

# Rhode Island Integrated Prevention & Care Comprehensive and Statewide Coordinated Statement of Need Plan

**CY 2017-2021**

**State of Rhode Island**



**Vision: To End HIV Infection in Rhode Island**



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# Mission Statement

The Rhode Island HIV Care and Prevention Planning Group has developed this jurisdictional plan in accordance with their mission statement. “Our mission is to eliminate the spread of HIV and to create a seamless continuum of care for all people infected and affected in Rhode Island by:

- Preventing new and secondary infections, diagnosing existing infections at the earliest possible stage through testing and counseling programs, and developing early intervention for existing infections to decrease morbidity and mortality.
- Linking HIV prevention, testing and counseling, early diagnosis, access to care and the provision of quality treatment services.
- Engaging and including individuals from every sector of our community in our planning process, particularly those persons whose lives have been directly touched by HIV/AIDS.”

# Executive Summary

Collectively, the Ryan White HIV, Provision of Care Program of the Executive Office of Health & Human Services (RI-EOHHS) and the Center for HIV, Viral Hepatitis, STDs, and TB Epidemiology of the Rhode Island Department of Health (RIDOH), provide prevention and care services for people infected and affected by the HIV/AIDS epidemic. Additionally, RIDOH and RI-EOHHS plan, coordinate and develop a comprehensive service delivery network of prevention, health care, and supportive services for people at risk for, or living with HIV/AIDS.

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was enacted in 1990 and reauthorized in 1996, 2000, 2006, 2009, and 2013. The CARE Act is a federal program supported by the HIV/AIDS Bureau (HAB) and Health Resources and Services Administration (HRSA) which are part of Federal Office of Health & Human Services. It is the centerpiece of the federal government's efforts to improve the quality and availability of care for medically underserved individuals and families affected by HIV/AIDS. HRSA allocates funding to programs created by the CARE Act under various Parts. Part B of the CARE Act provides health care and support services for individuals and families with HIV infection. These funds provide high quality, community based care for low-income individuals and families with HIV/AIDS. In Rhode Island, services are provided through contracts administered by RI-EOHHS with input from the Rhode Island HIV Care and Prevention Planning Group (CPPG) and the Consumer Advisory Board (CAB). Additionally, the Rhode Island Part B program also administers the Rhode Island AIDS Drug Assistance Program (ADAP) and the RI-EOHHS Health Insurance Premium Assistance Program.

The Rhode Island Department of Health is funded by the Centers for Disease Control and Prevention (CDC), as a part of its overall public health mission. The CDC provides leadership in helping control the HIV/AIDS epidemic by working with community, state, national, and international partners in surveillance, research, and prevention and evaluation activities. These activities are critically important because the CDC estimates that about 1.2 million Americans are living with HIV/AIDS, and that 12.8% of these persons do not know they are infected<sup>1</sup>. Most of the CDC's HIV/AIDS prevention efforts are the responsibility of the Office of Infectious Diseases. Within this Center is the Division of HIV/AIDS Prevention (DHAP), charged with the mission of preventing HIV infection and reducing the incidence of HIV-related illness and death.

The purpose of this Integrated Plan is to a) Present a detailed picture of the HIV landscape of Rhode Island's HIV epidemic, b) provide detailed goals and strategies of how we will map out an upgraded system of care, and c) Describe and map how our state is going to prioritize decisions about HIV-related services and resources in our area.

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<sup>1</sup> National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP)(<http://www.cdc.gov/nchhstp/>)

# Introduction

In accordance with the Health Resources and Service Administration's (HRSA) and the Centers for Disease Control and Prevention's (CDC) expectations, Rhode Island's 2017-2021 Comprehensive Plan includes data from an exhaustive needs assessment and planning process. This process included analyzing data from the epidemiological profile, a consumer survey, and a provider capacity and capability survey to identify gaps in HIV prevention and care (i.e. identifying clinical performance measures, and enhancing HIV testing) in order to develop smart objectives and goals for the next five years. This plan has many stakeholders including the Ryan White HIV Provision of Care Program of the Executive Office of Health & Human Services (RI-EOHHS), the Center for HIV, Viral Hepatitis, STDs, and TB Epidemiology of the Rhode Island Department of Health (RIDOH), John Snow Inc. (JSI), HIV care providers, community based agencies, consumers, and community members.

The plan integrates the efforts of RIDOH for preventative measures surrounding infectious diseases, through testing, referral, linkage to care and partner notification, and RI-EOHHS' Ryan White HIV Provision of Care Program by focusing on the care of the individual once they have been diagnosed with HIV/AIDS, through determination of eligibility for Ryan White services, intake, care plans, retention in care, medication adherence, viral suppression, outreach, and enrollment in the AIDS Drug Assistance Program (ADAP), if necessary.

Rhode Island is geographically the smallest state in the nation, and has a population of approximately 1,055,173 residents. 85.1% of the state's residents are White, 14% of the population is of Latino origin, 7.7% are Black/African American, 3.5% are Asian, 2.6% are two or more races, 0.9% are American Indian/Alaska Native, and 0.2 % are Native Hawaiian or other Pacific Islander. (U.S. Census Bureau: 2014). Due to the small population, and the extensive collaboration, this plan has the potential to positively impact the HIV epidemic in Rhode Island.

Throughout 2015 and 2016, the many stakeholders of the Comprehensive Plan thoroughly reviewed the *National HIV/AIDS Strategy (NHAS): Updated to 2020*<sup>2</sup> and have aligned this plan to reflect the current NHAS goals. This plan will: increase efforts to address treatment and care for PLWH/A; address the needs and gaps within the state; look at new early diagnostic testing modalities; maintain cross collaboration between RIDOH and RI-EOHHS; enhance Pre-Exposure Prophylaxis (PrEP) resources; and continue to improve the HIV Care Continuum outcomes, a priority within the state, by reducing new HIV infections and HIV health disparities.

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<sup>2</sup> White House Office of National AIDS Policy. (2015). *National HIV/AIDS Strategy*. Washington (DC). <https://www.aids.gov/federal-resources/national-hiv-aids-strategy/nhas-update.pdf>

# Section I: Statewide Coordinated Statement of Need/Needs Assessment

## A. Epidemiologic Overview

### (a) History of the HIV epidemic in Rhode Island

The Rhode Island Department of Health HIV Surveillance Program has maintained records on the HIV epidemic since 1982. The HIV Surveillance program captures, records, analyzes, and disseminates information related to persons newly diagnosed with HIV, all individuals living with HIV in Rhode Island, persons with HIV who have progressed to AIDS, HIV/AIDS-related deaths, and those populations that are experiencing a disproportionate burden of illness from HIV. The HIV Surveillance Program works closely with other RIDOH and RI-EOHHS programs to describe the HIV epidemic within the context of other public health issues, such as the concurrent STD epidemic, tuberculosis, and HCV infection. Data on these and other related issues can be found in the *Rhode Island HIV Epidemiological Profile and Surrogate Data*<sup>3</sup>.

In Rhode Island, 3,972 cases of HIV/AIDS and 1,679 deaths from HIV/AIDS have been reported as of 2014. Major advances in prevention and treatment have altered the pace and reach of the epidemic. Currently, Rhode Island is experiencing a mature HIV epidemic with a slight decline in newly identified cases over the last five years, with the exception of 2014, in which there was an increase. Preliminary 2015 data show a return to declining case counts. Continued work is needed to ensure at-risk individuals are tested and all those diagnosed with HIV/AIDS are connected to care and attain a suppressed viral load.

Between January 1, 2014 and December 31, 2014, there were a total of 97 Rhode Island residents newly-diagnosed with HIV and reported to the HIV Surveillance Program. This number provides a minimum estimate of HIV infection, as it does not include HIV-infected individuals who have not been tested yet and those who were tested anonymously.

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<sup>3</sup> 2014 RI HIV/AIDS Epidemiologic Profile with Surrogate Data  
<http://www.health.ri.gov/publications/epidemiologicalprofiles/2014HIVAIDSViralHepatitisWithSurrogateData.pdf>

**(b) Demographic Data of the Ninety -Seven (97) Newly Identified Cases of HIV, Rhode Island, 2014**

**Note:** Rates are based on the 2010 U.S. Census Demographic Profile. Race/ethnicity based on the U.S. Census combined race/ethnicity calculated variable.

**By Sex:**

- o Males accounted for 79% of cases (n=77, 15.1 cases per 100,000)
- o Females accounted for 21% of cases (n=20, 3.7 cases per 100,000)

**By Age:**

- o The majority of cases were 20-29 years old (28%, n=27) and 30-39 years old (27%, n=26)
- o The majority of male cases were 20-29 years old (33%, n=25)
- o The majority of female cases were 40-49 years old (40%, n=8)

**By Race/Ethnicity:**

**Among males**

White, non-Hispanic males accounted for the majority of cases (44%, n=34, 8.8 cases per 100,000) followed by Hispanic males (27%, n=21, 32.6 cases per 100,000) and Black, non-Hispanic males (20%, n=15, 57.7 cases per 100,000)

**Among females**

Black, non-Hispanic Females accounted for the majority of cases (40%, n=8, 31.3 cases per 100,000) followed by Hispanic females (30%, n=6, 9.1 cases per 100,000) and White, non-Hispanic females (25%, n=5, 1.2 cases per 100,000)

**By mode of exposure to HIV:**

- o Among all cases, gay, bisexual, and other men who have sex with men (GBMSM) was the leading reported transmission category (58%, n=56) followed by heterosexual contact (27%, n=26) and then “no risk reported” (11%, n=11)
- o Among males, GBMSM was reported by 73% of cases (n=56)
- o Among females, 70% reported heterosexual contact (n=14)

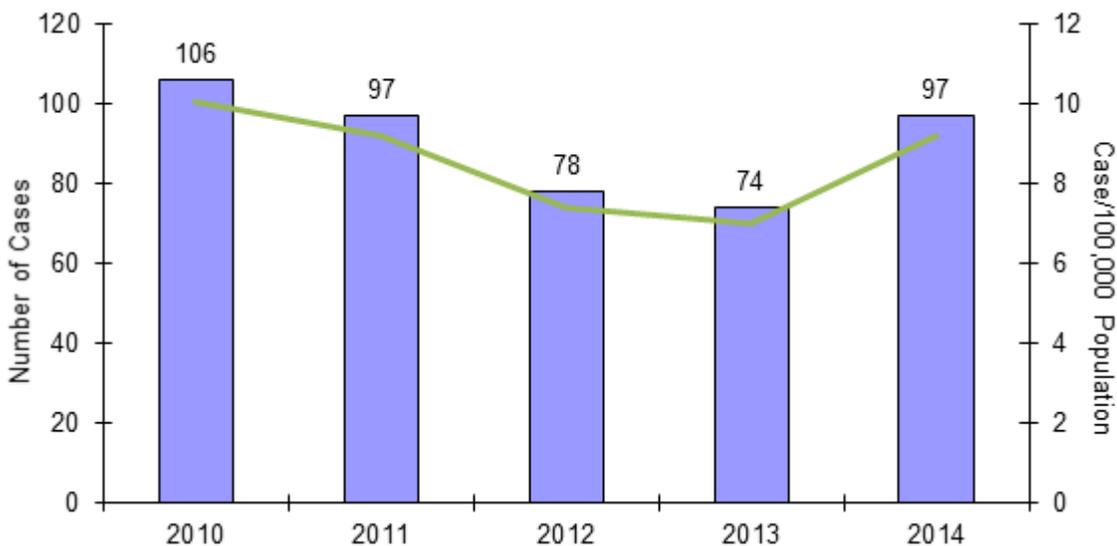
**By county of residence:**

- o The majority of cases (84%, n=81) were from Providence county

From 2013 to 2014 there was an increase in case counts among both men and women. The leading age group continued to be those aged 20-29 and 30-39. In both 2013 and 2014, most

HIV/AIDS cases were White (55%) in 2013 and (40.2%) in 2014 followed by Hispanics at 22% for 2013 and 27.8% in 2014. Over the past five years, GBMSM has continued to be the leading risk category among new cases of HIV. In 2014, the number of newly diagnosed cases of HIV increased after four years of continual reductions (**Figure 1**). The reasons for this increase are unclear at this time and may represent increased testing across the population or among high risk groups or changes in transmission dynamics. Increases were not seen across all groups, and further research is needed to determine what factors may contribute to this increase.

**Figure 1: Newly-Identified Cases of HIV, Rhode Island 2010-2014<sup>4</sup>**



**(c) Burden of HIV in the service area using HIV surveillance data and the characteristics of the population living with HIV:**

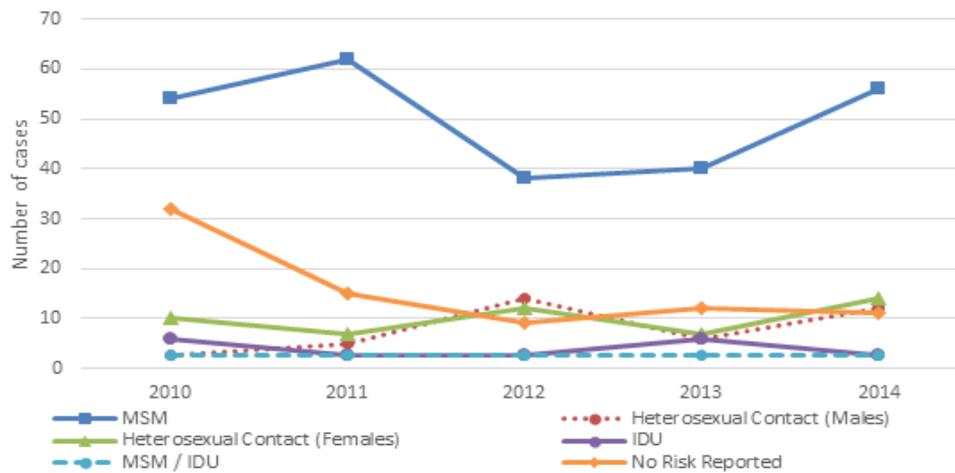
The Rhode Island HIV epidemic is concentrated in Providence County, with over 77% of cases being reported there, followed by Kent County (9%), Newport County (8%) and Washington County (6%). While the majority of cases are reported in White males, minority populations, as stated above, are experiencing disproportionate rates of disease burden. Rates of HIV are highest among African American/Black and Hispanic or Latino populations, both among men and women. All Ryan White-funded HIV/AIDS care services are located in Providence County. However, all funded agencies who perform case management (medical and non- medical) and other supportive services, having the ability to reach out beyond the center of the state. More male cases continue to be diagnosed in Rhode Island than females. Rates for both sexes were declining before the increase in 2014. The diagnosis rate for male HIV cases was 15.1/100,000 cases compared to the female HIV diagnosis rate of 3.7/100,000 cases, with an overall rate of

<sup>4</sup> 2014 RI HIV/AIDS Epidemiologic Profile with Surrogate Data  
<http://www.health.ri.gov/publications/epidemiologicalprofiles/2014HIVAIDSViralHepatitisWithSurrogateData.pdf>  
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9.2/100,000 for Rhode Island in 2014. Please see Appendix 1 for additional demographic information.

The Black/African American community is experiencing the highest impact of HIV/AIDS. They account for nearly 21% of newly-identified cases but only represent 7% of the state’s population. The diagnosis rate for Black/African Americans has declined but is still greater than all other racial/ethnic groups<sup>5</sup>. These data mirror national data according to the CDC which states in 2014, 44% (19,540) of estimated new HIV diagnoses in the United States were among African Americans, who comprise 12% of the US population. The Hispanic/Latino community is also disproportionately burdened by the HIV/AIDS epidemic. They account for nearly 25% of all HIV cases, whereas only 13% of the total population of Rhode Island is Hispanic/Latino. These disparities are present in both the male and female populations in Rhode Island<sup>6</sup>. The number of cases in the GBMSM population continues to increase and GBMSM is the predominant exposure category between 2010 and 2014 (**Figure 2**). Gay, bisexual, and other men who have sex with men, as a risk factor, has been reported more frequently than any other risk category by White non-Hispanic, Black/African American non-Hispanic and Hispanic/Latino males. Injection Drug Use (IDU), which is associated with HIV infection, has shown a marked decrease and is not a dominant risk category in Rhode Island. Likewise, GBMSM is the most common risk factor among males, whereas for females it is heterosexual exposure and in many cases “unknown” exposures in Rhode Island. This information holds true for our national counterparts as well.

**Figure 2: Newly Diagnosed Cases of HIV, By Reported Risk, Rhode Island, 2010-2014<sup>7</sup>**



<sup>5</sup> 2014 RI HIV/AIDS Epidemiologic Profile with Surrogate Data, Page 15

<http://www.health.ri.gov/publications/epidemiologicalprofiles/2014HIVAIDSViralHepatitisWithSurrogateData.pdf>

<sup>6</sup> 2014 RI HIV/AIDS Epidemiologic Profile with Surrogate Data, Pages 16-19

<http://www.health.ri.gov/publications/epidemiologicalprofiles/2014HIVAIDSViralHepatitisWithSurrogateData.pdf>

<sup>7</sup> 2014 RI HIV/AIDS Epidemiologic Profile with Surrogate Data

<http://www.health.ri.gov/publications/epidemiologicalprofiles/2014HIVAIDSViralHepatitisWithSurrogateData.pdf>

**Table 1: Demographic and Risk Factor Characteristics of Newly-Identified HIV Cases, Rhode Island, 2010 – 2014**

<i>Year</i>	<i>2010</i>	<i>2011</i>	<i>2012</i>	<i>2013</i>	<i>2014</i>
<b>Sex</b>					
<i>Male</i>	<i>84 (79%)</i>	<i>83 (86%)</i>	<i>61 (78%)</i>	<i>58 (78%)</i>	<i>77 (79.4%)</i>
<i>Female</i>	<i>22 (21%)</i>	<i>14 (14%)</i>	<i>17 (22%)</i>	<i>16 (22%)</i>	<i>20 (20.6%)</i>
<i>Total</i>	<i>106 (100%)</i>	<i>97 (100%)</i>	<i>78 (100%)</i>	<i>74 (100%)</i>	<i>97 (100%)</i>
<b>Age Category</b>					
<i>&lt;13</i>	<i>&lt;5*</i>	<i>&lt;5*</i>	<i>&lt;5*</i>	<i>&lt;5*</i>	<i>&lt;5*</i>
<i>13-19</i>	<i>8 (7%)</i>	<i>&lt;5*</i>	<i>&lt;5*</i>	<i>&lt;5*</i>	<i>&lt;5*</i>
<i>20-29</i>	<i>20 (19%)</i>	<i>24 (25%)</i>	<i>23 (30%)</i>	<i>27 (36%)</i>	<i>27 (27.6%)</i>
<i>30-39</i>	<i>27 (25%)</i>	<i>30 (31%)</i>	<i>21 (27%)</i>	<i>19 (26%)</i>	<i>26 (26.8%)</i>
<i>40-49</i>	<i>27 (25%)</i>	<i>29 (30%)</i>	<i>18 (23%)</i>	<i>13 (18%)</i>	<i>25 (25.8%)</i>
<i>50+</i>	<i>24 (23%)</i>	<i>13 (13%)</i>	<i>15 (19%)</i>	<i>13 (18%)</i>	<i>17 (17.5%)</i>
<i>Total</i>	<i>106 (100%)</i>	<i>97 (100%)</i>	<i>78 (100%)</i>	<i>74 (100%)</i>	<i>97 (100%)</i>
<b>Race/Ethnicity</b>					
<i>White, non-Hispanic</i>	<i>47 (44%)</i>	<i>54 (56%)</i>	<i>38 (49%)</i>	<i>41 (55%)</i>	<i>39 (40.2%)</i>
<i>Black/African American, non-Hispanic</i>	<i>26 (25%)</i>	<i>14 (14%)</i>	<i>17 (22%)</i>	<i>13 (18%)</i>	<i>23 (23.7%)</i>
<i>Hispanic or Latino</i>	<i>27 (26%)</i>	<i>22 (23%)</i>	<i>19 (24%)</i>	<i>16 (22%)</i>	<i>27 (27.8%)</i>
<i>Asian</i>	<i>&lt;5*</i>	<i>&lt;5*</i>	<i>&lt;5*</i>	<i>&lt;5*</i>	<i>&lt;5*</i>
<i>Native Hawaiian/Pacific Islander</i>	<i>&lt;5*</i>	<i>&lt;5*</i>	<i>&lt;5*</i>	<i>&lt;5*</i>	<i>&lt;5*</i>
<i>American Indian / AK Native</i>	<i>&lt;5*</i>	<i>&lt;5*</i>	<i>&lt;5*</i>	<i>&lt;5*</i>	<i>&lt;5*</i>
<i>Multiracial/Unknown/Other</i>	<i>&lt;5*</i>	<i>5 (5.2%)</i>	<i>&lt;5*</i>	<i>&lt;5*</i>	<i>5 (5.2%)</i>
<i>Total</i>	<i>106 (100%)</i>	<i>97 (100%)</i>	<i>78 (100%)</i>	<i>74 (100%)</i>	<i>97 (100%)</i>

**Table 1: Demographic and Risk Factor Characteristics of Newly-Identified HIV Cases, Rhode Island, 2010 – 2014 (Continued)**

<i>Year</i>	<i>2010</i>	<i>2011</i>	<i>2012</i>	<i>2013</i>	<i>2014</i>
<b><i>Risk Factor</i></b>					
<i>GBMSM</i>	54 (51%)	62 (64%)	38 (49%)	40 (54%)	56 (57.7%)
<i>Injection Drug Use</i>	6 (6%)	<5*	<5*	6 (8%)	<5*
<i>GBMSM and IDU</i>	<5*	<5*	<5*	<5*	<5*
<i>Heterosexual Contact</i>	13 (12%)	12 (12%)	26 (33%)	13 (18%)	26 (26.8%)
<i>Transfusion</i>	<5*	<5*	<5*	<5*	<5*
<i>Mother with HIV / HIV Risk</i>	<5*	<5*	<5*	<5*	<5*
<i>No Risk Reported</i>	32 (30%)	15 (15%)	9 (12%)	12 (16%)	11 (11.3%)
<i>Total</i>	106 (100%)	97 (100%)	78 (100%)	74 (100%)	97 (100%)
<b><i>County of Residence</i></b>					
<i>Homeless</i>	<5*	<5*	<5*	<5*	<5*
<i>Bristol</i>	<5*	<5*	<5*	6 (8%)	<5*
<i>Kent</i>	9 (9%)	8 (9%)	6 (8%)	5 (7%)	8 (8.2%)
<i>Newport</i>	8 (8%)	6 (7%)	<5*	<5*	<5*
<i>Providence</i>	81 (77%)	69 (76%)	67 (88%)	59 (81%)	81 (83.5%)
<i>Washington</i>	6 (6%)	<5*	<5*	<5*	<5*
<i>Total</i>	106 (100%)	97 (100%)	78 (100%)	74 (100%)	97 (100%)
<i>* Cell contains fewer than five cases</i>					

The age distribution of newly-identified HIV cases has changed in the past five years. As seen in **Table 1**, HIV cases diagnosed between 2010 and 2011 were predominantly in the 40-49 and 30-39 age groups. However, around the same time, HIV cases in the younger age group of 20-29 showed a gradual increase. In 2012 and 2013, the 20-29 age group was the predominant age group among new cases (30% and 36% respectively). In 2014, the 20-29 age group was once again the predominant age group (27.6%) but only marginally higher than cases among 30-39 year olds (26.8%) and 40-49 year olds (25.8%). The distribution of age was more prominent

among male HIV cases than females<sup>8</sup>. There has been an overall decrease in the number of individuals progressing to AIDS during the time period from 2010-2014. Additionally, there has been a more substantial decrease in the number of deaths reported among HIV/AIDS cases<sup>9</sup>.

#### **(d) Indicators of risk for HIV infection in the population**

##### **Behavioral Risk Factor Surveillance System Data:**

The Behavioral Risk Factor Surveillance System (BRFSS) is an ongoing population-based telephone interview survey, administered and supported by the CDC's National Center for Chronic Disease Prevention and Health Promotion. Surveys are developed and conducted to monitor state-level prevalence of the major behavioral risks among adults associated with premature morbidity and mortality. The information obtained from BRFSS annually is useful in describing the populations at risk for contracting HIV through their behaviors. In 2011, the data show that 40.9% of adults in Rhode Island indicated that they were never tested for HIV at some point in their life aside from routine testing when donating blood. This statistic was higher than the 2011 national average of 36% of adults never receiving an HIV test. In 2013, a question was asked about where individuals were tested, and by 2014 the percentage of individuals who had not received an HIV test decreased to 35% (36% nationally). The majority of individuals who were tested for HIV were tested at a doctor's office (51.4%) or a clinic (16.4%). Furthermore, the prevalence of any HIV risk behavior (IDU, treatment for STD, exchanging drugs/money for sex, or anal sex without a condom within the last 12 months), among Rhode Island adults was about the same as compared to the national median (3% vs. 4%).

##### **Youth Risk Behavior Survey:**

The Youth Risk Behavior Survey (YRBS) is an anonymous and voluntary survey conducted on alternate years among randomly selected high school students nationwide. It was developed by the Division of Adolescent and School Health at the CDC. More than 13,000 high school students participated in the 2013 National YRBS. Parental permission was obtained for students to participate in the survey. States and large urban school districts could modify the questionnaire for their own surveys to meet their needs. The YRBS in Rhode Island is administered by RIDOH and uses both national and state-added questions to assess risk taking among youth. **Table 2** describes sexual risk behavior among high school students in Rhode Island compared to the United States.

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<sup>8</sup> 2014 RI HIV/AIDS Epidemiologic Profile with Surrogate Data, Page 15

<http://www.health.ri.gov/publications/epidemiologicalprofiles/2014HIV/AIDS/ViralHepatitisWithSurrogateData.pdf>

<sup>9</sup> 2014 RI HIV/AIDS Epidemiologic Profile with Surrogate Data, Pages 21-22

<http://www.health.ri.gov/publications/epidemiologicalprofiles/2014HIV/AIDS/ViralHepatitisWithSurrogateData.pdf>

**Table 2: Sexual Risk Behavior among High School Students, Youth Risk Behavior Survey, 2013**

Question	Rhode Island 2013 (Confidence Interval)	United States 2013 (CI)	p-value
Ever had sexual intercourse	37.4 (31.8–43.4)	46.8 (43.7–49.8)	<.01
Had sexual intercourse before age 13 years (for the first time)	4.1 (2.6–6.5)	5.6 (4.9–6.5)	0.13
Had sexual intercourse with four or more persons (during their life)	7.9 (5.7–10.9)	15.0 (13.6–16.6)	<.01
Were currently sexually active (sexual intercourse with at least one person during the 3 months before the survey)	27.0 (22.1–32.5)	34.0 (31.6–36.5)	0.01
Did not use a condom (during last sexual intercourse among students who were currently sexually active)	32.4 (26.7–38.7)	40.9 (38.1–43.7)	0.01

**HIV surveillance data, including HIV testing program data:**

CDC estimates that more than 1.2 million people in the United States are living with HIV and that 12.8% (about one in eight) are not aware they are infected. Individuals who are diagnosed with AIDS at the same time as being diagnosed with HIV are considered late diagnoses. These cases may be representative of the population that is “infected but unaware” of their status. Of 452 new diagnoses from 2010-2014, 127 (28%) were diagnosed late in the disease and therefore were at increased risk for disease progression, death, and transmission of HIV to others. In 2012, an estimated 17,858 people with HIV died in the United States. The lifetime cost of medical care for a person with an early HIV diagnosis is about \$402,000. Early detection can slow disease progression, prevent transmission to others (via viral suppression), reduce lifetime medical cost and proves to be a useful metric for estimating the population of HIV-infected individuals who are unaware of their status. There may be several possibilities as to why an individual may not know their HIV status. Some people may not seek regular medical care due to homelessness, stigma, insurance or transportation. Others may not believe they are at risk, and still others may deny they have HIV despite preliminary test results.

The Rhode Island Department of Health administers a community-based rapid HIV testing program which provides counseling, testing, and referral (CTR) services. This program has the potential to identify individuals who may not be getting tested by the traditional health care system and may be valuable in reducing the number of late-stage diagnoses. Through 2015, as many as seven agencies were funded to provide testing in the community. In 2015, there were 4,725 tests that were performed at various sites throughout the state. Approximately 43% of the tests were performed in non-clinical settings, and the other 57% were performed in clinical settings. The majority of individuals who are being tested in non-clinical settings are non-

Hispanic whites, and males are more likely to be tested than females. Furthermore, those who tested reported their risk as being a man who had sex with other men. Gay, bisexual, and other men who have sex with men (GBMSM), currently have the highest rates of newly diagnosed HIV cases, and most of the tests being conducted are among GBMSM. Currently, there are three funded agencies that conduct activities in over fifty unique settings state-wide including aids service organizations, bars and clubs frequented by GBMSM, substance use treatment centers, colleges and universities, and recently implemented in high schools.

#### **Ryan White HIV/AIDS Program Services Report:**

The Rhode Island Executive Office of Health and Human Services submits a Ryan White Services Report on a yearly basis to the HIV/AIDS Bureau which is a data reporting system to report information on their programs and clients they serve. For client -level data reported on the Ryan White Services Report (RSR), the RI-EOHHS Ryan White Program had one federally funded contract agency contract; (Miriam Hospital) which reported client data on both Part B & C. This provider reported a total of 1618 clients. The remainder of the funded contracts with the RI-EOHHS Ryan White Program were funded with rebate funding, therefore, client-level data was not required for reporting purposes.

#### **Ryan White HIV/AIDS Program ADAP Data Report (ADR):**

The Rhode Island Executive Office of Health and Human Services Ryan White Program utilizes the ADR which is a reporting requirement for ADAPs to provide client-level data on individuals served, services being delivered, and costs associated with these services. For 2014, the Ryan White Program expended \$9,763,037 for ADAP expenditures which include pharmaceuticals, dispensing costs and insurance coverage (including co-pays, deductibles and premiums). In 2015, total expenditures were \$6,286,967 and 2016 brought a further decrease in total expenditures however; the expenditure for insurance coverage rose from \$631,493 in 2014 to \$1,720,949 in 2016 due to the RI-EOHHS Premium Drug Assistance Program which now pays for health insurance premiums for Ryan White eligible clients. This insurance coverage expenditure is expected to rise due to the increase in the program's Federal Poverty Level (FPL) limit to 500%.

#### **Other relevant demographic data:**

In 2014, reports of chlamydia, gonorrhea, early/infectious syphilis, and late syphilis increased compared to 2013<sup>10</sup>. There were no cases of congenital syphilis reported in 2014. In 2010, Rhode Island, like many other states, experienced a significant increase in the reports of infectious syphilis (primary, secondary, and early-latent stages), with reports increasing from 34 cases in 2009 to 61 cases in 2010. Most recently, Rhode Island has experienced another significant increase in infectious syphilis cases. Cases nearly doubled from 67 cases in 2013 to 120 cases in 2014. Cases reported in 2014 were distributed throughout the state with most

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<sup>10</sup> 2014 RI HIV/AIDS Epidemiologic Profile with Surrogate Data, Page 15

<http://www.health.ri.gov/publications/epidemiologicalprofiles/2014HIVAIDSViralHepatitisWithSurrogateData.pdf>

cases among residents of Providence County (80%) and Kent County (10%). This is similar to 2013 when 81% of infectious cases were among Providence County residents. During 2014, the STD Program staff attempted to interview each case. While non-Hispanic White males continue to account for the majority (58%) of infectious syphilis cases in Rhode Island, case rates remain highest for non-Hispanic African American/Black Males with 39 cases per 100,000 reported in 2014. Out of 120 infectious cases reported in 2014, 105 (87.5%) were male and 80 (76%) of the males identified as GBMSM. Of the 80 GBMSM cases, 26 (32.5%) were HIV-positive. Infectious syphilis cases in 2014 had an average age of 28.6 years for females and 34.6 years for males, with individuals older than 30 years accounting for 58% of reported cases. This age distribution differs from that of gonorrhea and chlamydia as only 21% of the reported infectious syphilis cases are 15-24 years old.

**Chlamydia-** Reports of chlamydia in Rhode Island remain high. In 2014, there were 4,349 cases of chlamydia, remaining relatively stable compared to the previous two years (4312 cases in 2012 and 4313 cases in 2013). Reported cases of chlamydia remain concentrated in Providence County, which represents 77% of cases reported statewide in 2014, and remains stable from the reported 79% in 2013. The city of Providence accounted for 37% of chlamydia cases reported throughout the state, which is comparable to 38% of cases observed in the city in 2013. There were no changes in the distribution of chlamydia cases by sex when compared to 2013. Males accounted for 30% of reported chlamydia cases (1,267 cases in 2013 and 1,312 cases in 2014), while females accounted for the majority (70%) of reported chlamydia cases (3,045 cases in 2013 and 3,037 cases in 2014). Individuals age 15-24 continue to represent nearly two-thirds of chlamydia cases in Rhode Island, and 93% of all cases are younger than 35 years of age. This trend held steady from 2013 to 2014. The racial/ethnic distribution of chlamydia cases in 2014 remained consistent with data seen during the previous five years. Non-Hispanic Whites accounted for 30% of reported cases, followed by Hispanics (25%) and non-Hispanics Blacks (14%). In 2014, 25% of the cases were missing race and ethnicity data, which was a decrease from the 29% of cases in 2013 that were missing this data. Race/ethnicity percentages reported in this section are estimated to adjust for unknown and missing data, assuming there is no bias in the reporting of cases for which race/ethnicity are known. From 2008 to 2014, surveillance data has shown that, on average, 6% of males diagnosed with chlamydia each year are GBMSM. When reviewing these percentages, it is important to note that, since the RIDOH STD Program does not routinely perform follow-up for chlamydia cases, data on sexual behavior of chlamydia cases is extremely limited and ascertained only from STD Case Report Forms (CRFs) prepared by the provider rather than through interviews with STD Program staff as is standard for gonorrhea and infectious syphilis cases.

**Gonorrhea-** Reports of gonorrhea in Rhode Island increased in 2014 by 30% from 454 cases in 2013 to 590 cases in 2014. In 2014, when looking at race/ethnicity, the highest percent of cases was reported in non-Hispanic Whites (35%), followed by Hispanics (22%) and non-Hispanic black (21%). Since 2009, case rates have consistently been higher in non-Hispanic blacks than other race/ethnic groups (314.3 cases per 100,000 in 2014). Geographically, Providence County continues to have the largest proportion of reported cases. From 2010-

2013, an average of 88% of reported cases lived in Providence County. Cases reported in 2014 have held to this trend with 84% of cases reported among Providence County residents. By city, trends are also stable, with 44% of cases residing in the City of Providence. As previously mentioned, reports of gonorrhea in Rhode Island began to increase in 2011, jumping 24% from the 291 cases reported in 2010 to 360 reported in 2011. Numbers increased another 40% from 2011 to 2012, with reports totaling 507 cases, and decreased in 2013 to 454 cases. Then, in 2014, a 30% increase was seen. This increase was not equal among both males and females, with a 41% increase in male cases and a 14% increase in female cases. Overall, males accounted for 63% of cases and 37% were females. Age distribution among males in 2014 was similar to previous years, with 47% of cases among males 20-29 years old. Among females, however, age distribution has changed slightly. In 2014, female ages 15-24 accounted for 50% of female gonorrhea cases, which is a decrease from the 65% seen among females of this age in 2013. Cases in females 30-34 year olds doubled from 2013 to 2014, accounting for 15% of cases in 2014 (versus 8% of females cases in 2013). From 2006 to 2013, surveillance data has shown that on average, 30% of males diagnosed with gonorrhea are GBMSM. In 2014, the percentage increased slightly, with 35% of male gonorrhea cases identifying as GBMSM. It is important to note that sexual behavior information is not available on 53 (14%) of male cases. The STD Program has investigated the possibility that the rising number of gonorrhea cases in Rhode Island may be associated with the closing of the state-funded Whitmarsh STD clinic in 2011. Prior to its closure, the STD Program was able to bring all stakeholders together to discuss the issue and come up with solutions to fill the service gaps that were anticipated. As a result, the Miriam Hospital Immunology Center agreed to host a free and confidential STD clinic one afternoon a week. Due to its overwhelming success, the clinic is now open three afternoons a week. Beginning in 2014, a RIDOH Disease Intervention Specialist (DIS) has been present onsite at the STD clinic to conduct partner services for identified STD cases. In addition, Planned Parenthood of Southern New England also agreed to take referrals from the STD Program for individuals or partners of cases seeking STD screening and treatment.

**STD/HIV Co-Infection-** In order to estimate STD/HIV co-infection in Rhode Island, gonorrhea and infectious syphilis cases reported to the STD Program are searched in E-hars, in real-time to determine HIV status. On average, 4% of gonorrhea cases and 33% of infectious syphilis cases reported each year are confirmed co-infections.

**Qualitative Data-** Rhode Island conducted a Consumer Survey in 2015 and two Focus Group sessions in 2016 lead by John Snow Inc. (JSI) in 2016. Additionally in 2013 JSI conducted a Provider Capability and Capacity Survey which was developed to identify which services directed to PLWH/A are accessible, available and appropriate. Data for the Consumer Survey according to respondents show the most common disease, health condition, or life situation in addition to HIV/AIDS that respondents had been dealing with over the past twelve months was depression or other mental health issues (44.5%) followed by 'none' (22%), another serious health problem (21%), not enough food or other necessities (21%), hepatitis C(21%), substance use (15%), and homelessness (10%). The top eight needed services are Dental/Oral health care(75%), primary medical care (67%) food bank and/or home-delivered meals (59%), mental

health services (54%), ADAP (54%), housing services (53%), home and community-based services (53%), and medical-case management (50%). Analysis for the Provider Capability & Capacity Survey showed the “top ten” core medical services provided to PLWH/A as: 1.) Mental health services, 2.) Substance Use (Treatment-Outpatient), 3.) Medical Case Management, 4.) Medications and/or co-payments and 5.) Outpatient medical care. The “top ten” Support Services provided to PLWH/A were 1.) Education about HIV (health education/risk reduction), 2.) Referral for Healthcare or supportive services, 3.) Non-medical case management, 4.) Psychological services, 5.) Food, 6.) Emergency Financial assistance, 7.) Outreach to bring people with HIV into care, 8.) Housing, 9.) Medical transportation and 10.) Treatment adherence counseling. Survey respondents also identified prevention, counseling and testing services provided by their agencies. These top areas included; 1.) HIV counseling, 2.) Prevention services for people who know they are negative or do not know their status, 3.) Prevention services for people who know they are positive, 4.) HIV testing-rapid test, 5.) Testing for other STDs, 6.) HIV testing- lab test, 7.) Partner identification and counseling services, and 8.) Other (misc.). Overall, the Focus Group revealed that participants communicated a general sense of satisfaction and appreciation for the quantity, quality and diversity of HIV services offered in Rhode Island.

### **Vital Statistics data**

Information on vital status is collected in partnership with the RIDOH Office of Vital Statistics, the National Death Index and the Social Security Death Master File. Annually, each of these resources are used to identify any existing HIV-infected individuals that may have died. Matching with death records is critical to accurately estimate the number of persons living with HIV/AIDS in Rhode Island. Due to matching with national databases, death ascertainment activities are typically completed one year after local surveillance data are analyzed, to account for reporting delays. From 2009-2013, 190 deaths occurred among persons with HIV/AIDS and since 1983, a total of 1,699 deaths have occurred among Rhode Island residents diagnosed with HIV/AIDS. Since the availability of highly active antiretroviral therapy (HAART), the number of HIV/AIDS related deaths has steadily declined in Rhode Island. Due to advances in clinical therapy and antiretroviral medications, the population living with HIV/AIDS has grown in the past several years<sup>11</sup>. **Table 3** shows that there was a higher number of deaths from 2009-2011, as compared to 2012 and 2013. The demographic profile of deaths among HIV/AIDS cases is similar to that of newly identified cases of HIV/AIDS with regard to sex, race, ethnicity, and exposure category.

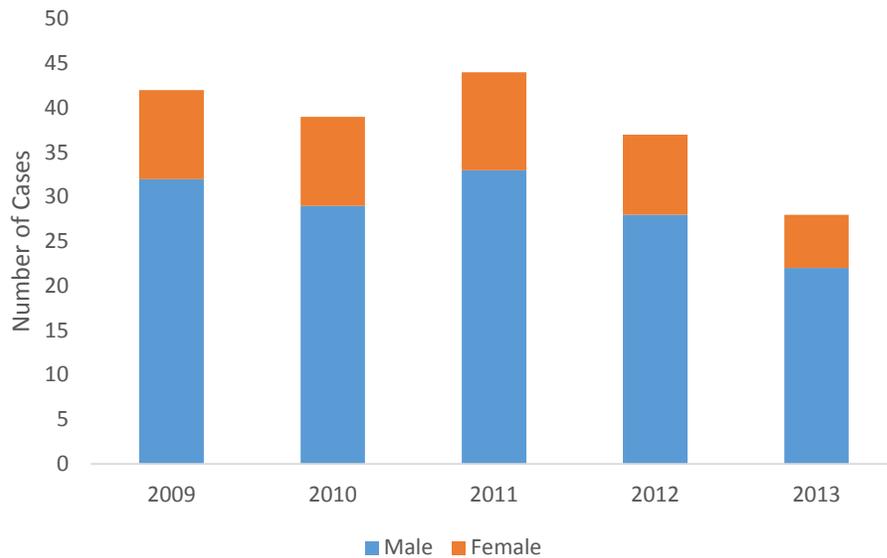
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<sup>11</sup> 2014 RI HIV/AIDS Epidemiologic Profile with Surrogate Data, Page 20  
<http://www.health.ri.gov/publications/epidemiologicalprofiles/2014HIVAIIDSViralHepatitisWithSurrogateData.pdf>  
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**Table 3: HIV/AIDS Deaths by Demographic Characteristics, Rhode Island, 2009-2013**

Demographic Characteristics	Count	Percent
<b>Gender</b>		
Male	144	75.8%
Female	46	24.2%
Total	190	100.0%
<b>Age Group</b>		
20-29	3	1.6%
30-39	15	7.9%
40-49	49	25.8%
50-59	91	47.9%
60-69	27	14.2%
70+	5	2.6%
<b>Race/Ethnicity</b>		
American Indian/ Alaska Native	1	0.7%
Asian	0	0.0%
Native Hawaiian / Pacific Islander	0	0.0%
Black/African American, non-Hispanic	57	30.1%
Hispanic or Latino	35	18.2%
White, non-Hispanic	92	49.0%
Multiracial/Other/Unknown	5	2.6%
<b>Country of Birth</b>		
US-Born	148	77.9%
Non-US Born	37	19.5%
Unknown	5	2.6%
<i>Note: US-Born includes the 50 U.S. States and the District of Columbia. Non-US Born includes foreign countries and U.S. territories</i>		

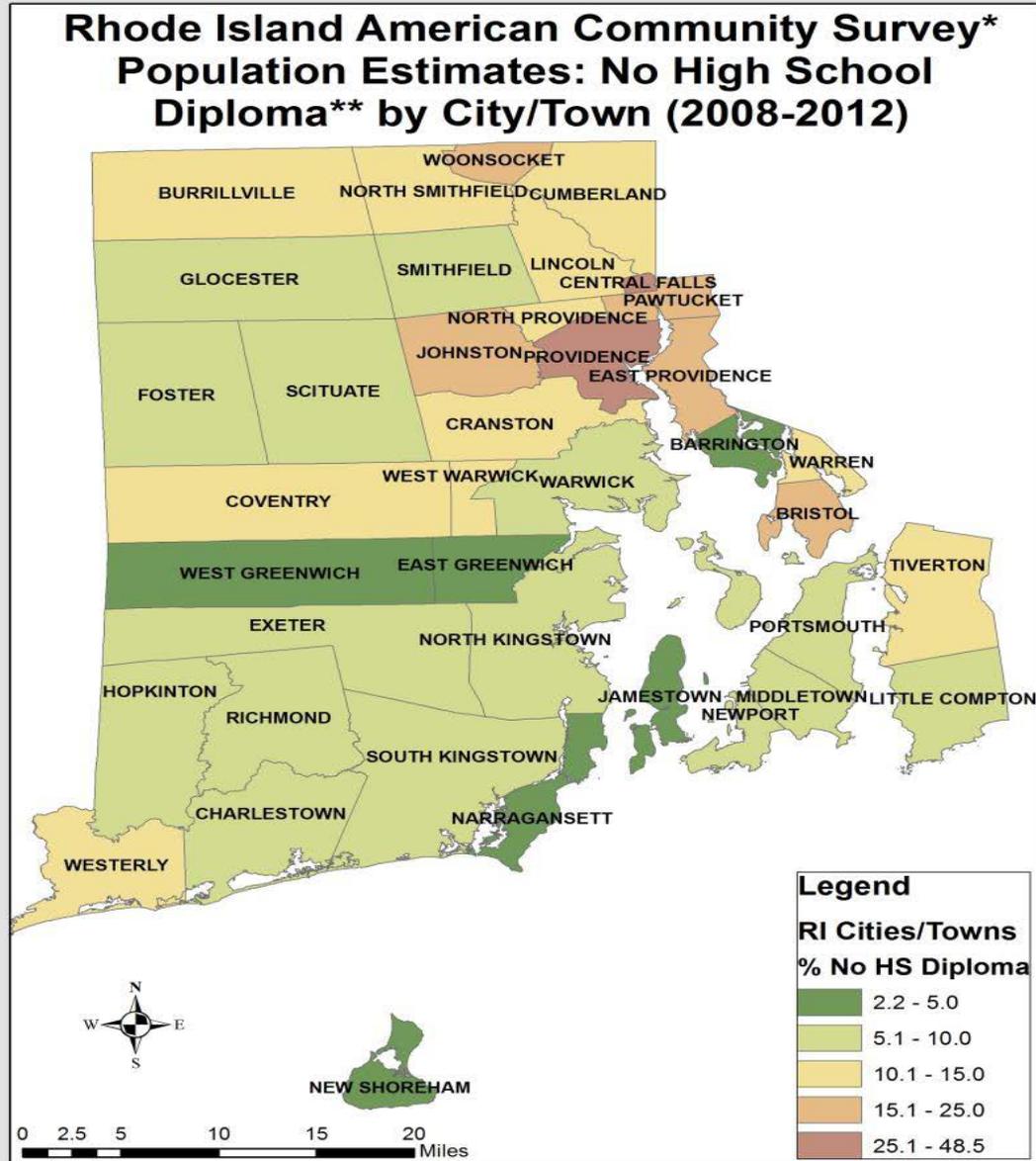
**Figure 3: HIV/AIDS Deaths by Sex, Rhode Island, 2009-2013**



**Other Relevant Program Data:** Thundermist (Ryan White Part C) runs one of Rhode Island’s two Ryan White Title III Early Intervention Services programs for comprehensive care to HIV positive patients, including provision of disease specialty care through its affiliation with Brown University, comprehensive primary care, clinical trials, mental health counseling, dental services and case management to over 75 individuals within a twelve month period. The clinics offer medical, dental, behavioral health, quick care, smoking cessation and after-hours emergency care in Rhode Island and also has seven locations throughout the state. Thundermist had a total of 127 HIV clients as of June 2014. Furthermore, Thundermist has the technological capacity to collect and report all clinical financial data required by HRSA and Part C CQI plan. The Health clinic has implemented a new practice management information system (PM) and an electronic health record (EHR) in 2008. The new EHR enables aggregation of health outcome data, provide decision support at the point of care, and ensure the integration of practices standards and protocols. Additionally, CAREWare is used to collect all patient demographic information including gender, age, race and ethnicity, exposure category, housing income, housing/living arrangements and insurance coverage. Miriam Hospital-Immunology Clinic- Offers services (including treatment adherence counseling and monitoring) to a total of 1575 PLWH/A, of which approximately one hundred and twenty (120) of those clients receive Part B services in a twelve month period within the jurisdiction. This number is expected to increase by fifty (50) clients for Part B services in each consecutive year by 2021. Ages range from 18 and up for both males and females. The Miriam Hospital, Project Bridge Program provides approximately forty (40) clients with transitional case management services to individuals recently released from the correctional facility. This program also utilizes Part B Minority AIDS Initiative (MAI) funding to ensure that eligible PLWH/A gain or maintain access to HIV-related care and treatment for which they are eligible.

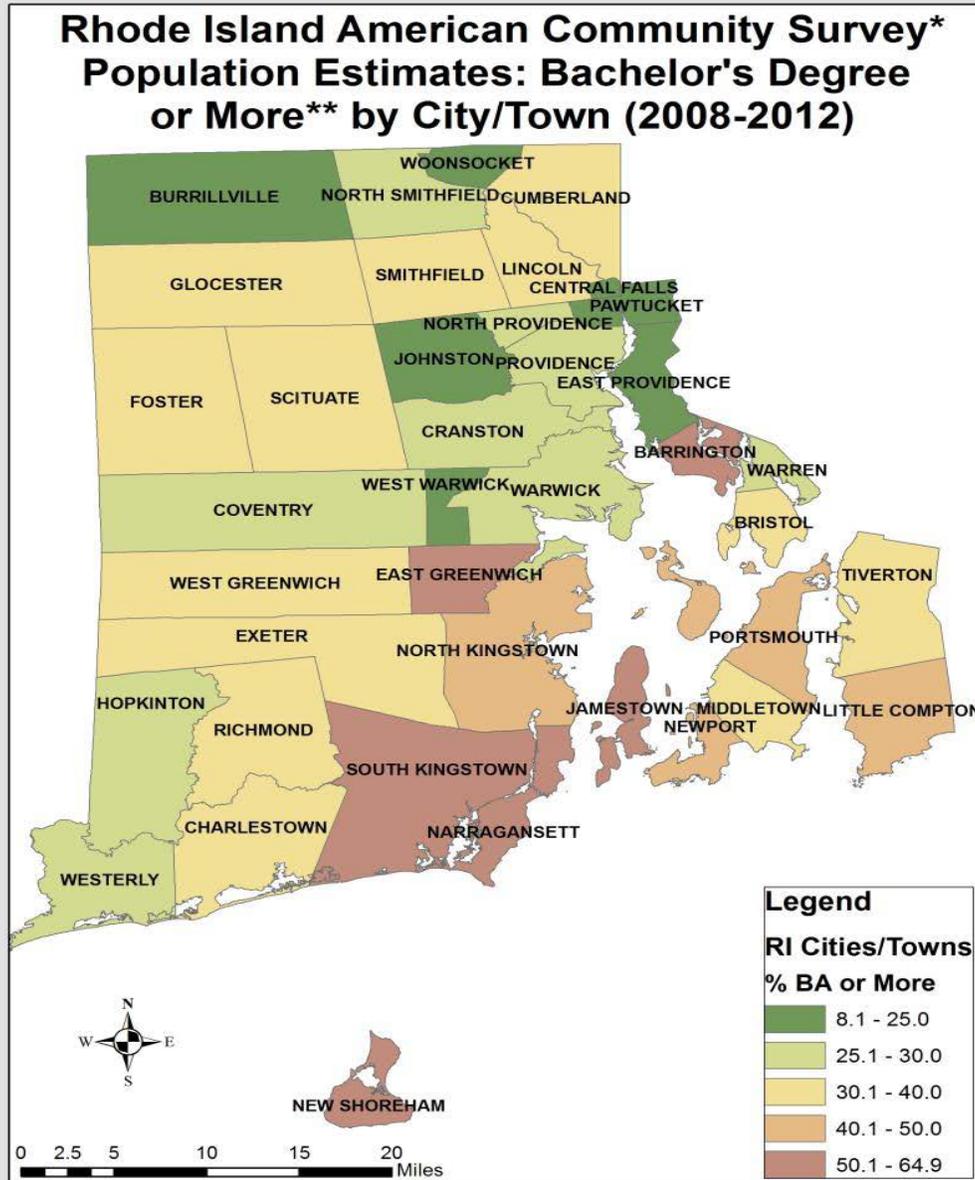
**Socioeconomic data:** Socio-demographic and economic data for Rhode Island’s population were obtained from the American Community Survey (ACS). The ACS is a nationwide survey designed to provide communities with a fresh look at how they are changing and represents a crucial component in the United States Census Bureau’s decennial census program. The ACS collects and produces population and housing information every year instead of every ten years, providing up-to-date information throughout the decade about the U.S. population at the local community level. In 2010, the Census Bureau released the first 5-year estimates for small areas (i.e. municipalities with fewer than 20,000 residents). The Rhode Island data presented in this report include 5-year estimates collected from 2008 through 2012 and are presented by cities/towns within the state. (Note: 5-year ACS data is not a mathematical average, but instead represents “pooled estimates” for a specific 5-year period). Estimates from the ACS report show eighty-four percent of people 25 years of age and over had at least graduated from high school and 31% had a bachelor’s degree or higher. However, educational attainment is not equally distributed across cities and towns in Rhode Island. *See Figures 4 and 5* for a detailed breakdown of educational attainment (e.g. no high school diploma, bachelor’s degree or more) by city/town. Disproportionately, cities and towns in Providence County, including Providence, Pawtucket, Central Falls, East Providence, Johnston, and Woonsocket have higher percentages of residents who have not completed high school.

Figure 4: Rhode Island Community Survey Population Estimates: No High School Diploma by City/Town<sup>12</sup>



\* The American Community Survey (ACS) 5-year summary data files from 2008 - 2012 are used to provide population estimates.  
 \*\* Education is determined for population 25 years and older.

Figure 5: Rhode Island American Community Survey Population Estimates: Bachelor's Degree or More by City/Town<sup>13</sup>



\* The American Community Survey (ACS) 5-year summary data files from 2008 - 2012 are used to provide population estimates.

\*\* Education is determined for population 25 years and older.

**Federal poverty in Rhode Island:** The Current Populations Survey (CPS) is a joint effort between the Bureau of Labor Statistics and the Census Bureau. It is the primary source of labor force statistics for the population of the United States and includes detailed information of numerous economic statistics. **See Appendix 3<sup>14</sup>** for the percentage of Rhode Island resident's ratio of income to poverty of 1.38%.

**Rhode Island Median Household Income:** According to the Rhode Island Census Bureau, Rhode Island's median household income from 2009-2013 was \$56,361. This is a decline from 2007 at \$59,321. According to 2012 ACS data, examining the median household income by race and ethnicity reveals stark disparities. Whites had a median household income (\$58,234) almost twice as high as for Latinos (\$30,329) and seventy percent higher than that of African American (\$34,591). Rhode Island's median household income was \$54,554 without children.

**Employment Status:** Data on employment were obtained from the 2011 American Community Survey. Of people age sixteen (16) or older, 66% were in the civilian labor force and 10% were unemployed<sup>15</sup>.

**Adult Insurance Coverage:** According to the CPS, in Rhode Island there were 125,000 people (14.3%) under age 65 without health insurance during 2011/2012<sup>16</sup>. Nationally, roughly 47.6 million people under age 65 (18.4%) had no health insurance during the same period. These data show that 63% of Rhode Islander's accessed health coverage through their employer during 2011/2012 and close to one in five residents (18%) was insured through the Medicaid Program. As of January 2014, under the Patient Protection and Affordable Care Act (ACA), some states, like Rhode Island, have opted to expand Medicaid. HealthSource Rhode Island (HSRI) is Rhode Island's state based Marketplace. Medicaid eligibility is based solely on income in expansion states. US citizens and legal immigrants with incomes of 138% of the FPL or less qualify for Medicaid benefits. This differs from previous eligibility criteria which were based on population categories. According to HSRI (Rhode Island's State -Based Marketplace), between November 15, 2014 and February 15, 2015, Rhode Islanders had their second opportunity to purchase health insurance. In 2015 HSRI saw a steady increase in enrollment. The number of individuals purchasing health insurance through HSRI grew by 20% and more than 9,000 new customer joined the marketplace. In all, the state enrolled 30,001 people. Additionally, 60,547 Medicaid eligibility determinations were made by HSRI's integrated eligibility and enrollment system during open enrollment. As of January 23, 2016, 33,506 individuals are enrolled in 2016 coverage through HSRI. This includes paid and unpaid (first month premium).

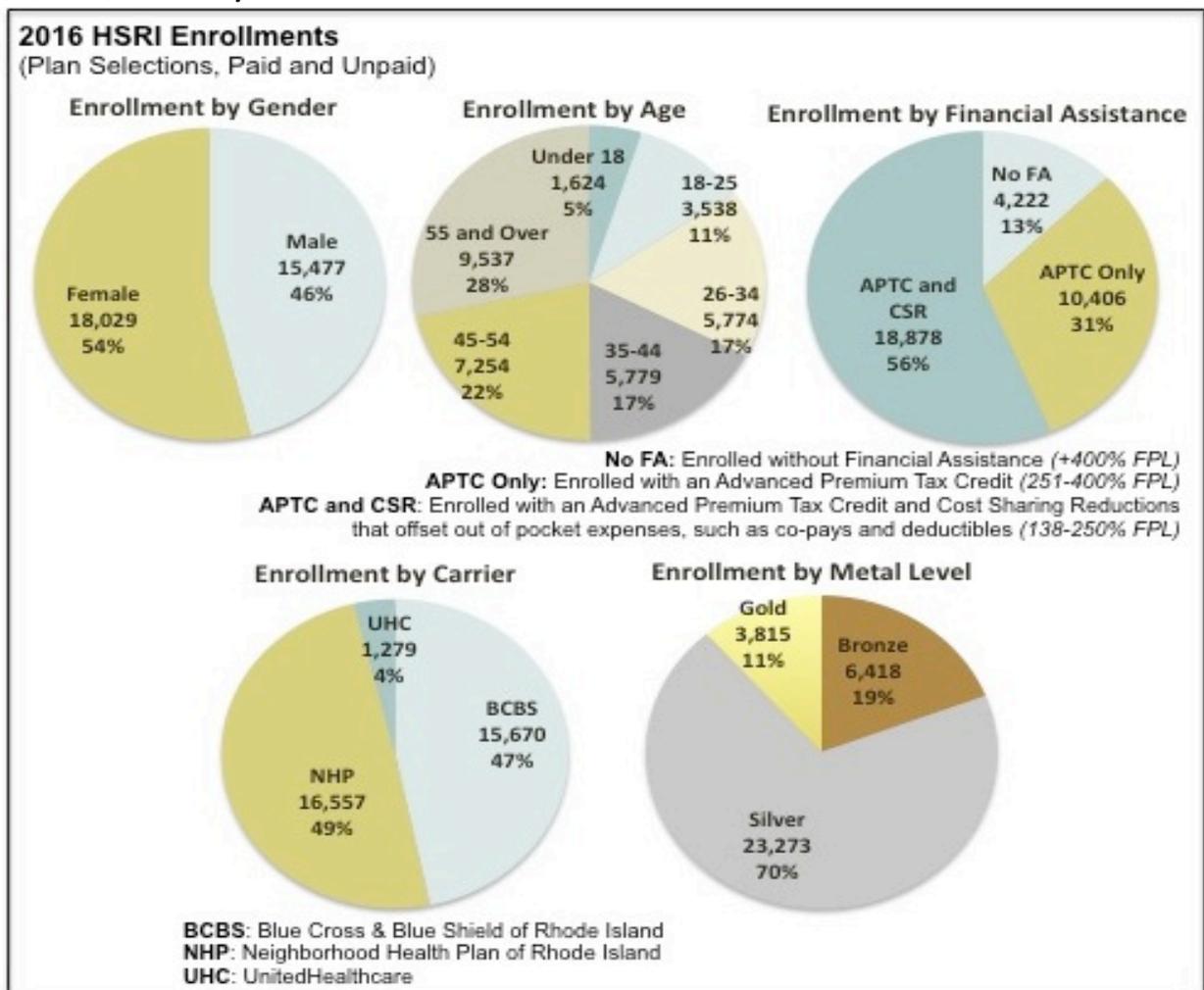
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<sup>14</sup> Appendix 3: JSI RI 2013 RW Survey Results: Provider Capacity in the Provision of Services; Page 20

<sup>15</sup> Appendix 3: JSI RI 2013 RW Survey Results: Provider Capacity in the Provision of Services; Page 17

<sup>16</sup> Appendix 3: JSI RI 2013 RW Survey Results: Provider Capacity in the Provision of Services; Page 19

**Figure 6: Enrollment Data for Health Source Rhode Island, 2016. Please note this is not exclusive to PLWH/A<sup>17</sup>**



**AIDS Drug Assistance Program:** ADAP is administered by RI-EOHHS’s Ryan White Part B HIV Provision of Care Program. This program provides access to necessary medications for PLWH/A in Rhode Island who meet the eligibility requirements. Without ADAP support, many PLWH/A would likely have limited or no access to medications and fall through the cracks in the state’s larger HIV/AIDS care system. Since 2006, ADAP has had a contract with Hewlett-Packard Enterprise Services (HP) to provide pharmacy benefits management functions for ADAP drug claims. In Rhode Island, HP is well positioned to provide this service because they have been providing fiscal agent services to the state’s Medicaid Management Information System (MMIS) for the past 16 years.

Financial and medical information needed to determine an individual’s eligibility for ADAP is submitted to and approved by the ADAP Eligibility Specialist. To be eligible for ADAP, an

<sup>17</sup> Healthsource RI 2016 <http://healthsourceri.com/>

individual must be a Rhode Island resident with a medically verified positive HIV diagnosis and have an income of no more than 500% of the FPL. In 2014, Rhode Island established a new insurance program under the HIV/AIDS Bureau (HAB) Policy Notice 07-05 and HAB Policy Clarification Notice 13-05 allowing States and Territories to use ADAP funds to purchase health insurance. In accordance with HRSA requirements, ADAP is required to be the payer of last resort, so if the applicant has no health insurance, ADAP covers the cost of all medications. If the applicant has health insurance, the health insurance is billed for the medications, and ADAP covers any remaining co-pays or deductibles. At this time, the State of Rhode Island is not reporting a waiting list. The last time the state implemented a waiting list was October 15, 2010. During this time, Rhode Island's ADAP received emergency relief funds to eliminate the waiting list and this was effectively done on December 1, 2010.

Although Rhode Island is not experiencing a waiting list, it is experiencing an elimination of State funding for both ADAP and other HIV/AIDS services over the last several years. These cuts have had a significant impact on the current program. As a result, ADAP relies heavily on a combination of federal Ryan White Part B funds and pharmaceutical rebate funds to support medications.

There may be limitations for antiretroviral (ARV) coverage, as some insurance plans do not cover all available ARV medications, specifically for individual marketplace health plans (those not affiliated with an employer, and purchased through the healthcare exchange) in RI. For this reason RI-EOHHS strives to provide outreach to PLWH/A and inform them that HRSA/HAB can provide assistance beyond tax subsidies for persons that qualify. With that said, RI ADAP still believes that by implementing the new ADAP-funded health insurance program, "The Rhode Island Ryan White Insurance Assistance Program," PLWH/A will be able to obtain a host of medications they were unable to receive previously. It is noteworthy to mention that the health insurance purchase by RI ADAP is cost effective. This cost saving strategy will improve the internal systems and procedures for back-billing Medicaid, expand the insurance assistance, help the program continue to collect the 340B rebates for insurance drug co-pays, and reduce ADAP administrative costs.

With a new open enrollment period just around the corner, ADAP has no way of determining how many other HIV positive Rhode Island residents with income levels between 139% - 500% will emerge. Since January 1, 2016 there have been 108 new clients enrolled in the program, 93 of which are still active to date. Of those, 7 are now enrolled in Medicaid, and 10 are undocumented, and therefore do not qualify for either Medicaid or a private insurance plan via the marketplace. It is also estimated that an additional 7-10 clients have not been legal, permanent residents of the U.S. for more than five years, therefore, they do not qualify for Medicaid either. The cost for a "full freight" ADAP client (the term used internally to refer to ADAP clients that are uninsured and for which the full cost of drugs are paid) is approximately \$18,994 per year per client. The total expenditures for assuming the full cost of drugs for these clients is \$2,450,231 annually.

In 2014, RI ADAP had an average enrollment of 820 PLWH/A per month. Currently, there are a total of 644 people actively enrolled in the program. Since January 1, 2016, RI ADAP has transitioned and assisted 108 clients to a Qualified Health Plan (QHP). Of the 93 clients who are still active on a QHP, all remain on ADAP to help with the wrap-around coverage as it relates to the drug co-payments and premiums.

**Transition from ADAP to Medicaid Expansion:** ADAP only provides assistance for antiretroviral and other limited drugs that are listed on the ADAP formulary. As of July 1, 2016, the Ryan White Program raised its FPL limit from 400% to 500% respectively. It is expected that due to this increase, the program will see an additional 120 individuals who will now be eligible for ADAP and other Ryan White services. The Rhode Island Executive Office of Health and Human Services and the AIDS Clinical Task Force collaborate to determine which drugs are listed on the formulary, considering issues such as patient needs and funding availability.

The ACA has extended health insurance coverage to uninsured Americans by expanding both private and public insurance. Rhode Island is a Medicaid Expansion State, therefore childless adults that have an annual income less than or equal to 138% FPL are now eligible for Medicaid. However, many have been reluctant to enroll due to a number of factors, including the stigma that surrounds HIV/AIDS, language/cultural barriers, education about the benefits of comprehensive health coverage, and homelessness. Subsequently, Rhode Island is following national suggestions and has implemented policies and procedures to vigorously pursue additional health insurance options to ensure that Ryan White/ADAP will be the payer of last resort.

In addition, RI ADAP has transitioned a total of 270 ADAP clients onto Medicaid, and most of these clients were transitioned off of ADAP within 1 month. RI ADAP made a policy decision to keep clients on ADAP temporarily to prevent any barriers to care as they transitioned onto Medicaid. However, this number is expected to rise significantly as more individuals may not qualify for cost-sharing reductions coupled with the lack of affordability of high-tiered drug co-payments. The average cost to ADAP each month per client is \$167.40. We anticipate to spend \$173,658.24 for FY2016 if we continue to pay for the 93 current active premium assistance clients without any anticipated new enrollees.

**Rhode Island Premium Assistance Program:** The Rhode Island premium assistance program is a fairly new benefit program which assists those individuals living with HIV/AIDS who meet Rhode Island Ryan White eligibility requirements, to acquire and/or maintain health insurance via the health insurance marketplace (HSRI). When a client enrolls in the premium assistance program, they are simultaneously enrolled in ADAP to cover the costs of their drug co-pays (if they were not previously enrolled). In RI, the health insurance marketplace offers 12 plans for individuals and their families from two health insurance providers: Blue Cross & Blue Shield of Rhode Island (BCBS) and Neighborhood Health Plan of Rhode Island (NHPRI). The Rhode Island Ryan White Insurance Assistance Program wanted to ensure that the health insurance plans to be

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purchased for PLWH/A included a formulary that is as comprehensive as our current ADAP formulary. The goal was to ARVs universally covered by some means, as well as to assist with paying insurance premiums beyond tax subsidies for PLWH/A. Whereas, this program was tailored to persons for an individual health plan, the RI-EOHHS Ryan White Program will be expanding these options by offering Ryan White eligible clients a “Family Plan” option with the next upcoming open enrollment in November 2016. Benefits include premium assistance as well as drug co-pays and deductibles for ADAP Formulary drugs. **Table 4** provides information regarding individuals enrolled in ADAP who have either transitioned to Medicaid or are assisted with their health insurance premiums by the RI-EOHHS Ryan White HIV Provision of Care Program.

Of the 108 clients the program has assisted with insurance premiums, approximately 30% are currently enrolled in a family plan. Rhode Island would like to use their newly awarded HRSA grant funding (XO8) to expand its insurance assistance to include family coverages. Currently the family coverage cost for individuals on the premium assistance program is \$3,607.52 per month, which amounts to \$43,290.24 for FY 2016 that are not covered at this time. The costs would go up drastically if family plan coverage were offered to all Ryan White eligible clients. This could amount to potentially costing the program an additional \$86,580.48 for FY 2016 if an additional 50% of QHP clients were to elect a family plan.

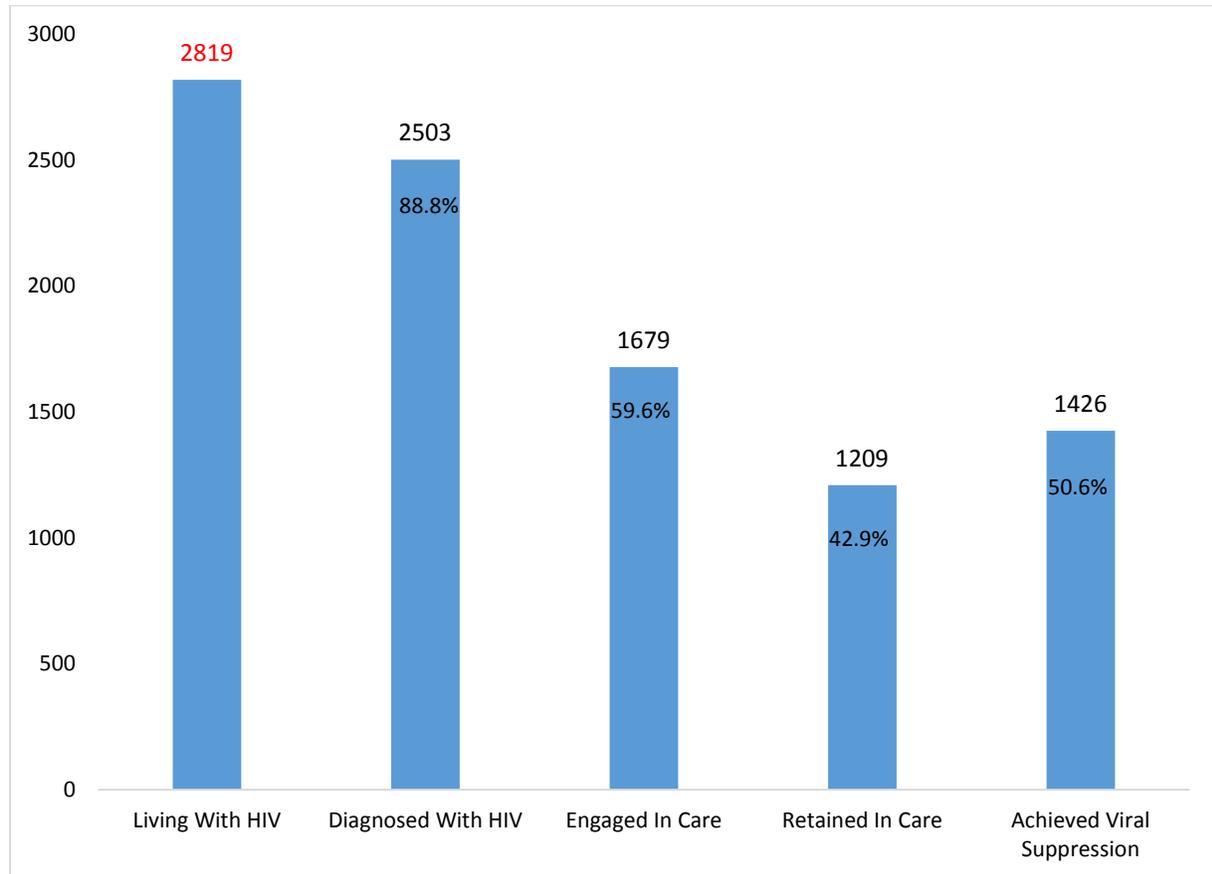
In addition to expanding the family plans for insurance premium assistance, Rhode Island would also like to use the XO8 supplemental funds to expand benefits to include dental coverage. Of the 93 clients provided premium assistance, 20 individuals have purchased dental insurance through the marketplace. The cost for the dental plan for these 20 individuals is \$964.80 per month, which amounts to \$11,577.60 for FY 2016. For FY 2017, if all Ryan White clients access dental coverage the costs could be as high as \$4,486.32 per month, which amounts to \$53,835.84 per year.

**Table 4: ADAP & Premium Assistance Enrollment Statistics**  
**As of June 24, 2014** **As of July 13, 2015**

<b>Category</b>	<b>Number of Individuals</b>	<b>Category</b>	<b>Number of Individuals</b>
Number of Persons Currently Active on ADAP	724	Number of Persons Currently Active on ADAP	610
Number of New ADAP Clients Since January 1, 2014	59	Number of New ADAP Clients Since January 1, 2014	137
Number of ADAP Clients Provided Premium Assistance	33	Number of ADAP Clients Provided Premium Assistance	77 (more than double from 2014)
Number of Undocumented Individuals on ADAP	50	Number of Undocumented Individuals on ADAP	44
Current ADAP individuals who may be Medicaid-eligible	308	ADAP individuals who may have been Medicaid-eligible as of 6/24/14	308
Total Number of ADAP Clients Who Converted to Medicaid Expansion as June 24, 2014	211	Total Number of ADAP Clients Who Converted to Medicaid Expansion as of 5/15/15	265
Percent of Clients Who Transitioned Into Medicaid	69%	Percent of Clients Who Transitioned Into Medicaid	86%

## B. HIV Care Continuum

**Figure 7. Rhode Island HIV Care Continuum**



*Notes: Living with HIV is based on CDC estimates using surveillance data reported to CDC through June 2014 and were adjusted for reporting delays, missing transmission category, incorrect diagnosis dates, and underreporting. This estimate was applied to the number diagnosed with HIV to determine an updated number estimated to be living with HIV in Rhode Island.*

*Persons diagnosed with HIV is based on persons diagnosed with HIV infection through 12/31/2013 and living with HIV on 12/31/2014, who reside in Rhode Island based on most recent residence.*

*Engaged in care is based on persons who have at least one CD4 or viral load or HIV-1 genotype test between 01/01/2014 through 12/31/2014 among persons residing in Rhode Island (based on most recent residence), diagnosed with HIV infection through 12/31/2013, and living with HIV on 12/31/2014.*

*Retained in care is based on persons who have at least two tests (CD4 or viral load or HIV-1 genotype) between 01/01/2014 through 12/31/2014, at least three months apart, among persons residing in Rhode Island (based on most recent residence), diagnosed with HIV infection through 12/31/2013, and living with HIV through 12/31/2014.*

*Viral suppression is based on persons who have most recent viral load test result <200 copies/mL between 01/01/2014 through 12/31/2014 among persons residing in Rhode Island (based on most recent residence), diagnosed with HIV infection through 12/31/2013, and living with HIV through 12/31/2014.*

*All data based on Rhode Island's HIV Surveillance Program's eHARS database, through June, 2016.*

## Methods

**Figure 7** provides a graphic description of the prevalence-based HIV Care Continuum for Rhode Island. This is a visual representation of the population estimated to be living with HIV, diagnosed, engaged in care, retained in care, and virally suppressed. The number of individuals diagnosed, engaged in care, retained in care, and virally suppressed are based on laboratory results and case report forms reported to RIDOH's HIV Surveillance Program. These calculations follow the CDC's guidance for developing a local continuum of care. The number of individuals estimated to be living with HIV, however, is an estimate. This estimate is based on CDC's 2015 publication which reported that 88.8% of individuals in Rhode Island living with HIV are estimated to be diagnosed as of the end of 2014. When applied to the 2,503 individuals diagnosed with HIV and living in Rhode Island, it is estimated that just over 2,800 are likely living in Rhode Island with HIV.

Calculating the percent diagnosed, percent engaged, percent retained, and percent virally suppressed is based off of the estimated number of people living with HIV in Rhode Island. This is different from only estimating these outcomes based on the number of people diagnosed. The percentages of persons engaged, retained, and achieving viral suppression will be reduced given this method of analysis. It is important to view the care continuum from this perspective to recognize the true gap in services being provided, beginning with the identification of persons living with HIV. This Rhode Island local analysis was conducted using HIV surveillance data reported and entered into eHARS through June 2016.

The notes below **Figure 7** describe, in more detail, how the measures of the care continuum are defined.

## Data Limitations

Linkage to medical care information is obtained through provider interview, laboratory reporting, and partner services investigations. Multiple data sources and active follow up has led to a high confidence in completeness of reporting. Routine CD4 and viral load reporting, which is crucial for the accurate estimation of retention in HIV medical care and achievement of viral suppression, is a more passive system that relies on laboratories reporting results to RIDOH, unprompted. In 2013, Rhode Island reporting regulations changed to mandate the reporting of all CD4 and viral load laboratory results. Some major laboratories delayed in instituting this new regulation in their laboratory information management system and RIDOH did not receive all CD4 laboratory results for 2014 by the writing of this report. Therefore, laboratory result-based retention in care metrics should be interpreted with caution as they may be underestimating the true population in care. Viral load reporting for 2014 was also delayed but has been resolved and the data reported here reflects a high level of completeness.

The percentage of people retained in care and achieving viral suppression is also subject to the availability of locating information. Some individuals may have moved out of Rhode Island to other states or countries. Without new address information their current address information

will remain as Rhode Island and they will be counted in this continuum. Measures are taken to protect against this. Routinely, the HIV Surveillance program conducts interstate duplicate review with all other reporting jurisdictions. Further, the HIV Surveillance matches to three vital statistics resources to identify individuals who may have died and can be removed from prevalence calculations. This is Rhode Island's first continuum and many individuals in the dataset have not had updated locating information or laboratory information for a number of years. Over the next year the HIV Surveillance program will be working to locate and update address information for these records and ensure that future continua are built off of the most accurate and complete data possible.

## **Discussion**

Rhode Island has nearly achieved the CDC's goal of having 90% of persons living with HIV know their status. Roughly 100 new cases are identified each year and linkage to care rates are well above 90%. Rhode Island maintains a very strong integration of HIV surveillance and HIV Partner Services Program activities and new cases are acted upon immediately to both identify sexual and/or drug use contacts and to ensure that cases are linked to proper HIV medical care. Despite these strong metrics, Rhode Island can still do better to identify new cases of HIV early in their course of disease. Roughly 30% of newly-identified cases are late diagnoses and are diagnosed with HIV and AIDS at the same time.

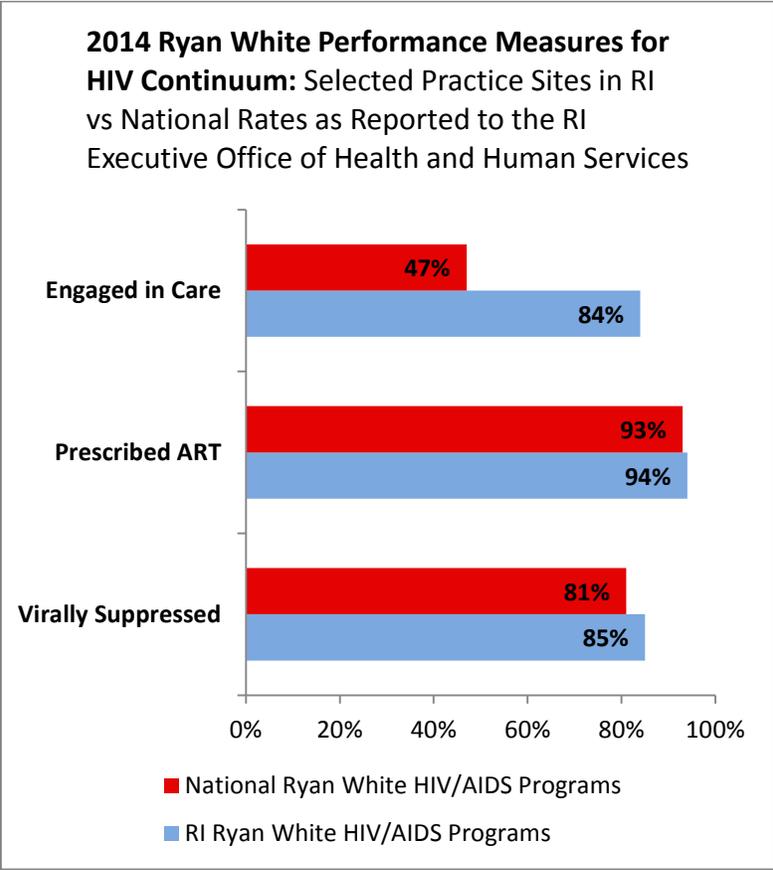
In 2014 the only noticeable disparity was in a reduced percentage of older individuals being linked to care within 3 months. Only 85% of individuals ages 55-64 were linked to care within 3 months. This is still above the national average but will be investigated to determine if different linkage strategies are needed for this population in the future.

The percentage of individuals retained in medical care is higher for females than males (52% versus 45% of known cases). Gay, bisexual, and other men who have sex with men have the lowest retention in care metrics of the reported transmission categories (43% versus 47% for the entire state).

Among individuals with at least one care visit in 2014, 71% had at least two care visits, three months apart. This shows that of individuals engaged in care (at least one visit), the majority are retained in care. This supports the idea that the percentage of cases retained in care is higher than indicated in this analysis, as many individuals not retained in care may simply be living outside of Rhode Island. The HIV Prevention Return to Care Program receives referrals from HIV medical providers for individuals who have not been in care for six months. In 2015 there was a reduction in the number of referrals, indicating that the program and referrals had reached saturation with the out of care population. Through the program (2013-2015), there were roughly 300 referrals to the program. This is yet another data source indicating that the out of care community is smaller than our data would suggest. Over 57% of known cases achieved viral suppression in 2014, and over 51% of all individuals estimated to be living with HIV in Rhode Island (diagnosed and undiagnosed) achieved viral suppression. Females had

higher percentages of viral suppression (62% versus 55% of known cases), similar to higher retention percentages. There were no major differences in viral suppression among racial/ethnic groups, age, or transmission category. Among individuals with at least one viral load in 2014, 87% achieved viral suppression indicating that any engagement in medical care appears to be followed by retention, medication adherence and ultimately, viral suppression.

**Figure 8: 2014 Rhode Island Ryan White Program HIV Continuum**



Nationally monitored performance measures on the HIV Continuum of Care include: 1) the percent of diagnosed cases that are engaged in care (i.e., have at least 2 outpatient visits per year); 2) percent prescribed antiretroviral therapy; and 3) the percent who achieve viral suppression. **Figure 8** compares the performance of three RI Ryan White Part B sites with national data from HRSA/HAB. These sites were selected on the basis of the fact they are the only Part B funded entities providing Medical Case Management. The populations sampled represent about 15% of the known PLWH/A in RI. Rates are reported as the percent of the diagnosed cases.

In Rhode Island, RI-EOHHS collaborates with Ryan White Part B Funded Medical Case Management Agencies to continuously improve the quality of the care provided to PLWH/A. Funded agencies are required to report clinical quality performance measures routinely. The Rhode Island Executive Office of Health and Human Services monitors these measures to identify where gaps may exist in connecting people living with HIV to sustained, quality care, and to implement system improvements and service enhancements that better support individuals through the continuum.

It is important to note that everyone in the Ryan White program has been diagnosed with HIV/AIDS and had at least some contact with the health care system to be included in the sample. As such, the engaged rates are not exactly comparable to national data. On the other hand, the percent prescribed ART and the percent virally suppressed are comparable from both samples. Over 90% of the patients are successfully placed on anti-viral therapy and over 80% of them achieve viral suppression. These results suggest that Ryan White agencies are exceeding national performance standards in treating HIV cases<sup>18,19</sup>.

### **HIV Care Continuum and Policy**

In November 2015, Rhode Island developed its first HIV Care Continuum and unveiled it at World AIDS Day while state and local leadership announced that the State of Rhode Island and the City of Providence will sign on to the Fast Track Cities Initiative, also known as the International Association of Providers of AIDS Care (IAPAC) 90-90-90 Initiative. This initiative states that the City of Providence and the State of Rhode Island will achieve the following metrics: (1) 90% of individuals living with HIV will know their status, (2) 90% of individuals living with HIV will be engaged in care, and (3) 90% of individuals living with HIV will achieve viral suppression. These are lofty goals but attainable ones in the eyes of local and state leadership. The HIV Care Continuum was used to set these targets and will be a resource to monitor 90-90-90 progress and help to evaluate our HIV testing efforts, linkage efforts, and return to care efforts. The continuum development process has also emphasized the importance of accurate and complete data systems. The Rhode Island Department of Health will continue to improve the completeness, timeliness, and accuracy of data maintained as part of the HIV Surveillance Program. This will be done by routinely identifying individuals who may have fallen out of care, updating current address information, and performing routine linkages to other data systems (vital records and interstate duplicate review). Through HIV prevention action and improvements to HIV Surveillance activities the continuum will become more useful tool for monitoring progress towards NHAS and IAPAC's 90-90-90 goals.

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<sup>18</sup> Ryan White HIV/AIDS Program Services Report (RSR) 2014

<http://hab.hrsa.gov/data/servicesdelivered/2014RWHAPDataReport.pdf>

<sup>19</sup> Vital Signs: HIV Diagnosis, Care, and Treatment Among Persons Living with HIV – United States, 2011

<http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6347a5.htm>

C. Financial and Human Resources Inventory

**Table 5: 2016 Financial Resources Inventory**

<b>2016 Financial Resources Inventory</b>				
<b>Funding Source</b>	<b>Amount of Funding</b>	<b>Funded Service Provider Agencies</b>	<b>Services Delivered</b>	<b>Impact on HIV Care Continuum</b>
CDC	\$753,824	RI Department of Health – HIV Prevention Program	Community-based HIV counseling, testing and referral; condom distribution; prevention for positives; policy development	HIV Diagnosed
CDC	\$201, 979	RI Department of Health – HIV Surveillance Program	State-wide HIV surveillance; monitor the HIV care Continuum	HIV Diagnosed, Linked to Care, Retained in Care, Viral Load Suppression
Sexually Transmitted Disease / HIV State Account	\$88,893	RI Department of Health – HIV Prevention Program	Community-based HIV counseling, testing and referral;	HIV- Diagnosed
Legislative grant (x2)	\$38,472	AIDS Care Ocean State, AIDS Project RI	Community-based HIV counseling, testing and referral; Non-medical case management,	HIV Diagnosed, Linked to Care, Retained in Care, Antiretroviral Use, Viral Load Suppression
Legislative grant, and Sexually Transmitted Disease / HIV State Account – ENCORE	\$103,350	AIDS Care Ocean State	Needle exchange	HIV Diagnosed
HRSA/HAB	\$800,574	The Miriam Hospital (The Immunology Center is the	Outpatient/ambulatory health services, medical case management, mental health services, outpatient	HIV Diagnosed, Linked to Care, Retained in Care, Antiretroviral Use,

2016 Financial Resources Inventory				
Funding Source	Amount of Funding	Funded Service Provider Agencies	Services Delivered	Impact on HIV Care Continuum
		service delivery site)	substance abuse services, Health Insurance Program (HIP), non-medical case management, outreach services, psychosocial support services, medical transportation, and health education/risk reduction	Viral Load Suppression
HRSA/HAB (Part B)	\$21,034	Executive Office of Health & Human Services, Ryan White HIV Provision of Care & Special Populations Part B	Minority AIDS Initiative (MAI)	Linked to Care, Outreach, and Education, Retained in Care, Antiretroviral Use, And Viral Load Suppression.
HRSA/HAB (Part B)	\$1,802,332	Executive Office of Health & Human Services, Ryan White HIV Provision of Care & Special Populations Part B	ADAP Medications, Health Insurance Assistance Services, Medical and Non-Medical Case Management, Outpatient/Ambulatory Care and Ryan White Support Services	Linked to Care, Retained in Care, Antiretroviral Use, Viral Load Suppression
HRSA/HAB (Part B)	\$182,129	Executive Office of Health & Human Services, Ryan White HIV Provision of Care & Special Populations Part B	Emerging Communities	Linked to Care, ADAP medications, Health Insurance Assistance Retained in Care, Antiretroviral Use, Viral Load Suppression

2016 Financial Resources Inventory				
Funding Source	Amount of Funding	Funded Service Provider Agencies	Services Delivered	Impact on HIV Care Continuum
Housing Opportunities for Persons Living With AIDS (HOPWA) Funding		AIDS Care Ocean State	Housing Opportunities	Linked to Care, Housing, Viral Load Suppression
HRSA Part C Funding	\$348,682	Thundermist Health Center	HIV Care, Oral Health	Linked to Care, Viral Load Suppression, Oral Health
RWHAP HRSA Part D Funding	\$548,914	AIDS Care Ocean State	Woman, infants, Children & Youth	Linked to Care, Education, full service dental for PLWH/A

**Workforce Capacity**

Rhode Island is fortunate to have a robust infrastructure of organizations that have created a strong network of “prevention” and “care” providers that generally meet the needs of individuals at risk for HIV and those who are living with HIV. Of note, Rhode Island’s small geographic size and public transportation system, easily lends itself to meeting the HIV prevention and care needs of Rhode Islanders from all of its 37 cities and towns. Specifically, Rhode Island has two primary AIDS service organizations, APRI and ACOS, which provide statewide services ranging from condom distribution and HIV testing, to non-medical case management services. Although these AIDS service organizations are based in Providence, they conduct testing and outreach at various locations throughout the state. In addition, Community Care Alliance provides non-medical case management and Ryan White support services to HIV+ individuals mostly residing in the northern part of Rhode Island. The Miriam Hospital Immunology Clinic, located in Providence and easily accessible by public transportation, serves as the major HIV center in the state. The clinic provides care to over 1,600 HIV+ patients, representing >75% of the HIV-diagnosed individuals in Rhode Island.

The state's pediatric HIV care program is located at Rhode Island Hospital and serves HIV+ patients from birth through adolescence. University Medical Group offers HIV+ adults with both primary care and specialty HIV care. The Rhode Island Department of Health subcontracts

counseling, testing, and referral (CTR) services in non-medical settings using rapid HIV and Hepatitis C tests with the following agencies: AIDS Project Rhode Island (APRI), AIDS Care Ocean State (ACOS), and Project Weber. HIV testing is also supported through federal CDC STD Prevention funds through the Miriam Hospital STD Specialty Clinic. The Rhode Island Department of Health has a contract with ACOS for the administration of the ENCORE Program – Rhode Island’s needle exchange program. The Rhode Island Department of Health manages a statewide condom distribution program that includes 75 community partners, including colleges, community-based organizations, and social services agencies, among others. The Rhode Island Executive Office of Health & Human Services contracts with five organizations to provide Part B care and services to individuals living HIV/AIDS. Below is a brief description of each organization and their service category:

**ACOS** Located in Providence and is one of the largest providers of direct care services to persons living with HIV and is Part B funded for non-medical case management and home & community based services. ACOS has an assisted living facility in Rhode Island for people with HIV (Sunrise House), which provides medical and social support, case management and has a total of ten (10) private bedrooms for all clients. Additionally, they administer the ENCORE needle exchange program, which is Rhode Island’s only syringe services program.

**APRI (Family Service of Rhode Island):** Located in Providence, and offers the following support services, Health Insurance Premium and Cost Sharing Assistance (COBRA), Mental Health, Medical Nutrition, Emergency Financial Assistance, Psychosocial Support, Oral Health, Home-Delivered Meals. This organization also provides non-medical case management services to eligible PLWH/A.

**Community Care Alliance (Agape Center),** is located in Woonsocket, RI and offers non-medical case management and medical transportation for eligible Ryan White PLWH/A, The center is open five days per week and services are centered both on psychosocial supports with the goal of broadening the quality of life and works closely with the medical and mental health community to ensure that clients maintain their consistent involvement in clinical services. Engagement for clients include, food pantry, case management services in Spanish and English, meals served on Mondays, linkages to family services, housing, emergency financial assistance and on-site dental examinations by Thundermist Health Center.

**Miriam Hospital- Immunology Clinic/Project Bridge-** is located in Providence and provides comprehensive medical case management care for HIV infected individuals. Project Bridge, which is also contracted under Part B, offers Non-Medical, Transitional Case Management (including treatment adherence and referral for health care/supportive services) for Incarcerated individuals.

**University Medical Group (Complete Care Program)** is located in Providence and provides Medical Case Management and Outpatient/Ambulatory Medical Care.

**Funding Sources to interact to ensure continuity of HIV prevention, care and treatment in the jurisdiction:**

Rhode Island's unique organization structure houses the HIV "prevention" side in the RIDOH and the "care" side in the RI-EOHHS Medicaid Office. Both of these organizational units work independently in the administration of their budgets, relationship with funders, and procurement activities. While RIDOH and RI-EOHHS both support care services, RIDOH specializes in all prevention efforts and RI-EOHHS specializes in treatment efforts. The prevention/care services supported by RIDOH target all Rhode Islanders, regardless of income, while the RI-EOHHS services are limited to those individuals whose incomes fall below FPL. As of July 1, 2016, the RI-EOHHS, Ryan White Program has raised its eligibility cutoff from 400% to 500% of FPL.

The Rhode Island Department of Health utilizes federal and state funding sources to ensure a full spectrum of prevention/care of services, including surveillance, partner services, condom distribution, needle exchange, PrEP program, public education, policy development, community-based HIV testing, STD specialty clinic HIV testing, return to care, and data to care (using surveillance data to support re-engagement in care for people who fall out of care). With the exception of the needle exchange program, the primary funding sources are from the CDC in the form of the HIV Prevention and HIV Surveillance cooperative agreements, and to a small degree, the STD Prevention grant. State funding provides support for the needle exchange program, as well as some community-based rapid HIV testing. In compliance with HRSA's rules for states that are under "restricted draw-down," status, no HRSA or rebate dollars are used to support RIDOH data to care, return to care, early identification/partner services, or HIV surveillance activities.

The Rhode Island Executive Office of Health and Human Services utilizes a multitude of funding to support their programs: Human Resources Services Administration (HRSA), ADAP Rebate, and Supplemental Grants to ensure both clinical and support services are available to PLWH/A in Rhode Island. These services include; medical and non-medical case management, outpatient ambulatory medical care, transitional case management for incarcerated individuals, home and community-based services and a host of support services inclusive of emergency financial assistance, health insurance and cost-sharing assistance, medical transportation, medical nutrition therapy, home delivered meals, psychosocial, mental health and oral health support.

Rhode Island has a wide range of services for PLWH/A and representatives from a diverse segment of funding sources who participate in the Rhode Island HIV Care and Prevention Planning Group (CPPG). These sources include Ryan White Part B, C & D, RIDOH, representatives for Housing Opportunities for PLWH/A (HOPWA), Medicaid, Mental Health and Substance use treatment and Department of Corrections. We find this collaboration especially important in light of the changing landscape of the healthcare environment. Rhode Island Executive Office of Health and Human Services Ryan White Part B HIV Provision of Care Program is incorporated under Medicaid, therefore the program is actively involved as an office in the development of addressing the challenges of entitlement programs. Our goal is to

analyze efficiency of service, costs and quality of care associated with these entitlement programs so that we may prepare for the ever changing landscaping of the health care system and its complexities. Furthermore, the Ryan White Part B contracts with HP Enterprises Services (HP) to provide pharmacy benefits management. HP Enterprises is the largest provider of Medicaid and Medicare process management services, administering more than \$100 billion in benefits each year throughout the nation. HP has been processing ADAP pharmacy claims since 2007 through the RI-EOHHS Medicaid Management Information System (MMIS) on behalf of the Rhode Island ADAP. In addition to claims processing and reporting, HP also provides recipient enrollment verification, drug rebate processing, drug prior authorization processing, and drug utilization review for pharmacy benefit management. This pharmacy benefit management enabled over 1020 ADAP clients in 2014 to utilize this service to assist with the provision of medically prescribed pharmaceuticals used in the prevention, management and treatment of HIV/AIDS in Rhode Island. Ryan White Part D funds provide women, infants, youth and children with HIV primary medical services directly, through contract or through memoranda of understanding. Thundermist Health Center in South Kingstown, West Warwick and Woonsocket utilizes Ryan White Part C funding to offer full service dental for HIV positive adults and offers diagnostic, therapeutic and preventative dental services to HIV adults who might not otherwise have access to care. There is collaboration on each side of the spectrum between RI-EOHHS and RIDOH in regards to the Continuum of Care. The Rhode Island Department of Health identifies, monitors, and provides HIV and STD testing, referral, linkage and engagement in medical care. Meanwhile, RI-EOHHS Ryan White Part B Program provide and monitor the care of PLWH/A in the state of Rhode Island.

## D. Assessing Needs, Gaps, and Barriers

### **Describe the HIV prevention and care service needs of persons at risk for HIV and PLWH/A.**

The prevention aspect of the Jurisdictional Plan Needs Assessment is divided into two sections. The first section includes a review and description of existing data sources, including surveillance information, program metrics, and evaluation outcomes. This information provides insight on disease trends, demands for program materials and services, and trends in program utilization. The second section is a description of a needs assessment conducted with members of the HIV Care and Prevention Planning Group (CPPG) and included return to care, condom distribution, partner services, needle exchange services and community based testing centers. Some of the information is provided in both sections which emphasizes its importance, both from a programmatic level, and from a consumer or provider level. The major programs and current challenges are summarized as follows:

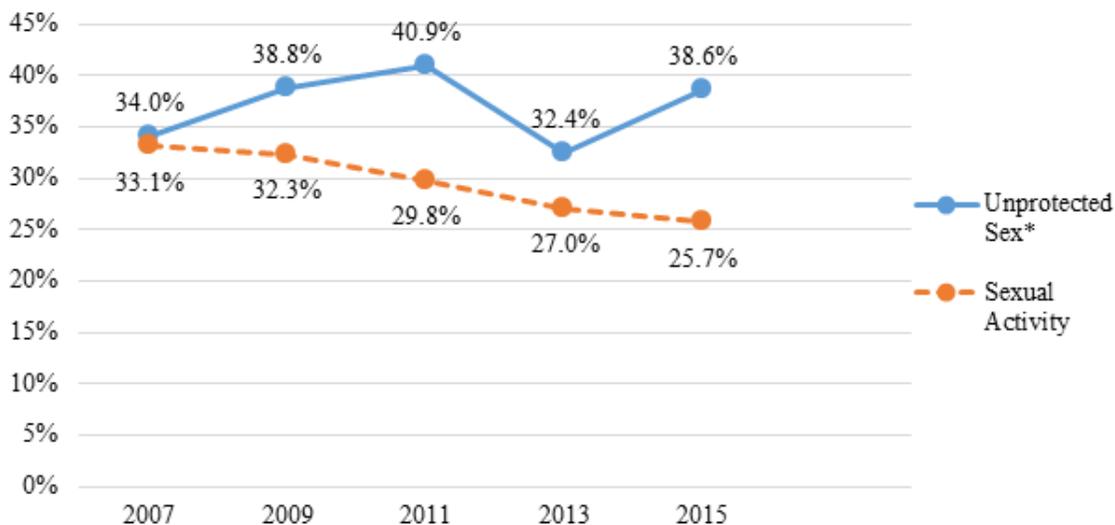
- Condoms
  - Over 350,000 condoms were distributed in 2015
  - Less than 20% of individuals over 35 used a condom during their last 10 sexual intercourse acts
  - Only 43% of gay men always use a condom
  - The number of gonorrhea cases doubled from 291 in 2010 to 590 in 2014
  - Chlamydia cases increased 25% from 2010-2014
- Syringe Exchange Program
  - From 2012-2015, 794 individuals accessed services through ENCORE
  - There are more than 20,000 individuals in RI with opioid use disorders
  - Options for exchanging syringes include home delivery, street outreach, and fixed sites
  - The number of drug-related overdose deaths has increased 50% from 2011-2015
- Community Based HIV Rapid Testing
  - 4,725 HIV tests performed in 2015
  - Majority of tested individuals were Non-Hispanic Whites, males, and self-identify as men who have sex with men
- Partner Services
  - In 2015, 488 contacts identified as needle sharing or sexual contacts from 80 index patients
  - More than 400 of those partners were anonymous and unable to be contacted
- Return to Care
  - Rhode Island Department of Health's Return To Care Provider Referral System identified 297 HIV-positive individuals out of care and navigated 81 back to care between 2013 and 2015
  - Rhode Island Department of Health's HIV Surveillance Program estimated there were additional individuals out of care in Rhode Island who were not referred for follow up and would benefit from re-engagement activities

## Part 1 - Review and description of existing data sources

### Condoms

Condoms have been proven to be one of the most effective methods of HIV prevention<sup>20</sup>. Consistent and correct use of a latex condom can reduce a person's risk of contracting or transmitting HIV as well as many other STDS by up to 85%<sup>21</sup>. The Rhode Island Department of Health provides free condoms to the general public with approximately 100 condom dispensers located throughout the state. In 2015, RIDOH distributed more than 350,000 condoms at the various locations. The high demand for free condoms indicates a significant need in the community as these individuals may be otherwise at risk for STDs, including HIV as well as unplanned pregnancy. **Figure 9** demonstrates the need for condom availability, as sexual activity among youth has been decreasing, and condomless sex has been increasing.

**Figure 9: Sexual Activity among High School Students in Rhode Island, 2007 – 2015**



Source: Youth Risk Behavior Survey, Rhode Island, 2007-2015

According to the Pregnancy Risk Assessment Monitoring System (PRAMS), the percentage of unplanned pregnancies in RI for 2011 was 38.8%<sup>22</sup>. The PRAMS survey indicated that those who had the highest rates of unplanned pregnancies were mothers that were younger than 20 years of age, black, Hispanic, unmarried, had less than 12 years of education, had public health insurance, and had participated in the federally supported supplemental nutrition program for Women Infants and Children (WIC). Although almost half of the individuals who reported an unplanned pregnancy mentioned that they did not mind if they got pregnant, the other half gave other reasons for not using a condom, including; not knowing that they could get pregnant at that time, the sex partner not wanting to use anything, having side effects from the birth control method being used, thinking one individual was sterile, or having problems acquiring birth control. This high percentage of unintended pregnancies further emphasizes the

<sup>20</sup> <http://www.cdc.gov/condomeffectiveness/brief.html>

<sup>21</sup> <http://www.aidsmap.com/Do-condoms-work/page/1746203/>

<sup>22</sup> <http://health.ri.gov/publications/issuebriefs/2015UnintendedPregnancyAmongWomenInRhodeIsland.pdf>

importance of using condoms. The United States Census estimates that approximately 45% of the population ages 15 and above are currently married, which may be a weak proxy for a monogamous relationship. It is known that there are some individuals who may be married and not in a monogamous relationship, as well as some individuals who are in a monogamous relationship and are not married. For the purposes of this analysis being unmarried indicates a higher potential for risky sexual behavior. Indiana University conducted a study evaluating sexual behaviors among adults. It was noted in their study that adults tend to be sexually active and sexual activity was still quite high after age 35<sup>23</sup>. However, many people believe since they can no longer get pregnant they do not need a condom, and less than 20% of individuals over age 35 utilized a condom during their last 10 sexual intercourse acts. These high numbers are startling as they indicate an ongoing need for education on condom use as part of HIV and STD prevention efforts.

### **Syringe Exchange Program**

According to the CDC, people who inject drugs can substantially lower their risk for HIV, viral hepatitis and other bloodborne infections by using a sterile needle and syringe for every injection<sup>24</sup>. ENCORE (education, needle exchange, counseling, outreach and referrals) is a collaborative syringe and needle exchange effort between ACOS and RIDOH. It is currently the only needle exchange program in the state of Rhode Island. In addition to needle exchange, the program offers education on HIV, viral hepatitis, and other bloodborne pathogens, as well as counseling on reducing risks. The ENCORE team travels to several areas in Rhode Island to reach various populations in different areas of the state<sup>25</sup>. It is estimated that in the year 2015 there were 190 unique individuals accessing services through the ENCORE Needle Exchange. In that same year, there were 41,718 needles that were exchanged to be disposed, and there were 53,410 needles that were distributed. These high numbers demonstrate that there is a substantial need for the ENCORE needle exchange in the community. From 2012-2015 there were 794 unique individuals who accessed services through ENCORE. More than two thirds of the population enrolled in the ENCORE program identified themselves as white and 22% identified themselves as Hispanic/Latino. It was determined that at least 60% of the population served by ENCORE was between the ages of 20 and 40. In the ENCORE population, 40% identified as heterosexual, white males, 18% identified as heterosexual, Hispanic males, and 14% identified as heterosexual, white females. The Rhode Island Strategic Plan on Addiction and Overdose, estimated that there are more than 20,000 individuals in RI with opioid use disorders. Opioid use disorder is a chronic relapsing disease that can develop with repeated exposure to opioids. In 2013, Rhode Island had the highest rates of illicit drug use in the nation. Many individuals typically begin with prescription pain medications and then transition to heroin use, typically in the form of injection drug use<sup>26</sup>. However, it is impossible to know the true prevalence of injection drug use as the 20,000 estimate includes both injection and non-

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<sup>23</sup> <http://www.nationalsexstudy.indiana.edu/>

<sup>24</sup> <http://www.cdc.gov/hiv/risk/ssps.html>

<sup>25</sup> <http://www.aidscares.org/ProgramsServices/PreventionCenter/NeedleExchange.aspx>

<sup>26</sup> <https://static1.squarespace.com/static/55d208f6e4b04baeaff02618/t/563a81abe4b0c152700ce49f/1446674859170/Strategic+Plan.pdf>

injection drug use. The high numbers of drug use indicate that there is a significant need, and the needle exchange is being accessed by a very small percentage of injection drug users.

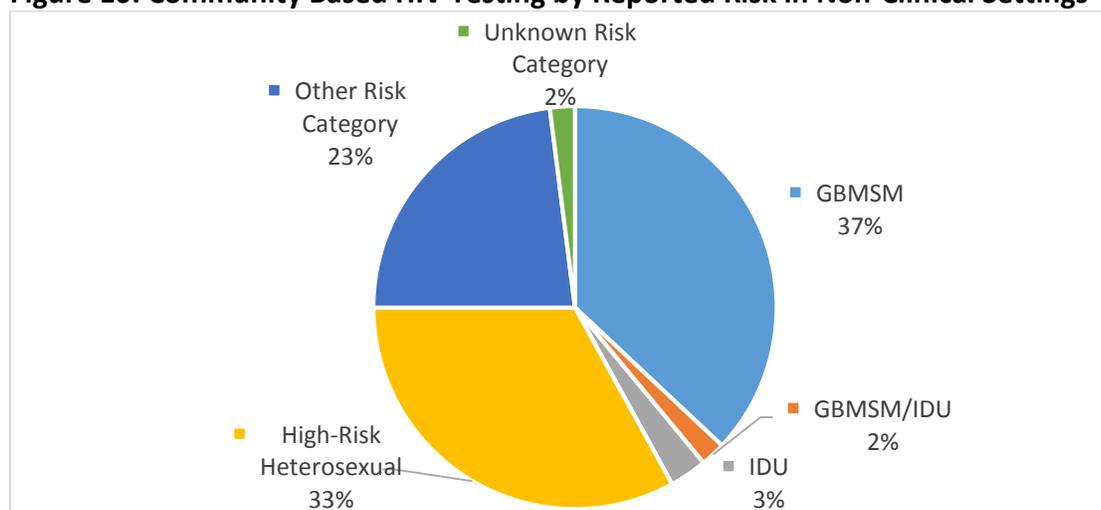
**Table 6: ENCORE Program by the Numbers – 2015**

724 Client Encounters
109 Newly Enrolled Clients
190 Unique Clients Accessing Services
53,410 Clean Needles Distributed
41,718 Dirty Needles Collected
572 Miles, and 1040 Hours of Street Outreach Conducted

**Community-Based HIV Rapid Testing**

HIV testing has proven to be in high demand in Rhode Island. In 2015, there were 4,725 tests that were performed at various sites throughout the state. Approximately 43% of the tests were performed in non-clinical settings, and the other 57% were performed in clinical settings. The majority of individuals who are being tested in non-clinical settings are non-Hispanic whites, and males are more likely to be tested than females. Furthermore, those who tested reported their risk as being a man who had sex with other men. Gay, bisexual and other men who have sex with men, currently have the highest rates of newly diagnosed HIV cases, and most of the tests being conducted are among GBMSM (**Figure 10**). Therefore, we conclude that we are targeting our testing efforts to minimize the number of individuals who are truly HIV positive and are currently unaware of their HIV status.

**Figure 10: Community Based HIV Testing by Reported Risk in Non-Clinical Settings**



### HIV Testing cost effectiveness

The Rhode Island Department of Health conducted a cost-effectiveness analysis to determine which HIV testing sites yield the highest number of HIV positive individuals. It was discovered that HIV screening in the STD clinical setting incurred the lowest cost per HIV case diagnosed, the lowest cost per test, and the highest number of cases diagnosed, furthermore it ranked second for HIV positivity. These results demonstrate the importance of HIV testing in STD clinics as co-infection rates may be high, and many of the risk factors overlap. Furthermore, they indicate the importance of collaboration between RIDOH and STD clinics to achieve mutual public health goals.

**Table 7: HIV Testing Cost Effectiveness Analysis**

	Total costs	STD clinic	Female CSW Support Program	Male CSW Support Program	College	Bath house	ASO	Sub Abuse, Behavioral, Homeless Facility	Corrections	RIDOH Partner Services
Total costs	1,100,400	87,136	73,467	86,982	47,373	36,673	208,457	119,245	3,766	278,208
No. of Positives	50	16	0	3	0	4	15	1	0	11
Total No. of tests	11,365	2,545	163	295	968	688	3,657	1,794	110	308
Average cost per positive test	22,008	5,446	-	28,994	-	9,168	13,897	119,245	-	25,292
Average cost per test	97	34	451	295	49	53	57	66	34	903

### Behavioral Risk Factor Surveillance System

The Behavioral Risk Factor Surveillance System (BRFSS) is a health-related telephone survey that collects state-level data about US residents regarding the health-related risk behaviors, chronic health conditions and their use of preventive services<sup>27</sup>. The 2014 data for the state of RI indicates that approximately 35% of the adult population has been previously tested for HIV. Although this is higher than the rates for the high school students, the CDC currently recommends routine HIV screening of all adolescents and adults ages 15 to 65<sup>28</sup>. It can be seen that there are significant disparities between individuals who should be getting tested, and the individuals who are being tested. Of the individuals who were tested about 50% of them were tested by their private doctors. Other high volume locations for HIV tests include a clinic, being inpatient at a hospital, or 'somewhere else'.

### Return to Care

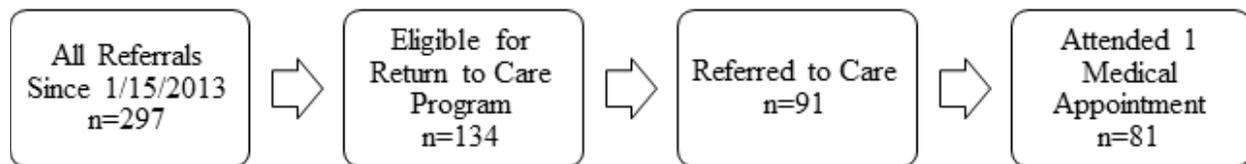
The purpose of the Return to Care Provider Referral System (RTC) was to reduce HIV transmission by increasing the proportion of HIV-infected persons in Rhode Island with an undetectable viral load. The referral system was built such that if a primary care provider identified an individual that appeared out of care for more than six months, RIDOH staff would investigate the client to determine their true care status and contact information. They would

<sup>27</sup> [http://www.cdc.gov/brfss/annual\\_data/annual\\_2014.html](http://www.cdc.gov/brfss/annual_data/annual_2014.html)

<sup>28</sup> <http://www.cdc.gov/hiv/testing/index.html>

learn about barriers to care and provide information to RIDOH on how to re-engage them in care. Between 2013 and 2015, there were 297 individuals who were deemed as out of HIV medical care, and they were referred to the RTC program by their primary care provider. Of those that were out of care, 134 were eligible for RI RTC services. Individuals were deemed ineligible if they had unconfirmed HIV status, were in care at a facility other than the reporting facility, resided in another state, incarcerated or deceased. Ninety-one of the total eligible participants agreed to re-enter care, and of those 81 had documentation of attending at least one HIV medical appointment (**Figure 11**). Through surveillance data we have identified additional individuals who may be out of care, but were not referred to the return to care program. This may be due to the fact that RTC relies on provider referrals and if the patients do not have a primary care/HIV physician or a case manager they would not be detected as out of care. The larger proportion of individuals who are out of care indicates a great need for this program.

**Figure 11: Return to Care Program Data, 2013 – 2015**

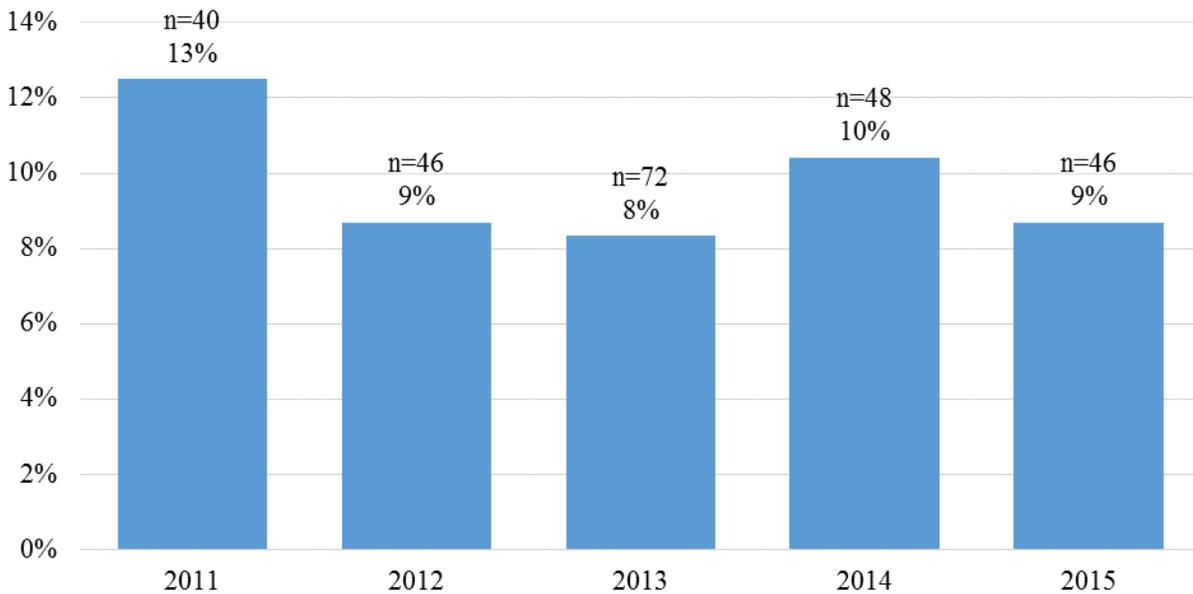


### Partner Services

According to the CDC, the purpose of partner services is to identify individuals who are infected with STDs including HIV and locate their sexual or needle-sharing partners and refer them to medical care due to the recent STD exposure<sup>29</sup>. Partner services is a clearly a needed service in Rhode Island. There were 80 index clients diagnosed with HIV in 2015, from whom there were a total of 488 sex or needle sharing partners identified who may have been at risk for HIV. Of these 488 sex or needle sharing partners, sufficient contact information was available on only 74 partners. The high number of individuals without sufficient contact information indicates the importance of continuing HIV prevention efforts as there were more 400 people who were potentially exposed to HIV, but were unable to be contacted about their exposure.

<sup>29</sup> <http://www.cdc.gov/std/program/partners.htm>

**Figure 12: Percentage Positivity of Tested Partner Services Contacts 2011-2015**



### **Youth Risk Behavior Survey**

The Youth Risk Behavior Surveillance System (YRBSS) monitors health-risk behaviors among youth and young adults over time. One of the major sections measured in this survey are sexual behaviors, and specifically those relating to unintended pregnancy and sexually transmitted diseases, including HIV<sup>30</sup>. Conducted in both middle schools and high schools throughout the state of Rhode Island, it creates a sample that is representative of the Rhode Island public school population. The middle school survey collects less data about sexual behaviors than the high school survey. In 2015, when middle schoolers were asked if they had ever had sexual intercourse 3.1% of 6<sup>th</sup> graders indicated they had previously had sex, however, among 8<sup>th</sup> graders that number was significantly higher at 9.6% (**Figure 13**). The results from the 2015 Rhode Island High School YRBS indicated that among 12<sup>th</sup> graders, 57% indicated that they had been sexually active, and 42% indicated that they were currently sexually active, and of those students, 43% did not use a condom during their last sexual intercourse. Furthermore, approximately 86% of high school students indicated that they had never been tested for HIV. It is also important to note that 10% of high school students identified as gay, lesbian or bisexual, and those individuals were more likely to engage in high risk sexual behaviors.

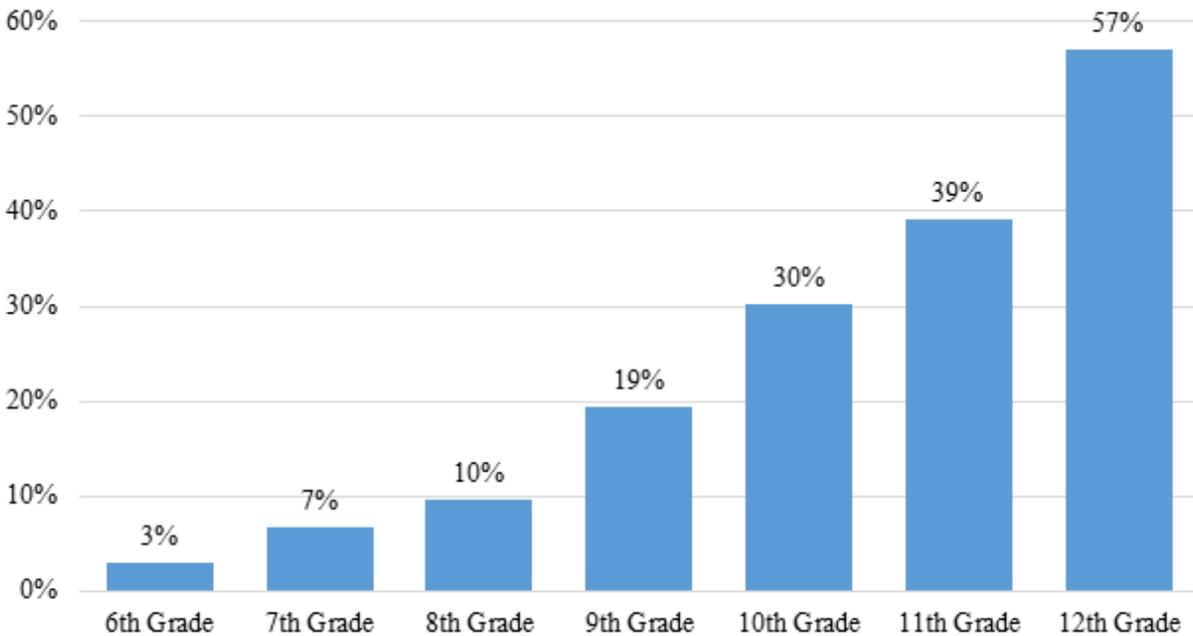
<sup>30</sup> <http://www.cdc.gov/healthyyouth/data/yrbs/index.htm>

**Table 8: Sexual Risk Behaviors by Sexual Orientation, Youth Risk Behavior Survey, High School, 2015**

Questions	Heterosexual	Gay, Lesbian or Bisexual
Ever had sex	37%	44%
Had sex before age 13	2%	7%*
Had sex with >4 partners in life	6%	15%*
Had sex with at least 1 person in the last 3 months	26%	31%
Did not use a condom	37%	49%*

\*Indicates that gay, lesbian, or bisexual students are significantly more likely than heterosexual students to engage in these high risk sexual behaviors,  $p < 0.05$

**Figure 13: Percentage of Students Ever Having Sex, by Grade, Rhode Island Youth Risk Behavior Survey, 2015**



**School-Based Sexual Health Education**

As part of the Youth Risk Behavior Survey, high school students are asked if they have been taught about the benefits of not having sexual intercourse to prevent pregnancy and sexually transmitted diseases (STDs). Only 75% of 9<sup>th</sup> graders and 86% of 12<sup>th</sup> graders indicated that they had been taught about these benefits. However, it is important to note that by 12<sup>th</sup> grade more

than 50% of students indicated that they had ever had sex. Therefore, the importance of public education, specifically for high school students, on pregnancy prevention and sexually transmitted disease prevention must be reinforced.

### **Gay Men's Health Survey**

The Rhode Island Gay Men's Health survey was conducted in June and July of 2015 at two separate events in Rhode Island. It provides insight into the sexual behaviors, preferences and experiences of gay men in Rhode Island. This is particularly relevant because according to the Emory Coalition for Applied Mathematics for Prevention, approximately 6% of the Rhode Island adult male population has had sex with another man. This percentage is higher than the national average which is estimated to be 4%<sup>31</sup>. The major findings of the Gay Men's Health Survey were that two out three respondents reported having anal sex in the past twelve months, and one out four respondents reported having anal sex with multiple partners in the past twelve months. It is also important to note that more than half of the respondents reported not always using a condom. The combination of having multiple anal sex partners and not always using a condom facilitate transmission of HIV as well as other STDs. Another very important finding is that while the majority of the respondents have a regular doctor, more than one third of them have not disclosed their sexual orientation to their doctor, and one out of four have not been tested for HIV or STDs by their doctor. Approximately one third of these individuals receive HIV tests at least once a year, and if their doctor knew their sexual orientation they may be able to offer these tests to the patients. This demonstrates an important gap in care as these individuals may not be comfortable disclosing their sexual orientation to their primary care physician, but if they did they may receive more comprehensive treatment.

### **Rise in STD rates**

According to the CDC if a person is diagnosed with an STD they may be more likely to become co-infected with HIV since many of the risk behaviors overlap<sup>32</sup>. Furthermore, having an STD may cause a sore or a break in the skin which could make a person biologically more susceptible to HIV and allow for an easier entry point for HIV. The total number of gonorrhea and chlamydia cases has increased since 2010. In 2010 there were 291 cases of gonorrhea reported, and in 2014 there were 590 cases reported (**Figure 14**). Additionally, there were 3480 cases of chlamydia in 2010 and 4349 cases of chlamydia in 2014 (**Figure 15**). Since 2010, the rates of newly identified cases of HIV among gay, bisexual and other men who have sex with men have been substantially higher than heterosexual men, with this rate being almost 10-fold in 2014 (**Figure 16**). Syphilis is an STD that is commonly spread by gay, bisexual and other men who have sex with men. In 2014, there were 80 people diagnosed with syphilis who identified as GBMSM and among those individuals 26 of them self-reported as HIV-Positive. HIV-positive men who are co-infected with infectious syphilis are more likely to spread HIV to their sexual partners than HIV-positive men who do not have infectious syphilis<sup>33</sup>.

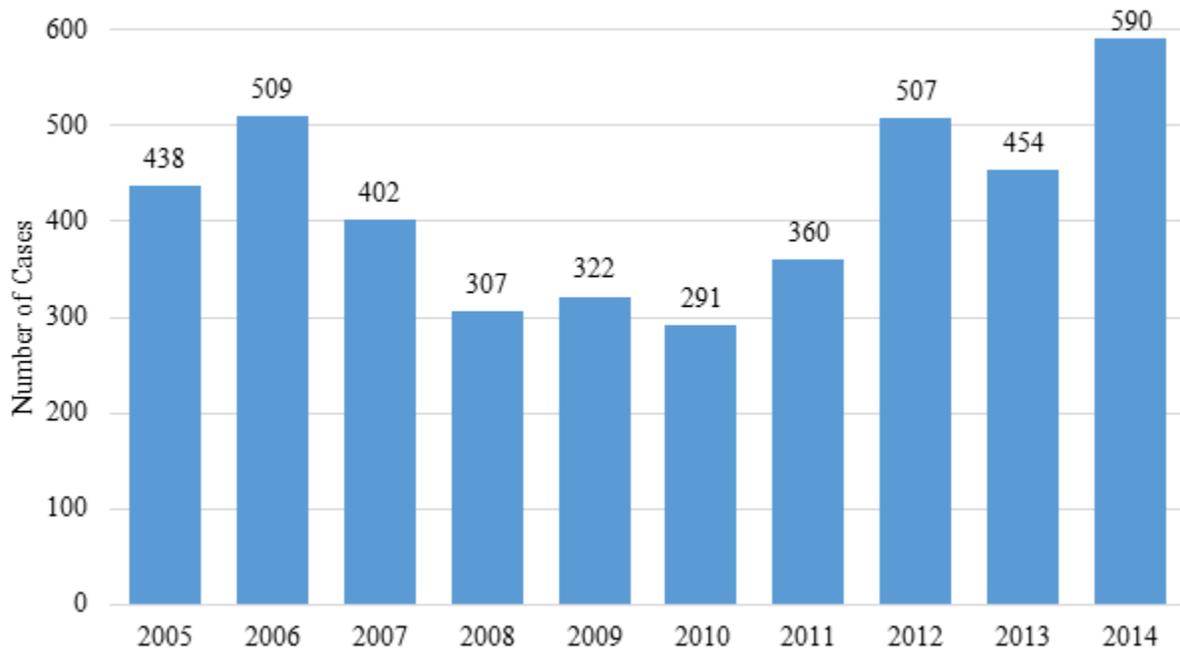
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<sup>31</sup> <http://emorycamp.org/item.php?i=50>

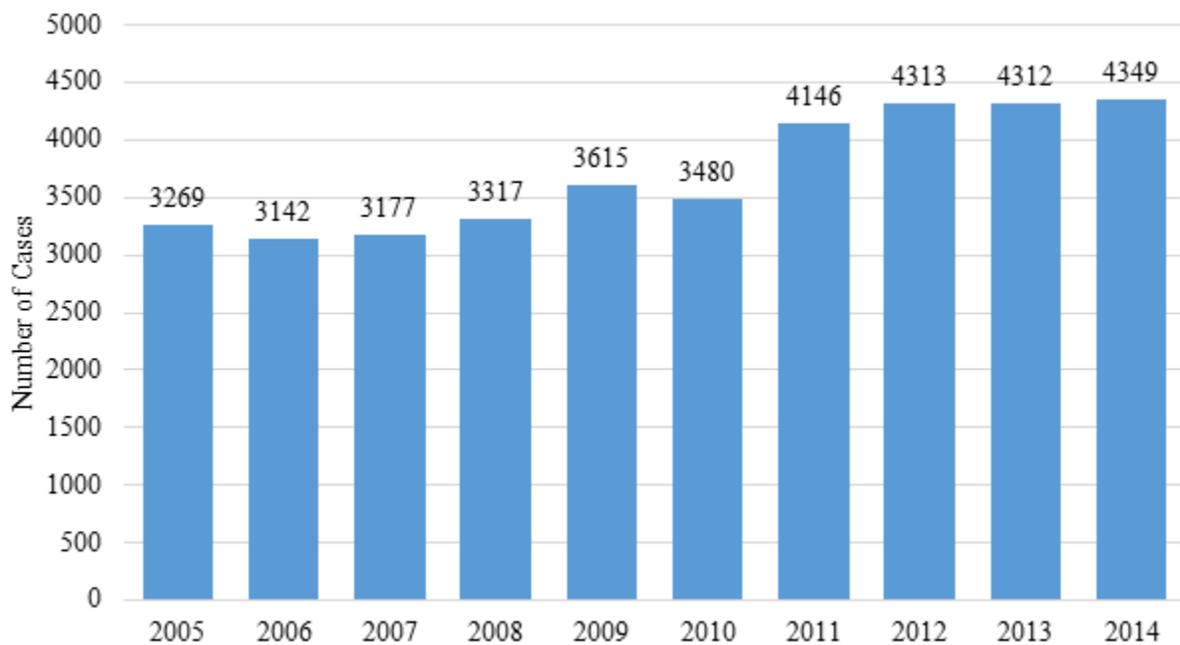
<sup>32</sup> <http://www.cdc.gov/std/hiv/STDFact-STD-HIV.htm>

<sup>33</sup> <http://www.cdc.gov/std/Syphilis/STDFact-MSM-Syphilis.htm>

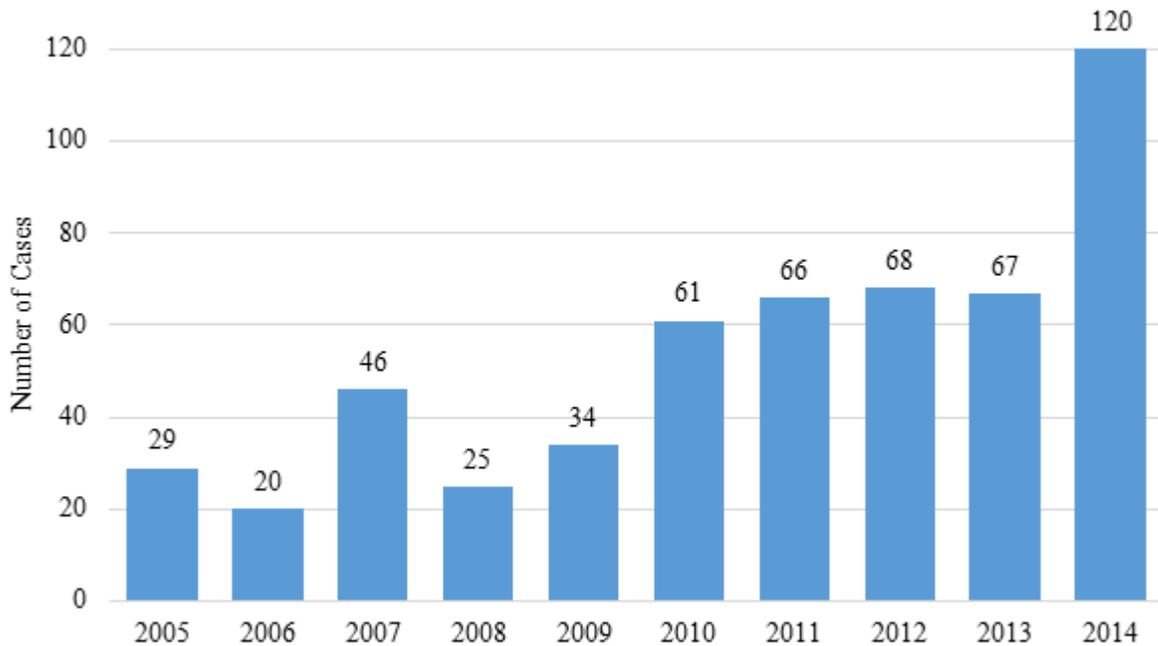
**Figure 14: Gonorrhea Cases, Rhode Island, 2005 – 2014**



**Figure 15: Chlamydia Cases, Rhode Island, 2005 – 2014**



**Figure 16: Infectious Syphilis Cases, Rhode Island, 2005 – 2014**



**Part 2**

The second component of the prevention needs assessment is the needs assessment that was conducted in conjunction with the CPPG. This group identified some key points within the 5 main prevention activities conducted by RIDOH, which are summarized below. For a complete list of the talking points see Appendix 6.

**Return to care**

One of the topics around the return to care program that surfaced multiple times was the need for transportation. Individuals who have to spend a whole day managing a few different bus schedules are very likely to fall out of care, or if they are only provided with 1 cab voucher it is enough to get them to their appointment, but not to take them home, and they may decide not to go. Another suggestion was greater collaboration with case managers and recommended that case managers could refer someone to the return to care program. Homelessness was also mentioned with utmost importance, since if individuals are struggling to live, and living on the streets, they may be less concerned with receiving medical care. This is especially important for individuals who are being released from the department of corrections as they have received care during their stay, but fall out of care if they are homeless once they are released. The Rhode Island Department of Health has recently started to integrate HIV surveillance with the Out of Care Program to determine if an individual is truly out of care or if they are receiving their HIV care elsewhere. It is necessary to ensure open communication ADAP, RIDOH and RI-EOHHS regarding return to care, and the barriers that are leading people to be out of care.

## **Condoms**

The CPPG suggested that it may be beneficial to have a survey regarding condom usage. This question has been added to the 2016 BRFSS, but unfortunately there will not be any data available until summer 2017. Another suggestion was to promote the distribution of other forms of contraceptives along with condoms. This may be beneficial in preventing unplanned pregnancy, and due to the introduction of the Affordable Care Act, these may be easier to access. However, some people do not realize the importance of STD prevention and assume since they will not get pregnant they will not use a condom. The Rhode Island Department of Health must weigh the implications of promoting alternative types of birth control, since it is estimated that only 8% of women use multiple methods to prevent pregnancy<sup>34</sup>. It was suggested that RIDOH distribute condoms at fairs or farmers markets, and although RIDOH is not doing this work directly there are over 70 different locations throughout the state where individuals can obtain free condoms. The Rhode Island Department of Health is currently in the process of mapping the condom distribution sites throughout the state, and making this map available online to the general public. A final suggestion was to utilize more eye catching posters to promote condom usage.

## **Partner services**

The advice that RIDOH received regarding partner services was for case managers to refer HIV positive patients who may need partner services. This need may indicate that individuals who are HIV infected may not be disclosing their infection status to their partners or if they are, they may not be using consistently using proper protection.

## **Needle Exchange**

One suggestion focused around the needle exchange program was to provide education for parents of teenagers on sex, STDs, HIV prevention, and symptoms of drug use. This education may encourage parents to recognize when their child is engaging in these more risky behaviors and allow them to help their child as necessary, whether that's encouraging the child to use condoms, or accessing drug treatment programs. Another important suggestion was to make sure that all case managers and providers know about the needle exchange program, including the hours and locations so they can provide referrals as necessary. Furthermore it was recommended to reach out to shelters as well as promote outreach mechanisms that do not rely solely on word of mouth such as advertisements in bars etc.

## **Community Based Testing**

Community based testing is a very important aspect of prevention. Partner services was the most successful non-clinical testing venue, and it is necessary that this detail is not overlooked. In 2015, among the individuals that were identified and tested through partner services approximately 10% of them were found to be HIV positive compared to less than 1% of community based testing at other venues. The CPPG suggested routine testing at the Department of Corrections as well as testing at city fairs, food co-ops and farmers markets.

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<sup>34</sup> <https://www.gutmacher.org/fact-sheet/contraceptive-use-united-states#10>

Another suggestion that was made was to collaborate with Youth Pride Inc. regarding testing, as young gay men have some of the highest rates of HIV.

### **2013 RI Ryan White Provider Capacity in the Provision of Services**

The Provider Capacity in the Provision of Services Survey was initiated in November 2012 and completed by providers in February 2013 and has been updated in 2015 in order to take a more in-depth look at the needs for PLWH/A in Rhode Island. The consulting group of John Snow Inc. (JSI) was responsible for developing the survey content, methodology and implementing the process of collecting and analyzing the survey data. This survey represents the providers' report of their capacity to render certain medical and support services to PLWH/A, their perception of clients' barriers to adequate care, and their reported needs for addressing service gaps. JSI initially sent out surveys to 95 organizations. JSI received 54 respondents representing 42 organizations starting the survey but 21 respondents subsequently opted out of the survey because they did not provide services to PLWH/A. Information was gathered from a variety of providers including Ryan White funded and non-funded providers, which included health centers, substance abuse providers, domestic violence agencies, social service agencies, hotlines, substance abuse treatment facilities and mental health centers throughout the state. Information about organizations including hours, location, services offered, languages spoken, potential barriers to care, and populations served was also collected. This survey is used to determine services offered and to increase capacity and capability and to enhance patient/client services and mental health centers throughout the state. In conclusion, the 20 provider respondents included in this survey represent 100% of the provider organizations who are funded by the Ryan White Care Act in Rhode Island. The dataset included in the survey is highly representative, however its limitations include the fact that respondents did not self-identify as a provider specifically for PLWH/A and that all data contained in the survey was self-reported.

### **Survey Methodology<sup>35</sup>**

#### **Provider Capability and Capacity Survey Process**

The survey process is outlined in the following steps:

1. Collecting participant contact information
2. Drafting the survey
3. Piloting and testing the survey
4. Surveying and Follow up
5. Data Cleaning and Review
6. Survey Results Write-up, Resource Inventory, and Referral Guide
7. Dissemination

1. Collecting participant contact information:

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<sup>35</sup> Appendix 3: 2013 RI Ryan White Provider Capacity in the Provision of Services Survey

The identification of potential survey participants began by reviewing a local-specific “Frequently Asked Questions” brochure for clients receiving a new HIV-positive diagnosis in Rhode Island. The referral guide titled “I just Found Out: Frequently Asked Questions About Your HIV Test In Rhode Island (2009 Update)” was developed by JSI. The guide includes a list of providers from non-HIV and HIV specific organizations, both funded and not funded by HRSA to provide HIV care and related services or other services to PLWH/A. Each organization on the list was called until an appropriate contact’s name and e-mail was identified. This list was reviewed and edited by the HIV Provision of Care Unit at RI-EOHHS. The Rhode Island Provision of Care Planning Body (PCPB) – the precursor to the CPPG – also provided input and identified additional participants. The final list of potential survey participants included 95 organizations/agencies/sites.

## 2. Drafting the survey:

The provider capacity survey was developed to identify which services to PLWH/A are accessible, available, and appropriate. JSI edited and added survey questions to a draft Provider Survey that was produced for the RI Ryan White program in 2010. JSI worked with RI-EOHHS to frame the survey and review the new survey draft. Throughout the survey development process the tool was reviewed to look specifically at HRSA’s guidance, requirements, and recommendations for developing a provider capacity survey and resource inventory. A 43-item survey was then finalized and the questions were entered into Survey Monkey.

## 3. Piloting and testing the survey:

Key representatives from the PCPB reviewed the draft survey and provided feedback. After piloting and testing the draft survey, the tool was revised to include appropriate skip patterns and opt-out to the electronic questionnaire. Based on input from RI-EOHHS and pilot participants, an introductory letter designed to encourage participation, an e-mail to introduce the survey, and adequate instructions to complete the survey were developed. The electronic survey was tested extensively by JSI staff and minor adjustments were made to improve user friendliness. A final version of the electronic survey and all related documents were sent to RI-EOHHS for approval.

## 4. Surveying and Follow up:

An electronic version of the survey was sent out via email to 95 organizations providing services available to PLWH/A in Rhode Island in November, 2013. Survey participants were encouraged to forward the survey to colleagues whom they thought would be appropriate to respond as well.

We followed up twice with e-mail reminders to participants that did not complete the survey to encourage participation.

## 5. Data Cleaning and Review:

Data were reviewed to assess the quality and completeness of the survey responses. This included an examination of non-responders, respondents who opted out, and incomplete surveys. Data were cleaned to ensure that each organization was only represented by one

response. It is important to note that many of these organizations have multiple physical locations. All locations are mapped using a Geographic Information System (GIS) and represented in the results section of this report, including respondents that represented one of more physical locations.

#### 6. Survey Results Write-up, Resource Inventory, and Referral Guide:

Data were analyzed and survey results are summarized in this report. In addition, the results of the survey will be used to develop a state resource inventory, as well as a referral guide.

#### 7. Dissemination:

Survey results were shared with the state's HIV/AIDS advisory groups, the Provision of Care Committee, and the CAB. Results continue to help RI-EOHHS make decisions regarding service gaps and needs throughout the State.

### **2015 RI Ryan White Consumer Survey, Survey Methodology**

#### **Survey Administration<sup>36</sup>**

##### IRB Approval

The JSI Institutional Review Board (IRB) approved the study design on November 11, 2015 (IRB #15-023). The submission received Expedited Review based on the applicable federal regulation. The IRB specifically considered (i) the risks and anticipated benefits, if any, to subjects; (ii) the selection of subjects; (iii) the procedures for securing and documenting informed consent; (iv) the safety of subjects; and (v) the privacy of subjects and confidentiality of the data.

##### Recruitment

Recruitment took place for approximately two and a half months, starting in mid-November 2015 and ending on January 31, 2016. Recruitment utilized support from HIV/AIDS care, treatment, and service agencies contracted with RI-EOHHS, physician practices, and other health and social service agencies that provide services to PLWH/A in Rhode Island. Agency staff and/or case managers at these agencies identified eligible consumers and facilitated their completion of the survey either in person or online.

##### Survey Distribution and Administration

The survey was available via paper and online modalities. The paper version was available in both English and Spanish. The online version was available in English only.

Agency staff and/or case managers were given copies of the RI RW HIV Care and Services Consumer Survey and cards printed with the online survey weblink (herein called "weblink cards"). Paper surveys were only administered by agency staff and were completed onsite at the agency. If the respondent preferred to complete the survey offsite, agency staff gave the individual a weblink card with instructions to complete the survey online or allowed the respondent to complete the paper survey offsite and return the completed survey at a later

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<sup>36</sup> Appendix 2: 2015 RI Ryan White Consumer Survey

time. Each agency kept completed surveys in a locked cabinet or box. JSI staff picked up completed surveys from each agency on a monthly basis.

### Consent process

Respondents accessing the survey through case managers were verbally consented to participate. Due to the sensitive nature of disclosing one's HIV status and the field-based aspects of these activities, having written consent forms linking respondents' names to the purpose of these activities was deemed an unnecessary risk of disclosure of a respondent's HIV status. Only agency staff consented respondents. IRB-approved consent information was included with the paper and online version of the survey to ensure each respondent:

1. had full understanding of the activities he or she is being asked to participate in;
2. had the ability to ask any clarifying questions regarding these activities; and,
3. was provided with the name and contact information for the JSI Project Associate for these activities.

The IRB-approved consent information included in the online and electronic survey was replicated in the weblink card.

### Respondent Screening

Before handing out weblink cards or paper surveys to consumers, agency staff determined whether a respondent was eligible to respond. These questions were asked verbally. Should a respondent screen ineligible to complete the survey, case managers did not administer the survey or hand out weblink cards. The questions were as follows. The required response is underlined.

1. Do you live in Rhode Island?
  - Yes
  - No
2. Are you HIV+?
  - Yes
  - No
3. Are you 18 years old or older?
  - Yes
  - No

These questions also appeared in the survey itself.

Case managers also asked respondents if they had taken the survey prior through their case manager or at another agency.

### Survey Tracking

All surveys had a unique ID associated with them. This unique ID was numeric and appeared random to the respondent (e.g. "5613906"). It encoded for the survey administration type (electronic vs paper), the distribution point (agency name), and the sequential survey number. JSI maintained a master list of ID numbers, associating each unique ID with the administration type and distribution point. This enabled JSI staff to track the number of respondents resulting

from each agency. Unique IDs were not linked with any identifying information from the respondent at any point during the survey administration or analysis process. All paper surveys were pre-printed with the unique ID on each page. All weblink cards were also pre-printed with unique ID numbers. When a respondent accessed the survey online, he/she was prompted to enter the unique ID. As with the paper versions, agency staff were responsible for tracking the unique IDs distributed in this way. Agency staff were responsible for letting JSI staff know if they required additional surveys and weblink cards.

### Incentives

Respondents who complete the survey received \$20 gift card to a local grocery chain, Stop & Shop, as a token of appreciation.

Agency staff handed out gifts cards at the completion of the paper survey. Each gift card was recorded on a gift card tracking form that includes the unique survey ID. No contact information other than the respondent's initials was included on this form. It was not possible to associate contact information with survey responses.

For respondents who complete the survey online, they were directed to a separate online survey to complete contact information for a gift card to be mailed to them. It was not possible to associate online contact information with online survey responses. JSI ensured that individuals did not receive more than one gift card by keeping track of names and addresses in a separate system. JSI mailed incentives (\$20 per response) to the respondents who completed the online survey within a month. Agency staff informed respondents of this time frame prior to distributing the card with the online link. Additionally, a description of the process and time frame was included in the introduction page of the online survey.

### Data Storage, Analysis, and Usage

Online surveys were administered through SurveyGizmo in Boulder, CO<sup>37</sup>.

All data downloaded from Survey Gizmo was housed at secure, password-protected JSI servers and drives and was accessible only to project staff. All paper surveys were stored in a locked cabinet in a JSI office.

## **Data Analysis**

### Data Entry

JSI manually entered all returned surveys into the online SurveyGizmo system. For questions that were not answered, JSI selected the "Choose not to answer" response option. This response option was only available on the online version of the survey to promote full responses by respondents on the paper version. If a respondent did not answer one of the three screening questions (Q02, Q03, or Q04), the data entry analysts checked corresponding questions in the survey (Q05 for age, Q10 for RI residence, and Q22 for HIV status). Only if the respondent did not answer both questions was the response excluded. If a respondent selected multiple options for a single-select question, then the first option selected was recorded.

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<sup>37</sup> Appendix 2: 2015 RI Ryan White Consumer Survey

For write-in questions, the data entry analyst transcribed the written text to the best of his/her ability. Incorrectly spelled words were not corrected. All Spanish surveys were entered by an analyst with intermediate Spanish reading skills.

### Data Cleaning

All data cleaning was completed in the statistical programming language of “R”. Data was downloaded from SurveyGizmo in the SPSS file format and converted to a data frame in “R”. JSI ensured that the same unique ID was not used to take the survey more than once. In the event that the same unique ID was used, only one survey response was included. If one survey was more complete than the other, that survey was used. If both surveys were equally complete, then the first survey was used.

If a respondent selected the “other (please specify)” response option and wrote a response that was consistent with an existing response option, that response was recoded to that response option. The JSI analyst consulted with the broader team to make these determinations.

### Analysis

All analyses were completed in the statistical programming language “R” with use of the dplyr, ggplot2, and rmarkdown packages.

For each question, the total number of respondents, total number of eligible respondents (based on the skip logic), and the response percentage (respondents divided by eligible respondents) was calculated.

For single-select questions and multi-select questions, the number of responses for each response option was calculated. This “Count” was divided by the eligible respondents to calculate the “Percentage.” Both the count and percentage were reported in both tabular and graphical format. Single-select questions have percentages that sum to one hundred. Multi-select questions may have percentages that sum to over one hundred because an individual respondent could select more than one response option. All questions were stratified by 8 demographic questions to identify response differences between racial, ethnic, social, and age groups. The demographic stratifications included gender, sexual identity, race, ethnicity, language, education, household income, and number of years with HIV. Additional stratifications between non-demographic questions were completed based on need. For stratifications, counts were calculated for each response option pair and divided by the total number of eligible respondents in that category. Only respondents that answered both questions were included in the percentage numerators and denominators. Survey demographic data was compared to 2014 statewide prevalence data to ensure that the sample adequately represents the state epidemic. Barriers to care data from the 2014 Rhode Island Provider Capacity Survey was included to compare provider perspectives on barriers to care to what the consumers report being most difficult about receiving care.

### Presentation

Only aggregate data was included in data reporting and presentation. Great effort was made to describe the population that responded to the survey to ensure those reading the findings will clearly understand any possible limitations related to sampling.

### **2016 RI Ryan White Consumer Focus Groups, Methodology<sup>38</sup>**

Three focus groups were convened with three separate consumer advisory boards or consumer groups. Existing groups were chosen due to the fact that members already know the HIV-status of fellow group members and there was no additional risk of status-disclosure. Participants were offered a \$20 gift card to a grocery store, Stop & Shop, in exchange for their participation.

A focus group guide containing questions and probes was developed by JSI for use by the facilitator. Questions were designed to introduce a topic and probes were designed to follow up on a topic based on the group's response. Questions were carefully chosen to further explore trends identified in the 2015 RI-EOHHS Ryan White Consumer Survey<sup>39</sup>.

The facilitator described the purpose of the focus group; the context of it (i.e. part of a needs assessment for the Ryan White HIV program in Rhode Island); and, how consumers' feedback, perspective and experiences are critical to HIV service delivery in Rhode Island. The facilitator also ensured that key questions were asked and facilitated discussion to identify key messages and ensure participation from all group members. Participants were asked to not only talk about their own experiences, but also those of their peers—some of whom may be out of care.

Demographic information was collected from participants. No identifying information was obtained as part of the survey process. This demographic information was analyzed in aggregate for summary statistics including frequencies and percentages.

During all focus groups, a note taker was present to record the conversation. An audio recorder was also used to assist in the notetaking process. Notes were taken in a manner that listed participant comments sequentially. Comments were not grouped by individual.

The focus group notes were analyzed in aggregate using thematic narrative analysis. Topics were iteratively identified in the text and tagged with a corresponding topic code. Topic codes were chosen based on the content of the participant's comments and were not predetermined. They were organized under the following category headings: mental health, substance use, system of care, self-care, and other. Some text was tagged with more than one topic code. Text chunks were then aggregated by topic code. Themes were identified through a contextual analysis of participant comments by code.

The software program 'QDA Miner Lite' was used to code the text and compile by theme. Wordle.net was used to make the wordclouds. The final report is organized by theme category.

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<sup>38</sup> Appendix 5: 2016 RI Ryan White Consumer Focus Groups

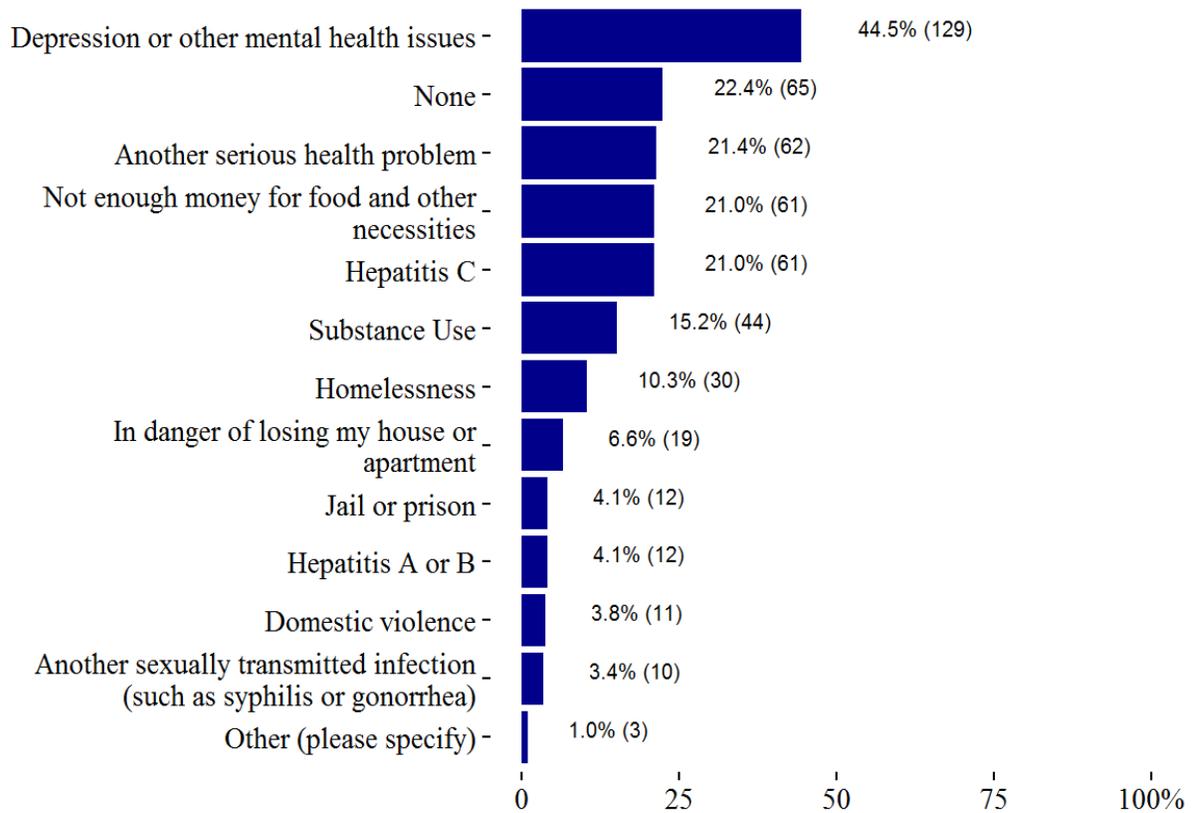
<sup>39</sup> Appendix 5: 2016 RI Ryan White Consumer Focus Groups: Methodology

**b. Describe the HIV prevention and care service needs of persons at risk for HIV and PLWH/A.**

**2015 RI Ryan White Consumer Survey Results<sup>40</sup>**

The most common disease, health condition, or life situation in addition to HIV/AIDS that respondents had been dealing with over the past 12 months was depression or other mental health issues (44.5%) followed by 'none' (22%), another serious health problem (21%), not enough money for food and other necessities (21%), hepatitis C (21%), substance use (15%), and homelessness (10%).

**Figure 17: Other Medical & Personal Issues (n=290), m.**



Notes: 'm.' indicates multi-select question.

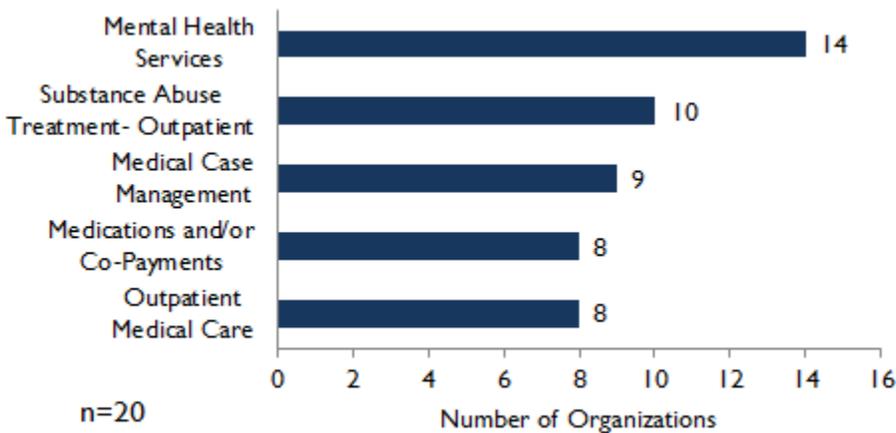
Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

<sup>40</sup> Appendix 2: 2015 RI Ryan White Consumer Survey

### 2013 RI Ryan White Provider Capacity in the Provision of Services, Survey Results<sup>41</sup>

Respondents were asked to report the types of core medical services that their respective agency directly provides to PLWH. **Figure 18** represents the top 5 core medical services that are provided by agencies responding to the survey. This figure is also reflective of top 5 services provided to the most PLWH by their agencies (asked in a separate question on the survey).

**Figure 18: Top Core Medical Services Provided to PLWH**



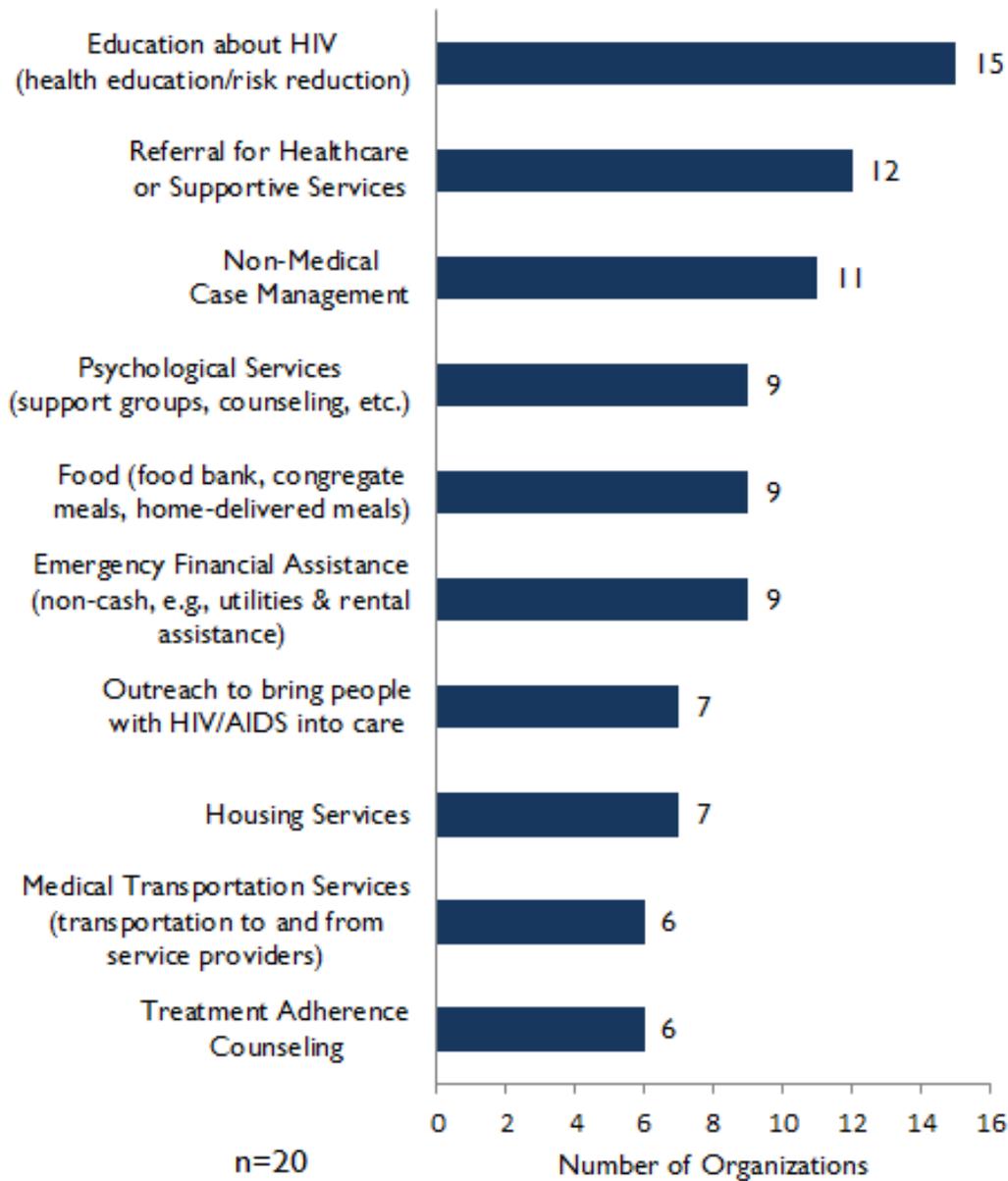
Other core medical services mentioned include: health insurance premium and cost-sharing assistance (5), home and community-based health services (5), early intervention services (5), dental/oral health (5), medical nutritional therapy (3), home health care (1) and hospice care (1). Five respondents reported that their agencies did not offer any of the “core medical services” listed.

Support services that are needed for people with HIV/AIDS to achieve their medical outcomes include respite care for caregivers of people with HIV/AIDS, outreach services, medical transportation, linguistic services, and referrals for health care and support services, among others.

**Figure 19:** represents the top 10 types of support services provided to PLWH. Other services reported that are not listed in the figure include: substance abuse treatment – residential (4), job training or placement assistance (4), linguistic services (interpretation and translation) (3), child care services (2), needle exchange services (2), respite care (1), emergency financial assistance - cash payments (1) and registered dietician (1).

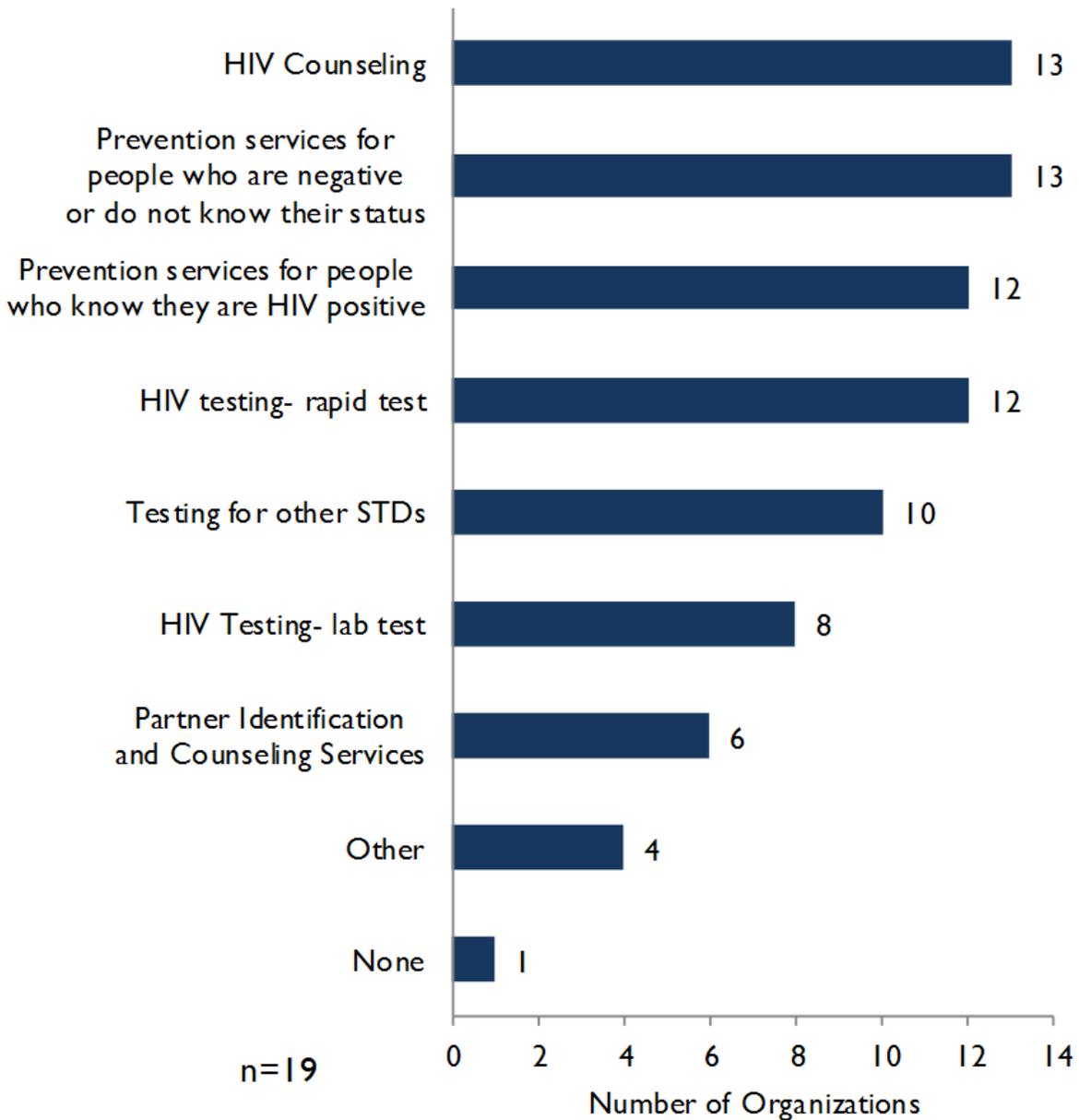
<sup>41</sup> Appendix 3: 2013 RI Ryan White Provider Capacity in the Provision of Services Survey

**Figure 19: Top 10 Support Services Provided to PLWH**



Survey respondents were also asked to identify prevention, counseling and testing services provided by their agencies (**Figure 20**). Respondents identified that other prevention, counseling and testing services included: needle exchange, primary care, Post-exposure Prophylaxis (PEP), Pre-exposure Prophylaxis (PrEP), crisis hotline/listening line, website, and collaborative work with other agencies that offer: prevention education, needle exchange, overdose prevention training, and naloxone distribution.

**Figure 20: Prevention, Counseling, and Testing Services**



Prevention programs that educate high-risk HIV negative individuals and/or HIV-positive individuals offered by participating agencies included the following: counseling, case management, education (via providers, groups and/ or materials), screening, specialized prevention services to specific populations (chronic homeless, cognitively impaired, and gap youth), free and anonymous testing services and events, opioid overdose prevention and naloxone distribution, and safe sex and injection supplies. Three respondents indicated that they did not have a prevention program.

***c. Describe the service gaps (i.e., prevention, care and treatment, and necessary support services e.g. housing assistance and support) identified by and for persons at higher risk for HIV and PLWH.***

### **2015 RI Ryan White Consumer Survey Results<sup>42</sup>**

The following three graphics represent this survey's findings around assessment of need. Respondents were asked to rate sixteen different services by whether they 'need but can't get the service,' 'need and use the service,' or 'don't need the service.' In this context, need is defined as the number of people who need the services and either are currently receiving it or not receiving it. 'Unmet Need' is defined as the number of people who the service and cannot get it.

The following graphs show need as a percentage of all individuals who responded to the question in blue. They show unmet need as a percentage of respondents who indicated a need.

**Need (Blue):**  $Need / AllRespondents (100)$ ; **'Unmet Need' (Red):**  $'Unmet Need' / Need (100)$

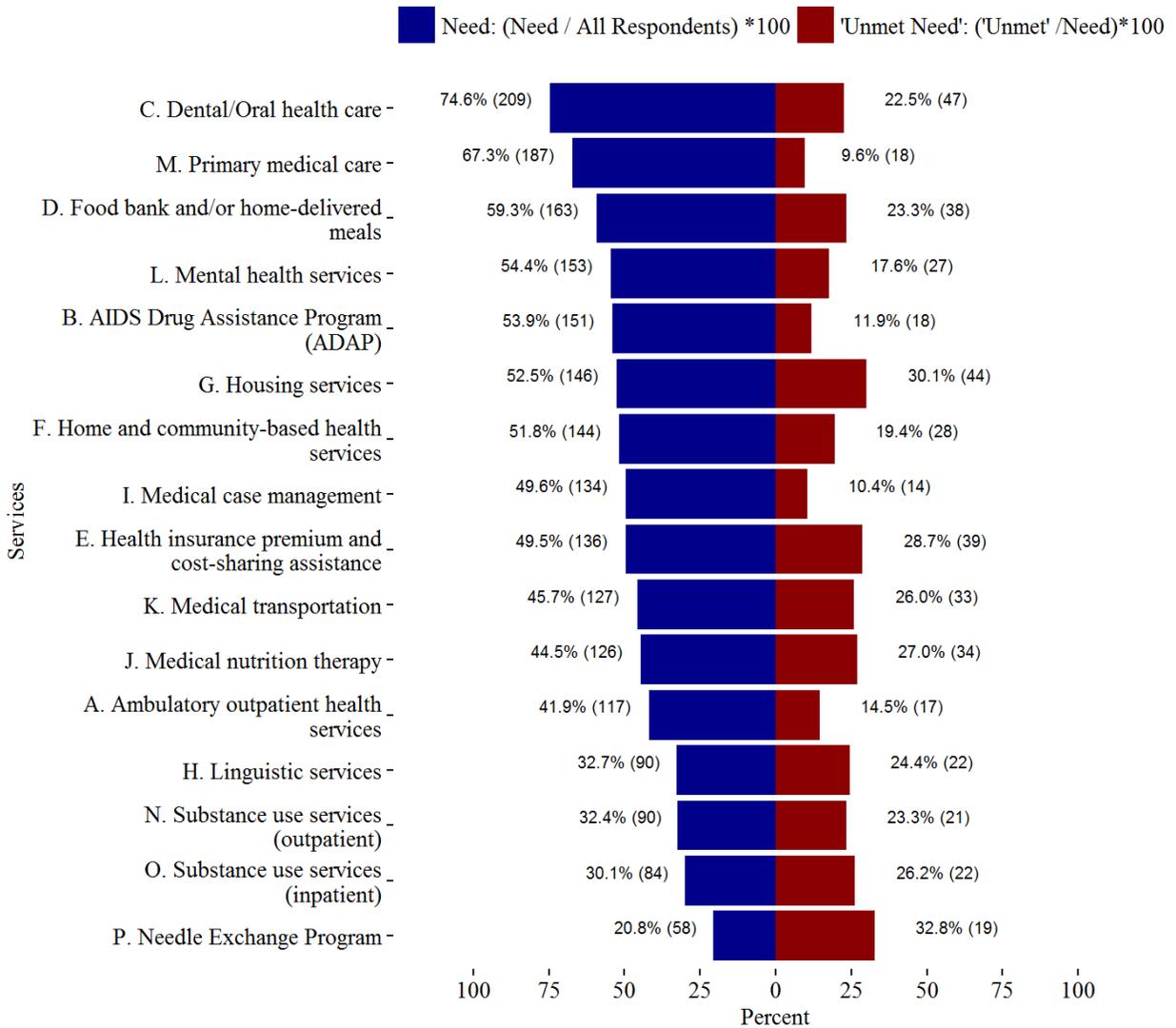
The graphs are presented in two fashions: sorted by need (Blue), and sorted by 'Unmet Need' (Red).

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<sup>42</sup> Appendix 2: 2015 RI Ryan White Consumer Survey

The following assessment of need graph that is sorted by need highlights the most commonly needed services by PLWH/A in Rhode Island (**Figure 21**). The top eight needed services are Dental/Oral health care (75%), primary medical care (67%), food bank and/or home-delivered meals (59%), mental health services (54%), ADAP (54%), housing services (53%), home and community-based health services (53%), and medical case management (50%). These percentages are reflective of the percent of the PLWH/A population in Rhode Island who are in need of the listed service.

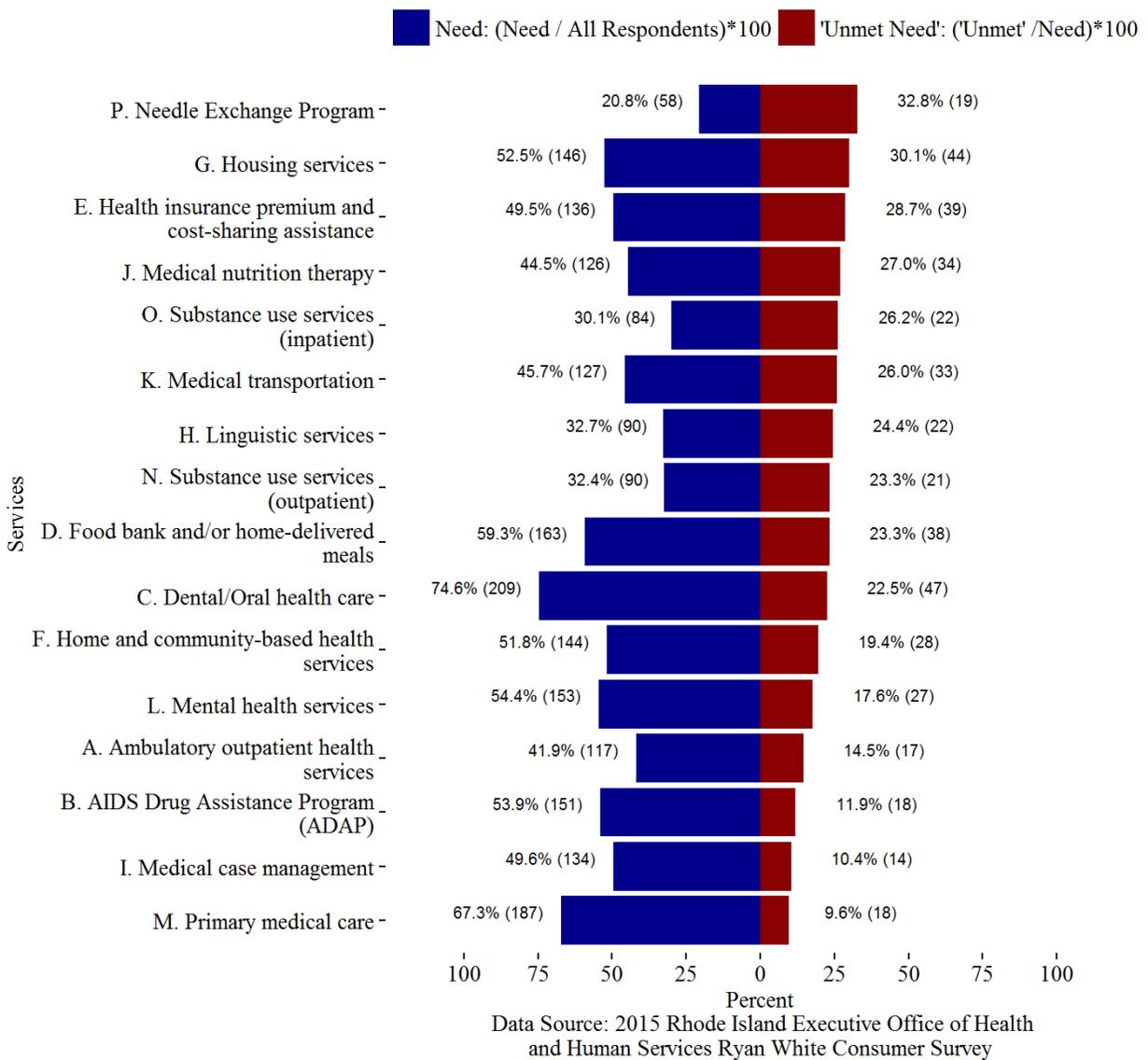
**Figure 21: Assessment of Need: Sorted by Need**



Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

The following graph that is sorted by 'unmet need' highlights the services with the highest percentage of people who need the services, but do not have access to them (Figure 22). The top eight services by percent of need that is unmet are needle exchange program (33%), housing services (30%), health insurance premium and cost-sharing assistance (29%), medical nutrition therapy (27%), substance use services inpatient (26%), medical transportation (26%), linguistic services (24%), and substance use services (outpatient) (23%). This graphic shows that while some services are needed by a relatively low percentage of the overall PLWHA population in Rhode Island (e.g. needle exchange, substance use services, and linguistic services), there is still a high percentage of the people who need the service that cannot access the service.

**Figure 22: Assessment of Need: Sorted by 'Unmet' Need**



**d. Describe barriers to HIV prevention and care services, including, but not limited to:  
i. Social and structural barriers (e.g., poverty, cultural barriers, stigma, etc.);**

**2015 RI Ryan White Consumer Survey Discussion<sup>43</sup>**

This section first presents a framework for achieving health equity and then summarizes key findings, insights, and recommendations.

*A Framework for Achieving Health Equity*

The results section offered numerous examples of social and economic conditions (e.g. household income, employment, education status), health processes (e.g. visiting the doctor, taking medications), and health outcomes (e.g. viral suppression) that differed by race, ethnicity, age, gender, and sexual identity. These are exceptionally clear real-world examples of social determinants of health. The **Introduction** to this report included a description of social determinants of health in the context of HIV/AIDS (included below).

Social determinants of health (SDH) are “economic and social conditions that influence the health of individuals and communities”<sup>44</sup>. Inherent to geographic locations and social demographics, they define how physical resources and personal agency are distributed across a population and determine who is subjected to stigma and discrimination. Lack of education, adequate income, or appropriate housing makes it more difficult for individuals to engage in appropriate prevention, health promotion, and self-care activities. The literature clearly demonstrates that educated, resource-rich individuals are more likely to be healthy while the less-educated, resource-poor are more likely to be unhealthy and lack adequate access to healthcare<sup>45</sup>.

HIV/AIDS is no exception. Its aggressive pathophysiology necessitates complex treatment, regular self-care, and consistent follow-up, making it especially difficult for resource-poor individuals to manage. Not only is it disproportionately present in minority populations such as Latino and Black gay men (i.e. MSM), but those groups also have worse health outcomes when compared to their non-Latino or white peers<sup>46 47 48</sup>. A primary mechanism for these observed

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<sup>43</sup> Appendix 2: 2015 RI Ryan White Consumer Survey

<sup>44</sup> Dean, H. D., & Fenton, K. A. (2013). Integrating a Social Determinants of Health Approach into Public Health Practice : A Five-Year Perspective of Actions Implemented by CDC ’ s National Center for HIV / AIDS , Viral Hepatitis , STD , and TB Prevention, *128*, 5–11.

<sup>45</sup> Abbott, L. S., & Williams, C. L. (2015). Influences of Social Determinants of Health on African Americans Living with HIV in the Rural Southeast: A Qualitative Meta-synthesis. *Journal of the Association of Nurses in AIDS Care*, *26*(4), 340–56. <http://doi.org/10.1016/j.jana.2015.03.004>

<sup>46</sup> Howe, C. J., Napravnik, S., Cole, S. R., Kaufman, J. S., Adimora, A. A., Elston, B., ... Mugavero, M. J. (2014). African American race and HIV virological suppression: Beyond disparities in clinic attendance. *American Journal of Epidemiology*, *179*(12), 1484–1492. <http://doi.org/10.1093/aje/kwu069>

<sup>47</sup> Mugavero, M. J., Lin, H., Allison, J. J., Thomas, P., Willig, J. H., Raper, J. L., ... Saag, M. S. (2009). Racial Disparities in HIV Virologic Failure: Do Missed Visits Matter? *Journal of Acquired Immune Deficiency Syndromes*, *50*(1), 100–108. <http://doi.org/10.1097/QAI.0b013e31818d5c37>.

<sup>48</sup> Oster, A. M., Russell, K., Wiegand, R. E., Valverde, E., Forrest, D. W., Cribbin, M., ... Paz-Bailey, G. (2013). HIV

disparities are missed medical visits, which are much higher among black and injection drug use patients and have been statistically shown to account for lack of viral suppression in these populations<sup>49</sup>.

It is important to not only have awareness of the existence of social determinants of health but also have a framework for developing a comprehensive plan that identifies actionable steps to move towards greater health equity. The HIV Care Continuum, also explicated in the introduction of this report, presents an analytic framework around the necessary stages of involvement of a person living with HIV/AIDS with their healthcare system and treatment. But it does not summarize the social and economic factors that cause disenfranchisement and poor health outcomes. Fortunately, ‘social determinants of health’ provides a strong foundation to develop a specific framework for identifying intervention points.

This report presents “A Framework for Achieving Health Equity” as the means to identify specific points of intervention that are relevant to this survey’s results around social determinants of health. This framework was adapted from the Bay Regional Health Initiative’s Framework for Achieving Health Equity. It is a compilation of both a socio-ecological model and a medical model.

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Infection and Testing among Latino Men Who Have Sex with Men in the United States: The Role of Location of Birth and Other Social Determinants. *PLoS ONE*, 8(9). <http://doi.org/10.1371/journal.pone.0073779>

<sup>49</sup> Zinski, A., Westfall, A. O., Gardner, L. I., Giordano, T. P., Wilson, T. E., Drainoni, M. L., ... Mugavero, M. J. (2015). The contribution of missed clinic visits to disparities in HIV viral load outcomes. *American Journal of Public Health*, 105(10), 2068–2075. <http://doi.org/10.2105/AJPH.2015.302695>



needed services), and increased likelihood of exposure to environmental toxins. Beyond the physical environment, individuals may also face a hostile social environment, complete with class-based, race-based, and gender-based violence. This could take the form of overt discriminatory statements or actions against a minority or the presence of pop culture, advertisements, and media that depict minorities in a negative manner. In the work environment, these forces, including prior limited access to educational opportunities, could manifest in fewer employment opportunities, less income, and additional occupation hazards. The socio-ecological model highlights upstream points of intervention that can take place before an individual becomes sick or injured. Policy changes can make institutional systems more effective for minority groups and promote the work of social service organizations to mitigate the consequences of poor living conditions through outreach programs, affordable housing, and other support services. However, to address the source of discrimination at its root, advocacy and social action are needed. They work to improve society's prevailing attitude towards minority populations.

In contrast to the socio-ecological model, the medical model focuses primarily on risk behaviors, clinical diagnosis, and medical intervention in the treatment of disease. Individuals who engage in risk behaviors such as smoking, poor nutrition, low physical activity, violence, alcohol & other drugs, and unsafe sex are more likely to be diagnosed with disease and have poor health outcomes. It is here that the medical model interfaces with the socio-ecological model. The individuals most at risk for risk behaviors are those who are disenfranchised through social inequities, institutional power structures, and inferior living conditions.

Within the medical model, there are several intervention points. The first is health education to reduce risk behaviors and promote healthy lifestyles. When individuals do become sick or injured, the healthcare system—made up of networks of doctors, nurses, therapists, administrative staff, and many others—works to treat the disease or heal the injury. But 'healthcare' is a type of institution itself, and thus risks conferring discrimination or not being structured for ease-of-use by minority populations. Case managers can mitigate this by helping patients navigate the complex system of care. They also can help address some of the underlying living condition problems by connecting their clients to support services. Stigma from HIV status may be experienced across all points of this framework, adding to an individual's existing social, economic, and medical challenges. The experience of stigma is multilayered and complex. It may manifest externally (e.g. a disparaging comment by a health provider, peer, or family member) or internally (e.g. a feeling of failure) and may be a result of existing cultural norms in a given population. Stigma from HIV may also compound the experience of racial or ethnic discrimination in minority populations.

While this framework is presented in a linear fashion, it is also cyclic and recursive. Sick, infirmed, and injured people have to overcome significant challenges to be productive, employed, and self-sustaining. As a result, they may be less likely to have the income required to maintain healthy living conditions and health-promoting behaviors. For some, these factors and forces may trap them in a vicious 'snowball-effect' cycle of poverty, unemployment, and

disease. For these individuals, it is incredibly important that they receive multiple interventions at all possible points in their trajectory: social service, health education, case management, and healthcare.

Thoughtful, robust, and effective efforts are needed to address discrimination and structural inequities. Thankfully, the federal government has made this a priority for the national HIV/AIDS system of care. The *National HIV/AIDS Strategy: Updated to 2020*, released in July 2015, notes that addressing living conditions, discrimination, and stigma is critical in achieving health equity:

To address disparities requires focusing on disproportionately affected communities and populations; implementing structural approaches to HIV prevention and care that address conditions such as housing, education, employment, and food security; and reducing stigma and eliminating discrimination associated with HIV infection.<sup>51</sup>

Likewise, addressing living conditions, discrimination, and stigma to reduce health disparities is a top priority in Rhode Island. As these survey results show, there are clear differences in health processes and outcomes between racial, ethnic, and socioeconomic groups. Recognizing these differences and understanding their origin allows efforts to not only focus on groups with greatest need but also target specific intervention points. Ultimately, the most sustainable solutions will result from addressing the upstream factors that drive health inequalities. Lastly, the framework for achieving health equity provides structural support for the key findings, insights, and recommendations that are presented in the next section.

### *Findings, Insights, & Recommendations*

The following section presents key findings, insights, and recommendations.

#### **Social Determinants of Health: Race, Sex, Income, Education**

Health disparities by racial, social, and economic categories among PLWH/A were a strong theme throughout nearly all of the results from the survey.

Individuals who identified as black were more likely than individuals who identified as white to have a household income of less than \$10,000 per year, use Medicaid, not have had a visit to an HIV medical provider within the last 6 months, report not being virally suppressed, and report trusting their provider as a barrier to care.

Individuals who identified as Hispanic or Latino/a were significantly more like than those that identified as not Hispanic or Latino/a to have a household income less than \$10,000 and report an education level of below high school.

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<sup>51</sup> White House Office of National AIDS Policy. (2015). *National HIV/AIDS Strategy*. Washington (DC).

<https://www.aids.gov/federal-resources/national-hiv-aids-strategy/nhas-update.pdf>

Individuals who identified as female were more likely than males to have a household income of less than \$10,000 per year, be disabled or unable to work, use Medicaid, not have had a visit to an HIV medical provider in the last 6 months, and report not being virally suppressed.

Individuals who identified as having a household income of less than \$10,000 per year were more likely than those with a household income of more than \$10,000 per year to report not being virally suppressed, report trusting their provider as a barrier to care, and report depression.

Individuals who identified as having an education level of less than high school were more likely than those with a higher level of education to have a household income of less than \$10,000 per year, be disabled or unable to work, use Medicaid, report needing time to deal with the diagnosis as a reason for delaying visit to an HIV medical provider after diagnosis, report not having a visit to an HIV medical provider in the last 6 months, report not being virally suppressed, report trusting their provider as a barrier to care, and report substance use.

These findings reflect well-documented vulnerabilities associated with individuals living in poverty and challenges related to being a racial or social minority in America. The following example demonstrates how poverty and lack of education can impact health in these populations:

People without a high school education may have fewer work-related skills to present to potential employers or may only qualify for low paying jobs. As a result, they are less likely to find work and be paid above minimum wage. To support themselves and their family, they may need to take on more work hours or additional part-time jobs, leaving less time for self-care and medical appointments. Inconsistent work schedules might make it more difficult to take medications on schedule and there may be limited time for other health promotion activities such as exercise and eating well. Furthermore, life's sudden disruptions, such as a leaky roof or broken car, may require forfeiting money for medications or planned time-off to see an HIV medical provider. And fluctuations in monthly income might pinball individuals between different levels of eligibility for housing programs and health insurance, requiring constant diligence to maintain access to basic human needs.

Poverty disproportionately impacts minority groups. This survey shows that Black people and Hispanic people living with HIV/AIDS in Rhode Island are more likely to have a household income of less than \$10,000 per year than white and non-Hispanic people. Generations of structural violence—social and institutional systems that prevent certain groups from meeting their basic needs—and racism bear responsibility for this unacceptable social reality.

When considering how to improve health outcomes for these populations, it is important to recognize the dual need for both non-medical supportive services and the medical system of care. Non-medical supportive services provide acute assistance to meet basic human needs like housing, food, and employment. Without a safe place to sleep and access to healthy food,

active engagement in self-care activities such as medication management becomes even more challenging. A stable home address and phone number make it much easier for HIV clinics to follow-up and ensure that the individual is linked to care.

Both sides, HIV medical and non-medical services, need to be continually evaluated on whether their services are ***easy to find, access, and use*** by impoverished and minority populations. It is an unfortunate reality that aspects of the system of care in Rhode Island and nationally place great burden on the individual to decipher the available set of social and medical services. Impoverished individuals, especially those with HIV or other chronic health care issues, with low education levels or health literacy are the least likely to have the time and skills necessary to successfully navigate the requisite paperwork, phone calls, eligibility requirements, and appointments. Yet they also are ones in greatest need of overcoming those barriers. The systems in place to support these populations must work to become more user-friendly to the people they serve.

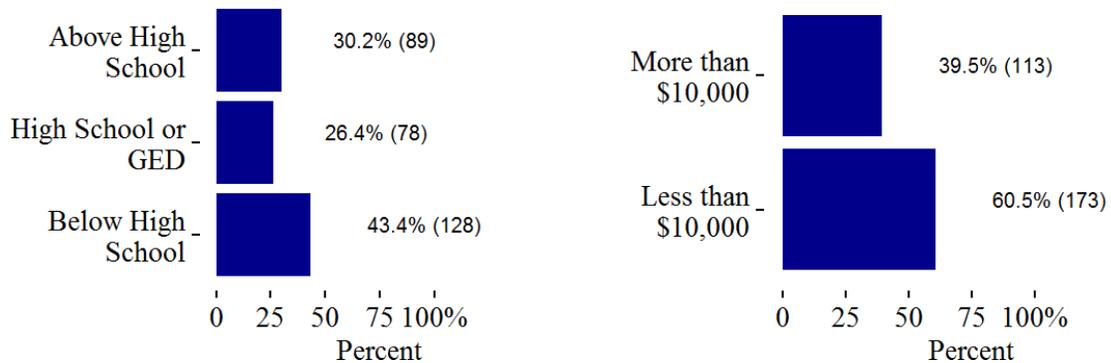
Recommendations:

- Inform HIV medical and non-medical providers that these disparities exist in the HIV system of care in Rhode Island.
- Target racial, social, and ethnic minorities in prevention and care outreach activities.
- Continue to emphasize social determinants of health during future quality improvement and monitoring activities.
- Continue to pursue system of care improvement activities that facilitate ease of use for disenfranchised, impoverished, and minority populations.

### 2015 RI Ryan White Consumer Survey Results

Thirty percent (30%) reported their education level to be above high school, 26% at high school or GED, and 43% at below high school. Sixty percent reported a household income of less than \$10,000 per year and 40% at more than \$10,000. Only 10% of respondents reported a household income over \$30,000 per year.

**Figure 24: Education (n=295) and Household Income (286)**



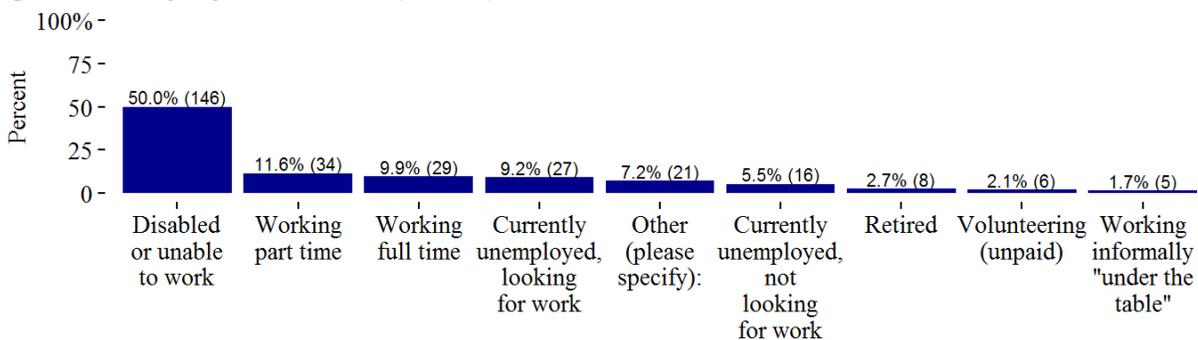
Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

Note: Income was asked in \$10,000 increments from \$0 to \$70,000+.

Fifty percent (50%) of respondents reported that they were disabled or unable to work. Twelve percent (12%) reported that they were working part time, 10% working full time, 9% currently unemployed but looking for work, 7% other, 6% currently unemployed and not looking for work, 3% retired, 2% volunteering (unpaid), and 2% working informally "under the table".

**Figure 25: Employment Statue (n=292)**



Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

### **Service gaps**

The completion of a Consumer and Provider Capacity and Capability Survey and Focus Group sessions show that, barriers of poverty, mental health/substance use, lack of transportation, cultural/linguistic incompetence, lack of information/knowledge, housing, expanded dental resources, stigma, and lack of resources are thoroughly documented. These barriers will require coordination and a well outlined strategy to address them during the next five years. Rhode Island, like other states have faced increasing state and federal budget cuts which ultimately has affected the delivery resources of HIV providers in the state. For drug assistance, Medicare's prescription drug benefit (Part D) remains a barrier to care for many who cannot afford the out of pocket expense after enrollment. The establishment of written Medicare Part D policies and guidelines by Rhode Island's ADAP and other Ryan White programs and the dissemination of those policies and guidelines are needed to help individuals living with HIV/AIDS make informed decisions. Furthermore, PLWH/A have co-morbidity health issues and require medications that are not currently on the ADAP formulary, for example, high blood pressure, asthma and high cholesterol medications. RI-EOHHS continues to work on expanding the current formulary to further meet the medication needs of PLWH/A.

For RIDOH, providing HIV testing for all partners of newly identified HIV cases proves to be a challenge in some cases due to a recent an increase in anonymous partners who are unable to be contacted for testing. For the RCT program it is important that HIV providers utilize a program within their agency to re-engage PLWH/A, however; the limited utilization of this program is a barrier to the re-engagement of care. In relationship to HIV testing, the Department of Corrections currently provides HIV testing five days after intake. Communicative efforts have taken place to advocate for initial HIV testing upon intake. Unaware or high risk individuals may be lost to early intervention services if they are released earlier than five days and are not tested.

Cultural issues and barriers play a critical role in identifying new HIV-infected populations. Providers must continually take these challenges into account and incorporate innovative and culturally responsive strategies to address them. Lack of dedicated funding play a crucial role in the limitations of education and effective prevention programs to address barriers surrounding community groups to create a Peer Education/Outreach programs to reach targeted populations such as the GBMSM and Black/African American populations. Women with children, abusive relationships and sex workers have significant barriers to accessing care. These barriers may include; stigma, or heterosexual who perceive they are at no or low risk for HIV/AIDS.

### ***Service provider barriers.***

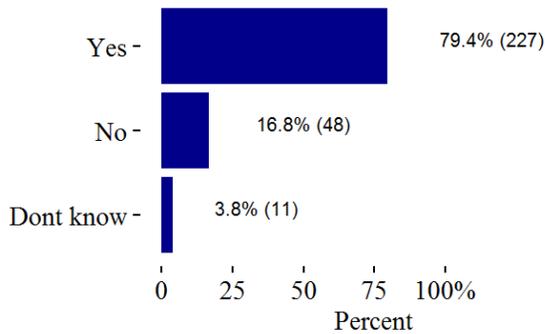
The RI-EOHHS Ryan White Program has been unsuccessful in a collaboration with the Veteran's Administration. This current barrier has the potential to enhance the HIV Care Continuum significantly if an on-going dialogue could ensue. As previously mentioned, the Department of Corrections currently provides HIV testing a five days after intake. Communicative efforts have taken place to advocate for initial HIV testing upon intake. Unaware or high-risk individuals may be lost to early intervention services if they are released earlier than five days and are not

tested. Rhode Island is also looking to further its collaboration with the Department of Developmental Disabilities to break down a significant gap pertaining to mental health barriers in the state. Both consumers and providers have discussed the challenges of obtaining a timely appointment in regards to mental health assessments for PLWH/A. Additionally, lack of behavioral health clinical staff has been identified as a service gap as well.

**2015 RI Ryan White Consumer Survey Results**

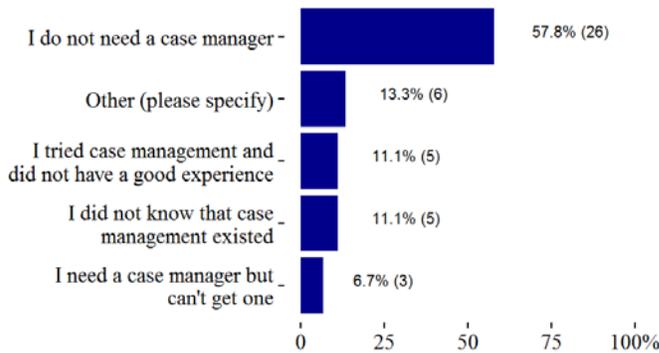
Seventy-nine percent (79%) of respondents indicated that they have a case manager. The most common reason for not having a case manager was 'I do not need a case manager' (58%) followed by 'other' (13%), 'I tried case management and did not have a good experience' (11%), 'I did not know that case management existed' (11%), and 'I need a case manager but can't get one' (7%).

**Figure 26: Do you have an HIV Case Manager (n=286)**



Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

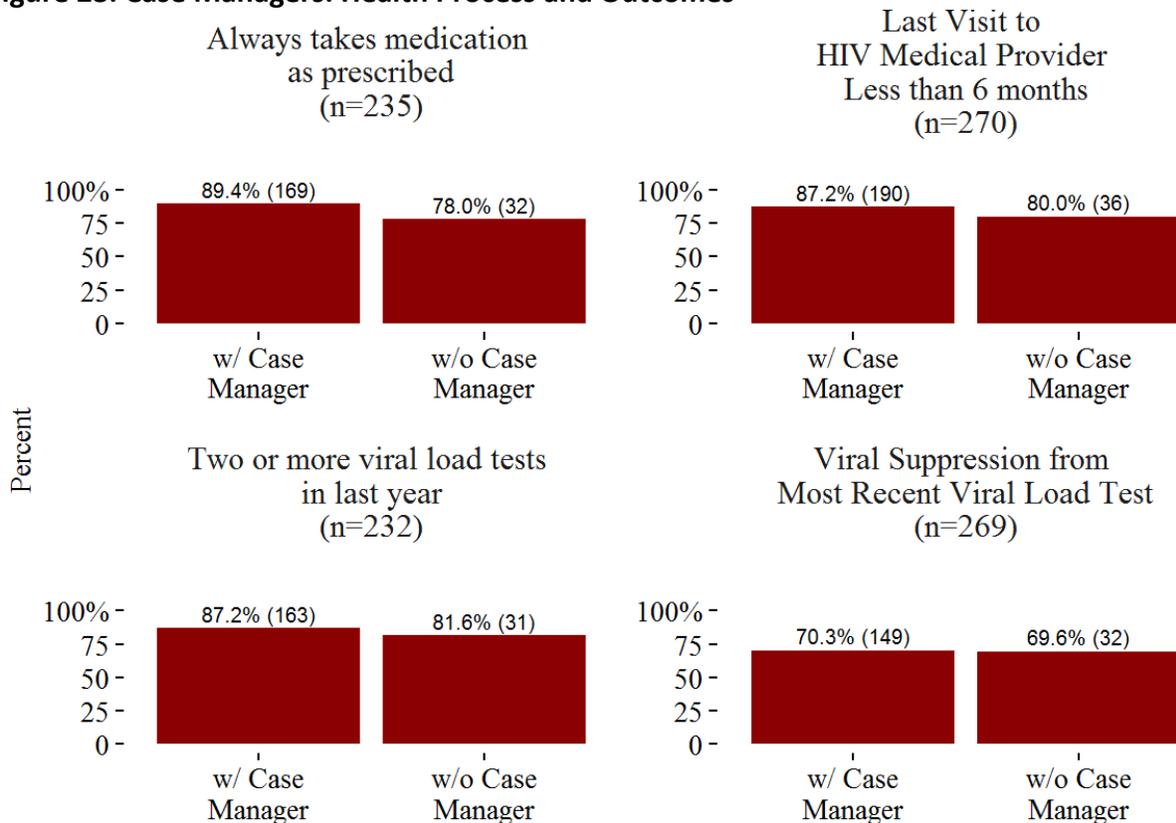
**Figure 27: If no case manager, why not? (n=45), m.**



Notes: 'm.' indicates multi-select question.  
Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

There were no significant differences in reported health processes or outcomes between the group of respondents with a case manager and the group of respondents without one (**Figure 28**). There may be several reasons for this. First of all, more people reported having a case manager (227) than not (48). This difference in group size may have made it more difficult to establish statistical significance with a Pearson's Chi-squared test. Secondly, variation in quality of case management across agencies and individuals may have muted the effect of 'good' case managers. This data should not be seen as a 'case against case managers' but rather a 'case for quality improvement.'

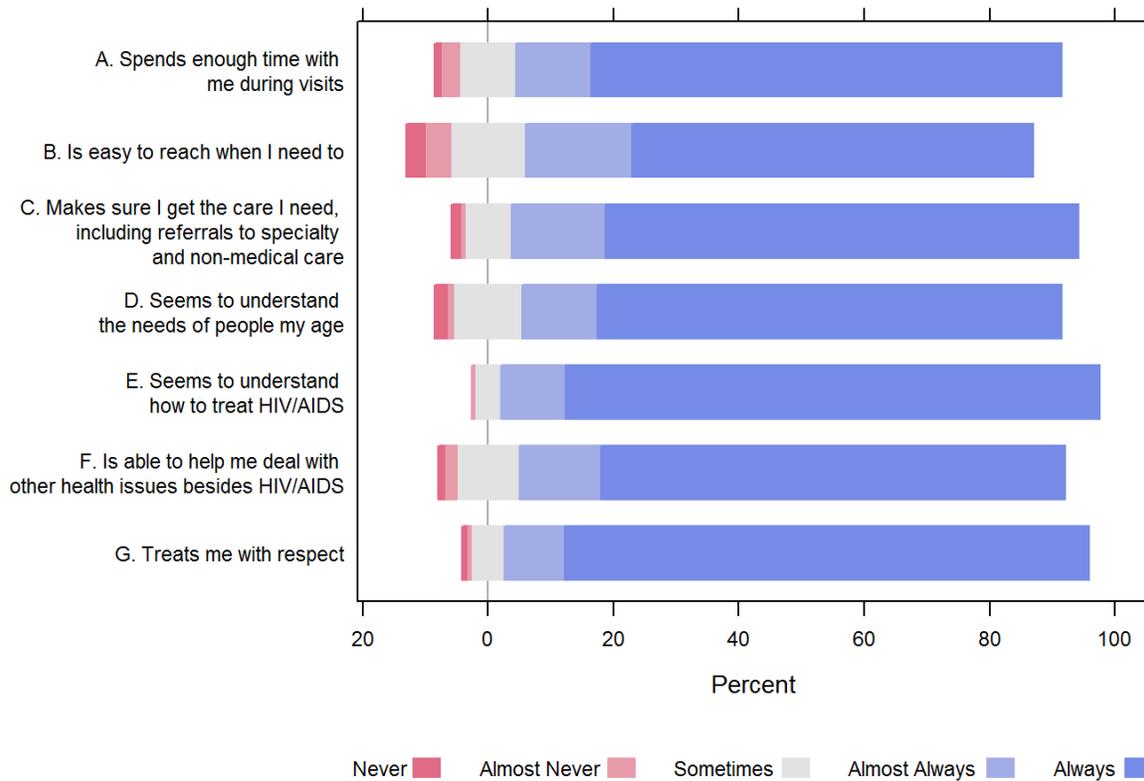
**Figure 28: Case Managers: Health Process and Outcomes**



Notes: '\*' indicates significance, Pearson's Chi-squared test ( $p < 0.05$ )  
 Data Source: 2015 Rhode Island Executive Office of Health and Human Services  
 Ryan White Consumer Survey

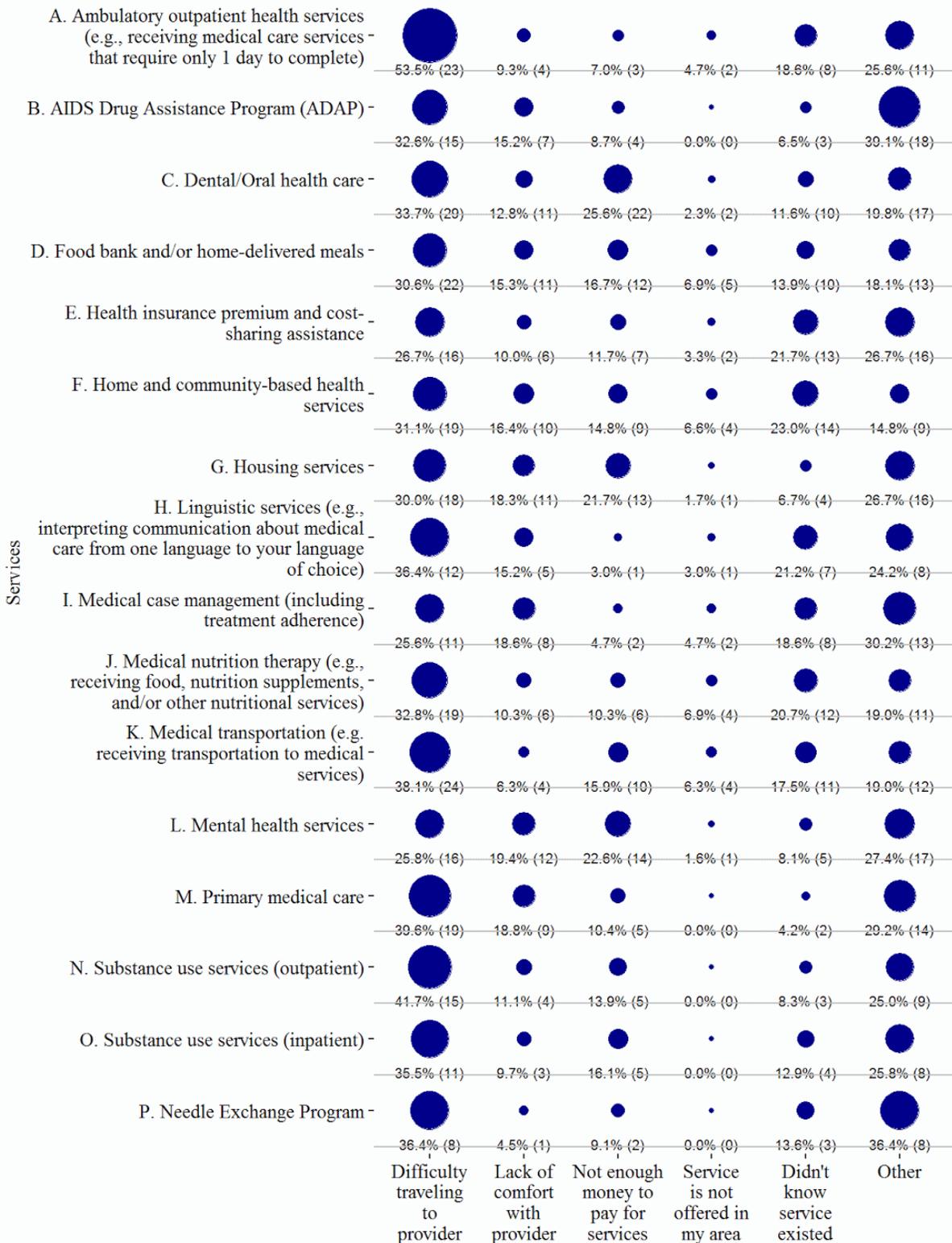
The following graphic summarizes responses to questions around consumers' satisfaction with their HIV medical provider. Positive responses are shown in blue to the right of the '0' axis and negative responses are shown in red to the left. It is clear that consumers are largely very satisfied with their HIV medical providers.

**Figure 29: Provider Satisfaction: My primary HIV medical provider...**



The following graph breaks the assessment of need services out by specific barriers to care. All responses of "No Challenge Experienced" and "NA" have been excluded so the percentages are specific to people who experience a barrier to care. 'Difficulty traveling to provider' was consistently the highest category across all services and 'service not offered in my area' is consistently the lowest. 'Lack of comfort with provider' was high in mental health services (19%), primary medical care (19%), and medical case management (19%). 'Not enough money to pay for services' was high in dental/oral health care (26%), mental health services (23%), housing services (22%), food bank and/or home-delivered meals (17%), and substance use services (inpatient) (16%). 'Didn't know service existed' was high in home and community-based health services (23%), health insurance premium and cost-sharing assistance (22%), linguistic services (21%), and medical nutrition therapy (21%).

**Figure 30: Assessment of Barriers and Challenges – ‘No Challenge’ and ‘NA’ Excluded, m.**



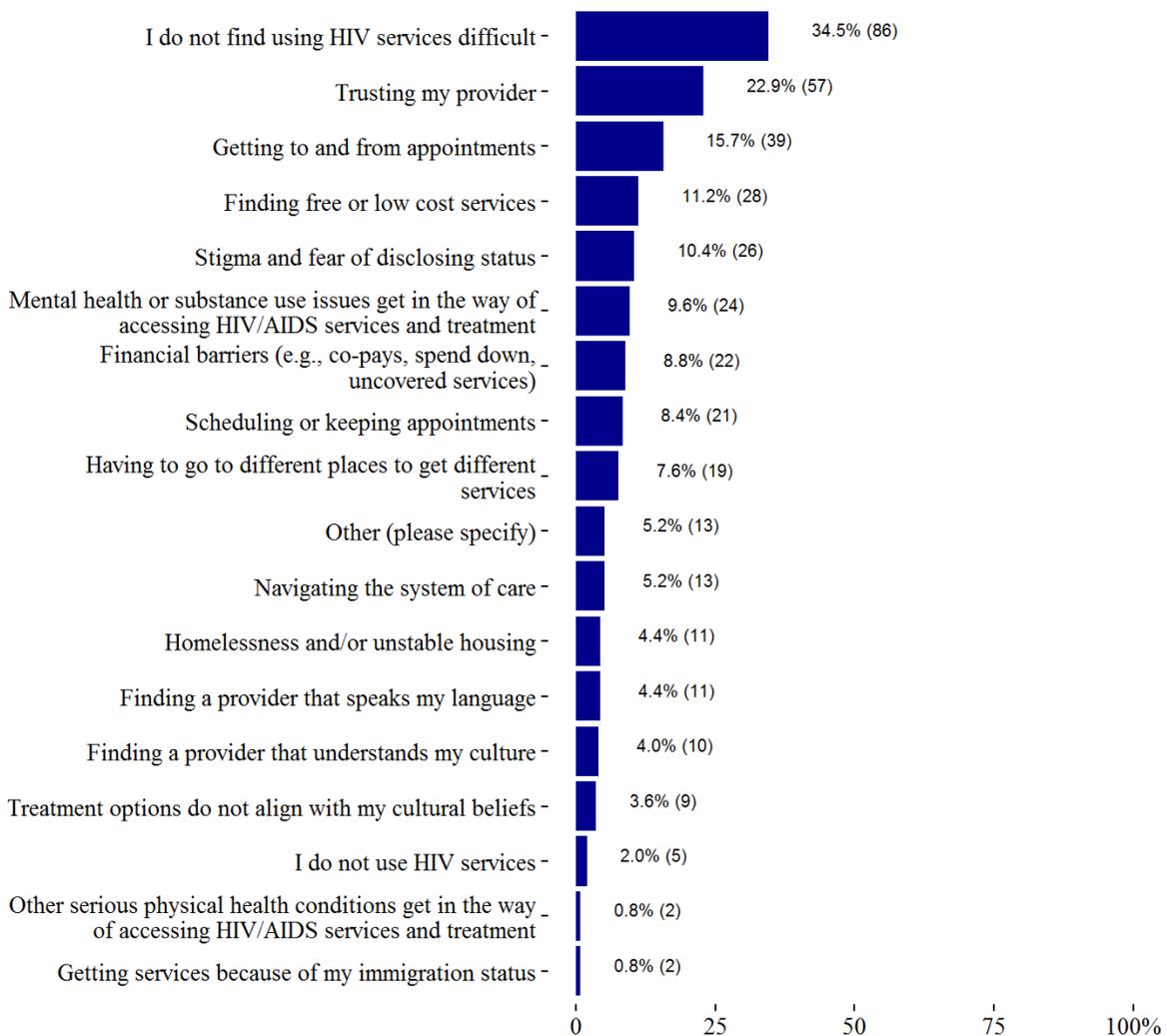
Notes: 'm.' indicates multi-select question.

Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

The most frequent reported barrier to care by respondents was 'trusting my provider' (23%) followed by 'getting to and from appointments' (16%), 'finding free or low cost services' (11%), 'stigma and fear of disclosing status' (10%), mental health or substance use issues (10%), 'scheduling or keeping appointments' (8%), and 'having to go to different places to get different services' (8%). Thirty-five percent (35%) of respondents reported that they do not find using HIV services difficult.

The following graphic shows the percentage of consumers that indicated that a barrier response category was one of the most difficult parts about using HIV services for them.

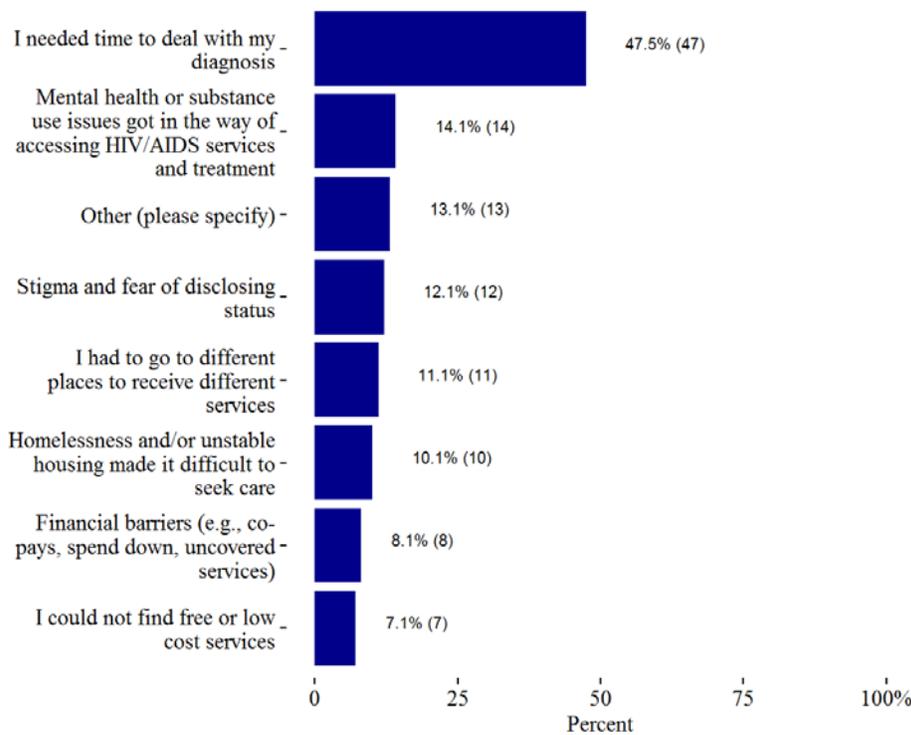
**Figure 31: Most Difficult about Using HIV Services (n=249), m.**



Notes: 'm.' indicates multi-select question.  
 Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

The most common reason for a delayed doctor visit for HIV/AIDS after diagnosis was 'I needed time to deal with my diagnosis' (48%). People who reported a language other than English as their primary language (73%) were significantly more likely than those who reported English (40%) to report that needing time to deal with their diagnosis delayed their doctor visit for HIV/AIDS after diagnosis. Respondents who identified as black (26%) were significantly less likely than those who identified as white (58%), other race (61%), or more than one race (67%). Differences were also observed within education level, ethnicity, gender, sexual identity, gender-sexual identity, and age categories but were not found to be significant. This may indicate that language is the most consistent and impactful cultural barrier that can exist between PLWH/A and their medical and non-medical providers.

**Figure 32: Reasons for Delayed Doctor Visit for HIV/AIDS after Diagnosis (Top 8) (n=122), m.**



Data Source: 2015 Rhode Island Executive Office of Health and Human Services Ryan White Consumer Survey

## 2015 RI Ryan White Focus Groups, Report

### *Rhode Island System of Care*

Participants communicated a general sense of satisfaction and appreciation for the quantity, quality, and diversity of HIV services offered in Rhode Island.

*“Excellent job”*

*“Very good”*

*“Lots of places that you can go to if you have HIV. You can get help.”*

*“The place I go to has doctors, nurses, psychiatrists, housing for everybody – not only for those with HIV.”*

Many thought Rhode Island compared very favorably to other states in the country based what they had heard from friends or from their own experience living outside of Rhode Island.

*“Compared to North Carolina, Rhode Island is good.”*

*“When I talk with people across the country, they say ‘we don’t have that [service] here’”*

*“Rhode Island is one of the best states for HIV”*

However, many comments indicated that *active* involvement by the patient was a crucial component to successfully receiving needed services. Services are available but they require the individual to seek them out. Savvy consumers, who know the system, are more likely to be successful.

*“It takes a lot of work to navigate the system of care and some people don’t have that will.”*

*“Everything in RI is accessible. If you want to get your needs met, you have to get [out] and ask.”*

*“Logistics of care drive me crazy. I got to remember all my appointments. Sometimes I forget whether I took my medication because I have so much on my mind.”*

### *HIV Medical Providers*

Individuals reported both strongly positive and strongly negative experiences with HIV medical providers.

One theme centered on a desire to not only receive care from a high quality provider but also one that is a good fit for the individual.

*“My doctor is fantastic. Because of him, I had tests done I wouldn’t have thought of. He has been an advocate for me more than my case manager.”*

*“I am particular in who I see. I want to speak with someone who is high up on the Richter scale.”*

Participants frequently shared how they had switched physicians after a bad experience or that they were currently considering looking for another.

*“You [my doctor] are going to be on that list of change.”*

A primary complaint about physicians among participants was that they felt the physicians often did not understand them as people, only focusing on their HIV and lab values.

*“You don’t know me, you know my labs. The same things that bothered me ten years ago bother me today. Get to know me as a person, not a lab.”*

Participants articulated that their needs go well beyond medical care and that their physicians did not always seem concerned about those other needs.

*“[The doctors] think: ‘You got HIV meds, so you can live.’ But HIV is no picnic! There are still things you need.”*

Multiple participants recommended to their peers to be as active as possible during conversations with their doctors. At several points during all three focus groups, other participants responded to an individual sharing a personal problem with a HIV medical provider by saying that the person should be more of an advocate for themselves or try to find a different provider.

*“A closed mouth doesn’t get fed.”*

*“Require that the patient be more actively involved. Don’t let him or her be a victim. Volunteer information as opposed to [the doctor’s] checklist.”*

#### *Transportation*

Participants shared that they find public transportation in Rhode Island to often be inconvenient and difficult to use. They expressed concern about RIPTA’s plans to start charging the elderly and the disabled a small fee per ride. They said that some people who are poor and suffering from depression take the bus just to get outside and be around other people. Charging them to ride the bus might prohibit them from seeing being able to even see another person some days.

*“Very difficult”*

*“I just hope that RIPTA tries to get better”*

One participant shared how in another place that he used to live, they would organize volunteer PLWH/A to drive others to appointments when needed.

*“Where I came from, they used to ask patients to volunteer drives. After a while, they paid you per mile.”*

#### *Stigma*

Participants discussed stigma from HIV in some form in responses to nearly every question that the facilitator asked. They shared stories of stigma in the context of family, peers, employment, medical care, and cultural background. In these comments, stigma was manifested in tangible

and non-tangible ways, either through a comment or action by another individual or a perception or feeling by the person living with HIV/AIDS.

*“Oh, you have HIV.”*

*“I have lost friends that I have had for a very long time. You just hate to be treated differently. If you can’t talk about it, then you weren’t my friend to begin with.”*

*“I was made to feel like an outcast to the hospital. Instant judgement. Signs on my door for masks. I became very outspoken and I made a statement, got the head nurse, the whole nine yards.”*

Participants also revealed that substance use is a source of stigma. The prevailing sentiment seemed to be that the stigma from HIV is worse than the stigma from substance use—but a comparison in this context may neither be clear nor productive.

*“Someone once told me that when you admit to having a substance use problem, you give the world a club to hit you over the head with.”*

*“People will forgive your drug use, but god forbid you are HIV positive”*

*“I’ve been told it’s another label. Just another label.”*

#### *Minority Populations*

Scattered throughout the focus groups conversations were comments indicating that participants felt that some minority populations or social subgroups either had increased difficulty accessing services or experienced more stigma. The three most identified minority populations were people who identify as black, Hispanic, or women.

*“In the Hispanic community, there is a lot of stigma. A lot of Hispanics don’t like to get tested, even if they have been with a partner who is positive. They just go into denial.”*

*“As a white man, I have noticed that black elderly men and woman have the hardest time getting what they need.”*

*“Women have a big stigma... They will show up but then they will start missing appointments. They won’t take time off to come and speak to someone. They don’t want to be seen at the clinic either.”*

#### *Access to Substance Use Treatment*

Participants thought that substance use treatment was generally easy to access but offered a few key pieces of feedback.

The most prominent access issue that was raised had to do with lack of adequate dissemination and promotion of available services.

*“[substance use and mental healthcare agencies] could help. But how do you know this stuff? If you don’t know, how do you find out?”*

*“Word of mouth that’s how we find out what’s going on”*

Participants shared that they thought that HIV medical providers should be able to connect patients with addiction services ‘right away’ and even recommended co-locating an intervention team within the HIV medical clinic. Several stated that their HIV medical provider had never asked about substance use issues or offered treatment options.

*“I think the doctor should set you up right away with addiction services if you come into the immunology clinic with substance use issues. [Have] an intervention team right in the office.”*  
*“I’ve had substance abuse issues for a long time and I have never been offered help once from doctors. I have been locked up in psyche units and in the morning when I wake up they just let me go.”*

Another recommendation by participants was to increase the number of residential homes that provide substance use services to residents. They shared that they felt there were too few ‘transitional’ housing opportunities and that they knew PLWH/A who were at risk of losing their housing due to ‘co-occurring mental health and substance issues.’

*“They need more [transitional] homes. They need more than two homes. The housing got me ontrack. If I didn’t go there, I wouldn’t be who I was today. I might not even be alive today.”*

One participant brought up how she has known individuals to lose access to substance use or mental health services due to prior offenses or infractions of facility rules.

*“[Some people] have no other choices because they have already used what they have. Medical won’t take them because they have used what they have [policy benefits]. This place won’t take them because they are violent, or used drugs on the premises, or beat up a doctor. I dealt with someone who couldn’t go to many places because of a prior offense or issue.”*

#### *Experience of Mental Health Treatment*

The most common theme throughout discussions on mental health treatment was the importance of a strong relationship and rapport with the mental health provider, whether it is a counselor, therapist, or psychiatrist. Frequent turnover of mental health providers makes it difficult for consumers to establish rapport and continuity.

*“I think it has to do with building a relationship. I’m on number four now. Seems like once you have a rapport with a provider, they leave. We get sick and tired of telling the same old story, reliving and rehashing.”*

Some individuals stated that they have “little trouble” opening up to doctors but struggle do so with mental health workers.

*“Sometimes I find it challenging to talk about these issues.”*

Others credited their ability to be honest with providers (and themselves) as a primary mechanism for how they overcame cycles of poor self-care and drug use.

*“I suppressed my feelings and when I did go seek help, I would leave feeling the same way when I came in because I kept my mouth closed. I would go and continue to use drugs to try to self-medicate. That was repetitive for a long period of time.”*

Participants did articulate that there is still stigma around receiving mental health services. They shared how some people don't want to admit they need services or be seen using them.

*“Perhaps there can be a back door way for counseling so that others don't see.”*

#### *Access to Mental Health Treatment*

Participants generally reported being very satisfied with the accessibility of mental health services. Participants who used the services in Woonsocket seemed particularly satisfied with the diversity of services available in the city. One focus group stated that they were excited about the upcoming introduction of mental health services into [one of the major HIV clinics].

The most commonly discussed barriers to mental health services were insurance and money. Participants stated that those who were able to pay had more mental health treatment options than who could not but did not provide any specific examples of being refused mental health care for financial reasons.

One participant talked about how his physical health prevented him from accessing some services, including mental health services.

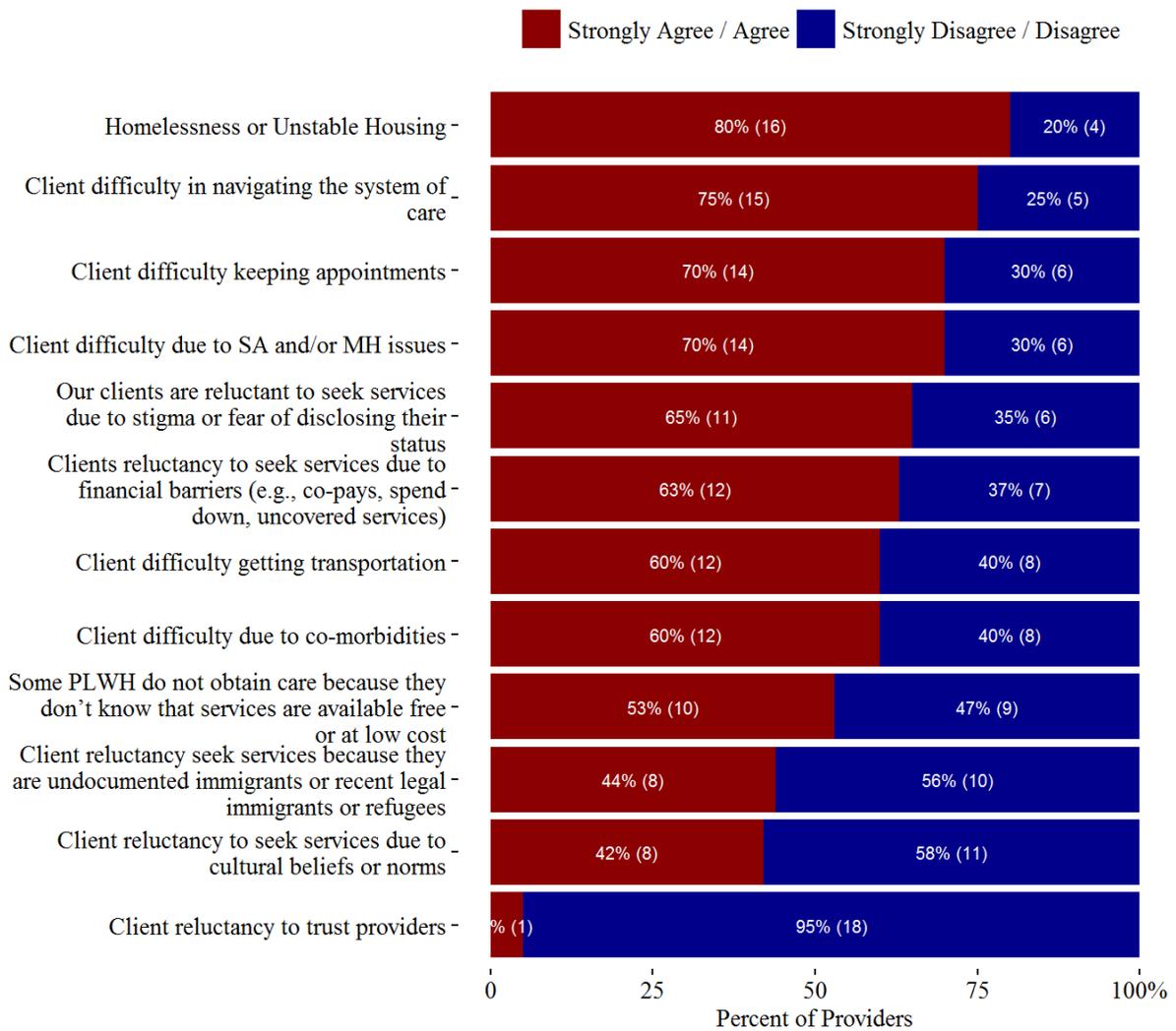
*“I ain't accessing them because my body won't let me, unless you got them right down on the first floor of my building.”*

#### **2013 RI Ryan White Provider Capacity in the Provision of Services Survey Results**

The following graphic shows the percentage of providers that indicated that they either agreed or disagree that a response category was a barrier to care for the PLWH/A that they work with. It is important to recognize that the percentages in this graph are *not* directly comparable to the percentages in the previous graph. As the questions were asked differently, the percentages have different meanings. Care was taken to ensure that barrier response categories in the 2014 survey of providers were reflected in the 2015-2016 survey of consumers.

Only 5% of providers identified 'client reluctance to trust providers' as a barrier care when asked during the during the 2014 Provider Capacity Capability Survey. In contrast, 'trusting my provider' was the top listed barrier to care by consumers in this survey.

**Figure 33: Barriers to Care: Provider Survey 2013**

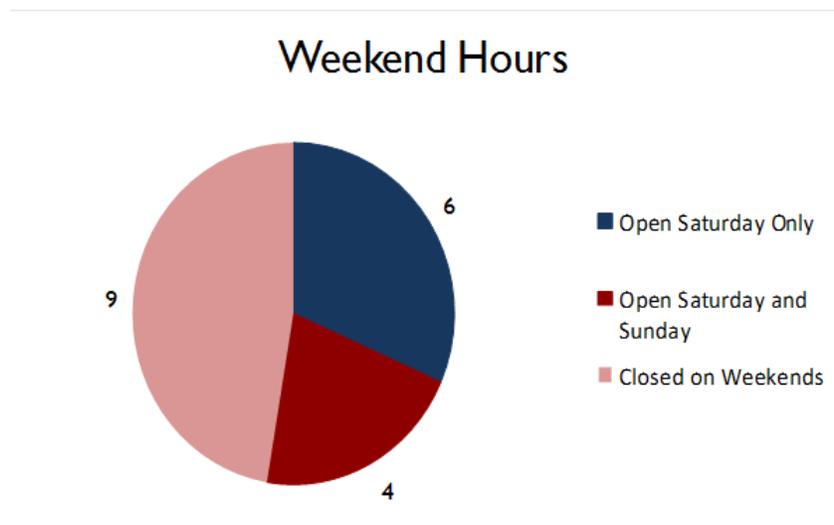
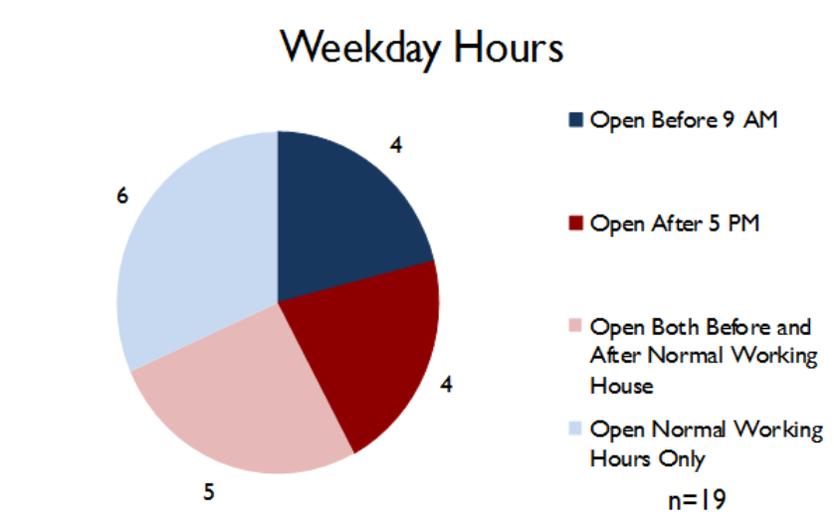


Data Source: Provider Capacity Capability Survey 2013, RI Executive Office of Health and Human Services (EOHHS)

Accessing services for PLWH/A can be impacted by the days and hours of operation at a given agency. Of the 19 agencies that provided their hours of operation, the majority (13) indicated that they provide services outside of normal working hours (9:00AM – 5:00PM) during weekdays. Eight respondents indicated their agencies provide services either before or after normal working hours (4 each) and five respondents reported services are available both before and after normal working hours.

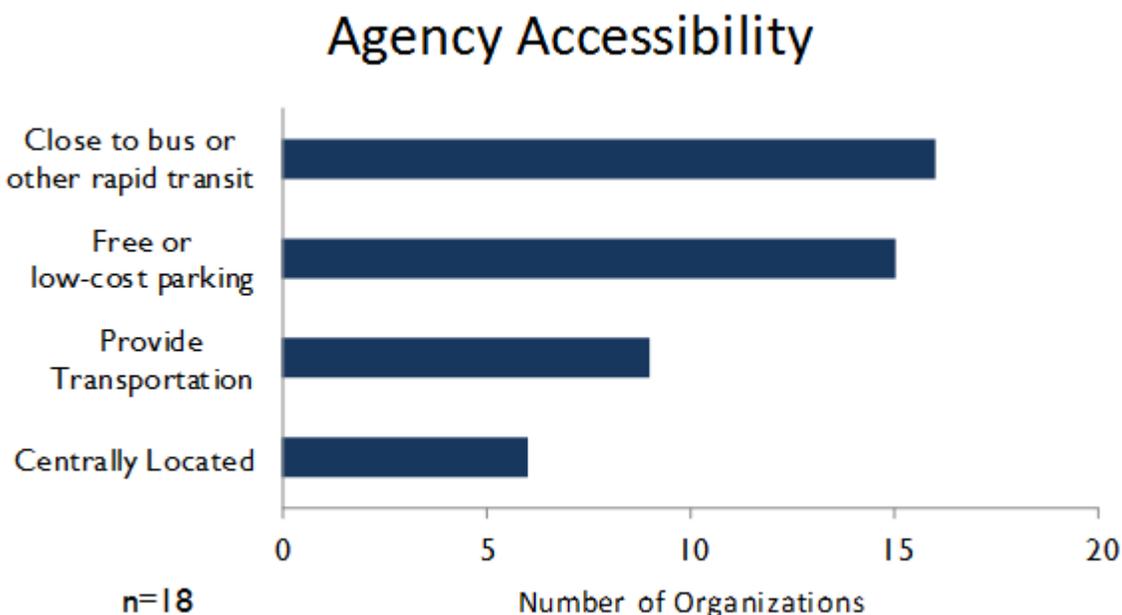
Just over half of the agencies reported the availability of services on weekends (**Figure 34**). This includes six agencies that provide services on Saturdays and four agencies that provide services on both Saturdays and Sundays – nine agencies are closed on the weekends.

Figure 34: Weekday and Weekend Hours



Most of the agencies were near a bus line (16), with a smaller number of providers reporting being located in a downtown area, and/or offering transportation options for clients including: taxi cab vouchers, RIPTIX, bus passes, and/or other transportation including case managers giving rides to clients (9) (Figure 35). While many agencies provide free or low-cost parking (15), most indicated that their clients don't tend to have cars. All of the sites' physical locations were wheel-chair accessible and one agency indicated full Americans with Disabilities Act (ADA) compliance.

**Figure 35: Agency Accessibility**



According to U.S. Census Bureau American Community Survey data (2006-2010), Rhode Island, like much of the U.S., is heavily dependent on transportation by automobiles, with 81 percent of RI residents driving alone to work. However, people of color are much more likely to rely on public transit than whites<sup>52</sup>.

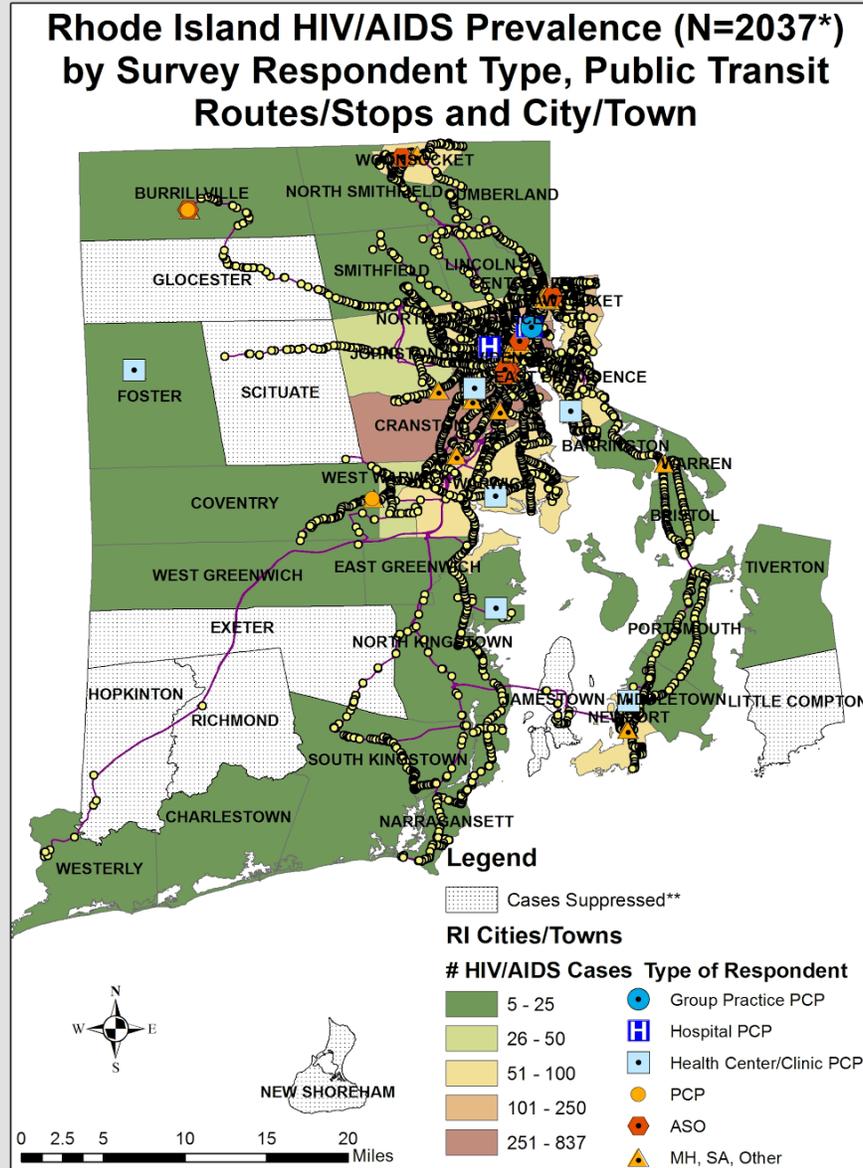
Income and race both play a role in determining who uses Rhode Island's transit system. Very low-income and upper-income whites use public transit at approximately the same rate as households of color do. Across the region, 92 percent of white households have at least one car, but among households headed by a person of color, only 83 percent do. People of other or mixed racial background, African American, and Latino households are the most likely to not have access to a car.

Rhode Island Public Transit Authority (RIPTA) data (2011, September) were geocoded onto maps that include both survey provider respondent locations and HIV/AIDS prevalence (for

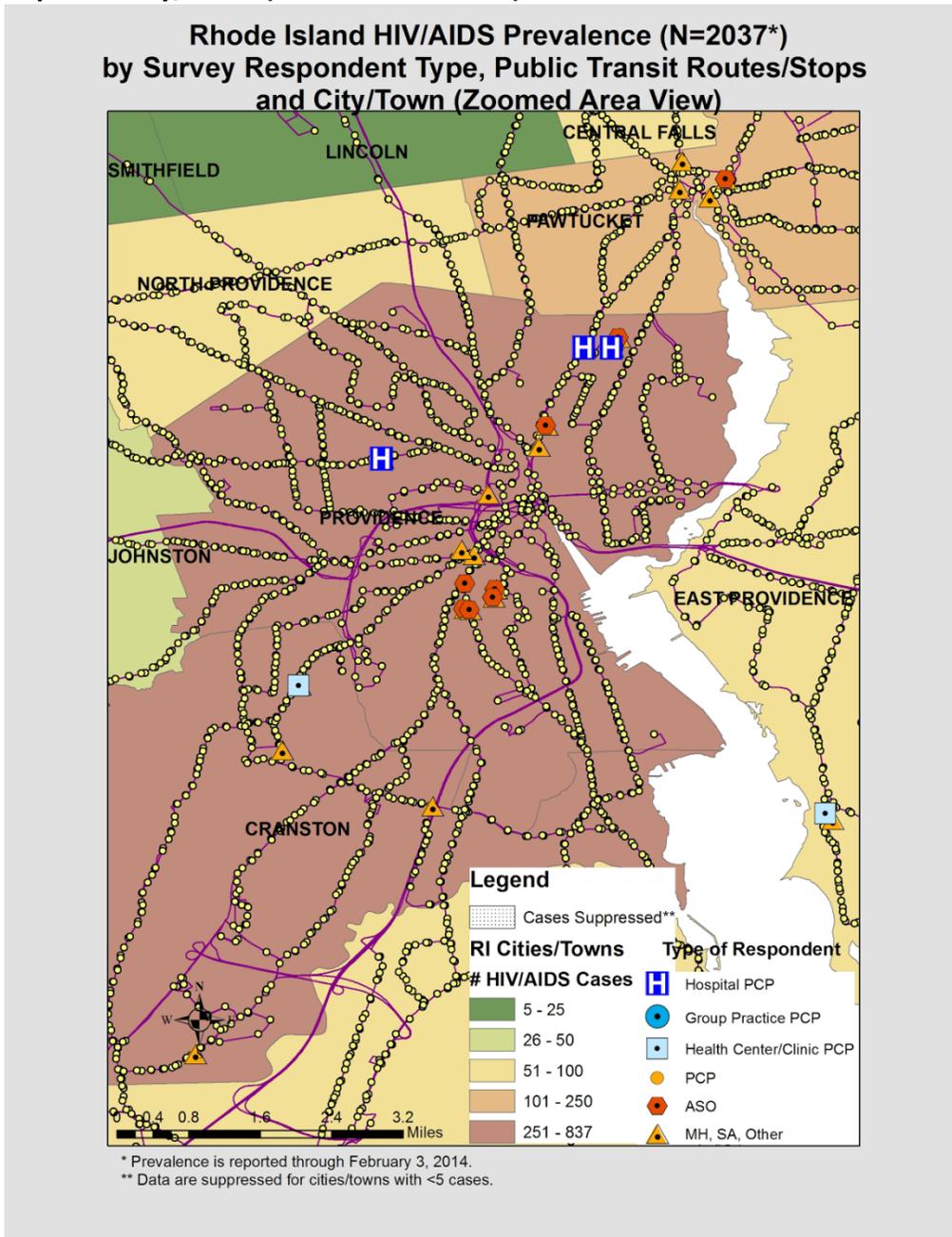
<sup>52</sup> 2013. *An Equity Profile Rhode Island*. Policy Link and PERE: USC Program for Environmental & Regional Equity. Retrieved from: [http://rhodemap.wpengine.com/wp-content/uploads/2013/08/Rhode\\_Island\\_31May\\_FINAL.pdf](http://rhodemap.wpengine.com/wp-content/uploads/2013/08/Rhode_Island_31May_FINAL.pdf)

absolute prevalence see **Figures 36 & 37**; relative prevalence see **Figures 38 & 39**). RIPTA data include both route and physical stop locations, but do not take into consideration the frequency and timing of individual transit stop data. These data are mapped to provide a general illustration of the connectivity of service providers via public transportation. Consistent with survey respondent reports, most agencies appear to be located near Rhode Island's public transit system networks. Public transportation appears more limited in the western and southern parts of the State that are more sparsely populated, typically rural areas.

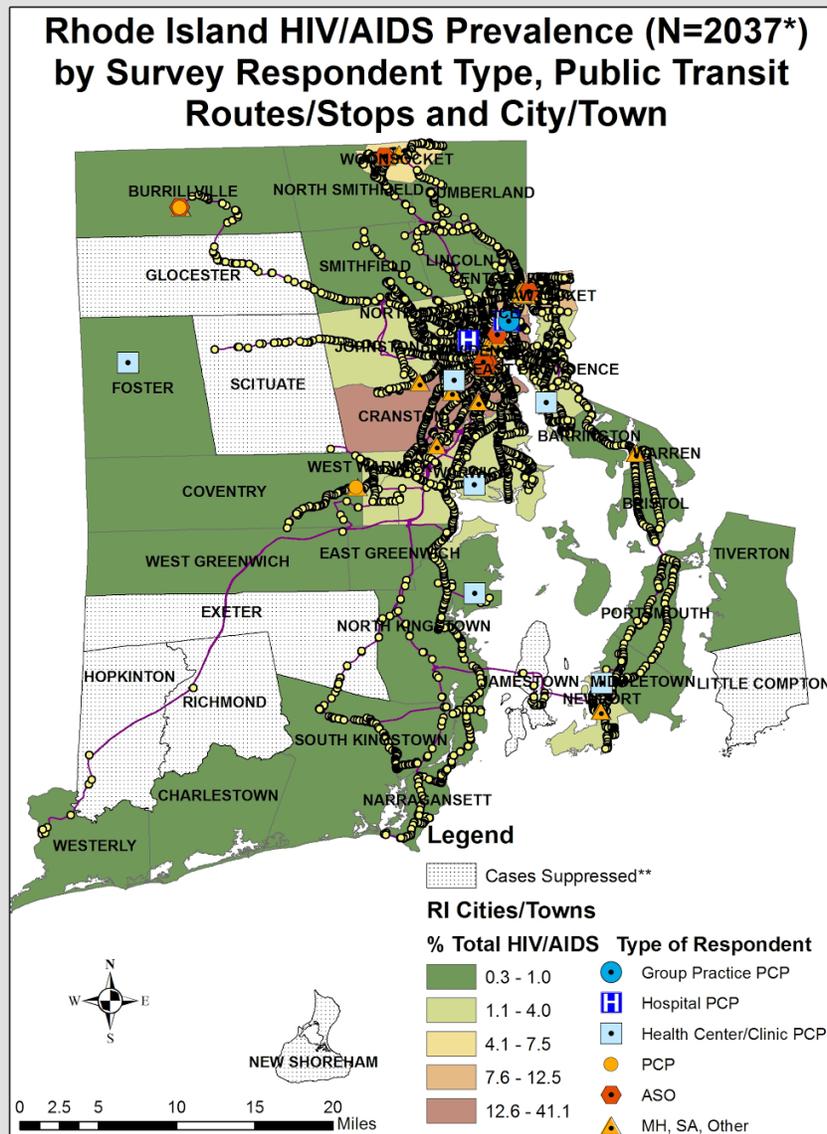
**Figure 36: Rhode Island HIV/AIDS Prevalence by Survey Respondent Type, Public Transit Routes/Stops and City/Town**



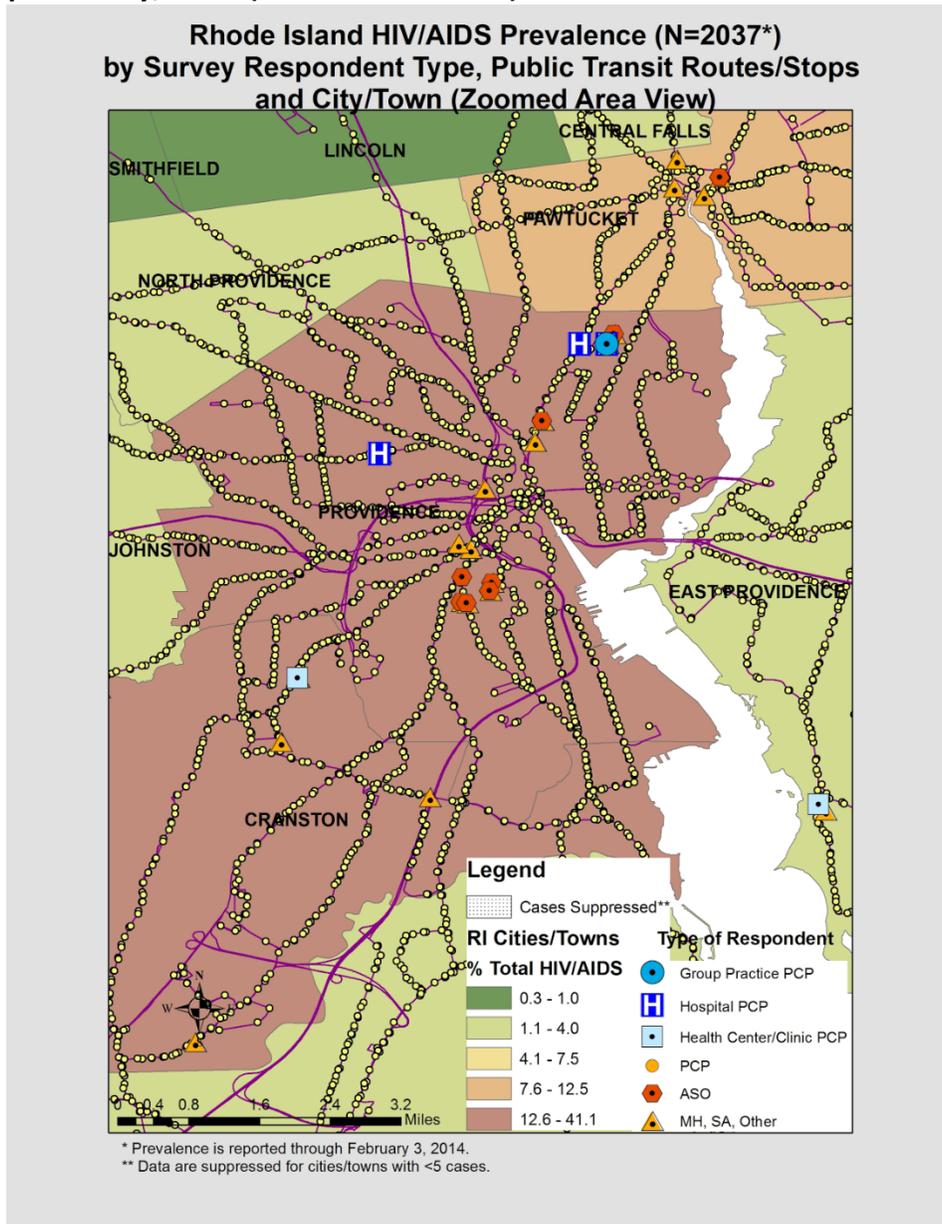
**Figure 37: Rhode Island HIV/AIDS Prevalence by Survey Respondent Type, Public Transit Routes/Stops and City/Town (Zoomed Area View)**



**Figure 38: Rhode Island HIV/AIDS Prevalence by Survey Respondent Type, Public Transit Routes/Stops and City/Town**



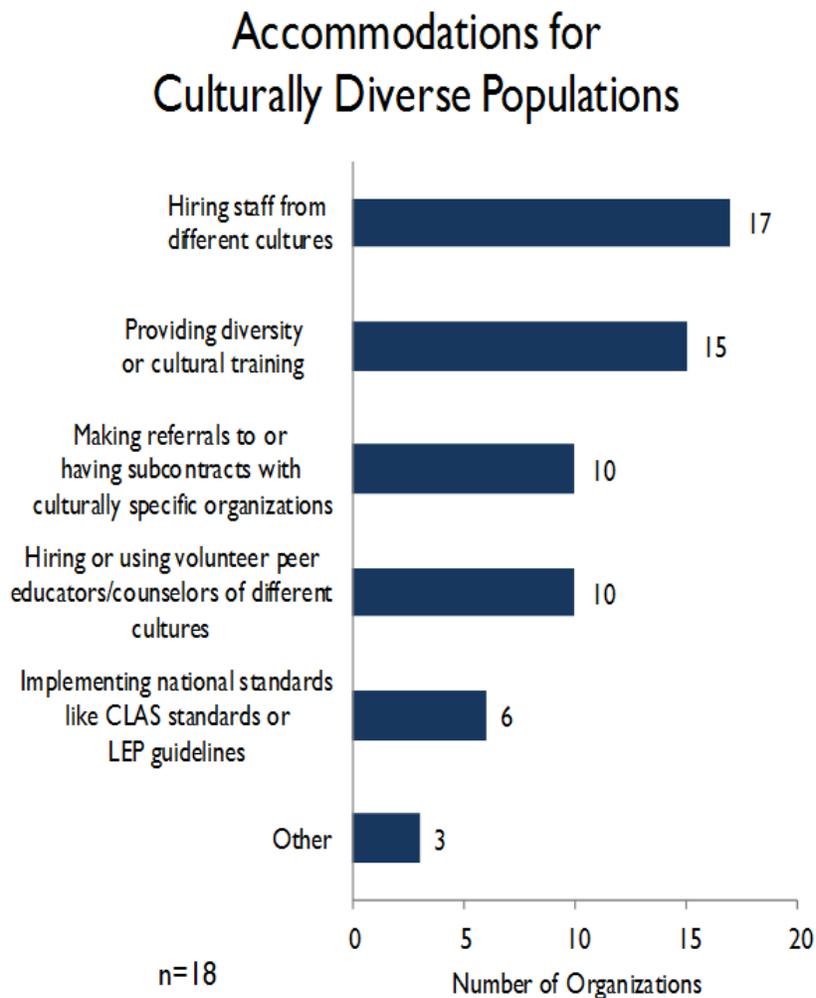
**Figure 39: Rhode Island HIV/AIDS Prevalence by Survey Respondent Type, Public Transit Routes/Stops and City/Town (Zoomed Area View)**



**Culture and Language:**

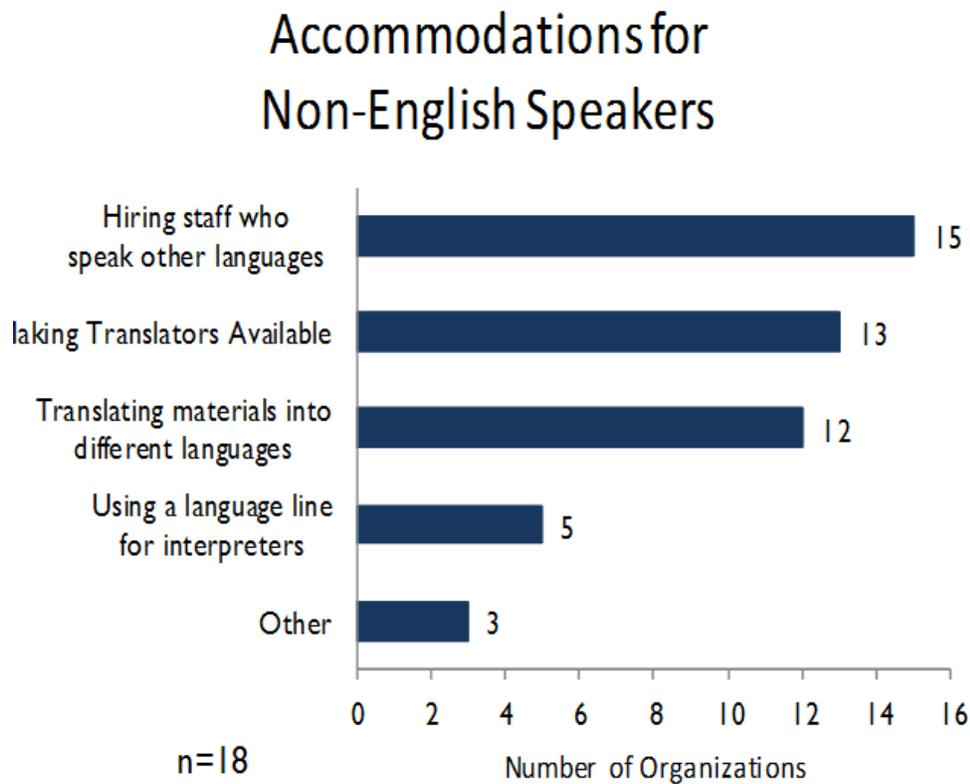
Culturally competent service providers are crucial to recruiting and retaining people living with HIV/AIDS into primary care, particularly when they are members of historically disenfranchised communities and populations such as people of color, gay men, women, and substance users. The majority of survey respondents noted several approaches in providing services to culturally diverse populations (**Figure 40**). The most widely reported accommodations include: hiring staff from different cultures (17); providing staff with diversity/cultural training (15); hiring or using volunteer peer educators/counselors from different cultures (10); making referrals to or having subcontracts with culturally specific organizations (10); and, implementing national standards (e.g. Culturally & Linguistically Appropriate Services [CLAS]) or guidelines (e.g. Limited English Proficiency [LEP]) intended to advance health equity, improve quality, and help eliminate healthcare disparities.

**Figure 40: Accommodations for Culturally Diverse Populations**



Respondents were also asked how they serve clients who do not speak English (**Figure 41**). The most common accommodations reported include: staff who speak languages other than English (15); the availability of translators or interpreters when needed (13); materials that are translated into different languages (12); and the availability of language lines to serve diverse language needs (5).

**Figure 41: Accommodations for Non-English Speakers**



Language needs of clients that providers indicated were difficult to meet included: Khmer or Cambodian, Wolof, Kishwahili or Swahili, Portuguese, Haitian (French or Creole was not indicated), American Sign Language, and Spanish at times. Many providers indicated that they had no other capacity than English or English and Spanish. Others indicated that there were no languages or population needs they found difficult to meet. One respondent indicated that patients often use friends as interpreters.

## E. Data: Access, Sources, and Systems

a.) Describe the main sources of data (e.g. RSR data, qualitative data, and surveillance data) and data systems (e.g. CAREWare , eHARS) used to conduct the needs assessment, including the development of the HIV Care Continuum.

**The epidemiological and surveillance data is derived from the following data repositories for RIDOH:**

Case surveillance of AIDS was initiated in Rhode Island in 1983, and HIV surveillance began in 2000. These surveillance systems provide information on risk factors, patient demographics, laboratory tests, and the clinical manifestations of disease over time. The present epidemiologic profile relies primarily on these case surveillance data. However, the program utilizes an array of data sources to establish the most complete and accurate picture of HIV and AIDS in Rhode Island and the populations at highest risk for infection. The list below identifies the sources of information used.

***HIV/AIDS Reporting System (HARS):*** Implemented in 1983, this was a repository of all AIDS cases by name; in 2000 HIV cases were added to this system. HARS data was synthesized into a composite database called eHARS in 2008.

***HIV Unique-Identifier Reporting System:*** Implemented in 2000, providers were required to report all cases of HIV infection with a unique patient identifier and *without* names until June 2006. These records were stored in the Unique-Identifier Reporting System database. This provides an unduplicated count of cases from January 2000 to June 2006. Starting in July 2006, HIV cases have been reported *with* names and are stored in the eHARS database described below.

***eHARS (enhanced HIV/AIDS Reporting System):*** Implemented in 2008 as an upgrade of HARS. eHARS is a repository of all AIDS cases reported since 1983 and all HIV cases reported, by name, since 2006. This system has the capacity to store multiple case reports and laboratory reports for each person. Records stored in the Unique-Identifier Reporting System database that were subsequently reported by name have been moved from the Unique-Identifier Reporting System database to eHARS.

***Cerner (State Health Laboratory Information Management System):*** Includes all positive and negative HIV test results submitted to the RIDOH State Laboratories.

***Evaluation Web:*** CDC-sponsored database which contains data on all HIV rapid-tests and services provided at RIDOH-funded counseling, testing, and referral (CTR) sites.

***BRFSS (Behavioral Risk Factor Surveillance System):*** A randomized telephone survey which is conducted annually focusing upon Rhode Islanders selected for the sample.

***YRBS (Youth Risk Behavior Survey):*** Focusing on adolescent youth, this survey is administered at schools for grades 9-12.

**STD\*MIS Database:** A repository of STD reports of chlamydia, gonorrhea and syphilis reports, from the RIDOH STD Program.

**NEDSS (National Electronic Disease Surveillance System):** Reportable disease database used by the RIDOH TB Program and for other reportable conditions besides HIV and STDs.

**Cancer Registry:** This reportable disease database is used for identifying individuals with AIDS-defining malignancies.

**Hospital Medical Records:** Patient medical records are utilized in AIDS validation studies and in the follow-up of previously reported cases.

**National HIV/AIDS Surveillance System (NHSS):** National surveillance system which compiles reports of HIV/AIDS from all US jurisdictions to inform national trends. Of note, names are not reportable to CDC. Instead, unique codes and Soundex codes are used as identifiers.

**Rhode Island Office of Vital Records Database:** This database maintains a record of all deaths that occur in Rhode Island. It is used to update vital status for individuals living with HIV.

**National Death Index (NDI):** Established by the National Center for Health Statistics, the NDI is a national database made up of data from state vital statistics offices. This database is used to update vital status for individuals in eHARS who may have died outside of Rhode Island.

**Social Security Death Index:** A database containing all deaths reported to the Social Security Administration. This database is used to update vital status for individuals in eHARS who may have died outside of Rhode Island.

**For RI-EOHHS the Data Repositories utilized are:**

**ADAP Database:** This database is used for client-level data for all ADAP clients (demographic, financial, medical, pharmacy claims, etc.)

**Quality Management Quarterly Reports:** These reports are received from contracted agencies each quarter, aggregate data for measuring agency performance in identified areas.

**RSR Data- Ryan White Service Report:** The RI-EOHHS submits a Ryan White Services Report on a yearly basis to the HIV/AIDS Bureau which is a data reporting system to report information on their programs and clients they serve. For client -level data reported on the Ryan White Services Report (RSR), the RI-EOHHS Ryan White Program had one federally funded contract agency contract; (Miriam Hospital) which reported client data on both Part B & C. This provider reported a total of 1618 clients. The remainder of the funded contracts with the RI-

EOHHS Ryan White Program were funded with Rebate funding, therefore, client-level data was not required for reporting purposes.

There were no data policy barriers to conducting the needs assessment including the development of the HIV Care Continuum.

**c. Data and Information the planning group would have liked to use to conduct the needs assessment/HIV Continuum of Care:**

There are limitations to HIV surveillance data as it is based on report of new diagnoses and is not true incidence-based surveillance. This means that the cases reported do not necessarily reflect new infections or the current state of the epidemic in Rhode Island. Providers may see many cases in a period of time which can create the perception of rapidly increasing case numbers. However, that does not necessarily translate into a surveillance measure of increasing incident cases, as many of the cases are importations from prior care in other states or countries, or are returning to care after a period of absence, and are already known to our surveillance system. The ideal HIV/AIDS surveillance system should be capable of detecting and accurately detailing all new HIV infections, in order to provide information to all stakeholders to accurately reflect the current epidemic. Further, these data do not account for the undiagnosed population.

The planning group would have also benefitted from a needs assessment that captured barriers to care and other information from those individuals not currently engaged in care. This information is difficult to collect because of the transient nature of this population. These insights would provide a more comprehensive view of gaps in service and areas for improvement. That being said, RI-EOHHS conducted an extensive needs assessment among their diverse Ryan White clients. The results from this assessment have proven to be valuable in the development of this integrated plan.

# Section II: Integrated HIV Prevention and Care Plan

## A. Table of Goals, Objectives, Strategies, Activities, and Resources

### NHAS Goal 1: Reduce new HIV infections

#### Objective 1.1: By 2021, reduce the number of new HIV diagnosis by 20% (from 67 cases in 2015 to 54 in 2021)

##### Strategy A: Improve access to condoms, especially among high-risk populations.

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/Barriers
Maintain and expand, as appropriate, a state-wide condom distribution program.	All at-risk sexually active individuals	RIDOH	# condoms distributed # distribution locations	2017-2021	None anticipated.

##### Strategy B: Prevent HIV infections among people who inject drugs.

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/Barriers
Maintain and expand, as appropriate, a state-wide needle exchange program.	People Who Inject Drugs (PWID)	RIDOH	# needles provided # needles returned #PWID enrolled # of individuals served	2017-2021	Securing and maintaining state funding.

**Strategy C: In secondary education settings, promote safe and supportive environments, improve sexual health services, and provide exemplary health education.**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/ Barriers
Administer and fund sexual health mini grants in 10 school districts participating in the RI Department of Education School Health Advisory Council.	Adolescents	RIDOH	# of districts who apply #grants administered # of sexual health educational initiatives started	2017	Potential lack of support/capacity from funded school districts.

**Objective 1.2 By 2021, 90% of individuals with HIV will be aware of their status.**

**Strategy A: Improve targeted testing efforts among populations most at risk for HIV.**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/ Barriers
Provide HIV testing for all partners of newly identified HIV cases.	Sexual and needle sharing partners of HIV cases	RIDOH	# newly diagnosed HIV cases # partners identified # partners tested #of sexual and/or needle sharing partners identified who are HIV positive	2017-2021	Recent data has shown an increase in anonymous partners who are unable to be contacted for testing.
Ensure partners who test positive for HIV are linked to confirmatory testing and HIV care.	Sexual and needle sharing partners of HIV cases	RIDOH	# partners testing positive for HIV # confirmatory tests # partners testing positive who attend 1 <sup>st</sup> medical appt.	2017-2021	None anticipated.

Maintain and improve targeted community-based HIV testing for at-risk populations.	GBMSM Racial/ethnic subpopulations PWID	RIDOH	# tests provided #/% tests for GBMSM #/% tests by race/ethnicity #/% tests for PWID	2017-2021	Understanding and/or capacity of contracted agencies to find and test target populations.
Provide HIV testing for individuals who access services at the Miriam Hospital STD specialty clinic and Roger Williams Medical Center.	At-risk men and women	RIDOH, Miriam Hospital STD Clinic, & Roger Williams Medical Center	# visits # HIV tests provided	2017-2021	Growing demand for safety-net services may be difficult to meet with current resource allocations.

**Strategy B: Prevent HIV infections among gay, bisexual, and other men who have sex with men (GBMSM).**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/Barriers
Reduce transmission among gay, bisexual, and other men who have sex with men; including racial and ethnic sub-populations, by working with community-based (funded) agencies to improve targeted testing strategies so that they are aware of their HIV status.	GBMSM	RIDOH	# tests performed for GBMSM # positive tests for GBMSM # of tests performed by race/ethnicity for GBMSM #of positive test for GBMSM by race/ethnicity	2017-2021	Understanding and/or capacity of contracted agencies to find and test target populations.

Screen and educate GBMSM who seek care at the Miriam Hospital STD clinic and Roger Williams Medical Center on PrEP.	GBMSM	RIDOH/ Miriam Hospital STD Clinic Roger Williams Medical Center	# GBMSM who seek care # GBMSM educated on PrEP # GBMSM prescribed PrEP	2017-2021	None anticipated.
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**NHAS Goal 2: Increase access to care and improve health outcomes for people living with HIV.**

**Objective 2.1 Reduce disparities in HIV care, access and services among underserved populations and communities.**

**Strategy A: Increase the number of available reimbursable HIV services at Ryan White funded agencies.**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/Barriers
Expand the procurement process to enhance client services, outreach efforts and client follow-up to underserved populations in a culturally competent way.	GBMSM, African- American and Latino/a Heterosexual s Women	RI- EOHHS/Ryan White Program	# of responsive agencies to RFP. # of individuals from target populations served by contracts. # of contracts issued to agencies that meet criteria for culturally competent care	2017-2021	None anticipated

**Strategy B: Maintain consumer participation in planning and implementation of HIV services.**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/Barriers
Maintain consumer involvement to focus upon the changing landscape and needs of people living with HIV/AIDS to further develop effective and efficient service delivery strategies.	GBMSM, African American and Latino Heterosexuals Women	RI-EOHHS/RIDOH /Planning Bodies/Community partners	# of consumer groups # of consumer meetings. # of educational sessions.	2017-2021	None anticipated.

**Strategy C: By 2021, increase appropriate HIV support service referrals to agencies and providers by 20% in a culturally competent way.**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/Barriers
Gather and track data from funded agencies related to social determinants to ensure appropriateness and effectiveness of referrals and follow-up in all appropriate HIV services in a culturally sensitive way.	RW funded clients	RI-EOHHS will collaborate with RIDOH	# of target population that are referred to case managers stratified by various social determinants (e.g. race/ethnicity, age, sexual identity, etc.). # of documented clients from targeted populations seen by case managers. # of clients linked to care. # of targeted/priority populations represented in the ADAP database.	2017-2021	Identify individuals who know their status but not in care.

**Strategy D: Improve cultural and linguistic competence of Ryan White providers.**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/ Barriers
<p>Improve culturally and linguistically competent services to HIV positive persons of color.</p>	<p>Hispanic/Latino Black/African American</p>	<p>RI-EOHHS</p>	<p># of agencies with written Culturally and Linguistically Appropriate Services (CLAS) policies. # of Ryan White providers trained in CLAS standards. # of communities of color clients that are accessing services. #/%of clients/patient satisfaction survey participants who indicate being treated in a culturally and linguistically competent way by providers. .</p>	<p>2017-2021</p>	<p>Patient Satisfaction Surveys that do not capture the cultural and linguistic needs of participants.</p>

**Objective 2.2: By 2021, increase insurance and/or medication coverage (i.e. ADAP, Medicaid, Medicare, RI-EOHHS Health Insurance Premium Assistance, State Marketplace) enrollment by 20% for all eligible Ryan White clients.**

**Strategy A: Increase access to ADAP among underserved.**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/ Barriers
Maintain the expansion of RI-ADAP from 400% to 500% of Federal Poverty Level (FPL).	All Ryan White eligible clients.	RI-ADAP/ RI-EOHHS	# of new clients enrolled in RI-EOHHS Premium Assistance due to FPL increase. # of new clients enrolled in RI-EOHHS ADAP due to FPL increase.	2017-2021	None anticipated.

**Strategy B: Ensure newly diagnosed individuals are identified and have access to appropriate insurance.**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/ Barriers
Refer individuals with a new HIV diagnosis to appropriate insurance within 3 months (i.e. ADAP, Medicaid, Medicare, RI-EOHHS Health Insurance Premium Assistance, and State Based Marketplace).	All Ryan White eligible clients	RI-EOHHS	# of RW case management clients recently diagnosed and enrolled in Medicaid or other insurance.	2017-2021	Clients that decline other eligible health insurance benefits.

**Objective 2.3: By 2021, 90% of individuals infected with HIV will be engaged in care (At least 2 HIV medical visits/year).**

**Strategy A: Quickly identify individuals who have fallen out of care and help link them back to HIV medical care.**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/ Barriers
Administer the “Return to Care Program” through a provider referral system to identify and return individuals to HIV care.	Out-of-care HIV positive individuals	RIDOH	# provider referrals # locatable individuals returned to care	2017-2021	Limited utilization of return to care program by HIV care providers.  Lack of designated funding to support Return to Care activities.
Administer a Data to Care Program that identifies individuals that have not had a viral load or CD4 count reported to the HIV surveillance system in the last twelve months. (There is mandatory laboratory reporting for viral loads and CD4s).	Out-of-care HIV positive individuals	RIDOH	# individuals flagged as out of care # locatable individuals returned to care	2017-2021	Incomplete or delayed laboratory reporting.  Lack of designated funding to support Data to Care activities

**Strategy B: Monitor ADAP utilization.**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/ Barriers
Utilize the 31 and 60 day report to identify clients who have not picked up their medications within the specified time frame.	All Ryan White ADAP clients	RI- ADAP/RI-EOHHS	# of clients who pick up medications in either 31 or 60 days. # of people who do not pick up medications within 31 or 60 days.	2017-2021	RI-EOHHS ACCESS database is outdated; limitations of Pharmacy Benefits Manager to provide this data to ADAP Access database.

**Strategy C: Increase monitoring of clients who are not retained or fall out of care**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/Barriers
Increase documentation from funded agencies, to record individuals who are not retained or fall out of care.	All Ryan White eligible clients	RI-EOHHS	# of clients with two(2) medical visits within a year. # of client encounters with medical and non-medical case managers.	2017-2021	Lack of adequate staff to provide increased documentation

**Objective 2.4: By 2021, 90% of individuals infected with HIV will be virally suppressed (VL<200).**

**Strategy A: Maintain and identify viral suppression for Ryan White clients.**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/Barriers
Identify and assess viral load suppression at intake and each six month re-assessment.	All Ryan White eligible clients	RI-EOHHS	# of clients who are virally suppressed at intake and each six month re-assessment. # of client's with a viral load test at intake and each 6 month re-assessment.	2017-2021	None anticipated.

**Strategy B: Increase monitoring efforts of 31 and 60 day data reports.**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/ Barriers
Utilize the 31 day and 60 day ADAP report to identify the clients who have not picked their medications. These reports are forwarded to case managers / HIV providers for them to follow up with their clients.	All Ryan White eligible ADAP clients	RI-EOHHS	# of clients who pick up medications in either 31 or 60 days. # of people who do not pick up medications within 31 or 60 days.	2017-2021	RI-EOHHS ACCESS database is outdated; limitations of Pharmacy Benefits Manager to provide this data to ADAP Access database

**Objective 2.5: By 2021, increase access to non-HIV care/treatment for PLWH/A to address co-morbidities.**

**Strategy A: Expand ADAP formulary to address co-morbidities.**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/ Barriers
Expand the ADAP formulary to cover additional medications for clients with co-morbidities.	All Ryan White eligible ADAP clients	RI-EOHHS	# of newly added drugs #/% existing ADAP clients using expanded formulary #/% of newly enrolled ADAP clients using expanded formulary # Referrals to ADAP in need of expanded formulary options # of new drugs prescribed # of new drugs taken as prescribed, as reflected in the 31 & 60 day report	2017-2021	Funding restrictions; Pharmacy Benefits Manager (HP) provision of an assessment of cost for formulary expansion.

**Strategy B: Expand Oral Health services.**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/ Barriers
Expand the Oral Health delivery system through the Ryan White Program.	All Ryan White eligible clients	RI-EOHHS	# of clients that access oral health services. # of individuals enrolled in Oral Health insurance.	2017-2021	No anticipated barriers

**Strategy C: Expand access to behavioral health services.**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/ Barriers
Expand referrals to behavioral health services.	All Ryan White eligible clients	RI-EOHHS	# of clients referred to behavioral health services. # of individuals that access behavioral health services.	2017-2021	Client access to behavioral services.
Increase access to Peer Recovery Supports.	All Ryan White eligible clients	RI-EOHHS	# of clients referred to Peer Recovery Supports. # of individuals that access Peer Recovery Supports	2017-2021	None anticipated.

**NHAS Goal 3: Reduce HIV related disparities and health inequalities**

**Objective 3.1: By 2021, reduce new HIV infections among GBMSM by 25%**

**Strategy A: Increase access to PrEP for GBMSM.**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/ Barriers
Screen and educate GBMSM who seek care at the Miriam Hospital STD clinic and Roger Williams Medical Center on PrEP.	GBMSM	RIDOH, Miriam Hospital STD Clinic, Roger Williams Medical Center	# GBMSM who seek care # GBMSM educated on PrEP # GBMSM prescribed PrEP	2017-2021	None anticipated.
Raise awareness through the development of a PrEP specific RIDOH webpage.	GBMSM	RIDOH	# unique page views	2017-2021	Lack of dedicated communications staff to support program activities.
Provide expert medical consultation and in-service training to clinical staff at Planned Parenthood and other clinical settings.	GBMSM	RIDOH	# in service trainings # providers trained # GBMSM prescribed PrEP	2017-2021	None anticipated.

**Strategy B: Increase provider awareness of GBMSM cultural competency.**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/ Barriers
Offer education and training on cultural competence related to GBMSM for HIV care providers.	GBMSM, GBMSM of color	RI-EOHHS/Ryan White funded providers	# of trainings # of providers that attend the training/s.	2017-2021	None anticipated.

**Strategy C: Prevent HIV infections among gay, bisexual, and other men who have sex with men (GBMSM).**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/ Barriers
Reduce transmission among gay, bisexual, and other men who have sex with men; including racial and ethnic sub-populations, by working with community-based (funded) agencies to improve targeted testing strategies so that they are aware of their HIV status.	GBMSM	RIDOH	# tests performed for GBMSM # positive tests for GBMSM # of tests performed by race/ethnicity for GBMSM #of positive test for GBMSM by race/ethnicity	2017-2021	Understanding and/or capacity of contracted agencies to find and test target populations.
Screen and educate GBMSM who seek care at the Miriam Hospital STD clinic and Roger Williams Medical Center on PrEP.	GBMSM	RIDOH/ Miriam Hospital STD Clinic Roger Williams Medical Center	# GBMSM who seek care # GBMSM educated on PrEP # GBMSM prescribed PrEP	2017-2021	None anticipated.

**Objective 3.2: By 2021, reduce new HIV infections among communities of color by 25%.**

**Strategy A: Promote Opt-out HIV screening in community health centers located in urban areas.**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/ Barriers
Work with community health centers to increase the number of individuals screened for HIV.	Hispanic/Latino Black/African American	RIDOH	# HIV tests performed at CHCs # newly-identified cases of HIV at CHCs by race/ethnicity #/% newly-identified cases with concurrent AIDS diagnosis	2017-2021	Participation by CHC to promote universal screening.  Providers or practices' ability to implement workflow changes.

**Strategy B: Promote the USPSTF Guidelines related to HIV and STD testing among primary care providers.**

Activity	Target Population	Responsible Parties	Data indicators	Timeframe	Anticipated Challenges/ Barriers
Work with insurance companies to educate their network providers and patients to promote routine HIV and STD screening.	All at-risk individuals	RIDOH	# of targeted communications to network providers # of targeted communications to patients	2017-2021	Participation of insurance companies to promote routine screening.  Insurance companies' ability to implement workflow changes.

## B. Collaborations, Partnerships, and Stakeholder Involvement

Central to the development of the plan was the Rhode Island HIV Care and Prevention Planning Group (CPPG). The mission of the CPPG is to eliminate the spread of HIV and to create a seamless continuum of care for all people infected and affected in Rhode Island, by:

- Preventing new infections, diagnosing existing infections at the earliest possible stage through testing and counseling programs, and developing early intervention for existing infections to decrease morbidity and mortality.
- Linking HIV education, prevention, testing and counseling, early diagnosis, access to care and the provision of quality treatment services for HIV and its associated comorbidities.
- Engaging and including individuals from every sector of our community in our planning process, particularly those persons whose lives have been directly touched by HIV/AIDS.

The Care and Prevention Planning Group was created in late 2014 by merging the RI Community Planning Group for Prevention (CPG) and the Provision of Care Planning Body (PCPB) after consensus was reached by group members. The first official meeting of the combined CPPG took place in early 2015. This group has over 30 members including representatives from medical providers who receive Part B, C, and D funding, social service organizations, AIDS service organizations, consumer advisory boards, and state agencies.

When the final Integrated HIV Prevention and Care Plan guidance was released, the CPPG discussed the process and determined a structure to ensure care, prevention, and consumer participation at all levels including the CPPG workgroups and monthly CAB meetings. All members were provided with updated information throughout the planning process. Member feedback was solicited and suggestions were incorporated. All members had the opportunity to review the final HRSA/CDC guidance.

The needs assessment process also required community collaboration at various levels. It included five components: a provider survey, a consumer survey, focus groups, an epidemiologic overview, and a resource assessment.

The Provider Capacity and Capability Survey was distributed to HIV providers, and providers specializing in substance use, mental health, and other supportive services. The questionnaire asked providers to share the types of services and the accommodations they offer, and the barriers to care their consumers most often encounter. The consumer survey was completed by more than 300 HIV service consumers in the state around demographics, sexual behavior, barriers to care, and needed services. The survey was administered through seven medical clinics, social services organizations, and AIDS service organizations. Both paper and online versions were available. The paper version was also available in Spanish. The RI Consumer Advisory Board piloted the survey before it was released and their suggestions and feedback were incorporated into the final document.

The focus groups followed up on trends identified in the consumer survey around mental health and substance use issues. Thirty-six consumers from three existing consumer groups and three different agencies participated in the focus groups.

The resource assessment involved an extensive provider survey, including follow up phone calls and confirmation of all contact information. Updates were added to the resource assessment in 2016 by contacting all RW funded agencies as well as other social service agencies to ascertain funding sources as well as menu of available services.

Stakeholders not involved in the planning process include; the Department of Behavioral Healthcare, Developmental Disabilities and Hospitals (BHDDH) and the Veteran's Administration. Rhode Island looks to foster more of a collaborative effort with these entities in order to enhance the HIV Care Continuum in the jurisdiction.

Letter of Concurrence- Please see Appendix B

### C. People Living with HIV and Community Engagement

The Rhode Island HIV Care & Prevention Planning Group Rhode Island is made up of a diverse group of planning parties inclusive of community based agency leaders, medical and non-medical case managers, physicians, dental representatives for PLWH/A, Ryan White Parts B, C & D, RIDOH Surveillance/ Epidemiology, Miriam Hospital Consumer Advisory Board Members and correctional facility representation. We find this collaboration especially important in light of the changing landscape of the healthcare environment.

In November 2015, John Snow Inc., conducted a Consumer Survey to elicit the thoughts of PLWH/A regarding a multitude of questions regarding HIV care, services, barriers, demographics, cultural diversity, socio-economic and risk behaviors.

The Consumer Advisory Board and the CPPG offer opportunities for participation of PLWH/A in the state delivery service. The Consumer Advisory Board meetings are facilitated on a monthly basis and focus on needs such as housing, transportation, and mental health. On September 30, 2016, the CAB and Miriam Hospital Consumer Group facilitated a forum that focused on "HIV and Aging." The Rhode Island CPPG is inclusive of both the Ryan White Part B Program and RIDOH which have involved all relevant stakeholders in Rhode Island, including consumers from RIDOH's Community Planning Group (CPG) and representatives of the Ryan White, Planning Body, Planning Committee (PCPB), Ryan White Part C and D programs as well as representatives from housing Opportunities for Persons with AIDS (HOPWA), Medicaid, mental health and substance use treatment and the Department of Corrections settings. The Consumer Advisory Board (CAB) is currently a separate advisory body and meet on a monthly basis. The CAB has expanded from an average of 15 members to an average of 20 members to better meet HRSA legislative language; including revising current by-laws, procedures, and policy. Membership is reflective of racial and ethnic diversity in epidemiological profile, and a new young member

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joined the group which brought a new perspective and much inspiration into the group. The current demographics of the CAB members include 10 male and seven female. Three members identify as Latino; nine members are Black/African American and eight are Caucasian. There are four male members that identify as GBMSM. CAB members were educated about the treatment cascade/continuum of care and were part of discussions around retention in care and out-of-care individuals. Topics have included: PrEP and PEP; Quality measures in Care; Self Advocacy and PLWH/A over age 55. This planning group strengthened its development stages in 2015 and will assist in the program development and the public advisory planning process of the Comprehensive Plan to reflect the epidemic in RI, including both consumers and providers. The CPGG and its associated integrated plan subcommittees and workgroups, incorporate the Comprehensive Plan into their meeting agendas, and are updated as to the progress and direction of the Comprehensive Plan by providing a progress report at each meeting.

# Section III: Monitoring and Improvement

## Description of the Process for Updating the Planning Bodies and Stakeholders on the Progress of Plan Implementation

Ongoing monitoring mechanisms are crucial to ensure that available services and resources are maximized and prioritized accordingly. An important part of monitoring includes being able to provide updates to key stakeholders for their awareness and important input. Over the last year the CPPG has been established and strengthened through the involvement of a diverse set of stakeholders, described above. The Care and Prevention Planning Group is attended by representatives from RI-EOHHS and RIDOH's prevention and surveillance programs, each of which have dedicated agenda time to provide key program updates. These updates will relate to the goals and objectives of the plan and allow for ongoing monitoring and dialogue between RI-EOHHS, RIDOH, and community stakeholders. These meetings are scheduled quarterly, or as needed, and are held separately from CAB events and the 90-90-90 Steering Committee meetings. Updates on prevention, care, and surveillance are also provided to stakeholders in those venues.

## Description of Plan to Monitor and Evaluate Implementation of the Goals and SMART Objectives

Each goal and objective in this plan has related strategies and activities which include responsible parties, data indicators, and monitoring and evaluation timeframes which form the basis of the monitoring and evaluation methodology. The HIV Care Continuum and the related initiative of 90-90-90 campaign provide an additional, overarching framework, both for statewide, and Ryan White-funded programs, to evaluate progress towards achieving the goals in this plan.

At an agency and program level, both RI-EOHHS and RIDOH have routine, ongoing processes in place to ensure complete, timely, and accurate data collection, entry, and analysis through the support of analytic staff and program consultants. Program specific data systems (eHARS, CareWare, ADAP, HIV Prevention-specific databases, etc.) will be used for ongoing data collection and routine analysis. At RIDOH, a quarterly dashboard is provided to Center Leadership with updates on the full portfolio of HIV prevention activities. Further, HIV Surveillance and HIV Prevention Program activities are part of Department and State-wide dashboards which report progress towards meeting the goals of the 90-90-90 Initiative. Multiple levels of reporting exist which emphasize the importance that HIV prevention has at all levels of State Government (Department, Agency, and through the Governor's Office) and the related assurance that work towards this plan's goals will be well supported and prioritized. Data, and progress on goals and objectives, will be discussed and shared with stakeholders that are charged with providing prevention services, medical care, and treatment to HIV positive consumers, and those at risk. These data will also be shared with the CAB and other consumers

as possible. These data will be used to monitor progress but also to create change if progress on certain objectives, strategies, or activities is slow. For example, program monitoring may help to isolate potential gaps in testing resources and translate to more efficient outreach activities, planning, needs assessments, and other activities and initiatives at the local level. Both RIDOH and RI-EOHHS will continue to work with stakeholders to ensure effective prevention service delivery, and develop outreach and quality management plans to address those HIV positive clients who know their HIV status but are not in care to bring them into treatment.

The metrics identified in this plan will be analyzed on a quarterly basis to determine progress towards the intended goals. This progress will be disseminated to the members of the CPPG regularly.

### **Description of the Strategy to Utilize Surveillance and Program Data to Improve Health Outcomes along the HIV Care Continuum.**

The HIV Surveillance Program will support many of the goals, objectives, strategies, and activities listed in this plan by providing the necessary baseline and follow up data to evaluate progress. The HIV Surveillance Program will monitor the number of new diagnoses and PLWH/A in Rhode Island which are important indicators. However, HIV surveillance data are able to provide a lot more value than just monitoring diagnoses and prevalence.

In November, 2015 RIDOH published its first local HIV Care Continuum and signed on to the 90-90-90 Initiative. This act was the culmination of many activities to improve the completeness and timeliness of data collection and entry into eHARS. Rhode Island has finally achieved a higher level of data quality and can begin using eHARS (statewide data), to monitor the HIV epidemic. This was achieved through technological improvements which have allowed electronic laboratory reporting and the reduction of data entry backlogs. The HIV care continuum framework will continue to be the method Rhode Island uses to measure its response to the HIV epidemic and its success in meeting the stated goals and objectives listed in this plan.

A core function of the HIV Surveillance Program is the prompt dissemination of HIV surveillance data to stakeholders to inform prevention and care efforts. HIV surveillance data are shared with the CPPG quarterly to provide a provisional, near-real-time, update on HIV diagnoses in Rhode Island. Demographic and risk information are analyzed and shared routinely to inform stakeholders of any changes to populations impacted and transmission dynamics.

Routine analysis and dissemination will provide crucial updates on many of the activities in this plan, including maintaining a strong needle exchange program (reducing transmission among PWID), reducing transmission among disproportionately impacted populations, and reducing new infections overall.

Further, HIV surveillance data will be analyzed as part of three-part strategy to identify individuals out of care. Individuals that have not had a viral load or CD4 laboratory result

reported to RIDOH within a specified time period will be referred to staff for follow up. The use of these data show that HIV surveillance will not only monitor progress on activities, but will also directly contribute to the implementation of planned activities (such as re-engagement in care activities).

Annually, per CDC guidance, a new Rhode Island HIV care continuum will be developed to report out on overarching progress. This continuum will summarize the combined progress being made on all of the activities within this plan.

# Acknowledgements

**Governor Gina M. Raimondo**

**Elizabeth Roberts- Secretary of the Executive Office of Health & Human Services**

**Executive Office of Health & Human Services**

Anya Wallack, PhD- Medicaid Director, Executive Office of Health & Human Services

Darren McDonald, PhD- Executive Office of Health & Human Services, Executive Office of Health & Human Services

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**Special thanks to:**

HIV Care and Prevention Planning Group