Newark EMA

HIV Health Services Planning Council

NEEDS ASSESSMENT UPDATE 2015

September 2015

NEWARK EMA HIV HEALTH SERVICES PLANNING COUNCIL
NEEDS ASSESSMENT - Update 2015

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LIST OF ABBREVIATIONS

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

ACA	Affordable Care Act of 2010 (Patient Protection and Affordable Care Act)
ADAP	AIDS Drug Assistance Program
ADDP	(New Jersey) AIDS Drug Distribution Program
ARV	Anti-Retroviral (therapies)
CARE Act	Comprehensive AIDS Resources Emergency (CARE) Act
CBO	Community Based Organization
CDC	U.S. Centers for Disease Control and Prevention
CHAMP	Comprehensive HIV/AIDS Management Program (the Newark EMA's Client Level Data Base)
CLD	Client Level Data (system)
CM	Case Management
CM-NM	Case Management – Non-Medical (nonmedical case management or managers)
Cmte	Committee
COC	Continuum Of Care Committee of NEMA Planning Council
CQM	Clinical Quality Management
CPC	Comprehensive Planning Committee of NEMA Planning Council
CTR	Counseling, Testing and Referral sites (for early identification of PLWHA)
DAYAM	Division of Adolescent and Young Adult Medicine (formerly at UMDNJ, now at Rutgers University)
DCHW	Newark Department of Health and Community Wellness (formerly Department of Child and Family Well Being)
DMAHS	Division of Medical Assistance and Health Services ("Medicaid Division" within the N.J. Department of Human Services)
DHTSS	Division of HIV/AIDS, TB and STD Services, formerly the Division of HIV/AIDS Services
EIIHA	Early Identification of Individuals Living with HIV/AIDS
EIRC	Early Intervention and Retention Collaborative (EIRCs as plural)
EIS	Early Intervention Services
EMA	Eligible Metropolitan Area
FG	Focus Group
FQHC	Federally Qualified Health Center
GLBTQ	Gay, Lesbian, Bisexual, Transgendered, Questioning
HAART	Highly Active Anti-Retroviral Therapy
HAB	HIV/AIDS Bureau (of HRSA)
HIPAA	Health Insurance Portability and Accountability Act
HOPWA	Housing Opportunities for Persons With AIDS

HRSA	Health Resources and Services Administration (of the U.S. Department of Health and Human Services)
IDU	Injection Drug User
KI	Key Informant [interviews]
LGBTQ	Lesbian, Gay, Bisexual, Transgendered, Questioning
MAI	Minority AIDS Initiative (formerly Congressional Black Caucus – CBC)
MCM	Medical Case Management
MH	Mental Health
MMC	Medicaid Managed Care (NJFC for categorically eligible individuals also receiving Temporary Assistance to Needy Families (TANF) or Supplemental Security Income (SSI))
MNT	Medical Nutritional Therapy
MOA, MOU	Memorandum of Agreement, Memorandum of Understanding
MSM	Men who have Sex with Men
MSW	Morris, Sussex, Warren counties in the Newark EMA
NEMA	Newark Eligible Metropolitan Area
NHAS	National HIV/AIDS Strategy
NJCRI	North Jersey Clinical Research Initiative (New Jersey AIDS Partnership)
NJDHS	N.J. Department of Human Services (administers NJ Medicaid and DMAHS)
NJDOH	N.J. Department of Health (formerly NJDHSS – NJ Department of Health and Senior Services)
NJDS	New Jersey Dental School (at Rutgers University)
NJFC	New Jersey Family Care (Medicaid Expansion)
NJ-CLAS	New Jersey Culturally and Linguistically Appropriate Standards
PLWHA	People Living With HIV or AIDS
PPACA	Patient Protection and Affordable Care Act (also known as the “Affordable Care Act”
REC	Research and Evaluation Committee of NEMA Planning Council
RIC	Retention In Care
RW	Ryan White [Program]
RWHAP	Ryan White HIV/AIDS Program
RWTEA	Ryan White HIV/AIDS Treatment Extension Act of 2009
RWTMA	Ryan White HIV/AIDS Treatment Modernization Act of 2006
SA	Substance Abuse
SAMHSA	Substance Abuse and Mental Health Services Administration (of the U.S. Department of Health and Human Services)
TGA	Transitional Grant Area
WICY	Women, Infants, Children and Youth
YMSM	Young Men who have Sex with Men

INTRODUCTION

The information below was extracted from the Ryan White Part A Manual published by HRSA/HAB in 2013 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 - Planning Council Duties

Completion of the needs assessment is a significant part of the **eight duties of the planning council**, as shown in federal law, most recently updated by the Ryan White Treatment Extension Act. Five sections - (4)(A), (B), (F), (G) and (H) - speak directly to the needs assessment. The purpose of the needs assessment is to assist the planning council in meeting Section (4)(C) – establish service priorities for the allocation of funds within the eligible area – and (4)(D) - develop a comprehensive plan for the organization and delivery of health and support services.

42 U.S. Code § 300ff–12 - Administration and planning council

(b) HIV health services planning council

(4) Duties: The planning council established or designated under paragraph (1) shall—

(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;

(C) establish priorities for the allocation of funds within the eligible area, including how best to meet each such priority and additional factors that a grantee should consider in allocating funds under a grant based on the—

(i) size and demographics of the population of individuals with HIV/AIDS (as determined under subparagraph (A)) and the needs of such population (as determined under subparagraph (B));
(ii) demonstrated (or probable) cost effectiveness and outcome effectiveness of proposed strategies and interventions, to the extent that data are reasonably available;
(iii) priorities of the communities with HIV/AIDS for whom the services are intended;
(iv) coordination in the provision of services to such individuals with programs for HIV prevention and for the prevention and treatment of substance abuse, including programs that provide comprehensive treatment for such abuse;
(v) availability of other governmental and non-governmental resources, including the State medicaid plan under title XIX of the Social Security Act [42 U.S.C. 1396 et seq.] and the State

Children's Health Insurance Program under title XXI of such Act [42 U.S.C. 1397aa et seq.] to cover health care costs of eligible individuals and families with HIV/AIDS; and
(vi) capacity development needs resulting from disparities in the availability of HIV-related services in historically underserved communities;

(D) develop a comprehensive plan for the organization and delivery of health and support services described in section 300ff–14 of this title that—
(i) includes a strategy for identifying individuals who know their HIV status and are not receiving such services and for informing the individuals of and enabling the individuals to utilize the services, giving particular attention to eliminating disparities in access and services among affected subpopulations and historically underserved communities, and including discrete goals, a timetable, and an appropriate allocation of funds;
(ii) includes a strategy to coordinate the provision of such services with programs for HIV prevention (including outreach and early intervention) and for the prevention and treatment of substance abuse (including programs that provide comprehensive treatment services for such abuse);
(iii) is compatible with any State or local plan for the provision of services to individuals with HIV/AIDS; and
(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 300ff–14 of this title, with particular attention to reducing barriers to routine testing and disparities in access and services among affected subpopulations and historically underserved communities;

(E) assess the efficiency of the administrative mechanism in rapidly allocating funds to the areas of greatest need within the eligible area, and at the discretion of the planning council, assess the effectiveness, either directly or through contractual arrangements, of the services offered in meeting the identified needs;

(F) 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 of this subchapter;

(G) establish methods for obtaining input on community needs and priorities which may include public meetings (in accordance with paragraph (7)), conducting focus groups, and convening ad-hoc panels; and

(H) coordinate with Federal grantees that provide HIV-related services within the eligible area.

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

- Address coordination with programs for HIV prevention and the prevention and treatment of substance abuse
- Include links with outreach and early intervention services
- 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 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 expects Part A needs assessments to meet all legislative requirements and to provide a sound information base for planning and decision making.

PURPOSE, RESEARCH QUESTION AND METHODOLOGY

Purpose

The purpose of the Needs Assessment – Update 2015 was to conduct an in-depth assessment of one or more issues identified in the full Needs Assessment of 2014. The 2014 Needs Assessment focused on implementation of the Affordable Care Act (ACA) including Medicaid Expansion in New Jersey starting on January 1, 2014. The major issue identified for 2015 was the impact of the ACA on the Ryan White HIV/AIDS Program (RWHAP) after one full year of operation - as of the end of 2014. Items of concern were enrollment of previously uninsured PLWHA into ACA, changes in both RWHAP service utilization and service expenditures, needs of consumers post-ACA and gaps in ACA services that RWHAP must continue to fill. The intent was to assist the Newark EMA HIV Health Services Planning Council in service priorities and resource allocations for FY 2016 and to make sure that the RWHAP Service System adjusted to the ACA and continued to respond to needs of underserved PLWHA in the Newark EMA.

Research Question

What are the core medical and support service gaps and needs of PLWHA newly enrolled in the Affordable Care Act (ACA) (both Medicaid Expansion/New Jersey Family Care (NJFC) and health insurance exchange marketplace) to help achieve Viral Load Suppression (VLS) including data on linkage to care and retention?

Methodology

The Needs Assessment – Update 2015 includes use of both quantitative and qualitative research methods. Quantitative methods included a review of the Comprehensive HIV/AIDS Management Program (CHAMP) Client Level Database(CLD) regarding service utilization and expenditures for both CY 2013 and CY 2014, and tabulation of a survey of 97 consumers regarding service needs and priorities. Qualitative methods included 13 focus groups of consumers and interviews of 20 Key Informants representing consumers – medical case managers (MCM) and non-medical case managers (CM-NM). **All tools – consumer survey, focus group guide, key informant questionnaire - are in Appendix A.**

Data on utilization of Part A and MAI (Part F) services was obtained from the Newark EMA Grantee and the CHAMP system. Results of the consumer survey were entered into an excel spreadsheet and were tabulated using SPSS software. We changed the Key Informant questionnaire tool from Microsoft Word format to Adobe to allow agencies to enter detailed information, with enough available space, and allow agencies to save the document to their desktop and complete the survey in increments as information was obtained. Upon completion, providers e-mailed the survey document to the Council. This method was easier for providers due to the length of the survey and need for comprehensive and detailed responses. The Council followed up by telephone interviews with individual Key Informants, to clarify any responses and obtain additional information. Results of the phone interviews were added to the hard copy survey, and all results were compiled. This method was found by providers to be appropriate for the information requested.

PART 1: PROFILE OF RYAN WHITE CLIENTS NEWLY ENROLLED IN ACA

Change in RW Service Utilization CY 2013 (Pre-ACA) and CY 2014 (ACA Implementation "Post-ACA") Among Newly Insured and Uninsured RW Clients

1.1 Background

Enacted in 2010, the U.S. Patient Protection and Affordable Care Act (ACA) including optional Medicaid Expansion requires individuals to purchase health insurance effective for 2014 including persons living with HIV/AIDS (PLWHA). New Jersey has chosen to implement Medicaid Expansion, termed New Jersey Family Care (NJFC), for low income individuals with incomes below 139% of Federal Poverty Level (FPL). The ACA provides an array of medical care services including ten (10) essential health benefits, some of which are currently provided by the Ryan White Program.

During 2014, uninsured Ryan White HIV/AIDS Program (RWHAP) clients in the Newark EMA (Part A/F) were assisted in enrolling into appropriate health insurance programs – NJFC and private health insurance marketplace. This section of the needs assessment reviews the impact of these efforts.

Research Question #1
What are the core medical and support service gaps and needs of PLWHA newly enrolled in the Affordable Care Act (ACA) (both Medicaid Expansion/New Jersey Family Care (NJFC) and health insurance exchange marketplace) to help achieve Viral Load Suppression (VLS) including data on linkage to care and retention?

1.1.1 Methodology

Profile of Ryan White Clients newly enrolled in ACA.

1. From CHAMP Client Level Database (CLD), determine service utilization before ACA (2013) and during ACA (2014) for PLWHA newly enrolled in ACA.
    a. Develop service utilization profile for 2013 and 2014. Include data on VLS where possible.
        i. Present data for total clients and three sub-populations – those in NJFC, private Health Insurance Marketplace, and existing RW clients.
    b. Compare both (all) profiles and identify differences – service gaps and needs.
    c. Make recommendations for service categories, service levels and need for FY 2016 priorities.

1.2 Baseline: Uninsured RWHAP Clients as of December 31 2013 ("Pre-ACA")

1.2.1 RWHAP Clients Potentially Eligible for ACA as of December 31, 2013

The first question to answer is **"Which Ryan White HIV/AIDS Program (RWHAP) clients are potentially eligible for ACA at the end of 2013?"** The answer is individuals whose income is below ACA limits AND who lack health insurance or are underinsured as of December 31, 2013. ACA income limits are <139% Federal Poverty Level (FPL) for Medicaid Expansion – New Jersey Family Care (NJFC) – and 139%-400% FPL for health insurance marketplaces which provide a subsidy.

RWHAP served 6,147 clients in CY 2013. At the end of CY 2013, a total of **2,478 or 40.3%** of these 6,147 RWHAP clients were uninsured. **Nearly all were potentially eligible for ACA – 2,157 (35%) uninsured with incomes under 139% FPL (eligible for NJFC)** and **293 (5%)** uninsured with **incomes 139%-400% FPL** (eligible for subsidies in the health insurance marketplace). An additional **28 (0.3%)** uninsured RWHAP clients had incomes above 400% or unknown incomes. See Table 1.

1.2.2 Study Population - RWHAP Clients Receiving Services in CY 2013 and CY 2014

In order to assess change in service needs for RWHAP clients who are newly insured, we must compare their services both in CY 2013 and CY 2014. However, of the **6,147 clients who received RWHAP services in CY2013, only 4,945 (80.1%) received services in CY 2014.** The remaining **1,202 or 19.6% dropped out** of Ryan White. Some relocated outside of the Newark EMA, others died, but most just stopped coming in for services.

This is a typical pattern for RW clients who **"cycle in and of care"** as tracked by CHAMP for well over 10 years. This may be a task for **Retention In Care (RIC)** initiatives within the EMA and at the provider level. Or it may be an indicator that a number of PLWHA no longer need RWHAP. See Table 1 below.

So the study population for assessing the impact of ACA on Ryan White consists of the **4,945 CY 2013 clients who also received RWHAP services in CY2014**. They are termed **"CY2013/CY2014 Clients." 1,925 (39%)** of these 4,945 clients were **uninsured in CY 2013.**

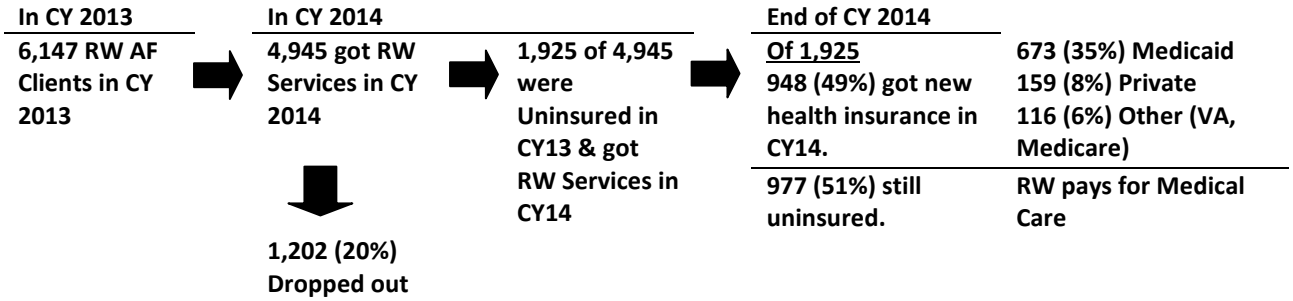
1.3 Uninsured RWHAP Clients in 2013 who Enrolled in Health Insurance in 2014

The Figure 1 below shows what happened to the RWHAP clients by health insurance in CY 2013 and CY 2014. Of the 6,147 CY 2013 clients, 20% dropped out and 4,945 received services in CY 2014. Of those, 1,925 were uninsured at the end of CY 2013. **Of these 1,925, nearly half or 948 obtained health**

insurance in 2014 and half or 977 remained uninsured. Most of the newly-insured obtained Medicaid (NJFC) and the rest obtained private insurance or other insurance (Medicare or VA healthcare).

The tables below - Table 2 (Baseline) and Table 3 (Endpoint in CY2014) - show the changes in their health insurance coverage in more detail. Table 4 shows a Profile of clients at the end of CY 2014.

Figure 1: Overview of "Study" Population and ACA Insurance (n=1,925 uninsured RW Clients at end of CY 2013 who received RW services in CY 2014)



Insurance Status End of CY 2014	#	%	
Medicaid	673	11%	
Private Insurance	159	3%	
Other Insurance	116	2%	
Subtotal Newly Insured	**948**	**16%**	**Health insurance pays for Medical Care***
Still Uninsured	**977**	**16%**	**Ryan White pays for Medical Care**
Total	**1,925**	**31%**	
Insured CY 2013	4,222	69%	
Total Part A/F CY2013	6,147	100%	

*RW pays for services not covered by insurance

Table 1: CY2013 RW Clients by ACA Income Eligibility and Health Insurance at end of CY 2013 (pre-ACA) and CY2014 Status at end of CY 2014 (ACA Implementation)

CY2013 Eligibility for ACA	CY 2013 RWHAP Clients							Status in CY 2014	
	Health Insurance in CY2013				SUBTOTAL INSURED	Uninsured	Total	CY13 Clients Missing*	CY13 Clients in CY14
	Medicaid	Medicare	VA Health Care	Private Insurance					
NJFC Eligible (<139% FPL)	0	0	0	0	0	2,157	2,157	500	**1,657**
Exchange Eligible (139%-400% FPL)	0	0	0	0	0	293	293	41	**252**
Uninsured FPL 401-500%	0	0	0	0	0	5	5	2	**3**
Uninsured RW Ineligible (FPL >500%)	0	0	0	0	0	7	7	5	**2**
Uninsured Unk Income	0	0	0	0	0	16	16	5	**11**
Insured (Incl Plan G)	2,176	789	206	498	3,669	0	3,669	649	**3,020**
Total	**2,176**	**789**	**206**	**498**	**3,669**	**2,478**	**6,147**	**1,202**	**4,945**
Distribution	**35.4%**	**12.8%**	**3.4%**	**8.1%**	**59.7%**	**40.3%**	**100.0%**	**19.6%**	**80.4%**

*Received No RW Services in CY14

4,945 is the baseline of CY 2013 clients to be measured for ACA health insurance enrollment in CY 2014.

They are **"CY2013/CY2014 Clients."**

Table 2: BASELINE PRE-ACA - CY2013 RW Clients by ACA Income Eligibility and Health Insurance at end of CY2013

ACA FPL CY13	Health Insurance CY2013							% Distribution		
	Medicaid	Medicare	VA Health Care	Private Insurance	SUBTOTAL INSURED	Uninsured	Total	Insured	Uninsured	Total
</= 138% FPL	1,641	585	120	203	2,549	**1,657**	4,206	**51.5%**	**33.5%**	**85.1%**
139%-400% FPL	98	82	53	176	409	**252**	661	8.3%	5.1%	**13.4%**
401%-500% FPL	1	1	1	17	20	**3**	23	0.4%	0.1%	0.5%
> 500% FPL	7	1	1	16	25	**2**	27	0.5%	0.0%	0.5%
Not Enough Data	14	1	0	2	17	**11**	28	0.3%	0.2%	0.6%
Total	**1,761**	**670**	**175**	**414**	**3,020**	**1,925**	**4,945**	**61.1%**	**38.9%**	**100.0%**

Table 3: ENDPOINT ACA IMPLEMENTATION - CY2013 RW Client by ACA Income Eligibility and Health Insurance at end of CY2014

ACA FPL CY13	Health Insurance CY2014									% Distribution		
	Medicaid	Medicaid Exp NJFC	Medicare	VA Health Care	Private Insurance	Pvt Ins Exchange	SUBTOTAL INSURED	Uninsured	Total	Insured	Uninsured	Total
</= 138% FPL	1,807	330	689	111	252	29	3,218	**988**	4,206	**65.1%**	**20.0%**	**85.1%**
139%-400% FPL	120	29	84	58	190	18	499	**162**	661	10.1%	3.3%	13.4%
401%-500% FPL	1	0	1	1	18	1	22	**1**	23	0.4%	0.0%	0.5%
> 500% FPL	7	0	2	1	15	0	25	**2**	27	0.5%	0.0%	0.5%
Not Enough Data	10	4	4	0	3	1	22	**6**	28	0.4%	0.1%	0.6%
Total	**1,945**	**363**	**780**	**171**	**478**	**49**	**3,786**	**1,159**	**4,945**	**76.6%**	**23.4%**	**100.0%**

A <u>total</u> of 948 RWHAP CY2013 clients gained health insurance in CY2014.

Table 4: Profile of UNINSURED CY2013 RW Clients (n=1,925) and Health Insurance Status at end of CY2014

ACA FPL CY13	Health Insurance in CY2014						Total Newly Insured	Still Uninsured	Total	% Dist.	
	Medicaid*	Medicaid Exp NJFC	Medicare	VA Health Care	Private Insurance	Pvt Ins Exchange				Total Newly Insured	Still Uninsured
</= 138% FPL	447	173	93	5	82	20	820	837	1,657	86%	86%
139%-400% FPL	37	12	16	1	43	9	118	134	252	12%	14%
401%-500% FPL	0	0	0	0	1	1	2	1	3	0%	0%
> 500% FPL	0	0	1	0	0	0	1	1	2	0%	0%
Not Enough Data	3	1	0	0	2	1	7	4	11	1%	0%
Total	**487**	**186**	**110**	**6**	**128**	**31**	**948**	**977**	**1,925**	**100%**	**100%**
% Dist.	**25%**	**10%**	**6%**	**0%**	**7%**	**2%**	**49%**	**51%**	**100%**		
% of 4,945 Clients	**10%**	**4%**	**2%**	**0%**	**3%**	**1%**	**19%**	**20%**	**39%**		
Total Medicaid	**673**	**35%**	**14%**								
Total Private Ins	**159**	**8%**	**4%**								

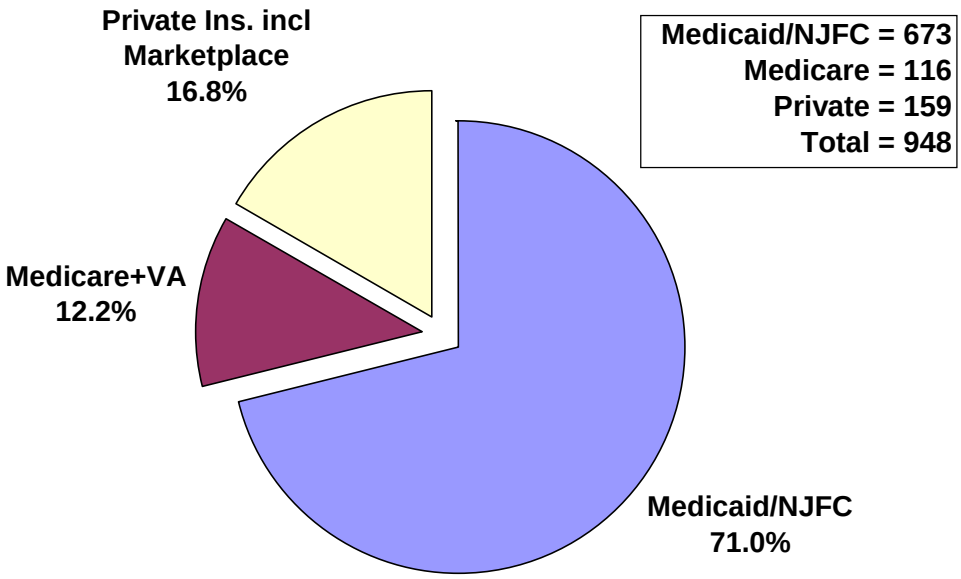
*** These are likely clients enrolled in NJFC Medicaid Expansion.**

1.3.1 Findings - CY2013 Clients Enrolling in Health Insurance in CY2014 ("CY2013/CY2014 Clients")

The findings from the above tables for CY2013/CY2014 clients are summarized below.

- A total of 4,945 clients received RWHAP services in both CY2013 and CY2014. These are termed **"CY2013/CY2014 Clients".**
- 1,925 (39%) were uninsured in CY2013.
- **948 (19%) of the CY2013/CY2014 Clients enrolled in health insurance in CY2014**.
    - Most enrolled in **Medicaid – 683 (14%)**
    - Another **159 (4%)** obtained **Private Insurance including through the marketplace.**
    - The rest obtained **Medicare (110 or 2%) or VA Health Care (6).**
- This leaves **977 (20%) CY2013/CY2014 Clients still uninsured** at the end of CY2014**.**
- By **ACA Income Category**, most individuals obtaining insurance were very low income with incomes under 139% of the Federal Poverty Level (FPL). This made them "income eligible" for ACA Medicaid Expansion, known as New Jersey FamilyCare (NJFC).
    - Of the **1,657 uninsured CY2013/CY2014 clients eligible for Medicaid Expansion (NJFC) <139% FPL:**
        - **620 (37%) enrolled in NJFC in CY2014.**
        - **200 (12%)** enrolled in other health insurance including private insurance.
        - **837 (51%) remained uninsured.**
    - Of the **252 uninsured CY2013/CY2014 clients eligible for Insurance in Health Marketplace 139%-400% FPL:**
        - **49 (20%)** enrolled in **Medicaid.**
        - **69 (27%)** enrolled **other insurance, mostly private insurance including Health Insurance Marketplace (52 or 21%)**
        - **134 (53%) remained uninsured.**

Figure 2: CY2013/CY2014 RW Clients Newly Enrolled in ACA by Type of Health Insurance



1.3.2 Demographics of CY2013/CY2014 Clients - Newly Insured vs. Still Uninsured

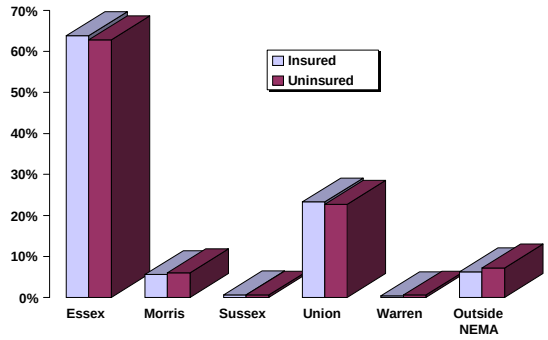
Of the 1,925 uninsured clients in CY 2013, 948 (49%) obtained health insurance and 977 (51%) remained uninsured. There were some differences between the two populations per **Figure 3** below.

- **County of Residence.** There was **no difference** in the distribution of newly insured vs. still uninsured by county. Union County had a higher percent of uninsured.
- **Race/Ethnicity. 73% of the newly insured were Black/African American** – slightly higher than their portion of the epidemic (67%). **31% of those remaining uninsured were Hispanic/Latino, much higher than their 20% portion of PLWHA in the EMA.**
- **Gender.** Females obtained insurance in a higher proportion to their representation in the epidemic (41% vs. 37%). A higher percent of **uninsured were males** (67% vs. 63% male PLWHA).
- **Housing Status.** It is well-known that housing status affects health and stable housing improves health outcomes. ("Housing is Healthcare.") 76% of the newly insured were in stable housing, while nearly 1/3 in temporary or unstable housing were uninsured.
- **Age.** Age of the newly insured and uninsured shows the most difference. 63% of those newly insured were age 45 and older – consistent with their percent of the epidemic (69% in 2014). **Nearly half (45%) of those remaining uninsured are young adults age 25-44** even though they are only 37% of PLWHA**.**

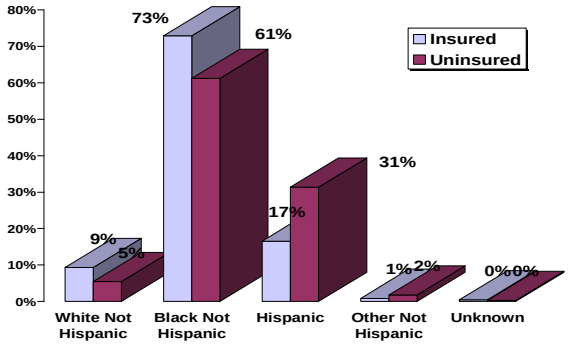
The uninsured are trending to males, Hispanic/Latino population, and young adults age 25-44. RWHAP services will have to be tailored accordingly.

Figure 3: Demographics of CY2013/CY2014 RW Clients Newly Insured vs. Still Uninsured

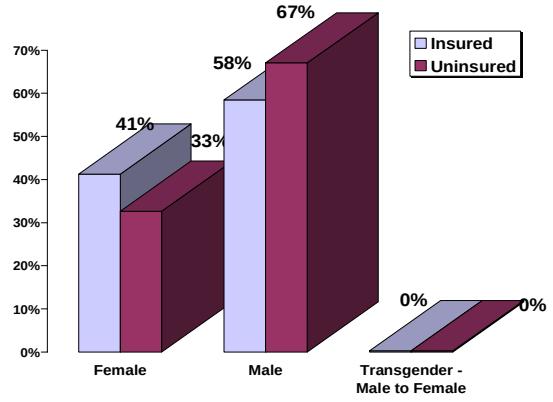
County of Residence



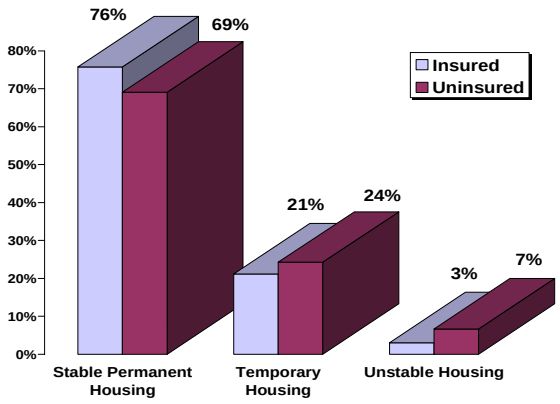
Race/Ethnicity



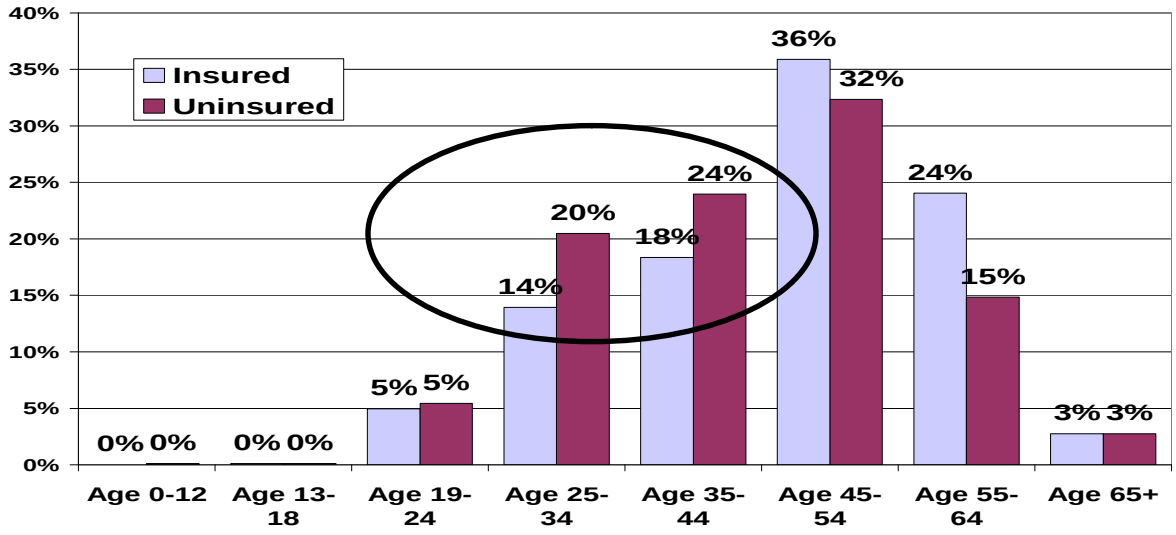
Gender



Housing Status



Age



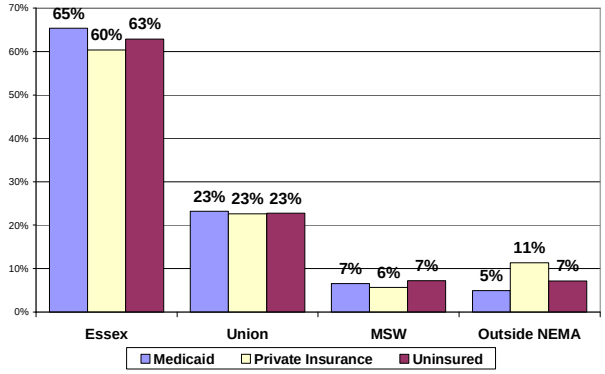
1.3.3 Comparison of Newly Insured Clients – Medicaid/NJFC and Private Insurance - vs. Still Uninsured in CY 2014

Comparing the newly insured by type of ACA insurance – Medicaid Expansion/NJFC and Private Insurance including through the marketplace – with those still uninsured shows the impact of the ACA on Ryan White.

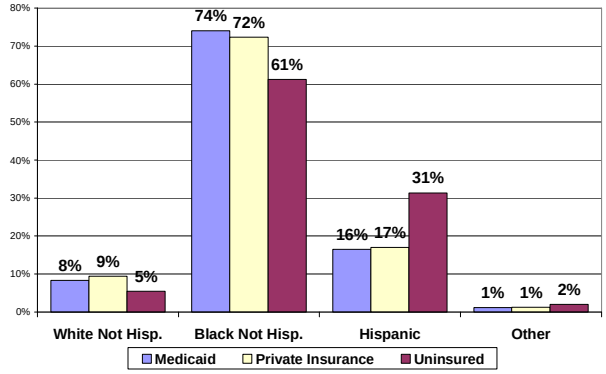
- **County of Residence.** There was **no difference** in the distribution of newly insured through the ACA vs. still uninsured by county.
- **Race/Ethnicity. 72%-74% of the newly insured through the ACA were Black/African American** – higher than their portion of the epidemic (67%). This reduced the percent of uninsured who were African Americans to 61%. **31% of those remaining uninsured were Hispanic/Latino, much higher than their 20% portion of PLWHA in the EMA.**
- **Gender. Females** obtained **Medicaid/NJFC insurance** in a higher proportion than their representation in the epidemic (44% vs. 37%), but lower for private insurance (33%). This helped reduce the percentage of uninsured female RWHAP clients to 33%. A higher percent of **individuals obtaining private insurance and uninsured were males** (67% vs. 63% male PLWHA).
- **Housing Status.** It is well-known that housing status affects health and stable housing improves health outcomes. ("Housing is Healthcare.") The vast majority clients newly insured through the marketplace (83%) were in stable housing, followed by those obtaining Medicaid (72%), while nearly 1/3 in temporary or unstable housing were uninsured.
- **Age.** Age of the newly insured and uninsured shows the most difference. Very few ACA enrollees were under age 12 or age 13-18. 63% of those newly insured were age 45 and older – consistent with their percent of the epidemic (69% in 2014). Over one third of new ACA enrollees - Medicaid/NJFC and the marketplace – were individuals age 25-44. **Nearly half (45%) of those remaining uninsured are young adults age 25-44** even though they are only 37% of PLWHA**.**
- **5 Cities.** The positive impact of ACA especially Medicaid/NJFC is shown in the 5 largest cities in the EMA which account for 72% of the EMA's epidemic.
    - 75% of new Medicaid/NJFC enrollees resided in the five cities, including 42% in Newark (equal to Newark's 42% of the EMA's PLWHA.) Only 65% of private insurance enrollees resided in the 5 cities, but this is still a significant proportion.
    - The combined effect reduced to 69% the percent of clients still uninsured in the 5 cities, slightly less than its proportion of the epidemic.
    - **Of the total 1,350 uninsured CY2013/CY2014 clients residing in these cities, 678 (50%) obtained insurance and 672 (50%) remained uninsured.**

Figure 4: Comparison of Newly Insured Clients – Medicaid/NJFC and Private Insurance - vs. Still Uninsured

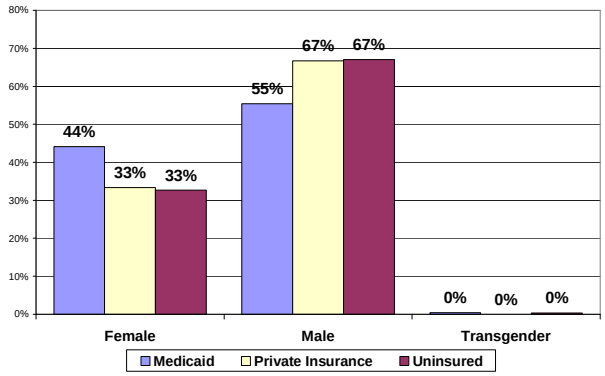
County of Residence



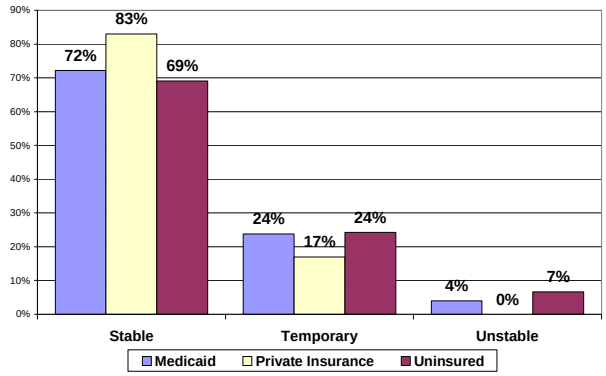
Race/Ethnicity



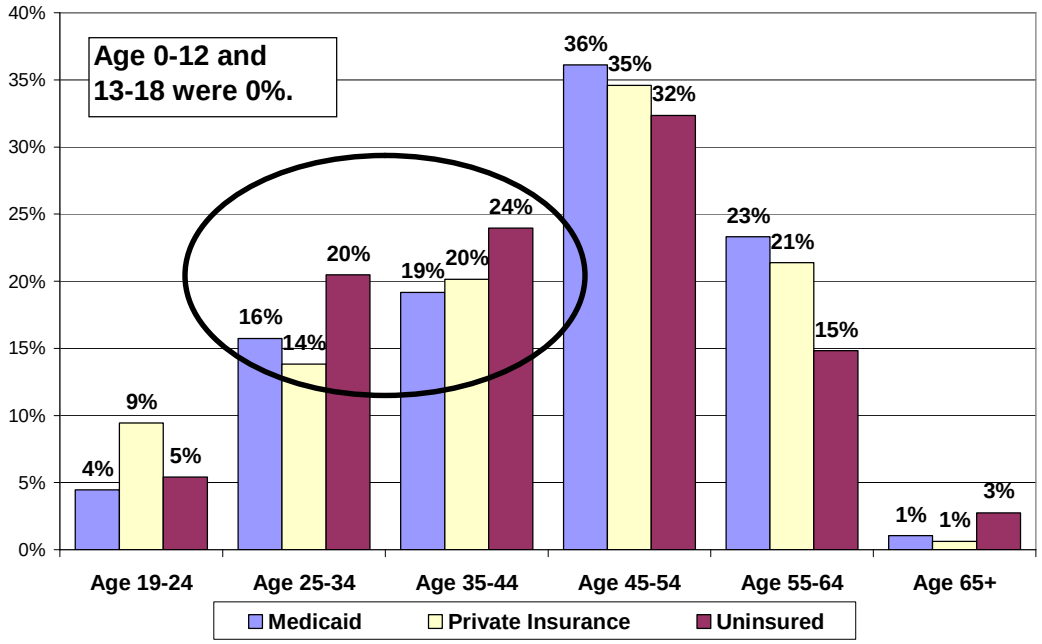
Gender



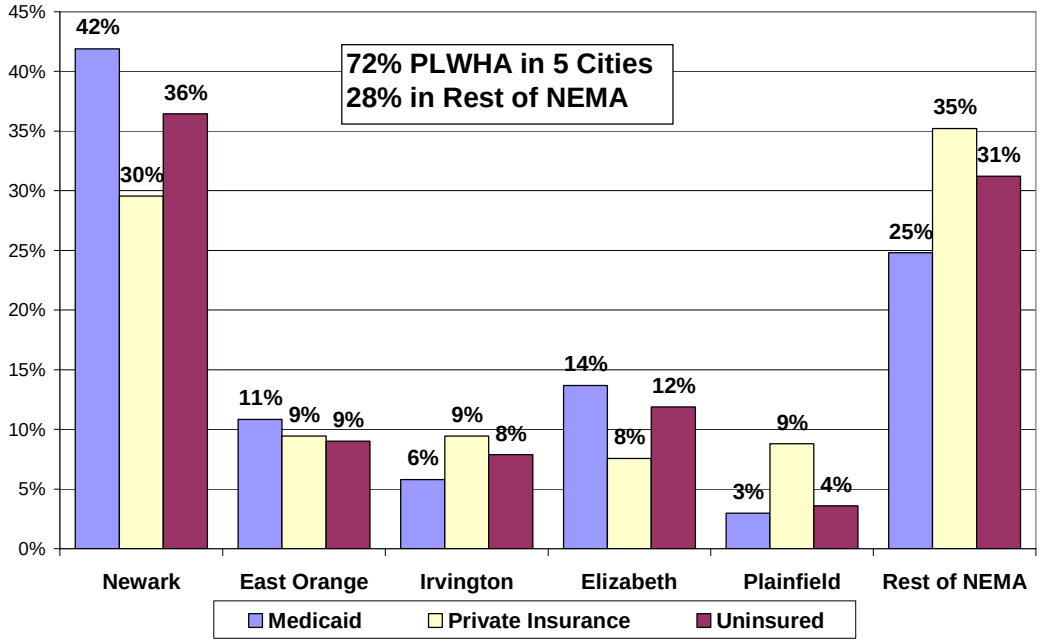
Housing Status



AGE



IMPACT ON 5 CITIES



1.3.4 Are Uninsured RWHAP Clients mostly Undocumented Immigrants?

One hypothesis of the RWHAP uninsured clients is that many are undocumented immigrants. Undocumented immigrants are ineligible for ACA health insurance, and legally admitted immigrants must have been in the United States for at least five years with supporting documentation.

The Ryan White program provides services to PLWHA regardless of immigrant status. The only way the EMA can assess undocumented status is when providers ask clients for their social security number (SSN). The last four digits of the 9-digit CHAMP Client Identifier represent the last four digits of the client SSN. For clients without a SSN, the provider enters "9999" in this field.

Of the total 977 uninsured CY2013/CY2014 clients at the end of CY2014, only **124 or 13% could be considered "undocumented"** according to the CHAMP client ID.

However, many undocumented individuals obtain **Tax ID Numbers or "TIN" from the Internal Revenue Service (IRS).** Providers will enter the last four digits of the TIN into the CHAMP Client ID. Thus, the **CHAMP data understate the extent of undocumented PLWHA receiving RWHAP services including those who are uninsured.**

It is up to providers to identify additional undocumented individuals who are ineligible for ACA health insurance. If they can provide data to the Planning Council and/or Grantee, this could assist us in determining a better estimate of uninsured – and uninsurable – undocumented PLWHA.

1.4 Services Used by Uninsured RWHAP Clients Pre-ACA and Post-ACA

This section looks at clients who were uninsured at the end of CY 2013 and compares services used in 2013 and 2014 – by type of insurance obtained in CY 2014 including those who remained uninsured.

All clients including those who remained uninsured used Ryan White-funded Primary Medical Care services including Medical Visits less in 2014. Likewise, all clients used Medical Case Management (MCM) at higher percentages in 2014. It is expected that insured clients would use less RW medical care but not the uninsured. It is expected that insured clients will use RW-funded MCM services more because MCM is not paid for by health insurance.

Additional changes in Ryan White-funded services used by RW clients' insurance type are:

Medicaid (Including NJ FamilyCare). Figure 5.

- Declines: **Mental Health. OP Substance Abuse, Dental, Medical Nutrition** slightly.
- Increases: **Transportation, Legal. Non-Medical Case Management, Housing** slightly.

Private Insurance Including through the Marketplace. Figure 6.

- Declines: **Dental. Medical Nutrition, Non-Medical Case Management, Housing** slightly.
- Increases: **Transportation. Mental Health, Legal** slightly.

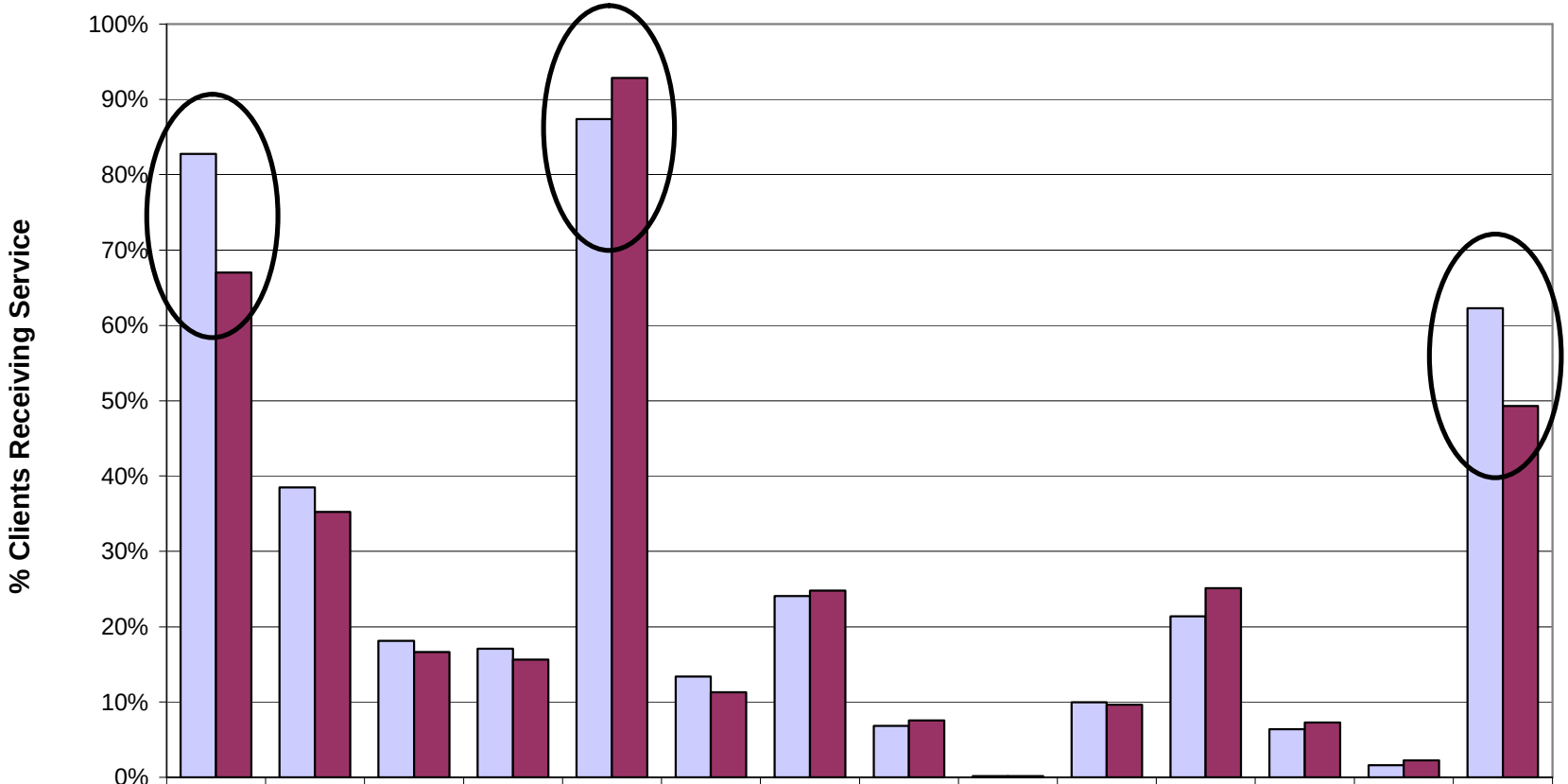
No Insurance (Still Uninsured). Figure 7.

- Declines: **Mental Health. Dental, Medical Nutrition, Non-Medical Case Management,** slightly.
- Increases: **Transportation. Legal, Food** slightly.

Total. Figure 8.

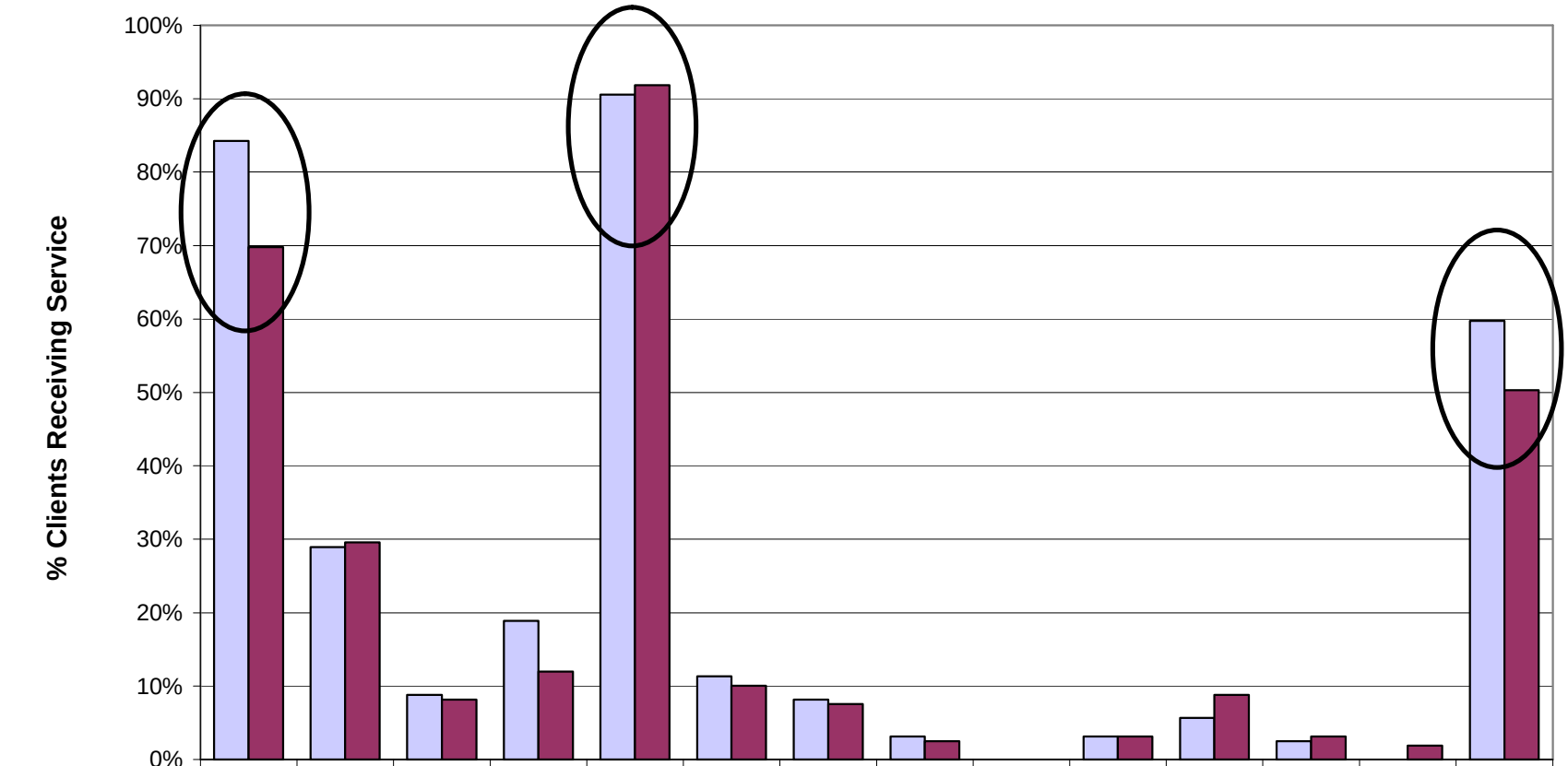
- Declines: **Mental Health. OP Substance Abuse, Dental, Medical Nutrition, Non-Medical Case Management** slightly.
- Increases: **Transportation. Legal, Food** slightly.

Figure 5: RW Service Utilization Pre-ACA and Post-ACA by Uninsured CY2013/CY2014 RW Clients who Obtained MEDICAID in CY2014 (n=673)



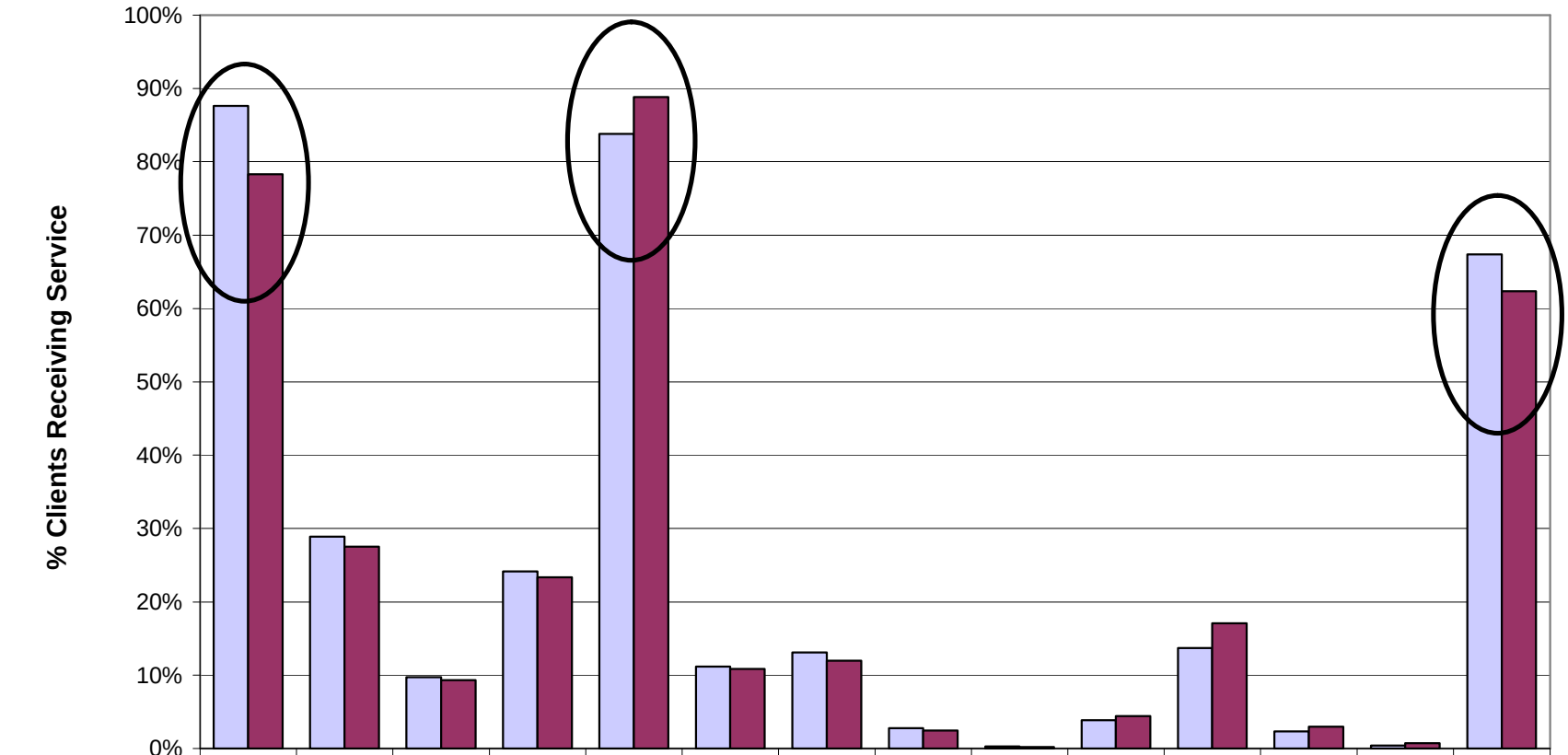
	Med Care	Mental Health	OP Subst Abuse	Dental	MCM	Med Nutrit	CM-NM	Housing	SA Resid	Food	Transp	Legal	Emerg Fin	Med Visit
CY13 Pre-ACA	82.8%	38.5%	18.1%	17.1%	87.4%	13.4%	24.1%	6.8%	0.1%	10.0%	21.4%	6.4%	1.6%	62.3%
CY14 ACA	67.0%	35.2%	16.6%	15.6%	92.9%	11.3%	24.8%	7.6%	0.1%	9.7%	25.1%	7.3%	2.2%	49.3%

Figure 6: RW Service Utilization Pre-ACA and Post-ACA by Uninsured CY2013/CY2014 RW Clients who Obtained PRIVATE INSURANCE INCLUDING THROUGH THE MARKETPLACE in CY2014 (n=159)



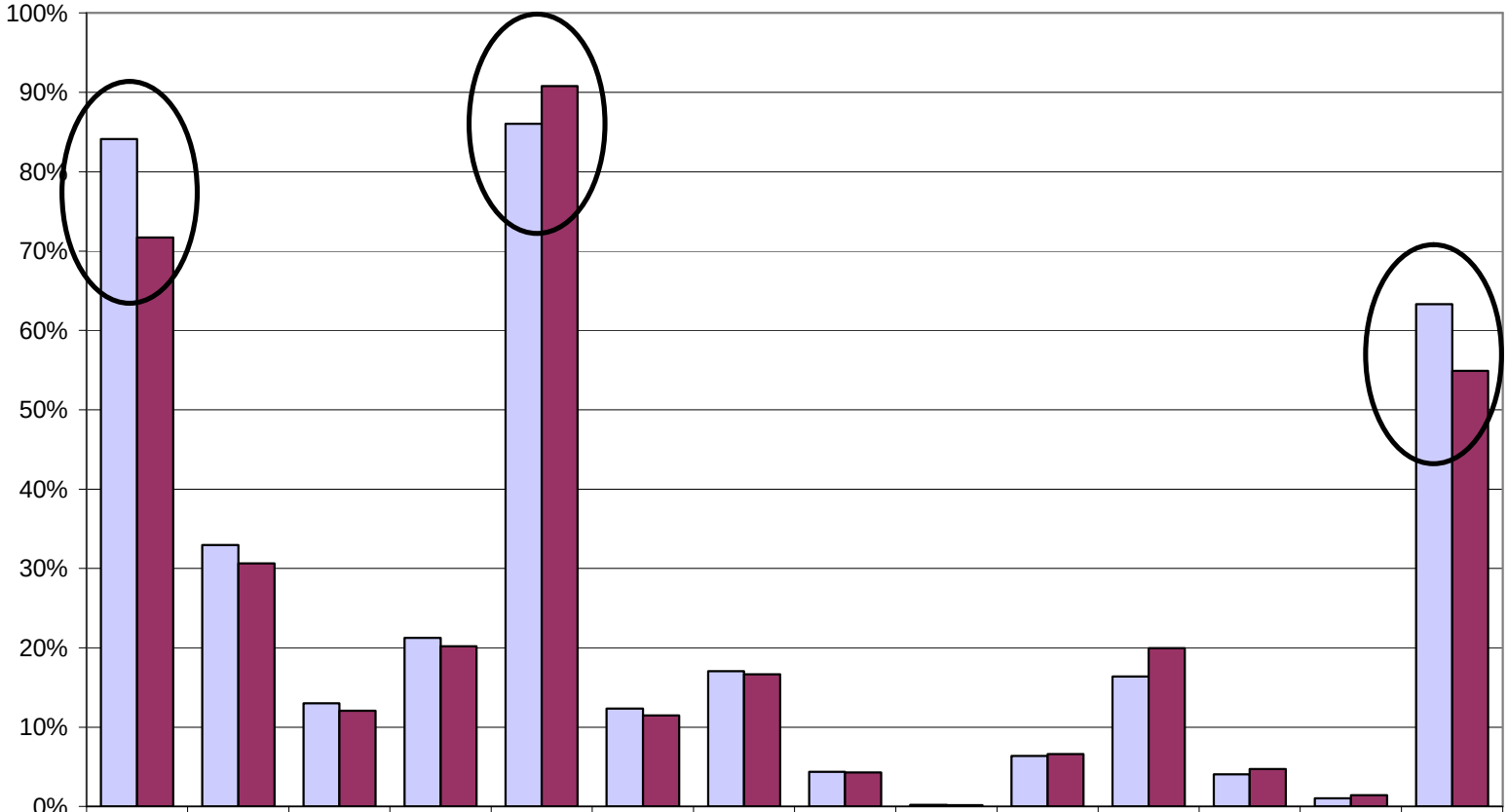
	Med Care	Mental Health	OP Subst Abuse	Dental	MCM	Med Nutrit	CM-NM	Housing	SA Resid	Food	Transp	Legal	Emerg Fin	Med Visit
CY13 Pre-ACA	84.3%	28.9%	8.8%	18.9%	90.6%	11.3%	8.2%	3.1%	0.0%	3.1%	5.7%	2.5%	0.0%	59.7%
CY14 ACA	69.8%	29.6%	8.2%	11.9%	91.8%	10.1%	7.5%	2.5%	0.0%	3.1%	8.8%	3.1%	1.9%	50.3%

Figure 7: RW Service Utilization Pre-ACA and Post-ACA by Uninsured CY2013/CY2014 RW Clients who REMAINED UNINSURED in CY2014 (n=977)



	Med Care	Mental Health	OP Subst Abuse	Dental	MCM	Med Nutrit	CM-NM	Housing	SA Resid	Food	Transp	Legal	Emerg Fin	Med Visit
CY13 Pre-ACA	87.6%	28.9%	9.7%	24.2%	83.8%	11.2%	13.1%	2.8%	0.3%	3.9%	13.7%	2.4%	0.4%	67.3%
CY14 ACA	78.3%	27.5%	9.3%	23.3%	88.8%	10.8%	12.0%	2.5%	0.2%	4.4%	17.1%	3.0%	0.7%	62.3%

Figure 8: RW Service Utilization Pre-ACA and Post-ACA by Uninsured CY2013/CY2014 RW Clients – TOTAL (n=1,925)



	Med Care	Mental Health	OP Subst Abuse	Dental	MCM	Med Nutrit	CM-NM	Housing	SA Resid	Food	Transp	Legal	Emerg Fin	Med Visit
CY13 Pre-ACA	84.1%	32.9%	13.0%	21.2%	86.0%	12.3%	17.0%	4.4%	0.2%	6.4%	16.4%	4.1%	1.0%	63.3%
CY14 ACA	71.7%	30.6%	12.1%	20.2%	90.8%	11.5%	16.7%	4.3%	0.2%	6.6%	19.9%	4.7%	1.4%	54.9%

1.5 Change in RW Service Dollars Used by Uninsured RWHAP Clients Pre-ACA and Post-ACA

The above data show a decline in service utilization. **How can the Newark EMA use this information for FY16 Priority Setting & Resource Allocation?** The answer is to **compare the Ryan White Service Dollars "SPENT" on these clients who were "uninsured" BEFORE ACA (2013) and AFTER ACA (2014) when many got health insurance.** This will indicate which services are not needed as much, and which are still needed or are needed more! As a result of this comparison:

- ➔ The EMA can start to **redefine the HIV service continuum** based on new/emerging needs of the newly insured RW clients.
- ➔ The EMA must **continue to serve PLWHA who remain uninsured and need RW-funded medical care**, and other core medical and supportive services.
- ➔ Resource allocations (percentages) can be adjusted/changed for FY 2016 to ensure that the **Ryan White System of Care continues to meet needs of the EMA's PLWHA regardless of health insurance, coordinates with and complements the ACA, and fills in gaps and continues to provide services not covered by the ACA.**

The following figures and tables show changes in service dollars spent on the 1,925 uninsured clients between CY 2013 and CY 2014.

1.5.1 Findings of Changes in RW Service Dollars Spent Pre-ACA and Post-ACA for Newly-Insured and Uninsured

- There was a decline in services used by these 1,925 clients from CY 2013 to CY 2014, measured by a **decline in service dollars spent, from $5.6 million to $4.7 million**.
  - This is a change of **minus (-16.2 %) or minus (-$914,708)** See Table 5.
- **Most change occurred among the newly insured (-21%). (Figure 9.)**
  - Also, **most change occurred among Core Medical Services.**
    - BUT, there was **an increase in 2 Core Medical Services** by the insured especially NJFC clients – **Oral Health and Medical Case Management (MCM).**
  - There was a slight reduction in **Support Services used, but RW Clients newly insured by NJ Family Care had an increase in the use of Support Services!**
    - The key support services showing increases were **Case Management Non-Medical (CM-NM) and Medical Transportation.**
- There were reductions in services to the **Uninsured, that is, current Ryan White clients.** This may be due to vigorous enforcement of payer of last resort policy, increased use of "nonbillable" services in CHAMP. This must be investigated further. **The EMA cannot short change or reduce services to uninsured RW clients.**

1.5.2 Recommendations

- Consider **adjusting the percent allocations by service category** to reflect these changes in RW services used by clients newly insured through ACA.
    - **Possible reductions:** Medical care.
    - **Possible increases:** MCM, Oral Health. Case Management – Non-Medical, Medical Transportation.
- Make adjustments in resource allocations **in coordination of other RW service information** - including the findings of the rest of this 2015 Needs Assessment Update, Grantee FY 2014 Service Utilization Report, FY 2016 Funding Stream Analysis, HRSA policy and recommendations for HIV Care Continuum.
- **Actual amounts of adjustments to service allocations will be determined by the Newark EMA HIV Health Services Planning Council following recommendations by the Comprehensive Planning Committee (CPC).**

Figure 9: Percent Change in Services Used by all RW Clients Newly Insured and Still Uninsured from CY 2013 to CY 2014

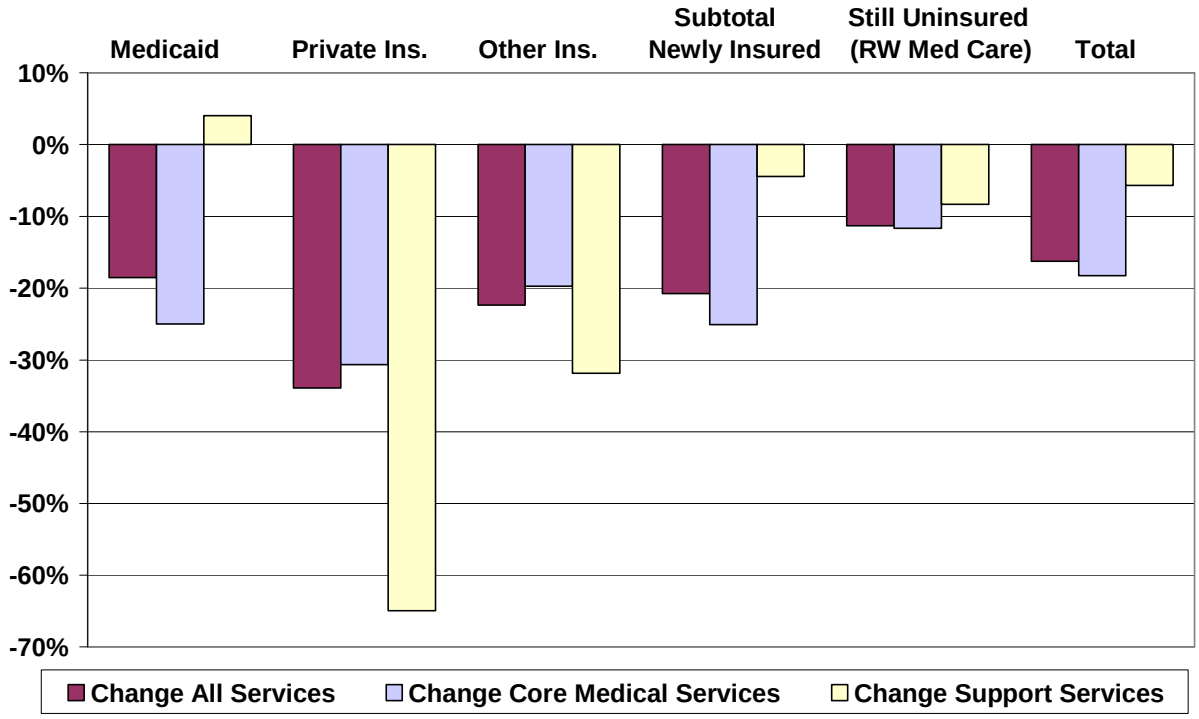


Table 5: Change In Ryan White HIV/AIDS PROGRAM (RWHAP) Service Dollars Used By These 1,925 Clients - CY 2013 TO CY 2014

TOTAL SERVICES	Type of New Insurance in CY2014			Subtotal New Insured	Still Uninsured	Total
	Medicaid	Private Ins	Other Ins			
CY 2013 Total	$2,220,326	$336,028	$380,734	**$2,937,088**	**$2,692,103**	**$5,629,190**
CY 2014 Total	$1,809,073	$222,105	$295,584	**$2,326,762**	**$2,387,720**	**$4,714,482**
Change CY13-CY14	**-$411,253**	**-$113,923**	**-$85,150**	**-$610,326**	**-$304,382**	**-$914,708**
Percent	**-18.5%**	**-33.9%**	**-22.4%**	**-20.8%**	**-11.3%**	**-16.2%**

CORE MEDICAL SERVICES	Type of New Insurance in CY2014			Subtotal New Insured	Still Uninsured	Total
	Medicaid	Private Ins	Other Ins			
CY 2013 Total	$1,724,319	$304,312	$297,468	**$2,326,098**	**$2,398,538**	**$4,724,637**
CY 2014 Total	$1,293,160	$210,988	$238,827	**$1,742,974**	**$2,118,525**	**$3,861,499**
Change CY13-CY14	**-$431,159**	**-$93,324**	**-$58,641**	**-$583,124**	**-$280,013**	**-$863,137**
Percent	**-25.0%**	**-30.7%**	**-19.7%**	**-25.1%**	**-11.7%**	**-18.3%**

SUPPORT SERVICES	Type of New Insurance in CY2014			Subtotal New Insured	Still Uninsured	Total
	Medicaid	Private Ins	Other Ins			
CY 2013 Total	$496,007	$31,716	$83,266	**$610,989**	**$293,564**	**$904,553**
CY 2014 Total	$515,913	$11,117	$56,757	**$583,788**	**$269,195**	**$852,982**
Change CY13-CY14	**$19,906**	**-$20,599**	**-$26,508**	**-$27,202**	**-$24,369**	**-$51,571**
Percent	**4.0%**	**-64.9%**	**-31.8%**	**-4.5%**	**-8.3%**	**-5.7%**

Table 6: Estimated RWHAP Service Dollars Used By These 1,925 Clients in CY 2013

Service Category	Type of New Insurance in CY2014			Subtotal New Insured	Still Uninsured	Total
	Medicaid	Private Ins	Other Ins			
Medical Care CY13	$852,215	$167,664	$104,288	$1,124,166	$1,308,622	$2,432,788
Medical Visit CY13	$469,814	$78,401	$55,308	$603,523	$752,575	$1,356,097
Mental Health CY13	$165,903	$21,655	$49,454	$237,011	$155,001	$392,012
OP Substance Abuse CY13	$161,808	$3,193	$30,343	$195,344	$81,074	$276,418
Oral Health CY13	$88,501	$20,344	$30,055	$138,900	$214,948	$353,848
Medical Case Mgt CY13	$434,174	$89,338	$78,661	$602,174	$616,468	$1,218,642
Med. Nutr. Therapy CY13	$21,718	$2,118	$4,667	$28,503	$22,426	$50,929
Case Mgt Non-Med. CY13	$105,157	$4,854	$14,080	$124,090	$73,555	$197,645
Housing CY13	$228,001	$19,973	$43,173	$291,146	$140,210	$431,357
Resid. Sub. Abuse CY13	$26,965	$0	$0	$26,965	$19,261	$46,226
Nutrition CY13	$11,837	$570	$1,353	$13,760	$7,321	$21,081
Med Transportation CY13	$31,261	$294	$8,410	$39,965	$26,702	$66,667
Legal CY13	$87,167	$6,026	$12,793	$105,986	$25,436	$131,422
Emerg. Financial CY13	$5,620	$0	$3,457	$9,077	$1,079	$10,156
Total Cost CY13	**$2,220,326**	**$336,028**	**$380,734**	**$2,937,088**	**$2,692,103**	**$5,629,190**

Table 7: Estimated RWHAP Service Dollars Used By These 1,925 Clients in CY 2014

Service Category	Type of New Insurance in CY2014			Subtotal New Insured	Still Uninsured	Total
	Medicaid	Private Ins	Other Ins			
Medical Care CY14	$404,131	$83,837	$54,506	$542,475	$1,019,494	$1,561,968
Medical Visit CY14	$254,696	$45,757	$31,548	$332,000	$632,342	$964,342
Mental Health CY14	$146,309	$16,802	$39,373	$202,484	$116,972	$319,456
OP Substance Abuse CY14	$128,249	$1,407	$18,967	$148,623	$73,328	$221,951
Oral Health CY14	$108,794	$14,691	$34,967	$158,452	$206,398	$364,850
Medical Case Mgt CY14	$488,029	$92,588	$87,197	$667,814	$684,298	$1,352,112
Med. Nutr. Therapy CY14	$17,647	$1,663	$3,816	$23,127	$18,035	$41,162 is
Case Mgt. Non-Med. CY14	$141,151	$2,780	$21,490	$165,421	$76,168	$241,589
Housing CY14	$227,030	$4,338	$7,337	$238,705	$120,622	$359,327
Resid. Sub. Abuse CY14	$15,838	$0	$0	$15,838	$24,545	$40,383
Nutrition CY14	$14,551	$498	$2,260	$17,309	$6,356	$23,665
Med. Transportation CY14	$36,020	$199	$4,493	$40,712	$24,815	$65,527
Legal CY14	$75,699	$2,455	$20,794	$98,947	$15,033	$113,981
Emerg. Financial CY14	$5,625	$847	$384	$6,856	$1,656	$8,511
Total Cost Client CY14	**$1,809,073**	**$222,105**	**$295,584**	**$2,326,762**	**$2,387,720**	**$4,714,482**

Table 8: Change in Estimated RWHAP Service Dollars Used By These 1,925 Clients from CY 2013 to CY 2014 by Service Category

Service Category	Type of New Insurance in CY2014			Subtotal New Insured	Still Uninsured	Total	% Chg
	Medicaid	Private Ins	Other Ins				
Medical Care CY13-CY14	-$448,083	-$83,827	-$49,781	-$581,692	-$289,128	-$870,820	-36%
Medical Visit CY13-CY14	-$215,118	-$32,644	-$23,760	-$271,523	-$120,232	-$391,755	-29%
Mental Health CY13-CY14	-$19,594	-$4,852	-$10,081	-$34,527	-$38,028	-$72,556	-19%
OP Subst Abuse CY13-CY14	-$33,559	-$1,786	-$11,376	-$46,721	-$7,746	-$54,467	-20%
Oral Health CY13-CY14	$20,293	-$5,653	$4,912	$19,552	-$8,550	$11,002	3%
Med Case Mgt CY13-CY14	$53,855	$3,250	$8,536	$65,640	$67,830	$133,470	11%
Med Nutr Therapy CY13-CY14	-$4,070	-$455	-$851	-$5,376	-$4,391	-$9,767	-19%
Case Mgt Non-Med CY13-CY14	$35,994	-$2,073	$7,410	$41,331	$2,613	$43,944	22%
Housing CY13-CY14	-$970	-$15,635	-$35,836	-$52,441	-$19,589	-$72,030	-17%
Resid. Sub. Abuse CY13-CY14	-$11,128	$0	$0	-$11,128	$5,284	-$5,844	-13%
Nutrition CY13-CY14	$2,714	-$72	$907	$3,549	-$964	$2,584	12%
Med Transportation CY13-CY14	$4,759	-$95	-$3,917	$747	-$1,888	-$1,140	-2%
Legal CY13-CY14	-$11,468	-$3,571	$8,001	-$7,039	-$10,402	-$17,441	-13%
Emerg. Financial CY13-CY14	$5	$847	-$3,073	-$2,221	$577	-$1,644	-16%
Change Total Cost CY13-CY14	**-$411,253**	**-$113,923**	**-$85,150**	**-$610,326**	**-$304,382**	**-$914,708**	**-16%**

YELLOW HIGHLIGHTING = INCREASE IN COSTS/SERVICES USED

PART 2: FOCUS GROUPS OF CONSUMER BARRIERS AND SERVICE NEEDS POST-ACA

2.1. Background

In order to address the Research Question and to ensure that the Council fulfilled its mandate to obtain consumer input, it was agreed for the Needs Assessment-Update 2015 that Focus Groups should be held with HIV+ consumers of Ryan White services who receive HIV care and are currently enrolled in either a Medicaid Expansion/NJFC or a health insurance exchange plan. These "Community Conversations" would help determine unmet need and service gaps experienced by PLWHA in ACA during 2014.

The objectives were to (1) identify which core medical and support services are needed since the consumers' transition to a Medicaid Expansion/NJFC or a health insurance exchange plan, and (2) Identify new needs, e.g., support groups, peer or patient navigators, psychosocial support services and other services **not currently funded by the Newark EMA RW program.**

A total of 13 focus groups were held at 11 agencies using a Focus Group Guide. Part of the focus group participation included completing a brief consumer survey. The results of this survey from 97 focus group participants are discussed further in this Needs Assessment Update. The Focus Group guide is in **Appendix B.** To the extent possible, the focus groups were conducted during regularly scheduled consumer meetings, e.g., Community Advisory Boards (CABs), support groups for women, LGBTQ youth, the Haitian population, persons in transitional housing, and other consumer support groups.

2.2. Focus Group Findings

A total of 97 individuals participated in the focus groups in Essex County, Union County, and the Morris, Sussex, Warren Region. The demographics in terms of gender, race ethnicity, age and county of residence pretty much reflected the HIV epidemic of the Newark EMA. (See detailed data and report of Consumer Survey.) Importantly, the focus groups provided unique perspectives of subpopulations including LGBTQ youth, persons at or near homelessness, HIV+ women, persons in suburban/rural areas, and of course the African-American and Hispanic/Latino populations who comprise the majority of the Newark EMA HIV epidemic.

2.2.1 Changes in HIV care since Enrollment in Health Insurance

Since you enrolled in Medicaid Expansion/NJFC or a health insurance exchange plan, what has changed in your HIV care since you received coverage? Specifically, (1) doctors, (2) medications, (3) payment – insurance, charity care, Ryan white.) These would be considered gaps. Do you feel like your access to HIV care is better or worse, and why?

- **Health Insurance Coverage.** Most participants were enrolled in Medicaid with a few still in Charity Care (that is, Ryan White-funded medical care). Specific insurance companies mentioned included United Healthcare, WellCare and Horizon. The majority had been enrolled

in Medicaid for more than one year and less than one quarter were newly enrolled in Medicaid/New Jersey Family Care in 2014-2015 under the Affordable Care Act.

  - Most of the consumers in the focus groups were enrolled in Medicaid. Some of the consumers were newly enrolled into Medicaid and some had been on Medicaid for quite some time. While most of the participants reported that they liked their Medicaid health insurers and did not have any complaints, a few consumers reported they had issues with Medicaid health insurers. Some reported displeasure with specific insurers.

- **Multiple Providers.** Some participants did not like the Medicaid requirement to see their primary care provider (PCP) AND their traditional Infectious Disease provider, while others did not mind this arrangement. A number of participants in Essex County found this multiple provider requirement a barrier to HIV care.

- **Ryan White Funded Medical Providers.** Consumers who receive services at Ryan White medical providers, regardless of the payment source, were pleased with their providers. This was true among consumers throughout the EMA - Essex County, Union County, and the Morris/Sussex/ Warren county region. Participants cited specific physicians at Ryan White funded medical providers during the focus groups and said their **HIV medical care continued to be excellent** from these providers even now that they had Medicaid.

- **Co-pays are/not Barriers.** Some consumers talked about how the co-pays prevent them from going to the doctor. Others found that there was little to no change in coverage in their HIV care other than the need for having a copayment. Patients also reported that there were no barriers and that their HIV care seems to be the same thus far.

- **Navigating the Health care System is a challenge.** A number of consumers raised questions in regards to navigating the healthcare system.

- **Veterans' Healthcare.** Participants in the focus group at the Veteran's Administration (VA) in East Orange had interesting insights into health insurance and the Ryan White system of care. All participants were newly enrolled in Medicaid, but none of the clients felt the need to utilize Medicaid because they received all their medical care needs at the Department of Veteran Affairs. However, when participants attempted to make use of their Medicaid services, they reported unpleasant experiences. They did not like sharing all of their history with a new doctor, only to be referred to see a specialist. One veteran also shared that the insurance company was going to switch his medication, which he had no desire to do. The clients felt as though it was a complete waste of time and they would rather continue to receive their medical services at the Department of Veteran Affairs. One client has been receiving care from the Department of Veteran Affairs for 20 years and others for more than four years. Everything is made convenient for the veterans at the Department of Veteran Affairs. The doctors at the Department of Veteran Affairs also work at area hospitals.

  - On a positive note, the Department of Veteran Affairs has the **new Hepatitis C medication available for the veterans.** This is an important medical benefit for co-infected Hepatitis C/HIV-positive veterans.

- **Providers Not in Network.** One participant shared that none of her doctors at the Ryan White-funded clinic are in one health insurer's network. This is frustrating because she is comfortable with her current group of doctors and does not want to change them.

- **Slow Dual Eligibility Determination.** One participant has Medicare but wanted supplemental care through Medicaid. The participant has tried to apply but hasn't heard back from them regarding her application. (It was unclear if the application was through their Medicaid health insurer or some other entity.)
- **Barriers Summarized by CAB.** One Consumer Advisory Board (CAB) summarized the experience of clients' HIV care before Medicaid Expansion versus after transfer to Medicaid. Participants stated that their infectious disease doctor used to be able to treat everything and now they must have both an infectious disease doctor and a primary care physician. Clients also talked about how referrals, 20% copay (Medicare Part B coinsurance?), and denial of treatment of services are issues they have to deal with.

2.2.2 Barriers Experienced

What barriers have you experienced?

- **Case Management.** Some consumers expressed displeasure with their case managers because of their lack of knowledge and other reasons.
- **Disparate Treatment.** A few consumers felt that they had been treated unfairly based on race and/or class. No further information or detail was provided.
- **Medicaid Transportation.** Participants in the Tri-County region – both male and female - had problems with the Medicaid transportation provider, Logisticare. They reported that drivers were routinely late for both appointments and pickups, and they had complained directly to Logisticare regarding this. Drivers also had clients sign pick up forms without filling out the time of pickup. Although some drivers were good, most are not up to par. Participants were "grateful for the transportation to their doctor appointment in any type of weather, but wish the drivers weren't always late."

  Consumers in the urban counties were displeased with medical transportation services and transportation in general. Consumers expressed that more funding should go towards medical transportation services. Participants stated that Logisticare is always late and they end up missing appointments and rescheduling them. Some agencies provide bus cards but one participant expressed that taking the bus is hard for PLWHA during the winter, when it's really cold and during the summer when it is really hot.

  Some said their medications require them to wear sunscreen but consumers can't afford sunscreen, which becomes an issue when clients have to take the bus.

  Veterans need transportation services. The only service the Department of Veterans' Affairs does not provide is medical transportation services.
- **Changes in Medications.** One consumer shared that every time he has to get his medications filled, he is told that he has another carrier (CBS) and it causes a delay in receiving medication. A woman shared that her health insurer took her off of Lyrica, which was working well for her, but was told by her doctor that it's up to the health insurer to allow her to take that medication.

- **Lack of Knowledge that Ryan White Covers Healthcare for Undocumented HIV+ Individuals.** One client shared that she was waiting for her citizenship status to be approved and because of that, her medical bills haven't been covered. The client is not aware of services that are available to assist with paying bills. **Comment: the Ryan White program pays for medical care regardless of immigrant status. All RW-funded agencies, not only case managers and medical case managers, should know this. This underscores a training need in the Newark EMA.**
- **Referrals to Specialty Care Not Approved.** One participant spoke about referrals to specialty care doctors, noting that her insurance company denied a referral to her cardiologist.
- **Being Billed for Specialty Care despite having Insurance.** Consumers also talked about the issues they have with seeing specialty care doctors and the numerous medical bills they receive for their doctors' appointments.
- **Different Medical Equipment/Devices.** One consumer shared that her insurance switched the machine that she used for one of her conditions. The insurer replaced her machine with an older machine that she has used in the past and doesn't like.
- **Uncovered Health Needs are not Affordable.** One participant said she needed eyeglasses, but had no way of paying for them. Vision care as a priority for clients as well, but clients are not able to pay for the glasses.
- **Mental Health not as Accessible.** One consumer had been able to have appointments with mental health counselors over the phone but they (health insurer) don't offer that service anymore. Being able to take appointments over the phone was helpful when the participant had no way to get to her mental health counselor.
- **"Proactive Service-Seeking".** As far as barriers to services, women in one focus group expressed that they have no barriers to services because they are very proactive in getting the care and help that they need.

2.2.3 Special Populations – LGBTQ Youth and Haitian PLWHA

Two focus groups were held in regularly scheduled support group meetings of two HIV+ populations with special needs and concerns. These are (1) Lesbian, Gay, Bisexual, Transgendered, Questioning (LGBTQ) Youth age 16 to 24, and (2) the Haitian subpopulation who were studied in the 2014 Needs Assessment. The author thought it would be useful to present their issues in a special section rather than to combine them with the rest of the PLWHA.

LGBTQ Youth

Participants of the LGBT focus group regularly attend a support group facilitated by a Ryan White-funded agency. Members of the group are between the ages of 16 and 24, but a few participants are over age 24.

- **Health Insurance.** Only one of the nine participants did not have insurance. The young man had applied for everything by himself but was denied. Because of his low income, he was advised to go the welfare office to be screened for state benefits including Medicaid. The youth

currently receives medication through ADAP and medical care from one of the Ryan White-funded medical providers in the EMA. The other participants have one of the three New Jersey Family Care Medicaid Insurance providers.

- **Barriers.** One of the complaints about insurance was the **high copayments**. Participants also expressed dissatisfaction with **preauthorizations**. One consumer has been waiting for two months for medicine that was prescribed by his doctor. The health insurer has yet to approve the **medication** so the client has been taking vitamins and Truvada.
- **Access to Medical Care.** The participants go to Ryan White-funded medical providers for their HIV care, who have helped some of them enroll in Medicaid. Some participants commented that the doctors at another Ryan White-funded medical provider are often switched and they don't like that. (**Continuity of care** issues.)
- **Medication Adherence.** One of the older participants (over age 24) expressed having a hard time adhering to the HIV medicine. The current medication gives him nightmares. (**Comment:** The focus group did not explore or report the reason that this individual did not consult the physician for a change in medication.)
- **Housing and Case Management.** Clients lastly spoke about their dissatisfaction with case management and housing. Participants agreed that case management services should be better in the Newark EMA. Housing is another concern amongst the youth. (**Comment:** The focus group did not explore the reasons or shortcomings of case management. It is assumed that the problem with housing is lack of affordability.)

Haitian PLWHA

A small focus group was held with Haitian PLWHA at a regularly scheduled support group meeting. The Case Manager helped translate the focus group questions into Creole.

- **Health Insurance.** One of the participants was newly enrolled in Medicaid while the other participant was waiting to be enrolled. Both participants receive regular medical care for HIV from a Ryan White-funded medical provider. Both clients prefer to this provider because they like the treatment and care that they receive.
- **Barriers.** Since being enrolled in Medicaid Expansion, the clients reported that it is difficult to navigate the system and it is too much of a hassle. One client reported that the system is definitely not built for people with a language barrier. They feel they must carry all their information (passport, green card, etc.) with them because they never know when they are going to need it and they don't know why they need it. Both clients stated they were accustomed to using Charity Care and the transition into Medicaid has been difficult.
- **Language Barriers.** The case manager reported that most of the Haitian clients coming to their clinic do not know how to read so that also adds to the difficulties they have with Medicaid. The clients wish there were more Creole speaking doctors and nurses. (**Comment:** It is unknown if the participants are illiterate or just cannot read/understand written English.)
- **Other Service Needs.** Outside of primary medical care, clients are having trouble accessing **vision care**. One client reported that she either lost her **eye glasses** or they were stolen, and now she must wait a year until she can receive another pair. Another service that clients are

having trouble accessing includes **referrals for jobs and clothing. Housing assistance** is another service the clients are having trouble accessing. Both have immediate family that they are trying to bring to America but they are not able to bring the family here unless they have stable housing that they are able to afford. **Furniture** is another need.

2.2.4 Services You Have Problems Accessing

What services, if any, are you having problems accessing?

Core Medical Services

Medicaid Expansion-New Jersey Family Care-gives access to considerable medical care. However, many barriers remain which are challenges to the continuity of care for PLWHA.

- **Medical care/specialty care.** Most participants transitioned into Medicaid Expansion through health insurance providers. While participants reported that HIV care has remained the same, receiving care for other ailments has become a challenge.
    - Instead of having an infectious disease doctor that takes care of everything, consumers are now referred to specialists. When trying to find **specialists through health insurance network, the lists of specialists are either no longer in practice or not taking new clients.** This is a huge issue for clients who need treatment for other illnesses.
    - **Waiting Time for Appointments with Specialists.** Clients additionally spoke about referrals to see specialists. One client in particular, stated that he was in a great deal of pain and was referred to see a neurologist. However, the wait time to see the neurologist was a month. The client was not sure how he would cope with the pain until his appointment with the neurologist.
- **Copays.** Another barrier for clients is providing an out of pocket copay for doctor visits. The quality of care is not the problem but being able to access care is now the dilemma.
- **Hepatitis C.** More than one participant shared that they have Hepatitis C and are not able to receive treatment because the medication is too expensive.

Support Services

With the emphasis of the Ryan White HIV/AIDS Program (RWHAP) on improving medical outcomes, Support Services appear to have been an afterthought with an allocation of only 25% of direct service funding. As the Affordable Care Act and Medicaid Expansion have been implemented, however, the significant need for support services has been uncovered. The lack of basic supports of stable housing and food lead to personal instability which impedes consistent adherence to medication regimens and improvement in health outcomes as measured by Viral Load Suppression. Focus group results confirm the need for the services.

- **Housing.** Housing is expensive and clients are having difficulty paying rent. One participant questioned if there is some transitional support for clients moving from subsidized housing.

Lack of permanent housing was the biggest barrier for PLWHA voiced in the urban focus groups. Almost everyone participating had concerns about housing. The availability of permanent, affordable housing is intertwined with the **HOPWA Program**. Clients voiced that the cost of living goes up every year but the HOPWA vouchers stay the same. Participants expressed the need for a **housing support group** and **funding for security deposits**. One client stated that without stable housing, PLWHA aren't able to take their medications requiring refrigeration.

- **Housing Opportunities for People With AIDS (HOPWA).** Participants expressed the drawbacks about HOPWA. Participants they felt the new HOPWA guidelines were unfair. Many PLWHA are on the waiting list for a long time - up to ten years. The housing options provided by HOPWA are in neighborhoods that are not safe (unsafe) or in buildings that are not in the best condition. One woman shared that she has been staying at one location for a while and she likes where she is living. She does not want to leave but she knows she will have to find another place once she is taken off of HOPWA. Many participants felt that other people were taking advantage of the HOPWA program and not adhering to their policies. The participants stated that they know people who are working and buying brand new cars but are living in HOPWA housing facilities.
- **Food Bank/Home Delivered Meals.** One participant in the Tri-County region expressed that more funding should be put towards food bank/home delivered meals. At the end of the month, participants are low on cash and food vouchers would be helpful, because some medications require taking food with them. Food pantries are okay for lunch and dinner, but a voucher would be good for breakfast. Consumers in Essex County expressed the need for more funding for food bank/home delivered meals. In Union County, clients also voiced their opinions about food vouchers. One agency provides a $15 food voucher to a supermarket located near the agency. However, food is overpriced and the meat isn't always in the best condition.
- **Some Ryan White Agencies.** Participants had several complaints about Ryan White agencies in Essex County. They did not like the fact that to be able to receive emergency financial assistance from a particular agency, they had to participate in a program offered at the agency. They felt that the program was of no use to them and they only needed the emergency financial assistance. Clients also complained about the same agency regarding other services offered. A few participants agreed that the services offered were terrible and that they do not offer assistance with housing, as promised. Clients also stated that a particular agency holds onto funds until it's time for the new budget.

  There was a discussion about the services provided at the Ryan White agencies in **Union County**. Clients stated that there were instances when they felt that they were mistreated by staff and they talked about the need for better case management. (**Comment on this section:** The Planning Council staff who conducted these focus groups should provide specific information to the Grantee for further investigation.)
- **Legal Services.** One client voiced dissatisfaction about legal services in Union County but no further detail was provided.
- **Other.** Participants in Union County voiced that agencies need to "change their guidelines" but no further information was provided about which services were involved.

2.2.5 Comments on Service Needs in Addition to Medical Care

These comments reinforce the above findings or are new.

- **Housing.** More funding and access to stable, permanent, affordable housing.
- **Emergency Financial Assistance.** Easier access to emergency funding when needed without going through special provider-specific programs.
- **Transportation.** More funding for transportation. Help to improve Medicaid transportation services of Logisticare or another vendor.
- **Oral Health Care.** Oral health care is a top priority. Most participants (in one group) are aware of the Dental Clinic at Rutgers. One participant was not aware of this service. Consumers seem to be pleased with services at the Dental Clinic and most receive regular oral health care. (**Comment:** There appears to be widespread need for knowledge of and referral to services in the comprehensive continuum of Ryan White Care as well as non-Ryan White services.)
- **Mental Health Services.** Participants in a women's focus group shared that mental health services are top priority.
- **Services for HIV+ veterans.** During the discussion on needed services, one of the veterans expressed that housing is a top priority along with emergency financial assistance. One of the veterans stated that, if they no longer have to worry about housing or emergency financial assistance, then that alleviates a lot of stress. One client would like Holistic services to be provided in the Newark EMA. In addition, transportation is another service needed by veterans that's not provided by the VA.
- **Support Groups.** Many participants expressed the need for **support groups** outside of mental health and substance abuse. (These would be funded under a new category of **"psychosocial support" services.**) Clients like being able to talk to others about their day to day issues.
    - Some participants noted the need for support groups for **discordant couples**.
    - However, a women's group noted a **caveat of these support groups**. The clients mentioned that they like having support groups because they'll always find one person who can relate to what they're going through. However, **there seems to be no resolution to their problems.** After they leave the support group, the participants expressed that "they feel as though the same problems occur all over again." In other words, the **support groups must provide practical methods to help clients address or solve the problems and concerns that brought them to the group in the first place.**
- **Buddy System.** Some participants stated that a buddy system is needed, where someone would help **advocate and speak out for them to receive the necessary care/treatment.**
- **Legal Services. Other participants stated** that there is a need for legal services particularly when applying for Social Security. There is a program called SOAR in Middlesex County that trains case managers to help consumers apply for social security and other programs. NEMA needs a program like SOAR. (**Comment:** It is possible that Ryan White-funded legal services assist PLWHA with Social Security applications. If this is the case, then the availability of this service should be made known to Ryan White funded agencies throughout the EMA.)

2.2.6 Additional Comments/Information

Do you have any questions for us? About Obamacare? Services? Use this time to follow up on any outstanding issues, concerns, etc. raised.

- **Additional Community Conversations.** Participants in the Tri-County region expressed interest in attending additional Community Conversations in the Newark EMA, but that will be a challenge to come from this region to Newark for forms held in the early evening hours.
- **Misconceptions about Availability of HIV Services based on Degree of Illness.** In one focus group, the facilitator talked about how there is a big push for viral load suppression in the Newark EMA and how the goal is to get the viral load low in order for PLWHA to remain healthy. One of the consumers asked if a PLWHA would receive more benefits if they were to get sicker. Participants explained how **there is a misconception that the sicker you are, the more benefits a PLWHA will receive.**
- When asked what services consumers would like to see in the Newark EMA, a young client asked if it was possible [for the RW-funded agency] to raise funds for **clients to do fun activities.**
- **Importance of Self-Advocacy.** One urban group understood the importance self-advocacy and the importance of providing input to the Newark EMA Planning Council. Participants talked about Ryan White providing speakers' advocacy training. The group attributed their lack of participation on the Planning Council to transportation, which was also a top priority for the group. Council staff told participants that the Planning Council can provide train tickets to any participants that would like to come to any of the Planning Council or committee meetings.
- **Lack of Information about Services.** One participant shared that years ago, he accessed services and attended advocacy groups but now he doesn't know where to go. He felt that services and information are not as readily available as they once were. The participant specifically didn't know where to go for dental services.
- **Concern about Funding Reductions.** Some participants had questions about funding and why it has decreased.
- **Concern about Stigma.** Some participants also had a discussion about stigma and fear of disclosure to the community. One participant shared that PLWHA should expose themselves to advocate for what the community needs. Others noted that PLWHA can advocate for services without disclosing their status.

PART 3: KEY INFORMANT INTERVIEWS OF MEDICAL AND NON-MEDICAL CASE MANAGERS – SERVICE NEEDS POST-ACA

3.1. Background

In order to address the Research Question and to ensure that the Council fulfilled its mandate to obtain information on demonstrated need, it was agreed for the Needs Assessment-Update 2015 that interviews with Key Informants (KI) should be conducted with all **Medical and Non-Medical Case Managers – MCM and CM-NM**. These KI interviews would help determine unmet need and service gaps experienced by PLWHA in ACA during 2014 from the perspective of providers and Ryan White-funded agencies serving PLWHA. Specifically, medical and non-medical case managers – MCM and CM-NM agencies.

A total of **35 agencies were targeted – 18 for MCM and 17 CM-NM.** A KI survey tool was developed and used. The KI tool is in Appendix A. The REC received KI responses and members of the REC conducted follow up phone interviews to clarify results of the KI survey responses where needed**.** The KI interviews were conducted from May 1, 2015 through June 30,2015.

3.2. Findings – Medicaid Expansion (NJFC)

#1 In thinking of the clients you work with, what number or percent of clients have enrolled in Medicaid expansion/NJFC?

This ranges by agency from a low of 30% to midpoint of 50% to high of 75%-95%. (See Part 1 for some actual numbers for the EMA using CHAMP data.)

#2 Transition from RW funded services to Medicaid Expansion/NJFC.

#2A In thinking of the clients who moved/enrolled into Medicaid Expansion/NJFC, please indicate what services you are currently providing under Ryan White, what services are being covered Medicaid Expansion/NJFC and what services are not covered by either Medicaid or Ryan White.

The responses to this question reflect the perceptions and knowledge of respondents. That is, this table **does not reflect the services actually provided by Ryan White (RW) or Medicaid/NJFC, but the perceptions of the respondents.**

	SERVICES	Currently Provided under RW	Currently Provided under Medicaid/NJFC	NOT COVERED BY RW or MEDICAID/NJFC
1	Outpatient and ambulatory health services	2	12	2
2	AIDS Drug Assistance Program (ADAP)	4	1	5
3	AIDS pharmaceutical assistance (local)	3	2	4
4	Oral Health Care	8	8	3
5	Early Intervention Services (EIS)	12	3	1
6	Health Insurance Premium and Cost-Sharing Assistance (HIPCA)	6	0	5
7	Home Health Care	1	6	3
8	Medical Nutrition Therapy	6	6	2
9	Hospice Services	0	5	3
10	Home and Community-based Health Services	1	4	3
11	Mental Health Services	11	9	1
12	Substance Abuse Services (Outpatient)	7	5	1
13	Medical Case Management	14	1	2
14	Case Management Services (non-medical)	14	0	1
15	Child Care Services	0	0	6
16	Emergency Financial Assistance	8	0	2
17	Food Bank/Home Delivered Meals	7	0	5
18	Health Education/Risk Reduction	12	1	2
19	Housing Services	8	1	4
20	Legal Services	4	0	5
21	Linguistics Services (interpretation and translation)	1	0	7
22	Medical Transportation Services	6	8	2
23	Outreach Services	6	0	4
24	Psychosocial Support Services (Support Groups)	5	1	6
25	Referral for Health Care/Supportive Services	15	2	1
26	Rehabilitation Services	0	7	2
27	Respite Care	0	1	5
28	Substance Abuse Services (Residential)	3	7	3
29	Treatment Adherence Counseling	14	2	2

#2B What additional services do you feel your clients need that are not covered by either Medicaid or Ryan White?

Additional services needed by clients not covered by NJFC included the following.

- **Medical Care & Core Medical Services.** Some medications/vaccines (denied by NJFC). Dental care. Hepatitis C cost of medications. Copays. Mental health is covered but there are limited providers.
- **Support services.** Bus tickets, food vouchers, rental assistance, energy assistance. Long term residential substance abuse treatment. Housing. Child care services. Affordable ophthalmology services. Support groups. Permanent housing. Employment training. Education assistance. Transportation. Complementary therapies.

#2C Since enrolling into Medicaid Expansion/NJFC, what barriers, if any, have you or your clients experienced? (i.e., being dropped from coverage, still waiting for coverage, etc.)?

Barriers experienced by clients to NJFC.

- **Long wait times for coverage.** Average is around three months. Many visits to local social service office. Pending eligibility completion at 18 Rector St. (Essex County Welfare Office). Long wait time for receiving card after approval.
- **Dropped from coverage** - without knowing or notification. Losing access to ART as a result. Being dropped from coverage without being informed about renewal.
- **Medications not covered.**[1] Medications that have been prescribed before or that clients are on are no longer covered and a Prior Authorization (PA) process needs to be started. Long delays and obstacles for HIV/Hep C drugs preauthorization.[2]
- **Covering of medical copayments.**
- **Geographic location of covered services.**
- **Referrals.** Patients not going to Primary Care Provider to get referrals. Access to appropriate medical referrals.
- **Agency not accepting some specific HMO plans.** Some providers are not credentialed on the panels of all NJFC HMOs.
- **Need for Prior Authorization (PA).** Certain procedures require a PA or are denied.
- **Incorrect billing.** Some clients are being billed from the providing facilities although they are covered by Medicaid at 100%.
- **Need for extensive MCM** – for negotiating with insurers. MCM time has increased significantly as a result.

[1] **"Medications not covered"** is an issue for clients with Medicaid/NJFC because HIV medications that were readily available under ADAP (e.g., single dose therapy or one pill per day) are now classified as Tier 2 or Tier 3 and require either prior authorization by the health insurer or in some cases have been denied despite justification by the physician.
[2] Members of the Council's Research and Evaluation Committee report that the **qualifying process for access to Hep C medication** and pre-qualification required is moving more smoothly with less wait time.

- **Housing.**
- **Medicaid recertification.** Medicaid backlog for renewals. Random HMOs/PCP assignments. HIV regimens not being renewed.

#3. What services are the clients accessing now that the clients couldn't access before?

The services are listed in order of frequency cited by respondents.

- **On site phlebotomy.** Ability to get lab work done.
- **Increase in ease/ability to refer to medical subspecialty care.** (But many specialists do not accept Medicaid so it is still a challenge.) Regular medical care with all specialists as needed. Non-Ryan White covered specialists. More specialty medical services.
- **Logisticare transportation.**
- **Oral health care.**
- **Flexibility in choosing physicians and services.**
- **Home healthcare services.**
- **Podiatry.**
- **Inpatient care.**
- **Lack of coverage for pneumonia or Hepatitis A/B vaccinations.**

4. Of the services you couldn't provide through your agency, please indicate where you referred your client. ***(Check all that apply)*** ****Regarding clients who moved/enrolled into Medicaid Expansion/NJFC (New Jersey Family Care)**

The responses to this question reflect the perceptions and knowledge of respondents. That is, this table **does not reflect the services actually provided by Ryan White (RW) or non-RW agencies, but the perceptions of the respondents.**

SERVICE TYPE		Able to refer to a RW agency	Able to refer to a NON-RW agency	NOT ABLE TO REFER TO ANYONE
1	Ambulatory/Outpatient/Primary Medical Care	6	5	0
2	Child Care Services	0	5	5
3	Diagnostic tests/Lab services	5	8	1
4	Early-Intervention Services	4	2	0
5	Emergency Financial Assistance	11	3	0
6	Family Planning	1	5	1
7	Food Bank/Home-Delivered Meals	8	9	0
8	Health Education/Risk Reduction	7	2	0
9	Home Healthcare	0	12	0
10	Hospital (inpatient)	5	8	0

SERVICE TYPE		Able to refer to a RW agency	Able to refer to a NON-RW agency	NOT ABLE TO REFER TO ANYONE
11	Housing Services	11	5	1
12	Legal Services	15	5	1
13	Language Interpretation/Translation Services	2	5	3
14	Medical Case Management	5	2	0
15	Mental Health: Inpatient	5	11	0
16	Mental Health: Outpatient	9	7	0
17	Mental Retardation/Developmental Disability Services	1	9	2
18	Nonemergency Medical Transportation	6	8	3
19	Nonmedical Case Management	8	3	0
20	Nursing Home Care	0	9	1
21	Nutritional Counseling	12	4	0
22	Obstetrics/Gynecology (OB/GYN)	5	10	0
23	Oral Healthcare	11	5	1
24	Outreach Services	8	5	0
25	Permanency Planning	5	4	1
26	Prenatal Services	2	7	1
27	Prescription Drugs	4	10	0
28	Psychosocial Support Services	5	6	1
29	Physical Therapy/Occupational Therapy/Speech Therapy	1	9	0
30	Referral for Healthcare/Support Services	5	5	0
31	Rehabilitation Services	1	8	1
32	Respite Care	0	9	1
33	Skilled Nursing Care	1	9	1
34	Social Services (welfare, food stamps, etc.)	2	12	1
35	Substance Abuse: Inpatient	5	11	1
36	Substance Abuse: Outpatient	9	8	0
37	Treatment Adherence Counseling	7	1	0
38	Utility Assistance	10	7	1
39	Other: (please specify)	1	1	1

#5A. Please describe any gaps in services that occurred because your clients gained Medicaid coverage.

- **Loss of ADDP services.** Patients often to not get their Pneumonia and Hep A/B vaccines from NJFC which are previously paid for by ADDP. Gap in transitioning from ADDP prescription coverage.
- **Barriers to ART.** NJFC has many barriers to ART and the single dose therapy. MCM must spend many hours per day per patient to obtain medication approval. Patients may go without ART and other meds for days or weeks due to Medicaid not covering a medication that was previously covered by ADDP.
- **Lapsed NJFC overage & ART Gaps.** Patients have lapsed coverage due to no advance notice (due to lack of permanent address/phone issues or lack of understanding of Medicaid system). They can continue to receive care and get meds but lots of MCM time spent rectifying Medicaid coverage. Ultimately time off meds can be detrimental to their health.
- **Few Medicaid providers.** Due to low Medicaid reimbursement rate, there are not many providers who accept Medicaid and serve NJFC patients.
- **HMO Panels/Credentialing.** Patient was not able to see certain providers because their office did not accept a particular HMO (were not credentialed).
- **Need for Prior Authorization.** This has resulted in gaps in coverage if patient needs care or ART and cannot get it timely.
- **Spanish programs.** Psychotherapy and substance abuse programs for Spanish speaking clients.

#5B. Please tell us any particular population that was disproportionately affected by those gaps in services.

- **Patients with larger barriers to medication and appointment adherence.** They tend to fall through the cracks when there is disruption in coverage. They may not know how to communicate these problems to staff. Sometimes they do not let us know until weeks or months later after being off medications. These patients are exactly those who need seamless coverage. They include patients with mental health comorbidities, drug addiction issues, homelessness issues, slight developmental delays that don't warrant constant care but possess an understanding deficit, as well as patients for other reasons don't maintain appointment adherence.
- **Undocumented individuals.**[3]
- **Low income individuals.** Those without other means of transportation. Those on limited income, e. g., SSI, GA.
- **All patients.** These individuals present themselves equally across our patient population. All individuals who qualified for NJFC.
- **Hispanic/Latino population.**

[3] Undocumented individuals are ineligible for Medicaid Expansion/NJFC. However, this ineligibility is a barrier to the [undocumented] individuals who may be the HIV+ population most in need of health insurance or coverage for medical expenses.

- **Incarcerated individuals transitioning to the community** must initiate the Medicaid process all over again.
- **African Americans.**

3.3. Findings – Health Insurance Marketplace ("Obamacare")

#6. In thinking of the clients you work with, what number or percentage moved/enrolled into a Marketplace-based plan?

In most agencies, less than 5% (and only 1%) had enrolled in the Health Insurance Marketplace. One agency reported that 15% of its RWHAP clients had enrolled in the marketplace.

#7 Transition from RW funded services to Health Insurance Marketplace.

#7A. In thinking of the clients who moved/enrolled into a Marketplace-based plan, please indicate what services you are currently providing under Ryan White, what services are being covered by a Marketplace-based plan, and what services are not covered by either a Marketplace-based plan or Ryan White.

The responses to this question reflect the perceptions and knowledge of respondents. That is, this table **does not reflect the services actually provided by Ryan White (RW) or Marketplace-based plans, but the perceptions of the respondents.**

SERVICES		Currently Provided under RW	Currently Provided under Marketplace Plan	NOT COVERED BY RW or Marketplace Plan
1	Outpatient and ambulatory health services	5	9	0
2	AIDS Drug Assistance Program (ADAP)	3	1	4
3	AIDS pharmaceutical assistance (local)	2	3	2
4	Oral Health Care	6	5	1
5	Early Intervention Services (EIS)	8	4	0
6	Health Insurance Premium and Cost-Sharing Assistance (HIPCA)	3	0	5
7	Home Health Care	0	4	3
8	Medical Nutrition Therapy	7	3	0
9	Hospice Services	1	4	1
10	Home and Community-based Health Services	2	5	0
11	Mental Health Services	11	5	0
12	Substance Abuse Services (Outpatient)	8	5	0
13	Medical Case Management	12	1	1

	SERVICES	Currently Provided under RW	Currently Provided under Marketplace Plan	NOT COVERED BY RW or Marketplace Plan
14	Case Management Services (non-medical)	13	0	1
15	Child Care Services	0	0	7
16	Emergency Financial Assistance	7	1	2
17	Food Bank/Home Delivered Meals	6	1	3
18	Health Education/Risk Reduction	8	2	2
19	Housing Services	7	0	3
20	Legal Services	7	0	2
21	Linguistics Services (interpretation and translation)	3	0	6
22	Medical Transportation Services	8	2	2
23	Outreach Services	5	0	3
24	Psychosocial Support Services (Support Groups)	3	1	5
25	Referral for Health Care/Supportive Services	8	1	0
26	Rehabilitation Services	1	5	1
27	Respite Care	1	3	3
28	Substance Abuse Services (Residential)	2	6	1
29	Treatment Adherence Counseling	9	1	1

#7B. What additional services do you feel your clients need that are not covered by either a Marketplace-based plan or Ryan White?

Respondents identified additional services as follows. Most identified co-pays or coinsurance as an issue; specifically citing co-insurance for labs, copayments and deductibles. Others cited the need for out of network privileges. Additional services not covered by Obamacare or Ryan White included substance abuse treatment, Hepatitis C treatment, prescription assistance, supportive services, group modality, medical transportation, and support groups. Respondents also mentioned affordable ophthalmology services and prescription assistance.

Some just reported the effects of Obamacare – that there is reduced coverage for medication/vaccines. Others did not answer because they had no clients enrolled in the marketplace plans. Others said there were no services not covered by either Obamacare or Ryan White.

#7C. Since enrolling into a Marketplace-based plan, what barriers, if any, have you or your clients experienced? (i.e., being dropped from coverage, still waiting for coverage, etc.)

The barriers seem to relate to administrative and coverage issues in Obamacare. The chief barrier was cost of care. There were extensive copayment and so-called "coinsurance" issues. **Coinsurance** is another way of saying that patients have to pay something toward the cost of care. Respondents reported that premiums are too high, and that paying premiums was a challenge. (Although they noted that copays for office visits are covered by Ryan White.) Coinsurance was a barrier on labs and lab-related costs. Respondents reported high deductibles, which is the amount that the patient must pay in cash before the insurance kicks in to pay for healthcare.

Notwithstanding the issues regarding coinsurance, the system created by Obamacare did not appear to be efficient. There still were long waits for coverage and long times for getting [health insurance] cards. with respect to payment for services, prior bills are not paid retroactively from the date of application. in terms of access, the hospital does not accept all marketplace plans. And finally there is the perception – Obamacare seems to limit services based on clients' income.

Several providers reported they had no clients enrolled in the marketplace plan therefore there were no barriers experienced.

#8 What services our clients accessing now that they could not access before?

The services are listed in order of the frequency cited by respondents. Newly accessed services include: regular medical care, medical care for specialists, oral health/dental care, and vision care. However, some respondents pointed out that patients were able to access these services before the ACA but through Ryan White. Others reported that PLWHA access to services under the ACA depends on clients' needs.

Some respondents could not address this issue because they had no clients enrolled in the marketplace plans. Others reported that gaps appear to be greater for marketplace plans than for NJFC.

#9. Of the services you couldn't provide through your agency, please indicate where you referred your client. ***(Check all that apply)*** ****Regarding clients who moved/enrolled into a Health Insurance Marketplace (Obamacare) plan.**

The responses to this question reflect the perceptions and knowledge of respondents. That is, this table **does not reflect the services actually provided by Ryan White (RW) or non-RW agencies, but the perceptions of the respondents.**

SERVICE TYPE		Able to refer to a RW agency	Able to refer to a NON-RW agency	NOT ABLE TO REFER TO ANYONE
1	Ambulatory/Outpatient/Primary Medical Care	5	4	0
2	Child Care Services	2	6	2
3	Diagnostic tests/Lab services	4	7	0
4	Early-Intervention Services	5	1	1
5	Emergency Financial Assistance	6	4	1
6	Family Planning	0	5	1
7	Food Bank/Home-Delivered Meals	5	4	2
8	Health Education/Risk Reduction	6	3	0
9	Home Healthcare	0	7	1
10	Hospital (inpatient)	2	8	0
11	Housing Services	9	4	1
12	Legal Services	9	4	1
13	Language Interpretation/Translation Services	3	4	3
14	Medical Case Management	6	4	0
15	Mental Health: Inpatient	3	7	2
16	Mental Health: Outpatient	5	7	1
17	Mental Retardation/Developmental Disability Services	0	7	1
18	Nonemergency Medical Transportation	4	6	1
19	Nonmedical Case Management	5	4	0
20	Nursing Home Care	1	5	1
21	Nutritional Counseling	8	4	0
22	Obstetrics/Gynecology (OB/GYN)	5	8	0
23	Oral Healthcare	7	4	0
24	Outreach Services	3	4	1
25	Permanency Planning	3	5	0
26	Prenatal Services	1	7	0
27	Prescription Drugs	5	8	0
28	Psychosocial Support Services	3	5	0
29	Physical Therapy/Occupational Therapy/Speech Therapy	1	9	0
30	Referral for Healthcare/Support Services	4	6	0
31	Rehabilitation Services	0	8	0
32	Respite Care	0	7	1

SERVICE TYPE		Able to refer to a RW agency	Able to refer to a NON-RW agency	NOT ABLE TO REFER TO ANYONE
33	Skilled Nursing Care	1	8	0
34	Social Services (welfare, food stamps, etc.)	0	9	1
35	Substance Abuse: Inpatient	3	8	0
36	Substance Abuse: Outpatient	5	5	0
37	Treatment Adherence Counseling	5	1	0
38	Utility Assistance	4	6	0
39	Other: (please specify)	0	0	1

#10A. Please describe any gaps in services that occurred because your clients gained Marketplace-based coverage.

A number of respondents said there were no gaps in services and others said they had no clients enrolled in the marketplace plan, so they had no way of gauging the gaps in service pre-and post-ACA.

Of those who had clients enrolled in the marketplace, they provided the following.

- **Cost-sharing creates barriers and gaps.** Respondents identified premium cost-sharing issues, high co-payments as gaps in services. They noted that some patients missed medical appointments to avoid their new copayments and deductible responsibilities. Others said that fear of high coinsurance payments and bills for labs leads to missed appointments. And others said that accrual of lab related costs has interrupted services.
- **Citizenship.** Clients who were required to provide proof of citizenship experienced interruptions or have been dropped from coverage.
- **Affordability and lack of access to care; networks.** Clients enrolled in affordable plans with minimal coverage due to affordability of premiums. Clients enrolled in plans that our agency is not in network with. Some cited lack of [affordable] transportation as a service gap.
- **Culturally-appropriate Services.** Barriers included the following. Lack of Spanish programs for the Latino HIV+ population. They would like psychotherapy and substance abuse programs for Spanish speaking clients.

#10B. Please tell us any particular population that was disproportionately affected by those gaps in services.

This section did not receive strong response. However, respondents identified the following populations disproportionately affected by the ACA gaps in service: (1) Patients not born in the US, (2) the Hispanic/Latino population, (3) African Americans and some Haitians, (4) clients who do not meet income guidelines for Medicaid, but remain low income.

Notwithstanding above responses, a number of agencies said they had no clients enrolled in the Obamacare marketplace options, and that no clients experienced barriers to care.

3.4. Overall ACA-Related Impacts

The following questions are regarding all of your clients who moved/enrolled into EITHER Medicaid Expansion/NJFC OR a Health Insurance Marketplace (Obamacare) plan.

#11. Please describe your process for assessing/ensuring that your clients receive HIV primary medical care.

Respondents viewed this question from several aspects and provided the following information.

- **HIV Primary Medical Care Services.** All patients are assessed on every medical visit for primary care needs. Standards of care per HRSA guidelines are adhered to. Patients are followed up as needed up to every six months, to ensure that all required annual health maintenance needs (mammogram, pap, eye, dental, vaccines and annual lab requirements) are met. Semiannual screenings/care coordination with providers. Use of CHAMP as a tool. Medical records requests. Chart review. All patients are evaluated by a physician and assisted with RW team (Nurse and MCMs).
- **Payment and Insurance.** All patients are eligible for on-site HIV primary medical care regardless of insurance type. All patients receive HIV primary medical care regardless of their ability to pay for services. For services not covered by Ryan White funds, the agency has a compassionate care allowance and all patients requiring assistance are assessed on a case-by-case basis.
    - **New/Returning Clients.** The client is asked if they have insurance, if they have applied (if so what is the status). Client is asked to provide documentation. If they have not enrolled, the client is enrolled on site. Assess for financial eligibility, assist in obtaining appropriate insurance. Check for benefits with insurance company and in network benefits.
- **Access and Retention by Provider.** Services are provided on-site. Letters, phone calls and outreach are used to contacting schedule patients. Assess for transportation needs. We provide comprehensive and intensive support to all of our clients in an effort to keep them connected to the HIV medical care which we provide. We have various ancillary services on-site including ARTAS, a Home Visit Team, a Patient Care Coordinator, a Patient Financial Services Department, an HIV specific support group, various treatment adherence services and the multidisciplinary clinical team that works to engage, link and retain patients in care.
- **Retention in Care (Client).** The assessing process is smooth, but long-term engagement relies on the client's will and knowledge of HIV.
- **Process for ensuring our clients receive HIV primary medical care.** Each agency had a specific process for ensuring that clients receive HIV primary medical care but there were commonalities. Listed below are several specific agency responses.
    - At this clinic, the process begins with our weekly chart reviews. Each MCM reviews his charts on a weekly basis to ensure that the client is actively participating in HIV medical

care. When a client has not complied with his appointments, the MCM will reach out to the client for follow-up through different channels. MCM also will utilize the assistance of the patient navigators to attempt to reengage and retain in treatment if the patient has been out for prolonged amount of time.

- Once a screening is completed and it is determined that the client is in need of medical care services or needs to be re-engaged into medical care, the client is provided with a list of the local hospitals or clinics to determine where the client would feel more comfortable going to. A phone call is then made to the provider of choice and an appointment is scheduled. The client is reminded the day before and follow-up is also done the day after the appointment.
- The process remains the same. Patients are reminded to come in for their lab work as needed. They are aware that they can call to make an appointment when they need to be seen.
- Upon initial intake, clients are questioned as to where their medical care is being provided. Release forms are signed, and case managers follow up with doctors to ensure clients are being medically adherent. For those who are not on medical care, referral is made within 15 days of initial assessment to medical care.
- Our primary care follow-up is built into our comprehensive six-month care plan and recertification reassessments.
- Appointments are made by the case manager and followed up by the case manager with written or verbal confirmation by telephone from the care provider. Follow-up appointments are documented along with updated lab work every 3 to 6 months.

#12. Of your clients who switched to Medicaid Expansion/NJFC or a Health Insurance Marketplace insurance plan, what number or percentage of them have continued to see their HIV medical provider at least every 6 months?

The range was 85% to 90% with up to 100% for many providers of clients who continue to see their HIV medical provider.

#13. If they are not being retained in care, why?

A few agencies reported that all of their clients are in care. However, the majority reported that the reasons for not being retained in care or "lost to follow up" are unstable personal lives – including comorbidities of mental health and substance abuse issues, homelessness, developmental delays – relocation outside away from the provider agency, denial/apathy, inability to afford copayments and deductibles, and the fact that clients have not provided the most recent contact information.

The actual responses are listed below.

- The remaining are lost to follow up for **all the reasons that the lost to follow up population falls out of care**. These are patients with mental health comorbidities, drug addiction issues, homelessness issues, slight developmental delays that do not warrant constant care but possess

an understanding deficit, as well as patients who for other reasons do not maintain appointment adherence (denial, apathy to care, moving out of the area, transferring care due to drug seeking behavior, etc.).

- Of those patients not retained in care that we were able to contact, the reasons report include: mental health, substance abuse, housing issues, some receive multiple refills (in excess of six months) and **do not come back until the refills are depleted**, concerns about medical bills for services not covered (including other services in the hospital outside of clinic).
- The barrier for the majority of clients who are not retained in care is not insurance-related but due to the **unstable nature of their lives**.
- No **contact number or updated address** on file. People move out of state without notice. We have lost contact with some of them.
- It is most likely due to the fact that the patient is either covered by **health insurance** or they are eligible for the marketplace coverage and do not want to pay the deductible or copayment. Client selected a plan but **we are not in that plan's network**.

3.5. Recommendations

The MCM and CM-NM agencies who completed the KI interviews and provided the information in this section appear to have a good understanding of the ACA health insurance – Medicaid Expansion/NJFC and the Health Insurance Marketplace ("Obamacare"). They appear to have adapted their HIV care systems to these new payment sources and newly-available medical services.

However, they may not be clear on what services are covered by Ryan White, the ACA, and which are not covered. The responses to questions #2A, #4, #7A and #9 indicate variability in the understanding of available RW services, as well as Medicaid/NJFC and marketplace options (which is to be expected given the newness of these programs). There is a real need for clarity on the RWHAP care continuum and available services. This knowledge is essential to the RWHAP going forward as it adapts to ACA-funded medical care and provides a **"System of Care for PLWHA."**

The RWHAP must give these front line staff the tools needed to operationalize this RW System of Care. Ongoing training and information sharing are needed – among providers, MCM and CM-NM on the ACA and RWHAP - to ensure that the EMA continues to provide a seamless continuum of HIV medical care across all payment sources. The following are needed at a minimum.

(1) Identification of the RWHAP continuum of care and inventory of resources available to HIV+ individuals in the EMA.

(2) A Resource Inventory directory – in terms of linkages to existing service inventories in the EMA and statewide.

(3) Training, training and re-training of Medical Case Managers and Non-Medical Case Managers on all available services as well giving them [online] access to non-RW resources in the EMA.

(4) Training or guidance to MCM and CM-NM on what a continuum of care is – a checklist of services that they should/must make available to RW clients if requested regardless of funding source.

(5) MCM/CM need to be knowledgeable on where and how services are billed – maybe there should be training of MCM and CM-NM on billing.

(6) At the level of Planning Council and Grantee, continue to work with New Jersey Medicaid and others to obtain current information on medical and related services provided under ACA.

(7) At the level of Planning Council and Grantee, keep current on what NJFC and insurance do NOT cover and ensure that RW provides completeness of care.