

**The Mid-Hudson Region:  
A Review of the Quality of Clinical Care & Supportive Services**

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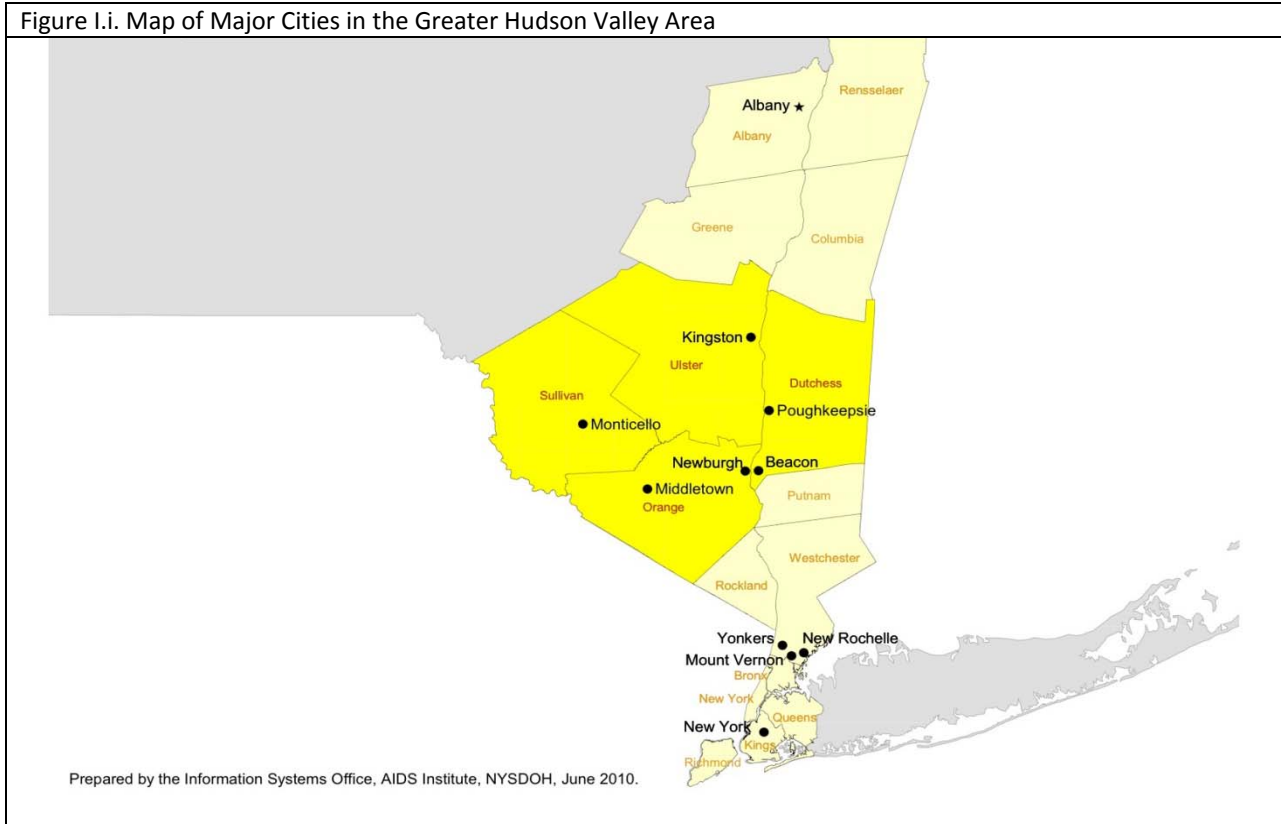
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## I. Purpose

The goal of this review was to better understand the quality of clinical care and supportive services for people living with HIV and AIDS (PLWHA) in the mid-Hudson region. This area includes Dutchess, Orange, Sullivan and Ulster counties, located between Albany and New York City and surrounding the Hudson River.

Figure I.i. Map of Major Cities in the Greater Hudson Valley Area



The review was initiated because of anecdotal reports and concerns over the past several years about the quality of comprehensive HIV care and services in the region. Providers and consumers have voiced these general concerns during advisory meetings, community forums sponsored by the Department of Health and during informal discussions. The review was designed to explore regional patterns and issues affecting the HIV/AIDS community and to contextualize and inform these concerns. Its purpose was not to assess or monitor the quality of care or services at any one agency or by any one provider. If gaps in care and services were identified, it was hoped that the data collected through this review would identify opportunities for improvement.

The MHR also has fewer resources and requirements for epidemiological and quality of care surveillance than other metropolitan and densely populated regions of New York. This year long in-depth analysis thus was an opportunity to explore care and services for the HIV/AIDS population in an area that usually does not receive this level of attention. It is hoped that this project will provide information that providers and county departments of health in the MHR would otherwise be unable to compile. Furthermore, it is hoped that this project could serve as a template for similar analyses in other relatively remote regions of New York.

## II. Methods

A combination of qualitative and quantitative methods was used to explore the availability and quality of HIV/AIDS care and services. The overall research approach was iterative, responding and adapting to emerging themes and questions. This is true of the qualitative and quantitative research independently and in combination; the different methods informed each other throughout the review process, suggesting arenas of further exploration and allowing for more in-depth interpretations. Only care and services provided to the non-incarcerated population of PLWHA were considered in the review.

### A. Quantitative methods

Quantitative analyses examined the prevalence of HIV/AIDS in the region, demographic characteristics of PLWHA, demographic characteristics of the PLWHA who receive services from Medicaid and AIRS providers in the region, the distribution and volume of different types of providers, care and services, and regional performance on HIV quality indicators. These analyses were based on pre-existing data sets in order to minimize reporting burdens on facilities. Staff in various departments of the AIDS Institute and New York State Department of Health compiled the data sets. All analyses were conducted using basic analytic methods such as calculating mean scores, cumulative values, percentages, and prevalence rates. Data sources and the individuals responsible for compiling MHR data sets include:

Figure II.A.i. Data sets utilized in the project	
Data Sources	Point Person(s)
Bureau of HIV/AIDS Epidemiology (BHA/E)	Julia Maslak
Medicaid Fee for Service claims	Dennis Tsui
AIDS Institute Reporting System (AIRS)	Laurence Spiegel
Information Services Office	Bonnie Schaffer, Judyth Avery
Contract Management Systems Database	Nicole Snow
AIDS Drug Assistance Program (ADAP)	Christine Rivera
HIVQUAL-US	Christopher Wells
I PRO	Dawn Lajeunesse

### B. Qualitative methods

Qualitative research methods were used to explore the subjective experiences of key stakeholders in the HIV/AIDS community of the MHR. These stakeholders included consumers, clinical providers, non-clinical providers, program administrators, and personnel from the New York State Department of Health and the County Health Departments of Dutchess, Orange, Sullivan and Ulster Counties. Qualitative research methods included informal interviews and focus groups, ranging from two to twelve participants, and were conducted between July 2010 and May 2011. Larger advocacy and network meetings in the MHR also were attended during this time period.

Email, phone, fax, regular mail, and word of mouth were used to recruit participants. With respect to providers, the intent was to include representatives from every major HIV/AIDS agency in the region and also any individual providers who offer services to a substantial portion of the PLWHA community. An initial list of such agencies and providers was developed by culling the "AIDS Institute Resource Directory, Dec 2009," available on the New York State Department of Health Website, and a database of ARV prescribers compiled by previous interns at the AIDS Institute's Office of the Medical Director. This list was progressively refined over the course of the review process based on where consumers reported to have received their services and feedback from other providers about key agencies and individuals in

their communities. Upon identifying a provider agency or individual to include, email, phone, and occasionally fax and regular mail were used to identify an appropriate point person and schedule a meeting. Letters were sent through regular mail and fax to Department of Health Commissioners and Public Health Directors in the four mid-Hudson counties, and AIDS Institute personnel to interview were identified by the Medical Director, Dr. Bruce Agins.

A total of 30 providers in the mid-Hudson region from ten facilities (Table II.B.i) and 33 individuals from the AIDS Institute and County Departments of Health (Table II.B.ii) were interviewed. Two provider agencies where attempts to arrange an interview were unsuccessful were the Mid-Hudson Care Center in Ulster County and Catharine Street Community Center in Dutchess County.

Agency	Provider Titles	County
AIDS Related Community Services (ARCS)	HIV Care Coordinator, Director of Client Services, Mid-Hudson County Managers, Case Manager	All
The Greater Hudson Valley Family Health Center	Chief Medical Director, HIV/AIDS Services Director	Orange
Hudson River Healthcare	Clinical Director of HIV and Hepatitis Programs, VP of Planning and Special Populations, Director of the Genesis Program, Medical Case Managers, Social Worker, Peer Educator	Dutchess Orange Sullivan
Institute for Family Health	Vice President of Social Services	Ulster
Middletown Community Health Center	HIV Program Coordinator	Orange
Pathstone	Deputy for Supportive Services	All
Private Physician	Infectious Disease Doctor	Sullivan
Recovery Center	Coordinator for HIV/AIDS Support Services	Sullivan
St. Francis Hospital, The Turning Point	Counselor, Psychologist	Dutchess
Steven Saunders Residence	Director	Orange
T.O.U.C.H.	Executive Director, Case Management Program Director	Orange

Table II.B.ii: AIDS Institute & County Department of Health Personnel Interviewed (n=33)	
Department	Title/Position
AIDS Institute	Director
AIDS Institute, Office of the Medical Director	Director Deputy Director QI Initiatives Director
AIDS Institute, Health Care and Policy	AI Deputy Director Director, AIDS Planning & Policy Director, Division of HIV and Hepatitis Health Care Director, Bureau of HIV Ambulatory Care Director, Primary Care Section, Bureau of HIV Ambulatory Care Consumer Advocate Director, Bureau of Community Support Services Director of Mental Health, Bureau of Community Support Services
AIDS Institute, Medicaid Policy and Programs	AI Deputy Director AIMS Program Administrator HIV Reimbursement and Program Administrator
AIDS Institute, HIV/STD/Hep C Prevention and Epidemiology	AI Deputy Director Director, Division of HIV/STD/Hep C Prevention Director, Division of Epidemiology, Evaluation, and Research Director, Bureau of Special Populations, Division of HIV Prevention
Dutchess County Department of Health	Commissioner Director of Communicable Disease Control Senior Public Health Education Coordinator
Orange County Department of Health	Commissioner Director of Patient Services Public Health Representative
Sullivan County Department of Health	Public Health Director
Ulster County Department of Health	Commissioner

With respect to consumers, the intent was to achieve a diverse and comprehensive sample that also reflected the general demographic distribution of PLWHA in the region. The two primary methods for contacting consumers were: meeting consumers at PLWHA community gatherings or events and scheduling subsequent private interviews; and facilitating a focus group discussion at a PLWHA support group meeting. All consumers were given the investigators contact information, either in the form of business cards or a handout with a description of the review, and were encouraged to distribute the information to any other consumers who might be interested in participating. Consumers often heard of the project through this method, but only once did this prompt a consumer contact. A consequence of these recruitment methods is that the consumer sample is biased towards individuals who are engaged in care or the PLWHA community to some extent. Otherwise, the consumer sample was loosely reflective of the overall PLWHA community in the region.

Table II.B.iii compares the distribution of the 44 consumers that were interviewed (sample) and total PLWHA in the region in 2008, the most current data available. Compared to the overall distribution of

PLWHAs, Dutchess County residents were over-represented in the sample and Ulster County residents were under-represented in the sample. This is consistent with the ease of connecting with consumers at health care facilities; the Hudson River Healthcare and St. Francis Hospital sites in Dutchess County invited the investigator to attend large consumer focus groups at their facilities, whereas it was extremely difficult to initiate provider or consumer contacts in Ulster County. This under-sampling of Ulster County stakeholders is a limitation in the data that is noted when relevant throughout this report. Females were over-sampled compared to their distribution among overall PLWHA in the region, which is consistent with the tendency for women to use health care services more frequently. Exposure category was either voluntarily self-reported by the consumer or, in one case, the distribution of exposure categories among a group of consumers was reported by their case manager. The categorizing exposure categories attempted to follow the hierarchy used by the BHAЕ as closely as possible. Among the sample of consumers interviewed, heterosexual transmission was under-represented and unknown transmission was over-represented. This is likely due to the crude classification methods employed. Race/ethnicity was even more crudely determined: through voluntary self-report, identification by a case manager, or approximate visual cues. This information thus needs to be interpreted with extreme caution.

Table II.B.iii: Distribution of consumers interviewed (Sample) compared to PLWHA in the MHR

		Sample (n=44)	PLWHA in MHR (n=2,143) (BHAЕ 2008)
County of Residence	Dutchess	36%	29%
	Orange	34%	38%
	Sullivan	18%	14%
	Ulster	11%	19%
Sex	Male	55%	64%
	Female	45%	36%
Exposure Method	MSM	23%	23%
	IDU	32%	28%
	Heterosexual	18%	28%
	Unknown	29%	14%
Race/Ethnicity	Hispanic	20%	22%
	White	30%	37%
	Black	48%	33%
	Other/Unknown	2%	0%

The interviews and focus groups with consumers and providers occurred in a variety of settings across the mid-Hudson region. Most providers and Department of Health officials were met at their place of work and interviews were conducted in offices or conference rooms. Some members of the AIDS Institute who worked in Albany were interviewed via phone. Consumers typically were interviewed at locations where they received care or services: in vacant offices, conference rooms, or community spaces.

A semi-structured format was followed for the interviews and focus groups; there was a reference list of key topics to address at some point but participants were allowed to dictate the pace, tone, and path of the conversation. Participants were instructed that the investigator wanted to learn from their personal experiences in the mid-Hudson region and was eager to hear about aspects of their care and services



that they believed were working well and aspects that needed improvement. Participants were told that their comments would be incorporated into this report, with all identifying information removed.

The discussions lasted between 20 minutes and three hours, but most took approximately one hour. Almost all were recorded using a small digital recorder; participants were informed of the recorder and consented to its use. Three large community gatherings and one support group for substance users living with HIV/AIDS were not recorded. Records of these encounters are based solely on observations and recollections. No compensation was offered to any participants, although some consumers received their regularly scheduled lunch or snacks during the support group meeting. All participants, consumers and providers, were assured that they would receive access to the final report findings.

All digital recordings were transcribed by hand, with most comments summarized and any cohesive or unique statements regarding the quality of and access to care and services copied verbatim. In the transcriptions, it was noted whether participants brought up topics independently or after direct questioning. Throughout the course of conducting interviews and transcribing, themes began to emerge. These themes were incorporated into the list of reference topics to address during conversations, and, as the research progressed, participants were invited to offer interpretations and reactions to the major findings. Such context and background to consumer statements are noted throughout the report when relevant.

Thematic analysis of the qualitative research was conducted with feedback from the Medical Director and Dan Tietz, Consumer Advocate in the AIDS Institute Department of Health Care and Policy. No formal methods or software were used.

### **C. Limitations**

The iterative nature of this work was both a strength and a limitation. It allowed the data trends and the participants to dictate the content and direction of research, facilitating a free and genuine exploration of the complex factors that affect the quality of care and services in this region. Outcomes established *a priori* would have prematurely narrowed the scope of exploration and limited the collective ownership of this work. At the same time, this iterative style is very susceptible to bias, as it relies on ongoing interpretation and flexibility. It is undeniable that previous interviews and data analyses shaped subsequent questions and the frame through which those responses were interpreted and transcribed. The best tool to counter this limitation is transparency, which has been implemented throughout this report to the greatest extent possible.

There are additional biases within the research design. First is selection bias. As noted above, the consumer sample is biased towards individuals engaged in care, and the provider sample is biased based on who was willing to conduct an interview and who the Medical Director identified as a key stakeholder within the AIDS Institute. Second is content bias. The investigator's affiliation with the AIDS Institute may have biased both consumer and provider responses during the interviews and focus groups, although this may have been slightly reduced due to the investigator's temporary and low-ranking position (Intern). Situational bias is another factor, in that the context of conducting the interviews, for instance, at a health care facility or with other individuals present, could have biased the content.

### **III. General Characteristics of the Mid-Hudson Region (MHR)**

Data about the general population in the mid-Hudson region (MHR) comes from the US Census Bureau ([http://quickfacts.census.gov/qfd/download\\_data.html](http://quickfacts.census.gov/qfd/download_data.html), accessed 4/13/11). Unless otherwise noted, estimates are as of July 1, 2009 – the most recent data available. The census data includes prisoners, and for the data used in this report, prisoners were counted as residents of their county of incarceration. This can have a significant impact on the demographics of smaller geographic regions with state prison facilities.

Approximately 5% of the New York State (NYS) population of 19.5 million people lives in the MHR. In 2009, this meant that 934,000 people were spread across the four MHR counties. Compared to NYS, the MHR has a lower population density but a faster rate of population growth. This fast rate of growth is due to Orange County, which was the fastest growing County in the United States from 2000 to 2009. The MHR has less racial and ethnic diversity than NYS overall, with larger White, English-speaking and American-born populations. This trend is especially prominent in Ulster County. The MHR has a slightly lower unemployment rate than NYS but also has lower average income. Overall, there is a smaller proportion of people living below the poverty line in MHR compared to NYS and the per capita federal government expenditure is lower.

There are a few key characteristics that distinguish each county. Dutchess County is the wealthiest and physically one of the smallest. Orange County is the largest, has the greatest population, the greatest population density, and the greatest total federal government expenditure. Sullivan County is the least populated, has the lowest population density, and is the poorest, with the highest per capita federal government expenditure. Finally, Ulster County is physically the largest, has the least ethnic or racial diversity, and is the second-poorest.

#### IV. Epidemiology of HIV/AIDS

The majority of data on the epidemiology of HIV/AIDS in the MHR and NYS was extracted from two documents produced by the New York State Department of Health in 2010: “New York State HIV/AIDS Surveillance Annual Report: For Cases Diagnosed Through December 2008” and “New York State HIV/AIDS County Surveillance Report (Excludes State Prison Inmates): For Cases Diagnosed Through December 2008”. All epidemiology data thus are current as of 2008, the most recent data available at the time of writing. Some additional data were generated by Julia Maslak at the Bureau of HIV/AIDS Epidemiology (BHAЕ).

This section can be divided into two main subsections: the prevalence of HIV/AIDS, which includes the number and distribution of PLWHA, newly diagnosed HIV and AIDS cases, and deaths among AIDS cases; and demographics of PLWHA in the MHR, which includes sex, age, race/ethnicity and risk category.

##### A. Prevalence of HIV/AIDS

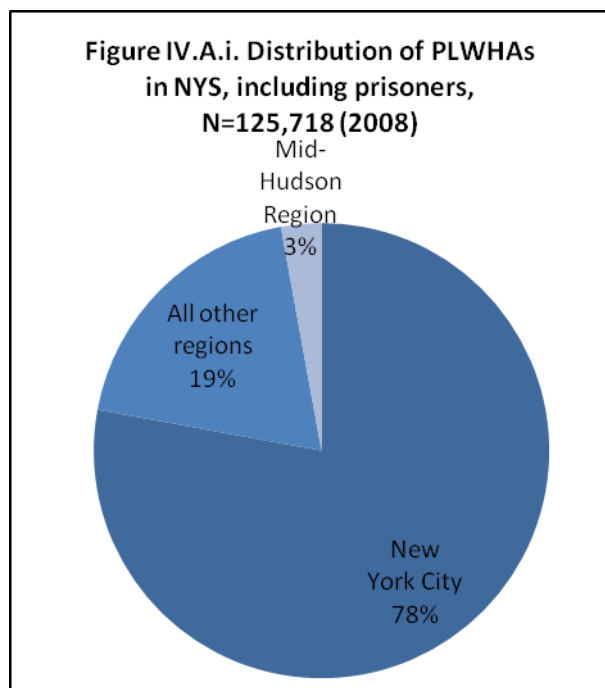
###### 1. Number and distribution of people living with HIV/AIDS (PLWHA)

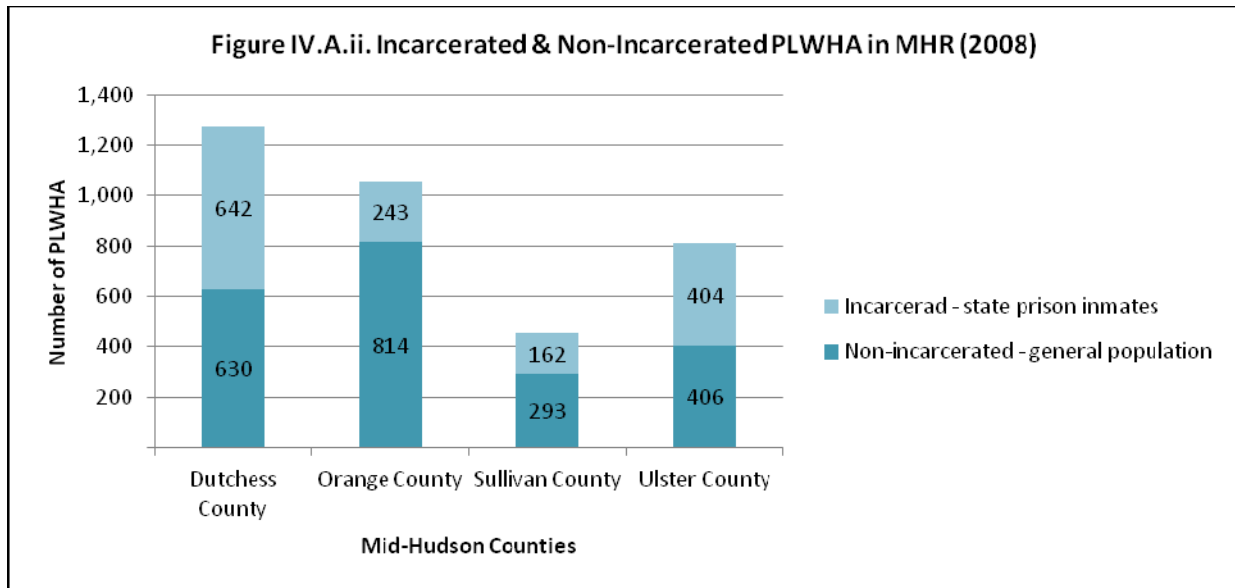
The number of PLWHA refers to the number of unduplicated living HIV/AIDS cases, which is the sum of all reported individuals living with HIV infection, including both those who have not developed AIDS and all reported persons living with AIDS.

Of the 125,718 PLWHA in New York State (NYS) in 2008, including state prison inmates, 3% resided in the mid-Hudson region, compared to the 5% of the entire NYS population that lives in the MHR. By contrast, New York City (NYC) had 43% of the overall population of NYS and 78% of all NYS PLWHA.

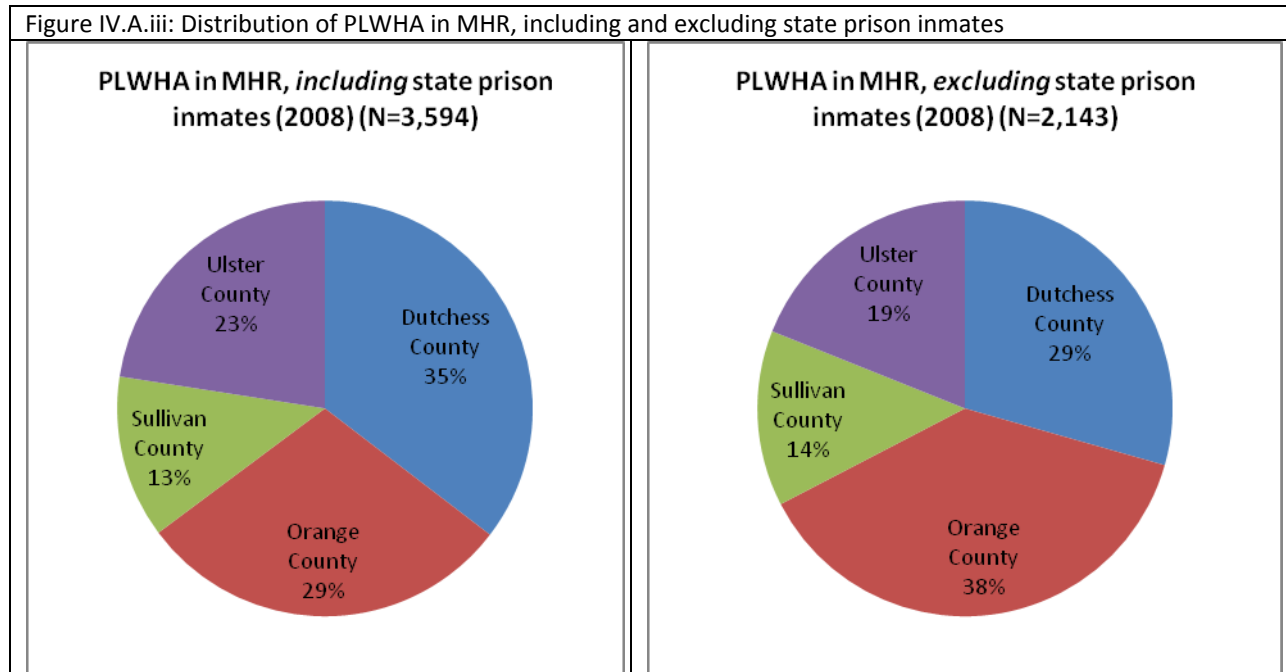
It is important to note, however, that county of residence for people living with HIV or AIDS as determined for the BHAЕ data is assessed at two time points only: at the time of HIV diagnosis and at the time of AIDS diagnosis. People who move after being diagnosed as HIV positive but before sero-converting, or people who move after being diagnosed with AIDS, therefore would be mis-classified in this data analysis.

Of the PLWHA in the mid-Hudson in 2008, 40.4% were state prison inmates, compared to 5.5% statewide. Excluding state prison inmates thus dramatically changes the number of PLWHA in the region, from 3,594 including inmates to 2,143 excluding inmates, and reduces the percentage of total PLWHA in NYS that reside in the MHR to 1.7%.





Data in this review describe the population excluding inmates, unless otherwise specified. This decision reflects the focus of this project on the non-incarcerated population and care and services provided to them. Additionally, prisoners can constitute a significant and shifting proportion of total people living with HIV/AIDS in smaller geographic regions. A brief examination of the effect of including vs. excluding state prison inmates in the mid-Hudson region is included here, because of its dramatic impact on the distribution of PLWHAs and the prevalence rates in each of the four counties.

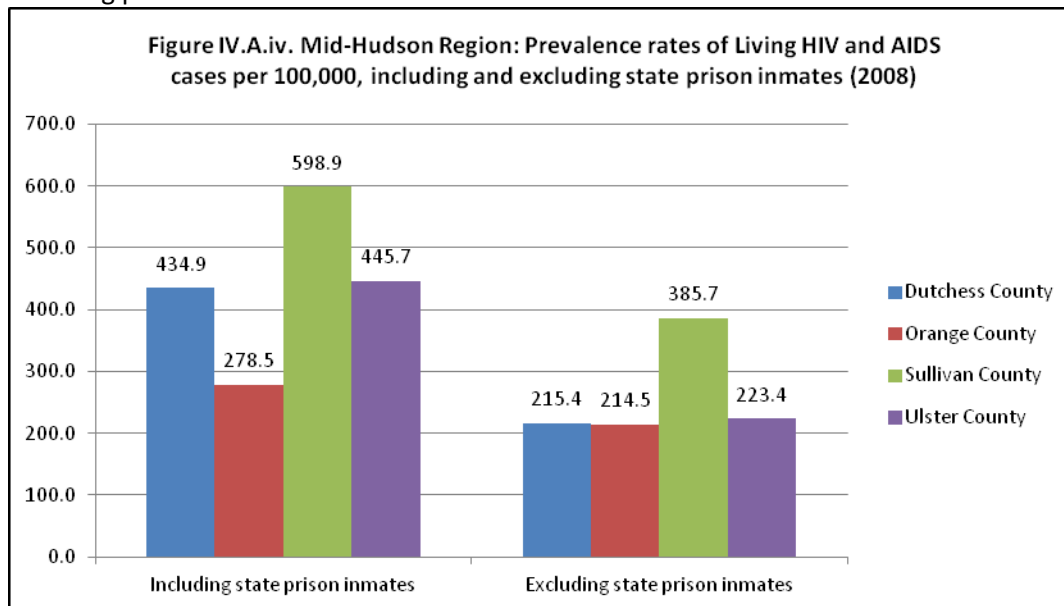


As shown in Figure IV.A.iii, when including prisoners, Dutchess County had the greatest number of PLWHA in 2008 and represented 35% of the total mid-Hudson PLWHA population. Orange County had the second largest population of PLWHA, with 29% of the total population. After excluding state prison inmates, the relative rankings of the two counties switch: Orange County had the largest number of

PLWHA, with 38% of the region, whereas Dutchess County had only 29% of the region. The distribution of cumulative AIDS cases since 1983, including both living and deceased people with AIDS, followed the same pattern with almost identical values when one included or excluded state prison inmates. This shift in which county had the largest burden is significant when considering the type and volume of services required for a larger proportion of PLWHA and when considering the different levels of funding in Orange County and Dutchess County over the past fifteen years.

For both including and excluding prisoners, Ulster County and Sullivan County had the third and fourth largest PLWHA populations and proportion of cumulative AIDS cases, respectively, although Sullivan County's proportion increased when removing prisoners whereas Ulster County's decreased.

Including versus excluding state prison inmates also substantially affected prevalence rates in each county. As shown in Figure IV.A.iv, Sullivan County had the highest prevalence rate including or excluding prisoners, although it also had the lowest raw number of PLWHA; this was due to the small number of total Sullivan County residents. After excluding prisoners, the three other counties all had very similar prevalence rates, which were considerably lower than that of Sullivan County. In fact, Sullivan County's prevalence rate for living AIDS cases only (not HIV) was still higher than that for living HIV and AIDS cases for the three other counties. All of these values were low compared to the NYS prevalence rate of 622.3 and the NYC prevalence rate of 1131.3, although those values included prisoners. The BHAЕ could not provide prevalence rates for NYS excluding prisoners at time of writing, although the office indicated that such rates should not be significantly different from the values when including prisoners.



Two final points on the issue of state prison inmates are warranted here. The first addresses a limitation of the data. The BHAЕ does not automatically update prisoners' status when they are released. Just as an individual's county of residence status is assessed only at the two diagnosis points, an individual's incarceration status is assessed or modified only at the two diagnosis points. Thus, some of the PLWHA classified as prisoners accordingly may not be incarcerated currently and some of PLWHA classified as "general population" may now be incarcerated. If the flow of people into and out of the state prison system occurs at a comparable rate, then these two should cancel out. The second point is that the

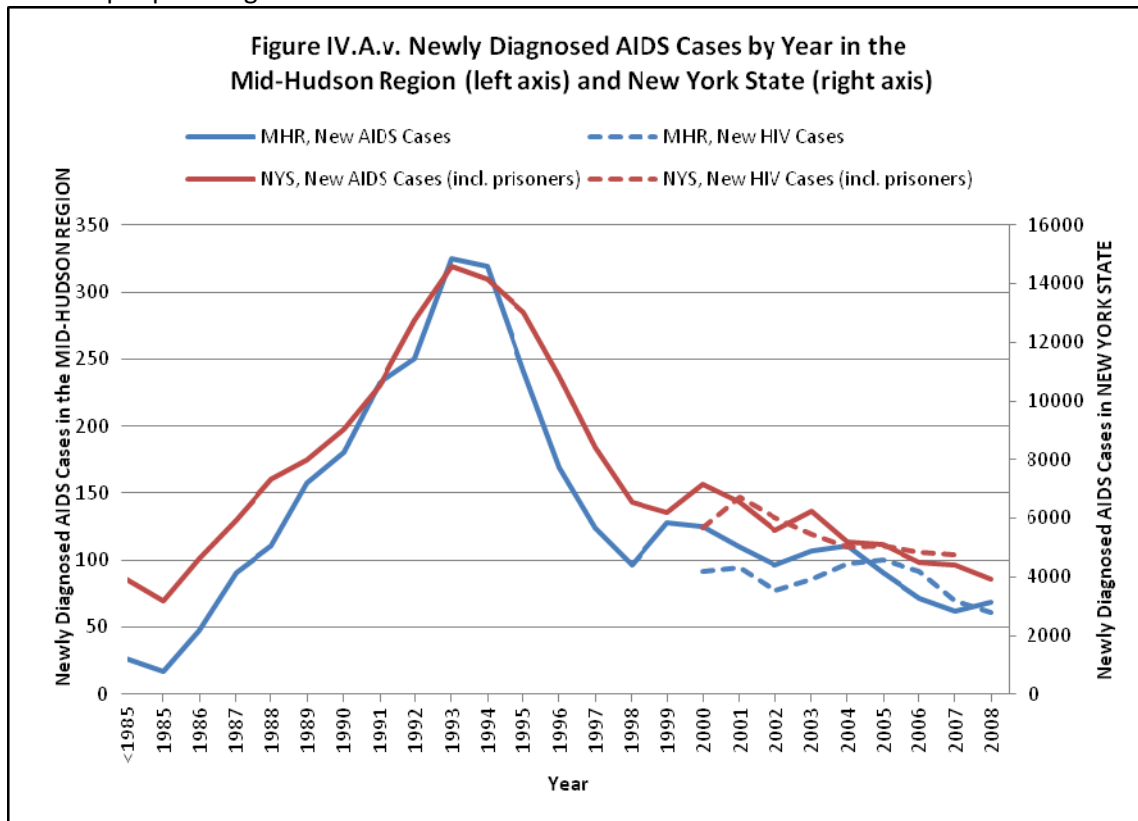
movement and service needs of recently released individuals are important issues for the mid-Hudson region that merit future investigation. Although beyond the scope of this project, an important component of the quality of care and services in the mid-Hudson region would be to where people incarcerated in the region live after being released, what types of transitional services they require, and if those services are currently available and of high quality.

2. Newly diagnosed HIV and AIDS cases

Newly diagnosed HIV cases are HIV cases reported for the first time, regardless of whether there was a concurrent or subsequent AIDS diagnosis. HIV reporting began in June 2000; no earlier data are available. Newly diagnosed AIDS cases are cases reported with AIDS for the first time. This includes HIV cases that were never reported before and HIV cases that have developed into AIDS. Persons diagnosed with HIV may also be diagnosed with AIDS in the same year or a later year. HIV diagnoses and AIDS diagnoses cannot be added in a meaningful way (BHA/E).

All data exclude state prison inmates, unless otherwise noted.

The overall trends of newly diagnosed AIDS cases and HIV cases in NYS and in the MHR have similar timelines. As shown in Figure IV.A.v, in both regions, the number of newly diagnosed AIDS cases peaked in 1993, and, within the past ten years, the number of newly diagnosed HIV cases has been similar to the number of newly diagnosed AIDS cases. This is discussed in greater depth below when looking at rates of late and concurrent HIV diagnoses. Although not shown here, the number of deaths among AIDS cases peaked in 1995 in both regions and both regions show steadily increasing numbers of people living with HIV and people living with AIDS.



Breaking down the MHR by county reveals that since peaking in 1994, Orange County has had the greatest number of newly diagnosed AIDS cases out of the four MHR counties for every year except 1996, when Dutchess County had slightly more. Sullivan County and Ulster County historically have had the lowest numbers of newly diagnosed HIV and AIDS cases. Because of its much smaller number of total cases, however, this represents a much higher than average case rate in Sullivan County than the rest of the region. Thus, although Orange County has had the greatest burden in number of cases, Sullivan County has had the greatest burden in terms of the proportion of the population infected with the virus.

The MHR had comparable case rates of newly diagnosed HIV cases in 2008 as the Rest of State (ROS), which is NYS excluding NYC. One prominent exception was a higher rate of newly diagnosed AIDS cases in Sullivan County. As noted above, this elevated rate does not reflect a larger number of cases but rather is reflective of the smaller overall population in Sullivan county and greater proportional burden. The rates for the MHR and ROS were much lower than those for NYC and consequently NYS.

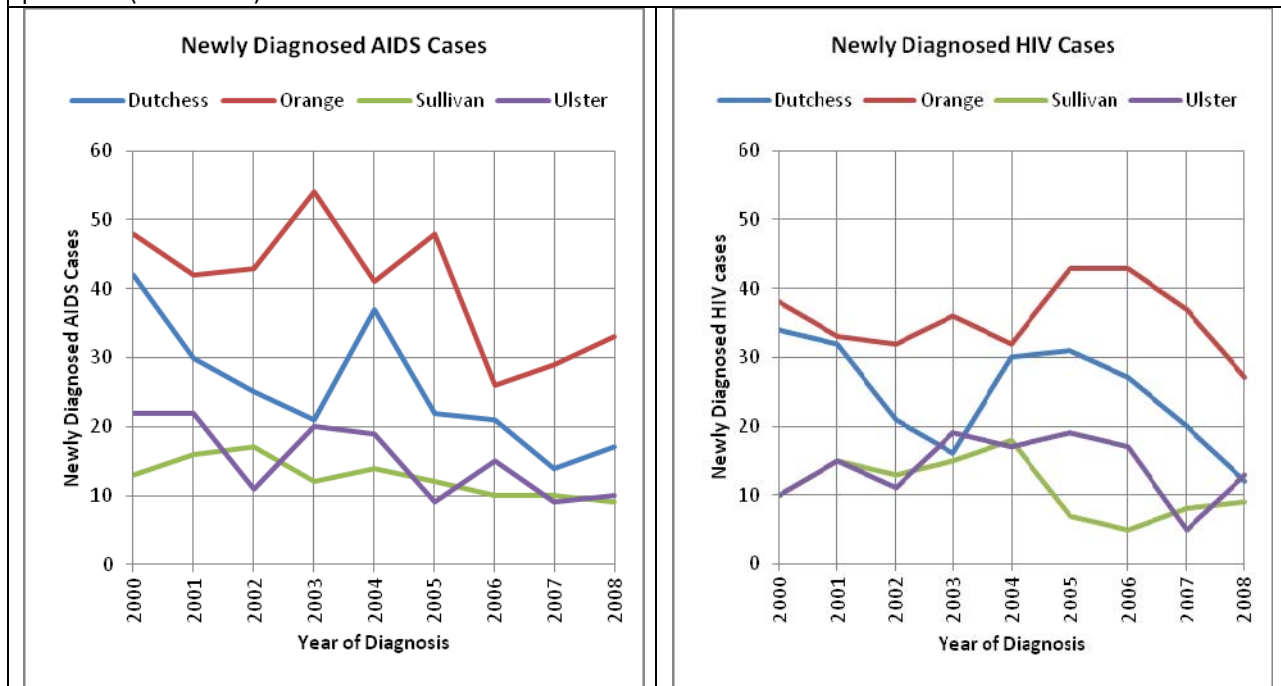
Table IV.A.vi. Number of Newly Diagnosed HIV Cases and AIDS Cases and Case Rates per 100,000 in the MHR and NYS (2008)							
	Dutchess <sup>+</sup>	Orange <sup>+</sup>	Sullivan <sup>+</sup>	Ulster <sup>+</sup>	ROS*	NYC*	NYS*
Newly Diagnosed HIV Cases							
Number	12	27	9	13	960	3,564	4,524
Rate	6.7	9.4	9.7	6.4	9.0	41.2	23.2
Newly Diagnosed AIDS Cases							
Number	17	33	9	10	825	3,086	3,911
Rate	5.9	7.7	12.7	6.2	7.6	35.7	19.9

\*Includes state prison inmates

<sup>+</sup>Case rates are not age adjusted

Within the past ten years, the number of newly diagnosed AIDS and HIV cases varied greatly in the MHR (see Figure IV.A.vii). Trends were not consistent between counties. Some of this variation occurred because of the small number of total cases, resulting in any change appearing to be larger. Nevertheless, this variation may be meaningful for each county and it speaks to a somewhat volatile epidemic in the region.

Figure IV.A.vii. Newly Diagnosed AIDS Cases and HIV Cases by Year and County of Residence at Diagnosis, excluding prisoners (2000-2008)



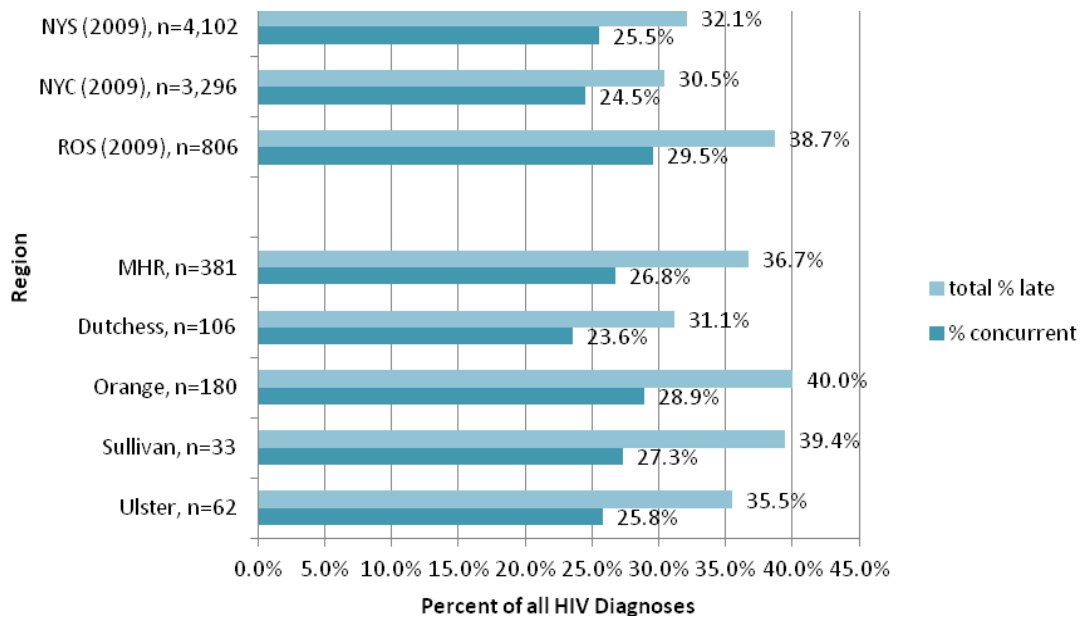
Some trends that can be observed within this variability are:

- The number of newly diagnosed AIDS cases in Orange County increased from 26 in 2006 to 33 in 2008. Given the large variation from year to year and the small number of cases, this change may not be significant. However, it is a trend to be watched once 2009 data is available. The same applies to the slight uptick in newly diagnosed AIDS cases in Dutchess county from 2007 to 2008; this was a very small change in raw numbers of cases, but it is important to observe if the increase continues in coming years.
- Both Dutchess County and Orange County had sustained and substantial decreases in newly diagnosed HIV cases from 2006 to 2008. This was not mirrored by similar decreases in the other two counties: Sullivan County had a slight increase and Ulster County had a significant decrease but subsequent increase. It will be important to note if these respective trends continue over coming years and to observe how numbers of new diagnoses are affected by the new regulations regarding HIV testing.
- As noted above, the fact that Dutchess County, Ulster County and Sullivan County had comparable raw numbers of AIDS and HIV diagnoses between 2006 and 2008 is particularly significant for Sullivan County, given its much smaller population. This is reflected in the higher than average case rate in Sullivan County for newly diagnosed HIV and AIDS cases.

Also, in all four counties of the MHR and generally in NYS as a whole, the number of newly diagnosed HIV cases in 2008 was similar to the number of newly diagnosed AIDS cases. This observation is better explored by looking at rates of current and late HIV diagnoses: “late” HIV diagnoses are followed by an AIDS diagnosis within 12 months; “concurrent” HIV diagnoses are followed by an AIDS diagnosis within one month (concurrent HIV diagnoses thus are a subset of total “late” diagnoses).



Figure S.IV.ii: Percent of New HIV Diagnoses that were Concurrent or Late in different regions of NYS (2005-2009)



\*Data for individual years is not available for mid-Hudson counties because of prohibitively small cell sizes. Data from NYS and ROS is for 2009 only.

Figure IV.A.viii shows the rates of concurrent and late HIV diagnoses for different regions of New York, including the four mid-Hudson counties, the overall MHR, NYS, NYC and ROS. Data for NYS, NYC and ROS is for 2009. Data for the overall MHR and each mid-Hudson county, however, are for 2005-2009 (inclusive). This is because the raw number of cases in each county for individual years is too small to be able to report; according to the New York State Department of Health data release guidelines for HIV/AIDS data, there must be at least three cases in a particular data cell for that data to be released in order to protect patient confidentiality. As noted above, all data excludes state prison inmates.

One can see in this figure that the percent of late and concurrent diagnoses in the MHR were fairly comparable to the percent in ROS. Within the MHR, Orange County had the highest percent of late and concurrent diagnoses and Dutchess County had the lowest. The percent of concurrent and late diagnoses in ROS and MHR, however, were much higher than in NYC and consequently NYS overall. The number of late and concurrent HIV diagnoses has been identified by the BHAЕ as an area of concern and focus in NYS overall, and this problem certainly is notable in the MHR as a potential opportunity for action and focus of resources.

### 3. Deaths among AIDS cases

Deaths among AIDS cases in the MHR over the past 10 years have been as variable as the number of newly diagnosed HIV and AIDS cases, with Orange County generally having the greatest number of deaths and Ulster County and Sullivan County with the smallest. It is important to note that this number reflects deaths among AIDS cases, not necessarily deaths due to AIDS. One worrisome trend is an increase in Ulster County from 2004 to 2008 in the number of deaths and a rate of 24.6 deaths among AIDS Cases per 1,000 PLWHA in 2008 (see Table IV.A.x); this was a higher rate than in NYS, NYC or ROS

for the same year. Orange County also had a higher rate than NYS, NYC and ROS at 20.9 deaths among AIDS cases per 1,000 PLWHA. A very important caveat to interpreting these data is the actual number of deaths and PLWHA in each county. As with the newly diagnosed cases, the small number of cases leads any variation to appear very large to raise questions about significance. Nevertheless, the increasing number of deaths in Ulster County and the elevated rates of deaths among AIDS cases in 2008 in Ulster and Orange Counties are important trends to watch.

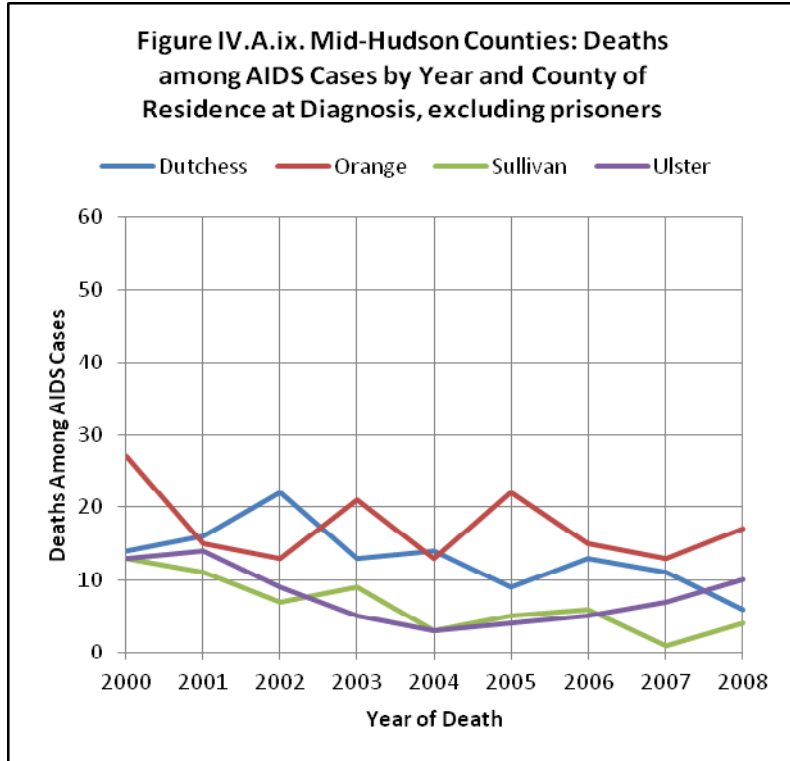


Table IV.A.x: Deaths among AIDS Cases per 1,000 PLWHA\*, excluding prisoners (2008)

Dutchess (n=6)	9.5
Orange (n=17)	20.9
Sullivan (n=4)	13.7
Ulster (n=10)	24.6
MHR (n=37)	17.3
ROS (n=310)	14.8
NYC (n=1,742)	17.8
NYS (n=2,052)	17.3

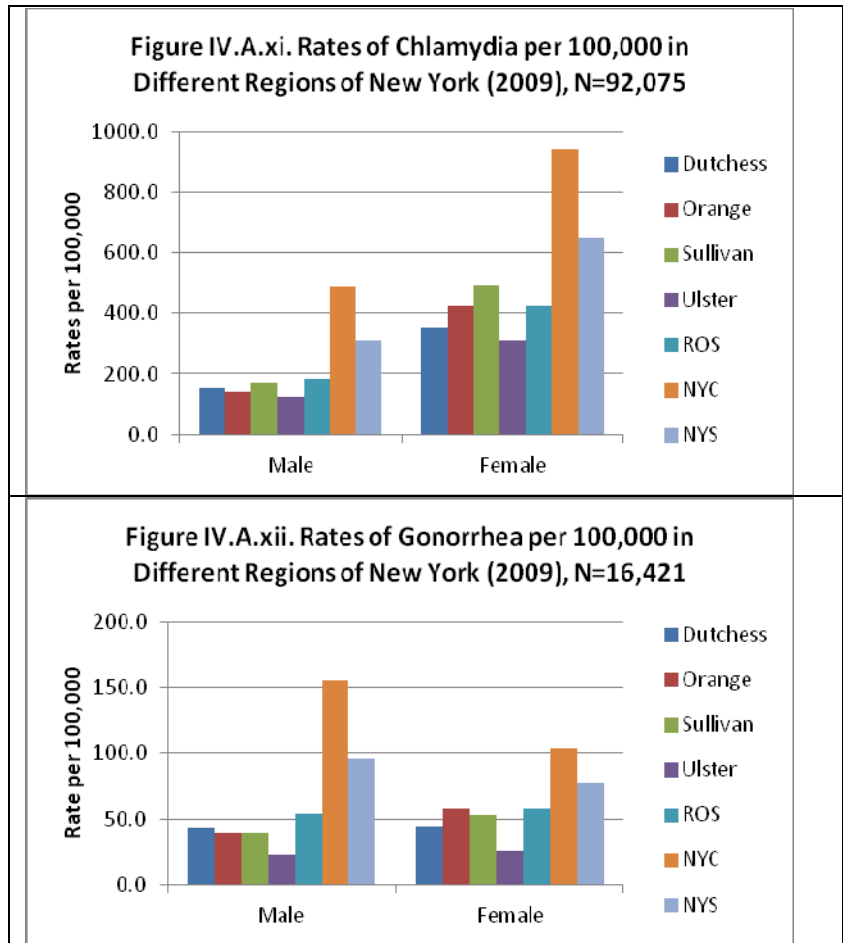
\*Not age adjusted

4. Prevalence of Sexually Transmitted Infections and Hepatitis A, B & C

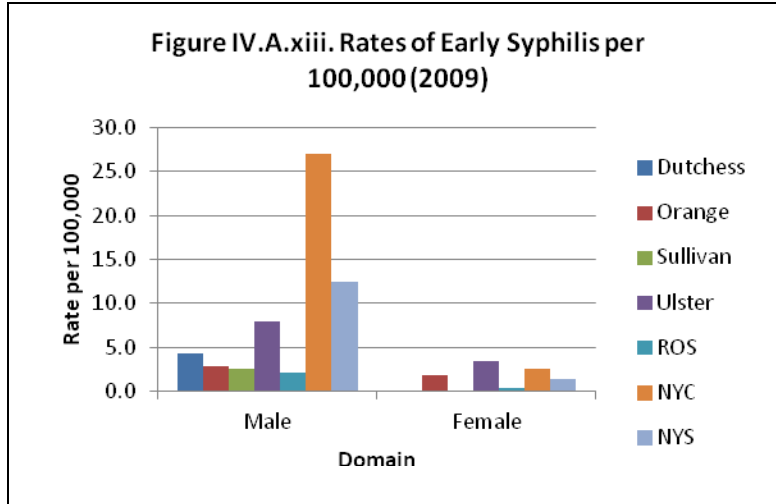
Statistics on the prevalence of gonorrhea, Chlamydia and early syphilis were obtained from the Bureau of STD Prevention and Epidemiology for 2009. The rates of the three infections (cases per 100,000 population) are presented in Figures IV.A.xi, IV.A.xii and IV.A.xiii and the number of early syphilis infections is presented in Table IV.A.xiv..

The following are observations regarding the rates of Chlamydia and gonorrhea:

- The rates of Chlamydia were considerably higher than those of gonorrhea for all regions of New York and for both males and females in 2009, as reflected in the different axes for Figure IV.A.xi and Figure IV.A.xii.
- Within the MHR, the rates of gonorrhea and Chlamydia were considerably lower than those in NYC and generally comparable to those in ROS.
- For Chlamydia, the rates among females were higher than the rates among males in all regions
- For gonorrhea, the rates among females were higher than among males in the MHR and ROS, but the reverse was true for NYC and NYS. This is likely due to the lower prevalence of MSM in the MHR and ROS compared to NYC, where the majority of NYS cases occur.
- For both gonorrhea and Chlamydia, the lowest rates in the MHR occurred in Ulster County.
- For Chlamydia, the rates were highest among Sullivan County females.
- For gonorrhea, the rates were highest among Orange County females.



There were many fewer cases of early syphilis in 2009 than there were cases of Chlamydia or gonorrhea: 1,268 cases of early syphilis in NYS in 2009 compared to 92,075 cases of Chlamydia and 16,421 cases of gonorrhea. The small number of early syphilis cases causes rate comparisons to be somewhat misleading, as discussed above in the context of the rate of deaths among AIDS cases. For this reason, the rates of early syphilis must be interpreted with caution and a table of the raw number of cases in included.



Region	Males	Females
Dutchess County	6	0
Orange County	5	3
Sullivan County	1	0
Ulster County	7	3
ROS	111	23
NYC	1,024	110
NYS	1,135	133

Among males, rates of early syphilis were higher in the MHR than ROS in 2009, although still much lower than in NYC. Ulster County had the highest rate of MHR counties with a total of seven cases. Among females, there were three cases each in Orange County and Ulster County and zero cases in the other two counties. Those three cases each led Ulster County to have a higher rate of early syphilis among females than ROS and even NYC, although the significance of this is unclear given the small number of total cases.

Information regarding the prevalence of Hepatitis A, B and C come from the Bureau of Communicable Disease Control in the New York State Department of Health. These data reflect the number of cases that were confirmed as defined by the Centers for Disease Control and Prevention in 2009 or, in the case of chronic Hepatitis C, in 2008. They do not represent incidence or prevalence and may change based on new information or corrections. As can be seen in Table IV.A.xv, approximately 10% of confirmed Hepatitis cases in NYS excluding NYC (ROS) occurred in the MHR. This proportion is slightly higher for chronic Hepatitis C, with 13% of confirmed cases occurring in the MHR, although those values are for 2008.

	Acute Hepatitis A	Acute Hepatitis B	Chronic Hepatitis B	Chronic Hepatitis C*
ROS	48	57	616	6437
MHR	5 (10%)	5 (9%)	56 (9%)	842 (13%)
Dutchess County	-	4	27	263
Orange County	3	1	14	269
Sullivan County	-	-	3	111
Ulster County	2	-	12	199

\*Data are from 2008 for cases of chronic Hepatitis C

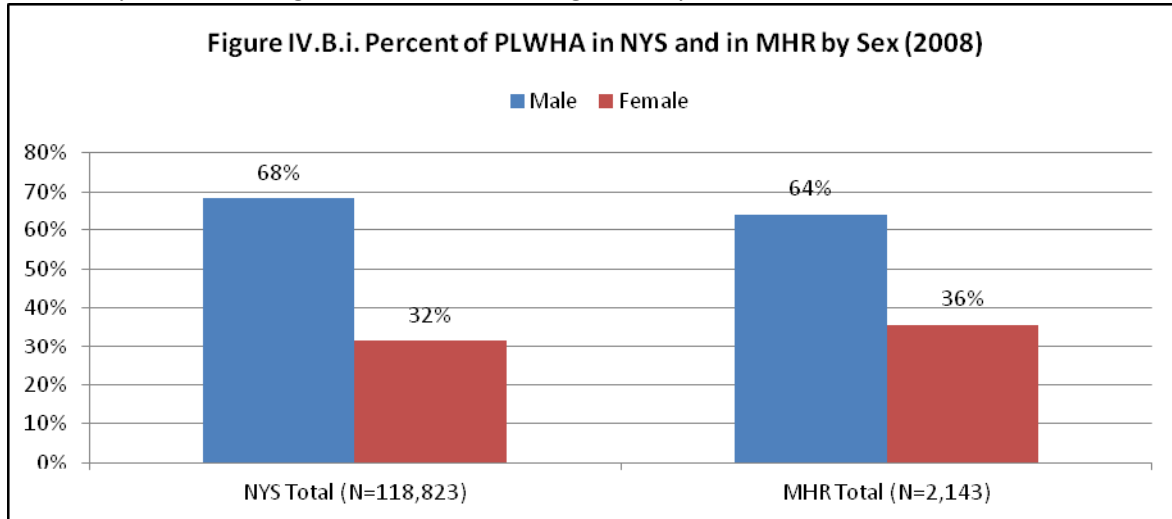
## B. Demographics of PLWHA

When comparing values for PLWHA and the overall population, it is important to remember that the population census data include prisoners whereas the data on PLWHA presented here do not. Inclusion of prisoners in the census data would significantly affect the distribution of sex, age, and race/ethnicity.

### 1. Sex

This report uses the “sex” terms of male and female instead of the gendered terms of men and women because no transgender category was included in the data or data analysis.

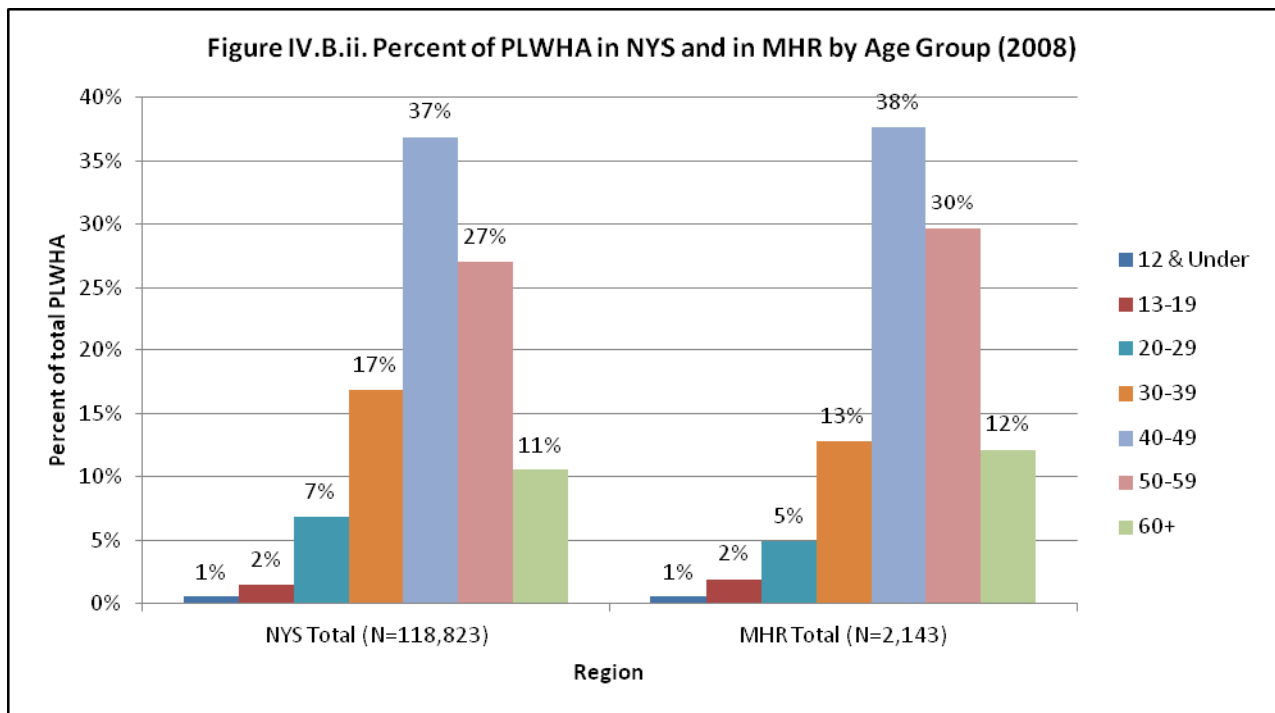
As shown in Figure IV.B.i, the MHR and NYS had very comparable distributions of sex, with males over-represented compared to the overall population, which was approximately 50% male and 50% female in NYS and the MHR in 2009. The over-representation of males was slightly greater in NYS (68% male) than in the MHR (64% male). The four mid-Hudson counties were fairly consistent in the distribution of PLWHA by sex, with a high of 67% male in Orange County and a low of 59% male in Sullivan County.



2. Age

“Age” is the current age of individuals for the time point being reporting: as of December 31, 2008 for data on PLWHA, and as of July 1, 2009 for data on the overall population.

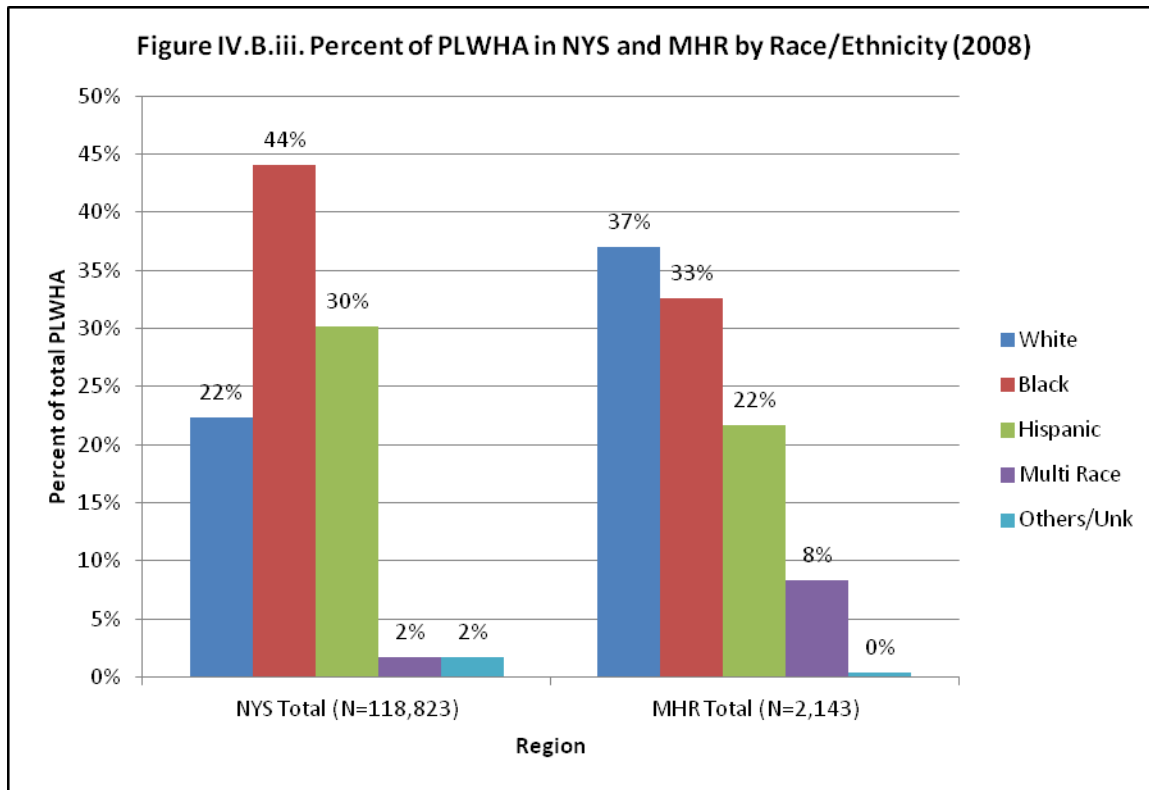
The distribution among age groups was similar for NYS, the MHR, and each mid-Hudson county, although the MHR appeared to have a slightly older population (see Figure IV.B.ii). For all regions, the age group with the largest proportion of the population was 40 to 49 years of age, followed by the 50 to 59 years of age group and then the 30 to 39 years of age group. In NYS, a total of 75% of PLWHA were over 40 years of age and in the MHR, 80% of PLWHA were over 40 years of age. This represents an over-representation of adults over 40 years of age compared to the general population; only 47% of the overall population in NYS in 2009 was over 40 years of age. Similarly, individuals younger than 19 years of age were under-represented among PLWHA in NYS and MHR. In 2009, people under 19 years of age constituted 26% of the overall population in NYS but only 3% of the PLWHA in NYS and 3% of PLWHA in MHR. The over-representation of adults over 40 years of age among PLWHA is consistent with national findings, is a testament to improved treatment regimens, and reflects the fact that HIV/AIDS should no longer be considered a young person’s disease.



### 3. Race/Ethnicity

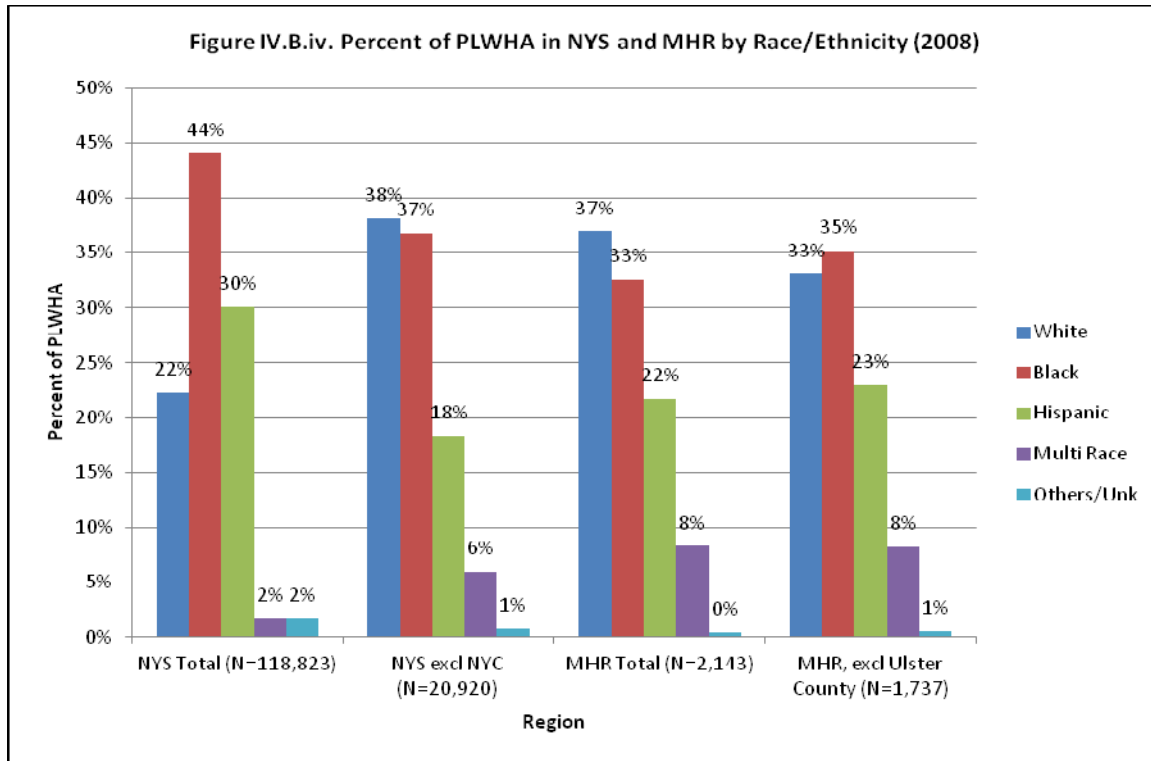
The BHAЕ records individuals’ race/ethnicity as Hispanic, White non-Hispanic, Black non-Hispanic, Asian/Pacific Islander non-Hispanic, Native American non-Hispanic, and Multiracial. The way that data are collected for individual patients varies by collection site and could be through self-report or provider assessment. As such, the following race/ethnicity observations should be interpreted with caution.

On first glance, the racial/ethnicity distribution of PLWHA in the MHR appeared to be very different from the distribution of PLWHA in NYS. As shown in Figure IV.B.iii, the largest racial/ethnic group of PLWHA in the MHR was White (37%), and the second largest racial/ethnic group was Black (33%). In NYS, the relative ranking of these two groups was inverted, with White people constituting 22% of PLWHA and Black people constituting 44% of PLWHA. Other prominent differences were that there was a larger proportion of Hispanic PLWHA in NYS than MHR and a larger proportion of Multi-Race PLWHA in the MHR than in NYS.



Closer examination revealed that these differences were mainly due to the racial/ethnic distribution of PLWHA in Ulster County and NYC; there was a significantly larger proportion of Black PLWHA in NYC than the rest of NYS and there was a significantly larger proportion of White PLWHA in Ulster County than the rest of the MHR. In fact, Ulster County was the only mid-Hudson county in which the number of White PLWHA exceeded the number of Black PLWHA, but there were so many more White PLWHA in Ulster County that they caused White individuals to be the most represented group in the MHR region overall. Figure IV.B.iv shows the impact of excluding NYC from NYS and Ulster County from the MHR on the racial/ethnic distributions of PLWHA in the two regions.

The Mid-Hudson Region, Section IV.



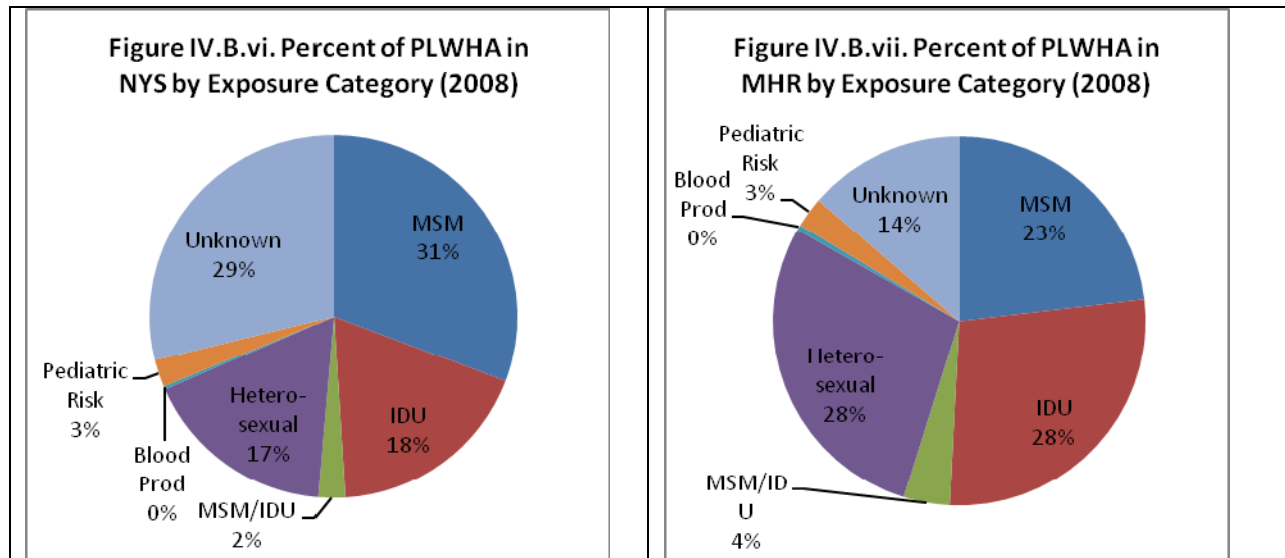
It is important to note that for each of these regions, there was disproportionate representation of Black, Hispanic and White individuals among PLWHA compared to the general population: Black and Hispanic individuals were over-represented whereas White individuals were under-represented (see Table IV.B.v).

	White	Black	Hispanic	Multi Race	Others/ Unknown
Overall population (US Census 2009)	60%	17%	17%	2%	8%
PLWHA (BHA 2008)	22%	44%	30%	2%	2%



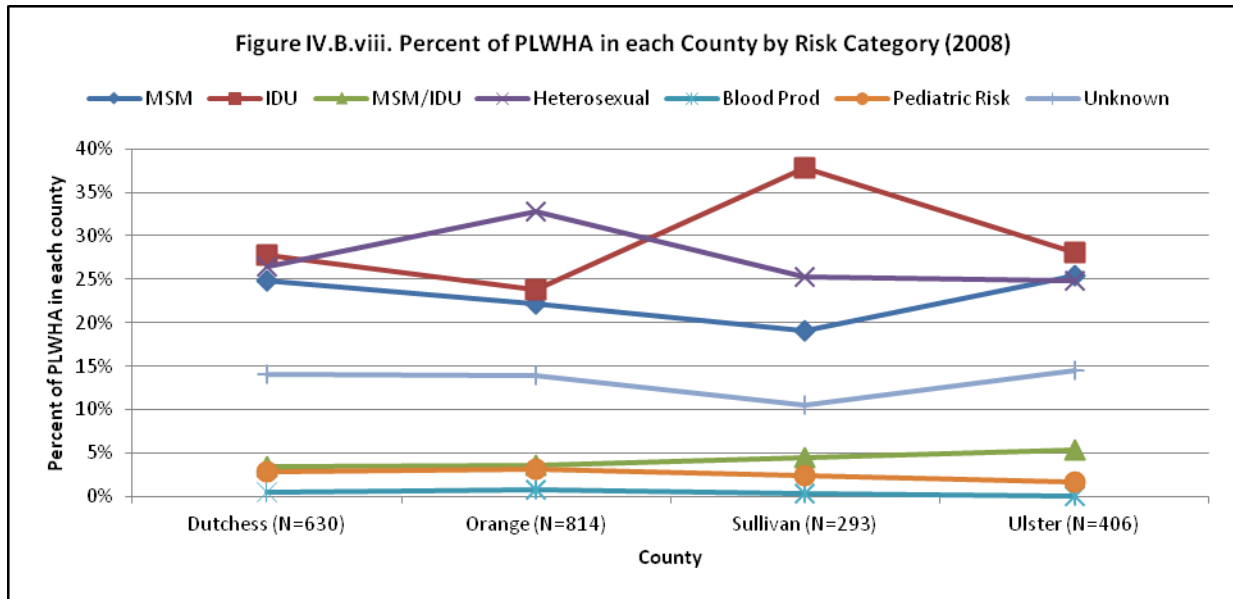
4. HIV Exposure or Transmission Risk

In 2008, the two most prevalent risk categories in the MHR were heterosexual transmission and injection drug use (IDU), each with 28% of the total distribution of exposure methods. Men having sex with men (MSM) followed with 23% of the total risk distribution. Compared to NYS, the MHR thus had a substantially larger percentage of heterosexual transmission and IDU transmission and a smaller percentage of MSM and Unknown transmission (see Figure IV.B.vi and Figure IV.B.vii).



There are no equivalent data for the general population to which these values can be compared. However, the finding of a smaller MSM community and larger heterosexual community in the MHR compared to NYC and therefore NYS as a whole is consistent with qualitative data and general perceptions of the region. Increased IDU transmission risk is more surprising. Possible explanations could include a reduced availability of syringe exchange programs and similar clean needle initiatives in the MHR compared to NYC and other more metropolitan areas: there are no syringe exchange programs between the Bronx and Albany, New York, although there are pharmacies in the MHR that participate in the Expanded Syringe Access Programs. Evaluating this possibility was outside the scope of this project but would be a meaningful topic for future investigation. Another possible explanation could include individuals who come to the MHR for drug treatment services and, while in treatment, are tested and diagnosed with HIV. This theory may be particularly relevant for Sullivan County, as discussed below.

The distribution of risk categories within each county in 2008 closely resembled that of the overall MHR region, with two exceptions: Sullivan County had a considerably larger than average percentage of IDU transmission (38%) and Orange County had a somewhat larger than average percentage of heterosexual transmission (33%) (see Figure IV.B.viii). The elevated IDU transmission in Sullivan County was predominantly among males, which is consistent with the trend that injection drug use tends to be more common among males than females, whereas the elevated heterosexual transmission in Orange County was evident for both males and females.



Several individuals interviewed for this project independently theorized that the elevated percentage of IDU in Sullivan County reflects the large number of inpatient substance use treatment facilities in the county. These facilities attract individuals from surrounding areas, mainly New York City, who come into Sullivan County for treatment, establish residence there and likely get tested for HIV/AIDS while in treatment. Unfortunately, there were very little data available within the data sources used in this project to evaluate this theory. Such evaluation, however, could be a promising area for future investigation, both to understand the risk distribution of PLWHA in the MHR and to develop targeted investigation in Sullivan County.

No clear explanations emerged for the larger than average proportion of heterosexual transmission risk in Orange County. One theory was that a larger than average sex worker population resides in the county, or that exchange of sex for drugs is more common. Members of the Orange County Department of Health recollected a significant population of women in the 1980s and 1990s engaging in sex work to fund their substance use in the major population centers of Orange County, but did not feel that there was a substantially higher level of such activities than in surrounding regions. Exploring the reasons behind the elevated heterosexual transmission could be a topic for future investigation to help develop programs in Orange County.

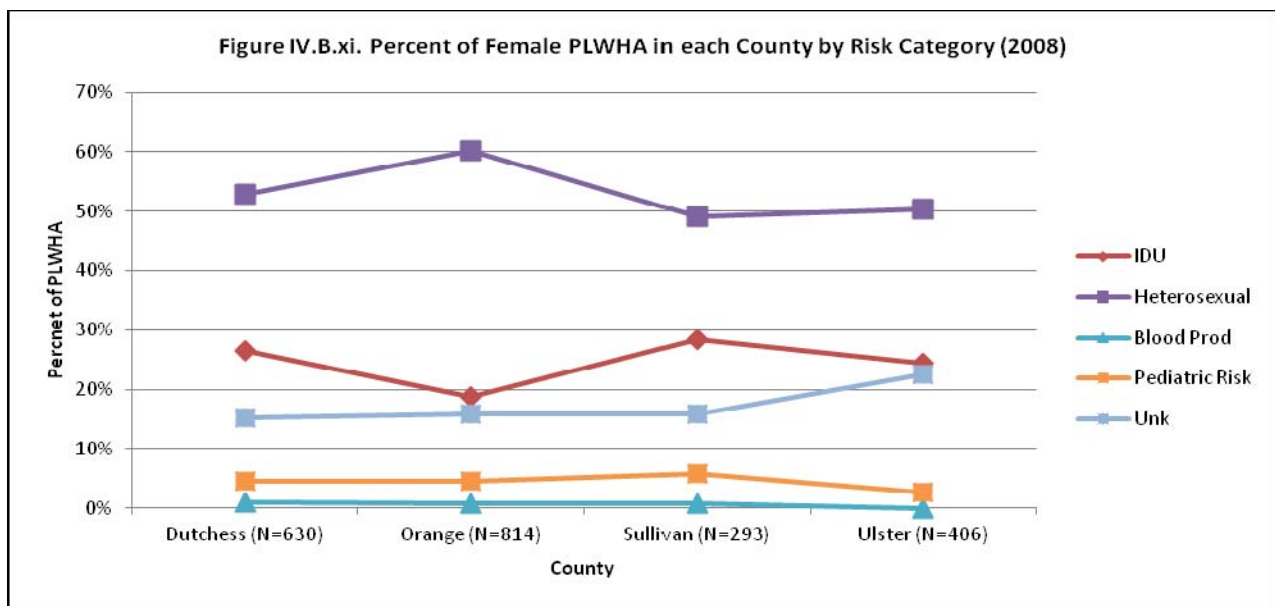
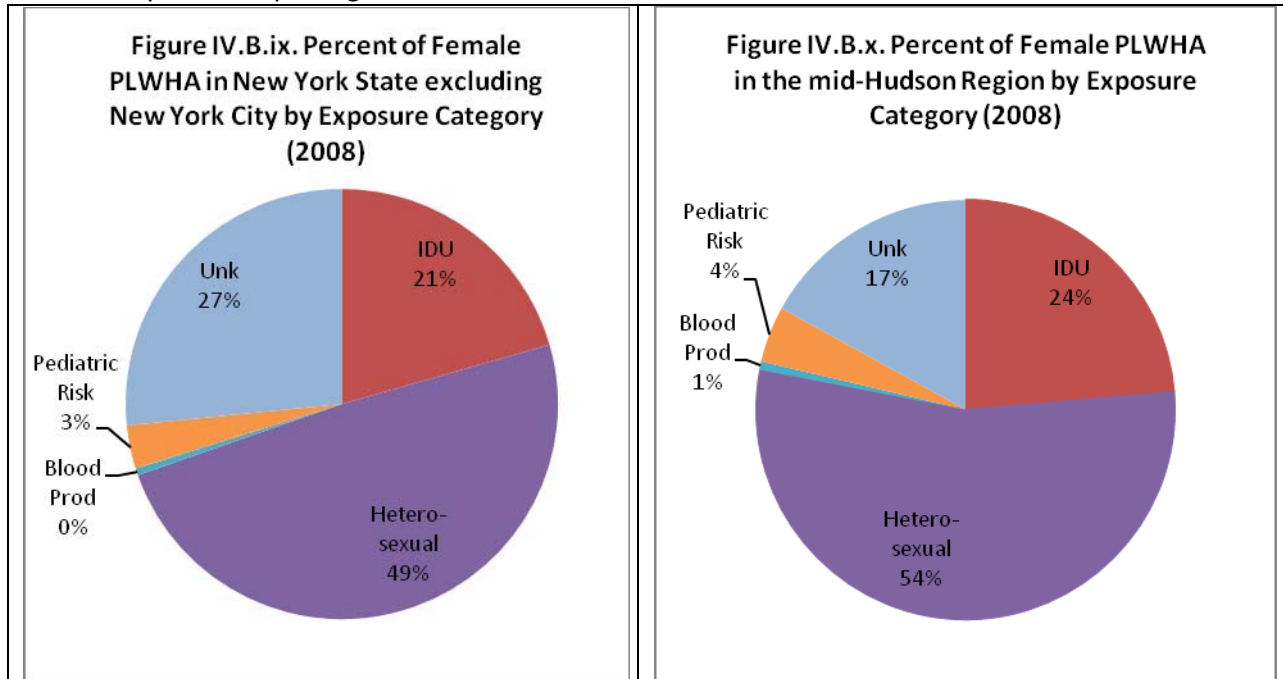
a. HIV Transmission Risk among Females

The most common exposure method in the MHR among females in 2008 was heterosexual transmission (54%), followed by IDU (24%) and Unknown (17%) (see Figure IV.B.ix). The female populations in the MHR and NYS excluding NYC<sup>1</sup> had similar differences as the overall PLWHA populations in the two regions (see Figure IV.B.x). In the MHR, females had a larger percentage of heterosexual transmission, a slightly larger percentage of IDU transmission, and a slightly smaller percentage of unknown

<sup>1</sup> Risk transmission data for females and for males is for NYS excluding NYC. This data excludes state prison inmates. Data on risk transmission in NYS separated by sex, excluding state prison inmates, but including NYC was not available at the time of writing.

transmission; in NYS excluding NYC, unknown transmission was actually more common than IDU as an exposure method among females, whereas the reverse was true for the MHR.

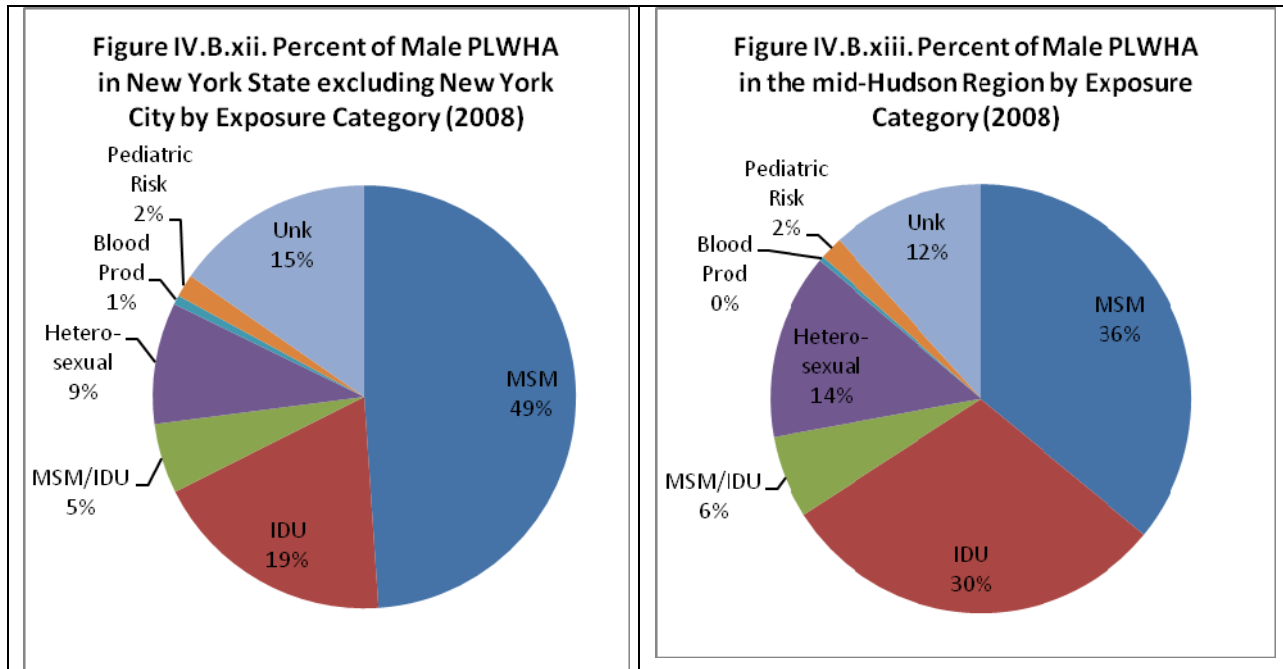
As discussed earlier and shown in Figure IV.B.xi, heterosexual transmission was elevated in Orange County among females, consistent with findings for the overall PLWHA population. Females in Sullivan County, however, only had a slightly larger percentage of IDU transmission compared to the MHR average (28% vs. 24%), indicating that the elevated IDU transmission risk in Sullivan County was mostly among males. Females in Ulster County had a higher than average rate of unknown transmission, but this is likely due to reporting variations.



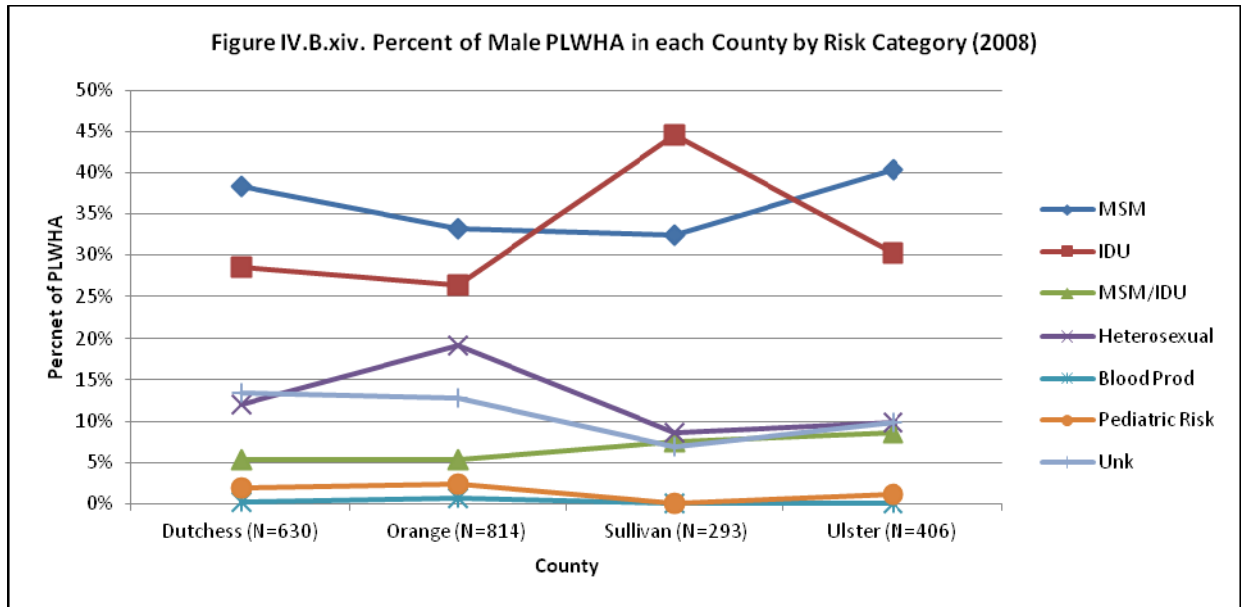
b. HIV Transmission Risk among Males

As shown in Figure IV.B.xii, the most common method of transmission risk for males in the MHR in 2008 was MSM (36%), followed closely by IDU (30%) and then by heterosexual transmission (14%). Compared to NYS excluding NYC<sup>2</sup>, there was a much lower percentage of MSM and a much higher percentage of IDU transmission risk in the MHR (see Figure IV.B.xiii). There also was a slightly larger percentage of heterosexual transmission risk among males in the MHR than in NYS excluding NYC, such that it was the third most common mode of exposure among males in the MHR but the fourth most common method among males statewide. The percentage of males who fall into the risk category of MSM-IDU was comparable between the two regions.

The percentage of MSM transmission was slightly higher in Dutchess and Ulster Counties than in Orange and Sullivan Counties (see Figure IV.B.xiv), consistent with the general impression from the qualitative research that Dutchess and Ulster Counties are more accepting of gay culture. Orange County had the largest heterosexual exposure percentage (19%) and Sullivan County had a dramatically larger percentage of IDU exposure (45%) compared to the other counties and NYS excluding NYC. Potential reasons for these elevated rates are discussed above.



<sup>2</sup> See Footnote 2



**V. Clients: PLWHA who receive care and services**

**A. About the data**

There is no, single comprehensive method of looking at clients in the MHR. Consequently, this project strove to pull together multiple data sources, each of which offers a specific perspective on the MHR clients that, when brought together, can create a more developed mosaic. In pulling together these diverse data sets, however, it is very important to remember the limitations of each data source and keep clear what each can tell us.

1. Medicaid

The Medicaid data used in this project are Medicaid Fee for Service claims data for HIV positive clients. Data are from fiscal year 2009 (FY2009), which capture bills generated from October 2008 to September 2009. The source of claims is critical to understanding this data set’s potential and limitations. One major limitation or caveat is that the location where the claim is filed is not necessarily the location where the service was provided. For instance, there could be multiple sites where a provider group offers care, but only one administrative site where all claims are submitted. These practices vary among providers. Another caveat is that facilities with multiple providers could appear as several providers or as only one provider, depending on how the facility chooses to file claims. Similar data inconsistencies apply to the client billing data. For instance, the address recorded in the billing and insurance information may or may not be where the client resides most of the time, and multiple addresses may be given. Medicaid data also were analyzed by client zip code, so that they reveal where Medicaid clients reside and where clients of particular counties travel for care. It is critical, however, to remember the data limitations associated with the addresses of providers and clients when interpreting these data. All care and service categories included in the Medicaid data are listed in Table V.A.i.

Overall, the Medicaid data report about services offered by a provider for which a Medicaid claim was submitted and demographics of the Medicaid recipients of those services as entered in the billing record.

2. AIRS

AIRS is the AIDS Institute Reporting System. Agencies that have a contractual relationship with the AIDS Institute submit data to the AIDS Institute, most frequently through the AIRS database, regarding services provided within that contract. This includes agencies that receive Ryan White Part B funding and other types of state funding that are allocated through contracts with the AIDS Institute. Agencies that receive Ryan White Parts A, C or D funding may or may not enter data into the AIRS system. If they enter data and if the agency has some type of contract with the AIDS Institute, then the AIDS Institute might be able to access this data through the AIRS database, depending on how the data was classified when entered. The agency-specific AIRS data can then be extracted into a centralized state SQL database called AIDA, which is a repository of data stripped of personal health information. It is this AIDA database that was

Medicaid Service Categories	AIRS Service Categories
<ul style="list-style-type: none"> <li>• Outpatient</li> <li>• Referred Ambulatory</li> <li>• Inpatient</li> <li>• Physician</li> <li>• Nurse Practitioner</li> <li>• Pharmacy</li> <li>• Dental</li> <li>• Psychology</li> <li>• Clinic Social Worker</li> <li>• Case Management</li> <li>• Transportation</li> <li>• Home &amp; Community Based Services</li> <li>• Home Health Care</li> <li>• Hospice</li> <li>• Eye Care</li> <li>• Podiatry</li> <li>• Long Term Care</li> <li>• Rehabilitation</li> <li>• Nursing</li> <li>• Medicare</li> <li>• Crossover</li> <li>• Laboratories</li> <li>• HMO</li> <li>• CHAP</li> <li>• DME &amp; Hearing</li> <li>• Aids</li> <li>• Child Care</li> <li>• Family Health Plus</li> </ul>	<ul style="list-style-type: none"> <li>• Primary Care</li> <li>• Primary Medical Care 5 Tier</li> <li>• Primary Medical Care 7 Tier</li> <li>• Medical Sub-specialty Care</li> <li>• Dental Care</li> <li>• Case Management</li> <li>• Medical Case Management</li> <li>• Care Coordination</li> <li>• Treatment Adherence</li> <li>• Retention in Care</li> <li>• Mental Health</li> <li>• Psychological Counseling</li> <li>• Substance Use</li> <li>• Syringe Exchange</li> <li>• Harm Reduction</li> <li>• HUD/HOPWA Housing</li> <li>• Housing</li> <li>• Transportation</li> <li>• Legal Services</li> <li>• Supportive Services</li> <li>• Nutrition and Food</li> <li>• Promoting Access to Care</li> </ul>

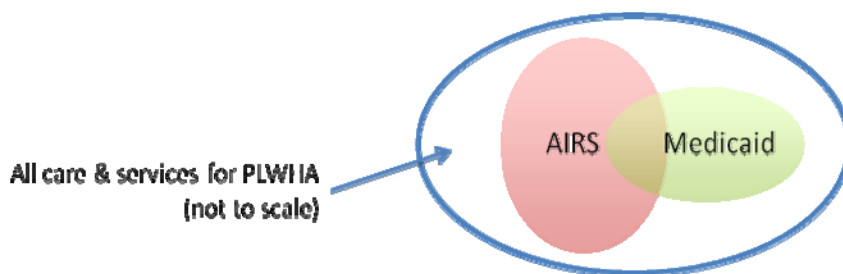
queried to generate reports on the MHR. For the purposes of simplicity, the resulting data are referred to as AIRS data throughout this report and agencies submitting information to AIRS will be referred to as AIRS sites, AIRS facilities, or AIRS agencies.

The key point regarding these matters for the current project is that the AIRS data set does not capture all services provided to PLWHA in the mid-Hudson region. Agencies that provide services to PLWHA but have no AIDS Institute contracts do not appear in this data set, nor do services at contracted agencies that are outside of the contract's scope. Additionally, each provider site assigns the demographic characteristics and service categories within the patient file and submits data to AIRS through self-report. This can introduce a significant degree of error or inconsistency in the data from site-to-site and year-to-year.

For this project, AIRS data were analyzed for 2009 and 2010 and the data were limited to only HIV positive clients who had a visit within any of the service categories listed in Table V.A.i during the relevant calendar year. This included services and clients at 14 agencies operating in 29 sites in the mid-Hudson region. The data were *not* restricted to only MHR residents who received services at these facilities. Although it is possible to produce this information from AIRS data, that level of analysis was not feasible within the timeframe of this project.

Overall, the AIRS data set can tell us about the services provided at AIRS facilities for which there was an AIDS Institute contract and about the facility-reported demographics of consumers who visit AIRS facilities.

The Medicaid and AIRS data sets overlap to some extent, in that services provided at AIRS facilities to clients on Medicaid for which a Medicaid claim was filed would appear in both data sets. Cumulatively, however, they still do not capture all care and services in the region. By looking for patterns and trends within the epidemiology, Medicaid and AIRS data sets and, when appropriate, noting how the data sets agree or diverge, this project hopes to capitalize on each source's compatibility and independence.



For both AIRS and Medicaid data sets, interpretations were for all types of care and services rendered (clinical care, non-clinical care, supportive services) unless otherwise specified.

## **B. Number of Unique Clients, Summed Clients, Total Clients & Total Visits**

There were 904 unique Medicaid clients with addresses in the mid-Hudson region in FY2009 based on unique patient identification numbers. This value includes clients who received services in areas of New York State outside of the MHR; it does not include clients who traveled to other states for care. All care and service categories were included and are listed in Table V.B.i. These 904 clients represent 1.4% of the total people in New York State for whom an HIV/AIDS associated Medicaid claim was submitted in NYS during FY2009 (N=64,041). They also represent 42.2% of the 2,143 PLWHA in the MHR in 2008



(BHAЕ), suggesting that less than half of the PLWHA living in the MHR had a Medicaid claim submitted on their behalf in FY2009. By comparison, the 64,041 unique Medicaid clients in NYS in FY2009 represent 50.9% of the 125,718 PLWHA statewide (BHAЕ 2008).

The AIRS data were analyzed with several different levels of unduplication, yielding different values for unique clients, summed clients, total clients and total visits that can be used to answer different types of questions:

- **Unique clients** are unduplicated across the entire MHR region. These clients are unduplicated by a unique record number that is independent from any agency patient identification number. This absolute number represents unique individuals who received contracted services at an AIRS facility within the calendar year.
- **Agency-summed clients** are the sum of unique clients at each agency. Rather than unduplicating all clients across the region through unique record numbers, clients are unduplicated within each agency by agency-specific identification numbers and summed together. It is this number of summed clients that is analyzed with respect to insurance status and demographic characteristics of sex, age, race/ethnicity and risk for the region<sup>3</sup>. **Agency-summed visits** are the number of visits used by agency-summed clients.
- **Site-summed clients** are the sum of unique clients at each site of each agency. This site-summed value was necessary for county comparisons along insurance and demographic characteristics<sup>4</sup> because several agencies have sites in multiple counties; to be able to compare county distributions of clients, it was necessary to have a way to break apart the client totals in these agencies by site and sum the relevant sites in each county. **Site-summed visits** are the number of visits used by site-summed clients.
- **Total clients** are unduplicated by site and the service categories listed in Table V.A.i. As such, this value reflects the overall volume of clients served at the AIRS facilities. **Total visits** are the number of visits used by total clients. This reflects the total volume of services within the specific service categories provided at AIRS facilities, regardless of recipient.

Each of these increasingly fine levels of unduplication is less effective, in that it eliminates a smaller and smaller number of duplicated clients. As an example, assume that there is a client named Joe who went to AIRS agencies A, B, and C within a calendar year. Joe would be counted **1 time** within unique clients, but he would be counted **3 times** within agency-summed clients because he visited three separate agencies. Furthermore, if Agency A actually has two sites and Joe visited each of them, then he would be counted **4 times** within site-summed clients: twice for the two sites of Agency A, once for the site of Agency B and once for the site of Agency C. Finally, if Joe received eight different types of services at these three agencies and had a total of twenty visits, then he would be counted **8 times** within total clients and would contribute **20 visits** to total visits. As indicated in the bulleted descriptions, each value can be used to answer a different question – the absolute number of unique people using AIRS facilities

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<sup>3</sup>It would be ideal to be able to analyze the insurance and demographic distribution of unique clients in addition to or instead of agency-summed and site-summed clients. However, at the time of writing, it was not possible to subdivide with any confidence the number of unique clients among demographic groups or counties. The AIRS system has the potential to produce this value, but data inconsistencies and disagreements meant that no value could be reliably determined yet. This would be a valuable area to continue pursuing, both for determining the number of unique clients using services in each county and for clarifying the changes in total clients and total visits.

<sup>4</sup> See Footnote 1

for care and services, the demographics of clients using AIRS facilities in a specific county or across the region, and the volume of care and services provided to an overall volume of clients.

The numbers of unique, agency-summed, site-summed, total clients and total visits at MHR AIRS facilities in 2009 and 2010 are listed in Table V.B.i, with an indication of how the value changed between the two years. As anticipated given the increasingly fine levels of unduplication, the number of clients increases from unique to agency-summed to site-summed to total clients.

Comparing these values reveals interesting insights as to the average number of sites or categories of services used by clients. For instance, the ratio of agency-summed clients to unique clients averages 1.46 for both years. This suggests that the average unique client of AIRS services in the MHR visited 1.5 different agencies. Similarly, the ratio of site-summed clients to agency-summed clients over the two years is 1.10, suggesting that the average client at an AIRS agency in the MHR visited 1.1 sites of that agency. Using multiple agencies thus appears more common than using multiple sites of the same agency, although that occurred to some extent, possibly by clients who were situated between two sites of an agency. Finally, the ratio of total clients to site-summed clients averages 2.38 over the two years, suggesting that, on average, clients at a particular site tend to use 2.4 different categories of service at that site. This reflects some level of co-located services, and it would be interesting to examine this ratio for other regions of NYS. It also would be interesting to compare the different values for number of clients for specific service categories and demographic groups. These could be potential areas for future investigation. The ratios of total visits to total clients within specific service categories are discussed in Sections VII and VIII.

	2009	2010	% decrease* (2009-2010)
Unique Clients	1,493	1,234	- 17.3%
Agency-Summed Clients	2,154	1,838	- 14.7%
Site-Summed Clients	2,329	2,073	- 11.0%
Total Clients	5,245	5,226	- 0.4 %
Total Visits	57,131	50,008	- 12.5%
*Decrease is percentage of 2009 value			

Another observation from looking at these five values is that all show considerable decreases from 2009 to 2010, except for total clients. There are many possible interpretations of these data. First, the decrease in unique clients indicates that a smaller number of distinct individuals used AIRS facilities in the MHR in 2010 than 2009. Second, the gradually diminishing decreases for unique clients (-17%), agency-summed clients (-15%) and site-summed clients (-11%) suggest that the clients who continued to use services may have increased the number of different agencies and the number of different sites that they visited, otherwise the agency-summed and site-summed client values also should have decreased by approximately 17%. This is only a tentative conclusion, as the varying amounts of decrease could be a consequence of the different unduplications. Third, the fact that total clients *does not* show a decrease but site-summed clients *does* suggests that the clients who continued to use AIRS facilities in the MHR in 2010 must have used additional types of services at the same sites (because total clients are unduplicated by site and by service category, whereas site-summed clients are just unduplicated by site). This could reflect increased co-location of services or could be a consequence of clients attempting to limit their transportation requirements. Finally, the decrease in total visits from 2009 to 2010 is somewhat inflated by a change in primary care visit reporting requirements, as discussed in Section VII.A.2. Even after removing the primary care visits from analysis, however, there remains a 7.8% decrease in total visits. This indicates that even with remaining clients using more service categories

than before, the overall decrease in the number of unique clients translated into a slight decrease in the volume of total services provided.

There are many possible explanations for a decrease in the number of individuals using AIRS facilities. These include:

- Reduced funding for programs leading to reduced availability of services
- Reduced personal funds of clients leading to a smaller number of clients to use health care services or to use them less frequently
- Fewer clients from outside the MHR traveling to the MHR AIRS facilities for services, due to diminished funds for travel or increased quality of care elsewhere
- More clients from within the MHR traveling outside the MHR for services, due to increased funds for travel or decreased quality of care in the MHR
- More clients within the MHR choosing to visit non-AIRS facilities, which could itself be explained by many different factors
- Less need for supportive services as health improves
- Related services coordinated or bundled within the same service category instead of listed separately
- Fewer clients engaged in care

Exploring the reasons behind this decrease is an area for future investigation.

The number of unique individuals according to each data set is summarized below.

Source	Description	Year	Number
BHAE	PLWHA living in the MHR	2008	2,143
Medicaid	Unique Medicaid clients with addresses in the MHR for whom a claim was submitted	FY2009	904
AIRS	Unique clients receiving contracted services at AIRS facilities in the MHR	2009	1,493
		2010	1,234

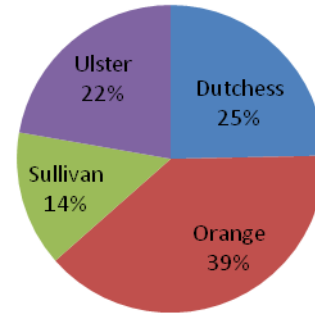
### C. Where clients live

As mentioned above, the Medicaid data were analyzed based on the zip code of clients for whom a Medicaid claim was submitted. Also as discussed above, a comparable analysis could be conducted with AIRS data, but was not undertaken within this project.

The Medicaid client zip code analysis revealed that of the 904 unique Medicaid clients in FY2009, 25% lived in Dutchess County, 39% lived in Orange County, 14% lived in Sullivan County and 22% lived in Ulster County (see Figure V.C.i). This is generally comparable to the distribution of PLWHA excluding state prison inmates in 2008 (29% in Dutchess County, 38% in Orange County, 14% in Sullivan County, 19% in Ulster County), except that Ulster County had a slightly larger proportion of Medicaid clients than total PLWHA and Dutchess County had a slightly smaller proportion of Medicaid clients than PLWHA. This is consistent with the general county demographics of Ulster County being the second-poorest county and Dutchess County being the most wealthy. Interestingly, however, it contradicts the AIRS findings regarding the insurance status of clients in each county, discussed in Section V.E.

Further analysis of the Medicaid client zip code data found that there were only 14 zip codes in the MHR with more than ten HIV+ clients for whom a Medicaid claim was submitted in FY2009. These zip codes, listed below, encompass 608 clients, which is 67% of unique MHR HIV+ Medicaid clients within that year. This concentration of clients suggests that these are zip codes with high HIV/AIDS burden and generally lower socio-economic status. Key areas include: Newburgh and Middletown, which cumulatively contained 60% of all clients in Orange County and 23% of all MHR clients; Poughkeepsie, which contained 43% of all clients in Dutchess County and 11% of all MHR clients; Eddyville, Kingston and Saint Remy, all in zip code 12401, which contained 26% of Ulster County clients; and Monticello, which contained 51% of all clients in Sullivan County.

**Figure V.C.i. Distribution of HIV+ Medicaid Clients in the MHR for whom a Claim was Submitted in FY2009**



**Table IV.C.ii. Distribution by zip code of residence of MHR HIV+ Medicaid clients for whom a claim was filed in FY2009**

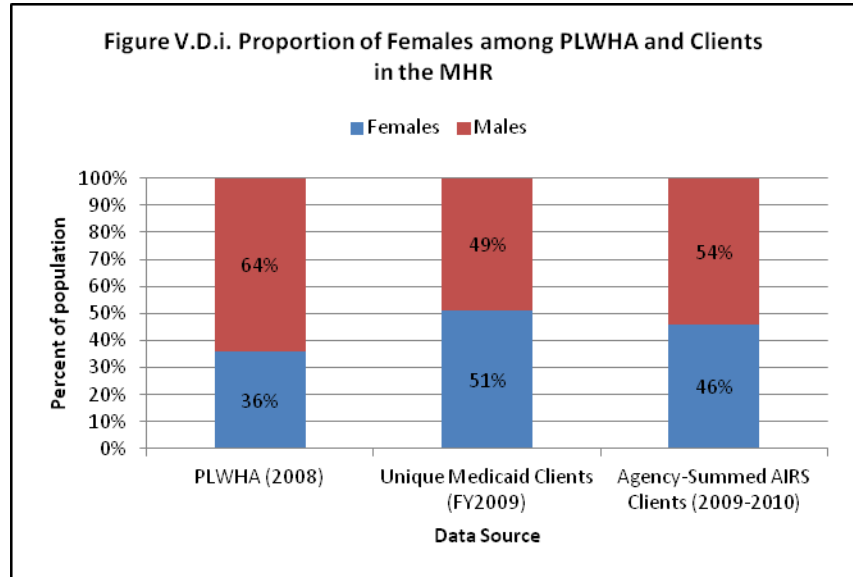
City	County	Zip code	Number of Clients	Percent of Total Clients in County	Percent of Total Clients in MHR
Newburgh	Orange	12550	121	34%	13%
Poughkeepsie	Dutchess	12601	96	43%	11%
Middletown, Scotchtown	Orange	10940	90	26%	10%
Eddyville, Kingston, Saint Remy	Ulster	12401	80	40%	9%
Monticello	Sullivan	12701	66	51%	7%
Beacon	Dutchess	12508	30	13%	3%
Arlington, Poughkeepsie	Dutchess	12603	24	11%	3%
Saugerties	Ulster	12477	23	11%	3%
Monroe	Orange	10950	16	5%	2%
New Windsor, Newburgh	Orange	12553	15	4%	2%
New Hamburg, Wappingers Falls	Dutchess	12590	13	6%	1%
Liberty	Sullivan	12754	12	9%	1%
Port Jervis	Orange	12771	12	3%	1%
New Paltz	Ulster	12561	10	5%	1%

### D. Demographics of Clients in the MHR

For the following demographics of clients, Medicaid data represent unique clients unduplicated by their unique patient identification number. When referring to regional demographics for the entire MHR, AIRS data represent agency-summed clients. When referring to county-wide demographics, AIRS data represent site-summed clients.

#### 1. Sex

Females appear to be over-represented in the Medicaid and AIRS databases compared to their proportion of PLWHA in the MHR. This is more evident among Medicaid clients than clients at AIRS facilities; females constituted 36% of PLWHA in 2008, but they were 51% of unique Medicaid clients in FY2009 and 46% of agency-summed clients at MHR AIRS facilities in 2009. The proportion of females among agency-summed clients at MHR AIRS facilities dropped slightly to 44% in 2010. Females consistently were seen at 47% of visits at MHR AIRS facilities in 2009 and 2010.



The over-representation of females among clients is consistent with general findings of females using health services more frequently than males. Statewide Medicaid data also show an over-representation of females among clients; whereas females were 31% of PLWHA in NYS in 2008, they were 43% of unique Medicaid clients in FY2009.

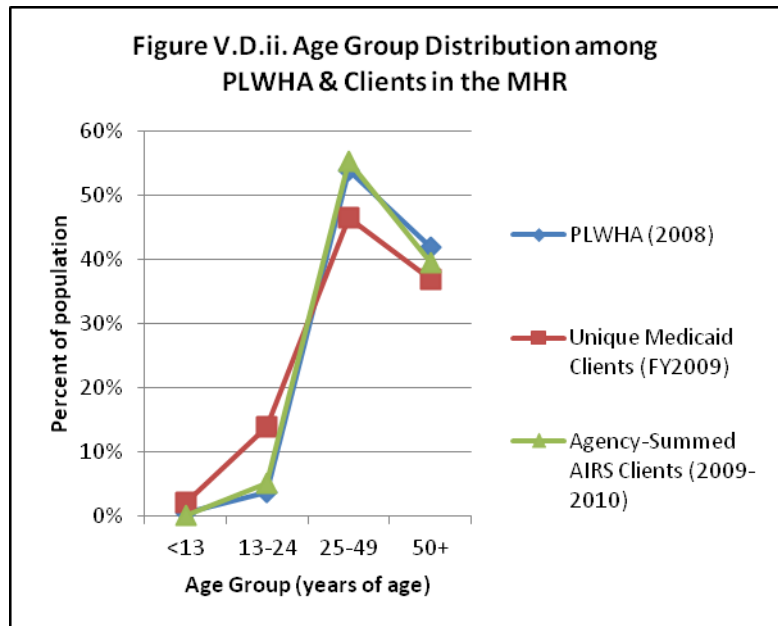
The slight decrease in the proportion of AIRS agency-summed female clients from 2009 to 2010 appears mostly due changes in Orange County. Whereas females were 50% of site-summed AIRS clients in Orange County in 2009, they constituted only 43% of clients in 2010. This is because 76% of the decrease in clients at Orange County AIRS facilities from 2009 to 2010 (N=186) was among female clients (n=142). This, in turn, appears to be mostly due to activities at the Middletown Community Health Center, where 80% of the decrease of 148 clients was among females (n=119). It is possible that a female-specific initiative ended in 2010, leading to this decrease and shift in overall client demographics. An important topic for future investigation would be whether this occurred and, if so, if it resulted in a gap in services for female PLWHA.

Other slight county variations include that Ulster County had a lower than average percentage of female clients according to Medicaid data for FY2009 (48%) and according to AIRS data for both 2009 and 2010 (41% and 39%, respectively), compared to the MHR overall. This likely reflects a larger MSM population among clients in Ulster County, which is discussed more below. Finally, Sullivan County had a higher than average percentage of female clients according to Medicaid data in FY2009 (54%), but a lower than average percentage of female clients according to AIRS data in 2009 (41%). This may reflect genuine

differences in the Medicaid and AIRS client populations, or may be just due to differences in the data sets. A lower than average percentage of female clients would have been consistent with a larger IDU population in Sullivan County, because injection drug use tends to be more common among males.

### 2. Age

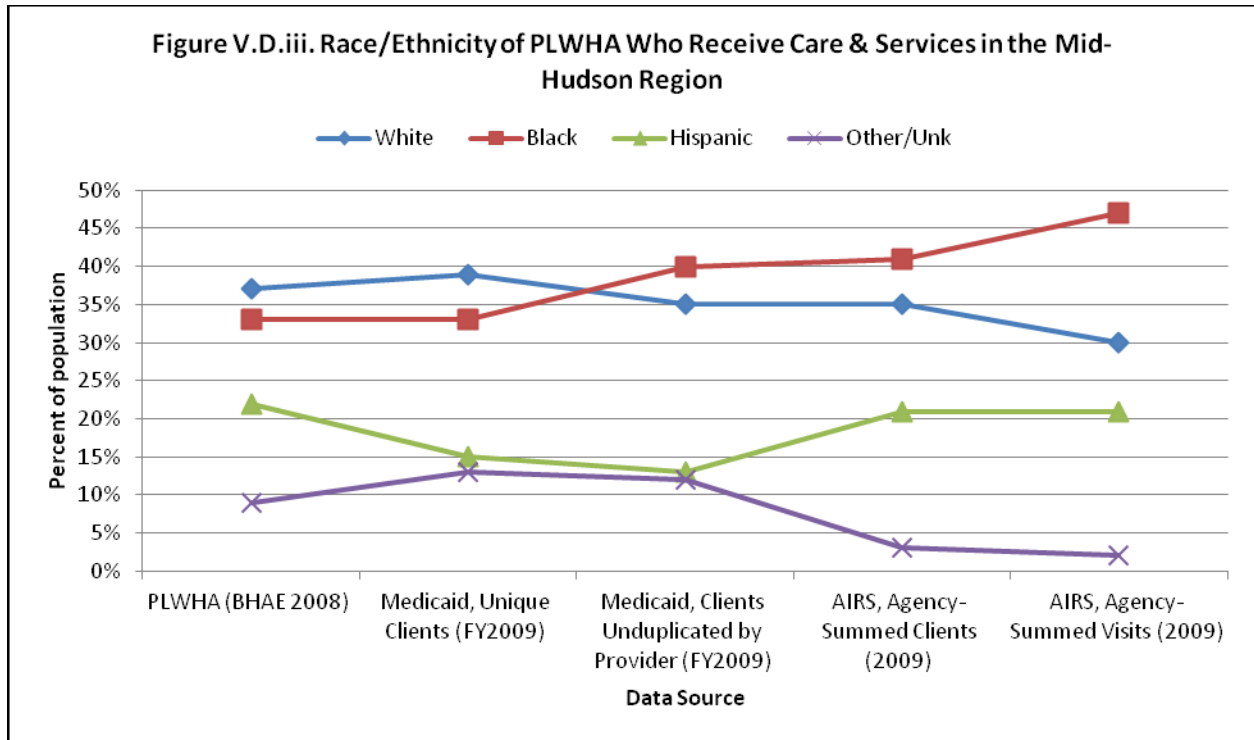
The proportion of clients in each age group was fairly consistent for PLWHA, unique Medicaid clients, and agency-summed AIRS clients. One difference is that clients who were between ages 13 and 24 were over-represented among Medicaid clients compared to PLWHA and AIRS clients and, possibly as a consequence, were slightly under-represented among clients ages 25 to 49. This, again, could reflect actual differences in the Medicaid and AIRS client populations or could be due to differences in the data sources. For both the MHR and NYS, 70% of unique Medicaid clients were over 40 in FY2009. In a similar vein, clients over 50 years of age were over-represented among total visits provided at MHR AIRS facilities in 2009 and 2010 (47%) compared to AIRS clients, consistent with general trends of older consumers needing additional medical care and typically being better retained in care.



### 3. Race/Ethnicity

The distribution of Medicaid unique clients in FY2009 by race/ethnicity was generally comparable to the distribution among PLWHA in 2008, as shown in the first two data columns of Figure V.D.iii. Notable differences are the proportion of Hispanic individuals, which was considerably lower among Medicaid clients than among PLWHA, and the proportion of individuals with “unknown” race/ethnicity, which was 12% among Medicaid clients but 0% among PLWHA according to the BHAЕ. The differences in the proportion of Hispanic clients probably were due to differences in how race/ethnicity was determined and recorded among Medicaid providers; whereas the BHAЕ classifies all individuals and either Hispanic or non-Hispanic and subsequently determines a racial categorization for all non-Hispanic individuals, it is highly unlikely that all Medicaid providers follow the same rigorous format or always consider ethnicity in addition to race. Another factor, however, could be that undocumented immigrants cannot be enrolled in Medicaid but could be counted according to the BHAЕ. Examining the race/ethnicity of ADAP clients could help elucidate this discrepancy.

The much higher proportion of clients with “unknown” race/ethnicity in the Medicaid data also reflects the inconsistency and relative unreliability of Medicaid data with respect to race/ethnicity, due to the unknown and varying practices of individual providers. A similar weakness exists for AIRS data regarding race/ethnicity, especially when compared to the rigor of BHAЕ classifications. As such, the following observations regarding the distribution of race/ethnicity are made tentatively and should be interpreted with caution.



Although the distribution of Medicaid *unique clients* in FY2009 was generally comparable to that of PLWHA in 2008 according to BHAЕ, the distribution of race/ethnicity among Medicaid clients *unduplicated by provider* suggests that Black clients were more likely to see multiple providers. Counting clients unduplicated by provider means that a client would be counted multiple times if the client saw multiple providers. As can be observed by comparing the second and third columns of data points in Figure V.D.iii, unduplicating by provider caused the proportion of Black clients to increase and exceed the proportion of White clients, suggesting that Black clients were more likely to see multiple providers and thus be counted multiple times.

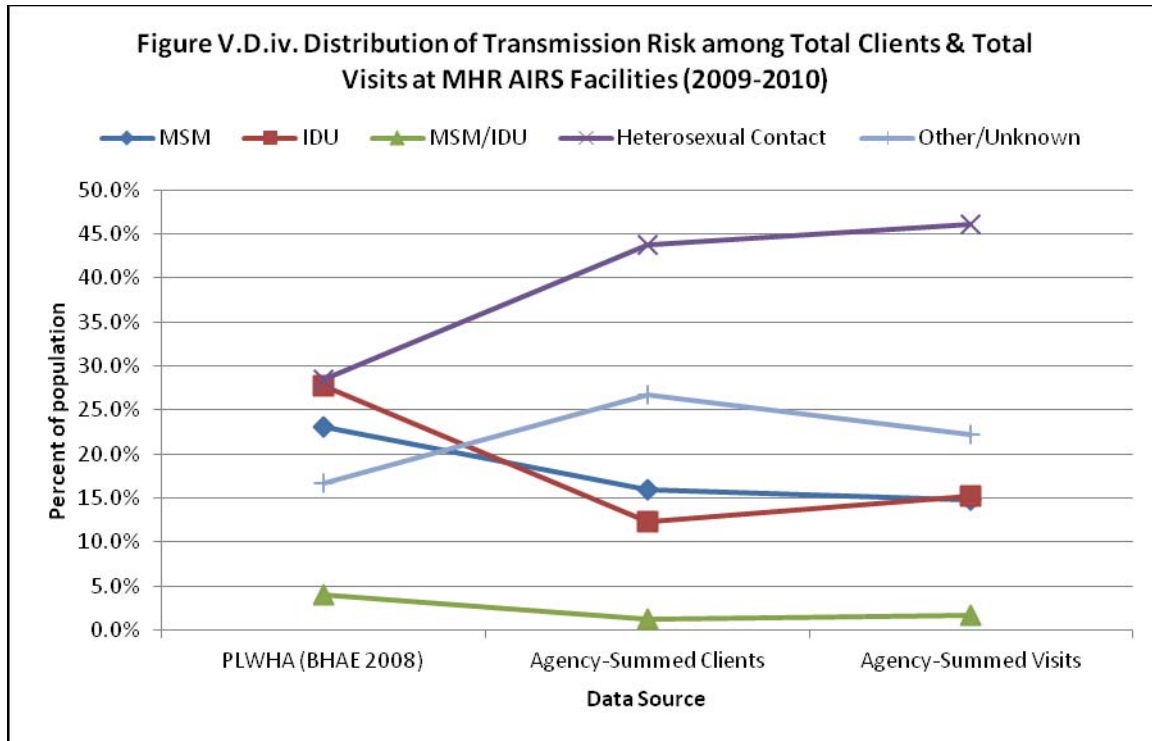
The AIRS data presented in columns four and five similarly suggest that Black clients were more likely to use a higher volume of services. Column four shows the distribution by race/ethnicity of AIRS agency-summed clients, who were unduplicated by agency. Just as with the Medicaid clients unduplicated by provider, this shows an increased proportion of Black clients compared to PLWHA, suggesting that Black clients were more likely than clients of other race/ethnicities to use care and services at multiple agencies. Furthermore, as displayed in column five, the proportion of Black clients was even larger for AIRS agency-summed visits than for AIRS agency-summed clients. These data collectively suggest that Black clients were more likely to see multiple providers, were more likely to use services at multiple AIRS agencies, and were more likely to utilize those services through a higher volume of visits.

There are many possible explanations or factors behind this observation, not least of which is the relative unreliability of AIRS and Medicaid race/ethnicity data. Interesting follow-up questions would be to determine if this is true for a particular group of Black clients – female or male, of a particular risk category, with certain co-morbidities, long-term ARV users, naïve ARV users, etc. Also interesting would be to explore whether this is related to provider relationships with Black patient populations that are a concern from the patient perspective or promote differences in health seeking behaviors. Such

questions would be important areas for future investigation, which could include following a cohort to explore the issue in greater depth.

#### 4. Method of Exposure

Only AIRS data are available to address this demographic variable, as transmission risk category is not included in the Medicaid claims data. Compared to the distribution among PLWHA in 2008 according to BHAЕ, people with heterosexual transmission risk were over-represented and people with MSM and IDU transmission risk were under-represented among agency-summed clients and agency-summed visits at AIRS facilities in the MHR in 2009 and 2010.



One factor contributing to the over-representation of clients with heterosexual risk transmission could be that females were over-represented among AIRS agency-summed clients and visits and females tend to have higher rates of heterosexual transmission. The under-representation of clients with MSM, IDU and MSM/IDU transmission risks could suggest that the MHR AIRS facilities were less welcoming to an MSM or gay community or could reflect lower levels of engagement in care among these populations. The under-representation of these groups is an important area for future investigation to ensure that there is not a gap in care and services.

A few prominent county variations include:

- In Orange County, clients with IDU transmission risk were particularly under-represented, constituting 24% of PLWHA in 2008 but only 7% of AIRS site-summed clients in 2009 and 9% of AIRS site-summed clients in 2010. This would be another valuable area for future investigation to ensure that PLWHA with IDU transmission in Orange County are not being lost to care.
- In Sullivan County, there was a higher than average percentage of IDU transmission risk among AIRS site-summed clients, which is consistent with the higher than average percentage of IDU transmission risk among PLWHA in Sullivan County.
- Ulster County was the only county in which site-summed AIRS clients with MSM transmission risk were not significantly under-represented (25% of PLWHA in 2008, 23% of site-summed



clients in 2009, 25% of site-summed clients in 2010). This suggests that Ulster County AIRS facilities may attract a larger MSM population, possibly drawing clients who have MSM transmission risk from other counties or from surrounding areas.

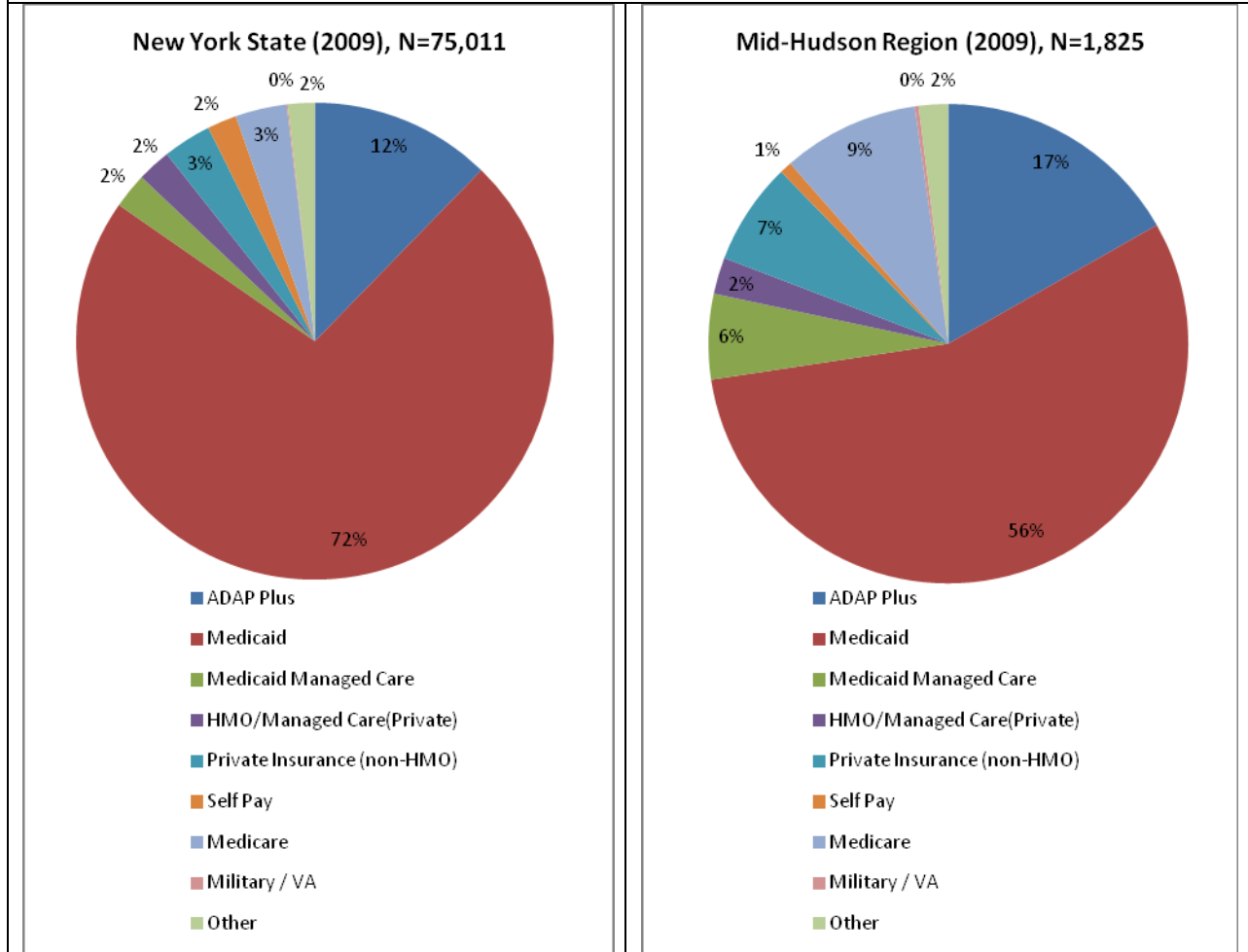
## **E. Insurance type**

Data on the insurance status of clients come only from the AIRS data source, as all clients in the Medicaid database are, by definition, on Medicaid. As mentioned above, data on insurance and on the demographic characteristics of clients, which follows, are based on the value of agency-summed clients (the sum of unique clients at each agency) and site-summed clients (the sum of unique clients at each site of each agency). A further nuance is that not all of the summed clients appear for the data on insurance status, whereas they do for the demographic data. This is because of how insurance information is entered into AIRS. Providers can list more than one insurance type for each client—primary, secondary, and tertiary—but clients do not need to have a primary insurance type selected in order for providers to list secondary and tertiary types. For this project, the AIRS insurance status data were restricted to only the primary insurance type in order to capture the most dominant insurance payor without double or triple counting clients with multiple insurance types. This, however, excluded all clients who received some type of services at the AIRS facility but only had a secondary or tertiary insurance type recorded: 329 clients in 2009 and 308 clients in 2010. Finally, insurance status can change over time. Providers can update what insurance is recorded, but do not always do so and, occasionally, providers list more than one primary insurance type for a client. Consequently, insurance type for this project was further restricted to the primary insurance type with the most recent date of initiation.

Figure V.E.i compares the distribution of insurance type in 2009 among clients at MHR AIRS facilities to clients at NYS AIRS facilities. As one can see, a smaller proportion of clients at MHR AIRS facilities had Medicaid insurance but a larger proportion had Medicaid Managed Care, Medicare, private insurance (non-HMO) and ADAP Plus compared to clients at AIRS facilities across all of NYS. The larger proportion of ADAP Plus could suggest a higher prevalence of undocumented immigrants, possibly among the migrant seasonal farm worker population, as ADAP Plus does not require proof of citizenship. The larger proportion of Medicaid Managed Care is initially surprising because of the creation of Special Needs Plans (SNPs) for PLWHA in NYC and the absence of SNPs in upstate New York. The significant increase in SNP enrollment in NYC, however, occurred during 2010-2011 and therefore wouldn't be captured by these data, and the smaller percentage of Medicaid Managed Care clients in NYS may be a consequence of the larger overall number of clients. The larger proportion of clients on Medicare in MHR compared to NYS suggests a larger population of older or disabled adults.

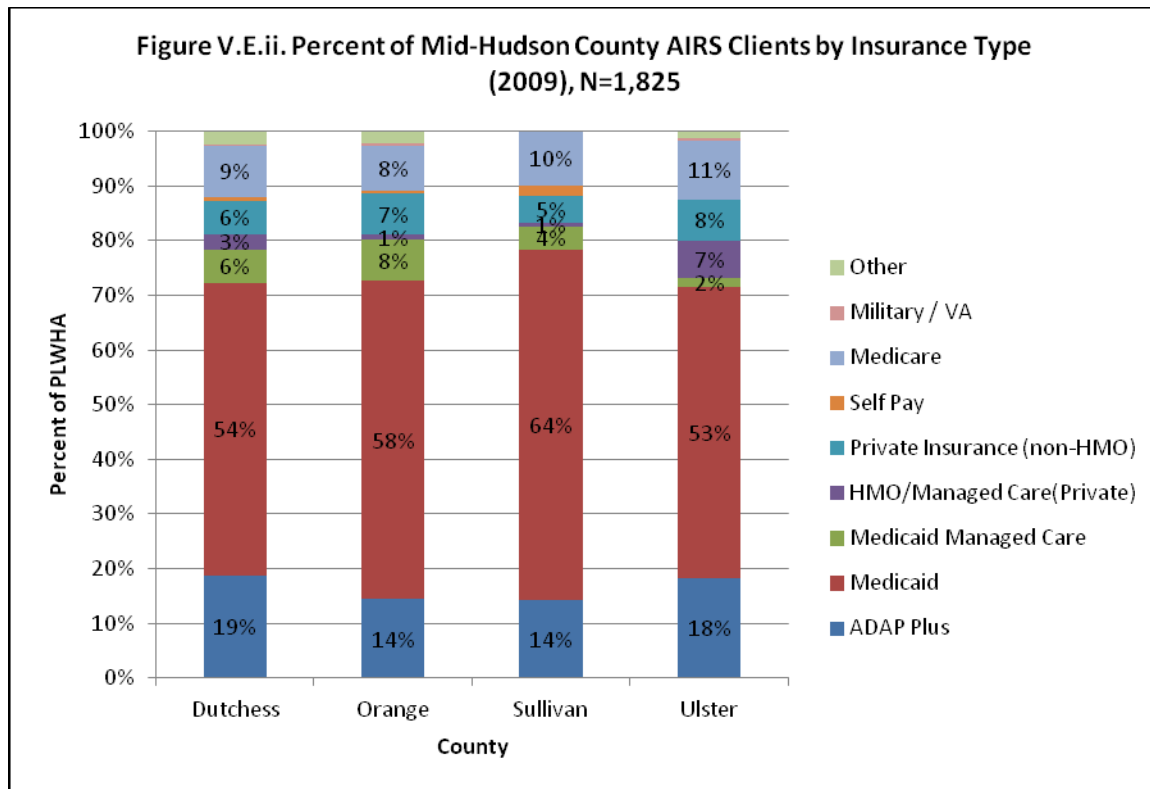
Finally, the larger proportion of private insurance and smaller proportion of Medicaid suggests that, compared to the population of AIRS clients across NYS, AIRS clients at MHR facilities were more likely to be employed and therefore have private insurance and be ineligible for Medicaid. This is consistent with the lower overall unemployment rate in the MHR than across NYS.

Figure V.E.i. Distribution of insurance types among clients at AIRS facilities in the MHR and NYS (2009)



The distribution of insurance types changed very little for NYS or MHR AIRS facilities from 2009 to 2010, despite the decreases in agency-summed and site-summed clients discussed above.

County variations in insurance status suggest relative wealth of Ulster County AIRS clients and relative poverty of Sullivan County AIRS clients. As shown in Figure V.E.ii, Sullivan County had the largest proportion of clients using Medicaid and Medicaid Managed Care (68%), while Ulster County had the smallest (55%). Additionally, Sullivan County had the smallest proportion of clients using private insurance (6%), while Ulster County had the largest (15%). This depiction of Ulster County clients as relatively wealthy is particularly interesting given the census data, which indicates that although Sullivan County is the poorest county, Ulster County is the second poorest.



One explanation for the relative wealth of Ulster County AIRS clients as suggested by the insurance data is that Ulster County providers, including AIRS facilities, draw a much larger out-of-county and out-of-region clientele than any other county. This is discussed below in the section on travel for care. Another possible factor is that Ulster County is known for having a significant “weekender” population – people with considerable means who live in NYC but have a second home in Ulster County. Conversations with consumers and providers also suggest that gay men constitute a significant proportion of this “weekender” population, which could explain the higher proportion of MSM among Ulster County clients.

## F. Travel for Care

Medicaid and AIRS data were used to explore where clients of particular counties travel for care. Examining travel for care was particularly important given the many comments from providers and consumers regarding the lack of choices with respect to service providers and the challenge of transportation in the MHR – both between MHR counties and to surrounding regions. As such, this analysis was conducted for different geographic ranges—within the MHR and for all of NYS—and from both the consumer and the provider perspective.

### 1. Travel for Care, Consumer Perspective: Where do MHR clients go for care?

The following discussion of travel for care from the consumer perspective is based on the number of unique Medicaid clients *in the MHR* for FY2009, *unduplicated by provider county*. This means that each county in NYS that a client visited for care of any type resulted in one count. As an example, if a Dutchess County client Jane went to Providers A, B, and C in Ulster County, then Jane would only be counted 1 time as a unique Dutchess County client going to Ulster County for care and services. If Jane also went to Providers D and E in Albany County, then she would be counted 1 time as a unique

Dutchess County client going to Ulster County for care and services and 1 time as a unique Dutchess County client going to Albany County for care and services. As noted earlier, AIRS data could be used to examine this, but zip code information for AIRS clients was not analyzed for this project due to time limitations.

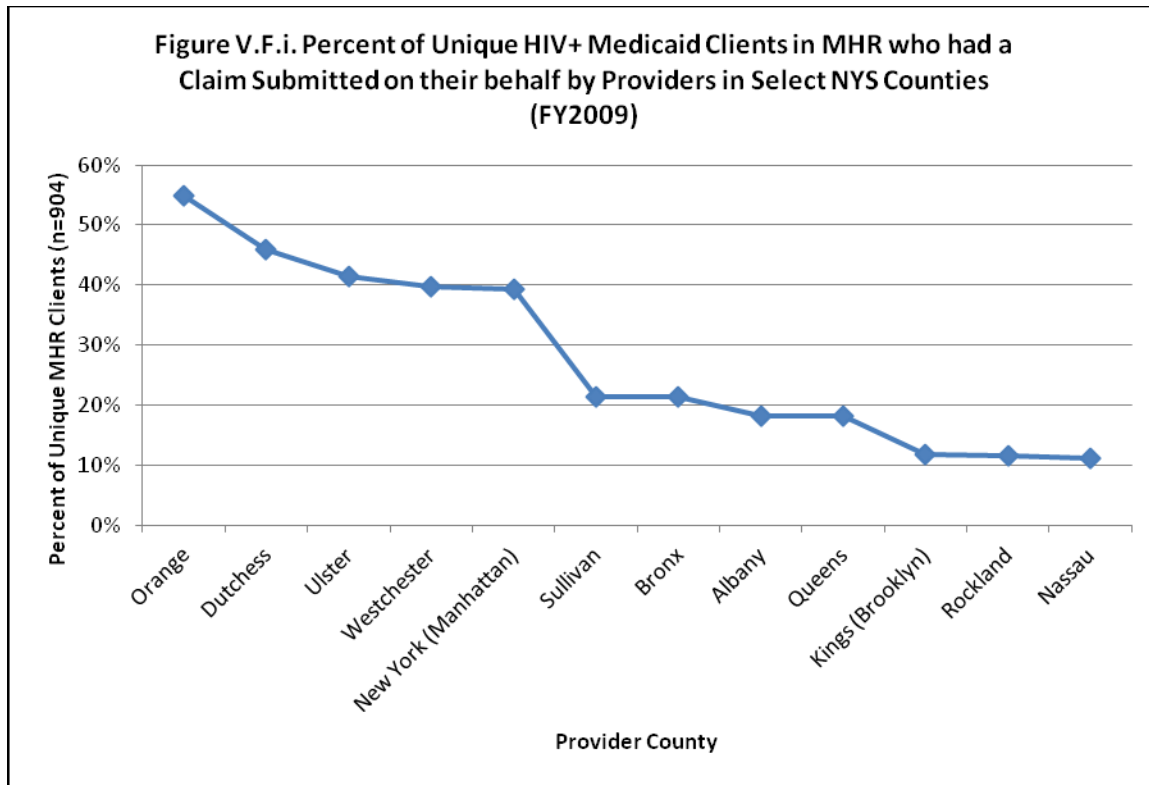
The analysis of 904 unique HIV+ Medicaid clients in the MHR unduplicated by provider county in FY2009 found that:

- 415 unique clients in the MHR (46% of all unique MHR clients) went to Dutchess County for care and services; 207 of these clients resided in Dutchess County (93% of the 223 unique Dutchess County clients)
- 497 unique clients in the MHR (55% of all unique MHR clients) went to Orange County for care and services; 334 of these clients resided in Orange County (95% of the 351 unique Orange County clients)
- 194 unique clients in the MHR (22% of all unique MHR clients) went to Sullivan County for care and services; 124 of these clients resided in Sullivan County (96% of the 129 unique Sullivan County clients)
- 375 unique clients in the MHR (42% of all unique MHR clients) went to Ulster County for care and services; 192 of these clients resided in Ulster County (96% of the 201 unique Ulster County clients)

Cumulatively, these data show a considerable in-county bias with the MHR; at least 93% of unique Medicaid clients in each MHR county had a claim submitted on their behalf by a provider in that county. The largest number of MHR clients went to Orange County for care and services, but this is largely due to the fact that Orange County has the greatest number of clients residing in it. Removing the number of in-county clients receiving care and services within each MHR provider county reveals that Dutchess County had the greatest number of out-of-county clients within the MHR (n=208, 31% of total out-of-county clients), suggesting a greater allure of Dutchess County Medicaid providers for clients within the MHR. Ulster County (n=183) had a greater number of out-of-county clients than Orange County (n=163), and Sullivan County had the smallest number (n=70). This means that very few MHR Medicaid clients who did not live in Sullivan County traveled to Sullivan County for care, reflecting a diminished allure of Sullivan County Medicaid providers.

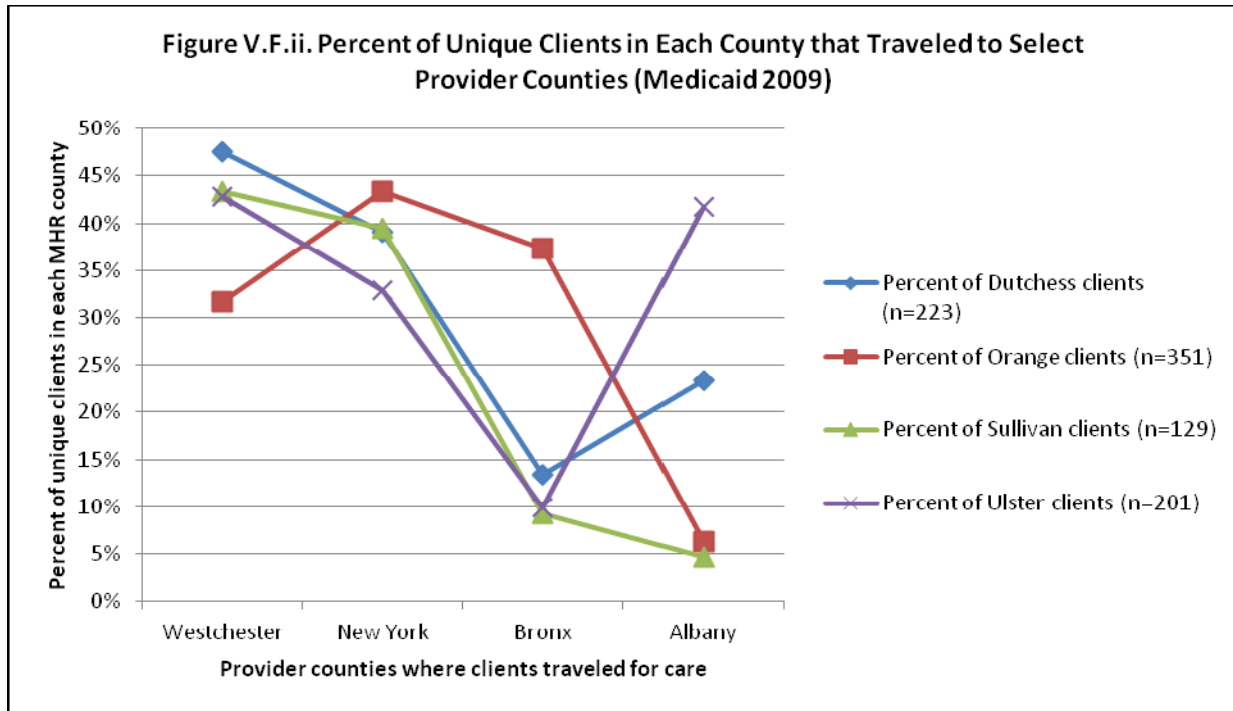
These data also indicate that many MHR clients visited multiple counties within the MHR. There was a total of 1,481 unique clients in the MHR *when unduplicated by MHR provider county*, but only 904 unique clients when unduplicated across the entire MHR. This means that the average MHR HIV+ Medicaid client went to providers in 1.64 MHR counties ( $1481 \div 904 = 1.64$ ) for care and services in FY2009.

In addition to travel within the MHR, there was considerable travel outside the MHR by MHR HIV positive Medicaid clients in FY2009. The percentage of unique MHR Medicaid clients who had a claim submitted on their behalf by providers in counties across NYS is presented in Figure V.F.i (only provider counties with more than 10% of unique MHR clients were included). Figure V.F.ii offers a closer analysis at the percent of unique MHR Medicaid clients from each MHR county who traveled to the four most common provider counties outside of the MHR.



As noted earlier, 55% of unique MHR clients went to Orange County, 46% went to Dutchess County, and 41% went to Ulster County. The next most common county to travel to was Westchester County (40% of unique MHR clients), followed by New York County (Manhattan) (39% of unique MHR clients). The large proportion of clients that traveled to Westchester County is consistent with expectations, given that the nearest Designated AIDS Centers (DACs) to the MHR are in Westchester County.

It is surprising, however, how small a proportion of clients traveled to Albany County (18%), where the other nearest DAC is located. As shown in Figure V.F.ii, only Ulster County clients traveled to Westchester and Albany Counties in comparable numbers; clients residing in the other three MHR counties significantly favored heading south to Westchester, New York County (Manhattan) or the Bronx over traveling north to Albany. This may be because of actual time and distance traveled; Ulster County and the population hub of Kingston is the most north out of all major population centers in the MHR. It also may reflect the fact that many consumers in the MHR have lived in NYC and may have sustained relationships with NYC providers or may have other reasons for wanting to travel into NYC. Additionally, there are likely more public transportation options for traveling to NYC than Albany, although there is scant public transportation of any type in the more remote regions of the MHR. Another factor to explain Ulster County clients' increased tendency to travel to Albany is that the Mid-Hudson Care Center, a major provider in Ulster County, is a clinic within the Albany Medical Center system, and many of the Mid-Hudson Care Center patients are referred to Albany for care.



Another surprising trend is that a larger percentage of unique Orange County clients traveled to New York County (Manhattan) and the Bronx than to Westchester, whereas the opposite was true for clients of the other three MHR counties. This is not explained by travel time, although it could be explained by travel route, in terms of where clients prefer to cross the Hudson River. The reduced tendency for Orange County Medicaid clients to go to Westchester would be an interesting topic to explore through future qualitative investigation.

As when looking at travel to providers within the MHR, these data also indicate that many MHR clients visited multiple counties across NYS. There were a total of 4,011 unique clients in the MHR *when unduplicated by NYS provider county*, compared to 1,481 unique clients when unduplicated by MHR provider county and 904 unique clients when unduplicated across the entire MHR. This means that the average MHR HIV positive Medicaid client went to providers in 4.44 NYS counties ( $4,011 \div 904 = 4.44$ ) for care and services in FY2009. This value appears very high for an average rate and could be inflated by the data limitations discussed earlier: the county where the service was provided is not always the same as the county where the claim was filed and these practices often vary within and between providers. For instance, client Jane could always go to the same site of Provider B in Dutchess County, but Provider B might have sites in five other counties across NYS and, although Jane is always physically seen in Dutchess County, her claims may be filed through the sites in different counties over the course of the year, making it appear that she had traveled to more counties than she actually had.

Nevertheless, comparing the values for average counties per client for each MHR county reveals that Ulster County clients have the highest value (average of 4.9 NYS counties per client) and Sullivan County clients have the lowest values (average of 4.2 NYS counties per client). As any data inflation due to claim filing should inflate all county values equally, this suggests that Ulster County clients have a slightly higher tendency to travel to multiple counties for care and services and Sullivan County clients have a slightly lower tendency. This could be because of the prevalence of private transportation, access to main travel routes, or several other factors.

2. Travel for Care, Provider Perspective: Who comes to MHR providers for care?

The following discussion of travel for care from the provider perspective is based on the number of unique Medicaid clients from across NYS *unduplicated by MHR provider*. Whereas the analysis from the consumer perspective limited data to just MHR clients but looked at all provider counties in NYS, this analysis looked at all clients in NYS but limited data to just MHR providers. An important caveat is that unlike the analysis from the consumer perspective above, these data are not unduplicated by provider county, but by individual providers.

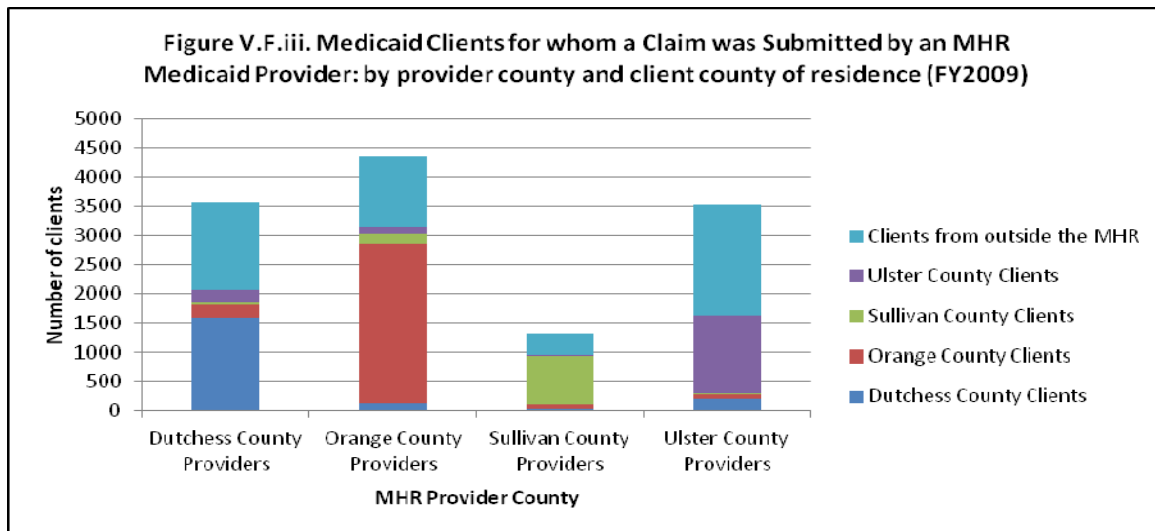
In FY2009, there were a total of 12,768 NYS clients, unduplicated by provider, for whom a claim was filed by a MHR provider. Of those 12,768 NYS clients, 7,821 or 61% were from the MHR. For the MHR clients:

- 27% had a claim filed on their behalf by a Dutchess County provider
- 40% had a claim filed on their behalf by an Orange County provider
- 12% had a claim filed on their behalf by a Sullivan County provider
- 21% had a claim filed on their behalf by an Ulster County provider

These values reflect the relative draw of MHR Medicaid providers among MHR Medicaid clients.

The proportion of NYS clients who had claims filed on their behalf by Dutchess County and Sullivan County clients is comparable to the MHR client data (28% and 10%, respectively), but only 34% of NYS clients had a claim filed on their behalf by an Orange County provider and 28% had a claim filed on their behalf by an Ulster County Provider. This reflects an increased draw of Ulster County Medicaid providers among Medicaid clients outside of the MHR and a decreased draw of Orange County Medicaid providers among clients outside of the immediate region. In fact, Ulster County is the only county in the MHR for which the number of claims submitted by Medicaid providers for clients outside of the MHR exceeds the number of claims submitted by Medicaid providers for clients inside the home-county. As noted above, this out-of-region draw of Ulster County providers could explain why clients at AIRS facilities in Ulster County appear to be relatively wealthy although the county itself is relatively poor.

The out-of-region draw of Ulster County providers can be seen visually in Figure V.F.iii in the larger than average size of the turquoise bar (clients from outside the MHR region) among Ulster County providers. This figure also shows how Orange County providers submitted the greatest number of claims but the vast majority of these were for clients within Orange County (red bar).



## **VI. Major Themes regarding Quality of Care and Quality of Life**

The following section discusses the issues regarding quality of care and quality of life for PLWHA in the MHR that emerged most frequently over the course of the interviews and focus groups. The topics discussed here apply generally to care and services or life in the MHR as perceived by consumers; issues that apply specifically to primary care or a particular type of non-clinical care or service are discussed when relevant in Sections VII and VIII. This list is not comprehensive nor are there firm boundaries between topics. The themes are offered as a way to group related issues and guide discussion.

### **A. Geographic location and comparisons to other regions**

Consumers and providers often made comparisons to other regions of New York when discussing the quality of HIV/AIDS care and services. They noted how other regions of the state face similar problems, particularly areas away from urban centers (Consumer 17, Orange; AI Members 2, 12, 11 & 21). These common challenges, such as limited provider options, difficulty with transportation, persistent stigma and discrimination and lack of anonymity, are discussed throughout this section and in those that follow. Many consumers also expressed gratitude or relief, believing that the care they were receiving in the MHR was better than in many other places in NYS or the United States: “we have it better than most places no matter what happens...we have it really good here, actually, we really do compared to some other big cities, you know, excluding the major [metropolitan areas]”(Consumer 4, Dutchess).

That final clause excluding major metropolitan areas, however, reflects what appeared to be a common underlying understanding: although there is quality care available in the MHR, it’s not as good as what you could find ninety miles to the north or south, in NYC or Albany. One expression of this sentiment was that consumers boasted when their clinical care provider was affiliated with a larger medical institution outside of the MHR, such as the Designated AIDS Center in Albany, or was trained in New York City (Consumers 11 & 15, Dutchess). Another demonstration was the extensive travel of MHR residents to other counties for care (see Section V.F).

Consumers who were prior residents of NYC or other areas in the nation often made explicit regional comparisons. For instance, one long-time resident of NYC and national AIDS advocate stated that “the Hudson valley is absolutely \*\*\*\*ing horrible to people with HIV” and comparable to rural Mississippi, “which is really sad”(Consumer 28, Orange). Another consumer explained how the environment of where one receives services has a significant impact on the quality of care, with the MHR comparing unfavorably:

Look where you going...You have to think about the environment. The environment plays a lot, you know, behind [what the quality of] the services are. Because in New York City, I lived in the city, and I got the best services...until I moved to the Bronx. And then I went to [a different agency]--okay. And then I went to [yet another agency] when I came to Monticello...This is the lousiest care I have ever seen. (Consumer 19, Orange)

In this consumer’s eyes, as one moves away from the center of NYC, the quality of care steadily decreases. Even the consumers who felt their current care was superb often spoke of harrowing earlier experiences in the MHR or how care elsewhere was significantly better.

Another frequent geographic comparison was between the MHR and the lower Hudson region (LHR), which is the area between the MHR and NYC and consists of Westchester, Putnam and Rockland Counties. Compared to the MHR, the LHR is a smaller geographic area and has considerably more PLWHA, such that the LHR receives Ryan White Part A funding, whereas the MHR does not. This means



that the LHR counties have significantly more financial resources and a more centralized administration of those funds for HIV/AIDS care and services.

The comparisons between the MHR and the LHR were made particularly prominent in 2008 when both Hudson regions were brought together within one Ryan White Part B Network. Several providers proposed that this union increased the dissatisfaction of MHR consumers because, against the LHR backdrop, the MHR consumers saw the type and volume of services that their counties lacked (Provider 1, multiple counties; AI Members 4-6). One provider described how the joining of the networks helped to encourage a combat mentality among consumers in the MHR: during network meetings, the LHR consumers would describe what services they had available, the MHR consumers who did not have that service would become upset with the disparity, and the LHR consumers would counsel them to fight louder and harder to get what they deserved, with neither group of consumers fully appreciating the significantly smaller financial resources available in the MHR (Provider 1, multiple counties). Not only did this dynamic increase the frustration among MHR consumers, it also led to an “us vs. them” culture developing between the two regions, which ran against the goals and undermined some of the benefits of the network.

Many providers and members of the AIDS Institute agreed that the MHR’s unique geographic and cultural position—being close enough to know what it doesn’t have—may be a critical component to understand perceptions of the quality of care and quality of life in the region (Provider 1, multiple counties; AI Members 17, 22 & 23).

## **B. Feeling overwhelmed, exhausted and frustrated**

Consumers frequently described feeling overwhelmed and exhausted. As one consumer explained regarding a housing crisis:

I’m drained, mama ...I in the fear that if I say anything, she’ll say, ‘well, pack up your sh\*\* and go.’ Where am I going to go, mama? Look, it’s snowing out there. I’m 58. I’m dealing with HIV. I’m dealing with mental issues, you know, and I just can’t do it, you know? And then I eat a lot of sh\*\*. And it’s a big pill to swallow, but I’ve been swallowing it. So I’m swallowing my pride and swallowing everything else with it.

And that’s all stressing me the he\*\* out. And it’s like, overburdened, you know. (Consumer 31, Orange)

Other consumers echoed those emotions; several individuals spoke about feeling powerless and isolated, and one man explained that he was barely hanging on (Consumers 11-15, Dutchess; Consumer 10, Dutchess; Consumer 16, Dutchess).

Some of this exhaustion appeared to be from many years of fighting for the cause. One consumer explained the experience as: “you do with what you have, with what you’ve got. Because you are too tired to fight anymore. I know for me, I’m just moving on”(Consumer 4, Dutchess). Another consumer who had been involved in HIV/AIDS advocacy for many years stated, “I am still very frustrated and overwhelmed...Everything that we fought for as PWAs, you know, 15 years ago, we’re getting. But for me, it’s so overwhelming right now”(Consumer 28, Orange). A third consumer remarked on the years of life spent waiting – waiting for help, waiting for services, waiting for change; “I have done so much waiting that it’s pathetic, but I get used to it”(Consumer 18, Orange).

While feeling overwhelmed and exhausted, many consumers also reported feeling frustrated at the system and at the lack of progress. The consumer quoted above regarding the housing crisis also described feeling like she was being “run-around”, that everything she tries to do, “it bites me in the a\*\*”, and not knowing how much more she could take (Consumer 31, Orange). One provider explained

that for many consumers, “The world just gets so, so, so small and nothing is reflected back to you except, um, frustration”(Provider 29, Orange).

### **C. Confidentiality, stigma and discrimination**

Fears of broken confidentiality were prominent for many consumers interviewed for this project and several providers identified confidentiality as a major issue for their clientele (Consumer 30, Orange; Providers 2-6, multiple counties; Provider 28, Dutchess; Provider 31, Orange; DOH Official 31). Providers explained that the small communities in the MHR exacerbate fears of broken confidentiality. For example, many consumers recognize the receptionist at the health center or know the other people waiting in line at the pharmacy (Provider 31, Orange); “Even if everything is kept confidential, it’s still uncomfortable for somebody to come in who is HIV positive and run into their neighbor” (DOH Official 31). Providers also explained that wait-times at medical care centers make recognizing someone more likely and thus tend to increase consumers’ fears and frustrations (Providers 2-6, multiple counties). Other providers speculated that the confidentiality concerns might lead some consumers to travel out of the area for care and may be behind some of the complaints regarding insufficient provider choices (see Section VII.A.3).

Confidentiality was a major concern for many consumers because of the stigma and discrimination still associated with HIV/AIDS. Consumers frequently spoke about the continued stigma and ignorance within their communities and the lack of public discourse (Consumers 17 & 19, Orange). One consumer explained that, “30 years after the fact, there is still people who say, ‘She’s sick. You can’t drink behind her’, you know what I’m saying? So those stigmas still arise”(Consumer 17, Orange). Consumers described how the stigma and discrimination persists to some extent even among medical providers (see Section VII.C.1) and among transportation providers (Consumer 18, Orange; Consumer 40, Ulster).

Consumers and providers gave several examples of how fear of stigma and broken confidentiality has negative impacts on consumers’ health and access to services. One provider pointed out that this fear and internalized stigma drive many people into isolation:

The stigma is what kills. And people isolate. People can’t forgive themselves. They are afraid of reaching out. I have had so many people who have said that this is the first place they ever talked about the disease. They’ve talked about the medicines, and they’ve talked about their mental health issues, but they have never talked about what it meant to live with the virus. (Provider 29, Orange)

More commonly, fear of broken confidentiality and the ensuing stigma caused consumers to avoid services and led to issues regarding signage and well-advertised programs. For instance, one woman explained that she would not go to a meeting if she had “to walk past everyone to get there” and objected to meetings that are “loudly” publicized, such as with signs in public places (Consumer 32, Sullivan). Another man described how people will not come to groups if they recognize other consumers there because, “[i]n this area, everybody tries to keep quiet”(Consumer 8, Dutchess). A third consumer agreed that agencies need to pick locations for groups that are more private and therefore more “safe” if they want people to come (Consumer 6, Dutchess).

Providers and consumers also described issues with the names of agencies or programs: if it had HIV or AIDS in its name, consumers were reluctant to go there. This was true for the name of the Infectious Disease department within a health center (Provider 30, Orange) and the ARCS (AIDS-Related Community Services) sign outside of its building. One consumer who used ARCS services explained his reaction to seeing a new, large ARCS sign as follows: “You look on the sign, you’ll see it, right? Straight out. Its AIDS...It was right outside where you can see it! And I’m telling you, everyone was so upset

about that. I was too. I wouldn't lie. I was very upset about that"(Consumer 38, Sullivan). Consumers also were reluctant to use the ARCS transportation service, even though it was free of charge, because they felt that everyone in their community knew they were getting into an "HIV cab"(Providers 2-6, multiple counties). Similarly, the manager of one residence for PLWHA explained that they were having trouble filling spots because the residence had become known as the "AIDS" house (Provider 29, Orange). The fear of broken confidentiality and subsequent stigma and discrimination thus is so strong that consumers walk away from some of the services they report needing most.

#### **D. Longing for compassion and respect from providers**

A common theme regarding clinical care and case management services was that consumers long for a loving, family-like environment. Several consumers explained that they were satisfied with their care and services because of the nurturing, supportive atmosphere. As one woman stated, "I think this is the best [agency] anywhere... I wouldn't change this for anything in the world...[because of the] support that they give...listening, care and concern that they have for us clients...overall genuine concern they have for people infected with the virus"(Consumer 37, Sullivan). Others explained that the support group and case managers were like a family (Consumers 32 & 37, Sullivan), and that they had found a good doctor who was also a friend and showed concern and compassion for all aspects of their lives (Consumer 44 & 44, Ulster; Consumer 23, Orange).

On the other hand, multiple consumers expressed frustration with the lack of compassion from providers and explained that this was a worsening problem over recent years. One woman stated that, "I find [that agency] to be uncaring, unloving, you know what I mean? When I first started at [that agency], everyone was loving and caring. They would listen to you. I don't find that to be like that no more. I think there's a lot of cold people"(Consumer 27, Orange). Another consumer reflected during a focus group that, "when I was diagnosed, the big difference is there were people there for me. It was totally different then. These newcomers that are coming in now, where, there's not.... You got to know that people care, you know, and it's hard to know that people care when, like you said, nobody, they give you the attitude that they don't want to help you when you are just trying to get your basic needs met"(Consumer 4, Dutchess). Many consumers wished that staff would be more compassionate (Consumer 31, Orange; Provider 1, multiple counties); one woman believed that the thing that would make care better in the region is, "Better people. Better understanding. That's what it really is"(Consumer 30, Orange).

Other consumers described a lack of compassion and respect that was manifested in provider indifference, unhelpfulness, or focus on financial gain instead of consumer wellbeing. For instance, one consumer felt that providers did not value consumer opinions or appreciate the meaning of patient centered care:

You could be talking, they could be writing, but you don't know whether or not they are really hearing what you are saying...becomes apparent that maybe they just don't think it is serious enough to address...There was so much bureaucratic stuff going on, the care was just being overshadowed...They don't seem to hear those words, 'client centered'. (Consumer 17, Orange).

Several others argued that providers are lazy, unwilling to do anything beyond write prescriptions, or only help when you are at death's door (Consumer 17, Orange; Consumer 14, Dutchess). Many consumers described a culture of unhelpfulness specifically within the Department of Social Services (Consumers 4 & 5, Dutchess), where, "they are not out to help you. Their purpose is to deny you if they can"(Consumer 3, Dutchess). Other individuals argued that providers were only interested in their paycheck and getting more money out of patients (Consumer 31, Orange; Provider 27, Dutchess). One

consumer felt that, “it’s not consumer and provider compatible anymore, you know. It’s more about financial thing, as far as I’m concerned”(Consumer 29, Orange).

## E. Reactions to diminished funds

Over the course of the year, there was substantial discussion among consumers and providers about diminishing funds. Several individuals explained how the funding reductions need to be understood within a new fiscal environment, a new national health care strategy, and a new approach to treating HIV/AIDS as a chronic disease (AI Members 4-6, 20 & 21; Provider 23, Orange). One member of the AIDS Institute described the situation as follows:

We created this system that, from today’s perspective, is duplicative, it has too many services that no other condition has, and part of the mainstreaming is bringing this disease back into the realm of other conditions. So, it’s an adjustment... We created dependency on many services. And those services are going to be going away...because the fiscal environment has changed, in addition to all the changes that I have mentioned to you about HIV as a disease. So this is part of big changes taking place in the country and big changes taking place in the concept of what HIV disease is. (AI Member 20)

Many other providers and consumers raised these issues of dependency, mainstreaming and entitlement throughout the interviews (Consumer 2, 4 & 10, Dutchess; Consumer 19 & 28, Orange; Provider 23, Orange; Provider 20, multiple counties).

MHR consumers had a variety of responses to the diminished funds, but three reactions emerged most frequently, although in different ways and different combinations. The first common reaction was pleading that those in power continue to help the PLWHA community. For instance, one consumer explained that he would say the following to chambers of congress:

See like they getting ready to cut one program, right, so what you going to do to replace that program? I mean, you won’t feel the repercussions, but we will. We will feel it. We will just give up on life. I mean, it’s a beautiful thing that you are helping, but don’t stop helping, you know. If it was a cure for it, I could understand you stopping. But it’s no cure. (Consumer 18, Orange)

Other consumers emphasized how the PLWHA community is still in need and many people’s lives rely on continued support (Consumers 35 & 37, Sullivan).

The second common reaction was fear and anger that additional services could vanish without warning. Within this fear, one consumer expressed feeling trapped, explaining that, “the worst thing you can do to a person is back them up into a corner and put fear in their hearts. And the reason why you are afraid, it’s not because you are afraid of them, don’t get me wrong. You are afraid because you don’t want to lose what you got”(Consumer 31, Orange). Other consumers spoke about their fear that the transportation program would be terminated (Provider 29, Orange) or housing wouldn’t get recertified (Consumer 16, Dutchess), and not knowing how they would be able to recover. The feeling that programs could disappear with no warning prompted anger and resentment in others. One consumer described and then acted out the dismissive nature in which he felt programs and people were thrown aside:

For them to cut stuff like that, its ridiculous. They don’t give you no reason, they just do, do what they want to do...And that’s what I’m talking about how [that agency] just *(slashing sound)* cuts stuff and it’s A-okay with them. But it’s not A-okay with me and it’s not A-okay with some other people either...I’m going to be her case manager. *(Picks up imaginary phone)* “Hi XX. I’m sorry, we’ve got to cut you off. Bye.” *(Slams down phone)* You know, no “We’re going to give you a chance to save up.” No, “Oh, we are going to do this, do this.” None of that...You are going to put me on a list that you are going to chop me?! Forewarn me! (Consumer 29, Orange)

The third common reaction was that in the face of this fear and anger regarding diminished funds, some consumers felt re-energized for advocacy and community mobilization. Consumers argued that more people needed to speak truth to power, borrowing the language and the grass-roots approach of early HIV/AIDS advocacy (Consumers 1 & 2, Dutchess). Similarly, community mobilization and grass-roots advocacy were the main topics raised at the final Hudson Valley Ryan White Part B Network Meeting in October 2010, with consumers agreeing that “anything we want we have to do by ourselves.”

This re-energizing the face of diminished funds and the dissolution of the Ryan White Part B Networks led to the creation of the Hudson Valley HIV Community Network. This volunteer group began meeting in January 2011 and includes consumers and providers from the lower-Hudson and MHR counties. Its main goals are fostering community, increasing awareness, sharing information, initiating legislative action, and promoting consumer empowerment. The importance of community and the value of the Ryan White Part B Network are discussed more in the section that follows.

## **F. Insufficient opportunities to connect**

Many individuals in the MHR spoke about the need for community among PLWHA (Consumers 3-8, Dutchess). As one provider explained:

The HIV community needs its community. And places that support community are really paramount. If you are given the HIV diagnosis, you retreat, you know, real fast and real far. I don't care who you are, where, when, how. If you, you will die faster with a cancer diagnosis, but you know who to call on when there is a cancer diagnosis. In this case, you know, there is nobody to turn to. And, turning to a doctor who says, here's another HIV positive. Turning to the social worker who says, here's another HIV positive, turning to, you know, a minister, who says, oh my god, another positive. It's old news to us, so we don't respect the incredible tsunami of emotional feelings of people...Within the community of people with the virus, it's the only safe place where there is a level of understanding.... Where people living with the virus come together. It's the only place where there can be hope for some kind of integrity of conversation, some kind of respectful care and relief. (Provider 29, Orange)

Consumers across the MHR explained that PLWHA need an outlet, a chance to hear other people's stories, and a space to vent their own stress and frustration and fight against the tendency to isolate (Consumer 18, Orange; Consumers 10 & 16, Dutchess).

Consumers frequently wished for more support groups to provide such an outlet, with some identifying more support groups as the number one thing that they would change about care and services in the region (Consumers 18 & 31, Orange; Consumers 7 & 9, Dutchess). They discussed how such support groups would be a chance to talk to someone else who understands what it means to live with HIV/AIDS and is knowledgeable about care and treatment. The support groups also could be a forum for additional education and training. One consumer who lived in a group housing complex explained that,

If I had the power, I would ask for more, like, residence like this. That would be for one. For two, would be, for like, where that people can, like, actually go to group and get some kind of help there in group where that you can talk about anything you wanted to. Sex. Crime. Taking your medicine. Being your own, what we just learned, being your own advocate. How to talk to doctors. You know, how to read your blood work. (Consumer 24, Orange)

In addition to wishing for more support groups, consumers vowed that if such support groups were available, they would attend all the time and that such attendance would help improve their overall behavior. One consumer stated that he would be there, “every day, every meeting” (Consumer 18, Orange). Another explained that, “We could come here all the time. And to me, really and honestly, I think it would cut off a lot of the bullsh\*\* that we do, if we had places really to go to” (Consumer 29, Orange).

Despite the longing for more support groups and promises to attend, however, consumers and providers acknowledged that it was hard to maintain attendance at existing support groups and community events (Consumer 2 & 3-8, Dutchess; Provider 7, Ulster; Providers 5, 13, 17, 18 & 36). Some factors behind this difficulty are the challenge of living in a low-density area, transportation difficulties, especially in winter, and consumer resistance to well-advertised or visible programs, as discussed in Section VI.C. These challenges are not insurmountable, but the difficulty of getting consumers to attend existing support groups does temper the call for more.

Nevertheless, the loss of the Ryan White Part B Networks was felt particularly strongly in light of the expressed need for community and desire for more opportunities to connect. The interviews for this project were started before the Ryan White Part B Networks were terminated and continued long enough beyond that date to witness the emergence of the Hudson Valley HIV Community Network, discussed above. Being in this critical time of transition led to many conversations about what the Part B Network offered, compared to other community or support group settings. Numerous consumers explained that the Part B Network brought people together from different regions (Consumer 2, Dutchess), which helped them to realize the number of people involved in the HIV/AIDS community and provided a safer environment for individuals who felt uncomfortable being openly HIV positive in their home county (Provider 17, Sullivan). One provider felt that the Part B Network also helped consumers develop more macro-thinking and to begin seeing things in terms of “we” not “I” (Provider 24, Orange). Other providers argued that the Part B Network may have fostered a “have” vs. “have-not” mentality between the MHR and LHR, as discussed in Section VI.A. Some also felt that the Part B Network did not fulfill its potential because it lacked the firm facilitation needed to guide a group of consumers and providers through productive collaboration (Provider 23, Orange; Provider 20, multiple counties).

Consumers and providers agreed, however, that the Part B Network helped all community members learn about what was happening in other counties and provided an opportunity for consumer education and empowerment (Consumer 16, Dutchess; Consumers 19-26, Orange). Consumers often described the importance of learning to be their own advocate, that it works if you work it” (Consumer 34, Sullivan), and people need to “talk up” to get the care and assistance they deserve (Consumer 32, Sullivan; Consumers 4 & 11, Dutchess). They also expressed deep appreciation for the empowerment and education programs, often sponsored through the Ryan White Network, that helped them develop these skills. One woman explained that she “was blessed” to go to a consumer empowerment training and recounted the ways that it had helped her improve her medical care (Consumer 16, Dutchess). Another explained that the Ryan White Network “was a tremendous asset because they sponsored workshops...These workshops help us to be informed”(Consumer 19, Orange).

The themes above, including community, support groups, consumer empowerment, compassion and information sharing, are discussed more throughout subsequent sections and in Section IX.B. Opportunities for Improvement.

## VII. Primary Care

The first part of this section reviews the distribution and volume of primary care providers for PLWHA in the MHR. This includes both general primary care and HIV specific primary care. The second part focuses on the quality of HIV primary care by examining the region’s mean performance on HIV quality indicators. The third part presents major themes from qualitative research regarding primary care.

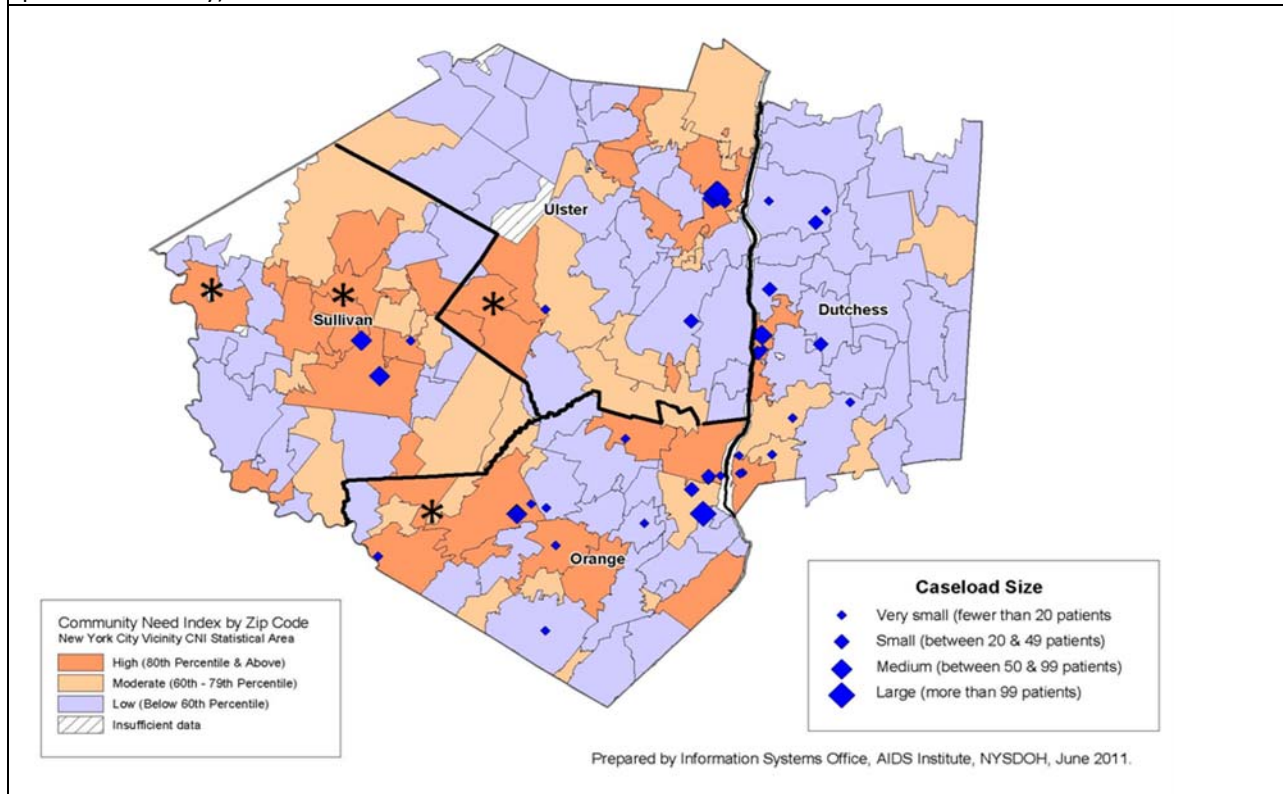
All maps in this and following sections were prepared by the Information Systems Office and are overlaid on the Community Need Index (CNI), 2006 Edition. The CNI was designed as a resource for HIV/AIDS-related need assessments, program planning, and evaluation. It is based on a composite measure determined from scores on nine health indicators that incorporate multiple sources of HIV/AIDS risk: teenage pregnancy, cocaine hospital discharges, opioid hospital discharges, sexually transmitted diseases, maternal seroprevalence, male HIV hospital discharges, female HIV hospital discharges, AIDS cases and HIV cases. The CNI then rank-orders zip codes across NYS by the CNI composite score. Zip codes scoring in the 80<sup>th</sup> percentile and above are considered areas of “high” need, zip codes in the 60<sup>th</sup> to 79<sup>th</sup> percentile are considered areas of “moderate” need, and zip codes below the 60<sup>th</sup> percentile are considered areas of “low” need.

### A. Distribution and volume of providers

#### 1. ARV prescribers (Medicaid & ADAP 2009)

Below is a map of ARV prescribers from Medicaid and ADAP (AIDS Drug Assistance Program) data sources for 2009. It includes all prescribers that had two or more patients during the year.

Figure VII.A.i. ARV prescribers (Medicaid & ADAP) in the MHR in 2009 ( \* represent area of high need & low prescriber density)



In 2009, there were a total of 57 ARV prescribers in the MHR, with the greatest number of prescribers in Orange County (n=25) and the smallest number prescribers in Sullivan County (n=5). As summarized in Table VII.A.ii, of the 57 prescribers, 39 or 68% were “low volume providers” with between 2 and 20 unique patients, and only 2 prescribers had more than 100 patients – one in Orange County and one in Ulster County.

Caseload Size	Number of ARV Prescribers (Percent of all prescribers)
2-19 patients	39 (68%)
20 to 49 patients	10 (18%)
50 to 99 patients	6 (11%)
More than 99 patients	2 (4%)

This and subsequent maps show the concentration of prescribers in certain metropolitan areas and, conversely, the absence of prescribers for larger, more remote areas of each county. The clustering of providers in zip codes of high need in each county refer to (clockwise):

- Poughkeepsie and Beacon in Dutchess County, where 56% of Dutchess County unique HIV positive Medicaid patients resided in FY2009
- Newburgh and Middletown in Orange County, where 60% of Orange County unique HIV positive Medicaid patients resided in FY2009
- Monticello and Harris in Sullivan County, where 52% of Sullivan County unique HIV positive Medicaid patients resided in FY2009
- Kingston in Ulster County, where 40% of Ulster County unique HIV positive Medicaid patients resided in FY2009

This clustering is repeated to some degree for all types of care and services, as shown by the maps in this section and in Section VIII. Non-Clinical Care & Supportive Services. Prominent areas of concern, given their high need status according to the CNI and low concentration of prescribers, are the southwest corner of Ulster County, central Sullivan County, the western edge of Sullivan County, and northwest Orange County. Each area is marked with an asterisk.

## 2. AIRS facilities (2009)

As noted above, the same clustering of ARV prescribers is evident among MHR AIRS facilities that provided primary care in 2009 (see Figure VII.A.iii). The greatest number of agencies reporting data to AIRS offering primary care and the largest number of clients were in Dutchess County, which had eight providers and saw 36% of total clients in the MHR (N=878). The remaining agencies and clients were fairly evenly distributed across Orange, Sullivan and Ulster counties. This is in contrast to the distribution of ARV prescribers, which were most prevalent in Orange County.

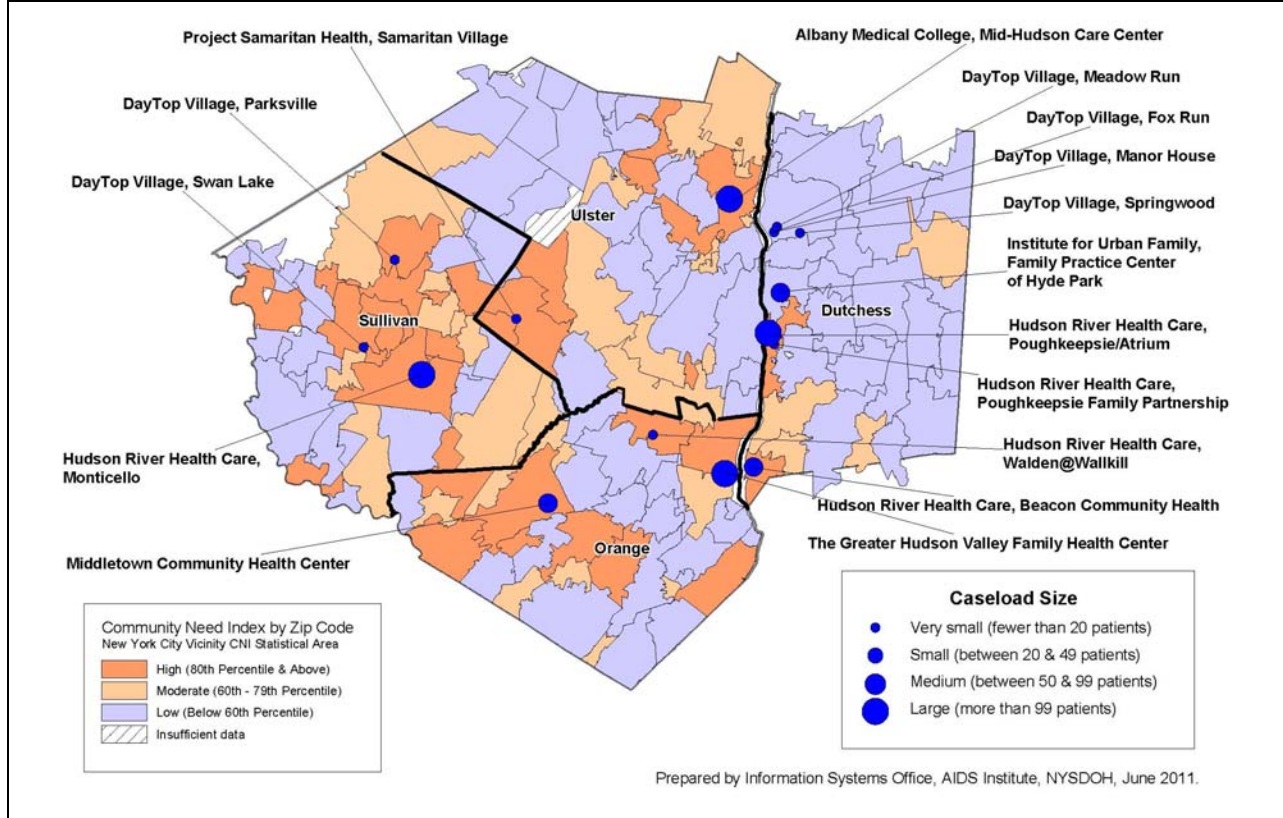
Clients in Table VII.A.iv. and clients as counted for the map above refer to unique clients who received some type of primary care – HIV care or general primary care—at each site. Total clients, as described in Section V.B., are unduplicated by site and service category. Because there are three different service categories pertaining to

County	Number of AIRS facilities	Total Clients (Percent of Total MHR Clients)
Dutchess	8	318 (36%)
Orange	3	195 (22%)
Sullivan	3	176 (20%)
Ulster	2	189 (21%)



primary care (Primary Care, Primary Medical Care 5 Tier, and Primary Medical Care 7 Tier), total clients receiving primary care services in 2009 at MHR AIRS facilities (N=1,322) is a higher value than unique clients that received some type of primary care (N=878).

Figure VII.A.iii. AIRS sites in the MHR offering primary care services (2009)



From 2009 to 2010, the number of total clients receiving primary care services at AIRS facilities in the MHR was fairly stable, with only a slight decrease of 5%. The number of total visits decreased by 40%, but this appears to be due to a change in reporting requirements in 2010. In 2009, AIRS providers were required to record all primary care visits in the AIRS system, but in 2010, they were only required to list up to two visits in the calendar year. Still, combining data for 2009 and 2010 data, the clients of primary care services in the MHR average 4.1 visits per year, a high level that indicates retention in care, if not some overutilization of services. Data from HIVQUAL (2009), however, suggests the opposite, as discussed below.

### 3. Consumer concern: not enough choices

A frequent concern raised by consumers was that there are not enough choices among providers. As one Dutchess County consumer stated, “there [are] really no choices. That’s the whole thing. There are no choices in some of these counties. I know Orange and Ulster counties have the same issues”(Consumer 2, Dutchess). Consistent with his assessment, another Orange County consumer explained that the main obstacle with respect to clinical care was not quality, but lack of options (Consumer 17, Orange). An Orange County provider echoed this perception, indicating that many consumers with whom she works want to change providers, but have nowhere to go (Provider 29, Orange). Finally, an official within the Orange County Department of Health stated that the main

complaint that the office hears from consumers is that they only have two real choices for HIV care, unless they have private insurance (DOH Official 29, Orange).

Consumers across the region discussed the importance having a choice and being able to find a primary care provider with whom they felt comfortable. They identified this as something that all people deserve and that it was critical for each person to find the right fit for him or herself (Consumers 2 and 4, Dutchess). One Sullivan County support group collectively coached a member on how, if she didn't feel like her doctor was spending enough time with her, then it was: "Time to get a new doctor" (Consumer 32, Sullivan). They talked at length about the importance of finding someone that works for you, that fits your personal preferences. This desire to visit a preferred doctor, however, bumps against the physical limitation of how many providers are available.

Providers, officials in the County Departments of Health and members of the AIDS Institute proposed three main factors behind the limited choices in the region. The first is the reality of the MHR being a less densely populated region where there are not enough patients to fiscally justify additional provider agencies or creating a major clinical site (AI Member 20; AI Member 21; DOH Official 29, Orange). It is more efficient to increase the capacity of current providers in response to increased need, and the MHR currently has sufficient providers to care for the PLWHA in the region. This reality of limited choices is true for all medical conditions in less densely populated regions and thus affects millions of people in upstate New York and across the United States.

The second major factor also is linked to geography and location and is a shared problem for many areas in upstate New York: more rural or distant regions tend to be less attractive locations for clinicians to establish a practice because they tend to have lower paying salaries and typically are farther away from the luxuries or lifestyles that the clinicians desire (AI Member 21; AI Member 11; Provider 20, Ulster; Provider 5, Sullivan). In this respect, the MHR may be slightly better off than other areas of upstate New York because the MHR is still within commuting distance to NYC. Nevertheless, several MHR providers indicated that they have struggled to attract and retain clinicians because they don't want to settle in the MHR communities or they are offered better paying jobs in metropolitan centers.

A third significant factor is insufficient physicians across NYS and the United States who are interested and experienced in providing HIV care. This is discussed in Section VII.C.1.

One reaction to limited provider choices is a tendency for consumers to "bounce" between providers. This was a term independently used by three providers during interviews for this project. There are many possible reasons for "bouncing" but those that providers identified as most likely are:

- dissatisfaction with care, either due to genuine quality of care issues or because of incompatible personalities or fit between a consumer and a provider agency -- "People, you know, yeah, just get, become dissatisfied with one provider as opposed to another and they move around a lot...they end up skipping around for different reasons. And for some individuals, it's just their own, they are never going to be satisfied. For others, it is, where, you know they are really dissatisfied with a provider and have had legitimate, you know issues with them" (Provider 3, multiple counties);
- consumers seeking pain medication prescriptions (Provider 20, Ulster);
- or "because they want to feel like they have a choice just like everyone else" (DOH Official 29, Orange).

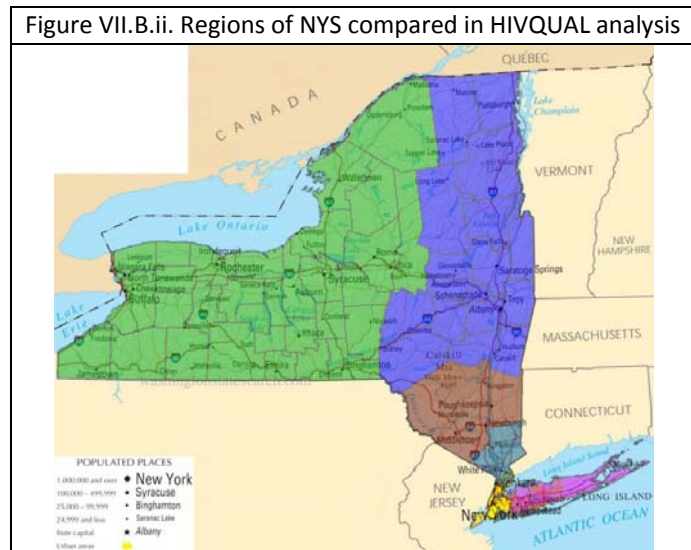
**B. Performance on quality indicators**

The following section describes the performance of the MHR based on performance data submitted through the NYS HIV Quality of Care (HIVQUAL) program in 2009. All programs that participate in the NYS Quality of Care Program and that provide primary care to at least 30 HIV positive patients submitted data through the eHIVQUAL application as part of the NYS program. One of the three major components of the HIVQUAL framework is performance management to shape quality improvement activities. Facilities report data on a set of quality indicators for a sample of eligible patients defined as those who have had a medical visit with an HIV provider with prescribing privileges at least once during each half of the calendar year. Facilities do not report on all patients but instead on a randomized sample large enough to ensure a 90% confidence interval,  $\pm 8\%$ .

The HIVQUAL data submission for NYS in 2009 included 200 clinics and a total of 10,361 patients. The HIVQUAL sample for the MHR in 2009 included 14 clinics and 361 patients. The distribution across the MHR counties is shown in Table VII.B.i.

The mean performance of MHR facilities (MHR mean) is discussed in comparison to the mean performance of NYS facilities (NYS mean) and the mean performance of the following regions of NYS, which are represented as different colors in Figure VII.B.ii: Long Island (pink), New York City (yellow), Lower Hudson (light blue), Northeast New York (purple), and Central and Western New York (green); the MHR appears as brown. The MHR mean was comparable to the NYS mean for conducting viral load and CD4 tests every six months, diabetes screening, colonoscopy screening, vaccinations and PCP prophylaxis. The MHR had mixed performance regarding hypertension screening and management. The MHR performed above the mean compared to NYS and the other regions on all viral load suppression indicators and generally had high rates of gynecological care and STI screenings, with the exception of syphilis screening. Scores on retention, health literacy and tuberculosis screening all were lower than the NYS mean.

County	Clinics	Total Patients (% of MHR Total)
Dutchess	3	74 (20%)
Orange	2	58 (16%)
Sullivan	3	98 (27%)
Ulster	4	131 (36%)

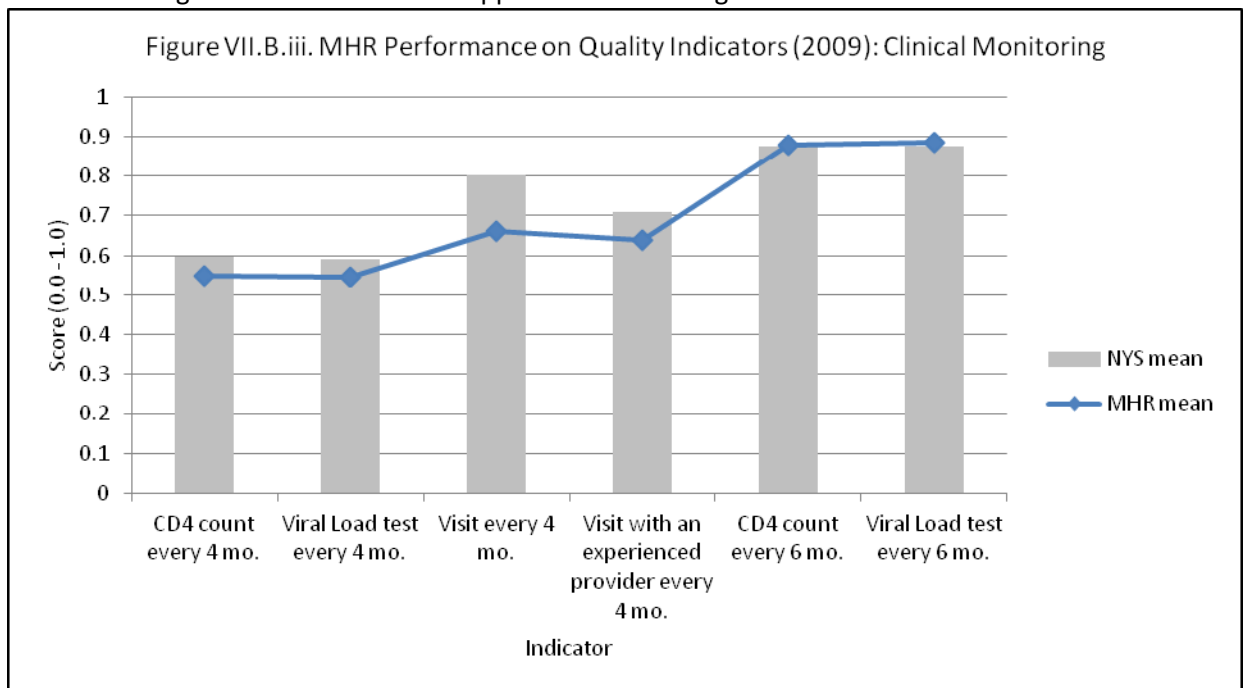


1. Visits & clinical monitoring

The visits and clinical monitoring indicators include:

- The percentage of eligible patients who had a CD4 count during each 4-month and 6-month interval within the review period
- The percentage of eligible patients who had a viral load (VL) test during each 4-month and 6-month interval within the review period
- The percentage of eligible patients who had a visit with an HIV provider with prescribing privileges during each 4-month interval within the review period
- Of those patients who had a visit with an HIV provider during each 4-month interval within the review period, the percentage of these patients who were seen by an HIV experienced provider; HIV experienced providers are those who meet the classification criteria of the American Academy of HIV Medicine, the HIV Medicine Association or Association of Nurses in AIDS Care.

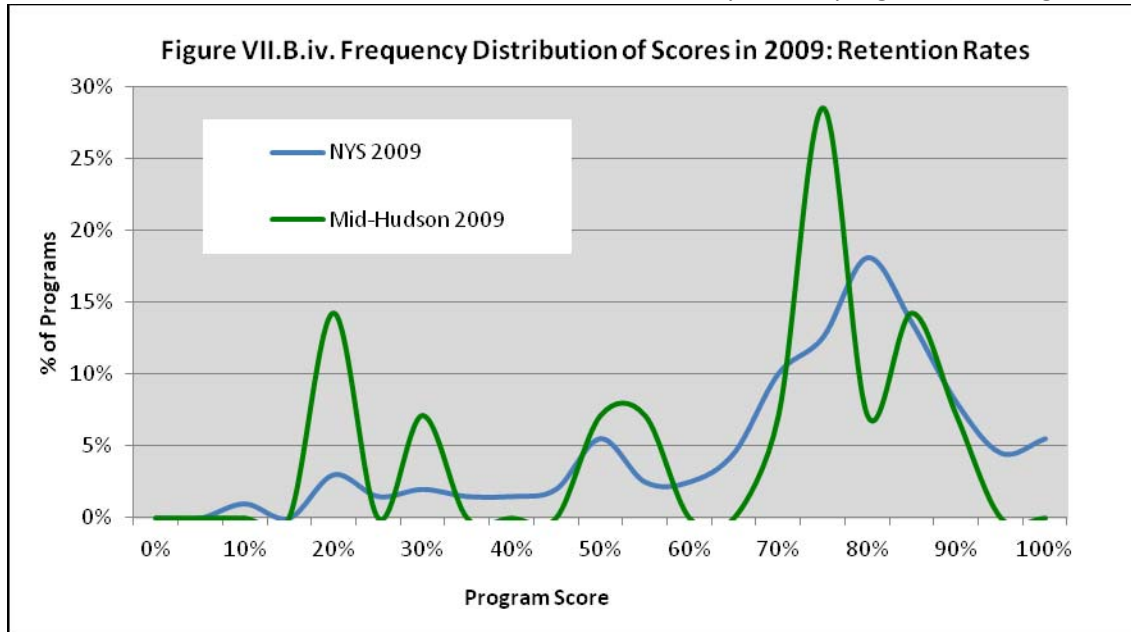
Mean rates for clinical monitoring during each 4-month interval were lower in the MHR than NYS, but mean rates for clinical monitoring during each 6-month interval were comparable or slightly higher in the MHR than NYS. The low scores on the every four months measures may reflect the transportation challenges in the MHR, which make it more difficult for consumers to come in for frequent visits. Given the high level of performance rates of viral load suppression, discussed below, the frequency of visits and monitoring at four months do not appear to be meaningful.



## 2. Retention in care

Retention rates measure the percentage of all patients who had a visit with an HIV provider with prescribing privileges at least once during each half of the calendar year. Note that this is the same definition as for “eligible patients” who then are sampled and reported on for all other HIVQUAL indicators.

Despite the comparable performance on clinical monitoring indicators every six months, the MHR retention rates were lowest among all regions: 61.4% mean retention rate in the MHR compared to 69.8% mean rate statewide. Similarly, the mode retention rate in the MHR (75%, achieved by 29% of sites) was lower than the mode rate in NYS (80%, achieved by 18% of programs) (see Figure VII.B.iv).

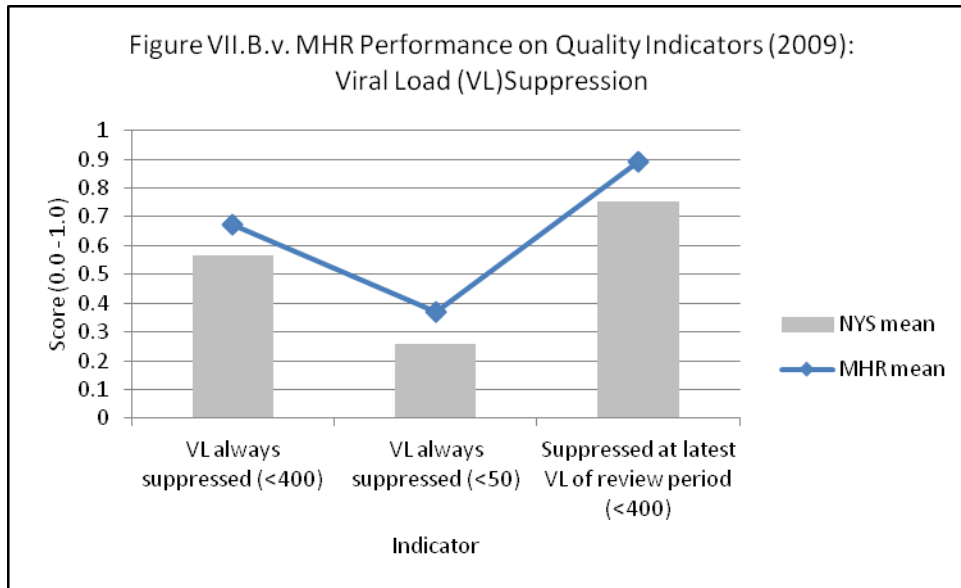


The fact that the MHR retention rates were lowest out of all regions but the MHR performed comparably to the NYS mean on viral load and CD4 testing every six months underscores the fact that the frequency of laboratory values is not a reliable proxy for the frequency of visits. These tend to differ because patients may avoid clinical visits with a provider but will still have their laboratory tests run.

The low retention rate in the MHR could reflect transportation problems that make it difficult for patients to get to care or to get to clinician’s offices in time for their appointments. These transportation issues are discussed in Section VIII.E. Exploring other reasons for retention in care would be an important area for future investigation.

3. Viral load suppression

Viral load suppression rates were higher in the MHR in 2009 than in NYS. Rates in the MHR also were second-highest in the state for assessing the percentage of eligible patients on ARV with at least two viral load tests in the calendar year who’s viral load remained below 400 copies per milliliter throughout the annual review period. Two other viral load suppression indicators included in Figure VII.B.v. refer to the percentage of patients on ARV with at least two viral load tests in the calendar year who were suppressed below 50 copies per milliliter throughout the annual review period, and the percentage of patients on ARV who were suppressed below 400 at the last viral load test of the review period. MHR viral load suppression rates are a positive indication regarding the quality of HIV care in the region and should prompt investigation of care models which grew to be successful in spite of geographic distance and efforts to identify practices that could be disseminated in similar circumstances.



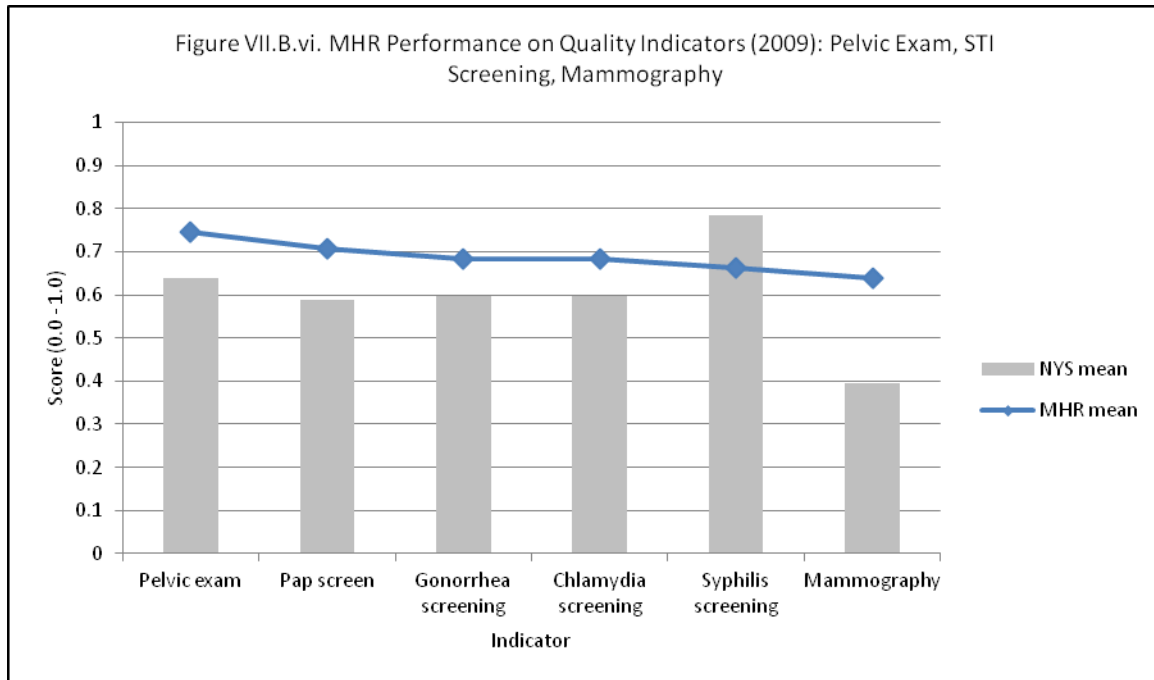
4. Pelvic exam, Pap smear, mammography and STI screening

The rates for pelvic exam, Pap smear and mammography in the MHR were higher than the NYS mean in 2009, with many scores among the highest in the state. The associated indicators assess the following:

- Pelvic exam indicator: the percentage of eligible female patients (females 18 years of age and older and sexually active patients ages 13 to 18) who received a pelvic examination during the review period
- Pap smear indicator: the percentage of eligible female patients with a pelvic examination who received a Pap smear during the review period
- Mammography indicator: the percentage of female patients over 40 years of age who received a mammogram during the review period

Scores in the MHR for gonorrhea and Chlamydia screening indicators were higher than in NYS in 2009. These indicators assess the percentage of eligible female, MSM and MSM/IDU patients who received a gonorrhea or Chlamydia screening test during the review period.

Syphilis screening rates, however, were lowest in the state in 2009. The syphilis screening indicator assesses the percentage of eligible patients who received a serum syphilis screening during the review period. Scores in the MHR for syphilis screening were higher than the NYS mean in 2007 (MHR mean of 88.0%, NYS mean of 83.2%), but the MHR score dropped to a low of 66.3% in 2009. A significant part of that decrease was due to the inclusion of two new clinics in 2009 that had a total of 3 patients and syphilis screening scores of 0. Removing those two clinics brings the MHR mean up to 77.4% for 2009, which is close to the NYS mean of 78.2%, but is still considerably lower than the 2007 score. Exploring why the two newly included clinics had low scores for syphilis screening could be a topic for future investigation and an opportunity for improvement.



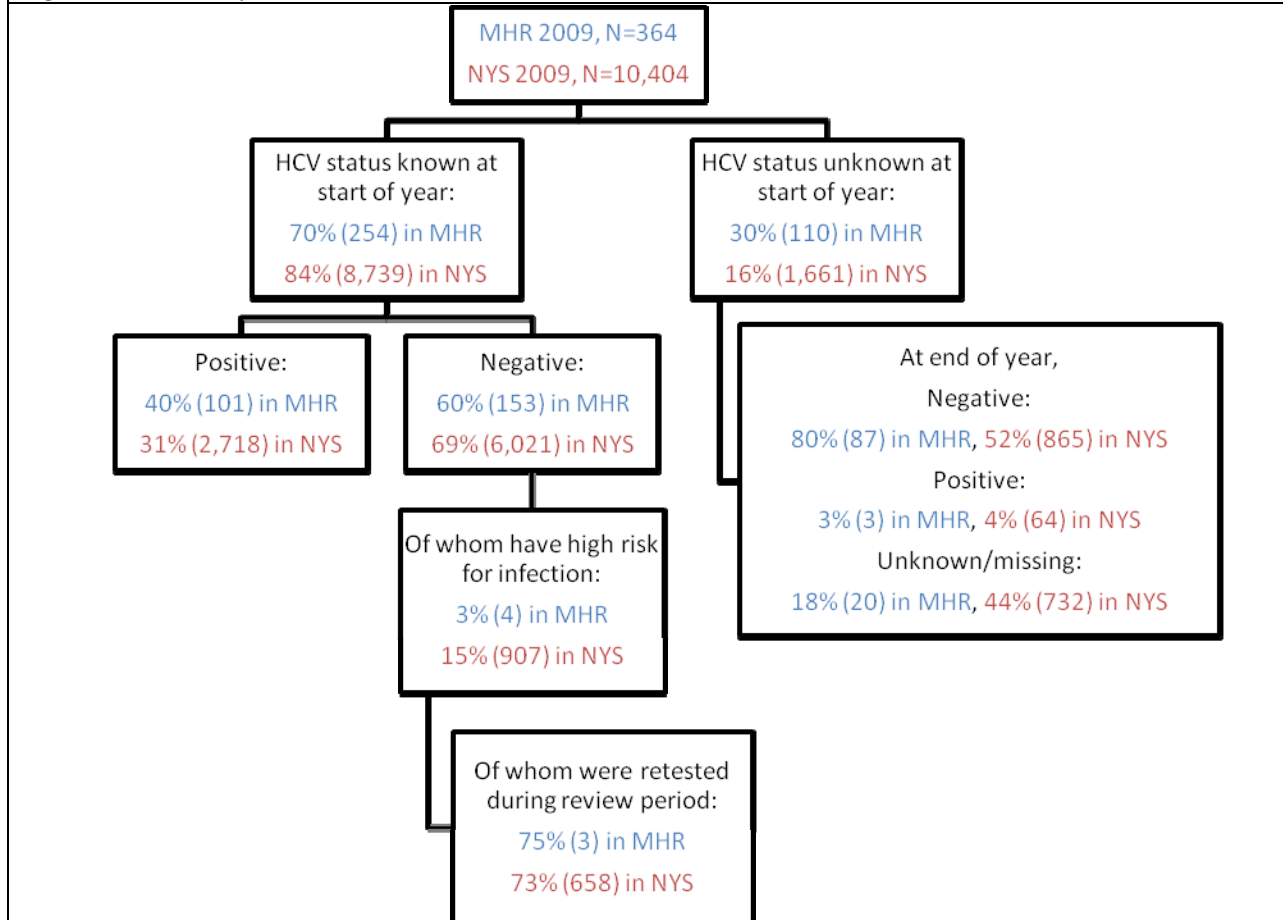
The prevalence of gonorrhea, Chlamydia and syphilis are discussed in Section IV.A.4.



5. Hepatitis C

The Hepatitis C (HCV) measure asks whether HCV status is known if the patient had either: a known positive status at the start of the year; or a known negative status at the start of the year and low risk for infection; or a known negative status at the start of the year, high risk for infection, but was retested during the year; or had an unknown status at the start of the year and had any result, positive or negative, by the end of the year. High risk for infection is classified by active injection drug use, multiple sexual partners, or new abnormal liver function tests. These values are displayed for 2009 for the MHR (blue text) and NYS (red text) in Figure VII.B.vii.

Figure VII.B.vii. Hepatitis C Virus (HCV) status and outcomes in the MHR and NYS (HIVQUAL 2009)



It can be seen that in 2009, compared to NYS, the MHR had:

- a slightly lower percentage of patients with known status at the start of the year;
- a slightly higher percentage of positive status among those with known status at the start of the year;
- of those with negative status at the start of the year, a much lower percentage of patients at high risk for infection;
- of those at high risk for infection, a comparable percentage of patients retested during the review period; and
- of those with unknown status at the start of the year, a much higher percentage of patients with negative status at the end of the year and consequently, a much higher percentage of patients with known status, positive or negative, at the end of the year.



### 6. Diabetes

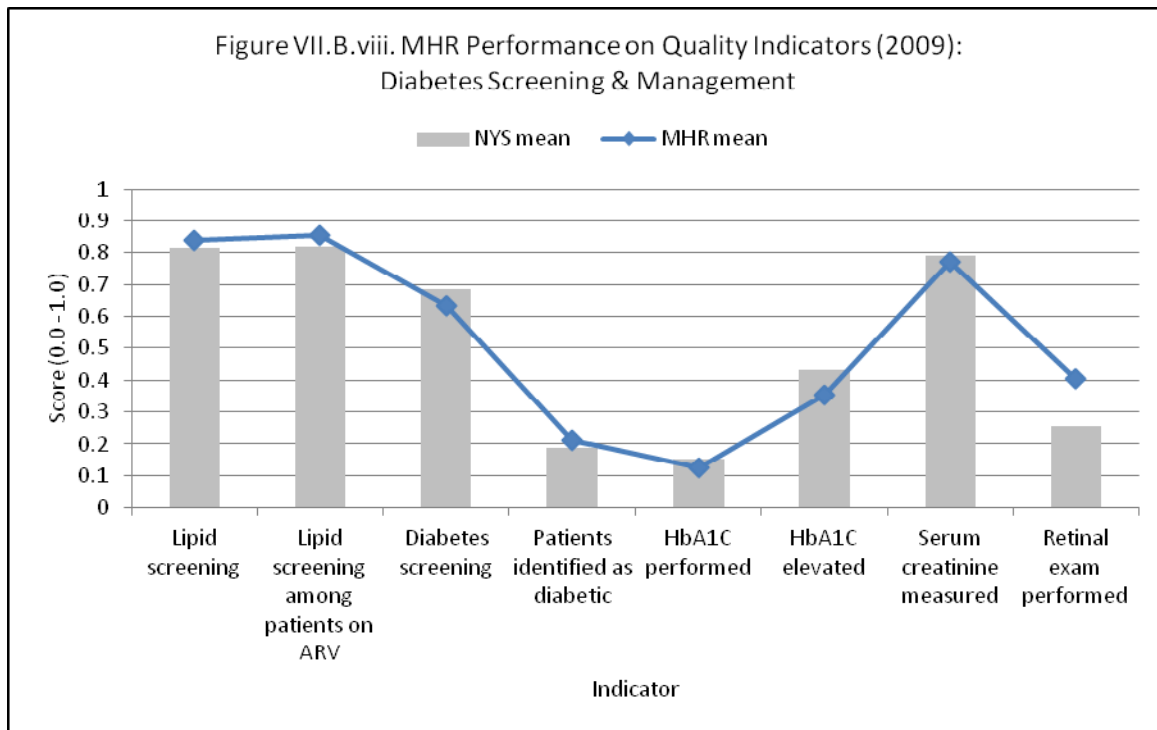
The indicators pertaining to diabetes screening include the following:

- Lipid screening: the percentage of eligible patients who receive a lipid screening test during the review period, which includes cholesterol levels; a separate indicator refers to the percentage of eligible patients on ARV who receive this lipid screening.
- Diabetes screening: the percentage of patients who receive a fasting blood glucose level, plasma glucose level obtained from OGTT or HbA1C test during the review period.
- Patients identified as diabetic: the percentage of patients who received the diabetes screening who have either a fasting blood glucose level above 126 milligrams per deciliter, have a plasma glucose level obtained from OGTT greater than 200 milligrams per deciliter, or have an HbA1C level greater than or equal to 6.5%.

Indicators pertaining to diabetes management include:

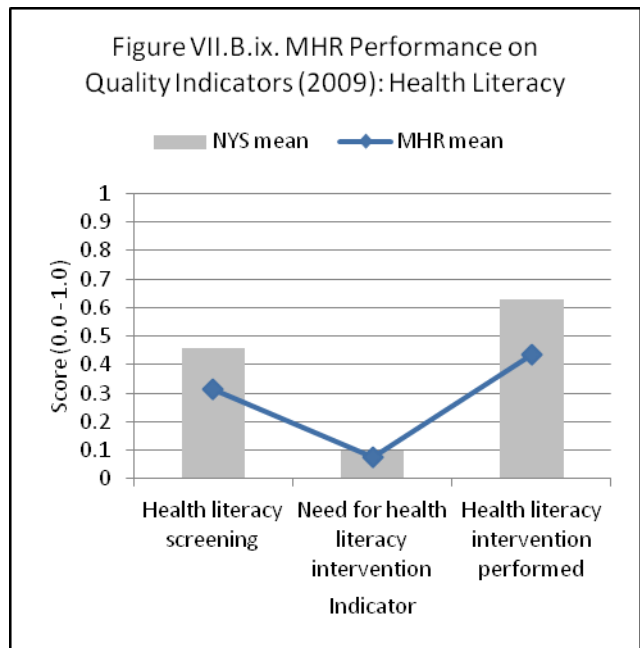
- Serum creatinine measured: the percentage of diabetic patients for whom a serum creatinine was measured during the review period.
- Retinal exam performed: the percentage of diabetic patients who received a retinal exam during the review period.

As can be seen in the graph below, the MHR scores for diabetes screening and diabetes management generally were comparable to NYS. Notable differences include a slightly lower rate of diabetes screening, a very slightly higher rate of patients identified as diabetic, a lower rate of patients found to have an elevated HbA1C level, and a considerably higher rate of retinal exams performed in the MHR compared to NYS.

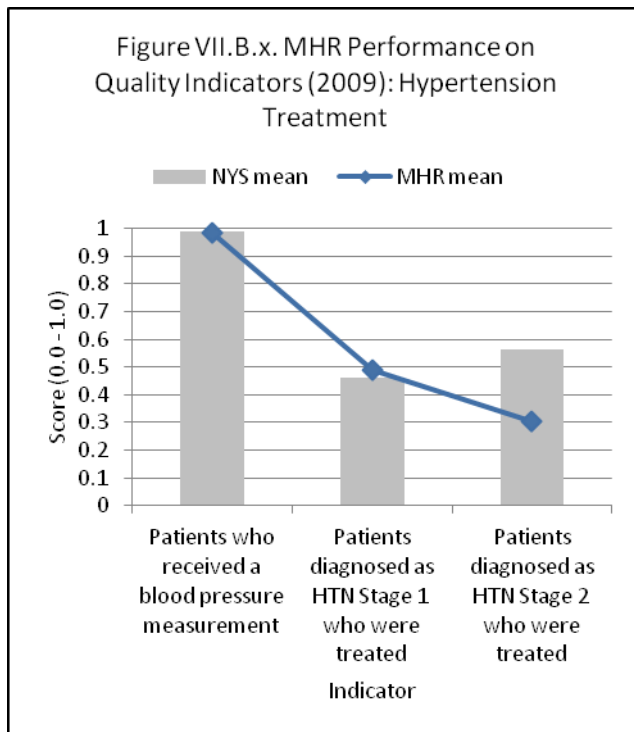


### 7. Health Literacy

The health literacy indicators assess three things: the percentage of eligible patients who received a health literacy screen during the review period, the percentage of screening patients for whom a need for an intervention was identified, and the percentage of those patients who received the needed intervention. Although the rate of patients who demonstrated a need for a health literacy intervention was comparable in the MHR to NYS, literacy screening rates and intervention rates were lower. Screening and providing interventions are important areas to improve given the strong associations between health literacy and overall health and may be particularly important for the MHR, where there appears to be high levels of untreated mental health and cognitive function problems, as discussed in Section VIII.C.



### 8. Hypertension



The hypertension screening indicator assesses the percentage of eligible patients for whom blood pressure was measured at least once during the review period. The hypertension management indicator assesses the percentage of patients diagnosed as hypertensive (either Stage 1 or Stage 2) who were treated with medication or lifestyle modification plan (Stage 1) or with two or more medications (Stage 2).

Mean scores in the MHR and NYS were high for hypertension screening; almost all eligible patients had a blood pressure measurement at least once during the review period. The MHR mean was slightly higher than the NYS mean for treating patients diagnosed as Stage 1 hypertensive, but was considerably lower for treating patients diagnosed as Stage 2 hypertensive. The reason behind this low performance for management of Stage 2 Hypertension is an important area for future investigation.

9. Tuberculosis

The Tuberculosis (TB) indicator measures the percentage of eligible patients who have not had a prior positive TB test or TB treatment and who received any type of latent TB infection screening within the last 24 months of the review period. The MHR scores were among the lowest in NYS for TB screening, although the range of scores was small: MHR mean of 0.62, NYS mean of 0.67.

10. Colonoscopy

The colonoscopy indicator measures the percentage of patients between 50 and 59 years of age and over 60 years of age who received a colon cancer screening (colonoscopy) within the past ten years. Mean colonoscopy rates in the MHR were comparable to NYS mean for both age groups.

11. Vaccinations

In 2009, the MHR scores on providing influenza and pneumococcal vaccinations were comparable to the NYS mean. These indicators include: the percentage of eligible patients who received an influenza vaccination within the review period; and the percentage of eligible patients who received a pneumococcal vaccination within the last five years.

12. PCP Prophylaxis

The rate for PCP prophylaxis in the MHR was slightly higher than in NYS in 2009, which assesses the percentage of eligible patients whose lowest CD4 count was and remained under 200 cells per cubic millimeter for six months who received *Pneumocystis carinii* pneumonia prophylaxis.

**C. Major themes regarding primary care**

1. Clinical provider experience and knowledge

Overall, qualitative data suggest substantial variety in the level of clinical care providers' knowledge and experience in the MHR. Some consumers were very satisfied with the quality of their clinical care, while others expressed frustration with provider unfamiliarity with HIV/AIDS and continued stigma and discrimination in medical settings. Providers and members of the AIDS Institute also remarked on the diminishing number of experienced medical providers in the HIV/AIDS field and proposed several factors contributing to the decrease.

There were many consumers who expressed great confidence in their clinical providers' knowledge and expertise. They felt that they had access to cutting edge science and new developments in the HIV field, that the clinical care was superb and that staff in the clinical practice were experienced and professional (Consumers 3, 4, 5, 6, 7 & 8, Dutchess; Consumer 25, Orange; Consumers 32, 33 & 34, Sullivan; Consumers 40 & 44, Ulster). There were, however, other individuals who expressed concern about the level of overall provider knowledge and experience. One case management provider who works for an agency in multiple counties reflected that, "we just hear stories from clients about misdiagnoses and then, like, having to go back and go back and go back for more tests and then they end up later on getting diagnosed with something they could have been diagnosed with six months earlier. Things like that, that seem to happen an awful lot" (Provider 3, multiple counties). Several consumers also expressed frustration with non-HIV clinical care providers' unfamiliarity with HIV/AIDS and particularly anti-retroviral medications. One Dutchess County consumer explained that the provider inexperience forces him to play the educator, a frustrating and exhausting burden: "I'm tired of having to explain exactly what's wrong with me and what my medicines do, when they don't know... I have had the

experience when they say, ‘I don’t know, you tell me’” (Consumer 2, Dutchess). Other consumers spoke about discrimination by clinical providers, borne out of ignorance about how HIV/AIDS is transmitted. They described times when they felt that clinicians in the intensive care unit, emergency room, ambulance or primary care office didn’t want to touch them or didn’t show the same level of compassion they otherwise would have because of the consumers’ HIV status (Consumer 18, Dutchess; Consumer 31 & 33, Orange; Consumer 41, Ulster).

Some providers and members of the AIDS Institute also expressed concern about the diminishing expertise and, in some cases, diminishing interest in providing HIV/AIDS care in a primary care setting. Several high-ranking members of the AIDS Institute discussed how providers with considerable HIV experience are leaving the field due to burnout or retirement, and there are not enough new providers to take their place (AI Members 2, 20 & 21). This may be due to the fact that HIV/AIDS has lost its appeal as a new, exciting disease and young clinicians are choosing other areas in which to specialize (AI Member 21). It also may reflect how the medical community needs to be incorporating HIV/AIDS into primary care training as early as residency in order to build a culture and expectation of primary care providers prepared to treat PLWHA (AI Member 20). These issues and concerns apply to all of New York and the United States.

One provider spoke more specifically about the lack of primary care providers within the MHR who are interested in treating HIV/AIDS patients. This provider identified four main reasons behind such reluctance: primary care physicians continue to feel intimidated by managing HIV/AIDS care; the PLWHA community tends to be a population with high levels of need, both medical and social; the amount of time that treating someone with HIV/AIDS requires, compared to patients with other medical conditions; and the significant data requirements associated with HIV/AIDS care. As the provider explained:

[The typical patient at the practice] comes with lots of psychosocial problems as well...Tend to be more low income, former drug addicts, sex workers, IDU, etc. So it is a little intimidating to manage these patients... the documentational requirements for AI are onerous...Time is always a problem. Time and reimbursement...The bottom line is that we don’t get paid enough to spend the amount of time that is expected of us to appropriately deal with these patients... If I now walk in the door and I see on my schedule two or three pt back-to-back with HIV/AIDS, I know...this is going to be, you know, really complicated. It’s really going to slow me down. (Provider 11, Orange)

The provider recognized that some of the documentation and thus time requirements will be eased as the practice develops its electronic medical records system. Nevertheless, he described these as tangible, fairly intractable reasons behind the small number of primary care physicians who want to become experienced in HIV/AIDS care in the MHR.

## 2. Time spent with patients and time spent waiting

Over the course of the interviews and focus groups, consumers identified several characteristics of a good doctor. They identified these by giving examples of doctors they like and those they don’t and by discussing aspects of high quality care. A key theme in these discussions was how much time a physician spends with a patient. Patients happy with their doctor often boasted about the average length of visits, explaining how their doctor looks them over tip to toe and won’t let them leave under an hour (Consumer 2, 12 & 15, Dutchess; Consumer 27, Orange; Consumer 33, Sullivan). Conversely, one of the biggest complaints among patients unhappy with their doctor was feeling rushed during a visit (Providers 2-6, multiple counties). Consumers did not insist that every visit be a long visit, but the sense of being able to take their time was very important. As one consumer explained, “That’s what I look at when I see doctors too. Like if they are rushing you, blowing you off, or if they are, like, asking you a lot of questions, from head to toe. I determine that as good care”(Consumer 40, Ulster).

A related issue that many consumers identified was the amount of time spent waiting for an appointment. Complaints about long wait times were primarily concentrated on one health care center, but the issue so deeply affected patient satisfaction and engagement in care that a brief discussion is included here.

Consumers were very frustrated by long wait times, and this appeared to compound other frustrations with transportation and perceptions of provider disrespect (discussed in Sections VIII.E and VI.D, respectively). One consumer explained that,

When they set [the infectious disease physician] up with 40 people for that day, it's intolerable. You got to wait three, four hours. It's frustrating. It's unnecessary...Some are happy with the service. But I'm not happy with the service if I got a 1:15 appointment and I'm not being seen til 4:00. (Consumer 19, Orange)

Other consumers who visited this agency echoed her sentiments (Consumers 29 & 31, Orange), and one consumer stopped attending the center for clinical monitoring because he was so enraged by the wait times. Some case management providers who work with patients of this center observed how the frustration with wait time connected with other challenges and frustrations that consumers often experience:

Part of the issue is that they'll see the doctor for five minutes, they have no attention, and they've spent three hours waiting for the doctor. So, the entire day is spent doing that. You are talking about folks who are already treated badly, are waiting there for three hours, and go in and have this experience, they don't want to go back. So that's a barrier. (Provider 1, multiple counties)

These case management providers consistently agreed that reducing wait times could have a significant impact on improving consumer satisfaction (Providers 2-6, multiple counties). Staff of the health center in question also are aware of the consumer frustration with wait times and have taken steps to try to improve the situation. The results of those efforts were not yet clear at the time of completing interviews.

## **VIII. Non-Clinical Care & Supportive Services**

The following section discusses quantitative and qualitative findings regarding the quality and availability of various types of non-clinical care and supportive services.

### **A. Dental Care**

Medicaid and HIVQUAL data suggest under-utilization of dental care services in the MHR. In 2009, the MHR scored higher than the NYS mean on the HIVQUAL indicator for dental exams, although both scores were low: 0.43 in the MHR vs. 0.29 in NYS (mean scores). This indicator measures percentage of eligible patients for whom the primary care physician documented a dental exam during the review period. As such, a low score on the indicator could reflect low rates of dental exams or it could reflect low rates of dental exam documentation within primary care facilities. Consistent with the low HIVQUAL score, Medicaid data showed that only 374 unique Medicaid clients from the MHR received dental care services in 2009 (42% of unique Medicaid clients in the MHR). The accuracy of AIRS data regarding dental exams is questionable given the extent of incomplete and missing data and therefore is not included here. This is a topic that merits further investigation to evaluate the extent to which reporting errors have underestimated the level of services provided and to understand reasons behind any under-utilization.

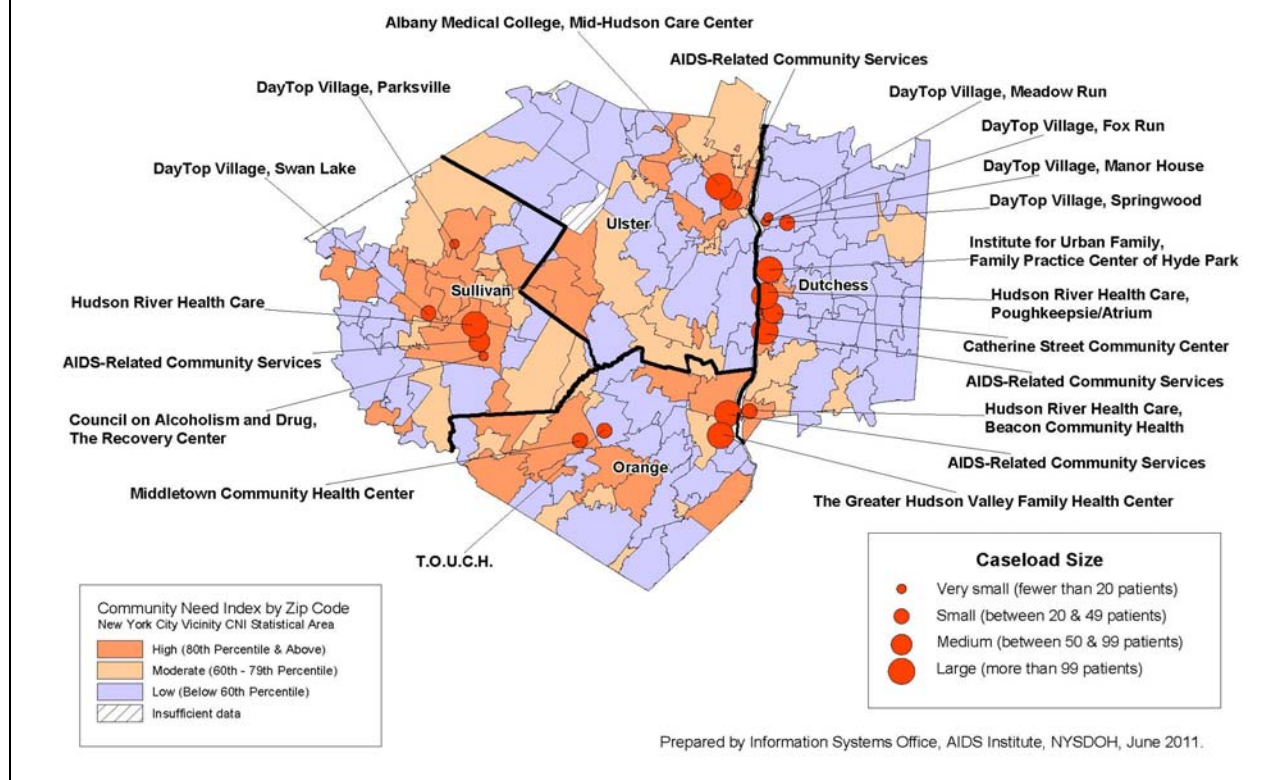
### **B. Case Management & Care Coordination**

In contrast to dental care services, case management and care coordination services appear to be heavily utilized in the MHR. The most prominent concerns related to these service categories involve staff turnover and insufficient coordination or collaboration among providers.

In 2009 and 2010, there were nine AIRS agencies and an average of 20 sites in the MHR providing case management and care coordination services. This made case management and care coordination the most frequent service category provided by AIRS facilities; by contrast, only seven AIRS agencies and an average of 15 sites in the MHR provided primary care services in 2009 and 2010. As shown in Figure VIII.B.i below and Figure VII.A.iii in Section VII.A, the AIRS sites offering case management and care coordination were in the same areas as sites offering primary care, but there were additional case management and care coordination sites in the most populated areas. The caseload sizes for this service category also tended to be much larger than for primary care. "Case management and care coordination" includes the following AIRS defined service categories: Case Management, Care Coordination, Case Management – Groups and Medical Case Management. Data for case management and care coordination were unduplicated within those four AIRS defined service categories for each site.

In 2009 and 2010, an average of 1,963 PLWHA received case management and care coordination services at AIRS facilities, representing 89% of site-summed clients in the MHR at all AIRS facilities. An average rate of 16.8 case management or care coordination visits per client in 2009 was noted, but only 13.5 visits per client in 2010 due to a 17% decrease in the total number of visits. This finding can be explained by many different factors, including quality of health, funding or transportation.

Figure VIII.B.i. AIRS facilities providing case management and care coordination services in the MHR in 2009



In FY2009, 6,624 Medicaid case management claims were submitted by providers in NYS for 242 unique Medicaid clients who reside in the MHR, averaging 27.4 claims per client. Medicaid providers in the MHR, however, only submitted 498 claims for case management services for 44 unique NYS Medical clients. This indicates that the vast majority (at least 82%) of Medicaid clients who reside in the MHR and received case management services from a Medicaid provider did so with a provider outside the MHR. This surprising finding merits future investigation to confirm its accuracy. Also surprising is that 40% of the claims were submitted for clients who reside in Ulster County, given that only 20% of unique Medicaid clients in the MHR reside in that county. This also merits further study.

The most frequent concern that consumers and provider raised regarding case management was the frequent turnover of staff. One consumer explained that “as soon as we get attached to somebody, they gone”(Consumer 45, Sullivan). This considerable turnover has a negative impact on consumer-provider relationships and is particularly difficult for individuals with trauma histories, as the arrival of a new case manager requires the client to retell his or her story, “over and over again” (Providers 2-6, multiple counties; Providers 23 & 31, Orange). One consumer had left a case management agency because of the high levels of turnover (Consumer 8, Dutchess) and another threatened to leave, explaining that her case managers were like older sisters to her: “This is my family. If they take them away from us, I would not come [back]”(Consumer 37, Sullivan).

Providers offered various explanations for the high levels of turnover among case managers. One is the nature of the position, with many managers suffering from “burnout” after having to manage difficult situations and serving clients with high levels of need (Providers 1-6, multiple counties). This burnout is compounded by the arduous demands of paperwork (Provider 31, Orange) and an emphasis on billing

(Provider 30, Orange). Providers also suggested that retaining case managers at private, non-profit agencies in the MHR is particularly difficult because agencies are unable to offer competitive benefits packages or salaries compared to government positions or agencies in more metropolitan regions (Providers 23 & 31, Orange; Providers 2-6, multiple counties). One provider noted that some case managers tend to use the MHR as a learning arena – somewhere they work immediately after school to develop their skills and knowledge and then move elsewhere for a more lucrative position (Provider 31, Orange).

Regarding care coordination, both consumers and providers raised concerns about insufficient communication and coordination between providers. One consumer who works as a peer educator expressed his shock at the lack of coordination, stating that, “It’s amazing to me how these doctors don’t talk” (Consumer 2, Dutchess). Another consumer explained what he perceived as lack of coordination as follows:

I believe it falls between doctors’ communication. Right now, the lack of doctors does not work together. That is one of the biggest complications. And I think that’s the biggest problem. Is doctors does not affiliated [sic]. Like I say before, the primary and the specialist does not work hand and hand together. And that’s what make consumers suffer. That’s the gap in medical care. That’s what’s happening.  
(Consumer 13, Dutchess)

Providers shared similar perceptions and fears. One argued that not enough providers in the MHR are thinking systematically and demonstrating how to collaborate; “[I]ike there is nobody role modeling in that county, like how organizations should work together, should come together, should collaborate and meet sort of common community objectives, that just doesn’t happen” (Provider 20, multiple counties).

Several providers remarked on the territoriality between agencies that prevents effective care coordination. Despite the lack of any billing conflicts or financial reasons for competition, one provider explained that, “it almost becomes like this sort of you know competitive thing. And people just hold on to information or don’t want to share information, and it ends up hurting the client because they aren’t getting the best care because everyone is not on the same page. I think we find that a lot” (Provider 1, multiple counties). Another provider from the same agency described her experiences similarly: “So, for me, I can tell you that’s my number one complaint about the county, is this kind of, ‘We are going to close in ranks and work with this client and nobody else can and stay away,’ and it’s like, No! We are all there for the same... even though we are doing different roles, we are doing this for the client. And that I think falls by the wayside a lot. It’s incredibly frustrating” (Provider 5, Sullivan).

Some providers and AIDS Institute members suggested that this type of territoriality is particularly common in HIV/AIDS services, because funding is data driven and provider agencies do not want to let go of certain clients due to fear that their overall patient volume will decline (Provider 20, multiple counties; AI Members 4-6). Another factor behind insufficient or inconsistent care coordination may be that there is no shared understanding of what care coordination means (AI Members 4-6). These issues of defining and improving care coordination are a focus of the New York State Quality Advisory Committee and Consumer Advisory Committee. They are also something that could be addressed within community networks, which are discussed in greater depth in Section IX.B.

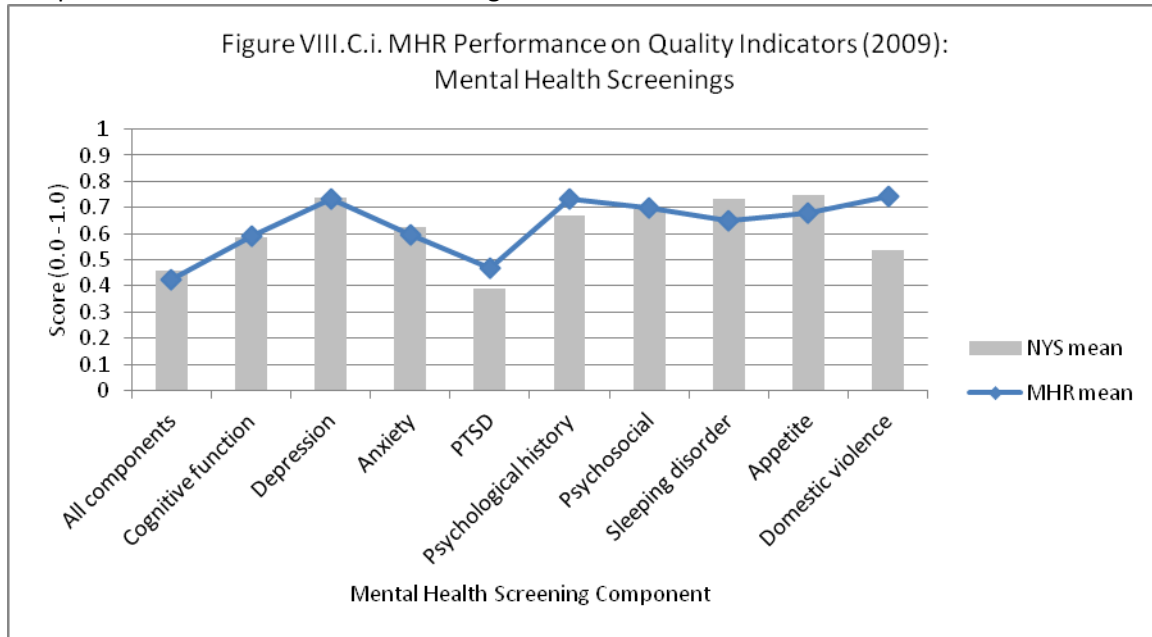
### **C. Mental Health**

Providers frequently identified insufficient mental health services as one of the largest problems for the HIV/AIDS community in the MHR. The three consumers who reported receiving mental health services all described positive experiences (Consumers 7 & 16, Dutchess; Consumer 44, Ulster), but the fact that only three consumers reported receiving mental health services is reflective of the problem of



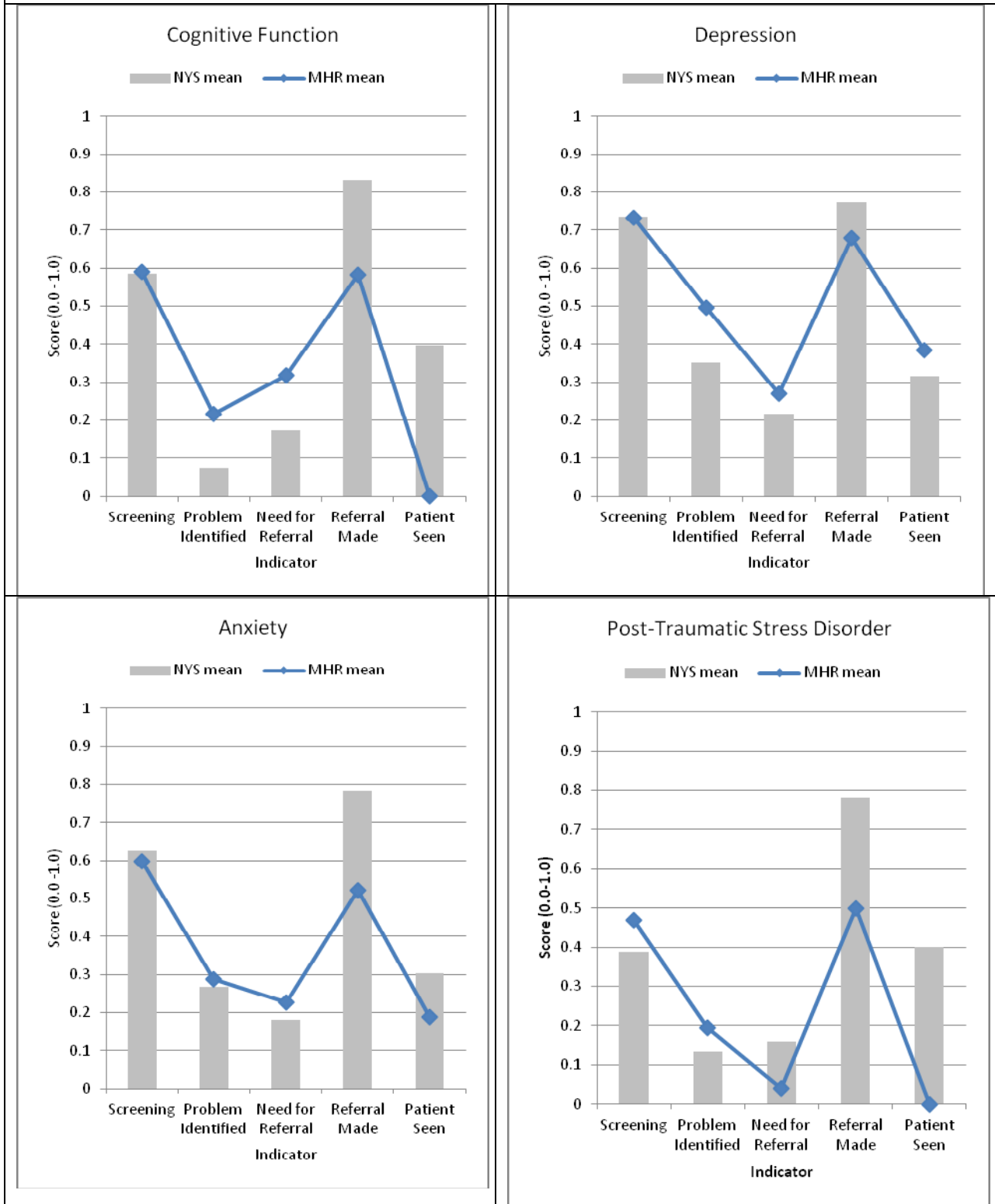
availability. HIVQUAL, AIRS and qualitative data all suggest a high level of mental health needs in the MHR and insufficient mental health services.

The HIVQUAL mental health data suggest that there were normal rates of mental health screening at primary care facilities in the MHR in 2009, but also a high prevalence of mental health needs, a high level of need for referrals, and a low rate of patients being seen by mental health providers in the region. As shown in Figure VIII.C.i, MHR rates for mental health screening were comparable to the NYS mean in 2009; these indicators assess the percentage of eligible patients who received various required components of a mental health screening.



An interesting pattern emerged, however, when looking at the four components for which there are additional indicators: cognitive function, depression, anxiety and post-traumatic stress disorder (PTSD). On these four components of mental health care, the MHR frequently showed high rates of problems identified, high rates of need for referral, low rates of referrals being made, and low rates of patients being seen following referral (see Figure VIII.C.ii).

Figure VIII.C.ii. MHR Performance on Quality Indicators (2009): Cognitive Function, Depression, Anxiety & Post-Traumatic Stress Disorder

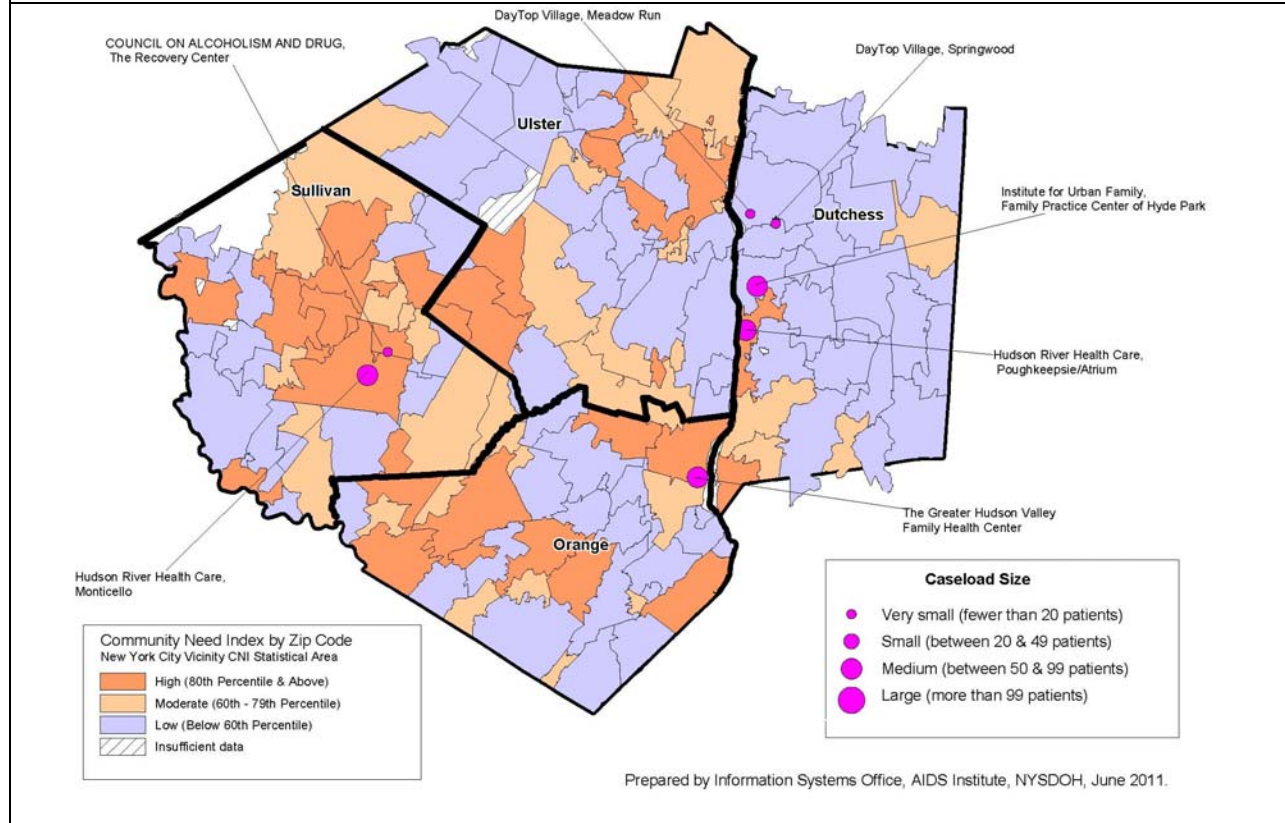


These discrepancies between the NYS mean and the MHR performance could be due to how the values were reported or calculated. However, the finding of high levels of need and low levels of treatment is consistent with qualitative and AIRS data.

Providers consistently described substantial need for mental health care in the MHR and insufficient treatment opportunities. They explained that consumers frequently have complex needs but are faced with wait lists for almost all long-term services (Provider 31, Orange; Provider 1, multiple counties; Provider 28, Dutchess), wait lists made worse by recent layoffs and hiring freezes (DOH Official 32). Other providers lamented insufficient mental health services that accept Medicaid or ADAP (Provider 23, Orange; Provider 19, multiple counties), very little available counseling or talk therapy even if a consumer is able to get a prescription for psychotropic medication (Providers 2-6, multiple counties), and the negative impact of limited mental health services on treatment adherence (Provider 30, Orange). One provider stated that, “[b]etter access to mental health care is the number one problem for people with HIV at [this agency]” (Provider 23, Orange). Providers also remarked that consumers often did not go to their appointments even when a referral was made (Provider 23, Orange; Provider 28, Dutchess). Possible reasons for this could be stigma associated with mental health needs, transportation issues, or the long wait lists. Finally, one provider and one member of the AIDS Institute described how primary care providers are uncomfortable addressing mental health needs and may refer unnecessarily for simple problems, thus “clogging up” the system (Provider 28, Dutchess; AI Member 17). These would be interesting topics for future investigation and possibly could help elucidate the performance on HIVQUAL referral and treatment indicators.

AIRS data similarly support the finding of limited mental health services being utilized in the MHR. In 2009, there were 349 total clients with an average of 3.6 visits per client who received mental health services or psychological counseling at seven AIRS facilities in the MHR. Four of the AIRS facilities were in Dutchess County and there were zero AIRS facilities providing mental health services in Ulster County (see Figure VIII.C.iii). These 349 clients constituted only 15% of site-summed clients in the MHR in 2009. In 2010, the number of total clients decreased to 266 or 11% of site-summed clients in the MHR that year. From 2009 to 2010, however, the total number of visits used by these clients actually increased by 73% due to a large increase in visits at the Institute for Family Health in Dutchess County. Opportunities for future investigation include: identifying why the increase in visits at the Institute for Family Health occurred, including whether it was caused by a change in how visits are reported or the type of visits that are offered; whether there would be similar uptake in visits if such services were offered at other sites in the MHR; and determining why the number of AIRS clients decreased from 2009 to 2010 and whether this reflects a gap in care.

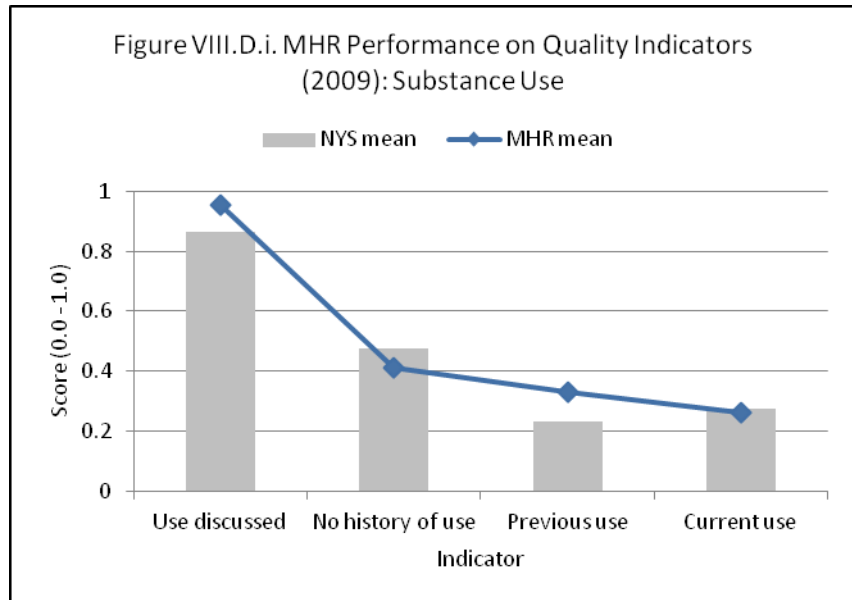
Figure VIII.C.iii. AIRS facilities providing mental health services in the MHR in 2009



### D. Substance Use

Within HIV primary care, HIVQUAL data reflect a high level of screening for substance use, high levels of previous use, and comparable levels of current use in the MHR in 2009 compared to the NYS mean (see Figure VIII.D.i). Note that these indicators exclude from analysis patients reviewed at drug treatment centers.

Among drug users in the MHR and NYS, the most commonly used substances were alcohol, followed by marijuana, cocaine, heroin and pills (see Table VIII.D.ii). The MHR had higher rates of alcohol and heroin use compared to NYS and lower rates of marijuana and cocaine use compared to NYS, but the MHR also had a much smaller sample overall, which could skew results (N=77 in the MHR



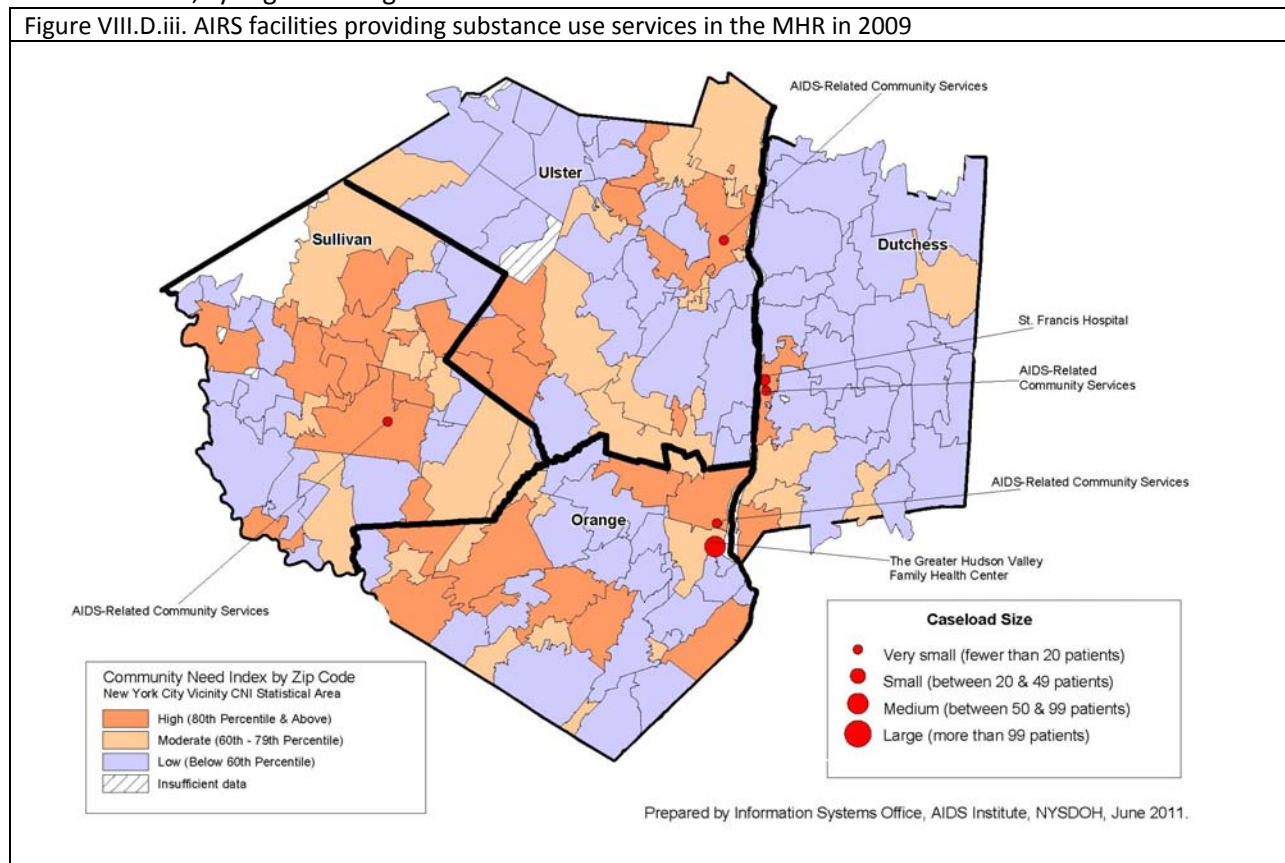
compared to N=1,855 in NYS). The MHR also had the highest rate of tobacco use, the lowest rate of tobacco use discussed, and the lowest rate of smoking cessation discussed in HIV primary care out of all regions in NYS. This could be an important area for improvement of overall health in the region.

Among “heavy drug users,” defined as anyone who used a substance besides alcohol or marijuana, the MHR had higher rates of patients receiving treatment and referrals than NYS overall. As mentioned above, however, the very small number of cases in the MHR could skew results. In 2009, the MHR had 20 heavy drug users in the HIVQUAL sample, 60% of users (n=12) were receiving treatment, and of those not in treatment, 42% of users (n=3) received a referral for treatment. In NYS in 2009, there were 929 heavy drug users in the HIVQUAL sample, only 46% of users (n=426) were receiving treatment, and of those not in treatment, only 23% (n=100) received a referral.

Substance	MHR (N=77)	NYS (N=1,855)
Alcohol	65%	55%
Marijuana	27%	34%
Cocaine	18%	25%
Heroin	14%	6%
Pills	4%	4%
Other drugs	3%	4%

In contrast to the high rates of screening and treatment shown by HIVQUAL data, AIRS data suggest a low level of substance use service utilization in the MHR (see Figure VIII.D.iii). This may be due to reporting processes, as only certain substance use service categories fall within the parameters of AIDS Institute funded programs and thus would appear in the AIRS database. These service categories include substance use, syringe exchange and harm reduction.

Figure VIII.D.iii. AIRS facilities providing substance use services in the MHR in 2009



According to the available data, 133 clients received substance use services at AIRS facilities in 2009 and only 74 clients received these services in 2010. The decrease in clients appears to be because ARCS (AIDS-Related Community Services) stopped providing contracted services in 2010. The termination of services at ARCS also meant that while AIRS facilities providing substance use services were located in all four MHR counties in 2009, there only were in two counties in 2010. Further investigation is required to determine if this low level of utilization reflects a lack of need or a lack of available services, or, if it is a bi-product of reporting procedures, what types and volume of substance use services are available to the HIV/AIDS community in the MHR.

Qualitative data on the availability of substance use services were mixed, possibly reflecting different perspectives or varying levels of service availability in the region. For instance, one Sullivan County Department of Health official explained that there are numerous inpatient substance use treatment options available in Sullivan County, whereas an Ulster County Department of Health official felt that substance use services in Ulster County were “strained” (DOH Officials 32 & 33). A primary care provider working in Dutchess and Ulster Counties similarly felt that there were not many providers available, despite a very high level of need (Provider 20, multiple counties). A few providers and consumers involved in substance use recovery also expressed concern that providers are insensitive to substance use; they recounted examples of providers prescribing controlled substances to recovering addicts immediately before discharge, failing to consider how substance use may be affecting treatment adherence or viral load measures, and not questioning patients about drug use even when they are visibly affected (Consumers 11-15, Dutchess; Consumer 17, Orange; Provider 27, Dutchess).

### E. Transportation

Transportation historically has been a major concern in the MHR and other regions in upstate New York. Distances between providers are larger and public transportation few. In the MHR, a small number of public buses must cover a large geographic area, resulting in long travel and wait times. The most common transportation option for individuals who do not have a car is to use taxi services that are provided by an agency or funded through Medicaid. Qualitative data indicate, however, that these services are not always reliable and cause considerable stress and frustration.

AIRS, Medicaid and qualitative data suggest that although transportation services are used throughout the region, transportation is most difficult and services are in highest demand for consumers in Orange County and, to a slightly lesser degree, in Sullivan County. AIRS data for 2009 and 2010 show an average of 233 total clients per year in the MHR, which is 11% of site-summed clients. These clients received transportation from AIRS facilities in all four counties, roughly in proportion to the number of PLWHA in each county. There were, however, substantially different values for average visits per client at AIRS facilities in the four counties, with the greatest values for Orange and Sullivan Counties (see Table VIII.E.i).

	AIRS (2009-2010): Average visits per client	Medicaid (2009): Average claims per client
Dutchess	8.9	21.2
Orange	18.9	58.0
Sullivan	15.1	21.7
Ulster	9.7	3.6

Medicaid data similarly indicate significantly more frequent use of transportation services in Orange County than the rest of the MHR. In FY2009, 411 unduplicated clients residing in the MHR had a claim

submitted on their behalf for transportation services, which constitutes 45% of unduplicated clients in the region. As with AIRS data, the distribution of clients with an associated transportation claim was roughly comparable to the distribution of overall clients, but the number of average claims per client varied between counties, with Orange County residents averaging more than 2.6 times as many claims as Dutchess and Sullivan County residents and more than 16 times as many claims as Ulster County residents (see Table VIII.E.i).

Finally, two providers in Sullivan County and one provider in Orange County identified transportation as the biggest issue for consumers in the region (Provider 19, multiple counties; DOH Officials 29 & 32). In contrast, most consumers interviewed from Dutchess County had their own transportation and none of the consumers interviewed from Ulster County expressed difficulty with transportation.

There are many possible reasons for one county having greater transportation use than another. Consumers may be less likely to have their own means of transportation, services may be more centrally located so that consumers can walk to care, consumers may be using more service types and thus have more appointments, or consumers could be sicker or could require more complicated care and thus have more frequent visits. Future investigation is necessary to identify which of these and other reasons may be behind the higher utilization trends in Orange County and Sullivan County.

During interviews and focus groups, consumers and providers frequently voiced concerns and complaints regarding transportation. They described how insufficient or unreliable transportation negatively impacts consumers' health by causing consumers to be late or to miss visits, by preventing attendance at support groups, and generally by limiting engagement, retention and continuity of care (Consumer 31, Orange; Provider 31, Orange; AI Member 22). One consumer expressed her frustration with the process of transportation and late drivers as follows:

They were doing fine in the beginning. But then what happen? I don't know what happened. I know is that they take me, they come late, and when they come late to pick me up, they take me to my appointment. If I'm fifteen minutes late, I can't, I can't be seen because I've missed my appointment and I have to reschedule. Then they take off and they leave me there. Then I have to wait an hour and a half to two hours for them to come back and bring me home! (Consumer 31, Orange)

Her experiences were echoed by many others across the region (Consumer 2, Dutchess; Consumer 19, Orange). This frustration applies to providers as well; one medical provider explained that transportation is "extremely onerous" to arrange due bureaucratic requirements that made it virtually impossible to successfully connect a patient to care (Provider 19, multiple counties).

Transportation consistently emerged as an emotional issue, loaded with frustration, stress and fear. Consumers stated that, "[t]he transportation issue is terrifying" (Consumer 13, Dutchess) and "very scary" (Consumer 9, Dutchess). Others explained that the stress is "un-called for" (Consumer 2, Dutchess) and compounds other frustrations surrounding wait time in the health centers (Consumer 19, Orange). Discussing transportation brought one woman to tears during the focus group (Consumer 14, Dutchess).

Consumers and providers also expressed that the transportation situation seems to be getting worse over time (Providers 2-6, multiple counties; Consumer 31, Orange). Some of that sentiment may be a result of funding changes that occurred with the medicalization of Ryan White funds after 2006 and the inability to fund transportation to the same services as before (AI Members 4-6). One provider also commented that the consumer outrage over lack of transportation and reluctance to use public

transportation or share cabs reflect the entitlement among PLWHA (Provider 23, Orange). These issues of entitlement and reaction to diminishing funds are discussed more in Section VI.E.

## **F. Housing**

Housing is another topic that has been historically problematic and remains emotionally fraught for many MHR consumers. Consumers and providers consistently agreed that there is not enough housing assistance available for PLWHA in the MHR and unstable housing negatively impacts quality of life and health.

In 2009 and 2010, there was only one AIRS facility in the MHR providing housing services: Pathstone. Pathstone offered housing assistance to 114 PLWHA in 2009 and 116 in 2010 across Dutchess, Orange and Sullivan Counties. As of 2011, Pathstone was able to broaden services to Ulster County, serving two consumers there, but staff described how significant budget cuts also forced them to terminate housing services for ten consumers at the end of 2010. They expressed concern as to how future budget crisis will affect their agency and clients (Provider 24, multiple counties). Other housing assistance is offered by the Department of Social Services and may be provided by other agencies in the region, but that was not captured by quantitative data sources used in this project.

Providers frequently identified housing as a major need, many identifying it as the number one issue for consumers in the region (Providers 2-6, 19 & 20, multiple counties; DOH Officials 28, 29 & 32). They described it as a “huge problem” (DOH Official 32), “dreadful” and problematic across the region (Provider 19, multiple counties), and consistently a prominent issue in county needs assessments (DOH Official 28). There also was general agreement that the problem with housing is affordability, not availability (DOH Officials 28, 29 & 32); it is possible to find fair market prices, but most consumers can’t afford the cost of rent without a subsidy (Providers 24, Orange). Consumers thus are forced to live in locations and structures that are not conducive to healthy, sober and adherent lifestyles (Provider 19, multiple counties; Provider 31, Orange).

Additionally, consumers often expressed frustration and anger regarding the housing system and lack of support. Regarding the Department of Social Services, one consumer from Orange County felt that, “we are in the, excuse my expression, we’re in the, what you call, the waiting game, and the mind f\*\*\*, in between those two” (Consumer 31, Orange). Another consumer explained that the system is “whacked out” (Consumer 32, Sullivan) and a third stated that, “It’s ridiculous. It really is...it’s robbery...you have people who are sick, you don’t want them on the street” (Consumer 4, Dutchess).

This frustration and anger towards the housing system often was coupled by fear and exhaustion. The consumer from Orange County went on to say,

You got a house to go to. You got a key, you know what I mean, at the end of the day. But I don’t, you know? And it’s frustrating. It’s really, really frustrating. How people could just play with other people’s emotions and minds the way they do? (Consumer 31, Orange)

Another returned to the topic of housing again and again in the course of an interview, explaining that this was the most stressful issue for her and pleading for assistance. Some of her words were: “I don’t want to worry about being homeless again...I have to get out of there...When I go to sleep at night, I can’t wait for the next day when I got a group or something, just to get out of there” (Consumer 10, Dutchess).

The stress, fear and exhaustion regarding housing tend to compromise consumers’ health and compound other frustrations (Provider 30, Orange). Furthermore, several providers and consumers felt



that the housing situation was getting worse with longer waiting lists and fewer resources available. Providers from one case management agency explained that consumers previously were able to get HOPWA within one week and emergency one-time assistance within the same week, but those services aren't even accepting applications anymore (Providers 2-6, multiple counties).

Interestingly, Ulster County consumers did not raise any concerns regarding housing and all expressed contentment when asked. This may be a consequence of the very small sample of Ulster County consumers or may reflect a different level of housing support or need in that county. This would be an interesting topic to revisit, especially given the great need in other parts of the MHR.

## **IX. Topics for Future Investigation & Opportunities for Improvement**

### **A. Topics for future investigation**

The following are points identified throughout previous sections as topics for future investigation.

#### Section IV. Epidemiology of HIV/AIDS

- The movement and service needs of individuals recently released from incarceration in the MHR, specifically where people incarcerated in the region live after being released, what types of transitional services they require, and if those services are currently available and of high quality (Section IV.A.1).
- Future changes in the number of newly diagnosed AIDS cases in Orange County and Dutchess County, to determine if increases between 2006 and 2008 represent a new trend (Section IV.A.2).
- Future changes in the number of newly diagnosed HIV cases in all MHR counties, to determine if fluctuations between 2006 and 2008 represent new trends and to ascertain the effects of the new HIV testing law (Section IV.A.2).
- Future changes in the number of deaths among AIDS cases in Ulster and Orange Counties to determine if earlier changes represent a new trend (Section IV.A.3).
- Reasons behind the higher IDU transmission risk in the MHR compared to NYS, especially in Sullivan County, including the availability of syringe exchange programs and the effect of individuals coming into the MHR for drug treatment services (Section IV.B.4).
- Reasons behind the higher heterosexual transmission risk in Orange County compared to the rest of the MHR, including the possibility of a larger sex worker population (Section IV.B.4).

#### Section V. Clients: PLWHA who receive care and services

- Comparing the ratio of total clients to site-summed clients for other regions of NYS and for specific service categories and demographic groups in order to assess varying levels of co-location of services (Section V.B).
- Reasons for the decrease in the number of individuals using AIRS facilities between 2009 and 2010, including those suggested in the text (Section V.B).
- Whether the decrease in the number of agency-summed female clients from 2009 to 2010 indicates reduced quality of care or a gap in services for female PLWHA (Section V.D.1).
- The validity and potential reasons behind the apparent tendency for Black clients to see multiple providers and use a higher volume of services (Section V.D.3).
- Whether the under-representation of clients with MSM, IDU and MSM/IDU transmission risks at MHR AIRS facilities suggests lower levels of engagement in care among these populations or a gap in care and services (Section V.D.4).
- Whether the under-representation of clients with IDU transmission risk in Orange County indicates a gap in care and services (Section V.D.4).
- Reasons behind the reduced tendency for Orange County Medicaid clients to travel to Westchester County for care (Section V.F.1).

### Section VII. Primary Care

- Whether residents of the following areas that have high need status according to the CNI and low concentrations of providers are receiving sufficient care and services: the southwest corner of Ulster County, central Sullivan County, the western edge of Sullivan County, and northwest Orange County (Section VII.A.1).
- Reasons behind the low retention in care in the MHR (Section VII.B.2).
- Care models involved in the MHR's high scores for viral load suppression and whether there are practices that could be disseminated to other communities (Section VII.B.3).
- Reasons behind the low scores in the MHR for syphilis screening, and in particular, why the two newly included clinics in 2009 had scores of zero (Section VII.B.4).
- Reasons behind the low scores in the MHR for assessing management of Stage 2 Hypertension (Section VII.B.8).

### Section VIII. Non-Clinical Care and Supportive Services

- The validity and potential reasons behind the low level of dental care utilization in the MHR (Section VIII.A).
- The validity and potential reasons behind why the majority of Medicaid clients who reside in the MHR and received case management services from a Medicaid provider did so with a provider outside the MHR (Section VIII.B).
- Reasons for why consumers did not receive mental health care services after a referral was made (Section VIII.C).
- Whether primary care providers are uncomfortable addressing mental health needs and make unnecessary referrals that overload mental health services (Section VIII.C).
- Reasons behind the large increase in mental health visits at the Institute for Family Health in Dutchess County and whether there would be similar uptake if such services were offered at other sites in the MHR (Section VIII.C).
- Reasons behind the decrease in AIRS clients for mental health services from 2009 to 2010 (Section VIII.C).
- The significance and reasons for the low level of AIRS substance use service utilization and other types and volume of substance use services available to the HIV/AIDS community in the MHR (Section VIII.D).
- Reasons for why consumers in Orange County and Sullivan County appear to use transportation services more frequently (Section VIII.E).
- Whether there are problems with affordable housing for PLWHA in Ulster County and, if not, how that county's services differ from other areas in the MHR (Section VIII.F).

## **B. Opportunities for improvement**

What follows is a summary of potential opportunities for improvement that were discussed in Sections IV – VIII and a more general discussion of how care and services in the region might be improved.

### Percent of late and concurrent diagnoses

The percent of late and concurrent diagnoses in the MHR were comparable to ROS but higher than NYC and thus NYS overall (Section IV.A.2). A member of the AIDS Institute identified reducing the rates of late and concurrent diagnoses as a statewide priority, which clearly applies to the MHR as well.

#### MHR mean scores on HIV quality of care indicators

Other opportunities for improvement were identified through analysis of mean scores in the MHR on HIVQUAL indicators. Areas where the MHR had low scores in 2009 compared to the NYS mean and other regional means were: retention in care, syphilis screening, health literacy screening and interventions, tuberculosis testing, tobacco screening and smoking cessation (Section VII.B; Section VIII.D). Addressing performance in any of these areas could be an opportunity to improve overall care in the region.

#### Wait time, provider experience, provider options, case management turnover and care coordination

Also pertaining to primary care, finding a way to reduce wait times in health centers could significantly improve patient satisfaction and retention (Section VII.C.2). Although some consumers were very satisfied with their primary care, increasing other providers' level of experience and knowledge and increasing the number of provider options available to consumers also could improve perceptions of quality of care (Section VII.C.1 & Section VII.A.3). Additional opportunities for improvement include reducing turnover among case managers and defining and improving care coordination (Section VIII.B).

#### Mental health, transportation and housing services

Three larger service categories that consumers and providers identified as key areas for improvement were mental health, transportation and housing services. As discussed in Section VIII.C, many providers argued that insufficient mental health services was one of the largest problems for PLWHA in the MHR, an assessment supported by HIVQUAL, AIRS and qualitative data that showed a high level of need and low level of treatment. As described in Sections VIII.E and VIII.F, transportation and housing services have been significant issues in the MHR historically and remain problematic and emotionally fraught today; any increase in the amount of transportation and housing support available could significantly improve consumers' wellbeing and overall satisfaction.

#### Support groups and opportunities for community development and consumer empowerment

Finally, one of the most common possibilities for improvement that consumers and providers identified was to provide more opportunities for community development and collaboration. The importance of community and consumers' longing for additional support groups and spaces to connect are discussed in Section VI.F. Such support groups and community events could help assuage some of the exhaustion, frustration, powerlessness and isolation that consumers described (Section VI.B). They could be a forum for conducting consumer empowerment and self-advocacy training, which consumers and providers identified as extremely valuable (Section VI.F), and could be a platform from which PLWHA could continue addressing stigma and discrimination in their communities (Section VI.C).

#### Collaboration among providers and consumers

Ideally, the community gatherings also could be a space to cultivate constructive collaboration among providers and between providers and consumers. Such collaboration could help clarify and improve shared understanding of what care coordination is and how to achieve it (Section VIII.B), consumer perceptions regarding provider compassion and time (Section VI.D), and reactions to diminished funding (Section VI.E). Finally, the collaboration could increase information sharing among providers and consumers, potentially minimizing duplications in service, identifying gaps in care and maximizing resources. Improving collaboration and cultivating community were some of the intended purposes of the Ryan White Part B Networks and many were incorporated into the goals of the newly developed Hudson Valley HIV Community Network; they are not new propositions or easy goals to achieve. Nevertheless, these are critical opportunities for continued improvement identified by consumers and providers and suggested by this overall body of work.