State of Illinois
Pat Quinn, Governor

Department of Public Health
Damon T. Arnold, M.D., M.P.H., Director

Illinois Ryan White HIV/AIDS Program

Statewide Coordinated Statement of Need and Comprehensive Plan for HIV/AIDS Services

April 2009

Illinois Department of PUBLIC HEALTH

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This document is made possible by a grant from the U.S. Health Resources and Services Administration (HRSA) under Part B of the Ryan White HIV/AIDS Treatment Modernization Act of 2006 (Ryan White HIV/AIDS Program), with the support of the Part B advisory group, through the Illinois Department of Public Health's Office of Health Protection, Division of Infectious Diseases-HIV/AIDS Section.

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Letter of Concurrence

Winnebago County Health Department

Promoting a Safer and Healthier Community Since 1854

J. Maichle Bacon M.P.H., R.S.
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5 February 2009

William Moran
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Dear Mr. Moran:

On behalf of the Ryan White Part B Advisory Group, we offer our full support to the Illinois Department of Public Health, Division of Infectious Diseases HIV/AIDS Sections' 2009-2011 Comprehensive Plan for HIV/AIDS services.

This plan is effective in presenting a roadmap that accurately outlines progressive steps toward a broad, integrated and effective network of HIV-related services throughout Illinois. We call on the elected officials in our communities to offer their support, and help lead the effort to ensure that all our citizens who need HIV treatment services have the access required to meet their needs.

We encourage local planning agencies, citizen groups, and elected officials to join with the Illinois Department of Public Health, the Office of Health Protection, and the Division of Infectious Diseases' HIV/AIDS Section in continuing to build a system of care that provides treatment and collaborates in prevention efforts to stem the rising rates of HIV infection in our communities.

With best regards,

Todd M. Kisner

Todd M. Kisner
Project Director
Winnebago HIV CARE Consortium

Executive Summary

The Statewide Coordinated Statement of Need (SCSN) and Ryan White Part B Comprehensive Plan for HIV/AIDS Services in Illinois 2009-2011 will provide a description of the development of the SCSN, Ryan White HIV/AIDS Program coordination, an overview of epidemiological data, and current needs assessments, as well as emerging trends affecting HIV/AIDS care and service delivery in Illinois. The SCSN also will address unmet need, crosscutting issues, and critical gaps in services for People Living with HIV/AIDS (PLWHA) throughout Illinois. It also will provide a comprehensive overview of the wide array of services available in the state of Illinois for people infected and affected by the disease. It is designed to serve as a guide to planning, funding, and service delivery for planning groups.

Methodology

Some of the sources of information utilized in this plan included the preceding SCSN and Comprehensive Plan created in FY 2006, the 2009 Part B grant application, data from the St. Louis Transitional Grant Area (TGA), and data from the Chicago Eligible Metropolitan Area (EMA). The Direct Service Unit of IDPH HIV/AIDS Section developed the plan. A number of resources were utilized to form the plan, including but not limited to focus groups, meetings with a variety of formats and purpose, consumer surveys and other ancillary materials. The advisory group has reviewed segments of the plan and the completed document will be subject to review and approval.

Profile of the Illinois Epidemic

The face of HIV/AIDS in Illinois has changed consistently with the changes that are being observed nationally. The HIV/AIDS epidemic has affected persons in all sex, age, and racial/ethnic groups in all public health regions in Illinois. The effect, however, has not been consistent for all groups. Recent trends suggest a shift in the HIV/AIDS epidemic toward women, African Americans, and high-risk heterosexual adults. New risk factors, such as the advent of methamphetamine in the rural areas, have had a substantial impact on the promulgation of the disease. The substantial decline in mortality from AIDS is specifically noted in this profile.

Summary of the Plan

The information in this document is organized in separate sections of the SCSN and Comprehensive Plan. The information is presented on Illinois as a whole.

The SCSN contains the HIV/AIDS epidemiological profile; a description of the process used to develop the SCSN and Comprehensive Plan; and a description of the emerging trends, cross-cutting issues, gaps and barriers identified through the multi-step process. The SCSN undertakes a need assessment and estimates unmet need in the state as well.

The Comprehensive Plan was based on the data and information gathered through the SCSN process, epidemiological data, and trends and the planning processes informed by the Part A

planning councils and statewide advisory group. The plan details the continuum of care of high quality core services by expanding on the shared vision and values for system changes in Illinois. The plan specifies broad goals and objectives for engaging and retaining clients in care, improving medical outcomes and enhancing the collaboration between HIV prevention and care. The plan also describes strategies to monitor progress in meeting short and long term goals and objectives.

Introduction

The Illinois Department of Public Health was created in 1877 to regulate medical practitioners and to promote sanitation. Today, the Department is responsible for protecting the state's 12.8 million residents, as well as countless visitors, through the prevention and control of disease and injury. The Department's nearly 200 programs touch virtually every age, aspect and cycle of life.

In 1986, the Illinois General Assembly acted on a request from the Department, granting $2.3 million for the establishment of the AIDS Section. On February 1, 1987, the AIDS Activity Section was formed to coordinate the state's response to this new disease. The program focused efforts towards disease surveillance, prevention and establishing HIV counseling and testing sites. AIDS prevention and education efforts were aimed at health care providers and the general public. In 1995, for the first time since 1981 when Illinois' first AIDS case was recorded, the annual number of reported cases of AIDS declined. Initially 2,186 cases were reported in 1995, down 28 percent from the previous year. At that time, the state's cumulative total of AIDS cases stood at 16,375, the sixth highest state total in the United States. Illinois' cumulative cases at the end of 2007 were 35,312.

When Congress passed the Ryan White Comprehensive AIDS Resource Emergency (CARE) Act to provide assistance to states and cities financially burdened by providing services to persons living with HIV and AIDS in 1990, Illinois used this funding to establish the Department's AIDS Drug Assistance Program (ADAP), the HIV CARE Consortia program, and the Continuation of Health Insurance Coverage (CHIC) program. The Ryan White Advisory Committee was formed in 1991. The initial committee had 18 members that included representatives from the HIV/AIDS Section, the Division of Family Health, the Department of Child and Family Services, the Chicago Title I Planning Council, infectious disease physicians, HIV service providers and two persons living with HIV. The committee was charged with assisting the Department in developing a statewide plan for addressing care issues for HIV-infected persons, along with an ongoing review of the effectiveness and appropriateness of services supported by Ryan White Title II funds. Currently, with Ryan White HIV/AIDS Treatment Modernization Act of 2006 (Ryan White HIV/AIDS Program) Part B funding, there are eight regional offices to manage subcontracts and quality assurance activities in support of persons living with HIV in Illinois. Each regional project director along with regional client representatives and the Department's Ryan White Program Part B staff attend the Ryan White Quarterly Advisory Group meeting convened by the grantee, Illinois Department of Public Health.

The Department has long been responsible for administering Ryan White HIV/AIDS Program funds in Illinois in conjunction with several other programs related to surveillance, prevention, and treatment of HIV/AIDS. The Illinois Statewide Coordinated Statement of Need (SCSN) and Ryan White Part B Comprehensive Plan were developed to document the significant issues related to the needs of persons living with HIV/AIDS (PLWHA) and the strategic approach that Illinois will take to address the significant issues and provide medical care and supportive services to PLWHA in Illinois. The development of this document was coordinated by the Illinois Department of Public Health HIV/AIDS Section and was made possible through a collaborative effort of collective input from grantees of all Parts of the Ryan White HIV/AIDS

Program, as well as representatives from HIV prevention providers, community advocates, PLWHA, and other public agencies.

I. Description of the 2009 SCSN Process

The SCSN was developed through a multi-step process. Client satisfaction surveys, community forums, workgroups, epidemiological data, and needs assessment information were gathered to develop this statement.

Client satisfaction surveys are conducted annually. The information from the surveys is assessed to determine service needs and barriers. A statewide needs assessment was conducted in 2007. Surveys and focus groups were conducted as part of the statewide needs assessment. The data from the statewide needs assessment also was evaluated. The HIV/AIDS Section updated the epidemiological profile and service utilization data to determine epidemiological trends and unmet need in the state.

The Illinois Department of Public Health, HIV/AIDS Section, assembled one statewide workgroup and five regional community forums to gather input from service providers, Ryan White grantees, PLWHA, and public agency representatives in preparation of the SCSN and Comprehensive Plan.

The two-day workgroup meeting was attended by 60 representatives from the Department's Ryan White HIV/AIDS Program, Part B staff, PLWHA, service providers, community-based organizations, and public agency representatives. During the meeting, Part B program staff presented a review of the 2005 SCSN, the current Comprehensive Plan, updated epidemiological data, client satisfaction survey results, and needs assessment results to the workgroup. This information guided the discussion of the impact, issues, and solutions for emerging trends, gaps, and service barriers. The group also identified additional trends, gaps, and barriers. Participants were grouped based on their expertise and preference in order to discuss the information presented. Each group developed recommendations to address identified service gaps, barriers, and trends. Each group presented a summary of the group's discussion and sought further input from the whole group.

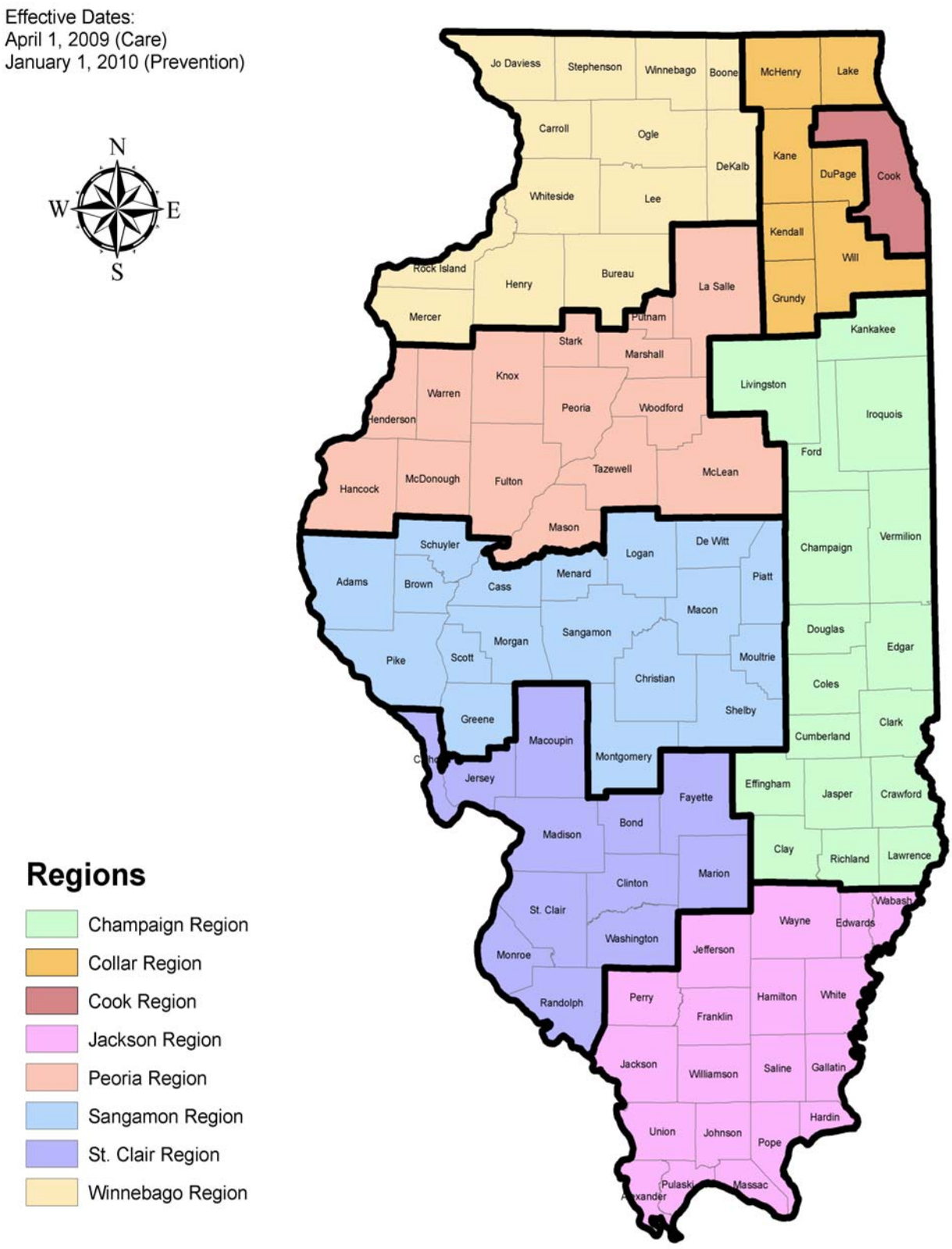
Due to the contrast between rural, suburban, and urban communities throughout Illinois, five regional community forums were conducted to gather local input on the issues affecting service delivery and address the needs of those affected by HIV/AIDS. Local service providers, PLWHA, and community-based organization representatives attended one-day meetings repeating the same format used for the statewide meeting.

Through this process, Part B program staff compiled input from partners and PLWHA, in addition to epidemiological trends to draft the SCSN, which serves as a tool to identify action steps, address needs, gaps, and barriers in HIV care services in Illinois.

II. Ryan White HIV/AIDS Programs in Illinois

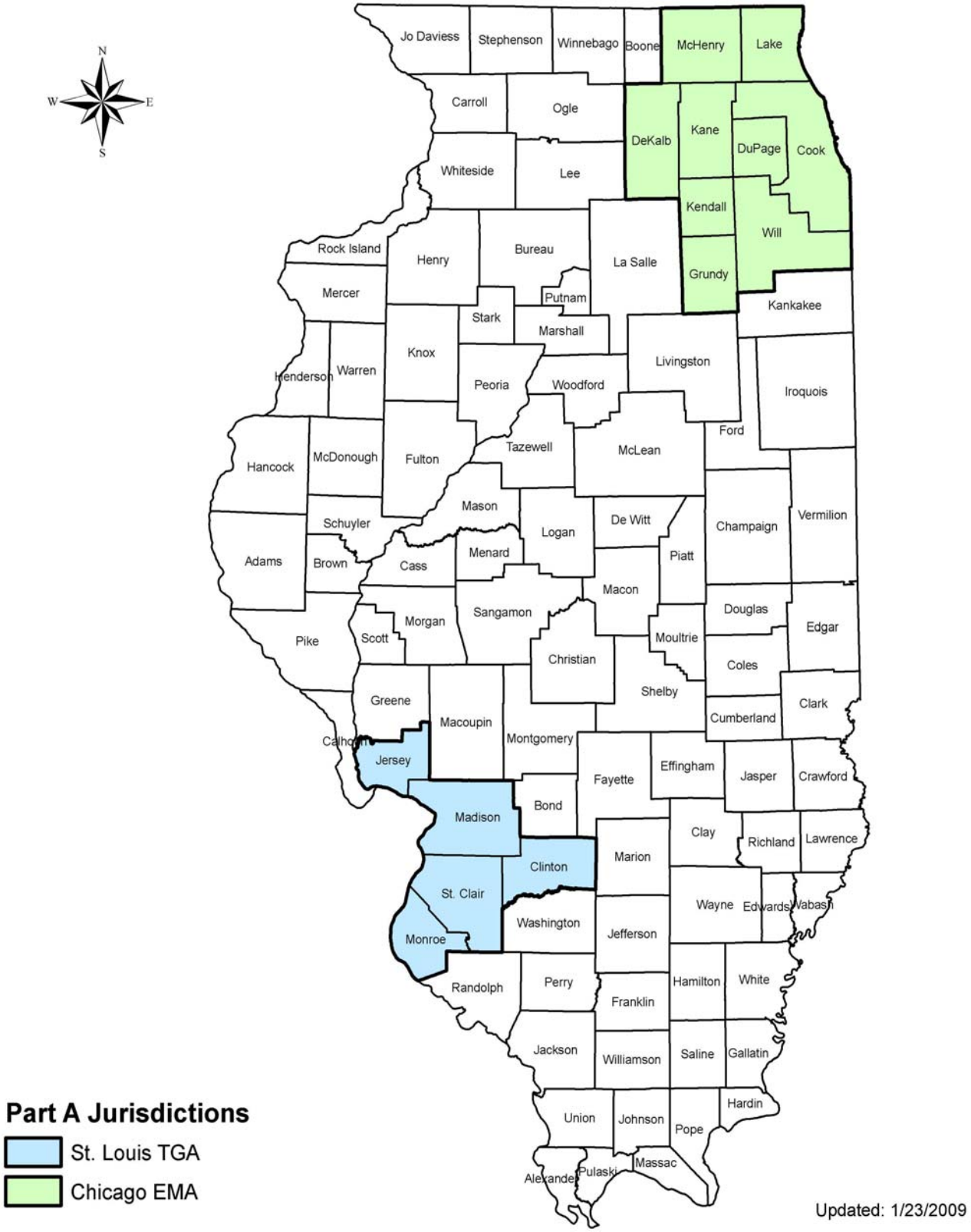
Illinois Department of Public Health is responsible for administering Part B of the Ryan White HIV/AIDS Program. The Department utilizes Part B funds, augmented with state general revenue funds, to support the AIDS Drug Assistance Program, the Continuation of Health Insurance Coverage program, and the provision of core and supportive services for PLWHA. Eight regional administrative offices encompass the 102 counties in Illinois, (Figure 1). Focusing on core services as defined by Health Resources and Services Administration, Illinois strives to provide a comprehensive continuum of medical care and supportive services for persons with HIV/AIDS. Regional project directors coordinate services, manage local programs, and convene local advisory boards to assist with assessing service needs and identifying gaps in services.

Figure 1. Illinois Care/Prevention Regional Map



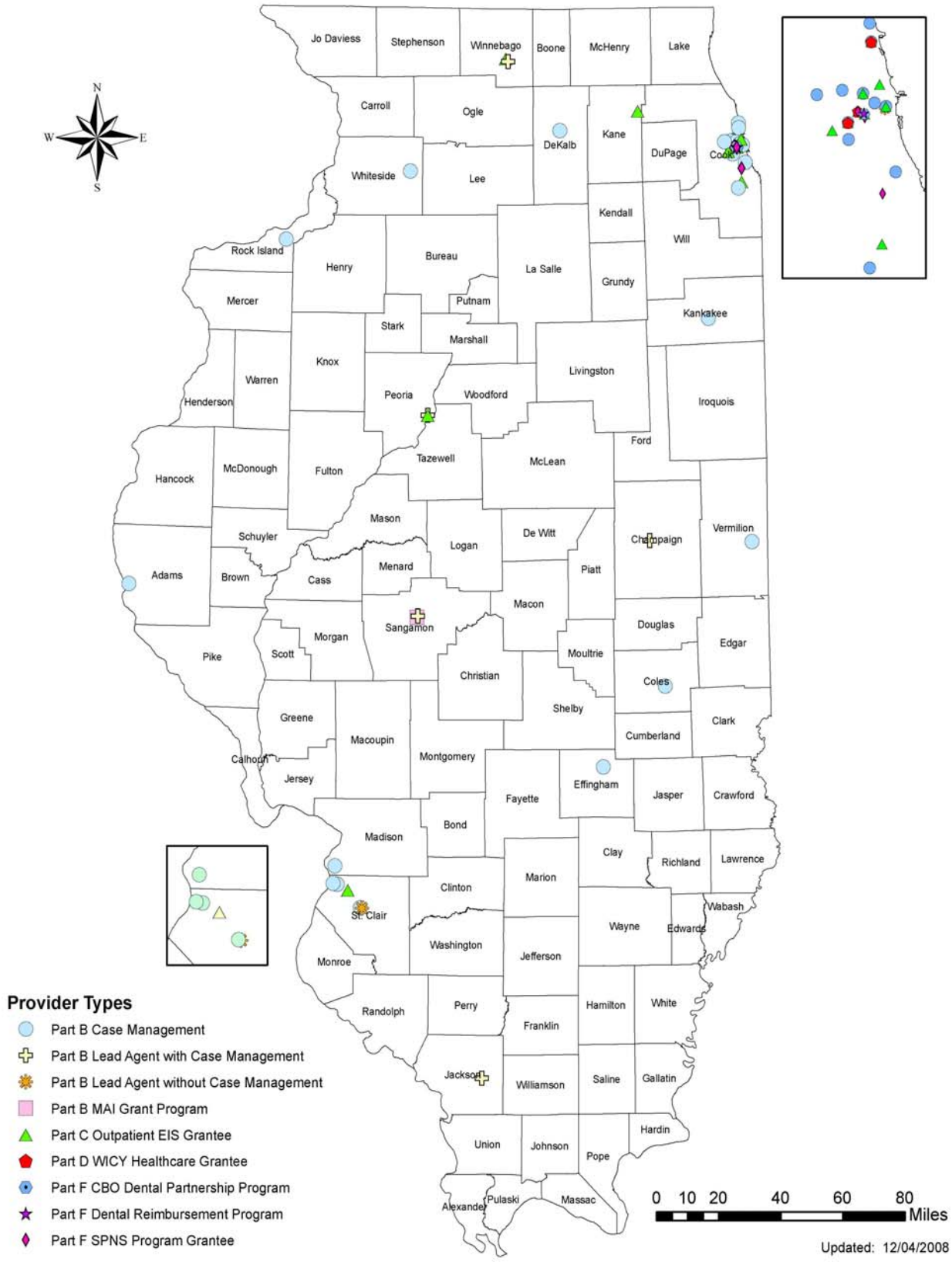
Illinois includes the entire Chicago Part A EMA and a portion of the St. Louis, MO TGA (Figure 2). The Chicago EMA includes the Illinois counties of Cook, DeKalb, DuPage, Grundy, Kane, Kendall, Lake, McHenry, and Will. The St. Louis TGA includes the Illinois counties of Clinton, Jersey, Madison, Monroe, and St. Clair. The Chicago Department of Public Health and the St. Louis City Health Department, respectively, administer and coordinate Part A services. The Part B lead agencies coordinate Ryan White Part B Program funded services in counties within the EMA and TGA.

Figure 2. Illinois Eligible Metropolitan/Transitional Grant Areas



In addition to the EMA and TGA, Illinois has multiple Ryan White HIV/AIDS Program Part C and D providers throughout the state (Figure 3). Illinois has 14 Part C grantees providing primary medical care, and other clinical diagnostic services. Ten grantees are located in Chicago: Access Community Health Network, Chicago Department of Public Health, Erie Family Health Center Inc., Heartland Health Outreach Inc., Hektoen Institute for Medical Research/CORE Center, Howard Brown Health Center, Lawndale Christian Health Center, Near North Health Service Corporation, Christian Community Health Center, and University of Illinois at Chicago. Four Part C grantees are located in Downstate Illinois: Crusader Central Clinic Association in Rockford serves western Illinois; Heart of Illinois HIV/AIDS Center at UIC College of Medicine in Peoria serves central Illinois; Open Door Clinic in Elgin serves northeastern Illinois; and Southern Illinois Healthcare Foundation in Centreville serves central and southern Illinois. Heartland Cares Inc. in Paducah, Ky. provides services to clients living in southern Illinois, Community Health Care Inc. /Quad Cities Regional Virology Center in Davenport, Iowa provides services to Illinois clients living on the western border of Illinois, and St Louis Connect Care and Washington University provide services to Illinois clients living in the St. Louis TGA.

Figure 3. Illinois Ryan White HIV/AIDS Program Providers



Four Ryan White Part D providers are located in Chicago: Access Community Health Network, Hektoen Institute-Division of Adolescent HIV Program, Hektoen Institute for Medical Research at The Stroger Hospital of Cook County, and Howard Brown Health Center. Washington University in St. Louis also provides Part D services to clients in the St. Louis TGA.

Illinois' Part F Special Projects of National Significance (SPNS) program grantees are Hektoen Institute for Medical Research, the University of Illinois and the community-based organization, Working for Togetherness, each located in Chicago. The Hektoen Institute project, The CORE Center Buprenorphine (BUP) Project, is part of a multi-center demonstration study to examine different ways of providing heroin/opioid dependence treatment to HIV/AIDS patients. The study evaluation period spanned from July 2004 until December 2008. The Part F Community Based Dental Partnership Program is located in Chicago at the University of Illinois and the Dental Reimbursement Program is located at the University of Illinois in Chicago College of Dentistry.

The Midwest AIDS Training and Education Center (MATEC) at the University of Illinois at Chicago is the regional AIDS Education and Training Center (AETC) funded through Part F. MATEC conducts HIV/AIDS provider training to primary care, social services, and other interested clinicians throughout Illinois.

Service Utilization

Illinois' Ryan White Part B Program provides funding to support the following core and support services defined by HRSA:

- Core
  - AIDS Drug Assistance Program
  - Medical case management
  - Medical nutritional therapy
  - Mental health services
  - Oral health care
  - Outpatient/ambulatory health services
  - Substance abuse services—outpatient
- Support services
  - Case management services (non-medical)
  - Child care
  - Emergency financial assistance
  - Food bank/home-delivered meals
  - Housing services
  - Legal assistance
  - Medical transportation services
  - Outreach
  - Psychosocial support services
  - Rehabilitation services
  - Treatment adherence

Additionally, state general revenue funds ($1,384,068) support program costs. Ryan White Part B funds supported services for 4,895 clients in 2007. Seventy-one percent of those served were male; 49 percent were African American and the majority was between 25 and 64 years of age. Minority clients show the largest decrease in clients receiving Part B services from 2005-2007. The number of Asian/Pacific Islanders, African Americans and clients identifying more than one race declined on an average of 28.7 percent during that time frame. Of the clients receiving Ryan White funded services in 2007, 32 percent were diagnosed with AIDS. Seventy-five

percent of the clients were at or below the federal poverty level. More clients received non-medical case management services (68%) than any other Ryan White funded service. Approximately 30 percent of clients served used Ryan White Part B funds to receive outpatient/ambulatory health services in 2007. This can be attributed to many clients receiving medical care through Ryan White Part C clinics throughout Illinois.

State general revenue funds also supported ADAP ($10.2 million). The 95-drug ADAP formulary includes all of the FDA approved antiretroviral therapies. ADAP allows up to a maximum of five antiretrovirals plus a reduced dosage of ritonavir (Norvir), treatments for opportunistic diseases (up to $2,000) a month and a limited number of slots for Fuzeon and oral Valcyte. There has never been a waiting list for these drugs. During the last funding year, ADAP proposed to increase the income ceiling to 500 percent of the federal poverty level, to allow applicants with gross annual income up to $52,000 (for a household of one; for each additional person add $18,000) to participate. At time of publication, the proposal was at the governor's office.

A total of 4,990 unduplicated clients received ADAP services during the last funding year; males represent 82 percent, females 18 percent. For race/ethnicity, 41.2 percent were black, 29.2 percent were white, 23.9 percent were Hispanic, 1.3 percent Asian /Pacific Islander, and 4.4 percent other or unknown. Utilization is anticipated to total 125,000 prescriptions for the 2008 funding year.

Illinois awarded $7.6 million regionally to serve PLWHA in state fiscal years 2008 and 2009 (July 1, 2007-June 30, 2008 and July 1, 2008-June 30, 2009 respectively). The majority of funds, 42 percent are awarded to the region that carries the majority of the disease burden, Cook County and Collar counties surrounding the Chicago area. Currently, regional funding is based on living HIV and AIDS cases plus clients being served in each region. An average cost per client was determined based on regional norms that range from $1,323-3,284 per person per year. Fifty-four percent of the total funds expended on core services during fiscal year 2008 were spent on Ambulatory/Outpatient Medical Care. Twenty-one percent was spent on oral care. ADAP has expended $14.2 million thus far this fiscal year out of $27.6 million (this includes Ryan White and General Revenue Funds from the state).

Ryan White Part A funds ($23.5 million) in the Chicago EMA supported the following services in fiscal year 2008:

- Core
  - Home health
  - Hospice
  - Medical case management
  - Mental health services
  - Oral health care
  - Outpatient/ambulatory health services
  - Substance abuse services—outpatient
- Support services
  - Case management services (non-medical)
  - Emergency financial assistance
  - Food bank/home-delivered meals
  - Housing services
  - Legal assistance
  - Medical transportation services
  - Psychosocial support services
  - Substance abuse services (residential)

The EMA obligated 36 percent of the funds to outpatient/ambulatory health services with 19 providers and 13 percent to mental health services with 16 providers. Ryan White Minority AIDS Initiative (MAI) funds (nearly $1.7 million) were used to support outpatient/ambulatory health services, mental health services, outpatient substance abuse treatment services, psychosocial support services, and residential substance abuse treatment services.

Illinois clients living in the St Louis, MO TGA make up approximately 14.6 percent of the total PLWHA population in the TGA. The Part A Planning Council allotted 19.8 percent ($904,156) of the available Ryan White Part A funds ($4.5 million) to serve clients living in the Illinois counties in the TGA. The St Louis TGA supported the following services for Illinois clients in fiscal year 2008:

- Core
  - AIDS Pharmaceutical Assistance
  - Health Insurance Continuation & Co-pay Assistance
  - Medical case management
  - Medical nutritional therapy
  - Oral health care
  - Outpatient/ambulatory health services
- Support services
  - Emergency financial assistance
  - Food bank/home-delivered meals
  - Housing services
  - Medical transportation services
  - HIV treatment adherence

Ryan White MAI funds ($379,776) were used to support linkage to care case management, perinatal case management, early intervention counseling and testing, psychosocial support, oral health care, and medical transportation.

III. Illinois' Demographics and Epidemiological Profile

In 2006, the U. S. Census Bureau estimated the total population of Illinois as 12.8 million persons, a 3.3 percent increase since the 2000 U.S. Census. Chicago is the largest city in the state, with a population of 2.8 million persons, a 2.2 percent decrease since 2000. Chicago is home to 22 percent of the state's total population. It is located in the state's most populated county – Cook County. Cook County, excluding Chicago, has a population of 2.4 million. The five counties bordering Cook County (often referred to as "collar counties" include DuPage, Kane, Lake, McHenry and Will) all rank within the top seven most populated counties in Illinois. According to the 2006 U.S. Census data, the racial and ethnic composition data estimated the Illinois population as 79.3 percent white, 15 percent black, 4.2 percent Asian, 0.3 percent American Indian and Alaskan Native, 0.1 percent Native Hawaiian and other Pacific Islander, and 1.1 percent identified two or more races. Persons of Hispanic origin comprise an estimated 14.7 percent of the total population.

In 2000, the median age of Illinois residents was 34.7 years. Twenty-six percent of the population was younger than 18 years of age; 12.1 percent of the population were 65 years or older. The proportion of females in the overall population was and continues to be slightly higher than the proportion of males (50.8 percent vs. 49.2 percent).

Epidemiological Profile

According to Kaiser Family Foundation State Health Facts, Illinois ranked sixth nationally for cumulative AIDS cases in 2006. New York, California, Florida, Texas, and New Jersey have more AIDS cases. Since the beginning of the epidemic, approximately 35,000 Illinoisans have been reported with an AIDS diagnosis.

The HIV/AIDS epidemic has affected persons in all sex, age, and racial/ ethnic groups and in all regions in Illinois. This effect, however, has not been the same for all groups. In the beginning of the epidemic, the number of AIDS cases increased most sharply among white men who have sex with men (MSM). Although the epidemic disproportionately affects white MSM, recent trends suggest a shift in the HIV/AIDS epidemic toward white and Hispanic women, Blacks, and high-risk adults. More recently, there has been a shift in the epidemic toward persons ages 13-29.

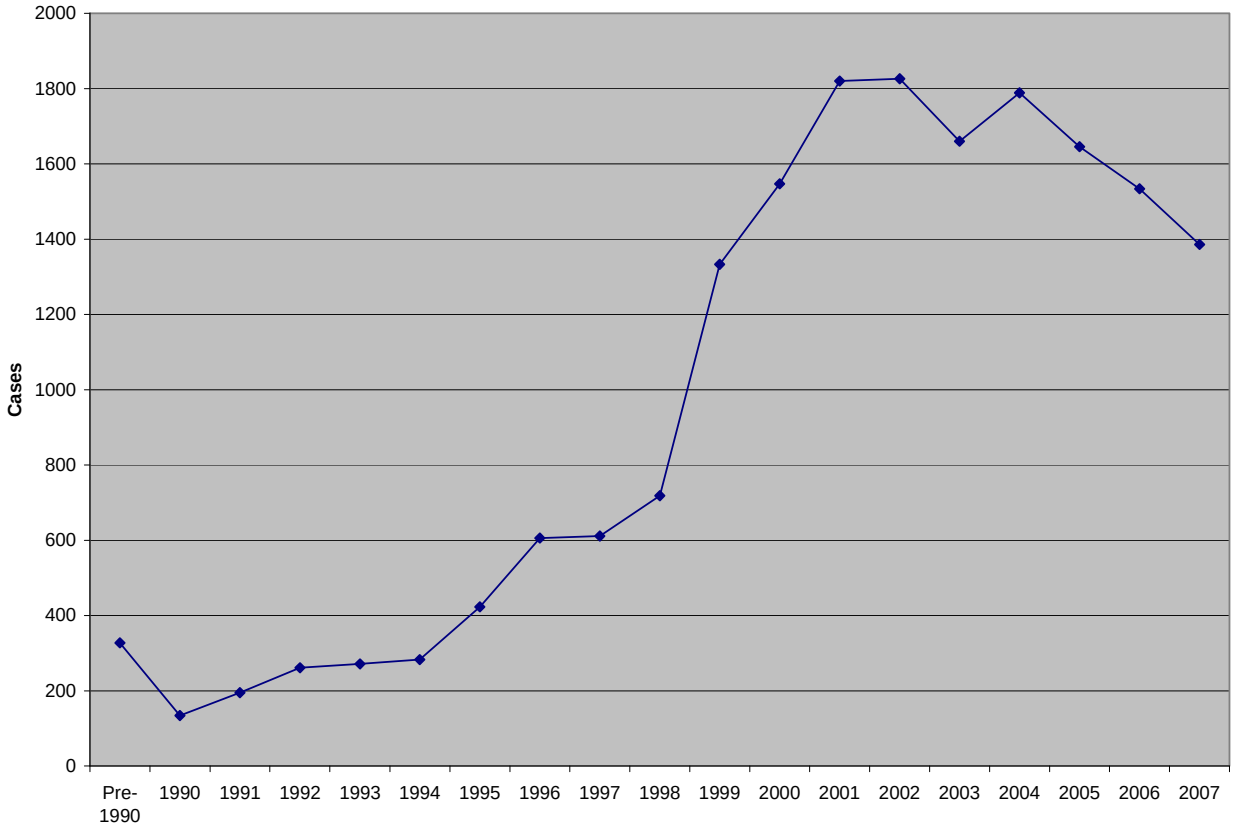
Planning for HIV prevention and care and allocating limited resources is a challenge. The epidemic continues to change, and the number of persons living with HIV continues to grow, so it is extremely important to identify those populations most affected and most at risk for HIV infection.

<u>HIV/AIDS Cases and Trends</u>

This section provides a brief description of demographics, risk characteristics of HIV-positive persons, and trends from 1999-2007 in the statewide epidemic. Unless otherwise noted, all data come from the HIV/AIDS reporting system as reported and entered through October 15, 2008.

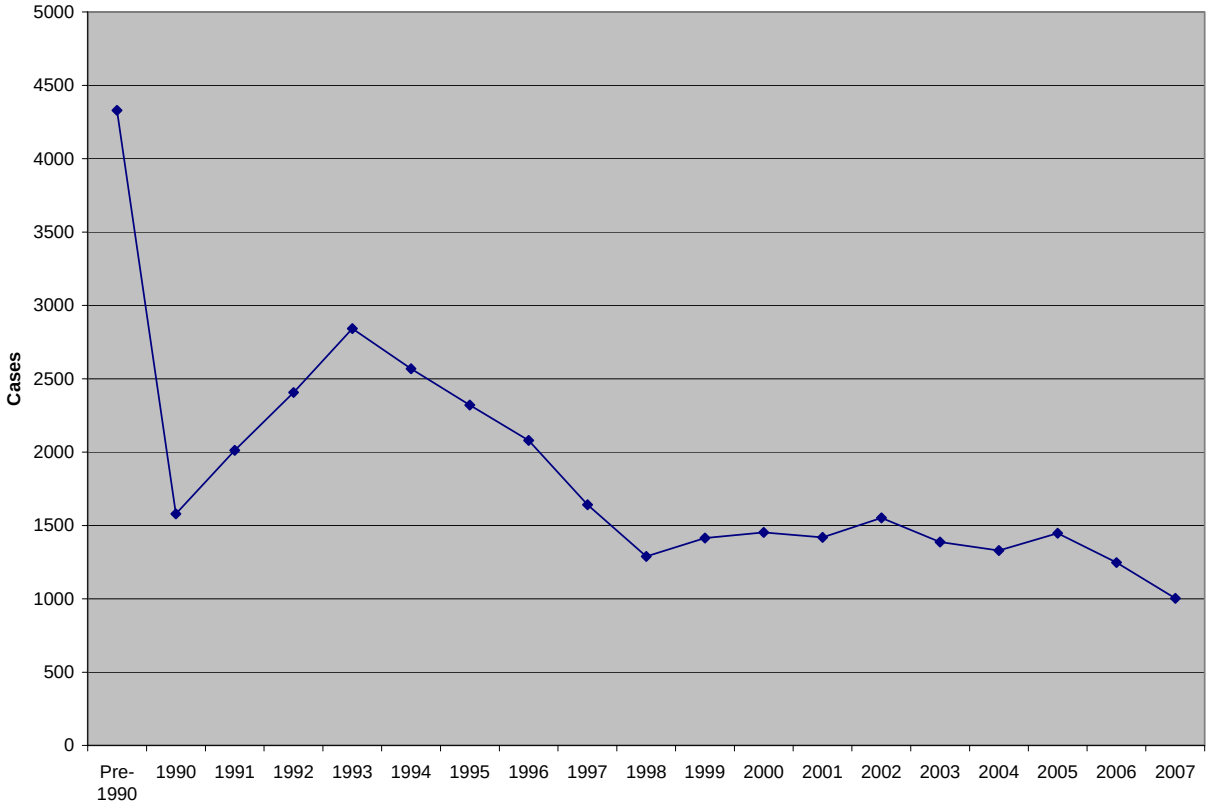
New cases of HIV steadily increased between 1990 and 2002, with the exception of a sharp increase between 1998 and 1999, coinciding with the implementation of rules requiring all HIV cases diagnosed on or after July 1, 1999 be reported using a Patient Code Number (PCN) (Figure 4). New diagnoses of HIV decreased 8 percent in 2005, 7 percent in 2006, and 10 percent in 2007. The total number of persons living with HIV through 2007 was 17,508 – up 54 percent from 11,389 in 2003.

Figure 4. HIV Cases Pre-1990 – 2007 by Year of Diagnosis



New diagnoses of AIDS have fluctuated since 1998 (Figure 5). Between 2002 and 2004, new diagnoses of AIDS decreased 14 percent. The number of new diagnoses increased 9 percent in 2005; however, new diagnoses have decreased steadily since 2005. In 2006, new diagnoses of AIDS decreased 14 percent, and in 2007, new diagnoses of AIDS decreased 20 percent. The total number of persons living with AIDS through 2007 was 16,901 – up 29 percent from 13,157 in 2003.

Figure 5. AIDS Cases Pre-1990 – 2007 by Year of Diagnosis



Through 2007, the number of cumulative living HIV cases was 17,508 (96 percent of the total cases) and the cumulative deceased HIV cases was 800 (4 percent of the total) (Figure 6). Through 2007, the cumulative number of persons living with AIDS was 16,901 (52 percent of the total) and the cumulative number of people who died with AIDS was 16,723 (48 percent of the total) (Figure 7).

Figure 6. Cumulative HIV Cases Through December 31, 2007

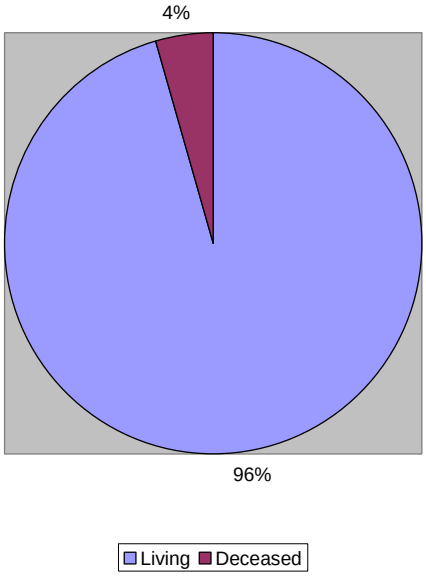
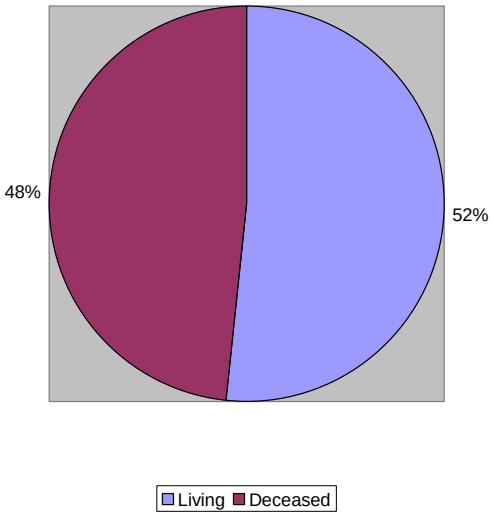
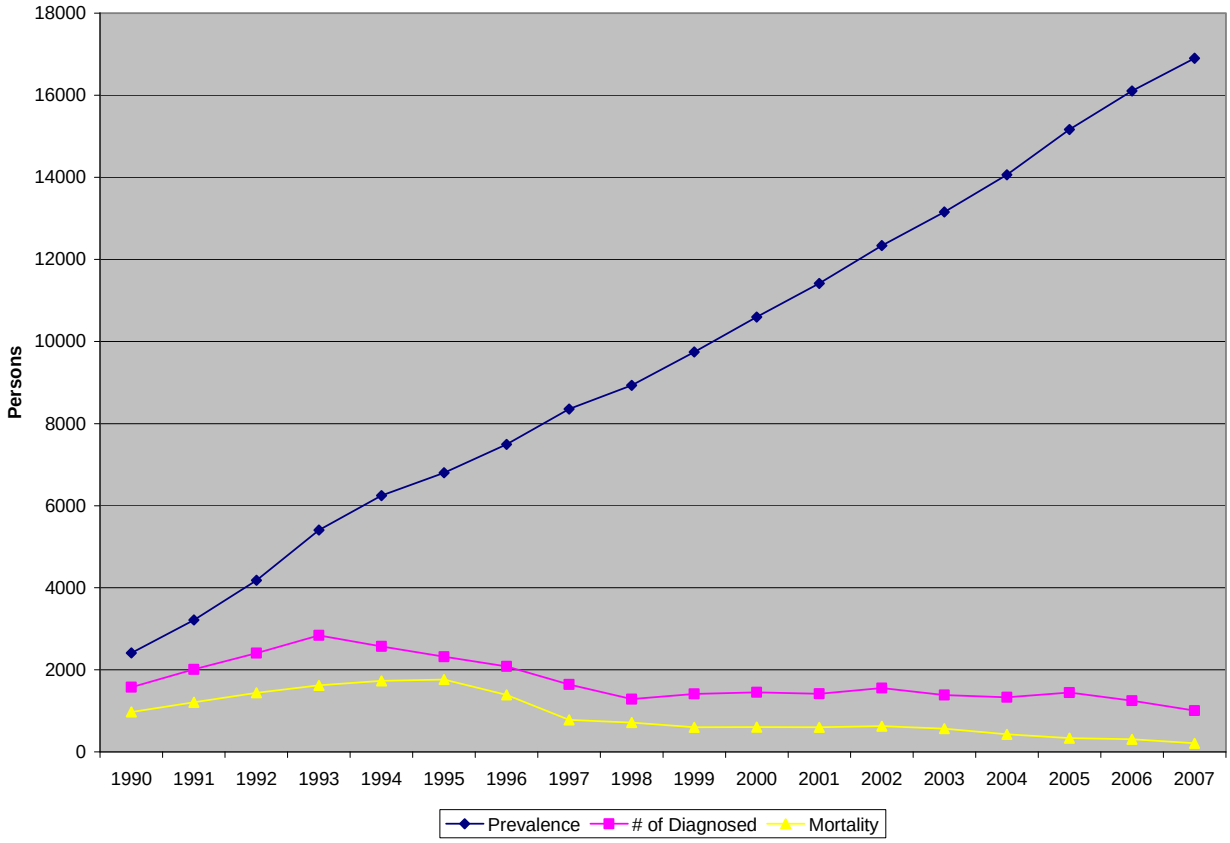


Figure 7. Cumulative AIDS Cases Through December 31, 2007



Mortality in AIDS cases peaked in 1995 and declined through 1999 (Figure 8). Mortality increased slightly between 2000 and 2002, and has declined each year since that time.

Figure 8. AIDS Comparison of Number Diagnosed, Prevalence, and Mortality by Year of Diagnosis

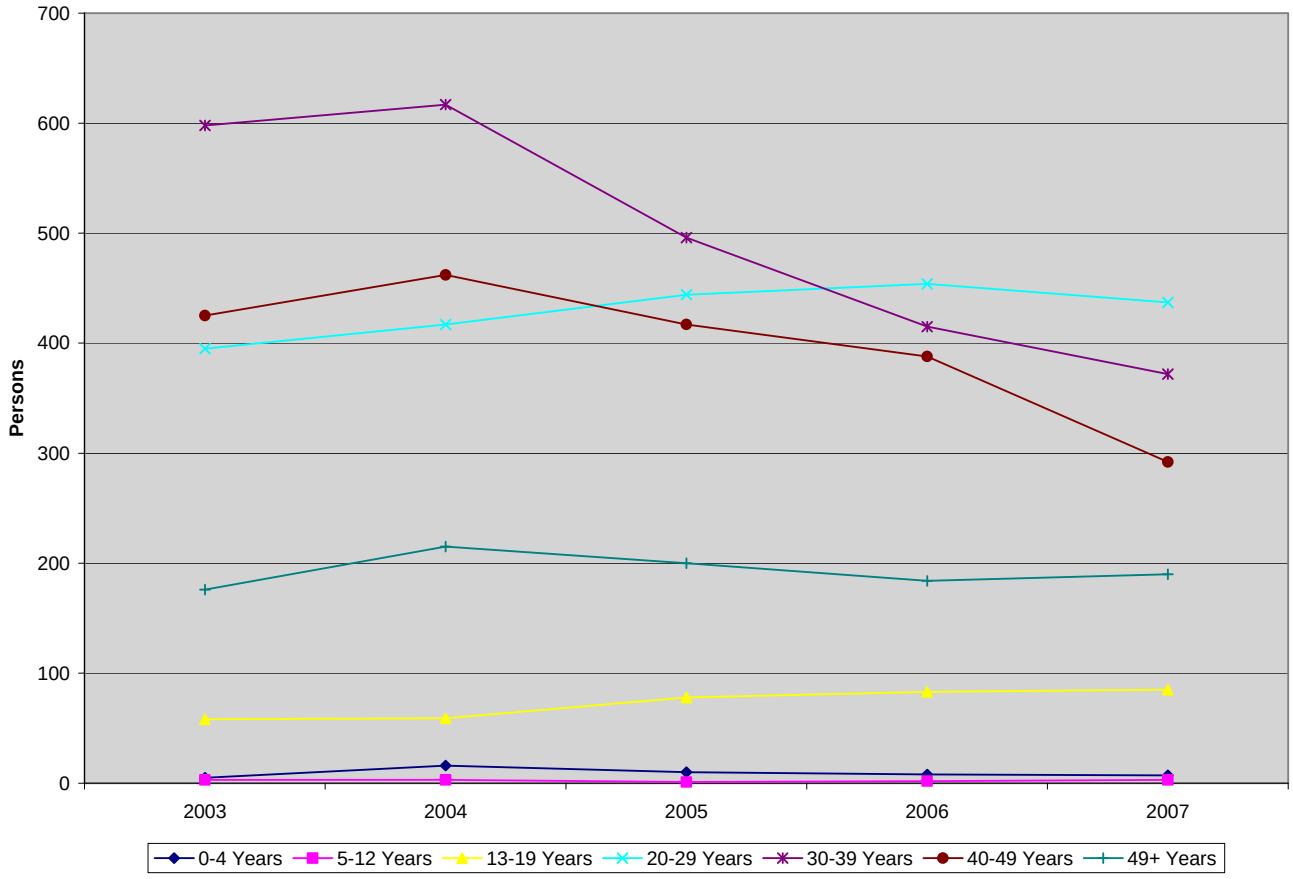


Trends in HIV cases by age group show that almost every age group experienced an increase in HIV diagnoses between 2003 and 2007 (Figure 9). Since 2004, each age category, with the exception of 13-to 19-year-olds and 20-to 29-year-olds, experienced a decrease in HIV diagnoses. From 2003 to 2007, diagnoses in 13-to 19-year-olds increased 47 percent, from 58 persons in 2003 to 85 persons in 2007. Diagnoses in 20-to 29-year-olds increased 11 percent, from 395 persons in 2003 to 437 persons in 2007. Diagnoses in 30-to 39-year-olds decreased 38 percent, from 598 persons in 2003 to 372 persons in 2007. Diagnoses in 40-to 49-year-olds decreased 55 percent, from 425 persons in 2003 to 292 persons in 2007. Diagnoses in individuals older than 49 years of age increased 8 percent, from 176 persons in 2003 to 190 persons in 2007. Diagnoses in children younger than the age of 5 and those aged 5-to 12-years remained relatively unchanged with seven and three cases diagnosed in 2007, respectively (compared to five and three cases diagnosed in 2003, respectively).

In 2003, 20-to 29-year-olds accounted for 24 percent of all new HIV diagnoses. By 2007, 20-to 29-year-olds accounted for 32 percent of new HIV diagnoses. In 2003, 30-to 39-year-olds accounted for 36 percent of all new HIV diagnoses. By 2007, 30-to 39-year-olds accounted for 27 percent of new HIV diagnoses. The percent of new HIV diagnoses among 40-to 49-year-olds decreased from 26 to 21 percent between 2003 and 2007, while the percent of new HIV diagnoses among persons older than the age of 49 increased from 11 to 14 percent.

Children older than the ages of 0 and 4 and 5 and 12 consistently account for less than 1 percent of new diagnoses between 2003 and 2007. Adolescents ages 13 to 19 accounted for 4 percent of new HIV diagnoses in 2003 and 6 percent of new HIV diagnoses in 2007.

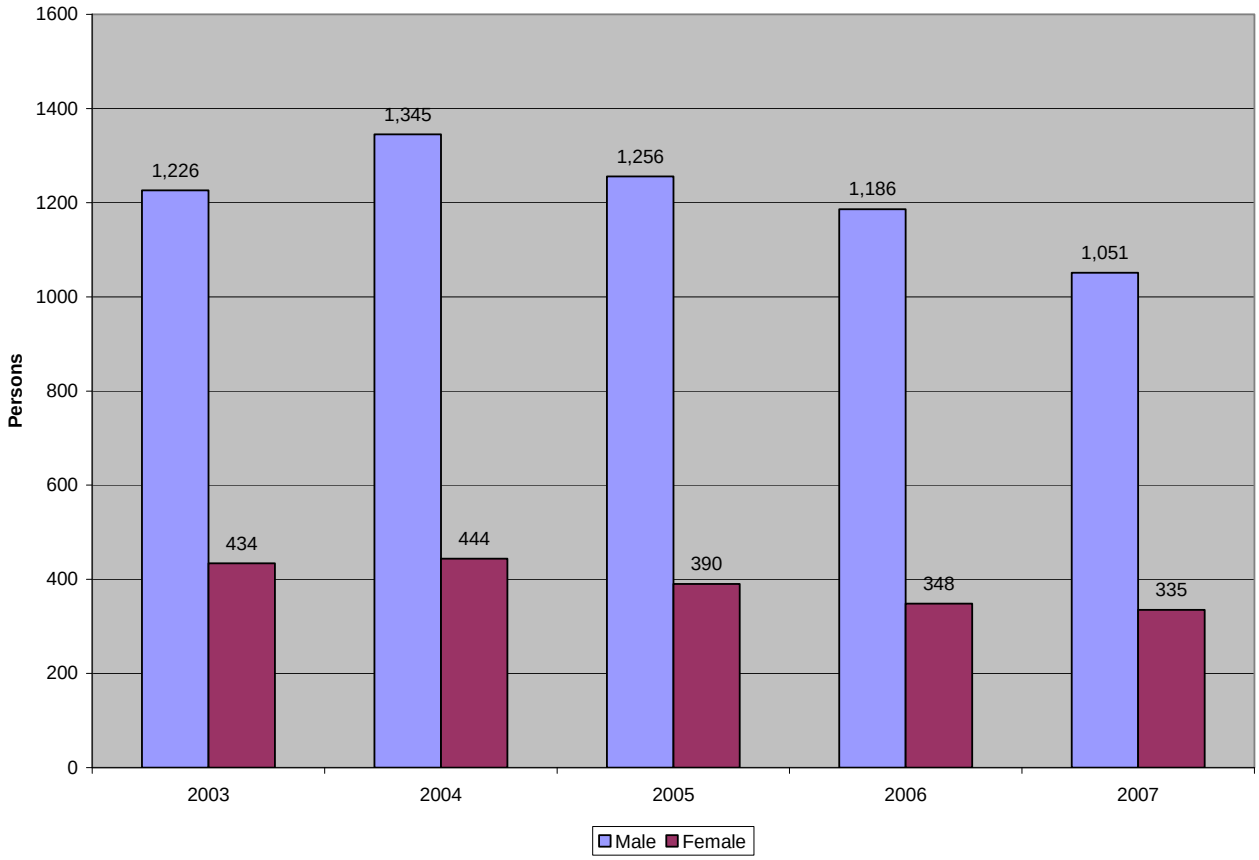
Figure 9. HIV Trends in Age by Year of Diagnosis



Trends by gender show HIV cases diagnosed in males and females steadily decreased from 2004 to 2007 (Figure 10). Male diagnoses decreased 22 percent, from 1,345 males in 2003 to 1,051 males in 2007. Female diagnoses decreased 25 percent, from 444 females in 2004 to 335 females in 2007.

In 2003, males accounted for 74 percent of new HIV diagnoses; females accounted for 26 percent. In 2007, males accounted for 76 percent of new HIV diagnoses; females accounted for 24 percent.

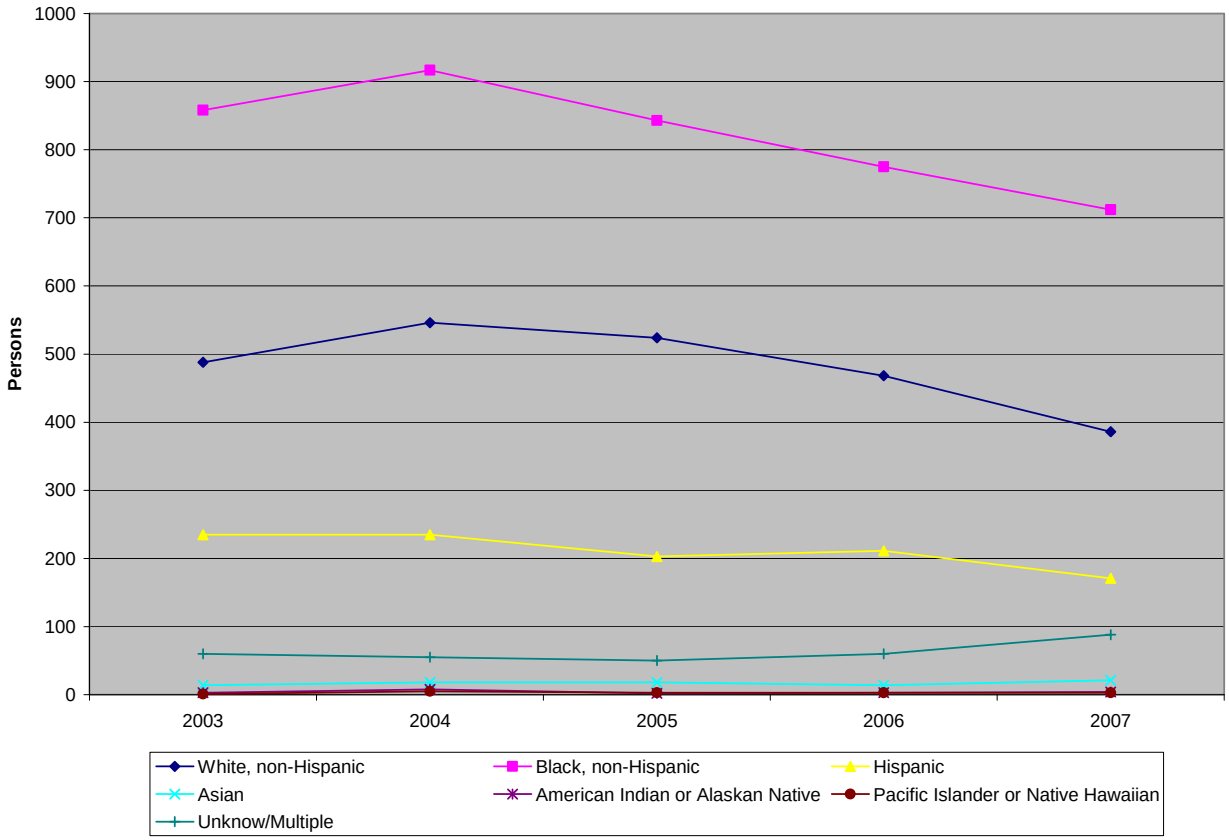
Figure 10. HIV Trends in Gender by Year of Diagnosis



HIV cases diagnosed by race/ethnicity show an overall increase in each category, with the exception of Hispanics, from 2003 to 2004, and an overall decrease among each category, with the exception of Asians, between 2004 and 2007 (Figure 11).

From 2004 to 2007, white, non-Hispanic diagnoses decreased 29 percent, from 546 persons in 2004 to 386 persons in 2007. Black, non-Hispanic diagnoses decreased 22 percent, from 917 persons in 2004 to 712 persons in 2007. Hispanic diagnoses decreased 27 percent, from 235 persons in 2004 to 171 persons in 2007. Asian diagnoses increased 17 percent, from 18 persons in 2003 to 21 persons in 2007. Pacific Islander or Native Hawaiian diagnoses decreased 40 percent, from five persons in 2004 to three persons in 2007. American Indian or Alaskan Native diagnoses decreased 50 percent, from eight persons in 2004 to four persons in 2007. Unknown or multiple race/ethnicity diagnoses increased 47 percent, from 60 persons in 2003 to 88 persons in 2007.

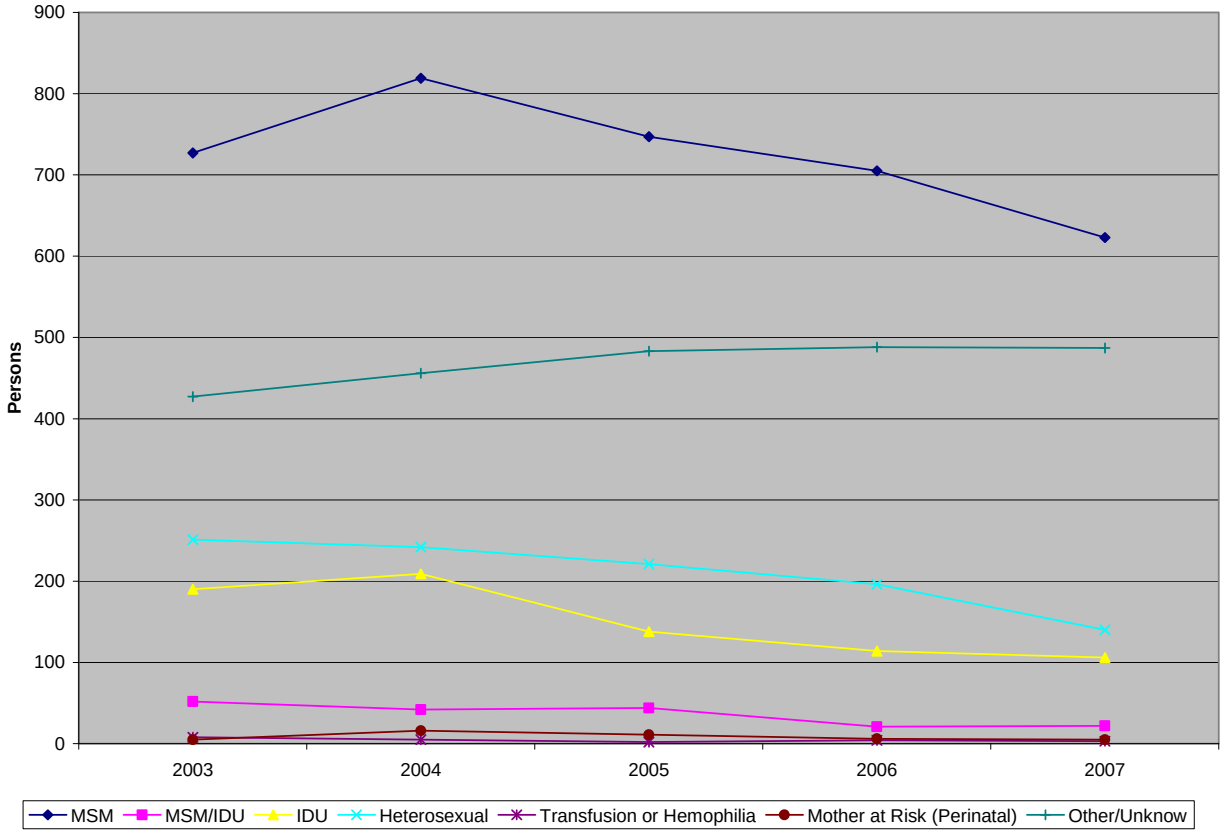
Figure 11. HIV Trends in Race/Ethnicity by Year of Diagnosis



White, non-Hispanics accounted for roughly 29 percent of new HIV diagnoses between 2003 and 2007; black, non-Hispanics accounted for roughly 52 percent. Hispanics accounted for roughly 13 percent of new HIV diagnoses between 2003 and 2007 while Asians, Pacific Islanders or Native Hawaiians, and American Indians or Alaskan Natives accounted for roughly 1 percent.

HIV cases diagnosed by risk of transmission show an overall increase for MSM, IDUs and mother at risk/perinatal exposure between 2003 and 2004 (Figure 12). From 2004 to 2007, diagnoses among all groups decreased.

Figure 12. HIV Trends in Risk by Year of Diagnosis

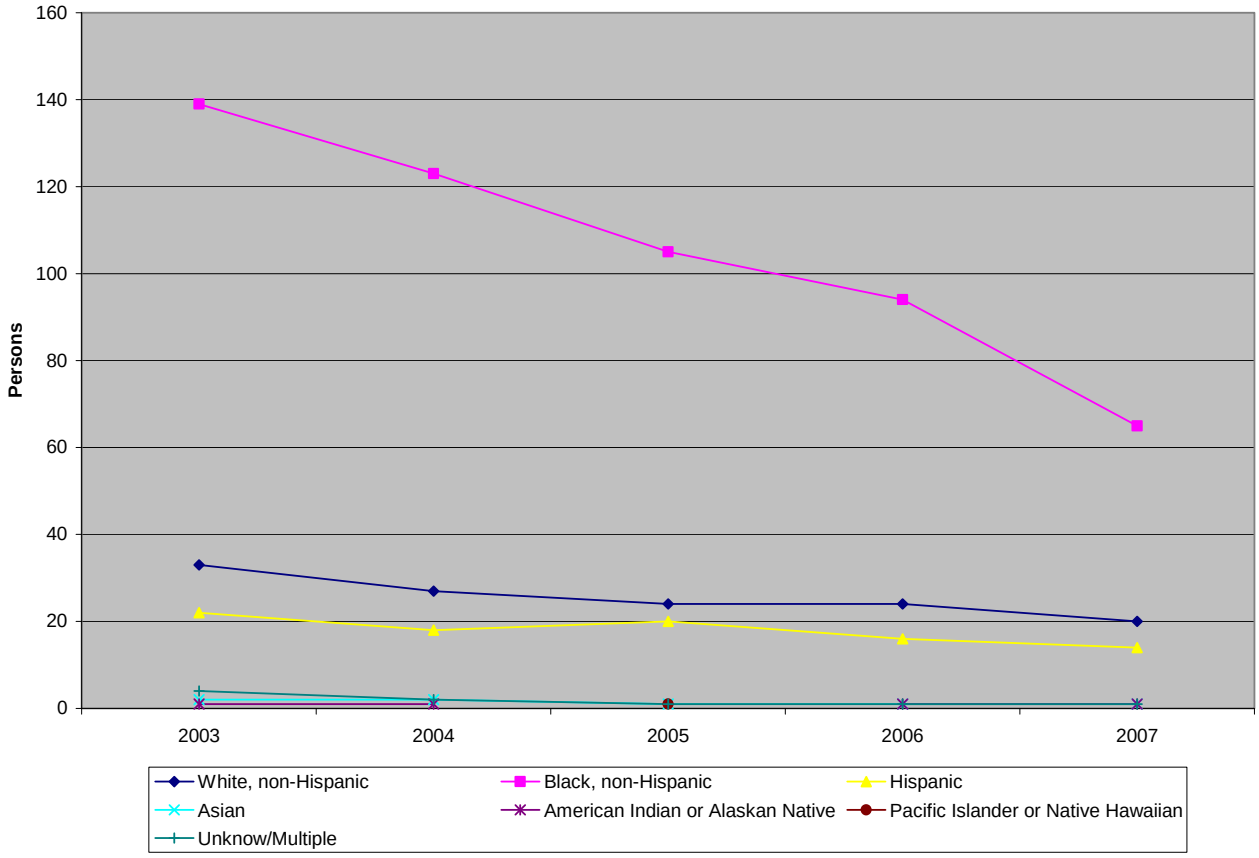


Diagnoses for MSM decreased 24 percent, from 819 persons in 2004 to 623 persons in 2007. Diagnoses by heterosexual exposure decreased 42 percent, from 242 persons in 2004 to 140 persons in 2007. Diagnoses for injection drug users (IDUs) decreased 49 percent, from 209 persons in 2004 to 106 persons in 2007. Diagnoses for MSM/IDUs decreased 48 percent, from 42 persons in 2004 to 22 persons in 2007. Diagnoses for mother at risk/perinatal exposure decreased 69 percent, from 16 persons in 2004 to five persons in 2007. Diagnoses for transfusion or hemophilia decreased by 40 percent, from five persons in 2003 to three persons in 2007. Diagnoses for other or unknown exposure risk increased 14 percent, from 427 persons in 2003 to 487 persons in 2007.

In 2003, MSM accounted for 44 percent of new HIV diagnoses. By 2007, MSM accounted for 45 percent of new HIV diagnoses. In 2003, heterosexual exposure accounted for 15 percent of new HIV diagnoses. By 2007, heterosexual exposure accounted for 10 percent of new HIV diagnoses. IDUs accounted for 11 percent of new HIV diagnoses in 2003. By 2007, IDUs accounted for 8 percent of new HIV diagnoses. The percentage of all new HIV cases attributed to MSM/IDUs remained relatively unchanged at 2 percent between 2003 and 2007. Between 2003 and 2007, the percentage of all new HIV cases attributed to mother at risk/perinatal exposure, or transfusion or hemophilia, was less than 1 percent for each category. The percentage of all new cases with unknown exposure risk increased from 26 percent in 2003 to 35 percent in 2007.

Analysis of cross tabulations of HIV diagnosis in females revealed the largest decrease by gender, risk of transmission, and race/ethnicity. Black, non-Hispanic heterosexual females experienced the largest decrease of HIV cases diagnosed from 2003 to 2007 (Figure 13). Black, non-Hispanic heterosexual female diagnoses decreased 53 percent, from 139 persons in 2003 to 65 persons in 2007. White, non-Hispanic heterosexual female diagnoses decreased 39 percent, from 33 persons in 2003 to 20 persons in 2007. Hispanic heterosexual female diagnoses decreased by 36 percent, from 22 persons in 2003 to 14 persons in 2007.

Figure 13. HIV Trends for Heterosexual Females by Race/Ethnicity by Year of Diagnosis



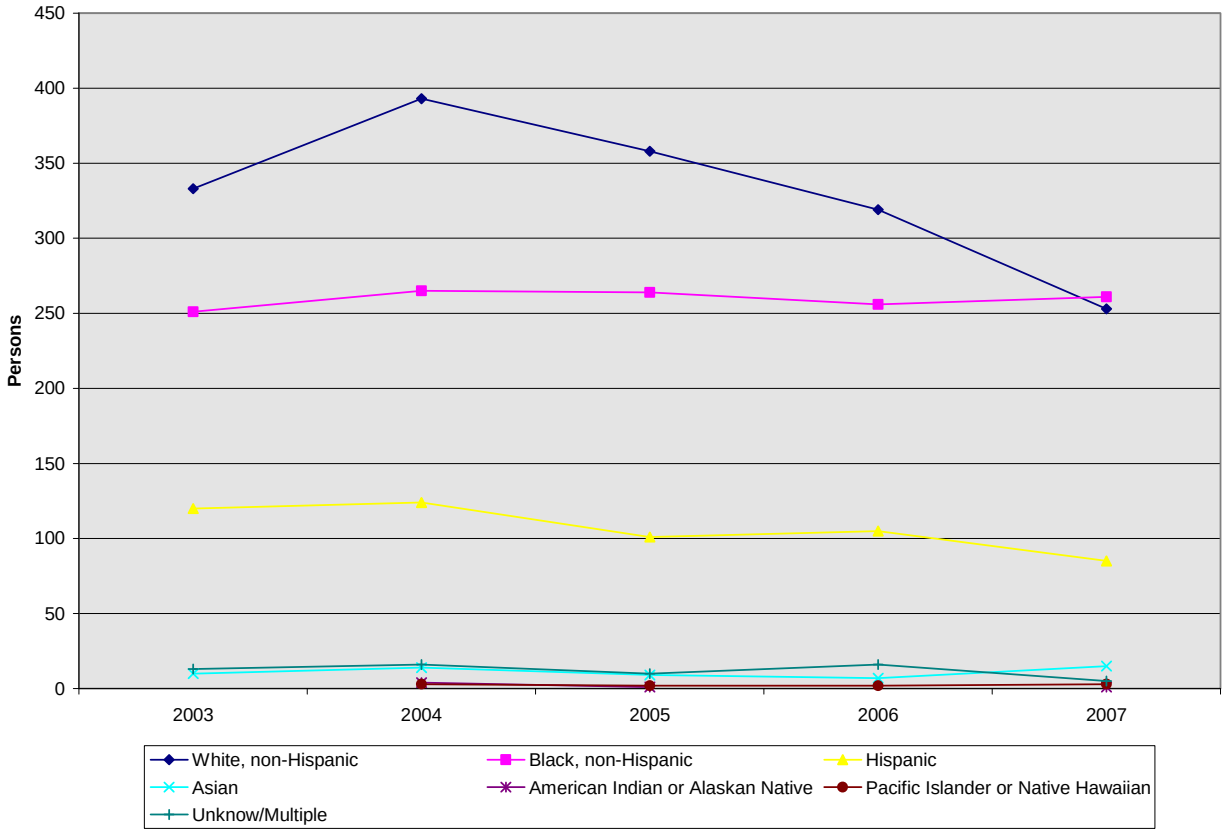
In 2003, black, non-Hispanic females accounted for 69 percent of all HIV diagnoses attributed to heterosexual exposure among women. By 2007, this number decreased to 64 percent of all such diagnoses. In 2003, white, non-Hispanic females accounted for 16 percent of all HIV diagnoses attributed to heterosexual exposure among women. By 2007, this number increased to 20 percent of all such diagnoses.

Cross tabulations of HIV diagnosis in males revealed the largest decrease by gender, risk of transmission, and race/ethnicity. White, non-Hispanic MSM experienced the largest decrease of HIV cases diagnosed from 2004 to 2007 (Figure 14). White, non-Hispanic MSM diagnoses decreased by 36 percent, from 393 persons in 2004 to 253 persons in 2007. Hispanic MSM diagnoses decreased 31 percent, from 124 persons in 2004 to 85 persons in 2007. Black, non-Hispanic MSM diagnoses decreased 2 percent, from 265 persons in 2004 to 261 persons in 2007.

In 2003, white, non-Hispanic males accounted for 46 percent of all HIV diagnoses attributed to MSM. By 2007, this number decreased to 41 percent of all such diagnoses. In 2003, black, non-Hispanic males accounted for 34 percent of all HIV diagnoses attributed to MSM. By 2007, this number increased to 42 percent of all such diagnoses.

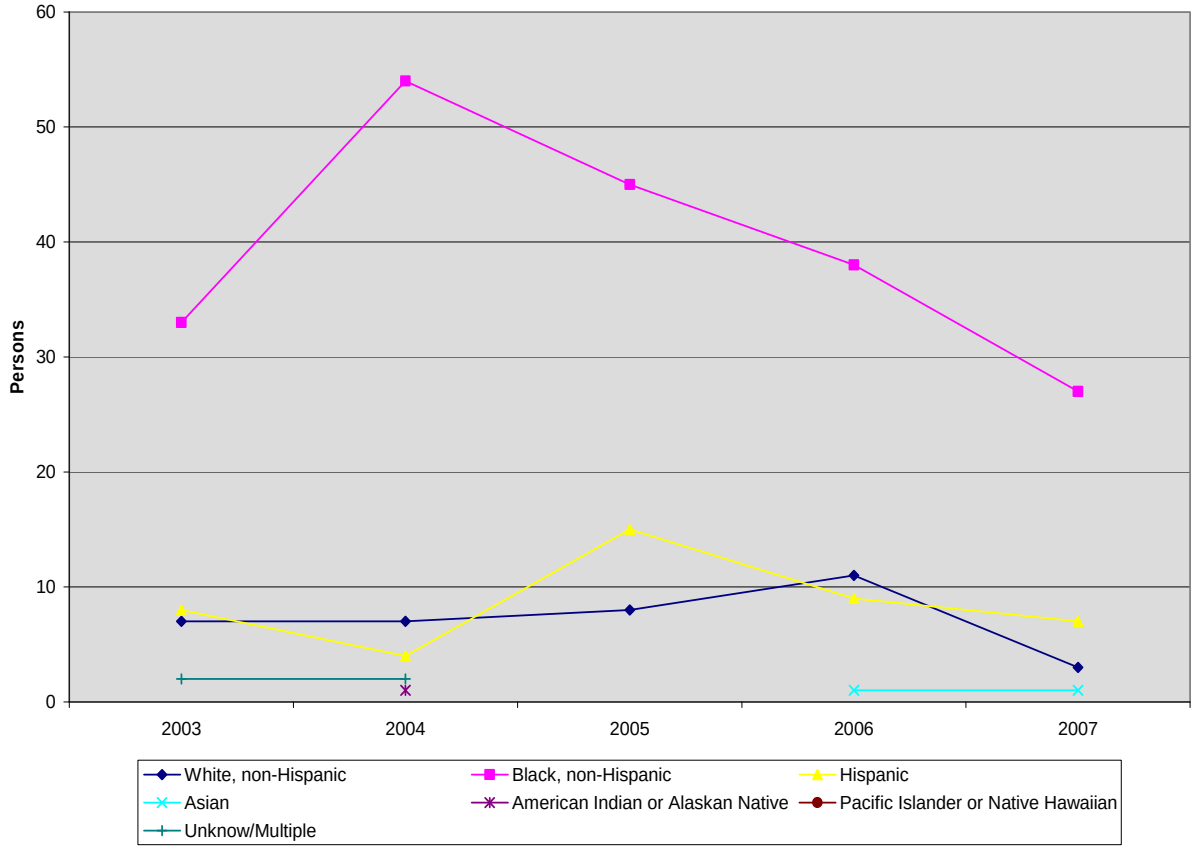
Black, non-Hispanic heterosexual male diagnoses decreased 50 percent, from 54 persons in 2004 to 27 persons in 2007 (Figure 15). White, non-Hispanic heterosexual male diagnoses increased 57 percent, from seven persons in 2003 to 11 persons in 2006, and subsequently decreased 73 percent, from 11 persons in 2006 to three persons in 2007. Hispanic heterosexual male diagnoses decreased 50 percent, from eight persons in 2003 to four persons in 2004, and subsequently increased 275 percent from four persons in 2004 to 15 persons in 2005. Between 2005 and 2007, Hispanic heterosexual male diagnoses decreased 53 percent, from 15 persons to seven, respectively.

Figure 14. HIV Trends for MSM by Race/Ethnicity by Year of Diagnosis



In 2003, white, non-Hispanic males accounted for 14 percent of all HIV diagnoses attributed to heterosexual exposure among men. By 2007, this number decreased to 8 percent of all such diagnoses. In 2003, black, non-Hispanic males accounted for 66 percent of all HIV diagnoses attributed to heterosexual exposure among men. By 2007, this number increased to 71 percent of all such diagnoses.

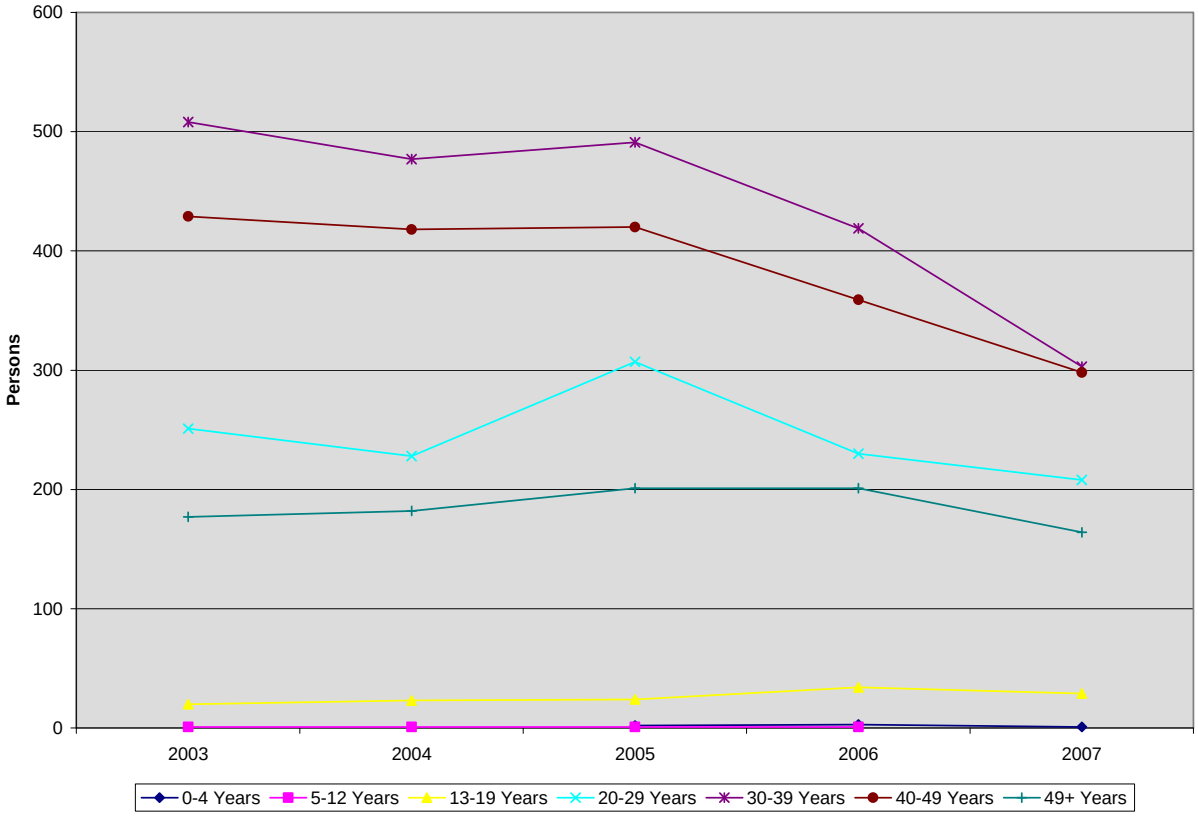
Figure 15. HIV Trends for Heterosexual Males by Race/Ethnicity by Year of Diagnosis



AIDS Cases and Trends

Since 1999, trends in AIDS cases by age group show that all age groups older than 19 experienced decreases in AIDS diagnosis (Figure 16).

Figure 16. AIDS Trends in Age by Year of Diagnosis



From 2003 to 2007, AIDS diagnoses in 20-to 29-year-olds decreased 17 percent, from 251 persons in 2003 to 208 persons in 2007. Diagnoses in 30-to 39-year-olds decreased 40 percent, from 508 persons in 2003 to 303 persons in 2007. Diagnoses in 40-to 49-year-olds decreased 31 percent, from 429 persons in 2003 to 298 persons in 2007. Diagnoses in individuals older than 49 years of age decreased 7 percent, from 177 persons in 2003 to 164 persons in 2007.

Diagnoses in children younger than the age of 5 and those aged 5-to 12-years remained relatively unchanged with seven and three cases diagnosed in 2007, respectively (compared to five and three cases diagnosed in 2003, respectively).

Diagnoses among 13-to 19-year-olds increased 45 percent, from 20 persons in 2003 to 29 persons in 2007. Diagnoses in children younger than the age of 5 and those aged 5-to 12-years remained relatively unchanged with one and zero cases diagnosed in 2007, respectively (compared to zero and one case diagnosed in 2003, respectively).

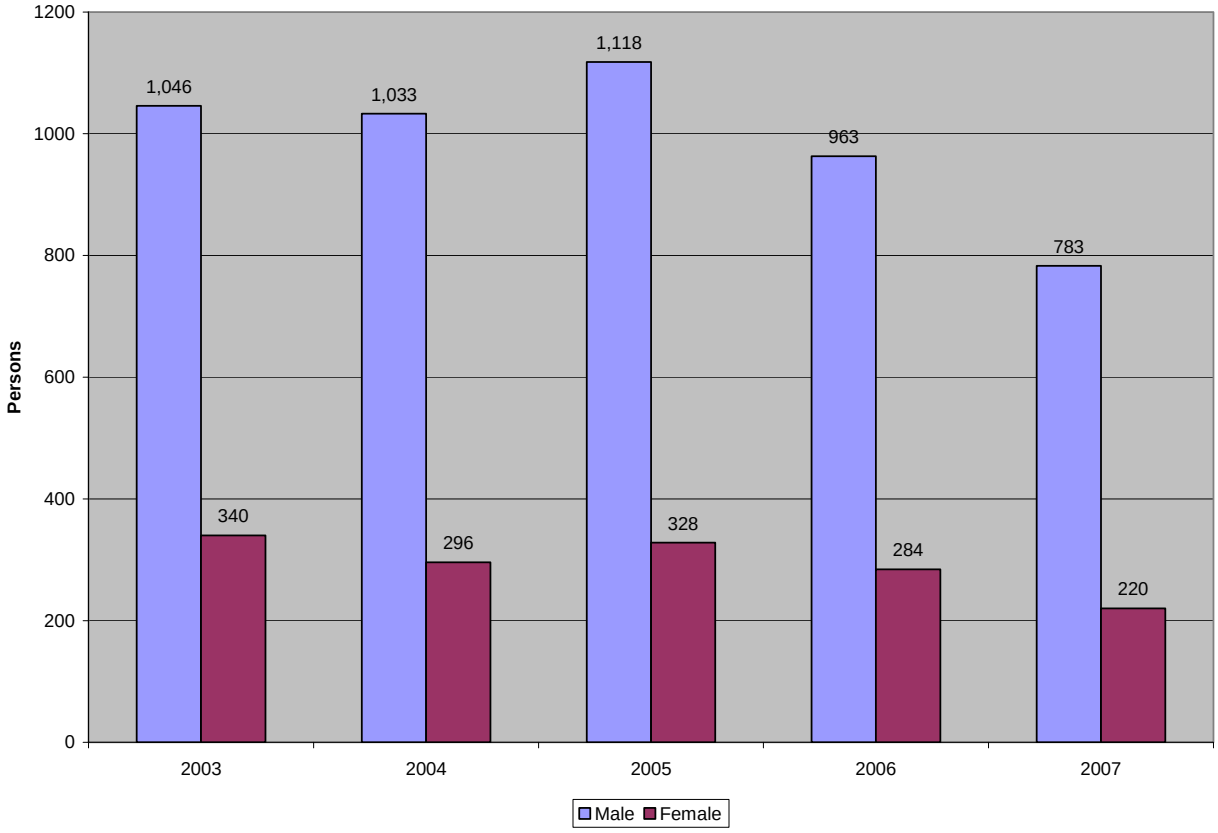
In 2003, 20-to 29-year-olds accounted for 18 percent of all new AIDS diagnoses. By 2007, 20-to 29-year-olds accounted for 21 percent of new AIDS diagnoses. In 2003, 30-to 39-year-olds accounted for 37 percent of all new AIDS diagnoses. By 2007, 30 to 39 year-olds accounted for 30 percent of new AIDS diagnoses. The percent of new AIDS diagnoses among 40-to 49-year-olds decreased from 31 to 30 percent between 2003 and 2007 while the percent of new AIDS diagnoses among ages 49 and older increased from 13 to 16 percent.

Children between the ages of zero to 4 and five to 12 consistently accounted for less than 1 percent of new diagnoses between 2003 and 2007. Adolescents ages 13 to 19 accounted for 1 percent of new AIDS diagnoses in 2003 and 3 percent of new AIDS diagnoses in 2007.

Trends by gender show AIDS cases diagnosed in males and females decreased steadily between 2005 and 2007 (Figure 17). Male diagnoses decreased 30 percent, from 1,118 males in 2005 to 783 males in 2007. Female diagnoses decreased 33 percent, from 328 females in 2005 to 220 in 2007.

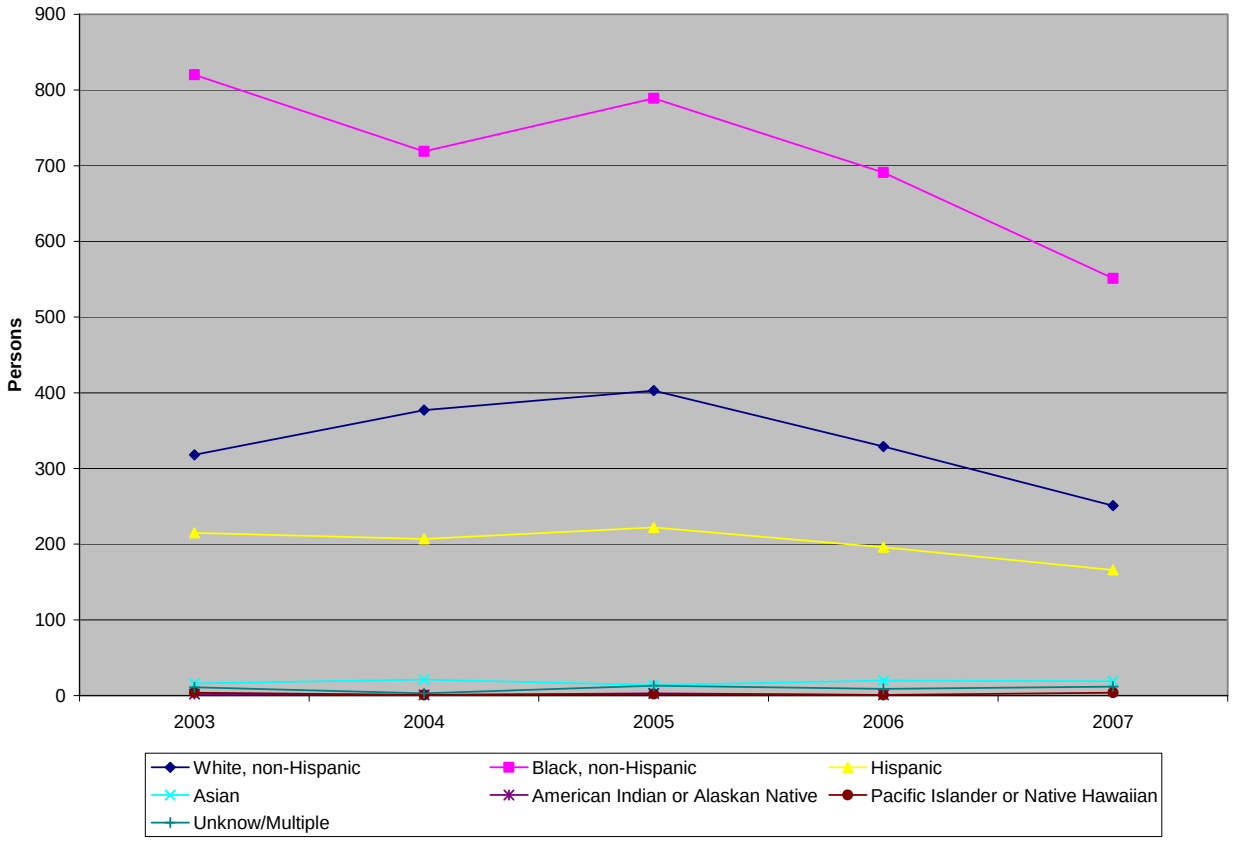
In 2003, males accounted for 75 percent of new AIDS diagnoses; females accounted for 25 percent. In 2007, males accounted for 78 percent of new AIDS diagnoses; females accounted for 22 percent.

Figure 17. AIDS Trends in Gender by Year of Diagnosis



AIDS cases diagnosed by race/ethnicity show an overall increase in each category, with the exception of Asian, from 2004 to 2005, and an overall decrease between 2005 and 2007 among each category, with the exception of Asian and Pacific Islander or Native Hawaiian (Figure 18).

Figure 18. AIDS Trends in Race/Ethnicity by Year of Diagnosis

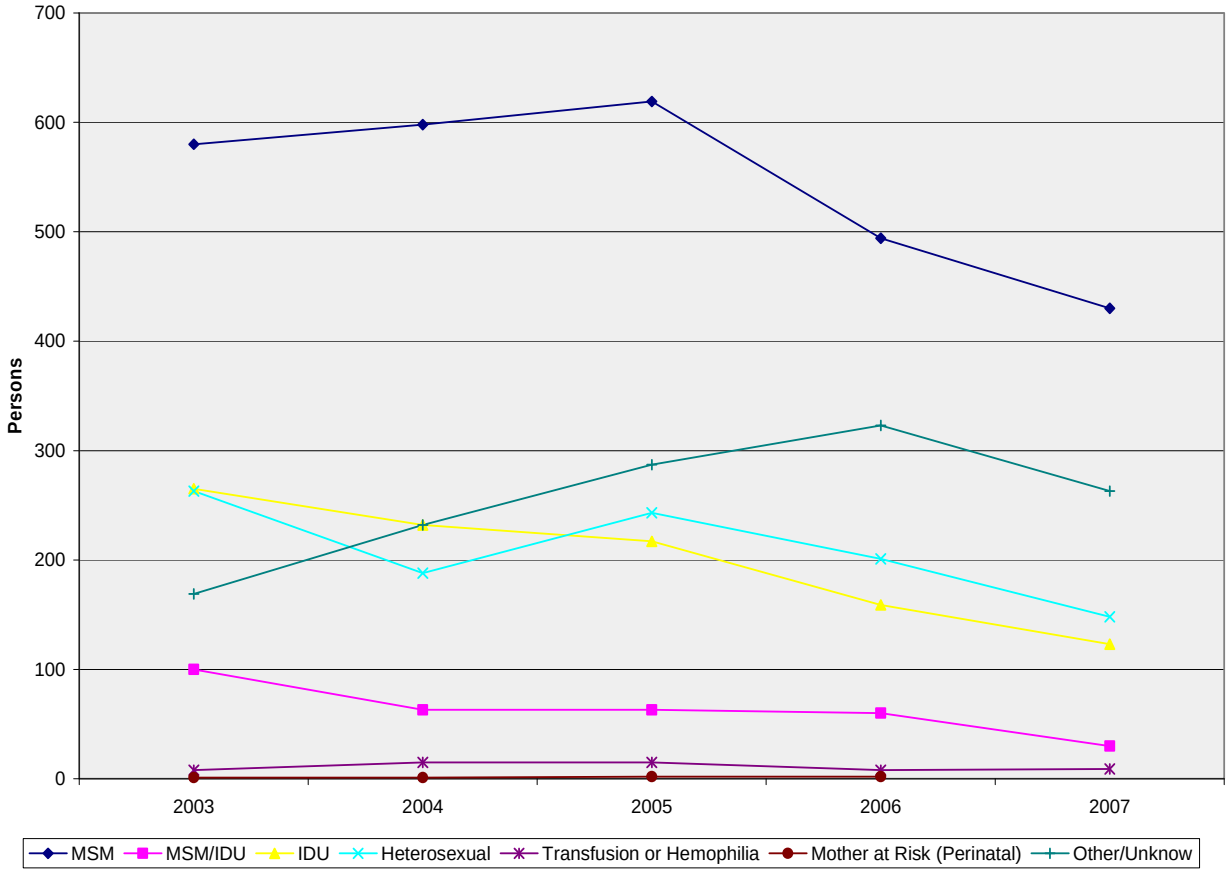


From 2005 to 2007, white, non-Hispanic diagnoses decreased 38 percent, from 403 persons in 2005 to 251 persons in 2007. Black, non-Hispanic diagnoses decreased 30 percent, from 789 persons in 2005 to 551 persons in 2007. Hispanic diagnoses decreased 25 percent, from 222 persons in 2005 to 166 persons in 2007. American Indian or Alaskan Native diagnoses decreased 100 percent, from three persons in 2005 to zero persons in 2007. Pacific Islander or Native Hawaiian diagnoses increased 50 percent, from two persons in 2005 to four persons in 2007. Asian diagnoses increased 36 percent, from 14 persons in 2005 to 19 persons in 2007. Unknown or multiple race/ethnicity diagnoses decreased 8 percent, from 13 persons in 2005 to 12 persons in 2007.

White, non-Hispanics accounted for 23 percent of new AIDS diagnoses in 2003 and 25 percent of new AIDS diagnoses in 2007. Black, non-Hispanics accounted for 59 percent of new AIDS diagnoses in 2003 and 55 percent of new AIDS diagnoses in 2007. Hispanics accounted for 16 percent of new HIV diagnoses in 2003 and 17 percent of new AIDS diagnoses in 2007. Asians, Pacific Islanders or Native Hawaiians, and American Indians or Alaskan Natives accounted for roughly 1 percent of new AIDS diagnoses in between 2003 and 2007.

AIDS cases diagnosed by risk of transmission show an overall decrease for each category between 2003 and 2007 (Figure 19). Between 2004 and 2005, diagnoses by heterosexual exposure increased 29 percent, from 188 to 243 persons.

Figure 19. AIDS Trends in Risk by Year of Diagnosis



Diagnoses for MSM decreased 26 percent, from 580 persons in 2003 to 430 persons in 2007. Diagnoses by heterosexual exposure decreased 44 percent, from 263 persons in 2003 to 148 persons in 2007. Diagnoses for IDUs decreased 54 percent, from 265 persons in 2003 to 123 persons in 2007. Diagnoses for MSM/IDUs decreased 70 percent, from 100 persons in 2003 to 30 persons in 2007. Diagnoses for mother at risk/perinatal exposure decreased 100 percent, from one person in 2003 to zero persons in 2007. Diagnoses for transfusion or hemophilia decreased by 13 percent, from eight persons in 2003 to nine persons in 2007. Diagnoses for other or unknown exposure risk increased 91 percent, from 169 persons in 2003 to 323 persons in 2006, and subsequently decreased 19 percent to 263 persons in 2007.

In 2003, MSM accounted for 42 percent of new AIDS diagnoses. By 2007, MSM accounted for 43 percent of new AIDS diagnoses. In 2003, heterosexual exposure accounted for 19 percent of new AIDS diagnoses. By 2007, heterosexual exposure accounted for 15 percent of new AIDS diagnoses. IDUs accounted for 19 percent of new AIDS diagnoses in 2003. By 2007, IDUs accounted for 12 percent of new AIDS diagnoses. The percentage of all new AIDS cases

attributed to MSM/IDUs decreased from 7 percent in 2003 to three percent in 2007. Between 2003 and 2007, the percentage of all new AIDS cases attributed to mother at risk/perinatal exposure, or transfusion or hemophilia, was 1 percent and less than 1 percent, respectively. The percentage of all new cases with unknown exposure risk increased from 12 percent in 2003 to 26 percent in 2007.

In 2002, the most recent year for which these data are available, HIV/AIDS was the ninth leading cause of death in non-Hispanic whites, the fifth leading cause of death in non-Hispanic Blacks and the sixth leading cause of deaths in the Hispanic population among persons 25 to 44 years**.** Statewide, HIV/AIDS was responsible for 9.5 percent of all deaths in blacks and 6.3 percent of Hispanics in this age group. Nearly three times as many blacks aged 25 to 44 years, compared with whites in this age group, died of HIV/AIDS.

IV. Estimate of Unmet Need in Illinois

This section presents information on unmet need for PLWHA in Illinois. The CARE Act as amended in 2000 required both Title I and Title II Grantees (now Parts A and B), as part of their applications for receiving funds, to determine the needs of persons living with HIV disease with particular attention to "individuals with HIV disease who know their HIV status and are not receiving HIV-related services." The HIV/AIDS Bureau (HAB) Unmet Need Workgroup defined the need for primary health care for such persons as "unmet need."

The unmet need framework has operational definitions for **unmet** and **met need** for HIV primary medical care. An individual with HIV or AIDS is considered to have an **unmet need** for care, or to be out of care when there is no evidence that he or she received any of the following three components of HIV primary care during a defined 12-month period: viral load (VL) testing, CD4 count, or provision of anti-retroviral therapy (ART). A person is considered to have met need (or to be in care) when there is evidence of any one of the aforementioned components in a 12-month period.

The data sources used to determine care patterns include state data sources of HARS and the ADAP database, and data from large Ryan White HIV/AIDS Program Part C and D providers serving Illinois clients from Community Health Care, CORE Center, Howard Brown Health Center, Lawndale Christian Health Center, Near North Health Services Corporation, Southern Illinois Healthcare Foundation, Heart of Illinois HIV/AIDS Center, Open Door Clinic, Heartland Cares and Erie Clinic. Illinois requires mandatory reporting of all detectible viral loads and CD4 counts below 200 or 14 percent. HARS is the most comprehensive database of viral load and CD4 count testing among people living with HIV/AIDS. Because a significant proportion of people living with HIV/AIDS receive antiretroviral medications through the state's ADAP, the ADAP database is considered to be another critical care pattern source. The CORE Center, located in Chicago, is the largest provider of comprehensive HIV outpatient care in Illinois. More than 4,000 HIV positive clients were served at the CORE Center in 2007. Howard Brown Health Center, also located in Chicago, is another large Part C entity that provided care to more than 2,000 HIV positive clients in 2007. Community Health Care and Heartland Cares are two Part C clinics just across the Illinois border, in Davenport, Iowa and Paducah, Ky., respectively, which provide services to hundreds of Illinois clients. Combined, these databases provided information on viral load testing, CD4 counts, and antiretroviral therapy. Illinois Medicaid data were not made available for analysis.

Information entered into HARS, which contains all HIV/AIDS cases reported and diagnosed in Illinois, was used to determine the population size of PLWH and PLWA in 2007, which is the most recent, complete year of HIV/AIDS case reports. As of Dec 31, 2007, there were 32,211 people living with HIV/AIDS in Illinois (16,675 PLWA and 15,536 PLWH) in 2007[1]. Each record in the data sets from the other data sources had a PCN in order to match up these records with HARS. The datasets included demographic information, such as race, gender, date of birth, ZIP code, HIV status, as well as three fields to denote whether the client had a CD4, viral load, or provision of antiretroviral therapy within the specified timeframe. Once all the data sets were

[1] The number of people living with AIDS (PLWA) and the number of people living with HIV (PLWH) include all cases in the HIV/AIDS Reporting Database.

collected, they were imported separately into a database. The datasets were then matched, one by one, to the HARS database using the PCN. If the record from the dataset matched with a record from the HARS database, the record was copied to the main dataset that would be used for the unmet need calculation. If the record did not match any record in HARS, the record was excluded from the main dataset

An analysis was performed to identify duplicate records (PCNs) in the main dataset. Once the duplicate PCNs were removed, what remained was one dataset containing unique PCNs. Unmet need was then calculated on this dataset using several programs and queries to determine how many clients had CD4, viral load, and antiretroviral therapy provided based on HRSA's definition of met need.

Framework. Department staff, including the Surveillance Unit and the DSU performed a quantitative estimate of unmet need in Illinois (Table 1). The Department consulted the HRSA recommended document, *A Practical Guide to Measuring Unmet Need for HIV-related Primary Medical Care: Using the Unmet Need Framework*, developed by the Institute for Health Policy Studies at the University of California at San Francisco to determine the unmet need for Illinois Ryan White HIV/AIDS Part B Program. This unmet need estimate framework does not include an adjustment for the proportion of persons with private medical insurance (as was done in 2003) because the source of this information (National Healthcare Cost and Utilization Project, HCUP) did not produce an estimate specifically for Illinois. Further, the possession of private medical insurance by an individual does not guarantee that his or her need was met for a particular period of time. The unmet need estimate also includes 813 individuals in the Illinois Department of Corrections that received HIV primary care in 2007. The quantified estimate of unmet need for Illinois Ryan White HIV/AIDS Part B Program is 15,781 or 49.0 percent.

Table 1. Unmet Need Estimate Framework

Input	Value	Data Source & Calculations
Population Sizes		
A. Number of persons living with AIDS (PLWA), recent time period (as of 12/07)	16,675	Based on PCN Match of Part B data to HARS
B. Number of persons living with HIV (PLWH, non-AIDS) and aware, recent time period (as of 12/07)	15,536	Based on PCN Match of Part B data to HARS
Care Patterns Among PLWA		
C1. Percent of PLWA who use private care only in a 12-month period	N/A	2007 State inpatient/discharge data among HIV+/AIDS aware from National HCUP project were not available
C2. Estimated number of PLWH/A with met need through private care in a 12-month period	N/A	A x C1
C3. Number of PLWA who received the specified HIV primary medical care services from public sources in 12-month period	9,492	Linked client data from those who received a Part A or Part B funded medical service in 2007, IDOC inmates who received medical care in 2007 (813).
C4 Number of PLWA with met need for HIV primary medical care in a 12-month period.	9,492	C2 + C3
Care Patterns Among PLWH (aware, non-AIDS)		
D1. Percent of PLWH/A who use private care only in a 12-month period	N/A	2007 State inpatient/discharge data among HIV+/AIDS aware from National HCUP project were not available
D2. Estimated number of PLWH (aware, non-AIDS) with met need through private care in a 12-month period	N/A	B x D1
D3. Number of PLWH (aware, non-AIDS) who received the specified HIV primary medical care services from public sources in 12-month period	6,938	Linked client data from those who received a Part A or Part B funded medical service in 2007, IDOC inmates who received medical care in 2007 (813).
D4. Number of PLWH (aware, non-AIDS) with met need for HIV primary medical care in a 12-month period.	6,938	D2 + D3
Calculated Results	**Value**	**Calculation**
E. Number of PLWA who did not receive specified HIV primary medical care services	7,183	= A – C4
F. Number of PLWH (aware, non-AIDS) who did not receive specified HIV primary medical care services	8,598	= B – D4
G. Total HIV+ and AIDS aware, but not receiving specified HIV primary medical care services (quantified estimate of unmet need)	15,781	= E + F
H. Percentage of Unmet Need	49.0%	= G/(A+B)

Demographic and Geographic Analysis of Unmet Need

In order to conduct a demographic and geographic analysis of unmet need, the Department utilized the raw data for the unmet need estimate (Table 2).

Table 2. Unmet Estimate for Demographic and Geographic Analysis

Input	Value	Data Source
Population Sizes		
A. Number of persons living with AIDS (PLWA), 2007	16,675	2007 HARS
B. Number of persons living with HIV (PLWH non-AIDS/aware), 2007	15,536	2007 HARS
Care Patterns		
C. Number/percent of PLWA who received the specified primary medical care services in 12-month period	9,492	2007 VL + CD4 Lab Reports + Linked Service Providers
D. Number/percent of PLWH (aware, non-AIDS) who received the specified primary medical care services in 12-month period	6,938	2007 VL + CD4 Lab Reports + Linked Service Providers
Calculated Results	**Value**	**Calculation**
E. Number of PLWA who did not receive primary medical services	7,183	16,675 – 9,492
F. Number of PLWH (non-AIDS, aware) who did not receive primary medical services.	8,598	15,536 – 6,938
G. Total HIV+/aware not receiving specified primary medical care services (quantified estimate of unmet need)	15,781	15,781 out of 32,211 or 49.0% with unmet need

The characteristics of individuals (Figure 20) show that of those with unmet need, 76 percent (12,056 out of 15,781) were men and 24 percent (3,743 out of 15,781) were women. Women living with HIV or AIDS were more likely to not receive care than men living with HIV or AIDS (52.5 percent for women versus 48.0 percent for men).

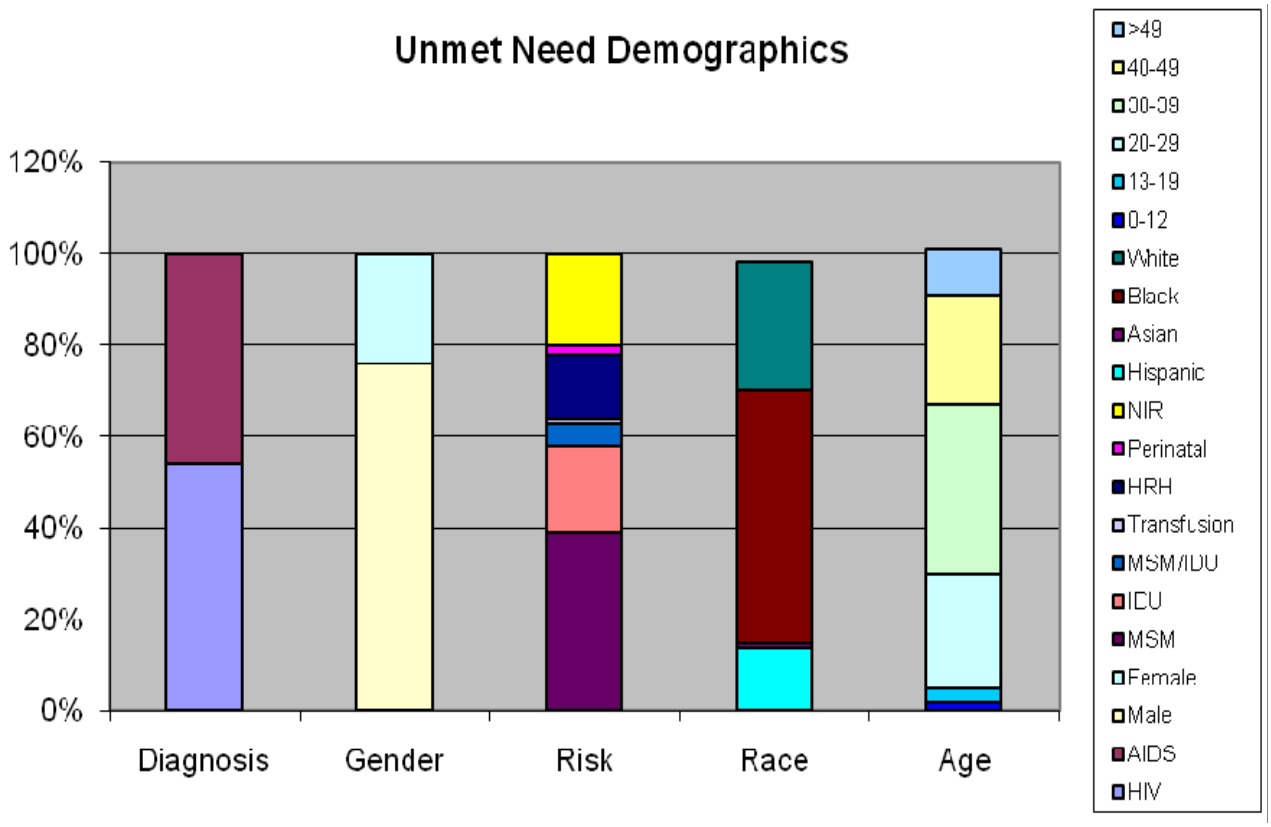
Of the 32,211 people living with HIV or AIDS, 16,150 or 50.1 percent were non-Hispanic blacks and 10,410 or 32.3 percent were non-Hispanic whites. The race/ethnicity with the largest percentage of unmet need was non-Hispanic blacks with 8,600 individuals or 53.3 percent. Hispanics had 2,187 people or 47.0 percent with unmet need. Non-Hispanic whites had 4,495 people or 43.2 percent with unmet need.

By age category, 37.6 percent or 12,114 of PLWH/A were 30 to 39 years of age, followed by 40 to 49 years of age with 25.2 percent or 8,098 people, and 20 to 29 years of age with 23.7 percent or 7,643 people. Approximately 75 percent (245) of the children aged zero to 4 years had unmet need, followed by 5 to 12 years of age with 54.7 percent or 41 people, and 20 to 29 years of age with 50.6 percent or 3,866 people.

When examining unmet need by risk groups, 46.0 percent of PLWH/A were MSM, 16.4 percent were IDU, and 14.2 percent were heterosexual. Individuals with the risk factor of mother

with/at-risk for HIV infection had the largest percentage of unmet need at 72.7 percent or 245 out of 337 total cases, followed by IDU at 57.5 percent or 3,032 out of 5,273 cases, and transfusion/hemophilia at 53.2 percent or 151 out of 284 cases, and heterosexuals with 49.5 percent unmet need or 2,265 out of 4,573 total cases.

Figure 20. Characteristics of Those with Unmet Need



The breakdown of the percentage of PLWH/A, separately and combined, shows the unmet need by the most current HIV Care Consortia region (Table 3). Clients with the largest percentage of unmet need were those reported in the Effingham region or southeast area of the state (63.5 percent); those with the smallest percentage of unmet need were reported in the Peoria region (41.0 percent), located in central Illinois, and served by a Ryan White Part C clinic.

Table 3. Unmet Need Estimate by Care Consortia Area of Diagnosis

	Consortium Area	Total	Met Need (HARS + Linked Providers)	Unmet Need (HARS + Linked Providers)	Percent Unmet Need, Linked Estimate
PLWH	Champaign Region	374	150	224	59.9%
	Collar Region	1,082	498	584	54.0%
	Cook Region	12,190	5,460	6,730	55.2%
	Effingham Region	135	37	98	72.6%
	Jackson Region	246	96	150	61.0%
	Peoria Region	304	154	150	49.3%
	Rock Island Region	121	65	56	46.3%
	Sangamon Region	412	136	276	67.0%
	St. Clair Region	418	214	204	48.8%
	Winnebago Region	250	128	122	48.8%
	County Unknown	4	0	4	100.0%
	Total	**15,536**	**6,938**	**8,598**	**55.3%**
PLWA	Champaign Region	460	267	193	42.0%
	Collar Region	1,449	822	627	43.3%
	Cook Region	12,711	7,261	5,450	42.9%
	Effingham Region	166	73	93	56.0%
	Jackson Region	198	105	93	47.0%
	Peoria Region	394	258	136	34.5%
	Rock Island Region	134	72	62	46.3%
	Sangamon Region	423	214	209	49.4%
	St. Clair Region	417	225	192	46.0%
	Winnebago Region	320	194	126	39.4%
	County Unknown	3	1	2	66.7%
	Total	**16,675**	**9,492**	**7,183**	**43.1%**
PLWA+ PLWH	Champaign Region	834	417	417	50.0%
	Collar Region	2,531	1,320	1,211	47.8%
	Cook Region	24,901	12,721	12,180	48.9%
	Effingham Region	301	110	191	63.5%
	Jackson Region	444	201	243	54.7%
	Peoria Region	698	412	286	41.0%
	Rock Island Region	255	137	118	46.3%
	Sangamon Region	835	350	485	58.1%
	St. Clair Region	835	439	396	47.4%
	Winnebago Region	570	322	248	43.5%
	County Unknown	7	1	6	85.7%
	Total	**32,211**	**16,430**	**15,781**	**49.0%**

V. Emerging Trends and Cross-Cutting Issues

Surveillance data, assessment data, and participation in public meetings have provided quality input regarding emerging trends and cross-cutting issues. This section describes trends noted statewide and regionally that impact the HIV/AIDS epidemic in Illinois. The trends and issues are presented in the order prioritized by the workgroups. The process to implement the recommendations is discussed in the Comprehensive Plan goals section.

Co-Morbidity/Multi-Diagnosis

A significant number of persons living with HIV/AIDS are also living with other mental and/or medical conditions that make HIV disease management more challenging. Co-infections of hepatitis C, tuberculosis, and others STDs are more common. Multiple diagnoses such as mental illness or substance abuse are common. Proactive and coordinated case management and communication are required to meet these challenges. Scarcity of resources (providers, funding, and expertise) must be considered when planning services for clients with multiple diagnoses. The priority in dealing with this trend will be to identify services and financial resources to address the growing need. Secondly, case managers and providers will need continued education and training to coordinate services and treatment.

People Living Longer with HIV/AIDS

Aging of the HIV positive population and their needs presents its own set of concerns. Question presented at the community forums and workgroups were:

- How will care reach out to older Illinoisans and how will care reach out to these individuals in culturally competent ways (age and ethnicity)?
- Has research advanced enough to address these impending issues?

Providers and long-term survivors must consider the effects of medications that have been taken for many years that may have accelerated conditions normally affected by the normal aging process. HIV is now treated as a chronic illness. Providers must be prepared to address issues with continued adherence due to treatment fatigue and the clients desire to remain in care. Quality of life issues must be considered as well for the long-term survivor. Persons diagnosed with HIV many years ago may have left the work force and now may be considering or realizing that they need to return to the workforce. Helping clients transition back to work in an ever-changing economic climate, re-establish meaningful relationships that may have suffered due to the HIV diagnosis, and manage meager incomes to maintain a meaningful lifestyle are challenging. Medical needs are not and will not be the only challenge for those living with HIV; the planning for PLWHA must be long term and considerate.

Routine Testing for HIV Infection

Routine testing may increase the burden on care services. The effects of routine HIV testing have not been seen yet, but planning for the need of more financial resources and providers is a priority in this area. Input from community forum participants suggest that much of the

information provided to the general population does not de-mystify or provide benefit of knowing your status. The benefits are not clearly stated in the public marketing and the general public is not prepared to know their HIV status if they are positive. One of the priorities in this area is to provide effective, meaningful public information that will educate the public and de-stigmatize HIV.

Uninsured/Underinsured

Increasing numbers of uninsured and underinsured is an emerging trend. According to the Henry J. Kaiser Family Foundation, 14 percent of HIV-positive persons living in Illinois are uninsured. Newly diagnosed persons may delay treatment due to concerns about medical coverage. An individual without insurance may not have adequate health care or medications. Due to the changing economy, job loss may result in loss of health and life insurance. While CHIC is available now, the increased financial burden on a health care system that will soon be in transition leaves case managers, counselors and providers on every level wondering what options will be available for clients with HIV. In addition, the working poor may not have the opportunity to have private insurance coverage. Some individuals with insurance may have insurance plans that do not cover pre-existing conditions, such as HIV or AIDS, which may result in no insurance coverage, gaps in coverage or increased premiums that may not be affordable. It is important to ensure that public benefit counselors help clients navigate the Medicaid/Medicare/Social Security Income system; ensure that clients and case managers increase their knowledge of public benefit programs and insurance options; and ensure case managers and physicians work with clients to obtain free medications through pharmaceutical assistance programs. Counselors, case managers, and providers must be well versed on the latest options and benefits and ensure clients receive the best information and assistance possible.

Focus on Primary Care and Medical Outcomes

Service trends for PLWHA have moved toward primary medical services, with less of a focus on supportive services. Medical case management has replaced case management. HRSA has developed quality assurance indicators. A standard model for service evaluation and health outcomes across providers and agencies is being implemented. Local development of continuous quality improvement (CQI) measurements and assurances of standards of care for providers is taking place and the standardized indicators for health outcomes developed by HRSA are being shared with providers. Training and continued implementation are the priorities in this area. Training will have to include the appropriate use of supportive services to supplement and enhance “core” services.

Epidemiological Data

Different population sets are emerging. People of color continue to be disproportionately impacted; diagnosis of the very young (teens and young adults) and those older than 50 is rising. Monitoring of the disease rate in the transgender population is required to accurately determine the prevention and care needs of this population. The need to identify emerging groups in Illinois, such as undocumented individuals and the impact these groups have on service provision is a must. Examination of these emerging populations is a top priority. Clients of color report a

lack of access to health care and a mistrust of health care providers. Undocumented individuals may experience limited access to service due to lack of identification and fear of exposure. The transgender population has traditionally been included in the epidemiological data of MSM. The unique needs of this population require that accurate data be collected to develop effective prevention and care services. Additionally, noted during the workgroups was that epidemiological data affects funding, however, surveillance data notes where you are diagnosed but not where you live. Epidemiological trends indicate diagnosis locations, but do not reflect current patterns for funding purposes.

Service Demands and Decreasing Resources

Level federal funding is in essence decreased funding. The cost of treatment for the newly diagnosed and sustaining treatment for those already infected will place undue burden on limited resources. While there is much discussion concerning publicly funded health care, federal resources are not increasing. There is concern that local providers will not have adequate funding to provide services to an increased client base. Fewer services will be available for more people. Clients may have difficulties understanding and dealing with decreases in services. The development of rapid testing has increased the number of newly diagnosed individuals. Now the implementation of routine testing is expected to do the same. Advances in HIV/AIDS treatment has enabled persons living with HIV to live longer, which extends the length of time a person utilizes Ryan White HIV/AIDS Program services. The greatest impact may be on clients who have developed a sense of entitlement for services that we may not be able to be provide at the same level. Clients that have multiple diagnoses, such as HIV infection, substance abuse, mental illness, or co-infections, require more services. Providers require more funding to provide these services. The Ryan White Part B Program must increase coordination and collaboration among organizations to enhance client services and minimize costs. It will be increasingly difficult to maintain adequate services with inadequate resources.

Housing Assistance for PLWHA

An on-going discussion regarding the change to limit Ryan White Short-Term Housing Assistance and the lasting effects of that change has been in the forefront this year. The trend to limit resources to a population with increasing numbers and constant need is stark. The state is struggling to meet the gap that will result from such a change. PLWHA are more affected by the poor economy, shelter services are limited. The solutions that would be considered to address the limiting of funds (i.e., returning to work) are affected by the slowing economy.
The other housing program, Housing Opportunities for Persons with AIDS (HOPWA), also is a limited resource and is used for emergency assistance.

VI. Service Gaps and Barriers

Needs Assessment

The Illinois Department of Public Health contracted with Mediacall Inc. to conduct an assessment of the needs of people living with HIV/AIDS in Illinois who receive services supported by Ryan White Part B funding. The statewide needs assessment was conducted through the use of a mail-back survey and conducting local focus groups. In addition to surveying and conducting focus groups, Mediacall, Inc. developed a resource inventory of service providers. Mediacall Inc. worked with the Department to develop the survey instrument that was hand delivered to clients along with a postage paid envelope during scheduled case management appointments. A total of 410 surveys (approximately 10% of clients in care) with valid information were returned. Focus groups were held in each of the 10 regions with 122 people participating. Focus group questions centered around four main topics: entry into care, medical care, treatment adherence, and support services. In addition to the assessment conducted by Mediacall Inc., the project directors in local regions conducted focused needs assessments in their service areas.

Annual client satisfaction surveys also are conducted to gather information on client needs and service delivery. Regional project directors use the information gathered to provide feedback to Department Part B staff and their advisory boards to determine service priorities.

Factors noted as barriers to entering or delaying entry into care included:

- The client being told he/she did not meet income qualifications to receive Ryan White funded services, but soon realizing that without the funds they would be bankrupt;
- The client's delay in getting into care because he/she did not have a detectable level of infection or did not feel sick. In some cases, denial was a factor;
- The case manager's inexperience in directing the person to the proper services;
- The client's fear of being stigmatized by being seen at the treatment center; and
- Transportation issues and the location of medical or other service providers.

Transportation services and dental care continue to be significant needs that were not being met or were very difficult to receive without significant barriers in all areas of the state. Additionally, many clients in rural areas noted the impression that the stigma associated with HIV still negatively impacted the medical services that they received. Other issues expressed during some of the focus group sessions were life expectancy, future service needs, and the impact of HIV/AIDS medications on the body and treatment of related diseases (mental health, diabetes, high blood pressure). Many participants shared that they did not know that they would live as long as they have and that they could not estimate what services would be needed in the future.

Most focus group members said they felt as though they were involved with their medical care. Their doctors freely share test results and their meanings with clients. Most felt that CD4 and viral load tests should be conducted every three months.

Almost all clients said they consider themselves adhering to their treatment schedule, although some indicated that there were barriers at times and some have been "off and on" with their treatment. Clients indicated the following as reasons that they may not always have adhered to treatment:

- Lack of transportation to medical appointments
- Services were not in their immediate area
- Too long of a wait for services
- Concerns over confidentiality or being stigmatized
- Other self-oriented barriers, such as:
    - Taking a "holiday" from medications
    - Forgetting to take medications
    - Being confused by the abundance of pills to take for various medical conditions
    - Having depression or mental health issues

Dental services appear to be both important and with significant barriers. In some areas, dentists have refused to see Ryan White-eligible patients because the reimbursement levels are being compared to "public aid" reimbursement levels, are not adequate and payments are slow. In some areas, there is only one or no dentist available. Still other clients have encountered dentists who do not want to treat a patient who is HIV positive.

Another barrier to services is transportation. Concerns exist about the limited amount of transportation reimbursement funding available and inadequate funding. Another transportation-related barrier is the inability of the lead agency to coordinate car-pooling. Clients believe the problem may be the lead agency's concern with sharing information about other clients and perhaps liability should there be an accident.

The survey indicated that dental visits had the highest percentage of individuals having "a lot" of trouble getting the service. "A lot" was indicated by circling a "5" on a five-point scale. Of the six medical services listed, the top three barriers to medical services include the absence of a particular service not provided in the client's area, the long wait for service, or the lack of transportation ("it's hard for me to get there").

The survey also asked respondents to list up to five important funded services from a given list of services. Those answers receiving more than 100 mentions include:

- Case management;
- ADAP;
- Rental assistance;
- Utility assistance;
- Dental services;
- Food bank/Home delivered meals;
- Transportation services; and
- Mental health services.

Client satisfaction surveys are conducted annually. The average return rate for surveys from 2005-2007 was 24 percent, with a two-to-one male/female return rate. Statistically, satisfaction with core services remained the same. More than 90 percent rated their satisfaction with dental, mental health, substance abuse treatment, and outpatient/ ambulatory medical care as average or above average. Less than 90 percent (83%, 88% in 2006 and 2007, respectively) rated the ease of getting a dental appointment and location of dental care as average or above average. Most indicated that they were treated courteously, that their privacy was respected and that services helped them access or remain in primary care.

A significant number of clients found legal services less than average and continued to note that they did not know where syringe exchange and methadone treatment is located. Clients found prevention services easy to access, knew where to receive counseling regarding risk reduction and felt comfortable discussing risk reduction issues with their case manager.

Prevention Needs

In 2009, the Department and the Illinois HIV Prevention Community Planning Group (PCPG) will create a new, multi-year Comprehensive Plan to detail activities to further reduce HIV infections among Illinois residents. A required component of prevention community planning, the community services assessment (CSA) will be conducted. The CSA identifies HIV prevention services currently available throughout the state, HIV prevention needs in at-risk population groups and where gaps between services and needs exist. The PCPG will prioritize and rank priority populations and sub-populations that will be targeted by services funded through federal HIV prevention dollars in 2010.

The Department will use private consultants to assist the PCPG in developing a Community Services Assessment Guidance for use by the PCPG. This guidance will describe each of the components necessary for completing the CSA, provide suggested data collection methods and tools, and approximate timelines for completion of each phase of the assessment, so that the group can develop and implement single or multi-year CSA planning cycles. The guidance will contain a review of the process and major components of HIV prevention community planning and the Comprehensive Plan, and the relationship of the CSA in the larger planning process. Definitions, purposes and detailed descriptions of the CSA and its component parts, i.e., population-based HIV community needs assessment, the resource inventory, and gaps analysis will be included, as well as flow charts illustrating the recommended steps and corresponding timelines for completing CSA processes.

For completion of the need assessment component of the CSA, the PCPG members have formed workgroups around risk populations. For 2009, four workgroups are being convened to assess risk in men who have sex with men (MSM), injection drug users (IDU), high risk heterosexuals (HRH), and transgender individuals. The first three of these workgroups also were convened in 2008. Each workgroup developed and administered approximately 1,200 surveys to individuals in high-risk subpopulations. Survey data will be supplemented in 2009 by additional surveys conducted in areas not covered by the previous survey. In addition to assessing the needs of persons who are currently receiving HIV prevention services, the workgroups intend to gather

input from high-risk individuals who are not accessing prevention services. The workgroups plan to reach these individuals through social networking and by conducting an on-line version of the survey.

Information obtained from the surveys indicated the following barriers to HIV prevention:

1. Lack of culturally and/or linguistically appropriate materials
2. Distrust of providers
3. Lack of transportation/access to services
4. Inadequate knowledge about services
5. Limited access to sterile syringes
6. Substance use and mental health concerns

The prioritized risk factors are as follows.

1. Limited use of materials to prevent HIV infections
2. Increased number of high-risk partners
3. Use of alcohol and other non-injection drugs
4. Trading sex for drugs
5. High prevalence of STDs

Metro St. Louis HIV Health Services Planning Council 2006 Case Manager Survey Results

In addition to needs assessments and client satisfaction surveys conducted throughout the state of Illinois, an assessment of services for clients that receive service through the St Louis TGA was conducted through a *Case Manager Survey* in March 2006.

Case managers were asked a series of questions regarding the characteristics of HIV positive clients they serve. Case managers (12) in Illinois indicated that they served between 30 and 59 clients (total number of clients was 452). The majority of clients were male (76.2%) and most were between 25 to 44 years of age (62.4%). Overall, the providers served more African-American clients (59.3%). Many (375) Illinois clients served in the TGA live at 200 percent or less than the federal poverty level and most speak English as their primary language. Medicaid was listed as the funding source for insurance for 48.4 percent of the clients from Illinois. The two largest HIV transmission groups were MSM and heterosexual transmission.

Missouri and Illinois case manager responses were similar for current chemical dependency and jail or prison. However, proportionally, Illinois case managers indicated having many more clients residing in rural areas, while Missouri case managers indicated having higher proportions of clients with diagnosed mental illness and homeless clients. Illinois case managers indicated that 25.5 percent of their clients had current problems with chemical dependency, 19.7 percent had been diagnosed with mental illness, 7.5 percent had been homeless in the past 12 months, and 5.1 percent had been in jail or prison in the last 12 months.

Case managers selected utility assistance first, followed by rent/mortgage assistance, case management, medical care, and transportation as services most important for their clients. Case managers identified low income housing, benefits counseling and massage therapy as services

that were needed, but not easily accessed by clients. Case managers selected HIV case management, transportation, rent/mortgage assistance, and utility assistance as the top four services needed to help clients access/stay in medical care.

Case managers were asked to identify the problems or barriers that their HIV/AIDS clients experience that prevent or deter them from accessing medical care. Their top four selections were:

- Fear of disclosure,
- Fatigue with maintenance required for HIV treatment and care,
- Ineligible for disability benefits, cost of prescription, and
- Denial of HIV/AIDS status.

Case Management Activities

At the request of the case management supervisors, a section was included in order to better document the needs of case managers and plan for improvement. Case managers were asked to identify the problems or barriers that they experience in providing case management services to HIV/AIDS clients. They could select up to six responses as needed from a presented list, with the option to write-in any additional responses. Most participants (65%) chose at least four or five responses. Difficulty contacting clients and misperception of the case manager's role in the community were the top two barriers identified.

Most case managers (11/12) indicated that they discuss prevention issues with the clients more than once a year. Case managers noted that they would like to share updated prevention information with clients and that it is easier to discuss prevention when a client is honest about their activities.

Gaps and Barriers

The SCSN workgroups identified and discussed gaps and barriers in service delivery, and strategies to address these gaps and barriers as well.

Access to Treatment

The inability to receive services for any reason would hinder access to treatment. There is a shortage of available medical and support resources, specifically oral health care throughout the state. There is a shortage of providers in some areas of the state that are willing to serve HIV positive clients. In some clinics, clients will see a different physician each time they come for an appointment. Clients have reported the frustration of repeating the same information over and over again to a different physician at each appointment. Clients report that vision care accessibility seems to be a problem as well. Some program requirements are counterproductive to access to treatment. Clients are told they must see a primary care physician before an infectious disease doctor will see them. This is an issue with payer source, i.e. Ryan White cannot pay for primary care, and many newly diagnosed clients may not have a primary care physician. Physicians accepting Medicaid or new Medicaid clients are becoming far and few

between. A lack of access to sub-specialty services like neurology and cardiology is the result of these shortages. Clients noted that there is also a shortage of female medical providers. A comprehensive continuum of women focused HIV services is needed. This is because women have such gender-specific needs that the current male model of HIV care does not adequately address.

In the area of oral health, lack of dental care, difficulty getting dentist to contract for services, and the stigma associated with HIV creates a gap.

Many variables factor into access to treatment. The availability, capacity, and knowledge of medical providers, case managers and other providers were highlighted by the workgroup participants. At each forum, participants noted a lack of specialty providers, educational opportunities for providers and the perception that some providers lack a working knowledge of treatment recommendations for persons living with HIV/AIDS. Additionally, participants recommended that the focus be placed on HIV specific curriculum and programs, incentives for providers that work in the field of HIV prevention and care; and address ways to reduce provider turn-over rates in the field. Specific concerns are noted below:

- Shortage of new physicians to specialize in treatment of HIV
- Lack of oral health providers
- Lack of training and ongoing experience with doctors and providers
- Lack of education regarding the types of medications now available to HIV positive persons
- Lack of psychiatric treatment providers
- Providers should have a better understanding of the types of Ryan White services available in the community
- Cultural sensitivity needs of the provider, whether the provider is mental health or primary care, they need to be educated
- Burnout not only for those living with AIDS but also for the service providers (loss of expertise)
- Some providers feel “stuck” because they are the only providers in the area.
- Lack of culturally competent providers, face of the epidemic has changed but not the face of the provider
- Distance between HIV clinics
- Some clinics experience problems coordinating services and resources with other programs such as Medicaid Part D carriers.
- Increase client awareness of services

Improving educational and training opportunities for providers, case managers, and clients is an ongoing objective of the Ryan White HIV/AIDS Program Part B grantee in Illinois. Providers, case managers, and clients receive annual surveys to determine training needs and annual training is coordinated with MATEC, the Ryan White HIV/AIDS Part F Provider. Recommendations from workgroup participants included recruitment of and training of medical providers and case managers, as well as offering incentives to medical providers that provide HIV care.

Confidentiality and Stigma

Fear of disclosure is still a tremendous barrier to accessing care. The stigma has created the need for tightened confidentiality, which in turn has created increased fear of disclosure and stigma. Clients experience anxiety and fear when case managers discuss the release of client information to the state. Tension increases between expectations and needs of data with fear of disclosure. HIV stigma is related to other stigmas such as substance abuse and sexual orientation.

Workgroup participants recommended education as a tool to reduce this barrier. Educate PLWHA on reporting requirements, record maintenance requirements, and state laws and rules governing the release of information, and educate providers on cultural competence to reduce stigma.

HIV-Positive Formerly Incarcerated Population

A lack of a continuum of care exists for the HIV-positive formerly incarcerated population. The formerly incarcerated may not be consistently provided with discharge planning or an assessment of needs, or linked to primary care, ADAP, or a Ryan White case manager prior to their release. Inconsistent care while incarcerated may result in acute care needs upon release. Formerly incarcerated people are not able to apply for many benefits, such as Social Security, without a state identification (ID) card, which they are not able to acquire until after their release. Clients with prior felony convictions and history of substance abuse may be ineligible for the Section 8 voucher program or public housing. The Ryan White Part B Program grantee has initiated a pilot program to determine the needs of recently released PLWHA in an effort to bridge the gap in services for this population. Increased collaboration with the parole system to ensure that the formerly incarcerated are linked to Ryan White and other care systems after release, increased education within jails and prisons about the availability of community HIV care systems, increased collaboration between Department of Corrections and Ryan White programs, and ensuring the provision of comprehensive pre-release discharge planning for all services, i.e. HIV care, housing, ADAP, etc., continue to be priorities in addressing this issue.

Available, Affordable Housing for PLWHA

Lack of available housing and decreasing financial support to sustain housing negatively affects the medical outcomes of PLWHA. Funding cuts are occurring despite the increased need for housing. The clients that need housing assistance the most are often the poorest, sickest clients and have no method to address the financial shortfall. These individuals may not be concerned about treatment adherence or medical care when they cannot pay their rent or may be on the verge of becoming homeless. Most local housing authorities have wait lists for public housing and Section 8 or wait lists that are closed. Clients living on disability income often cannot afford fair market rent. A lack of housing options may increase participation in illegal activities. State and federal budgets are not sufficient to adequately address housing needs. Limited community resources make it a challenge for clients to maintain affordable housing including utilities. Illinois has begun work with the Social Security Administration and local programs to raise awareness about “return-to-work” programs as one approach to the issue. Continued collaboration with community partners is necessary to lessen the gap in housing needs.

Transportation

Transportation is an essential service for our clients. Available community resources for transportation are limited, especially in rural areas. Without transportation, individuals are not able to access medical, case management, mental health, oral health, or substance abuse services. The unavailability of infectious disease doctors in rural areas creates more transportation problems since rural clients must travel great distances to access care. Many rural clients may not have cars or family members available for transportation. Public transportation is virtually non-existent in rural communities. Illinois will be conducting a provider profile to determine the availability of other local resources in all areas of the state. Where public transportation is not available, there may be other transportation resources that are not aware of the need and are willing to work with program. This is one step in addressing the ongoing gap in transportation.

Delivery of Services

The way services are delivered can affect treatment outcome more than any other variable. The needs assessments noted concerns with cultural competence. Workgroup participants noted issues with cultural competence and work competence. One participant noted that "…lack of knowledge among doctors and hurtful discriminatory attitudes by physicians can be detrimental to treatment adherence." Another participant noted that language barriers and not being served by people who look like you creates issues for clients in treatment. Clients served by teaching institutions listed that these institutions have several different doctors; patients see a different doctor each time and constantly have to repeat the history. Lack of sufficient staffing results in staff turnover which impacts patient attendance. It is necessary to collect basic information each time a patient is seen because there is no continuity with providers. Clients also reported problems with timely referrals from providers and that providers are not collaborating to determine ways to provide effective continuum of care.

Staff will sometimes assume that all clients speak English or that all clients can read and comprehend questionnaires. Some clients noted that being handed a long questionnaire and pen, then left to figure it out is often overwhelming and is discouraging. All clients are not empowered to speak for themselves and fear repercussion if they do.

Some participants shared a concern with the delivery of medications through ADAP. ADAP requires patients to use the mail-order pharmacies, which creates a problem for some clients. They perceive that when people go to mail-order pharmacies neither a doctor nor pharmacist is involved in their care. Participants also believe that mail-order pharmacists have little or no training regarding HIV medications or the importance of medication adherence. When clients use mail-order pharmacies; they do not receive adherence counseling. To enhance the quality of life for PLWHA, a doctor and a pharmacy must be involved in care. Another issue arises when using a local store pharmacy. At pharmacies such as those in stores, privacy can be an issue. The pharmacist may not provide necessary information about a drug and the consumer may feel hesitant about discussing medications standing at the counter. Client education in this area may relieve some of the misperceptions concerning provider knowledge. Additionally, providers of mail order pharmaceuticals should receive training to be able to answer basic questions concerning medication adherence.

Workgroup participants suggested training in the areas of cultural competence and disease management to address service delivery issues.

Quality of Life Issues

Quality of life issues may result in barriers to receiving or remaining in care. PLWHA that lack sufficient resources to meet basic living needs will not make medical care their primary focus. Resources include financial support, shelter, food, and clothing. Employability and questions concerning the loss of benefits if employed was a major topic during workgroup discussions. Some of the comments and questions posed in the discussion included:

- Employment is threatened or lost because the clients often get ill from the medication and feel embarrassed about having to get a doctors permit to return to work.
- Will a person lose their benefits (Ryan White, insurance assistance, ADAP, rental assistance) if they return to work?
- Do the benefits (self-esteem, extra money, etc) of going back to work out-weigh the possible loss of some benefits?

It is recommended that PLWHA incorporate a healthy lifestyle that includes proper diet and exercise, managing resources, and adherence to medical treatment.

Policies

Federal, state, and local laws and policies often present barriers to remaining in care. Policies governing insurance, employment, housing, benefit eligibility, etc. can be confusing and frustrating. Providers and case managers must be well versed on program requirements and policies to ensure adherence and be willing and able to assist clients as they work through requirements, guidelines, etc. to receive benefits.

VII. Comprehensive Plan

Section 1 Where Are We Now: What is Our Current System of Care?

1.1 Description of the Part B Program

The Illinois Department of Public Health is the agency responsible for administering Part B of the Ryan White HIV/AIDS Program in Illinois. In accordance with legislative requirements, the Direct Services Unit (DSU) obligates approximately 90 percent of the annual Part B award to provide services to 102 counties and approximately 5,000 PLWHA in Illinois.

The IDPH Office of Health Protection oversees the Division of Infectious Diseases, which includes the HIV/AIDS Section. The section chief has overall responsibility for the administration of the Part B base award, in addition to providing leadership and strategic planning.

The ADAP administrator has overall responsibility for the ADAP and CHIC programs. Other ADAP staff includes the client services coordinator, formulary specialist/data manager, client services support specialist, and benefits manager. The DSU administrator has overall responsibility for the Part B program operations. Other DSU staff includes the Ryan White Program coordinator, housing coordinator, direct services IT coordinator, policy coordinator, data assistant, and quality assurance coordinator. The training administrator and the training associate coordinate, develop, and implement all of the trainings and conferences, in collaboration with the DSU and other staff.

During fiscal year 2008, Illinois funded 165 agencies or individuals through contracts or subcontracts. All lead agencies and case management agencies are required annually to screen clients for eligibility for Medicaid, Medicare, veterans' health benefits, private health insurance, and other entitlement or mainstream programs, such as the Section 8 voucher program. This screening process is incorporated into the routine intake and assessment process required for all Part B clients. It enables the DSU to ensure that Part B funds are indeed the payer of last resort. Case managers are required to maintain documentation of this screening in client files, which are reviewed during quality assurance site visits.

All Part B funded service providers who offer Medicaid reimbursable services to Medicaid beneficiaries are required to be Medicaid-certified. Remote, rural areas continue to have a lack of available Medicaid certified providers and other providers unwilling to contract with the Part B program. Because of the lack of Medicaid certified primary care and dental providers, clients are sometimes forced to travel several hundred miles to receive care. Lead agencies also have been directed to contract with Medicaid certified providers to facilitate third-party reimbursement for services provided to Medicaid beneficiaries.

The lead agency and case management agencies are required to assess all clients receiving Part B services at enrollment and on an annual basis. The assessment form collects information on the client's demographics, employment status, sources of income, in addition to medical information. Case management agencies are required to document client eligibility for

Medicare, Medicaid, veteran's health care benefits, private insurance, or other insurance programs to ensure Ryan White funds are the payer of last resort. The client level database, Provide® Enterprise, requires case managers to enter and update the client's medical insurance status, ADAP status, and CHIC status.

The DSU staff is currently updating the manual. The manual includes detailed guidelines for all services and the stipulation that all clients who are Medicaid or Medicare eligible beneficiaries receive services from Medicaid or Medicare providers before accessing Part B funded services. All clients must meet the current Part B income eligibility guidelines for services, as indicated in the (Figure 21) chart.

Figure 21. Client Eligibility

Service	Yearly Maximum Expenditure Per Client	Income Eligibility Based on Individual Federal Poverty Levels (FPL) or Household Median Income (MI)
Core Services		
Medical Case Management	N/A	None
Medical Nutritional Therapy	$1,000	400% (FPL)
Mental Health Care	$2,000	400% (FPL)
Oral Health Care	$3,000	400% (FPL)
Outpatient/Ambulatory Health Care	$4,000	400% (FPL)
Substance Abuse Services-Outpatient	$2,000	400% (FPL)
Support Services		
Child Care	$500	200% (FPL)
Emergency Financial Assistance:		
Utility Assistance	$2,000 Part B (max. 7 months year*) $2,000 HOPWA (max. 21 weeks or 5 months per year*)	50% MI (household)
Food Bank/Home Delivered Meals	N/A	200% (FPL)
Housing Assistance:		
Rental Assistance	$2,000 Part B (max. 7 months per year*, 24 months lifetime total per household) $2,000 HOPWA (max. 21 weeks or 5 months per year*)	50% MI (household)
Emergency Rent	$1,000 Part B only (max. 2 payments year*)	50% MI (household)
Mortgage Assistance	$2,000 HOPWA only (max. 21 weeks or 5 months per year*)	50% MI (household)
Legal Assistance Only covers powers of attorney, do-not-resuscitate orders, or access to eligible benefits	$1,000	200% (FPL)
Linguistic Services	N/A	400% (FPL)
Medical and Support Transportation	N/A	300% (FPL)
Outreach Services	N/A	400% (FPL)
Psychosocial Support Services	$500	400% (FPL)
Rehabilitation Services Physical and occupational therapy, speech pathology, and low-vision training	$500	200% (FPL)
Treatment Adherence Outside of medical case management or clinical setting	$500	400% (FPL)
GRF Services (services only available as long as State GRF are available)		
Massage Therapy (GRF only)	$500	200% (FPL)
Permanency Planning (GRF only) Wills, trusts, or adoption/foster care assistance	$500	200% (FPL)

All persons who receive Ryan White Part B services must apply by filling out enrollment, intake, and release of information forms at the case management agency, following the medical case management model. Illinois has developed a medical case management model, which will be implemented effective April 1, 2009. The initial client intake/assessment form must be completed within 30 days of intake. All clients must be reassessed for continued eligibility annually.

1.2 Epidemiological Profile

Since the beginning of the epidemic, approximately 35,000 individuals have been diagnosed with either HIV or AIDS in Illinois. Current trends indicate a shift in the HIV/AIDS epidemic toward adolescents. Overall, infection rates among IDUs and high-risk heterosexuals have declined. In Illinois, African Americans are 15 percent of the population, but make up 52 percent of new HIV cases and 55 percent of AIDS cases. Males are 49 percent of the population and make up 76 percent of the HIV cases and 78 percent of the AIDS cases.

At the end of 2007, there were 17,508 PLWH and 16,901 PLWA with males comprising the majority of each group. This represents an increase of 2,156 PLWHA compared to the number of PLWHA in 2006, a 6.7 percent increase. The state reported 1,386 new HIV (non-AIDS) cases and 1,003 AIDS cases in 2007, representing a 9.6 percent decrease in new HIV (non-AIDS) cases and a 19.6 percent decrease in AIDS cases compared to 2006 figures.

Among racial/ethnic groups, non-Hispanic blacks represent more than one-half (53.5%) of PLWHA in 2007, although non-Hispanic blacks comprise only 15 percent of the Illinois population. Non-Hispanic blacks remain overrepresented among new HIV (non-AIDS) and new AIDS cases as well, with approximately 50 percent of new cases occurring in this group in both 2006 and 2007. In 2007, 32 percent of PLWH/A were non-Hispanic white and 14 percent were Hispanic. Among new HIV/AIDS cases, there was a slight decrease in the proportion of cases among non-Hispanic whites and an increase among Asians. The proportion of HIV/AIDS cases among non-Hispanic blacks was unchanged between 2006 and 2007.

Looking at the current ages of PLWHA, the largest proportion of persons are between the ages 35 to 44 years (33%); however, there is also a large proportion between 45 to 54 years (32%). About 27 percent of PLWH are younger than 35 years-old, compared to just 12 percent of PLWA. While this age differential most likely represents the fact that HIV infection takes time to progress to AIDS (resulting in an older population living with AIDS), there is some evidence to suggest a shift toward a younger population being infected with HIV: in 2007, persons aged 13 to 34 years comprised 20 percent of PLWHA but represented 42 percent of new case reports of HIV/AIDS.

In regards to exposure categories among PLWHA in 2007, MSM continues to contribute the largest proportion of cases overall (46%), with IDU the next-largest category, accounting for 17 percent of cases. The combination category MSM/IDU contributed another 5 percent of cases. Since reporting of exposure category remains incomplete for new HIV/AIDS cases reported in 2007, the 2006 data may be more reliable for examining trends in exposure category. In 2006, there was a small decrease in the proportion of new cases attributed to IDU (down 2% from

2005). Newly reported cases attributed to perinatal transmission represent less than 1 percent of all cases in 2006. However, the proportion of newly-reported HIV/AIDS cases with "risk not specified" remains quite high (29%). Some of these cases will likely be re-assigned to other categories upon further investigation by surveillance staff.

Black, non-Hispanic heterosexual females experienced the largest decrease of HIV cases diagnosed from 2003 to 2007. In 2003, black, non-Hispanic females accounted for 69 percent of all HIV diagnoses attributed to heterosexual exposure among women. By 2007, this number decreased to 64 percent of all such diagnoses. In 2003, white, non-Hispanic females accounted for 16 percent of all HIV diagnoses attributed to heterosexual exposure among women. By 2007, this number increased to 20 percent of all such diagnoses.

Black, non-Hispanic heterosexual male diagnoses decreased 50 percent from 2004 to 2007 while White, non-Hispanic heterosexual male diagnoses decreased 73 percent from 2004 to 2007. Hispanic heterosexual male diagnoses fluctuated from 2003 to 2007. In 2003 there were eight persons diagnosed with HIV. In 2004 it dropped to four, and subsequently increased to 15 persons in 2005. Between 2005 and 2007, Hispanic heterosexual male diagnoses decreased from 15 persons to seven annually.

White, non-Hispanic MSM experienced the largest decrease of HIV cases diagnosed from 2004 to 2007. White, non-Hispanic MSM diagnoses decreased by 36 percent from 2004 to 2007. Hispanic MSM diagnoses decreased 31 percent from 2004 to 2007. Black, non-Hispanic MSM diagnoses decreased two percent from 2004 to 2007. In 2003, white, non-Hispanic males accounted for 46 percent of all HIV diagnoses attributed to MSM. By 2007, this number decreased to 41 percent of all such diagnoses. In 2003, black, non-Hispanic males accounted for 34 percent of all HIV diagnoses attributed to MSM. By 2007, this number increased to 42 percent of all such diagnoses.

Special Populations

Special populations are persons who maintain a higher than average risk for contracting HIV and have been traditionally labeled as hard to reach and, therefore, hard to treat. These populations include persons with diagnosed STD infections, known substance abusers, prison populations, homeless persons, migrant farm workers and persons with pulmonary tuberculosis. These at-risk populations are profiled below.

Persons with Sexually Transmitted Diseases

Persons with sexually transmitted disease (STD) are considered to have a three to five times greater risk for HIV infection than the general population. The law requires all cases of Chlamydia, gonorrhea, syphilis, and cancroids to be reported to a local or state health department. The following tables show incidence rates for syphilis and total syphilis cases for the period January 1997 through December 2007 (Table 4-6). Similar data for incidence rates and cases of gonorrhea and Chlamydia also have been provided.

Illinois has consistently exceeded the national STD rates. In 2006 the national rate for primary and secondary syphilis was 3.3, the Illinois rate was 3.5. The national rate for Gonorrhea was

120.9 in 2006, Illinois' rate was 162.5; and the national rate for Chlamydia was 347.8 while Illinois' rate was 431.5.

African Americans continue to be disproportionately affected by reportable STDs in Illinois and nationally. Illinois' STD rates are higher in African-American men and women.

Table 4. Cases and Incidence Rates for Primary and Secondary Syphilis by Year, Illinois, 1997 – 2007

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007
Cases	435	396	422	412	409	479	374	386	525	431	464
Rates	3.8	3.5	3.7	3.3	3.3	3.9	3.0	3.1	4.2	3.5	3.7

Note: Rates are per 100,000 population.

Table 5. Cases and Incidence Rates for Gonorrhea by Year, Illinois, 1997 – 2007

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007
Cases	19,524	22,499	24,136	24,812	24,025	24,025	21,817	20,597	20,019	20,186	20,813
Rates	170.8	196.8	211.2	199.8	193.4	193.5	175.7	165.8	161.2	162.5	167.6

Note: Rates are per 100,000 population.

Table 6. Cases and Incidence Rates for Chlamydia by Year, Illinois, 1997– 2007

	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007
Cases	29,184	32,861	36,409	40,350	43,716	48,101	48,294	47,185	50,559	53,586	55,470
Rates	255.3	287.5	318.5	324.9	352.0	387.3	388.9	379.9	407.1	431.5	446.6

Note: Rates are per 100,000 population.

The Sexually Transmitted Disease numbers in Illinois are high. Coupled with the known increased risk for contracting HIV among persons with STDs, these trends suggest a clear focus for prevention efforts.

Alcohol and Substance Abusers

Illinois Department of Public Health and the Illinois Department of Human Services (DHS) Division of Alcohol and Substance Abuse (DASA) partner to provide HIV prevention education, counseling and testing in 37 DASA licensed and funded agencies. During 2007, HIV testing was provided to 9,952 clients with 87 clients testing positive for HIV. DASA providers work with local regional directors to ensure that HIV positive clients are linked to HIV medical and support services.

Homeless Population

The Illinois Department of Human Services Emergency Food and Shelter Program tracks statistics on the homeless population in Illinois. In fiscal year 2008, 45,418 homeless persons were served in shelters funded by Illinois Department of Human Services. The total identified

in the Special Need Section, which would includes those identified as HIV positive was 262 persons or .6 percent of the total homeless population.

Incarcerated Persons

The Illinois Department of Public Health Surveillance Unit currently reports 2,774 inmates with HIV/AIDS. Based on current unmet need estimates, 813 or 29.3 percent are reported as receiving medical treatment for HIV. Surveillance records indicate that 1,191 incarcerated persons with HIV identified injection drug use as their risk for HIV and 279 identified MSM as their risk for HIV. The majority (2,054) of the HIV positive individuals in the state correction system are between 25 to 44 and African American (2,106).

Persons with Viral Hepatitis

All cases of acute and/or chronic hepatitis A, B and C must be reported to the local authority under Illinois Administrative Code part 690. Surveillance for viral hepatitis is maintained by the Illinois Department of Public Health's Division of Infectious Disease Communicable Disease (Hepatitis A and C) and Immunization (Hepatitis B) Sections (Table 7).

Table 7. Incidence of Acute Viral Hepatitis

Acute Cases	Reported for United States				Reported for Illinois				Rate per 100,000*
Year	2004	2005	2006	2007	2004	2005	2006	2007	
Hepatitis A	5,683	4,488	3,579	2,708	147	130	109	118	0.98
Hepatitis B	6,212	5,494	4,713	3,936	111	157	166	129	1.09
Hepatitis C	758	694	802	722	15	3	13	16	0.09

* Number of Cases and Rates (per 100,000 persons) of Reported Acute Hepatitis A, Acute Hepatitis B, and Acute Hepatitis C in Illinois, 2004-2007

The number of reported cases of acute hepatitis A (HAV) during the years 2004-2007 ranged from 147 in 2004 to 118 in 2007, with an average annual rate of 126 cases reported. The number of reported cases of acute hepatitis B (HBV) during the same time period ranged from 111 in 2004 to 166 in 2007 with an average annual rate of 140 cases reported. Hepatitis C (HCV) became reportable in April 2001. The number of reported cases of acute hepatitis C during the years 2004-2007 ranged from 16 in 2007 to three in 2005, with an annual average of 12. Projected rates of acute hepatitis A, B, and C averaged at 0.72 cases per 100,000 (Table 5).

Burden of Chronic Hepatitis

Although it is believed that reports received of chronic hepatitis B and C greatly underestimate the true disease burden, the national estimate of chronic hepatitis B infection accounts for at least 1.3 million persons; chronic hepatitis C accounts for an additional 3.2 million persons. Approximately 4.9 percent of the U.S. population has been infected with the hepatitis B virus and 6 percent to 10 percent of those infections progress to chronic disease. According to that

formula, the true disease burden of chronic hepatitis B in Illinois is between 37,726 and 62,876 persons. In Illinois, the number of cases of chronic hepatitis B reported to the Illinois Department of Public Health ranged from 1,988 in 2005, when it became reportable; to 2,325 cases of chronic hepatitis B in 2007. Annual reports of hepatitis C ranged from 3,542 in 2004 to 7,789 cases in 2007.

The morbidity data provided in Table 6 on reported cases of chronic hepatitis B virus (HBV) and hepatitis C virus (HCV) from 2007 suggest the imperative need to raise the awareness and priority of hepatitis and continue enhancing coordination between HIV, STD, and viral hepatitis programs throughout the state.

Table 8. Selected Demographic Characteristics of Reported Cases of Chronic Hepatitis B Virus (HBV) and Hepatitis C Virus (HCV) – Illinois, 2007

	HBV Cases (n = 2,325)	Percentage Total	HCV Cases (n = 7,789)	Percentage Total
Gender				
Male	1,245	54%	4,791	62%
Female	1,080	46%	2,998	38%
Race				
Asian	497	21%	67	1%
Black/African American	212	9%	1,058	14%
Native American	6	0.2%	28	0.3%
Other/Unknown	1,265	54%	3,681	47%
White	344	15%	2,955	38%
Ethnicity				
Hispanic	70	3%	239	3%
Non-Hispanic	998	43%	3,612	46%
Unknown	1,257	54%	3,938	51%

About one-quarter of HIV-infected persons in the United States are also infected with HCV. Co-infection with HIV and HCV is common among HIV-infected injection drug users. HIV-positive persons who become infected with hepatitis B virus (HBV) and/or hepatitis C virus (HCV) are at increased risk for developing *chronic* HBV and/or HCV infections. Co-infected persons have twice the risk of cirrhosis compared to those with chronic HBV or HCV alone. Infection with HBV or HCV infections also may impact the course and management of HIV infection. The U.S. Public Health Service/Infectious Diseases Society of America guidelines recommend that all HIV-infected persons be tested for both HBV and HCV. To prevent HBV infection in HIV-infected persons, the Advisory Committee on Immunization Practices recommends universal hepatitis B vaccination of susceptible patients with HIV/AIDS. Because fulminant hepatic failure from HAV infection occurs at increased frequency among persons with chronic liver disease, persons susceptible to HAV also should receive two doses of hepatitis A vaccine.

During calendar year 2007, 100 recipients of Part B services received the Hepatitis A vaccination and 77 received the Hepatitis B vaccination.

Although up to 90 percent of HIV-1 infected persons have at least one serum marker of previous exposure to HBV, only about 10 percent develop chronic hepatitis B, as evidenced by the detection of hepatitis B surface antigen (HBsAg) in the serum persisting for a minimum of six months. In 2006, three antiviral treatments for HBV (lamivudine, adefovir, and tenofovir) were added to the ADAP formulary. During 2007, 324 ADAP recipients had documented treatment (316 were prescribed lamivudine, four were prescribed entecavir and four prescribed adefovir) against HBV chronic infection.

1.3 Response to the Epidemic

In an effort to address the continued disproportionate effect of HIV in the African American community the Illinois legislature passed the African American HIV/AIDS Response Act in 2005. The act specifically acknowledges HIV/AIDS as a crisis in the African American community. Particular emphasis is placed on the incarcerated and formerly incarcerated populations. The act also provided for financial support to local community based organizations to develop and improve infrastructure within their agencies in order to provide effective HIV prevention and care services and raise awareness in their communities.

The Department has expanded the Brothers and Sisters United Against HIV/AIDS (BASUAH) program. The program provides free rapid testing through local events designed to raise awareness about HIV/AIDS. BASUAH also has developed an online virtual world called "Second Life." In Second Life, BASUAH ambassadors practice role playing and presentations skills and hold discussion forums specifically addressing HIV/AIDS topics with others online. They also have an opportunity to explore different personas and learn what it would be like to be in someone else's shoes. A BASUAH ambassador is a peer educator trained to provide information that is understood and accepted.

Through additional legislation, Illinois has expanded the focus on prevention of perinatal transmission. Now, opt-out testing is offered to all expectant mothers. If indicated, testing may be offered later in the pregnancy. If a new mother has no record of HIV testing and her HIV status is unknown during the current pregnancy, the infant child will be tested upon delivery.

Based on the Center for Disease Control and Prevention (CDC) recommendations for routine testing, the Illinois legislature passed legislation to revise the AIDS Confidentiality Act. The revision allows for HIV testing without written informed consent and opt-out testing. Illinois Department of Public Health has taken steps to develop opt-out testing in hospital emergency departments and STD clinics and has applied for additional funding from CDC to expand routine testing in the state.

The Part B program and Prevention program are restructuring the regional boundaries to bring the Care and Prevention regions in line. By January 2010, both Care and Prevention regions will match, making planning and current services more congruent.

1.4 Assessment of Need

The assessment of need, including local client satisfaction surveys, state and regional assessments and input from regional workgroups is included in *Chapter VI. Service Gaps and Barriers*. Extensive discussion regarding assessment of need can be found therein.

1.5 Description of Current Continuum of Care

Focusing on core services as defined by HRSA, the Department strives to provide a comprehensive continuum of medical care and supportive services for persons with HIV/AIDS. Regional lead agencies provide services through the coordination of local providers and assist

local advisory boards in assessing service needs and identifying gaps in services. The ADAP policies allow for a maximum of a two-month supply of drugs to assist a client who is relocating to another state, transitioning to Medicare Part D with wrap-around benefits or while applying for COBRA continuation, if there is no other payer source for accessing prescription drugs.

1.6 Resource Inventory

An expansive resource inventory was completed in 2007 by Mediacall Inc. The resource inventory is presently in Microsoft Excel format and includes 33 color-coded tabs with more than 1,500 entries. Services can be looked up by service category. Each entry contains agency contact information, location, brief description of the agency, primary language, available services, and populations served. This resource inventory will be made available electronically.

1.7 Profile of the Ryan White Program Funded Providers by Service Category

The current HIV Care Consortia network is being restructured and will be composed of eight regions with regional lead agents throughout the state. The size and demographics of populations living with HIV/AIDS in Illinois, the needs of the populations including needs resulting from disparities in the availability of HIV-related services in historically underserved and rural communities, and the availability of other governmental and non-governmental resources are considered in the allocation of funding.

The following services have been identified as allowable Ryan White Part B services in FY2008: ADAP, CHIC, outpatient/ambulatory health services, case management, child care services, emergency financial assistance, food bank/home delivered meals services, housing assistance, legal services, medical nutritional therapy, mental health services, oral health care, outreach, psychosocial support services, rehabilitative services, substance abuse services (outpatient), transportation services, and treatment adherence services.

Focusing on core services, the Department strives to provide a comprehensive continuum of medical care and supportive services for persons with HIV/AIDS. Regional lead agencies coordinate services, manage the programs, and convene local advisory boards to assist with assessing service needs and identifying gaps in services. A brief profile of Ryan White Part B funded service providers can be found in the appendix.

The following table shows the history of service allocations in Illinois from 2006 to 2009. Using the unmet need, gaps, barrier, trends, and cross-cutting issues, the focus of services in Illinois is transitioning to focus more on core medical services and to meet the needs of clients, while remaining the payer of last resort.

Table 9. Service Allocation History

	FY2006	FY2007	FY2008	FY2009
Core Medical Services				
Outpatient /Ambulatory Health Services	$1,053,554.00	$1,144,658.52	$1,152,843.00	$1,216,727.74
Oral Health Care	$189,155.00	$246,489.92	$385,029.30	$421,049.00
Home Health Care	$0.00	$0.00	$0.00	$0.00
Mental Health Services	$369,944.00	$379,720.36	$387,865.00	$399,910.00
Medical Nutrition Therapy	$25,487.00	$0.00	$25,000.00	$38,090.00
Medical Case Management				$1,852,807.68
Substance Abuse Services–Outpatient	$152,186.00	$161,587.17	$177,789.00	$194,555.00
Support Services				
Case Management (non-Medical)	$2,042,981.00	$2,136,103.31	$2,244,157.38	$512,652.00
Child Care Services	$40,084.00	$32,175.35	$49,825.00	$0.00
Emergency Financial Assistance	$327,798.00	$354,318.86	$425,806.78	$320,933.00
Food Bank/Home-Delivered Meals	$456,448.00	$600,517.61	$526,903.18	$595,117.00
Housing Services	$658,605.00	$638,367.00	$465,655.12	$529,935.00
Legal Services	$82,755.00	$97,936.18	$102,066.06	$100,408.00
Medical Transportation Services	$152,418.00	$157,145.74	$109,929.00	$193,312.97
Outreach Services	$0.00	$59,163.61	$40,000.00	$40,000.00
Psychosocial Support Services	$43,279.00	$35,572.34	$41,512.00	$4,420.00
Rehabilitation Services	$18,573.00	$13,748.53	$2,000.00	$0.00
Respite Care	$0.00	$0.00	$0.00	$0.00
Treatment Adherence Counseling	$0.00	$169,619.70	$15,000.00	$0.00
Total Services	**$5,613,267.00**	**$6,227,124.20**	**$6,151,380.82**	**$6,419,917.39**

FY2006 - FY2007 dollar amounts are final expenditures. FY2008 and FY2009 dollar amounts are budgeted amounts.

1.8 Barriers to Care

Barriers to care that include various perspectives, policies/regulatory issues, infrastructure constraints, changes to state Medicaid/Medicare and Medicare Part D are included in *Chapter VI. Service Gaps and Barriers.* Extensive discussion regarding these barriers can be found therein.

Section 2 Where Do We Need to Go? Next Steps

2.1 Continuum of Care for High Quality Core Services

2.1.1 Shared Vision for System Changes – Operational Definition of Continuum of Care and Core Services

The vision put forth in this document is a result of input from a variety of sources. The current care system is being restructured. This system will continue to consist of geographically divided regions, but the HIV Prevention and Care regions will be congruent. The system is implementing a medical case management model that will provide coordinated medical and support services to persons living with HIV in Illinois.

How the Plan was Formulated

Preceding sections of this plan acknowledge the interrelationship and collaboration between programs funded and developed under the auspices of the Ryan White HIV/AIDS Program that provide support and services to persons with HIV/AIDS in Illinois. This section enumerates the steps taken to formulate this plan, the direction of the state in responding to the changing epidemic, and a discussion of the priorities. These priorities form the basis of the states operational definition of continuum of care.

In 2008, the Department assembled workgroups to update both the Statewide Coordinated Statement of Need and the Comprehensive Plan. These workgroup meetings consisted of representatives from all Ryan White HIV/AIDS program parts in Illinois, Part B program staff, HIV Prevention program staff, prevention providers, consumer representatives, service providers, community-based organizations, Midwest AIDS Training and Education Center (MATEC), public agency representatives, and regional lead agents project directors. An update of epidemiological data for the state was reviewed, as well as data from the most recent needs assessment. The workgroup then reviewed the goals and objectives from the preceding Comprehensive Plan, specifically examining the accomplishments.

These data guided the discussion of the development of priorities and goals for this plan, based on the emerging trends and gaps in service delivery identified in the Statewide Coordinated Statement of Need. The overarching theme and spirit of these discussions was that success of an ideal system of care to deliver HIV/AIDS services rest on the development of essential shared philosophical foundations that respect and embrace the vision and values of all stakeholders affected by HIV. These stakeholders include, but are not limited to, consumers (those infected and affected), direct service providers, administrators, and collaborators.

Vision Statement

Ryan White Part B in Illinois, with public and private community partners, will build an integrated, culturally competent continuum of state-of-the-art care and services for all HIV-infected and affected individuals, improving and maintaining their quality of life and assuring

equitable access to appropriate treatment and support services for all those impacted by HIV disease.

2.1.2 Shared Values for Delivery of Care

The following principles will guide the Ryan White HIV/AIDS Part B care system in Illinois and inform the *Part B Comprehensive Plan for HIV/AIDS Services.*

- HIV-positive clients should be assured ongoing participation in development and planning of the continuum of care and consumers should be empowered through training, coordination, and administrative assistance.

- All stakeholders in public, professional, or personal venues impacted by HIV-disease should have the opportunity for regular input to planning and advisory processes that affect Part B services.

- The quality of life and health status of all people living with HIV can be improved through programs and services responsive to the changing needs of consumers and the care environment.

- HIV-positive individuals who are not in care and/or may not be aware of their HIV-positive status need to be identified and assured full and equitable access to comprehensive care and services.

- Medical and psychosocial services are needed to address the increasing complexity of HIV disease and co-morbid conditions; including substance abuse and mental illness must be made available.

- The provision of care and services must be responsive to the impact of new treatment advances and related adherence and side effect issues on the changing health status of people living with HIV/AIDS.

- Ongoing assessment of needs of populations infected with HIV disease as well as evaluation and continuous quality improvement of the Department processes and Part B services must be assured.

- The capacity to provide culturally competent services responsive to the diversity of all communities affected by HIV must be improved.

- The equitable access of underserved groups and disproportionately affected subpopulations to the provision of care and services must be ensured.

- The Department should partner with other agencies to coordinate, facilitate, and provide equitable access to early intervention services (Part C) for individuals, families, and groups affected by HIV.

- State and community agencies must collaborate with each other to coordinate planning, access to and delivery of HIV prevention, HIV counseling and testing, HIV outreach,

substance abuse prevention, and substance abuse treatment services to HIV-affected groups.

- Public and private resources must be maximized through coordination and collaboration among providers serving HIV-affected individuals, thereby avoiding duplication and maintaining cost-effectiveness.

- The impact of federal/state political and policy changes affecting funding, access to or delivery of treatment and support services to PLWHA and those affected by HIV disease must be monitored.

- Policies and programs must be responsive to the impact of changing economic conditions on the continuum of care and the quality of life of people living with HIV/AIDS.

Public Health Model for HIV Continuum of Care Services

Adopting a public health approach to reducing the burden or impact of HIV/AIDS has been proposed, defined, and refined over the past 15 years into the following definition:

> "A broad, multi-disciplinary perspective that is concerned with improving outcomes in all people who have HIV/AIDS with attention to equity and the most efficient use of resources in ways that enhance patient and community quality of life."

For purposes of this *Part B Comprehensive Plan for the Delivery of HIV/AIDS Services*, equity explicitly reflects responsiveness to such issues as:

- *Parity* (equality) in the distribution of services;

- *Inclusion* in care of all individuals regardless of personal characteristics or circumstances;

- *Representativeness* (resource allocation and utilization reflect the epidemiology of the epidemic statewide); and

- *Accessibility* (easily obtainable services).

This definition reflects the ideal; the Comprehensive Plan is envisioned as a means of obtaining this ideal.

Public health interventions, like the one proposed here for service delivery are community/population focused rather than individual/client focused. These interventions are aimed at preventing the spread of HIV infection (primary prevention through mechanisms such as health education), preventing disability in those who have these conditions (secondary prevention, or reducing impact through adequate access to proven treatment interventions), limiting further deterioration and postponing mortality (tertiary prevention or reducing the consequences through adequate access to proven treatment interventions).

Public health interventions are not focused on questions of appropriate treatment service delivery for one individual or a single group of individuals, for example, the foster child with HIV/AIDS. Rather, practitioners adopting a public health approach that examines ways to distribute services that promise the maximum benefit for the largest number of people while still addressing the needs of constituent groups that make up the larger population of those affected by HIV/AIDS. It is important to recognize that the public health approach does *not abandon care of individual patients*. On the contrary, it broadens the reach of the health care system to include all persons, particularly those who are underserved or those who have special needs.

In adopting a public health approach to reducing the burden of HIV/AIDS in Illinois, this Comprehensive Plan incorporates certain core functions:

- Assessing and monitoring the health of at-risk communities and populations to identify specific priorities in the delivery of HIV/AIDS services;

- Assuring all populations have access to appropriate and cost-effective care, including health promotion and disease prevention services and that the effectiveness of such care and service is adequately evaluated; and

- Formulating public policies, in collaboration with community and government leaders, designed to solve identified local and state problems, priorities, gaps, and barriers associated with delivery of services for HIV/AIDS.

As it currently operates, the Part B structure lends itself well to a public health approach. The state's Part B system of care is a regionally validated model that is well accepted and recognized in Illinois as a structure that efficiently supports the delivery of services for several chronic diseases (e.g., cancer, arthritis, asthma). The Comprehensive Plan capitalizes on strengths within the current system – strengths that are consistent with a public health model. The proposed system continues to be regionally implemented and administered.

The use of regional directors allows the flexibility needed to develop a support service system responsive to Illinois' diverse geography and demography. Further, the model supports a structure that allows local processing of problems, a strength in the current system. The model continues the stipulation of continuous administrative improvement, another important component in the system as it presently operates. ADAP and CHIC programs continue to be centrally administered a strategy that also meets the diverse needs of PLWHA in Illinois.

Consistent with the current system's structure, a public health approach also was taken for developing the Comprehensive Plan. The planning effort was collaborative and informed by a multi-disciplinary perspective derived from providers, consumers, and collaborators across the Part B network. The assurance component of the plan preserves the structure of the current system, which relies heavily on the state's public health structure. Many regional project directors operate as key components of local public health departments. This system has competently overseen the delivery of services for more than 10 years and the Comprehensive Plan provides a roadmap to assure that the continuum of care and services continues to be

responsive to the HIV/AIDS epidemic in Illinois. The Comprehensive Plan supports the development of policies related to service delivery, adding new facets that are consistent with the existing public health model. The interrelationship of the care system's components reflects the vision and values outlined below.

2.1.3 Vision and Values for a Public Health Model of Continuum of Care

A public health continuum of care model is --

- Population based
- Regionally focused
- A foundation of collaboration
- Responsible for ongoing assessment
- Dedicated to assuring services through monitoring and evaluation
- A forum for policy development

Section 3 How Will We Get There: How Does Our System Need to Change to Assure Availability of and Accessibility to Core Services?

The priorities, objectives, and strategies are the result of input received directly from stakeholders across the state's continuum of care and services. The development of these priorities, objectives, and strategies began with a process of objectively evaluating the care and services provided in the state. This was followed by a needs assessment, which consisted of a series of meetings, focus groups, and public hearings, as described in the preceding sections. With the epidemiological profile as a guiding document, the strategies for these priorities and objectives were developed. As the priorities and objectives crystallized, the allocation of resources emerged consistent with the priorities and objectives.

The Illinois Part B program has maintained service and resource allocation priorities/goals and objectives for each grant year since the inception of the CARE Act. These priorities and objectives have been essential to the realization of the shared vision of care for Part B in Illinois. The goals and objectives of the 2009-2011 Comprehensive Plan for HIV/AIDS services in Illinois was developed based on information gathered through surveys, focus groups, facilitated meetings and review of secondary data sources.

While many of the priorities and objectives in this Comprehensive Plan have been predicated on maintaining and supporting the current continuum of care in Illinois, many of the goals, objectives, and strategies that were developed address needed changes to existing structures and processes in the plan.

Priorities/Goals for Part B Comprehensive Plan, 2009-2011

1. Reduce unmet need by March 31, 2012
2. Improve medical outcomes by March 31, 2012
3. Improve collaboration with the Illinois Department of Corrections (IDOC)
4. Improve collaboration between prevention and care programs
5. Enhance HIV care and services education of medical providers
6. Address health disparities and barriers to care

Goal 1. Reduce Unmet Need by March 31, 2012				
OBJECTIVES	**ACTIVITY**	**RESPONSIBLE AGENT**	**OUTCOME**	**EVALUATION**
1A. Identify and address local unmet need by subsets based on gender, race, risk, and age.	1A. Department Surveillance will develop a regional unmet need analysis specifically noting gender, race, risk, and age.	Department Surveillance	1A. Written analysis of regional unmet need by gender, race, risk, and age delivered to regional project directors by the second quarter Advisory Council meeting.	1A. An annual regional unmet need reassessment
1B. Increase data sets used to complete the unmet need analysis	1B. Regional project directors will develop strategic plans to address local unmet need based on analysis provided.	Regional Project Directors	1B. Written strategic plans to reduce unmet need included in annual work plans submitted to department.	1B1. Annual written assessment of activities completed to address unmet need.
				1B2. Annual regional unmet need reassessment.
Goal 2. Improve Medical Outcomes by March 31, 2012				
OBJECTIVES	**ACTIVITY**	**RESPONSIBLE AGENT**	**OUTCOME**	**EVALUATION**
2A. Establish a baseline for documentation of client level data and quality assurance indicators.	2A1. Review HRSA performance indicators, and identify measurable outcomes to be evaluated	Direct Service Unit staff	Improved client level data for medical outcome monitoring	2A. Annual monitoring of client level data documentation
	2A2. Collect and review data to establish baselines within first six months of 2009.			
2B. Implement medical case management in FY 2009.	2B1. Develop and deliver comprehensive MCM training to case managers.	Direct Service Unit and MATEC	Standard comprehensive training available to case managers with updates available as necessary	2B. Case managers complete training evaluations. Evaluations are tallied and assessed. Revisions made as necessary
	2B2. Assess effectiveness of MCM through monitoring of documentation and medical outcomes	Regional directors		
	2B3. Develop Web-based training on client assessment, documentation of client data and medical outcomes	Training Unit and Direct Service Unit		

Goal 3. Improve Collaboration with the Illinois Department of Corrections (IDOC)				
OBJECTIVES	**ACTIVITY**	**RESPONSIBLE AGENT**	**OUTCOME**	**EVALUATION**
3A. Create more consistent communication with the medical directors of IDOC facilities.	3A1. Hire a Correction's coordinator to provide constant collaboration with IDOC	Direct Service Unit/Illinois Public Health Association	Improved transition of recently released HIV positive persons to medical and supportive services in their local community	3A. Establish regular meeting schedule, monitor
	3A2. Create discharge packets and provide to DOC contacts			
	3A3. DOC representative on the Interagency AIDS Taskforce			
3B. Develop comprehensive written and electronic materials to raise awareness of available services.	3B1. Create Web page with links to local services			3B. Monitor use of Web site, survey users for effectiveness of Web site content
	3B2. Create discharge packets and provide to DOC contacts.			
Goal 4. Improve Collaboration Between Prevention and Care				
OBJECTIVES	**ACTIVITY**	**RESPONSIBLE AGENT**	**OUTCOME**	**EVALUATION**
4A. Alignment of Prevention and Care Regional boundaries by January 2010	4A. Develop work group to define task, monitor progress.	Prevention Administrator, PCPG Coordinator, Care Administrator	4A1. Unified physical boundaries	4A1. Complete realignment of regions by January 2010.
			4A2. Improved collaboration of prevention and care programs	4A2. Monitor referrals from case managers to Prevention for Positive services, partner services and other services/interventions provided by prevention providers.
			4A3. Ease of transition from HIV testing to Care case management	
4B. Identify and assess current level of collaboration by June 2009.	4B1. Identify "best practices" for integrated care/prevention model	Prevention Administrator and Care Administrator	4B1. Defined list of collaborative efforts already undertaken	4B. Assess data/information gathered for completeness.
	4B2. Assemble care and prevention staff, providers, and community stakeholders to review findings and develop recommendations.		4B2.Define level of collaboration expected	

	4B3. Conduct regional meetings with prevention and Ryan White lead agents to assess current relationship.		4B3.List of task to accomplish to reach level of collaboration expected	
4C. Develop standing committee/workgroup by January 2010.	4C1. Develop cross-reference training guide for prevention and care.	Prevention Administrator and Care Administrator	4C. Collaborative group versed in both prevention and care issues that can inform planning task for HIV care and prevention in Illinois	4C. Assess group membership, mission statement and defined responsibilities
	4C2. Develop statewide Web site for resource and reference.			
	4C3. Identify regional representatives, and Department staff participants.			
	4C4. Define committee/workgroup roles and responsibilities and goals.			
	4C5. Define parameters of group, mission statement, meeting schedule, funding source, etc.			
Goal 5. Enhance HIV Care and Services Education of Medical Providers				
OBJECTIVES	**ACTIVITY**	**RESPONSIBLE AGENT**	**OUTCOME**	**EVALUATION**
5A. Create and implement Web-based training curriculum that addresses core medical indicators, cultural competence and federal guidelines that govern service for PLWHA by April 2010.	5A1. Identify and notify key providers of medicine, dentistry, nursing, mental health, and pharmacy.	Illinois Public Health Association MATEC Care Administrator	5A. Medical providers will have better understanding of special needs and expectations for providing services to PLWHA.	5A. Track course completion and participation surveys.
	5A2. Expand training programs specific to the discipline (dentists, PCP, MH, etc.)			
	5A3. Identify incentives to encourage participation			

5B. Produce medical core services toolkit with linkage to resources accessible both hard-copy and online by April 2011	5B1. Identify and notify key providers of medicine, dentistry, nursing, mental health, and pharmacy.		Medical providers will have access to useful tools to better serve PLWHA	5B. Track usage of toolkit
	5B2. Hold meetings in each region to gather input on toolkit content.			5B. Conduct survey to determine usefulness and effectiveness of toolkit
	5B3. Conduct regional training on how to use toolkit.			
Goal 6. Address Health Disparities and Barriers to Care				
OBJECTIVES	**ACTIVITY**	**RESPONSIBLE AGENT**	**OUTCOME**	**EVALUATION**
6A. Develop a strategic plan to reduce barriers to care and health disparities identified during the SCSN process.	6A1. Identify data sources that provide a true depiction of the health care system for PLWHA in Illinois.	Care Administrator Illinois Public Health Association	6A. Service needs identified based on region, race, and special populations.	6A. Annual reassessment of data.
	6A2. Evaluate data sources			
	6A3. Develop written assessment of data analysis		6A. Barriers and disparities will be addressed using working document.	
	6A4. Create working document to address specific health disparities and barriers			
6B. Assess quality of life issues that affect a clients ability to remain in care.	6B1. Develop a standardized assessment tool to use with new clients as a precursor to treatment planning to determine quality of life needs.		6B. Assessment of quality of life issues and the affect on care issues for PLWHA.	6B. Conduct client surveys by Dec. 31, 2010 to assess status of quality of life issues.
	6B2. By Dec. 13, 2009, survey clients and complete data analysis on quality of life issues.			

Section 4 How Will We Monitor Our Progress: How Will We Evaluate Our Progress in Meeting Our Short-and Long-Term Goals?

This section describes monitoring and evaluation activities to benchmark progress toward the comprehensive quality of HIV care identified in the plan. The foundation of HIV care and treatment service administration is effective evaluation and quality assurance. Evaluation and quality assurance efforts across all care activities ensure the soundness of programs, their link to best practices, and their accessibility, both structurally and culturally, for all clients served by the Illinois Department of Public Health and its provider organizations.

Evaluation and quality assurance activities administered by the Department are founded on classical principles of continuous quality improvement, which assert these initiatives:

- Determine the degree of attainment of program objectives;
- Document strengths and weaknesses of a program or component when making decisions and planning;
- Monitor standards of performance and establish quality control mechanisms; and
- Improve professional staff's skill in the performance of program planning, implementation, and evaluation activities.

As evaluation and quality assurance are rooted in the concept of continuous quality improvement and the guidance of organizations to continually improve upon their systems, functions and practices, the Department has administered its evaluation and quality assurance plans to guide all program goals and objectives.

Key to this evaluation is the monitoring of progress on core objectives and outcomes. The care administrator and program coordinator will be responsible for overseeing the progress of all the Comprehensive Plan goals. The policy coordinator will manage all policy-related goals. The quality assurance coordinator will direct all quality assurance and quality management goals. The IT data coordinator will manage all date-related issues.

The priorities and objectives for this Comprehensive Plan and the evaluation and monitoring of these activities are thoroughly outlined in this document, and suggested activities have been further delineated in Section 3.

4.1 Improving Client Level Data

Illinois Department of Public Health has been collecting client level data from all its subcontracted providers electronically for several years. The Department uses Provide® Enterprise in all case management sites in downstate Illinois. The system allows subcontracted providers to input client and service utilization data directly into the system. This process provides the Department direct access to the data in real time. Through case manager's entries into the data system, we can track all HRSA required measures. With the transition to Medical Case Management, The Department will be concentrating on collecting and reporting on several performance measures, including the HRSA recommended core clinical measures. These measures will be used in our quality management activities.

4.2 Using Data for Evaluation

CD4 and Viral Load testing, client diagnosis and hepatitis A and B vaccine are currently reported and monitored through the electronic data system. The system is being updated to collect all HRSA required measures by April 2009. Electronic data will be used to identify the percentage of clients in medical case management that have received the Hepatitis A and B vaccination with the inclusion of influenza and pneumococcal vaccines in the fall of 2008. These areas will be expanded as the electronic system is updated.

Annually, data is presented to the Quality Management Committee and the Direct Service Unit Advisory Committee. These committees review data and make comments and recommendations regarding problem areas that could be addressed. This process has resulted in continued improvement in record keeping, data collection and the identification of further technical assistance necessary for improvement of overall client care. Project directors are provided with information regarding potential support of case management staff that may be needed from a third party's observation. When the results are discussed in the quarterly committee meetings, problem solving, suggestions, and further areas of need can be identified.

4.3 Measuring Clinical Outcomes

The Clinical Quality Management Committee was re-established in January of 2007 to provide oversight to the Department, Direct Service Unit's quality management (QM) program. The mission was to enhance HIV related patient core services. The committee sought to look at services currently provided and evaluate the focus of the current Ryan White Part B services in Illinois. The goals that were identified included reviewing current data and understanding the effectiveness of the overall electronic reporting system in monitoring client health. In addition, the committee wanted to review appropriate methods of assuring quality in subcontracted services. Membership includes client representatives and regional project officers interested in improving overall outcomes.

The measuring of clinical outcomes will be a two-pronged approached. The Medical Case Management model will allow continual assessment of client medical adherence, thus providing data to determine medical outcomes; and the quality management site visits process will allow IDPH to assess the completeness of data collected and compliance with performance measures by providers.

Appendices

Appendix A: SCSN Participants

Appendix B: Unmet Need Tables

Appendix C: Metro St. Louis HIV Health Services Planning Council 2006 Case Manager Survey

Appendix D: Profile of the Ryan White Program Funded Providers

APPENDIX A: STATEWIDE COORDINATED STATEMENT OF NEED MEETING PARTICIPANTS

Name	Title/Program	Organization
Nancy Abraham-Budds	ADAP	Illinois Department of Public Health
Michelle Agnoli	Part F AETC	Midwest AIDS Training and Education Center
Darren Ahlgren	Part C	Crusader Clinic
David Allen	Housing and Supportive Service	Canticle Ministries
Cheryl Aredia	Part B and Primary Care	Lake County Health Department
Kendra Arnold	Case Manager	UI College of Medicine
Marcy Ashby	Part B Project Director	SIU-School of Medicine
Linda Avery	Case Manager	UI College of Medicine
Erica Barnes	Mental Health	Clinical Expression
Gilbert Barrett	Part B Client Representative	Rock Island Care Advisory Group
Jessica Batey	Case Manager	Champaign-Urbana Public Health District
Michael Benner	Outreach Specialist	Greater Community AIDS Project
Amanda Berenguel-Smolka	Case Manager	Rock Island County Council on Addictions
Dan Bigg	Prevention Provider	Chicago Recovery Alliance
Ann Birt	Case Manager	Champaign-Urbana Health District
Michael Bissell	Case Manager	Champaign-Urbana Health District
Brian Bongner	Part B and Primary Care	Lake County Health Department
Tracy Box	Case Manager	Winnebago County Health Department
Pamela Briggs	Part B	UI College of Medicine
Britta Brown	Housing Resources	Doorways/Interfaith Residence
Ed Bruner	Co-Chair	Prevention Community Planning Group
Richard Bryson	Part B Client Representative	Metro East HIV Prevention and Care Advisory Group
Roman Buenostra	Part A EMA	AIDS Foundation of Chicago
Alicia Bunton	Medical Provider	Jackson Park Hospital
Jamie Burns	Meeting Facilitator	Illinois Department of Public Health
Lilla Burnett	Part B Provider	Rock Island County Council on Addictions
Lola Butler	Housing	Fifth Street Renaissance/SARA Center
Rebecca Caldwell	Case Manager	UI College of Medicine
Marie Carde	State Agency	Illinois Department of Human Services, Division of Rehabilitation
Judy Cassioppi	Substance Abuse Treatment	Discovery House
Paula Clark	Part B Project Director	Jackson County Health Department
Steve Clark	Housing	Professional Development Group Midwest
Teneesha Clark	Medical Provider	University of Illinois at Chicago
Elizabeth Clayton	Case Manager	UI College of Medicine
Azella Collins	Perinatal Coordinator	Illinois Department of Public Health
Jonna Cooley	Housing	Phoenix Center
David Croan	Part B Client Representative	Metro East HIV Prevention and Care Advisory Group
Crystal Culler	Corrections	Metropolitan Chicago Corrections

Name	Title/Program	Organization
Jerry Cunningham	Case Manager	Rock Island County Center on Addictions
Michael Cutts	Consumer Advocacy	Advocate
Bradley Daehn	Prevention Provider	Winnebago County Health Department
Andrea Danner	Training Administrator	Illinois Department of Public Health
Lynn Demain	Client Representative	Effingham Consortium Advisory Group
Gail DeVito	Community Planning Co-Chair	Illinois Department of Public Health
Stephan Draughan	Pharmacy Intern	SIU at Edwardsville
Gary Dunn	Part B Project Director	Champaign-Urbana Public Health District
Sara Eifrid	Medical Provider	Howard Brown
Jeffrey Erdman	Prevention Lead Agent	Champaign-Urbana Health District
Willie Fair	Housing/Prevention	Christian Community Health Center
Anne Fisher	Legal Provider	AIDS Legal Counsel
Beryl Fitzpatrick	Primary Care	Hektoen Institute
Deyania Flores	Case Manager	Access Community Health Network
Robyn Folks	Prevention	McLean County AIDS Task Force
Marla Francisco	Part B Client Representative	East Central Illinois Advisory Group
LaBraunna Friend	Part A TGA	St Louis Planning Council
Richard Gardner	Prevention Administrator	Illinois Department of Public Health
Cindy Gorbett	Case Manager	SIU School of Medicine
Deborah Grant	Housing Coordinator	Illinois Department of Public Health
Marilyn Green	Regional Health Officer	Illinois Department of Public Health
Joe Greene	Client Representative	Central Illinois Advisory Group
Belinda Gunning	Mental Health Provider	Behavioral Health
Lawrence Harris	Housing Coordinator	Fifth Street Renaissance
Christine Harrison	Prevention Coordinator	Community Health Improvement Center
Kristin Harrison	Epidemiologist	Winnebago County Health Department
Kristin Hartsaw	Case Manager	DuPage County Health Department
Denise Henkel	Prevention	Illinois Public Health Association
Carole Hoke	Case Manager	UI College of Medicine
Katrina Holmes	Case Manager	Access Community Health Network
Tracy Hopkins	Part B	Rock Island County Council on Addictions
Vallery Huston	Pharmacist	Walgreens Pharmacy
Melinda Isaacs	Pharmacist	Walgreens Pharmacy
Bernard Johnson	Laboratory Director	Illinois Department of Public Health
Caprice Johnson	Case Manager	Bethany Place
Clay Johnson	Case Manager	UI College of Medicine
Erin Johnson	Oral Health	McLean County Health Department
Juandalyn Johnson	Part A	Chicago Department of Public Health
Jill Jones	Case Manager	UI College of Medicine
Johnny Jones	Advisory Board Co-Chair	Metro East HIV Prevention and Care Advisory Board
Jack Kanady	Part A and B provider	University of Illinois at Chicago
Linda Kasebier	Ryan White Program Coordinator	Illinois Department of Public Health
Shelton Kay	Part C Clinic	Crusader Clinic

Name	Title/Program	Organization
Chet Kelly	Part C	Ruth M. Rothstein Core Center
Todd Kisner	Part B Project Director	Winnebago County Health Department
Richard Klinkerfuss	Part B Client Representative	Southern Illinois Advisory Group
Korey Kooistra	Part B QI Manager	AIDS Foundation of Chicago
Shannon Lane	Case Manager	DuPage County Health Department
Patricia Langehennig	Provider	Regional Care
Casie Lasowski	Case Manager	SIU School of Medicine
Gladys Lasu	Legal Provider	Prairie State Legal Services
J. Bryan Latham	Prevention Provider	THAT Place
Deborah Leroy	Case Manager	Whiteside County Health Department
Teri McCarthy	Housing/Food bank	Greater Community AIDS Project
Fred Maclin	Housing/Case Management	Christian Community Health Center
Mike Maginn	Part B Client Representative	Central Illinois Friends of People with AIDS
Andrea Mahanay	Case Manager	Coordinated Youth and Human Services
Perry Maier	Mental Health/Substance Abuse Provider	Open Door Clinic
Tina Markovich	Part B Project Director	St Clair County Health Department
Sharon Maxwell	Planning Council	Metro East HIV Prevention and Care Advisory Group
Larry Mayhew	Part B, Part C	Southern Illinois Healthcare Foundation
Kara McCluskey	Prevention	Winnebago County Health Department
Michael McFadden	MCM/MH/SA	Howard Brown Health Center
Donna Shea McGee-Boyce	Primary Care	Ruth M. Rothstein Core Center
Holly Mehawich	Part B Project Director	Peoria City/County Health Department
Sonji Miller	Provider	Lawndale
Shyam Misra	Epidemiologist	Illinois Department of Public Health
Elizabeth Monk	Specialty Staff Administrator	Department of Child and Family Services
Mykinna Montgomery	Case Manager	Bethany Place
Bill Moran	Ryan White Administrator	Illinois Department of Public Health
Kim Mosby	Housing Resource Specialist	Doorways/Interfaith Residence
Pam Muir	Part B Quality Assurance Coordinator	Illinois Department of Public Health
Jean Muntan	Part C-Outpatient Care	Kenneth Hall Regional Hospital
Dorothy Murphy-Swallow	Coordinator	Cermak Correctional Facility
Pat Murrell	Mental Health Provider	Patricia Murrell
Greg Myer	Case Manager	Winnebago County Health Department
Heidi Nelson	Part C Provider	Heartland Health Outreach, Inc
Vickie Nollman	Local Health Department Partner	Jefferson County Health Department
Kim Norton	Nurse-Outpatient Care	Springfield Clinic

Name	Title/Program	Organization
Melinda Oxford	Case Manager	Coordinated Youth and Human Service
Sheryl Packer	Part B Project Director	Heartland Human Services
Trish Paesani	Case Manager	Winnebago County Health Department
Daryl Page	Effingham Consortium Advisory Board Member	Effingham Consortium Advisory Group
Anqunette Parham	Part C Clinic	Crusader Clinic
Kathy Pearson	Mental Health Professional	
Karen Pendergrass	Policy Coordinator	Illinois Department of Public Health
Cheryl Piper	Substance Abuse Treatment	PHASE, Inc
Michael Polasek	Part B Client Representative	Effingham Consortium Advisory Group
Erline Pooler	Nurse-Outpatient Care	St Clair County Health Department
Cheryl Potts	Part B Project Director	AIDS Foundation of Chicago
Cassaundra Powell	Community Planner	Planned Parenthood
Wendell Richardson	Part B Client Representative	Rock Island Advisory Group
Julie Roberts	Part B	St Clair County Health Department
Charlotte Rodems	Family Planning	Illinois Department of Human Services
Felicia Rodriguez	Part C/D	Hektoen Institute/ Division of Adolescent Medicine at CORE
Lisa Roeder	Part B, C	University of Illinois College of Medicine at Peoria
David Roesler	Part B/MH/SA	Open Door Clinic
Larry Rogers	Prevention	Champaign-Urbana Health District
Sean Rose	Housing Coordinator	Phoenix Center
Stacia Runge	Part B Case Manager	DeKalb City Health Department
Chardial Samuel	Part C	Washington University-Project ARK
Roger Schoonover	Client Representative	Peoria Advisory Board
Darrell Scott	Outpatient Care/Treatment Adherence	Carle Clinic Association
Lauren Seemeyer	Psychosocial Support/Legal	FCAN
Dawn Skaggs	Oral Health	Macon County Health Department
Edward Smith	Case Management	Southern Illinois Healthcare Foundation
Beverly Solon	Family Planning	Illinois Department of Human Services
Steven St. Julian	Prevention Community Planning	Jackson County Health Department
Ramona Stevens	Case Manager	Champaign-Urbana Health District
Joan Stevens-Thome	Prevention Lead Agent	Sangamon County Health Department
Jeana Stewart	Housing and Supportive Services	Canticle Ministries
Lisa Stief	Case Manager	Coordinated Youth and Human Services
Megan Tataren	Social Work	Bob Michel Veterans' Affair Outpatient Clinic
Deane Taylor	Perinatal Provider	Ruth Rothstein Core Center
Sharon Tear	Part C Clinic Director	UI College of Medicine
Patrick Thomas	Part A TGA	St Louis Department of Health
William Thomas	Part A TGA	St Louis Department of Health
Jarrett Thompson	Administrative Director	University Of Illinois

Name	Title/Program	Organization
Fertonya Tucker	Part A Planning Council	St Louis TGA
Vicki Vandeveer	Mental Health /Substance Abuse Counselor	Personal Counseling Services
Tracey Vogelsang	Case Manager	UI College of Medicine
Sarah Vujanov	Case Manager	UI College of Medicine
Rick Wadlow	Part B Client Representative	Southern Illinois Advisory Board
Cheryl Ward	Surveillance Coordinator	Illinois Department of Public Health
Sharon Wiegel	Substance Abuse	Prairie Center
Johnny Wiggins	Housing	Alexian Brothers
Amanda Wilkins	Immunizations/Pediatrics	Illinois Chapter, American Academy of Pediatrics
Kenis Williams	Substance Abuse, Case Management	Haymarket Center
Mildred Williamson	Section Chief	Illinois Department of Public Health
Lloyd Winston	Part B Client Representative	Champaign-Urbana Health District
David Woods	Effingham Consortium Advisory Board Member	Effingham Consortium Advisory Group
Al Viscarra	Effingham Consortium Advisory Board Chair	Effingham Consortium Advisory Group

APPENDIX B: UNMET NEED TABLES

The following tables show the demographic and geographic characteristics of those with unmet need.

Unmet Need Estimate by Gender

	Gender	Total	Met Need (HARS + Linked Providers)	Unmet Need (HARS + Linked Providers)	Percent Unmet Need
PLWH	Male	11,741	5,444	6,297	53.6%
	Female	3,813	1,494	2,319	60.8%
	Total	**15,537**	**6,938**	**8,598**	**55.3%**
PLWA	Male	13,358	7,599	5,759	43.1%
	Female	3,317	1,893	1,424	42.9%
	Total	**16,675**	**9,492**	**7,183**	**43.1%**
PLWA+ PLWH	Male	25,081	13,043	12,038	48.0%
	Female	7,130	3,387	3,743	52.5%
	Total	**32,211**	**16,430**	**15,781**	**49.0%**

Unmet Need Estimate by Race/Ethnicity

	Race/Ethnicity	Total	Met Need (HARS + Linked Providers)	Unmet Need (HARS + Linked Providers)	Percent Unmet Need
PLWH	Hispanic	2,047	994	1,053	51.4%
	Non-Hispanic American Indian/Alaskan Native	26	11	15	57.7%
	Non-Hispanic Asian	146	89	57	39.0%
	Non-Hispanic Black	7,619	2,750	4,869	63.9%
	Non-Hispanic Native Hawaiian/Pacific Islander	30	16	14	46.7%
	Non-Hispanic White	5,199	2,905	2,294	44.1%
	Legacy Asian/Pacific Islander	7	1	6	85.7%
	Non-Hispanic Multi-Race	75	48	27	36.0%
	Unknown	379	124	255	67.3%
	Total	**15,528**	**6,938**	**8,590**	**55.3%**
PLWA	Hispanic	2,604	1,470	1,134	43.5%
	Non-Hispanic American Indian/Alaskan Native	26	10	16	61.5%
	Non-Hispanic Asian	144	101	43	29.9%
	Non-Hispanic Black	8,531	4,800	3,731	43.7%
	Non-Hispanic Native Hawaiian/Pacific Islander	13	6	7	53.8%
	Non-Hispanic White	5,211	3,010	2,201	42.2%
	Legacy Asian/Pacific Islander	35	15	20	57.1%
	Non-Hispanic Multi-Race	109	78	31	28.4%
	Unknown	1	1	0	0.0%
	Total	**16,674**	**9,491**	**7,183**	**43.1%**

PLWA+ PLWH	Hispanic	4,651	2,464	2,187	47.0%
	Non-Hispanic American Indian/Alaskan Native	52	21	31	59.6%
	Non-Hispanic Asian	290	190	100	34.5%
	Non-Hispanic Black	16,150	7,550	8,600	53.3%
	Non-Hispanic Native Hawaiian/Pacific Islander	43	22	21	48.8%
	Non-Hispanic White	10,410	5,915	4,495	43.2%
	Legacy Asian/Pacific Islander	43	17	26	60.5%
	Non-Hispanic Multi-Race	184	126	58	31.5%
	Unknown	380	125	255	67.1%
	Total	**32,203**	**16,430**	**15,773**	**49.0%**

Unmet Need Estimate by Age Group

	Age Group	Total	Met Need (HARS + Linked Providers)	Unmet Need (HARS + Linked Providers)	Percent Unmet Need
PLWH	0-4	210	52	158	75.2%
	5-12	49	22	27	55.1%
	13-19	584	236	348	59.6%
	20-29	4,038	1,745	2,293	56.8%
	30-39	5,524	2,579	2,945	53.3%
	40-49	3,658	1,677	1,981	54.2%
	Older than 49	1,473	627	846	57.4%
	Unknown	0	0	0	N/A
	Total	**15,536**	**6,938**	**8,598**	**55.3%**
PLWA	0-4	117	30	87	74.4%
	5-12	26	12	14	53.8%
	13-19	289	163	126	43.6%
	20-29	3,605	2,032	1,573	43.6%
	30-39	6,581	3,766	2,815	42.8%
	40-49	4,440	2,604	1,836	41.4%
	Older than 49	1,617	885	732	45.3%
	Unknown	0	0	0	N/A
	Total	**16,675**	**9,492**	**7,183**	43.1%
PLWA+ PLWH	0-4	327	82	245	74.9%
	5-12	75	34	41	54.7%
	13-19	873	399	474	54.3%
	20-29	7,643	3,777	3,866	50.6%
	30-39	12,114	6,354	5,760	47.5%
	40-49	8,098	4,281	3,817	47.1%
	Older than 49	3,090	1,512	1,578	51.1%
	Unknown	0	0	0	N/A
	Total	**32,211**	**16,430**	**15,781**	**49.0%**

Unmet Need Estimate by Risk Group

	Risk Factor	Total	Met Need (HARS + Linked Providers)	Unmet Need (HARS + Linked Providers)	Percent Unmet Need
PLWH	MSM	7,117	3,963	3,154	44.3%
	Injection drug use (IDU)	1,995	634	1,361	68.2%
	MSM/IDU	476	224	252	52.9%
	Transfusion/hemophilia	98	41	57	58.2%
	Heterosexual contact	2,187	928	1,259	57.6%
	Mother with, or at risk for, HIV infection	215	61	154	71.6%
	Risk not reported, or unknown	3,448	1,087	2,361	68.5%
	Total	**15,536**	**6,938**	**8,598**	**55.3%**
PLWA	MSM	7,695	4,624	3,071	39.9%
	Injection drug use (IDU)	3,278	1,607	1,671	51.0%
	MSM/IDU	1,158	675	483	41.7%
	Transfusion/hemophilia	186	92	94	50.5%
	Heterosexual contact	2,386	1,380	1,006	42.2%
	Mother with, or at risk for, HIV infection	122	31	91	74.6%
	Risk not reported, or unknown	1,850	1,083	767	41.5%
	Total	**16,675**	**9,492**	**7,183**	**43.1%**
PLWA+ PLWH	MSM	14,812	8,587	6,225	42.0%
	Injection drug use (IDU)	5,273	2,241	3,032	57.5%
	MSM/IDU	1,634	899	735	45.0%
	Transfusion/hemophilia	284	133	151	53.2%
	Heterosexual contact	4,573	2,308	2,265	49.5%
	Mother with, or at risk for, HIV infection	337	92	245	72.7%
	Risk not reported, or unknown	5,298	2,170	3,128	59.0%
	Total	**32,211**	**16,430**	**15,781**	**49.0%**

APPENDIX C: METRO ST. LOUIS HIV HEALTH SERVICES PLANNING COUNCIL 2006 CASE MANAGER SURVEY

The following questions were asked of the providers, with their response summarized in the table below.

- How many of your clients have a current problem with chemical dependency?
- How many of your clients have been diagnosed with a mental illness?
- How many of your clients have been homeless in the past 12 months?
- How many of your clients have been in jail or prison in the past 12 months?
- How many of your clients reside in rural counties (not St. Louis City, St. Louis County, or St. Clair County)?

Special Population Indicators for Illinois case managers by client number and percentage* Rural counties were defined as outside of St. Louis City, St. Louis County, and St. Clair County

	Current chemical dependency	**Diagnosed mental illness**	**Homeless in past 12 months**	**Jail or prison in past 12 months**	**Reside in rural county***
Illinois (n=12, 452 clients)	114 (25.2%)	89 (19.7%)	34 (7.5%)	23 (5.1%)	135 (29.9%)
Missouri	392 (25.6%) (n=26, 1,531 clients)	494 (32.3%) (n=26, 1,531 clients)	284 (17.2%) (n=27, 1,650 clients)	129 (7.8%) (n=27, 1,650 clients)	95 (6.0%) (n=26, 1,575 clients)
TOTAL	25.5% 506	29.4% 583	15.1% 318	7.2% 152	11.3% 230

Case managers were asked to identify the services that a substantial number of these clients need, but are having trouble accessing. The responses are listed in order of frequency selected in the table below.

Services needed but not easily accessed by clients

Service	IL (10)
Finding low income housing	4
Benefits counseling (other than case manager) to help access Medicaid, Medicare, etc.	4
Massage therapy	4
Emergency housing	3
Inpatient substance abuse treatment	3
One-to-one peer emotional support	3
Dental/Oral health care	3
Utility assistance	2
Rent assistance/mortgage	2
Child care	2
Durable medical equipment (DME)	2
Vocational rehabilitation	2
Spiritual or religious counseling	2
Medical insurance continuation	2
Medical information about HIV, treatments, etc.	2
Skilled nursing facility	2
Home health	2
Transportation/rides	1
Mental health counseling or therapy	1
Legal assistance	1
Prescription drug program/AIDS Drug Assistance Program	1
Interpreter services	1
Nutritional counseling	1
Medical care (doctor, nurse, etc.)	1
Rehabilitation services	1
HIV case management	1
Food bank/receiving free groceries	1
Social support groups/events	0
Outpatient substance abuse treatment	0
Home delivered meals	0
Treatment adherence support (help taking HIV medications correctly)	0

Case managers were asked to identify the most needed services that help people with HIV disease access and stay in medical care. They could select up to 10 responses from a presented list, with the option to write-in any additional responses. The responses are listed in order of frequency selected in the table below.

Case manager-selected services needed to help clients access/stay in medical care

Service	IL (12)
HIV case management	11
Rent assistance/mortgage	10
Transportation/rides	11
Prescription drug program/AIDS Drug Assistance Program	8
Utility assistance	9
Medical information about HIV, treatment, etc.	7
Mental health counseling or therapy	2
Benefits counseling (other than case manager) to help access Medicaid, Medicare, etc.	2
Medical insurance continuation	1
Social support groups/events	4
Finding low income housing	3
Treatment adherence support (help taking HIV medications correctly)	2
Dental/oral health care	4
Food bank/receiving free groceries	5
Emergency housing	1
Home health	0
Inpatient substance abuse treatment	0
Prevention counseling (safer sex of safer drug use)	0
Nutritional counseling	2
One-to-one peer emotional support	1
Outpatient substance abuse treatment	0
Child care	0
Home delivered meals	0
Interpreter services	0
Massage therapy	1
Spiritual or religious counseling	1
Other:	

Case managers were asked to identify the problems or barriers that their HIV/AIDS clients experience that prevent or deter them from accessing medical care. They could select up to 10 responses as needed from a presented list, with the option to write-in any additional responses. The responses are listed in order of frequency selected in the table below.

Case manager-selected problems or barriers clients experience that may deter access to medical care

Problems or Barriers	IL (12)
Substance use	4
Fatigue with maintenance required for HIV treatment and care	7
Cost of prescriptions	6
Access to Medicaid/Medicare	5
Private insurance with high co-pays or deductibles	3
Client funding for transportation	4
Fear of disclosure	9
Difficult to use and understand Medicaid and Medicare	1
Stigma associated with HIV/AIDS	3
Denial of HIV/AIDS status	6
Reliable transportation providers	1
Homelessness	1
Ineligible for disability benefits	7
Private insurance with high premiums	2
Transient lifestyles	1
Problems with adherence to antiretroviral treatments	2
Lack of social support systems	3
Cognitive impairment prevents from accessing services	1
Lack of awareness of services	3
Confidentiality issues	4
Long-term housing assistance	0
Availability of Medicaid/Medicare providers	2
Inconvenient location of providers	3
Limited access to transportation in rural areas	3
Difficulty with health problems (related or not related to HIV)	3
Long distance transportation	3
Belief that HIV/AIDS is imminently fatal	1
Childcare	1
Long wait lists for public housing programs	0
Transportation providers do not accept Medicaid	1
Cultural beliefs preventing medical care	1
Culturally competent medical providers	0
Lack of experienced medical providers	2
Difficulty understanding test results	1
Discharge planning to HIV-positive inmates	0
Health related problems due to aging	1

Case managers were asked to identify the problems or barriers that their rural HIV/AIDS clients experience that prevent or deter them from accessing medical care. "Rural" was defined as clients living outside of St. Louis City or County and St. Clair County. They could select up to 10 responses as needed from a presented list, with the option to write-in any additional responses. Case managers chose from none to 10 responses, with an average of 7.3 and a median of 10. Sixty-seven percent of the Illinois case managers, and 53 percent of the Missouri case managers served rural clients and responded. One response did include 11 responses, but was included in the analysis. Four case managers indicated they were not serving any rural clients, but did respond to this question; their responses were excluded since it was unclear if they had ever served rural clients. The responses are listed in order of frequency selected in the table below.

Case manager-selected problems or barriers rural clients experience that may deter access to medical care (n=23)

Problems or Barriers	IL (8)	MO (13)	TOTAL # selecting this service
Long distance transportation	5	10	15
Limited access to transportation in rural areas	5	9	14
Stigma associated with HIV/AIDS	4	7	11
Fear of disclosure	4	6	10
Client funding for transportation	4	5	9
Confidentiality issues	5	4	9
Inconvenient location of providers	3	6	9
Availability of Medicaid/Medicare providers	3	5	8
Lack of awareness of services	2	6	8
Lack of social support systems	3	5	8
Cost of prescriptions	2	5	7
Reliable transportation providers	3	4	7
Private insurance with high premiums	3	3	6
Access to Medicaid/Medicare	0	5	5
Fatigue with maintenance required for HIV treatment and care	3	2	5
Denial of HIV/AIDS status	2	3	5
Lack of experienced medical providers	3	2	5
Private insurance with high co-pays/deductibles	2	3	5
Substance use	0	5	5
Difficult to use and understand Medicaid/Medicare	0	4	4
Belief that HIV/AIDS is imminently fatal	2	1	3
Long-term housing assistance	0	3	3
Childcare	1	1	2
Difficulty with health problems (related or not related to HIV)	2	0	2
Ineligible for disability benefits	1	1	2
Culturally competent medical care providers	0	2	2

Long wait lists for public housing programs	1	1	2
Problems with adherence to antiretrovirals	1	1	2
Transient lifestyles	2	0	2
Transportation providers do not accept Medicaid	0	2	2
Homelessness	1	1	2
Cognitive impairment prevents from accessing services	0	1	1
Difficulty understanding test results	1	0	1
Nutritional services	0	1	1

Case managers were asked to identify the problems or barriers that their newly diagnosed HIV/AIDS clients experience that prevent or deter them from accessing medical care. They could select up to 10 responses as needed from a presented list, with the option to write-in any additional responses. The responses are listed in order of frequency selected in the table below.

Case manager-selected problems or barriers newly diagnosed client's experience that may deter access to medical care.

Problems or Barriers	IL (12)
Lack of awareness of services	9
Fear of disclosure	9
Denial of HIV/AIDS status	9
Confidentiality issues	10
Stigma associated with HIV/AIDS	5
Lack of social support systems	8
Access to Medicaid/Medicare	4
Belief that HIV/AIDS is imminently fatal	5
Cost of prescriptions	5
Difficult to use and understand Medicaid and Medicare	2
Difficulty understanding test results	5
Ineligible for disability benefits	3
Substance use	1
Difficulty with health problems (related or not related to HIV)	2
Homelessness	1
Private insurance with high co-pays or deductibles	1
Transient lifestyles	1
Reliable transportation providers	1
Cultural beliefs preventing medical care	0
Fatigue with maintenance required for HIV treatment and care	2
Long wait lists for public housing programs	2
Long-term housing assistance	0
Private insurance with high premiums	0
Availability of Medicaid/Medicare providers	0
Childcare	1
Cognitive impairment prevents from accessing services	1
Inconvenient location of providers	1
Transportation providers do not accept Medicaid	0
Problems with adherence to antiretroviral treatments	1
Client funding for transportation	0
Culturally competent medical care providers	0
Discharge planning for HIV-positive inmates	0
Long distance transportation	1
Limited access to transportation in rural areas	1
Nutritional services (food stamps, food pantries, grocery vouchers, etc)	0
Other:	

Case Management Activities

At the request of the case management supervisors, a section was included in order to better document the needs of case managers and plan for improvement. Case managers were asked to identify the problems or barriers that they experience in providing case management services to HIV/AIDS clients. They could select up to six responses as needed from a presented list, with the option to write-in any additional responses. Most participants (65%) chose at least four or five responses. The responses are listed in order of frequency selected in the table below.

Problems or barriers in providing case management services

Problems or barriers	IL (12)
Difficulty locating services outside of Ryan White	4
Funding for needed services	3
Clients with continuing substance abuse/mental health problems	4
Misperception of case manager role in community	6
Difficulty contacting clients	7
Lack of consistent training	4
Collaboration of Ryan White service providers	3
Lack of funds to send people to training	2
High case load/client size	4
Case manager turnover	2
Difficultly locating services within Ryan White	0
Many high-acuity clients (many issues outside HIV)	3
Lack of community support	1
Lack of agency supervisory support	1
Lack of and ineffective history of QSM (for Missouri only)	----
Other	(1) non-compliant clients

Case managers were asked to assess their own effectiveness on a scale of one to seven, with one being least effective and seven being most effective. Illinois (n=12) and Missouri (n=28) case managers responded with nearly identical ratings, so their results are presented together: the average effectiveness score was 5.68, with a median of six, and a range of four to seven.

Case managers were asked what they felt was the largest barrier for them to improve as a case manager right now. Case managers were given the opportunity to write-in a response. The table below summarizes their responses, and notes when more than one case manager indicated the same response. A few case managers listed more than one barrier, which is why there are a few more responses than participants.

Barriers to improving as a case manager (n=30)

IL (n=8)	MO (n=25)
(3) Frequent changes to the program	(5) Lack of funding for services
(2) New case manager, getting to know clients and the services	(4) Grants administration and keeping both case managers and clients informed in a timely manner/ lack of comprehensive knowledge and communication regarding available services and resources
(2) Paperwork/documentation changes	(3) Not enough time/high case load
(2) Lead agency (SCCHD) problems	(3) Changing services and service eligibility
(1) Lack of available services	(3) Knowledge of/ease of locating services outside of Ryan White
(1) Too many job responsibilities	(3) Lack of state direction, the current philosophy, and consistency
(1) Understanding the role of CM in the community/time spent with clients	(2) Problems with Ryan White providers
	(2) State requirements, paperwork
	(2) Lack of resources
	(1) DFS
	(1) Burnout/lack of opportunity for training
	(1) People not positive enrolling in case management

Case managers were asked to rate the responsiveness of their lead agency on a scale of one to seven, with one being the least effective and seven being the most effective. The lead agency for Illinois is St. Clair County Health Department. Illinois (n=12) and Missouri (n=28) case managers responded with nearly identical ratings, so their results are presented together: the average score was 4.9, with a median of five, and a range of one to seven. Case managers were given the opportunity to share examples and comments, which are summarized and displayed in the table below. A few case managers listed more than one idea, which is why there are a few more responses than participants.

Case manager comments regarding how responsive their lead agency is in addressing case management issues (n=17)

IL (7 responses)	MO (11 responses)
(4) Positive comments: timely responses, find answers to questions, do a good job when informed	(8) Grants administration does not respond in a timely manner; many comments specifically mentioned lack of response with Ryan White provider issues
(1) Did not receive a response to both calls and e-mails until supervisor was contacted	(4) Lack of grants administration contact; not present at case management meetings, not as much contact as in the past, no direct connection
(1) Many changes, more requirements, some lack of communication, but this seems to be improving	(1) I feel they are more responsive than in the past
(1) Taxi services, client supplies, chart reviews, utility assistance	

When asked to rate the effectiveness of their lead agency in communicating regarding HIV and related services to case managers, Illinois and Missouri case managers responded with ratings that were slightly different though not significant. Case managers were given the opportunity to share examples and comments, which are summarized and displayed below. A few case managers listed more than one idea, which is why there are a few more responses than participants.

Case manager rating of how effective their lead agency is in communicating regarding HIV and related services to case managers (n=40)

	Illinois (n=12)	Missouri (n=28)	Combined (n=37)
Average	4.8	5.1	5.0
Median	5	5	5
Range	1 to 7	2 to 7	1 to 7

Case manager comments regarding how effective their lead agency is in communicating about HIV and related services (n=11)

IL (4)	MO (7)
(2) Case management information is not delivered in a timely manner.	(4) Lack of communication from grants administration: not at case management meeting, only hear from Case Manager supervisor, not sure who is suppose to communicate about services
(2) Much communication is about mandatory issues (not necessarily related to case management)	(2) Suggestion of providing information (i.e. weekly bulletin or website) with the status of resources at the time and how to access them, also include other referrals for clients
(1) SCCHD forwards e-mails from the Department	(1) Grants administration does not provide timely responses
	(1) Information is provided as grants administration can
	(1) Sometimes I am aware of services, and sometimes I am not

Case managers were given a range of options to select regarding their level of HIV prevention training, and how prepared they are to discuss prevention information with clients, presented below.

Case manager indicated level of prevention training and ability to discuss prevention with clients (n=39)

	IL (n=12)	MO (n=27)
I have had little or no HIV prevention training, but feel I can discuss with clients	1	0
I have had some HIV prevention training, but feel I am not prepared for clients	0	2
I have had some HIV prevention training, and feel I can discuss with clients	5	11
I have had plenty of HIV prevention training, and am prepared to discuss with clients	6	14

Most case managers (11/12) indicated that they discuss prevention issues with the clients more than once a year. Case managers noted that they would like to share updated prevention information with clients and that it is easier to discuss prevention when a client is honest about their activities.

APPENDIX D: PROFILE OF THE RYAN WHITE FUNDED PROVIDERS

The following listing presents information about the Ryan White Part B funded providers by service category for FY2008

Name	City	Minority Provider	Faith-Based Organization	CBC/MAI Organization
Ambulatory/Outpatient Medical Care				
Cape Radiology Group	Cape Girardeau, Mo.	No	No	No
Carle Clinic	Urbana, Ill.	No	No	No
Carle Clinic Association	Urbana, Ill.	No	No	No
Carle Clinic Physician Services	Mattoon, Ill.	No	No	No
Community Health & Emergency Services, Inc.	Carbondale, Ill.	No	No	No
Crusader Central Clinic Association	Rockford, Ill.	No	No	No
Danville Polyclinic	Danville, Ill.	No	No	No
Decatur Memorial Hospital	Decatur, Ill.	No	No	No
DeKalb County Health Department	DeKalb, Ill.	No	No	No
Francis Nelson Health Center	Champaign, Ill.	No	No	No
Heartland CARES, Inc.	Paducah, Ky.	No	No	No
Hektoen Institute/ CORE Center	Chicago, Ill.	No	No	No
Jackson County Health Department	Murphysboro, Ill.	No	No	No
KMB Service Corporation	St. Louis, Mo.	No	No	No
Lake County Health Department	Waukegan, Ill.	No	No	No
Memorial Medical Center	Springfield, Ill.	No	No	No
Open Door Clinic	Elgin, Ill.	No	No	No
OSF Healthcare Systems	Peoria, Ill.	No	Yes	No
Quincy Medical Group	Quincy, Ill.	No	No	No
Ram Ramani, M.D.	Kankakee, Ill.	No	No	No
Regional Care Association	Joliet, Ill.	No	No	Yes
SIU School of Medicine	Springfield, Ill.	No	No	No
Southampton Healthcare	St. Louis, Mo.	No	No	No
Southern Illinois Healthcare	Carbondale, Ill.	No	No	No
Southern Illinois Hematology/Oncology	Centralia, Ill.	No	No	Yes
Southern Illinois Medical Services	Carbondale, Ill.	No	No	No
Springfield Clinic Infectious Diseases	Springfield, Ill.	No	No	No
St. Anthony's Memorial Hospital	Effingham, Ill.	No	Yes	No
Sterling - Rock Falls Clinic	Sterling, Ill.	No	No	No
Swedish American Reference Laboratory	Rockford, Ill.	No	No	No
Tri-County Community Health Center	Malta, Ill.	No	No	No
University of Illinois - Board of Trustees	Chicago, Ill.	No	No	No
University of Illinois College of Medicine	Rockford, Ill.	No	No	No
Venkat Minnaganti	Decatur, Ill.	No	No	Yes
Washington University School of Medicine	St. Louis, Mo.	No	No	Yes
Whiteside County Health Department	Rock Falls, Ill.	No	No	No
Winnebago County Health Department	Rockford, Ill.	No	No	No
Case Management (non-Medical)				
Access Community Health Network	Chicago, Ill.	No	No	No

Adams County Health Department	Quincy, Ill.	No	No	No
AIDS Care Network	Rockford, Ill.	No	No	No
Bethany Place	Belleville, Ill.	No	No	No
Cermak Health Services	Chicago, Ill.	No	No	No
Champaign-Urbana Public Health District	Champaign, Ill.	No	No	No
Chicago Women's AIDS Project	Chicago, Ill.	No	No	Yes
Children's Place Association	Chicago, Ill.	No	No	No
Community Health Care, Inc.	Davenport, Iowa	No	No	No
Coordinated Youth & Human Services	Granite City, Ill.	No	No	No
Crusader Central Clinic Association	Rockford, Ill.	No	No	No
DeKalb County Health Department	DeKalb, Ill.	No	No	No
East Side Health District	East St. Louis, Ill.	Yes	No	Yes
Erie Family Health Center	Chicago, Ill.	No	No	Yes
Fifth Street Renaissance	Springfield, Ill.	No	Yes	Yes
Genesis House	Chicago, Ill.	No	Yes	Yes
Haymarket Center	Chicago, Ill.	No	No	Yes
Heartland Human Care Services/TIA	Chicago, Ill.	No	No	No
Heartland Human Services	Effingham, Ill.	No	No	No
Howard Brown Health Center	Chicago, Ill.	No	No	No
Human Resources Development Institute	Chicago, Ill.	No	No	Yes
Jackson County Health Department	Murphysboro, Ill.	No	No	No
Kankakee Public Health Department	Kankakee, Ill.	No	No	No
Rock Island County Council on Addictions	East Moline, Ill.	No	No	No
SIU School of Medicine	Springfield, Ill.	No	No	No
Southern Illinois Healthcare Foundation	East St. Louis, Ill.	No	Yes	Yes
Southside Health Association	Chicago, Ill.	No	No	Yes
University of Illinois	Peoria, Ill.	No	No	No
Westside Health Center/Hektoen	Chicago, Ill.	No	No	Yes
Whiteside County Health Department	Rock Falls, Ill.	No	No	No
Mental Health Services				
A & E Behavioral Health Care Associates, P.C.	Decatur, Ill.	No	No	No
Behavioral Health Alternatives	Wood River, Ill.	No	No	No
Catholic Charities of Lake County	Waukegan, Ill.	Yes	No	No
Catholic Social Services	Belleville, Ill.	Yes	No	No
Chicago Women's AIDS Project	Chicago, Ill.	No	No	Yes
Children's Place Association	Chicago, Ill.	No	No	No
Clinical Expressions	DeKalb, Ill.	Yes	No	No
Community Resource Center	Centralia, Ill.	No	No	No
Comprehensive Services Inc.	Mt. Vernon, Ill.	No	No	No
Crosspoint Human Services	Danville, Ill.	No	No	No
Dianne C. Whitehead, LCSW	Granite City , Ill.	No	No	No
Cynthia Clark, M.D.	Carbondale, Ill.	No	No	No
DuPage County Health Department	Wheaton, Ill	No	No	No
El Rincon	Chicago, Ill.	Yes	No	No
Family Counseling Service	Rockford, Ill.	No	No	No
Get A Life Coaching and Counseling Services, P.C.	Springfield, Ill.	Yes	No	No

Heartland Human Services	Effingham, Ill.	No	No	No
Hektoen Institute/ CORE Center	Chicago, Ill.	No	No	No
Kevin Elliott, LCPC	Champaign, Ill.	No	No	No
Patricia Murrell, LCSW	Alton, Ill.	No	No	No
Ruth Kathryn Pearson, M.A.,L.C.P.C.	Springfield, Ill.	No	No	No
SIU School of Medicine	Springfield, Ill.	No	No	No
South Park Psychology	Moline, Ill.	No	No	No
Southeastern Illinois Counseling Center, Inc.	Olney, Ill.	No	No	No
Tim Shea	Champaign, Ill.	No	No	No
Universal Family Connection, Inc.	Chicago, Ill.	No	No	Yes
Vital Bridges	Chicago, Ill.	No	No	No
Oral Health				
Adams County Health Department	Quincy, Ill.	No	No	No
Aunt Martha's Youth Service	Danville, Ill.	No	No	No
Champaign Dental Care	Champaign, Ill.	No	No	No
Community Health and Emergency Services	Cairo, Ill.	No	No	No
Crusader Central Clinic Association	Rockford, Ill.	No	No	No
Dental Dreams, LLC	Rockford, Ill.	No	No	No
Denzel D. Jines II, D.M.D. ,P.C.	St. Louis, Mo.	No	No	No
Dr. Kathryn Kell	Davenport, Iowa	No	No	No
Dr. Troy Roeder, D.D.S.	Moline, Ill.	No	No	No
Duane Davis, D.M.D.	Mt. Vernon, Ill.	No	No	No
Heartland Family Dental	Effingham, Ill.	No	No	No
Helen G. McDonal, LCSW, MSW	Champaign, Ill.	No	No	No
JMJ Dental	Springfield Ill.	No	No	No
John Vallone, D.D.S	Bourbonnais, Ill.	No	No	No
Kirk Noraian, D.D.S	Urbana, Ill.	No	No	No
Macon County Health Department	Decatur, Ill.	No	No	No
Open Door Clinic	Elgin, Ill.	No	No	No
Peoria City/County Health Department	Peoria, Ill.	No	No	No
Philip Banghart, D.D.S.	Mattoon, Ill.	No	No	No
Raffi Leblebijian, D.D.S., L.L.C.	Kankakee, Ill.	No	No	No
Smile Team Dental	Belleville, Ill.	No	No	No
Southampton Dental	St. Louis, Mo.	No	No	No
Steve Tabb	Springfield, Ill.	No	No	No
Timothy Case, D.M.D.	St. Louis, Mo	No	No	No
Vanessa Cole, D.M.D.	Centralia, Ill.	No	No	No
Substance Abuse Services-Outpatient				
Better Existence with HIV – BEHIV	Evanston, Ill.	No	No	Yes
Chicago House & Social Service Agency	Chicago, Ill.	No	No	No
Community Resource Center	Centralia, Ill.	No	No	No
Comprehensive Services Inc.	Mt. Vernon, Ill.	No	No	No
Gateway Foundation	Chicago, Ill.	No	No	No
Haymarket Center	Chicago, Ill.	No	No	Yes
Heartland Human Services	Effingham, Ill.	No	No	No
Personal Counseling Services, Inc.	Springfield, Ill.	No	No	No
Regional Care Association	Joliet, Ill.	Yes	No	No

Research and Education Foundation of Michael Reese Hospital	Chicago, Ill.	No	No	No
ADAP				
Amerisource Bergen	Glen Allen, Va.	No	No	No
PharmaCare	Pittsburgh, Pa.	No	No	No
Child Care Services				
Chicago Women's AIDS Project	Chicago, Ill.	No	No	Yes
Children's Place Association	Chicago, Ill.	No	No	No
Emergency Financial Assistance				
Agape Missions, Inc.	Joliet, Ill.	Yes	No	No
Central IL Friends of PWA, Inc.	Peoria, Ill.	No	No	Yes
Champaign-Urbana Public Health District	Champaign, Ill.	No	No	No
Coordinated Youth & Human Services	Granite City, Ill.	No	No	No
DOVE, Inc.	Decatur, Ill.	No	No	No
Heartland Human Services	Effingham, Ill.	No	No	No
Jackson County Health Department	Murphysboro, Ill.	No	No	No
Rock Island County Council on Addiction	East Moline, Ill.	No	No	No
Winnebago County Health Department	Rockford, Ill.	No	No	No
Legal Services				
AIDS Legal Council of Chicago	Chicago, Ill.	No	No	No
Heartland Human Services	Effingham, Ill.	No	No	No
Land of Lincoln Legal Assistance Foundation	E. St. Louis, Ill.	No	No	No
Prairie State Legal Services, Inc.	Carol Stream, Ill.	No	No	No
Prairie State Legal Services, Inc.	Rockford, Ill.	No	No	No
Food Bank/Home-Delivered Meals				
AIDS Foundation of Chicago	Chicago, Ill.	No	No	No
Catholic Charities of Lake County	Waukegan, Ill.	No	Yes	No
Catholic Urban Programs	East St. Louis, Ill.	Yes	Yes	No
Champaign-Urbana Public Health District	Champaign, Ill.	No	No	No
Community Kitchen, Inc.	Rockford, Ill.	No	No	No
Food Outreach	St. Louis, Mo.	No	No	No
Greater Community AIDS Project	Champaign, Ill.	No	No	No
Heartland Human Care Services/TIA	Chicago, Ill.	No	No	No
Heartland Human Services	Effingham, Ill.	No	No	No
Jackson County Health Department	Murphysboro, Ill.	No	No	No
Peoples Resource Center	Wheaton, Ill.	Yes	No	No
Peoria City/County Health Department	Peoria, Ill.	No	No	No
Rock Island County Council on Addiction	East Moline, Ill.	No	No	No
Rock River Valley Pantry	Rockford, Ill.	No	No	No
SIU School of Medicine	Springfield, Ill.	No	No	No
St. Clair County Health Department	Belleville, Ill.	No	No	No
St. Elizabeth Hospital	Belleville, Ill.	No	Yes	No
Vital Bridges	Chicago, Ill.	No	No	No
Voluntary Action Center of DeKalb County	Sycamore, Ill.	No	No	No
Winnebago County Health Department	Rockford, Ill.	No	No	No
Housing Services				
Agape Missions, Inc.	Joliet, Ill.	No	No	Yes

Alexian Brothers (The Harbor)	Waukegan, Ill.	Yes	No	No
AMA Investment Inc., D/B/A Homestyle Inn & Suites	Springfield, Ill.	No	No	No
Bonaventure House - Alexian Brothers	Chicago, Ill.	Yes	No	No
Central IL Friends of PWA, Inc.	Peoria, Ill.	No	No	Yes
Champaign-Urbana Public Health District	Champaign, Ill.	No	No	No
Chicago House & Social Service Agency	Chicago, Ill.	No	No	No
Children's Place Association	Chicago, Ill.	No	No	No
Dove, Inc.	Decatur, Ill.	No	Yes	No
Heartland Human Services	Effingham, Ill.	No	No	No
Interfaith House	Chicago, Ill.	Yes	No	No
Interfaith Residence, D/B/A Doorways	St. Louis, Mo.	No	No	Yes
Jackson County Health Department	Murphysboro, Ill.	No	No	No
Winnebago County Health Department	Rockford, Ill.	No	No	No
Medical Nutrition Therapy				
Lake County Health Department	Waukegan, Ill.	No	No	No
Open Door Clinic	Elgin, Ill.	No	No	No
Rehabilitation Services –No Services Funded During This Cycle				
Medical Transportation Services				
Action Taxi Service	Rockford, Ill.	No	No	No
AIDS Foundation of Chicago	Chicago, Ill.	No	No	No
Carbondale Cab, Inc.	Carbondale, Ill.	No	No	No
CEFS Economic Opportunity Corporation	Effingham, Ill.	No	No	No
CHELP, Inc.	Decatur, Ill.	No	No	No
Heartland Human Services	Effingham, Ill.	No	No	No
Helping Hands, Inc.	Belleville, Ill.	No	No	No
Jackson County Health Department	Murphysboro, Ill.	No	No	No
Peoria City/County Health Department	Peoria, Ill.	No	No	No
Retired and Senior Volunteer Program, RSVP (Board of Trustees)	Quincy, Ill.	No	No	No
Rock Island County Council on Addictions	East Moline, Ill.	No	No	No
SIU School of Medicine	Springfield, Ill.	No	No	No
Smart Transportation	Ullin, Ill.	No	No	No
South Central Transit	Centralia, Ill.	No	No	No
St. Clair County Health Department	Belleville, Ill.	No	No	No
Voluntary Action Center	Sycamore, Ill.	No	No	No
Winnebago County Health Department	Rockford, Ill.	No	No	No
Outreach Services				
East Side Health District	East St. Louis, Ill.	Yes	No	No
Jackson County Health Department	Murphysboro, Ill.	No	No	No
Jackson County Health Department Pilot Prison Outreach Program	Murphysboro, Ill.	No	No	No
Psychosocial Support Services				
Chicago Women's AIDS Project	Chicago, Ill.	No	No	Yes
Department of Children and Family Services	Chicago Ill.	No	No	No
Families and Children's AIDS Network	Chicago, Ill.	No	No	No
Heartland Human Services	Effingham, Ill.	No	No	No

Jackson County Health Department	Murphysboro, Ill.	No	No	No
Test Positive Aware Network	Chicago, Ill.	No	No	No
Health Insurance Premium & Cost Sharing Assistance				
Illinois Public Health Association	Springfield, Ill.	Yes	No	No
Treatment Adherence Counseling				
Jackson County Health Department	Murphysboro, Ill.	No	No	No

Printed by Authority of the State of Illinois
P.O. #519261 200 4/09