

HIV-Positive Voices in America

A Project to Listen to People Living with HIV/AIDS
Through
Interviews, Surveys and Town Halls
Throughout the United States

By
People Living with HIV/AIDS

The CAEAR Coalition - People Living with HIV/AIDS Caucus
And
The National Association of People with AIDS

April 27, 2009



The Mission Statements of the Collaborating Organization



The Communities Advocating Emergency AIDS Relief (CAEAR) Coalition is a national membership organization which advocates for federal appropriations, legislation, policy and regulations to meet the care, treatment, support service and prevention needs of people living with HIV/AIDS and the organizations that serve them. CAEAR Coalition's proactive national leadership is focused on the Ryan White Program as a central part of the nation's response to HIV/AIDS. CAEAR Coalition's members include Ryan White Program Part A, Part B, and Part C consumers, grantees, and providers.

The Communities Advocating Emergency AIDS Relief (CAEAR) Coalition People Living With HIV / AIDS (PLWHA) Caucus is committed to ensuring that the diverse voice and leadership of PLWHA be a significant aspect of the Coalition's advocacy efforts on all federal appropriations, legislation, policy and regulations to meet the care, treatment, support services and prevention needs of PLWHA and the organizations that serve us.



Mission

NAPWA advocates for the lives and dignity of all people living with and affected by HIV/AIDS.

Vision Statement

NAPWA envisions a world free of AIDS-related stigma, a world with universal access to high-quality medical care, and a world in which people living with HIV/AIDS serve as visionary public health leaders.

NAPWA advances its vision by:

- Promoting human rights, dignity and independence for people affected by HIV/AIDS
- Creating and advocating for responsible public policies and programs
- Raising educational levels and awareness about HIV disease
- Improving access to prevention, care and support services
- Developing strategies to end the pandemic

Dedication

The National Association of People with AIDS was founded by the people who wrote the Denver Principles in 1983. The Denver Principles is a manifesto of self-empowerment. The Denver Principles demanded that the voices of people living with HIV be heard. It asserted the right of people living with HIV to participate in all decision-making processes—at all levels—that would fundamentally affect their lives.

The CAEAR PLWHA Caucus is committed to the Denver Principles which empower PLWHA to be involved in every level of decision making that effects our dignity, choice and quality of life; collaborating with organizations that reflect our commitment to the empowerment and leadership of PLHWA; and developing strategies that strive to meaningfully bring the diverse voices of PLWHA throughout the country to the CAEAR Coalition's leadership role in developing a national response to HIV / AIDS that is centered on the needs of the diverse PLWHA in the United States and all of its territories.

We therefore dedicate this report to those individuals that created The Denver Principles and recommit ourselves to their integrity, passion and dedication:

*Bobbi Campbell
Michael Callen
Bobby Reynolds
Michael Helquist
Phil Lanazaratta
Artie Felson
Richard Berkowitz
Bill Burke
Bob Cecchi
Matthew Sarnier
Tom Nasrallah
Gar Traynor*

And other courageous advocates whose names were not recorded in the minutes of the original meeting

Acknowledgements

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TJ Lee provided invaluable clerical support to the author.

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HIV-Positive Voices in America Executive Summary

A. Project Summary

HIV Positive Voices in America was an initiative developed and organized by people living with HIV/AIDS (PLWHA) from the Communities Advocating Emergency AIDS Relief (CAEAR) Coalition People Living with HIV/AIDS (PLWHA) Caucus and the National Association of People with AIDS (NAPWA). The goal of the project was to hear from our fellow PLWHAs throughout the United States about the needs of our community – the disparate needs based on identity, geography, socioeconomic status, familial situation, and the extent of our disability. To be effective advocates for our over one million brothers and sisters living with HIV/AIDS in the United States, we wanted to learn more about what our community needs are; what sustains our lives and optimizes individual and community opportunities for a better quality of life, all while building on our hope for the future. The information gleaned from this comprehensive study should provide a valuable tool for decision-makers in Washington D.C. as they reexamine Ryan White, engage in a discussion on healthcare reform, and the Obama Administration develops a comprehensive, coordinated, and results-driven National AIDS Strategy.

This initiative was conceived following a strong request from Senator Kennedy's staff shortly after the 2006 Ryan White reauthorization process to hear from "real people"- the grassroots and people living with HIV who are not normally involved in advocacy and policy making. The organizers of this initiative were clear from the outset that this project must be a grassroots-driven process that empowers and listens to people living with HIV/AIDS through a community-organizing model.

HIV Positive Voices in America reports quantitative data collected from surveys completed at various community meetings and an on-line survey that remained available over an approximately six-month timeframe. The survey was made available in both English and Spanish. Qualitative data has been compiled from: 1) open-ended question responses on the surveys and 2) town hall testimonies with people living with HIV/AIDS.

Written and oral responses were collected from eleven local community meetings in Albany N.Y., Atlanta G.A., Baltimore M.D., Bronx N.Y., Brooklyn, N.Y., Chicago I.L., Miami /Fort Lauderdale F.L., Manhattan N.Y., Minneapolis M.N., Palm Springs C.A., Rochester N.Y., one Southeast regional meeting in Tampa F.L., one statewide meeting in Massachusetts, and two national meetings- AIDSWatch 2008 in Washington D.C., and the National Conference on African Americans and AIDS in Philadelphia P.A. All or a majority of participants at each of these meetings were people living with HIV/AIDS, with the exception of the National Conference on African Americans and AIDS.

We collected responses from people living with HIV/AIDS in all regions throughout the United States. Survey respondents articulated a full array of needs - both those being met and remaining unmet. The 1,802 respondents reside in 42 of the fifty United States, Puerto Rico and the District of Columbia and come from ranging socioeconomic backgrounds. This initiative did not attempt to mirror the demographics of the domestic AIDS epidemic, but reached far and wide to collect responses from a diverse group of people on the basis of race, ethnicity, gender, and sexual orientation.

Since many of our respondents were contacted through city-wide or state-wide HIV/AIDS planning groups, the vast majority of people that we heard from were in medical care. More than 97% reported being in care and more than 94% reported seeing a provider within the last 6 months. These percentages remained consistent throughout participants' responses regardless of ethnic, racial or gender distinction. This allowed us to find out what factors facilitate individual retention in care and what prior and current barriers exist to care.

The initial goal of this project was to inform the national HIV/AIDS community and Congress about the needs of PLWHA for conversations to reauthorize Ryan White in 2009. Resulting from immature HIV data and current Congressional activity to reform health care, the majority of the AIDS community has come to consensus to extend Ryan White legislation for three years. With this understanding and after looking carefully at the information provided by the project, this report will discuss broader healthcare, treatment, and supportive services for PLWHA not limited exclusively to Ryan White legislation. This report can also be used to augment the essential voices of PLWHA when informing the development of a national AIDS strategy and national conversations on healthcare reform.

B. Project Demographic

While the participants were ethnically and racially diverse, they were not completely reflective of the national prevalence data provided by the Centers for Disease Control and Prevention (CDC) in its *New Estimates of U.S. HIV Prevalence, 2006 Report* published in the October 3, 2008 issue of *CDC's research journal, Morbidity and Mortality Weekly Report (MMWR)*. Recruitment efforts did not attempt to mirror the demographics of the United States AIDS epidemic, but all project partners intended to collect responses from as diverse a population as possible.

Responses were collected from a self-reported population of 965 Caucasian Americans, 518 African Americans, 216 Latino/a Americans, and smaller numbers of Asian Americans, Pacific Islanders, Native Hawaiians, Alaskan Natives, Native Americans, and Biracial individuals.

Race Ethnicity	CDC Estimate of Prevalence of People living with HIV/AIDS	United States Census on Population by Ethnicity	HIV-Positive Voices in America Demographics by Ethnicity
Whites	32%	66.0%	54.0%
Blacks	46%	12.8%	28.7%
Latinos/Hispanics	18%	15.1%	12.0%
Asians/Pacific-Islanders	1%	4.6%	1.38%
Native Americans/Alaskan Natives	<1%	1.0%	1.33%
Other			6.48%

Respondents included 477 females, 1,292 males and 33 transgendered individuals. Females, males and transgendered people made up 26.6% and 72.1 %, and 1.25% of survey respondents respectively, The CDC estimates 75% of people living with HIV/AIDS are male and 25% are female. The CDC does not include any information on transgendered people in its estimate.

Gender Identification	CDC Estimate of Prevalence of People living with HIV/AIDS	HIV-Positive Voices in America Demographics by Gender
Male	75%	72.1%
Female	25%	26.6%
Transgender	N/A	1.25%

With respect to sexual orientation, 1,005 people self-identified as gay or lesbian or 55.76%, 614 self-identified as heterosexual or 34%, 142 self-identified as bisexual or 8.20% and 1.70% self-identified as other.

The CDC does not estimate HIV/AIDS prevalence by sexual orientation but instead provides estimates of prevalence by transmission category. According to the CDC In 2006, the largest estimated proportion of HIV/AIDS diagnoses among adults and adolescents were for men who have sex with men (MSM), followed by persons infected through high-risk heterosexual contact. As of the report released by the CDC in August 2008, HIV incidence was the highest among men who have sex with men (MSM), who made up 50% of those who were diagnosed with HIV in 2006. Another 3% are MSM who are also intravenous drug users (IDU), 33% are people who engage in high-risk heterosexual activity, 13% are IDU and 1% from an unidentified transmission route.

C. Low Income, Poverty, Cost of Care and HIV/AIDS

A majority of participants in the project who answered the question about income level- 52.7%- earned wages equal to or below 200% of the Federal Poverty Level (FPL) and 26.6% were below the FPL. The Federal Poverty Level (FPL) for 2009 is \$10,830 for an individual. The Federal Poverty Level in 2008 when responses were collected was \$10,400 for an individual.

Respondents who reported living below 200% of the FPL varied widely based on demographics. The most significant outliers were:

- Sixty-six percent (66%) of African American respondents lived at or below 200% of FPL and 42% were below the FPL
- Sixty-three percent (63%) of female respondents lived at or below 200% of the FPL and 37.5% were below the FPL. Furthermore, with respect to African American female respondents - 64.1% were living below 200% of the FPL and 42.7% were living below the FPL. African American women were the most likely group to live below the Federal Poverty Level.
- Hispanics reported a slightly higher percentage (55.4%) of individuals who live below 200% of the FPL than the average of all survey respondents, and a significantly higher than average percentage (31.7%) of individuals who live below FPL
- Those who have been living with HIV for more than 10 years reported slightly lower levels of income than the average respondent, with 55% living at below 200% of the FPL.

Conversations around poverty are essential when addressing HIV/AIDS and that empirical data continues to show a correlation between poverty, race, ethnicity and gender.

Poverty is a clear and present issue for the majority of people living with HIV/AIDS in this report and disproportionately affects African Americans, Women - especially African American women, and Hispanics. Therefore, it is critical to address poverty in efforts to address the HIV/AIDS epidemic in the United States. Conversations around poverty must address the poverty requirements for people living with HIV/AIDS to access healthcare.

In our current system, people in the United States who learn they have HIV but don't have health insurance must make changes to their lives to become eligible for health care. This requirement forces some individuals to liquidate or transfer their assets, in addition to allowing their illness to progress to a disability (Medicaid eligibility requires an individual to meet income and, in most states, a disability requirements to qualify for services). Even more saddening is the threat of losing access to health care and treatment experienced by people living with HIV/AIDS when they attempt to return to work or hold onto employment. Regardless of an AIDS diagnosis or need, people living with HIV/AIDS may lose their healthcare if their income exceeds program income requirements, regardless of whether or not their employer offers health care. Health care access is not only a concern for those with very limited resources, but also those with limited but insufficient access to health care and treatment services.

Poverty and limited income can provide a barrier to accessing care or having access to information about how to get care according to our survey respondents.

According to a number of respondents, the burden of cost for working people without insurance and the working poor can often result in difficult decisions. As one respondent from North Carolina said, *"I either have to quit working and be poor or make more money and have no health insurance. That's like choosing between to (sic) dead ends."*

D. HIV Health Payers – Medicaid, Medicare and Ryan White

In every town hall and survey, access to medical care and treatment were identified as the most critical need for people living with HIV/AIDS. In the federally funded public sector Medicaid, Medicare and Ryan White are the programs that pay for most of the care received by people living with HIV/AIDS. The Department of Veterans Affairs (VA) also provides medical care, however this survey did not focus on the VA. This section will look at the importance of Medicaid, Medicare and Ryan White and how our project participants utilized these programs, highlighting both successes and challenges.

According to the Kaiser Family Foundation's February 2009 fact sheets on HIV/AIDS and Medicaid and HIV/AIDS and Medicare, the federal portion of Medicaid (Medicaid is financed by both the federal and state government) and Medicare account for a combined total of 74% of Federal Funding for HIV/AIDS Care.

According to the Kaiser Family Foundation, Medicaid provides coverage to an estimated 200,000 to 240,000 people living with HIV/AIDS and Medicare provides coverage to approximately 100,000. Most Medicare beneficiaries with HIV are also covered by Medicaid (so-called "dual eligibles")

While reliance on Medicaid and Medicare among our project participants did not seem to have significant variance in utilization patterns from region to region, there were distinct patterns of utilization within certain demographic groups of survey respondents.

- African Americans and Latinos/Hispanics reported the use of Medicaid exclusively at a rate that is twice that of the overall surveyed population. This disproportionate utilization rate underscores a higher rate of poverty and limited access to health care insurers for minority populations. Among all survey respondents, 14.7% reported use of Medicaid “only”. The utilization rate for African Americans and Latino/Hispanic Americans who rely on Medicaid exclusively to pay for their health care and treatment is 28.5% and 29.6% respectively.
- African American women reported the highest rate for utilization of Medicaid and/or Medicare; 63.4% reported receiving services from one or both programs
- African American women reported the highest rate (32.5%) for utilization of Medicaid “only” to pay for their health care.
- Latino/Hispanic reported the lowest utilization rate of Medicare “only” with only 9.9% relying on Medicare. Throughout all survey respondents, those that utilize Medicare “only” accounted for 19.6%.
- People who have lived with HIV for more than 10 years reported significant dependence on Medicare exclusively to pay for their health care and treatment comprising 24% of Medicare-only users.
- People aged 50 years and older reported the highest rate of dependence on Medicare exclusively to pay for their health care and treatment at 27.3%. People aged 50 years and older also reported the most utilization of both Medicaid and Medicare (dual eligible) to pay for their health care and treatment at 48%

The Ryan White Program is the single largest federal program designed specifically for people with HIV in the United States, estimated to reach more than half a million people with HIV each year. First enacted in 1990, it provides health care and support services to individuals and families who are living with HIV. Functioning as the “payer of last resort”, the Ryan White Program fills many service gaps for people living with HIV/AIDS who have no other source of coverage or face coverage limits. Ryan White is often utilized to provide services that are not otherwise covered by Medicaid or Medicare.

It is clear that the Ryan White Program is an essential Federal program. However, eligibility for Ryan White services varies by jurisdiction. As one participant from Michigan stated, *“ADAP benefits & eligibility should not vary by state ...I would like to relocate to a less expensive state for housing, but often the state I want would not provide ADAP benefits.”* The concern being shared by this individual illustrates the tragic reality for many who are living with HIV/AIDS who have to choose between quality of life and life-saving healthcare and treatment.

Survey respondents reported on many of the on-going gaps in access to healthcare and treatment services further supporting the importance of the Ryan White Program.

Due to varying eligibility requirements and different documentation to verify eligibility for each program, Medicaid, Medicare, Ryan White and other state and local healthcare systems are extremely cumbersome and difficult to navigate. One participant from Mississippi stated *“Medicaid can be difficult to understand or negotiate for person with low literacy”*.

Testimonies from people living with HIV/AIDS continue to describe these difficult to access and uncoordinated systems of care act as barriers to their own healthcare and treatment. The difficulty reported from individuals seeking eligibility for these programs further illustrates the importance of qualified and knowledgeable case management and benefits counseling services.

Many of the survey respondents prioritized assistance with navigating these complex systems as a significant need.

The barriers created by these complex systems should be addressed in efforts to develop a National AIDS Strategy and reform healthcare.

Our survey asked respondents to identify the services that improved their quality of life, health outcomes, and adherence to prescribed treatment. Since approximately 94% of survey respondents were currently in care (defined as seeing a primary care provider within the past 6 months), their responses provide valuable information about current experiences with the health care access and quality.

This report provides significant testimony to the critical need for support services to access medical care and remain adherent to treatment.

It is essential that medical providers have flexibility to tailor care and treatment to maximize individual health goals. Patient adherence is contingent upon each person's ability to manage their treatment program as prescribed. Where certain services emerge as essential for patient adherence; both the healthcare provider and the patient would greatly benefit from afforded flexibility to respond to individual need.

Medical support services such as the AIDS Drug Assistance Program, Mental Health Services, Health Insurance Assistance, Substance Use Services and Dental Services were all identified as critical components of comprehensive healthcare from those who completed the survey. Dental care was identified as the highest unmet need by survey respondents.

Social services are essential to health care access and treatment success. Many of these services provide a lifeline and stabilize people's lives thereby allowing them to attend to their prescribed regimen. There is a variety of social services that were indicated as important. Without access to these services, many stated that they would have fallen through the cracks and would not be in care.

The two most significantly unmet needs identified by PLWHA with respect to supportive services were housing and transportation. Safe and affordable housing and timely and accessible transportation remain essential to health care and treatment access. Sadly, the majority of PLWHA continue to report these services as their highest unmet need.

Survey respondents identified social supportive services as equally essential to their healthcare as medical support services. The correlation between health improvement and social and medical needs being met is inextricably linked. An individual living with HIV/AIDS cannot improve their life without access to health care and treatment and cannot improve their health without access to supportive services.

It is clear that health improvement for PLWHA be afforded the flexibility to allow specificity to individual need. Case-specific treatment regimens are critical to enabling PLWHA to have healthy lives with HIV/AIDS. Flexibility is also important on the local, regional and national level. Survey respondents reported the importance and need for services throughout the country, however access to services is varied based on where you live.

Ryan White is an essential component of providing medical care, medical support services and the social support services critical to the healthcare of people living with

HIV/AIDS. The Ryan White model of local community planning attempts to address the need for these programs in a way that is responsive to the local community.

E. Housing

Housing is an essential need for people living with HIV/AIDS and was cited as one of the highest unmet needs, and this report includes some important statistics on housing from our respondents. For a person living with AIDS, homelessness or even the threat of homelessness, can lead to unnecessary illness and premature death. For many with HIV/AIDS, permanent housing means the difference between having access to medication, being able to manage a prescribed treatment regiment, safe and reliable living accommodations, and ability to pursue reentering the labor force. Pure and simple: Housing equals healthcare for People Living with HIV/AIDS.

Among survey respondents, the large percentages of individuals who rely on government resources to afford housing cannot be ignored when addressing the needs of people living with HIV/AIDS.

Among all of our respondents 36.10% rely on subsidized housing, are living in transitional housing or are marginally housed (staying with friends/family, living in congregate living facility, or shelter. 0.6% or just under one percent reported being on the street or homeless.

Among African Americans 54.40% rely on subsidized housing, are living in transitional or are marginally housed. 0.9% reported being on the street or homeless

Among African American Women 55.40% rely on subsidized housing, are living in transitional or are marginally housed. 1.6% reported living on the street or homeless.

Among women of all races 48% rely on subsidized housing, are living in transitional or are marginally housed. 1% of all women reported living on the street or homeless.

Among Latinos / Hispanics 46.4% rely on subsidized housing, are living in transitional or are marginally housed. 1.2% reported living on the street or homeless.

While the data does not directly prove that housing results in being in medical care- the fact that a significant percentage of our project participants rely on subsidized housing and that more than 94% have seen a medical provider within the last six months and that housing is repeatedly listed as a top priority to help access and maintain care makes a persuasive and compelling argument as to the importance of housing to staying in medical care for our project participants.

While it is heartening to see the number of people who have been fortunate enough to find stable housing with government support, the number of respondents (22.3%) who reported either living in transitional housing or having marginal housing is significant. The likelihood that these individuals will be fortunate enough to access stable housing in the future cannot be taken for granted. Meanwhile, the stress of not having a stable living environment and the concomitant problems unstable housing brings may increase the possibility that they end up homeless.

From looking at the data and information from our participants it seems that housing is a critical component of care. With more than 1 in 5 of our respondents relying on transitional housing or being marginally housed, it is clear the current investment in housing needs to be reexamined.

If any one of these 22.3% found themselves homeless in the future it is an unacceptable outcome.

Housing is more than an important issue for people living with HIV/AIDS, it is a priority. Housing needs must be considered when developing a National AIDS Strategy and in the national discussion on healthcare reform.

As we address the development of a National AIDS Strategy, national healthcare reform and the future of Ryan White, our report indicates that wrap around health support and social support services as well as housing are essential for people living with HIV/AIDS and because they help with treatment adherence and continued maintenance in medical care, they are likely to result in more positive health outcomes.

1. Introduction

HIV Positive Voices in America was an initiative developed and organized by people living with HIV/AIDS (PLWHA) from the Communities Advocating Emergency AIDS Relief (CAEAR) Coalition People Living with HIV/AIDS (PLWHA) Caucus and the National Association of People with AIDS (NAPWA). The goal of the project was to hear from our fellow PLWHAs throughout the United States about the needs of our community – the disparate needs based on identity, geography, socioeconomic status, familial situation, and the extent of our disability. To be effective advocates for our over one million brothers and sisters living with HIV/AIDS in the United States, we wanted to learn more about what our community needs are; what sustains our lives and optimizes individual and community opportunities for a better quality of life, all while building on our hope for the future. The information gleaned from this comprehensive study should provide a valuable tool for decision-makers in Washington D.C. as they reexamine Ryan White, engage in a discussion on healthcare reform, and the Obama Administration develops a comprehensive, coordinated, and results-driven National AIDS Strategy.

HIV Positive Voices in America provided quantitative data reported from over 1,800 surveys that had been completed at community meetings and through an on-line survey that had been open for approximately six months. Eleven local community meetings were held in Albany NY, Atlanta GA, Baltimore MD, Bronx NY, Brooklyn, NY, Chicago IL, Miami /Ft. Lauderdale FL, Manhattan NY, Minneapolis MN, Palm Springs CA, Rochester NY, one Southeast regional meeting was held in Tampa FL, one statewide meeting was held in Massachusetts organized by the Massachusetts Office of HIV/AIDS Community Advisory Board, and two national meetings- AIDSWatch 2008 held in Washington DC and a National Leadership Conference for African Americans living with HIV/AIDS in Philadelphia PA.

Qualitative data reported from: 1) answers to open ended questions on the surveys completed at the community meetings and online and 2) the town hall dialogues with consumers at these community meetings.

Survey results: Data from 1,802 people living with AIDS in 42 states, the District of Columbia and Puerto Rico

This initiative was driven by a strong request from Senator Kennedy's staff after the 2006 Ryan White reauthorization process to hear from "the real people"- the grassroots and persons living with HIV/AIDS who are not normally involved in advocacy activities. The organizers of this initiative were clear from the outset that this be a process led by grassroots groups through a mechanism that empowers and listens to people living with HIV/AIDS through a community organizing model.

As in all community driven processes of this nature, we recognize some of the challenges in the data. While the survey instrument was developed within the standards of accepted evaluation and was reviewed by Dr. Wayne Steward of UCSF and the questions used for the community meeting dialogue were developed by the CAEAR PLWHA Caucus which includes 6 CAEAR Board members; the survey was not a "scientific sampling".

It is clearly biased towards individuals who have an interest in voicing their thoughts about HIV/AIDS issues. Individuals who attended town hall meetings, often through outreach from their local provider community, are probably more likely to access some level of HIV/AIDS services. The on-line survey is biased towards respondents with internet access.

At the core of the missions of both NAPWA and the CAEAR PLWHA Caucus are the Denver Principles- a manifesto of self empowerment for people living with HIV/AIDS that was developed in 1983 by people living with AIDS.

Three specific points of the Denver Principles are the guiding force of the Positive Voices in America project:

1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies.
2. Be involved at every level of decision-making and specifically serve on the board of directors of provider organizations.
3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.

The values of the Denver Principles guided the development and execution of this project. The integrity of the project hinged on PLWHAs leading the effort, participating in the effort and speaking with a united voice reflecting our own diversity. PLWHAs are the ultimate stakeholders in the system of care that we use, and are best positioned to measure whether the system of care provides for long, healthy lives with the highest possible quality of life.

The collaboration between the CAEAR PLWHA Caucus and NAPWA was a model of partnership and teamwork, and the project developed its own life. During the planning in late 2007 and early 2008, it was assumed that this project would generate data with the sole goal of developing a report that would be used in concert many other reports to help guide reauthorization of the Ryan White program. However, over the course of 2008 it became clear that this was more than just a project leading to a report. By attending the numerous town halls, reviewing the survey data and reading the comments from the surveys and town hall sessions- we began to know these 1,802 people. They no longer were just statistics but people who, like us, struggle with this disease every day of our lives; people who want nothing but a life with dignity and hope.

In the autumn of 2007, when this project was conceived, the goal was to provide the national HIV/AIDS community and Congress with a report that would contribute to Ryan White Reauthorization in 2009. With the likely extension of Ryan White legislation for three years, and looking carefully at the information provided by the project, we concluded that this report is about more than giving feedback about Ryan White legislation. The rich data contained in this report will be an essential guide when developing a national AIDS strategy and in the national conversation on healthcare reform.

2. Who did we talk to?

The Project's Demographic Breakdown

We talked to people living with HIV/AIDS in the United States from all regions of the country with an array of needs- both met and unmet. The 1,802 people we spoke with came from 42 states¹ and a variety of income levels (the issue of income and its relation to HIV/AIDS will be analyzed more fully later in this report). Our efforts were not scientific in our recruitment for participation. In the town hall meetings, outreach was done through a variety of efforts, but primarily with the great assistance of service providers. Outreach for the On-Line survey was done through a variety of blogs, newsletters and email blasts. But the basic philosophy of the organizers of this project was that we wanted to hear from anyone with anything to say.

The vast majority of people that we heard from were in medical care. More than 97% were in care and more than 94% in care have seen a provider within the last 6 months. This allowed us to find out what factors were important to keeping these individuals in care and what barriers they faced before getting into care.

Even though there was no recruitment effort that attempted to ensure a representative demographic sampling, the demographics of the participants naturally fell into a very diverse representation.

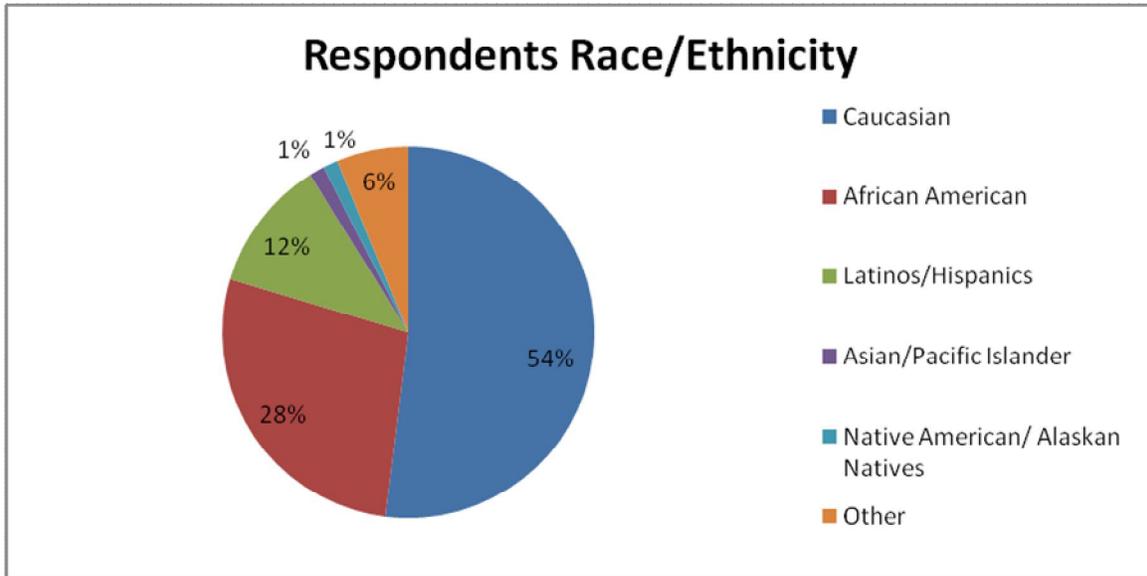
We heard from 965 Caucasians, 518 African Americans, 216 Latinos as well as Asians, Pacific Islanders, Native Hawaiians, Alaskan Natives, Native Americans, and Biracial identified individuals.

We heard from 477 women, 1292 men as well as transgendered women and men.

We heard from 1,005 people who identified as gay or lesbian, 614 who identify as heterosexual and 142 who identify as bisexual.

On the next two pages are charts that show the breakdown of the project participants' demographics in the areas of race/ethnicity, gender identity and sexual orientation. We have also provided a comparison to the most recent CDC prevalence data as much as possible.

¹ Delaware, Hawaii, Idaho, Montana, North Dakota, South Dakota, Utah and Wyoming are the 8 states that did not have representation in the data



While the participants were ethnically and racially diverse, they were not completely reflective of the national prevalence data provided by the CDC in its *New Estimates of U.S. HIV Prevalence, 2006* published in the October 3, 2008 issue of *CDC's Morbidity and Mortality Weekly Report*. Due to the self select nature of the project and that it was not designed to be a scientific study. There was no recruiting for any particular demographic representation. It should be noted that the town hall meetings tended to be more reflective of the CDC's estimates. The online survey participants were disproportionately Caucasian. The representation of African Americans and Caucasians were the two groups that showed significant deviation from the CDC data. Representation of Latinos and Asians / Pacific Islanders showed a slight deviation.

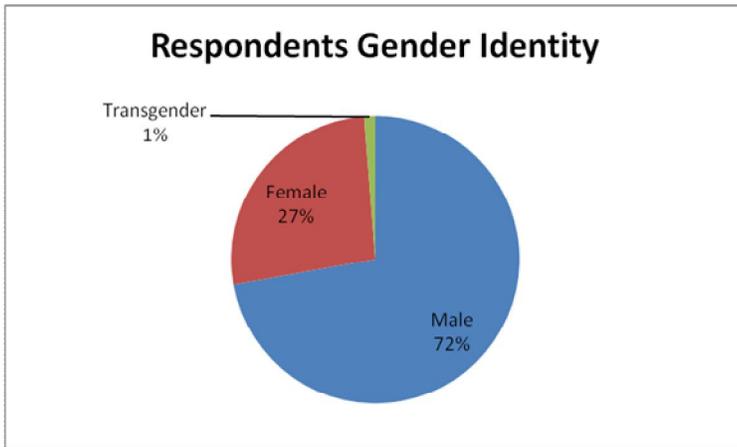
The CDC estimates that African Americans represent 46% of people living with HIV/AIDS in the US. 28.7% of the participants in this project were African American

The CDC estimates that Caucasians represent 35 % of people living with HIV/AIDS in the US. 54% of the participants in this project were Caucasian

The CDC estimates that Latinos/ Hispanics represent 18 % of people living with HIV/AIDS in the US. 12% of the participants in this project were Latinos / Hispanics.

The CDC estimates that 1% of Asians / Pacific Islanders and less than 1% of Native Americans represent people living with HIV/AIDS in the US
 1.38% of the participants in this project identify as Asian or Pacific Islander
 1.33% of participants in this project identify as Native American / Alaskan Native

The CDC does not have estimates for Biracial / Multiracial however 3.38% of participants in this project identified as Biracial / Multiracial
 3.1% of project participants indicated that their race/ethnicity was not listed.



1791 Respondents answered the question on gender identity.

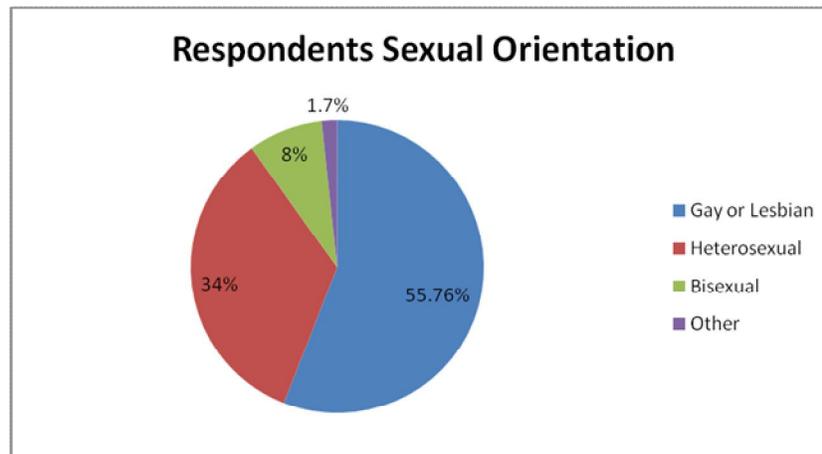
26.6% of the participants in this project identify as female.

72.1% of the participants in this project identify as male.

1.25% of the participants identified as either transgender male or transgender female.

The CDC estimates that 25% of people living with HIV/AIDS in the US are female and 75% of people living with HIV/AIDS are male.

The CDC does not include any information on transgendered people in its estimate.



1800 respondents answered the question on sexual orientation.

The CDC does not estimate HIV/AIDS prevalence by sexual orientation, but instead provides estimates of prevalence by transmission category. According to the CDC In 2006, the largest estimated proportion of HIV/AIDS diagnoses among adults and adolescents were for men who have sex with men (MSM), followed by persons infected through high-risk heterosexual contact. 50% are men who have sex with men (MSM), 3% MSM who are also intravenous drug users (IDU), 33% are people who engage in high risk heterosexual activity, 13% IDU and 1% other.

Since our question asked about sexual orientation identification and not transmission category, a true comparison cannot be drawn. However if broad assumptions are drawn regarding transmission categories and their relationship to sexual orientation, it might be concluded that our demographics may be relatively reflective of the epidemic.

3. Who is in care?

Most of the people we heard from were in care and there was little variance when analyzed by some key demographic variables. As mentioned previously in this report individuals who attended town hall meetings were mostly recruited to participate via outreach by their local service provider and/or community planning group, and town hall meeting participants were therefore more likely to be “in care”. Individuals who participated on-line were likely to link to the survey through a blog, email blast, or other communication that would have an audience that would likely be in care.

Below are results of cumulative data and key demographic specific data from the participants. These tables indicate that there was little if any variance among key demographic groups

a. Cumulative Data - Current Medical Care

Do you have a doctor or other medical provider?

Source	Yes	No	No Answer
Online	954	17	113
AIDSWatch	34	0	4
Albany	20	0	2
Atlanta	31	0	1
Baltimore	27	1	1
Bronx	61	6	9
Brooklyn	37	3	7
Chicago	39	1	0
FL/NAPWA	69	4	7
Miami/FtL	52	5	11
Manhattan	28	0	6
Minneap	50	1	2
Palm Sp	26	1	0
Phil AAC	14	0	5
Rochester	12	0	0
Mass	123	2	16
TOTAL	1577	41	184
	97.40%	2.60%	

1618 Respondents answered this question

Percentage is based N=1618

97.4% of Respondents answering the question have a medical provider

2.6% of Respondents answering the question do not have a medical provider

If you have a medical provider have you had a medical visit with your doctor provider in-

Source	Not within 6 months	Last 3-6 months	Last 3 Months
Online	19	91	829
AIDSWatch	1	2	27
Albany	0	2	17
Atlanta	0	2	26
Baltimore	0	3	22
Bronx	2	3	54
Brooklyn	1	6	31
Chicago	1	1	36
FL/NAPWA	1	7	60
Maimi/FtL	3	3	45
Manhattan	3	2	22
Minneap	1	1	45
Palm Sp	2	0	21
Phil AAC	0	2	12
Rochester	0	0	12
Mass	1	5	94
TOTAL	35	130	1353

Using the N of respondents who indicated that they had a doctor or medical provier N=1577
 Using the definition of Currently in care as having a medical visit within 6 months
 94% of those who have a provider are currentntly in care (1483)

b. Data for African Americans - Current Medical Care

Do you have a doctor or other medical provider?

Source	Yes	No	No Answer
Online	155	9	23
AIDSWatch	13	0	3
Albany	6	0	1
Atlanta	17	0	1
Baltimore	20	1	1
Bronx	33	3	7
Brooklyn	14	2	4
Chicago	24	1	0
FL/NAPWA	30	3	3
Maimi/FtL	34	3	8
Manhattan	13	0	3
Minneap	11	0	1
Palm Sp	0	0	0
Phil AAC	9		4
Rochester	3	0	0
Mass	44	2	6
TOTAL	426	24	65
%	94.60%	5.40%	

450 Respondents answered this question

Percentage is based N=450

97.4% of Respondents answering the question have a medical provider

2.6% of Respondents answering the question do not have a medical provider

If you have a medical provider have you had a medical visit with your doctor provider in-

Source	Not within 6 months	Last 3-6 months	Last 3 Months
Online	5	15	135
AIDSWatch	0	0	11
Albany	0	0	5
Atlanta	0	2	12
Baltimore	0	3	16
Bronx	0	1	33
Brooklyn	1	4	11
Chicago	1	1	21
FL/NAPWA	7	3	16
Miami/FtL	3	3	27
Manhattan	0	1	12
Minneap	0	0	9
Palm Sp	0	0	0
Phil AAC		2	7
Rochester	0	0	3
Mass	0	2	38
TOTAL	17	37	356

Using the N of respondents who indicated that they had a doctor or medical provier N=426
 Using the definition of Currently in care as having a medical visit within 6 months
 92% of those who have a provider are currently in care (426)

c. Data for Hispanic - Current Medical Care

Do you have a doctor or other medical provider?

Source	Yes	No	No Answer
Online	75	2	19
AIDSWatch	7	0	0
Albany	5	0	0
Atlanta	1	0	0
Baltimore	2	0	0
Bronx	20	3	2
Brooklyn	10	0	0
Chicago	3	0	0
FL/NAPWA	5	0	0
Miami/FtL	16	1	2
Manhattan	8	0	1
Minneap	4	0	0
Palm Sp	2	0	0
Phil AAC	0	0	0
Rochester	0	0	0
Mass	25	0	6
TOTAL	183	6	

189 Respondents answered this question

Percentage is based N=189

96.8% of Respondents answering the question have a medical provider

3.2% of Respondents answering the question do not have a medical provider

If you have a medical provider have you had a medical visit with your doctor provider in-

Source	Not within 6 months	Last 3-6 months	Last 3 Months
Online	1	6	67
AIDSWatch	1	1	5
Albany	0	1	4
Atlanta	0	0	1
Baltimore	0	0	2
Bronx	1	2	16
Brooklyn	0	0	9
Chicago	0	0	3
FL/NAPWA	1	1	3
Miami/FtL	0	1	15
Manhattan	1	1	6
Minneap	0	0	4
Palm Sp	0	0	2
Phil AAC	0	0	0
Rochester	0	0	0
Mass	0	0	23
TOTAL	5	13	160

Using the N of respondents who indicated that they had a doctor or medical provier N=183

Using the definition of Currently in care as having a medical visit within 6 months

94.5% of those who have a provider are currently in care (173)

d. Data for Women- Current Medical Care

Do you have a doctor or other medical provider?

Source	Yes	No	No Answer
Online	174	3	30
AIDSWatch	9	0	2
Albany	8	0	1
Atlanta	8	0	1
Baltimore	13	1	0
Bronx	26	2	5
Brooklyn	11	0	2
Chicago	9	0	0
FL/NAPWA	27	3	2
Miami/FtL	28	3	0
Manhattan	7	0	4
Minneap	15	0	1
Palm Sp	0	0	0
Phil AAC	6	0	2
Rochester	2	0	0
Mass	63	1	6
TOTAL	406	13	56

419 Respondents answered this question

Percentage is based N= 419

96.9% of Respondents answering the question have a medical provider

3.1% of Respondents answering the question do not have a medical provider

If you have a medical provider have you had a medical visit with your doctor provider in-

Source	Not within 6 months	Last 3-6 months	Last 3 Months
Online	3	22	147
AIDSWatch	0	0	7
Albany	7	0	0
Atlanta	0	0	5
Baltimore	0	3	9
Bronx	2	3	20
Brooklyn	2	5	3
Chicago	0	1	8
FL/NAPWA	1	4	24
Miami/FtL	2	3	23
Manhattan	1	1	6
Minneap	1	0	13
Palm Sp	0	0	0
Phil AAC	0	0	5
Rochester	0	0	2
Mass	0	2	52
TOTAL	19	44	324

Using the N of respondents who indicated that they had a doctor or medical provier N= 406
 Using the definition of Currently in care as having a medical visit within 6 months
 91% of those who have a provider are currenntly in care (368)

This data is provided in order to establish that the respondents across demographic lines were overwhelmingly in care. This allows for a greater analysis of what services are key to accessing care, maintaining care and what barriers these individuals faced before getting in care and what variables may exist regarding barriers, access and maintenance of care.

4. Low Income, Poverty, Cost of Care and HIV/AIDS

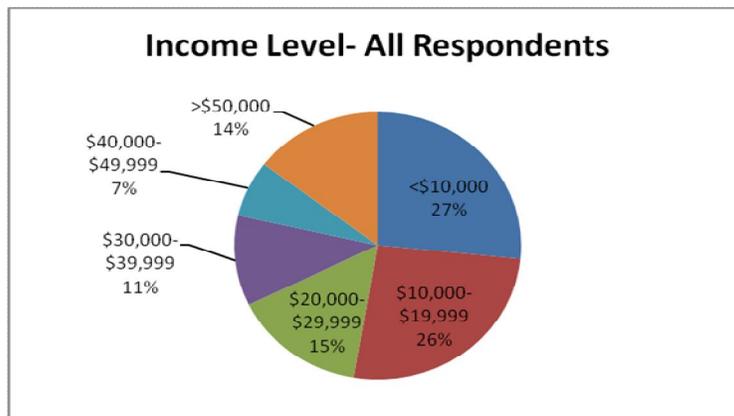
A. Income and Poverty

A majority of participants in the project who answered the question about income level (52.7%) have incomes at 200% of the Federal Poverty Level (FPL) or below. 26.6% were below the FPL. The Federal Poverty Level (FPL) for 2009 is \$10,830 for an individual. The Federal Poverty Level in 2008 when this project collected data was \$10,400 for an individual. The Massachusetts state meeting did not ask a question about income.

The percentage of respondents living below 200% of FPL and below the FPL does shift significantly among our project participants based on demographics. The most striking shifts were for:

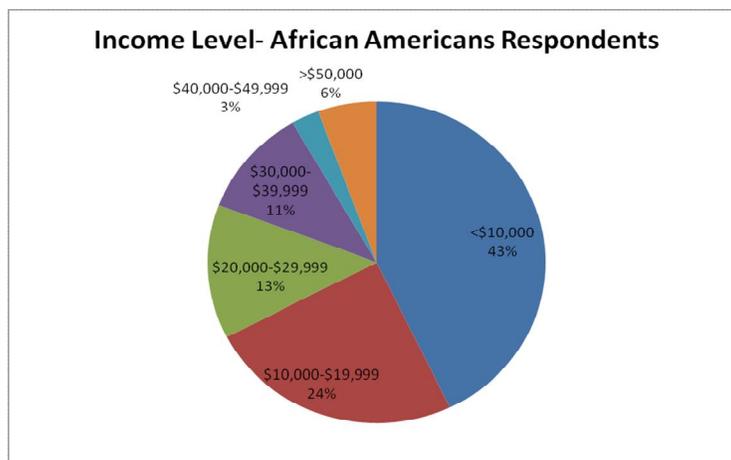
- 1) African American respondents: 66% live at below 200% of FPL and 42% were below the FPL
 - 2) Women respondents: 63% live at below 200% of FPL and 37.5% were below the FPL
 - 3) African American Women: 64.1% were living below 200% of FPL and 42.7% lived below the FPL. African American women were the most likely group to live below the Federal Poverty Level.
- Hispanics have a slightly higher percentage of individuals living at below 200% of FPL than the average – 55.4%, but a higher than average percentage living below FPL- 31.7%.

The data from this project indicates that addressing poverty is a critical component when addressing HIV/AIDS and that there is a direct link between poverty and race, ethnicity and gender.



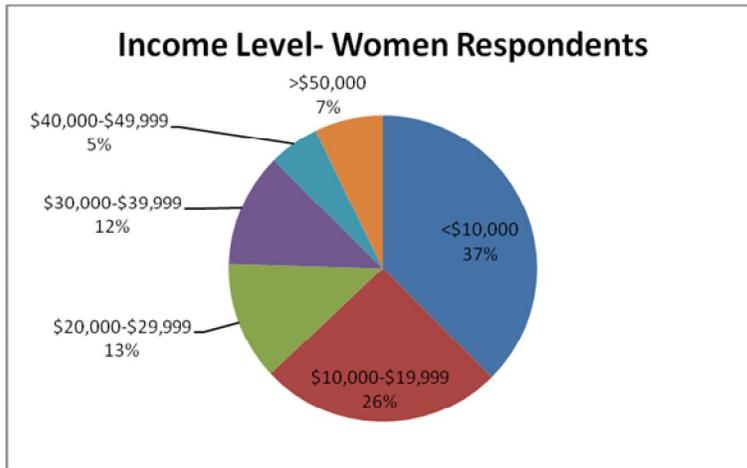
N= 1596

53% of Respondents are living below 200% of FPL
27% of Respondents are living below FPL

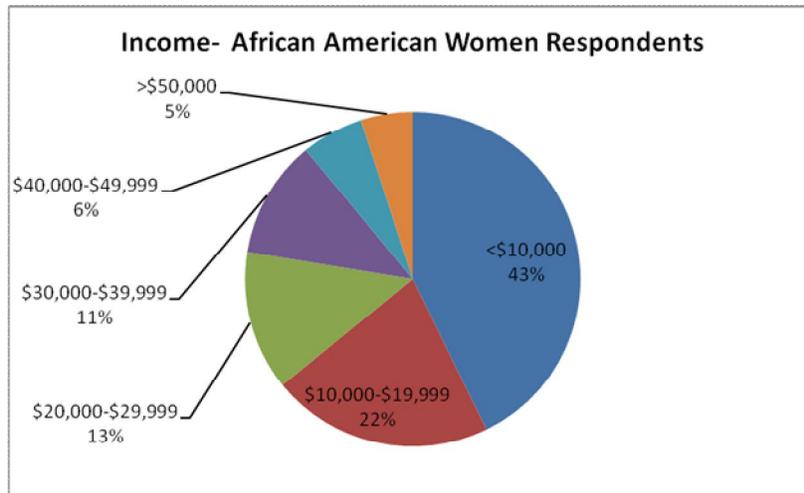


N= 439

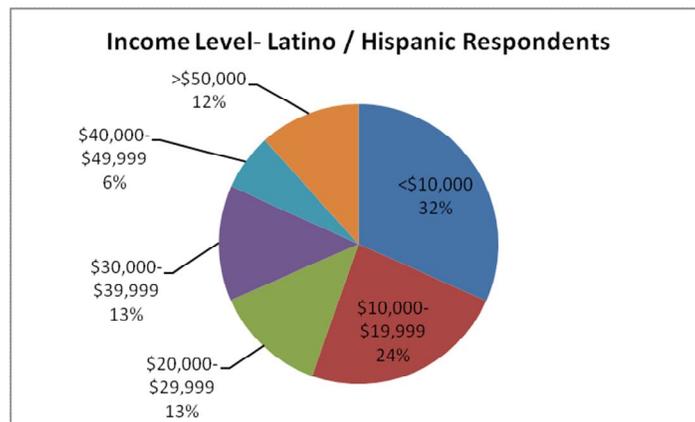
66% of African American Respondents live below 200% of FPL
43% of African American Respondents live below FPL



N=383 63% of Women respondents live below 200% of FPL
 37% of Women respondents live below FPL



N= 201 65% of African Women respondents live below 200% of FPL
 43% of African American Women respondents live below FPL



N= 186 56% of Latino/ Hispanic Respondents live below 200% FPL
 32% of Latino / Hispanic Respondents live below FPL

B. Cost of Care

In our town halls and in response to a question on our survey- "*Please describe any problems you have had in getting medical care*", a substantial number of participants mentioned that cost is a barrier to care. Below is a sampling of comments:

Just paying the deductible of \$1,000.00 on my PPO insurance each year from my employer is more than I can afford.

- Massachusetts

No Medical Insurance Medicaid or Medicare. What am I to do?

-South Carolina

I was uninsured and had ADAP cover visits

-New York

I was on Medicaid because I was raising my grandson. He is a special needs child and has gone to a residential care facility. When that happened, I lost my Medicaid eligibility. I have had to self-pay for an exam for hernia and possible hernia surgery, and I have to request samples from my gynecologist for hormone replacement therapy and samples as well for my antidepressant. Thank heavens I do have ADAP for my HIV meds!

-Illinois

Cost of Insurance. And time when I go to the free doctor, it is also a problem because I work and doctor's office are only open M-F.

-Texas

Cannot get help with my co pay ongoing basis so I cannot go to appointment all the time.

- Ohio

My psychiatrist does not take any kind of insurance. I have to pay him by cash, check or credit card (\$150 per hour/ \$100 per half hour/ \$75 per quarter hour). I now see him once every 2-3 months for an hour visit. My psychologist takes a \$30 Aetna Co-pay, since at present, I am covered under COBRA insurance from my previous employer, for which I pay \$316 per month. I see the psychologist every 2 weeks. I am waiting for Medicare coverage, but I will also need supplemental insurance coverage. My appointments at the dental clinic at the University of Pennsylvania Dental School are "few and far between" because of their volume of patients, and perhaps, the assigned student's availability. Also, regarding dental care, I am likely to need some kind of dental bridge work for which I am I will not be covered, and have to pay or go "toothless." I cannot afford dental bridge work. My round-trip expense for gas for dental clinic visits is \$13 and metered parking is an additional \$2 on average per visit. My HIV/AIDS doctor is located in Philadelphia, and it costs \$13 in gas (round-trip) by car for each visit.

- Pennsylvania

Unable to refill prescriptions because I didn't have the co pay,

- Florida

Keeping insurance is very difficult and exclusion rules mean I am uncovered much of the time. Because I make more than 150% of the poverty level, though, I either have to quit working and be poor or make more money and have no health insurance. That's like choosing between to(sic) dead ends.

-North Carolina

My co-pays keep me from getting care when I need it.

-Louisiana

It's very difficult dealing with "Surplus/Spend Down" Medicaid. Periodic trips to the Medicaid Office at times when I was too sick to go out.

-New York

This State of Mississippi has 100% of Federal poverty level and they change their law in 2005 December. And they made in their law \$871.00 to qualify for QMB program, and if you make over that amount you will be place on the SLMB program in which you have to pay for all of your co-pays in Doctors visits, Prescriptions, all medical equipment, and you do not qualify for food stamps, HOPA, OR state assistance for other items which is very limited.

-Mississippi

I don't have insurance and cannot afford private insurance. I am currently unemployed and receiving no financial assistance from anywhere other than my family with whom I live. I cannot even afford an office visit fee.

-Colorado

I have not been able to afford the co-payment for medications, and Lab work. My doctor is only in his office three days a week and those are half days, because he does research. His staff gets angry and frustrated with me when I don't get blood work done, even though I explain that I simply cannot afford a bill for \$1000

-California

Could not get hernia surgery paid for; am paying for 4 hernia operations and need a fifth; all AIDS related.

- Arizona

Services are set up for people who are not working—it's hard, when you are low income, to sit at the clinic ALL DAY LONG.

-Washington

Care is good but expense is enormous even with insurance. Paperwork/bill paying is out of control.

- Minnesota

Low Income, Poverty, Cost of Care and HIV/AIDS Summary of Findings

Poverty is major issue for most people living with HIV/AIDS and disproportionately affects African Americans, women, especially African American women, and to some extent Hispanics. It seems that addressing poverty is critical in addressing HIV/AIDS.

Poverty and low income can provide a barrier to seeking care or knowing where to access care, according to our project's participants.

According to a number of respondents, issues associated with the cost of medical care for working people without insurance and the working poor can often result in difficult decisions. As one respondent from North Carolina quoted above said, "*I either have to quit working and be poor or make more money and have no health insurance. That's like choosing between to (sic) dead ends.*"

5. HIV Health Payers for Medical Care – Medicaid, Medicare and Ryan White

In every town hall and survey, access to medical care and treatment were identified as the most critical need for people living with HIV/AIDS. Medicaid, Medicare and Ryan White are the programs that provide most of the care for PLWHAs. The Department of Veterans Affairs (VA) also provides medical care. However, this project did not focus on the VA. This section will look at the importance of Medicaid, Medicare and Ryan White, and how our project participants utilized these programs and highlights both successes and challenges.

According to February 2009 fact sheets produced by the Kaiser Family Foundation on HIV/AIDS and Medicaid and HIV/AIDS and Medicare, the federal portion of Medicaid (Medicaid is funded by the federal government and state governments) and Medicare account for a combined total of 74% of Federal funding for HIV/AIDS Care.

According to the Kaiser Family Foundation, these two programs provide care to approximately 300,000 to 340,000 people living with HIV/AIDS.^{2 3}

Medicaid has played a critical role in HIV care since the epidemic began and is the single largest source of coverage for people with HIV in the United States. It covers approximately four in ten people with HIV estimated to be receiving care in the U.S.

Medicare, the federal health insurance program for people age 65 and older and younger adults with permanent disabilities is an important source of health coverage for an estimated 100,000 people with HIV. It covers approximately one fifth of people with HIV estimated to be receiving care in the United States. With the implementation of the Medicare Part D prescription drug benefit in 2006, Medicare assumed an even more critical role for people with HIV, as it began to pay for prescription drugs.

Most people with HIV on Medicaid qualify because they are both low-income and permanently disabled (approximately 70%). Most people with HIV on Medicare are under age 65 and qualify because they are disabled and receiving Social Security Disability Insurance (SSDI) payments (93% of beneficiaries), which entitle them to Medicare after a two-year waiting period. A small share (7%) are eligible as senior citizens.

Since these programs are critical programs for people living with HIV and, for the most part, require an individual to be disabled with HIV, we wanted to get a sense of the utilization of Medicare and Medicaid by our project participants.

Medicaid programs vary from state to state in terms of the array of services available, the quality of care and income eligibility so we looked to see if there were utilization patterns for Medicaid in various regions of the country by our project's participants.

The Ryan White Program is the single largest federal program designed specifically for people with HIV in the United States, estimated to reach more than half a million people with HIV each year. First enacted in 1990, it provides care and support services to individuals and families affected by the disease. The program functions as the "payer of last resort", filling in the gaps for those who have no other source of coverage or face coverage limits.⁴ Ryan White is often utilized to fill in the gaps where Medicaid and Medicare may fail to provide adequate medical care for people living with HIV/AIDS, and we asked participants about Ryan White and medical care.

² Fact Sheet: Medicaid and HIV/AIDS, Kaiser Family Foundation, February 2009

³ Fact Sheet: Medicare and HIV/AIDS, Kaiser Family Foundation, February 2009

⁴ Fact Sheet: Ryan White Program, Kaiser Family Foundation, February 2009

The analysis below provides cumulative data, data based on some key demographics and regional data on Medicare and Medicaid and information on the importance of Ryan White in filling in the gaps in medical care. A section of this analysis also addresses the challenges project participants had in accessing some services and “patching them together.”

A. Medicare Medicaid Program Utilization

a. Cumulative Project Data – All Respondents

Medicare/Medicaid Status						
Do you receive Medicaid and/or Medicare? (Check all that apply)						
Source	No	Only Medicaid	Only Medicare	Medicaid and Medicare	Private Insurance	I don't know
Online	347	66	216	172	252	22
AIDSWatch	12	7	6	12	N/A	0
Albany	5	11	1	5	N/A	0
Atlanta	15	4	6	4	N/A	0
Baltimore	6	4	11	3	N/A	3
Bronx	9	45	2	8	N/A	3
Brooklyn	6	24	2	6	N/A	1
Chicago	14	7	7	8	N/A	2
FL/NAPWA	29	7	17	19	N/A	1
Miami Ft Lauderdale	18	24	7	9	N/A	1
Manhattan	3	16	0	8	N/A	1
Minneapolis	11	10	14	10	N/A	5
Palm Sp	7	1	10	9	N/A	0
Phil AAC	5	2	4	4	N/A	0
Rochester	1	2	3	4	N/A	1
Mass	N/A	N/A	N/A	N/A	N/A	N/A/
TOTAL	488	230	306	281	252	40
%		14.70%	19.60%	18.10%		

Question is interested only in Medicaid /Medicare Status and therefore percentages only tallied for Medicaid, Medicare and Medicare/Medicaid based on total N (1557)

Massachusetts did not ask the question about Medicaid/Medicare Status

The On-Line Survey was the only source to ask about Private Insurance

In addition to the MA surveys (141 respondents) 64 other respondents did not ask the question

40 respondents did not know their status and are subtracted from the N

N is 1597-40=1557

52.4% of Respondents answering the question and knowing their Medicare/Medicaid status rely on Medicare, Medicaid or both

b. Key Demographics

ii. African American Data Respondents

Medicare/Medicaid Status						
Do you receive Medicaid and/or Medicare? (Check all that apply)						
Source	No	Only Medicaid	Only Medicare	Medicaid and Medicare	Private Insurance	I don't know
Online	64	22	32	21	33	1
AIDSWatch	5	4	3	4	N/A	0
Albany	2	5	0	0	N/A	0
Atlanta	7	4	2	2	N/A	0
Baltimore	3	4	9	2	N/A	2
Bronx	3	26	1	5	N/A	1
Brooklyn	3	9	0	3	N/A	0
Chicago	6	4	5	7	N/A	2
FL/NAPWA	9	5	6	12	N/A	0
Miami Ft Lauderdale	9	18	6	6	N/A	1
Manhattan	0	11	0	4	N/A	0
Minneapolis	3	3	2	2	N/A	0
Palm Sp	0	0	0	0	N/A	0
Phil AAC	2	1	3	4	N/A	0
Rochester	0	0	0	1	N/A	1
Mass	N/A	N/A	N/A	N/A	N/A	N/A
TOTAL	116	116	69	73	33	8
%		28.50%	17.00%	18.00%		

Question is interested only in Medicaid /Medicare Status and therefore percentages only tallied for Medicaid, Medicare and Medicare/Medicaid based on total N (407)

Massachusetts did not ask the question about Medicaid/Medicare Status

The On-Line Survey was the only source to ask about Private Insurance

8 respondents did not know their status and are subtracted from the N

N is 415- 8= 407

63 % of African American Respondents answering the question and knowing their Medicare/Medicaid status rely on Medicare, Medicaid or both

iii. African American Women Respondents

Medicare/Medicaid Status						
Do you receive Medicaid and/or Medicare? (Check all that apply)						
Source	No	Only Medicaid	Only Medicare	Medicaid and Medicare	Private Insurance	I don't know
Online	24	13	11	10	14	0
AIDSWatch	2	1	2	2	N/A	0
Albany	2	5	0	0	N/A	1
Atlanta	2	3	0	1	N/A	0
Baltimore	2	2	7	1	N/A	1
Bronx	2	10	0	0	N/A	1
Brooklyn	0	3	0	0	N/A	4
Chicago	1	1	2	0	N/A	1
FL/NAPWA	7	4	2	7	N/A	0
Miami Ft Lauderdale	7	10	5	2	N/A	1
Manhattan	0	5	0	1	N/A	1
Minneapolis	0	1	0	1	N/A	2
Palm Sp	0	0	0	0	0	0
Phil AAC	1	0	1	1	N/A	3
Rochester	0	0	0	0	0	0
Mass	N/A	N/A	N/A	N/A	N/A	N/A
TOTAL	50	58	30	26	14	15
%		32.50%	16.80%	15.00%		

Question is interested only in Medicaid /Medicare Status and therefore percentages only tallied for Medicaid, Medicare and Medicare/Medicaid based on total N (178)
 Massachusetts did not ask the question about Medicaid/Medicare Status
 The On-Line Survey was the only source to ask about Private Insurance
 15 respondents did not know their status and are subtracted from the N
 N is 193-15=178

64.3% of African American Women Respondents answering the question and knowing their Medicare/Medicaid status rely on Medicare, Medicaid or both

iv. Hispanic / Latino Respondents

Medicare/Medicaid Status						
Do you receive Medicaid and/or Medicare? (Check all that apply)						
Source	No	Only Medicaid	Only Medicare	Medicaid and Medicare	Private Insurance	I don't know
Online	27	6	11	15	23	1
AIDSWatch	0	2	0	4	N/A	0
Albany	0	2	0	3	N/A	0
Atlanta	1	0	0	0	N/A	0
Baltimore	1	0	0	0	N/A	1
Bronx	3	15	1	2	N/A	1
Brooklyn	0	7	0	3	N/A	0
Chicago	1	2	0	0	N/A	0
FL/NAPWA	1	1	1	2	N/A	1
Miami Ft Lauderdale	6	7	1	2	N/A	3
Manhattan	0	5	0	1	N/A	3
Minneapolis	0	1	2	1	N/A	0
Palm Sp	1	0	0	1	N/A	0
Phil AAC	0	0	0	0	N/A	0
Rochester	0	0	0	0	N/A	0
Mass	N/A	N/A	N/A	N/A	N/A	N/A
TOTAL	41	48	16	34	23	10
%		29.60%	9.90%	21.00%		

Question is interested only in Medicaid /Medicare Status and therefore% only tallied for Medicaid, Medicare and Medicare/Medicaid based on total N (162)

Massachusetts did not ask the question about Medicaid/Medicare Status
 The On-Line Survey was the only source to ask about Private Insurance
 10 respondents did not know their status and are subtracted from the N
 N is 172-10=162

60.5% of Hispanic / Latino Respondents answering the question and knowing their Medicare/Medicaid status rely on Medicare, Medicaid or both

v. Women Respondents

Medicare/Medicaid Status							
Do you receive Medicaid and/or Medicare? (Check all that apply)							
Source	No	Only Medicaid	Only Medicare	Medicaid and Medicare	Private Insurance	I don't know	
Online	51	29	26	35	44	5	190
AIDSWatch	1	3	5	0	N/A	0	9
Albany	3	5	0	1	N/A	0	9
Atlanta	2	3	1	1	N/A	0	7
Baltimore	3	2	7	1	N/A	1	14
Bronx	5	19	0	0	N/A	2	26
Brooklyn	0	9	0	0	N/A	0	9
Chicago	3	1	3	1	N/A	1	9
FL/NAPWA	12	5	3	8	N/A	0	28
Miami Ft Lauderdale	10	13	5	3	N/A	1	32
Manhattan	2	6	0	1	N/A	1	10
Minneapolis	1	3	3	6	N/A	1	14
Palm Sp	0	0	0	0	N/A	0	0
Phil AAC	3	0	1	1	N/A	0	5
Rochester	0	2	0	0	N/A	0	2
Mass	N/A	N/A	N/A	N/A	N/A	N/A	
TOTAL	96	100	54	58	44	12	364
%		28.40%	15.30%	16.50%			

Question is interested only in Medicaid /Medicare Status and therefore percentages only tallied for Medicaid, Medicare and Medicare/Medicaid based on total N (352)
 Massachusetts did not ask the question about Medicaid/Medicare Status
 The On-Line Survey was the only source to ask about Private Insurance
 12 respondents did not know their status and are subtracted from the N

N is 364-12=352

60.2% of Respondents answering the question and knowing their Medicare/Medicaid status rely on Medicare, Medicaid or both

vi. Respondents with an HIV Diagnosis 10 Years or More

Medicare/Medicaid Status						
Do you receive Medicaid and/or Medicare? (Check all that apply)						
Source	No	Only Medicaid	Only Medicare	Medicaid and Medicare	Private Insurance	I don't know
Online	151	41	152	121	144	8
AIDSWatch	9	5	5	9	N/A	0
Albany	3	7	1	4	N/A	0
Atlanta	6	3	5	3	N/A	0
Baltimore	5	2	7	3	N/A	0
Bronx	4	19	1	3	N/A	1
Brooklyn	3	10	1	4	N/A	1
Chicago	9	3	6	6	N/A	1
FL/NAPWA	N/A	N/A	N/A	N/A	N/A	N/A
Miami Ft Lauderdale	2	2	0	0	N/A	0
Manhattan	1	9	0	5	N/A	0
Minneapolis	7	6	12	9	N/A	2
Palm Sp	4	1	8	6	N/A	0
Phil AAC	N/A	N/A	N/A	N/A	N/A	N/A
Rochester	1	2	2	3	N/A	1
Mass	N/A	N/A	N/A	N/A	N/A	N/A
TOTAL	205	110	200	176	144	14
%		13.20%	24%	21.10%		

Question is interested only in Medicaid /Medicare Status and therefore percentages only tallied for Medicaid, Medicare and Medicare/Medicaid based on total N (835)

Massachusetts did not ask the question about Medicaid/Medicare Status

FL/NAPWA, and Phil AA did not sort for this demographic

The On-Line Survey was the only source to ask about Private Insurance

14 respondents did not know their status and are subtracted from the N

N is 849-40=835

58.3% of Respondents diagnosed with HIV for more than 10 years answering the question and knowing their Medicare/Medicaid status rely on Medicare, Medicaid or both

vii. Respondents that are 50 Years and Older

Medicare/Medicaid Status						
Do you receive Medicaid and/or Medicare? (Check all that apply)						
Source	No	Only Medicaid	Only Medicare	Medicaid and Medicare	Private Insurance	I don't know
Online	97	16	106	68	85	6
AIDSWatch	3	3	3	3	N/A	0
Albany	0	3	1	3	N/A	0
Atlanta	3	1	1	2	N/A	0
Baltimore	4	1	5	1	N/A	1
Bronx	3	11	2	4	N/A	2
Brooklyn	2	2	0	2	N/A	1
Chicago	2	2	4	3	N/A	0
FL/NAPWA	5	1	6	8	N/A	1
Miami Ft Lauderdale	6	6	3	4	N/A	1
Manhattan	1	4	0	4	N/A	0
Minneapolis	7	5	3	4	N/A	1
Palm Sp	4	1	8	3	N/A	0
Phil AAC	0	0	3	1	N/A	0
Rochester	0	0	1	1	N/A	1
Mass	N/A	N/A	N/A	N/A	N/A	N/A
TOTAL	137	56	146	111	85	14
%		10.20%	27.30%	20.70%		

Question is interested only in Medicaid /Medicare Status and therefore percentages only tallied for Medicaid, Medicare and Medicare/Medicaid based on total N (1557)
 Massachusetts did not ask the question about Medicaid/Medicare Status
 The On-Line Survey was the only source to ask about Private Insurance
 14 respondents did not know their status and are subtracted from the N
 N is 549-14=535

58.2% of Respondents answering the question and knowing their Medicare/Medicaid status rely on Medicare, Medicaid or both

Summary of findings on Medicare and Medicaid Status for Project Respondents

- African Americans and Latinos/Hispanics have double the utilization of Medicaid “only” in comparison to the overall cumulative population of respondents. The overall utilization of Medicaid “only” is 14.7%. African Americans utilization is 28.5% and Latino/Hispanic is 29.6%
- African American women have the highest utilization of Medicaid and/or Medicare with 63.4% relying on either of both of the programs
- African American women have the highest utilization of Medicaid “only” with 32.5% relying solely on Medicaid.
- Latino/ Hispanic are the lowest utilizers of Medicare “only” with only 9.9% relying on Medicare “only”. The overall cumulative utilization of Medicare “only” is 19.6%.
- African Americans and Women vary slightly from the overall utilization of 19.6% for Medicare only with African Americans at 17% and Women at 15.3%
- People diagnosed with HIV for more than 10 years have a higher use of Medicare “only” with 24% utilization.
- People 50 years of age and older have the highest percentage relying on Medicare only with 27.3%
- People 50 years of age and older have the highest “dual eligible” percentage- 48%

Because Medicaid varies greatly from state to state and Medicare Advantage Programs and programs for dual eligible Medicare/ Medicaid beneficiaries and low income Medicare beneficiaries can vary regionally, we analyzed the data from our respondents regionally. However, running the data on Medicare, Medicaid and Medicare/Medicaid dual eligible beneficiaries regionally has provided no clear trends that can point to any meaningful conclusions. Since no conclusions can be made from this study, we suggest that future projects ask more probing questions about these programs.

B. Ryan White as a source of healthcare payment and source to fill in gaps with Medicare and Medicaid

Most Medicaid and Medicare beneficiaries are aware that their healthcare is provided through these programs because these programs issue cards for beneficiaries. Health care provided through Ryan White funds are often less identifiable to clients. Additionally some programs may use a mix of Ryan White, other federal funding, local and state funding sources. The most identifiable Ryan White medical core service is the AIDS Drug Assistance Program (ADAP). Because it is difficult to identify most Ryan White funded programs by clients, no quantitative data were collected on Ryan White utilization for medical care. Instead, we relied on the qualitative information from our survey’s open ended questions and comments at town halls.

In our town halls and in comments on our survey, our project participants expressed the importance of Ryan White in filling in the gaps in their medical care.

Below are some of the quotes from participants that highlight the successes.

- *When I'm in Orange County I can get to see the Dr. in my Ryan White clinic within a few days if I need to.*
-California
- *I have had HIV/AIDS for half of my life and used many services over the years, although here in Austin Texas I have seen and received the best medical as well as anything to do with services for people living with HIV/AIDS that I have ever experienced.*
-Texas

- *Services have so far been good!*
-Georgia
- *It was touch and go when I moved from Connecticut to Florida in 2004. I finally got into the Ryan White before my Cobra ran out*
-Florida
- *I also receive coverage from Minnesota Comprehensive Health Care, Ryan White funds- it works well.*
-Minnesota
- *Continue ADAP!!*
-Tennessee
- *We are very blessed in Peoria County to have outstanding care.*
-Illinois
- *Keep ADAP your number one priority. Getting us our meds is number one! Funding priorities after that should be regular medical services and then dental services*
- *I have both private and Medicare and it works well.*
-Wisconsin
- *My current HIV clinic and University Dental School HIV clinic are keeping me healthy, and alive. Without them, neither service would be available to me. Both are critical to continue living, and maintaining my quality of life.*
-California
- *Since 1997, the health care I have received in Indiana using Title II dollars to purchase health insurance coverage and to pay deductibles has provided me a level of care not seen in over 47 other states.*
-Indiana
- *I receive help from the county and ADAP pays for my medication's copayments.*
-Georgia
- *I think the ADAP's need to have continued funding as they are a critical piece in maintaining a healthy lifestyle and reducing the risk of transmission by making it possible for people to have access to medications and health care insurance coverage.*
-District of Columbia
- *If it was not for Ryan White the services/assistance I need would not be available. Because of this I am receiving the care and assistance I need that would not be available in this rural area away from large cities. Because of this I have a better quality of life. Thank you.*
-Maryland
- *EVERYONE AND EVERYTHING HAS BEEN GREAT. THANKS AGAIN.*
-Florida
- *ALL OF THE SERVICES THAT I GET AT THIS TIME HELPS ME TO STAY WELL.*
-Virginia
- *I live for the most part a healthy life as direct results of services I receive thank you.*
-Colorado

- *I feel that the health programs for youth here are absolutely an essential part of living with the virus at such a young age*
-New York
- *I think, for me, an educated person, the services I receive from the state and local organizations are quite good.*
-Oregon
- *if i did not have the prescription drug service (ADAP and Medicare), I would not be able to afford to get my medicine to keep me alive.*
-California

Below are some comments from our Town Halls and Surveys that highlight the challenges of navigating a fragmented system with multiple payers (Medicaid, Medicare and Ryan White), and frustrations about the burden this places on people with AIDS.

- *The only problem is navigating the required referral system which is frustrating also can't make appointments outside of the current month.*
-New Jersey
- *Sometimes have to wait up to 3 months to get a doctor's appointment. Sometimes have to wait a couple of weeks to have a prescription refilled because his staff takes their time in authorizing the refill. Medicare covers doctor visits partially, no medications and no dental.*
-Illinois
- *When I first got Medicaid I was unable my ID appointments were all cancelled as my primary physician (assigned through Medicaid) retired and I was unable to get a referral. While I pleaded that my visit be charged then through Ryan White, the clinic informed me they could not do that. It took four months to get this all straightened out.*
-Florida
- *It's very difficult dealing with "Surplus/Spend Down" Medicaid. Periodic trips to the Medicaid Office at times when I was too sick to go out.*
-New York
- *The main issue is that if anything happens on a Friday afternoon, it would be until Monday before I could be seen unless I went straight to the public hospital - which could be an unnecessary amount of public expense and resources.*
-Georgia
- *When ADAP plus disqualified me after having it for many years my PCP dropped me like a hot potato. They were also not very helpful in finding me a doctor who took my private insurance. It all worked out fine, however if I were someone who didn't work in this field and did not know how to advocate, I might not have found new care.*
-New York
- *My cost for seeing a rectal specialist is very low however to see a dermatologist, the cost is very high. Medicare does not explain why this is. Also I have had many problems with ADAP coverage which has delayed my ability to take meds on time.*
-Oregon
- *I have a Medicare Advantage HMO, and my most recent doctor dissolved his practice because of financial reasons. Many new doctors who were in my plan are no longer accepting HMO patients (presumably due to the low reimbursement rate). It took several months to get an appointment with a new doc in my plan. Also, many are not accepting new patients at all.*
-Indiana

- *The Medicare Part D Prescription Drug Plan donut hole has made it extremely difficult for me to get ADAP. During the first two years of that drug plan, I had to pay the \$3000 - \$4000 donut hole and did not receive ADAP. That took all of my life savings. This year ADAP paid once I got close to the donut hole. This leaves me with almost nothing in my Medicare HMO drug plan for 2008. I will most likely go without any medications I need that I don't already get from ADAP until the end of this year.*
-Pennsylvania
- *I have insurance through my employer and am employed FT - am doing fine. Our patients who rely on Ryan White, though, have great difficulty getting access to mental health, AODA, and medical services for things OTHER THAN HIV-related.*
-Tennessee
- *Approval/verification times too long. Need to expedite services to those in need. Shared access to records and applications amongst all agencies to benefit the patient, reducing stress associated with the application process.*
-Connecticut
- *Systems are way too complicated and sometimes think they are poorly managed.*
-Colorado
- *It is very inconvenient for everyone to have to get the Ryan White updated at the BCC Duval health department. It was better for us when we could get it done by our case managers.*
-Florida
- *People at the Medicaid office are inconsiderate and add to my stress level in dealing with my entitlements.*
-Alabama
- *I have been active in HIV/AIDS advocacy since 1984 and think that my familiarity "behind the scenes" may help me to navigate the system more easily.*
-District of Columbia
- *I expect to be covered by Medicare within the next 2-3 months, but I am going to need a supplemental health insurance policy to go along with it. I will need to shop for a policy that offers the most coverage for the cheapest price. Family Services of Bucks County feels that I have too much of an income to receive their services. My yearly disability income is approximately \$27,000... but in view of my debt and expenses, that amount is not very much. Also, I do not want to change any of my doctors (both medical and mental) as they know me and my history very well, and we have good patient/doctor relationships. I like and trust their care.*
-Pennsylvania
- *ADAP benefits & eligibility should not vary by state ...would like to relocate to a less expensive state for housing but often the state I want would not provide ADAP benefits*
-Michigan
- *The financial guidelines to qualify for certain programs, like ADAP, are too low. My meds cost a fortune in co-pay (over \$150 just in co-pay, and psych meds of about \$150 are free due to my being seriously mentally ill - or my co-pays alone would be over \$300/month, plus Medicare premium + secondary premium (now at \$275/mo). Because I receive SSDI and a retirement check (for working over 30 years), I do not qualify for Ryan White funding resources.*
-Washington
- *Although I receive Medicare, I spend 90% of my income on medicine and am told I do not qualify for any assistance.*
-New Jersey

- *The ADAP program in Illinois wants you to have Medicare Part D insurance and Medicare Part D wants you to go through ADAP. The paperwork required to maintain any kind of benefits, even once you are on them, requires a full-time case manager for most individuals and those requiring supplemental food stamps must fill out mountains of paperwork each year and make more photocopies of things already submitted to the State. The whole HIV medicine and benefits systems require you to work full-time at being an advocate for yourself and don't give you time to do anything else.*
-Illinois
- *IT'S VERY DIFFICULT FOR EVERYBODY TO HAVE SERVICES 'CAUSE ALL THE SAME PAPERWORK HAVE TO BE REPEATED HUNDREDS OF TIME. IT'S VERY DIFICULT TO NAVIGATE THE SISTEM. IT'S A LOT OF BUROCRACY. FOR A SICK PERSON THIS IS NOT GOOD TO GO EVERYDAY FROM A PLACE TO ANOTHER, WITHOUT TRANSPORTATION OR BY MYSELF. STOP THIS BUROCRACY.PLEASE!!!!!!*
-Georgia
- *Medicare Part D needs to get rid of the "coverage gap" and keep co-pays at a sensible level. ADAP needs to broaden its scope to include drugs for heart disease.*
-Ohio
- *Medicaid can be difficult to understand or negotiate for person with low literacy*
-Mississippi
- *In order to get Medicaid, I have a "SPEND down" of 1,600/mo. My total Medicaid is 1,686/month. How is this possible to get Medicaid at that amount?*
-State Unknown
- *Specialists who will take Medicaid where I live are becoming very rare. Also, I'm 55 and aging issues are coming up early, having HIV disease for so long.*
-Texas
- *California ADAP requires me to apply for Medi-Cal in order to be granted coverage. Considering Med-Cal does not provide drug coverage for dual-eligibles, such a constraint on services is intolerable and unnecessary*
-California
- *I recently applied for Medi-Cal. It is very difficult to learn how to use the system. The quality of care has left me feeling very uneasy. I have fears that the low-income health care services are going to be detrimental to my health. I am used to private health care treatment, which I am no longer eligible for due to my recent disability. The system scares me.*
-California
- *Due to COLA adjustments to my SSDI, I am no longer eligible for some of the assistance I used to receive. Program income qualifiers need to be tied to the COLA adjustments as well.*
-North Carolina

HIV Medical Care – Medicaid, Medicare and Ryan White Summary of Findings

Currently, Medicaid and Medicare are critical sources of care for people living with HIV/AIDS. Among our project participants 52.4% of our participants relied on these programs for their healthcare. While some of the 47.6% of these individuals that are not in Medicaid or Medicare have private insurance, many rely on other programs to fill the void due to Medicaid and Medicare restrictions such as eligibility based on a disability determination and the added burden of very restrictive means testing for Medicaid that vary from state to state.

It is clear that Ryan White is the federal program that provides much of the needed gap filling. However restrictions on eligibility for Ryan White eligibility vary from jurisdiction to jurisdiction. As one participant from Michigan stated, *“ADAP benefits & eligibility should not vary by state ...would like to relocate to a less expensive state for housing but often the state I want would not provide ADAP benefits.”*

While reliance on Medicaid and Medicare among our project participants did not seem to have significant variance in utilization patterns from region to region, there were distinct patterns of utilization of Medicaid and Medicare within certain demographic groups of our project participants.

African Americans and Latinos/Hispanics have double the utilization of Medicaid “only” in comparison to the overall cumulative population of respondents. The overall utilization of Medicaid “only” is 14.7%. African Americans utilization is 28.5% and Latino/Hispanic is 29.6% African American women have the highest utilization of Medicaid “only” with 32.5% relying solely on Medicaid. People diagnosed with HIV for more than 10 years have a higher use of Medicare “only”, with 24% utilization compared to the overall overage of 19.6%. Project participants that are 50 years of age and older have the highest percentage relying on Medicare only with 27.3%. People 50 years of age and older have the highest “dual eligible” percentage- 48% compared to 37.7% overall.

Project participants commented often about the gaps that need to be filled and the importance of Ryan White in filling these gaps.

Through many comments made at the town halls and on our surveys it seems clear that often these programs do not operate seamlessly. Due to varying eligibility requirements and the different documentation to verify eligibility for each program the patchwork of Medicaid, Medicare, Ryan White and other funding (local and state) is a cumbersome system that is difficult to navigate. One participant from Mississippi stated *“Medicaid can be difficult to understand or negotiate for person with low literacy”*.

From many of the comments made, the Medicare Part D prescription drug plan has added confusion.

There were also many comments about how difficult the health care system is for people who are working poor, who often are not making enough to be insured but not poor enough to qualify for publicly funded programs.

While this report cannot say definitively that this cumbersome system of care acts as a barrier to care, it is worth considering. What it does illustrate is that because there is so much paper work, so much documentation needed, different eligibility criteria for Medicare, Medicaid, Ryan White and other programs providing care, many of our project’s participants need help navigating the complexities of the system, a robust case management and benefits counseling is a priority for PLWHAs.

The complexity of this system should also be considered when looking at developing a National AIDS Strategy and when looking at models for healthcare reform.

6. Support Services

a. Services Important to Accessing and Maintaining Care

Through our town hall meetings, comments made on our surveys and a specific question in our survey, we asked project participants to identify the services that help them access medical care and maintenance in medical care. Since approximately 94% of our project participants are currently in care (defined as seeing a primary care provider within the past 6 months) their input on the services that are important to their continued ability to be in care is quite valuable.

This section will look at the results of the 1) survey question 2) results from the town hall meetings and 3) comments from project participants

i. Survey Question

The survey asked respondents to rate the following question on a scale from "1" to "5" (with "1" being "not important" and "5" being "very important").

“Which services have made a difference in your ability to start receiving primary medical care and to continue receiving that care?”

The top six responses from each survey are reported below. Please note that when two services received the same rating they were ranked the same and additional services were added to ensure there were rankings of 1, 2, 3, 4, 5 and 6

The Online results are reported in aggregate and were also sorted by region in order to provide more textured data.

Online - National (n= 968)

1. ADAP-Rx Assist	4.69
2. Health Insurance Assistance	4.59
3. Dental Care	4.42
4. Housing Subsidy	4.38
5. Mental Health Services	4.32
6. Housing/Finding Housing	4.27

a. Online- South (AL, MS, LA, AR, GA, FL, SC, NC, TN, TX, OK, KY, PR) (n= 250)

1. ADAP- Rx Assist	4.69
2. Health Insurance Assistance	4.68
3. Dental Care	4.53
4. <i>Housing Subsidy</i>	4.48
4. <i>Emergency Financial Assistance</i>	4.48
5. Mental Health Services	4.42
6. Housing/ Finding Housing	4.32

**b. Online- Northeast (NY, NJ, PA, CT, RI, MA, VT, ME, NH)
(n=182)**

1. Health Insurance Assistance	4.70
2. Housing Subsidy	4.58
3. Housing/Finding Housing	4.52
4. ADAP- Rx Assist	4.52
5. Dental Care	4.39
6. Mental Health Services	4.31

**c. Online- Mid Atlantic- (WV, VA, MD, DE, DC)
(n=75)**

1. ADAP- Rx Assist	4.81
2. Emergency Financial Assistance	4.71
3. Housing Subsidy	4.63
4. Transportation Services	4.62
5. Food Services/ Meal Services	4.61
6. Mental Health Services	4.48

**d. Online- Midwest (ND, SD, NE, KS,OK, MN, IA, MO, WI, IL, IN, OH)
(n=134)**

1. ADAP- Rx Assist	4.66
2. Health Insurance Assistance	4.56
3. Dental Care	4.38
4. Housing Subsidy	4.30
5. Mental Health Services	4.28
6. Housing/Finding Housing	4.20

**e. Online- Mountain (NM, AZ, ID, UT, CO, WY, MT)
(n=53)**

1. Dental Care	4.59
2. ADAP- Rx Assist	4.43
3. Health Insurance Assistance	4.29
4. Peer Support Services	4.26
5. Mental Health Services	4.18
6. Nutrition/ Dietician Counseling Education	4.00

**f. Online- West / Pacific (CA, WA, OR,NV,HI, AK)
(n=276)**

1. ADAP- Rx Assist	4.82
2. Health Insurance Assistance	4.53
3. Dental Care	4.35
4. Housing Subsidy	4.28
5. Mental Health Services	4.27
6. Housing/Finding Housing	4.15

Regional Meetings:

Bronx NY

1. Case Management	4.50
2. Housing Subsidy	4.41
3. Dental Care	4.28
4. Housing/Finding Housing	4.25
5. Food/Meal Services	4.22
6. Mental Health Services	4.20

Brooklyn NY

1. Health Insurance Assistance	4.63
2. Case Management	4.58
3. Food/Meal Services	4.44
4. Housing/Finding	4.35
5. Housing Subsidy	4.33
6. Nutrition/Dietician Counseling/Education	4.27

Albany NY

1. ADAP-Rx Assist	4.46
2. <i>Transportation Services</i>	4.36
2. <i>Health Insurance Assistance</i>	4.36
3. Peer Support Services	4.23
4. Mental Health Services	4.13
5. Child Care	3.90
6. Housing Subsidy	3.89

Baltimore MD

1. Case Management	4.64
2. Peer Support	4.53
3. <i>Dental Care</i>	4.52
3. <i>Health Insurance Assistance</i>	4.52
4. ADAP-Rx Assist	4.50
5. Emergency Financial Assistance	4.14
6. Housing Subsidy	4.05

Florida Regional

1. ADAP-Rx Assist	4.66
2. Case Management	4.65
3. Emergency Financial Assistance	4.56
4. Housing Subsidy	4.54
5. Peer Support Services	4.49
6. <i>Nutrition/Dietician Counseling/Education</i>	4.47
6. <i>Dental Care</i>	4.47

Manhattan NY

1. ADAP-Rx Assist	4.60
2. Food/Meal Services	4.42
3. Mental Health Services	4.40
4. Emergency Financial Assistance	4.39
5. Housing/Finding Housing	4.35
6. Peer Support Services	4.33

Minneapolis MN

1. Health Insurance Assistance	4.82
2. ADAP-Rx Assist	4.79
3. Emergency Financial Assistance	4.69
4. Transportation Services	4.54
5. <i>Housing Subsidy</i>	4.50
5. <i>Case Management</i>	4.50
6. Housing/Finding Housing	4.46

Rochester NY

1. Dental Care	4.55
2. Case Management	4.50
3. Health Insurance Assistance	4.40
4. Transportation Services	4.30
5. Emergency Financial Assistance	4.38
6. Peer Support Services	4.11

Philadelphia Conference on African Americans and AIDS

1. ADAP-Rx Assist	4.60
2. Case Management	4.50
3. Peer Support	4.38
4. Health Insurance Assistance	3.67
5. <i>Child Care</i>	3.50
5. <i>Dental Care</i>	3.50
6. Substance Abuse Treatment	3.43

AIDSWatch

1. ADAP-Rx Assist	4.95
2. Housing Subsidy	4.94
3. Housing/Finding Housing	4.80
4. Food/Meal	4.75
5. Substance Abuse Treatment	4.70
6. Transportation Services	4.69

Chicago IL

1. Transportation Services	4.81
2. Housing/Finding Housing	4.80
3. Emergency Financial	4.76
4. Housing Subsidy	4.70
5. Substance Abuse Treatment	4.52
6. Food/Meal Services	4.50

Palm Springs CA

1. ADAP-Rx Assist	5.00
2. Dental Care	4.55
3. Case Management	4.48
4. Health Insurance Assistance	4.40
5. Mental Health	4.36
6. Peer Support Services	4.29

Massachusetts

1. Health Insurance Assistance	4.66
2. Housing Subsidy	4.55
3. ADAP-Rx Assist	4.54
4. <i>Peer Support Services</i>	4.52
4. <i>Emergency Financial Assistance</i>	4.52
5. Transportation Services	4.49
6. Dental Care	4.48

Atlanta GA

1. Dental Care	4.89
2. ADAP- Rx Assist	4.68
3. Case Management	4.67
4. Mental Health Services	4.44
5. Emergency Financial Assistance	4.35
6. Health Insurance Assistance	4.20

Miami / Ft Lauderdale FL

1. Health Insurance Assistance	4.70
2. Case Management	4.60
3. Mental Health Services	4.58
4. Dental Care	4.53
5. Housing Subsidy	4.52
5. Peer Support Services	4.52
5. Transportation Services	4.52
6. Housing/ Finding Housing	4.42

1. Housing: The most common service identified as making a difference in one's ability to start receiving primary medical care and to continue receiving that care was housing. Housing subsidy, housing information and/or both was identified in 11 of the 15 community meetings and nationally online and in 4 of 5 regions online (only the Mountain Region – which has the smallest n- did not identify a housing related service among the top 6..
2. ADAP-RX Assistance was identified in 10 out of 15 community meetings, nationally and in all regions on line.
3. Health insurance Assistance was identified in 10 of 15 community meetings, nationally and in all regions on line
4. Dental Care was identified in 9 of 15 community meetings, nationally and in 4 of 5 regions (only the Mid-Atlantic Region did not identify dental care among the top 6) online.
5. Case Management was identified in 10 of 15 community meetings but did not make it to the top 6 in the national data or the regional data on line

6. Peer Support was identified in 9 of 15 community meetings and in the Mountain region on line.
7. Transportation was identified in 7 of 15 community meetings and in the Mountain region online. While transportation made it to the top six in 7 of the 15 community meetings and in the Mountain region. It is striking that this service rose to the top in town hall meetings that were held in areas where public transportation is limited—Albany, Rochester, Minneapolis, and Massachusetts (a statewide meeting that drew from all corners of the state). AIDSWatch and Chicago, Fort Lauderdale/ Miami and the Mountain Region on line also identified transportation as one of the most important services to keep individuals in healthcare.

ii. Community Meeting Feedback⁵

During the conversations that took place at town halls, three of these events- Chicago, Baltimore and Minneapolis- specifically asked the question:

What support services are important to your ability to access and stay in care?

Below are the list of services that were identified in each of these three meetings.

1. Chicago

1. Access to medical care and drugs
2. Access to psychosocial service, training programs to re-enter the work force, need skills building for those living with HIV (job related)
3. Lake County doesn't have transportation to access services
4. Need information specialist to know how to navigate the system
5. Case Management
6. More Transportation supported is needed
7. Mental Health
8. Food Services
9. Alternative Therapies

2. Baltimore

1. Housing
2. Transportation
3. Case management
4. Emergency financial assistance
5. Child care
6. Legal services
7. Pharmacy assistance
8. Food assistance
9. Mental health services
10. Dental programs
11. Substance abuse treatment services
12. Peer advocacy programs (funded/paid peer-advocates-not volunteer)
13. Outreach programs (traditional and non-traditional)
14. Buddy companion programs
15. Life insurance (financially affordable)
16. Support groups/retreats

⁵ All community meetings had time for conversation about unmet critical services and unmet need but most community meetings did not supply a detailed report and instead used the surveys that were distributed as their method of reporting. Palm Springs CA did supply a report but its format was different than those in Chicago, Minneapolis and Baltimore. The complete reports from all four of these meetings are found in the Appendix.

17. Language interpretation services
18. American Sign Language interpretation services
19. Assistance for visually-impaired
20. Funding for ADAP (treatment)

3. Minneapolis

1. Substance Abuse Services
2. HERR Health Education and Risk Reduction Activities
3. Family Counseling
4. Benefits Counseling
5. Bus Cards (Transportation)
6. Meals
7. Daycare for work and school / med appts.
8. Transportation
9. Peer Support
10. Case Management
11. Info & Referral/Resources
12. Health Care must be a given
13. Outreach Services
14. Support services needed not just to access Med Care but to survive/live well

iii. Comments from Project Participants

Below are some comments from project participants about the services that are important in keeping them in care.

Dental treatment and help with housing are important.

-Maryland

Housing is the biggest issue in San Francisco. It took me almost 10 years to get a subsidy & it is hard to find landlords who will take it.

-California

Same age (peer) support groups are vital.

-New York

I need and get para-transportation

-Florida

Housing subsidies and food are extremely important to me.

-Washington

While I am not accessing services anymore, it was due to the excellent services I received when I was ill/newly diagnosed that I am self reliant and working now. These services included case management, support group, emergency financial assistance, and meal delivery

-Minnesota

The most important thing to me is having health coverage and drug assistance all the rest will fall into place

-Washington

Help with medications has been extremely helpful! Also, access to a dentist has been helpful.

-Georgia

I would not be in medical care and taking my medication if not for Peer Support Services.

-Colorado

Ryan White funded services have allowed me to stay in care. I am concerned with this goes away what will happen to the services I receive.

-Vermont

In my state if you have EVER been convicted of a drug charge you do not ever qualify for food stamp assistance...therefore... food assistance is VERY important to me

-Arizona

Non-medical services often help me stay connected to medical services. Cuts to non medical services will make it harder for me to access medical services.

-Michigan

If it was not for Ryan White the services/assistance I need would not be available. Because of this I am receiving the care and assistance I need that would not be available in this rural area away from large cities. Because of this I have a better quality of life. Thank you.

-Maryland

Overall the level of care that I receive in my hometown is very good.

-Texas

Thank God for my Housing

-Alabama

HOUSING SUBSIDY AND FOOD ARE ESSENTIAL

-Oregon

It works mostly. I 'should' be dead- but I am alive well.

-Nevada

The services I receive have helped me go back to work full time.

-Arizona

Without ADAP paying for approx. \$1700. a month in Meds, I would be dead

-Connecticut

Currently am not Ryan White eligible due to my income, but have utilized Ryan White services in the past and must say that the ADAP and health insurance access services were the two most valuable services I accessed.

-Wisconsin

The qualitative and quantitative data demonstrate the regional and individual variability of need for support services. The Ryan White Care Act and other healthcare provision programs should provide a mechanism for service tailoring on the individual level. Patient adherence is contingent upon each person's ability to manage their treatment program as prescribed. Where certain services emerge as essential for patient adherence; there should be a mechanism to respond to that that individual need.

Future research efforts must understand patient level need much better. The availability of antiretroviral therapy (ART) requires some investment in quality management. The current system matches the patient to ART that is non-resistant to their current virus, without support for mitigated potential barriers to adherence caused by non-treatment or care related issues. We need to better understand how much of a role support services have on patient success. With less desirable health outcomes being reported by minority communities, this is an urgent question to answer.

Clearly housing seems a very critical factor in stabilizing people's lives in order to be successful in maintaining healthcare. Because housing is such a priority, the issue will be addressed separately in chapter 7.

b. Unmet Service Needs

We asked people about “unmet” needs- services that are difficult to obtain or that are unavailable.

Through our town hall meetings, comments made on our surveys and a specific question in our survey, we asked project participants to identify unmet service needs 94% of our project participants are currently in care (defined as seeing a primary care provider within the past 6 months) their input on the services that are important to their continued ability to be in care is quite valuable.

This section will look at the results of the 1) survey question 2) results from the town hall meetings and 3) comments from project participants

i. Survey Question

Respondents were asked for to indicate how available a needed service is and given the choice

- a) “I use this service and never have to wait more than 30 days”
- b) “I use this service but in some cases (less than 50% of the time) have to wait more than 30 days”
- c) “I use this service but I often (more than 50% of the time) have to wait more than 30 days.”
- d) “I use this service and always have to wait more than 30 days.
- e) “I need this service but cannot get it”
- f) “I do not use this service”

The results below indicate the services report the “I need this service but cannot get it” in order of the least available first through the fifth least available last. Respondents that answered “I do not use this service” were not factored in.

Please note that a percentage number may be different for the same number of respondents indicating that this service is unavailable due to varying numbers of respondents answering the question about the specific services.

Online

- | | |
|-----------------------------------|-------------|
| 1. Emergency Financial Assistance | 20.2% (184) |
| 2. Dental Care | 18.3% (169) |
| 3. Housing Subsidy | 18.6% (168) |
| 4. Health Insurance Assistance | 15.6% (143) |
| 5. Peer Support Services | 13.5% (123) |

a. Online- South (AL, MS, LA, AR, GA, FL, SC, NC, TN, TX, OK, KY, PR)

- | | |
|-----------------------------------|------------|
| 1. Emergency Financial Assistance | 23.8% (55) |
| 2. Health Insurance Assistance | 22.0% (51) |
| 3. Dental Care | 21.3% (49) |
| 4. Peer Support Services | 19.6% (44) |
| 5. Housing Subsidy | 19.5% (44) |

b. Online- Northeast (NY, NJ, PA, CT, RI, MA, VT, ME, NH)

- | | |
|-----------------------------------|------------|
| 1. Housing Subsidy | 21.8% (37) |
| 2. Emergency Financial Assistance | 21.7% (37) |
| 3. Dental Care | 16.8% (30) |
| 4. Food / Meal Services | 13.6% (24) |
| 5. Housing / Finding Housing | 13.1% (23) |

c. Online- Mid Atlantic- (WV, VA, MD, DE, DC)

1. Dental Care	25.4% (17)
2. <i>Health Insurance Assistance</i>	14.1% (9)
2. <i>Housing Subsidy</i>	14.1% (9)
3. Peer Support Services	12.5% (8)
4. Emergency Financial Assistance	12.3% (8)
5. Nutrition/ Dietician Counseling	10.9%(7)

d. Online- Midwest (ND, SD, NE, KS,OK, MN, IA, MO, WI, IL, IN, OH)

1. Emergency Financial Assistance	21.1% (28)
2. Dental Care	14.2% (19)
3. Health Insurance Assistance	14.0% (18)
4. Peer Support Services	13.6% (18)
5. Housing Subsidy	13.0% (17)

e. Online- Mountain (NM, AZ, ID, UT, CO, WY, MT)

1. Emergency Financial Assistance	32.3% (10)
2. Housing Subsidy	22.0% (9)
3. Health Insurance Assistance	20.9% (9)
3. Peer Support Services	20.9% (9)
4. Dental Care	19.0% (8)
5. Transportation Services	14.0% (6)

f. Online- West / Pacific (CA, WA, OR,NV,HI, AK)

1. Housing Subsidy	20.4% (54)
2. Emergency Financial Assistance	17.9% (47)
3. Dental Care	17.5% (47)
4. Health Insurance Assistance	13.8% (37)
5. Housing/ Finding Housing	13.0% (34)

Regional Meetings

Bronx NY

1. Housing Subsidy	27.9% (12)
2. Housing/Finding	21.2% (11)
3. <i>Health Insurance Assistance</i>	11.5% (6)
3. <i>Food/Meal Services</i>	11.5% (6)
4. Transportation Services	11.1% (6)
5. Dental Care	9.8% (5)

Brooklyn NY

1. Emergency Financial Assistance	14.8% (4)
2. Housing Subsidy	8.0% (2)
3. Dental Care	6.5% (2)
4. Peer Support Services	4.2% (1)
5. Child Care	4.0% (1)

Albany NY

1. Dental Care	18.8% (3)
2. Translation/Interpretive Services	13.3% (2)
3. Housing Subsidy	13.3% (2)
4. Transportation Services	12.5% (2)
5. <i>Housing/Finding Housing</i>	7.1% (1)
5. <i>Health Insurance Assistance</i>	7.1% (1)

Baltimore NY

1. Dental Care	17.9% (5)
2. Peer Support Services	16.7% (4)
3. ADAP-Rx Assist	16.0% (4)
4. Mental Health Services	13.0% (3)
5. Child Care	11.1% (2)

Florida Regional

1. Housing Subsidy	28.6% (16)
2. Emergency Financial Assistance	23.7% (14)
3. Peer Support Services	23.3% (14)
4. Nutrition/Dietician	19.0% (12)
5. Housing/ Finding Housing	19.0% (11)

Manhattan NY

1. Emergency Financial Assistance	21.1% (4)
2. Dental Care	19.0% (4)
3. Housing Subsidy	11.8% (2)
4. Housing/Finding Housing	10.0% (2)
5. Mental Health Services	4.5% (1)

Minneapolis

1. Housing Subsidy	13.6% (6)
2. Housing/Finding Housing	11.6% (5)
3. Peer Support Services	11.1% (5)
4. Emergency Financial Assistance	10.4% (5)
5. Dental Care	8.2% (4)

Rochester NY

1. Child Care	11.1% (1)
2. Housing/Finding Housing	10.0% (1)
3. Mental Health Services	10.0% (1)
4. Health Insurance Assistance	10.0% (1)
5. <i>Dental Care</i>	10.0% (1)
5. <i>Mental Health Services</i>	10.0% (1)

Philadelphia Conference on African Americans and AIDS

1. Mental Health Services	33.3% (4)
2. Nutrition / Dietician	25.0% (3)
3. Housing / Finding Housing	18.2% (2)
4. <i>Emergency Financial Assistance</i>	16.7% (2)
4. <i>Food / Meal Service</i>	16.7% (2)
5. Peer Support Services	14.3% (2)

AIDSWatch

1. Housing Subsidy	20.6% (7)
2. Housing / Finding Housing	14.7% (5)
3. Transportation Services	14.3% (5)
4. Emergency Financial Assistance	11.4% (4)
5. Food/Meal Services	5.9% (2)

Chicago IL

1. Health Insurance Assistance	17.3% (4)
2. <i>Housing Subsidy</i>	13.6% (3)
2. <i>Housing/Finding Housing</i>	13.6% (3)
3. Emergency Financial Assistance	12.5% (3)
4. Transportation Services	11.1% (3)
5. Dental Care	10.0% (3)

Palm Springs CA

1. Dental Care	33.3% (9)
2. Nutrition/ Dietician	30.8% (8)
3. <i>Peer Support Services</i>	28.0% (7)
3. <i>Health Insurance Assistance</i>	28.0% (7)
4. Transportation Services	19.2% (5)
5. <i>Housing Subsidy</i>	22.2% (6)
5. <i>Mental Health Services</i>	22.2% (6)
5. <i>Emergency Financial Assistance</i>	22.2% (6)

Massachusetts

1. Emergency Financial Assistance	15.3% (21)
2. Housing Subsidy	14.2% (19)
3. Housing/Finding Housing	13.4% (18)
4. Transportation Services	10.9% (15)
5. Peer Support Services	7.3% (10)

Atlanta GA

1. Dental Services	34.5% (10)
2. Health Insurance Assistance	29.2% (7)
3. Housing Subsidy	28.6% (6)
4. Emergency Financial Assistance	20.8% (5)
5. Housing/ Finding Housing	18.2% (4)

Miami / Ft. Lauderdale

1. Housing Subsidy	36.1% (13)
2. Housing / Finding Housing	35.0% (14)
3. Emergency Financial Assistance	28.9% (11)
4. Food Meal Services	25.7% (9)
5. Nutrition / Dietician Counseling	23.5% (8)

Trends in Unmet Needs

The survey asked questions about services that are currently fundable through Ryan White.

A few trends are clear from this very preliminary data that merit further exploration.

Housing: The availability of housing subsidies or assistance with locating housing is an unmet need in 15 of the 16 community meetings, nationally through our on-line survey and in every region of the nation through our on-line survey and is clearly the most critical unmet need through our surveys of project participants

Dental: Dental services appear in 12 of 16 community meetings, nationally through our on-line survey and in every region of the nation through our on-line survey. An interesting note is that the only community meetings were regional, statewide or national- the FL Region meeting, the Massachusetts statewide meeting, AIDSWatch and the National Philadelphia Conference on African Americans and AIDS. While no conclusion can be made about why these events were the only data sources that did not list Dental Care as an unmet need, it is worth noting because this is the only anomaly found when looking at this information. Clearly, dental services are a high unmet need among the surveys of our project participants

ii. Community Meeting Feedback

The community meetings in Baltimore MD, Chicago IL and Minneapolis MN asked the question- **What services and support does not currently exist that you would like to see available for people living with HIV/AIDS?**

The results of the conversation that resulted from this question at these three meetings are reported below. Participants at the meetings were not limited to discussing Ryan White funded programs .

1. Baltimore

- Employment training
- Better coordination of and education about disability determination
- Support groups
- Extend Americans with Disabilities Act protections so that deaf PLWHA could have equal access to HIV/AIDS programs and services
- Life insurance
- Fast track for eligibility determination for HIV services
- Expanded funding for HOPWA
- Officials in all branches of government need to work to reduce stigma and improve quality-of-life for PLWHA
- A single, universal application for all HIV/AIDS programs
- Guaranteed local telephone service access for acutely ill persons
- Universal healthcare
- Auto-renewal for HIV/AIDS services
- Eliminate or streamline recertification process for HIV status qualification
- Government think tank for an HIV cure
- Continued consumer presence in planning/evaluation of HIV/AIDS services

2. Minneapolis

- Peer support and clinics
- Funding for education
- HIV service employment for PLWH
- Seamless insurance / benefits
- Continuation
- Medicare / Medical / Program HH private
- One System
- Support for volunteers
- Prevention in CD
- Substance Abuse Prevention
- Education-HIV Testing

3. Chicago

- Need increased access to fair market housing, subsidized housing in new developments where a portion of housing is for HIV/AIDS and disabled.
- Need to develop more outreach to men who have sex with men
- Rapid mobilization unit where numbers of HIV infections are rising
- Need crisis managers
- Understanding lab work
- Need for more compassionate case managers
- Complementary therapies need to be brought back
- Support for a inclusive speakers bureau to go into communities to help break down stigma
- More services for people living with HIV- expanded eligibility
- More services on the south and west side for women living with HIV

iii. Comments from Project Participants

Below are comments below regarding unmet need from our participants across the country

Housing

North Carolina

I need family therapy services. I have a 13 year

New York

Life Insurance

Pennsylvania

Financial assistance is important, but hard to find. It is very difficult to live on SSDI alone

Texas

I would like to see more housing options and a faster turnover rate

Connecticut

I went to the dentist to have work done on my teeth, but was not able to pay the out of pocket expense. Therefore, I have not been back.

Louisiana

Alternative assistance with health food, vitamins, acupuncture.

California

Housing support is critical.

Massachusetts

Transportation-gas vouchers for people with cars

Florida

Please restore access to alternative therapies

Illinois

More affordable housing is needed for people living with HIV/AIDS.

Georgia

Housing/Housing subsidy waiting list can take up to 2 years to have significant movement

California

In this state or all across the states funding has become a serious problem that had directly impacted families regarding food vouchers(every six months, shortage of food in the food bank) when a client has a financial emergency, loss of food stamps a \$50 food voucher is gives and this is the same for a single person and a family. With the rising cost of food prices that amount doesn't get you much.

Massachusetts

There needs to be more programs of support (not group support) More assistant programs like a food program and other programs offer financial assistants, patient advocates are need here as well .

Arkansas

Life insurance

Washington

It takes so long to get an appointment to see the dentist. I realize that they are over loaded doing the scheduling. And the funds are limited. Some of the work that I need done won't get done because there is not enough funds for me to have the service (a cap for a root canal that was done 3 years ago) done. Something is always omitted from my care list. And it frustrating because these are the services that I have a need for, not what I want

Florida

I need dental treatment and I need help with housing.

Michigan

There need to be more support groups for HIV/AIDS patients especially when you have mental health issues. Most of us do. Just learning how to deal with disease is hard and then the prejudice that comes with it. When your depressed it hard to keep up your health.

-New Jersey

Transportation assistance would be very helpful, I wish my parents would receive something for providing me with housing for the past 13 years

Iowa

There are NO ASO's within 150 miles of our home. There is was NO information given or discussed about the side-effects of medications, and the health / mental implications of contracting the virus in-utero.

West Virginia

Transportation, including the cost of gas, is a huge problem.

Mississippi

Desperately need dental work but unable to afford. I have lost 2 teeth and am ready to lose third and feel very uncomfortable and embarrassed about gaps in teeth.

Georgia

Rural West Texas has NO HIV/AIDS services. Nearest services are 75miles and getting there is difficult. In Boulder there is only one place to go to get HIV care. They require that you get you other medical care elsewhere. When I went to see a doctor that the HIV clinic recommended, I was prescribed a drug that had adverse reactions when taken with my HIV medications. Now I go all the way to Denver (one hour each way) so that I can get comprehensive care.

Colorado

There are no free or low-cost good dental services in Alameda county for a single female. The healthcare for HIV/AIDS patients is severely lacking in the US

California

More faith-based community support for HIV/AIDS individuals

Indiana

Dental help.

Illinois

There are huge barriers to dental care and urgent care services

Texas

There needs to be more programs of support (not group support. More assistant programs like a food program and other programs offer financial assistance, patient advocates are need here as well

South Carolina

Through an adoption subsidy in NY I was given Medicaid until I reached 21 we relocated to NC this year and they will not accept the agreement i will no longer have Medicaid after June 30, 2008 parents are scrambling

North Carolina

Transportation services and more food assistance would be very helpful

Arkansas

One stop shop method is a lot more preferable than traveling all over town trying to get help and services.

California

Need Housing assistance very bad! I really die than have to ask a family member can I stay with them until my section eight open up or HOPWA open up.

Ohio

Need help paying my rent, and have a decent place to stay where I can take my Meds. everyday on time!

Alabama

Hormone therapy for transgender people and Medicaid also even if the person is not positive

New York

I feel there should be job assistance in addition to the positive care and assistance that I receive.

Georgia

Cultural Competency, Spiritual Healing, Language, Native American Case Managers, Social Workers, Physicians.

New Mexico

Finding an apartment that accepts HOPWA, no, credit check, and no criminal background check for Felony Revoked DL/DUI

Florida

Find a way to help addicts find a healthy way to get on with life. We battle the feeling of no energy as long as possible, but from what I've seen most end up going back to street drugs, why? Because they can get them, knowing that there are other drugs that could help in this battle but due to red-tape, or laws, or just personal belief system of their doctors they cannot get these drugs. It's crazy that policies make far more criminals than communities.

Iowa

I travel over 100 miles round trip. I live where I can afford but cannot get on the section 8 waiting list for San Bernardino county as the list is closed. I have had to cancel appointments due to transportation problems

California

I need Dental Care and Pain Management

Louisiana

We need a stronger return to work program

Oregon

I live in Tupelo Miss. But I CHOOSE to drive 100 miles to Memphis Tn. for medical care....Reason, the un-professional actions of local care-givers. I know all about HIPA and such, but that still doesn't keep tongues from wagging in this small town.

Mississippi

There needs to be greater housing and transportation assistance in my county. Even if I chose to see a local doctor, it is still a 110 mile round trip for me. I also, unfortunately, live in an extremely high-cost area, even though it is rural in nature, and housing assistance is desperately needed.

Wisconsin

Florida

There is a need for support group that are sensitive to different ethnic groups.

Texas

I'm on waiting list for subsidy funding was told it's a 15 month waiting for people with aids.

Pennsylvania

These following items apply especially to the people who DO NOT live in a major city. Living in outlying areas is a HUGE drawback and disadvantage. COMPLETE Nutrition services, Eye care and Dental care. Transportation assistance for doctor visits, support services and Holistic services. Access to free or much cheaper Nutritional Supplements. HIV/AIDS exercise programs (low cost or free). REAL incentives to help clients go back to work. There are none now. If you make an extra \$10, everyone wants a piece of that money. Your fuel assistance goes down, food stamps go down, your Health Insurance Premium goes up and your rent goes up. Even stipend income works against you now. WHY would anyone want to go back to work? Let's take an accurate look at the cost of living and consider EVERYTHING that works against people on disability. Some HIV friendly work environments would be huge too.

Massachusetts

Everything is very far away from me. I drive an hour (one way) for every doctor's visit, not everyone is able to work to afford a car and gas.

Maryland

I need job counseling

New Jersey

I need food, rental assistance but it's impossible in Pensacola to get help if you have no transportation... I even have to miss doctors appt because i can't there for the pre visit blood work or visit. They say I don't qualify for food assistance because other people can fix for me...but I fix for myself and buy for myself... I get \$10 in food stamps a month and that's it. I have even begged the local places for just some dried milk and they won't even do that.

Florida

Additional support services are needed to address the social isolation associated with having HIV disease. The lack of interaction opportunities definitely affects my mental health. Feeling alone and diseased only increases the affect of depression and low self-esteem.

Oregon

How about a MD knows Native American Culture

New York

Dental, Dental, Dental. We need to build capacity and find funding. It's a shame that we do not make a clear link between health care and dental care. I believe this to be a systemic problem throughout the health care field.

Maine

Return to work issues and vocational rehabilitation are essential and would help me get off public benefits.

Missouri

I have to travel 212 miles, each way, to receive competent medical care. Rural ASO's have no funding for transportation for their clients. I am a NAPWA member, and will always work towards equitable treatment for all HIV positive individuals!

Georgia

I will need a place to live when my rent goes up in a few months. At present, I am spending 95% of my income on rent.

Illinois

This information does urge the HIV/AIDS community to look more closely at the role of significant support services in the treatment success of people living with HIV/AIDS. With the majority of ART being orally consumed and better tolerated when taken with food, limited access to equitable dental and nutrition services cannot continue to be overlooked. Certainly the entire country is plagued with a housing crisis, and people living with HIV/AIDS are managing a double-dilemma, lacking basic hygiene needs and sacrificing their medical needs. The next chapter of this report will examine some specific data on the crucial issue of housing.

Transportation is a key issue, especially in rural areas. A difficult or non-existent public transportation system and/or the personal expense involved can make accessing care a barrier and is clearly a need that isn't being met very well by many people who participated in our project.

Issues of culturally sensitive programs, family programs, programs aimed at lessening social isolation, employment and vocational rehabilitation services, peer support, support for addicts, services for ex-offenders, food and nutrition services are among the services that have been identified as important services that help people living with HIV/AIDS have better stability in their lives thus making adherence to treatment and maintaining primary care more successful. However our project participants often identified these programs as an unmet need.

**Support Services
Services Important to Accessing and Maintaining Care
And
Unmet Need
Summary of Findings**

There can be no doubt from any of the data we have collected, the information from our town halls or the poignant comments made by our project participants that support services are critical to successfully maintaining a healthier life through treatment adherence and ongoing medical care.

It is essential that a mechanism for service tailoring on the individual level exists. Patient adherence to treatment is contingent upon each person's ability to manage their treatment program as prescribed. Where certain services emerge as essential for patient adherence; there should be a mechanism to respond to that individual need.

Medical support services such as ADAP, Mental Health Services, Health Insurance Assistance, Substance Use Services and Dental Services are all critical to providing healthcare to the people we talked to, and are essential partners to primary medical care for people living with HIV/AIDS. Dental care is the highest unmet needs in medical support services for our project participants.

Social services are essential as well. Many of these services provide a lifeline and stabilize people's lives so accessing medical care is possible. There is a broad array of social services that are important to the people we spoke to and without these services many would have fallen through the cracks and would not be in care.

Among these social support services housing and transportation are among the most often identified as essential and sadly, are also cited among the highest unmet need.

For the participants in our project social services were as essential to their healthcare as were medical support services. The fabric of social and medical needs is woven together and is inextricably linked.

It is clear that each individual has specific needs that are critical to his/her own ability to have a healthy life living with HIV/AIDS. But the service needs have patterns locally, regionally and nationally.

Ryan White is an essential component of providing both the needed medical support services and the social support services critical to the healthcare of people living with HIV/AIDS. The Ryan White model of local community planning attempts to address the need for these programs in a way that is responsive to the particular needs of the local community.

As we address the development of a National AIDS Strategy, national healthcare reform and the future of Ryan White, our report indicates that wrap around health support and social support services are essential for people living with HIV/AIDS and because they add to treatment adherence and continued medical care, they are likely to result in more positive health outcomes.

7. Housing

Because Housing was identified as such an important issue for people living with HIV/AIDS and was also cited as one of the highest unmet needs, we think it is important to look at some additional statistics on housing that support the need to highlight this very important topic.

For a person living with AIDS, homelessness or even the threat of homelessness, can lead to unnecessary illness and premature death. For many with HIV/AIDS, permanent housing is the difference in having access to medication, to stability, and, ultimately, re-entry into the labor market. Pure and simple: Housing equals healthcare and health for People Living with HIV/AIDS.

We asked our project participants about their current housing status. Because more than 97% were seeing a medical provider and more than 94% had seen their medical provider within the last six months, knowing about their housing status may supply some information on the just how critical it is to ensure adequate resources for supportive housing.

The charts below show the current housing status of our project's participants. The housing status data are reported in aggregate as well as divided along certain key demographics.

The percentage of individuals relying on sources of housing other than owning or renting provides evidence of the importance of investment in housing as part of addressing the needs of people living with HIV/AIDS.

Among all of our respondents 36.10% rely on subsidized housing⁶, are living in transitional housing or are marginally housed⁷. 0.6% reported being on the street or homeless.

Among African Americans 54.40% rely on subsidized housing, are living in transitional or are marginally housed. 0.9% reported being on the street or homeless

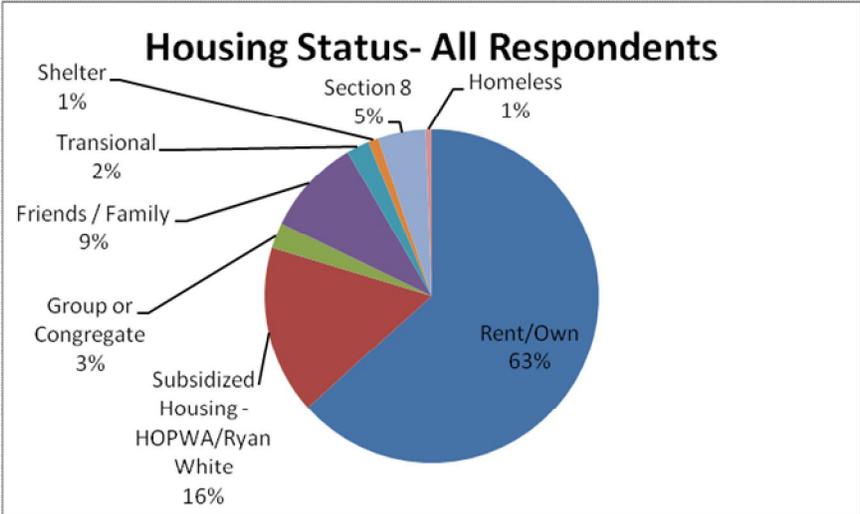
Among African American Women 55.40% rely on subsidized housing, are living in transitional or are marginally housed. 1.6% reported living on the street or homeless.

Among women of all races 48% rely on subsidized housing, are living in transitional or are marginally housed. 1% of all women reported living on the street or homeless.

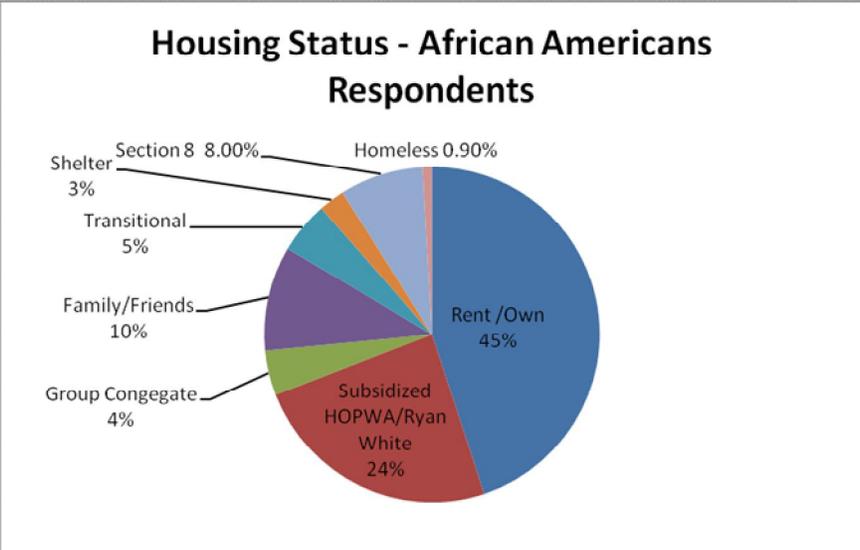
Among Latinos / Hispanics 46.4% rely on subsidized housing, are living in transitional or are marginally housed. 1.2% reported living on the street or homeless.

⁶ For the purposes of this report "Subsidized Housing" includes both Ryan White / HOPWA subsidized housing and Section 8 housing categories from the charts on Housing Status.

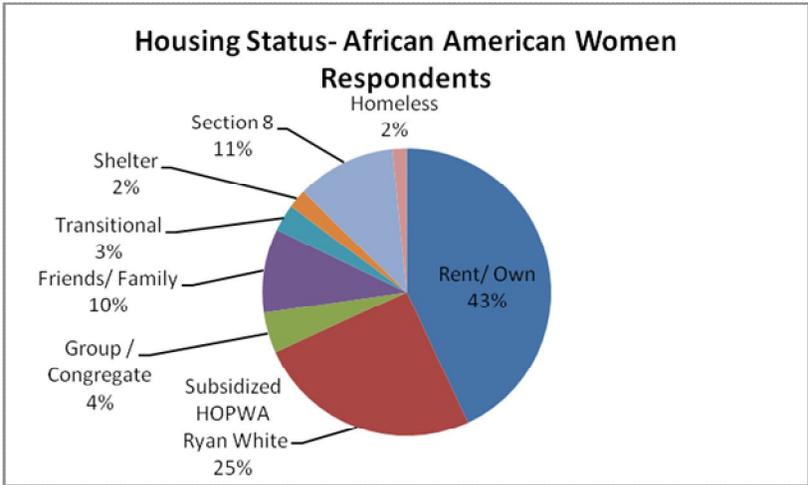
⁷ For the purposes of this report "Living in transitional housing or are marginally housed" includes Group or Congregate, Staying with Family / Friends, Transitional, and Shelter categories from the charts on Housing Status.



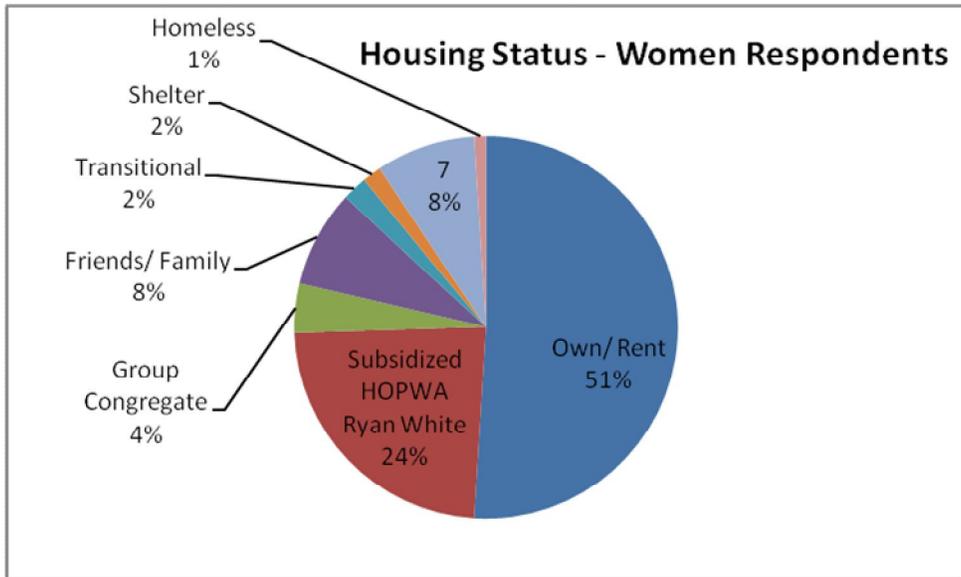
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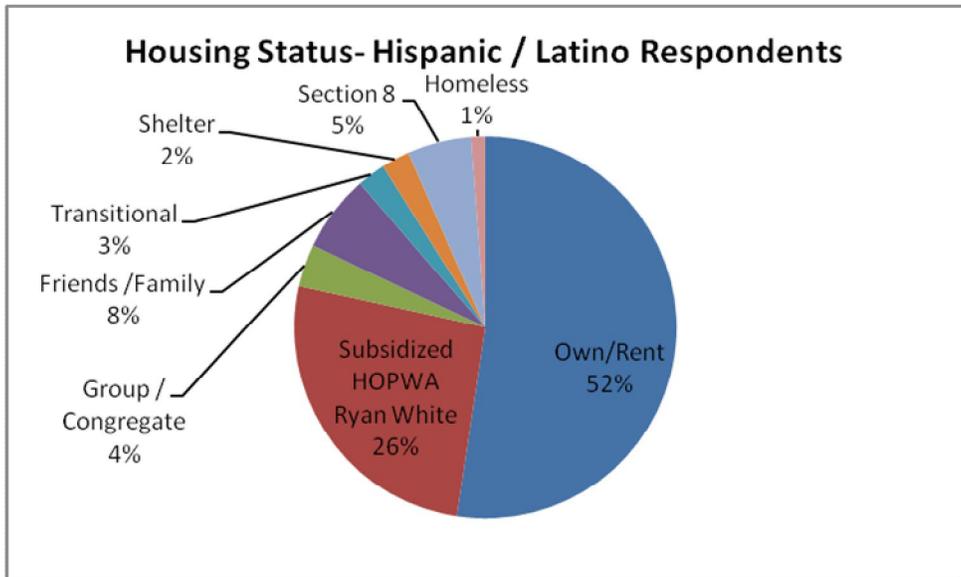
N=433



N=198



N=380



N=168

The people who participated in our project significantly rely on subsidized housing; more than 1 in 5 relied on subsidized housing. About 1 in 3 African Americans relies on subsidized housing. More than 1 in 3 African American women and about 1 in 3 of all women relies on subsidized housing and about 1 in 3 of Latino/Hispanics relies on subsidized housing.

Clearly the reliance on subsidized housing has a direct correlation to low income and poverty (See charts in Chapter 4 on Income Level) with African Americans, women and Latinos having higher percentages of low income and poverty and also higher percentages relying on subsidized housing.

While the data does not directly prove that housing results in being in medical care- the fact that a significant percentage of our project participants rely on subsidized housing and that more than 94%

have seen a medical provider within the last six months, and that housing is repeatedly listed as a top priority to help access and maintain care, makes a persuasive and compelling argument as to the importance of housing to staying in medical care for our project participants.

While it is heartening to see the number of people who have been fortunate enough to find stability through subsidized housing, the number of our project participants that are either in transitional housing or are marginally housed is significant-22.3%. These individuals may be fortunate enough to find their way to stable housing but they also may continue to experience the stress from not having a stable living environment and all of the concomitant problems this status brings or they may find themselves entering the ranks of the homeless.

From looking at the data and information from our participants it seems that housing is a critical component of care. With more than 1 in 5 of these people relying on transitional housing or being marginally housed, it is clear the current investment in housing needs to be reexamined. If any one of these 22.3% found themselves homeless in the future it is an unacceptable outcome.

Housing is more than an important issue for people living with HIV/AIDS, it is essential. Housing needs to be considered when developing a National AIDS Strategy and it needs to be a critical component in the national discussion on healthcare reform.

Conclusions

We were charged with reaching out to “real people” living with HIV, to find out what their health care and supportive services needs are. Our hope is that this survey and its results will be an important resource as Congress and the Obama Administration considers extension of the Ryan White program, the development of a National AIDS Strategy and undergoes a major expansion of health insurance. The information from the survey and town halls contain a rich amount of data on the complex health care and supportive service needs of persons living with HIV/AIDS in the United States. This report does not purpose to make recommendations on the subject of Ryan White extension, the National AIDS Strategy or health care reform. Rather, we hope that HIV advocates and policy makers will draw their own conclusions from the data this study reports on.

APPENDICES

1. Survey Instrument
2. CAEAR Coalition Community Suggested Meeting Template
3. Suggested Guide for CAEAR Coalition Consumer Breakout Session
4. Report from Chicago IL Community Meeting
5. Report from Minneapolis MN Community Meeting
6. Report Back from Baltimore MD Community Meeting
7. Report from Palm Springs CA Community Meeting

HIV Consumer Needs Questionnaire

This HIV consumer questionnaire is your chance to let policy makers and planners know what services are priorities for your continued health and quality of life. Your input will help inform important decisions about future services and resource recommendations. We want to reassure you that the survey does not ask for your name. It is completely anonymous. However, if you would like to volunteer for future activities, you can add your name and contact information on the last page. All the information we receive will be combined, so no one will be able to identify you as an individual.

1. What town or city do you live in? _____
2. What is your zip code? _____
3. What is your gender? Male _____ Female _____ Transgender Female _____ Transgender Male _____
4. How do you identify?
Straight _____ Gay _____ Lesbian _____ Bisexual _____ Other _____
5. What is your age group?

Under 19 _____	46-50 _____
20-25 _____	51-55 _____
26-30 _____	56-60 _____
31-35 _____	61-65 _____
36-40 _____	66 or older _____
41-45 _____	
6. Were you born in the United States? Yes _____ No _____
7. What is your race? (*check one*)

<input type="checkbox"/> Asian <input type="checkbox"/> African American/Black <input type="checkbox"/> Caucasian/White <input type="checkbox"/> Another race not listed above, please specify _____	<input type="checkbox"/> Native American/Alaskan Native <input type="checkbox"/> Native Hawaiian/Pacific Islander <input type="checkbox"/> Biracial/Multiracial
---	---
8. Are you Hispanic/Latino(a)?
 Yes
 No
9. What language do you speak most of the time? (*check one*)
 English
 Spanish
 Creole
 Asian Languages (i.e. Chinese, Korean, Vietnamese, etc.)
 Another language not listed above _____
10. What is the highest education level you completed? (*check one*)
 8th grade or less
 Some high school, but did not graduate
 High school graduate or GED

Continue →

- Some college, but did not graduate
- Vocational/Technical certification
- College graduate (2 or more years degree)

11. What kind of housing do you have now? (*check one*)

- Rent or own house or apartment (non-subsidized)
- Rent or own house or apartment (subsidized)
- Group/congregant housing for people living with HIV/AIDS
- Staying with family or friends
- Transitional (i.e. Halfway houses or drug treatment program)
- Shelter (homeless or other)
- Section 8/Assistant Housing
- On the street – no home
- Another type of housing not listed above _____

12. What is your annual income? (*check one*)

- | | |
|---|--|
| <input type="checkbox"/> Less than \$10,000 | <input type="checkbox"/> \$30,000 – 39,999 |
| <input type="checkbox"/> \$10,000 - 19,999 | <input type="checkbox"/> \$40,000 – 49,999 |
| <input type="checkbox"/> \$20,000 – 29,999 | <input type="checkbox"/> \$50,000 or more |

13. What is your diagnosis? (*check one*)

- HIV positive, but not AIDS
- AIDS (*AIDS is defined as a HIV positive individual who has a CD4 (T-cell) count less than 200 and/or an opportunistic infection*)

14. In what year were you diagnosed with HIV? _____ with AIDS (if applicable)? _____

(If you have not been diagnosed with AIDS, please skip to question 16)

15. Did you learn you had AIDS at the same time that you were diagnosed with HIV? (*check one*)

- Yes
- No, that was later
- Don't know

16. After you learned you had HIV or AIDS, how soon did you seek HIV-related medical care? (*check one*)

- Have not had care yet
- Right away
- Within 6 months of learning my diagnosis
- Within a year of learning my diagnosis
- More than one year
- When I got sick
- Another time frame not listed above, please specify _____

Continue →

17. Access to Services

For each service listed below, please check (✓) the most appropriate column.

	I use this service and never have to wait more than 30 days for an appointment	I use this service but in some cases (less than 50% of the time) have to wait more than 30 days to get an appointment	I use this service but I often (more than 50% of the time) have to wait more than 30 days to get an appointment	I use this service and always have to wait more than 30 days to get an appointment	I need this service but can't get it	I do not need this service
ADAP – Rx Assist Program						
Case Management						
Child Care						
Dental Care						
Emergency Financial Assistance						
Food/Meal Services						
Health Insurance Assistance						
Housing/Finding Housing						
Housing/Subsidy						
Mental Health Services						
Nutrition/Dietician Counseling/Education						
Peer Support Services						
Primary Medical Care						
Substance Abuse Treatment						
Translation/Interpretive Services						
Transportation						

18. For each of the services listed below that you receive, rate on a scale from 1 to 5 if they have **made a difference in your ability to start receiving primary medical care and to continue receiving that care**. If you do not receive the service listed, check the box in the "Do not receive" column and do not rate the service:

		←-----→					
		1	2	3	4	5	
		Not Important		Somewhat Important		Very Important	
I do not receive this service							
<input type="checkbox"/>	ADAP – Rx Assist Program	←-----→	1	2	3	4	5
<input type="checkbox"/>	Case Management	←-----→	1	2	3	4	5
<input type="checkbox"/>	Child Care	←-----→	1	2	3	4	5
<input type="checkbox"/>	Dental Care	←-----→	1	2	3	4	5
<input type="checkbox"/>	Emergency Financial Assistance	←-----→	1	2	3	4	5
<input type="checkbox"/>	Food/Meal Services	←-----→	1	2	3	4	5
<input type="checkbox"/>	Health Insurance Assistance	←-----→	1	2	3	4	5
<input type="checkbox"/>	Housing/Finding Housing	←-----→	1	2	3	4	5
<input type="checkbox"/>	Housing/Subsidy	←-----→	1	2	3	4	5
<input type="checkbox"/>	Mental Health Services	←-----→	1	2	3	4	5
<input type="checkbox"/>	Nutrition/Dietician Counseling/Education	←-----→	1	2	3	4	5
<input type="checkbox"/>	Peer Support Services	←-----→	1	2	3	4	5
<input type="checkbox"/>	Substance Abuse Treatment	←-----→	1	2	3	4	5
<input type="checkbox"/>	Translation/Interpretive Services	←-----→	1	2	3	4	5
<input type="checkbox"/>	Transportation	←-----→	1	2	3	4	5

19. Do you CURRENTLY have a doctor or other provider of medical care? Yes _____ No _____
Please describe any problems you have had in getting medical care?

(If you do not have doctor or other provider of medical care, please skip to question 22)

20. If you do have a doctor or other provider, have you had a medical visit with your doctor or provider:

- In the last 3 months
- In the last 6 months
- I have not had a visit in the past six months

21. Is your **primary medical provider's office** located in a: *(check one)*

- Neighborhood Community Health Center
- Hospital outpatient department
- Private doctor's office
- Other (please define) _____

22. Is your **dental care** located in a: *(check one)*

- Neighborhood Community Health Center
- Hospital outpatient department
- Private dentist's office
- University dental school program
- Other (please define) _____
- I do not receive dental care

23. Have you received **mental health services** in the last 12 months from staff working in a (check all that apply):

- Neighborhood Community Health Center
- Hospital outpatient department
- Private doctor's office
- Inpatient facility
- Other (please define) _____
- I have not received mental health services in the last 12 months
- I need mental health services but am unable to access them

24. Have you received **treatment for alcohol use or other substances** in the last 12 months from staff working in a (check all that apply):

- Neighborhood Community Health Center
- Outpatient substance abuse treatment program
- Inpatient substance abuse treatment program
- Hospital outpatient department
- Private doctor's office
- Other (please define) _____
- I have not received substance abuse services in the last 12 months
- I need substance abuse services but am unable to access them

25. How many organizations provide you with HIV/AIDS-related services?

- One
- Two
- Three

- Four
- Five
- More than five

26. Do you receive Medicaid and/or Medicare?

- I do not receive Medicaid or Medicare
- I receive only Medicaid
- I receive only Medicare
- I receive both Medicaid and Medicare
- I don't know

27. Is there anything else you think we should know about the services you receive or the services you need to help you remain well?

OPTIONAL: If you would like us to be in touch about future consumer advocacy initiatives, please provide the following information:

Name:

Phone number:

E-mail address:



Model of Community Meeting

Welcoming Session for Consumers and Provider
An Opportunity to Discuss the Days Events
Snacks
Suggested Time 30 minutes

Consumer Breakout
Suggested Time 90 minutes

Provider Breakout
Suggested Time 90 minutes

Report Back From Breakouts
Suggested Time 30 minutes

Survey Section
Opportunity for Participants to Complete Survey
Suggested Time 30 Minutes

Lunch / Dinner
Suggested 45 Minutes

Empowerment Session
Politics, Advocacy and What you can do!
Suggested Time 90 Minutes

Guide for Consumer Breakout (90 Minutes)

Overview

This session is envisioned as a 2 part session. The first half is an “open mike” format to hear participants’ thoughts and the second half is to take the participants comments from the first half and to “drill down” to some of the key themes (if any) that might be found when reviewing the comment.

Session Needs

a. 2 session leaders

1 person to facilitate the “open mike” and to lead the “drill down” discussion and one recorder - who will can use either on PowerPoint or Butcher Block Paper to record the comments made during the open mike session and then the conclusions of the “drill down” discussion.

b. PowerPoint Computer, Projector and Screen or Butcher Block Paper Pad, Easel and Markers.

Breakout Facilitator Guide

1. Open Mike Session (suggested time- 45 minutes)

As the group thinks about the community’s needs and how HIV/AIDS issues move forward during the federal 2009 Ryan White re-authorization, there are a few questions that might help frame this discussion. These questions are intended to be provocative and to elicit conversation and they are not intended to necessarily be answered. They should be posted in the room as a reference that will help keep the “Open Mike” session focused.

1. What are the top priorities in life for people living with HIV?
2. Are these priorities being addressed adequately?
3. What support services are important to your ability to access and stay in care?”
4. What services and support does not currently exist that you would like to see available for people living with HIV/AIDS?

The facilitator should put a time limit on individuals’ comments (e.g., everyone has 3 minutes) so that no one person has the opportunity to dominate the session and that everyone has an opportunity to speak.

The recorder should capture the essence of each person’s remarks.

2. “Drill Down” Session

The facilitator should lead the group in reviewing the comments from the open mike session and point out any common themes and priorities that emerge from this review and separate out the themes and priorities that are relevant to the federal level (Ryan White) and which may be more of a local issue. The facilitator should try to achieve some consensus from the group that the themes and priorities identified do in fact capture the spirit of the open mike session.

The recorder should record the themes and priorities that come out of the breakout for report back to the larger group and to pass on to the CAEAR Coalition.

CHICAGO COMMUNITY INPUT FORUM

February 29, 2008

Harold Washington Library

1. WHAT ARE THE TOP PRIORITIES IN LIFE FOR PEOPLE LIVING WITH HIV?

- SUPPORT SERVICES UNDER CASE MANAGEMENT, TRANSPORTATION, FOOD BANK, LEGAL, EMERGENCY HOUSING ASSISTANCE, EMERGENCY FINANCIAL ASSISTANCE
- LACK OF FUNDING FOR NON MEDICAL APPT. TRANSPORTATION
- ELIMINATION OF TREATMENT ADHERANCE
- CASE MANAGEMENT WORKS, INFORMATION SPECIALIST
- MORE EDUCATION NEEDED ABOUT HIV AND SUBSTANCE ABUSE, THE IMPORTANCE OF MEDICATION ADHERANCE, POSSIBILITY OF RE-INFECTION
- MORE CASE MANAGERS ARE NEEDED TO ADEQUATELY DEAL WITH DIFFERENT REGIONS OF THE CITY
- LONG TERM HOUSING FOR TREATMENT, SHORT TERM IS A REVOLING DOOR. NEED TO BE ABLE TO LEAVE TREATMENT CENTER AND GO TO STABLE LONG TERM HOUSING

2. ARE THESE PRIORITIES BEING ADDRESSED ADEQUATELY?

- NO, SPLIT & DIVISION OF MONEY IS RIDICULOUS, NEED STRAIGHT PATH OF FUNDING
- TREATMENT & PREVENTION IS CLEAR, SOUTH SIDE IS NOT GETTING THE MESSAGE. NEW METHODS & NEW MESSAGES ARE NEEDED. DOLLARS ARE NOT FOLLOWING THE NUMBERS OF THE EPIDEMIC. THIS EPIDEMIC IS ON THE SOUTH SIDE, MONEY NEEDS TO REFLECT THIS.
- AMBULATORY CARE IS ADDRESSED ADEQUATELY, RESOURCE AMBULATORY GUIDE IS AVAILABLE VIA TPAN IS SET UP BY COUNTY.
- PRIORITIES ARE BEING MET GIVEN THE LEVEL OF FUNDING WE HAVE TO MEET THEM, PROBLEM IS REPUBLICANS HAVE BEEN FLAT LINING RYAN WHITE FOR YEARS. THERE AREN'T MANY OTHER ILLNESSES THAT GET THE KIND OF FINANCIAL SUPPORT THAT HIV/AIDS GETS. COMPARTMENTILIZING THE EPIDEMIC WILL DILUTE THE EFFORTS TO END IT. HOW CAN WE PRESERVE THIS ACT FOR THE NEXT GENERATION?

3. WHAT SUPPORT SERVICES ARE IMPORTANT FOR YOUR ABILITY TO ACCESS AND STAY IN CARE?

- ACCESS TO MEDICAL CARE & DRUGS
- ACCESS TO PSYCHOSOCIAL SERVICE, TRAINING PROGRAMS TO RE-ENTER THE WORK FORCE, NEED SKILLS BUILDING FOR THOSE LIVNG WITH HIV (JOB RELATED)
- LAKE COUNTY DOESN'T HAVE TRANSPORTATION TO ACCESS SERVICES, NEED INFORMATION SPECIALIST TO KNOW HOW TO NAVIGATE THE SYSTEM
- CASE MANAGEMENT
- MORE TRANSPORTATION SUPPORT IS NEEDED
- MENTAL HEALTH
- FOOD SERVICES
- ALTERNATIVE THERAPIES NEEDS TO BE BROUGHT BACK

4.WHAT SERVICES & SUPPORT DOES NOT CURRENTLY EXIST THAT YOU WOULD LIKE TO SEE AVAILABLE FOR PEOPLE LIVING WITH HIV/AIDS?

- HOMESTEAD ACT-ALLOWS FOR MOVEMENT FROM NURSING HOME TO INDEPENDENT LIVING.
- NEED INCREASED ACCESS TO FAIR MARKET HOUSING, SUBSIDIZED HOUSING IN NEW DEVELOPMENTS WHERE A PORTION OF HOUSING IS FOR HIV/AIDS AND DISABLED.
- NEED TO DEVELOP MORE OUTREACH TO MSM
- RAPID MOBILIZATION UNIT WHERE NUMBERS ARE RISING (SOUTHSIDE)
- NEED TO RECLASSIFY CASE MANAGERS INTO CRISIS MANAGERS
- MORE RESOURCES ARE NEEDED IN LAKE COUNTY, SOCIAL SERVICES (CASE MANAGEMENT SERVICES ARE NOT APPROPRIATE FOR ALL POPULATIONS IN THE AREA)
- UNDERSTANDING LAB WORK
- NEED FOR MORE COMPASSIONATE CASE MANAGERS
- COMPLEMENTARY THERAPIES NEED TO BE BROUGHT BACK
- SUPPORT FOR A INCLUSIVE SPEAKER BUREAU TO GO INTO COMMUNITIES TO HELP BREAK DOWN STIGMA
- MORE SERVICES FOR PEOPLE LIVING WITH HIV (EXPANDED ELIGIBILITY)
- MORE SERVICES ON THE SOUTH & WEST SIDE FOR WOMEN LIVING WITH HIV
- PREVENTION FOR POSITIVES

OPEN MIC 14 CONSUMER SPEAKERS:

- ALL SERVICE CATEGORIES ARE IMPORTANT, NEED TO LOOK AT WHERE THE GREATEST NEEDS LIE. NEED TO NOT JUST ACCEPT WHAT WE ARE GIVEN. NEED ADEQUATE FUNDING FOR ALL SERVICE CATEGORIES.
- NOT ELIGIBLE FOR SERVICES BECAUSE HAVE HIV NOT AIDS
- FEELING LIKE CREATING HOUSING SOLEY FOR THOSE LIVING WITH HIV/AIDS PROMOTES STIGMA AND CREATES "AIDSVILLE" ENVIRONMENT
- STATISTIC BETWEEN WHEN SOMEONE IS DIAGNOSED WITH HIV AND WHEN THEY BEGIN CARE IS UNACCEPTABLE. NEED CASE MANAGERS TO BE MORE PRO-ACTIVE IN DEALING WITH ALL CLIENTS REGARDLESS OF THEIR ACUITY LEVEL.
- LONG WAITNG LIST FOR HOUSING, NO ASSISTANCE TO MOVE INTO A ROOMING HOUSE/BOARDING HOUSE
- PEOPLE ARE STILL UNAWARE OF WHAT SERVICES ARE AVAILABLE FOR PEOPLE LIVING WITH HIV/AIDS, NEED TO BE A LOCAL SEMINAR ON WHAT'S AVAILABLE
- INFORMATION ABOUT HIV/AIDS IS DISTORTED, WOULD LIKE TO HAVE ACCESS TO BETTER INFORMATION, NEED MORE GRASSROOTS EFFORTS TO EDUCATE THE COMMUNITY WITHIN THE COMMUNITY
- CAN BE DIFFICULT TO ACCESS SERVICES IF YOU DON'T HAVE A GOOD CASE MANAGER....SOME DON'T KNOW, DON'T CARE BUT IT IS NECESSARY TO USE THEM IN ORDER TO GET REFERRALS FOR ADDITIONAL SERVICES. CASE MANAGERS AND CONSUMERS NEED TO BE BETTER EDUCATED ABOUT WHAT IS AVAILABLE. JOINT TRAINING FOR BOTH.
- PREVENTION NEEDS TO BE INCLUDED
- MORE CASE MANAGERS THAT ARE PWA/HIV AND BETTER-EDUCATED PEER EDUCATORS.

GENERAL COMMENTS (PROVIDERS & CONSUMERS):

- BE PREPARED AND HAVE A STRATEGY FOR WHAT WILL HAPPEN 4 YEARS FROM NOW IN CHICAGO
- WOULD LIKE TO SEE \$50 BILLION DOMESTICALLY FOR HIV/AIDS FUNDING. AIDS IN AMERICA IS A MOVEMENT FOCUSED ON STOPPING THE EPIDEMIC IN OUR OWN BACKYARDS
- INTERESTING THAT BOTH CONSUMERS & PROVIDERS HAD THE SAME ISSUES FOR SUPPORT SERVICES.
- ISSUE OF HOW FUNDING IS APPROPRIATED. WANTS LOCAL AUTONOMY. WANT SHORTEST PATH TO FUNDING.
- FOR THE PROVIDERS: CONSUMERS APPRECIATE WHAT YOU ARE DOING, WHAT WOULD MAKE IT BETTER IS IF YOU SUPPORTED THE CLIENT DURING LOBBY DAYS.
- STOP AIDS 08 IS FOCUSED ON GLOBAL ISSUES, AIDS VOTE IS FOCUSED ON DOMESTIC ISSUES, AIDS WATCH PRIMARY THEME IS FOCUSED ON DOMESTIC HIV & AIDS CRISIS AND DEVELOPING NATIONAL STRATEGY WITH LOCAL COMPONENTS. WILL ADDRESS STIGMA. PWA/HIV ARE WANTED TO DO THE TRAININGS IN WASHINGTON, D.C. AIDS WATCH IS APRIL 28 –30.
- CONSUMERS NEED TO GET INVOLVED WITH LOCAL CASE MANAGEMENT, CONSUMERS TO TRAIN CASE MANAGERS ON HOW TO BEST MEET THEIR NEEDS
- IT IS IMPORTANT TO EDUCATE ON HOW THIS ALL BEGAN IN ORDER TO BRING AN END TO IT.

Summary of Minneapolis – St. Paul Community Meeting Consumer Breakout Session

General Comments from Recorder: 36 PLWHA participated in breakout session. Participants were very engaged and discussions were rich. Much of the discussion focused on peer support, supportive services that provide basic needs, quality of case management services and the complexity of the HIV care system. There was not much concern expressed about accessibility of core medical services.

Question #1: What are the top priorities in life for people living with HIV? (Responses group by service category, then clustered by similarity)

<p><u>Core Medical</u></p> <ul style="list-style-type: none"> • Medical Care • Insurance • Medication med Adherence Support • Mental Health Services • CD Tx services specific for PLWH • Dental Care • Eyeglasses • Case Management • Access to Case Management • Quality Case Management 	<p><u>Supportive Services</u></p> <ul style="list-style-type: none"> • Broader than “Medical” • Initial fear – counseling to help with initial diagnosis. Peer support/connections – community groups • Support groups “female” by affinity • Connections with others LWH • Social Networks • Both formal and Informal Support Groups • Rural Transportation • Transportation • Medical Transportation • Transportation to grocery store • Food and Nutrition (2 comments) • On-site Meals • HIV Tx/Health Education • Emergency Financial Assistance • Housing Subsidies • Benefits Counseling • Day Care
<p><u>Employment</u></p> <ul style="list-style-type: none"> • Employment services • Back to work programs • Job placement 	<p><u>Other</u></p> <ul style="list-style-type: none"> • Sense of stability • Alternative Therapies

Question #2: Are these priorities being address adequately? (Clustered by similarity)

Complexity of System

- Bureaucracy – so much (i.e. Case Mgmt) cut out
- Bureaucracy consumers suffer
- System too complicated
- Complexity of providing HIV services
 1. Specific services
- One stop shop-consolidated services
- Linkages to other services

Case Management Improvement

- Quality of Case Mgmt
 1. Inconsistent
 2. Case Manager Training
 3. Standards
 4. Networking Opportunities for Case Managers
- Case Management – overloaded
 1. Wait time (3 months)

Housing Assistance

- Homeowner
 1. Home Maintenance
 2. Mortgage Assistance
- Housing
 1. CD
 2. Formerly incarcerated
- More intensive Housing Assistance
 1. System navigation
- Wait for Section 8 and other housing
- Rental assistance when income is down (unemployment)
- More HIV Specific Subsidies
- Housing for Homeless
- Felony / CD barriers lifted
- Paying for utilities

Mental & Chemical Health

- Psychiatrists
 1. Wait
- CD Tx
 1. HIV Competency
 2. Safety to disclose
 3. Not enough emphasis on addressing HIV
- More Tx models
 1. Not enough Therapeutic Counseling
 2. Counseling
- Meth Tx
- Mental Health/Counseling, more providers knowledge of services
- Med Adherence Counseling in CD Tx
 1. Safe disclosure of HIV status in CD Tx

Other

- Prevention
- Transportation (Rural)

- Social Network Opportunities
- Medical Care is adequately addressed

Question #3: What support services are important to your ability to access and stay in care?

- Substance Abuse Services
- HERR
- Family Counseling
- Benefits Counseling
- Bus Cards amt
- Meals
- Daycare for work and school / med appts.
- Transportation
- Peer Support
- Case Management
- Info & Referral/Resources
- Health Care must be a given
- Outreach Services
- Support services needed not just to access Med Care but to survive/live well

Question #4: What services and support does not currently exist that you would like to see available for people living with HIV?

- Peer support and clinics
- Funding for education
- HIV service employment for PLWH
- Seamless insurance / benefits
- Continuation
- Medicare / Medical / Program HH private
- One System
- Support for volunteers
- Prevention in CD
- Substance Abuse Prevention
- Education-HIV Testing
- Connecting to Care
- Financial Planning
- Harm reduction Support Groups
- More Prevention to Minorities
- Clinician Training – Aging
- Prevention w/transgendered
- Long-Term
- Back to work / employment services
- Ins through employment universal
- Services for Seniors
- Health Ed – HIV Stories – opportunities for empowerment

Themes:

- Need seamless transitions
- Complexity of system
 1. Disconnect/better
 2. Connections throughout

- Peer Support
- Health Care should be an entitlement for all
- Gratitude for what we have
- Information and access to Medical and Support
- Education is essential
- Advocacy
- Living for life
- Access to CD Tx and Mental
 1. Health Services
- Difficult to distinguish services
- Eliminating bureaucracy

**Summary of Consumer Breakout
Baltimore Community Meeting
May 5, 2008**

Please provide us with the summary of information from the Consumer Breakout that was presented during the "Report Back Session"

1. What are the top priorities in life for people living with HIV?

- Primary care (access)
- Assistance w/language barriers
- Linkages to services
- Support groups for Hispanics
- Culturally specific case management
- Financial assistance upon hardship
- Health insurance
- Timely emergency assistance
- Housing (adequate)
- Substance abuse treatment
- Comprehensive sex education in middle and high schools
- Increased access to information and resources once diagnosed
- Transportation
- Access to eye care
- Planning for disaster response and healthcare access
- Funding for sign-language interpretation and increased access
- Holistic and alternative therapy services
- Life insurance/burial assistance
- Integrate spiritual leaders into prevention
- Child care

2. Are these priorities being addressed adequately?

- Inadequate information about available services
- Extended services for acutely ill
- Poor information/awareness (especially African American women)
- Inconvenient service locations
- No, due to increasing prevalence yet inadequate funding
- Response time for services is too slow

3. What support services are important to your ability to access and stay in care?

- Housing
- Transportation
- Case management
- Emergency financial assistance
- Child care
- Legal services
- Pharmacy assistance
- Food assistance
- Mental health services
- Dental programs
- Substance abuse treatment services
- Peer advocacy programs (funded/paid peer-advocates-not volunteer)
- Outreach programs (traditional and non-traditional)
- Buddy companion programs
- Life insurance (financially affordable)
- Support groups/retreats
- Language interpretation services
- American Sign Language interpretation services
- Assistance for visually-impaired
- Funding for ADAP (treatment)

4. What services and support does not currently exist that you would like to see available for people living with HIV/AIDS?

- Employment training
- Better coordination of and education about disability determination
- Support groups
- Extend Americans with Disabilities Act protections so that deaf PLWHA could have equal access to HIV/AIDS programs and services
- Life insurance
- Fast track for eligibility determination for HIV services
- Expanded funding for HOPWA
- Officials in all branches of government need to work to reduce stigma and improve quality-of-life for PLWHA
- A single, universal application for all HIV/AIDS programs
- Guaranteed local telephone service access for acutely ill persons
- Universal healthcare
- Auto-renewal for HIV/AIDS services
- Eliminate or streamline recertification process for HIV status qualification
- Government think tank for an HIV cure
- Continued consumer presence in planning/evaluation of HIV/AIDS services

PALM SPRINGS CALIFORNIA IDENTIFIED ISSUES

Our Community's major concerns are:

1. Ensure adequate funding for ADAP and all other government assistance programs to promote fair and equal access to medical care, medications, and all therapies necessary to keep a body and mind free from disease and functioning to the greatest capacity despite HIV and its co-morbidities including Hepatitis C.
 2. Specific programming to mitigate the interaction of HIV and aging whether accelerated aging from HIV or long-term survivor/medical therapy side effect related issues such as metabolic disorders, cardiovascular disease, cancers, mental health disorders and a host of other diseases related to HIV both prevalent and emerging
 3. Housing must be comprehensive to include availability of adequate housing options, equal access to housing and continuing support to enable People with HIV to maintain safe, stable housing
 4. Food and nutrition therapies offered so as to provide a stable, adequate supply of food and the skills and knowledge to maintain maximum health benefits from nutrition should be part of a comprehensive approach to nutrition including equal access to dietary professionals trained in the needs of People living with HIV
 5. Full disclosure of available benefits for People with HIV should be made readily accessible through integration of services, communication between federal, state and local agencies, standardization and portability of eligibility nationwide and extensive community outreach regarding HIV programming
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1. MEDICATION

- a. ADAP Funding -- Critical!
 - b. Assistance in paying for medication (and other aspects of treatment) for the "side-effect" conditions which result from long-term treatment for HIV/AIDS.
 - c. Co-infection Treatment Payment Programs
 - d. Medicare Part D "Doughnut Hole" – Closing the Gap
 - e. Treatment of AIDS as a "Chronic Disease"
 - f. The patient as a whole – Why is AIDS "separated" as a treatment issue?
 - g. Advertising Budget to Counter Unrealistic Pharmaceutical Company Drug Claims.
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2. AGING

- a. Dietary Counseling
 - b. Living past our life expectancy (as determined by an HIV/AIDS diagnosis).
 - c. Effects on older people of long-term treatment regimes.
 - d. Newly diagnosed seniors.
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3. HOUSING

- a. Rent Assistance for Basic Housing
 - b. In-Home Care (Volunteer Caregivers)
 - c. In-Home Nursing Programs
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- d. Nursing Home Treatment
 - e. Hospice Care
 - f. Utilities
 - g. Transportation
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4. TREATMENTS

- a. No local services available in some areas.
 - b. Transferability/portability of services. (State, HRSA, SAMHSA, community, local service differences.)
 - c. Standardization of services across geographic boundaries. (Establishing a consistent minimal level of care.)
 - d. Dental care. (Dental issues can create serious problems in other body systems.)
 - e. Conflict: Prioritization of who gets treated—"New" patients vs. "Long-term Survivors"
 - f. Anonymous Testing & Counseling. (Gov't. won't provide funding.)
 - g. Drug Counseling (Crystal meth, etc.)
 - h. Vision
 - i. Mental Health
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- 1. Dementia
 - 2. Bi-polar Disorders
 - 3. Psychological Behaviors
 - 4. Alzheimer's
 - 5. Anxiety & Stress
 - 6. Depression
 - 7. Grief Counseling
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- j. Pet Care for Ill People
 - k. MEDICARE – Funding is being cut, reimbursement amounts for physicians are inadequate and result in refusal to accept patients for treatment.
 - l. "Cosmetic" treatments (lipo, facial filling, etc.)—psychological and direct effects.
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5. FOOD

- a. Nutritional counseling.
 - b. Vouchers
 - c. Meals on Wheels
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6. ALTERNATIVE & SUPPORTIVE THERAPIES

- a. Exercise Therapy
 - b. Massage Therapy
 - c. Accupuncture
 - d. Alternative & Homeopathic Therapies
 - e. Peer Counseling – "Mentor" Program
 - f. Helping Each Other.
 - g. Minority Outreach.
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7. BENEFITS

- a. Benefits counseling.
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- b. Communication of program availability.
 - c. Resource codification / Sources of information.
 - d. Privacy vs. Access
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8. MISCELLANEOUS

- a. HIV vs. AIDS as a means of determining access/eligibility for funding.
 - b. Reexamination of the Thresholds and Classifications of Individuals as "HIV Positive" vs. "AIDS".
 - c. Increases in funding as long as the number of infected/effected individuals continues to grow.
 - d. No "sunset" provision to legislation as long as there is no cure.
 - e. Job skills training.
 - f. Employment counseling.
 - g. Working while under treatment—invalidation of access to care programs as a result of income / asset accumulation.
 - h. Participation in Federal Programs can make you ineligible for other programs. (SSI / SSDI)
 - i. Back to work programs.
 - j. Part time work.
 - k. Veteran's Services
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- 1. Emergency Care
 - 2. VA Status making you ineligible for other programs (dental, vision, etc.)
 - 3. Integration of Federal & Community Programs
 - 4. Transportation.
 - 5. More Local VA Clinics.
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I. EDUCATION

- 1. In Schools. AIDS CANNOT CURRENTLY BE CURED!!
 - 2. Abstinence as the primary focus is not reasonable.
 - 3. Sensible, realistic prevention.
 - 4. Peer-to-Peer Programs.
 - 5. Public Education.
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