



*North Central District AIDS Coalition  
Needs Assessment for 2000-2003*

**Final Report**

*Prepared for:*

NCDAC  
8 North Grove Street, P.O. Box 658  
Lock Haven, PA 17745

Mary Jane Isenberg, Executive Director

*Prepared by:*

**By The Numbers**  
702 Windsor Court  
State College, PA 16801  
814-867-0661 (Phone)  
814-235-7618 (Fax)  
Email: [info@bnumbers.com](mailto:info@bnumbers.com)  
Web: <http://www.bnumbers.com/>

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# ***North Central District AIDS Coalition*** **Needs Assessment for 2000-2003**

## **Final Report**

### ***Introduction***

The Ryan White CARE Act, originally passed in 1990, provides funds to assist states and localities in the provision of health care and support services to individuals and families affected by the HIV infection. The Act funds services for person who are HIV positive as well as those with AIDS. It also funds services for family members affected by HIV/AIDS, such as a parent, spouse or partner. The Act requires states and localities to engage in a comprehensive planning process in order to provide services to the HIV/AIDS infected and affected populations. The North Central District AIDS Coalition (NCDAC) was formed in May 1991 in response to the Pennsylvania Department of Health's Bureau of HIV/AIDS regionalized planning strategy. The NCDAC coincides with the North Central Health District established by the Pennsylvania Department of Health. The 12 counties in this district are Potter, Clinton, Centre, Tioga, Lycoming, Union, Snyder, Bradford, Sullivan, Columbia, Montour, and Northumberland.

The NCDAC allocates federal and state funds to organizations in its region that provide services to people living with or affected by HIV/AIDS. NCDAC currently funds five case management agencies: The AIDS Project of Centre County, The AIDS Resource Alliance, Inc., Guthrie Advantage, Potter County Human Services, and Tioga County Women's Coalition. As of spring 2000, these five agencies served 170 people infected or affected by HIV/AIDS.

In January of 2000, NCDAC contracted with By The Numbers to conduct their agency's needs assessment in coordination with the NCDAC. The NCDAC sponsors a needs assessment once every three years; this information is used in the strategic planning process for establishing funding priorities for upcoming fiscal years.

Several different sources of data were used in conducting this needs assessment. These include secondary data from government statistics, including the Bureau of Epidemiology in the Pennsylvania Department of Health, the Pennsylvania Office of Rural Health, and the LifePlan database used by the NCDAC. LifePlan is used by NCDAC to monitor services provided to consumers of the case management agencies funded through the NCDAC, as well as critical characteristics of these consumers. This needs assessment also relies on a survey of consumers of the HIV/AIDS case management services, a survey of health and human service providers located in the 12-county NCDAC region, and focus groups and interviews with health and social service providers, HIV/AIDS case managers (of agencies funded through the NCDAC), and mothers of children who have AIDS.

The first section of this report uses secondary data from government statistics to describe the prevalence of HIV/AIDS in the North Central region of Pennsylvania. Characteristics of the

HIV/AIDS population in the region are described and compared with Pennsylvania as a whole. The services that are most frequently used by consumers of the case management agencies funded through the NCDAC are described. This section also discusses the extent to which there are health professional shortages in the region. The information in this section is useful in determining the needs of HIV/AIDS infected and affected persons in the region, how these needs differ from the needs of those for the state of Pennsylvania as a whole, and the extent to which health professional shortages in the region will impact on strategies for meeting these needs.

The second section of this report summarizes results from a consumer survey conducted during the spring of 2000. At that time, 170 consumers were served by the five case management agencies funded through the NCDAC. Consumers were asked various questions about the types of services offered by their case management agency, their use of emergency financial services and the speed with which those services were received, their satisfaction with the agency and their medical providers, whether they would like to receive nutrition counseling or regular dental check-ups, and problems with transportation. The survey also contained questions asking whether the respondent's case manager had provided information about the Consumer Advisory Board, a list of services that are offered by the agency, and information related to HIV/AIDS. The overall response rate for the survey was 48.2%. Also in this section, results from the focus group of mothers of children with AIDS are described. These two components permit a fuller perspective on the needs and views of people living with and affected by HIV/AIDS in the North Central region.

The third section of this report summarizes results from a survey of health and human service providers in the 12-county region. A wide range of providers was surveyed, including dentists, physicians, nurses, home health and hospice providers, and human service providers. A total of 135 usable surveys were returned, representing an overall response rate of 18.7%. However there was considerable variation by type of provider; for instance, 56% of the home health and hospice providers returned the survey compared to 11% of the dentists. The survey asked providers about the number of HIV/AIDS infected and affected clients/patients being served, the demographic and health status characteristics of these clients/patients, the availability of a various services to persons living with or affected by HIV/AIDS, the use of these services, which services are most urgently needed, which services are underutilized, and barriers to accessing services. The survey also asked providers about their attitudes regarding the accessibility and quality of services provided to persons living with HIV/AIDS, as well as those using Medical Assistance, in their service area. When appropriate, this section of the report highlights differences in survey results between providers serving the two cities of Williamsport and State College and providers serving rural areas of the 12-county NCDAC region.

The fourth section synthesizes results from the focus groups and interviews with health and human service providers, and the case managers from the NCDAC funded agencies.

The last section of this report synthesizes results from prior sections. The most critical needs of persons living with and affected by HIV/AIDS are highlighted, and a list of recommendations for establishing funding priorities is presented. Strategies for addressing these needs are discussed.

## ***A. Characteristics of the HIV/AIDS Population***

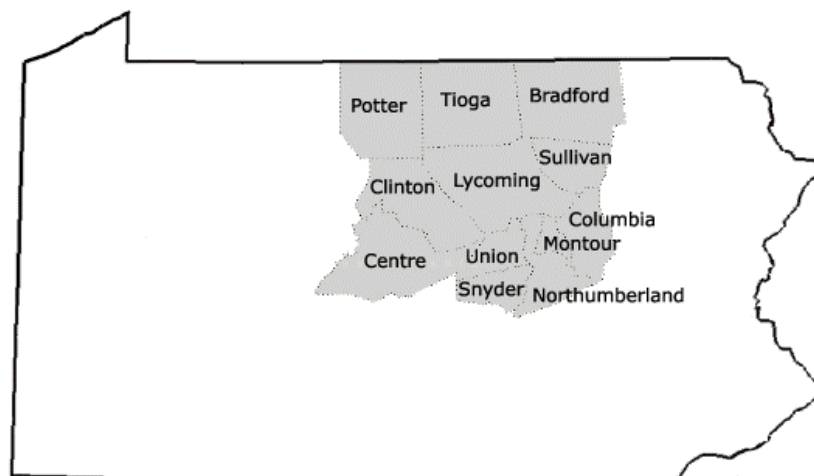
### ***What Does North Central Pennsylvania Look Like?***

A total of 665,458 people live in the 12 counties of the North Central region, comprising 5.5% of the population living in Pennsylvania (1999 population estimates). At the same time, the 12-counties cover nearly 9,000 square miles, which is about the same size as the state of New Jersey. This means that there are 76 people per square mile living in the North Central region. In contrast, there are 268 people per square mile in the state of Pennsylvania, as a whole.

While the region is predominantly rural, there are marked differences across counties in the region. While none (0%) of the people living in Sullivan county reside in an urban area, 54% and 57% of those living in Lycoming and Centre counties do so, respectively (as based on 1990 census figures). Lycoming and Centre counties contain the two major population centers in the region (Williamsport and State College, respectively). By comparison, 69% of the people living in Pennsylvania live in an urban area. Consequently, even the most urbanized areas in the region are less urbanized than the state as a whole. Also, the region is primarily Caucasian (97%, as based on 1990 census figures).

There is considerable diversity in the extent to which poverty and financial hardship characterize the region. The percent living in poverty ranges from 9.7% to 14.7% – that is, from less than one-tenth of the population to one-seventh of the population in that county. As a point of comparison, the percent living in poverty for Pennsylvania, as a whole, is 11.5%.

The percentage of the population eligible for Medical Assistance across the 12 counties is even more divergent. As of December 1999, percentages ranged from a low of 5.4% and 7.0% in Centre and Union counties, respectively, to a high of 14.6% and 15.5% in Sullivan and Potter counties, respectively. The percentage for Pennsylvania is 11.6%. The diversity characterizing the populations living in these 12 counties is depicted in Table A-1 on the next page. The counties are listed from north to south, starting at the most eastern portion of the region (refer to the map, below). These data are from the health profiles published by the Pennsylvania Department of Health, Bureau of Health Statistics.



**Table A-1**  
**Selected Characteristics of North Central Region**

North Central Region	Urban Population	Income Below Poverty Level	Eligible for Medical Assistance
		<i>Percent</i>	
Bradford	20.5%	13.2%	13.0%
Sullivan	0%	12.8%	14.6%
Columbia	37.0%	10.0%	9.2%
Montour	44.9%	9.7%	10.5%
Northumberland	49.0%	11.7%	10.9%
Tioga	16.9%	13.8%	12.0%
Lycoming	54.3%	12.1%	11.2%
Union	25.6%	10.8%	7.0%
Snyder	14.7%	10.0%	9.2%
Potter	17.1%	14.7%	15.5%
Clinton	24.8%	14.2%	13.3%
Centre	57.1%	10.8%	5.4%
Pennsylvania as a whole	68.9%	11.4%	11.6%

The region is characterized by the presence of various health professional shortage areas. Health professional shortage areas have been defined by the Bureau of Primary Health Care of the Health Resources and Services Administration to be geographic-based as well as population-based. A geographic-based shortage area indicates that the entire county, and everyone in it, is affected by a shortage. A population-based shortage area indicates that some segment in the county's population is affected by the shortage. All population-based shortages in the region affected low-income persons. To achieve a shortage designation, individuals within an area apply for such a status. These designations are used by various government programs when making awards or dispersing funds, such as the National Health Services Corps (i.e., recruitment of health professionals). If an area does not have a shortage designation, it does not necessarily imply that a shortage does not exist.

Portions of nine of the 12 counties in the region contain geographic primary care health professional shortage areas, while parts of three counties in the region contain population primary care health professional shortage areas. There appear to be dental health and mental health shortages in the region, as well. One of the counties (Bradford) is a population dental health professional shortage area; this means that the Bureau of Primary Health Care has determined that there is a shortage of dentists for low-income persons in Bradford County. Three of the counties in the region (Tioga, Lycoming, and Clinton) are considered geographic mental health shortage areas – this means that these shortages affect all persons in those counties. These data were taken from the Pennsylvania Office of Rural Health's *Provider Atlas*, 2000.

Also, there is a limited supply of health care facilities in the region. Table A-2 presents the number of general acute care hospitals, nursing homes, and licensed drug and alcohol treatment facilities (state supported) in each county and the region.<sup>1</sup> There are only 19 general acute care hospitals in the North Central region. There are no general acute care hospitals in two counties (Sullivan and Snyder). These data are from the health profiles published by the Pennsylvania Department of Health, Bureau of Health Statistics.

**Table A-2**  
**Selected Characteristics of North Central Region**

	General Acute Care Hospitals	Nursing Homes	Licensed Drug & Alcohol Facilities*
	<i>Number</i>		
Bradford	3	5	5
Sullivan	0	2	1
Columbia	2	5	5
Montour	1	3	4
Northumberland	2	10	8
Tioga	1	3	6
Lycoming	4	8	10
Union	1	4	3
Snyder	0	2	1
Potter	1	2	2
Clinton	2	3	3
Centre	2	8	6
North Central Region	19	55	54

\* Includes outpatient facilities

### ***How Prevalent is AIDS in the North Central Region?***

The Pennsylvania Department of Public Health reported a cumulative total of 528 AIDS cases in the North Central region as of December 1999. About one-half (51%) of these people were presumed alive, as of that date. This is larger than the percentage presumed alive in the state or the United States, as a whole. The percentage of AIDS cases presumed alive in Pennsylvania (as of 12/99) was 45% while for the United States it was 41%. The percentage presumed alive is reported (rather than percent dead) because those who are living with AIDS require services, and the need for services is the focus of this report.

Lycoming county is ranked 16<sup>th</sup> in the state in terms of cumulative AIDS cases (out of the 67 counties). Centre, Northumberland and Union are ranked 24<sup>th</sup>, 27<sup>th</sup>, and 29<sup>th</sup>. Columbia and

<sup>1</sup> Data on the number of acute care hospitals is for the 7/97 to 6/98 period; data on number of nursing homes is for 1998; and data on the number of (state-supported) licensed drug and alcohol treatment facilities is for the 7/98-6/99 period.

Bradford are ranked 42<sup>nd</sup> and 43<sup>rd</sup>. Tioga, Snyder, Montour, and Potter are ranked 51<sup>st</sup>, 52<sup>nd</sup>, 58<sup>th</sup>, and 59<sup>th</sup>, while Clinton and Sullivan are ranked 62<sup>nd</sup> and 64<sup>th</sup>. Table A-3 lists the number of cumulative AIDS cases in each county, the number and percent presumed alive (as of 12/99), and the ranking of the county in Pennsylvania in terms of the number of cumulative AIDS cases. These data are from the Pennsylvania Department of Health, Bureau of Health Statistics, Bureau of Epidemiology.

**Table A-3**  
**Prevalence of AIDS in the North Central Region**

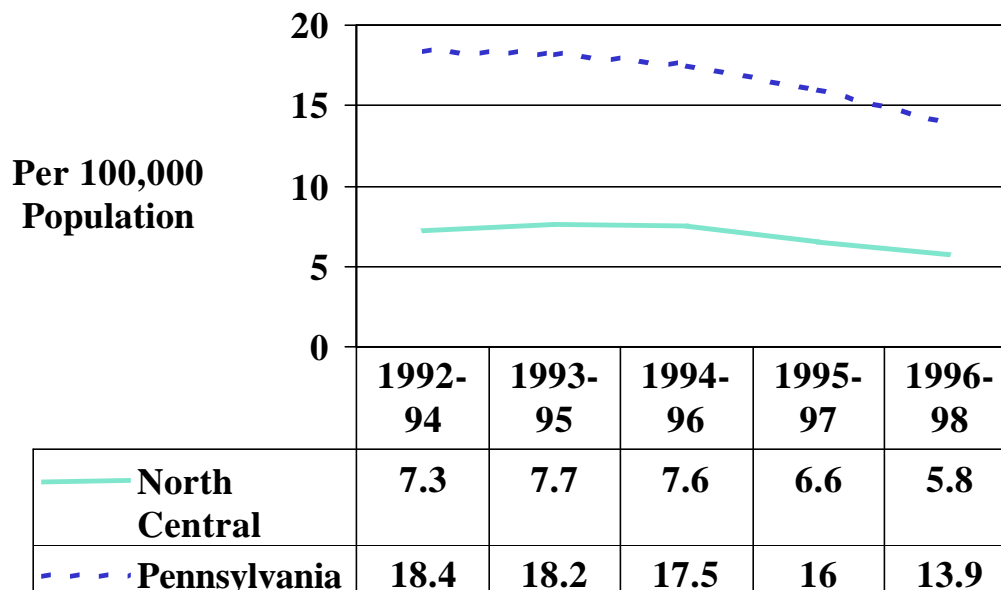
	Cumulative AIDS Cases	Number Presumed Alive	Percent Presumed Alive	County Rank
Bradford	27	9	33%	43
Sullivan	5	2	40%	64
Columbia	30	17	57%	42
Montour	9	4	44%	58
Northumberland	75	38	51%	27
Tioga	17	4	24%	51
Lycoming	182	91	50%	16
Union	68	46	68%	29
Snyder	16	8	50%	52
Potter	7	2	28%	59
Clinton	5	0	0%	62
Centre	87	47	54%	24
North Central Region	528	268	51%	—

As of December, 1999

Four-fifths (80%) of the 528 cumulative AIDS cases in the North Central region are male and 20% female. About one-half (51%) are white (non-Hispanic) and over one-third (36%) are African-American (non-Hispanic). Close to one-seventh of all AIDS cases are Hispanic. The largest percentage (49%) of cases is 30-39 years of age. Nearly one-half (46%) of the cases acquired AIDS via injecting drug use (IVDU); less than one-third (31%) are men who have sex with men (MSM). One-tenth (10%) of the cases are a combination of these two modes of transmission. These figures are from the Pennsylvania Department of Health, Bureau of Health Statistics, Bureau of Epidemiology.

Figure A-1 presents the incidence rate of AIDS in the North Central region from the 1992-1994 to the 1996-1998 period. The rates for Pennsylvania are presented, as well. The incidence rate (per 100,000 population) is considerably higher for the state of Pennsylvania than it is for the North Central region. However, the North Central region did not experience as large a drop in the incidence rate during the 1996-98 period as the state as a whole. The drop in the incidence rate during this period is due to more effective therapies resulting in decreases in the incidence of AIDS. These data are from the Pennsylvania Department of Health, *Health Status Indicators*.

**Figure A-1  
Trends in the Incidence Rate of AIDS**



Source: Pennsylvania Department of Health, Health Status Indicators

***How Prevalent is HIV in the Region?***

Currently, Pennsylvania does not report counts of persons who are HIV positive to the Centers for Disease Control and Prevention (CDC). However, the U.S. General Accounting Office (GAO) has recommended that counts of persons with HIV infection in geographic areas be incorporated into formulas for dispersing Ryan White CARE Act funds rather than relying only on counts of person with AIDS, as is the current practice. The CDC estimates that all states will be reporting new HIV cases as of 2003, but that an additional one to three years may be needed to include existing cases into their state reporting system. It is unknown how well states will be able to identify HIV cases prior to 2003. Consequently, it becomes even more important for planning purposes to estimate the prevalence of the HIV infection in the region, not only because services are provided to this population but also because future funding will be affected by these estimates.

Table A-4 presents the number of visits persons made for publicly funded HIV counseling and testing between 1995 and 1999; data for 1999 may not be complete. A visit is comprised of a client receiving counseling or counseling and testing; clients consented to counseling in 90% of the visits in 1998. On average (across all counties in the state), 1.7% of visits resulted in a positive test (i.e., indicating HIV infection). Data are from the Pennsylvania Department of Health, Bureau of Communicable Diseases, Division of HIV/AIDS.

**Table A-4**  
**Number of Visits for Publicly Funded HIV Counseling and Testing in the North Central Region**

	1995	1996	1997	1998	1999*	Total
Bradford	186	155	139	148	53	681
Sullivan	43	35	25	33	23	159
Columbia	495	589	533	587	306	2,510
Montour	53	159	186	255	111	764
Northumberland	380	310	293	293	208	1,484
Tioga	218	181	135	149	61	744
Lycoming	1,157	1,225	1,126	1,283	516	5,307
Union	312	315	281	232	108	1,248
Snyder	179	253	173	145	151	901
Potter	36	40	28	36	16	156
Clinton	238	200	197	253	81	969
Centre	932	1,248	1,091	738	389	4,398
North Central Region	4,229	4,710	4,207	4,152	2,023	19,321
1.7% of Visits	72	80	72	71	34	328

\* Data for 1999 may not be complete

Data in Table A-4 suggest that between 71 and 80 visits each year were positive in the North Central region. The data for 1999 is apparently incomplete because the number of visits is about one-half that of the other years. Even so, it appears that at least 328 tests were positive for HIV between 1995 and 1999 in the North Central region.

An alternative method of estimating the prevalence of HIV was employed by the Pennsylvania Department of Health, Bureau of Epidemiology, HIV/AIDS Surveillance & Epidemiology Section in their Year 2000 update of the *Epidemiologic Profile of HIV/AIDS in Pennsylvania*. They began with the number of women testing positive for HIV in the serosurvey of childbearing women. Then, assuming that the age distribution of HIV infected females is the same as that for living female AIDS cases, and assuming that the distribution of HIV infection by sex, geographic coalition area, race/ethnicity, mode of transmission, etc. is the same as that for diagnosed AIDS cases, they proceeded to estimate HIV prevalence rates for 1997. They estimated an overall HIV prevalence rate of 193.20 per 100,000 population in the North Central region. Given the region's population of 665,458, that works out to an estimated 1,286 persons in the region who are HIV positive.

The two HIV prevalence figures (328 and 1,286) differ because of differences in methodology. The figure of 328 is based on the number of persons who chose to obtain publicly funded HIV counseling and testing during 1995-1999. It excludes those who obtained private testing, those who were tested before 1995, and those who have not been tested at all. The figure of 1,286 is based on an extrapolation from HIV estimates for childbearing women in 1997 to the

population at large. This figure is valid to the extent that the assumptions underlying the extrapolation are valid.

The Pennsylvania Department of Health's HIV estimates indicate an HIV prevalence rate for females of 82.12 (per 100,000 population) and for males of 306.95 in the North Central region. A breakdown of estimates by race/ethnicity indicates an HIV prevalence rate of 98.26 for white non-Hispanics. The estimated prevalence rates for black non-Hispanics and Hispanics are not reliable because of the small numbers of African Americans and Hispanics living in the North Central region.

The estimated HIV prevalence rate for the North Central region as a whole (193.20 per 100,000 population) is the second highest among regions in Pennsylvania. The lowest was the Northwest region, with an estimated prevalence rate of zero. The South Central region had an estimated prevalence rate of 97.22; the Southwest region had an estimated rate of 100.69; while the Northeast region had an estimated rate of 169.70. The region with the highest estimated HIV prevalence rate was the Southeast, with a rate of 376.19 per 100,000 population.

### ***Who Is Receiving NCDAC Services?***

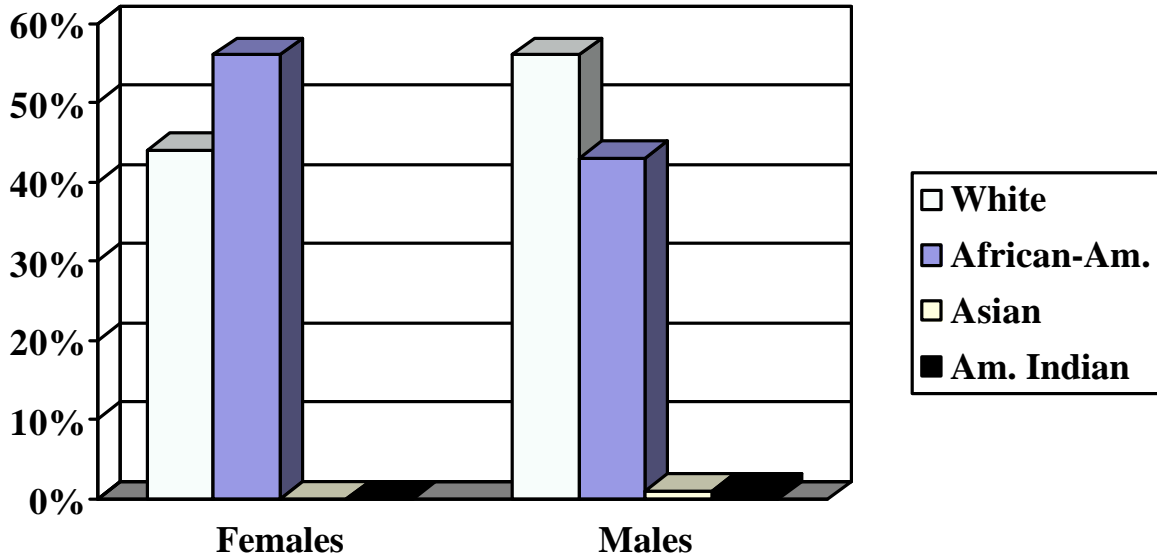
NCDAC made available to By The Numbers aggregate data tables from the LifePlan database. These tables contained information on the socio-economic characteristics of HIV/AIDS infected and affected persons being served through the case management agencies funded through the NCDAC. Data tables on service use by clients were also provided. As indicated above, only aggregate data were released; it was not possible to identify any individual in the database.

Between January 1, 1999 and December 31, 1999, the five case management agencies and the NCDAC served 216 persons living with or affected by HIV/AIDS. About three-fourths (74%) of the HIV-infected clients were diagnosed with AIDS.

While the population of the North Central region is primarily Caucasian, the racial composition of NCDAC clients is more evenly distributed between Caucasians and African-Americans. About one-half (51%) of the clients are Caucasian and 48% are African-American. However, this breakdown does not accurately portray the racial composition of any individual case management agency – in two agencies, all of the clients are Caucasian, while in one agency more than one-half of the clients are African-American. Between 16% and 30% of the clients are African-American in two other agencies. Across all agencies, only 1% of the clients are either American Indian or Asian.

Over one-third (37%) of the clients are female. Figure A-2 depicts the racial composition of female and male clients. While 56% of the males are Caucasian, only 43% of the females are Caucasian. However, this does not accurately depict the racial characteristics of four of the five case management agencies – in four out of the five agencies, females are predominantly Caucasian.

**Figure A-2**  
**Racial Composition of Male and Female HIV/AIDS Clients**



Clients are predominantly non-Hispanic. Only 7% of the clients are Hispanic. While 10% of the females are Hispanic, only 4% of the males are Hispanic. Ten of the 14 Hispanic clients are served by one case management agency.

Nearly all (97%) of the clients are 20 years or older. Six clients are children under the age of 13 years, and one client is an adolescent (13 to 19 years). HIV was transmitted to all six children via the mother (perinatal transmission), and the one adolescent acquired HIV through heterosexual contact. Table A-5 depicts the mode of transmission for persons 20 years or older.

**Table A-5**  
**Mode of Transmission of HIV to Adult Clients**

	Number	Percent
Men Sex With Men (MSM)	71	35%
Injecting Drug Use (IVDU)	49	24%
MSM & IVDU	4	2%
Heterosexual Contact	76	38%
Other Adult Contact	2	1%
<b>Total</b>	<b>202</b>	<b>100%</b>

Differences are apparent in the mode of transmission among Caucasians and African-Americans, as indicated in Table A-6. A larger percentage of Caucasian clients acquired HIV/AIDS via homosexual contact (MSM) than African-American clients. In contrast, African-American clients were more likely to acquire HIV/AIDS via heterosexual contact or injecting drug use.

**Table A-6**  
**Mode of Transmission for Caucasian and African-American Clients**

	Caucasian		African-American	
	Number	Percent	Number	Percent
Men Sex With Men (MSM)	52	50%	18	17%
Injecting Drug Use (IVDU)	15	14%	34	33%
MSM & IVDU	3	3%	1	1%
Heterosexual Contact	32	30%	45	44%
Other Adult Contact	2	2%	0	0%
Mother	1	1%	5	5%
<b>Total</b>	<b>105</b>	<b>100%</b>	<b>103</b>	<b>100%</b>

Over one-third (35%) of the clients reported their HIV status prior to 1993. The percentage whose HIV status was reported each year during 1993 to 1996 was fairly stable (9% to 13%). The percentage reporting their HIV status in 1997 was 19%. Table A-7 presents these results as well as a breakdown by male and female clients. Two-fifths (41%) of the male clients reported their HIV status prior to 1993 compared to 26% of the female clients. The difference in the percentage of male and female clients reporting their HIV status is smaller for those most recently reporting their HIV status.

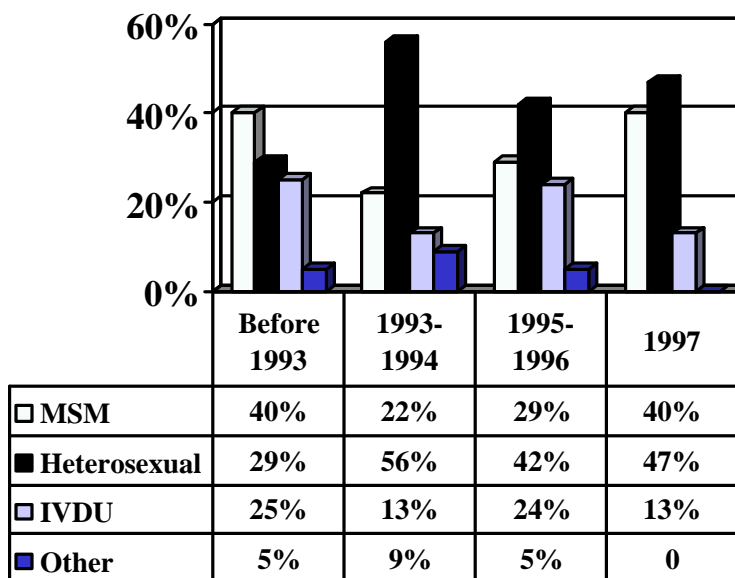
**Table A-7**  
**Year of Report for Female and Male Clients**

	Overall		Female		Male	
	Number	Percent	Number	Percent	Number	Percent
Before 1993	56	35%	16	26%	40	41%
1993	17	11%	12	19%	5	5%
1994	15	9%	5	8%	10	10%
1995	21	13%	12	19%	9	9%
1996	20	13%	6	10%	14	14%
1997	30	19%	11	18%	19	20%
<b>Total</b>	<b>159</b>	<b>100%</b>	<b>62</b>	<b>100%</b>	<b>97</b>	<b>99%</b>

One total does not equal 100% due to round-off error.

Figure A-3 illustrates changes in the mode of transmission across time, specifically the year of report. This information suggests that new AIDS/HIV clients are increasingly more likely to acquire the disease via heterosexual contact (ignoring the blip in 1993-1994). The percentage of clients who acquired HIV/AIDS via injecting drug use within any given (report) year fluctuates, while the percentage of clients who acquired the disease via homosexual contact appears to be increasing since 1993.

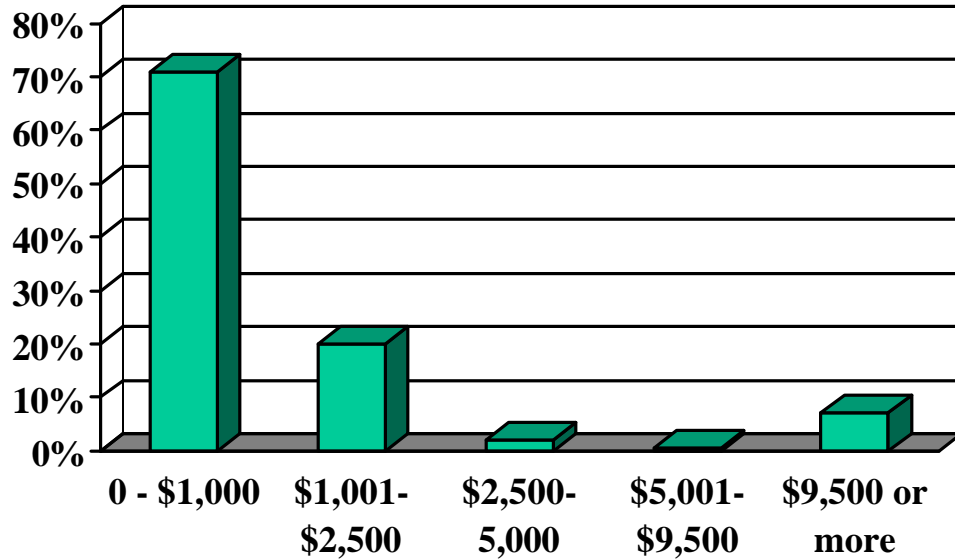
**Figure A-3  
Mode of Transmission Within Year of Report**



Gross monthly income of clients is portrayed in Figure A-4. This figure illustrates the financial hardship characterizing over two-thirds of the clients – the monthly income for 70% of the clients ranged from \$0 to \$1,000.

Table A-8 presents the insurance status of clients. The majority (59%) of the clients rely on Medical Assistance. Only 12% have private health care insurance, while about the same percentage have no health care coverage (13%).

**Figure A-4  
Gross Monthly Household Income**



**Table A-8  
Health Care Coverage of HIV/AIDS Clients**

	Number	Percent
None	28	13%
Medical Assistance	126	59%
Medicare	18	8%
Public	8	4%
VA	1	0%
Private	26	12%
Other	5	2%
Unspecified	2	1%
<b>Total</b>	<b>214</b>	<b>99%</b>

Total does not sum to 100% due to round-off error.

### ***What Are the Most Frequently Used Services?***

Table A-9 presents the most frequently used services by AIDS and HIV-infected clients. Services designed to alleviate problems associated with limited financial resources are the most frequently used by AIDS and HIV-infected clients, specifically the food bank and emergency financial assistance for utilities, and to a lesser extent, for rent. Other frequently used services relate to the nutritional needs of clients. Client education is also frequently provided.

**Table A-9  
Most Frequently Used Services Among AIDS and HIV-Infected Clients**

	AIDS		HIV-Infected	
	Number	Percent	Number	Percent
Food bank	120	78%	41	73%
Emergency financial assistance	93	61%	27	48%
Nutritional supplements	58	38%	25	45%
Tenant-based rental assistance	41	27%	14	25%
Education/risk reduction	40	26%	14	25%
Individual Treatment Education	27	18%	12	21%
Self-help group	16	10%	7	12%
Transportation	11	7%	6	11%
Outpatient medical care	11	7%	0	0%
Buddy/companion	2	1%	2	4%
Legal services	0	0%	2	4%

Results from the Consumer Survey, described in section B of this report, indicate that about one-half of the respondents to the survey know that their case management agency provides some of the lesser used services – 59% know that their agency provides buddy/companion services and 54% are aware that transportation services are provided by their agency. In contrast, 88% of the respondents to the survey know that their case management agency provides emergency financial assistance for rent and utilities. Emergency financial assistance is one of the most frequently used services by clients. These results, while by no means conclusive, suggest that some services may be underutilized because clients are not aware of them. For instance, transportation is used by about one-tenth of the clients. However, findings presented throughout this report emphasize that transportation is a critical need that appears to be going unmet, especially for those people with limited financial resources living outside of the State College or Williamsport city areas.

## ***B. Consumers' Perspectives on the Needs of HIV/AIDS Infected & Affected Persons***

### ***Consumer Survey – Use, Satisfaction, and Barriers to Service***

During the spring of 2000, the North Central District AIDS Coalition (NCDAC) worked with the five case management agencies they fund to administer a survey to consumers of HIV/AIDS case management services. Consumers were asked various questions about the types of services offered by their case management agency, their use of emergency financial services and the speed with which those services were received, their satisfaction with the agency and their medical providers, whether they would like to receive nutrition counseling or regular dental check-ups, and problems with transportation. The survey also contained questions asking whether the respondent's case manager had provided information about the Consumer Advisory Board, a list of services that are offered by the agency, and information related to HIV/AIDS.

A total of 170 HIV/AIDS consumers were served by these five agencies at that time. Eighty-two consumers returned the survey, representing a 48.2% response rate. The key findings from the surveys are grouped into seven major areas: (1) knowledge of services offered by the case management agency; (2) use of emergency financial services, speed of service delivery, and knowledge of requirements; (3) types of information provided by the case management agency; (4) satisfaction with the agency and medical providers, (5) the need for nutrition counseling or dental services; (6) problems with transportation, and (7) responses to the open-ended question asking for comments.

#### ***Knowledge of Services Offered***

Table B-1 presents the percentage of respondents who correctly indicated that their case management agency offered the listed services, as well as the percentage incorrectly indicating that the service was not offered by their agency and the percentage who were not sure whether the service was offered. All case management agencies do in fact offer the services listed.

Results indicate that the majority of respondents are aware of the different types of emergency financial services offered by their case management agency. Most are aware of food or rent/utilities emergency financial assistance services, while fewer are aware of medication or transportation emergency financial assistance. About one-half of the respondents are aware of nutrition counseling or transportation services. A few more respondents are aware of Buddy Services.

**Table B-1**  
**Knowledge of Services Offered by Case Management Agency**

Service	Number Responding	Percent			Total
		Offered	Not Offered	Not Sure	
Buddy Services	81	59%	17%	24%	100%
Nutrition counseling by a licensed nutritionist	81	53%	21%	26%	100%
Transportation to and from medical appointments	80	54%	27%	19%	100%
Emergency Financial Assistance for:					
Rent/Utilities	80	88%	1%	11%	100%
Medication	80	74%	5%	21%	100%
Food	82	92%	2%	6%	100%
Transportation	77	60%	18%	22%	100%

Consumers were also asked if they know how to get Buddy Services. These results are presented in Table B-2. Overall, 53% of the respondents know how to get Buddy Services, 36% did not know how to access the service, and 11% were not sure. However, these results are best interpreted in the context of whether the respondent knew whether the case management agency provided Buddy Services. These results are presented in Table B-2, as well.

**Table B-2**  
**Knows About Buddy Services**

Knows that Agency Provides Service	Number	Knows How to Get Buddy Services			Total
		Yes	No	Not Sure	
Yes	48	85%	6%	8%	99%
No/Not Sure	33	6%	79%	15%	100%
Overall	81	53%	36%	11%	100%

Some totals do not equal 100% due to round-off error.

The majority of respondents (48 out of 81) know that their case management agency offers Buddy Services. Most of these respondents (85%) indicated knowing how to get Buddy Services. However, over two-fifths (41%, that is 33 out of 81) of the respondents did not realize that their case management agency provided Buddy Services. Only 6% of these respondents (2 out of 33) knew how to get Buddy Services.

### ***Use of Emergency Financial Services, Speed of Service Delivery, and Knowledge of Requirements***

Over three-fourths (78%) of the respondents indicated that they had requested emergency financial assistance of some type. Only 62% of the respondents who requested emergency financial assistance received it within one to three days after requesting it. With three exceptions, all respondents who did not receive help within one to three days after requesting it did receive it within four to seven days. Nearly three-fourths (72%) of the respondents knew that an eviction or termination notice was required by their agency in order to receive rent or utilities emergency financial assistance, although 21% were not sure.

### ***Information Provided***

Table B-3 presents the percentage of respondents indicating that their case management agency has provided information or helped them understand about the following topics: HIV treatment options; dangers of re-infection; services available through the program; and Consumer Advisory Board (CAB).

**Table B-3**  
**Information Received from Case Management Agency**

Topic	Number Responding	Percent Indicating 'Yes'
My agency provides me with HIV treatment information.	82	90%
My Case Manager has helped me to understand the dangers of being re-infected.	82	78%
I have been given a list of all the services my HIV/AIDS program provides.	81	70%
My agency has told me about the Consumer Advisory Board (CAB).	80	68%

Most (90%) of the respondents indicated that their case management agency had provided them with HIV treatment information. Considerably fewer indicated that they had been helped to understand the dangers of re-infection by their Case Manger (78%), been given a list of all services that their HIV/AIDS program provides (70%), or been told about the CAB (68%).

### ***Satisfaction with Services and Providers***

Table B-4 presents the percentage of respondents who indicated being satisfied with their case management agency and doctor. In addition, the table presents the percentage of respondents who indicated that they receive services when they need them and that their agency is open during posted hours. The percentage of respondents who have a Medical Assess Card is also listed.

**Table B-4**  
**Satisfaction with Agency, Medical Providers, and Related Factors**

Topic	Number Responding	Percent Indicating 'Yes'
I am satisfied with my service provider (in other words, my Case Management agency).	79	89%
I am satisfied with my medical providers (in other words, my doctor).	81	80%
I receive the services I need when I need them.	79	89%
In my experience, my agency is always open during posted office hours.	81	88%
I have a Medical Access Card.	81	60%

Most of the respondents (89%) indicated that they are satisfied with their case management agency, and four-fifths (80%) indicated being satisfied with their doctor. Most of the respondents indicated that they receive the services they need when they need them (89%) and that their agency is always open during posted office hours (88%). Three-fifths (60%) of the respondents have a Medical Access Card.

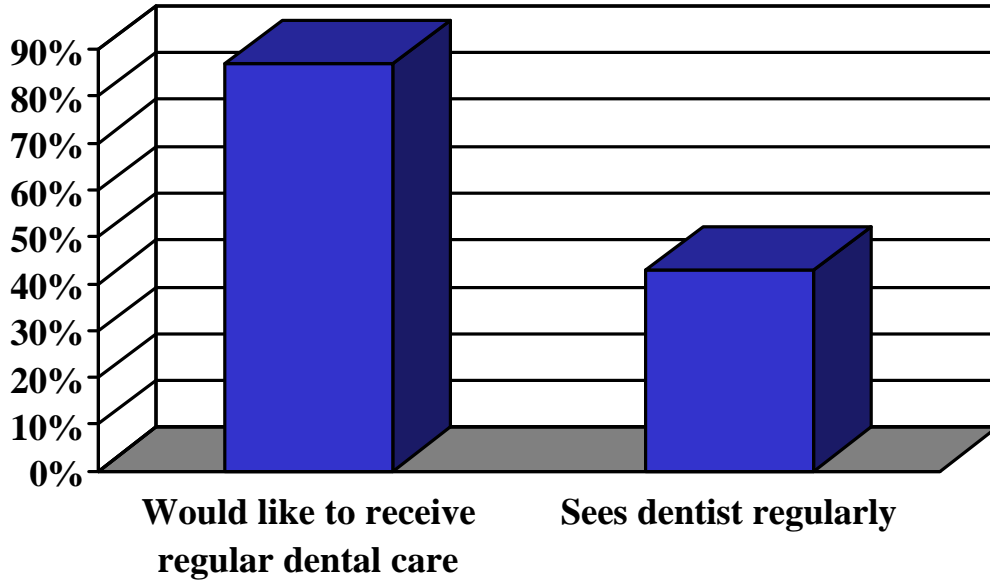
***Need for Nutrition Counseling or Dental Services***

Over one-half (57%) of the respondents indicated that they would like to receive nutrition counseling by a licensed nutritionist. However, only 53% of the respondents were aware that this service is offered by the agency. In fact, 58% of those who did not know that the service is offered indicated that they would like to receive nutritional counseling. Similarly, 56% of those who do know the service is offered indicated that they would like to receive the service.

Also, 87% of the 82 respondents indicated that they would like to have regular dental check-ups. Consumers were also asked if they see a dentist regularly. However, only 43% of the respondents who would like to see a dentist regularly actually see one regularly. This indicates there is a considerable unmet need for dental services among respondents, as illustrated in Figure B-1.

Respondents who did not see a dentist regularly were asked to indicate why this was the case. Results are presented in Table B-5. Eighty percent of the 49 respondents who indicated that they did *not* see a dentist regularly answered the questions listed in Table B-5.

**Figure B-1**  
**Unmet Need for Dental Services Among Consumers**



**Table B-5**  
**Reasons Respondents Did Not See a Dentist Regularly**

	Number Responding	Percent Indicating 'Yes'
I do not have enough money to pay for a dental visit.	39	80%
I cannot find a dentist who will accept my Medical Access Card.	39	36%
I have to travel too far to get to a dentist.	39	36%

The most frequently indicated reason for not seeing a dentist regularly is not having enough money to pay for a dental visit (80%). Also, over one-third indicated that they could not find a dentist who would accept their Medical Access Card (36%) or that they would have to travel too far to get to a dentist (36%). In addition, several respondents indicated that they did not need to see a dentist regularly because they did not need such care – either they had no teeth or they had dentures.

Reasons for not seeing a dentist are related to the type of health care coverage the respondent has (Medical Assistance, private insurance which typically requires a co-payment, or not having dental coverage at all). The percentage of respondents indicating the reasons listed

above for *not* seeing a dentist is broken down by whether or not the respondent had a Medical Access Card. Results are presented in Table B-6.

**Table B-6**  
**Reasons for Not Seeing Dentist Regularly by Whether Respondent Has Medical Access Card**

Reasons for Not Seeing Dentist Regularly	Has Card ( <i>n</i> =25)	Does Not Have Card ( <i>n</i> =13)
Percent indicating reason		
Not enough money to pay for visit	68%	100%
Cannot find a dentist accepting Medical Access Card	52%	8%
Have to travel too far	48%	15%

Number in parentheses (*n*) is number responding to questions.

All (100%) 13 respondents who did not have a Medical Access Card and did not see a dentist regularly cited not having enough money to pay for a visit as a barrier. This result highlights the financial hardship characterizing many of those receiving services through the case management agencies. Over two-thirds (68%) of the 25 respondents with a Medical Access Card cited this reason as a barrier.

Having to travel too far to get to a dentist was indicated by nearly one-half (48%) of the respondents with a Medical Access Card in contrast to only 15% of those without a card. This result indicates that respondents probably have to travel some distance in order to find dental care and those with a Medical Access Card are probably less likely to have a reliable vehicle. About one-half (52%) of the respondents with a Medical Access Card indicated that not being able to find a dentist who would take their card was a barrier in contrast to only 8% of those without a card. The latter finding may reflect those people who qualify for Medical Assistance but have not applied. (Perhaps one of the reasons some people have not applied for Medical Assistance is due to expectations of having difficulties finding providers willing to accept the Card.)

***Problems with Transportation***

Transportation is a problem for about one-third of the respondents (32%), although respondents who know that their agency provides transportation to and from medical and social service appointments are less likely to indicate that it is a problem. Respondents were asked to indicate reasons why transportation is a barrier. These results are presented in Table B-7. The two most frequently indicated reasons are that the respondent does not have enough money to pay for gas (54%) and the respondent does not have a car (50%). About one-third (31%) indicated that they have a car but cannot afford gas.

**Table B-7**  
**Reasons Transportation Is a Problem for Respondents**

	Number Responding	Percent Indicating 'Yes'
I have no money to pay for transportation.	26	54%
I have no car.	26	50%
I have a car, but I cannot pay for gas.	26	31%
My agency does not provide help with transportation *	26	23%
There is no public transportation in my town.	26	23%
I have a car, but it doesn't run.	26	12%
I have a car, but I cannot afford insurance.	26	8%
The Medical Assistance van doesn't go to my doctor's office.	26	4%

\* Five out of the six respondents indicating this barrier did not know or were not sure that their agency provided transportation services.

Three-quarters (75%) of the respondents indicated that they would use public transportation if it were available to them.

These results cast considerable light upon the findings reported by the Consumer Input Project for the North Central region. The Consumer Input Project reported that provider location was a greater concern than money or transportation for respondents from the North Central region. These results, as well as those from the Providers Survey reported in the next section, indicate that it is not provider location per se that is the primary barrier, but rather the financial hardship that clients face. Many of the clients in the North Central region live outside of the two (small) cities in the region (State College and Williamsport). Consequently, they must arrange for their own transportation in order to obtain services from providers. Often, those with limited resources do not own reliable vehicles or cannot afford gas. Many have difficulties traveling any distance (for appointments, and so on).

***Responses to Open-ended Question***

Twenty-two of the 82 respondents (27%) recorded a comment in the space provided on the survey. Seven of the 22 respondents (32%) thanked their case manager/case management agency or commented positively on them. Five of the 22 respondents (23%) indicated problems with service offerings, communication about services, or with the case manager. The remaining comments focused on services that are not currently provided by the agency or are not provided at a level that meets the needs of clients. The need for better transportation services, as well as services for eye care such as glasses, life insurance for adopted children, and counseling for family or friends affected by the disease was listed.

## ***Focus Group: Mothers of Children with AIDS***

On September 6, 2000, a focus group was held with two mothers of HIV-positive children. The focus group covered many of the same topics as the consumer survey and helps provide additional insights into the challenges facing consumers of HIV/AIDS case management services.

The mothers were first asked how satisfied they have been with the health care providers treating their HIV-positive children. Both reported that, on the whole, they were extremely happy, but one mother sometimes felt that her children were “guinea pigs” and that many of the tests seemed unnecessary.

When asked about other health problems their children with HIV/AIDS have, one mother reported that her son has speech problems and obsessive-compulsive disorder while her daughter has attention-deficit disorder. This mother had mixed opinions about the quality of care: “My son with speech problems had speech therapy for three years at least. We’re getting help but it doesn’t seem to be competent. The doctor that helped us with the OCD [obsessive-compulsive] disorder was extremely caring and helped us get on track. We had to put him on medicine and it has just done wonders.” The other mother mentioned eating disorders, rashes, and asthma; problems she said were related to HIV.

The mothers reported significant concerns about the availability and quality of dental care for their children with HIV/AIDS. According to one of the mothers, “We finally found [a dentist] up in New York State and he agreed he would work on [my daughter] but it would have to be after he was done with all his other patients. There was no way that he would let anybody see her come in. I did not go back. Plus, he wouldn’t take the Access card. We found a dentist, a periodontist in Scranton and she is excellent, excellent, excellent. It is a drive but it is well worth it. She cares about the children’s health more than just their teeth.”

The other mother had even more concerns, in that the dentist her children first attended “didn’t even put us in a room. They put us in a little tiny area that was a closet and the dentist came in with gloves, gown and mask and she didn’t stick any tools in [my son’s] mouth because she knew that he was HIV and she wanted to warn me. ... She never did put him in a chair.”

The mothers did not report any major concerns about vision care for their children with HIV/AIDS. One mother has not had to deal with this issue yet, while the other goes to Geisinger in Danville and did not indicate any problems. Likewise, neither mother has felt the need to use mental health services for themselves or other family members.

When asked about problems with confidentiality, both mothers reported that keeping their children’s illness a secret from other children has been a major challenge: “It gets to be really difficult keeping this secret. Your whole life revolves around these children that are HIV. ... We don’t want people to know and you share it with very few people and you just can’t have the support that would be wonderful to have but there is no choice. You need to protect these children in every way possible to get them a normal life as much as we can.” “Your doctor will tell you, don’t tell people at school because then all the kids are going to find out and then all the

parents are going to find out.” According to one of the mothers, sleepovers pose a particular problem: “You have to be so secretive when you have guests and it is time for them to take medicine before they go to bed because as I’m giving my little girl her medicine, who has no problems whatsoever and she doesn’t like she has a problem at all and these people say why is she on medicine, and you have to drum something up.”

Both mothers also reported that medication adherence is a major challenge for their HIV-positive children. One mother stated that her youngest child has trouble keeping the medication down and often throws up before school. According to the other mother, “Frankly, we just skip medicine when she has gone to somebody’s house after school, which isn’t a lot. But it just seemed like the only way to do it because it is so important to her.”

Both mothers stated that transportation difficulties are an issue affecting the health status of their children with HIV/AIDS, but that they have been able to deal with this issue. According to one mother, “Our pediatric infectious disease doctor is over 150 miles away. So if the kids are really sick it is difficult driving that far but it is well worth it because he does such an excellent job.” The other mother indicated that, “our school system has done awesome by the children in providing them a van that they go to school in.”

When asked about how well informed their children’s medical and dental providers were in regard to their children’s HIV/AIDS related problems, both mothers felt that the specialist their children see is “very up on it.” By contrast, one of the mothers felt that her family physician “took care of my other children for years and he does an excellent job but he knows nothing about HIV. We had to explain everything. ... They do excellent on the well baby care but if you are sick with HIV, they are not up on it.”

Both mothers said that the [HIV/AIDS agency] has been helpful to them and their children: “Any questions I have I can call. If they don’t know the answers, they’ll try to find them.” “They also get nutritional supplements for us and give us ideas of all different things to feed them when they won’t eat.”

When asked about ways to educate people about HIV/AIDS, one mother said that, “We need to start at an earlier age than fourth grade. ... People should be educating their children right from the start not to be biting because you can get a very bad disease when you bite somebody that has HIV. ... And when children walk over to other children and want to help them with their boo-boos. It is only the parents’ fault at large that a child would get HIV from another child because they ... were not warned about not touching other people’s blood.”

### ***C. Providers' Perspectives on the Needs of HIV/AIDS Infected & Affected Persons – Providers Survey***

In summer 2000, a questionnaire was distributed to 727 health and human service providers in the 12-county North Central region. A wide range of providers was surveyed, including dentists, physicians, nurses, home health and hospice providers, and human service providers. The survey asked providers about the number of HIV/AIDS infected and affected clients/patients being served, the demographic and health status characteristics of these clients/patients, the availability of a various services to persons living with or affected by HIV/AIDS, the use of these services, which services are most urgently needed, which services are underutilized, and barriers to accessing services. The survey also asked providers about their attitudes regarding the accessibility and quality of services provided to persons living with HIV/AIDS, as well as those using Medical Assistance, in their service area.

A total of 140 surveys were returned, although five were not usable for several reasons, such as the respondent being no longer in practice (i.e., retirement) or the organization was no longer in operation. Consequently, 135 out of the 722 surveys that were distributed to persons and organizations believed to be actively providing health and human services were returned, resulting in an effective response rate of 18.7%. However, there was considerable variation by type of provider, as indicated below in Table C-1. The response rate for human service providers was 41%. Examples of human service providers include AIDS Service Organizations (ASOs), drug and alcohol centers, counseling organizations, emergency assistance organizations, and housing organizations. Home health and hospice providers had the highest response rate at 56%, although only a small number were sampled. Dental service providers (dentists, periodontists) and physicians had the lowest response rates (11% and 14%, respectively), and nurses, nurse practitioners, and midwives had a response rate of 25%.

**Table C-1  
Response Rate by Type of Provider**

Provider	Number Mailed	Number Returned	Response Rate
Dental Services	133	15	11.3%
Physicians	453	65	14.3%
Nurses, Nurse Practitioners, Mid-wives	16	4	25.0%
Home Health & Hospice	9	5	55.6%
Human Services	111	46	41.4%
<b>Total</b>	<b>722</b>	<b>135</b>	<b>18.7%</b>

Table 1 in the Appendix provides a breakdown of the percentage of surveys returned within each of the 12 counties in the region. Because the distribution of providers is not even across the counties – for instance, Centre County has a larger percentage of dental service providers than would be expected by chance – this table lists the response rate within each county by type of provider.

Overall, nearly one-half (48%) of the returned surveys are from physicians. Over one-third (34%) of the surveys are from human service agencies. Surveys from dental service providers constitute 11% of the surveys that were returned. Surveys from nurses and home health and hospice agencies constitute 7% of the returned surveys.<sup>2</sup> These two groups are combined in analyses that break responses down by type of provider due to the small number in each group. Table C-2 presents the percentage of surveys returned from each type of provider.

**Table C-2**  
**Sample Composition: Type of Provider**

Provider	Number	Percent
Dental Services	15	11%
Physicians	65	48%
Nurses/Home Health & Hospice	9	7%
Human Services	46	34%
Total	135	100%

The next section presents results from the survey regarding the number of HIV/AIDS infected and affected persons being served by respondents and the demographic and health status characteristics of these clients and patients. Differences by type of provider are highlighted when the statistical analyses indicated that these differences are meaningful. When appropriate, differences in the characteristics of the HIV/AIDS population living in Williamsport (in Lycoming County) compared to the HIV/AIDS population living elsewhere in the 12-county NCDAC region are discussed. Appendix B provides a general description of the types of statistical procedures used in analyzing data from the providers survey.

### ***Who Do the Providers Serve?***

Overall, 72 providers (54% of those responding to the question) indicated that their organization/office currently provides services to people living with HIV/AIDS. Different types of providers were equally likely to serve the HIV/AIDS population. Nearly one-third (30%) of the respondents indicated that they do not currently provide services to people living with HIV/AIDS. It is likely that many of these respondents do in fact provide services to such clients but are not serving any people living with HIV/AIDS at the current time. About one-sixth (16%) of the respondents did not know if their organization was serving clients living with HIV/AIDS. Many of these respondents indicated that this is data that they do not collect from their clientele.

About three-fourths (78%) of the providers serving the HIV-infected population indicated the number of clients/patients living with HIV/AIDS they served during the 1999 fiscal year. On average, these 56 providers supplied services to two or three people each during this one-year period. However, this figure is somewhat misleading. Each of the human service providers

<sup>2</sup> In order to maintain brevity, respondents referred to as “nurses” include nurses, nurse practitioners, and midwives.

served 11 HIV/AIDS clients, on average, during the 1999 fiscal year, while dentists, physicians, nurses, and home health and hospice agencies served an average of two or three patients each during the one-year period.

In total, these 56 providers served 601 clients/patients living with HIV/AIDS during the 1999 fiscal year. Of course, some of the providers responding to the survey may have provided services to the same respondents; it is not possible to determine from the survey data the extent to which different providers were serving the same clients/patients.

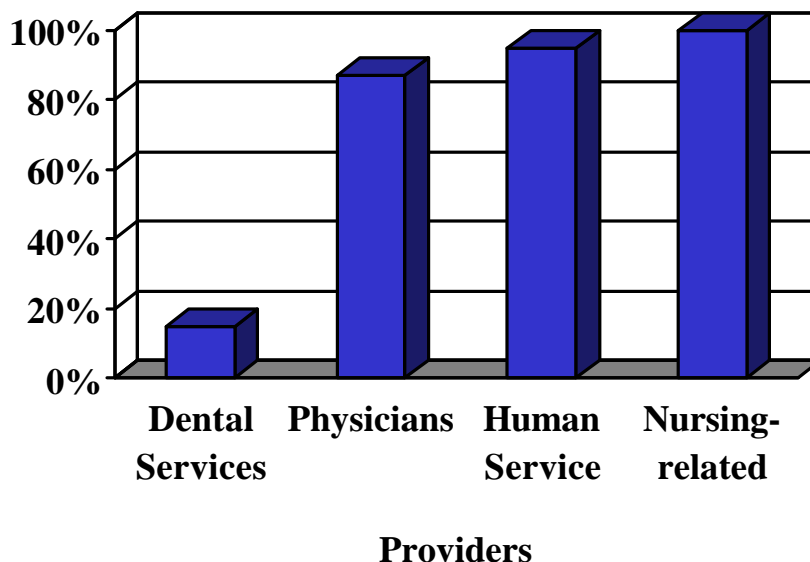
Somewhat fewer respondents indicated that they currently provide services to people affected by HIV/AIDS, such as a spouse or partner, parent, child, sibling, or caregiver. Overall, 59 providers (46% of those responding to the question) indicated that they serve this population. About one-quarter (25%) of the respondents indicated they did not know if their organization were providing services to people affected by HIV/AIDS, often because this information was not collected.

Again, the different types of providers were equally likely to serve this group. On average, respondents indicated that they served four clients or patients who are affected by HIV/AIDS. About three-fourths (74%) of the providers serving this population indicated the number of clients/patients affected by HIV/AIDS served by their organization during the 1999 fiscal year. Overall, these 44 providers served a total of 153 clients or patients who were affected by HIV/AIDS.

Results presented in the first section of this report indicated that oftentimes people living with HIV/AIDS in the North Central region have limited financial resources. Many rely on Medical Assistance in order to obtain health care services. Results from the providers survey indicate that 80% of the providers are currently accepting clients/patients paying through Medical Assistance – however, this estimate is somewhat biased because those providing dental services were considerably less likely to be accepting Medical Assistance patients than the other types of providers. Only 15% of the dental services providers (two out of the 13) indicated that they were currently accepting Medical Assistance patients. In contrast, 87% of the physicians, 95% of the human service organizations, and 100% of those associated with the nursing profession (nurses, home health and hospice) are currently accepting Medical Assistance clients/patients. The percentage of providers accepting Medical Assistance clients/patients is illustrated in Figure C-1.

The most frequently indicated reason for not accepting Medical Assistance patients is insufficient reimbursement rates, as indicated by 100% of the dental service providers and 50% of the physicians who were not currently accepting such clients. Too much paperwork was the second-most frequently indicated reason for not accepting such patients, as indicated by 91% of the dentists and 50% of the physicians. Two of the dental service providers (18%) indicated that Medical Assistance patients were not being accepted because of complaints from other patients. No other provider indicated this as a reason for not currently accepting Medical Assistance patients.

**Figure C-1  
Providers Accepting Medical Assistance Clients/Patients**



Respondents indicated some other reasons for not currently accepting such patients/clients: these reasons focused on the financial implications of the Medical Assistance bureaucracy (i.e., long reimbursement delays) as well as generalizations about the population (i.e., tendency not to show for appointments/general irresponsibility; such persons do not fit the practice). Three of 20 respondents (15%) who are not currently accepting Medical Assistance clients/patients indicated that they are not accepting any new patients. Table C-3 lists the reasons why respondents who are not currently accepting Medical Assistance are not doing so.

**Table C-3  
Reasons for Not Accepting Medical Assistance Clients/Patients (n=20)**

Topic	Number Indicating Reason
Insufficient reimbursement rates	15
Too much paperwork	14
Complaints from other clients/patients	2
Other	
Not accepting any new patients	3
Don't show for appointments/general irresponsibility	3
They don't fit our practice	2
Long reimbursement delays	1
Social support	1

Providers were asked to supply information about the demographic and health status characteristics of the clients/patients living with HIV/AIDS that they serve. As indicated above, 72 providers (56% of those responding to the question) indicated that their organization provides services to persons living with HIV/AIDS; however, six (6) of these providers did not serve any persons living with HIV/AIDS during the 1999 fiscal year. Consequently, only 66 providers were expected to answer the questions dealing with the demographic and health status characteristics of their HIV/AIDS clients/patients.

Most (88%) of these 66 providers answered the question asking about the age distribution of their HIV/AIDS clients/patients. The percentage of providers supplying services to HIV/AIDS patients in various age groups is presented in Table C-4.

Providers are most likely to serve HIV/AIDS clients/patients who are 30 to 39 years of age – 48% of the providers who currently have clients/patients living with HIV/AIDS indicated that they have at least one client in this age group. On average, these providers serve two people living with HIV/AIDS. One-third (33%) of the providers who have clients/patients living with HIV/AIDS indicated that their HIV/AIDS patients/clients are 40 to 49 years of age. These providers had two clients/patients in this age group, on average

**Table C-4**  
**Age of Persons Living with HIV/AIDS Receiving Services From Providers (n=58)**

*Providers indicating that they have clients/patients who are...*

Age	Number	Percent	Average Number HIV/AIDS Persons Served*
12 yrs or less	5	9%	2
13 – 19 yrs	9	16%	1
20 – 29 yrs	13	22%	3
30 – 39 yrs	28	48%	2
40 – 49 yrs	19	33%	2
50 – 59 yrs	10	17%	2
60 – 64 yrs	1	2%	2
65 or older	1	2%	1
Don't know	17	29%	—

\* Data from providers who indicated that they serve at least one person living with HIV/AIDS in each age group are included in the calculations.

About one-fifth of the providers indicated that they have patients/clients who are young adults or adolescents – 22% indicated they have clients/patients who are 20 to 29 years of age and 16% indicated having clients/patients who are 13 to 19 years of age. On average, providers served three people in the 20 to 29 years age group and one person in the 13 to 19 years age

group. Five providers (9%) indicated that they have clients/patients who are 12 years of age or younger; these five providers served two clients/patients each, on average.

Providers serving the Williamsport city area are more likely to serve younger clients/patients living with HIV/AIDS as well as the more mature age groups. One-third (33%) of the providers serving clients/patients living in Williamsport provide services to clients/patients who are adolescents (13 to 19 years) while only 8% of the other providers are serving this age group. Also, 50% of the providers with clients/patients living in Williamsport have clients/patients who are young adults (20 to 29 years). Only 10% of the other providers have clients/patients in this age range.

Between 39% and 50% of the providers with clients/patients living in the Williamsport have clients/patients who are 40 to 59 years of age. Less than one-quarter of the other providers have clients/patients in the 40 to 59 years age range.

Again, most (86%) of the 66 providers answered the question asking about the race/ethnicity of their HIV/AIDS clients/patients. The percentage of providers supplying services to HIV/AIDS patients in various groups is presented in Table C-5.

**Table C-5**  
**Race/Ethnicity of Persons Living with HIV/AIDS Receiving Services From Providers (n=57)**

*Providers indicating that they have clients/patients who are...*

Race/Ethnicity	Number	Percent	Average Number HIV/AIDS Persons Served*
African-American	20	35%	3
Asian/Pacific Islander	2	4%	1
Caucasian	34	60%	2
Hispanic	9	16%	1
Native American	1	2%	1
Other	2	4%	2
Don't know	17	30%	—

\* Data from providers who indicated that they serve at least one person living with HIV/AIDS in each group are included in these calculations.

The North Central region of Pennsylvania is primarily Caucasian (97%, based on the 1990 census). It is surprising to see that over one-third (35%) of the 57 providers have clients/patients living with HIV/AIDS who are African-American. Each of these providers serves three clients/patients, on average. However, the majority (70%) of these providers serve clients living in the Williamsport area. In fact, most (82%) of the providers with clients/patients living in Williamsport have clients who are African-American, while only 15% of the other providers serve this group. About one-sixth of the providers have clients who are Hispanic.

Nearly all (91%) of the 66 providers answered the question asking about the gender of their HIV/AIDS clients/patients. The prevalence of male, female, and transgendered clients/patients among providers is presented in Table C-6.

**Table C-6**  
**Gender of Persons Living with HIV/AIDS Receiving Services From Providers**  
*(n=60)*

*Providers indicating that they have clients/patients who are...*

Gender	Number	Percent	Average Number HIV/AIDS Persons Served*
Male	34	57%	2
Female	28	47%	2
Transgendered	2	3%	1
Don't know	17	28%	—

\* Data from providers who indicated that they serve at least one person living with HIV/AIDS in each group are included in these calculations.

Nearly one-half (47%) of the 60 providers supplying information about the gender of their HIV/AIDS clients/patients indicated that they have at least one female patient. Females are less likely to be among the clientele of providers who are not serving urban populations (i.e., those in State College or Williamsport). The majority of providers with clients/patients living in Williamsport and State College are serving at least one female client/patient (67% and 83%, respectively). In contrast, only 40% of providers not serving these urban populations indicated that at least one of their clients/patients is female. The two providers that have transgendered clients/patients serve the Williamsport area.

Again, most (89%) of the 66 providers answered the question asking about the residence of their HIV/AIDS clients/patients. The rural/urban residence of clients/patients is presented in Table C-7. For the purposes of this report, the State College and Williamsport city areas are considered urban and all areas in the region outside of these two city areas are considered rural.

**Table C-7**  
**Rural/Urban Residence of Persons Living with HIV/AIDS Receiving Services From Providers (n=59)**

*Providers indicating that they have clients/patients who...*

Residence of clients/patients	Number	Percent	Average Number HIV/AIDS Persons Served*
Live in urban areas only	17	29%	2
Live in urban and rural areas or region	8	13%	2
Live in rural areas only	23	39%	2
Don't know	11	19%	—
<b>Total</b>	<b>59</b>	<b>100%</b>	

\* Data from providers who indicated that they serve at least one person living with HIV/AIDS in each group are included in these calculations.

Over one-quarter (29%) of the providers have clients/patients in the State College or Williamsport city areas only. Another eight (13%) providers serve clients in these two urban areas as well as areas outside of these two (small) cities. About two-fifths (39%) of the providers have clients who reside only in the rural areas of the region (i.e., outside of the State College and Williamsport city areas).

Fifty-nine of the 66 providers (89%) answered the question asking about the types of health care coverage their HIV/AIDS clients/patients have, if any. These results are presented in Table C-8.

Less than one-third (30%) of the 59 providers have at least one client with private health insurance. In contrast, over one-half (58%) of the providers indicated that one or more of their HIV/AIDS clients/patients have Medical Assistance – this result is indicative of the financial hardship typifying this population. Moreover, 19% of the providers have at least one client who has no health insurance coverage. On average, these 11 providers have six clients/patients in this situation. Nearly two-thirds (64%) of the providers who have HIV/AIDS clients/patients with no health care coverage are human service agencies, which would explain why the average number of clients being served is unusually high (human service agencies are more likely to serve a large number of HIV/AIDS clients compared to the other providers).

**Table C-8**  
**Types of Health Care Coverage of Persons Living with HIV/AIDS and Receiving Services From Providers (n=59)**

*Providers indicating that they have clients/patients who have...*

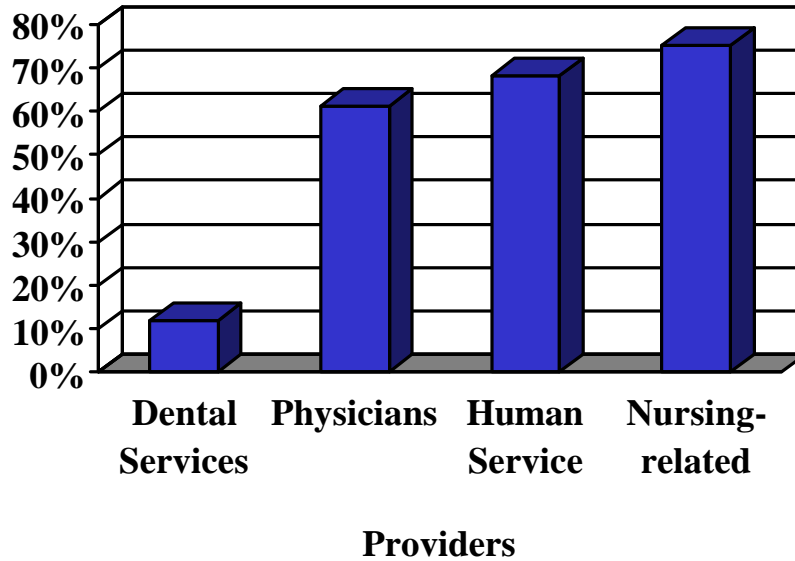
Types of Coverage	Number	Percent	Average Number HIV/AIDS Persons Served*
Private health insurance	18	30%	2
Medicare	12	20%	2
Medical Assistance	34	58%	2
Other	4	7%	3
None	11	19%	6
Don't know	19	32%	—

\* Data from providers who indicated that they serve at least one person living with HIV/AIDS in each group are included in these calculations.

Those providing dental services are less likely to have any clients using Medical Assistance. Only one out of the eight providers (12%) supplying dental services have HIV/AIDS patients using Medical Assistance. In contrast, 61% of the physicians, 68% of the human service providers, and 75% of those providing home health & hospice/nursing services have at least one HIV/AIDS client using Medical Assistance (see Figure C-2). In addition, those providing dental services are less likely to have any patients actually using Medical Assistance to pay for their services. Results presented earlier in this section clearly indicate that providers supplying dental services are less likely to be currently accepting new patients paying through Medical Assistance (refer again to Figure C-1). Consequently, not only are providers of dental services less likely to have Medical Assistance patients on their caseload, but they are also less likely to be accepting such patients. These results are indicative of a shortage of providers supplying dental services to Medical Assistance patients.

Fifty-nine of the 66 providers (89%) answered the question asking about the health status of provider's HIV/AIDS clients/patients. These results are presented in Table C-9.

**Figure C-2**  
**Providers with Clients/Patients Using Medical Assistance**



**Table C-9**  
**Health Status of Persons Living with HIV/AIDS Receiving Services From Providers**  
*(n=59)*

*Providers indicating that they have clients/patients who are...*

General Health Status	Number	Percent	Average Number HIV/AIDS Persons Served*
Very sick	14	24%	2
Somewhat sick	14	24%	4
Somewhat healthy	30	51%	4
Very healthy	17	29%	2
Don't know	19	32%	—

\* Data from providers who indicated that they serve at least one person living with HIV/AIDS in each group are included in these calculations.

About one-half (51%) of the providers with HIV/AIDS clients/patients have at least one who is somewhat healthy – on average, these organizations have four clients/patients they consider somewhat healthy. Nearly one-third (29%) have at least one client who is very healthy. In fact, on a 10-point scale with ‘1’ indicating very sick and ‘10’ indicating very healthy, providers rated the general health status of the HIV/AIDS clients/patients as a 6.5.

Despite advances in treatment over the past three years, substantial numbers of persons living with HIV/AIDS are quite sick. Referring back to Table C-8, one-quarter of the providers have clients who are very sick or somewhat sick, respectively. In the latter case, a substantial number of patients/clients within each of the provider organizations are sick – on average, four clients/patients are somewhat sick in these organizations.

Home health & hospice/nurses and human service agencies are more likely to be serving HIV/AIDS clients/patients who are very sick or somewhat sick. Three out of the four (75%) home health & hospice agencies/nurses responding to the question indicated that at least one of their patients/clients is very sick. Also, close to one-half of the human service organizations (47%) have at least one very sick HIV/AIDS client. Similarly, two of the four (50%) home health & hospice/nurses and 42% of the human service agencies have at least one HIV/AIDS client who is somewhat sick. In contrast, only 7% of the physicians and none (0%) of the dental service providers have an HIV/AIDS client who is very sick. About one-seventh (15%) of the physicians and none (0%) of the dental service providers have at least one client who is somewhat sick.

Only 14% of the respondents did not think that there is a difference in the health status of the HIV/AIDS clients/patients entering their organization over the last three years compared to those entering prior to 1997 (after the introduction of the more aggressive combination therapies). Most (60%) of the respondents indicated that they did not know whether there was a difference.

However, one-quarter (25%) of the providers with HIV/AIDS clients/patients thought that there is a difference in the health status of their HIV-infected clients who have entered their organization over the last three years. Most (71%) of the respondents indicating this to be the case felt that clients entering over the past three years are healthier than those entering prior to 1997. Over two-fifths (43%) indicated that persons living with HIV/AIDS are more likely to show an improvement in health status after entering compared to those who entered prior to 1997.

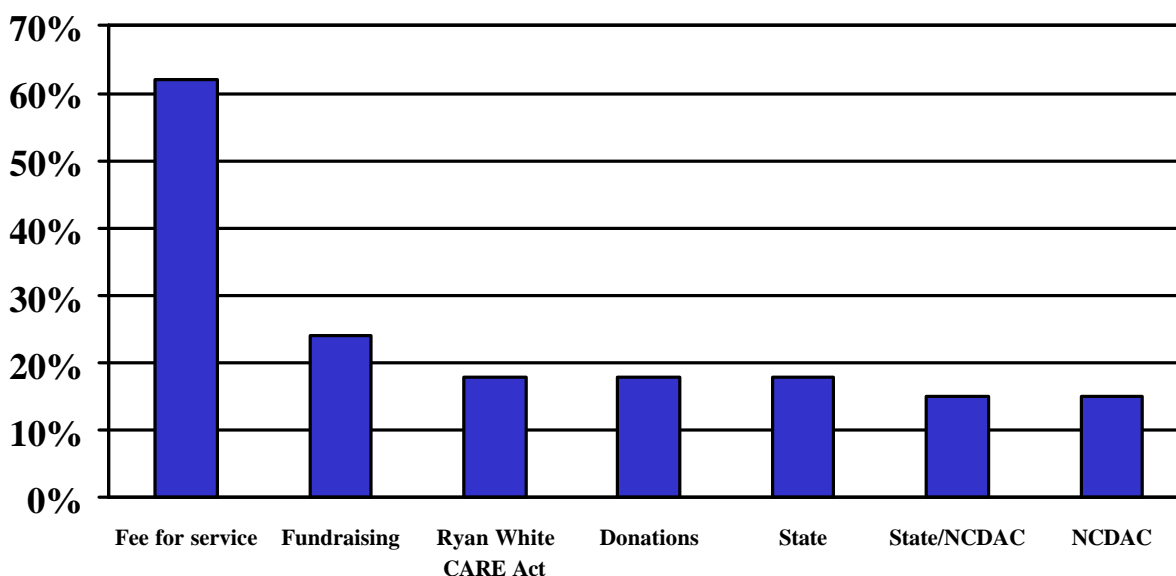
### ***How are Providers Supplying Services to Persons Living with HIV/AIDS?***

Providers were asked to indicate the percentage of their organization's 1999 fiscal budget that was spent on services to people living with HIV/AIDS, as well as on services for persons affected by HIV/AIDS. On average, one percent of the 1999 fiscal budget was used for such services among those providers whose organization did budget some dollars for such services. However, two-fifths of the providers who are currently providing services to people living with or affected by HIV/AIDS indicated that none (0%) of their budget was marked for such services. At the other extreme, a few organizations used 90% or more of their budget on services for persons living with HIV/AIDS, and one indicated that 25% of their budget was used for services for persons affected by HIV/AIDS.

Respondents were asked to indicate the funding sources their organization uses to provide services for people living with or affected by HIV/AIDS. Among the 34 providers who receive

funding or payment for this purpose, the most frequently mentioned funding source is fee for services provided (62%). Other funding sources include the organization's own fundraising efforts (24%), Ryan White CARE Act funds through NCDAC (18%), donations (18%), state funds other than through NCDAC (18%), state funds through NCDAC (15%), and NCDAC (15%). Less frequently mentioned funding sources include federal funds other than through NCDAC (9%), United Way (9%), foundations (9%), HOPWA through NCDAC (6%), and corporations (3%). No provider (0%) indicated that they get funds from their city for such services. The frequency with which respondents use these various funding sources is portrayed in Figure C-3.

**Figure C-3  
Funding Sources for Services to HIV/AIDS Infected and Affected Persons**



About one-tenth of the human service, home health & hospice/nurses, and physicians indicated that their organization plans on providing new services for people living with or affected by HIV/AIDS over the next three years (13%, 11%, and 9%, respectively). None (0%) of the dentists, however, plan on providing new services for this population.

Among those providers who indicated that their organization provides services to people living with HIV/AIDS, 11% (seven providers) thought that one or two of their clients/patients rely solely on their organization for AIDS-related services. Five of the seven providers are physicians and two are human service agencies. Four of these seven providers do not have any HIV/AIDS clients/patients living in State College or Williamsport – all of their clients/patients live in rural areas of the region. Three of the seven providers indicated that their organization

could not meet all of the health and welfare needs of these clients/patients. Needs not being met included access to dental providers, therapists, local access to an infectious disease specialist, money for medications, and adequate legal representation.

On average, respondents indicated that their HIV/AIDS clients/patients travel no more than 15 miles (one way) to receive their services. However, one provider indicated that at least one of their HIV/AIDS clients/patients travels 180 miles for their services, and five providers indicated that some travel 50 to 65 miles for services.

One-quarter (25%) of the providers with HIV/AIDS clients/patients indicated that representatives from their organization travel to the homes of clients/patients living with HIV/AIDS. Three-fourths (75%) of the home health & hospice/nurses and 53% of the human service agencies indicated that their representatives traveled to clients' homes. One physician (4%) also indicated that a representative from the office travels to the home of HIV/AIDS patients.

### ***Are Services Available & Adequate for Persons Living with or Affected By HIV/AIDS?***

Providers were asked to indicate the extent to which an array of medical, dental, and other health and human services were available and adequate for persons living with or affected by HIV/AIDS. This information is used to determine which services are available and adequate in the region as a whole, which are available but not adequate, and which are not available.<sup>3</sup> Appendix Table 2 lists the percentage of respondents indicating each of these choices for each of the services listed in the questionnaire. The results are summarized here. Appendix Tables 3-7 provide this information for each of the regions within the North Central region served by the five case management agencies funded through the NCDAC.

Typically, a substantial percentage of respondents were not sure about the availability of any particular service. For the most part, the remaining respondents indicated that services are available and adequate. However, there are some notable exceptions:

- *Dental care, subsidized* – 32% of the respondents indicated that this service is available but not adequate; 16% indicated it is not available. Only 12% indicated that it is available and adequate.
- *Mental health services, outpatient* – 33% of the respondents indicated that this is available but not adequate; only 3% indicated the service is not available. At the same time, 33% indicated that it is available and adequate.

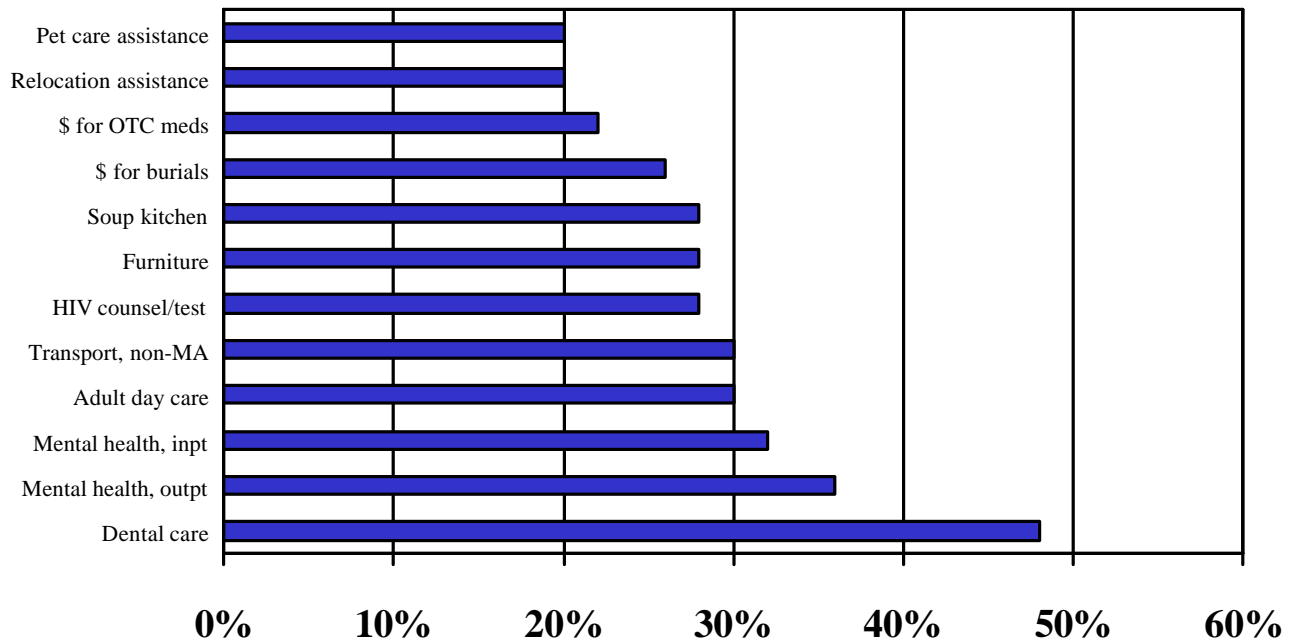
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<sup>3</sup> Only those providers who indicated that they serve clients/patients who are living with or affected by HIV/AIDS are included in this analysis. Results from a series of statistical analyses indicated that respondents who indicated that they do not serve this population have significantly different responses to this series of questions. Typically, the latter group of providers was more likely to indicate that they were not sure about the availability of a service or that a service was not available than providers serving HIV/AIDS infected and affected populations.

- *Mental health services, inpatient* – 23% indicated that this is available but not adequate, and another 9% indicated it is not available. However, 38% indicated that it is available and adequate.
- *Day care for adults* – 17% indicated that this service is available but not adequate, and 13% indicated that it is not available. Only 6% indicated that it is available and adequate.
- *Transportation, non-Medicaid reimbursed* – 19% indicated that this service is available but not adequate, and another 11% indicated that it is not available. Only 9% indicated that it is available and adequate.
- *HIV counseling/testing* – 18% indicated that this service is available but not adequate, and 10% indicated that it is not available. Only 14% indicated that it is available and adequate.
- *Furniture/household items* – 18% indicated that this service is available but not adequate, and 10% indicated that it is not available. 14% indicated that the service is available and adequate.
- *Soup kitchen* – 23% indicated that this service is not available, and 5% indicated it is available but not adequate. 21% indicated that it is available and adequate.
- *Financial assistance for burials or funerals* – 13% indicated that this service is not available, and another 13% indicated that it is available but not adequate. Only 8% indicated that it is available and adequate.
- *Financial assistance for over-the-counter medications* – 16% indicated that this is available but not adequate, and 6% indicated it is not available. Only 13% indicated that this service is available and adequate.
- *Relocation/moving assistance* – 11% indicated that this service is available but not adequate, and another 9% indicated that it is not available. Only 5% indicated that it is available and adequate.
- *Pet care assistance* – 14% indicated that this is not available, and another 6% indicated that the service is available but not adequate. Only 5% indicated that it is available.

Figure C-4 depicts the percentage of providers indicating that these services are either available but not adequate or not available at all in their service area. The shortage of dental and mental health services in the region is partially explained by the fact that one of the counties in the North Central region (Bradford) is considered a (population-based) dental health professional shortage area and three counties are (geographic-based) mental health professional shortage areas (Tioga, Clinton, and Lycoming); this information, prepared by the Pennsylvania Office of Rural Health, is discussed more fully in the first section of this report.

**Figure C-4**  
**Services Not Available or Not Adequate at Available Levels**



A substantial percentage of respondents indicated that several other services are not adequate. These services are:

- *Alcohol treatment, inpatient* – 21% of the respondents indicated that this service is available but not adequate, although 30% indicated that it is available and adequate.
- *Alcohol treatment, outpatient* – 18% indicated that it is available but not adequate, although 37% indicated that it is available and adequate.
- *Drug treatment, inpatient* – 21% indicated that it is available but not adequate, although 35% indicated that it is available and adequate.
- *Drug treatment, outpatient* – 18% indicated that this service is available but not adequate, although 44% indicated that it is available and adequate.
- *Eyeglasses* – 18% indicated that this service is available but not adequate, while 32% indicated that it is available and adequate.
- *Eye care* – 16% indicated that this service is available but not adequate, while 33% indicated that it is available and adequate.

- *Employment assistance* – 16% of the respondents indicated that this service is available but not adequate, although 24% indicated that it is available and adequate.
- *Rental/housing assistance* – 16% of the respondents indicated that this service is available but not adequate, although 24% indicated that it is available and adequate.

The services listed above do not appear to be adequate for the needs of the HIV/AIDS population in the region, as a whole. In addition, providers were asked to indicate three services that were the most urgently needed in their service area. Providers listed a wide range of services, and all but three of the services listed above are considered to be urgently needed by at least one provider.<sup>4</sup>

Dental care was listed as the most urgently needed service by the greatest number of providers. The following services are considered to be the most urgently needed by three or more providers:

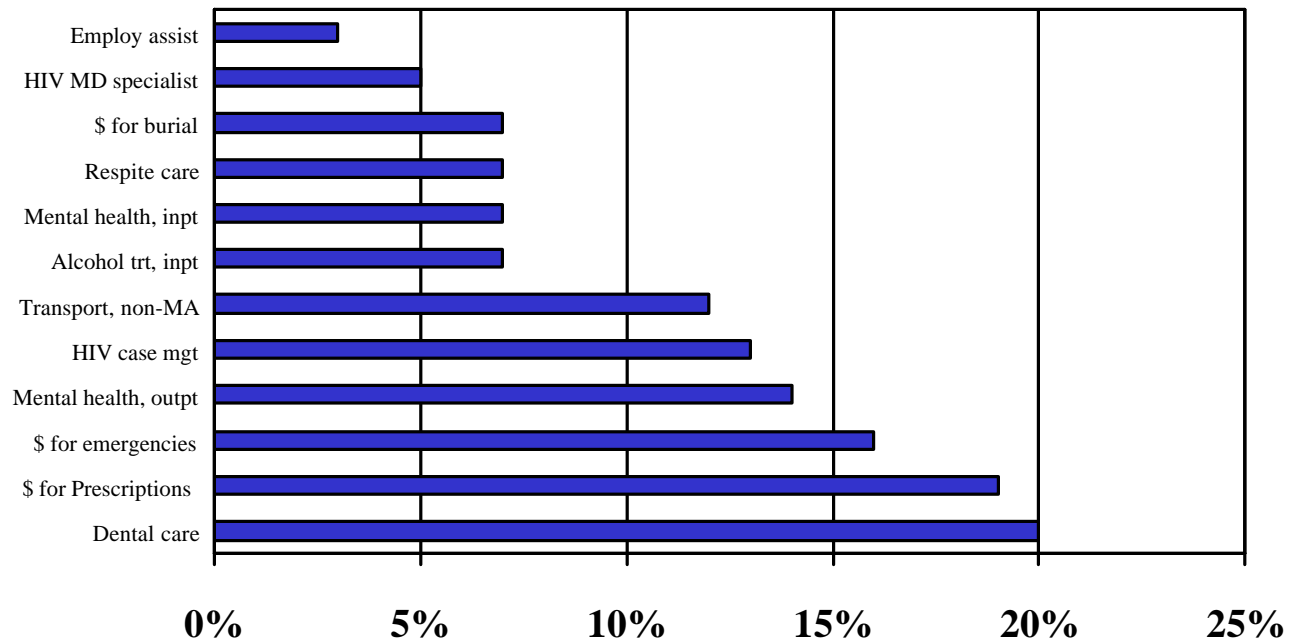
- Dental care
- Financial assistance for prescribed medications
- HIV medical specialist care
- Transportation services, non-Medicaid reimbursed
- Mental health services, outpatient
- Alcohol treatment, inpatient
- Case management for HIV
- Employment assistance
- Financial assistance for emergencies
- Respite care
- Financial assistance for burials/funerals
- Mental health services, inpatient

Figure C-5 presents the percentage of providers who indicated that they provide these urgently needed services. Between 3% and 20% of the 64 providers answering this series of questions provide these urgently needed services. One-fifth of the respondents provide dental services. This result is somewhat surprising given the results reported above indicating that the availability of dental services is not adequate or not available. Apparently, human service providers are supplying subsidized dental care as well as dental service providers. Analyses indicate that five of the 26 human service providers (19%) are supplying subsidized dental care as well as all seven (100%) of the dental service providers answering this series of questions on the survey. Also, one of the 27 physicians (4%) answering the question indicated that subsidized dental care is provided by their organization.

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<sup>4</sup> The three services that were not included in respondent's lists of what was most urgently needed were relocation/moving assistance, furniture/household items, and outpatient drug treatment.

**Figure C-5  
Providers Supplying Urgently Needed Services**



About one-fifth (19%) of the providers indicated that they supply financial assistance for prescribed medications. This percentage also seems high given the critical need for this service. Eleven providers out of the 58 responding to this question indicated that this service is provided – 10 human service agencies and one physician.

Only 5% of the providers supply HIV medical specialist care. Also, only 5% of the providers supply inpatient mental health services and 7% provide inpatient alcohol treatment. Mental health outpatient services are provided by a larger percentage of respondents – 14%. This service is provided by a mixture of human service agency, physician, and home health & hospice/nurses providers.

***Are Available Services Underutilized?***

Providers were asked if any of the services listed in Appendix Table 2 are available but underutilized in their service area by persons living with or affected by HIV/AIDS. While most (82%) of the providers who provide services to people living with or affected by HIV/AIDS indicated that they did not know, nine (12%) providers indicated that some services are underutilized. Providers were asked to list services that are underutilized and to suggest a reason for this, if possible.

Respondents indicated that the following services are underutilized by persons living with or affected by HIV/AIDS in their service area:

- Drug and alcohol counseling
- Food bank/nutritional services
- Utility and fuel assistance
- HIV medical specialist care
- Medicaid
- Mental health services
- Spiritual care
- Case management

Most of these services are also listed as among those that are most urgently needed. Six of the nine providers offered several reasons why these services are underutilized. Two of the six attributed it to a lack of awareness of services on the part of people living with or affected by HIV/AIDS. According to one respondent, “Probably individuals [have] eligibility for Medicaid but don’t know it is available.”

Two respondents attributed underutilization of services to a lack of awareness on the part of providers. According to one respondent, “Health providers themselves seem to be uneducated in the services that are available so they cannot or will not pass information on to those affected by HIV/AIDS.” The other respondent stated that, “The persons offering these services generally have inadequate knowledge about HIV; and are insensitive to the issues that are specific to individuals infected and affected with HIV/AIDS.”

One respondent attributed underutilization to confidentiality concerns: “There are services available in the community that are underutilized due to confidentiality concerns, i.e., county D&A [drug and alcohol] counseling, food bank.”

One respondent felt that drug and alcohol services are underutilized because people affected by HIV/AIDS did not want to utilize such services: “People with HIV tend to use more D&A [drugs and alcohol] as stress management when health concerns should cause a decrease in such use.”

### ***What Are the Barriers to Service Access and Use?***

The questionnaire contained a series of attitudinal questions focusing on barriers to access among various clients/patient groups, including those with HIV/AIDS and Medical Assistance. Providers were asked to indicate for each statement whether they strongly agreed, agreed, were neutral, disagreed, strongly disagreed, or did not know. Responses were coded so that strongly agree equals ‘1’, agree equals ‘2’, neutral equals ‘3’, disagree equals ‘4’, and strongly disagree equals ‘5.’ “Don’t know” responses were excluded from the calculations for that question. Provider responses are presented in Table C-10.

**Table C-10**  
**Attitudes About the Provision of Health and Human Services in Providers Service Areas**

	Number Responding	Average Response
A low level of literacy is a problem among the HIV-infected population.	70	3.3
Maintaining the confidentiality of the HIV status for clients living with HIV/AIDS is a priority for provider organizations.	98	1.7
Medical Assistance clients (in general) receive about the same quality of care as others.	96	2.6
People living with HIV/AIDS receive about the same quality of care as others.	82	2.6
Medical Assistance clients (in general) wait about the same amount of time to receive an appointment with a provider as others.	89	2.3
People living with HIV/AIDS wait about the same amount of time to receive an appointment with a provider as others.	75	2.1
Providers are hesitant to serve HIV-infected intravenous (IV) drug users because their presence in the waiting room makes other clients feel uncomfortable.	78	3.3
Providers are hesitant to serve HIV-infected people who have recently relocated to the area.	81	3.3
People living with HIV/AIDS in rural areas have <u>more difficulty</u> accessing providers than those living in more urban areas.	84	2.2
HIV-infected African-Americans have <u>more difficulty</u> accessing providers than those who are Caucasian.	69	3.3
Appropriate primary health care services are adequate for people living with HIV/AIDS.	79	2.7
Mental health and related support services are adequate for people <u>living with</u> HIV/AIDS.	72	3.1
Mental health and related support services are adequate for people <u>affected by</u> HIV/AIDS.	71	3.2
HIV-infected persons entering the community after being in prison is a concern.	83	2.3
Primary care providers have an adequate understanding of HIV/AIDS.	88	2.9
Dentists and other dental care workers have an adequate understanding of HIV/AIDS.	81	3.0

1=strongly agree; 2=agree; 3=neutral; 4=disagree; 5=strongly disagree

Providers tended to disagree with the statement that low levels of literacy is a problem among the HIV-infected population – over 50% disagreed or strongly disagreed with the statement. There was very strong agreement among providers that maintaining the confidentiality of the HIV status of clients is a priority; 88% agreed or strongly agreed with the statement.

Providers also tended to agree that those using Medical Assistance and those living with HIV/AIDS receive the same quality of care as others, although some disagreement was evident – 31% and 21% indicated that Medical Assistance and HIV-infected persons, respectively, do not receive the same quality of care as others. Dental care providers and human service providers were more likely to indicate that Medical Assistance clients/patients do not receive the same quality of care as others. Compared to the other types of providers, human service providers were more likely to indicate that people living with HIV/AIDS do not receive the same quality of care as others.

Providers also tended to agree that those using Medical Assistance and persons living with HIV/AIDS wait about the same amount of time to receive an appointment as others – only 17% and 20% disagreed, respectively. Human service providers were less likely to agree that Medical Assistance waited the same amount of time to receive an appointment with a provider as others.

Providers tended to disagree with the statement that providers are hesitant to serve HIV-infected drug users because their presence in the waiting room makes other clients feel uncomfortable – however, 26% felt this statement was accurate. Also, providers tended to disagree with the statement that there is hesitation to serve HIV-infected persons who have recently relocated to the community; again, however, one-third (33%) of the respondents indicated that this does occur in their service area.

Providers showed fairly strong agreement that persons with HIV/AIDS living in rural areas have more difficulties accessing providers than those in urban areas – 80% of the respondents agreed with the statement. Those providing dental services were less likely to agree with this assessment than the other providers. Respondents tended to disagree with the statement that HIV-infected African-Americans have more difficulties accessing providers than Caucasians – although 26% of the respondents thought this assessment was accurate.

Providers tended to agree that appropriate primary health care services are adequate for persons living with HIV/AIDS, although about one-quarter (24%) disagreed that these services are adequate. Providers with clients/patients living in Williamsport were less likely to agree that appropriate primary care services are adequate for persons living with HIV/AIDS.

Providers were not as positive in their assessment of mental health services. Overall, providers were unsure or disagreed with the statement that mental health services for HIV-infected and affected persons are adequate. Nevertheless, a substantial minority of providers indicated that these services are adequate for HIV infected and affected persons (36% and 34%, respectively).

Providers showed fairly strong agreement that HIV-infected persons entering the community after being in prison is a concern – less than 10% disagreed with this statement.

Providers were split in their assessment of the level of understanding that primary care providers and dentists/other dental workers have of HIV/AIDS. About two-fifths (42% and 37%, respectively) agreed that the level of understanding among these two groups of providers is adequate. Similar percentages indicated the opposite – that the level of understanding among primary care providers and dentists/other dental care workers of HIV/AIDS is not adequate (36% and 34%, respectively). Dental care providers were more likely to indicate that the level of understanding among primary care providers and dentists/other dental care workers is adequate than physicians or human service providers.

In addition, providers were asked to indicate what some of the greatest barriers are to obtaining services in their service area for persons living with or affected by HIV/AIDS. Results are presented in Table C-11.

The greatest barriers to obtaining services for persons infected or affected by HIV/AIDS are financial and physical barriers, and barriers imposed by community attitudes about such persons. About two-thirds of the providers indicated that the lack of money or insurance coverage and the lack of knowledge about HIV/AIDS among the general public are some of the greatest barriers (67% and 64%, respectively). In addition, over one-half of the providers felt that negative attitudes among the general public about people living with HIV/AIDS (54%) and about people who have/are using drugs (51%) are barriers. Related to this, providers felt that client concerns about confidentiality and being afraid that people will learn of their HIV/AIDS diagnosis act as barriers to obtaining services, as indicated by 53% of the providers. Human service providers were more likely to indicate this as a barrier than the other providers.

Transportation difficulties are a serious barrier, as indicated by 54% of the providers; human service providers were more likely to perceive this as a major barrier as well. This barrier is strongly related to the amount of monetary resources available to the client/patient. Services not being conveniently located was indicated as a barrier by well over one-third (39%) of the providers. This situation aggravates barriers for persons with transportation and monetary difficulties.

About one-half (51%) of the providers thought that some persons who are infected or affected by HIV/AIDS do not access services because they are too embarrassed or too proud to apply for such services; human service providers were more likely to indicate this as a reason than the other providers. One-half (50%) of the providers indicated that some do not know how to apply for services. Inadequate dissemination of information about existing services was indicated by 46% of the providers as one of the greatest barriers; human service providers were more likely to consider this a barrier compared to the other providers. Also, about one-quarter (28%) of the providers indicated that lack of inter-agency cooperation was a barrier. These latter two barriers exacerbate the situation whereby persons do not know how to apply for services.

**Table C-11**  
**Barriers to Obtaining Services for Persons Living With or Affected by HIV/AIDS\***

Barrier	Percent Indicating Reason
<i>Financial or Physical Barriers</i>	
Lack of money or insurance coverage	67%
Transportation difficulties	54%
Services are not conveniently located	39%
<i>Organizational Barriers</i>	
Inadequate dissemination of information about existing services	46%
Lack of inter-agency cooperation	28%
Provider office hours are too limited	4%
<i>Barriers in the Community</i>	
Lack of knowledge about HIV/AIDS among the general public	64%
Negative attitudes about people living with HIV/AIDS among the general public	54%
Negative attitudes about people with past or present IV drug use	51%
Sexual orientation discrimination	36%
Lack of knowledge about HIV/AIDS among providers/staff	30%
Negative provider/staff attitudes toward HIV/AIDS clients	28%
Racial/ethnic discrimination	25%
<i>Client Concerns</i>	
Concerns about client confidentiality/Afraid people will learn of HIV/AIDS diagnosis	53%
Too embarrassed or proud to apply for service	51%
Don't know how to apply for service	50%
<i>Other</i>	6%
<i>Don't know</i>	18%

\* Only providers who indicated that they provide services to HIV/AIDS infected or affected are included in the calculations. The sample size ranges from 67 to 68.

About one-third of the providers indicated that sexual orientation discrimination and lack of knowledge about HIV/AIDS among providers/staff are major barriers (36% and 30%, respectively). Racial/ethnic discrimination was indicated as a major barrier by 25% of the providers.

About one-quarter (28%) of the providers felt that negative provider/staff attitudes toward HIV/AIDS clients is a major barrier. Providers who serve clients/patients from Williamsport or State College are more likely to perceive negative provider attitudes as a barrier than providers who do not have any clients/patients living in these two cities.

***How Can These Barriers Be Overcome?***

Providers were asked if they had any suggestions for dealing with these barriers. Sixteen respondents provided a response. Nine of the 15 providers suggested some type of education, either for providers, students, or the general public. According to one respondent, “Educate our physicians and health care providers. There is such a stigmatism in regards to whom may have HIV/AIDS. Middle class Caucasians are not even acknowledged as possibly having the disease so testing isn’t suggested.” According to another respondent, there should be “teen education about safe practices.”

Respondents had a variety of other suggestions as well. One provider felt that there should be “an AIDS clinic with multidisciplinary services all located in one area.” Another suggested publicizing the names of doctors who are willing to treat HIV/AIDS patients. One respondent suggested a three-part strategy: “1. Community-wise, true leaders need to understand the illness. 2. Develop effective preventive services through DOH [Department of Health]. 3. Report HIV infections to DOH to adequately know the numbers of potential ill people & track them.”

One respondent felt there should be greater focus on prevention: “HIV is almost always preventable. If HIV is prevented, we don’t have to worry about barriers. For people presently HIV +, the only barrier I can think of is money, but this is certainly not unique to HIV.”

One respondent was skeptical about the possibility of dealing with barriers to obtaining services: “Good luck – we can’t get dentists to serve MA [Medical Assistance], especially, expect HIV clinic would be next to impossible. Maybe via county dental association?”

As indicated above, educating the public about HIV/AIDS is a critical component of strategies seeking to deal with the negative impact of public attitudes and the lack of knowledge about the disease. Providers were asked if they had any ideas on ways to educate the public about HIV/AIDS. Twenty-six respondents provided a response to this question. These ideas are summarized in Table C-12.

**Table C-12  
Strategies for Educating the Public About HIV/AIDS**

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Use the mass media
Additional HIV/AIDS education in the schools
Use seminars, lectures, or public forums
Get those living with or affected by HIV/AIDS involved in education
More HIV/AIDS prevention education

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Seven respondents suggested use of the mass media – television, radio, newspapers, and the Internet. Two of these six respondents suggested using public service announcements on TV or radio.

Four of the providers suggested additional HIV/AIDS education in the schools. According to one: "More education in our schools is an absolute must." Four respondents suggested using seminars, lectures, or public forums. One of these providers suggested holding seminars or lectures at area churches and outpatient clinics. Three respondents suggested getting those living with or affected by HIV/AIDS more involved in the education process. According to one, it would be "useful for victims (infected people and families) to be open in their trials and to encourage behaviors which prevent the disease." Two other providers recommended more HIV/AIDS prevention education in general.

One provider suggested asking doctors to help educate the public: "More doctors that can handle HIV/AIDS and can educate families, clients." Another suggested involving drug and alcohol agencies in HIV/AIDS education. One provider recommended targeting at-risk populations in education efforts: "Targeting at-risk populations through individual or small group outreach (ex. Mansfield University students)." Another recommended taking a regional approach to HIV/AIDS education: "More organized approach to regional education – we have the venues – World AIDS Day, AIDS Walks--need to work together to get the word out with involvement at all levels!"

#### ***D. Providers' Perspectives on the Needs of HIV/AIDS Infected & Affected Persons – Focus Groups***

This section synthesizes results from three focus groups and one key informant interview held with health and human service providers as well as case managers from NCDAC-funded case management agencies. A focus group was held on August 22, 2000 with representatives of one of the regional health systems. Focus group participants included a doctor who is an infectious disease specialist, a pharmacist, a social worker, and a chaplain. A focus group was held on August 23, 2000 with social service providers. Participants included two Department of Health workers, two drug and alcohol representatives, and one family planning representative. A third focus group was held on August 30, 2000 with several HIV/AIDS case managers. A key informant interview was held on September 7, 2000 with a physician who specializes in internal medicine and serves a large number of HIV/AIDS patients.

The focus groups and key informant interview covered the ten major topic areas shown below, with several probes and sub-questions. Some of the specific questions asked within each topic area differed from one focus group to another, as well as between the focus groups and the key informant interview. A few topic areas were not covered at all in some groups or in the interview because the questions were not considered appropriate for that group.

<b><i>Focus Group and Interview Topic Areas</i></b>
1. Do your HIV/AIDS clients have access to adequate medical care?
2. Is there a need for nurse case managers?
3. What are the major health needs of your HIV/AIDS clients when they first enter care?
4. What are the major issues affecting your clients' health status?
5. What are some barriers to your HIV/AIDS clients' care?
6. What is the availability of mental health care in your service area for HIV/AIDS patients?
7. What is the availability of dental care in your service area for HIV/AIDS patients and their caregivers?
8. What is the availability of vision care in your service area for HIV/AIDS patients?
9. Are there other services your clients need that are not readily accessible?
10. Are you aware of people with HIV/AIDS in your service area who are not part of your provider network?

## ***1. Do Your HIV/AIDS Clients Have Access to Adequate Medical Care?***

Participants in one of the focus groups generally felt that HIV/AIDS clients had access to primary medical care. According to one participant, “In 12 years in the business I have not had anybody who couldn’t get care somewhere. It is not that we can’t get them connected. It is that sometimes they fall away on their own.” Participants in another group felt that access to primary medical care was good in Centre County, particularly State College, and in Clinton County, where clients can go to Danville or Williamsport. However, they also felt that there were problems in more remote areas within the region. According to one case manager, “We have one general practitioner, one, who is willing to see HIV clients in Wellsboro.”

Focus group participants felt that access to specialists was more problematic. Participants in one of the groups stated that transportation to specialists in places such as Pittsburgh and Hershey was a major issue for some of their clients. According to one participant, “We don’t have an infectious disease specialist within an hour-and-a-half.” One participant felt that a failure on the part of HIV/AIDS clients to show up for appointments had “ruined” the relationship with infectious disease specialists serving their area, and that these specialists were only willing to accept a referral from another physician if a patient had “established a commitment to attend appointments.”

A participant in the case managers focus group stated that, “I just lost our first client yesterday but what he went through in the last three months I can’t describe. The ignorance and lack of compassion and the narrow mindedness that I witnessed in the medical facility ..., the care that he did not receive. He was turned away from the emergency room because he had AIDS. They said that they couldn’t help him, to go all the way to ... at 11:30 at night.”

With respect to coordination of care between primary care doctors and specialists, participants felt that coordination was fairly good. One person indicated that difficulties were more patient-derived than doctor-derived. On the other hand, participants in another group felt that coordination has been a problem at times. According to one of these participants, the largest problem has been with clients who switch insurance companies and have an appointment scheduled with a specialist before receiving a referral from their new primary care physician.

Participants in two of the focus groups generally did not perceive significant differences in the quality of care available to Medical Assistance versus other patients. However, one participant stated that, “sometimes Medical Assistance patients are slighted by some physicians and service providers although I think that is more an individual, personal issue than an institutional issue.” A participant indicated that a regional health care network usually refers low-income HIV patients to their own HIV social worker, who works with patients to sign them up for Medical Assistance.

On the other hand, a participant in the third focus group felt that there was a significant difference in care for Medical Assistance versus other patients: “To be a Medical Assistance client in Centre County, they can’t just call up and get a physician. They have to call Social Services, disclose their status to somebody they don’t know who will then contact a rotating set of doctors and the next one available will take them as a patient.”

Participants in two focus groups were asked whether complaints from non-HIV/AIDS patients about HIV/AIDS patients were an issue in their service area. Some felt that complaints were directed more against drug users than against HIV/AIDS patients.

## ***2. Is There a Need for Nurse Case Managers?***

Participants in all three focus groups saw a role for nurse case managers but felt that other case managers were also needed. One participant stated that nurse case managers were effective at coordinating a patient's medical care needs (e.g., by identifying drug interactions) but that they generally did not look at broader issues affecting a patient's well being. This participant thought that nurse case managers were best used in conjunction with other case managers such as social workers: "You can't replace a social worker with a nurse. It doesn't work."

Another participant indicated that a nurse case manager could educate patients about "the disease process, the medications, the importance of blood work, what blood work means, transmissibility, in-home care to reduce infection." According to another participant, a nurse case manager could help clients access available services. At the same time, participants felt that experience with HIV (medication compliance, drug interactions, transmissions, supplements, etc.) was essential before becoming a case manager, and that an internship or mentoring program could help a nurse acquire this experience. They also felt that it would be best to "have a team of case managers with different levels of expertise."

Some participants were concerned that a nurse case manager might be "biased" by the doctor's opinions and be unable to offer independent advice. Social worker case managers have an advantage in this regard: "So that is something that is an advantage of being separate ... when a client ... says they want a separate opinion."

## ***3. What Are the Major Health Needs of Your HIV/AIDS Clients When They First Enter Care?***

Focus group participants had diverse opinions about the major health needs of their HIV/AIDS clients when they first enter care. Participants in one of the groups indicated that they often do not see HIV/AIDS clients until they are acutely ill and, as such, are in need of emergency medical assistance. "Most of them are acutely ill and need immediate admittance to the hospital." Others felt that medication and the means to pay for it were major health needs.

On the other hand, some participants identified mental health as the "number one need." Both transitory and more intractable problems were identified by participants as mental health needs of their HIV/AIDS clients when they first enter care. One participant stated, "With us, clients have mental health issues. ... I've read these studies and things that say when a person first finds out they tested HIV positive and they first start getting treatment, they go through a real depression thing. And I've seen it with some of our clients in the beginning, and we've had clients who got involved in behavior science treatment and it has really worked for them. And

then other people haven't, so I think it is an issue, more so for people when they first find out they are HIV positive. We do have a few clients, though, that have mental health issues that go beyond just their HIV disease, other things."

According to another participant, "there are other issues than just disease. There is usually drugs, alcohol, shattered families, guilt of having infected other people, transient fractured families, kids here and kids out of the home." Another participant mentioned social, emotional, and counseling needs. Focus group participants also mentioned economic problems and transportation problems. The bottom line, according to one participant, is that there are "many other immediate needs before you even get to the HIV complication."

Participants also indicated that complications from infections in addition to HIV are a major health need. One participant stated that, "Whenever I come across somebody who is HIV positive they also have HCV [hepatitis C virus]. And I think is going to become even more and more prevalent." Another participant indicated that clients sometimes have hepatitis A and B as well. One participant noted that an HIV positive client was recently diagnosed with tuberculosis, which they had not seen in their locality for some time.

When asked how the health needs of clients today compare with the needs of clients prior to 1997, some participants felt that many health needs were the same. At the same time, participants indicated that medications that have become available in the last few years have changed the focus of patients beyond mere survival. Related to this, participants felt the increase in the availability of medications has been accompanied by significant concerns about how to pay for the medications. Others indicated that the range of support services has improved in the last few years.

Participants in one of the groups felt that the mental health needs of their HIV/AIDS clients were about the same now as three years ago. However, they indicated that the composition of their clientele has changed in recent years from predominantly men who had sex with men to drug users and partners of drug users.

#### ***4. What Are the Major Issues Affecting Your Clients' Health Status?***

Participants in all three focus groups indicated that medication adherence and nutrition are significant problems for their clients. As one participant stated, "Nutrition is a problem for so many who just never learned how to eat properly and then the terrible drug regimens once they get on them. ...It is just very difficult with all the issues they are dealing with anyway to stick to that drug regimen." According to one participant, "Food is such a big deal for our clients. The food bank ... is only available four times a year. Generally they need something more consistent than that."

Participants in one of the groups generally did not see differences in medication adherence between Medical Assistance patients and other patients, except possibly for patients who are too poor to afford medications but are not on Medical Assistance. One participant felt that medication adherence had more to do with a person's educational level than with whether or

not that person was on Medical Assistance. However, a participant in another group felt that education and being on Medical Assistance were related: “Often the people who are on Medical Assistance have a lower level of education and don’t continue to read and understand the importance [of adhering to their medication regimen], so I would say there is a lower rate of compliance.”

One person stated that 20% of HIV patients could not cope with the side effects of medications. These patients stop and start medications, leading to a failure of the medications. This person also felt that HIV patients on Medical Assistance had a lower level of medication compliance.

Participants in two of the focus groups identified drug and alcohol addiction as another major issue affecting their clients’ health status. According to one, addiction affects medication compliance: “For folks who are still dealing with addiction issues and some overwhelming need then compliance is an issue.”

Participants also discussed the problem of HIV re-infection. They indicated that they try to educate their clients on the dangers of re-infection and how it could lead to different types of drug resistance.

One participant stated that one client, who is deceased now, had needed housing and home care to enable him to stay at home.

## ***5. What Are Some Barriers to Your HIV/AIDS Clients’ Care?***

Focus group and key informant interview participants were asked to discuss the degree to which confidentiality concerns and transportation difficulties were barriers to their HIV/AIDS clients’ care. They were also asked whether there were any problems specific to HIV/AIDS clients who had been incarcerated.

Several people indicated that there had been no problems with confidentiality in recent years or they were not aware of any such problems. However, participants indicated that some patients used one of the regional health systems because of concerns about confidentiality with other providers.

One participant stated that HIV/AIDS clients were less concerned about confidentiality now than in the past, and that “requests for anonymous testing have almost disappeared.” This participant felt that the stigma associated with HIV/AIDS has declined in recent years because “people are not as sick and they don’t see as many people dying.” However, other participants indicated that some people who come to be tested for HIV/AIDS are very concerned about confidentiality. According to one participant, “We see a lot of college students and they are very concerned about confidentiality and making sure nobody knows.” According to another participant, “I don’t think it is HIV that [college students] are worried about. I think they don’t want anything charged to their parents’ insurance.”

Participants in the case managers focus group were more concerned about confidentiality. They highlighted cases where they provide assistance to an HIV-positive client and the name of their agency itself lead to disclosure of the client's HIV status. According to one participant, getting "... set up a special account where we could pay certain bills and not have it state that it was from the [HIV/AIDS agency]." This effort "...really took a lot of work on a lot of people's parts." Another participant stated that, "you have to have a referral to be able to go to the food bank and if it comes from me, that means that every staff person in the food bank now knows this person's status. ... Also, I hear pretty consistent complaints about the hospital not respecting people's privacy."

Participants in all three focus groups felt that transportation was a major issue. One of the participants stated that, "there is no access to public transportation and people's cars break down." Another indicated that, "We do have a bus system but that doesn't mean it is accessible to some clients. And we do have some clients who go to [a regional hospital], which makes it very hard for them to get transportation to get there." A participant stated that clients "can ride the ... van, but you have to stay all day. The ... van likes to go full and if your appointment is at 9:00, too bad, you are not coming home until 4:00 or 5:00." Another indicated that, "I've got people 50, 55 miles out who don't have transportation at all. And it is a real problem to line up services, to help them get in to see me or to make their doctor's appointments."

Participants in one of the focus groups identified transportation as a barrier not only for patients but also for providers: "Case managers spend a whole lot more time [in our area] just traveling around. ... Often half of our day is on the road, just getting to and from."

Participants in another group stated that some patients were reluctant to request transportation to medical services out of fear their illness might be disclosed. One participant added that their agency currently has a grant to transport their WIC [Women, Infants and Children] program clients to appointments, and that "it would be nice to have that for HIV as well."

On the other hand, another felt that transportation has not been a problem. Friends, social workers, and emergency medical personnel have been willing and able to transport patients.

With respect to persons who had been incarcerated and are living with HIV/AIDS, most focus group participants indicated that this was a very small percentage of their clientele. One participant stated this group was "0.5 percent. Very small. Very small." However, another stated that this group was about 25% of their clientele.

Participants in one of the focus group stated that, "We test in the prison so we identify [inmates with HIV/AIDS] there." Once they leave prison, if they choose to live in the area, "we will refer them to the community health clinic." A problem in treating former inmates is that, "When they are feeling poorly they will call and want services immediately, and when they are not feeling poorly they won't keep appointments or they don't call."

Participants in one of the groups stated that, "The biggest issue with [former inmates] is not being gainfully employed and often for disability, which if there no medical grounds will not

be given to them.” However, they also indicated that, “It is such a small number of patients that ... we can contact them and make sure how to address that.”

Focus group participants felt there was public resistance to putting former inmates in halfway houses, but that this resistance was not due to HIV/AIDS. According to one participant, “The resistance [to halfway houses] doesn’t have anything to do with HIV. The resistance comes from the neighborhoods where they are placed, so that any negativity attached to the halfway houses is a community-based problem and not a health-based one.”

## ***6. What is the Availability of Mental Health Care in Your Service Area for HIV/AIDS Patients?***

Focus group participants felt that there were a number of gaps in the availability of mental health care for HIV/AIDS patients. One gap was a lack of psychotherapists and psychiatrists familiar with treating HIV/AIDS patients. Participants in one of the focus groups stated that, “There is the county system [for psychotherapy] that is available to folks but again they to be on a waiting list. ... I really worry about referring a client...who is afraid to go to therapy in the first place and then they wait all this time and they get to somebody and it doesn’t work.” Psychotherapists and psychiatrists “don’t know anything about HIV and they don’t want to know anything about HIV. It is a very draining type of therapy for people to get involved in and it is much easier to get involved in short-term things.”

Participants also felt this was a relatively common problem: “I have either 30 or 40% of people who are diagnosed with a personality disorder with secondary HIV. Serious issues. They are not getting therapy. ... They drop through the wholes of the system and then are referred to therapists and frustrated and not comfortable with them, and stop going and they just kind of bump along on antidepressants.”

A related barrier is the physical shortage of mental health providers located in the area. One participant stated that access to mental health services needed to be improved. Another participant indicated that a change in available mental health services in the region has sometimes led to problems. One regional health care network used to provide outpatient psychiatric and psychological care, but now leaves that to other providers.

Several persons indicated that they rely on referrals to deal with addiction and mental health problems. According to one participant, “We have no in-house ability to deal with those issues other than to listen to them at the time and give the best support you can but we have to refer out.” Participants also indicated that they refer clients to other agencies, taking into account what clients can afford

Another gap was a lack of funding to pay for mental health care. A participant indicated that, “There usually is just not that much money in the budget so we can’t help very many people.”

Focus group participants indicated that support groups had not been successful in their communities. According to a participant in one of the groups, “There have been several [support groups] in the ... area that have come and gone. Currently there is one.”

Participants offered several reasons why participation in support groups is limited. Participants felt that many patients were not interested in joining a support group. According to one participant, “A lot of the clients don’t come to support groups because they don’t need them. ... A lot of our clients are gay men in a small community within a small community, so they don’t want to see each other in the support group arena.”

Focus group participants also felt the limited participation in support groups was attributable to a lack of common ground among patients. One person stated, “We only have about 35 clients to begin with ... and they don’t have anything in common.” According to one of the focus group participants, “When the only thing people [in a support group] have in common is HIV, it’s not nice. It is hard to mix gay men with IV drug users because their lifestyles are so entirely different.” In addition, participants saw distance as an obstacle: “It is a different animal when you are so rural and spread out than it is when you are in a more metropolitan area.”

## ***7. What is the Availability of Dental Care in Your Service Area for HIV/AIDS Patients?***

Focus group participants felt that there were a number of gaps in the availability of dental care for HIV/AIDS patients. The first was a simple lack of dental care providers. One of the participants stated that, “There are no providers. The waiting list is so long that they’ll see them in six months.” According to another participant, there is a dental clinic, “but the waiting period is really long – 3 to 4 months usually.”

Participants felt that this lack of dental care providers was compounded by the unwillingness of dentists to serve Medical Assistance patients. Regarding the availability of dental care for Medical Assistance patients, one participant responded, “Lacking, lacking, lacking.” Another participant stated that, “It is poor for even just folks on welfare to get good dental care. We have one dentist ... who does it and that is it.” According to participants in another focus group, “The way that most of our clients get dental care is that we pay for it. ... It is not because they accept an Access card. It is because we pay for it.” “We have one Medical Assistance provider and they are not that good, and ... periodontal care is not covered by Medical Assistance anyway.”

One participant reported working with a Medical Assistance client whose dentist “would only tell him about the procedures that Medical Assistance would pay for, which were late-stage, not-in-his-best-interest procedures.” This participant felt that this problem was “pretty common.”

A participant in one of the groups stated that, “I understand the rates have gone up for MA for dentists. I wonder if dentists know about that.” Another participant responded, “They

still don't meet the normal payment and they can probably fill their patient loads with normal payment loads so there is no impetus to take [Medical Assistance patients]."

### ***8. What is the Availability of Vision Care in Your Service Area for HIV/AIDS Patients?***

Focus group participants were split over the availability of vision care for HIV/AIDS patients. Participants in two of the focus groups felt that availability was on the whole good, and they saw no difference in availability for patients on Medical Assistance versus other patients.

On the other hand, participants in the third focus group felt there was a problem of access for Medical Assistance patients: "We don't have a problem getting [providers]. ... The problem is that Medical Assistance won't cover the glasses themselves. And then we have a whole group of people who work and don't qualify for Medical Assistance and they don't qualify for insurance or don't have it." "Some of the people I have worked with, if they had an Access card, I've had them go to ... and they've helped them that way. So there is an agency in town but sometimes they are even limited in what they can do because it is non-profit and for so many people."

### ***9. Are There Other Services Your Clients Need that Are Not Easily Accessible?***

Focus group participants were asked whether the availability of gynecological care for women with HIV/AIDS was an issue. By and large, they did not perceive this to be a major problem. According to one participant, "I've actually talked to a few women about this and they felt things were OK as far as the services they were getting ...." On the other hand, another participant stated that, "I just heard from a patient ... and I felt the patient did not get the best service."

For the most part, focus group participants also felt that the availability of intermediate care settings such as halfway houses, hospices, and nursing homes was not a major issue. However, one participant described the case of a client who lived alone, was dying, and might have been a candidate for hospice care, but he was ineligible because he lived alone: "You can't even get hospice [care] if you live alone. They will not provide care to you unless you have a caregiver living with you."

Participants in one of the groups felt that job training services would be helpful: "Job training for people that want to work and are capable of working."

A participant also commented that, "We get a lot of people from another coalition's region. But they don't receive services there. They live close to [an NCDAC county], receive services at [one of the regional health facilities], and lots of times are referred by ... clinics in outlying areas. It's hard to provide viable services when we can't do for them the same things we can do for our clients here. ... They come here because of confidentiality, anonymity, available

Infection Disease specialists, transportation, familiarity within the system. The question is should funding be based on where they live or where the service is provided?"

### ***10. Are You Aware of People with HIV/AIDS in Your Service Area Who Are Not Part of Your Provider Network?***

Participants in two of the focus groups were aware of people with HIV/AIDS who did not utilize area AIDS Service Organizations (ASOs). They identified a number of reasons for this. Some people are evidently unaware of the existence of ASOs. A participant stated that, "I think some of them really don't know that there are ASOs. Because we have had phone calls from people who have been in the area for several months and did not know about it, so we'd give a referral."

Participants in two of the focus groups also felt that confidentiality concerns were another reason why some do not utilize ASOs. One participant said that, "I think confidentiality plays a big part in it, too. Some people may have it but they don't want to come into the agency because they don't want others to see them."

At the same time, others are of higher socioeconomic status and capable of creating their own support systems. One of the case managers stated that, "there are folks who have plenty of resources. ... They have a lot of money and they have a lot of their own support systems so they have no need for our agency." Another participant felt that, "the higher the socioeconomic status of the person, the less [support services] they are going to use. They will create their own support systems."

Others are unaware that they are HIV-positive. According to one participant: "I think there are people out there living with the virus who don't know it. ... I think they are probably lower income folks."

Focus group participants listed other reasons as well. According to one participant, "the clientele at different organizations are predominantly one or the other [gay men or drug users], and then if this service is all gay men then you don't see any drug users go there. If it is a drug using population then gay men don't go." According to another participant, "Some don't want to take charity, either. They feel like it's taking charity and they can take care of themselves." One participant said that some people do not utilize local ASOs because they feel they would be depriving others of the organization's assistance: "I hear that a lot. People don't want to take it from somebody else."

Related to this question, focus group participants also discussed education and testing for people who might be at risk for HIV/AIDS. A participant stated that, "In our area, I feel we have a huge obligation to educate people so that they can determine if they are at risk. And this is one of the things I have been working really hard on in our agency, to make sure every client that comes in for domestic violence or sexual assault will have an HIV risk assessment."

Participants in one of the focus groups felt there needed to be more prevention education for teenagers and preteens: “When we are talking about experimenting with sex [it] is now happening at 11, 12 and 13 rather than where we thought it was, at 14, 15 and 16. ... If you are not going to give them the information and the wherewith to practice safely or to practice safer techniques, how can you then come along five years later and talk risk reduction, when now it has become habitual. ... The virus could have been there are we are not going to see it for 5-6 years.”

## ***E. Synthesis and Recommendations***

Results from the surveys, focus groups and interview, and analysis of secondary data indicate that the following needs of people living with or affected by HIV/AIDS are not being met in the North Central region.

*The three most critical needs in the North Central region are:*

- 1. Dental Care.** One of the most drastic needs going unmet in the region is the availability of professionals to provide dental care, particularly to Medical Assistance patients.
- 2. Mental Health Services.** Another need going unmet in the region is the availability of mental health services for people with HIV/AIDS.
- 3. Transportation.** Transportation, particularly non-Medicaid reimbursed, is a serious problem. This problem is particularly acute among those with limited financial resources living outside of the Williamsport or State College city areas (i.e., outside of the public transit system). Even if a client owns a vehicle, it may not be reliable or the person may not be able to afford gas or insurance.

*A fourth seriously unmet need is:*

- 4. Limited Access to HIV Medical Specialists.** While this problem is also very critical in the region, strategies that help alleviate problems with transportation (listed above) will also help alleviate this serious problem.

*Other barriers and problems in the North Central region that are creating unmet needs among the HIV/AIDS infected and affected populations include:*

- 5. Drug and Alcohol Treatment.** The analysis suggests that there is a need for increased accessibility to drug and alcohol treatment.
- 6. Greater Understanding among Health Care Providers.** Results from the providers survey as well as the focus groups indicate a need to increase primary care providers, dental and mental health providers understanding of HIV/AIDS, as well as a need to make them aware of services for people who are living with or affected by HIV/AIDS.
- 7. Nutritional Counseling and Supplements.** Results from the consumer survey reviewed in conjunction with results from the LifePlan database indicate the need for nutritional counseling and supplements for HIV/AIDS clients. Focus group results also indicate a need to attend to nutrition.
- 8. Financial Assistance for Medications.** Financial assistance for medications, particularly for prescriptions, was cited as a need by persons interviewed and focus group participants, as well as identified as a critical need on the providers survey. In addition, patients sometime have difficulties accessing over-the-counter (OTC) drugs.

The importance of obtaining medications speaks to the need for continued client education about the importance of adherence to a medication regimens, as well as re-infection issues.

*Human service organizations in the North Central region have partially met needs related to the following. However, there still appears to be some unmet needs with regard to:*

**9. Emergency Financial Assistance.** HIV/AIDS clients appear to be aware of and have used NCDAC resources for emergency financial assistance. The question remains whether additional resources are needed in this area.

**10. Eyeglasses.** Results from the surveys and focus groups indicated that HIV/AIDS clients are having difficulties acquiring eyeglasses.

**11. Employment Assistance.** Employment assistance was cited as a need for HIV/AIDS clients. The use of more effective therapies means that clients are able to remain in the workforce (or join the workforce in the case of those who were incarcerated). Assistance may be needed to help train clients in job skills or to locate employment where they are able to take medications while on the job or to be excused from work for visits to the doctor.

### ***Strategies for Addressing Unmet Needs***

Strategies for addressing these needs cannot be single-pronged. It will most likely take a combination of education, additional provision of services, and inter-agency collaboration to alleviate some of these unmet needs. In addition, many of these needs are not new – they have plagued the people living in the region for sometime, particularly those needs stemming from limited financial resources and the rural character of the region. These problems affect many in the region, although the HIV/AIDS population also has the added problem of stigma attached to HIV/AIDS. The needs of the HIV/AIDS population are more likely to be addressed if NCDAC and the agencies it funds work in collaboration with other groups seeking to address some of these problems.

For instance, the shortage of dental health care professionals serving the HIV/AIDS population stems at least in part from the shortage of dental health professionals serving some of the region's low-income populations. Because many of the HIV/AIDS clients being served by NCDAC-funded groups have limited financial resources, these people face the same shortages affecting other limited resource individuals. In addition, those with HIV/AIDS have the added burden of finding dental health professionals who are willing and prepared to serve their dental health needs. Similarly, shortages of mental health professionals in parts of the region aggravate the problems that HIV/AIDS infected and affected persons have finding qualified professionals to help them.

One partial solution may be to work with other groups dedicated to similar goals, i.e., increasing the number of dental and mental health professionals in the region, particularly those willing to work with low-income groups. For instance, municipalities and other local governments can apply to the Bureau of Primary Health Care of the Health Resources and Services Administration (HRSA) to have their locality designated as a health professional health shortage area. This designation is a prerequisite to applying for National Health Service Corps recruitment assistance.

A second strategy is to work with other, non-traditional providers to supply some of these needed services. For example, some of the ASOs have arranged to provide dental services for their clients. It may be advantageous to work in collaboration with human service agencies already working on these issues.

A third strategy is to educate dental and mental health providers about HIV/AIDS. This may help increase the availability of persons willing to serve HIV/AIDS persons.

Information from the focus groups indicates that some dental health providers do not yet wear barriers such as gloves and a face shield (or mask and protective eyewear) as standard practice when working with all patients. This indicates that educational programs designed for dental health professionals should emphasize the importance of following the universal precautions established by the CDC. Perhaps combining education with an incentive to induce dental health providers to incorporate universal precautions into their practice when treating all patients would help increase the availability of dental care providers prepared to treat the HIV/AIDS population. Increased use of acceptable barriers when treating all patients may indirectly decrease the stigma associated with HIV/AIDS.

Transportation is a problem that sometimes seems immutable, particularly when attempting to resolve the problems faced by low-income populations in rural areas when trying to access needed services. While the availability of vans to transport clients is an important strategy, many problems remain. As described in the prior section, there are difficulties for clients in relying on an organization's van to take them to doctor's appointments. These are often all day trips because the van makes only one round-trip a day, meaning that a client must set aside an entire day for a single doctor's appointment. An alternative strategy for dealing with this problem would be to offer vouchers to clients who have access to a vehicle – the voucher could pay the cost of gas to doctors appointments, or appointments that the case management agency has approved.

Another approach, related to access to HIV medical specialists, would be to arrange to have the HIV medical specialist travel to certain places in the region periodically. Perhaps pick-up/drop-off transportation services could be arranged for patients to ensure they show for their appointments. A related approach would be to work with other groups in the region to prepare and submit a grant to develop a telemedicine network in the region. For instance, HRSA's Office for the Advancement of Telehealth (OAT) was to have awarded 12-15 grants totaling \$5 million by September 1, 2000 under their Rural Telemedicine Grant Program.

Results from the surveys and focus groups emphasize the importance of educational efforts to increase the understanding of HIV/AIDS among primary care providers, dental health providers, and mental health providers. Not only is it important to increase providers' understanding of HIV/AIDS and reduce the stigma attached to HIV/AIDS, but also to increase their awareness of services available in the community for HIV/AIDS infected and affected persons. Related to this, the financial constraints facing many people who have HIV/AIDS mean that purchasing OTC drugs poses a financial burden. However, not all providers appear sensitive to this constraint. (A solution is for the provider to prescribe the drug instead.)

In addition, increasing the general public's understanding of HIV/AIDS and how to reduce the chances of contracting HIV/AIDS is important. Results from the focus groups and surveys indicate that educational efforts need to be directed toward younger as well as older adolescents, particularly because many adolescents are sexually active and because heterosexual contact is increasing as a mode of transmission.

When results from the consumer survey were analyzed in conjunction with results from the LifePlan database, it appeared that several services were being underutilized, such as nutrition-related services. Focus group results also indicated a need to attend to nutrition. It is critical for people living with HIV/AIDS to receive proper nutrition. While all the case management agencies offer nutrition services, only about one-half of the consumer survey respondents knew that the service was offered. These results speak to the importance of informing (and probably re-informing) clients about the services that are offered by case management agencies, particularly those that could have a major impact on the person's health status.

Education about re-infection and the importance of adhering to a medication regimen also needs to be reinforced. It is important to discover why certain clients/patients have difficulties adhering to a medication regimen. For some, it may be that drug use is interfering with a patient's compliance. But for others, adhering to a regimen may interfere with their desire for a "normal" life. As a case in point, the focus group of mothers of HIV children indicated that this was one of the major reasons that their children did not take their medications as prescribed. In order to deal with adherence problems, it is important that health care providers as well as case managers understand the reasons why this is occurring. Such an understanding may lead to more effective strategies for increasing compliance.

Clients appear to be aware of NCDAC resources earmarked for emergency financial assistance. It is important to keep track of the extent to which these resources are exhausted, thereby indicating that needs are still going unmet. Other needs that apparently are not being met include the need for eyeglasses. This is a problem that affects all persons with limited financial resources, regardless of the type of health care coverage they have. Private insurance often does not cover the cost of purchasing prescription glasses or provides only limited coverage.

Client and case manager concerns surrounding confidentiality appear to be very real. The stigma attached to HIV/AIDS means that clients are hesitant to make use of community services, such as the food bank. Again, educating the public about HIV/AIDS may help reduce some of this stigma.

Also, clients may benefit from assertiveness training or sessions designed to empower them. Increasing one's self-esteem and feelings of competency can help one deal with such community barriers. Empowerment training may help clients who are employed to ask their employer if they can take their medication when needed while on the job (e.g., receiving permission to leave the factory line). Literacy programs designed to help clients find out what community and health agencies are available in their area may also be useful.