

Chapter

2

## Ryan White CARE Act

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act is Federal legislation that addresses the unmet health needs of persons living with HIV disease by funding primary health care and support services that enhance access to and retention in care. The CARE Act was named after Ryan White, an Indiana teenager whose courageous struggle with HIV/AIDS and against AIDS-related discrimination helped educate the nation.

First enacted by Congress in 1990, it was amended and reauthorized in 1996 and again in 2000. The CARE Act reaches over 500,000 individuals each year, making it the Federal Government's largest program specifically for people living with HIV disease.

The Program is administered by the Health Resources and Services Administration (HRSA) which is within the U.S. Department of Health and Human Services (DHHS).

The four Titles and Part F of the Ryan White CARE Act are administered by the HIV/AIDS Bureau of HRSA. CARE funds cannot offset state and local expenditures including Medicaid.

### **Title I**

Grants are awarded to eligible metropolitan areas based on case rates. Allocation decisions are made by local consortia. Major services funded under Title 1 are:

- Outpatient health care
- Support services including case management, home health, hospice care, housing, transportation, nutrition.

Currently, Indiana is not receiving any funds under Title I.

## **Title II**

Grants are to states for health care and support services for persons with HIV/AIDS. Allocation decisions are by states. Major services funded under Title II are:

- Home and community-based health care and support services
- Pharmacy support through ADAP (AIDS Drug Assistance Program)
- Local consortia to assess needs and organize a regional plan for delivery of HIV/AIDS services
- Medical care and support services.

## **Title III**

Support is provided to primary care providers through local health departments, homeless programs, community and migrant health centers, hemophilia centers and family planning centers. Major services provided under Title III are:

- Primary care services for low-income, medically underserved persons in existing primary care systems
- Clinical prevention services through medical, educational and psychosocial services.

Indiana is receiving Title III funds in two cities, Gary and Indianapolis.

## **Title IV**

Title IV is intended to provide health care and support services for children, adolescents, women and families utilizing comprehensive, community-based care systems.

Currently, Indiana is not receiving any funds under Title IV.

## **Part F**

Special Projects of National Significance (SPNS) are competitively awarded to support the development of innovative models of HIV/AIDS care with particular emphasis on hard to reach populations including Native Americans, minorities, etc. Targeted areas include managed care, infrastructure development, training, comprehensive primary care, and access to care.

In the current fiscal year, that runs from April 1, 2006 to March 31, 2007, the funding for Title II of the Ryan White CARE Act to Indiana added up to a total of \$11,706,817. The budget included allocations for medical and social services, as well as administrative costs to administer these federal funds. Table 58 gives a detailed breakout of the total budget.

**Table 58: Title II Budget for Indiana, Fiscal Year 2007/2008**

Program		Total	Percent of Budget
Medical Services	ADAP	\$542,160.00	4.64%
	HIAP 1	\$9,896,970.00	84.72%
Administrative Services	HIAP 2	\$395,000.00	3.38%
	Planning and Evaluation	\$40,000.00	0.34%
	Quality Management	\$100,536.00	.86%
	Administrative	\$706,820.00	6.05%
<b>Total</b>		<b>\$11,681,486.00</b>	<b>100.0%</b>

The total budget can be broken out into roughly two areas, Medical Services and Administrative Services. The Medical Services include the AIDS Drug Assistance Program (ADAP), the Health Insurance Assistance Program (HIAP 1) and the State Direct Services component. Medical Services make up 89.36% of the budget. The Administrative Services part, 10.29%, covers Administrative costs, the Quality Management Component, as well as the administrative costs for the Health Insurance Assistance Program (HIAP), which is listed in Table 58 under title HIAP 2.

## Question 4

# What are the patterns of service utilization of HIV-infected people?

### Utilization Pattern of HIV Infected Persons

The purpose of the Indiana AIDS Drug Assistance Plan (ADAP) is to assist persons who have tested positive for HIV to access certain approved drugs. ADAP pays for certain FDA approved therapeutic drugs through participating pharmacies.

The Health Insurance Assistance Plan (HIAP) program provides a complete health care benefit program, which includes coverage for non-HIV related illnesses and injuries. This program purchases comprehensive health insurance policies for eligible individuals through the Indiana Comprehensive Health Insurance Association (ICHIA). HIAP also covers the cost of any co-insurance and deductibles. There is a three-month waiting period for "pre-existing conditions", including HIV/AIDS. HIAP enables HIV-infected residents of Indiana to obtain insurance, allowing them to maintain their independence, return to the workforce if they desire, and improve their quality of life.

ADAP, HIAP, and the Early Intervention Plan (EIP) are funded by a grant from the Indiana State Department of Health (ISDH) through Title II of the Ryan White CARE Act and State AIDS dollars. Services can be obtained by contacting one of the fourteen Standard Care Coordination sites located regionally throughout the state. On July 1, 2004 the number of Standard Care Coordination sites in the state was reduced from fourteen to thirteen.

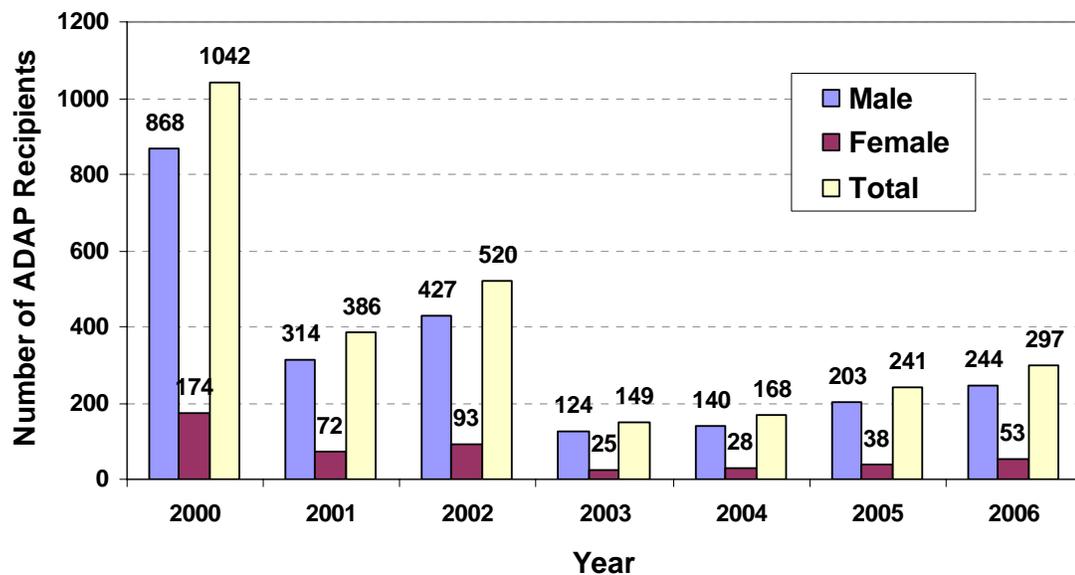
Eligibility applies to Indiana residents who meet program financial guidelines, are able to provide verification of positive HIV status, are without private or public health insurance, and are determined by a physician to be an appropriate candidate for approved drugs.

Participants are referred to and encouraged to use the services of a Care Coordinator (case manager) whenever possible, so that all their needs may be addressed. Participants may choose or be referred to a primary care physician and other providers. There is no charge to program participants for covered services.

Among the services provided under the CARE Act are the AIDS Drug Assistance Program (ADAP) and the Health Insurance Assistance Plan (HIAP).

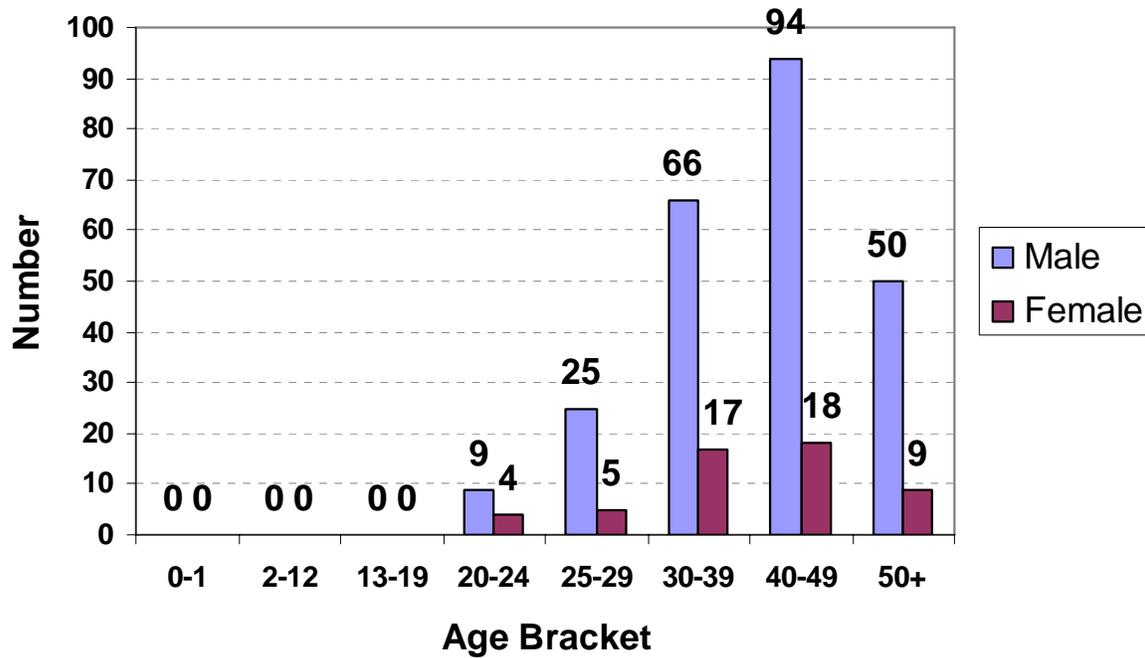
Under ADAP, a total of 297 persons received assistance with the cost for medications in 2006, up from 241 in 2005. Over the past four years, the number of recipients of this assistance program has dropped sharply mainly due to the shift of eligible persons from the ADAP program to the state funded ICHIA program. In addition, the Indiana legislature changed the ICHIA enrollment for high-risk pool insurance from a residency requirement of 90 days to 365 days before a person is eligible for medical services.

**Figure 68: Number of ADAP Recipients in Indiana by Year and Sex, 2000-2006**



Consistent with the findings for the HIV infected population at large male recipients outnumber their female counterparts. A look at the age distribution of the enrolled population is shown in Figure 69.

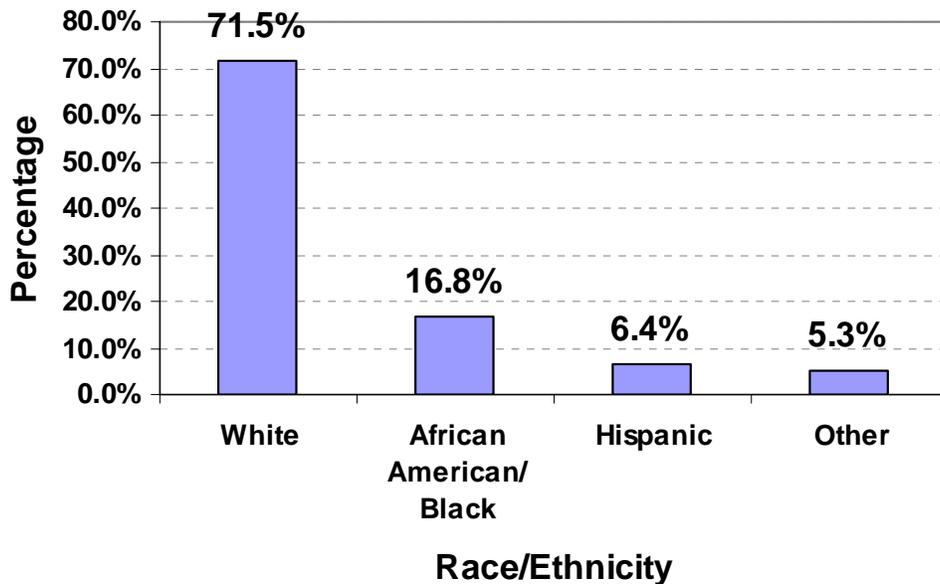
**Figure 69: Number of Unduplicated Males and Females by Age Category Enrolled in ADAP, April 2006 to March 2007**



For the period April 2006 to March 2007 there were 244 (82.2%) unduplicated males and 53 (17.8%) unduplicated females enrolled in ADAP. Unduplicated means that no recipient was counted twice, regardless of where the services were provided to a person enrolled in the program. As shown in Figure 69, apart from the differences in absolute numbers, no real difference age-wise was evident between males and females. The majority of enrolled persons were ages 40 to 49, with the group of 30 to 39 year olds in second position.

The racial and ethnic distribution of ADAP recipients has been changing over the past 5 years. Figure 70 shows the racial and ethnic percentage distribution in 2006.

**Figure 70: Percentages of ADAP Recipients by Race/Ethnicity, April 2006 to March 2007**



About seven out of ten recipients were White in 2006, followed by African Americans with 16.8%. The numbers and percentages of ADAP recipients for the past five years is shown in Table 59.

**Table 59: Numbers and Percentages of ADAP Recipients by Year and Race/Ethnicity, 2002-2006**

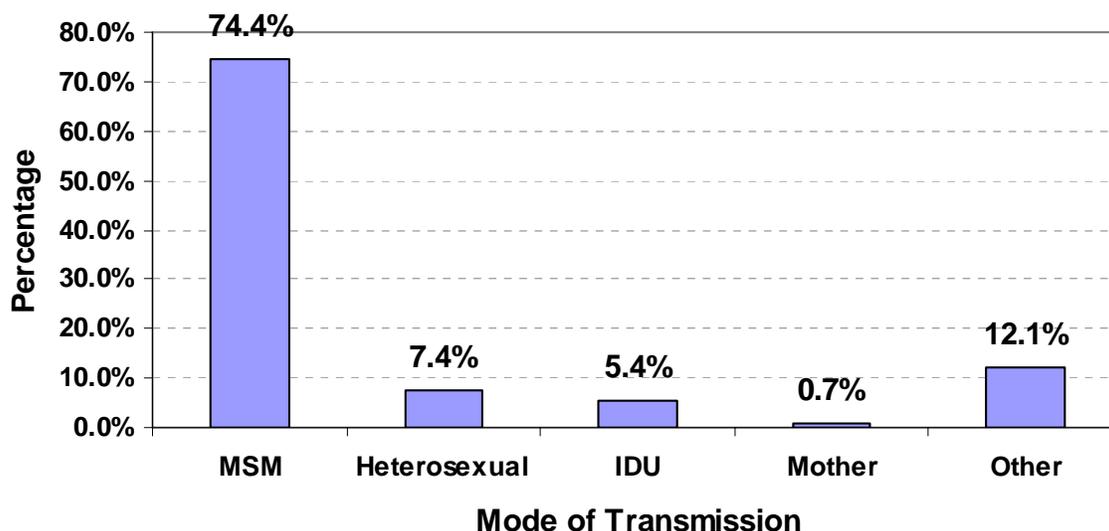
Race/ Ethnicity	2002		2003		2004		2005		2006	
	Number	%								
White	346	66.5	89	59.7	108	64.3	167	69.3	212	71.4
African American	153	29.4	34	22.8	27	16.1	38	15.8	50	16.8
Other	21	4.0	26	17.4	8	4.8	15	6.2	16	5.4
Hispanic*	39	7.5	15	10.1	25	14.9	21	8.7	19	6.4

\*Note: Hispanic can be of any race, Percentages will therefore exceed 100%

Several trends can be seen over the course of the past five years in Table 59. The share of White recipients increased in 2006 from 2005, which is comparable to the number from 2002 and has been increasing since 2004. At the same time, the share of Hispanic

recipients dropped from last year to its current value of 6.4%. The share of the African-American population rose from last year, where it showed its lowest level in five years.

**Figure 71: Percentages of Unduplicated Males and Females Enrolled in ADAP by Risk Factor, April 2006 to March 2007**



Nearly three-quarters of all recipients are associated with MSM as their primary risk category, consistent with the distribution of the HIV infected population overall. In terms of CD4 count, Table 60 lists the corresponding percentages.

**Table 60: Unduplicated Clients Enrolled in ADAP by CD4 Count Category (April 2006 to March 2007)**

CD4 Count Category	Unduplicated Clients	Percent
< 200	29	9.8
200-350	44	14.8
351-500	50	16.8
> 500	78	26.3
Unknown	96	32.3
<b>Total</b>	<b>297</b>	<b>100.0</b>

In terms of income of the recipients there are definitive differences between the enrolled clients.

**Table 61: Unduplicated Clients Enrolled in ADAP by Income Category, April 2006 to March 2007**

<b>Income Category</b>	<b>Unduplicated Clients</b>	<b>Percent</b>
< 100% Federal Poverty Level (\$9,570)	68	22.9
101%-200% Federal Poverty Level (\$9,571 - \$19,140)	56	18.9
201%-300% Federal Poverty Level (\$19,141 - \$28,710)	17	5.7
No Data Collected	156	52.5
<b>Total</b>	<b>297</b>	<b>100.0</b>

Almost one quarter of all enrolled clients have incomes of less than 100% of the Federal Poverty Level definition. An additional 18.9% have incomes of between 101% and 200% of the Federal Poverty Level. Only about one in twenty recipients had an income between \$19,141 and \$28,710 in 2006.

Since 1999, the yearly total costs for the ADAP program have decreased dramatically due to the transition of most enrolled to HIAP within the first six months. At the same time, the annual and monthly costs per client decreased from 2005, where it displayed its highest total in 5 years. Table 62 lists the trends of expenditures for the ADAP program.

**Table 62: Program Expenditures for ADAP by Year, 2000-2006**

<b>ADAP</b>	<b>2000</b>	<b>2001</b>	<b>2002</b>	<b>2003</b>	<b>2004</b>	<b>2005</b>	<b>2006</b>
Annual cost per client	\$2,852	\$2,422	\$2,442	\$3,154	\$3,821	\$5,950	\$4787
Monthly cost per client	\$238	\$201	\$203	\$263	\$318	\$495	\$399
<b>Annual cost</b>	<b>\$2,971,846</b>	<b>\$934,873</b>	<b>\$1,269,498</b>	<b>\$470,001</b>	<b>\$641,873</b>	<b>\$815,218</b>	<b>\$1,421,594</b>

Table 63 lists the types of medications and drugs that are paid for by ADAP funds for the year 2006. The single largest share of the ADAP budget (56.1%) has been used for Antiretroviral drugs, while the rest covers medication to combat the side effects and symptoms of the combined disease.

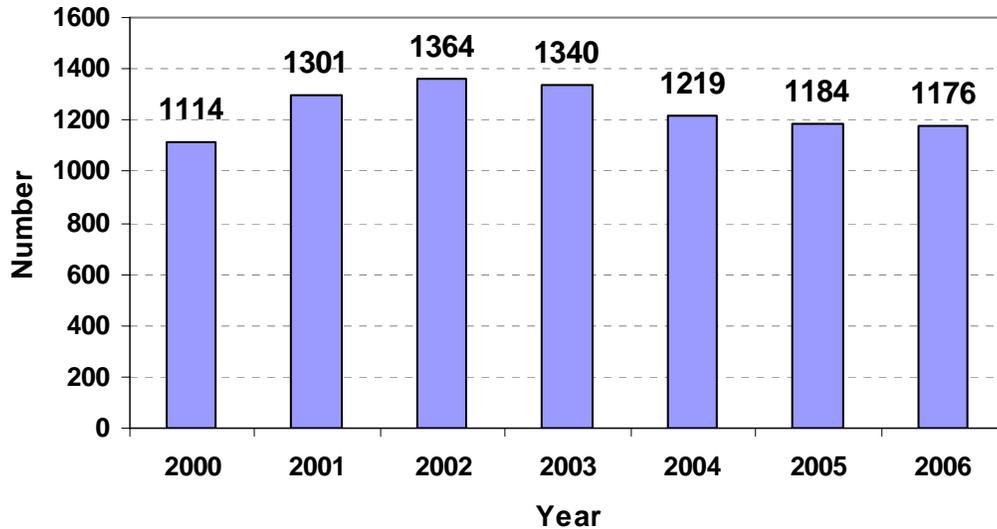
**Table 63: Number of Claims and Expenditures for ADAP Covered Drugs by Category, April 2006 to March 2007**

<b>Drug Type</b>	<b>Claims</b>	<b>Expenditures</b>
Antianxiety/Antidepressants	217	\$12,269.80
Antifungal	54	\$1,569.57
Antinausea	42	\$574.58
Antiretroviral	942	\$470,886.91
Antiviral	71	\$24,936.48
Cholesterol Lowering	86	\$4,422.03
Fusion Inhibitors	24	\$45,558.83
Mood Stabilizers	26	\$212.27
Pain Management	189	\$3,102.26
Prophylaxis and Treatment	194	\$4,757.29
Protease Inhibitors	432	\$250,388.68
Sleep Medications	116	\$5,356.73
Other	151	\$14,764.08
<b>Total</b>	<b>2,544</b>	<b>\$838,829.51</b>

The costs for immunizations and TB tests are covered under neither the EIP (Emergency Intervention Program) nor the ICHIA program. They are therefore not listed here, nor are these expenditures tracked in this report.

The number of HIAP recipients declined over the past four years from its peak in 2002. Figure 72 shows the trend for the past seven years in HIAP enrollment.

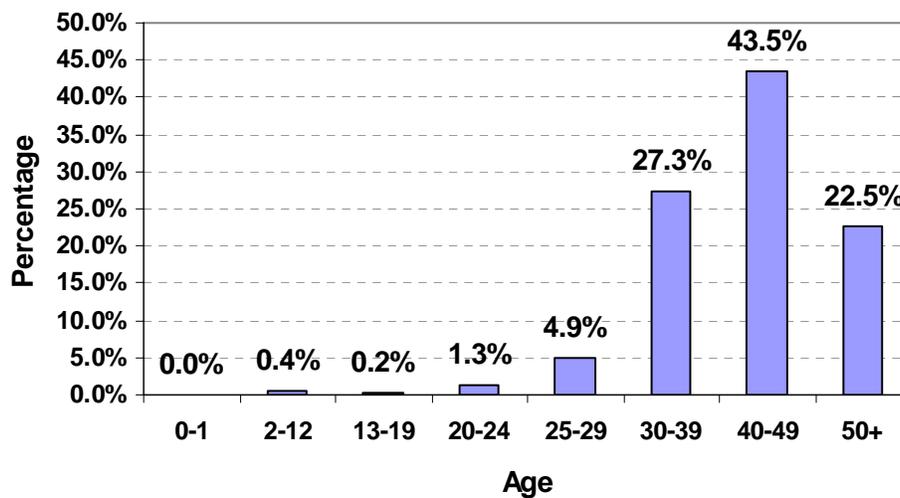
**Figure 72: Number of HIAP Recipients in Indiana by Year, 2000-2006**



Similar to the ADAP program, the clients enrolled in the HIAP program are predominantly male. In the year from April 2006 to March 2007, 1,176 clients were enrolled in HIAP. Of those, 997 (or 84.8%) were male and 179 (or 15.2%) were female.

The distribution of age among the HIAP clients is shown in Figure 73.

**Figure 73: Percentages of HIAP Clients by Age Category, April 2006 to March 2007**



More than four in ten HIAP clients are in the age group of 40 to 49 years of age.

In terms of overall costs for the HIAP program, 2006 continues to show increases over the previous year. Table 64 below shows the trend numbers in costs for the past seven years.

**Table 64: Program Expenditures for HIAP by Year, 2000-2006**

<b>HIAP</b>	<b>2000</b>	<b>2001</b>	<b>2002</b>	<b>2003</b>	<b>2004</b>	<b>2005</b>	<b>2006</b>
<b>Annual cost</b>	\$434,337	\$4,335,507	\$5,708,890	\$7,920,395	\$8,660,889	\$8,834,983	\$8,837,655
<b>Annual cost per client</b>	\$390	\$3,332	\$4,185	\$5,911	\$7,105	\$7,461	\$7,515
<b>Monthly cost per client</b>	\$33	\$278	\$349	\$660	\$562	\$621	\$626

In 2006 the Annual Expenditures increased slightly over the previous year, as did the annual costs per client.

## Care Coordination Services

Currently there are 18 Care Coordination sites in Indiana that provide health and human services for people living with HIV/AIDS (2006).

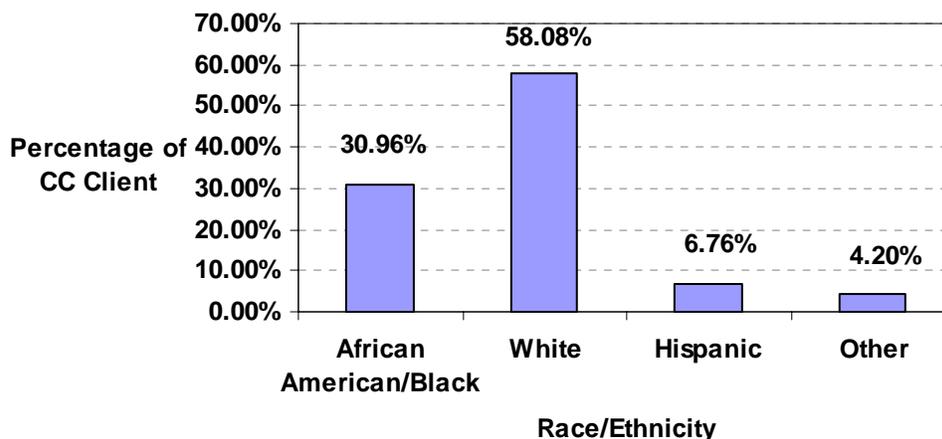
This report will present the demographic characteristics of the persons that use those services. In Table 65, the users of care services are broken out by sex and the quarter in which they used some of Care Coordination services.

**Table 65: Percentages and Total Number of Care Utilization Services by Gender and Quarter, April 2006 – March 2007.**

	April - June 2006	July – September 2006	October - December 2006	January – March 2007	Average
<b>Male</b>	78.2%	77.9%	77.5%	77.4%	77.8%
<b>Female</b>	21.8%	22.1%	22.5%	22.6%	22.2%
<b>Total</b>	<b>3,280</b>	<b>3,254</b>	<b>3,280</b>	<b>3,224</b>	<b>3,260</b>

Consistent with the HIV infected population at large, more than three-quarters of recipients were male in 2004. In terms of race and ethnicity, the distribution of care recipients is shown in Figure 74.

**Figure 74: Percentages of Care Utilization Services by Race/Ethnicity, 2006**



The majority of service recipients were White (50.08%), followed by Black/African-Americans (30.96%). The share of Hispanics (6.76%) among Care Utilization users is almost twice their

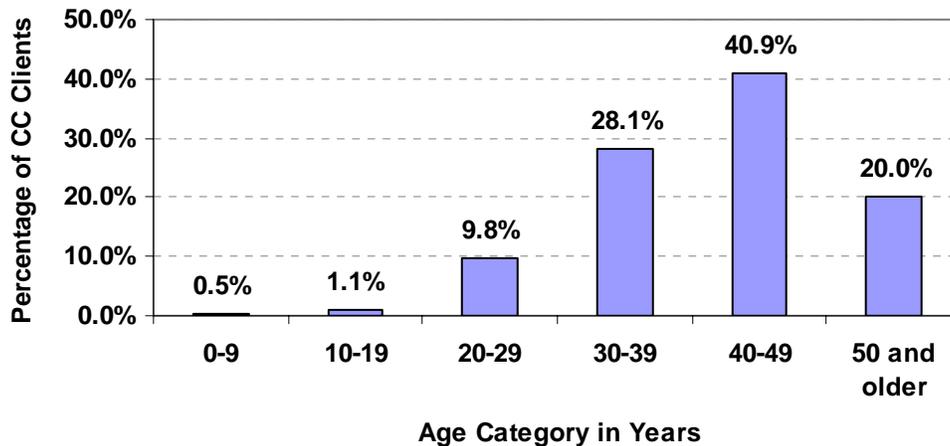
share of the general population in Indiana. Table 66 below lists the racial and ethnic percentages by quarter and by race/ethnicity.

**Table 66: Percentages and Total Number of Care Utilization Services by Race/Ethnicity and Quarter, 2006**

<b>Race</b>	<b>April - June 2006</b>	<b>July – September 2006</b>	<b>October - December 2006</b>	<b>January – March 2007</b>	<b>Average</b>
<b>Black</b>	30.9%	30.7%	31.7%	30.5%	30.9%
<b>White</b>	58.8%	58.6%	57.1%	57.7%	58.1%
<b>Hispanic</b>	6.7%	6.5%	6.7%	7.2%	6.8%
<b>Other</b>	3.6%	4.2%	4.5%	4.6%	4.2%
<b>Total</b>	<b>3,280</b>	<b>3,254</b>	<b>3,280</b>	<b>3,224</b>	<b>3,260</b>

Figure 75 shows the percentages of Care Coordination services recipients by age group for 2006.

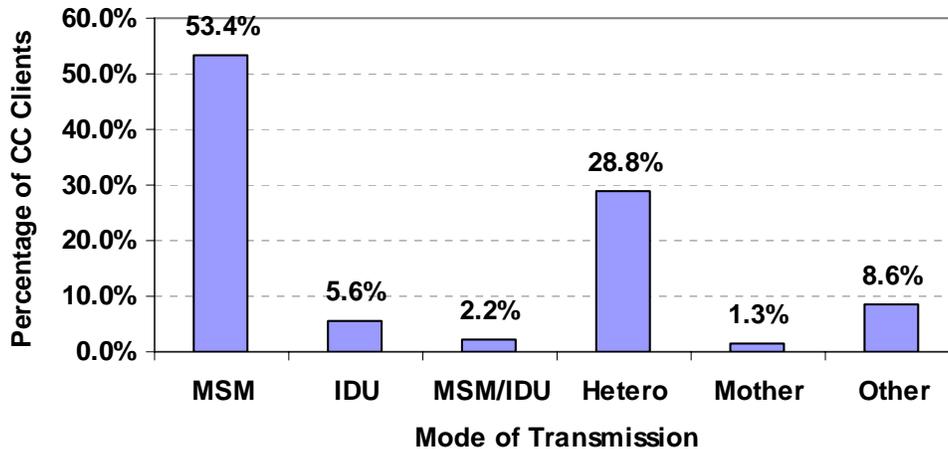
**Figure 75: Percentages of Care Coordinator Clients by Age Category, 2006**



The majority of the 3,260 clients receiving care services in 2006 were in the age range of 40 to 49 years of age.

The distribution of risk categories among the service recipients is shown in Figure 76.

**Figure 76: Percentages of Care Utilization Services by Exposure for 2006**



Over half of all recipients are associated with MSM as their primary risk category, consistent with the risk category distribution of the HIV/AIDS infected population overall.

Table 67 lists the corresponding percentages and totals by risk category and quarter for 2006.

**Table 67: Percentages and Total Number of Care Utilization Services Percentages by Exposure and Quarter for 2006**

Exposure	April - June 2006	July - September 2006	October - December 2006	January - March 2007	Average
MSM	53.5%	53.7%	53.4%	53.0%	53.4%
IDU	5.6%	5.6%	5.6%	5.6%	5.6%
MSM/IDU	2.3%	2.3%	2.1%	2.3%	2.3%
Hetero	28.2%	28.3%	28.8%	30.0%	28.8%
Mother	1.4%	1.3%	1.3%	1.3%	1.3%
Other	9.0%	8.8%	8.8%	7.7%	8.6%
<b>Total</b>	<b>3,280</b>	<b>3,254</b>	<b>3,280</b>	<b>3,224</b>	<b>3,260</b>

## Unmet Needs

The Indiana State Department of Health Staff administered the HIV Services Needs Assessment Survey for 2005 to 520 clients receiving HIV services in Indiana. This is the most recent version of this survey. Most respondents completed the survey in English, though 6 respondents completed a Spanish version. To identify the respondents' geographic location, the survey asked for zip code. Note that 51 respondents did not give their zip code; they are included in the total in the "Missing" row in Table 68.

**Table 68: Numbers and Percentages of Respondents by Community Planning Region, Indiana 2005**

<b>Planning Region</b>	<b>Primary City</b>	<b>Number of Respondents</b>	<b>Percent</b>
<b>1</b>	Gary	57	11.0
<b>2</b>	Elkhart	32	6.2
<b>3</b>	Fort Wayne	58	11.2
<b>4</b>	Lafayette	14	2.7
<b>5</b>	Muncie	48	9.2
<b>6</b>	Indianapolis	142	27.3
<b>7</b>	Evansville/Terre Haute	51	9.8
<b>8</b>	Bloomington	26	5.0
<b>9</b>	Cincinnati Area	13	2.5
<b>10</b>	Louisville Area	28	5.4
<b>Missing</b>		51	9.8
<b>Total</b>		<b>520</b>	<b>100.0</b>

A majority of the respondents are male (419 or 80.6%), the remaining are female (90 or 17.4%) and transgender (7 or 1.3%). Four respondents did not offer their gender. The survey had relatively few respondents indicating their race as Asian (1), "Multi-racial" (14), and "Other" (2). For this reason, they are condensed into "Other Races." Table 69 shows the racial and ethnic distribution of the survey respondents.

**Table 69: Numbers and Percentages of Survey Respondents by Race and Ethnicity, Indiana 2005**

<b>Race</b>	<b>Number of Respondents</b>	<b>Percent</b>
Black	101	19.4
Hispanic	32	6.2
White	369	71.0
Other Races	17	3.3
Missing	1	0.2
<b>Total</b>	<b>520</b>	<b>100.0</b>

A majority (432 or 83.1%) of respondents has been in Care Coordination for more than 12 months; the remaining 15.1% has been in Care Coordination for less than 12 months. See Table 70 for a breakdown.

**Table 70: Numbers and Percentages of Survey Respondents by Length of Time in Care Coordination Services, Indiana 2005**

<b>Length</b>	<b>Number of Respondents</b>	<b>Percent</b>
Less than 3 months	26	5.0
3 to 12 months	51	9.8
More than 12 months	432	83.1
Missing	11	2.1
<b>Total</b>	<b>520</b>	<b>100.0</b>

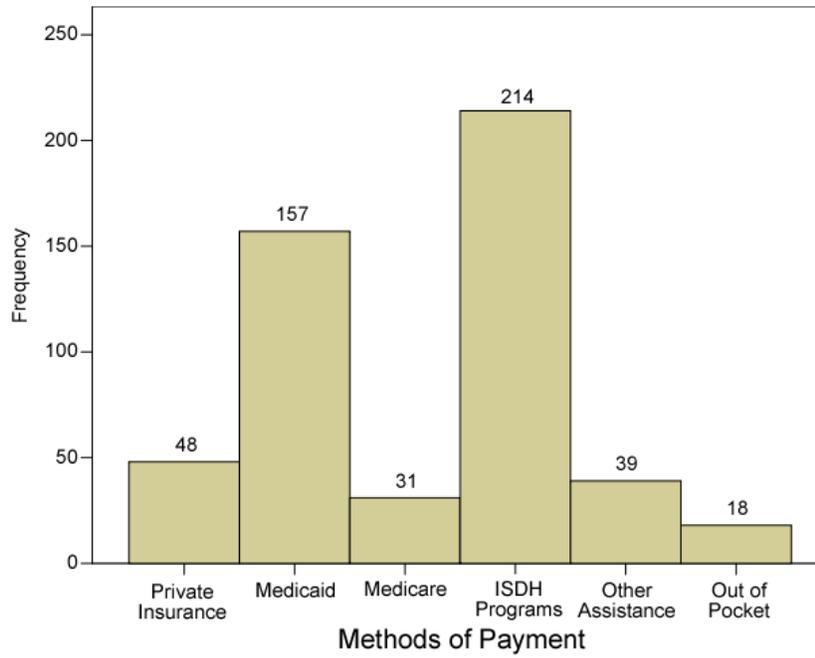
A majority (57.9%) of respondents earns \$12,000 or less. See Table 71 for a complete breakdown of the annual household income of the respondents.

**Table 71: Numbers and Percentages of Survey Respondents by Annual Household Income, Indiana 2005**

<b>Annual Income</b>	<b>Number of Respondents</b>	<b>Percent</b>
Less than \$6,000	140	26.9
\$6,000 to \$12,000	161	31.0
\$12,001 to \$18,000	83	16.0
\$18,001 to \$24,000	67	12.9
\$24,001 to \$30,000	33	6.3
More than \$30,000	22	4.2
Missing	14	2.7
<b>Total</b>	<b>520</b>	<b>100.0</b>

Most respondents rely upon ISDH Programs (214 or 41.2%) or Medicaid (157 or 30.2%) to pay for their medical expenses. See Figure 77 for a complete breakdown of how respondents pay for their medical expenses.

**Figure 77: Number of Survey Respondents by Method of Medical Expense Payments, Indiana 2005**



## About the Gaps

Respondents were asked a series of questions about the number of days or time in which they experienced a particular hardship (e.g. the number of days in the last month the respondent was hungry or unable to get food). The respondents were able to answer "None," "1 to 2," "3 to 4," "5 to 6," or "7 or more." See Table 72 for the complete responses. To aid analysis, each of these items was condensed into a dichotomous variable (i.e. two possible responses, none or 1 or more). In consultation with ISDH staff, percentages of respondents expected to fall in the "None" and "1 or more" categories were determined. Table 72 contains the questions and expected percentages.

Question	Expected %	
	None	1 or more
8. How many days in the last month were you hungry and unable to get food?	90	10
9. How many times in the last month did you miss work, school, or a doctor's appointment due to illness?	50	50
10. How many times in the last month did you miss work, school, or a doctor's appointment due to lack of transportation?	80	20
11. How many times in the last year were you prevented from getting your medications due to lack of transportation?	90	10
12. How many times in the last year were you prevented from getting your medications due to lack of insurance?	80	20
13. How many times in the last year were you prevented from getting your medications due to lack of money to pay for the co-payments or deductibles?	80	20
14. How many times in the last year have you been notified of possible eviction from your home or disconnection from your utilities?	50	50
15. How many times in the last year have you had trouble accessing dental care?	50	50
16. How many times in the last year have you had trouble accessing vision care?	50	50
17. How many times in the last year have you had trouble accessing specialty medical care (such as cardiology, endocrinology, or gynecology)?	50	50
18. How many times in the last year have you gone to the Emergency Room?	80	20
19. How many times in the last year have you felt that services were withheld from you due to discrimination against your HIV status?	90	10

The actual responses are summarized in Table 73.

**Table 73: Numbers and Percentages of Responses to Gaps Questions in Survey, Indiana 2005**

Question	Number of Respondents (%)				
	None	1 to 2	3 to 4	5 to 6	7 or more
8. Days hungry	344 (66.2)	85 (16.3)	38 (7.3)	24 (4.6)	29 (5.3)
9. Missed work (illness)	310 (59.6)	116 (22.3)	51 (9.8)	10 (1.9)	33 (6.3)
10. Missed work (transportation)	405 (77.9)	70 (13.5)	28 (5.4)	8 (1.5)	9 (1.7)
11. Unable to take medications (transportation)	444 (85.4)	48 (9.2)	13 (2.5)	4 (.8)	11 (2.1)
12. Unable to take medications (lack of insurance)	411 (79.0)	51 (9.8)	25 (4.8)	9 (1.7)	24 (4.6)
13. Unable to take medications (no money)	360 (69.2)	70 (13.5)	40 (7.7)	16 (3.1)	34 (6.5)
14. Eviction / Utility disconnect	335 (64.4)	98 (18.8)	46 (8.8)	19 (3.7)	22 (4.2)
15. Trouble accessing dental care	293 (56.3)	118 (22.7)	42 (8.1)	13 (2.5)	54 (10.4)
16. Trouble accessing vision care	341 (65.6)	102 (19.6)	32 (6.2)	8 (1.5)	37 (7.1)
17. Trouble accessing specialty medical care	427 (82.1)	52 (10.0)	19 (3.7)	8 (1.5)	14 (2.7)
18. Times in the emergency room	255 (49.0)	161 (31.0)	68 (13.1)	20 (3.8)	16 (3.1)
19. Services withheld because of discrimination	392 (75.4)	88 (16.9)	22 (4.2)	5 (1.0)	13 (2.5)

**Table 74: Numbers and Percentages of Responses by Comparisons between Estimated Answers and Given Answers, Indiana 2005**

Question	Predicted Percentage "None" / "1 or More"	Frequency (%)		Outcome
		None	1 or more	
8. Days hungry	90 / 10	344 (66.2)	176 (33.8)	Worse
9. Missed work (illness)	50 / 50	310 (59.6)	210 (40.4)	Better
10. Missed work (transportation)	80 / 20	405 (77.9)	115 (22.1)	Same <sup>a</sup>
11. Unable to take medications (transportation)	90 / 10	444 (85.4)	76 (14.6)	Worse
12. Unable to take medications (lack of insurance)	80 / 20	411 (79.0)	109 (21.0)	Same <sup>a</sup>
13. Unable to take medications (no money)	80 / 20	360 (69.2)	160 (30.8)	Worse
14. Eviction / Utility disconnect	50 / 50	335 (64.4)	185 (35.6)	Better
15. Trouble accessing dental care	50 / 50	293 (56.3)	227 (43.7)	Better
16. Trouble accessing vision care	50 / 50	341 (65.6)	179 (34.4)	Better
17. Trouble accessing specialty medical care	50 / 50	427 (82.1)	93 (17.9)	Better
18. Times in the emergency room	80 / 20	255 (49.0)	265 (51.0)	Worse
19. Services withheld because of discrimination	90 / 10	392 (75.4)	128 (24.6)	Worse

<sup>a</sup> Those that are marked "Same" did not reach statistical significance; that is, the probability that the actual value is different than the prediction is higher than standard tolerance (5% error), so it is more likely that the actual value is the same as the predicted values, despite appearing numerically different.

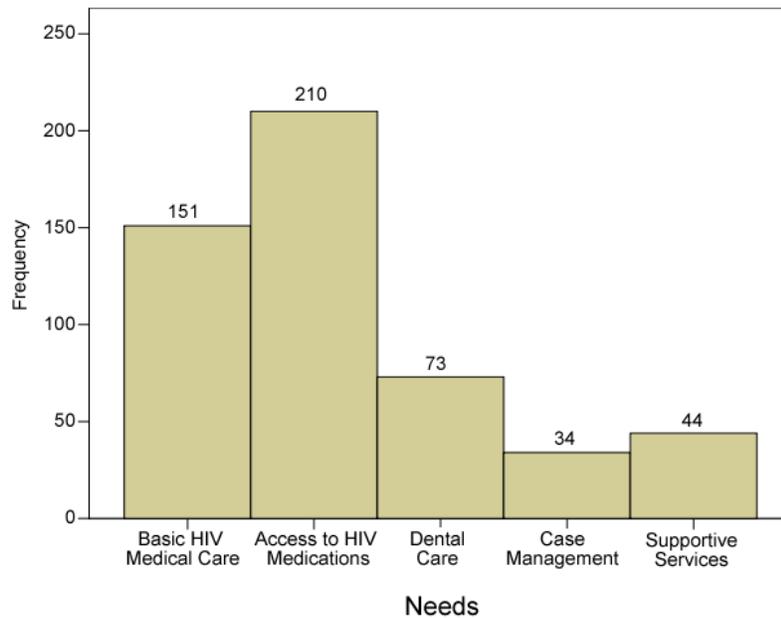
For each question, it was analyzed if the actual percentage breakdown is statistically the same as the predicted percentages in Table 74. In cases where the actual percentages were not statistically the same as the prediction, an assessment was made as to whether the survey responses were "better" or "worse" than expected. As these items are negative events or hardships, a "better" outcome would be one where a higher percentage of respondents than expected indicated that they have never experienced the particular hardship (i.e. those that are in the "None" category). This technique is called a chi-square goodness-of-fit test. This statistical test gives the probability that a data set fits a particular prediction (i.e. the predicted percentages in Table 74). A limitation of this technique is that it relies upon predicted percentages that were suggested by a discussion with ISDH staff, not empirically derived data. Therefore, the outcome is only meant to be judged upon the specific prediction made for the question.

More respondents have experienced hunger or were unable to procure food in the prior month than expected. Fewer people missed work, school, or appointments due to illness than expected and the same amount, as expected, missed work, school, and appointments due to lack of transportation. However, more respondents were prevented from taking medications due to lack of transportation. The same amount of respondents as expected was prevented from taking medications due to lack of insurance. More than expected were prevented from taking medications due to lack of money for co-payments or deductibles. Slightly more than expected never experienced a possible eviction or utility disconnection.

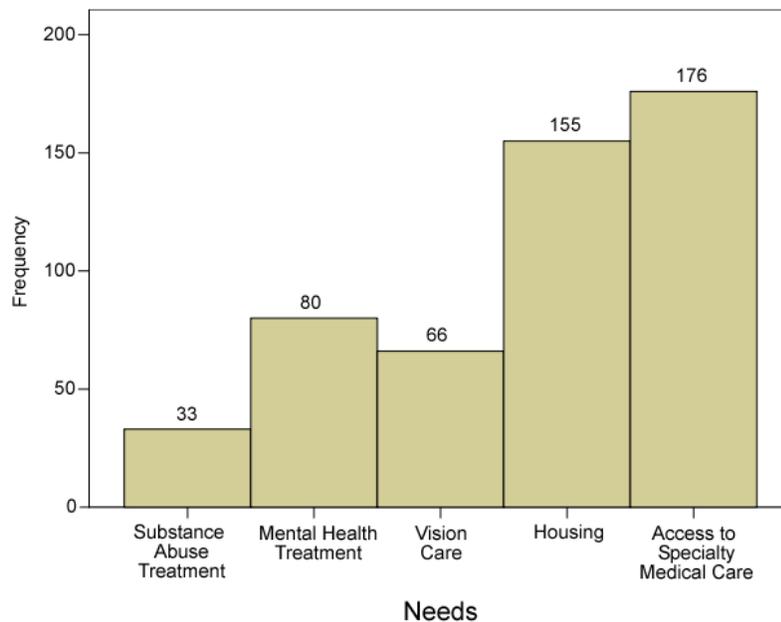
More respondents than expected never experienced trouble accessing dental, vision, and specialty medical care. Specialty medical care, in particular, showed a better result than expected; 82% of respondents did not have difficulty accessing specialty care such as cardiology, endocrinology, or gynecology. More respondents than expected had used an emergency room at least once in the past year. It is unclear whether respondents experienced an actual medical emergency that necessitated going to an ER or going to an ER was due to a lack of other available medical care. Additionally, the question does not capture whether the ER visit was due to HIV or an unrelated cause, such as an accident. Unfortunately, almost 25% of respondents had felt that services were withheld from them because of discrimination against their HIV status. This is much higher than the expected 10%.

Most respondents (437 or 84%) felt that their care coordinators are knowledgeable about services available in their community; 31 (6%) felt that their care coordinator are not knowledgeable about services and 41 (7.1%) had no opinion on the matter. Respondents indicated which of the top five needs ISDH identified for people living with HIV was most important to them. Most respondents indicated that "Access to HIV Medications" and "Basic HIV Medical Care" were most important. See Figure 78 to see the complete breakdown. Respondents also indicated other needs that are important to them; "Access to Specialty Services" and "Housing" were indicated as most important. See Figure 78 to for complete results.

**Figure 78: Most Important Needs to Respondents of the Survey, Indiana 2005**



**Figure 79: Other Needs that are Important to Respondents, Indiana 2005**



Respondents to the survey had barriers to taking their medications in the form of lack of transportation, insurance, and funds to cover co-payments. This is consistent with more

respondents citing "Access to HIV Medications" as their top need than any other. Though respondents cited "Access to Specialty Medical Care" most often as another important need, over 80% of respondents never experienced trouble accessing such care. Respondents cited dental care as a top need, which is consistent with the almost 44% that had experienced trouble accessing dental services at least once; 10% of respondents had experienced 7 or more instances of trouble accessing dental care. Many of the needs suggested by this survey need to be explored in more depth before general conclusions can be drawn about gaps in Indiana HIV care.