Newark EMA

HIV Health Services Planning Council

NEEDS ASSESSMENT UPDATE - 2017

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September 2017

NEWARK EMA HIV HEALTH SERVICES PLANNING COUNCIL NEEDS ASSESSMENT – UPDATE 2017

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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)
DHCW	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)
DHSTS	Division of HIV/AIDS, STD, and TB 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)
HCC	HIV Care Continuum
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
IHAP	Integrated HIV/AIDS Prevention and Care Plan 2017-2021
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
VLS	Viral Load Suppression
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 QUESTIONS AND METHODOLOGY

Purpose

The purposes of the Needs Assessment – Update 2017 were (1) to continue to assess the ongoing impact of the changing healthcare landscape on the Ryan White HIV/AIDS Program (RWHAP) by building upon the results of previous 2014-2016 assessments, (2) to continue to assess the extent to which outcomes along the HIV Care Continuum (HCC) are improving among PLWHA receiving RWHAP services and (3) identify gaps and disparities in HCC outcomes which may be filled by RWHAP services.

The HIV Care Continuum, formerly called the HIV Treatment Cascade, was formalized in President Obama's Executive Order of August 2013 as the framework for HIV/AIDS among all federal agencies. The National HIV/AIDS Strategy 2020 issued in July 2015 incorporated the HCC as the measurement framework. The diagnosed-based HCC has five measures: (1) diagnosed, (2) linkage of newly-diagnosed to medical care, (3) retention in care, (4) antiretroviral use, and (5) viral suppression. The Needs Assessment – Update 2017 studies **all four measures for three populations – transgendered persons, youth age 13-24 and "former youth" age 25-34** with a focus on **retention in care and viral load suppression.**

As background, 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 Needs Assessment - Update 2015 assessed the impact of the ACA on the RWHAP after one full year of operation and began to identify the core medical and support service gaps and needs of PLWHA newly enrolled in the ACA and what was needed to help achieve Viral Load Suppression (VLS) including data on linkage to care and retention. The 2016 Needs Assessment examined the health outcomes post-ACA implementation and especially with respect to the key indicators of the HCC – retention and viral suppression – needed to reduce HIV transmission rates and improve health outcomes which are equivalent to containing the HIV epidemic.

The results of the Needs Assessment – Update 2017 are being used as baseline information for two target populations in the Newark EMA Integrated HIV/AIDS Prevention and Care Plan for 2017-2021 (IHAP) and thus to assist in the implementation of IHAP.

Research Questions

<u>Part 1:</u> What are the needs of the Transgender population of PLWHA in the Newark EMA?

<u>Part 2:</u> What are the needs of the Youth (Age 13-24) and Former Youth (Age 25-34) population of PLWHA in the Newark EMA?

Methodology

In 2017 the responsibilities of the Planning Council (PC) Support function were transferred to a different, nonprofit entity, after 25 years. This transfer was required by a finding of the HRSA HAB Site Visit in November 2015. This transition to the different agency included a learning curve of PC responsibilities and functions. As a result, it was determined that the Needs Assessment – Update 2017 would consist

mostly of an analysis of CHAMP client level data. This analysis could provide clients needs along the HCC, could be completed within a relatively short timeframe, thus providing information needed for the FY 2018 Priority Setting and Resource Allocation (PSRA) process.

The Needs Assessment – Update 2017 used primarily quantitative research methods which were supplemented by qualitative research methods. Quantitative methods included a review of the Comprehensive HIV/AIDS Management Program (CHAMP) Client Level Database (CLD) regarding outcomes along the HIV Care Continuum – linkage to care, retention in care, prescribed antiretrovirals and viral load suppression - demographics, geographic area, and service utilization for CY 2016 and CY 2015. Data on utilization of Part A and MAI (Part F) services was obtained from the Newark EMA Recipient (formerly, Grantee) and the CHAMP system and tabulated using SPSS software.

Interviews of Key Informants (KI) were conducted among 10 of 20 RWHAP funded agencies which served transgendered individuals in 2016 to supplement the quantitative information regarding available services and service needs. **The KI tool is in Appendix A.**

PART 1: TRANSGENDER INDIVIDUALS

1.1 Introduction

The Research Question #1 to be answered is:

What are the needs of the Transgender population of PLWHA in the Newark EMA?

The goal of this question is to identify the transgender population of PLWHA served by RWHAP in 2016 from CHAMP data files, identify demographics (race/ethnicity, age), geography, services used, housing status, compute HIV Care Continuum (HCC) outcomes measures – viral load suppression (VLS) and retention in care (RIC), compare to the EMA total and identify any gaps and associated service needs for transgender PLWHA.

The second goal was to obtain more in-depth findings from Key Informants (KIs) who served the largest numbers of transgender RWHAP clients.

1.2 Findings Regarding Transgender RWHAP Clients from CHAMP CLD including HCC

- **In the Newark EMA, a total of 45 transgendered individuals received RWHAP services in 2016 (year ending 12/31/16).**
- **By demographics,** the transgendered PLWHA mirrored the EMA by **race ethnicity (78% Black/African American, 20% Hispanic/Latino.** By **age,** the plurality were **age 25-34, followed by age 35-44 which corresponds to US transgenders – but not the RWHAP PLWHA, where a majority are age .**
- **Residence. 58% lived in Newark**, and 80% in the EMA's 4 largest cities and 80% lived in Essex County.
- **Income. 82% have incomes below 100% of Federal Poverty Level (FPL)** which is the same as all RWHAP clients.
- **Health Insurance.** 51% have Medicaid and 38% are uninsured.
- **Housing.** 62% are in stable housing and **13% are in unstable housing – homeless, emergency shelter, jail/prison – which is twice the 6% rate of RWHAP clients EMA-wide.**
- **Services Used.** Medical Case Management (MCM) was the service used most, followed by medical care. This is consistent with RWHAP EMA-wide.
- **Service providers. The 45 transgender PLWHA accessed services from 20 Part A agencies**, both core medical and support services.

- **HCC Outcomes.** In 2016, **Retention In Care (RIC) was 72% for transgender RWHAP clients compared to 87% EMA-wide, prescribed ARVs was 88% for transgender clients compared to 95% EMA-wide, and Viral Suppression (VLS) was 79% for transgender clients versus 81% EMA-wide.**

In response to these findings, more detailed follow up analyses were completed for two subpopulations of transgendered RWHAP clients.

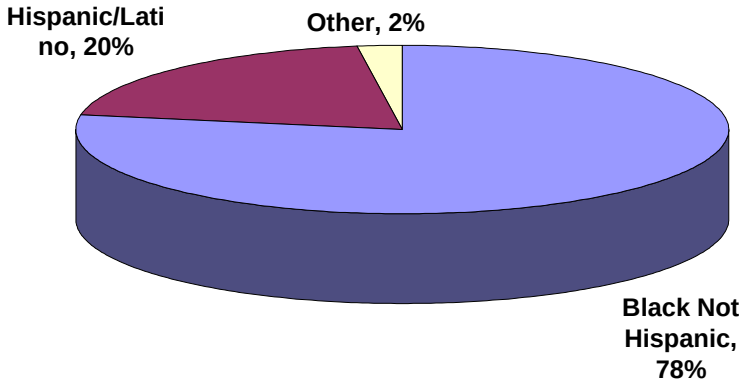
- **Characteristics of the 14 Transgender RWHAP clients who did not receive RWHAP medical care in 2016.** A total of 45 transgender clients received RWHAP services in 2016, and 31 of them received RWHAP funded medical care. The characteristics of the 14 who did not receive RWHAP funded medical care – race/ethnicity, age, health insurance, income, residence – did not differ significantly from the 31 who received Part A medical care. As a result, it was determined that more research is needed, possibly by interviewing the individual transgender clients. This is a recommendation for future research and needs assessments.

- **Characteristics of the Transgender RWHAP clients who did not receive Antiretroviral (ARV) medications as recorded in the RWHAP in 2016.** A total of 45 transgender clients received RWHAP services in 2016, and 24 received ARVs as recorded in RWHAP and 21 did not. The characteristics of the 21 who did not receive ARVs – race/ethnicity, age, health insurance, income, residence – did not differ significantly from the 24 who received Part A medical care. As a result, it was determined that more research is needed, possibly by interviewing the individual transgender clients. This is a recommendation for future research and needs assessments.

1.2.1 Data Findings regarding Transgender RWHAP Clients from CHAMP CLD including HCC

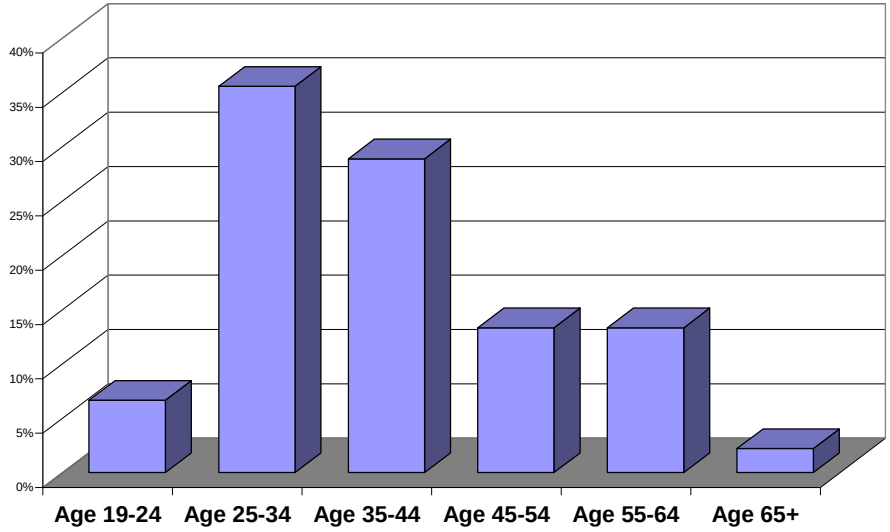
Race/Ethnicity.

Of the 45 total, 35 (78%) are Non-Hispanic Black/African American, 9 (20%) are Hispanic (all races), and one (2%) is of another race.



Age.

In 2016, three (7%) were age 19-24, **16 (36%) were age 25-34**, 13 (29%) were age 35-44, six each were age 45-54 (13%) and age 55-64 (13%) and one (2%) was age 65+.



Residence

More than half – 26 or 58% - of the Transgender RWHAP clients lived in Newark in 2016.

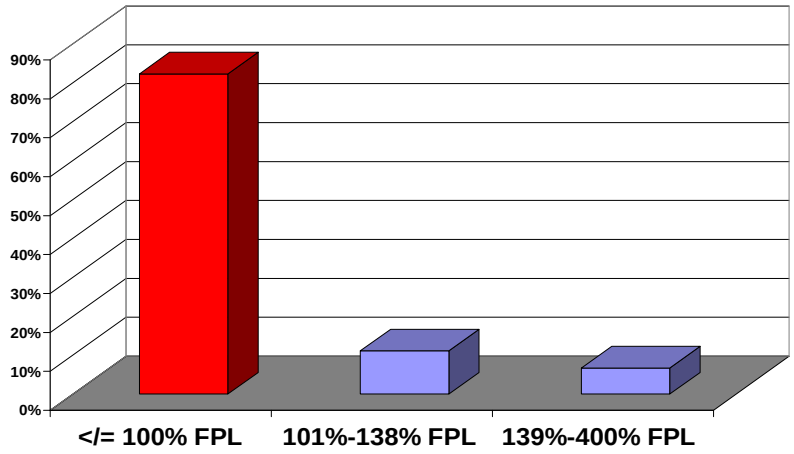
80% or 33 lived in 4 of the EMA's 5 largest cities also termed **"5 Cities"**. No transgender clients reported living in Plainfield.

By county, 80% (36) lived in Essex, 11% (5) in Union, 4% (2) in Morris and 4% (2) lived in neighboring counties outside of the EMA.

City of Residence	Essex	Morris	Union	Outside NEMA	Total	%
Newark	**26**	0	0	0	26	**58%**
East Orange	5	0	0	0	5	11%
Irvington	2	0	0	0	2	4%
Elizabeth	0	0	3	0	3	7%
Subtotal 5 Cities	**33**		**3**		**36**	**80%**
Rest of Essex	3				3	7%
Dover		2			2	4%
Rest of Union			2		2	4%
Hudson, Middlesex				2	2	4%
Total	**36**	**2**	**5**	**2**	**45**	**100%**
% by County	**80%**	**4%**	**11%**	**4%**	**100%**	

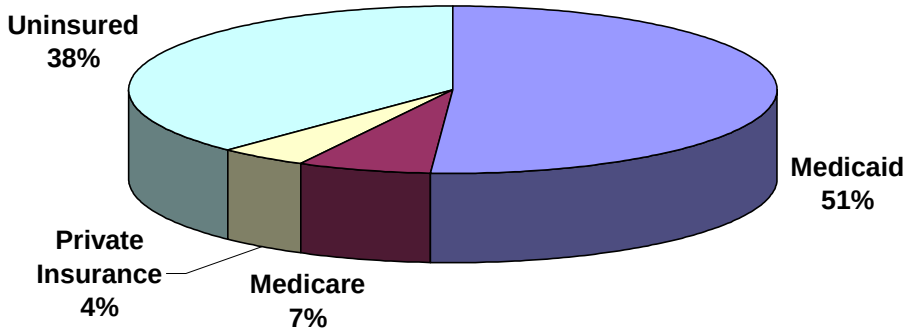
Income.

The majority of transgender individuals served by RWHAP have incomes at or below poverty – **37 or 82%**. **(This is the same % as all RWHAP clients.)** The rest have slightly higher incomes – five or 11% with incomes between 101%-138% Federal Poverty Level (FPL) and eligible for Medicaid Expansion, and three (7%) with incomes between 139%-400% FPL eligible for ACA subsidies.



Health Insurance.

Half (51% or 23 transgender individuals) had Medicaid, three (7%) had Medicare, two (4%) had private insurance, and 17 or 38% are uninsured. RWHAP pays for HIV health care for uninsured HIV+ individuals.



Housing Status.

Housing status categories are defined by the federal RWHAP – stable permanent, temporary, unstable. CHAMP collects data about the individual's living arrangement and then assigns it to the federal categories.

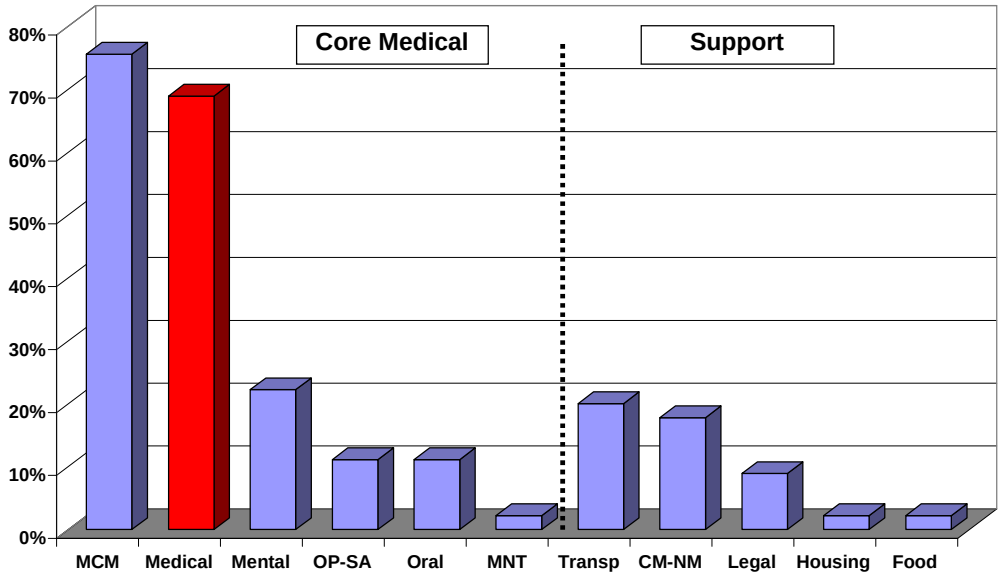
Of the 45 transgender RWHAP clients, 28 or 62% were living in Stable Permanent Housing, 11 or 24% in Transitional Housing, and six or 13% were in Unstable Housing.

Housing Category	Housing of Transgender Clients as of 12/31/16	#	%
Stable Permanent Housing	HOPWA - Long Term, House/Apartment - Rent or Own Unsubsidized, House/Apartment - Subsidized Non HOPWA	28	62%
Temporary Housing	House/Apartment - Doubling up, staying w/ family, Transitional Housing - Ryan White	11	25%
Unstable Housing	Homeless, Jail/Prison	6	13%
Total		**45**	**100%**

RWHAP Services Used in 2016

- **Medical Case Management (MCM) was the service most-used** by Transgender clients in 2016 – with 34 unduplicated clients or 76% of the 45.
- RWHAP-funded **Outpatient/ambulatory medical care was second most-used, by 31 or 69% of clients.** Mental health was third, used by 10 or 22% of clients.
- With respect to **Support Services, medical transportation was most used by 9 or 20% of clients.** This was followed by non-medical case management (8 clients or 18%), then legal services (4 clients or 9%).
- Service utilization follows patterns of general RWHAP clients.
- The **total cost** of RWHAP-funded services for transgender clients in 2016 was approximately $43,100 or less than $1,000 per client ($957) with a median cost of $600 per client.

Service & Category	Clients	
	#	%
Core Medical		
Medical Case Management	34	76%
OP Medical Care	31	69%
Mental Health	10	22%
OP Substance Abuse	5	11%
Oral Health	5	11%
Medical Nutr Therapy	1	2%
Support Services		
Transportation	9	20%
Case Management-Nonmedical	8	18%
Legal	4	9%
Housing	1	2%
Food/Nutrition	1	2%
Not Used		
Residential Substance Abuse		
Emergency Financial		

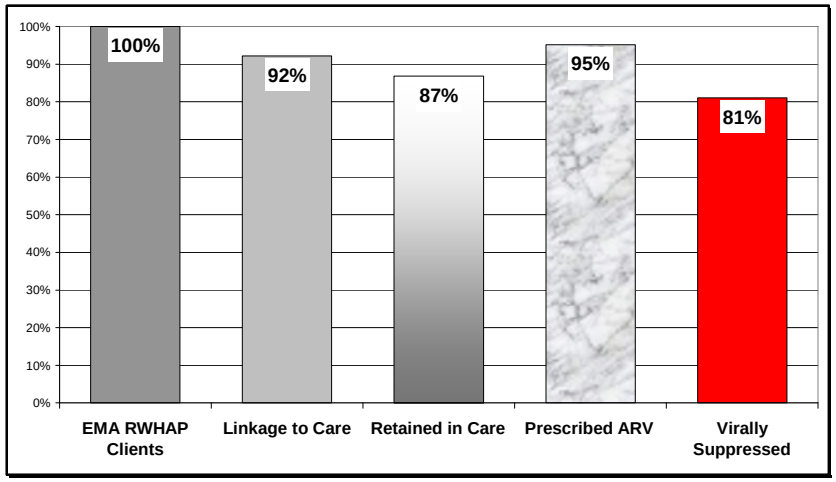


HIV Care Continuum (HCC) Outcomes for Transgender RWHAP Clients in 2016

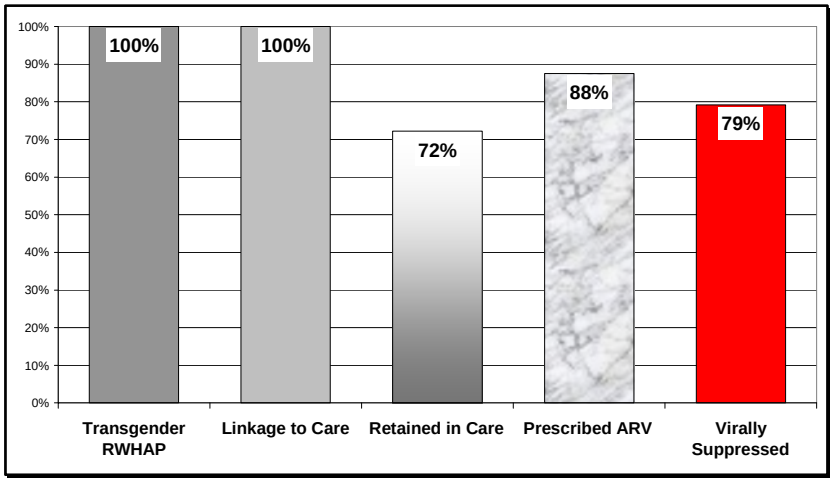
The HIV Care Continuum (HCC) has specific definitions for inclusion of PLWHA in the measurements. Of the 31 transgender RWHAP clients receiving medical care in 2016, 24 or 77% were counted for Prescription of Antiretrovirals (ARVs) and Viral Load Suppression (VLS). Only 18 or 58% were counted for Retention In Care (RIC) as measured by the "Reverse Gap" measure. Six newly diagnosed transgender clients were included in the Linkage to Care measure. **Benchmarks or targets are set by HRSA HIV/AIDS Bureau (HAB) and the National HIV/AIDS Strategy (NHAS) 2020.**

Figure 1: HIV Care Continuum – RWHAP Clients in 2016 for Both Newark EMA Total Clients and Transgender Clients

RWHAP Total Clients Newark EMA 2016



RWHAP Transgender Clients Newark EMA 2016



Linkage to Care. The current HAB goal is that 85% of individuals newly-diagnosed with HIV should be linked to HIV medical care within **three months** of diagnosis. In 2016, **92% (190) of newly diagnosed RWHAP clients and 100% (6) of newly-diagnosed transgender clients** were linked to medical care within 3 months of diagnosis.

The **NHAS 2020 goal** is that 85% of newly diagnosed individuals should be linked to medical care within **one month** of diagnosis. In 2016, 71% of newly-diagnosed RWHAP clients(147 of 206) were linked to care within 30 days of diagnosis, and 83% of newly diagnosed transgender clients (5 of 6) were linked to medical care within 30 days of diagnosis.

Retained in Care or "Retention in Care" (RIC). Retention in HIV medical care is measured by two or more CD4 tests, viral load tests or medical visits at least 90 days apart (CDC). The HAB measure of "HIV Medical Visit Frequency" considers retention in care to be one visit at least every 6 months in a 24-month measurement period – that is, measured over 2 years. This measure has challenges. To align with the CDC measure, the Newark EMA, all TGAs in New Jersey and the New Jersey Cross Part Collaborative (NJCPC) of the NJ Department of Health use a one-year measure, the "Reverse Gap" measure. The measure "Gap in HIV Medical Visits" measures the percentage of patients, regardless of age, with a diagnosis of HIV who did not have a medical visit with a provider with prescribing privileges in the last 6 months of the measurement year – but had a visit in the first 6 months. The "Reverse Gap" measures patients who had a HIV medical visit in both the first 6 months and last 6 months of the measurement year. There is no HAB measure or target for Gap but the data show that the In+Care campaign Gap mean was 14% in 2013 with a Reverse Gap or Retention of 86%.

In 2016 using the "Reverse Gap" measure, **87% of RWHAP clients were retained in care but only 72% (13 of 18) of transgender clients were retained in care**.

The **NHAS 2020 goal** is to increase the percentage of persons with diagnosed HIV infection who are retained in HIV medical care to at least 90 percent. While the EMA is approaching this target, the results for transgender RWHAP clients are not as promising.

Prescribed Antiretroviral Medications or "Prescribed ARVs". Antiretroviral therapy (ART) is recommended for all HIV-infected individuals to reduce the risk of disease progression and to prevent transmission of HIV. In the HAB measure, the percent of adults with ARV was 91% in 2012 the year before the 2013 HAB measures were published. The expectation is much higher today.

In 2016, **over 95% of total RWHAP clients receiving HIV medical care were prescribed ARVs compared to only 88% of transgender clients**.

There are no **NHAS 2020** goals regarding Prescription of ARVs.

Viral Suppression or Viral Load Suppression (VLS). When a person's viral load (VL) (as measured by HIV RNA) is reduced to an undetectable level. With an undetectable VL, it is very unlikely that the HIV virus will be transmitted and is the closest state to a cure for HIV. VLS is achieved mostly through regular use of ARVs. "Undetectable" or VLS means a viral load that is less than 200 copies of the HIV virus per milliliter of blood. HAB measures VLS as the percentage of patients, regardless of age, with a diagnosis of HIV with a HIV viral load less than 200 copies/mL at last HIV viral load test during the measurement year.

At the end of 2016, **81% of total RWHAP clients receiving HIV medical care achieved VLS as did 79% of transgender clients.**

The **NHAS 2020 goal** is to increase the percentage of persons with diagnosed HIV infection who are who are virally suppressed to at least 80 percent. **The EMA has achieved this goal for the universe of RWHAP clients, and transgender clients are approaching this goal.**

It is recommended that the EMA implement a specific corrective action/performance improvement plan (Plan-Do-Study-Act or "PDSA") within the Newark EMA Clinical Quality Management Committee (CQM) to improve the VLS of RWHAP transgender clients.

Table 1: Newark EMA RWHAP Resources Serving Transgender Clients in 2016 – Clients Served by Agency Type and Services

		# RWHAP Transgender Clients Served in 2016											
		Core Medical Services						Support Services					
	Agency Type	Medical Care	Mental Health	OP Sub-stance	Oral Health	Med. Case Mgt	Med Nutrit	Case Mgt- NM	Housing	Food	Transp	Legal	TOTAL CLIENTS
1	Medical Provider-Essex	**10**	2			**10**		1		1	1		**10**
2	Medical Provider-Essex	**1**	2	2		**7**							**7**
3	Medical Provider-Essex	**5**	3			**3**							**5**
4	Support Service Provider - Essex							4					**4**
5	Medical Provider-Essex	**4**	1			**4**					3		**4**
6	Medical Provider-Essex	**4**			2	**4**					4		**4**
7	Dental Provider – Essex				4								**4**
8	Medical Provider-Essex	**3**			1	**2**	1						**3**
9	Support Service Provider - Essex											3	**3**
10	Support Service Provider – Essex					**2**		1				1	**2**
11	Support Service Provider - Essex			2				2					**2**
12	Medical Provider-Union	**2**	1	1		**2**							**2**
13	Support Service Provider - Essex							1			1		**1**
14	Support Service Provider - Essex							1	1				**1**
15	Medical Provider-MSW	**1**											**1**
16	Medical Provider-Essex					**1**							**1**
17	Medical Provider-MSW	**1**				**1**							**1**
18	Medical Provider-Essex	**1**				**1**							**1**
19	Support Service Provider - Essex		1					1					**1**
20	Support Service Provider - Essex							1		1			**1**
	Total	**32**	**10**	**5**	**7**	**37**	**1**	**12**	**1**	**2**	**9**	**4**	**58**
	Total Unduplicated	**31**	**10**	**5**	**5**	**34**	**1**	**8**	**1**	**1**	**9**	**4**	**45**

A total of **20 RWHAP-funded agencies served Transgender clients in 2016**. The table ranks agencies by type of agency and the total number of Transgender clients served. #1 one agency served 10 transgender clients, #2 one served 7, #3 one served 5, four agencies served 4, two agencies served 3, three agencies served 2, and eight agencies served one transgender client.
There was little duplication in services – as shown by the total clients served by the agencies and total unduplicated transgender clients.

1.2.2 Data Findings regarding Transgender RWHAP Clients Not Receiving RWHAP Medical Care

Table 2: Characteristics of 2016 RWHAP Transgender Clients by Receipt of RW Medical Care

Characteristic	Number		% Dist.	
	No RW Med. Care	WITH RW Med. Care	No RW Med Care	RW Med Care
Race/Ethnicity				
Black/African American	13	22	93%	71%
Hispanic	1	8	7%	26%
White	0	0	0%	0%
Other	0	1	0%	3%
Total	**14**	**31**	**100%**	**100%**
Age Category				
Age 19-24	2	1	14%	3%
Age 25-34	2	14	14%	45%
Age 35-44	3	10	21%	32%
Age 45-54	3	3	21%	10%
Age 55-64	3	3	21%	10%
Age 65+	1		7%	0%
Total	**14**	**31**	**100%**	**100%**
HIV Status				
AIDS	4	12	29%	39%
HIV Not AIDS	10	19	71%	61%
Total	**14**	**31**	**100%**	**100%**
County of Residence				
Essex	12	24	86%	77%
Union	1	4	7%	13%
MSW	1	1	7%	3%
Outside NEMA		2	0%	6%
Total	**14**	**31**	**100%**	**100%**
5 Cities of Residence				
Newark	11	15	79%	48%
East Orange	1	4	7%	13%
Irvington		2	0%	6%
Elizabeth		3	0%	10%
Subtotal	**12**	**24**	**86%**	**77%**
Elsewhere	2	7	14%	23%
Total	**14**	**31**	**100%**	**100%**
Income				
</= 100% FPL	10	27	71%	87%
101%-138% FPL	2	3	14%	10%
201%-300% FPL	1	1	7%	3%
301%-400% FPL	1		7%	0%

Characteristic	Number		% Dist.	
	No RW Med. Care	WITH RW Med. Care	No RW Med Care	RW Med Care
Total	**14**	**31**	**100%**	**100%**
ACA Income				
</= 138% FPL	12	30	86%	97%
139%-400% FPL	2	1	14%	3%
Total	**14**	**31**	**100%**	**100%**
Health Insurance				
Medicaid	6	17	43%	55%
Medicare		3	0%	10%
Private Insurance	2		14%	10%
Uninsured	6	11	43%	35%
Total	**14**	**31**	**100%**	**110%**
Housing Status				
Stable Permanent Housing	8	20	57%	65%
Temporary Housing	3	8	21%	26%
Unstable Housing	3	3	21%	10%
Total	**14**	**31**	**100%**	**100%**

Table 3: Services Used by 2016 RWHAP Transgender Clients by Receipt of RW Medical Care and Health Insurance

RWHAP Service Category	Source of Health Insurance									
	Medicaid	Medicare	Private Insurance	Uninsured	Total	Medicaid	Medicare	Private Insurance	Uninsured	Total
	Number of Clients Receiving by Health Insurance					RWHAP Service Dollars by Health Insurance				
RECEIVED NO RWHAP Medical Care in 2015										
Medical Care										
Mental Health	1				1	$245				**$245**
OP-Substance	2				2	$239				**$239**
Dental				1	1				$542	**$542**
MCM	3		2	2	7	$470		$218	$354	**$1,042**
Med Nutr										
CM-NM	2			1	3	$817			$202	**$1,019**
Housing	1				1	$693				**$693**
Resid SA										
Food										
Transportation										
EFA										
Legal				3	3				$2,983	**$2,983**
HIPCS										
Total by Service	**9**	**0**	**2**	**7**	**18**	**$2,463**	**$0**	**$218**	**$4,081**	**$6,762**
Unduplicated Clients	**6**	**0**	**2**	**6**	**14**					

RWHAP Service Category	Source of Health Insurance									
	Medicaid	**Medicare**	**Private Insurance**	**Uninsured**	**Total**	**Medicaid**	**Medicare**	**Private Insurance**	**Uninsured**	**Total**
	Number of Clients Receiving by Health Insurance					RWHAP Service Dollars by Health Insurance				
RECEIVED RWHAP Medical Care in 2016										
Medical Care	17	3		11	31	$2,794	$0		$6,710	**$9,504**
Mental Health	5	1		3	9	$1,110	$222		$288	**$1,620**
OP-Substance	2	1			3	$1,778	$1,446			**$3,224**
Dental	2	1		1	4	$1,075	$215		$2	**$1,292**
MCM	14	3		10	27	$10,841	$2,775		$4,385	**$18,001**
Med Nutr				1	1				$1	**$1**
CM-NM	3	1		1	5	$1,564	$240		$210	**$2,014**
Housing										
Resid SA										
Food	1				1	$442				**$442**
Transportation	5	2		2	9	$101	$59		$12	**$172**
EFA										
Legal		1			1		$49			**$49**
HIPCS										
Total by Service	**49**	**13**	**0**	**29**	**91**	**$19,705**	**$5,006**	**$0**	**$11,608**	**$36,319**
Unduplicated Clients	**17**	**3**	**0**	**11**	**31**					
Total Service Dollars						**$22,169**	**$5,006**	**$218**	**$15,689**	**$43,082**

1.2.3 Data Findings regarding Transgender RWHAP Clients Not Prescribed Antiretrovirals (ARVs)

Table 4: Characteristics of 2016 RWHAP Transgender Clients by Receipt of ARVs

Characteristic	Number		% Dist.	
	No ARV	WITH ARV	No ARV	WITH ARV
Race/Ethnicity				
Black/African American	19	16	90%	67%
Hispanic	2	7	10%	29%
White			0%	0%
Other		1	0%	4%
Total	**21**	**24**	**100%**	**100%**
Age Category				
Age 19-24	2	1	10%	4%
Age 25-34	4	12	19%	50%
Age 35-44	6	7	29%	29%
Age 45-54	3	3	14%	13%
Age 55-64	5	1	24%	4%
Age 65+	1		5%	0%
Total	**21**	**24**	**100%**	**100%**
HIV Status				
AIDS	7	9	33%	38%
HIV Not AIDS	14	15	67%	63%
Total	**21**	**24**	**100%**	**100%**
County of Residence				
Essex	18	18	86%	75%
Union	1	4	5%	17%
MSW	2		10%	0%
Outside NEMA		2	0%	8%
Total	**14**	**24**	**100%**	**100%**
5 Cities of Residence				
Newark	15	11	71%	46%
East Orange	2	3	10%	13%
Irvington		2	0%	8%
Elizabeth		3	0%	13%
Subtotal	17	19	81%	79%
Elsewhere	4	5	19%	21%
Total	**21**	**24**	**100%**	**100%**
Income				
</= 100% FPL	16	21	76%	88%
101%-138% FPL	3	2	14%	8%
201%-300% FPL	1	1	5%	4%
301%-400% FPL	1		5%	0%
Total	**21**	**24**	**100%**	**100%**

Characteristic	Number		% Dist.	
	No ARV	WITH ARV	No ARV	WITH ARV
ACA Income				
</= 138% FPL	19	23	90%	96%
139%-400% FPL	2	1	10%	4%
Total	**21**	**24**	**100%**	**100%**
Health Insurance				
Medicaid	10	13	48%	54%
Medicare		3	0%	13%
Private Insurance	2		10%	0%
Uninsured	9	8	43%	33%
Total	**21**	**24**	**100%**	**100%**
Housing Status				
Stable Permanent Housing	11	17	57%	65%
Temporary Housing	6	5	21%	26%
Unstable Housing	4	2	21%	10%
Total	**21**	**24**	**100%**	**100%**

Table 5: Services Used by 2016 RWHAP Transgender Clients by Receipt of ARVs and Health Insurance

RWHAP Service Category	Source of Health Insurance									
	Medicaid	Medicare	Private Insurance	Uninsured	Total	Medicaid	Medicare	Private Insurance	Uninsured	Total
	Number of Clients by Health Insurance					RWHAP Service Dollars by Health Insurance				
RECEIVED NO ARV Per RWHAP in 2016										
Medical Care	4			3	**7**	$0			$244	**$244**
Mental Health	3				**3**	$378				**$378**
OP-Substance	2				**2**	$239				**$239**
Dental				1	**1**				$542	**$542**
MCM	5		2	4	**11**	$1,039		$218	$941	**$2,199**
Med Nutr										
CM-NM	2			2	**4**	$817			$412	**$1,229**
Housing	1				**1**	$693				**$693**
Resid SA										
Food										
Transportation				1	**1**				$6	**$6**
EFA										
Legal				3	**3**				$2,983	**$2,983**
HIPCS										
Total by Service	**17**	**0**	**2**	**14**	**33**	**$3,166**	**$0**	**$218**	**$5,128**	**$8,512**
Unduplicated Clients	**10**	**0**	**2**	**9**	**21**					

RWHAP Service Category	Source of Health Insurance									
	Medicaid	**Medicare**	**Private Insurance**	**Uninsured**	**Total**	**Medicaid**	**Medicare**	**Private Insurance**	**Uninsured**	**Total**
	Number of Clients by Health Insurance					RWHAP Service Dollars by Health Insurance				
RECEIVED ARV per RWHAP in 2016										
Medical Care	13	3		8	**24**	$2,794	$0		$6,466	**$9,261**
Mental Health	3	1		3	**7**	$977	$222		$288	**$1,487**
OP-Substance	2	1			**3**	$1,778	$1,446			**$3,224**
Dental	2	1		1	**4**	$1,075	$215		$2	**$1,292**
MCM	12	3		8	**23**	$10,271	$2,775		$3,798	**$16,845**
Med Nutr				1	**1**				$1	**$1**
CM-NM	3	1			**4**	$1,564	$240			**$1,804**
Housing										
Resid SA										
Food	1				**1**	$442				**$442**
Transportation	5	2		1	**8**	$101	$59		$6	**$166**
EFA										
Legal		1			**1**		$49			**$49**
HIPCS										
Total by Service	**41**	**13**	**0**	**22**	**76**	**$19,003**	**$5,006**	**$0**	**$10,561**	**$34,569**
Unduplicated Clients	**13**	**3**	**0**	**8**	**24**					
Total Service Dollars						**$22,169**	**$5,006**	**$218**	**$15,689**	**$43,082**

1.2 Findings Regarding Transgender RWHAP Clients from Key Informant (KI) Interviews

The Planning Council (REC) reviewed the blinded data on RWHAP agencies which had served Transgender PLWHA in 2016. The REC identified a total of **nine (9) respondents for the Key Informant (KI) survey**. These were top seven (7) agencies with the most Transgender clients – five (5) medical providers, two (2) support service/case management agencies, as well as one HIV prevention agency serving the Transgender population and one Transgender woman. **Responses were received from all nine KIs.**

Responses to Questions For Key Informants

1. What kind of services do you (your agency) provide to HIV-positive transgender individuals? (e.g., medical care, medical case management, support services – list, etc.)

The respondents' agencies provided a range of medical, health, behavioral and support services. There are some gaps that might be remedied by better linkages among existing agencies in the EMA.

Medical providers. The medical provider agencies, located mostly in Newark, offered similar services as follows.

- Medical Care, Medical Case Management, all support services. This agency has no specific exclusions, and transgender patients receive the same treatment and services as any other patient in the clinic.
- Counseling and Testing, Medical Management of HIV throughout the spectrum of the disease, Medical and Non Medical Case Management, Prevention interventions ARTAS and CLEAR, Intensive Patient Navigation, PrEP, Treatment Adherence Counseling, Support Groups, HOPWA
- Medical Care for Adults, adolescents, pediatrics and LGBTQ, medical case management, Addictions services, Mental health and psychiatry, dental screenings, hepatitis care and treatment, PrEP (Pre-Exposure Prophylaxis,) Syringe Exchange, intensive outpatient substance abuse and counseling.
- Primary medical care (including hormone replacement therapy), medical case management, transportation (bus tickets), mental health (individual psychiatric care)
- Primary Medical Care, onsite psychiatry, dental, hepatology, and gynecology including anal pap smears, anoscopy; medical case management; mental health and substance abuse; medical nutrition therapy; support services (education/counseling and support); Gender affirming hormone therapy under supervision of a physician (nurses are available to give injections to clients on-site); Referrals (psychology, psychiatry, plastic surgery, voice training, fertility clinics); Clinical trials

Non-medical/Support service agencies. (The agencies provide other services not funded by RWHAP).

- One agency provides Medical Care, Medical Case Management, Non-Medical Case Management, Individual Mental Health Therapy, Wellness Groups (Co-ed or Women's groups), Individual and Group Substance Abuse Counseling, Housing Placement Assistance. These

services are offered to all HIV positive individuals of the EMA. We consider our office to be Transgender friendly. All staff participated in a Transgender training. We have performed specific outreach activities to the transgender population of the area.
- Another agency provides housing, case management and support services

HIV Prevention agency serving the Transgender population.
- We have a HIV prevention program for Transgender persons of color where we serve high risk Trans persons. Most of Transgender persons we serve are Male to Female (MTF) Trans and are predominately African American. Support services like health education and risk reduction interventions as well as HIV testing.

Transgender Person as key informant.
- I volunteer at The Newark LGBTQ Center. At this time we have limited services.

2. How many HIV-negative transgender clients do you serve? (Discuss, including estimated number of clients, types of services – medical, supportive services)

There are a range of responses but for the most part agencies serve relatively few HIV-negative transgender clients. One medical provider served none, and another reported serving four – all male to female transitions. According to another medical provider's HIV Counseling and testing center, the agency had seen a total of eight (8) transgender HIV negative patients – and actively is assisting one out of those eight. A majority of the transgender patients that come in normally do not stay. They transfer their services to another medical provider which caters to the MSM population. This provider reports having about 50 transgender patients and growing by the week with its new transgender medical clinic which is on Wednesdays.

Another medical provider reported serving only transgender clients living with HIV because of funding – and provides gender affirming hormone therapy for a majority of these clients. The agency provides referrals for social and other medical services needed.

The support service agency encountered and tested seven (7) transgender clients during our outreach events this year. In addition, we have one negative client that is enrolled in our Community Promise Program (Thrive). This client attends the weekly women's group facilitated by a Community Promise staff person. The other support service agency served no HIV-negative transgender clients.

The HIV Prevention agency reported serving on average 20 Trans-identified individuals for HIV prevention services as well as referrals to other services.

3. Based on your experience serving the transgender population, is it worth establishing primarily one agency to serve the transgender HIV+ population in the EMA? E.g., similar to Callen Lorde in NYC.
Why or why not?

There were a range of responses. Two said this would not be worth it, due to small number of

transgender clients served, and because it might limit patient choice - some people do not feel comfortable with some providers and prefer to go to other providers or prefer to have all their services in one location.

Five respondents supported the idea. One agency said that "In my opinion, Yes – This population would benefit from providers and counselors that have been specifically trained to assist with needs, concerns, barriers, etc. exclusive to transgendered HIV+ individuals. A program that is developed with the cultural sensitivity, social challenges, medical complexities, etc of transgendered persons would enhance adherence and retention and promote medical and emotional stability." A support service agency noted that, "that transgender population has particular needs and that a single agency could add another component of understanding of HIV case management and medical needs."

Another said "Yes, for their hormone therapy and other healthcare issues." There are not many providers who are culturally competent in the area of servicing the Transgender community. Most importantly, to prevent them from taking dangerous risk when they need to access hormone therapy legally.

The HIV prevention provider opined that it would make more sense to have a full services agency to deal with the unique services of Transgender whether they are HIV positive or negative. The Transgender respondent said, "Yes it would be nice to have a place to service transgender people positive and/or negative."

Two agencies pointed out pros and cons to this approach. One noted that the obvious pros are that this one agency would gain experience in transgender care due to the nature of treating it more often. 45 patients is a small fraction of the PLWHA in the Newark EMA. Centralizing those patients would ensure that the provider was well versed in the latest guidelines to optimize hormone therapy and provide standardized care and preventative maintenance. This would ultimately be better for the patients. Also, to have one centralized location would help other providers in the area know where to refer patients seeking transgender care. As of right now, if a provider is uncomfortable providing transgender care it is difficult to know where to send that patient or worse they might provide that care without the knowledge of optimal care and treatment guidelines. The main con is anonymity is reduced. If your center is known as the place to receive transgendered care for HIV positive patients seeking anonymity might avoid care all together. Another con is lack of options for the patient if they are unhappy with that provider for whatever reason.

The other agency noted that transgender clients may benefit from receiving services from one agency if that agency can provide comprehensive gender-affirming care including hormone therapy and referrals, as we are able to do. However, other factors will need to be weighed, including location and ease of transportation, convenience, confidentiality, and existing relationships with providers that clients may not want to change. Perhaps the best answer to this question will originate from the stake-holders (e.g. trans clients) themselves. As an alternative, members of the Newark EMA could initiate training in trans health that could include periodic case discussions and collaboration across agencies.

4. Is your agency doing anything specifically to attract and retain its transgender caseload?

Most agencies (except one) have special services, programs or efforts to attract and/or retain their

transgender caseload.

Medical provider agencies offer the following.

- We maintain a linkage agreement with the African American Office of Gay Concerns (AAOGC) in Newark, and refer as necessary. As a [part of a major hospital] system, we have access to the new RWJ PROUD Family Health Center. Our staff participates in local training/webinars that discuss transgender specific issues when available.
- Yes, we have a clinic that is specifically for this population that has non-traditional hours and coincides with our youth LGBTQ drop in center, we have a designated case manager for this population to help navigate and follow up with them on their appointments and care.
- We do not specifically attempt to attract transgendered patients but we do provide hormone therapy. Thus, a transgendered patient is more likely to stay if they know we are able to provide them with complete care.

Other support agencies offer the following:

- Our agency has always hired staff that represent the community it serves. We currently have both staff recruiting volunteers for the office. In addition, outreaching to locations where the transgender community fellowship to offer HIV testing and distribute our flyers about our services such as PrEP, Medical Care and STD screenings.
- The HIV prevention agency has a Trans person on staff to help facilitate the name change process with Trans people and other unique servicers which helps because she knows what issue they go through being Trans identified
- The Transgender respondent reported that the Newark LGBT program has resumed its transgender [support] group.

One medical provider agency noted a major effort to serve the transgender population. This agency is working with major state healthcare institutions – University Hospital and Rutgers University New Jersey Medical School – which are establishing statewide health resources to serve the transgender population.

> "Over the past year, we have initiated multiple training sessions for the staff of the our agency on culturally-competent LGBTQ care (Safe Zone training, agency retreat training on LGBTQ care, pronoun training led by a trans woman). We have also put into place a pronoun policy and have updated the signs and waiting room materials to make the space more welcoming for trans-identified individuals. Since the fall of 2016, our agency offers gender affirming hormone therapy and has a referral system in place for psychiatry and for gender-affirming surgery. Currently at our referral University Hospital, the Plastic Surgery and Obstetrics/gynecology departments have partnered to develop a transgender surgery program and are offering both breast/chest and genital gender-affirming surgeries for trans men and women. This program will be one of the only surgical programs available to trans clients in the state. The hospital administration, under the leadership of its CNO, has developed an LGBTQ task force and is committed to enhancing care for this population. A similar task force at New Jersey Medical School ensures that education efforts across departments and for medical students include relevant LGBTQ topics. We also have an active clinical trials unit with several clinical HIV

prevention trials focusing on the transgender population. Lastly, we are developing a resource guide for special services (housing, fertility clinics/sperm cryopreservation, mental health services, voice training, community-based organizations, etc)."

5. For RWHAP transgender medical clients, do they have higher priority medical [care] needs other than for treatment of HIV?

Most agencies which responded said that they did not have higher priority needs than HIV, but that needs might be more complex.

> "Definitely potentially more complex medical needs when surgeries and hormone therapy are involved."
>
> "Yes. Many are in need of hormone therapy and have other medical conditions that are not under control as well as their HIV. We provide these services for the primary care, HIV and hormone therapy."
>
> "These patients have a clear list of maintenance and guidelines we follow for patients starting on and continuing on hormone therapy. This is separate from their HIV care but of same priority."

One agency reported in detail on the existence of higher priority needs other than HIV care, as follows.

> "Transgender clients are frequently vulnerable to many psychosocial stressors. The state of living in a society that discriminates against trans individuals can be very difficult to negotiate, and can lead to significant dysphoria and depression. Many of our transgender clients living with HIV suffer from psychiatric illnesses, rejection from family/friends (100%), under- or unemployment (50%), poverty, unstable housing/homelessness (33%), assault (25%), survival sex work (67%), sexually-transmitted infections (83%) and prior lack of access to culturally-competent medical care leading to purchasing of hormones from friends or off-market (80%). The literature on the care of HIV+ trans women also shows us that many may fear medication interactions between ART and hormones which can impact adherence to ART. All of these factors can lead to lower access to care, and lower retention and rates of viral suppression. A holistic, comprehensive approach that includes gender-affirming strategies, psychiatric care, surgery referrals, and robust social services can provide the best opportunity for improving outcomes for the trans population."

a. [Do you know] What payment sources cover hormone therapy? Medicaid? ADAP?

A few respondents knew which payment sources covered hormone therapy – Medicaid, ADAP, Medicare, private insurance. Most were unsure or did not know, or felt these sources covered some forms of hormone therapy or only if it was medically necessary, or certain private insurance companies and Medicaid HMO plans do cover it but it requires need prior authorization. One reported that in speaking with a staff person who identifies as Transgender woman, she shared that Medicaid used to cover the shots and pills. Now Medicaid only covers the pills.

This is an area – accurate information on insurance payment for hormone therapy - which could benefit from clarification - by the Planning Council and its Continuum of Care Committee or training or

some other source, including the Northeastern/Caribbean AETC.

b. Any additional comments.

One agency commented that a directory of local transgender specific resources would be helpful.

The Council should work with AAOGC and other agencies to identify these resources.

6. Is receiving hormone therapy a barrier to HIV medical care? In other words, do [your] transgender patients feel/want/believe they must receive or have access to hormone therapy before or in conjunction with HIV medical care?

One agency did not believe that receipt of hormone therapy was a barrier to HIV medical care, but most felt or experienced that hormone therapy is an essential part of medical care.

- If clients are seeking or in the process of receiving hormone therapy or if they are experiencing emotional, medical, legal or financial barriers associated with transitioning, this can impede consistent HIV follow up. However, the requirements to receive hormone therapy before or in conjunction with HIV medical care, can be the case but for some but not for all patients.
- They want to receive in conjunction with their HIV medical care. Most have access in conjunction with the HIV care
- "I have always treated transgendered patients with HRT (hormone replacement therapy) if they are seeking this. Thus, I don't know if they would leave my care if they didn't receive it. However, all of my transgendered patients consider their HRT of high importance."
- "Yes this a barrier to treatment because all of our Trans identified clients prioritize hormone treatment above all things."
- "Most of our transgender clients recognize the need for HIV care and have generally made it a priority. That said, since we have started to offer gender-affirming hormone therapy, our clients have demonstrated a greater engagement in care and all but 2 are virally suppressed (one is not on hormone therapy and has significant psychiatric barriers to adherence, and the other is a new diagnosis just recently started on ART). No-shows are rare, and satisfaction with care has improved."

Do any of your patients refuse HIV medical care if they cannot get hormone therapy?

Six providers said no, that patients do not refuse HIV care if cannot get hormone therapy. One reported that, however, they may disengage from regular HIV care while establishing hormone therapy options, etc. Another said that the agency did not really have any patients that refuse HIV medical care if they cannot get hormone therapy. A third has never refused to prescribe HRT, and so cannot answer this question. A final agency noted that, "At first we had one client who refused HIV medical care. She is currently receiving hormone therapy with (specified provider)."

7. Would you prefer <u>one agency</u> to provide key services to transgender PLWHA? Or one day per week? Or special hours?

There were a range of responses to this question. Several medical provider agencies said no, these two work together to serve a relatively large Transgender population. Another would not prefer this option but would not be opposed to it. A support service agency noted that "if only one agency provides all the services there will be no choices for our clients." Another provider agency gave the following detail.

> "Currently, our transgender clients can make appointments in any available slots, and are not seen on any particular day. Special hours may be appropriate, but again feedback from clients would be best for guiding us. For example, some clients may cherish confidentiality and not want to be seen regularly by others in their peer community receiving care in an Infectious Disease clinic. We also have the benefit at our agency of providing PrEP for HIV-negative clients in conjunction with hormone therapy and we see other HIV-negative hospital follow-ups. In this setting we hope that clients could maintain confidentiality with respect to their HIV status. It may also be important for our clinic as a whole to ensure that we maintain an atmosphere that is welcoming for all patients at all times, rather than arranging for special hours for a specific group that would necessarily separate them from other clients seeking care at out agency."

Another agency supported the idea. "In my opinion, one agency that encompassed the entire spectrum of needs would be beneficial. Designated days or times at other agencies may make people accessing services feel segregated. A specific agency dedicated to providing relevant and quality care could be perceived as a "safe space" for clients who may otherwise avoid traditional organizations or self medicate."

The HIV Prevention agency serving transgender people noted, "I think special days would probably be best and keep in mind alternative times because Trans keep odd hours."

8. Please provide any other information and/or comments that would assist the Newark EMA RWHAP in serving the transgender PLWHA population.

One medical provider noted that an important need is conducting education classes for our transgender population. Another medical provider recommended (1) Staff training to serve the transgender population (needs for this population, mental health), and (2)Available community resources for this population (housing, support groups and other supportive services). The Transgender KI noted that helping the community is important.

1.3 Recommendations – Transgender Population

It is not necessary to establish or designate a single agency to provide medical care and other services to transgender RWHAP clients, since access appears to be adequate.

It is recommended that standards of care for services to transgender RWHAP clients be establish to ensure uniformity and quality within the EMA. The **Worldwide Professional Association for Transgender Health (WPATH)** has developed standards which are available at www.wpath.org and will be attached to this assessment.

PART 2: YOUTH (Age 13-24) AND "FORMER YOUTH" (Age 25-34)

2.1 Introduction

The Research Question #2 to be answered is:

What are the needs of the Youth (Age 13-24) and Former Youth (Age 25-34) population of PLWHA in the Newark EMA?

The needs assessment uses the term **"former youth" for individuals age 25-34. The reason is that this age cohort has similar behaviors and outcomes with respect to HIV disease – Viral Suppression - as youth age 13-24 compared to adults age 35 and older.**

This method is very similar to the methodology for the transgendered population. The difference is that CHAMP client level data are reviewed for two years – 2016 and 2015 – to determine if there are any differences between years for the two populations - youth age 13-24 and "former youth" age 25-34 receiving RWHAP services in the Newark EMA in 2016 and 2015. Data captured included demographics (race/ethnicity, gender, age), geography, services used, housing status, and computation of HIV Care Continuum (HCC) outcomes measures – viral load suppression (VLS) and retention in care (RIC) – for 2015 and 2016.

For better analysis, each age group was subdivided by age into subpopulations. The subpopulations in Youth Age 13-24 were Age 13-18 and Age 19-24. The subpopulations in "Former Youth" (Age 25-34) were Age 24026 ad Age 30-34. The additional reasons were that there are different demographic, economic and behavioral characteristics among the subpopulations. For example, youth age 13-18 are still considered minors, under the care of a parent or caregiver (dependent) which affects health insurance and access to medical care. Youth age 19-24 are independent, no longer legally minors, which affects income, health insurance eligibility, access to housing, etc. As individuals age into the late twenties and early thirties, their behavior becomes more "adult-like" and self-care and adherence to medications increase.

2.2 Findings Regarding Youth (Age 13-24) and Former Youth (Age 25-34) RWHAP Clients

In general, there were minimal differences for each group between years 2015 and 2016. however, when the age groups were subdivided the differences are more noticeable.

2.2.1 Findings – Youth (Age 13-24)

- **In 2016, a total of 218 youth (age 13-24) received RWHAP services in the EMA, down slightly from the total of 242 youth in 2015.**
    - In 2016, 26 or 12% were age 13-18 and 192 (88%) were age 19-24.
    - The percentages were the same in 2015 – with 28 (12%) age 13-18 and 214 (88%) age 19-24.
- **Demographics.**
    - **By race/ethnicity, in 2016 approximately 72% of youth are Black/African American and 21% Hispanic Latino consistent with all RWHAP clients.** However, for **youth age 13-18 only 57% are African American and over one third (35%) were Hispanic/Latino.**
    - **Gender.** In 2016, **youth reflect the EMA with 64% male, 34% male and 1% transgender.** For those **age 13-18, 58% are male and 42% female – reflecting perinatal transmission.** At age 19-24, males are 67% reflecting young MSM transmission.
- **Geographic residence.** Most youth (70%-72%) reside in Essex County (similar to EMA totals), but many are outside of the EMA, reflecting the EMA's special care for pediatric and adolescent/adult HIV care.
- **Income. On average, 82% of youth have incomes below 100% FPL.** However, youth age 13-18 have higher incomes up to 400% FPL, reflecting their parents' and caregivers' incomes and eligibility for the **State Children's Health Insurance Program (SCHIP)**
- **Health Insurance. Two thirds (64%) of total youth have Medicaid and one quarter (26%) are uninsured.** Of the **youth age 13-18, 81% have Medicaid** and 19% are uninsured.
- **Housing. Housing arrangements for total youth follow the EMA totals** – 59% stable housing, 36% temporary, and 5% unstable housing (emergency shelter, homeless, jail/prison). **Youth age 13-18 have more stable housing arrangements (92%).**
- **RWHAP Services Used.** As with most RWHAP clients, the top core medical services used by youth of all ages were medical case management and medical care. Youth age 19-24 also used support services of non-medical case management and transportation.
- **HCC Outcomes in 2016.** Youth of all ages had the following with respect to HCC outcomes in 2016.
    - **Linkage to Care – 97%** higher than the EMA at 87%.
    - **Retention In Care – 92%** higher than the EMA at 87%.
    - **Prescribed ARVs – 89%** lower than the EMA at 95%.
    - **Viral Suppression (VLS) – 67% much lower than the EMA at 81%.**

2.2.2 Findings – "Former Youth" (Age 25-24)

- **In 2016, a total of 908 former youth (age 25-34) received RWHAP services in the EMA, up slightly from the total of 853 former youth in 2015.**
  - In 2016, 441 or 49% were age 25-29 and 467 (51%) were age 30-34.
  - The percentages were the different in 2015 – with 399 (47%) age 25-29 and 454 (53%) age 30-34. **There was in increase in the percentage of RWHAP clients age 25-29 in 2016.**
- **Demographics.**
  - **By race/ethnicity, in 2016 approximately 68% of former youth are Black/African American and 24% Hispanic Latino.** There is a slight increase in Hispanic/Latino former youth over 2015. **Distribution is similar for ages 25-29 and 30-34.**
  - **Gender.** In 2016, there are much **more male former youth (71%) than female (27%) than the EMA wide distribution** at 63% male, 37% male and 1% transgender. The higher male percentage is among those age 25-29 reflecting higher young MSM transmission.
- **Geographic residence.** The residence of most former youth reflects the EMA wide distribution - 68% in Essex County, 18% in Union county but a higher percentage (10%) outside of the EMA.
- **Income. Incomes of former youth are slightly better than the EMA – 69% with incomes below 100% FPL compared to 82% EMA wide.** A higher percent (20%) have incomes 139%-400% FPL.
- **Health Insurance. Half (49%) of former youth have Medicaid and nearly one third (30%) are uninsured.** One in five (17%) have private insurance.
- **Housing. Housing arrangements for former youth follow the EMA totals** – 65% stable housing, 30% temporary, and 5% unstable housing (emergency shelter, homeless, jail/prison, hotel/motel with subsidy/voucher).
- **RWHAP Services Used.** As with most RWHAP clients, in 2016 the top core medical services used by former youth of all ages were medical case management and medical care. Mental health and outpatient substance abuse services were used as well. They used support services of non-medical case management and transportation but at lower percentages than 2015.
- **HCC Outcomes in 2016.** Youth of all ages had the following with respect to HCC outcomes in 2016.
  - **Linkage to Care – 90%** higher than the EMA at 87%.
  - **Retention In Care – 85%** slightly lower than the EMA at 87%.
  - **Prescribed ARVs – 93%** slightly lower than the EMA at 95%.
  - **Viral Suppression (VLS) – 73% much lower than the EMA at 81%.**

As RWHAP clients age, their compliance with ARV medications increases and their Viral Load Suppression (VLS) rates improve. This aging process offers opportunities for interventions to improve VLS, especially among those "former youth" whose gap between the EMA-wide VLS rate is relatively small.

2.2.3 Data Findings regarding Youth Age 13-24

See Pages at the end of this section - ANALYSIS OF DATA FOR YOUTH AGE 13 – 24 - 2016 and 2015.

2.2.4 Data Findings regarding "Former Youth" Age 25-34

See Pages at the end of this section - ANALYSIS OF DATA FOR "FORMER YOUTH" AGE 25 – 34 - 2016 and 2015.

2.3 Recommendations – Youth (Age 13-24) and "Former Youth (Age 25-34)

Research presented at the International AIDS Society 2017 Clinical Meeting underscored that treatment adherence and improved viral suppression are challenges worldwide. Some effective interventions include Youth Consumer Advisory Boards (Youth CABs) and Treatment Adherence Clubs at the agency or community level.

It is recommended that the Council and its committees continue to research and identify effective interventions for youth. One such source is the National Quality Center (NQC) (nationalqualitycenter.org) and its End+Disparities Campaign, specifically its "Share Lab" function. http://enddisparitiesexchange.org/portfolio_item/sharelab/. This site has tools for serving target populations including transgender PLWHA and youth (children and adolescents).

ANALYSIS OF DATA FOR YOUTH AGE 13 – 24

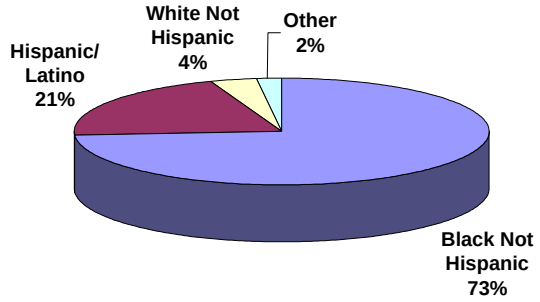
2016 and 2015

YOUTH (AGE 13-24)

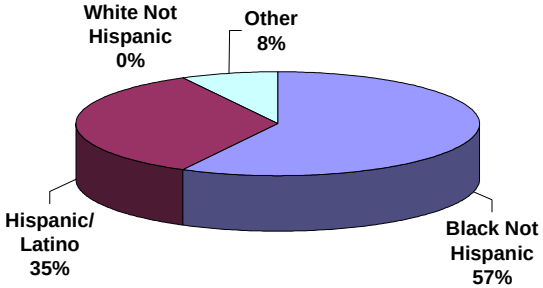
Race/Ethnicity.

- **2016.** Of the **218 youth age 13-24**, 74% (161) were Black/African American, 21% (45) were Hispanic/Latino, 4% (8) were White and 2% (4) of another race. By age subcategory, the 26 youth age 13-18 had different characteristics with 15 (58%) African American, 9 (35%) Hispanic, and two (8%) other races. The 192 youth age 19-24 mirrored the totals – 146 (76%) Black, 36 (19%) Hispanic, 8 (4%) white and 2 (1%) Other.
- **2015. Race/ethnicity reflected a higher percentage of Black/African American youth.** Of the **total 242 youth age 13-24**, 79% (193) were Black, 36 (14%) were Hispanic, 9 (4%) were white and two (1%) of another race. For the 28 youth age 13-18, 20 (71%) were Black, 6 (21%) were Hispanic, and two 7%) were of another race. Of the 214 youth age 19-24, 81% (173) were Black, 14% (30) Hispanic, 9 (4%) white and four (2%) of another race.

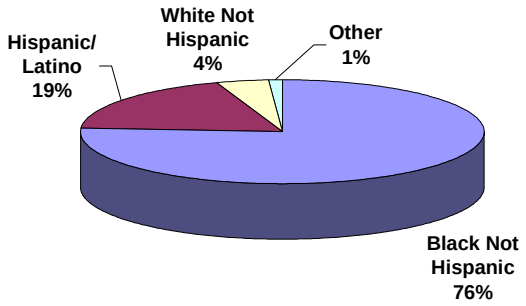
2016: TOTAL YOUTH



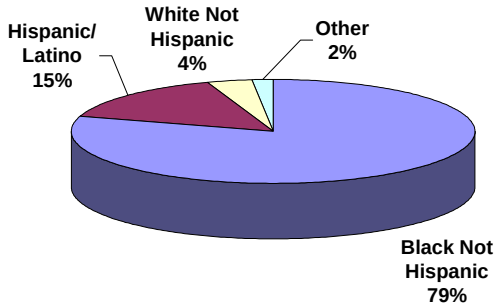
2016: YOUTH AGE 13-18



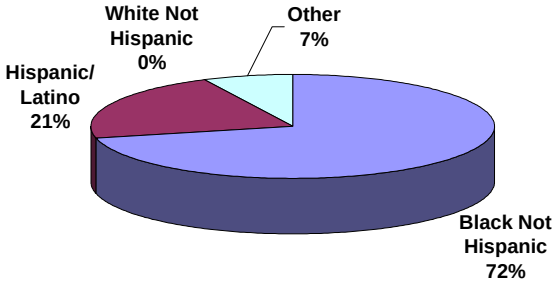
2016: YOUTH AGE 19-24



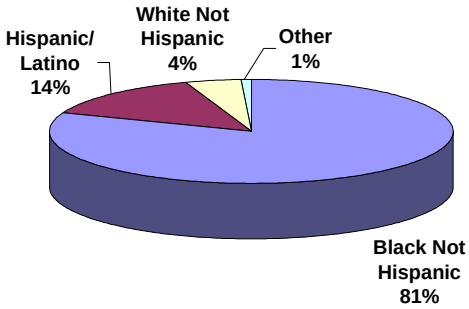
2015: TOTAL YOUTH



2015: YOUTH AGE 13-18



2015: YOUTH AGE 19-24



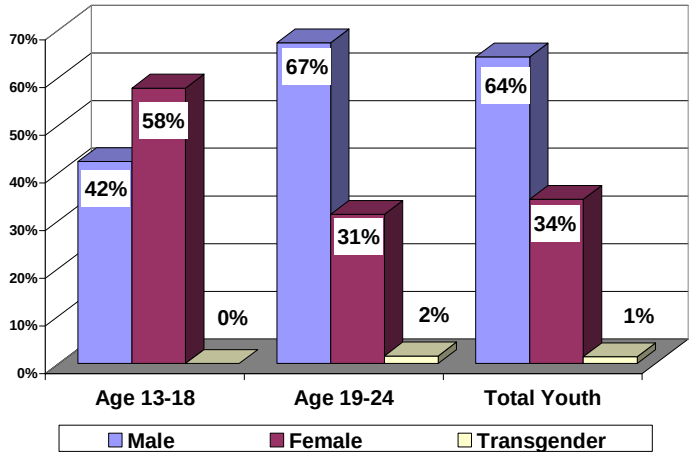
YOUTH (AGE 13-24) (Cont.)

Gender.

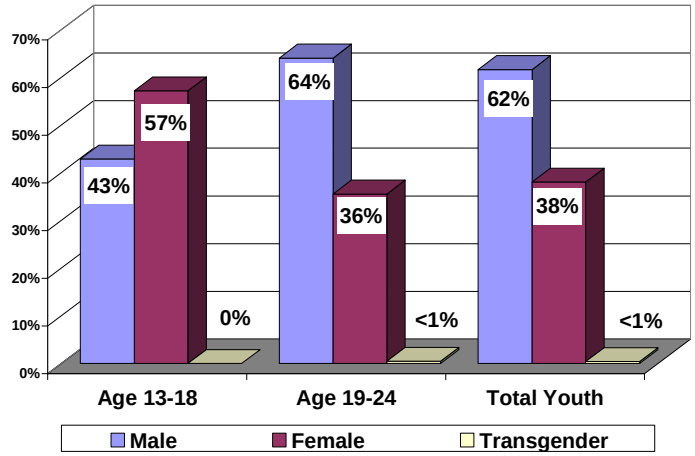
Although the gender of youth RWHAP clients reflects the general EMA gender distribution as of 2015 (62% male, 38% female and <1% transgender), the gender of RWHAP youth clients differs by age subcategory.

- **2016.** Of the **218 youth age 13-24**, 64% (140) were male, 34% (75) were female with 1% (3) transgender. By age subcategory, of the 26 **youth age 13-18** – 11 (42%) were male, and **15 (58%) were female,** and three (2%) were transgender. The **192 youth age 19-24** reflected a higher percent of males – **129 (67%) male**, 60 (31%) female, and three (2%) Transgender.
- **2015.** Of the **total 242 youth age 13-24**, 62% (149) were male, 92 (38%) were female, and one (<1%) transgender. For the 28 youth age 13-18, 12 (43%) were male, and 16 (57%) were female. Of the 214 youth age 19-24, 64% (137) were male, 36% (76) female, and one (<1%) transgender.

2016: YOUTH



2015: YOUTH



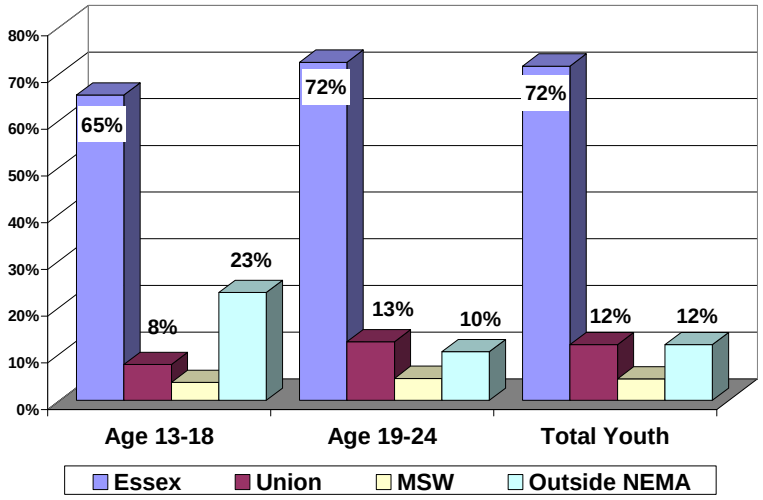
YOUTH (AGE 13-24) (Cont.)

Residence.

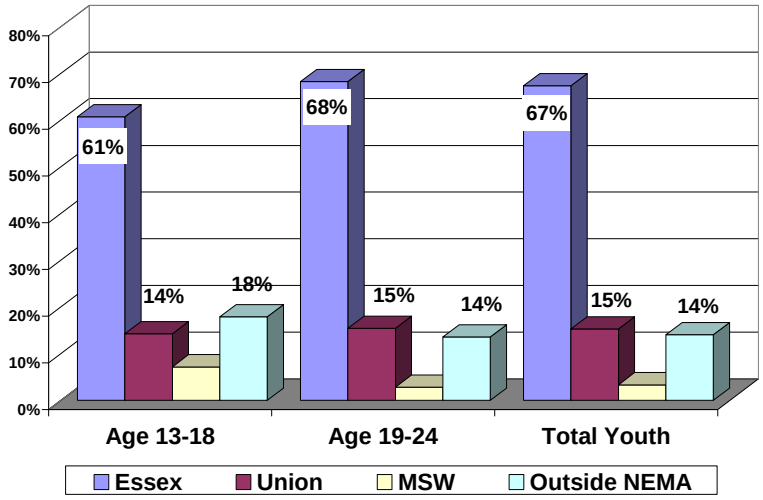
By county of residence, youth appear to follow distribution of RWHAP clients, with some differences. About **2/3 of youth live in Essex County**, slightly less than **70% of RWHAP Clients.** The next highest area is Outside of the EMA, especially for those under age 18 and under at 12%-14% compared to 7% of RWHAP clients. This is probably due to the quality of the specialty care available in the EMA for HIV+ mothers and their HIV+ children who acquired HIV by perinatal transmission. When the children reach age of majority (age 18), they can obtain medical care wherever they want.

By city, approximately 45% of youth of all ages resided in Newark in both 2015 and 2016. Nearly 2/3 of youth resided in the EMA's five largest cities, slightly less than the total of RWHAP clients living in the 5 largest cities (Newark, East Orange, Irvington, Elizabeth, and Plainfield).

2016: YOUTH



2015: YOUTH



YOUTH (AGE 13-24) (Cont.)

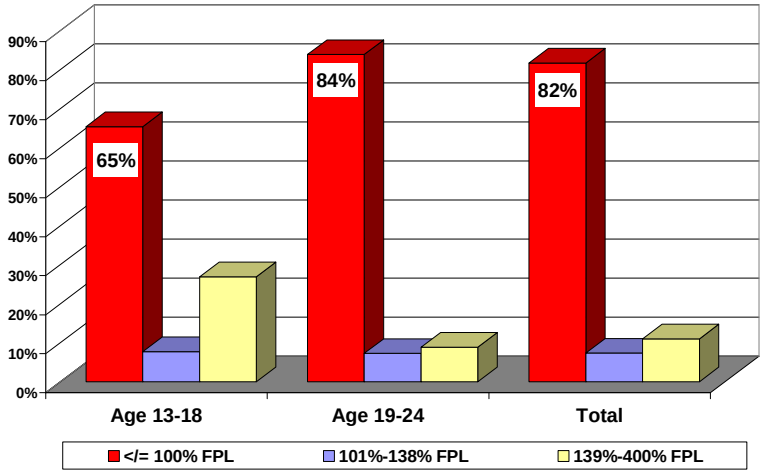
Income.

The majority of total youth (age 13-24) served by RWHAP have incomes at or below poverty – **77%-82% (same % as all RWHAP clients)**. A few more have incomes 101-138% eligible for Medicaid Expansion.

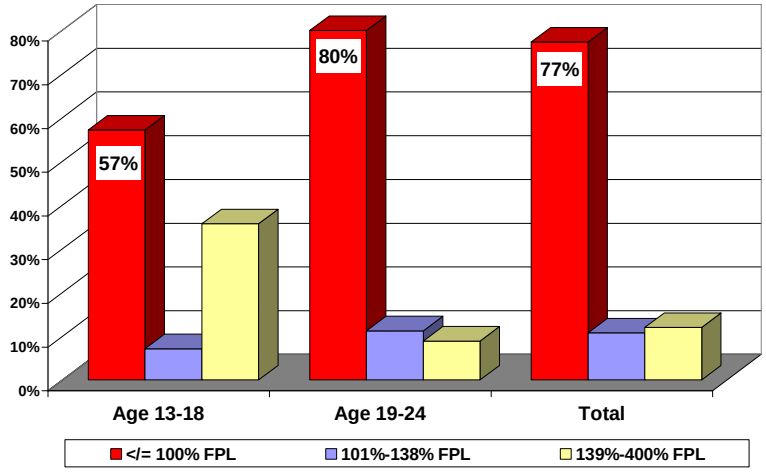
However, there are differences by age subgroup. Less than 2/3 of younger clients age 13-18 have lowest incomes, and 1/3 have incomes from 139%-400% FPL. This reflects health insurance from NJ Family Care (NJFC) State Children's Health Insurance Program (SCHIP) which has higher income limits.

	2016			2015		
Income Range	**Age 13-18**	**Age 19-24**	**Total**	**Age 13-18**	**Age 19-24**	**Total**
</= 100% FPL	**17**	**161**	**178**	**16**	**171**	**187**
101%-138% FPL	2	14	16	2	24	26
139%-400% FPL	7	17	24	10	19	29
401%-500% FPL	0	0	0	0	0	0
Total	**26**	**192**	**218**	**28**	**214**	**242**
</= 100% FPL	**65.4%**	**83.9%**	**81.7%**	**57.1%**	**79.9%**	**77.3%**
101%-138% FPL	7.7%	7.3%	7.3%	7.1%	11.2%	10.7%
139%-400% FPL	**26.9%**	8.9%	11.0%	**35.7%**	8.9%	12.0%
401%-500% FPL	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
Total	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

2016: YOUTH



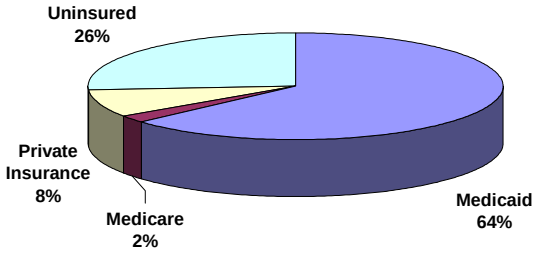
2015: YOUTH



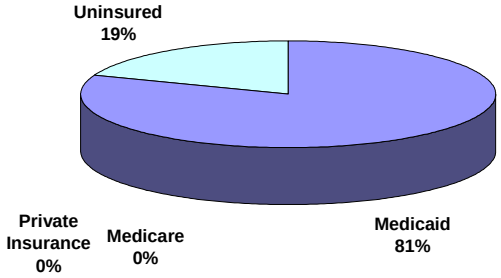
Health Insurance.

- **2016.** Of the **218 youth age 13-24**, **74% (161) had health insurance** – 64% (138) Medicaid, 8% (18) private insurance, 2% (5) Medicare – and **26% (57) were uninsured**. By age subcategory, the 26 youth age 13-18 had different characteristics - 21 (81%) had Medicaid and 5 (19%) were uninsured, and none had private insurance or Medicare. The 192 youth age 19-24 mirrored the totals – 117 (61%) Medicaid, 5 (3%) Medicare, 18 (9%) with private insurance and 52 (27%) uninsured.
- **2015.** Of the **242 youth age 13-24**, **78% (189) had health insurance** – 61% (148) Medicaid, 13% (32) private insurance, 4% (9) Medicare – and **22% (53) were uninsured**. By age subcategory, the 28 youth age 13-18 had slightly different characteristics - 24 (86%) had Medicaid, 1 (4%) had private insurance, 1 (4%) Medicare, and 2 (7%) were uninsured. The 214 youth age 19-24 mirrored the totals – 124 (58%) Medicaid, 8 (4%) Medicare, 31 (14%) with private insurance and 51 (24%) uninsured.

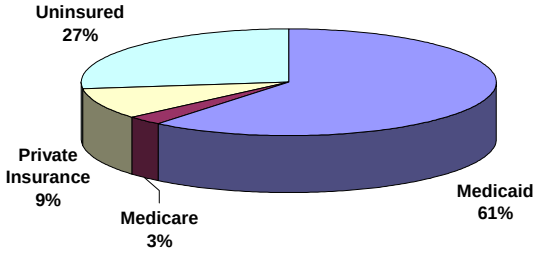
2016: TOTAL YOUTH



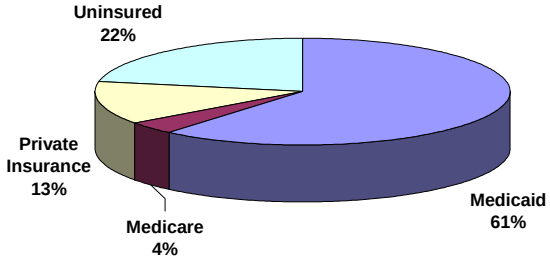
2016: YOUTH AGE 13-18



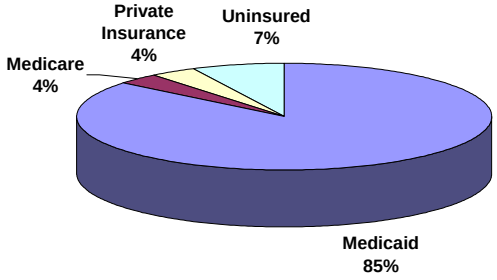
2016: YOUTH AGE 19-24



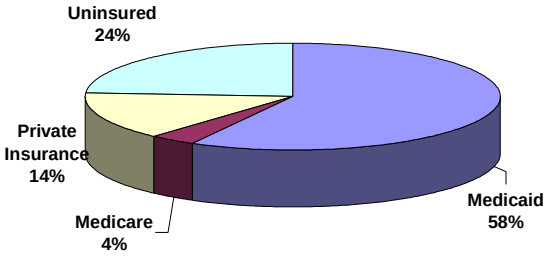
2015: TOTAL YOUTH



2015: YOUTH AGE 13-18



2015: YOUTH AGE 19-24



Housing Status.

A higher percentage of youth, especially those age 19-24, were living in temporary housing arrangements in 2016 compared to 2015.

- **2016.** Of the **218 youth age 13-24**, **59% (129) were living in stable permanent housing.** The majority were in a house/apartment rented or owned and unsubsidized. **36% were in temporary housing** (mostly doubling up/staying with family/friends), and another **5% were in unstable housing** – homeless, emergency shelter, jail/prison. **Nearly all 26 youth age 13-18 were in stable housing.** The 193 youth age 19-24 followed EMA trends.
- **2015.** Of the **242 youth age 13-24**, **70% (170) were living in stable permanent housing**, mostly unsubsidized house/apartment. **26% were in temporary housing and 4% in unstable housing. Nearly all 28 youth age 13-18 were in stable housing.** The 214 youth age 19-24 followed EMA trends – with 29% in temporary housing (mostly doubling up) and 4% in unstable arrangements.

Housing Status/Living Arrangements	2016			2015		
	Total	Age 13-18	Age 19-24	Total	Age 13-18	Age 19-24
Stable Permanent Housing						
House/Apartment - Rent or Own Unsubsidized	119	24	95	151	26	125
House/Apartment - Subsidized Non HOPWA	5		5	10		10
HOPWA - Long Term	1		1	7		7
SRO or Group Housing	2		2	2	1	1
Nursing Home/Hospice	2		2			
Subtotal –Stable Permanent	**129**	**24**	**105**	**170**	**27**	**143**
% Total	**59%**	**92%**	**55%**	**70%**	**96%**	**67%**
Temporary Housing						
House/Apartment - Doubling up, staying w/ family	69	2	67	61	1	60
Residential Treatment Program	1		1	1		1
Ryan White Housing	1		1			
Transitional Housing - Ryan White	3		3			
Transitional Housing - Not Ryan White	1		1			
Institution (Hospital, Psych.)	1		1	1		1
Residential Treatment Program	2		2			
Subtotal - Temporary	**78**	**2**	**76**	**63**	**1**	**62**
% Total	**36%**	**8%**	**39%**	**26%**	**4%**	**29%**
Unstable Housing						
Emergency Shelter, Homeless, Jail/Prison	12		12	9		9
Subtotal - Unstable	**12**	**0**	**12**	**9**	**0**	**9**
% Total	**5%**	**0%**	**6%**	**4%**	**0%**	**4%**
Total Youth	**219**	**26**	**193**	**242**	**28**	**214**
%	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**

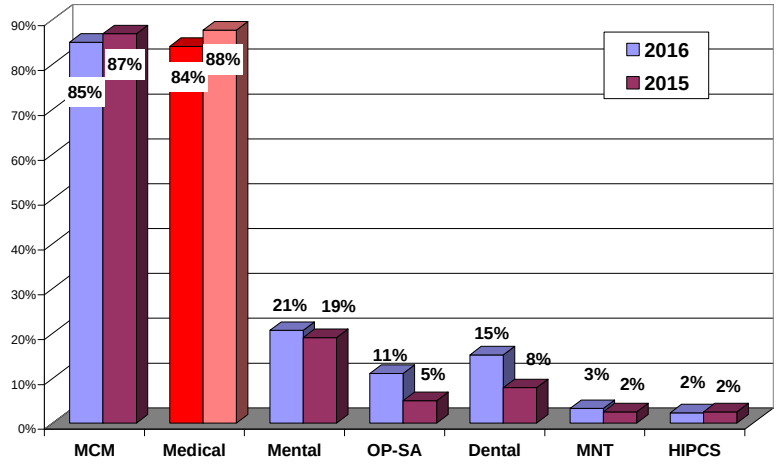
YOUTH (AGE 13-24) (Cont.)

RWHAP Services Used

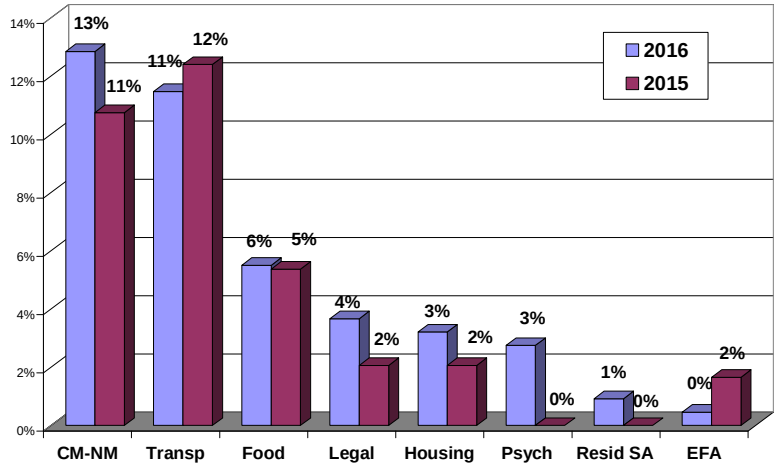
The figures below show the use of core medical and support services by Total Youth Age 13-24 – the **percent of youth receiving each RWHAP service in 2015 and 2016.**

The use of medical care and medical case management (MCM) is roughly equal. However there are significant differences by age subcategory.

Core Medical Services – Total Youth Age 13-24



Support Services – Total Youth Age 13-24

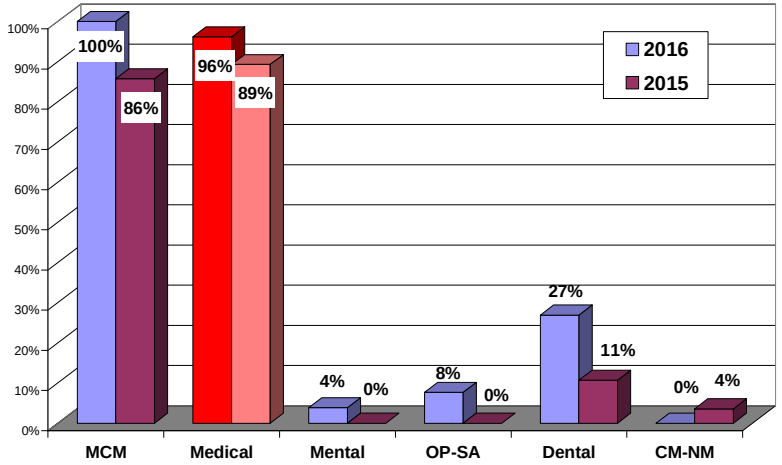


YOUTH (AGE 13-24) (Cont.)

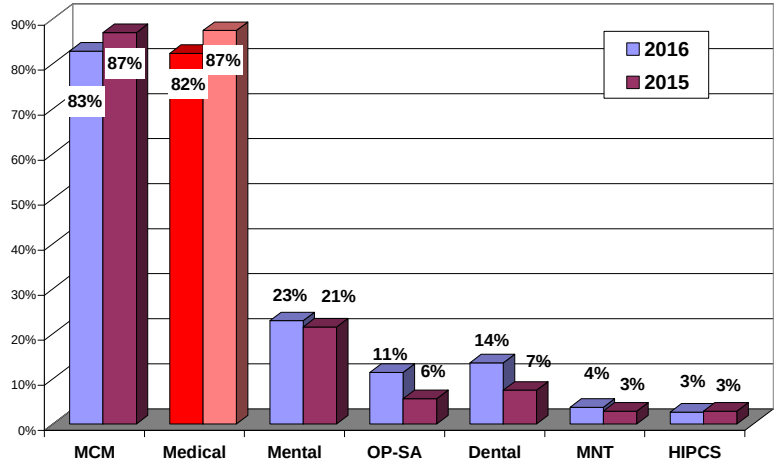
Youth Age 13-18 used mostly medical care and MCM services in both 2016 and 2015. Additional services were dental/oral health, some mental health. The only support service used was non-medical case management. (2016 n=26, 2015 n=28)

In contrast, **Youth age 19-24 used all RWHAP services. Medical care and MCM were used most – at 87% and 83% respectively.** Mental health was 3rd, followed by oral health, and outpatient substance abuse. With respect to ***support services***, **non-medical case management** was used most, followed closely by **transportation**. Youth age 19-24 used food, legal services, housing in modest amounts. **In 2016 3% of youth age 19-24 used the new category of psychosocial support** services. (2016 n=192, 2015 n=214)

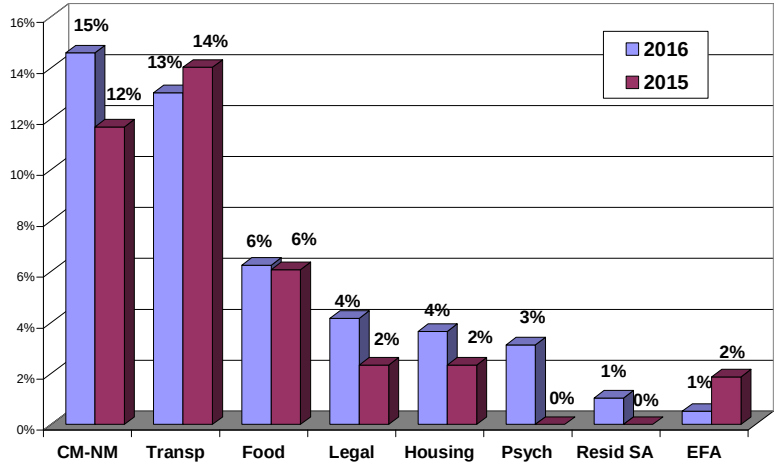
Youth Age 13-18 – Total Services



Core Medical Services – Youth Age 19-24



Support Services – Youth Age 19-24



YOUTH (AGE 13-24) (Cont.)

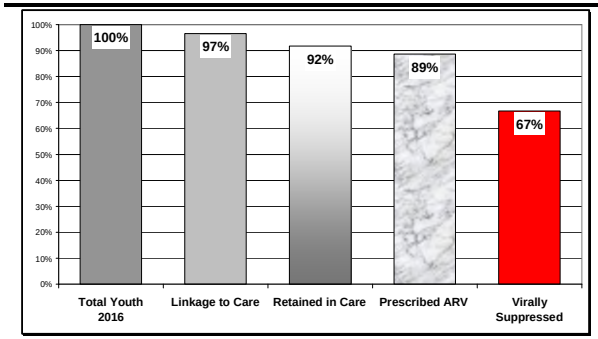
HIV Care Continuum (HCC) Outcomes for Youth in 2016 and 2015

The HIV Care Continuum (HCC) has specific definitions for inclusion of PLWHA in the measurements. The table to the right shows the total number of youth who were counted in the measurement of Prescription of Antiretrovirals (ARVs) and Viral Load Suppression (VLS). (Linkage to care is slightly less.)

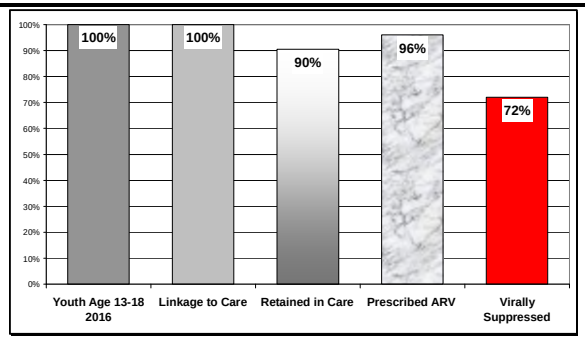
Age Group	Number ARV & VLS	
	2016	2015
Age 13-18	25	24
Age 19-24	134	162
Youth Total	**159**	**186**

The National HIV/AIDS Strategy 2020 (NHAS) goal is to increase the percentage of persons with diagnosed HIV infection who are virally suppressed to at least 80 percent. RWHAP Viral Load Suppression (VLS) rates for the Newark EMA were **79.8% in 2015 and 81% in 2016, respectively.** VLS rates for most RWHAP clients when viewed by age category are close to these measures. The exceptions are RWHAP clients who are young. **Youth age 13-24 and "former youth" age 25-34 have VLS rates at 67% - much lower then EMA averages of 80%-81%.** See below.

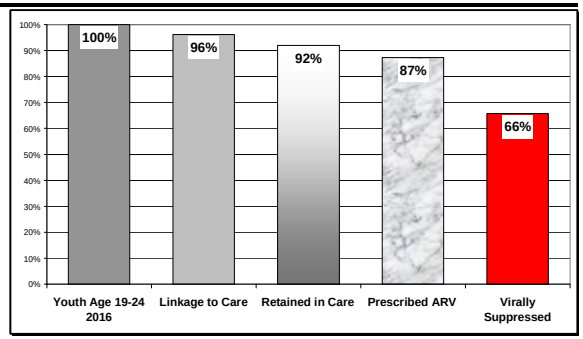
2016: TOTAL YOUTH



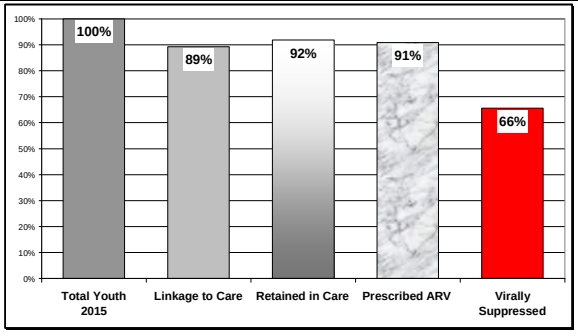
2016: YOUTH AGE 13-18



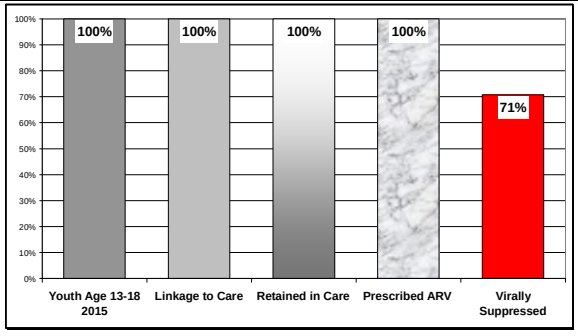
2016: YOUTH AGE 19-24



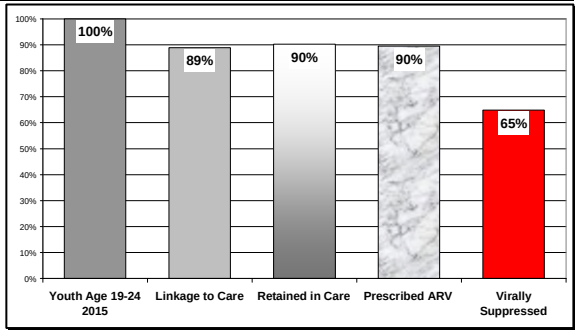
2015: TOTAL YOUTH



2015: YOUTH AGE 13-18



2015: YOUTH AGE 19-24



ANALYSIS OF DATA FOR "FORMER" YOUTH AGE 25 – 34 2016 and 2015

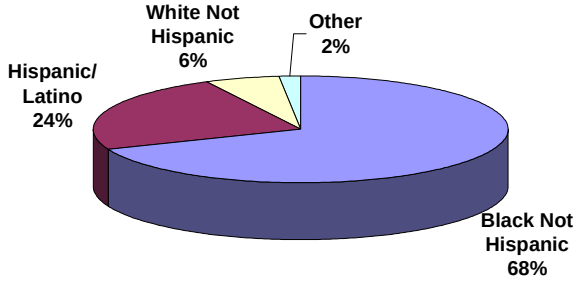
FORMER YOUTH (AGE 25-34)

Race/Ethnicity.

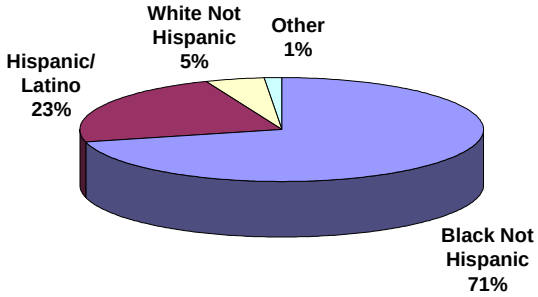
The race/ethnicity for former youth clients differs slightly from the **EMA RWHAP clients as of 2016 – Black/African American 71%, Hispanic/ Latino 19%, White Not Hispanic 7% and Other 2%.**

- **2016.** Of the **908 former youth age 25-34**, 68% (626) were Black/African American, 24% (214) were Hispanic/Latino, 6% (53) were White and 2% (15) of another race. By age subcategory, there were differences in the percent of Black/African Americans, but **Hispanic/Latino former youth accounted for nearly one quarter of this age cohort.**
- **2015. Race/ethnicity reflected a slightly higher percentage of Black/African American former youth.** Of the **total 853 former youth age 25-34**, 70% (602) were Black, 22% (188) were Hispanic, 6% (47) were white and 2% (16) of another race. For the 399 former youth age 25-29, 19% (74) were Hispanic compared to 25% (114) of the 454 former youth age 30-34.

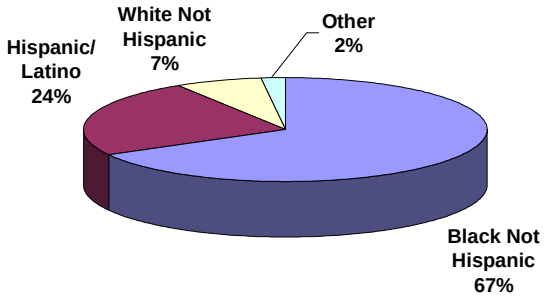
2016: TOTAL FORMER YOUTH



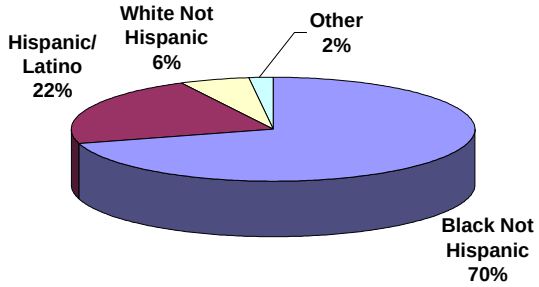
2016: FORMER YOUTH AGE 25-29



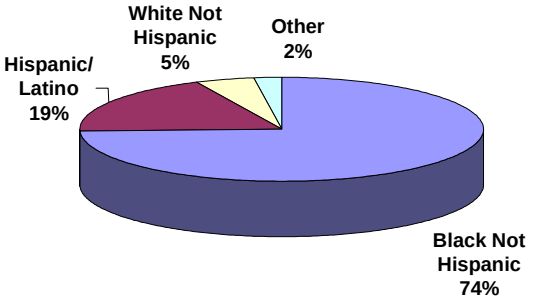
2016: FORMER YOUTH AGE 30-34



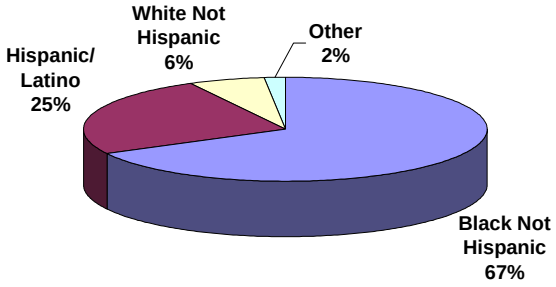
2015: TOTAL FORMER YOUTH



2015: FORMER YOUTH AGE 25-29



2015: FORMER YOUTH AGE 30-34



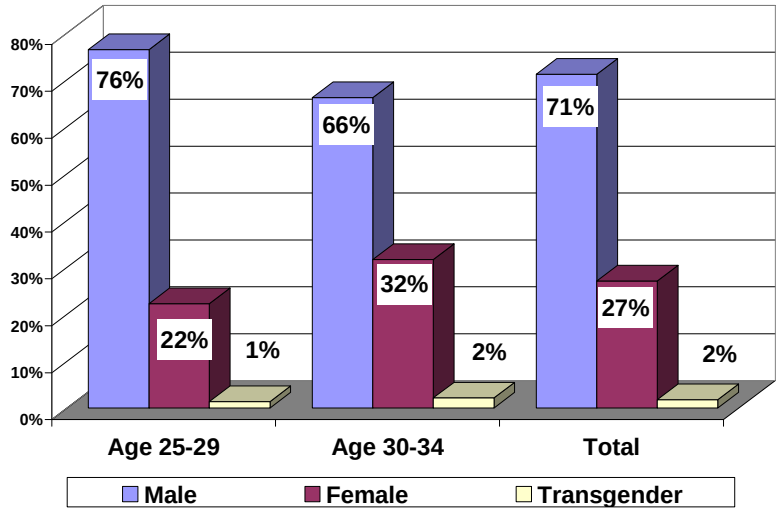
FORMER YOUTH (AGE 25-34)

Gender.

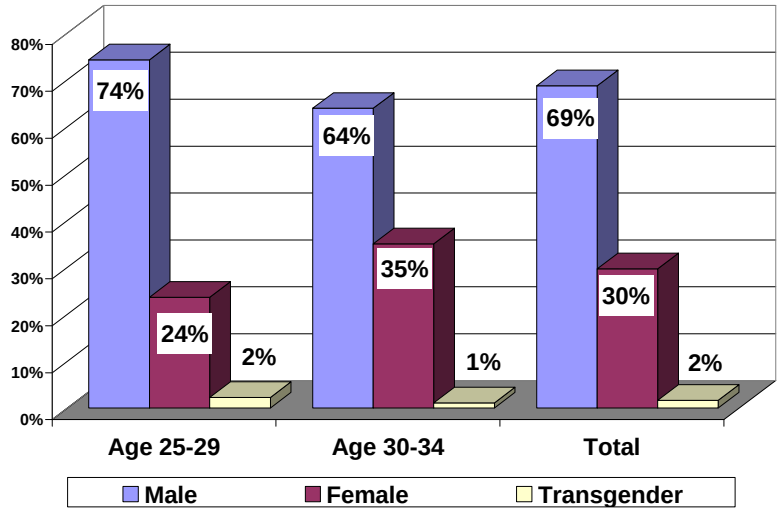
The **gender of former youth RWHAP clients does NOT reflect the general EMA RWHAP gender distribution** as of 2016 (602% male, 39% female and 1% transgender). As of 2016, over 3/4 of the former youth RWHAP clients are male, and 22% are female, with minor differences for compared to 2015. **the gender of RWHAP youth clients differs by age subcategory.**

- **2016.** Of the **908 former youth age 25-34**, 71% (646) were male, 27% (2246) were female with 2% (16) transgender. By age subcategory, of the 441 **former youth age 25-29 – 337 (76%) were male**, and 98 (22%) were female, and 6 (1%) were transgender. The **467 former youth age 30-34** reflected a higher percent of females – 309 (66%) male, **148 (32%) female**, and 10 (2%) Transgender.
- **2015.** Of the **total 853 former youth age 25-34**, 586 (69%) were male, 253(30%) were female, and 14 (2%) transgender. For the 399 former youth age 25-29, 296 (74%) were male, and 94 (24%) were female and 9 (2%) were Transgender. Of the 454 former youth age 30-34, 290 (64%) were male, 159 (35%) female, and five (1%) transgender.

2016: FORMER YOUTH



2015: FORMER YOUTH



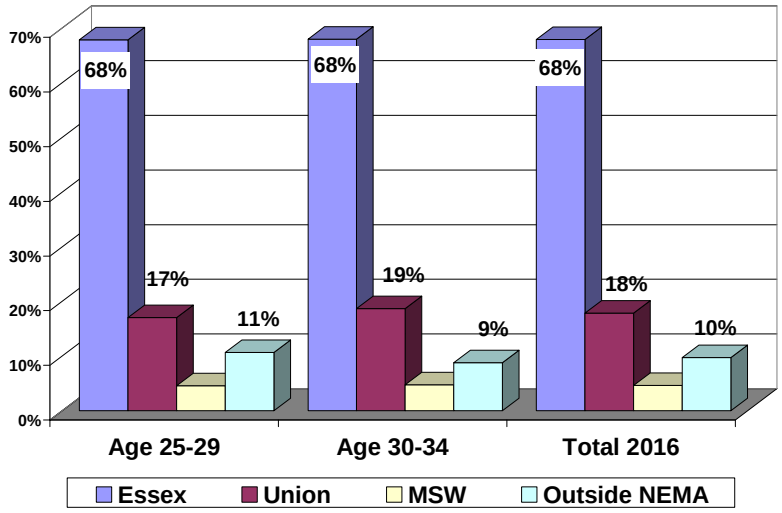
FORMER YOUTH (AGE 25-34)

Residence.

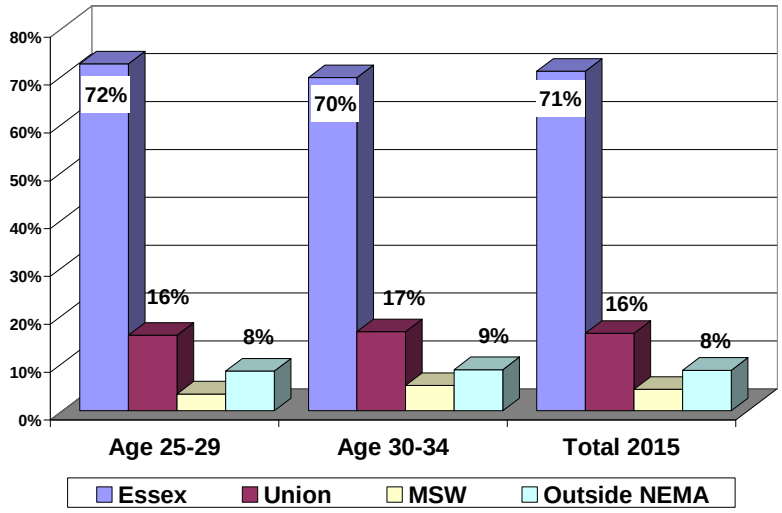
By county of residence, former youth appear to follow distribution of RWHAP clients, with some differences. More than **2/3 of former youth live in Essex County**, approximately the same as **69% of all RWHAP clients.** The next highest area is Union County at 17% (18% RWHAP clients EMA-wide), followed by Outside of the EMA at 11% (versus 7% NEMA) and 5% in Morris, Sussex, Warren (MSW) region, the same as the EMA 5%.

By city, residence of former youth followed distribution of all RWHAP clients. Nearly ¾ (73%) resided in the EMA's five largest cities - 46% in Newark, 7% in East Orange, 7% in Irvington, 8% in Elizabeth, and 4% in Plainfield.

2016: FORMER YOUTH



2015: FORMER YOUTH



FORMER YOUTH (AGE 25-34)

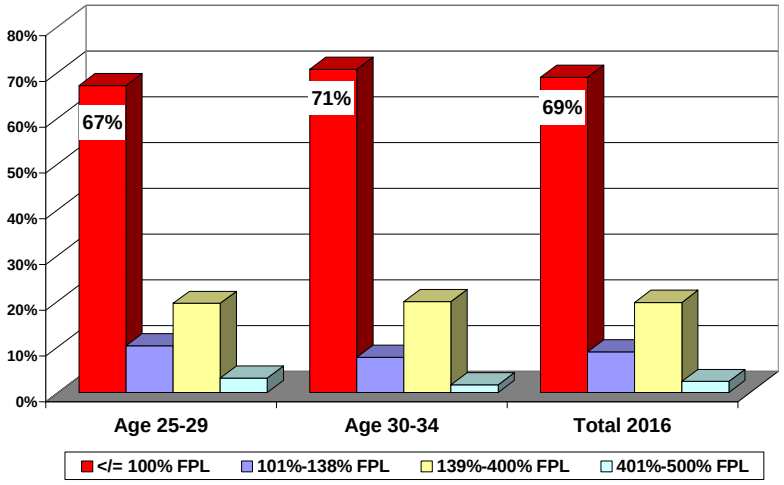
Income.

The majority of total former youth (age 25-34) served by RWHAP have incomes at or below poverty – **67%-74% (slightly less than 80% of all RWHAP clients)**. A few more have incomes 101-138% FPL eligible for Medicaid Expansion.

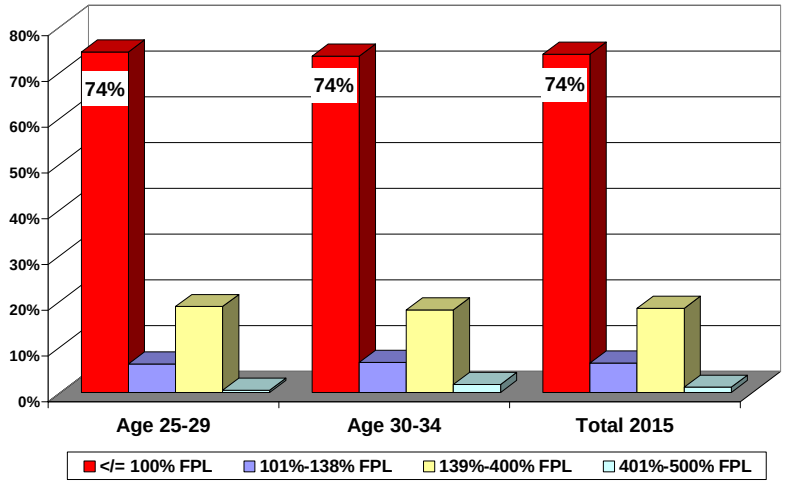
There are minimal differences by age subgroup. Only 2/3 of clients age 25-29 have lowest incomes. In both age subgroups 77% have incomes at/below 138% FPL, and 20% have incomes from 139%-400% FPL. A few have higher incomes 401%-500% FPL.

	2016			2015		
Income Range	**Age 25-29**	**Age 30-34**	**Total**	**Age 25-29**	**Age 30-34**	**Total**
</= 100% FPL	**296**	**330**	**626**	**297**	**334**	**631**
101%-138% FPL	45	36	81	25	30	55
139%-400% FPL	86	93	179	75	82	157
401%-500% FPL	14	8	22	2	8	10
Total	**441**	**467**	**908**	**399**	**454**	**853**
</= 100% FPL	**67.1%**	**70.7%**	**68.9%**	**74.4%**	**73.6%**	**74.0%**
101%-138% FPL	10.2%	7.7%	8.9%	6.3%	6.6%	6.4%
139%-400% FPL	19.5%	19.9%	19.7%	18.8%	18.1%	18.4%
401%-500% FPL	3.2%	1.7%	2.4%	0.5%	1.8%	1.2%
Total	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

2016: FORMER YOUTH



2015: FORMER YOUTH

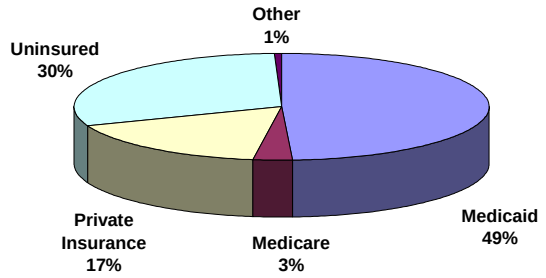


Health Insurance.

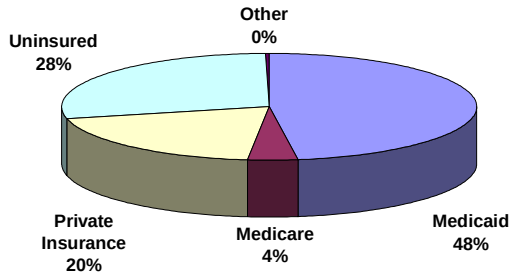
On average, half (50%) of former youth age 25-34 had Medicaid with 30% uninsured. 16% had private insurance, 3% Medicare, and 1% other.

- **2016.** Of the **908 former youth age 25-34**, **70% (632) had health insurance** – 49% (446) Medicaid, 17% (154) private insurance, 3% (27) Medicare, 1% (5) Other – and **30% (276) were uninsured**. By age subcategory, the 441 former youth age 25-29 had slight differences - 48% (211) had Medicaid and 28% (125) were uninsured, 20% had private insurance and 4% with Medicare. Of the 467 youth age 30-34 -51% (235) had Medicaid, 32% (151) were uninsured, 14% (67) had private insurance, 2% (10) Medicare, 1% Other insurance.
- **2015.** Of the **853 former youth age 25-34**, **68% (579) had health insurance** – 50% (428) Medicaid, 14% (119) private insurance, 3% (27) Medicare, 1% Other – and **32% (274) were uninsured**. By age subcategory, the 399 former youth age 25-29 and 454 former youth age 30-34 had slightly different characteristics. 29% (117) of former youth age 25-29 were uninsured compared to 35% (157) of those age 30-34. Of the insured – 51% - 50% had Medicaid, 15%-13% had private insurance, 4%-2% Medicare, and 1% had other insurance.

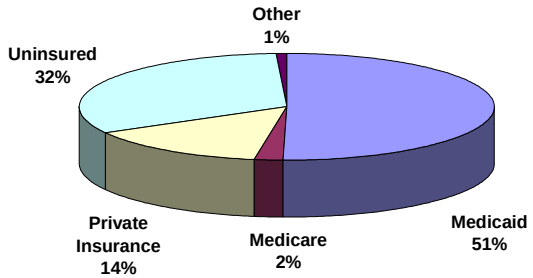
2016: TOTAL FORMER YOUTH



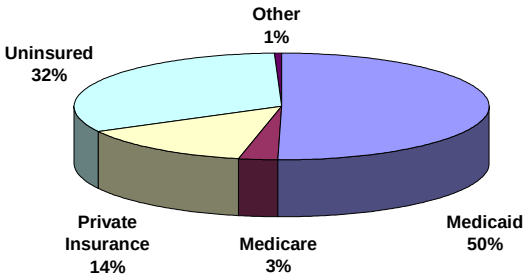
2016: FORMER YOUTH AGE 25-29



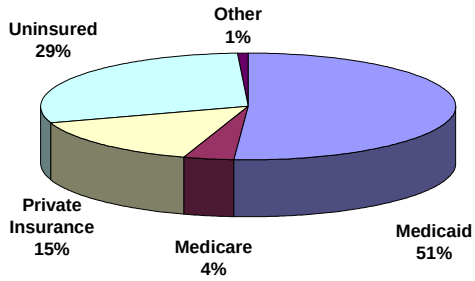
2016: FORMER YOUTH AGE 30-34



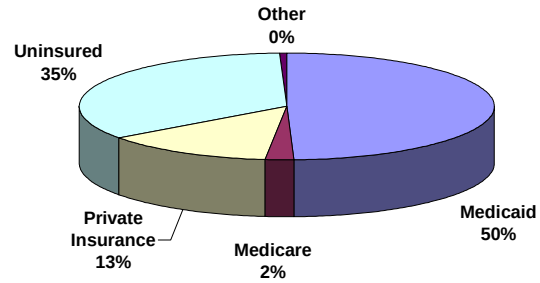
2015: TOTAL YOUTH



2015: FORMER YOUTH AGE 25-29



2015: FORMER YOUTH AGE 30-34



Housing Status.

A higher percentage of former youth, especially those age 25-29, were living in temporary housing arrangements in 2016 compared to 2015.

- **2016.** Of the **908 former youth age 25-34**, **65% (589) were living in stable permanent housing** – mostly in a rented unsubsidized house/ apartment. **30% were in temporary housing** (mostly doubling up/staying with family/friends), and another **5% were in unstable housing** – homeless, emergency shelter, jail/prison. Living arrangements did not vary by age subgroup.
- **2015. Patterns were similar to 2016.** Of the **853 former youth age 25-34**, **70% (693) were living in stable permanent housing**, mostly unsubsidized house/apartment. **25% were in temporary housing and 5% in unstable housing.** There were no differences by age group.

Housing Status/Living Arrangements	2016			2015		
	Total	Age 25-29	Age 30-34	Total	Age 25-29	Age 30-34
Stable Permanent Housing						
House/Apartment - Rent or Own Unsubsidized	513	251	262	524	252	272
House/Apartment - Subsidized Non HOPWA	41	15	26	41	16	25
HOPWA - Long Term	27	12	15	17	5	12
SRO or Group Housing	4	3	1	5	2	3
Nursing Home/Hospice	4	2	2	6	2	4
Subtotal –Stable Permanent	**589**	**283**	**306**	**593**	**277**	**316**
% Total	**65%**	**64%**	**66%**	**70%**	**69%**	**70%**
Temporary Housing						
House/Apartment - Doubling up, staying w/ family	252	123	129	205	101	104
Ryan White Housing	2		2	1	1	
Transitional Housing - Ryan White	12	10	2	7	2	5
Transitional Housing - Not Ryan White	3	1	2	2		2
Institution (Hospital, Psych.)	2	1	1	1		1
Residential Treatment Program	5	4	1	1	1	
Subtotal - Temporary	**276**	**139**	**137**	**217**	**105**	**112**
% Total	**30%**	**32%**	**29%**	**25%**	**26%**	**25%**
Unstable Housing						
Emergency Shelter	5	2	3	7	3	4
Homeless	13	9	4	8	5	3
Jail/Prison	24	7	17	27	8	19
Hotel or motel with subsidy-voucher	1	1		1	1	
Subtotal - Unstable	**43**	**19**	**24**	**43**	**17**	**26**
% Total	**5%**	**4%**	**5%**	**5%**	**4%**	**6%**
Total Former Youth	**908**	**441**	**467**	**853**	**399**	**454**
%	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**

FORMER YOUTH (AGE 25-34) (Cont.)

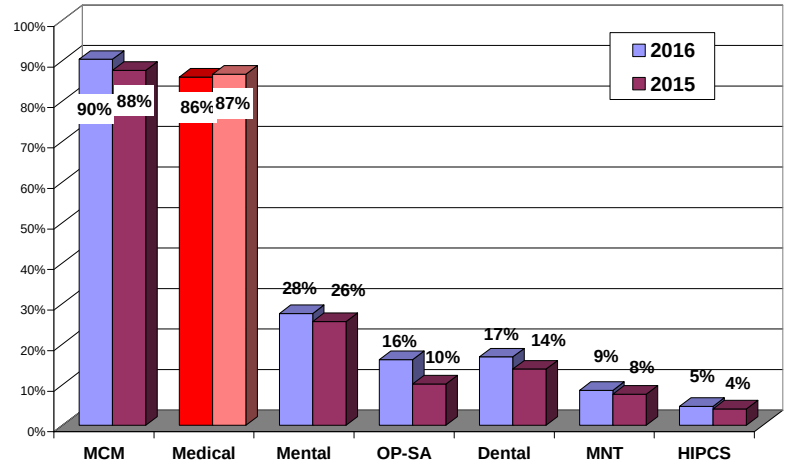
RWHAP Services Used

The figures below show the **percent of "former" youth receiving each RWHAP service in 2015 and 2016.** That is, use of total RWHAP services, core medical and support services by Total Former Youth Age 25-34 – and by subcategory of Former Youth age 25-29 and Age 30-34.

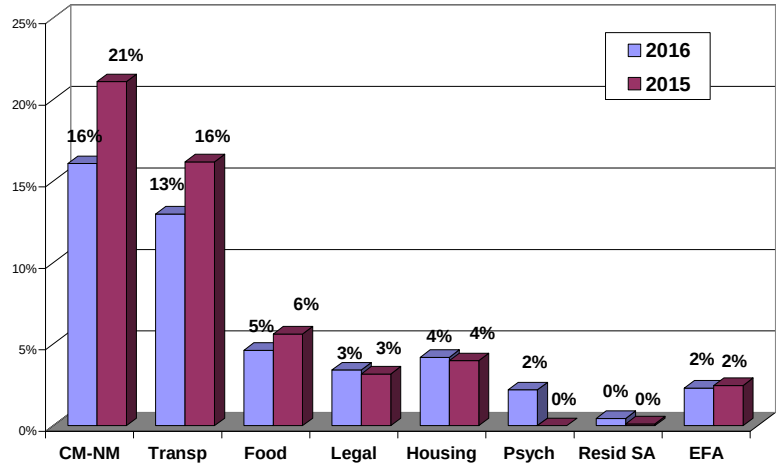
In both 2015 and 2016, and by age subcategory, the use of **medical care and medical case management (MCM) is roughly equal and nearly 90% of Former Youth receive these services.** In contrast to the Youth Age 13-24, service utilization by the "former" youth age 25-34 was consistent among age subgroups. Core medical services used most were medical case management (MCM) and medical care, and the highest support services used were non-medical case management (linking clients to support services) and [medical] transportation, to enable PLWHA to access services.

Age Group	2016	2015
Age 25-29	441	399
Age 30-34	467	454
Total Former Youth	**908**	**853**

Core Medical Services – Total Former Youth Age 25-34

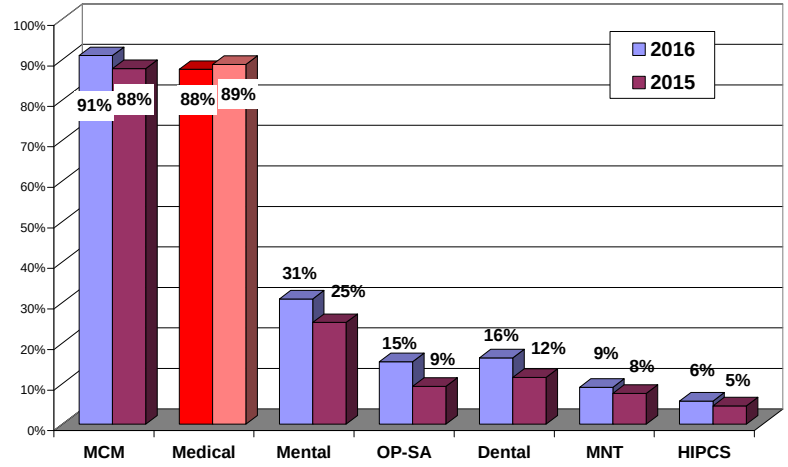


Support Services – Total Former Youth Age 25-34

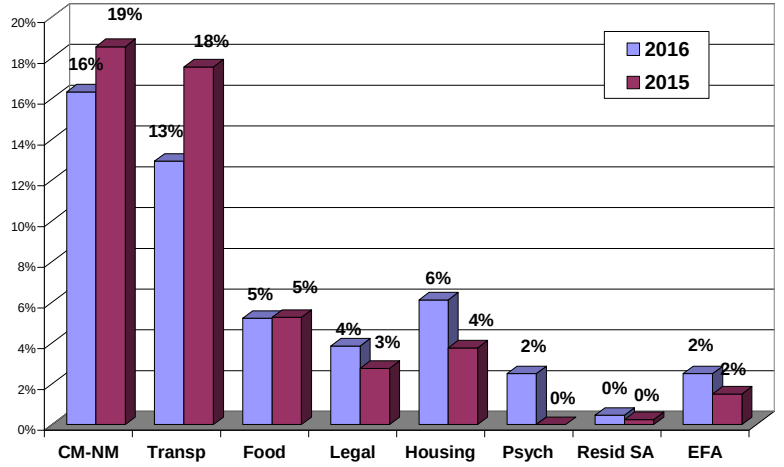


FORMER YOUTH (AGE 25-34) (Cont.)

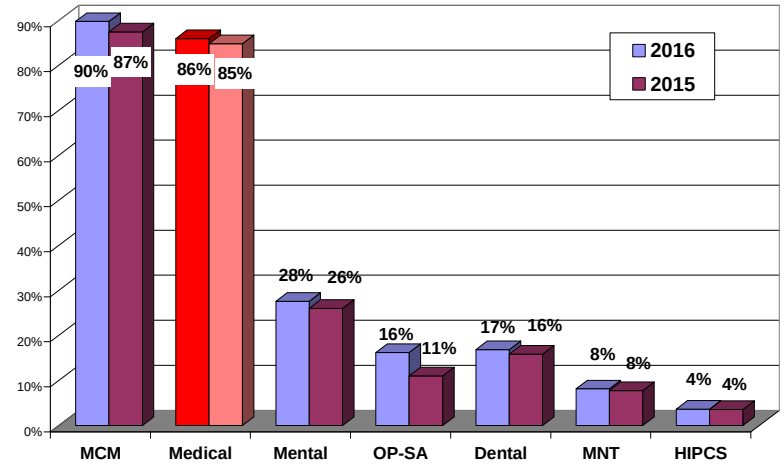
Core Medical Services – Former Youth Age 25-29



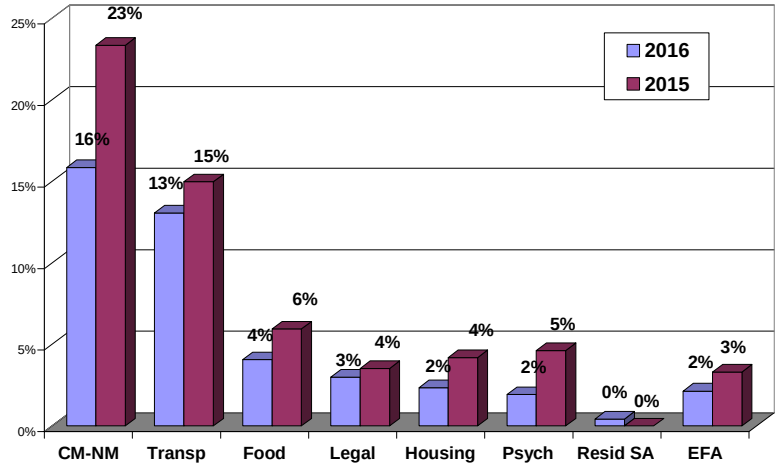
Support Services – Former Youth Age 25-29



Core Medical Services – Former Youth Age 30-34



Support Services – Former Youth Age 30-34



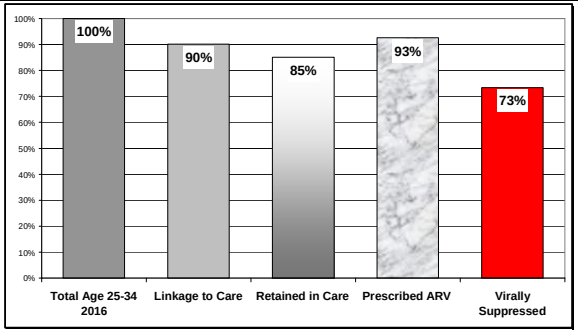
HIV Care Continuum (HCC) Outcomes for Former Youth in 2016 and 2015

The HIV Care Continuum (HCC) has specific definitions for inclusion of PLWHA in the measurements. The table to the right shows the total number of former youth who were counted in the measurement of Prescription of Antiretrovirals (ARVs) and Viral Load Suppression (VLS). (Linkage to care is slightly less.)

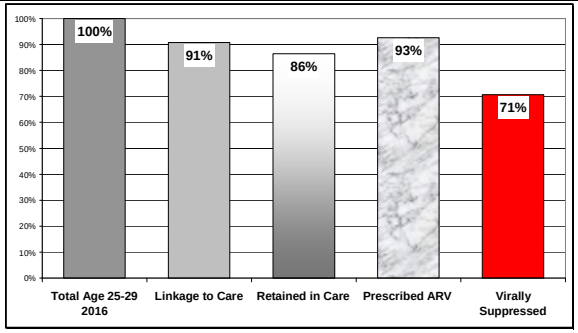
Age Group	Number ARV & VLS	
	2016	2015
Age 25-29	327	295
Age 30-34	345	336
Age 25-34 Total	**672**	**631**

The National HIV/AIDS Strategy 2020 (NHAS) goal is to increase the percentage of persons with diagnosed HIV infection who are virally suppressed to at least 80 percent. RWHAP Viral Load Suppression (VLS) rates for the Newark EMA were **79.8% in 2015 and 81% in 2016, respectively.** VLS rates for most RWHAP clients when viewed by age category are close to these measures. The exceptions are RWHAP clients who are young. **Youth age 13-24 and "former youth" age 25-34 have VLS rates at 67% - much lower then EMA averages of 80%-81%.** See below.

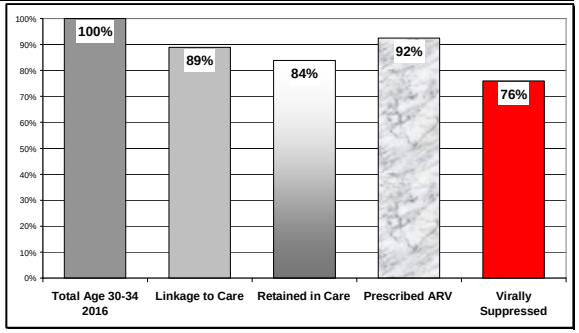
2016: TOTAL FORMER YOUTH



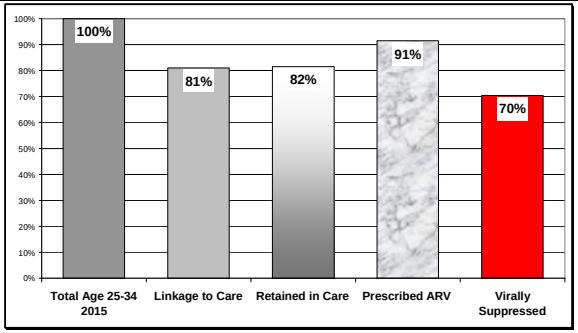
2016: FORMER YOUTH AGE 25-29



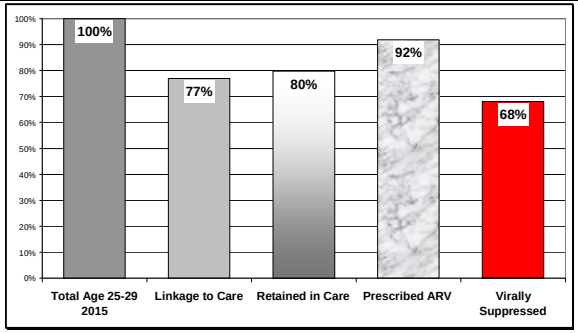
2016: FORMER YOUTH AGE 30-34



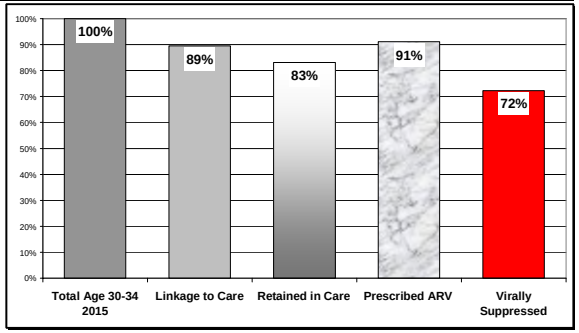
2015: TOTAL FORMER YOUTH



2015: FORMER YOUTH AGE 25-29



2015: FORMER YOUTH AGE 30-34

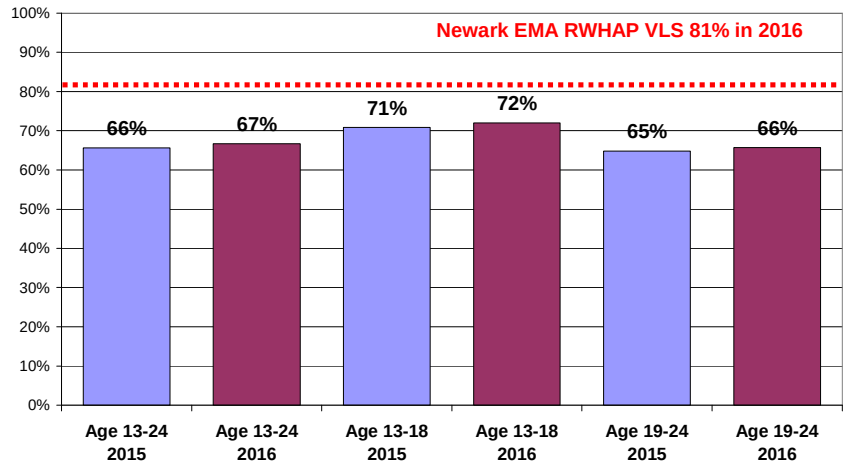


Comparison of Viral Suppression of Youth Age 13-24 and Former Youth Age 25-34

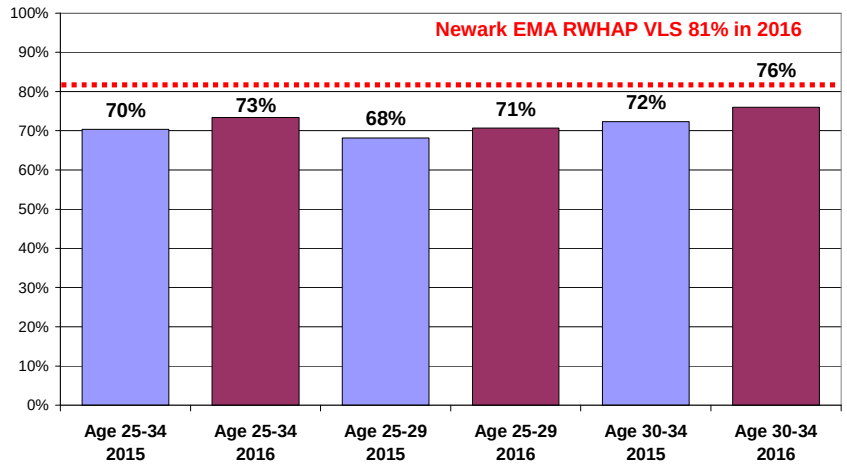
The charts below show the Viral Load Suppression (VLS) outcomes for RWHAP clients age 13-24 and age 25-34 for 2015 and 2016 compared to the EMA RWHAP total of 81% in 2016. The trends show a slight increase in VLS for "former" youth in 2016.

This indicates that there are opportunities for improving VLS among RWHAP clients age 30-34. As PLWHA age into the cohort of age 35 and older, compliance with HIV medication regimens improves.

Viral Suppression of Youth Age 13-24 vs. EMA



Viral Suppression of Former Youth Age 25-34 vs. EMA



APPENDIX A: KEY INFORMANT SURVEY TOOL

TRANSGENDER RWHAP CLIENTS

TRANSGENDER PLWHA KEY INFORMANT TOOL
July 21, 2017

Purpose
The Newark EMA HIV Health Services Planning Council is researching the transgender population of Persons Living With HIV/AIDS (PLWHA) in the EMA and is attempting to determine what Ryan White HIV/AIDS Program (RWHAP) Part A services are needed by these individuals.

Background
Thus far, we have reviewed data on RWHAP services used in 2016 from the CHAMP Client Level Data (CLD) system by the **total 45 PLWHA who self-identified as transgender**. A draft summary of findings is attached. For the most part, the characteristics of transgender PLWHA were similar to the general population of PLWHA served by RWHAP.

Demographics and SES. 80% were African American, 20% Hispanic/Latino. 82% incomes at/below 100% Federal Poverty Level. 57% lived in Newark and 80% lived in 4 largest cities – Newark, East Orange, Irvington, Elizabeth. 51% had Medicaid and 38% were uninsured (RW paid for medical care). RWHAP also served 2 transgender from outside of the EMA – Hudson and Middlesex County.

Services used. 76% received medical case management (highest used service), 31 or 69% received medical care. The most used support service was medical transportation (n=9 or 20%), followed by non-medical case management at 8 or 18%. Not used were residential substance abuse, emergency financial assistance, and health insurance premium assistance.

20 RWHAP-funded agencies served one or more transgender PLWHA in 2016, with one agency serving 10, another at 7, a third at 5, six agencies serving from 4-2 clients, with 8 agencies serving 1 transgender client each. **See the attached table.**

The Council needs information about needs of transgender PLWHA in the EMA, beyond this demographic, SES and service utilization data.

Questions For Key Informants

1. What kind of services do you (your agency) provide to HIV-positive transgender individuals? (e.g., medical care, medical case management, support services – list, etc.)

2. How many HIV-negative transgender clients do you serve?
   (Discuss, including estimated number of clients, types of services – medical, supportive services)

3. Based on your experience serving the transgender population, is it worth establishing primarily one agency to serve the transgender HIV+ population in the EMA? E.g., similar to Callen Lorde in NYC.

Why or why not?

4. Is your agency doing anything specifically to attract and retain its transgender caseload?

5. For RWHAP transgender medical clients, do they have higher priority medical [care] needs other than for treatment of HIV? Yes No Please identify.

   a. [Do you know] What payment sources cover hormone therapy?
   Medicaid? Yes No Don't know
   ADAP? Yes No Don't know

   Any additional comments.

6. Is receiving hormone therapy a barrier to HIV medical care? In other words, do [your] transgender patients feel/want/believe they must receive or have access to hormone therapy before or in conjunction with HIV medical care?

   Do any of your patients refuse HIV medical care if they cannot get hormone therapy?

7. Would you prefer **one agency** to provide key services to transgender PLWHA?

   Or **one day** (per week)?

   Or **special hours?**

7. Please provide any other information and/or comments that would assist the Newark EMA RWHAP in serving the transgender PLWHA population.

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Thank you for your input and assistance!

Attachment

Table 1: Newark EMA RWHAP Resources Serving Transgender Clients in 2016 – Clients Served by Agency Type and Services

		# RWHAP Transgender Clients Served in 2016											
		Core Medical Services						Support Services					
	Agency Type	Medical Care	Mental Health	OP Sub-stance	Oral Health	Med. Case Mgt	Med Nutrit	Case Mgt- NM	Housing	Food	Transp	Legal	TOTAL CLIENTS
1	Medical Provider-Essex	**10**	2			**10**		1		1	1		**10**
2	Medical Provider-Essex	**1**	2	2		**7**							**7**
3	Medical Provider-Essex	**5**	3			**3**							**5**
4	Support Service Provider - Essex							4					**4**
5	Medical Provider-Essex	**4**	1			**4**					3		**4**
6	Medical Provider-Essex	**4**			2	**4**					4		**4**
7	Dental Provider – Essex				4								**4**
8	Medical Provider-Essex	**3**			1	**2**	1						**3**
9	Support Service Provider - Essex											3	**3**
10	Support Service Provider – Essex					**2**		1				1	**2**
11	Support Service Provider - Essex			2				2					**2**
12	Medical Provider-Union	**2**	1	1		**2**							**2**
13	Support Service Provider - Essex							1			1		**1**
14	Support Service Provider - Essex							1	1				**1**
15	Medical Provider-MSW	**1**											**1**
16	Medical Provider-Essex					**1**							**1**
17	Medical Provider-MSW	**1**				**1**							**1**
18	Medical Provider-Essex	**1**				**1**							**1**
19	Support Service Provider - Essex		1					1					**1**
20	Support Service Provider - Essex							1		1			**1**
	Total	**32**	**10**	**5**	**7**	**37**	**1**	**12**	**1**	**2**	**9**	**4**	**58**
	Total Unduplicated	**31**	**10**	**5**	**5**	**34**	**1**	**8**	**1**	**1**	**9**	**4**	**45**