

Part D: Prevention and Care Priorities

Chapter 7:

Priority Populations for Prevention Activities



Gap Analysis

The need for HIV prevention services can be categorized as follows:

- A **met need** is a need for HIV prevention services within a specific target population that is currently addressed through resources that are available, appropriate, and accessible.
- An **unmet need** is a need for HIV prevention services within a specific target population that is not currently addressed because no services are currently available, or available services are inappropriate or inaccessible.

A gap analysis identifies unmet HIV prevention needs or service gaps for high-risk populations. A gap analysis also shows how and where resources are being used. It helps to identify areas where resources may need to be redirected, or areas where more resources are needed and new interventions should be implemented. Determining unmet needs helps in the process of prioritizing populations and interventions by identifying which interventions are successful and which populations' needs have not been met.

In 2006, the CPG conducted a gap analysis of HIV prevention needs. The analysis included a review of epidemiological data, an inventory of local resources and assessments, the results of the STD/HIV/AIDS Provider Services Survey, and a summary of the currently funded HIV prevention projects. The goals of the gap analysis were to identify:

- Populations with the highest need for services to prevent future infections;
- Specific services that each population needed most;
- Barriers to accessing the services that exist; and
- Degree to which the needs of high-risk populations are currently being met.

To supply the CPG with an idea of the level of services currently being provided for the identified populations, comparisons were made between the perception of the level of services identified in the STD/HIV/AIDS Provider Services Survey and the results of the evaluation and summary of the CDC-funded HIV prevention projects.

The following table reflects the results of the Gap Analysis.



Potential Target Populations	Need	Met Need	Unmet Need
HIV+ Persons	As of December 31, 2005, there were 529 HIV cases and 813 AIDS cases in Iowa, for a total of 1,342 known cases.	<ul style="list-style-type: none"> • Three projects funded to provide CRCS with HIV+ individuals and their partners. • Three projects funded to provide GLIs with HIV+ individuals. • Good relationships with Ryan White Part C agencies, HIV doctors, drug rehabilitation centers. • Offered testing to partners of HIV+ persons. • Involved HIV- partners, who brought in HIV+ partners. • Provider Survey showed that 74% of prevention providers serve persons living with HIV/AIDS. 	<ul style="list-style-type: none"> • The Provider Survey showed that the perception of the adequacy of prevention services for HIV+ for CRCS was that of “Somewhat provided but not sufficient to meet demand.” • There was a perception on the Provider Survey that HIV+ individuals were receiving ILI interventions; however, there were no ILI projects funded during the last RFP cycle. • Challenges included client recruitment and retention, peer advocate recruitment, lack of CRCS models, stigma, and isolation (lack of social connection to community). • Estimate: Unmet need
MSM	<p>HIV Diagnoses – Average # diagnoses/yr 2003-2005: 49</p> <p>HIV Diagnoses per 100,000 pop – Average # diagnoses/yr/100,000 population: 202</p> <p>AIDS Diagnoses – Average # diagnoses/yr 2003-2005: 33</p> <p>Total Living with HIV/AIDS as of 12/31/2005: 714</p>	<ul style="list-style-type: none"> • Four projects funded to conduct GLIs were most effective when they had consistently high visibility at gathering places (e.g., bars, events, parks, etc.). • The Provider Survey showed that 86% of responding prevention providers served MSM. • Good collaboration with community GLBT groups. • 1,280 outreach contacts were made (as a component of other funded interventions). • Use of peer advocates to reach the target population. • Participation in CDC’s Rapid Behavioral Assessment at Gay Pride Events. 	<ul style="list-style-type: none"> • On the Provider Survey, the overall perception of prevention services for all interventions was that “Services were provided but not in sufficient quantity to meet demand.” • 44% of providers indicated that they were unaware if GLIs were provided for MSM. • 43% of providers were unaware of whether CLIs were provided. • Challenges include lack of interest on the part of clients (i.e., prevention burnout; apathy and disinterest for HIV prevention messages; providers’ abilities to tailor and adapt programs.) • Rural MSM, non-gay-identifying MSM and MSM of color continue to be hard to reach. • Estimate: Unmet need

Potential Target Populations	Need	Met Need	Unmet Need
IDU	<p>HIV Diagnoses – Average # diagnoses/yr 2003–2005: 22</p> <p>HIV Diagnoses per 100,000 pop – Average # diagnoses/yr/100,000 population: 296</p> <p>AIDS Diagnoses – Average # diagnoses/yr 2003–2005: 18</p> <p>Total Living with HIV/AIDS as of 12/31/2005: 285</p>	<ul style="list-style-type: none"> • Three projects funded to do GLIs • Good outreach with IDU not in treatment. • All projects exceeded their projections. • Regular contact helped with trust and disclosure issues. • Strengthened relationships with community organizations. • Large numbers of high-risk offenders reached within the Department of Corrections. • Provider Survey showed that 72% of prevention providers are serving IDU. • Use of peer advocates for outreach. 	<ul style="list-style-type: none"> • The Provider Survey showed that IDU’s were one of the populations for whom participants indicated that a variety of interventions were less than adequately provided as compared to other populations. • Challenges include recruitment for GLI and access for outreach of high-risk clients and sites, disclosure issues, staff turnover, integration of programs into facilities. • Lack of syringe access and syringe exchange. • Lack of safe disposal sites for used injection equipment. • Estimate: Unmet need
High-Risk Heterosexual	<p>HIV Diagnoses – Average # diagnoses/yr 2003–2005: 31</p> <p>HIV Diagnoses per 100,000 population – Average # diagnoses/yr/100,000 population: 74</p> <p>AIDS Diagnoses – Average # diagnoses/yr 2003–2005: 19</p> <p>Total Living with HIV/AIDS as of 12/31/2005: 289</p>	<ul style="list-style-type: none"> • Five projects funded to do GLIs. • Offered testing to partners of HIV+ people. • Good partnerships and collaborations with other organizations. • Provider Survey showed that 86% of prevention providers work with high-risk heterosexuals. • Use of peer advocates for outreach. 	<ul style="list-style-type: none"> • The Provider Survey indicated the overall perception of prevention services for all interventions was that “Services were provided but not in sufficient quantity to meet demand.” • Challenges included recruiting people who trade sex for drugs, money, or favors. • Lack of knowledge or denial about behavior(s) of partner(s) that may put them at risk. • Estimate: Unmet need
Corrections	<p>HIV Diagnoses – Average # diagnoses/yr 2003–2005: 4</p> <p>HIV Diagnoses per 100,000 population – Average # diagnoses/yr/100,000 population: 67</p> <p>AIDS Diagnoses –</p>	<ul style="list-style-type: none"> • Four projects were funded for GLIs. • Successful implementation of peer educators. • Inmates were given personalized risk assessments, risk reduction information and linkages to community resources. • Participants often recruited other 	<ul style="list-style-type: none"> • 33% of Provider Survey respondents felt services were somewhat adequately provided. • Challenges include increasing number of offenders trying to get into the program (project becoming too large). • Budgetary problems at the facilities. • Staff changes.

Potential Target Populations	Need	Met Need	Unmet Need
(Corrections)	Average # diagnoses/yr 2003-2005: 3 Total Living with HIV/AIDS as of 12/31/2005: 59	<ul style="list-style-type: none"> inmates into the program Evaluations showed that the course was of benefit to the inmates, large increase in knowledge shown. The Provider Survey showed that 62% of all prevention providers were serving incarcerated persons. 	<ul style="list-style-type: none"> Funding cuts to treatment programs. Transitional programs from corrections to the community are needed. Estimate: Unmet need
High-Risk Youth	HIV Diagnoses – Average # diagnoses/yr 2003-2005: 14 HIV Diagnoses per 100,000 pop – Average # diagnoses/yr/100,000 population: 3 AIDS Diagnoses – Average # diagnoses/yr 2003-2005: 4 Total Living with HIV/AIDS as of 12/31/2005: 186	<ul style="list-style-type: none"> Five projects were funded to provide GLIs. From the Provider Survey, 79% of all prevention providers served young adults (13-24). Building relationships with the agencies to reach youth. Increase in willingness to use condoms after completing a GLL. 	<ul style="list-style-type: none"> The Provider Survey indicated that services provided to high-risk youth were the most adequately provided. Although large numbers of youth are seen; many of the youth were too transient to complete sessions. Staff turnover and loss of shelters also contributed to programs not being completed. Estimate: Somewhat unmet need

Prioritization of Target Populations

Setting priorities in HIV prevention planning creates programs that are responsive to community-validated needs. Epidemiological data, evaluation data from funded prevention projects, focus groups, key informant interviews, and reviews of the literature provided the data for defining the target populations for HIV prevention efforts in Iowa. The CPG considered the following population characteristics to describe the current epidemic in Iowa: Age, race, ethnicity, gender, sexual orientation, and geographic distribution. To understand the target populations and refine priorities, the CPG developed tools to assist in identifying the following:

- Issues/needs/barriers/gaps of target populations related to accessing HIV/AIDS prevention services;
- Resources available to target populations; and
- Recommended prevention strategies for target populations.

In selecting populations, the CPG used “modified consensus;” in those cases where the CPG could not reach consensus, a super majority vote (2/3 or 66%) was required. Populations were then prioritized using a nominal group process, which is described below.

Identify Populations

To define populations, the CPG reviewed past priority populations, epidemiological profiles, needs assessments, and research literature. Populations were described as specifically and as mutually exclusively as possible.

“There are not enough dollars for HIV prevention, and there are likely to be fewer in the future. HIV prevention efforts have to be focused on people most at risk. The question that all groups need to answer is: How can we prevent the most infections in our community?”

The CPG defined populations by HIV risk behavior(s), age, HIV status, and incarceration status. Risk behavior categories are males who have high-risk unprotected sex with other males, injecting drug users who share contaminated injecting equipment, and high-risk unprotected heterosexual sex. Age categories are youth (13 to 24 years of age) and adults (25 years and over).

Target Population	Definition
HIV-Positive Persons	<i>HIV-positive persons who continue to engage in high-risk sex and needle sharing behaviors and partners of HIV-positive persons</i>
Men Who Have Sex with Men	<i>Men who have unprotected sex with men</i>
Injecting Drug Users	<i>Injecting drug users who have ever shared contaminated injection equipment</i>
High-Risk Heterosexual	<i>Heterosexuals who have been diagnosed with an STD or who have unprotected sex with a bisexual male, an injecting drug user, or someone who exchanges sex for money, drugs, or favors</i>
Youth (ages 13-24) Who Engage In High-Risk Activities	<i>Youth who engage in high-risk behaviors and who are in shelters and residential care, in alternative schools, in substance abuse facilities, and in juvenile detention facilities</i>

Description of Target Populations

HIV-POSITIVE PERSONS

HIV-positive persons who continue to engage in high-risk sex and needle sharing behaviors and partners of HIV-positive persons

HIV-positive persons are an important population for preventing further transmission of HIV infection and for preventing co-infection with other STDs or blood borne pathogens. The availability of increasingly effective therapies for HIV disease has contributed significantly to longer, healthier lives for persons with HIV.

It is critical to increase the proportion of infected individuals who are aware of their HIV status and who participate in medical care, treatment, and other services supportive of primary and secondary prevention. Primary prevention refers to helping persons avoid contracting HIV infections while secondary prevention refers to reducing or alleviating adverse consequences among persons who are living with HIV disease, generally through early detection of HIV and prompt treatment. Studies indicate a high proportion of persons who learn that they are HIV infected adopt behaviors that are known to reduce the risk for transmitting HIV (CDC, 2000). Data from national studies and HIV partner notification services conducted by the state HIV/AIDS and STD programs indicate the continued presence of risk behaviors among some HIV-positive persons.

MEN WHO HAVE SEX WITH MEN

Men who have unprotected sex with men

In Iowa, Men Who Have Sex with Men (MSM) remains the group predominately affected by the HIV epidemic. Since AIDS case reporting began in 1983, persons in this exposure category have remained the most frequently reported. The proportion of cases with this mode of exposure declined after peaking at 72% of all AIDS cases from 1988 - 1992.

In 2004 and 2005, new HIV diagnoses in Iowa were primarily among white, U.S.-born males. Nearly 75% of these males reported sex with males as their risk. Therefore, MSM continues to be a high-risk and high-priority population in need of prevention efforts.

MSM but identify as heterosexual are a hidden population that is difficult to reach (House, 1993). Men who have sex with other men and do not identify as gay or bisexual were found to have higher rates of unprotected sex than those that identified as being gay or bisexual.

A study of MSM conducted in five urban areas (Baltimore, Los Angeles, Miami, New York, and San Francisco) showed that of the Black MSM who were tested for HIV, 46 percent were HIV-positive, and approximately two-thirds or 67 percent of Black MSM were unaware of their status (CDC, 2005).

INJECTING DRUG USERS

Injecting drug users who have ever shared contaminated injection equipment

Substance abuse as an agent of HIV transmission encompasses a range of behaviors, including both addictive and casual use of alcohol and other drugs. Injection drug use with unsterilized needles is the primary risk factor placing substance users at risk for HIV infection.

To date, more than a third of all reported AIDS cases in the United States have occurred as a direct or indirect result of injection drug use. Indirectly, HIV may be transmitted to an injection drug user's heterosexual sex partners, or to children whose mothers were injecting drug users or were sex partners of injecting drug users.

In Iowa, nearly 20% of persons living with HIV/AIDS are IDU (11%) or MSM/IDU (8%) In 2005, 7% of HIV diagnoses among adults and adolescents were among IDU and another 12% were among MSM/IDU.

In the injection drug-using community, many researchers agree that the key means for preventing the widespread use of unsterilized needles and works by IDUs will depend on a shift in norms within the drug community. This shift must make it socially unacceptable to share needles within a group-shooting situation. IDUs who had been able to significantly reduce their potential for exposure were less likely to inject in settings where there would be strangers present, or were limiting their circle of acquaintances to no more than five people with whom they shared needles (Rhodes & Wolitski, 1989).

Sexual contact with an IDU continues to be a factor in expanding the number of heterosexual cases in Iowa. Sexual transmission of HIV from IDUs to their sex partners may present a greater risk for women than for men. Although both male and female IDUs are likely to have IDU partners, this possibility is particularly high among women (Mandell, Vlahov, Latkin, Oziemkowska, & Cohn, 1994). One study showed that 75 to 90 percent of female IDUs have a male injection-drug-using partner compared with 20 to 50 percent of male users (Donoghoe, 1992).

HETEROSEXUAL SEX

Heterosexuals who have been diagnosed with an STD or who have unprotected sex with a bisexual male, an injecting drug user, or someone who exchanges sex for money, drugs, or favors

Heterosexual transmission accounted for nearly 20% of cases among persons living with HIV/AIDS, second only to men having unprotected sex with men. More strikingly, heterosexual contact accounts for well over half of all transmissions to women. Because classification of an exposure as heterosexual requires that the HIV-infected person identify a partner known to have HIV or to have a specific risk factor (e.g., a bisexual male, injection drug user, or person with hemophilia), heterosexual transmission is likely to be seriously underreported. Even so, cases among heterosexuals have risen slowly but steadily since 1995.

The over-representation of minorities among cases of sexually transmitted diseases, which are more traditionally associated with heterosexual transmission, is substantial; particularly for Black, non-Hispanic persons in Iowa. Incidence rates of *Chlamydia* are 13 times higher and incidence rates of gonorrhea are 48 times higher for Black, non-Hispanic persons than for White, non-Hispanic persons. Black, non-Hispanic males have an incidence rate of gonorrhea that is over 100 times that of White, non-Hispanic males.

YOUTH (13-24) WHO ENGAGE IN HIGH RISK ACTIVITIES

Youth who engage in high-risk behaviors and who are in shelters and residential care, in alternative schools, in substance abuse facilities, and in juvenile detention facilities

Adolescence is a time of exploration of self and risk-taking, and sexual behavior is a natural part of this exploratory pattern. This makes it difficult to estimate, for example, how many adolescents and young adults are gay or bisexual or how great a risk the adolescent population faces. Research shows that high teenage pregnancy and STD transmission rates point to high levels of risky behavior.

In Iowa in 2005, females ages 15 – 24 had 35% of all live births. Teen pregnancy rates also indicate high levels of unprotected sex. There were 5,511 pregnancies reported in females aged 15-19 years in 2005. In addition to this, 56% of the total cases of gonorrhea, 27% of early syphilis, and 75% of chlamydia cases occurred in people aged 15-24 years. Data from the 2001 Iowa Youth Risk Behavior Survey (YRBS) indicate that 43% of high school youth and 88% of youth in alternative high schools have had sexual intercourse, with 18% reporting their first sexual encounter before age 13. Over one-fourth of adolescents in alternative high schools have been pregnant or have gotten someone pregnant. Data from the 2005 YRBS indicate increases in some risk behaviors. YRBS data showed an increase from 1997 to 2005 in the number of high school students who reported ever having sexual intercourse, from 42.8% to 43.5%. Fortunately, condom use among sexually active students has increased since 1997. In 2005, 61.8% of sexually active high school students reported having used a condom during the last instance of sexual intercourse compared to 47.6% in 1997.

Youth in out-of-home placement facilities are particularly at risk for HIV infection because of high rates of vaginal, anal, and oral intercourse; inconsistent condom use; high rates of alcohol use prior to sexual intercourse; and a high prevalence of forced sex.

Over half of the students interviewed from the 2001 YRBS had four or more partners in the last three months. Among those students who indicated they had sexual intercourse during the past three months, 46% used a condom during their last sexual intercourse.

Youth who are not in school have higher frequencies of behaviors that put them at risk for HIV/STDs, and are less accessible to prevention efforts. Out-of-school youth were significantly more likely than in-school youth to have had sexual intercourse, had four or more sex partners, and had used alcohol, marijuana and cocaine (*AIDS Community Demonstration Projects: What We have Learned, 1985-1990, 1992*). More intensive STD/HIV and substance abuse prevention programs should be aimed at out-of-school youth or youth at risk for dropping out of school.

Determining the Selecting Factors

The CPG agreed to use the following selecting factors to identify and rank populations at greatest risk for HIV in Iowa.

Selecting Factor	Definition
Average HIV Diagnoses	The number of HIV cases diagnosed in a defined population in a specified period of time. (2003 – 2005)
Average HIV Diagnoses per 100,000 population	The average number of persons diagnosed per 100,000 population. (2003 – 2005)
HIV/AIDS Prevalence	The number of people living with diagnosed HIV in a defined population, at a specified point in time.
Key Indicators/Frequency of Risk Behaviors	Data that document how widespread or frequent HIV risk behaviors are within the target populations.
Riskiness of Population Behaviors	The nature and relative risk of behaviors that occur in the target populations.
Difficulty of Meeting Population Needs	The complexity of need and whether the population has been reached by current programs, whether service providers have capacity, etc.

Weights Assigned to Selecting Factors

The CPG used weights to indicate the relative importance of each selecting factor. Numeric weights were based on a scale of ascending importance. The most important factors were weighted more heavily than other factors. A numerical weighting system (1 = low, 2 = medium, 3 = high) was developed for each selecting factor. Weights were assigned by the CPG by modified consensus.



Selecting Factor	CPG Weight Results
Average HIV Diagnoses	5
Average HIV Diagnoses per 100,000 population	4
HIV/AIDS Prevalence	3
Key Indicators/Frequency of Risk Behaviors	2
Riskiness of Population Behaviors	4
Difficulty of Meeting Population Needs	4

Rating Target Populations Using Weighted Factors

After the CPG had assigned a weight to each selecting factor, the next step was to rate each of the potential target populations using a rating scale. The rating scale evaluates the extent to which each factor applies to a specific population. The following table was used.

Factor	Population Data	Rating Scale																										
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* includes MSM/IDU

Cases without risk were redistributed to other risk groups according to historical redistribution patterns for the Midwest region.

Scoring the Target Population

Each CPG member determined a score for each factor for each target population. This was done by multiplying the factor's rating by its weight (**Rating x Weight**). In this way, factors that were determined by the CPG to be more important had a larger impact on the final decision.



Ranking Populations



The rank for each target population was obtained by adding the individual scores of all CPG members, then averaging them, thereby producing an overall score for that target population. The overall score reflected the combined impact of all the factors used to rate that target population.

<i>Rank</i>		<i>Score</i>
1	HIV-Positive Persons	-
2	Men Who Have Sex With Men	99
3	Injecting Drug Users	92
4	High-Risk Heterosexuals	82
5	High-Risk Youth	58

The CPG reviewed the results and agreed upon the final list of target populations. Discussion ensued regarding over representation of African American and Hispanic persons. The CPG concurred that prevention funding targeting African American and Hispanic persons must be proportional to the epidemic.

Part D: Prevention and Care Priorities

Chapter 8:

Care Statewide Coordinated Statement of Need



**State of Iowa
Ryan White CARE Act HIV/AIDS Programs
Statewide Coordinated Statement of Need (SCSN)**

Introduction

The Iowa Statewide Coordinated Statement of Need (SCSN) provides a formal mechanism for identifying and addressing significant HIV care issues of people living with HIV/AIDS. The goal of the SCSN is to maximize coordination, integration, and effective linkages across Ryan White CARE Act titles. The SCSN provides an opportunity for collaboration between HIV-specific programs and larger health and human services systems.

The Statement of Need includes an overview of the HIV epidemic, emerging trends within the service delivery system, and a summary of key issues affecting the HIV continuum of care in Iowa. The SCSN work group meetings provided a forum for Ryan White CARE Act grantees and other service providers to discuss crosscutting issues that affect the care of people living with HIV/AIDS. By illuminating the complex issues Iowa faces in delivering quality, cost-effective, and accessible services, the Statement of Need answers the first question in comprehensive planning: “Where are we now?”

ISCSN Organization

The ISCSN has two sections: (1) An overview of HIV/AIDS in Iowa, including epidemiological data, a service overview, and an overview of the estimate of the state’s unmet need for HIV primary health care; and (2) cross-cutting themes and issues identified by the ISCSN work group. The appendixes contain a list of participants, a resource inventory, the 2005 epidemiological summary, and handouts used for work group presentations.

Section 1: HIV/AIDS in Iowa

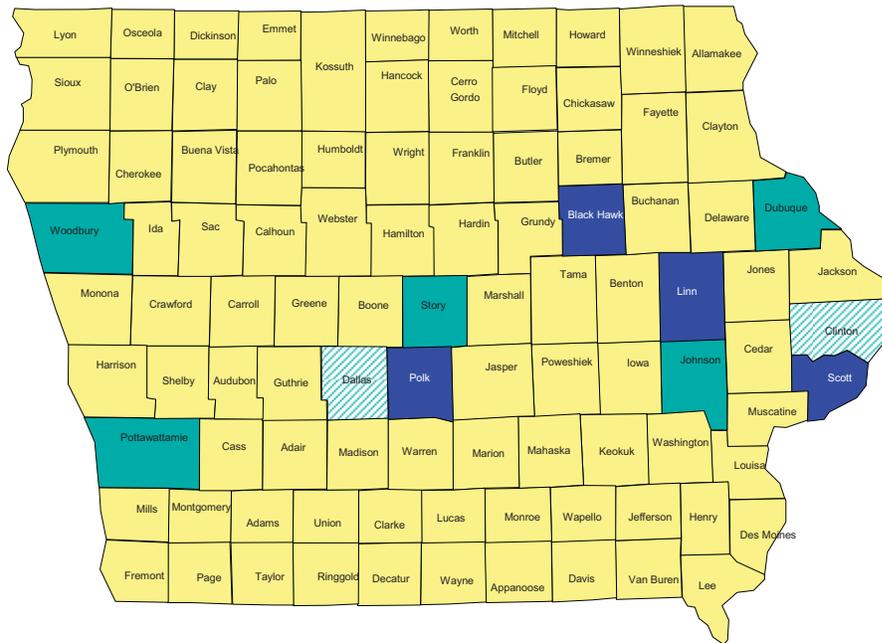
Overview of the state of Iowa

A: EPIDEMIOLOGICAL PROFILE

Iowa is an agricultural state, with a land area of 55,875 square miles. Iowa is composed of 99 counties (Figure 1), with an estimated 2004 population of 2,954,451 persons. The state’s population ranks 30th in the nation. Five counties (Dubuque, Johnson, Pottawattamie, Story, and Woodbury) have between 50,000 and 120,000 residents. Four counties (Black Hawk, Linn, Polk, and Scott) have more than 120,000 residents. Two counties have just fewer than 50,000 residents. One of these, Clinton County, is decreasing in population while the other, Dallas County, has been growing rapidly.

Iowa's population has shifted over the past ten years from rural to urban centers, with the most significant growth occurring in and around the capital of Des Moines and in the Interstate-380 corridor between Iowa City and Cedar Rapids. The state population is expected to exceed 3 million by 2020 (Statistical Abstract of the United States, 1999).

Figure 1
Iowa's Most Populous Counties



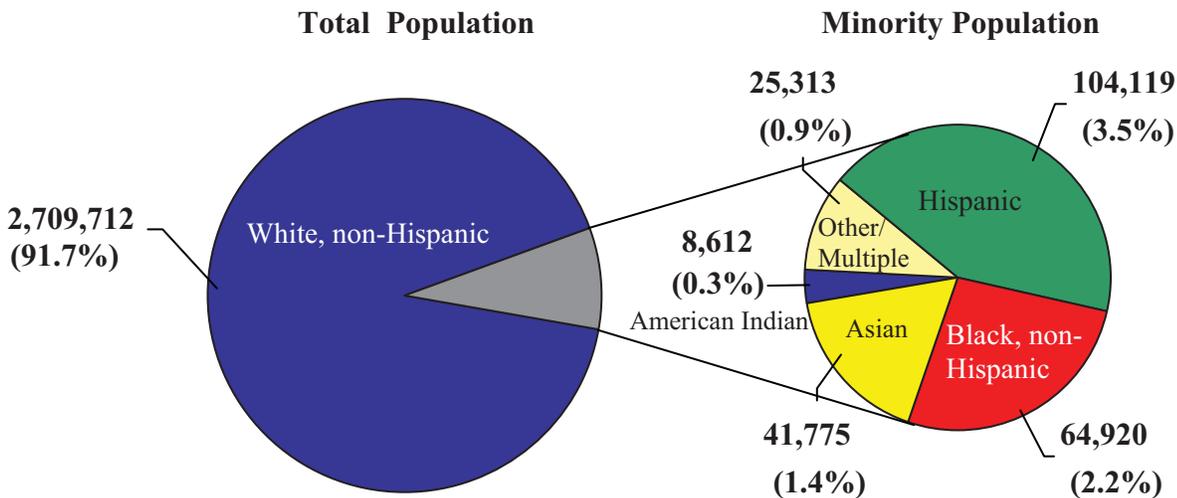
- Counties less than 49,000 population
- Counties between 49,000 and 50,000 population
- Counties between 50,000 and 120,000 population
- Counties greater than 120,000 population

Racial and Ethnic Distribution

Ninety-two percent of Iowa’s population is white and non-Hispanic (Figure 2). Hispanic residents were estimated to have become the largest minority population in Iowa for the first time in 1998. Residents of Hispanic origin are now estimated to account for 3.5% of the population, slightly more than black, non-Hispanic residents. The Hispanic population increased 153% since 1990, the largest increase of any minority group in the state. At the time of the 2000 Census, nearly one-half of the state’s Hispanic residents lived in Marshall, Muscatine, Polk, Scott, or Woodbury counties.

The next largest minority group is black, non-Hispanic residents, accounting for an estimated 2.2% of the population and reflecting a slight increase from 1.7% in the 1990 census. Black Hawk, Polk, and Scott counties account for nearly two-thirds (61%) of the state’s total black, non-Hispanic residents.

Figure 2
Population by Race and Ethnicity
Iowa, Estimated Population 2004



Source: U.S. Census Bureau

Iowa’s Asian population increased from 0.9% in 1990 to 1.4% in 2004. More than one-half (51%) of the state’s Asian population lived in Johnson, Polk, or Story counties in 2000. American Indians constitute Iowa’s smallest ethnic population, making up 0.3% of the total population. In 2000, most of this ethnic group lived in Tama, Polk, and Woodbury counties.

Net *immigration* (i.e., net movement of foreign and/or domestic persons **into** Iowa) was 19,000 persons from April 1990 to July 1998, when individuals moving to and from Iowa from other countries were included in migration counts. Net immigration from *within* the United States was negative. In other words, more people moved out of Iowa than moved into the state from elsewhere in the U.S. The increasing diversity in Iowa’s population is mainly the result of persons moving into Iowa from other countries rather than an influx of minorities from elsewhere in the U.S. (Iowa’s Counties: Selected Population Trends, Vital Statistics and Socioeconomic Data, 1999).

Age Distribution

Iowa's population is aging. The median age of the population is 36.6 years, up from 34.0 years in 1990. By year 2020, the median age is expected to climb to 42.4 years (Iowa's Counties: Selected Population Trends, Vital Statistics and Socioeconomic Data, 1999). With 14.9% of its population 65 years or older, Iowa ranks 5th in the nation in the percentage of elderly persons residing in the state. The percentage of the population over age 65 is expected to increase from 15% in 1990 (Table 1) to 21% by 2020; the percentage of youths (under the age of 20) is expected to decrease from 29% in 1990 to 24% by 2020. The percentage of persons ages 20 to 64 years is expected to increase throughout the first decade of the century, though not as dramatically as the 65 and older age group.

Table 1

**Iowa's Population by Age and Gender
Population Estimate, 2004**

Age group (yrs)	Females #	Males #	Total #	%
Less than 2	36,179	37,918	74,097	3
2 – 12	196,355	206,260	402,615	14
13 – 24	254,379	265,750	520,129	18
25 –44	387,840	399,193	787,033	27
45 –64	370,829	366,609	737,438	25
65 or older	254,762	178,377	433,139	15
Total	1,500,344	1,454,107	2,954,451	

Source: U.S. Census Bureau.

Percentage totals may not equal 100 due to rounding of numbers.

Poverty, Health Insurance, and Employment

According to 2002 model-based estimates from the U.S. Census Bureau, 9.1% of Iowa's population was living below the poverty level, compared to the national average of 12.1%. However, 10.9% of Iowa's youth 17 years or younger live in poverty compared to 16.7% nationally.

Approximately 11% of Iowa's residents are without health insurance. Iowa residents aged 18 to 24 years were least likely to have health insurance, and males in that age group were nearly twice as likely as females to be without insurance. Twenty-four percent of residents aged 18 to 24 were without insurance, but 31% of males in this age group had no insurance (Table 2; IDPH Behavioral Risk Factor Surveillance System, 2004).

Iowans who report lower household incomes are more likely not to have health insurance. Of people reporting annual income of less than \$15,000, 25% reported having no health insurance coverage. Only 3% of people reporting annual income of \$75,000 or more did not have health care coverage (IDPH Behavioral Risk Factor Surveillance System, 2004).

Iowa's reported unemployment rate for 2004 was 4.8%, up from 2.7% in 2000, compared to 5.5% nationally in 2004 (2005 Factbook, Legislative Fiscal Bureau, State of Iowa). Iowa's unemployment was ranked 17th lowest in the nation. In Iowa, men experience a higher rate of unemployment than women. The lower unemployment rate for women is due, in part, to their

accepting part-time employment, temporary employment, and working out of their homes more often than men (Kahn, Iowa Workforce Development). Minority workers experience an unemployment rate two to three times higher than white, non-Hispanic workers.

Table 2
Percentage Uninsured by Age
2004

Age group (yrs)	% Uninsured		
	Females	Males	Total
18-24	18.0	30.9	24.2
25-34	13.7	16.3	15.1
35-44	11.0	8.4	9.7
45-54	9.7	9.4	9.5
55-64	8.4	8.3	8.3
65 or older	0.0	1.7	0.8
Total adults	1.8	2.3	2.0

Source: Behavioral Risk Factor Surveillance System, Iowa Department of Public Health.

Corrections

Iowa has nine state correctional facilities, and a community-based correctional system. The prison inmate population at the nine correctional facilities increased by 209% between July 1987 and July 2004. There were 8,611 state inmates at the end of fiscal year 2004. Nearly 6,000 offenders were released into the community during that year. The Criminal and Juvenile Justice Planning Division predicts that if criminal/incarceration practices remain the same, the prison population will reach 10,582 inmates by July 2014. The prison population is projected to be 143% of design capacity at that time (Department of Corrections; Iowa Legislative Factbook, 2004).

The community-based correctional system has 17 residential facilities, 3 work release facilities, and one OWI (operating a motor vehicle while intoxicated) facility. At the end of fiscal year 2004, the community-based population was 29,320. This population increased 85% between 1990 and 2004.

Substance Abuse

The state has reported increasing numbers of drug offenses, up from 22% in FY 1999 to 32% of new prison admissions in FY 2004 (July 1, 2003 to June 30, 2004). According to the Department of Corrections, inmate admissions for drug offenses increased 229% from FY 1999 to FY 2004. The percentage identifying alcohol as their primary drug decreased from 85% to 56%, while the percentage identifying other drugs (marijuana, methamphetamine, and crack) increased from 15% to 44%. Over one-fourth of persons admitted for methamphetamine use reported their primary mode of use was injection. From 1994 through FY 2004, methamphetamine use, in particular, has been increasing. Data from publicly funded substance abuse treatment facilities show that the number of persons treated for drug addictions increased from FY 1992 to FY 2005 (Table 3). Throughout that time period, the percentage of persons who identified alcohol as their

Table 3
Primary Drug for Clients in Publicly Funded Treatment Programs
Iowa, FY 1992 – FY 2005

Fiscal Year	Primary Problem – Type of Drug						Total Clients ¹
	Alcohol	Marijuana	Methamphetamine	Crack	Heroin	Other	
1992	85%	7%	1%	5%	.5%	1.5%	22,471
1993	82%	9%	1%	5%	.7%	2%	22,567
1994	78%	11%	2%	6%	.8%	4%	25,328
1995	69%	14%	7%	6%	.8%	3%	29,377
1996	64%	18%	9%	6%	.5%	2%	33,269
1997	63%	19%	10%	6%	.6%	2%	38,297
1998	60%	20%	12%	6%	.5%	2%	38,347
1999	63%	20%	8%	6%	.5%	1%	40,424
2000	62%	21%	9%	5%	.5%	1.5%	43,217
2001	61%	22%	11%	5%	.5%	1.5%	44,147
2002	59%	23%	12%	4%	.5%	1.8%	42,911
2003	58%	22%	13%	5%	.6%	1.9%	40,925
2004	56%	23%	15%	5%	.6%	1.8%	42,449
2005	56%	22%	14%	5%	.6%	1.9%	43,692

Source: Iowa Department of Public Health, Division of Health Promotion, Prevention, and Addictive Behaviors

¹ In some instances, screens/admissions may be double counted if a client is screened and later admitted for different substances.

HIV/AIDS in Iowa

After a decline in 2003, HIV diagnoses increased in 2004. One hundred six persons were diagnosed in 2004, above Iowa's ten-year average of 100 cases per year, and up 15% from 2003. The increase in 2004 was limited to one demographic group: white, U.S.-born males. Most of the diagnoses were in men who have sex with men, but there were also small increases among men who inject drugs and those without a known risk. In 2004, the median age at first diagnosis was 41 years, slightly older than the overall median age of 38 years. Eighty percent were residents of the 10 most populous Iowa counties. The counties with the highest number of new diagnoses were Polk, Pottawattamie, Johnson, Linn, Scott, Story, and Woodbury.

The number of diagnoses among U.S.-born females remained steady from 2003 to 2004, and accounted for 25% of diagnoses among U.S.-born persons.

Diagnoses among foreign-born persons decreased for the second straight year. Foreign-born persons accounted for 17% of all diagnoses in 2004, but they accounted for 30% of diagnoses in 2003.

Late testing continues to be a concern. Over half of all Iowans diagnosed with HIV in 2003 were diagnosed with AIDS within a year. This indicates that people are not being tested early in the course of the infection, which is associated with poorer outcomes and earlier deaths.

Other notable trends in diagnoses in 2004 include:

- The first decrease in diagnoses among African-born persons since 1998; seven African-born persons were diagnosed in 2004 compared to 15 in 2003;

- A continued increase in minorities living with HIV/AIDS. Black, non-Hispanic persons account for 19% of people living with HIV/AIDS in Iowa, despite making up only 2% of the population. Hispanic persons, who make up 4% of the population, account for 8% of persons living with HIV/AIDS;
- A decrease in diagnoses of AIDS in all groups except U.S.-born males;
- A slight decrease in deaths among persons with HIV/AIDS: twenty-five Iowans with HIV/AIDS died in 2004.

The most significant feature of Iowa's HIV epidemic is the continued increase in the number of persons living with HIV and AIDS. Steady diagnoses of HIV infection, combined with widespread use of highly active, antiretroviral therapies that have delayed the onset of AIDS and decreased the number of deaths among persons with HIV/AIDS, have increased the number of persons living with HIV disease to unprecedented levels. This increase has taxed limited resources for care and treatment. On December 31, 2004, 1,240 Iowans were reported to be living with HIV or AIDS. The Iowa Department of Public Health estimates that another 460 persons are infected but not diagnosed.

B. SERVICE OVERVIEW

Organization and Delivery of Health Care and Support Services through Ryan White Care Act Titles and other mechanisms.

Care Funding in Iowa

- **Ryan White Title II**
 - **ADAP**
 - **Supportive Services**
- **Ryan White Title III**
- **Housing Opportunities for People with AIDS (HOPWA)**
- **Medicaid**
- **Medicare**

Title II: Overview

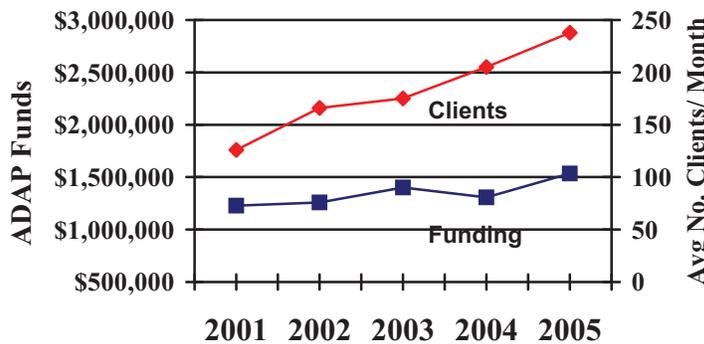
The mission of the Ryan White Title II Program, which includes the AIDS Drug Assistance Program (ADAP), is to meet the health care needs of persons living with HIV disease by funding primary health care and support services. The goals of the services are to get people into primary medical care and to help them stay in care. The Title II Program includes access to life-saving drugs through the ADAP. The intention of the programs is to reduce the use of more costly inpatient care, increase access to care for underserved populations, and improve quality of life for those affected by the epidemic.

Title II: AIDS Drug Assistance Program (ADAP)

The ADAP provides life-saving drugs for low income, HIV-positive Americans without health insurance. As of October 2005, 335 Iowans (approximately 25% of the people living with HIV/AIDS in the state) were enrolled in Iowa’s ADAP. Individuals have to make less than 200% of the Federal Poverty Level to qualify for assistance.

Due to increased demand (see box below), the program was closed to new enrollees in May 2004. By June 2005, there were 108 Iowans waiting to enroll. Thanks to an unprecedented state allocation of \$375,000, the program opened to new enrollees, and the waiting list was eliminated as of July 1, 2005.

**Figure 3
Total Funding and Average number of Clients per Month Receiving Medications from the AIDS Drug Assistance Program 2001 – 2005**



ADAP Benefits Iowa

With the availability of effective treatment:

- People with HIV are living longer, healthier lives, and are remaining contributing members of their communities.
- The number of hospital visits is reduced, the onset of disabilities is delayed, and the burden on the Medicaid program is decreased.
- Patients’ viral loads are lowered, which may reduce the risk of HIV transmission to their partners.

Title II: Supportive Services

The Iowa Department of Public Health’s HIV/AIDS Program contracts with 11 agencies to provide services throughout the state. Contractors provide essential health and support services to financially eligible clients living with HIV. All Ryan White programs are “payers of last resort”, meaning that all other resources, including Medicaid, need to be exhausted to be eligible. Ryan White supportive services include case management and financial assistance for mental health, substance abuse, doctor and dental bills, and transportation expenses. In 2005, 750 persons living with HIV received services. The Iowa Department of Public Health publicizes services to health care and social service providers throughout Iowa.

The table below shows contracting agencies and the counties they served in 2005.

**Table 4
Ryan White Contracting Agencies in Iowa and Counties Served**

Siouxland Community Health Center Sioux City, Iowa	Lyon, Osceola, Dickinson, Sioux, O’Brien, Clay, Plymouth, Cherokee, Buena Vista, Woodbury, Ida, Sac, Monona, Crawford, Carroll
Nebraska AIDS Project Omaha, Nebraska	Harrison, Shelby, Audubon, Pottawattamie, Cass, Mills, Montgomery, Adams, Fremont, Page, Taylor
Ft. Dodge AIDS Coalition Ft. Dodge, Iowa	Emmet, Kossuth, Winnebago, Worth, Mitchell, Palo Alto, Hancock, Cerro Gordo, Floyd, Pocahontas, Humbolt, Wright, Franklin, Calhoun, Webster
Mid-Iowa Community Action Agency Ames, Iowa	Hamilton, Hardin, Greene, Boone, Story, Marshall
AIDS Project of Central Iowa Des Moines, Iowa	Guthrie, Dallas, Polk, Jasper, Adair, Madison, Warren, Marion, Union, Clarke, Lucas, Ringgold, Decatur, Wayne
Cedar AIDS Support System Waterloo, Iowa	Howard, Winneshiek, Allamakee, Chickasaw, Fayette, Butler, Bremer, Grundy, Black Hawk, Buchanan
Dubuque Regional AIDS Coalition Dubuque, Iowa	Dubuque, Clayton
Rapids AIDS Project Cedar Rapids, Iowa	Delaware, Tama, Benton, Linn, Jones
AIDS Project Quad Cities, Inc. Davenport, Iowa	Jackson, Clinton, Poweshiek, Iowa, Johnson, Cedar, Scott, Mahaska, Keokuk, Washington, Muscatine, Louisa, Monroe, Wapello, Jefferson, Henry, Des Moines, Appanoose, Davis, Van Buren, Lee
ICARE Iowa City, Iowa	
University of Iowa HIV Program Iowa City, Iowa	

Title III: Outpatient Primary Medical Care and Early Intervention Services

The following programs provide comprehensive primary health care for Iowans living with HIV disease:

- Virology Clinic, University of Iowa, Iowa City, Iowa;
- Primary Health Care Inc., Des Moines, Iowa;
- Siouxland Community Health Center, Sioux City, Iowa;
- Community Health Care Inc., Davenport, Iowa; and
- University of Nebraska Medical Center, Omaha, Nebraska

Title III services include:

- Risk-reduction counseling, antibody testing, medical evaluation, and clinical care;
- Antiretroviral therapies; protection against opportunistic infections; and ongoing medical, oral health, nutritional, psychosocial, and other care services for HIV-infected clients;
- Case management to ensure access to services and continuity of care for HIV-infected clients; and
- Attention to other health problems that occur frequently with HIV infection, including tuberculosis and substance abuse.

In FY 2005, Iowa's Title III clinics received nearly two million dollars in CARE Act funds.

Housing Opportunities for People with AIDS (HOPWA):

HOPWA is a federal program funded by the United States Department of Housing and Urban Development. HOPWA provides housing assistance and related supportive services to address specific needs of low-income people living with HIV and their families. Services include rental assistance, utility deposits and payments, transportation, emergency shelter, food, and other supportive care for those living with HIV/AIDS.

The Iowa Finance Authority (IFA) received competitive HOPWA funding in 2001 to create the AIDS Housing Network of Iowa (AHNI). IFA partnered with AIDS service organizations and housing agencies across the state, including

- Siouxland Community Health Center in Sioux City, IA;
- AIDS Project of Central Iowa in Des Moines, IA;
- American Red Cross Grant Wood Area Chapter in Cedar Rapids, IA;
- Community Housing Initiatives in Waterloo, IA;
- Iowa Center for AIDS Resources and Education in Iowa City, IA; and
- John Lewis Coffee Shop in Davenport, IA;

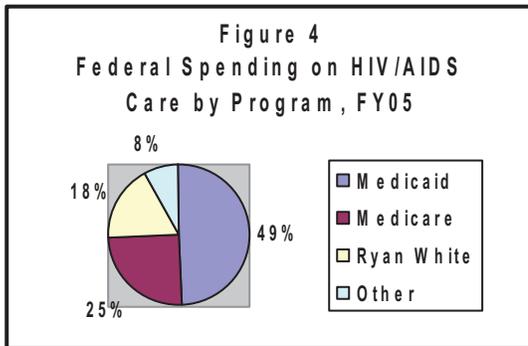
The competitive grant allowed development of a model program in competition with other programs across the nation. There was an expectation that Iowa would receive renewed competitive funding concurrent with a formula-based award. Formula-based awards are given to

states when the number of cumulative AIDS cases reported reaches 1500. In 2004, when Iowa became eligible for formula funds, the state was no longer eligible for competitive grants. Consequently, funds through this program will decrease significantly over the next few years.

Medicaid

Medicaid is the nation’s major public health program for low-income Americans, financing health and long-term care services for more than 50 million people nationwide.¹ It is an entitlement program jointly financed by federal and state governments. Consequently, programs vary from state to state. To qualify for Medicaid, individuals must be both low-income and part of a group that is “categorically eligible.” Low-income, childless adults are not eligible for Medicaid unless they are disabled (see disability definition in Table 5). Although there are several paths to Medicaid eligibility, people with HIV may have trouble meeting eligibility requirements because having HIV does not automatically qualify as a disability, even if the infected person is low-income.

Nevertheless, Medicaid is a critical source of coverage for many low-income Iowans living with HIV. Although expenditures of Iowa’s Medicaid program are not available for HIV, federal estimates suggest that about half of Iowa’s federal spending on HIV/AIDS is done through the Medicaid program. (See Figure 4).



Category	Criteria
SSI Beneficiaries	Disabled (having a physical or mental impairment that prevents one from working for a year or more or that is expected to result in death) AND Low-income
Parents, children, pregnant women	Pregnant women or parent with dependent children under the age of 18 that meet income and resource eligibility
Medically Needy	Allows those who meet categorical eligibility, such as disability, to spend down on medical expenses to meet state’s income criteria
Disabled workers (Medicaid for Employed People with Disabilities-MEPD)	Disabled; Low-income
IowaCare Program	Must receive medical care at University of Iowa Hospitals and Clinics or Broadlawns Hospital (Polk county residents only) and meet income eligibility.

¹ Kaiser Family Foundation, HIV/AIDS Policy Fact Sheet, Medicaid and HIV/AIDS, September 2005

Medicare

Medicare is the federal health insurance program that covers more than 41 million Americans, including 35 million senior citizens and 6 million people under the age of 65 with permanent disabilities.² As noted in Figure 4 on the previous page, Medicare is the second largest source of federal spending for HIV/AIDS in the United States. Most Medicare beneficiaries with HIV/AIDS are under age 65 and are eligible as a result of qualifying for Social Security Disability Insurance (SSDI) (see table 2).

Eligibility Category	Eligibility Criteria
Individuals age 65 and older	Sufficient number of work credits to qualify for Social Security payments
Individuals under age 65 with permanent disability	Sufficient number of work credits to qualify for SSDI payments due to disability; and Have been receiving SSDI payments for at least 24 months
Individuals with End-Stage Renal Disease (ESRD), any age	Sufficient number of work credits to qualify for Social Security payments

Medicare provides broad coverage of basic health care service but has high cost-sharing requirements, no cap on out-of-pocket spending, and doesn't cover long-term care. Beginning January 2006, Medicare began offering a prescription drug benefit for the first time. Although this new benefit could potentially save the Iowa ADAP money, it is unclear at this time if that amount will be at all significant. Over 75% of Iowa HIV/AIDS Medicare beneficiaries are also eligible for Medicaid.

Forecasting growth in the number of Medicare beneficiaries with HIV/AIDS is difficult. On one hand, the number may grow as more people with HIV/AIDS live longer; on the other, the success of combination antiretroviral therapy may keep people with HIV from meeting SSDI eligibility criteria to receive Medicare coverage.

C. ESTIMATED UNMET NEED FOR PRIMARY MEDICAL CARE

In 2000, Congress wrote into the Ryan White Care Act a mandate for grantees to respond to "unmet need" for primary medical care. Unmet need refers to the number of HIV-positive individuals who are aware of their infection but who are not receiving HIV primary medical care³. Primary medical care is defined as receiving at least one viral load or CD4+ cell count during the year, or being on antiretroviral therapy at some point in a given year. In the United States, the Centers for Disease Control and Prevention estimates that 1/3 of people diagnosed with HIV are not receiving regular medical care necessary to:

- Educate about HIV disease and its transmission;
- Manage infection, diagnostics, and treatment; and

² Kaiser Family Foundation, HIV/AIDS Policy Fact Sheet, Medicare and HIV/AIDS, September 2004.

³ Connecting to Care, 2005 Regional Training on Addressing Unmet Need in HIV.

- Ensure positive health outcomes and a longer life.⁴

A solution is to help HIV-positive individuals establish a continuous relationship to primary medical care by identifying and implementing activities in diverse agency settings with the objective of connecting HIV-positive people to medical care and keeping them connected.⁵

To this end, Iowa has conducted a study to estimate the unmet need and to identify possible contributing factors. The study used HIV/AIDS surveillance data and information provided by infectious disease providers across the state. It focused on calendar year 2003. The study found no evidence that 25% of Iowans diagnosed with HIV/AIDS received primary medical care in 2003. Those most likely to be out of care included:

- Persons with HIV diagnoses, but without AIDS diagnoses;
- Minorities;
- Persons aged 20-39 years;
- Injection drug users or persons without a known risk;
- Foreign-born persons or persons whose place of birth was unknown; and
- Persons diagnosed with HIV five years or more ago.

There were also differences according to county of residence not accounted for by population size or proximity to a public HIV clinic.

Through care providers, an Iowa consumer needs assessment (CNA) was distributed to over 800 people living with HIV (PLWH). Three hundred seventy-four responses were received, for a return rate of about 45%. The survey was available in Spanish and English. All Ryan White Title II and III clients received a survey in the mail or in person. Two private providers in Des Moines had surveys available, and HIV-infected county and state inmates were surveyed.

One section of the survey was devoted to determining whether respondents had ever been “out of care” (according to the HRSA definition) and if so, reasons for the lapse. Barriers to receiving care fell into three sub-groups: Fear, cost, and lack of knowledge. Forty-five percent of respondents said not wanting to deal with HIV status was their primary reason for not seeking medical care. Forty-five percent said they were out of care because they thought they could not afford care. Forty percent said that not having insurance kept them out of care. Forty percent cited a lack of symptoms or not feeling ill, and thirty-seven percent said they dropped out of care because the medications made them ill.⁶

Summary

Iowa has a relatively low incidence of HIV/AIDS, and a handful of programs for residents affected by the disease. Yet, significant obstacles and gaps in services for those living with HIV/AIDS continue. Affected residents wanting to become and stay healthy are challenged by

⁴ "Advancing HIV Prevention: New Strategies for a Changing Epidemic --- United States, 2003", MMWR Weekly 52(15), 18 April 2003

⁵ Connecting to Care, 2005 Regional Training on Addressing Unmet Need in HIV

⁶ Iowa Consumer Needs Assessment, 2005

funding shortages and gaps in coverage. In addition, 25% of Iowa residents know that they are HIV positive, but are not receiving regular medical care.

Section 2 of the ISCSN examines in more depth three broad areas that challenge Iowans living with HIV and those who serve them. They include:

- 1) Access to and maintenance of care
- 2) Coordination and Collaboration
- 3) Quality Assurance

Section 2: Crosscutting Themes and Issues

I. Access and Maintenance of Care Issues

Navigating a health care system is challenging even for the most organized among us. People living with HIV/AIDS often must overcome many obstacles in accessing and maintaining care. Disparities in access to quality HIV care correlate with differences in survival rates, as reflected in AIDS mortality rates.⁷ The ISCSN work group identified a number of barriers to accessing and/or maintaining quality medical care.

Low Income/Poverty

Demographic trends indicate that the number of Americans vulnerable to suffering the effects of health care disparities will rise over the next half century. Current data show that low-income families, whatever their race or ethnicity, tend to be in poorer health than other Americans. Gaps in income between the richest and poorest households in America are widening.⁸ The most striking health disparities involve shorter life expectancy among the poor, as well as higher rates of cancer, birth defects, infant mortality, asthma, diabetes, and cardiovascular disease. Health care access accounts for much of this disparity.⁹ Poverty-related issues significantly impact the ability of many PLWH/A to access and remain in medical care. The likelihood of co-existing conditions, such as mental illness or substance abuse is substantially increased. In fact, many Iowans living with HIV require assistance with meeting basic needs like food, shelter, and transportation. Indeed, the Consumer Needs Assessment identified the top service needs as help paying bills (50%), housing (46%), health insurance assistance (39%), transportation (37%), and food bank (33%).

Transportation

Iowans living with HIV travel great distances to access providers: Few specialized HIV medical providers practice in rural areas, limiting PLWH/A access to medical care. Federally funded primary medical providers are located in five cities in Iowa. Although they practice in several areas of the state, many rural Iowans still must travel great distances to access their services. Approximately 40% of Iowans living with HIV/AIDS travel more than 70 miles round trip to reach a medical clinic, and 10% of clients travel 2 hours or more each way to access HIV specialists and support services.¹⁰

Many in need of transportation assistance: Twenty-four percent of clients responding to Iowa's Consumer Needs Assessment (CAN) had used transportation services to get to appointments in the past 12 months. Another 13% said the service was unavailable to them, but that they would use it if it were available.

⁷ HRSA Care ACTION, August 2002

⁸ Agency for Health Care Research and Quality, US Department of Health and Human Services, <http://www.ahrq.gov/qual/nhdr03/nhdrsum03.htm#ref2>, Accessed, July 2006

⁹ National Institute of Environmental Health Sciences, National Institute of Health, US Department of Health and Human Services, <http://www.niehs.nih.gov/oc/factsheets/disparity/home.htm>, Accessed July 2006

¹⁰ Iowa Consumer Needs Assessment, 2005

Challenges to providing transportation: Transportation barriers exist in both rural and urban locations. Rural patients may not have access to any form of public transportation and live hours from core services. Some urban clients find it difficult to get to their appointments because the agency is located blocks from the bus stop or in a neighborhood where sidewalks are not available. Volunteers from some organizations drive patients to their appointments, but once strong networks of buddy systems and volunteers have declined due to lack of interest. Providers often do not have funds to meet client transportation needs. For example, increased gasoline prices have made mileage reimbursement more difficult for agencies and community groups.

Stigma

Throughout history, societies have stigmatized groups of all kinds for various reasons, mostly as a result of ignorance, misconception, and superstition. AIDS is a disease-nothing more.¹¹ Nevertheless, people living with HIV/AIDS have always been confronted with stigma and often face overt and covert discrimination. Outside established AIDS service organizations and specialized clinics, clients encounter ignorance, bias, and lack of education about HIV disease. The stigma associated with HIV is pervasive in many areas where PLWH/A work and live. It sometimes even permeates the system established to provide care. Stigma often prevents people from accessing or remaining in care.

Theodore de Bruyn, who has studied stigma among persons with HIV/AIDS, says that “stigma and discrimination feed on cultural differences and block out common humanity. This happens through social processes whereby the negative associations of HIV/AIDS lead people - inadvertently or deliberately - to shun, avoid, shame, degrade, or discriminate against PLWH.”¹²

According to the World AIDS Campaign,

“Stigma and discrimination are the major obstacles to effective HIV/AIDS prevention and care. Fear of discrimination may prevent people from seeking treatment for AIDS or from acknowledging their HIV status publicly. People with, or suspected of having, HIV may be turned away from health care services, denied housing and employment, shunned by friends and colleagues, refused insurance coverage or entry into foreign countries. In some cases, they may be evicted from home by their families, divorced by their spouses, and suffer physical violence or even murder.”¹³

The health care system can be a source of stigma: Health care professionals, particularly those who infrequently encounter people living with HIV/AIDS, such as in rural areas, may be unaware of and therefore insensitive to stigma-related concerns, such as sexuality, cultural

¹¹ HRSA CARE ACTION, August 2003

¹² HIV/AIDS and Discrimination: A Discussion Paper by Theodore de Bruyn
© Canadian HIV/AIDS Legal Network and Canadian AIDS Society, Montréal, 1998
ISBN 1-896735-14-2

¹³ World AIDS Campaign 2002-2003 on eliminating stigma and discrimination.

origin, mental health, and substance abuse issues. Conversely, health care professionals in urban areas, who deal with HIV/AIDS on a daily basis, may become less sensitive to the stigma their clients may face. Procedures for maintaining patient comfort and confidentiality in these areas may be lax or not adhered to by all agency employees.

Health care providers may fear stigmatization because of their work with HIV-positive patients. The prevalence of such fears may have declined over time, but no evidence indicates they have been eliminated.¹⁴

Stigma Questionnaire: The Iowa HIV community was so concerned about this topic that they included a 40-question section on stigma in the 2005 Consumer Needs Assessment. *The HIV Stigma Scale*, developed by Barbara Berger, is a self-report questionnaire developed to assess stigmatization perceived and experienced by PLWHA. It is considered the standard instrument for assessing HIV stigma in psychosocial studies of PLWHA. The stigma scale includes an overall measure of stigma and four subscales that measure personalized stigma, stigma associated with disclosure of HIV status, negative self-image, and public attitudes. Results of the assessment were combined with results from South Carolina for an oral presentation at the XVI International AIDS Conference in 2006. The combined survey had 541 respondents (224 black and 317 white).

Results of Questionnaire (Iowa only): Females reported slightly higher total stigma scores than males. Minorities reported more stigma than whites. Specifically, persons reporting their race as American Indian/Alaskan Native, Asian, or “other” had much higher stigma scores than other races. Hispanics scored higher than blacks, who scored only slightly higher than white, non-Hispanic persons. Rural clients reported slightly more stigma than urban clients. Clients who reported ever being homeless scored higher on stigma scales than clients who had never been homeless.

Results of Questionnaire (Iowa and South Carolina combined): Black respondents reported greater stigmatization than white respondents on items that described experiences of judgment and discrimination by others. White respondents reported greater stigmatization than blacks on items regarding keeping their status a secret and fears of others’ negative reactions. Blacks living with HIV/AIDS face multiple stigmas, including those associated with social inequality, racism, and HIV/AIDS. The results suggest that initiatives aimed at reducing HIV stigma should consider the experiences of ethnic and racial groups.¹⁵

Cultural Barriers

Cultural barriers to receiving care are becoming more apparent. According to a 2002 HRSA report,

“Cultural differences between providers and patients affect the provider-patient relationship. How patients feel about the quality of that relationship

¹⁴ HRSA CARE ACTION, August 2003

¹⁵ Abstract for the XVI International AIDS conference; **Identifying Ethnic/Racial Differences on the HIV Stigma Scale Using Item Response Theory** Rao D.1, Pryor J.B.2, Gaddist B.W.3, Mayer R.4

is directly linked to patient satisfaction, adherence, and subsequent health outcomes. It has also been shown to influence whether patients continue to see a physician or even remain enrolled in a health care plan. If the cultural differences between patients and providers are not recognized, explored, and reflected in the medical encounter, patient health outcomes may suffer.

Bridging cultural differences presents a challenge, however. One problem that both patients and providers bring to their interaction is biases, many of which are rooted in culture.”¹⁶

Differences in language, sexual orientation, gender, and race/ethnicity may inhibit clients from accessing/maintaining care: A disproportionate number of racial and ethnic minorities make up the Iowa HIV epidemic. As described in Section 1 of this document, 2% of the general Iowa population is black and 4% is Hispanic; however, 19% of Iowans living with HIV are black and 8% are Hispanic. At the time of the 2000 Census, nearly one-half of the state’s Hispanic residents lived in Marshall, Muscatine, Polk, Scott, or Woodbury counties. Providers in some of these areas report that their caseloads are up to 21% Hispanic.

When asked on the CNA what social service providers should do to serve clients better, 14% of respondents said more providers of the same sexual orientation should be available, 9% said service providers of the same gender should be more available, 5% said more providers of the same race should be available, and 8% said that translation services should be more available.

Cultural Norms: Within specific communities, cultural norms create barriers for understanding HIV disease. Persons living with HIV in these communities may find it difficult to access medical and support services.

For example, speaking a different language than the dominant culture is a major barrier to clients accessing and understanding care. Many clients introduce a young child or other family member into the client/provider relationship to serve as an interpreter. Due to the nature and context of this disease, it is inappropriate to rely on a child or other family member as an interpreter. Variations on the following scenario have been reported across Iowa. It serves as an example of how this issue can interfere with clients staying in care.

“Hector” is originally from El Salvador and only speaks Spanish. He goes to his health clinic to see a physician for HIV care. The physician needs interpretation in order to treat Hector, so he calls in the Spanish-speaking receptionist to help. Hector is taken by surprise; the receptionist is related to his boss at work. Now, he fears that she will tell his boss that he is HIV positive and that word will spread through out the small Latino community in his town. He leaves the clinic upset and afraid.

Examples of cultural barriers: Many Latino cultures dictate that through ‘machismo’ a man is strong and should not have to rely on anyone but himself. Presented with the need to seek medical attention, men often choose not to access care so as not to appear weak.

¹⁶ HRSA Care ACTION, August 2002.

With the epidemic increasing among women, cultural issues arise that are not present in the male community. Consider the influence of *marianismo* among some Hispanic women. Latin-American women are often treated as subservient, are held in less esteem, and are not allowed to seek outside help or attention unless the dominant spouse has given permission.

The strong presence of the church in the Latino community leads to a sense of deserved guilt that keeps clients from seeking services: "I must have done something wrong and God is punishing me with this disease." Clients may resign themselves to suffer instead of seeking assistance.

The presumption by a large portion of the Latino community that if you have HIV/AIDS, you must be gay hinders a client's ability to seek support and services.

The African-born population has barriers, such as language and cultural norms that inhibit accessing some types of support. Clients from some populations believe they have been cursed with this disease by an enemy, and that only culturally specific medication or healers can cure them. Women in these communities are relegated to a subservient role. They may not be allowed to seek outside care without permission from the dominant male.

Lack of Materials: Other than Spanish, there is a lack of translated educational material and few appropriate interpreters to communicate between providers and clients. Spanish translation also continues to be a challenge in some of the more rural areas of the state. Iowa has geographical pockets of Vietnamese, Congolese, Sudanese, and other minorities. Clinics serving PLWHA report that these populations are increasing, and so are challenges related to translation and interpretation services. Every minority community has specific needs that not all service providers have been adequately trained to address. Often providers have not had opportunities to seek additional training to meet the needs.

Rural Challenges for Care Providers

People living with HIV often appear in rural emergency rooms or at general practitioner offices. The providers may believe that HIV is not a problem in the area. They may not conduct proper patient risk assessments, and may not properly diagnose cases. Misdiagnoses and improper diagnoses have been reported in rural Iowa, resulting in patients not receiving timely care. Rural physicians may be reluctant to become known as "the AIDS doctor," for fear of scaring off other patients.¹⁷

Well trained providers are better able to help people living with HIV access and maintain care. Support service providers report difficulty maintaining updated knowledge of the various programs available for people living with HIV, and how to address the many biopsychosocial issues that affect their clients. Support service providers often wear many hats, and find it difficult to devote the time necessary to maintain this capacity. In fact, in the 2005 consumer needs assessment, respondents reported frustration with case managers' and other service providers' difficulty navigating the system.

¹⁷ Frazier EM, Gabel LL. HIV/AIDS in family practice: an approach to care in rural areas. Family Practice Recertification. 1996;18:59-77.

Heavy case loads contribute to service providers' difficulty delivering the quality care that helps high-need clients stay in care. Title II case managers saw 750 clients in 2005, with less funding than in 2001, when they saw 550 clients. The increased case load is in part due to the success of Highly Active Anti-Retroviral Therapy (HAART), and to the migration of HIV+ patients, who may have become infected in urban centers and returned home to rural areas for care.¹⁸ It is important to note that these cases are not counted in the federal funding formula for Ryan White services in Iowa.

Testing

The number of late testers is a concern in Iowa. Late testing is associated with poorer health outcomes and earlier deaths. Late testers benefit less from antiretroviral therapy, and have more opportunities to spread HIV to partners. According to a study by the Centers for Disease Control and Prevention, late testers are more likely than early testers to have been previously tested. The authors of the study surmised that, because they previously tested negative, late testers may erroneously presume they are not at risk.¹⁹ Fifty-two percent of persons diagnosed with HIV in Iowa in 2003 received a diagnosis of AIDS within 1 year. This was an increase from 45% in 2002 and compares to about 43% nationally from 1994 to 1999. According to the CDC study, late testers are more likely to be heterosexual, have lower education levels, and be members of racial and ethnic minorities.

Barriers to early testing: Barriers to early testing include not perceiving yourself to be at risk, not wanting to know your status (i.e., denial), and the stigma associated with HIV. Because HIV funds are limited, the public testing system focuses only on high-risk populations. Cases may be missed among those who do not realize they are at risk. Other barriers may include lack of rapid testing, limited anonymous testing options, the limited number of public testing sites, and the location of existing testing sites.

Co-Morbidity (Substance Abuse/Mental Illness)

Co-morbidities affect health outcomes: Active substance abuse and untreated mental health issues, including depression, are relatively consistent predictors of poor adherence to (HAART)²⁰ and poor health outcomes. This is due, in part, to this population's difficulty with accessing and maintaining care. In Iowa, over 30% of HIV-positive injection drug users are not receiving primary medical care, compared to 25% of all HIV-positive Iowans.²¹

Lack of funding for treatment: Substance abuse and mental health treatment greatly improve adherence to medications and overall health. Insufficient funding limits PLWH/A access to needed mental health and substance abuse treatment. Although substance abuse and mental

¹⁸Rumley RL, Shappley NC, Waivers LE, et al. AIDS in rural eastern North Carolina. Patient migration: a rural AIDS burden. AIDS. 1991;5:1373-1378.

¹⁹ CDC. Late versus early testing of HIV --- 16 sites, United States, 2000—2003. MMWR 2003;52(25);581-586. (see <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5225a2.htm>)

²⁰ New York State Department of Health. Adherence to antiretroviral therapy among substance users. New York (NY): New York State Department of Health; 2005 June

²¹ 2003 Iowa Unmet Need study

health are “Core Services” for Ryan White Title II funds, no Iowa Title II provider was able to devote sufficient funds to these expensive treatment services.

Lack of availability of treatment: In Iowa, substance abuse treatment is in short supply, even though it is crucial for staying in HIV care and adhering to a treatment regimen. Providers report that, even when their clients are ready to receive care and a payer has been identified, there are often long waiting lists and the opportunity is missed. Mental health and addiction treatment are not well integrated with HIV care systems and health HIV coverage. There are no clear guidelines regarding sharing of client-level information between systems, leaving case managers, treatment providers, and clinicians to navigate complex laws regarding sharing confidential information.

Capacity: CARE Act and prevention case managers often do not have the training or time to provide the needed level of mental health or substance abuse counseling.

Housing

A stable home environment is critical for persons managing complex drug therapies and potential side effects.

Lack of adequate housing affects a large number of persons living with HIV in Iowa, as evidenced by the 2005 Consumer Needs Assessment. Thirty-six percent of respondents reported receiving assistance with housing. Of those, 58% were African American, 31% were Caucasian, and 29% were Hispanic. More women (46%) than men (32%) received housing assistance.

Although 36% of respondents received housing assistance, 46% of respondents reported needing such assistance. Of the 46% of respondents needing housing assistance, the need was met for only 65%. Females who needed housing were less likely than males to receive assistance, and those with HIV (not AIDS) were less likely to receive housing assistance.

Thirty-two percent of respondents reported ever having been homeless,. This number may be even higher, since many consumers are doubtless unaware of HUD’s homelessness-defining criteria, which include staying with friends or family without adequate housing space. Of those who reported being homeless at some point, 49% were African American, 35% Hispanic, and 28% Caucasian. Categorized by risk factors, the consumer needs assessment showed that injecting drug users (IDUs) were much more likely than others to have experienced homelessness at some point in their lives. Fifty-six percent of IDUs reported ever being homeless.

Housing Opportunities for People With AIDS (HOPWA): Iowa has received federal HOPWA funds since 2002. The HOPWA program is designed to help very low-income Iowans living with HIV stabilize their housing situations, which is essential to health and well-being. Rental assistance and case management are provided to enable those on the verge of homelessness, or in unsafe housing, secure and maintain an affordable, safe place to live. It is important to note, however, that the program cannot assist those who are already homeless, Leaving a considerable number of Iowans living with HIV homeless.

While the need for housing assistance remains high, HOPWA funding in Iowa will decrease by nearly 50% over the next few years. The agency that administers the program, Iowa Finance Authority, projects the following:

FY05	9.7% decrease in HOPWA funding
FY06	14% decrease in HOPWA funding
FY07	41% decrease in HOPWA funding
FY08	50% decrease in HOPWA funding

These cuts in HOPWA assistance, along with expected decreases in Section 8 housing assistance programs, higher energy costs, and restrictive programmatic policies, suggest an imminent housing crisis for PLWH/A in Iowa.

Dental Care:

Access to dental care remains difficult, even for those with Medicaid. Dentists are not required to accept Medicaid, and a large majority refuse to accept it. The 2005 Consumer Needs Assessment reports that 54% of respondents needed to access dental care. Of these, 22% were unable to access needed services.

People Living Longer with HIV/AIDS

Over the past ten years, HIV has evolved from a terminal illness to a chronic disease as (HAART) regimens have slowed the progression of infection and increased quality of life. As people with HIV live longer, providers face a number of new challenges which can impact keeping patients in medical care, including:

- Changing demographics, including continued increase in cases among minority populations;
- Increasing age of people living with HIV;
- Engaging and retaining HIV-positive people in care;
- Recognizing prevalence of co-morbidities, especially mental health issues, substance abuse, and hepatitis;
- Simplifying complex treatment regimens to maximize adherence;
- Identifying and managing long-term effects of HAART;
- Reducing disparities of HIV care between subpopulations;
- Integrating ongoing prevention counseling into care, including educating providers about strategies to help patients change behaviors and reduce risk;
- Managing general medical and preventive health care for people in middle age and the elderly; and

- Differentiating treatment side effects from symptoms related to other common, non-HIV medical problems.²²

A thorough examination of several models for addressing these complex issues will be necessary in the near future.

Funding

In Iowa, persons living with HIV must have an income of less than 200% of the Federal Poverty Guideline to qualify for most Ryan White services. This income cap prevents many from accessing these services. Case managers routinely report that a significant number of people who do not qualify for Ryan White services are unable to pay private insurance premiums, co-pays, or the cost of medications needed for treatment.

Clients qualified for Medicare and Medicaid may still be required to pay co-pays and premiums. There are concerns about the effectiveness of the Medicare Part D prescription drug Program. Persons with HIV are living longer, and need to access health care services for non-HIV-related medical conditions, which adds to their overall expenses.

For the last five years, increases in the AIDS Drug Assistance Program have been inadequate. Iowa Ryan White Title II & III programs have been cut or flat funded. Iowa's client caseload has increased from 550 in 2001 to 750 in 2005. In this environment, spending caps are quickly surpassed. In fact, for fourteen months in 2004 and 2005, the ADAP was closed to new enrollees. Iowa advocates were successful in securing unprecedented state funding to re-open the much-needed drug program. By the time the program reopened, over 100 Iowans were waiting to enroll. Current projections indicate that, without a substantial increase in budgets, both the ADAP and the supportive services program will face severe cuts, resulting in substantial difficulties for clients in accessing care and maintaining drug regimens.

Summary

Although the outlined barriers to accessing care are complex, their crosscutting issue is lack of funding. Increased funding could be used to:

- Establish specialty satellite clinics throughout the state;
- Implement programs that reduce stigma and discrimination;
- Provide HIV/AIDS education for providers;
- Offer HIV testing as part of routine medical care;
- Fund substance abuse and mental health treatment so that people in need are not turned away;
- Increase supportive service program staffing to handle increased caseloads; and
- Expand assistance programs to include the working poor.

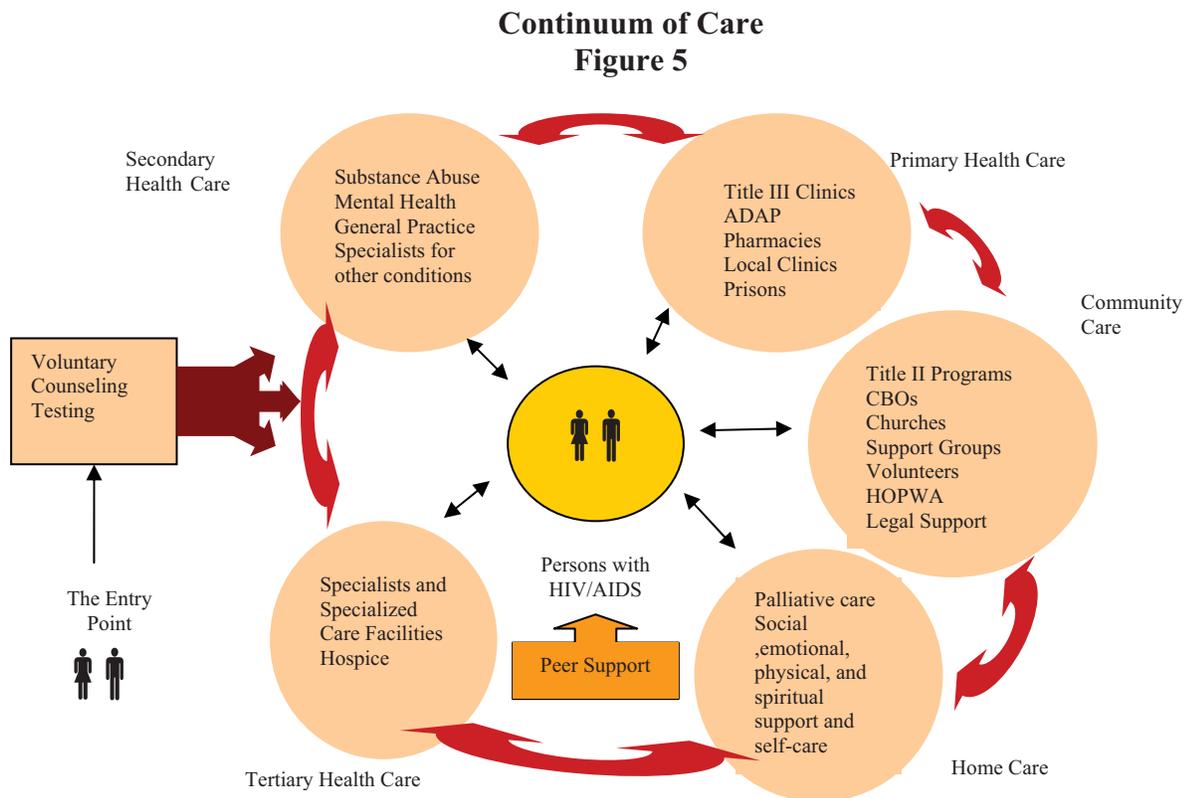
²² Agins, Bruce D., Medical Director, New York State Department of Health, AIDS Institute, excerpted from <http://www.ihl.org/IHI/Topics/HIVAIDS/HIVAIDSExpertHost.htm>

Until Iowa can secure sufficient funding to pursue these programmatic expansions, it is necessary to continue to identify the greatest needs and barriers among the populations served and to work more efficiently and collaboratively within our communities and our current state infrastructure to accomplish our goals.

II. Challenges in Coordination and Collaboration

A coordinated approach is needed to address the challenges presented by the health care and service environment, information gaps, disparate and incomplete data systems, and co-existing conditions such as mental illness, substance abuse, STDs, and hepatitis C. Coordination implies not only communication and sharing of information, but also shared understanding of the importance of working together to ensure a true continuum of HIV care.

Figure 5 illustrates the linkages needed between various care domains to ensure that persons living with HIV receive clinical and non-clinical care.²³



²³ The Comprehensive Continuum of Care. Adopted from WHO 2000. Key elements in Care, Treatment and Support.

Coordination issues are complex and challenging, and may involve service providers; clients; state and county public health agencies; federal agencies; private, community-based organizations; and public officials. The various federal and state funding streams for HIV prevention, medical care, and support services have different reporting requirements, and program goals and objectives are not coordinated across the HIV continuum of care. Integrating approaches across disciplines and agencies requires an understanding of several philosophical approaches to prevention and treatment as well as different priorities. The need for coordinated planning should be demonstrated to local medical care providers, substance abuse treatment and mental health care providers, case managers, and the larger agencies that affect standards and protocols.

Communication between Ryan White Grantees (Titles II, III, and MATEC)

Little or no communication: Because Iowa is a rural state, Ryan White grantees, which include Title II, III and MATEC, often know each other or see each other at various functions; however, there is very little planned communication between them. Staff turnover, growing workloads, and lack of contact information are some cited reasons for limited communication. Grantees are not always sure what services other grantees' provide and whom they serve.

Need to share success stories: Whether in a large metropolitan city or a rural state, sharing success stories and challenges among programs can reduce duplication of services, time, and effort. It is especially important to avoid "re-inventing the wheel" in a rural state with limited resources. Geographic distance, lack of time and limited funding make it difficult for Ryan White grantees to create a forum where this kind of exchange can happen.

Mental Health and Substance Abuse

Active substance abuse and untreated mental health issues, including depression, are relatively consistent predictors of poor adherence to HAART, which leads to poor health outcomes.²⁴ In Iowa, over 30% of HIV-positive injection drug users are not receiving primary medical care. This compares to 25% of all HIV-positive Iowans.²⁵ Forty-seven percent of consumer needs assessment respondents said that they struggle with depression, anxiety, and/or another mental health issue. Nine percent of respondents report problems with alcohol use and 8% report problems with drug use. Depression, other mental health issues, and substance abuse are strongly correlated with criminal activity. Of the respondents who said they had suffered depression, anxiety, or another mental illness, 34% have spent some time in prison or jail. Over 75% of IDU's reported that they have been in jail or prison.

Importance of systems development: It is important for HIV, substance abuse, and mental health professionals to be knowledgeable about available services and how to access them. It is also important that each professional understand specific issues related to each condition. A system for coordinating and ensuring the care and treatment of all health conditions of Iowans living with HIV should result in better health outcomes and lower costs.

²⁴ New York State Department of Health. Adherence to antiretroviral therapy among substance users. New York (NY): New York State Department of Health; 2005 June

²⁵ 2003 Iowa Unmet Need study

Lack of knowledge and understanding: Mental health, substance abuse, and HIV have their own complex sets of services, which generally operate independently of one another. Each system has its own culture, vocabulary, and acronyms. Professionals trained in one field often feel inadequate to navigate the others' systems. This is the reported experience of Iowa providers. HIV providers feel that substance abuse and mental health professionals do not understand the complex issues their clients face. Likewise, they are often overwhelmed by the complexity of co-morbidities and tri-morbidities. It is sometimes difficult to identify the providers of mental health and substance abuse services in a given community .

No formal mechanism: Although there are some areas in the state with cross training, education, and collaboration mechanisms in place, no consistent structure exists in all areas of the state, or at the state level. For example, statewide substance abuse professional licensure standards²⁶ are vague, and lack clear language regarding the role of substance abuse professionals working with persons living with HIV. Consequently, licensed substance abuse professionals may not understand the scope of the epidemic in their target population, or their role in the care of these individuals.

Challenges: HIV, mental health, and substance abuse all experienced funding cuts in FY2006. Nationally, substance abuse and mental health block grants project \$18 million and \$4 million cuts, respectively.²⁷ Many programs have already been operating at “bare-bones” capacity. Further cuts make setting up systems of collaboration even more difficult.

Department of Corrections and County Jails

Correctional facilities provide both opportunities and challenges to ensuring care for incarcerated PLWH/A. Incarceration provides a unique opportunity to identify and address HIV infection, with direct access to prevention messages, testing, and health care. A significant proportion of PLWH/A have some history of incarceration. In Iowa, 28% of respondents to the 2005 Consumer Needs Assessment said they have been in prison at some time in their lives. There was no difference between the incarceration rate of male and female respondents. Blacks were more likely than whites to have been incarcerated (43% vs. 25%), and IDU's and MSM/IDU's were very likely to have spent time in prison – 74% and 80%, respectively. Thirty-four percent of those stating they suffered depression had been in prison, and 43% of those that had been homeless have been in prison. For this reason, collaboration with the department of corrections and county jails has been a priority for many years. The collaborative process could be improved by becoming more formalized.

Sexually Transmitted Diseases and Hepatitis C: Recent trends in STD and hepatitis C rates among PLWH/A and key groups at risk for HIV indicate the need for increased prevention education, other harm reduction work, and collaboration. Both STDs and hepatitis C can complicate HIV treatment and care.

²⁶ Iowa Code 643, Chapter 3, 3.21(11)

²⁷ House Report 109-337- Departments of Labor, Health and Human Services, and Education, and Related Agencies, Appropriation Bill, 2006

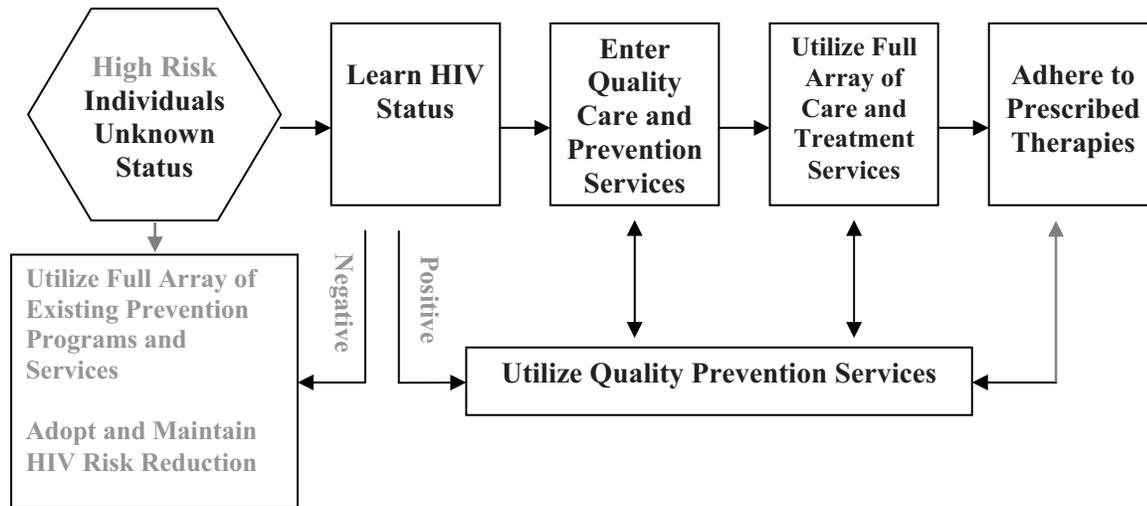
The continuum of care model shown earlier in this section assumes that health care providers have innate or learned ability to talk about prevention and harm reduction. As noted in the *Access to Care* section of this document and the 2005 Consumer Needs Assessment, providers and PLWH/A are unsatisfied with the level of training, awareness, and cultural competence about these issues. Work is needed to ensure culturally competent counseling and testing that encourage utilization of essential health and supportive services.

Hepatitis C virus (HCV) is the most common chronic, blood-borne viral infection in the United States. It is estimated that 1.8% of the U.S. population is infected, including approximately 52,000 Iowans. Many are unaware of their infections. The most common route of transmission is injection drug use; other risk factors include receiving blood transfusions or organ transplants prior to mid-1992, treatment with blood products before 1987, and long-term kidney dialysis. Both HIV and HCV can be transmitted through blood to blood contact. Iowans living with HIV who were infected through injection drug use or blood transfusion may also be infected with HCV. The 2005 Iowa Consumer Needs Assessment asked Iowans living with HIV if they were co-infected with HCV. Twelve percent of respondents reported co-infection. CDC estimates that approximately one quarter of HIV-infected persons in the United States are also infected with HCV. Coinfection with HIV and HCV is common (50%-90%) among HIV-infected injection drug users (IDUs).

The effects of HCV coinfection on HIV disease progression are less certain. Some studies have suggested that infection with certain HCV genotypes is associated with more rapid progression to AIDS or death. The subject remains controversial. Since coinfecting patients are living longer on HAART, more data are needed to determine if HCV infection influences the long-term natural history of HIV infection.

Prevention-Care-Prevention Continuum: The Iowa Department of Public Health’s HIV/AIDS Program and other Iowa Ryan White grantees believe in the following prevention-care-prevention continuum:

Figure 6



CDC’s initiative, *Advancing HIV Prevention*, emphasizes prioritizing prevention with positives, and provides another incentive and motivator for ensuring that there is a connection between prevention and care.

Challenges: There are few CDC-approved curricula for prevention with positives. Iowa’s HIV prevention projects have chosen to implement “Prevention Case Management” and “Healthy Relationships,” two such interventions. The former is an intensive, individual-level intervention and the latter is a group-level intervention. Appropriate staffing and client participation have proved challenging in the implementation of prevention case management. Implementation of Healthy Relationships, too, has been challenging. It has been difficult to get PLWH/A to participate in groups for a number of years, and this group is no exception.

While physicians and nurses specializing in HIV care are familiar with the CDC’s *Prevention-Care-Prevention Continuum* and *Advancing HIV Prevention* initiative, they find it difficult to deliver appropriate prevention messages in the patient time allotted.

Summary To ensure the most efficient use of resources, the HIV/AIDS community in Iowa must focus on increased communication and collaboration:

- between Ryan White Grantees;
- with mental health and substance abuse professionals;
- with Iowa Department of Corrections and county jails;
- with STD and Hepatitis C programs; and
- with HIV prevention programs.

III. Challenges in Quality Management

Quality is the degree to which health or social services meet or exceed established professional standards and user expectations. Quality assurance involves identifying successes and challenges in service delivery, and designing continuous quality improvement activities to overcome them. Quality management supports the development of higher quality care for people living with HIV disease, improves the performance of local HIV service delivery networks and providers, and helps them function as a system.

Quality assurance programs need to accomplish three goals:

1. Assist direct CARE Act-funded medical providers to ensure their services adhere to established HIV treatment guidelines;
2. Ensure that health-related supportive services enhance access to care and adherence to HIV medical regimens; and
3. Ensure that available demographic, clinical, and health care use information are used to monitor HIV-related illnesses and epidemic trends.²⁸

Quality Assurance Issues in Iowa

Data Collection

Staff: The first priority for case managers is assisting clients in meeting medical and daily life needs. Documentation and data entry are difficult due to clients' increasingly complex issues and the continuously increasing client caseload. To ensure accurate documentation and data collection, service providers need to hire staff to collect and enter data and to provide technical support. Large agencies find that inadequate funding makes it difficult to attract and retain program evaluators. Small agencies are not able to maintain information technology staff needed to deal with complex data management.

Training: State-specific training in CAREWare, the state's database for collecting client-level data, is nonexistent. Software upgrades, report generation, and conversions are problematic for untrained personnel.

Multiple Systems: Multiple systems are required to track data across diverse funding streams. Agencies that receive HOPWA funds must enter data into CAREWare and the Servicepoint system. Similarly, agencies that provide mental health or medical care and Ryan White services must enter data into more than one system.

Outcome Measures

Consistency/Continuity: Iowa data captured for outcome measures lack consistency and continuity. Each agency uses its own client assessment and service plan form. Standardized information or forms on which to base outcome measures do not exist. Iowa has formed two statewide committees (Quality Management and Case Management Standards) to address this

²⁸ HRSA 2002 Ryan White CARE Act Manual

issue. However, because committee members are volunteers from agencies and clinics serving an ever-growing population of PLWH with fewer resources, it is difficult to devote adequate time to this cumbersome endeavor.

Quality: Challenges exist in determining performance measures. For example, some argue that the current CD4 or viral load is not reflective of the long-term health of the client. Sometimes indicators or outcomes are open to interpretation, and can be skewed by client or case manager judgment or report. With a measure such as adherence, accuracy may be questionable since it is primarily based on client self-report. Allocated resources to an improved quality management program at the state level to investigate solutions to these issues would be beneficial.

Response to the Evolving Epidemic

Increased Demand

As new diagnoses remain constant and PLWH/A live longer, HIV agency caseloads are increasing. In 2001, Ryan White Title II contractors saw 550 clients. By 2005, the caseload had increased 36%. With flat funding since 2001, Title II providers saw 750 clients in 2005. Newly infected individuals are more likely than others to be low-income²⁹; consequently, the newly infected have particularly complex and extensive needs. As the number and complexity of cases increases without concurrent increases in funding, delivering “quality” services and finding resources to monitor and evaluate those services becomes more difficult.

Cultural Competency

Language Issues: Both spoken (interpretation) and written (translation) language issues are becoming more prevalent. Iowa’s Spanish-speaking population is growing. It is sometimes difficult to compete with higher-paying corporations for competent bilingual staff. Staff who are verbally competent are not always competent or comfortable with written translation.

Iowa is home to an increasing number of Africans who speak a variety of languages, some tribal or geographical and not widely spoken or known. Very few written materials are available in African languages. Limited resources often make it difficult to provide quality service to these clients.

Literacy: Literacy is an issue among Central American and African clients, especially females. Even if written information is available in their primary languages, clients are often unable to access the information. Staff must spend more time than usual providing and reviewing information verbally. The high volume of clients, and limited staff and interpreters, cause a definite gap.

Cultural Mores and Beliefs: As client diversity increases, so does the number of cultural systems providers must navigate to serve them. Cultural systems impact risk reduction, gender roles, and health care beliefs. It is nearly impossible for staff to be culturally competent in every

²⁹ Kaiser Family Foundation , HIV/AIDS Policy Fact Sheet, Medicare and HIV/AIDS, September 2004.

aspect of care. Case managers need ongoing training and resources for translation, consultation, and problem solving.

Quality of Services

Evaluation activities are critical to determine whether provided services are achieving the intended outcomes of improved access to and retention in care and adherence to HIV medical regimes.

Standards of Care: Standards of care are principles and practices for the delivery of health and social services. Standards provide guidelines that ensure that program funds are spent on services that comply with accepted principles of professional practice. Additionally, standards ensure that PLWH/A and their families receive high quality, professional, cost-effective, and appropriate services through the Ryan White Care Act. Standards of care are used in developing quality improvement initiatives based on process measures. Case management standards were developed and implemented in April 2004. Implementation of the standards has been essential to developing the Title II quality management program. Work continues on determining baseline performance and subsequent continuous quality improvement goals.

Units of service: One component of developing standards is identifying common definitions for units of service, which assist in standardized reporting. These units have not been established in Iowa.

Case management staff: Iowa does not have a certification program nor minimum qualifications required for case management staff. This has impacted quality and outcome measures.

Summary

To ensure quality health and supportive care to Iowans living with HIV, Iowa needs to continue to implement and improve quality management programs. Special attention should be paid to data collection and outcome measures, including coordinating systems and ensuring consistency and continuity. As the epidemic continues to grow, challenges such as inadequate funding and staff time, and increased cultural considerations will need to be addressed.