Newark EMA

HIV Health Services Planning Council

NEEDS ASSESSMENT UPDATE 2013

August 2013

(Approved by the Planning Council September 18, 2013)

NEWARK EMA HIV HEALTH SERVICES PLANNING COUNCIL NEEDS ASSESSMENT - UPDATE 2013

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LIST OF ABBREVIATIONS

The following abbreviations and acronyms are used in this Needs Assessment.

AAOGC	African American Office of Gay Concerns
ACA	Affordable Care Act of 2010 (Patient Protection and Affordable Care Act)
ACS	American Community Survey (of the US Census Bureau)
ADAP	AIDS Drug Assistance Program
ADDP	(New Jersey) AIDS Drug Distribution Program
AETC	AIDS Education and Training Center
ARV	Anti-Retroviral (therapies)
ASI	Addiction Severity Index
CARE Act	Comprehensive AIDS Resources Emergency (CARE) Act
CBO	Community Based Organization
CDC	U.S. Centers for Disease Control and Prevention
CHAMP	Comprehensive HIV/AIDS Management Program (the Newark EMA's Client Level Data Base)
CLD	Client Level Data (system)
CM	Case Management
CM-NM	Case Management – Non-Medical (nonmedical case management)
Cmte	Committee
COC	Continuum of Care Committee of NEMA Planning Council
CQM	Clinical Quality Management
CPC	Comprehensive Planning Committee of NEMA Planning Council
CRCS	Comprehensive Risk Counseling and Services (formerly HIV Prevention Case Management, a program of CDC)
CSAC	Community Services Advisory Committee of NEMA Planning Council
CTR	Counseling, Testing and Referral sites (for early identification of PLWHA)
DAYAM	Division of Adolescent and Young Adult Medicine (formerly at UMDNJ, now at Rutgers University)
DCFWB	Newark Department of Child and Family Well Being (Formerly, the Newark Department of Health and Human Services – DHHS)
DOT	Direct Observational Therapy
DYFS	Division of Youth and Family Services (New Jersey child welfare agency with in the NJ Department of Children and Families – NJDCF)
DHAS	Division of HIV/AIDS Services. In 2012 this division became the Division of HIV/AIDS, TB and STD Services (DHTSS)

DHTSS	Division of HIV/AIDS, TB and STD Services, formerly the Division of HIV/AIDS Services
EBI	Evidence Based Intervention
EIIHA	Early Identification of Individuals Living with HIV/AIDS
EIRC	Early Intervention and Retention Collaborative (EIRCs as plural)
EIS	Early Intervention Services
EMA	Eligible Metropolitan Area
ENT	Ears, Nose and Throat (specialist, care)
FQHC	Federally Qualified Health Center
GLBTQ	Gay, Lesbian, Bisexual, Transgendered, Questioning
HAART	Highly Active Anti-Retroviral Therapy
HAB	HIV/AIDS Bureau (of HRSA)
HIPAA	Health Insurance Portability and Accountability Act
HOPWA	Housing Opportunities for Persons With AIDS
HRSA	Health Resources and Services Administration (of the U.S. Department of Health and Human Services)
IDU	Injection Drug User
IDRC	Intoxicated Driver Resource Center
IP	Implementation Plan
KI	Key Informant [interviews]
MAI	Minority AIDS Initiative (formerly Congressional Black Caucus – CBC)
MCM	Medical Case Management
MH	Mental Health
MMC	Medicaid Managed Care
MNT	Medical Nutritional Therapy
MOA, MOU	Memorandum of Agreement, Memorandum of Understanding
MSM	Men who have Sex with Men
MSW	Morris, Sussex, Warren counties in the Newark EMA
NEMA	Newark Eligible Metropolitan Area
NHAS	National HIV/AIDS Strategy
NJCRI	North Jersey Clinical Research Initiative (New Jersey AIDS Partnership)
NJDOH	N.J. Department of Health (formerly NJDHSS – NJ Department of Health and Senior Services)
NJDS	New Jersey Dental School (at UMDNJ)
NJ-CLAS	New Jersey Culturally and Linguistically Appropriate Standards
NSDUH	National Survey of Drug Use and Health (administered by the Substance Abuse and Mental Health Services Administration of the US Department of Health and Human Services)
PAAD	(New Jersey) Pharmaceutical Assistance to the Aged and Disabled Program

PHS	(U.S.) Public Health Service
PLWHA	People Living With HIV or AIDS
REC	Research and Evaluation Committee of NEMA Planning Council
RIC	Retention In Care
RW	Ryan White [Program]
RWTEA	Ryan White HIV/AIDS Treatment Extension Act of 2009
RWTMA	Ryan White HIV/AIDS Treatment Modernization Act of 2006
SA	Substance Abuse
SAMHSA	Substance Abuse and Mental Health Services Administration (of the U.S. Department of Health and Human Services)
SAMISS	Substance Abuse Mental Illness Screening Survey
SCSN	Statewide Coordinated Statement of Need
TGA	Transitional Grant Area
UBHC	University Behavioral Health Care (of UMDNJ)
UDS	Urine Drug Screen
UMDNJ	University of Medicine and Dentistry of New Jersey (was merged into Rutgers, the State University effective July 1, 2013)
WICY	Women, Infants, Children and Youth
YMSM	Young Men who have Sex with Men

INTRODUCTION

The information below was extracted from the Ryan White Part A Manual published by HRSA/HAB in 2009 on its website. It reflects requirements of the Ryan White HIV/AIDS Treatment Extension Act (RWTEA) of 2009, Public Law 111-87, October 30, 2009. The citations are referenced to the Public Health Service Act (42 U.S.C. 300ff-11).

Legislative Background

Section 2602(b)(4) requires the planning council to:[1]

A. "determine the size and demographics of the population of individuals with HIV/AIDS, **as well as the size and demographics of the estimated population of individuals with HIV/AIDS who are unaware of their HIV status''**;

B. "determine the needs of such population, with particular attention to:

   i. individuals with HIV/AIDS who know their HIV status and are not receiving HIV-related services;

   ii. disparities in access and services among affected subpopulations and historically underserved communities; and"

   iii. **individuals with HIV/AIDS who do not know their HIV status."**

2602(b)(4)(G) requires planning councils to "establish methods for obtaining input on community needs and priorities which may include public meetings, conducting focus groups, and convening ad-hoc panels."

Section 2602(b)(4)(F) calls for the planning council and grantee to "participate in the development of the statewide coordinated statement of need initiated by the State public health agency responsible for administering grants under Part B."

Section 2602(b)(4)(H) requires the planning council to "coordinate with Federal grantees that provide HIV-related services within the eligible area."

Needs assessment data are critical to conducting other planning tasks. Needs assessment results must be reflected in both the planning council's priority setting and resource allocations and in the EMA's/TGA's comprehensive plan. Planning councils are required to:

- Address coordination with programs for HIV prevention and the prevention and treatment of substance abuse
- Include links with outreach and early intervention services

[1] HRSA. HIV/AIDS Bureau. http://hab.hrsa.gov/tools/parta/parta/ptAsec6chap1.htm#SecVIChap1a

- Address capacity development needs
- Be closely linked with comprehensive planning and annual implementation plan development, as interconnected parts of an ongoing planning process.

Section 2603(b)(1) specifies that in seeking supplemental funding, the EMA/TGA is expected to include in its application for funding an array of information, including needs assessment data that demonstrate need.

Section 2603(b)(2)(B) specifies that, in making awards for **demonstrated need**, the Secretary may consider any or all of the following factors:

i. "The unmet need for such services, as determined under section 2602(b)(4) or other community input process as defined under section 2609(d)(1)(A).

ii. An increasing need for HIV/AIDS-related services, including relative rates of increase in the number of cases of HIV/AIDS.

iii. The relative rates of increase in the number of cases of HIV/AIDS within new or emerging subpopulations.

iv. The current prevalence of HIV/AIDS.

v. Relevant factors related to the cost and complexity of delivering health care to individuals with HIV/AIDS in the eligible area.

vi. The impact of co-morbid factors, including co-occurring conditions, determined relevant by the Secretary.

vii. The prevalence of homelessness.

viii. The prevalence of individuals described under section 2602(b)(2)(M).

ix. The relevant factors that limit access to health care, including geographic variation, adequacy of health insurance coverage, and language barriers."

HAB/DSS Expectations

Needs assessment is expected to generate information about:

- The size and demographics of the HIV/AIDS population within the service area, including those who are unaware of their HIV status (not tested), and

- The needs of PLWHA, with emphasis on individuals with HIV/AIDS who know their HIV status and are not receiving primary health care, and on disparities in access and services among affected subpopulations and historically underserved communities.

HAB/DSS expects Part A needs assessments to meet all legislative requirements and to provide a sound information base for planning and decision making.

PURPOSE AND METHODOLOGY

The purpose of the Needs Assessment - Update 2013 was to conduct an in depth assessment of important issues raised by the 2011 Needs Assessment, and issues emerging in the Ryan White Program as we transition to national healthcare reform. The Council and its committees were asked to identify the most important issues to be addressed by the Update 2013. A comprehensive list was developed, and the top three issues were substance abuse and treatment needs, particularly the extent to which Ryan White funded substance abuse treatment addresses these needs, the emerging population of Young Men who have Sex with Men (YMSM), and retention in care (in follow up to the 2011 Needs Assessment and Update 2012), specifically the extent to which the EMA's retention in care policy changes have affected retention in care.

The Needs Assessment – Update 2013 continued to be mindful of the National HIV/AIDS Strategy and sought information that would enable the EMA to improve access to and retention in care.

The goal of the Needs Assessment - Update 2013 was to obtain as much input as possible about the community from consumers and provider agencies, while utilizing existing sources and work done by the Council. The Council utilized quantitative methods including a consumer survey and review of CHAMP client level data for FY 2011 and FY 2012, and qualitative methods including interviews of key informants to obtain comprehensive and detailed input from providers. For the consumer survey, the EMA continued to use a two-page questionnaire which was entered by EMA staff and masters-level college interns into a new data collection tool, Kwiksurveys, for entering and tabulating responses. We continued to use a Key Informant questionnaire in Microsoft Word format to allow agencies to enter detailed information, with enough available space, and allow agencies to save the document to their desktop and complete the survey in increments as information was obtained. (This method was begun in 2012.) Upon completion, providers e-mailed the survey document to the Council. This method was easier for providers due to the length of the survey and need for comprehensive and detailed responses. The Council followed up with individual Key Informant telephone interviews with each provider, to clarify any responses and obtain additional information. Results of the phone interviews were added to the hard copy survey, and all results were tabulated. This method was found by providers to be appropriate for the information requested.

Information was also obtained through public testimony, information discussions and reports, and additional analysis of client level data (CLD) from the EMA's Comprehensive HIV/AIDS Management Program (CHAMP) system. The methodologies are discussed in each chapter.

Data on utilization of Part A and MAI (Part F) services was obtained from the Newark EMA Grantee and the Comprehensive HIV/AIDS Management Program (CHAMP) system.

The Needs Assessment - Update 2013 incorporates directions from HRSA/HAB and reflects current policies and information including the National HIV/AIDS Strategy, retention in care, ands New Jersey's upcoming implementation of Medicaid Expansion in 2014 under the federal Affordable Care Act (ACA).

PART 1: SUBSTANCE ABUSE UPDATE

1.1 Background

Substance use, particularly Injection Drug Use (IDU), has been a leading exposure category for HIV infection in the Newark EMA. Substance use is also a comorbid factor in the spread of HIV infection by heterosexual contact and men who have sex with men (MSM). However, IDU has declined over the past 5-10 years and use of other drugs has increased. This trend has been attributed to the increasing purity of heroin which does not require injection and increased availability of other non-injecting drugs including prescription drugs and alcohol. The Council has questioned whether the substance abuse treatment continuum funded by Ryan White continues to address the needs of the new substance using population, or should changes be made.

Research Question #1
What are patterns of substance use among PLWHA in the EMA, particularly non-injection drugs, what treatment modalities are needed by non-injection drug users, what is the availability of those modalities, and how can Ryan White help fill any gaps?

Specific services include:

- **Key Informant Interview – NJ substance abuse treatment system.** Develop an outline or Key Informant tool to obtain information about substance abuse services statewide, to be used when interviewing the NJ Department of Human Services, Division of Mental Health and Substance abuse Services (DMHAS) with a concentration on non-injection drugs and the drug treatment policy approach, system and funding.
- **Key Informant Interviews – substance abuse system within the Newark EMA.** Develop an outline or Key Informant tool to obtain information about substance abuse services within the EMA, with a concentration on local providers regardless of Ryan White funding and County substance abuse planning entities.
- Develop a questionnaire or tool to **survey consumers** throughout the EMA regarding their substance use. Include tobacco, alcohol, injection drugs and non-injection drugs including prescription drugs. Follow established protocols including those from the USDHHS and SAMHSA and other sources. Administer the survey with assistance from Council staff. Council will take the lead on disseminating the survey and receiving responses.
- Assist in conducting the key informant interviews for both the state and county entities.
- Review results of KI interviews and obtain clarification as needed.
- Prepare tabulation and report of consumer surveys using SPSS or other mechanisms. Review results and conduct analysis of results.

Report. Prepare report of findings and recommendations for possible changes in substance abuse services funded by the Newark EMA Ryan White Program. Include recommendations for changes in substance abuse allocations and for specific directives to the grantee as appropriate based on findings.

Methodology

This section of the Needs Assessment included development of three tools by the Research and Evaluation Committee (REC) - (1) key informant interview guide for state substance abuse agency – NJDHS, DMHAS (2) key informant interview guide for substance abuse provider agencies in the Newark EMA (both Ryan White and non-Ryan White funded), and (3) development of a Consumer Survey of Health Issues.

Key informant (KI) interview guides were based on current needs and an assessment of the impact of emerging polices including health care reform – the Affordable Care Act (ACA) and Medicaid Expansion in New Jersey.

The consumer survey prepared based on prior consumer surveys (questions regarding demographic information, HIV diagnosis, and HIV medical care) and from the SAMHSA 2010 National Survey on Drug Use and Health (NSDUH) which is a validated tool used in annual nationwide surveys on substance use.

1.2 New Jersey and County Substance Abuse Treatment System

The purpose of this section was to survey the NJ Department of Human Services, Division of Mental Health and Addiction Services (DMHAS) to assess statewide policy and perspective regarding emerging trends in substance use. However, the Council decided to survey the County Drug and Alcohol Directors within the EMA. **Three of the five county agencies responded – Sussex, Union and Warren counties.**

The KIs were administrators for the county drug and alcohol programs. They manage funding the counties receives from the state N.J. Department of Human Service (NJDHS), Division of Mental Health and Addiction Services (DMHAS), particularly for those who are medically indigent (i.e., those who do not have insurance or money to pay for services). Administrators in the smaller counties also have other roles. One also provides case management for individuals convicted of DUI (Driving Under the Influence) who have been mandated to complete treatment.

1. **Do you have any estimates about substance abuse prevalence in New Jersey – for the state, by county, and for the Newark EMA and Newark area in particular? Substances include: (1) tobacco, (2) alcohol, and (3) illegal drugs and prescription drugs. In other words, what percent of the population uses these substances and what percent abuses them? (Abuse to the extent of needing treatment or other measure that you have or that is recognized by the SA treatment community.)**

The three KIs provided data on substance abuse prevalence from the most recent versions of two sources published by DMHAS: **NJ-SAMS Substance Abuse Overview 2012** and the **2013 NJ Chartbook of Substance Abuse Related Social Indicators.** The following table shows treatment admissions by substance for all five counties. In all counties the primary drug for treatment admission was heroin and other opiates, followed by alcohol and marijuana.

Current substance use in available in the 2013 NJ Chartbook of Substance Abuse Related Social Indicators. For five counties in the EMA, 31%-56% of high school students and 45%-64% of adults reported alcohol use within the past 30 days; 16%-21% of high school students and 17%-21% of adults

reported 30 day tobacco use; and 12%-19% of high school students and 2%-4% of adults reported 30 day marijuana use. Also 20%-31% of high school and 2%-7% of adults reported past year marijuana use.

The KIs agreed that many more people needed treatment but could not access it for various reasons, so the treatment numbers are only minimums. Most KIs had no way to estimate the number of people who need treatment but do not get it. However, the Warren KI advised as follows. It is estimated that approximately 10% of the total population would meet requirements for substance abuse treatment. The estimated population of Warren County in 2013 eligible for treatment admission by age is approximately 109,000, therefore, approximately 11,000 people would meet criteria for substance abuse treatment. This is much less (90%) than the 1,109 residents of Warren County who received treatment in 2012.

Table 1: Substance Abuse Treatment Admissions in 2012 – 5 Counties and New Jersey

Primary Drug	Essex	Morris	Sussex	Union	Warren	Total	NJ
Number of Admissions							
Alcohol	1,387	1,090	442	1,097	372	4,388	23,156
Heroin & Other Opiates	3,175	1,174	700	1,411	441	6,901	33,507
Cocaine	515	126	35	311	54	1,041	4,415
Marijuana	1,339	370	117	780	201	2,807	12,447
Other Drugs	162	66	23	92	41	384	2,312
Total	**6,578**	**2,826**	**1,317**	**3,691**	**1,109**	**15,521**	**75,837**
IDUs	1,250	773	534	654	322	3,533	19,323
Smoke Tobacco (Yes)	4,597	1,913	992	2,571	803	10,876	53,176
Percent of Total							
Alcohol	21%	39%	33%	30%	33%	28%	31%
Heroin & Other Opiates	48%	42%	53%	38%	40%	44%	44%
Cocaine	8%	4%	3%	8%	5%	7%	6%
Marijuana	20%	13%	9%	21%	18%	18%	16%
Other Drugs	3%	2%	2%	3%	4%	3%	3%
Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**
IDUs	19%	27%	41%	18%	29%	23%	25%
Smoke Tobacco (Yes)	70%	68%	75%	70%	72%	70%	70%

Lack of funding is the biggest problem or reason that people cannot get access to treatment. Counties are funded on a calendar year basis. As of July 2012, Sussex County has already spent our county funds for inpatient services and detox programs for the year. Transportation may be a problem for some people, but I think most people have a way to get to the providers they need to access. There may also be a problem with waiting lists. Some providers are serving multiple sites and draw clients from various agencies so they may have waiting lists. It is typical to run through that funding within the first 6 months of the year. There may be state funds available for those programs, but county funds usually run out within the first 6 months.

a. Illegal drugs and prescription drugs have been outlined in the SAMHSA 2010 National Survey on Drug Use and Health. We have summarized them in the consumer survey

to be administered shortly within the EMA (attached). Can you identify any problems of importance to NJ and the Newark area?

In Sussex County, heroin and alcohol are the two primary problems. (The KI added anecdotally that "I wouldn't be surprised if crime rates have increased, but I don't have any data on that.")

In Warren County, the problems are problem drinking/binge drinking/underage drinking, medication misuse, heroin addiction and new and emerging drug abuse.

Union County answered as follows. In the **New York/New Jersey High Intensity Drug Trafficking Area (HIDTA) Drug Abuse Assessment 2012**, the report states that in "Union County, total admissions for heroin, opiates, marijuana, and cocaine increased 14% from 2,207 admissions in 2006 to 2,512 in 2011. The rate of admissions for heroin peaked in 2007 at 324 admissions per 100,000 residents. It has since declined to 231 admissions per 100,000 residents in 2011. Heroin accounted for 57% of admissions in Union County during the 2006 to 2011 period, more than any other drug category. Cocaine admissions peaked in 2007 at a rate of 85 per 100,000 residents but have since declined to a rate of 57 in 2011. Opiate admissions increased from a rate of 6 per 100,000 in 2006 to 33 in 2011. The number of admissions for opiates rose from 33 to 178 during the six-year period 2006-2011. The rate of marijuana admissions rose from 86 per 100,000 residents in 2006 to 145 in 2011. During the 2006-2011 period, marijuana admissions accounted for 25% of the total admissions in Union County."

It is important to note that the HIDTA report does not track alcohol admissions, which was the second highest primary drug for admission at 30% of admissions for Union County in 2012 per NJ-SAMS.

b. Can you give us an idea of the sources of these estimates? What are the sources that NJDHS relies on for SA? (This documentation would be very helpful to assist in our own analysis.)

The two primary data sources are the annual **NJ-SAMS Substance Abuse Overview 2012** and the **NJ Chartbook of Substance Abuse Related Social Indicators.** A third source for Union County was the **New York/New Jersey High Intensity Drug Trafficking Area (HIDTA) Drug Abuse Assessment 2012.** It was noted that the Chartbook draws its data from multiple sources (e.g., school surveys) which can get data for subpopulations including youth.

Sussex County recently conducted a focus group mainly among treatment providers (but some consumers participated) for co-occurring disorders. They found an increase in the number of consumers with both mental health and substance abuse problems. These individuals are difficult to treat within the state system because it is felt that the state system is not conducive to treating these clients. Some providers in Sussex County can treat these clients and they do a good job. It is possible that health reform (expanded insurance) may help in this regard, but there are too many unknowns to say for sure.

c. Do you have any estimates for PLWHA? Do you know if substance abuse is higher for PLWHA than the general population? Can that be quantified? If so, what are these estimates?

The agencies had no estimates for PLWHA served by their programs. They were aware of HIV surveillance data and transmission by Injection Drug Use (IDU). There was no one in their specific departments who could speak to the needs of PLWHA with respect to substance use.

2. What substances are used and abused? Specifically, illicit drugs and prescription drugs.

The counties reported that both illicit and prescription drugs are used and abused. There is a problem with Oxycodone. People start on that because it is easily available and then move on to heroin because it's cheap and available. It is evident that opioid use has increased. Typically it starts with prescription drug use and abuse which leads to heroin use/addiction. They reported that providers would have better information on the specific substances abused.

3. What are the trends for specific substances? Which are increasing and decreasing?
- **a. What are the [possible] reasons for these trends?**
- **b. Do you see any trends specific to the Newark EMA?**

Heroin use continues to increase; it is mainly among younger people (18 to 24). The reasons are that heroin is cheap and easy to get, and there is increasing current cultural acceptance of over-medication, and need for immediate gratification. The common trend in the counties is prescription drug abuse among young adults that leads to heroin addiction.

4. How would you describe the need for substance abuse treatment in New Jersey (and Newark EMA to extent possible)?
- **a. Trends - Increasing? Decreasing? No change.**
- **b. Types of substances used – changing or static? Describe.**

The need for substance abuse treatment is increasing in all counties.

The types of substances used which are feeding the increase are prescription drugs and heroin, particularly among young adults. The trends in Union County point to an increase in heroin and other opioid abuse, alcohol abuse, and an increase in admissions for marijuana abuse.

Inpatient and detox services are seeing most of the increase in need. You can't move on to other types of care (e.g., outpatient services) until you complete 4-5 days of detox. Many patients need extended inpatient services besides detox to avoid relapse. All services are needed but you need these services first for other programs to work effectively.

Warren County has limited substance abuse treatment resources as we do not have in-county detoxification or residential substance abuse programs. Little Hill Alina Lodge, a private long term residential substance abuse facility in Blairstown is not accessible to most Warren County residents due to its high cost. Warren County could use additional outpatient and intensive outpatient services for adults and adolescents. In-county detoxification and residential treatment programs for adults and adolescents would benefit county residents seeking treatment.

5. Describe the substance abuse treatment system in New Jersey (and Newark EMA to extent possible).

a. What types of programs are available?
b. What types of facilities?
c. Has the system changed over the past 10 years? Expanded, contracted, changed focus, etc.
d. Have the changes helped to better address need?
e. What are the gaps if any in the system?

Types of programs available. In Sussex County, available programs include detox, short term inpatient, and outpatient services. There are [types of] additional ambulatory outpatient programs but it is unknown if they are approved in the state. There are also halfway houses (i.e., residential facilities that are not considered outpatient treatment). Sussex County funds some within the county and even one located outside of the county.

In Sussex County, there are three outpatient facilities in the main area of Newton. It takes about one hour to get from one end of the county to the other and there really are no facilities in the northern part of the county (i.e., in Vernon) even though there is a big population there in need of services. There is no public transportation available, but people find a way to get to appointments.
For Union County, the following substance abuse treatment services are currently available in county: outpatient detox services, intensive outpatient services, outpatient services for adults and adolescents and a halfway house for men. Through the County's DMHAS Alcohol & Drug Abuse grant, Union County funds treatment services out of county for low-income, uninsured adults and adolescents in the following modalities: inpatient detox services, short-term residential services, and halfway house services for women. There is a detox unit and a short-term residential program in county at Summit Oaks Hospital in Summit, but they do not accept Medicaid or offer charity care at this time.

In Warren County, available programs are outpatient treatment for adults and adolescents, and intensive out patient treatment for clients with co-occurring disorders.

Types of facilities. In Sussex there are private practices but none receive county funds.

In Union County, there are large regional medical centers, non-profit agencies, as well as individual practitioners providing substance abuse treatment services. The County subcontracts with inpatient facilities out of county to provide the following services for low-income, uninsured residents: inpatient detox, short-term residential services and halfway house services for women.

The Family Guidance Center of Warren County offers mental health services and substance abuse treatment services. Hackettstown Community Hospital offers outpatient and intensive outpatient services for adults and adolescents.

Changes in the System over the past 10 years. In Sussex County the system has expanded in that there are more outpatient providers. (There are two or three new providers. One insurance-based provider new in the past few years does not receive state or county funds. Another is relatively new but has existed for nearly 10 years.)

In Union County, some agencies have changed ownership, and some agencies have changed the focus of the services that they provide. For the most part the overall service delivery system in the county has not changed dramatically in the last ten years.

Warren County KI noted that the system is driven by state and county funding; therefore, due to the economic constraints, levels of service have remained same or decreased.

Have the changes helped to better address need? Yes and no in Sussex County. More funding is needed for individuals who do not have insurance or money to pay for treatment. The percentage of people needing care who either have no insurance or need money varies by the type of treatment and substance abused. For example, many people who abuse heroin have lost their jobs and are dealing with drug court, so a large percentage of them need money to cover services.

The need for services is greater in Union County than the available funding or the capacity of the agencies to meet the demand for substance abuse treatment services. This has been a consistent condition in the county.

Warren County continues to collaborate with our neighboring counties to provide services to our residents.

Gaps in the system. In Sussex County the only detox provider has a small number of beds and many funding sources, so there is not always immediate access to treatment. Recruitment of additional providers is beyond the scope of county duties. One new agency provides outpatient mental health/ substance abuse services for co-occurring disorders, but helping to open this service was not initiated by the county. The state would have to issue a request for funding proposals to start the process of recruiting more treatment agencies.

Union County currently does not have an inpatient detox unit or short-term residential program that accepts Medicaid or has a County or State contract to provide these services to low income, uninsured citizens. Summit Oaks Hospital provides these services, but does not accept Medicaid or provide charity care. A halfway house for women and children in Union County can accommodate five families. The County has a subcontract with a halfway house for women in another county, but the county does not have a great deal of funding for that modality. There is a greater need for this service in county. Transportation to treatment services continues to be a gap in service that is not always easily addressed.

In Warren County, the gaps are lack of in-county detox and residential treatment programs (adults and adolescents). Additional gaps are lengthy waiting lists for outpatient services due to insufficient funding, limited public transportation, and poverty, lack of employment, inadequate or lack of health insurance.

6. What are the funding sources for substance abuse treatment? SA block grant, health insurance, Medicaid, Medicare, etc.

All of above are funding sources for substance abuse treatment. Actually, Medicaid and Medicare are not really sources of funding. There are no providers [in Sussex County] that rely on them because their rates are too low. There are also the drug courts and the DUI Initiative (a program that uses fines from DUI arrests/convictions to fund treatment services). The Substance Abuse Block Grant comes to counties from DMHAS through Chapter 51. This is the predominant source of County substance abuse treatment funding.

a. Does NJ provide any state funding for SA treatment? (Amount, estimated allocation for Newark EMA, trends). Current dollar amount for 2013. (By county if possible.)

DMHAS provides funding from the Block Grant. The county only provides the minimum match required by the Chapter 51 legislation. Through the County's Alcohol & Drug Abuse grant from DMHAS and the County's matching funds, substance abuse treatment funding will be available to low-income, uninsured adults and adolescents by County as follows.

Table 2: Estimated 2013 Substance Abuse Block Grant Funding and County Match for 3 Counties

	DMHAS	County	Total
Sussex	N/A	N/A	**$43,352**
Union	N/A	N/A	**$903,358**
Warren	$188,739	$110,781	**$299,520**
Total			**$1,246,230**

b. Does NJ or the county provide any state funding for SA treatment for PLWHA? (Amount for 2013 = total NJ, for Newark EMA (by county if applicable).

There is no separate allocation of county or state funds for substance abuse treatment for PLWHA. Either they receive services as low income, uninsured individuals or through Ryan White funding. The amounts of Ryan White funding are available from the City of Newark and Ryan White Grantee.

c. What are the trends in these funding sources? (Increasing, decreasing, static)

These funding sources are static over time, notwithstanding slight fluctuations year to year.

d. What are the gaps in these funding sources? How much is not covered? What is the service gap or unmet need?

Sussex County found that there are no current gaps in services (all appropriate types of treatment services are available). However, demand exceeds availability of funding, and sometimes availability of detox or inpatient beds. In other words, the demand for the types of services exceeds the supply. Technically, this is not a service gap but a funding gap.

Union County reported that each year, the funding for low-income, uninsured individuals is not adequate to meet the demand for services. The subcontracts to agencies run on the calendar year and by the third and fourth quarter, many of the 2013 subcontracts will be fully expended.

Warren County found that current funding levels only provide treatment to approximately 10% of the need, leaving 90% as unmet need for substance abuse treatment.

With respect to perceived lack of services in the northern part of the state (Sussex County), this is not seen as a gap in coverage. This is because people in those areas are able to access the services that are currently provided and available in the county. There are no efforts underway to try to increase coverage in the north. There would have to be more than the need for services in that specific area to justify the expense of locating services there because the county is mostly rural.

7. What effect will the proposed Medicaid expansion help fill funding gaps in SA treatment? Does the Essential Health Benefits package include substance abuse treatment (tobacco, alcohol, illegal and prescription drugs)? If Yes, to what extent?

In general, the counties have little information about the impact of healthcare reform and Medicaid Expansion on substance abuse treatment services. The impact "remains to be seen", but help in filling gaps is "what is expected." Hopefully, many more individual will be able to receive substance abuse services through Medicaid. However, we are still concerned that are going to be many individuals who will have no health insurance but do not qualify for Medicaid benefits.

Although Medicaid (or the Marketplace) might be another source of insurance coverage, it will be helpful only if providers are willing to accept those sources of coverage. This may be a problem, because the detox providers are expected to accept Medicaid but they may decide not to.

Counties do not know whether the Essential Health Benefits package includes substance abuse treatment (tobacco, alcohol, illegal and prescription drugs), because this is a statewide decision not a county decision.

8. Could you please provide an assessment of the adequacy of SA treatment in the Newark EMA versus the need? What substances are covered well and what are the gaps?

Treatment is not based on the substance used but level of care needed. Treatment is determined by the level of individual functioning. It depends on how much substance abuse has made their lives unmanageable. The substance itself doesn't determine the level of care needed.

In Sussex County, the treatment is not adequate because the need is greater than what is available due to lack of funding and only one detox and inpatient provider in the county.

In Union County, intensive outpatient and outpatient services are the highest priority modality in our current grant cycle based upon the last Alcohol and Drug Abuse Needs Assessment. Union County allocates the highest level of funding overall to these services for adults and adolescents. The need for detox services and short-term residential services continues to outstrip the available funding and is an area along with halfway house funding for women and children that remains a gap in our system of care.

In Warren County, through careful planning and collaboration, we make every effort to meet the treatment needs of our residents. However, this is becoming more challenging as the demand increases and the treatment capacity has decreased over the past years.

9. Based on the overall trends in substance use, availability of treatment and funding sources, what are some recommendations for use of Ryan White funds to fill gaps for SA treatment in the Newark EMA for PLWHA?

- **a. What kinds of services? Intensive outpatient, residential, other (identify).**
- **b. What kinds of substances?**
- **c. Is there any emerging need that is not being covered by traditional sources that Ryan White could fill in gaps and help meet need?**

Treatment needs of PLWHA are not necessarily distinguished from other populations in two counties. In Warren County, PLWHA have not been identified as a priority population (in their substance abuse needs assessment). More outreach needs to done to identify individuals needing services.

In Union County, it would be very beneficial to our efforts to effectively coordinate substance abuse care within the county if the Ryan White funds were directed toward (1) funding in-patient detox and short-term residential programs and (2) the expansion of halfway house services for women and for women with children. I would also propose that Ryan White funds be directed toward recovery/wellness services that included transportation and Wellness Coordinators to facilitate participation in programs as a vitally needed recovery support service. This funding would address gaps in the current system of care in the county. These services would be used by all individuals in need of substance abuse treatment and would be beneficial no matter what substance is abused.

1.3 Substance Abuse System within the Newark EMA

The Key Informant Substance Abuse Interview Guide was distributed to **over 20** substance abuse providers in the Newark EMA both funded and not funded by the Ryan White Program in April 2013. It took a while to get responses even from the RW-funded providers. In the end, **10 agencies responded as key informants.**

10. Do you have any estimates about substance abuse prevalence in the Newark EMA? Substances include: (1) tobacco, (2) alcohol, and (3) illegal drugs and prescription drugs. In other words, what percent of the population uses these substances and what percent abuses them? (Abuse to the extent of needing treatment or other measure that you have or that is recognized by the SA treatment community.)

Some of the agencies did not have estimates on substance abuse prevalence in the EMA. Most agencies said that the prevalence of substance abuse was extensive. Some agencies provided data on treatment admissions for their Ryan White clients.

One agency cited data from a number of sources – state-level data on treatment admissions provided by NJDHS/DMHAS, and nationwide data on substance use and abuse from SAMHSA. State data are discussed in the above section for New Jersey and County Substance Abuse Treatment System. The table below is based on data from the SAMHSA 2011 National Survey on Drug Use and Health (NSDUH).

Table 3: Estimate of Substance Abuse and Treatment by NSDUH in Newark EMA - 2011

County	Population Age 12+	Abuse Drugs/Alcohol		Treated	
		#	%	#	%
Essex	783,969	69,960	8.9%	6,996	10%
Morris	492,276	34,720	7.1%	3,472	10%
Sussex	149,265	17,480	11.7%	1,748	10%
Union	536,499	35,100	6.5%	3,510	10%
Warren	108,692	11,470	10.6%	1,147	10%
Total EMA	**2,070,701**	**168,730**	**8.1%**	**16,873**	**10%**

Source: SAMHSA, National Survey of Drug Use and Health, 2011.

http://www.icpsr.umich.edu/icpsrweb/SAMHDA/studies/34481

- **Tobacco usage** is estimated by SAMHSA for New Jersey statewide. A total of 1,795,000 New Jerseyans are estimated to have used a tobacco product during the past month in 2008-2009. This represents 20.4% of the population statewide. County-level tobacco usage data has not been found.
- **Nonmedical Use of Prescription Pain Relievers** in NJ in 2010-2011 for persons aged 12 and older is 4.14%, which is a relatively low rate – 39th out of the 50 states. This calculates out, however, to 363,984 New Jerseyans who abuse prescription pain relievers annually. Since the 5-county NEMA area constitutes 24% of the state population, it is reasonable to calculate that the 5 NEMA counties include at least 86,000 individuals who abuse prescription pain relievers.
- All providers were aware that substance use increases the likelihood of HIV transmission.

Another Ryan White–funded substance abuse treatment provider reported the data to the right for its client population. The agency uses the Harm Reduction Model of Treatment. The goal is abstinence – but the use of illegal drugs and the abuse of prescription drugs is being reduced toward achieving the ultimate goal of complete abstinence.

Substance	Abuse	Use
Tobacco	51%	46%
Alcohol	31%	74%
Illegal Substances	9%	66%
Prescription Drugs	96%	100%*

*This agency provides methadone maintenance

a. Illegal drugs and prescription drugs have been outlined in the SAMHSA 2010 National Survey on Drug Use and Health. We have summarized them in the consumer survey to be administered shortly within the EMA (attached). Can you identify any problems of importance to the Newark area?

NJDHS/DMHAS data confirm that the Newark area suffers from a disproportional dependence on and abuse of illicit drugs, but the percentages vary by county. Roughly 3.5 times the number of individuals were admitted into treatment for the abuse of drugs in Essex County (5,432) as for the abuse of alcohol (1,564). In Morris County, by contrast, drug abusers admitted into treatment (1,904) represent only 1.2 times the number of alcohol abusers admitted into treatment (1,568).

Specific substance abuse issues cited are:

- Alcohol, crack-cocaine, and heroin are the most problematic drugs in the Newark area.
- Sharing needles is still a very common form of injecting illicit drugs.
- Illicit use and re-sale of prescription drugs has increased substantially. News agencies have cited a 40% increase in the illicit use of prescription drugs from 2005 to 2013, primarily due to low cost and easy availability. Drugs include Xanax, Percocet, Oxycontin (used in place of heroin), and suboxone, an opioid medication (narcotic) used in detox.
- Most PLWHA are not only using prescription drugs but they're abusing them. The dependence on these prescription drugs is extremely high which looks as if they've replaced their former substance abuse habit with a dependency on prescription drugs.
- The problem is consumers selling their medication. Our counselors have discovered some of our consumers have been going to their infectious disease, primary care doctor and psychiatric

doctor requesting the same medication around the same time. Unfortunately there is no medication monitoring and no consistent communication with doctor-to-doctor.

- Union County noted consistent use and abuse of Xanax, Oxycodone, and Heroin, and an increase use and abuse of "Molly" especially in the Young MSM population.

b. Do you have any estimates for PLWHA? Do you know if substance abuse is higher for PLWHA than the general population? Can that be quantified? If so, what are these estimates?

For the most part, respondents did not have estimates of substance abuse among PLWHA versus the general population. One agency cited the prevalence of HIV stigma as a reason for high rates of substance abuse among PLWHA. A high population of consumers has not disclosed their HIV status and feels that they have no one in their family as their "go to" person.

One agency provided estimates. Our experience is that PLWHA abuse substances at a far higher rate than the general public. Based upon eight years of admissions and treatment data for 1,950 PLWHA admitted to our facility from 1995-2013, fully 85% to 90% of our residents suffer from substance abuse compared to a statewide estimated percentage of 7.46%. Individuals suffering from mental health issues use substances to self-medicate and, during the periods when they are abusing substances, they engage in risky behaviors including IV drug needle sharing and/or sex with multiple partners which results in their becoming infected with the HIV virus. For these reasons, a high percentage of PLWHA are also substance abusers.

11. What substances are used and abused? Specifically, illicit drugs and prescription drugs.

#1 Alcohol. All providers agreed that alcohol may arguably represent the most significant proportion of substance abuse among the PLWHA population because of its availability, social acceptance and relatively inexpensive cost.

#2 Heroin and Other Opiates. These were the 2nd most abused drugs reported by respondents. Heroin is much cheaper than cocaine, is very pure, and therefore is more widely used. Heroin and opiates are the primary drugs used by some agency clients.

#3 Prescription Drugs. All respondents reported that prescription drug abuse is a growing and major problem in the EMA.

#4 Crack Cocaine, Marijuana (no specific order).

- Crack-cocaine is extremely cheap and extremely addictive. It is much more prevalent in the Newark area than in other areas of the state.
- To our agency, marijuana is the second most commonly abused substance, because it is so cheap and also because you have to be in possession of a lot of marijuana in order to be arrested. Possessing a small amount doesn't generally result in an arrest.

#5 Other Substances (no specific order)

- Inhalants are very popular with teens. They will inhale anything: Wite Out Correction Fluid, glue, paint thinner, cleaning fluids, gases. Inhaling is exciting and the substances are very cheap and available. They are also very damaging.

- Prescription drugs such as Xanax, Percocet, Oxycontin (used in place of heroin), and suboxone, an opioid medication (narcotic) used in detox.
- Mollies – a newish party drug popular with teens; in powder and capsule form. Also known by its acronym "MDMA" which stands for methalinedioximethamphetamine.
- Cocaine – expensive, and therefore usage not increasing in the Newark area during this economic recession.
- Ecstasy – tends to be more popular in more affluent areas, not in the Newark area.
- LSD is not as popular as it used to be.

The following provider comments show individual agency experiences.

- I have also observed a preponderance of prescription drug abuse, specifically benzodiazepine and opioid medication (such as Xanax and Oxycodone respectively) and to a lesser degree, antidepressant medication, e.g., Elavil. Crack cocaine, heroin and marijuana are also among the most prevalently abused substances by the PLWHA population.
- We found that the data entered into the NJSAMS website does not generate reports on the other opiates which include prescription drugs such as Xanax, hydrocodone, Oxycontin, Lorazepam, etc.
- Substances being abused amongst PLWHA are illicit drugs such as Cocaine (Sniff), Cocaine (Injection), Cocaine (Crack), Marijuana, Heroin (Sniff), Heroine (Needle), Hallucinogens, Inhalants, and prescription drugs such as Xanax, Valium, Pain Relievers, Oxycodone, Stimulants, Sedatives.
- Additional substances include Xanax, Percocet, Ativan, Oxycontin, Oxycodone, PCP, Suboxone, THC, and even beer.

12. What are the trends for specific substances that you see in the Newark EMA? Which are increasing and decreasing?

One conspicuously increasing trend of substance abuse among PLWHA seems to be a proliferation of abuse of the prescription pain medication, possibly because it may be freely prescribed by physicians with little or no regard to the patient's substance abuse history, and/or because the patients may be selling the medication to help meet their financial needs.

Most agencies are seeing increases in abuse of the substances discussed above. Specifically, heroin and other opiates, known prescription drugs (Xanax, hydrocodone, Oxycontin, Lorazepam, Percocet, etc.). There is a significant increase in consumption among young adults for other opiates, despite the fact that this population is educated.

a. What are the [possible] reasons for these trends?

One agency reported that the economic recession, higher than usual unemployment, and cut-backs in government support programs are all reducing the amount of money that substance abusers have available to purchase drugs, alcohol, and tobacco. Consequently, we are seeing an increase in the use of the cheapest substances, like prescription drugs, especially among the young and indigent populations. These factors may also be contributing to what seems to be an increase in teens stealing and abusing prescription drugs from their elders.

The accessibility and availability of heroin and prescription drugs, including the high quality of heroin, contribute to its widespread abuse. These drugs produce the desired affect, and the method of administration is varied. Likewise, marijuana is readily and inexpensive.

Addiction to prescription drugs often starts with minor medical procedures. One client had recently been to a dentist, had minor surgery, and was prescribed some opiates for pain and discomfort. Clients take these drugs to ease the pain and then get high and addicted. Clients are prescribed pain killers easily through their primary healthcare physicians.

Some physicians prescribed these drugs without concern for the clients' prior or current addiction history. Some physicians may be too liberal with prescription drugs that are addictive to clients with addictive disorders. Clients state that when they are done with their prescribed medications they turn to heroin which is very accessible and inexpensive in Newark.

13. How would you describe the need for substance abuse treatment in the Newark EMA?
- **a. Trends - Increasing? Decreasing? No change.**
- **b. Types of substances used – changing or static? Describe.**

Increasing Trends in Need for Substance Abuse Treatment. All agencies agreed that the need for substance abuse treatment in the Newark EMA is increasing.

There is a DEFINITE increase in the need for substance abuse treatment services in the NEMA especially addressing the use of prescription drugs. Providers need to be educated as well regarding the damage being caused by their use of these drugs in patient treatment plans. The types of substances used have not changed much with the exception of "Molly" which is increasing in the younger patient population.

We believe that substance abuse treatment in the Newark EMA area is a need that will never be fulfilled. In the 40 years we have been in operation especially in Newark we have never seen a decrease in need. Treatment needs are becoming more complex with an increase in co-occurring disorders. Funding to support this comorbidity is not available on a uniform basis or for all treatment modalities. Providing mental health services is so critical while in treatment.

We can expect to see an increase in addictions and demand for treatment when the Affordable Care Act (ACA) becomes available for all individuals in NJ, specifically, through Medicaid Expansion. If we already recognize an increase in prescription drug abuse with limited access to healthcare, we can only assume that there will be an increase in addictions when health care is more widely available.

We expect to see additional demand for services of the substance abuse/behavioral team - the psychiatrist and Licensed Clinical Social Worker (LCSW) who provide treatment for mental health disorders in an Outpatient basis in coordination with the substance abuse treatment. Without sufficient funding, we must refer those with co-occurring disorders to an outpatient mental health treatment provider.

Regardless of whether substance abuse is increasing, decreasing, or remaining static, another dynamic is making it harder for substance abusers to kick the habit: <u>The barriers to receiving treatment are increasing</u>. Reductions in funding for substance abuse treatment translate into fewer slots and less treatment being available. The economic recession and unemployment also mean that individuals who

need treatment are even less likely to be able to afford it. It also means that substance-abusing mothers are facing increased barriers to accessing treatment because of the reduction or disappearance of programs which might have cared for their children while the mother is in treatment. Hospitals are also merging or shutting down, representing another decrease in the availability of substance abuse treatment options. Detox, the critical first step in SA treatment, is almost unavailable. Bergen Pines has become one of the few places where detox services are available. However, if an addict can find detox, s/he really needs a residential program following detox. Otherwise, the addict will cycle in an out of detox, falling back into drug use soon after leaving detox. And the availability of these residential SA beds is virtually non-existent. Without a continuum of care that substantially funds 1) detox, 2) follow-on residential SA treatment, and 3) intensive SA outpatient services, most addicts will not be able to kick their habits.

State budgetary issues put pressure on the availability of Charity Care, which appears to be decreasing.[2] This further decreases the availability of SA Treatment, especially for the indigent and the formerly incarcerated who are not eligible for Medicaid or other funding.

Types of Substances. The increase in the types of substances used is discussed above.

One sees the slight increases in the cheaper and extremely physically damaging drugs like alcohol, crack-cocaine, heroin, and inhalants. Crack cocaine is still in high use because it is cheaper and more addictive than cocaine; however it causes brain damage, resulting in schizophrenia and paranoia. Some heroin usage appears to be decreasing because the dosages on the street are so weak that addicts are no longer getting the effect they want. The heroin is being cut with Xanax. In the place of heroin, addicts are using prescription drugs like Percocet and Oxycontin – they get the same high for less money and the effect lasts longer. There is still a high usage of cocaine, even though it is costly. Overall, there may be little change in the numbers, perhaps even a slight overall decrease due to the recession. One significant increase is in the illicit use of prescription drugs.

14. Describe the substance abuse treatment system in the Newark EMA as you see it. Reference any trends or changes statewide as needed.

a. What types of programs are available? The following are available in Newark EMA.

- Outpatient Care (OP): OP is the most prevalent.
- Intensive Outpatient (IOP): There are too few of these slots. Also, the Drug Courts seem to be sending their people to IOP and taking up the few slots that are available.
- Hospitalization: Funding for hospital-based Substance Abuse treatment has decreased to the point where individuals needing such care are claiming Mental Health problems (risk of suicide or depression), since funding for MH is better than for SA.
- Detox: Availability has been drastically reduced. The EMA needs significantly more drug detox capacity. There used to be 5-7 days of detox at all acute care hospitals. This has pretty much evaporated. There is still some alcohol detox available at acute care facilities (vitamin regime, hydration) perhaps because the risk of death from alcohol cessation is

[2] Funding for the New Jersey Hospital Care Payment Assistance Program (a.k.a. "Charity Care") has been either stable or increasing over the past few years. Increases in the cost of living and cost of treatment have the effect of making level funding appear to be a decrease. http://www.state.nj.us/health/charitycare/index.shtml

greater than for most drugs. Heroin detox still takes place in the acute care setting. Detox is currently available at

- Bergen Pines – co-located with other SA services, including some residential SA treatment. The facility had an increase in State funding.
- Salvation Army – a "work" program, where work is a pre-condition.
- Turning Point – services are decreasing because funding is tight.
- CURA – provides SA rehab, residential long-term. Have recently started a SA Outpatient program.
- Integrity House – provides therapeutic long-term residential SA treatment linked with Bergen Pines detox.
- Straight & Narrow (Paterson) – provides both therapeutic long-term residential SA treatment and supportive housing even for those in methadone treatment (Methadone treatment frequently precludes an addict entering a housing program because the housing program cannot deal with the Methadone regimen).
- Walter Hoving, in NY State – A women's residential SA treatment program.
- High Focus (Bergen County) offers both MH and SA treatment.

- Short Term Residential.
- Long Term Residential.
  - Residential SA treatment: Virtually non-existent, but greatly needed.
- Therapeutic Community.
- Methadone Outpatient.
- Methadone Maintenance.
- Alcoholics Anonymous (AA).
- Narcotics Anonymous (NA).

b. What types of facilities?

The types of facilities include residential, hospital-based residential, transitional/extended care, halfway house, hospital partial care/day program, and community based agencies/non-profits organizations and for-profit organizations which provide outpatient services. The types of facilities are detailed above based on the type of treatment.

c. Has the system changed over the past 10 years? Expanded, contracted, changed focus, etc.

The substance abuse treatment system in the Newark EMA is inadequate and shrinking. There are fewer treatment options available for individuals lacking in financial resources and health insurance. E.g., the only detox currently available for such individuals is Freedom Ministries' Friday morning "lottery." Otherwise, one must travel to Bergen Regional Medical Center in Bergen County for detox.

More facilities offering Outpatient services have opened.

The system has changed focus. It is no longer client centered. Presently, the focus is on the funding and the funding source and not so much the case for the consumer.

Changes in substance abuse treatment policy and reimbursement at the state level have adversely impacted the treatment system in the Newark EMA. The following examples were cited.

- Detox: Substance-abusing individuals used to cycle in and out of expensive acute care detox hospital beds every 30-60-90 days as a condition of maintaining welfare or other benefits, or as a condition of seeing their children involved in the child welfare system (Division of Youth and Family Services-DYFS). After detox, they would go right back to using illicit substances. So hospitals just closed down their detox units, as too costly and nonproductive.
- Outpatient: Has increased because it reduces the cost of using hospital beds.
- Intensive Outpatient (IOP): Has increased over the past 10 years because it is seen as a lower cost alternative to costly residential care. Unfortunately, IOP still facilitates the addict pursuing drugs because it does not remove the addict from the street and drug availability.
- Residential SA Treatment: Has been reduced to the point of virtual unavailability.
- Hospitalization: There has been a decrease in the number of bed slots for SA treatment, because the average cost of a hospital bed is now more than $3,000/day.

d. Have the changes helped to better address need?

The consensus among respondents is that changes have **not** helped to better address need.

- Detox is grossly unavailable.
- Also, while shifting funding from costly residential beds to less costly outpatient or intensive outpatient treatment slots looks like a cost-effective move, the continuum of care is significantly crippled because addicts in outpatient programs still have easy access to drugs, drug dealers, and drug-using acquaintances.
- Shifting people from one treatment location to another achieves nothing if there is no accountability and no way to even track clients after they leave one treatment location or one provider. The care and treatment system needs a more centralized, statewide tracking system with immediate input of usage data, contemporaneous with the delivery of service – beyond what is available in CHAMP, Medicaid, Medicare or insurance programs. For instance, data from these four systems are not centralized. Also, the pharmacies are not included in these systems and pharmacies are the central source of prescription drugs.
- We have lost treatment facilities, and there is limited detox facility treatment as a whole.

On the positive side, changes have helped addicts who may not qualify for inpatient residential services receive treatment in an outpatient setting. However this has resulted in an increased demand for community based agencies.

e. What are the gaps if any in the system?

The overall gap is insufficient resources to treat the need and demand. The National Council on Alcoholism and Drug Dependence (NCADD) of New Jersey reports that 42% (50,000) New Jersey residents who seek treatment were unable to access it due to limited capacity. Providers feel this is an understatement of the gap between demand and treatment need/availability.

One provider reported that there is not enough collaboration.

Another provider reported gaps between the substance abuse system and ancillary, supportive services.

- Substance Abuse Counselors need more Ethics training regarding relationship issues with clients, the abuse of power by counselors.

- They also need more training regarding area resources and where to refer people who need specific services not available at a given facility
- The whole healthcare system needs an electronic tracking capability to keep clients from hopping around and abusing the system. CHAMP has this capability for providers receiving Ryan White funding and the Homeless Management Information System (HMIS) system for tracking homeless clients is also available. These are limited tracking systems.
- Need to improve coordination between Substance Abuse counselors and the legal system (the courts and prisons). Clients moving out of prison and the court system should move seamlessly into a Substance Abuse program. Instead, because they have a criminal record, they are denied insurance, prevented from entering the programs they need. Thus those individuals involved with the court and prisons are being set up for recidivism when they move into the community and cannot access the services they need.

15. What are the funding sources for substance abuse treatment that you are aware of? SA block grant, health insurance, Medicaid, Medicare, NJ State funding, etc.

Funding sources for substance abuse treatment include the Substance Abuse Block Grant from NJDHS/ DMHAS which is the primary source, as well as health insurance, Medicaid, Medicare, Ryan White and County funds. Additional funding for specific populations is available from Work First NJ (WFNJ) Substance Abuse Initiative (SAI), and Drug Courts and Intoxicated Driver Resource Centers (IDRC).

a. Does NJ provide any state funding for SA treatment for PLWHA? (Amount for 2013 = total NJ, for Newark EMA (by county if applicable).

Some agencies provided their funding and others did not. Total funding for substance abuse treatment by funding source is available through the Newark EMA annual **Funding Stream Analysis** produced by the Planning Council.

b. What are the trends in these funding sources? (Increasing, decreasing, static)

All funding is static or decreasing relative to the need. Most PLWHA with substance abuse issues rely upon Medicaid, Medicare or charity care, which are increasingly inadequate, and Ryan White funds.

c. What are the gaps in these funding sources? How much is not covered? What is the service gap or unmet need?

The following gaps were identified.

- Need funding for services for individuals with a criminal history, who are denied access to so many needed services.
- Need funding for ID documentation, especially for the homeless service population. Both City of Newark Ryan White funding and NJDHSS-DHSTS funding appear to focus on salaries and fringe benefit costs and do not cover other expenses, even when minimal, that would enable services to be successfully delivered, such as funding to pay for helping clients obtain personal identification documents – key to their obtaining other needed services such as housing, welfare, other healthcare services not covered by Ryan White. Also, Vital Statistics office for Jersey City has moved down to Trenton and appears all Vital Statistics offices may soon move

down to Trenton – which means that indigent/low-income individuals needing Birth Certificates, for instance, who have to find a way to fund a round-trip commute to Trenton just to get a Birth Certificate, and pay for the Birth Certificate as well.

- Funding for services that would care for children of mothers seeking Substance Abuse treatment. They fear that DYFS will take their children away if there is no one to watch them.
- Ryan White program funding supports substance abusing PLWHA. If funding were to decrease we would have to put this population into a pool of clients that are admitted by Division of Mental Health and Addiction Services (DMHAS) into treatment under this grant.
- HOPWA funding is decreasing which helps support and provide stability to low income PLWHA while they are in treatment.

Substance Abuse Treatment Providers will transition into a Fee for Services contract with DMHAS in July of 2014. Contracted slots will no longer be awarded. This may or may not impact the capacity the agency will have to serve clients with or without HIV/AIDS. When the State completes its study and research on what services will be billable and share it with providers, it may or may not cover staffing and residential services resulting in some programs being lost or closed. There is much uncertainty as to what will be covered or not.

16. What effect do you think the proposed Medicaid expansion will have in helping to fill funding gaps in SA treatment? In what ways or areas (tobacco, alcohol, illegal and prescription drugs)? Please provide any additional comments.

Responses ranged from positive and hopeful to cautious and wary. The following topics were discussed.

Access to Substance Abuse Treatment. We believe that the affordable Care Act (Medicaid expansion) will bring more people into the healthcare system who will be seeking care for chronic diseases, which may or may not increase addictions due to illicit drug use. Funding will be made available for ambulatory and outpatient care.

We hope Medicaid expansion will help increase Substance Abuse treatment accessibility. At this point, no one seems to know what the effect of Medicaid Expansion or the ACA in general will have on healthcare access. Medicaid Expansion will be used in some capacity for treatment.

Additional Funding Stream/Source of Revenue. The proposed Medicaid expansion would greatly help fill the funding gaps in substance abuse treatment. The expansion will provide a new source of income to substance abuse treatment programs along with increased clientele. The expansion will provide for a population of individuals who could not afford treatment prior to the ACA, and the means to address substance abuse issues. This new population becomes the new revenue source for much needed additions to programs that have been dismantled, downsized, and disbanded, due to lack of funding.

Concerns about Types of Treatment to be Funded through Medicaid Expansion. The proposed Medicaid Expansion may be helpful in the areas of tobacco use/abuse, Intensive Outpatient (IOP) services, and counseling. But we are not sure if it will cover the growing need for inpatient detoxification and long term inpatient rehabilitation, and whether treatment in a residential facility setting will be reimbursable.

17. Could you please provide an assessment of the adequacy of SA treatment in the Newark EMA versus the need? What substances are covered well and what are the gaps?

Respondents said that the quality of substance abuse treatment programs in the Newark EMA is good. On the other hand, all respondents agreed that the substance abuse treatment system - capacity to treat the need - in the Newark EMA is inadequate to meet the need and is shrinking.

With respect to substances covered well by treatment, what is clinically important is the patient's subjective experience and not the specific substance abused. Substance abuse treatment has a wide variation in practices that are influenced by differences in program philosophy, goals, client needs, funding requirements and guidelines. However, no single treatment is appropriate for everyone; a comprehensive assessment is needed.

Gaps in the system have been discussed in previous questions but are summarized as follows. With the Medicaid expansion expected for 2014 under the federal Affordable Care Act more people will be seeking treatment and Treatment Facilities will need to prepare for an increase of clients.

- The overall problem is lack of funding.
- By **type of facility and program**, more outpatient services, more intensive outpatient (IOP) services, more hospital-based treatment, more residential substance abuse treatment, and more detox capacity is needed.
    - There are adequate services for patients willing to be enrolled in outpatient counseling programs, but the need for inpatient detox in extremely high and the services are inadequate. Patients abusing benzos and alcohol must be medically detoxed safely before they can enter IOP type services.
- The need for psychiatric evaluation and treatment of underlying disorders is inadequate, especially in patients who are abusing Xanax and other benzodiazepines.
- More treatment is needed for alcohol and heroin addicts as well as for addicts of crack-cocaine, which is so prevalent especially among the poorest of the poor.
- Most especially, greater accountability is needed both 1) by being able to electronically track clients throughout the healthcare system and 2) by holding providers accountable to increase evaluation of treatment outcomes by strengthening relationships between clients and agencies and expanding follow-up with clients.
- Treatment needs to be readily available for clients when they are ready to enter. However due to limited funding patients are referred to other facilities.
    - Because of the inadequate number of providers available for treatment, there are many times when the patient is ready for treatment, but the service is not available.
    - Having to call daily to see if there is an available slot for admission is frustrating and defeating to the patient. This frustration frequently pushes them back into substance use.

18. Based on the overall trends in substance use, availability of treatment and funding sources, what are some recommendations for use of Ryan White funds to fill gaps for SA treatment in the Newark EMA for PLWHA?

The general comment in summary is that the Newark EMA is woefully lacking in funding for individual counseling, prevention services, outpatient services, intensive outpatient services, detox, rehab, and therapeutic communities.

a. What kinds of services? Intensive outpatient, residential, other (identify).

Respondents listed the entire array of substance abuse treatment services: inpatient detoxification, residential treatment including 28-day programs, Intensive Outpatient (IOP) services, outpatient services, individual counseling, prevention services, and therapeutic communities.

It was underscored that inpatient **detoxification** cannot be funded alone but must be part of a fully funded, responsive continuum of substance abuse treatment. Detox needs to be followed by residential substance abuse treatment. Criteria should be placed on the addict for getting into detox and for moving from detox to residential or outpatient treatment. There needs to be close monitoring of outcomes – which translates into a need for more Case Managers through whom an addict must go to get to detox and to move on past detox to treatment. This should cut down on detox recidivism.

Additional **residential substance abuse treatment** should be available following detox. But in order for these two services to be cost-effective, there has to be both more accountability for the client and for the provider, AND, there needs to be a statewide centralized database to track treatment so that clients will not hop in and out of treatment and cycle in and out of detox and SA programs over and over again, costing huge sums of money and achieving no sobriety/drug-free results.

The EMA also needs better **Methadone** programs. There is such stigma attached to Methadone programs because all the clients look like they are high. All Methadone clients should be in a program where dosages are titrated so they will get off Methadone with 6 months to a year to 3 years, depending on the client. Goals should be established on an individual basis for getting off methadone.

Additional funding is needed to support Intensive Outpatient and Outpatient services for **co-occurring disorders** of mental health problems and substance abuse which are increasing. In conjunction, **psychiatric services** need to be expanded.

One provider underscored the need for more **supportive services** to support individuals while they are in treatment and assist in maintaining them in treatment. Supportive services include transitional housing, transportation, food and nutritional supplements.

b. What kinds of substances?

Treatment is needed for abuse of illicit drugs and prescription drugs.

Trying to stop alcohol usage, or heroin or crack cocaine usage cold turkey can lead to death. These substances need a full detox and treatment continuum of care, closely monitored by Case Managers.

Treatment is needed for opiates, “benzos”, and specifically cocaine. It is difficult to find treatment sites for clients who just use cocaine. Rehabilitation programs are more willing to take clients who use opiates, molly, heroin, etc.

c. Is there any emerging need that is not being covered by traditional sources that Ryan White could fill in gaps and help meet need?

One respondent noted that Ryan White has been in the forefront to cover emerging needs in the past. Future demands will need for Ryan White to aggressively look at the trends.

There is an increased need for treatment programs for clients who **use marijuana only**. These clients will have a positive Urine Drug Screen (UDS) for cannabinoids (marijuana use which is illegal) yet these individuals are unable to locate treatment programs that address this group only. These clients do not always blend well with heavy Oxycodone or heroin users and will not seek treatment.

There should be linkage agreements with specific detox and or residential programs where there are a set amount of slotted beds available for Ryan White consumers just like **Drug Court, New Jersey Work First-Substance Abuse Initiative (SAI)** and DUI/**Intoxicated Driving Resource Center** (**IDRC)** Programs.

1.4 Consumer Survey

Methodology

The Consumer Health Issues Survey was finalized by the Research and Evaluation Committee (REC) in March 2013. In April 2013 the survey was sent to all substance abuse treatment providers in the Newark EMA, with the request that they share with their clients (regardless of HIV positivity) and return completed forms to the Newark EMA Planning Council. All responses were received by the end of June 2013. A total of **700 individuals responded to the survey.** This is a record for the Newark EMA consumer surveys!

With respect to tabulating the results, it was determined that the two tabulations would be prepared for each question. The first tabulation would be for all respondents by detailed frequency of the particular substance used – never, monthly or less, on weekends, during the week, every day, and missing. The second tabulation would summarize the "use" categories - monthly or less, on weekends, during the week, every day - into a single category of "Yes, used the substance."

The results would be tabulated for specific demographic groups requested by the REC – (1) total respondents, (2) HIV positive and HIV negative, (3) gender - male and female, and (4) Race/ethnicity - Black/African-American, Hispanic/Latino, and White Non-Hispanic. To the extent possible, a fifth category would be added showing results of substance use for the General Population from sources outside of the survey. These sources would include the SAMHSA NSDUH survey and the CDC Behavioral Risk Factor Surveillance System (BRFSS). Results for the General Population would be used for comparison purposes to determine the extent of deviation of PLWHA and all survey responses, if any.

1.4.1 Demographics of Consumers

The demographics of survey respondents reflected the EMA HIV epidemic more or less with exception of age. There was a disproportionate number of youth (age unknown) but this is due to a data entry error for the survey. Despite this, there was still a higher percent of youth than in the HIV epidemic.

- **Gender.** Male 61%. Female 39%. Transgendered (0.1%). Missing (1%)
- **Sexual Identification**. Heterosexual 66%. Men who have Sex with Men 10%. Bisexual 6%. Women who have Sex with Women 2%. Missing 16%.
- **Race/Ethnicity.** African American 64%. Hispanic/Latino 19%. White Not Hispanic 10%. Other Not Hispanic 4%. Race/ethnicity Missing 3%.
- **Age (Category**). Age category shows a high proportion of youth which is different from the EMA's HIV epidemic.
- **County of Residence.** Essex 71%. Union 14%. Morris, Sussex, Warren (MSW) 10%. Outside NEMA 5%
    - **Outside NEMA included:** Hudson 1%, Passaic, Bergen, Middlesex 2%, Somerset, Monmouth, Mercer, Burlington, Camden, Florida, Homeless, Missing.

Age Category	#	%
Youth Age Unknown*	75	11%
Age 18-24	72	10%
Age 25-29	58	8%
Age 30-34	91	13%
Age 35-39	105	15%
Age 40-44	117	17%
Age 45-49	88	13%
Age 50-54	23	3%
Age 55-59	12	2%
Age 60-64	3	0%
Age 65-69	2	0%
Missing	54	8%
Total	700	100%

*Data entry error. Estimated for youth

- **When were you diagnosed with HIV/AIDS?**

Within past year	5%	32
2-4 Years Ago	8%	56
5-10 Years Ago	18%	124
11-15 Years Ago	16%	111
15+ Years Ago	29%	205
Not HIV+	**17%**	**119**
Missing	7%	53
Total	**100%**	**700**
HIV+ (Minimum	**76%**	**528**

- **Where were you tested and diagnosed?** ER 5%. Hospital 31%. Clinic 27%. Other 23%. Missing 14%.
- Do you currently receive **Medical Care for your HIV**? Yes 71%. No 19%. Missing 10%. **80% of those with HIV receive Medical care for their HIV.**
    - **If no medical care, why not?** Only a few did not receive medical care for their HIV. Of those responding, reasons in order were:
        - I do not feel sick
        - I cannot afford the cost
        - I do not trust the system
        - HIV can be cured with a pill
        - No rush.

1.4.2 Use of Tobacco and Alcohol, and Illicit Substances

Tobacco Use

#11 How often do you use tobacco (smoke cigarettes or cigars; use other tobacco products) Check all that apply. a. Use tobacco alone. b. Use tobacco with alcohol. c. Use tobacco with other drugs or substances

Tobacco was the substance reported most widely used among respondents. 38% reported daily use, 7% use tobacco during the week, 2% on the weekends and 5% monthly or less, for a total of 51% of respondents using tobacco.

When the question was probed further, the responses dropped. Only 23% use tobacco with alcohol and under 20% use tobacco with other drugs or substances.

When tobacco use is analyzed by demographic category, it is found that nearly 2/3 of respondents who were HIV negative report using tobacco at least monthly or more frequently. This was followed by White respondents, Hispanic respondents, and Male respondents.

The average tobacco use for the general population in New Jersey is 28%. This number is from the SAMHSA National Survey of Drug Use and Health (NSDUH) for 2011. The relevant question in this survey is "Past Month Tobacco Product Use." Tobacco Products include cigarettes, smokeless tobacco (i.e., chewing tobacco or snuff), cigars, or pipe tobacco.

Figure 1: Tobacco Use – Alone, with Alcohol, with Other Substances

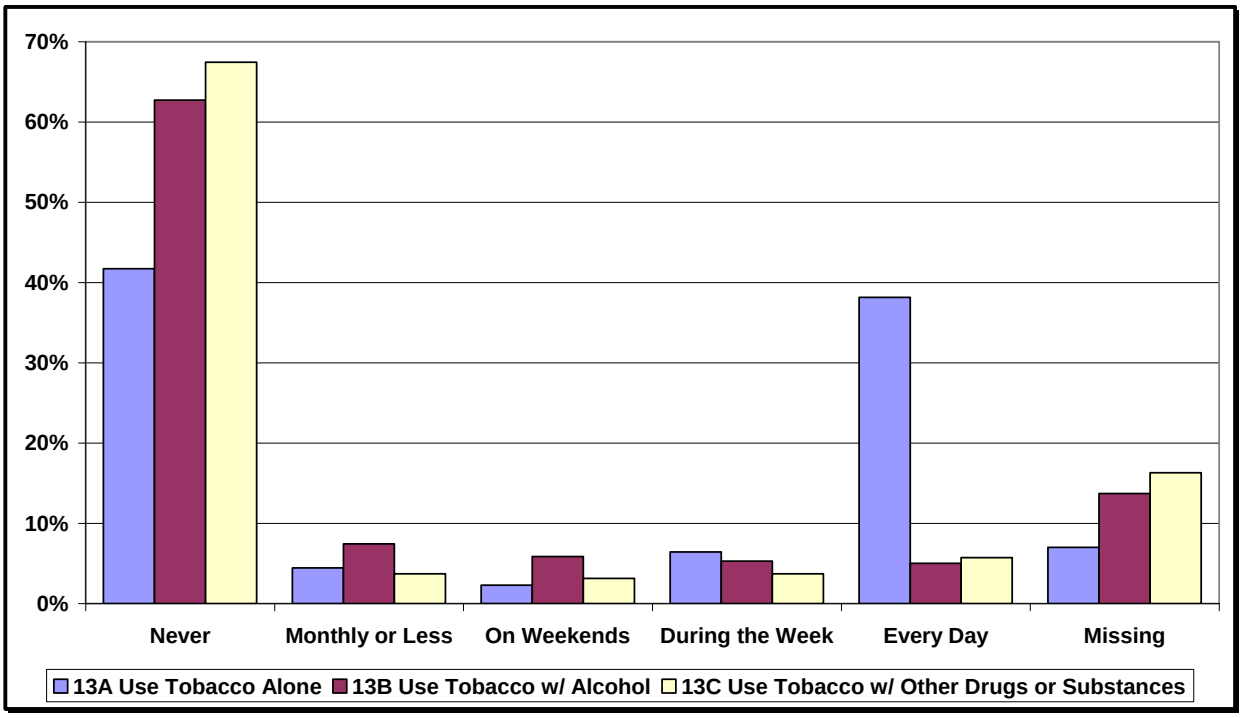
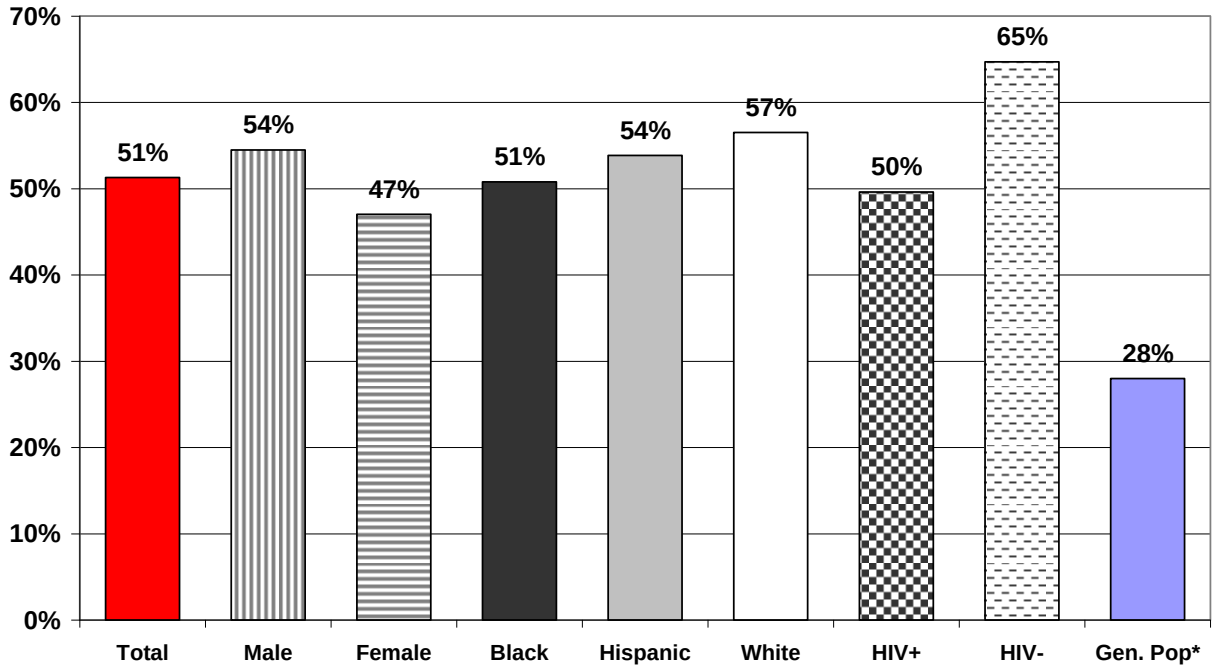


Figure 2: Use of Tobacco Alone by Demographic Category



Alcohol Use

#12 How often do you have a drink containing alcohol? Check all that apply. a. Use alcohol alone. b. Use alcohol with tobacco. c. Use alcohol with other drugs or substances

A total of 40% of respondents reported using alcohol at some point in time. 40% use alcohol alone, 23% use alcohol with tobacco, and nearly 40% use alcohol in combination with other drugs.

By demographic category, Hispanic respondents reported highest use of alcohol at 45%, followed by Males at 43%.

Alcohol use was much higher among the general population, but this is because of the nature of the question which was, "Past Month Alcohol Use." 61% of the New Jersey population had a drink within the month prior to the survey. There is no further data shown in the figure regarding the extent of alcohol use. However, 26% of New Jerseyans surveyed reported Past Month Binge Alcohol Use. Binge Alcohol Use is defined as drinking five or more drinks on the same occasion (i.e., at the same time or within a couple of hours of each other) on at least 1 day in the past 30 days.

Figure 3: Alcohol Use – Alone, with Tobacco, with Other Substances

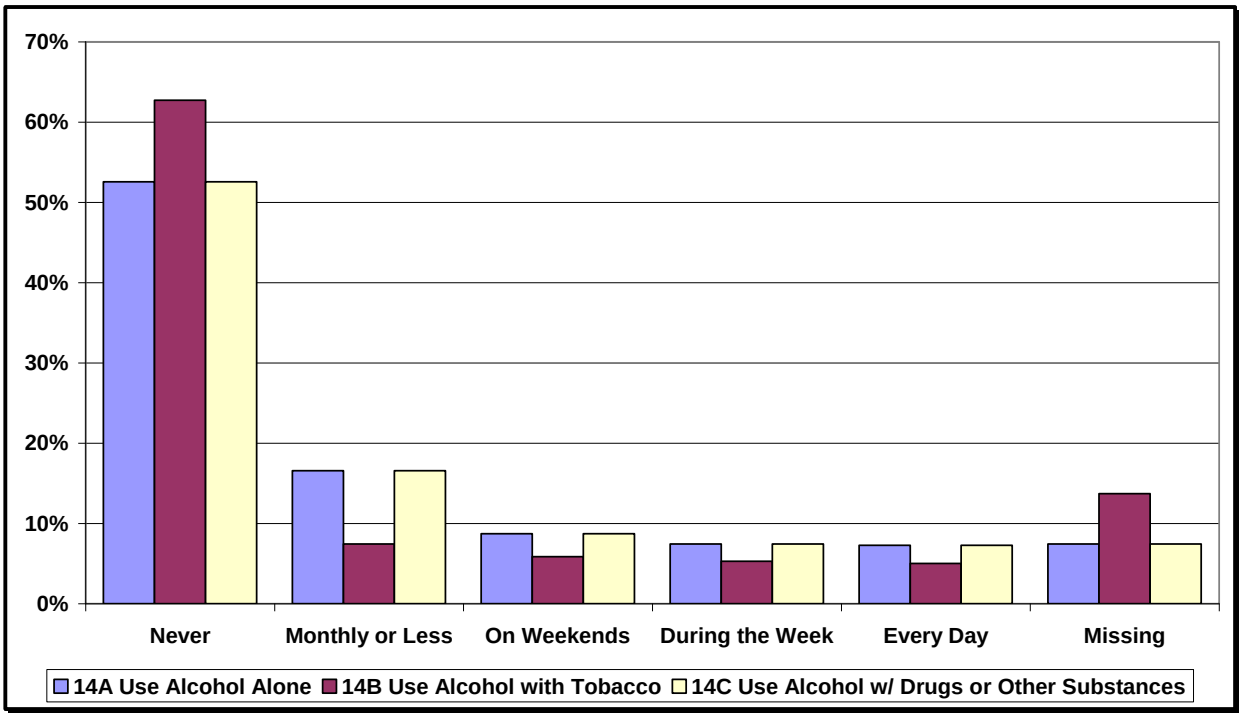
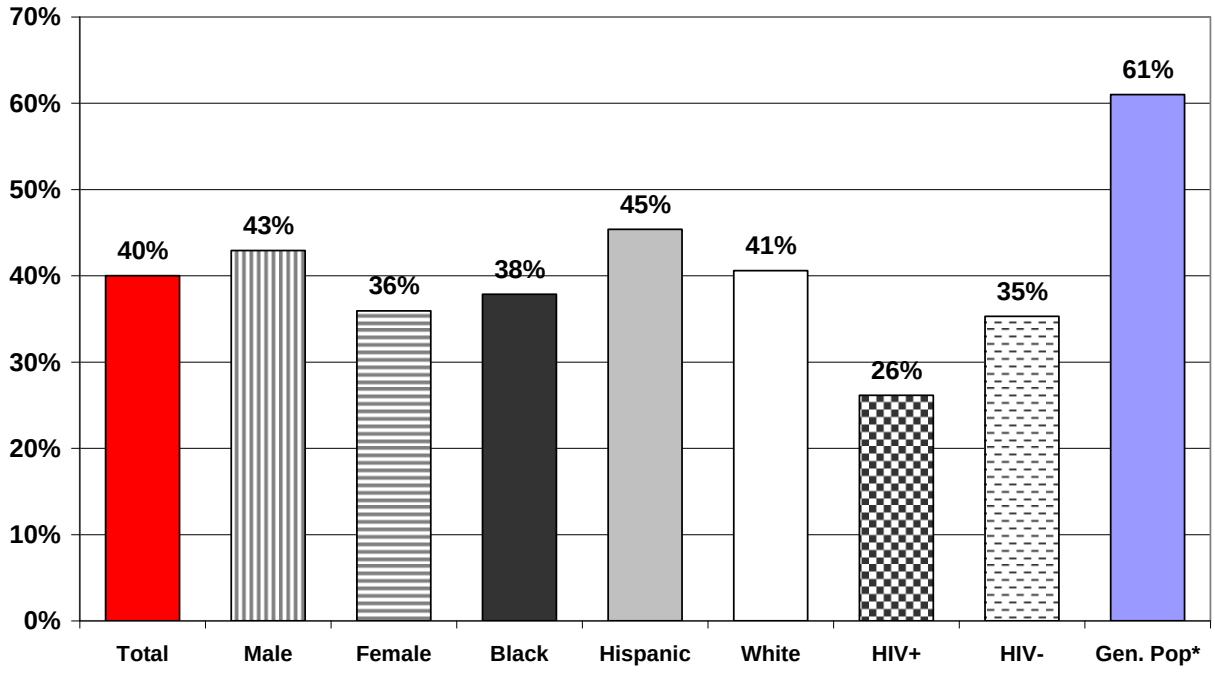


Figure 4: Use of Alcohol Alone by Demographic Category



1.4.3 Use of Illegal Drugs

Marijuana

#13 How often do you use the following substances? Check all that apply.

Over one in five (22%) of respondents reported using marijuana monthly or more, with 5% reporting use every day and 8% reporting use during the week or on weekends.

The highest use was among HIV negative individuals and White respondents. Hispanic respondents and males where the next highest groups.

Marijuana use reported by respondents far exceeded the average 6% for New Jerseyans who reported marijuana use in the Past Month. Only 3% of New Jerseyans reported marijuana use in the Past Year.

Figure 5: Marijuana Use

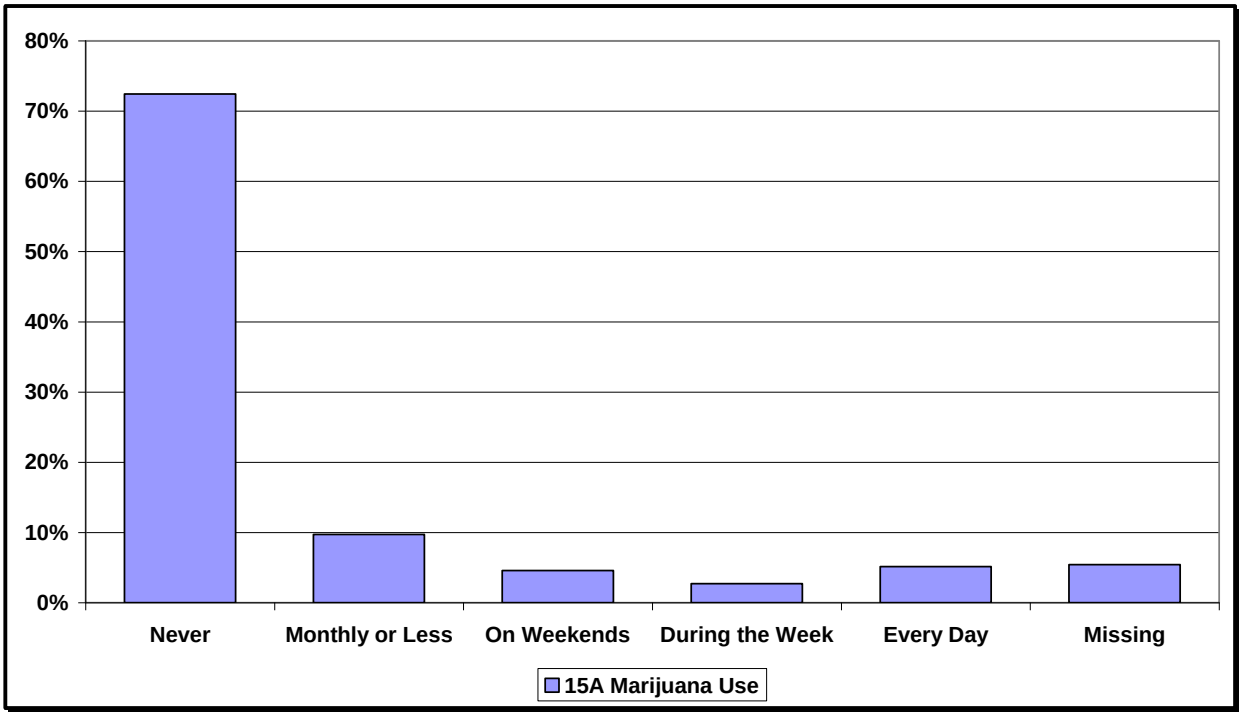
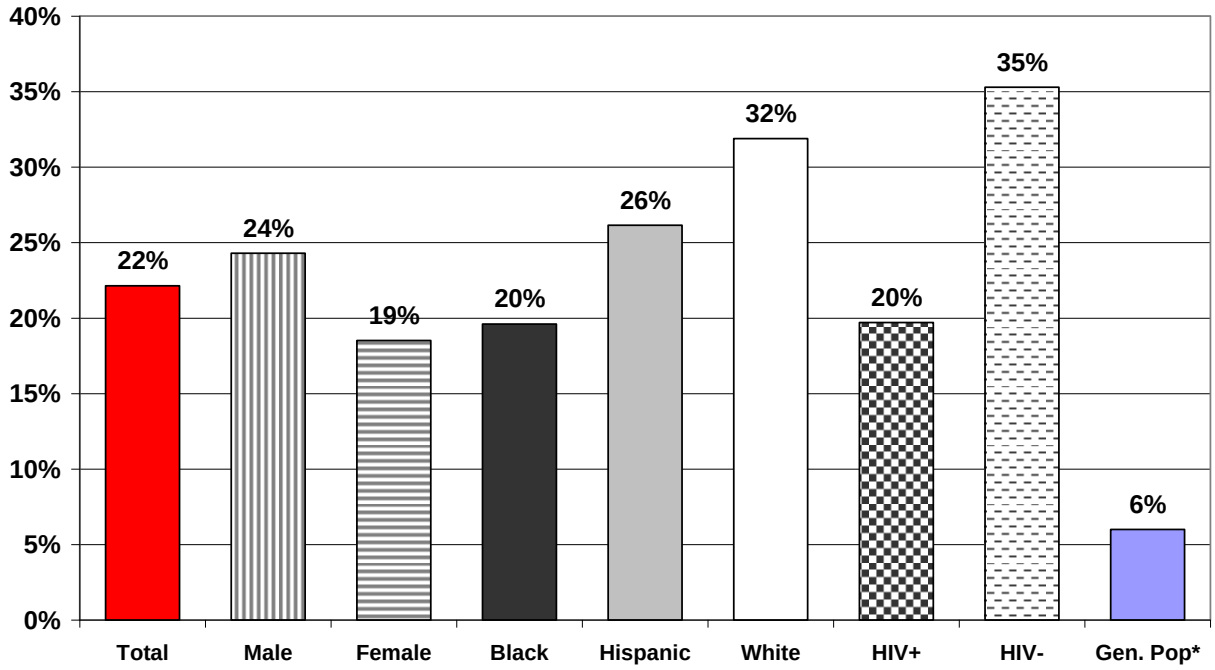


Figure 6: Use of Marijuana by Demographic Category



Cocaine

Cocaine use varies by how the substance is taken. 11% of respondents reported using cocaine (not crack) monthly or more often. Lower percents reported using cocaine by injection and crack cocaine.

When viewed by demographic category, the highest percent of cocaine users were White respondents, HIV negative respondents, and Hispanic respondents.

Among the general population, only 2% of New Jerseyans reported using cocaine within the past year.

Figure 7: Use of Cocaine – Not Crack, Injection, Crack

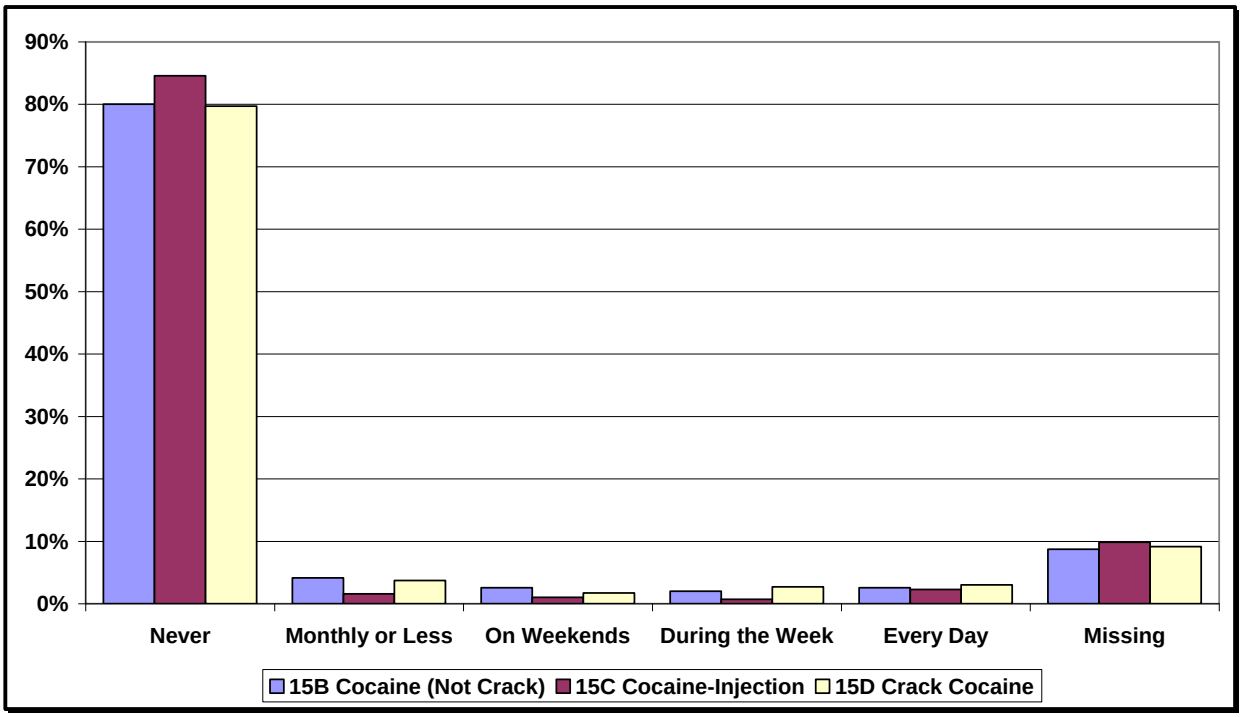


Figure 8: Use of Cocaine (Not Crack) by Demographic Category

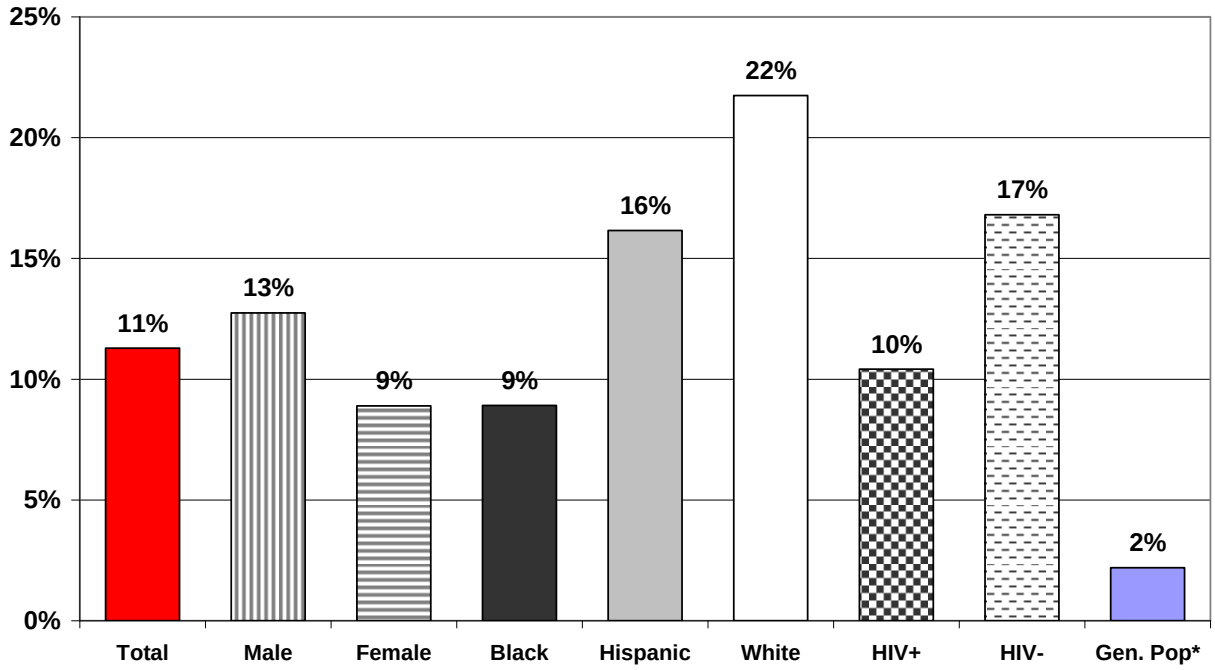


Figure 9: Use of Cocaine (Injection) by Demographic Category

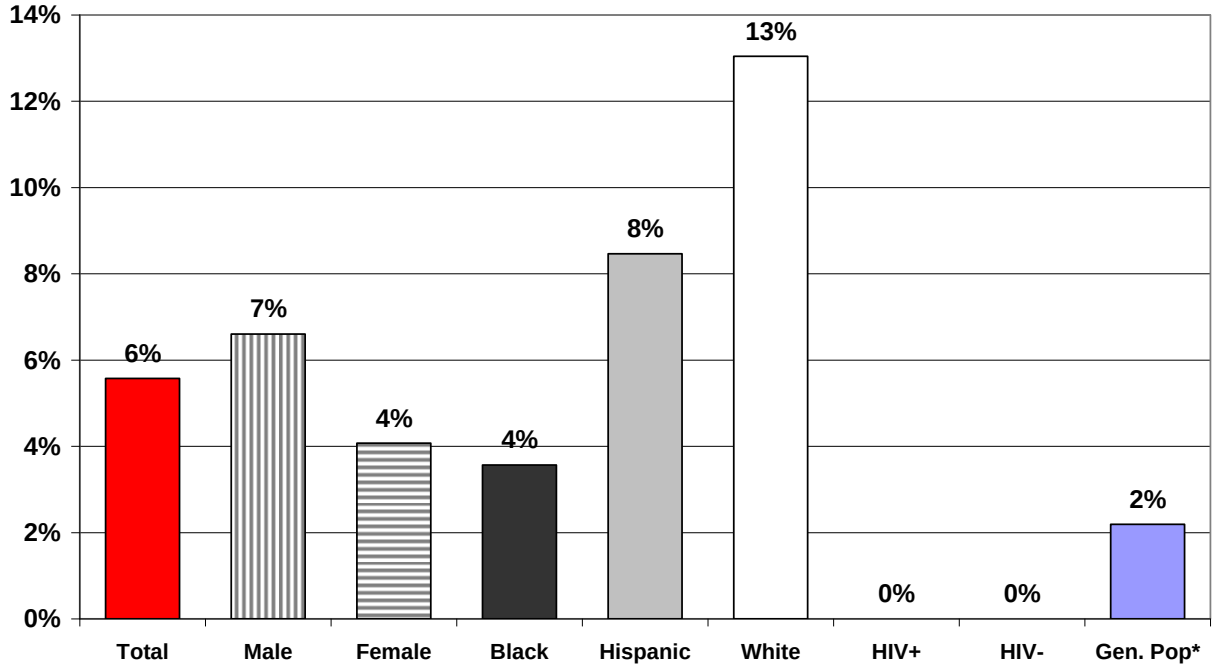
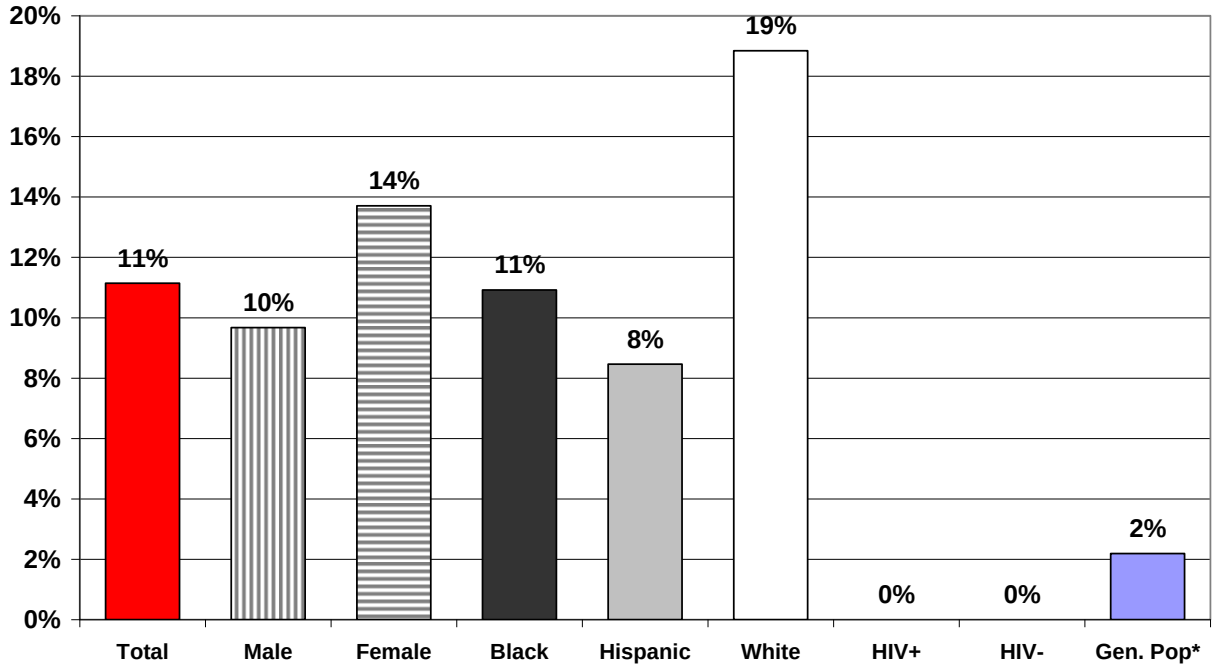


Figure 10: Use of Crack Cocaine by Demographic Category



Heroin

Less than 10% of respondents reported using heroin – either by injection or by other means, such as snorting, sniffing, etc. This contradicts findings of County Drug Abuse Coordinators and substance abuse providers in the EMA.

Approximately 8% of New Jersey's population reports use of heroin by injection or non-injection. However, this 8% applies to use of all Illicit Drugs.

Illicit Drugs include marijuana/hashish, cocaine (including crack), heroin, hallucinogens, inhalants, or prescription-type psychotherapeutics used non-medically. Illicit Drugs Other Than Marijuana include cocaine (including crack), heroin, and hallucinogens. These 8% will be used for all of the remaining analysis which may or may not accurately reflect the various types of substance abuse among the general population.

Figure 11: Use of Heroin – Injection, Non-injection – Snort, Smoke

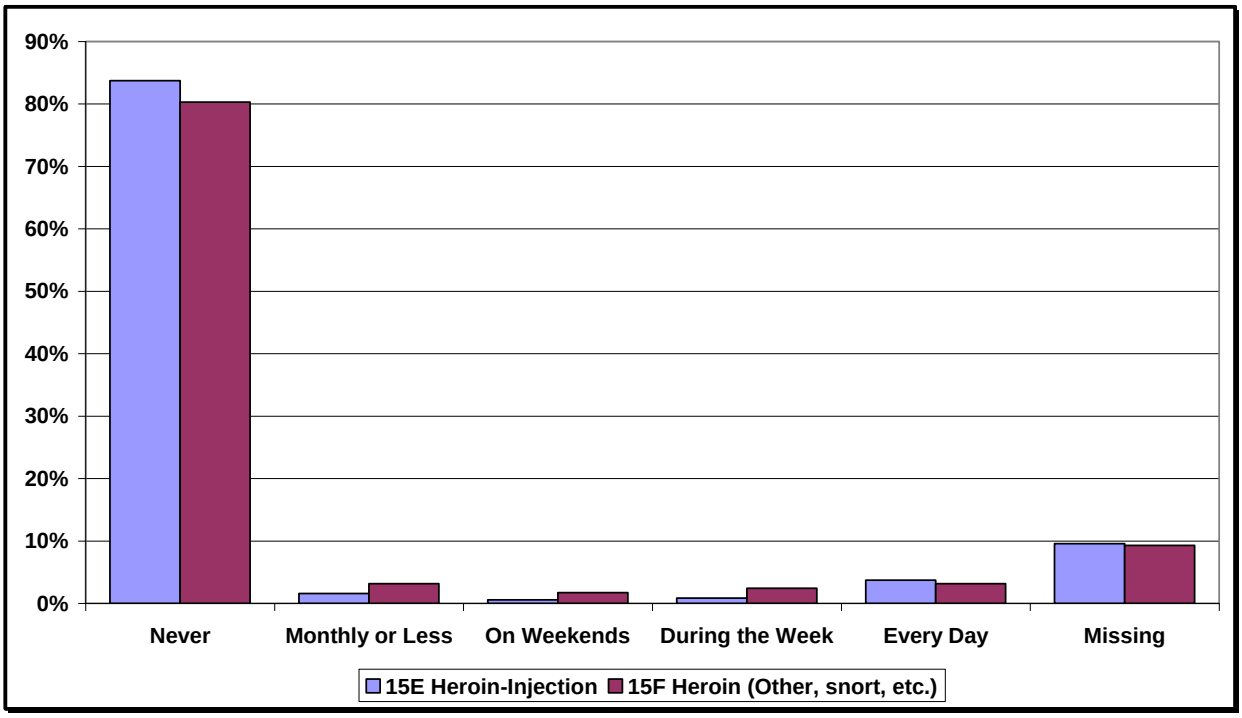


Figure 12: Use of Heroin (Injection) by Demographic Category

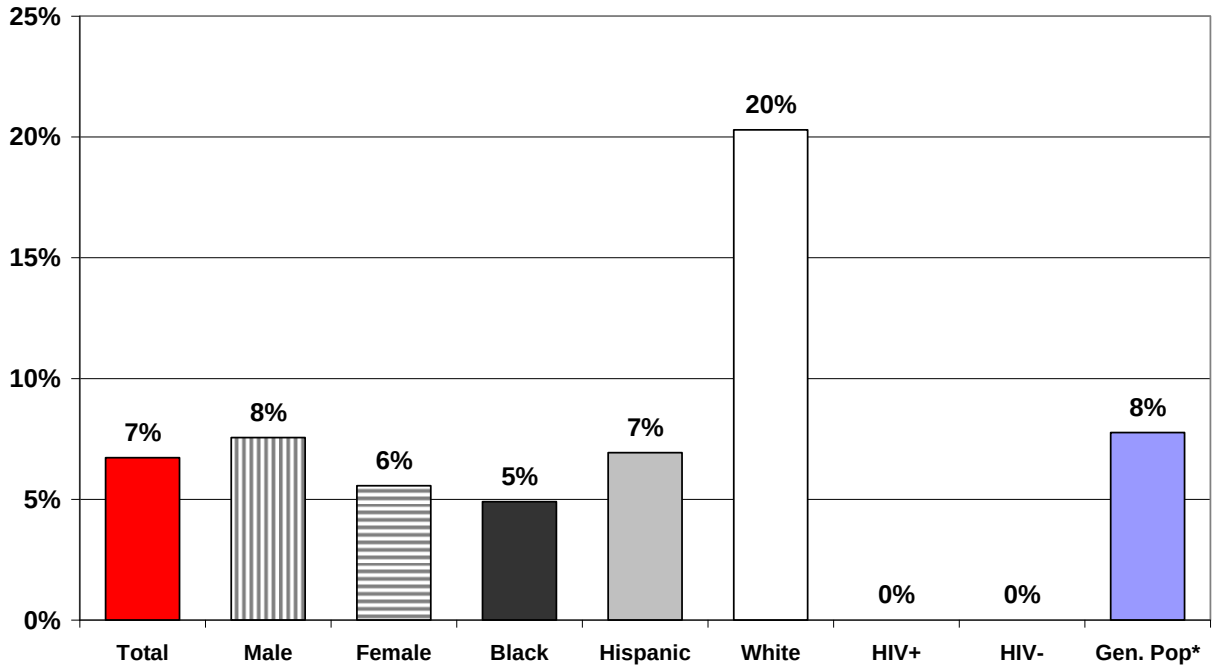
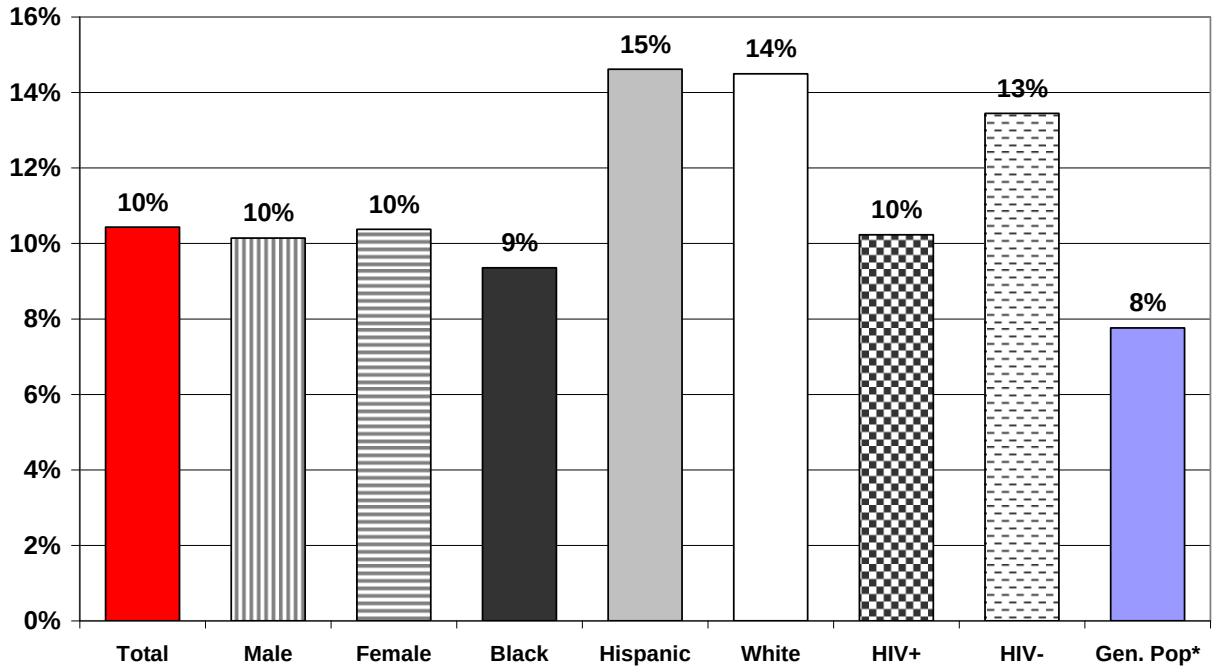


Figure 13: Use of Heroin (Non-Injection) by Demographic Category



Hallucinogens and Inhalants

Only 3% of respondents reported using hallucinogens and 2% reported use of inhalants.

This is much less than the 8% of the general population reporting use of illicit drugs.

Figure 14: Use of Hallucinogens and Inhalants

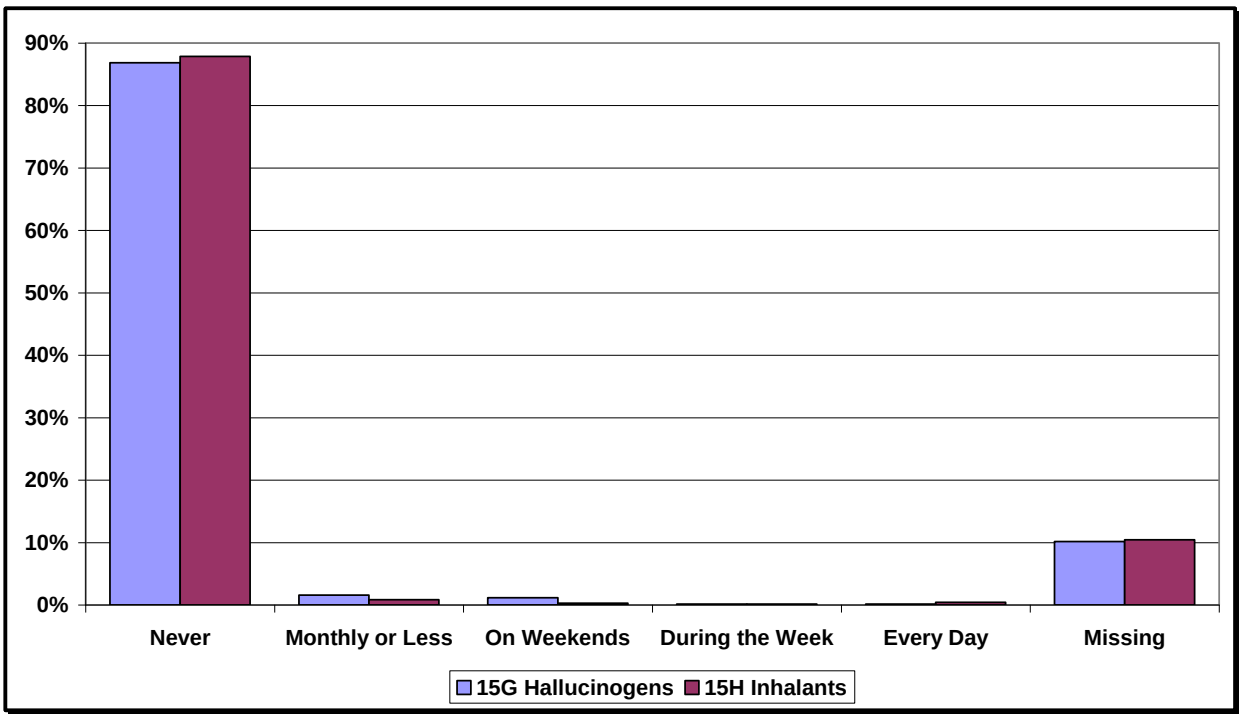


Figure 15: Use of Hallucinogens by Demographic Category

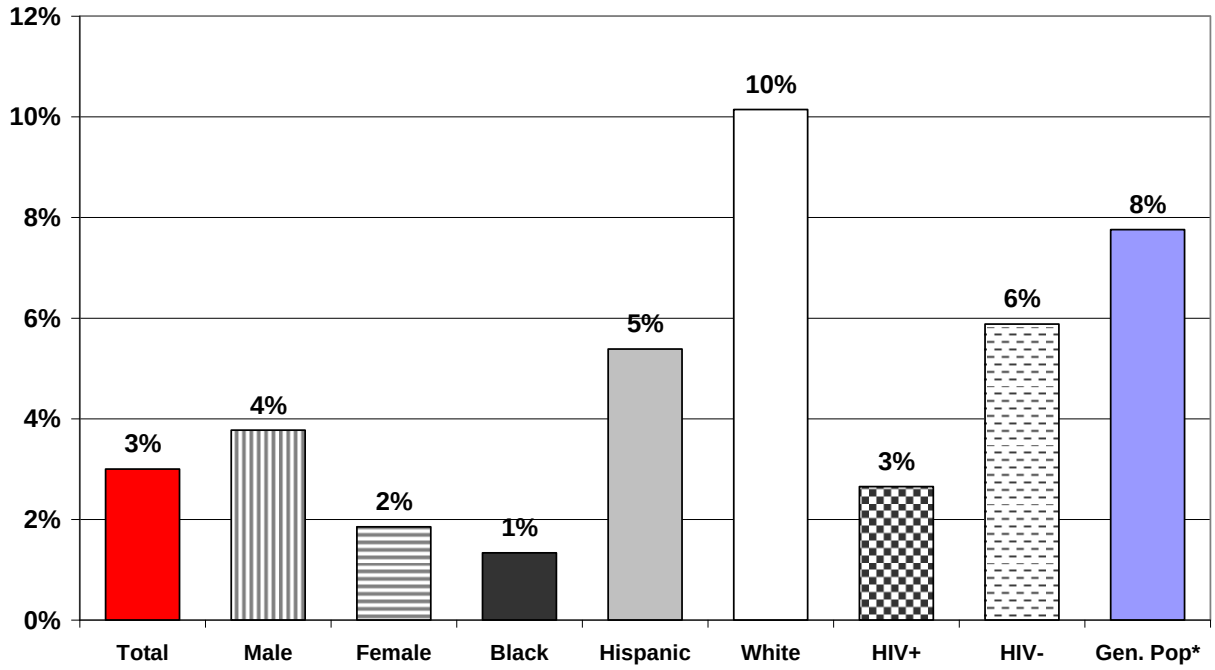
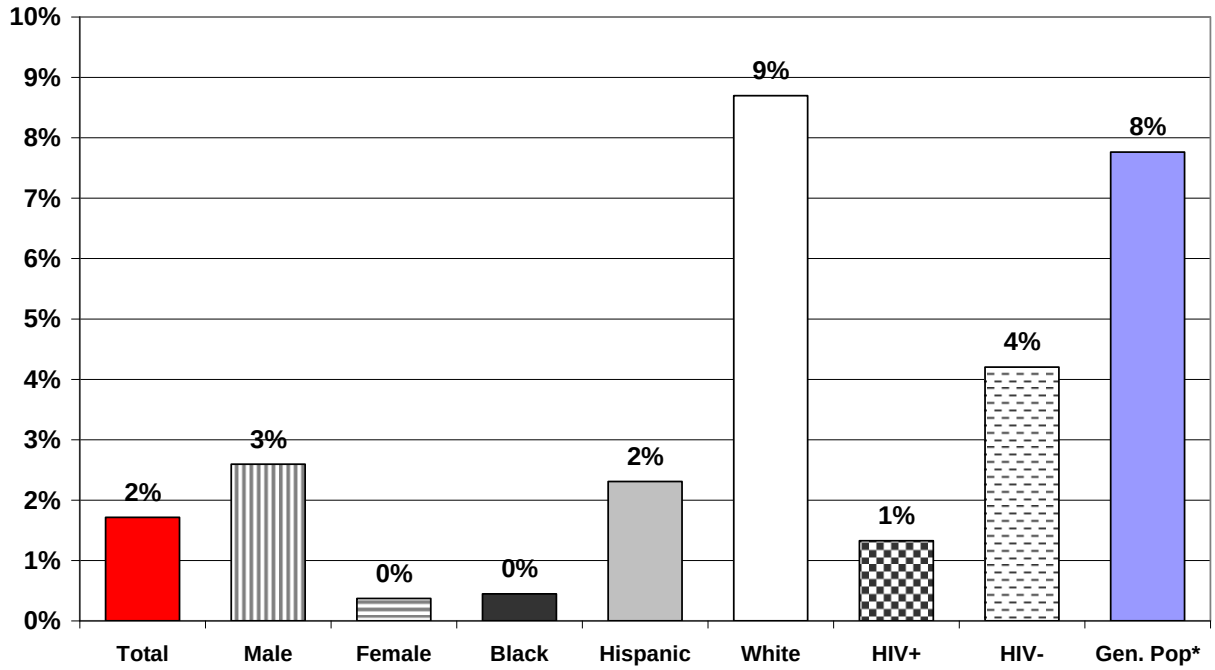


Figure 16: Use of Inhalants by Demographic Category



1.4.4 Use of Prescription Drugs Not Prescribed for You or For the Feeling It Caused

Pain Relievers and Oxycontin/Oxycodone

#14 How often do you use the following substances that <u>were not prescribed for you OR for the feeling it caused</u>? <u>Check all that apply.</u>

Almost one in five (19%) respondents reported use of pain relievers that were not prescribed for them. The highest percent of respondents were White, HIV negative or Male.

The EMA percentage is more than twice as high as the statewide usage of 8%.

Figure 17: Use of Pain Relievers and Oxycontin/Oxycodone

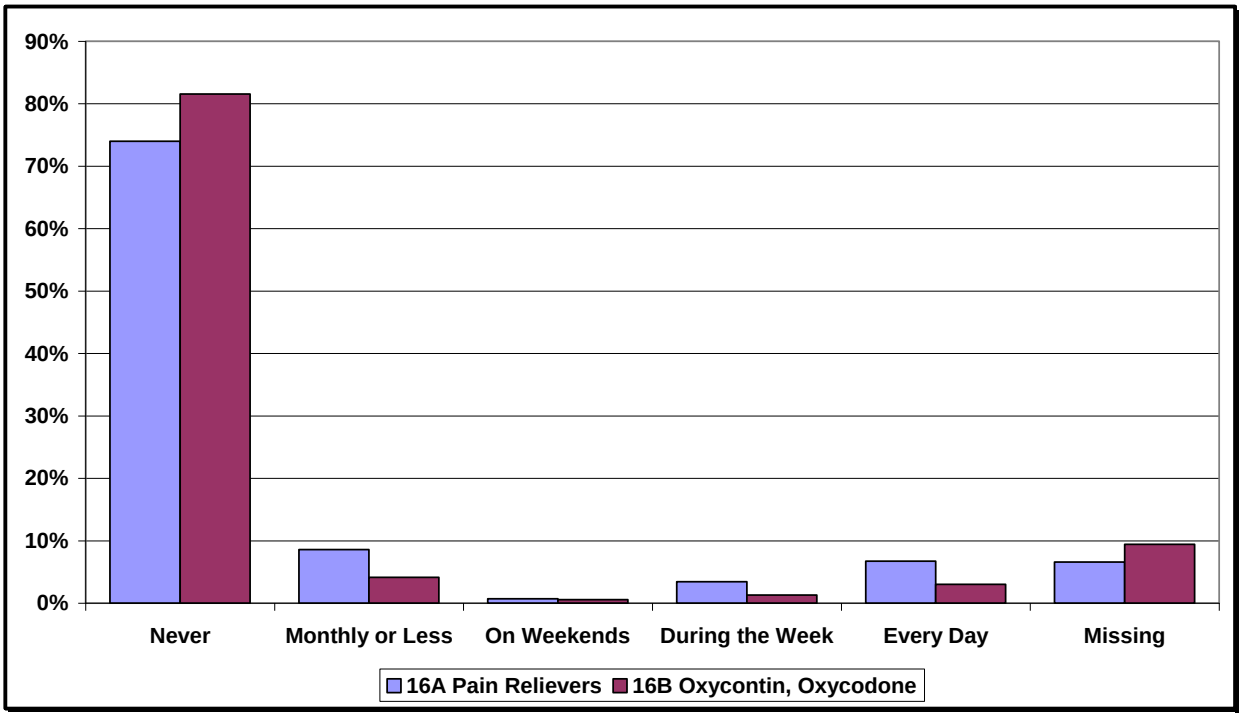


Figure 18: Use of Pain Relievers by Demographic Category

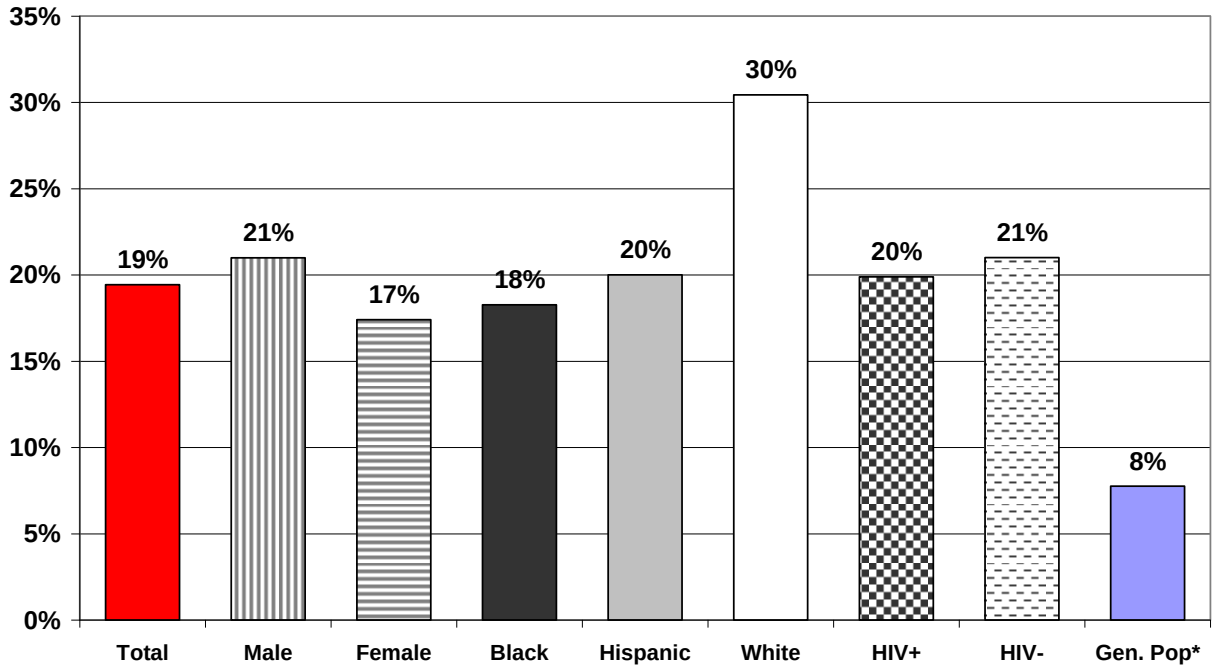
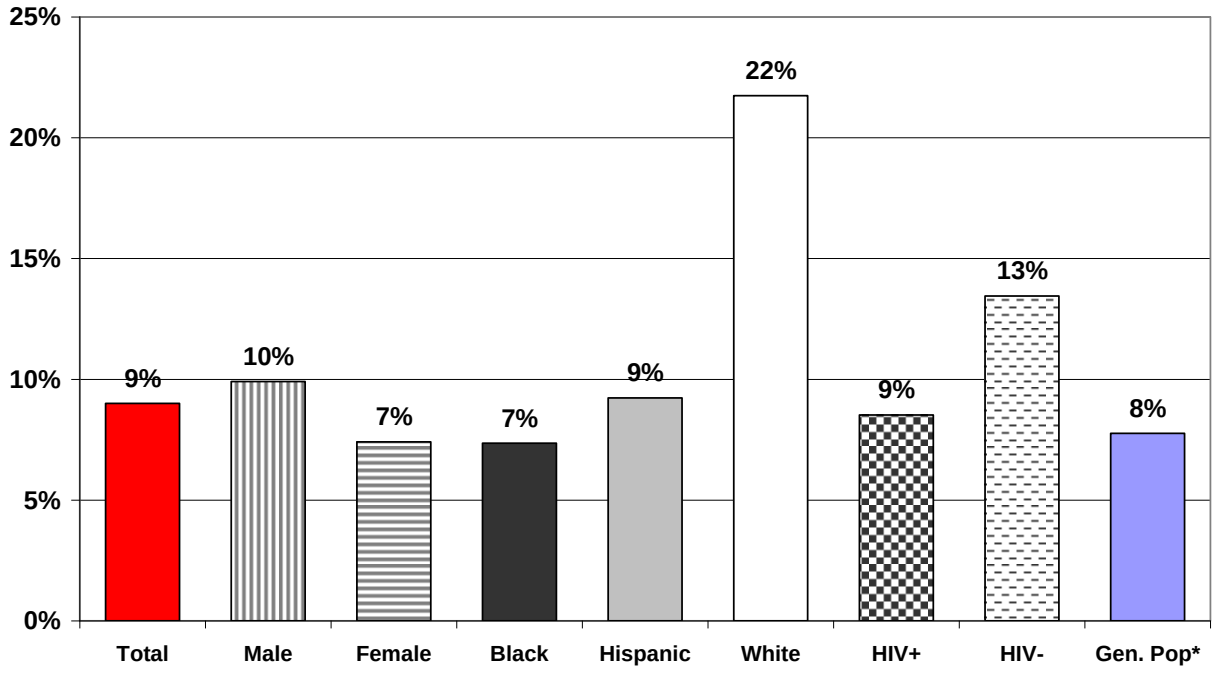


Figure 19: Use of Oxycontin by Demographic Category



Methadone, Morphine, Tranquilizers

11% of respondents reported using methadone, morphine are tranquilizers not prescribed for them.

Figure 20: Use of Methadone, Morphine, Tranquilizers

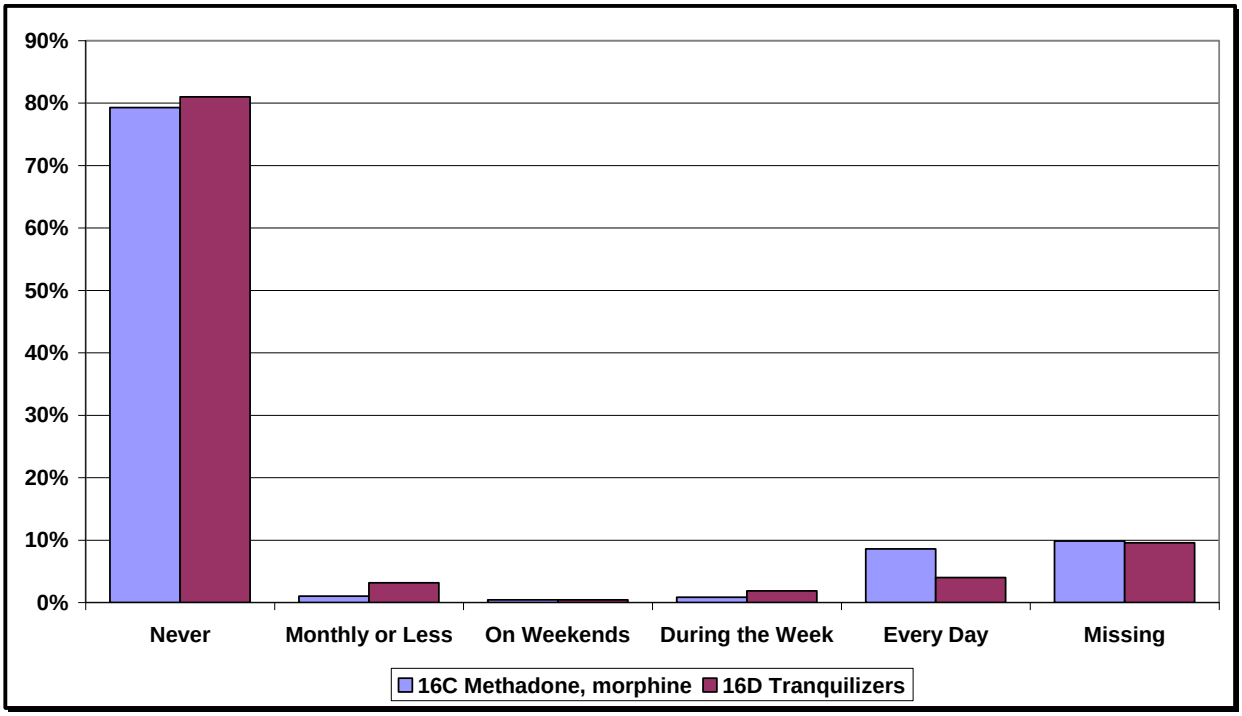
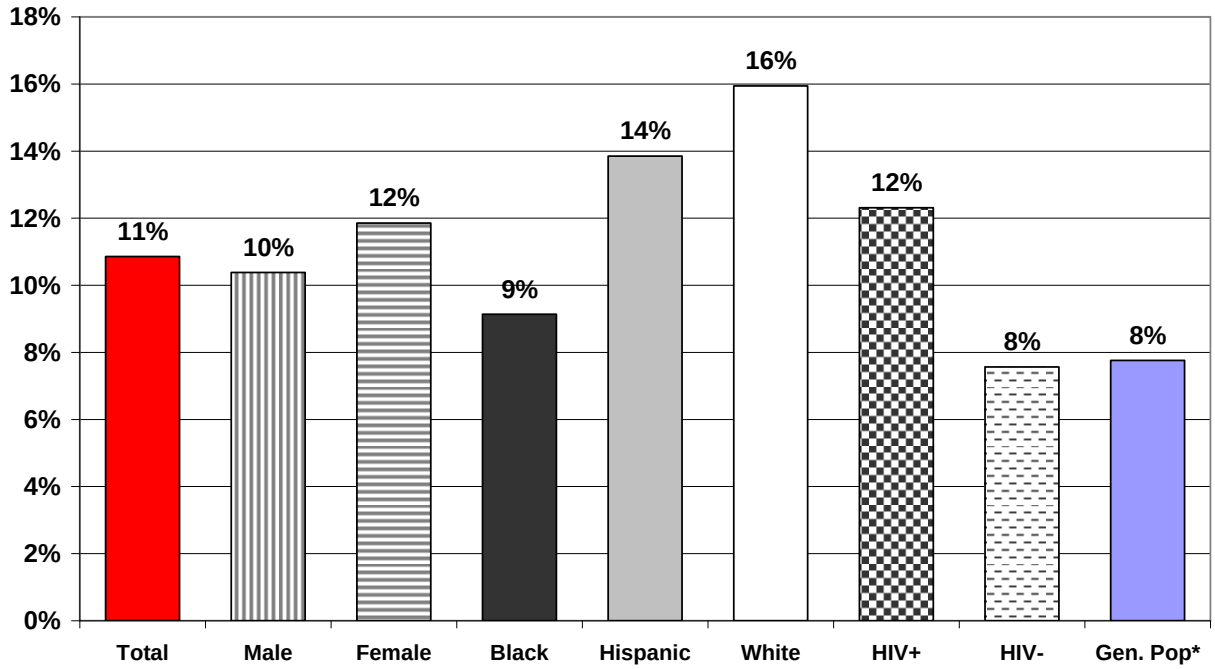


Figure 21: Use of Morphine by Demographic Category



Valium, Stimulants, Sedatives

Less than one in 10 (9%) of respondents reported using Valium, stimulants or sedatives or other tranquilizers that were not prescribed for them. This is approximately the same as the percent for the general population of New Jersey.

Figure 22: Use of Valium, Stimulants, Sedatives

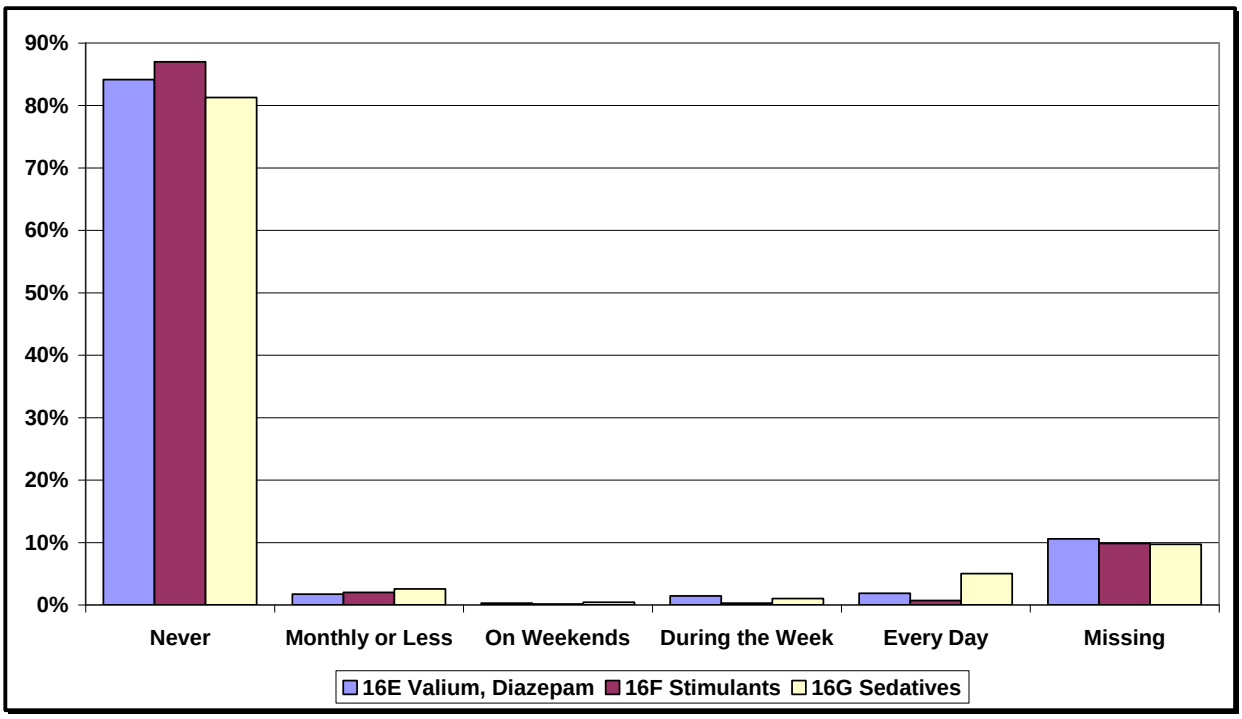


Figure 23: Use of Tranquilizers by Demographic Category

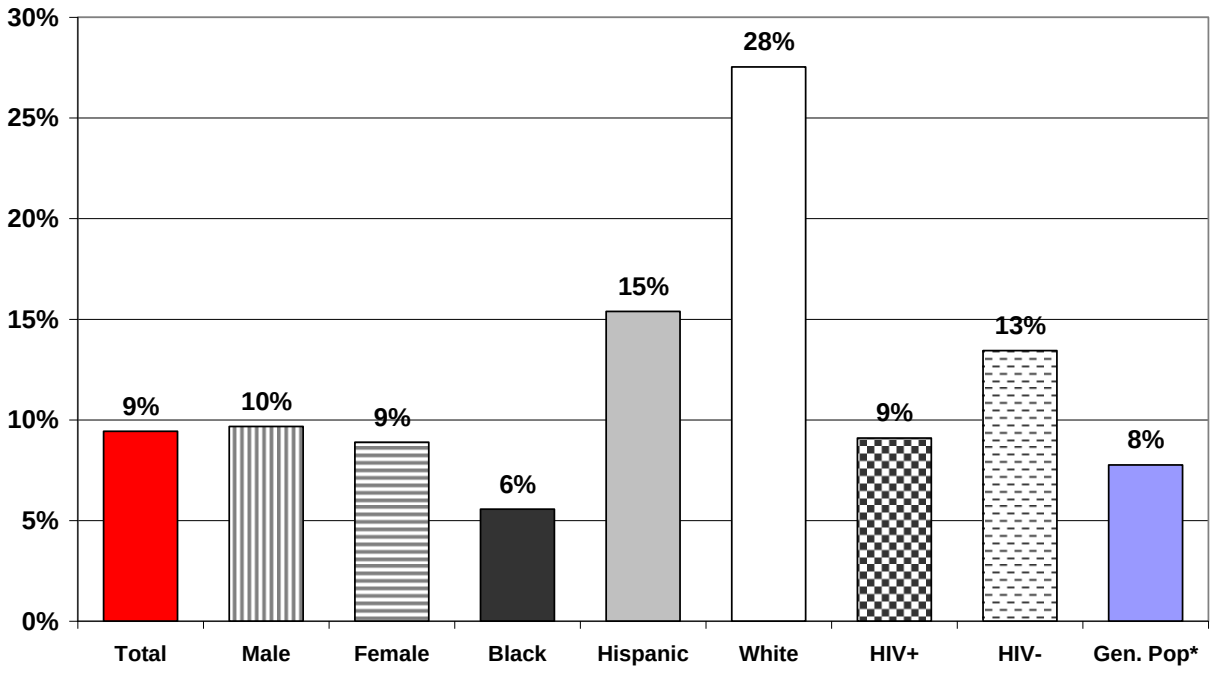


Figure 24: Use of Valium by Demographic Category

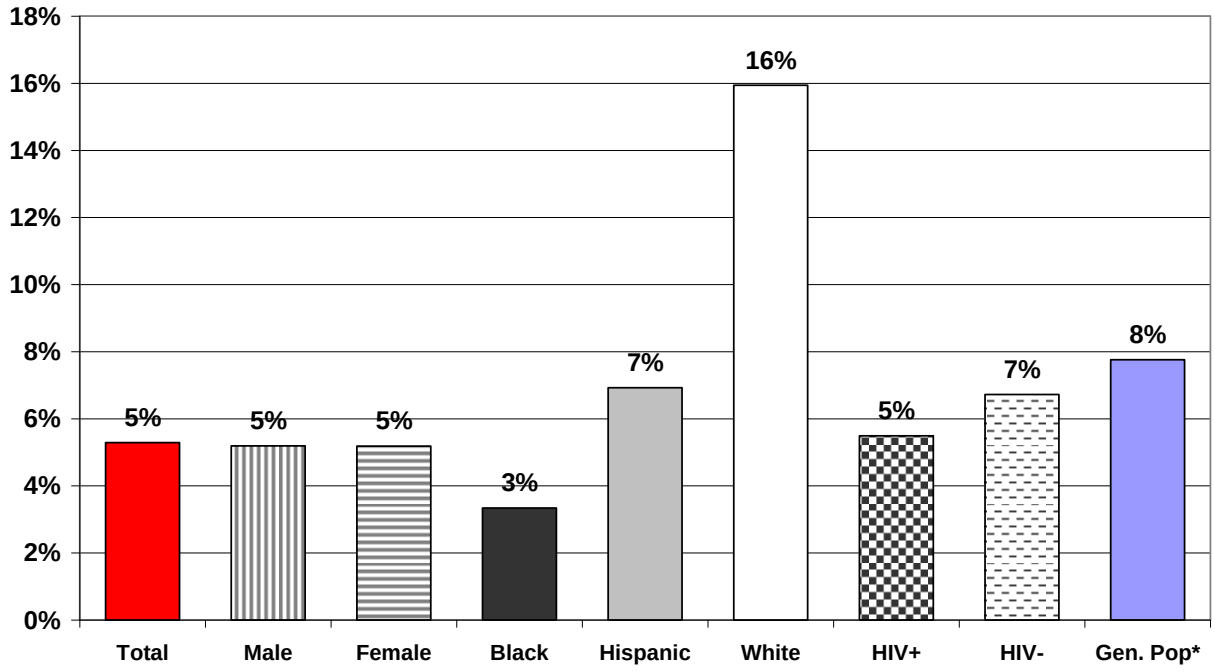
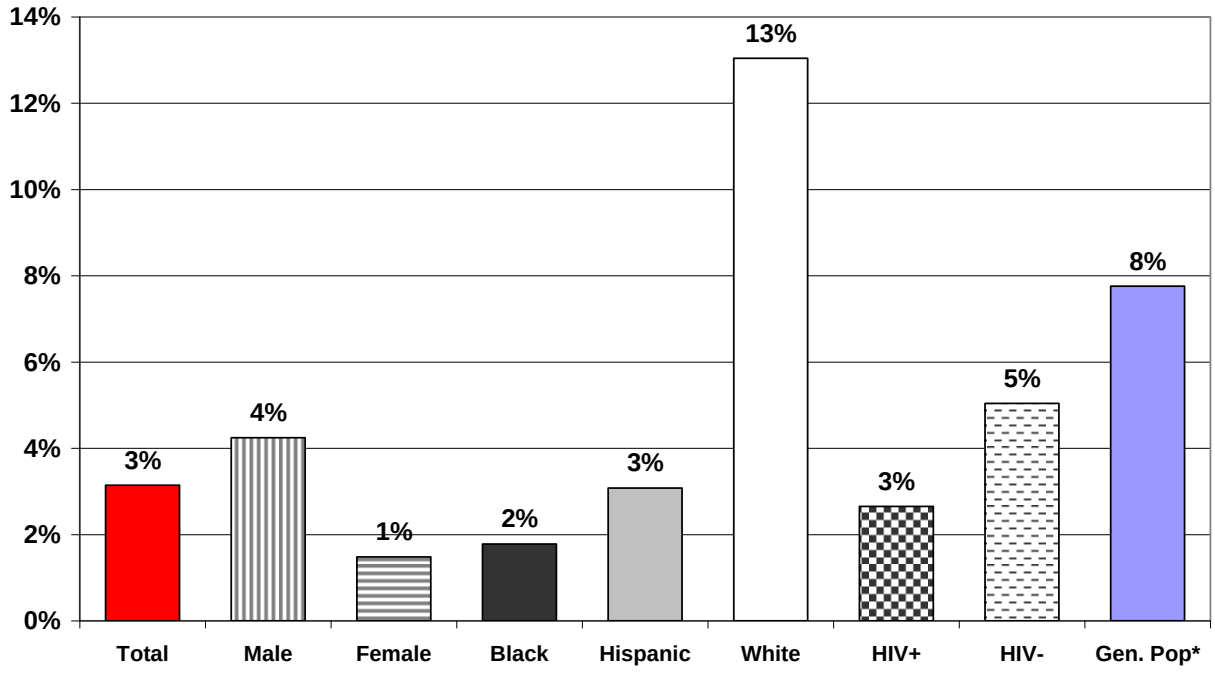


Figure 25: Use of Stimulants by Demographic Category

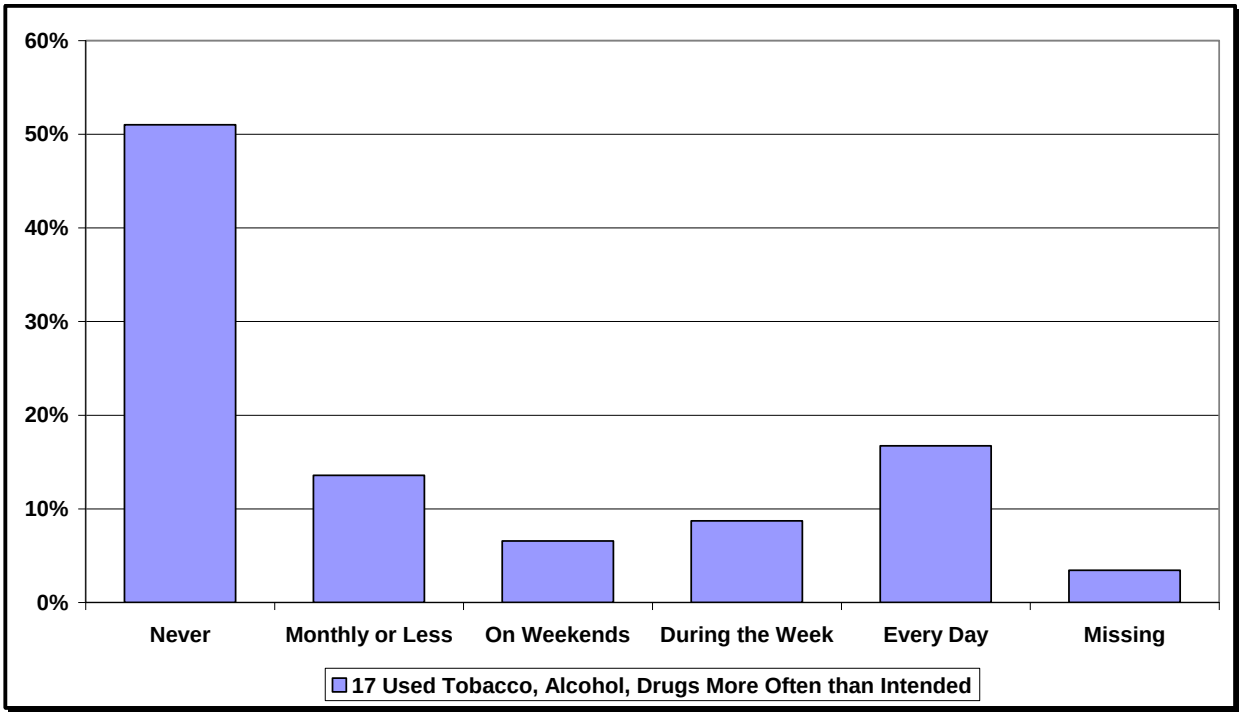


1.4.5 Substance Abuse Treatment Need and Experience

Substance Abuse Treatment Need and Experience

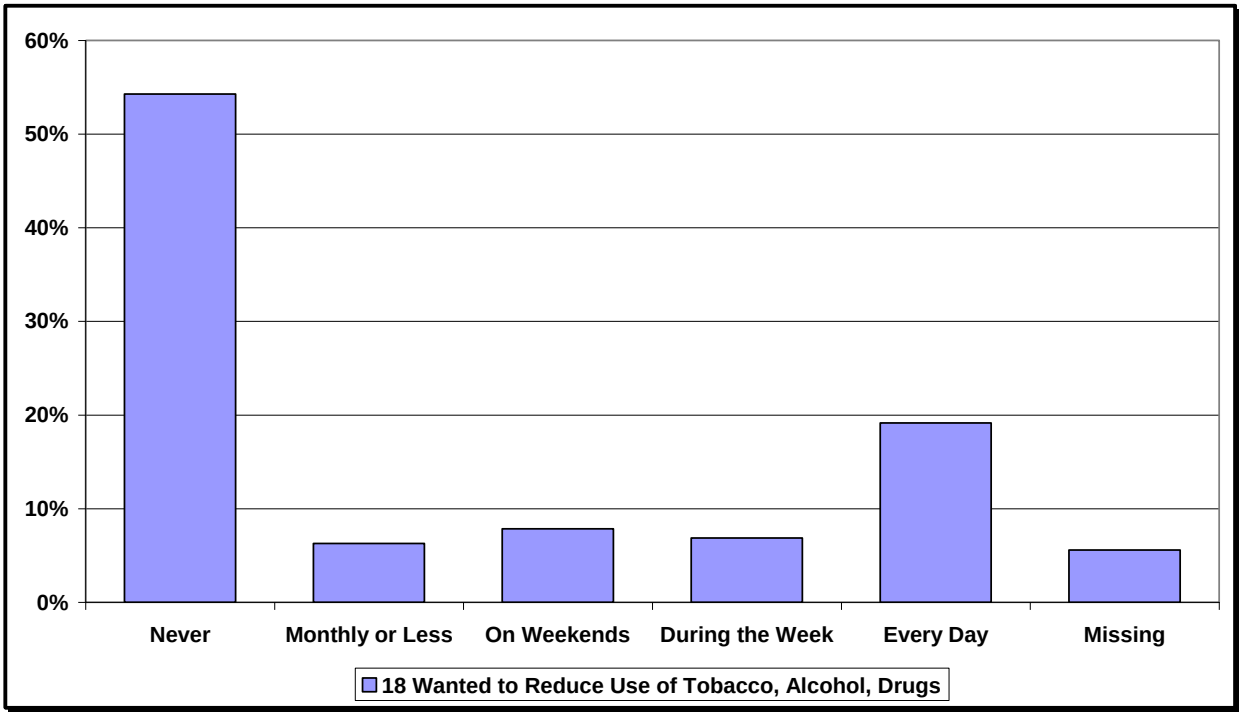
Nearly 45% of respondents reported using substances more often than they intended to. It is important that 15% felt this way every day. This indicates self-recognition of substance use and the possible need for treatment.

#15 In the past year, how often did you drink, use tobacco or other drugs more than you meant to?



Similarly, 40% of respondents felt they wanted to or needed to cut down on their substance use during the past year or not able to do so. Again this indicates potential need for substance abuse treatment.

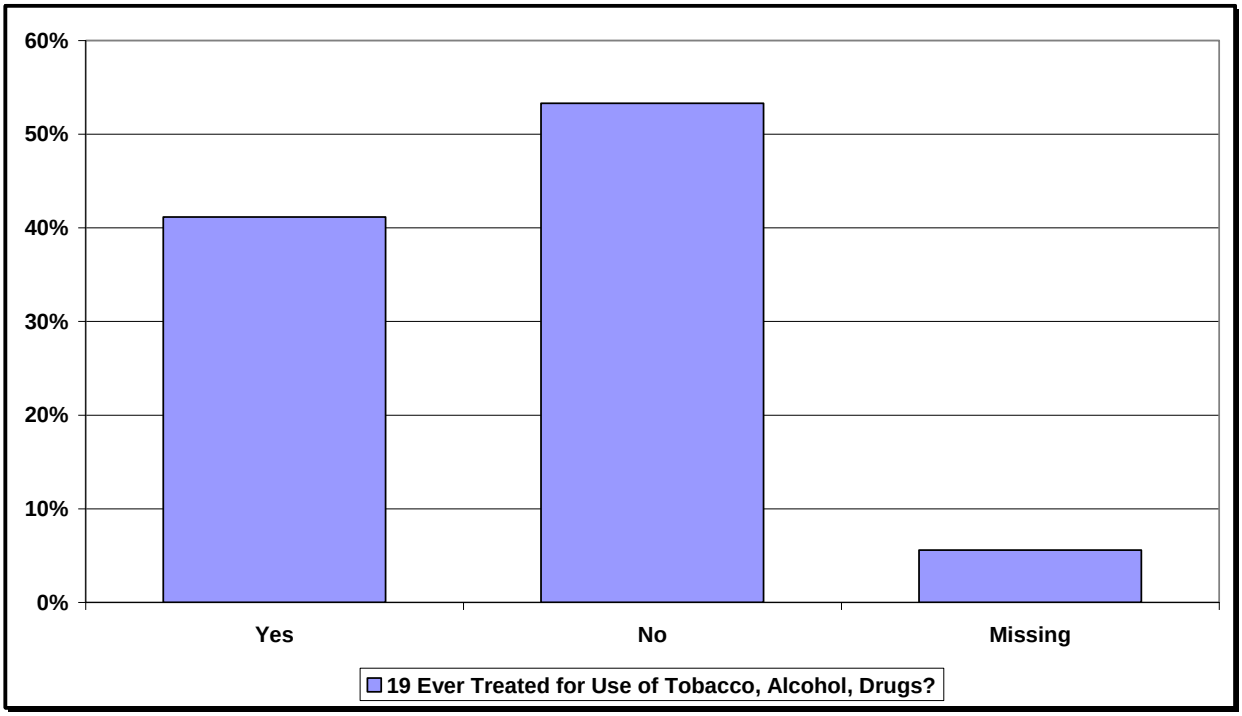
#16 How often did you feel you wanted or needed to cut down on your drinking, tobacco use or drug use in the past year, and were not able to?



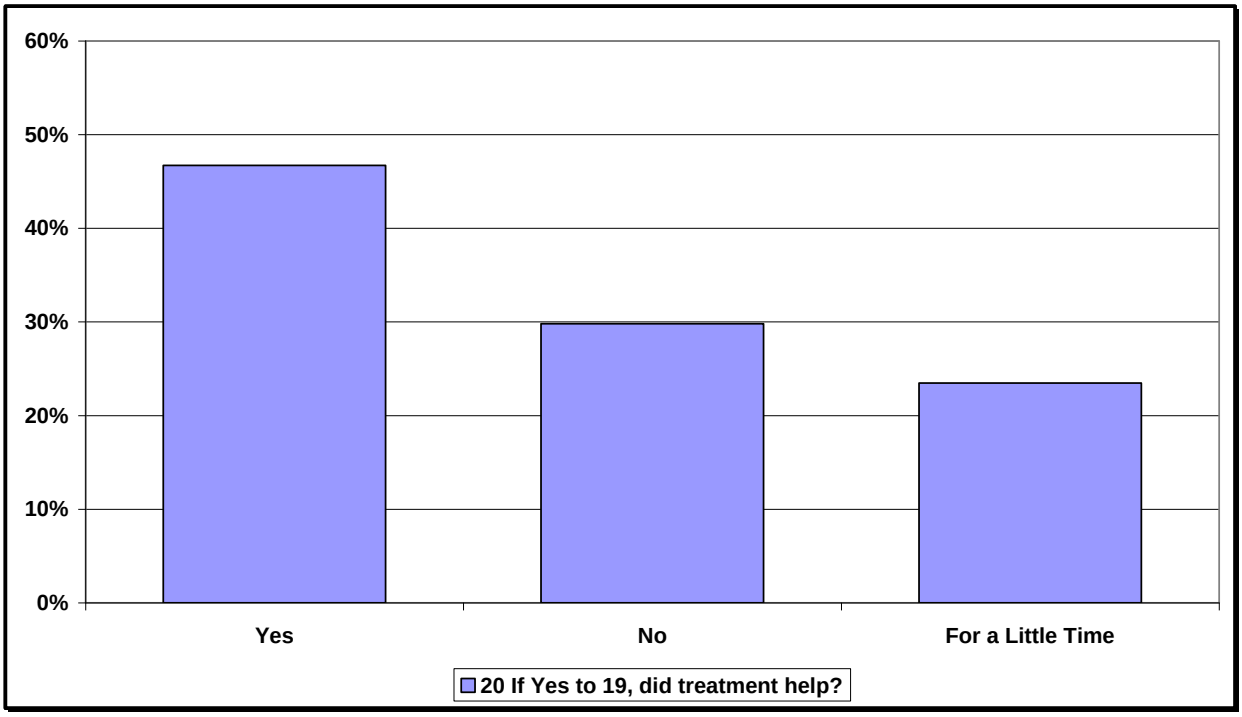
Approximately 42% of respondents had been treated for substance use. Of those, slightly less than half said the treatment had been successful, 30% said that it had not been successful, and 25% said it had been successful for some time.

These findings indicate the need for further substance abuse treatment, stronger aftercare support, or more effective treatment models.

#17 Have you ever been treated for alcohol, tobacco, substance use?



#18 If Yes, did your treatment address/fix/help your problem?



1.5 Significant Findings from Follow Up Telephone Interviews of Key Informants

Over the course of several weeks in June and July 2013 (through August 15, 2013) 15 Key Informant questionnaires were reviewed and phone call interviews were conducted. Interviews were for the most part spent confirming responses in the questionnaires and obtaining clarification where needed. A general sense of apathy and frustrated acceptance of an old and broken system permeated the interviews. New and alarming findings came from interviews with the Newark Syringe Exchange Program (SEP) and a KI in Newark serving Youth.

Key Issues in Substances Use:

- The over prescribing of Opiates to PLWHA in urban areas and
- Increased use of Heroin due to ease of access, availability and affordability in some communities. Use of prescription drugs often precedes heroin use especially for younger individuals.

Treatment Systems and Capacity:

- The general agreement among respondents is that the current treatment infrastructure is fragmented and unworkable. The overall substance abuse treatment system is inadequate to treat and meet the needs of this community. Gaps are detailed in responses to the questionnaires.
- There is a need for inpatient detox on demand, more comprehensive long-term treatment, half way houses that care for women and their children, services for adolescents, and more practical after-care services.

Newark Syringe Exchange Program (SEP) is a window to emerging substance use and treatment needs.

- Over **20,000 (200,000?)** syringes being dispensed by the Newark SEP **per month**, and similar patterns observed in all 5 SEP's throughout NJ, are largely to white suburban youth.
- Abuse of prescribed opiates is the gateway to intravenous Heroin Addiction.
- Heroin is cheaper, the purest in the nation, and easily accessible in Newark.
- The impact of prescription abuse and ensuing heroin addiction among youth throughout the EMA and on health status of New Jersey residents is potentially devastating.
- Although clean needles are accessed, the potential of needle sharing is great with youth already exhibiting these high-risk behaviors. Respondents pointed to an inevitable increase in Hepatitis C infections and the potential for HIV transmission.

Unique issues facing Youth and Transgendered Community

- In the young transgendered community, substance abuse not seen as an issue although the use of needles to inject illegally acquired hormones is occurring.
- Many of these youth will eventually become involved in the sex trade, and although they may not be HIV positive currently, HIV-positivity is perhaps a forgone conclusion.
- The funding shift to the medical model focused on linking positives back into care seen as a dangerous impediment to community based prevention initiatives.

Barriers to Changing the Substance Abuse Treatment System

- The issue impeding an overhaul of this system was identified as cost and unwillingness by some providers to give up the status quo.
- Some respondents described the current fee for service system as comparable to the warehousing of people seen in the corrections system.
- There is financial pressure to fill the available beds creating a revolving door of individuals returning to the community lacking the tools needed for long-term success.
- Additionally, individuals mandated into treatment (by drug court, DUI) are grouped in with clients who are genuinely seeking recovery. As one respondent noted, "there are drug dealers mixed in with drug addicts." The presence of the drug dealers is distracting, and diluting the treatment experience for others.

1.6 Conclusions and Recommendations for Substance Abuse Treatment Services

The findings of this section of the needs assessment identified the need for both short-term recommendations for Ryan White services and longer term issues related to the effectiveness of the current treatment system and the emerging substance abuse epidemic among youth.

- The existing substance abuse treatment system is inadequate to meet need and/or demand. The Council should explore achieving greater efficiencies with current resources as part of its **Resource Inventory** function.
    - **Recommendation.** The Planning Council should work with county organizations including the Municipal Alliance and health departments to identify substance abuse resources and gaps and **coordinate county-based substance abuse services** with those available in Ryan White.
    - **Recommendation.** The Council and Grantee should work with the regional Medicaid Office in Newark to clarify mental health and substance abuse benefits available under New Jersey's **Medicaid Expansion** effective January 2014. Amounts should be quantified to the extent possible. CHAMP and other delivery systems should be adapted to use these resources first for PLWHA receiving expanded Medicaid.

- The current substance abuse treatment model does not work. To improve substance abuse treatment access and outcomes and improve health of PLWHA, the Council should conduct research on **improving the treatment model**. Questions to be addressed include:
    Is there a model that works?
    Who will pay for a model that works?
    Is there a willingness to develop a model with the dollars that are available?
    Is there an inclination or agenda to sustain what is in place. Who is profiting from this?
    - **Recommendation.** The Council in conjunction with other agencies in the EMA and the state, should start working on identifying evidence-based, improved treatment models. Those that are readily available could be proposed for Ryan White funding.

- Technology through Electronic Medical/Health Records (EMR and EHR) is being used for patient medical care including HIV medical care under federal HI-TECH programs and the ACA. The EMA should seek to incorporate **technology in substance abuse treatment programs** and regimens through innovative programs. Questions to be addressed include:

  Could an evidence-based model that exploits the availability of technology and innovation be more cost efficient and effective?

  Smart-phone applications ("APPS") are available for coordinating GPS guided sexual encounters; what about an APP that facilitates treatment and recovery? What would that look like?

  How could effective aspects of treatment be translated through technology and delivered within a less costly system?

  - **Recommendation.** The Council in conjunction with other agencies in the EMA and the state, should start researching these **models that incorporate technology**. Those that are readily available could be proposed for Ryan White funding.

- Over-prescription of addictive drugs has been identified as a statewide and nationwide problem leading to addiction. This has been overlooked in the EMA as we have focused on IDU and other apparent substance use. Who is monitoring the prescribing of opiates to PLWHA in the Newark EMA?
  - **Recommendation.** The Planning Council in conjunction with other agencies in the EMA and the Continuum Of Care (COC) Committee, should start researching and identifying **prescribing practices** and who is responsible for oversight.

- It is clear that there is a major heroin epidemic growing in the suburbs that is unnoticed or ignored by the mainstream media and most of the state and nation. The impact of this addiction, both directly and through increase in risky behaviors, has been discussed above. Action must be taken both directly and through policy. Universities, Hospitals, Insurance Companies, and Public Health providers need to be organized, and combine resources to address this next looming epidemic.
  - **Recommendation.** The Council and Grantee should initiate this conversation with public health officials in the EMA, starting with the City of Newark. The Newark DCFWB in its public health and regulatory role can convene a body of all key players to start addressing this substance abuse issue. The question to be addressed is **"What is the impact of heroin addiction in suburban youth on Newark, and on the State of NJ?"** If other bodies are already addressing this issue, the public health and Ryan White and addiction treatment systems can participate.

PART 2: YOUNG MEN WHO HAVE SEX WITH MEN

2.1 Background

Youth, and particularly young men who have sex with men (MSM), are a growing population of new HIV infections. Rates are highest among the African-American youth MSM population. The Newark EMA provides funding to agencies serving HIV+ youth and works with prevention agencies who reach HIV+ youth. The purpose of this part of the 2013 Needs Assessment Update is to identify the continuum of services available to youth – specifically MSM youth – and how it engages youth in testing for HIV and care for their HIV disease and overall health if not HIV+. The purpose is to determine if current Ryan White funding is adequate for HIV+ youth services or should it be adjusted to help meet any increasing needs.

Research Question #2
What is the continuum of care for Young Men who have Sex with Men within the Newark EMA, what are their needs and gaps in services, and should current Ryan White funding for services to YMSM be adjusted to help meet any increasing needs.

Specific services include:

- **Research** as to why MSM youth are an emerging population based on CDC findings and those of the Newark EMA. Identify **Key Informants (KI)** in the Newark EMA, prepare KI survey tool, and conduct interviews as needed.
- **Examine existing programs in the Newark EMA serving HIV+ youth and identify their services.** Where are they? What services to they provide? What is the goal, e.g., to get newly diagnosed HIV+ youth into medical care with 24-48 hrs of diagnosis. What are the barriers to achieving this goal? Prepare **KI guide or tool** to assist in this examination that includes the following.
    - Identify the continuum of prevention, diagnosis, and treatment from the perspective of agencies serving HIV+ youth in the EMA.
    - Identify the existing health system in the EMA serving HIV+ youth.
    - How are at risk young individuals getting into medical care - by referral, walk in, etc.
    - Identify whether health-related agencies who may be serving youth MSM are also referring the youth back to services regardless of HIV status, e.g., STI testing agencies. Do they have special services for youth?
    - Identify the extent to which stigma appears to impact access to HIV care, youth perceptions of stigma, and recommendations/suggestions for overcoming these perceptions.
- Assess the availability of **primary medical care** for youth. Assess their eligibility for the Medicaid Expansion available in New Jersey starting in January 2014.
- Conduct **KI interviews** as needed and discussed above.
- Conduct Focus Groups as needed to obtain additional information.
- Incorporate findings of Youth Focus Groups conducted by the NEMA Council in January – March 2013.

Report. Prepare report of findings regarding Youth MSM. Identify recommendations made by participants and key informants. Include recommendations for FY 2014 Ryan White service priorities and resource allocations.

Methodology

The method was to use agencies funded by Ryan White and HIV Prevention who serve youth as **Key Informants (KIs).** A typical KI process includes an interview using an Interview Tool. As the Research and Evaluation Committee (REC) developed the tool and information to be obtained, however, it was apparent that the "tool" would be more of questionnaire. But we agreed that we would need to talk to KIs to get more information and clarification that might not be covered in the questionnaire. It was decided that the KI portion would have two steps: Step 1 – Completion of KI questionnaire, and Step 2 – Follow up KI interview after review of questionnaire responses to get more clarification and fill in information gaps. This approach is discussed in the Introduction.

For Step 1, the REC developed the questionnaire to capture information regarding youth and young MSM, shown in Appendix A. The questionnaire was sent out to **XX** agencies. Two agencies responded. For Step 2, the Needs Assessment contractor conducted the follow up interviews with two agencies. Use of a single individual ensured consistency of follow up questions, and the ability to follow up on one agency's response with other agencies. This section incorporates all responses to KI questionnaires and interviews.

2.2 Profile of Youth and YMSM

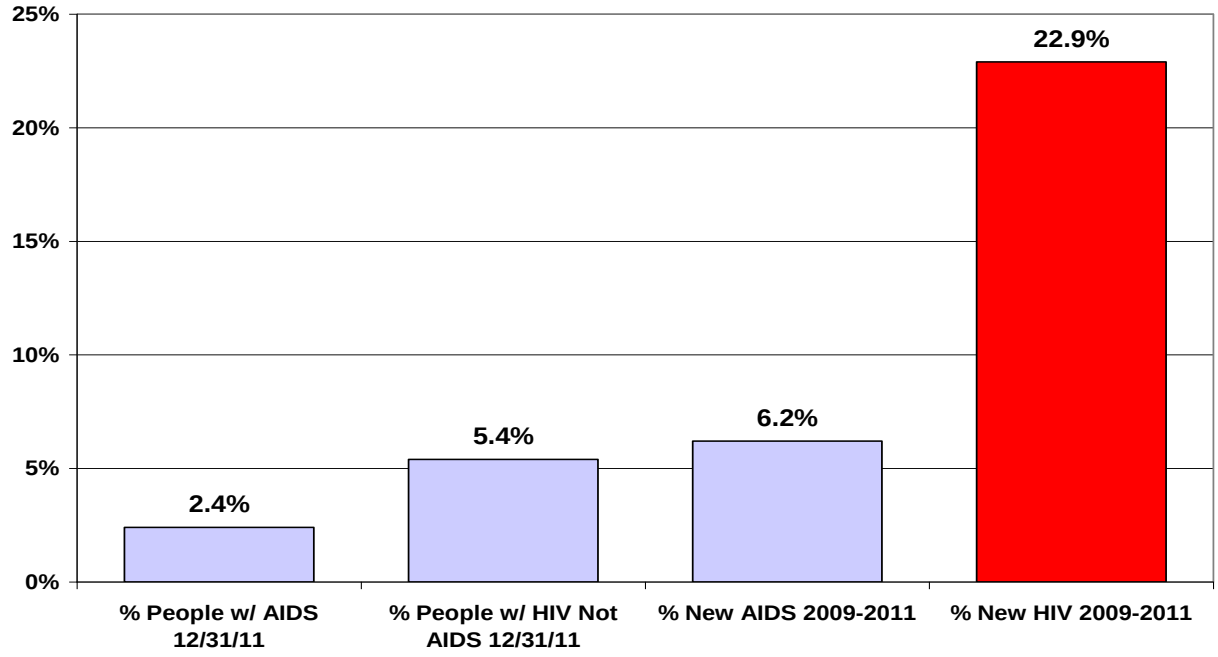
In order to better understand the needs of the YMSM population, we examined HIV surveillance data for Youth (Age 13-24) which is the only data available for the "youth" category and current utilization of Ryan White HIV/AIDS Program (RWHAP) services by YMSM in the Newark EMA. Data sources were HIV surveillance data as of 12/31/11 and 12/31/12 from the N.J. Department of Health, Division of HIV, STD and TB Services, and the FY 2012 CHAMP file covering the period March 1, 2012 – February 28, 2013. CHAMP data were based on **self-reported exposure category by age**.

2.2.1 Youth with HIV/AIDS

HIV surveillance data are available for the category of "youth" age 13-24. A total of 510 individuals age 13-24 are living with HIV/AIDS n the Newark EMA – 167 with AIDS and 343 with HIV. This is 3.8 % of the total 13,476 PLWHA in the Newark EMA.

Youth account for only 2.4% of persons living with AIDS and 5.4% living with HIV, but nearly 23% of new HIV infections in the Newark EMA as of 12/31/11. See Figure 26. Care and treatment resources must ensure that youth are diagnosed early, are immediately linked to medical care and treatment of the new infections.

Figure 26: Youth As Percent of PLWHA and New AIDS and HIV Infections in Newark EMA as of 12/31/11

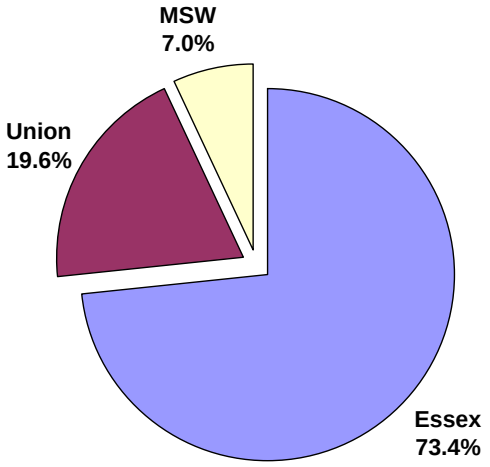


Newly-released HIV surveillance data as of 12/31/12 shows that a total of 510 Youth are living with HIV/AIDS in the Newark EMA. Of these, 316 or 62% are male and 194 or 38% are female. The distribution by gender for youth is the same as for the overall PLWHA.

Table 4: Youth in Newark EMA by Gender, 2012

	Male	Female	Total
Essex	232	153	385
Union	62	33	95
Morris, Sussex, Warren (MSW)	22	8	30
Newark EMA	**316**	**194**	**510**
5 Cities	241	149	390
5 Cities/NEMA	76.3%	76.8%	76.5%
NJ	808	427	1,235
NEMA/NJ	**39.1%**	**45.4%**	**41.3%**

Figure 27: Distribution of Male Youth by County, 2012



2.2.2 Ryan White Clients - Youth Age 13-29 and Young MSM Served by Newark EMA Ryan White

Youth Age 13-24. During FY 2012, a total of 317 individuals age 13-24 received Ryan White services from Part A and or Part F. Of these, 271 (85%) resided in the EMA and 46 (15%) lived outside of NEMA. In other words, Part A/F served 53% of youth PLWHA.

An additional 315 individuals age 25-29 received RW services. In the 2011 Needs Assessment, the EMA defined **"youth" as individuals age 13-29 (under age 30)**. Using this definition, a total of 632 RW clients are considered "youth". Of those, 408 or 65% are male. Based on self-reported exposure category, a total of 229 or 36% of HIV+ youth are Men who have Sex with Men. The universe for analysis is **229 Young Men Who have Sex with Men (YMSM).**

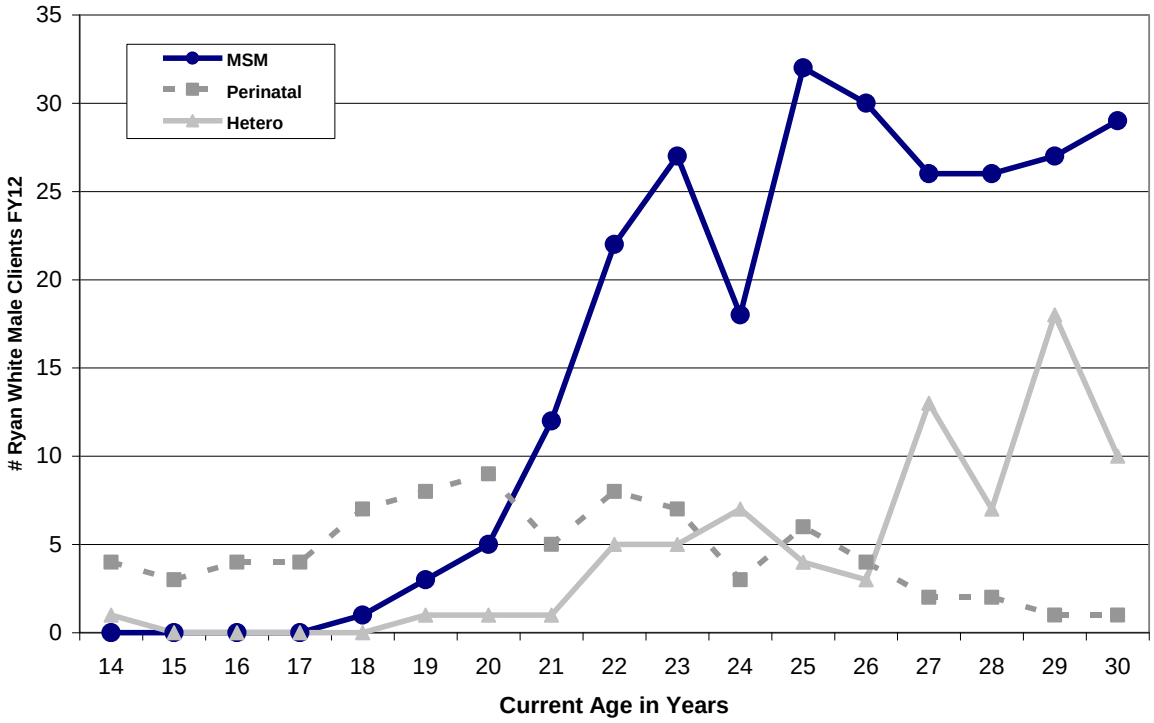
Table 5: Youth Age 13-29 Served by NEMA Ryan White (CHAMP) in FY 2012

	Exposure Category						
Total #	**Hetero**	**IDU**	**MSM**	**Mother**	**Other**	**Unk/NR**	**TOTAL**
In NEMA							
Age 13-24	49	3	**80**	119	4	16	271
Age 25-29	94	1	**123**	26	3	27	274
Total	**143**	**4**	**203**	**145**	**7**	**43**	**545**
Outside NEMA							
Age 13-24	2		**8**	26	3	7	46
Age 25-29	10		**18**	6	3	4	41
Total	**12**		**26**	**32**	**6**	**11**	**87**
Total FY 12							
Age 13-24	51	3	**88**	145	7	23	317
Age 25-29	104	1	**141**	32	6	31	315
Total	**155**	**4**	**229**	**177**	**13**	**54**	**632**
Distribution by Exposure Category							
	Hetero	**IDU**	**MSM**	**Mother**	**Other**	**Unk/NR**	**TOTAL**
In NEMA							
Age 13-24	18%	1%	**30%**	**44%**	1%	6%	100%
Age 25-29	34%	0%	**45%**	9%	1%	10%	100%
Total	26%	1%	**37%**	27%	1%	8%	100%
Outside NEMA							
Age 13-24	4%	0%	**17%**	**57%**	7%	15%	100%
Age 25-29	24%	0%	**44%**	15%	7%	10%	100%
Total	14%	0%	**30%**	37%	7%	13%	100%
Total FY 12							
Age 13-24	16%	1%	**28%**	**46%**	2%	7%	100%
Age 25-29	33%	0%	**45%**	10%	2%	10%	100%
Total	25%	1%	**36%**	28%	2%	9%	100%

Male Clients Age 13-30 by Exposure Category. Of the 457 males age 13-29 served by Newark EMA Ryan White Part A/F in FY 2012, self-reported exposure categories were: 258 (56%) MSM, 78 (17%) perinatal transmission, 76 (17%) heterosexual transmission, 5 (1%) Other, 1 (0%) IDU, and 39 or 9% Unknown or Not Reported.

The figure below shows the top three self-reported exposure categories of male Ryan White clients age 13-29. (There were no male clients aged 13 in FY 12). Younger male teens age 13-19 were exposed primarily by perinatal transmission (HIV-infected mother at birth). Starting at age 20, more males are exposed by MSM and the number increases up to age 30. A few males age 22-29 were exposed by heterosexual transmission.

Figure 28: FY 12 Male Part A/F Clients Age 13-29 by Exposure Category – MSM, Perinatal, Heterosexual



2.3 Current System in the EMA Serving Youth and YMSM, Needs and Gaps

Two key informants (KIs) serving youth completed the interview guide and participated in follow up telephone interviews. The agencies provided the following responses.

KI Questions

19. What kind of services do you provide for YMSM? What is the goal of your services, e.g., to get newly diagnosed HIV+ youth into medical care with 24-48 hrs of diagnosis.

One KI agency provides HIV prevention resources to the YMSM in the Greater Newark area including:

- the BROTHER Project for young MSM, and
- T.G.I.F. for young trans-women.
- Facilitating the "Many Men, Many Voices" CDC-approved multi-session group intervention for MSM.
- For transgender women, SISTA-T, the only multi-session group intervention totally designed for trans-women in the State.
- Free HIV Rapid Testing. An incentive program attracts youth, including McDonalds' gift certificates, bus tickets and movie vouchers. Any client tested with a preliminary positive result is immediately hooked with the designated Navigator at UMDNJ. We do everything in our power to ensure a quick linkage into care.

The other KI agency provides Project LOL services to YMSM in the Northern New Jersey community by providing access to free HIV testing and STD screenings, treatment, access to condoms and safer sex supplies. Additional services include risk reduction and health education workshops and engaging the peer networks of YMSM via social media.

Services for newly diagnosed HIV+ youth include linkage and follow-up services to newly identified and re-linked individuals and the following:

- In-house referrals to treatment adherence and client navigation, and
- Comprehensive Risk Counseling and Services (CRCS) with CLEAR and Mpowerment Evidence Based Interventions (EBIs) to address the bio-psychosocial needs of young men.

20. Approximately how many YMSM do you serve? How many are HIV+?

One agency in Newark sees approximately 40 YMSM and YTG (young transgenders) monthly. They seem to come and go in waves—like cliques—so it varies. We do not keep stats on the number of HIV-positive clients who visit our programs, but our Rapid Testing program has identified 7 HIV-positive young people within the last eight months that we've been testing.

The other agency with statewide presence services over 5,000 YMSM throughout Northern New Jersey as a result of Counseling, Testing and Referral (CTR) programs, Mpowerment outreach events, CLEAR services, Condom distribution activities, peer to peer networking and social media outlets. Since only

two programs collect information regarding an individual's serostatus (CTR and CLEAR), an accurate number of HIV+ YMSM serviced by the project is not available.

(**Comment:** The number served by the Newark agency would total 240 per year, which is consistent with the 510 total youth PLWHA age 13-24 in the EMA, 385 in Essex County and 222 in Newark as of 12/31/12.)

21. To what extent do your services provide (1) prevention, (2) diagnosis, or (3) treatment of HIV disease?

The one KI agency is devoted to HIV prevention and has been providing these services to this population for a decade now. The testing is relatively new. This is the first year that we've been funded to provide HIV testing service. We do not provide HIV diagnosis or HIV treatment.

For the other agency, HIV Prevention is the primary work of their project. (1) Prevention services include direct and indirect health education, skill building and risk reduction information to individuals, groups and the community via CLEAR and Mpowement. (2) Regarding diagnosis, the agency's CTR unit provides rapid HIV testing using StatPak and provides linkages to confirmatory testing to confirm Preliminary Positive diagnoses. (3) Treatment is handled by local medical facilities with supportive services being provided by the agency's Treatment Adherence Counselors and Wellness Navigators

22. Do you work with other agencies for prevention, diagnosis or treatment of HIV disease? Please identify and discuss your continuum of care.

One agency reported that, while we have several Memorandums of Understanding, our main collaboration is with the Infectious Disease Practice of UMDNJ.[3] We work diligently with their Navigator program and thus far, all of our preliminary positives have been sent to them. It is there that patients get a confirmatory test, as well as linked into medical treatment.

The other agency reported that under NJDOH requirements it utilizes a **Rapid to Rapid** method for its linkage network to care for newly identify positives. Individuals with a preliminary positive test are immediately referred and transported to Jersey City Medical Center or another regional site for confirmatory testing. This is done within 36 hours of the initial test to ensure a smooth transition for the client. Treatment can be provided for the client at the confirmatory medical site or a provider of their choosing. The agency currently works with Hudson Pride Connections Center's Outreach Team to provide linkage services to confirmatory HIV tests via Liberty Medical Services and follow-up to client's initial medical appointment.

23. What are the barriers to achieving your goal(s)?

The biggest barrier in trying to keep HIV infections out of this population of YMSM could be measured by the social drivers, which include homophobia, stigma, risky behaviors, multiple partners, and attitudes. This is a population that assumes HIV infection at some point in their lives already.

[3] Effective July 1, 2013, UMDNJ was dissolved and merged into Rutgers University.

Another problem is the lack of interventions specifically geared for this ever-changing population. The current interventions are actually based on very old data, and while they claim to be culturally competent, the increase in infections within this population should prove otherwise.

The other agency reported that one primary barrier to our linkage to treatment process is the physical barrier as a result of having to refer out for confirmatory HIV testing. Since most of our testing services are provided by mobile outreach, we have experienced some barriers in having client's follow-up for confirmatory testing and medical care. Given that our unit works during unconventional hours and at community venues, client confidentially and privacy also becomes an issue when we must obtain a confirmatory test off-site.

24. Where (geographically) do your YMSM come from? (In other words, how would you describe your service area?)

The Newark-based agency serves the Greater Newark area, which includes Essex County, East Orange and parts of Elizabeth. We also have participants from Jersey City. Many of our clients go back and forth between living in New Jersey and New York City.

The other agency's service area includes the Northern New Jersey counties of Hudson, Bergen, Essex, Passaic, Morris and Union. Most of our clients reside in Hudson and Essex counties, particularly Jersey City, Union City, West New York and Newark.

25. How would you identify the existing health system in the EMA serving HIV+ youth? Who are the providers, what are the strengths and gaps from your perspective?

While the Newark-based agency does not identify participants as HIV-positive or HIV-negative, our agency is aware of what YMSM who are positive are going through. Many feel that they cannot get assistance in Newark, which is why many seek services in NYC. The youth have more places that they can go to, including the Ali Forney Center, or Green Chimneys, because what they really need is housing. While there is Covenant House in Newark, or St. Bridget's, housing remains a big barrier, especially for transgender men and women. Shelters seem not to be the choice of trans-people because they have to conform to gender biases.

For transgender women, places like UMDNJ[3] or St. Michael's Medical Center have staff that may or may not be comfortable in dealing with this population. We've heard good and bad. Dr. Anita Vaughn, a local physician, has a good reputation for treating trans-women. However, for transitional therapy, many clients prefer to go to the Callen-Lorde Health Center in New York. The Newark Dept. of Health does not have a good reputation with this population, although many will go because they can be treated for STDs for free. North Jersey Clinical Research Initiative (NJCRI) and Project WOW still represent a good outlet, although many young people will not seek treatment there because they might run into someone they know.

For the most part, Newark still has a small-town mentality, where everyone knows everyone else's business. Confidentiality; or the perceptions that there is none, still plagues this city.

The North Jersey-based agency finds that there is a drought of health providers who service youth,

especially for GLBTQ youth. Most of the providers have very little knowledge on MSM health issues and lack cultural competency as it pertains to the GLBTQ community. Gaps in services result because there are not enough community-based centers or sites that are centrally located and accessible to YMSM.

26. How are at risk young individuals getting into medical care - by referral, walk in, etc.

In Newark, you have to catch them when you can. If they want to get tested, you have to "do it now." If you want to treat them or enroll them in charity care, you have to do it immediately, or you lose them. Promises to see the doctor "next week" must, unfortunately, be met with skepticism, because kids are kids, and that's how they think… No shade… In many cases, you have to take them by the hand in order to get them to do the right thing.

The other agency reported that at-risk individuals seek medical care mostly via referral and walk-in, most often on an emergency rather than preventative basis.

27. Identify whether health-related agencies who may be serving YMSM are also referring the youth back to services regardless of HIV status, e.g., STI testing agencies. Do these agencies have special services for youth to the best of your knowledge?

Newark: Currently, we do not see a lot of referrals coming from other agencies. We believe that many agencies feel that our agency is already known to YMSM, when that is not the case. We find that doing outreach activities, many young people have not been exposed to our very existence. Also, various programs, Division of Adolescent and Young Adult Medicine (DAYAM) at UMDNJ[3] for example, do not seem to be actively involved within the community the way they used to—if they're still around.

North Jersey: In our immediate area, we collaborate with Hudson Pride Connections Center to provide and exchange of services to the YMSM population here in Hudson County. Our testing linkage partner, Liberty Medical Center, does not provide services tailored to the YMSM community and does not refer back to our project for supportive services on behalf of their YMSM clients. Throughout Northern New Jersey, we have collaborative agreements with the following agencies also servicing YMSM: African American Office of Gay Concerns (AAOGC), Newark Beth Israel, East Orange General, Trinitas Hospital and NJCRI.

28. What are co-morbid factors affecting care for YMSM? E.g., substance use, mental health problems, other.

YMSM are reporting active participation in alcohol and marijuana use. We hear anecdotal information about pot substitutes (K2 or Spice), but that is only a handful. With respect to mental health, we recognize that it is a big problem, but because we are non-clinical, we can only try to make referrals to professionals.

There are also social/life skills that are lacking in this population. Kids often stop by our office when they are supposed to be in school. When questioned, it seems they're all going for their GED. Once again, this has to be viewed with a grain of salt, because you may get a different story depending on what day of the week it is. Fortunately, there are places like Project WOW, Liberation In Truth social

Justice Center, and the Hetrick-Martin after-school program that the young people can take advantage of to learn social skills.

There are numerous co-morbidity factors for the YMSM we service including mental health challenges, substance use (particularly alcohol and marijuana), domestic violence/ family disruptions, homelessness, unemployment and low educational attainment.

29. Identify the extent to which stigma appears to impact access to HIV care, youth perceptions of stigma, and recommendations/suggestions for overcoming these perceptions.

One of the downsides to being an agency that works with HIV+ individuals is that a lot of the kids identity us as strictly an HIV agency. Many don't want to be associated with HIV/AIDS in any way shape of form, so they shy away. However, since there are limited outlets for them, sometimes they have no choice but to be seen here. However, if their peers are willing to come in, so will the group. They do realize, after all, that we are still a safe space for them. We also have to be role models for the community. Too many do not have people they can look up to, so we, as providers, have to be out there showing them it's okay to be openly GLBTQ. With respect to HIV, though, they don't fear getting infected, although most are probably not equipped to deal with the situation in a positive, healthy manner.

Stigma has significant effects on YMSM access to HIV care and preventive services in both perceived and real means. General HIV stigma in society dissuades many from seeking preventative sexual health services including health education, partner negotiation skills and HIV/STD testing and screening services. Pertaining to men of color, there is a general stigma regarding both HIV and healthcare due to lack of education and distrust in community institutions. This is a significant barrier to many YMSM of color accessing services as some have experienced providers that were not so compassionate or culturally competent.

In our experience, health care providers should take an interest in serving the whole person of GLBTQ youth by understanding not only the physical health of such persons but also their emotional well-being. Providers should strive to be more in tune with issues that GLBTQ youth face such as depression, low self-esteem, domestic violence, homelessness and substance use. They should also develop programs to find relevancy with the GLBTQ community, seeking gatekeepers and key informants to achieve buy-in for those they intend on serving. This can also be done by reaching out and forging partnerships with GLBTQ service agencies.

30. What are the funding sources for services for programs for YMSM that you are aware of? Health insurance, Medicaid, Medicare, NJ State funding, etc.

Most of the services locally for YMSM are preventive health services funded by the New Jersey Dept. of Health (NJDOH) or CDC. Additionally, supportive services for HIV positive individuals exist via Medicaid, Medicare, ADAP and Ryan White.

a. What are the trends in these funding sources? (Increasing, decreasing, static)

In the prevention field much emphasis has been placed on Treatment as Prevention, causing a shift in the share of HIV prevention dollars going to linkage to care versus behavioral interventions and

traditional prevention efforts. This shift has significantly reduced dollars dedicated to impactful programs such as Many Men Many Voices. Funding for medical care and biomedical interventions such as PrEP has not seen increases in funding.

b. What are the gaps in these funding sources? How much is not covered? What is the service gap or unmet need?

One significant gap in services for YMSM is behavioral health and substance use assistance. In the state of New Jersey there is a significant lack of providers who focus on either issue and none that specialize in either youth or GLBTQ persons.

The other KI agency firmly believes that the federal, state and local governments are not doing the right thing when it comes to funding for programs for YMSM. With the latest information released by the CDC, YMSM of color continues to be the most at-risk population in the United States. Unfortunately, funding—especially for prevention-does not match their concern. While leaders insist they are focusing on this population, they aren't writing checks to match the rhetoric.

31. What effect do you think the proposed Medicaid expansion to all individuals with incomes under 133% Federal Poverty Level will have in helping YMSM to access and obtain medical care, other health services, medications) for their HIV disease? For YMSM who are not HIV+? Please provide any additional comments.

Seriously, YMSM could care less about FPL. They have no idea what it means, or how it affects them as individuals. Most of them have never had insurance for themselves, and have been covered under their Mothers' plans, if any. We have tried to teach them about such coverage, including ADAP and Charity Care, but they are not interested in the facts—just the results if it happens to them. Most do not have a clue as to what the Affordable Care Act means. This is an area in which Navigators could play an important role.

The other agency believes that Medicaid expansion will greatly benefit these YMSM by giving them access to life-saving and sustaining care as well as other health services that will enhance their quality of life. For YMSM who are not HIV+ yet at the highest risk of HIV infection, expanded health services can provide access to preventative care including PrEP.

32. Please provide any recommendations or other information that could assist the Newark EMA in serving YMSM both HIV+ and not HIV+.

One thing the NEMA could do is to insist that the City of Newark produce or fund some kind of prevention campaign, much like the "Status Is Everything" campaign, which was paid for with CDC funds (by way of the NJ Dept. of Health). This is still a silent community where only a handful will stand up for the majority. If the city takes the lead, we just might save some young people from getting infected.

In our work with the YMSM population in Northern New Jersey, we have identified that YMSM in the region are quite active and mobile. There is a high degree of transient nature to most of the youth we encounter on a day to day basis, with many engaging in sexual relations and social interactions with

other men all across the region. One might live in West New York and often travel frequently to New York City, Jersey City, Newark and even Paterson to engage with other YMSM.

As a result, any attempt to service YMSM in the Newark-Essex county community must also coincide and be compatible with services provided in Hudson, Bergen and other counties throughout the region.

2.4 Conclusions and Recommendations for Youth and YMSM

Although Youth and YMSM are a small percentage of PLWHA, they are a relatively high proportion of newly diagnosed HIV Infection. Given their young age, they should not be saddled with a serious illness, but be given opportunities to understand their risk, adjust their behavior and take control of their lives in order to live a long, full life with or without HIV. For those who are HIV+, they should be able to manage their health with available and tailored resources.

- **Access to information about risk.** The REC members raised questions about the extent of preventive HIV education for youth. Although not part of this survey, the issue should be reviewed by the EMA.
    - **Recommendation:** The EMA's Ryan White program should obtain more information about HIV/STI-related educational activities for youth occurring in the EMA. This can be done by the Planning Council and through the regional Early Intervention and Retention Collaboratives (EIRCs). This is an important part of the service continuum for HIV+ YMSM.

- **Access to testing.** It appears that there is considerable access to HIV testing through confidential on-site resources and outreach by mobile van and other methods. One agency cannot perform confirmatory tests on the van but must refer to a medical provider. This delay can result in new HIV+ youth being lost and not linked to care immediately.
    - **Recommendation:** Testing agencies should explore the **Rapid-Rapid testing** which may be state policy. If so, the policy should be implemented so that newly-diagnosed HIV+ youth can learn of their status and be linked to care immediately.
    - **Recommendation:** The EMA's EIRCs should obtain information from the member CTR agencies on the **policy for confirmatory HIV testing** and linkage to care and any gaps that occur including failure to link.

- **Access to medical care.** Medical care specific to the needs of youth seems to be available in the EMA even for HIV+ youth living outside of the EMA. However, special populations such as transgendered women may have trouble accessing appropriate medical care. The youth and YMSM population is transient, moving in and out of the Newark EMA.
    - **Recommendation:** The Planning Council in coordination with the Grantee should get better and more concrete information about **medical providers serving youth** and transgendered individuals, among others, and patient flow from testing to treatment and retention in care. This can be done through the Continuum of Care (COC) committee and the EIRCs.
    - **Recommendation:** The EMA should not impose unduly restrictive **residency requirements** for Ryan White clients, including youth. This is because, as stated by one

Key Informant, the HIV medical services in one TGA are not targeted to youth and the agency makes referrals to appropriate services in the Newark EMA.

- **Recommendation:** The EMA should ensure that all youth receiving medical care are enrolled in **Expanded Medicaid** which starts January 1, 2014.

- **Other services.** There is a need for mental health and substance abuse treatment services that address the specific needs of youth, particularly HIV+ youth. The current models of prevention, education, testing and care and treatment services are said to be outdated, not addressing needs of current youth. Lack of available, affordable housing is a barrier.
  - **Recommendation:** The EMA (Grantee) and agencies serving youth should determine appropriate models of **mental health and substance abuse** treatment services for youth so that Ryan White can fund provider(s) for those services.
  - **Recommendation:** The **Medicaid Expansion** includes funding for mental health and substance abuse services. These resources should be coordinated with Ryan White for programs for youth.
  - **Recommendation**: As part of its function to assess resources available to PLWHA ("**Resource Inventory**"), the Planning Council should explore housing options available to youth in the EMA. This can be done by subcommittee, work group, and other means involving providers serving youth and housing agencies. Results should be made available to providers and youth in the EMA by directory, social media, etc.
  - **Recommendation**: The Grantee should ensure that housing agencies serving youth receive the **annual Ryan White RFP** which includes funding for emergency and transitional housing. The Council should identify providers not currently receiving RW funding and reach out to them and encourage them to apply.

- **Barriers/Obstacles/Challenges to treatment and care.** The nature and characteristics of the youth population – need/desire for immediate services, frequent relocation, risky behaviors and personal instability - are challenges to prevention and continuous care. Also, external factors including homophobia and stigma impact long term participation in stable care. KIs say that the current care models are outdated, not addressing needs of current youth. It seems as though Newark and its HIV-agencies are considered too close to home with the perception is that confidentiality may be compromised or peers may learn of their HIV status.
  - **Recommendation:** To the extent possible, agencies serving youth should develop **rapid, one-stop care models** or other service models that combine testing, diagnosis, enrollment in insurance and medical care in a single visit or intervention. The providers who are experienced in serving youth and transgendered can work on and implement these with assistance from the Grantee and EIRCs.
  - **Recommendation:** As part of the **CQM Plan** function, the EMA should examine key clinical performance measures by youth compared to the rest of PLWHA. If outcomes are below EMA averages, appropriate Plan-Do-Study-Act (PDSA) Cycles should be developed and implemented to improve outcomes. If outcomes exceed EMA averages, then the agencies, through the COC, should identify and continue best practices.
  - **Recommendation:** As part of its Resource Inventory and Comprehensive Plan functions, the Council should research **newer models** of prevention, education, testing and care and treatment services which have the potential of serving more youth.

- **Recommendation:** All providers and agencies serving youth in the EMA should dispel the notion of lack of confidentiality, since the EMA's agencies strictly enforce all HIPAA and confidentiality policies and requirements. The Planning Council can take the lead in this campaign through the **Community Services Advisory Committee**, its website, and other methods. Agencies serving youth should be known as a **"safe place"** where confidentiality is maintained.

- **Newark Health Department.** The **Newark Department of Child and Family Well-Being (DCFWB)** which is the local health department, performs an essential role of free testing for STIs and HIV and immediately linking HIV+ individuals with medical care through its Special Care Clinic. DCFWB is also the Grantee for the Newark EMA Part A Ryan White grant.
  - **Recommendation:** The Grantee and DCFWB should review their **customer service** policies and practices and ensure they are appropriate to the needs of youth coming to them for services. Provide updated customer service training if required.
  - **Recommendation:** Representatives of DCFWB STI Testing and Special Care Clinic should "reacquaint" youth to their services through **education to youth** groups and other venues to remove barriers to youth accessing needed services.
  - **Recommendation:** The Council and Grantee should follow up with the **Mayor's Task Force on GLBT Issues** and its programs regarding HIV testing. Coordinate publicity efforts with Mayor's Office, prevention and other providers in Newark, and the Community Services Advisory Committee.

PART 3: RETENTION IN CARE FOLLOW UP

3.1 Background

Background. The Council and committees were interested in a progress report on whether performance had improved regarding "retention in care" and clients "lost to service" as reported in the 2011 Need Assessment. Information is to include a review of CHAMP longitudinal data from 2010-2012 in comparison to 2008-2010 to determine if rates had improved regarding clients who dropped out and returned to care and those who dropped out and did not return. The purpose is to determine if the recommended corrective actions, e.g., the CHAMP "nine-month reminder" of no client contact, and grantee actions, e.g., Early Intervention and Retention Collaboratives (EIRCs), had resulted in improvement in retention in care.

Research Question #3
What are the changes between PLWHA who were "lost to service" in 2010 versus 2012 and have there been any improvements in the number, percent, demographics in the three year period? (Lost to service is defined as those who received care in 2008 and dropped out and did not return to care by 2010, and those who received care in 2010 and dropped out and did not return to care by 2012.)

Specific services include:

- **Data Review and Analysis.** Prepare a longitudinal file of CHAMP data for FY 2010, FY 2011, and FY 2012 using SPSS and other programming, determine subpopulations of those who did and did not return to care in FY 2012. Prepare cross tabulations by relevant demographic and geographic categories as well as other statistical analyses. Review the longitudinal file of CHAMP data for FY 2008, FY 2009 and FY 2010 for all Part A/F clients developed for the 2011 Needs Assessment. Consult with the Council and committees for any specific tabulations they are interested in and perform tabulations.
- **Report of Data Review.** Prepare initial report of findings including tables and graphs showing clients lost to follow up in FY 2011 by whether or not they returned in FY 2012. Include demographics, geography and services received including subtypes and provider types. Include comparison to clients who dropped out in FY 2009 and did not return in FY 2010.

Final Report. Consolidate the above information and prepare final report for this assessment update. Identify areas where Council can allocate resources and/or make directives to grantee to improve retention in care and reduce lost to follow up.

3.2 Trends in "Client Status"

What is Client Status? Client status is the indicator in CHAMP of the client's current situation within an agency and the Ryan White program. An agency can enter client status due to a change in circumstances (e.g., discharge or suspend for no contact). CHAMP will compute client status automatically, e.g., "active" if the client continues to receive services indicated by an update to the CHAMP client record or "suspend" if no contact within the prior 12 months. **Clients with status of**

"active" or "suspended" are followed for "Lost to Service" or Retention In Care (RIC). A client who has been "discharged" does not require RIC follow up.

Table 6: CHAMP Client Status Options

Active
Active
Active - Shared Other Agency
Active – Transferred Inside Agency
Discharged
Discharged - Case Resolved
Discharged – Died
Discharged – Incarcerated
Discharged – Moved
Discharged - Other Source of care
Discharged - Removed from treatment
Discharged - Transferred Out
Discharged – Withdrew
Suspended
Suspended - No Contact
Suspended – Stable

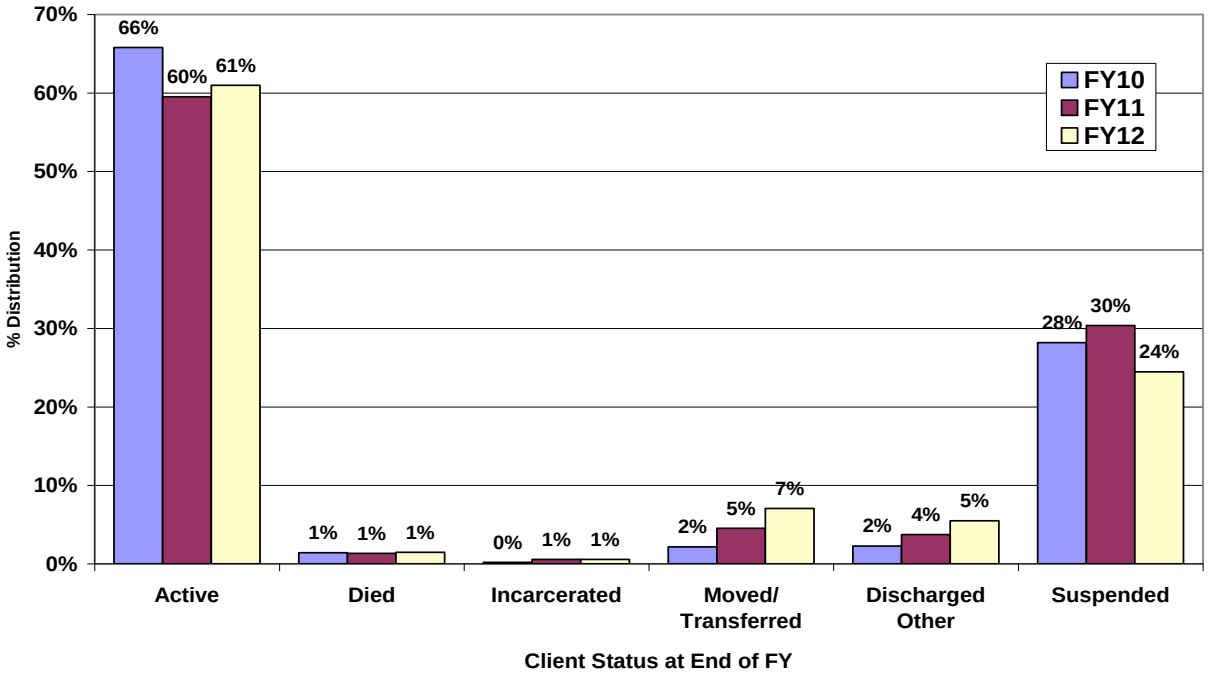
3.2.1 Impact of 2011 Needs Assessment RIC Recommendations

Following recommendations of the **2011 Needs Assessment**, CHAMP implemented a **"9-month" alert** to improve retention in care. Whenever an agency staff member logs onto CHAMP, this alert identifies every case/client with no activity for 9 months or more. The purpose is to improve patient follow up and retention in care and to sure that agencies maintain current Ryan White case records and CHAMP records.

Step 1 in RIC analysis was to review client status over the past three years from FY 2010 through FY 2012. The goal was to identify any changes and improvements from FY 2008 – to see if the percent "active" clients had increased and "suspended" clients had decreased. We wanted to see if the "9 month alert" had worked.

It appears as though the "9 month alert" has had a positive impact. In FY 2012 less than one quarter of clients were "suspended-no contact", down from 30% the prior year. More clients were documented as "Moved/Transferred" or "Discharged", indicating that some agency action had been taken to follow up and make a determination on the case and circumstances. See Figure 29 and Table 7.

Figure 29: Ryan White Client Status, FY 2010 – FY 2012



There has been a **5% annual decrease in Ryan White Part A/F clients in FY 2011 (-339) and FY 2012 (-336)**. This will affect the retention in care statistics.

Table 7: Ryan White Client Status, FY 2010 – FY 2012

Client Status Categories	FY 2010		FY 2011		FY 2012	
	#	%	#	%	#	%
Active	4,365	65.8%	3,746	59.5%	3,634	61.0%
Discharged	400	6.1%	638	10.1%	868	14.7%
Died	94	1.4%	83	1.3%	88	1.5%
Incarcerated	13	0.2%	35	0.6%	33	0.6%
Moved/Transferred	143	2.2%	285	4.5%	421	7.1%
Discharged – Other Reason	150	2.3%	235	3.7%	326	5.5%
Suspended	1,869	28.2%	1,911	30.4%	1,457	24.5%
Total	**6,634**	**100.0%**	**6,295**	**100.0%**	**5,959**	**100.0%**

3.2.2 Impact of Residence – Within and Outside NEMA

The Ryan White Program serves persons regardless of residence. The Newark EMA has considerable resources for HIV-specific medical care and has served PLWHA living outside of the 5 counties. **The percentage of Ryan White clients living outside of the Newark EMA has declined over the past years from 18% in FY 2001 to 7% as of FY 2012.**

Step 2 of RIC review is examining client status by residence – in and out of the EMA to determine if residence had any effect on retention in care. It was thought that clients living outside of the EMA would have a higher percent of "suspend" than NEMA residents – just because they may be transient or could find care closer to home.

In fact, the reverse is true. **Clients residing outside the EMA have a higher percent of "active" status and lower "suspend" than those in the NEMA**. The reason is likely that those outside of the EMA value their medical care and maintain contact with providers. On the other hand, clients living outside NEMA have higher percentages of moved/transferred and discharged, which shows that agencies are reviewing eligibility and taking action in response to changes in circumstances. See Figure 30, Figure 31 and Figure 32.

Figure 30: Ryan White Client Status by Residence In and Outside NEMA, FY 2012

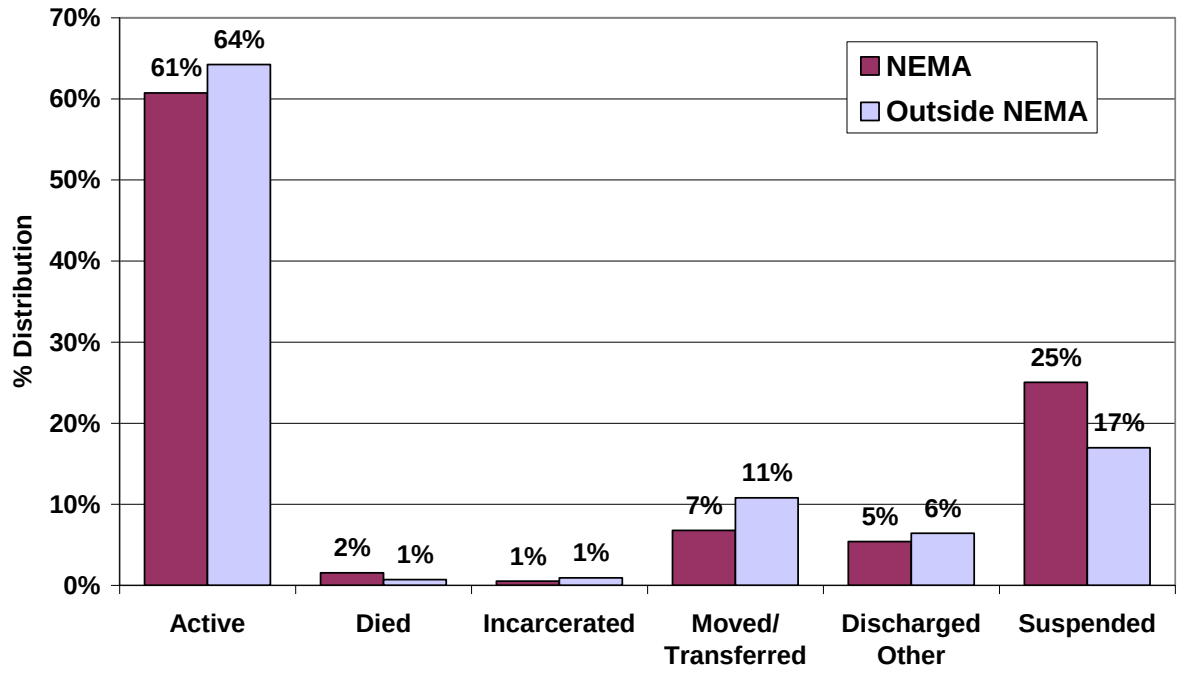


Figure 31: Active Client Status by Residence In and Outside of NEMA, FY10-FY12

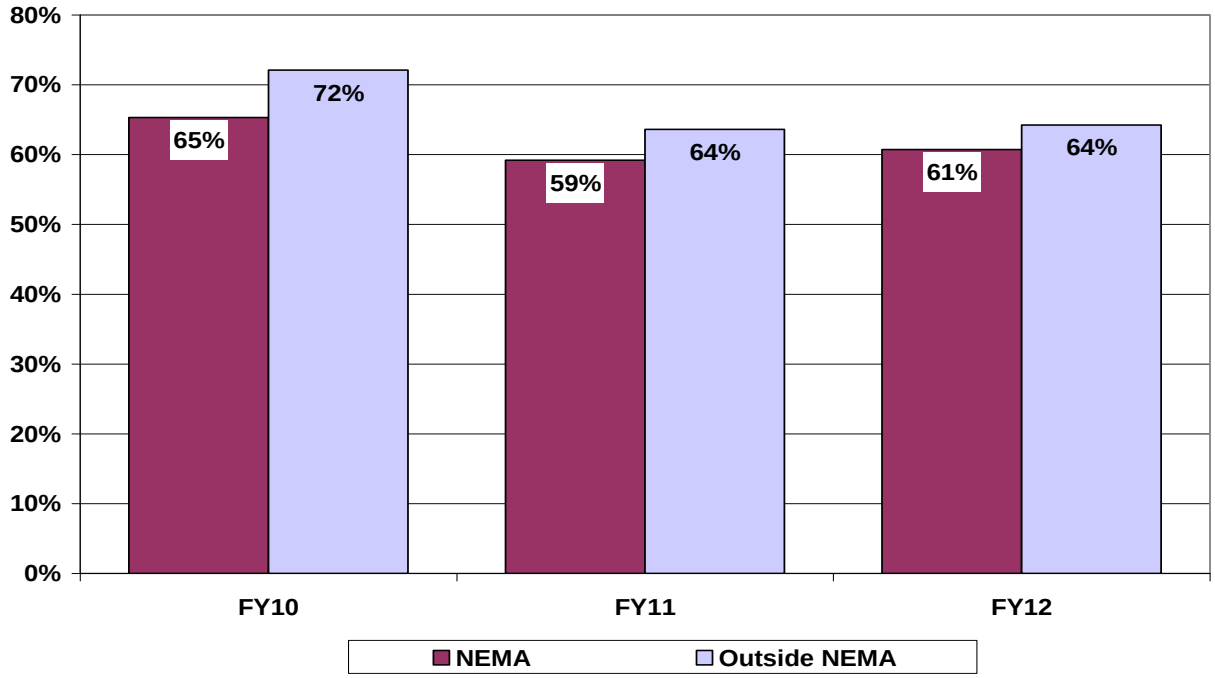
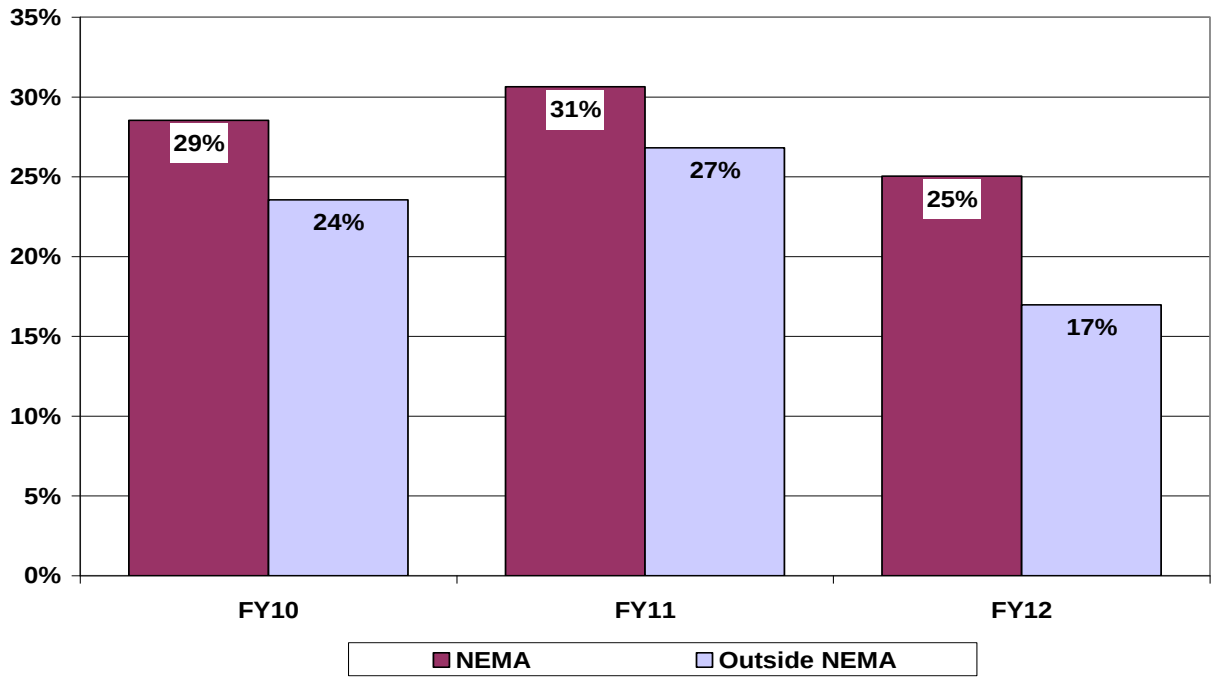


Figure 32: Suspended Client Status by Residence In and Outside of NEMA, FY10-FY12



3.2.3 Impact of Receipt of Medical Care and Medical Case Management

Step 3 was to analyze client status by receipt of medical care and medical case management. It was thought that individuals "in care" through Ryan White and other pay sources (e.g., Medicaid, Medicare) as demonstrated by receipt of Medical Case Management (MCM) would have higher rates of "active" status and lower suspended.

This was found to be true. **Clients in medical care had higher rates of active status.** Also, medical clients living outside of the EMA had higher rates of "active" status than those residing in the EMA. The same findings were true of clients receiving Ryan White MCM services. However, **comparing clients in Medical Care and Medical Case Management in FY12 showed identical rates of client status across all categories.** See Figure 33, Figure 34, and Figure 35.

Figure 33: Client Status by Receipt of Ryan White Medical Care or Medical Case Management, FY12

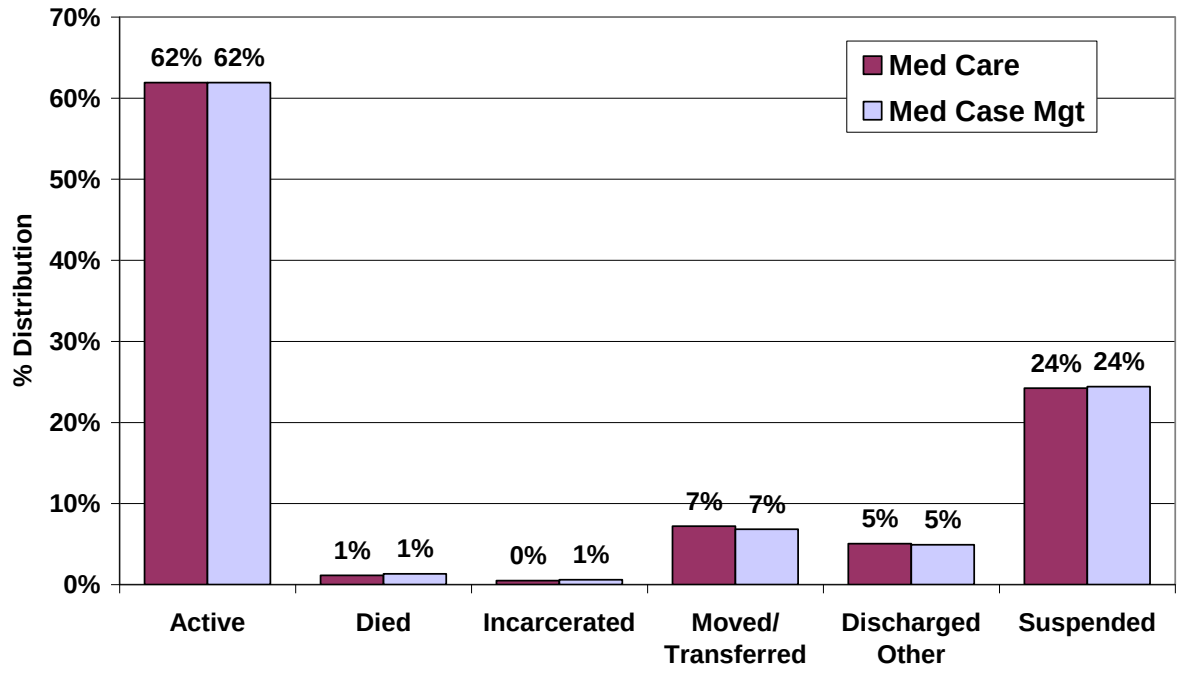


Figure 34: Client Status by Receipt of Ryan White Medical Care, FY10-FY12

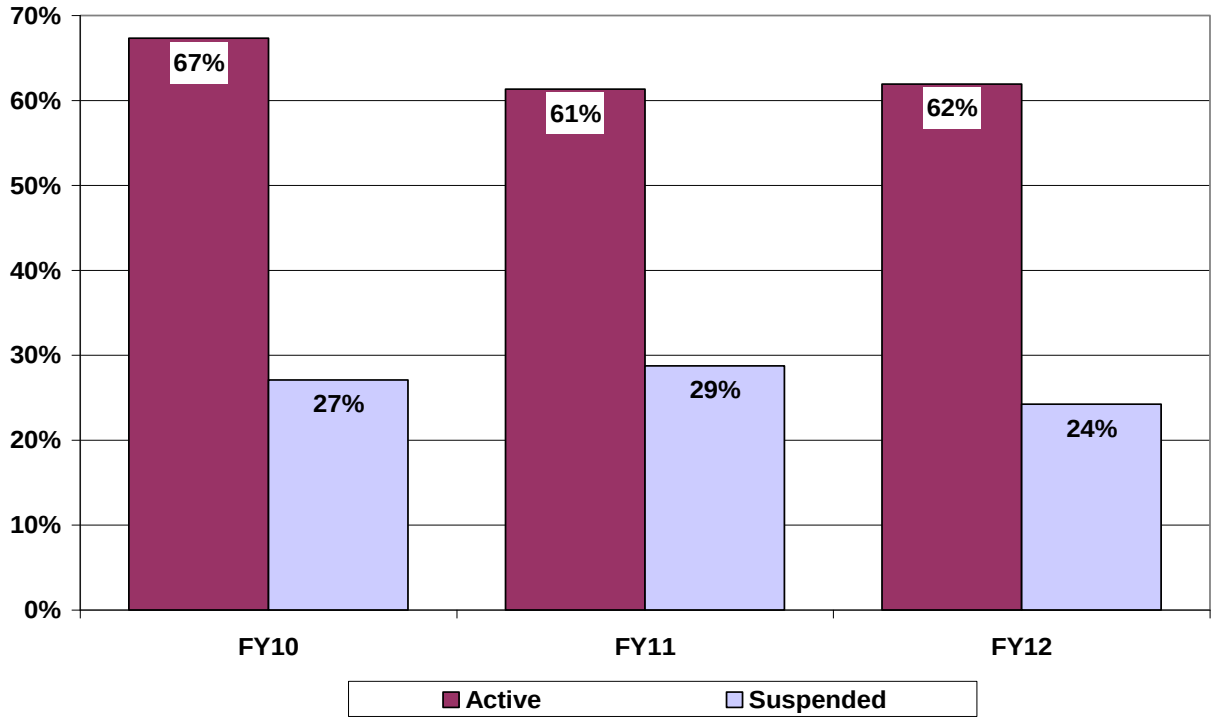
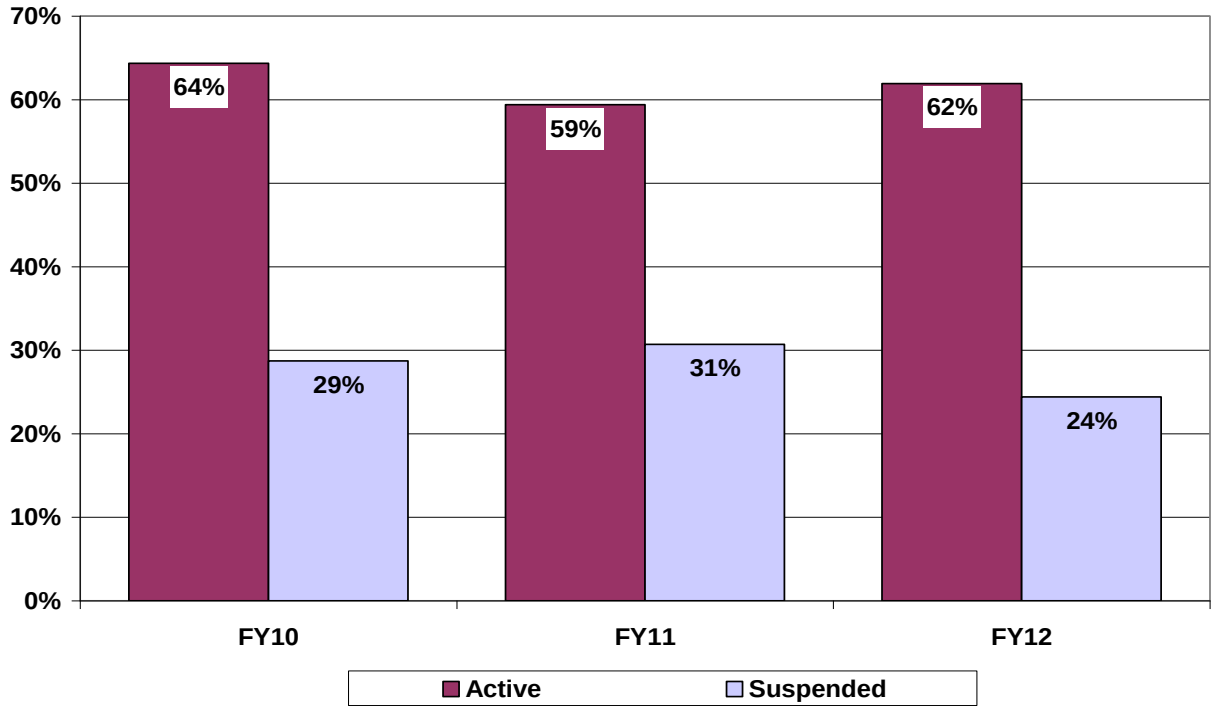


Figure 35: Client Status by Receipt of Ryan White Medical Case Management, FY10-FY12



3.3 FY 2010 Clients Lost to Service

3.3.1 FY 2010 Clients to be Followed

A total of 6,634 clients received Ryan White services in FY 2010.

- Of these, **6% or 400 were discharged from Ryan White** due to death, incarceration, moved/transferred or other discharge reasons.
- The remaining **6,234 (94%) Active or Suspended clients were followed for "Lost to Service" and RIC.** The breakdown is 4,365 or 66% Active clients and 1,869 or 28% Suspended clients.

All 6,634 clients will be reviewed because some clients discharged in FY10 returned to service in FY11.

Of the 6,234 clients, 70% received Ryan White primary medical care (PMC) and 73% received medical case management (MCM) in FY 2010. See Table 8.

Table 8: Baseline of FY 2010 Part A/F Clients for Lost to Service or RIC Follow Up

Status FY 10	FY 10 Clients	PMC in FY10		MCM in FY10	
		#	% Total Clients	#	% Total Clients
TOTAL Clients FY10	6,634	4,615	**70%**	4,881	**74%**
Discharged[4]	400	276	**69%**	332	**83%**
Active	4,365	3,107	**71%**	3,170	**73%**
Suspended	1,869	1,232	**66%**	1,379	**74%**
Total Starting in FY11	**6,234**	**4,339**	**70%**	**4,549**	**73%**

The "Total Starting in FY 11" is the total number of clients served in FY 2010 who were not discharged and need to be followed up in FY 2011. The follow up can include any service – continued care, case closing, discharge, etc. Some action should be taken on all of these clients and recorded in CHAMP.

3.3.2 What Happened to These Clients in FY 2011?

Status in FY 2011. Of the 6,234 Active/Suspended FY 2010 clients:

- **496 or 8% were discharged in FY 2011** for death, incarceration, moved/transferred or other reasons.
- **4,269 (68%)** received some service and continued to be Active Clients (40% or 2,508) or were Suspended for no contact (28% or 1,761).
- The remaining **1,469 (24%) did not receive any Part A/F service in FY 2011 and were Lost to Service. This is the same percentage Lost to Service as in FY 2008.**

[4] "Discharged" includes died, incarcerated, moved/transferred, discharged for other reasons.

Table 9: FY 2010 Clients Receiving Services and Lost to Service in FY 2011 by Client Status

Client Status in FY 10	FY 2010 # Clients	FY 2010 Clients in FY 2011				
		# Served in FY11	%	# Lost to Service in FY11	%	Total % FY 10
Discharged Total	400	251	63%	**149**	**37%**	100%
Died	94	37	39%	**57**	**61%**	100%
Incarcerated	13	8	62%	**5**	**38%**	100%
Moved/Transferred	143	96	67%	**47**	**33%**	100%
Discharged Other	150	110	73%	**40**	**27%**	100%
Active	4,365	3,356	77%	**1,009**	**23%**	100%
Suspended	1,869	1,409	75%	**460**	**25%**	100%
Total	**6,634**	**5,016**	**76%**	**1,618**	**24%**	**100%**

Discharged clients DO Return! Of the 400 clients discharged in FY 2010, a total of 251 (63%) received Ryan White services in FY 2011 as follows. Some (130 or 33%) of the discharged clients returned to "active" status in FY 11, and the remaining were discharged per Table 10. **This indicates a very fluid population which must continue to be tracked by RW.**

- Eight (62%) of the 13 incarcerated clients,
- 96 (67%) of the 143 clients who had moved or transferred in FY 10,
- 110 (73%) of the 150 who had been discharged for other reasons, and
- 37 (39%) of 94 clients listed as "died" at the end of FY 2010 received services in FY 2011!

Table 10: Status of FY 2010 Clients Served in FY 2011 at of the End of FY 2011

Status in FY10	Status at the end of FY11						Total
	Active	Died	Incarcer-ated	Moved/ Transferred	Discharged Other	Sus-pended	
Discharged Total	130	4	4	26	15	72	251
Died	21	1	0	2	2	11	37
Incarcerated	3	0	4	0	0	1	8
Moved/Transferred	46	1	0	15	3	31	96
Discharged Other	60	2	0	9	10	29	110
Active	1,714	53	15	163	134	1,277	3,356
Suspended	794	19	11	45	56	484	1,409
Total	**2,638**	**76**	**30**	**234**	**205**	**1,833**	**5,016**
% Distn FY11 Status	**53%**	**2%**	**1%**	**5%**	**4%**	**37%**	**100%**

3.3.3 Characteristics of Clients Lost to Service

Characteristics of FY 2010 Clients Lost to Service in FY 2011

The Table 11 and Figure 36 below shows the characteristics of FY 2010 clients served in FY 2011 and those Lost to Service in FY 2011. There were no major differences by race/ethnicity.

A higher percent of the following were lost to service than their representation among Part A/F clients:

- Gender: Males
- Age: New Clients <age 2 and age 13-34
- Residence: Residents of Essex County, Newark, outside of the 5 large cities and Newark EMA
- Health Insurance: Medicaid recipients and uninsured clients
- Poverty Status: Those whose poverty status was unknown (but this is a one-time issue that was corrected during FY 2011).
- Medical Care: Fewer received Part A/F medical care
- Medical Case Management: Fewer received Part A/F medical case management

In FY 2011 the EMA is starting to see the impact of Medicaid and Medicaid managed care on Part A/F clients. For example, new clients who are infants and youth appear to be lost to service but received Part A/F services particularly medical care pending enrollment in Medicaid.

Characteristics of FY 2011 Clients Lost to Service in FY 2012

Although not part of the scope of this Needs Assessment, we also reviewed the **FY 2011 clients lost to service in FY 2012** to see if there are any differences or trends that could relate back to FY 2010 and prior years.

At the start of FY 2012, a total of 5,657 FY11 clients were on CHAMP as eligible for service (not discharged). During FY 2012 – **4,342 (77%) of these clients were served and 1,315 (23%) received no Ryan White Part A/F service and were "Lost to Service"**.

The Table 11 and Figure 37 below show the characteristics of FY 2011 clients served in FY 2012 and those who were Lost to Service in FY 2012.

FY11 clients lost to service in FY12 had the same characteristics as those in FY10. A higher percent of the following were lost to service than their representation among Part A/F clients. There were no major differences by race/ethnicity.

- Gender: Males
- Age: New Clients <age 2 and age 13-34
- Residence: Residents of Essex County, Newark, outside of the 5 large cities and Newark EMA
- Health Insurance: Medicaid recipients and uninsured clients
- Medical Care: Fewer received Part A/F medical care
- Medical Case Management: Fewer received Part A/F medical case management

In FY 2012 the EMA continued to see impact of Medicaid and Medicaid managed care on Part A/F clients.

Table 11: Characteristics of FY 2010 Clients Lost to Service in FY 2011 and FY 2011 Clients Lost to Service in FY 2012

Characteristic	FY 2010 CLIENTS				FY 2011 CLIENTS			
	FY10 Clients Served in FY11	FY10 Clients Lost in FY11	New FY10 Clients Lost in FY11	Comments FY10-FY11	FY11 Clients Served in FY12	FY11 Clients Lost in FY12	New FY11 Clients Lost in FY12	Comments FY11-FY12
TOTAL	**100%**	**100%**	**100%**		**100%**	**100%**	**100%**	
Gender								
Female	44%	38%	36%	**Higher % males lost**	43%	41%	34%	**Higher % new males lost**
Male	56%	62%	63%		57%	58%	65%	
Transgendered	0.2%	0.7%	1%		0.2%	0.6%	1%	
Race/Ethnicity								
White Not Hispanic	8%	8%	8%	**No major differences by race or ethnicity**	8%	8%	7%	**No major differences by race or ethnicity**
Black Not Hispanic	73%	74%	71%		73%	74%	74%	
Hispanic	17%	16%	18%		17%	17%	18%	
Other/Unknown	2%	2%	3%		2%	1%	1%	
Age Category								
SEE Figure 36 and Figure 37 BELOW.				**Higher % new clients <age 2 & Age 13-34**				**Higher % new clients <age 2 & Age 13-34**
County of Residence								
Essex	69%	74%	73%	**Lost reside in Essex & outside NEMA.**	69%	76%	77%	**Lost reside in Essex & outside NEMA.**
Union	19%	11%	10%		19%	11%	6%	
MSW	6%	4%	2%		5%	4%	4%	
Outside NEMA	6%	11%	15%		7%	10%	13%	
Residence in 5 Cities								
Newark	46%	50%	49%	**Slightly higher Newark and new clients outside of the 5 cities**	45%	53%	51%	**Slightly higher Newark and new clients outside of the 5 cities**
East Orange	9%	10%	7%		9%	9%	8%	
Irvington	7%	7%	7%		8%	7%	9%	
Elizabeth	9%	5%	6%		9%	5%	2%	
Plainfield	4%	2%	2%		5%	3%	1%	
Total 5 Cities	**75%**	**74%**	**71%**		**76%**	**77%**	**71%**	
Outside 5 Cities	25%	26%	29%		24%	23%	29%	

Characteristic	FY 2010 CLIENTS				FY 2011 CLIENTS			
	FY10 Clients Served in FY11	FY10 Clients Lost in FY11	New FY10 Clients Lost in FY11	Comments FY10-FY11	FY11 Clients Served in FY12	FY11 Clients Lost in FY12	New FY11 Clients Lost in FY12	Comments FY11-FY12
Health Insurance								
Medicaid	34%	37%	35%	**Higher % of Medicaid and uninsured new clients**	31%	35%	23%	**Higher % of Medicaid and uninsured new clients**
Medicare	12%	13%	7%		11%	15%	7%	
Private Insurance	8%	9%	7%		8%	13%	13%	
Uninsured	46%	41%	51%		50%	37%	57%	
Poverty Status								
</= 100% FPL	61%	61%	50%	**Not enough data on poverty status. Agency issue.**	80%	79%	80%	**No difference in incomes or FPL.**
101%-200% FPL	11%	7%	8%		12%	10%	10%	
201%-300% FPL	4%	2%	3%		4%	3%	2%	
>300% FPL	2%	2%	2%		2%	2%	3%	
Not Enough Data	22%	28%	37%		2%	5%	5%	
Ryan White Services								
Medical Care	75%	51%	53%	**Less RW Medical Care**	59%	34%	35%	**Less RW Medical Care**
Medical Case Mgt	78%	57%	59%	**Less RW MCM**	83%	63%	65%	**Less RW MCM**

Figure 36: FY 2010 Clients Served and Lost to Service in FY 2011 by Age

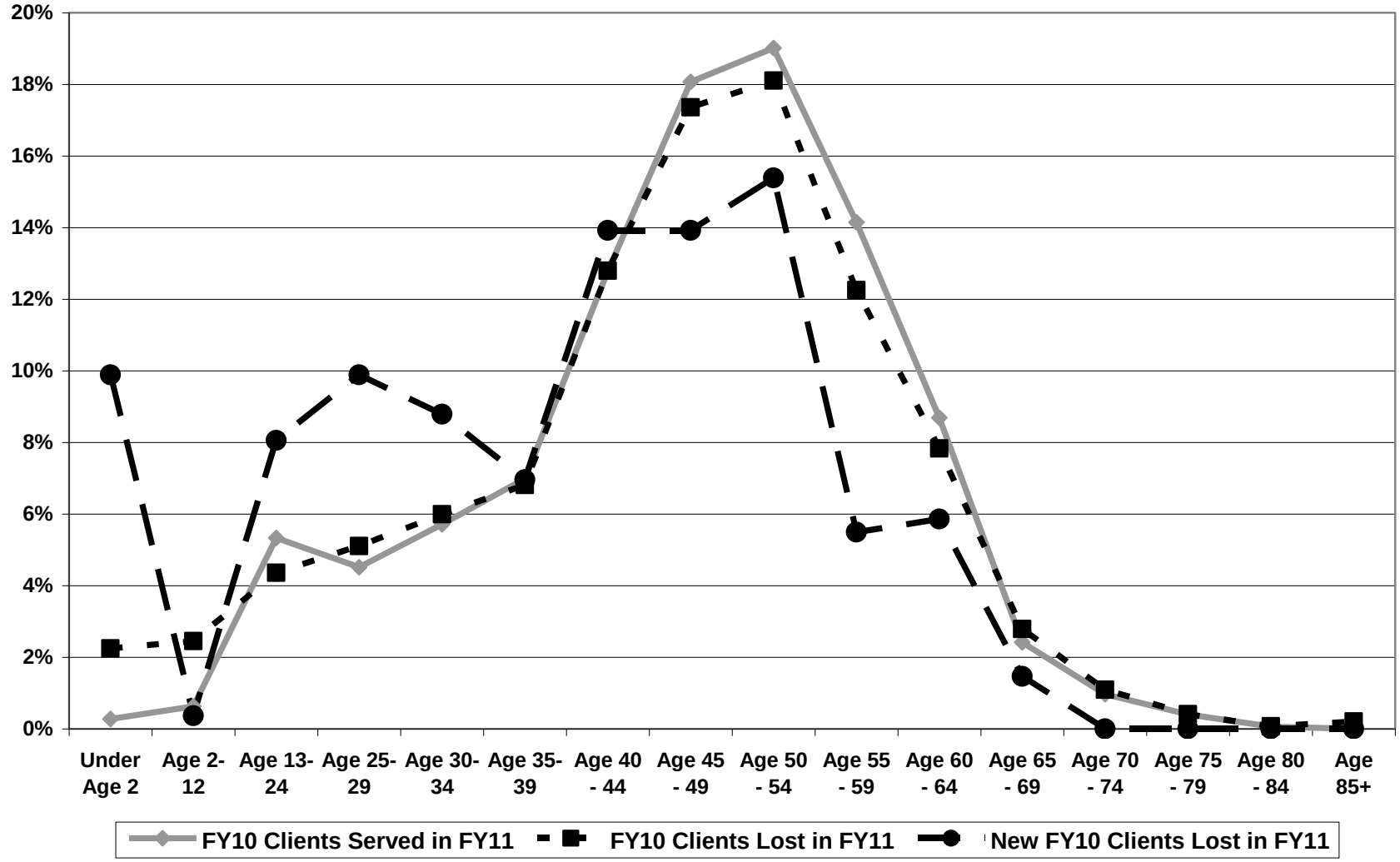
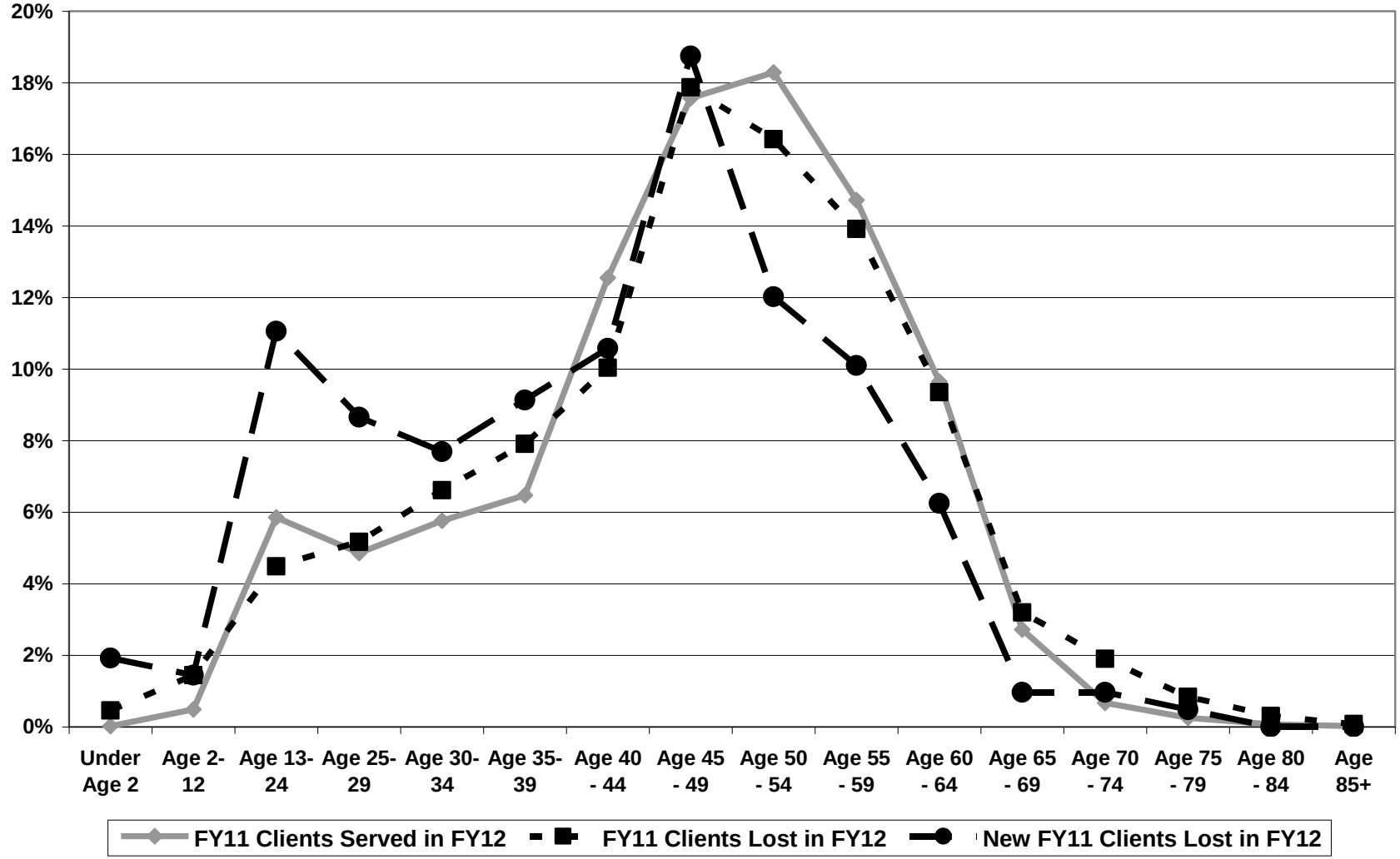


Figure 37: FY 2011 Clients Served and Lost to Service in FY 2012 by Age



3.3.4 FY 2010 Clients Lost to Service in FY 2011 Who Returned in FY 2012

Of the FY 2010 clients lost to service in FY 2011, a total of **228 or 14% of the 1,469 FY10 Lost to Service and 4% of the 6,234 FY10 eligible as of FY11 returned to Ryan White Part A/F in FY 2012.**

Characteristics of Returning Clients. Returning clients had mostly the same characteristics as those who had left. And the percent returning by characteristic within each category shown in the above table was proportional. That is, 16% of the total lost clients returned, and within the age category 15%-17% of females and males returned.

A slightly higher percent returned in the following categories:

- Gender: Transgendered
- Age: Age 13-24, 30-39, 75-79
- Residence: Morris/Sussex/Warren; Newark
- Health Insurance: Medicare
- Poverty: 201%-300% FPL

A slightly lower percent returned in the following categories:

- Race/ethnicity: White Not Hispanic, Other Not Hispanic/Unknown
- Age: Age 60-64
- Residence: Union County, Outside NEMA
- New clients: New FY10 clients
- Health Insurance: Those with private insurance
- Poverty: Those at 101%-200% FPL

There were no differences regarding receipt of Part A/F medical care or medical case management.

Comparison of Returning and Non-Returning Clients. There was no difference in the characteristics of the 228 clients lost to service in FY 2011 who returned in FY 2012 compared to clients lost to service in FY 2011 who did not return with respect to gender, race/ethnicity, and age, county of residence, poverty, health insurance and receipt of medical case management.

However, major differences were found with respect to new clients, residents of the 5 cities, and receipt of medical care as follows:

- **New Clients** – Only 10% of returning clients were "new" versus 18% of lost clients who were new. **The EMA is losing new clients as "lost to service".**

- **5 Cities -** 83% of returning clients lived in the 5 cities including 59% living in Newark vs. 76% of 5 cities clients lost to service (47% residing in Newark). **Outreach and retention in care efforts should be targeted to the 5 Cities.**

- **Medical Care** – 57% of those who returned to Ryan White Part A/F received Medical care in FY2012. **Medical care providers should intensify outreach and RIC activities.**

3.3.5 Comparison to 2011 Needs Assessment Findings

The 2011 Needs Assessment reviewed FY 2008 Part A clients lost to service in FY 2009 and status (returning or not) in FY 2010. Part A only was used because Part F (Minority AIDS Initiative or MAI) was just starting to be recorded as a separate program in FY 2008 and data might underestimate the total Part F clients.

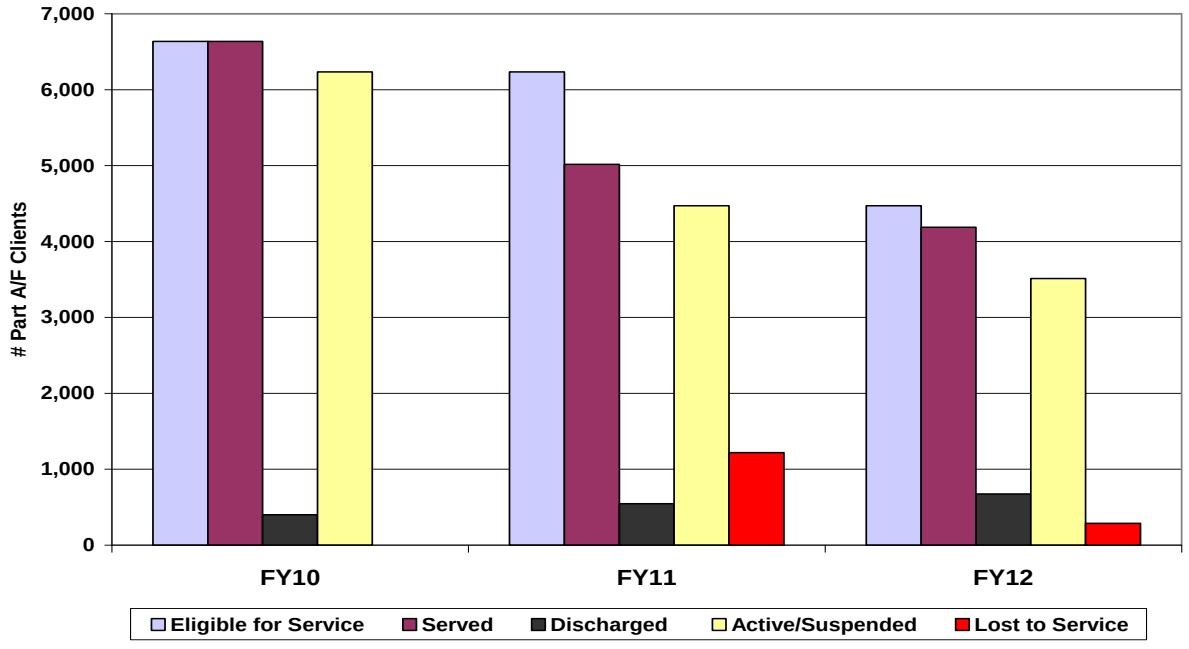
In FY 2008 a total of 6,541 Part A clients were served, 109 (2%) were discharged for a variety of reasons, and 1,597 (24%) were active/suspended and Lost to Service in FY 2009. Of those lost, 274 (17%) returned to service in FY 2010.

In both FY 2008-FY 2010 and FY 2010-FY 2012 the same percentage of clients were lost to service (24%) and returned to service after one year (16%-17%). Also, demographic characteristics were the same in both periods of study. **However, a much higher percent were discharged in FY 2010-FY2012 (16%) than in FY 2008-FY 2010 (2%).** This reflects the EMA's Retention in Care policies and work with the Early Intervention and Retention Collaboratives (EIRCs) to dispose of cases – which can be re-opened at a later date.

3.3.6 Summary of Retention in Care and Lost to Service

The total FY 2010 Part A/F clients served, discharged, and lost to service are shown below. An increasing number of clients were discharged by agencies due to client contact and recording of correct status. The highest number of FY 2010 clients lost to service occurred between FY 2011 and FY 2011. Only a small number were lost between FY 2011 and FY 2012. At the end of FY 2012, approximately 53% of the FY 2010 clients are still eligible for service and are in active/suspend status.

Figure 38: FY 2010 Part A/F Clients Served and Lost to Service in FY 2011 and FY 2012



3.4 Conclusions and Recommendations for Retention In Care Follow Up

- It appears as though the **CHAMP "9 month alert"** is working and that agencies are updating client status of those not contacted within the past 9 months. This status appears to be either "moved/ transferred" or "discharged" for a variety of reasons.

    - **Recommendation: Continue this CHAMP alert.**
    - **Recommendation: Monitoring follow up.** Ryan White monitors should follow up with agencies on their performance regarding this alert.

- It appears as though approximately **¼ of clients are lost to service regardless of type of services including medical care and medical case management**, and do not contact the agency. This is an improvement over the 1/3 in previous years. However, lost clients continue to present challenges. When they do come back to care they are in crisis and cost more to they system.

    - **Recommendation:** An active outreach activity or program should be added onto agency Retention in Care and EIRC activities. It must be structured differently and include more innovative methods to reach clients who do not keep appointments, particularly medical appointments.
    - **Recommendation:** Put support into Medical Case Management (MCM) to ensure that they capture clients in medical care. Provide training to MCM in retention activities starting with engagement of the client at first appointment to follow up on no shows for appointments and those not seen for 9 months or longer.

- It appears as though the EMA's Retention In Care (RIC) polices and procedures implemented in 2011 – including the CHAMP 9 month alert, mandatory agency Retention in Care policies as a condition of Ryan White contract, and Early Intervention and Retention Collaboratives (EIRCs) – are effective. The percent of FY 2010 clients "lost to service" in FY 2012 decreased significantly (1% - 6%) over the previous FY 2011 (19% - 24%).

    - **Recommendation:** The Council, Grantee and agencies should continue to focus on increasing retention in care. These efforts will be especially important as the EMA transitions from Ryan White-funded medical care to Medicaid Expansion.
    - **Recommendation:** Medical Case Managers should be trained on RIC for the Medicaid Expansion and other client follow up.

- Agencies are recording clients "discharged – died" when some are not in fact deceased. This is a problem because the annual HRSA Ryan White Services Report (**RSR**) for all Ryan White–funded agencies is starting to check for date of death for deceased clients and prohibits services provision of Ryan White services after the date of death.

    - **Recommendation:** Agencies should not use the status code "discharged – died" unless they have some verification of the client's death. Without this verification, agencies should use another "discharged" status code listed on CHAMP.

- **Recommendation:** Change CHAMP to require agencies to identify the date of death if they enter client status of "Discharged – Died". **Note: As a result of preliminary findings of the Needs Assessment – Update 2013, this change was included in the July 2013 CHAMP Release and is now operational. In addition, at the All-Provider Meeting of June 28, 2013 the Grantee educated all providers about this issue and the need for confirmation of death.**

- FY 2010 clients lost to service in FY 2011 and returning in FY 2012 show where to target outreach and RIC efforts.

    - **Recommendation:** Part A/F outreach and RIC efforts must target **new clients, living in the EMA's 5 largest cities, and who are receiving Part A/F medical care.**

- There is a slight but steady annual decline in PLWHA receiving Part A/F services. The reasons are not known but it can be due to other funding sources or need for medical care only from non-Ryan White sources.

    - **Recommendation:** There should be more rigorous follow up on clients who leave Ryan White services and the types of services and providers the departing clients last used. **The EMA and all Ryan White providers must be more vigilant in preparation for implementation of the Affordable Care Act and Medicaid Expansion starting January 2014 and make sure no eligible clients are falling "through the cracks" or out of care.**

- The number and percent of PLWHA receiving Ryan White Part A/F medical care has declined significantly from 70**%** in FY 2010, to 53% in FY 2011 to 50% in FY 2012. This is due to the shift of PLWHA eligible for SSI-related Medicaid from fee for service to Medicaid Managed Care. This change will accelerate in 2014 with the statewide Medicaid Expansion for individuals with incomes under 133%-138% of Federal Poverty Level (FPL), who account for at least 80% of the EMA's Part A/F clients.

    - **Recommendation:** The Council should take these policy changes into account in setting its **FY 2014 Service Priorities and Resource Allocations**.

- The Council may want to continue to track Retention In Care in FY 2013 and beyond to determine if the slowing trend shown from FY 2011 to FY 2012 will continue.

    - **Recommendation:** The Council should determine whether to include review of Retention In Care in subsequent needs assessments.

APPENDIX A:

Materials for Needs Assessment Update 2013

Key Informant Guide – NJ/County Substance Abuse System

Key Informant Guide – Substance Abuse System within the EMA

Consumer Health Issues Survey

Key Informant Guide – Providers Working With Young MSM

NEWARK EMA HIV HEALTH SERVICES PLANNING COUNCIL
NEEDS ASSESSMENT – 2013 UPDATE

KEY INFORMANT QUESTIONNAIRE
NJ COUNTY DRUG AND ALCOHOL DIRECTORS
(March 18, 2013)

Introduction

The purpose of this Key Informant (KI) questionnaire guide is to obtain overall information about the current status of Substance Abuse prevalence in New Jersey and the Newark EMA (to the extent possible), the key substance abuse issues facing residents and substances abused, the substance abuse treatment system and ability and capacity of that system to address needs, and gaps that the Newark EMA Ryan White System can fill with its funding – for HIV+ substance users.

We will use this information along with surveys of providers in the EMA and client surveys to identify the nature of substance abuse among persons living with HIV/AIDS (PLWHA) in the Newark EMA and to better target Ryan White Part A resources to help meet the SA treatment needs of PLWHA.

Abbreviations

EMA = Eligible Metropolitan Area. Newark EMA = Essex, Morris, Sussex, Union, Warren counties
KI = Key informant
PLWHA = persons living with HIV/AIDS
SA = substance abuse

KI Questions

1. Do you have any estimates about substance abuse prevalence in your County? Substances include: (1) tobacco, (2) alcohol, and (3) illegal drugs and prescription drugs. In other words, what percent of the population uses these substances and what percent abuses them? (Abuse to the extent of needing treatment or other measure that you have or that is recognized by the SA treatment community.)

    a. Illegal drugs and prescription drugs have been outlined in the SAMHSA 2010 National Survey on Drug Use and Health. We have summarized them in the consumer survey to be administered shortly within the EMA (attached). Can you identify any problems of importance to NJ , your county, and/or the Newark area?

    b. Can you give us an idea of the sources of these estimates? What are the sources that your County relies on for SA? (This documentation would be very helpful to assist in our own analysis.)

    c. Do you have any estimates for PLWHA? Do you know if substance abuse is higher for PLWHA than the general population? Can that be quantified? If so, what are these estimates?

2. What substances are used and abused? Specifically, illicit drugs and prescription drugs.

3. What are the trends for specific substances? Which are increasing and decreasing?
   a. What are the [possible] reasons for these trends?
   b. Do you see any trends specific to your County?

4. How would you describe the need for substance abuse treatment in your County?
   a. Trends - Increasing? Decreasing? No change.
   b. Types of substances used – changing or static? Describe.

5. Describe the substance abuse treatment system in your County.

   a. What types of programs are available?
   b. What types of facilities?
   c. Has the system changed over the past 10 years? Expanded, contracted, changed focus, etc.
   d. Have the changes helped to better address need?
   e. What are the gaps if any in the system?

6. What are the funding sources for substance abuse treatment? (SA block grant, health insurance, Medicaid, Medicare, etc.)
   a. Does your County provide any funding for SA treatment? (Amount, trends, etc.). Current dollar amount for 2013.
   b. Does your County provide any funding for SA treatment for PLWHA? (Amount for 2013 =).
   c. **What are the trends in these funding sources?** (Increasing, decreasing, static)
   d. **What are the gaps in these funding sources?** How much is not covered? What is the service gap or unmet need?

7. What effect will the proposed Medicaid expansion help fill funding gaps in SA treatment?

   Does the Essential Health Benefits package include substance abuse treatment (tobacco, alcohol, illegal and prescription drugs)? If Yes, to what extent?

8. Could you please provide an assessment of the adequacy of SA treatment in your County versus the need? What substances are covered well and what are the gaps?

9. Based on the overall trends in substance use, availability of treatment and funding sources, what are some recommendations for use of Ryan White funds to fill gaps for SA treatment in your County for PLWHA?
   a. What kinds of services? Intensive outpatient, residential, other (identify).
   b. What kinds of substances?
   c. Is there any emerging need that is not being covered by traditional sources that Ryan White could fill in gaps and help meet need?

NEWARK EMA HIV HEALTH SERVICES PLANNING COUNCIL
NEEDS ASSESSMENT – 2013 UPDATE

KEY INFORMANT QUESTIONNAIRE
SUBSTANCE ABUSE PROVIDERS
(March 18, 2013)

Introduction

The purpose of this Key Informant (KI) questionnaire guide is to obtain overall information about the current status of Substance Abuse prevalence and treatment in the Newark based on your treatment experience, the key substance abuse issues facing residents and substances abused, the substance abuse treatment system and ability and capacity of that system to address needs, and gaps that the Newark EMA Ryan White System can fill with its funding – for HIV+ substance users.

We will use this information along with surveys of the NJ Department of Human Services and client surveys to identify the nature of substance abuse among persons living with HIV/AIDS (PLWHA) in the Newark EMA and to better target Ryan White Part A resources to help meet the SA treatment needs of PLWHA.

Abbreviations

EMA = Eligible Metropolitan Area. Newark EMA = Essex, Morris, Sussex, Union, Warren counties
KI = Key informant
PLWHA = persons living with HIV/AIDS
SA = substance abuse

KI Questions

1. Do you have any estimates about substance abuse prevalence in the Newark EMA? Substances include: (1) tobacco, (2) alcohol, and (3) illegal drugs and prescription drugs. In other words, what percent of the population uses these substances and what percent abuses them? (Abuse to the extent of needing treatment or other measure that you have or that is recognized by the SA treatment community.)

    a. Illegal drugs and prescription drugs have been outlined in the SAMHSA 2010 National Survey on Drug Use and Health. We have summarized them in the consumer survey to be administered shortly within the EMA (attached). Can you identify any problems of importance to the Newark area?

    b. Do you have any estimates for PLWHA? Do you know if substance abuse is higher for PLWHA than the general population? Can that be quantified? If so, what are these estimates?

2. What substances are used and abused? Specifically, illicit drugs and prescription drugs.

3. What are the trends for specific substances that you see in the Newark EMA? Which are increasing and decreasing?
   a. What are the [possible] reasons for these trends?

4. How would you describe the need for substance abuse treatment in the Newark EMA?
   a. Trends - Increasing? Decreasing? No change.
   b. Types of substances used – changing or static? Describe.

5. Describe the substance abuse treatment system in the Newark EMA as you see it. Reference any trends or changes statewide as needed.

   a. What types of programs are available?
   b. What types of facilities?
   c. Has the system changed over the past 10 years? Expanded, contracted, changed focus, etc.
   d. Have the changes helped to better address need?
   e. What are the gaps if any in the system?

6. What are the funding sources for substance abuse treatment that you are aware of? SA block grant, health insurance, Medicaid, Medicare, NJ state funding, etc.
   a. Does NJ provide any state funding for SA treatment for PLWHA? (Amount for 2013 = total NJ, for Newark EMA (by county if applicable).
   b. **What are the trends in these funding sources?** (Increasing, decreasing, static)
   c. **What are the gaps in these funding sources?** How much is not covered? What is the service gap or unmet need?

7. What effect do you think the proposed Medicaid expansion will have in helping to fill funding gaps in SA treatment? In what ways or areas (tobacco, alcohol, illegal and prescription drugs)? Please provide any additional comments.

8. Could you please provide an assessment of the adequacy of SA treatment in the Newark EMA versus the need? What substances are covered well and what are the gaps?

9. Based on the overall trends in substance use, availability of treatment and funding sources, what are some recommendations for use of Ryan White funds to fill gaps for SA treatment in the Newark EMA for PLWHA?
   a. What kinds of services? Intensive outpatient, residential, other (identify).
   b. What kinds of substances?
   c. Is there any emerging need that is not being covered by traditional sources that Ryan White could fill in gaps and help meet need?

Attachment: Consumer Health Survey – Newark EMA

Consumer HEALTH ISSUES Survey

For Office Use
Date: _____
Site: _____

We are conducting a survey on the needs of people regarding health issues and substance use. The purpose is to determine the need for substance use treatment and how best we can allocate [Ryan White and other] resources for substance use treatment. This will take only a few minutes to complete. Your participation is voluntary, your responses will be kept confidential, and you can decline to answer any of the questions.
Have you answered this survey before? If YES, please do not complete another survey form.

1. **Gender** ☐ Male ☐ Female ☐ Transgendered

2. **Sexual Identification** ☐ Heterosexual ☐ Men who have sex with men ☐ Women who have sex with women ☐ Bisexual

3. Are you **Hispanic or Latino?** ☐ No ☐ Yes Country: _____

4. **Race** ☐ American Indian/Alaska Native ☐ Asian ☐ White ☐ Black or African American ☐ Native Hawaiian/Other Pacific Islander

5. **Current Age: (Please list your age in years)** _____

6. In what **county do you reside?**
☐ Essex ☐ Union ☐ Morris ☐ Warren ☐ Sussex ☐ Other _____

7. What is your **ZIP Code** where you currently live? (Enter) _____

8. **When were you diagnosed with HIV/AIDS?** ☐ Within the past year ☐ 2 to 4 years ago ☐ 5 to 10 years ago ☐ 11 to 15 years ago ☐ 15+ years ago ☐ Not HIV+

9. **Where were you tested and diagnosed?** ☐ ER ☐ Hospital ☐ Clinic ☐ Other

10. Do you currently receive **Medical Care for your HIV**? ☐ Yes ☐ No

10a. If no, why not? ☐ I do not feel sick ☐ I cannot afford the cost ☐ No rush. ☐ HIV can be cured with a pill ☐ I do not trust the system ☐ Other _____

11. How often do you use **tobacco** (smoke cigarettes or cigars; use other tobacco products) **Check all that apply.**

	Never	Monthly or less	On Weekends	During the Week	Every day
a. Use tobacco alone					
b. Use tobacco with alcohol					
c. Use tobacco with other drugs or substances					

12. How often do you have a drink containing **alcohol**? **Check all that apply.**

	Never	Monthly or less	On Weekends	During the Week	Every day
a. Use alcohol alone					
b. Use alcohol with tobacco					
c. Use alcohol with other drugs or substances					

PLEASE CONTINUE ON THE OTHER SIDE

13. How often do you use the following substances? **Check all that apply.**

	Never	Monthly or less	On Weekends	During the Week	Every day
a. **Marijuana** (pot, weed, grass, hash, blunts)					
b. **Cocaine** (NOT crack)					
c. **Cocaine - Injection**					
d. **Crack Cocaine**					
e. **Heroin-Injection** (use needles)					
f. **Heroin-Other** (Snort, smoke, no needles)					
g. **Hallucinogens** (acid, LSD, angel dust, PCP, MDMA, ecstasy, Molly)					
h. **Inhalants** (poppers, sprays, nitrous oxide, whippits, spray paint, lighter fluid)					

14. How often do you use the following substances that **were not prescribed for you OR for the feeling it caused**? **Check all that apply.**

	Never	Monthly or less	On Weekends	During the Week	Every day
a. **Pain relievers** (Percocet, percodan, vicodin, codeine, Demerol, other)					
b. Oxycontin, Oxycodone					
c. Methadone, morphine					
d. **Tranquilizers** (Xanax, Alprazolam, Ativan, or Lorazepam)					
e. Valium, Diazepam					
f. **Stimulants** (Methamphetamine, crank, crystal, ice, speed, Desoxyn, or Methedrine, prescription diet pills, Viagra, Cialis, etc.)					
g. **Sedatives** (sleeping pills, downers, barbiturates, Seconal, Nembutal, etc.)					

15. In the past year, how often did you drink, use tobacco or other drugs more than you meant to?
☐ Never ☐ Less than Monthly ☐ Monthly ☐ Weekly ☐ Daily or almost daily

16. How often did you feel you wanted or needed to cut down on your drinking, tobacco use or drug use in the past year, and were not able to?
☐ Never ☐ Less than Monthly ☐ Monthly ☐ Weekly ☐ Daily or almost daily

17. Have you ever been treated for alcohol, tobacco, substance use? ☐ Yes ☐ No

18. If Yes, did your treatment address/fix/help your problem? ☐ Yes ☐ No ☐ For a little time

19. **Do you have any other comments that you would like to make?**

_____

_____

Thank you for participating! Your responses will help the Newark EMA HIV Health Services Planning Council make recommendations about the needs of individuals with HIV in the counties of Essex, Morris, Sussex, Union and Warren. If you would like to see the results of this survey, they will be available by contacting the Newark EMA HIV Health Services Planning Council at (973) 485-5220 after July 31, 2013.

NEWARK EMA HIV HEALTH SERVICES PLANNING COUNCIL
NEEDS ASSESSMENT – 2013 UPDATE

KEY INFORMANT QUESTIONNAIRE
PROVIDERS WORKING WITH YOUNG MSM
(April 10, 2013)

Introduction

The purpose of this Key Informant (KI) questionnaire guide is to obtain overall information about the current status of programs serving Young Men who have Sex with Men (YMSM) in the Newark EMA based on your program experience, the issues facing YMSM, the HIV system of HIV care, health and support services for YMSM, and capacity of that system to address needs, and gaps that the Newark EMA Ryan White System can fill with its funding – for HIV+ YMSM.

We will use this information along with focus group results and other information to identify the needs of YMSM who are living with HIV/AIDS (PLWHA) in the Newark EMA and to better target Ryan White Part A resources to help meet the medical and other needs of YMSM PLWHA.

Abbreviations

EMA = Eligible Metropolitan Area. Newark EMA = Essex, Morris, Sussex, Union, Warren counties
KI = Key informant
PLWHA = persons living with HIV/AIDS
SA = substance abuse
YMSM = Young Men who have Sex with Men

KI Questions

1. What kind of services do you provide for YMSM? What is the goal of your services, e.g., to get newly diagnosed HIV+ youth into medical care with 24-48 hrs of diagnosis.

2. Approximately how many YMSM do you serve? How many are HIV+?

3. To what extent do your services provide (1) prevention, (2) diagnosis, or (3) treatment of HIV disease?

4. Do you work with other agencies for prevention, diagnosis or treatment of HIV disease? Please identify and discuss your continuum of care.

5. What are the barriers to achieving your goal(s)?

6. Where (geographically) do your YMSM come from? (In other words, how would you describe your service area?)

7. How would you identify the existing health system in the EMA serving HIV+ youth? Who are the providers, what are the strengths and gaps from your perspective?

8. How are at risk young individuals getting into medical care - by referral, walk in, etc.

9. Identify whether health-related agencies who may be serving YMSM are also referring the youth back to services regardless of HIV status, e.g., STI testing agencies. Do these agencies have special services for youth to the best of your knowledge?

10. What are co-morbid factors affecting care for YMSM? E.g., substance use, mental health problems, other.

11. Identify the extent to which stigma appears to impact access to HIV care, youth perceptions of stigma, and recommendations/suggestions for overcoming these perceptions.

12. What are the funding sources for services for programs for YMSM that you are aware of? Health insurance, Medicaid, Medicare, NJ state funding, etc.
    a. **What are the trends in these funding sources?** (Increasing, decreasing, static)
    b. **What are the gaps in these funding sources?** How much is not covered? What is the service gap or unmet need?

13. What effect do you think the proposed Medicaid expansion to all individuals with incomes under 133% Federal Poverty Level will have in helping YMSM to access and obtain medical care, other health services, medications) for their HIV disease? For YMSM who are not HIV+? Please provide any additional comments.

14. Please provide any recommendations or other information that could assist the Newark EMA in serving YMSM both HIV+ and not HIV+.