Newark EMA

HIV Health Services Planning Council

NEEDS ASSESSMENT 2014

August 2014

NEWARK EMA HIV HEALTH SERVICES PLANNING COUNCIL NEEDS ASSESSMENT 2014

TABLE OF CONTENTS

LIST OF TABLES ..... **ii**

LIST OF FIGURES ..... **ii**

LIST OF ABBREVIATIONS ..... **iii**

INTRODUCTION ..... **v**
Legislative Background v
HAB Expectations vi

PURPOSE AND METHODOLOGY ..... **vii**

PART 1: PLWHA INELIGIBLE FOR ACA CONTINUING TO NEED RWHAP SERVICES **1**
1.1. Background **1**
Methodology 2
1.2 Focus Group Findings – Hispanic/Latinos and Haitians **3**
Hispanic/Latinos 3
Knowledge about Ryan White Program 3
Barriers to Accessing Health Care 3
Stigma 5
Recommendations for Improving Access to Health Care 6
Haitians 6
Barriers to Accessing Health Care 6
Health Issues 7
Recommendations for Improving Access to Health Care 8
1.3 Key Informant Interview Results - Hispanic/Latinos and Haitians **8**
Services 9
Culturally Appropriate Services 9
Health Insurance 11
Access and Barriers to Care 13
Additional Information and Recommendations 14
1.4 Consumer Survey **16**
Consumer Survey Findings 16
Overview and Characteristics of Respondents 16
HIV+ Individuals 19
Females 20
Youth Age 13-24 21
Young Adults Age 25-34 22
Hispanic/Latino 23
Haitians 24
1.5 Recommendations for PLWHA Ineligible for ACA **25**
Both Populations 25

Hispanic/Latinos 25
Haitians 25

PART 2: COMPLETENESS OF CARE FOR PLWHA IN ACA BY RWHAP SERVICES 26
2.1. Background 26
Methodology 27
2.2 Key Informant Interview Results – RWHAP vs. Medicaid Expansion (NJFC) and ACA Thus Far 27
2.3 Key Informant Interview Results – New Jersey Medicaid and Medicaid Expansion (NJFC) and ACA 36
2.4 Recommendations for Completeness of Care within RWHAP 41

APPENDICES

APPENDIX A: Focus Group and Key Informant Tools A-1
APPENDIX B: Consumer Survey Tool B-1
APPENDIX C: NJ Family Care Expansion C-1

LIST OF TABLES

Table 1: Consumer Survey 2014 – Services Received by Respondents (n=595) 18
Table 2: Consumer Survey 2014 – Profile of HIV+ Respondents (n=557) 19
Table 3: Services Received by HIV+ Respondents - Consumer Survey 2014 19
Table 4: Consumer Survey 2014 – Profile of Female Respondents (n=233) 20
Table 5: Services Received by Female Respondents - Consumer Survey 2014 20
Table 6: Consumer Survey 2014 – Profile of Youth Respondents (n=22) 21
Table 7: Services Received by Youth Respondents - Consumer Survey 2014 21
Table 8: Consumer Survey 2014 – Profile of Young Adult Respondents (n=57) 22
Table 9: Services Received by Young Adult Respondents - Consumer Survey 2014 22
Table 10: Consumer Survey 2014 – Profile of Hispanic/Latino Respondents (n=141) 23
Table 11: Services Received by Hispanic/Latino Respondents - Consumer Survey 2014 23
Table 12: Consumer Survey 2014 – Profile of Haitian Respondents (n=21) 24
Table 13: Services Received by Haitian Respondents - Consumer Survey 2014 24

LIST OF FIGURES

(None)

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)
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)
DCFWB	Newark Department of Child and Family Well Being (Being renamed to Department of Health & Community Wellness)
DMAHS	Division of Medical Assistance and Health Services ("Medicaid Division" within the N.J. Department of Human Services)
DHTSS	Division of HIV/AIDS, TB and STD Services, formerly the Division of HIV/AIDS Services
EIIHA	Early Identification of Individuals Living with HIV/AIDS
EIRC	Early Intervention and Retention Collaborative (EIRCs as plural)
EIS	Early Intervention Services
EMA	Eligible Metropolitan Area
FG	Focus Group
FQHC	Federally Qualified Health Center
GLBTQ	Gay, Lesbian, Bisexual, Transgendered, Questioning
HAART	Highly Active Anti-Retroviral Therapy
HAB	HIV/AIDS Bureau (of HRSA)

HIPAA	Health Insurance Portability and Accountability Act
HOPWA	Housing Opportunities for Persons With AIDS
HRSA	Health Resources and Services Administration (of the U.S. Department of Health and Human Services)
IDU	Injection Drug User
KI	Key Informant [interviews]
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)
NJDOH	N.J. Department of Health (formerly NJDHSS – NJ Department of Health and Senior Services)
NJDS	New Jersey Dental School (at Rutgers University)
NJFC	New Jersey Family Care (Medicaid Expansion)
NJ-CLAS	New Jersey Culturally and Linguistically Appropriate Standards
PLWHA	People Living With HIV or AIDS
PPACA	Patient Protection and Affordable Care Act (also known as the “Affordable Care Act”
REC	Research and Evaluation Committee of NEMA Planning Council
RIC	Retention In Care
RW	Ryan White [Program]
RWHAP	Ryan White HIV/AIDS Program
RWTEA	Ryan White HIV/AIDS Treatment Extension Act of 2009
RWTMA	Ryan White HIV/AIDS Treatment Modernization Act of 2006
SA	Substance Abuse
SAMHSA	Substance Abuse and Mental Health Services Administration (of the U.S. Department of Health and Human Services)
TGA	Transitional Grant Area
WICY	Women, Infants, Children and Youth
YMSM	Young Men who have Sex with Men

INTRODUCTION

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

Legislative Background

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

iv. The current prevalence of HIV/AIDS.

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

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

vii. The prevalence of homelessness.

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

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

HAB 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 AND METHODOLOGY

The purpose of the Needs Assessment 2014 was to conduct a full assessment of important issues emerging in the Ryan White Program including implementation of the Affordable Care Act (ACA) and Medicaid Expansion in New Jersey, both of which were implemented January 1, 2014. The Council and its committees were asked to identify the most important issues to be addressed by the 2014 Needs Assessment. A list was developed, but it was agreed by all committees that the 2014 Needs Assessment should focus on the transition to health care reform and the role of the Ryan White HIV/AIDS Program (RWHAP) in continue to meet needs of PLWHA and the Newark EMA. The 2014 Needs Assessment incorporates directions from HRSA/HAB and reflects current policies and information including the National HIV/AIDS Strategy.

The goal of the 2014 Needs Assessment was to obtain information regarding PLWHA who might not be covered by health care reform and Medicaid Expansion, and the impact of Medicaid Expansion on the existing Ryan White medical system and gaps that were becoming apparent among the Ryan White medical providers. The needs assessment would obtain as much input as possible about the community from consumers and provider agencies, while utilizing existing sources and work done by the Council.

The Council utilized qualitative methods including focus groups of consumers and interviews of Key Informants representing consumers. The assessment also included Quantitative methods including a consumer survey and review of CHAMP client level data for FY 2012. The focus group interviews included a tool which is in Appendix A. Interviews of Key Informants, included two interview tools – one regarding special populations not covered by the Affordable Care Act including Hispanic/Latinos and Haitians, and the other regarding the current impact of Medicaid Expansion – New Jersey Family Care (NJFC). All tools are in Appendix A. For the consumer survey, the EMA developed a two-page questionnaire. The results were entered by EMA staff and masters-level college interns into a new data collection tool, Kwiksurveys, for entering and tabulating responses.

We continued to use a Key Informant questionnaire in Microsoft Word format to allow agencies to enter detailed information, with enough available space, and allow agencies to save the document to their desktop and complete the survey in increments as information was obtained. (This method was begun in 2012 and continued in 2013.) Upon completion, providers e-mailed the survey document to the Council. This method was easier for providers due to the length of the survey and need for comprehensive and detailed responses. The Council followed up with individual Key Informant telephone interviews with each provider, to clarify any responses and obtain additional information. Results of the phone interviews were added to the hard copy survey, and all results were tabulated. This method was found by providers to be appropriate for the information requested.

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

PART 1: PLWHA INELIGIBLE FOR ACA CONTINUING TO NEED RWHAP SERVICES

1.1. Background

Enacted in 2010, the U.S. Patient Protection and Affordable Care Act (ACA) including optional Medicaid Expansion requires individuals to purchase health insurance effective for 2014 including persons living with HIV/AIDS (PLWHA). New Jersey has chosen to implement Medicaid Expansion, termed New Jersey Family Care (NJFC), for low income individuals with incomes below 138% of Federal Poverty Level (FPL). The ACA provides an array of medical care services including ten (10) essential health benefits, some of which are currently provided by the Ryan White Program. However, some individuals are not eligible for subsidies under the ACA or Medicaid Expansion. These include undocumented immigrants or those legally admitted who have been in the US for under five years and others. We also have individuals who may not be accessing medical care in proportion to their representation in the epidemic, or who are accessing care late ("late testers").

Newark EMA research-related activities in 2013 show that two groups who may be ineligible for ACA and NJFC are the Hispanic/Latino population and Haitians. These two populations will be the focus of Research Question #1.

Research Question #1
What are the characteristics of people living with HIV/AIDS (PLWHA) ineligible for the Affordable Care Act (ACA) and Medicaid Expansion who might continue to be served by Ryan White?

Specific services include:

- **Develop and assemble research team.** Identity individuals in the EMA who can reach these two populations of Hispanic/Latino and Haitian PLWHA, including providers serving these populations and individuals who speak Spanish and/or French Creole.
    - ***The Planning Council's Research and Evaluation Committee (REC) will assemble the research team to assist in the work involved in this component (Research Question #1) of the NA.***
- **Research.** Conduct online and other research regarding the two populations and challenges they face in acknowledging risk for HIV (stigma, etc.), accessing HIV testing and care, etc. Identify individuals or populations who are not eligible for health insurance under ACA or Medicaid Expansion (NJFC).
    - ***The REC will assist in conducting this research.***
- **CHAMP.** Work with the Grantee and CHAMP vendor to determine if current CHAMP coding can identify individuals who may not be eligible for ACA or NJFC based on certain indictors, or if there is a way we can insert an indicator for this purpose to ensure eligibility for RW. (This can also be part of recommendations in the final report.)
- **Determine research methods** including Focus Groups (FG) and Key Informant (KI) Interviews to obtain EMA-specific information. Work with research team to identify and target research efforts. Develop research plan which can include providing refreshments at focus groups.

  - ***The REC research team will provide input into the final research methods to be used in this component based on available Planning Council resources.***
- **Develop focus group guide.** Identify themes and information to be obtained based on research and EMA provider experience. Test and translate into Spanish and Creole as appropriate.
  - ***The REC research team will assist in developing the focus group guide.***
- **Develop Key Informant questionnaire.** Identify themes and information to be obtained based on research and EMA provider experience – and specific questions not obtainable or appropriate for focus groups of PLWHA. Test and translate into Spanish and Creole as appropriate.
  - ***The REC research team will assist in developing the Key Informant questionnaire.***
- **Conduct Focus Groups and prepare summary reports.** Identify composition of focus groups and where to be conducted (venues, agencies, etc.) Conduct among groups of PLWHA or those affected by HIV. If conducted in Spanish or Creole, provide for translation into English.
  - ***The REC research team will assist in conducting focus groups and preparing summary reports.***
  - ***The Planning Council, REC and research team will provide translation services for the focus groups – translating Spanish and Haitian/Creole into English. The written summary reports will be prepared in English (as well as Spanish and Haitian/Creole if Planning Council wants).***
- **Conduct KI interviews and prepare summary reports.** Identify KIs to be interviewed based on their expertise and experience with 2 populations. If conducted in Spanish or Creole, provide for translation into English.
  - ***The REC research team will assist in identifying KIs.***
  - ***The REC research team will assist in conducting KI interviews and preparing summary reports.***
  - ***The Planning Council, REC and research team will provide translation services for the KI interviews – translating Spanish and Haitian/Creole into English. The written summary reports will be prepared in English (as well as Spanish and Haitian/Creole if Planning Council wants).***

Report. Prepare a report of findings of consumers (in focus groups) and Key Informants. Share with research team for review and comment. Prepare final report including recommendations for Council regarding service priorities and resource allocations.

Methodology

The methodology consists of **Focus Groups (FGs) and Key Informant (KI) Interviews.** Focus Group guides and KI guides were prepared, reviewed, tested, and finalized by the REC. See Appendix A. Following the methodology in past Needs Assessments and updates, the KI interview tools would be sent to KIs for completion, and would be followed up by a telephone interview by REC members.

The design included four Focus Groups (FGs) of consumers - three comprising the Hispanic/Latino population and one of the Haitian population of PLWHA. However, a total of seven groups were held.

Focus Groups - Hispanic/Latino community. Four FGs were held. On Wednesday, June 25, 2014 at PROCEED, Inc. in Elizabeth, the group consisted of seven (7) participants who were all Hispanic/Latino.

On Friday, May 30, 2014 at the Newark Department of Child and Family Well-Being (DCFWB) Special Care Clinic the group consisted of 17 participants who were all patients of Dr. Figueroa, the majority of whom were not Hispanic. Latino. On Wednesday May 7, 2014 and May 28, 2014 (12pm to 1pm), at CURA, Inc. adult residential substance abuse treatment center in Newark, the groups totaled 11 Hispanic/Latino PLWHA.

Focus Groups - Haitian community. Three FGs were held. On Thursday, June 26, 2014 7:00pm at CEA Church of God in Elizabeth, the group consisted of six (6) Haitian adults (including one of the pastors at the church) who were all English speaking. On Saturday, June 21, 2014 at St. Patrick's Parish in Jersey City, the group consisted of six (6) participants; five of whom were young adults who spoke English and Creole. One participant was an older male who only spoke Creole. The young adults belonged to Haitian's Unified for Development and Education (HUDE), an organization established in 2009 to, "support and empower the Haitian community socially, politically, and academically by developing programs, workshops and extracurricular activities to bond, nurture and educate our community" (www.myhude.org). On May 22, 2014 at Newark Community Health Centers in Irvington, the group included two HIV+ Haitian individuals.

Key Informants. Interviews were conducted of **12 Key Informants** serving the Hispanic/Latino and Haitian population. (A 13th KI did not respond.)

1.2 Focus Group Findings – Hispanic/Latinos and Haitians

Hispanic/Latinos

Knowledge about Ryan White Program

A majority of participants had heard of the Ryan White Program but knew very little about the services offered or available to them. One participant knew quite a bit about the Ryan White Program and he shared his knowledge with the other participants. One participant wanted to know why Ryan White doesn't cover the 20% copay that clients have to pay for medical services (through Medicaid Expansion).

Participants were familiar with Medicaid/Affordable Care Act and were accessing healthcare.

Barriers to Accessing Health Care

Participants have experienced difficulties accessing HIV health care due to the healthcare system changes from Medicaid Expansion/Affordable Care Act.

One medical provider facilitating one group stated that prior authorization of non-preferred HIV medications is a big issue. Clients must use the health insurance company's preferred medications before they use any other HIV medications. When the physician prescribes HIV medicine other than the preferred medication, it gets denied by the health insurance company. The physician also stated that the issues experienced with medications shows a lack of respect for both the patient and the doctor.

Participants reported quite a few insurance related issues. A client expressed her frustrations with her

health insurance provider not accepting the doctors she already had, and she had difficulties figuring out which doctors were in her insurance's network. The client also stated that accessing treatment with specialists through her insurance was challenging.

One participant shared that certain medical specialists aren't available under Horizon. Another participant had made a mistake with his date of birth when applying for NJ FamilyCare. He was told that because of the error, he would have to wait 45 days for the change to be fixed. However, 45 days have passed and he is still waiting to be enrolled. A number of clients are still waiting to be enrolled into NJ FamilyCare. Many were told that they would be enrolled in June but some are still waiting. A participant shared that not all of his medication is covered through NJ FamilyCare. Another client mentioned that he received a bill in the mail for services he received at University Hospital which he thought should have been taken care of. Offering some additional advice, a participant shared that when he receives medical bills, he sends his Charity Care information to the biller and it seems to be taken care of. Besides complaints about billing and insurance, no one reported any issues about any particular medical facilities.

In terms of the quality of service, the majority of the clients expressed that they were upset about the wait time at the DCFWB Special Care Clinic. Clients complained that the doctors were overbooked there and at the Rutgers School of Dental Medicine. There is a three to four month waiting period to receive dental care at Rutgers School of Dental Medicine. A few clients complained about the medical case manager (MCM) because of her inability to reach out to patients. One client expressed that the MCM has never reached out to her personally and she would like her to be more involved with the clients as well as attend more patient educational session. At the Special Care Clinic, there is a need for more medical case managers and more sharing of information with the clients. Clients are not aware of all services available through the Ryan White Program and it is the responsibility of the medical case manager to provide this information. The nurse, who is new to the facility, shared that the facility is currently short staffed and there is a lot of transitioning going on at the DCFWB.

Clients agreed that prior authorization of non-preferred HIV/AIDS medications is a major barrier. Although they expressed issues with care and treatment at DCFWB and the Rutgers School of Dental Medicine, they were not going to any other facilities to receive needed medical/dental care.

Participants expressed pitfalls with HIV/AIDS services in their community. A language barrier prevented one client from getting the care she needed. At one point, this client was lost to care because she had difficulties finding a Spanish speaking case manager. The client is now receiving medical care with a Spanish-speaking provider. A male client reported that a medication was giving him problems but because he is a quiet person, he has not told the doctors about the side effects.

Another participant who had originally lived in New York pointed out major differences between New York and New Jersey's Ryan White services. He knows a lot of New Jersey residents who access healthcare services in New York because it's a lot easier. New York has patient advocates and he wishes New Jersey had the same. He felt that services are harder to navigate in New Jersey. One agency was supposed to help him with rent but was unable to do so but did not provide him with a referral to another agency. A female participant has been on the HOPWA waiting list for six years and her family has been paying her bills for the last three years. She has trouble finding a job because of her criminal record. Housing is also difficult to find because she has a pit bull. A focus group member recommended she make her dog a service dog.

The Hispanic/Latino clients from the focus group all access healthcare services and, although most were pleased with the overall quality of services, a few felt that services could be improved. Clients like that they can receive all of their health services at one location and doctors at those locations seem to collaborate with each other. Clients expressed their dissatisfaction with housing services. Improvements are needed for housing services and there should be collaboration between different agencies. There is also a need for patient advocacy. It should be easier to access and navigate services.

Stigma

HIV stigma is prevalent in the Hispanic/Latino community. It exists at the places they go to receive services and in the facilities they live. Aside from medical care providers and case managers, most clients are selective and choose to confide with only a few family members and their sexual partner about their condition. For the most part, Hispanic/Latino clients aren't allowing HIV stigma to stop them from getting the care they need.

One participant shared that when she goes to her AA meetings and they talk about HIV/AIDS, she feels like she is being discriminated against. The participant went on to say that she wished there was an HIV support group available.

Regarding HIV (stigma), a participant client shared that when people hear the word AIDS, they automatically act funny. Clients also expressed that they have to be selective about who they share information with. Most only told certain family members. One woman confided her HIV status with her daughters but not her two sons. One son worked at the pharmacy where she got her HIV prescriptions filled and learned her status while he was at work. He felt betrayed and the two haven't spoken in seven years. Another participant got into a physical fight with her sister when she learned her sister told someone outside of the family that she had HIV/AIDS. Since that incident, the participant and her sister aren't as close as they were.

Several participants felt that confidentiality could become an issue at agencies where they received services because staff are always changing. One individual felt that an agency had disclosed her status, because her son and his high school friends learned that she has HIV and she did not tell them.

Participants shared stories about how they are treated when receiving medical and dental services at Ryan White medical facilities. During a hospital stay, one participant stated that his food was never brought directly to his bed, but left just close enough to where he could reach for it himself. Another talked about an incident that occurred when receiving dental services. Once the dental assistant found out that he was HIV positive, he felt as though he was treated differently. The client originally came for a root canal but ended up being sent to another area in the hospital for an extraction. Another participant shared that she hasn't been to the dentist in 8 years because she didn't like the way she was treated when she last visited a dentist.

Regarding treatment in their community and places where they reside, an older client stated he was having issues with someone switching his medication at his assisted living home, which has occurred on multiple occasions. Another found out when he was incarcerated that discrimination existed in the prison system, based on HIV status, race and gender.

Regarding relationships and dating, one participant lets his partner know that he has HIV and he lets them decide whether they want to date him or not. Other participants also shared that they take necessary precautions when having sex.

As far as how participants feel about themselves, one client shared that he does not pay attention to the comments that people make and his mindset doesn't allow him to feel bad about having HIV. His attitude is such that people don't believe him when he tells them he has HIV.

Recommendations for Improving Access to Health Care

Most barriers to health care seemed to be insurance related. Since most PLWHA will be transitioning from Ryan White funded medical care to NJ Family Care (Medicaid Expansion), the insurance system must be streamlined to the extent possible by the NJ Department of Human Services, Medicaid division.

Since most participants knew very little about the Ryan White services, there is a need for medical case managers (MCM) and case managers to educate clients about Ryan White services available to them.

Agencies must have adequate MCM and other staffing to reduce wait times. Wait times for services should be communicated to patients. Where times are too long, MCM should refer clients to other Ryan White service providers.

Consider establishing a support group for the Hispanic/Latino PLWHA at the Planning Council Office.

Haitians

Barriers to Accessing Health Care

The major barrier to accessing health care is language. Discrimination and poor treatment, and lack of knowledge, money, and transportation also limit Haitians from accessing care.

It is difficult for older Haitians to access care because they don't speak English and they can't always find someone to translate their illness. Those who don't know English won't take the medication given to them because they don't know what they're taking. An older participant has been in America for a year and still hasn't visited the doctor due to the language barrier (he does not speak any English).

There are also cultural reasons why Haitians don't access healthcare. The Haitian culture (community) is very private and closed off from each other when it comes to discussion of personal matters especially health issues. In Haiti, they don't visit the doctor. Participants explained how their parents have an herbal tea for any ailment. One also explained how older Haitians attribute sickness to superstitious reasons. He gave an example of a young man who had an abscess on his leg. He went to the hospital and the doctor explained how the abscess would have to be removed but the young man's mother declined the treatment and figured they could go to Haiti to heal her son's leg. The boy ended up dying.

With respect to HIV+ Haitians, the major barrier to care is stigma by other Haitians. Haitians unaffected with the virus are *cruelly* ignorant and present a true dilemma. Haitian PLWHA are very knowledgeable of the available care and treatment options. However, they fear disclosure of their status. Due to reactions and or comments by the non-HIV+ community, Haitian individuals infected with the virus do

not seek the help needed, simply to avoid the HIV stigma. This is especially true for men. They would rather die than live with HIV. As a result many men do not seek treatment. They rarely interact with each other, although they are aware of the fact that together they can end the HIV stigma.

Some focus group participants had health insurance through their employer or were waiting to be enrolled and others were uninsured. Participants stated that there is a lot of confusion with applying for health insurance. Many people within the Haitian community do not know how to navigate the healthcare system. One man stated that his mother is a nursing assistant and she doesn't have health insurance. He stated that a lot of Haitians work in factories and they also don't have health insurance.

Participants were asked if a "navigator" program for the Haitian community would be helpful in improving access to health care and health insurance. Some said that this would be essential. However, a participant who was a pastor stated that a Haitian navigator system might not even work because Haitians have trust issues and won't share their problems with other Haitians. They think their personal business will be talked about with others in the community.

Participants had vague knowledge about "Obamacare" and the Affordable Care Act, but since there is a language barrier, would need more information (in Creole).

Health Issues

Diabetes, high blood pressure, HIV/AIDS, cholesterol and cancer are prevalent in Haitian community. They aren't going to the doctor for preventive care. If something is wrong, they attribute it to gas.

Participants explained how both cancer and HIV/AIDS are looked down upon but HIV/AIDS is looked down upon more than cancer. HIV/AIDS is a disease that no one wants to talk about. Members of the Haitian community feel as though a person's actions are the reason they have HIV/AIDS and no one is to blame but themselves. It is taboo to talk about the sickness and there is still a lot of hurt from being blamed for starting HIV/AIDS.

One participant whose friend works at a nearby hospital shared that even when some Haitians find out they have HIV/AIDS, they refuse treatment. People are continuing with their sexual activities and they'll even go back to Haiti to live. Another older participant believes there are a lot of Haitians who have HIV/AIDS but they hide it. Even when they go to the doctors, they keep it to themselves. Somehow healthcare providers need to reach out to those living with HIV/AIDS and everyone in the community about preventive health.

Another participant shared that it is taboo to talk about sex in general. The English translation for sex in Creole is, "the thing". It's not just HIV/AIDS that the Haitian community doesn't want to talk about. They don't want to talk about anything that has to do with sex. It's hard for parents to sit down and talk about sex with their child. They have to teach people how to talk about sex and sexuality. It is easier to talk to the younger generation about sex than it is to talk to the older generation. The participant shared that she thinks the older generation wants to talk about sex but they don't have the right platform.

Focus group participants also talked about how **mental health** must be addressed in the Haitian community. One reason people within the Haitian community are depressed is because of their current livelihood in America. They came to America for better opportunities and sometimes things don't turn

out as planned. People become depressed when they find out they have a certain illness. If they have an illness like cancer or HIV/AIDS, their mentality is that they're as good as dead. Instead of seeking treatment for their illness, they'll suffer internally. Diseases are highly stigmatized in the Haitian community. Participants say that it comes from the lack of education.

Other participants noted that Haitians often attribute mental health to superstitious reasons as well. It is so intertwined into the Haitian community. Dealing with loss and stress is something that often isn't discussed. Everything is internalized because it is a private culture. When asked if the Haitian community would get help if mental health services were offered, most participants did not think so, because there is a stigma against mental health problems and people who have it are usually in denial about it.

Recommendations for Improving Access to Health Care

The most important item recommendation for improving access to care by the Haitian community is to have more Creole speaking staff and resources available at medical facilities and clinics. Staff includes medical providers, medical case managers and case managers. Another participant expressed that the Haitian community should advocate for these resources.

Other recommendations included: (1) More outreach at churches, (2) A directory of all the Haitian doctors or a facilities with Haitian speaking staff, (3) A health fair at church with all medical doctors is something they also think would be a great idea although retention may be a problem, and (4) having healthcare professionals connect with Haitian organizations (like HUDE and the Haitian Flag Association). Also, a focus group or a separate committee within the Planning Council could be beneficial. This would help HIV+ Haitians interact more with each other and support each other.

Participants agreed that in order to get Haitians involved in accessing health care, the leaders of the community (pastors and other church clergy) will have to lead the way. The leaders will have to be educated and in turn they can use their influence to educate the community about health practices and the importance of accessing healthcare. This is especially true for the issues of HIV/AIDS and mental health. Making the Haitian community feel comfortable about talking about HIV/AIDS has to be done. All leaders of the community (priest, pastors, organization heads) should be met with first and they can help connect the community to healthcare.

Another way to get the Haitian community involved is through the family. The Haitian community is very family oriented. Cultural competency and medical adherence is key for helping the Haitian community accessing healthcare.

1.3 Key Informant Interview Results - Hispanic/Latinos and Haitians

Twelve of the 13 Key Informants (RW-funded medical providers) responded. The final survey included a question asking providers to estimate the percent of clients in these two populations who were likely ineligible for ACA and Medicaid Expansion insurance, but this was not included in the KI tool distributed.

Services

1. Services. Does your agency serve either of these populations – Hispanic/Latino or Haitian?

a. If yes, which?

Ten of the 12 (83%) agencies serve both Hispanic/Latino and Haitian populations (have clients of both race/ethnicities). Two agencies have Hispanic/Latino clients but not Haitian.

b. If yes, what is the approximate number or percent of your clients for each of the populations?

The percentages of the Hispanic/Latino and Haitian populations served by the KI providers is reflective of the population of the area surrounding the agencies. The percent of Haitian clients served ranged from less than 1% to 10%. The percent of Hispanic/Latino clients served ranged from 5% to 40%.

c. Where (from what agency) do these individuals get their medical care for HIV?

All populations receive their HIV medical care from the KI agency which is a RW-funded medical provider.

d. What kinds of services do these populations receive from your agency?

The populations receive all RW-funded services and other services provided by the agencies. These include **core medical services** of primary medical care, oral healthcare, medical case management, and depending on the agency, mental health services, substance abuse outpatient services, and medical nutritional therapy. Additional medical care includes services of a psychiatrist and psychologist, labs, gynecological care, podiatry, vision care, Suboxone and Subspecialty care (Hepatology).

Support services include assistance with transportation (including bus tickets), food/nutrition services including food vouchers, prevention education, Prevention With Positives, drop-in center, and HOPWA.

e. What kinds of services do you refer out to other agencies?

Services referred out to other agencies include both support services and specialty medical care. These include housing assistance including shelters, transportation, food assistance including food pantries, employment assistance, application for health insurance and ADAP, utility assistance, and legal aid assistance. Specialty medical care includes but is not limited to ophthalmology, radiology, eyes for the needy, cardiology, nephrology, podiatry, urology, inpatient detoxification, dietitian, psychiatry, and oral health. One KI noted that Insurance is a factor with referrals. If a patient does not have insurance there are not many agencies/hospitals that will accept referrals.

Culturally Appropriate Services

2. Culturally appropriate services. Please describe the services you provide which address the cultural needs of these populations.

a. Translation services? Please describe, including methods, staffing, services.

Most agencies have bilingual staff fluent in English and Spanish at a minimum. Others have staff conversant with French Creole, Spanish and Portuguese. The complement of bilingual or multilingual staff typically depends on the patient population served. The agencies also have access to Cyracom, ATT language line, and other translation services by contract. Some rely on English-speaking family members who accompany patients to provide translation, which is the method preferred by these patients.

b. Other culturally appropriate services?

Agencies have a variety of methods of ensuring culturally appropriate services. These include bilingual or multilingual staff, regular training in cultural sensitivity and cultural diversity, educational and or support groups in Spanish, Portuguese or Haitian/French Creole language, health literacy offered in Spanish language, and literature and educational materials available in Spanish, Portuguese, and French Creole.

c. Do the agencies you refer these clients to provide culturally appropriate services? Please describe to the best of your knowledge.

To the best knowledge of the KIs, their agencies refer clients to other agencies which have experience in providing culturally appropriate services for the Hispanic/Latino population and Haitian population including bilingual and translation services. These agencies are well known within the Newark EMA. Hispanic/Latino patients are referred to facilities where they can receive services in the language of their choice. Providing referrals to the Haitian population is challenging in that many of them are fearful of full disclosure and do not wish to be seen by others outside the clinic site. To assist in the referral process, "When we know a patient will need paperwork completed prior to a referral service we ask the agency to forward the papers here so we can assist the client with completion prior to their visit."

d. Are their any gaps in services that do not address these clients' linguistic or cultural needs? Please describe. If possible, include the impact.

The KIs had a range of responses.

Language. The biggest gap is language and we address that effectively in our facility. We try to use the language bank to help those clients that need any help or services.

Haitian population. There is a need for **Outreach Services** for Creole speaking patients.

- The Haitian community is still feeling the stigma of being blamed during the early days of the epidemic. More personal contact is needed to encourage this community to feel comfortable accessing services.
- With the emerging Haitian population in this area I feel we need to have more agencies that are culturally sensitive to this population. Their fear of disclosure and the strong stigma remaining prevents these folks from reaching out to service providers. Providing an environment that addresses their cultural needs is essential.
- Organizations or programs targeting specific needs of the Haitian population would be helpful.

Support Groups. We are assessing the need for language specific support groups for these populations.

Culturally Appropriate Health Education Materials for Specific Diseases. One gap is in the availability of linguistically and culturally appropriate health education materials particularly for Hepatitis C. Due to budget constraints, several of the services that provided free brochures do not sponsor those programs

any longer. Unfortunately, the unavailability and inaccessibility of the information in their language leads to a lack of understanding about the illness and can lead to non-adherence to the treatment plan.

Undocumented. It can be difficult to secure services (specialty, pharmaceutical, housing, etc.) for undocumented individuals who are ineligible for many entitlements due to their [immigration] status.

Patient Satisfaction Surveys. None identified as per patient satisfaction surveys.

Culture – Those Not In Care. The challenge is not so much with the clients that do enter into care, but with reaching those that do not. Many cultures foster stereotypes about HIV and do not feel comfortable openly seeking testing and treatment. Culture is a barrier that impacts HIV significantly.

Health Insurance

3. Health insurance. To what extent do these individuals have health insurance? (Private or public – Medicaid, Medicare, VA). Please provide number or percent or both.

a. Would you say that most lack health insurance? Please provide number or percent.

KIs said that a significant number and portion of their Hispanic/Latino and Haitian clients lack health insurance. The percents range from 25% up to 70% without insurance. Most agreed that one third (33%) of patients have Medicaid. And another 10% to 30% have Medicare. A maximum of 10% have private insurance or other insurance.

Providers gave insight regarding the health insurance status of their patients as follows.

- 12% of our RW patients do not have any form of insurance based on the fact that the **premiums are too high** or the fact that they are **undocumented**. Some clients might apply for the marketplace but because the premiums are high they choose to stay on the RW program. These clients might need more information and education on the marketplace and on the availability of subsidies to address premium cost.
- Approximately 50% have **Medicaid** HMO and 50% have **no health insurance**.
- Most of the **undocumented** cases are from these populations which oftentimes become an issue when proper paperwork or identification is needed to secure medical coverage or services. Those without insurance are treated with Ryan White funds. Approximately 30% of our patients are uninsured.
- Individuals conforming to the patient ethnicity 'Hispanic/Latino' are an under-insured population. Approximately 40% of patients whose ethnicity is Hispanic/Latino or Haitian do not have insurance.
- Many (approximately 50%) lack health insurance secondary to **immigration status** and are presently ineligible for ACA coverage, but those patients are typically still eligible for charity care so this should not impact access to care.

b. What are the barriers to their obtaining health insurance?

- **Undocumented/Immigration Status.** Many reported that the chief barrier to obtaining health insurance was the undocumented status of the populations in this Needs Assessment or their immigration status (legally admitted to the United States but residing here for less than five years).

- **Affordability.** We hear that the premiums for the insurance options available on the Healthcare Exchanges are too expensive for these clients. Some clients are unable to afford payments for premiums and or co-pays or deductibles. Co-pays are mostly for prescriptions.
- **Applications Pending with NJ Family Care (NJFC).** Some patients' applications are still pending with NJFC.
- **Ineligible for Medicaid Expansion.** Some of our patients were deemed ineligible for Medicaid Expansion.
- **Patients Refusing to Apply.** Some patients simply do not want to apply for health insurance.
- **Charity Care.** We refer our undocumented clients unable to qualify for NJFC to our Charity Care office. They apply and most times are eligible for 100% Charity Care. Clients who have never applied for NJFC and are eligible are assisted with the enrollment process.
- **Unable to Produce Documents.** Not being able to provide the required documents is sometimes a barrier for our clients. Some do not have official paperwork such as a birth certificate from their countries of origin.
- **Fear of Deportation.** Undocumented persons are frequently afraid to go to the physician because they fear their illegal immigrant status will be disclosed. Members of this population are ambivalent about pursing medical services for fear of being questioned about their residency status. Routine questions asked by registration staff can be anxiety provoking for individuals who lack proper documentation and social security numbers. Many individuals wish to remain invisible and are reluctant to provide identifying information.
- **Lack of Understanding.** Some patients lack understanding about the process of applying for health insurance and the Affordable Care Act.
- **Time Consuming Insurance Application Process.** If they qualify for insurance, some have incomes above the Medicaid eligibility limits and need to access insurance from the marketplace. Many find the process labor intensive. Many clients start the process, but stop and have to restart again. The clients are referred to the insurance navigators but they have difficulties completing the process. Some do not complete paperwork.
- **Fear of HIV Status.** Some are concerned that a positive HIV status will affect citizenship.

c. To what extent is lack of documentation a factor? (How many or % are undocumented?)

The lack of documentation was a factor for clients of most providers. KIs gave either percent of target population (Hispanic/Latino and Haitians) or percent of total patient population.

- **Percent undocumented of target patient populations.** Percents included 30%, 50% and another 25% in process of obtaining citizenship documents, 57%, 100%.
- **Percent undocumented of total patient population.** Percent of total population undocumented were <1%, 2%, 5%, 10%, 12%, 14%, 17%, 53%,

As stated above, clients who present and are undocumented are referred to charity care and they qualify for charity care coverage. No one is ever denied care due to inability to pay.
Patients who lack documentation and identification - even if they have a current visa - are unable to qualify for any government assistance programs. There is always a concern that their HIV positive status will negatively impact their progress towards becoming officially documented.

Access and Barriers to Care

4. <u>Access and Barriers to care.</u> What additional barriers do these individuals face in accessing care – or what are the barriers?

Shame and Stigma. HIV-related stigma and cultural values are a barrier in the Haitian population. Folks are very cautious re: disclosure and this prevents them from accessing care when and where they should. With a portion of our center's Haitian population privacy is a big concern. Many are very leery of seeking out HIV care due to a fear of being labeled as HIV+ or the stigma from their community. Also, some people choose not to seek care because they don't know how to find a near by HIV treatment center. Our center takes great caution to protect patient's privacy - we are an infectious diseases clinic and not just an HIV clinic. Therefore, not everyone presents to our center for HIV thus protecting the privacy of patients in the waiting room.

Lack of education about the disease.

Lack of Transportation. Besides transportation issues I do not really see barriers to care in the Hispanic/Latino population. Lack of transportation in suburban/rural areas. Lack of or limited access to transportation so that medical/referral appointments can be kept even in urban areas.

Lack of affordable housing.

Inflexible employer/work schedule. Many immigrant families are low income and working so schedules are not flexible. The 5 year time frame that people must be in this country for before being eligible for benefits serves as an obstacle.

Lack of payment for diagnostic testing and specialty providers. We experience not being able to get blood work done; hence, the physician is unable to properly assess treatment. Charity Care does not cover diagnostic testing. Not able to get diagnostic testing can lead to delayed diagnosis. For uninsured patients (undocumented ineligible for insurance) lack of access to specialty providers and medical imaging/screening procedures. Some of these issues would be addressed if the clients had insurance.

Language barriers. Additional barriers to care experienced by these individuals include a lack of available translators or interpretation services at various referral agencies. Becoming a citizen is often a lengthy and expensive process. A language barrier can prevent patients from advocating for themselves. Fear of involvement by officials when undocumented often results in avoidance.

a. How can RWHAP help to improve access or reduce these barriers?

Funding for transportation. Our agency pays for taxi services for some patients – one way is about 45 minutes to 1 hour. This is very expensive.

Funding for education. Education for staff on dealing with biases which may translate into stigmatizing experiences for patients.

Same-Language Providers. Mental Health services are more effective when the provider speaks the same language as opposed to using a translation line. Provide funding for mental health providers that are fluent in these languages.

Haitian community. I am not sure. The cultural issue in the Haitian population is difficult to overcome and getting these folks to come out to receive care is a true challenge. Many live in absolute fear that their status will be revealed to their community.

Improved education to community about Ryan White Services. Increasing Newark EMA residents' knowledge of all Ryan White providers in their area. I often hear patients say they had no idea where to go for HIV care. Well-distributed education materials in multiple languages would help patients seek out care more efficiently.

Funding laboratory testing and insurance premiums. Funds available to assist with premiums and laboratory testing. She was unaware that her agency could apply for funding for testing.

Funding for specialty care visits. Provide dollar for dollar coverage of medical specialty provider visits, and medical imaging/screening procedures. The reimbursement process should be changed and so that different pools of money are available for specialty visits, screening services and labs.

Improved RW Medical Case Management. RWHAP can help improve access or reduce barriers to care by continuing to fund medical case management services so that well qualified Case Managers and/or Social Workers can be hired to help this population navigate services and get their needs met. Continued economic assistance in the form of food vouchers, bus tickets and pharmacy assistance is a critical need for this population. Continue to have case managers have the availability to go with people to appointments at the Medicaid office, continue to cover services for those ineligible.

Legal services. Offer more low cost legal/immigration services.

Funding for insurance copays or premiums. Create additional funding to help those pay for the costs of their co-pays or premiums.

Additional Information and Recommendations

5. Please provide any <u>additional information</u> about these populations not addressed above that would shed light on the challenges and problems faced in dealing with their HIV disease.

Fear Loss of Employment. For the most part our undocumented clients face the following when attempting to keep medical appointments: Unpaid time off, fear of termination of employment for taking time off, privacy issues (fearful of employer discovering diagnosis).

Stigma. A personal observation is that there still exists a very strong stigma with HIV/AIDS in the Haitian community which may cause this population not to seek testing or treatment for this disease. This population continues to experience stigma associated with their disease which can make otherwise mundane social transactions appear complex and overwhelming. It is imperative that this population has ample opportunity to receive support in the form of groups or one-to-one counseling.

Multiple and Compound Comorbidities. The issues of substance abuse, employment, behavioral health, stigma and prejudice as it relates to HIV and AIDS is an ongoing challenge for our population of clients.

Affordable housing. This population requires access to affordable housing units, specifically accommodation that can house females with children.

Hidden PLWHA. If people connect to care we can usually provide them with assistance at some level but reaching those in the community that do not access care has a significant impact on our community. People who do not seek healthcare services are not being HIV tested, treated, etc.

Barrier related to Outside Laboratory Testing, Need for Primary Care Provider (PCP) Referral and Copays. A new problem has presented with patients now on NJFC (Medicaid Expansion). In the past they were able to have lab tests done at the agency clinic. Now their NJFC insurance plans requires labs

to be done at an outside lab such as Quest or LabCorp. This is an additional trip for people who may already have transportation issues or compliance issues. If the patient did not have their labs drawn we cannot treat them accurately when they come to the office delaying care delivery. If they cannot get to the outside lab, they do not go. This delay has a snowball effect on the whole system.
Also not wanting to go to PCP office for referrals, immunizations, etc. because they do not want to make an additional trip to a physician that they barely know! We are dealing with a population that inherently has adherence issues and now we have placed two more barriers to their adherence in front of them.
We also must look at the co-pay issue. If folks do not have the money for co-pay they will avoid seeking treatment. We as Ryan White providers have SOME ability to assist with their co-pays when it comes to our setting but what happens in outside settings (specialists, PCP, etc.) The concern is that treatment will be delayed.

6. Please provide any <u>recommendations or suggestions</u> you have for improving the RWHAP for these HIV+ individuals.

Outreach. As stated before, Outreach is needed. A health fair that is not specific to HIV in the Haitian Community would be advantageous in making contact and stressing the need for health care.

Support Groups. Offering funding for support groups in the issues involving PLWHA, i.e., substance abuse, behavioral health, etc.

Medical Care Coordination. As patients enroll in health plans with the increased opportunities through ACA and Medicaid expansion, it will continue to be important that medical care coordination for the patient is maintained and even increased as working through the system for the HIV population is difficult. "Medical care coordination" – provision of more Medical Case Management.

As above, continued RWHAP funding which focuses on the importance of medical case management and psycho-social support is imperative for this population.

Partnering with culturally respected community members in churches or local organizations may be a way to access the marginalized population, disseminate information to them and engage them in care.

1.4 Consumer Survey

The REC agreed to conduct a survey of consumers regarding their service utilization. This would be in addition to information in the CHAMP system, and would contain additional services beyond services funded by RWHAP. A **survey tool** was developed by the Research and Evaluation Committee, reviewed and approved. The tool is in Appendix B.

The tool was disseminated to all Ryan White agencies in the EMA who were asked to have their clients to complete it, who came to the agency during a two week period. A total of **595 surveys were received.**

Consumer Survey Findings

Overview and Characteristics of Respondents

The characteristics of the 595 respondents are shown below.

Gender

- 60% of respondents were male and 40% female.
- <1% were Transgender – either Female to Male or Male to Female.

Gender	#	% Dist.
Male	356	59.8%
Female	233	39.2%
Transgender-F to M	2	0.3%
Transgender-M to F	2	0.3%
Total	593	99.7%
Missing	2	0.3%
Total	**595**	**100.0%**

HIV Status

- **94% (557) were HIV+** and 3% (20) HIV negative.
- HIV status of the remaining 3% was Unknown (6) or not provided (12).

Age Category

- All populations were well-represented by age category.
- Nearly 10% (56) were Age 13-29.
- Over half – 56% or 331 – were age 45-59.
- 14% (81) were age 60+

Age Category	#	% Dist.
Age 13-24	22	3.7%
Age 25-29	34	5.7%
Age 30-34	23	3.9%
Age 35-39	39	6.6%
Age 40-44	61	10.3%
Age 45-49	93	15.6%
Age 50-54	139	23.4%
Age 55-59	99	16.6%
Age 60-64	53	8.9%
Age 65-69	21	3.5%
Age 70-74	7	1.2%
Age Unknown	4	0.7%
Total	**595**	**100.0%**

Haitian

- 4% (21) were Haitian.

Hispanic/Latino Ethnicity

- One quarter – 24% or 141 – were of Hispanic Ethnicity.
- 65% (92) reported country of origin, the remaining 35% (49) did not.

Hispanic/Latino by Country of Origin (n=92 or 65%)

- **Puerto Rico** – 40% (56)
- **Colombia** – 6% (8)
- **Ecuador** – 4% (5)
- **Next countries (2% or 3 respondents)** – Venezuela, Brazil, Dominican Republic, Mexico

- **Next countries (1% or 2 respondents)** – Spain, Honduras, Peru, El Salvador
- **One respondent (<1%)** – Cuba, Guatemala, Costa Rico

Current Insurance

- 64% (378) reported having health insurance. Most (355) provided the type of insurance.
- 12% (73) had no insurance and 24% (144) did not answer the question.

Health Insurance Type (Those with Current Insurance)

- **4/5 had Medicaid** – 66% Medicaid, 2% Medicaid + Other insurance, 11% Dual eligibles (Medicaid + Medicare)
- **12%** had **Medicare**
- **2%** had **VA healthcare**
- **3%** had **Employer provided health insurance**
- **4%** reported obtaining insurance from the **Health Insurance Exchange**

Health Insurance Type	#	% Dist.
Medicaid	233	66%
Medicaid + Other	6	2%
Medicare	44	12%
Dual Medicaid Medicare	39	11%
VA	7	2%
Employer Provided	12	3%
Health Ins Exchange	14	4%
Total Current Insurance	355	100%

Did Uninsured Apply for Insurance? (n=173)

- **47%** of uninsured have applied to NJFC.
- **10%** applied to Marketplace
- **2%** applied to both NJFC and Marketplace
- **42%** (72) have not applied for health insurance.

Apply for Insurance?	#	% Dist.
No	72	42%
Applied NJFC	81	47%
Applied Marketplace	17	10%
NJFC & ACA	3	2%
Total	**173**	**100%**

Services

The survey collected responses on **38 service categories** and whether services were received **in any of 3 locations or not received:** (1) At This Clinic, (2) Another Provider, (3) This Clinic and Another Provider, (4) Do Not Receive Service. We also captured data on those who did not answer the question. The following table shows responses for all 595 surveys.

- ¾ of respondents received **outpatient medical care, laboratory services, and prescription drugs.**
- **Over half but less than ¾** received **treatment adherence counseling, Health Education/Risk Reduction (HERR) counseling, oral health care.**
- **½** received **mental health outpatient, referral services, social services.**

Table 1: Consumer Survey 2014 – Services Received by Respondents (n=595)

Service	N=595				Total = 100%			
	Total Receiving Service*	Do Not Receive Service	Total Respond	Missing	% Receiving Service*	% Not Receive Service	Total Respond	Missing
Amb/Op Medical Care	440	63	503	92	**74%**	11%	85%	15%
Child Care	13	420	433	162	**2%**	71%	73%	27%
Lab Services	466	41	507	88	**78%**	7%	85%	15%
EIS	138	290	428	167	**23%**	49%	72%	28%
Emerg Fin Assist	124	312	436	159	**21%**	52%	73%	27%
Family Planning	31	392	423	172	**5%**	66%	71%	29%
Food Bank/Meals	152	295	447	148	**26%**	50%	75%	25%
HERR	341	119	460	135	**57%**	20%	77%	23%
Home Health Care	32	397	429	166	**5%**	67%	72%	28%
Hospital IP	209	246	455	140	**35%**	41%	76%	24%
Housing	268	192	460	135	**45%**	32%	77%	23%
Legal Services	160	272	432	163	**27%**	46%	73%	27%
Translation	46	376	422	173	**8%**	63%	71%	29%
MCM	436	86	522	73	**73%**	14%	88%	12%
Mental Health IP	74	357	431	164	**12%**	60%	72%	28%
Mental Health OP	296	184	480	115	**50%**	31%	81%	19%
Devel Disabil Svc	30	403	424	171	**5%**	68%	71%	29%
Medical Transp	191	240	431	164	**32%**	40%	72%	28%
CM-NM	223	206	429	166	**37%**	35%	72%	28%
Nursing Home	80	346	426	169	**13%**	58%	72%	28%
Nutritional Counseling	278	206	484	111	**47%**	35%	81%	19%
OB/GYN	174	283	457	138	**29%**	48%	77%	23%
Oral Health	331	139	470	125	**56%**	23%	79%	21%
Outreach	178	263	441	154	**30%**	44%	74%	26%
Perm Planning	34	388	422	173	**6%**	65%	71%	29%
Prenatal Svc	26	394	420	175	**4%**	66%	71%	29%
Prescrip Drugs	444	62	506	89	**75%**	10%	85%	15%
Psychosocial Support	268	205	473	122	**45%**	34%	79%	21%
Phys Therapy	124	309	433	162	**21%**	52%	73%	27%
Referral Svc	308	155	463	132	**52%**	26%	78%	22%
Rehab Svc	110	323	433	162	**18%**	54%	73%	27%
Respite Care	8	409	417	178	**1%**	69%	70%	30%
Skilled Nursing Care	92	329	421	174	**15%**	55%	71%	29%
Social Services	300	170	470	125	**50%**	29%	79%	21%
Subst Abuse IP	57	370	427	168	**10%**	62%	72%	28%
Subst Abuse OP	182	269	451	144	**31%**	45%	76%	24%
Treat Adhere Counsel	362	134	496	99	**61%**	23%	83%	17%
Utility Assist	150	295	445	150	**25%**	50%	75%	25%

*** Received at This Clinic, Another Clinic, This and Another Clinic.**

The REC reviewed the initial tabulations of the 595 consumer surveys and identified populations for more analysis. These populations are shown below.

HIV+ Individuals

The vast majority of respondents (557 or 94%) were HIV+. Their responses are very similar to those of all respondents.

Table 2: Consumer Survey 2014 – Profile of HIV+ Respondents (n=557)

Gender	Male	**61%**	Female	**38%**	Transgender	**1%**
Race/Ethnicity	Black/Afr Amer	**63%**	Hispanic	**23%**	White Not Hisp	**10%**
	Other Not Hisp	**4%**	Unknown	**0%**		
Age Category	Age 13-24	**3%**	Age 40-44	**11%**	Age 60-64	**9%**
	Age 25-29	**6%**	Age 45-49	**15%**	Age 65-69	**3%**
	Age 30-34	**4%**	Age 50-54	**23%**	Age 70-74	**1%**
	Age 35-39	**7%**	Age 55-59	**17%**	Age Unknown	**<1%**
	Age 13-34	**13%**	**Age 50+**	**54%**		
Current Health Insurance	Yes	**64%**	No	**13%**	No Answer	**23%**
Health Insurance	Medicaid	**43%**	Medicare	**8%**	Dual Eligibles	**7%**
	VA	**1%**	Employer	**2%**	Health Ins Exch.	**2%**
Applied for Insurance	NJFC	**4%**	Marketplace	**1%**	No Answer	**2%**
	No	**6%**				

Table 3: Services Received by HIV+ Respondents - Consumer Survey 2014

Service	% Rec'g Svc*
Amb/Op Medical Care	76%
Child Care	2%
Lab Services	80%
EIS	24%
Emerg Fin Assist	21%
Family Planning	5%
Food Bank/Meals	27%
HERR	59%
Home Health Care	5%
Hospital IP	36%
Housing	46%
Legal Services	27%
Translation	8%
MCM	76%
Mental Health IP	13%
Mental Health OP	52%
Devel Disabil Svc	4%
Medical Transp	33%
``CM-NM	39%

Service	% Rec'g Svc*
Nursing Home	14%
Nutritional Counseling	48%
OB/GYN	30%
Oral Health	57%
Outreach	31%
Perm Planning	6%
Prenatal Svc	4%
Prescrip Drugs	77%
Psychosocial Support	47%
Phys Therapy	21%
Referral Svc	53%
Rehab Svc	19%
Respite Care	1%
Skilled Nursing Care	16%
Social Services	52%
Subst Abuse IP	10%
Subst Abuse OP	31%
Treat Adhere Counsel	64%
Utility Assist	26%

*** Received at This Clinic, Another Clinic, This and Another Clinic.**

Females

Of the total respondents 39% or 233 were female.

Table 4: Consumer Survey 2014 – Profile of Female Respondents (n=233)

HIV Status	HIV+	**92%**	HIV Negative	**5%**	Unknown	**3%**
Race/Ethnicity	Black/Afr Amer	**62%**	Hispanic	**22%**	White Not Hisp	**12%**
	Other Not Hisp	**4**	Unknown	**0%**		
Age Category	Age 13-24	**2%**	Age 40-44	**14%**	Age 60-64	**8%**
	Age 25-29	**5%**	Age 45-49	**18%**	Age 65-69	**3%**
	Age 30-34	**2%**	Age 50-54	**27%**	Age 70-74	**1%**
	Age 35-39	**7%**	Age 55-59	**12%**	Age Unknown	**1%**
	Age 13-34	**9%**	**Age 50+**	**54%**		
Current Health Insurance	Yes	**61%**	No	**12%**	No Answer	**27%**
Health Insurance	Medicaid	**45%**	Medicare	**6%**	Dual Eligibles	**5%**
	VA	**1%**	Employer	**2%**	Health Ins Exch.	**2%**
Applied for Insurance	NJFC	**3%**	Marketplace	**1%**	No Answer	**2%**
	No	**6%**				

Table 5: Services Received by Female Respondents - Consumer Survey 2014

Service	% Rec'g Svc*	Service	% Rec'g Svc*
Amb/Op Medical Care	70%	Nursing Home	15%
Child Care	3%	Nutritional Counseling	48%
Lab Services	80%	OB/GYN	68%
EIS	22%	Oral Health	56%
Emerg Fin Assist	21%	Outreach	28%
Family Planning	7%	Perm Planning	6%
Food Bank/Meals	23%	Prenatal Svc	4%
HERR	54%	Prescrip Drugs	75%
Home Health Care	4%	Psychosocial Support	45%
Hospital IP	33%	Phys Therapy	20%
Housing	46%	Referral Svc	55%
Legal Services	24%	Rehab Svc	20%
Translation	6%	Respite Care	2%
MCM	70%	Skilled Nursing Care	17%
Mental Health IP	12%	Social Services	54%
Mental Health OP	56%	Subst Abuse IP	7%
Devel Disabil Svc	2%	Subst Abuse OP	27%
Medical Transp	35%	Treat Adhere Counsel	57%
CM-NM	34%	Utility Assist	27%

*** Received at This Clinic, Another Clinic, This and Another Clinic.**

Youth Age 13-24

Of the total respondents 4% or 22 were Youth Age 13-24.

Table 6: Consumer Survey 2014 – Profile of Youth Respondents (n=22)

Gender	Male	**77%**	Female	**23%**	Transgender	**0%**
HIV Status	HIV+	**82%**	HIV Negative	**18%**	Unknown	**0%**
Race/Ethnicity	Black/Afr Amer	**55%**	Hispanic	**41%**	White Not Hisp	**4%**
	Other Not Hisp	**0%**	Unknown	**0%**		
Current Health Insurance	Yes	**73%**	No	**0%**	No Answer	**27%**
Health Insurance	Medicaid	**68%**	Medicare	**0%**	Dual Eligibles	**0%**
	VA	**0%**	Employer	**5%**	Health Ins Exch.	**0%**
Applied for Insurance	NJFC	**14%**	Marketplace	**0%**	No Answer	**4%**
	No	**9%**				

Table 7: Services Received by Youth Respondents - Consumer Survey 2014

Service	% Rec'g Svc*
Amb/Op Medical Care	73%
Child Care	9%
Lab Services	86%
EIS	32%
Emerg Fin Assist	68%
Family Planning	5%
Food Bank/Meals	14%
HERR	59%
Home Health Care	5%
Hospital IP	23%
Housing	59%
Legal Services	18%
Translation	14%
MCM	77%
Mental Health IP	9%
Mental Health OP	27%
Devel Disabil Svc	9%
Medical Transp	64%
CM-NM	18%

Service	% Rec'g Svc*
Nursing Home	5%
Nutritional Counseling	32%
OB/GYN	18%
Oral Health	50%
Outreach	59%
Perm Planning	14%
Prenatal Svc	5%
Prescrip Drugs	77%
Psychosocial Support	14%
Phys Therapy	0%
Referral Svc	27%
Rehab Svc	0%
Respite Care	9%
Skilled Nursing Care	9%
Social Services	50%
Subst Abuse IP	5%
Subst Abuse OP	5%
Treat Adhere Counsel	50%
Utility Assist	32%

*** Received at This Clinic, Another Clinic, This and Another Clinic.**

Young Adults Age 25-34

Of the total respondents 10% or 57 were Young Adults Age 25-34. Of these, 34 (6%) were Age 25-29 and 23 (4%) were Age 30-34.

Table 8: Consumer Survey 2014 – Profile of Young Adult Respondents (n=57)

Gender	Male	**68%**	Female	**30%**	Transgender	**2%**	
HIV Status	HIV+	**93%**	HIV Negative	**0%**	Unknown	**7%**	
Race/Ethnicity	Black/Afr Amer	**69%**	Hispanic	**21%**	White Not Hisp	**5%**	
	Other Not Hisp	**5%**	Unknown	**0%**			
Current Health Insurance	Yes	**60%**	No	**28%**	No Answer	**12%**	
Health Insurance	Medicaid	**51%**	Medicare	**0%**	Dual Eligibles	**1%**	
	VA	**0%**	Employer	**4%**	Health Ins Exch.	**4%**	
Applied for Insurance	NJFC	**16%**	Marketplace	**4%**	No Answer	**4%**	
	No	**16%**					

Table 9: Services Received by Young Adult Respondents - Consumer Survey 2014

Service	% Rec'g Svc*	Service	% Rec'g Svc*
Amb/Op Medical Care	67%	Nursing Home	2%
Child Care	4%	Nutritional Counseling	40%
Lab Services	68%	OB/GYN	19%
EIS	19%	Oral Health	47%
Emerg Fin Assist	14%	Outreach	33%
Family Planning	4%	Perm Planning	4%
Food Bank/Meals	18%	Prenatal Svc	2%
HERR	54%	Prescrip Drugs	61%
Home Health Care	0%	Psychosocial Support	30%
Hospital IP	16%	Phys Therapy	9%
Housing	32%	Referral Svc	37%
Legal Services	18%	Rehab Svc	7%
Translation	4%	Respite Care	0%
MCM	74%	Skilled Nursing Care	11%
Mental Health IP	4%	Social Services	37%
Mental Health OP	23%	Subst Abuse IP	7%
Devel Disabil Svc	0%	Subst Abuse OP	19%
Medical Transp	21%	Treat Adhere Counsel	63%
CM-NM	26%	Utility Assist	21%

*** Received at This Clinic, Another Clinic, This and Another Clinic.**

Hispanic/Latino

Of the total respondents 24% or 141 were Hispanic/Latino.

Table 10: Consumer Survey 2014 – Profile of Hispanic/Latino Respondents (n=141)

Gender	Male	**62%**	Female	**37%**	Transgender	**1%**
HIV Status	HIV+	**91%**	HIV Negative	**5%**	Unknown	**4%**
Age Category	Age 13-24	**6%**	Age 40-44	**12%**	Age 60-64	**6%**
	Age 25-29	**2%**	Age 45-49	**16%**	Age 65-69	**4%**
	Age 30-34	**6%**	Age 50-54	**23%**	Age 70-74	**1%**
	Age 35-39	**11%**	Age 55-59	**11%**	Age Unknown	**1%**
	Age 13-34	**14%**	**Age 50+**	**45%**		
Current Health Insurance	Yes	**71%**	No	**3%**	No Answer	**26%**
Health Insurance	Medicaid	**54%**	Medicare	**8%**	Dual Eligibles	**4%**
	VA	**0%**	Employer	**4%**	Health Ins Exch.	**1%**
Applied for Insurance	NJFC	**15%**	Marketplace	**1%**	No Answer	**2%**
	No	**11%**				

Table 11: Services Received by Hispanic/Latino Respondents - Consumer Survey 2014

Service	% Rec'g Svc*
Amb/Op Medical Care	71%
Child Care	1%
Lab Services	72%
EIS	35%
Emerg Fin Assist	23%
Family Planning	6%
Food Bank/Meals	22%
HERR	55%
Home Health Care	9%
Hospital IP	28%
Housing	44%
Legal Services	26%
Translation	17%
MCM	74%
Mental Health IP	18%
Mental Health OP	43%
Devel Disabil Svc	5%
Medical Transp	22%
CM-NM	37%

Service	% Rec'g Svc*
Nursing Home	11%
Nutritional Counseling	40%
OB/GYN	26%
Oral Health	57%
Outreach	24%
Perm Planning	6%
Prenatal Svc	4%
Prescrip Drugs	70%
Psychosocial Support	46%
Phys Therapy	20%
Referral Svc	49%
Rehab Svc	21%
Respite Care	2%
Skilled Nursing Care	13%
Social Services	43%
Subst Abuse IP	7%
Subst Abuse OP	24%
Treat Adhere Counsel	55%
Utility Assist	33%

*** Received at This Clinic, Another Clinic, This and Another Clinic.**

Haitians

Of the total respondents 4% or 21 identified themselves as Haitian.

Table 12: Consumer Survey 2014 – Profile of Haitian Respondents (n=21)

Gender	Male	**57%**	Female	**43%**	Transgender	**0%**
HIV Status	HIV+	**81%**	HIV Negative	**10%**	Unknown	**9%**
Age Category	Age 13-24	**5%**	Age 40-44	**14%**	Age 60-64	**14%**
	Age 25-29	**0%**	Age 45-49	**19%**	Age 65-69	**5%**
	Age 30-34	**5%**	Age 50-54	**19%**	Age 70-74	**0%**
	Age 35-39	**0%**	Age 55-59	**19%**	Age Unknown	**0%**
	Age 13-34	**10%**	**Age 50+**	**57%**		
Current Health Insurance	Yes	**57%**	No	**19%**	No Answer	**24%**
Health Insurance	Medicaid	**36%**	Medicare	**14%**	Dual Eligibles	**5%**
	VA	**0%**	Employer	**2%**	Health Ins Exch.	**0%**
Applied for Insurance	NJFC	**5%**	Marketplace	**0%**	No Answer	**0%**
	No	**14%**				

Table 13: Services Received by Haitian Respondents - Consumer Survey 2014

Service	% Rec'g Svc*	Service	% Rec'g Svc*
Amb/Op Medical Care	76%	Nursing Home	10%
Child Care	0%	Nutritional Counseling	52%
Lab Services	81%	OB/GYN	24%
EIS	29%	Oral Health	52%
Emerg Fin Assist	29%	Outreach	33%
Family Planning	5%	Perm Planning	5%
Food Bank/Meals	24%	Prenatal Svc	0%
HERR	67%	Prescrip Drugs	71%
Home Health Care	5%	Psychosocial Support	43%
Hospital IP	29%	Phys Therapy	14%
Housing	29%	Referral Svc	52%
Legal Services	19%	Rehab Svc	14%
Translation	10%	Respite Care	0%
MCM	71%	Skilled Nursing Care	14%
Mental Health IP	5%	Social Services	38%
Mental Health OP	48%	Subst Abuse IP	10%
Devel Disabil Svc	0%	Subst Abuse OP	24%
Medical Transp	14%	Treat Adhere Counsel	57%
CM-NM	33%	Utility Assist	14%

*** Received at This Clinic, Another Clinic, This and Another Clinic.**

1.5 Recommendations for PLWHA Ineligible for ACA

Both Populations

- The **Planning Council** should consider holding or facilitating **support groups for Hispanic/Latino and Haitian PLWHA.** This can be done as part of the Council's mandate to provide input from the HIV+ community into the needs assessment, comprehensive planning, priority setting and resource allocation.
- Work with NJ Medicaid regarding **removing barriers to continuity of care** for PLWHA transitioning from RW funded medical care to NJFC. This includes streamlining pre-authorizations, prior approvals, and need for outside lab services to the extent possible.
- Ensure that **Medical Case Managers (MCM) educate clients about Ryan White services available** to them. Provide appropriate training and standards of care to facilitate this.
- **Adequately fund MCM** services to reduce wait times for care. Wait times for services should be communicated to patients. Where times are too long, MCM should refer clients to other Ryan White service providers.

Hispanic/Latinos

- Continue to ensure that **medical care and other services are available in Spanish language.** Particularly, continue to fund **Spanish-speaking mental health providers** – psychologists and psychiatrists.

Haitians

- Have more **Creole speaking staff and resources available at medical facilities and clinics**. Staff includes medical providers, medical case managers and case managers.
- **Work with and through trusted community leaders (pastors, priests and churches-related, etc.) to reach and educate the Haitian community about** health practices and the importance of accessing healthcare. Use these venues to begin the discussion about HIV/AIDS and mental health issues.
- Consider having medical providers conduct more **outreach at churches**, including support for a **health fair** [at churches].
- Consider preparing or supporting preparation of a **directory of all the Haitian doctors or a facilities** with Haitian speaking staff.
- Support having healthcare professionals connect with Haitian organizations (like HUDE and the Haitian Flag Association).

PART 2: COMPLETENESS OF CARE FOR PLWHA IN ACA BY RWHAP SERVICES

2.1. Background

Health insurance options available under the ACA including Medicaid Expansion will provide medical and health care services for individuals previously uninsured including persons living with HIV/AIDS (PLWHA). The ACA offers some of the same service categories available from Ryan White Part A/F. However the actual services and extent of the services and service limits are unknown.

The purpose is to help to determine how and where to reshape the Ryan White service continuum and mix (including resource allocation percentages) to meet needs of PLWHA in the Newark EMA regardless if they are insured by ACA private insurance or Medicaid Expansion. Because insurance companies whether privately or publicly funded will not be able to meet the varied and multiple health and support service needs of PLWHA especially those with low incomes, it essential to identify service gaps that RW funding can [continue to] fill.

Research Question #2
What are the gaps in services to PLWHA that remain after the implementation of ACA and Medicaid expansion and what will Ryan White continue to provide?
(The focus will be Medicaid Expansion/New Jersey FamilyCare (NJFC) because over 85% of RW clients have incomes under 138% FPL and are eligible for NJFC.)

Specific services include:

- **Research.** Conduct research with NJ Department of Human Services (NJDHS) Division of Medical Assistance and Health Services (DMAHS) regarding the Ryan White service categories and subcategories covered by Medicaid Expansion - New Jersey FamilyCare (NJFC). Identify the approved plans (insurers) for NJFC. Review the New Jersey Medicaid State Plan, regulations and HMO websites and contracts. Focus on all services but specifically seven (7) categories: (1) outpatient medical care, (2) medications, (3) mental health services, (4) substance abuse treatment services (outpatient and residential), (5) oral health care, (6) nutritional services, and (7) medical case management.
  a. ***The Grantee and Planning Council will assist in arranging contacts for this research component as needed.***
- **Key Informants (KI).** Key informants will be used to identify additional needs, issues or gaps in services for PLWHA in the Newark EMA. Identify individuals to serve as KIs to obtain detailed information regarding (1) NJFC coverage and (2) extent of need and use of the above RW services by PLWHA and RW clients. These KIs will likely be government representatives and physicians or other healthcare providers, respectively. Determine the number of individuals to be interviewed and identify specific candidates.
  a. ***The REC will assist in identifying the KIs to be interviews.***
- **Key Informant Guide.** Prepare two (2) guides for KI interviews of the government officials and health providers. Submit for review, comment approval to the Research and Evaluation

Committee (REC) and other Council committees if appropriate. Include in the provider KI interviews whether providers are credentialed in the NJFC health plans.

a. ***The REC will assist in developing the KI guide.***

- **Key Informant Interviews.** Conduct interviews of KIs and prepare written report of responses of each interview. Identify top issues discussed by KIs.
  a. ***The REC will perform some of the KI interviews and written reports of KI responses.***
- **Report of KI Interviews.** Prepare written report of activities and findings of KI interviews, top issues, and possible recommendations.

Written Gaps Analysis. For each Ryan White service category (core medical and support services), identify the specific services provided by Medicaid Expansion (and to the extent possible, ACA private insurance plans) in the Newark EMA. Include the types of services (and subtypes where applicable), units of service, and limits in a given year. This can be in table format or narrative and table. Compare with current RW policy and services and identify gaps.

Report on Completeness of Care. Prepare written summary of findings, comparing coverage of NJFC and RW services, identifying any limits or gaps recommendations. Include recommendations for use by the Planning Council for service options and for FY 2015 Ryan White service priorities and resource allocations.

Methodology

Key Informants. Interviews were conducted of **12 Key Informants** who were RWHAP Part A/F medical providers. (A 13th KI did not respond.)

Another Key Informant was from the NJ Dept. Human Services, Division of Medical Assistance and Health Services (DMAHS) or "NJ Medicaid Division". This individual provided senior state management input about New Jersey's implementation of the Affordable Care Act and Medicaid Expansion – New Jersey Family Care.

2.2 Key Informant Interview Results – RWHAP vs. Medicaid Expansion (NJFC) and ACA Thus Far

Research Question #2
What are the gaps in services to PLWHA that remain after the implementation of ACA and Medicaid expansion and what will Ryan White continue to provide?
(The focus will be Medicaid Expansion/New Jersey FamilyCare (NJFC) because over 85% of RW clients have incomes under 138% FPL and are eligible for NJFC.)

1. Does your agency accept Medicaid Managed Care (MMC) as a payer for HIV care? MMC includes Medicaid Expansion – New Jersey Family Care (NJFC) – which was implemented January 1, 2014.

All 12 agencies accept Medicaid Managed Care (MMC) including Medicaid Expansion - New Jersey Family Care (NJFC).

a. If yes, what is the approximate number and percent of MMC patients?

The percent of patients ranged from 20% to 45% to even 60% - 77%. One provider noted that the percent will continue to increase when those pending coverage are approved.

b. Has this percent changed over the past 2-3 years (increased, decreased, no change)?

Most providers reported that the percent of MMC patients has increased over the past 2 to 3 years. Two agencies reported no increase or slight increase.

c. If yes, from which sources (if you know). Medicaid managed care (SSI-related), Medicaid Expansion starting January 1, 2014 for all low income individuals.

Most providers expect to continue to see an increase in Medicaid Expansion (NJFC) patients in the coming year. The following comments were provided. The recent passage of ACA and emphasis on Medicaid Expansion has made our clients more aware of medical insurance and made it more easily applied for. Patients who previously had no insurance or straight Medicaid/Medicaid Plan G account for the influx of newly insured with Medicaid HMO patients. NJFC patients were previously Charity Care patients. When some clients receive their card they are opting to go to private doctors, but many are circling back after awhile.

d. Do you [know if you] have any patients with ACA private insurance purchased on the health exchange?

Most providers reported that they had some patients with ACA private insurance purchased on the health asked exchange, but this was a very small percentage, even less than 1%.

2. How many of your agency's medical providers are credentialed on one or more managed care panels?

Most agencies' medical providers are credentialed on one or more managed care panels. Several reported that only a few were credentialed.

a. Are they on all of the state's MMC, Medicaid Expansion and ACA panels?

Of those who were credentialed on the managed care panels, most were credentialed on all NJFC, MMC, and similar panels. Two agencies reported that not all of their providers were so credentialed.

b. If no, which are the credentialed for? (Number of insurers)

The two agencies shared the list of HMOs their providers were credentialed for. One hospital-based clinic reported that its providers are credentialed for all of the insurers accepted by the medical facility where their program is housed.

c. If no, does this pose a barrier to care for your HIV+ patients?

For the two agencies whose providers were not 100% credentialed on all NJFC/MMC panels, one agency found that this was a barrier to care and the other did not.

3. Do your medical staff members serve as the primary care provider (PCP) for MMC clients? (Yes/No).

The medical staff members of 10 of the 12 KIs serve as the primary care provider for their MMC clients. Providers in two of the KI agencies do not serve as the PCP; their physicians are specialty care providers. One of the 10 agencies reported a very small percentage of clients receiving PCP care from the agency.

a. If Yes, what is the number of providers who are PCPs.

The number of providers who are PCPs ranged from one to 16, depending upon the size of the agency.

b. If No, what function(s) do your medical staff members perform?

The functions performed by medical staff members who are not PCPs are specialty HIV and Infectious Disease Care.

c. If No, how is your agency coordinating with the managed care primary care provider and how are your HIV patients getting approvals for referrals?

Agencies have developed solutions specific to their clinic, staff, agency and patient population.

- Our agency functions as a specialty clinic for HIV – 2 Infectious Disease (identify) physicians and 1 ID Nurse Practitioner. Patients have primary care providers located in the Main Campus Medical Clinic. However, the providers in the ID clinic provide the majority of care to patients. Patients see providers in the Medical Clinic as needed. If patients are seen onsite by our specialist no referrals are needed. Our ID Clinic has a good mix of staff with licensed Medical Social Workers providing medical case management. Two staff help with administrative support services – answering the phone, etc., but one person functions as a case manager and the second as a Medical Assistant. With the rollout of the new insurances, the volume of Prior Authorizations has increased for medications and testing. Everyone is helping but this is overwhelming at times.
- Medical Case Managers review and assist patients with the process of getting referrals from their Primary Care Physicians. Our agency has a Primary Care Center and patients that choose to use them for their PCP can get referrals as needed.
- Based on the patients' insurance plan, they are required to bring a referral from their PCP before they are seen at the clinic. There is dialogue with the PCP as needed by the provider. However, if the patient comes without a referral our social services team often will reach out to the PCP's office and request the referral to be faxed and then mailed to our clinic.
- For the most part, our patients are requesting to be assigned to a PCP in the same building in which we are located. We already have pre-established relationships and the process of obtaining referrals is much simpler.
- We call the primary physicians when the client is unable to obtain the referral.

- We assist patients with the Primary Care selection process and encourage them to choose providers within our facility so that we do not experience barriers obtaining referrals when necessary.

4. Have you noticed an increase in patients with Medicaid Managed Care (MMC) or Medicaid Expansion (NJFC)?

All agencies have noticed an increase in patients with MMC or NJFC.

a. If Yes, how has this affected your practice?

The following comments were provided.

- For providers who are not PCPs, there have been increased requests for PCP referrals and prior authorizations (for medications and tests).
- For other providers who are PCPs, there is a dramatic increase in paperwork and bureaucratic functions associated with prior authorizations.
    a. The requirement to use outside labs and PCP referrals has led to a delay in treatment. The increase in the number of prior authorizations required for medications has led to patient/staff frustration and delay in medication acquisition from the Pharmacy. In the early stages of the ACA and Expanded Medicaid everything involves a delayed response which means a delay in services of care and treatment for all our clients.
    b. We are inundated with prior authorizations for radiology, diagnostic testing and medications, even though the patients have been on them for years. Prior authorization is required for each test, prescriptions at least every 6 months.
    c. We have noticed an increase which has impacted the administrative tasks required by the medical care team. There has been an increased need for referrals, lab slips to outside facilities, authorizations for medications and authorizations for procedures.
- Patients now have more options for health care and some are finding private practices for a variety of reasons.
- In some ways it is helped increase access to labs and some medications. We have always accepted patients with no insurance so access to our services hasn't changed. In fact we haven't been able to draw down from our Ryan White grant as much since there are less patients we can enter into CHAMP as billable for primary medical care services. That being said, our medical care of patients does not change based on the type of insurance. ADDP has always been an excellent payer for medications and vaccines. Ryan White requires us to offer Hepatitis B vaccination, Pneumococcal vaccination and Influenza vaccination. These immunizations are always immediately covered when a patient has ADDP.
    a. However, the MMC/Medicaid HMOs often do not cover these immunizations or require lengthy prior authorizations. I frequently have a vaccine that is not covered due to poor coverage or denial due to age/disease state, etc. They also at times don't pay for certain HIV medications. For example, Stribild was not covered for a patient of mine recently who had United Healthcare Medicaid. Although I know that having patients on ADDP and Ryan

White reimbursement is costly to the Ryan White Grant, these patients were always better covered for medications/vaccinations

- Fewer patients needing NJ Charity Care.
- Lower rates of reimbursement and lower income to the health center.
- One said there were no major differences noted.

b. If Yes, have your MMC or NJFC clients been able to access the full formulary of medications?

There is a range of perceptions about access to the full formulary of medications. Five KIs felt there was this access. The remaining providers had caveats, mostly related to prior authorization.

One agency said no there was not the same access, which was based on whatever the insurance company recommends. Otherwise, for non-formulary, it requires prior authorization. Another concurred citing restrictions.

Another agency said yes, for the most part, but we have had to do a LOT of paperwork, make a lot of phone calls and do a lot of back tracking to get prescriptions filled, especially right after the switchover. There have been some concerns of patients being asked to use mail order pharmacies. This is not a safe means of obtaining prescriptions for some of our patients as they are at risk for their medications being stolen, privacy issues, and change of medication issues. This agency noted that most of the ACA and Expanded Medicaid is offering pharmacists who provide three months' supply of medication because it is less costly for insurance. But this is more dangerous for the clients. As we are all aware the medications are very expensive and can be sold on the black market.

Another agency said that some patients have been assigned to plans that were not appropriate for coverage of HIV medications. In this scenario, our medical case management team will assist the patient with obtaining ancillary coverage through other sources such as ADDP.

One FQHC noted that it provides assistance in helping patients obtain medications at a low cost.

5. Does MMC or Medicaid Expansion present any advantages or benefits for treating HIV patients? E.g., easier access to services, payment for treatments, etc. Please describe.

There were a range of responses to this question. Three KIs said that no advantages were noticed thus far. Another provider noted that the many phone calls for preauthorizations shortens the time spent in patient care. Medications are denied many times due to non formulary issues (not in Tier 1), or because the patient must have failed previous regimes, etc. High deductibles and co-pays are a barrier to care. The appeal process is too long for denials of medications.

The remaining providers reported easier access to certain services. There is easier access to medication (no need to recertify every 6 months as with ADDP). Patients now have coverage for all hospital/ physician services. It is also easier for patients to access sub–specialty care as they now have insurance, versus NJ Charity Care which did not pay for these services. For patients who are no longer "charity care", I have better access to and control over ordering needed labs. I am also able to refer these patients to specialty medical care more easily. Medicaid expansion has (1) opened up a list of specialty

physicians available to our patients who in the past did not see patients without insurance coverage, and (2) Improved reimbursement for services rendered. There is increased and faster access for medically necessary services and tests such as x-rays, MRIs, and surgical procedures, oral healthcare and ophthalmology, etc.

6. Does MMC or Medicaid Expansion present any barriers to treating HIV patients? E.g., need for prior approval from primary care provider for HIV care, etc. Please answer with respect to the following 4 issues. (If not applicable or not experienced, please indicate so.)

(1) patient copays,

Although there are no co-pays with NJFC and MMC for medical visits, there are co-pays for medications and other services. The significant barriers associated with these co-pays are lack of affordability, patients having difficulty in making co-pays which leads to avoidance of care and fewer visits, providers making special arrangements for antiretrovirals including offering co-pay cards. One provider reported that co-pays for medications is the most frequent complaint received from the patients. The FQHCs report that patients never pay a co-pay in our clinic if they are part of the Ryan White Program regardless of their insurance status.

Another provider reported that Copays for some of the new insurance plans have been as high as $75 per specialty office visit. This would absolutely be a barrier to compliance with treatment if we did not have the cost sharing funds to offset these costs for our patients.

(2) insurance premiums,

Although there are no insurance premiums with NJFC, there are premiums with ACA health insurance purchased on the insurance exchanges. One provider saw no barrier at this time.

Three KIs said that insurance premiums were a barrier – even significant barrier – to care. One cited affordability. Another said that if the patient has no money and premiums are not paid, the plan will drop the patient which impedes access to care.

The high cost of premiums has deterred some patients from applying for the ACA. On the exchange, premiums are unaffordable for most patients and they refuse to enroll because they are “already covered” under Ryan White. They tend to disregard the legal ramifications. Another noted that some patients have premiums but we never charge copays for office visits. One provider noted that we have not experienced challenges with retention as a result of costly premiums yet, but patients are still in the initial stages of obtaining coverage so we anticipate this may present a barrier in the near future.

(3) insurance deductibles, and

There are no insurance deductibles with Medicaid and NJFC. Four KIs did not address this issue.

Eight KIs found that insurance deductibles were a significant barrier to care. The high deductibles make health insurance – and hence access to care – unaffordable. The high cost of insurance deductibles has deterred some patients from applying for ACA, especially for our patients who are low income and have no extra money. Some patients refuse labs because they have too large a deductible on their annual lab

allotment. One agency reported that in general these are very high, and that it has stopped participating [with Amerihealth] and their high deductibles are part of the reason.

Another stated that we have not experienced challenges with retention as a result of costly deductibles yet, but patients are still in the initial stages of obtaining coverage so we anticipate this may present a barrier in the near future.

(4) need for prior authorization from insurers for treatment and/or medications.

Two KIs have not seen this as a barrier to care, although one saw a slight increase in the need for preauthorization for medications. Some have adapted and are educating patients about the new process.

- "Initially, once patients are oriented to the process with the assistance of the Medical Case Manager, they are typically able to get referrals. We also remind patients that referrals will be due on their next visit to give them ample time to obtain referrals."

The remaining found that prior authorizations delayed care.

- Horizon BCBS and Horizon NJ Health request prior authorization. This results in delays in patient's getting prescriptions filled and having tests in a timely manner.
- This is an added burden to patients and providers…causes delays in treatment delivery. Meds may be missed as we are having trouble getting prior authorization for meds.
- The number of prior authorizations has gone up exponentially. I have a full-time employee dedicated to authorizing medication, vaccines, specialty referrals and tests such as imaging, etc.
- The amount of prior authorizations required has increased dramatically with ACA and Medicaid expansion. Authorizations are being required for drug (regimens), both HIV and non-HIV medications, that patients have been on for a long time. We have had many cases where a patient has been on certain HAART medication/regimen for years but now being denied; for example on Atripla for the last 4 years. One of the most difficult medications to obtain approval for is HCV treatment drugs in which several patients have been denied and the nurse needs to call to re-appeal the cases. The second type of prior authorizations are for diagnostic testing such as MRIs, CT Scans, and bone scans which often require a skilled/trained person to complete them as they are much more difficult to successfully obtain approval. Depending on the test for prior auth the process can take up to 1-3 hours over the phone providing the information and at least 48-72 hours for a determination to be made. In some instances, the nurse or physician performs a peer to peer review over the phone for approvals. The other side to this is that we have several patients who are noncompliant once the approvals and appt set-up has been completed and we have to redo the process again. **The requirements of ACA have greatly increased the paper work and time for the doctors and nurses.**
- The significant increase in the need for prior authorizations for medications has created a delay in patients receiving their meds from the pharmacy and has imposed an additional administrative burden on the nursing staff.

(5) Pending status – waiting final eligibility determination and enrollment.

Only one KI found that pending status was not a barrier to care. The remaining 11 cited delays in care.

- The waiting period between application, eligibility determination and receiving the insurance card results in delays in getting labs done.
- Some of our clients have waited up to three months and some are still waiting for approval letters.
- We still have several patients awaiting final eligibility determination for Medicaid expansion and ACA. This has delayed the patients receiving the diagnostic testing ordered.
- This is also a major problem. The process is labor intensive and complicated. Patients get impatient or get lost in the shuffle.
- Some patients experiencing delay in final approval.
- This has impacted our patients because they have to apply for charity care approval for each individual scheduled visit while their coverage status is pending.

Two reported interim solutions pending final eligibility determination.

- Patients who are pending are still being covered by Ryan White funding. Patients are followed by their Medical Case Managers for assistance with process.
- I often have a patient that "isn't eligible to become active until a later date". For these patients we enroll them in ADDP/charity care while we wait.

7. Do you have any recommendations for improving the system between Ryan White and managed care for your HIV patients?

Six KIs had no recommendations. The remaining six offered the following:

- One time referrals to patients being treated for HIV.
- One time authorization for ongoing medications.
- Reconsider the requirement of NJFC HMOs to use outside labs for blood draws. It is very difficult for some of our patients to get to LabCorp and Quest draw stations. When faced with a barrier they may avoid getting the service which will interrupt the care delivery. We need to find a way to get lab services done at the hospital covered by insurance providers. This will remove a barrier of a second visit which may not be kept because the patient does not have transportation assistance or just forgets to keep the lab appointment. Labs that are not available at time of the medical visit delays appropriate treatment.
- Keep assisting patients who are undocumented and ensure that medications and specialized care will not be effected in anyway.
- Consider providing a subsidy with Ryan White funds for services not covered by the NJFC HMO. If there was a subsidy available for patients who have insurance but are denied specific medication/tests/labs/vaccines we wouldn't have any gap in medical care.
- I recommend that we continually stay on top of the changes impacting HIV/AIDS care.

- One provider recommended a novel approach to the Ryan White Program. Become a Medicaid Expansion/ACA insurance program for HIV+ patients. They apply as any other insurance and if they qualify the will have an insurance based in Ryan white present management of care.
- Organize a conference or training for health care insurance and Ryan White-eligible clients.
- Maintain ongoing education with NJ Medicaid that Ryan White is different regarding care and does not have the barriers of NJFC HMOs.
- Provide more education to clients and providers about the specifics of the plans and how to select the coverage that is best suited for our HIV positive patients would be beneficial when we need to advocate for them regarding plan formularies, laboratory costs, etc.

2.3 Key Informant Interview Results – New Jersey Medicaid and Medicaid Expansion (NJFC) and ACA

1. **Service categories/types. We have seen the general service categories on websites of NJFC and health insurers. Can you tell us specifically what categories of services are covered under the Medicaid Expansion and ACA Essential Health Benefits (EHB)? Are they service categories and types in both programs the same?**
    a. **That is, do ACA/EHB and Medicaid Expansion cover the same benefits/categories of benefits/services?**

Yes they do. ACA/EHB and Medicaid Expansion cover the same benefits/categories of benefits/services.

    b. **Can you please list or verify the service types and/or categories in the table below.**

For NJ Family Care (Medicaid Expansion) services categories are: physician visits , prescriptions, lab tests, x-rays, hospitalization, dental, eyeglasses, mental health services, specialist visits.

2. **Eligibility criteria. Can you clarify/confirm the following eligibility criteria.**
    a. **Immigrants. Excludes qualified aliens for 5 years from entry date. (8 USC 1613)**

This is correct. Immigrants who are qualified aliens in the US for less than five years are not eligible for Medicaid Expansion or ACA.

    b. **CDS – Controlled dangerous substance. Are individuals convicted of CDS offense eligible for Medicaid Expansion? If not, for how long?**

Yes, they are. Effective January 1, 2014, Work First NJ was delinked from Medicaid. Work First NJ restricts eligibility of some persons convicted of a CDS offense. Since Medicaid is a federal program, with no bar for past drug convictions, individuals with any type of past drug conviction will be eligible for Medicaid as long as they meet Medicaid's other eligibility requirements.

    c. **Other. Can you please identify other categories of [low income] individuals ineligible for Medicaid Expansion or ACA – who might typically reside in NJ.**

Immigrant clients who have been residing in New Jersey for less than 5 years are not eligible for Medicaid Expansion.

3. **Co-pays. What Are the Medicaid expansion co-pays? Are they uniform? Do they vary based on type of medical service, e.g., physician visit versus mental health visit? Do they vary based on type of prescription?**

There are no Medicaid Expansion copays for outpatient medical care visits. There are copays for prescription drugs under Medicaid Expansion.

Generic Drugs. Medicaid Copays for generic drugs are between $1.10 - $2.50.
Brand Name Drugs. Medicaid Copays for name brand drugs are $3.30 - $6.30

Prescription drugs are categorized by "Tier" within health insurance companies. Preference is give to drugs in Tier 1, then Tier 2 and finally Tier 3.

a. Likewise, ACA copays

The amount of copays for medical visits and prescription drugs depends on the tier and plan selected by the patient. The ACA as four plans – Bronze, Silver, Gold and Platinum. Each plan has specific amounts for copays (medical care and prescriptions), premiums and deductibles. The copay is the amount that must be paid at time of medical visit or pharmacy visit for a medication. The premium is the monthly amount paid to the insurance company for the cost of the insurance policy. Deductible is the amount that must be paid out of pocket before insurance will pay for care.

b. ACA premiums

The amount of premiums for health insurance depends on the plan selected by the patient. See above.

c. ACA subsidies

ACA Subsidies are available for those clients with incomes below 400% of the Federal Poverty Level. See subsidy information attached in Appendix C from Kaiser Family Foundation.

4. <u>Drug formulary.</u> Medicaid Expansion formulary – is it the same as ADAP? More expansive. Where can we get this list?

A recent study detailing the impact of the Affordable Care Act on New Jersey residents, specifically those with HIV/AIDS, was provided by this Key Informant. The study is, **"State Health Reform Impact Project – New Jersey, January 2013"** prepared by the Center for Health Law and Policy Innovation of the Harvard Law School and the Treatment Expansion Access Project. It is set forth in Appendix C. Table 2 in this report compares prescription drugs covered by ADAP, Medicaid and Horizon HMO which is the benchmark plan for the Affordable Care Act in New Jersey. This table is extracted below, but is shown in the Harvard report. This table indicates that some of the prescriptions available in ADAP may be available in Medicaid but may not be available in Horizon HMO.

Table 2. ADAP Versus Medicaid and the Benchmark Plan Used to Define Essential Health Benefits: Covered Drugs[49]

Benefits applying only to beneficiaries under 21 years of age are not assessed in this report.

Drugs (ART class indicated in bold; brand name in normal type; generic in italics)	ADAP[50]	Medicaid[51]	Horizon HMO
Multiclass Combination Drugs	**3 Drugs Covered**	**3 Drugs Covered**	**2 Drugs Covered**
Atripla; *efavirenz + emtricitabine + tenofovir DF*	X	X	X (tier 2)
Complera; *emtricitabine + rilpivirine + tenofovir disoproxil fumarate*	X	X	X (tier 2)
Stribild; *elvitegravir + cobicistat + emtricitabine + tenofovir disoproxil fumarate*	X	X	

NRTIs	12 Drugs Covered	12 Drugs Covered	12 Drugs Covered
Combivir; *zidovudine + lamivudine*	X	X	X (tier 3)
Emtriva; *emtricitabine*	X	X	X (tier 2)
Epivir; *lamivudine*	X	X	X (generic tier 1; brand name tier 3)
Epzicom; *abacavir sulfate + lamivudine*	X	X	X (tier 2)
Retrovir; *zidovudine*	X	X	X (generic tier 1; brand name tier 3)
Trizivir; *abacavir + zidovudine + lamivudine*	X	X	X (tier 2)
Truvada; *tenofovir DF + emtricitabine*	X	X	X (tier 2; PA)
Videx; *didanosine (buffered versions)*	X	X	X (generic tier 1; brand name tier 2)
Videx EC; *didanosine (delayed–release capsules)*	X	X	X (generic tier 1; brand name tier 3)
Viread; *tenofovir disoproxil fumarate DF*	X	X	X (tier 2)
Zerit; *stavudine*	X	X	X (generic tier 1; brand name tier 3)
Ziagen; *abacavir*	X	X	X (tier 2)
NNRTIs	**5 Drugs Covered**	**5 Drugs Covered**	**3 Drugs Covered**
Intelence; *etravirine*	X	X	X (tier 2)
Rescriptor; *delavirdine mesylate*	X	X	X (tier 3)
Sustiva; *efavirenz*	X	X	
Viramune; *nevirapine*	X	X	
Edurant; *rilpivirine*	X (PA)[52]	X	X (tier 2)
Protease Inhibitors	**10 Drugs Covered**	**10 Drugs Covered**	**9 Drugs Covered**
Agenerase; *amprenavir*	X	X	
Aptivus; *tipranavir*	X	X	X (tier 2)
Crixivan; *indinavir sulfate*	X	X	X (tier 2)
Invirase; *saquinavir mesylate*	X	X	X (tier 2)
Kaletra; *lopinavir + ritonavir*	X	X	X (tier 2)
Lexiva; *fosamprenavir*	X	X	X (tier 2)
Norvir; *ritonavir*	X	X	X (tier 2; tablets tier 3)
Prezista; *darunavir*	X	X	X (tier 2)
Reyataz; *atazanavir sulfate*	X	X	X (tier 2)
Viracept; *nelfinavir sulfate*	X	X	X (tier 2)
Fusion Inhibitors	**1 Drug Covered**	**1 Drug Covered**	**1 Drug Covered**
Fuzeon; *enfuvirtide*	X	X	X (tier 2; SP; QL)

Entry Inhibitors – CCR-5 Coreceptor Antagonist	**1 Drug Covered**	**1 Drug Covered**	**1 Drug Covered**
Selzentry; *maraviroc*	X	X	X (tier 2; PA; QL)
HIV Integrase Strand Transfer Inhibitors	**1 Drug Covered**	**1 Drug Covered**	**1 Drug Covered**
Isentress; *raltegravir*	X	X	X (tier 2)
"A1" Opportunistic Infection Medications	**30 Drugs Covered**	**30 Drugs Covered**	**28 Drugs Covered**
Ancobon; *flucytosine*	X	X	X (generic tier 1; brand name tier 3)
Bactrim DS; *sulfamethoxazole/trimethoprim DS*	X	X	X (generic tier 1; brand name tier 3)
Biaxin; *clarithromycin*	X	X	X (generic tier 1; brand name tier 3; QL)
Cleocin; *clindamycin*	X	X	X (generic tier 1; 75 mg brand name tier 2; other dosages tier 3)
Dapsone	X	X	X (tier 1)
Daraprim; *pyrimethamine*	X	X	X (tier 2)
Deltasone; *prednisone*	X	X	X (tier 1; oral concentrate tier 2; oral solution tier 3)
Diflucan; *fluconazole*	X	X	X (generic tier 1; brand name tier 3)
Famvir; *famciclovir*	X	X	X (generic tier 1; brand name tier 3)
Foscavir; *foscarnet*	X	X	X (generic tier 1; brand name tier 3)
Fungizone; *amphotericin B*	X	X	
INH; *isoniazid*	X	X	X (tier 1)
Megace; *megestrol*	X	X	X (generic tier 1; brand name 400 mL tier 2; 5 mL tier 3)
Mepron; *atovaquone*	X	X	X (tier 2)
Myambutol; *ethambutol*	X	X	X (generic tier 1; brand name tier 3)
Mycobutin; *rifabutin*	X	X	X (tier 2)
NebuPent; *pentamidine*	X	X	X (tier 2)
Probenecid	X	X	X (tier 1)
Procrit; *erythropoietin*	X	X	X (tier 2)
Pyrazinamide (PZA)	X	X	X (tier 3)
Rifadin; *rifampin*	X	X	X (generic tier 1; brand name tier 3)
Sporanox; *itraconazole*	X	X	X (tier 1)
Sulfadiazine	X	X	X (tier 1)

Valcyte; *valganciclovir*	X	X	X (tier 2)
Valtrex; *valacyclovir*	X	X	X (generic tier 1; brand name tier 3)
VFEND; *voriconazole*	X	X	X (generic tier 1; brand name tier 3)
Vistide; *cidofovir*	X	X	
Wellcovorin; *leucovorin*	X	X	X (tier 1)
Zithromax; *azithromycin*	X	X	X (generic tier 1; brand name tier 3; QL)
Zovirax; *acyclovir*	X	X	X (generic tier 1; brand name tier 3)

PA = prior authorization; QL = quantity limited

a. Likewise, ACA formulary.

As indicated in the above table, many of the HIV medications require prior authorization. There also may be a preference for a the generic version of the drug versus the brand-name.

5. Other issues (to be determined based on KI responses.)

Medical/Non-Medical Case Management. It is important to note that Ryan White clients who have transitioned into Medicaid **will not be getting the case management services that they need - Medical Case Management (MCM) or Case Management – Non-Medical (CM-NM).** ***Case management is not a covered service within the HMO including NJFC.***

Support Services. Clients living with HIV will also not be getting ancillary support services from the HMO (Marketplace insurance options) that are part of Ryan White services such as: Early intervention services, food bank, non-emergency transportation, treatment adherence counseling, health education, risk reduction counseling, nutritional counseling, and outreach services.

Substance Abuse Services. Substance abuse treatment within the HMO (marketplace options) is **OUTPATIENT FIRST** and it has a **$20.00 copay for each visit**.

Mental Health Services. HMO Mental Health services (marketplace options) also have a **$20.00 copay per visit**, and are limited to 30 visits per year including Occupational Therapy (OT), Physical Therapy (PT), and Speech Therapy (ST) sessions.

Diagnostic tests within the HMO (marketplace options) have a **$20.00 copay**. While there is easier access to diagnostic tests within NJFC compared to NJ Charity Care, the co-pay required in the marketplace options may be a barrier to receiving these tests for low income PLWHA.

Prior Authorization for HIV Medications. As seen in Table 2 in the Harvard report, many of the HIV-related drugs require prior authorization from the HMO, which presents barriers to treatment adherence, and some of the name brand HIV medications are not covered in the HMO drug formularies.

Conclusion. It will be essential for Ryan White Primary Medical Care and the RWHAP program to fill in the gaps for HIV clients who are not getting or unable to afford copays for services that they need within the Medicaid and ACA systems.

It will also be essential for the RWHAP to **monitor for every client** services provided by the NJFC HMO, any gaps that remain, and the need for RWHAP to fill these gaps through the Ryan White – funded services.

2.4 Recommendations for Completeness of Care within RWHAP

- **Case Management services – Medical Case Management (MCM) and Non-Medical Case Management (CM-NM) - are NOT covered by Medicaid Expansion or the ACA. The RWHAP MUST continue to fund these services to ensuring coordination of medical care and other services and increase funding as needed.** The **standards of care** for both must ensure coordination of care and services regardless of payer (health insurance). We do not want to lose the gains made in RWHAP as measured by Viral Load Suppression because of health insurance bureaucracy.
- The RWHAP must monitor every client who receives **NJFC services with copays – substance abuse treatment and mental health – to identify gaps and need for Health Insurance Premium and Cost Sharing (HIPCS) Assistance**. And fill those gaps with RW HIPCS funding.
- Maintain ongoing education with NJ Medicaid that the Ryan White system is different regarding care and does not have the barriers of NJFC HMOs.
- **Work with NJ Medicaid and HMOs to ease up on prior authorizations and other requirements (based on track record of 20+ years treating HIV) including feasibility of:**
  a. One time referrals to patients being treated for HIV.
  b. One time authorization for ongoing medications.
  c. Not needing to use outside labs for blood draws.
- Consider providing a subsidy with Ryan White funds for services not covered by the NJFC HMO. If there was a subsidy available for patients who have insurance but are denied specific medication/tests/labs/vaccines we wouldn't have any gap in medical care.
- Continually stay on top of the changes impacting HIV/AIDS care.
- Organize a conference or training for health care insurance and Ryan White-eligible clients.
- Provide more **education to clients and providers** about the specifics of the plans and how to select the coverage that is best suited for our HIV positive patients would be beneficial when we need to advocate for them regarding plan formularies, laboratory costs, etc.