

2005 Kentucky Comprehensive Plan

Prepared by:

David E. Clark, M.P.A.

Ryan White Title II Program Administrator

Kentucky Cabinet for Health Services

275 East Main Street HS2E-C

Frankfort, Kentucky 40621

Davide.clark@ky.gov

(502) 564-6539 ext. 3554

Table of Contents

Executive Summary

Introduction

Section I

Overview of Kentucky HIV/AIDS Care Coordinator Program

Updated Kentucky Epidemiological Profile

Section II

Key Funding Questions and Responses (Focus Groups)

Intended Use of Funds

Organization and Delivery of Services

Service Priorities

Identifying HIV+ Kentuckians Who Are Not Receiving Services

Goals, Timetable, and Allocation of Funds

Kentucky Cabinet for health and Family Services

Kentucky Department for Public Health

HIV/AIDS Branch

dc

**Kentucky State Comprehensive Plan
2005**

Table of Contents (cont)

Coordinating Title II Funds with HIV Prevention Services
Coordinating Title II Funds with Substance Abuse Prevention Services
Coordinating Activities with Other CARE Act Titles
Coordinating Activities with Other Federal Programs

Section III

HRSA Comprehensive Plan priorities
Kentucky agenda for Comprehensive Plan

Section IV

Monitoring Progress

Kentucky State Comprehensive Plan 2005

Executive Summary

The Kentucky 2005 HIV/AIDS Comprehensive Plan draws on information gathered from three focus groups with HIV+ clients of the HIV/AIDS Care Coordinator Program. This material is supplemented by the 2002 Kentucky HIV/AIDS Needs Assessment and various program and the most recent epidemiological data provided by the Kentucky Care Coordinator Program (KHCCP).

This plan includes a number of specific enhancements to the existing program services. There are also eight priority recommendations:

Key Funding Questions for Kentucky

The following questions and responses are required for Comprehensive Plans for Title II programs such as the Kentucky HIV/AIDS Care Coordinator Program.

Priorities of the Comprehensive Plan

***Priority One:** Ensure the availability of core services (HIV related medications, mental health and substance abuse treatment, oral health and case management)*

***Priority Two:** Eliminate disparities in access to services*

***Priority Three:** Specific strategies for identifying individuals who know their status but are not in care.*

***Priority Four:** Address the primary health care and treatment of those who know their status but are not in care, as well as those current in the HIV/AIDS care system.*

***Priority Five:** Provide goals, objectives, timelines, funds, etc., based on the needs assessment*

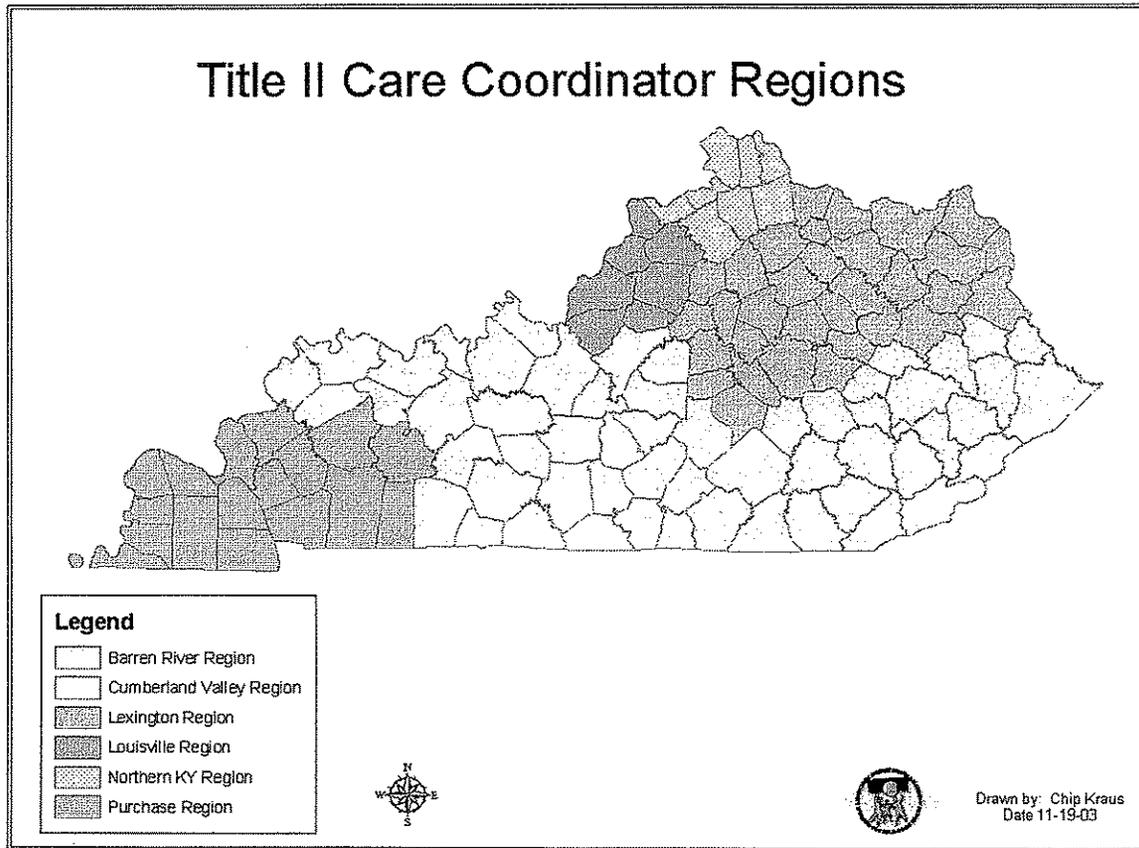
***Priority Six:** Coordinate services with HIV prevention programs*

***Priority Seven:** Coordinate services with substance abuse prevention and treatment programs.*

**Kentucky State Comprehensive Plan
2005**

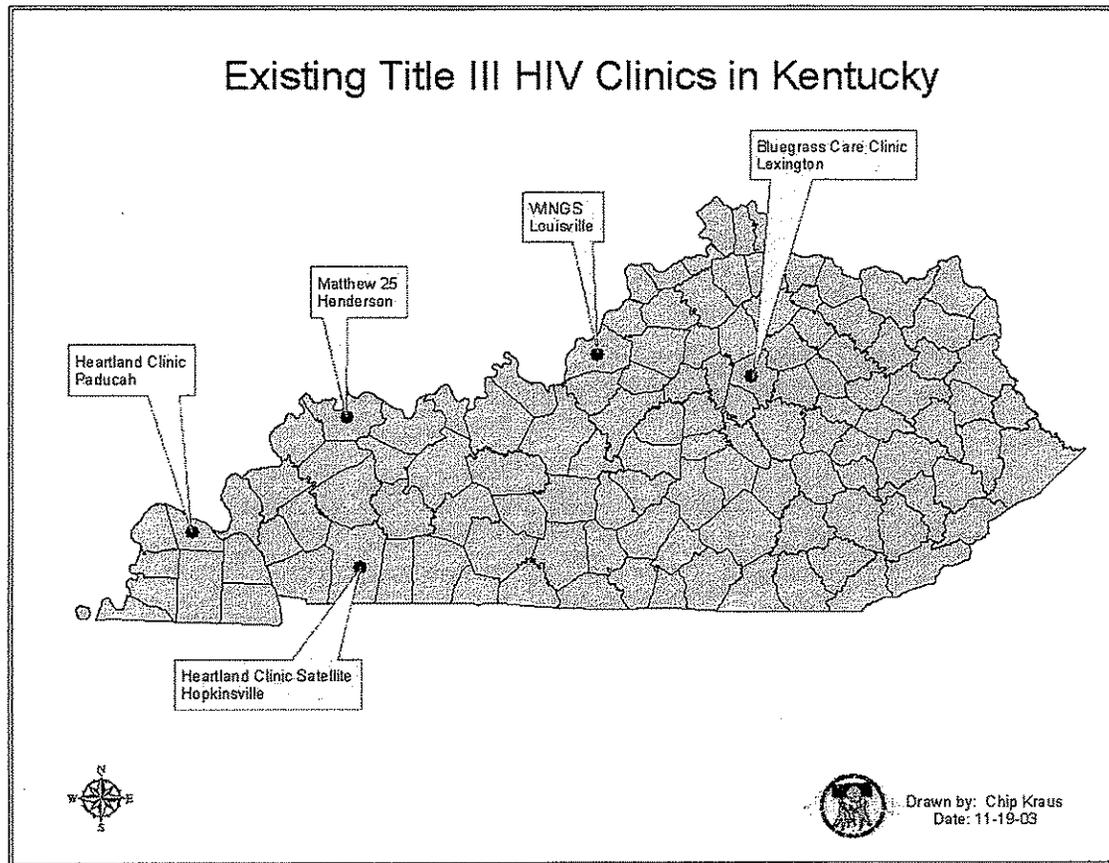
Map 1

Map courtesy of Barren River Health District, Chip Kraus



Map 2

Courtesy of Barren River Health District, Chip Kraus



Bluegrass Care Clinic

- Service Area
- Clinic



SECTION 1- Where are we now?

Introduction

The 2005 Kentucky HIV/AIDS Statewide Comprehensive Plan is part of a continuing effort by the Kentucky Care Coordinator Program (KCCP) to respond to clients' needs. Federal funding is also linked to having a statewide comprehensive plan that addresses key health care priorities and delivery questions. This document builds upon findings from the 2002 Kentucky HIV/AIDS Needs Assessment Survey conducted in the fall of 2001.

Focus Groups for SCSN and Needs Assessment

On Wednesday, October 19, 2005, Dr. Jeff Jones and Sharmi Ray with the University Of Kentucky College Of Public Health conducted three focus groups at the Lexington Public Library's conference room with a broad range of service agencies and clients. Through contacts provided by the Kentucky Department for Public Health's HIV/AIDS Branch, twenty-eight individuals were scheduled to attend. Because of last minute problems for some attendees, twenty-three actually were able to make the trip to Lexington and participate. Represented stakeholders included:

- Five clients
- Heartland Cares, Title III clinic, Paducah, Hopkinsville, and Carbondale, IL
- Matthew 25, Title III clinic, Henderson, Owensboro, and Evansville, IN
- WINGS, Title III clinic, Louisville
- Northern Kentucky Health Department, Title II care coordination site
- Barren River Health District, Title II care coordination site, Bowling Green
- Kentucky Department for Public Health, Frankfort
- Kentucky Department of Disability Determination Services, Frankfort
- University of Kentucky Area Health Education Center (AHEC), Lexington
- University of Louisville, dentistry program, Louisville
- Bluegrass Farmworkers Health Center, Richmond
- Volunteers of America, Title II care coordination site, Louisville

To respect clients' confidentiality, no participant was asked about their HIV status. The five clients self-disclosed their status.

Kentucky State Comprehensive Plan 2005

Demographically, all five clients were male. Two were African-American while the other three were white. While the other clients appeared to be in their late 20s to early 40s, one client disclosed that he was over 50. Two others reported that they had been released from prison within the last two months.

Participants received \$50 for their participation as well as refreshments and travel reimbursement. Individuals traveling more than three hours to attend were also provided housing (hotel) and a per diem for meals.

Unlike the 2003 Needs Assessment process, Care Coordinators were represented in the focus group process.

Overview of Kentucky HIV/AIDS Care Coordinator Program

The 1990 Omnibus Kentucky AIDS Act established the Kentucky HIV/AIDS Care Coordinator Program within the Cabinet for Health Services' Department for Public Health to coordinate care services for Kentucky residents infected with HIV. These services are primarily federally funded through the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. Within the Ryan White CARE Act are several different Title series. Generally these Titles conform to the following funding issues:

1. Title I: Special programs for metropolitan areas with high numbers of people living with HIV/AIDS involving inter-agency planning councils
2. Title II: Care coordinator services
3. Title III: HIV/AIDS clinics
4. Title IV: Special programs for women and children living with HIV disease
5. Part F: Special Projects of National Significance (SPNS); AIDS Education and Training Centers (AETC); and the HIV/AIDS Dental Reimbursement Programs

Kentucky has programs funded through Titles II, III, IV and Part F (dental/University of Louisville). The Title II program funds the Kentucky Care Coordinator Program (KHCCP).

The KCCP operates through six regional offices coordinated by the Department of Public Health's HIV/AIDS Branch in Frankfort:

1. Matthew 25 AIDS Services, Inc. (Henderson)
2. Cumberland Valley District Health Department (London)
3. Lexington/Fayette County Health Department (Lexington)
4. Volunteers of America (VOA) (Louisville)
5. Northern Kentucky District Health Department (Ft. Mitchell)

Kentucky Cabinet for health and Family Services
Kentucky Department for Public Health
HIV/AIDS Branch
dc

**Kentucky State Comprehensive Plan
2005**

6. Heartland CARES, Inc. (Paducah)

Heartland CARES, Inc., and Matthew 25 AIDS Services are the only regional contractors which receive both Title II and III funding. Subsequently, these agencies possess both case management (Title II) and clinical treatment (Title III) capabilities. Heartland CARES, Inc. also participates in a Special Projects of National Significance (SPNS).

Each region contains significant variations in operating context. For instance, each regional office defines how it will spend particular Ryan White Grant funds to best serve their clients. Available services, client demographics, and social climates between the six Care Coordinator offices also vary. Even the buildings housing the regional offices are very different and reflect the availability and cost of clinic space in urban versus rural areas.

Caseloads per Care Coordinator also differ, as demonstrated below:

Caseload Per Each Care Coordinator in FY 2005

Cumberland Valley:	59
Lexington:	76
VOA-Louisville:	82
Northern Kentucky:	67
Heartland CARES:	83*
Matthew 25	92*

Source: Kentucky HIV/AIDS Care Coordinator Program, Frankfort, KY

*As a Title III clinic, Paducah's Heartland CARES Clinic and Henderson's Matthew 25 AIDS Services serve clients from contiguous states.

Since the 2003 Assessment, overall KHCCP caseloads continue to increase due to increasing rates of new infections, and the availability of life extending pharmaceuticals. As noted in 2003, Kentucky continues to see a decline in new cases of full-blown AIDS cases. However the influx of new HIV+ clients requiring drug assistance and case management continues to grow, which is reflected in the increase in KHCCP caseloads. It must be noted, that after approximately 7 years of flat State funding for KADAP, the Kentucky General Assembly authorized an additional \$90,000 dollars, to a grand total of \$180,000 for KADAP. While appreciated, this small increase, combined with annual percent decreases in

Kentucky State Comprehensive Plan 2005

federal Ryan White Title II funding, will not eradicate the State's KADAP waiting list for life-sustaining medications. In 2002, KADAP had a waiting list of over 100, by the end of calendar year 2005 the waiting list reached 256.

General Kentucky Demographics

According to the 2000 U.S. Census, Kentucky has a population of 4,041,769. Since 1990 Kentucky has grown by 9.6% compared to the 13.1% growth for the country as a whole. Ethnically, however, Kentucky remains one of the least diverse states. Nine out of every ten Kentuckians is white and non-Hispanic:

1. 89.3% White/European-American, non-Hispanic
2. 7.3% Black/African-American
3. 1.5% Hispanic/Latino of any race
4. 1.1% Kentuckians reporting two or more races

(Source: 2000 U.S. Census)

Only 2% of Kentuckians are foreign born and only 3.9% speak a language other than English at home. According to the Kentucky Department of Education, Spanish and Bosnian are the two most commonly spoken primary languages for students entering the public schools' English as a Second Language classes. The Spanish component results from a fairly recent influx of Spanish-speaking immigrants primarily from Mexico. Kentucky also serves as a refugee resettlement site and has become the home of a number of Bosnian refugees.

Kentucky also is among the poorer states. According to the Census Bureau, 15.8% of Kentuckians lived below the poverty limit in 1999. For the U.S. as a whole, 12.4% of Americans lived below the poverty limit in 1999. Also in 1999, the median household income was \$33,672 compared to the \$41,994 for the U.S. as a whole.

Kentucky also lags behind the rest of the U.S. in education with only 74.1% of Kentuckians over 25 years of age having graduated high school. This compares unfavorably to the national average of 80.4%. While one in four Americans over the age of 25 nationwide have graduated from college with a bachelor's degree or higher, only one in six Kentuckians have attained a college degree.

Nearly one in every 900 Kentuckians had tested positive for HIV by 2000.

Kentucky's Epidemiological Profile

Kentucky Cabinet for Health and Family Services
Kentucky Department for Public Health
HIV/AIDS Branch

dc

Kentucky State Comprehensive Plan 2005

2. Epidemiology

The following is a brief narrative description of Kentucky's HIV/AIDS epidemiological data.

A. Table 3 has been completed and included.

Source of AIDS Prevalence data

In Table 3 of the Ryan White CARE Act Title II grant application, AIDS prevalence and incidence data provided by the Centers for Disease Control and Prevention (CDC), which were adjusted for reporting delay, were used. These data however, were too limited to use in a complete profile therefore data collected by Kentucky Department for Public health were used for more detailed analyses in the epidemiologic profile. This narrative contains data reported through June 30, 2005.

Sources of HIV Prevalence data

In 2001, the CDC provided estimates of the number of adults and adolescents living with diagnosed HIV infection (non-AIDS) for areas with newly implemented systems or no HIV case surveillance yet in place. This year the CDC will not be providing modeled estimates for diagnosed HIV prevalence in areas that have implemented HIV reporting since 1995 or for those areas that have not yet implemented HIV reporting. Although Kentucky has implemented the name-based reporting system as of July 15, 2004, the recent implementation of this reporting system prevents any HIV data from being released at this time. Therefore, previous HIV prevalence estimates will be adjusted using an adjustment factor based on the change in AIDS prevalence. This adjustment factor was then multiplied by the diagnosed HIV prevalence estimate at the end of 2003 to obtain an estimate of diagnosed HIV prevalence at the end of December 2004.

Trends and Changes in Kentucky's HIV/AIDS Cases

As of June 30, 2005 there were 4,253 AIDS cases reported to the Kentucky Department for Public Health. A dramatic decline in the AIDS incidence rate in Kentucky, based on year of AIDS diagnosis, was observed from 1996 to 2000 and can be attributed mainly to the introduction of highly active anti-retroviral treatment (HAART) in the mid-990s. In the year 2001, for the first time since 1995, a slight increase in the AIDS incidence rate was observed in Kentucky and has continued through 2002. In 2003, the AIDS rate has shown a decrease from 6.3 per 100,000 in 2002 to 5.0 per 100,000 in 2003. This trend will continue to be monitored as more data becomes available. AIDS prevalence, or the number of persons living with AIDS in Kentucky has increased in recent years. AIDS prevalence has increased 33 percent from 1,774 persons living with AIDS as of June 30, 2001 to 2,359 persons living with AIDS as of June 30, 2005. According to adjusted HIV (not AIDS) estimates provided by the CDC there are approximately 4,078 persons living with HIV (not AIDS) in Kentucky.

Demographics of Kentucky's HIV/AIDS Cases by Gender

Males represent a sizable majority of AIDS cases in Kentucky with 85% of total AIDS cases reported and 77% of cases diagnosed with AIDS in 2003. The AIDS incidence rate among males is approximately four times higher than the rate for females. Diagnosed AIDS cases among males increased 18% from 176 cases diagnosed in 2000 to 208 cases diagnosed in 2002, while AIDS cases decreased by ~23% from 2002 to 2003.

Kentucky State Comprehensive Plan 2005

Race

Whites comprise the majority of cumulative AIDS cases at 67%. However, African Americans are affected disproportionately by the epidemic in Kentucky. For instance, in 2003 African Americans comprised 7.5 percent of Kentucky's total population, yet accounted for 37% of diagnosed AIDS cases. The AIDS incidence rate for African Americans is approximately eight times higher than the rate for whites and other races. However, in recent years an increase in newly diagnosed cases among whites has been observed in Kentucky. Diagnosed AIDS cases among Whites increased by 38% from 115 cases diagnosed in 2000 to 159 cases diagnosed in 2002, but has decreased by 27% from 2002 to 116 cases in 2003.

Age

In 2003, the largest percent of Kentucky AIDS cases (64%) were diagnosed between the ages of 24 and 44 years. The next highest percentage of AIDS cases is among adults between the ages of 45 and 64 years (27%), followed by those between the ages of 13-23 years of age (9%). A decrease in the number of AIDS cases diagnosed between the ages of 24 and 44 as well as those ages 45 to 64 was observed in 2003, whereas the age group of 13-24 showed an increase in AIDS diagnosis.

Mode of Exposure

Men having sex with men (MSM) represents the main HIV mode of exposure among AIDS cases in the state of Kentucky. MSM comprise the majority (56%) of all AIDS cases reported. The second highest risk behavior is injecting drug use (IDU) at 14%, followed by Heterosexual contact at 12% and MSM/IDU at 6%. In recent years,

the number of AIDS cases with undetermined mode of exposure information has decreased (9%), however, the high numbers of undetermined cases makes comparison of cases by mode of exposure difficult.

Geographic Variations of HIV/AIDS Cases in Kentucky

The impact of the AIDS epidemic in Kentucky is not uniformly distributed across the state. The majority of AIDS cases reside in the urban areas of Kentucky. The largest number of AIDS cases (46%) residing in Kentucky at the time of diagnosis were reported in the North Central Area Development District (ADD) which includes the city of Louisville. The Bluegrass ADD had the second largest number of AIDS cases (19%) reported in Kentucky which includes the city of Lexington, followed by the Northern Kentucky ADD with the third largest number of AIDS cases 8% reported in the state of Kentucky.

2. Estimated number of Kentuckians not in care as calculated using the unmet need framework

Strategies have begun in Kentucky to measure the unmet need of persons with HIV/AIDS living in Kentucky. Currently, HIV data is unavailable in Kentucky. HIV data cannot be obtained due to a new legislative passed in 2004 changing the current reporting system from code-based reporting to name-based reporting as accepted by the CDC. Switching from the code-based reporting methods to the name-based reporting method has required a system wide audit of Kentucky HIV records in which many were no longer valid in accordance with the name-based reporting system as advised by the CDC guidelines. However, unmet needs for patients living with AIDS in Kentucky are available for report and will be included in this section.

Measuring Unmet Need by Using Laboratory Data

Kentucky law 902 KAR 2:020 section 7 requires that all laboratories report all CD4 and viral load counts regardless of disease or infection for all persons testing within the state of Kentucky. The laboratory results pertaining to HIV/AIDS patients are entered into a database and are matched to the AIDS cases entered into the HIV/AIDS

Kentucky State Comprehensive Plan 2005

Reporting System (HARS) database as established by the CDC. Those diagnosed within a certain time period can be characterized as having care needs “met” or “unmet” by whether they have had these laboratory tests within the last 12-month period (this period is defined for this measurement to be between November 2004 and October 2005). This method assumes that all laboratories are in compliance with reporting as well as that laboratory information is complete. A limitation to this method is the unavailability of Kentucky HIV data due to the recent change from the ‘Unique Identifier’ HIV reporting system to the ‘Confidential Name-based HIV reporting system.

Unmet Needs Calculation

As of October 2004, there were 2,379 individuals living with AIDS in Kentucky. Also as of October 2004, there were 893 individuals living with AIDS receiving primary medical care as defined by the following: (1) viral load testing or (2) CD4 counts as reported by Kentucky laboratories as previously mentioned. Kentucky’s unmet need for individuals living with AIDS is calculated below:

$$1 - \left[\frac{1,019 \text{ individuals LWA in Kentucky receiving care(as defined)}}{2,383 \text{ individuals LWA in Kentucky}} \right] * 100 = 57\%$$

As of October 2004, 57% of Kentucky’s population living with AIDS is not receiving primary HIV medical care as previously defined. As stated previously, a limitation to our unmet needs data at this time is the unavailability of HIV data and therefore unmet need for those with HIV cannot be calculated at this time.

ASSESSMENT OF HIV+ INDIVIDUALS WITH AN UNMET NEED IN KENTUCKY

The information listed below is the demographic and subpopulation analyses of the people who are not in care in the state of Kentucky based on the results of our Unmet Needs Framework using laboratory data reported to the Kentucky HIV/AIDS Surveillance Program.

Race

Of the 1,364 individuals currently living with AIDS who have not had their HIV primary care needs met, 65% are white, 30% African-American, 4% Hispanic, and <1% are of other races. Of the 1,514 white living AIDS cases, 58% have an unmet need; of the 762 African-American living AIDS cases, 55% have an unmet need; and of the 91 Hispanic living AIDS cases, 60% have an unmet need.

Gender

Of the 1,364 individuals currently living with AIDS who have not had their HIV primary care needs met, 85% are male and 15% are female. Of the 1,970 living male AIDS cases, 59% have an unmet need and of the 413 living female AIDS cases, 49% have an unmet need.

Geographical

Of the 1,364 individuals currently living with AIDS who have not had their HIV primary care needs met, 75% are from urban areas and 25% are from rural areas. Of the 580 living in rural AIDS cases, 60% have an unmet need and of the 1,802 living urban AIDS cases, 56% have an unmet need.

Age

Of the 1,364 individuals currently living with AIDS who have not had their HIV primary care needs met, the majority, 74% were between the ages of 25 and 44 years. Seventeen percent of living AIDS cases who have not had their HIV primary care needs met are between the ages of 20 and 29 years, 44% between the ages of 30 and 39 years, and 29% between 40 and 49 years. Ten percent of AIDS cases with an unmet need are 50 years or older. Of the 16 living AIDS cases diagnosed in individuals <13 years of age, 60% have an unmet need; of the 18 living AIDS

**Kentucky State Comprehensive Plan
2005**

cases between 13 and 19 years of age, 61% have an unmet need; of the 401 living AIDS cases between 20 and 29 years of age, 57% have an unmet need; of the 1,031 living AIDS cases between the ages of 30 and 39, 58% have an unmet need; of the 685 living AIDS cases between the ages of 40 and 49, 57% have an unmet need; and of the 232 living AIDS cases 50 years or older, 58% have an unmet need.

Risk Factor

Of the 1,354 individuals currently living with AIDS who have not had their HIV primary care needs met, the majority, 53% are MSM, 15% are IDU, 13% are heterosexual, and 6% are MSM/IDU. Of the 1,250 living MSM AIDS cases, 58% have an unmet need; of the 343 IDU AIDS cases, 59% have an unmet need; of the 335 Heterosexual cases, 51% have an unmet need; and of the 126 combined MSM/IDU living AIDS cases, 60% have an unmet need.

SECTION TWO- Where do we need to go?

A quarter century into the AIDS pandemic, Kentucky's care response is increasingly operates in a period of growing client loads and relatively static funding. The economic recession and its aftermath have left many low income clients under increased financial stress. Many are growing older and in need of medications not available through the HIV formulary. Agencies in turn are increasingly devoting more resources to pharmaceutical assistance and relying upon clients to keep appointments and take a greater responsibility for accessing the care system. Clients and agencies alike wish for the staffing and time to conduct more home visits that might reach severely depressed clients who have dropped out of the care system. While there remain ways to tweak the system to improve care for clients, many of the critical needs can only be met with significant structural changes to the funding of not only HIV/AIDS care but the entire patchwork of public and private health care and health insurance systems. Focus group participants, however, offered no clear, enthusiastic organizational design for advocating for such changes. Rather pessimistically but perhaps pragmatically from their experience, most care workers believe the on-going trend of reducing services and focusing limited spending on drug assistance and medical care will continue indefinitely the immediate future.

Focus Group Questions

The focus groups involved in the 2005 sessions, were essentially assessing HIV/AIDS care continuum in Kentucky. The 2005 focus groups were essentially assessing the HIV/AIDS care continuum in Kentucky. For operational purposes, the state HIV/AIDS program defines continuum of care as; the network of available HIV/AIDS referral and treatment services in Kentucky. For Title II in Kentucky, this means HRS'a core services;

- **Case Management**
- **Oral health**
- **HIV-related Medications**
- **Primary Medical Care**
- **Mental Health Treatment**
- **Substance Abuse Treatment**

Participants were asked six questions. Their responses at times would lead to other questions or topics among participants. The six questions were:

1. Participants were asked to allocate a total Title II budget of \$100 towards various categories and to then explain why they prioritized their budget items the way they did.
2. *Besides medications, what is the most important and positive aspect of the Care Coordination Program to you?*
3. *On the other hand, what is the least effective part of the Care Coordination Program?*
4. *You or your clients already access the Care Coordination Program regularly. What types of people do you know of that are not in the program but would benefit from it? How do you suggest reaching out to these people in a way to get them into services? What are some of the barriers that keep these people from coming in for services?*

**Kentucky State Comprehensive Plan
2005**

5. *What do you think is the average education level of your community? Of clients?*

5. *Do you know individuals (including yourself) who are willing to advocate for getting more state dollars for HIV/AIDS treatment and prevention? Are there reasons that these individuals cannot or do not want to advocate?*

Responses

Participants' responses are aggregated by specific questions, suggestions or themes that emerged from the focus groups.

1. Budget Exercise

Participants were asked to allocate a total Title II budget of \$100 towards various categories and to then explain why they prioritized their budget items the way they did.

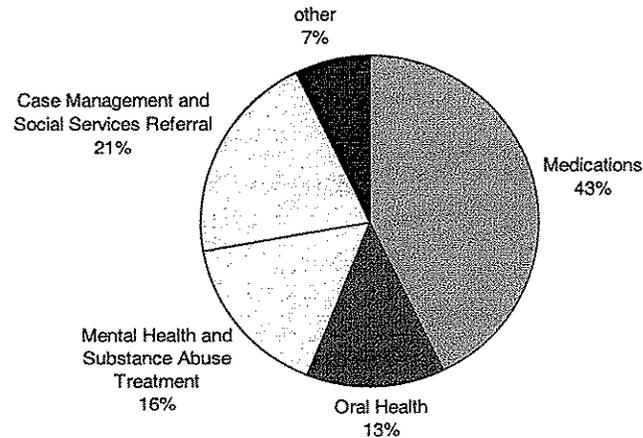
When forced to prioritize spending areas, the participants would allocate funds in this order:

- *Clients' Medications*
- *Case Management and Social Services Referrals*
- *Mental Health and Substance Abuse Treatment*
- *Oral Health*
- *Transportation*
- *Housing, Provider Education, and "Assisting with Healthy Living"*

Having an allocation of only \$100 to provide all Title II services, participants were asked to create a prioritized budget. The graph below shows the average responses for each of the four categories (medications, oral health, mental health/substance abuse treatment, and case management/social services referrals).

Kentucky State Comprehensive Plan
2005

Budget Exercise Results



Based on averages¹ of the 23 participants' responses, priority is given to using Title II funds to provide clients' medications. Responses from the three focus groups were largely parallel. The one exception is that the focus group consisting primarily of northern Kentucky clients and staff allocated a greater amount towards mental health and substance abuse treatment than the other two focus groups.

I think that medication is the most important... if the client is ready to take them. And the oral health is import[ant] because a lot of bacteria[!] infection are [sic] prominent. They are all important!!!

Comment from budget exercise

Clients could also designate a portion of their budget to a category outside of the four listed. Three participants allocated funds for transportation. Housing, "assisting with healthy living", and "provider

and individual) were not significantly different than the averages. Therefore, the

**Kentucky State Comprehensive Plan
2005**

education” were each listed by a single participant as another category to fund.

The participants almost universally believed that all the listed budget areas were necessary and felt that this exercise was particularly difficult.

2. Care Coordinators: It Takes a Village

Question 2: Besides medications, what is the most important and positive aspect of the Care Coordination Program to you?

HIV+ clients in the focus groups and service providers who regularly work with care coordinators were highly complimentary of care coordinators as hardworking and dedicated. While care coordinators are paid service providers in the strictest sense, clients and other service providers have come to view care coordinators as ‘village leaders’ who create and maintain communities through their work. Clients also report that creating, maintaining, and belonging to a community of care providers, the infected, and the affected is a key element of maintaining health.

Clients and service providers view care coordinators as giving stability and structure to the entire HIV/AIDS care network. As often the most trusted point of clients sense that care coordinators referrals. Moreover, they view their Clients in the focus groups also coordinators as the *community* for the coordinators are seen as creating HIV and the service community clients, they initially knew no one else when clients initially were wrestling with concerns about disclosing their infection, clients did not feel comfortable attending support groups or functions with other HIV+ Kentuckians. Thus, in some cases for years, a client’s only contact with a perceived community of fellow HIV-infected people has been through their care coordinator.

We’ll keep them alive, and you do the touchy feely stuff.

Physician to care coordinator over their shared roles to keep clients physically and emotionally healthy

contact for clients in the care network, are critical sources of information and care coordinator as a trusted friend. interestingly describe their local care HIV infected and affected. Care *villages* consisting of families infected by interacting with these families. For some who was infected. During the period

Care coordinators are the community for this disease...they are the village that provides the stability and the friend who you can communicate with as with no one else.

Participant explaining the most positive aspects of the care coordination system

Yet, the clients in the focus groups say that peer-to-peer contacts have had the greatest impact on their personal lives. Through shared community events such as dances, bowling nights, and holiday parties, clients have been able to process their fears and experiences with HIV/AIDS stigma.

**Kentucky State Comprehensive Plan
2005**

These events also provide a forum for clients to intentionally or unintentionally model examples of healthy lives and set community norms around adherence.

Service providers also see care coordinators as vital. For instance, it is the care coordinators who funnel client referrals into dental services. Medical care workers also find that clients will tell clinic staff one thing and care coordinators another. Sharing information often allows both clinician and care coordinator to better serve clients who may be embarrassed, afraid, or avoiding an issue critical to their care.

Another sometimes overlooked function of care coordination that participants raised is data collection. Several participants report that they depend on statistics such as the number of dental referrals that are available

They [care coordinators] go to work [for you] when people say "no".

Client describing the role of his care coordinator

on statistics such as the number of only from care coordinators.

3. Care Coordination: Less
Question 3: On the other the Care Coordination

Effective Areas
hand, what is the least effective part of Program?

Participants raised a number of areas where they felt the care coordination system was less effective.

The issues where the care coordination system is less effective according to participants can largely be summed up as structural. Inadequate funding for KADAP and other service programs to provide substance abuse treatment, housing, mental health counseling, transportation, and a host of client needs is the most frequent challenge that Kentucky's care coordinators face. Several participants further report that their agencies lack sufficient space to house service staff and properly care for clients. They also wish that care coordinators could make more home visits. Unfortunately, the nature of care coordinators' work keeps many bound to their offices and phones. Volunteers of America, for instance, only conduct home visits when a client is hospitalized or receiving hospice care at her/his home.

Transportation challenges for clients are a common problem cited by participants. The impact on the rural infected and their corresponding care agency is often greater and worsening with recent rising gasoline prices.

Participants from several agencies also point to the long intakes (often up to four hours) facing new clients. Agencies throughout the state now try to coordinate intakes, medical exams, and service referrals for clients, but such coordination can lead to long days that exhaust clients.

Kentucky State Comprehensive Plan 2005

Every participant mentioned the importance of trust in the care coordinator-client relationship. Burnout and the resulting turnover rate among care coordinators were listed as a problem for the care coordination system.

Finally, care coordinators in the focus groups point to the need to *meet the client where they are* and of the difficulties in providing care when a client first needs help addressing issues of homelessness, depression, or substance abuse. Physicians and medical personnel in the focus groups similarly describe problems not only in the waiting list for KADAP but also with the lack of funding for a growing list of co-morbidities associated with a high-risk, increasingly aging client base. In both areas of the care network, participants are stymied by the lack of services and funding for issues that may be blocking their clients from leading healthy lives. In other words, the structure of the U.S. health care system with its funded and unfunded silos of care does not allow service providers to easily care for the client as a whole. Instead, the system is structured to provide specialty care rather than holistic care.

4. Barriers to Access in a Time of Triage

Question 4. You or your clients already access the Care Coordination Program regularly. What types of people do you know of that are not in the program but would benefit from it? How do you suggest reaching out to these people in a way to get them into services? What are some of the barriers that keep these people from coming in for services?

For years HRSA has emphasized identifying infected individuals and getting them into care. Clients and service providers report a number of barriers that they believe keep individuals from being tested and/or seeking care services.

Yet, another theme arises among participants: triage. Participants portray their agencies as often swamped by their existing clientele and facing constant funding shortages to meet ever increasing client loads. While sympathetic to providing care to individuals in need, several of the participants say they focus on treating and helping those clients who actively seek care. In a health care system of scarcity, there is a greater reliance on clients to actively be involved in their care by seeking assistance, attending appointments, and adhering to medications. Thus, one method for triaging those needing care is to focus on those who seek and show up for care. While agencies report they continue outreach efforts to get more people to be tested and into care, they feel that they do not know how they could find the resources to actually care for many more new clients.

Participants could readily list many of the barriers to entering care found by earlier studies: fear, past experiences of bias, and ignorance. Clients and service providers alike say that they know of HIV+ individuals who refuse to come to clinics or

**Kentucky State Comprehensive Plan
2005**

service agencies out of fear of being identified as positive. Such individuals often have fears of being stigmatized by family, friends, and employers if their HIV status is discovered. Participants say such individuals also can have negative stereotypes of service providers. In the case of minorities (racial, ethnic, or sexual), health services in general may be distrusted based on perceptions of public agencies based on past bias incidents. Ignorance of HIV/AIDS and a person's individual risks can also result in people not being aware they need to be tested and may be infected. In fact, several care coordinators report a pattern of many low-income and low educated clients not realizing they were infected until they enter a hospital seriously ill. Focus group participants also report ignorance of personal risk is further compounded by a general impression in American society that AIDS is now a treatable chronic disease whose numbers are declining.

Several care coordinators also related that a number of both clients and potential clients face more immediate issues of hunger, homelessness, mental illness, and substance abuse that prevent them from seeking care or adhering to treatment regimens. If they are wandering between cities because they are homeless, infected individuals may not stay in an area long enough to establish care.

One group that did come up as specifically overlooked by care and prevention efforts is trans-gendered Kentuckians. Clinicians usually do not have training in the health issues related to transgender. Care coordinators also report that trans-gendered individuals often enter the care network late in their disease.

Participants who regularly work with HIV infected Kentuckians feel that the reported and/or known numbers of infected are greatly underreported. One participant believes that there may be 3-4 infected Kentuckians who either do not know their

There is a big learning curve with patients to teach them that we can't provide non-HIV meds.

Focus group participant

status or who are not in care for every 1 infected person in care. This number is speculation but represents the perception among care providers and clients alike that the breadth of the pandemic in Kentucky is much greater than known.

At the same time, participants give an impression of resignation to difficult circumstances. Case loads and the waiting list for KADAP are growing. Funding and state/local support are not adequate. HIV/AIDS competes

with other health and social issues such as diabetes, obesity, and bio-terrorism for the public's attention and dollars. In this climate, clinicians especially (but also other service providers) report they employ triage: contextualizing services to the needs and openness of clients to use and participate in programming. One participant explains the situation facing service providers in this way:

Kentucky State Comprehensive Plan 2005

We have lots of clients needing appointments. Then we have some who repeatedly miss appointments. This lost time impacts other clients. You begin to schedule around such clients because you know they probably aren't actually going to show up.

Other participants say they seek to explain to clients early in their care about limitations in federal funding. They want to build a foundation for understanding that the care agencies have limited resources and can pay for only particular aspects of the client's needs. Moreover, some clients who are homeless and low-income may lack the knowledge of how and where to access the health care system or other basic life skills:

Some clients have had few or no interactions with a health care system until they hit the hospitals. We have to first teach them normal life skills in some cases and how the health care system works.

5. Education Levels

Question 5. What do you think is the average education level of your community? Of clients?

Participants could not easily categorize their clients' education levels because of their diversity, but feel that many read on a 6th-7th grade reading level. While individuals with only a high school education perhaps make up the bulk of clients, the service providers say they have clients whose educational backgrounds range from high school dropouts to graduates with Masters degrees.

Several agencies have edited and re-written materials at a lower reading level to make them more accessible to clients. Often regardless of educational levels, the specialized medical, insurance, and referral service terminology involved in navigating the HIV/AIDS care system and understanding immune systems can be daunting. Some participants thus report using diagrams and pictures to better explain complex information to clients.

Participants who regularly work with immigrant Hispanic populations report that literacy levels in both Spanish and English are often low. The workers mostly use illustrations to convey health and other messages to migrant farm workers and other Hispanics with low reading levels.

The dentists participating reported that about ten percent of their dental patients could not read their original intake form well enough to complete it. So, they changed the form to a lower reading level.

6. The Role of Legislative Advocacy

**Kentucky State Comprehensive Plan
2005**

Question 6. Do you know individuals (including yourself) who are willing to advocate for getting more state dollars for HIV/AIDS treatment and prevention? Are there reasons that these individuals cannot or do not want to advocate?

Participants were largely negative about their expectations and experiences with advocating or lobbying legislators for greater funding for HIV/AIDS treatment and prevention. While participants in all three focus groups felt that there needed to be greater public pressure put on Frankfort to secure much needed funding, participants felt such efforts were unlikely to succeed. These negative perceptions focused on five areas:

- **Overall shortages within the state budget**
- **A growing lack of awareness of rising HIV infections**
- **A continuing stigmatization of AIDS compounded by a politically conservative climate**
- **Lack of time or ability by care providers to advocate**
- **In-fighting and negative experiences with past advocacy**

Participants feel that advocates face challenges in getting greater funding for HIV/AIDS services from the Kentucky legislature. In part, participants believe that all social services are likely to be funded at current or reduced levels because of a tight state budget and rising Medicaid costs. They also feel that HIV infection remains stigmatized as a disease affecting marginalized groups. One woman also explained that she had personally spoken with a number of friends and acquaintances who falsely believe that the numbers of newly infected people are *declining*. Many of the service providers also reported that they believe their jobs prevent them from actively lobbying legislators. Participants who believe they have such workplace university employees. restrictions include state and public

In turn, several people spoke of efforts. Participants report a disorganized lobbying, and including the Community Council. Thus, the impression the state legislature was largely

I left for personal reasons. The existing [advocacy] groups got very political and heated.

Participant on why she no longer seeks to advocate to the General Assembly on behalf of increased HIV/AIDS funding

negative prior experiences with advocacy history of in-fighting, personality conflicts, clashing ideologies in various groups Planning Group and Governor's Advisory Group given by participants was that lobbying futile in outcome and frustrating from the

Kentucky State Comprehensive Plan 2005

disorganization and in-fighting over issues among advocates. It was “a waste of time” as one participant expressed, but others believed that such efforts could work but required training on how to lobby. In lieu of lobbying, participants pointed to seeking public and private grants and patient assistance dollars as their means to raise additional funds more effectively.

Additional Issues and Suggestions Raised in the Focus Groups:

A. Grant Writing

Most of the agencies rely heavily on grants. Initially one focus group raised the idea of having the state employ a person specifically to seek out and write grants to support the Title agencies. This suggestion then led into a longer discussion about whether such a position was feasible in light of the demands that at least ten agencies would make on such a person. Moreover, each agency has its own specific needs and context that would pose problems for a Frankfort-based grant writer to adequately convey. Instead, the group concluded that the state could assist with grants by:

We would be assisted by thinking about what grants could do and focus Title II funds on medications. Perhaps put 50% to medications and 50% to care coordination and have grants to support everything else.

Focus group participant

a. Providing funds for agencies to contract with a local grant writer to compose grant applications. Large organizations such as Volunteers of America already have access to a full-time grant writer employed by their organization. In other agencies, a diligent worker writes grants in addition to other duties, or the agency has a person with whom they have contracted to write grants in the past.

b. Providing a computer mailing list of grant opportunities that can go out to agencies.

B. A Trend towards Greater Coordination of Services Under One Roof

Participants feel that providing multiple services, intakes, and/or contact personnel at the Title III clinics are beneficial to client satisfaction, inter-service coordination, and paperwork efficiency. Greater coordination is hampered by the lack of space and/or appropriate facilities at the clinics.

The 2003 Kentucky SCSN detailed the network of HIV/AIDS services in the state. A pattern emerged where larger urban areas initiated the first HIV/AIDS care services by linking services provided by different, often pre-existing agencies. Sites

**Kentucky State Comprehensive Plan
2005**

in the small towns of western Kentucky, however, usually had to create services and have developed “one-stop shops” providing multiple services under one roof.

The October 2005 focus groups find participants pointing to this historical development of services and working to increase coordination of services in the metropolitan clinics. Lexington’s Bluegrass Care Clinic for instance has for some years had care coordinators from the Lexington-Fayette County Health Department on-site to work with clients around medication access and referral issues. The Heartland Cares Clinic and Matthew 25 Clinic in western Kentucky have both their areas’ Title II and Title III housed within the same building and agency. While not yet implemented, Louisville’s Title III clinic, WINGS, is planning to have care coordinators from Volunteers of America (VOA), the Title II care coordination agency, in the clinic on a routine basis. VOA’s care coordinators will also serve clients at the Title IV site located at the University of Louisville.

Similarly, the University of Louisville’s College of Dentistry receives a grant to provide oral health services to HIV+ clients. Initially arranging appointments and conducting intakes with clients in the WINGS Clinic, lack of space led to the move of the dental intake to a building behind the clinic. Clients, however, had to navigate through several turns and hallways within the medical complex. The dentistry group felt that clients were becoming lost, frustrated, and skipping appointments. The dental services have now moved their intake and some services back into the clinic itself.

Title III Clinic Sites

	Matthew 25	Bluegrass Care Clinic (University of Kentucky)	WINGS (University of Louisville)	Heartland Cares
	Henderson	Lexington	Louisville	Paducah
Services On-Site or Within University Health Center				
Medical Clinic	YES	YES	YES	YES

**Kentucky State Comprehensive Plan
2005**

Care Coordination	YES	YES	Planned	YES
Mental Health and/or Substance Abuse Counseling	YES	YES	YES	YES
Pharmacy	Use retail pharmacy across the street from clinic	YES	YES	No
Dental Services	Provided through visiting dentists from the University of Louisville	YES	YES	No

C. Frustrations with Epidemiology Reports

Participants in the morning focus group expressed frustrations over state epidemiology reporting. Specifically, they were not aware of any recent reports being released. A bigger concern was the lack of HIV (rather than solely full blown AIDS) numbers being reported more than a year after names reporting went into effect. By only being able to list AIDS numbers rather than the larger percentage of clients who are HIV+ but do not meet the clinical definition of AIDS, federal funds allocated by the number of infected residents are limited and do not account for HIV+ clients. In the afternoon focus group, however, a participant familiar with these reports explained that the CDC requires Kentucky to collect two years of data and to have this data studied for accuracy before releasing it to the public. Names reporting began in July 2004. The HIV numbers will thus likely begin to be released in January 2007.

Participants also would like KADAP and surveillance numbers linked.

D. Regular Inter-Agency Meetings

Kentucky State Comprehensive Plan 2005

Participants reported that they believe the Federally funded agencies should have regular quarterly meetings. There was a discussion about whether such a meeting should rotate between sites, but participants concluded that the best solution would be to meet at a central location such as Bowling Green.

Participants brought up that the state regularly arranges training meetings. Participants, however, felt that these meetings weren't as productive as the actual focus group in which they were participating that morning. They came to a conclusion that inter-agency meetings should be less structured, open forums rather than trainings. Content should focus on policy changes, grant opportunities, innovative programs, epidemiology reports, etc. Participants also reported that they wish there was a better listing of statewide care agencies so that other agencies would know who to contact about new programs. Participants, however, placed much of the blame for the failure of existing meetings to generate discussion on themselves. In prior such meetings participants said they often did not speak up. One possible explanation is that the focus group consisted of only ten people while an inter-agency meeting is often considerably larger. Individuals are often less likely to brainstorm or share with a large group.

E. Medications Not Covered

Clinicians expressed on-going problems with prescription drug coverage. Specifically, KADAP covered their patients' HIV medications but not the prescription drugs for co-morbidities such as diabetes, high blood pressure, and other ailments. Physicians also experienced conflicts where they prescribe a particular medication only to find that the patient's PPO, HMO, or state Medicaid formulary does not include this drug.

F. An Increasing Awareness of the Importance of Oral Health

In the SCSN focus groups in 2003, oral health went almost unmentioned as a priority health concern. Two years later, participants are more aware of the importance of good oral health in helping their clients' overall health. In turn, participants want greater access to oral health care for their clients and find that clients face a number of barriers.

The morning focus group included participants from the University of Louisville College of Dentistry. Perhaps because the presence of these participants brought oral health to the minds of the other participants or perhaps because of the greater level of funding and oral health initiatives from HRSA, the morning focus group spoke out the most on this issue. In a later focus group, one participant pointed out that while Volunteers of America uses the University of Louisville dental services,

Kentucky State Comprehensive Plan 2005

it is one of the least used services. This participant, however, wondered if perhaps more referrals to dentists came through the Title III physicians than the care coordinators.

A grant to the University of Louisville now provides dental outreach to HIV+ Kentuckians through clinics in Jefferson County and, via other clinics, to clients from Matthew 25. Heartland Cares on the other hand currently does not have a ready provider of dental services for its clients and voiced that this was a priority need for their clients.

Participants described a number of barriers that their clients face in trying to get oral health care: discrimination, lack of affordability, fear of disclosing their HIV status to a dentistry provider, and transportation. The rising abuse of crystal methamphetamine and the associated damage to teeth and gums is a condition that participants are seeing in some of their clients. This damage is highlighting for them the need for better access to affordable oral health care for their clients.

G. Widespread Abuse

The afternoon focus group raised the issue of clients abusing the care system. While the participants felt that the majority of clients did not abuse the system, abuse by some clients was relatively widespread. This abuse came in the form of selling transportation, hygiene, or other vouchers for cash or drugs. Another form of abusing the care system was listing that only one person lived in a home when the client actually had another person living with him/her. At least one agency now requires receipts to show that clients are not using hygiene or food vouchers at self-scan checkout lanes to buy alcohol, cigarettes, or other unintended items.

H. Faster Flow of Funds

Participants also had a complaint about a perennial issue: funds that flow from the federal government and through various bureaucracies (local/state governments, universities, etc.) usually require contracts, accounting, and/or paperwork

**Kentucky State Comprehensive Plan
2005**

that delay implementation of spending on an account. Recipient agencies say they sometimes do not have enough time to spend their funds before they expire. Some participants asked if the levels of committees and other approval gateways could be reduced to more quickly get funds from the state level to the local agencies? With some funds timed to end by a particular date, delays can limit the time over which an agency can expend the funds.

I. Revert to Annual Reapplication

HRSA moved from having clients reapply for KADAP once per year to having such checks performed every six months. Participants described this change as being very difficult:

Impossible!

We really struggled.

For people who work and only use the care coordinators for KADAP, it was hard to set up appointments. The face-to-face component made it hard to complete the process ...on top of everything else we do...and to do it every 6 months.

They would very much like the process to revert to an annual event rather than twice per year.

J. Women and Support Groups

Participants expressed that there needed to be more support groups. The clients attending especially liked them, but care providers mentioned that such groups were often hard to maintain over time. They felt that women were especially unlikely to continue with a support group. Reasons for this included lack of childcare, late cabs that impact picking up children from babysitters, fears of being out late at night, or simply being too sick. Northern Kentucky has tried having support groups for women that offered a meal and childcare but met with limited success.

Kentucky State Comprehensive Plan 2005

K. Getting the Message Out There

Several participants had suggestions about how to reach the public about the on-going pandemic and needs for prevention and funding. One participant told a story about having various HIV+ speakers at a high school event. The students largely were ignoring the speakers until an elderly grandmother spoke and announced she was positive. She broke the students' stereotype of the type of person who is positive, and they listened to her.

In a similar case, a handsome young African-American man staffed a table at a prevention event. Several of the young women at the event were flirting with him and not really paying attention to the message until later when he was on stage and announced he was HIV+. The young women were shocked because 'he looked healthy.'

Another young African-American woman who participated felt that people of her generation would listen if more shocking ads were used. She believed that many young female friends of hers did not use condoms because they did not like the feel of them. They needed more education with a strong shock value to shake them out of their complacency.

L. Kentucky Department of Disability Determination Services

One care coordinator reported difficulties for clients filing claims with the KY Department of Disability Determination Services. In some cases, clients have been seriously ill but required to personally come to the local DDS office to sign paperwork. A representative from DDS was in this same focus group and reported that this requirement of signing in front of a witness at DDS was a federal requirement, but that DDS was open to having training for its staff on working with individuals living with HIV/AIDS.

Section Three- How will we get there?

Kentucky continues to focus its federal resources on the six core service areas mandated by HRSA. Aside from ADAP services, Kentucky clients solicit a considerable degree of mental health and substance abuse services. These areas continue to be budget intensive service categories. The October 2005 focus group responses reflect this dynamic in the state services program.

**Kentucky State Comprehensive Plan
2005**

Also, Prevention Case Management will continue to be a high collaborative priority between the state Prevention and Services programs. KHCCP staff has received training regarding PCM, and a joint training with the state Prevention program will take place on June 22, 2006 in Louisville, Kentucky for further discussion and training regarding PCM.

Kentucky faces a tragic dilemma, being one of a handful of "waiting list state". As February 2006, there are 215 Kentuckians desperately waiting for enrollment into KADAP and the KHCCP. These applicants are currently receiving medications through patience assistance and various other means as available. These factors were the backdrop for the focus groups.

Priority One (Core Services)

Beginning in Grant Year 2005, The KHCCP mandated that core services must be addressed prior to allocating any funding to other services listed by HRSA. As federal and state resources continue to decrease, Kentucky must remain focused on the most essential services that HRSA offers.

Priority Two (Disparities)

Since the 2003 Needs Assessment, Kentucky has maintained a contract with the Bluegrass Migrant Farmworkers Program, providing outreach services to central Kentucky's Hispanic population.

Priorities Three and Four (Identifying HIV+ Kentuckians who are not in care)

The Kentucky Care Coordinator Program is currently coordinating with the HIV/AIDS Prevention Program to institute a *Prevention Case Management (PCM)* system to work with such clients. PCM is an intensive, client-centered, one-on-one, multi-session interaction for individuals who are HIV+. It builds upon clients' strengths to facilitate sustained risk reduction management. PCM counselors will be urged to develop the skills of HIV+ clients to provide outreach to HIV+ Kentuckians not currently receiving services. Individuals are referred by the PCM counselor to the Care Coordinator Regions in order to receive needed services. This method utilizes these "ambassadors" to reach out through self-disclosure about how services have improved their lives.

Priority Five (Goals, Timetable, and Allocation of Funds)

Contingent on the amount of Grant Year 2006 State and federal funding, timetables and goals will be implemented.

**Kentucky State Comprehensive Plan
2005**

Priority Six (Coordinating Title II Funds with HIV Prevention Services)

Since FY 2003, the Kentucky HIV/AIDS Care Coordinator Program has coordinated with the HIV/AIDS Prevention Program through Prevention Case Management (PCM) activities. Collaboration will continue through FY 2006. Joint trainings also allowed these two groups to become familiar with each program and establish referrals between the two programs. Additionally, these staffs have worked jointly on a project directed toward HIV+ minorities who are not in care using the Minority Aids Initiative monies. The Care Coordinator staff will be working closely with the HIV/AIDS Prevention staff and other agencies to identify these individuals. Central office staff and the Care Coordinators in the regional offices are working with the Bluegrass Migrant Farm Workers Program in Lexington, Kentucky, Sisters and Brothers Surviving AIDS (SABSA) in Louisville and residential substance abuse programs in Northern Kentucky.

Priority Seven (Coordinating Title II and Substance Abuse Prevention Services)

Volunteers of America (VOA), a Ryan White Title II recipient in Louisville, established a care coordinator position that is dedicated to working with clients who have substance abuse issues and offers referral services to VOA's substance abuse treatment program. Heartland CARES, Inc., which houses the Ryan White Title II Care Coordinator Program and also a Ryan White Title III clinic, participates in a SPNS project with an inpatient substance abuse program. Also, Matthew 25 AIDS Services., Inc, has Title III funds which assist KHCCP clients with substance abuse treatment and care.

The Kentucky HIV/AIDS program also coordinates with other CARE Act Titles to provide services (including mental health and substance abuse)

1. *Service and funding for joint programs between Title II programs and other CARE Act programs,* The Care Coordinator program coordinates services such as referrals and travel vouchers for clients attending one of four Title III clinics in Kentucky, as well as the Title IV clinic in Louisville.

**Kentucky State Comprehensive Plan
2005**

2. Associations with Title I, Title III and Title IV Grantees,
Kentucky does not have a Title I program. Close coordination with four Title III clinics and a Title IV program in Louisville is on-going. Heartland CARES, Inc., a Ryan White Title III recipient since 1999, in Paducah, Kentucky now houses the KCCP for Western Kentucky. Clients receive case management services, medical care, substance abuse treatment, nutrition and medication adherence counseling and life skills training. The WINGS Clinic, a Title III recipient at the University of Louisville, receives funding for clients in Louisville and Southern Indiana through the Louisville Emerging Community Supplemental Award. Also, Care Coordinators from the Lexington-Fayette County Health Department coordinates visits with the Bluegrass Care Clinic, a Title III recipient at the University of Kentucky Medical Center. Each day the clinic is open, a Care Coordinator is in attendance to focus on the social needs of existing KCCP clients and to assist potential clients with KCCP forms.
3. Relationship with the AETC,
The Care Coordinator Program annually hosts a Kentucky HIV/AIDS conference in conjunction with other Community Based Organizations (CBO) in Kentucky. The University of Kentucky's AIDS Education Training Center (AETC) provides current AIDS training, AIDS material, and high profile speakers to the conference each year.

Coordinating Activities with Other Federal Programs

Q.D8. A Comprehensive Plan must include a description of activities coordinated with other federal programs. Thus, the plan should describe how the Title II program coordinates delivery of services and funding mechanisms for HIV/AIDS services with programs other than CARE Act programs. Examples of such programs include:

4. ***Other HRSA funded programs, including Maternal and Child Health, Migrant Health Programs, and Community Health Centers.***

Heartland CARES, Inc., a Ryan White Title III recipient since 1999, in Paducah, Kentucky now houses the KCCP for Western Kentucky. Clients receive case management services, medical care, substance abuse treatment, nutrition and medication adherence counseling and life skills training. The WINGS Clinic, a Title III recipient at the University of Louisville, receives funding for clients in Louisville and Southern Indiana through the Louisville Emerging Community Supplemental Award.

**Kentucky State Comprehensive Plan
2005**

Each care coordinator region is equipped with the knowledge of available resources within their region and within the state for women, infants, children and youth. The following paragraphs provide a brief synopsis of such resources.

The Commission for Children with Special Health Care Needs is a program that provides medical treatment to children with physically disabling conditions. Patients receive case management services from registered nurses (RNs) who work with pediatric specialists to determine a plan of treatment and ensure that every child receives appropriate, state of the art medical care. The Commission also offers Youth Transitions, helping young people move from school to work, pediatric to adult health care, and living at home to independent living.

First Steps is Kentucky's Early Intervention System that serves children from birth to age 3 who have developmental delay or a particular medical condition that is known to cause developmental delay.

Kentucky's Newborn Screening Program provides for early identification of infants at increased risk for illnesses such as phenylketonuria (PKU), galactosemia, congenital hypothyroidism, and sickle cell disease so that medical treatment can be promptly initiated and medical crises avoided.

The Health Access Nurturing Developing Services (HANDS) program is a voluntary intensive home visitation program designed to assist parents at critical development points during their child's first two years of life. First time parents may be eligible for HANDS to assist with child development, parenting skills, health services and other needed resources.

Kentucky Invests in Developing Success Now (KIDS NOW) promotes healthy child development. KIDS NOW has three core initiatives: ensuring maternal and child health, supporting families, and enhancing early care and education by offering a range of services and supports targeting pregnant women and families with children from birth to age eight. In addition, several key programs primarily target infants and toddlers.

5. *Medicaid, including Medicaid managed care,*

Medicaid services provided through the Department for Medicaid Services have not changed. Kentucky AIDS Drug Assistance Program (KADAP) applied for the Bridge Program, which allows KADAP to screen for Medicaid recipients. The program has been installed on the computers of the KADAP administrator and the

KADAP coordinator. However, they have not yet received training on how to access the system. They should receive training by February 2003 and begin entering data immediately thereafter.

KADAP clients who receive temporary Medicaid (defined as receiving Medicaid benefits for 6 months or less) remain on KADAP. To remain on KADAP, clients must continue to fill their prescriptions through the University of Louisville Pharmacy, who bills Medicaid for the prescriptions for the life of the client's card. This ensures that KADAP remains the payor of last resort. Also, the pharmacy credits KADAP's account when Medicaid notifies them that a client has received a card that is back-dated. This is possible because the pharmacy bills Medicaid for the prescriptions that were filled during the post-date period. Through November 2002, KADAP received over \$24,000 in credits because of the pharmacy's efforts to back-bill Medicaid.

6. **Medicare and Medicare Part "D"**

The KHCCP regional care coordinator sites are available to assist clients in completing all forms required by Medicare. Also, regional care coordinators work with the Medicare staff to help clients understand what services they receive through Medicare, including the recent implementation of the "Part D" pharmaceutical component. The short term goal is to transition clients into the appropriate insurance/Medicare "Part D", considering all related factors including cost savings. The long term goal is to track costs saving and reinvest in other services that benefit Kentucky's clientele.

7. **Veterans Affairs programs,**

KADAP requires that applicants who are potentially eligible for medical services through the Veteran's Administration (VA) apply for these services. The regional care coordinators are available to assist clients in contacting the VA, scheduling an appointment, completing any preliminary paperwork, and transportation to the appointment. Also, KADAP works with the VA to ensure clients eligible for VA medical services has a smooth transition without treatment interruption.

8. **State funds**

State funds are distributed to each regional care coordinator program for administrative, personnel, and case management purposes. Each region is required to submit a quarterly report that details how funds, both state and federal, are dispersed. In addition, in FY 2005, the state HIV/AIDS program received an increase in state funding from \$90,000 to \$180,000 for KADAP. However, this minor funding increase did not decrease the state's waiting list, or enhance the KADAP formulary.

**Kentucky State Comprehensive Plan
2005**

9. *The State Child Health Insurance Program*

Each regional care coordinator program is trained on the specific requirements for Kentucky Child Health Insurance Program (KCHIP) eligibility. Potentially eligible families and/or clients are referred to the closest Department for Community-Based Services (DCBS). Care Coordinators are available to contact DCBS and schedule appointments, when necessary and assist clients with KCHIP applications. This provides additional benefits to the clients as well as ensures the KCCP remains the payor of last resort.

10. *Programs and initiatives such as substance abuse prevention and treatment services as well as State social, welfare, and immigration services, and*

Three Care Coordinator regions, (Louisville, Lexington, and Northern Kentucky) have staff positions which charged with a focus on minorities who know their status but are not in care. These staffers continue to work closely with the state HIV/AIDS Prevention staff and other agencies to identify these individuals. Grantee staff (Central Office) and other KHCCP are collaborating with the Bluegrass Migrant Farm Workers Program at the University of Kentucky, Sisters and Brothers Surviving AIDS (SABSA) in Louisville and residential substance abuse programs in Northern Kentucky. Also, residents at Droeghe House in Northern Kentucky, which is a substance abuse treatment program, receive care coordination services through the Northern Kentucky Care Coordinator Region.

11. *Housing Opportunities for People Living with AIDS (HOPWA).*

Five of the regional care coordinator sites are also HOPWA grant recipients. KCCP clients who are in need of housing assistance are able to contact their care coordinator for these services □ putting these regions closer to a one-stop-shop.□

The KCCP administrator annually participates in review of HOPWA grant applications submitted to the Kentucky Housing Corporation, the state entity that distributes HOPWA funds.

Services by Region

The services offered by each regional Care Coordinator Program office vary. Please see Appendix 3 for a listing of these services.

Services By Region

**Kentucky State Comprehensive Plan
2005**

Region	Offer Food Vouchers?	Offer Hygiene Vouchers?	Offer Rent/Housing Assistance?	Pharmacy On-Site?	Infectious Disease Physician On-Site?	Closest Infectious Disease Physician	Number of Support Groups Offered On-Site	Support Groups Offered To A Specific Population	Office's Caseload	Year Office Opened
Barren River	Yes**	Yes****	No***	No	No	Bowling Green	2	women	160	?
Cumberland Valley	Yes**	Yes****	No***	No	No	Lexington or Pikeville	1	no specialized groups	84	c. 1996
Lexington	No***	No*	Yes**	Yes**	No	Lexington or Ashland	1	women	464	1991
Louisville	Yes**	Yes****	Yes**	No	No	Louisville	0	no specialized groups	701	c. 1991, Volunteers of American since 1999
Northern Kentucky	Yes	Yes	Yes**	No	No	Crestview Hills or Cincinnati	0	no specialized groups	153	1991
Purchase-Pennyrite	Yes**	Yes****	Yes**	No	Yes	Paducah	9	substance abuse, couples	250	1996

*Because of feedback from the focus groups, all sites will now begin offering hygiene vouchers.

**See Notes

***Referrals for this service available from other local organizations.

**** Food vouchers allow purchase of toilet paper, soap, etc.

Title III Clinic Sites

	Bluegrass Care Clinic (University of Kentucky)		WINGS (University of Louisville)		Heartland Cares	
	Matthew 25 of Kentucky)	Lexington	Louisville	Paducah		
Services On-Site or Within University Health Center						
Medical Clinic	YES	YES	YES	YES		
Care Coordination	YES	YES	Planned			
Mental Health and/or Substance Abuse Counseling	YES	YES	YES	YES		YES
Pharmacy	Use retail pharmacy across the street from clinic	YES	YES	YES		No
Dental Services	Provided through visiting dentists from the University of Louisville	YES	YES	YES		No

C. Frustrations with Epidemiology Reports

Participants in the morning focus group expressed frustrations over state epidemiology reporting. Specifically, they were not aware of any recent reports being released. A bigger concern was the lack of HIV (rather than solely full blown AIDS) numbers being reported more than a year after names reporting went into effect. By only being able to list AIDS numbers rather than the larger percentage of clients who are HIV+ but do not meet the clinical definition of AIDS, federal funds allocated by the number of infected residents are limited and do not account for HIV+ clients. In the afternoon focus group, however, a participant familiar with these reports explained that the CDC requires Kentucky to collect two years of data and to have this data studied for accuracy before releasing it to the public. Names reporting began in July 2004. The HIV numbers will thus likely begin to be released in January 2007.

Participants also would like KADAP and surveillance numbers linked.

D. Regular Inter-Agency Meetings

Participants reported that they believe the federally funded agencies should have regular quarterly meetings. There was a discussion about whether such a meeting should rotate between sites, but participants concluded that the best solution would be to meet at a central location such as Bowling Green.

Participants brought up that the state regularly arranges training meetings. Participants, however, felt that these meetings weren't as productive as the actual focus group in which they were participating that morning. They came to a conclusion that inter-agency meetings should be less structured, open forums rather than trainings. Content should focus on policy changes, grant opportunities, innovative programs, epidemiology reports, etc. Participants also reported that they wish there was a better listing of statewide care agencies so that other agencies would know who to contact about new programs. Participants, however, placed much of the blame for the failure of existing meetings to generate discussion on themselves. In prior such meetings participants said they often did not speak up. One possible explanation is that the focus group consisted of only ten people while an inter-agency meeting is often considerably larger. Individuals are often less likely to brainstorm or share with a large group.

E. Medications Not Covered

Clinicians expressed on-going problems with prescription drug coverage. Specifically, KADAP covered their patients' HIV medications but not the prescription drugs for co-morbidities such as diabetes, high blood pressure, and other ailments. Physicians also experienced conflicts where they prescribe a particular medication only to find that the patient's PPO, HMO, or state Medicaid formulary does not include this drug.

F. An Increasing Awareness of the Importance of Oral Health

In the SCSN focus groups in 2003, oral health went almost unmentioned as a priority health concern. Two years later, participants are more aware of the importance of good oral health in helping their clients' overall health. In turn, participants want greater access to oral health care for their clients and find that clients face a number of barriers.

Kentucky State Comprehensive Plan 2005

The morning focus group included participants from the University Of Louisville College Of Dentistry. Perhaps because the presence of these participants brought oral health to the minds of the other participants or perhaps because of the greater level of funding and oral health initiatives from HRSA, the morning focus group spoke out the most on this issue. In a later focus group, one participant pointed out that while Volunteers of America uses the University of Louisville dental services, it is one of the least used services. This participant, however, wondered if perhaps more referrals to dentists came through the Title III physicians than the care coordinators.

A grant to the University of Louisville now provides dental outreach to HIV+ Kentuckians through clinics in Jefferson County and, via other clinics, to clients from Matthew 25. Heartland Cares on the other hand currently does not have a ready provider of dental services for its clients and voiced that this was a priority need for their clients.

Participants described a number of barriers that their clients face in trying to get oral health care: discrimination, lack of affordability, fear of disclosing their HIV status to a dentistry provider, and transportation. The rising abuse of crystal methamphetamine and the associated damage to teeth and gums is a condition that participants are seeing in some of their clients. This damage is highlighting for them the need for better access to affordable oral health care for their clients.

G. Widespread Abuse

The afternoon focus group raised the issue of clients abusing the care system. While the participants felt that the majority of clients did not abuse the system, abuse by some clients was relatively widespread. This abuse came in the form of selling transportation, hygiene, or other vouchers for cash or drugs. Another form of abusing the care system was listing that only one person lived in a home when the client actually had another person living with him/her. At least one agency now requires receipts to show that clients are not using hygiene or food vouchers at self-scan checkout lanes to buy alcohol, cigarettes, or other unintended items.

H. Faster Flow of Funds

Participants also had a complaint about a perennial issue: funds that flow from the federal government and through various bureaucracies (local/state governments, universities, etc.) usually require contracts, accounting, and/or paperwork that delay implementation of spending on an account. Recipient agencies say they sometimes do not have enough time to spend their funds before they expire. Some participants asked if the levels of committees and other approval gateways could be reduced to more quickly get funds from the

Kentucky Cabinet for Health and Family Services
Kentucky Department for Public Health
HIV/AIDS Branch

state level to the local agencies? With some funds timed to end by a particular date, delays can limit the time over which an agency can expend the funds.

I. Revert to Annual Reapplication

HRSA moved from having clients reapply for KADAP once per year to having such checks performed every six months. Participants described this change as being very difficult:

Impossible!

We really struggled.

For people who work and only use the care coordinators for KADAP, it was hard to set up appointments. The face-to-face component made it hard to complete the process ...on top of everything else we do...and to do it every 6 months.

They would very much like the process to revert to an annual event rather than twice per year.

J. Women and Support Groups

Participants expressed that there needed to be more support groups. The clients attending especially liked them, but care providers pointed out those groups were often hard to maintain over time. They felt that women were especially unlikely to continue with a support group. Reasons for this included lack of childcare, late cabs that impact picking up children from babysitters, fears of being out late at night, or simply being too sick. Northern Kentucky has tried having support groups for women that offered a meal and childcare but met with limited success.

K. Getting the Message Out There

Several participants had suggestions about how to reach the public about the ongoing pandemic and needs for prevention and funding. One participant told a story about having various HIV+ speakers at a high school event. The students largely were ignoring the speakers until an elderly grandmother spoke and announced she was positive. She broke the students' stereotype of the type of person who is positive, and they listened to her.

In a similar case, a handsome young African-American man staffed a table at a prevention event. Several of the young women at the event were flirting with him and not really paying attention to the message until later when he was on stage

and announced he was HIV+. The young women were shocked because 'he looked healthy.'

Another young African-American woman who participated felt that people of her generation would listen if more shocking ads were used. She believed that many young female friends of hers did not use condoms because they did not like the feel of them. They needed more education with a strong shock value to shake them out of their complacency.

L. Kentucky Department of Disability Determination Services

One care coordinator reported difficulties for clients filing claims with the KY Department of Disability Determination Services. In some cases, clients have been seriously ill but required to personally come to the local DDS office to sign paperwork. A representative from DDS was in this same focus group and reported that this requirement of signing in front of a witness at DDS was a federal requirement, but that DDS was open to having training for its staff on working with individuals living with HIV/AIDS.

Summary and Recommendations from the Focus Group Participants

Kentucky is on the process of reviewing the recommendations below, and will consider appropriate modifications to its program by April 1, 2006.

- 1. Structural Changes:** Many of the changes that would most greatly help agencies and clients are structural and difficult to change. Increasing funding for HIV/AIDS care services remains the top priority for a broad range of clients, care coordinators, physicians, and other agency workers. This finding is "nothing new" as the saying goes. Participants in the focus groups are acutely aware that funding is limited and has remained relatively static. As a result, agencies are cutting services to divert ever more increasing funds to KADAP and pharmaceuticals.

Increasing numbers of clients, costly medications, and relatively little increase in funding has created a sense of triage among agencies. Care workers are very aware of the need for increased expenditures for transportation, mental health services, oral health, and other services, but feel that pharmaceuticals ultimately take first spending priority. Increased funding for other services is again a critical need.

The other growing need is the national crisis in affordable health care. While KADAP and other programs assist with HIV medications, other medication

assistance for concurrent health problems is often unavailable. The structural system of public health assistance is lacking a holistic approach. Thus, an HIV+ person with high blood pressure may be able to get HIV medications but not high blood pressure medication. A broad formulary that includes both HIV and non-HIV medications for concurrent health issues would be a great boon to clients.

One more easily enacted suggestion to increase funding via structural changes is to reduce the time and committee approvals required before regional agencies receive federal funds from Frankfort. Increasing the time that agencies have to spend these funds reduces the amount of unspent funds that have to be returned.

CDC approval of Kentucky's new names reporting system for HIV+ clients will also hopefully increase the client base used to calculate funding to the Commonwealth.

2. **Return to an Annual Reapplication Process:** Care coordinators report considerable difficulties in carrying out the new six month reapplication process. A return to an annual reapplication process would reduce paperwork, improve morale, and reduce stress on clients and care coordinators.
3. **Capital Improvements:** The service model that clients and providers alike would like to create is that of the "one-stop shop" where multiple services are housed within one location. Either as a single agency or a group of agencies sharing a joint space, multi-service sites offering clinical, care coordination, and other services are a model that every region is seeking to employ in some fashion. Especially in Louisville and Lexington, having adequate space to house a dental clinic, a care coordinator, and a clinician (for example) is an on-going challenge. Finding or building a joint infectious disease center serving clients with HIV, chronic hepatitis and perhaps other infections would facilitate client care, increase inter-agency coordination, and reduce transportation costs.
4. **Grants:** Agencies also look to the state to provide assistance with grants. Many agencies depend on federal, state, and private grants to support key additional services. Some agencies such as Volunteers of America are large and have their own grant writers. Other smaller agencies depend on a staff member or local grant writer. Increasing the grant dollars flowing into Kentucky is seen as a way to improve the agencies' financial and service challenges. Having some state or federal funds earmarked to support grant writing and having the state regularly communicate grant opportunities to agencies via email are seen as ways in which the state can assist local agencies.

Section Four- How will we monitor our Progress?

Progress will be monitored through the current system of KHCCP quarterly meetings, site visits, monitoring visits and meetings. Contract and fiscal monitoring will also be utilized. Also, all KHCCP contractors utilize surveys to help gauge the effectiveness of the services offered in Kentucky. Strengthened Outcome and performance measures will be developed and utilized as well.