2004 Needs Assessment Report
Maine Ryan White Title II Program

March 2005

Prepared By:
Diane Haley, MPH and Courtney Jackson, MA
University of Southern Maine
Institute for Public Sector Innovation
Edmund S. Muskie School of Public Service
University of Southern Maine
295 Water Street
Augusta, ME 04330
P: 207.626-5200
Email: dhaley@usm.maine.edu

Submitted To:
Ryan White Title II Program
Bureau of Health
Division of Disease Control
Maine Department of Health and Human Service
286 Water Street
Augusta, ME 04331

Acknowledgements

The Ryan White Title II CARE Act Needs Assessment would not have been completed without the very capable and willing assistance of many individuals and partner agencies. We would like to acknowledge the following for their invaluable contribution to this project.

Members of the Needs Assessment Planning Committee: Christine Canty-Brooks, Butch Beaulieu, Ken Bartuka, Jean Lavigne, Bob Woods and Shelley White. These individuals participated actively in the needs assessment planning, preparation, implementation, analysis and report writing. For more than a year, they provided direction and substantive feedback to project staff on overall design, data collection tools, methods, sampling, recruitment materials, and the final report. The project benefited tremendously from the unique perspective of each member and his or her thoughtful input every step of the way.

We are indebted to all of the AIDS Service Organizations around the state, and their staff, for assistance with data collection efforts. The following organizations were instrumental in advertising focus groups and the public hearing, and in distributing surveys to consumers of case management: St. Mary's Regional Medical Center, Frannie Peabody Center, Eastern Maine AIDS Network, Down East AIDS Network, Dayspring AIDS Support Services, and Coastal AIDS Network.

In particular, we wish to thank the persons living HIV/AIDS in Maine who responded to our requests for information, sharing their stories through focus groups, and survey questionnaires. In return, we sincerely hope that this report will lead to positive changes in the way that services are delivered in Mai

Table of Contents

Appendices

EXECUTIVE SUMMARY

Introduction

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act is administered by the federal HIV/AIDS Bureau, Health Resources and Services Administration (HRSA), Department of Health and Human Services. The intent is to improve the quality, availability, and organization of health care and support services for individuals and families with HIV infection.

Ryan White Title II CARE Act funds have been used to provide two programs for People Living With HIV/AIDS (PLWHA) in Maine. The first program is the AIDS Drug Assistance Program (ADAP), which assists PLWHA who cannot afford their HIV-related medications. HIV Case Management, the second program, is provided through six community-based agencies whose catchment areas together cover the entire state. The goal of the Title II-funded case management services is to enhance the quality of life and self-sufficiency of persons who are living with HIV/AIDS.

Though Maine has received Ryan White Title II CARE Act funds since 1992 and utilized them to fund ADAP and HIV Case Management for PLWHA, program decisions have not been informed by a comprehensive Needs Assessment. In order to determine service gaps in the continuum of care for PLWHA in Maine, a comprehensive Needs Assessment was planned and implemented. As recommended by the Ryan White Title II CARE Act program, a planning committee was first established to guide the Needs Assessment process, ensuring the involvement of a diverse group of stakeholders. Findings will provide policymakers with the information necessary to ensure that funds are used where they are most needed.

This report presents the results of a comprehensive Needs Assessment, conducted for the Maine Bureau of Health, to inform the state’s Ryan White Title II CARE Act program and to meet Health Resources and Services Administration (HRSA) requirements for Title II funded programs. It summarizes data that were gathered between October, 2004 and February, 2005, from consumers of Ryan White Title II funded services, as well as a small number of providers, program administrators, and PLWHA who were not in care. The Needs Assessment was designed to establish service priorities by documenting needs for specific services, describing barriers to care, and providing baseline data for comprehensive planning including capacity building. In addition the data will help providers improve access to care and quality of service.

Methods

As recommended by the Ryan White Title II CARE Act program, a planning committee was first established to guide the Needs Assessment process. Committee membership was made up of consumers, Bureau of Health representatives, University and non-profit employees. Together, the members of this group reviewed and selected tools, came to agreement on overall design issues, and provided regular feedback on the process.

There were four components to the Needs Assessment: Consumer Surveys, Out of Care Client Surveys, Focus Groups, and a Public Hearing. Data from all four components are contained in this report. Survey and focus group respondents were recruited through the six AIDS Service Organizations (ASOs) in Maine that receive Title II funds for case management. Incentives for participation were provided in both the surveys ($10 phone cards) and focus groups ($50 cash)[1]. Of the 270 surveys that were distributed to consumers by the ASOs between October 26, 2004 and February 15, 2005, 163 were completed and returned. This number represents roughly 34% of the total caseload (475) at those agencies. Five focus groups were conducted with 46 consumers in five of the cities located within ASO catchment areas. Out of Care surveys were completed with 28 individuals who had not accessed primary medical care or received medication for HIV, within the previous 12 months. The final component to the Needs Assessment was an HIV/AIDS public hearing sponsored by the Bureau of Health, at which 22 testimonies were heard.

In addition to the four methods of data collection mentioned above, epidemiological data on HIV in Maine are presented in this report and compared to Needs Assessment data.

Key Findings

Utilizing four methods of data collection allowed us to cross-reference results from each, adding strength to the validity of findings that were similar.

Based on results of the Public Hearing, Focus groups, and the Consumer Survey, HIV Case Management was an important, highly utilized service, however respondents identified several ways in which it could better serve their needs. Assistance with the cost of medications was also mentioned across the board as an important and highly utilized service. Dental Care came out as one of the most used services, as well as most needed but difficult to receive. Also needed, but difficult to receive, were the following: consistent, high quality HIV Case Management; providers who focus on living rather than dying; and opportunities to meet other PLWHA.

Overall, the most frequently cited services that consumers were using include: HIV Case Management (69%), prescription drugs (63%), dental care (49%), medical care (50%), client advocacy (42%) and mental health (32%). The least used services included home delivered meals (2%) and daycare (1%).

Services Used
- Case management, prescription medications, dental care and medical care were the most frequently used services.

Services Needed
- Continued funding for medications is critical.
- HIV case management services, adequately staffed, and guided by a set of standards and quality assurance controls, are needed.
- People living with HIV/AIDS need opportunities to connect with each other.
- Services needed but not received:
  Dental care and emergency housing are most commonly reported across all regions.

Linkages to Care
- Half of all HIV diagnoses were made at a doctor's office.
- Younger age (under 29) is associated with delayed care and medication .

Health Insurance
- 18% of survey respondents were without insurance at some time during the previous 12 months.

---

[1] *Cash reimbursements were drawn from state prevention funds.*

Overall, nearly three-quarters of the sample reported seeking care within a month of diagnosis. Those who were diagnosed at an older age (over 29) were more likely to seek care within a month. Those diagnosed at a younger age (under 29) were less likely to start medication within a month.

The vast majority of survey respondents reported some type of insurance coverage (88%). Nearly two-thirds (63%) reported that they were covered by MaineCare/Medicaid. Over half (52%) said they have Medicare and nearly half (44%) reported some form of private insurance.[2]

Patterns of service use differ slightly between men and women. Though not statistically significant, women were less likely to report accessing health-related services such as dental care and medical care than men, but were more likely to access food bank, emergency services, and bus fares. Women were also more likely to access substance abuse services. Women were significantly more likely to use day care services.

Dental care and emergency housing were the most common needs identified by women. Dental care and food bank were the most common needs identified by men.

Gender Patterns

Women were more likely to report accessing day care services.

Women identified dental care and emergency housing most often, under ‘needed services’.

Men more often identified dental care and food banks as needed.

Dental care, emergency housing assistance and food bank were the categories of *needed* services most frequently identified by the entire sample.

Responses were looked at by geographic region: north, central and south (see table 4.2 for definition of regions), and some differences were evident. Emergency housing assistance was a need across all regions. Dental care was needed in the central and southern region. Mental health care was needed in the south and bus fares were needed in the central region. Dental care was the most common need identified regardless of income and insurance type.

Regional Patterns

Central Region: Dental care and bus fares most commonly needed services

Southern Region: Mental health and dental care most commonly needed services

Northern Region: Help paying for health insurance and Emergency Assistance most commonly needed services

Discussion

The purpose of this Needs Assessment was to inform decision-making regarding utilization of Ryan White Title II CARE Act funds in Maine. It was designed to examine access to care, utilization, barriers to services and unmet needs.

---

[2] *Respondents could check off more than one type of insurance coverage.*

This Needs Assessment reports the results of a survey completed by 163 HIV+ clients of AIDS Service Organizations (ASOs), an out of care survey completed by 28 respondents, five focus groups, a public hearing, and state epidemiological data. As we drew our sample for both the survey and the focus groups from the ASOs, we can not assume that the results are representative of the HIV+ population in Maine. Clients of ASOs are more likely than the general population to be connected with services. In addition, women are slightly overrepresented in the survey (24.5% vs 16% in the general HIV+ population) and in the focus groups. Older age groups are also overrepresented in the focus groups. However, on other demographic characteristics, the survey sample closely reflects the state epidemiological profile of PLWHA.

Service Needs and Gaps

With the decline in AIDS-related mortality over the past ten years, services for PLWHA are shifting to a focus on chronic disease management, including an expensive and difficult treatment regimen. Financial assistance will continue to be among the greatest of needs, enabling PLWHA to receive life-saving treatment. In addition to critical services such as medical care, drugs and housing, it is essential that services to support daily living are also available.

One hundred and thirty three (82%) of the survey respondents reported currently taking HIV medications. MaineCare[3] was the most frequently cited source of assistance with payment for drugs, clearly a valuable resource. Still, nearly 15% reported out-of-pocket costs in excess of $100 per month. Though most reported having insurance coverage during the previous year, those in the moderate income category of $20,000 to $29,999 were somewhat more likely to have gone without insurance at some point in the year. This income group also bears more costs for insurance deductibles and premiums (only 26% reported no such costs, vs 62% and 63% of those with lower incomes), perhaps explaining why some of them lacked insurance altogether. Over one third of this group pays more than $1,000 annually for insurance deductibles.

Treatment

Most respondents had their first medical care visit within one month after diagnosis with HIV. However, those under the age of 29 were more likely to delay getting into care and taking medication, than older respondents.

Close to half of the respondents had been diagnosed with HIV at a doctor's office, which may suggest a connection to medical care. Therefore, it is somewhat surprising that 51.7% of the simultaneous HIV and AIDS diagnoses occurred in a doctor's office. Overall, 47.5% of respondents who reported an AIDS diagnosis (61), reported receiving their HIV and AIDS diagnoses simultaneously. This is consistent with statewide data on late to care issues.

Approximately 20% of respondents reported sometimes or often missing a dose of medication without the advice of a doctor in the past year. The most common reasons reported for missed doses were: 1) forgot, 2) side effects, 3) ran out of medications. Focus Group participants

---

[3] The MaineCare Special Benefit Program for PLWH provides a number of treatment-related services, including medications, for low-income Maine residents who have a documented HIV infection and whose individual income is less than or equal to 250% of the Federal Poverty Level. The MaineCare program has a medication copay of $10 per prescription.

mentioned problems filling prescriptions, either because medications were not in stock, or there was a delay in getting the necessary approval required for certain medications. Cost was also mentioned as a barrier to medications.

HIV Case Management

HIV Case Management was mentioned frequently in focus groups and the public hearing, and was cited most frequently (69%) among services utilized by the survey population, followed by information (50%) and client advocacy (43%). The general theme derived from both focus groups and the public hearing was a request for consistent, high standards to be developed and implemented for HIV Case Management, including greater knowledge about HIV/AIDS. Consumers also expressed an interest in having ASOs facilitate more opportunities to meet other PLWHA, to encourage sharing of information, and to decrease isolation.

Unmet Needs

Dental care was mentioned in all focus groups as one of the top services that was needed but not easy to receive. This finding was supported by the survey results which show that dental care was the most common unmet need identified by people in all income and insurance categories. According to focus group participants, adequate dental care for PLWHA isn't available, unless one can travel to Boston, spending many hours on transportation and at the clinic. In addition to dental care, legal assistance, emergency housing and food bank were the categories of service most frequently identified as needed but not available. Focus group participants also identified public assistance, such as SSI/SSD/HUD Section 8, as services that they have had difficulty receiving and/or maintaining.

Barriers to Care

Cost is a major barrier to dental care as well as health insurance and using prescription drugs. Other barriers identified in the focus groups included: lack of information about resources, lack of knowledgeable providers, poor customer service at ASOs, lack of communication between providers (general practitioners and specialists) and between clients and their providers, transportation, and care issues related to multiple diagnosis.

Recommendations

Based on the results of the Needs Assessment, the Ryan White Title II program should continue with at least the current level of financial assistance to consumers. In addition, new standards must be developed for case management services, with quality controls built into contracts. Those standards should require the ASOs to provide comprehensive information on resources, to facilitate social opportunities, and to create a client-friendly atmosphere.

Epidemiological data for Maine provide evidence that there is a 'late to care' problem, where a large proportion of those receiving an HIV diagnosis were simultaneously diagnosed with AIDS, a trend that is also reflected in the Needs Assessment data. The state needs a strategy to decrease this number. One approach might be a public awareness campaign promoting the benefits of early testing and treatment. Doctors should also be targeted with these messages, as most of the simultaneous diagnoses were given at doctor's offices.

The state should examine strategies for drawing consumers into care, and should evaluate the continuum of care currently available. It is clear that there is a gap in coverage of dental care and that middle-income and low-income individuals experience significant out of pocket costs and barriers to care. Barriers to care include cost and transportation. These issues should be considered when examining the uses of emergency financial assistance and creating policies to better define its use.

Additional research is recommended in order to complete this Needs Assessment, and to fill in the picture of HIV/AIDS services in the state. Future research should examine the factors associated with delays in testing for HIV, and delays in obtaining treatment. The Ryan White Title II CARE Act Program should undertake a resource inventory and profile of provider capacity and capability. Ideally, the Needs Assessment will be conducted every three years hereafter.

II. INTRODUCTION

As of December 31, 2004, there were 1,002 people with a known HIV diagnosis living in Maine. The Centers for Disease Control and Prevention estimate that between 1/4 and 1/3 of PLWHA do not know their status, meaning that an additional 300 to 400 persons in Maine may be unknowingly infected with the virus. Forty-six new HIV diagnoses were reported to the Bureau of Health in 2004. Males who have sex with males (MSM) continue to be disproportionately affected by HIV in Maine, accounting for 33 of the 46 cases diagnosed in 2004, or 72%. Twenty of the individuals diagnosed in 2004, or 43%, were simultaneously diagnosed with AIDS, likely indicating they have been infected with HIV for a long while before seeking testing. It is estimated that approximately 1,300 people in Maine are living with HIV.

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act is administered by the federal HIV/AIDS Bureau, Health Resources and Services Administration (HRSA), Department of Health and Human Services. The intent is to improve the quality, availability, and organization of health care and support services for individuals and families with HIV infection.

Title II of the 1990 Ryan White CARE Act provides financial assistance to states or other public or private nonprofit entities for the delivery of essential services to individuals and families with HIV disease. The Bureau of Health is the primary grantee in Maine for distribution and utilization of Title II funds. These funds may be used to deliver the following services:

- Ambulatory (non-hospital) health care, including HIV specialty care, substance abuse and mental health treatment, oral health, home health, and hospice;
- Comprehensive treatment services including treatment education, antiretroviral therapies, and prophylaxis/treatment for opportunistic infections;
- Case management that prevents unnecessary hospitalization or delays in releases.
- Support services that "facilitate, enhance, support, or sustain the delivery, continuity, or benefits of health services for individuals and families with HIV disease;"
- Outreach and early intervention services (EIS) to identify people with HIV disease who know their HIV status but are not receiving HIV-related services in order to bring them into care. EIS can be funded as long as the grantee can demonstrate that other sources of funds are insufficient to meet current needs.

Ryan White Title II CARE Act funds have been used to provide two programs for PLWHA in Maine. The first program is the AIDS Drug Assistance Program (ADAP) which assists PLWHA who cannot afford their HIV-related medications. HIV Case Management, the second program, is provided through six community-based agencies, AIDS Service Organizations (ASOs) whose catchment areas together cover the entire state. The following is a list of those agencies and the counties that fall within their catchment areas.

Coastal AIDS Network Warren, ME	Waldo, Knox
Down East AIDS Network Ellsworth, ME	Hancock, Washington
Eastern Maine AIDS Network Bangor, ME	Penobscot, Aroostook, Piscataquis
Frannie Peabody Center Portland, ME	Cumberland, York
St. Mary's Regional Medical Center Lewiston, ME	Androscoggin, Oxford
Dayspring AIDS Support Services Augusta, ME	Kennebec, Lincoln, Sagadahoc, Somerset, Franklin

The goal of the Title II-funded case management services is to enhance the quality of life and self-sufficiency of persons who are living with HIV/AIDS.

Though Maine has received Ryan White Title II CARE Act funds since 1992 and utilized them to fund ADAP and HIV Case Management for People Living With HIV/AIDS (PLWHA), program decisions have not been informed by a comprehensive Needs Assessment. In order to determine service gaps in the continuum of care for PLWHA in Maine, a comprehensive Needs Assessment was planned and implemented under the guidance of a planning committee made up of consumers, Bureau of Health representatives, University and non-profit employees. Findings will provide policymakers with the information necessary to ensure that funds are used where they are most needed.

III. EPIDEMIOLOGICAL PROFILE

Table 3.1 below shows demographic characteristics for PLWHA diagnosed in 2004, and for the total PLWHA population in Maine.

Table 3.1: Demographics for 2004 New HIV Diagnoses and Total PLWHA in Maine

Mode of Transmission	New HIV Diagnoses 1/1/04 to 12/31/04	People living in Maine with diagnosed HIV
Males Who Have Sex with Males (MSM)	72%	56%
Injection Drug Users (IDU)	2%	15%
MSM/IDU	0%	4%
Received Contaminated Blood Products	0%	2%
Heterosexual Contact with at Risk Partners	13%	12%
Heterosexual, No At Risk Partners Disclosed	7%	6%
Child Born to Mother with HIV	2%	1%
Undetermined	4%	5%
Total	(46)	(1002)
Sex		
Male	85%	84%
Female	15%	16%
Total	(46)	(1002)
Race		
White	91%	92%
Black or African American	9%	7%
Asian	0%	<1%
American Indian/Alaska Native	0%	1%
Unknown	0%	1%
Total	(46)	(1002)
Ethnicity		
Hispanic	3 .7%	5.5%
Not Hispanic	96.3%	94.5%
Total	(46)	(1002)

Table 3.1 Cont'd

Age at Diagnosis	**New HIV Diagnoses 1/1/04 to 12/31/04**	**People living in Maine with diagnosed HIV**
Less than 13	0%	1%
13-19	0%	2%
20-29	20%	23%
30-39	26%	40%
40-49	41%	25%
Over 49	11%	8%
Unknown	0%	11%
Total	(46)	(1002)
Region of Residence		
Northern (Aroostook, Hancock, Penobscot, Piscataquis, Washington counties)	17%	17%
Central (Androscoggin, Franklin, Kennebec, Knox, Lincoln, Oxford, Sagadahoc, Somerset and Waldo counties)	37%	30%
Southern (Cumberland and York counties)	46%	53%
Unknown	0	<1%
Total	(46)	(1002)

Compared to other states, Maine has a relatively low incidence of HIV, ranking 46th out of 51 (including the District of Columbia)[4]. The AIDS Case Rate per 100,000 population is 2.2 or 47th out of 51[5]. The majority of PLWHA in the state are white (92%), two thirds are between the ages of 30 and 49, and most reside in the counties of Central and Southern Maine.

---

[4] State Health Facts, *Kaiser Foundation*

[5] ibid

IV. CONSUMER SURVEY

Methods

Between October 26, 2004, and February 10, 2005, surveys were sent to Ryan White Title II funded HIV Case Management organizations throughout the state. Each survey was packaged, along with a $10 phone card and a self-addressed return envelope, for delivery to clients. Two different strategies were used to obtain a reasonable sample. During the weeks of October 26th to November 10th, agency staff were asked to hand deliver surveys to every client they saw until they ran out. Each agency was initially provided with just enough to sample 50% of their caseload (client caseload at all agencies totals 475). In February, this was followed by another mailing in areas where there had been a response rate of zero. Altogether, 270 surveys were distributed and 163 were returned. This number represents roughly 34% of the total caseload (475 at the time) of the AIDS Service Organizations (ASOs). This section of the Needs Assessment summarizes important findings from the surveys. Due to some participants choosing not to answer every question, the total number of respondents varies between questions.

Results

A. Description of Survey Participants

Table 4.1 outlines the combined total of client response by county and key demographic variables after the second phase of data collection was completed.

Three-quarters of the Consumer Survey respondents were men, and one-quarter were women. Ninety-two percent were white and 6% were African American. In addition, 6% of the respondents reported they are of Hispanic origin. Nearly a quarter of the survey respondents were between the ages of 20-29. Forty-three percent were ages 30-39 and 23% were between the ages of 40-49.

A comparison of these distributions to the epidemiological profile reveals that, for the most part, the survey respondents are similar to the total PLWHA population in Maine. The one exception is gender; women are slightly over-represented in the survey based on a comparison of sample demographics with the epidemiological profile.

Table 4.1: Consumer Survey Respondents by Demographic Characteristics

Demographic Characteristics	Survey Participants %	People in Maine with diagnosed HIV %
Sex		
Male	75.5	84
Female	24.5	16
Total	(163)	(1002)
Race		
White	92.0	92
Black or African American	5.6	7
Asian	2.5	1
American Indian/Alaska Native	2.5	1
No answer/unknown	5.6[6]	1
Total	(163)	(1002)
Ethnicity		
Hispanic	6.1	5
Not Hispanic	91.4	95
No answer/unknown	2.5	0
Total	(163)	(1002)
Age at Diagnosis		
Less than 13	0	1
13-19	.6	2
20-29	22.2	23
30-39	42.9	40
40-49	23.3	25
Over 49	7.4	8
No answer/unknown	5.5	22
Total	(163)	(1002)

Table 4.2 includes information about where survey respondents reside along with a comparison to the epidemiological profile data. The survey drew disproportionately from people in the central region of the state and included fewer people from the southern region of the state.

Table 4.3 includes a summary of survey respondents by county of residence. No responses were received from persons living with HIV/AIDS residing in Piscataquis County. Piscataquis County has the lowest rate of PLWHA in the state, with 23 cases per 100,000 residents.

---

[6] Percentages for survey respondent race do not add to 100 because respondents were asked to check all that apply. Some respondents identified multiple racial categories.

Table 4.2: Distribution of Survey Respondents by Region

Region of Residence	Total Survey Participants %	People in Maine with diagnosed HIV %
Northern (Aroostook, Hancock, Penobscot, Piscataquis, Washington counties)	17.8	17
Central (Androscoggin, Franklin, Kennebec, Knox, Lincoln, Oxford, Sagadahoc, Somerset and Waldo counties)	44.2	30
Southern (Cumberland and York counties)	35.0	53
Unknown	3.1	<1
Total	(163)	(1002)

Table 4.3: Distribution of Survey Respondents by County

County	Total Survey Participants %	HIV Cases Per 100,000 Population in Maine
Not reported	3.1	--
Androscoggin	15.3	84.8
Aroostook	3.1	32.5
Cumberland	19.6	141.2
Franklin	2.5	30.5
Hancock	8.6	61.8
Kennebec	10.4	76.8
Knox	2.5	53
Lincoln	3.1	50.6
Oxford	0.6	32.9
Penobscot	4.3	65.6
Piscataquis	0	23.2
Sagadahoc	0.6	51.1
Somerset	6.1	45.2
Waldo	3.1	55.1
Washington	1.8	44.2
York	15.3	82.5
Total	(163)	(1002)

Summary

The Needs Assessment sample, though not randomly selected, resembles the demographic profile of PLWHA in Maine, with the one exception of gender. Women are slightly overrepresented in the study sample.

B. Linkages to Care

This section reports information about when and how PLWHA in Maine access care. Data reported in this section include location of diagnosis, time between HIV and AIDS diagnoses and time between diagnosis and care. Location of diagnosis and length of time between HIV and AIDS diagnosis are indicators of linkages to care. The time between initial diagnosis of HIV and the onset of AIDS is typically 7 to 10 years. Knowing when people are diagnosed with HIV in relation to when they are diagnosed with AIDS provides some understanding of how well connected people are to systems of care. Simultaneous diagnosis of HIV and AIDS is an indicator of poor linkages to care, as is diagnosis in an emergency room. The advantages of early treatment are numerous for both individuals and society so the number of people who were simultaneously diagnosed with HIV and AIDS in Maine is of concern.

1. In Care and Out of Care

Survey respondents were classified as "in" or "out" of care based on their self report of taking medication for HIV and having HIV-related lab tests. Classifications are based on the HRSA definition of "in care", which is defined as taking medication for HIV and/or having a viral load test or T-cell count test within the past year. Results presented in Table 4.4 indicate that the majority (91%) of survey respondents reported being in care – either having tests within the past year or taking medication for HIV. Nine percent did not report having tests done, nor did they report taking medications during the past year. As reported in Table 4.5, among the overall population of PLWHA in Maine, 62.4% had not received CD-4 or viral load tests between 03/04 and 02/05 (reported by Maine labs). Though data on medication are not available for the PLWHA population at large, this likely reflects a significant difference between the survey sample and the general population of PLWHA.

Table 4.4: In-Care Status of Survey Respondents

In Care/Out of Care Status	%
No tests, no drugs	9.2
Receiving tests or drugs	90.8
Total	(163)

Table 4.5: CD4 or viral load test between 03/04 and 02/05 Among PLWHA in Maine

Received Tests Within Past Year	%
Yes	37.6
No	62.4
Total	(1006)

2. Place of Diagnosis

Table 4.6 includes information about the respondent's diagnosis and where they received their initial diagnosis. Forty-five percent of the sample reporting having been diagnosed with AIDS while 53% reported no AIDS. Nearly half (49.7%) of the sample received their initial HIV diagnosis in a doctor's office. One-fifth (19.5%) were diagnosed at a public health clinic and 8% were diagnosed in an Emergency Room.

Table 4.6: Diagnosis and Place of Diagnosis

Diagnosis	%
No AIDS	53.4
HIV/AIDS	44.8
Did not disclose	1.8
Total	(163)
Place of HIV Diagnosis	**%**
Doctor's Office	49.7
Public Health Clinic	19.5
Other	14.5
Emergency Room	7.5
AIDS Service Organization	6.9
Blood Bank / Plasma Center	1.9
Total	(159)

Table 4.7 presents an analysis of the relationship between length of time between HIV and AIDS diagnosis and where people were originally diagnosed. This analysis includes only the 61 people who reported having been diagnosed with AIDS, and who answered the question about location of diagnosis.

The most common place for diagnosis, regardless of length of time diagnosed with HIV before diagnosis with AIDS, is a doctor's office.

Table 4.7: Relationship Between Length of Time Between HIV Diagnosis and AIDS Diagnosis and Location of Initial Diagnosis

	Time Between Diagnosis of HIV and AIDS		
Diagnosis Location	At time of diagnosis %	1 to 5 years %	6 or more years %
Emergency Room	17.2	6.3	12.5
Blood Bank / Plasma center	3.4	0	0.0
Public Health Clinic	17.2	31.3	18.8
Doctor's Office	51.7	43.8	50.0
AIDS Service Organization	0	0	12.5
Other	10.3	18.8	6.3
Total	(29)	(16)	(16)

3. *Length of Time Between Diagnosis and Care*

Table 4.8 includes the length of time between diagnosis and seeking care reported by survey respondents. The overall total is presented, as well as percentages for each category of age of diagnosis. Overall, nearly three-quarters of the sample reported seeking care within a month of diagnosis. As age increases, the likelihood of seeking care within a month increases (X^2=32.2, p<.05). Eighty-two percent of those diagnosed between the ages of 30-39, 74% of those diagnosed between ages 40-49 and 83% of those diagnosed between ages of 50-59 went to a doctor within a month of diagnosis compared to only 47% of those diagnosed at ages under 29.

Overall nearly half of the sample, 49%, started taking medication within a month of diagnosis. Nearly one quarter (24%) began medication after one year. Starting medication revealed a pattern similar to that of first doctor's visit, though this difference is not statistically significant. Those diagnosed at a younger age were less likely to start medication within a month. Twenty-nine percent of people diagnosed before the age of 29 were taking medication within a month compared to 53% of people diagnosed at age 30-49 and 67% of people diagnosed at ages 50-59. It should be noted that PLWHA are not always encouraged by medical providers to begin treatment immediately after diagnosis. As treatment standards have changed, PLWHA have been encouraged to wait to reach particular levels of viral load and/or CD4 count before starting treatment. Therefore, length of time between diagnosis and start of medications should be interpreted with this in mind.

Older consumers sought both types of care – visiting a doctor and taking medication – more than younger consumers. This is most likely due to two contributing factors: a) younger people are more likely to lack health insurance; and b) younger people are generally in better health and are therefore less connected to the healthcare system.

Table 4.8: Length of Time Before Seeking Care by Age of Diagnosis

Time between diagnosis and first doctor visit	**Total %**	**Under 29 %**	**30-39 %**	**40-49 %**	**50-59 %**
I have not seen a Dr. for my HIV	3.3	8.8	1.5	2.6	0
Within a month	72.4	47.1	82.4	73.7	83.3
Within 3 months	7.9	11.8	4.4	13.2	0
Within 6 months	1.3	2.9	1.5	0	0
Within a year	6.6	11.8	5.9	2.6	8.3
Over a year	8.6	17.6	4.4	7.9	8.3
Total	(152)	(34)	(68)	(38)	(12)
Time between diagnosis and first HIV medications	**Total %**	**Under 29 %**	**30-39 %**	**40-49 %**	**50-59 %**
I have not gotten a prescription for drugs to fight my HIV	8.0	9.7	4.3	13.2	8.3
Within a month	48.7	29.0	52.2	52.6	66.7
Within 3 months	8.0	6.5	7.2	7.9	16.7
Within 6 months	4.0	9.7	2.9	2.6	0
Within a year	7.3	3.2	11.6	5.3	0
Over a year	24.0	41.9	21.7	18.4	8.3
Total	(150)	(31)	(69)	(38)	(12)

The protocols for treating HIV/AIDS changed dramatically in 1996 with the development of new medications. It is important to consider the era of diagnosis when interpreting trends in linkages to care. As reported below in Table 4.9, while not statistically significant, those diagnosed after 1996 were more likely to report seeing their doctor within a month of diagnosis. Eighty-three percent of those diagnosed after 1996 visited their doctor within a month compared to only two-thirds (65.6%) of those diagnosed prior to 1996.

Also reported in Table 4.9, those diagnosed after 1996 are more likely to begin medication sooner (X^2=30.4, p<.05). Over one third of those diagnosed prior to 1996 delayed medication over a year compared to only 6% of those diagnosed after 1996.

Table 4.9: Length of Time Between Diagnosis and Care and Era of Diagnosis

Time between diagnosis and first doctor visit	**HIV Diagnosis Before 1996**	**HIV Diagnosis 1996 or Later**
I have not seen a Dr. for my HIV	4.3	1.5
Within a month	65.6	83.1
Within 3 months	7.5	9.2
Within 6 months	2.2	0
Within a year	8.6	3.1
Over a year	11.8	3.1
Total	(93)	(65)
Time between diagnosis and first HIV medications	**HIV Diagnosis Before 1996**	**HIV Diagnosis 1996 or Later**
I have not gotten a prescription for drugs to fight my HIV	3.3	15.9
Within a month	47.8	52.4
Within 3 months	2.2	15.9
Within 6 months	3.3	4.8
Within a year	8.7	4.8
Over a year	34.8	6.3
Total	(92)	(63)

Summary

The vast majority (90.8%) of the Needs Assessment participants reported taking medication or receiving tests within the past twelve months. However a sizeable 9% are not in care by the HRSA definition. Less than half (45%) of the survey sample has been diagnosed with AIDS. Most of the initial HIV diagnoses took place in a Doctor's office (50%) or public health clinic (20%). The majority (72%) of people sought care within a month of diagnosis. Less than half (49%) started taking medications within a month. Older people are more likely to seek both of these types of care within a month. Those diagnosed prior to 1996 were more likely than those diagnosed after 1996 to have delayed medication over one year.

C. Medical Coverage and Costs of Care

Data reported in this section relate to access to medical coverage and out-of-pocket costs or insurance. Table 4.10 includes medical coverage broken down by income categories. Specific data include whether or not a person had medical coverage at the time they completed the survey, the type of coverage, and if/for how long they went without coverage during the past year.

1. Access to Medical Coverage

The vast majority of survey respondents reported having some type of coverage (88%). Those with higher incomes were slightly more likely to have coverage, but this is not statistically significant. Ninety-two percent of those earning between $20,000 and $29,999 and 100% who earn over $30,000 reported having health coverage, compared to 84% of those earning between $10,000 and $19,999 and 89% of those earning under $10,000.

Respondents were asked to select all of the different forms of medical coverage they were covered by. Nearly two-thirds (63%) of respondents reported they were covered by MaineCare/Medicaid. Over half (52%) were covered by Medicare. Over one-third (36%) reported they had coverage through both MaineCare and Medicare. Nearly half (44%) were covered by some form of private insurance, either private insurance (21%), private insurance through work or COBRA (16%), private insurance not through work (3%) or through their partner’s plan (4%).

Nearly one-fifth (18%) of respondents reported that they lacked coverage at some time during the past year. Lacking health coverage varied slightly by income, though these differences were not statistically significant. The relationship between income and access to health coverage is curvilinear, meaning that those with the least and those with the most income were less likely to be without health insurance compared to those with incomes in the middle. None of the highest income group reported being without health insurance during the year. Seventy seven percent of those with moderate incomes, between $20,000 and $29,999 a year reported “never” being without health insurance. Half of those in this income category who were without health coverage last year, lacked insurance for four months or more. Eighty-six percent of those in the lowest income category reported there was never a time they lacked health insurance during the past year. However, for the remaining 14% of people within this income category who did lack coverage, paying the costs of medical expenses out of pocket would have been quite a financial burden.

Table 4.10 Access to Medical Coverage by Income

Health Insurance	**Total %**	**$9,999 & under %**	**$10,000-$19,999 %**	**$20,000- $29,999 %**	**Over $30,000 %**
"Yes" - has health insurance	88.3	89.2	84.4	92.3	100.0
Type of Insurance	**Total %**	**$9,999 & under %**	**$10,000-$19,999 %**	**$20,000- $29,999 %**	**Over $30,000 %**
Private	21.0	6.2	12.5	57.7	100.0
Private through work or COBRA	16.0	1.5	10.9	46.2	85.7
Private - not through work	2.5	4.6	1.6	0	0
Partner's/Parent's plan at work	3.7	1.5	1.6	11.5	14.3
Medicare	51.9	53.8	56.3	50.0	0
Veterans Administration	3.7	4.6	1.6	7.7	0
MaineCare/Medicaid	63.0	80.0	65.6	30.8	0
Other	3.1	3.1	3.1	3.8	0
Time without insurance in past year	**Total %**	**$9,999 & under %**	**$10,000-$19,999 %**	**$20,000- $29,999 %**	**Over $30,000 %**
Never	82.1	86.2	78.1	76.9	100.0
Less than a month	5.6	4.6	7.8	3.8	0
1-3 months	4.9	3.1	6.3	7.7	0
4 months to a year	6.2	4.6	6.3	11.5	0
Total	(162)	(65)	(64)	(26)	(7)

2. Cost of Medical Coverage

As shown in Table 4.11, over half (55%) of the total sample paid nothing each month for a premium for their medical coverage and 24% paid less than $100.

Table 4.11 also shows how costs of premiums and deductibles varied by income (X^2=42.8, p<.05). Those with lower incomes were more likely to report no costs for health insurance premiums (62% with incomes under $10,000 and 63% with income between $10,000 and $19,999), compared to 26% of those with incomes between $20,000 and $29,999 and 14% of those with incomes over $30,000).

Over one-third of the sample paid nothing in deductibles over the year but this again varied by income with those earning less being more likely to report paying no deductible (X^2=34.3, p<.05). Those with moderate incomes ($20,000-$29,999) were once again in the worst position with nearly one-third of this income category paying at least $1,000/year in deductibles (9% of those earning $20,000 to $29,999 paid $1000-$1500, 4% paid over $1,500-$2,000, and 17% paid over $2,500, for a combined total of 30% paying at least $1,000).

Table 4.11: Out-of-Pocket Costs for Insurance by Income

Cost of Insurance Premiums	Total %	Under $9,999 %	$10,000-$19,999 %	$20,000- $29,999 %	Over $30,000 %
Nothing	54.5	62.3	63.0	26.1	14.3
Less than $100/month	24.1	23.0	20.4	26.1	57.1
$101 - $200/month	8.3	3.3	3.7	26.1	28.6
$201 - 300/month	4.1	1.6	5.6	8.7	0
$301 - 400/month	1.4	0	1.9	4.3	0
$401 - 500/month	0.7	0		4.3	0
More than $500/month	1.4	0	1.9	4.3	0
I don't know	5.5	9.8	3.7	0	0
Total	(145)	(61)	(54)	(23)	(7)
Insurance deductibles	**Total %**	**Under $9,999 %**	**$10,000-$19,999 %**	**$20,000- $29,999 %**	**Over $30,000 %**
Nothing	38.1	47.4	42.3	13.0	14.3
Less than $500/year	21.6	26.3	15.4	26.1	14.3
$501 - 1000/year	11.5	5.3	15.4	17.4	14.3
$1001 - 1500/year	5.8	1.8	5.8	8.7	28.6
Over $1500/year	2.2	0	3.8	4.3	0
Over $2500	4.3	1.8	1.9	17.4	0
I don't know	16.5	17.5	15.4	13.0	28.6
Total	(139)	(57)	(52)	(23)	(7)

Summary

While most Consumer Survey respondents reported access to some form of medical coverage (88%), the remaining 12 % who lacked insurance coverage faced a major barrier to care. Those with lower incomes were more likely to be eligible for public funded care, while those in the highest income bracket were more likely to have insurance through other means. Those consumers in the moderate income category ($20,000 to $29,999) faced a dilemma that many earn too much money to qualify for MaineCare, but did not have access to other forms of insurance. Those in this income bracket pay more out of pocket than other income categories.

D. Medication

This section addresses issues related to medication. Respondents were asked a variety of questions about medication including whether or not they took various medications, the costs of meds and co-pays, whether they ever stopped taking their medication, and reasons for missing doses of their medication.

1. Type of Medication

Tables 4.12 and 4.13 include information about the medications survey respondents reported taking. Eighty-two percent reported taking some type of medication to treat their HIV infection. Among those taking any kind of medication to treat their HIV infection, most (92%) reported taking HIV medications. Sixty-six percent reported taking other medications. See table A.8 in Appendix A for a list of these medications. Nearly half (49%) reported taking anti-depressants, and just under one half (40%) reported taking antibiotics. Over one-quarter reported taking antifungal medications, 16% reported taking hormones, and 14% reported taking steroids.

Table 4.12: Current Status of HIV Medications

Are you currently taking medications to treat your HIV infection?	%
Yes	82.1
No	17.9
Total	(162)

Table 4.13: Type of Medication

Type of Medication	Yes	No	Don't Know	Total
	%	%	%	N
HIV medications	91.8	6	2.2	(134)
Other	66.4	28.7	4.9	(122)
Antidepressants	49.2	48.4	2.4	(124)
Antibiotics	39.7	57.9	2.5	(121)
Antifungal	28.8	66.4	4.8	(125)
Hormones	15.6	82.6	1.8	(109)
Steroids	13.9	81.7	4.3	(115)

2. Medication Costs

Costs of medication are reported below in Table 4.14. Only 17% reported no costs. A third (34%) reported costs between $1 and $25 per month. However, nearly 15% reported costs in excess of $100 per month.

Table 4.14: Out-of-Pocket Expenses for Medications

Out of Pocket Expenses for Medications	%
Nothing	17.2
$1- $25 per month	33.6
$26 - $50 per month	16.4
$51 - $100 per month	14.1
More than $100 per month	14.8
I don't know	3.9
Total	(128)

Given the relatively small number of respondents who reported no out-of-pocket costs for medication, as well as the relatively low income of the majority of the respondents, assistance with payment for medications can be a valuable resource. Table 4.15 below includes responses to a question in the survey that asked respondents if they received assistance with payment for HIV/AIDS drugs.

MaineCare was the most frequently sited source of assistance with payment for drugs. Three-quarters (75%) reported assistance from MaineCare. A third (34%) reported assistance from a local AIDS service organization and a quarter (24%) mentioned assistance from private insurance or their HMO. Sixteen percent of survey participants reported they received help paying for HIV/AIDS medication from the AIDS Drug Assistance Program.

Table 4.15: Assistance with Payment for HIV/AIDS Drugs

Do the following help pay for your HIV/AIDS Drugs?	Yes	No	Don't Know	Total
MaineCare/Medicaid	75.7	21.6	2.7	(148)
Local AIDS Service Organization	33.6	61.2	5.2	(134)
Private Insurance or HMO	24.1	75.9	0.0	(116)
AIDS Drug Assistance Program	15.8	78.1	6.1	(114)
Medicare Prescription Card	9.3	88.1	2.5	(118)
Veterans Administration Medical Assistance	6.1	91.3	2.6	(115)
Other	2.3	89.8	8.0	(88)
Patient Assistance Programs from Drug Companies	1.7	95.7	2.6	(116)
Clinical Trials	0.0	97.4	2.6	(114)

3. Missed Doses of Medication

Respondents were also asked to report whether they had missed a dose of medication, both upon the advice of a doctor and without the advice of a doctor. The question was asked in these two ways to distinguish missed medication that was medically recommended from missed doses that were not medically recommended. If a respondent reported they had missed a dose of medicine without the advice of their doctor, they were then asked to identify reasons for missing their medication.

Table 4.16 summarizes the percentage of respondents who reported missing a dose of medicine upon the advice of a doctor. Half, 53% reported never missing a dose upon the advice of a doctor. One-quarter, 24% said they rarely miss their medication upon the advice of a doctor. Eleven percent missed it some of the time and only 2% reported often missing their medicine upon the advice of a doctor.

Two-thirds of respondents reported that they had missed their medication without the advice of a doctor. While many, 40%, said they rarely missed a dose of medication, 17% reported sometimes and only 3% reported often missing medications.

Table 4.16: Missed Medication

How often in the past year have you missed a dose or stopped taking your HIV medication with the advice of a doctor?	%
Never	53.3
Rarely	24.4
Some of the time	11.1
Often	2.2
I have stopped taking my medicine	8.9
Total	(135)
How often in the past year have you missed a dose or stopped taking your HIV medication without the advice of a doctor?	**%**
Never	35.5
Rarely	40.6
Some of the time	16.7
Often	2.9
I have stopped taking my medicine	4.3
Total	(138)

Those who missed medication (n=89) without the advice of a doctor were asked to report reasons why they missed a dose of medication. A summary of these reasons is reported in Table 4.17. The most frequently cited reasons are: 1) forgot (83%); 2) side effects (36%); 3) ran out of medication (30%). Although not common responses, 16% reported not being able to fill prescriptions as a reason for missing a dose and 12% reported that they had missed a dose because they could not afford the medication.

This table also includes reasons broken down by how frequently respondents missed their medication. The total numbers of respondents who reported "often" missing medication and "I stopped taking my medication" are quite small, n=4 and 6 respectively; small changes in numbers increase percentages dramatically in these two response categories. Therefore, interpretation will focus on those who reported missing medication "rarely" and "some of the time." Those who reported missing their medication some of the time identified similar reasons to those who "rarely" missed medication with forgetting being the most common reason for both groups. Those who missed medication some of the time also identified: 1) difficult schedule and requirements (39%); 2)hard to coordinate with food (26%); 3)don't want others to see medication (22%).

Table 4.17: Reasons reported for stopping medication without the advice of a doctor by frequency of missing a dose

If you have missed a dose, or stopped taking your meds without the advice of a doctor, which of the following were the reasons:	Total %	How often have you missed a dose or stopped taking your medication without the advice of a doctor?			
		Rarely %	Some of the time %	Often %	I stopped taking my medicine %
Forgot to take the medication	83.1	78.6	78.3	100.0	16.7
Side effects	36.0	14.3	39.1	50.0	100.0
Ran out of medication	30.3	26.8	34.8	0.0	0.0
Difficult schedule and requirements	19.1	8.9	39.1	0.0	16.7
Hard to coordinate with food	18.0	5.4	26.1	25.0	33.3
Didn't want others to see the medication	18.0	5.4	21.7	50.0	0.0
Wasn't able to fill prescription	15.7	10.7	8.7	25.0	0.0
Could not afford the medication	12.4	7.1	13.0	0.0	0.0
Felt that the medication didn't work	9.0	3.6	8.7	0.0	33.3
No place to keep medications	4.5	0.0	4.3	0.0	0.0
Didn't understand the instructions	2.2	0.0	0.0	0.0	0.0
To share medications with others	2.2	0.0	0.0	0.0	0.0
Total	(89)	(56)	(23)	(4)	(6)

Summary

The majority of respondents reported taking medication (82%) during the past year. The vast majority of these were taking HIV antiviral medications. MaineCare and insurance were the most commonly cited source of assistance for paying for medications, yet 15% paid more than $100 per month out-of-pocket for their medications. One-fifth of the respondents reported missing their medication at least some of the time or often without the advice of a doctor during the past year. The most common reason identified for missing a dose was forgetting, side effects or ran out of medication. Cost of the medication was identified by 12.4% of those who missed a dose.

V. SERVICE USE AND NEEDS

A number of questions in the Consumer Survey addressed service use and needs. In addition, there was a long list of services at the end of the questionnaire, and respondents were asked to indicate whether they had used these services within the past twelve months or had needed but not been able to receive them. If the latter, they were asked to indicate the reason for not receiving the service.

Results

1. Service Use

Respondents were asked a series of questions related to the services that they actually use.

Analyses of service use by region, income, insurance type, gender, sexual orientation and health status are presented in Tables 5.3 (page 30), 5.4 (page 31) and 5.5 (page 32).

Overall, the most frequently cited services were: HIV Case Management (69%), prescription drugs (63%), medical care (50%), information (49%), dental care (49%), client advocacy (42%) and mental health (32%). The fact that HIV Case Management was the most frequently cited service used is not terribly surprising given the fact that surveys were distributed to consumers through their case managers. It is somewhat surprising that the percent reporting HIV Case Management was not 100%. The least used services included home delivered meals (2%) and daycare (1%).

Table 5.3, also includes use of service by region and service agency. Region is based on county of residence (see Table 4.2 on page 13 for the counties included in each region). With the exception of help paying for health insurance and home health care and hospice, consumers in the South reported using fewer services across the board than consumers from other regions. This table also includes service use by AIDS Service Organization. AIDS Service Organization (ASO) was inferred based on survey participants' self reported county of residence. It is important to note that there is not a 100% correspondence between county of residence and ASO. Clients can and do cross counties to access needed services. For this reason, data reported by service agency should be interpreted with caution.

As reported in Table 5.4, those with private insurance (either from their work, COBRA or a partner's work) were less likely to access services across the board than those with other forms of insurance. As income increased, use of services declined (transportation - X^2=12.2, p<.05; prescription drugs - X^2=8.9, p<.05; foodbank - X^2=8.6 p<.05; emergency housing assistance, X2=10.9, p<.05). The only exception to this trend is dental care where those with the most income (over $30,000) reported slightly more use of dental care services than those with moderate incomes ($20,000-$29,999), but this difference was not statistically significant.

Though not statistically significant, women were slightly less likely to access health-related services like dental care and medical care and slightly more likely to access food bank, emergency services and bus fares (see Table 5.5). Women were significantly more likely to access Day Care services (X^2=6.2, p<.05). Service use did not differ significantly between groups defined by sexual orientation. Numbers of lesbians, bisexual and other sexualities are quite small, with small changes in numbers causing large changes in percentages. Therefore, comparison will focus on that between heterosexuals and gay men. In addition to case management, heterosexuals reported accessing prescription drugs (68%), information (55%), and medical care (46%). Gay men also reported accessing prescription drugs (65%) and medical care (54%), in addition to dental care (55%) and client advocacy services (51%).

Respondents reported using a variety of complimentary, mental health care and substance abuse services. Reports of complimentary service use are presented in Table 5.1. Nearly two-thirds (62.9%) reported receiving individual therapy with a non-psychiatrist. Sixty percent reported using vitamins and antioxidants. Nearly one half (48%) used individual therapy with a psychiatrist. Thirty-eight percent used medication prescribed by a psychiatrist. Just over one-third (35%) reported using dietary supplements and one quarter (25%) used massage.

Table 5.1: Percent Who Reported Using Services

	%	Total
Individual therapy with a non-psychiatrist	62.9	(159)
Vitamins/antioxidants	60.1	(158)
Individual therapy with a psychiatrist	48.1	(160)
Medication prescribed by a psychiatrist	38.4	(159)
Dietary supplements	35.9	(153)
Group therapy	31.6	(158)
Massage	24.7	(154)
Treatment for alcohol or drug use	19.1	(162)
Chiropractor	16.2	(154)
Herbal treatments	9.8	(153)
Other	9.2	(98)
Acupuncture	5.3	(152)

2. Service Needs

Respondents were asked to report the services they currently need but are unable to get. Responses to these questions are reported in Tables 5.6 (page 33), 5.7 (page 34), and 5.8 (page 35).

Dental care, emergency housing assistance and food bank were the categories of services most frequently identified by the entire sample.

Examining subgroups revealed some interesting similarities and differences. Emergency housing assistance is a common need across all regions, and dental care is the most common need identified by people in all income and insurance categories. Reported need for services declines as income increases with those in the highest income category (over $30,000) reporting fewer needs for services. Those with incomes between $20,000 and $29,999 reported greater need for some services like dental care and HIV Case Management than those in lower income categories, though these differences are not statistically significant. Those in the lowest income category (less than $10,000) reported the greatest need for emergency housing assistance (X^2=10.9, p<.05).

Dental care and emergency housing were the most common needs identified by women. Dental care and the food bank were the most common needs identified by men.

Survey respondents were classified as being in “good” or “poor” health, based on self reports of T-cell counts and viral loads. Those with viral loads greater than 100,000 or T-cell counts of less than 200 were considered to be in “poor” health (n=20). Those with T-cell counts of more than 200 or viral loads less than 100,000 were classified as being in “good” health (n=90). Fifty-three respondents did not provide their T-cell or Viral Load data.

Reported service needs were greater for those in poor health than those in good health. A quarter of those in poor health reported needing dental care. Emergency housing assistance and home delivered meals were reported as needed by 15% of those in poor health. Fourteen percent of those in good health reported needing dental care and 9% in good health reported needing emergency housing assistance.

3. Barriers to Care

Barriers to care were assessed in two ways: 1) an assessment of ease of access to services; and 2) a report of unmet need for specific service categories. First, to measure ease of access to various services, a question in the survey asked respondents to report if they think it is “easy” to get from their house to a variety of services including medical services, human services, and childcare. Results from this question are presented below in table 5.2.

Around 20% reported it was “not easy” to access each of the different types of services. This suggests that for nearly one-fifth of the sample, lack of easy access from their place of living to essential services is a barrier to care. Though not statistically significant, differences were found. Table A.11 in Appendix A includes a breakdown of those who reported no easy access to theses services by key variables: those who lack insurance, income, age, health status and region.

Table 5.2: Perception of Easy Access to Services

Please indicate if you think it's easy to get from your house to each of the following services	Yes %	No %	Not Applicable %	Total %
Medical Services	78.1	21.2	0.7	(151)
Human Services	72.8	20.9	6.3	(158)
Basic services like food pantry, etc.	61.3	21.3	17.4	(155)
Transportation	65.6	19.5	14.9	(154)
Child Care	9.1	9.1	81.8	(143)

Secondly, a comparison was made between services that respondents said they needed, and services they reported currently using. If respondents identified needing a service, but not using it, they were asked to report why they were unable to get that service. Results for this question are presented in Table 5.9 (page 36). Cost was identified as a major barrier to dental care with 16 people identifying that as a reason for not accessing dental services. Cost was also a barrier to paying for health insurance and using prescription drugs. A few clients listed transportation as a barrier to accessing a variety of services. This suggests that while transportation might not be a problem for the vast majority of clients, those who do lack transportation have trouble accessing a wide range of services. Hours of service was not mentioned as a barrier to many services but it was mentioned by three people as a barrier to dental care. Eligibility was mentioned as a reason why respondents were not accessing particular services 25 times.

No respondent reported "not knowing it was offered" as a barrier to accessing Case Management, daycare; hospice, and prescription drugs. Additionally, no respondent mentioned "don't know where to go" for these services plus mental health treatment. Aside from these services, all other service categories had a few respondents that did not know what services were available or where to go to access services, suggesting that some consumers need better information about the full range of services provided and location of services.

Summary

The analysis of use, needs, and barriers, revealed important information about which services clients access, which services they are unable to access and why they can't access needed services. While there were some notable differences by region, income, gender and health status, HIV Case Management and prescription drugs were the services that clients reported using the most. This finding is not surprising given the way in which survey participants were selected to participate – through Case Management agencies.

Dental care and emergency housing assistance were the services that consumers most frequently reported needing. Cost appears to be a barrier to a range of services, but especially for dental care, health insurance and prescription drugs. Consumers also reported eligibility requirements as a reason they were not accessing needed services.

Limitations of the Consumer Survey Results

The Consumer Survey had some limitations that need to be considered when interpreting these results. Sampling for the survey was not ideal. Resources were too limited to attempt a statewide, random sample of the known HIV positive population. Therefore, we elected to sample the clients of Ryan White Title II funded agencies, a convenience sample. Concerns around confidentiality required that we depend on the agencies to deliver the surveys, either through mail or by hand, resulting in a somewhat haphazard sampling method. However, despite the lack of a true random sample, the demographic similarities between the survey sample and the overall population of Maine PLWHA provides confidence that this data accurately reflects the overall population.

Other limitations include some measurement concerns with the questions that asked respondents to identify which services they currently used, which services they needed and the barriers to services. Given the large number of apparent “no’s” (no circle completed), it appears that many respondents were either confused by the service grid or chose not to answer it. One question in the service grid, “have you taken prescription drugs in the past year?”, was asked in a slightly different format earlier in the questionnaire. Results reveal far fewer reporting “yes” in the service grid compared to the earlier question. It is possible therefore, that this tool under-represents use of services and needs for services.

Table 5.3: Percent Reporting Use of Services by Region

		Region				Service Agency						
	Overall	**North**	**Central**	**South**	**Unknown**	**Coastal**	**Down East**	**Eastern Maine**	**Health Reach**	**Frannie Peabody**	**St. Mary's**	**Not reported**
Substance Abuse treatment	10.4	17.2	9.7	7.0	20.0	11.1	17.6	16.7	10.8	7.0	7.7	20.0
Case Management	69.3	65.5	81.9	57.9	40.0	77.8	52.9	83.3	78.4	57.9	88.5	40.0
Client Advocacy	41.7	51.7	43.1	36.8	20.0	33.3	47.1	58.3	37.8	36.8	53.8	20.0
Day Care for children	1.2	0.0	2.8	0.0	0.0	0.0	0.0	0.0	5.4	0.0	0.0	0.0
Dental Care	49.1	62.1	50.0	42.1	40.0	55.6	58.8	66.7	54.1	42.1	42.3	40.0
Information on HIV/AIDS	49.7	65.5	62.5	--	20.0	55.6	52.9	83.3	59.5	--	69.2	20.0
Emergency Housing Assistance	16.6	20.7	18.1	12.3	20.0	11.1	29.4	8.3	18.9	12.3	19.2	20.0
Emergency Assistance	12.3	17.2	12.5	10.5	0.0	11.1	17.6	16.7	13.5	10.5	11.5	0.0
Food Bank	37.4	44.8	33.3	38.6	40.0	55.6	29.4	66.7	29.7	38.6	30.8	40.0
Help Paying for Health Insurance	12.9	13.8	11.1	15.8	0.0	0.0	23.5	0.0	18.9	15.8	3.8	0.0
Home Delivered Meals	1.8	0.0	4.2	0.0	0.0	0.0	0.0	0.0	8.1	0.0	0.0	0.0
Home Health Care	4.9	3.4	5.6	5.3	0.0	0.0	0.0	8.3	5.4	5.3	7.7	0.0
Hospice Care	0.6	0.0	0.0	1.8	0.0	0.0	0.0	0.0	0.0	1.8	0.0	0.0
Medical Care	49.7	51.7	51.4	49.1	20.0	55.6	41.2	66.7	54.1	49.1	46.2	20.0
Mental Health/Support Group/Counseling	31.9	51.7	33.3	21.1	20.0	22.2	47.1	58.3	32.4	21.1	38.5	20.0
Prescription Drugs	63.2	69.0	66.7	57.9	40.0	77.8	64.7	75.0	62.2	57.9	69.2	40.0
Bus Fares, Taxi Vouchers or rides	17.2	20.7	22.2	8.8	20.0	11.1	11.8	33.3	18.9	8.8	30.8	20.0
Other	6.7	24.1	2.8	3.5	0.0	0.0	35.3	8.3	2.7	3.5	3.8	0.0
Total	(163)	(29)	(72)	(57)	(5)	(9)	(17)	(12)	(37)	(57)	(25)	(5)

Table 5.4: Percent Reporting Use of Services by Insurance Type and Income

	Type of Insurance					Income			
	Private Insurance	Medicare	Maine Care	Other	No Insurance	under $10,000	$10,000- $19,999	$20,000 - $29,999	over $30,000
SA treatment	8.8	11.9	13.6	0.0	0	10.8	12.5	7.7	0.0
Case Management	58.8	69.0	69.9	60.0	83.3	63.1	81.3	65.4	42.9
Client Advocacy	41.2	45.2	44.7	60.0	16.7	36.9	51.6	34.6	28.6
Day Care for children	0.0	1.2	1.0	0.0	0	0.0	1.6	3.8	0.0
Dental Care	41.2	53.6	48.5	60.0	50.0	58.5	46.9	34.6	42.9
Information on HIV/AIDS and treatment	44.1	46.4	50.5	60.0	58.3	50.8	56.3	34.6	42.9
Emergency Housing Assistance	5.9	15.5	21.4	0.0	8.3	26.2	15.6	0.0	0.0
Emergency Assistance	2.9	11.9	13.6	0.0	8.3	16.9	14.1	0.0	0.0
Food Bank	20.6	36.9	39.8	40.0	41.7	46.2	39.1	23.1	0.0
Help Paying for Health Insurance	14.7	10.7	13.6	20.0	8.3	9.2	14.1	15.4	28.6
Home Delivered Meals	0.0	2.4	2.9	0.0	0	1.5	3.1	0.0	0.0
Home Health Care	2.9	3.6	6.8	0.0	0	9.2	1.6	3.8	0.0
Hospice Care	0.0	1.2	1.0	0.0	0	1.5	0.0	0.0	0.0
Medical Care	32.4	52.4	57.3	60.0	33.3	56.9	51.6	38.5	14.3
Mental Health/Support Group/Counseling	32.4	40.5	35.0	20.0	8.3	32.3	32.8	38.5	0.0
Prescription Drugs	58.8	67.9	68.9	60.0	41.7	70.8	67.2	46.2	28.6
Bus Fares, Taxi Vouchers or rides	8.8	17.9	24.3	0.0	0	29.2	12.5	3.8	0.0
Other	2.9	8.3	8.7	0.0	8.3	6.2	10.9	0.0	0.0
Total	(34)	(84)	(103)	(5)	(12)	(65)	(64)	(26)	(7)

Table 5.5: Percent Reporting Use of Services by Gender and Sexual Orientation

	Gender		Sexual Orientation					Health Status	
	Male	Female	Heterosexual/ Straight	Gay Man	Lesbian	Bisexual	Other	Poor Health	Good Health
Substance Abuse treatment	8.9	15.0	16.1	7.0	0.0	11.1	16.7	15.0	8.9
Case Management	71.5	62.5	64.3	73.3	0.0	77.8	83.3	70.0	68.9
Client Advocacy	45.5	30.0	32.1	51.2	0.0	11.1	66.7	55.0	43.3
Day Care for children	0.0	5.0	0.0	0.0	0.0	11.1	0.0	5.0	0.0
Dental Care	49.6	47.5	41.1	54.7	100.0	44.4	50.0	40.0	51.1
Information on HIV/AIDS and treatment	50.4	47.5	55.4	47.7	50.0	33.3	66.7	40.0	51.1
Emergency Housing Assistance	16.3	17.5	17.9	14.0	0.0	11.1	50.0	25.0	15.6
Emergency Assistance	11.4	15.0	10.7	11.6	0.0	0.0	50.0	5.0	13.3
Food Bank	34.1	47.5	39.3	36.0	0.0	22.2	66.7	40.0	38.9
Help Paying for Health Insurance	13.0	12.5	16.1	10.5	0.0	22.2	0.0	20.0	8.9
Home Delivered Meals	1.6	2.5	3.6	1.2	0.0	0.0	0.0	5.0	1.1
Home Health Care	4.1	7.5	5.4	1.2	0.0	22.2	33.3	5.0	4.4
Hospice Care	0.8	0.0	0.0	1.2	0.0	0.0	0.0	0.0	0.0
Medical Care	53.7	37.5	46.4	53.5	50.0	44.4	50.0	65.0	50.0
Mental Health/Support Group/Counseling	32.5	30.0	30.4	29.1	50.0	44.4	66.7	45.0	34.4
Prescription Drugs	65.9	55.0	67.9	65.1	50.0	44.4	50.0	65.0	67.8
Bus Fares, Taxi Vouchers or rides	16.3	20.0	21.4	14.0	0.0	22.2	33.3	30.0	15.6
Other	5.7	10.0	8.9	4.7	0.0	0.0	33.3	10.0	5.6
Total	(123)	(40)	(56)	(86)	(2)	(9)	(6)	(20)	(90)

Table 5.6: Percent Reporting Need for Service by Region and Service and Agency

	Total	Region				Service Agency						
		North	Central	South	Unknown	Coastal	Down East	Eastern Maine	Health Reach	Frannie Peabody	St. Mary's	Not reported
Substance Abuse treatment	2.5	0.0	2.8	3.5	0.0	11.1	0.0	0.0	0.0	3.5	3.8	0.0
Case Management	1.8	0.0	1.4	3.5	0.0	0.0	0.0	0.0	2.7	3.5	0.0	0.0
Client Advocacy	3.7	0.0	2.8	7.0	0.0	0.0	0.0	0.0	2.7	7.0	3.8	0.0
Day Care for children	2.5	3.4	1.4	3.5	0.0	0.0	0.0	8.3	2.7	3.5	0.0	0.0
Dental Care	14.1	3.4	13.9	21.1	0.0	22.2	5.9	0.0	8.1	21.1	19.2	0.0
Information on HIV/AIDS	3.1	0.0	2.8	5.3	0.0	0.0	0.0	0.0	5.4	5.3	0.0	0.0
Emergency Housing Assistance	8.6	6.9	9.7	8.8	0.0	0.0	11.8	0.0	13.5	8.8	7.7	0.0
Emergency Assistance	5.5	10.3	2.8	7.0	0.0	0.0	11.8	8.3	2.7	7.0	3.8	0.0
Food Bank	6.7	6.9	5.6	8.8	0.0	0.0	5.9	8.3	5.4	8.8	7.7	0.0
Help Paying for Health Ins.	8.6	13.8	6.9	8.8	0.0		11.8	16.7	10.8	8.8	3.8	0.0
Home Delivered Meals	4.3	3.4	6.9	1.8	0.0	0.0	0.0	8.3	10.8	1.8	3.8	0.0
Home Health Care	2.5	0.0	4.2	1.8	0.0	0.0	0.0	0.0	5.4	1.8	3.8	0.0
Hospice Care	0.6	0.0	1.4	0.0	0.0	0.0	0.0	0.0	2.7	0.0	0.0	0.0
Medical Care	1.2	0.0	0.0	3.5	0.0	0.0	0.0	0.0	0.0	3.5	0.0	0.0
Mental Health/Support Group/Counseling	6.1	0.0	5.6	10.5	0.0	22.2	0.0	0.0	5.4	10.5	0.0	0.0
Prescription Drugs	3.1	0.0	2.8	5.3	0.0	0.0	0.0	0.0	5.4	5.3	0.0	0.0
Bus Fares, Taxi Vouchers or rides	5.5	3.4	9.7	1.8	0.0	0.0	5.9	0.0	13.5	1.8	7.7	0.0
Other	3.1	3.4	5.6	0.0	0.0	0.0	5.9	0.0	8.1	0.0	3.8	0.0
Total	(163)	(29)	(72)	(57)	(5)	(9)	(17)	(12)	(37)	(57)	(26)	(5)

Table 5.7: Percent Reporting Need for Service by Type of Insurance and Income

	Insurance Status					Income			
	Private Insurance	**Medicare**	**Maine Care**	**Other**	**No Insurance**	**under $10,000**	**$10,000-$19,999**	**$20,000 - $29,999**	**over $30,000**
SA treatment	2.9	2.4	2.9	0.0	0.0	4.6	1.6	0.0	0.0
Case Management	2.9	2.4	2.9	0.0	0.0	1.5	1.6	3.8	0.0
Client Advocacy	2.9	6.0	3.9	0.0	0.0	7.7	0.0	3.8	0.0
Day Care for children	0.0	2.4	3.9	0.0	0.0	4.6	1.6	0.0	0.0
Dental Care	17.6	16.7	15.5	20.0	16.7	7.7	17.2	23.1	14.3
Information on HIV/AIDS and treatment	5.9	4.8	2.9	0.0	0.0	4.6	0.0	7.7	0.0
Emergency Housing Assistance	0.0	9.5	9.7	0.0	16.7	15.4	3.1	7.7	0.0
Emergency Assistance	0.0	4.8	6.8	0.0	0.0	7.7	3.1	7.7	0.0
Food Bank	8.8	9.5	9.7	0.0	0.0	9.2	4.7	7.7	0.0
Help Paying for Health Insurance	14.7	9.5	7.8	20.0	0.0	0.0	0.0	3.8	0.0
Home Delivered Meals	2.9	4.8	6.8	0.0	0.0	6.2	4.7	0.0	0.0
Home Health Care	0.0	2.4	3.9	0.0	0.0	6.2	0.0	0.0	0.0
Hospice Care	0.0	1.2	1.0	0.0	0.0	1.5	0.0	0.0	0.0
Medical Care	0.0	1.2	1.9	0.0	0.0	1.5	1.6	0.0	0.0
Mental Health/Support Group/Counseling	2.9	8.3	7.8	0.0	8.3	6.2	7.8	3.8	0.0
Prescription Drugs	2.9	2.4	2.9	0.0	0.0	1.5	4.7	0.0	14.3
Bus Fares, Taxi Vouchers or rides	5.9	3.6	5.8	0.0	0.0	7.7	4.7	3.8	0.0
Other	2.9	3.6	1.9	20.0	0.0	1.5	4.7	3.8	0.0
Total	(34)	(84)	(103)	(5)	(12)	(65)	(64)	(26)	(7)

Table 5.8: Percent Reporting Need for Service by Gender, Sexual Orientation and Health Status

	Gender		Sexual Orientation					Health Status	
	Male	Female	Heterosexual/ Straight	Gay Man	Lesbian	Bisexual	Other	Poor Health	Good Health
Substance Abuse treatment	3.3	0.0	0.0	3.5	0.0	0.0	16.7	5.0	2.2
Case Management	2.4	0.0	1.8	2.3	0.0	0.0	0.0	5.0	1.1
Client Advocacy	4.9	0.0	1.8	3.5	0.0	22.2	0.0	5.0	4.4
Day Care for children	1.6	5.0	3.6	2.3	0.0	0.0	0.0	10.0	1.1
Dental Care	14.6	12.5	10.7	18.6	0.0	11.1	0.0	25.0	14.4
Information on HIV/AIDS and treatment	3.3	2.5	0.0	4.7	0.0	11.1	0.0	10.0	1.1
Emergency Housing Assistance	7.3	12.5	8.9	7.0	0.0	33.3	0.0	15.0	8.9
Emergency Assistance	4.1	10.0	7.1	4.7	0.0	11.1	0.0	10.0	4.4
Food Bank	8.9	0.0	5.4	7.0	0.0	22.2	0.0	10.0	7.8
Help Paying for Health Insurance	8.1	10.0	10.7	8.1	0.0	11.1		10.0	8.9
Home Delivered Meals	4.9	2.5	7.1	3.5	0.0	0.0	0.0	15.0	3.3
Home Health Care	2.4	2.5	1.8	3.5	0.0	0.0	0.0	10.0	2.2
Hospice Care	0.8	0.0	0.0	1.2	0.0	0.0	0.0	5.0	0.0
Medical Care	1.6	0.0	0.0	2.3	0.0	0.0	0.0	5.0	0.0
Mental Health/Support Group/Counseling	8.1	0.0	3.6	9.3	0.0	0.0	0.0	10.0	7.8
Prescription Drugs	4.1	0.0	1.8	3.5	0.0	11.1	0.0	0.0	2.2
Bus Fares, Taxi Vouchers or rides	7.3	0.0	1.8	8.1	0.0	0.0	16.7	5.0	6.7
Other	2.4	5.0	3.6	3.5	0.0	0.0	0.0	5.0	3.3
Total	(123)	(40)	(56)	(86)	(2)	(9)	(6)	(20)	(90)

Table 5.9: Number of Responses to “Why Aren’t You Getting This Service” by Service Area

	Cost	Trans-portation	Location	Hours	Did not know it was offered	Not eligible	Don't know where to go	Worried about confidentiality	Discrim-ination
Dental Care	16	3	4	3	4	4	5	3	1
Bus Fairs	4	3	3	2	4	3	3	2	1
Emergency Housing Assistance	2		2		5	6	4	2	
Paying for Health Insurance	5	1	1		4	4	6		
Emergency Assistance	1	1	2		7	3	4	1	
Client Advocacy	1	3	2		2	3	4	1	2
Food Bank		3	5	2	2	2	1	1	1
Other	4	2	3		2	2	3		
Substance Abuse Treatment	1	1	1		1	7		2	1
Mental Health	1	1	1		4	3		2	2
Home Delivered Meals			1		3	6	2	1	
Prescription Drugs	5		1			2	2	1	
Home Healthcare					3	5	1	1	
Case Management		3		1		2		1	1
Hospice			1			6		1	
Medical Care		1	2		1	2	2		
Daycare for Children						7			
Information on HIV/AIDS					2	1	3	1	

VI. FOCUS GROUPS

As one component of Maine's Ryan White Title II Needs Assessment, researchers from the Muskie School at the University of Southern Maine conducted five focus groups with PLWHA in three different regions of the state. Methodology and questions were developed with guidance from the Needs Assessment planning committee and Bureau of Health staff.

Groups were convened to answer the following questions:

1. Can you tell me the **top three services** you need to help you live with HIV?
2. Of these services, are there any that you have trouble receiving?
3. What services do you need that you don't get at all?
4. Name the top three issues that make it hard for you to access medical services
5. How would you change services to make them easier to use?
6. What efforts can providers make to get people back into care if they've stopped?

Methods

Five focus groups were planned in three distinct regions of the state: 1) Northern Maine, 2) Central Maine, and 3) Southern Maine. Recruitment was facilitated through the AIDS service organizations (ASOs) currently providing Ryan White Title II HIV Case Management, so that confidentiality would be assured. An informational flyer was developed, and each agency mailed them to all of their HIV+ clients (N=475). Persons who wanted to participate in the focus group called the toll-free number on the flyer, answered a few initial screening questions and registered to come to one of the groups. Enrollment was limited to ten or twelve participants per group. Once this number was achieved, no others were registered. Four of the groups were filled quickly, and only seven individuals called to attend the fifth group. A $50 cash incentive was provided to participants at the end of each group to compensate for their time and travel expenses.

All of the groups were co-facilitated by the same two people from the University of Southern Maine. In addition to taking notes, every session was audio-taped and the tapes were transcribed. Prior to beginning the discussion, confidentiality was discussed, the purpose of the group was explained, and participants were told that their names would not be associated with their responses. Any names mentioned during the session were not to be transcribed, and tapes would be destroyed as soon as the final report was completed.

Results

Using a mix of focus group and nominal group techniques, the facilitators were to have participants list, then rank, their answers to the first four questions, followed by a more open discussion of the issues. Attendance was high, probably due to the incentive as well as personal interest in being heard and hearing from others. With as many as ten or eleven participants it was not possible to complete the nominal group procedures with every group, or to ask each question. Adjustments were made as necessary, in order to obtain good information on the first four questions.

Ranking was always completed on the first question, and resulted in the following list of the top three services needed to live with HIV:

1. Medications
2. Medical Care
3. Dental Care/Assistance, and more informed HIV Case Management (received equal number of votes)

Services that many respondents had difficulty receiving and/or maintaining include:

- Financial Assistance SSI/SSDI/HUD Sec 8
- Dental care / Legal Assistance (received equal emphasis)
- Medications

Under question three, “what services do you need that you don’t get at all?”, legal assistance, dental care, and food support stood out slightly. However, several other services were mentioned as well, including Day Care and discounted gym membership.

Among the issues that make it hard to access medical services, a few did stand out:

- Few knowledgeable providers
- Poor customer service at ASOs
- Lack of communication, between providers and with clients
- Transportation
- Care issues related to multiple diagnoses

The following discussion provides further detail on these questions and more. However, a theme that warrants mention here, because it arose repeatedly, was that of social isolation. That there is social isolation was indicated in many comments about lack of information, not knowing others who are HIV+ to talk to, expressing a wish to exchange information and share experience, wanting a place to hang out at the ASOs where they could meet each other informally, and requests for ASOs to arrange more social gatherings.

All group members were current recipients of Ryan White Title II HIV Case Management services. Group sizes ranged from seven to eleven people, for a total of forty-seven participants. Table 6.1 displays the demographic makeup of focus groups, compared to PLWHA in Maine. Older age groups are overrepresented in the focus groups, and there were no participants under the age of 30. It is likely, therefore, that the following focus group results discussed are skewed towards the experience of older members of the HIV+ population in Maine. Women too are slightly overrepresented, but the actual number is quite small and not likely to introduce a significant bias.

Table 6.1: Demographics

Race/Ethnicity	**State of Maine %**	**Focus groups %**
White	92	88
Black or African American	7	4
American Indian/Alaskan Native	1	4
Asian	<1	0
Unidentified	0	4
Total	1002 (100)	47 (100)
Hispanic (separate from race)	5	0
Gender		
Male	84	76
Female	16	24
Total	1002 (100)	47 (100)
Age Group		
Less than 13	1	0
13-19	2	0
20-29	18	0
30-39	31	14
40-49	19	46
50+	7	38
Unknown	22	2
Total	1002 (100)	47 (100)
HIV Status		
HIV only	52	74
AIDS	48	26
Total	1002 (100)	47 (100)
One male drop-in, no demographics		
One female drop-in, no demographics		

Question Summaries

A note on counting: Focus groups are a qualitative data gathering technique. Some tables and discussion in this report refer to the number of times an item is rated or mentioned. These counts were derived from flip charts, notes, and transcripts of the group discussions. The counts are reported as accurately as the facilitators can determine from these data sources. That said, the possibility that some items were mentioned more frequently than reported is strong. No item is reported that does not occur within the data sources.

1. Can you tell me the top three services you need to help you live with HIV?

Participants at all five groups first listed services they considered to be important to helping them live with HIV/AIDS. Table 6.2 contains a list of services mentioned by at least five persons. A complete listing of all services that were mentioned is contained in the attachments section.

The services that attendees mentioned most frequently include medications (22), legal/financial assistance (18), and dental care, HIV Case Management and transportation (15).

Table 6.2: Unranked List of Important Services

Services	#Mentions
Medications	22
Legal/Financial Assistance	18
Dental care/assistance	15
More informed case management	15
Transportation	15
Medical Care	14
Counseling /Mental Health	10
Positively oriented support groups	9
Housing Assistance	8
Communication/social support	5

Additional services attendees selected as important

The facilitators showed participants a list of possible services and asked group members if any of them would replace those already listed. Though a few, such as co-pay reimbursements, Day Care, food support and respite care, were added to the list, they did not affect the ranking.

Ranking Services

After completing the list of services, the facilitators asked the group to rank the three services most important to them. This process substantially reduced the list, and those that ranked from one to three most frequently were medications (25), Medical Care (24) and well-informed HIV Case Management and dental care/assistance (13). Case Management was mentioned with more frequency in the Lewiston group than others, as the most important service for them (they also expressed a high level of satisfaction with the case management service provided by their ASO). Table 6.3 contains the list of services that were ranked in the top three, ten or more times.

Table 6.3: Services Ranked most often in Top Three

Service	Total times ranked 1-3
Medications	25
Medical Care	24
Dental care/assistance	13
More informed case management	13
Financial Assistance	12
Positively oriented support groups	12
Transportation	10

<u>Quotes</u>

Lewiston Focus group:

> "Support groups, case management, medications and doctors. There really should be more infectious disease doctors. We only have ONE!"

2. **Of these services (listed above) are there any that you have trouble receiving and maintaining?**

   Reflecting on the services that had been listed and ranked as important, the facilitators asked participants which of these services they have trouble receiving or maintaining. Twenty-nine services were mentioned at least once. Table 6.4 lists those that were mentioned at least four times, and at the top of the list are: financial assistance (15), dental care (13), and legal assistance (13).

Table 6.4: Services You Have Difficulty Receiving and Maintaining

Services	#Mentions
Financial Assistance SSI/SSDI/HUD Sec 8	15
Dental care	13
Legal Assistance	13
Medications	12
Transportation	8
Case management (including continuity)	4
Co-pays/co-pay reimbursement	4
Positive support groups	4

Concerns with financial assistance covered a broad swath of issues including the lack of flexibility of income qualification for indexed programs like SSI, Section 8 housing assistance, Maine Care, prescription drug co-payment support and the Low-Income Home Energy Assistance Program (LIHEAP). Specific difficulties group members cited included:

- Several attendees told of the need to hire legal representation to obtain SSI supports. In each of the instances related during the focus groups, the presiding judge issued an order that they be awarded the benefit. Group members also mentioned waiting periods of up to two years to receive SSI benefits.

- In relation to income qualification requirements, one group member explained that he qualified for assistance but was disqualified after he got married. He and his spouse divorced in order for him to remain qualified for income indexed benefits.

- Several group members also talked about the need to go through disability review every five years, “as if my HIV+ status will change,” in the words of one participant.

Participants in all groups mentioned difficulty accessing dental services other than cleaning and tooth extractions. Several people discussed receiving dental services through the Boston University (BU) Dental Clinic. Group members able to access these services are generally appreciative of the ability to access dental services not available to them in Maine, however there are some difficulties:

- Long waits, often requiring several applications, to begin receiving services at the clinic (some participants expressed uncertainty over whether or not case managers were staying on top of the dental clinic applications).

- Traveling from various regions in Maine to the Boston clinic is a time-consuming and complex endeavor, giving rise to difficulties around child care, and the fear of traveling alone. Travel costs for a companion are not covered.

- The final set of difficulties related to dental services at the BU Clinic concern the long periods required to complete complex dental work. It may take several trips over many months. One client told the group that he was able to shorten the time span by volunteering to sit for prolonged sessions (up to 12 hours) to get his dental work completed in fewer visits.

Legal assistance was described as difficult to obtain, totally unavailable, or just unheard of. While several participants mentioned hiring attorneys to assist them with disability benefits, others cited the need to access legal assistance for matters like wills, and living wills.

Participants listed medications as their second most important service, and it shows up in this list as the fourth most mentioned service among those that are difficult to receive. Overall, while group members are usually able to access the medications they need, difficulties involving medications include:

- Local pharmacies not having the medication in stock; resulting in needing to wait for medications or partially filled prescriptions.

- Difficulties in obtaining prior authorizations for non-formulary drugs, including what participants report as the need to fail with formulary drugs before receiving prior authorization for non-formulary medications. The “need to fail” requires a separate trip to the doctor for each prescription in succession.

- The need to stop working in order to income qualify for prescription drug assistance.

- Difficulty obtaining financial assistance with prescription co-payments.

3. What services do you need that you don’t get at all?

Participants were asked which services they need but don’t get at all. The most common responses are listed below in Table 6.5. Fortunately, only one service on this list is among the services participants ranked among the most important services they need (dental).

Extensive, specialized dental care was not considered to be available by participants in groups north of Portland. Dental care was referenced above as a service that is difficult to access or maintain. Members of all groups alluded to the difficulty of accessing dental services beyond cleaning and extractions however, group members in southern Maine are able to access dental services through the BU clinic. Several groups mentioned physical fitness issues, emphasizing the importance of physical activity to feeling well. Participants discussed physical fitness both in the context of needs for information and guidance on physical activity from doctors and in the context of access to exercise facilities. Table 6.5 below lists all services mentioned at least once, that are needed but not received. Legal assistance was mentioned more often than the others.

Table 6.5: Services you don’t get at all

Service
Legal assistance
Dental
Food support
Discounted gym memberships
Doctor's guidance on fitness
Financial services
Financial support (heat)
Information on fitness resources
Daycare
Mental health services
Paying for Maine Care

4. Name the top three issues that make it hard for you to access medical services.

Participants supplied a long list of issues that make it hard for them to access medical services. Many of the issues listed in response to Question 4 related to individual barriers. Table 6.6 contains the eight issues mentioned by more than two participants. The entire list is contained in the attachments section.

Communication issues were cited several times. Communication was mentioned as a general concern, but was also discussed in terms of communication with and communications between medical providers. Similarly, case management and customer service issues at ASOs are cited in multiple contexts including the need for better customer service, the need for consistent and quality HIV Case Management, and participant perception of poor training and support of case managers on the part of ASOs. Transportation issues arose throughout the discussions, with participants from rural areas placing greater emphasis on the difficulties caused by transportation issues.

Table 6.6: Top three issues that make it hard to access medical services

Issue
Competent providers
Better customer service at ASO
Communication
Primary Care Provider /Specialist communication
Transportation
Care issues related to multiple diagnoses

5a. How would you change services to make them easier to use?

Participants generated a long list of changes but as in Question 4 several themes emerged. The issue of the atmosphere at the ASO arose in three groups; however the focus was on two ASO's. Clients of these two ASOs offered several suggestions regarding possible changes at the ASO.

- Make them more client-friendly (value the clients, offer waiting space with coffee, etc., offer social opportunities)
- Consistent standards of care and HIV Case Management across all agencies working with the HIV population
- Consistent qualification standards and experience requirements for case managers.
- One attendee referenced ISO 9002 standards, available at http://www.praxiom.com/.

The theme of coordination and communication of information, through both formal and informal venues, recurred throughout the five focus group sessions. Participants in all five groups referenced the difficulty of obtaining consistent information regarding available services; and how much they feel they could learn from each other. The need for a resource guide was mentioned several times.

The concept of services geared toward *living* (italics to emphasize living) with HIV is also a theme that recurred throughout the discussions, members of every group expressed support for the concept of positively oriented support groups emphasizing, “How to live life and find things you can do.” Table 6.7 lists all responses that were mentioned at least once.

Table 6.7: Recommended changes to services

Changes
Consistency throughout system
Friendlier, more client focused atmosphere at ASO
Communicating with all clients
Coordination/communication of information
Easier access to affordable health care
Food Services (Access top meals on wheels)
Health services that accommodate people's schedules
Information clearinghouse
Job services for HIV/AIDS patients
Mental health services at same time as medical clinic at ASO
More case management
More case management support negotiating bureaucracy
More consumer education
More HIV/AIDS knowledgeable physicians available locally
One access point for all support programs
Opportunity to spend more time with physician
Peer education
Social centers for HIV+ people
SSI information
Services geared toward living with HIV, not dying

5b. What supports help KEEP you in care?

The supports participants listed focused on relationships with providers, peer support, and individual education. Table 6.8 displays all responses mentioned at least once.

Table 6.8: Supports that help keep you in care

Supports
Adherence and struggling to find what's right for me
Bangor support group for HIV+
Doctor's advice
Informed HIV specialist in Augusta
Keeping informed through seminars
Mental health
Support group in Portland
Trusting relationship with caregiver

6. **What efforts can providers make to get people back into care if they've stopped?**
   Three groups addressed Question six. Respondents contributed the following suggestions to bring people back into care:

   - Community outreach, including dinners, speakers (reference to Penn Community outreach program)
   - Establish immediate peer contacts
   - Opportunities to meet others with HIV
   - Drug rehabilitation to facilitate reentry to HIV/AIDS treatment
   - Information on health maintenance including medication.
   - Immediate referral to psychological supports on receiving HIV+ notification including outlines for counseling and treatment
   - Implement an intervention: Case management team should make contact with client's family and other supportive contacts
   - Case management should make personal contact with their clients periodically
   - Better communication with doctors
   - Better communication between doctors

Q7. Is there anything else you would like to tell us about the needs of PLWHIV?

Participants mentioned that HIV Case Management needs to be:

- Compassionate
- Caring
- Understanding, and
- Knowledgeable

Participants also mentioned that health maintenance is a very important issue. A holistic approach to client needs is needed, e.g. some clients need a gym membership, others have different needs. Participants mentioned that services should be tailored to meet individual needs and preferences.

Observations

All five groups discussed HIV Case Management services at length during the discussion of important services. One group was very positive about the case management services they receive, noting "We have the best case manager in the state." However this group also asserted the need for another case manger in their service area, adding that the ASO had established a waiting list.

Three of the other four groups were considerably less positive about both case management services and their respective ASOs. Comments in the fourth group were modest in number, and more balanced between positive and negative.

Discussion about HIV Case Management services had several common themes:

- Turnover of case managers negatively impacts continuity of care;
- Case managers are not well informed;
- Some staff are not sensitive or caring; and
- Case managers are difficult to reach

Two of the ASOs received comments as well, stressing the following:

- The need for a friendlier more welcoming atmosphere at the ASOs;
- The need for standard operating procedures at the ASOs; and,
- Difficulty reaching the ASO.

Limitations of the Focus Group Results

Both focus group and nominal group methods are qualitative methods of data collection. Focus groups are useful for soliciting group opinions and interpretations; nominal groups can be useful for prioritizing and reaching consensus. Results reflect the opinions of those who participated and may be weighted by particularly vocal participants. Another likely bias is that the respondents were all consumers of HIV Case Management services, as compared to the general population of PLWHA in Maine, over half of whom do not receive Ryan White Title II funded case management services and a large proportion of whom had not had CD-4 or viral load tests within the previous 12 months.

VII. OUT OF CARE SURVEY

Methods

This survey targeted persons who were 'Out of Care' (OOC). According to HRSA, populations that are out of care have not accessed any of the following in the past 12 months:
1) antiretroviral therapy 2) CD-4 lab counts 3) Viral load lab testing. Out of Care includes those who are HIV positive and are 'erratically' in care and those who are HIV positive and never accessed primary medical care. The methodology for accessing this population consisted of three approaches. First, those individuals who responded to the focus group flyers or consumer survey and met OOC criteria were surveyed using a long-distance, toll-free line (7/28 or 25%). This method was magnified using 'snowball sampling' or minor incentives given to respondents of surveys and focus group registrants who referred out of care individuals to participate in the OOC survey (11/28 or 39%). Finally, a few case managers volunteered to locate erratically out of care PLWHA or never in care individuals who accessed only support services. (10/28 = 36%) All surveys were completed over the phone, via a toll-free line, and each survey lasted approximately 15-20 minutes.

Results

Of the 28 OOC survey respondents, 75% (21/28) had once accessed primary medical care and 25% (7/28) had never accessed primary medical care following a positive HIV diagnosis. The Out of Care survey respondents consisted of 28 respondents from the State of Maine. The majority of Out of Care respondents were from Kennebec, Penobscot, York, Cumberland, Waldo and Androscoggin counties (79%). However, because of the sampling methods used, and the small number of respondents, this likely does not reflect actual distribution of people out of care in the State of Maine. Most were male (61%), gay (54%) and reported transmission as MSM (64%). Twenty-five percent of the out of care clients reported having an AIDS diagnosis. Forty-six percent (13/28) were long-term survivors (diagnosed over 15 years ago).

Respondents were asked why they have not accessed primary medical care for HIV:

- Most replied that they couldn't afford it (43%) or didn't need it (43%). Eleven percent, all of whom had never received any care, chose 'don't trust doctors' as their reason for not accessing care.

- Long term survivors noted that peers who were treated with AZT in the early days of the epidemic still died. This left them with a fear of HIV medications to this day.

- There appears to be a (related) tendency to self-manage, notably among Anglo MSM. They go to providers to have blood tested, but refuse to take HIV medications.

- Of the female out of care respondents, (11/28 or 39%) cost was mentioned most often (6/11 or 55%), followed by concerns that services were not female-oriented (3/11 or 27%), then fear of disclosure/stigma (2/11 or 18%).
- Only 1 OOC respondent referenced using substances as their reason for being OOC.

Respondents were asked why other people don’t get care for HIV. Table 7.1 below displays the responses. By far the most common response was: “Worried people will find out.”

Table 7.1 Why don’t other people get medical care for HIV?

Reason OOC (all respondents)	N	%
a. Worried people will find out	12	43%
b. Language/culture	6	21%
c. Feel healthy/not sick	3	11%
d. Can’t afford it	4	14%
e. No transportation	3	11%
f. Using drugs		
g. Don’t want to take meds		
Total	**28**	**100**

What it would take to get respondents to enter care:

When asked what would get them to go to a doctor, acute illness was the most common response (46%), followed by transportation (32%). Other things mentioned included:

- ‘Proof’ that medications are superior to being off medications (value is worth the side effects, structure of regimen, cost)
- Assistance with filing for cost assistance of meds
- Confidentiality of diagnosis if part time or full time employed
- Support services to elevate primary medical care to essential need (over other needs like housing)
- Transportation
- Becoming ill with AIDS-related symptoms (night sweats, wasting)

<u>Limitations of the Out Of Care Survey</u>

There were several limitations to this survey. First, the Out Of Care population is not known to us, and time was too limited to attempt a comprehensive, statewide search for persons who would meet the criteria. Sampling was purely convenient, with recruitment facilitated by ASOs using their client lists, and then asking clients to refer friends. Some ASO staff were more responsive than others when asked to identify individuals who might be out of care, giving us a regional bias. It’s likely that there are many other PLWHA in Maine who are not connected to ASOs, yet the sampling methods used here were limited primarily to persons known to the ASOs. Findings cannot be generalized; they reflect only the experience of the 28 respondents.

VIII. PUBLIC HEARING SUMMARY

On October 13, 2004, the Bureau of Health conducted a public hearing on HIV/AIDS issues at the Augusta Civic Center. The purpose of the hearing was to offer PLWHA and those who live with, care for, or work with them, a chance to describe what they believe is needed for PLWHA in Maine to best manage HIV disease. The public hearing was advertised through radio, TV, newspaper and fliers posted at ASOs.

Results

Twenty-two testimonies were heard at this event (13 PLWH, 8 providers/administrators and 1 unidentified). Eighteen of them were delivered in person and the four that came in writing were read by the program coordinator. Listed below are themes and suggestions that arose at least once throughout the testimonies:

- Educate providers and the general public, to reduce stigma, myths, and mistreatment

- Increase cultural sensitivity of services and efforts to reach out to HIV+ minorities, including those who have disabilities and those within deaf communities.

- Develop HIV Case Management standards, require consistency across agencies, and provide assistance with transfer of clients between agencies.

  "I am also concerned that there is not a set standard of services so that all the AIDS service organizations deliver the same quality of service."

  "There also seems to be no set of requirements other than being HIV positive to qualify for financial assistance from an AIDS service organization. The decisions around this are left to the discretion of the case manager or director and are often arbitrary decisions."

  "Case managers not only need the right educational requirements but they need training. They need training specifically on the disease of HIV and not just an overview of the medical model but understanding the social, psychological and political realities."

- Listen to consumers, give them an opportunity to be involved in the planning, implementation and evaluation of services

- Reduce isolation, create opportunities for PLWHA to connect with each other and the community

  "It is not uncommon for me to meet people who have never met another person who is HIV positive."

> *"If a peer program was in place, it would complement regular HIV Case Management services. There is no close second. Nothing replaces HIV positive people connecting with another HIV positive person."*

- Maintain funding for medications

> *"Put as simply as possible, without ADAP funds for HIV meds, although I currently have a nondetectable viral load and 600+ CD4s, I have been told that stopping meds would likely mean a year or two to death."*

- Increase coverage for mental health drugs and ease the prior authorization rules

- More case managers are needed to ensure that this service is available immediately to those with acute needs, and the newly diagnosed, as well as those who need ongoing support

- Assist PLWHA to engage in meaningful activities of living

> *"..work is the single most normative experience for adults in our society, and if we believe that individuals have futures, most of those futures have to include work."*
>
> *"If there was one thing that I could do or ask the State of Maine to do on behalf of folks living with HIV, is to designate an ombudsman for each one of the counties to advocate for the men and women who are currently living with HIV/AIDS."*
>
> *"The AIDS epidemic has evolved over the past 20 years and the delivery of HIV Case Management services has remained the same. They were in the business of helping us to die, and now they need to shift and help us to live."*

- Increase state funding of the Ryan White Title II program

Limitations of Public Hearing Results

There was no systematic attempt to sample the entire HIV population, their providers, caregivers or families, for the pubic hearing. Those who came were self-selected, motivated individuals who responded to the advertisement or word of mouth. Public hearing results are qualitative and represent only the opinions of those who gave testimony.

IX. DISCUSSION

The purpose of this Needs Assessment was to inform decision-making regarding utilization of Ryan White Title II CARE Act funds in Maine. This was the first attempt at a comprehensive CARE Act Needs Assessment in Maine. Given limited resources and time, the focus was placed on gathering data from PLWHA, with the intention of completing a resource inventory and profile of provider capacity and capability at a later date.

This Needs Assessment reports the results of a survey completed by 163 HIV+ clients of AIDS Service Organizations (ASOs), an out of care survey completed by 28 respondents, five focus groups, a public hearing, and state epidemiological data. As we drew our sample for both the survey and the focus groups from the ASOs, we can not assume that the results are representative of the HIV+ population in Maine. Clients of ASOs are more likely than the general population to be connected with services. In addition, women are slightly overrepresented in the survey (24.5% vs 16% in the general HIV+ population) and in the groups. Older age groups are also overrepresented in the focus groups. However, on other demographic characteristics, the survey sample closely reflects the epidemiological profile.

Service Needs and Gaps

The goal of the Ryan White Title II CARE Act is to enable states to improve the quality, availability, and organization of health care and support services for individuals and families with HIV disease. As the nature of the epidemic has changed, the challenge for the Maine Ryan White Title II program will be the continuing provision of critical services along with services to support daily living.

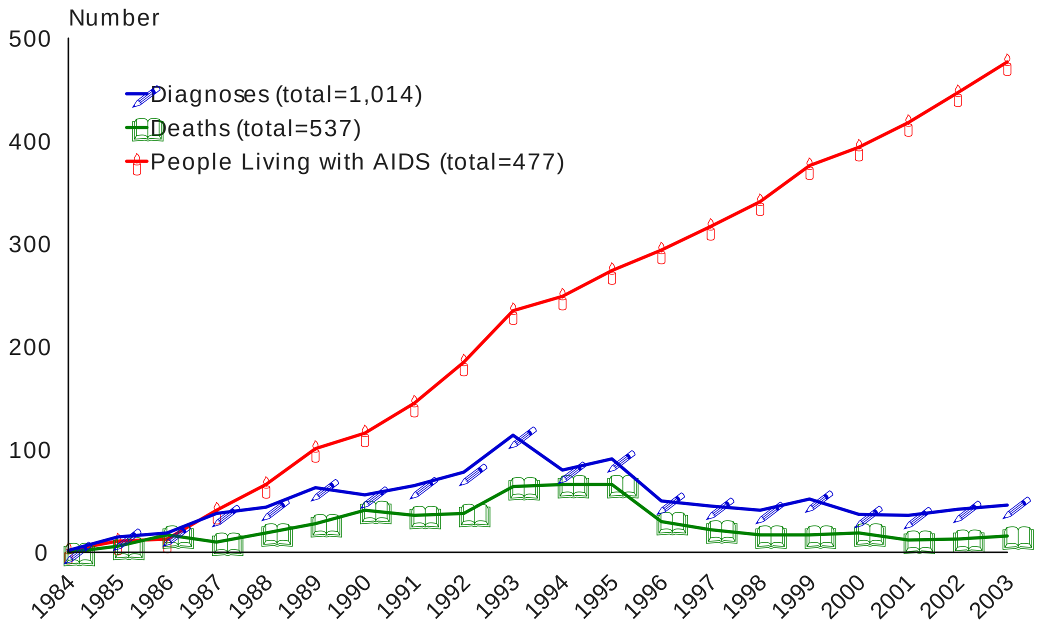
Over the past ten years, service needs among PLWHA in Maine have changed, shifting from end-stage services to service needs typical of a population confronted with a chronic disease and difficult treatment regimen. When the affected population is disproportionately poor, the ongoing needs are even greater.

On the positive side, the decline in AIDS-related mortality does indicate that the HIV/AIDS care system in Maine has been effective in treating PLWHA. While new HIV diagnosis and number of AIDS-related deaths declined significantly and have remained relatively stable since 1997, the number of people living with AIDS in Maine has increased steadily. This provides some evidence that care and treatment are being made available to PLWHA to manage their disease. Mortality has decreased from 114 AIDS-related deaths in 1993, to 46 in 2003.[7]

---

[7] State of Maine Bureau of Health, HIV/STD Program, 2004

Figure 8: Maine AIDS Cases, Deaths and AIDS Prevalence, 1984 to 2003



The Needs Assessment examined access to care, utilization, barriers to services and unmet needs. Unmet need goes beyond discussion of medical, financial and treatment services, to discussion of needs that are essential to daily living, as PLWHA expect to survive HIV and wish to be active participants in society.

Medications, Medical Coverage and Costs of Care

Consistently among the most important and necessary services in the focus groups, medical services and medications were utilized by most survey respondents. The majority reported always having insurance coverage during the previous year. However, those in the moderate income category of $20,000 to $29,999 were somewhat more likely to have gone without insurance at some point in the year.

Costs of insurance deductibles and premiums fell most heavily on the moderate income group (only 26% reported no such costs, vs 62% and 63% of those with lower incomes), perhaps explaining why some of them lacked insurance altogether. Over one-third of this group paid more than $1,000 annually for insurance deductibles.

One hundred thirty-three of the survey respondents reported currently taking HIV medications. Of those, most reported modest monthly out-of-pocket expenses for medications. Nearly 15%, however, reported costs in excess of $100 per month. MaineCare was the most frequently cited source of assistance with payment for drugs, clearly a valuable resource.

Treatment

The Needs Assessment looked at time between HIV diagnosis, first medical care visit, and AIDS diagnosis. Nearly three-quarters of the sample reported seeking care within a month of diagnosis. Those under the age of 29 were more likely to delay getting into care than older respondents. This may be associated with lack of insurance, and better overall health status. The same pattern is seen when we looked at time between diagnosis and taking medication**.** One explanation for this may be the medically-recommended delay in treatment based on CD4 and/or viral load levels, according to current treatment standards.

Close to half of the respondents had been diagnosed with HIV at a doctor's office, indicating a connection to medical care. However, 51.7% of the simultaneous HIV and AIDS diagnoses occurred in a doctor's office, a somewhat surprising finding. Overall, 47.5% of respondents who reported an AIDS diagnosis (61), reported receiving their HIV and AIDS diagnoses simultaneously. This is consistent with statewide data on late to care issues.

Though most of the survey respondents reported currently taking HIV medications, many (67%), had missed doses of their medication without the advice of a doctor. Asked why, the most common responses were: 1) forgot, 2) side effects, 3) ran out of medications. Focus group participants mentioned problems filling prescriptions, either because medications were not in stock, or there was a delay in getting the necessary approval required for certain drugs. Twelve percent of those who had missed medications, without the advice of a doctor, reported cost to be the reason. They were not able to afford their medications.

HIV Case Management

HIV Case Management was cited most frequently (69%) among services utilized by the survey population. Another 50% cited information as being utilized, and 43% cited client advocacy, both of which might be linked to case management. More consumers in the central region of the state cited HIV Case Management than did consumers in other regions. There may be a couple of reasons for this, one of which is the high popularity of a particular case manager in the central region. Given that the sample was drawn from ASOs, it was somewhat surprising that more respondents didn't list HIV Case Management as a service they utilize.

HIV Case Management received many mentions in the focus groups, and at the public hearing. The general theme that was derived from both, was a request for consistent, high standards to be developed and implemented for HIV Case Management, including greater knowledge about HIV/AIDS. Consumers also expressed an interest in having ASOs facilitate more opportunities to meet other PLWHA, to encourage sharing of information, and to decrease isolation.

Unmet Needs

Dental care was mentioned in all groups as one of the top services that is needed but not easy to receive. This finding was supported by the survey results which show that dental care was the most common unmet need identified by people in all income and insurance categories. According to focus group participants, adequate dental care for PLWHA isn't available, unless one can travel to Boston, spending many hours on transportation and at the clinic. There also may be resistance among local providers, to treating HIV+ clients.

In addition to dental care, emergency housing and food bank were the categories of service most frequently identified as needed but not available. Group participants also identified public assistance, such as SSI/SSD/HUD Section 8 as services that they have difficulty receiving and/or maintaining.

Respondents mentioned many other services that they would like to receive but for a variety of reasons are not getting. They included family counseling, information about resources, alternative medical therapies, vitamins, financial and legal advice, and gym membership.

Barriers to Care

Cost is a major barrier to dental care as well as health insurance and using prescription drugs. Other barriers identified in the groups included: lack of information about resources, lack of knowledgeable providers, poor customer service at ASOs, lack of communication between providers (general practitioners and specialists) and between clients and their providers, transportation, and care issues related to multiple diagnosis.

X. RECOMMENDATIONS

Policy and Practice Implications for Maine's Ryan White Title II Program

Financial assistance with medications and medical services is clearly an essential service for the respondents from whom we gathered data for this assessment. Almost 76% of survey respondents receive MaineCare/Medicaid, 16% receive ADAP, and 33.6% reported receiving assistance from their local ASO to pay for drugs. If the state and the Ryan White Title II program are to live up to the commitment to PLWHA in need, they must continue to provide these types of assistance.

Too many people are receiving simultaneous HIV and AIDS diagnoses in Maine. Something must be done to encourage earlier HIV testing, in order to bring people into care sooner. A public awareness campaign to provide information about the benefits of early testing and treatment might also decrease the number of people who are aware but not in care.

The state should examine strategies for drawing consumers into care, and should evaluate the continuum of care currently available. It is clear that there is a gap in coverage of dental care and that middle-income and low-income individuals experience significant out of pocket costs and barriers to care. Barriers to care include cost and transportation. These issues should be considered when examining the uses of emergency financial assistance and creating policies to better define its use.

Consistent standards of care should be created and/or adopted for HIV case management, and ongoing quality assurance should be a focus of the Ryan White Title II Program.

Findings suggest that consumers need better information about the full range of services available, and location of those services. Many indicated that they "didn't know it was offered" for several of the services listed on the consumer survey. The state should compile a consumer resource guide to be distributed to consumers of care as well as newly diagnosed people (to provide consistent information about statewide services, their eligibility criteria, etc.).

Case Management Services

Consumers expressed an interest in meeting more HIV+ persons, to share information and to reduce feelings of isolation. ASOs are in a unique position to facilitate social opportunities for consumers, and should make efforts to address these needs. Some of the ASOs will need to start by improving accessibility and consumer-friendliness.

Adherence to medications is an issue for some consumers (based on missed medications without medical advice). Case management agencies should play a larger role in educating and supporting consumers to achieve medication adherence.

Additional Research

Additional research is recommended in order to complete this Needs Assessment, and fill in the picture of HIV/AIDS services in the state. The Ryan White Title II CARE Act Program should undertake a resource inventory and profile of provider capacity and capability. Given the late to care issue, future research should examine the factors associated with delays in testing, and obtaining treatment. While we know that about half of the simultaneous diagnoses occur in a doctor's office, we don't know if those individuals have been under the care of a physician. It would be advisable to conduct the Needs Assessment every three years, using the same design and measurement tools (with as little change as possible), in order to make comparisons.

Appendix A

Table A.1: State Location of HIV Diagnosis

	N	%
Not reported	2	1.2
Arizona	1	0.6
California	12	7.3
Connecticut	2	1.2
Delaware	2	1.2
Florida	10	6.1
Maine	89	54.6
Maryland	1	0.6
Massachusetts	14	8.6
Michigan	1	0.6
Missouri	1	0.6
New Hampshire	4	2.5
New York	11	6.8
New Jersey	4	2.5
Ohio	1	0.6
Texas	5	3.1
Vermont	1	0.6
Egypt	1	0.6
South Africa	1	0.6
Total	163	100.0

Table A2: Distribution of Respondents by Whether or Not They Report Living With Children

	N	%
Yes	25	15.7
No	134	84.3
Total	159	100

Table A3: Reported Sources of Income During Past Year

	N	%
Full-time employment	33	20.4
Part-time employment	40	24.7
Supplemental Security Income	35	21.6
Social Security Disability Income	94	58.0
Temporary Assistance for Needy Families	4	2.5
Veterans Administration benefits	5	3.1
Long-term disability	12	7.4
Workers Compensation	0	0.0
Food Stamps	60	37.0
Rent Supplement	23	14.2
Retirement/pension	11	6.8
Other	10	6.2
Total Persons Responding	162	--

Table A4: Length of Time Reported Living in Different Places/Situations During the Past 2 Years (n=162)

	Never	Less than 1 month	1-3 months	4 months to a year	More than a year
In my own apartment/house	8.0	0.6	1.9	8.0	74.7
Someone else's apartment/house	42.0	1.2	7.4	8.0	13.0
In a rooming or boarding house	58.0	0.0	2.5	0.6	1.2
In a "supportive living facility"	60.5	0.0	0.6	0.6	0.0
In a group home or residence	60.5	0.0	0.6	0.0	0.6
In a half-way house, traditional housing or treatment facility	61.7	0.0	0.0	0.6	0.0
Skilled nursing home	61.7	0.0	0.0	0.0	0.0
Homeless	58.6	1.9	1.2	0.6	0.0
Homeless shelter	58.6	1.2	1.9	0.0	0.0
Jail or correctional facility	57.4	3.7	0.0	0.6	0.0
Other housing provided by city or state	58.6	0.0	0.6	0.0	1.9
Residential hospice facility	61.1	0.0	0.0	0.0	0.0
Other	48.8	0.0	0.0	0.6	3.1

Table A5: Have you ever been diagnosed with the following?

	Yes	No	Don't Know	Total
Primary Syphilis	7.1	92.9	0.0	141
Secondary Syphilis	1.4	97.9	0.7	140
Herpes (genital)	21.2	77.4	1.4	146
Gonorrhea	22.1	77.9	0.0	145
Chlamydia	9.8	88.1	2.1	143
Genital warts	19.6	78.3	2.1	143
Hepatitis A	9.4	85.5	5.1	138
Hepatitis B	18.9	76.2	4.9	143
Hepatitis C	22.3	73.4	4.3	139
Yeast Infections	37.8	60.1	2.0	148
Other	21.7	69.9	8.4	83

Table A.6: If you received mental health treatment, was it:

	N	%
Outpatient	93	91.2
Inpatient	9	8.8
Total	102	100

Table A.7: Distribution of Survey Respondents by Sexual Orientation

Sexual Orientation	N	%
Heterosexual/Straight	56	35.2
Gay Man	86	54.1
Lesbian	2	1.3
Bisexual	9	5.7
Other	6	3.8
Total	159	100

Table A.8: Other Medications Reported

Type of Medication	N
Advair, Albuteral, Zinc	1
Ambien	2
Antiviral, Acyclovir	1
Aspririn, nitroquick, imitrex, protonix, fluoexetune, cyclobenzaprine, lisinprolol, flonase, metaprolol, bachofen, zetic, crestor	1
B 2 Vitam C, Q10	1
Beta Alucen	1
Claritin, Nasonex, Klonopin	1
Concerta, Xanax, Trileptal, Prem Pro Naproxin, Imitrex, Protonix	1
enalapril, vasotec, remeron, nascobal, hydrochlorothiazide, effexor, prozac, androgel	1
Garlic, Vi - C, Antioxident Formula, B Complex, Centrum Solution	1
Ginger Capsules, Mulitvitamins	1
Heart Med., Fungal Med.	1
High Blood Pressure - Gout- Vitamins	1
High Blood Pressure	1
Lipitor	2
Lipitor, lisinopril	1
Oxycontin, sulfar, ciprofloxacin, prozac, B12 injections, neurontin, protonic, zanax, centrum, ibuprofen	1
Pain Killers, Muscle relaxers, Neurontin	1
Ranitadine / Propranolol	1
Ritalin	1
Vitamin C and A Multivitamin	1
Total	163

Table A.9 examines the relationship between use of alternative therapies and use of medical care and prescription drugs. The question posed here is do people who rely on alternative forms of treatment access more "traditional" forms of care.

There are no major differences between those who access medical care and those who don't and who report using complimentary medicine. Nor is there any difference in use of massage between those who take medications and those who don't. Those who take meds are slightly more likely to see a chiropractor. Those who take medications are less likely to use herbal treatments, but more likely to use vitamins.

Table A.9: Use of Complimentary Services by "In-Care" Status

	Have used Medical Care within the past 12 months		Currently Taking HIV Medication	
	Yes %	No %	Yes %	No %
Massage	25.3	24.1	24.6	25.9
Acupuncture	6.6	3.9	4.8	7.7
Chiropractor	15.8	16.7	17.6	10.7
Biofeedback	4.1	1.3	3.2	
Herbal treatments	10.5	9.1	8.8	14.8
Vitamins/antioxidants	61.5	58.8	62.5	51.7
Dietary supplements	34.2	37.7	36.3	35.7
Other	6.4	11.8	9.6	7.1

Table A.10: Health Status(Poor Health=T-cell count lower than 200 and/or Viral Load >100,000)

	N	%
Poor	20	12.3
Good	90	55.2
Missing	53	32.5
	163	100

Table A.11: Percent Who Reported They Did NOT Have "Easy" Access to Services

Please indicate if you think it's easy to get from your house to each of the following services	Insurance	Income				Age				
	No Insurance % No	under $9,999 % No	$10,000- $19,999 % No	$20,000 - $29,999 % No	over $30,000 % No	20 to 29 % No	30 to 39 % No	40to 49 % No	50 to 59 % No	60 and over % No
Medical Services	23.5	22.0	23.7	16.0	0.0	33.3	19.0	22.2	14.9	45.5
Human Services	23.5	21.3	19.0	19.2	28.6	66.7	19.0	22.4	12.5	46.2
Basic services like food pantry	29.4	24.6	18.0	16.0	28.6	33.3	28.6	24.2	12.8	30.8
Transportation	29.4	23.0	16.9	7.7	42.9	33.3	28.6	13.6	21.7	30.8
Child Care	0.0	10.9	3.6	8.0	28.6	33.3	10.0	7.8	9.5	10.0

Please indicate if you think it's easy to get from your house to each of the following services	Health Status		Region			
	Poor Health % No	Good Health % No	Northern % No	Central % No	Southern % No	Unknown % No
Medical Services	33.3	18.1	11.5	23.1	21.1	66.7
Human Services	31.6	15.9	10.7	22.9	22.8	33.3
Basic services like food pantry	31.6	18.6	10.7	23.9	22.8	33.3
Transportation	15.8	17.2	7.1	25.8	17.5	33.3
Child Care	5.6	7.4	8.0	9.7	7.4	50.0

Appendix B: Consumer Survey Tool

PLEASE ANSWER EACH OF THE FOLLOWING QUESTIONS BY FILLING IN THE APPROPRIATE CIRCLE OR PROVIDING THE INFORMATION REQUESTED.

- Read each question
- Read all the choices before you choose an answer
- **Fill in the circle next to (or underneath) your answer**
- Please do not select more than one answer unless the question asks you to (for example: select all that apply)
- If you need help, please call the number given on the cover page.

1. When were you **first** diagnosed with HIV?   Month___________   Year____________

2. Have you ever been diagnosed with AIDS?

○ YES   Year___________

○ NO

3. Where were you **first** diagnosed with HIV?

City______________________________   State_____________

4. What type of place diagnosed you?   **(Select one)**

○ Emergency Room

○ Blood Bank/plasma center

○ Public Health Clinic

○ Doctor’s Office

○ AIDS Service Organizations

○ Others, please specify____

5. Are you: **(Select one)**

○ Male

○ Female

○ Transgender – Female to Male

○ Transgender – Male to Female

If you are female, please answer questions 6 and 6a, if not, please go to question 7

6. Are you currently pregnant or have you been pregnant within the past 12 months?

YES	NO	DON’T KNOW
○	○	○

6a. If yes, are you currently receiving, or did you receive, HIV medication during pregnancy?

YES	NO	DON’T KNOW
○	○	○

7. Do you consider yourself: **(Select one)**

○ **Heterosexual/Straight**
○ Gay Man
○ Lesbian
○ Bisexual
○ Other

8. Are you Hispanic/Latino?

○ YES
○ NO

9. What is your race? **(Select ALL that apply to you)**

○ **African American/Black**
○ Asian
○ Native American/Alaskan Native
○ Pacific Islander
○ White/Caucasian
○ Other, please specify____

10. What **year** were you born? _________________

11. What **county** do you live in? **(Select One)**

○ Androscoggin
○ Aroostook
○ Cumberland
○ Franklin
○ Hancock
○ Kennebec
○ Knox
○ Lincoln
○ Oxford
○ Penobscot
○ Piscataquis
○ Sagadahoc
○ Somerset
○ Waldo
○ Washington
○ York

12. Do you have children living with you?

○ YES, How many children live with you?_________

○ NO

12b. **IF YES**, Are any of those children HIV+?

○ YES

○ NO

13. Over the past **2 years**, how long (total time) have you lived in any of the following places/situations? (**select a response for each one**)

	Never	**Less than 1 month**	**1-3 months**	**4 months to a year**	**More than a year**
In my own apartment/house	O	O	O	O	O
Someone else's apartment/house	O	O	O	O	O
In a rooming or boarding house	O	O	O	O	O
In a "supportive living" facility (Assisted Living Facility)	O	O	O	O	O
In a group home or residence	O	O	O	O	O
In a half-way house, transitional housing or treatment facility (drug or psychiatric)	O	O	O	O	O
Skilled nursing home	O	O	O	O	O
Homeless (on the street/in car)	O	O	O	O	O
Homeless shelter	O	O	O	O	O
Jail or correctional facility	O	O	O	O	O
Other housing provided by the city or state	O	O	O	O	O
Residential hospice facility	O	O	O	O	O
Other (Specify)______________________________	O	O	O	O	O

14. Please indicate if you think it's **easy** to get from your house to each of the following services: **(Select YES, NO or Not Applicable for each one)**

	YES	**NO**	**Not Applicable**
Medical Services	O	O	O
Human Services (Case Managers, Welfare, etc.)	O	O	O
Basic services like food pantry, etc.	O	O	O
Transportation	O	O	O
Child Care	O	O	O

15. What sources of income did you have in the past year? (**Select ALL that apply to you)**

- ○ Full-time employment
- ○ Part-time employment
- ○ Supplemental Security Income (SSI)
- ○ Social Security Disability Income (SSDI)
- ○ Temporary Assistance for Needy Families (TANF) – formerly AFDC
- ○ Veterans Administration benefits
- ○ Long-term disability (from work)
- ○ Workers Compensation
- ○ Food Stamps
- ○ Rent supplement
- ○ Retirement/pension
- ○ Other (please specify):____

16. Which of the following **best** describes your current yearly income from **all** income sources? **(Select one)**

- ○ $0 - $9,999
- ○ $10,000 - $19,999
- ○ $20,000 - $29,999
- ○ $30,000 - $39,999
- ○ $40,000 - $49,999
- ○ Greater than $50,000

17. Do you have health insurance?

- ○ YES
- ○ NO **(IF "NO," Go to question 20)**

17a. **IF YES to Question 17**, what kind of insurance do you have?

	YES	**NO**
Private insurance through work or COBRA (insurance received from your last employer)	O	O
Private insurance – not through work	O	O
Insurance through my partner's/parent's plan at work	O	O
Medicare	O	O
Veterans Administration (VA)	O	O
MaineCare/Medicaid	O	O
Other (please specify)	O	O

18. How much do you pay for insurance premiums out of your own pocket? **(Select One)**

O Nothing/not applicable
O Less than $100/month
O $101 - $200/month
O $201 - $300/month
O $301 - $400/month
O $401 - $500/month
O More than $500/month
O I don't know

19. What is your total cost for insurance deductible(s) (regardless of who pays for the insurance) **(Select One)**

O Nothing/not applicable
O Less than $500/year
O $501 - $1,000/year
O $1,001 - $1,500/year
O Over $1,500/year
O Over $2500
O I don't know

20. Are you currently taking any medicines to treat your HIV infection?

O YES

O NO **(IF "NO," GO TO QUESTION 22)**

21. **(IF TAKING PRESCRIBED MEDICATION FOR HIV OR RELATED CONDITIONS),** How much do you pay, out of pocket, each month for "HIV meds" – prescription meds & co-pays? **(Select one)**

O Nothing/not applicable

O $1-$25 per month

O $26-$50 per month

O $51-$100 per month

O More than $100 per month

O I don't know

21a. Are you taking any of the following? (**Fill in the circle for YES, NO, or DON'T KNOW for each of the following medications).**

	YES	**NO**	**Don't Know**
HIV medications (antiretrovirals)	O	O	O
Antibiotics (such as Bactrim) that fight off infections	O	O	O
Antifungal (such as Diflucan) that are for body rashes or thrush	O	O	O
Steroids which help you with your appetite or to build weight	O	O	O
Antidepressants for depression or anxiety	O	O	O
Hormones	O	O	O
Other (Prescription, Non-Prescription, Herbal, etc.) Please list:	O	O	O

22. During the past year, how long were you **without** any insurance that covers treatment for HIV or AIDS? **(Select One)**

O Never

O Less than a month

O 1-3 months

O 4 months to a year

23. Do any of the following program(s) help to pay for your HIV/AIDS drugs? **(Select YES, NO or Don’t Know for each one)**

	YES	**NO**	**Don’t Know**
AIDS Drug Assistance Program (ADAP)	○	○	○
MaineCare/Medicaid	○	○	○
Veterans Administration Medical Assistance	○	○	○
Private Insurance or HMO	○	○	○
Patient Assistance Programs from Drug Companies	○	○	○
Clinical Trials	○	○	○
Medicare Prescription Card	○	○	○
Local AIDS Service Organization	○	○	○
Other (please specify)	○	○	○

24. How long after you learned you were HIV positive did you see a doctor about your HIV? **(Select One)**

○ I have not seen a doctor for my HIV

○ Within a month

○ Within 3 months

○ Within 6 months

○ Within a year

○ Over a year: (how long?______________________)

25. How long after you learned that you were HIV positive did you get your first prescription for drugs to treat the HIV? **(Select One)**

○ I have not gotten a prescription for drugs to fight my HIV

○ Within a month

○ Within 3 months

○ Within 6 months

○ Within a year

○ Over a year: (how long?________________________)

26. When was your lowest, highest and most recent T-cell count?

○ I never had my T-cell count measured, **SKIP To Question 28**

	Date	**Don't Know the date**	**Count**	**Don't Know the count**
Lowest T-cell count	____/____/____	○	_______	○
Highest T-cell count	____/____/____	○	_______	○
Most recent T-cell count	____/____/____	○	_______	○

27. When was your lowest, highest and most recent viral load test?

○ I never had my viral load measured, **SKIP To Question 28**

	Date	**Don't Know the date**	**Count**	**Don't Know the count**
Lowest viral load	____/____/____	○	_______	○
Highest viral load	____/____/____	○	_______	○
Most recent viral load	____/____/____	○	_______	○

28. Have you ever been diagnosed with any of the following:
(Select YES, NO or Don't Know for each one)

	YES	**NO**	**Don't Know**
Primary Syphilis	○	○	○
Secondary Syphilis	○	○	○
Herpes (genital)	○	○	○
Gonorrhea	○	○	○
Chlamydia	○	○	○
Genital warts	○	○	○
Hepatitis A	○	○	○
Hepatitis B	○	○	○
Hepatitis C	○	○	○
Yeast infections	○	○	○
Other (specify)___________________	○	○	○

IF YOU'VE TAKEN HIV MEDICATIONS AT ANY TIME IN THE PAST YEAR, PLEASE ANSWER QUESTIONS 29 – 31. IF NOT, SKIP TO QUESTION 32

29. How often (in the past year) have you missed a dose or stopped taking your HIV medication(s), **with** the advice of a doctor? **(Select One)**

○ Never
○ Rarely
○ Some of the time
○ Often
○ I have stopped taking my medicine

30. How often (in the past year) have you missed a dose or stopped taking your HIV medication(s), **without** the advice of a doctor? **(Select One)**

○ Never
○ Rarely
○ Some of the time
○ Often
○ I have stopped taking my medicine

31. **IF YOU HAVE MISSED A DOSE, OR STOPPED TAKING YOUR MEDS** without the advice of a doctor, which of the following were the reasons? (**Select all that apply)**

○ Side effects
○ Difficult schedule and requirements
○ Felt that the medication didn't work
○ Could not afford the medication
○ Forgot to take the medication
○ Hard to coordinate with food
○ Didn't understand the instructions
○ No place to keep medications
○ To share medication with others
○ Ran out of medication
○ Didn't want others to see the medication
○ Wasn't able to fill prescription (specify)________________________________
○ Other (specify)____

32. Have you used any of the following treatments in the past year? **(Select YES or NO for each one.**

	YES	**NO**
Massage	O	O
Acupuncture	O	O
Chiropractor	O	O
Biofeedback	O	O
Herbal treatments (such as St. John’s Wort, Kava Kava or Gingko)	O	O
Vitamins/antioxidants	O	O
Dietary supplements	O	O
Other (please specify)	O	O

33. Since you were infected with HIV, have you received any of the following: **(Select YES, NO or Don’t Know for each one)**

	YES	**NO**	**DON’T KNOW**
Individual therapy with a psychiatrist?	O	O	O
Medication prescribed by a psychiatrist?	O	O	O
Individual therapy with a psychologist, social worker, licensed professional counselor, nurse clinician, or licensed chemical dependency counselor?	O	O	O
Group therapy with a psychologist, social worker, licensed professional counselor, nurse clinician, or licensed chemical dependency counselor?	O	O	O

34. If you received treatment, was it:**(Select One)**

O Outpatient (by a doctor or counselor)

O Inpatient (in a hospital at least overnight)

35. Since you were infected with HIV, have you received any treatment for alcohol or drug use?

O YES

O NO

36. What is the most likely way that you were infected with HIV? (**Select One**)

- ○ Having Sex with a man
- ○ Sharing needles or “works”
- ○ Having sex with an injection drug user
- ○ **Having sex with a woman**
- ○ Other
- ○ Don’t know

37. During **the past 6 months**, how often have you used any of the following substances?

	NOT USED AT ALL	**DAILY**	**WEEKLY**	**MONTHLY**
Alcohol	○	○	○	○
Tobacco	○	○	○	○
Marijuana or hash	○	○	○	○
Crack	○	○	○	○
Cocaine	○	○	○	○
Heroin	○	○	○	○
Crystal Meth/Methamphetamines	○	○	○	○
Speedball	○	○	○	○
Ecstasy	○	○	○	○
Poppers	○	○	○	○
Methadone	○	○	○	○
Oxycontin	○	○	○	○
LSD	○	○	○	○
Special K	○	○	○	○
Pills not prescribed by my doctor (specify:________________________)	○	○	○	○
Other substances (specify:________________________)	○	○	○	○

38. If you are currently injecting substances (such as street drugs, hormones, prescribed medications), how often do you share needles or works? **(Select one)**

○ Not applicable, I am not currently injecting
○ All the time
○ Usually, but not always
○ Sometimes
○ Never

39. In the last 12 months, were you in a partnered relationship with one other person (such as a girlfriend/boyfriend, spouse, partner)?

○ YES ○ NO

a. IF YES, The person's HIV status was/is: **(Select one)**

○ HIV positive
○ HIV negative
○ Unknown
○ I don't know

b. About how many times did you have anal or vaginal sex (in the past 12 months)? ____

c. About how many times did you have anal or vaginal sex **without** a condom (in the past 12 months)? _____

d. In the last 12 months, did you have sex with someone (such as a friend, date, or anonymous partner) you were **not** in a partnered relationship with?

○ YES ○ NO

IF YES:

About how many people did you have sex with in the past 12 months? ____

About how many times did you have anal or vaginal sex in the past 12 months? ____

About how many times did you have anal or vaginal sex **without** a condom in the past 12 months? ____

Of the times I had sex without a condom, my partners' HIV status was **(select all that apply)**:

○ HIV positive
○ HIV negative
○ Unknown
○ I don't know

Please take a few minutes to fill out the chart on the following page. Your answers will provide us with important information about services. Thank you!

After you complete these questions, please place the questionnaire in the self-addressed envelope and drop it in the mail. THANK YOU SO MUCH!!

	Please check ONE of the columns below for each service			**Why aren't you receiving these services? PLEASE CHECK ALL THAT APPLY**									
SERVICE CATEGORY	I use or have used this service within past 12 months	**OR**	I need this Service but cannot get it	Cost	Transportation	Location	Hours	Did not know it is/was offered	Not eligible	Don't know where to go	Worried about Confidentiality	Discrimination	Some other reason (please specify)
A. Alcohol/Drug Recovery Services/Treatment	O	**OR**	O	O	O	O	O	O	O	O	O	O	
B. Case Management (ongoing help to get services, not one-time)	O	**OR**	O	O	O	O	O	O	O	O	O	O	
C. Client Advocacy (help getting health and support care services)	O	**OR**	O	O	O	O	O	O	O	O	O	O	
D. Day Care for Children	O	**OR**	O	O	O	O	O	O	O	O	O	O	
E. Dental Care	O	**OR**	O	O	O	O	O	O	O	O	O	O	
F. Emergency Housing Assistance (rent)	O	**OR**	O	O	O	O	O	O	O	O	O	O	
G. Emergency Assistance (public service, phone, etc.)	O	**OR**	O	O	O	O	O	O	O	O	O	O	
H. Food Bank	O	**OR**	O	O	O	O	O	O	O	O	O	O	
I. Help Paying for Health Insurance	O	**OR**	O	O	O	O	O	O	O	O	O	O	
J. Home Delivered Meals	O	**OR**	O	O	O	O	O	O	O	O	O	O	
K. Home Health Care (nurse, attendant, physical therapy)	O	**OR**	O	O	O	O	O	O	O	O	O	O	
L. Hospice Care	O	**OR**	O	O	O	O	O	O	O	O	O	O	
M. Medical Care	O	**OR**	O	O	O	O	O	O	O	O	O	O	
N. Mental Health/Support Group/Counseling	O	**OR**	O	O	O	O	O	O	O	O	O	O	
O. Prescription Drugs	O	**OR**	O	O	O	O	O	O	O	O	O	O	
P. Bus Fares, Taxi Vouchers or rides	O	**OR**	O	O	O	O	O	O	O	O	O	O	
Q. Other	O	**OR**	O	O	O	O	O	O	O	O	O	O	

Appendix C: Focus Group Screening Questionnaire and Guide

FOCUS GROUP RESPONDENT QUESTIONNAIRE

Note: All the information collected here will be kept strictly confidential. If you feel uncomfortable answering any question, you can leave it blank.

1. Are you:

[ ]Female
[ ] Male
[ ] Transgender male to female
[ ] Transgender female to male

2. How old are you? _______________

3. Do you consider yourself Hispanic or Latino?

[ ] Yes
[ ] No

4. What is your Race?: (C*hoose all that apply*.)

[ ] Asian
[ ] Black or African American
[ ] Native American or Alaska Native
[ ] Native Hawaiian or other Pacific Islander
[ ] White
[ ] Other_________________________

5. Are you HIV positive?

[ ] Yes [ ] No

F YES, When were you diagnosed with HIV?
Year diagnosed with HIV: _________

6. Has your HIV progressed to AIDS?

[ ] Yes [ ] No

IF YES, When were you diagnosed with AIDS?
Year diagnosed with AIDS: __________

7. Do you know how you acquired HIV/AIDS?

[ ] Male sex w/male
[ ] Injection Drug Use
[ ] Sex with injection drug user
[ ] Heterosexual Sex
[ ] Sexual Assault
[ ] Prison
[ ] Mother w/HIV/AIDS
[ ] Contaminated blood products
[ ] Don’t know

8. What is your sexual orientation?

[ ] Heterosexual/straight
[ ] Gay/Lesbian
[ ] Bisexual
[ ] Unsure/questioning
[ ] Other

9. Do you currently have any health insurance? *(check all that apply)*

[ ] MaineCare
[ ] Medicare
[ ] Private insurance (not an HMO)
[ ] Private insurance (HMO)
[ ] VA
[ ]Other____________________
[ ] None

10. When was the last time you saw a doctor? Month___ Year___

11. When was the last time you had a CD4 Count? Month___ Year___

12. When was the last time you had a Viral Load test? Month___ Year___

13. Where do you see your HIV doctor?

[ ] Hospital
[ ] Private Clinic
[ ] Public Health clinic
[ ] Somewhere else:

14. Have you ever been diagnosed with or treated for:

A mental illness

[ ] Yes [ ] No

Substance Abuse

[ ] Yes [ ] No

Sexually Transmitted Diseases (STD's)

[ ] Yes [ ] No

Diseases other than HIV?
[ ] Yes [ ] No

15. Are you currently taking HIV drugs?

[ ] Yes [ ] No

16. How do you get (cover the cost of) your medications? (choose all that apply)

[ ] Pay for them myself or get help from family or friends
[ ] Private insurance
[ ] MaineCare
[ ] Clinical Trials
[ ] AIDS Drug Assistance Program (ADAP)
[ ] Compassionate use from drug companies
[ ]Other __________________

17. Do you currently:

- [ ] Own your own home
- [ ] Rent
- [ ] Live with a friend or relative
- [ ] Live in subsidized housing
- [ ] Live in a shelter

18. What county do you live in?

O Androscoggin
O Aroostook
O Cumberland
O Franklin
O Hancock
O Kennebec
O Knox
O Lincoln
O Oxford
O Penobscot
O Piscataquis
O Sagadahoc
O Somerset
O Waldo
O Washington
O York

Thank You!

Ryan White Title II, Needs Assessment Focus Groups

- **Sample: Adults (18 or older) living with, HIV/AIDS in Maine**
- **Groups to be held in November will target consumers of agencies receiving Ryan White Title II funds.**
- **Each group will have between six and twelve participants**

Date: ________________________________
Time: ________________________________a.m./p.m.
Place: ________________________________ (Agency or Other Location)
Facilitated by: _______________________________

Hello, my name is _______ and this is (introduce note-taker) We are both from the University of Southern Maine. We've been contracted by the Bureau of Health to gather feedback from people living with HIV or AIDS in Maine, about the services they need.

So, the reason for being here today, the reason we've asked you to come to this group is so that we can hear from you about whether or not HIV+ people have real access to the services they need to manage their disease. This process is required by the federal government, and is the way the affected community has a voice in what, how and how much care is provided to help them with their disease.

With just two hours, it's crucial that we stay focused so that everyone can be heard and we come out of this with recommendations for the Ryan White program. Though it may be tempting to talk about current services, what we must focus on are the services you need to help you manage your HIV disease.

____ and I are independent consultants, so none of your individual statements will be passed on to the Bureau of Health, the Ryan White Advisory Committee, or any of the providers you are involved with. This process is confidential, with the tape player recording information to help us with the summary of your comments.

Transcripts (with names removed) and a summary report will be provided to the Ryan White Title II program and the Bureau of Health. This report will not include names and responses won't be associated with any individuals.

Your participation in this focus group will not effect your receiving services.

Is it okay if we begin the interview?

7. Can you tell me the **top three services** you need to help you live with HIV?
List responses on flip chart – asking participants to list them in order of importance.

After every participant has had a chance to respond, hand out list and ask if there's anything else on that list that would replace one of the top three priorities they already gave me.

8. Of these services, are there any that you have trouble receiving? *Again, go around the room, asking participants to list up to three services that they have difficulty obtaining.*
(list on separate flip chart paper)

9. What services do you need that you don't get at all? *Again, go around the room, asking participants to list up to three services they need but aren't able to obtain at all.*
(list on separate flip chart paper)

10. Name the top three issues that make it hard for you to access medical services – *please be brief: for example – have to drive too far, long wait for appointment, and so on*
(list on separate flip chart paper)

If there's time, ask the following questions:

11. How would you change services to make them easier to use? What support helps KEEP you in care?

12. What efforts can providers make to get people back into care if they've stopped?

13. Is there anything else you would like to tell us about the needs of PLWH and/or barriers to service?

Thank you very much for taking the time to talk with us. Your responses will help to determine what services are funded by identifying the needs, gaps in and barriers to care for persons like you living with HIV.

Appendix D: Out of Care Survey Tool

State of Maine

Comprehensive Needs Assessment
Out of Care Client Survey

- **"I understand that my completion of this needs assessment client survey is strictly voluntary. If I choose not to complete the survey, it will not affect the services that I receive."**

- All information collected through this survey is completely **confidential**. **Do not put your name on this survey.**

- The survey asks for some personal background information (to help in planning services that respond to your needs). **This personal information will never be used to identify you as an individual.**

Filling out this survey should take about **10 minutes** of your time.

PLEASE ANSWER EACH OF THE FOLLOWING QUESTIONS BY PUTTING A CHECK ON THE LINE OR PROVIDING THE INFORMATION ASKED FOR. (You may need to check more than one box to answer a question.)

I. Demographics/Disease Status

	YES	**NO**	**Don't Know**
1. Are you currently			
HIV positive	____	____	____
AIDS diagnosis	____	____	____
Unknown HIV status	____	____	____
Never tested	____	____	____

2. Are you currently

HIV positive and receiving services __**5**__ (Yes) ____(NO)
What services? **Mental health (1), Food Bank (4)**
HIV positive and not receiving services __**23**__(Yes) ____(NO)

Are you

_____ Male
_____ Female
_____ Transgender
_____ Other (specify): ____________________

2. Do you consider yourself

_____ Heterosexual/straight
_____ Homosexual – Gay man
_____ Homosexual – Lesbian
_____ Bisexual
_____ Other (specify): __**both transgender, both male to female**__________

3. What do you consider your ethnic background?

_____ American Indian or Alaska Native
_____ Asian
_____ Black or African-American
_____ Hispanic or Latino/Latina
_____ Native Hawaiian or other Pacific Islander
_____ White
_____ Other (specify): ____

4. **Which language do you prefer to speak? (Please circle only one)**

English – 100%
Spanish

5. What is the name of the county in which you live?

II. Care Status, Testing Circumstance

1. **When did you first test positive for HIV? Please indicate the year of your first positive test**. _______ Year

2. **What caused you to get tested for HIV?**
   a. Curious about risk
   b. Notified by partner/friend
   c. Outreach
   d. Donated blood or plasma
   e. Went to hospital or emergency department for other reason
   f. Tested as part of routine physical
   g. Tested for pregnancy
   h. Felt sick

3. How do you think you acquired HIV/AIDS?

4. How long has it been since you accessed medical care from a doctor or clinic for your HIV?

(Please select one only)
   a. I have never received care for HIV
   b. Longer than 1 year

5. **If you *did not seek medical care from a doctor or a nurse within one (1) year of finding out you were HIV positive*, please indicate why.**

(Please check all that apply)
   a. Never received medical care (go to 6a)
   b. Can't afford it.
   c. Don't need medical care.
   d. Can't get transportation.
   e. Don't know where to go to get medical care.
   f. Don't trust doctors.
   g. Didn't think I needed it.
   h. I am/was depressed
   i. Using substances—don't want to come clean

5a. If never received medical care why not?

III. Reason Out of Care/Never in Care

1. If you have not seen a doctor for over 12 months…Why not?

a) Felt better
b) Was undetectable
c) Had problems with medications
d) Couldn't afford medications
e) Other (specify)

2) If you haven't gotten medical care in the <u>last 12 months</u> which of the following things would get you to go to a doctor*:*

a) Transportation
b) Acute illness
c) Free medical care
d) Insurance
e) Better quality of services
f) Referrals or advice
g) More information about services
h) A job
i) Substance abuse treatment
j) Nothing

3) Why don't other people get medical care for HIV?

a) Worried that others will find out/Fear of telling someone
b) Language/cultural concerns
c) Feel healthy/Not sick
d) Can't afford it
e) Don't have transportation
f) Using drugs
g) Don't want to take HIV medications

Thank you for taking this survey

Appendix E: Public Hearing Flyer

Need Help with HIV Disease?

The Bureau of Health wants to know what you
need to best manage HIV disease.
You can tell us at the...

HIV/AIDS Public Hearing

Wednesday, October 13, 2004

1:00-4:00 P.M.

Augusta Civic Center

Augusta, Maine

Make Your Voice Heard...

If you...

- have HIV disease
- live with or care for someone with HIV disease
- work with people with HIV disease

The Bureau of Health wants to hear from you.

How can you tell us?

- Come to the Public Hearing and tell us
- Send us your written comments (see below for information)

Your comments will guide the Bureau of Health in planning HIV care services
funded by the Ryan White CARE Act, Title II.

Special needs? More information?

If you require special accommodations or would like more information,
please contact Tammy McLaughlin at AdCare Educational Institute of Maine, Inc.
75 Stone Street, Augusta, ME 04330.

Phone: 626-3615 Fax: 621-2550 TTY: 623-0830

Sponsored by Maine Dept. of Health and Human Services, Bureau of Health, HIV/STD Program