

Part 1: Unmet Need for Primary Medical Care within the Newark EMA Title I System

Introduction

The primary purpose of the Title I Emergency CARE Act is to ensure that people living with HIV/AIDS (PLWHA) have access to primary medical care at standards that meet or exceed guidelines of the U.S. Public Health Service (PHS). Title I pays for needed medical care as well as specific support services to enable PLWHA to access and remain “in care.” Title I fills gaps in the health insurance system, and enables PLWHA who do not have health insurance – from private sources or public programs (e.g., Medicaid, Medicare, State Children’s Health Insurance Program or SCHIP) - to receive medical care to treat their HIV disease. PLWHA served by Title I have incomes under 300% of the Federal Poverty Level, and Title I is considered the payor of last resort after all other health insurance programs are utilized.

In FY 2002 a total of 8,792 PLWHA in the Newark EMA received services from Title I. Of these, 4,853 or 55% received Title I medical care and were “*in care*” as “met need” and 3,939 or 45% received other services but not Title I medical care. Of this 45%, approximately 21% (1,800) clients reported having Medicaid, Medicare, or private insurance, and 24% (2,100) reported having no health insurance. What is not known, however, is the number of clients actually receiving medical care from these other sources versus the number not receiving medical care at all. The Planning Council felt that the EMA must ensure that all of our current Title I clients have access to medical care and receive such care before we initiate extensive efforts to reach out to unserved clients.

The purpose of this part of the needs assessment was to determine (1) the [unmet] need for primary medical care among the Newark EMA’s own Title I clients, and (2) the services needed to get Title I clients into medical care and to keep them in care.

The primary research question to be addressed was “**Why is an HIV-positive person in the Newark EMA not receiving primary medical care?**” For the purposes of this research plan, HIV-positive persons were grouped into four categories:

1. Undiagnosed;
2. Diagnosed, not receiving any Title I services;
3. Diagnosed, receiving some Title I service, and reporting a source of health insurance - private health insurance, Medicaid or Medicare; and
4. Diagnosed, receiving some Title I service, and reporting no source of health insurance or no payor for medical care (other than Title I).

PLWHA in Categories 1, 2, and 3 were excluded from study for the following reasons. No one in Category 1 is receiving HIV primary medical care because they are not aware of their HIV status. (According to the N.J. Department of Health and Senior Services (NJDHSS), there were 11,623¹ PLWHA in the Newark EMA as of 12/31/02. It is estimated that the ratio of diagnosed to undiagnosed is approximately 75% to 25%.² Therefore, there may be as many as 4,000 undiagnosed persons in the EMA.)³ Members of Categories 2 and 3 may or may not be receiving HIV primary medical care. However, the Planning Council does not have easy access to persons in Category 2 because they are not Title I clients. Title I clients in Category 3 have self-reported private or public insurance and were presumed to have access to care.

PLWHA in Category 4 – diagnosed, receiving some Title I service and reporting no health insurance - were accessible by the Planning Council and were the population studied in this section.

The purpose of Part 1 was to describe the population in Category 4, to learn what barriers are keeping them from care, and to explore what services they would need when they do come into care. Part 1A was to include a review of CHAMP Title I data on service utilization data and client demographics to determine if common characteristics existed among PLWHA not receiving Title I medical care. Part 1B was to consist of a survey of a sample of PLWHA who did not appear to have any source of health insurance and who did not receive Title I medical care. The survey would ascertain whether they are receiving medical care for their HIV, and if not, the services needed to bring them into care. It was presumed that these individuals would be more likely than others to be brought into medical care because they have an existing connection to the Title I system through receipt of some service(s) from at least one Ryan White Title I provider.

Part 1A: Comparison of Title I Clients Receiving Title I Medical Care and Those Not Receiving Title I Medical Care

Methods

Existing CHAMP data showing Title I services provided during **Calendar Year (CY) 2003** (not HRSA Fiscal Year 2003) was used to explore connections between clients' characteristics (gender, age, race/ethnicity, county/municipality of residence, etc.) and whether or not they received primary medical care. Statistical techniques were used to identify relationships between the predictors (client characteristics) and the outcome ("in care" versus "not in care"). These techniques were utilized to answer such questions as:

"Are men more or less likely than women to receive medical care?"

¹ N.J. Dept. Health and Senior Services, Division of HIV/AIDS Services. *HIV/AIDS Surveillance Report, December 31, 2002.*

² FLEMING PL, Bayers RH, Sweeney PA, Daniels D, Karon JM, & Jenssen RS. *HIV Prevalence in the United States, 2000.*

“Do older clients receive medical care more or less than younger clients?”

“Are there differences in receipt of medical care for particular ethnic groups?”

Development of Universe to be studied in Part 1

The total number of CHAMP clients receiving any service in CY 2003 was reviewed. PLWHA who were not active Title I clients were removed, where the “Client Status” indicated discharged or suspended (no activity on CHAMP within the preceding six months). Affected individuals were removed. Individuals with self-reported source of health insurance were removed, where the “Health Insurance Status” field contained entries of private insurance, Medicaid, Medicare or SCHIP (New Jersey FamilyCare - NJFC). (However, no Title I clients reported receipt of NJFC in CY 2003). Individuals whose self-reported entries in “Health Insurance Status” were none, missing, and charity care or self-pay were considered to have no source of health insurance as required by Category 4. The process used to develop the universe for Part 1 is in **Table 1-1**.

Table 1-1: Development of Universe for Part 1 Based on Newark EMA Title I Clients in Calendar Year 2003

	Subgroup	Universe
Title I clients in Newark EMA CY 2003		8,933
Discharged or Suspended (no activity on CHAMP in prior 6 months as of 12/31/03)	3,204	
Estimated affected population (preliminary)*	625	
Individuals with reported source of health insurance of Medicaid, Medicare, private insurance (Health Insurance Status)	2,023	
HIV+ Active Title I Clients with no reported source of health insurance in CY 2003 (“Category 4”)		3,081
HIV+ Active Title I clients with no health insurance who received Title I Primary Medical Care Service in CY 2003 (Received Title I Medical Care)		2,124
HIV+ Active Title I Clients with no health insurance who did not receive Title I Funded Medical Care in CY 2003. (Did not receive Title I Medical Care)		957

Source: Newark DHHS. CHAMP.

* NOTE: Title I services are available for individuals “affected” by the HIV epidemic in limited situations – e.g. children of HIV+ parents who are in child care while parents are in medical care, or who receive permanency planning services.

There were 3,081 HIV+ “active” Title I clients in 2003 who reported no source of health insurance. Of this number, 2,124 or 69% received Title I funded medical care at some point

during CY 2003 and 957 or 31% did not. The universe of 957 individuals not receiving Title I medical care was compared with the 2,124 individuals who received Title I medical care to determine any differences.

Findings

The findings of Part 1A were consistent with results of prior Needs Assessments and analyses of data on Title I service utilization. In general, there were few differences in the characteristics of uninsured Title I clients who received Title I medical care and those who did not. The results are shown in **Tables 1-2 – 1-9** below.

Gender

Among Title I clients with no health insurance, men and women received Title I medical care in the same proportions. There were no differences in receipt of Title I medical care by gender (**Table 1-2**). Of the 1,163 women who reported no health insurance in 2003, 70% (815) received Title I medical care and 30% (348) did not. Likewise, of the 1,918 males who reported no health insurance in 2003, 68% (1,309) received Title I medical care and 32% (609) did not. Thus, among Title I clients with no health insurance, men are just as likely as women to receive Title I medical care.

Table 1-2: 2003 Newark EMA HIV+ Clients with No Reported Health Insurance by Receipt of Title I Medical Care and Gender

Gender	Receiving Title I Medical Care		Not Receiving Title I Medical Care		Total	
	#	%	#	%	#	%
Female	815	70%	348	30%	1,163	100%
Male	1,309	68%	609	32%	1,918	100%
Total	2,124	69%	957	31%	3,081	100%

Furthermore, male and female PLWHA without health insurance had access to Title I medical care in proportion to their representation in the HIV epidemic (**Table 1-3**). Of the 2,124 PLWHA who received Title I medical care, 38% were female and 62% were male. Of the 957 PLWHA who did not receive Title I medical care, 36% were female and 64% were male. These percentages are nearly equal to the distribution of the total PLWHA in the Newark EMA as of 12/31/03 - 40% female and 60% male.

These findings are consistent with the Newark EMA's 2003 Needs Assessment as reported in the 2004-2006 Comprehensive Health Plan. It was found that men (61%) and women (63%) were equally likely to be in medical care.

Table 1-3: Comparison of 2003 Newark EMA HIV+ Clients with No Reported Health Insurance With PLWHA as of 12/31/03 – by Gender

Gender	Received Title I Medical Care in 2003		PLWHA in Newark EMA as of 12/31/03*	
	Yes	No	#	%
Female	38%	36%	4,749	40%
Male	62%	64%	7,207	60%
Total	100%	100%	11,956	100%

*Source: N.J. Dept. Health & Senior Services, Division of HIV/AIDS Services

Current Age

Among Title I clients with no health insurance categorized by age, PLWHA received Title I medical care or did not receive such care in relatively the same proportions. There were only small differences in receipt of Title I medical care among three age groups (**Table 1-4**). Of the 114 PLWHA under age 13 who reported no health insurance in 2003, 63% (72) received Title I medical care and 37% (42) did not. Of the 1,477 PLWHA ages 25-44 who reported no health insurance in 2003, 69% (1,109) received Title I medical care and 31% (458) did not. Of the 1,295 PLWHA age 45 and older who reported no health insurance in 2003, 67% (866) received Title I medical care and 33% (429) did not. Among the 194 uninsured youth age 13-24, however, a higher proportion received Title I medical care in 2003 – 86% (167) – versus the 14% (27) who did not.

Table 1-4: 2003 Newark EMA HIV+ Clients with No Reported Health Insurance By Receipt of Title I Medical Care and Current Age

Current Age	Receiving Title I Medical Care		Not Receiving Title I Medical Care		Total	
	#	%	#	%	#	%
< Age 13	72	63%	42	37%	114	100%
Age 13-24	167	86%	27	14%	194	100%
Age 25-44	1,019	69%	458	31%	1,477	100%
Age 45+	866	67%	429	33%	1,295	100%
Age Missing	0	0%	1	100%	1	100%
Total	2,124	69%	957	31%	3,081	100%

Regardless of their age, PLWHA without health insurance had access to Title I medical care in proportion to their representation in the HIV epidemic (**Table 1-5**). Of the 2,124 PLWHA who received Title I medical care, 3% were under age 13, 8% were youth age 13-24, 48% were young adults age 25-44, and the remaining 41% were age 45 and older. Of the 957 PLWHA who did not receive Title I medical care, 4% were under age 13, 3% were age 13-24, 48% were age 25-44, and 45% were age 45 and older. These percentages are nearly equal to the distribution of the total PLWHA in the Newark EMA as of 12/31/03 - 2% under age 13, 4% youth age 13-24, 48% age 25-44, and 46% age 45 and older. (Note that distribution of total PLWHA by age in **Table 1-5** was estimated proportionately, because NJDHSS data are reported in different age categories than shown in this table.)

Table 1-5: Comparison of 2003 Newark EMA HIV+ Clients with No Reported Health Insurance and PLWHA as of 12/31/03 – by Current Age

Current Age	Received Title I Medical Care in 2003		PLWHA in Newark EMA as of 12/31/03*	
	Yes	No	#	%
< Age 13	3%	4%	183	2%
Age 13-24	8%	3%	453	4%
Age 25-44	48%	48%	5,758	48%
Age 45+	41%	45%	5,562	46%
Total	100%	100%	11,956	100%

*Source: N.J. Dept. Health & Senior Services, Division of HIV/AIDS Services. Totals for each group are estimated using proportional distribution among age categories.

It should be noted that when adolescents reach age 18 they are no longer eligible for government insurance such as Medicaid or NJFC as single individuals. Lack of health insurance for this category, particularly those ages 18-24, can be a barrier to care. Providers in the Newark EMA have sought to enroll these PLWHA in Title I medical care, which accounts for the relatively higher percentage of youth who receive Title I medical care versus their proportion in the HIV epidemic.

Race/Ethnicity

There were differences in receipt of Title I medical care by race/ethnicity among PLWHA with no reported health insurance (**Table 1-6**). Some of these differences are genuine, and one may be due to error in coding race/ethnicity. Of the 188 NonHispanic White PLWHA who reported no health insurance in 2003, 50% (94) received Title I medical care and 50% (94) did not. The rate of 50% uninsured whites receiving Title I medical care is less than the 69% EMA-wide rate of all PLWHA reporting no health insurance. Of the 1,724 NonHispanic Black PLWHA who reported no health insurance in 2003, 63% (1,090) received Title I medical care and 37% (634) did not. The rate of 63% uninsured African-Americans receiving Title I medical care is also lower than

the EMA-wide rate of 69%. However, of the 952 Hispanic PLWHA who reported no health insurance in 2003, 87% (825) received Title I medical care and 13% (127) did not. Based on a review of CHAMP coding options and internal reports, it is believed that Hispanic ethnicity may be “overcoded”. That is, a number of Title I clients are being coded as “Hispanic” without exploring their true race/ethnicity, which is most likely not Hispanic or Latino.

To address this coding error, in **Table 1-6** the total number of NonHispanic Blacks and Hispanics were added together to determine overall participation in Title I medical care. The results more accurately reflect medical participation as reported by Title I medical providers. Of the 2,767 Black and Hispanic PLWHA reporting no health insurance in 2003, 72% (1,915) received Title I medical care and 28% (761) did not.

With respect to individuals of other races or ethnic origins and those for whom the information was not reported or was missing, of the 217 PLWHA in this category, 53% (115) received Title I medical care and 47% (102) did not.

Table 1-6: 2003 Newark EMA HIV+ Clients with No Reported Health Insurance By Receipt of Title I Medical Care and Race/Ethnicity

Race/Ethnicity	Receiving Title I Medical Care		Not Receiving Title I Medical Care		Total	
	#	%	#	%	#	%
White, Not Hisp.	94	50%	94	50%	188	100%
Black, Not Hisp.	1,090	63%	634	37%	1,724	100%
Hispanic	825	87%	127	13%	952	100%
Other	2	100%	1	0%	3	100%
Unknown	32	64%	18	36%	50	100%
Missing	81	49%	83	51%	164	100%
Total	2,124	69%	957	31%	3,081	100%
Black, Not Hisp. + Hispanic	1,915	72%	761	28%	2,676	100%

There were differences in the distribution of uninsured PLWHA by race/ethnicity and receipt Title I medical care. NonHispanic Whites comprised 4% of the 2,124 PLWHA receiving Title I medical care and 10% of the 957 PLWHA who did not. The combined total of NonHispanic Blacks and Hispanics comprised 90% of uninsured PLWHA who received Title I medical care and 80% who did not. Individuals of other/unknown/missing race/ethnicity comprised 5% of uninsured PLWHA who received Title I medical care and 11% of those who did not.

When categorized by race/ethnicity, PLWHA with no health insurance received Title I medical care in varying proportions to their representation in the HIV epidemic (**Table 1-7**). NonHispanic Whites comprised only 4% of uninsured Title I medical clients but 12% of PLWHA. Individuals

of other/unknown/missing race/ethnicity comprised 6% of Title I clients with no health insurance but 1% of total PLWHA. The combined total of NonHispanic Blacks and Hispanics comprised 90% of Title I clients with no health insurance who received Title I medical care, slightly higher than their combined representation in the epidemic at 87% of PLWHA.

Table 1-7: Comparison of 2003 Newark EMA HIV+ Clients with No Reported Health Insurance and PLWHA as of 12/31/03 – by Race/Ethnicity

Race/Ethnicity	Received Title I Medical Care in 2003		PLWHA in Newark EMA as of 12/31/03*	
	Yes	No	#	%
White, Not Hisp.	4%	10%	1,432	12%
Black, Not Hisp.	51%	66%	8,608	72%
Hispanic	39%	13%	1,746	15%
Other/Unk./Missing	6%	11%	170	1%
Total	100%	100%	11,956	100%
Black, Not Hispanic + Hispanic	90%	82%	10,354	87%

*Source: N.J. Dept. Health & Senior Services, Division of HIV/AIDS Services.

It is important to note that in 2004 CHAMP will be addressing the coding issue related to Hispanic ethnicity. There will be two mandatory coding fields for each client – one for Hispanic/Latino ethnicity and the second for race. This change is consistent with federal coding requirements and protocols which are being implemented nationwide for all federal programs including Title I. All Title I clients will be recoded according to these protocols.

Geography

There were differences in receipt of Title I medical care in 2003 by county of residence among PLWHA with no reported health insurance (**Table 1-8**). PLWHA with no health insurance residing in urban counties received Title I medical care at higher rates than those in the three suburban/rural counties. Of the 2,477 PLWHA residing in Essex County who reported no health insurance in 2003, 71% (1,753) received Title I medical care and 29% (724) did not. This rate is slightly higher than the EMA-wide rating of 69% of all uninsured Title I clients who receive Title I medical care. Of the 469 PLWHA residing in Union County who reported no health insurance, 64% (302) received Title I medical care and 36% (167) did not. The Union County rate of 64% is slightly lower than the EMA-wide rate of 69%.

Differences are greater in the remaining counties, where only half or fewer of Title I clients without health insurance received Title I funded medical care in 2003. In Morris County, 53%

(61) of PLWHA with no health insurance received Title I medical care in 2003 and 47% (54) did not. In Sussex County, 33% of PLWHA with no health insurance received Title I medical care in 2003 (three individuals), and 67% did not (six individuals). Likewise, in Warren County 45% of PLWHA with no health insurance received Title I medical care in 2003 (five individuals), and 55% did not (six individuals).

Table 1-8: 2003 Newark EMA HIV+ Clients with No Reported Health Insurance by Receipt of Title I Medical Care and County

County of Residence	Receiving Title I Medical Care		Not Receiving Title I Medical Care		Total	
	#	%	#	%	#	%
Essex	1,753	71%	724	29%	2,477	100%
Morris	61	53%	54	47%	115	100%
Sussex	3	33%	6	67%	9	100%
Union	302	64%	167	36%	469	100%
Warren	5	45%	6	55%	11	100%
Total	2,124	69%	957	31%	3,081	100%

Title I clients with no health insurance who reside in Essex County received Title I medical care in greater proportion than their representation in the HIV epidemic, and uninsured clients in the remaining counties received proportionately less (**Table 1-9**). Of all Title I clients with no health insurance, 83% who received Title I medical care in 2003 resided in Essex County, which is greater than Essex County's share (74%) of the EMA's total PLWHA as of 12/31/03. Only fourteen percent (14%) of uninsured clients who received Title I medical care resided in Union County, which is less than Union County's share (19%) of the EMA's PLWHA. HIV+ residents of Morris, Sussex and Warren counties with no medical payor received Title I medical care at less than their representation in the HIV epidemic – Morris (3% Title I medical care versus 5% of NEMA PLWHA), and Sussex and Warren each with less than 1% of uninsured Title I clients receiving Title I medical care and approximately 1% of PLWHA each.

Table 1-9: Comparison of 2003 Newark EMA HIV+ Clients with No Reported Health Insurance and PLWHA as of 12/31/03 – by County of Residence

County of Residence	Received Title I Medical Care in 2003		PLWHA in Newark EMA as of 12/31/03*	
	Yes	No	#	%
Essex	83%	76%	8,822	74%
Morris	3%	6%	595	5%
Sussex	0%	0.5%	117	1%
Union	14%	17%	2,325	19%
Warren	0%	0.5%	97	1%
Total	100%	100%	11,956	100%

*Source: N.J. Dept. Health & Senior Services, Division of HIV/AIDS Services.

Conclusions Regarding Gender, Age, Race/Ethnicity, Geography

Gender and age are not strong predictors of receipt of Title I medical care by Title I clients with no reported source of health insurance. As shown above, clients participate in Title I medical care in proportion to their gender and age within the EMA’s HIV epidemic. Race/ethnicity has some predictive value in that NonHispanic Whites without a reported source of health insurance are less likely to access Title I medical care. It is difficult to determine whether NonHispanic Black PLWHA and Hispanic PLWHA as individual racial/ethnic groups can predict access to Title I medical care due to CHAMP coding issues. When both categories are combined, however, they receive Title I medical care at a slightly higher proportion than their representation in the HIV epidemic.

Geography – county/municipality of residence – as a client characteristic cannot be used to predict receipt of Title I medical care because a client can change county of residence but continue to receive medical care with the same provider and at the same location. This is particularly true within the densely-populated urban counties. For example, a client can move from Newark (Essex County) to neighboring Elizabeth (Union County) and continue to receive Title I medical care in Essex County. However, geography may play an important role in predicting access to care when combined with other variables, such as poverty.

Poverty and Utilization of Title I Medical Care

There appears to be a strong correlation between geographical areas with high levels of poverty and utilization of Title I medical care by those with no health insurance. This is best illustrated by comparing poverty with utilization of Title I medical care by municipality and zip code area.

Table 1-10 is an expanded version of **Table 1-8** and shows receipt of Title I medical care by clients who report no health insurance. The table shows Title I medical care utilization for larger (population) municipalities as well as for ZIP code areas within Newark, the largest city in the EMA and in New Jersey. It is noteworthy that of the 1,886 uninsured Title I clients residing in Newark, 73% (1,385) received Title I medical care in 2003 and only 27% (501) did not.

Table 1-11 is an expanded version of **Table 1-9** by municipality and ZIP code. As with **Table 1-9** it shows the percent distribution of uninsured Title I clients who received and did not receive Title I medical care in 2003. It also shows the number of residents living below the Federal Poverty Level as reported in the 2000 Census, and the percent distribution of these individuals within the Newark EMA. "Poverty" is computed based the "ratio of income to poverty" data element as reported by the U.S. Census. The total number of individuals whose ratio of income to poverty is less than 1.0 is considered to be living below poverty. (It should be noted that this data element is commonly used by EMAs to estimate the total number of residents living below 300% of the Federal Poverty Level for the annual Title I grant applications.)

Within the five counties of the Newark EMA, poverty is disproportionately concentrated in Essex County. Of the EMA's residents living below poverty, 62.4% reside in Essex. However, Essex contains only 39% of the EMA's total population of 2.1 million. Union County has a relative proportionate share of residents below poverty at 22.5%, compared to 26% of the EMA's total residents. The suburban/rural region of Morris, Sussex and Warren has much less poverty at 15.1% of the EMA's total but 35% of the EMA's total population. Poverty is further concentrated in Essex cities of Newark, East Orange, Irvington and Orange.

Figure 1-1 depicts the distribution within the EMA of Title I clients without health insurance who received Title I medical care in 2003 and of residents living below poverty. With the exception of one ZIP area in Newark, there is a strong correlation between poverty – the percent of EMA residents living below poverty – and uninsured Title I clients who received Title I medical care.

Newark ZIP area 07104 contains a large long-term care facility which houses many uninsured PLWHA, which may account for the high portion of NEMA uninsured Title I clients. The city of Elizabeth has a high percent of NEMA residents living below poverty versus uninsured PLWHA in Title I medical care and a large population of Hispanics/Latinos and immigrant groups who do not appear to be using Title I medical care. This disparity may be the subject of future research.

It appears that the most accurate predictor of receipt of Title I medical care by PLWHA with no reported health insurance is relative poverty within the specific geographical area. The higher the percent or concentration of individuals living below poverty, the greater the utilization of Title I medical care by PLWHA with no source of health insurance. Since the purpose of Title I is to provide access as "payor of last resort" to medical care for PLWHA living below 300% of poverty, these data show that the Newark EMA is fulfilling this mandate, particularly for those under 100% of poverty most in need of assistance.

**Table 1-10: 2003 Newark EMA HIV+ Clients with No Health Insurance
By Receipt of Title I Medical Care and County/Municipality of Residence**

County/ Municipality/ ZIP Area of Residence	Receiving Title I Medical Care		Not Receiving Title I Medical Care		Total	
	#	%	#	%	#	%
Essex County						
Newark 07102	121	52%	111	48%	232	100%
Newark 07103	142	60%	96	40%	238	100%
Newark 07104	427	90%	46	10%	473	100%
Newark 07105	46	74%	16	26%	62	100%
Newark 07106	68	63%	40	37%	108	100%
Newark 07107	125	76%	40	24%	165	100%
Newark 07108	103	52%	94	48%	197	100%
Newark 07112	66	65%	36	35%	102	100%
Newark 07114	35	64%	20	36%	55	100%
Newark Total*	1,385	73%	501	27%	1,886	100%
East Orange	158	59%	111	41%	269	100%
Irvington	98	66%	51	34%	149	100%
Orange	43	63%	25	37%	68	100%
Rest of Essex	69	66%	36	34%	105	100%
Total	1,753	71%	724	29%	2,477	100%
Union County						
Elizabeth	154	64%	86	36%	240	100%
Plainfield	66	76%	21	24%	87	100%
Hillside	14	74%	5	26%	19	100%
Union Twp.	13	59%	9	41%	22	100%
Roselle	18	55%	15	45%	33	100%
Linden	15	60%	10	40%	25	100%
Rest of Union	22	51%	21	49%	43	100%
Total	302	64%	167	36%	469	100%
Morris-Sussex-Warren						
Dover	13	57%	10	43%	23	100%
Morristown	28	57%	21	43%	49	100%
Rest of Morris	20	47%	23	53%	43	100%
Sussex	3	33%	6	67%	9	100%
Warren	5	45%	6	55%	11	100%
Total	69	51%	66	49%	135	100%
EMA Total	2,124	69%	957	31%	3,081	100%

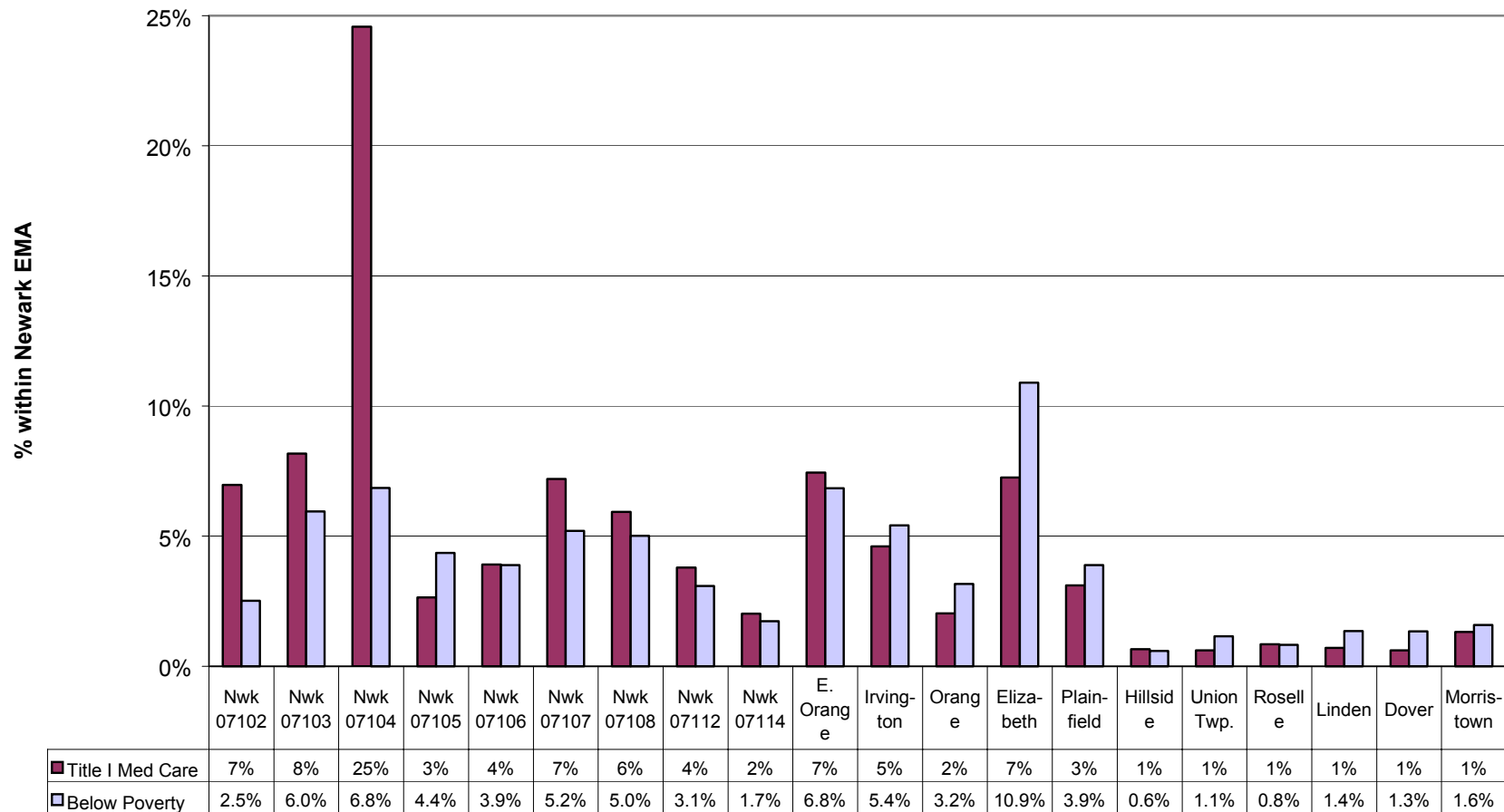
* Newark Total includes 254 Title I clients with no health insurance who record 07101 (Post Office) as ZIP of residence – 252 in Title I medical care and 2 not in Title I medical care in 2003.

Table 1-11: Distribution within Newark EMA of 2003 HIV+ Clients with No Reported Health Insurance by Title I Medical Care and Residents Below Poverty

County/ Municipality/ ZIP Area of Residence	Received Title I Medical Care in 2003		Residents Below Poverty – 2000	
	Yes	No	#	%
Essex County				
Newark 07102*	7%	12%	4,844	2.5%
Newark 07103*	8%	10%	11,456	6.0%
Newark 07104*	25%	5%	13,169	6.8%
Newark 07105*	3%	2%	8,380	4.4%
Newark 07106*	4%	4%	7,491	3.9%
Newark 07107*	7%	4%	10,001	5.2%
Newark 07108*	6%	10%	9,631	5.0%
Newark 07112*	4%	4%	5,938	3.1%
Newark 07114*	2%	2%	3,339	1.7%
Newark Total	65%	52%	74,249	38.6%
East Orange	7%	12%	13,159	6.8%
Irvington	5%	5%	10,420	5.4%
Orange	2%	3%	6,078	3.2%
Rest of Essex	3%	4%	16,100	8.4%
Total	83%	76%	120,006	62.4%
Union County				
Elizabeth	7%	9%	20,963	10.9%
Plainfield	3%	2%	7,476	3.9%
Hillside	1%	1%	1,147	0.6%
Union Twp.	1%	1%	2,212	1.1%
Roselle	1%	2%	1,582	0.8%
Linden	1%	1%	2,603	1.4%
Rest of Union	1%	2%	7,336	3.8%
Total	14%	17%	43,319	22.5%
Morris-Sussex-Warren	0%	0%		
Dover	1%	1%	2,585	1.3%
Morristown	1%	2%	3,047	1.6%
Rest of Morris	1%	2%	12,240	6.4%
Sussex	0%	1%	5,693	3.0%
Warren	0%	1%	5,492	2.9%
Total	3%	7%	29,057	15.1%
EMA Total	100%	100%	192,382	100.0%

* The total of 252 Title I clients with no health insurance who record 07101 (Post Office) as ZIP of residence and received Title I medical care in 2003 were redistributed among all Newark residents.

Figure 1-1: Comparison of Percent of Uninsured Title I Clients who Received Title I Medical Care in 2003 and Percent of Residents Below Poverty in 2000 - By ZIP Area and Municipality within Newark EMA



Part 1B: Study of a Sample of Title I Clients Not Receiving Title I Medical Care to Determine Barriers to Care

Introduction

The purpose of Part 1B was to collect additional data from clients who have not received primary medical care to learn about their health-care beliefs and their health care behavior. The target population was the 957 Active HIV+ Title I clients who reported no health insurance and received a Title I service in CY 2003 but not Title I medical care (see **Table 1-1**). It was determined that stratified random sampling could produce a subgroup of a manageable size which would be representative of the entire group. The results of Part 1A, particularly those characteristics which were predictive of Title I medical care utilization, were to have helped determine what types of clients might be of particular interest for Part 1B.

The study was designed initially as a mail survey to the sample of clients. Clients with known mailing addresses could be reached with a written questionnaire. Oral interviews could be done by the client's case manager, either face-to-face or over the telephone. The case manager would be a person already known to the client. The method was later revised to have the client contacted via mail or phone by the case manager. The client would then make a telephone call to the Newark EMA Planning Council office. The questionnaire would be administered as a telephone interview by Council staff. Some incentive, perhaps a \$10 voucher, was to be offered to increase participation.

Preliminary questions in the questionnaire would determine whether the client had received any HIV-related primary medical care during the time period, and whether he or she had any source of health insurance (other than Ryan White Title I) for medical care. The main part of the interview was to cover the client's service needs: What services are required to connect or re-connect the person into HIV medical care? What barriers would prevent the person from staying in HIV medical care? What core services would the person need in addition to primary medical care?

For ethical reasons, each participant in the study was to be encouraged to begin or resume primary medical care. This educational intervention would follow the interview so as not to affect the responses.

It was estimated that Part 1B would take approximately three months: one month to develop and pre-test the questionnaire and interview, one month (or more) to administer the questionnaire, and a third month to analyze the results.

It was determined that an initial sample size of approximately 180 clients not receiving Title I funded primary medical care would provide representative results. This number included 10% of the population (957) to serve as the representative sample (97), with an additional 10%

selected to allow for client nonresponse and replacement by clients with similar demographic and geographic characteristics.

Due to reduction in FY 2004 Title I funding, in March 2004 the scope and methodology of the Part 1B research were scaled back. The Council decided to proceed with selection of a 10% representative sample, but to utilize focus group research instead of a mailed questionnaire. See **Appendix B** for draft questionnaire.

Methods

The original tasks for Part 1B included utilizing CHAMP to identify consumers not in medical care and conducting personal interviews with those consumers. The Research Committee of the Planning Council recommended using a focus group to obtain the information that would have been collected via the questionnaire. This approach was less labor intensive than interviews, would require less staff time and travel time to complete, and would avoid feelings of anxiety and pressure that might be present among PLWHA who were not receiving medical care. A focus group could allow consumers to participate anonymously. In addition, incentives, such as food and food vouchers, could more easily be implemented in a focus group setting.

The focus group participants were selected from the CY 2003 CHAMP data file that had been utilized in Part 1A to identify clients who did not receive Ryan White Title I medical care and had no reported health insurance. As shown in **Table 1-1**, there were 957 clients in the universe to be sampled. A 10% sample size yielded 97 clients to be reached for the focus group. Although use of a stratified random sampling method was recommended initially, stratification became unnecessary because the four client characteristics of gender, age, race/ethnicity, and geography did not yield measurable differences warranting more in-depth study. A random sample was determined to be adequate for Part 1B. Utilizing a SPSS random selection program, the sample of 97 clients was selected. The sample was representative of the EMA in terms of gender, age, race/ethnicity, and geographical area including municipality and ZIP code level. Consistent with the distribution of the EMA's HIV epidemic, the majority of sample clients were from Essex County, followed by Union County, with a small portion from Morris, Sussex and Warren counties. Clients were selected for the sample by CHAMP unique coding only; no information was available which could identify any individual consumer.

Clients were invited to the focus group via mailing. To ensure client confidentiality, the Planning Council recommended that the mailing come from the Title I agencies which had provided one or more services to the 97 clients, and not from the Planning Council or staff.

It took approximately one month to complete all work for the focus group mailing. Council staff completed all draft letters, certificates, envelopes and labels for the mailing. These materials were sent to the provider agencies for mailing on their letterhead to their selected Title I clients. A special CHAMP program was then utilized to identify the Ryan White Title I funded agencies where the 97 consumers received support services. However, many consumers had received support services from more than one agency. Council staff reviewed and cross-checked all 61 providers and clients to avoid duplication among providers and confusion among consumers. Utilizing an Excel spreadsheet, the lists were consolidated into an unduplicated listing of 23 providers who served the largest numbers of clients and had provided services most recently.

In many instances, agencies were providing services to more than 10 of the consumers listed. This effort helped to reduce the number of agencies contacted.

Confidentiality of consumers was an ongoing theme during this process, and many steps were taken to ensure that confidentiality had not been compromised. To maintain confidentiality of consumers in the sample, Council staff prepared individual packets which invited consumers to the focus group. Each agency was sent the appropriate number of packets and a list of client identifiers for the mailing, which further decreased the work asked of the agencies. The mailing to each agency included the following:

- A cover letter from the Grantee – Director of Ryan White Unit, Newark Department of Health and Human Services (DHHS) – to the Title I provider agency, which stated the purpose of the research, provided instructions for completing the mailing, and included CHAMP coding for consumers who had received services from the agency;
- A letter of invitation from the Executive Director of the Planning Council, which was to be sent to the consumers. This letter explained the purpose of the focus group;
- Directions to the Planning Council office; and
- Certificates which consumers were asked to bring to the focus group. These certificates enabled the participants to retrieve their incentive, which was a \$10 gift card from Shop Rite Supermarket.

The invitations stated that hot lunch would be provided in addition to an incentive. It was suggested that food and incentives would increase the number of participants. The mailing was sent to 23 agencies approximately one month prior to the scheduled focus group date of June 17, 2004.

Approximately one week after the mailing, the Planning Council started to receive phone calls from the agencies who had received the information. The agencies commented that the consumers listed would be unable to attend the focus group, citing reasons such as incarceration, health concerns including hospitalization, inability to locate a current address for the consumer, and unwillingness on the part of the consumer to participate. It is unknown if these providers ever sent the mailing to the clients despite their concerns. Furthermore, Council staff had received no client phone calls although the mailing had asked consumers to contact the Council before the focus group date. As of June 16, 2004, Council staff did not know if anyone would show up for the focus group on the following day.

Results of the Focus Group

The focus group was held at the offices of the Newark EMA HIV Health Services Planning Council on Thursday, June 17, 2004 from 10:30 a.m. to 12 noon. The group was facilitated by Deloris Dockrey, MPH, Executive Director of the Planning Council.

Participant Demographics

Two consumers participated in the focus group, one male and one female. The demographic questionnaire used in Part 2 focus groups was administered. Both resided in Essex County, both speak English primarily, and both identified as Black/African American. One resides in a shared apartment/home with a partner and children, while the other resides in a rented apartment/ house with a significant other. One participant was over age 45, while the other was between age 25 and 44. One participant identified as heterosexual, while the other identified as heterosexual and filled in "questioning" under the category "Other". Both participants identified as being HIV-positive. **Both receive primary medical care for their HIV and visit their primary care physician on a regular basis.** One participant, who receives primary medical care in Monmouth County, visits the doctor once a month, and reported Medicaid as source of health insurance. The other participant, who receives medical care in Essex County, sees the doctor every three months, and reported charity care (and Ryan White Title I) as source of health insurance. During the focus group, the facilitator paid special attention to themes that were identified by participants.

Risk Factors

Do risk factors vary by age? Both participants agreed that risk factors do not vary by age, noting anyone is vulnerable to HIV if they engage in risky behavior. One participant commented that while youth are at risk because they explore and engage in unprotected sex with multiple partners, seniors are also at a great risk. Seniors are often "settled in their ways" and are not as accepting of the need to change their behaviors, i.e., practice safe sex.

Do risk factors vary geographically? Both participants agreed that risk factors do not vary geographically, commenting that as long as there "is a drug infested area, all the risk factors will be there".

Do risk factors vary by culture? One participant commented that risk factors do not vary by culture, commenting that anyone can contract the virus. The other participant suggested risk factors may vary by culture, specifically for those cultures who do not openly discuss HIV or other sexually transmitted diseases.

Do risk factors vary by education and income? The participants agreed that risk factors may vary by education and culture, noting that many people are in denial.

Medical Care

Is the medical care you receive adequate? Both participants agreed the medical care they receive is not appropriate. One participant commented on frequently feeling rushed when seeing the doctor. This participant wanted to spend [more] time with the physician, and to be spoken to. This participant does not receive medical care in the EMA and travels to Monmouth County for care. The reason for traveling out of county is the reported treatment by the providers in Counties outside of the EMA. This participant stated that in his experience, medical care in Essex County is dominated by rushing through appointments and a lack of dialogue between the patient and the provider. For this reason, this participant has chosen to see a

doctor in Monmouth County, where he says his doctor spends time with him and talks to him. The other participant commented it often takes a long time to see the doctor, specifically in the waiting room. Although there is a long waiting time to see the doctor; once she is with the doctor, the physician spends a very short amount of time with them. This participant feels rushed out the door, stating "I need a doctor I can talk to".

Are the medical services you receive culturally and linguistically appropriate? The participants commented that the language used by many physicians may be difficult to understand, specifically for the newly diagnosed. Participants also commented that when they are unable to understand what they physician is explaining to them, they rely on their case managers, psychiatrists and social workers for clarification.

Support Services

What support services are necessary to help you maintain medical care? Both participants agreed that transportation is "one of, if not the most important" service to help HIV-positive individuals access medical care. One participant commented on the importance of mental health services, psychiatric services, support groups and nutritional counseling. Both participants agreed that education is also important to help consumers maintain medical care.

Consumers Not in Care

What prevents HIV-positive consumers from accessing medical services?

Substance use. Both participants agreed that persons who are actively using will not seek primary medical care, stating they "don't care because of their drug use". Substance use helps to alleviate the pain of diagnosis, and helps the individual "not face reality".

Death wish. Participants commented that for some HIV-positive consumers, an HIV diagnosis may be so devastating that individuals may have a death wish. In addition, many consumers do not seek medical care because they "claim they are going to die anyway".

Lack of income/insurance. Participants agreed that a lack of income or health insurance can significantly impact an individual's ability to seek primary medical care. One participant commented that consumers "can't get help if they don't have any money".

Stigma associated with sites providing medical services. Participants commented on the reluctance of some to visit medical providers who are primarily known for treating HIV-positive patients, noting that by going to these facilities their status is often "broadcast" openly to others.

Mental health concerns. The participants noted that many HIV-positive individuals are not emotionally prepared to disclose their status, which prevents consumers from obtaining medical care. In addition, one participant commented that the mental turmoil of living with HIV can impact a person's willingness to access medical care. This participant commented "We tend to stuff a lot of our feelings. By stuffing our feelings, it only makes us sick". Participants also commented on the need to be able to trust others when disclosing their status, which may be as

difficult to deal with as stigma which still pervades public perception of HIV. In addition, the fear of rejection was cited as a reason consumers do not access medical services.

Non-compliance with anti-retroviral medications. One participant commented that many HIV-positive consumers do not regularly take their antiretroviral medications, or do not take the medications as prescribed by their physician. This result in blood tests indicating the medications are not working, which frustrates consumers. These consumers then conclude that the medications do not help with their health, and subsequently sell the medications on the streets.

What can be done to motivate HIV-positive consumers to access primary medical services?

Outreach. One participant suggested that outreach is essential, but noted that it “needs to be done from the heart”. This participant stressed the importance of meeting people where they are, noting that beliefs cannot be imposed on others. This participant suggested that outreach would be more effective if done by individuals who are themselves HIV-positive, because “they can better understand where the people are coming from”.

Participant Suggestions

One participant suggested training for providers, noting “there is no respect by the providers of those living with the virus”. Participants suggested that training that specifically details the needs of HIV-positive patients is essential.

Participants also commented that there are many individuals who do not want others to disclose their HIV status. If an individual was met with resistance when they disclosed in the past, they may be reluctant to disclose in the future, which may impact their willingness to access services, including primary medical care.

Final Notes

While the participants in this focus group provided detailed and important information, they were not the target population for this focus group. Both participants receive medical care on a monthly or quarterly basis. One participant receives care in Monmouth County, and thus would not be listed in CHAMP as not receiving medical care. As both consumers actively participate in primary medical care, this suggests that the CHAMP database may need to be updated. It also suggests that a larger portion of consumers may be receiving medical care than CHAMP data suggest.

While it was important to maintain confidentiality of consumers, this may have significantly impacted the outcome of the focus group. Mailings were sent to providers but Council staff had no mechanisms to ensure that those consumers had, in fact, been contacted. Follow-up with consumers to confirm or encourage them to attend was not possible, because staff were not able to contact the consumers directly. Asking providers to follow-up with consumers would have created more work for them, particularly for agencies serving a large number of consumers on the list.

Future research is necessary regarding HIV-positive consumers who do not receive primary medical care. While the current research did not yield the anticipated results, it served as a catalyst for such research. Those receiving support services and not primary medical care may be a difficult population to reach, not only for the above reasons, but also because they may access support services only during times of crisis. However, it is essential to identify these consumers, and to understand their specific reasons for not seeking medical care.