

A Needs Assessment
for Advanced Stage Care Services for Persons Living with
HIV/AIDS in the Portland Eligible Metropolitan Area

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Prepared for
Multnomah County Health Department

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Section I: Introduction

Overview



In 1994, a six-county area centered around Portland, Oregon, became eligible to receive funds from Title I — the “HIV Emergency Relief Grant Program” — of the Federal Ryan White CARE Act. The Portland Eligible Metropolitan Area (EMA) includes Multnomah, Clackamas, Columbia, Washington, and Yamhill counties in Oregon and Clark County in Washington. The Title I program provides essential health and support services for individuals and families affected by HIV disease. The

Multnomah County Health Department administers the program on behalf of the Chair of the Board of County Commissioners.

The HIV Services Planning Council, appointed by the Multnomah County Chair, is responsible for determining priorities for Title I-funded services and allocating these funds to specific priorities. The HIV Services Planning Council ranked advanced stage care services 7th among 22 service categories for fiscal year 1999–2000, and requested that a needs assessment study for this category be completed during this time period.

The HIV Services Planning Council requested the following information about consumers assessed to need residential, in-home or respite care services and the system providing these services:

1. An estimate of the size of the HIV positive population assessed to need residential, in-home or respite care services;
2. A description of the characteristics of this target population;

3. The overall capacity of the current system for residential, in-home care, and respite services for individuals living in the Portland EMA;
4. A profile of insurance providing agencies and the services they cover;
5. An estimate of the number of clients who can be served in a given period of time;
6. Unmet needs for these services in the Portland EMA;
7. Barriers to meeting these needs; and
8. Recommendations for a Council/community plan of action to respond to unmet/underserved needs.

To gather this information, the Multnomah County Health Department contracted with Northwest Professional Consortium, Inc. (NPC) in October 1998.

Advanced stage care services can be defined as those services crucial to maintaining health as a consumer reaches a level of intense need. These services include (1) residential care services (in a skilled facility, foster care home or assisted living apartments); (2) medical, non-medical and hospice in-home care services; and (3) respite care services. While these categories of service were once viewed as "end of life" care, persons living with HIV/AIDS now may have episodic need for these intensive services. To care adequately for persons living with HIV/AIDS, we must understand the breadth and scope of these three categories of services, the characteristics of the individuals served, and barriers consumers face in accessing care.

It is estimated that as many as 3,500 Portland Eligible Metropolitan Area residents have been diagnosed with AIDS since record-keeping on the epidemic began in 1981 (Oregon HIV/AIDS 1997 Annual Report, Oregon Health Division, and SW Washington Health District). The number of persons newly diagnosed with AIDS has continued to drop significantly over the past 3 years. According to the Oregon Health Division, in 1996, there were 328 newly reported AIDS diagnoses in the Portland EMA. The following year, the number dropped by

31 percent to a total of 228. In 1998, 98 persons were reported to be diagnosed with AIDS. The death rate has slowed as well. According to the Oregon Health Division and SW Washington Health District, 193 persons died of AIDS-related causes in 1996, compared with 75 in 1997 and 37 in 1998. This decline is significant.

These local figures parallel national trends. In 1996, 54,237 individuals were diagnosed with AIDS. There were 34,557 AIDS related deaths in 1996. In 1997, 30,986 people were reported as diagnosed with AIDS, and there were 14,185 deaths. This trend represents a 43 percent decrease in diagnoses and a 59 percent drop in deaths from 1996 to 1997 (HIV/AIDS Surveillance Report, U.S. Department of Health and Human Services, 1998). A declining number of people needing end of life care, however, does not necessarily imply a decreased need for advanced stage care services.

Despite the decreasing death and diagnosis rates, HIV/AIDS has become increasingly complex to manage. Medication management, living situation, poverty, co-occurring disorders, insurance coverage, and corresponding eligibility for services are just a few of the issues that complicate the care needs of individuals needing advanced stage care services.

Recent breakthroughs in the medical research conducted to find a cure and curative therapy for HIV/AIDS have changed the epidemic. New medication regimens have changed HIV status from a terminal to a chronic disease, according to local hospice agencies. The medical and social service needs of people living with HIV have also changed. New combination drug therapies are extending lives and allowing many individuals the opportunity to regain levels of functioning that were not before possible. Despite these advances and efforts, HIV infection and AIDS continue to be a life-threatening illness with unique care concerns. Anecdotally, between one-third and one-half of consumers seeking curative

therapies in the form of medication are unable to tolerate them either immediately or after some treatment (Comprehensive HIV/AIDS Services Plan, 1998).

An estimated 12 to 19 percent of people who are HIV positive have some immunosuppression, and are at high risk for HIV-related morbidity, but do not have an AIDS-indicator disease. These resulting diseases are the primary causes of impairment and service needs for people with AIDS (1993 Revised Classification System for HIV Infection and Expanded Surveillance Case Definition for AIDS Among Adolescents and Adults, 1992). Individuals with AIDS-related diseases face dramatic physical and social limitations and require an intense network of services.

It is estimated that at least 1,300 people were living with AIDS in the Portland EMA in 1997 (Oregon HIV/AIDS 1997 Annual Report, 1998; SW Washington Health District, 1998), and 98 new cases were reported in 1998. Varied outcomes of medication therapies and the general nature of the disease continue to create a need for intensive care services despite the progress made in maintaining health. An acute need for advanced stage care services is apparent. Residential, in-home, and respite care services for people living with HIV/AIDS will remain necessary to provide an adequate continuum of care for the entire population of PLWH/A.

An acute need for advanced stage care services is apparent.

This report has four major sections.

- ❖ The first section introduces the research and describes the issues that warranted this study and are crucial to future planning by the Council.
- ❖ The second section explains the methods and evaluation techniques used to conduct this needs assessment.
- ❖ The third section is a thematic representation of key findings, including the number of consumers assessed to need residential, in-home and respite care services, current service availability and insurance coverage, unmet

needs in the Portland EMA, and obstacles to consumers receiving services.

- ❖ The fourth section provides recommendations for action, and suggestions for monitoring the care needs of this population in the future.

Section II: Description of Methodology

Design



To comprehensively cover the range of issues surrounding advanced stage care from a variety of perspectives, Northwest Professional Consortium used multiple methods to collect data. NPC conducted a literature review to identify current knowledge about the population of persons living with HIV/AIDS. Local archival data supplemented this literature. In addition, NPC gathered local, state, and national data regarding the incidence and prevalence of HIV/AIDS. Insurance

providers were consulted on the coverage they provide to their policy holders and the agencies they work with to provide services. NPC surveyed community-based service providers who provide, or could potentially provide, residential, in-home or respite care services regarding barriers to service provision and the capacity of their agencies to care for consumers. Case managers working in the Portland EMA were asked to provide information on unmet needs, barriers to receiving services and recommendations. Consumer case study interviews were conducted in the consumers' homes to gain information on the care services they are receiving or have received within the Portland EMA.

Measures and Procedures

The measures used in this study were developed based on the needs of the HIV Planning Council, conversations with the HIV Client Services Administration Office, conversations with the Partnership Project, the current literature, and other HIV needs assessments.

Archival Data Search

In collaboration with the HIV Client Services Administration Office, researchers from NPC generated a comprehensive list of services that fall under the categories of residential, respite, and in-home care services. This list includes:

❖ Residential Services

- Assisted living facilities
- Foster care homes
- Short-term skilled care (e.g., rehabilitation or recovery from an acute episode or illness)
- Long-term skilled care (e.g., nursing home care)
- Residential hospice care

❖ In-Home Care

- Non-medical (e.g., homemaker, home health aide, and personal/attendant care)
- Medical (e.g., skilled nursing, intravenous and aerosolized medication treatments, diagnostic testing, parenteral feedings and other high tech. services)
- Hospice
- Durable Medical Equipment (e.g., prosthetics, devices and equipment used by clients in a home/residential setting, such as wheelchairs inhalation therapy equipment or hospital beds)

❖ Respite Care

- Short-term residential
- Community-based day care
- Homemaker (e.g., non-medical support)
- Home care aide (e.g., some medical support)
- Home health aide (e.g., certified or licensed caregiver)

Four key assessment and referral agencies in the Portland EMA were asked to provide archival data on their caseloads:

- The Partnership Project

- SW Washington Health District
- Multnomah County Health Department (HIV Clinic)
- Kaiser Immune Deficiency Clinic (IDC)

Data were gathered on clients who were assessed by their case manager to need residential, respite, or in-home care services from January 1998 through March 1999. Eligibility was determined by searching case managers' service or care plans. The sample includes consumers who have passed away since their assessment in 1998 or 1999.

For those clients identified as needing one or more of these categories of service, the following information was requested:

- ❖ demographics (gender, ethnicity, age, co-occurring disorder/s, county of residence, rural/urban residence);
- ❖ insurance status (public, private, none) and insurance provider; and
- ❖ agencies they were referred to, and from which they received services.

Data management systems varied greatly, so different information and methods for extracting it were available from each agency. For example, data from one agency were provided by creating comprehensive database reports, while another required searching through paper records and files.

Consumer Interviews

Because of concerns regarding consumer confidentiality and a desire to minimize the imposition on PLWH/A, NPC worked with case management staff at Kaiser IDC, SW Washington Health District, the Multnomah County HIV Clinic, and the Partnership Project to identify consumers from the archival data search who would be appropriate for consumer interviews. Case management agencies were asked to provide the names of twelve consumers assessed to need these services. Two were requested from both Kaiser IDC and SW Washington, three from the HIV Clinic, and five from the Partnership Project.

In an attempt to cover the breadth of diversity of PLWH/A, NPC asked the agencies to identify consumers who fit one or more of the following categories and could thus bring a range of perspectives to the study. The categories included consumers who:

- ❖ are female
- ❖ are persons of color
- ❖ were assessed to need many services and received some
- ❖ were assessed to need some services and received none, either because they didn't want them or because the system couldn't meet their needs
- ❖ have complicated needs
- ❖ are covered by private insurance
- ❖ are covered by public insurance (OHP/Medicaid or Medicare)
- ❖ who have had episodes of needing advanced stage care services
- ❖ who are probably using advanced stage care services for end of life needs
- ❖ who have a long history with the disease

Kaiser and SW Washington each provided two consumers from their caseloads, the HIV Clinic and Partnership Project provided a combined six respondents who were in the Partnership Project database. An effort was made to include consumers whose cases were managed solely through the HIV Clinic. However, consumers whose needs include residential, in-home or respite care services — and who receive services at the HIV Clinic — are typically included in the Partnership Project database to ensure every effort is made to meet their intense needs.

The consumer instrument asked respondents to address issues including:

- ❖ whether they were a current or previous consumer of residential, in-home, or respite care services
- ❖ where they lived when they were diagnosed with HIV
- ❖ where they currently lived
- ❖ whether they had been diagnosed with AIDS and when

- ❖ how they covered most of their medical expenses
- ❖ age, gender and ethnicity
- ❖ which advanced stage care services they (or someone who cared about them) thought they needed and which of these services they received
- ❖ which obstacles they faced in trying to receive residential, in-home or respite care
- ❖ the situation that caused them to need intense services
- ❖ whether they had barrier free, adequate access to services
- ❖ whom they relied on for support in getting the services they needed
- ❖ the difference in the services they received from HIV-specific agencies and those that serve a broader population
- ❖ any discrimination they may have experienced from service providers
- ❖ recommendations

The consumer interviews were constructed as in-depth case studies of individuals' needs for the advanced stage care services being studied. NPC staff made appointments and then visited consumers in their homes. Respondents were reimbursed for their time and expertise with a \$20 incentive and a small gift. Interviews took between 45 minutes and 3 ½ hours to complete.

A total of ten consumers were interviewed in their private residence or the residential facility where they currently reside.

Insurance Provider Questionnaire

Nine key health insurance providers were identified as frequently used by consumers of advanced stage care services through the archival data search at the four case management agencies and conversations with the HIV Client Services Administration Office for initial study. These agencies include private coverage providers such as Kaiser, CareOregon, Providence, ODS, and Regence Blue Cross Blue Shield, as well as publicly-funded organizations such as the Veteran's Administration, Oregon Medical Insurance Pool, Oregon Health Plan/Medicaid, and Medicare. Representatives from these agencies were contacted to gather information on coverage for residential, in-home and respite care services; eligibility requirements; and limitations, if any. Insurance providers were also asked to indicate local agencies they contracted with to provide services, to obtain a list of service providers for that module of the needs assessment study.

Once a contact person was identified at each of the eight participating insurance providers an Insurance Provider Questionnaire was faxed to her/him. A follow-up call was placed the following day to inquire if the respondent had any questions regarding the fax. These calls were for the most part met with responses that the survey had been passed on to a different individual.

The Insurance Provider Questionnaire asked respondents to check the residential, in-home and respite care services they provide coverage or some reimbursement for, and then talk about eligibility requirements for coverage and any limitations to coverage consumers may face.

In all, two insurance agencies returned the survey by fax, five agencies answered questions over the telephone regarding coverage, and information on Medicare and Social Security was gained through a visit to a local Social Security Administration Office to collect literature. Several agencies also mailed literature in addition to completing parts of the Questionnaire.

Service Provider Questionnaire

A list of 32 service providers was compiled using four sources: data from an archival data search of commonly used providers of residential, in-home and respite care services, data from the Insurance Provider Questionnaires, data from local physicians specializing in the care of PLWH/A, and conversations with the HIV Client Services Administration Office. This list included mainstream and HIV-specific residential and in-home care providers, and a day care/respite care facility.

Eligible service providers were initially contacted by phone to invite them to participate in the study. The survey was then faxed and follow-up calls were made to each organization. The average organization required 5 calls to return the survey, and the number of calls ranged from 3 to 10.

The Service Provider Questionnaire covered the following domains:

- ❖ obstacles consumers faced in accessing residential, in-home and respite care services
- ❖ required and available training on HIV/AIDS
- ❖ how the changing nature of HIV disease affected their service provision
- ❖ capacity of this agency to provide service
- ❖ the percentage of clients they served who were HIV positive
- ❖ the barriers that consumers face in accessing their services
- ❖ recommendations

In all, 21 of the 32 agencies provided information on the services they offer, with 14 agencies responding by fax and 7 agreeing to complete the survey over the phone. Although providers tended only to answer questions about services they specifically offered, most agencies provided data on barriers consumers face to trying to receive their services.

Case Manager Questionnaire

As an addendum to the original proposal, it was determined that the experience and expertise of case managers and the close relationship they have with many consumers was a valuable resource. A case manager module was added to the original scope of work to create a more complete needs assessment study. Case managers from the Partnership Project, the Multnomah County HIV Clinic, SW Washington Health District, and Kaiser's Immune Deficiency Clinic were asked to participate.

The Case Manager Questionnaire included an opportunity to identify:

- ❖ unmet needs and service areas for development
- ❖ obstacles consumers faced in accessing services
- ❖ capacity, availability, accessibility of the three categories of services being studied
- ❖ barriers consumers faced in accessing these particular services
- ❖ recommendations

Case managers were asked to consider the consumers they work with who have been assessed to need residential, in-home, or respite care services when completing the Questionnaire and to also speak from their experience. Case managers at Partnership Project and the HIV Clinic were given a list of consumers in their caseload eligible for the study to consider as they completed the Questionnaire.

Survey administration took place at the Partnership Project for case managers from that agency and the HIV Clinic. Surveys were faxed to Kaiser and SW Washington Health District with directions and information on returning the surveys to NPC. In all, fifteen case managers completed all or part of the Questionnaire.

Analysis Strategy

A quantitative approach to our analysis was coupled with a qualitative approach, thereby allowing for rigorous analysis without losing the complexity of the responses. This approach is evident throughout the key findings section of this report.

Quantitative Data

This report presents highlights and identifies themes that emerged from the data. The tables in Section III are a comprehensive presentation of the descriptive statistics and significant findings. Several software applications were employed to analyze the data for the present volume in order to determine the information most meaningful to the HIV Services Planning Council.

Descriptive statistics were used throughout this report to encapsulate findings. Data have been analyzed and reported as percentages of total respondents, actual numbers of respondents, or mean (average) ratings. Cross-tabulations with demographic data have been studied to extract more specific data from the surveys. All sample sizes are reported throughout the report due to the targeted small sample sizes for these surveys.

A quantitative approach to our analysis was coupled with a qualitative approach...

Qualitative Data

Qualitative data were analyzed and synthesized to reveal themes in the data. Excerpts from the consumer interviews, Service Provider Questionnaires, Case Manager Questionnaires, and Insurance Provider Questionnaires have been added where appropriate.

Profile of the Consumer, Service Provider, and Case Manager Samples

The consumers who participated in the case study interviews:

- ❖ were Oregon (8) or Washington (2) residents
- ❖ were Multnomah County, Oregon (7), Clark County, Washington (2), or Washington County, Oregon (1) residents
- ❖ covered most of their medical expenses with OHP/Medicaid (10), some also had Medicare (7), and some had private insurance (2)
- ❖ were between the ages of 33 and 49 (8), or 50 and 67 (2)
- ❖ were male (8) or female (2)
- ❖ were Caucasian (8) or of Hispanic/Latino origin (2)
- ❖ lived in residential facilities (4) or at home (6)
- ❖ either had a caregiver recently (5) or relied solely on community-based services (5)

Case managers came from four agencies in the Portland EMA:

- ❖ Partnership Project (7)
- ❖ Multnomah County HIV Clinic (4)
- ❖ Kaiser Immune Deficiency Clinic (1)
- ❖ SW Washington Health District (3)

Characteristics of service providers:

- ❖ 9 residential care providers, 11 in-home care providers, and 1 physician
- ❖ 10 were HIV-specific, and 11 provided services to the general public

Section III: Key Findings

Key Findings



The key findings are organized according to the scope of work originally proposed by the Multnomah County Health Department's HIV Client Services Administration Office. Specifically, these results address: an estimate of the size of the HIV positive population assessed to need residential, in-home or respite care services; a description of the characteristics of this target population; the overall capacity of the current system for residential, respite, and in-home care services for person living with HIV/AIDS — including an

estimate of the number of clients who can be served in a given time period; the unmet needs for these services in the Portland EMA; and the barriers to meeting these needs.

Estimate of the Number of PLWH/A Assessed to Need Advanced Stage Care Services in the Portland EMA

Although challenging, it is essential to begin the process of identifying the number of persons assessed to need residential, in-home and respite care services in order to plan for a comprehensive continuum of services. To achieve an estimate, archival data were collected from the primary case management agencies throughout the Portland EMA. This estimate does not include those consumers who may be assessed to need these services but are not currently connected with the provider system.

The archival data search revealed that 188 consumers were assessed to need residential, in-home, or respite care services by their case manager between

January 1998 and March 1999 (see Table 3-1). This is 11.4% (188/1654) of the total PLWH receiving services from the Partnership Project, the HIV Clinic, SW Washington Health District, or Kaiser IDC. This number represents those assessed to need these services regardless of whether they received them. The services used to identify these consumers include: adult foster care, durable medical equipment, hospice care, nursing home, residential care facility, skilled home care, unskilled home care, volunteer assignment, and delivered meals.

The archival data search revealed that 188 consumers were assessed to need residential, in-home or respite care services.

Table 3-1: A Summary of the Number of Consumers Assessed to Need Residential, In-home or Respite Care Services in the Portland EMA	
	Number of consumers
Partnership Project (includes Legacy)	150
Multnomah County HIV Clinic	8
Kaiser Immune Deficiency Clinic	12
Southwest Washington Health District	18
TOTAL	188

Some consumers included in this table may be deceased.

Characteristics of Consumers Assessed to Need Advanced Stage Care

Consumers who have been assessed in their care or service plans to need residential, in-home or respite care services are primarily white and male, live in urban neighborhoods in Multnomah County and are covered by publicly-funded health insurance. Tables 3-2 to 3-6 outline demographic data describing this population.

Table 3-2: Ethnicity of Consumers Assessed to Need Residential, In-home or Respite Care Services

	African American	Asian	Caucasian	Hispanic/Latino	Native American	Other
Partnership Project (includes Legacy)	14	1	110	17	5	3
Multnomah County HIV Clinic	1		6	1		
Kaiser Immune Deficiency Clinic			11			1
Southwest Washington Health District	1		16	1		
TOTAL	16	1	143	19	5	4
Percent of TOTAL	8.5%	.5%	76.1%	10.1%	2.7%	2.1%

Table 3-3: Gender of Consumers Assessed to Need Residential, In-home or Respite Care Services

	Male	Female
Partnership Project (includes Legacy)	122	28
Multnomah County HIV Clinic	7	1
Kaiser Immune Deficiency Clinic	9	3
Southwest Washington Health District	17	1
TOTAL	155	33
Percent of TOTAL	82.4%	17.6%

Table 3-4: Age of Consumers Assessed to Need Residential, In-home or Respite Care Services

	20-30	31-40	41-50	51-60	61+
Partnership Project (includes Legacy)	16	52	58	19	5
Multnomah County HIV Clinic		5	2		1
Kaiser Immune Deficiency Clinic		4	5	2	1
Southwest Washington Health District	3	5	6	1	3
TOTAL	19	66	71	22	10
Percent of TOTAL	10.1%	35.1%	37.8%	11.7%	5.3%

Table 3-5: County of Residence of Consumers Assessed to Need Residential, In-home or Respite Care Services (N=187)						
	Clackamas	Clark	Columbia	Multnomah	Washington	Yamhill
Partnership Project (includes Legacy)	9	2		128	10	1
Multnomah County HIV Clinic	2			4	1	
Kaiser Immune Deficiency Clinic		1		11		
Southwest Washington Health District		18				
TOTAL	11	21	0	143	11	1
Percent of TOTAL	5.9%	11.2%	0	76.5%	5.9%	.5%

Table 3-6: Type of Insurance Coverage of Consumers Assessed to Need Residential, In-home or Respite Care Services (N=188)			
	Public	Private	No Coverage
Partnership Project (includes Legacy)	127	22	1
Multnomah County HIV Clinic	8		
Kaiser Immune Deficiency Clinic	8	4	
Southwest Washington Health District	17	1	
TOTAL	160	27	1
Percent of TOTAL	85.1%	14.4%	.5%

Oregon Health Division data from 1997 suggest that AIDS diagnoses in the state of Oregon are primarily among white (84%) male (91%) residents of Multnomah County (59%), between the ages of 30 and 39 (48%) (Oregon HIV/AIDS 1997 Annual Report, 1998). Within the Portland EMA, reported AIDS diagnoses for 1998 are also primarily among white (80%) males (95%). Table 3-7 is an illustration of these demographic characteristics. Consumers assessed to need residential, in-home or respite care services are also primarily white (76%) and male (83%) residents of Multnomah County (73%) between the ages of 31 and

40 (35%). These percentages show a slightly higher number of women and People of Color among those assessed to need advanced stage care services.

Table 3-7: Number of Persons With an AIDS Diagnosis in the Portland EMA by Demographic Characteristic			
	1996	1997	1998*
Male	450	282	90
Female	49	31	5
White	426	259	76
Non-White	73	54	19
IV Drug Users**		67	27

* Demographic data are available for 8 of the reported 11 people diagnosed with AIDS in 1998 for Clark County.

** Data not available for Clark County.

Mental Illness and Substance Abuse

An important characteristic of the population of consumers needing advanced stage care services is the number of persons with co-occurring disorders. Of those assessed to need residential, in-home or respite care, two-thirds (65.4%) have additional diagnoses, either substance abuse or mental health issues or both.

Table 3-8: Diagnoses In Addition to HIV of Consumers Assessed to Need Residential, In-home or Respite Care Services				
	Mental Health	Substance Abuse	Both	Total
Partnership Project (includes Legacy)	52	27	28	107
Multnomah County HIV Clinic	2		6	8
Kaiser Immune Deficiency Clinic		2		2
Southwest Washington Health District	3	1	2	6
TOTAL	57	30	36	123
Percent of total need population	30.3%	16.0%	19.1%	65.4%

Of the 86 residents of Our House from 1996–1998, 29 (34%) were diagnosed with a mental illness, a substance abuse disorder, or dementia. Of those 29 consumers, 15 were diagnosed with more than one condition. This finding suggests that 17% of residents at Our House between 1996-1998 were dually or triply diagnosed.

Oregon Health Division data indicate that the number of people who contracted the disease through intravenous drug use is fairly consistent over time (e.g., 32% of AIDS diagnoses in 1997, compared to 31% in 1998). Providers list dually diagnosed consumers as individuals they have difficulty serving. The number of consumers who have co-occurring disorders is significant and demands further attention, as these are most often those clients who require the largest quantity of care and the most specialized services. This group of clients is most at risk for needing publicly-funded advanced stage residential treatment and in-home services due to the following factors: addiction, mental health issues, poverty, publicly-provided health care insurance limitations, ineligibility for services, and less ability or willingness to seek treatment. Providers expressed a variety of opinions on the importance of addressing the issue of co-occurring disorders. One provider put it this way:

The people we get at the end, with AIDS, and I am seeing fewer numbers, but a higher concentration of those whose situation is enormously complex. Those who are choosing not to go to a facility, or even to be properly taken care of in a non-facility, whatever that might be... they are ending up in hospice programs, because they have burned out two or three physicians. You are keeping drugs in the house for comfort care, but you also know they are being abused, by the client and maybe other people who live there. (Paraphrased from the 1/13/99 Provider Focus Group).

Summary of Consumer Characteristics

As stated earlier, 188 out of 1654 consumers in the Portland EMA were assessed by case managers from the Partnership Project, the HIV Clinic, Kaiser IDC or SW Washington Health District to need residential, in-home or respite care services between January 1998 and March 1999. Not all of these consumers' needs are being met by the services available in the community. Although there has been a marked decrease in the number of AIDS diagnoses and deaths related to HIV and AIDS, this large number of consumers seeking advanced stage care services signals the need for enlarging the capacity of the care system available to meet these consumers needs.

Overall, PLWH/A in the Portland EMA are primarily white males, though the numbers of non-white consumers are increasing. Most of the clients live in urban areas and rely on publicly funded medical assistance. More than one-half of these consumers are dealing with a serious mental health or substance abuse disorder, or are facing both these issues, in addition to their physical health problems.

Consumers assessed to need residential, in-home or respite care services are also primarily white (76%) and male (83%) residents of Multnomah County (73%) between the ages of 31-50 (76%). Two-thirds of these individuals have mental health issues, substance abuse issues, or both, creating an intense need for services.

Service Utilization Patterns

It is evident that in recent years there has been a shift in advanced stage care service needs and utilization. Before the advent of the current drug therapies, persons living with HIV/AIDS generally received residential, in-home and respite care services as part of their progression toward the end of life. Currently, service providers might provide these services to the same consumer more than once during his/her lifetime. One-fifth of providers surveyed describe serving

consumers through multiple service episodes. Respondents included providers of residential, medical, respite, and hospice services. Overwhelmingly, urban providers responded to this increase in episodic service patterns as a factor in how their work has changed. In addition, some clients are experiencing a period of substantial improvement, but then a rapid deterioration, which was not seen in the same way before the use of the newer pharmacological treatments.

Providers repeatedly mentioned the need for improved understanding of both the experiences of persons fluctuating between different service needs and how to provide appropriate services and support for the consumer and their caregivers.

This change in service episodes has implications for:

- ❖ how services are provided,
- ❖ what types of services are necessary, and
- ❖ the relative quantity needed of various services.

When consumers' level of functioning improves and then deteriorates these individuals face:

- ❖ hospice eligibility restrictions,
- ❖ differential levels of funding for their health care coverage (primarily OHP/Medicaid and Medicare) for various services, and
- ❖ changes in the level of care they are eligible for.

Summary of Service Utilization Patterns

The pattern of service utilization has changed in recent years from what used to be a systematic progression toward increasingly intensive service needs through the end of life. Clients now may face the need for advanced stage care services more than one time, due to periodic improvements in functioning. In addition, their improvements and deterioration may occur more rapidly, with less time for preparation. These patterns have serious implications for the consumers' service needs, the importance of service responsiveness, and the urgency of flexibility and rapidity in the determination of service eligibility.

Current Service Availability

Service Capacity of Residential and In-home Care Providers

To determine the current availability of services needed to maintain a high quality of life for people assessed to need advanced stage care services insurance providers were asked to report the services they covered and under what circumstances, and service providers were asked to report the numbers of people they can serve with their current staff and resources. Many service providers care for consumers throughout the Portland EMA.

Insurance Provision

Insurance providers play a complicated role in the continuum of care for PLWH/A who have been assessed to need residential, in-home or respite care services.

Insurance agencies proved to be a difficult group to study. Numerous phone calls were required simply to identify the appropriate individual to provide this information, and additional calls to reach that person made the process cumbersome. As a result, limited concrete information was learned about service coverage and in one instance (Regence Blue Cross Blue Shield) no contact person was successfully identified. The effort to gain information on this important issue to consumers is a subject that warrants further study and observation by the community.

For many PLWH/A in need of intense services, publicly-funded health coverage is a necessity. Many consumers are on disability assistance and thus are automatically eligible for Medicare after 29 months. Depending on the state of residence and the level of disability assessed, getting access to certain services can be difficult. With some agencies offering over 200 plans, learning what services are covered can be a challenge for consumers.

However difficult collecting this information was, it was even harder to discern which services are covered. The variety of programs and the amount of coverage

that is decided on a case by case basis creates a lack of standardization. Thus, covered services are described in this section, but each individual consumer's situation may be different.

Overall, skilled care in a residential facility or provided in the home is covered when medically necessary by all insurance providers. Hospice care is frequently covered, although it typically includes only palliative care. Many insurance providers, when asked if they cover non-medical in-home care, custodial care, or respite care for in-home caregivers, suggested that consumers rely on the community (church volunteers, neighbors, friends, or family members) to provide these resources.

Capacity of the Service System

Case managers were asked to rate advanced stage care services for the extent to which there is capacity overall in the system, the availability and accessibility of a service to consumers, and then also the category of barriers most responsible for keeping consumers from receiving a service. Highlights from this data are included in Table 3-9. Overall, respite care and residential care have the lowest capacity and availability and respite care has the lowest accessibility. Ratings originally provided on a 0 to 3 scale have been reassigned to 1 to 4 scale for analysis purposes (0=1, 1=2, 2=3, 3=4).

Table 3-9: Service Ratings by Case Managers			
Category of Service	Capacity	Availability	Accessibility
Residential Care Services	2.1	2.2	2.7
In-Home Care Services	2.6	2.4	2.5
Respite Care Services	2.0	2.0	2.3
Advanced Stage Care Services Overall	2.5	2.3	2.5

Scale: 1=not at all → 2=slight → 3=moderate → 4=extreme
(N=15)

Case managers rated specific services for capacity, availability and accessibility to consumers. Overall, community-based day care, short-term residential care as respite, and homemaker as respite have the lowest ratings for all three categories. Table 3-10 lists the five services receiving the lowest ratings for each of the three areas (capacity, availability, and accessibility). Interestingly, foster care is rated among the highest for capacity in the Portland EMA, but is among the services rated the lowest for availability and accessibility. Ratings originally provided on a 0 to 3 scale have been reassigned to 1 to 4 scale for analysis purposes (0=1, 1=2, 2=3, 3=4).

Interestingly, foster care is rated among the highest for capacity in the Portland EMA, but is among the services rated the lowest for availability and accessibility.

Table 3-10: Lowest Capacity, Availability and Accessibility Ratings by Case Managers			
	Capacity	Availability	Accessibility
Community-based day care	0	0	0
Short-term residential care as respite	0	0	0
Homemaker as respite	0	0	0
Non-medical in-home care	0	0	
Assisted living facilities	0		0
Foster care		0	0

Scale: 1=none, not at all → 2=slight → 3=moderate → 4=plentiful, extreme (N=15)

Highest ratings for each of the three areas (capacity, availability, and accessibility) were assigned to durable medical equipment, in-home hospice care, and short- and long-term skilled residential care. Medical in-home care is rated high for accessibility, while non-medical in-home care is among the services rated the lowest for capacity and availability. Table 3-10 lists the five services receiving the highest ratings for each of the three areas.

Medical in-home care is rated high for accessibility, while non-medical in-home care is among the services rated the lowest for capacity and availability.

Table 3-11: Highest Capacity, Availability and Accessibility Ratings by Case Managers			
	Capacity	Availability	Accessibility
Durable medical equipment	0	0	0
In-home hospice care	0	0	0
Short-term skilled residential care	0	0	0
Long-term skilled residential care	0	0	
Residential hospice care		0	0
Medical in-home care			0
Foster care	0		

Scale: 1=none, not at all → 2=slight → 3=moderate → 4=plentiful, extreme
(N=15)

Case managers, because of the expertise and experience they have trying to find services for their clients, were asked to identify which category of barriers is responsible for keeping consumers from accessing the specific services they need. These categories of barriers include System/Community Limitations (such as system capacity and lack of services for specific client groups), Financial Constraints (such as lack of insurance coverage for specific clients or certain services), Client Characteristics (such as those with mental health needs or substance abuse issues), and Organizational/Agency Factors (such as training issues or eligibility requirements).

Overall, case managers agreed that:

- ❖ system/community limitations are the most prevalent barriers in seeking in-home non-medical care (9 case managers);
- ❖ financial constraints were the barrier keeping consumers from receiving residential hospice care (8 case managers);
- ❖ organizational/agency factors as the problems keeping consumers from foster care (6 case managers);
- ❖ financial constraints prevent consumers from getting the durable medical equipment they need (6 case managers); and

- ❖ system/community limitations are barriers to receiving home care aid services as respite (6 case managers).

Case managers chose system/community limitations (6), financial constraints (5), and client characteristics (1) as the barriers they felt were causing the most problems for consumers trying to receive advanced stage care services overall.

Case manager responses to some of these issues include:

I rely heavily on Our House for hassle free placement.

There are limitations on patients qualifying for medical in-home care.

I have had trouble finding willing foster care homes.

It is difficult to find home care aides as respite care for PLWH/A, and dual-diagnosed clients.

Suggestions for bridging gaps in service include:

Provide services in Spanish and to undocumented clients.

Insurance issues must be addressed, there is inadequate coverage for short-term and long-term skilled care and residential hospice.

Non-medical, in-home care is very needed, it is hard to find someone to fill this position.

It is difficult to place multiply diagnosed clients in an assisted living facility.

We need more long-term living facilities that are equipped to handle mental health and A&D clients. We must also have medical support at these facilities.

Develop residential programs to meet the needs of chemically dependent clients.

Hopewell House needs to be able to accept Medicare.

Funding and support for Our House and Hopewell House is needed to provide short-term acute need residential care.

Increase the hourly rate for in-home non-medical caregiver via the state system to attract better providers.

Enhance the payment and training available to in-home non-medical care providers.

Insurance inadequacies are an issue with medical in-home care and OHP benefits are too low to cover residential hospice facilities.

Short-term residential care as respite is virtually unavailable.

We need better reimbursement mechanisms for in-home care as respite. Most insurance does not cover this service. Training is also an issue.

There should be better insurance coverage for residential care.

We need better training, pay sources and insurance coverage for in-home care as respite.

There should be training in HIV for foster care providers.

HIV-specific assisted living/skilled care facilities in the Portland EMA include three programs, Our House, Care House, and Swan House. These facilities can care for up to 23 individuals. Highlights from HIV-specific assisted living facilities capacity data include:

- ❖ Our House in Multnomah County is currently caring for 12 medically-eligible PLWH/A, which is their full capacity.
- ❖ Care House in Clark County is currently caring for 3 low income qualified PLWH/A and has room for three more.
- ❖ Swan House will provide foster care to up to 5 low income PLWH/A in Clackamas County in September. They will be staffed with nurses and volunteers.

Hopewell House and Care Center East also completed the Service Provider Questionnaire. Together, these facilities can provide care for 100 individuals.

Mainstream assisted living/skilled care facilities capacity data include:

- ❖ Hopewell House is currently caring for 12 individuals, none of which are HIV+. Capacity at Hopewell House is 15 residents. Hopewell House welcomes consumers with a life expectancy of six months or less.

- ❖ Care Center East, a mainstream, skilled residential care facility offers short-term, long-term, and hospice care to up to 85 residents. They may currently be serving one or two PLWH/A and have 76 residents.

The use of skilled residential facilities is not entirely for hospice purposes. Between January 1996 and December 1998, 40 people received residential services at Care House in Clark County or at Our House in Multnomah County for improving health or rehabilitation after an acute illness, while 61 people took part in an end-of-life program at one of these facilities or at Hopewell House. The data demonstrate how residential programs have adapted to the changing face of HIV/AIDS by offering services at more than one stage of the disease.

Table 3-12: Residential Care Use in the Portland EMA 1996–1998		
	Improving Health	Hospice
Our House	33	49
Care House	7	6
Hopewell House	0	6
Total	40	61

Skilled care facilities list financial constraints as the category of barriers that most prevents consumers from accessing their services.

Three apartment style HIV-specific residential facilities completed the survey, Rosewood Apartments, Project Open Door, and Hopewell Apartments. These facilities combined house 63 individuals and are currently at capacity. Nathaniel's Way, a housing program through CAP has four family units and

Three apartment style HIV-specific residential facilities... combined house 63 individuals and are currently at capacity.

is also at capacity. Rosewood Apartments offer living space to PLWH/A who are low income and recovering from substance abuse. Consumers with mental health issues, in addition to their HIV status are welcomed at Hopewell Apartments. Project Open Door provides apartments for low income PLWH/A in

a community setting, where they share an apartment with another PLWH/A and provide some care for each other.

One assisted living facilities/apartment responded to the request for barriers to providing their services to clients. The most significant barriers were the client characteristics and organizational/agency factors categories.

The numbers of consumers seeking in-home care in the form of skilled nursing care or medical care utilization is significant. Requests for capacity from service providing agencies that participated in the study estimates 100 consumers are receiving non-hospice in-home care. This estimate does not include service providers who were unable to approximate the number of PLWH/A in their caseload, or those from agencies who chose not to participate in the study.

Highlights from in-home medical care capacity data include:

- ❖ All in-home medical care providers report being able to care for all of the people who need their services, providing the services are doctor ordered and they have the appropriate insurance coverage.

A large percentage of the consumers interviewed have been assessed to need in-home non-medical care. Non-medical, in-home care, while scarce in any formal format, can be provided by two volunteer agencies who report that they are currently not at capacity for those the service is appropriate for.

- ❖ Metropolitan Community Church's Care Team is currently providing emotional support, transportation, shopping, housekeeping, respite care, and yard work for six people. The Care Team reports having the capacity to provide services to up to 100 consumers.
- ❖ CAP's PAL Program reports serving 188 consumers for Fiscal Year 1998. Of these, 43 are currently receiving services ranging from emotional support for symptomatic consumers or those with an AIDS diagnosis to practical support for all eligible consumers, including transportation, housekeeping, moving assistance, meal preparation, short- and long-term respite care, errands and yard work. Volunteer efforts can currently

provide services for up to 80 consumers. All PLWH/A are eligible for the PAL Program, however, an active substance abuse issue cause the environment to be considered unsafe for a volunteer to provide services.

The percentage of HIV positive individuals utilizing home-based mainstream hospice service has increased, but the numbers of people requesting this type of care is small. Thirty-five percent of persons who died of AIDS-related causes in 1994 used hospice care, compared with 58 percent of persons who died of AIDS-related causes in 1997 (1998 Fact Sheet, Oregon Hospice Association). During 1998, 13 people living with HIV/AIDS received in-home hospice care in the Portland EMA. Within this group, eight were served by Legacy Visiting Nurses Association of Portland; two by Community Home Health and Hospice; and one each by Health Dynamics Hospice of Yamhill County, Hospice Southwest, and Kaiser Home Health.

Summary of Current Service Provision

Skilled care facilities cared for 38 clients in 1998 [Our House cared for 28 consumers, Care House reported caring for 8 clients, and Hopewell House had 2 HIV positive residents]. Assisted living facilities are currently housing 63 individuals. In-home non-medical care is available through two volunteer agencies, neither of which are at capacity. Medical in-home care is available through various insurance plans for an unlimited number of eligible consumers. Hospice programs in the EMA report serving 13 consumers. According to the number of existing providers and their client capacity, most of the services listed seem to have coverage in the Portland EMA. The remaining questions include 1) How many more individuals may be in need but are not currently utilizing services? and 2) Are there categories of services that are needed but do not currently exist?

While HIV-specific residential care services are at capacity, none of the in-home medical care or hospice care providers reported being at or beyond their capacity. This may indicate that current services are adequate for meeting the medical in-home care needs of PLWH/A in the numbers that exist today, and skilled care in a facility is available, although not HIV-specific.

Unmet Needs in the Portland EMA

Two sources of data were used to investigate the unmet needs for advanced stage care services in the Portland EMA. These data include the consumer interviews and the unmet needs component of the Case Manager Questionnaire. The findings are delineated based on the data source. Common themes found throughout the various data sources are presented at the end of this section.

Consumers were asked to indicate which services they or someone who cared about them thought they needed and which of those services they actually received. Consumers report receiving the services they were assessed to need, but not to the extent that their needs were met. The notable exception is one consumer desire for in-home respite care to relieve his primary caregiver, which has gone unmet.

The services consumers participating in this study have been assessed to need include: assisted living facilities (50%; including apartment style living), non-medical in-home care (80%), medical in-home care (40%), durable medical equipment (60%) and in-home respite care (40%).

While all consumers who needed in-home non-medical care have received this service at times, there have been many problems with the provision of custodial care.

Most insurance coverage plans will cover some non-medical care if the person is also receiving in-home medical care, but this is limited to personal care.

OHP/Medicaid covers non-medical in-home care through the Client Employed

Providers (CEP) Program from Aging and Disability Services. Clients choose a potential caregiver from a list and then make arrangements for care services. Consumers may also choose someone not on the list, such as a partner (no spouses), family member, someone who lives near them or who answers an ad placed by the consumer. These individuals need to register as an in-home caregiver with the state and pass a criminal records check. Consumers report having problems with all of these choices, ranging from caregivers having honesty issues and stealing from their homes -- to partners/family members lacking caregiving skills and training in HIV. Other issues include:

- ❖ caregiver/client resistance to the style or abilities of available in-home care providers;
- ❖ honesty issues;
- ❖ meal services providing poorly prepared food;
- ❖ a lack of respite care available for family members/partners who choose to become paid caregivers;
- ❖ inconsistency of care provider hours and days worked;
- ❖ lack of caregivers available for the times of the day the clients need help;
- ❖ lack of caregivers on the list who are willing to work with PLWH/A; and
- ❖ caregivers terminating relationships suddenly and for no apparent reasons.

Case managers were asked to identify which categories of service they felt is the greatest need in the Portland EMA, and then which category is most in need of development or improvement. Overall, the greatest need appears to be for in-home care, with the greatest areas of development being in-home and respite care.

Table 3-13: Case Managers Perceptions of Unmet Needs		
Category of Service	Number of Case Managers Ranking a 1 or 2 (Greatest Need)	Number of Case Managers Ranking a 1 or 2 (Most in Need of Development)
Residential	6	6
In-Home	15	12
Respite	9	12

(N=15)

Case managers were also asked to rank the services available within each category for greatest need and to identify which services are the most in need of development. Within residential care, case managers see the most dramatic need for assisted living facilities, and also consider these types of residential care the most in need of development.

Table 3-14: Case Managers Perceptions of Unmet Needs for Residential Care		
Residential Services	Number of Case Managers Ranking a 1 or 2 (Greatest Need)	Number of Case Managers Ranking a 1 or 2 (Most in Need of Development)
Assisted Living Facilities	12	15
Foster Care Facilities	6	9
Short-term Skilled Care Facilities	6	5
Long-term Skilled Care Facilities	2	0
Residential Hospice care	2	1

(N=15)

Within the category of in-home care services, case managers ranked non-medical care as the service with the greatest need in the Portland EMA, and also the most in need of development, with medical care falling shortly behind.

Table 3-15: Case Managers Perceptions of Unmet Needs for In-home Care

In-home Care Services	Number of Case Managers Ranking a 1 or 2 (Greatest Need)	Number of Case Managers Ranking a 1 or 2 (Most in Need of Development)
Non-medical Care	13	14
Medical Care	9	11
Hospice Care	5	2
Durable Medical Equipment	3	3

(N=15)

The greatest need within respite care according to case managers is for in-home care, with short-term residential also receiving a significant number of responses. Interestingly, both of these types of respite care are seen as in need of development within the Portland EMA.

Table 3-16: Case Managers Perceptions of Unmet Needs for Respite Care

Respite Care Services	Number of Case Managers Ranking a 1 or 2 (Greatest Need)	Number of Case Managers Ranking a 1 or 2 (Most in Need of Development)
Short-term Residential	11	12
Community-based Day Care	5	6
In-home Care	14	12

(N=15)

Participants were passionate and articulate around the issue of limited resources, and their concerns spanned a broad range of suggested areas for investment:

It is hard to find skilled 24-hour in home care. It is also difficult to get consistent respite care of partners.

We need financial resources to cover the uninsured and fund skilled at-home care givers.

Clients and the community need information on what current services are available.

People need places to go after they get better.

In-home care services for consumers at different stages of the disease were discussed at the Advanced Stage HIV/AIDS Services Focus Group. Transitional care, either in the form of housing or skilled/unskilled in-home care was reported as an area of unmet need. Providers discussed the challenge for consumers of advanced stage care services when they are able to return to independent living after intensive care at a facility. While full-time care may no longer be necessary, daily living assistance and support services to begin living independently again are essential. In-home care is a key component, as residential facilities are expensive to maintain and can only provide services for a limited number of consumers. The current lack of organized HIV-specific in-home care requires careful attention. The following paraphrased remarks from the Advanced Stage HIV/AIDS Services Focus Group articulate the need for quality in-home care:

I think there is a range of things that are needed to keep people stable in their homes when they are in need of advanced stage care. That can be hard to piece together from whatever is existing. Whether it is home health attendant care, or a respite type of thing... it has to be more robust, right now it is a delicate balance of an incredible number of people that as a case manager you have to build on to create an unfortunately unstable structure, and it all just balances correctly if everyone shows up on time.

Trained, in-home care givers, period, are very difficult to find, even if they have state funding to pay for it, they pay \$6–6.50 an hour, and you can't get good qualified people to go in and do in-home care. We are constantly dealing with dishonest people going into consumers' homes, or the consumer fires them after one or two days. Their alternative is to have a PAL, which is really a minimal level of support. So there's this gap between people who can function with just the support of a PAL, people who need 20 hours a week of in-home care but can't afford it — and then they would still have to find someone who is qualified — and those who need more intensive services.

Foster care is another situation, finding foster homes that are really trained to care for people with HIV, it is almost nonexistent.

Summary of Unmet Needs in the Portland EMA

The most frequently mentioned unmet needs, according to consumers and case managers are in the realm of in-home care, specifically non-medical, custodial care with some development of medical in-home care services. A pervasive need that is also not being met is respite for caregivers in the form of short-term residential facilities or in-home care. Existing HIV-specific assisted living facilities are currently at capacity and therefore unavailable to consumers.

Obstacles to Receiving Services

As part of the needs assessment NPC provided respondents with a comprehensive list of barriers to service that consumers might experience in accessing advanced stage care services (see Appendices A, D and E). All respondents (case managers, consumers and providers) were asked to rate the same series of potential barriers to service within the following domains: System/Community Limitations, Financial Constraints, Client Characteristics, and Organization/Agency Factors. Within each of these domains, respondents ranked

each barrier as either: no barrier, a slight barrier, moderate barrier, or a significant barrier. The results of these rankings demonstrate those barriers respondents believe to be most significant to accessing services. Ratings originally provided on a 0 to 3 scale have been reassigned to 1 to 4 scale for analysis purposes (0=1, 1=2, 2=3, 3=4).

Table 3-17: Barriers to Receiving Services by Consumers, Case Managers, and Service Providers			
Category of Barriers	Residential	In-home	Respite
System/Community Limitations	2.4	2.2	3.3
Financial Constraints	2.2	1.9	3.3
Client Characteristics	2.4	1.9	3.3
Organizational/Agency Factors	2.5	2.1	3.1

Scale: 1=no → 2=slight → 3=moderate → 4=significant

Table 3-18 on the next page lists the highest rated barriers within each barrier category (System/Community Limitations, Financial Constraints, Client Characteristics, and Organizational/Agency Factors) for each service category (residential, in-home, and respite care) rated by consumers, case managers and service providers. Overall, capacity, child care, insurance coverage, undocumented clients, mismatch between client needs/preferences and available services, co-occurring disorders and eligibility requirements are the most significant barriers to receiving all three categories of services. Ratings originally provided on a 0 to 3 scale have been reassigned to 1 to 4 scale for analysis purposes (0=1, 1=2, 2=3, 3=4).

Table 3-18: Specific Barriers to Receiving Services by Consumers, Case Managers, and Service Providers

Barriers	Residential	In-home	Respite
Lack of available services for co-occurring disorders	0	0	
Service capacity of system	0	0	0
Lack of available child care	0	0	0
Lack of culturally appropriate services			0
Lack of private insurance coverage for specific services	0	0	
Lack of community/government funding of specific services	0	0	
Lack of insurance coverage for specific clients	0	0	0
Lack of private insurance coverage for specific clients			0
Substance use/abuse issues	0	0	0
Mental health treatment needs	0	0	0
Undocumented clients	0	0	0
Mismatch between client needs/preferences and available services	0	0	0
Training issues for staff around HIV/AIDS	0		
Training issues for staff around co-occurring disorders	0	0	0
Agencies eligibility requirements for services	0	0	0

Scale: 1=no → 2=slight → 3=moderate → 4=significant

The following data reflect how the various populations that completed the survey rated the potential barriers to accessing advanced stage care services. Table 3-19 lists frequent responses for each respondent type. The three most significant barriers are broken down by domain and demonstrate the barriers to accessing the categories of advanced stage care service.

Table 3-19 Frequent Responses to Barriers by Respondent Type

Respondent Type	Frequent Responses to Residential Barriers	Frequent Responses to In-Home Barriers	Frequent Responses to Respite Barriers
Male Consumers (n=8)	<ul style="list-style-type: none"> A. Lack of social support for persons living with HIV/AIDS B. Lack of insurance for specific clients C. Caregiver resistance to available services 	<ul style="list-style-type: none"> A. Lack of community/government funding of specific services B. Financial constraints C. Service capacity of the system 	<ul style="list-style-type: none"> A. Financial constraints B. Lack of community/ government funding for specific services C. Limits of coverage
Female Consumers (n=2)	<ul style="list-style-type: none"> A. Training issues for staff around HIV/AIDS B. Mismatch between client needs/preferences and available services C. Lack of confidentiality protection by agency staff D. Lack of providers willing to work with PLWH/A 	<ul style="list-style-type: none"> A. Service capacity of current system B. Lack of available transportation C. Mismatch between client needs/preferences and available services D. Lack of providers willing to work with persons living with HIV/AIDS 	No Data
Case Managers from Oregon (n=12)	<ul style="list-style-type: none"> A. Mental health treatment needs B. Substance use/abuse C. Undocumented clients 	<ul style="list-style-type: none"> A. Substance use/abuse B. Undocumented clients C. Lack of available services for co-occurring disorders 	<ul style="list-style-type: none"> A. Mental health needs B. Substance use/abuse C. Undocumented clients
Case Managers from Washington (n=3)	<ul style="list-style-type: none"> A. Lack of available child care B. Lack of available services for co-occurring disorders C. Lack of available gender appropriate services D. Lack of social support for person living with HIV/AIDS E. Lack of insurance coverage for specific clients F. Training issues for staff around co-occurring disorders G. Lack of providers willing to work with PLWH/A 	<ul style="list-style-type: none"> A. Service capacity of the system B. Lack of available transportation C. Lack of available services for co-occurring disorders D. Lack of available gender specific services E. Lack of social support for person living with HIV/AIDS F. Lack of private insurance coverage for specific services/clients G. Training issues for staff around co-occurring disorders 	<ul style="list-style-type: none"> A. Service capacity of the system B. Lack of available services for co-occurring disorders C. Lack of available gender specific services D. Lack of social support for person living with HIV/AIDS E. Lack of private insurance coverage for specific services/clients F. Training issues for staff around co-occurring

continued

Mainstream Providers (n=11)	A. Undocumented clients B. Training issues for staff around HIV/AIDS C. Mismatch between client needs/preferences and available services D. Training issues for staff around co-occurring disorders	A. Lack of available transportation B. Lack of private insurance coverage for specific clients C. Lack of private insurance coverage for specific services	A. Service capacity of the system B. Lack of available childcare C. Lack of culturally appropriate services D. Lack of private insurance coverage for specific services E. Limits to coverage F. Substance use/abuse G. Undocumented clients
HIV Specific Providers (n=10)	A. Substance use/abuse B. Lack of available services for co-occurring disorder C. Undocumented clients	A. Undocumented clients B. Substance use/abuse C. Lack of available services for co-occurring disorders D. Language barriers	A. Lack of available services for co-occurring disorders B. Substance use/abuse C. Undocumented clients

Summary of Obstacle to Receiving Services

Overwhelmingly, barriers having to do with co-occurring disorders (lack of availability of services for co-occurring disorders, mental health treatment, substance abuse treatment, training issues for staff around co-occurring disorders) top the list of significant barriers for all three categories of service. While gender-specific services and culturally appropriate service are not among the top rated barriers they are still significant issues for female consumers and people of color. Citizenship status is also a major barrier to receiving services.

Interestingly, a lack of private insurance coverage for specific services is among the most highly rated barrier to consumers receiving in-home care. Barriers to receiving respite care services, particularly those in the categories of financial constraints and client characteristics are rated as the most significant barriers in the study.

Summary of Key Findings

Currently, 188 consumers in the Portland EMA have been assessed to need residential, in-home or respite care services by their case managers. Although there has been a marked decrease in the number of AIDS diagnoses and deaths related to HIV and AIDS, this large number of consumers seeking advanced stage care services signals the need for broadening the capacity of the care system available to meet these consumers needs.

Consumers assessed to need residential, in-home or respite care services in the Portland EMA are primarily Caucasian, male, residents of Multnomah County. Many of these individuals have mental health issues and some have substance abuse issues or both.

Clients face a pattern of service utilization that is new and complex to understand, needing advanced stage care services often more than once, and not just at the end of life. These patterns have serious implications for the service needs.

Insurance provision defines the majority of the care available to consumers. Skilled care in a residential facility or provided in the home is covered when medically necessary by all insurance providers. Hospice care is frequently covered. Medicaid covers some non-medical in-home care for eligible consumers. Private insurance providers, when asked if they cover non-medical in-home care, custodial care, or respite care for in-home caregivers, suggested that consumers rely on the community (church volunteers, neighbors, friends, or family members) to provide these resources.

While HIV-specific residential care services are at capacity, none of the in-home medical care or hospice care providers reported being at or beyond their capacity. This may indicate that current services are adequate for meeting the medical in-home care needs of the advanced stage HIV/AIDS population in the

numbers that exist today, and skilled care in a facility is available, although not an HIV-specific, which case managers and consumers prefer.

The most frequently mentioned unmet needs, according to consumers and case managers are in the realm of in-home care, specifically non-medical, custodial care with some development of medical in-home care services. A pervasive need that is also not being met is respite for caregivers in the form of short-term residential facilities or in-home care.

Barriers having to do with co-occurring disorders and citizenship status top the list of significant barriers for all three categories of service. A lack of private insurance coverage for specific services is a significant barrier to consumers attempting to receive in-home care. Barriers to receiving respite care services, particularly those in the categories of financial constraints and client characteristics are rated as the most significant barriers in the study.

The average consumer of advanced stage HIV/AIDS services has very limited financial resources and a complex set of social service and medical needs. Consumers listed in-home non-medical care at the top of the list of their under-met/unmet needs. Providers added that housing is also needed. The need for improved service coordination and collaboration, especially regarding relationships with prospective funding sources/insurance agencies is critical.

The findings from this needs assessment provide valuable data for consideration by the HIV Services Planning Council, advanced stage service providers, and the community at large. The following section provides suggestions for service emphases and policy changes that could benefit people living with HIV/AIDS in the Portland EMA.

Section IV: Conclusion

Conclusion



The HIV Services Planning Council, appointed by the Multnomah County Chair, is responsible for determining priorities for Title I funded services and allocating these funds to specific priorities. The Council has already prioritized advanced stage care services as 7th out of 22 service categories for Fiscal Year 1999–2000. The results of this needs assessment study for residential, in-home and respite care services provide a baseline description of the number of persons needing these services, availability of these services, barriers to accessing these services, and identifying service needs that are currently unmet. This section of the report provides recommendations to the HIV Services Planning Council and to the community at large for a plan of action.

At the outset, it is important to mention that this needs assessment studies the need for services at a distinct point in time. Although data were available in some cases from 1996 and many providers and consumers spoke from a historical perspective, care must be taken not to infer continuing trends based on the data. In this context, assessment and evaluation of services must continue on a regular basis.

Recommendations for Action

Following are the recommendations for action that address the current residential, in-home and respite care capacity, unmet needs and barriers.

◆ **Coordinate advanced stage care service providers to work together to streamline the continuum of care.**

It is clear from conversations with the many HIV-specific and mainstream providers of residential, in-home and respite care services that there is no forum for the individuals directing these organizations to collaborate and streamline care. A common goal of caring for all individuals assessed to need residential, in-home and respite care services should be reinforced by action teams consisting of agencies that can actually provide the services. A meeting once a month, organized by the County, for example, could facilitate these conversations, create an arena where one service can complement another, and allow for gaps in service to be identified for the system as a whole and for certain individuals. Community-based service providers whether volunteer or paid (reimbursed by insurance or consumers) have indicated a willingness to work together to provide seamless service delivery for consumers as their needs change over the course of their disease.

Provide and support in-home, non-medical care for better respite and custodial care purposes. Overwhelmingly, consumers, case managers and providers suggest supporting or creating non-medical, in-home care services for both respite and custodial care provision. Specific recommendations include:

◆ **Provide additional funding and support for the CEP Program (Client Employed Provider) for in-home non-medical caregivers through Aging and Disability Services.**

Currently, the CEP Program consists of a list of potential caregivers, maintained in the East Portland Office of Aging and Disability Services for Multnomah County. To register as a potential caregiver, individuals must pass a criminal records check and may complete a 4-hour orientation that includes a packet of information about caring for persons living with HIV/AIDS. Until 1996, CAP staff presented the specific care needs of

PLWH/A at this training. Currently, only the packet of information is available to these caregivers at the orientation. Caregivers can choose to attend an additional training for free that will make them eligible for a higher rate of pay (currently \$.20/hour more). Another option for consumers in the CEP Program is to choose their own caregiver. This caregiver can be a family member, but not a spouse, who meets these same requirements. The current rate of pay for this position has just increased to \$7.80/hour. This new rate of pay may still be too small to attract capable providers for PLWH/A. Supporting this program is an important step in encouraging caregivers to provide services to PLWH/A.

◆ **Develop an outreach/recruitment plan for non-medical in-home caregivers.**

Working with the CEP Program, develop an outreach plan that invites potential caregivers to learn more about the positions available. Host a table at health care job fairs and contact the unemployment offices throughout the Portland EMA to recruit individuals. Appeal to undergraduate college students in the health care professions at OHSU with flexible hours and the opportunity to begin working in the HIV/AIDS field to gain experience.

◆ **Support in-home non-medical caregivers.**

Provide TriMet monthly bus passes, scholarships for relevant courses, paid vacations, and benefits to increase the number of capable non-medical in-home caregivers available to consumers. To increase reliability and longevity in these positions being filled, (1) make an initial contact to those registered on the potential caregiver list to answer questions and (2) hold support groups throughout the care provision process.

◆ **Address mental health and substance abuse recovery issues for persons requiring residential, in-home and respite care services.**

The mental health and substance abuse recovery issues of consumers were rated among the most significant barriers in all categories of services. Because large proportions of consumers are faced with these challenges, service providers must deal with these issues as well. Training for direct service staff members on strategies for dealing with multiple diagnoses and for working effectively with these clients is important to support. Collaborative relationships between mental health, substance abuse treatment and advanced stage care service providers will help weave a network of service for consumers who are at risk of falling through the cracks of a traditionally fragmented care delivery system.

◆ **Create a system of in-home non-medical care providers with experience caring for multiply diagnosed consumers.**

Consumers with multiple diagnoses may not be eligible for the PAL program or other volunteer-based care services. It will be important to consider their needs as non-medical in-home care services are developed. Provide funding for skilled caregivers to provide these services to consumers. Train CEP Program caregivers on these issues to provide them with the background necessary to care for this population.

Develop and support foster care capabilities. There are over 600 licensed home-based foster care facilities in Multnomah County alone. These facilities are an untapped resource of transitional and permanent assisted living care homes.

Specific recommendations include:

◆ **Design a curriculum for an Institute for Health Professionals course at PCC.**

Working with Judy Harris at PCC and Shelly Immel at the Adult Care Home Program of Aging and Disability Services of Multnomah County, design a curriculum and provide an instructor for an Institute for Health Professional course on caring for PLWH/A. Include in the curriculum: (1) the diverse populations affected by HIV, with profiles of PLWH/A; (2) advances that have been made in medication therapies and treatment; (3) an update on the chronic vs. terminal illness status of HIV; (4) dealing with the specific needs of PLWH/A including placement, screening, and the types of care required; (5) resources available in the community, support groups, alternative therapies; (6) universally accepted precautions in preventing transmission of the virus; (7) identification of symptoms of deterioration; (8) pain management; (9) medication adherence; and (10) mental health and substance abuse recovery issues. This course should appeal to foster care and CEP Program providers by offering continuing education credits, scholarships, and a higher pay/reimbursement rate upon completion. A similar course could be offered at Mt. Hood Community College. Cascade AIDS and Our House have offered similar programs as recently as 1996; use them as a resource for developing this new curriculum.

◆ **Use the Multnomah County Foster Care Monthly Provider Meetings as a forum for encouraging foster care providers to open their doors to PLWH/A.**

The Adult Care Home Program of Aging and Disability Services of Multnomah County holds monthly meetings for foster care providers, six of which are mandatory for state licensing. Shelly Immel has extended an invitation to host a training sponsored by the HIV Services Planning Council at a meeting in the Fall of this year. To sign up as a presenter, provide information on the presenter and topics to be included in advance

of the meeting. Use this time to challenge foster care providers to be a part of the continuum of care for PLWH/A.

◆ **Coordinate the foster care presentation with the scheduling of a course for health care providers on caring for PLWH/A.**

In an effort to supply service providers with the tools they need to meet this new challenge, announce the course offered through PCC or MHCC at the presentation and schedule the two events in close proximity.

◆ **Develop additional residential facility capacity for PLWH/A.**

Consumers and case managers mentioned the need for more residential beds for PLWH/A because most of the current HIV-specific facilities are at capacity. This capacity could take the form of a new facility or result from better utilizing mainstream services. Currently, consumers, case managers and providers are not willing to utilize these mainstream services although there is capacity. A new facility for PLWH/A should provide independent living with services available on site. A facility with different levels of care is preferable. An area with 24-hour skilled nursing care is critical and welcomed for those consumers who are living in the less- assisted areas to move into as they enter a stage of more intense need. Apartment-style living floors for consumers recovering from substance abuse issues or mental health issues and an all women's floor would begin to meet the needs of consumers. Air conditioning, filtered water and meal services are suggestions consumers made to make the space more comfortable for them. Of course, these suggestions would also apply to the current residential facilities.

◆ **Develop community-based volunteer organizations as legitimate service providers.**

When asked if they covered non-medical in-home care, several insurance agencies pointed out that they expect consumers to rely on church organizations, family members, friends and neighbors to meet this need. Some care is available if a consumer has doctor-ordered medical in-home care, but this benefit is usually limited to assistance with bathing, and does not include housekeeping, meal preparation, assistance with managing household finances (e.g., balancing checkbook and paying bills), or errands. The Metropolitan Community Church's Care Team is an excellent example of how successful volunteer efforts have made a difference in the lives of consumers of in-home and respite care services. Currently this resource is under-utilized. This program is currently able to provide in-home non-medical services to an unlimited number of consumers, yet only six consumers are receiving care at this time. Coordinate with and provide supplemental funding for programs of this nature to fill some of the gaps in custodial or in-home non-medical care. Work with programs like Cascade AIDS PAL program and the Care Team to develop the volunteer resources in the community. A trained team of volunteers, coupled with accurate and current information to consumers on service availability, will begin to fill the largest gap in the continuum of care related to advanced stage care services.

◆ **Provide training for mainstream providers of residential, in-home and respite care services.**

Many agencies, specifically in-home care providers mentioned they would like more training on HIV. Medical in-home service providers often see homebound PLWH/A and have an existing wealth of information on their care; however, they requested more specific up-to-date information. Host training sessions at these organizations that cover symptom management

and identification, signs of deterioration, the resources available in the community, new therapies, medications, and side effects.

◆ **Develop a program that supports family members as caregivers for persons living with HIV.**

A consumer's existing support network is likely to be the most cost effective and stable provider of basic assistance. One caregiver expressed the necessity of being involved with the agencies and individuals that provide services to PLWH/A. Provide a forum for caregivers to meet with agency staff, express their needs for services, training and general help. Enhance or create respite care and training for family members and partners caring for PLWH/A so that they can (1) assist the consumer for longer in their home, avoiding earlier burnout and (2) help with a greater variety of needed services. Support will be needed for family members as they adjust to the changing needs of the client during the course of the disease.

◆ **Provide assistance in understanding insurance coverage and eligibility issues.**

The insurance system that funds residential, in-home and respite care services is confusing at best. Case managers are often too busy to help each consumer navigate the various funding systems. Consumers, often fending for themselves, must be clear on what is available to them at the differing levels of disability and which services are available through the community for free. Learning what services are available is complicated and general coverage information can be misleading. A Benefits Coordinator for the Portland EMA would help solve this problem by identifying insurance regulations, available services (both through volunteer organizations and the state), and consumer needs.

◆ **Support PLWH/A who use their talents to care for others in the community.**

Currently, the volunteer facet of the system of care for PLWH/A consists of many people who are also living with HIV/AIDS. Half of the consumers interviewed, despite the progression of their disease, were currently or had just recently volunteered time and offered their limited resources to care for other PLWH/A. As individuals with experience in HIV, these consumers may be the best qualified to provide support and non-medical care for their peers. Support and fund volunteer organizations that are currently using this resource.

◆ **Continue studying consumers assessed to need residential, in-home and respite care services.**

Request data from the four case management agencies identifying the number of consumers assessed to need these services annually. Encourage all service providing agencies to keep accurate records and update databases often.

One thing is clear: the face of HIV/AIDS has changed dramatically over the years as have the corresponding needs of those individuals affected by the disease and those committed to providing them with care and services. Both service providers and consumers spoke eloquently and generously about the strengths and challenges of the current HIV/AIDS care service system. Their ideas shape the beginning of a plan of action to respond to unmet needs.

Additional areas that warrant attention include housing, transportation, access to prescription medication, including information on funding sources for prescriptions, access to alternative therapies, especially in the home, and specialized services for women and children.

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