



*North Central District AIDS Coalition
Needs Assessment for 2004-2007*

Final Report

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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 persons 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 four case management agencies: The AIDS Project of Centre County, The AIDS Resource Alliance, Inc., Caring Communities for AIDS, and HIV/AIDS Support Network. In total, 230 clients are served per year.

In August 2003, 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. The focus of the current needs assessment is on primary and secondary prevention.

Several different sources of data were used in conducting this needs assessment. These include (a) government statistics from the Pennsylvania Department of Health, (b) a survey of consumers of the four case management agencies regarding secondary prevention and risk, (c) a survey of participants who received instruction from prevention outreach workers regarding primary prevention, and (d) a survey of social service providers located in the 12-county NCDAC region who work with a variety of clients. In addition, a focus group and interviews were conducted with case managers who work for the four case management agencies and the prevention outreach workers, respectively. Also interviews were conducted with infectious disease and gastro-intestinal physicians serving NCDAC consumers and others at risk in the NCDAC region.

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. This section also discusses characteristics of people currently living with AIDS and how these characteristics have changed over time for the period for which data are available. Also presented are statistics on the number of visits to publicly funded HIV counseling and testing sites in the region during the 1998 to 2003 period.

The second section of this report summarizes results from a consumer survey conducted during the winter of 2004. At that time, 197 consumers were receiving services by the four case management agencies funded through the NCDAC. A total of 144 consumers responded to the survey, resulting in a 73% response rate. Consumers were asked various questions about the frequency and nature of their contacts with their case manager; discussions about re-infection, infecting others, and reducing those risks; the development and usefulness of plans for reducing risk; and knowledge of and implementation of behaviors that reduce risk. Consumers were also asked about the length of time they have received case management services through their agency, how they became infected with the HIV virus, as well as some socio-demographic questions. Also in this section, results from the focus group of case managers are described. These two components permit a fuller perspective on the effectiveness of current prevention strategies among people living with and affected by HIV/AIDS in the North Central region, and areas where prevention strategies spearheaded by the case management agencies can be improved.

The third section of this report summarizes results from the survey of participants who received instruction on primary prevention of HIV/AIDS by prevention outreach workers. This survey was distributed by the outreach workers to participants over a three-week period from February 23 to March 12 (2004) *after participants received instruction*. A total of 106 participants completed the survey. The survey asked questions measuring knowledge of how one can become infected with HIV/AIDS, whether the participant knows why they are at risk, how one can prevent infection with HIV/AIDS, and where to get a free test for HIV. The survey also asked questions about whether the prevention outreach worker developed a risk reduction plan with the participant and the effectiveness of that plan, as well as whether the participant has had past contact with HIV/AIDS prevention workers. Respondents also answered socio-demographic questions about themselves. Results from the interviews of the prevention outreach workers are also summarized in this section to provide a better understanding of current primary prevention efforts being undertaken by the case management agencies, and the effectiveness of these strategies.

The fourth section synthesizes results from a series of interviews with physicians. Interviews were conducted with two of the seven infectious disease physicians serving the NCDAC region. Also, an interview was conducted with a gastro-intestinal physician who serves patients in the NCDAC region at-risk of contracting HIV/AIDS.

The fifth section of this report summarizes results from a survey of social service agencies in the 12-county region. Providers who serve a variety of clients, particularly those at risk of contracting HIV/AIDS, were mailed a copy of the survey. Providers were asked to copy and distribute the surveys to all employees involved in direct client services. Providers could

also answer a web-based version of the survey on the By The Numbers website. Each agency was assigned a unique identification number that was required in order to gain access to the web-based version of the survey. Surveys were mailed to 350 agencies. A total of 95 surveys from 65 agencies were returned, representing a 19% response rate.

The survey asked whether the agency serves people infected with the HIV virus, has written policies for discussing HIV/AIDS prevention with their clients, and whether the respondent has any formal training on educating the public or their clients about HIV/AIDS risk prevention. Respondents' attitudes about talking about HIV/AIDS risk prevention with their clients were measured, as well as the conditions under which respondents discuss HIV/AIDS risk prevention with their clients. Barriers to discussing HIV/AIDS risk prevention were measured and strategies for dealing with these barriers were discussed. Respondents were asked whether they serve clients who are at risk of becoming infected with HIV – that is, IV drug users, men who have sex with men (MSM), and clients with multiple sexual partners (simultaneously or serially). Respondents answered a series of questions about clients falling into each of these at-risk groups, such as whether they suggest to these clients that they be tested for HIV/AIDS, conditions under which respondents talk about HIV/AIDS risk prevention with these at-risk clients, and the barriers to doing this. Respondents also answered questions regarding the socio-demographic characteristics of each of these at-risk client groups.

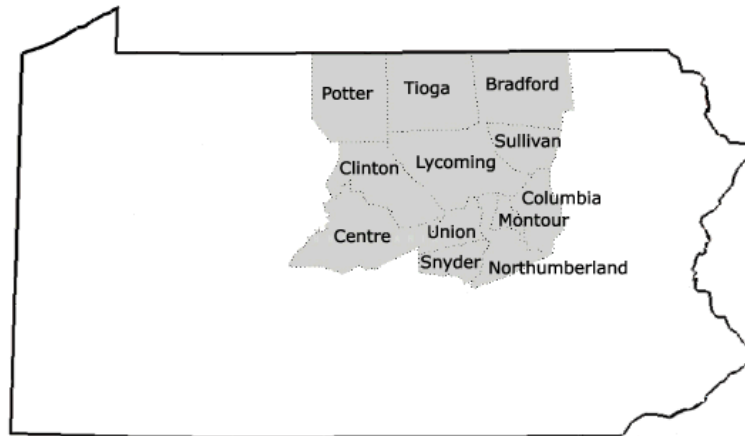
The last section of this report synthesizes results from prior sections. The most critical prevention service needs in the region are highlighted, and a list of recommendations for establishing funding priorities is presented. Strategies for addressing these needs are discussed.

A. Characteristics of the HIV/AIDS Population

How Prevalent is AIDS in the North Central Region?

The focus of this needs assessment is on prevention and risk reduction, both among those persons who currently are living with the HIV virus, as well as among those who have not do not have the virus. This section focuses on the prevalence of AIDS in the North Central region and its incidence. This section also addresses characteristics of people currently living with the HIV virus in the region and changes in these characteristics for the period for which data are available. Also presented are number of visits to publicly funded HIV counseling and testing sites in the region during the 1998 to 2003 period. The counties in the North Central region are pictured below in the map of Pennsylvania.

Figure A-1. Counties in the North Central District AIDS Coalition



The Pennsylvania Department of Health reported a cumulative total of 654 AIDS cases in the North Central region from 1980 to 2003. As of December 31, 2003, over one-half (57%) of these people were presumed alive, that is 373 people living with AIDS were presumed alive. This is larger than the percentage presumed alive in the state, as a whole. The percentage of AIDS cases presumed alive in the state of Pennsylvania (during the 1980-2003 period) was 52%.

Lycoming County is ranked 16th in the state in terms of cumulative AIDS cases from 1980 to 2003 (out of the 67 counties). Lycoming County has seen 230 cumulative AIDS cases during the 1980-2003 period. Centre, Union, and Northumberland Counties are ranked 25th, 26th, and 28th in the state in terms of cumulative AIDS cases during this period; between 91 and 100 AIDS cases has been reported for these counties during the 1980-2003 period. The remaining counties in the region have experienced 34 or fewer cumulative AIDS cases during the 1980-2003 period. Columbia and Bradford rank 42nd and 44th in the state. Snyder, Tioga, and Montour rank 50th, 54th, and 58th in the state, while Potter, Sullivan, and Clinton are ranked 61st, 62nd and 63rd. Table A-1 lists the number of cumulative AIDS cases in each county 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 and Research, Bureau of Epidemiology.

Also presented in Table A-1 are the number and percentage of AIDS cases presumed alive. This information is useful when gauging the effort needed when providing secondary prevention services. For counties with 90 or more cumulative AIDS cases from 1980-2003, anywhere from 55% to 74% were presumed alive as of December 31, 2003 – that is, between 50 and 128 people were presumed to be living with AIDS in Lycoming (128 cases), Centre (58), Union (69), and Northumberland (50) Counties. Between 15 and 21 people were presumed to be living with AIDS in each of the following counties: Columbia, Bradford, and Snyder. Four to eight people were presumed to be living with AIDS in the smaller counties of Tioga, Montour, and Sullivan. One or two people were presumed to be living with AIDS as of December 31, 2003 in Clinton and Potter Counties, respectively.

Table A-1
Prevalence of AIDS in the North Central Region: 1980-2003

	Cumulative AIDS Cases	County Rank	Number Presumed Alive	Percent Presumed Alive
Lycoming	230	16	128	56%
Centre	100	25	58	58%
Union	93	26	69	74%
Northumberland	91	28	50	55%
Columbia	34	42	21	62%
Bradford	32	44	13	41%
Snyder	23	50	15	65%
Tioga	18	54	4	22%
Montour	13	58	8	62%
Sullivan	7	62	4	57%
Clinton	6	63	1	17%
Potter	7	61	2	28%
North Central Region	654	—	373	57%

Based on data for 2001, between 1 and 19 new cases of AIDS were expected to occur in each of the counties in the North Central region except for Potter, Tioga, Clinton, and Montour counties. In these four latter counties, no new cases were expected. The incidence of AIDS in counties in the North Central region is presented in Table A-2. The incidence is considerably higher than the state total in Union county, and slightly higher than the state total in Lycoming County. The incidence in Sullivan County is also higher than the state total, although the number of AIDS cases and population of Sullivan County is small, resulting in the incidence rate being an unreliable indicator for that county.

Table A-2
Incidence Rate of AIDS in the North Central Region
(per 100,000 population)

County	2001 Incidence per 100,000
Lycoming	12.61
Centre	2.94
Union	16.79
Northumberland	5.34
Columbia	3.12
Bradford	1.59
Snyder	7.95
Tioga	0.00
Montour	0.00
Sullivan	15.31
Clinton	0.00

Table A-2
Incidence Rate of AIDS in the North Central Region
(per 100,000 population)

County	2001 Incidence per 100,000
Potter	0.00
Pennsylvania as a whole	12.10

Incidence rate based on 2001 population.

As indicated in Table A-3, about four-fifths (77%) of the 373 people currently living with AIDS in the North Central region in 2003 were male and 23% were female. About one-half (46%) of those currently living with AIDS in 2003 were African American (non-Hispanic) and two-fifths (43%) were White. Only 10% of those currently living with AIDS in the North Central region were Hispanic. Among age groups, the largest percentage (48%) of cases was 30-39 years of age, with another 28% being 40-49 years of age. One-half (50%) of the people currently living with AIDS in the North Central region in 2003 acquired it via injecting drug use (IDU); about one-quarter (24%) were men who have/had sex with men (MSM). One-tenth (10%) of the cases were a combination of these two modes of transmission. The percentage of cases in 2003 acquiring AIDS via heterosexual contact was 11%. These figures are from the Pennsylvania Department of Health, Bureau of Health Statistics and Research, Bureau of Epidemiology.

Table A-3
Characteristics of Currently Living AIDS Cases: North Central Region, 2003
(n=373)

Characteristics	Number	Percent
Gender		
Male	288	77%
Female	85	23%
Total	373	100%
Race/Ethnicity		
White (non-Hispanic)	159	43%
African American (non-Hispanic)	173	46%
Hispanic	38	10%
Asian/Pacific Islander	3	1%
Native American	0	0%
Total	373	100%

Table A-3
Characteristics of Currently Living AIDS Cases: North Central Region, 2003
(n=373)

Characteristics	Number	Percent
Age		
0-12 years	2	1%
13-19 years	1	0%
20-29 years	53	14%
30-39 years	178	48%
40-49 years	105	28%
50 or older	34	9%
Total	373	100%
Mode of Transmission		
Men who have sex with men (MSM)	88	24%
Injecting drugs (IDU)	188	50%
MSM & IDU	37	10%
Coagulation DIS	4	1%
Heterosexual contact	42	11%
Transfusion	1	0%
Undetermined/other	11	3%
All pediatric	2	1%
Total	373	100%

The characteristics of people with AIDS in the North Central region appear to have changed over time. Table A-4 presents the percentage of cumulative AIDS cases with various socio-demographic characteristics for the 1980-1997 time period and the 1998-2003 time period. The percentage of AIDS cases who are men have decreased. For instance, 80% of cumulative AIDS cases from 1980-1997 were men, while 75% of the cumulative AIDS cases from 1998-2003 were men. Consistent with this, the percentage of cases who acquired the HIV virus via heterosexual contact increased from 7% during the 1980-1997 period to 16% during the 1998-2003 period. On the other hand, the percentage who acquired the virus via MSM decreased from 33% to 27% between these two time periods. Also, the percentage of White (non-Hispanic) and Hispanic AIDS cases decreased between these two time periods, while the percentage of African American (non-Hispanic) AIDS cases increased. The age distribution has become older, with a smaller percentage in their 20's and a larger percentage of cases in their 40's.

Table A-4
Changes in Characteristics of AIDS Cases: North Central Region

Characteristics	1980-1997 481 Cumulative AIDS Cases	1998-2003 173 Cumulative AIDS Cases
Gender		
Male	80%	75%
Female	20%	25%
Total	100%	100%
Race/Ethnicity		
White (non-Hispanic)	52%	44%
African American (non-Hispanic)	35%	49%
Hispanic	13%	6%
Asian/Pacific Islander	0%	1%
Native American	0%	0%
Total	100%	100%
Age		
0-12 years	1%	0%
13-19 years	0%	0%
20-29 years	17%	9%
30-39 years	49%	46%
40-49 years	22%	32%
50 or older	10%	13%
Total	99%	100%
Mode of Transmission		
Men who have sex with men (MSM)	33%	27%
Injecting drugs (IDU)	44%	45%
MSM & IDU	10%	6%
Coagulation DIS	3%	0%
Heterosexual contact	7%	16%
Transfusion	1%	1%
Undetermined/other	0%	6%
All pediatric	1%	0%
Total	99%	101%

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

How Prevalent is HIV in the Region?

Table A-5 presents the number of visits made for publicly funded HIV counseling and testing between 1999 and 2003 in the counties in the North Central region. A visit is comprised of a “client meeting face-to-face with a counselor for counseling only, or counseling and testing. In 2003, approximately 89% of clients counseled consented to testing.” Data are from the Pennsylvania Department of Health, Bureau of Communicable Diseases, Division of HIV/AIDS, HIV/AIDS Surveillance Biannual Summary, December 31, 2003. There are some important limitations to these data. Studies for Pennsylvania indicate that 44% of all persons included in these counts were previously counseled and tested. At the same time, the Centers for Disease Control and Prevention (CDC) reported results from a study indicating that publicly funded sites provide counseling and testing to about one-third of all people who receive it.

From 1999 to 2003, the percentage of all visits in the state of Pennsylvania that resulted in a positive test (i.e., indicating HIV infection) averaged 1.3% over the 5-year period. The number of cases expected to be positive in the North Central region for each year is indicated in Table A-5, as well. Data in Table A-5 suggest that from 1999 to 2002, between 54 and 58 visits each year were positive in the North Central region. The data for 2003 is apparently incomplete because the number of visits is about two-thirds that of the other years. Even so, it appears that at least 258 tests were positive for HIV between 1999 and 2003 in the North Central region.

Table A-5
Number of Visits for Publicly Funded HIV Counseling and Testing in the North Central Region: 1999-2003*

	1999	2000	2001	2002	2003*	Total
Bradford	102	103	101	86	58	450
Sullivan	38	9	3	4	2	56
Columbia	586	435	369	347	239	1,976
Montour	251	260	222	181	73	987
Northumberland	418	559	775	752	405	2,909
Tioga	133	164	129	161	57	644
Lycoming	1,212	1,197	1,125	1,357	783	5,674
Union	245	349	324	239	112	1,269
Snyder	238	193	124	132	62	749
Potter	26	10	22	11	4	73
Clinton	201	190	197	177	77	842
Centre	730	718	882	1,034	878	4,242
North Central Region	4,180	4,187	4,273	4,481	2,750	19,871
1.3% of all visits: number of expected positive tests for North Central region	54	54	56	58	36	258

* Data for 2003 may not be complete.

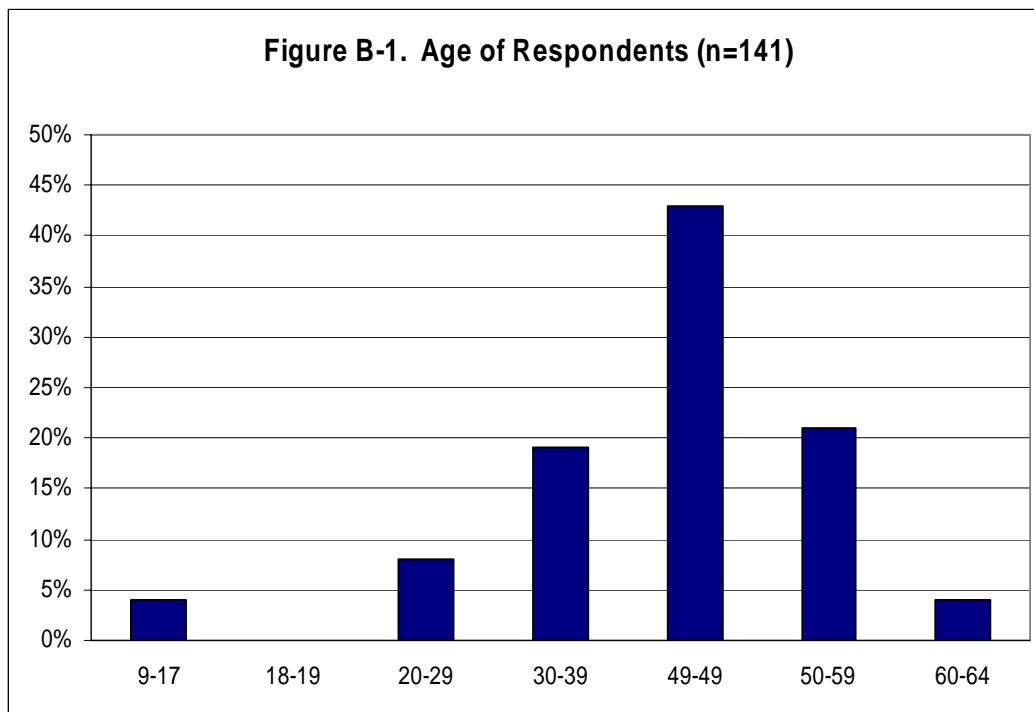
B. Prevention and Risk Reduction among NCDAC Consumers

Consumer Survey on Prevention and Risk Reduction

During the winter of 2004, the North Central District AIDS Coalition (NCDAC) worked with the four case management agencies they fund to administer a survey to consumers of HIV/AIDS case management services. A total of 197 HIV/AIDS consumers were being served by these four agencies at the time of the survey. A total of 144 consumers responded to the survey, representing a 73% response rate. Consumers were asked various questions about the length of time they have received case management services through their agency and how they became infected with the HIV virus; the frequency and nature of their contact with the case manager; discussions about re-infection, infecting others, and reducing those risks; the development and usefulness of plans for reducing risk; and knowledge of and implementation of behaviors that reduce risk.

About the Consumers

On average, respondents are 43 years old, with nearly one-half (43%) of the respondents indicating that they are in their 40's (refer to Figure B-1). At the same time, the youngest consumer is only 9 with about 4% of the consumers being under the age of 18 years. Another 4% of the consumers are in their 60's with the oldest being 64 years.



About two-thirds (65%) of the consumers responding to the survey were male while a little over one-third (35%) were female. Over two-fifths (41%) of the respondents were African American, and 50% were Caucasian. A small percentage of respondents indicated some other

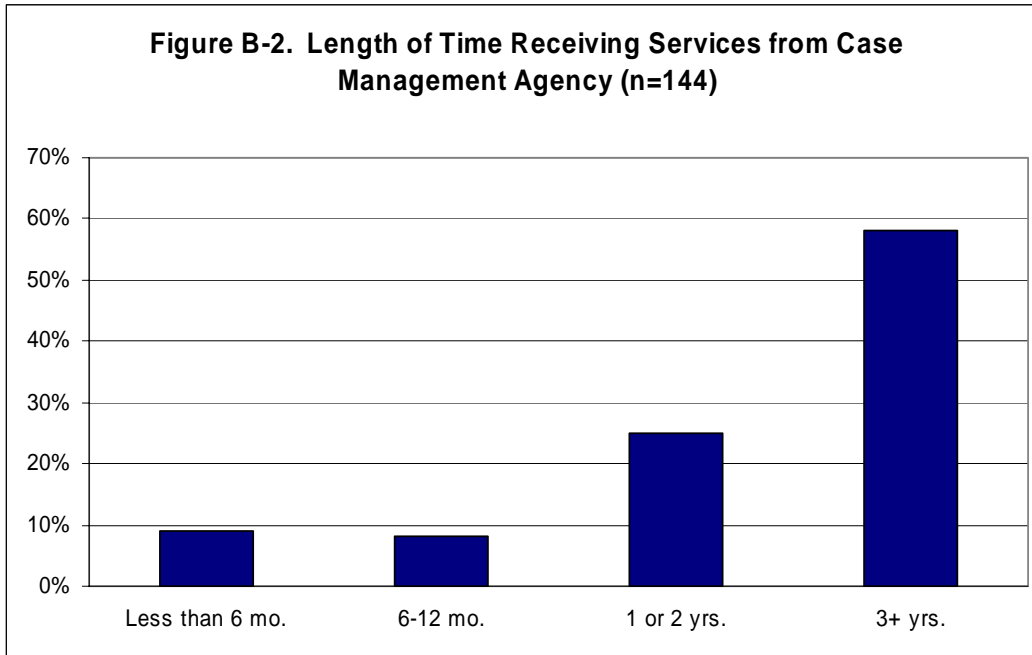
race or ethnicity: 6% indicated being Hispanic, 4% indicated being Native American, 1% indicated some other race/ethnicity. Three respondents (2%) indicated being multiple races/ethnicities. Gender and race/ethnicity breakdowns are presented in Table B-1.

Male respondents were more likely to indicate being White than females (56% of males are white compared to 39% of females). On the other hand, 47% of the female respondents indicated being African American compared to 38% of the males. Also, 12% of the females indicated being Hispanic while only 3% of the males indicated such.

Table B-1
Gender and Race/Ethnicity of Consumers Responding to Survey

	Number	Percent
Gender		
Male	93	65%
Female	51	35%
Total	144	100%
Race/Ethnicity (n=144)		
White	72	50%
African American	59	41%
Hispanic	9	6%
Native American	5	3%
Other	2	1%

Over one-half (58%) of the respondents have been receiving case management services through their case management agency for 3 or more years. Less than one-fifth of the respondents are new to the Agency, as indicated in Figure B-2. Another 25% have been receiving services for 1 or 2 years. Only 13 respondents (9%) have been receiving services from their case management agency for less than 6 months, and other 12 have been receiving services for 6 to 12 months.



Consumers were also asked about how they became infected with the HIV virus; results are presented in Table B-2. The majority (72%) of respondents acquired the HIV virus through sexual contact. About one-fifth (18%) acquired it by sharing needles, while 16% indicated some other mode of transmission. Nearly all (94%) of the respondents indicated a single source of the virus. Eight respondents (6%) indicated that they acquired the virus through multiple modes of transmission (i.e., sexual contact and sharing needles).

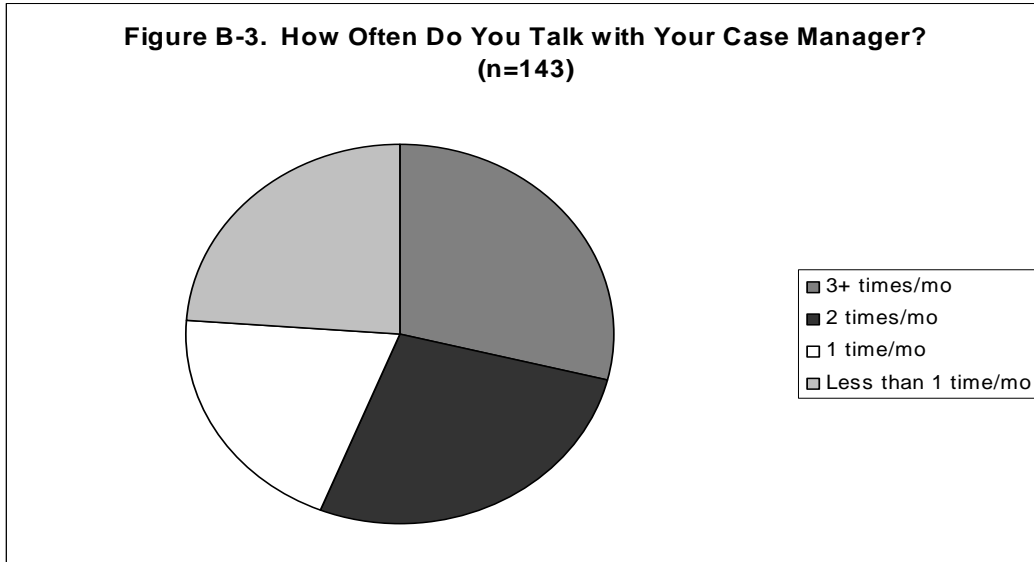
**Table B-2
Mode of Transmission (n=142)**

Mode of Transmission	Number	Percent
Sexual Contact	102	72%
Sharing Needles	26	18%
Other	23	16%

Frequency and Nature of Contact with the Case Manager

The majority (76%) of respondents indicated that they talk their case manager at least once a month. In fact, over one-quarter (29%) of the respondents indicated talking with their case manager 3 or more times per month, and another 27% indicated talking with them 2 times per month, on average. At the same time, 24% of the respondents indicated talking with their case manager less than once a month, on average. Results are depicted in Figure B-3.

**Figure B-3. How Often Do You Talk with Your Case Manager?
(n=143)**



Consumers also answered a series of questions about the nature of their contact with their case manager; results are presented in Table B-3. The majority (74%) of the respondents indicated that their case manager is usually or always sensitive to their living circumstances and cultural background. However, about one-seventh (14%) of the respondents indicated that this is the case only occasionally, while 12% indicated that their case manager is hardly ever or never sensitive to their living circumstances and cultural background. Also, 82% of the respondents indicated that they hardly ever or never have trouble understanding the information about risk reduction and prevention their case managers give them. One-tenth of the respondents indicated that they occasionally have trouble understanding this information, and another 8% indicated that they usually or always have trouble understanding the information on prevention and risk reduction that their case manager gives them.

Only 27% of the respondents indicated that their case manager goes with them to their doctor appointments at least occasionally. The majority (73%) of respondents said that their case manager hardly ever or never goes with them.

To summarize, results indicate that, for the most part, case managers are sensitive to consumers and communicate with them clearly, although there are exceptions. Typically, case managers do not go with consumers to their doctor appointments.

**Table B-3
Contact with Case Manager**

	Number	Percent			Total
		Usually or Always	Occasionally	Hardly Ever or Never	
Is your case manager sensitive to your living circumstances and cultural background?	137	74%	14%	12%	100%
Do you ever have trouble understanding the information about risk reduction and prevention that your case manager gives you?	141	8%	10%	82%	100%
How often does your case manager go with you to your doctor appointments?	142	6%	20%	73%	99%

Some totals do not sum to 100% because of round-off error.

Discussions with Case Managers about Re-infection, Secondary Prevention & Risk Reduction

Only 35% of the respondents indicated that they talk about re-infection with their case manager; refer to Figure B-4. The majority of respondents who talk about re-infection with their case manager do so occasionally. As indicated in Table B-4, only 14% of the respondents indicated talking about becoming re-infected through IV drug use every time or most times they met with their case manager, and 22% of the respondents indicated talking about becoming re-infected through unprotected sexual contact every time or most times they met with their case manager.

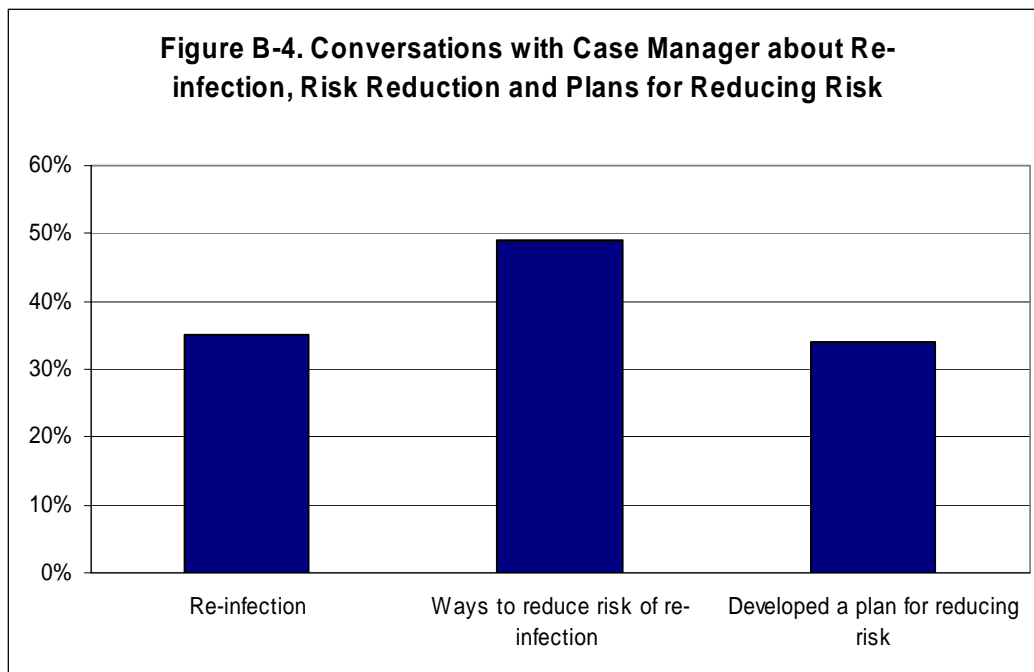


Table B-4
Frequency Talk about Re-infection and Secondary Prevention with Case Manager

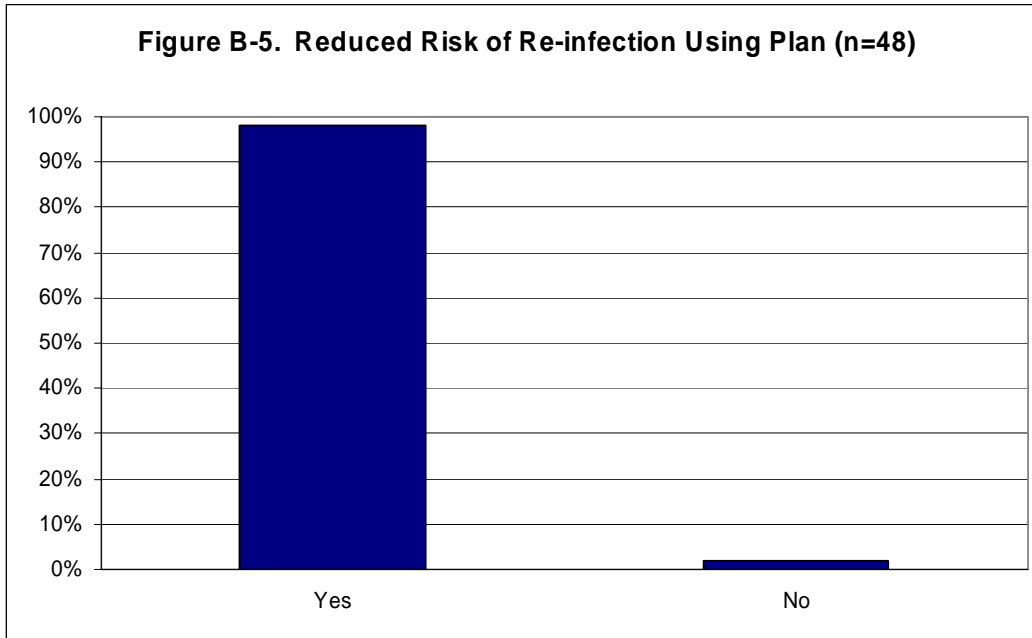
How often do you talk with your case manager about ...	Number	Percent
<i>Becoming re-infected through IV drug use</i>		
Every time or most times meet	3	14%
Occasionally	11	52%
Hardly ever or never	7	33%
Total	21	99%
<i>Becoming re-infected through unprotected sexual contact</i>		
Every time or most times meet	9	22%
Occasionally	23	56%
Hardly ever or never	9	22%
Total	41	100%
<i>Ways to prevent spreading the HIV virus to others</i>		
Every time or most times meet	21	15%
Occasionally	67	46%
Hardly ever or never	56	39%
Total	144	100%

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

In addition, all of the consumers were asked how often they talked with their case manager about ways to prevent spreading the HIV virus to others. Only 15% of the respondents said they talked about this every time or most times they met with their case manager. Close to one-half (46%) talked about it occasionally and a full 39% hardly ever or never talked about secondary prevention with their case manager. These results are presented in Table B-4, as well.

Only about one-half (49%) of the respondents indicated that they talk about ways to reduce their risk of becoming re-infected with their case manager, and even fewer (33%) have developed a plan for reducing their risk with their case manager. These results are also depicted in Figure B-4, above.

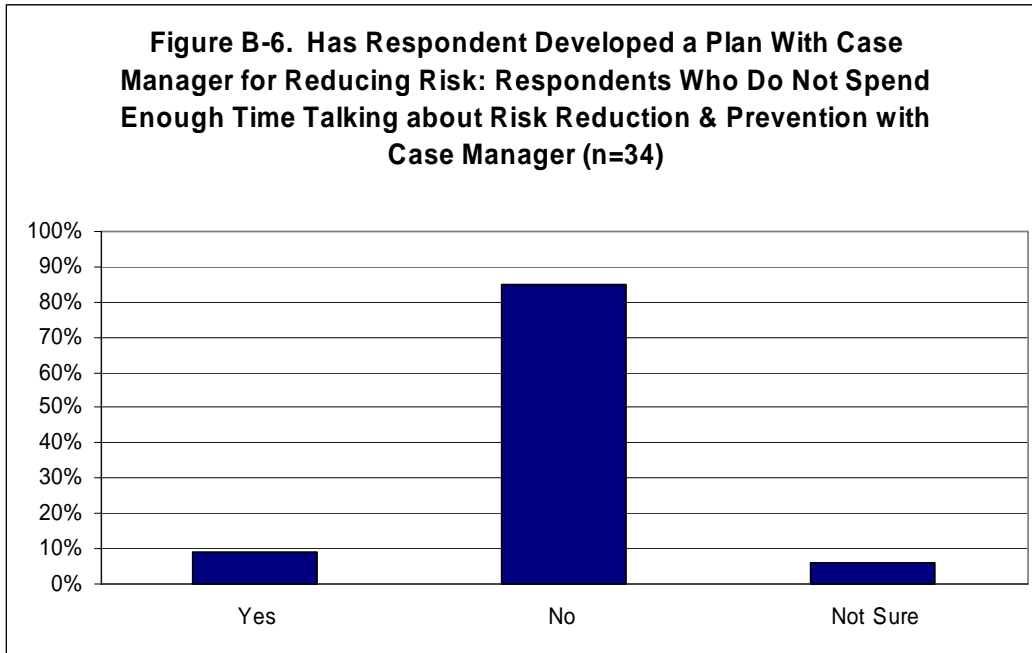
Although only one-third of the consumers have a risk reduction plan, it appears to be an effective tool for reducing risk. Nearly all (98%) of the respondents who have a risk reduction plan indicated that they have reduced their risk by using it. These results are illustrated in Figure B-5.



As indicated in Table B-5, about one-fourth (24%) of the respondents indicated that they do not spend enough time talking about risk reduction and prevention with their case manager. Only 1% indicated that they spent too much time talking about this with their case manager. However, nearly all of the consumers who indicated that they do **not** spend enough time talking about risk reduction and prevention with their case manager have **not** developed a risk reduction plan for becoming re-infected with their case manager. This result, which is presented in Figure B-6, clearly highlights the importance of having a risk reduction plan in place.

**Table B-5
Amount of Time Spent Talking About Risk Reduction and Prevention with Case Manager**

Amount of time spent talking about risk reduction & prevention	Number	Percent
Too much time	1	1%
Not enough time	34	24%
About the right amount of time	104	75%
Total	139	100%



Most (80%) of the respondents indicated that they are very open and honest with their case manager when they talk about their risk behaviors. Only 4% indicated that they were not open and honest with their case manager. This finding is presented in Table B-6.

**Table B-6
Nature of Discussions about Re-infection and Secondary Prevention with Case Manager**

When you talk with your case manager ...	Number	Percent
<i>How open & honest are you</i>		
Very open & honest	109	80%
Somewhat open & honest	21	15%
Not open & honest	6	4%
Total	136	99%
<i>How comfortable are you talking about your risk behaviors</i>		
Very comfortable	90	64%
Somewhat comfortable	36	26%
Not comfortable	14	10%
Total	140	100%

Table B-6
Nature of Discussions about Re-infection and Secondary Prevention with Case Manager

When you talk with your case manager ...	Number	Percent
<i>Has your case manager ever helped you figure out how to tell people who you are or may become physically intimate with that you are HIV+</i>		
No	54	59%
Yes	38	41%
Total	92	100%

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

Consumers were also asked how comfortable they felt talking about their risk behaviors with their case manager. About two-thirds (64%) of the respondents felt very comfortable talking about this topic with their case managers, while 26% felt somewhat comfortable. Only 10% felt uncomfortable; refer to Table B-6, above.

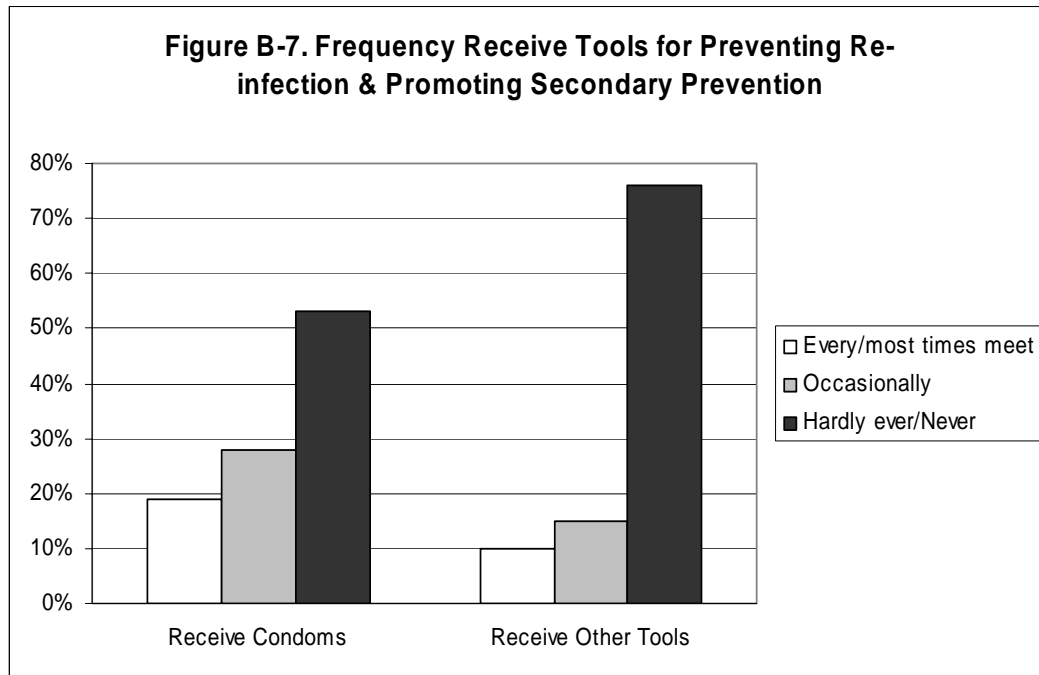
Only two-fifths (41%) of the respondents indicated that their case managers has helped them figure out how to tell people who they may become physically intimate with that they are HIV+ (Table B-6). In fact, there is a relationship between how comfortable a consumer is talking about their risk behaviors with their case manager and whether the case manager has helped them figure out how to tell people they may be intimate with that they are HIV+. Respondents who are more comfortable talking about their risk behaviors with their case manager are more likely to have talked with their case manager about how to tell intimates that they are HIV+. Conversely, those who are least comfortable talking about their risk behaviors are less likely to have discussed with their case manager how to tell sexual intimates about their HIV status. Similarly, consumers who have a risk reduction plan are more likely to have discussed with their case manager how to tell intimates that they are HIV+.

These results highlight two trends. First, having a risk reduction plan is an important proactive measure for preventing re-infection and promoting secondary infection. Secondly, consumers who shy away from these discussions are less likely to have a risk reduction plan – so case managers may need to better ensure that consumers who are least comfortable talking about their risk behaviors have a risk reduction plan in place and, despite the consumers discomfort, try to discuss proactive measures to better prevent re-infection and promote secondary prevention.

Receiving Tools from Case Manager to Prevent Re-infection & Promote Secondary Prevention

Respondents were asked how often their case manager gave them tools for preventing transmission of the HIV virus to others. Results, presented in Figure B-7, indicate that only 19% of the respondents indicated that they received condoms every time or most times they met with their case manager. In fact 53% of the respondents indicated that they hardly ever or never received condoms from their case manager. Fewer respondents indicated receiving other tools, such as dental dams or lubes. Only 10% of the respondents indicated receiving these tools every

time or most times they met with their case manager, and 76% indicated that they hardly ever or never received them.



Knowledge about & Implementation of Risk Reduction Behaviors

Consumers were asked if they know what the universal precautions are, and if so, whether their doctor or case manager has talked about them with the respondent or people living with the respondent. About two-thirds (68%) of the respondents indicated that they know what the universal precautions are. About three-fourths (76%) of these respondents indicated that their case manager or doctor did talk with them about the universal precautions. About two-fifths (39%) of the respondents who indicated knowing what the universal precautions are responded that their case manager or doctor also talked about them with people living with the respondent. These results are presented in Table B-7.

**Table B-7
Universal Precautions**

	Number	Percent
Know what universal precautions are		
Yes	97	68%
No	20	14%
Not sure	25	18%
Total	142	100%

Table B-7
Universal Precautions

	Number	Percent
<i>If know what universal precautions are: Did case manager of doctor talk about these to respondent?</i>		
Yes	71	76%
No	18	19%
Not sure	4	4%
Total	93	99%
<i>If know what universal precautions are: Did case manager of doctor talk about these with people living with respondent?</i>		
Yes	31	39%
No	42	53%
Not sure	6	8%
Total	79	100%

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

Most (85%) of the respondents indicated that they know how to prevent themselves from becoming re-infected with HIV/AIDS. None (0%) of the respondents indicated that other people use their toothbrush, even occasionally. However, a substantial percentage of respondents indicated having *unprotected* sex within the past six months. Over one-quarter (27%) of respondents who have been receiving case management services for at least 6 months had unprotected sex within the past six months. Moreover, 32% of respondents who acquired the HIV virus through sexual contact and who have been receiving case management services for at least 6 months had unprotected sex within the past six months. These results are presented in Table B-8.

Only 3% of the respondents who have been receiving case management services for at least 6 months injected non-prescription drugs (such as heroin, cocaine, speed, etc.) or used injectable steroids within the past six months. However, 13% (3 of the 23 respondents) who acquired the HIV virus by sharing needles and who have been receiving case management services for at least 6 months injected non-prescription drugs (such as heroin, cocaine, speed, etc.) or used injectable steroids within the past six months. These results are also shown in Table B-8.

**Table B-8
Knowledge & Implementation of Risk Reduction Behaviors**

	Number	Percent
Know how to prevent self from becoming re-infected with HIV/AIDS		
Yes	122	85%
No	11	8%
Not sure	10	7%
Total	143	100%
Other people use respondent's toothbrush, even occasionally		
Yes	0	0%
No	144	100%
Not sure	0	0%
Total	144	100%
Among those receiving case management services for 6 months or longer & acquired HIV through sexual contact (n=96)		
Had unprotected sex within last 6 months	31	32%
Among those receiving case management services for 6 months or longer & acquired HIV by sharing needles (n=23)		
Injected non-prescription drugs or injectable steroids within last 6 months	3	13%

Focus Group of Consumer Case Managers

During September 2003, a focus group was held with the case managers from the four case management agencies. The focus group helped frame many of the questions asked on the Consumer Survey, described above. Results from the focus group provide an additional avenue for gaining insights into the challenges of designing effective prevention and risk reduction programs for consumers of case management services.

Questions addressed the nature and character of discussions with clients when talking about prevention and risk behaviors; frequency and time spent discussing prevention and personal risk behaviors; whether personal risk behaviors are re-assessed; types of barriers clients face in preventing secondary infection; comfort felt by the client and case manager when talking about the client's personal risk behaviors; need for additional training on risk behaviors and prevention issues; types of curriculum or particular resources used when talking about risk

behaviors and prevention, and whether prevention is an area covered in the service coordination plans for clients.

Typically clients are seen by case managers on a one-to-one basis. Some case managers hold support groups, and achieve 100% attendance. Another case manager indicated that they have trouble getting groups going because clients are concerned that “word gets around that so-and-so has HIV....”

One case manager indicated that they are required to see clients at least once a month, but that clients are typically seen more often than that. Another case manager indicated that it varies. Some she sees almost on a daily basis, while others she only sees about once every three months when they review their service coordination plans.

Case managers described the nature of their discussions with their clients as “give and take,” although sometimes it can be more instructional with the case manager reviewing prevention material or something else. Whether the conversation is more give and take, with both the case manager and client asking and answering questions depends on how open the client is when talking about their personal risk behaviors. One case manager indicated that she does role playing with her clients who are struggling with issues, such as how the client may tell someone who they may become physically intimate that they are HIV+.

For the most part, prevention is discussed with clients on intake, and then again whenever the topic comes up. Case managers indicated that the topic comes up “all the time,” particularly during the initial period after the client starts receiving case management services. One case manager talked about how new clients have trouble being forthright about their risk behaviors when they first start receiving case management services. It takes awhile for trust to build and the client to realize that being forthright affects their life. When the case manager feels that clients are not being forthright about their personal risk behaviors, the case manager will discuss risk behaviors and HIV, and how risk behaviors affect one’s life, every time the case manager meets with these clients. Most of the case managers indicated that they talked about prevention for about 10 minutes when they talk about it with their clients, although for some clients the discussion may continue for about an hour. With clients who are resisting or not accepting their HIV diagnosis, talking about prevention and risk behaviors can be a “struggle”.

Typically the client’s personal risk behaviors are re-assessed during these discussions. One case manager indicated that if she has determined the client to be “high-risk” then she makes a point of bringing up the issue of prevention and risk reduction every time she sees them.

Case managers described the frustration of working with clients who do not practice prevention, for various reasons. A client described by one case manager has been HIV+ for eight years and the disease has not progressed.

“I have a client who, for whatever reason, his HIV just hasn’t progressed. You know, he’s been positive for eight years and he’s like a phenomenon. His levels are excellent and they’ve always been that way, but he takes that as that means I don’t have it so I tell him no, it doesn’t mean that. And I tell the doctor, tell him

what that means so the doctor tells him what it means, but then it's a few hours, minutes, weeks later, it's I don't have it. Well you do have it and my biggest thing that most concerns me is that you're going to not...you're going to have unprotected sex and obviously that's a huge problem, you know, and when I say it to him like that then it's okay, do you really want to pass that on to somebody? No, no, that's not right but I have to...because he does that I have to all the time bring that up to make sure that he is conscious of really what that means, and I have to reiterate that with the doctor all the time too because he gives him hope just by saying the numbers are so good. He translates it totally different."

Another case manager described the situation of a woman who will not inform people she is or will become intimate with out of fear of rejection.

"... she wants to be in a relationship and she is not going to reveal so every time she's about to start a new relationship she'll call me constantly. She'll come in and collect a bag of condoms but still wonder how she's going to bring that out in the relationship, and she will try to find ways and means of having unprotected sex rather than tell the partner. Sometimes she'll come in after all that education and she'll say I'm pregnant. I'll say how did that happen after all that we've talked about and that bag of condoms you took? ... So by that time I know she must have exposed a partner and I really don't know what to do after that, so it depends on the client. Some clients you can talk over and over and they're still going to do something like that and other clients get so shaken with the diagnosis that they don't engage in sex at all. They don't."

Case managers indicated that some clients firmly decide not to have sex again after they find out they are HIV+. One case manager stated, "Yep, it's a non-issue. I've had several clients who say I'm never having sex again and they mean it."

Comments by case managers centered on prevention related to sexual behavior and drug use, and did not focus on other forms of secondary prevention. One of the case managers indicated an additional venue for providing prevention services to their consumers is their agency's monthly newsletter. The newsletter contains important information about prevention, new information on ways to protect oneself, and general health prevention information such as the appropriate vaccines to have.

Case managers indicated that they are very comfortable talking about risk behaviors and prevention with their clients. Instead, one case manager described her discomfort when she found out one of her clients is pregnant and the client's partner is HIV-. The case manager had difficulty not being judgmental, and she felt it was important to "hold back" her reaction to this situation.

"... Where it gets uncomfortable sometimes is where I'm being too bold, too honest. Like if I have a client who says, you know, I'm pregnant and my partner is HIV negative and then I say, what are you thinking? How could you not understand? Things like that I have to hold back my...it's not even

judgment...well I guess it is judgment, but it's totally justified so I have to hold back on how honest I am with them, and I think that comes in with relationship too about how honest I can be with them. What's our relationship? Is it the kind of relationship where they're going to take that and understand that or appreciate that or am I really going to offend them? So that's the discomfort. It's not to bring up something controversial or risky. It's to just hold back. That's where it gets uncomfortable."

Instead, some of the clients seem to feel inhibited when discussing their risk behaviors, particularly risk factors related to drug use. As one case manager indicated,

"... the clients are more uncomfortable discussing drug use with me than sexual behaviors. That's a very private thing and I think that's something that, especially since I live in that community as well, I think they're worried about that with the legal issues and everything ... but probably the drug issue is the biggest one that they're uncomfortable talking about."

Case managers indicated that they have enough knowledge and training to talk about risk behaviors and prevention issues with their clients. However, several indicated that they always welcome getting more information, and that it is important to stay up-to-date on new information coming out. There was some interest in training that focused on how to make clients feel comfortable when talking about sensitive issues. Some of the case managers indicated that this area is touched upon in the 3-day counseling training course. Case managers stated that they had no problems finding enough time to provide sufficient attention to prevention and risk behaviors when meeting with clients.

For the most part, case managers did not indicate using a particular curriculum or resources. Instead, case managers relied on published brochures or coloring books for children that are published by organizations such as the CDC. One case management agency uses a risk reduction questionnaire as a tool. Case managers did indicate that flexibility is important, but prepared material that provided "markers" that would be useful in providing guidance on topics that should be addressed under certain situations.

Case managers from different agencies have access to different materials. During the focus group, the case managers shared information with each other on what materials they found useful, such as coloring books that explain germ and hand washing. Each case management agency appeared to be locating and obtaining their own educational materials to share with consumers.

One case manager indicated that at their agency, prevention workers and case managers do not duplicate services. For instance, the case manager does not instruct her clients on how to use a condom since that is the purview of the prevention workers.

Case managers indicated that one of the major barriers clients face in preventing secondary infection is rejection. As stated by one case manager, "Especially rejection. That's a big thing. They don't want to be lonely for the rest of their lives." Stigma was also mentioned

as a barrier. A third barrier is client's feelings about using a condom. As stated by one case manager, "... you hear that it's not natural. It doesn't feel good, and all that kind of stuff and being told that they really should be using the condoms from now on, that's a depression. I mean you don't want to hear that, to hear that kind of stuff, so I think the actual condom itself is a barrier."

Case managers were asked if they put prevention in their service coordination plans. Case managers indicate they do when it is applicable, such as when it is an ongoing issue.

C. Instruction in Prevention & Risk Reduction among the At-Risk Public

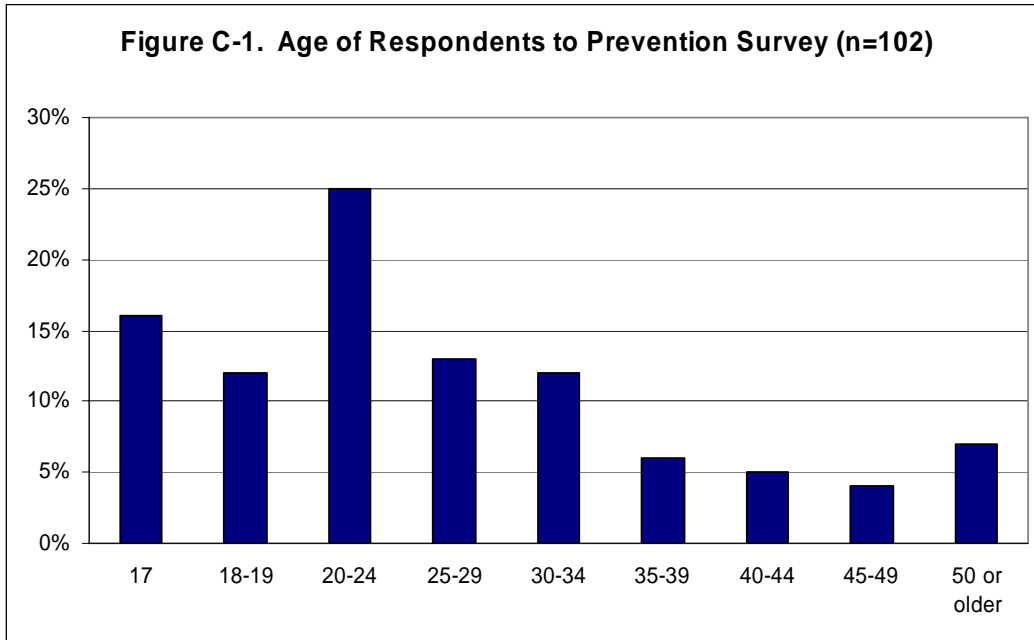
Outreach in Primary Prevention: Survey of Participants

Participants receiving instruction by prevention outreach workers were administered a short survey. This survey was distributed by the outreach workers to participants over a three-week period from February 23 to March 12 (2004) *after participants received instruction*. A total of 106 participants completed the survey. The survey asked questions measuring knowledge of how one can become infected with HIV/AIDS, whether the participant knows why they are at risk, how one can prevent infection with HIV/AIDS, and where to get a free test for HIV. The survey also asked questions about whether the prevention outreach worker developed a risk reduction plan with the participant and the effectiveness of that plan, as well as whether the participant has had past contact with HIV/AIDS prevention workers. Respondents also answered socio-demographic questions about themselves.

While results from this survey are useful for developing a needs assessment, it does not provide a good measure of the effectiveness of the outreach intervention since there is no control group or pretest data to provide a comparison.

About Respondents to the Primary Prevention Survey

On average, respondents are 28 years old. However, a substantial percentage of respondents are teens or young adults in their early twenties. Over one-quarter (28%) of the respondents are 17 to 19 years old, and another 25% are between 20 and 24 years (refer to Figure C-1). Only 8% of the respondents are 50 or older, with the oldest respondent being 68.



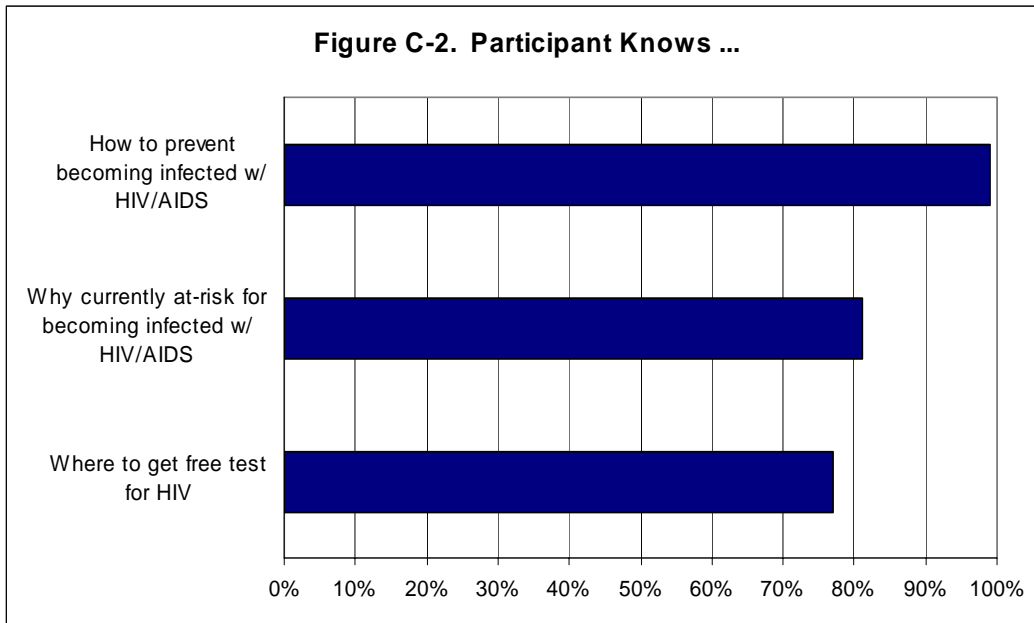
Respondents to the Prevention survey were fairly evenly split between males (52%) and females (48%). Most (88%) of the respondents to the prevention survey were White. About one-tenth (11%) identified themselves as African American, and 1 person (1%) identified himself as Native American. No one identified themselves as Hispanic or some other race/ethnicity. Gender and race/ethnicity breakdowns are presented in Table C-1.

**Table C-1
Gender and Race/Ethnicity of Respondents to Prevention Survey**

	Number	Percent
Gender		
Male	51	48%
Female	55	52%
Total	106	100%
Race/Ethnicity (n=106)		
White	93	88%
African American	12	11%
Hispanic	0	0%
Native American	1	1%
Other	0	0%

Knowledge about HIV/AIDS: Primary Prevention

After receiving instruction in primary prevention, 77% of the participants knew where they can get a free test for HIV. In addition, 81% of the participants indicated that they know why they are currently at risk for becoming infected with HIV/AIDS. Moreover, 99% of the participants indicated that they know how to prevent themselves from becoming infected with HIV/AIDS. All of these results are illustrated in Figure C-2. It is not possible to determine if these participants learned this information in the educational session with the prevention worker or already knew it prior to the session because participants were not administered a survey before the session, nor was there a control group.

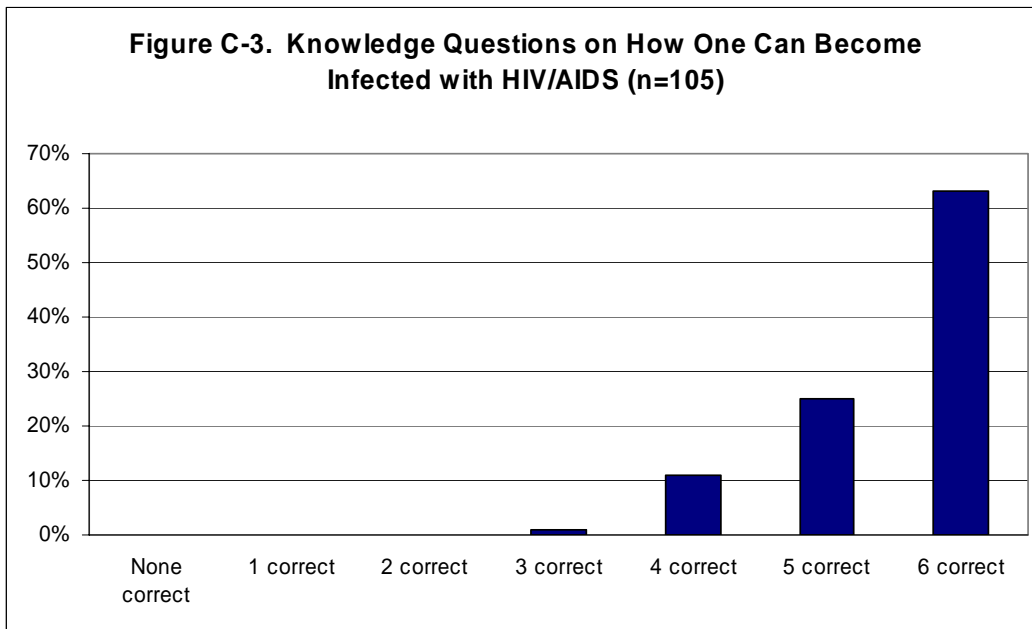


As a check on participant’s self-perception of knowledge about primary prevention, participants were also a series of six questions measuring their knowledge about of how one can become infected with HIV/AIDS. These six items and the percentage of participants answered each correctly are presented in Table C-2. All in all, participants appear to have a fairly good level of knowledge on how to avoid becoming infected with HIV/AIDS. Participants were least likely to answer correctly those questions that are unrelated to acquiring HIV/AIDS, creating the possibility that participants may engage in behaviors that are irrelevant to HIV/AIDS prevention. Nearly all of the participants answered correctly the questions about behavior that puts the person at-risk of acquiring HIV/AIDS.

Table C-2
HIV/AIDS Primary Prevention: Percentage of Participants Answering Questions Correctly
(n=105)

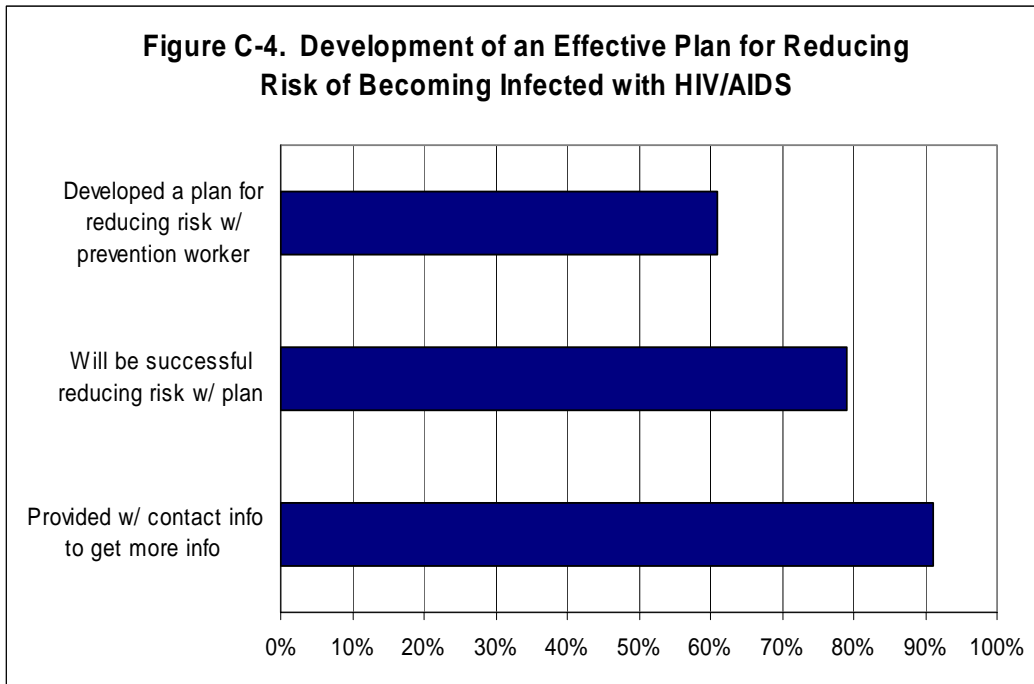
You can become infected with HIV/AIDS by ...	Number	Percent
Sitting on a toilet seat (<i>false</i>)	91	87%
Sexual contact (<i>true</i>)	103	98%
Sharing needles when injecting drugs (<i>true</i>)	104	99%
Sharing needles rinsed with bleach when injecting drugs (<i>false</i>)	70	67%
Having multiple sexual partners (simultaneously or serially) (<i>true</i>)	104	99%
Having sex with someone who is HIV+ or has AIDS (<i>true</i>)	105	100%

On average, participants answered 5 of the 6 questions correctly. Nearly two-thirds (63%) of the participants answered all six questions correctly. One-quarter (25%) answered five of the six questions correctly, and 12% answered three or four questions correctly. No one answered fewer than three questions correctly. Figure C-3 depicts these results.



Development of a Risk Reduction Plan and Behavior Change

Participants were asked if they developed a plan for reducing their risk of becoming infected with HIV/AIDS with the HIV/AIDS prevention worker. Less than two-thirds (61%) of the participants said they did this. However, the effectiveness of these plans is highlighted by the finding that 79% of those who developed a plan feel that they will successfully reduce their risk of HIV/AIDS using this plan. The vast majority (91%) of the participants did receive contact information from the HIV/AIDS prevention worker so they can find out more about HIV/AIDS prevention & risk reduction. These findings are illustrated in Figure C-4.



Close to one-half (45%) of the participants indicated that they had talked with a HIV/AIDS prevention worker before the current session with the prevention outreach worker. Again, the effectiveness of prevention outreach is highlighted by the finding that 77% of those who did have prior contact have changed at least some of their risk behaviors for contracting HIV/AIDS since that time. These results are presented in Table C-3.

Table C-3
Past Contact with HIV/AIDS Prevention Worker and Changes in Behavior

	Number	Percent
Talked with HIV/AIDS prevention worker before current contact		
Yes	46	45%
No	50	49%
Not sure	6	6%
Total	102	100%
If Yes: Risk behaviors for contracting HIV/AIDS were changed since prior contact (n=43)		
Yes	33	77%
No	7	16%
Not sure	3	7%
Total	43	100%

Interviews with Prevention Outreach Workers

A series of three interviews with prevention outreach workers at two case management agencies were conducted in November, 2003. Questions focused on the characteristics of people served; the nature and frequency of outreach and follow-up; the nature and character of discussions about personal risk and prevention; comfort felt by the outreach worker when talking about the participant's personal risk behaviors; need for additional training on risk behaviors and prevention issues; types of curriculum or particular resources used when talking about risk behaviors and prevention; and barriers that participants face in practicing prevention. Only two of the three outreach workers interviewed were available to answer the first series of questions.

Prevention outreach workers provide services to target groups that are, in part, defined by the demographics of their service area. One outreach worker indicated that they predominantly serve youth (13-25 years of age), as well as the parents of younger/middle school children, because of the demographics of their agency's service area and the presence of universities. The other outreach workers described a variety of target groups, including the general public, IV drug users, African American female partners of IV drug users, and to a lesser extent MSM and youth (up to 24 years of age). The goal of one agency is to serve 3,000 to 5,000 participants a year.

Both outreach workers meet participants one-to-one as well as in a group setting. The format of the meeting is designed by one outreach worker to meet the needs of the audience. Generally, participants meet with the outreach worker only once, although in some cases, participants meet more than once (e.g., MSM participants who go to a gay bar).

Follow-up is more likely to occur with certain groups of people, such as those coming in for HIV testing. One approach that has resulted in follow-up contact with participants is when

outreach workers talk one-on-one with participants. They are told that if they come back they will be provided with condoms. This approach tends to result in the participant coming back about five times, after which the incentive loses its appeal and the participant stops coming back. In general, however, it is difficult to conduct follow-ups with participants. Participants are given cards so they know where to call if they want more information or assistance. However, the participant determines whether they will make the follow-up contact. One outreach worker described the difficulty in conducting a follow-up meeting with participants as follows. Participants have gained knowledge and information, and so it is difficult to induce them to come back to a second meeting. An effective incentive is needed, such as a monetary incentive. However, the program does not have the resources to provide this.

Prevention is addressed in all individual meetings, and in fact prevention is the purpose of these meetings. The goal of these interventions is to change personal risk behaviors. Outreach workers indicated that they ask participants to complete a short survey that helps a person to assess their risk, and the personal risk assessment form is used as a basis for intervention. One outreach worker indicated that when the participant completes the survey in one-to-one meetings, the participant and outreach worker are better able to discuss personal risk behaviors. In contrast, when doing a presentation in a group meeting, information on prevention is presented and participants complete the survey, but the format prevents targeting any one individual's specific risk behaviors. The other outreach worker indicated that in the group meetings she conducts, participants are asked to complete a personal risk assessment and that they discuss different prevention strategies as a group. Participants' skill-building abilities increase as a result of this education/discussion format.

Outreach workers stated that their goal is to have one-to-one meetings that continue for at least 15 minutes since the agency is reimbursed in 15-minute units. However, interventions may be as short as 5 minutes or continue for 30 minutes or more. Both individual and group meetings have a give-and-take format.

According to one outreach worker, personal risk case management *per se* does not occur at their agency since there are no individual identifiers on the personal risk assessment and the agency is not funded to engage in case management. The other prevention worker indicated that they use the risk assessment survey to see if any behaviors have changed. Personal risk is assessed and preventive tools are distributed to help ensure that the participant is doing what they said they would do. One outreach worker indicated that he sees some participants every week, and he is able to assess their personal risk frequently to see if there is any behavioral change. All of the outreach workers interviewed indicated that they feel comfortable talking with participants about their personal risk behaviors and prevention. One prevention worker described some difficulties in rural areas, and that sometimes he is viewed as a "cop" in some settings. In certain settings he takes a partner.

All three outreach workers felt that they have enough knowledge and training to discuss risk behaviors and prevention issues with participants. However, they also indicated that they find going to additional trainings worthwhile because there is always something else to learn. One outreach worker indicated an interest in attending training that focused on helping others open up due to the large amount of denial evident among participants.

The outreach workers indicated that they personally have enough time to talk about prevention and risk prevention issues with participants. However, sometime participants are rushed, particularly when the client works and the intervention occurs during the workday.

Some of the resources used by outreach workers are drawn from websites such as CDC, avert.org, StopHIV.com, and a directory of resources for prisoners. Brochures such as “Becoming a Responsible Teen” and material from the Pennsylvania Department of Health’s Resource Clearinghouse are also used. One of the outreach workers mentioned consulting with researchers at Penn State University who are engaged in HIV research. Outreach workers also develop their own worksheets and use the personal risk assessment survey as a springboard for education and intervention.

One outreach worker prefers to use material directly from the CDC due to differences in interpretation of materials. Another outreach worker indicated that it is very useful for people to have materials in their hands that can be reviewed later. She mentioned that a little card from the NCDAC that indicates high, medium, and low risk behaviors on the front side, and NCDAC’s name and phone number on back, is very valuable and she “loves” to hand it out. The information on the card makes them think about their behaviors and it also provides necessary follow-up information.

One outreach worker indicated that there are many brochures that would be useful but the agency can not afford them, such as those dealing with hepatitis, drug and alcohol use, and IV and other drug use. When the agency purchases brochures, it is necessary to purchase those on relevant but general topics. The outreach workers relate the general information to each group when they do the session.

The outreach workers were asked to discuss barriers that participants face in practicing prevention. One of the outreach workers indicated that many participants have weak communication skills. Another indicated that participants might not have access to tools when they are needed. The expense of the preventive tools can also be a barrier for some participants. Other barriers include partners refusing to practice safe sex, as well as whether the participant is under the influence of drugs or alcohol. One outreach worker mentioned that older people with the HIV virus can be harder to work with; these people often feel that because they have lived a long time with the disease without having problems in the past, they will not have a problem in the future. Denial is also a barrier – some people do not think they are at risk of contracting the HIV virus.

D. Interviews with Physicians

Interviews were conducted with two of the seven infectious disease physicians serving the NCDAC region. Also, an interview was conducted with a gastro-intestinal physician who serves patients in the NCDAC region at-risk of contracting HIV/AIDS. Questions focused on the socio-demographic characteristics of their patients who are HIV+ or have AIDS; discussions

about prevention and personal risk behaviors with their patients; barriers their patients face in preventing infection; for patients who are NCDAC consumers, the nature of the physicians' interactions with their patients' case managers.

Both of the infectious disease physicians indicated that they see a number of HIV/AIDS patients who use IV drugs, although one doctor indicated that he is seeing a greater number of patients who are MSM. The latter physician sees about an equal number of White and African American patients, while the former sees a higher percentage of White patients. The gastro-intestinal physician indicated seeing primarily IV drug users; these patients tend to be young, but equally distributed across different racial groups and gender. About 15% of the gastro-intestinal physician's patients are HIV+ or have AIDS; these patients are already clients of an AID organization, and he works collaboratively with an infectious disease specialist. The socio-demographic characteristics of these patients are similar to the others that the doctor treats. The doctor noted that the HIV/AIDS patients tend to have a low self-worth and are looking for something that makes them feel better.

While both of the infectious disease physicians indicated that they talked about secondary prevention with their patients some of the time or occasionally, the gastro-intestinal physician indicated that he spent a little time talking about prevention on every visit. Topics discussed include whether the patient is using drugs now, and if so the types of drugs used. Typically these patients are using heroin, and so Suboxone, a maintenance treatment for opioid addiction that also reduces the risk of co-infection and Hepatitis C, is offered in order to bring the heroin addiction under control. Sometimes these patients will ask how they can quit using heroin.

The infectious disease physicians typically advise all patients to be tested for Hepatitis C. The one doctor also tests for Hepatitis B and Hepatitis A, while the other infectious disease physician tests for TB and does routine blood work. The gastro-intestinal physician typically asks his Hepatitis C patients to be tested for HIV – he indicated that it is a standard procedure. He also tests for Hepatitis A and Hepatitis B. All three physicians interviewed indicated that they receive the results of these tests.

Both of the infectious disease specialists indicated that they talked about the personal risk behaviors of their HIV/AIDS patients occasionally at best, and they typically do not talk about specific risk behaviors such as IV drug use or sexual behaviors. Time limitations prevent them from addressing with these issues. When time does allow for a discussion of risk behaviors, one physician indicates that he talks to his patients about controlling their drug use, adherence to their medication, and condom use. Occasionally at most one of the infectious disease physicians talks to his HIV/AIDS patients about changing his/her behavior in order to reduce risk. The nature of these discussions tends to be instructional in nature, although sometimes they have a give and take character.

In contrast, the gastro-intestinal physician addresses patients' personal risk behaviors related to HIV/AIDS every time they come in for a visit, although he is not able to spend much time on the topic (about 30 seconds). He tells the patient that HIV/AIDS is a communicable disease, and that the patient's partner needs to know about it. He also mentions the importance

of safe sex and using condoms. The gastro-intestinal physician does take the time to talk about specific risk behaviors like IV drug use or the patient's sexual behaviors.

Two of the three physicians indicated that their patients have never refused to stop the behaviors putting them at risk. The third physician (infectious disease) said this has occurred, and that he would not put the patient on a medication regimen unless the person discontinued their drug use.

All three physicians indicated that they feel very comfortable talking about risk behaviors and prevention with their patients. One physician indicated that he does prefer knowing a little more background information about the person before broaching the subject.

The three physicians' perceptions of how comfortable their patients feel talking about prevention and their own personal risk behaviors differed. One of the physicians indicated that he thinks he is very approachable and that his patients feel comfortable talking about these topics. The second physician was unsure how his patients feel since he does not spend much time on this topic. The third physician indicated that his patients are becoming more comfortable. It has been difficult for his patients who are IV drug users to open up to him because of the stigma attached to IV drug use.

None of the physicians felt they spent enough attention on prevention and risk behavior issues with their patients. Time limitations prevent this from occurring. One physician also noted that it is difficult finding help (i.e., nurse practitioners or physician assistants) who are knowledgeable about the topic.

The three physicians discussed the types of barriers their patients face in preventing infection (primary and secondary). Barriers mentioned include:

- Access to medical care, especially for with no health insurance or those on medical assistance.
- Stigma, since no one wants to talk about HIV/AIDS.
- Not seeing the patient frequently enough or inability to see all patients coming into the clinic.
- A shortage of time, resulting in a focus solely on medical issues during visits.
- A high rate of patients not showing up for their appointments.
- Non-compliance on the part of the patients.
- Dysfunctional individuals who do not chose healthy behaviors.
- Language used by medical personnel.
- Hospital policies that prevent medical staff from distributing condoms.
- Physicians who are unwilling to see patients who are IV drug users.

The two infectious disease physicians were asked a series of questions about AIDS Service Organizations and case managers for their HIV/AIDS patients. Both doctors indicated that they inform patients who do **not** have a case manager about agencies such as AIDS Service Organizations, although they do not refer them *per se*. For patients who do have a case manager, neither doctor felt they had adequate contact with the case manager. One doctor mentioned that

contact should be limited to those clients who need assistance at the doctor's office. The other mentioned that greater case manager involvement would help with the coordination of care.

One physician indicated that only 50% of his HIV/AIDS patients say they have a case manager. The other 50% say either that they do not see their case manager or that they do not know who their case manager is because case managers keep changing. Neither infectious disease physician sees case managers very often. One physician indicated that there is one case manager who comes with her clients, although the case manager cannot go into the exam room with the patient.

Neither infectious disease physician discusses risk reduction with the patient's case manager. Both physicians think that it is the responsibility of both the physician and the case manager to be discussing risk reduction with the patient. However, because of time limitations, it may be easier for the patient to discuss risk reduction with their case manager.

E. Social Service Providers Survey: Prevention Service Needs in the NCDAC Region

In winter 2004, a questionnaire was distributed to 350 social service providers in the 12-county North Central region. Providers who serve a variety of clients, particularly those at risk of contracting HIV/AIDS were mailed a copy of the survey, and copies were distributed to employees involved in direct client services. Providers could also answer a web-based version of the survey on the By The Numbers website. A total of 95 surveys from 65 agencies were returned, resulting in an effective response rate of 19%.

The survey asked a variety of questions, including whether the agency serves people infected with the HIV virus, has written policies for discussing HIV/AIDS prevention with their clients, and whether the respondent has any formal training on educating the public or their clients about HIV/AIDS risk prevention. Respondents' attitudes about discussing HIV/AIDS risk prevention with their clients were measured, as well as the conditions under which respondents discuss HIV/AIDS risk prevention with their clients. Barriers to discussing HIV/AIDS risk prevention were measured and respondents were asked about strategies for dealing with these barriers. Respondents were also asked whether they serve clients who are at risk of becoming infected with HIV – that is, IV drug users, men who have sex with men (MSM), and clients with multiple sexual partners (simultaneously or serially). Respondents answered a series of questions about clients falling into each of these at-risk groups, such as whether they suggest to these clients that they be tested for HIV/AIDS, conditions under which respondents talk about HIV/AIDS risk prevention with these at-risk clients, and the barriers to doing this. Respondents also answered questions regarding the socio-demographic characteristics of each of these at-risk client groups.

About the Respondent, the Agency, and the Community

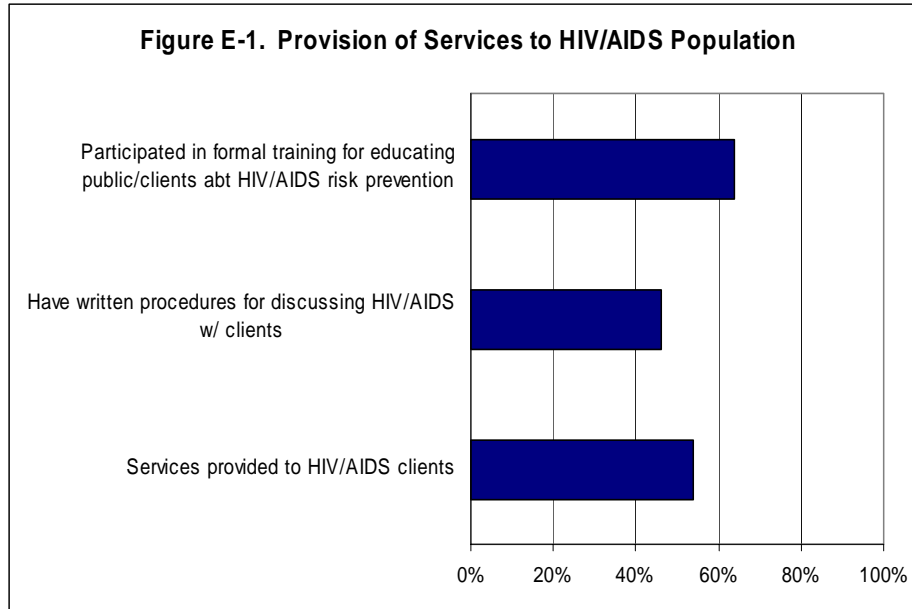
Respondents were asked to indicate what job functions they perform for their organization; respondents could list multiple job functions. About one-half (45%) of the respondents indicated that they are a counselor or provide case management, and about one-quarter (23%) are program administrators. About one-tenth of the respondents fall into the each of the following job categories: instructor (14%), probation/parole (12%), and data entry (9%). About two-fifths (41%) of the respondent indicated working in other areas as well, such as corrections (other than probation/parole), health care, and psychotherapy. Other job functions mentioned by respondents included nurse (in a school, prison, or clinic), physician assistant, psychologist, and police officer.

About one-half (51%) of the respondents indicated that they were aware of the existence of the NCDAC prior to being contacted about completing this survey. About one-third (31%) of the respondents indicated that either they or someone else from their organization had participated in an NCDAC activity or attended an NCDAC event.

Over one-half (56%) of the respondents indicated that their agency was headquartered in Lycoming, Clinton, or Northumberland Counties. Another 27% were headquartered in Centre or Union Counties, and 6% were headquartered in Bradford County. Less than 5% of the respondents indicated that their agency headquarters were in any of the other counties in the NCDAC region.

Respondents were asked about the types of clients served by their organization. A wide variety of client types were mentioned. Responses included juveniles/adolescents/teens, junior high school students, senior high school students, pregnant teenage girls, teenage mothers, youth with drug and alcohol problems, people in general with drug and alcohol problems, victims of domestic violence, victims of sexual assault, women seeking reproductive health care, women in general, adults in general, college students, people with mental health problems, homeless people, prison inmates, and those on probation or parole. Some respondents indicated that they serve the general public, using phrases such as “all clients” and “all ages.”

About one-half (54%) of the respondents indicated that their agency provides services to people infected with the HIV virus. Respondents were asked to indicate the number of clients served by their agency in 2003 fiscal year who were living with HIV/AIDS. On average, agencies served 3 clients during 2003 with HIV/AIDS. Close to one-half (46%) of the respondents indicated that their organization has written procedures for discussing HIV/AIDS risk prevention with clients. Close to two-thirds (64%) of the respondents indicated that they had participated in formal training focusing on educating the public or their clients about HIV/AIDS risk prevention. These results are illustrated in Figure E-1.



The questionnaire contained a series of attitudinal questions focusing on the ability of the respondent to talk about HIV/AIDS with his/her clients. Respondents 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. Responses are presented in Table E-1.

**Table E-1
Talking with Clients About HIV/AIDS**

	Number Responding	Average Response
Negative <i>community</i> attitudes about HIV/AIDS inhibit my ability to talk about the subject with my clients.	89	3.9
Negative attitudes about HIV/AIDS <i>in my place of work</i> inhibit my ability to talk about the subject with my clients.	90	4.3
I feel comfortable talking about HIV/AIDS risk prevention with my clients.	91	1.9
I do <i>not</i> feel as though I have adequate background and training to talk about HIV/AIDS risk prevention with my clients.	92	3.5
My clients who are at risk of contracting HIV/AIDS feel comfortable when we talk about HIV/AIDS risk prevention.	72	2.5

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

On average, respondents disagreed with the statements that negative community attitudes and negative attitudes about HIV/AIDS in their workplace inhibit their ability to talk about HIV/AIDS with clients. Community attitudes and attitudes in the respondent's place of work do not appear to hamper respondents' ability to talk about HIV/AIDS with clients.

Respondents appear somewhat neutral about the adequacy of their background and training to talk about HIV/AIDS risk prevention with their clients. Results indicate that about one-quarter (24%) of the respondents do **not** feel they have an adequate background or training to discuss HIV/AIDS risk prevention. One-half (50%) of the respondents indicated that their clients who are at risk of contracting HIV/AIDS feel comfortable talking about risk prevention with the respondent. About 30% were unsure of how their clients felt.

On average, respondents indicated they feel comfortable talking about HIV/AIDS risk prevention with their clients. Over four-fifths (84%) indicated being comfortable talking about the subject with their clients.

Talking about HIV/AIDS Risk Prevention with Clients

Respondents were asked to indicate whether they ever talk about HIV/AIDS risk prevention with their clients. One-quarter (25%) of the respondents indicated that they talk about it with all their clients, but most (70%) of the respondents indicated that they talk about it under certain circumstances. Only 5% of respondents never talk about HIV/AIDS risk prevention. Results are presented in Table E-2.

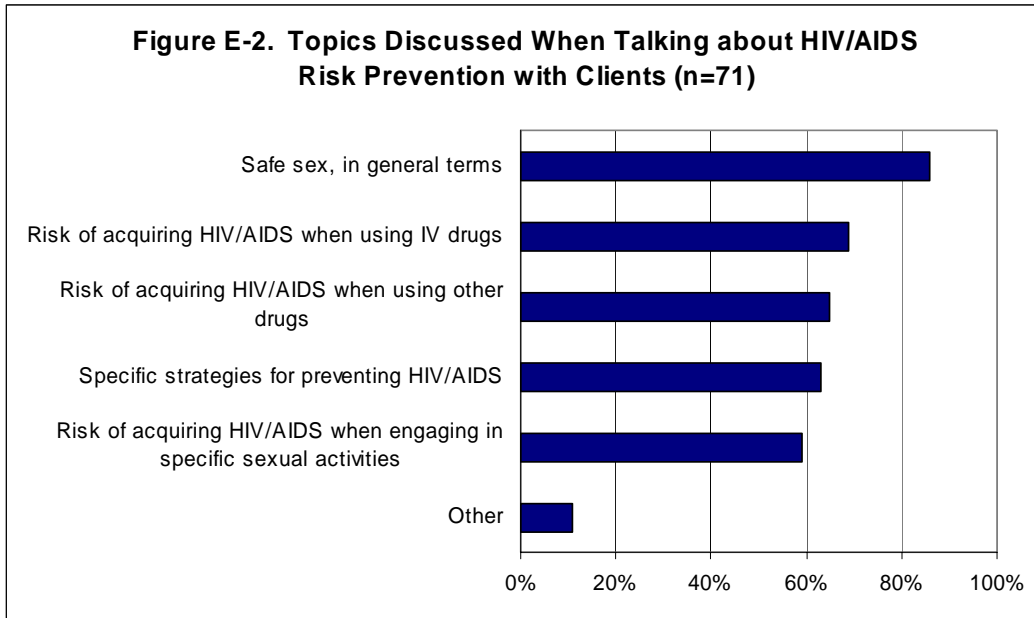
**Table E-2
Ever Talk about HIV/AIDS Risk Prevention with Clients?**

Do you ever talk about HIV/AIDS risk prevention with your clients?	Number	Percent
No, never talk about it	4	5%
Yes, talk about it with all my clients	19	25%
Yes, talk about it under certain circumstances	54	70%
Total	77	100%

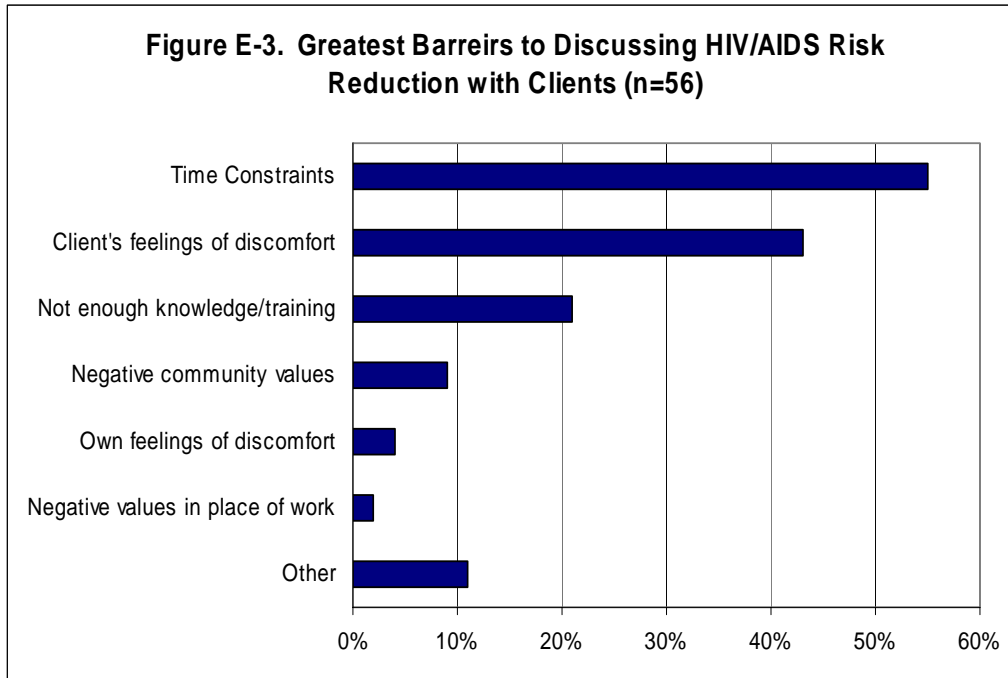
Respondents who talk about HIV/AIDS risk prevention were asked to describe the conditions under which they do talk about it with their clients. Respondents indicated that they talk about HIV/AIDS risk prevention if the client is sexually active, if the client is a drug user, if the client brings it up during a meeting, if it comes up in a conversation with the client, and in educational programs that the respondents conduct in schools.

Respondents were asked to indicate what topics they discuss with their clients when talking about HIV/AIDS risk prevention. Results are depicted in Figure E-2. Nearly all (86%) of the respondents indicated talking about safe sex in general terms. About two-thirds indicated that they talk about the risk of contracting HIV/AIDS when using IV drugs (69%) and when

using other (non-IV) drugs such as alcohol, marijuana, etc. (65%). Also, about two-thirds (63%) talk about specific strategies for preventing HIV/AIDS with their clients. Over one-half (59%) of respondents talk about the risk of contracting HIV/AIDS associated with engaging in specific sexual activities. Only 11% of the respondents talked about some other topic when discussing HIV/AIDS risk prevention.



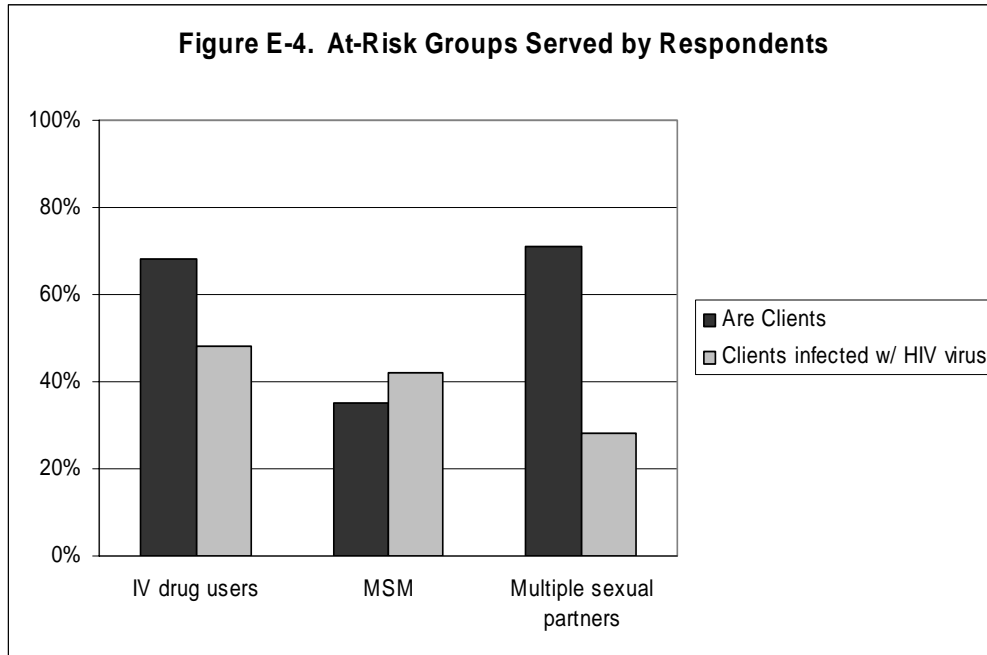
The survey also asked respondents what some of the greatest barriers are to discussing HIV/AIDS risk prevention with their clients. As depicted in Figure E-3, the most frequently indicated barrier was time constraints (55%), followed by client's feelings of discomfort with the topic (43%). About one-fifth (21%) of the respondents indicated that they do not have enough knowledge or training on the topic. About one-tenth (9%) of the respondents indicated negative community values/views on the topic was a barrier to discussing the topic with their clients. Only a small number indicated their own feelings of discomfort with the topic (4%) and negative values/views about the topic in the respondent's workplace (2%). About one-tenth (11%) of the respondents indicated some other barrier to discussing HIV/AIDS risk prevention with their clients, such as the client's denial that they get HIV, parental constraints, or fear of breaking legal confidentiality rules.



Respondents were asked about strategies for dealing with these barriers. Respondents mentioned more education in the community, more education in schools, additional education for parents on HIV/AIDS risk reduction among teenagers, and training for service providers and educators. On the other hand, one respondent stated, “Our area is rural conservative and curriculum is approved by school board members.” Respondents also indicated that they themselves would benefit from training. One respondent suggested “more training for professionals on how to interact with clients and not break legal confidentiality.” Another respondent suggested that “probation officers ... get advanced HIV training to better deal with clients’ needs.”

Serving At-Risk Clients

Three groups at particular risk of contracting the HIV virus are IV drug users, men who have sex with men (MSM), and people who have or have had multiple sexual partners, either simultaneously or serially. The percentage of respondents indicating that they have clients in each of these groups is presented in Figure E-4. The majority of respondents have clients who have/had multiple sexual partners (71%). About one-quarter (28%) of the respondents who have clients who have/had multiple sexual partners also have clients who are infected with the HIV virus. About two-thirds (68%) of the respondents indicated that they have clients who have used IV drugs in the past. Nearly one-half (48%) of these respondents indicated that they also have clients who are/were IV drug users who are living with HIV/AIDS. About one-third (35%) of the respondents have clients who are MSM. About two-fifths (42%) of these respondents indicated that they have clients who are MSM and are infected with the HIV virus.



Serving Clients Who Are IV Drug Users

This section discusses results for respondents who have clients who are IV drug users. Other respondents are not included in this section. As indicated above, 68% of the respondents indicated that they have clients who have used IV drugs in the past. Nearly one-half (48%) of the respondents indicated that at least one of their clients who is/was an IV drug user is infected with the HIV virus.

On average, respondents had 25 clients during the 2003 fiscal year who are/were IV drug users. Most (72%) of the respondents indicated that the frequency with which they see these clients varies from client to client. About one-fifth (21%) of the respondents indicated that they see their clients who are IV drug users two or more times, while only 6% indicated seeing them once.

Over one-half (58%) of the respondents who have clients who are IV drug users suggest to all of these clients that they be tested for HIV/AIDS. However, 26% seldom or never suggest it to these clients. These results are presented in Table E-3.

In addition, 62% of the respondents indicated that they talk about HIV/AIDS risk prevention with all their clients who are/were IV drug users. About one-fifth (21%) talk about HIV/AIDS risk prevention under certain circumstances, and another 17% never talk about it. These results are also presented in Table E-3.

**Table E-3
Talking About HIV Testing and Risk Prevention with Clients Who Are IV Drug Users**

	Number	Percent
How often do you suggest that you clients who are/were IV drug users be tested for HIV/AIDS?		
Seldom or never suggest it	14	26%
Suggest it to all my clients who are IV drug users	32	58%
Suggest it sometimes or under certain circumstances	9	16%
Total	55	100%
Do you ever talk about HIV/AIDS risk prevention with your clients who are/were IV drug users?		
No, never talk about it	10	17%
Yes, talk about it with all my clients who are/were IV drug users	36	62%
Yes, talk about it under certain circumstances	12	21%
Total	58	100%

Respondents were asked about barriers to discussing HIV risk prevention with clients who are IV drug users. Themes mentioned by respondents included limited contact with clients, a lack of time during meetings with clients, denial on the part of IV drug users that they use drugs, a lack of privacy in the setting where they meet with clients, clients' discomfort with the subject, clients who are unwilling to listen because they have "heard it all before," and legal issues related to confidentiality. Five respondents stated that they did not face any barriers in discussing HIV risk prevention with clients who are IV drug users.

The survey collected data on the characteristics of clients who are IV drug users. These results are presented in Table E-4.

Clients who are IV drug users tend to be young. Most (72%) of the respondents indicated that one of the primary age groups for these clients was 18-24 years old, and over one-half (54%) indicated that a primary age group was 25-29 years old. Most (74%) of the respondents indicated that their clients who are IV drug users are primarily male, although 54% indicated that a bulk of their clients are female. Nearly all (96%) of the respondents indicated that a primary racial/ethnic group for their clients who are IV drug users is White. About one-quarter (27%) of the respondents stated that a primary racial/ethnic group is African American. The majority of respondents indicated that their clients who are IV drug users have less than a high school degree (70%) or a high school diploma or its equivalent (66%). Over one-half of the respondents indicated that their clients who are IV drug users are unemployed most or all of the year (62%) or employed off and on (55%). About two-thirds (67%) of the respondents indicated that their clients who are IV drug users primarily live outside of the State College and Williamsport city areas. Only 37% indicated that a bulk of these clients live within these two metropolitan areas. In addition, 67% of the respondents indicated that some of their clients who are IV drug users are

currently incarcerated or have a prison record. Nearly one-fifth (18%) indicated that none of their clients are incarcerated or have a prison record.

Table E-4
Characteristics of Clients Who are IV Drug Users

	Number	Percent
Primary Age Groups of Clients (n=57)		
12 yrs or under	1	2%
13-17 yrs	19	33%
18-24 yrs	41	72%
25-29 yrs	31	54%
30-39 yrs	20	21%
40-49 yrs	9	16%
50-59 yrs	2	4%
60-64 yrs	1	2%
65 or older	0	0%
Primary Gender of Clients (n=49)		
Male	36	74%
Female	28	57%
Primary Race/Ethnicity of Clients (n=56)		
White	54	96%
African American	15	27%
Hispanic	7	13%
Native American	0	0%
Other	0	0%
Primary Educational Background of Clients (n=50)		
Less than HS	35	70%
HS diploma or equivalent	33	66%
Some college, 2-yr degree or post-secondary technical training	9	18%
4-yr degree or more	3	6%
Primary Employment Status of Clients (n=47)		
Employed full-time all year	3	6%
Employed part-time all year	4	9%
Employed off & on	26	55%
Unemployed most or all of the year	29	62%
Primarily Residence of Clients (n=57)		
Live in State College or Williamsport city areas	21	37%
Live elsewhere	38	67%

Table E-4
Characteristics of Clients Who are IV Drug Users

	Number	Percent
Are Any IV Drug User Clients Currently Incarcerated or Have a Prison Record?		
No	9	18%
Yes, some of them	33	67%
Yes, all of them	7	14%
Total	49	100%

Serving Clients Who Are MSM

This section discusses results for respondents who have clients who are MSM. Other respondents are not included in this section. As indicated above, 35% of the respondents indicated that they have clients who are MSM. About two-fifths (42%) of the respondents indicated that at least one of their clients who is MSM is infected with the HIV virus.

On average, respondents had 5 clients during the 2003 fiscal year who are MSM. For the most part, respondents see these clients either two or more times (44% of respondents) or it varies from client to client (44%). Only 11% indicated seeing them once.

About two-thirds (67%) of the respondents who have clients who are MSM suggest to all of these clients that they be tested for HIV/AIDS. Nearly one-fifth (18%) of the respondents seldom or never suggest it to these clients. These results are presented in Table E-5.

In addition, 71% of the respondents indicated that they talk about HIV/AIDS risk prevention with all their clients who are/were MSM. About one-tenth (11%) talk about HIV/AIDS risk prevention under certain circumstances, and another 18% never talk about it. These results are also presented in Table E-5.

Table E-5
Talking About HIV Testing and Risk Prevention with Clients Who Are MSM

	Number	Percent
How often do you suggest that you clients who are/were MSM be tested for HIV/AIDS?		
Seldom or never suggest it	5	18%
Suggest it to all my clients who are MSM	19	68%
Suggest it sometimes or under certain circumstances	4	14%
Total	28	100%

Table E-5
Talking About HIV Testing and Risk Prevention with Clients Who Are MSM

	Number	Percent
Do you ever talk about HIV/AIDS risk prevention with your clients who are/were MSM?		
No, never talk about it	5	18%
Yes, talk about it with all my clients who are/were MSM	20	71%
Yes, talk about it under certain circumstances	3	11%
Total	28	100%

Respondents were asked about barriers to discussing HIV risk prevention with clients who are MSM. Themes mentioned by respondents included time constraints, client discomfort, shame and secretiveness, therapist discomfort with the topic, clients' unwillingness to listen, and the client's age (one respondent had a juvenile client whose case was under investigation as potential abuse or criminal behavior). Two respondents stated that they did not face any barriers in discussing HIV risk prevention with their MSM clients.

The survey collected data on the characteristics of clients who are MSM. These results are presented in Table E-6.

There appears to be considerable variability in the ages of clients who are MSM. Over one-half (58%) of the respondents indicated that one of the primary age groups for these clients is 18-24 years old, while just under one-half (46%) of the respondents indicated that another primary age group is 25-29 years old. About two-fifths (39%) of the respondents indicated that a primary age group is 30-39 years, and another 31% indicated that a primary age group is 40-49 years. Nearly all (92%) of the respondents indicated that a primary racial/ethnic group for their MSM clients is White. About one-third (31%) of the respondents indicated that a primary racial/ethnic group is African American. There is also considerable diversity in the educational background of respondents' MSM clients. One-half (50%) of the respondents indicated that their clients who are MSM primarily have less than a high school degree, while another 55% indicated that a bulk of these have a high school diploma or its equivalent. Also, 40% of the respondents indicated that a bulk of these clients have some college, a two-year degree or post-secondary technical training. There is considerable variability in the employment status of respondents' MSM clients, as well. About two-fifths (43%) of the respondents indicated that a bulk of their MSM clients are employed full-time all year, 43% indicated that a bulk of these clients are employed off and on, and 38% indicated that their MSM clients are unemployed most or all of the year. About one-half (52%) of the respondents indicated that their MSM clients primarily live in State College or Williamsport city areas, and 52% indicated that a bulk of their MSM clients live outside of the State College and Williamsport city areas. In addition, 53% of the respondents indicated that some of their clients who are MSM are currently incarcerated or have a prison record. Over two-fifths (42%) indicated that none of these clients are incarcerated or have a prison record.

Table E-6
Characteristics of Clients Who are MSM

	Number	Percent
Primary Age Groups of Clients (n=26)		
12 yrs or under	1	4%
13-17 yrs	4	15%
18-24 yrs	15	58%
25-29 yrs	12	46%
30-39 yrs	10	39%
40-49 yrs	8	31%
50-59 yrs	4	15%
60-64 yrs	1	4%
65 or older	1	4%
Primary Race/Ethnicity of Clients (n=26)		
White	24	92%
African American	8	31%
Hispanic	2	8%
Native American	0	0%
Other	2	8%
Primary Educational Background of Clients (n=20)		
Less than HS	10	50%
HS diploma or equivalent	11	55%
Some college, 2-yr degree or post-secondary technical training	8	40%
4-yr degree or more	4	20%
Primary Employment Status of Clients (n=21)		
Employed full-time all year	9	43%
Employed part-time all year	4	19%
Employed off & on	9	43%
Unemployed most or all of the year	8	38%
Primarily Residence of Clients (n=25)		
Live in State College or Williamsport city areas	13	52%
Live elsewhere	13	52%
Are Any IV Drug User Clients Currently Incarcerated or Have a Prison Record?		
No	8	42%
Yes, some of them	10	53%
Yes, all of them	1	5%
Total	19	100%

Serving Clients Who Have/Had Multiple Sexual Partners

This section discusses results for respondents who have/had multiple sexual partners, either simultaneously or serially. Other respondents are not included in this section. As indicated above, 71% of the respondents indicated that they have clients who have have/had multiple sexual partners. About one-quarter (28%) of the respondents indicated that at least one of their clients who has/had multiple sexual partners is infected with the HIV virus.

On average, respondents had 124 clients during the 2003 fiscal year who have/had multiple sexual partners. Nearly two-thirds (63%) of the respondents indicated that the frequency they see these clients varies from client to client. Over one-third (35%) indicated that they see their clients who have/had multiple sexual partners two or more times, and only 2% indicated seeing them once.

About two-thirds (69%) of the respondents who have clients who have/had multiple sexual partners suggest to all of these clients that they be tested for HIV/AIDS. Only 16% seldom or never suggest it to these clients. These results are presented in Table E-7.

In addition, 68% of the respondents indicated that they talk about HIV/AIDS risk prevention with all their clients who have/had multiple sexual partners. About one-quarter (24%) talk about HIV/AIDS risk prevention under certain circumstances. Only 8% never talk about it. These results are also presented in Table E-7.

Table E-7
Talking About HIV Testing and Risk Prevention with Clients Who Have/Had Multiple Sexual Partners

	Number	Percent
How often do you suggest that you clients who have/had multiple sexual partners be tested for HIV/AIDS?		
Seldom or never suggest it	9	16%
Suggest it to all my clients who have/had multiple sexual partners	40	69%
Suggest it sometimes or under certain circumstances	9	16%
Total	58	101%
Do you ever talk about HIV/AIDS risk prevention with your clients who have/had multiple sexual partners?		
No, never talk about it	5	8%
Yes, talk about it with all my clients who have/had multiple sexual partners	40	68%
Yes, talk about it under certain circumstances	14	24%
Total	59	100%

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

Respondents were asked about barriers to discussing HIV risk prevention with clients who have/had multiple sexual partners. Themes mentioned by respondents included denial on the part of clients that they could get HIV, client concern about the stigma associated with HIV, lack of understanding of HIV on the part of clients, clients' embarrassment about the topic, clients' unwillingness to listen, and clients' lack of understanding of HIV/AIDS. According to one respondent, "many think they are safe because their partner told them they had been tested or because the sex act did not include ejaculation." Other themes mentioned by respondents included concern on the part of the respondent about offending the client, time constraints in meeting with clients, the presence of parents when meeting with juvenile clients, and legal issues related to confidentiality. Five respondents stated that they did not face any barriers in discussing HIV risk prevention with their clients who have/had multiple sexual partners.

The survey collected data on the characteristics of clients who have/had multiple sexual partners. These results are presented in Table E-8.

Clients who have/had multiple sexual partners are primarily under 30 years of age. Most (74%) of the respondents indicated that one of the primary age groups for these clients is 18-24 years old. Also, 67% of the respondents indicated that another primary age group is 25-29 years. Most (80%) of the respondents indicated that their clients who have/had multiple sexual partners are primarily female, although 55% indicated that a bulk of these clients are male. Nearly all (96%) of the respondents indicated that one of the primary racial/ethnic groups for their clients who have/had multiple sexual partners is White. About one-third (30%) of the respondents indicated that a primary racial/ethnic group for these clients is African American. The majority of respondents indicated that their clients who have/had multiple sexual partners have less than a high school degree (72%) or a high school diploma or its equivalent (70%). Nearly two-thirds of the respondents indicated that their clients who have/had multiple sexual partners are employed off and on (71%) or unemployed most or all of the year (64%). About two-thirds (69%) of the respondents indicated that their clients who have/had multiple sexual partners primarily live outside of the State College and Williamsport city areas. Only 37% indicated that a bulk of these clients primarily live within these two metropolitan areas. In addition, 64% of the respondents indicated that some of their clients who have/had multiple sexual partners are currently incarcerated or have a prison record. About one-quarter (26%) indicated that none of these clients are incarcerated or have a prison record.

Table E-8
Characteristics of Clients Who Have/Had Multiple Sexual Partners

	Number	Percent
Primary Age Groups of Clients (n=54)		
12 yrs or under	0	0%
13-17 yrs	18	33%
18-24 yrs	40	74%
25-29 yrs	36	67%
30-39 yrs	25	46%
40-49 yrs	17	32%
50-59 yrs	5	9%
60-64 yrs	0	0%
65 or older	0	0%
Primary Gender of Clients (n=49)		
Male	27	55%
Female	39	80%
Primary Race/Ethnicity of Clients (n=53)		
White	51	96%
African American	16	30%
Hispanic	6	11%
Native American	2	4%
Other	1	2%
Primary Educational Background of Clients (n=47)		
Less than HS	34	72%
HS diploma or equivalent	33	70%
Some college, 2-yr degree or post-secondary technical training	12	26%
4-yr degree or more	5	11%
Primary Employment Status of Clients (n=44)		
Employed full-time all year	10	23%
Employed part-time all year	10	23%
Employed off & on	31	71%
Unemployed most or all of the year	28	64%
Primarily Residence of Clients (n=52)		
Live in State College or Williamsport city areas	19	37%
Live elsewhere	36	69%

**Table E-8
Characteristics of Clients Who Have/Had Multiple Sexual Partners**

	Number	Percent
Are Any Clients Who Have/Had Multiple Sexual Partners Currently Incarcerated or Have a Prison Record?		
No	11	26%
Yes, some of them	27	64%
Yes, all of them	4	10%
Total	42	100%

E. Synthesis and Recommendations

This needs assessment is based on data from multiple sources, including government statistics from the state of Pennsylvania, a survey of consumers of the four case management agencies, a focus group comprised of case managers from these agencies, a survey of participants who received instruction from prevention outreach workers, personal interviews of prevention outreach workers, a survey of social service providers in the 12-county NCDAC region, and personal interviews of infectious disease and gastro-intestinal physicians serving NCDAC consumers and others at risk in the NCDAC region. While each of these sources of information has limitations, conclusions are drawn from the synthesis across these different sources of data. Greater confidence can be placed on results that appear consistently across different sources of information.

Overall, case managers and prevention outreach workers appear to be effective in educating their clients and the public on primary and secondary prevention. This is evidenced by the fact that the vast majority of consumers and participants in the prevention intervention indicated that they know how to prevent themselves from becoming re-infected or infected with HIV/AIDS. Also, those respondents who had a risk reduction plan felt the plan was effective in helping them reduce their risk.

There are several areas that could be improved when working with clients and participants of NCDAC-funded programs:

- A significant percentage of consumers and participants in the prevention program did not indicate having a risk reduction plan. Results indicate that consumers who shy away from discussions about risk reduction because of denial or fear of stigma associated with HIV/AIDS may be the least likely to have a plan.
- A concerted effort by case managers and prevention workers is needed to continue distributing tools for preventing infection and re-infection, as well as information on risk factors and where to get more information. Cards distributed by the NCDAC describing risk behaviors and providing contact information appear to be highly effective.

- Results from the consumer survey and physician interviews indicate that some consumers need greater involvement on the part of the case manager in the management and coordination of their care.
- One of the most disturbing findings was that 32% of consumers who had acquired the HIV virus through sexual contact had unprotected sex within the past six months. This finding indicates that a significant percentage of consumers are in situations where they are unable or unwilling to protect themselves and their partners.
- While knowledge about risk and where to get a free HIV test was good among participants who completed the prevention survey, one would expect percentages to be better since respondents just received the prevention outreach.

Time constraints among physicians and social service providers limit the amount of time these professionals can spend talking with clients about HIV/AIDS prevention and risk reduction. Other barriers include some of the same barriers that case managers and prevention workers face: denial of risk, stigma associated with HIV/AIDS, fear of rejection if others know about a person's HIV status, and inability or unwillingness to effectively use preventive measures.

Recommendations and Strategies

Eight recommendations emerge from our findings. First, greater involvement by case managers in the coordination of their clients' medical care would help address some of the gaps mentioned by physicians and consumers. For example, case managers could accompany their clients on visits to an infectious disease physician on a regular basis (say, once or twice a year). This could serve several purposes:

- the case manager could reinforce and expand upon what the physician says about prevention and risk reduction;
- the case manager could help reduce the impact of literacy and cultural barriers on effective communication between the physician and client;
- the case manager could better follow-up with clients to ensure that they are complying with physician instructions;
- the case manager would be aware of medical appointments and could help insure that clients show up for appointments with their physicians.

Second, case management agencies could require clients to meet with their case managers on a monthly basis. This appears to be occurring already in the majority of cases but there is room for improvement. Clients who currently have low involvement with the programs offered by their case management agency will benefit from the additional contact.

Third, NCDAC could form a committee to establish best practices for case managers and prevention outreach workers. The best practices would provide guidance on topics that should be addressed under certain circumstances and strategies for working with clients and participants on different issues (for example, denial and fear of rejection). Experienced case managers and prevention workers from the case management agencies could help compile these best practices. Developing a best practices standard would help new employees “get up to speed,” which is particularly important at agencies where there is high staff turnover. Best practices could also provide ideas for more seasoned workers.

Fourth, NCDAC could provide a list of recommended materials to distribute to clients and participants of case management agencies. Results indicate that many case managers and prevention outreach workers currently search for these materials on their own. Case managers and prevention outreach workers could help develop this list of recommended materials. Case management agencies would be expected to purchase at least some materials from this list, although the list should recognize agencies’ limited budgets.

Fifth, NCDAC could regularly include an information sheet in its newsletter that is designed for specific social service providers (for example, probation/parole, schools) and which contains key prevention and risk reduction points most relevant for that particular group of clients. This could help address time constraints faced by social service providers when working with their at-risk clients by providing information directed to each provider’s clientele. The information sheet could be designed and written so that providers could photocopy and distribute it to their clients. An associated article or information sheet could be included in the newsletter that gives providers tips on how to deal with issues such as denial of risk, fear of rejection, and stigma, and also lists behaviors that put people at risk of becoming infected with HIV.

Sixth, NCDAC could reinforce the importance of case managers and prevention outreach workers attending training that focuses on barriers that inhibit or prevent effective prevention and risk reduction behaviors, such as client/participant denial, fear of rejection, or stigma, and strategies for dealing with these barriers. NCDAC could work with other agencies in Pennsylvania or elsewhere to develop and seek funding for a training course on these topics.

Seventh, NCDAC should reinforce to case managers and prevention outreach workers the importance of developing a risk reduction plan with all clients and participants. Survey results indicate that having a plan is helpful. Also, NCDAC should reinforce the importance of distributing a card containing contact and risk reduction information to all consumers and participants.

Finally, prevention strategies by case management agencies and NCDAC should recognize that the characteristics of people who are most likely to engage in risky behavior for contracting HIV/AIDS appear to be changing. Results from the Pennsylvania Department of Health indicate that the percentage of people with AIDS who acquired the virus through heterosexual contact has increased over time. At the same time, the percentage of women with AIDS has increased. The percentage of people with AIDS who are African American has also increased, while the percentage of AIDS cases who are White or Hispanic has decreased. While

the age distribution of people with AIDS in the North Central region has become older over time, results from the social service providers survey indicate that the people currently most at risk of acquiring HIV/AIDS are in the younger age groups, particularly 18-24 years old.