement among all respondents was related to PLWH being rejected when people find out. The statement with the highest level of agreement among respondents in the TGA is related to feeling judged for having HIV.

⁴⁶ Thapa et. al. (2018). Theorizing the Complexity of HIV Disclosure in Vulnerable Populations: A Grounded Theory Study. *BMC Public Health*. 18:162. DOI 10.1186/s12889-018-5073-x.



#	Statement	All Respondents N	Respondents in TGA N
1	Most people with HIV are rejected when others find out.	170	51
2	I feel judged for having HIV.	174	52
3	People with HIV are treated like outcasts.	175	52
4	I work hard to keep my HIV a secret from others.	175	52
5	Since learning I have HIV, I feel set apart or isolated from the rest of the world.	174	52
6	Having HIV negatively affects how I feel about myself.	173	52
7	It is hard for people living with HIV to have long-term relationships.	174	52
8	I have lost friends or family members by telling them I have HIV.	174	52
9	I feel guilty because I have HIV.	173	51
10	People's attitudes about HIV make me feel worse about myself.	174	52
11	I have stopped hanging out with some people because of their reactions to my having HIV.	174	52

Because feelings of perceived discrimination may prevent PLWH from accessing services, the level of unmet need was analyzed for respondents who agreed with at least three of the stigma-related statements above. All respondents who reported higher levels of perceived discrimination also reported having at least one unmet need, as seen in Figure 21. Two-in-five have at least four unmet needs. Level of unmet need could not be analyzed for all respondents who agreed with fewer than three of the stigma-related statements or respondents in the TGA due to low n.



Almost all respondents have disclosed their HIV status to at least one person other than their HIV medical provider. Table 21 shows the individuals, other than their HIV medical providers, whom survey participants have told they are living with HIV. Only seven respondents reported that no one else knows they have HIV. Friends, case managers, and family members are the most common people in all respondents' lives who know about their HIV status.

Table 21: People (other than HIV medical providers) who know respondents are living with HIV

	All Respondents (n=178)	Respondents in TGA (n=52)
Friend	73.0%	80.8%
Case Manager	70.2%	80.8%
Another family member	68.0%	76.9%
Dentist	62.9%	69.2%
Other medical provider	60.1%	63.5%
Husband/wife/partner/significant other	37.1%	38.5%
My children	25.8%	23.1%
Other service provider	22.5%	25.0%
Religious or spiritual leader	15.2%	21.2%
OB/GYN	14.0%	15.4%
Co-worker	9.6%	13.5%
Manager, supervisor, or human resources person	7.3%	15.4%
No one else knows	3.9%	0.0%

Most survey participants experience concerns when considering telling someone they are living with HIV. Table 22 shows the share of respondents who reported having felt certain concerns when thinking about telling someone they are living with HIV. The most commonly named concerns were being afraid how others will react, being afraid people will judge them, and the fact that it is not anyone else's business.

Table 22: Respondents' concerns about telling someone their HIV status

	All Respondents (n=178)	Respondents in TGA (n=52)
I am afraid of how others will react.	58.4%	40.4%
I am afraid people will judge me.	45.5%	38.5%
It is my own business, and no one else needs to know.	41.6%	51.9%
I feel like I can manage on my own.	19.7%	23.1%
I am afraid I will lose my job.	19.1%	13.5%
I am afraid for my own safety.	14.0%	11.5%
I am still coming to terms with my status myself.	8.4%	7.7%
I am afraid because of my immigration status.	1.7%	0.0%
Other	5.6%	9.6%
None of these	15.7%	21.2%

Aging while Living with HIV

In the more than 30 years since the start of the HIV epidemic, great improvements have been made in antiretroviral therapy, meaning that PLWH who are diagnosed early and get and adhere to treatment can suppress the virus and have greater duration and quality of life.⁴⁷ With longer duration of life, there is a growing population of PLWH who are age 50 and older. However, in addition to the general challenges that occur with aging, this population can face additional complications and stressors due to having long-term HIV.⁴⁸

This section discusses data related to study participants' perspectives on issues facing PLWH as they age. Respondents have many concerns as they age with HIV, with the most common concerns related to their overall health and end of life care.

Almost all survey participants have some concerns about aging while living with HIV, and many have several types of concerns. Table 23 below shows the share of respondents who reported at least one concern in each category. Only six respondents did not report any concerns related to aging with HIV. Most respondents have concerns about their overall health, followed by end of life care. However, at least three-quarters of respondents have at least one concern in each category.

Table 23: Respondents' concerns as they age

	All Respondents (n=178)	Respondents in TGA (n=52)
Overall health	92.7%	92.3%
End of life care	84.3%	75.0%
Relationships and Social Networks	78.1%	67.3%
Ongoing HIV care	74.7%	69.2%
Other factors	73.6%	71.2%
None of these	3.4%	3.8%

⁴⁷ HIV.gov. (2019). Growing Older with HIV. Retrieved from <https://www.hiv.gov/hiv-basics/living-well-with-hiv/taking-care-of-yourself/aging-with-hiv>

⁴⁸ Ibid.

Most survey participants are concerned about their ongoing HIV care as they age. Table 24 shows survey respondents' concerns regarding ongoing HIV care as they age. Only one-quarter of respondents reported that they did not have any concerns about their ongoing HIV care. The most common concerns are the cost of HIV medications and maintaining access to HIV services.

Table 24: Respondents' concerns about ongoing HIV care as they age

	All Respondents (n=178)	Respondents in TGA (n=52)
The costs of my HIV medications	51.1%	57.7%
Maintaining access to or getting the HIV services I need	51.1%	50.0%
Finding medical providers who understand HIV and aging	31.5%	28.8%
Other	6.7%	5.8%
None of these	25.3%	30.8%

Almost all participants are concerned about their overall health as they age. Table 25 shows survey respondents' concerns regarding their overall health as they age. Only about 7% of respondents did not report any concerns about their overall health as they age while living with HIV. While many respondents named multiple concerns, the most common were staying healthy, managing HIV and other aging-related conditions, and the long-term impact of HIV medications.

Table 25: Respondents' concerns about their overall health as they age

	All Respondents (n=178)	Respondents in TGA (n=52)
Staying healthy	69.1%	67.3%
Managing HIV and other conditions that come with aging	68.0%	67.3%
Long-term impacts of HIV medications	61.2%	61.5%
Maintaining my mental/emotional wellbeing	53.9%	51.9%
The impact of HIV on my quality of life	53.9%	44.2%
Maintaining healthy behaviors (like safer sex) over time	18.5%	13.5%
Other	2.8%	1.9%
None of these	7.3%	7.7%

Most study participants are concerned about their relationships and social networks as they age. Table 26 shows survey respondents' concerns regarding their relationships and social networks as they age. Only one-in-five respondents did not report any social or relationship concerns related to aging with HIV. The most common concern is finding or having someone to share their lives with.

Table 26: Respondents' concerns about relationships and social networks as they age

	All Respondents (n=178)	Respondents in TGA (n=52)
Finding or having someone to share my life with	52.2%	48.1%
Telling people about my HIV status	35.4%	30.8%
Dating	34.3%	28.8%
Taking care of my husband, wife, partner, significant other, or other family members	24.7%	25.0%
Having a family	14.6%	11.5%
Other	3.4%	1.9%
None of these	21.9%	32.7%

Most respondents are concerned about end of life care as they age with HIV. Table 27 shows survey respondents' concerns about end of life care. Fewer than one-in-six respondents did not report any end of life concerns (one-in-four respondents in the TGA). The most commonly reported were being a burden on the those who will take care of them end of life planning.

Table 27: Respondents' concerns about end of life care

	All Respondents (n=178)	Respondents in TGA (n=52)
Being a burden on friends, family, or people who will take care of me	66.9%	59.6%
Planning for the end of my life (making a will, long-term care, etc.)	52.2%	44.2%
Finding retirement or nursing home providers who understand HIV	41.6%	36.5%
Other	2.8%	5.8%
None of these	15.7%	25.0%

Most participants are concerned about other self-sufficiency factors as they age. Table 28 shows survey respondents' concerns about end of life care. Only one-in-four respondents did not report any concerns about other factors that might impact their lives as they age. The most commonly reported concerns are maintaining stable housing and paying off debt.

Table 28: Respondents' concerns about other factors as they age

	All Respondents (n=178)	Respondents in TGA (n=52)
Maintaining stable housing	43.8%	40.4%
Paying off debt	40.4%	44.2%
Going to work or having a job	29.2%	28.8%
Finding stable housing	25.8%	25.0%
Getting more education	7.3%	1.9%
Other	3.4%	1.9%
None of these	26.4%	28.8%

Positive Prevention

Positive Prevention is aimed to help PLWH protect their health and avoid transmitting HIV to other people by increasing the self-esteem, well-being, and solidarity of PLWH.⁴⁹ There are ever-increasing numbers of strategies that PLWH can use to prevent the transmission of HIV to others, include: abstinence, limiting sexual partners, not sharing needles, and proper condom use.⁵⁰ It is critical that HIV prevention education be included in ongoing care for PLWH in order to protect their health and the health of potential partners.⁵¹ HIV medical providers and case managers, along with others who regularly provide care to PLWH, are an important resource for prevention information and strategies for PLWH.⁵²

In addition to reducing individual risk behaviors among PLWH, there are other strategies that can be used to prevent new HIV transmissions. There is a strong correlation between housing stability and reduced HIV risk behavior among PLWH, making housing an important prevention strategy.⁵³ Studies have also proven that PrEP, a daily antiretroviral medication taken by people who do not have HIV, dramatically reduce their chances of acquiring HIV and

⁴⁹ World Health Organization. (2008). Positive Prevention. Retrieved from https://www.who.int/hiv/pub/plhiv/living2008_wg_posprev.pdf

⁵⁰ Centers for Disease Control and Prevention. (2019). Prevention. Retrieved from <https://www.cdc.gov/hiv/basics/prevention.html>

⁵¹ Centers for Disease Control and Prevention. (2003). Incorporating HIV Prevention into Medical Care of Persons Living with HIV. *MMWR* 52(RR12) :1-24.

⁵² Ibid.

⁵³ Shubert, V. and N. Berstine. (2007). Moving from Fact to Policy: Housing is HIV Prevention and Health Care. *AIDS and Behavior* 11(2):172. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/17705094>

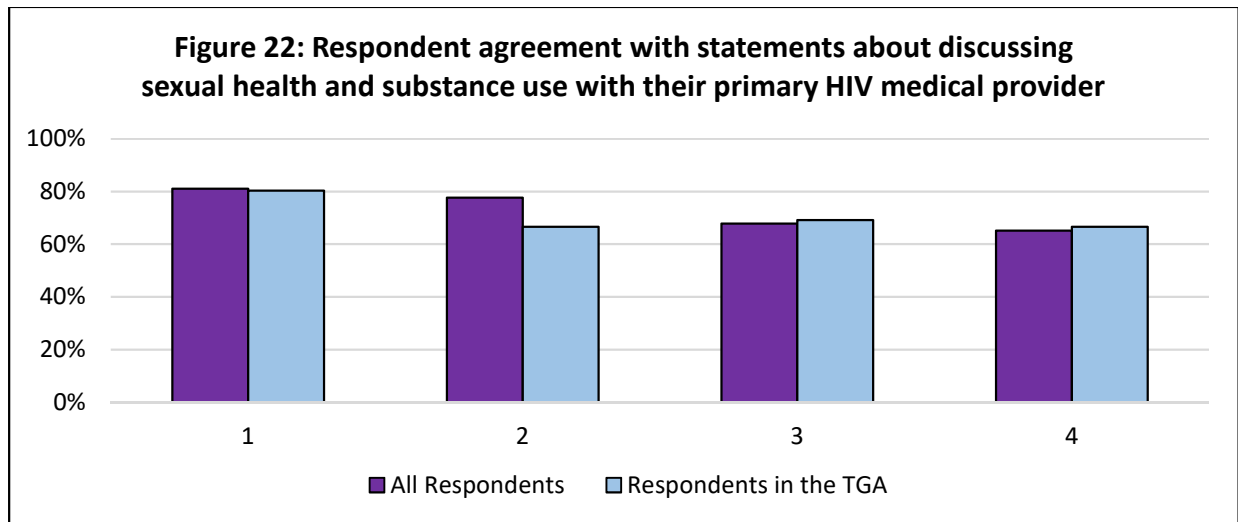
the number of new cases of HIV.⁵⁴ However, perhaps the most important component in preventing new HIV cases is education. Lack of knowledge about HIV, HIV transmission, and effective prevention strategies has been identified as the leading factors in HIV transmission, leaving people most vulnerable to acquiring HIV.⁵⁵

This section discusses study participants' experiences with individual prevention behaviors, feelings on other prevention activities, and general knowledge of HIV and HIV transmission. Feeling comfortable discussing issues of prevention with their HIV care team is still an issue for a significant minority of study participants, particularly around substance use. They are less comfortable discussing issues of sex and substance use with their medical providers than their case managers. Even though more survey participants are comfortable discussing sex than substance use, many have not recently discussed their sexual health, related to positive prevention, with anyone. Survey participants have a mixed understanding of the effectiveness of certain HIV prevention strategies, knowledge of HIV transmission, and knowledge of HIV facts.

⁵⁴ Centers for Disease Control and Prevention. (2017). HIV Prevention Works. Retrieved from <https://www.cdc.gov/hiv/policies/hip/works.html>

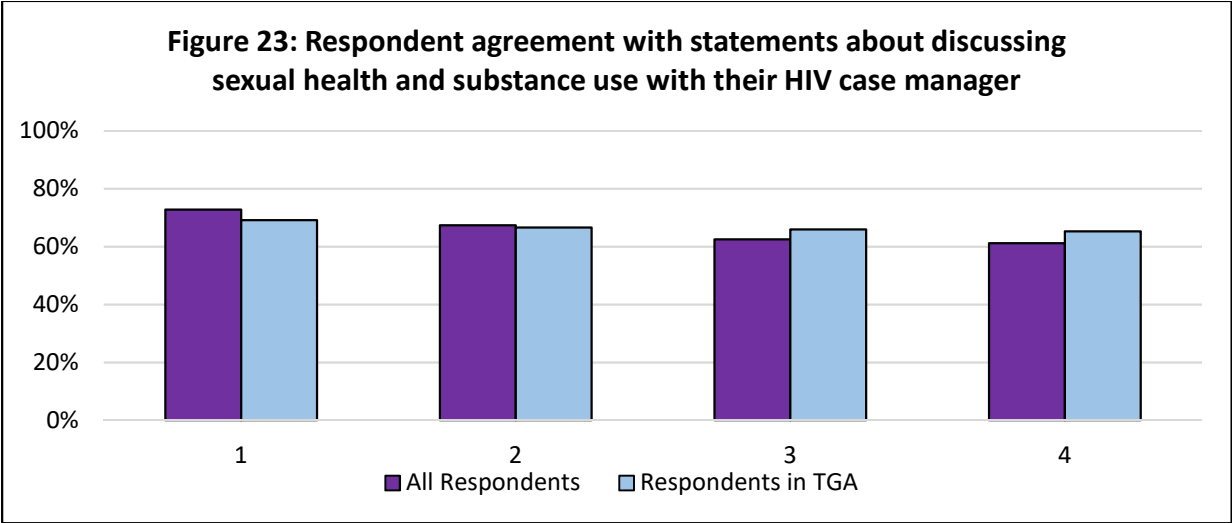
⁵⁵ Sarma, H., & Oliveras, E. (2013). Implementing HIV/AIDS education: impact of teachers' training on HIV/AIDS education in Bangladesh. *Journal of health, population, and nutrition*, 31(1), 20–27. doi:10.3329/jhpn.v31i1.14745.

While many survey participants are discussing their sexual health and substance use with providers, a notable share is not, and respondents are less comfortable discussing substance use. Figure 22 shows the shares of respondents who agreed with a series of statements about their comfort in discussing sex or substance use with their HIV medical provider, and their HIV medical provider’s comfort in doing the same. One-third of respondents are not comfortable discussing alcohol or drug use with their HIV medical provider, and about the same share reported that their medical provider is not comfortable discussing substance use with them. One-in-five respondents are not comfortable discussing sex with their providers, and about the same share do not feel their provider is comfortable discussing sex with them.



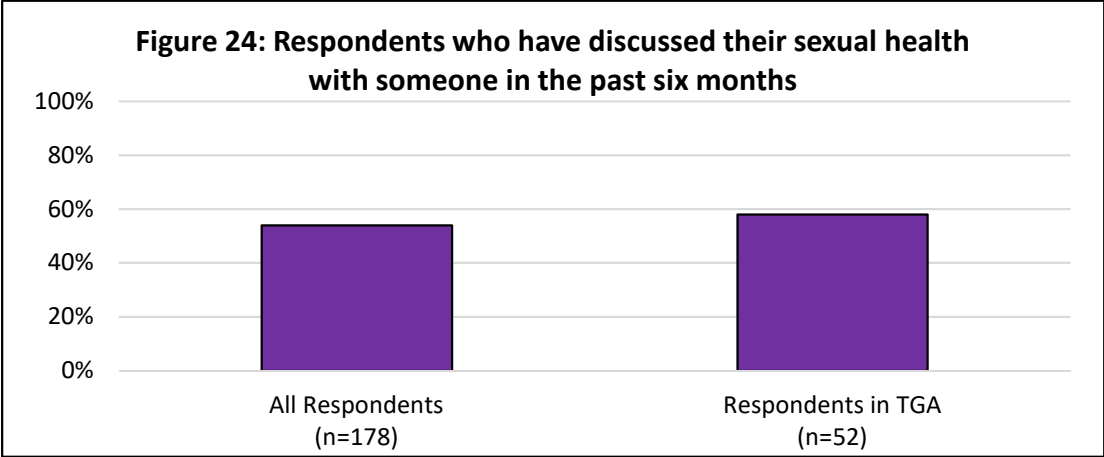
#	Statement	All Respondents n	Respondents in TGA n
1	My HIV medical provider seems comfortable discussing sex with me, including ways to keep my partner (s) and me healthy.	149	51
2	I am comfortable discussing sex with my HIV medical provider, including ways to keep my partner (s) and me healthy.	148	52
3	My HIV medical provider seems comfortable discussing alcohol and/or drug use with me.	123	52
4	I am comfortable discussing alcohol and/or drug use with my HIV medical provider.	124	52

Survey participants are slightly less comfortable discussing sex and substance use with their HIV case managers than with their medical providers. Figure 23 shows the shares of respondents who agreed with a series of statements about their comfort in discussing sex or substance use with their HIV case manager, and their HIV case manager’s comfort in doing the same. Three-in-five respondents are not comfortable discussing alcohol or drug use with their case manager, and about the same share reported that their case manager is not comfortable discussing substance use with them. Two-thirds of respondents are not comfortable discussing sex with their providers, and one-quarter do not feel their provider is comfortable discussing sex with them.

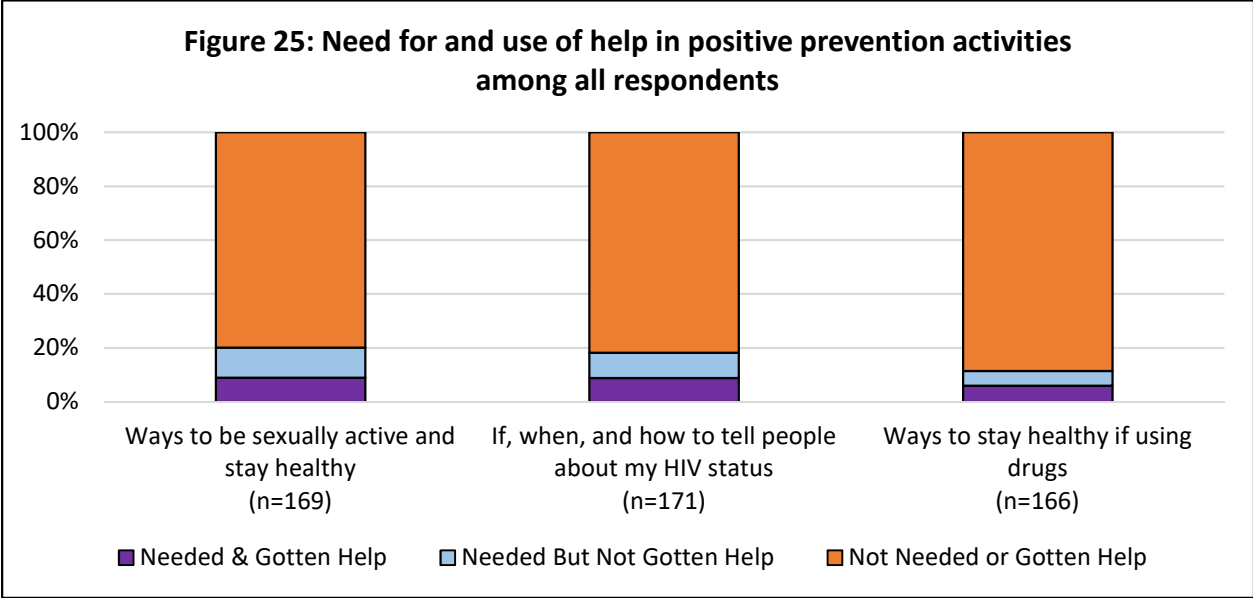


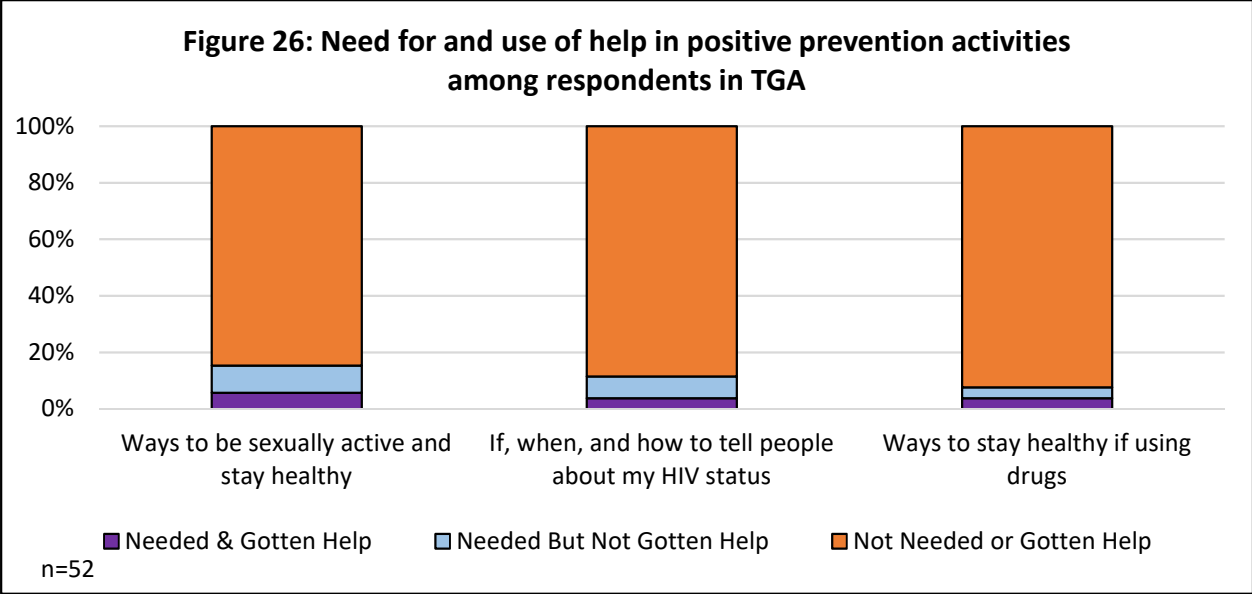
#	Statement	All Respondents N	Respondents in TGA N
1	My case manager seems comfortable discussing sex with me, including ways to keep my partner (s) and me healthy.	137	40
2	I am comfortable discussing sex with my HIV case manager, including ways to keep my partner (s) and me healthy.	133	39
3	My HIV case manager seems comfortable discussing alcohol and/or drug use with me.	116	37
4	I am comfortable discussing alcohol and/or drug use with my case manager.	116	37

Many study participants have not discussed ways to maintain their sexual health, specifically related to ways to reduce the transmission of STDs and Hepatitis, with someone in the past six months. Figure 24 below shows that only about one-half of respondents have recently discussed their sexual health with someone. For additional details about who respondents discussed their sexual health with, see Appendix C.

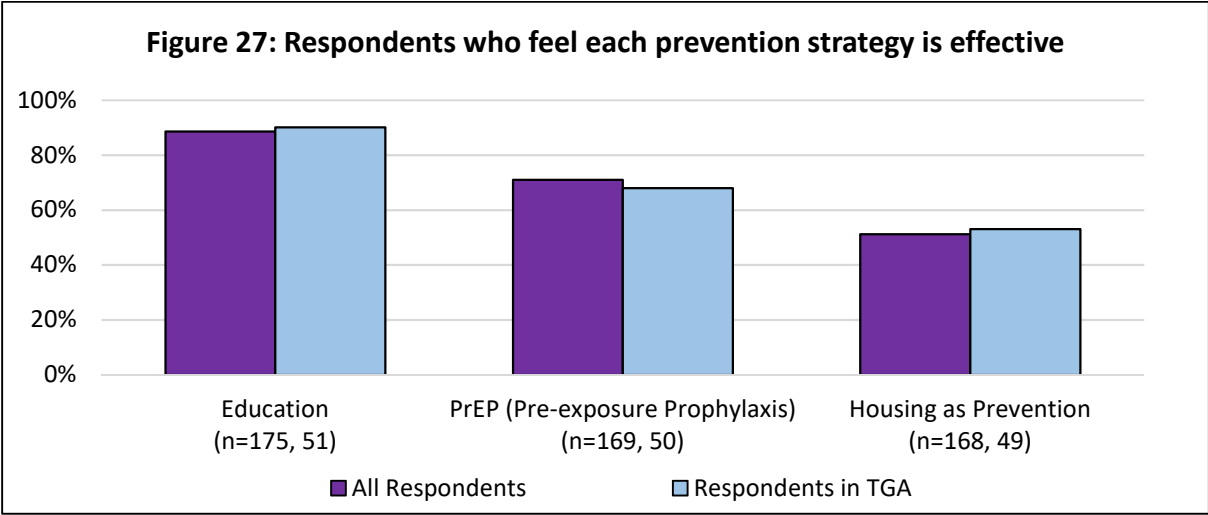


Most respondents have not needed or used help in figuring out ways to stay healthy and sexually active, how to disclose their HIV status, or stay healthy while using drugs. Figures 25 and 26 show survey participants’ reported need for and use of help in positive prevention activities among all respondents and respondents in the TGA, respectively. At least four-in-five reported that they did not need or get help with any of the activities. The greatest shares of respondents needed help with ways to be sexually active and stay healthy and disclosure.





In addition to asking about respondents’ individual behaviors related to positive prevention, survey participants were asked about their views on the effectiveness of evidence-based prevention strategies. While most respondents agreed that education and PrEP were effective prevention strategies, they were less sure about the effectiveness of housing as prevention. Figure 27 shows survey participants’ opinions on whether certain HIV prevention strategies are effective. About nine-in-ten respondents agreed that education is at least somewhat effective, seven-in-ten feel PrEP is effective, but only about one-half feel housing is an effective prevention strategy.



Survey participants were asked a series of True/False questions to gauge their knowledge of HIV and HIV transmission. Respondents were generally knowledgeable about HIV transmission; a majority could not define a T-cell test. Table 29 shows the shares of survey respondents who correctly answered the True/False questions. Almost all respondents correctly identified the statement that an “undetectable” viral load does not mean someone is cured of HIV. Fewer than one-half of all respondents correctly answered that a T-cell test does not measure the amount of HIV in someone’s body.

Table 29: Share of respondents who correctly answered HIV-related questions

True/False Statement	Correct Answer	All Respondents (n=176)	Respondents in TGA (n=52)
If a person with HIV has a viral load that is "undetectable" that means he/she/they are cured of HIV.	FALSE	96.0%	94.2%
Using a condom is an effective way to prevent HIV transmission during sex.	TRUE	89.7%	88.5%
The use of recreational drugs can impact the effectiveness of HIV medications.	TRUE	83.4%	84.6%
A woman with HIV can give birth to a child without having a baby with HIV.	TRUE	59.7%	61.5%
A T-cell (CD4) test measures the amount of HIV in the body of a person living with HIV.	FALSE	42.8%	52.9%

Service Needs, Access, and Barriers

Understanding the health, treatment, and support service needs of PLWH is critical to the development of programs, policies, and interventions designed to reduce the burden of HIV in Indiana. The positive benefits of resources and services designed to increase social support, create employment opportunities, reduce financial problems, and discourage high-risk behaviors are well-documented in the literature. For example, a longitudinal study assessing engagement in HIV primary care found that variations in access to services and structural barriers were among the factors associated with the engagement in care. In fact, after introducing interventions to reduce barriers and more effectively meet needs, 58% of individuals who were not engaged in care at baseline became fully engaged at the 12-month follow up.⁵⁶

To understand their service needs and the barriers they face in accessing those service needs, survey participants were asked to review a list of 20 types of services and indicate the role each service plays in maintaining their health, whether they have had needed each of the service types in the recent past, and, if so, whether their service needs were met or unmet. Specifically, respondents were asked to indicate whether each of the services is/has been:

- Essential in maintaining overall health (Essential)
- Needed and used in the past 6 months (Met Need)
- Needed, but could not get in the past 6 months (Unmet Need)
- Not needed and not used in the past 6 months (Not Needed)

A complete list of the services included in the survey is on page 50.

Level of Need

Level of need was assessed based on the relative number of services for which respondents indicated a need. Overall, the study population reported a fairly high need for services. Table 30 shows the distribution of number of needs for all respondents and respondents in the TGA. Only five respondents (1.7%) reported not needing any of the listed services, and two (0.7%) reported needing all 20. On average, respondents reported needing six of the 20 services.

Table 30: Distribution of number of services needed

	Range	Mean	Median	Std Dev
All Respondents (n=289)	0-20	6	6	4.9
Respondents in TGA (n=95)	0-20	6	6	4.7

⁵⁶ Rumptz, M. H., Tobias, C., Rajabiun, S., Bradford, J., Cabral, H., Young, R., & Cunningham, W. E. (2007). Factors associated with engaging socially marginalized HIV-positive persons in primary care. *AIDS Patient Care and STDs*, 21(S1), S-30.

In addition to assessing the relative need for services, in general, among respondents, the level of need for each service type was assessed. Respondents were asked to identify which of the service types are essential and which of the service types are not needed. Table 31 lists the three most common services reported for each category among all respondents and respondents in the TGA. The services the most respondents identified as essential are regular medical care, financial support for HIV drugs and services, and HIV case management. The most common services that were not needed are help with issues related to immigration, help taking care of children, and help taking care of another adult loved one.

Table 31: Top three services identified, by level of need

Category	All Respondents (n=289)	Respondents in TGA (n=95)
Essential	<ol style="list-style-type: none"> 1. Regular medical care from a doctor, nurse, or OB/GYN, including HIV care 2. Help paying for or getting drugs for HIV and related health issues 3. Help coordinating and planning for HIV care and other services (case management) 	<ol style="list-style-type: none"> 1. Regular medical care from a doctor, nurse, or OB/GYN, including HIV care 2. Help paying for or getting drugs for HIV and related health issues 3. Help coordinating and planning for HIV care and other services (case management)
Not Needed	<ol style="list-style-type: none"> 1. Help with issues related to immigration status 2. Help taking care of children 3. Help taking care of a partner, parent, or other adult family member. 	<ol style="list-style-type: none"> 1. Help taking care of children 2. Help with issues related to immigration status 3. Help taking care of a partner, parent, or other adult family member.

Overall, respondents considered most of the services essential, and the ones that were most commonly deemed essential were related to health, at least seven-in-ten respondents identifying the following services as essential: regular medical care that includes HIV care, getting help paying for HIV drugs and services, and regular dental care. The services that were less likely to be deemed essential were related to social support. The only services that at less than one-quarter of respondents felt are essential include help taking care of children or adult family members, meals delivered to their homes, group meals delivered somewhere other than their homes, and help with immigration issues. These were also the services that were most commonly cited as not needed.

The large share of respondents who said they did not need immigration services is unsurprising. Services that assist with immigration issues are most likely to be needed by individuals born outside of the U.S., which is the case for fewer than one-in-ten survey respondents. Given that about one-half of survey respondents reported that they live alone, it is also unsurprising that few indicated needing help taking care of children or other family members.

Table 32 shows the services that were selected by at least one-in-four respondents for each level of need category among all respondents (essential and not needed). The top three services in each category are highlighted in blue. Figure 28 displays the share of all survey respondents

who identified each service type by the level of need and level of access (met need and unmet need) categories. Table 33 and Figure 29 show the same information for respondents in the TGA. These tables and charts are followed by a detailed discussion about the survey respondents' level of access to services.

Table 32: Most commonly reported services by level of need (essential and not needed) for all respondents

Services	LEVEL OF NEED	
	Essential	Not Needed
Food vouchers or groceries that can be picked up from food bank	X	
Group meals delivered somewhere other than my home		X
Help coordinating and planning for HIV care and other services (case management)	X	
Help finding a place to live	X	X
Help finding and keeping a job	X	X
Help getting benefits such as health, social security, or disability	X	
Help paying for or getting drugs for HIV and related health issues	X	X
Help paying rent	X	X
Help taking care of children		X
Help taking care of partner, parent, or other adult family member		X
Help taking medications regularly and dealing with side effects	X	X
Help understanding and planning for nutrition needs	X	X
Help with issues related to immigration status		X
Help with legal issues	X	X
Meals delivered to my home	X	X
Professional counseling or treatment for a diagnosed mental health issue	X	X
Regular dental care from a dentist or hygienist	X	
Regular medical care from a doctor, nurse, or OB/GYN, including HIV care	X	
Services that help deal with alcohol and/or drug use	X	X
Support from other PLWH (one-on-one or groups)	X	X
n=289		
X indicates at least 25% of respondents selected that category for the service		
■ Indicates the top three services identified in that category		

Figure 28: Service priority, need, access, and use among all respondents

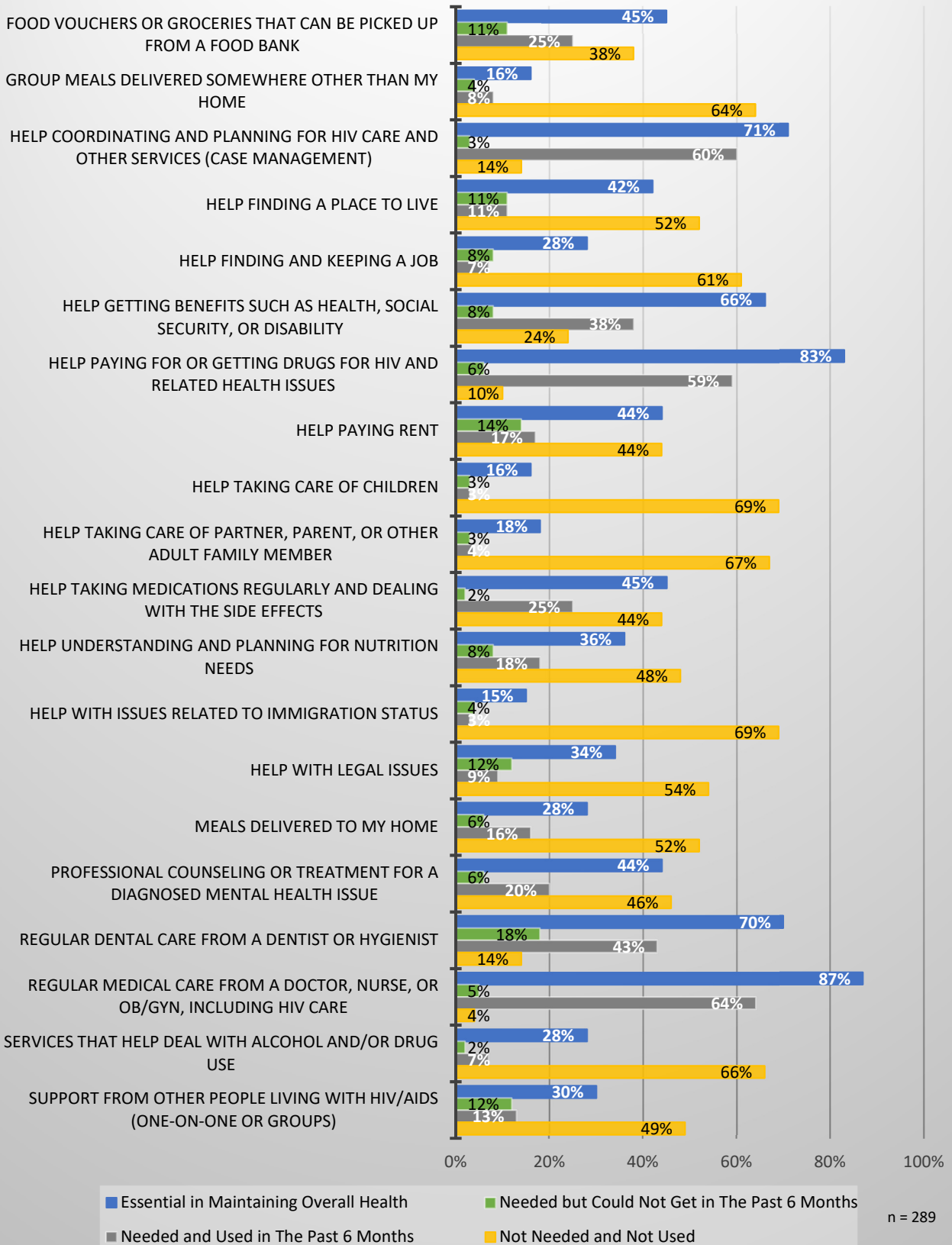
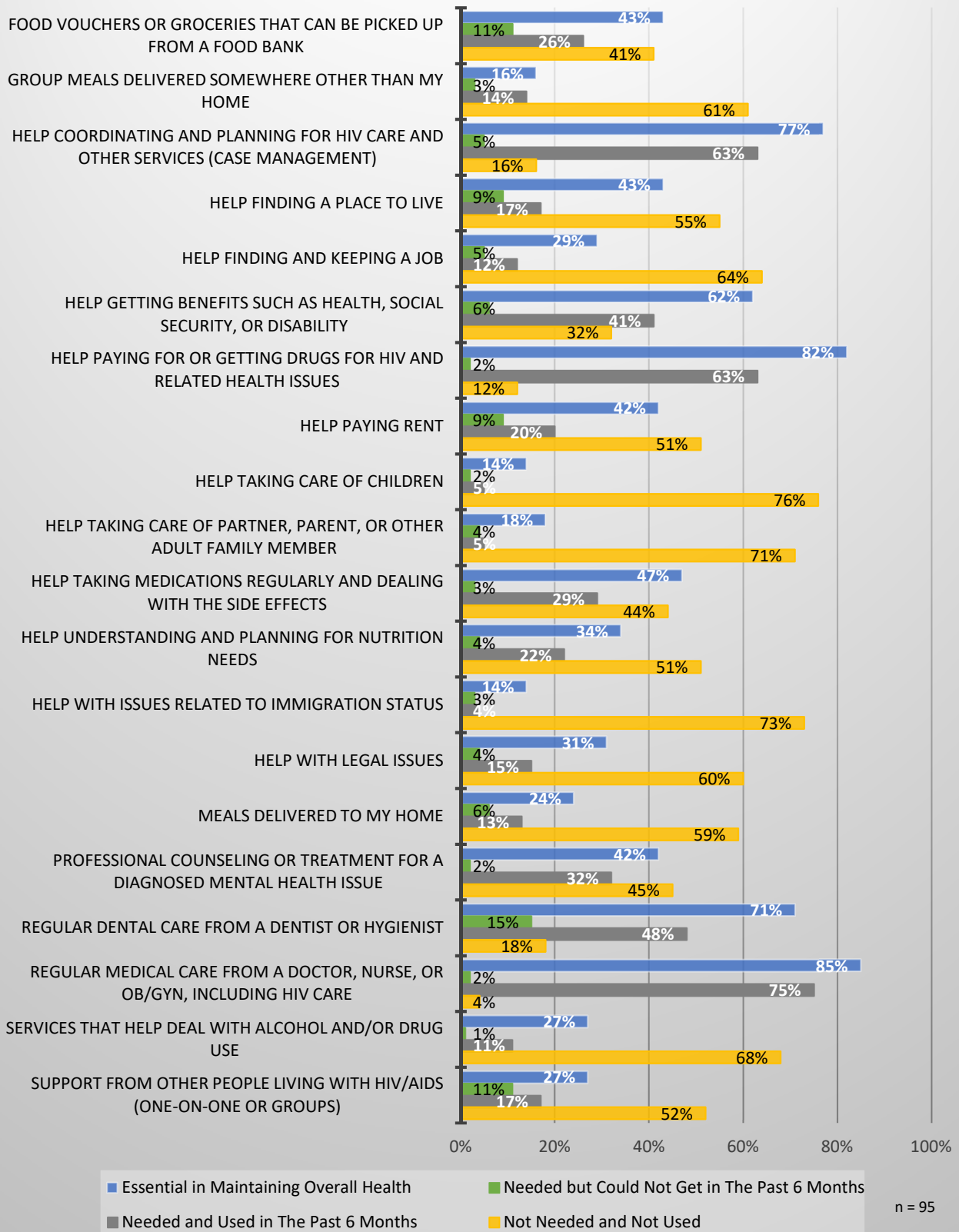


Table 33: Most commonly reported services by level of need (essential and not needed) for respondents in TGA

Services	LEVEL OF NEED	
	Essential	No Need/ Use
Food vouchers or groceries that can be picked up from food bank	X	X
Group meals delivered somewhere other than my home		X
Help coordinating and planning for HIV care and other services (case management)	X	
Help finding a place to live	X	X
Help finding and keeping a job	X	X
Help getting benefits such as health, social security, or disability	X	X
Help paying for or getting drugs for HIV and related health issues	X	
Help paying rent	X	X
Help taking care of children		X
Help taking care of partner, parent, or other adult family member		X
Help taking medications regularly and dealing with side effects	X	X
Help understanding and planning for nutrition needs	X	X
Help with issues related to immigration status		X
Help with legal issues	X	X
Meals delivered to my home		X
Professional counseling or treatment for a diagnosed mental health issue	X	X
Regular dental care from a dentist or hygienist	X	
Regular medical care from a doctor, nurse, or OB/GYN, including HIV care	X	
Services that help deal with alcohol and/or drug use	X	X
Support from other PLWH (one-on-one or groups)	X	X
n=95		
X indicates at least 25% of respondents selected that category for the service		
■ Indicates the top three services identified in that category		

Figure 29: Service priority, need, access, and use among respondents in TGA



Level of Service Access

To assess the extent to which study participants can access services they need, the level of met need was compared with the level of unmet need. Table 34 shows the services that were selected by at least one-in-four respondents for each level of access category among all respondents. The top three services in each category are highlighted in orange. Table 35 shows the same information for respondents in the TGA. Tables showing all level of need and level of access categories are included as Appendix E.

Table 34: Most commonly reported services by level of access (met needs and unmet needs) for all respondents


Services	LEVEL OF ACCESS	
	Met Need	Unmet Need
Food vouchers or groceries that can be picked up from food bank	X	
Group meals delivered somewhere other than my home		
Help coordinating and planning for HIV care and other services (case management)	X	
Help finding a place to live		
Help finding and keeping a job		
Help getting benefits such as health, social security, or disability	X	
Help paying for or getting drugs for HIV and related health issues	X	
Help paying rent		
Help taking care of children		
Help taking care of partner, parent, or other adult family member		
Help taking medications regularly and dealing with side effects	X	
Help understanding and planning for nutrition needs		
Help with issues related to immigration status		
Help with legal issues		
Meals delivered to my home		
Professional counseling or treatment for a diagnosed mental health issue		
Regular dental care from a dentist or hygienist	X	
Regular medical care from a doctor, nurse, or OB/GYN, including HIV care	X	
Services that help deal with alcohol and/or drug use		
Support from other PLWH (one-on-one or groups)		
n=289		
X indicates at least 25% of respondents selected that category for the service		
 Indicates the top three services identified in that category		

Table 35: Most commonly reported services by level of access (met needs and unmet needs) for respondents in TGA

Services	LEVEL OF ACCESS	
	Met Need	Unmet Need
Food vouchers or groceries that can be picked up from food bank	X	
Group meals delivered somewhere other than my home		
Help coordinating and planning for HIV care and other services (case management)	X	
Help finding a place to live		
Help finding and keeping a job		
Help getting benefits such as health, social security, or disability	X	
Help paying for or getting drugs for HIV and related health issues	X	
Help paying rent		
Help taking care of children		
Help taking care of partner, parent, or other adult family member		
Help taking medications regularly and dealing with side effects	X	
Help understanding and planning for nutrition needs		
Help with issues related to immigration status		
Help with legal issues		
Meals delivered to my home		
Professional counseling or treatment for a diagnosed mental health issue	X	
Regular dental care from a dentist or hygienist	X	
Regular medical care from a doctor, nurse, or OB/GYN, including HIV care	X	
Services that help deal with alcohol and/or drug use		
Support from other PLWH (one-on-one or groups)		
n=95		
X indicates at least 25% of respondents selected that category for the service		
■ Indicates the top three services identified in that category		

Table 36 shows the top three reported met needs and unmet needs. The most common met needs were regular medical care, financial support for HIV drugs and services, and HIV case management. The most common unmet needs among all respondents are regular dental care, help paying rent, and legal support. The most common unmet needs among respondents in the TGA are regular dental care, support from other PLWH, and food bank vouchers.

Table 36: Top three services reported as met needs and unmet needs

Category	All Respondents (n=289)	Respondents in TGA (n=95)
Met Need	<ol style="list-style-type: none"> 1. Regular medical care from a doctor, nurse, or OB/GYN, including HIV care 2. Help coordinating and planning for HIV care and other services (case management) 3. Help paying for or getting drugs for HIV and related health issues 	<ol style="list-style-type: none"> 1. Regular medical care from a doctor, nurse, or OB/GYN, including HIV care 2. Help coordinating and planning for HIV care and other services (case management) 3. Help paying for or getting drugs for HIV and related health issues
Unmet Need	<ol style="list-style-type: none"> 1. Regular dental care from a dentist or hygienist 2. Help paying rent 3. Help with legal issues 	<ol style="list-style-type: none"> 1. Regular dental care from a dentist or hygienist 2. Support from other PLWH (one-on-one or groups) 3. Food vouchers or groceries that can be picked up from a food bank

Differences in Level of Access

The relative level of unmet needs among subpopulations was assessed to identify potential disparities in access to services. Pearson chi-square tests were used to determine statistically significant differences in who is unable to access each service by demographic groups, including race, gender, MSM status, age, and viral suppression status. A p-value of less than 0.05 was considered statistically significant. Additional data are included in the Data Supplement (Appendix F).

By Population

In order to look at differences in level of access by population, analyses were used to compare respondents with at least one unmet need with respondents who did not report any unmet needs, and respondents with at least three unmet needs to respondents who reported fewer than three unmet needs. Almost one-half of all respondents (45%) reported at least one unmet need, and one-fifth (20%) had at least three unmet needs (64% and 13%, respectively for respondents in the TGA).

Among all survey participants with at least one unmet need, there were statistically significant differences based on gender and age. Women and younger people were more likely to need at least one service that they could not access. Almost three-in-five women (57%) had at least one unmet need, compared with two-fifths of men. More than one-half of people ages 18-39 (55%) had at least one unmet need, compared with 46% of people ages 40-64 and 31% of people ages 65 and older.

When looking at all survey participants who reported low access to services, meaning they had at least three unmet service needs, there are statistically significant differences based on age. Younger people are more likely to have low access to services, as 30% of people ages 18-39 reported at least three service needs, compared with 20% of people ages 40-64 and 11% of people ages 65 and older. Table 37 shows the summary of significant variations in level of access among all respondents by population.

Table 37: Summary of significant variations in level of access among all respondents by population

Level of Access	All Respondents (n=289)				
	Race	Gender	MSM	Age	Viral Suppression
At least one unmet need		*		*	
At least three unmet needs (low access)				*	
<i>* indicates a p-value less than 0.05</i>					

Among respondents in the TGA, younger people were more likely to have any unmet service needs, while older adults were far less likely to report any unmet needs at all. Almost one-half of people ages 18-39 reported at least one unmet need, compared with 39% of people ages 40-64 and 6% of people ages 65 and older. There were no statistically significant differences in low access to services by population. Table 38 shows the summary of significant variations in level of access among respondents in the TGA by population.

Table 38: Summary of significant variations in level of access among respondents in TGA by population

Level of Access	Respondents in TGA (n=95)				
	Race	Gender	MSM	Age	Viral Suppression
At least one unmet need				*	
At least three unmet needs (low access)					
<i>* indicates a p-value less than 0.05</i>					

By Service

In order to identify potential disparities in access to particular types of services, the level of access to each service type was assessed by demographic subgroups, as well. There are statistically significant differences in reported unmet needs for seven service types based on race, gender, MSM status, and age groups. Listed below are the seven services and the groups for which there is a greater proportion of unmet need.

- **Help getting benefits such as health, social security, or disability:** females and individuals who are non-MSM
- **Regular medical care that includes HIV care:** individuals who are non-MSM
- **Help with issues related to immigration status:** individuals who are non-MSM
- **Group meals delivered somewhere other than their homes:** individuals who are non-MSM
- **Support from other PLWH:** respondents ages 18-39
- **Food vouchers or groceries that can be picked up from a food bank:** respondents ages 18-39
- **Help paying rent:** people of color

Table 39 summarizes the service categories and the groups with statistically significant differences for unmet service needs.

Table 39: Summary of significant variations in unmet service needs among all respondents by population

Services	All Respondents (n=289)				
	Race	Gender	MSM	Age	Viral Suppression
Help getting benefits such as health, social security, or disability		*	*		
Regular medical care from a doctor, nurse, or OB/GYN, including HIV care			*		
Support from other PLWH (one-on-one or groups)				*	
Help paying rent	*				
Group meals delivered somewhere other than my home			*		
Food vouchers or groceries that can be picked up from a food bank				*	
Help with issues related to immigration status			*		
<i>* indicates a p-value less than 0.05</i>					

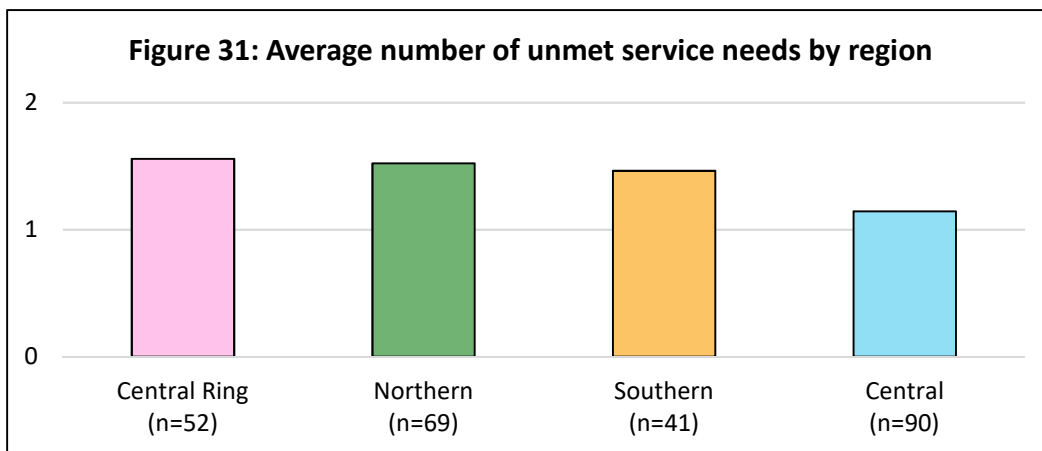
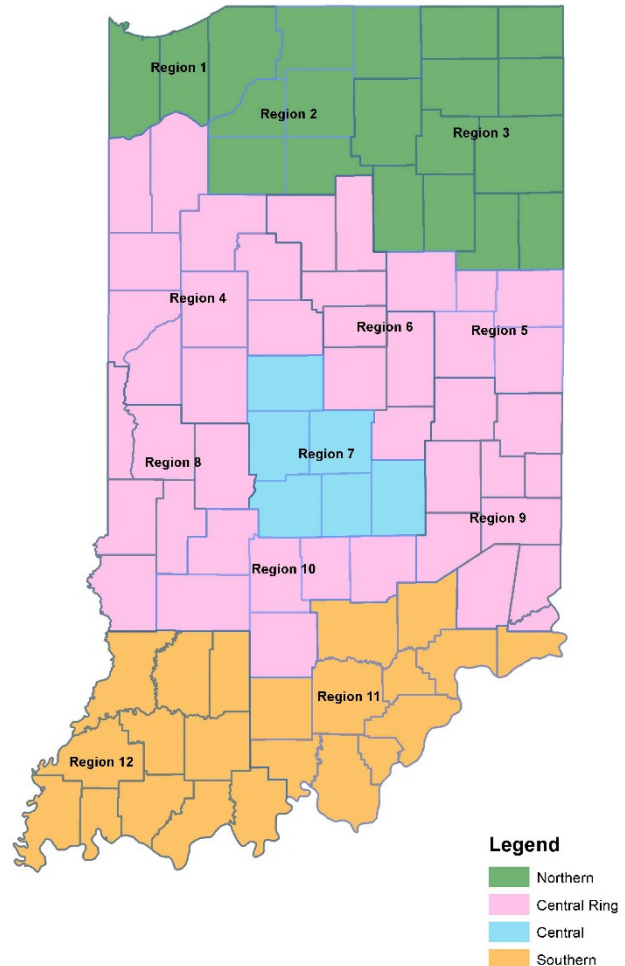
There were no statistically significant variations in unmet service needs by population for respondents in the TGA.

By Geography

Participants' levels of unmet need were analyzed by regional subgroups for potential disparities in access to services. The geographic areas of comparison are based on Indiana's HIV Care Coordination Regions. Due to the low number of participants in some Regions, Regions were combined to form the geographic areas used for analysis. The Northern Region is made up of Regions 1, 2, and 3. The Central Ring Region is made up of Regions 4, 5, 6, 8, 9, 10. The Central Region is made up of Region 7, which contains most of the counties that make up the TGA. The Southern Region is made up of Regions 9 and 10. Figure 30 shows a map of the geographic regions used for analysis.

In order to compare the service needs by geographic region, the aggregate number of unmet service needs for all respondents from each region were averaged and analyzed using the Kruskal-Wallis test to identify statistically significant differences in level of access by region. The average number of unmet needs range from 1.14 (Central) to 1.56 (Central Ring), as seen in Figure 31. There were no statistically significant differences by geographic region, but this may be because all of the new geographic regions used for analysis encompass both urban and rural areas, so they are similar in composition.

Figure 30: Geographic regions used for analysis



Barriers to Access

Respondents were asked to identify barriers they may have experienced while attempting to access 20 types of services. At least one-in-seven study participants reported barriers to accessing each service type. Table 40 lists each service type and displays the share of respondents who reported at least one barrier to access. At least two-in-five respondents faced barriers trying to access support from other PLWH, regular dental care, help with legal issues, food bank vouchers, and help paying rent.

Table 40: Share of respondents who reported barriers in accessing each service

	All Respondents		Respondents in TGA	
	%	N	%	N
Support from other PLWH (one-on-one or groups)	46.4%	261	41.7%	84
Regular dental care from a dentist or hygienist	45.4%	273	40.1%	93
Help with legal issues	42.6%	242	29.3%	82
Food vouchers or groceries that can be picked up from a food bank	41.9%	241	41.5%	82
Help paying rent	39.9%	248	34.4%	79
Help finding a place to live	37.7%	247	32.9%	82
Help finding and keeping a job	36.7%	240	33.8%	80
Meals delivered to my home	36.5%	244	40.7%	86
Help getting benefits such as health, social security, or disability	35.4%	246	29.0%	76
Professional counseling or treatment for a diagnosed mental health issue	34.7%	251	29.4%	85
Group meals delivered somewhere other than my home	34.5%	232	31.2%	77
Regular medical care from a doctor, nurse, or OB/GYN, including HIV care	33.0%	267	25.8%	89
Help taking care of partner, parent, or other adult family member	32.4%	231	31.3%	80
Help coordinating and planning for HIV care and other services (case management)	32.3%	269	32.3%	93
Help with issues related to immigration status	31.7%	221	27.0%	74
Help understanding and planning for nutrition needs	30.5%	233	24.4%	78
Help taking care of children	28.2%	220	22.7%	75
Help paying for or getting drugs for HIV and related health issues	27.5%	251	22.9%	83
Services that help deal with alcohol and/or drug use	21.3%	221	18.4%	76
Help taking medications regularly and dealing with the side effects	15.8%	228	15.4%	78

Respondents were asked to indicate what types of barriers limited their ability to access needed services. Three-in-five respondents (61.2%) reported at least one barrier for one service. The most commonly identified barriers were related to lack of awareness. Table 41 shows the share of respondents who reported each type of barrier at least once.

Table 41: Share of participants who experienced each barrier

	All Respondents (n=263)	Respondents in TGA (n=92)
Did not know it existed	36.1%	31.5%
Did not know how to get	33.5%	32.6%
Too expensive	19.0%	12.0%
Told not eligible for service	17.5%	20.7%
Transportation problems	14.4%	9.8%
Not available in my area	12.9%	6.5%
Hard to get appointment	12.2%	16.3%
Afraid people will find out I have HIV	9.1%	6.5%
Chose not to go	8.7%	12.0%
Cannot take time off work	5.3%	5.4%
Not comfortable with my provider	4.9%	8.7%
Provider doesn't speak my language	3.0%	2.2%
Too sick to go	3.0%	1.1%
No childcare	2.3%	2.2%
Other reason	21.7%	16.3%

Analysis for variances in barriers by population did not yield any notable differences.

Perspectives on Funding Prioritization

Survey participants were asked to imagine that they had the ability to give out funding to support services for PLWH and identify the three types of services that they would be most likely to fund. Options included:

- **Medical care**, including doctors, nurses, physical therapy, non-HIV medications for ongoing conditions like hypertension and diabetes, other medical care at an agency or clinic.
- **Antiretroviral medications**, including protease inhibitors.
- **HIV medications other than antiretrovirals**, including medications that prevent you from getting sick like Bactrim.
- **Dental care**
- **Home health care**, including home nursing or infusion care; skilled nursing facility; rehabilitation care, such as physical/speech therapy at home; paid helper to assist with bathing, feeding, shaving; medical equipment
- **Hospice care**, including care in your home or at a facility when you have late-stage HIV disease.

- **Case management**, including help with referrals for services you need, filling out forms, finding out about what services you are able to get
- **Support services**, including adoption/foster care; help with shopping or cooking; one-on-one peer counseling or support groups; child care; food bank or home-delivered meals; emergency help paying for groceries or utilities; help finding an affordable place to live; transportation assistance; translator/interpreter services; and legal services.
- **Mental health services with trained counselor**, including treatment by a professional or specially-trained individuals to help you talk about your feelings in one-on-one or group settings.
- **Drug or alcohol counseling or treatment by a trained staff person**, including treatment by a professional or specially-trained individuals in a hospital, program run by a hospital, or substance abuse day program

The services most commonly chosen as funding priorities correspond closely with the services respondents described as essential. Table 42 lists the services in descending order of priority, according to survey respondents. The highest priority service type was medical care, followed by antiretroviral medications and HIV medications other than antiretrovirals. The services that were least often identified as a top three priority includes home health care, drug or alcohol counseling, and hospice care.

Table 42: Respondents’ prioritization of funding for services

Services	All Respondents (n=289)	Respondents in TGA (n=95)
Medical care	70%	68%
Antiretroviral medications	49%	51%
HIV medications other than antiretrovirals	39%	41%
Dental care	29%	28%
Support services	27%	25%
Case management	19%	19%
Mental health services with trained counselor	19%	19%
Home health care	9%	9%
Drug or alcohol counseling or treatment by a trained staff person	8%	8%
Hospice Care	8%	7%

CONCLUSIONS AND RECOMMENDATIONS

Recommendations based on the findings from the needs assessment survey are included below. They include recommendations for enhancing access to and the quality of HIV programs and services in Indiana, as well as recommendations for future assessment of the service needs and barriers of PLWH in Indiana.

Enhancing Access to and Quality of HIV Services

The needs assessment yielded a great deal of information from PLWH in Indiana about the care system barriers they face and the priorities they have for their own health and wellness. The data collected were used to identify the following recommendations for the ISDH and partners to consider for planning and decision making for HIV programs and services in Indiana.

Funding and programming decisions should be made to:

- Create resources and campaigns to promote the types of HIV services that exist in Indiana, who is eligible for them, and how to access them.
- Expand access and reduce barriers to services for non-majority populations, specifically: young people, women, people of color, and people who are non-MSM.
- Prioritize primary medical care services for PLWH that incorporates regular medical care and monitoring of HIV and other chronic conditions.
- Prioritize services that help PLWH pay for their medications and services, with specific programs or outreach for the population of people aging with HIV.
- Prioritize HIV case management services that help PLWH coordinate their care, connect with essential HIV and non-HIV services, and overcome barriers to access.
- Increase the number and/or capacity of services that provide regular dental care, food bank vouchers, peer-to-peer support, and legal support for PLWH.
- Increase outreach to and resources for people who do not have stable housing. Resources include financial support for mortgage/rent and utilities and helping place PLWH in housing.
- Support PLWH who are not working or are working but facing challenges related to the effects of or side effects of medications to control their HIV, e.g., their energy levels or fear of disclosing their HIV status at work.
- Increase awareness and accessibility of resources for mental health counseling or treatment.
- Educate medical providers, especially those in private practice, at hospitals, or in community health clinics, to increase their comfort level and expertise around treating PLWH and discussing sensitive topics, such as substance use, mental health, and sexual health.

- Provide resources for individuals struggling with perceived discrimination and fear of disclosure.
- Incorporate long-term life planning for PLWH, especially around long-term health and end of life planning.
- Educate PLWH about HIV, HIV transmission, and modes of positive prevention.

Future Assessment

The What Matters to YOU? Needs Assessment for PLWH in Indiana was an important step in understanding the needs, experiences, and barriers to service faced by PLWH in Indiana, but it was not designed to be the sole instrument for future assessment. As the population of PLWH in Indiana change and their service needs, resources, and issues accessing services change, regular assessment must be done for use in program and service planning.

Listed below are recommendations for future assessment. Future needs assessments should be done every one-to-three years and utilize a mixed methods approach, including survey and qualitative data collection through focus groups or interviews, to gather contextual information.

The survey method should:

- Utilize a single-phase survey approach. The vast majority of Part I respondents completed Part II.
- Oversample for non-English speakers, people under the age of 40, and people of color.
- Blend random sample methodology with other approaches to collect information from hard-to-reach populations, including individuals who are not stably housed, immigrants, and those with lower reading levels than the survey may accommodate. Examples include INMMP, working through grassroots organizations, and administering surveys at care sites serving large shares of clients in the oversample categories.

Areas to explore in future study include:

- Specific barriers in access to services for non-majority populations, specifically people of color, female, individuals who are non-MSM, or ages 18-39.
- Variations the levels and types of needs and barriers experienced, by urbanity.

APPENDIX A: ABRREVIATIONS

HIP	Healthy Indiana Plan
HSP	HIV-Services Program
HRSA	Health Resources and Services Administration
ISDH	Indiana State Department of Health
INMMP	Indiana Medical Monitoring Project
MSM	Men who have sex with men
NMCM	Non-Medical Case Management
PLWH	People Living with HIV
TGA	Transitional Grant Area

APPENDIX B: GLOSSARY

Acquired Immunodeficiency Syndrome (AIDS): A chronic, potentially life-threatening condition caused by HIV.

Antiretroviral: The combination of drugs used to treat HIV.

CD4 Cell Count: An indication of the health of your immune system. CD4 cells are also called T-cells they are white blood cells that fight infection. A higher count of CD4 cells indicates a stronger immune system.

Federal Poverty Level: A measure of income used by the U.S. government to determine eligibility for programs and benefits.

Healthy Indiana Plan (HIP): A health insurance plan for adults aged 19 to 64 living in Indiana who meet specific income levels.

Human Immunodeficiency Virus (HIV): A disease that attacks the body's immune system. It targets CD4 cells which are meant to help the immune system fight off infection.

Health Resources and Services Administration (HRSA): A division of the U.S. Department of Health and Human Services. It is the primary federal agency for improving health care access to uninsured, isolated, or vulnerable individuals.

Indiana Medical Monitoring Project (INMMP): A special HIV Disease surveillance project funded by the Centers for Disease Control and Prevention (CDC) in collaboration with the Indiana State Department of Health (ISDH)

Non-Medical Case Management: The delivery of a range of client-centered activities that focus on improving access and adherence to core medical and supportive services.

Ryan White Program: A federal program administered by the HRSA that provides a comprehensive system of HIV medical care, support services, and medications for individuals who are low income, underserved, or uninsured.

Transitional Grant Area (TGA): Group of nine Central Indiana counties receiving assistance through Part A of the Ryan White HIV/AIDS Treatment Extension Act as it has been identified as one of 28 areas in the country most severely impacted by the HIV epidemic. The Indianapolis TGA includes Marion and the surrounding counties (Boone, Brown, Hamilton, Hendricks, Johnson, Morgan, Putnam, and Shelby).

Viral Load: A measure of the HIV particles in a milliliter (mL) of blood.

APPENDIX C: DATA ON DISCUSSING SENSITIVE TOPICS

Throughout the survey, participants were asked who they have discussed certain topics with, specifically: mental health, substance use, medication adherence, and sexual health. Information about the share of respondents who have spoken to someone is included in the body of the report. This section includes tables on the types of people respondents most commonly discuss these issues with, as well as tables showing the share of respondents who spoke with each type of person about each issue.

Table 1: Share of respondents who have discussed at least one topic with each type of person

	All Respondents (n=178)	Respondents in TGA (n=52)
Medical Provider (doctor, nurse, nurse practitioner, physician's asst)	71.9%	75.0%
Case manager	47.2%	46.2%
Family/friends	24.2%	21.2%
Other HIV service provider or outreach/community health worker	21.3%	25.0%
Mental health counselor (therapist or psychiatrist)	17.4%	21.2%
Other PLWH who I know	10.7%	11.5%
Support group members	6.7%	3.8%
Substance abuse counselor	2.2%	0.0%
Peer leader	0.0%	0.0%
No one	0.0%	0.0%

Table 2: Others with whom respondents have discussed mental health topics in the past six months

	All Respondents (n=178)	Respondents in TGA (n=52)
Medical provider	34.8%	40.4%
Case manager	29.2%	28.8%
Mental health counselor	14.0%	17.3%
Other HIV service provider	13.5%	15.4%
Family/Friends	11.8%	13.5%
Support group members	3.9%	1.9%
Other PLWH I know	3.9%	1.9%
Substance abuse counselor	2.2%	0.0%
Peer leader	0.0%	0.0%

Table 3: Others with whom respondents have discussed alcohol and recreational drug use in the past six months

	All Respondents (n=178)	Respondents in TGA (n=52)
Medical provider	27.5%	38.5%
Case manager	20.8%	26.9%
Other HIV service provide	8.4%	17.3%
Family/friends	8.4%	13.5%
Mental health counselor	6.2%	7.7%
Other PLWH I know	3.4%	3.8%
Support group members	2.2%	1.9%
Substance abuse counselor	1.7%	0.0%
Peer Leaders	0.0%	0.0%

Table 4: Others with whom respondents have discussed medication adherence in the past three months

	All Respondents (n=171)	Respondents in TGA (n=52)
Medical provider	57.9%	59.6%
Case manager	24.6%	25.0%
Family/friends	11.7%	5.8%
Other HIV service provider	9.9%	13.5%
Mental health counselor	7.6%	9.6%
Other PLWH I know	2.3%	3.8%
Support group members	2.3%	0.0%
Substance abuse counselor	0.6%	0.0%
Peer leader	0.0%	0.0%

Table 5: Others with whom respondents have discussed their sexual health in the past six months

	All Respondents (n=178)	Respondents in TGA (n=52)
Medical Provider	42.7%	44.2%
Case manager	34.8%	36.5%
Other HIV service provider	10.7%	11.5%
Family/Friends	8.4%	5.8%
Other PLWH I know	4.5%	5.8%
Mental health counselor	4.5%	3.8%
Support group members	3.4%	0.0%
Substance abuse counselor	1.1%	0.0%
Peer leader	0.0%	0.0%

APPENDIX D: DATA ON HIV TESTING AND DIAGNOSIS

The tables below are the survey responses for location where people had HIV testing and diagnosis, their reasons for getting tested and reasons for avoiding testing.

Table 1: Respondents HIV diagnosis testing location

	All Respondents (n=169)	Respondents in TGA (n=49)
Private doctor's office, hospital or hospital clinic (not ER), community health center or clinic	61.6%	53.1%
HIV counseling, testing, and service site	8.9%	14.3%
STD clinic	4.7%	10.2%
Emergency room (ER)	4.1%	2.0%
Jail or prison	4.1%	2.0%
AIDS service organization or other community-based organization	3.6%	4.1%
Family planning clinic	3.0%	4.1%
Jail or prison	4.1%	2.0%
Other	6.5%	6.1%

Table 2: Reasons respondents got tested for HIV when they were diagnosed

	All Respondents (n=178)	Respondents in TGA (n=52)
I felt sick or had an illness (other than suspected STD).	28.1%	21.2%
I was concerned because I had sex without a condom.	24.7%	21.2%
I was getting a routine HIV test.	19.1%	26.9%
I was told that a sexual partner was HIV positive.	18.0%	21.2%
A healthcare provider recommended I get tested.	15.2%	19.2%
I was testing for other STDs.	6.2%	9.6%
I was concerned because I had injected drugs with a needle.	4.5%	3.8%
I was pregnant.	3.4%	5.8%
I experienced sexual assault.	3.4%	1.9%
I was required by the military, court order, insurance, etc.	2.8%	5.8%
I was tested before giving blood.	1.1%	0.0%
Other	15.2%	5.8%

Table 3: Reasons respondents avoided getting tested for HIV

	All Respondents (n=178)	Respondents in TGA (n=52)
I was afraid of a positive result	28.1%	26.9%
I didn't know where to go get tested	6.7%	1.9%
I don't like needles/syringes	3.9%	3.8%
I was stressed about having to wait for my results	2.8%	11.5%
I don't like having blood taken for the test	2.8%	3.8%
It costs too much to get tested	2.8%	0.0%
It was hard to find time to get tested	2.2%	1.9%
I had a hard time getting or making an appointment	1.1%	0.0%
None of these	58.4%	63.5%

APPENDIX E: LEVEL OF NEED AND LEVEL OF ACCESS BY SERVICE TABLES

Level of need and level of access by service for all respondents and respondents in the TGA.

Table 1: Most commonly reported services by met need, unmet need, not needed/used, and essential services for all respondents

Services	LEVEL OF NEED		LEVEL OF ACCESS	
	Essential	No Need/ Use	Met Need	Unmet Need
Food vouchers or groceries that can be picked up from food bank	X		X	
Group meals delivered somewhere other than my home		X		
Help coordinating and planning for HIV care and other services (case management)	X		X	
Help finding a place to live	X	X		
Help finding and keeping a job	X	X		
Help getting benefits such as health, social security, or disability	X		X	
Help paying for or getting drugs for HIV and related health issues	X	X	X	
Help paying rent	X	X		
Help taking care of children		X		
Help taking care of partner, parent, or other adult family member		X		
Help taking medications regularly and dealing with side effects	X	X	X	
Help understanding and planning for nutrition needs	X	X		
Help with issues related to immigration status		X		
Help with legal issues	X	X		
Meals delivered to my home	X	X		
Professional counseling or treatment for a diagnosed mental health issue	X	X		
Regular dental care from a dentist or hygienist	X		X	
Regular medical care from a doctor, nurse, or OB/GYN, including HIV care	X		X	
Services that help deal with alcohol and/or drug use	X	X		
Support from other PLWH (one-on-one or groups)	X	X		

n=289
 X indicates at least 25% of respondents selected that category for the service
 Indicates the top three services identified in that category

Table 2: Most commonly reported services by met need, unmet need, not needed/used, and essential services for respondents in the TGA

Services	LEVEL OF NEED		LEVEL OF ACCESS	
	Essential	No Need/ Use	Met Need	Unmet Need
Food vouchers or groceries that can be picked up from food bank	X	X	X	
Group meals delivered somewhere other than my home		X		
Help coordinating and planning for HIV care and other services (case management)	X		X	
Help finding a place to live	X	X		
Help finding and keeping a job	X	X		
Help getting benefits such as health, social security, or disability	X	X	X	
Help paying for or getting drugs for HIV and related health issues	X		X	
Help paying rent	X	X		
Help taking care of children		X		
Help taking care of partner, parent, or other adult family member		X		
Help taking medications regularly and dealing with side effects	X	X	X	
Help understanding and planning for nutrition needs	X	X		
Help with issues related to immigration status		X		
Help with legal issues	X	X		
Meals delivered to my home		X		
Professional counseling or treatment for a diagnosed mental health issue	X	X	X	
Regular dental care from a dentist or hygienist	X		X	
Regular medical care from a doctor, nurse, or OB/GYN, including HIV care	X		X	
Services that help deal with alcohol and/or drug use	X	X		
Support from other PLWH (one-on-one or groups)	X	X		

n=95
X indicates at least 25% of respondents selected that category for the service
 Indicates the top three services identified in that category

APPENDIX F: DATA SUPPLEMENT

This tables below present additional data on statistical analyses performed.

Table 1: Pearson Chi-Square Test p-values for met needs.

Service	All Respondents (n=289)				Respondents in TGA (n=95)			
	Race	Gender	MSM- Status	Age	Race	Gender	MSM- Status	Age
Help coordinating and planning for HIV care and other services (case management)	0.618	0.860	0.470	0.542	0.392**	0.149	1.000	0.237
Help getting benefits such as health, social security, or disability	0.476	0.151	0.052	0.407	0.181**	0.452	0.268	0.086
Regular dental care from a dentist or hygienist	0.674	0.091	0.112	0.792	0.597**	0.979	0.557	0.389
Regular medical care from a doctor, nurse, or OB/GYN, including HIV care	0.004*	0.018*	0.003*	0.637	0.772	0.620	0.247	0.152
Help paying for or getting drugs for HIV and related health issues	0.101	0.990	0.538	0.363	0.902**	0.675	1.000	0.372
Help taking medications regularly and dealing with the side effects	0.686	0.690	0.915	0.009*	0.604**	0.572	0.312	0.034*
Professional counseling or treatment for a diagnosed mental health issue	0.072	0.315	0.165	0.134	0.027**	0.366	0.368	0.193
Support from other PLWH (one-on-one or groups)	0.365	0.624	0.758	0.976	0.137	0.348*8	0.371	0.305**

Services that help deal with alcohol and/or drug use	0.026*	0.541	0.125	0.101**	0.094**	0.851**	0.495**	0.089**
Meals delivered to my home	0.238	0.737	0.839	0.143	0.025**	0.813**	0.449**	0.103**
Help finding a place to live	0.000*	0.208	0.178	0.04*	0.001*	0.779**	0.737	0.093**
Help paying rent	0.181	0.029*	0.605	0.052	0.020*	0.88**	0.834	0.019**
Help finding and keeping a job	0.304	0.068	0.732	0.030**	0.439**	0.676**	0.695**	0.172
Help understanding and planning for nutrition needs	0.268	0.540	0.409	0.992	0.075	0.681**	0.480	0.345**
Group meals served somewhere other than my home	0.373	0.764	0.855	0.889**	0.063	0.432**	0.273	0.462**
Food vouchers or groceries that can be picked up from a food bank	0.023*	0.470	0.322	0.365	0.001*	0.056	0.057	0.879
Help with legal issues	0.346	0.298	0.422	0.833	0.724	0.433**	0.345	0.695**
Help with issues related to immigration status	0.072**	0.592**	0.274**	0.011**	0.046**	0.896**	0.144**	0.041**
Help taking care of children	0.034**	0.075**	0.005**	0.024**	0.046**	0.896**	0.144**	0.041**
Help taking care of partner, parent, or other adult family member	0.246**	0.887**	0.702	0.193**	0.594**	0.897**	1.000**	0.112**
* indicates statistical significance								
** indicates invalid expected cell counts								

Table 2: Pearson Chi-Square Test p-values for unmet needs.

Service	All Respondents				TGA			
	Race	Gender	MSM- Status	Age	Race	Gender	MSM- Status	Age
Help coordinating and planning for HIV care and other services (case management)	0.606**	0.436**	0.287**	0.225**	0.089**	0.218**	1.000**	0.58**
Help getting benefits such as health, social security, or disability	0.437	0.024*	0.009*	0.08**	0.731**	0.093**	0.168**	0.58**
Regular dental care from a dentist or hygienist	0.700	0.060	0.138	0.223	0.515	0.193**	0.408	0.264**
Regular medical care from a doctor, nurse, or OB/GYN, including HIV care	0.303	0.022**	0.031*	0.336**	0.391**	0.590*	0.771	0.458**
Help paying for or getting drugs for HIV and related health issues	0.271**	0.715**	0.836	0.859**	0.05**	0.443**	0.243	0.458**
Help taking medications regularly and dealing with the side effects	0.548**	0.979**	0.968**	0.979**	0.616**	0.345**	0.811**	0.679**
Professional counseling or treatment for a diagnosed mental health issue	0.675	0.091**	0.291	0.118**	0.391**	0.443**	0.770**	0.190**
Support from other PLWH (one-on-one or groups)	0.451	0.391	0.788	0.013*	0.716**	0.321**	0.495**	0.278**
Services that help deal with alcohol and/or drug use	0.867**	0.253**	0.464**	0.004**	0.475**	0.59**	0.412**	0.19**

Meals delivered to my home	0.693**	0.255	0.701	0.739	0.665**	0.5044**	0.606**	0.433**
Help finding a place to live	0.1220	0.781	0.548	0.084	0.85**	0.85**	0.775**	0.319**
Help paying rent	0.040*	0.309	0.056	0.058	0.85**	0.485**	0.668**	0.750**
Help finding and keeping a job	0.291	0.111	0.129	0.080	0.175**	0.897**	0.348**	0.668**
Help understanding and planning for nutrition needs	0.065	0.147	0.281	0.012**	0.344**	0.896**	0.677**	0.592**
Group meals served somewhere other than my home	0.519	0.102	0.005*	0.459	0.616**	0.642**	0.031**	0.592**
Food vouchers or groceries that can be picked up from a food bank	0.198	0.329	0.569	0.003*	0.616**	0.395**	0.495**	0.105**
Help with legal issues	0.856	0.127	0.408	0.241	0.616**	0.345**	0.677**	0.305**
Help with issues related to immigration status	0.040**	0.324**	.025*	0.446**	0.616**	0.642**	0.338	0.592
Help taking care of children	0.410**	0.012**	.003**	0.204**	0.616**	0.590**	0.080**	0.679**
Help taking care of partner, parent, or other adult family member	0.826**	0.075**	0.087**	0.720**	0.616**	0.061**	0.012**	0.305**
* indicates statistical significance								
** indicates invalid expected cell counts								

Table 3: Kruskal-Wallis test results for met needs by region

	Chi-Square	DF	Pr > Chisq
Met Needs	7.80	3	0.046*
Unmet Needs	5.15	3	0.161
Not needed	3.28	3	0.351
* indicates statistical significance			