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Social and Structural Drivers of HIV: A Thematic Analysis of Partner Services Narratives

Division of HIV Epidemiology, Evaluation and Partner Services
AIDS Institute
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"New York State's progress in reducing HIV has been built on strong surveillance, prevention, and care systems. This report builds on that foundation by illuminating how social and structural drivers, such as poverty, housing instability, and behavioral health challenges, interact with HIV and related conditions. Understanding these dynamics is essential to delivering a more effective and equitable public health response."

– Joseph Kerwin,

AIDS Institute Director at New York State Department of Health

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1. Executive Summary

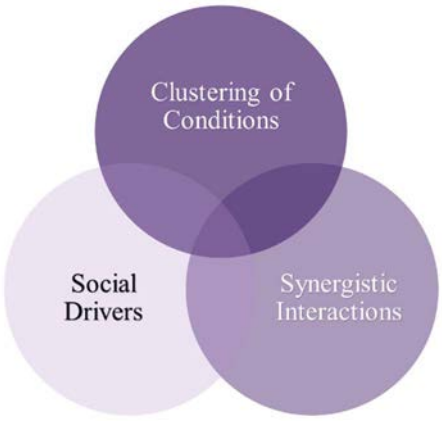
New York State has made substantial progress in reducing new HIV diagnoses and expanding access to treatment, however, persistent disparities remain across regions and populations. To better understand the upstream drivers of these disparities, the AIDS Institute initiated the *New York State HIV/AIDS Syndemic Surveillance Report*, integrating traditional surveillance techniques with qualitative analysis. This approach reflects the AIDS Institute's commitment to syndemic thinking, recognizing that HIV exists within an ecosystem of overlapping conditions including substance use, mental health challenges, poverty, stigma, and other structural inequities.

The *New York State HIV/AIDS Syndemic Surveillance Report, Supplemental Volume 1* presents a comprehensive examination of the social, structural, and behavioral conditions influencing HIV transmission and outcomes across New York State, outside of New York City. Building upon HIV surveillance infrastructure, this report expands traditional epidemiologic monitoring to include a qualitative analysis illuminating the broader social determinants of health that drive HIV risk, delay diagnosis, and undermine care engagement.

This report draws on qualitative data sources to describe the social landscape of HIV in New York State outside of NewYork City. A thematic analysis of Partner Services narratives writted by Disease Intervention Specialist was conducted to explore the social drivers shaping individual risk, diagnosis, and care experiences. Partner Services notes were coded for recurrent themes related to behavioral, psychosocial, and structural contexts, with frequencies examined across demographic groups.

Across findings, the data demonstrate that HIV vulnerability and poor outcomes are sustained by overlapping syndemics, interacting epidemics of trauma, substance use, poverty, and social marginalization, deeply rooted in the social and structural determinants of health. Economic instability, housing insecurity, food scarcity, and limited access to transportation emerged as recurring forces that shape both exposure risk and care engagement. These conditions, compounded by stigma, racism, and fragmented systems of care, magnify barriers to testing, delay diagnosis, and disrupt continuity of treatment.

The syndemic framework underscores that HIV outcomes cannot be disentangled from these broader social realities. Addressing them requires multi-sector coordination that integrates behavioral health, housing, economic support, and public health interventions. By aligning surveillance, policy, and program design around the root causes of vulnerability, rather than isolated risk behaviors, New York State can strengthen health equity and advance a more holistic, person-centered approach to ending the HIV epidemic.



2. Introducing New York State Syndemic Surveillance Report, Supplemental Volume 1

Background

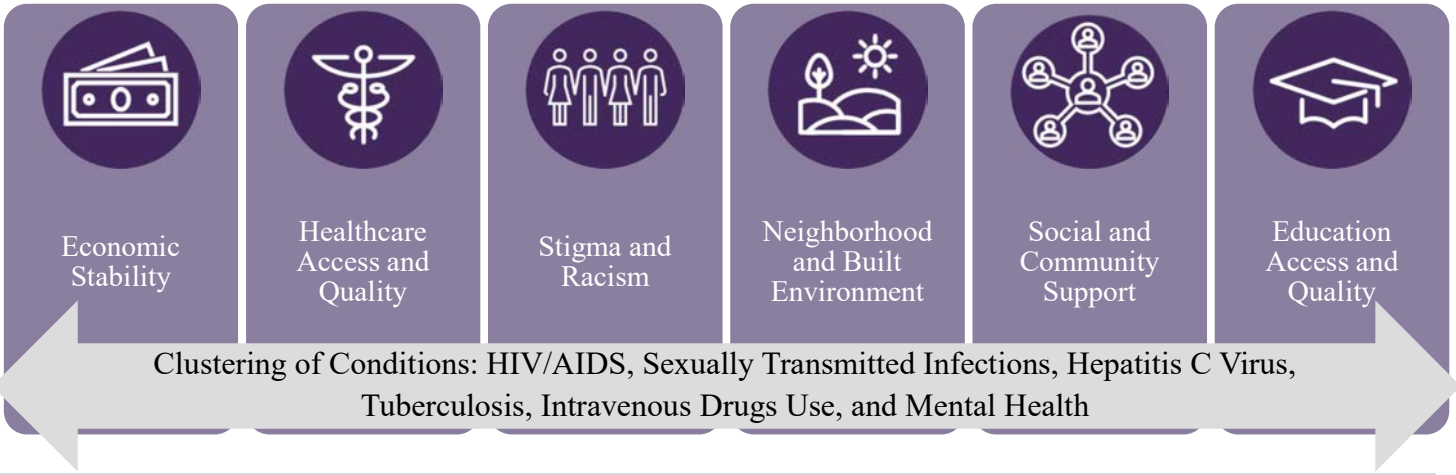
Syndemic theory challenges us to reimagine how we study, conceptualize, and intervene in health crises. In the context of overlapping epidemics in New York State, syndemics provide a framework for understanding how macro-level factors perpetuate structural vulnerabilities, how this cumulative disadvantage leads to micro-level effects, and how policy and clinical interventions can address them. Instead of treating diseases in isolation, syndemics propose addressing the root cause of the disease by strengthening strategies of prevention and care that factor in structural vulnerabilities. In summary, syndemics are not just additive, they are multiplicative and addressing them requires integrated, interdisciplinary, and justice-oriented public health solutions.

Report Overview

The New York State HIV/AIDS Syndemic Surveillance Report presents findings from the first statewide outside of New York City effort to integrate surveillance data across multiple overlapping epidemics that influence HIV transmission, care, and outcomes. The report is produced by the Division of HIV Epidemiology, Evaluation, and Partner Services within the AIDS Institute, New York State Department of Health, and is based on 2024 HIV Surveillance Data. Volume 1 of the inaugural report builds upon the syndemic framework for HIV surveillance in New York State, which recognizes that biological interactions between co-occurring infections are shaped by social, economic, and structural conditions that amplify disease burden and health inequities.

Objectives of Supplemental Volume 1

This report provides a descriptive summary of social and structural drivers that contribute to the syndemic burden in New York State. While the New York State HIV/AIDS Annual Surveillance Report describes the epidemiology of HIV alone. This supplemental volume expands on it by capturing their shared determinants of health. The report is organized to present (1) the distribution of thematic codes by demographic and co-infection and (2) insights from partner services interviews on social drivers. The findings are intended to inform prevention and care strategies, guide public health planning, and strengthen New York State's capacity to respond to overlapping epidemics.



3. Data Sources and Methodology

3.1 Data Sources

This report integrates multiple complementary data sources, including HIV surveillance data, sexually transmitted infection diagnosis records, hepatitis C exposure data, and Partner Services investigation notes, to capture overlapping clinical and contextual factors. Analyses are limited to individuals residing in New York State outside of New York City.

Partner Services Investigation Notes

Within the Bureau of HIV/STI Field Services, investigation notes are written by Disease Intervention Specialists as part of their contact tracing of individuals newly diagnosed with HIV, where they help in finding treatment by assessing any potential barrier to receiving care. In pursuit of interrupting the transmission chain, they also contact partners of individuals diagnosed with HIV to inform them of their potential exposure.

The primary objective of the notes is to collect information from the investigation that may not be captured in the pre-established fields related to risk behavior and healthcare engagement. However, due to the nature of HIV investigations, barriers such as mental health, housing instability, economic instability, limited transportation, and domestic violence may also be recorded. This broader social context emerges organically during the disease investigative process; hence the partner services notes provide valuable insight into the challenges experienced by people diagnosed with HIV when linking to care or accessing supporting services.

3.2 Analytical Methods

Partner Services records were reviewed to identify structural and social drivers associated with HIV acquisition and care engagement among people newly diagnosed with HIV in 2024. The qualitative component of this analysis used thematic analysis to identify recurring contextual patterns within narrative notes.

Data Source and Cohort Selection

The analytic cohort included a random selection of 200 individuals newly diagnosed with HIV living in New York State outside of New York City between January 1, 2024, and December 31, 2024, out of a total of 734 newly diagnosed individuals. Each record was matched to corresponding Partner Services assignments in the HIV Surveillance Registry. Assignment records were included if the individual diagnosed with HIV was successfully interviewed by Partner Services staff, and if they had associated narrative text fields. Assignments with no free-text narrative, or containing only structured fields, were excluded. To ensure completeness, all notes associated with the 2024 diagnosis event were included, regardless of assignment closure date. Personally identifiable information was redacted prior to analysis.

The initial random sample included 200 individuals. To ensure adequate representation of co-infection contexts, an additional seven HIV/hepatitis C co-infection cases were purposefully added to the initial random sample of

200, resulting in a final qualitative cohort of 207 individuals. This sample size provided sufficient saturation for identifying themes related to syndemic and social drivers of health among newly diagnosed individuals.

Analytic Procedure

Narrative data were reviewed and coded manually using a structured qualitative analysis tool developed by the U.S. Centers for Disease Control and Prevention, National Center for Emerging and Zoonotic Infectious Diseases. Each text entry was reviewed for references to social or behavioral factors, coded into broad categories, and further refined into specific subcodes.

The coding approach combined deductive and inductive techniques. Deductive codes were drawn from existing public health frameworks describing syndemic and social determinant domains (e.g., housing, stigma, mental health, substance use, and healthcare access). Inductive coding allowed new themes to be identified directly from participant narratives. Codes were consolidated through iterative review to ensure internal consistency and accuracy.

Interpretation and Limitations

The qualitative findings presented in this report are intended to describe recurring social and structural factors observed among newly diagnosed individuals. Counts of themes should not be interpreted as measures of prevalence or statistical association. Because Partner Services notes are primarily collected for public health follow-up rather than surveillance purposes, completeness and level of detail vary across cases. Data should be interpreted as illustrative of contextual factors influencing HIV risk and care outcomes.

4. Distribution of Qualitative Sample

Introduction

Partner Services notes, recorded by Disease Intervention Specialists during client interviews, provide qualitative insight into the social and structural contexts influencing HIV transmission and care. Although collected primarily for case investigation, these notes often document information related to housing instability, stigma, incarceration, substance use, and other barriers to care. For this analysis, Partner Services narratives linked to individuals newly diagnosed with HIV in 2024 were reviewed to identify recurring social and structural factors (Table 1). Themes were derived through systematic coding of narrative text and organized into categories representing key social drivers of HIV acquisition and outcomes. The findings describe patterns observed across the dataset and are intended to supplement quantitative surveillance data with contextual information relevant to prevention and care.

Table 1. Representativeness of HIV Newly Diagnosed in 2024 by Co-infection

	Sample		All Rest of State Newly Diagnosed (New York State Excluding New York City)		
	Number	Percent	Number	Percent	Ratio
Total Final Sample	207		734		
STI Diagnosis On or After Date of HIV Diagnosis					
Yes	66	32%	202	28%	1.16
No	141	68%	532	72%	0.94
Any Hepatitis C Diagnosis (Final Sample)					
Yes	8	4%	11	2%	2.58
No	199	96%	723	98%	0.98

4.1 Demographic Characteristics of the Qualitative Sample

The qualitative sample reflected the demographic composition of individuals newly diagnosed with HIV in New York State outside of New York City in 2024. Most individuals identified as non-Hispanic Black, Hispanic, or non-Hispanic White, reflecting the racial and ethnic distribution of new HIV diagnoses statewide (Table 2). Individuals were predominantly young adults between the ages of 25 and 44, with fewer individuals under 25 or over 45 years of age. The primary reported transmission category was male-to-male sexual contact, followed by heterosexual contact and injection drug use. Most individuals were male at birth and identified as cisgender men, with cisgender and transgender women making up a smaller proportion of the sample (Table 2). Overall, the sample represents a cross-section of the populations most affected by HIV across New York State, excluding New York City.

Table 2. Representativeness of HIV Newly Diagnosed in 2024 by Demographic

	Sample		All Rest of State Newly Diagnosed (New York State Excluding New York City)		
	Number	Percent	Number	Percent	Ratio
Total Final Sample	207		734		
Race and Ethnicity					
Asian	7	3%	26	4%	0.95
Hispanic	49	24%	181	25%	0.96
Non-Hispanic Black	81	39%	281	38%	1.02
Non-Hispanic White	69	33%	236	32%	1.04
Multi-Race	0	0%	4	1%	0
Native American	1	1%	5	1%	0.71
Native Hawaiian or Pacific Islander	0	0%	1	0%	0
Age at the End of 2024					
13-24	38	18%	131	18%	1.03
25-34	80	39%	282	38%	1.01
35-44	44	21%	157	21%	0.99
45-54	24	12%	92	13%	0.93
55+	21	10%	72	10%	1.03
Transmission Risk Group					
Heterosexual	45	22%	177	24%	0.90
Injection Drug Use (IDU)	9	4%	33	5%	0.97
Male-to-Male Sexual Contact (MSM)	113	55%	378	52%	1.06
Male-to-Male Sexual Contact and Injection Drug Use	13	6%	30	4%	1.54
Pediatric Risk	1	1%	1	0%	3.55
Unknown	26	13%	115	16%	0.80
Sex at Birth					
Yes	36	17.4%	149	20%	0.86

No	171	82.6%	585	80%	1.03
Current Gender					
Non-Binary	1	0.5%	8	1%	0.44
Declined Answer	1	0.5%	3	0%	1.18
Cisgender Woman	35	17%	147	20%	0.84
Transgender Man	0	0%	1	0%	0
Cisgender Man	161	78%	555	76%	1.03
Transgender Woman	9	4%	20	3%	1.60
Ever Incarcerated					
Yes	6	3%	19	3%	1.12
No	201	97%	715	97%	1.00

The qualitative analytic sample included 207 individuals newly diagnosed with HIV in 2024 across all eight Ryan White regions outside of New York City (Table 3). The distribution of the sample closely reflected that of all newly diagnosed individuals statewide. The largest proportion of individuals resided in the Long Island (31%), Rochester (16%), and Albany (15%) regions, followed by Syracuse (10%), Lower Hudson (11%), Buffalo (10%), Binghamton (4%), and Mid-Hudson (3%) on this epidemiological analogy, it is important to consider how each metric can guide interpretation in qualitative analysis.

Table 3. Representativeness of HIV Newly Diagnosed in 2024 by Ryan White Region

	Sample		All Rest of State Newly Diagnosed (New York State Excluding New York City)		
	Number	Percent	Number	Percent	Ratio
Total Final Sample	207		734		
Ryan White Region					
Albany	30	15%	86	12%	1.24
Binghamton	9	4%	12	2%	2.70
Buffalo	20	10%	73	10%	0.97
Lower Hudson	22	11%	97	13%	0.80
Mid Hudson	7	3%	58	8%	0.43
Long Island	64	31%	221	30%	1.03
Rochester	34	16%	101	14%	1.19
Syracuse	21	10%	86	12%	0.87

4.2 Distribution of Social and Structural Codes by Demographic

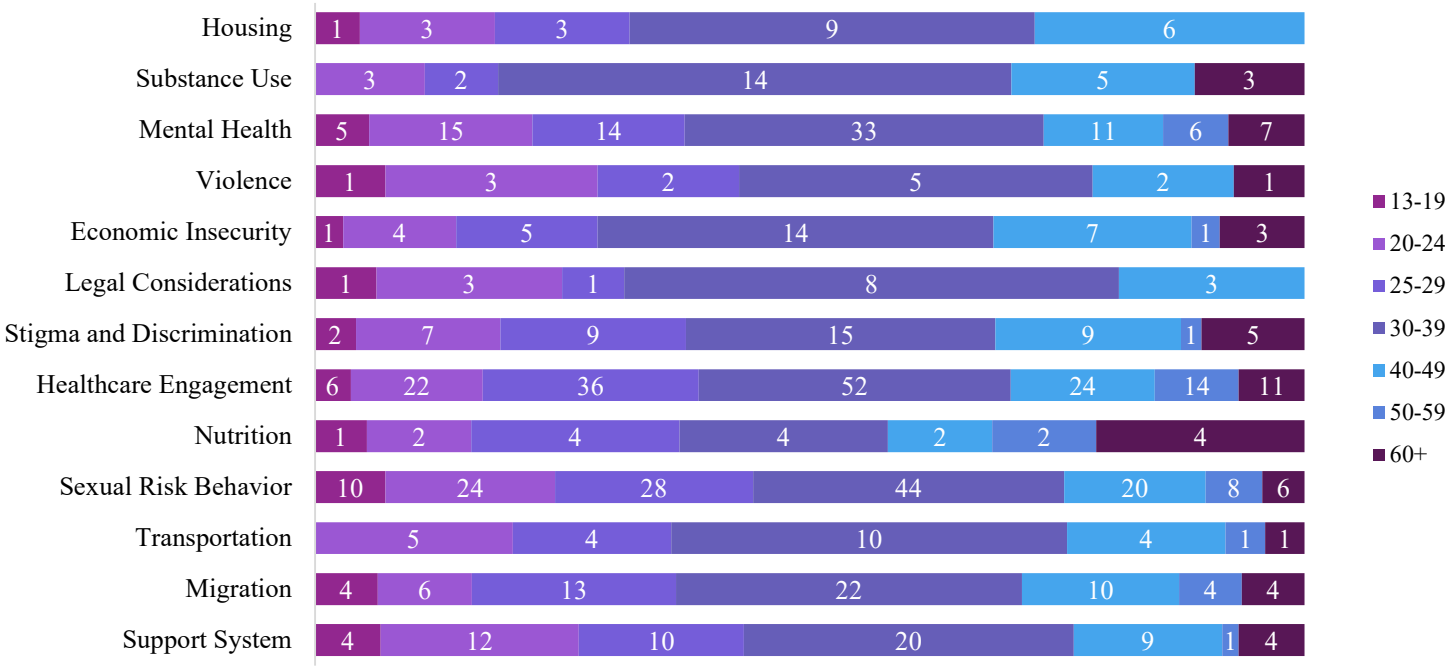
Introduction

The distribution of identified social and structural drivers across key demographic characteristics of individuals newly diagnosed with HIV in 2024. The analysis examines how broad code categories such as housing instability, stigma, substance use, and healthcare engagement appeared within partner services narratives across age groups, race and ethnicity, gender, and transmission categories. The figures below illustrate the proportion of individuals within each demographic category whose narratives referenced each theme. These comparisons provide context for understanding how social drivers of health vary across populations affected by HIV in New York State, excluding New York City. The results are descriptive and intended to highlight broad patterns observed in the qualitative data, complementing the epidemiologic findings presented elsewhere in this report.

Age Groups

Across most themes, individuals aged 30–39 and 40–49 represented the largest share of cases, reflecting their predominance among newly diagnosed persons in the sample. Themes related to healthcare engagement, sexual risk behavior, and stigma and discrimination appeared consistently across all age categories, suggesting that these experiences are common across adults. Younger adults aged 20–29 more frequently referenced housing instability, economic insecurity, and transportation barriers, indicating greater exposure to structural challenges affecting stability and care access. Narratives from individuals aged 40 years and older more often included substance use and mental health themes, pointing to behavioral health factors influencing ongoing risk and care engagement. Reports of migration and immigration-related issues appeared primarily among younger adults.

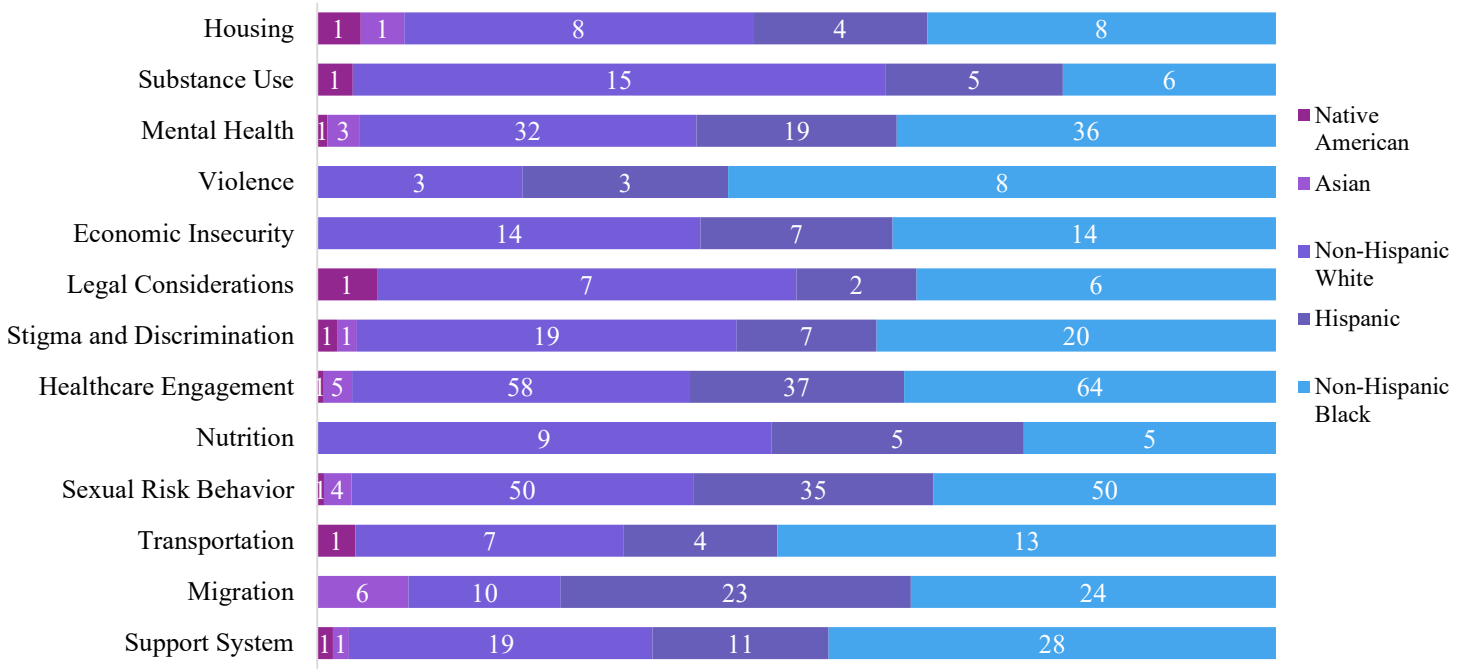
Figure 1. Distribution of Age Group by Distinct Count of Broad Codes



Race and Ethnicity

Non-Hispanic Black individuals accounted for the largest proportion of cases referencing healthcare engagement, sexual risk behavior, and stigma or discrimination, underscoring the social and structural pressures shaping care access and risk environments in this population. Hispanic individuals more frequently reported themes related to economic insecurity, migration or immigration, and support systems, reflecting the broader socioeconomic and cultural factors influencing care engagement. Non-Hispanic White individuals were more often represented among narratives describing substance use, mental health, and housing instability, pointing to the intersection of behavioral health and structural vulnerability in this group.

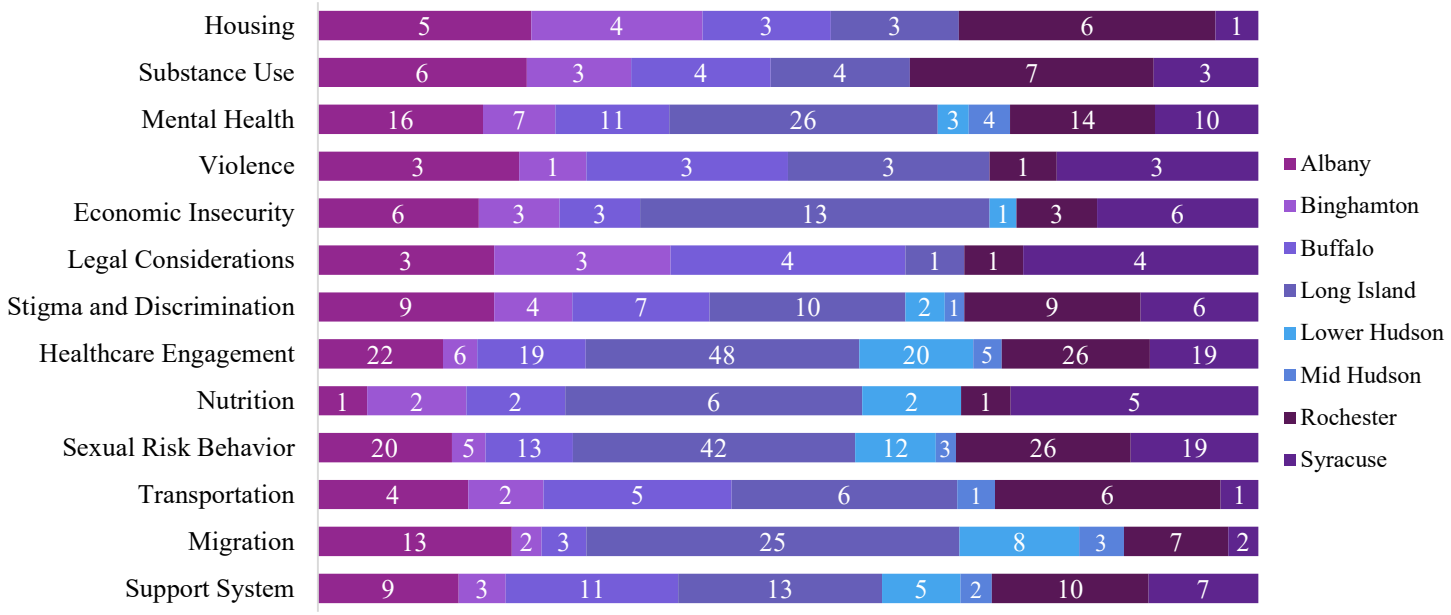
Figure 2. Distribution of Race/Ethnicity by Distinct Count of Broad Codes



Regional Distribution

Patterns varied across regions, reflecting geographic differences in the social and structural environments influencing HIV risk and care engagement. Themes related to healthcare engagement and sexual risk behavior were broadly represented across all regions, but were most frequently reported in the Long Island, Rochester, and Albany regions, which together accounted for a substantial portion of the analytic sample. Stigma and discrimination, economic insecurity, and housing instability were also prominent across multiple regions, with relatively higher proportions noted in Rochester, Syracuse, and Long Island. Reports of immigration-related concerns were concentrated in Long Island and Lower Hudson. Themes related to substance use and mental health appeared most often in Rochester and Albany.

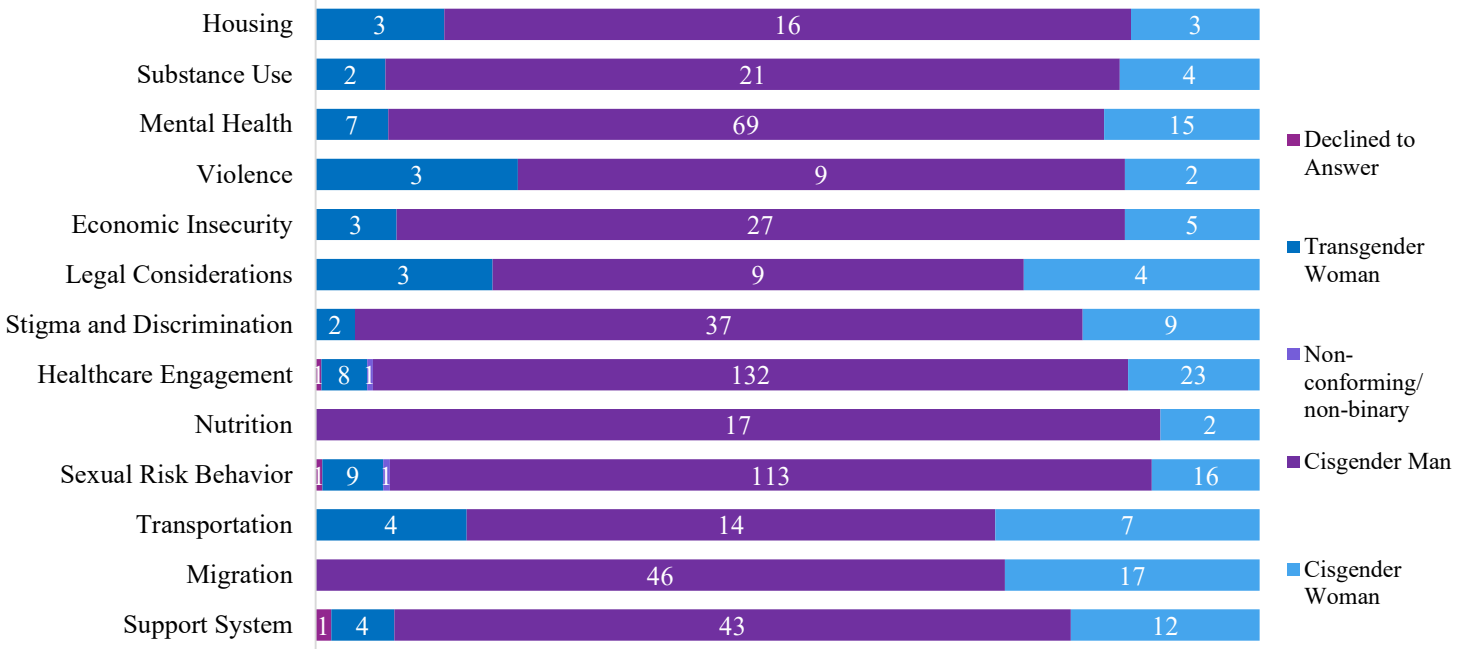
Figure 3. Distribution of Ryan White Region by Distinct Count of Broad Code



Gender

Cisgender men comprised the majority of cases across all themes, reflecting their predominance among newly diagnosed individuals in the analytic sample. Thematic representation among cisgender women was also notable, particularly for issues related to economic insecurity, housing instability, and transportation barriers. While smaller in number, transgender women and non-conforming/non-binary individuals were represented across several themes, most prominently in stigma and discrimination, healthcare engagement, and support system categories. These narratives frequently reflected experiences of social marginalization and structural barriers to care. Cisgender men reported the broadest range of themes, particularly sexual risk behavior, mental health, and substance use, while women's narratives often centered on economic and logistical barriers to care continuity.

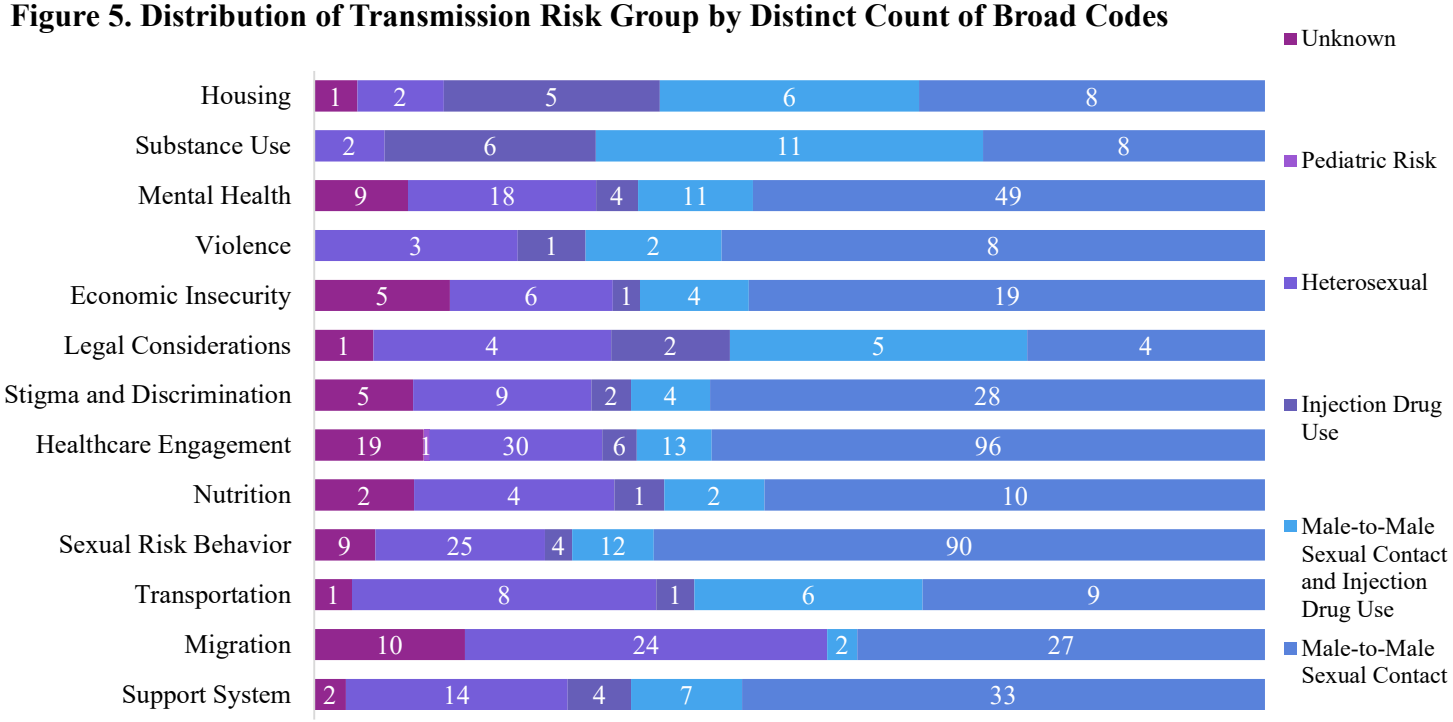
Figure 4. Distribution of Gender by Distinct Count of Broad Codes



Transmission Risk Group

Male-to-male sexual contact accounted for the largest share of individuals across nearly all themes, reflecting their predominance among newly diagnosed persons in the analytic sample. Themes related to healthcare engagement, sexual risk behavior, and stigma and discrimination were most frequently reported within this group, underscoring their ongoing social and structural challenges that influence prevention, testing, and linkage to care.

Figure 5. Distribution of Transmission Risk Group by Distinct Count of Broad Codes



Individuals reporting heterosexual contact as their primary transmission risk more frequently described economic insecurity, housing instability, and transportation barriers, highlighting the influence of structural conditions on care access and retention. Persons with a history of injection drug use alone or in combination with risk from male-to-male sexual contact; were overrepresented in themes involving substance use, mental health, and criminal or legal involvement, consistent with overlapping behavioral and structural vulnerabilities observed in syndemic contexts. Reports among individuals with pediatric risk or unknown transmission were less common, but when present, they often referenced healthcare engagement and social support challenges.

4.2 Distribution of Social and Structural Codes by Co-Infection

Sexually Transmitted Infection and HIV Co-Infection

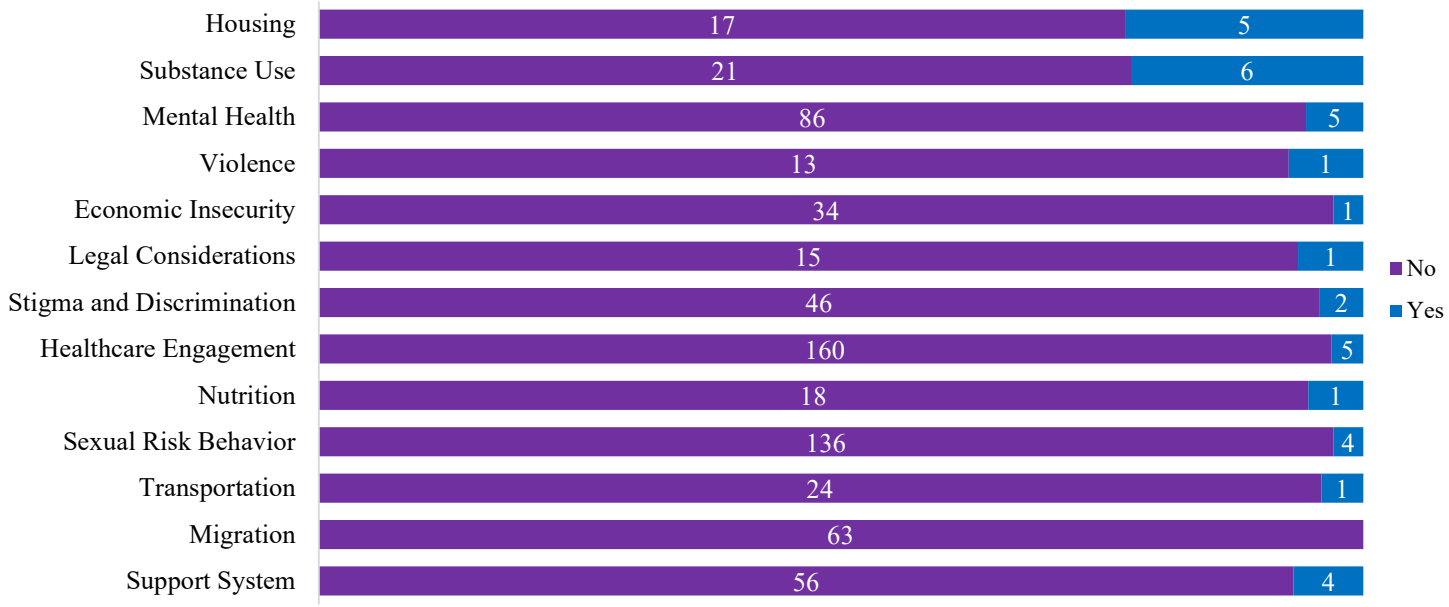
Individuals with a diagnosis of a sexually transmitted infection represented a substantial portion of the analytic sample and showed distinct thematic patterns compared to those without. Those with a documented diagnosis more frequently referenced themes related to mental health, stigma and discrimination, healthcare engagement, and sexual risk behavior. In contrast, individuals without a diagnosis more often referenced economic insecurity, housing instability, and transportation barriers.

Figure 6. Distribution of STI Diagnosis On or After HIV Diagnosis by Distinct Count of Broad Code

Hepatitis C and HIV Co-Infection

Most individuals in the analytic sample did not have a prior hepatitis C diagnosis; however, among those who did, patterns suggest heightened representation in specific social and structural domains. Individuals with a prior hepatitis C diagnosis were more likely to reference themes related to substance use, mental health, criminal or legal involvement, and housing instability, consistent with overlapping behavioral and structural vulnerabilities associated with injection drug use and syndemic risk. In contrast, individuals without a prior hepatitis C diagnosis were more often represented in themes of healthcare engagement, sexual risk behavior, and stigma or discrimination, reflecting pathways more commonly linked to sexual transmission and care-seeking contexts.

Figure 7. Distribution of Hepatitis C Diagnosis Prior to HIV Diagnosis by Distinct Count of Broad Codes



5. Results of Thematic Findings

Descriptive Results of Broad Codes

The analysis revealed a range of contextual factors shaping risk behaviors, care engagement, and overall well-being, where themes explored the primary social drivers documented across narratives. This included barriers related to housing instability, substance use, mental health, and economic insecurity, as well as challenges related to stigma, violence, and criminal justice. Additional themes reflected issues of healthcare engagement, transportation, nutrition, migration, and social support. Collectively, these findings illustrate the complexity of the social environments in which new HIV diagnoses occur and highlight the intersecting conditions that influence timely diagnosis, linkage to care, and treatment adherence.

Overview of Themes

In pursuit of characterizing the social and structural contexts shaping HIV outcomes in New York State excluding New York City, Partner Services narratives from Disease Intervention Specialists were analyzed using Thematic Analysis. The analysis identified four overarching themes that illustrate how behavioral risk, psychological distress, socioeconomic hardship, and violence intersect to influence diagnosis, engagement, and care across the HIV continuum.

The first theme, High-Risk Individuals Encounter Systemic Barriers Leading to Emergency-Based Diagnosis and Poor Continuity of Care, describes how individuals with elevated behavioral risk factors, such as multiple partnerships, inconsistent condom use, and anonymous sex, were often diagnosed in emergency or acute care settings rather than through preventive services.

The second theme, Psychological Distress and Substance Use Undermine Engagement Across the HIV Continuum, captures how emotional trauma, mental health challenges, and substance use disrupted care adherence and amplified isolation and stigma.

The third theme, Socioeconomic and Structural Vulnerabilities Increase Risk and Subvert Stability, highlights how poverty, housing insecurity, transportation barriers, and limited insurance access constrained individuals' ability to prioritize health and sustain engagement in care.

Finally, the fourth theme, Violence, Legal Vulnerability, and Structural Barriers Undermine Safety, Autonomy, and Engagement in Care, explores how experiences of intimate partner violence, exploitation, and systemic neglect created persistent threats to safety and trust, further impeding access to prevention and treatment.

Together, these themes reveal a network of interdependent social and structural conditions that sustain HIV vulnerability. Thus, underscoring the importance of syndemic-informed approaches, integrating behavioral, clinical, and structural interventions to advance equity and improve health outcomes across New York State.

5.1 Theme 1: High-Risk Individuals Encounter Systemic Barriers Leading to Emergency-Based Diagnosis and Poor Continuity of Care

Across Partner Services narratives, individuals engaging in high-risk behaviors often entered the healthcare system only after developing symptoms of advanced disease. Rather than being identified through preventive HIV testing or routine screening, individuals were diagnosed in non-traditional healthcare settings including emergency departments or urgent care facilities. Behavioral vulnerabilities, such as multiple or anonymous partnerships, inconsistent condom use, and substance use, intersected with structural barriers including limited access to preventive services, stigma, and mistrust of the healthcare system. Together, these patterns show how individual risk behaviors are compounded by systemic failures that delay diagnosis and compromise care continuity.

A. High Level Category: Exposure to High-Risk Behaviors and Structural Drivers

Partner Services narratives frequently described exposure to behavioral and social environments that heightened vulnerability to HIV transmission. Individuals reported multiple concurrent partnerships and anonymous sexual encounters that further complicated prevention, as the inability to identify partners made contact tracing nearly impossible. Even if not participating in seemingly risky activities, involvement with key populations highlighted the imperative role of preventive measures. Ultimately, unprotected sex was the most persistent behavioral driver, with several patients noting how condom use decreased over time in presumed monogamous relationships.

Specific Codes	***Count***	***Percent***
Multiple Partners – Concurrent sexual relations.	73	35%
Anonymous Sex – Partners whose identify is unknown.	48	23%
Sex with Key Population – Encounter with transgender, men who have sex with men, or other key population.	58	28%
Unprotected sex – Inconsistent or absent condom use.	34	16%

Patients described online and in-person solicitation as central spaces for socialization and partner-seeking. Encounters with partners of positive or unknown HIV status were occasionally reported, reflecting both awareness of risk and limited ability to negotiate safer practices. Finally, travel to high-prevalence regions emerged as both a behavioral and structural driver where mobility across borders exposed individuals to new risk environments.

Specific Codes	***Count***	***Percent***
Online/Virtual Solicitation – Use of apps, internet, and other online platforms.	46	22%
In-person Solicitation – Solicitation in public or outdoor spaces.	2	1%
Known Exposure – Sex with known positive or another potential event.	43	21%
Travel to Endemic Region – Visited country with high prevalence of HIV.	27	13%

B. High-Level Category: Suboptimal Engagement with Healthcare System and Poor Continuity of Care

Narratives revealed that many individuals entered care through acute or emergency settings rather than preventive screening, resulting in delayed diagnosis and treatment initiation. Individuals often described presenting to

emergency departments or urgent care for nonspecific symptoms, such as fever, fatigue, or weight loss; where HIV testing was deferred or overlooked. Several individuals were only diagnosed after developing opportunistic infections or other advanced disease manifestations, suggesting prolonged periods of undetected infection.

Specific Codes	***Count***	***Percent***
Symptom-driven Care Seeking – Patient seeks urgent care, emergency department, or primary care for acute symptoms.	80	39%
Co-infection – Diagnosed with another infection or condition.	64	31%
Advanced HIV Disease – Advanced illness at diagnosis or opportunistic infections.	17	8%
Malnutrition – Documented weight loss or wasting.	18	9%

These narratives illustrate gaps in the healthcare system's capacity to identify HIV early, particularly in non-specialized or high-turnover settings. Missed testing opportunities were compounded by fragmented referral processes and limited provider familiarity with HIV staging or confirmatory testing protocols. Inconsistent use of PrEP kept individuals vulnerable to infection, while lapses in antiretroviral therapy (ART) compromised viral suppression and treatment-as-prevention efforts. For some, linkage delays were further exacerbated by stigma, mistrust, or previous negative experiences with medical institutions.

Specific Codes	***Count***	***Percent***
Linkage Delays – Long waits, provider shortage, or mishandled urgency.	15	7%
PrEP Non-adherence – Missed or inconsistent PrEP medication.	26	13%
ART Non-adherence – Missed or inconsistent HIV medication.	7	3%

Findings from this theme underscore the convergence of behavioral and structural determinants driving late HIV diagnosis. High-risk individuals were not reached through prevention or testing programs, resulting in symptom-driven encounters that occurred primarily in emergency or urgent care settings. This reactive approach often led to fragmented follow-up, delayed initiation of antiretroviral therapy, and reduced engagement in long-term care. The narratives collectively highlight critical gaps in prevention outreach, early testing, and linkage systems, areas where targeted intervention could shift diagnoses upstream and strengthen the HIV care continuum.

5.2 Theme 2. Psychological Distress and Substance Use Undermine Engagement Across the HIV Continuum

The emotional impact of an HIV diagnosis often shaped an individual's ability to engage in care. Narratives described initial reactions of disbelief or denial that frequently progressed to sadness, hopelessness, and withdrawal. Anxiety and fear of stigma compounded these reactions, disrupting daily functioning and delaying linkage to care. In several cases, prolonged distress led to thoughts of self-harm or suicidal ideation, underscoring the psychological toll of diagnosis without adequate emotional support. These experiences highlight how emotional distress can erode confidence in the healthcare system, reduce adherence to treatment, and contribute to isolation from family, peers, and providers.

C. High-Level Category: Psychological and Mental Health Stressors

The psychological response to an HIV diagnosis often shaped individuals' ability to engage in care. Narratives described early reactions of disbelief, denial, and emotional withdrawal, which frequently progressed to sadness, hopelessness, and loss of motivation. Anxiety and panic further compounded these reactions, interfering with daily functioning and delaying linkage to treatment. In some cases, persistent distress led to thoughts of self-harm or suicide, underscoring the intensity of the psychological toll when emotional support was limited. These experiences illustrate how mental health challenges can erode confidence in the healthcare system, disrupt adherence, and contribute to isolation from supportive networks.

Specific Codes	***Count***	***Percent***
Shock – Disbelief, denial, or avoidance of diagnosis.	38	18%
Sadness – Reported depression, hopelessness, or grievance.	29	14%
Anxiety – Worry, panic, or social withdrawal.	20	10%
Suicide – Ideation, attempts, or self-harm.	7	3%

Trauma and stigma frequently compounded emotional distress associated with an HIV diagnosis. Individuals described experiences of shame, guilt, and fear of rejection that reinforced isolation and mistrust. Reactions from family or community members often deepened this trauma, while fear of disclosure emerged as a means of self-protection against anticipated judgment. Consequently, withholding disclosure and lacking emotional support limited opportunities to seek care or connect with trusted providers. This interplay between trauma, stigma, and social withdrawal created a feedback loop in which psychological distress was both a cause and consequence of disengagement from care. Collectively, these experiences underscore how social and emotional pressures can erode trust, hinder treatment adherence, and magnify the long-term psychosocial burden of living with HIV.

Specific Codes	***Count***	***Percent***
Internalized Stigma – Shame or self-blame.	5	2%
Community Stigma – Rejection from family or community.	5	2%
Fear of Disclosure – Concern for personal safety or retaliation.	8	4%
Distrust – Suspicion, doubt, or questioning.	17	8%

D. High-Level Category: Substance Use as a Coping Mechanism

Substance use emerged as both a coping mechanism and an avenue for escape from emotional distress, trauma, and socioeconomic instability. Individuals described patterns of polysubstance use, including alcohol, cannabis, methamphetamine, and cocaine, often linked to depression, anxiety, and loss of social support. Several individuals also reported past or ongoing injection drug use, which increased transmission risk through needle sharing. Even among those who did not inject, substance use was frequently described as a way to manage psychological distress or avoid confronting the realities of diagnosis. Over time, these behaviors intensified emotional strain and reinforced cycles of dependency and continued risk exposure.

Specific Codes	***Count***	***Percent***
Polysubstance Use – Multiple drugs used simultaneously.	9	4%
History of IDU – Past or ongoing injection of drugs	12	6%
Non-Injection Use – Pills, meth, alcohol, or cannabis.	15	7%

Substance use and addiction management significantly influenced engagement in HIV prevention and care. Individuals described how drug use disrupted adherence to PrEP and HIV treatment, increasing vulnerability to infection and poor disease control. Access to methadone, buprenorphine, and rehabilitation services was reported, yet program confidentiality and restrictions often limited coordination with disease intervention specialists. Withdrawal symptoms frequently hindered treatment completion, with some individuals leaving rehabilitation against medical advice. The absence of trauma-informed care further perpetuated transmission risk, however, harm reduction services such as syringe exchange programs served as a counterbalance. These narratives show how structural gaps in addiction and mental health reinforce cycles of dependency and disengagement from care.

Specific Codes	***Count***	***Percent***
Treatment Access – Engaged in methadone, buprenorphine, or rehab.	5	2%
Withdrawal Symptoms –Unmanaged withdrawal leading to leaving against medical advice (AMA).	1	0.5%
Treatment Gap – Dropped out of or denied rehab.	6	3%
Safe Practices – Access to clean syringes.	8	4%

E. High-Level Category: Missed Opportunities and the Role of Support Systems

Mental health challenges and systemic barriers frequently disrupted continuity of care for individuals diagnosed with HIV. Individuals described discontinuing mental health services, missing appointments, or declining partner services due to fear of judgment, stigma, or privacy concerns. Rooted in the emotional distress of their diagnosis, these behaviors compromised sustained engagement. In several instances, providers initiated mental health referrals, but inconsistent follow-up and weak linkage systems led to fragmentation across services. Individuals experiencing untreated depression or anxiety were more likely to delay or discontinue antiretroviral therapy (ART), as emotional distress overshadowed adherence. Across narratives, opportunities for redirecting care trajectories were instead marked by isolation and mistrust, reinforcing a cycle of disengagement from care.

Specific Codes	***Count***	***Percent***
Treatment Gaps – Not in mental health care.	12	6%
Care Avoidance – Skipped care due to anticipated stigma.	5	2%
Partners Services Refusal – Refused to provide contacts or further engagement.	68	33%
PrEP Non-adherence – Missed or inconsistent PrEP medication.	26	13%
Antiretroviral therapy Non-adherence – Missed or inconsistent HIV medication.	7	3%

Emotional, social, and professional support played a critical role in shaping care engagement. Individuals who lacked supportive networks frequently described isolation and difficulty coping with their diagnosis, which contributed to disengagement from care. In contrast, those with support from family, friends, or healthcare providers often identified this connection as a turning point in their adjustment and treatment adherence. Compassionate interactions with providers, particularly disease intervention specialists, helped restore trust and continuity when personal networks were limited. Across narratives, social support functioned as both a buffer against emotional distress and a catalyst for sustained engagement in care.

Specific Codes	*Count*	*Percent*
Lack of Support – Social, emotional, or community isolation.	13	6%
Friends/family Support – Emotional, financial, or caretaking support.	29	14%
Provider Support – Positive engagement from healthcare staff.	23	11%

Across narratives, mental health distress and substance use emerged as interconnected syndemic factors that disrupted engagement throughout the HIV care continuum. Emotional trauma, stigma, and limited access to behavioral health services compounded one another, leading to avoidance of testing, inconsistent adherence, and delayed treatment. Substance use often functioned as both a coping mechanism and a barrier to care, while the presence of social and professional support was consistently associated with improved engagement and stability. Together, these findings highlight how psychological and behavioral vulnerabilities, shaped by broader structural conditions, create missed opportunities for prevention and continuity of care.

5.3 Theme 3: Socioeconomic and Structural Vulnerabilities Increase Risk and Undermine Stability

Economic hardship, housing instability, and structural barriers were recurrent themes that shaped individuals' ability to maintain health, safety, and continuity of HIV care. Across narratives, individuals described how unemployment, housing insecurity, and limited access to transportation or insurance created environments where survival often took precedence over health. These vulnerabilities intersected to perpetuate cycles of poverty, exposure to violence, and disengagement from prevention and care services.

F. High-Level Category: Economic Insecurity Leads to Adverse Consequences

Economic instability emerged as a central driver of vulnerability, affecting both daily survival and long-term health. Individuals described periods of unemployment or underemployment that left them dependent on others for food, housing, and transportation. Those employed in temporary or hourly positions faced income fluctuation and job insecurity that intensified financial strain. Frequent medical appointments and illness-related absences further threatened job retention, forcing difficult choices between earning income and attending care visits. In some cases, individuals resorted to transactional sex to meet basic needs, illustrating the severe consequences of economic insecurity.

Specific Codes	*Count*	*Percent*
Unemployment – No formal work.	3	1.5%
Underemployment – Gig jobs or temporary work.	3	1.5%
Clinic Hours – Incompatibility with work or life schedules.	13	6%
Missed Appointment(s) – Does not attend scheduled visit(s).	18	9%
Transactional Sex – Sex exchanged for money, drugs, food, shelter, etc.	3	1.5%

Beyond immediate hardship, poverty often sets off a cascade of social and structural harms. Individuals linked financial strain to environments marked by exploitation, violence, and criminalization. Those engaged in sex work described limited control and exposure to coercion, while others recounted violence and victimization linked to unstable housing or unsafe shelters. Substance use often appeared as a coping strategy, deepening vulnerability and increasing HIV transmission risk. Encounters with the criminal justice system, often resulting from poverty-related offenses, further restricted access to care within punitive systems that prioritize control over rehabilitation.

Specific Codes	*Count*	*Percent*
Exploitation – Trafficking or coercive exchange.	2	1%
Community Violence – Gang activity or assault(s).	1	0.5%
History of Injection Drug Use (IDU) – Past or ongoing injection of drugs.	12	6%
Current Incarceration – Presently jailed or imprisoned.	7	3%

G. High-Level Category: Structural Barriers Result in Material Deprivation

Structural barriers compounded economic hardship and deepened material deprivation. Housing instability emerged as both a cause and consequence of vulnerability. Individuals described displacement resulting from eviction, family conflict, or economic precarity, leading to periods of homelessness or temporary shelter. Many relied on short-term arrangements, staying with friends, relatives, or shelters, to avoid sleeping outdoors. However, when these fragile networks collapsed, individuals faced exposure to violence and illness, disrupting communication with providers and undermining continuity of care.

Specific Codes	*Count*	*Percent*
Housing Loss – Eviction or displacement.	5	2%
Couch Surfing – Staying intermittently with families or friends.	6	3%
Unsheltered – Sleeping outdoors or encampments.	11	5%

Transportation barriers also limited access to essential services. Individuals in rural or isolated areas described long distances and lack of public transit, making even routine appointments difficult to attend. Those without vehicles depended on others for rides or relied on inconsistent transportation programs, which added financial and logistical strain. Legal restrictions, such as suspended driver's licenses, further reduced independence.

Specific Codes	*Count*	*Percent*
Geographic Isolation – Rural or remote areas lacking transport entirely.	2	1%
No Vehicle – Reliance on others or public transport.	12	6%
Missed Appointments – Care lost due to transport issues.	3	1.5%

Financial and insurance barriers further constrained access to prevention and treatment. Individuals without insurance reported being unable to obtain timely testing or medications, while those with limited coverage faced high out-of-pocket costs or delayed benefit approvals. Sudden lapses in Medicare or Medicaid interrupted continuity of antiretroviral therapy and increased the risk of treatment interruption.

Specific Codes	*Count*	*Percent*
Unaffordable Healthcare – No insurance, underinsured, or other financial barriers.	12	6%
Benefit Gaps – Pending, denial, or loss of benefits.	6	3%

H. High-Level Category: Imperative Social Programs and Other Support Systems

Public assistance programs and community support emerged as critical stabilizing forces for individuals facing poverty and instability. Programs such as the AIDS Drug Assistance Program, housing services, and transportation

assistance reduced financial barriers and facilitated linkage to care. Individuals frequently credit caseworkers, social workers, and disease intervention specialists with helping them navigate complex benefit systems and sustain engagement in treatment.

Specific Codes	*Count*	*Percent*
Reliance on Benefits – ADAP, SNAP, TANF, or SSI reliance.	24	12%
Housing Services – Linkage to housing programs.	8	4%
Clinic Transport Services – Van or ride program use.	14	7%

Informal networks also played a vital role in mitigating instability. Family members, friends, and peers offered emotional and material support that strengthened resilience and improved adherence. In contrast, the absence of such networks often coincided with cycles of homelessness, exploitation, and substance use. Disease intervention specialists frequently bridged this gap, providing encouragement, small incentives, and referrals that connected individuals to community resources.

Specific Codes	*Count*	*Percent*
Lack of Support – Social, emotional, or community isolation.	13	6%
Friends/family Support – Emotional, financial, or caretaking support.	29	14%
Provider Support – Positive engagement from healthcare staff.	23	11%

Economic hardship, housing instability, and structural barriers emerged as powerful determinants of vulnerability, shaping both exposure risk and continuity of HIV care. Poverty and material deprivation fostered environments of instability, violence, and exploitation, while transportation and insurance barriers further constrained access to prevention and treatment. Social programs and informal support networks played a critical role in mitigating these effects, underscoring the importance of coordinated, equity-focused systems that address the social and structural determinants of health underlying the HIV epidemic.

5.4 Theme 4: Violence, Legal Vulnerability, and Structural Barriers Undermine Safety, Autonomy, and Engagement in Care

Experiences of violence, coercion, and legal instability emerged as powerful determinants of health and engagement across the HIV continuum. Partner Services notes' narratives revealed how intimate partner violence, sexual assault, exploitation, and structural neglect created persistent threats to safety and autonomy. These harms were often compounded by systemic failures, within both the healthcare and legal systems, that left individuals without adequate protection or support. Together, these experiences illustrate how violence and legal precarity intersect with social and health inequities to obstruct access to care and undermine trust in institutions.

I. High-Level Category: The Ripple Effects of Violence

Individuals' accounts of intimate partner and sexual violence revealed the profound and multifaceted ways abuse undermines autonomy, safety, and well-being. Intimate partner violence occurred across both heterosexual and same-sex relationships, with individuals describing displacement, fear of disclosure, and direct interference in daily life. Sexual violence, including assault, coercion, and rape, was reported in both domestic and community

contexts, often accompanied by substance use, financial manipulation, or forced sex work. These forms of abuse perpetuated physical danger and emotional trauma while obstructing access to care and support systems.

Specific Codes	*Count*	*Percent*
IPV – Intimate partner violence.	3	1.5%
Sexual Violence – Assault, coercion, or rape.	4	2%
Exploitation – Trafficking or coercive exchange.	2	1%

The psychological consequences of violence rippled outward, shaping individuals' behaviors and relationships with healthcare providers. Fear, anger, and coercion were often used as mechanisms of control, leading victims to withhold or recant disclosures of abuse. In several instances, abusers interfered with clinic visits, controlled transportation, or denied privacy, creating barriers to safe communication and treatment adherence. Fear of retaliation, particularly in cases involving undisclosed HIV status or same-sex relationships, reinforced secrecy and disengagement from care. These narratives demonstrate how violence produces enduring effects, eroding trust, limiting autonomy, and deepening vulnerability within healthcare and social systems.

Specific Codes	*Count*	*Percent*
Anger – History of aggression or hostility.	4	2%
Distrust – Suspicion, doubt, or questioning.	17	8%
Fear of Disclosure – Concern for personal safety or retaliation.	8	4%

J. High-Level Category: Legal and Structural Vulnerabilities

Experiences of violence were further complicated by interactions with legal and institutional systems that often failed to provide protection or resolution. Police involvement was reported in some cases of crisis or domestic violence, but individuals described inconsistent follow-up, disbelief, or fear of reprisal that limited their willingness to pursue justice. Civil and criminal proceedings could also reinforce vulnerability, as abusers used lawsuits or custodial threats to intimidate victims and isolate them from support. These dynamics obstructed both safety and HIV prevention efforts, as fear of retaliation discouraged disclosure and hindered partner services.

Specific Codes	*Count*	*Percent*
Police Involvement – Violence incidents involving law enforcement.	3	1%
Civil/Criminal Court – Legal disputes or lawsuits.	5	2%
Partners Services Refusal – Refused to provide contacts or further engagement.	68	33%

K. High-Level Category: The Imperative Role of Support Systems

Amid these challenges, the presence of strong social and professional support networks played a protective role. Individuals with supportive partners, family members, or providers described greater emotional stability and improved engagement in care. Disease investigation specialists, case managers, and social workers were frequently identified as critical connectors, offering empathy, safety planning, and linkage to housing, counseling, and legal services. These interventions helped rebuild trust and foster re-engagement in the HIV care continuum.

Specific Codes	*Count*	*Percent*
Lack of Support – Social, emotional, or community isolation.	13	6%
Spousal/Partner Support – Emotional, financial support, or disclosure acceptance.	3	1.5%
Other Community Support – Community organizations or social networks.	4	2%
Provider Support – Positive engagement from healthcare staff.	23	11%

Violence and perceived legal risk emerged as compounding factors that erode safety, autonomy, and trust, intensifying barriers to HIV prevention and care. Intimate partner and sexual violence limited individuals' ability to disclose, seek help, or maintain treatment, while legal systems often failed to provide adequate protection or intervention. Supportive relationships, with partners, providers, or caseworkers, proved critical in mitigating these harms, demonstrating that safety, empathy, and coordinated care are foundational to equitable health engagement.

6. Conclusions

This supplemental volume of the New York State HIV/AIDS Syndemic Surveillance Report provides a qualitative examination of the social, structural, and behavioral contexts shaping HIV risk, diagnosis, and care engagement across New York State. Through thematic analysis of Partner Services' narratives, the findings offer a deeper understanding of the lived experiences that underline patterns observed in traditional surveillance data.

These narratives reveal that HIV vulnerability and outcomes are not driven by isolated behaviors, but by the convergence of interconnected conditions, including economic instability, housing insecurity, mental health challenges, substance use, stigma, and exposure to violence. These factors interact in ways that delay diagnosis, disrupt continuity of care, and limit engagement across the HIV care continuum. In this way, the findings illustrate the lived reality of HIV syndemics, where overlapping social and structural forces shape both risk and resilience.

Importantly, Partner Services narratives illuminate how individuals encounter the healthcare system, often through acute or crisis-driven entry points, and how systemic barriers, mistrust, and competing life priorities influence care trajectories. At the same time, these narratives highlight the critical role of support systems, including healthcare providers, disease intervention specialists, and community networks, in fostering trust, facilitating linkage to care, and supporting long-term engagement.

By centering qualitative insights, this volume expands the function of surveillance beyond measurement to include context, interpretation, and meaning. Partner Services narratives serve as a vital source of public health intelligence, offering real-time insight into the conditions shaping HIV transmission and care outcomes. When integrated with quantitative data, these insights strengthen the ability of the AIDS Institute to design more responsive, person-centered, and equity-focused interventions.

Taken together, the findings reinforce the value of a syndemic framework for understanding HIV in New York State. Addressing HIV requires approaches that extend beyond clinical care to engage with the broader social and structural determinants of health. The themes identified in this analysis point to the need for integrated strategies that align public health, behavioral health, social services, and community-based support.