

**RHODE ISLAND 2013 RYAN WHITE SURVEY RESULTS:
Provider Capacity in the Provision of Services**

**The Division of Medicaid, HIV Provision of Care Unit at the Executive Office of Health &
Human Services (EOHHS)**

Survey Development, Management, and Analysis Conducted by:

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SURVEY BACKGROUND

The Division of Medicaid, HIV Provision of Care Unit at the Executive Office of Health & Human Services (EOHHS) conducted a survey related to provider capacity in the provision services in the fall of 2013. EOHHS administers all aspects of HIV provision of care, including the Ryan White program. Results to the survey provided valuable information regarding available services, across a variety of disciplines, for people living with HIV/AIDS (PLWH). This survey, the Profile of Provider Capacity and Capability, is part of an assessment that is required by the Health Resources Services Administration (HRSA) and will contribute to Rhode Island's 2016 Comprehensive Plan for HIV Service Delivery.

The Profile of Provider Capacity and Capability attempts to assess the current landscape of available services for PLWH in Rhode Island in order to determine which services are accessible, available, and appropriate. Surveying the providers, the profile describes how much of which services each agency can deliver. It is an essential tool for policymakers because it contributes to an accurate understanding of the current state of HIV/AIDS support and care in the state and enables the identification of critical service gaps.

An electronic version of the survey was sent to organizations providing services to PLWH in Rhode Island. Participants in the survey included providers from non-HIV and HIV specific organizations and those both funded and not funded by HRSA to provide HIV care and related services or other services to PLWH. Surveys were completed in November, 2013. The results will be included as a part of the State's overall needs assessment process and comprehensive plan for HIV provision of care going forward.

The survey was developed in partnership with and managed by an independent organization, John Snow, Inc. (JSI). JSI was also responsible for the analysis and summary of survey results.

Survey results will be shared with the State's HIV/AIDS advisory groups, the Provision of Care Committee, and the Rhode Island Consumer Group. Results will help the Executive Office of Health & Human Services make decisions regarding service gaps and needs throughout the State.

HIV/AIDS IN RHODE ISLAND

According to the *2012 Rhode Island HIV/AIDS/Viral Hepatitis Epidemiologic Profile with Surrogate Data* published by the Rhode Island Department of Health:

...In RI 3,612 cases of HIV and AIDS and 1591 deaths from this virus have been reported in the last 30 years as of 2012. Major strides in prevention and treatment have altered the pace and reach of the epidemic, and after a plateau we are in a phase of decline. However, much work still needs to happen to get us to zero native transmissions in RI. One of the major interventions will be to keep the estimated 2500 persons living with HIV and AIDS in RI connected to care and have their viral loads suppressed to prevent transmission...

Detailed information related to demographic and risk factor characteristics among PLWH in Rhode Island can be found at:

<http://www.health.ri.gov/publications/epidemiologicalprofiles/2012HIVAIDSViralHepatitisWithSurrogateData.pdf>

Figures 1, 2, and 3 show the prevalence of HIV/AIDS cases in Rhode Island by city/town in 3 different ways: as the absolute number of cases (Figure 1); as a relative percentage of the total HIV/AIDS cases (Figure 2); and lastly, standardized by the population - for each city/town (Figure 3).

These maps show that Providence and Cranston contain the highest absolute number and highest percentage of total HIV/AIDS cases in Rhode Island and that Woonsocket, Pawtucket, North Providence, Newport, Cranston, and Providence have the highest number of HIV/AIDS cases per their population. As demonstrated here, HIV/AIDS cases in Rhode Island are predominantly centered within more densely populated, urban environments.

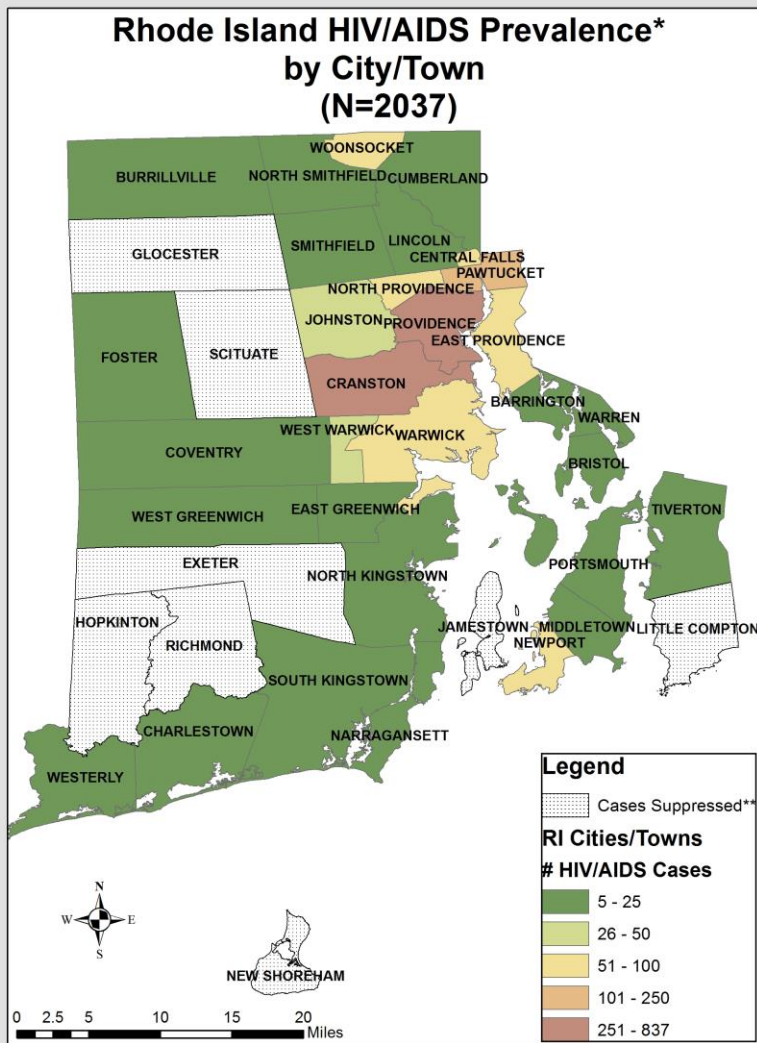


Figure 1: Rhode Island HIV/AIDS Prevalence by City/Town

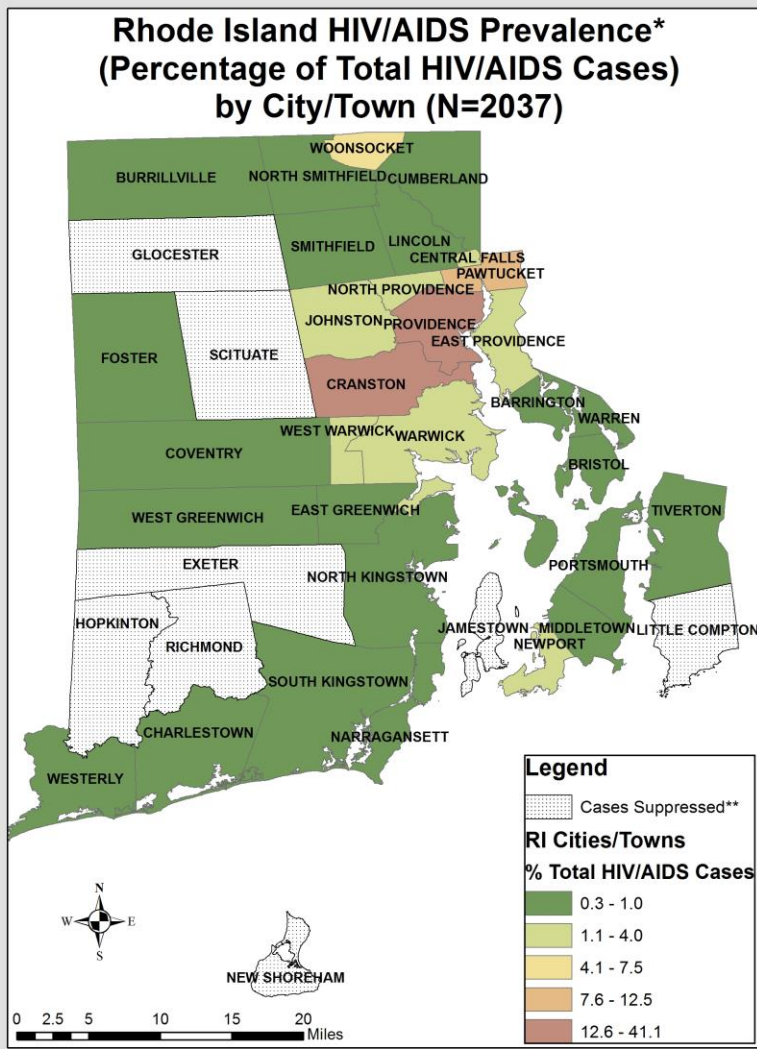


Figure 2: Rhode Island HIV/AIDS Prevalence (Percentage of Total HIV/AIDS Cases) by City/Town

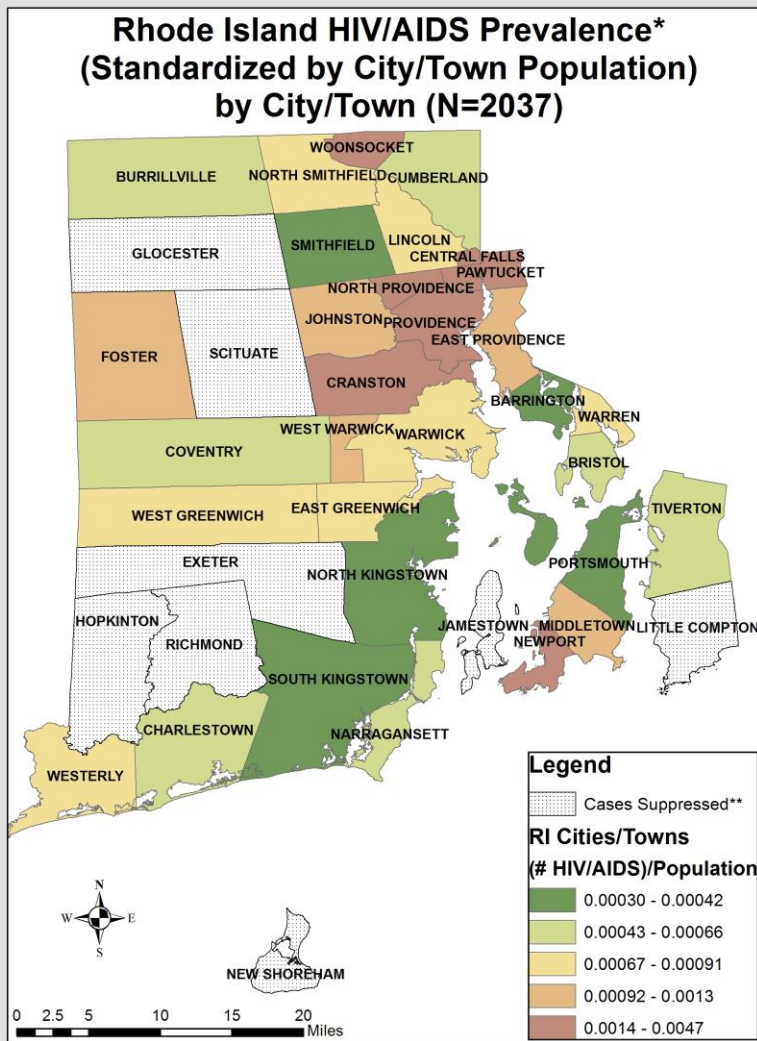


Figure 3: Rhode Island HIV/AIDS Prevalence (Standardized by City/Town Population) by City/Town

Socio-Demographic and Economic Population Characteristics

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).

Rhode Island is a small but densely populated state—the fourth most densely populated in the United States. According to 2008-2012 ACS estimates, Rhode Island had a total population of 1,052,471. Of these, 543,950 (52 percent) were female and 508,521 (48 percent) were male. The median age was 39.8 years. Twenty one percent of the population were under 18 years of age and 15 percent were 65 years and older.

See *Figure 4* for a breakdown of Rhode Island's population estimates presented by city/town.

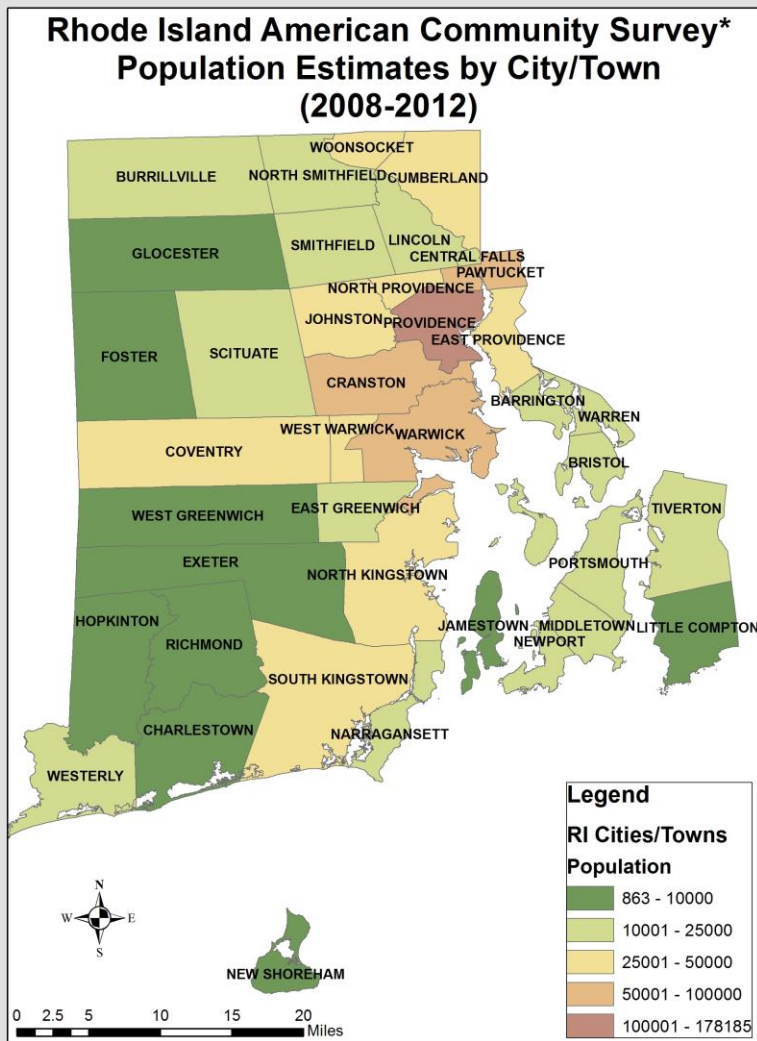


Figure 4: Rhode Island American Community Survey Population Estimates by City/Town

Education: Estimates from the ACS report eighty-four percent of people 25 years of age and over had at least graduated from high school and 31 percent had a bachelor's degree or higher. However, educational attainment is not equally distributed across cities and towns in Rhode Island. See *Figures 5 and 8* 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.

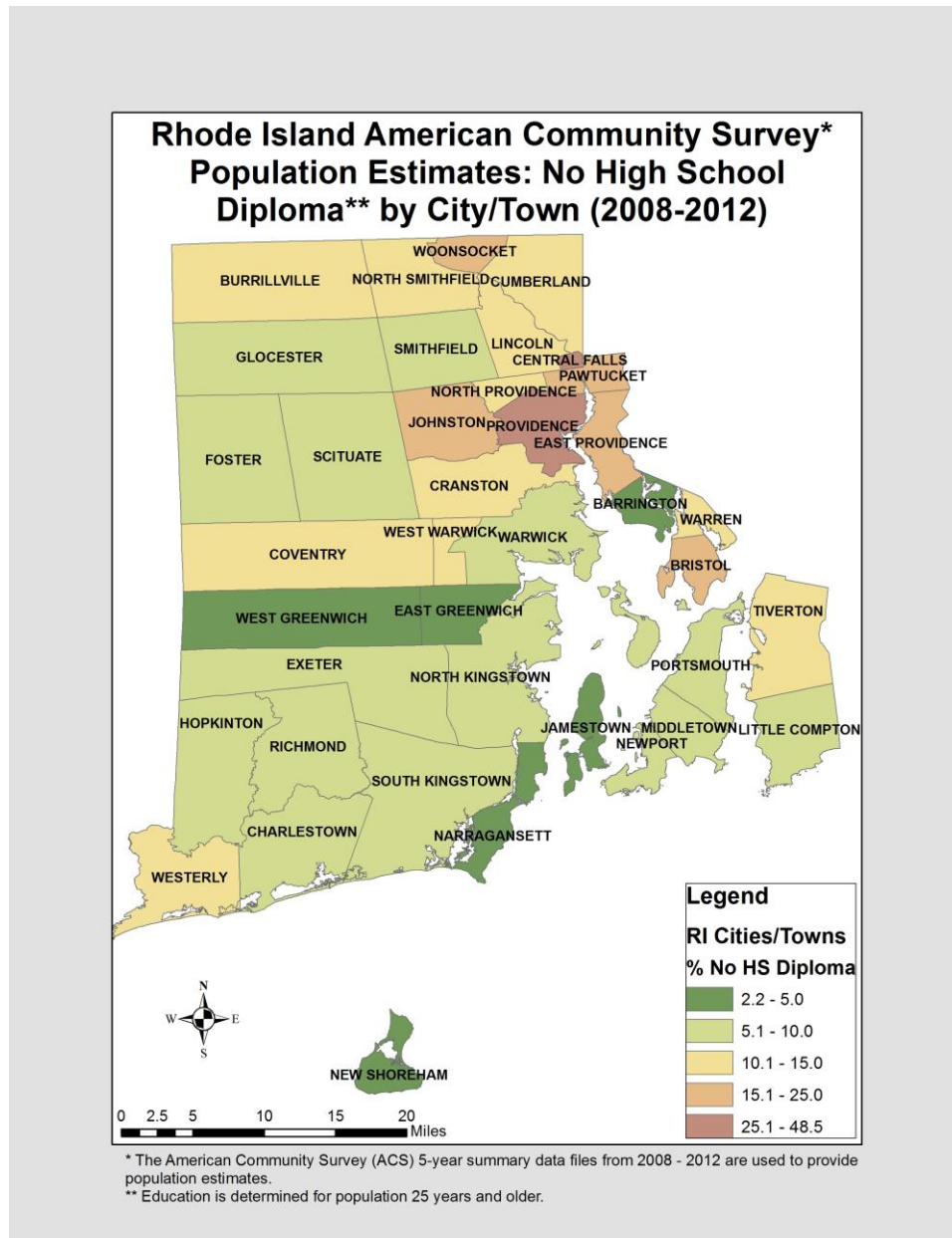


Figure 5: Rhode Island American Community Survey Population Estimates: No High School Diploma by City/Town

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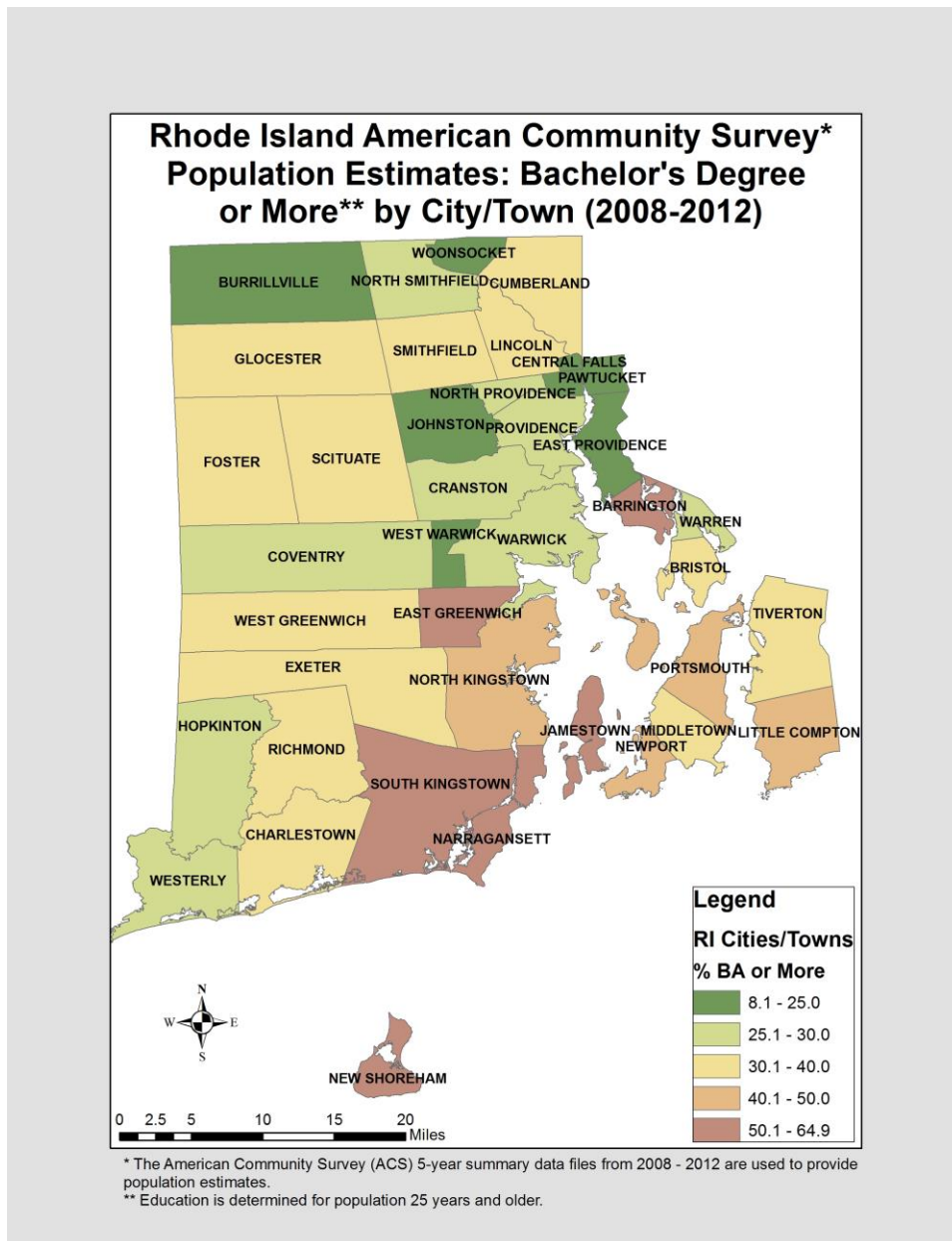


Figure 8: Rhode Island American Community Survey Population Estimates: Bachelor's Degree of More by City/Town

Immigrant Communities and Language

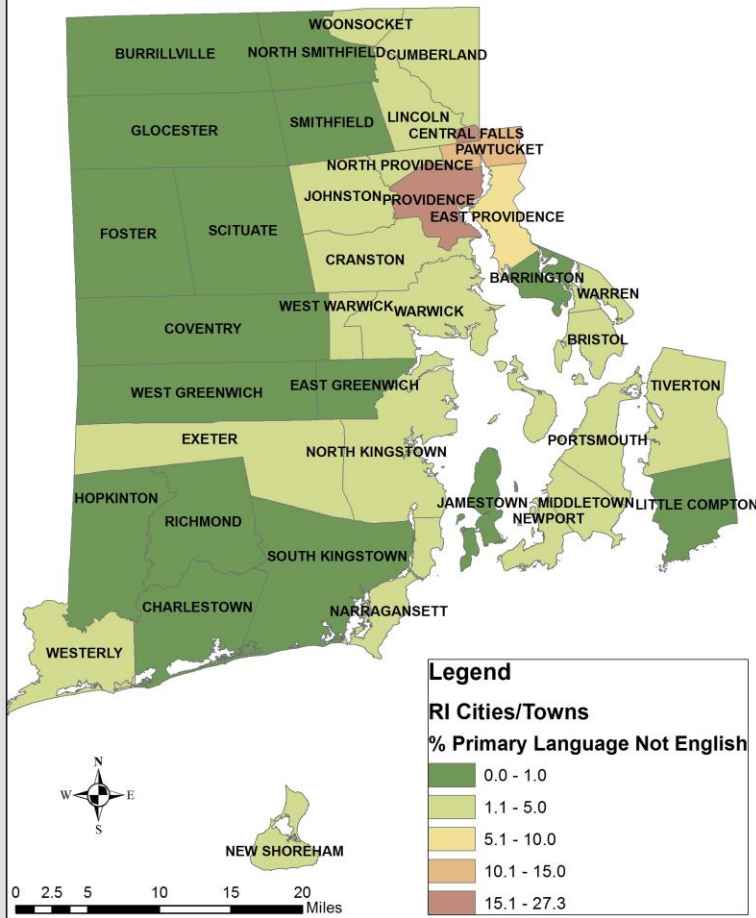
Immigrants to Rhode Island represent a growing share of our state's population. Between 2000 and 2012, the number of foreign-born Rhode Island residents grew from 120,000 to 140,000 accounting for 13.3% of the state's population today. During this period, estimates of total population remained relatively stable.

Rhode Island's immigrant populations reflect a diversity of backgrounds. Latin American immigrants, the largest group of immigrants living in the state, account for less than half of all foreign-born residents of the state (44.5%). The Rhode Island immigrant community includes tens of thousands of residents who were born in Europe (23.1%), Asia (17.0%), Africa (12.5%), Foreign-born from North America (2.5%), or Oceania (Islands of the tropical Pacific Ocean) (0.3%).¹

The majority of immigrants (83.9%) in Rhode Island speak a language other than English at home, and about half speak English less than "very well" (See *Figure 9* for a detailed breakdown by city/town).

¹ (2014). Rhode Island State Data Center: Census Data Bulletin: March 2014. Retrieved from http://www.planning.ri.gov/documents/census/bulletin/bulletin_march2014.pdf.

**Rhode Island American Community Survey*
Population Estimates: Primary Language Not English**
& "Doesn't Speak Very Well" by City/Town (2008-2012)**



* The American Community Survey (ACS) 5-year summary data files from 2008 - 2012 are used to provide population estimates.
 ** Estimates are determined for individuals 14 and over who do not speak English only and reported "does not speak English very well."

Figure 9: Rhode Island American Community Survey Population Estimates: Primary Language Not English & "Doesn't Speak Very Well" by City/Town (2008-2012)

Poverty and Adult Insurance Coverage:

According to 2012 ACS data, Rhode Island's median household income was \$54,554— an eight percent decline from 2007 (\$59,321). 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).

Figure 10 shows the cities and towns in Rhode Island with the highest percentage of residents living below 100% poverty. These include: Providence, Woonsocket, Pawtucket, and Central Falls.

The Current Population 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. According to the CPS, in Rhode Island there are 125,000 people (14.3%) under age 65 without health insurance during 2011/2012* (See Figure 11 for a breakdown of the percentage of individuals without insurance by city/town). Rhode Island has the highest percentage of uninsured residents in New England. 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 Islanders 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. Medicaid eligibility will be based solely on income in expansion states. US citizens and legal immigrants with incomes of 138% of the Federal Poverty Level (FPL) or less will qualify for Medicaid benefits. This is different than previous eligibility criteria which are based on population categories. Children, pregnant women, parents with dependent children, people with disabilities, and low-income seniors may qualify for Medicaid benefits prior to expansion, depending on their income. However, nondisabled adults without children, such as young, childless, low-income men – who are disproportionately infected with HIV – were not eligible for Medicaid prior to the ACA.

Medicaid expansion is important for PLWH because, unless they were disabled, they were ineligible for Medicaid prior to ACA. Not all states, however, have opted to expand Medicaid under the ACA. In these states PLWH are still not eligible for Medicaid under the new income requirements. PLWH in non-expansion states continue to have to rely solely on Ryan White, while piecing together safety-net programs to obtain care. However, many of these programs are not designed to treat all of a patient's medical and behavioral health care needs. For this reason, obtaining comprehensive healthcare services is difficult without Medicaid expansion. See Figure 12 for the percentage of Rhode Island residents with a ratio of income to poverty of 1.38.

**Note: National data from the CPS are for just one year, and the small sample size requires pooling two years of data for state trends.*

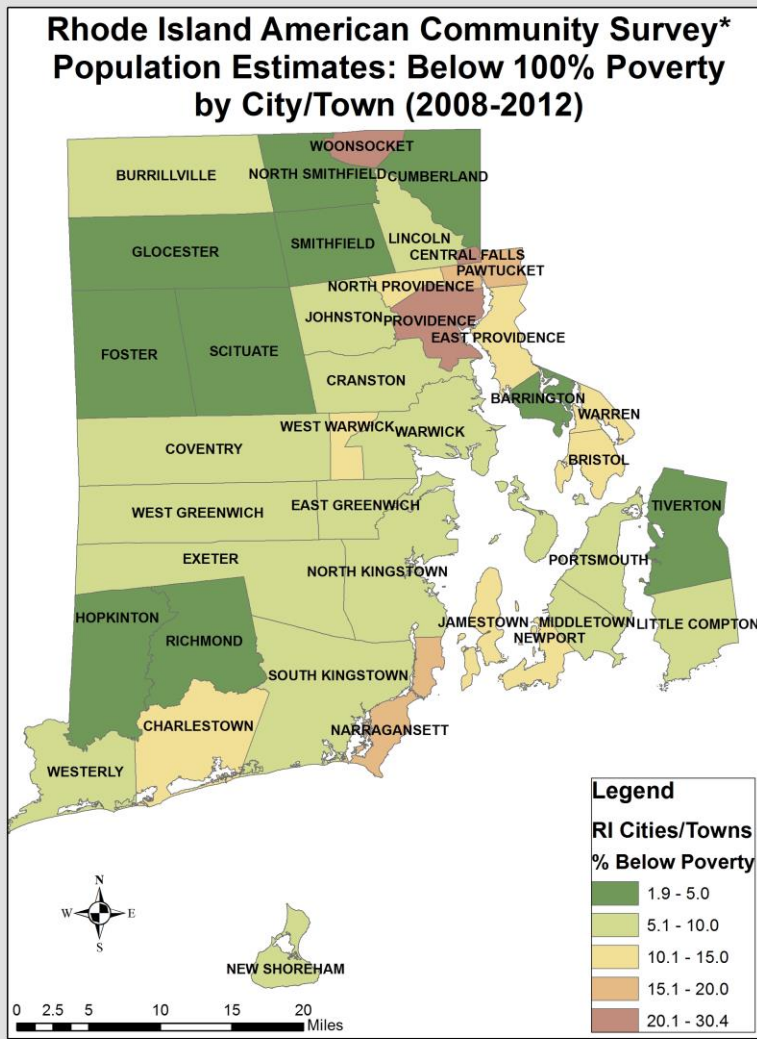
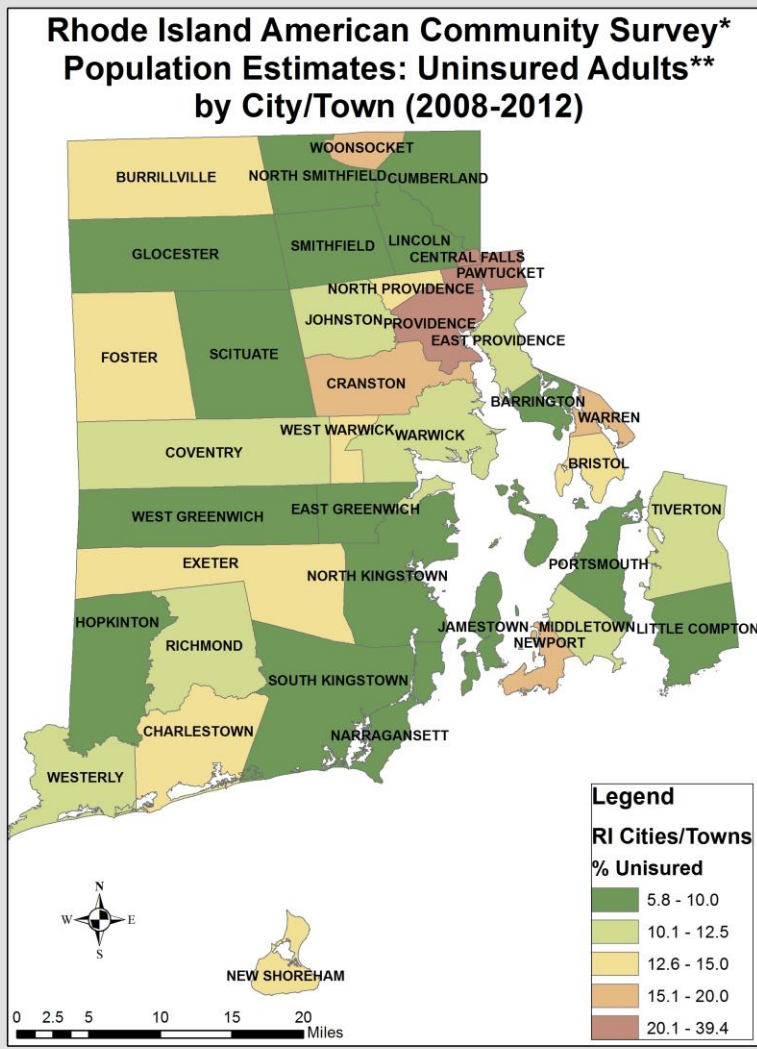


Figure 10: Rhode Island American Community Survey Population Estimates: Below 100% Poverty by City/Town (2008-2012)



* The American Community Survey (ACS) 5-year summary data files from 2008 - 2012 are used to provide population estimates.
 ** Insurance status is determined for the adult population between 18-64 years of age.

Figure 11: Rhode Island American Community Survey Population Estimates: Uninsured Adults by City/Town (2008-2012)

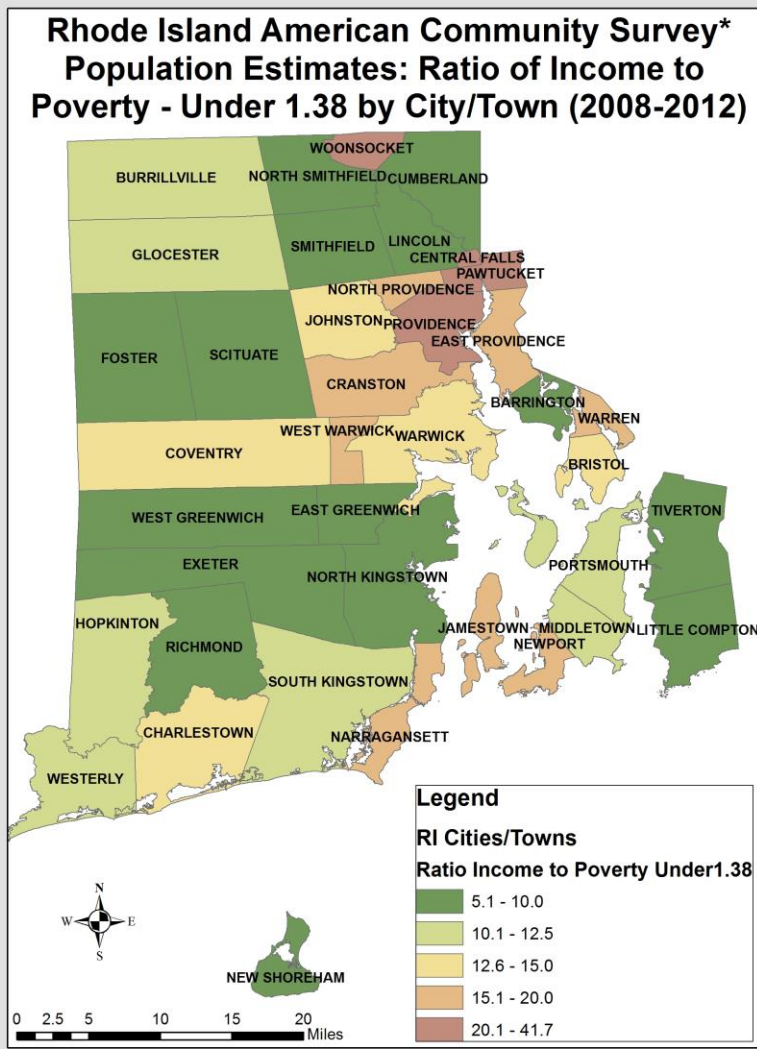


Figure 12: Rhode Island American Community Survey Population Estimates: Ratio of Income to Poverty – Under 1.38 by City/Town (2008-2012)

Race and Ethnicity

According to 2012 population estimates from the U.S. Census Bureau, for people reporting one race alone, 86 percent were White; 7 percent were Black or African American; less than 1 percent were American Indian and Alaskan Native; 3 percent were Asian; less than 0.5 percent were Native Hawaiian and Other Pacific Islander. Thirteen percent of the people in Rhode Island are Hispanic or Latino. And three percent reported two or more races.

For a detailed look at race and ethnicity by city/town, see Figure 13 (White Alone), Figure 14 (Black Alone) and Figure 15 (Hispanic or Latino).

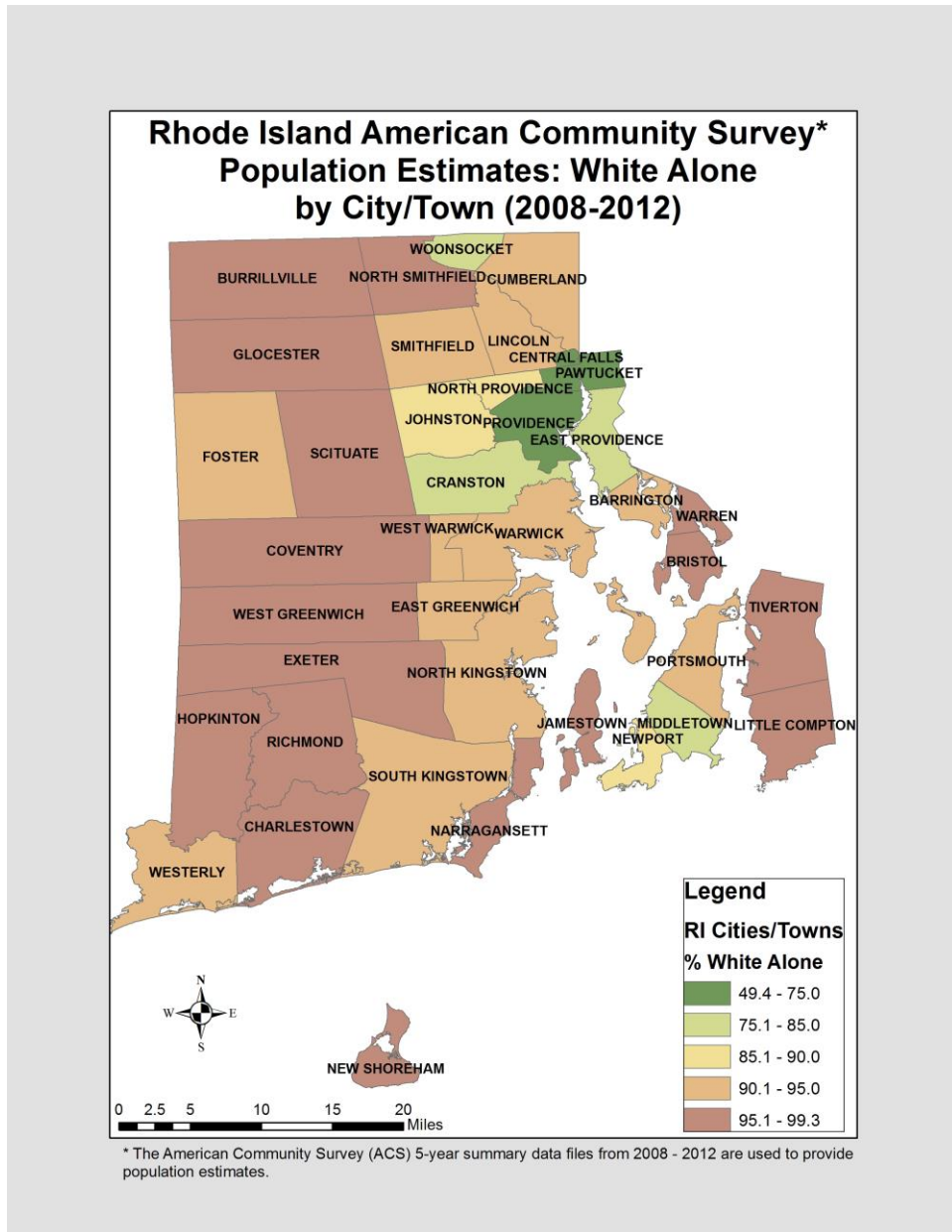


Figure 13: Rhode Island American Community Survey Population Estimates: White Alone by City/Town (2008-2012)

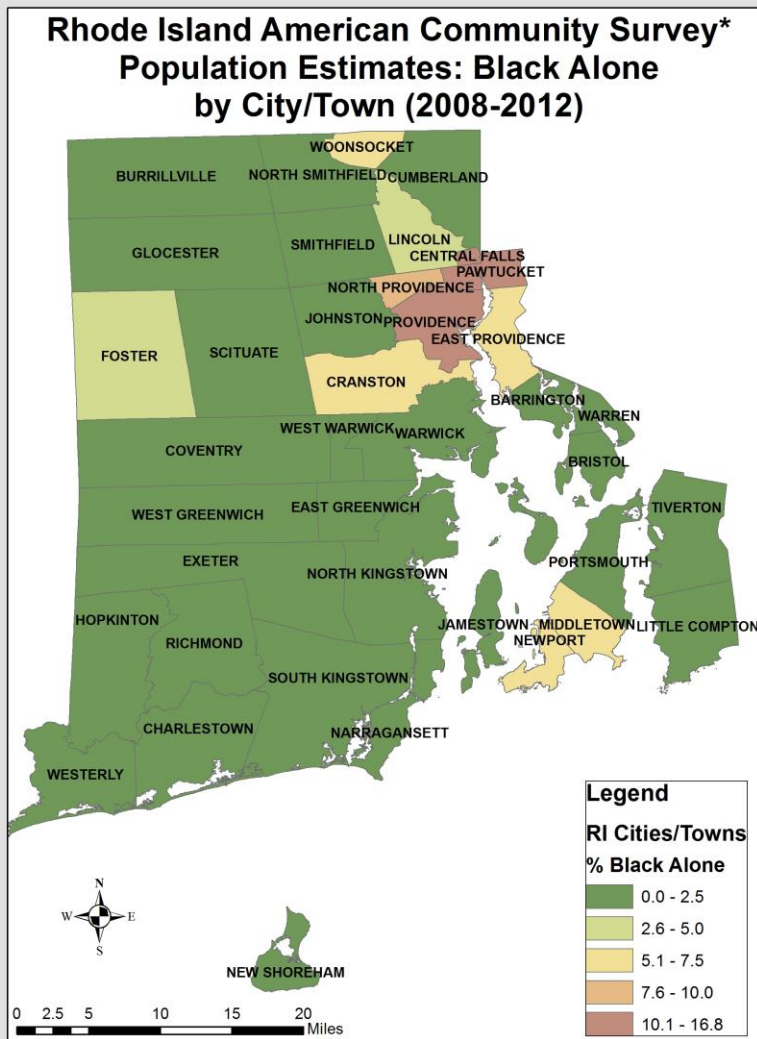
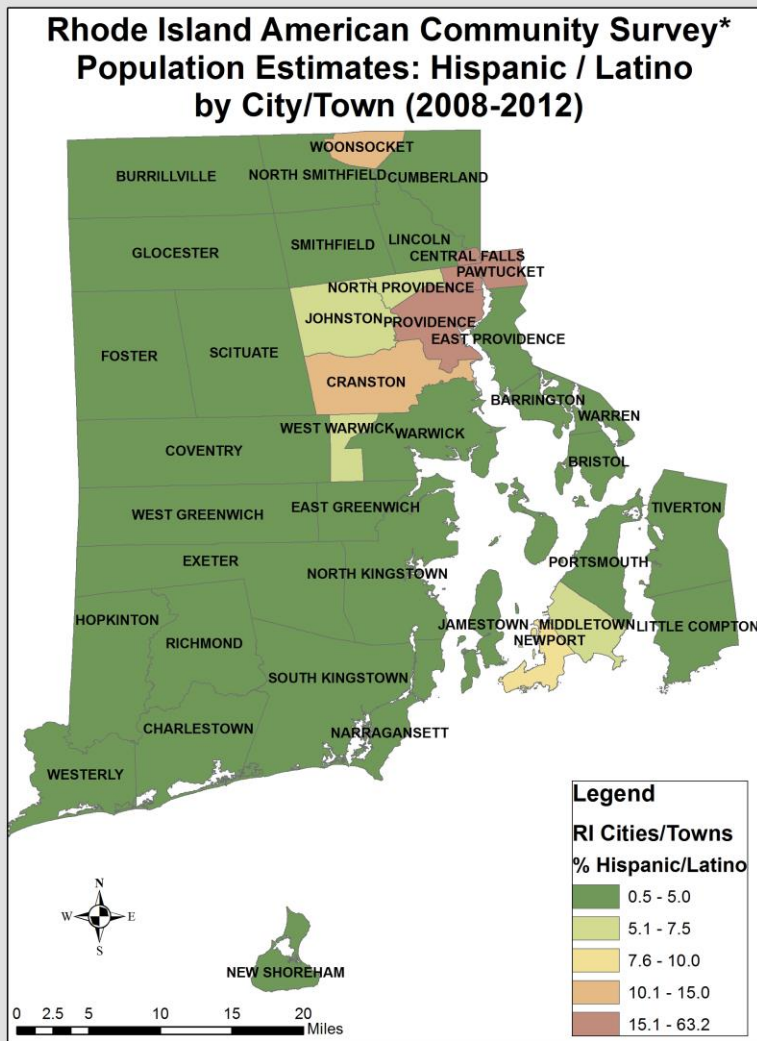


Figure 14: Rhode Island American Community Survey Population Estimates: Black Alone by City/Town (2008-2012)



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

Figure 15: Rhode Island American Community Survey Population Estimates: Hispanic / Latino by City/Town (2008-2012)

In summary, the state of Rhode Island has had significant success in managing the HIV/AIDS epidemic but is still far from the ultimate goal of zero transmission. Moving forward, any and all interventions must take into account the prevailing state demographic information and trends as they relate to HIV/AIDS. The disease is disproportionately concentrated in more impoverished and racially diverse areas. It resides among young, minority MSM individuals to a greater extent than any other demographic category—it is fastest growing among this population as well. And there are still more than 100,000 people living in the state without adequate health insurance, likely not adequately connected to the resources and support they need to manage their disease.

METHODS

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:

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. 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 the Executive Office of Health & Human Services (EOHHS). The Rhode Island Provision of Care Planning Body (PCPB) 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 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 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 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 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 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 will be shared with the State's HIV/AIDS advisory groups, the Provision of Care Committee, and the Rhode Island Consumer Group. Results will help the Executive Office of Health & Human Services make decisions regarding service gaps and needs throughout the State and will be included as a part of the State's overall needs assessment process and comprehensive plan for HIV.

RESULTS

Of the original 95 organizations that were sent the survey, 54 respondents representing 42 organizations started the survey with 21 respondents opting out of the survey because they did not provide services to PLWH.

8 of these surveys were deemed "incomplete" although of these incomplete, 5 either took the survey again to completion/disqualification or another representative from the organization completed the survey. There are 3 organizations that were classified as a "true" incomplete.

25 respondents did not opt out and completed the survey representing 20 distinct organizations. The analyses included in this report represent these 20 distinct or unique organizations providing services to PLWH. Together, these 20 respondents represent 100% of providers funded by the Ryan White Care Act in Rhode Island.

Survey respondents were asked if their organization targets one or more particular population(s). Of the 20 distinct organizations represented in this survey, 11 reported that they serve all populations within the State and 8 reported that they target specific populations (see Figure 16).

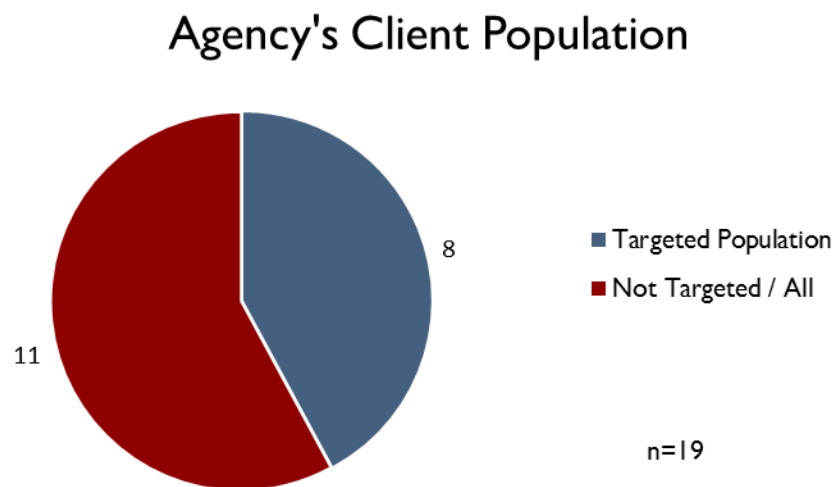


Figure 16: Agency's Client Population

Figure 17 provides a breakdown of the specific populations targeted by organizations who reported targeting individuals based on particular social, demographic, economic, and/or behavioral characteristics.

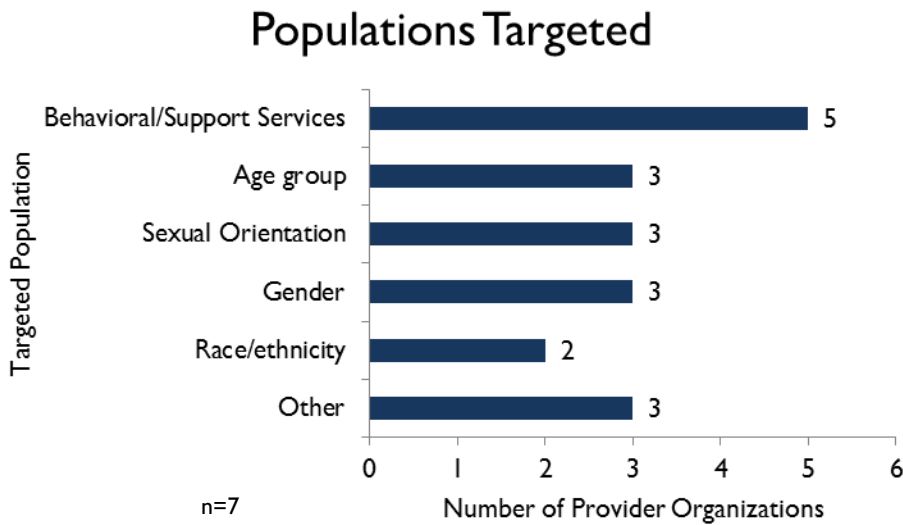


Figure 17: Populations Targeted

Figure 18 represents the 25 respondents who completed the survey (did not opt out) representing 20 distinct organizations. The diagram further classifies each organization by geography (i.e. whether they serve all of the State or provide services that serve specific cities) and target population (i.e. whether they serve all populations or target specific populations).

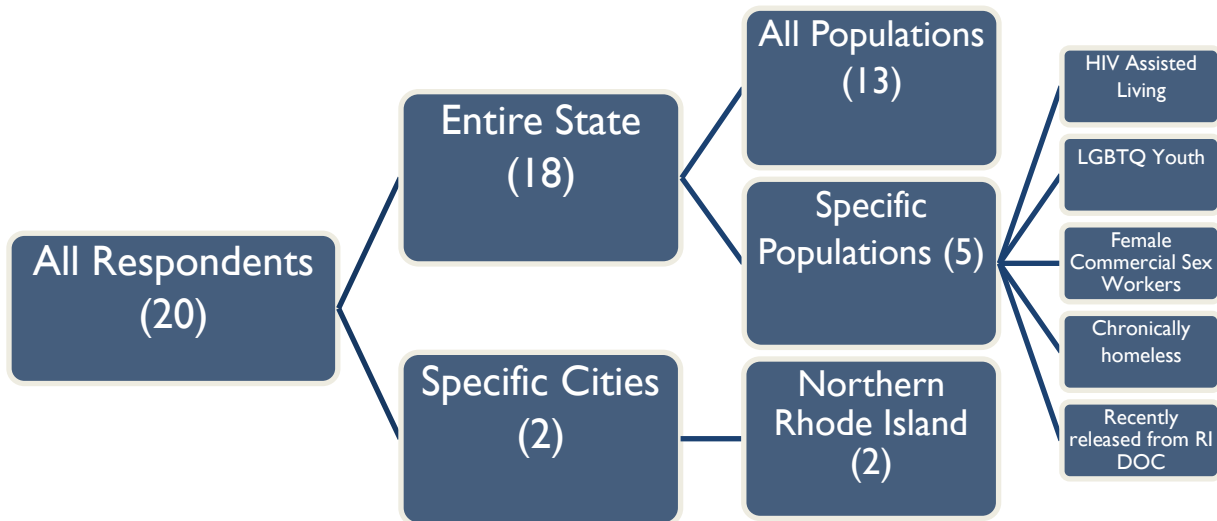


Figure 18: Populations Targeted Breakdown

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 or more physical locations. Figure 19 includes the total geographic distribution of survey respondents, including affiliate locations. These individual locations were geocoded onto a map that illustrates the HIV/AIDS prevalence as an absolute measure representing the number of cases by city/town. The prevalence of HIV/AIDS in Rhode Island was 2,037 cases through February 3, 2014.

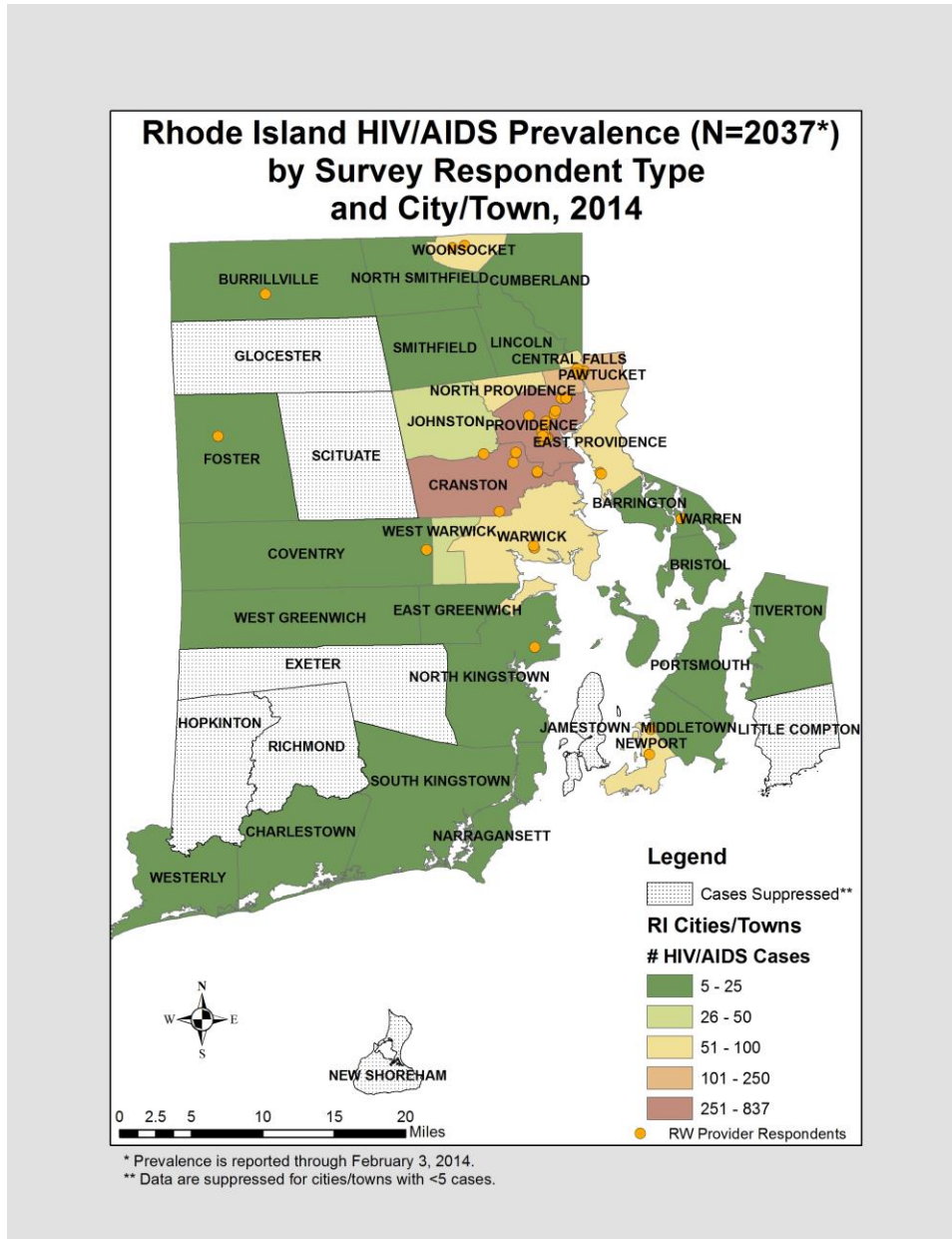


Figure 19: Rhode Island HIV/AIDS Prevalence by Survey Respondent Type and City/Town, 2014

Figure 20 further classifies each location into provider service categories including: primary care provider (PCP), group practice PCP, Hospital-based PCP, Health Center or Clinic-based PCP, AIDS Service Organization (ASO), and/or mental health, substance abuse, or other provider. Figure 21 shows a zoomed area view for the City of Providence (and immediately surrounding areas), which include the highest density of both service providers and PLWH.

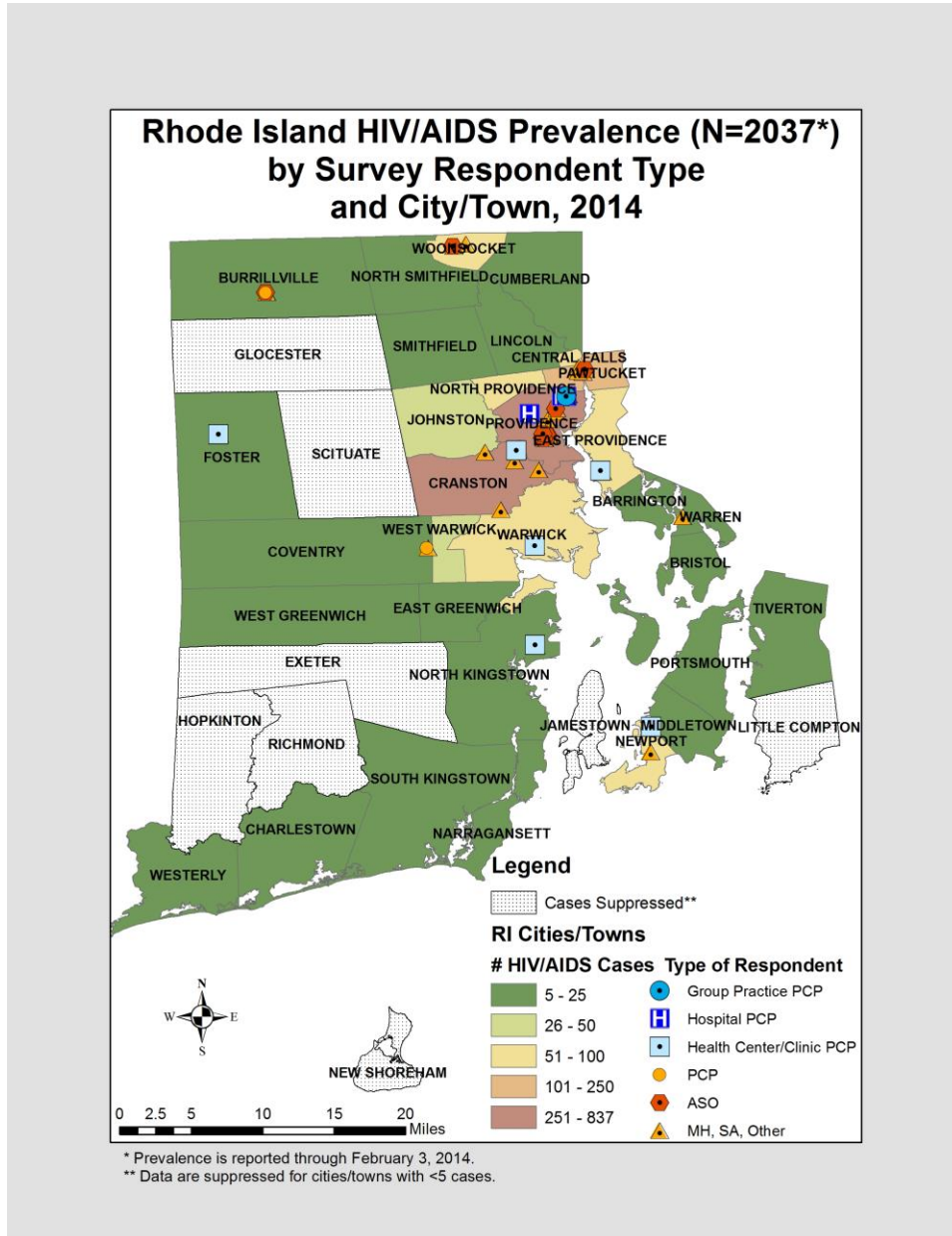


Figure 20: Rhode Island HIV/AIDS Prevalence by Survey Respondent Type and City/Town, 2014

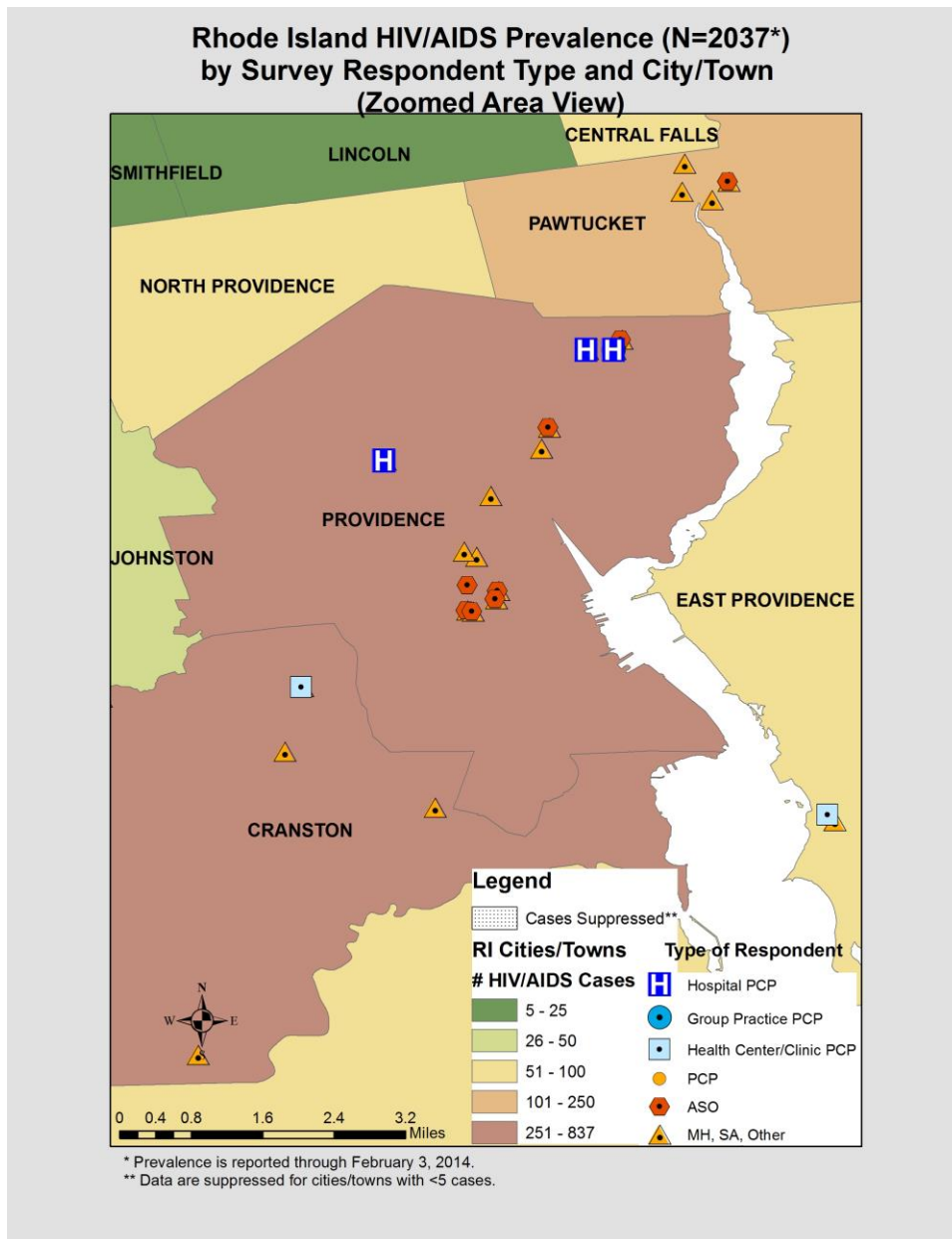


Figure 21: Rhode Island HIV/AIDS Prevalence by Survey Respondent Type and City/Town (Zoomed Area View)

Figures 22 geocodes each service provider category location, illustrating HIV/AIDS prevalence as a relative measure representation of the percentage of total HIV/AIDS for each city/town. Figure 23 shows a zoomed area view for the City of Providence (and immediately surrounding areas), also as a relative measure of the number of HIV/AIDS cases by city/town.

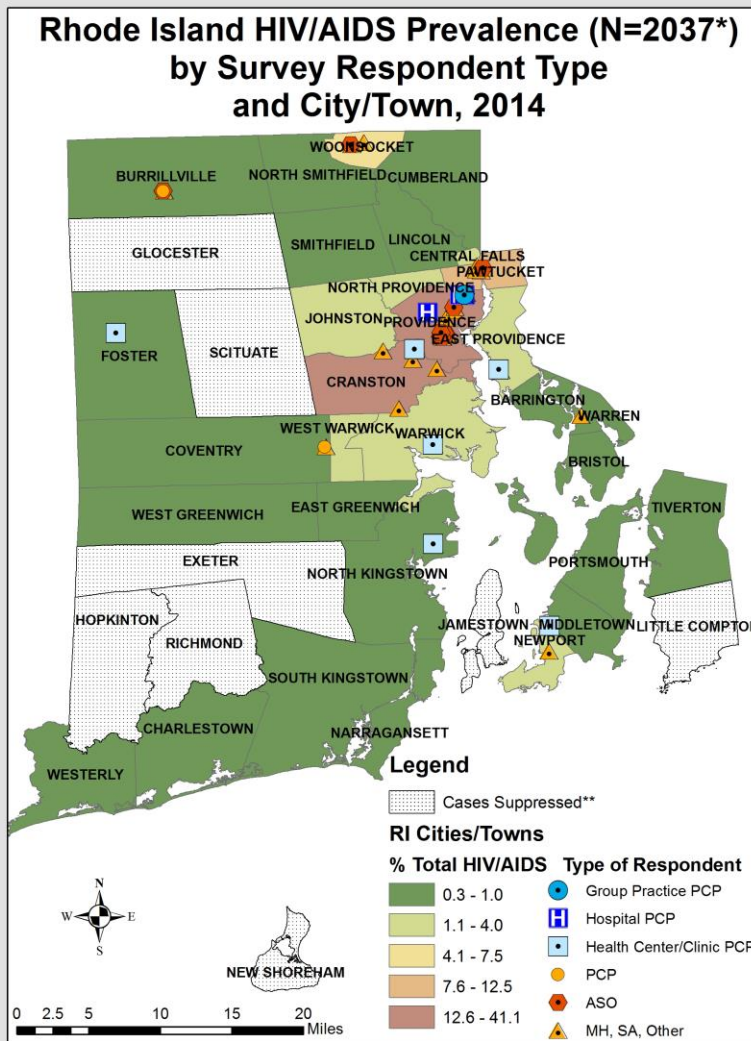


Figure 22: Rhode Island HIV/AIDS Prevalence by Survey Respondent Type and City/Town, 2014

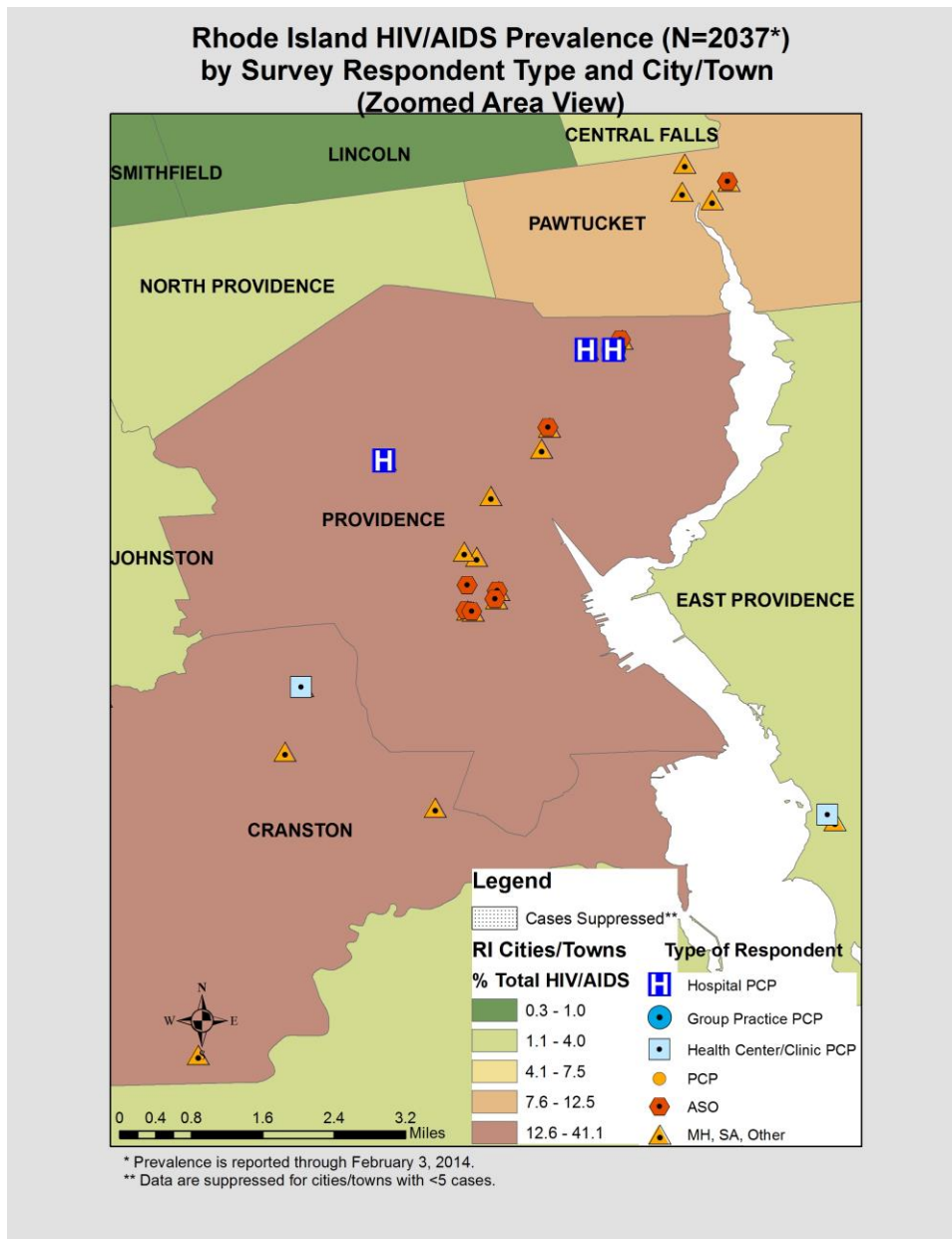


Figure 23: Rhode Island HIV/AIDS Prevalence by Survey Respondent Type and City/Town (Zoomed Area View)

Survey respondents were asked if their agency services are specifically provided to PLWH. Of the 20 distinct organizations responding to the survey, six organizations reported that their services are only provided to PLWH and 13 provided services to both PLWH, as well as other populations (Figure 24).

Agency Services Provided to PLWH

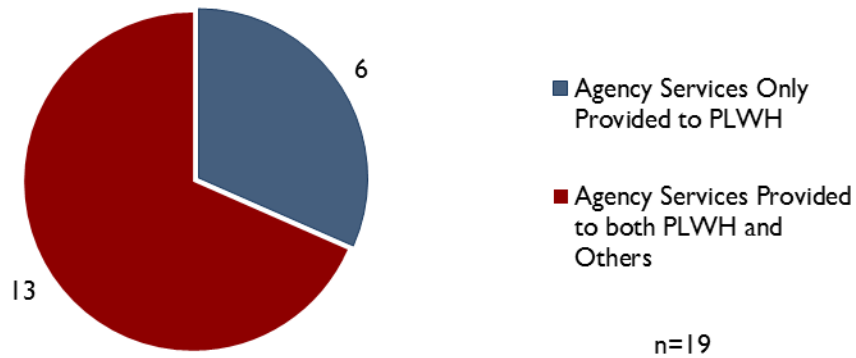


Figure 24: Agency Services Provided to PLWH

The majority of survey respondents reported less than 5% of clients seeking services at their respective organizations are HIV+ (8), or did not know the percentage of HIV+ clients seen by their agencies (Figure 25). Seven organizations saw a majority of clients (51 - 100%) who are HIV+.

Percentage of Clients who are HIV+

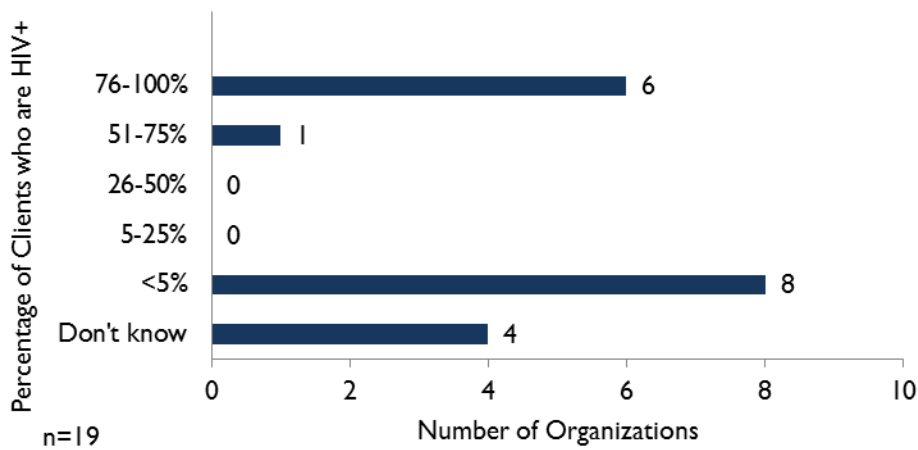


Figure 25: Percentage of Clients who are HIV+

There was a wide range of number of clients with HIV/AIDS served by responding agencies. The number of clients ranged from 0 -1,600 with five responding that they did not know (Table 1).

Number of Clients with HIV/AIDS Currently Served

	Zero Clients	Under 10 Clients	11-100 Clients	101-500 Clients	1000-2000 Clients	Unknown
Number of Organizations	3	3	1	4	2	5

Table 1: Number of Clients with HIV/AIDS Currently Served

Note: There were inconsistencies in how respondents answered the “don’t know” and “unknown” response options in the two questions detailed by Figure 25 and Table 1 respectively.

Most responding agencies that target PLWH have been providing HIV/AIDS care-related services for more than ten years (10), only one agency indicated they have been providing services for 1-4 years, and all other agencies indicated that they do not target services specifically to PLWH, but do serve them (8). The majority of respondents (17) asked their HIV positive clients whether they are receiving HIV-related primary care; only two agencies indicated that they do not ask.

A summary of providers or agencies by type including a review of the general services offered and populations served is provided in Table 2.

Type of Provider or Agency	Services and Populations Targeted
Primary Care Provider (PCP) including: Hospital-based, Group Practice, Health Center/Clinic	Summary: These primary care organizations provide a wide range of services including: primary medical care, dental care, behavioral health services, community-based care, safety-net and sliding scale services, coordination of patient care, human services, obstetrics, and basic needs to individuals, families and underserved populations across the state of Rhode Island.
AIDS Service Organizations (ASO)	Summary: These organizations include agencies that offer clinical care and treatment, wrap around services, primary care, prevention, advocacy, case management, education, testing, basic needs, housing, etc. specifically for people (including children and youth) living with HIV (PLWH) and people at risk for HIV infection. Specific services for individuals leaving the RI Department of Corrections and six month post release are also available.
Mental Health (MH)	Summary: These organizations provide mental health and behavioral health services, case management, counseling, out-patient, residential, education, housing, advocacy, benefits assistance, etc. for adults, children, families and homeless individuals.
Substance Abuse (SA)	Summary: These organizations provide services to specific populations including: men, women, pregnant women and new mothers, youth, incarcerated youth and adults, families, students, affected family members. They offer the following services: substance abuse treatment, recovery housing, 24 hour helpline, individual and group counseling, outpatient care, residential care, opioid detoxification, medication assisted treatment, tobacco cessation, school-based counseling, education, anger management, trauma groups, music therapy, AA and NA meetings, drug testing, referral, and population specific services.
Domestic Violence (DV)	Summary: These organizations provide services to individuals, families, and women affected by domestic violence, interpersonal violence, and sexual assault. These services include: community education, advocacy, prevention, shelter, safety, and support.
Other	Summary: These organizations work with specific populations or issues including: homeless, LGBTQ youth, suicide, social service partnerships, female commercial sex workers and public health threats.

Table 2: Service Provider or Agency by Type, Services, and Population(s)

Survey respondents reported funding for services provided to PLWH came from the following sources: Ryan White or other HIV/AIDS specific funding (8), Non-AIDS specific funding sources that support specific services (7), General support/unrestricted fund (10), and Other (5). Additional funding sources (“other”) for agencies included: billing third-party, medical insurance, Medicaid, Medicare, Housing and Urban Development (HUD), R.I. Housing Neighborhood Opportunity Program (NOP), Housing Opportunities for People with AIDS (HOPWA), and not applicable (Figure 26).

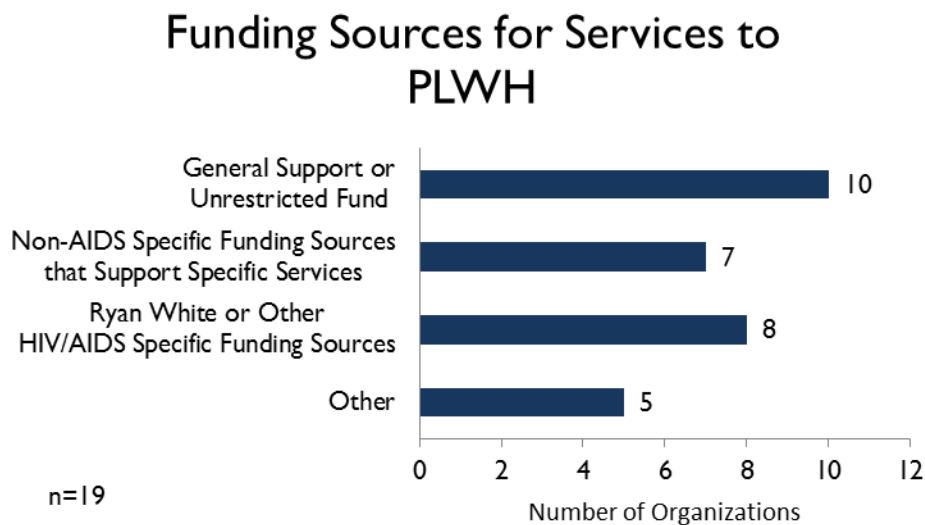


Figure 26: Funding Sources for Services to PLWH

Respondents in describing their agency’ fees indicated that they offer free services to low-income people, services at a sliding scale base on income, and other payment mechanisms that included billing Medicaid for eligible clients or providing insurance based services. No respondents indicated that their agency charged a fixed fee.

Figure 27 shows a more detailed breakdown of the type of funding for services provided to PLWH in Rhode Island, while Figure 28 focuses specifically on organizations that receive Ryan White funding by part (i.e. Parts B, C, D, and F).

Funding for Services to PLWH

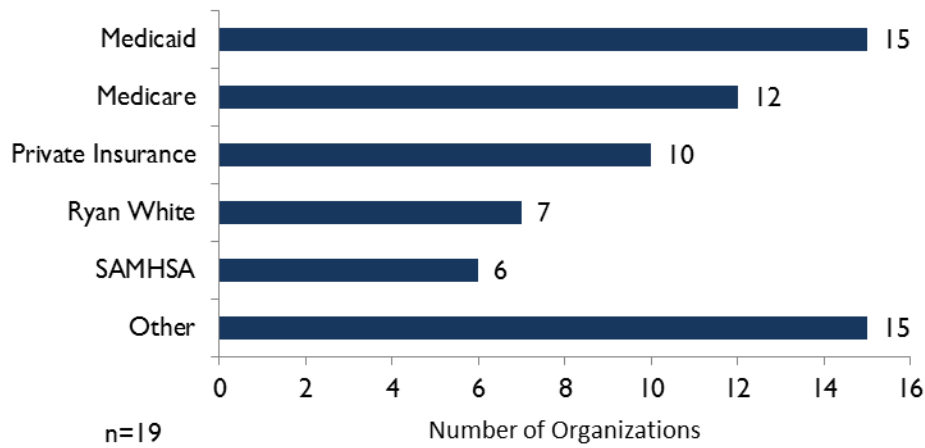


Figure 27: Funding for Services to PLWH

Ryan White Funding Source: Detailed Breakdown

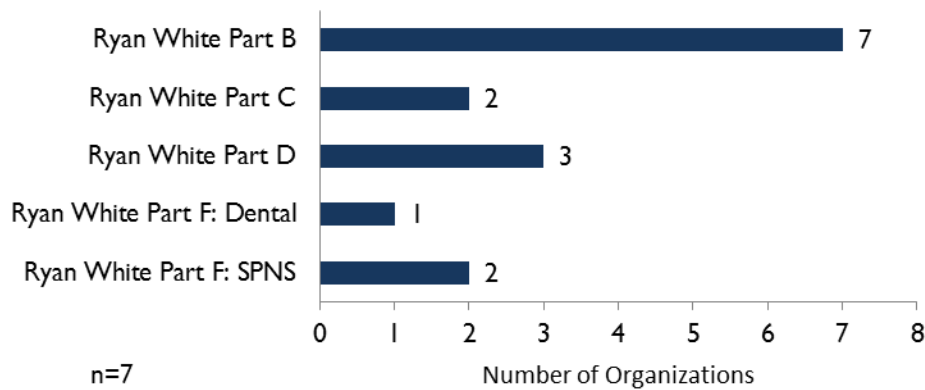


Figure 28: Ryan White Funding Source: Detailed Breakdown

The majority of respondents that report receiving Ryan White funding obtain Part B support, which funds core medical services and support services. Core medical services include outpatient and ambulatory health services, ADAP, AIDS pharmaceutical assistance, oral health care, early intervention services, health insurance premium and cost-sharing assistance, home health care, medical nutrition therapy, hospice care, home and community-based health services, mental health, outpatient substance

abuse care, medical case management, and treatment adherence services (see discussion of support services below).

Grantees are required to spend at least 75 percent of the award on core medical services and no more than 25 percent on support services.

Respondents were asked to report the types of core medical services that their respective agency directly provides to PLWH. Figure 29 represents the top 5 core medical services that are provided by agencies responding to the survey. The figure is also reflective of top 5 services provided to the most PLWH by their agencies (asked in a separate question on the survey).

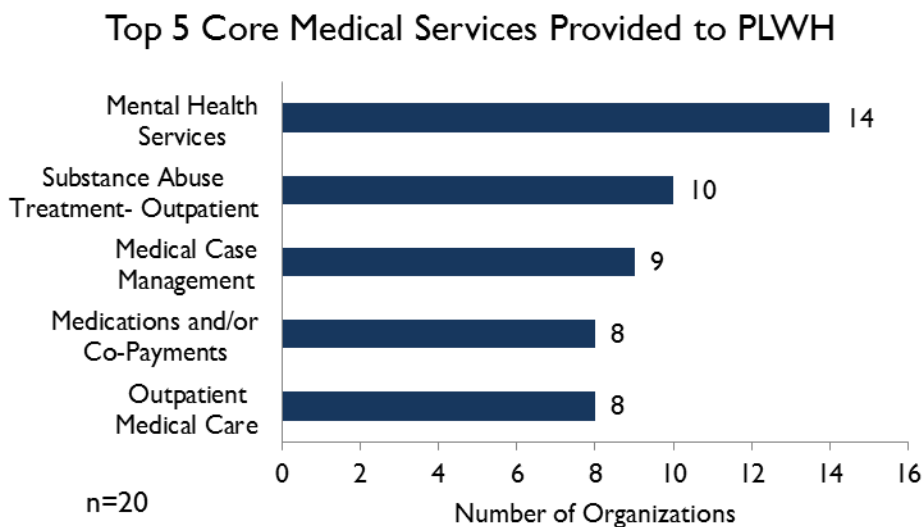


Figure 29: Top 5 Core Medical Services Provided to PLWH

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 30 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).

Top 10 Support Services Provided to PLWH

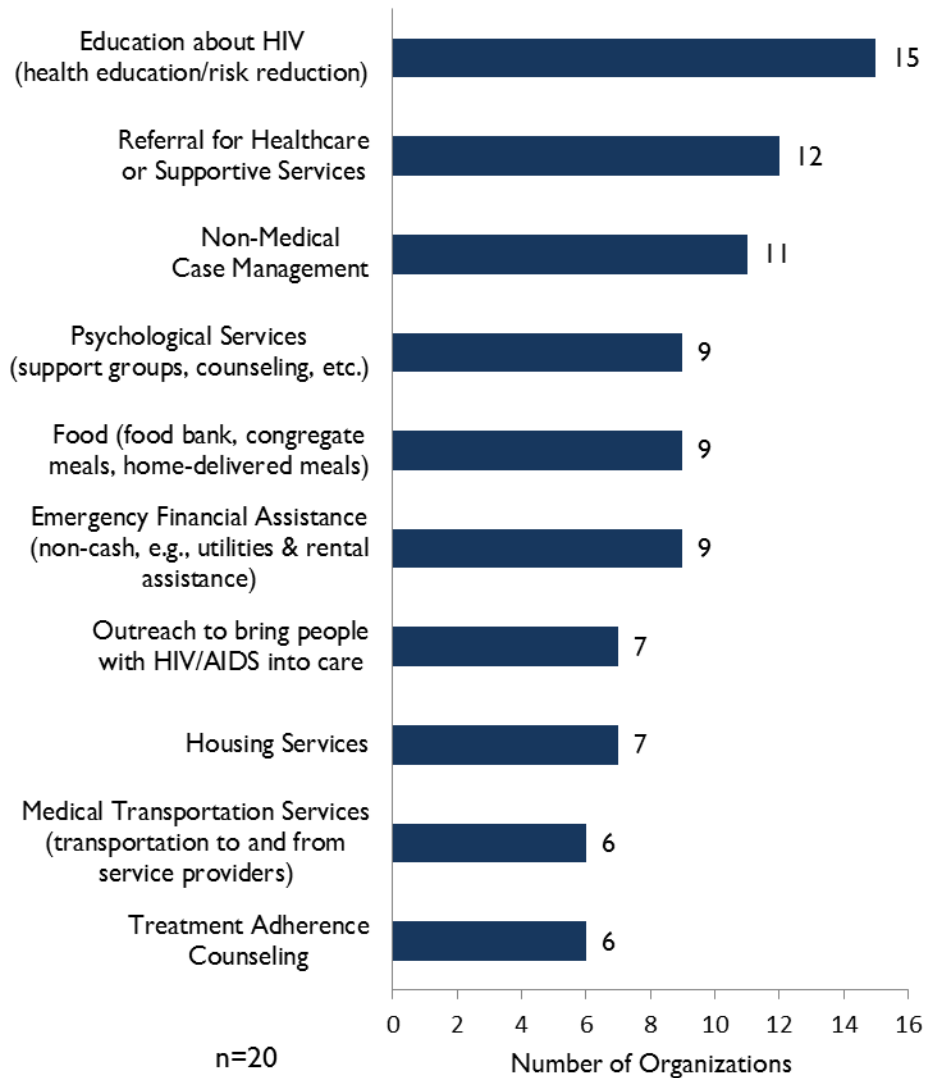


Figure 30: Top 10 Support Services Provided to PLWH

Survey respondents were also asked to identify prevention, counseling and testing services provided by their agencies. 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 (see Figure 31).

Prevention, Counseling, and Testing Services

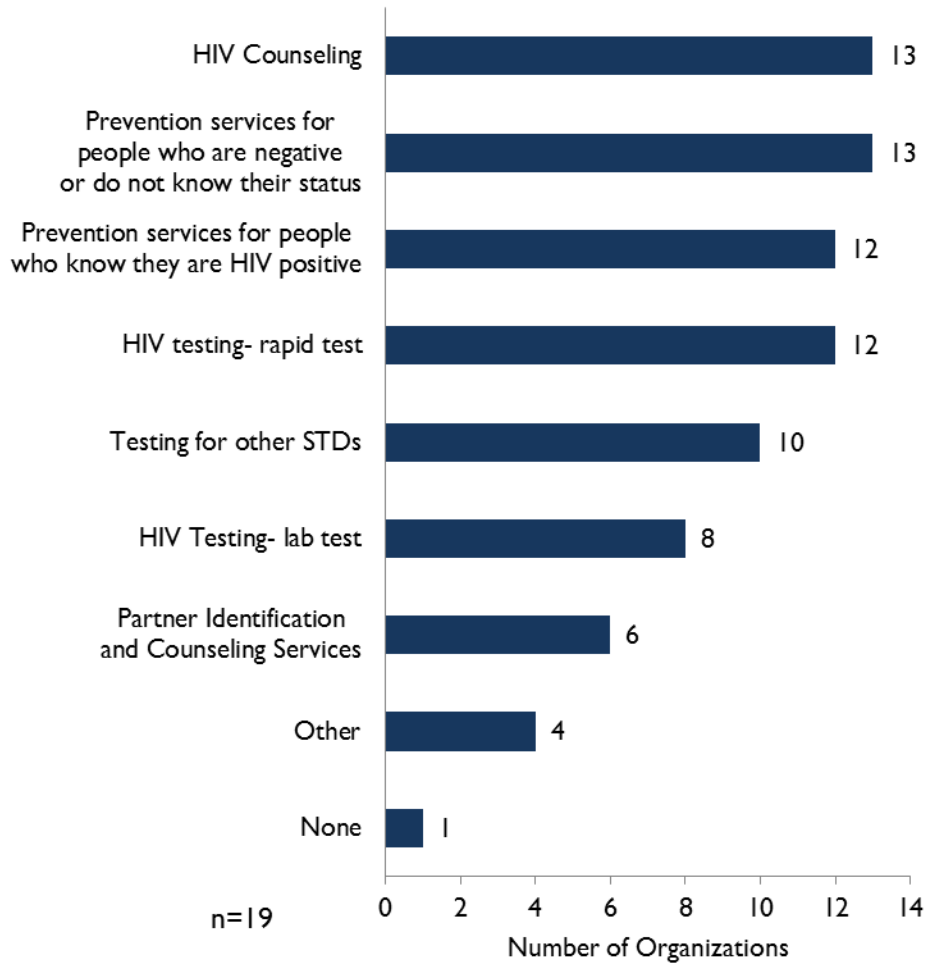


Figure 31: Prevention, Counseling, and Testing Services

Prevention programs that educate high-risk 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.

Accessing Services and Potential Barriers to Care:

Respondents were asked to describe how people access services at their agency. Most agencies reported that clients are seen by appointment (15), but the majority (13) also provide walk-in services or same day appointments and several (7) make home visits (Figure 32). Five respondents noted other ways clients can access services that included: on-call services for medical emergencies; outreach conducted at homeless shelters, the street and/or institutional care settings; and, staff that are available at other agencies to see clients on certain days/hours.

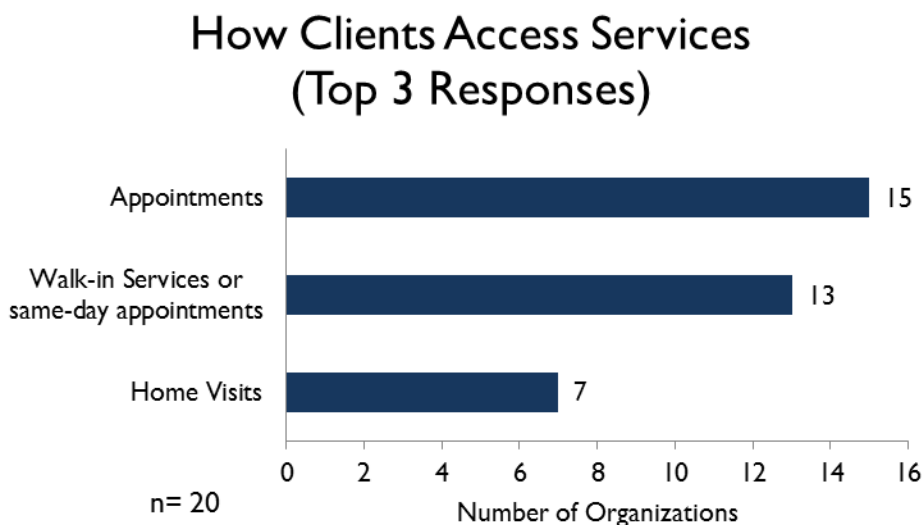


Figure 32: How Clients Access Services (Top 3 Responses)

The majority of respondents indicated that their agency had no wait list or wait time (13). Most agencies that had a waiting time or list (7) indicated that they had between a 1-2 week waiting period (5), although wait time also may be dependent on the service being accessed. One agency responded that their wait time was less than 24 hours for acute need, and one that the waiting list was specifically for housing.

Providers were asked about some common barriers that people with HIV/AIDS face when accessing services. Based on experiences over the past year, respondents were asked to indicate the extent to which they agreed or disagreed about potential barriers for their clients.

Providers identified the largest barriers to accessing and engaging in care as: 1. client homeless or unstable housing, 2. client difficulty navigating the system of care, 3. client difficulty keeping appointments, 4. client substance abuse/addiction and/or mental health issues, and 5. client reluctance to seek services due to stigma or fear of disclosing their status (Figure 33).

Perceived Barriers to Care

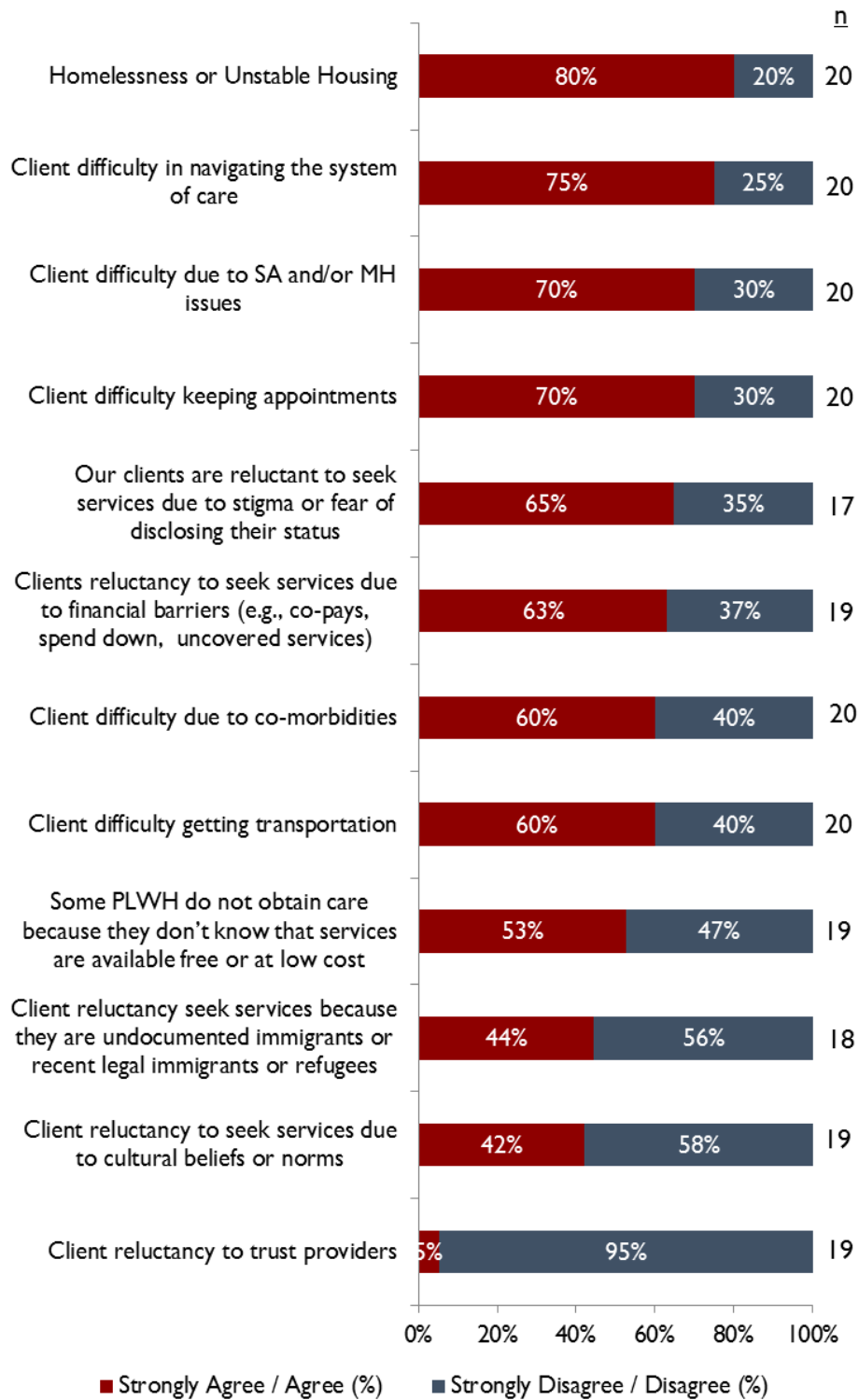


Figure 33: Perceived Barriers to Care

Accessing services for PLWH 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 (Figure 34). 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 35). 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.

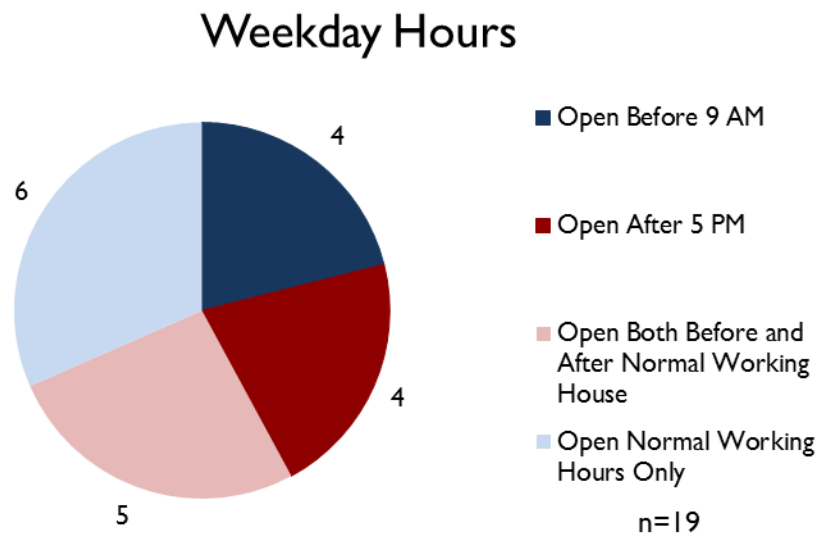


Figure 34: Weekday Hours

Weekend Hours

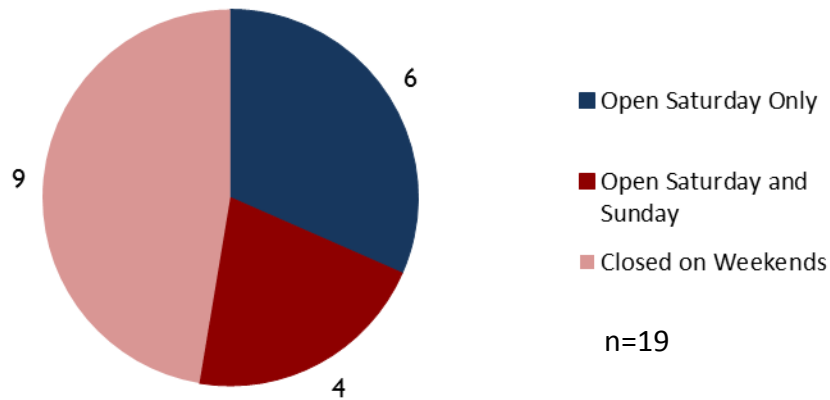


Figure 35: Weekend Hours

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 36). 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.

Agency Accessibility

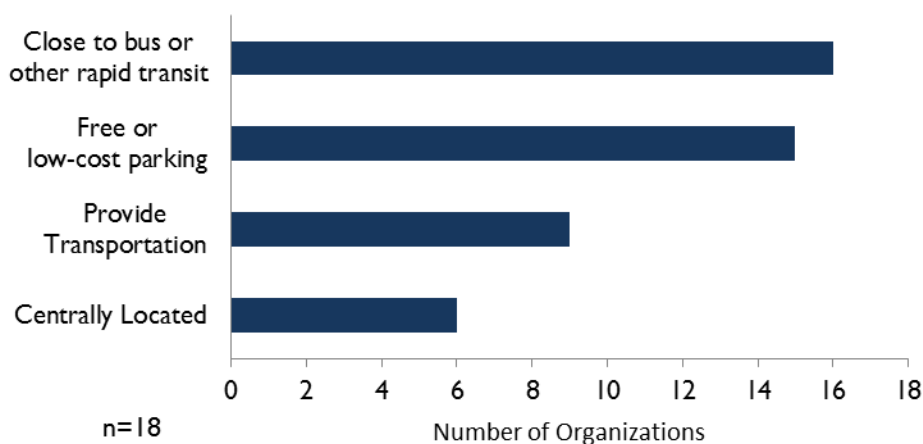


Figure 36: Agency Accessibility

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 whites².

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 absolute prevalence see Figures 37 & 38; relative prevalence see Figures 39 & 40). 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.

² 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

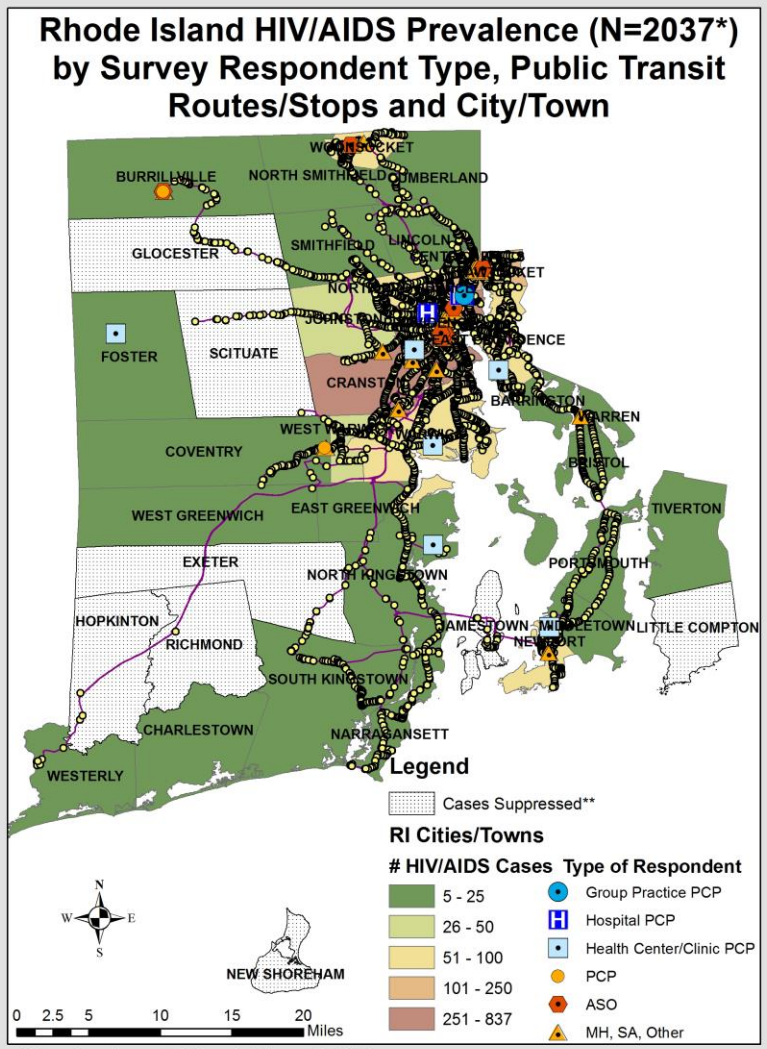
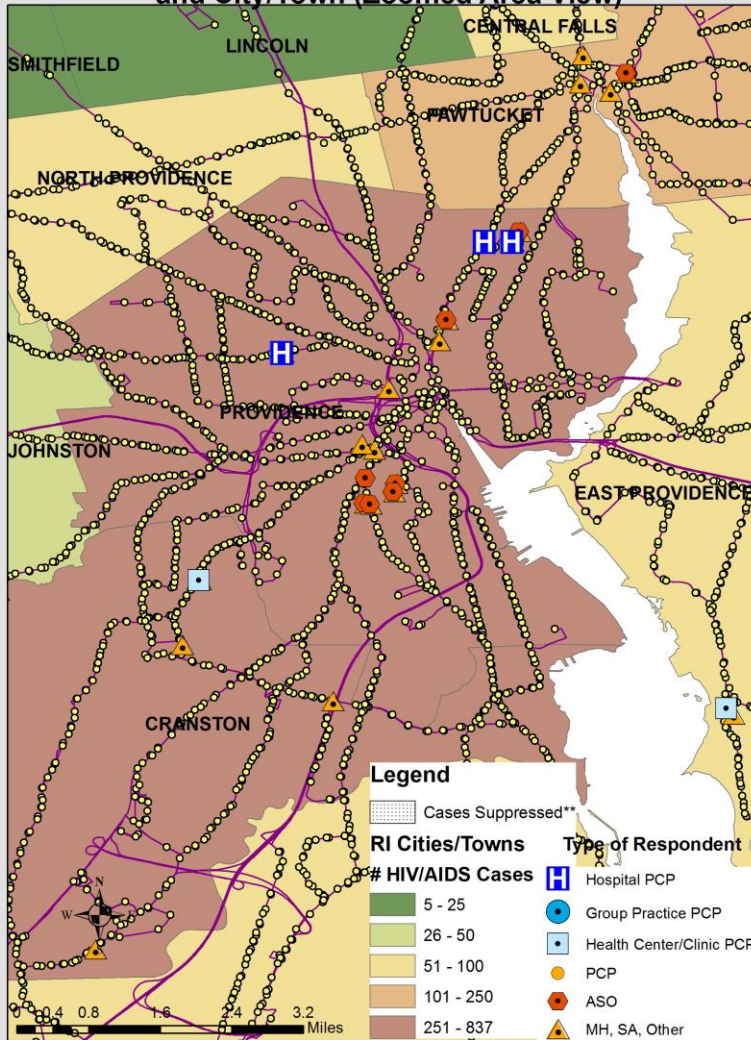


Figure 37: Rhode Island HIV/AIDS Prevalence by Survey Respondent Type, Public Transit Routes/Stops and City/Town

**Rhode Island HIV/AIDS Prevalence (N=2037*)
by Survey Respondent Type, Public Transit Routes/Stops
and City/Town (Zoomed Area View)**



* Prevalence is reported through February 3, 2014.
** Data are suppressed for cities/towns with <5 cases.

Figure 38: Rhode Island HIV/AIDS Prevalence by Survey Respondent Type, Public Transit Routes/Stops and City/Town (Zoomed Area View)

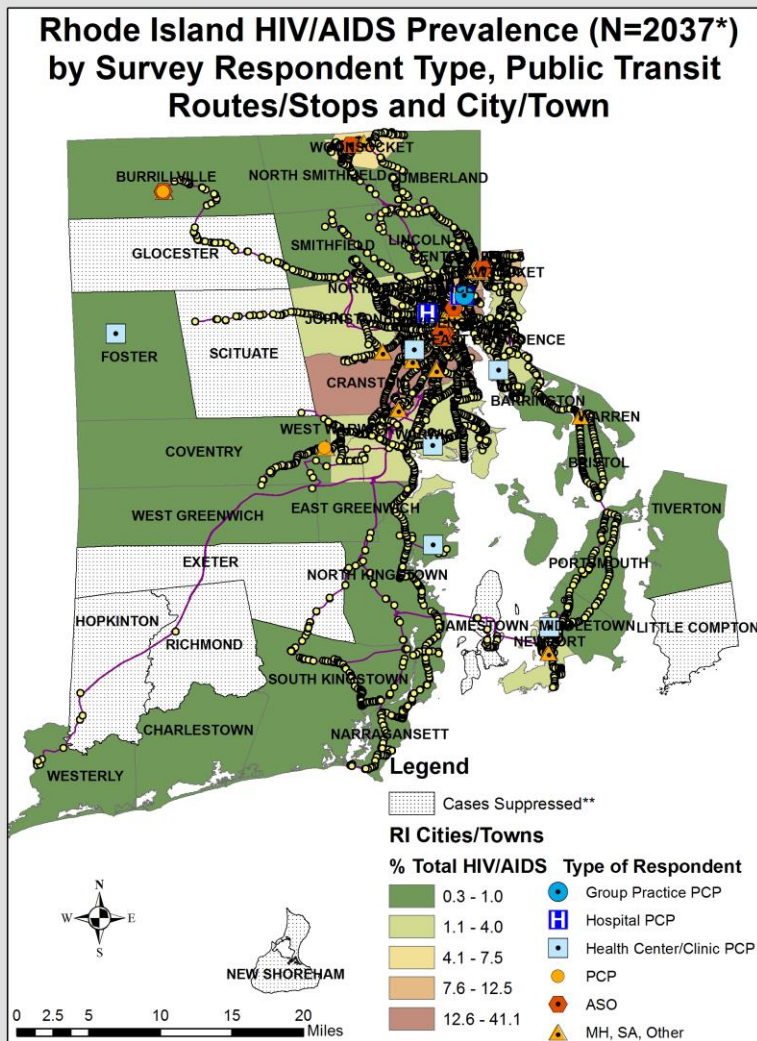
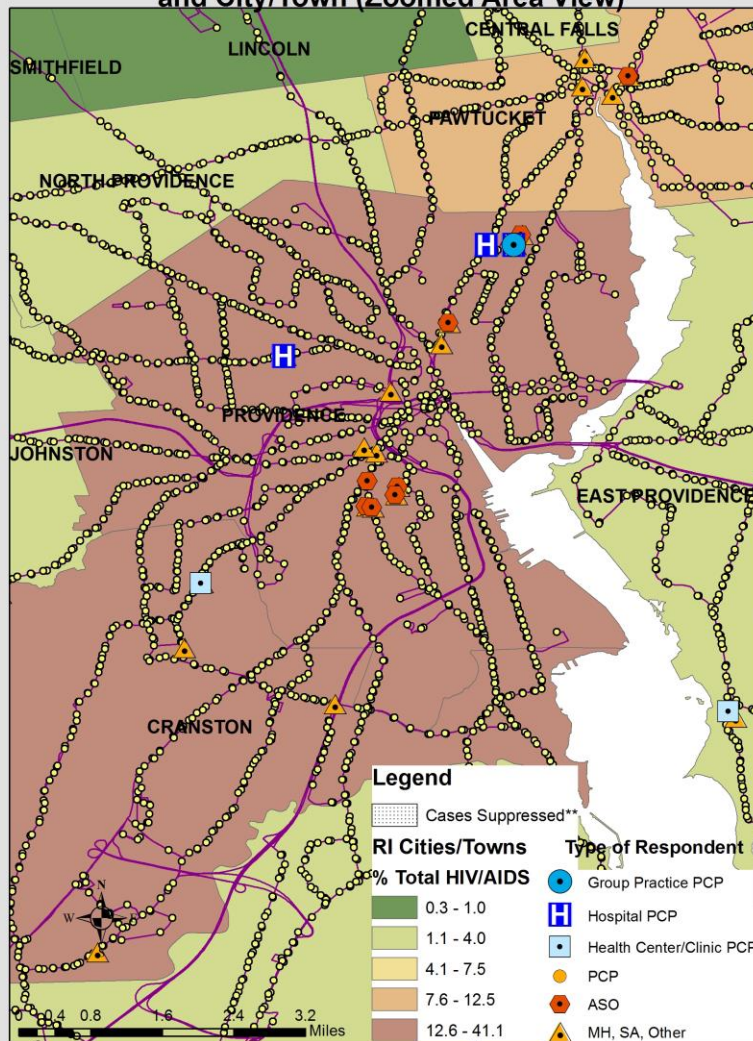


Figure 39: Rhode Island HIV/AIDS Prevalence by Survey Respondent Type, Public Transit Routes/Stops and City/Town

**Rhode Island HIV/AIDS Prevalence (N=2037*)
by Survey Respondent Type, Public Transit Routes/Stops
and City/Town (Zoomed Area View)**



* Prevalence is reported through February 3, 2014.
** Data are suppressed for cities/towns with <5 cases.

Figure 40: 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 41). 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 health care disparities.

Accommodations for Culturally Diverse Populations

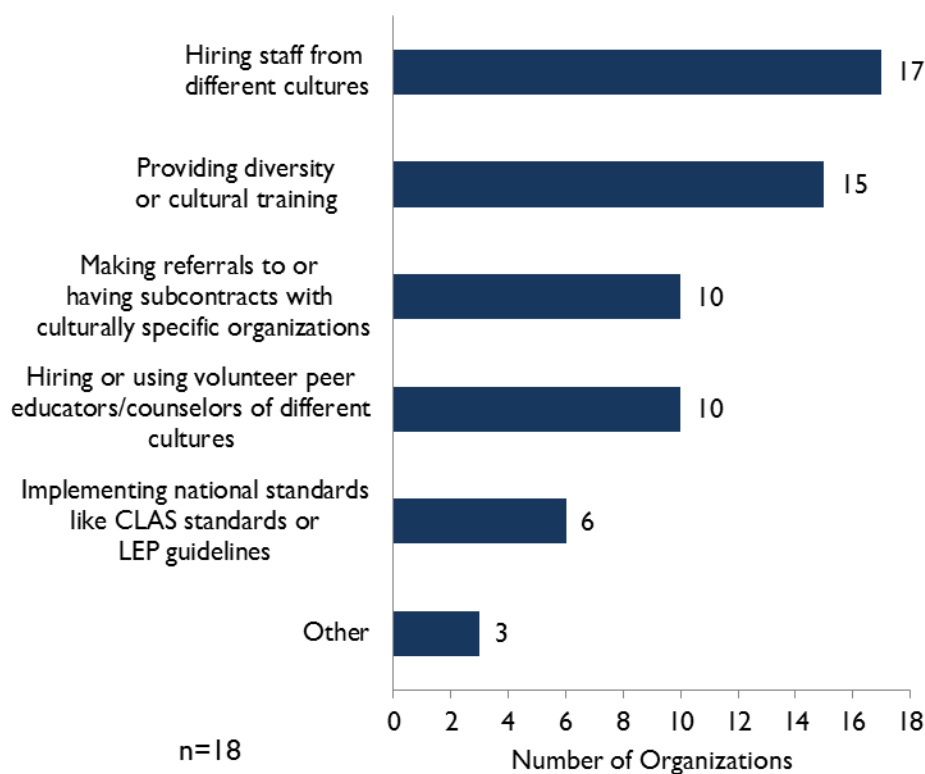


Figure 41: Accommodations for Culturally Diverse Populations

Respondents were also asked how they serve clients who do not speak English (Figure 42). 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).

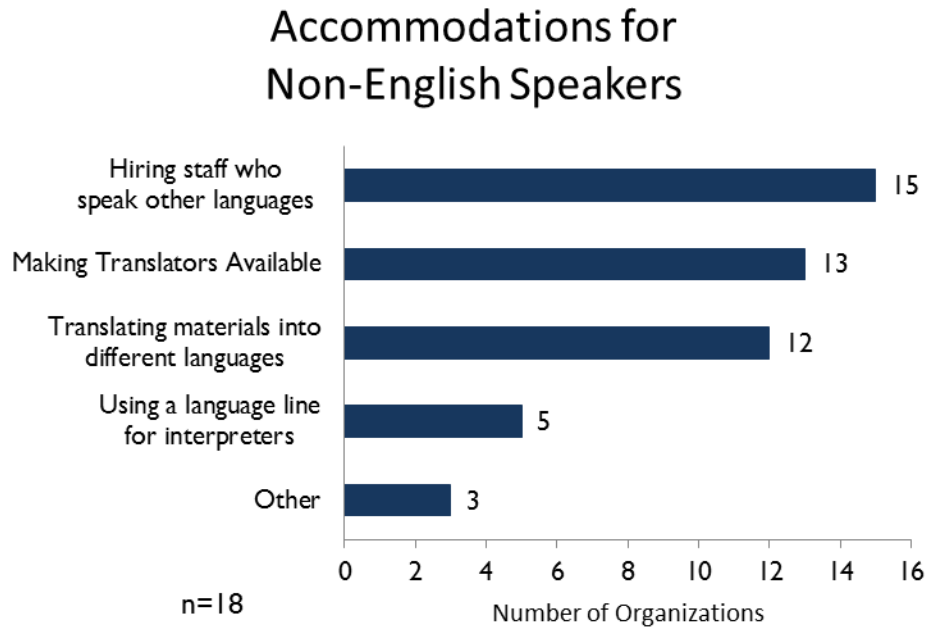


Figure 42: Accommodations for Non-English Speakers

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.

Lastly, all survey respondents were asked to identify their agency's needs in regards to building their capacity to serve PLWH. Table 3 below summarizes their responses.

Summary of Survey Respondents Reported Needs
<ol style="list-style-type: none">1. Targeted and continued funding to offer education, testing, and linkage to care services;2. Training around prevention, available resources to assist with care coordination, newest treatments and outcomes, and de-escalation training;3. Public education around eligibility and options for HIV medical care, confidentiality laws, availability of crisis hotline/listening line, websites, and other HIV-specific resources;4. Health insurance related needs including assistance understanding patient information on health insurance and transportation options, information on Affordable Care Act (ACA) and Managed Care Organization (MCO) health plans implementation, and the Medicaid eligibility of and sign up option for incarcerated individuals prior to release;5. Linkage to care assistance and integration of agency services;6. Program needs including more support staff to accommodate number of clients, needle exchange and harm reduction techniques around needle use, assistance discussing HIV status at case management level, and improved referral systems;7. Agency support from the Executive Office of Health & Human Services (EOHHS) including clear communication, efficient meetings and coordination with Prevention Program at the Department of HEALTH, and working with the leadership of agencies to support physician work with underinsured populations.

Table 3: Summary of Survey Respondents Reported Needs

ACHIEVING VIRAL LOAD SUPPRESSION (VLS): RHODE ISLAND CITIES AND TOWNS

The primary goal of HIV care and treatment is to suppress the reproduction (replication) of HIV in order to bring the HIV viral load measurement as low as possible – the ultimate goal being viral load suppression (VLS). The term "viral load" refers to the number of copies of HIV per mL of blood (i.e. the amount of virus in the blood). People with higher viral loads have a greater risk for immune system damage that in turn leaves the body at risk for opportunistic infections. Moreover, treatment can reduce HIV transmission because suppressed levels of circulating virus in the body makes HIV-infected persons less infectious³. Thus, viral load testing serves as a surrogate marker for an individual's response to antiretroviral therapy and can be useful in predicting the clinical progression and the potential for transmission of the disease.

According to the National HIV/AIDS Strategy (NHAS) Federal Implementation Plan (2010)⁴, a key factor in reducing HIV-related health disparities is to increase the proportion of high risk HIV communities that achieve VLS. In August 2011, the Centers for Disease Control and Prevention (CDC)⁵ released *Guidance on Community Viral Load: Measures, Definitions, and Methods for Calculation* to describe the concept of community viral load and provide definitions of and methods for calculating community viral load and related measures. The Guidance proposes common language for viral load (VL) measurements, which include four measures of viral load for an HIV-infected population. The HIV-infected population can be described by five component measures, depending on what information is available on the level of care, viral load, and diagnosis.

³ 2013. *Guidelines for the use of antiretroviral agents in HIV-infected adults and adolescents*. US Department of Health and Human Services Panel on Antiretroviral Guidelines for Adults and Adolescents. Rockville, MD: US Department of Health and Human Services; 2013. Retrieved from: <http://aidsinfo.nih.gov/contentfiles/lvguidelines/adultandadolescentgl.pdf>

⁴ 2010. *National HIV/AIDS Strategy: Federal Implementation Plan*. The White House Office of National AIDS Policy. Retrieved from: <http://www.whitehouse.gov/files/documents/nhas-implementation.pdf>.

⁵ 2011. *Guidance on Community Viral Load: A Family of Measures, Definitions, and Method for Calculation*. Center for Disease Control and Prevention. Retrieved from: http://www.ct.gov/dph/lib/dph/aids_and_chronic/surveillance/statewide/community_viralload_guidance.pdf.

Estimating Measures of Viral Load

The CDC Guidance on Community Viral Load outlines the following four measures and their corresponding population component measures:

Population Viral Load: This is the most comprehensive measure; however, it is a conceptual measure, which cannot be directly calculated. This would require having viral load measurements for the entire population of PLWH in a jurisdiction (i.e. those who know their HIV status, as well as those who are unaware; those linked to care, as well as those who are not, etc.)

Community Viral Load: At this time, calculation is not feasible for most jurisdictions. For jurisdictions to be able to estimate this measure, they would need to address missing VL data among residents with an HIV diagnosis or obtain data by increasing testing and maximizing linkage to, and retention in, care. Imputing data for diagnosed cases with missing VL data would require supplemental data that are not available in most areas. Valid information on current address is required for residents with an HIV diagnosis to ensure that persons no longer residing in the area are excluded from the analysis.

In-Care Viral Load: At this time, calculation is not feasible for most jurisdictions. For jurisdictions to be able to estimate this measure, they would need to address missing VL data to maximize the proportion of persons in care who have VL data in the HIV surveillance system. Inputting data for diagnosed cases with missing VL data would require supplemental data, such as antiretroviral therapy data, that are not available in most jurisdictions.

Monitored Viral Load: Most jurisdictions can calculate this measure for residents with an HIV diagnosis.

Additionally, standardized categorical measures have been defined and can be used to assess the quality of HIV care or the possible transmission potential for the HIV-infected population that is receiving care:

- Suppressed/not suppressed (where ≤ 200 copies/mL is suppressed and > 200 copies/mL is not suppressed)
- Undetectable VL (≤ 50 copies/mL)
- High VL ($> 100,000$ copies/mL)

As of July 2013, Rhode Island requires reporting of all CD4 and viral load results (including undetectable results) for surveillance purposes⁶. The availability of data, as well as the sample size needed for adequate power and significance testing precludes the calculation of community viral load measures by cities and towns in Rhode Island. Therefore, standardized categorical measures are used to assess the

⁶ CDC. HIV and the Law [website]. Updated Sep 2013. Retrieved from: <http://www.cdc.gov/hiv/policies/law/>

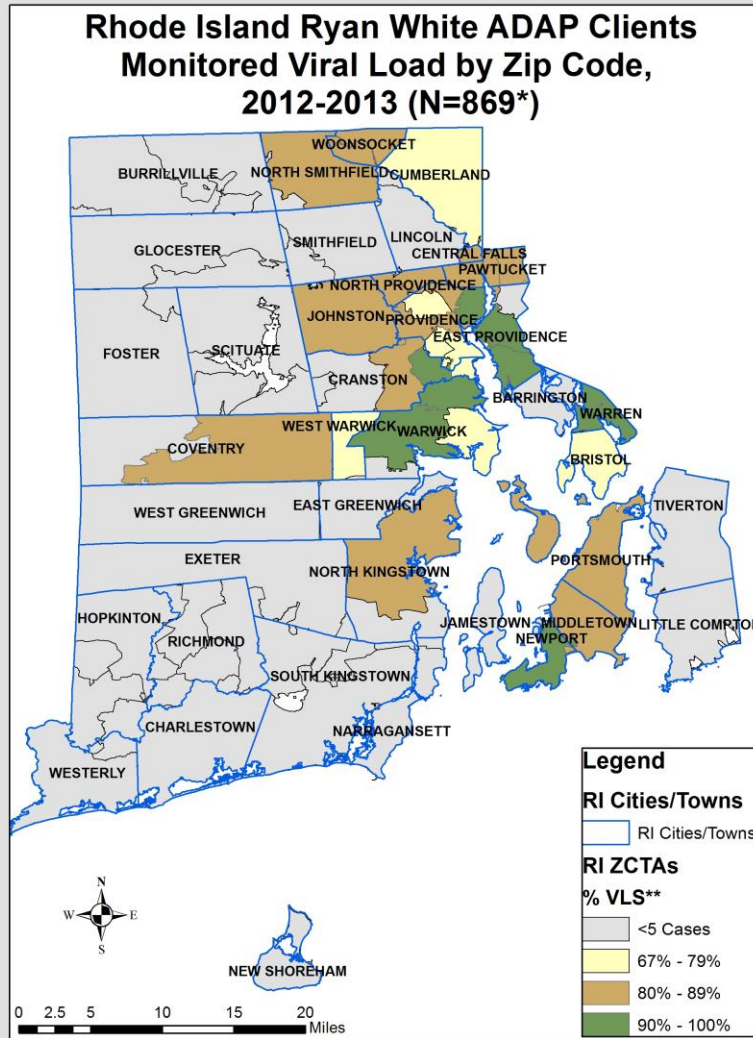
quality of HIV care and/or the possible transmission potential for the HIV-infected population that is receiving care.

For the purpose of this report, data were obtained for PLWH enrolled in the State's AIDS Drug Assistance Program (ADAP). The analysis and mapping of data includes unduplicated ADAP consumers with a reported viral load test reported in either 2012 or 2013. See Table 4 for a breakdown of the demographic and economic characteristics of 2013 Rhode Island ADAP consumers.

Table 4: Demographic and Economic Characteristics of Rhode Island ADAP Consumers, 2013

Demographic Characteristics		
Gender	(N=730)	%
Male	554	75.9
Female	172	23.6
Transgender	4	0.5
Age	(N=730)	%
2-12	6	0.8
13-24	18	2.5
25-44	231	31.6
45-64	424	58.1
65 years+	51	7.0
Race / Ethnicity	(N=730)	%
White (Non-Hispanic)	349	47.8
Black or African American (Non-Hispanic)	149	20.4
Asian (Non-Hispanic)	11	1.5
American Indian or Alaska Native (Non-Hispanic)	10	1.4
Native Hawaiian/Pacific Islander (Non-Hispanic)	3	0.4
More Than One Race (Non-Hispanic)	12	1.6
Other (Non-Hispanic)	6	0.8
White (Hispanic)	84	11.5
Black or African American (Hispanic)	48	6.6
Hispanic or Latino	53	7.3
Missing	5	0.7
Economic Characteristics		
Federal Poverty Level (FPL)	(N=945)	%
Below 200% of FPL	813	86.0
Greater than 200% of FPL	125	13.3
Missing	7	0.7

Mapped data in this section will be presented as a percentage of RI RW consumers who achieve VLS (i.e. ≤ 200 copies/mL is suppressed) by zip codes nested within cities and towns (See Figure 43). ADAP consumers residing within zip codes located in Providence, Cranston, Warwick, West Warwick, and Bristol appear to have lower percentages of VLS, compared to other parts of the State.



* Represents deduplicated clients with a most recent viral load test done in either 2012 or 2013.
 ** Viral suppression is defined as a viral load < 200 copies/mL.

Figure 43: Rhode Island Ryan White ADAP Clients Monitored Viral Load by Zip Code 2012-2013

Figure 43 shows the geocoded survey respondent locations by type (included in the body of this report) mapped over the percentage of ADAP consumers achieving VLS by zip code within cities and towns, with Figure 43 providing a zoomed area view of the great Providence area.

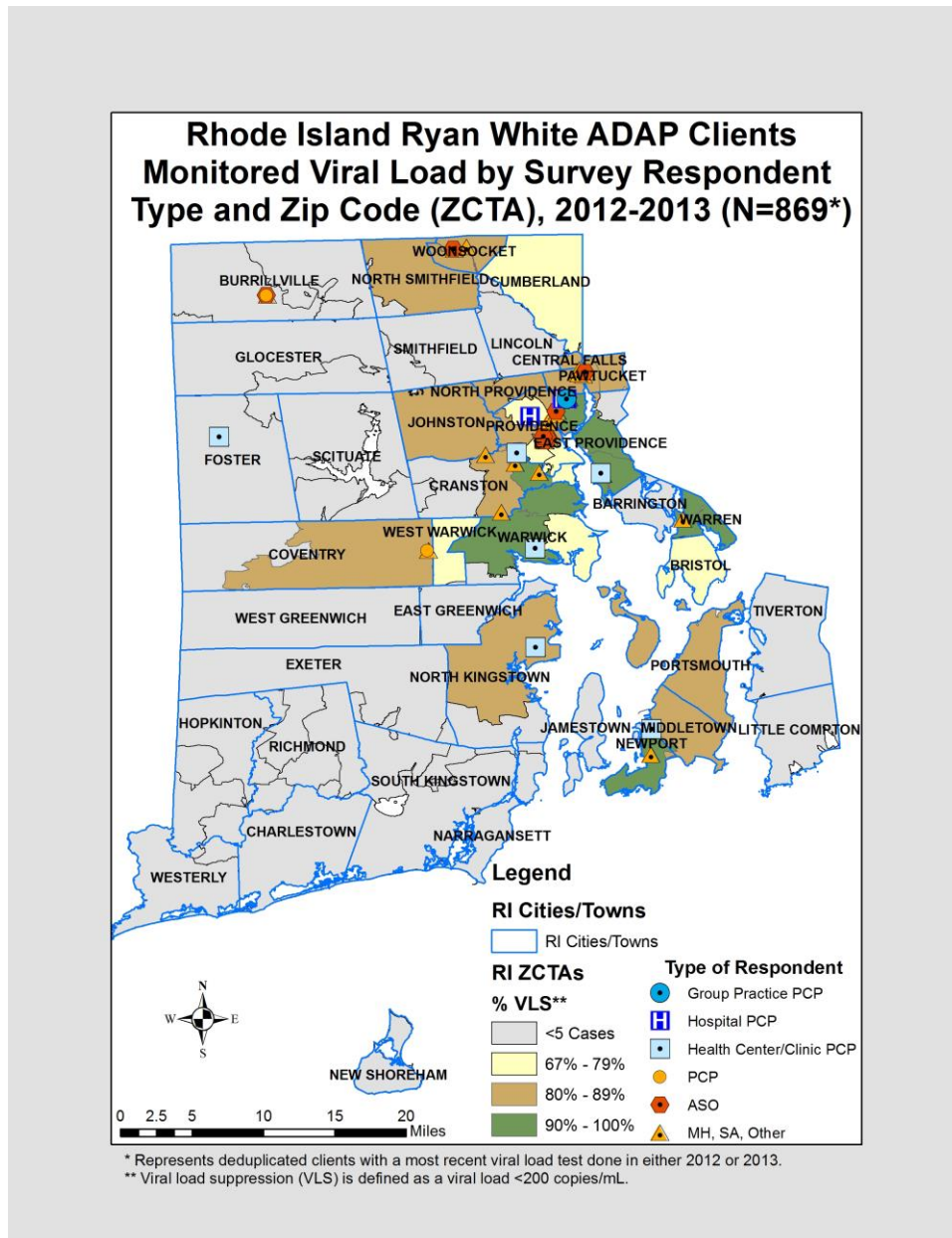


Figure 44: Rhode Island Ryan White ADAP Clients Monitored Viral Load by Survey Respondent Type and Zip Code (ZCTA), 2012-2013

What we can see from these maps, as well as other maps presented throughout this report, is that there appears to be a greater density of service providers who identify as serving PLWHA in

communities with higher rates of HIV/AIDS. Additionally, many of these communities with higher rates of HIV/AIDS include populations at greater risk for the disease, both in terms of the social and cultural determinants of the disease and the percentage of individuals who achieve VLS.

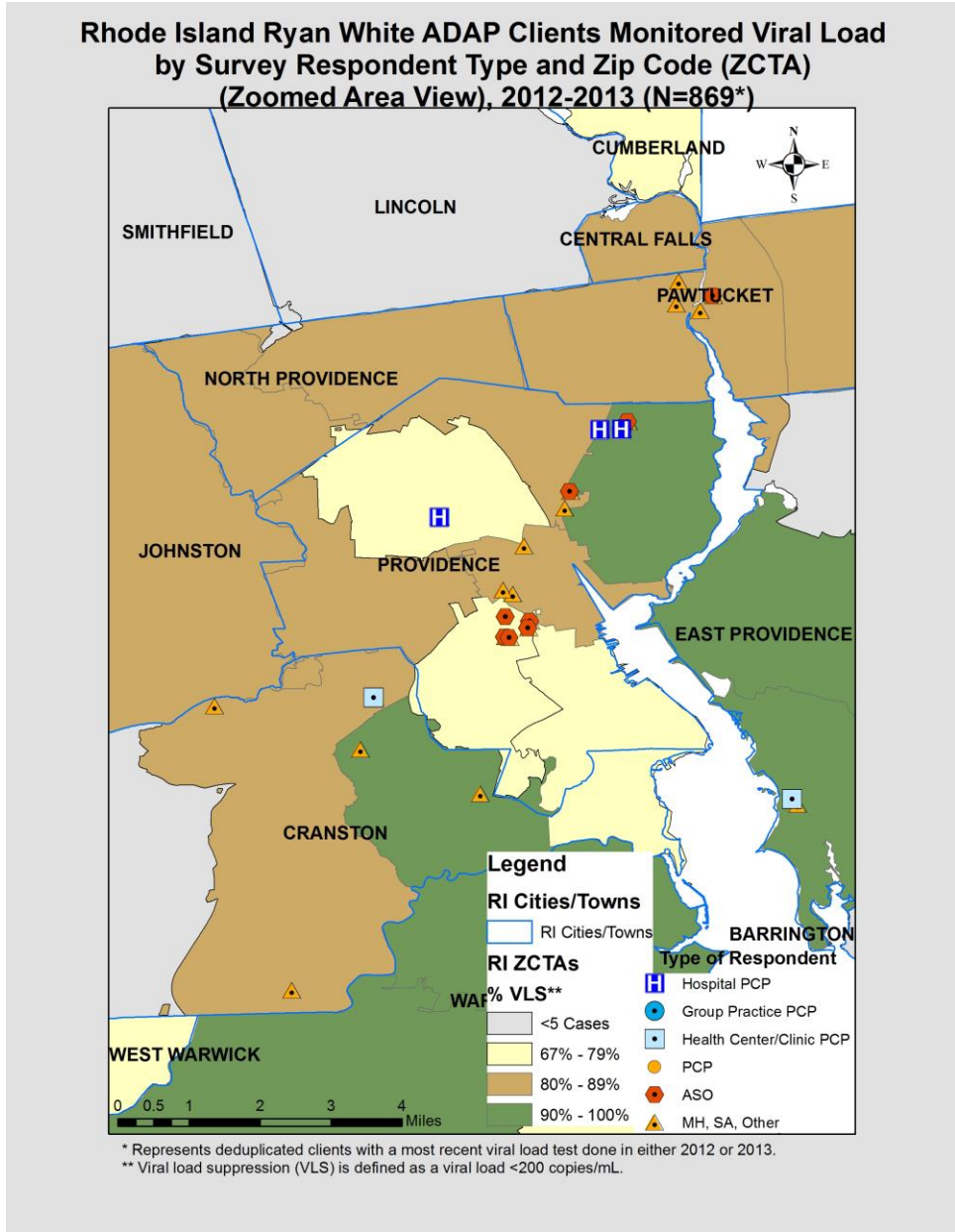


Figure 45: Rhode Island Ryan White ADAP Clients Monitored Viral Load by Survey Respondent Type and Zip Code (ZCTA) (Zoomed Area View), 2012-2013

From Figures 44 and 45 we can see that the greatest density of public transportation stops and routes are also located in areas of the State that have the highest percentage of PLWHA, are most densely populated and populations that are diverse demographically, culturally, and economically. This connectivity may provide greater opportunities for HIV care options for PLWHA, but may also provide increased opportunities for the transmission of the disease in areas with few individuals achieving VLS.

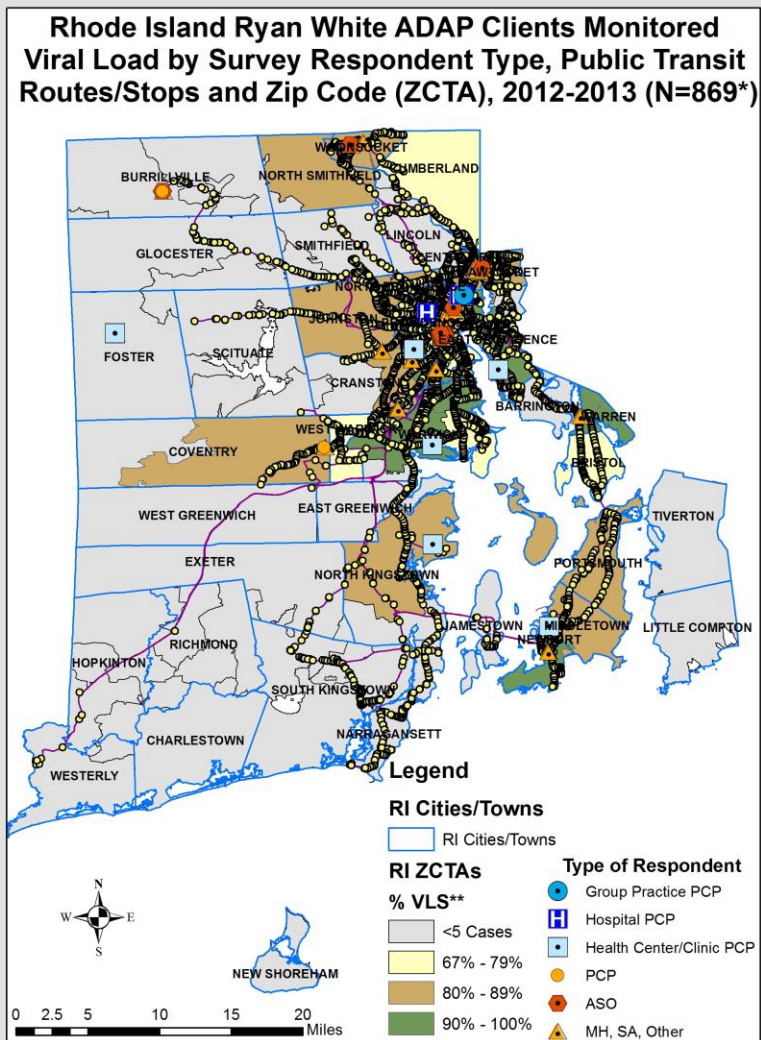
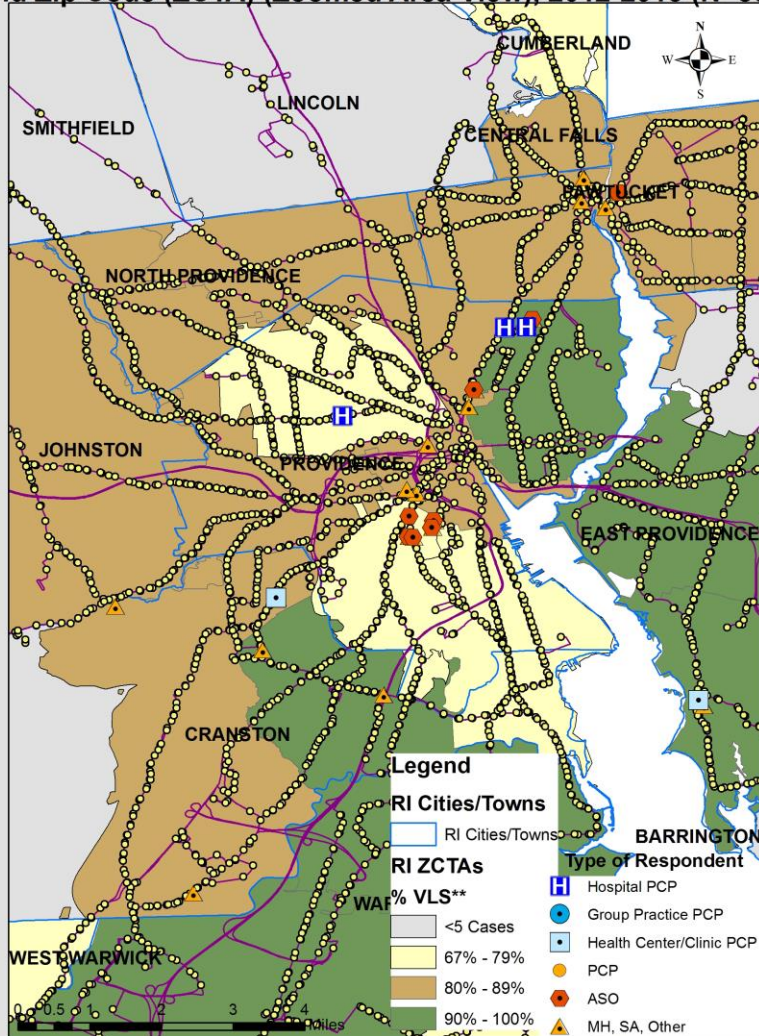


Figure 46: Rhode Island Ryan White ADAP Clients Monitored Viral Load by Survey Respondent Type, Public Transit Routes/Stops and Zip Code (ZCTA), 2012-2013

Measuring and monitoring of community viral load is highlighted in NHAS as a key step in adopting community-level approaches to reduce HIV infection in high risk communities. As presented in this report and documented by other jurisdictions outside of Rhode Island, HIV viral load data among PLWHA are potentially useful as indicators of program effectiveness. By identifying gaps, implementing improvements, and connecting people living with HIV to sustained, quality care we can increase the

proportion of people living with HIV who are prescribed ART and are able to adhere to their treatment so that they can achieve viral load suppression. This will allow them to live healthier, longer lives and reduce the chances that they will transmit HIV to others.

Rhode Island Ryan White ADAP Clients Monitored Viral Load by Survey Respondent Type, Public Transit Routes/Stops and Zip Code (ZCTA) (Zoomed Area View), 2012-2013 (N=869*)



* Represents deduplicated clients with a most recent viral load test done in either 2012 or 2013.
 ** Viral load suppression (VLS) is defined as a viral load <200 copies/mL.

Figure 47: Rhode Island Ryan White ADAP Clients Monitored Viral Load by Survey Respondent Type, Public Transit Routes/Stops and Zip Code (ZCTA) (Zoomed Area View), 2012-2013

CONCLUSION

This profile of Provider Capacity and Capability will be one of several data collection efforts supporting Rhode Island's Comprehensive Plan for HIV Service in 2016. It represents the providers' reporting their capacity to render certain medical and support services to PLWH, their perception of clients' barriers to adequate care, and their reported needs for addressing service gaps. Other data collection efforts that will inform the Comprehensive Plan include an epidemiological profile, consumer needs assessment and focus groups, and key informant interviews. Together these efforts will describe the current landscape of HIV/AIDS in Rhode Island, assess consumer needs, evaluate services rendered, and identify gaps in service and barriers to care.

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. Therefore, this dataset can be considered highly representative. However, its limitations include the fact that respondents did not self-identify as a provider specifically for PLWH and that all data contained in the survey was self-reported.

This report has identified five significant trends and findings from the survey results. They are as follows and are discussed in greater detail throughout this section. **(1)** Provider resources are appropriately distributed geographically but there are still unanswered questions concerning whether current transportation options are adequate. **(2)** Agencies are appropriately responding to diverse consumer needs, clearly demonstrating the complementarity between medical and support services. **(3)** However, homelessness, unstable housing, and related social problems continue to be a significant barrier to care. **(4)** Thus, the intractable challenges associated with caring for underinsured PLWH populations require continued work to improve consumer-centered care coordination and integration of services. **(5)** Looking forward, continued monitoring and quality improvement through the current period of unprecedented uncertainty is imperative to maintaining and progressing HIV/AIDS care on a state, local, and individual level.

(1) Provider resources are appropriately distributed geographically but there are still unanswered questions concerning whether current transportation offerings are adequate.

In Rhode Island, the highest HIV/AIDS prevalence is in Providence and Cranston—areas of high racial diversity and poverty. Likewise, most of the organizations surveyed are concentrated in those cities and towns. Pawtucket, Woonsocket, North Providence, East Providence, Warwick, and Newport also have a higher concentration and variety of providers providing services to PLWH, in line with their higher HIV/AIDS prevalence in comparison to other townships in the state.

The percentage of Ryan White ADAP clients that achieve viral load suppression may be related to their distance from the City of Providence's high density and diversity of agencies providing services to PLWH. With Newport as a notable exception, cities and towns of high viral suppression are more likely to be located closer to Providence. Conversely, with Providence and Cumberland as the exception, cities and towns with lower % VLS are more likely to be located closer to Providence.

This may indicate that while resources are being appropriately concentrated in the city of Providence, where prevalence is highest, individuals living further from the city may be at a slight geographic disadvantage for receiving the care they need. This report's analysis of public transportation demonstrates that these individuals are physically connected to provider agencies. Providers are mostly located close to public transportation stops and there are a significant and adequate number of public

transportation stops in and around the city. However, many providers (60%) still cite transportation as a barrier to care. And six provider agencies offer additional non-public transportation services, perhaps to address client transportation needs that are unmet within public options. This question warrants follow-up in the consumer needs assessment and key informant interviews in order to determine what specific characteristics of the transportation system create the most challenges for consumers.

(2) Agencies are appropriately responding to a diverse set of consumer needs, clearly demonstrating the complementarity between medical and support services.

The variety of medical and support services offered by provider agencies in Rhode Island demonstrates a clear need by PLWH for multiple types of related services (Figures 30 and 31). These agencies deliver a comprehensive set of medical and supportive services to their clients ranging from outpatient medical care to housing services. Mental health services and substance abuse services, in particular, are reported as widely provided and deeply needed. 70% of the agencies surveyed provide some type of mental health services and 70% of providers agree that substance abuse and mental health services represent a significant barrier to care for their clients (Figure 33).

Other types of support services offered to clients address concerns that arise from financial or social circumstance. These wrap-around services include the provisioning of food, emergency financial assistance, and housing services—all of which have been shown to impact adherence and treatment outcomes in PLWH⁷. They are crucial in establishing and improving the care continuum for PLWH, especially for those who are underinsured and/or living below the federal poverty line. Improving viral suppression at the individual and population level will hinge on the successful application of these wrap-around support services because they impact every step in the care continuum, including diagnosed, linked, retained, and treated, that then ultimately lead to viral suppression.

(3) However, homelessness, unstable housing, and related social problems continue to be a significant barrier to care.

Providers report homelessness as a significant barrier to care for the consumers they work with. Often related issues, including difficulty keeping appointments, difficulty due to SA and/or MH issues, difficulty navigating the system of care, and client reluctance because of financial barriers are also highly ranked barriers of care amongst providers surveyed (Figure 33).

This is unsurprising given the demographic reality of HIV/AIDS in Rhode Island, where it is most prevalent in the city of Providence where poverty levels are higher than in the surrounding area. More people are uninsured and below 100% poverty in Providence than any other city/town in the state—both in absolute number and relative to the total population of each city/town. While HIV/AIDS certainly does not fall solely along socioeconomic lines, it is clear that those with the least are struggling the most to manage their disease and its treatment.

This reality is reflected within the provider responses to this survey. They understand that their greatest challenge lies among the indigent and many had tangible recommendations for how they could better address the needs of this population. One of most noted reported needs by providers (Table 3) was improvement in linkage to care, indicating that many believe that their clients, as well as potentially

⁷ 2014. *Limitations to Treatment Safety and Efficacy: Adherence to Antiretroviral Therapy*. AIDSinfo. Retrieved from: <http://aidsinfo.nih.gov/guidelines/html/1/adult-and-adolescent-arv-guidelines/30/adherence-to-art>

undiagnosed individuals, are not adequately connected to the services they need to be supported socially and financially, adherent with the medications, and healthy.

Provider recommendations also included targeted and continued funding to offer education, particularly around eligibility and options for HIV medical care; increased focus on harm reduction policies, including needle exchange; and further offering certain HIV-specific resources, including a crisis hotline and website.

(4) Furthermore, the intractable challenges associated with caring for underinsured PLWH populations require continued work to improve consumer-centered care coordination and integration of services.

Reducing the prevalence of HIV/AIDS in Rhode Island will require continued improvement around care coordination precisely because the most affected populations need a plethora of interconnected medical and support services yet are also so challenging to reach, retain, and treat. 75% of providers surveyed report client difficulty navigating the system of care as a significant barrier for the people they serve. And 60% of providers agreed that difficulty with co-morbidities was a significant barrier to care, underscoring the complex and challenging reality of this demographic. Furthermore, integration of services and care coordination were often discussed when providers were asked to report needs and provide recommendations for EOHHS.

Provider's reported needs (Table 3) also indicated a desire for improved referral programs, additional resources to assist with care coordination, and better integration of agency services. These responses speak to a need to continue to focus on improving teamwork among provider agencies and leadership around key issues. Clearer communication between provider agencies, more efficient meetings, and further coordination with the Prevention Program at the Department of HEALTH would help achieve these goals.

(5) Looking forward, continued monitoring and quality improvement through the current period of unprecedented uncertainty are imperative to maintaining and progressing HIV/AIDS care on a national, state, local, and individual level.

With Medicaid expansion, the Affordable Care Act, and HRSA's new 2016 emphasis on integrating prevention and treatment, it is an exciting but uncertain time for HIV/AIDS agencies, providers, and clients. With so much change, it is critically important that the most disadvantaged consumers do not get lost in transition. This report clearly demonstrates that these hard-to-reach, retain, and treat demographics require a complex array of interconnected services and the special focus that goes with them. As the payment landscape shifts, it is these populations that are most at risk and will require the closest monitoring both individually through case-management and as a demographic through population health profiling.

This report, along with other programmatic efforts initiated by the Division of Medicaid HIV Provision of Care Unit at the Executive Office of Health and Human Services such as the consumer needs assessment, represents a strong foundation to the data collection efforts necessary to monitor the state of HIV/AIDS care in Rhode Island through this shifting payment landscape. However, renewed conversations centered on data monitoring are warranted to determine how best to collect, organize, store, and analyze the plethora of available data metrics and sources. Of particular importance is how to contextualize and report parameters, such as viral suppression, with the more traditionally reported metrics, such as viral load and CD4 count.

One critical monitoring tool that addresses these questions is the HIV Care Continuum⁸. It integrates a number of metrics into a comprehensive and detailed representation of HIV/AIDS patient status in Rhode Island and outlines the number of individuals within each of its five stages of care (HIV diagnosis, linked to care, retained in care, prescribed antiretroviral therapy, and virally suppressed), allowing both policymakers and service providers to identify gaps in the provisioning of care and allocate resources appropriately.

Viral suppression for all individuals with HIV is the ultimate goal. These monitoring efforts will contribute to that goal by informing local, state, and regional quality improvement and planning processes that are already in place and are only made more important by the current shifting payment landscape.

⁸ 2014. *HIV/AIDS Care Continuum*. AIDS.gov. Retrieved from: <http://aids.gov/federal-resources/policies/care-continuum/>