



# C.H.A.I.N. REPORT 2019-4

## Young Adults with HIV

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## INTRODUCTION

In 2020, the most recent year for which data is available, youth ages 13-24 accounted for one-fifth (20%) of new HIV diagnoses in the United States (Centers for Disease Control (CDC), 2022). In the year prior, almost half (45%) of new HIV infections were concentrated in gay and bisexual men under 35 years of age (The White House, 2021). However, people with HIV (PWH) under the age of 35 had the lowest percentage of linkage to care within one month of their diagnosis among all age groups diagnosed with HIV in the United States in 2020 as well as some of the lowest rates of viral suppression at their last viral load test (CDC, 2022).<sup>1,2</sup> Thus, identifying the specific needs of PWH under 35 years of age in the United States is crucial to Ending the Epidemic.

Understanding disparities in health and social service needs and outcomes between young and older PWH is one of the most important factors when considering engagement and retention in care, as well as HIV viral suppression. A number of studies consistently highlight that young PWH have worse HIV medical outcomes than older PWH (Anderson et al., 2020; Beer et al., 2016; Lao-Tzu et al., 2021). One survey of literature comparing the testing and healthcare experiences between young and older PWH estimates 62% of young PWH are linked to care within one year of their diagnosis, whereas three-quarters of older PWH are (Zanoni & Mayer, 2014). Other studies estimate 29-73% of youth are linked to care within one year of diagnosis (Lao-Tzu et al., 2021). Recent national-level data, referenced above, and surveillance data from New York State (NYS) reflect these disparities between young and older PWH. The highest number of new HIV diagnoses in NYS in 2020 was in young adults ages 20-29; this number was more than twice that of older adults in each of the following age ranges: 40-49, 50-59, and 60+ years (CUNY Institute for Implementation Science in Population Health (CUNY IISPH), n.d.a.). Young PWH, particularly those ages 20-29, also had some of the lowest levels of receipt of HIV medical care and viral suppression among PWH in NYS in 2020 (CUNY IISPH, n.d.b., n.d.c.).<sup>3,4</sup>

Difficulties accessing healthcare and treatment, fewer resources, and negative interactions with providers are all common barriers to young PWH's engagement with HIV medical care. PWH are less likely to have health insurance than those without HIV and even among young adults with insurance, retention in care is far from HRSA recommended visit frequency (Zanoni & Mayer, 2014; Tanner et al., 2022). Young PWH's access to needed medical appointments may be further constrained by financial difficulties and/or lack of transportation, as young adults tend to have fewer resources than older adults (Zanoni & Mayer, 2014). Other barriers to retention in care of young PWH include "internalized stigma, shame, denial, low educational achievement," poor provider rapport, housing instability, and mental health and/or substance use challenges (Brooks et al., 2020).

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<sup>1</sup> Eighty percent of youth ages 13-24 linked to care within one month of their diagnosis, followed by 82% of young adults ages 25-34 (CDC, 2022).

<sup>2</sup> PWH ages 25-34 had the lowest levels of viral suppression in 2020 (62.0%), followed by PWH ages 35-44 (62.4%), and then PWH ages 13-24 (63.5%) (CDC, 2022).

<sup>3</sup> PWH ages 30-39 had the lowest level of receipt of HIV medical care in NYS in 2020 (80%), followed by PWH ages 20-29 (82%) (CUNY IISPH, n.d.b.).

<sup>4</sup> Persons living with diagnosed HIV (PLWDH) ages 20-29 and 30-39 had the lowest levels of viral suppression (67%) (CUNY IISPH, n.d.c.).

Lack of knowledge and low motivation to commit to medical treatment may contribute to non-compliance with antiretroviral therapy (ART) in young PWH. Young adults are more likely to have limited knowledge about HIV infection and the benefits of treatment, which may reduce their motivation to take their medications (Lynn et al., 2020). Other documented factors deterring young PWH from taking their antiretrovirals (ARVs) as prescribed include complicated medical regimens, not experiencing symptoms, side effects, issues with their provider or health insurance, inconvenience, disruptions to daily routines, depression/anxiety, stigma, racism, lack of support, substance use, housing insecurity, and/or transportation challenges (Zanoni & Mayer, 2014; Lao-Tzu et al., 2021). Young PWH, particularly those recently diagnosed, may also struggle with medical adherence due to forgetfulness or wanting to avoid a reminder of their infection prompted by their medication (Brooks et al., 2020). Young adults also report aversion to consistent medication usage due to disliking the taste of the medications (Lynn et al., 2020). Lack of adherence in ART usage results in loss of viral load control and may account for young PWH's poorer health outcomes relative to older PWH (Fastenackels et al., 2019). Finally, in a study of behaviorally infected American youth with HIV, housing insecurity and contact with the criminal justice system were associated with lack of viral suppression (Lally et al., 2018).

While there are many studies on young PWH and older PWH, few compare the two populations. The purpose of this report is to highlight differences in the health, experiences, and medical and social service needs of young and older PWH living in New York City (NYC).

## **KEY FINDINGS**

- Young PWH in NYC have distinct and underserved needs. When compared to older PWH, young adults had, on average, higher levels of need, but received lower levels of assistance for each of the following service categories: employment, housing, food, and mental health.
- A greater percentage of young adults engaged in sexual behaviors related to increased risk of HIV transmission than older adults including multiple partners and condomless sex with HIV negative or status unknown partners.
- The reason most commonly given by young adults for delaying or not getting needed medical care was lack of knowledge or not knowing where to go. Issues of access, specifically transportation and affordability, were the next most common barriers, followed by concerns about staff competence and sensitivity.
- Young adults exhibited higher levels of stress than older adults and slightly higher levels of stigma.
- Need for professional substance use treatment reduced the odds of engaging with HIV medical care as well as viral suppression in both young and older adults.
- Higher levels of self-efficacy were significantly associated with improved HIV care and health outcomes in young adults.
- Stress was associated with worse engagement with HIV medical care and outcomes. Younger adults experiencing higher levels of stress were less likely to have consistent HIV care, adherent ARV use, or be virally suppressed.

## METHODS

### Sample

This report used data from the Community Health Advisory and Information Network (CHAIN) Project, an ongoing, prospective cohort study of PWH living in New York. Participants are recruited through a two-stage sampling process designed to be representative of PWH who have had some contact with a publicly funded service provider in the past 12 months. First, medical and social service providers located across NYC are randomly selected. Then individuals ages 18 and older, proportional to the provider’s total enrollment, are recruited from agency rosters or through sequential enrollment procedures with the support of agency staff.<sup>5</sup> The study sample included 575 NYC CHAIN participants ages 55 and under recruited between 2009 and 2020 and their interviews conducted between 2011 and 2020 (Wave 7 – Wave 10). A total of 1,168 interviews were included in the analysis.

### Measures

The CHAIN Project collects information on multiple aspects of an individual’s life, including detailed housing status and use of social and medical services, as well as sociodemographic, behavioral, and well-being measures relevant to need for these services. Study variables for this analysis were chosen based on theoretical and empirical evidence suggesting the variable has an effect on access to and retention in HIV medical care as well as HIV health outcomes.

#### *HIV medical care outcome measures*

The outcome measures for this study are selected to indicate care continuum markers of positive engagement in HIV medical care and viral load outcomes (**Table 1**).

**Table 1. Outcome Measures – Variable Definitions**

HIV Care Outcomes	Definition
<b>Access to Comprehensive Primary Care</b>	This variable is based on three items in the survey: (1) Always had someone for routine check-ups, vaccinations, or medical tests in last 6 months; (2) Always had someone for information or advice about health in last 6 months; (3) Always had someone you could call 24 hours for medical emergency in last 6 months. Access to comprehensive primary care is a binary measure: when participants indicate that their current primary care doctor provides all three services, it is treated as present.
<b>Consistent HIV Care</b>	No or 1 missed scheduled appointments for HIV medical care during the past 6 months AND did not have a period of ‘drop out’— intentionally stopped going to the doctor and had no HIV medical appointments for 6 months or more, since last interview.

<sup>5</sup> Prior to 2017, CHAIN recruitment was limited to PWH ages 20 years and older.

**Table 1. Outcome Measures – Variable Definitions**

HIV Care Outcomes	Definition
<b>Adherent ARV Use</b>	Adherent ARV indicated by taking any recommended ARV regimen and participant report of taking medications “exactly as prescribed, almost never missing a dose” and not missing any medications in the two days preceding the interview. Not adherent to recommended ARV regimen includes those who are not taking any antiretroviral medications and those taking medications not consistent with DHHS’s guidelines in effect at the time of the interview (NIH, AIDSinfo.nih.gov).
<b>Viral Suppression</b>	Self-reported most recent HIV viral load as an actual numerical value or report medical provider designation as “undetectable,” or “good.” Viral load of <400 copies (or <200 copies from November 2009 and after), or provider report as “undetectable,” or “good” were coded as “suppressed viral load” and >400 copies (or >200 copies from November 2009 and after) or reported as “bad” as “unsuppressed viral load.”

**Subgroup variables**

A number of subgroup variables were used to describe CHAIN participants’ characteristics and contextual factors that other research has shown to affect engagement with HIV medical care and viral suppression (Table 2). Some of these variables are recoded when entered in the logistic regression analysis described below.

**Table 2. Individual Characteristics**

Subgroup Variables	Definition
<b>Gender</b>	Men, women, transgender individuals
<b>MSM</b>	MSM (men reporting sex with men), non-MSM
<b>Race/Ethnicity</b>	White, Black, Hispanic/Latino/a, other
<b>Borough of Residence</b>	Bronx, Brooklyn, Manhattan, Queens, Staten Island
<b>Education</b>	Less than high school, high school or GED, more than high school
<b>Employment</b>	Unemployed not looking for work, unemployed looking for work, employed part-time, employed full-time
<b>Exchanged Sex</b>	Reported giving or getting sex in exchange for money or drugs in the past 6 months
<b>Self-Efficacy</b>	5 questions assessing self-efficacy. Higher scores indicate greater self-efficacy. (Bandura, 1997).
<b>Perceived Stress</b>	Using the Perceived Stress Scale (PSS-4) (Cohen et al., 1983), responses of “never” (0) to “very often” (4) to 4 questions assessing stress levels are summed. Higher scores indicate greater levels of stress.
<b>Year of Diagnosis</b>	<2002, 2002-2011, 2012+

*Service need, service receipt, and service gap variables*

Service needs, receipts, and gaps are defined for domains of housing, food, mental health, and problem substance use service areas. First, we defined service need and receipt of the service for each area. Then “service gap” is defined as those in need of a service who have not received the service. Detailed definitions are described below in **Table 3**.

**Table 3. Service Need, Service Receipt, and Service Gap Variables**

<b>Variables</b>	<b>Definition</b>
<b>Housing Status</b>	<ul style="list-style-type: none"> <li>• Stable individuals in permanent housing</li> <li>• Unstable individuals not currently in permanent housing but not literally homeless, including those in a transitional housing program, in alcohol or drug (AOD) treatment housing with no other address, or temporarily doubled up with friends or family</li> <li>• Homeless individuals who describe themselves as homeless or report sleeping on the street, in a shelter, or in a single room occupancy (SRO) or welfare hotel with no services in last 6 months</li> </ul>
<b>Receipt of Housing Services</b>	Received tenant-based or facility-based permanent rental assistance OR received “practical” housing assistance in the past 6 months that resolved need or problem or made “some” or “a great deal” of progress with resolving housing needs
<b>Gap in Housing Services</b>	Homeless or unstably housed and no receipt of housing services
<b>Food Insecurity</b>	Reporting not enough money for food that the individual or family needs ‘sometimes’ to ‘very often’ in the past 6 months; or ‘sometimes/often’ there is not enough to eat; or the participant has gone a whole day without eating in the last 30 days; or they report need for services or help with food, groceries, or meals in the past 6 months
<b>Receipt of Food Services</b>	Received one or more of the following services in the past 6 months: meals provided in a group setting, prepared meals delivered to home, receipt of food voucher, or food from a food pantry
<b>Gap in Food Services</b>	Food insecure and no receipt of food services
<b>Poor Mental Health Functioning</b>	Very poor mental health functioning indicated by SF12 Mental Component Summary Score (MCS) <37, the mean score seen in psychiatric inpatient populations (Ware et al. 2002)
<b>Receipt of Mental Health Services</b>	Received counseling or treatment from a licensed mental health care professional or clinical social worker in the past 6 months
<b>Gap in Mental Health Services</b>	Very poor mental health functioning and no receipt of mental health services
<b>Hard Drug Use</b>	5+ times lifetime use of heroin, cocaine, crack, and/or methamphetamine. Timing of use is defined as currently or within 6 months of interview (current use), prior to 6 months ago (past use), or never.
<b>Current Problem Drinking</b>	Indicated by the CAGE instrument (Ewing, 1984) OR drinking weekly, consuming 5 or more drinks when drinking.
<b>Receipt of Substance Use Treatment</b>	Received any type of professional treatment in the past 6 months, excluding self-help groups such as Alcoholics Anonymous (AA)/Narcotics Anonymous (NA)

<b>Variables</b>	<b>Definition</b>
<b>Gap in Substance Use Treatment</b>	Current hard drug use and/or current problem drinking and no receipt of substance use treatment
<b>Medical Case Management</b>	(1) Help from a case manager with access or referrals to medical services during the last 6 months OR (2) support services for taking ARVs from professional providers in the last 6 months
<b>Social Service Case Management</b>	Help from a case manager with at least 1 of the following in the past 6 months: (1) revising or developing a plan for dealing with needs OR (2) helping with a referral for a specific social service need OR (3) filling out forms for benefits or entitlements

## Analysis

For the sample description (**Table 4**), data are from the baseline interview of all 575 individuals: 102 recruited during 2009 (Wave 5), 72 recruited during 2010 (Wave 6), 323 recruited during 2015 – 2017 (Wave 9), and 78 recruited during 2018 – 2020 (Wave 10). For the rest of the descriptive analyses, the individual’s most recent interview was used, resulting in 530 participants included. The loss of 45 individuals is due to their aging out of the study’s age cut-off of 55 by the time of their most recent interview. All results are disaggregated by age. Young adults are those ages 18-35, while older adults are ages 36-55.

In order to assess the association between study variables of interest and young and older adults’ access to and engagement with HIV medical care and viral suppression, multivariate analyses were performed using population-averaged models with robust standard errors. Separate models were fit for young and older respondents to identify potential age-specific predictors. All analyses were performed in Stata 17 (StataCorp LLC, College Station, TX).



## RESULTS

### Sample Characteristics

**Table 4** presents a demographic overview of the study sample using data from respondents' baseline interviews. While the majority of both young and older participants were male, fewer young adults were female and a greater percentage identified as transgender. The racial/ethnic composition of young and older respondents was similar. Nearly half were Black and about 40% were Hispanic/Latino/a. Young adult respondents most commonly lived in the Bronx (42%), while about one-third of older respondents lived in the Bronx and another third in Brooklyn. Young adult respondents were, on average, more educated than older respondents. Unemployment levels and interest in work differed by age group. Just over two-thirds of young adults were unemployed, while more than 80% of those ages 36-55 were. Among the unemployed, three-quarters of young adults were interested in returning to work, whereas less than half of older adults felt similarly. A respondent's housing situation also differed by age group. Less than half of young adults reported a stable housing situation, while three-quarters of older adults were in a stable living environment. Almost 30% of young adults were homeless. Nearly three-quarters of both age groups lived below the federal poverty threshold. More young adults, 62%, experienced food insecurity than older adults (53%).

**Table 5** presents participant behavioral characteristics, focusing on factors that may increase the risk of HIV infection and/or transmission. Substance use was, on average, less common among young adults. Thirty-eight percent (38%) of young adults had ever used hard drugs, compared to 47% of older adults. Rates of current problem drinking were similar between the age groups (13-14%). Young adults exhibited much poorer mental health; 43% of young adults had very low mental health functioning, indicative of need for psychiatric inpatient care, relative to just over one-third of older adults. The percentage of young adults who have ever been incarcerated was less than half that of older adults.

A greater percentage of young adults participated in sexual behaviors related to increased risk of HIV infection and/or transmission. More than half of young adults reported two or more sexual partners in the past six months, compared to 29% of older adults. The percentage of young adults who have ever had a sex partner who was unaware of the respondent's HIV status was nearly twice that of older adults. More than one-third of young adults have ever had condomless sex with a partner who is either HIV negative or whose status was unknown. Just under one in five older adults reported the same. Few young or older adults exchanged sex for money or drugs in the past six months. Pre-exposure prophylaxis (PrEP) or medication taken to decrease the risk of HIV infection by regular HIV-negative partners of young adults was nearly double that of older adults' partners.

**Table 4. Participants' Demographic Characteristics**

	<b>Age 18-35 (n=298)</b>	<b>Age 36-55 (n=277)</b>
	Column %	Column %
<b>Gender***</b>		
Men	68%	60%
<i>MSM***</i>	88%	57%
Women	29%	40%
Transgender individuals	4%	<1%
<b>Race/ Ethnicity</b>		
White	3%	7%
Black	49%	47%
Hispanic/Latino/a	40%	41%
Other <sup>1</sup>	7%	5%
<b>Borough of residence</b>		
Bronx	42%	34%
Brooklyn	26%	31%
Manhattan	17%	17%
Queens	9%	10%
Staten Island	6%	8%
<b>Education*</b>		
Less than high school	28%	38%
High school or GED	52%	44%
More than high school	20%	18%
<b>Employment***</b>		
Unemployed	68%	81%
<i>Unemployed not looking for work***</i>	26%	53%
<i>Unemployed looking for work</i>	74%	47%
Employed part-time	22%	12%
Employed full-time	10%	7%
<b>Household income below 100% federal poverty threshold <sup>2</sup></b>		
	73%	75%
<b>Housing***</b>		
Stably housed	49%	75%
Unstably housed <sup>3</sup>	22%	13%
Homeless <sup>4</sup>	29%	12%
<b>Food insecure<sup>4*</sup></b>		
	62%	53%

Data from baseline interviews; significant differences indicated by \* p<=.05, \*\* p<=.01, \*\*\*p<=.001.

<sup>1</sup> 'Other' includes Asian/ Pacific Islander and 'other' not specified

<sup>2</sup> Below the U.S. Census Poverty Threshold calculated by household composition and household income

<sup>3</sup> Individuals not currently in permanent housing but not literally homeless, e.g., those in a transitional housing program, AOD treatment housing with no other address, or temporarily doubled up with friends or family in last 6 months

<sup>4</sup> Individuals who describe themselves as homeless or report sleeping on the street, in a shelter, or in an SRO or welfare hotel with no services in last 6 months

<sup>5</sup> Reporting not enough money for food that the individual or family needs 'sometimes' to 'very often' in the past 6 months; or 'sometimes/often' there is not enough to eat; or the participant has gone a whole day without eating in the last 30 days; or they report need for services or help with food, groceries, or meals in the past 6 months

**Table 5. Participants' Risk Related Behaviors and Experiences**

	<b>Age 18-35 (n=264)</b>	<b>Age 36-55 (n=266)</b>
	Column %	Column %
<b>Substance use</b>		
Hard drug use <sup>1***</sup>		
Never used	72%	53%
Past use	12%	29%
Current use	16%	18%
Current problem drinking <sup>2</sup>	13%	14%
<b>Mental health</b> <sup>3</sup>		
Poor mental health functioning	43%	36%
Very poor mental health functioning	43%	36%
<b>Ever incarcerated</b> <sup>***</sup>	18%	41%
<b>Sexual behaviors</b>		
>2 Sex partners during the past 6 months <sup>***</sup>	53%	29%
Any of sex partners unaware of respondent's HIV status <sup>**</sup>	22%	12%
Any condomless sex with HIV- partner <sup>***</sup>	34%	19%
Partner use of PrEP among those with regular HIV negative partner	30%	16%
Exchanged sex for money or drugs during the past 6 months	5%	4%

Data from most recent interviews, Significant differences indicated by \* p<=.05, \*\* p<=.01, \*\*\*p<=.001.

<sup>1</sup> Any use of heroin, other opiates, cocaine, crack, methamphetamine, other stimulants, current use in past 6 months

<sup>2</sup> Indicated by the CAGE assessment or drinking weekly, consuming 5+ drinks when drinking

<sup>3</sup> Medical Outcomes Study (MOS) SF-12v2 Mental Component Summary Score (MCS). A score <42.0 indicates 'poor' and 'very poor' is a score of less than 37.0 which is below the score of psychiatric inpatient patients (Ware et al., 2002).

## Medical and Social Service Use

Rates of use of social or medical services by young adults were similar to that of older adults (**Table 6**). Just under two-thirds (64%) of young adults had access to comprehensive primary care, compared to 69% of older adults. Similarly, 74% of young adults were engaged in consistent care, while 77% of older adults reported the same. Sixty-eight percent of young adults used ARVs exactly as prescribed, almost never missing a dose, while 74% of older adults did. Finally, nine out of ten young and older adults, 91%, were virally suppressed.

For each social service type, a lower percentage of young adults received assistance than older adults. The majority of young and older adults, more than 80%, received housing services. Only 31% of young adults received food services and 35% received professional mental health services. Few young or older adults received professional substance abuse treatment.

About one in five of both young and older adults felt they received poorer services than others when receiving health care. When asked about barriers that delayed or deterred respondents from getting needed medical care, young adults most commonly cited lack of knowledge or not knowing where to go. Issues of access, specifically transportation and affordability, were the next most common barriers, followed by concerns about staff competence and sensitivity. Older adults also cited not knowing where to go as their most common medical service barrier. Older adults' second most common deterrent was believing the staff was not good at listening to their problems or needs.

Among the young adults in this study, 25 had received HIV care from an Adolescent/Young Adult HIV Specialized Care Center (AYA Care Center), designed to provide comprehensive and coordinated primary health care and supportive services.<sup>6</sup> Young adults ever reporting receiving care at an AYA Care Center were more likely to report access to comprehensive primary care at their most recent interview compared to the general sample of young adults (82% and 64% respectively) and none indicated that “not knowing where to go” was a reason for their delaying or not getting needed medical care in the prior six months. Few differences were observed in the care continuum outcomes of young adults likely receiving care from an AYA specialty care center: 76% were engaged in consistent care, 72% were adherent ARV users, and 89% were virally suppressed (data not shown).

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<sup>6</sup> Respondents were coded as likely receiving HIV primary care from a provider of comprehensive care for adolescents and young adults if the agency where they received HIV primary care was an Adolescent/Young Adult HIV Specialized Care Center as listed in the NY AIDS Institute Service Directory and if they were under the age of 26. Services at adolescent and young adult centers may continue to be offered to clients over the age of 24 as they transition to adult care (J. Natt, personal communication, April 25, 2023).

**Table 6. Social and Medical Services Utilization**

	Age 18-35 (n=264) Column %	Age 36-55 (n=266) Column %
<b>Care continuum outcomes</b>		
Consistent Care	74%	77%
Adherent ARV Use	68%	74%
Suppressed Viral Load	91%	91%
<b>Primary care, behavioral health, and social services</b>		
Access to comprehensive primary care	64%	69%
Received housing services <sup>1**</sup>	81%	89%
Received food services <sup>2</sup>	31%	38%
Received professional mental health services <sup>3*</sup>	35%	44%
Received professional substance abuse treatment <sup>4</sup>	4%	6%
<b>Received poorer service than other people when getting health care</b>	22%	21%
<b>Delayed or did not get medical care you needed during the last 6 months because...</b>		
<i>you didn't know or weren't sure where to go</i>	14%	15%
<i>it was too difficult to get transportation there</i>	10%	8%
<i>it cost too much or it wasn't covered by insurance</i>	9%	8%
<i>you felt the staff at the office or clinic was not competent to deal with your problem</i>	9%	6%
<i>the staff at the office or clinic are often not polite, are disrespectful, or are insensitive to your needs</i>	8%	8%
<i>you felt that the staff is not good at listening to your problems or needs*</i>	7%	10%
<i>you weren't sure that the staff at the office or clinic would understand your problems**</i>	7%	6%
<i>you needed someone to take care of your children</i>	6%	3%
<i>you were nervous or afraid of what the doctor/service provider might say</i>	3%	3%
<i>the office or clinic was not open at a convenient time</i>	2%	5%
<i>the staff at the office or clinic do not speak your language</i>	2%	2%
<i>you didn't trust the providers to be confidential about your HIV status*</i>	2%	0%

Data from most recent interviews

Significant differences indicated by \*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$ .

<sup>1</sup> Received tenant-based or facility-based permanent rental assistance OR “practical” housing assistance in the past 6 months that resolved need or problem or made “some” or “a great deal” of progress with resolving housing needs

<sup>2</sup> One or more of the following services in the past 6 months: food voucher, food from a food pantry, meals provided in a group setting, or prepared meals delivered to home

<sup>3</sup> Psychological or emotional counseling or therapy from a licensed mental health care professional or clinical social worker in the past 6 months

<sup>4</sup> Alcohol and substance abuse treatment services include any type of professional treatment in the past 6 months excluding AA/NA

## **Self-Efficacy, Stress, and Stigma**

While little difference was observed between the young and older adults' mean self-efficacy scores, a slightly greater percentage of young adults, on average, expressed doubt about their ability to shape their lives (**Table 7**). More than 80% of young and older adults felt they were in control of their feelings and behavior and could handle most things in their lives. Nearly half, 45%, of young adults observed that when trying to get ahead, they encountered a barrier. Almost one in five young adults felt luck was more important than hard work to achieve success. Sixteen percent of young adults doubted their chances of being successful in life.

Young adults exhibited higher mean levels of stress than older adults. While more than one-third of young adults felt "nervous or stressed," 60% expressed confidence in their ability to handle their problems, and another third felt things were going their way.

On average, young adults faced slightly higher levels of stigma when compared to older adults. A greater percentage of young adults internalized stigma, with 30% affirming they felt guilty because they have HIV. More than half of young adults have been hurt by reactions of others to whom they disclosed their HIV status and almost half stopped socializing with some people due to their reaction to the respondent's status. Young and older adults faced comparable levels of disclosure stigma. More than two-thirds of both young and older adults had many areas of their lives in which no one was aware of their status and about 85% of both age groups were very careful with whom they shared their status.

**Table 7. Participants' Self-Efficacy, Stress, and HIV Stigma**

	<b>Age 18-35 (n=264) Mean (SD)</b>	<b>Age 36-55 (n=266) Mean (SD)</b>
<b>Self-efficacy scale score<sup>1</sup></b>	65.2 (15.2)	64.7 (14.0)
There is not much chance that people will really do anything to make this a better world	39%	41%
Every time I try to get ahead, something or someone stops me	45%	40%
People like me don't have a very good chance to be successful in life	16%	12%
For success, good luck is more important than hard work	18%	15%
Most of the time I am in firm control of my feelings and behavior	83%	88%
I can handle most things that happen in my life	88%	90%
<b>Perceived stress scale score<sup>2</sup></b>	8.18 (3.7)	7.53 (3.8)
Felt that you were unable to control the important things in your life	16%	10%
Felt nervous and "stressed"	35%	28%
Did not feel confident about your ability to handle your personal problems	30%	42%
Felt that things were not going your way	66%	65%
Felt difficulties were piling up so high that you could not overcome them	15%	14%
<b>Internal HIV stigma scale score<sup>3</sup></b>	1.89 (0.7)	1.85 (0.7)
I feel I am not as good a person as others because I have HIV	21%	13%
Having HIV makes me feel unclean	25%	19%
Having HIV makes me feel that I am a bad person	10%	8%
I feel guilty because I have HIV	30%	18%
<b>Enacted HIV stigma scale score</b>	2.47 (0.8)	2.33 (0.8)
I have lost friends by telling them I have HIV	35%	33%
I have been hurt by how people reacted to learning I have HIV	56%	43%
I have stopped socializing with some people due to their reaction to my HIV status	48%	41%
<b>Disclosure HIV stigma scale score</b>	2.88 (0.7)	2.82 (0.7)
I am very careful who I tell I have HIV	84%	85%
I work hard to keep my HIV a secret	54%	50%
I worry that people who know I have HIV will tell others	56%	52%
In many areas of my life, no one knows that I have HIV	66%	67%

Mean scale scores with standard deviations in parentheses given per age group. For self-efficacy and stigma, percentages indicate "agree" or "strongly agree" with each statement. For perceived stress, percentages indicate answering "fairly often" or "very often."

<sup>1</sup> Scores can range from 0 to 100; higher scores indicate higher self-efficacy or ability to exert control over one's own motivation, behavior, and social environment.

<sup>2</sup> Scores can range from 0 to 20; higher scores indicate greater stress.

<sup>3</sup> Scores can range from 1 to 4; higher scores indicate experiencing greater internal, enacted, or disclosure stigma.

## **HIV Medical Care and Health Outcomes**

We explore rates of access to and engagement with HIV primary care and care continuum indicators (consistent HIV care or retention, adherent ARV use, and viral suppression) among young and older adults by sociodemographic and psychological characteristics, and service need and utilization experience (**Table 8** and **Table 9**). We then present results of multivariable logistic analyses of sociodemographic characteristics, service need and utilization, and HIV diagnosis year as predictors of young and older adults' access to and engagement with HIV medical care, adherent ARV use, and viral suppression (**Table 10**).

### ***Access to Comprehensive Primary Care***

Examining bivariate patterns of association, without controlling for other factors, young adults who identify as transgender or racially/ethnically White or other, as well as those with a gap in housing services, had the lowest levels of access to comprehensive primary care (**Table 8**). However, caution must be used when considering these statistical estimates since the number of study participants in these subgroups is relatively small. Receipt of food assistance, mental health services, and case management were associated with higher rates of comprehensive primary care.

In the multivariable analyses, among young adults, controlling for other factors, those who received professional substance use treatment in the past six months had lower odds of having access to comprehensive primary care (**Table 10**). Race/ethnicity (Black or Hispanic/Latino/a), higher self-efficiency scores, and professional mental health treatment in the past six months were associated with higher odds of having access to such care. On the other hand, among older adults, being male, not working, and both receiving and needing but not receiving (service gap) food assistance, were associated with increased odds of having access to comprehensive primary care.

### ***Consistent Care***

Young adult PWH with higher education and those who did not report needs for housing, food, or mental health services, had higher levels of consistent HIV care; those who had exchanged sex for money, a place to stay, or drugs in the last six months had the lowest rates of consistent HIV care (**Table 8**).

For young adults, the multivariate model was not statistically significant, meaning that the model did not predict engagement in consistent care with the variables in the model (**Table 10**). Nevertheless, recent transactional sex was significantly associated with decreased odds of engagement with consistent care among young adults. For older adults, both receipt of and gaps in receiving behavioral health services (to address mental health and/or substance use issues) were associated with decreased odds of engagement with consistent care when other factors are controlled, as was perceived stress score.

### ***Adherent ARV Use***

The lowest levels of adherent ARV use were observed in young adults with recent transactional sex, although numbers are small (**Table 9**). Young PWH who experienced service gaps – needing but not receiving services in the areas of housing, food, mental health and/or substance use treatment – had rates



of adherent ARV use that were 10-15% lower than the overall sample. Receipt of substance use treatment or services was also associated with relatively low rates of adherent ARV use.

For young adults, service gaps regarding food services and substance use treatment (needing the service but not having received the service) and higher a perceived stress score were significant predictors of lower odds of adherent ARV use, controlling for other factors in the multivariable analysis (**Table 10**). For older adults, having received housing assistance in the past six months was the only significant predictor of lower odds of adherent ARV use when controlling for other factors.

### ***Suppressed Viral Load***

Viral suppression was generally high across all subgroups (**Table 9**). Young adults with a gap in receipt of housing services had the lowest rates of viral suppression and transgender individuals and recent transactional sex were also associated with relatively low rates of suppression.

In the full adjusted models, receipt of substance use treatment or services as well as need for but no receipt of substance use treatment (service gap) were significant predictors of lower odds of HIV viral suppression among young adults (**Table 10**). No variables in the model were significantly associated with increased odds of viral suppression. Among older adults, the only statistically significant predictor of viral suppression when other factors were controlled for was recent receipt of substance use treatment which was associated with lower odds.

**Table 8. Access to Comprehensive Primary Care and Consistent HIV Care by Age and Respondent Characteristics**

2015-2021 interviews		Comprehensive Primary Care		Consistent HIV Care		
		Age	18 – 35	36 – 55	18 – 35	36 – 55
<b>Total Sample</b>			<b>62%</b>	<b>69%</b>	<b>72%</b>	<b>78%</b>
<b>Demographics</b>						
Gender:	Male		63%	71%	74%	73%
	Female		70%	66%	75%	83%
	Transgender		33%	--	67%	--
Race/Ethnicity:	White/Other		48%	71%	74%	75%
	Black		68%	72%	75%	77%
	Hispanic/Latino/a		65%	66%	74%	77%
<b>Socioeconomic Factors</b>						
Education:	Less than HS education		58%	73%	72%	75%
	HS diploma or equivalent		70%	69%	74%	77%
	More than HS education		57%	61%	80%	79%
Work:	Not currently working		69%	71%	72%	75%
	Employed, part-time or full-time		56%	63%	78%	83%
Sex exchange:	Exchanged sex past 6 months		55%	80%	46%	64%
<b>Service Needs, Service Receipt, and Gaps</b>						
Housing:	No housing service needs		53%	71%	81%	73%
	Gap in housing services		46%	82%	75%	54%
	Received housing services		67%	68%	73%	79%
Food:	No food service needs		57%	68%	80%	85%
	Gap in food services		63%	73%	74%	75%
	Received food services		72%	66%	68%	72%
Mental Health:	No mental health service needs		52%	75%	80%	84%
	Gap in mental health services		65%	61%	68%	73%
	Received mental health services		76%	67%	73%	72%
Substance Use:	No substance use treatment needs		67%	69%	75%	86%
	Gap in substance use treatment		56%	75%	65%	56%
	Received substance use treatment		50%	47%	67%	56%
Case Managmt:	Received Medical Case Management		76%	54%	75%	63%
	Received Social Service Case Management		72%	69%	73%	77%
<b>Psychological Factors</b>						
	Self-efficacy scale score, mean (sd)		66.8(14.9)	65.4(14.0)	65.6(15.2)	65.1(13.6)
	Perceived stress scale score, mean (sd)		8.4(3.8)	7.1(3.7)	7.9(3.8)	7.1(3.8)
<b>HIV Diagnosis Year</b>						
	< 2002		63%	75%	74%	77%
	2002-2011		72%	65%	75%	78%
	≥ 2012		54%	58%	73%	74%

Note: Shown are column percentages. Data from most recent interview. N=264 for ages 18 to 35, N=266 for ages 35 – 55. Gray shaded cells indicate too few respondents for reliable estimates (n<25).

**Table 9. Adherent ARV Use and Suppressed Viral Load by Age and Respondent Characteristics**

2015-2021 interviews		Adherent ARV Use		Suppressed Viral Load		
		Age	18 – 35	36 – 55	18 – 35	36 – 55
<b>Total Sample</b>			<b>72%</b>	<b>78%</b>	<b>91%</b>	<b>91%</b>
<b>Demographics</b>						
Gender:	Male		69%	77%	88%	90%
	Female		67%	71%	93%	91%
	Transgender		75%	--	83%	--
Race/ethnicity:	White/Other		63%	82%	92%	90%
	Black		69%	78%	91%	91%
	Hispanic/Latino/a		69%	69%	92%	90%
<b>Socioeconomic Factors</b>						
Education:	Less than HS education		63%	73%	91%	92%
	HS diploma or equivalent		70%	73%	91%	91%
	More than HS education		72%	79%	94%	89%
Work:	Not currently working		74%	78%	91%	88%
	Employed, part-time or full-time		69%	79%	92%	97%
Sex exchange:	Exchanged sex in the past 6 months		38%	55%	82%	67%
<b>Service Needs, Service Receipt, and Gaps</b>						
Housing:	No housing service needs		76%	80%	91%	100%
	Gap in housing services		56%	62%	73%	92%
	Received housing services		68%	75%	92%	90%
Food:	No food service needs		75%	81%	90%	95%
	Gap in food services		59%	69%	92%	88%
	Received food services		70%	73%	92%	89%
Mental Health:	No mental health service needs		70%	79%	93%	94%
	Gap in mental health services		61%	58%	88%	92%
	Received mental health services		72%	77%	92%	86%
Substance Use:	No substance use treatment needs		74%	74%	93%	93%
	Gap in substance use treatment		53%	71%	88%	87%
	Received substance use treatment		50%	69%	89%	58%
Case Managmt:	Received Medical Case Management		67%	73%	89%	85%
	Received Social Service Case Management		68%	77%	91%	89%
<b>Psychological Factors</b>						
	Self-efficacy scale score, mean (sd)		65.4(15.6)	64.7(13.8)	65.6(14.8)	65.6(14.1)
	Perceived stress scale score, mean (sd)		7.8(3.8)	7.3(3.7)	8.0(3.7)	7.3(3.8)
<b>HIV Diagnosis Year</b>						
	< 2002		71%	76%	89%	91%
	2002-2011		65%	71%	89%	90%
	≥ 2012		70%	79%	95%	90%

Note: Shown are column percentages. Data from most recent interview. N=264 for ages 18 to 35, N=266 for ages 35 – 55. Gray shaded cells indicate too few respondents for reliable estimates (n<25).

**Table 10. Association of Respondent Characteristics, Service Needs and Receipt, with HIV Care Outcomes: Adjusted Odds Ratios**

2015-2021 interviews	Comprehensive Primary Care		Consistent HIV Care		Adherent ARV Use		Suppressed Viral Load		
	AOR		AOR		AOR		AOR		
	Age	18 – 35	36 – 55	18 – 35 <sup>4</sup>	36 – 55	18 – 35	36 – 55	18 – 35	36 – 55
<b>Demographics<sup>1</sup></b>									
Male		0.707	<b>1.846*</b>	0.736	1.028	0.920	1.311	2.270	0.653
Black		<b>2.700*</b>	1.548	0.560	0.877	1.020	1.004	0.518	0.790
Hispanic/Latino/a		<b>2.756*</b>	1.633	0.582	1.058	1.503	0.803	1.528	0.735
<b>Socioeconomic Factors</b>									
Less than HS education		0.885	1.436	0.854	1.213	0.721	1.274	0.718	1.687
Not currently working		1.396	<b>1.775*</b>	0.768	0.717	1.500	1.587	1.557	0.477
Exchanged Sex in the past 6 months		0.444	1.813	<b>0.291*</b>	1.386	0.364	0.674	0.496	0.751
<b>Service Needs, Receipts, and Gaps<sup>2</sup></b>									
Gap in housing service		0.715	2.347	2.305	2.113	0.600	0.274	0.517	0.927
Received housing service		0.855	0.653	1.448	1.835	0.748	<b>0.237*</b>	1.334	0.457
Gap in food service		1.200	<b>2.997***</b>	0.984	0.775	<b>0.512*</b>	0.717	2.699	0.576
Received food service		0.728	<b>1.857*</b>	0.695	0.694	1.023	0.648	1.522	0.629
Gap in mental health service		0.991	0.889	0.947	<b>0.340**</b>	0.974	0.652	0.635	2.340
Received mental health treatment		<b>4.106***</b>	1.050	0.642	<b>0.468**</b>	1.123	1.160	0.662	1.027
Gap in substance use treatment		0.763	0.742	0.629	<b>0.363***</b>	<b>0.442**</b>	0.796	<b>0.280**</b>	0.507
Received substance use treatment		<b>0.227**</b>	0.655	0.652	<b>0.492*</b>	0.617	0.787	<b>0.132**</b>	<b>0.357*</b>
<b>Received Medical Case Management</b>									
		1.035	0.637	1.084	0.637	0.804	1.441	0.910	0.684
<b>Received Social Services Case Management</b>									
		1.293	1.046	0.955	0.799	0.951	1.258	1.356	0.695
<b>Psychological Factors</b>									
Self-efficacy scale score		<b>1.037**</b>	1.017	0.996	0.993	1.016	0.996	1.007	1.005
Perceived stress scale score		1.066	0.946	0.932	<b>0.900**</b>	0.980	0.939	0.844	0.968
<b>HIV Diagnosis Year<sup>3</sup></b>									
2002 - 2011		1.614	0.736	0.796	0.861	1.137	0.918	0.983	0.949
≥ 2012		0.631	0.451	0.792	0.909	1.970	1.155	1.796	0.681

N=367 for ages 18 to 35, N=624 for ages 35 – 55 \* p<.05, \*\* p<=.01, \*\*\*p<.001

1. Reference category for gender is female, reference category race/ethnicity is White/other.

2. Reference category for service needs, service receipt, and service gap is no service need. Those who need a service are allocated into service receipt or service gap.

3. Reference category for HIV diagnosis year is <2002.

## Summary and Discussion

Despite their designation as a priority population in each national HIV/AIDS strategy published since 2015, many young PWH in NYC lack needed services that may improve their engagement with HIV medical care and viral suppression (The White House, 2015; DHHS, 2021; The White House, 2021). The results of this study demonstrate that the lives and experiences as well as the predictors of access to and engagement with HIV medical care and viral suppression differ between young and older PWH.

Young PWH in NYC have distinct and underserved needs. Across several service categories, including employment, housing, food, and mental health, young PWH have, on average, a higher level of need, yet lower level of service receipt than older PWH. These needs detract from young PWH's engagement with medical services and, ultimately, their health. In particular, the need for substance use treatment (i.e., recent problem substance use) reduces the odds of all engagement in HIV medical care and health outcomes of interest. Moreover, young adults who receive substance use treatment have a higher likelihood of *not* achieving the positive outcomes than those who are not receiving treatment. This is likely due to young adults in treatment having more severe problem substance use than their counterparts. The most common self-reported barrier to accessing medical services for both young and older PWH was not knowing where to go. Higher perceived stress scores are negatively correlated with most of the care continuum outcomes for both age groups, although the significance of these relationships are lost was controlling for other factors.

These findings suggest many young PWH in NYC would benefit from additional support for access and sustained engagement in care and positive health and behavioral health outcomes. CHAIN as well as other research support care recommendations that advise that consideration must be taken to ensure all medical and service interactions with young PWH are developmentally appropriate, respectful, delivered with cultural humility, and address issues of patient concern in their own social worlds such as disclosure and sexual behavior as well as medical care (Hsu & Rakhmanina, 2022; Momplaisir et al., 2023; Jaiswal et al., 2018). Stigmatizing interactions, reported more commonly by young PWH than older PWH, with provider staff and/or intake forms that fail to accommodate diverse identities risk alienating young PWH and the opportunity to connect them with needed care. Accessibility of providers is also a concern for young PWH (Monplaisiret et al., 2023). Thus social media and mobile technologies (SMMT) can be potential tools for supporting young PWH to remain engaged along the care continuum. PWH under 35 participating in a SMMT intervention delivering medication and appointment reminders through text and consolidating their medical care information in one application appreciated the convenient accessibility of having their medical information in one place. They also expressed feeling supported by the communication, even from automated messages, less alone, and less stigmatized due to their status (Brooks et al., 2020).

In addition to their higher levels of need for medical and social services, young PWH in NYC live more unstable or precarious lives than older PWH. Fewer than half of young PWH lived in a stable housing environment, whereas three-quarters of older PWH were stably housed. Of those young PWH who were working, the majority held part-time positions, with the likely complications of unpredictable scheduling and/or limited to no paid time off. To improve the accessibility of medical and social services, young PWH need flexibility in both the timing and modality (e.g., in-person or telehealth options) of support. Providers must also be sensitive to and accommodating of the precarity of young PWH's lives. Offering multiple services at one provider may reduce access-related challenges and connect young PWH to a greater number of needed services.

Finally, young PWH in NYC are clustered in more disadvantaged areas, specifically the Bronx and Brooklyn. The HIV Health and Human Services Planning Council of New York (Planning Council) Needs Assessment Committee identified both the Bronx and parts of Brooklyn as areas in need of additional supportive services. The lower number of locally-available service providers and/or the time or transportation cost to get to another location complicate young PWH's ability to obtain assistance. Related, young PWH identified transportation as their second most common barrier to accessing needed medical services.

In addition to the socioeconomic and structural barriers that affect all PWH, young adults in NYC have unique, unmet medical and social service needs. Unaddressed, these may prevent young PWH from accessing or staying in needed medical care, complicate young PWH's ability to take their ARV medication exactly as prescribed, and reduce young PWH's likelihood of viral suppression. Future studies should focus on the attitudes of young PWH toward medical and social service provision, especially the role of SMMT in improving service access, to identify specific interventions that best support their health and well-being. Youth-friendly, flexible, coordinated, comprehensive, culturally humble care is vital to address the specific needs of young PWH.

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