Newark EMA

HIV Health Services Planning Council

NEEDS ASSESSMENT 2011

August 2011

NEWARK EMA HIV HEALTH SERVICES PLANNING COUNCIL NEEDS ASSESSMENT - 2011

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LIST OF ABBREVIATIONS

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

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
CBO	Community Based Organization
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
CSAC	Community Services Advisory Committee of NEMA Planning Council
CTR	Counseling, Testing and Referral sites (for early identification of PLWHA)
DCFWB	Newark Department of Child and Family Well Being (Formerly, the Newark Department of Health and Human Services – DHHS)
DHAS	Division of HIV/AIDS Services (New Jersey)
EIIHA	Early Identification of Individuals Living with HIV/AIDS
EIS	Early Intervention Services
EMA	Eligible Metropolitan Area
FQHC	Federally Qualified Health Center
GLBTQ	Gay, Lesbian, Bisexual, Transgendered, Questioning
HAART	Highly Active Anti-Retroviral Therapy
HAB	HIV/AIDS Bureau (of HRSA)
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
MAI	Minority AIDS Initiative (formerly Congressional Black Caucus – CBC)

MCM	Medical Case Management
MH	Mental Health
MNT	Medical Nutritional Therapy
MSM	Men who have Sex with Men
MSW	Morris, Sussex, Warren counties in the Newark EMA
MOA, MOU	Memorandum of Agreement, Memorandum of Understanding
NEMA	Newark Eligible Metropolitan Area
NJDHSS	N.J. Department of Health and Senior 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
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
UBHC	University Behavioral Health Care (of UMDNJ)
UMDNJ	University of Medicine and Dentistry of New Jersey
WICY	Women, Infants, Children and Youth

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

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

- Include links with outreach and early intervention services
- 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.

RWTEA Amendments

In addition to expanding the scope of the needs assessment, the RWTEA added responsibilities regarding the comprehensive plan.

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

> (D) develop a comprehensive plan for the organization and delivery of health and support services described in section 2604 that-
>
> > **''(iv) includes a strategy, coordinated as appropriate with other community strategies and efforts, including discrete goals, a timetable, and appropriate funding, for identifying individuals with HIV/AIDS who do not know their HIV status, making such individuals aware of such status, and enabling such individuals to use the health and support services described in section 2604, with particular attention to reducing barriers to routine testing and disparities in access and services among affected subpopulations and historically underserved communities;''**

As required by HRSA HAB, the Newark EMA prepared a plan for FY 2011 for early identification of PLWHA which is in the Needs Assessment – 2010 Update. For FY 2012, this plan will be included in the EMA's Comprehensive Health Plan 2012.

PURPOSE AND METHODOLOGY

The purpose of the 2011 Needs Assessment was to conduct a full assessment of key issues raised by HIV surveillance data, client level data 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 2011 Assessment. A comprehensive list was developed, and the top three issues were PLWHA dropping out of care, youth and mental health services (in follow up to the 2010 Updated to the Needs Assessment).

The 2001 Needs Assessment was 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 2011 Needs Assessment was to obtain as much input as possible from the community and provider agencies, while utilizing existing sources and work done by the Council. The Council utilized quantitative methods including surveys of providers and youth, and qualitative methods including focus groups to obtain consumer input. We utilized new technology – online Survey Monkey – to make it easier for consumers and providers to complete our surveys. After a few glitches, it was very successful and we received much more information than by hard copy survey forms (based on past experience).

Information was also obtained through public testimony, information discussions and reports, and new 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 2011 Needs Assessment incorporates directions from HRSA/HAB and reflects current policies and information including the National HIV/AIDS Strategy and retention in care.

Part 1: Clients Lost to Follow Up

1.1 Introduction

Background. It is well-documented through the CHAMP client level data (CLD) system that Part A/F clients "cycle in and out" of services and particularly HIV medical care. In any year, 900-1,000 or 12% of Part A/F clients "drop out" or do not receive Part A/F services provided by the Newark EMA. The term used by HRSA/HAB[2] is "lost to follow up". Simultaneously, approximately the same number of "new" clients start receiving Part A/F services. ("New" is never having received a Part A/F service before, that is, they are not in the CHAMP data base.) We have anecdotal information about what happens to the clients lost to follow up but not a full accounting. Likewise we do not know how many of these clients return to Part A/F in a subsequent year.

This is a major assessment involving review of longitudinal CHAMP records to determine those clients receiving services in FY 2008, not receiving services in FY 2009, and status in FY 2010 – whether clients returned to Part A/F. For those not receiving services in FY 2009, it involves referral of all cases to respective providers for their research including examination of patient records. The result is expected to be an accounting of all clients "lost to care" by geography and demographics so that the Council can make recommendations to improve retention in care including resources allocations into appropriate service categories and directives to the grantee.

Research Question #1: The research question to be addressed is:

> **The number of people who dropped out of Ryan White care, who they are; have they re-entered the system; are they getting support services from Ryan White and medical care elsewhere? Providers are to be surveyed for this information.**

The scope of this section included the following:

- **Data Collection and Analysis.** Obtain CHAMP data for FY 2008, FY 2009 and FY 2010 for all Part A/F clients. Using SPSS and other programming, develop longitudinal file combining all three years of data. Perform relevant computations using SPSS and other programs which identify clients lost to follow up in FY 2009 and status in FY 2010. This component will require extensive effort related to analyzing three years' of client activity.
- **Report.** Prepare initial report of findings including tables and graphs showing clients lost to follow up in FY 2009 by demographics, geography and services received including subtypes and provider types. Identify clients who have dropped out, re-entered, or totally dropped out of Ryan White. Determine reasons based on CHAMP. Include extensive written analysis of data. Work with REC to determine additional data needed. Identify any significant items needing

[2] USDHHS. HRSA. HIV/AIDS Bureau. Special Projects of National Significance Program. "FY 2011 Systems Linkages and Access to Care for Populations at High Risk of HIV Infection Initiative – Demonstration States". Announcement Number: HRSA-11-098. CFDA No. 93.928. Issued February 2, 2011. Pages 2, 7.

further review and follow up with providers to obtain data on status and possible reasons and circumstances surrounding clients lost to follow up. Prepare final report.

- **Provider survey and client review.** Identify clients (CHAMP ID) lost to follow up with no reason discernible. Providers will be asked to research case records to determine reason lost to follow up (e.g., if reason was not entered into CHAMP) for each of these clients.
    - Prepare survey tool to assist in collection of reasons lost to follow up. Work with REC, CPC and others to determine scope, content. Finalize tool.
    - Administer survey to providers. Council will administer survey with assistance of Grantee. (Council staff can assist providers as needed.) Collect and compile results.
- **Report.** Prepare report of findings including tables and graphs showing clients by medical care and support services, and identifying reasons lost to follow up. Prepare written analysis.
- **Final Report.** Consolidate above two reports and prepare final report for this assessment. Include analysis of normal client turnover and those lost to care for no reason, and current grantee requirements for retention in care and provider policies. Include recommendations for improving client follow up, based on responses from providers, Council committees, and for re-engagement in care. Identify areas where Council can allocate resources and/or make directives to grantee to improve retention in care and reduce lost to follow up.

1.2 FY 2008 Clients Lost to Follow Up in FY 2009

Note. For purposes of this section, Ryan White clients include those receiving services funded by Part A only. According to CHAMP, the total number of clients receiving Part A services were: 6,541 in FY 2008, 6,393 in FY 2009 and 6,380 in FY 2010.

1.2.1 Findings – Total Clients and Client Status

A total of **1,706 Part A clients in FY 2008 did NOT receive Part A services in FY 2009. This is 26% of total 6,541 Part A clients in FY 2008.** This percent is comparable to previous years and the number of clients lost to follow up has declined from 2,205 for FY 2006 and 2,166 for FY 2005.

Client Status. Client status indicates the participation in the Ryan White system. Status is entered mostly by the provider based on client circumstances. Status can be entered by CHAMP after a period of inactivity. Among clients lost to follow up, client status indicates whether the individual left the Ryan White program with knowledge of the provider, or is still active or suspended, meaning that the provider does not have current information about the client.

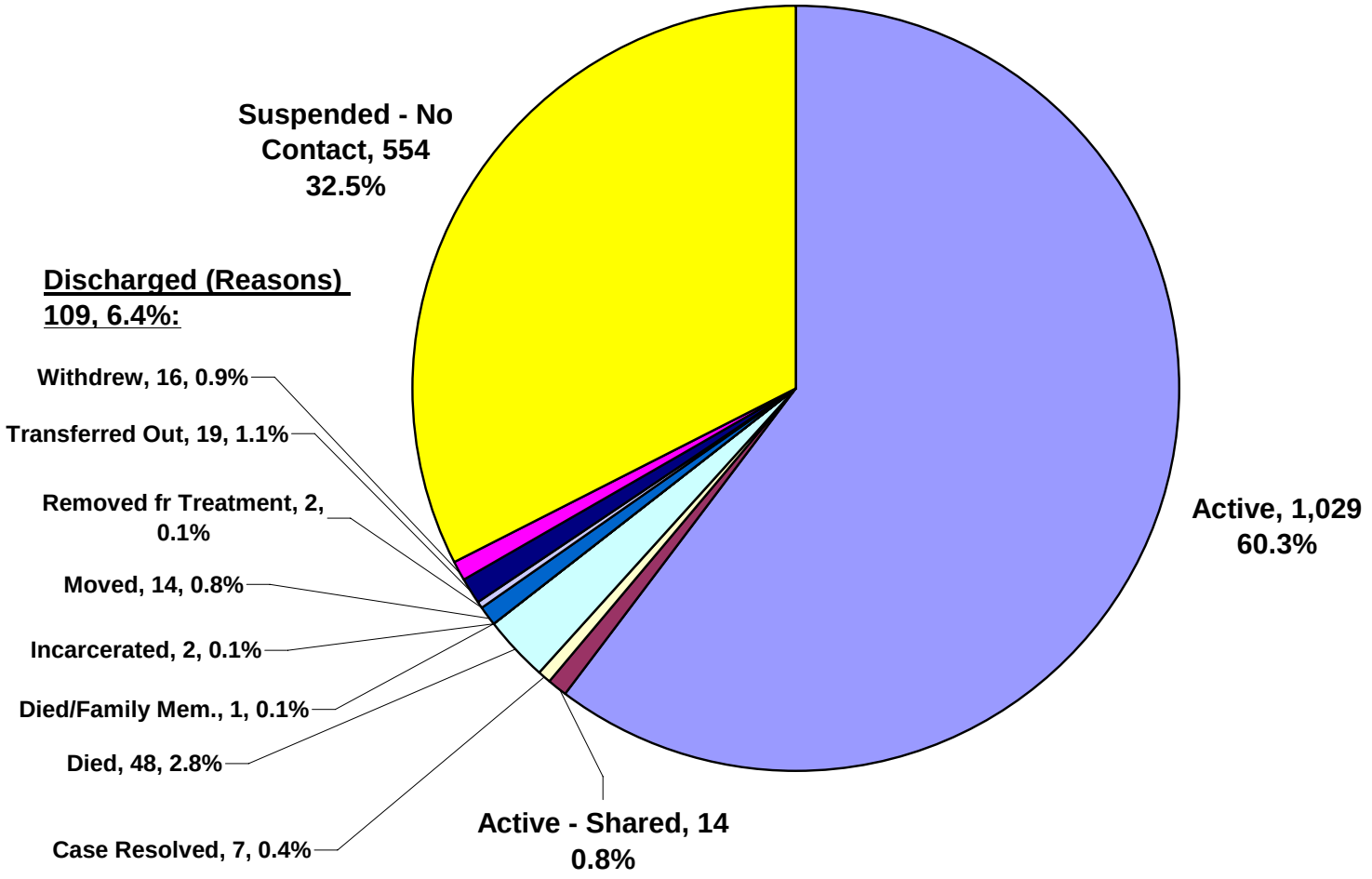
Table 1: CHAMP Client Status Categories

CHAMP Client Status	Who Determines/Enters/Updates
Active	Entered by provider and maintained by CHAMP as long as the client is receiving services regularly.
Active – Shared Other Agency	Provider enters.
Discharged – Died	Provider enters based on event.
Discharged – Moved	Same.
Discharged – Withdrew	Same.
Discharged – Transferred Out	Same.
Discharged - Died/Family Member Death	Same.
Discharged - Case Resolved	Same.
Discharged – Incarcerated	Same.
Discharged - Removed from treatment	Same.
Suspended – No Contact	CHAMP enters after 12 months of inactivity and no data entry by the provider.

As shown in Figure 1, **of the FY 2008 clients lost to follow up, only 109 or 6.4% were discharged from the Ryan White program due to discernable reasons.** One third (544) were suspended by CHAMP at the end of FY 2008 due to no contact in the prior 12 months, and 61% were active participants in Ryan White Part A - 60.3% or **1,029 listed as "active" and 0.8% (14) "active – shared with another agency."**

The active clients are the top priority for provider follow up, and then those who have been suspended due to no contact.

Figure 1: FY 2008 Clients Lost to Follow Up in FY 2009 by CHAMP Status at End of FY 2008 - 1,706 Total Clients



1.2.2 Findings - Demographics of Participants

Geography - County of Residence. There are slight differences by county of residence in the percent of clients lost to follow up. Three quarters (76%) reside in Essex, 13% in Union, 3% in Morris/Sussex/ Warren (MSW) region and 9% outside of the EMA. However, there **no differences in client status within each county or region.** Within each county 60% of this group of clients are "active" and potentially lost to service. See Table 2.

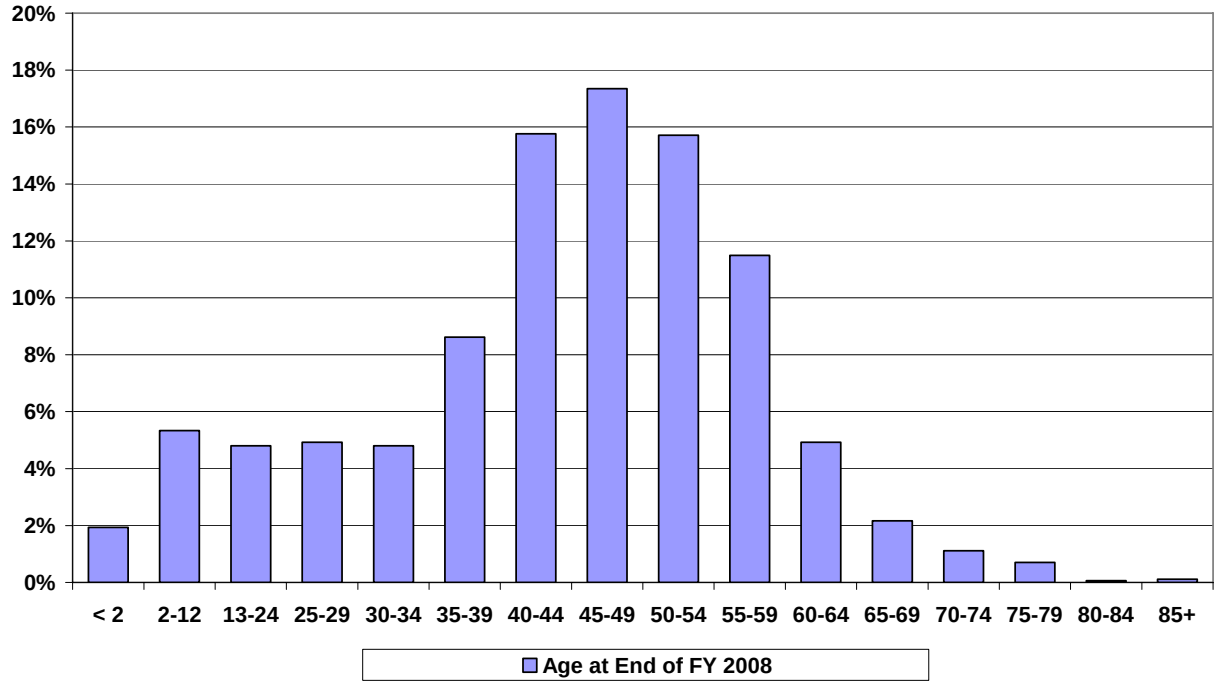
Table 2: FY 2008 Clients Lost to Service in FY 2009 by County/Region and CHAMP Client Status

Client Status	Essex	Union	MSW	NEMA	Outside	Total
Active	**773**	**133**	**29**	**935**	**94**	**1,029**
Active - Shared Other	13	0	1	14	0	14
Discharged - Case Resolved	5	2	0	7	0	7
Discharged – Died	28	12	1	41	7	48
Discharged - Died/Family Mem.	1	0	0	1	0	1
Discharged – Incarcerated	1	0	1	2	0	2
Discharged – Moved	11	1	2	14	0	14
Discharged - Removed fr Treat.	2	0	0	2	0	2
Discharged – Transferred	13	2	0	15	4	19
Discharged – Withdrew	9	2	2	13	3	16
Suspended - No Contact	**430**	**65**	**16**	**511**	**43**	**554**
Total	**1,286**	**217**	**52**	**1,555**	**151**	**1,706**
Distribution within County/Region						
Active	**60.1%**	**61.3%**	**55.8%**	**60.1%**	**62.3%**	**60.3%**
Active - Shared Other	1.0%	0.0%	1.9%	**0.9%**	0.0%	**0.8%**
Discharged – All Reasons	5.5%	8.7%	11.5%	**6.1%**	9.2%	**6.4%**
Suspended - No Contact	**33.4%**	**30.0%**	**30.8%**	**32.9%**	**28.5%**	**32.5%**
Total	100.0%	100.0%	100.0%	**100.0%**	100.0%	**100.0%**

Gender. By gender, clients lost to follow up are proportionate to their representation in the Ryan White program and in the epidemic – 57% male (977), 42% female (719). In addition, one was transgendered (0.1%) and for nine (0.6%) gender was missing or unknown.

Age. Compared to the percent of Part A clients and PLWHA, a disproportionate percent of younger clients (under age 25 in FY 2008) were lost to follow up, especially clients under age 13. All other age groups were proportionate to their representation in Part A and the epidemic. See Figure 2.

Figure 2: FY 2008 Clients Lost to Follow Up in FY 2009 by Age at End of FY 2008



Race/Ethnicity. There is little difference in clients lost to follow up in FY 2008 by race/ethnicity compared to their representation in the epidemic or Part A – 74% were African American, 17% were Hispanic/Latino, 6% White Not Hispanic, and 3% Other/Unknown.

1.2.3 Findings – Part A Medical Care and Services Received

It appears that the clients lost to follow up were well-engaged in the Part A system in FY 2008. Over half (52%) had received Part A medical care (888) and 31% (536) had a medical visit within FY 2008. Half (849) received medical case management, 18% received mental health services, 16% received outpatient substance abuse treatment, and 10% received oral health care.

Table 3: Part A Services Received in FY 2008 by Clients Lost to Follow Up

Part A Service	# Clients	% Total (1,706)
Medical Care	888	52.1%
Medical Visit	536	31.4%
Mental Health	306	17.9%
Outpatient Substance Abuse	271	15.9%
Oral Health	179	10.5%
Medical Case Management	849	49.8%
Medical Nutritional Therapy	67	3.9%
Case Management (Non-Medical)	35	2.1%
Housing	40	2.3%
Residential Substance Abuse Treat.	24	1.4%
Food/Nutrition Services	125	7.3%
Transportation	172	10.1%
Legal	33	1.9%
DEA	19	1.1%

Years Active in Ryan White

A question regarding retention in care and clients lost to follow up is – how long were the clients participating in Ryan White? One theory is that the "newer" the client, the more likely he/she is to "drop out" of care and Ryan White. The relationship between "drop outs" and length of engagement in Ryan White services can be determined by **"years active"** measure in CHAMP.

Figure 3 and Table 4 below show an inverse relationship between years active and drop outs. That is, a higher percent of FY 2008 Part A clients lost to service in FY 2009 were in Ryan White for a long term - 6+ years, receiving medical care and having medical visits. Furthermore, the highest percent had a medical visit in FY 2008 and were in Ryan White for 6+ years. The question becomes: **Why are these long-term RW clients no longer in the system? What happened and why was this not recorded – e.g., as a discharge?**

Figure 3: Distribution of FY 2008 Clients Lost to Follow Up by Years Active in Ryan White – Total Clients, Clients Receiving Part A Medical Care, and Clients with Part A Medical Visits

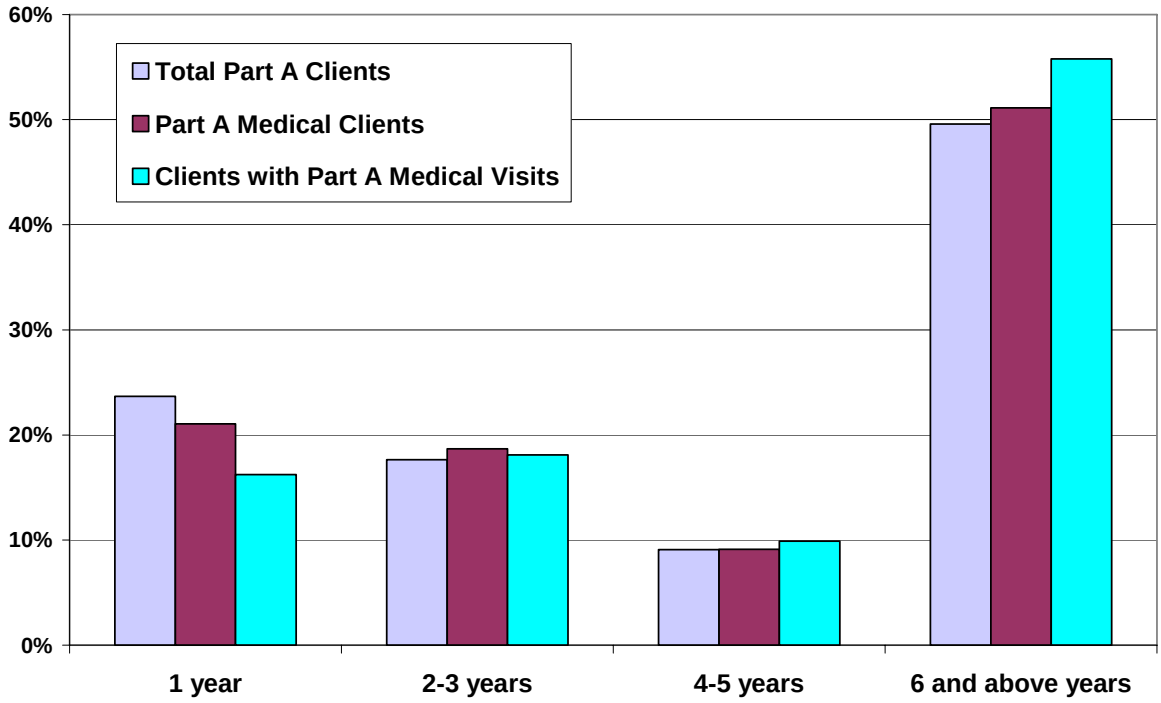


Table 4: FY 2008 Clients Lost to Service by Years Active in Ryan White – Total Clients, Clients Receiving Part A Medical Care, and Clients with Part A Medical Visits

Years Active In Ryan White	Total FY 2008 Part A Clients Lost to Service in FY 2009		FY 2008 Part A Medical Clients Lost to Service in FY 2009		FY 2008 Clients with Part A Medical Visits Lost to Service in FY 2009	
	#	%	#	%	#	%
1 year	404	23.7%	187	21.1%	87	16.2%
2-3 years	301	17.6%	166	18.7%	97	18.1%
4-5 years	155	9.1%	81	9.1%	53	9.9%
6 and above years	**846**	**49.6%**	**454**	**51.1%**	**299**	**55.8%**
Total	1,706	100.0%	888	100.0%	536	100.0%

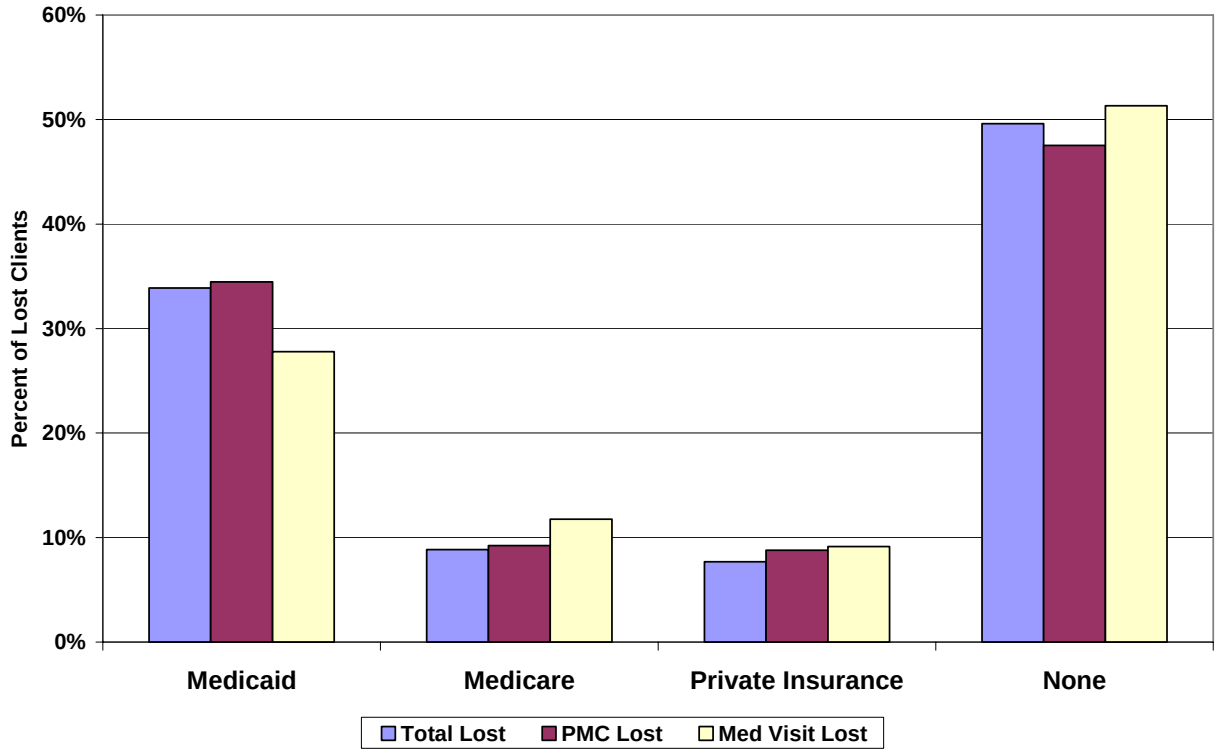
Source of Health Insurance

One theory is that clients "dropping out" of Ryan White may have Medicaid or other insurance which pays for their medical care – and that they have transitioned from care funded by Part A to these insurance sources. Figure 4 shows distribution of "lost" clients by CHAMP "pay source" which indicates health insurance or no insurance.

Findings: The distribution of health insurance by clients lost to follow up is relatively the same for total clients and those receiving Part A medical care – **34% Medicaid, 9% Medicare, 9% private insurance, and 47%-49% no insurance (including charity care, private pay and unknown/missing).** For those with a medical visit, the percent with Medicaid was slightly lower at 28% and with no insurance slightly higher at 51%. Percentages were also computed for only active or suspended clients and there was identical distribution by health insurance source.

It is not possible to determine when the patients with insurance received this insurance – that is, did the client have a Part A funded medical visit early in FY 2008 and then become enrolled in Medicaid toward the end of the year? This information can be obtained only by review of the patient's chart.

Figure 4: FY 2008 Clients Lost to Follow Up by Health Insurance – Total Clients, Clients Receiving Part A Medical Care, and Clients with Part A Medical Visits



1.3 FY 2008 Clients Lost to Follow Up in FY 2009 who Returned in FY 2010

1.3.1 Total Clients and Status of Returning Clients

Of the 1,706 clients who dropped out of Ryan White in FY 2008, a total of **274 or 16.1% returned to Ryan White in FY 2010.**

Client Status. The majority of clients returning (67% or 184) were listed as "active" status in FY 2008. Nearly one third (30% or 83) had been suspended by CHAMP at the end of FY 2008 due to no activity within the prior year. The remaining 3% (seven clients) had been discharged – due to incarceration (1), moving or transfer (3), case resolution (1). Two had been listed as "died" in FY 2008 who were resurrected in FY 2010. See Table 5.

The conclusion is that either the active and suspended clients should be followed up OR that if agencies just wait, some of those lost to follow up will return. Also, agencies should confirm the status of clients listed as "died" and this should be documented in the patient chart.

Table 5: FY 2008 Clients Lost to Follow Up who Returned in FY 2010 by FY 2008 Client Status

Status at End of FY 2008	# Clients	% Distn
Active	181	66.1%
Active - Shared Other	3	1.1%
Discharged – Case Resolved	1	0.4%
Discharged – Died	2	0.7%
Discharged – Incarceration	1	0.4%
Discharged – Moved	2	0.7%
Discharged – Transferred	1	0.4%
Suspended - No Contact	83	30.3%
Total	**274**	**100.0%**

1.3.2 Demographics and Service Utilization of Returning Clients

This section shows the distribution of returning clients within the categories listed. "**Return Rate" or the percent of lost clients who returned is shown in Table 6 by various characteristics.**

Demographics

Gender. Of the 274 returning clients, 37% (102) were female and 63% (172) were male. A higher percent of males returned than females.

Race/Ethnicity. Of the 274 returning clients, 201 (73%) were African American, 46 (17%) were Hispanic/Latino, 24 (9%) were white Not Hispanic, and three (1%) were other/unknown race/ethnicity. This is proportionate to Part A clients and the NEMA epidemic.

County of Residence. A higher percent of those returning to care resided in Essex County (75% or 205) versus Union County (12% or 33) and Morris/Sussex/Warren region (5% or 13). 8% (23) were from outside the EMA.

Current Age. The distribution of those returning to care follows the epidemic, but with a higher percent of those age 35-44. Under age 13 – 3% or seven clients, age 13-24 6% or 16 clients, age 25-34 13% or 35 clients, age 45-54 34% or 92 clients and age 55 and older 19% or 53 clients. Over half (53% or 144) clients were age 45 and older.

Health Insurance. Of those returning, in FY 2008 one third (91) had Medicaid, 12% (33) had Medicare, 5% (13) had private insurance, and half had no insurance. In FY 2010, more of these clients had health insurance – only 40% were uninsured, 36% had Medicaid, 17% Medicare and 6% had private insurance.

Table 6: Return Rate – Percent of FY 2008 Clients Lost to Follow Up who Returned in FY 2010

	FY 2008 Lost	Returned in FY 2010	Return Rate
Total Clients	**1,706**	**274**	**16.1%**
Gender			
Female	719	102	14.2%
Male	977	172	17.6%
Transgender/Unknown	10	0	0%
Race/Ethnicity			
White Not Hispanic	102	24	23.5%
African American	1,254	201	16.0%
Hispanic	293	46	15.7%
Other/Unknown	57	3	5.3%
County of Residence			
Essex	1,286	205	15.9%
Union	217	33	15.2%
Morris, Sussex, Warren	52	13	25.0%
Outside NEMA	151	23	15.2%
Current Age			
Under Age 13	124	7	5.6%
Age 13-24	82	16	19.5%
Age 25-34	166	35	21.1%
Age 35-44	416	71	17.1%
Age 45-54	564	92	16.3%
Age 55+	351	53	15.1%

	FY 2008 Lost	Returned in FY 2010	Return Rate
Health Insurance Source			
Medicaid	578	91	15.7%
Medicare	151	33	21.9%
Private Insurance	131	13	9.9%
No Health Insurance	846	137	16.2%

Services Utilized in FY 2010

Table 7 shows Part A services received by clients returning to Ryan White after over one year.

Core Medical Services. FY 2008 clients lost to follow up and returning in FY 2010 appeared to be engaged in medical care. Nearly 43% (117) clients received Part A medical care and 30% (82) had a medical visit. The majority of returning clients – 69% or 189 - received medical case management. 20% (55) received mental health services and 8% received oral health (23) and outpatient substance abuse services (21). 9% even received medical nutritional therapy (26).

Support Services. Returning clients also received support services. 17% (47) received transportation services, 11% (30) received Food/Nutrition services, 10% (28) Non-Medical Case Management, 4% received emergency housing (10) and legal services (10) and less than 1% received residential substance abuse (1) and DEA - Direct Emergency assistance (2).

Table 7: Part A Services Received in FY 2010 by Returning Clients Lost to Service in FY 2009

Part A Service	# Clients	% Total (274)
Medical Care	117	42.7%
Medical Visit	82	29.9%
Mental Health	55	20.1%
Outpatient Substance Abuse	21	7.7%
Oral Health	23	8.4%
Medical Case Management	189	69.0%
Medical Nutritional Therapy	26	9.5%
Case Management (Non-Medical)	28	10.2%
Housing	10	3.6%
Residential Substance Abuse Treat.	1	0.4%
Food/Nutrition Services	30	10.9%
Transportation	47	17.2%
Legal	10	3.6%
DEA	2	0.7%

1.3.3 Recommendations for Further Study

The above analysis shows that the following areas should be studied with Ryan White providers.

- Why are so many clients with active status not followed up for one year?
- Younger clients – under age 24 – what is happening to them, where are the pediatric PLWHA going?
- Why are so many clients with a medical visit in the year not followed up for one year, especially those who have been in Ryan White for a long time?
- Based on the percent of returning clients who were in active or suspended status as of the end of the year, providers should review all clients listed in this status to determine circumstances.
- What actions are taken – especially by medical case management - when clients return to care?

1.4 Provider Survey: FY 2008 Clients Lost to Services in FY 2009 - Overview

The next step in this part of the 2011 Needs Assessment was to determine the reasons that clients were lost to services (follow up). It was determined that a survey of providers would be the best method to gather this information consisting of a chart review of a sample of patients who were lost to service.

1.4.1 Methodology

Survey Tools. Two survey tools to collect this information were developed by the Research and Evaluation Committee (REC). Survey #1 was for FY 2008 clients returning in FY 2010 and a shorter Survey #2 for those who did not return. Both surveys are in Appendix A. We agreed to use online Survey Monkey for data entry. The features of Survey Monkey allow for responses to be downloaded in a format for SPSS and other computation. The online format is better than hard copy surveys and manual data entry into a spreadsheet because it reduces costs (eliminates extra time needed for staff data entry) and reduces likelihood of data entry errors. Council staff entered both surveys into Survey Monkey and formatted them for ease of use by providers.

Sample size and selection. Using the two CHAMP historical files (returned to Ryan White in FY 2010 and not returning), we developed a statistically valid sample for each population. The sample sizes are **153 records** for FY 2008 clients lost in FY 2009 returning in FY 2010, and **298 records** for FY 2008 clients lost in FY 2009 who did not return.

We identified the CHAMP client IDs for each client and service provider. We used random sampling methodology to select cases, and adjusted the sample size to minimize volume on any single provider. We prepared a list of cases for each provider agency, listing the Client IDs and which Survey #1 or #2 was to be used for each client ID. (The client IDs matched up with the master sample size list.)

Grantee. Because the survey contained client IDs, it was administered by the Ryan White Grantee, Newark Department of Child and Family Well-Being (DCFWB). The Council sent the list of cases by provider to the Grantee, who then sent it out to all providers on May 11, 2011**.** The universe of providers was 27 for Survey #1 and 34 for Survey #2. As of May 31, 2010 we received only 27%-28% of surveys from less than half of providers. In mid-July the Grantee followed up with providers which increased the rate of return somewhat. But many Part A agencies chose not to respond.

1.4.2 Responses

FY 2008 Clients Lost to Service in FY 2009 who Returned in FY 2010. The goal was to sample 153 clients and 27 providers. However, one agency was no longer providing Part A services in FY 2010, which reduced the sample size to 147 and 26 providers. We received **99 usable responses** for clients/cases (67% of 147 clients) from 15 (58%) of the 26 providers surveyed. See Table 8.

FY 2008 Clients Lost to Service in FY 2009 who Did NOT Return in FY 2010. The goal was to sample 298 clients and 34 providers. However, one agency was no longer providing Part A services in FY 2010,

which reduced the sample size to 293 and 33 providers. We received **155 usable responses** for clients/cases (52% of 293) from 19 (58%) of the 33 providers surveyed. See Table 8.

Respondents. Agencies who responded included many hospital based clinics with the most Part A clients, one community health center, long term care facility, behavioral providers, oral health providers and CBOs. Those who did not respond included two community health centers, and support service providers. See Appendix A for the blinded list of providers by sample size and response.

For the most part, the same providers did not respond to either survey, regardless of the sample size. That is, some providers with very small sample sizes did not respond. Fortunately, providers with some of the largest sample sizes did respond.

Table 8: Sample Size and Response Rate for Lost to Services Surveys

	Total	Usable	Initial Response*		Final Response*	
Clients/Cases	**Sample**	**Sample**	**#**	**Rate**	**#**	**Rate**
Survey #1 - Returned	153	147	40	27%	**99**	67%
Survey #2 – No Return	298	293	84	28%	**155**	52%
Providers						
Survey #1 - Returned	27	26	9	35%	**15**	58%
Survey #2 – No Return	34	33	13	39%	**19**	58%

*Usable responses – Surveys for client ID's received matched the client ID's sampled and sent out.

1.5 Provider Survey: FY 2008 Clients Lost to Service in FY 2009 Returning in FY 2010

1.5.1 Total Clients and Status of Returning Clients

Services Received by Clients in FY 2008

Medical care and health insurance. Of the 99 total clients, 81% (80) received Part A medical care in FY 2008 and the remaining 19% (19) did not. Source of health insurance for those 80 receiving medical care was no insurance (including charity care) at 29% (23), Medicaid at 26% (21), Medicare at 9% (7), private insurance at 6% (5) and VA medical care at 4% (3). Over one quarter (26% or 21) had no answer.

Services received by those In Medical Care in FY 2008

Core Medical Services received by those in medical care. Two thirds of clients in medical care (53) also received one or more core medical services in FY 2008. Over half (55% or 44) received medical case management, 16% (13) received medical nutritional therapy, 14% (11) received mental health services, 10% (8) received outpatient substance abuse services, and 8% (six) received oral health care. Five clients (6%) received both mental health and outpatient substance abuse treatment services.

Support Services received by those in medical care. Less than half (48% or 38) of clients in medical care also received support services. Twenty one percent (17) clients received non-medical case management services, 16% (13) received transportation, 13% (10) received food/nutrition services, 3% (2) received housing and 1% (one) each received DEA and legal services. No clients received residential substance abuse treatment.

Case Management. One third (15) of the 44 clients receiving medical case management also received non-medical case management. In other words, **there were many points of contact by MCM and CM-NM to ensure retention in care.**

Services received by those NOT in Medical Care in FY 2008

Core Medical Services received by those NOT in medical care. Only eight (42%) clients NOT in medical care also received one or more core medical services in FY 2008. Four (21%) received medical case management, four (21%) received mental health services, and one (5%) received outpatient substance abuse services. No clients received oral health services or medical nutritional therapy. No clients received both mental health and outpatient substance abuse treatment services.

Support Services received by those NOT in medical care. Only eight (42%) of clients NOT in medical care also received support services. Two clients (11%) received non-medical case management, two (11%) received transportation, 2 (11%) received housing, and 2 (11%) received legal services. No clients received food/nutrition services, DEA, or residential substance abuse treatment.

Case Management. Only six (32% of clients not receiving medical care in FY 2008 received either medical case management (4 or 21%) or non-medical case management. The remaining 13 clients (68%) had no such contact. In other words, **there were few points of contact by MCM or CM-NM to ensure retention in the Ryan White service continuum, much less giving them entry to medical care.**

Last Client Contact in FY 2008

Providers reported that, for the most part, the last client contact in FY 2008 was a face to face contact (50%), followed by telephone call and letter to client. See Table 9. Dates of the last client contact in FY 2008 ranged from April 2008 to February 2009. **The last client contact was predominantly face to face.**

Table 9: Type of Last Client Contact in FY 2008

Method of Last Client Contact	Medical Care		No Medical Care		Total	
	#	%	#	%	#	%
Telephone Call	14	17%	4	21%	18	18%
Letter to Client	11	14%	4	21%	15	15%
Face-to-face contact	48	60%	11	58%	59	60%
Other Contact	4	5%	0	0%	4	4%
No Answer	3	4%	0	0%	3	3%
Total	**80**	**100%**	**19**	**100%**	**99**	**100%**

Providers reported "other" types of client contact including medical visit, gynecological visit, outreach visit, home visit, came in for blood work/TB test/hepatology visit, discharged plan to nursing home/other facility (YMCA), client in clinical trial.

Living Arrangement in FY 2008

The majority of clients (60 or 61%) were living in a House or Apartment. Five (5%) were in a nursing home/hospital, three (3%) lived in transitional housing, two (5%) were homeless, one (1%) lived in an emergency shelter, and one (1%) was living with a relative. Residence of 15 (15%) was unknown and no responses were provided for 10 (10%) clients.

Client Contact in FY 2009

Although the CHAMP file indicated no client contact in FY 2009, providers were asked if their case chart indicated if the client was contacted in FY 2009. More than half – 58% or 57 - of clients were contacted in FY 2009. Most (52) had been receiving medical care and only five were not receiving medical care. 39% were not contacted in FY 2009 and no answer was given for 3%.

The types of client contact were face to face contact (32%), telephone call (10%), letter to client (8%), and other (9%). "Other" client contacts include: outreach, client discharged to YMCA, client came in for blood work, primary care visit, gynecological visit, home visit, and copy of labs received to continue client eligibility. Type of contact was not given for 12%. None of these contacts had been recorded in CHAMP.

Reason Returned to Ryan White in FY 2010

Agencies listed numerous reasons for clients returning to Ryan White in FY 2010. The top reason was need for medical care (52%). See Table 10.

Table 10: Reasons for Return to Ryan White in FY 2010

#	%	Reason for Return
99	**100%**	**TOTAL**
51	52%	Needed Medical Care
11	11%	Needed Support Services
7	7%	Returned to the EMA
3	3%	Released from Institution
1	1%	Released from Incarceration
1	1%	Stopped Substance Abuse
0	0%	Lost health Insurance
25	25%	Other
		"Other Reasons"
5	5%	A chart review was done on this day to try to reach out to this client.
3	3%	Did not return physically but outreach to client done
2	2%	Completed Clinical Trial (at NJCRI, SMMC) and returned to our care.

#	%	Reason for Return
2	2%	Client did not return. Went to another Part A provider (UMDNJ, NJCRI).
1	1%	Regular scheduled visit for care from physician
1	1%	Returned to follow up care
1	1%	Indeterminate status follow up
1	1%	Moved back to NJ
1	1%	Medication refills
1	1%	Dental care
1	1%	Recertification for Housing/Housing Assistance
1	1%	Needed medical records
1	1%	Patient was seeing a non Ryan White provider for medical services
1	1%	New Foster parent wanted to discuss prior testing.
1	1%	Follow up on HIV exposed status.
1	1%	Patient only had intake visit. Homeless with no contact information or Emergency contact
1	1%	Patient did not return to agency. Patient in treatment with private provider. Case was terminated on 6/19/2009
1	1%	Discharge to home hospice 6/2/2008

Services Received in FY 2010

The clients who returned in FY 2010 essentially returned to their service package which they were receiving in FY 2008. Those in medical care continued to receive a package of core medical services. Those not in medical care received needed support services, and some core medical services. Again, it shows existence of two distinct populations of Ryan White clients.

Table 11: Services Received in FY 2010 by FY 2008 Clients Lost to Service in FY 2009 Who Returned in FY 2010

Service	Med Care FY08		No Med Care FY08		Total	
	#	%	#	%	#	%
Medical Care	**57**	**71%**	**2**	**11%**	**59**	**60%**
Core Medical Services	**43**	**54%**	**2**	**11%**	**45**	**45%**
MCM	34	43%	2	11%	36	36%
Mental Health	8	10%	2	11%	10	10%
Med Nutr Therapy	6	8%	1	5%	7	7%
OP Substance Abuse	3	4%	1	5%	4	4%
Oral Health	4	5%	0	0%	4	4%
Support Services	**25**	**31%**	**4**	**21%**	**29**	**29%**
Case Mgt-Non Med.	14	11%	2	11%	16	16%
Food/Nutrition	10	13%	1	5%	11	11%
Transportation	9	11%	1	5%	10	10%
Housing	2	3%	1	5%	3	3%
Legal	1	1%	1	5%	2	2%
Subs Abuse Residential	1	1%	0	0%	1	1%
DEA	1	1%	0	0%	1	1%
Total Clients	**80**	**100%**	**19**	**100%**	**99**	**100%**

1.5.2 Summary of Clients' Status as of FY 2010 and Agency Observations

Agencies gave considerable comments about the status of clients and recommendations. These are shown in Table 12 and give an indication of the characteristics of clients lost to service and challenges facing the agencies.

Reasons for Lost to Service

When combined, the comments also indicate the reasons clients are "lost to service". The three chief reasons are: (1) Agency follow up, (2) Client non-adherence or noncompliance, and (3) change in circumstances that was not recorded in CHAMP. There are other services issues which may be unique to providers or clients but these are a minority of clients.

"Never Lost to Service"

Agency comments for 23 of the cases indicated that the client was "never lost to service". They had received medical care, kept appointments, etc. The 23 client ID's were compared with the FY 2009 CHAMP files for Part A and Minority AIDS Initiative (MAI) or Part F. It was found that only one case had been included incorrectly and had received services Part A services in FY 2009.

It was confirmed that 96% (22) of the clients had NOT received Part A or MAI services in FY 2009. This is 22% of the total 99 clients. Services must have been provided by another funding source. There should be a way to record these services so that clients do not show up as "lost".

Table 12: FY 2008 Clients Lost in FY 2009 and Returning in FY 2010 – Summary Of Client Status and Observations/Recommendations

CLIENTS IN MEDICAL CARE IN FY 2008 RETURNING TO SERVICE IN FY 2010	
Summary of Client's "Lost to Service" Status	**Recommendations for this or all Lost to Service Clients**
Agency Follow Up Issue (15 responses)	
Never returned to care.	Unsure.
No comment , several ER visits.	Unsure.
Again like many of our lost to services clients, they moved out of state or the EMA area for some time but then came back.	Nothing at this time.
Had blood work done in clinic on 11/22/2010 but did not return for clinic appt.	Unsure.
Indeterminate HIV status follow up. Not lost to services.	Indeterminate HIV status follow up .
Left to go home to be with family at the end of life no return.	Transient population physical and mental fear and adherence
Client did not want people at nursing home to know his status, was not making his appointments.	When client is in denial, you have to allow client to become client ready on their own when returning to treatment.
Not seen between 6/08-2/2010. No reason given.	Unsure.
Nothing noted as to where client had been, but client was being followed by Tb center.	Unsure.
This client went to a VA inpatient treatment program in NY for some time in 2009, returned once for medical care at the NJ VA in 2009. Was incarcerated for some time and then returned in 2010. Has been in substance abuse treatment here at the VA and comes to clinic sporadically	None at this time.
Client came in need of medical and mental health. Client was currently living with a family member. We tried to get in contact with him by phone and mail.	We need to do more outreach.
FY 2009 the patient was living with friend in an apartment.	Patient had minimal family support.
Patient was working and could not take time off for every appointment.	Schedule appointments around patients work hours.
Client was working and could not take days off from work for every appointment.	Clients priorities must be handled first (if mot medical) before client will return for services.
We try to get in contact with client by phone and mail. Client had her own apartment. We need to do outreach.	We need to do outreach.
Client Non-Adherence/Noncompliance (14 responses)	
Patient had issues with compliance in 2008 regarding her treatment plan. However, patient moved to Virginia and we assisted her in getting connected with medical and case management services in Dufrees VA. She returned to clinic after moving back to area. Currently, she is engaged in multiple services at clinic and outside resources.	A tab in CHAMP to prompt the agency to change the patient status.

CLIENTS IN MEDICAL CARE IN FY 2008 RETURNING TO SERVICE IN FY 2010	
Summary of Client's "Lost to Service" Status	**Recommendations for this or all Lost to Service Clients**
Currently active in care.	
Patient was lost to services for 10/10/2009 to 6/8/2010. Patient was off his meds for 3 weeks.	Patient was lost to services for less than one year. Phone calls, follow up letters sent to home and home visits are ways that our organization practices to encourage patients to return and receive care.
Client was discharged from the Psych ER. Was given a Nursing intake and labs. MCM referred patient to shelter. Patient did not return for follow up services.	Patient had mental issues, homeless with no contact information and no emergency contacts.
Client came to agency in 2008 in need of back rent or security deposit . Client received security deposit assistance in the amount of $1,425.00. No services were noted for 2009. Attempts were made at contacting the client via telephone and mail with no success. Lab results dated 4/14/2008 were provided in the chart.	Please note that this chart was acquired from the prior agency (El club del Barrio) and very limited information was noted in the chart.
Patient was depressed and in denial of HIV status, stopped taking meds...had several ER visits	Inreach to patient in hospitals with HIV diagnosis.
Phone calls continued to patient until she returned to service. She is currently not in service.	Patient has intermittent medical care. Continued outreach is done so that when Patient is ready to come in to service, the care is available.
Following patient last visit to MD on 6/6/08 he visited case manager on 6/11/08 seeking a letter to excuse him from welfare work duty due to HIV status. Patient was told our doctor did not see patients HIV status as a basis for not working. Patient said that he would try to get another doctor to sign the papers for him. Patient did not return to care until 4/9/10.	When a patient is lost to care it is our normal practice to contact patient through phone calls, letters sent to home and home visits and all these practices were exercised in regards to this patient. Unfortunately patients do develop personal resentment towards staff when the staff doesn't respond to some or their personal requests that are made and deny themselves the care that they need or maybe receive care elsewhere because of their own personal reasons. Patient has returned to care.
Client was actively abusing drugs Intensive Outpatient Services with urine screening and Residential Treatment were offered he refused both. He was informed he can continue to receive case management but would not receive transportation or nutritional vouchers unless he did an Outpatient program. Client no longer contacted agency; he was under medical treatment at UMDNJ. He was living in girlfriend's apartment.	Client's that have Substance Abuse problems have tendency to go in and out of treatment; many may keep appointments to sell their medications but at least are seen by a doctor. Others stray away for periods of time and may become incarcerated or stop medical treatment due to their addiction. We have seen clients who will continue medical treatment even if abusing drugs. Many clients who have Substance Abuse history will benefit from mental health therapy with an outpatient or residential program. The problem is getting clients to accept treatment especially long term.
Patient has intermittent medical care. Continued outreach is done so that when	Patient has intermittent medical care. Continued outreach is done

CLIENTS IN MEDICAL CARE IN FY 2008 RETURNING TO SERVICE IN FY 2010	
Summary of Client's "Lost to Service" Status	**Recommendations for this or all Lost to Service Clients**
Patient is ready to come in to service, the care is available.	so that when Patient is ready to come in to service, the care is available.
Transient population: Client was in and out of BH has a long history of admission and discharges. when she is medically cleared she is discharged and when she in medical need she is admitted. Currently resides in the community last discharge place was Urban Renewal.	Transient population. Disease process (physical and mental) Substance Abuse Fear and Adherence.
Client return to the clinic because he was feeling sick. He was recently laid off and receiving unemployment benefits. In 2009 he stated that he was not in need of medical care. Client came in on 2010 and until today he never came back.	We needed to do more outreach.
Patient has been in care for many years, but has been inconsistent. He calls for appointments but does not show up. Team follows up with reminders.	Client, who had consistent medical care as a child, is not interested in it at this time.
Patient has been inconsistent following up with his appointments. There was a 5 month gap 8/25/08 to 1/22/09. Yet managed to stay on medications and show good lab reports. Then patient left for 16 months (1/27/09 to 5/18/10). This time he was not on meds and did not have good labs.	Phone calls have been made, letters have been sent to patient and home visits have been made. Patient is still non-adherent to doctor's visits and labs. Now lost to care again for 15 months. We will continue to follow our regimen of reaching out to the patient with the hope that he would return to care and receive the medical care that is needed.
Client stated that she had not been feeling well those months she lapsed in treatment	Client has to be ready to receive treatment.
Change in Circumstances - Not Recorded in CHAMP (17 responses)	
Not lost to services. Infant declared HIV negative.	Not lost to service. Patient discharged.
Client returned in 2010 for copies of medical records as they were moving to North Carolina.	Client moved out of state.
This client never stopped coming to the VA for his medical appointments. He was not lost to services. He moved away from the EMA in 2008 so he did not qualify for RW services, however in 2010 moved back to a county within EMA and can again receive RW services.	Some clients aren't "lost". Still come to the clinic, but no longer in the approved RW area.
Did not return to care in 2009 or 2010.	Unsure.
Patient moved out of state in 2009 and then returned to NJ.	NA
In 2008 patient had regular visits to see the doctor although he was not compliant with taking his medications. In 2009 he talked about moving to California he had met a girl on line. He had several visits with us and receive his requested medical records and relocated to California. In 2010, he returned from California in 12/2010. He came in for only one visit. Patient was not taking his medication in California. Patient	Patient moved out of state.

CLIENTS IN MEDICAL CARE IN FY 2008 RETURNING TO SERVICE IN FY 2010	
Summary of Client's "Lost to Service" Status	**Recommendations for this or all Lost to Service Clients**
returned to California in 2011.	
Client was incarcerated in FY2008 and was not released until 7/10.	When clients are lost to services, CHAMP Lookup should be first option used.
Patient did not adhere to visits, deteriorated and was hospitalized. Patient was discharged into Broadway House and health improved. Patient has been released from Broadway House and has returned to care at NBIMC.	Patient was in rehabilitation program and once released coordination with facility along with family members allowed a smooth transition and return to care.
In FY 2008 was living with family in house but still not strictly adherent to medical care. Lost contact with client despite continued letters and phone contact attempts	Outreach.
Patient had a hard time accepting HIV status and was in denial and that has affected their visits. Patient has been active with case management and mental health support and has built a strong relationship in that area.	Patients that are lost to care, we normally respond with phone calls, letters sent to home and home visits and all of these practices were exercised with this patient. Our case management support has helped us in patient returning to care.
Patient fell back into active substance abuse and was not adherent to medical care...living on the streets...now receiving behavioral health services and is adherent to medical care	Outreach worker could have possibly found him when he was living on street and re-engaged him into care earlier.
Client transferred to UMDNJ.	Clients sometimes transfer treatment without saying anything to former clinic.
Patient moved out of state and transferred services to a new provider when she moved, Return to NJ in FY 2010	not applicable
In 2008 patient had 2 visits she was not ready to start ART treatment. She came for follow up care in 2009 patient had one visit to see the doctor. Again she was not ready to start ART treatment. In 2010 patient had two visits, the first visit 3/25/2010 was not started on medication. The second visit 7/29/10 she was start on Atripla and patient told us she was moving to Georgia. All patient records were given to patient.	Patient moved out of state.
Patient was in regular treatment at NBIMC when determined by doctor that patient would be a good candidate for clinical trial at SMMC. Once the trial was completed he returned to our care.	Patient was referred to clinical trials at St Michaels and had completed trial and has returned to our care.
Incarcerated.	Case finding in prison system.
Client transferred to NJCRI.	All agencies should be held accountable for keeping chaps data base updated.
Other Service Issues (6 responses)	
HIV affected infant-exposed infant schedule	HIV affected infant-exposed infant schedule
Patient at UMDNJ not NJCRI.	Patient at UMDNJ not NJCRI.

CLIENTS IN MEDICAL CARE IN FY 2008 RETURNING TO SERVICE IN FY 2010	
Summary of Client's "Lost to Service" Status	**Recommendations for this or all Lost to Service Clients**
Patient never came to us for medical care as she sees a private provider. Patient came to us for dental care only. Patient returned to us to re-establish dental follow up.	Patient being lost to services from Ryan White was for dental services only. Returned when she needed follow up care.
This patient was not lost to follow up. His RW Client ID changed. Information in this survey should not be used. It was entered just to get to this screen to explain ID change.	Not lost to follow. ID change issue.
Patient was not lost to follow up. On exposed infant modified schedule.	Patient not lost to follow up. On exposed infant modified schedule.
Patient is an infant. Mother needed encouragement over a span of two years to bring Patient back for testing.	Patient's mother needed strong encouragement to bring Patient back in for testing.

CLIENTS NOT IN MEDICAL CARE IN FY 2008 RETURNING TO SERVICE IN FY 2010	
Summary of Client's "Lost to Service" Status	**Recommendations for this or all Lost to Service Clients**
Agency Follow Up Issue (2 responses)	
Client was seen last on 1/14/2009 as initial visit. Client had her own apartment.	We try get in contact with client several times through phone calls and contact letter. We need to do outreach for this client.
Client was lost to contact with no forwarding address.	It appears that the client was never consistent with Hope House services.
Client Non-Adherence/Noncompliance (6 responses)	
Patient had total hip replacement 6/6/08. Several home visits. Patient did not return to care until 5/4/10.	Some patients tend to stay away if there numbers are good and they feel and look better, even with counseling advising them not to do so.
Client was referred to a higher level of substance abuse treatment and did not return to Hope House. The client's current status is unknown.	Client appears to have a significant substance abuse issue which may have impaired his ability to receive treatment.
Patient was on probation being assisted with housing by Project Connect. Loss of address. No means for further contact.	Outreach services.
The last known residence was her parent's home and she had medical issues unrelated to her HIV/AIDS that were causing her pain. Attempt of contact was made in 2010, she did not respond. Client was informed to return to Hope House if services were needed in the future.	Client appears to have family support and connected to medical care and thus not interested in additional services.

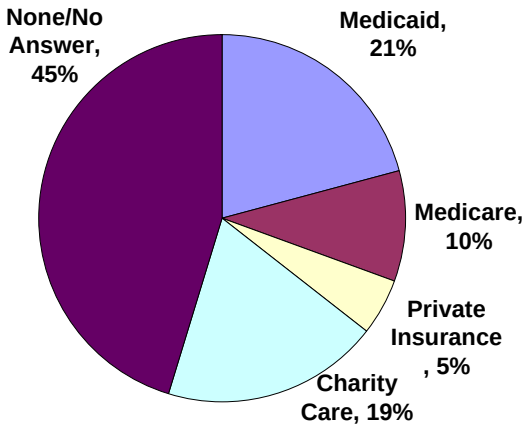
CLIENTS NOT IN MEDICAL CARE IN FY 2008 RETURNING TO SERVICE IN FY 2010	
Summary of Client's "Lost to Service" Status	**Recommendations for this or all Lost to Service Clients**
Client came in for the first time on 4-22-2008, a mental health assessment was done on 6/11/2008, but then client never returned after that date. A letter was sent out but client never replied. Labs dated 2-12-2008 are enclosed in the chart including a list of her medications.	Based on the information provided in the chart, no further attempts to contact the client were made by the case manager. Please note that this chart was acquired from the prior agency (El Club del Barrio) and very limited information was noted.
Patient registered at EIP in 07 - living w/ relatives-poor adherence 08-reported to MCM he was homeless and arrangements were made for shelter 7/08 - Discharged from hospital with no forwarding contact address 2009 - attempted outreach to previous address and phone #.	Loss of permanent address left it unable to contact patient. Active substance abuser.
Change in Circumstances - Not Recorded in CHAMP (4 responses)	
Patient was only accessing psych services at our agency in FY 2008 until we could coordinate services with his private insurance.	Assisted patient in transferring services so he would not be lost to care
Client needed assistance with ADAP application in 2010. She is currently active in case management services.	Client's primary need from Hope House is assistance with ADAP. She is in compliance with her medical care.
In April 2011, client asked that his case be closed as he felt he did not need services.	It appears that client utilized Hope House for support services and no longer felt the need for this.
Patient with intense mental health issues. Referred to mobile crisis for ? suicide attempt...refused all MH services.	Patient relocated to Pennsylvania with family on 12/29/10.
Other Service Issues (3 responses)	
Client began receiving services with the agency since 1996 based on the information in the chart, she continued to receive mental health and case management until April 2006. In 2010 a letter was sent out to try to contact client. No medical information was noted in the chart.	Please note that this chart was acquired from the prior agency(El club del Barrio) and very limited information was noted.
Client came to the agency only one time in 2008, but after that the client never returned. Client at the time was residing with family and friends. No medical information was noted in the chart.	Please note that this chart was acquired by the prior agency (El club del Barrio) and very limited information was noted.
Client's first initial intake was on 10/1/2008, he then received mental health services 1 more time after that . Client was sharing an apartment with a friend at the time. Labs dated 8/22/2008 is the only medical information noted in the chart.	Please note that this chart was acquired from the prior agency(El club del Barrio) and very limited information is noted.

1.6 Provider Survey: FY 2008 Clients Lost to Follow Up in FY 2009 NOT Returning in FY 2010

1.6.1 Total Clients

Services Received by Clients in Medical Care in FY 2008

Medical care and health insurance.
Of the 155 total clients, 115 (74%) were receiving medical care in FY 2008 and the remaining 40 (26%) were not. Source of health insurance for those receiving medical care was Medicaid - 21% (24), Medicare - 10% (11), private insurance - 5% (6). The rest **(64% or 74 clients) had no insurance including charity care.**



Finding:
The majority of "lost" clients are uninsured, relying on Part A funding for medical care. With no other means of accessing care for HIV, it is important that agencies maintain the link between clients and medical care.

Core Medical Services received by those In Medical Care in FY 2008

65% (75) of clients in medical care also received one or more core medical services in FY 2008. 50% (58) received medical case management, 24% (27) received medical nutritional therapy, 22% (25) received outpatient substance abuse services, 18% (21) received mental health services, and 10% (11) received oral health care. For 3% of clients (4) no specific core medical service was indicated. Over half of clients received only one core medical service (mostly medical case management) and the rest received anywhere from two to five core medical services in FY 2008. See Table 13.

Table 13: Core Medical Services Received in FY 2008 by Medical Clients Lost to Service

# Services	# Clients	Core Medical Services Received in FY 2008				
		MH	SA	MNT	MCM	Oral
1 Service	39	2	3	4	30	0
2 Services (16 clients)	1	1	1			
	3	3			3	
	4		4		4	
	3		3	3		
	5			5	5	
3 Services (4 clients)	1	1	1		1	
	2	2		2	2	
	1		1	1	1	
4 Services	1	1	1	1	1	
5 Services	11	11	11	11	11	11
TOTAL	**71**	**21**	**25**	**27**	**58**	**11**

Findings:
One third of lost clients receiving medical care did not receive any other core medical service including medical case management. It appears that these clients are not really connected to the full Ryan White service continuum despite receipt of medical care.

Of the 2/3 that were connected to Ryan White through other core medical services, it appears that the medical case manager should have followed up during FY 2009. Especially since MCM is purported to be a much-needed service.

Support Services received by those in medical care in FY 2008.

Over half (63 or 55%) of clients in medical care also received support services. Forty-one clients (36%) received non-medical case management services, 29% (33) received transportation, 30 (26%) received food/nutrition services, 13 (11%) received emergency housing, six (5%) received Direct Emergency Assistance (DEA), and two (2%) received legal services. No clients received residential substance abuse treatment and one client received support services but no types were listed. A majority of clients received more than one support service (33%). See Table 14.

Table 14: Support Services Received in FY 2008 by Medical Clients Lost to Service

# Services	# Clients	Support Medical Services Received in FY 2008					
		CM-NM	Housing	Transp	Food	DEA	Legal
1 Service	24	11		9	2	1	1
2 Services	7	7	7				
(17 clients)	2	2			2		
	1		1	1			
	7			7	7		
3 Services	2	2	2		2		
(17 clients)	12	12		12	12		
	2	2			2	2	
	1	1	1			1	
4 Services	1	1		1	1	1	
(4 clients)	1	1	1	1		1	
	1	1	1	1	1		
	1	1		1	1		1
TOTAL	**62**	**41**	**13**	**33**	**30**	**6**	**2**

Finding:
Given utilization of support services among medical clients lost to service, support service providers must be engaged in retention activities, including keeping in contact with clients and asking about their medical care.

Services Received by Clients NOT in Medical Care in FY 2008

Core Medical Services received by those NOT in medical care in FY 2008.

Of the 40 clients who did not receive medical care in FY 2008, only 15 (38%) received one or more core medical services in FY 2008. Twelve (30%) received medical case management, two (5%) received

mental health services, two (5%) received medical nutritional therapy, and one (5%) received oral health services. No patients received outpatient substance abuse services. Only one client received two core medical services – mental health and medical case management.

Support Services received by those NOT in medical care in FY 2008.

Less than half (13 or 33%) of clients NOT in medical care in FY 2008 received support services. Six clients (15%) received non-medical case management services, four (10%) received legal services, and two (5%) received transportation, 2 (5%) received housing, and 2 (5%)received DEA. No clients received food/nutrition services or residential substance abuse treatment.

Two clients receiving MCM also received non-medical case management.

A total of 22 clients (55%) received some service – core medical or support – in FY 2008. Two additional clients (5%) were grounds for discharged (one died and the other was not seen by the agency for several years). The remaining 16 (4%) received no core medical or support service in FY 2008 – or medical care. This latter number indicates that the agencies did not provide correct information for the clients or did not have the information.

Findings:

Clients who are not in Part A medical care do not receive sufficient core medical services or support services to provide a strong link to the Part A system. Agencies must make a special effort for these clients to engage them in care.

Last Client Contact in FY 2008

Providers reported that, for the most part, the last client contact in FY 2008 was a face to face contact (58%), followed by a letter to client and a telephone call. See Table 9. Dates of the last client contact in FY 2008 ranged from April 2008 to February 2009.

Table 15: Non-Returning Clients - Type of Last Client Contact in FY 2008

Method of Last Client Contact	Medical Care		No Medical Care		Total	
	#	%	#	%	#	%
Telephone Call	13	11%	12	30%	25	16%
Letter to Client	33	29%	7	18%	40	26%
Face-to-face contact	69	60%	19	30%	88	58%
Other Contact	0	0%	0	0%	0	0%
Total	**115**	**100%**	**38**	**100%**	**153**	**100%**

Living Arrangement in FY 2008

The majority of clients (108 or 70%) were living in a House or Apartment. Seventeen (11%) were in a nursing home/hospital, 14 (9%) were living in a shelter/transitional housing or were homeless, two (1%) were in prison (incarceration), and living arrangements of 14 (9%) was unknown. Clients not in medical

care were less likely to live in an apartment (58%) and more likely to live in shelter/transitional housing or to be homeless (15%), or have other/unknown living arrangements (18%).

Client Contact in FY 2009

Although the CHAMP file indicated no client contact in FY 2009, providers were asked if their case chart indicated if the client was contacted in FY 2009. One third (52) of clients were contacted in FY 2009. Most (85% or 44) had been receiving medical care and only 15% were not receiving medical care.

The types of client contact were face to face contact (29 or 19% of the 52 clients), letter to client (21 or 8%), telephone call (nine or 6%), and other (one or 1% - corrections close out). None of these contacts had been recorded in CHAMP.

1.6.2 Summary of Nonreturning Clients' Status and Agency Observations

Agencies gave considerable comments about the status of clients and recommendations. These are shown in Table 16 and give an indication of the characteristics of clients lost to service and challenges facing the agencies. The recommendations are very different from those for returning clients.

Reasons for Lost to Service and No Return

When combined, the comments also indicate the reasons clients are "lost to service". The three chief reasons are: (1) Agency follow up issues (29%), (2) Client non-adherence or noncompliance (27%), and (3) change in circumstances that was not recorded in CHAMP (30%). There are other services issues which may be unique to providers or clients but these are a minority of clients (8%).

For those not receiving medical care, the reason that half of clients were lost to service was due to client non-adherence/noncompliance. They just did not engage in the Ryan White system.

"Never Lost to Service"

Agency comments for nine of the cases indicated that the client was "never lost to service". They were still in medical care, in clinic, etc. The nine client ID's were compared with the FY 2009 CHAMP files for Part A and MAI or Part F. It was found that none of the clients had received services Part A services in FY 2009 which is **8% of the total 112 clients** with reasons given for lost to service. **Services must have been provided by another funding source.** There should be a way to record these services so that clients do not show up as "lost".

Table 16: FY 2008 Clients Lost in FY 2009 Who Did NOT Return – Summary Of Client Status and Observations/Recommendations

CLIENTS IN MEDICAL CARE IN FY 2008 WHO DID NOT RETURN TO SERVICE	
Summary of Client's "Lost to Service" Status	**Recommendations for this or all Lost to Service Clients**
Agency Follow Up Issue (35 responses)	
Patient was last seen in ED on 8/9 and discharged on 8/10/2009.	Unknown
No medical service in 2009 & 2010 but came back 2011	N/A
Letter was sent on 4/14/2009 then a phone call made to Greystone to see if still admitted there on 4/28/2009. Last seen in clinic on 2/4/2009.	Unknown
Followed up with cardiologist on 2/24/2009. Last seen at clinic on 2/19/2009.	Unknown
Patient last seen in clinic on 6/10/2008. Patient discharged from ER on 10/4/2009.	Unknown
Patient last seen in clinic on 8/5/2008.	Unknown
Last seen in clinic on 4/22/2008.	Unknown
Patient last seen in clinic on 5/28/2008.	Unknown
Patient last seen in clinic on 12/30/2008	Unknown
Patient had surgery on 8/6/2008 and letter sent on 9/9/2008	Unknown
Patient last seen in clinic on 3/6/2008	Unknown
Patient last seen in clinic on 6/3/2008	Unknown
Patient was last seen in clinic on 8/5/2009	Unknown
Patient last seen in clinic on 11/13/2008	Unknown
Letter sent on 6/23/2009.	Unknown
Patient last seen in clinic on 8/12/2008.	Unknown
LAST seen in clinic 4/13/2010	Unknown
Patient last seen in GI Dept. 6/23/2009 for stomach biopsy	Unknown
Patient was contacted by letter last on 6/3/2008	Unknown
Patient was last seen in clinic on 7/21/2008	Unknown
Last seen in ER on 7/4/2008	Unknown
Patient last contacted by letter on 8/12/2008. Last seen in ER on 7/15/2008.	Unknown
Patient was contacted by letter on 9/4/2008 Patient last seen in ER on 6/27/2008.	Unknown
Patient returned to clinic, last seen 5/6/2010.	Unknown
Patient went to ER on 9/3/2008 and left ED on 9/4/2008 without informing staff.	Unknown

CLIENTS IN MEDICAL CARE IN FY 2008 WHO DID NOT RETURN TO SERVICE	
Summary of Client's "Lost to Service" Status	**Recommendations for this or all Lost to Service Clients**
Last letter sent to client on 5/23/2008.	Unknown
Patient last seen in clinic on 9/21/2009 after release from jail by Social Worker.	Unknown
Another clinic attempted to contact client in 1/14/09 phone disconnected & unable to contact him.	none at this time.
He was in the hospital & discharged received home care. He returned to clinic on 1/29/2009.	None at this time.
He missed one appointment but returned on 4/29/09.	None at this time.
He was admitted to hospital & was discharged on 6/19/08 & has not been in any clinic since the. Letter sent out to contact clinic was returned by post office.	None
Client was currently homeless. Client didn't have income or any medical insurance. Last visit 3/27/2008.	We need to do outreach.
Client was currently stable as far as housing, Medicaid and income. Last visit on 2/17/2009.	We need to do outreach.
Client was currently homeless. Referred to St. Bridget's Shelter. Last medical visit on 08/25/2008.	We need to outreach this client.
Client was discharged from this residence due to illegal activities.	Client was receiving medical care so should have continued in CHAMP even though not living in Ryan White housing
Client Non-Adherence/Noncompliance (24 responses)	
Unable to determine client's permanent living arrangements, poor adherence to medical care.	Outreach needed.
Poor adherence missing appointments.	Outreach workers to help locate missing clients.
Poor adherence to medical care.	Moving around between addresses, phone disconnections, clients easily get lost. outreach workers might help to locate missing patients
Not exactly lost to services - not always adherent with scheduled appointments - frequently re-schedules.	Need outreach services to locate patients who do not respond to attempts to contact.
Patient had history of poor adherence...did not return phone calls/letter contact.	Need stronger outreach to find lost clients.
Came in for intake, never returned.	Adjust services for high functioning clients.
Patient's viral load high and living in apartment.	Hard to track patient if not utilizing EMA.
Client medical care was standard and lived in apartment.	Client's address should be updated by registrar upon every visit.
Client lost contact with the agency.	None at this time.
Client's viral load was high and lived in apartment.	Do not know what has happened to client and can't track .

CLIENTS IN MEDICAL CARE IN FY 2008 WHO DID NOT RETURN TO SERVICE	
Summary of Client's "Lost to Service" Status	**Recommendations for this or all Lost to Service Clients**
Client medical care was okay and was living in apartment.	If client is not receiving treatment in the surrounding EMA is hard to track clients down.
Client had Medicaid living in apartment with spouse.	Client's needs must be met before trying to persuade them to return to treatment.
Client did not keep appointment.	Keeping in touch with client with up date on status regarding health and clinic services.
Client drop out of services unable to contact. No reason given at this time.	Attempt to provide client with understanding services & health care.
Client had recently been released from prison, was living at Isaiah House, was involved with Hyacinth, attending NA, and had been seen at UH/ID Clinic. Was seen for initial evaluation and one therapy appt. Failed to keep five follow up appts and did not respond to outreach letters.	Generally there are RW case managers who are more closely involved with clients and who are usually more aware of life events/changes that may affect clients' service involvement. Though it isn't the sole solution in all cases, when case managers learn of circumstances that impact service adherence (e.g., hospitalization, incarceration, relocation, admit to nursing home or rehab, etc), it would be helpful to disseminate this information (when appropriate authorizations have been obtained). The benefits of this knowledge are not only that there is heightened awareness among providers of one's status but also that information on one's status can be shared with subsequent providers. The ability to discriminate clients who are lost to service because of non-adherence (vs. change in life events) also helps providers focus efforts/energy on re-engagement where it may be more consequential.
Client did not keep appointments	Provide Client more information status and education.
Client was informed by the doctor that the needed to start taking medication and comply with making and keeping medical appointments. In addition, legal advocate helped client complete a letter for municipal court where they had outstanding warrants.	N/A
The clients living arrangements were critical at the time of lost of services. We applied for short term HOPWA. The client remained active in medical care.	N/A
Client was an active case management client since 2/14/94. Client was on SSI and had Medicaid. Client wanted to better himself went to school and became a School Bus	A feedback that we get here at CURA from clients is that Medical Case Management in a hospital/clinic setting is too impersonal,

CLIENTS IN MEDICAL CARE IN FY 2008 WHO DID NOT RETURN TO SERVICE	
Summary of Client's "Lost to Service" Status	**Recommendations for this or all Lost to Service Clients**
Driver (temporarily), during this time he married and due to change in status SSI, Medicaid and HOPWA stopped. He was trying to get a permanent job with Board of Ed so he could qualify for health insurance. Case closed due to lack of client contact because of work schedule, at that time he was seeing Dr. Slim at St. Michael's and living with family in an apartment.	staff have to see too many clients. They are unable to service clients when need arises, at times given appointments for later in week if not later in month. By that time reason client had to see Med. Case Manager has been resolved by another agency or too late to resolve. At a community based organization, such as ours, we do our best to address client's needs immediately, if possible and in their language (Spanish). Clients have commented they do not feel like a number and our records show that the majority of our clients are long term so we encourage them to seek and follow medical care especially when they get tired or depressed from taking medications or having to do a lot of doctor visits. One of our goals is to assist clients in becoming self-sufficient, empowered and stable in as many areas in their life as possible with respect to income, housing, healthcare, etc.
Client started receiving case management services on 3/20/95; she maintained contact with her case manager. She received various services for 11 years' meeting a lot of her goals, she had even started attending college. Contact started diminishing in 2007 when due to financial problems she had to leave school and began working part time. This led to a full time job but contacts became fewer and spread out. Attempts were made for her to return for services thru mail and phone calls but no contact was made. Case closed due to consumer lack of contact. Client had been living in an apartment and receiving medical treatment at UMDNJ.	Due to funding cuts staff size is smaller before able to do home visits more regularly, unfortunately now only can do in emergency cases at times staff does visit on own time.
After 05-29-2009 Client did not keep doctors visits	Provide better standing of services
Client did not keep appointments.	Over all better observation on client status
Client was active with agency. He lived in his own apt. He attended his medical appts regularly.	The client has been active with Positive Health Care, Inc. agency. However he had a name change in 2009. As a result all information entered in the computer is under client's new ID# XXX000000
Patient was not comfortable with disclosing her status with family and friends and would withdraw from treatment due to depression.	There is a need for assistance with disclosure to family and friends.
Change in Circumstances - Not Recorded in CHAMP (38 responses)	
Patient Died - 17 (Not documented in CHAMP)	
Patient deceased on Oct 31, 2008	N/A

CLIENTS IN MEDICAL CARE IN FY 2008 WHO DID NOT RETURN TO SERVICE	
Summary of Client's "Lost to Service" Status	**Recommendations for this or all Lost to Service Clients**
Patient deceased on Dec 30, 2008	N/A
Patient deceased on April 21, 2009	N/A
Patient deceased on 8/2/2010	N/A
Patient deceased on Dec 17, 2008	N/A
Patient deceased December 14, 2008	N/A
he was placed on hospice & died on 2/25/09	none
Multiple hospitalization and disease process	expired 9/06/2008
resident expired 5/21/2008	Multiple hospital admissions
Due to disease process client was in and out of hospital several times. Client passed away at the hospital 3/9/09 so he was not lost to contact he expired.	Consider a instrument to track those who expire and are not labeled lost to contact.
Client expired 3/17/08	Client expired
Patient expired 2/11/09	Patient expired
Client entered our case management program on 11/27/95 he was an active participant until his health condition started to deteriorate both physically and mentally. Wife had Alzheimer's and became scared of him, her daughter and family moved her to Puerto Rico. Client was not properly taking care of himself, Dr. Slim admitted him into St. Michael's Hospital than referred him to Broadway House on 6/16/08 at first temporarily but than became a permanent resident until he passed on 1/3/11.	I would not consider this client lost to service but because of health issues entered nursing home.
Client was not doing well in terms of health and living in apartment. Client deceased 12/5/08.	Client deceased 12/05/08.
Client lived in an apartment and was under medical care when he passed away on 8/12/08.	This client was not lost to services, he was always an active client here at CURA from 9/14/98 until his death on 8/12/08. Do hospitals have a mechanism to keep track and report on HIV+ clients, especially if payment source is not Ryan White?
Client expired on 4/20/2008	Client expired on 04/20/2008
Client left on her own due to substance abuse relapse and was later incarcerated. She was accepted back into the program upon her release from incarceration, however, she died due to complications of AIDS before being released.	A method for capturing this data in CHAMP
Moved Outside of EMA - 10 (Not Documented in CHAMP)	
Patient was on a 6 month visa and returned to Mexico at the end of April 2008.	N/A
Patient was just starting in care in FY 2008 but apparently relocated back to Georgia.	N/A as patient moved

CLIENTS IN MEDICAL CARE IN FY 2008 WHO DID NOT RETURN TO SERVICE	
Summary of Client's "Lost to Service" Status	**Recommendations for this or all Lost to Service Clients**
Patient told nurse that she was returning to Brazil.	N/A
Patient called on 3/31/2009 stating he is in Nigeria.	N/A
Client was admitted to substance abuse program on 1/08/09 & was transferred to a long term rehab out of state & now has relocated.	none at this time
Went to visit family in another state.	none at this time.
Patient came once a year before moving.	Patient had erratic medical care and then moved.
Client left of her own accord to live with family who resided in another city.	Ability to enter out-of-area status into CHAMP.
Client medically cleared and discharged to daughter's home in South Carolina. All medical arrangements set up prior to discharge with family assistance. follow up appt will be Christopher Clinic 1151 Camden Ave Rock Hill SC 29732.	none.
Client left of her own accord to live with family located outside the Newark EMA.	N/A
Discharged to Another Institution - 7 (Not Documented in CHAMP)	
Multiple hospitalization stays. 3/27/2007 UMDNJ readmitted on 3/29/07 4/9/2007 admitted to UMDNJ readmitted to BH 4/12/2007 Admitted 4/17/2007 to UMDNJ readmitted to BH 4/20/2007 admitted 6/12/2007 to UMDNJ readmitted to BH 6/18/2007 admitted 7/27/2007 UMDNJ readmitted to BH 7/30/2007 admitted 10/12/2007 UMDNJ readmitted to BH 10/14/2007 admitted 3/3/2008 UMDNJ readmitted to BH 3/6/2008. Client was discharged on 4/12/2010 to St. Bridget's.	Not lost to contact discharge to transitional (St. Bridget's)
Multiple hospitalizations.	Client not lost to services admitted to hospital SMMC.
Client was not lost to services but transferred to Bergen Regional Medical Center Dementia Unit on 7/29/2008.	Needed a more specific level of mental care and was transferred.
11/13/2008 transferred to hospital SMMC 11/25/2008 returned to BH 12/10/2008 out to hospital SMMC 12/15/2008 return to BH 12/20/2008. Out to hospital no return to BH.	11/13/2008 transferred to hospital SMMC 11/25/2008 returned to BH 12/10/2008 out to hospital SMMC 12/15/2008 return to BH 12/20/2008 out to hospital no return to BH
Transferred to hospital for services with no return due to disease process 6/27/2008.	Transferred to hospital for services with no return due to disease process 6/27/2008.
Client was not lost to contact she was discharged home on hospice care services.	This client wanted to go home for end of life care to be with family.
The client is currently living in transitional housing and continuing care at UMDNJ.	N/A
Discharged - 2 (Not Documented in CHAMP)	
Patient was discharged in 2008; May have been documented incorrectly in CHAMP.	See 13.
Patient was not lost to service. Was discharged. May have been documented incorrectly in CHAMP	See 12

CLIENTS IN MEDICAL CARE IN FY 2008 WHO DID NOT RETURN TO SERVICE	
Summary of Client's "Lost to Service" Status	**Recommendations for this or all Lost to Service Clients**
Other Service Issues (5 responses)	
Left Ryan White Medical Care – 4	
Patient got private insurance and transferred services to private provider in insurance plan. Assisted Patient in transfer of services so he would not be lost to care.	Assisted patient in process of transferring care so he would not be lost into care
Client signed out against medical advice (by proxy) and went home with proxy (sister).	Client was resistant to care with several family meeting still wanted to sign out AMA. Family was instructed to get her into care.
Client was engaged in consistent medical care and residing in a subsidized apartment through HOPWA. Client was experiencing medical issues related to cancer and appeared to drop out of services to focus on this issue.	Increase collaborative efforts between medical specialist and case manager to ensure client is provided adequate support
Client was under medical care and lived in an apartment, she was inconsistent in keeping appointments and was abusing drugs periodically.	This client was institutionalized at Newark Extended Care Facility for 3 years until she signed herself out on 2/3/11, she had been under medical care while there. She returned for support services here at CURA her last contact was 3/23/11. She was seeking HOPWA, nutritional vouchers and transportation assistance. She is on SSI has Medicaid and is seeing a private doctor.
Patient was not lost to services. HIV exposed infant who was found to be negative and discharged.	See 13.

CLIENTS NOT IN MEDICAL CARE IN FY 2008 WHO DID NOT RETURN TO SERVICE	
Summary of Client's "Lost to Service" Status	**Recommendations for this or all Lost to Service Clients**
Agency Follow Up Issue (6 responses)	
Patient never came her for medical services. Only for support services.	There should be a prompt in CHAMP to change the patient status.
Patient was not in care as NJCRI since 2000. We do not know the status of this patient.	There should be a prompt in CHAMP to change the patient status.
Sporadic contact in 2006 and 2007.	Better intake notes were needed.
Client appears to have been living at another agency.	Enhance collaboration between RW funded agencies.
Client received nutritional therapy in 2008 and at the time she was residing in an apartment. Client then was assisted with back rent in June 2008 in the amount of $ 1,380.00. Labs dated 5-6-2008 was the only medical documentation provided.	I believe that the case manager should conducted a home visit to find out why client didn't return to the agency because only one attempt was made with this client.

CLIENTS NOT IN MEDICAL CARE IN FY 2008 WHO DID NOT RETURN TO SERVICE	
Summary of Client's "Lost to Service" Status	**Recommendations for this or all Lost to Service Clients**
CM was able to contact client on 05/16/11. He stated he was out of town. Call and make new appointment.	CM will do follow up.
Client Non-Adherence/Noncompliance (14 responses)	
Letter was sent on 2/6/2009. Phone call made on 2/6 & 2/20 but mailbox full.	Unknown.
No response to follow up contacts. No evidence of change of address.	I feel that once a client has decided they are not going to adhere to treatment for whatever their reason it is essential that we have people who can physically go out and contact them...try to get them re-engaged into care. It is very easy to ignore a call or letter.
Client started the intake/reassessment process. An additional appointment was made to complete services and client never returned.	Client approached agency for rental assistance. When asked to supply the necessary documents to achieve the goal, client never returned.
Client was unemployed and needed housing assistance. Client admitted to neglecting medical care and sleeping in a hotel.	A follow up appointment was scheduled and client never returned to agency.
No client contact thereafter.	Client main concern was financially related
Patient was incarcerated until 2/2008 - released and re-registered at EIP, met with MCM but no show for medical visit. MCM follow up with patient and CM from Hyacinth. Multiple attempts to locate patient but no response.	This client needed stronger SAS and outreach services to locate him on the street
History of poor adherence. Would only come to EIP when in need of MCM services or new prescription. Did not respond to follow up attempts.	Active substance abuser. Refused all SAS services perhaps an outreach worker to locate clients lost to contact would help.
Client inactive in 2008, mental health services in 2007.	Client in denial about illness.
Several miss appointments and reschedules.	Client appears to have history of substance abuse.
Client had not been to clinic FY08 and lived in house.	When clients do not want to be bothered they know how not to be found.
Client began services on August 7th, 2006 and she received Mental health counseling twice in 2008 and 5 times in 2009. She was then discharged on March 3, 2009 because she moved to Peru. No medical information had been noted in the chart. Client was homeless in 2006.	No recommendations regarding this client.
There was no contact made with the client since 2006.	N/A
Client was first seen on 6/9/2008 for an initial intake, she then came in for a mental health assessment on 6/18/2008. Client then returned for her initial nutritional assessment on 6/28/2008 but after that date 4 letters were sent out to her home with no success. No information regarding her medical care had been documented.	I believe that continuity is key to keeping clients in care, my opinion of why clients don't remain in care are: Lack of medical transportation Lack of a support system Physicians, nurses and case managers not following up with patient after a missed

CLIENTS NOT IN MEDICAL CARE IN FY 2008 WHO DID NOT RETURN TO SERVICE	
Summary of Client's "Lost to Service" Status	**Recommendations for this or all Lost to Service Clients**
	appointment due to not having enough staff on board.
Client did not keep appointments.	More observation of clients' appointments.
Change in Circumstances - Not Recorded in CHAMP (4 responses)	
Patient Died - 3 (Not Documented in CHAMP)	
Client received all care and expired on 2/25/2005.	Client was not lost to services expired 2/25/2005.
Client came to BH on 8/2/2007 and expired on 8/9/2007. Client was very ill and only lived 7 days.	Expired within 7 days of admission.
Client passed away in 2008.	N. A.
Moved Outside of EMA - 1 (Not Documented in CHAMP)	
Client moved. Not lost to follow up.	There should be a prompt in CHAMP to change the patient status.
Other Service Issues (6 responses)	
As of 3/1/2008 EIP was no longer funded for supportive case mgt. Patient was referred to PROCEED and Home First for case mgt services.	Change in grant funding.
Originally patient only came to EIP for MCM services and was receiving primary health care from another MD. When RW contract changed patient decided to stay with his own MD.	Only lost due to change in RW standards.
The client's services was disconnected due to completion of services with corrections in January 2009.	N/A
Patient was accessing services through this agency for dental services only. Patient has private medical provider and declined need for any other services. Patient's last dental service was March 2009 when services were completed.	Patient was only being serviced for oral health issues. Services completed and patient declined need for other services offered through our facility.
Client did not wish to participate in case management.	Services for high functioning clients need to developed.
Client is homeless and makes poor decisions about activities. Outreach continues to re-engage in care.	

1.7 Provider Survey: Conclusions and Recommendations

1.7.1 Conclusions

The Planning Council and Grantee want to thank the agencies who participated in this survey for their time and effort involved in chart review. The information provided has been extremely useful in identifying the service challenges serving PLWHA in an urban area and indicating the extent of "met" need and unmet need in the EMA.

It is evident from agency responses that there is a lot of effort involved in patient follow up and case management and for a wide variety of patient circumstances and behaviors. Agencies are to be commented for these efforts.

Patients lost to service is a major health problem – because the longer a patient is out of care and not taking medications the worse their health is becoming. Also, they may become more resistant to certain ARVs which complicates medical care and increases costs and can result in poorer health outcomes.

Conclusions – Clients Lost and Returning to Service in FY 2010

- With respect to engagement in the Ryan White system, there appear to be **two distinct populations** – those receiving medical care who are also receiving core medical support services, and those not receiving medical care who receive minimal core medical services and support services.
- Even though the "more engaged" clients are receiving medical care and core medical services, they are plagued with **substance abuse and mental health issues which affect retention in care**.
- The "less engaged" clients receiving only support services tend to be more difficult to locate or follow up on.
- Transient lifestyles, homelessness, incarceration, frequent relocation in and out of the EMA, lack of support from family members or others, leads individuals to drop out of care. All of these factors have a direct impact on retention in care.
- Most clients return to the Ryan White program when circumstances change, when they need services, when they return to the EMA. There appears to be no pattern or trigger for return to care, and no particular efforts by agencies cause a return to care.
- A few clients leave for legitimate reasons – relocation to another state, discharged for hospice care – and the agency provides assistance. But these changes are not documented in CHAMP.
- The level of effort of agencies to reach clients and return them to care is unknown. Agencies have made attempts but if patients cannot be located the agency efforts are stonewalled. (The Newark EMA Ryan White Program has mandated that agencies demonstrate retention in care policies.)

Conclusions – Clients Lost Who Did NOT Return

- Many clients who dropped out of care had been compliant with regimens, but just stopped coming to appointments. Others had a change in living circumstances which made them stop coming to Ryan White. Others had a history of noncompliance and the agency just lost track of them.
- Nearly 30% of clients listed were incorrectly recorded as "lost to service" when they really had a change in circumstances and should have been discharged – due to death, relocation outside of EMA, no longer needed RW services. This is an agency management and CHAMP data entry issue.
    - A number of **clients had died (17 of the 142 or 12%** of clients whom agencies commented on in Table 16). This information was not recorded in CHAMP.
- Agencies were unable to determine why clients did not keep appointments, and recommended outreach to assist in follow up.
- Most of the clients lost to service who did not return had participated in Ryan White for some time or had begun such participation but just stopped.

Reasons for "Lost to Service"

The "Lost to Service" problem is not as great as indicated by CHAMP data. Many clients are not lost to service at all – agencies simply have not updated CHAMP. This administrative problem must be fixed so that the EMA can focus on efforts to reach those who have really dropped out.

There are three main reasons for clients showing up as "lost to service": (1) agency did not follow up on the client (25%), (2) client behavior and noncompliance (25%), and (3) the agency did not update CHAMP with change in client status and other information (28%).

A fourth reason - clients identified as "not lost to service" (12%) – were confirmed not to be receiving any Part A or MAI as recorded in CHAMP during FY 2009. Most had been receiving medical care or services from another funding source not recorded on CHAMP. Others had died or had relocated outside the EMA or other reason qualifying as CHAMP "discharge".

A fifth reason - other service issues (9%) - cannot be categorized in the above groups and are legitimate, unique or one-time issues.

Table 17: Summary of Reasons for Lost to Service from Agency Chart Reviews

	Returned		No Return		Total	
	#	%	#	%	#	%
Agency Follow Up Issues	17	20%	41	29%	58	25%
Client Non-adherence/Noncompliance	20	23%	38	27%	58	25%
Change in Circumstances – Not in CHAMP	21	24%	42	30%	63	28%
Other Service Issues	9	10%	12	8%	21	9%
Not Lost to Service (Medical care elsewhere)*	19	22%	9	6%	28	12%
Total	**86**	**100%**	**142**	**100%**	**228**	**100%**

* Not Part A or MAI. Not recorded in CHAMP

Summary of FY 2008 Clients and Overall Status

After all of this work, Table 18 below shows the disposition of the total FY 2008 Part A clients. This includes PLWHA who received and did not receive Part A services in FY 2009, and, of those who did not receive services in FY 2009, findings from both CHAMP data and provider surveys. These percentages can be used for future planning for corrective action, retention in care activities, and for benchmarks regarding PLWHA whose behavior is outside of agency control.

Table 18: Summary of FY 2008 Clients, Status and Disposition

	# Clients	%
Total Part A Clients in FY 2008	**6,541**	**100.0%**
Active – Received Services in FY 2009	**4,835**	**73.9%**
Did Not Receive Services in FY 2009	**1,706**	**26.1%**
CHAMP Client Status as of 2/28/09 End of FY 2008		
Discharged	109	1.7%
Suspended No Contact	554	8.5%
"Active" in FY 2008	**1,043**	**15.9%**
Change in Circumstances – Not recorded in CHAMP*	288	4.4%
Agency Follow Up Issues*	265	4.1%
Client Non-adherence/Noncompliance**	**265**	**4.1%**
Other Service Issues*	96	1.5%
Not Lost to Service (Medical care elsewhere)***	129	1.9%

*Percent is estimated based on 2011 Needs Assessment Results

**** These are true "drop outs" – clients who stopped coming to Ryan White and need follow up for Retention Care Initiatives**

*** Providers reported that clients were not lost to follow up and had received services in FY 2009, but services were not recorded in CHAMP. This is likely due to a non-Part A funding source for medical care and other services.

1.7.2 Recommendations

The HRSA HAB Core Clinical Performance Measures and National HIV/AIDS Strategy are shifting focus toward access to and retention in care. This is an extension of Early Identification of Individuals with HIV/AIDS (EIIHA). The EMA should focus on measuring and improving retention in care consistent with these national HIV/AIDS policies.

There are three recommendations. The first two can be accomplished by agencies themselves just by doing what their Ryan White contract requires. The third recommendation involves more planning and coordination throughout the EMA.

#1 Agencies must improve documentation of patient status in CHAMP Client Level Data (CLD) system. Accurate CHAMP documentation will immediately reduce BY ONE THIRD the number of clients incorrectly reported as "lost to services."

Since 2006, HRSA HAB has mandated all Ryan White programs, grantees and providers to maintain a client level data (CLD) system. **CHAMP is the federally-mandated Client Level Data (CLD) system for Ryan White in the Newark EMA.** Agencies must maintain and update CLD because the federal funder requires it and it is a contractual requirement for funding from Newark and Union County.

- Agencies must adhere to the grantee requirement to enter data into CHAMP within 5 days of service delivery.
- Agencies must update CHAMP every time there is a change in ANY client circumstances – especially residence, living arrangement, health insurance, and status ("discharged").

  Agencies could perform a routine review of patient charts or revise their CHAMP checklist indicating a change in circumstances. (For example, it is not known where agencies got information about clients who died, but it appears that this information was in the patient chart. It should have been put into CHAMP for accuracy of client level data and discharging the agencies of further responsibility on that client.)
- RWU and UC monitors must enforce the CHAMP data entry requirement aggressively.
- RWU & UC must enforce the requirement that agency staff attend update training on CHAMP annually. This must be a contractual requirement for **all staff involved in Ryan White not just data entry staff.** (CHAMP training is available every Wednesday at FutureBridge offices from 11am to 2pm and can be scheduled on other days if needed.)
- The grantee should consider imposing a penalty for delayed data entry, e.g., delayed reimbursement, for agencies who fail to enter CHAMP CLD data timely.
- CHAMP can consider incorporating a "reminder" mechanism to notify agencies to contact the client after a certain time period of no contact, e.g., 6 months. This could be a CHAMP notice, reminder "flag", an exception report or other tickler notice. The problem is that the person opening up CHAMP often ignores these online notices. An exception report and RWU + UC follow up might be more effective. The **NEMA CHAMP Committee** can explore the best methods and make recommendations.

- CHAMP should explore ways to indicate that client is in medical care elsewhere. The Medical Case Management screen requires clients receiving MCM services to be updated every six months with information on medical visit, consistent with HRSA HAB Core Clinical Performance Measures for Medical Case Management. This entry should be enforced. The **NEMA CHAMP Committee** can explore the best methods and make recommendations.

#2 Agencies should review, update and enforce their own retention in care policies. These policies are mandated in the annual Ryan White contract. This would help agencies identify more changes in circumstances which could be recorded in CHAMP, and so that the client would not be "lost to service" and could be discharged appropriately.

- RW and UC monitors must ensure that these policies are current and being practiced.

#3 Retention In Care Initiatives. Retention in care – **"In + Care"** is the next national HIV/AIDS Quality Management initiative. Here is where agency efforts are focused on reaching those who have truly dropped out of service, to re-engage them where possible.

- The Council, Grantee and all agencies must make a commitment to improving retention in care, reducing the incidence of lost to service and taking appropriate action.
- Retention in Care should be a goal of the Newark EMA 2012 Comprehensive Health Plan (CHP) with objectives and activities for the Council, each committee and the Grantee. This will ensure that the EMA CHP comports with the National HIV/AIDS Strategy.
- The Council may consider a separate Retention in Care workgroup – or coordination of several committees such as Continuum of Care (COC) and Community Services Advisory Committee (CSAC) – to address this cross-cutting issue.
- The EMA should research, develop and pilot-test cost-effective models of outreach and patient follow up. Models should be available from the National Quality Center (NQC) and other sources.

  (it is noted that previous outreach services in the EMA were very costly and did not produce desired results of reaching clients and returning them into care. Newer models may overcome this barrier.)
- The EMA's providers should identify successful models or best practices that they have been used to improve retention and implement them.
- We should work with national and statewide retention in care initiatives, such as the New Jersey Cross Part Collaborative committee, to identify usable best practices.
- There may be a variety of best practices depending upon the subpopulation of PLWHA, demographics, geography, resources, etc. To support "In+Care", Council staff could develop an initial inventory of best practices that are feasible for the EMA with ongoing updates.
- It is recognized that, despite best practices and agency efforts - there is a population of clients who will not remain in care or in Ryan White due to lifestyles – transience, substance use, instability, lack of family and/or social support. This was evident in agency responses in Table 12 and Table 16. We should indentify this population as best as we can. The EMA goal should be to reduce this population to a minimum – similar to unmet need.

Part 2: Youth

2.1 Introduction

Background. The Council and community members identified youth as a priority population for early identification and entry into HIV-related services. Youth, particularly those who engage in risky sexual and other behaviors, should be tested for HIV, and for those who are diagnosed HIV+, that they start medical care as soon as possible.

Research Question #2. The research question to be addressed is:

> **Regarding Youth (13 –30) study how long a period elapses between diagnosis and entry into care; is there an increase in the infection rate among members of the minority MSM and Transgender community in NEMA?**

Specific services include:

- **Data Collection and Analysis.** Obtain CHAMP data for FY 2010 and prior years on youth age 13-30, specifically their year of diagnosis and when they started Part A/F services and Part A/F medical care. Compare to HIV Surveillance data from NJDHSS to determine coverage.
  - Request data from NJDHSS/DHAS on HIV testing regarding MSM of color.
  - Request information from NJ HIV Planning Group on testing, HIV incidence and prevalence, and other relevant data. Try to get data specific to Newark EMA.
- **Report.** Prepare report of findings to determine gap between testing and entry into medical care, percent in Part A/F medical care and other relevant data. Identify any significant items needing further review.
- **Research.** Determine additional information to be obtained about HIV+ youth and entry into and retention in medical care. Include MSM of color, especially those in houses (transgender), use of social media, providers serving this population such as African American Office of Gay Concerns (AAOGC), access to planned events. This component will be ongoing subject to further review by the REC, CSAC and Council.
- **Report.** Prepare a report of findings with relevant recommendations, including improving access to and entry into care where needed and use of other mechanisms to reach youth and bring them into medical care.

2.2 Length of Time between HIV Diagnosis and Entry into Medical Care

Data on the length of time between HIV diagnosis and entry into medical care is obtained from CHAMP for medical care funded by Ryan White Part A and Part F. Data are for new clients only, that is, clients new to the CHAMP system who have never received Part A or F before in the Newark EMA. "Year of HIV

Diagnosis" is a required field in CHAMP. For the 2011 Needs Assessment, the length of time between HIV diagnosis and date the first Part A/F medical care service was computed based on the midpoint of the year of HIV diagnosis.

For purposes of the *2011 Needs Assessment*, the definition of "youth" was expanded from the standard age 13 to 24 to age 13 to 30 years old. The reason is that in the experience of medical providers, this "20 something" category identifies more with younger individuals than the older individuals over age 30. Data on the standard youth population age 13-24 are included where relevant.

2.2.1 Findings – Total Clients and Youth

For FY 2010, a total of 576 "new" Part A and F clients had never received Ryan White before in the Newark EMA. Of these, 26% or 149 were youth age 13 through 30 years old. Only 11% or 64 were age 13 through 24.

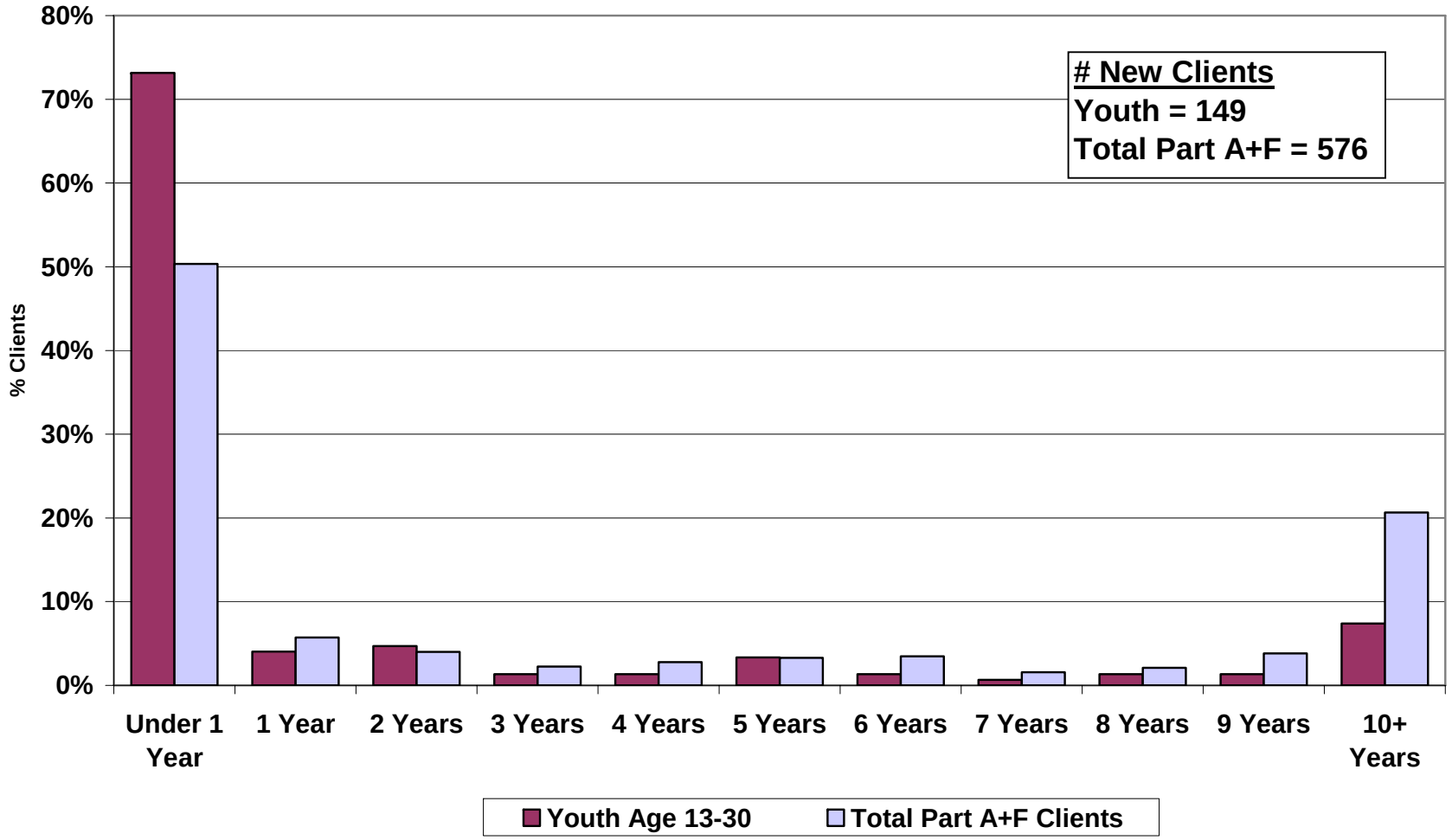
Among youth (age 13-30) the vast majority – **73% or 109 individuals** - entered Part A or F medical care within one year of diagnosis. This is much higher than the total new Part A/F clients* – 50% or 290 – who entered care within one year of diagnosis. The percent was also high for youth age 13-24, where 69% or 44 entered medical care within a year of diagnosis. See Table 19 and Figure 1.

Table 19: Length of Time Between HIV Diagnosis and Part A/F Medical Care for New Clients – Youth and Total

Years from Diagnosis to Medical Care	Age 13-30		Age 13-24		Total New Clients	
	#	% Distn	#	% Distn	#	% Distn
Under 1 Year	109	73.2%	44	68.8%	290	50.3%
1 Year	6	4.0%	5	7.8%	33	5.7%
2 Years	7	4.7%	3	4.7%	23	4.0%
3 Years	2	1.3%	1	1.6%	13	2.3%
4 Years	2	1.3%	0	0.0%	16	2.8%
5 Years	5	3.4%	0	0.0%	19	3.3%
6 Years	2	1.3%	2	3.1%	20	3.5%
7 Years	1	0.7%	0	0.0%	9	1.6%
8 Years	2	1.3%	1	1.6%	12	2.1%
9 Years	2	1.3%	1	1.6%	22	3.8%
10+ Years	11	7.4%	7	10.9%	119	20.7%
Total	**149**	**100.0%**	**64**	**100.0%**	**576**	**100.0%**

* The number of new Part A and F and new Part A clients is not that much different. In FY 2010, there were 788 (12%) new Part A clients and 562 new Part A medical clients, and 807 (12%) new Part A+F clients and 576 new Part A+F medical clients. For both, 71% of new clients received Ryan White medical care services.

Figure 5: Length of Time between HIV Diagnosis and Start of Medical Care FY 2010
New Clients – Total and Youth (Age 13-30)



2.3 HIV Infection Among MSM and Youth

To assess the extent of the HIV infection rate among MSM in the Newark EMA, the Council requested HIV surveillance data from the NJDHSS DHAS. Data included (1) newly diagnosed MSM in the Newark EMA over the past 10 years, and (2) Men aged 13-29 at diagnosis by exposure category and race/ethnicity, and (3) MSM (age 13+ at 12/31/2010) excluding MSM+IDU living with HIV/AIDS.

NJDHSS provided data for the **entire state of New Jersey and not just the Newark EMA.** The request for EMA-specific data was resubmitted to NJDHSS. Pending receipt of data specifically for the Newark EMA, we have completed analysis of the statewide data.

Trends. The number of youth age 13-29 diagnosed with HIV increased by 28% from 1999-2008. The number and percent of newly-diagnosed HIV+ youth who indicate exposure by men who have sex with men (MSM) has increased from 107 and 48% of total youth in 1999 to 180 and 64% in 2008. See Table 20 and Figure 7.

New HIV diagnoses (2006-2008) among youth were primarily due to MSM (61%). Less than one quarter were due to heterosexual contact, and only 3% were due to injection drug use (IDU). See Figure 6.

Table 20: MSM Among Newly Diagnosed NJ Youth 1999-2008

Year	MSM	Total
1999	107	221
2000	111	243
2001	118	236
2002	86	188
2003	131	237
2004	147	264
2005	138	261
2006	154	264
2007	153	252
2008	180	283

Figure 6: New HIV Diagnoses Among NJ Youth 2006-2008 by Exposure Category

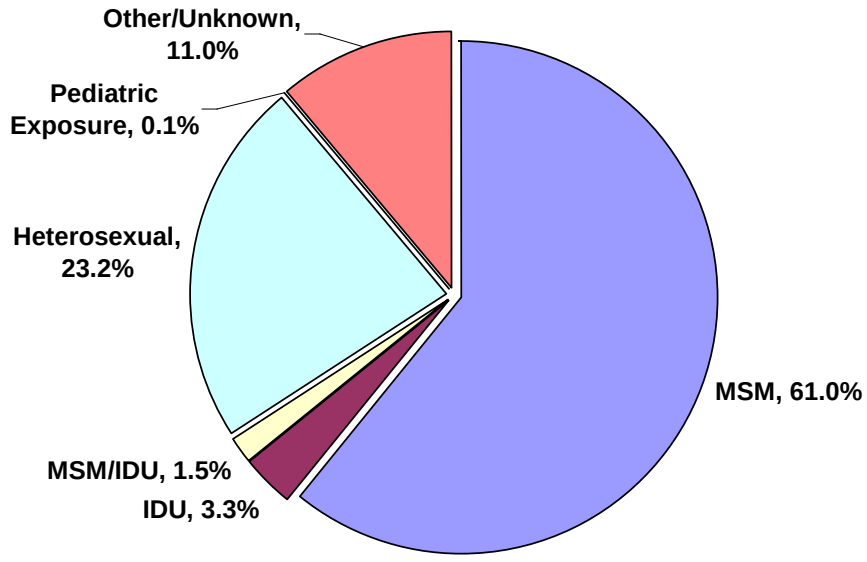
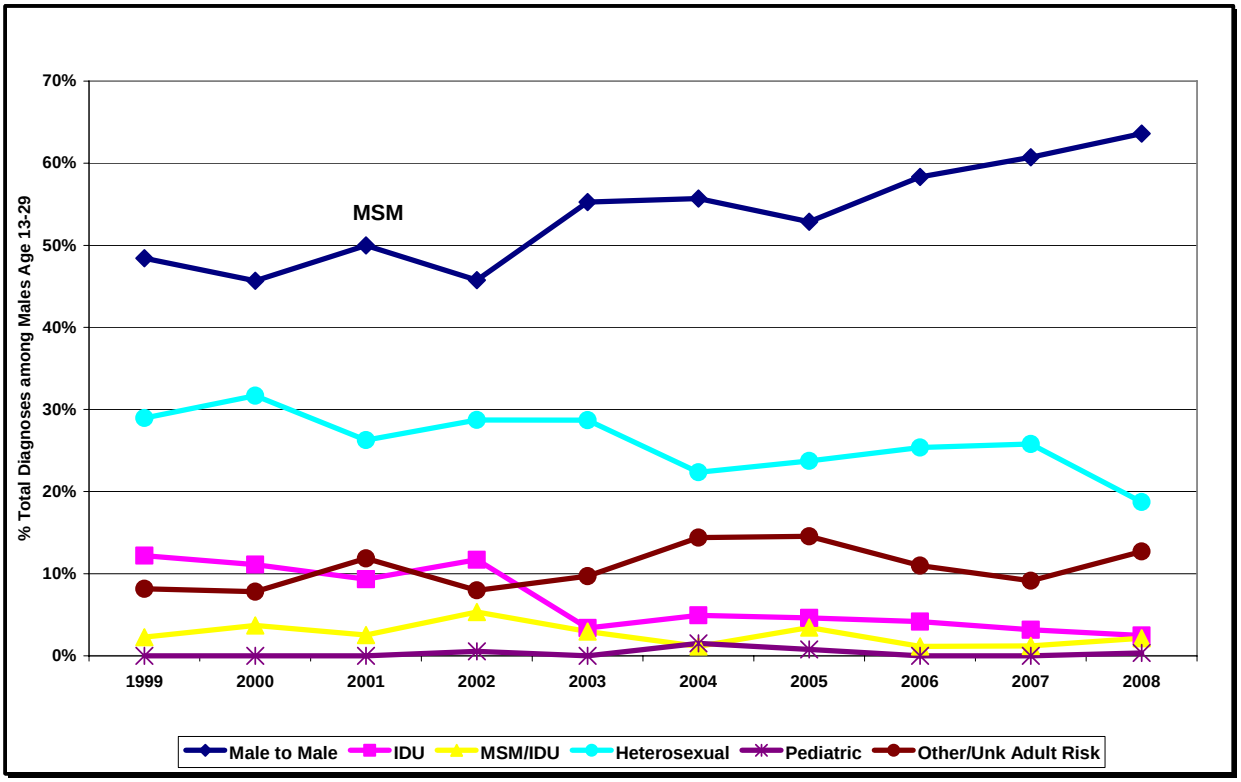


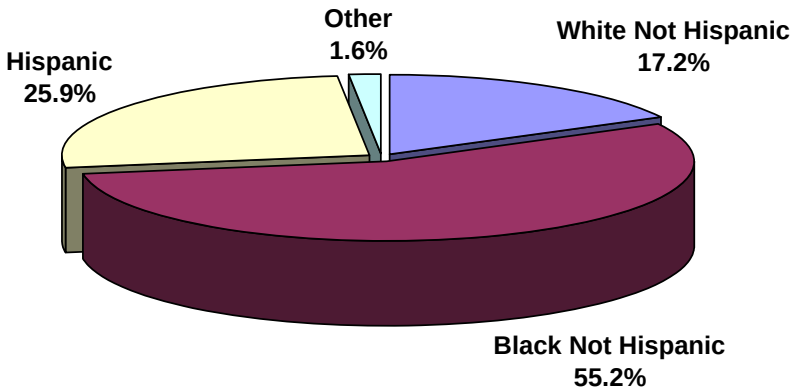
Figure 7: Trends in HIV Diagnoses Among Youth Age 13-29 in New Jersey by Exposure Category – 1999-2008



Race/Ethnicity of Newly Diagnosed MSM Age 13-29.

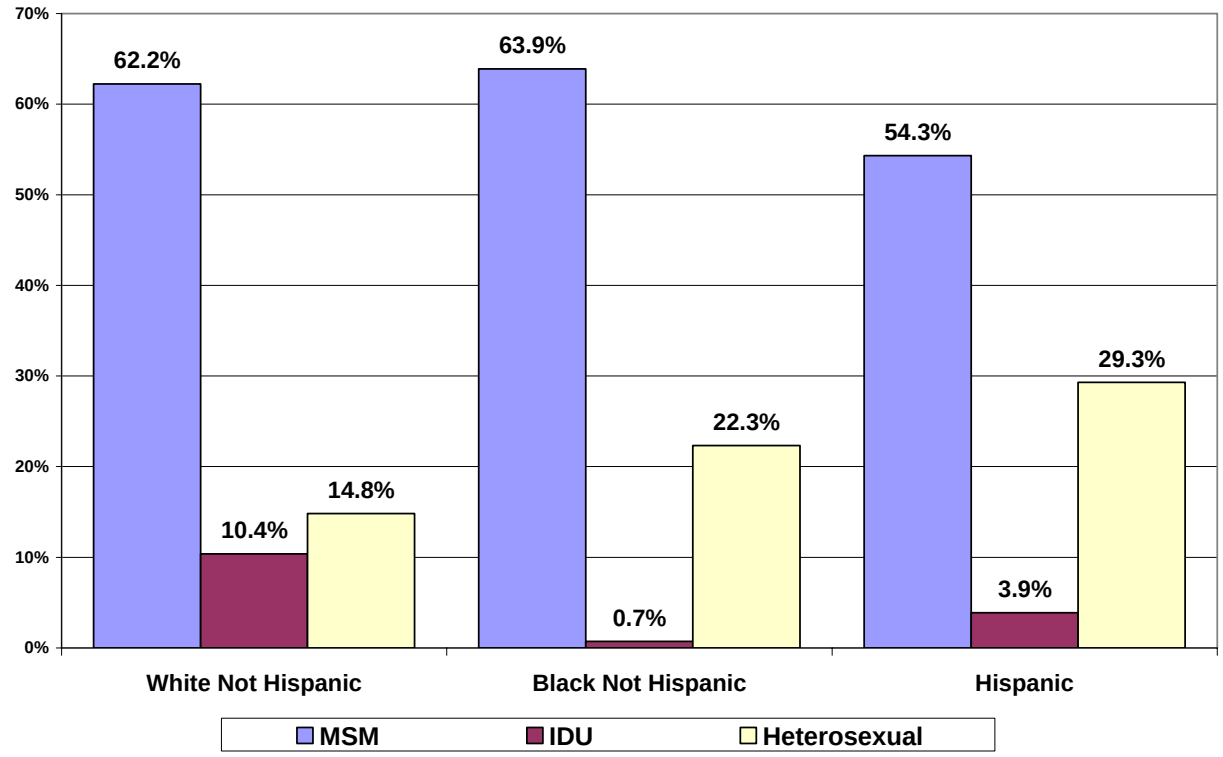
Among 487 MSM age 13-29 newly diagnosed from 2006-2008 in New Jersey, more than half (269) were African American and 126 were Hispanic/Latino. In other words, **81% of newly diagnosed MSM were racial/ethnic minority.**

Only 84 were White (not Hispanic) and eight were other race/ethnicity.



MSM is by far the leading HIV exposure category among all race/ethnicities at 54% of Hispanic/Latino youth, 62% of white youth, and 64% of African American youth. See Figure 8.

Figure 8: Newly Diagnosed Youth 2006-2008 in New Jersey by Leading Exposure Category within Race/Ethnicity



Age of MSM PLWHA in New Jersey by Race/Ethnicity.

As of December 31, 2010, there were 7,679 PLWHA in New Jersey age 13 and older with MSM exposure category. This is **22%** of 35,582 total PLWHA in New Jersey age 13 and older. (There are 35,688 total PLWHA in New Jersey as of 12/31/10.)

By Race/ethnicity, however, there are differences. Nearly one half (46%) of White MSM are age 50 and older, and 40% are age 40-49 – in other words, the vast majority (86%) are age 40 and older.

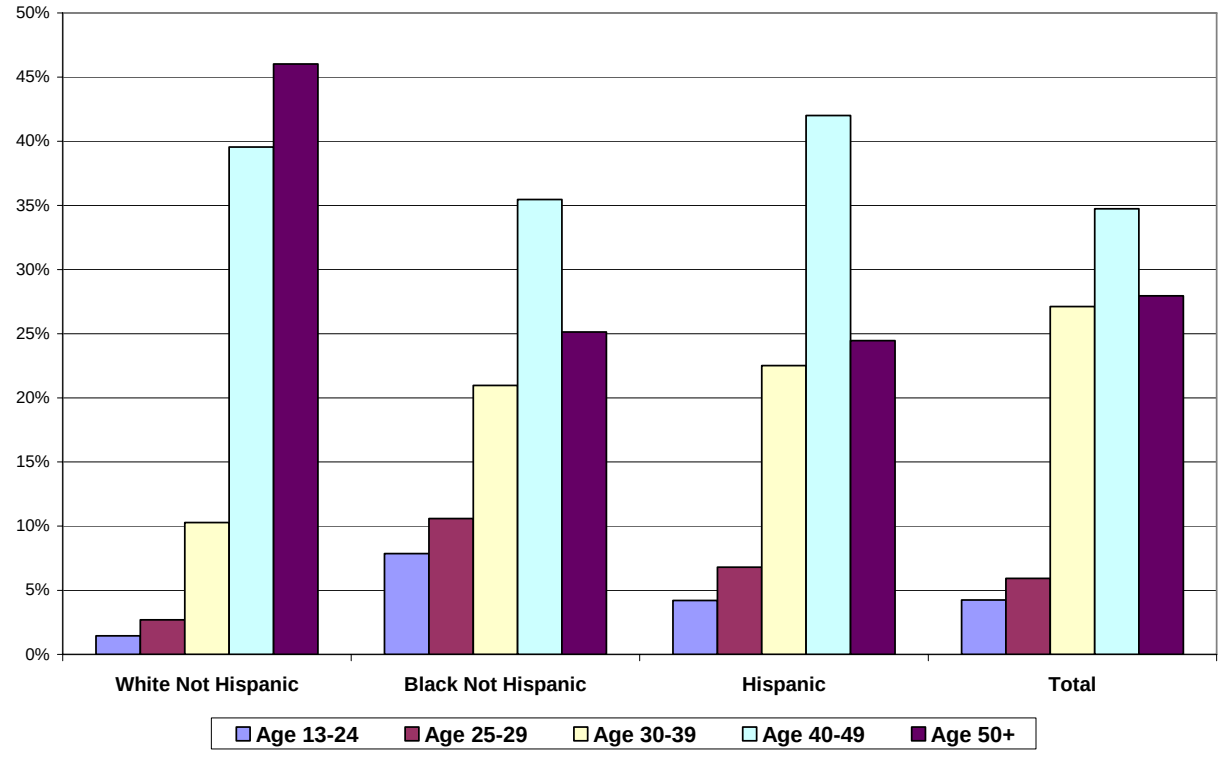
In contrast, the HIV epidemic among African American MSM is much younger. Most MSM are age 40-49 (36%) with only one quarter age 50+ and 21% age 30-39 and 11% age 20-29.

The HIV epidemic among Hispanic/Latino MSM is slightly older and between Whites and African Americans. 42% are age 40-49 and 24% are age 50 and older – with two thirds over age 40. But the same percentage (23%) is age 30-39 and 7% are age 20-29. There is a younger component to HIV among Hispanic/Latino MSM. See Table 21 and Figure 9.

Table 21: MSM Age 13+ Living with HIV/AIDS as of December 31, 2010 in New Jersey.

	White Not Hispanic	Black Not Hispanic	Hispanic	Other	Total
Age 13-24	43	219	76	5	343
Age 25-29	80	295	123	7	505
Age 30-39	305	584	407	32	1,328
Age 40-49	1,174	988	759	41	2,962
Age 50+	1,366	700	442	33	2,541
Total	**2,968**	**2,786**	**1,807**	**118**	**7,679**

Figure 9: Age within Race/Ethnicity of MSM Age 13+ Living with HIV/AIDS in New Jersey as of December 31, 2010



2.4 Youth Surveys and Focus Groups

During the Needs Assessment deliberations, it was agreed that the Needs assessment should include a survey of youth. To capture the most information, we decided to use both focus groups and a survey (online survey of anonymous youth using Survey Monkey). The survey tool and focus group guide are in Appendix B.

2.4.1 Characteristics of Youth Participating in the Survey and Focus Groups

A total of 39 youth answered the online survey. Of those responding:

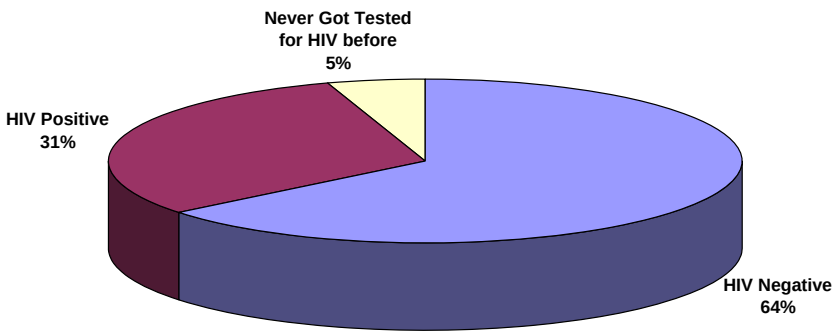
- **Gender:** 22 (56%) were male, 11 (28%) female, 5 (13%) transgendered (male to female), and one (3%) was intersex.
- **Sexual identification:** 16 (41%) were MSM (Man who has sex with men), 11 (28%) straight/ heterosexual, 6 (15%) bisexual, 4 (10%) Gay, one (3%) lesbian, and one (3%) questioning.
- **Age:** Age range was 16 to 29 with the median age of 23 and average age of 24.
- **Race/ethnicity:** 26 (67%) were African American, 10 (26%) were Hispanic/Latino, 2 (5%) were White (Not Hispanic), and one (3%) was American Indian/Alaskan Native.
    - **Hispanic origin:** 3 (8%) were from Puerto Rico, 2 (5%) Dominican Republic, one (3%) each from Honduras and Nicaragua, and 3 (8%) did not respond.
- **County of Residence:** 28 (72%) live in Essex County, 4 (10%) Union County, one (3%) in Morris County, and 6 (15%) from outside of the EMA including Hudson (3 or 8%), one from Somerset (3%), one from Bergen (3%) and one from New York State (3%).
    - Based on zip code, the majority of respondents live in Newark (20 or 51%) or East Orange (8 or 21%).

Most of these individuals also participated in the focus groups. So the demographics of focus group participants are roughly the same as those in the online survey.

2.4.2 HIV Status of Youth Participating in the Survey and Focus Groups

Of the 39 youth, 25 (64%) were HIV Negative, **12 or 31% were HIV Positive,** and two or 5% never got tested for HIV before.

The rest of this study will show results for HIV+ and HIV- individuals.



2.4.3 Profile of HIV Positive Youth Participating in Survey/Focus Groups

Demographics of the 12 HIV+ youth are as follows.

- **Gender:** 11 (92%) were male, 1 (9%) female.
- **Sexual identification:** 7 (58%) were MSM (Man who has sex with men), 3 (25%) bisexual, 1 (8%) straight/heterosexual, 1 (8%) Gay.
- **Age:** Age range was 21 to 29 with the median age of 27 and average age of 26.
- **Race/ethnicity:** 7 (58%) were African American, 4 (33%) were Hispanic/Latino, 1 (8%) was White (Not Hispanic).
    - **Hispanic origin:** One each (8%) were from Puerto Rico, Honduras and Nicaragua, and one (8%) did not respond.
- **County of Residence:** 8 (67%) live in Essex County, one (8%) in Morris County, and 3 (25%) from outside of the EMA including one each from Hudson, Somerset, and Bergen.
    - Based on zip code, the majority of respondents live in Newark (7 or 62%) with one in East Orange (8%).

HIV Diagnosis.

- **When Diagnosed with HIV.** 25% of respondents were diagnosed with HIV within the past year, 1-2 years ago, 3-4 Years ago, and 5 or more years ago.
- **Age at Diagnosis.** Age at diagnosis ranged from 17 to 28 years old. The average age at diagnosis was 23.8 years old and median age was 24 years old.
- **Where tested and diagnosed with HIV.** Most (8 or 67%) were diagnosed at a clinic and two (17%) were diagnosed at a hospital. Two (17%) did not respond.
- **Reason for HIV test.** One third (4) were not practicing safe sex and were concerned, 33% (4) got an HIV test when tested for other STD's, 33% (4) felt sick, 17% (2) got tested because their friend/partner was HIV+, and one (8%) got tested when the doctor offered them an HIV test.

Medical care for HIV

- **Medical care for HIV.** All 12 (100%) receive medical care for their HIV.
- **Characteristics of medical care.**
    - Nearly all 11 or (92%) reported that **medical care for HIV was easy to get.** However, one person had been concerned about accessing medical care because of **lack of health insurance.**
    - **Location of medical care.** Seven (58%) receive medical care in the same area where they live, and four (33%) receive medical care in another state/county/city from where they live. One did not respond. One person who receives medical care in the county of residence had been concerned because of **confidentiality and stigma.**

Other Services Needed

- **Nearly all – 11 or 92% - reported that they needed other services in addition to HIV medical care.** The service most needed is housing, followed by Dental Care and legal services.

Figure 10: Youth Survey – Services Needed in Addition to HIV Medical Care

Service	#	100%	
Housing	7		64%
Dental Care	6		55%
Legal Services	6		55%
Financial Assistance	5		45%
Food	4		36%
Mental Health Counseling/Treatment	2		18%
Substance Use Counseling/Treatment	2		18%
Support from HIV+ Peers	2		18%
Case Management	1		9%
Support from Friends	1		9%

HIV Medications

- Nearly all (11 or 92%) respondents take HIV medications for their HIV disease. The physician did not prescribe HIV medications for one individual.
- More than half (6 or 55%) reported that their meds were easy to take. With respect to the experience of taking HIV meds:
  - Three (27%) said that they sometimes forget to take their meds.
  - One (9%) did not like the regimen that the physician gave me.
  - Two (18%) did not like how the meds made them feel. And one of them did not like the side effects.
  - Two (18%) said they felt OK.

Other comments and recommendations. Three individuals provided the following comments on other aspects of their HIV disease.

> "Awareness of status is necessary for best/healthy changes of living."
>
> "See doctor, talk to someone."
>
> "I'm just lazy and don't follow my good doctor recommendations."

2.4.4 Perceived Barriers to HIV Care

Nine (75%) of the 12 HIV+ youth felt that there were barriers to HIV care. They are listed in descending order. The chief barrier to HIV care was **fear that their family would find out.**

Afraid family will find out	8	89%
No health insurance	7	78%
Afraid of family reaction	5	56%
If I ignore it, it will go away	4	44%
Stigma of HIV	4	44%
Do not know where to go	2	22%

2.4.5 Perceived Increased Risk of HIV Among Youth

Respondents regardless of HIV infection, the majority of respondents (62%) felt that there was an increase in risk of HIV transmission among their peers (youth). 75% of HIV+ youth felt that there was increased risk for HIV.

Table 22: Do you feel/believe that there is an increase in risk of HIV transmission among your peers?

	HIV Positive	HIV Negative	Never Tested	Total	HIV Positive	HIV Negative	Never Tested	Total
No	3	1	1	5	25%	4%	50%	13%
Yes	**9**	**14**	**1**	**24**	**75%**	**56%**	**50%**	**62%**
No Response	0	10	0	10	0%	40%	0%	26%
Total	12	25	2	39	100%	100%	100%	100%

The main reason for increase risk is that **they do not practice safer sex (21 or 54%)**, followed by:

- They do not feel they are at risk for HIV (14 or 36%)
- They do not know risks of HIV (10 or 26%)
- They are not afraid because you will not die from HIV (6 or 15%).
- They are unafraid because HIV can be cured with a pill (6 or 15%).
- Other: We are a minority which struggles and sex work is very common among us (1 or 3%).

2.4.6 Recommendations on How to Reach Youth – HIV+ and in General

There were two open-ended questions and respondents gave a range of answers.

Do you have any recommendations for how to reach young people who are HIV positive?

Outreach
Do more outreach.
Community outreach.
Functions, outreach at gay clubs.
The village, balls, clinics, bathhouses, sex theatres.
Flash Mobs
Go to the stroll
Create a facebook or some type of social networking site.
Education
Promoting awareness is the best outreach for young people
Be truthful and honest.
Reinforce that they are at risk for contracting HIV and other STI's.
Schools the age for sexual health classes must be brought down there are kids as young as 11 experimenting already and the parents are not telling them what they need to hear.
Keep talking.
Prevention and Testing
I recommend more activities encouraging youth to participate in groups.
Always get checked
No, I guess give them condoms. I take care of my health as should everyone else.
After HIV Diagnosis
I would let them know how important it is to get cured.
More encouragement of understanding that HIV is not a death sentence, it doesn't make you any less of a human being, and it doesn't change who you are as an individual.
I would say that were all human and humans make mistakes.
Letting them know that even though they're HIV positive, that their lives aren't over, & they can still take control of their sex lives & health.
Keep using medications and just continue to live your life. Don't let this disease affect or bother you.
Yes, give out money and food.

Do you have any recommendations for how to reach young people that do not know their HIV status?

Outreach
The village, balls, clinics, bathhouses, sex theatres
Ask at schools.
Flash mobs.

Go to the stroll.
Media, talking to high school students, community house balls, clubs where young people hang out.
Education
Advertise getting tested.
Promoting awareness would be the best way to reach those who may be unaware of the HIV/STD status
Talk about safe sex of how to prevent it.
Schools the age for sexual health classes must be brought down there are kids as young as 11 experimenting already and the parents are not telling them what they need to hear.
More education.
Keep talking.
No, young people think HIV is something bad. I don't like to talk about it.
Prevention
Take their medicine and use condoms.
Protect yourself at all times, and mainly just have safer sex.
Testing
Get checked out.
Get tested.
Encourage everyone to get tested.
Get Tested. It is better to know.
Other
Give them more gifts.
Yes give out money and food.
Not really other then youth programs.

2.4.7 Youth Focus Group Results

Three focus groups were held among youth (age 13 to 29) to obtain more first hand information regarding their experiences with the health care system in the Newark EMA. We sought input in terms of satisfaction/dissatisfaction with their encounters with the system and their views on what would improve the system and make it a positive and desirable source of health care for them.

The initial group was held on June 9, 2011 at Project WOW! Youth Center to test the focus group discussion guide and introduce the online survey. Results were not summarized. On June 23, 2011 a second group was held at La Casa de Don Pedro comprised of youth age 14-18, male and female, Hispanic/Latino and African American. A third group comprised of transgender youth was held on July 7, 2011 at African American Office of Gay Concerns (AAOGC).

The youth felt more comfortable discussing their personal experiences with peers than with an adult. There were group dynamics and group leaders. However, once they started talking about their experiences, we learned the following.

Experiences with medical care. Some of their experiences with medical care were not too positive.

Complaints included:

- Long waits to be seen by a doctor, even when they had an appointment,
- Arriving at a medical facility and discovering that several people had been given the same appointment time,
- Feeling that they were not treated with respect by office personal,
- Doctors were sometimes lacking in compassion when dealing with a sensitive subject or possibly embarrassing procedure with a patient, and
- Impersonal or brusque experience frequently.
- Health related concerns about sitting in waiting rooms with others who might have communicable health issues, such as colds and flu.
- Transgender youth indicated the need for medical forms to indicate gender identity, and for medical providers to ask how clients wished to be addressed publicly for fear of possible violence resulting from being addressed as the opposite gender from that in which they appeared.

Response to perceived brusque treatment:

- Some participants stated that when they felt they were being treated with disrespect, they returned the same behavior. Although this sometimes escalated the situation, they felt better, having vented their frustration at being treated in such a manner.

Positive experiences:

- One participant stated that his medical visits always went well, because he was always clear in his communication with medical and office personnel regarding his particular health issue, and what he needed assistance with.

Recommendations regarding medical care.

- Would like to be welcomed on coming to a doctor's office or clinic - since they already felt sick and uncomfortable before going, a welcoming face and comforting manner would assist them to feel better while they waited to be seen by the doctor.
- Would like to be given some explanation or warning before, for example, being asked to disrobe for an examination, to feel more at ease with the process.
- A thirty minute wait upon arriving for an appointment with a doctor was acceptable. If times are longer, they asked to be kept courteously informed about the status of wait time.
- More pleasant offices would make the experience better, including youth-related materials.
- Air filtration devices and hand sanitation devices to prevent spread of communicable diseases in small waiting rooms.
- The importance of medical personnel being trained to treat transgender clients was underlined.
- Hormone treatments which are a medical necessity for the transgendered patient and not a cosmetic procedure should be universally covered by health insurers. This is not the case for all insurers. Treatments should be covered by Medicaid/Medicare.

Knowledge of HIV disease. All had taken part in a class on HIV/AIDS, and appeared to be aware of basic issues and practices about prevention. They knew that HIV infection is on the rise among youth of color, and knew how the virus was spread including sharing contaminated needles from IV drug use.

Prevention practices. One reason discussed for not using a condom and/or not negotiating safer sex practices as a means of prevention, was the difficulty posed by wanting to please, or being intimidated

by a partner and afraid of losing them.

Education and reaching youth about HIV. Attempts to reach and communicate with youth should be interesting, and done verbally or through some sort of media presentation, such as focused skits. Youth would more likely read brochures accompanying the presentations if they were clear and concise.

One of their final statements was that the priority should be on the person and their treatment, instead of how it was going to be paid for.

2.5 Conclusions and Recommendations Regarding Youth

2.5.1 Conclusions

- Youth are aware of the risks of HIV among their peers. Their recommendations include the need to continue and intensify education regarding HIV and Sexually Transmitted Diseases (STD's).
- Although youth age 18 and older are considered adults, they are still transitioning into adulthood. As a result, they fear disappointing or losing their friends or sexual partners and so do not practice safe sex. Also, they do not know about the health system or how to negotiate it. They respond to perceived disrespectful or rude behavior of providers in-kind – they "give it back". (Provider behavior may in fact be rude or may be typically brusque behavior.) They need someone to take time to explain what to expect at medical providers, what services are available, how to behave, what questions to ask, etc.
- Gender identification of transgender youth, how they are addressed and treated by medical personnel are issues to be considered.

2.5.2 Recommendations

- Continue funding youth-specific HIV medical care services and other core medical and support services.
- Educate providers on being sensitive to youth as patients and clients – the needs of youth in understanding their HIV, other sexually transmitted infections, medical care and other care.
- Continue to educate youth about risks of HIV and STD's and the need to practice safer sex. Educate and empower youth to insist on safer sex with partners.
- Ensure that the Part A system of care for medical, core medical and support services are readily available and accessible to HIV+ youth and consider their needs, including those of transgender youth.

Part 3: Mental Health

3.1 Introduction

In the Newark EMA *Needs Assessment – Update 2010*, the Council reviewed the prevalence of mental health and substance abuse problems among PLWHA using a number of research methods and tools, including the SAMHSA Substance Abuse and Mental Illness Symptoms Screener (SAMISS). In FY 2010 CHAMP implemented new subtypes for the service category of Mental Health (MH) Services as recommended by the Planning Council and its committees - Continuum of Care (COC) and Research and Evaluation (REC) among others – to better match Part A/F MH services to the current state of MH therapies. These service categories are consistent with those of the NJ state mental health agency – New Jersey Department of Human Services, Division of Mental Health Services – and practicing MH providers.

This component of the 2011 Needs Assessment is the next step to the 2010 Update – assessing whether these mental health services are sufficient for the Part A/F population and identifying service gaps and additional needs

Research Question #3. The research question to be addressed is:

> **What levels of Mental Health services are provided by Ryan White Part A/F according to the revised service subtypes implemented in FY 2010 based on CHAMP service utilization data; what is the level of referrals outside Ryan White; is there a waiting list for care?**

The scope of this section included the following:

- **Data Collection and Analysis.** Obtain CHAMP data for FY 2010 on utilization of mental health services by service subtype, provider, receipt of medical care, etc. Perform relevant analysis using SPSS and other programs.
- **Report.** Prepare report of findings including tables showing service subtypes, demographics, geography and written analysis of data including level of therapy needed based on CHAMP coding subtypes. Identify any significant items needing further review.
- **Survey of providers.** Conduct a survey of Part A/F mental health (MH) providers to identify any gaps in mental health services in the Ryan White Program and other non-Ryan White resources, including types of services referred out and waiting lists (by type of service if applicable). Address following: (1) how do Part A/F services and new subtypes help address the mental health issues identified in 2010 Needs Assessment Update and (2) are any additional changes to Part A/F mental health services required to address any needs and gaps?
    - Develop a survey tool in coordination with relevant Council committees including REC and COC and other Council committees.
    - Administer survey among all Part A/F providers of MH services (estimated at 20 MH providers).
    - Receive and tabulate results.

- **Report.** Prepare report of findings which identifies service gaps for mental health services among Part A/F clients and recommendations to help address these gaps through Ryan White.

3.2 Utilization of Ryan White Part A/F Mental Health Services

Note. For purposes of this section, Ryan White clients include those receiving services funded by Part A, Part F (Minority AIDS Initiative – MAI) or both. In FY 2010 a total of 6,535 clients received Part A or F – 6,380 receiving Part A and 145 receiving Part F but not Part A. Since Part A and F have the same funding year and serve the same populations in the Newark EMA, these clients are combined for purposes of analysis and needs assessment.

According to the CHAMP FY 2010 client data file, in FY 2010 a total of 1,618 clients received mental health services funded by Ryan White Part A, Part F (MAI) or both. This is **25%** of 6,535 total Ryan White Part A/F clients.

3.2.1 Findings - Demographics of Participants

The following data are for clients receiving Ryan White Part A/F Mental Health Services.

- **Geography.** 93% (1,501) of mental health clients resided in the Newark EMA's five counties. The remaining 7% (117) lived outside NEMA.
    - Within NEMA, 77% (1,160) resided in Essex County, 15% (221) in Union, and 8% (120) in Morris, Sussex and Warren region. This is fairly proportionate to the epidemic and distribution of Ryan White clients – with a slightly higher percent of clients residing in Essex receiving MH services (77% vs. 73% PLWHA) but a slightly lower percent in Union receiving MH services (15% vs. 20% PLWHA).
- **Gender.** Nearly half were female (49.4% or 799) with 50.4% (816) male. Three individuals (0.2%) were transgendered.
    - The ratio of females to males receiving mental health services is much different than their percent in the epidemic (40% female, 60% male) and Ryan White Part A/F services (42% female, 58% male and 0.3% transgender).
- **Race/Ethnicity.** 70% (1,132) of clients were African American (Not Hispanic), 19% (300) were Hispanic/Latino, 10% (165) were White Not Hispanic) and 1% (21) were of Other NonHispanic race/ethnicity. This is proportionate to the epidemic and Ryan White clients.
- **Age.** Individuals in all age categories received some mental health service – from age group 2-12 through age group 75-79. 40% of clients (667) were between the ages of 45-54. Another 22% (361) were age 55 and older. This is 62% age 45 and older which is consistent with HIV/AIDS prevalence in the EMA.

- **HIV Status.** One third of clients (551) had AIDS, one third (544) were HIV positive (not AIDS), 31% (500) were HIV positive (AIDS status unknown), and the remaining 1% (23) were HIV Affected.
    - This is different than the epidemic of 51% AIDS and 49% HIV.
- **New Clients.** 201 or 12% were new clients in FY 2010, that is, never received Ryan White services in the Newark EMA before.

3.3.2 Findings – Types of Mental Health Services Used

This section reviews the new CHAMP Part A/F mental health services subtypes and utilization. Table 23 shows the available Ryan White mental health services and the number of clients receiving them in FY 2010. Services were provided to 2,264 clients – which means that 40% of the 1,618 mental health clients received at least two services.

Table 23: Types of Part A/F Mental Health Services and Number of Clients Receiving Each Service in FY 2010

Mental Health Service (CHAMP Subtype)	# Clients	Percent Distn	% MH clients (1,618)
Individual Counseling – Level I	1,078	47.6%	**66.7%**
Individual Counseling- Level II - Intensive Outpatient	5	0.2%	**0.3%**
Individual Counseling - Level III - Partial Care	34	1.5%	**2.1%**
Individual – Psychiatric	572	25.3%	**35.4%**
Individual - Family Counseling	60	2.7%	**3.7%**
Individual - Co-occurring Disorders (COD)	32	1.4%	**2.0%**
Mental Health Assessment	245	10.8%	**15.1%**
Group Counseling - Level I	231	10.2%	**14.3%**
Group Counseling - Level II - Intensive Outpatient	4	0.2%	**0.2%**
Group Counseling - Level III – Partial Care	0	0.0%	**0.0%**
Group - Family Counseling	3	0.1%	**0.2%**
Total Clients	**2,264**	**100.0%**	

Funding Source

Of the 1,618 clients receiving Ryan White mental health services, 1,444 or 89% received MH services funded by Part A, 52 or 3% received Part F funded MH services, and 122 or 8% received services funded by both Part A and F.

Service Utilization

- **Individual therapy.** Individual Counseling (Level I) was the most utilized service – with two thirds (1,078) of mental health clients receiving this service.

- Individual therapy with a psychiatrist was the second most utilized service at 35% (572) of mental health clients.
- Other individual therapies - including Co-occurring Disorders - were used by 2%-3% of mental health clients

- **Group therapy.** Group Counseling – Level I – was the third most used service at 14% (245) of clients. The remaining group therapies had very low to no utilization.
- **Mental Health Assessment.** A total of 245 (15%) individuals received a mental health assessment by a mental heath provider – which is considered a gateway to the remaining mental health services.
- **Family Counseling** was used by nearly 4% of individuals but only 0.2% participated in group family counseling.

New Clients

Table 24 shows the mental health services utilized by 201 new Part A/F Ryan White clients. Since services were provided to 272 clients, this indicates that over one third (36%) received two or more mental health services.

Table 24: Types of Part A/F Mental Health Services Used by New Mental Health Clients in FY 2010

Mental Health Service (CHAMP Subtype)	# Clients	Percent Distn	% new MH clients (201)
Individual Counseling - Level I	118	43.4%	**58.7%**
Individual Counseling- Level II - Intensive Outpatient	1	0.4%	**0.5%**
Individual Counseling - Level III - Partial Care	2	0.7%	**1.0%**
Individual – Psychiatric	81	29.8%	**40.3%**
Individual - Family Counseling	6	2.2%	**3.0%**
Mental Health Assessment	50	18.4%	**24.9%**
Group Counseling - Level I	14	5.1%	**7.0%**
Total Clients	**272**	**100.0%**	

The service most used by new Ryan White mental health clients was Individual Counseling – Level I (59% or 118 clients), followed by Individual –Psychiatric services (40% or 81). Only 25% (50) received a Mental Health Assessment by mental health provider.

The issue for further follow up is clarification of the path to entry into mental health services - is a mental health assessment required for all clients before further service, e.g., individual therapy or interview by a psychiatrist – or are there several pathways which are consistent with the EMA's Mental Health Standards of Care and recognized practice in the field of mental health.

Clients Receiving Part A/F Medical Care

Of the 1,618 clients receiving mental health services, 1,189 or 74% received Part A/F medical care.

Table 25: Types of Part A/F Mental Health Services and Number of Primary Medical Care Clients Receiving Each Service in FY 2010

Mental Health Service (CHAMP Subtype)	# Clients	Percent Distn	% MH clients w/ PMC (1,189)
Individual Counseling – Level I	759	48.1%	**63.8%**
Individual Counseling- Level II - Intensive Outpatient	2	0.1%	**0.2%**
Individual Counseling - Level III - Partial Care	25	1.6%	**2.1%**
Individual – Psychiatric	444	28.1%	**37.3%**
Individual - Family Counseling	36	2.3%	**3.0%**
Individual - Co-occurring Disorders (COD)	12	0.8%	**1.0%**
Mental Health Assessment	176	11.1%	**14.8%**
Group Counseling - Level I	121	7.7%	**10.2%**
Group Counseling - Level II - Intensive Outpatient	1	0.1%	**0.1%**
Group Counseling - Level III – Partial Care	0	0.0%	**0.0%**
Group - Family Counseling	1	0.1%	**0.1%**
Total Clients	**1,577**	**100.0%**	

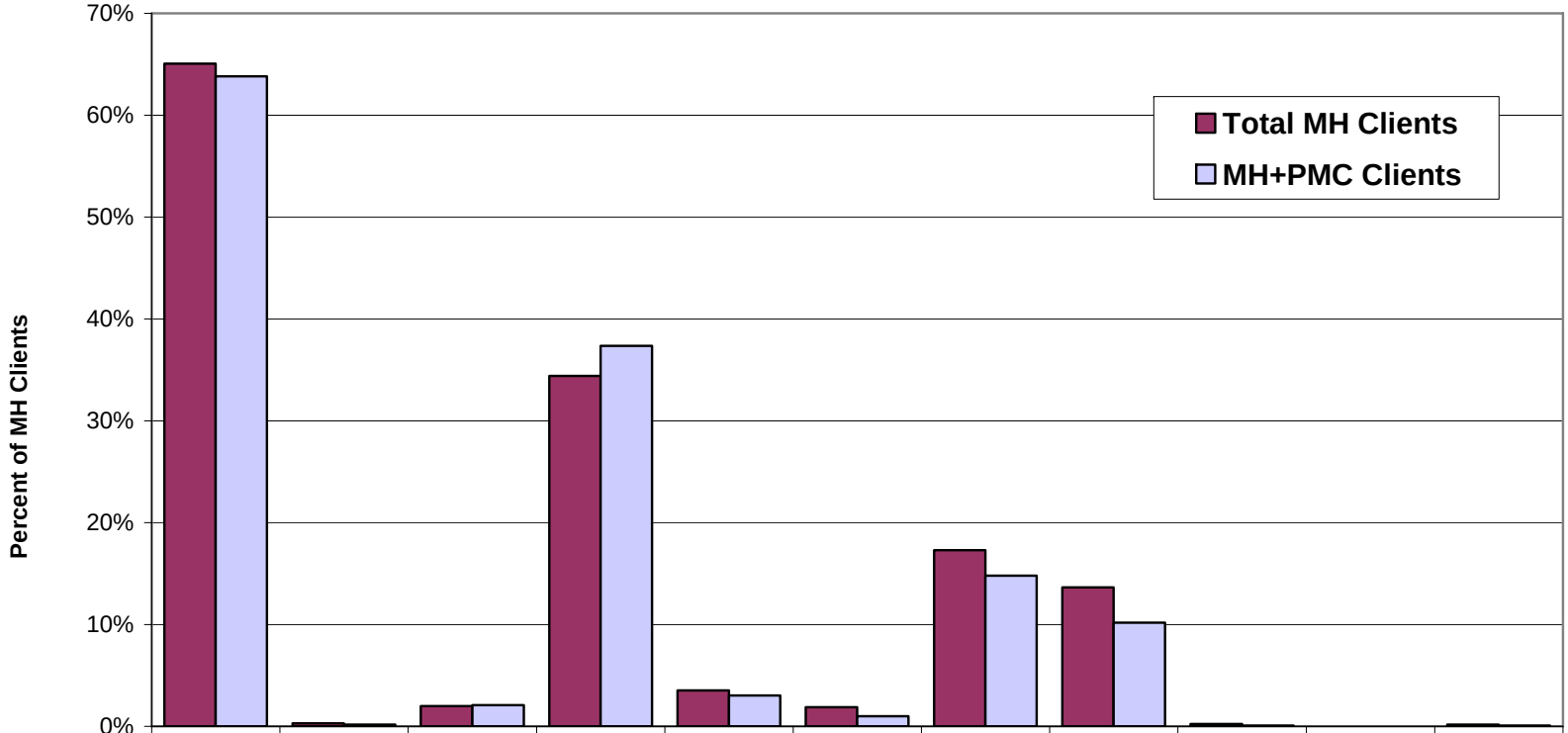
Figure 11 shows that Part A/F clients receive the same types of mental health services in the same proportions regardless if they are receiving Ryan White medical care or not. There is no difference between the types of services received based on whether they get Ryan White medical care.

3.3.3 Recommendations for Further Study

The above analysis shows that the following areas should be studied with Ryan White mental health providers.

- Why is mental health service utilization among males so much different than their proportion of the epidemic and Ryan White system?
- Why is mental health service utilization in Union County lower than its percentage of PLWHA?
- Clarification of the path to entry into mental health services - is a mental health assessment required for all clients before further service, e.g., individual therapy or interview by a psychiatrist – or are there several pathways which are consistent with the EMA's Mental Health Standards of Care and recognized practice in the field of mental health.

Figure 11: Percent of FY 2010 MH Clients Receiving Each Type of MH Service – Total and Medical Care



	Indiv Couns - Level I	Indiv Couns-Level II - IOP	Indiv Couns - Level III - Partial Care	Indiv - Psychiatric	Indiv - Family Couns	Indiv - Co-occurring Disorders	Mental Health Assess	Group Couns - Level I	Group Couns - Level II - IOP	Group Couns - Level III	Group - Family Couns
Total MH Clients	65.1%	0.3%	2.0%	34.4%	3.5%	1.9%	17.3%	13.6%	0.2%	0.0%	0.2%
MH+PMC Clients	63.8%	0.2%	2.1%	37.3%	3.0%	1.0%	14.8%	10.2%	0.1%	0.0%	0.1%

3.3 Survey of Mental Health Providers

The purpose of this section is to conduct a survey of Part A/F mental health (MH) providers to identify any gaps in mental health services in the Ryan White Program and other non-Ryan White resources, including types of services referred out and waiting lists (by type of service if applicable). Address the following: (1) how do Part A/F services and new subtypes help address the mental health issues identified in 2010 Needs Assessment Update, and (2) are any additional changes to Part A/F mental health services required to address any needs and gaps?

A survey tool was developed in coordination with the Council's Research and Evaluation Committee (REC) and Continuum of Care (COC) committee. The tool included questions which were designed to obtain further information on these issues. The tool is in Appendix C. It was agreed that the online "Survey Monkey" would be used to collect responses. Council staff created the survey online using questions in the survey tool. It was tested and finalized.

In April 2011 the Council sent a letter to all providers attaching the tool with the link to the survey on Survey Monkey with a due date of May 2, 2011. The survey was sent to all providers because the Grantee advised that the Council could not identify specific providers, including only those who provided mental health services. Council staff conducted ongoing follow up during May to ensure an adequate number of responses.

Responses were received from **20 agencies**. Of these, nine (45%) provide medical care, four (20%) are community based organizations who provide mental health services, three (15%) are substance abuse treatment providers, two (10%) provide housing and supportive services, and two (10%) provide supportive services of food/nutritional services and but do not provide mental health services

3.3.1 Survey Results

Results from the survey are listed by question below.

Question #1: Are you aware of the change in Part A/F Ryan White Mental Health Service definitions?

In FY 2010 the "Mental Health" service subtypes in CHAMP were changed to better match the service definitions used by the behavioral profession throughout the state, as set forth by the N.J. Department of Human Services (NJDHS). The purpose of this question was to determine if providers were aware of these changes.

Fifteen (15) respondents (75%) answered "yes", three (15%) were not aware of the changes, and two (10%) left the question blank. Of the two who left the question blank, one did not provide mental health services.

Question #2: If YES, has this improved how you provide and record services?

This question was not asked on Survey Monkey.

Question #3: What Mental Health services does your agency provide? (Check all that apply)

The types of mental health services are listed below. Nearly all agencies provided more than one service. Individual Counseling – Level 1 was provided most often (70% of providers) followed by Individual-Family Counseling at (45%) - that is, within the context of family counseling, providing counseling to an individual family member away from the family/group. The third service most provided is Group Counseling – Level 1 at 25% of providers. Psychiatric services were provided by four (20%) providers.

More than half – 11 or 55% - provide an in-depth mental health assessment.
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Table 26: Types of Mental Health Services Provided by Ryan White Part A/F Agencies - 2011

Service Subtype	# Providers	% Providers (20)
Individual Counseling - Level I	14	70%
Individual Counseling - Level II	3	15%
Individual Counseling - Level III Partial Care	0	0%
Individual – Psychiatric	4	20%
Individual - Co-Occurring Disorders (COD)	0	0%
Group Counseling - Level I	5	25%
Group Counseling - Level II - Intensive Outpatient	2	10%
Group Counseling - Level III - Partial Care	0	0%
Individual - Family Counseling	9	45%
Group - Family Counseling	2	10%
Mental Health Assessment	11	55%
Total	**50**	

Question #4: Does your agency provide a separate Mental Health Assessment for all clients entering your facility?

More than half of providers – 11 or 55% - reported providing a separate mental health assessment for all clients entering their facility. Seven (35%) providers answered “no” and two (10%) left the question blank.

However, some providers answering “yes” to this question do NOT provide a “mental health assessment” in Question #3.

Question #5: If NO, how do you determine the patient's need for mental health services? (Please describe)

Six of the seven providers (30%) who do not provide a separate mental health assessment for all clients entering the facility gave the following answers.

> “Based on the overall assessment that has mental health questions and on their status with the jail mental health department.”

(Agency provides discharge planning and case management in a correctional setting.)

"There is a Mental Health Screening which determines whether immediate Mental Health issues are present. Although clients are encouraged, some, not all clients will see the Clinician Supervisor and he will complete a Mental Health Assessment."
(Agency serves a special population of youth.)

"Agency Client Assessment Form - screening tool is used."
(Agency provides a range of services but not medical care.)

"Assessment through a standard ASI provided by the State Dept of Human Services Division of Addiction Services as a licensed Substance Abuse provider and licensed mental health counselors."
(Agency provides substance abuse treatment and mental health services.)

"Mental health services are provided only to transitional house residents."
(Agency provides a range of services but not medical care.)

"Based on the clinical staff's assessment or self-reported by patients."
(Agency provides a medical care and a range of services.)

It appears as though providers who do not provide a mental health assessment routinely have special circumstances – such as serving special populations, relying on other professionals in the agency to perform the function, may not be warranted because the agency does not provide medical care, use of special instruments for behavioral health.

For agencies providing medical care, it may be useful to use simple screening tools for all clients, e.g., SAMISS (Substance Abuse and Mental Illness Symptom Screener) or other validated instrument, so that the medical team can begin to identify and address any mental health issues experienced by the patient.

Question #6: In your agency, what is the typical path or entry into mental health services from Ryan White Part A/F intake or re-assessment? That is, what staff are involved and what steps are followed (e.g., screening, in-depth assessment, psychiatric interview, etc.)? (Please describe)

This question elicited very interesting responses from 17 (85%) of the 20 providers. All are listed below and are grouped by the type of provider. Although the extent of response varies, it appears as though the respondents have a standard, agency-specific protocol which is followed for mental health assessment and needed treatment.

Substance Abuse Providers

At intake, the client sees the primary doctor who screens client and, if needed, refers to our in-house psychiatrist for assessment and treatment.

Social Service Case Manager does Initial Intake at which time a Mental Health Screening is performed and consumer is referred out for mental health services.

Intake, screening and in depth assessment - using the Addiction Severity Index (ASI) of the NJ Dept. Human Services, Division of Addiction Services.

Discharge Planning Providers

Case manager completes a basic screening, referral for assessment if needed and then referral for services if needed.

Initial screening by corrections, treatment or benefits staff and then an in-depth assessment by mental health provider.

Medical Provider (Youth)

Clients are usually referred to our program and meet with the Medical Case Manager (MCM) to determine clients' immediate needs. A few days later clients will see physician who will complete a full medical evaluation and any treatment required. Mental Health and Substance Abuse Screenings are also completed at this time. Clients will be introduced by the MCM to the other staff on the team and Clinician Supervisor will encourage client to meet with him. This encouragement is reiterated by the MCM and Physician. Clinician Supervisor will meet with client and complete Mental Health Assessment. If necessary, client receives ongoing mental health counseling and psychiatric consultation with psychiatrist at UMDNJ Behavioral Health.

Medical Providers

All patients receive initial mental health evaluation/screening by on site staff psychiatrist. Patients in need have regular follow up with psychiatrist as needed. Also, all patients receive annual re-screening with psychiatrist.

Initial screening done by MCM. If need is identified, patient is screened by Mental Health counselor, followed by in-depth assessment and formulation of treatment plan.

At clinical intake with provider. Also at the medical case management assessments.

The client comes in to meet with the MCM and a mental health (MH) screening is performed. The patient is then referred to the MH counselor for the MH assessment and acuity scale. The MH counselor then provides a treatment/counseling plan for the patient and refers to psychiatrist as needed.

All patients, new or established, that are scheduled for a medical evaluation also receive a comprehensive mental health assessment. Based on the outcome, patients receive ongoing mental health services and/or are referred for more intensive follow up at our on-site mental health department. All clients receive a 6-month treatment plan review that addresses any changes, ongoing needs, or barriers encountered from original plan. The Family Treatment Center social work staff conducts all interventions.

All patients are screen by clinical case managers during intake process and continued through on-going contacts with the individuals. In addition, all medical clients are annually asked to complete a mental health assessment tool (PRIME MD) unless they are already in active

treatment. Clients are also referred to social workers for further assessment and referral by medical providers if issues come up during a medical visit. If referral for psychiatric assessment is deemed appropriate, we refer the patient for a mental health assessment by our onsite psychiatric nurse practitioner who will do in depth psychiatric assessment and who will follow for medication monitoring as applicable. If referral for therapy is required, the social workers will refer to outside programs and provide additional supportive counseling as needed/requested. Ongoing collaboration between service providers is strongly pursued in such situations. Cyracom phones are available to assist with interpretation services for any non English speaking clients on site.

Mental Health Counselors, Substance Abuse Counselors, Nurse Practitioners, Nurses, Medical Case Managers, Psychiatrists.

Community-Based Organization (Non-medical)

Clients that are applying for transitional housing must have a mental health assessment done.

Our Mental Health assessment is done as part of our intake process.

Mental Health Provider and CBO

Initial intake completed by MCM/CM/Social Work Intern. This is followed by a MH screening by seasoned staff and a full biopsychosocial assessment with MH diagnosis and recommendation for treatment Reassessment every six months (typical) unless clinician deems it necessary for earlier assessment, including recommending psychotropic medications, hospitalization, etc.

Upon referral by their Case Manager to New Jersey AIDS Services for mental health services, each client will meet with the Mental Health Therapist for a comprehensive assessment of their mental health status. An initial GAF is recorded and Individualized Treatment Plan developed.

Question #7: Are you able to treat or address the mental health needs of your clients on-site at your agency?

Sixteen (80%) of providers said they were ale to treat or address the mental health needs of their clients on-site at their agencies. One CBO (5%) providing substance abuse counseling was not able to meet this need. Two agencies (10%) did not provide mental health services and one medical provider (5%) did not respond.

Question #8: If NO, what additional needs are there? (Please describe)

No agencies answered this question, which is to be expected since only one answered “no” to the previous Question #7.

Question #9: Do you refer clients to other agencies for mental health treatment?

Seventeen (85%) agencies answered this question – and 14 (70%) said they referred clients to other agencies for mental health services. Three (15%) did not refer out and another three (15%) did not answer the question.

Question #10: If YES, for what types of services? (Describe using the list in Question #3 or other categories)

Twelve providers (60%) answered yes to this question and listed the types of services as shown below.

- Level II Intensive outpatient
- Psychiatric services
- Individual Counseling, Group Counseling, Family Counseling, In-patient treatment.
- Individual Psychiatric & Family Counseling
- Level 2 and Level 3 care. Addiction Services. Psych ER services
- Psychiatric assessment, groups, meds, etc.
- Crisis intervention, in-depth evaluations, medication administering.
- If a client prefers to go to another provider for MH services we will refer them.
- Psychiatric follow up and evaluation.
- Assessment for psychiatric medication, medication monitoring, and medication follow-up.
- Therapy as requested.
- Substance Abuse Treatment Programs. Mental Health Facilities. Community psychologist and Licensed Clinical Social Workers, LPAs.

Table 27 lists the types of services by frequency and category.

Table 27: Types of Mental Health Services Referred Out by Ryan White Part A/F Agencies - 2011

Services Referred Out	# Responses	% (12 Providers)
Psychiatric services (excluding medications)	5	38%
Psychiatric services - Medications (including assessment, monitoring, follow up)	2	17%
Community psychologist, LCSW, LPA	1	8%
Level 2 Intensive outpatient or Level 3 partial care services	2	17%
Individual Counseling	1	8%
Family Counseling	2	17%
Group Counseling	1	8%
Inpatient treatment	1	8%
Therapy	1	8%
Addiction/Substance Abuse Treatment services	2	17%
Crisis Intervention/Psychiatric ER	2	17%
Mental health facilities	1	8%
Client request for another MH provider	1	8%

The types of services include more specialty and medical professional care. These include: psychiatric services, follow up and evaluation, medications and medication monitoring/follow up, Level II and III individual services, crisis intervention and ER services, therapy as requested, group and family counseling. Providers also refer to other agencies for patients who prefer to go to another provider.

Question #11: What are the gaps in mental health services for your clients?

Seventeen (85%) of providers responded. Two (10%) said there were no gaps at this time. Others listed specific gaps as follows.

Lack of specific services on-site and lack of adequate psychiatric services

- Frequency and time the Psychiatrist is available
- No Psychiatrist on staff
- With no on site counselor there can be a gap while trying to obtain appointment for counseling services. At times this gap can be bridged by our on site psychiatrist.
- Individual Psychiatric, Family Counseling, Couples Counseling
- Provider availability and significant **stigma** attached to mental health services.
- Funding. We are not provided with sufficient funding to cover bilingual mental health or monolingual (Spanish). Psychiatric services are also limited; we depend on primary care doctors to assist with medication (not best scenario).
- Resources can be limited based on insurance coverage (e.g., Medicaid/Medicare) due to limited providers available or co-pays that may be required under Medicare guidelines. Wait lists may also created additional barriers to care.
- Services for clients with Co-occurring disorders.

Appointment wait times

- Appointment wait time, catchment areas.

Client behaviors and noncompliance

- The major gaps are when clients do not consistently come in for services. As soon as they begin feeling better they stop coming for counseling and psychiatric treatment and as a result return when they are in crisis mode.
- Consumer non-compliance.
- We used to have funding for MH psychiatric at our facility. We no longer receive that funding and therefore need to refer to patients needing psychiatric treatment to other facilities; sometimes the clients do not show to their appointments..
- Clients not coming back for sessions.

Lack of inpatient services

- Unable to get clients detoxed.
- Lack of funding streams to support need for intensive inpatient hospitalization.

Although most of the providers say they are able to treat clients, there are definite gaps in services. These gaps include lack of sufficient psychiatrists, lack of adequate mental health staff, wait times for appointments (the converse of lack of adequate staff), and need to pay for mental health services for the uninsured and inadequate insurance. Client behavior and noncompliance is a service gap which providers often cannot control. A final gap is unavailability of funding or providers of inpatient services.

Question #12: Are there waiting lists for mental health services for your clients? (Please describe.)

Seventeen (85%) providers answered this question. Ten (50%) reported that there were no waiting lists. Two additional providers (10%) said "no" but with qualifications. One said there were no waiting lists, but they refer out if the caseload is too heavy. Another said "not at this time", implying that there may be waiting lists during the year.

The remaining five providers (25%) noted gaps in certain areas.

> "There is no wait list for psychiatric medication monitoring at our program. Referrals to outside agencies may have wait lists but we are often able to access needed supports to enable patients to get support during this period."
>
> "Due to funding, Psychiatrist hours are limited; clients may have to wait to be seen by Psychiatrist."
>
> "Only for Psychiatrist and medication - Spanish speaking."
>
> "Counseling services can have waiting list times that vary."
>
> "Yes, at hospital based behavioral health clinics."

Question #13: What recommendations do you have regarding mental health services for HIV+ individuals in the Newark EMA? (Please list as much as possible)

Seventeen providers (85%) answered this question. Three (15%) had no recommendations at this time. Three (15%) asked for more funding for mental health services. The remaining 14 (70%) included specific recommendations for additional mental health services and mental health screening, transportation for removal of barriers to care, and assistance to the uninsured for mental health services. They are listed below.

- Have a Mental Health Technician available to assist when the Psychiatrist is not available.
- More accessible counseling services with social workers, psychologist, etc.
- Couples Counseling
- Need greater access to psychiatrists who are willing to treat clients who are still actively using drugs (self medicating)
- Spiritual counseling in conjunction with cognitive behavioral counseling and treatment, medication adherence, support groups, Art Therapy
- We need more Spanish speaking providers.
- More funding for psychiatric and group counseling.
- Should be part of intake. Should be required to see a MH person at least twice a year.
- More availability of reliable resources and more accessible and timely linkage to service.
- To provide appropriate funding allocation for agencies providing mental healthy counseling (individual, family, group and social support).
- To provide designated MH to funding for transportation/vouchers to ensure consistent treatment. Transportation assistance also needs to be prioritized to remove this barrier to care.
- Consideration for support of mental health retreats and increased support for specialized group mental health counseling.

- Continue to focus on prioritizing mental health services.
- Continue to increase funding opportunities for services to ensure those individuals without coverage or who are underinsured can access needed services by minimizing barriers to care.
- Issues with co-pays for those with limited funds should also be addressed. Encourage co-location of services as much as possible.
- Continue providing advanced skill trainings for providers to enable consistent and appropriate mental health assessments.
- More cohesive programs for HIV+ Co-occurring clients.

These recommendations included specific types of providers and services, improvements in the system of care involving mental health screening and assessment, improved skills among MH providers.

Question #14: What are the changes you would recommend for Part A/F Ryan White Mental Health services? (Please describe)

This question is a refinement of Question #13 and deals specifically with Ryan White Part A/F mental health services. Seventeen (85%) providers answered this question – seven (35%) had no recommendations at this time. Another (5%) referred back to recommendations in Question #13. Specific recommendations for Part A/F are below.

- More hours for Psychiatrist. Funding for psychiatric/psychological services within our FTC department so we would not have to refer out. More psychiatric services and inpatient programs available. (3 responses.)
- Limited number of psychiatric providers for those only covered by Part A. Increase network of providers to offer clients quicker access to service and options in choosing a provider.
- Given the degree of mental health in the Newark EMA, more places where patients can go for counseling and therapy beyond psychiatrist treatment.
- Increase in access to addiction services.
- Art Therapy-Using non-verbal means of increasing self-esteem and identifying feelings relating to the virus and living successfully with it through education and art expression.
- Training for general mental health professionals regarding issues specific to HIV.
- Definition of Co-occurring Disorders (COD/MICA) is being confused with Axis I co-disorders. Clarification is needed
- More assessment tools.

3.3.2 Survey Conclusions and Recommendations

Listed below are the conclusions from the mental health provider survey and recommendations for the Council and Grantee.

- Most providers are aware of the changes in Ryan White Mental Health services subtypes and are using them. We could not determine if these changes affected provision of mental health services positively or negatively because this question was not asked on Survey Monkey.

  Recommendation: No additional training on CHAMP mental health service subtypes appears to be needed.

- Most mental health services are provided in an individual setting rather than group setting - individual counseling (Level 1), family counseling-individual and psychiatric services. Some group services are provided.

  Recommendation: The Council should be aware of and consider this service configuration in its planning and resource allocations.

  However, the type of therapy – single visit, short-term, and longer term, is not known. The Grantee might ask CHAMP to run a special report showing the number of clients and percent distribution of these services and dollars spent. This report is not needed for FY 2012 planning but may be for strategic planning.

- Most mental health providers have agency-specific protocols for performing mental health screening, in depth assessment (either routinely or in specific circumstances), referral to mental health services and psychiatric services. These protocols appear to use appropriate staff resources and to use those resources appropriately.

  Recommendation: The Grantee should obtain these written protocols from mental health providers for a better understanding of the process and need for services, both EMA-wide and agency-specific need based on the populations served. This will assist the Council and Grantee in annual and longer-term planning in response to upcoming changes in the healthcare system.

  Recommendation: The grantee should also obtain the numbers and percents of clients involved in the patient flow – from initial screening, to in-depth [biopsychosocial] assessment, to referral and provision of mental health services. Determine if these data can be obtained by special report from CHAMP or whether an agency survey is needed. These results will improve Council planning for mental health services.

  Recommendation: The Council should work with providers to identify **"models of care for mental health services"** including a psychiatrist, LCSW, psychiatric nurse practitioner (CNP), and other support staff to address patient needs and improve patient flow internally and to other providers. These models can explain how they provide services efficiently and effectively. This activity will assist the Council in planning for the transition of the scope of Ryan White services as national health care reform is implemented.

- For the most part, providers report that they are able to treat or address the mental health needs of their clients at their agency. However, they also refer clients to other agencies for more intensive individual services, particularly to psychiatrists for more in-depth/intense evaluation and for psychotropic medications, medication management and monitoring.

  Recommendation: The Council should consider increased funding for mental health services so that these services can be provided in-house, or to increase capacity and reduce waiting times for these external providers.

- There are specific gaps in mental health services, specifically, for psychiatrists and bilingual (Spanish-speaking) providers.
- More Part A/F funding is needed to fill gaps in existing mental health services.

Recommendation: The Council should consider allocating more Part A/F resources for mental health services for FY 2012 and beyond. Work with the Grantee to determine current spending and performance, gaps, capacity, and the extent of additional funding needed.

Recommendation: The Grantee should include specific instructions in the FY 2012 RFP for psychiatric services. This Council can include this recommendation in "instructions to the grantee" in the FY 2012 Priority Setting and Resource Allocation document.

Recommendation: The mental health needs of uninsured patients should be considered and an assessment made of the dollar amount of funding required to address those heeds.

Recommendation: As part of strategic planning for upcoming changes in health care funding, e.g., the transition from Medicaid fee for service to Medicaid Managed Care and for implementation of health care reform, the Grantee and Council should assess how and to what extent any unused/unneeded Primary Medical Care funding can be redirected to mental health services. This assessment should include an understanding of the scope of mental health services to be provided by these non-Ryan White sources.

- Lack of adequate transportation assistance has been indentified as a barrier to receiving mental health services.

  Recommendation: Assess the extent of this service gap, informally from mental health providers or formally by a short survey.

  Recommendation: In coordination with mental health services, ensure sufficient funding for transportation so that clients can keep mental health appointments. Increase transportation funding for FY 2012 as needed and/or increase access to transportation resources by mental health providers.

- Gaps or needs for other mental health services have been indentified including co-occurring disorders, specific therapies.

  Recommendation: The Council should identify services which could address these specific gaps and include recommendations in instructions to the Grantee in the FY 2012 Priority Setting document for the FY 2012 RFP. This will allow providers to propose these new services and enable the Council and grantee to assess their impact in FY 2012.

The overall recommendation is to increase funding for mental health services for FY 2012 and to target specifically more psychiatric services, including bilingual providers.

In general, there is considerable need for mental health services among PLWHA and the Newark EMA Ryan White Part A/F providers are doing a good job of addressing immediate and apparent needs. As changes in the health system are rolled out, the EMA needs to better understand the role of mental health care and how we can improve coordination between medical care and mental health care to improve health outcomes for PLWHA.