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10/06/99

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October 6, 1999

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It was good to see you again yesterday and have the opportunity to chat a bit, as well. It was also wonderful to see Deb Runions again after a few months up here.

While I understand and agree in principle with many of the criticisms leveled at Secretary Shalala and the Department of Health and Human Services, I was disappointed with the tone and negative encouchment of the remarks. Having lived with HIV since at least early 1988, I remember all too well the days when we had essentially no meaningful support of the past administrations; virtually no hope. We could, of course. All ruminate about "missed opportunities" and conjure angry exchange, but I hope the catharsis has been realized and we can all begin to work increasingly closely without resentment, rivalries and other counterproductive drain of our individual and collective creativity.

I was pleased to hear some good news in the Secretary's presentation. The intent to expand Title III of the Ryan White CARE Act, together with a resolve to enhance access to technical assistance for "bringing a new generation of community groups" into the community-based primary care programs of Ryan White are refreshing. This is exactly the focus of a new initiative I am leading through T*II*CANN with respect to the area identified as the "South" by CDC in its semi-annual HIV/AIDS Surveillance Report.

This program, Southern Emergency Response Coalition for AIDS, "SERCA", is an organizational framework to bring together many of us living with and/or advocating for persons living with HIV who have a dedication to ensuring access to care and treatment for everyone living with HIV in the South. As you know, the HIV epidemic rages on largely unchecked in the South, where basic infrastructure and community-based organizations providing care, treatment, and services are almost completely lacking.

Prior to joining the Executive Board of T*II*CANN and formalizing this initiative, I went through the process of establishing a non-profit corporation in 1997, developing the organizational legal and tax-exempt status, writing several grant applications. The organization was awarded a Title III planning grant later in 1997 and was awarded an Early Intervention Services (EIS) grant in July 1998. The organization, Heartland CARES, Inc. is based in my hometown of Paducah, Kentucky and serves well over a hundred persons living with HIV in the surrounding 39-county area, the vast majority of whom were previously not in care. A major challenge of the project was convincing the community that HIV *is* a problem in the Paducah area and in all similar communities across the South. Heartland also receives funding through the HOPWA and Supportive

Housing Programs of the Department of Housing and Urban Development. This program is in partnership with the regional domestic violence agency and collaboration with the Paducah Housing Authority, providing housing and supportive services to a broad population in need in the surrounding area of Western Kentucky and Southern Illinois.

Early in the Heartland project I discovered there was really no source for technical assistance, therefore much of the work was created as it moved forward. I have taken the experiences, both good and not-so-good from the Heartland project and organized them into a general format for providing technical assistance to groups in other communities, particularly in the rural Southern context. Although still a work in process, the product is the SERCA program. Enclosed is the basic SERCA program document together with a booklet I prepared to accompany a slide presentation of the program. The program document contains:

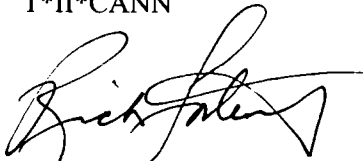
- Summary of the current epidemiology of HIV in the South
- Discussion of the unique challenges of developing service systems in rural areas
- Outline of key areas of technical assistance generally needed
- Workplan chart indicating the sequential design of the technical assistance service
- HRSA / HAB / Division of Community-Based Programs expectations from the most recent program guidances for the Title III programs, planning and EIS
- The Heartland planning grant application, 1997 (Yellow pages)
- The Heartland Title III EIS application

As the Secretary pointed out, possession of insurance coverage does not equate with access to adequate care for HIV. In this respect, the infrastructure we propose to promote and assist will offer to fill the gap between having public or private insurance and actually accessing HIV-appropriate care.

We have circulated the program information to several pharmaceutical companies inviting sponsoring partners to support this effort. We are also interested in pursuing foundation support, as well. If DHHS does pursue the direction described by the Secretary, we are eager to collaborate and bring private support and effort to a larger strategy to extend a helping hand to "a new generation of community-based groups" to develop the critically needed organizational infrastructure needed, particularly in the South.

We would appreciate knowing your assessment of and suggestions regarding the enclosed material and the technical assistance model. The Board and growing group of associates of T*II*CANN represent a broad variety of expertise both geographically and in professional / experiential backgrounds relevant to this endeavor.

Sincerely,
T*II*CANN



Rich Fortenbery
Executive Board,
Director of Community Program Development and Technical Assistance

Enc: SERCA Program & Presentation set



Southern Emergency Response Coalition for AIDS

*An Initiative to Develop Access To Care and Treatment for HIV in
The Southern United States*



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HIV / AIDS in the Southern United States

Contents

2	The Southern States Identified
3	Abstract: Purpose and Goal; Methods
5	1 NEED: Rapidly Growing Public Health Emergency
9	2 IMPLICATIONS OF SOUTHERN CULTURAL ENVIRONMENT
13	3 PROPOSAL FOR EDUCATIONAL AND TECHNICAL ASSISTANCE SERVICES
	➤ The Conceptual Model Outlined ➤ Components of Technical Assistance ➤ The Model Programs - Heartland CARES, Inc. / Heartland Clinic - Whitman-Walker Clinic
21	4 SERCA Program Work Plan
23	5 RYAN WHITE TITLE III and the HEARTLAND PROJECT
	➤ Ryan White Title III Program Expectations (<i>pink pages</i>) ➤ Heartland Ryan White Title III Planning Grant (<i>yellow pages</i>) ➤ Heartland Ryan White Title III EIS Grant (<i>white pages</i>)

The Southern States

The "Southern States" for purposes of this monograph and the proposal contained herein are those states so identified by the Centers for Disease Control and Prevention (CDC) for its semi-annual HIV / AIDS Surveillance Report:



"The characteristics of persons living with AIDS have changed, reflecting changes in the populations affected by the HIV/AIDS epidemic. Women accounted for 13.8% of persons living with AIDS in 1992, compared with 19.1 % in 1997. By the end of 1997, the number of blacks living with AIDS, which increased from 32.7% of persons living with AIDS in 1992 to 39.2% of persons living with AIDS in 1997, almost identical to the number of whites living with AIDS. Persons living in the South accounted for 33.6% of cases in 1992 and 36.7% in 1997..."

-CDC. HIV/AIDS Surveillance Report, 1998; 10(No.2):5 in "Commentary"

HIV / AIDS In the Southern United States

Abstract: This monograph presents a description of the current HIV / AIDS epidemic in the South as reported by the Centers for Disease Control and Prevention (CDC) at the end of 1998 and a view to the scope of the epidemic in practical terms. Cultural, political and economic climate and implications are discussed, together with identifying gaps in service delivery resources and barriers to HIV+ client access to care. A proposal is presented for a comprehensive, long-term program providing educational and technical assistance for community-based groups and organizations to develop the infrastructure and capacity necessary to provide comprehensive primary care for HIV and related supportive services, with on-going support. A major focus of this effort will include assisting organizations to apply for funding through various public and private sources to support care operations, particularly the Ryan White Title III program. A workplan and budget for the first year of the program are included. Finally, supportive documentation including organizational and key individual capacities are included, together with information describing the Ryan White Title III program.

Purpose and Goal: The purpose of the program is to establish the Southern Emergency Response Coalition for AIDS, **SERCA**, to be coordinated by the Ryan White Title II Community AIDS National Network (T*II*CANN). This approach brings the project to the level of a nationally-recognized sponsor, highly collaborative with other national AIDS organizations and currently active at the state level nationwide with respect to the Ryan White Title II program. **SERCA** will solidify, enhance and continually develop a regional network of currently active persons and organizations variously experienced in advocacy for care and services for persons living with HIV in the South who are familiar with the "territory".

SERCA seeks to make available a comprehensive organizational system for mutual support and assistance for existing resources providing care and services for persons living with HIV and foster development of aspiring groups in areas of need where care and services are lacking. A specific and on-going effort will be educational advocacy for access to treatments recommended in current U.S. Public Health Service Guidelines for Use of Antiretrovirals and Prevention and Treatment of Opportunistic Infections. These efforts will be addressed to 1) All state ADAP Programs [AIDS Drug Assistance Program], 2) All State Medicaid programs, as needed, and 3) Any other provider program with whom coalition members are experiencing problems in receiving reasonable service by clients in meeting the guidelines.

Method: The primary approach to fulfilling the goals and objectives will be educational. Many of these activities are already underway to some extent through current activities of T*II*CANN and others. Educational presentations and workshops will be made available at the community, state, and national levels. **SERCA** will respond to needs for factual, scientific information regarding HIV and need for access to care and treatment with each cognizant Congressional office staff in Washington and in the Congressional state and field offices, state administration of health departments and Governors' offices, and key state legislators such as Health and Welfare or similar committee members. Technical assistance activities will provide practical, on-site assistance in developing organizational infrastructure, capacity, and program construction that meets the requirements of the Ryan White Title III program and assistance in application for funding through that program, together with practical strategies for meeting other needs as identified by the parties.

The Pictures (or Graphs) Tell the Story...

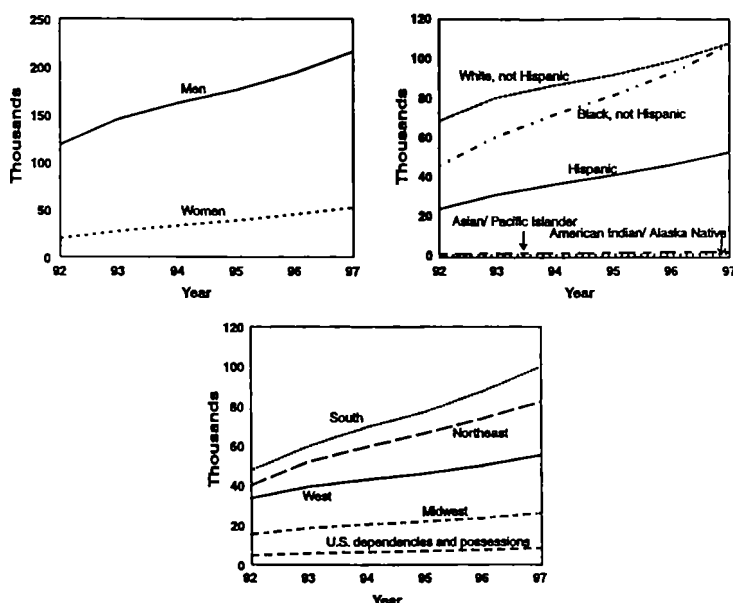
HIV/AIDS

Surveillance Report

U.S. HIV and AIDS cases reported through December 1998

Year-end edition Vol. 10, No. 2

Estimated number of persons living with AIDS, 1992 through 1997, by sex, race/ethnicity, and region, United States



Acquired immunodeficiency syndrome (AIDS) is a specific group of diseases or conditions which are indicative of severe immunosuppression related to infection with the human immunodeficiency virus (HIV).



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
Centers for Disease Control and Prevention
National Center for HIV, STD, and TB Prevention
Atlanta, Georgia 30333



The cover of the latest **HIV/AIDS Surveillance Report**, the official source reference document published semi-annually by the Centers for Disease Control and Prevention (CDC) reveal the troubling trends: **Upper left:** The number of women living with AIDS is increasing; moreover approximately one-third of newly reported cases of AIDS and perhaps a larger proportion of women with HIV infection are coming into care with later stage HIV disease. **Upper right:** while these data (up to 1997) reflect that AIDS cases among blacks have equaled cases among whites, the lines have now crossed (see pg. 8). **Lower:** Since the *beginning* of the HIV epidemic, the prevalence of AIDS cases has been highest in the South compared to the Northeast, West and Midwest.

Rapidly Growing Public Health Emergency

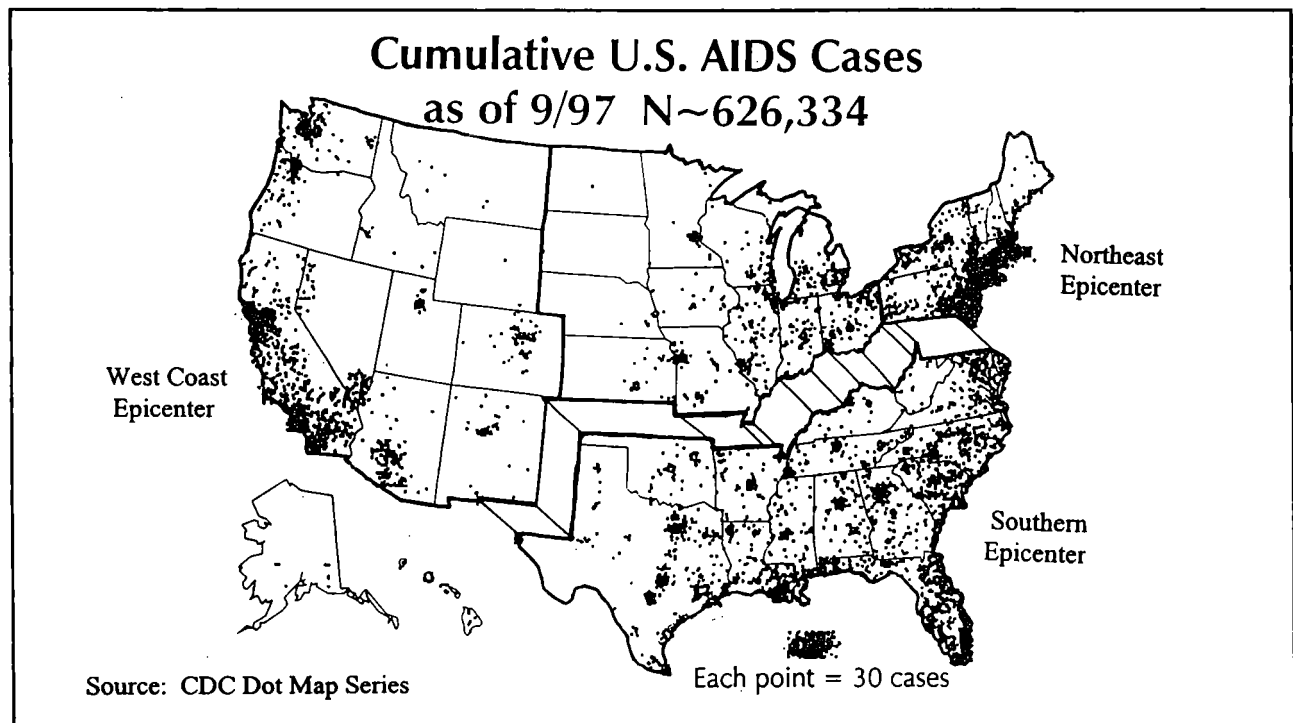
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HIV and AIDS in the Southern United States

A Destiny of Doom

There are disturbing misconceptions regarding the HIV epidemic that the "AIDS Crisis" in America is over and HIV is not a problem in rural America, particularly in the South. Newly available treatments for HIV and its complications are accessible to many living with HIV disease in areas where the epidemic first hit hardest and necessary organizational infrastructure to address the epidemic was developed early. In places like New York City, San Francisco, Boston and Los Angeles, the East and West Coast areas have seen remarkable decreases in the number of persons progressing from HIV infection to AIDS. In areas with access to appropriate care and treatment, the number of AIDS deaths has plummeted. Incidence of opportunistic infections and other complications of AIDS have "gone South".

This good news in the Northeast and on the West coast has captivated the attention of the media and encouraged complacency among the public and unfortunately among some HIV AIDS advocacy organizations, as well. Despite relatively easy access to the growing range of treatment options in these original epicenters, persons living with HIV in the Midwest and particularly in the Southern states have far less access to these treatments and the health care necessary to benefit from their availability. Indeed, more people have been diagnosed with AIDS in actual numbers as well as *per capita* in the South than in any other region of the country since comparative regional figures were published by the Centers for Disease Control and Prevention (CDC) beginning in 1991. This trend continues to increase.



There are essentially three epicenters of AIDS in the United States today. The original epicenters are in the Northeast and along the West coast. The South is emerging as the new epicenter, with challenges of a vastly wider geographic area, lack of public health infrastructure as well as political and economic contexts that are largely unmotivated to address the emerging epidemic with the early effectiveness of HIV advocacy communities in the Northeast and on the West coast.

While actual numbers of people diagnosed and reported with AIDS have always been higher in the South than the Northeast or West coast epicenters individually, the increasingly greater prevalence of AIDS (cases per 100,000 persons in the general population) in the Southern states portends a much more protracted and difficult epidemic to effectively grapple and control. The systems of public health available to identify and report persons with HIV in the South are notoriously poor, resulting in disproportionate under-reporting of both HIV infection and AIDS. For tens of thousands of persons living with HIV in the American South most of whom are *not reported in official CDC statistics*, likely including thousands with "full-blown AIDS", access to HIV knowledgeable care and the miraculous treatments is blocked by state bureaucracy, budget restraints and unreasonable financial eligibility, waiting lists, and limited ADAP formularies in almost every state of the South.

This epidemiologic scenario is overlaid on a largely under-informed and unconcerned cultural and political environment of the South, which contrasts sharply with the relatively more progressive, responsive social context of the Northeast and West coast. The national trends of increasing proportions of women, minorities, and rural folks with AIDS are particularly acute in the South. HIV is rampant in the South, as is syphilis and other sexually transmitted diseases.

God's Wrath on Homosexuals? Early in the HIV epidemic, a handful of fundamentalist religious zealots declared HIV to be God's wrath on homosexuality. Clearly, this attitude

discounts the fact that the vast majority of those infected with HIV worldwide are not "gay". In 1998, 35.6% of all newly reported cases of HIV and 23.4% of all newly reported cases of AIDS in the South were reported among women. Ironically, lesbians -- homosexual women -- are among the lowest risk groups for HIV.

Twelve of the sixteen Southern states, as well as DC have 1998 AIDS prevalence rates among women that are greater than the AIDS prevalence rate among women in California. **Six of the Southern states and DC have higher new AIDS prevalence rates among Southern men than among men in California.**

Characterizing HIV as a gay disease lulled countless thousands into believing they were not at risk for infection and established public policy, galvanizing much of public opinion to believe those with HIV are being "punished for their sins." This attitude still permeates Southern culture, particularly in rural areas and fosters bigotry that underpins the lack of political will to address HIV as a public health emergency rather than a "moral" issue.

A Larger "Hidden Epidemic" and Implications for Pediatric Risk of HIV without Prenatal Care. Tremendous progress has been made during the past several years in reducing the incidence of mother-to-child transmission of HIV. Administration of antiretroviral medications to the mother prior during the second and third trimesters of pregnancy, intravenous zidovudine (AZT) at labor, and antiretroviral therapy for the infant during early weeks of life have dramatically reduced perinatal transmission of HIV. This benefit was recognized and reported through the findings of ACTG 076 and is widely implemented today in the urban centers where HIV is a recognized risk for the general population. This success presumes access to proper prenatal care and obstetric management for HIV, of course.

Lack of resources for basic prenatal care as well as primary care for HIV in the South, together with lack of acceptance of HIV as a local risk frequently prevent young mothers-to-be from receiving essential counseling, testing, and follow-up. This condition is alarmingly ripe for emergence of a new pediatric HIV epidemic in the South.

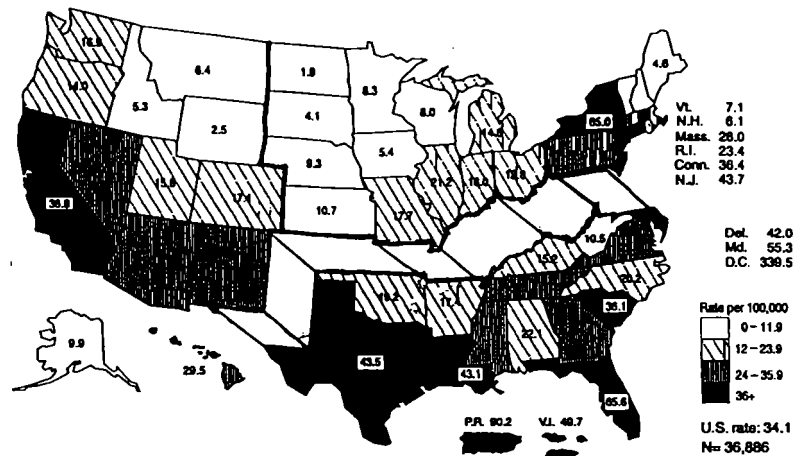
Twelve of the sixteen Southern states, as well as DC have 1998 Newly Reported AIDS prevalence rates among women that are greater than the AIDS prevalence rate among women in California. Six of the Southern states and Washington, DC have higher AIDS prevalence rates among men than California. This data dispels the mistaken notion that HIV is a "gay" disease, particularly in the Southern States.

HIV Prevalence in Southern Males Compared to California Males

Newly reported AIDS cases are more prevalent among *males* in these Southern States than among males in California:

Delaware
District of Columbia
Florida
Louisiana
Maryland
Texas

Figure 1. Male adult/adolescent annual AIDS rates per 100,000 population, for cases reported in 1998, United States

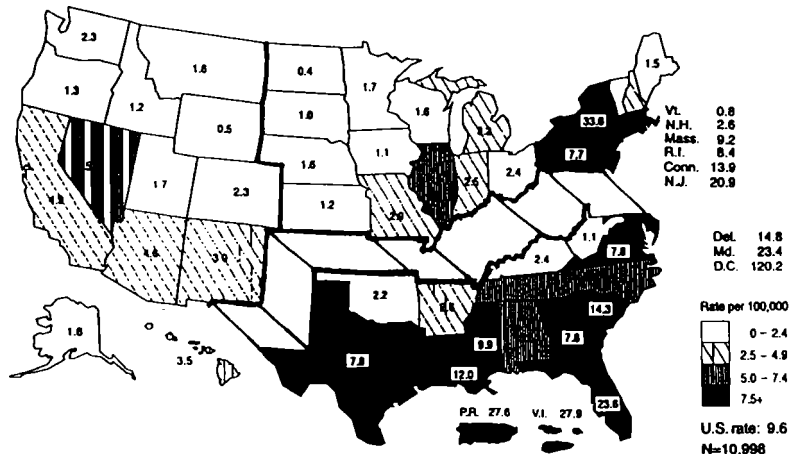


HIV Prevalence in Southern Females Compared to California Females

Newly reported AIDS cases are more prevalent in *females* in these Southern States than among females in California:

Alabama
Delaware
District of Columbia
Florida
Georgia
Louisiana
Maryland
Mississippi
North Carolina
South Carolina
Tennessee
Texas
Virginia

Figure 2. Female adult/adolescent annual AIDS rates per 100,000 population, for cases reported in 1998, United States



AIDS Disproportionately Affects African-Americans. This may be assumed particularly true in the South where large proportions of the population are African-American relative to other areas of the nation. A particularly difficult-to-reach population is those at risk who live in rural areas. As indicated by the map at right, over 90% of the African-American population who live outside metropolitan areas live in the South.

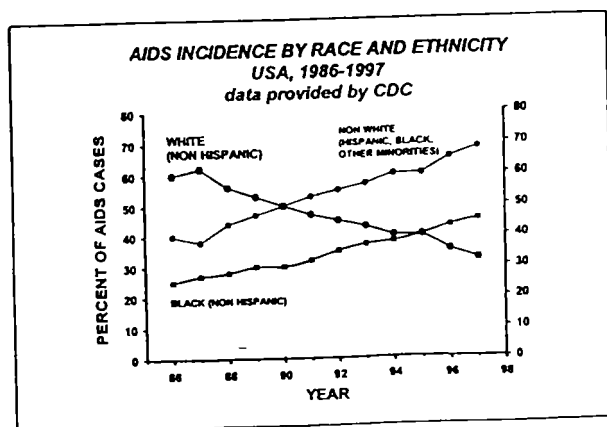
The graph below indicates the trends of new AIDS cases reported by race progressively through the past several years. The incidence of AIDS among African-Americans has exceeded that among whites and continues to increase with growing disparity. The average period of progression from HIV infection to AIDS appears to be approximately 5 to 7 years. Since this data relates only to AIDS, a 5- to 7-year extrapolation can be reflective of the current trends of new HIV infection. Likewise, current AIDS data can be assumed reflective of the true state of HIV infection 5 to 7 years ago.

Rural Populations in General are Increasingly Affected by HIV. Rural African-Americans are among a growing trend of increasing HIV and AIDS in rural areas in general. Since 1991, the rate of increase in incidence of HIV has been roughly three times the rate of increase in urban

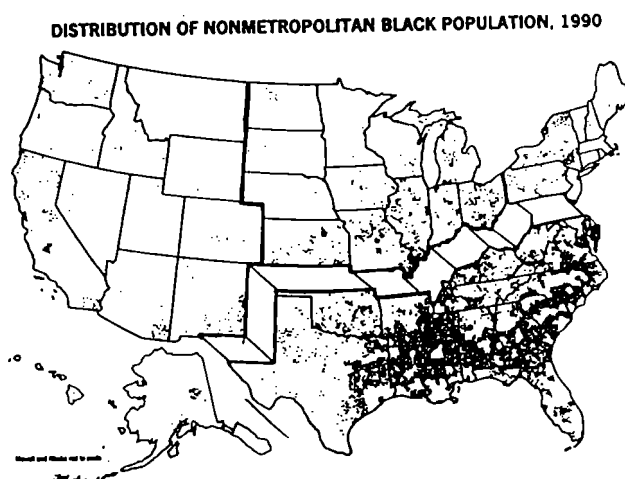
areas. According to CDC, the number of AIDS cases in non-metropolitan areas between 1991 and 1994 increased 9.4%, compared with 3.3% in metropolitan areas of 50,000 to 500,000 population and 3.1% in metropolitan areas with 500,000 and more.

Between 1988 and 1990, the 25 counties with the highest rate of increase in AIDS cases were primarily rural counties with an average county population of 73,000. This is contrasted with the early years of the epidemic between 1982 and 1984, when the 25 counties with the highest rate of increase of AIDS cases had an average population of 1.1 million.

Conclusion. HIV and AIDS have quietly become a major public health emergency in the Southern United States. Indeed, the current trends in the epidemic may lead to a state of social and economic crisis, as well. HIV is rapidly becoming more prevalent among females, African-Americans and rural populations, particularly in the South. The growing need for intervention through a fragmented and somewhat ineffectual public health system in many areas of the South increase the urgency of need for education as well as practical technical assistance at the community level to meet the explosively growing need for care and treatment of HIV.



Source: Neal Nathanson, M.D., Director, Office of AIDS Research, National Institutes of Health at the 1999 Natl Conference on African-Americans and AIDS. Feb. 25-26, 1999 in Washington, DC



Source: North Carolina Rural Health Research and Policy Analysis Center, UNC at Chapel Hill
Original source: U.S. Bureau of the Census, 1990
1 dot = 200 persons.

Challenges to Community Organizing for "Self-Care"

2

Implications of the Southern Cultural and Political Environment on Access to Care for HIV

The population emerging in the recent statistics as newly diagnosed with AIDS and/or seeking care for HIV in the South is increasingly female, youthful, African-American and increasingly rural. The expanding youthful HIV-positive population of both sexes and all races and risk groups suggests increased barriers to access care and treatment for those who are uninsured and marginally employed and needing early intervention for HIV. —

Cultural Factors as Barriers to Care and Services. The rural Southern culture presents a formidable set of barriers to development of and access to services needed in all areas of the nation in today's world of HIV, substance abuse and myriad other social problems. These stem largely from a general resistance to acknowledging the need for such services in the region and lack of will to address the problems.

Susan Becker (1994) proposed a model of barriers to development of substance abuse treatment programs in rural areas that is appropriate to the development of HIV primary care services, particularly in view of the strong mental health and substance abuse treatment components required for a continuum of care.

1. **Flawed views of rural America**
2. **Serious limitations to social and health data**
3. **View of rural problems as disconnected from U.S. society**
4. **Perceived lack of a viable political solution**
5. **Absence of a unified rural constituency**
6. **State and Federal fiscal crises**

Becker, Susan L. **Bringing excellence to rural and frontier America: Advocacy for substance abuse services in the 1990s.** *Rural Issues in Alcohol and Other Drug Abuse Treatment.* (Rockville, MD: USDHHS / Center for Substance Abuse Treatment [DHHS Pub. No. SMA 94-2063]) 1994:1-6

Flawed views of rural America.

Stereotypic images of the "country bumpkin" can lead metropolitan populations to view rural Americans as inherently inferior and somehow less worthy of services commonly found in urban areas. From a rural perspective the sparse population, relatively low educational achievement of past generations and dedication to preservation of the "simple country life" lulls many rural residents to believe that "*city problems don't affect us*." Both views deny the simple reality that in the age of the Internet and MTV, American society in youthful generations is a great deal more homogenous than most Americans realize.

Serious limitations to social and health data exist due to lack of academic resources to gather, analyze and report data as well as a general reluctance of rural residents to acknowledge problems at home. Unfortunately, this reticence to identify or acknowledge problems and needs frequently includes physicians, health department personnel and local policy-makers. "*Out of sight - Out of mind*" is a strong cultural tenet, particularly in the rural South. Denial and minimization are a traditional societal coping strategy, particularly among the older rural population who continue to dominate social institutions such as politics, religion and available charitable service organizations.

Much of the charm of rural life is centered on a false sense of security that ***rural problems are separate and distinct from social problems*** in the nation at-large. Problems such as HIV and substance abuse are "somebody else's problem." This belief is rooted in the much-valued but largely antiquated notion of a rustic pride reminiscent of simpler past times, where acknowledging problems was paramount to admitting weakness or flaws. Historically, every extended family had a member whose mental or

physical illness made them the "afflicted or disturbed, the black sheep" of the family, an embarrassment to be hidden from society-at-large and never discussed in "polite company."

Perceived lack of a viable political solution to problems is frequently cited by community leaders as a reason to justify **not** addressing a problem once identified. In this context, "political" implies public support for such an effort, and includes issues of the magnitude of a problem, economic considerations, concerns that addressing a problem condones and contributes to its spread, attracting "undesirables" who may seek the services and competition with other more valued social service groups. Attitudes may imply that the proposed service population is being divinely punished for unacceptable behavior. Addressing the problem is loosely regarded as condoning the offending behavior.

Absence of a unified rural constituency is a particularly challenging barrier to development HIV service systems. In the past, several service development projects have been challenged by some local and state officials on the basis of lack of a visible and cohesive population of affected persons. This argument against service development is based on "official" figures which we believe grossly under-represent the true epidemiologic picture of the region. *Absence of evidence* is thereby misconstrued as *evidence of absence*.

State and Federal fiscal crises affect both urban and rural social services. Our experience in the service area consistently indicates the resources for all service programs are generally reduced first in the rural areas, where a lower number of vocal advocates are expected, legislative representation is weaker and populations at-risk are less numerous, less cohesive and more politically impotent. Rural residents are somehow perceived to be better able to *take care of their own* and political rhetoric tends to support the widening of the gap by extolling virtues of self-sufficiency and a vague notion of community pride and spirit.

Rural areas generally suffer from *lack of public transportation* adequate to access care in the nearest metropolitan areas. Isolation exacerbates economic hardship and greatly limits ability to access and afford reliable

transportation for long distances when needed to reach care. The vast majority of roads in the region are treacherous in inclement weather, making lengthy travel impossible in much of the winter season. Multiple barriers to service development result in the generalized lack of social & health service resources available, particularly for persons not perceived as "innocent victims" of their plight. While much of the South does not have a significantly large non-English-speaking population, *absolute and functional illiteracy are significant*, particularly among target populations.

The cultural characteristics of rural America are intensified in the South where strong traditions of fundamentalist religion permeate every aspect of society. The "Bible belt" theology frequently views illness and misfortune as the *natural consequence of sinful behavior* and provides subtle but potent resistance to efforts to address human needs perceived as resulting from "behavioral causes". Some behavioral consequences are more heavily sanctioned than others in inverse proportion to the population perceived to be so afflicted. Alcohol, tobacco and high-fat country cooking all contribute to behaviorally-induced health problems, but are not perceived as rooted in the degree of "evil" as are HIV infection and substance abuse. The judgmental penchant of rural society greatly influences the community's charitable attitude toward *illness it may perceive as earned*.

Many cultural traditions of the South continue to influence attitudes, although more subtle and covert than in the relatively recent era of a generation or two ago. Racism, sexism and homophobic thought and action persist. Self-esteem is subconsciously rooted in comparison of self-perception to others. Self-esteem is bolstered by deriding of others, albeit unspoken. Charity is extended preferentially to "people like us *except for . . .*" and is frequently conditioned on demonstrating acceptable conformity to standards prescribed by the charitable organization or individual. An example is a local homeless shelter that requires daily participation in its proselytizing worship service as a condition of assistance.

Fortunately, attitudes of some in rural America are becoming more tolerant of human diversity and individual liberty than in the past. However, collective attitude and behavior still reflect Southern rural tradition while the individual may express more acceptance of others outside the context of conformity to societal standards. Fundamentalism-driven moral judgement is evident in law, ordinance and matters of public finance.

Residual Racism and Separatist Attitudes. Unfortunately, there is residual racism and separatist attitude that persists today in the South. This highly sensitive but very real phenomenon must be considered in the context of the cultural and political climate of the South. Much of the African-American political power is in the urbanized areas, leaving the rural areas largely dominated by a white majority politically.

Recognizing the disparities between AIDS survival rates and access to care wherein African-Americans are disproportionately affected by HIV with higher incidence of progression to AIDS and death, as well as higher rates of pediatric AIDS, the Congressional Black Caucus and Congress have launched an initiative to direct funding to address this growing disparity.

The article to the right is from the Federal Register notice of funding available for technical assistance funding available on a competitive basis to enhance care for minority communities in highly impacted metropolitan areas. No such initiative has been directed to rural areas. The SERCA initiative complements the Federal government's efforts to enhance access to care for minorities.

The philosophy of the SERCA program is oriented to targeting technical assistance to groups and organizations in the most difficult to reach and serve populations, and seeking an integrated care and service environment that makes access equal and comfortable for all.

In some communities, this will be a challenging objective. Through participation of a multi-racial technical assistance network, we will seek to encourage, by example, a community-wide cooperative program that can be of top-quality service for all living with HIV.

33864

Federal Register

Disproportionate Effect of HIV/AIDS on Minorities

Current statistics indicate that although advances have been made in the treatment of HIV/AIDS, this epidemic continues as a significant threat to the public health of the United States (U.S.). Despite showing a decline in the past two years, it remains a disproportionate threat to minorities. While African-Americans and Hispanics respectively represent approximately 13% and 10% of the U.S. population, approximately 36% of the more than 640,000 reported total AIDS cases are African-American and 18% are Hispanic.

In 1997, more African-Americans were reported with AIDS than any other racial/ethnic group. Of the total AIDS cases reported that year, 45% (27,075) were reported among African-Americans, 33% (20,197) were reported among whites, and 21% (12,466) were reported among Hispanics. Among women and children with AIDS, African-Americans have been especially affected, representing 60% of all women reported with AIDS in 1997 and 62% of reported pediatric AIDS cases in 1997. During 1997, the rate of new AIDS cases per 100,000 population in the U.S. was 83.7 among African-Americans, 37.7 among Hispanics, 10.4 among whites, 10.4 among American Indians/Alaska Natives, and 4.5 among Asians/Pacific Islanders.

Data from a recent Centers for Disease Control and Prevention study (Trends in the HIV and AIDS Epidemic, 1998) comparing HIV and AIDS diagnoses in 25 states with integrated reporting systems provide a clearer picture of recent shifts in the epidemic. The study indicates that many of the new HIV diagnoses are occurring among African-Americans, women, and people infected heterosexually, with an increase also observed among Hispanics. During the period from January 1994 through June 1997, African-Americans represented 45% of all AIDS diagnoses, but 57% of all HIV diagnoses. Among young people (ages 13 to 24) diagnosed with HIV, 63% were among African-Americans and 5% were among Hispanics. Although some of the states with large Hispanic populations did not have integrated HIV/AIDS reporting and could not be included in this study, HIV diagnoses among Hispanics increased 10% between 1995 and 1996.

Proposal for Educational and Technical Assistance Services

3

The Conceptual Model Outline

We are beginning our third decade as a nation **Living With HIV**. The face of the epidemic has changed in ways that are increasingly challenging to existing systems of providing health care and services. The availability of new diagnostic technology and a variety of promising treatment options point to the increasing need for community-based care and service delivery systems and resources necessary to support and operate those systems.

Early in the epidemic, the only group known to be widely affected by HIV was gay men. Unfortunately, HIV became labeled as a "gay disease". At nearly 20 years following the first reports of gay-related immune disease, "GRID", precious time and opportunities for effective response to the epidemic have been lost. While new infection rates among gay white men has been decreasing for the past several years, new HIV infections rage forward among groups that represent the "new face" of HIV in America:

Increasingly **female**, infected through heterosexual contact with male sexual partners who are infected

Increasingly **young** indicating infection occurs during adolescence and care is sought earlier in infection

Increasingly **non-white** ethnic groups who are traditionally medically underserved in general

Increasingly **rural** where primary care systems are least likely to be prepared for providing primary care

Increasingly likely to be **un-insured** or under-insured with health care and treatment costs borne by public programs

Much of the nation's current existing HIV-specific care and service infrastructure was built by gay and lesbian communities of metropolitan areas in the early years. Advocacy and case management were developed within that context, as well. As communities across America recognize the presence of HIV "in their own back yard", the importance of accessing experience and technical expertise in designing and funding care and services systems and programs becomes apparent. Such technical assistance services are generally needed from the beginning of the planning process becoming ready to provide a comprehensive continuum of care for people living with HIV.

Frequently Asked Questions

What is "Technical Assistance"? Community-based **Technical Assistance**, also called "TA" is a process that links community groups with (a) person(s) with experience in developing and implementing programs providing care and services for people living with HIV. Some larger communities have or hire consultants to coordinate planning, application for funding, and program construction.

What Can TA Do for Our Community Based Project? TA can be helpful in developing an over-all working plan for a community-based project. This can begin with facilitating a committed group of community leaders or members in concept design through all steps of the planning and implementation process. T*II*CANN always includes working with the state's Title II and ADAP programs to develop cooperative relationships.

How Can TA Help Us in Planning and Programming? Each community is unique with its own strengths and needs in system

development. In rural and underserved areas, the typical community's public health service infrastructure is generally unable to respond adequately to HIV, if at all. TA can help organize the planning and development process,

as well as guidance in implementing and evaluating care and service systems that have already been developed.

What Activities Does TA Include?

The Conceptual Model of Technical Assistance

Typically, technical assistance will include the following component activities or some combination of these activities:

- Epidemiologic profile of the community
- Defining the *Comprehensive Continuum of Care* needed in the community
- Resource inventory to identify and evaluate current continuum components
- Need assessment across the community constituencies
- Organizational capacity development appropriate to the needed activities
- Identifying and reaching stakeholders in the process
- Outreach, active participation and involvement of persons living with HIV
- Coalition-building tied back to the resource inventory
- Preparation of the comprehensive program plan and proposal
- Designing program evaluation components for care and services
- Software for clinical outcomes tracking and reporting
- Research of potential funding sources, public and private
- Preparation of application for funding through appropriate funding sources
- Development of operational plans and assistance in initial implementation
- Assessment of current programs and application for continuation funding
- Specialized services needed on a case-by-case, time-to-time basis
- Linkage with appropriate national-level AIDS Service Organizations ASOs)

Isn't TA Just the Same as Hiring a "Grant Writer"? In a few ways *yes*, but in some important ways, *no*. TA includes on going guidance in preparing the comprehensive program planning document, which is then crafted into proposal and/or grant applications. In contrast with traditional "grant-writer" consultation, comprehensive planning and development is the focus of TA, rather than just applying for money through a particular funding opportunity.

Aren't Consultants VERY expensive? Indeed, consultants are very expensive. In reality, consultants are far too expensive for most programs in the early stages of planning and development. This is actually when the greatest need for TA generally exists. T*II*CANN seeks to provide access to affordable TA consultation services at the cost

of expenses and receives support from other interested parties, including pharmaceutical manufacturers who are supportive of expansion of access to care and treatment for HIV.

Which Funding Programs Can We Apply For? ... Is The TA Provider Experienced in Those Programs? Depending on the needs identified following the resource inventory, funding may be sought from several sources. One question that should always be asked is "How many recent grants have you written that have been approved and funded?" During the past three years, Rich Fortenbery, TA coordinator of T*II*CANN, has developed successful systems component applications for several key programs that provide financial support for community-based programs.

SUCCESSFUL GRANT APPLICATIONS 1997-99

- Ryan White Title III *Early Intervention Services ("EIS")* funding
- Ryan White Title III Planning Grant
- HOPWA (Housing Opportunities for Persons With AIDS)
- Supportive Housing Program (*HUD Continuum of Care*)
- Shelter Plus Care program (*HUD Continuum of Care*)

Important Considerations with Respect to Access to Care for Persons Living with HIV

- The explosion of knowledge and complexity of care for persons Living with HIV during the past three years indicates the growing need for specialized and experienced care for HIV infection
- Substantial evidence indicates that *early intervention* (treatment) for HIV and prevention of opportunistic complications is considerably more cost effective, as well as more humane and potentially successful in preventing or delaying progression from uncomplicated HIV infection to AIDS.
- Increasingly successful treatment of HIV and prevention and/or treatment for the three dozen or so opportunistic complications of HIV means those of us living with HIV are living longer; therefore there is increasing need for on going care associated with aging, as would be expected among an aging population without HIV infection
- Primary care includes several key components:
 - HIV counseling and testing service
 - Diagnostic services such as lab work, X-ray, and physical exam
 - Therapeutics to treat HIV and opportunistic infections
 - Mental health care services
 - Substance use intervention and treatment
 - Oral health (dental) care
 - Nutritional assessment and counseling
 - Case management
 - Client education and risk-reduction, including secondary prevention of co-infection or re-infection
- Associated services such as housing stabilization and assistance as needed
- Linkage with other organizations providing essential care and services, especially organizations, public and private, funded by the Ryan White CARE Act

Access to Care and ***Access to Treatment*** are inseparable but distinct components of the Continuum of Care. Without informed, competent primary care for HIV through greatly lacking health care delivery infrastructure, access to treatment is sometimes counterproductive in the hands of inexperienced providers. Without access to treatment as recommended by the USPHS guidelines and access to FDA-approved antiretrovirals, treatment cannot occur even in the hands of experts. **SERCA** seeks to address both of these deficits in the South.

Components of Technical Assistance

- Epidemiologic profile of the community
- Defining the *Comprehensive Continuum of Care* needed in the community
- Resource inventory to identify and evaluate current continuum components
- Need assessment across the community constituencies
- Organizational capacity development appropriate to the needed activities
- Identifying and reaching stakeholders in the process
- Outreach, active participation and involvement of persons living with HIV
- Coalition-building tied back to the resource inventory
- Preparation of the comprehensive program plan and proposal
- Designing program evaluation components for care and services
- Software for clinical outcomes tracking and reporting
- Research of potential funding sources, public and private
- Preparation of application for funding through appropriate funding sources
- Development of operational plans and assistance in initial implementation
- Assessment of current programs and application for continuation funding
- Specialized services needed on a case-by-case, time-to-time basis
- Linkage with appropriate national-level AIDS Service Organizations ASOs)

Epidemiologic profile of the community.

The first step in planning a comprehensive program is to gather and analyze data from the community or region to assess the current and projected needs for care and services. This data can generally be provided from the state department of health. The Centers for Disease Control and Prevention (CDC) has developed a set a of model suggested guidelines for developing an epidemiologic profile for community-based HIV prevention planning. This program guide can be accessed at:

http://www.cdc.gov/nchstp/hiv_aids/pubs/sugguid.htm

Generally, different formats for organizing much of the same data will be needed to fulfill the requirements of the various sources of funding assistance. Consult the program guidance or NOFA for specifications and/or forms for the data type and format needed.

Defining the *Comprehensive Continuum of Care* needed in the community. Generally, a comprehensive continuum of care will

provide access to the key components of primary care (health, mental health, dental, and nutritional care), supported by case management services and linked to emergency financial assistance, housing stabilization, and referral sources for specialized and/or hospital inpatient care. A good model of the comprehensive continuum of care and services is specified by the Title III Ryan White program.

Resource inventory to identify and evaluate current existing continuum components. After defining the scope of the continuum of care components needed in the community, a resource inventory is compiled which identifies agencies providing various components, their accessibility, and capacities. Each resource agency should be evaluated in context of *availability* and *accessibility* of HIV-specific services.

Need assessment across the community's constituencies. A need assessment consolidates the findings of the community's epidemiologic profile in terms of the defined comprehensive continuum of care and resource inventory findings. The need assessment then identifies specifics in terms of the nature and scope of missing or needed program components that build upon existing resources to complete the comprehensive continuum. The need assessment includes data and information provided by clients and members of the population to be served, linking the essential components with essential community-specific information.

Organizational capacity development appropriate to the needed activities. Groups seeking to expand their current services and especially those that are newly established need to develop an appropriate organizational infrastructure that will be able to properly manage and execute the programs they seek to provide. As part of this process, a detailed plan including policies and procedures, clinical protocols and systems, as well as fiscal management and information management systems must be developed. For existing care and/or services providers seeking to enhance or expand their current services mix to focus on care and services for persons living with HIV, technical assistance provides a review of the existing management and administrative systems, with recommendations to adapt to the enhanced mission where appropriate.

Identifying and reaching stakeholders in the process. The resource inventory and need assessment will identify agencies and providers that should logically have a close collaborative relationship with the community-based care and service program. Organizing and convening a meeting of those stakeholders is an essential part of the program development process. Maintaining the collaborative group through the planning and implementation phases of the project is crucial, as well.

Outreach, participation and involvement of persons living with HIV. Any program developed to provide care and services for persons living with HIV *must include active and substantive participation of persons living with HIV* in the community to be served. This is a statutory requirement of the various federal programs that provide funding needed by community-based groups such as the Ryan White CARE Act and HUD's HOPWA program.

Coalition-building tied back to the resource inventory. The complexity of the comprehensive continuum of care requires substantive input and participation from all community resources that can and should work with the care and services development program. A community coalition needs to be developed in order to provide the broadly-based support and collaboration necessary to develop existing resources to meet the needs as well as build new capacity in the program.

Preparation of the comprehensive program plan. The planning process should lead to a comprehensive program plan that serves as the master template for program development activities which will lead to preparing organizational documents, proposal and application documents for funding, operating policies and procedures for clinical, administrative, information, and fiscal management.

Designing program evaluation components for care and services. The program envisioned in the comprehensive program plan must be evaluated in an on going and "benchmark" context to determine the effectiveness of the program in meeting needs and fulfilling expectations. Through this process, strengths and weaknesses can be identified, planning and program design can be reviewed, *quality assurance ("QA")* and *continuing quality assurance ("CQI")* mechanisms can be in place from the beginning of the program.

Developing software for clinical outcomes tracking and reporting. Computer software programs for maintaining records, including clinical progress and outcomes is an essential part of QA and CQI programs. Additionally, reporting various details of program information is necessary in reporting to funders and oversight agencies.

Research of potential funding resources, public and private. There is generally no single source of funding that will be able to support the development of a comprehensive continuum of care system. A comprehensive research of public and private resources of direct financial and *in-kind* support, at the federal, state, regional, and community levels is essential for assembling a comprehensive, adequate financing package for the program.

Preparation of application for funding through appropriate sources. This is the traditional function of "grantwriting" consultant services. Comprehensive technical assistance includes this function, as well as the many others described here. While the application for funding must be carefully and properly prepared, it largely re-states the terms of the comprehensive program plan in the context of requirements and expectations of the funder.

Development of operational plans and assistance in implementation. As an essential part of the program plan and proposal, the operational plans are essential in development and implementation. The technical assistance consultant will be available and participate closely in the implementation process, as needed and appropriate.

Assessment of current programs and application for continuation funding. Program funding resources are not guaranteed "forever" and no agencies or programs provide funding without requirements for program performance. This is particularly true for publicly-funded programs. Community-based technical assistance will be available for

evaluation, assessment of performance and evolving needs. Comprehensive technical assistance will be there when needed to apply for continuation funding. Hiring a "grantwriter" to work with continuation can be very cumbersome in terms of time and cost as the grantwriter must invest time to the research activities related to each funding source. Technical assistance should include anticipating this process "down the road" and should be done with continuity between the initial planning and development and the renewal process.

Specialized services needed on a case-by-case, time-to-time basis. At various times, specialized services are needed that cannot be performed by in-house staff and administration. These can include matters that arise somewhat unexpectedly. A common example is the emergence of managed care systems for Medicaid programs, which has a tremendous impact on the operating environment of programs providing care and services for persons living with HIV. Changes in legislation, regulation, and expectations of funding sources, as well as changes in regulatory and administrative agencies can create such needs.

Linkage with appropriate national-level AIDS Service Organizations. There is a rapidly growing number of national-level ASO's that frequently address a single problem or set of problems or issues that confront the evolving world of HIV-related CBO's. Community-based technical assistance will provide appropriate linkage with national organizations and contact persons that can provide information, assistance and services needed by the program.

The Model Programs: Linking the Direct Experiences of Rural and Urban Providers of Top-Quality Care and Treatment for HIV

The Heartland Project. The SERCA program team leader / director, Rich Fortenbery, led the establishment and development of Heartland CARES, Inc. from its beginning in May 1996 through May 1999.

Heartland CARES, Inc., the non-profit community-based organization (CBO) provides comprehensive care and services for people living with HIV in Western Kentucky and Southern Illinois from its headquarters in Paducah, Kentucky. The Heartland Clinic opened in August 1998 with funding from successful applications for Ryan White Title III EIS funding following a planning grant project funded in October 1997. Today, the Heartland Clinic serves over one hundred persons previously not in care for HIV. This number exceeds the previous cumulative case count for the region.

The Heartland "Project" serves as the primary model for the SERCA initiative as the only program developed and broadly funded from a totally conceptual context. The clinic staff now includes two board-certified infectious disease specialist physicians and will expand to include nurse practitioners as primary care providers.

In addition to comprehensive primary care services, Heartland also operates a region-wide housing stabilization and assistance program for persons living with HIV and collaborates with several regional care and services providers, including the regional domestic violence agency for Western Kentucky. Those program components are supported through funding from the US Department of Housing and Urban Development.

Fortenbery coordinated the planning and authored the grant applications for the Heartland CARES, Inc. programs. Both the Ryan White

Title III planning and EIS grants were written by Fortenbery and funded on first submission for review. These applications are included in this document as section 5 to serve as specimens for the SERCA projects.

Whitman Walker Clinic. WWC is the largest clinical care network for HIV in Washington, DC and is the second largest HIV clinical program in the world. WWC operates four clinical sites in the greater DC area. The clinic provides comprehensive health and supportive services for over 4,000 clients in the area.

Whitman-Walker is a non-profit, volunteer-based lesbian and gay community health organization service organization founded in 1973. It has been a regional and national leader in providing high-quality, accessible and culturally sensitive health, mental health, and addictions treatment services to the area's gay, lesbian, bisexual and transgender communities. WWC also operates the Max Robinson Center in Anacostia, a predominantly African-American area of DC and has developed culturally-specific and culturally-sensitive programs for the minority communities, as well.

Other services provided by Whitman Walker include comprehensive case management and supportive services, such as legal support and housing assistance, as well.

Both Heartland and the Whitman Walker Clinic system will serve as resource programs for project modeling and will serve as preceptor sites for administrative clinical services staff for the projects of the SERCA program.

SERCA Program Work Plan

4

Three work plans are presented in this larger document. The workplan below outlines the sequential process of selecting candidate projects for this program and executing the technical assistance model previously outlined and described with respect to its seventeen components. The workplan for the Ryan White Title III Planning Grant and Early Intervention Services (EIS) Grant applications for the Heartland Project are included within each of those appended application documents. These are representative of a work plan for a typical project from basic through advanced stages. Project workplans for each project will be similar to those specimens presented.

SERCA Oversight Committee. An oversight committee will be created which will include the program director of the *SERCA* project, with the CEO and CFO of T*II*CANN as ex-officio members. The group will also include an additional member of the T*II*CANN executive board of directors and a representative of each program sponsor contributing the requested basic budget amount for the program as a major sponsor. The committee will meet and/or hold conference calls for review of candidate project applications and prepare recommendations for selection of projects for assistance. In conformance with the principles of unrestricted educational grants, those individuals representing sponsors will not be included in "voting" on candidate programs or with respect to any of the financial management issues vis-à-vis the *SERCA* program.

Program Management. The *SERCA* program will be managed by the program leader and the CEO of T*II*CANN under auspices of the board of directors of T*II*CANN within the customary context of non-profit organizational operations.

Program Implementation and Staffing. In a general sense, the program will be implemented by the program leader/director with the integral

assistance of an administrative coordinator and an administrative support specialist in concert with a geographically diverse group of consultants across the South. Most of these individuals are HIV-positive with extensive and diverse experience in community organizing and organizational development, as well as programmatic systems design and implementation, advocacy, and educational presentations.

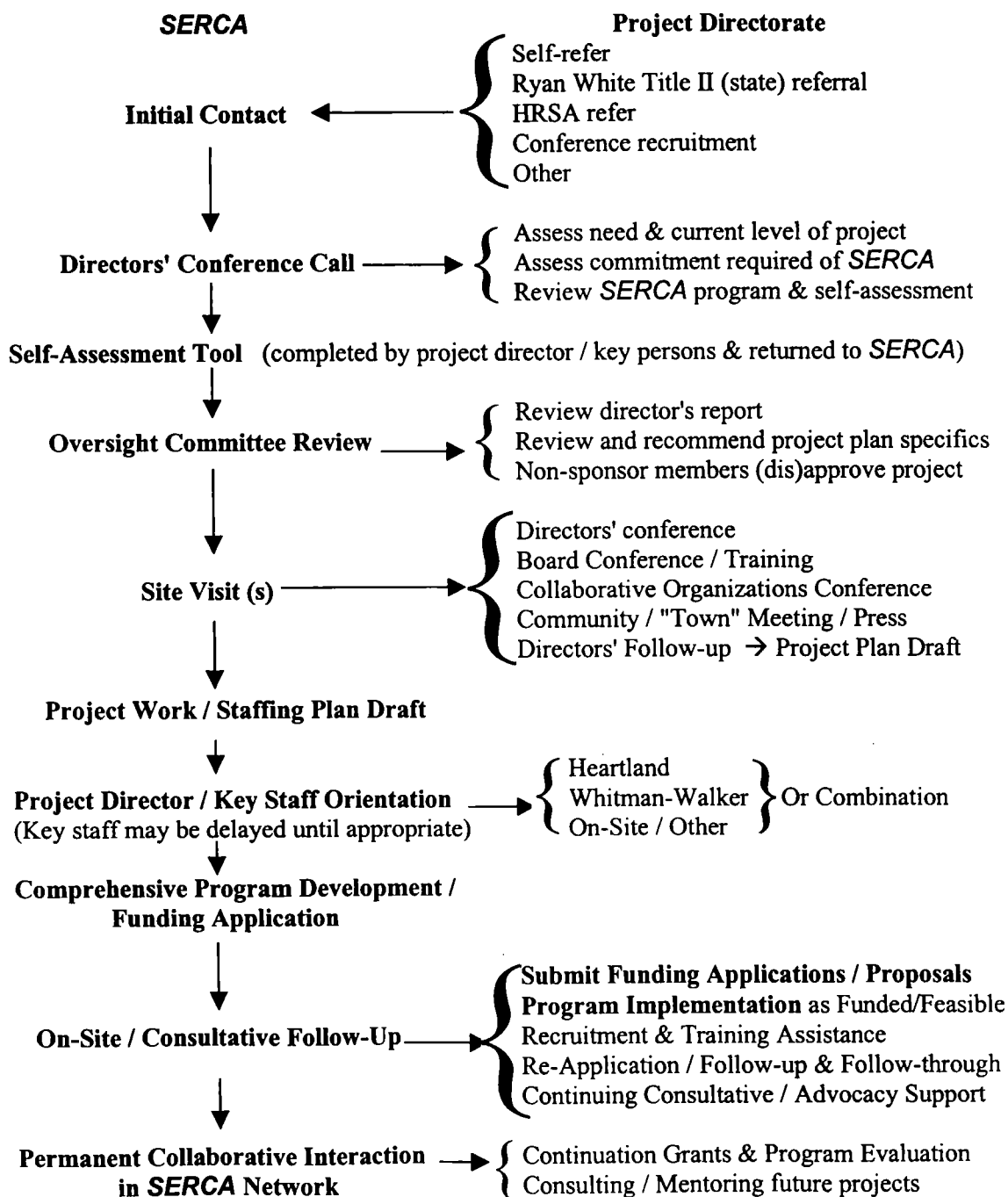
General Project Workplan. The chart on the following page indicates the sequence of activities within which projects will be implemented. Each of the previously identified seventeen components of technical assistance will be assessed and addressed with respect to the plan in appropriate detail.

The *SERCA* program leader/director and the candidate/client project director will serve as the primary respective contacts. As appropriate, agreed portions of project plans may be developed in detail and/or executed by program staff and project staff.

On-site consultation and direct assistance services will focus on orientation and collaborative development needs. Once functional internal and external relationships of the project group are developed, follow-up by conference call and correspondence will be implemented as appropriate and feasible to minimize cost of travel.

Timelines of individual projects will be dependent on several factors. The level of project readiness will, of course, be an initial significant factor. Perhaps the over-riding factor will be the deadlines imposed by the funding agencies for submitting application. The number of programs presented for competitive funding at any funding cycle should be reasonably limited to prevent conflict of interest, "internal" competition among projects, inordinate demand on program resources, and adverse effect on the quality of assistance and follow-up provided by *SERCA*.

General **SERCA** Project Sequence



TIMELINES: Timelines for sequencing will depend on the nature and level of comprehensiveness of technical assistance requirements and largely determined by the funding cycle schedules of the agencies and organizations providing funding. These are variable within the environment of legislative appropriations and final administrative budgets in terms of deadlines and funding levels.

Ryan White Title III and The Heartland Project

As previously described, the primary model for the **SERCA** program is Heartland CARES, Inc. of Paducah, Kentucky. The core operational and funding program for the Heartland Clinic is the Ryan White Title III program. This section provides information on the Title III program and includes the Ryan White Title III Planning Grant application of Heartland filed in May 1997 and awarded in September 1997, and the Ryan White Title III *Early Intervention Services with Respect to HIV*, referenced as "EIS", which provides actual operational support funding. Both of these applications were approved and funded with the first application submitted for each of the Title III program phases.

The core text of the applications is included. Names of individuals have been removed since some of those persons are no longer employed in the positions cited. For consistency, all individual names have been removed from the texts presented here. Attachments, assurance and certification forms and supporting documents referenced in the core text are available on request. Such requests should be addressed to Rich Fortenbery at T*II*CANN, (202) 588-1775 or by e-mail at richf.t2cann@mindspring.com.

Ryan White Title III Program Information. Information regarding the Ryan White Title III program is included on *pink pages* throughout this section. This material is copied in directly from official program information published by

the Division of Community-Based Programs (DCBP) of the HIV/AIDS Bureau (HAB), the bureau of the Health Resources and Services Administration (HRSA) which administers the Ryan White programs.

Ryan White Title III Planning Grant. The Heartland application for the Title III planning grant is printed on *yellow pages* to distinguish it from the Ryan White Title III EIS grant application and related materials, which follow the planning grant section. The Notice of Grant Award (NGA) is included at the beginning. Attachments to the application are not included. Official HRSA information copied in for explanation is printed on pink pages, as previously described.

Ryan White Title III EIS Grant. The Heartland application for the Title III EIS operations grant is presented, together with the official HRSA Notice of Grant Award (NGA). The core text is printed on white paper. As with the Ryan White Title III Planning grant application, the core text of the application is presented and names of individuals have been removed. Referenced attachments, assurance and certification forms, and extraneous materials are not included here but are available upon request as outlined above.

Ryan White Title III

Planning Grant

I. INTRODUCTION - RYAN WHITE TITLE III PLANNING GRANTS

The HIV/AIDS Bureau announces the availability of Title III Early Intervention Services (EIS) Planning Grants under its 1999 Expanded Planning Grant Initiative. Under this expanded initiative there will be two targeted efforts:

Section A: Rural and Underserved Initiative

The purpose of this initiative is to support public and private non-profit entities in their planning efforts to develop a high quality and broad scope of primary health care services for people who are living with HIV or at risk of infection. These planning efforts should be targeted to persons living with HIV in rural communities or communities which can be shown to be underserved.

In FY 1999, it is anticipated that 19 planning grants will be awarded under this initiative.

Section B: African American Populations Initiative

The purpose of this initiative is to support public and private non-profit entities in their planning efforts to develop a high quality and broad scope of primary health care services specifically for African Americans who are living with HIV or at risk of infection. Applicants must propose planning activities so that a comprehensive continuum of outpatient HIV primary care services may become available in their communities through the applicant agency.

In FY 1999, It is anticipated that 60 planning grants will be awarded under this initiative.

The applicant should indicate which initiative they are applying under on the Expanded Planning Grant Options Form (see page 28). This form should be submitted as page 1 when the application is submitted.

This grant program supports activities of the planning process and does not fund any service delivery or patient care. Applicants are encouraged to submit under one section only.

The awarding of Planning Grants will not obligate the Federal

Government to support applicants for future operational funding. In accordance with the Ryan White Title III legislation, Section 2654 Part C, preference in awarding the HIV Planning Grants will be given to applicants located in rural or underserved areas where emerging or ongoing HIV primary health care needs have not been adequately met.

A. Funding Options

The HIV/AIDS Bureau recognizes that different geographic areas and populations may be at varying stages in planning for HIV primary care service delivery in their communities. Under this expanded initiative, applicants will be able to select from several funding options. **Please indicate which funding option is being applied for on the Expanded Planning Grant Options Form (page 28).**

Section A: Rural and Underserved Initiative

Planning grant applications will be accepted from private non-profit or public organizations. These planning grants must be designed to improve the HIV Primary Care services in rural and underserved communities.

The following funding options are available:

- Option 1:** Applicants may apply for a one year \$50,000 planning grant.
- Option 2:** Applicants may apply for a \$50,000 one year planning grant plus a \$50,000 transition grant to support a second year of planning activities.

Section B: African American Populations Initiative

Planning grant applications will be accepted from indigenous private non-profit or public organizations serving the African American community. These planning grants must be designed to build the HIV primary care capacity of organizations serving African American communities highly impacted by HIV/AIDS. To facilitate the planning process and allow for the greatest flexibility in program design, the following funding options are available:

- Option 1:** Applicants may apply for a one year \$50,000 planning grant.

Option 2: Applicants may apply for a \$50,000 one year planning grant plus a \$50,000 transition grant to support a second year of planning activities.

Option 3: Two applicants in the same community, one a primary care provider organization and one an indigenous AIDS Service Organization (ASO) or Community Based Organization (CBO), may each submit a one year \$50,000 planning grant and propose to collaborate in conducting the planning grant activities and developing the EIS program. This option could result in \$100,000 in planning grant funds being awarded to the community for a one year planning period. **The HIV/AIDS Bureau expectation is that at the end of this process the community would submit one joint EIS application through the primary care agency.** Applicants pursuing Option 3 must include a written Memorandum of Agreement in the appendix of the application which outlines how the two organizations propose to collaborate.

B. Eligible Applicants

The following lists eligibility requirements for each section of the 1999 Expanded Planning Grant Initiative:

Section A. Rural and Underserved Initiative

1. Applicants must be public or private nonprofit entities that are, or intend to become, eligible to apply for the Title III EIS grant. **See Attachment A for EIS grantee eligibility information.**
2. Applicants can not be current Ryan White Title III Early Intervention Services Program grant recipients.
3. Preference will be given to applicants located in rural or underserved communities where HIV primary health care resources, including financial resources available under the Ryan White Care Act, remain insufficient to meet the need for services or plan for such services.

Section B. African American Populations Initiative

1. Applicants must be public or private nonprofit entities that are, or intend to become, eligible to apply for the Title III EIS grant. **See Attachment A for EIS grantee eligibility information.**
2. Applicants can not be current Ryan White Title III Early Intervention Services Program grant recipients **unless** they are proposing to open a new site in their current service area or in a new service area to serve African American communities highly impacted by HIV/AIDS. Preference in the review process will be given to applicants who are not current Ryan White Title III Early Intervention Service Program grant recipients.
3. Preference will be given to applicants located in rural or underserved communities where HIV primary health care resources, including financial resources available under the Ryan White Care Act, remain insufficient to meet the need for services or plan for such services.
4. Applicants must be organizations indigenous to the African American community. The exception is under funding option #3, where the co-applicant can be a primary care provider that is coordinating with an organization indigenous to the African American community (refer to Funding Options Section B, Option 3 on page 2).

For purpose of this application guidance "indigenous organizations serving the African American community" is defined as:

"A community-based or public organization local to and supported by the African American population proposed to be served."

C. Program Expectations

Proposed planning activities should lead to the establishment of comprehensive outpatient HIV primary care services, developed in accordance with the requirements of the Ryan White Title III Early Intervention Services Program. See Attachment A for a description of the Title III Early Intervention Services Program, which is specified in the Public Health Service (PHS) Act, Part C, Subpart 2.

The outcome of a planning process, funded under this grant, is that the grant recipient becomes prepared, through the planning process, to offer outpatient comprehensive HIV primary care services to its community.

Applications for operational funds from the Ryan White Title III Early Intervention Services Program, or other grant programs which support the delivery of outpatient HIV primary care services, may proceed from the planning process. It is expected that HIV Planning Grantees who choose to apply for operational funding under the Ryan White Title III Early Intervention Services Program would apply **after** their planning grant project period has ended and their planning activities have concluded.

Planning Activities - Planning Grants support HIV health services planning activities that include, but are not limited to:

- identifying key stakeholders and engaging and coordinating potential partners in the planning process;
- convening a formal advisory group to plan for the establishment of services;
- conducting an in-depth assessment of the nature and extent of need for HIV primary care services in the community. This should include a local epidemiologic profile, an evaluation of the community's service provider capacity, and a profile of the target population;
- identifying, establishing and strengthening clinical, administrative, managerial and management information system (MIS) structures so that the applicant may

become able to offer comprehensive HIV primary health care;

- defining the components of care and forming essential programmatic linkages with related providers in the community;
- researching funding sources and applying for operational grants; and
- examining existing HIV Early Intervention Services programs of similar communities in order to develop the most appropriate model of care for the community.

Planning Grant applicants are strongly encouraged to refer to the Ryan White Title III Early Intervention Services Program Guidance document (CFDA 93.918B) to help them understand the scope of services that constitute the continuum of comprehensive HIV primary care and the eligibility criteria for Ryan White Title III EIS grantees. Copies of this document can be obtained by calling the Primary Care Program Branch at 301-443-0735.

HEARTLAND CARES, INC.

CONSORTIUM OF AIDS RESOURCES, EDUCATION, AND SERVICES
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PRESIDENT
RICH FORTENBERY

RYAN WHITE TITLE III PLANNING GRANT APPLICATION

Reference Number 03211A
CFDA # 93-918

May 23, 1997

TABLE OF CONTENTS

Page	
2	Project Abstract
3	Need for Assistance - Narrative
5	HIV Population Profile
6	Proposed Planning Activities
7	1. Comprehensive Regional Needs Assessment / Resource Inventory
8	2. Program Research, Site Visits, and Program Design
9	3. Management and Information Systems Development
10	Role in the Community / Collaboration with Other Organizations
11	Budget
13	Involvement of People Living with HIV/AIDS (PLWH)
13	Evaluation Plan
	Attachment A
	Other Attachment Appendices

Heartland CARES, Inc. was incorporated March 4, 1997 as a consortium of Ryan White Title II and state HIV program consortia, community-based organizations, and relevant agencies in Western Kentucky and Southern Illinois. The mission of this organization, defined in its Articles of Incorporation (Attachment C) is to plan, develop, and facilitate a comprehensive continuum of care for those living with HIV and those at risk for HIV infection in our service area. Our Articles specifically commit the organization to establish and operate a system of care as defined and specified by Title III of the Ryan White CARE Act and provide flexibility as defined by amendments to the Act. Heartland CARES is unique in its grass-roots origin and its interstate collaboration developed independently of State government. Services provided by Heartland CARES include networking and collaboration among its member organizations and individual participants in assessment, planning, resource development and coordination, and evaluation processes. Services of each of the constituent organizations are outlined in their letters of collaboration, institutional capacity, and services. (Attachment D-F).

The proposed service area consists of 17 counties of Western Kentucky and 15 counties of Southern Illinois as illustrated on the attached service area map set (Attachment G). The entire service area is rural with 24 counties designated as medically under served, four as partially under served, and four undesignated in the BPHC State Profiles, October 1996 edition. As explained in detail in the regional epidemiologic profile (Attachment A), the estimated number of persons infected with HIV in the service region is 2667. An available epidemiologic profile of persons living with AIDS in Southern Illinois is consistent with the national average, while the profile for Western Kentucky, which includes persons living with HIV as well as AIDS, shows a significantly younger infected population compared to the national average (Attachment H). The rate of increase in HIV infection in the Southern Illinois region is difficult to accurately establish independently of the rest of the State. From June 30, 1996 to March 31, 1997 the rate of net increase (not factoring in deaths) in HIV/AIDS persons seeking care in the Western Kentucky portion of the service area is increasing at an annualized rate of 38%.

Current resources for care and service for those living with HIV and AIDS in our service area are very sparse. No community in the area has a system of resources that constitutes a "comprehensive continuum of care". Primary care from an infectious disease specialist is available only in the Northeastern-most county of the Western Kentucky region, and only two communities have community-based organizations whose missions include providing services to any significant degree.

Heartland CARES has been engaged in planning and organizing activities since its incorporation, including previous planning activities by Paducah CARES, a constituent organization. Proposed planning activities include expanding and strengthening the current base of agency collaboration, integration of the Early Intervention Services program into our currently developing Comprehensive HIV Housing Program, retaining a program consultant experienced in program development in HIV-specific primary care, conference and negotiation with our prospective Medical Director (available in July 1998), site visits by key personnel to existing model Ryan White Title III programs, and acquisition of computer hardware and supplies necessary for management information systems.

1. Needs Assessment Data (Attachment A)**2. Needs Assessment Narrative**

Since the advent of the HIV epidemic, available primary care for those infected in the service area has been limited to a relatively few family practice physicians willing to provide care. While anti-discrimination laws in both Kentucky and Illinois prohibit discrimination against HIV-infected persons, physicians who feel the specialized care required is not within their field of practice are exempt from these prohibitions. A partnership of two oncologist / hematologists in Paducah, Kentucky have provided primary care for HIV-infected clients but are no longer accepting new clients. Their practice includes five clinical sites and they are not in the Paducah clinic more than two days per week. This limits both their capacity for clients and availability of readily accessible primary care for the clients they currently serve.

In February 1994, the Comprehensive Care Center in Nashville, Tennessee opened and a large number of Western Kentucky clients have sought primary care at the Center (Attachment I), or at the Infectious Disease clinic of Vanderbilt University Medical Center in Nashville. The distance from Paducah, Kentucky to Nashville is approximately 160 miles and travel time round trip is five to six hours. Other clients from Paducah and Southern Illinois currently travel to the Infectious Disease clinic at Washington University Medical Center in St. Louis, Missouri. The distance from Paducah to St. Louis is approximately 185 miles, with travel time comparable to or slightly greater than travel to Nashville. The Comprehensive Care Center currently provides service to Kentucky Medicaid enrollees but difficulty in collection from Kentucky's Medicaid program may result in the necessity of the Center discontinuing this payment program.

An infectious disease specialist currently practices in a large multi-specialty practice in Hopkins County, Kentucky which is located in the Northeastern-most corner of the Western Kentucky service area. No other infectious disease specialist primary care resources are currently available in the area. No public health departments in the service area offer primary care services designed or staffed for persons with HIV infection. Sources of primary care in the service area are therefore non-specialized and sparse, while the nearest sites of qualified specialized care are quite remote, requiring a full day of travel for a routine office visit.

Those who are able to access specialized care in Nashville and St. Louis are those who are able to obtain or provide their own transportation and those who are able to invest an entire day for a physician visit. This severely limits access to care by those unable to arrange and/or afford transportation to out-of-state providers and those who are employed. Presumably, those least able to obtain transportation and/or arrange child-care for accommodating such travel are the lower income population, especially women of color and of childbearing age.

A significant gap in available healthcare payment sources in Kentucky exists. Those persons qualified for and receiving Supplemental Security Income (SSI) payments based on a determination of disability are enrolled in the Kentucky Medicaid program on a month-to-month basis. This is also true in Illinois. Those receiving Social Security Disability Insurance (SSDI) exceed the income limits for SSI and therefore do not qualify for Medicaid coverage. This leaves a significant number of persons without health care coverage during their 24-month waiting period for Medicare eligibility following initiation of SSDI benefits.

In the Western Kentucky portion of the service area, per-client benefits for Ryan White Title II assistance were capped at \$1,000 annually during the 1996-97 program year and regional funding for the Home- and Community-Based Care program for the Western Kentucky region was reduced from \$58,341 in 1996-97 to \$41,576 in 1997-98. These are "gross figures" before deduction of "case management" and administrative costs. The State-funded assistance program for the Western Kentucky region was reduced from \$20,000 annually to \$5,367 in the 1997-98 program year. These reductions resulted from the Kentucky Department for Public Health, as Title II grantee, instituting a "formula reallocation" effective in the 1997-98 program year.

The formula considers AIDS cases only, and does not include HIV-positive persons without a CDC-defined AIDS diagnosis. This formula favors the urban/metropolitan areas of Louisville and Lexington for funding since those population centers have a higher AIDS case registry. This may be due to greater resources for diagnosis and service, reflecting a lower mortality rate in urban areas relative to rural and under served areas, such as ours. Further, exclusion of newly-diagnosed HIV-positive persons does not address the need for Early Intervention Services to prevent progression of HIV-positive persons to AIDS diagnosis. Unfortunately, this basis of allocating Title II funding widens the gap in resources between urban and rural areas, as well. Together with the rapidly increasing rate of persons seeking care in our area previously cited at 38% and rather drastic reductions in Title II and state-funded assistance, the acuity of our need for the Early Intervention Services program of Title III is a function of both increase in caseload and decrease in resources.

The Kentucky Drug Assistance Program (KADAP) formulary covers cost of 18 specified medications, none of which are protease inhibitors. A limited number of clients statewide (currently 30) may receive protease inhibitors through KADAP via a competitive selection process managed by Community Health Trust in Louisville on behalf of the KADAP program.

The Southern Illinois Ryan White Title II Consortium was first funded in 1996-97. In the 1997-98 program year, the funding was increased 10% to \$175,000. Although this regional funding is significantly higher than in Western Kentucky, it is still insufficient to adequately meet the needs of the growing HIV infected population in Southern Illinois. Annual service caps have been instituted for service categories. Due to the significant gap that exists in available health care payment sources in Southern Illinois, the severe shortage of medical providers, and the high level of assistance needed for housing and transportation across long distances to access services in this rural area, the available Title II funding is currently strained.

The AIDS Drug Assistance Program in Illinois received increased funding and expanded its formulary this year but is instituting a \$1,000 per-month-per-client cap. This is expected to cover the "cocktail" combination, but no additional medications that the client may require, such as prophylaxis or other medication.

Update Note: As of inclusion in the **SERCA** proposal (9/99), the Kentucky ADAP formulary has been expanded to include all current FDA-approved antiretrovirals plus hydroxyurea and doubling the number of drugs for prevention and treatment of opportunistic infections. Rich Fortenbery worked with others to build a case which was instrumental in this progress. Recently, the monthly per client limit of the Illinois ADAP was raised to \$2,000 per month.

3. HIV Population Profile

5

EPIDEMIOLOGIC PROFILE PERSONS LIVING WITH AIDS Heartland CARES Service Area 12/31/96

This epidemiologic profile is based on persons known **living with AIDS** as of 12/31/96. Illinois does not report this data for those with HIV but without an AIDS diagnosis. Attachment H includes analysis of persons living with HIV and AIDS in Western Kentucky, reported exclusively, and reflects the localized epidemiology of the newly-identified cases and hence, more recent epidemiologic trends.

	Western KENTUCKY		Southern ILLINOIS		COMPOSITE REGIONAL	
	N	%	N	%	N	%
GENDER						
Male	53	85.5%	46	95.8%	99	90.0%
Female	9	18.9	2	4.2	11	10.0
TOTAL	62	100.0	48	100.0	110	100.0
AGE						
<13	0	0.0	0	0.0	0	0.0
13-19	0	0.0	2	4.2	2	0.2
20-29	15	24.2	8	16.7	23	20.9
30-39	27	43.6	27	56.2	54	49.1
40-49	15	24.2	10	20.8	25	22.7
>49	5	8.0	1	2.1	6	5.5
TOTAL	62	100.0	48	100.0	110	100.0
RACE						
White	43	69.4	29	60.4	72	65.4
African-American	19	30.6	13	27.1	32	29.1
Hispanic	0	0.0	6	12.5	6	5.5
TOTAL	62	100.0	48	100.0	110	100.0
RISK FACTOR						
MSM	36	58.1	22	45.9	58	52.7
IDU	10	16.1	16	33.3	26	23.6
MSM & IDU	5	8.1	2	4.2	7	6.4
Hemophiliac	0	0.0	1	2.1	1	0.9
Heterosexual	8	12.9	3	6.2	11	10.0
Transfusion	2	3.2	0	0.0	2	1.8
Perinatal	0	0.0	0	0.0	0	0.0
Undetermined	1	1.6	4	8.3	5	4.6
TOTAL	62	100.0	48	100.0	110	100.0

Sources: Kentucky Department for Public Health, (502) 564-6539 275 East Main Street, Frankfort, KY 40621 / Illinois Department of Public Health, (312) 814-4846 160 N. LaSalle, 7-South, Chicago, IL 60601

Regional census data of the two State regions are tabulated in attachment K. These 1990 figures represent the most recent available to reflect such detailed data of regional demographics. Further, these data reflect the general populations. Investigation of such demographics in the target populations would be included in the planning activity of needs assessment (Activity C.1.)

The HRSA/BPHC State Profiles, October 1996, reports the following poverty levels and medically uninsured percentages on a statewide basis:

	Kentucky	Illinois
Income at Poverty Level		
<100%	19.0%	11.9%
<200%	41.1	27.1
% Without Medical Insurance	15.8	11.9

We tentatively identify the unmet needs of the target population of our region as lack of locally available primary care specific to HIV, expense and time of travel to access care, and economic barriers to care across the income spectrum of the population. Significant gaps are widening in the Title II funding availability and services provided through Home- and Community-Based Care and AIDS Drug Assistance Programs. State-sponsored support for HIV-related assistance programs is decreasing by 70% in Kentucky. **In this environment, the Title II project sponsor in the Western Kentucky region, has announced it is withdrawing from participation in all HIV-related programs effective May 30, 1997 (Attachment B).** This leaves our proposed program as the apparent sole-source provider of supportive services in the "comprehensive continuum of care", as well as the only group regionally working to provide primary care services for those living with and at-risk for HIV infection.

C. PROPOSED PLANNING ACTIVITIES

A significant amount of planning and organizing has already been accomplished locally and regionally. Paducah CARES, a constituent of Heartland CARES, has entered agreement with the Housing Authority of Paducah to jointly operate the Comprehensive HIV Care and Housing Program as described in Attachment 0). This plan utilizes the Housing Opportunities for Persons With AIDS (HOPWA) program and the Supportive Housing Program of the U.S. Dept. of H.U.D. Continuum of Care program to build infrastructure providing emergency shelter, community living, and transitional housing facilities. The Housing Authority of Paducah will also construct a clinical facility to house a Community Health Center operated within the design of Section 330 and subsections 330 (h & i) of the U.S. Public Health Service Act. This local contribution will provide the capital property resources needed to implement the Ryan White Title III Early Intervention Services Program.

Planning activities proposed to be funded with this Ryan White Title III Planning Grant include:

1. Comprehensive Regional Needs Assessment / Resource Inventory
2. Program Research, Site Visits, and Program Design
3. Management and Information Systems Development

1. Comprehensive Regional Needs Assessment / Resource Inventory

While some secondary data suitable for program planning is available from the respective States' various agencies and other local and regional sources, we realize a comprehensive assessment model is needed to provide both static and longitudinal assessment of needs of the population in general in early detection through HIV counseling and testing services and the HIV-infected population in particular in providing a comprehensive continuum of care including early intervention services. Heartland CARES has enlisted the participation of the Center for Rural Health and Social Services Development of the University of Southern Illinois in Carbondale, IL to provide initial and on-going assistance in assessment, research, monitoring, and evaluation. (Attachment L). This early participation by SIUC is in anticipation of documenting our development experiences for the assistance of others in similar projects in rural and under served areas and Heartland CARES' future participation in Special Projects of National Significance (SPNS) projects within the Ryan White and HOPWA programs.

GOAL: Develop a needs assessment and resource inventory model and component practical tools to:

- a.) Provide a realistic static (fixed-time) needs profile for early detection of HIV infection in the general population and early intervention services needs of the HIV-infected population, including all components of a comprehensive continuum of care (to be defined in Activity 2, below);
- b.) Conduct periodic follow-up assessments to track longitudinal changes in needs;
- c.) Contribute to specific program design and evaluation models and practical tools for operational monitoring; and
- d.) Provide documentation of needs for initial and on-going program planning and application for other sources of funding, licensing, Certificate of Need (Kentucky requirement), and other purposes.

TIMEFRAME: Initial design of the assessment tool (Attachment N) has begun and peer-review among various HIV-positive organizations and support groups is currently underway. Planning funding budgeted from the Purchase/Pennyrile HOPWA allocation funding (available June 1, 1997) will also contribute to this goal and will provide interim funding to proceed with this activity. This preliminary activity is in anticipation of completion of the initial assessment and resource inventory by October of 1997. The "permanent" model for baseline and longitudinal needs assessment and resource inventory will be completed by May of 1998 and conducted annually thereafter.

MEASURABLE OBJECTIVES: The key person/organization will produce the model and practical tools cited above, together with timely reports as outlined above.

KEY ORGANIZATION: Southern Illinois University
Center for Rural Health and Social Services Development

KEY PERSON: *****

2. Program Research, Site Visits, and Program Design

We strive to design an Early Intervention Services program which includes all components of "comprehensive continuum of care" as defined in the Ryan White CARE Act, with particular focus on Part C ("Title III"). Our vision of "comprehensive continuum of care" also includes the components of housing and supportive services as defined in the HOPWA (Housing Opportunities for Persons With AIDS) and Continuum of Care (C.O.C.) programs of the U.S. Dept. of Housing and Urban Development. We are currently working with the C.O.C. Boards of the region to access and implement these programs in an integrated program which includes Ryan White Title III, as well as Section 330 (h & i) programs of the U.S. Public Health Service Act. This includes the Multiple Diagnoses Initiatives jointly sponsored by DHHS and HUD.

As outlined in Section B, "NEED FOR ASSISTANCE", we are essentially working from a "start-from-square-one" position. While this presents a tremendous challenge in the process leading to service delivery, we sense a unique opportunity we seek to maximize to our advantage. We realize many existing programs enter such ventures with a challenge of changing, adapting, and reorganizing which frequently becomes as or more difficult than starting from the drawing board, as we must do. To this end, we seek to build a strong foundation of research of existing Title III programs through correspondence and site visits so we can design a fully compliant, responsive, and effective program. Technical assistance from and close consultation with current providers accessed by HIV-positive persons outside but near our region will be included. Close and frequent consultation with our Medical Director will be required, as well.

GOAL: Produce a program design and plan for the Early Intervention Services for HIV program through sound program research and program/provider networking by:

- a.) Retaining assistance of a program consultant experienced as former development director for our principal primary care provider in Nashville;
- b.) Identifying and contacting appropriately similar grantee programs currently participating in the Ryan White Title III program for consultation and technical assistance;
- c.) Conducting site visits to the identified Title III programs by key personnel in designing our operational program plan;
- d.) Consultation with and site visits to the current clinical site of our proposed Medical Director (currently located in Chicago at Rush-Presbyterian Medical Center);
- e.) Obtaining and evaluating current protocols for Nurse Practitioner primary care models from various programs currently providing primary care services for persons living with HIV; and
- f.) Producing an operational plan document to include all components necessary to prepare a complete and competitive application for funding under the Early Intervention Services program of Ryan White Title III.

TIMELINE: Items "a", "b", and "e" have been initiated at this date. Items "c" and "d" will be initiated and scheduled upon receipt of notice of award of this grant application. Items a, b, d, and e should be completed by December 1997 with Item d completed by March 1, 1998. Item "f", the final program design, will be initiated by August 1, 1997 and will be completed by May 1, 1998. This will accommodate a projected application date of June 1, 1998 for the Section 330 and

subparts application and anticipated application for a Ryan White Early Intervention Services grant application during the Autumn of 1998. A preliminary program plan will be completed by November of 1997.

MEASURABLE OBJECTIVE: Goal components will be achieved in a timely manner as outlined above. A preliminary program plan will be produced by November 1, 1997 incorporating, at a minimum:

- a.) Mandatory requirements of the Early Intervention Services program together with all other statutory and regulatory requirements of the various programs, departments, and agencies contributing financial and/or material support;
- b.) Mandatory requirements of licensing and regulatory agencies with competent jurisdiction;
- c.) Medicaid/Medicare requirements of the respective States; and
- d.) Findings of the preliminary regional needs assessment to be produced by October of 1997.

KEY ORGANIZATION: Heartland CARES, Inc.

KEY PERSONS: ***** (formerly) Development Director, Comprehensive Care Center, Nashville, Tennessee
 Rich Fortenbery, President, Heartland CARES, Inc.
 (R.N., Retired, HIV+ since 1988, Secretary, Purchase/Pennyrile HIV Care Services Consortium)
 ***** BSW, Vice President, Heartland CARES, Inc.
 (Illinois coordinator)
 ***** R.N., B.S.N.
 ***** R.N., C.F.N.P.
 ***** LSW (Madisonville, KY Satellite Site)
 ***** J.D., Executive Director, Housing Authority of Paducah

3. Management and Information Systems Development

Design of management and information systems development will be required since we are working from a "square-one" position of planning. This activity will include elements of information systems research, medical records management, integration of record keeping for on-going program assessment and evaluation, and systems for financial accounting, reporting, and auditing.

Key persons will participate in site visits as described in Activity 2, above, and some elements of this system will be defined in Activity 1. In addition, consultation with a Certified Public Accounting agency for financial systems design will be conducted with an appropriate system defined. Computer hardware capable of operating HRSA program management and reporting software will be procured, as will basic accessory items.

GOAL: Design an information management system that will:

- a.) Accommodate all record keeping and reporting needs mandated by the Ryan White CARE Act Title III Early Intervention Services program;
- b.) Accommodate all record keeping and reporting needs mandated by other programs of funding which interface in the consolidated program funding stream;
- c.) Meet all financial recording and reporting requirements necessary for operation of the clinical care program as required by the various regulatory and funding agencies, and to facilitate financial audits;
- d.) Meet all medical record-keeping requirements defined by funding and regulatory agencies and as further defined by program planning from Activity 2; and
- e.) Accommodate capacity expansion and/or "up-grade" in the future

TIMEFRAME: A preliminary program design will be prepared by December, 1997 to address each of the goal components cited above. A complete management information system program will be prepared by May, 1998. Computer hardware, including accessory items will be purchased upon availability of funding under the funding sought herein.

MEASURABLE OBJECTIVE: The key persons/organization will produce the MIS program model described above within the timeframe cited.

KEY ORGANIZATION: Housing Authority of Paducah
C.P.A. Firm (to be selected)
Computer Systems Consultant (to be selected)

KEY PERSON: ***** , J.D., Paducah Housing Authority
Housing Authority of Paducah, Financial Officer (to be designated)
Liason to C.P.A. firm selected

D. ROLE IN THE COMMUNITY / COLLABORATION WITH OTHER ORGANIZATIONS

Heartland CARES, Inc. is a collaborative consortium of Ryan White Title II consortia and State consortia in the proposed service area. Other agencies participating are the Housing Authority of Paducah, the West Kentucky Mental Health and Mental Retardation Board, Inc., Paducah CARES, Inc., and several unincorporated and informal HIV support groups within the service region. Services currently provided by collaborating groups are outlined in various letters of collaboration and support. The mission of Heartland CARES is to foster such collaboration to provide assessment, planning, organizing, and coordination of local resource agencies to develop a regional comprehensive continuum of care for persons living with HIV. This includes identifying and "filling the gaps". The geographic area served is indicated on the map set (Attachment G), which includes 17 counties of Western Kentucky and 15 counties of Southern Illinois.

Tentative collaboration with a current care provider in Hopkins County, Kentucky is pending, as is similar potential collaboration with a provider in Southern Illinois. We envision a system of three clinical sites which places primary care for HIV within one hour's travel from any point in the region. The centralized clinic in Paducah would serve as the "hub" center for the

system. Paducah CARES and (CBO) are exploring a collaborative HIV prevention program effort to regionalize current community prevention programs. We have sought the participation of our State Departments for Public Health, but they are not in a position to provide active participation, ostensibly due to staffing shortages and excessive existing administrative requirements.

We welcome the participation of all local and county health departments, as well as all interested agencies, but have historically found their capacity and willingness to participate in Consortia and HIV-related activities limited by both staffing constraints and continuing intense stigma associated with all HIV-related activities. Health, housing, and social service agencies located in communities and counties outlying from Paducah in the region largely retain a generalized "societal denial" that HIV exists in their counties. We seek to educate and enhance capacity of those agencies in responding to the rapidly growing HIV infection rate in our Rural/Southern/Midwestern region. Collaboration has been and will continue to be key to successful regional implementation of the early detection and Early Intervention Services program for HIV.

The recent announcement of the Purchase District Health Department of its imminent withdrawal from HIV-related program project sponsorship (attachment B), leaves Heartland CARES as the only organization dedicated to the stated mission. We are developing and strengthening collaboration with current providers of HIV primary care outside our region who currently serve our client base to assure continuity of service availability during our program development.

E. BUDGET

1. Line-Item Budget and Narrative (Listed by Proposed Activity)

Activity 1. Comprehensive Regional Needs Assessment / Resource Inventory

Contract: Center for Rural Health and Social
Services Development - Southern Illinois University \$7,500

This provides funding to contract with RHSSD/SIU to coordinate and execute activity 1. Funding support for Paducah CARES' participation is budgeted under the regional HOPWA allocation for planning activities. All personnel of the contractor will be employed by that organization.

Activity 2. Program Research, Site Visits, Program Design

Contract: ***** 7,500
Site Visits (Travel) 10,750

The contractor, *****, is formerly Development Director for the Comprehensive Care Center in Nashville, Tennessee. Ms. ***** participated in the design of the "Centers for Excellence" clinical site satellite replication program of the Center. Ms. ***** offers unique and rare successful experience in developing HIV-specific clinical care services in our region and will facilitate our program development through her recent research activities with Comprehensive Care Center, the Ryan White Programs, and development of community involvement to support the program. Site visits (14 person-visits at approximately \$750 per visit) will facilitate program planning by providing for key planning personnel of the Heartland CARES group to visit four (4) selected current Ryan White Title III programs. This provides two site visits by two persons and two site visits by three persons.

Activity 3. Management Information Systems Development

Acquisition of Computer System	7,500
C.P.A. Firm Consultancy	2,500
Computer Systems Consultancy	2,500

Miscellaneous Expenses

Printing, Copying, Postage, Supplies	3,000
Telephone / Fax / Internet	5,000
Administrative	3,750

SUMMARY OF LINE-ITEM BUDGET

Contract - *****	\$ 7,500
Contract - *****	7,500
Site Visits (Travel)	10,750
Acquisition of Computer System	7,500
C.P.A. Firm Consultant	2,500
Computer Systems Consultant	2,500
Printing, Copying, Postage, Supplies	3,000
Telephone / Fax / Internet	5,000
Administrative	3,750

TOTAL PROJECT BUDGET \$50,000

COORDINATION WITH OTHER FUNDING SOURCES

Planning funding is also budgeted in the regional HOPWA allocation program at \$14,796. Attachment M includes budget summaries and narratives of applications for HOPWA carry-over, allocations, and the Supportive Housing program. These documents detail other funding sources. The "HOPWA Fund Application and Leveraged Resources from Other Sources" indicates the leverage between the programs. The "supportive services" may be accessed only by persons who qualify as disabled and homeless as defined at 24 CFR Parts 574 and 583.13

F. INVOLVEMENT OF PEOPLE LIVING WITH HIV/AIDS (PLWH)

The majority of the Board of Directors and two of the officers of Heartland CARES, Inc. are HIV-positive. The majority of the Board of Directors of Paducah CARES, Inc. is also HIV-positive. Rich Fortenbery, President of Heartland CARES has been HIV-positive since March 1988 and holds associate degrees in Nursing, and Hotel-Restaurant Management, having graduated Cum Laude. Active involvement and substantive participation by PLWH's in planning and operation of both the Ryan White Title III Planning and operational programs, as well as all phases of the Comprehensive HIV Housing Program will be assured.

A group of formerly homeless PLWH's will provide program monitoring and planning participation in management of the Comprehensive HIV Housing Program, including its clinical services aspects. This active involvement of the homeless will continue with a plan for daily "community meetings" of current residents of the facility fostering suggestions and discussion of matters and concerns to optimize the effectiveness of the program and ensure responsiveness to changes in needs as the HIV/AIDS epidemic changes dynamically.

Outreach for Targeted Populations: Outreach will include key contacts in existing networks of at-risk populations such as gay bars and gathering places of gay men (CDC defined MSM risk category), the National Association of Colored People (NAACP) in all communities of the service area, mailings to all faith congregational groups in the service area, and media coverage in local general media and in regional publications targeted to the at-risk populations. While actively homeless individuals may not read such publications, persons they may contact will have become aware of the Comprehensive HIV Housing Program.

G. EVALUATION PLAN

Timelines and measurable objectives are stated in Section C. "PROPOSED PLANNING ACTIVITIES", above, for each of the proposed activities to be funded with this program.

The expected outcomes of this planning program with respect to the Early Intervention Services are:

- a.) Preliminary and final reports and program plan documents will be produced as stated in the individual planning activities as outlined in Section C.;
- b.) A formally organized provider system will be defined to provide clinical services; and
- c.) A complete and competitive grant application for a Ryan White Title III Early Intervention Services Grant will be prepared by the due date for applications in 1998, tentatively anticipated at November 1, 1998.

Update Note: Successful application for EIS funding was filed 10/10/97
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APPENDICES

Attachment

- A Attachment "A" Needs Assessment
- B Notice of Withdrawal of Purchase District Health Department from HIV-Related Programs
- C Articles of Incorporation of Heartland CARES, Inc. (Purpose)
- D Letter of Collaboration - Jackson County (IL) Health Dept.
- E Letter of Collaboration - Purchase / Pennyrile (KY) HIV Care Services Consortium
- F Letters of Collaboration Housing Authority of Paducah
Purchase Housing Corporation
Pennyrile Continuum of Care Board
- G Map Set of Service Area
- H Epidemiologic Profile of Western Kentucky service area
- I Letter of Support - Comprehensive Care Center
- J Comprehensive Care Center - Program Description
- K Regional Census / Demographics (1990)
- L Letter of Collaboration - Center for Rural Health and Social Services Development - Southern Illinois University
- M HOPWA / Supportive Housing Program application Budgets
Update Note: These applications were both successful and funded
- N Preliminary Needs Assessment Tool
- O Comprehensive HIV Housing Program

Ryan White Title III

EIS Grant

*Early Intervention Services with
Respect to HIV Disease*

I. INTRODUCTION

The HIV/AIDS Bureau, Health Resources and Services Administration, announces the availability of funds for fiscal year (FY) 1999 for discretionary grants to provide outpatient HIV early intervention services/primary care. In FY 1999, a total of \$94.3 million was appropriated for these same services, of which approximately \$9 million is available to fund new programs. This announcement implements HRSA-related provisions of Subparts II and III of Part C of the Public Health Service Act Title XXVI, as amended by Part III of the Ryan White CARE Amendments of 1996.

The Department of Health and Human Services (DHHS) is committed to achieving the health promotion and disease prevention objectives of *Healthy People 2000*, a DHHS-led national activity for setting priority areas. Under this program guidance announcement, the grants will address the following *Healthy People 2000* objectives: 1) increase the percentage of HIV-infected persons who receive the HIV serology test; 2) increase the percentage of primary care providers who provide age-appropriate counseling; and, 3) increase the percentage of family planning and primary care providers who provide a comprehensive HIV service program. The grants will also support the Department of Health and Human Services' program direction to reduce the risk of HIV infection among minority and low income persons.

1.1 Program Background

In 1988, the Bureau of Health Care Delivery and Assistance, which later became the Bureau of Primary Health Care, joined with the Centers for Disease Control and Prevention to fund three pilot projects that incorporated HIV prevention services into selected community health centers. In an effort to build upon the lessons learned from the three pilot projects, Congress appropriated \$10.7 million to support this initiative. An additional 30 primary care providers were funded to provide services ranging from risk assessment, HIV counseling and testing to clinical care for people with HIV or at-risk for contracting HIV.

When Congress signed into law the Ryan White Comprehensive AIDS Resource Emergency (CARE) Act of 1990, approximately \$45 million was appropriated for early intervention activities. A total of 121 programs were supported with the appropriations. This noted the establishment of the Ryan White Title III(b) program. In FY 1998, a total of 174 projects were funded at \$76.3 million. The projects represent a cross section of community-based organizations and medical institutions which include community health centers, health departments, health care for the homeless centers, family planning agencies, comprehensive hemophilia centers, hospitals and university-based medical centers.

1.2 Program Authority

The authority for this grant program is the Public Health Service Act as amended by Public Law 104-146, the Ryan White Comprehensive AIDS Resources Emergency Act Amendments of 1996, 42 U.S. Code 300ff-51 through 300ff-67 (Attachment A).

1.3 Purpose

The purpose of the grant is to provide, on an outpatient basis, high quality early intervention services/primary care to individuals with HIV infection. This is to be accomplished by increasing the present capacity and capability of eligible ambulatory health service entities to provide these services as part of a continuum of HIV prevention for at-risk individuals and care for individuals who are HIV-infected. This grant will enable primary health care providers to render the continuum of services detailed in Section 2651 of the Statute with respect to HIV disease. Specific program expectations are discussed below under *Program Expectations*.

Preference for funding in new Ryan White Title III areas will be given to applicants which help to achieve an equitable geographical distribution of programs across all States and territories, especially programs that provide services in rural or underserved communities where the HIV/AIDS epidemic is increasing and in areas that receive limited or no Ryan White CARE Act monies.

The Ryan White CARE Act Amendments of 1996 require funded organizations to coordinate services with other providers of health care services under the Ryan White CARE Act. These programs include organizations funded by Title I, Grants to Localities Disproportionately Affected by HIV; Title II, Financial Assistance to States and Territories; Title IV, Grants for Coordinated Services and Access to Research for Women, Infants, Children, and Youth; and, Part F, Special Projects of National Significance, and the AIDS Education and Training Centers. If other Title III funded programs are located in nearby service areas, the grantee should coordinate and collaborate with these programs. All proposed programs must be consistent with the Statewide Coordinated Statement of Need and must agree to participate in the ongoing revisions of such statement of need.

II. PROGRAM EXPECTATIONS

2.1 General Requirements

Any grant award under this statutory authority requires that the program has:

- 1) experienced and demonstrated an increasing burden of providing HIV-related health services over the past two years;
- 2) shown a clear relationship between the community's HIV burden and the applicant's role as the primary source of health care services for the targeted populations; and
- 3) demonstrated the ability to incorporate into and provide comprehensive primary HIV care within the organization's existing primary care infrastructure (this does not apply to HIV dedicated providers).

In the face of the rapidly changing clinical management of HIV disease, it is necessary that continuing education opportunities be provided to ensure providers stay abreast of, and practice, current treatment guidelines, such as antiretroviral therapies and prophylactic regimens. It is necessary that the program demonstrate established treatment protocols that reflect the most recent treatment guidelines. It is also necessary that the program provide for education of patients regarding treatment options and adherence and compliance requirements of drug regimens. The program must establish a Continuous Quality Improvement (CQI) Program that addresses clinical goals and outcomes.

EIS programs are expected to have existing mechanisms to collect and analyze data for reporting and to guide program management. Programs should be able to integrate clinical, utilization, and financial information to reflect the operations and status of the program as a whole.

If an organization operates or proposes to operate a separate facility or clinic exclusively for the treatment of patients with HIV disease and that facility/clinic segregates the HIV-positive patients from the general patient population, a written justification, not to exceed two pages, must be submitted to the national program office for written approval **prior** to operation. Request for this approval needs to be obtained only at the beginning of each project period. If circumstances justify the continued operation of such a facility, programs will need to request approval again at the beginning of any subsequent new project period.

2.2 HIV Early Intervention Services/Primary Care

HIV early intervention services/primary care, applied in the outpatient setting, assures a continuum of care which includes: 1) identifying persons at-risk for HIV infection and offering to them counseling, testing and referral services; and, 2) **providing lifelong comprehensive primary care** for those living with HIV/AIDS. Programs must demonstrate their ability to provide HIV primary care at their facility or at another facility.

By providing early intervention services/primary care, the EIS program is seen by clients and their families as the primary source of care for their HIV disease. **This is not to suggest that all services must be rendered on site by the program, but it does mean that the program retains the primary responsibility for the care of the client throughout the course of HIV infection.**

Early Intervention Services (EIS)/primary care include an initial clinical and laboratory evaluation with subsequent primary care services provided on an outpatient basis. Ideally, EIS is initiated early in the course of HIV disease when CD4 counts are relatively high (above 500 cells per cu. mm.), however, entry into EIS care may take place at any point in the spectrum of disease.

Early Intervention Services/Primary Care Programs **must** provide on site or at another facility the following services:

- HIV counseling, testing and referral;
- counseling and education on living with HIV disease, including availability and use of treatment therapies;
- appropriate medical evaluation and clinical care, such as CD4 cell monitoring, viral load testing, antiretroviral therapy, prophylaxis and treatment of opportunistic infections, malignancies, and other related conditions;
- oral health care, outpatient mental health care, outpatient substance abuse treatment, nutritional services and specialty medical care either directly or through a formal referral mechanism; and
- appropriate referrals for other health services.

These services must be provided to all persons living with HIV/AIDS, including women and children.

A minimum of 50% of funds awarded MUST be spent on providing primary care services to HIV-positive individuals. The HIV/AIDS Bureau encourages applicants to exceed this minimum requirement. Grant funds may be

used to pay the costs of providing optional services **but only to the extent that** these services are necessary to support the specified early intervention services/primary care. A clear justification as to why these services cannot be paid for through other appropriate funding sources must be provided in order for optional services to be approved. Optional services include outreach, case management or eligibility assistance. Specific information related to required and optional services are further explained in the following two sections of the program guidance.

The proposed services may be provided directly and/or through formal agreements with public or nonprofit private entities. For-profit entities may be contracted with to provide some of the services if such entities are the only available providers of quality HIV care in the area.

2.3 Required Services

2.3.1 Counseling, Testing and Referral Services

Counseling, testing and referral services for HIV should be available at the program's health care facility or at another readily accessible site and should be made available to all individuals in the targeted service population. If counseling and testing is not available on site, the program must demonstrate a formal referral mechanism with the testing site(s) that ensures availability of referral for HIV positive persons from the testing site to the Title III program. In Ryan White Title I eligible metropolitan areas (EMA's) and all communities where seroprevalence studies indicate an HIV incidence rate of at least 1% or an AIDS rate of at least 0.1%, HIV testing, counseling and referral should be offered **routinely** to **all** patients ages 15-54 years. Pregnant women and women of childbearing age should also be counseled about the use of Zidovudine therapy and other antiviral options to reduce vertical transmission of HIV.

The counseling services offered through the applicant must comply with several general provisions stipulated in the statute, Sections 2661, 2662 and 2663 (see Attachment A). The entity agrees to ensure the confidentiality of patient information in compliance with applicable State and local law.

The testing activities must provide for informed consent and must include pretest counseling so that any testing decision is voluntarily made. All funded entities must make provision for anonymous testing to the extent permitted by State law, regulation, or rule, with referral of those testing HIV positive to primary care. The entities must ensure that counseling will be provided under conditions appropriate to the needs of the clients and be culturally sensitive and gender and age appropriate.

Counseling and testing must be conducted in accordance with Section 2662, and must contain the following elements:

Pretest Counseling: No test for the presence of HIV will be done without informed consent and appropriate counseling that includes information on:

- ▶ measures for the prevention of, exposure to, and transmission of, HIV;
- ▶ the accuracy and reliability of the results of testing for HIV disease;
- ▶ the significance of the results of such testing, including the potential for developing acquired immune deficiency syndrome;
- ▶ encouraging the individual, as appropriate, to undergo such testing;
- ▶ the benefits of such testing, including the medical benefits of diagnosing HIV disease in the early stages and the medical benefits of receiving early intervention services during such stages;
- ▶ the confidentiality of receiving early intervention services and the availability of anonymous testing; and
- ▶ applicable law relating to discrimination against individuals with HIV disease.

Counseling Individuals with Negative Test Results: Post-test counseling clients with negative test results should be conducted in such a way that it contains all the information on risk reduction, accuracy and reliability of test results, and the significance of the test results. The counseling should also include information on the appropriateness of further HIV counseling, testing and education for the individual, including referral to HIV prevention services.

Counseling Individuals with Positive Test Results: Post-test counseling individuals with positive test results should be conducted in such a way that it contains all the information on risk reduction including the use of Zidovudine and other antiretroviral options to reduce vertical transmission of HIV, accuracy and reliability of test results and the significance of test results. The counseling must also include information on the appropriateness of further HIV counseling, testing and education for the individual. It must also include appropriate counseling regarding the

- ▶ availability in the geographic area of appropriate health care, mental health care, and social and support services, including providing referrals for these services, as appropriate;
- ▶ availability, through the applicant, of early intervention services/primary care;
- ▶ benefits of locating and counseling any individual by whom the HIV-positive client may have been exposed to HIV and any individual whom the infected individual may have exposed to HIV;
- ▶ the availability of the services of public health authorities with respect to locating and counseling the exposed individual(s) described above; and,
- ▶ the availability of antiretroviral therapies to treat HIV infection.

The counseling and testing component of an Early Intervention Services program must provide a formal mechanism for referral of clients to primary care for follow up and evaluation.

2.3.2 Ambulatory Diagnostic and Treatment Services

Individuals must be offered a comprehensive continuum of HIV care including primary medical care and, when applicable, perinatal care. An EIS program must offer a system of care that includes HIV counseling and testing, including tests to confirm the presence of HIV infection, and tests to diagnose the extent of deficiency in the immune system. The system of care must also provide appropriate diagnostic and therapeutic measures for preventing and treating the deterioration of the immune system and related conditions. This includes periodic medical evaluations, appropriate treatment of HIV infection, prophylactic and treatment interventions for complications of

HIV infection, including opportunistic infections, opportunistic malignancies and other AIDS defining conditions.

In the face of the rapidly changing clinical management of HIV disease, it is necessary that providers stay abreast of, and practice, state-of-the-art medical care. At a minimum, all primary medical care supported by Title III funds must be consistent with the published guidelines for the treatment of adults, adolescents and children and for the prevention of perinatal transmission. The EIS program must demonstrate its use of the *Guidelines for the Use of Antiretroviral Agents in HIV-infected Adults and Adolescents* and *Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection* as published in the MMWR on April 24 and April 17, 1998 respectively and updates subsequent to their publication; *Guidelines for the Prevention of Opportunistic Infections in Persons Infected with HIV* as published in the MMWR on June 27, 1997 and any subsequent updates; and the *Perinatal Guidelines* published in the MMWR January 30, 1998, and any subsequent updates.

Title III projects are expected to have systems in place to assess the primary health care provided to assure care meets current standards and guidelines and to have a system of continuous quality improvement (CQI) to assure that deficiencies are identified and addressed. If Title III grantees subcontract funds for primary care to other organizations or providers, the Title III grantee is responsible for assuring that similar systems are in place at that organization. This may require contract language regarding monitoring and CQI, with appropriate reports to the grantee.

Patient education regarding HIV drug therapies, particularly issues of compliance, resistance, and drug interactions, is a critical component of HIV primary medical care. Patient education may be done by the primary medical care provider (physician, nurse practitioner, physicians assistant, nurse) or by professional health education personnel. Patient education on these topics should be reinforced by all program staff.

STD evaluation and treatment are indispensable components of an HIV primary care program. To the extent that a service area or sub-population within the service area is experiencing accelerating case rates of tuberculosis, HIV programs should develop TB diagnosis, prophylaxis and treatment strategies, including, where appropriate, directly observed therapy. Tuberculosis screening should be routine follow-up for all patients diagnosed as HIV positive.

The risk of perinatal transmission of HIV was significantly reduced in AIDS Clinical Trial Group 076 when Zidovudine (ZDV) was administered to pregnant, HIV-positive women during pregnancy and labor and for the first six weeks of the infants' lives. *Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection*, MMWR, April 17, 1998; and the *Perinatal Guidelines* (MMWR, January 30, 1998) are guidances that should be utilized in the provision of perinatal care.

Programs are expected to implement recommendations as presented in these and subsequent clinical guidelines.

As other treatment regimens prove successful, applicant organization's are expected to stay abreast of clinical advances and adjust the clinical protocols accordingly.

Oral health care is an essential component of comprehensive primary health care, and is considered an integral part of any HIV primary care program. Grant funds may be used by grant recipients to support the provision of oral health services by general dental practitioners, dental specialists, dental hygienists and auxiliaries, and other trained primary care providers, in on-site facilities. These funds may also be used to secure or subsidize such services obtained off-site by referral. Programs should document whether a HRSA supported Dental Reimbursement Program exists within the service area, and if so, efforts to collaborate with that program. A listing of HRSA supported Dental reimbursement programs may be obtained by calling (301)443-9051.

If determined necessary by the primary medical and dental care providers, referrals to subspecialty or consultant services must be made available; such services include, but are not limited to infectious diseases, oncology, dermatology, ophthalmology, pulmonary as well as oral health specialists. These funds may be used for the process of referring the patient, and for related evaluation, diagnostic and treatment services. Referrals may also be made for mental health and substance abuse assessment and diagnosis, and nutrition assessment and counseling. **Use of funds for specialty consultations and treatment must not occur at the expense of providing basic HIV primary care services.** Title III funds can be used only as the payment of last resort for any specialty consultation and treatment. The emphasis of Title III funding is for primary care.

2.3.3 Referral Services

Formal arrangements must be established with appropriate providers of health services to facilitate referrals for clients as appropriate. Examples of such entities include, but are not limited to:

- ▶ organizations receiving funds under Title I, Title II, Title IV, or Part F of the Ryan White CARE Act; and
- ▶ biomedical research facilities, community-based organizations or other entities that offer experimental treatment for HIV disease. For information on these protocols, call 1-800-TRIALS-A.

Patient referral is an expected and often times necessary part of providing care for individuals with HIV infection. However, continuity and consistency of care must be maintained by the grantee. In order to ensure the continuity of care, all inpatient care and referrals should be tracked by the grantee's clinical staff. Coordination with admission and Emergency Department staff, and discharge planners around necessary hospital admissions and subsequent discharges is a vital component in maintaining consistency and continuity of care. **Plans should be in place for the resumption of the patient's care at EIS program site once the patient is discharged from the hospital.**

The cost of inpatient and hospice care and home health care is not supported by this grant. Grant funds may not be used to support the hospital costs associated with inpatient care.

2.4. Optional Services

The EIS program may provide, if needed, limited optional services. These include:

- outreach to those who may have HIV disease, or who may be at high risk of contracting the disease, in order to explain the benefits of early intervention;
- outreach to providers to make them aware of the availability and benefits of EIS/primary care;
- providing assistance to individuals in establishing eligibility for financial assistance and services under Federal, State, or local programs providing for health services, mental health services, social services, or other appropriate services; or
- case management to persons infected with HIV including referrals for appropriate social support services.

Optional services may be supported only to the extent necessary to provide the continuum of required primary care services (e.g. counseling and testing, ambulatory diagnostic and treatment, referral and follow-up) and when they can not be funded by other sources. The outreach and case management services must be coordinated with the outreach and case management activities funded under either Title I or Title II of the Ryan White CARE Act and may not be duplicative.

2.5 Consumer Involvement

Programs supported by this grant are expected to involve the affected community in the EIS program. EIS programs may establish a Consumer Advisory Board of persons living with HIV/AIDS to provide input into program planning, training programs, and program evaluation. As part of their quality improvement program, EIS programs should also have written procedures to ensure consumers have the opportunity to actively participate in decision-making about their personal health care regimen.

There are a variety of ways in which consumers may be effectively involved in Title III programs, and each program should design consumer involvement that best suits their situation. Examples of ways in which a program may demonstrate consumer involvement are:

- *HIV consumer representation on the organization's Board of Directors;
- *Establishment of an HIV specific Consumer Advisory Board;

- *HIV consumer representation on an existing consumer advisory board;
- *Involvement of HIV consumers on workgroups, committees and task forces, such as a Program Committee, an Outreach Task Force, the Patient Education Committee, etc.;
- *HIV consumers as volunteers, such as peer educators or outreach workers, or staff in the clinic;
- *HIV consumer surveys and consumer forums;
- *HIV peer trainers related to making healthy decisions and taking care of one's health, clinical trials, managed care, etc..

To accomplish effective consumer involvement, programs should be prepared to provide necessary training, mentoring, supervision and reimbursement of expenses.

2.6 Program Evaluation

Programs funded in FY 1999 will be required to participate in a special HIV/AIDS Bureau initiative designed to assist grantees in gaining the capacity to provide and monitor high quality HIV care. Under this initiative, the Bureau will work with grantees to participate in a process leading to the development of quality improvement outcomes. All newly funded grantees will be required to commit grant funds to this program activity.

2.7 Drug Discount Purchasing Program

Programs funded under this grant are eligible for and strongly encouraged to participate in the Bureau of Primary Health Care's 340(B) drug discount purchasing program which enables Title III programs to purchase medications at a reduced rate. For more information or to enroll in the program, programs can call 1-800-628-6297 or use the Internet web site at [HTTP://WWW.bphc.hrsa.dhhs.gov/odpp/drug/1.htm](http://www.bphc.hrsa.dhhs.gov/odpp/drug/1.htm)

2.8 Medicaid Participation and Discounted Fee Schedule

The EIS program must be a participating Medicaid entity for all services that are covered under the respective State plan. If the program has entered into an agreement with a public or private entity under which that entity will provide services, that entity must also be a participating provider under Medicaid. A waiver of this requirement is available if requested by an applicant when the application is submitted. If the provider with whom the program has entered into an agreement does not impose a charge or accept reimbursement for health services from

any third party, a waiver may be granted. Donations and basic support from foundations and trusts are not to be considered in the waiver request [§2652(b)].

The EIS program must agree to provide services utilizing a sliding discounted fee schedule that is made available to the public. The statute prohibits imposing a first party charge on individuals whose income is below 100 percent of the official poverty level. The statute limits the annual cumulative charges to an individual for HIV-related services to the following limits for incomes:

- above 100 percent but below 200 percent of poverty, a limit of 5 percent of the annual gross income;
- between 200 and 300 percent of poverty, a limit of 7 percent; and
- above 300 percent of poverty, a limit of 10 percent.

EIS programs must develop appropriate policies and procedures related to verification of patients' financial status, implementation of a sliding fee scale and ensuring a cap on patient charges for HIV-related services. Staff training, development of patient education materials and placing notices in clinic areas are often needed in order to comply with these requirements.

2.9 Financial and Budget Issues

Programs must have appropriate financial systems in place that provide for internal controls, safeguarding assets, ensuring stewardship of Federal funds, maintaining adequate cash flow to meet daily operations, assuring access to care, and maximizing revenue from non-Federal sources.

Programs are required to maximize the service reimbursement available from private insurance, Medicaid, Medicare, and other third-party sources. Many reimbursement sources have established special rates for HIV-related care. Clients who need medications and are eligible for State drug reimbursement programs funded under Title II of the Ryan White CARE Act should be assisted to access these resources prior to the use of Title III grant funds.

There is no required match or other cost participation requirement for these categorical grants; however, the level of non-Federal expenditures for HIV early intervention services/primary care must be maintained at the level for the year prior to the grant award. Grantees are expected to maximize revenues from grant supported services and other

government/private grants and not supplant existing services using these grant funds.

Not more than 7.5% of the approved Federal grant funds may be used for administrative costs. This limitation is statutorily imposed on the administrative costs charged to the Federal share of the budget (Section 2664 (g)).

Clinton Presidential Records Digital Records Marker

This is not a presidential record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

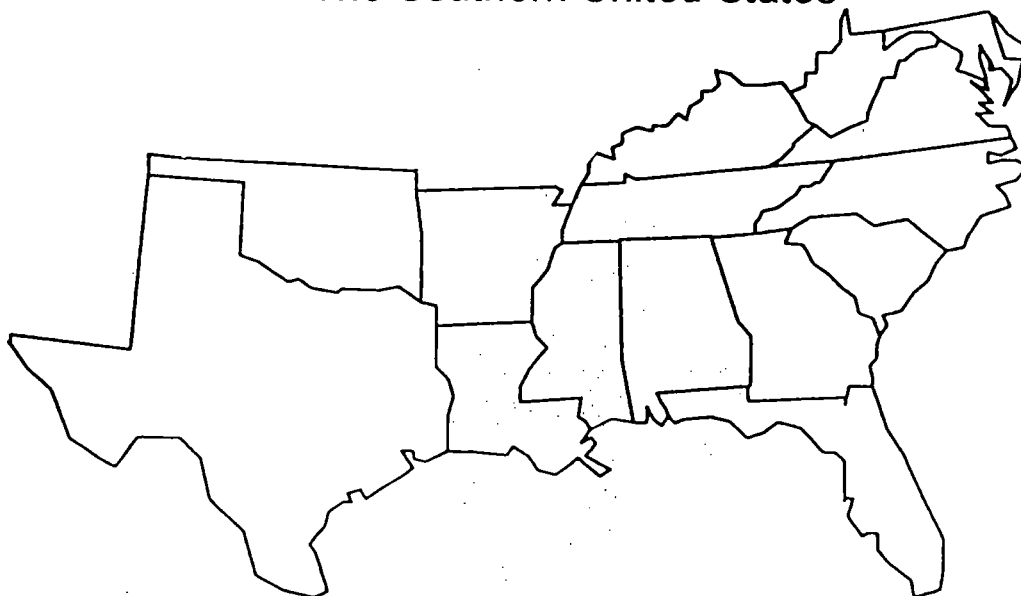
This marker identifies the place of a publication.

Publications have not been scanned in their entirety for the purpose of digitization. To see the full publication please search online or visit the Clinton Presidential Library's Research Room.



Southern Emergency Response Coalition for AIDS

*An Initiative to Develop Access To Care and Treatment for HIV in
The Southern United States*



Ryan White Title II Community AIDS National Network

1775 "T" Street, NW
Washington, DC 20009

(202) 588-1775

FAX (202) 588-8868

richf.t2cann@mindspring.com



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

HIV/AIDS Bureau

Health Resources and
Services Administration
Rockville MD 20857

Rich Fortenberry
HIV Program Coordinator
Heartland CARES
2110 Broadway, P.O. Box 2875
Paducah, Kentucky 42002

Dear Mr. Fortenberry:

On behalf of the Health Resources and Services Administration's HIV/AIDS Bureau, Primary Care Services Branch, I would like to welcome your organization to the Ryan White Title III HIV Early Intervention Services (EIS) Program. Please note that the project period for your grant is July 1, 1998 through June 30, 2001, and your first year budget period is July 1, 1998 to June 30, 1999.

If you have not already done so, the Title III EIS Program recommends you undertake the following activities within the next month:

1. Please designate the point of contact at your organization for the HIV EIS Grant. This should be the main person who will interact with the Federal Title III Office about your grant activities. **We need the name, mailing address, telephone and fax number for this point of contact which can be mailed or faxed to your project officer at the address listed below.** Please inform your project officer if any of the contact information changes over the year.
2. Make sure that your financial account with the Federal Payment Management System (FPMS) is set up so that you will be able to draw down your Federal grant funds. Should you need assistance, please contact Ms. Glenna Wilcom of the Office of Grants Management at 301-443-2728.
3. Contact the other Ryan White funded programs within your State to inform them that you have been awarded a Title III HIV EIS Grant. The other Ryan White programs are a good resource for your organization in terms of learning more about the Ryan White C.A.R.E. Act and getting involved in the collaboration activities of your State's Title II Consortium and other regional meetings regarding the delivery of HIV care services. Also, feel free to contact any of the other EIS grantees to share information and ideas.

Page Two - New Title III EIS Grantees

Enclosed are factsheets describing the Title I, II, III, IV, and SPNS programs and a packet which lists all the contact information for these grantees by State. In addition, a listing of the 10 new Title III EIS grantees and a complete list of Title III grantees is enclosed. If you would like to download the most recent Department of Health and Human Services HIV treatment guidelines off the Internet, visit www.hivatis.org.

Please feel free to contact your Title III program project officer if you have any questions. Attached is a list of the Project Officers' assignments including the ten new EIS projects. The program contact information is:

HRSA, HIV/AIDS Bureau
Ryan White Title III Program
Room 7-90, Parklawn Building
5600 Fishers Lane
Rockville, MD 20857
Phone: 301-443-0735
Fax: 301-443-1884

Thank you for your commitment and efforts to improve the health care system for people living with HIV in your community.

Sincerely,

A handwritten signature in black ink, appearing to read "Andrew Kruzich", written in a cursive style.

Andrew Kruzich
Chief, Primary Care Services Branch
Ryan White Title III Program

Enclosures

1. DATE ISSUED (MO./DAY/YR.) 9/30/98		2. CFDA NO. 93.918		DEPARTMENT OF HEALTH AND HUMAN SERVICES HEALTH RESOURCES & SERVICES ADMINISTRATION  NOTICE OF GRANT AWARD																					
3. SUPERSEDES AWARD NOTICE dat _____ except that any additions or restrictions previously imposed remain in effect unless specifically rescinded.																									
4. GRANT NO. 1 H76 HA 00208-01		5. FORMER GRANT NO.																							
6. PROJECT PERIOD Mo./Day/Yr. From 7/ 1/98		Through 6/30/01																							
7. BUDGET PERIOD Mo./Day/Yr. From 7/ 1/98		Through 6/30/99		☐ FORMULA ☐ CONSTRUCTION ☐ RESEARCH		☐ BLOCK ☐ TRAINING ☒ SERVICE		☐ COOP AGREEMENT																	
AUTHORIZATION (Legislation/Regulation) SECTION 2651-266																									
8. GRANTOR HIV/AIDS BUREAU																									
9. TITLE OF PROJECT (OR PROGRAM) OP EARLY INTERVENTION SERVICES WITH RESPECT TO HIV DISEASE																									
10. GRANTEE NAME AND ADDRESS HEARTLAND CARES, INC. P.O BOX 2875 PADUCAH, KY 42002-2875					11. DIRECTOR OF PROGRAM (LAST NAME FIRST & ADDRESS) FORTENBERY, RICH MR. P.O. BOX 2875 PADUCAH, KY 42002-2875																				
12. AWARD COMPUTATION FOR FINANCIAL ASSISTANCE					13. RECOMMENDED FUTURE SUPPORT (SUBJECT TO THE AVAILABILITY OF FUNDS AND SATISFACTORY PROGRESS OF THE PROJECT):																				
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II Total project costs including grant funds & all other financial participation (Select one and place NUMBER in box.) I					14. APPROVED DIRECT ASSISTANCE BUDGET (IN LIEU OF CASH)																				
a. TOTAL APPROVED BUDGET..... 421,050					a. Amount of PHS Direct Assistance.....																				
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ii. Federal Share..... 421,050					c. AMOUNT OF DIRECT ASSISTANCE THIS ACTION \$																				
b. Unobligated Balance From the Prior Budget Periods.....\$ 0					15. PROGRAM INCOME SUBJECT TO 45 CFR PART 74, SUBPART F, OR 45 CFR 92 SHALL BE USED IN ACCORD WITH ONE THE FOLLOWING ALTERNATIVE																				
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c. Less Cumulative Prior Award(s) This Budget Period.....\$																									
d. AMOUNT OF FINANCIAL ASSISTANCE THIS ACTION.....\$ 421,050					A=Additional Cost, B=Deduction, C=Finance Non-Federal Share																				
REMARKS: (Other Terms and Conditions Attached)																									

GRANTS MANAGEMENT OFFICER: (Signature)

(Name-Type/Print)

Glenna Wilcom
 GLENNA WILCOM

GRANTS MANAGEMENT OFFICER

17. OBJ. CLASS 41.51 FY-CAN 83770891		18. CRS-EIN 1311525402A1 DOCUMENT NO. H7600208A		19. LIST NO. ADMINISTRATIVE CODE		AMT. ACTION FIN. ASST. 421,050		AMT. ACTION DIR. ASST 0	
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NOTE: This is the Notice of Grant Award for the Heartland Ryan White Title III EIS application. The total award is for \$1,263,150 for three (3) years. Each year award is \$421,050.

Paducah HIV clinic becomes model for rural health care

BY LEIGH LANDINI
SUN FEATURES EDITOR

Until this fall, HIV-positive people in far western Kentucky and southern Illinois had to travel to Nashville or St. Louis for much of their medical care. A few had found doctors willing to take on their cases locally.

The former Broadway office of Dr. Nona Setler-Logan, who was Paducah's only African-American physician, is now home to the Heartland Clinic, which specializes in caring for those who are HIV-positive. The clinic, which opened very quietly in late August, is an outgrowth of Heartland CARES (Consortium of Assistance, Resources, Education and Services), formed two years ago to help meet the needs of HIV-positive people in the region.

"This program has become, in a way, a demonstration program," said Rich Fortenbery, the clinic's director. "We will be one of the model programs for the reauthorization of the Ryan White legislation."

The Heartland Clinic is funded through the federal government's Ryan White Title III program, named for the Indiana youngster who died from AIDS. The legislation provided funding for metropolitan areas with high AIDS cases and for community-based primary care programs.

The clinic also receives funding

through Housing Opportunities for Persons with AIDS in cooperation with the Health Resources and Services Administration, the U.S. Department of Housing and Urban Development and the Kentucky Housing Corporation.

The Paducah clinic is one of the first programs to be funded in which a primary care practice was not already set up, Fortenbery said. Anita Fleenor, whose medical specialty is infectious diseases, is the clinic's medical director.

The clinic has about 50 clients

of whom two-thirds are male and one-third female. Clients are two-thirds Caucasian and one-third minority.

"We're seeing a surprisingly high rate of people here who contracted HIV heterosexually," Fortenbery said. "The HIV epidemic has moved more rapidly into the rural areas."

He said the fastest-growing group is



FORTENBERY

young African-American females.

Fortenbery describes the clinic's offerings as holistic, meaning that it tends to the medical, psychological and social needs of clients. For instance, a person who seeks an HIV test at the clinic and whose results are positive will receive immediate counseling. The client also will receive nutritional counseling.

The clinic also gives tests for sexually-transmitted diseases and offers counseling.

Fleenor said her clinic offers blood work and manages a client's medication. She explained that most clients need a minimum of three drugs to treat the virus itself.

Since the clinic opened, she has dealt with people experiencing opportunistic infections, or those that a normally healthy person's body would fight off. Because a person with HIV has a poor immune system, he cannot fight those infections.

"We've had a couple of patients who are very sick that came in here in time," she said. "They're now on treatment and getting better."

Seventy-five percent of the center's clients are already diagnosed with CD4, which means their T-cell count or lymphocytes are low. "Those cells are responsible for coordinating the immune response," he

See **HIV** / 10D

HIV clinic offers hope

Continued from 1D

depletes the cells and destroys the immune system."

Fortenbery said clients' greatest need is for treatment medication. "The cornerstone protease inhibitors are not covered by the Kentucky program." (Protease inhibitors were introduced for long-term usage several years ago. It is commonly known as the "AIDS cocktail.")

Fortenbery said there are 80 slots available for the protease inhibitors trials, and 14 people on the waiting list are from the region.

He also is working with various pharmaceutical companies to receive access to drugs in the final stages of approval such as Ziagen, a new drug in the nucleoside analogues; Agenerase, the fifth drug in a class of protease inhibitors; and Preveon, the first in a new class of antiviral drugs known as nucleotide analogues.

The clinic also can provide access to antibiotics.

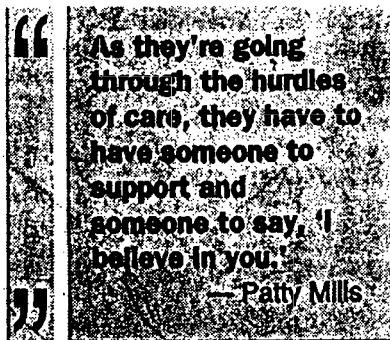
"We have found that the clients coming to us are the folks who have never been receiving care or folks who have been in care but they are out of options with their medicine."

While the clinic does provide access to medication, Fortenbery said its primary goal is preventative care. "We help identify those at high risk and tell them how to protect themselves and others," he said. "We want to stop the progress of infections that are likely to occur."

Each client also is given an EKG test during the first visit, and that is monitored throughout the care.

"I think the medical community is appreciative that we're here," Fortenbery said. "They understand the importance of having specialty care providers that can keep track with the rapid changes and work with clients with the complex changes of health and lifestyle. We also stay on the cutting edge of research."

The clinic also has a contract with West Kentucky Mental Health-Mental Retardation to



"As they're going through the hurdles of care, they have to have someone to support and someone to say, 'I believe in you.'"

— Patty Mills

provide mental health care. A registered dietician from Southeast Missouri State University in Cape Girardeau works with nutritional counseling, and an intern from Lourdes hospital soon will assist.

Patty Mills, a registered nurse therapist, said counseling is a big part of the clinic's services. "Of course it's a pretty devastating change of life to go through," Mills said. "We have to look at patients and how they are coping with a potentially fatal illness and change their style of living."

Mills said the news of an HIV-positive diagnosis can push some toward mental breakdowns, and some people do consider suicide. "They feel society hates them and that they let society down," Mills said.

For many with HIV or AIDS, working full time becomes extremely difficult because employers may not want the person in the office and co-workers may shy away from contact. Additionally, the medication needs change constantly as the virus becomes immune to the treatment.

"As they're going through the hurdles of care, they have to have someone to support and someone to say, 'I believe in you.'"

"... They need a lot of TLC. I'm seeing some (clients) every week and some of them I see twice a week."

The clinic offers care that is paid for on a sliding economic scale. Medicare and Medicaid clients who are not employed receive free care.

The clinic accepts appointments. For information, phone 444-8183.

Heartland CARES, Inc.

*Dedicated to Hope and Healing Through People
Helping People Help each Other*

THE HEARTLAND CLINIC

2110 Broadway • Paducah, KY 42002-2875

KRISTA WOOD

~~Rich Fortenbery~~

Program Director

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Post-Script

In June 1999 Rich Fortenbery began working full-time with Ryan White Title II Community AIDS National Network (T*II*CANN) and the AIDS Drug Assistance Program ADAP Working Group in their Washington DC offices. In this capacity, Fortenbery currently serves as a policy analyst for the Southeastern United States region with particular focus on providing technical assistance to community-based organizations (CBOs), groups interested in developing programs similar to the Heartland Clinic project in their own communities. Particular emphasis is placed on rural and underserved areas and populations in the Southeast, especially with respect to minority communities.

Fortenbery is succeeded by Krista Wood, Executive Director of Heartland CARES, Inc. Formerly Executive Director of Women Aware, Inc., the regional domestic violence agency for Western Kentucky, Wood and Fortenbery have been working for a year and a half on a joint supportive housing program shared by the agencies. The program was funded by Kentucky Housing Corporation and the U.S. Dept. of Housing and Urban Development effective July 1, 1999.

Rich Fortenbery, RN*, MA

CBO Development and Technical Assistance

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PRESIDENT
RICH FORTENBERY

The Heartland Clinic Project

Early Intervention Services with Respect to HIV Disease
Application for Funding Under the
Ryan White CARE Act, Title III
CFDA # 93.918
October 10, 1997

Table of Contents

1	Abstract.
3	Project Narrative
3	Need Assessment
13	Organizational Capacity
16	Program Plan.
17	Coordination With Other Programs
25	Statement of Problems and Goals
27	Program Evaluation
31	Staffing Plan
33	Workplan
43	Line Item Budget
45	Budget Narrative / Justification
52	Required Tables
56	Appendices

PROJECT ABSTRACT

Heartland CARES, Inc.

Heartland CARES, Inc. (HCI) is a collaborative non-profit corporation whose mission is to plan, implement and operate a comprehensive continuum of care for persons living with HIV in the Heartland of America. Constituent organizations of Heartland CARES include community-based AIDS service organizations, HIV consortia and current providers of various components of care for those living with HIV and AIDS in our service area. Our guidance in this process is the system of primary care defined by the Ryan White CARE Act and supportive services specified in the Housing Opportunities for Persons With AIDS (HOPWA) program and the Multiple Diagnoses Initiative, a joint program co-sponsored by the Department of Health and Human Services and the Department of Housing and Urban Development. Our philosophy is holistically-based and strives to encourage self-sufficiency while fostering personal responsibility with adequate appropriate health and social service support. Our strategy is to reach out to enlist the support and technical assistance of our nearest current HIV care providers, some 150 to 200 miles to the Southeast and Northwest.

Targeted Population. Heartland CARES' service area consists of 32 counties, which comprise two HIV consortium regions. The Purchase Pennyrite HIV Care consortium includes 17 counties in Western Kentucky. The Southern Illinois Ryan White Title II consortium includes 15 counties. A map of the service area is found in Attachment B. Within the Heartland CARES service area, some 400 persons are known to be living with HIV. We estimate approximately one in five or six persons infected with HIV are reported. We project an actual HIV-infected population of some 2,000 to 2,500 persons, the majority of whom are unaware or unsure of their HIV serostatus and/or have not presented for care yet. Of these, we expect some five to six hundred will seek care during the next three years. The state health departments are currently experiencing an annual increase of some 35 to 40% in newly reported HIV cases.

HIV epidemiologic data from the state health departments are neither complete nor uniform in format. A client survey conducted recently by the regional state consortia and HCI indicate an increasingly youthful population presenting for care of HIV. When contrasted with age and other demographics of those reported Living With AIDS (LWA), the presumably more recently infected population Living With HIV (LWH) is *increasingly younger, increasingly female and increasingly non-white*. The conservative rural environment of the service area presents myriad practical and cultural barriers to the spectrum of care necessary to maintain health and reduce progression of persons living with HIV to persons living with AIDS. Transportation, economic and literacy barriers are common in our service area. Social institutions and charitable services still prefer to frame HIV as a problem that will go away on its own. Behaviors popularly associated with HIV infection often elicit more sanction than compassion in rural faith congregations.

Current HIV Service Activities. Limited HIV-specific services currently exist in the region. Many persons in the service area living with HIV travel to Nashville, TN or St. Louis, MO for primary care. Many are unable to manage their own transportation, so several organizations and individuals in the Heartland CARES group assist with transportation to access care. Others who have been receiving care from family

physicians locally are frequently referred to primary care providers in these cities when they progress toward AIDS. Local health departments provide HIV counseling & testing with varying consistency and quality of service. A regional mental health agency provides general mental health and substance abuse treatment in 9 of the 32 counties. Agencies in each of the two consortium regions provide case management and limited financial assistance through Ryan White Title II programs. Otherwise, no HIV-specific service resources exist in the area.

Heartland CARES is proud to be a recipient of the Ryan White Title III planning grant. This assistance greatly enhances our ability to effectively and efficiently develop our program. The planning grant has afforded us the opportunity to seek expert technical assistance and guidance, conduct site visits to successful Title III programs, and develop financial and management information systems. The planning grant funding will terminate if this application for EIS funding is approved.

Problem. Essential components of primary care providing early detection and intervention with respect to HIV are fragmented and frequently require unreasonable travel time, distance, and expense. As one's condition deteriorates, the frequency of travel increases, as does the cost and stress of travel on health. We are indeed fortunate to have the commitment of an infectious disease specialist physician to relocate in Paducah, the center of the Heartland CARES service area, in July 1998. In this context, our challenge lies in developing and organizing the infrastructure and supportive organization necessary to deliver high-quality holistic care. We have identified and enlisted key stakeholders in the design and development of a comprehensive continuum of care for HIV.

Goals and Objectives. Our goals and objectives are extensively developed in the workplan of this application document. In summary, **the Heartland Clinic project seeks to ensure:**

1. Availability of **high-quality HIV counseling and testing** service will be increased by providing at least 500 C&T encounters by July 1, 1998 through innovative approaches to implementing the CDC guidelines and applicable sections of the Ryan White CARE Act; at least 500 C&T encounters will be provided each year during 1999 and 2000;
2. **Comprehensive primary care** for 500 clients living with HIV will be ensured by June 30, 2000 through developing the necessary clinical infrastructure;
3. **Mental health and substance abuse treatment** will be accessible by 100% of HCI clients by Sept. 31, 1998 through increasing current provider capacity;
4. **Oral health care services** will be accessible for persons living with HIV in the region through developing provider networking and agreements by June 30, 1999;
5. **Case management services** of the existing Ryan White Title II programs will be coordinated with and enhanced by the Heartland Clinic project by Sept. 31, 1998 to increase quality of service for 100% of current and new clients; and
6. **Resource procurement and asset management** will ensure continually increasing high-quality, responsive primary care and supportive services for all persons living with HIV in the *Heartland of America* by June 30, 2000.

PROJECT NARRATIVE

Needs Assessment

The proposed service area of the Heartland Clinic project consists of 17 counties in Western Kentucky and 15 counties in Southern Illinois. As indicated by the map on Attachment B, the area sits at the juncture of the South and Midwest, generally regarded as the *Heartland* of the nation. While spanning contiguous portions of two States, the cultural, socioeconomic and geographic characteristics of the service area are largely homogenous. The area's rural conservative culture encourages continuing denial of the presence of HIV in our area. Even populations at high risk continue to perceive HIV in a very negative light and are reticent to acknowledge HIV within their own communities.

The majority of impressions and conclusions contained in this narrative description are based on focus groups and comments from key informants. The area lacks the employment, service, and economic resources of the metropolitan areas. A greater proportion of the general population is at or near poverty and are largely uninsured or underinsured medically. Agriculture and mining are major occupations in both the Kentucky and Illinois portions of the service area. **No public transportation system is available in the vast majority of the region.** Twenty-eight (28) of the 32 counties have been designated medically underserved areas (MUA's) by the Bureau of Primary Health Care.

Increasing Burden in HIV Care (Past 2 Years). As indicated in Table 1 and Attachment A, the burden in HIV care in the region is increasing, both in number of identified cases and the rate of increase. During 1996, HIV-positive persons reported by the state health departments initially seeking care for HIV increased 38% in the Kentucky¹ area and 43% in the Illinois² service area. During a comparable period of September 1996-97, the Western Kentucky area's principal primary care provider in Nashville, Tennessee³ reports an increase of Kentucky residents from 68 to over 100, an increase of more than 47%. Findings from focus group discussions indicate a strong inclination to seek counseling and testing services, and subsequent care, out-of-state to both protect anonymity and access quality care.

HIV Seroprevalence. The HIV seroprevalence figures in the service area are derived from data reported by the states as of December 31, 1996. Included are persons currently reported living with HIV and AIDS in the respective state areas.

	<u>HIV/AIDS Seroprevalence (per 100,000 population)</u>		
	<u>HIV Reported</u>	<u>AIDS Reported</u>	<u>HIV Estimate</u>
Western Kentucky ¹	44.9	15.5	269.2
Southern Illinois ²	63.6	14.6	381.9
Composite Service Area	53.1	15.3	318.7

Sources: ¹Kentucky Dept. for Public Health, ²Illinois Health Dept., ³Comprehensive Care Center
Census figures are 1996 estimates from US Bureau of Census

Characteristics of Target Populations. Comparing the data above to corresponding data one year ago indicates the population newly seeking care for HIV is increasingly youthful, increasingly African-American and increasingly female. Each of these characteristics are suggestive of an expanding population whose access to care, transportation and self-advocacy are significantly less than the HIV-infected GWM (gay white male) population whose social networking and mutual support systems have evolved somewhat to accommodate the three or four hour travel each way currently required to access appropriate care. The expanding youthful HIV-positive population of both sexes and all races and risk groups suggests increased barriers to access care. ____

Cultural Factors as Barriers to Care and Services. The rural South/Midwest culture of the service area presents a formidable set of barriers to development of and access to services needed in all areas of the nation in today's world of HIV, substance abuse and myriad other social problems. These stem largely from a general resistance to acknowledging the need for such services in the region.

Becker (1994)¹ proposed a model of barriers to development of substance abuse treatment programs in rural areas that is appropriate to the development of HIV primary care services, particularly in view of the strong mental health and substance abuse treatment components required for a continuum of HIV care.

Barrier #1. Flawed views of rural America

#2. Serious limitations to social and health data

#3. View of rural problems as disconnected from U.S. society

#4. Perceived lack of a viable political solution

#5. Absence of a unified rural constituency

#6. State and Federal fiscal crises

Flawed views of rural America Stereotypic images of the "country bumpkin" can lead metropolitan populations to view rural Americans as inherently inferior and somehow less worthy of services commonly found in urban areas. From a rural perspective, the sparse population, relatively low educational achievement of past generations and dedication to preservation of the "simple country life" lulls many rural residents to believe that "*city problems*" *don't affect us*. Both views deny the simple reality that in the age of the Internet and MTV, American society in youthful generations is a great deal more homogenous than most Americans realize.

Serious limitations to social and health data exist due to lack of academic resources to gather, analyze and report data as well as a general reluctance of rural residents to acknowledge problems at home. Unfortunately, this reticence to identify or

¹ Becker, Susan L. Bringing excellence to rural and frontier America: Advocacy for substance abuse services in the 1990s. *Rural Issues in Alcohol and Other Drug Abuse Treatment.* (Rockville, MD: USDHHS / Center for Substance Abuse Treatment [DHHS Pub. No. SMA 94-2063]) 1994:1-6. (After: Swanson, Louis E. Dilemma confronting rural policies in the United States. *National Rural Studies Committee: A Proceedings.* (Corvallis, OR: Oregon State University Western Rural Development Center) 1990:21-9.

acknowledge problems and needs frequently includes physicians, health department personnel and local policy-makers. "*Out of sight - Out of mind*" is a strong cultural tenet, particularly in the rural South. Denial is a traditional social coping strategy, particularly among the older rural population who continue to dominate institutions such as politics, religion and available charitable service organizations.

Much of the charm of rural life is centered on a false sense of security that *rural problems are separate and distinct from social problems* in the nation at-large. Problems such as HIV and substance abuse are "somebody else's problem." This belief is rooted in the much-valued but largely antiquated notion of a rustic pride reminiscent of simpler past times, where acknowledging problems was paramount to admitting weakness or flaws. Historically, every extended family had a member whose mental or physical illness made them the "afflicted or disturbed, the black sheep" of the family, an embarrassment to be hidden from society-at-large and never discussed in "polite company."

Perceived lack of a viable political solution to problems is frequently cited by community leaders as a reason to justify not addressing a problem once identified. In this context, "political" implies public support for such an effort, and includes issues of the magnitude of a problem, economic considerations, concerns that addressing a problem contributes to its spread, attracting "undesirables" who may seek the services and competition with other more valued social service groups. Attitudes may imply that the proposed service population is being divinely punished for unacceptable behavior. Addressing the problem is loosely regarded as condoning the offending behavior. The letter from Kentucky's governor (Attachment G) attests the state government's lack of will to address the need for quality HIV primary care in rural Kentucky.

Absence of a unified rural constituency is a particularly challenging barrier to development HIV service systems. During the past year, our project has been continuously challenged by some local and state officials on the basis of lack of a visible and cohesive population of affected persons. This argument against service development is based on "official" figures which we believe grossly under-represent the true epidemiologic picture of the region. *Absence of evidence* is thereby misconstrued as *evidence of absence*.

State and Federal fiscal crises affect both urban and rural social services. Our experience in the service area consistently indicates the resources for all service programs are generally reduced first in the rural areas, where a lower number of vocal advocates are expected, legislative representation is weaker and populations at-risk are less numerous, less cohesive and more politically impotent. Rural residents are somehow perceived to be better able to *take care of their own* and political rhetoric tends to support the widening of the gap by extolling virtues of self-sufficiency and a vague notion of community pride and spirit.

Rural areas generally suffer from *lack of public transportation* adequate to access care in the nearest metropolitan areas. *Isolation exacerbates economic hardship* and more heavily *limits ability to access and afford reliable transportation* for long distances. The vast majority of roads in the region are treacherous in inclement weather, making lengthy travel impossible in much of the winter season. Multiple barriers to service

development result in the generalized lack of social & health service resources available, particularly for persons not perceived as "innocent victims" of their plight. While the service area does not have a significant non-English-speaking population, absolute and functional illiteracy are significant, particularly among target populations.

The cultural characteristics of rural America are intensified in the South and Midwest, the *Heartland of America*, where strong traditions of fundamentalist religion permeate every aspect of society. The "Bible belt" theology frequently views illness and misfortune as the *natural consequence of sinful behavior* and provides subtle but potent resistance to efforts to address human needs perceived as resulting from "behavioral causes". Some behavioral consequences are more heavily sanctioned than others in inverse proportion to the population perceived to be so afflicted. Alcohol, tobacco and high-fat country cooking all contribute to behaviorally-induced health problems, but are not perceived as rooted in the degree of "evil" as are HIV infection and substance abuse. The judgmental penchant of rural society greatly influences the community's charitable attitude toward *illness it may perceive as earned*.

Many cultural traditions of the South continue to influence attitudes, although more subtle and covert than in the relatively recent era of a generation or two ago. Racism, sexism and homophobic thought and action persist. Self-esteem is subconsciously rooted in comparison of self-perception to others. Self-esteem is bolstered by deprecation of others, albeit unspoken. Charity is extended preferentially to "people like us *except for . . .*" and is frequently conditioned on demonstrating acceptable conformity to standards prescribed by the charitable organization or individual. An example is a local homeless shelter that requires daily participation in its proselytizing worship service as a condition of assistance.

Fortunately, attitudes of some in rural America are becoming more tolerant of human diversity and individual liberty than in the past. However, collective attitude and behavior still reflect rural tradition while the individual may express more acceptance of others outside the context of conformity to societal standards. Fundamentalist-driven moral judgement is evident in law, ordinance and matters of public finance.

Behavioral and Attitudinal Risk Factors. Risk factors for HIV transmission are identical in both rural and urban areas. Unprotected sex, both homosexual and heterosexual, is the primary mode of transmission. Experimental homosexual encounters are an unspoken but somewhat common experience in late childhood and early adolescence for males. Most gay males recall initial sexual encounters with significantly older (and potentially HIV-infected) males. In rural areas, many bisexual males strongly deny being homosexual. Males engaging in prostitution frequently do not regard their activities as "gay", rationalizing their sexual activity as solely for money.

Dramatically increasing substance abuse in the region is also increasing sexual risk in either exchange for money or drugs directly. Focus group discussions and increasingly frequent news reports reveal the alarming rate of methamphetamine use regionally. Increased manufacturing of the illicit drug in the area has been reported throughout the Heartland CARES service area.² Highly addictive and inclined to intravenous use, "crystal meth" or "crank" has been highly correlated with HIV incidence. "In contrast to opiate or crack cocaine use, methamphetamine or 'speed', appears much more highly correlated with HIV infection in the West."³ A documentary aired October 5,

1997 reported that more than 500 methamphetamine "labs" have been raided thusfar this year in Missouri, immediately to our West.⁴

Cocaine, "crack", and to a lesser extent, heroin, have found their place in the region along with marijuana, alcohol and hallucinogens. Societal reticence to acknowledge a problem stimulates little more than a "get tough" law enforcement policy oriented to deterrence, primarily toward users. As experience with this drug continues, intravenous use will doubtless increase as users seek a "better high". We believe this may also contribute to injection drug use as an increasingly common mode of transmission of HIV. Existing laws prohibiting availability of clean injection equipment will surely result in "needle sharing" or ineffectual "cleaning" of works.

At-risk populations, particularly other than the gay white male (GWM) population, remain largely convinced "it can't happen here and it can't happen to me." Increases in across-the-board substance abuse are primarily noted in the African American communities of the region. With pervasive community denial in this context, young women of color are increasingly exposed to high risk sexual behavior through heterosexual contact with users. In the Heartland, HIV and AIDS are still largely regarded as the "gay plague"; heterosexual contact is not considered risky.

Three particularly disturbing rural / Southern traditions are operant here. First, young women of color are the most vulnerable of the general population. Many have little or no experience or capacity in advocating for themselves. This leaves them incapable of refusing sex, questioning a sex partners' substance abuse or negotiating safer sex. In many minority communities, sex is viewed as a commodity and a young girl's most appropriate and effective means of survival. Secondly, maternal duty is regarded as the primary purpose of many minority and underprivileged women in the rural South and Midwest. Having a baby is viewed as a milestone of adulthood, regardless of age or capacity to parent. Young women of all races who are descendents of "drawing the check" as the primary occupational support of the family readily recognize the value of children in increasing benefits of public assistance. Finally, having young children confers a privilege of being excused from working outside the home or completing educational expectations. Strong motivators to engaging in unprotected sex persist particularly for many young minority women.

Currently some 90% of the annual aggregate \$1.7 million payment of public assistance in Paducah, McCracken County, Kentucky is paid to recipients in single mother households where the mother is under 30 years of age and generally a

² Paducah Sun, Page 10A, Vol. 119, No. 253; Friday September 12, 1997

³ NASTAD (National Alliance of State & Territorial AIDS Directors) HIV Prevention Research in Action: Methamphetamine Use among High Risk Gay & Bisexual Men. HIV Prevention Community Planning Bulletin (Washington, DC: NASTAD), Sept. 96:7.

⁴ Cable News Network (CNN) "Impact": High in the Heartland, aired 10/5/97 8p.m. CST.

a member of a minority.⁵ Pending welfare reform changes will leave a large number of young women without accustomed benefits. Many can be reasonably expected to resort to the world's oldest profession, as a primary or supplementary source of income. Loss of benefits will also include loss of the "medical card", necessary for accessing primary medical care. Maternal instinct and acculturation will predictably result in the mother foregoing primary care to attend to the health needs of her child, and even the health and social needs of her sexual partner.

Teen pregnancy rates and gonorrhea incidence included in Table 1 attest the prevalence of unprotected sex in the adolescent and general population of the region. Adolescents with access to oral contraceptives may decrease risk of pregnancy but not transmission of HIV. Gonorrhea is reported much more frequently due to its painful manifestations contrasted to the relatively mild symptomatology of syphilis and its perceived "cure" in remission. While these facts are true in both urban and rural settings, the lack of *assuredly anonymous* treatment from small-town physicians and health departments results in seeking care for and reporting of more obvious conditions while milder conditions such as syphilis and primary HIV infection may go untreated and unreported.

Existing HIV Service Delivery

In this context, availability of free *HIV counseling and testing service (HIV C&T)* is limited largely to the county health departments. An independent study of HIV C&T services in county health departments across Western Kentucky⁶ revealed significant shortcomings of confidentiality, adherence to CDC guidelines and non-compliance with state mandates regarding availability and conduct of C&T services. While the cognizant state agency is addressing these matters region-wide, the reputation for poor service has unfortunately been earned. Many physicians and providers are understandably reluctant to readily refer clients to county health departments, as are clients reluctant to seek services there. *No county health department in the region offers primary care services.* Clinical services are limited to family planning, well-child care and W.I.C. programs.

Primary care services available for persons living with HIV in the region are currently limited largely to non-specialist physicians in private practice. A privately practicing physician sees a small number of clients with infectious diseases in a multi-specialty practice in the Northeastern-most county of the Western Kentucky service area. The principal provider of primary care for HIV in Western Kentucky is the Comprehensive Care Center in Nashville, Tennessee. (Attachment C) The current principal provider in the Southern Illinois area is Dr*****, an internist/ pediatrician with the ***** Clinic. (Attachment D)

⁵ Kentucky Cabinet for Children and Families, McCracken County Welfare Reform Task Force, of which the author, Rich Fortenbery, is a member representing medical and housing concerns vis-a-vis vulnerable and high-risk populations.

⁶ White and Nicholson. "Phantom Shopper for HIV Counseling and Testing." Department of Public Health, **Western Kentucky University**, 1996., In press in *Journal of AGLHCP*, Oct. 1997. (Note: The author, Rich Fortenbery, served with the investigators on the Western Kentucky Community Planning Group (CPG) for HIV prevention planning until the regional CPG system was dissolved and centralized by the Kentucky Dept. for Public Health in November, 1996.

Ryan White Title II case management and financial assistance services are currently provided by the Jackson County Health Department and Pennyriple Allied Community Services (PACS) in Southern Illinois and Western Kentucky, respectively (Attachments E & F). PACS only recently began administering the Kentucky HIV Care Coordinator program in Western Kentucky September 2, 1997. PACS is the successor to the Purchase District Health Department, which discontinued its participation in the program effective May 30, 1997. The HIV Care Coordinator program is the mechanism of administering Ryan White Title II in Kentucky. The Housing Opportunities for Persons With AIDS (HOPWA) program in the Western Kentucky region is currently under development with sponsorship by the Housing Authority of Paducah in cooperation with Paducah CARES, Inc., a constituent community based organization of Heartland CARES. Jackson County Health Department has been administering Title II in Southern Illinois since 1995. In 1997 Jackson County Health Department first received funding through the HOPWA program.

Existing Regional Funding for HIV Prevention and Services

Funding Program (1997)	Western Kentucky 1,3	Southern Illinois ²	Regional TOTAL
State consortium funds	\$ 5,365	\$42,500	\$47,865
State case management	32,037	*	32,037
Ryan White Title II			
Home/Comm Based Care	41,576	175,000	216,576
Insurance premium subsidy	27,223	*	27,223
HOPWA Funding	48,793	31,049	81,793
TOTALS	<u>\$154,994</u>	<u>\$250,500</u>	<u>\$405,494</u>

1 Kentucky Dept. for Public Health Ryan White Title II Program, 1997 Application

2 Jackson County Health Department, Murphysboro, IL

3 Kentucky Housing Corporation (HOPWA), Frankfort, KY

* **Centralized Program.** ADAP and Prevention programs are managed centrally in both Illinois and Kentucky.

NOTE: None of the funding listed above is received by Heartland CARES, Inc.

Current Gaps in Existing HIV-Related Services. Levels of funding and service availability are significantly greater in the Southern Illinois portion of the service area than in the Western Kentucky area. Our attempts to enlist the participation of the Kentucky Title II grantee in developing EIS and primary care resources have been unsuccessful. This is evidenced by the letter to Rich Fortenbery from Kentucky Governor Paul Patton of March 25, 1997 (Attachment G), which states , **"it is not the role of the HIV/AIDS Program [of Kentucky] to provide services directly, other than case management, nor to be involved in recruiting specialist physicians or establishing medical services."**

Current gaps exist in all areas of primary care services as defined by Ryan White Title III. As noted previously, many HIV counseling and testing sites in the region are not well regarded for accessing C&T services. **Primary health care** resources are

significantly lacking as evidenced by 1.) lack of local accessibility of infectious disease specialists or other providers with significant HIV experience and 2.) the rapidly increasing enrollment of Kentucky residents as clients of the Comprehensive Care Center in Nashville, Tennessee. **Mental health and substance abuse treatment** resources are not uniformly available and existing resources lack culturally appropriate services for the HIV-infected and populations at-risk. **Oral health care** is difficult for HIV-positive clients to obtain in the region, particularly in Kentucky.

Epidemiologic Profile. The epidemiologic profile of persons reported living with HIV in the service area cannot be constructed from data reported by the state health departments. Illinois only collects demographic data on persons reported with an AIDS diagnosis. Kentucky began collecting data on HIV at the end of 1996. Therefore, we report two sets of demographic profile data. Known data reported at year's end 1996 by each state for persons living with AIDS are reported below:

Persons Reported in Care, <i>Living With AIDS</i>^{2a}, 12/31/96						
	Western KY		Southern IL		REGIONAL	
	N	%	N	%	N	%
Gender						
Male	53	85.8%	46	95.8%	99	90.0%
Female	9	18.9	2	4.2	11	10.0
Race						
Caucasian	43	69.4%	29	60.0%	72	65.4%
African-American	19	30.6	13	27.1	32	29.1
Other	0	0.0	6	12.5	6	5.5
Age						
<13	0	0.0%	0	0.0%	0	0.0%
13-19	0	0.0	2	4.2	2	1.8
20-29	15	24.2	8	16.7	23	20.9
30-39	27	43.6	27	56.2	54	49.1
40-49	15	24.2	10	20.8	25	22.7
50+	5	8.0	1	2.1	6	5.5

¹ LWA = Living with AIDS diagnosis.

² LWH = Living with HIV without AIDS diagnosis. 2a Epi profile for LWH in IL not available.

³ Cumulative Deaths calculated by subtracting current LWA from cumulative AIDS reported

⁴ Kentucky figures calculated from county data reported by Ky. Dept. for Public Health

⁵ Illinois figures calculated from county data reported by Ill. Department of Health

"Not Reported" is factored out in all categories listed.

The foregoing epidemiologic profile data for persons reported in care with an AIDS diagnosis is inclusive of both states. Illinois does not report county or regional data of persons reported in care with HIV (non-AIDS). Comparing data of persons living with HIV (LWH) and living with AIDS (LWA) gives longitudinal insight into the recent (5-7 years) direction of the epidemic in demographic terms.

Comparative data of persons living with HIV and living with AIDS is available for the Western Kentucky portion of the service area and is reported as follows. We believe this data set fairly represents the entire service area with regard to this comparison.

Western Kentucky
Persons Reported In Care, Living With HIV and AIDS, 6/30/97

	LWH		LWA		Difference
	N	%	N	%	%
Gender					
Male	99	80.5%	62	83.8%	-3.3%
Female	24	19.5	12	16.2	+3.3
Race					
Caucasian	82	67.8%	50	67.6%	+0.2%
African-American	37	30.6	23	31.1	-0.5
Other	2	1.6	1	1.3	+0.3
Age					
<13	1	1.0%	0	0%	+1.0%
13-19	1	1.0	0	0	+1.0
20-29	51	50.0*	17	22.9	+27.1*
30-39	29	28.4	33	44.6	-16.2*
40-49	16	15.7	16	21.6	-5.9
50+	4	3.9	8	10.8	-6.9
Risk Factor					
MSM	43	52.4%	39	54.2%	-1.8%
IDU	15	18.3	12	16.7	+1.6
MSM & IDU	2	2.4	5	6.9	-4.5
Hemophiliac	0	0.0	1	13.9	-13.9
Heterosexual	17	20.7	13	18.1	+2.6
Transfusion	4	4.9	2	2.8	+2.1
Perinatal	1	1.2	0	0	+1.2

*Statistically significant variance of Age of LWH and LWA are in bold typeface

Source: Kentucky Dept. for Public Health

Data on persons living with HIV in the Southern Illinois region not available

"Not reported" is factored out in the above comparisons.

Data Source Contacts:

Kentucky Dept. for Public Health
 275 East Main St.
 Frankfort, KY 40621
 (502) 564-6539

Illinois Department of Health
 160 N. LaSalle, 7-South
 Chicago, IL 60601
 (312) 814-4846

1997 Regional HIV Services Assessment. In September 1997, Heartland CARES conducted a comprehensive regional needs assessment of *current clients* in collaboration with the regional Ryan White Title II agencies in the service area (Jackson Co. Health Dept. and PACS). A summary of preliminary socioeconomic findings is presented below. The complete report of the assessment will be submitted to the Division of Community Services in November 1997.

1997 Regional HIV Services Assessment.
Socioeconomic and Care Patterns

<u>Parameter</u>	<u>Western KY</u>	<u>Southern IL</u>	<u>Service Region</u>
<u>Median Income</u>	\$5,080	\$6,120	\$5,175
<100% Poverty Level	40.6%	36.2%	38.4%
100 - 199% Poverty	38.4	39.4	39.2%
200 - 299% Poverty	17.6	21.7	18.4
>300% Poverty	2.7	4.0	3.4
<u>Source of Primary Care</u>			
In region	18.4%	38.5%	26.7%
Outside region	68.5	46.4	57.3
No current care	13.1	15.1	16.0
<u>Average travel to provider</u>	112 mi.	57 mi.	84 mi.
<u>Transportation problem ("yes")</u>	42.3%	37.6%	39.3%
<u>Health care payments:</u>			
Private insurance	12.5%	18.4%	16.3%
Medicaid	34.4	42.8	38.6
Medicare	24.0	32.5	28.6
No insurance	41.8	38.0	40.6
ADAP	31.6	38.0	36.4

Conclusions of Assessed Need. In consideration of all the foregoing data and information, we identify the essential needs of our service region as follow. Program design and evaluation models are built upon these conclusions:

1. **HIV counseling and testing** services must be enhanced to facilitate early identification of and promote early intervention for HIV infection, coupled with risk reduction;
2. **Primary care (EIS) infrastructure** must be developed centrally in Paducah, Kentucky with satellite clinical access sites in existing public and community health sites within the region;
3. **Mental health and substance abuse treatment** resources must be developed and enhanced together with
4. **Oral health care services** as integral components of primary care for HIV;
5. Existing resources of **case management**, access to existing financial and service **resources**, and **outreach** efforts must be coordinated and enhanced.
6. **Financial resources** to ensure uniform access to the above services not provided through other financial sources must be ensured through aggressive funding procurement and asset management.

Organizational Capabilities & Expertise

Prior Experience. Heartland CARES was incorporated March 4, 1997 as a client-driven and client-managed consortium dedicated to developing a system of primary care services in the region, specifically within the scope and definitions of the Ryan White Title III Early Intervention Services program. While Heartland CARES is a young organization, its Board of Directors includes nurses, social workers and personal caregivers of persons living with HIV/AIDS, as well as HIV-positive persons. **HIV-positive members constitute the majority of the Board and include an HIV-positive nurse, attorney, experienced outreach worker and business managers.** Also included is the program manager of the Southern Illinois Ryan White Title II Consortium and the Chair and Secretary of the Purchase/Pennyrile state consortium of Western Kentucky. Kentucky is exempt from Ryan White Title II consortia requirements. Only state consortia exist in Kentucky. Two members serve on the Kentucky Statewide HOPWA evaluation committee. Three are members of the Southern Illinois Ryan White Title II consortium; six are members of the Western Kentucky Purchase HIV Care consortium. Three members are women and two are African-American. Summaries of experience and affiliations of officers and Board members are included in Attachment H.

Scope of Services. Current services of Heartland CARES include **assurance of access to primary care and clinical research** opportunities (Attachments C & I). This is accomplished through referral and assisting with transportation. Heartland CARES is currently finalizing negotiation with a prospective medical director, who has committed to moving to Paducah in July 1998. She is currently finishing her final year of fellowship in infectious disease medicine. In the interim, access to care is assured through current providers while development of the Paducah clinical site proceeds in anticipation of **full operations beginning upon arrival of the medical director.**

In September 1997, Heartland CARES entered agreement with LabCorp, Inc. to **increase availability of laboratory services** relative to primary care for HIV at a negotiated rate at a minimum 60% discount "off book." This discount is extended to the regional Ryan White Title II agencies, as well. In this way, **all Ryan White resources are immediately conserved.** LabCorp is currently the principal provider of lab services in the patchwork of care of the region. Cost benefits will be realized not only from the future discounts, but also in avoiding costly baseline laboratory workup necessary when changing lab contractors, a cost frequently associated with changing providers. A similar **pharmaceutical** provider agreement is being explored with a major regional retail pharmacy chain and a nationwide mail-order pharmacy service.

Heartland CARES is currently in the final phases of agreement with Western Kentucky Mental Health and Mental Retardation Board, Inc. (WKMH) wherein Heartland CARES will contract with WKMH to provide **mental health and substance abuse treatment** services for clients of the Heartland Clinic program. WKMH will bill directly for third party payment, which will offset Heartland CARES' liability for the salary guarantee. In this way, a dedicated provider is accessed within an existing mental health / AOD agency with capitated cost to Heartland CARES and assurance of coverage of cost for WKMH.

A regional system for **oral health care for persons living with HIV** is also in the process of development. This includes a resource inventory in process and consultation with schools of dentistry nearest the service region. A key component of this activity is development of a program conducive to the design of the Dental Reimbursement Program of Ryan White part f. Ongoing organizational development includes coordinating planning and program development with the existing Ryan White Title II agencies in the service area to enhance **case management**, including access to other financial and service resources as well as **outreach** to the target population and to other potential collaborating agencies and providers.

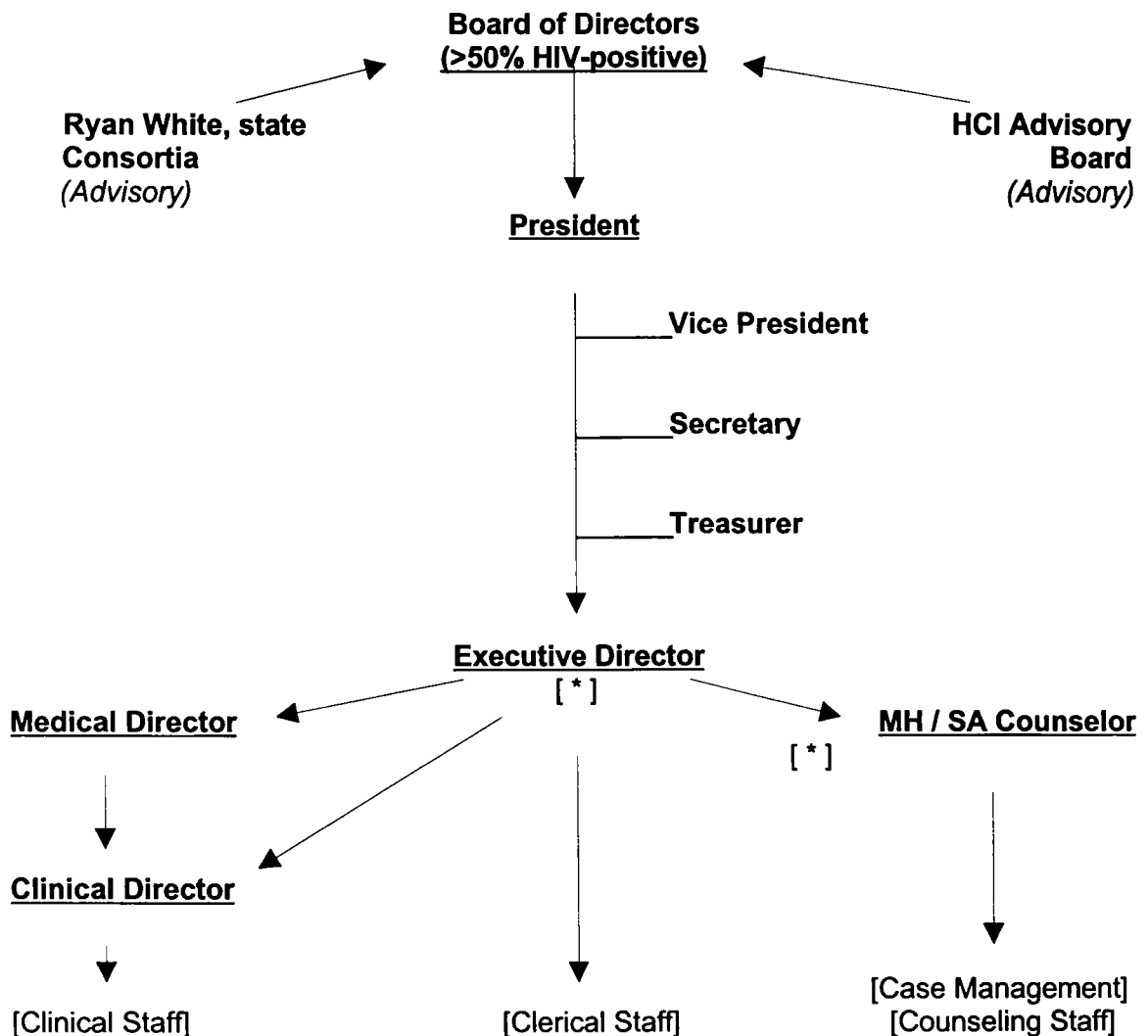
Paducah CARES, a constituent community-based organization is currently implementing a **Comprehensive HIV Care and Housing program** in partnership with the Housing Authority of Paducah (Attachment N), offering essential housing and supportive services, including primary care and case management, for persons who are homeless and living with HIV. The consortium's formula allocation of the Housing Opportunities for Persons with AIDS (HOPWA) program provides basic funding for this program. Funding is being sought through other HUD Continuum of Care programs (Supportive Housing Program [SHP] and Shelter Plus Care [S+C]) to enhance housing and care resources for persons living with HIV as well as other disabilities. Within this partnership, the Housing Authority will provide **physical space and plant support for the Heartland Clinic** and the Clinic will provide health care services across the spectrum of HUD-qualified clients, drawing operational **funding from the assortment of integrated programs** as appropriate.

This program integration will coordinate the Ryan White Title III EIS program with the larger comprehensive care and housing program which will include SHP, S+C and the Primary Care for Residents of Public Housing Program, as well as the Drug Elimination in Public Housing Program sponsored by HUD and administered by the Housing Authority and WKMH. Programs will share infrastructure and basic costs *pro-rata* based on utilization patterns. **While Heartland CARES is a new entity, its organizational capacity is evidenced by the broad experience of its constituents and Board of Directors, and demonstrated by the recent and current organizational activities outlined above.**

Organizational Mission. The mission of Heartland CARES, Inc. is defined precisely in its Articles of Incorporation (Attachment M) and Bylaws (Attachment N) is to develop a client founded, client-driven, client-centered and client-managed holistically-and-wellness-oriented system of comprehensive primary care for persons living with HIV and other disabilities in Western Kentucky and Southern Illinois. Through on-going assessment, review and modification, this system will maintain **flexibility and responsiveness** to the needs of those served as they evolve and are identified. **Further, we believe access to adequate primary preventive health care is a fundamental right in modern civilized society** and we strive to assure access to care for HIV within the larger context of **assured accessible care** to all in the service region who are otherwise unable to obtain such basic essential care.

Organizational Structure. Heartland CARES is organized in accordance with the applicable requirements of Kentucky Revised Statutes Chapter 273, its Articles of Incorporation and its Corporate By-laws. This organization is typical of non-profit Corporations chartered by the Commonwealth of Kentucky and in the traditional design for process as described in Roberts Rules of Order.

Organization Chart
Heartland CARES, Inc.



Bold Type indicates management / supervisory roles. Consortia and Advisory Board provide consultation to the HCI Board and officers. Positions noted with [*] brackets indicates a currently vacant position. During the first program year, the President may serve as the Executive Director until operational revenue streams are functional and the position can be supported within administrative expense limitations of the Ryan White program.

Program Plan

The Heartland Clinic project is a multi-phasic plan to develop a central clinic to provide HIV early intervention services and a satellite clinical site in each of the two states. The central clinic, to be located in Paducah, Kentucky will be opened on or about July 1, 1998. Within the second program year, a clinical satellite site will be opened in the Southern Illinois region of the service area. Within the second or third program year, a satellite clinic will be opened in the Pennyryle region of Western Kentucky.

Utilization experience gained in the first year of operation of the Paducah clinic will provide insight into the logical location of each of the two satellites and the appropriate timing for opening. Other considerations in site selection will be availability of an appropriate facility within the county or regional public health system, siting in communities most heavily impacted by HIV and AIDS and proximity to relatively large populations at risk, such as universities and the military base at Fort Campbell, KY.

In this context, we have tentatively designated satellite sites in Carterville, Illinois and Hopkinsville, Kentucky. This places our central and satellite sites in the most populous counties in the service area as well as those counties most heavily impacted in the epidemic. These sites are near the Ryan White Title II agencies in each state and have current primary care oriented or capable facilities we believe are suitable for our satellites. The Carterville site is the headquarters of the Southern Illinois Healthcare Partnership (SIHP) program of the Shawnee Health Service and Development Corporation. SIHP was funded in fiscal year 1994 in the Bureau of Primary Health Care's Integrated Service Network (ISN) Development Initiative. The ISN program "includes a Section 330 health center with at least one other health care provider or health care entity to form a horizontally and/or vertically integrated delivery system for managed care purposes that will ensure access for the medically underserved."⁶

"The Southern Illinois Healthcare Partnership's mission is to provide a collaborative structure which unites healthcare providers and others in Southern Illinois who share compatible values. SIHP seeks to achieve an effective, economical and comprehensive integration of healthcare resources designed to improve the health status of our communities, address employer (needs) while maintaining the core values of excellence, compassionate care and respect for the individual."⁷

Carterville is located near the juncture of Jackson and Williamson counties, the two most heavily populated and HIV-impacted counties in the Southern Illinois portion of the service area. In addition, the Carterville site is within 15 minutes travel from the campus of Southern Illinois University - Carbondale, which is the largest academic institution in the Southern Illinois service area and includes the only medical college in the Heartland CARES service area. The Jackson County Health Department, the Southern Illinois Ryan White Title II agency, is within 20 minutes travel from Carterville.

⁷ Bureau of Primary Health Care, HRSA. The Integrated Service Network Development Initiative. The First Cohort, Spring 1995. (Excerpted from introduction by Marilyn H. Gaston, Assistant Surgeon General)

⁸ Ibid., page 17.

We have tentatively selected Hopkinsville, the county seat of Christian county, Kentucky as the site for the Western Kentucky satellite clinical site. Christian county is the most heavily populated and HIV-impacted other than Paducah, the county seat of McCracken County, Kentucky and the site of the central clinic. Christian county has the highest proportion of African-American population of all 120 counties in Kentucky.⁹ Christian county includes most of Fort Campbell, Kentucky. This base of the U.S. Army is home of the 101st Airborne/Air Assault division.

Hopkinsville is the home office location of Pennyryle Allied Community Services (PACS), the regional agency administering Ryan White Title II in the Western Kentucky portion of the Heartland CARES service area. The Christian County Health Department acts as the pass-through agency between the Kentucky Dept. for Public Health as the Ryan White Title II grantee and PACS. We believe the health department may be an appropriate location for siting the satellite clinic. In addition, we have held some discussion with a large group practice which operates a clinic in Hopkinsville. They have expressed interest in exploring the satellite program further as the overall program of Heartland CARES develops.

These proposed satellite sites are in the northwestern and southeastern portions of the proposed service area. This will enable the satellite sites to offer primary care for HIV to persons beyond the currently proposed service area, as well. Neighboring consortia are amenable to joining our program in the future to provide EIS services to a larger population and geographic area. Our experience in the first half of the proposed project period, supported by ongoing need assessment will guide our future plans to expand the program.

Coordination with Other Programs. As previously outlined, the Heartland Clinic project will be closely coordinated with other HIV-related programs in the region. The Ryan White Title II grantee agencies at the state and regional levels will be regularly consulted and informed of our program progress. Their counsel will be sought in all matters regarding program coordination. Neither Ryan White Title II program provides primary care services for HIV. Their current and future role is to provide case management and financial assistance in accessing primary care.^{10,11} The Heartland Clinic will not duplicate any existing resources, rather it will greatly enhance the continuum of services and provide primary care more efficiently and economically than the current fee-for-service payment system.

The Heartland Clinic program is coordinated and consistent with the planning of the Ryan White Title II consortium in Southern Illinois and the state HIV consortium in Western Kentucky. As a relatively low-incidence state, Kentucky is currently exempt from the requirements of Title II regarding formation and operation of consortia. Kentucky consortia are advisory groups without specific authority to implement plans or determine allocations of Ryan White Title II funding. Letters of support for the Heartland

⁹ Kentucky Census Data, 1990.

¹⁰ Kentucky Dept. for Public Health, Ryan White Title II grant application, page 34.

¹¹ Illinois Dept. of Public Health, Ryan White Title II grant application, page 22.

Clinic project from the respective consortium chairpersons are included as Attachments E and F.

The Heartland Clinic and Ryan White Title II case management programs will be coordinated with the Comprehensive HIV Care and Housing Program administered by the Housing Authority of Paducah in cooperation with Paducah CARES, a constituent community based organization of Heartland CARES. This program, sponsored by the HOPWA program and in application for funding through the Supportive Housing Program helps ensure adequate resources of emergency and transitional housing for homeless persons living with HIV and other disabilities. Ryan White Title III funding will not be used for residential care in this context. Ryan White Title II agencies in the region retain responsibility for providing home health service support.

Heartland CARES is represented on the regional consortium of each state. Participation is outlined in **Prior Experience** on page 13 of this document. ***No funding received through these Title II agencies or consortia supports Heartland CARES.*** Heartland CARES will participate in the Statewide Consolidated Statement of Need process in cooperation with other Ryan White grantees in both states. The SCSN conference of Illinois grantees will be held October 21-23, 1997 in Chicago and four Heartland CARES representatives will attend. On October 1, 1997 Rich Fortenbery, President of Heartland CARES, attended an HIV housing conference also attended by the program manager of Kentucky's Title II program and discussed the need for scheduling the SCSN process in Kentucky this year (Attachment R).

Program linkage with tuberculosis control agencies has been assured through the Title II grantees in each state. (Attachments O and P.) Program linkage with CDC-funded C&T and prevention programs is documented in Attachments Q and R.

ATEC. Collaboration with AIDS Training and Education Centers will be a key component of the program. These include the Kentucky ATEC at the University of Kentucky and regional ATECs in Atlanta and Chicago. Heartland has adopted the Midwest ATEC (Chicago) protocol for mid-level practitioners as its structural format for continuing review and revision. We look forward to working with KAETC, MATEC and the Southeastern AETC in Atlanta on a continuing basis to ensure current state-of-the-art clinical information for the provider staff of the Heartland Clinic and facilitation of continuing education for regional providers in all areas of practice.

Research and Academic Affiliations. As previously outlined, Heartland CARES will engage clinical trials and research activities from regional medical centers, including Vanderbilt, Washington University and the Universities of Kentucky and Louisville, as they may so desire. In this way, our clients and clinicians will have access to the most current knowledge and care in this dynamic field of health and medicine. Heartland CARES senses a unique opportunity and duty to substantially contribute to advancing the burgeoning knowledge of holistically-oriented client-centered primary care oriented to Living Positively with HIV with maximum self-affirming support across the continuum of care.

Required Early Intervention Services / Primary Care. The Heartland Clinic program will provide complement current services of case management by providing specialized comprehensive primary care and specialty referral for persons living with HIV in the

services area. Heartland CARES was established and incorporated to provide a formal linkage among community and regional providers of various continuum of care components. Heartland CARES was founded by HIV-positive persons in the region who saw the need for a non-profit entity capable of serving as a regional consortium and fiscal agent.

Counseling and Testing for HIV. The Heartland Clinic project will provide the required early intervention services in the context of outpatient primary care. These will include enhancing the current capacity for HIV counseling and testing services by offering C&T together with partner involvement in risk reduction counseling, community outreach through a volunteer **CareCorps** and its "HIV 101" program (Attachment S) which addresses a spectrum of 10 subjects providing client education relating to living with HIV. A peer counseling program will be developed to provide individual counseling in living with HIV, which will supplement the mental health counseling provided.

Anonymous and confidential testing are allowable by the current laws of both Kentucky and Illinois. Both will be offered by Heartland CARES in accordance with current policies published by the respective state. All persons providing C&T services under the auspices of Heartland CARES / Heartland Clinic will be trained and certified by the standards established by the cognizant agency of the respective state. Strict standards of confidentiality will be maintained at all levels of service in the Heartland Clinic program. Ongoing clinical updates for C&T providers will keep them abreast of the latest in therapeutic standards and options to be communicated to the client in both pre- and post-test counseling. Processing of test specimens will be in accordance with the policies and procedures prescribed by the respective state laboratory system. Clinical staff providing C&T will be professionally trained and licensed providers of care and/or will be certified by the respective state to provide HIV counseling and testing services.

Reducing Perinatal Transmission of HIV. Special emphasis will be placed on counseling pregnant women and women of childbearing age regarding the findings of ACTG 076 and subsequent PHS recommendations, which document the efficacy of antiretroviral therapy during pregnancy and intravenous zidovudine ("AZT") during delivery in preventing perinatal transmission of HIV to the infant. The Heartland Clinic will work closely with the AIDS Clinical Trial Center (ACTC) of Vanderbilt University in Nashville in providing opportunities for AIDS clinical trials. The Vanderbilt ACTC has established a new pediatric ACTC program which is affiliated with the pediatric ACTG at St. Jude's Children's Hospital in Memphis, TN. This networking facilitates consultation and referral with the leading investigators and clinicians in obstetrical and pediatric HIV care.

Ambulatory Diagnostic and Treatment Services. As described above, Heartland CARES will provide and/or coordinate existing services and resources to ensure a comprehensive continuum of care with respect to HIV infection. HIV infection will be confirmed with each client through written documentation from a prior provider. When such documentation cannot be reasonably obtained or a question of HIV serostatus exists, the Heartland Clinic will collect and submit a specimen of blood or other material as appropriate (such as the OraSure test when implemented) to confirm infection with HIV.

A physician medical director specializing in infectious disease will supervise mid-level practitioners in providing appropriate medical evaluation and clinical care. This will include initial examination, ongoing monitoring of indicators of HIV disease and progression such as CD4+ T-cell lymphocyte and PCR HIV-1 Viral RNA ("viral load"), as well as complete blood cell counts and serum chemistry panel reflecting renal, pancreatic and hepatic function. Other laboratory parameters will be monitored as indicated by the clinical picture with which the client presents. Other diagnostic procedures such as X-ray examination, especially chest X-ray as indicated, will be provided by outsourcing through specialized providers. *In general, outsourcing of essential services will be applied whenever specialized equipment or personnel cannot be cost-effectively provided and/or maintained directly by the Heartland Clinic.* Treatment for HIV infection and diagnosis, prophylaxis, and treatment of opportunistic complications of HIV will be provided by the Heartland Clinic provider staff.

Frequency of medical examination visits and laboratory monitoring will be determined by the practitioner as indicated by the historical and current clinical presentation of the client. Treatment will be prescribed by the practitioner as indicated following clinical evaluation. Every reasonable effort will be made to access payment for medications and therapeutics through third-party payers, including the Title II AIDS Drug Assistance Program (ADAP) of the respective state. An ongoing process of application for manufacturer-sponsored compassionate use, patient assistance and expanded access pharmaceutical programs will be maintained.

Access to AIDS Clinical Trials. Heartland CARES will coordinate access to clinical trials with the AIDS Clinical Trials Center (ACTC) of Vanderbilt University Medical Center in Nashville, TN. Several persons in the service area currently participate in Vanderbilt's program. Initially, Heartland CARES will continue to coordinate transportation to facilitate access to trials. When practical, the Heartland Clinic will provide space for clinical investigators from Vanderbilt to see participants locally. Please refer to Attachment I. In the future, we intend to invite participation by Washington University Medical Center in St. Louis, MO and the Universities of Louisville and Kentucky to participate in this satellite clinical trials site, as well. Vanderbilt and Washington are also two of the six AIDS Vaccine Evaluation Unit (AVEU) sites in the nation. Heartland CARES clinicians will communicate regularly with the ACTC to be apprised of current protocols. Rich Fortenbery, President of Heartland CARES, is a consumer member of the ACTC Community Advisory Group for the Vanderbilt program.

Comprehensive Oral Health Care. Initial plans for assuring access to oral health care for clients of the Heartland Clinic will be formalization of referral and negotiation of pricing with current private providers of oral health care. A full-service dental provider has been identified in Paducah. At least one oral health care provider will be sought near each of the satellite clinical sites. Future plans include equipping a dental operator suite in the Heartland Clinic site and participation in the *Ryan White part f* dental reimbursement program in cooperation with the University of Kentucky and/or Southern Illinois University

Estimated allowance for basic oral health care per client is itemized in the budget narrative section. Included are basic examination, annual Panorex® (full-mouth X-ray) examination, cleaning/scaling procedure and an allowance for two (2) extractions and/or amalgam/composite treatments. These represent *average estimate of three (3) services*

required annually. Some clients will require more or less frequent oral health care as indicated by their clinical condition.

Mental Health and Outpatient or Non-residential Substance Abuse Treatment. Heartland CARES is currently in the final phases of agreement with West Kentucky Mental Health and Mental Retardation Board, Inc. (WKMH) to provide mental health and substance abuse treatment through outsourcing contract. Terms of this agreement are outlined in Attachment K. Inpatient mental health and substance abuse treatment is available through WKMH and may be accessed through the Medicaid spend-down program. No funding from Ryan White Title III will be used to pay for any inpatient treatment. Similar arrangements will be sought in or near the proposed satellite clinical sites.

Nutritional Assessment and Counseling services. Nutritional services will be provided on a fee-for service basis through the outpatient education department of Lourdes Hospital in Paducah. Similar arrangements will be sought in or near the proposed satellite clinical sites. Nutritional issues are also addressed in "HIV 101" (Attachment S)._

Laboratory Services. Laboratory services will be out-sourced through LabCorp (Attachment J). A discount of *60% off-book pricing* has been negotiated through our affiliation with the Comprehensive Care Center in Nashville, one of LabCorp's largest provider accounts. LabCorp will provide all collection supplies and cover costs of shipping. When volume of lab work justifies, LabCorp will provide an on-site phlebotomist in the Heartland Clinic. LabCorp offers extensive and comprehensive service and includes T-lymphocyte profile (CD4+) and PCR viral burden in ranges of 400-800,000 copies/ml and 50-30,000 copies/ml of its newly available ultra-sensitive PCR.

LabCorp will bill third-party payers directly, at the discounted price, including Medicaid, Medicare, and Ryan White Title II agencies before billing Heartland CARES. Extending this discount to the Title II programs in the region will assist in conserving all Ryan White resources in the service region. During an unspecified period, two PCR viral burden analyses will be provided at no cost through compassionate service if no payer other than Heartland CARES can be accessed.

Pharmaceutical Services. Pharmaceutical services will be preferentially accessed through third-party payers, including ADAP programs of the respective states. An ongoing process of application for manufacturer-sponsored compassionate use, patient assistance and expanded access pharmaceutical programs will be maintained. Clients will also be referred to AIDS clinical trials which are increasingly providing basic standard of care control arms. Currently, treatment naive clients without advanced disease are eligible for clinical trials at Vanderbilt with such standard of care controls.

The threshold for Medicaid spend-down assistance is currently \$238.00 per month. Current supplemental security income (SSI) payments are \$470.00 per month. This leaves a potential difference of \$232.00 out-of-pocket expense per client per month. Heartland CARES proposes pharmaceutical assistance to cover 50% of this "gap", up to \$116.00 per month per client in pharmaceuticals. This may also be applied to cover co-payments imposed by third party payers up to the monthly ceiling of \$116.00 per client per month. Changes in the Medicaid spend-down threshold and/or SSI payment will be

reviewed to consider adjustment of the \$116.00 monthly maximum.

Pharmaceutical service payments will be limited to medications approved by the Food and Drug Administration and prescribed for treatment associated with primary care services as defined by Ryan White Title III.

Staff Education Related to HIV Primary Care will be provided on an ongoing basis. Provider education programs are being offered regularly in Nashville, TN. Most are offered through co-sponsorship of Vanderbilt University, Meharry Medical College and unrestricted educational grants from pharmaceutical manufacturers. Heartland CARES has been invited to co-sponsor provider education programs locally. Offers have been made by pharmaceutical manufacturers and by referral specialty providers in Nashville who have extensive experience in early intervention services and diagnosis and management of opportunistic infections.

We also look forward to working closely with the AIDS Educational and Training Centers, particularly the Midwest (MATEC) program. As noted previously, we have adopted the MATEC protocol for mid-level practitioners for adult HIV care as our master framework for ongoing review and revision. We plan to maintain close communication with MATEC in this ongoing process.

Specialty referrals will be made as indicated to include oncologic, hematologic, ophthalmologic, dermatologic, pulmonary, pediatric, gynecologic and other services. Heartland CARES will provide supplemental payment for specialty referrals as necessary to ensure access to specialty care. Transportation assistance to access specialty care outside the Heartland Clinic will also be assured.

Other out-sourced services will be coordinated by the Heartland Clinic staff to include oral health care, nutritional assessment and counseling as well as outpatient mental health and substance abuse treatment. Referral to outsourced providers will be made preferentially to public or private nonprofit entities, unless the sole provider of a specific high-quality HIV care service is a private for-profit entity or a practitioner in private practice. Upon notice of funding of this application, Heartland CARES will develop formal agreements with each referral provider documenting procedures for referral and pricing of services, as well as procedures for billing third party payors or billing directly to Heartland CARES as payor of last resort. We understand and agree that Ryan White Title III funding may not be used to pay for in-patient, in-hospital, or residential care of any nature. Ryan White Title II funding is provided for this purpose, to the extent of assisting clients with meeting requirements of medicaid spend-down in case of in-patient treatment.

Referrals to outsourced specialty providers for consultation and/or treatment will be recorded in the client's medical record and tracked through a written referral authorization signed by the clinician providing the client's care. Appropriate background information will be provided on or appended to the authorization form. A written statement of findings and recommendations will be requested of the outsourced provider. Ongoing specialty care will require regular communication between the clinician and the specialist.

When a client of the Heartland Clinic is admitted for hospitalization, the clinician

will follow the client through the hospitalization. The admitting physician will be requested to provide ongoing consultation during hospitalization and order, if necessary, coordination of discharge planning with the Heartland clinician. When possible, coordination with admission / emergency department staff will be provided. All Heartland Clinic clients will be requested to notify their clinician as soon as possible of any hospital admission, emergency room visit or other service from another provider.

Optional Services. We believe the Heartland CARES program can be coordinated with the Ryan White Title II agencies in the service area to enhance their responsiveness to client needs through existing systems of case management. Outreach, case management and assistance in accessing other financial assistance and services is currently funded through Title II dollars and we see no present need to dedicate Title III dollars to any significant degree. We will maintain ongoing consultation on a case-by-case basis with the Title II case managers to coordinate services and payment for services. Duplication of services will be avoided and service gaps and barriers identified and addressed in this context. No Title I, IV or other Title III program currently exists in the service area to our knowledge.

Consumer Involvement. A description of the majority composition of the Board of Directors of Heartland CARES, Inc. is included on page 12. HCI's history of grass-roots origin and organization attest the initial, continuing and future involvement of consumers in program design, implementation, and review. We will not repeat the description here.

Drug Discount Purchasing Program. We are currently exploring and weighing our options with regard to drug purchasing. We appreciate the opportunity to participate with other BPHC programs in the 340(b) drug discount purchasing program. We are also following the respective state's ADAP programs as they seek to streamline their programs through a single-provider mail order pharmacy program. Illinois began such a program June 1, 1997. Kentucky appears to be inclined to implement a similar program within the first half of 1998.

We will follow the progress and experience of the states closely and seek to devise a *cooperative plan* to maximize discounting, simplify billing and certainly to maximize convenience and minimize confusion for clients. This is a primary issue for discussion in SCSN conferences. We are also considering direct dispensing of some medications needed immediately but over a short course, such as antibiotics for acute bacterial infections. We will also consider direct dispensing for medications needed immediately but dispensed by the mail-order service after the initial dispensing.

We recognize the "lead time" of a week to 10 days required for any mail order pharmacy service and seek to address this as outlined above. However, we see distinct advantage in mail order in decreasing the necessity of travel, particularly in the inclement weather of Heartland winters, particularly our *ice storms*. Herein lies the overriding advantage for the client.

Medicaid Participation and Discounted Fee Schedule. Heartland CARES is currently working with its financial / receivables firm (Medical Account Receivables System [MARS], Attachment W) in establishing Medicaid provider status in both Kentucky and Illinois. Currently, Kentucky's legislature is considering sweeping changes in Medicaid and "high-risk" health care insurance. We will notify our Ryan White Title III Project

Officer of developments in this area as they become known to us.

Current legislative action appears to involve consideration of legal issues related to coverage of care for persons with HIV and other disabilities in light of Title II of the Americans With Disabilities Act. Potential discounted fee schedules and/or caps on benefits related to HIV are potential areas of change. The possibility of a managed care Medicaid system is strong at this point and will perhaps greatly impact our operational revenues. The uncertainty of the future course of the larger question of health care financing in Kentucky is perhaps our greatest challenge in longitudinal planning.

Problem Statement and Goal Sets

Methodologic Note: Four focus group meetings of current Title II clients were held during the summer of 1997 where discussion was directed toward reviewing the program components of the Ryan White Early Intervention Services program and assessing these in light of our regional picture of existing services and needs. Rich Fortenbery conducted program and background research which identified the six specific areas of Ryan White Title III primary care services, other program components of the comprehensive continuum of care model and linkages with existing resources in the region. The group of problem / goal sets that follow is a consensus summary of the findings of the focus group process. Key informants and providers in various agencies also offered their observations in these areas. The result is a comprehensive statement of need and articulation of the goals of the Heartland Clinic project of Heartland CARES, Inc. Program evaluation design was developed in the focus group context, as well.

The six goals of the Heartland Clinic project are based on the needs identified on page 12. Identified needs have been restated in terms of issues or problems from the perspective of the client. The **Workplan**, beginning on page 31 develops each problem / goal set into time-framed, quantified measurable objectives with specific evaluation criteria and identification of key persons and interagency contacts responsible for meeting each objective.

1. Problem: *The limited client choices for HIV counseling and testing (C&T) services provided free of charge to the public are available only at public health departments. Clients feel reluctant to seek counseling and testing at these sites because of fear of being known to have sought an HIV test, regardless of the result. An unpleasant experience in the initial visit greatly reduces the likelihood the client will return for the results.*

GOAL 1: Heartland CARES will enhance availability of C&T services through innovative approaches of bringing the test to the client. Training and certification in C&T as defined by CDC guidelines including findings of ACTG 076 will be sponsored in cooperation with the state health departments. We will train and certify all interested health / mental health providers and others who may be the first individual approached by the client seeking this service.

2. Problem: *Appropriately specialized primary care for HIV from qualified providers is not readily available and is inaccessible to most clients in the service area. Accessing such care requires traveling 2 to 3 hours each way to the nearest cities outside Kentucky and Illinois. Transportation is not accessible to many and travelling is detrimental to those who are sicker and must travel more frequently. As more clients seek care out-of-state those providers may soon be forced to limit care to residents of their state, endangering access to primary care for new clients and perhaps those already in care.*

GOAL 2: Heartland CARES will ensure continued access to existing resources for primary care, especially in Nashville, Tennessee while developing a comprehensive continuum of care system based in Paducah, Kentucky with at least one satellite care program in each state in the service area.

3. Problem: *Culturally appropriate outpatient mental health and substance abuse treatment are not available to most clients in the service area. The agency currently providing these services in less than one-third of the service area counties is experiencing a waiting list of up to 3 weeks for clients in the general population.*

GOAL 3: Heartland CARES will contract with Western Kentucky Mental Health and Mental Retardation Board, Inc. (WKMh) to employ a licensed psychologist or licensed clinical social worker who will be dedicated to providing outpatient mental health and substance abuse treatment services for clients of the Heartland Clinic and consultation with other MH / AOD treatment providers caring for clients of HCI.

4. Problem: *Clients are experiencing difficulty in accessing oral health care services. Area dentists have almost universally discontinued accepting Medicaid payment. Clients believe some dentists are not willing to provide care for persons with HIV infection.*

GOAL 4: Heartland CARES, Inc. will conduct an extensive provider outreach program to identify dentists willing to provide care for the HIV-infected client and identify financial and other barriers to care. A list of interested providers will be compiled for client referral. Regional dental and dental hygienist schools will be contacted and encouraged to participate in the dental reimbursement program provided in *part f* of the Ryan White CARE Act.

5. Problem: *Current HIV case management providers in the service area are inconsistent in available services offered and vary in experience in working with clients living with HIV. Title II resources are unable to meet the primary health care needs of the rapidly increasing client population. Clients have experienced confusion and frustration in accessing basic services in the past. Case managers are now in place in both state areas of the service region.*

GOAL 5: Heartland CARES will coordinate closely with the Title II program sponsors and housing program providers in the service area to streamline the comprehensive continuum of care components currently under development and proposed programs, including the Heartland Clinic project. This will facilitate a "client-friendly" system with ready accessibility through all case management services. Heartland CARES will continue to negotiate collaborative service pricing in essential areas such as laboratory services and pharmaceuticals to be extended to Title II agencies, as well.

6. Problem: *Clients experience difficulty in accessing services due to increasingly cost and limited resources being accessed by increasing numbers of clients.*

GOAL 6: Heartland CARES will aggressively pursue negotiated price discounts from appropriate out-sourced providers. Opportunities for funding through public and private programs will be continuously researched and monitored and appropriate funding programs will be vigorously sought through on-going grant application. Sources of revenue of the Heartland Clinic will be identified and accessed to the maximum degree practicable. Multiple funding sources will be sought to maintain the self-sustainability of the program.

Program Evaluation

Heartland CARES seeks to pioneer innovative approaches to continuous quality improvement with ongoing qualitative and quantitative evaluation models, methods and tools. HCI's client-centered philosophy focuses on high quality of primary care as perceived and measured from the consumer perspective as the primary tenet of evaluation. Second, HCI will utilize physical parameters and clinical markers to evaluate therapeutic strategies. Our goal is exploring and integrating linkages between both approaches to examine the increasingly complex lifestyle and adherence issues closely paralleling with the medical issues of living with HIV.

Workplan Evaluation. The officers of HCI will meet weekly to evaluate fulfillment of the objectives enumerated in the Workplan. Progress in each goal area will be examined and compared to the evaluation methods and standards prescribed in the Workplan.

Evaluation Methods. Ongoing evaluation of program activities comprises the Continuous Quality Improvement (CQI) strategy of the Heartland Clinic project. Both qualitative and quantitative approaches to gathering data and impressions are employed from both the consumer and provider perspectives.

Comprehensive HIV Care Assessment. At the time of application, Heartland CARES is in the process of conducting a comprehensive regional HIV care assessment (RHCA) designed to: 1) reassess issues studied in separate assessments in Illinois (Ceto, 1994) and Kentucky (Conviser, 1996) to evaluate responsiveness to client needs in the interim; 2) collect and analyze data related to treatment and service issues which have emerged and/or evolved since the introduction of protease inhibitor therapy; 3) determine current primary care utilization patterns in the region; 4) assess current health insurance and medical assistance program enrollment among the current Title II clientele and others seeking care with known providers; and 5) provide a comprehensive set of baseline data for longitudinal assessment. This assessment has been possible through funding from the Ryan White Title III planning grant Heartland CARES was awarded in September 1997.

HCI plans to conduct the Comprehensive HIV Care Assessment annually to quantify changes of needs, perceptions, preferences and opinions of the clientele. To achieve parity among various levels of literacy, the assessment tools are reviewed in at least four focus groups to subjectively assess the *client-friendly* quality of the tool.

Client Groups (*support, focus, therapy, etc.*) Heartland CARES includes a "*support group with something extra*," which continues the model in which Heartland CARES was conceived. To encourage self-empowerment and a sense of ownership among clients in the collective spirit of Heartland CARES, client groups are asked to seek creative consensus-based solutions to the problem-sharing opportunity support groups have traditionally provided.

Establishing and *maintaining* "groups" has proven a perennial problem with AIDS service organizations. While groups are certainly not for everyone, they can be quite empowering personally and collectively if they have a sense of purpose and value

leading to constructive productive results. Results must be observable and at least perceptually tangible for participants to sense purpose, accomplishment and maintain inspiration to continue.

While group facilitation will be a responsibility of the mental health/substance abuse counselor, we plan to involve all clinicians in the process of group interactions. We believe the opportunity to involve clients in consensus-based interaction with their providers is key to ensuring a dialogue that will enhance the client-provider and client-organization relationships. Confidentiality of the individual client will be assured and any disclosure will be at the client's initiative. Of course, clients will be aware they are not empowered to formulate clinical practice policy or protocol but are welcome to provide advisory input.

Any issues under evaluation with respect to the policies, procedures, protocols and in particular issues related to clinical trials protocols will be presented and discussed in the client groups. Each session of the group will be concluded with formulation of a consensus statement to be summarized and made available in an informational publication, a "newsletter", for clients.

The Quarterly Review. Each client will be seen in the Heartland Clinic at least once every quarter. During the inevitable "waiting time" the client will be given a brief questionnaire to fill out. Several topics will be offered for comment and discussion with the clinician, if the client so desires. An opportunity for the client to confidentially address comments to the clinical staff will be provided at every visit. The executive director or designee will summarize the responses and present these at the weekly grand rounds of all clinicians (described below).

The quarterly review is intended to provide an ongoing process to provide a comprehensive assessment to obtain feedback on any question within 90 days. We believe an enlightened and substantively engaged clientele will maximize the active participation of each client in his or her care and promote adherence to the treatment plan.

Grand Rounds. In the tradition of continuing education and clinical collaboration, a grand rounds will be held each week for clinical staff. At this time, information gathered through group processes and the client review will be presented by the executive director. Each clinician will be encouraged to *present a case history and study* of clinical significance in primary care for HIV. The medical director will present protocol updates and a discussion period will be offered to share experience and knowledge.

Other providers in the community will be welcomed to join the HCI staff for grand rounds. Referral providers and research clinicians working in collaboration with Heartland CARES will be invited to join Grand Rounds. We hope to videotape these conferences, particularly when guest presentations are offered.

Evaluation and CQI Resources

Program Review and Technical Assistance. Heartland CARES has contracted with Training Resources Network (TRN) to provide consultative services to assist in on-going program evaluation and CQI model design and implementation (Attachment T). We have chosen TRN both for their extensive experience with and networking among current and developing EIS programs. This provides a venue to draw on the experiences of others and share our experiences as we develop and implement our program. Having been the beneficiary of enormous assistance and inspiration from others, we sense a strong duty to record and disseminate our experience for others. We believe TRN is uniquely qualified to work with Heartland CARES in this endeavor.

While our current work is dedicated to building the foundation for an exemplary EIS primary care program and implementation in July 1998, we look forward to the challenge of developing experience in EIS program replication by establishing our satellite clinical sites in creative collaboration with other program partners. A long-term goal of Heartland CARES is to work with TRN, the AETC and academic programs, and others to develop and implement a special project of national significance oriented to mapping the path for developing EIS systems in rural America.

Evaluation Tools

Qualitative CQI. We interpret qualitative CQI to encompass the clients' and providers' general feeling of well-being and satisfaction with the Heartland Clinic program. This assessment will be derived from the client groups and grand rounds gatherings on a frequent and continuing basis. The executive director will maintain a log of key issues and their resolution with respect to the clinical grand rounds. The facilitator and clinical staff participant of the client groups will summarize and log the issues and resolutions that emerge in that context.

We believe qualitative evaluation is most accurately assessed by observation and interaction over time. We believe this rather "passive" approach fosters the uniquely creative source of issue formulation among groups, rather than an approach that continually asks, "Do you prefer A, B, or C?"

Quantitative CQI. Quantitative CQI is oriented toward numbers and statistics, as contrasted to the feelings assessed in qualitative tools. The annual Regional HIV Care Assessment will provide a comprehensive regular collection of "hard data". The quarterly review process will produce "data-bytes" of specific information useful in guiding program development. The quarterly review process will examine a particular area of concern, such as oral health care, nutritional issues or organizational issues as appropriate. Results of these quantitative assessments will be reported to the clientele and the implementation of the findings will be reported, as well.

Implementation of CQI Findings.

Application of CQI Findings. The Board of Directors of Heartland CARES will meet monthly. At each meeting, the executive director will present CQI findings in the following format:

Issue statement. Articulation of the issue (or problem) in client-oriented terms

Background research. Experience of others (written

Qualitative elements. How the HCI staff and clientele feel about the problem

Grand rounds. Provider feelings

Client groups. Client feelings

Quantitative elements. Articulation of what we now know about the problem.

Quarterly reviews

Regional HIV Care Assessment

Discussion

Solution brainstorming

Solution formulation and articulation

Reporting resolution to staff and clientele

Follow-up assigned to a responsible person (who emerges as the *principal of the issue* during process

Maintaining Flexibility. Quantitative methods and process models tend to instill an inappropriate sense of rigid structure. Timeframes, objective formulation and strategy should always reflect the complexity of the qualitative feelings surrounding an issue and respect the significance of the issue. While CQI seeks to enhance efficiency and responsiveness, it must not be designed or implemented in such a way it dehumanizes the CQI process. CQI must always meet the primary test of being user-friendly, particularly from the perspective of the client.

Staffing Plan

Heartland CARES will be staffed with three general categories of personnel: 1.) clinical staff, 2) counseling staff and 3) administrative / clerical staff. The Organizational chart on page 15 of this document indicates the position of these categories in the overall organization.

Management. Each category of personnel will be managed by a director:

Clinical Director manages and supervises clinical staff (NOTE: the *medical director* oversees the clinical director and clinical staff)

Executive Director manages and supervises clerical staff

Mental Health / Substance abuse counselor manages and oversees counseling staff.

Each of the managers report to the Board of Directors of HCI directly or through the President.

Clinical Staff. The clinical staff is supervised by the clinical director. The medical director oversees the medical aspects of clinical care by the clinical director and staff. The clinical protocol for mid-level practitioners will be subject to approval of the medical director. Initially, the clinical director and medical director will provide primary care services for all clients of the Heartland Clinic. A registered nurse will be employed as well to support primary care activities, provide client/partner/family education and counseling, and administer treatments such as intravenous infusion therapy and aerosolized pentamidine treatment for prophylaxis against *Pneumocystis carinii* pneumonia (PCP). Full-time equivalent designations and allocation of funding to each of the program areas are indicated on page 42 in the line item budget. We anticipate a clinical caseload per provider to be 200 to 250 clients.

During the second program year, the experience and activities of the first year will be analyzed to define the staffing needs as the Heartland Clinic program grows. We anticipate adding 0.5 to 1.0 FTE staffing by a nurse practitioner or physicians assistant as the Heartland Clinic program grows and particularly as the satellite clinics are opened. Training and experience of initial clinical staff are indicated in Attachment H, together with the position description. Mid-level clinicians will serve a one-week internship with the Comprehensive Care Center and Stones River Medical Consultants in Nashville, TN upon employment (ref. page 35).

Counseling Staff. The counselor will train, supervise and support a staff of peer counselors to provide companion/buddy services and provide HIV C&T counseling services. The peer counselors will be trained and certified by the respective state's health department within CDC and Ryan White guidelines and specifications. Peer counselors will be trained in short-term crisis intervention techniques and will be oriented to recognize common psychological complications of HIV disease such as anxiety and depression. They will refer to the counselor for treatment following any crisis or other manifestation of need for therapy. A position description of the peer counselor is included in Attachment H.

With program growth, additional professional counseling staff will be needed. The counselor will participate in selection and orientation of new counseling staff and will serve as a consultant to other counselors providing care for HCI clients. All professional

counseling staff will serve a one-week internship with Nashville CARES for orientation to counseling persons living with HIV. The initial counselor position will be full-time and will be sponsored and cooperatively managed by Heartland CARES, Inc. and the West Kentucky Mental Health and Mental Retardation Board, Inc. (WKMh). Attachment K outlines the proposed agreement between HCI and WKMh. A position description is included in Attachment H.

Clerical Staff. Clerical staff will not be employed during the first program year, but may be added in subsequent years, particularly as satellite clinical programs are established. The first year's experience of HCI will guide the future clerical staffing needs.

Initially after opening, the President of HCI will serve as the Executive Director and will coordinate all administrative activities. When additional funding streams and program revenue have developed adequately to support clerical personnel, the Board of Directors will consider the administrative needs of HCI and design the position description of clerical support personnel. The curriculum vitae of the President (Rich Fortenbery) and the position description of the Executive Director (vacant) are included in Attachment H.

WORKPLAN FOR RYAN WHITE TITLE III E.I.S. PROGRAM -- Heartland CARES, Inc.

1. Problem: There are limited client choices for HIV counseling and testing (C&T) services with high loss to follow-up for results and post-test counseling.

GOAL 1. Heartland CARES will enhance availability of C&T services through innovative approaches of bringing the test to the client. Training and certification in C&T as defined by CDC guidelines including findings of ACTG 076 will be sponsored in cooperation with state health depts. to train and certify all interested health / mental health providers and others who may be the first person approached by the client seeking C&T services.

Objective	Action Steps	Evaluation Methods	Responsible Persons
1.1. <u>By 5/98</u> enhance C&T capacity in the region by training <u>15 new counselors</u> in each state semi-annually	1.1.1. Coordinate and schedule C&T training programs with the state health depts <u>by 3/98</u> 1.1.2. Contact currently certified counselors and invite to an update program <u>by 3/98</u>	1.1.1. At <u>least 15</u> newly certified counselors will be trained and certified in each state <u>by 5/98</u> and <u>semi-annually</u> thereafter	
3 1.2. <u>By 5/98</u> provide notice of enhanced C&T service to at least 30 potential site sponsors	1.2.1. Include C&T service program in provider and service agency outreach materials <u>by 5/98</u> 1.2.3. Request interested contact person with each provider agency <u>by 5/98</u> 1.2.2. Offer to provide on-site C&T for service providers encountering high-risk target population <u>by 6/98</u> 1.2.4. Request referral to other potential sponsoring persons / agencies <u>by 6/98</u> 1.2.5. Begin C&T outreach <u>by 6/98</u>	Appropriate sites for C&T will be identified and <u>at least 6</u> C&T outreach visits will be scheduled and conducted each quarter	
1.3. <u>By 3/98</u> and periodically (<u>at least annually</u>) review the C&T format to ensure compliance with CDC guidelines and <i>client-friendliness</i>	1.3.1. Develop C&T program evaluation tool <u>by 3/98</u> 1.3.2. Review C&T format <u>at least annually</u> to reflect up-to-date information on treatment / care available	A peer / client review committee judges the C&T format to be relevant, supportive of informed and positive response to format of pre- and post-test counseling, especially with positive results.	

1. HIV C&T services (Continued)

Objective	Action Steps	Evaluation Methods	Responsible Persons
1.4. By 7/98 provide C&T service on request by appt. or walk-in at clinic.	1.4.1. Certified HIV C&T counselor will be present at clinic during regular hours by 7/98 1.4.2. Availability of C&T service will be <i>advertised</i> through posters in the clinic and with all source-of-referral agencies by 7/98	All clients will be provided high-quality C&T service on request at the Heartland Clinic	
1.5. By 7/99 HCI will provide at least 500 C&T encounters and 500 encounters per year in the second and third program years.	1.5.1. Client outreach and community engagement programs 1.5.2. Recommendation of C&T for all pregnant women in primary care settings 1.5.3. Disseminate findings of ACTG 076 (as updated) to OB/Gyn & primary care docs annually	Surveillance activities will be judged easily accessible and affirming by client / peer review board and "phantom shoppers" to monitor CQI efforts,	["Phantom shopper"] [AETC contact]

2. Problem: Appropriately specialized primary care for HIV is not readily available and is inaccessible to most HIV-infected clients in the service area. Current out-of-state providers cannot continue to provide care indefinitely.

GOAL 2: Heartland CARES will ensure continued access to existing resources for primary care, especially in Nashville, Tennessee while developing a comprehensive continuum of primary outpatient care system based in Paducah, Kentucky with at least one satellite outpatient primary care clinical site in each state of the service area.

Objective	Action Steps	Evaluation Methods	Responsible Persons
2.1. By 3/98 develop a regional resource list of care and service agencies and furnish a summary of the HCI program	2.1.1. Identify existing key providers of related care and services through feedback of clients and RWII case managers by 4/98 2.1.2. Compile and publish a program description of HCI and mail / deliver to key providers, seek written agreements by 5/98	All identified key providers are furnished with current information which explains the Heartland Clinic program Develop and maintain written agreements with key providers and referrals in each of the primary care areas (medical, dental, nutritional, mental health & subst. abuse)	

2. Primary care services (Con't)

Objective	Action Steps	Evaluation Methods	Responsible Persons
2.2. Maintain program committee work on protocol development and review, with up-dates <u>at least quarterly</u> (Initiated 8/97)	2.2.1. Maintain communication with medical director designee to develop clinical protocol <u>thru 5/98</u> 2.2.2. Integrate Midwest ATEC model protocol with Comp. Care & 1997 USPHS guidelines for anti-retroviral therapy <u>by 5/98</u> 2.2.3. Meet and/or teleconference at least monthly with M.D. <u>until 7/98</u> RE: update and protocol	A complete protocol structure and detailed document is produced by 5/98 which will be comprehensive as judged with the MATEC standard and to the satisfaction of the medical director	
2.3. <u>By 5/98</u> secure written agreements with key referral providers, including alternate providers where possible	Negotiate provider agreements with 2.3.1. Mental health / SA tx. 2.3.2. Oral health providers 2.3.3. Nutritional services 2.3.4. Laboratory 2.3.5. Radiology 2.3.6. Dermatology 2.3.7. Ophthalmology 2.3.8. Neurology 2.3.9. Oncology - Hematology 2.3.10. OB/Gyn 2.3.11. Pediatrics 2.3.12. Surgery	A set of written agreements outlining referral procedures including billing procedures will be developed and maintained. All key areas will have <u>at least one</u> designated provider A similar set of agreements will be negotiated in the satellite clinical sites selected	
2.4. <u>Until 6/98</u> : Work with Lourdes Center for Aging & Paducah Housing Authority to prepare the clinical site	2.4.1. Begin preparing application for FQHC-look alike status <u>by 1/98</u> 2.4.2. Support and participate in clinical site development as requested by Lourdes and the Hsg. Authority. 2.4.3. Coordinate with Lourdes & Shawnee Healthcare Dev. Corp.	Clinical site will be ready to provide EIS primary care services <u>by 6/98</u>	

2. Primary care services (Con't)

Objective	Action Steps	Evaluation Methods	Responsible Persons
2.5. <u>By 4/98</u> facilitate clinical orientation of professional and clinical staff with current and referral providers in Nashville (RN & FNP)	2.5.1. Schedule each for one week minimum with Comp. Care Ctr. & Stones River Med. Consultants. 2.5.2. Provide accommodations for each (lodging & travel) <u>by 4/98</u> 2.5.3. Coordinate documentation of orientation experience and draft orientation guide for clinicians by <u>by 12/99.</u>	Each clinician will complete at least one week each with Comprehensive Care Center and Stones River Medical Consultants An orientation guide will be developed for nurses and mid-level practitioners in primary care for HIV	
2.6. <u>By 6/98</u> : Draft and publish a regional plan for EIS for HIV	2.6.1. Consortium meetings for for regional planning scheduled <u>by 12/97.</u> 2.6.2. Attend Illinois SCSN conf. <u>10/20-21/97</u> in Chicago 2.6.3. Attend KY SCSN conference <u>(When scheduled)</u> 2.6.4. Review SCSN with each consortium <u>by 4/98</u> 2.6.5. Monthly meetings of HCI officers to review and record program development process 2.6.6. Review and refocus work plan <u>by 3/98 and 6/98</u> 2.6.7. Meet with each consortium to review regional plan <u>by 6/98</u>	A regional plan for early intervention svcs. in the HCI service area will be published before clinical services begin. A project log will be maintained to record experiences in development of the HCI program leading to opening the central clinical site	
2.7. <u>By 5/98</u> : Complete all legal requirements for clinical operations	2.7.1. KY Cert. of Need (Done) 2.7.2. KY Licensure 2.7.3. FQHC Certification 2.7.4. Medicaid provider # (KY) 2.7.5. Medicaid provider # (IL) 2.7.6. Blue Cross provider status	All applicable licensure and other legal requirements, as well as certification(s) required to establish third party billing will be completed before clinical services are provided	

2. Primary care services (Con't)

Objective	Action Steps	Evaluation Methods	Responsible Persons
2.9. <u>By 7/98 enroll 50 clients in the Heartland Clinic program</u>	2.9.1. Begin enrollment with current Title II agency clients <u>by 5/98</u> 2.9.2. Conduct provider outreach to notify current primary care / family physicians of HCI program enrollment <u>by 5/98</u> .	Client census will begin with <u>at least 50 clients</u>	
2.10. <u>By 12/98 enroll an additional 50 clients</u>	2.10.1. Continue outreach to Title II clients 2.10.2. Outreach through C&T	Client census will be <u>at least 100 by 12/98</u> .	
2.11. <u>By 7/99 enroll an additional 50 clients</u>	2.11.1. Continue outreach strategies	Client census will be <u>at least 150 by 7/99 (end of first program year)</u>	
2.12. <u>By 7/2000 enroll an additional 100 clients</u>	2.12.1. Continue outreach strategies	Client census will be <u>at least 250 by 7/2000 (end of second program year)</u>	
2.13. <u>By 7/2000 open Illinois satellite clinic</u>	2.13.1. Develop satellite clinic plan <u>by 3/2000</u> 2.13.2. Negotiate agreement with site host <u>by 5/2000</u>	Illinois satellite clinic will be open <u>by the end of the second program year</u>	
2.14. <u>By 7/2001 enroll an additional 100 clients</u>	2.14.1. Continued outreach 2.14.2. Outreach to Title II clients with Effingham (IL) clients	Client census will be <u>at least 350 by 7/2001 (end of third program year)</u>	
2.15. <u>By 7/2001 open Kentucky satellite clinic</u>	2.15.1. Develop satellite clinic plan <u>by 3/2001</u> 2.15.2. Negotiate agreement with site host <u>by 5/2001</u>	Kentucky satellite clinic will be open <u>by the end of the third program year</u>	

NOTE: As listed above, client census figures are minimum projections. Program capacity is estimated at 500 clients at the end of the second program year. *Budgeting is based on 150% of minimum census projections.* Projections of opening the central and satellite clinical sites is based on opening one site in each of the three program years.

3. Problem: Culturally appropriate mental health and substance abuse treatment services are not available to most clients in the service area.

GOAL 3: Heartland CARES will contract with Western Kentucky Mental Health (WKMH) to employ a licensed psychologist or licensed clinical social worker who will be dedicated to providing outpatient mental health and substance abuse treatment services for clients of the Heartland Clinic and consultation for other MH/AOD treatment providers caring for clients of HCI.

Objective	Action Steps	Evaluation Methods	Responsible Persons
3.1. <u>By 12/97</u> complete current development of the job description and terms of contract with WKMH	3.1.1. Finalize job description and draft agreement with WKMH by <u>11/97</u> 3.1.2. Obtain approval by cognizant Boards of WKMH and HCI <u>by 12/97</u>	Mutually acceptable contract will be executed <u>by 12/97</u>	
3.2. <u>By 2/98</u> advertise the counselor position opening	3.2.1. Mailings to regional universities and organizations offering internships in HIV setting <u>by 2/98</u>	Notice of position opening is disseminated	
3.3. <u>By 4/98</u> complete search and interview <u>3 candidates</u>	3.3.1. Review panel meets <u>by 3/98</u> and reviews resume's received	Review panel selects <u>three (3) candidates</u> to invite to interview	<u>Review panel:</u>
3.4. <u>By 5/98</u> select and employ counselor	3.4.1. Review panel selects <u>by 5/98</u>	Successful candidate is selected	
3.5. <u>By 7/98</u> counselor will be oriented by Nashville CARES	3.5.1. Schedule and facilitate preceptorship with Nash CARES and Dr. ***** (private practice)	Counselor completes orientation preceptorship as indicated	
3.6. <u>By 7/98</u> counseling services will be provided <u>all clients upon enrollment</u> and outpatient therapy as indicated periodically thereafter	3.6.1. Intake interview is provided for all HCI clients upon enrollment 3.6.2. Support / therapy groups are established as needed by clients 3.6.3. Clients will be offered individual, couple, family and/or group counseling as may be deemed appropriate 3.6.4. Clients will be re-assessed <u>at least quarterly</u>	All HCI clients receive psychosocial assessments and are encouraged to participate in individual and/or group therapy activity.	

4. Problem: Clients are experiencing difficulty in accessing oral health care services. Area dentists have almost universally discontinued accepting Medicaid payment. Clients believe some dentists are not willing to provide care for persons with HIV infection.

GOAL 4: Heartland CARES will conduct an extensive provider outreach program to identify dentists willing to provide care for the HIV-infected client and identify financial and other barriers to care. A list of interested providers will be compiled for client referral. Regional dental and dental hygienist schools will be contacted and encouraged to participate in the dental reimbursement program, provided in *part f* of the Ryan White CARE Act.

Objective	Action Steps	Evaluation Methods	Responsible Persons
4.1. By 3/98, identify at least 6 dentists in each state who are providing general oral health care for HIV+	4.1.1. Mail out questionnaire to all current clients through Title II case managers by 11/97 4.1.2. Formulate list of dentists who are currently serving clients 4.1.3. Contact ID'ed dentists for provider interview by 1/98	Questionnaire will identify dentists currently providing dental care to clients and measure client satisfaction with care they are receiving	
4.2. By 4/98 seek negotiated pricing agreement with at least 3 dentists in each state	4.2.1. Formulate pricing guide for general oral health care using Title II payment experience, Medicaid dental rates and provider interview pricing data by 3/98 4.2.2. Contact dentists (4.1.3.) and negotiate service at the HCI pricing.	HCI will formulate a pricing schedule which will accommodate the budget oral health care for each client Written provider agreements will be developed with at least 3 dentists in each state (includes HCI & Title II	
4.3. By 7/98 all HCI clients will be referred for an oral health exam and prophylactic cleaning within 30 days. By 12/98 all HCI clients will receive oral care exams every 3 - 6 months as indicated.	4.3.1. All clients enrolling will be provided with written information on the HCI oral health program. 4.4.1. Clients may choose to stay with their current dentist or see any dentist they choose. (HCI will pay the <u>negotiated rate</u> to any dentist) 4.4.2. Frequency of exams & cleaning will be determined by providers	Clients are educated about the oral health program, need for regular oral care, and how the HCI oral health program is designed. The <u>primary care provider</u> will refer for initial and subsequent oral health care. All clients will be offered oral health care as indicated	

4. Oral health care services (Con't)

Objective	Action Steps	Evaluation Methods	Responsible Persons
4.4. By 3/98 explore the Ryan White <u>dental reimbursement program</u> (DRP) and seek to work with Title II grantees in implementation	4.4.1. Seek program information from HRSA by 10/15/97 4.4.2. Raise the DRP for discussion at both states' SCSN meetings 4.4.3. Comprehensive study of implementation	DRP participation in both states will be pursued	

5. **Problem:** Clients are experiencing confusion and frustration in accessing services through a patchwork of case management.

GOAL 5: Heartland CARES will coordinate closely with the Title II program sponsors and housing program providers in the service area to streamline the comprehensive continuum of care components currently under development and proposed programs, including the Heartland Clinic project. This will facilitate a "client-friendly" system with ready accessibility to HCI enrollment through all case management services.

Objective	Action Steps	Evaluation Methods	Responsible Persons
5.1. By 12/97 obtain copies of Case mgt. protocols from KY, IL, MO, Atlanta, GA	5.1.1. Review all protocols to establish common areas and differences 5.1.2. Prepare written protocol summary for review by 2/98	Protocols are reviewed to compare and identify primary care related CM models	
5.2. By 2/98 convene a mtg of Title II case mgt staff to define relationship of HCI to Title II agencies	5.2.1. Schedule mtg. by 1/98 5.2.2. Present protocol review 5.2.3. Formulate CM plan for HCI & Title II agencies referral system	A plan for coordinating HCI and Title II CM will be outlined which will be designed to be maximally "client-friendly"	
5.3. By 7/98 all clients may enroll in HCI clinical program either directly or through the Title II CM system	5.3.1. Enrollment forms will be provided to Title II CM agencies as well as all health depts in the svc. area - all are C&T sites) by 5/98	Clients may be enrolled in the HCI program directly by HCI or through Title II agencies or health depts.	
5.4. By 7/98 all new Title II and HCI clients will be referred for enrollment in the other program as well.	5.4.1. Each Title II agency and C&T sites will refer and enroll clients (ongoing)	Clients will easily access enrollment in HCI from the CM or C&T service	

6. Problem: Clients experience difficulty in accessing HIV services due to cost and limited resources being accessed by increasing numbers of clients.

GOAL 6: Heartland CARES will aggressively pursue negotiated price discounts from appropriate out-sourced providers. Opportunities for funding through public and private funding programs will be continuously researched and monitored and appropriate funding programs will be vigorously sought through on-going grant application. Sources of revenue of the Heartland Clinic will be identified and accessed to the maximum degree practicable. Multiple funding sources will be sought to maintain the self-sustainability of the program.

Objective	Action Steps	Evaluation Methods	Responsible Persons
6.1. By 2/98 develop admin, financial and MIS protocol to manage HCI operations	6.1.1. Continue to work with MARS to develop protocol 6.1.2. Provide copies of all financial info from DHHS/OMB to MARS as 6.1.3. Integrate DHHS/OMB into general accounting system	An appropriate and comprehensive financial / MIS plan will be in place before clinical operations begin	
6.2. By 4/98 survey Title II clients in the service area to profile current healthcare payment resources	6.2.1. Mail questionnaires to Title II clients in both states by 2/98 6.2.2. Tabulate client resource profile by 4/98	A coverage profile of the current healthcare resources of current clients	
6.3. By 5/98 review budget, revise to reflect current KY and IL laws	6.3.1. Review results of Medicaid/ health insurance "reform" by KY 6.3.2. Revise revenue forecast to realistically reflect current payment schedules and resource profile, 6.2.	Operational budget will reflect pending changes in Medicaid and health insurance laws	
6.4. By 8/98 develop profile assessment tool for ongoing monitoring of resource profile of HCI clients	6.4.1. Review 6.2. and 6.3. findings and formulate into assessment model for periodic ongoing monitoring of operations revenue sources 6.4.2. Implement assessment and share findings with Title II CMs	A longitudinal assessment tool will be produced which monitors the revenue sources and profile of HCI client enrollment in payment sources	
6.5. Ongoing application for supplemental funding	6.5.1. Continue monitoring CDFA	Ongoing grant research will identify opportunities for program funding	

6. Financial and information management (Con't)

Objective	Action Steps	Evaluation Methods	Responsible Persons
6.6. By 3/98 aggressively pursue cost-savings in all areas of fee-for-service and share discounting with Title II agencies so <u>ALL Ryan White resources</u> are maximally conserved	6.6.1. Lab services (done) 6.6.2. Pharmaceuticals a. ADAP enrollment b. Mail order with ADAPS c. Pt. assistance / compassionate use / expanded access 6.6.3. Oral health (Goal #4) 6.6.4. X-ray and Diagnostics 6.6.5. Specialty care referrals 6.6.6. Clinical & office supplies	All controllable cost items are minimized through pricing negotiations and group discount agreements with Title II programs and affiliated providers	
6.7. By 7/98 maximize direct third-party billing by outsourced providers	6.7.1. Seek to specify third party billing in all outsource provider agreements	Maximum billing by outsourced providers will minimize billing tasks of HCI clerical personnel and MARS	
6.8. By 7/98 third-party billing will be outsourced to MARS including collection on a contingency basis	6.8.1. Necessary provider account numbers will be obtained by HCI 6.8.2. Establish computer link-up with MARS for account receivables and general financial management	HCI staff will not be required for billing or collection tasks	
6.9. Advocate for regional Title II and other HIV-related funding whenever possible (<u>Ongoing effort</u>)	6.9.1. Maintain membership on as many program/funding oversight boards as possible	Other funding for HIV-related svcs will be increased or at least maintained for the region.	
6.10. Work with Title II and other appropriate agencies to review eligibility of clients for other financial and svc. resources <u>on a quarterly basis</u>	6.10.1. Title II CMs review all cases at least quarterly (existing policy) to ensure eligible clients are appropriate 6.10.2. HCI supports Title II CMs by timely provision of medical statements to document eligibility	Client access and enrollment in all appropriate financial assistance and direct service programs.	
6.11. <u>Every month</u> HCI Bd. of Directors reviews financial status	6.11.1. Ongoing financial monitoring guides operational plans 6.11.2. CQI is ensured in program	Financial management of HCI is directed toward maximum self-sustaining program operation	

Line Item Budget and Justification

<u>Line Item</u>	<u>Annual Salary</u>	<u>FTE</u>	<u>Primary Care</u>	<u>Program</u>	<u>Administrative</u>	<u>TOTAL</u>
<i>A. Personnel</i>						
Project director	\$40,000	0.125			\$ 5,000	\$ 5,000
Administrative assistant	17,250	0.5			8,750	8,750
Nurse practitioner	50,000	0.25	10,000	2,500		12,500
Registered nurse	36,000	0.34	8,000	4,000		12,000
TOTAL			18,000	6,500	13,750	38,250
<i>B. Fringe Benefits (34%)</i>						
			6,000	2,210	4,675	12,885
TOTAL			6,000	2,210	4,675	12,885
<i>C. Equipment</i>						
			12,000			12,000
TOTAL			12,000			12,000
<i>D. Travel</i>						
Local travel				1,500		1,500
Title III conference				1,000		1,000
Continuing education			2,000			2,000
TOTAL			2,000	2,500		4,500
<i>E. Supplies</i>						
Medical Supplies			16,962			16,962
Outreach, Counseling & Testing supplies				3,000		3,000
Office supplies					1,153	4,153
TOTAL			16,962	3,000	1,153	21,115
<i>Subtotal Forward</i>						
			54,962	14,210	19,578	88,750

Line Item Budget and Justification (Con't)

Line Item	FTE	Primary Care	Program	Administration	TOTAL
<i>Subtotal Forward</i>		54,962	14,210	19,578	88,750
<i>F. Contractual</i>					
Physician 250,000	0.4	100,000			100,000
Dental		30,000			30,000
Specialty care		30,000			30,000
Laboratory		50,000			50,000
Diagnostics (X-ray)		7,500			7,500
Mental health / Substance abuse	0.75	37,500			37,500
Nutritional services		10,000			10,000
TOTAL		265,000			265,000
<i>G. Other</i>					
Pharmaceuticals		36,000			40,000
Professional Liability (malpractice) Insurance		12,000			12,000
Cont. Education Fees		1,000			1,000
Title III Conference Fees		300			300
Occupancy (\$1,500 per month)		9,000		9,000	18,000
TOTAL		58,300		9,000	67,300
PROGRAM GRAND TOTAL		\$378,262	14,210	28,578	\$421,050
Budget Share by Category		89.8%	3.4%	6.8%	100.0%

**Heartland CARES, Inc. d/b/a
The Heartland Clinic**

**Ryan White Title III
Early Intervention Services with Respect to HIV Disease
CFDA # 93.918**

Budget Justification Narrative

(Revised July 24, 1998)

A. Personnel

\$38,250

Primary Care Services (\$18,000)

The physician is listed in the contractual category below. The nurse practitioner (0.4 FTE in primary care) will work with the physician in providing outpatient primary care services for HIV-infected patients. A registered nurse (0.23 FTE in primary care) will assist directly including administration of intravenous medications on an outpatient basis. The registered nurse will be employed from opening of the clinic. The nurse practitioner is expected to be employed at approximately the mid-point of the first year. The nurse practitioner salary will be divided equally between the Ryan White Title III program grant and the Supportive Housing Program (SHP).

Other Programmatic Services (\$6,500)

The project director will serve as liaison in case management coordination and assisting clients in accessing services, particularly with respect to enrolling clients in pharmaceutical assistance, compassionate use and expanded access programs and in accessing participation in clinical trials, particularly those whose protocols provide standard of care in control arms. The nurse practitioner will dedicate 0.1 FTE in facilitating and tracking client referrals to other specialist physicians, dentist, nutritionist, or in hospitalization. The registered nurse (0.1 FTE) will assist in coordinating with other agencies' case management services and in client, partner, and family education and counseling including safer sex, risk reduction, self-care, and stress management techniques.

Administrative (\$13,750)

The project director will oversee the implementation of the Heartland Clinic program and will coordinate with MARS (Medical Account Receivables System) in financial and management systems implementation. The administrative assistant will implement and follow through administrative activities in consultation with the project director. The administrative assistant time will be roughly equally divided between the Ryan White Title III program and the SHP and HOPWA programs.

B. Fringe benefits

\$12,885

Fringe benefits are based on FICA/Medicare (7.345%), unemployment compensation (6.2%), workers compensation (5%) comprehensive health insurance (13%) and retirement (3%) Contractors are not allocated fringe benefits. Fringe benefits are allocated as follows:

<i>Primary Care:</i>	\$6,000
<i>Other Program Costs:</i>	2,210
<i>Administrative:</i>	4,675

C. Equipment**\$12,000***Primary Care Services* (\$12,000)

Equipment needed for primary care includes the basic furnishings for each of four (4) examination rooms in the clinical site:

- Examination table / matching cabinet
- Metal Mayo table with removable tray
- Rolling stool
- Gooseneck lamp
- Otoscope / ophthalmoscope (Wall-mount)

Used surplus equipment in good and serviceable condition will be purchased at a fair discounted price from the lessor of the clinical site.

D. Travel**\$4,500***Primary Care Services* (\$2,000)

Travel for primary care is provided for 0.5 costs of four (4) persons attending continuing educational programs relative to EIS services. Travel includes lodging.

- Continuing education 2,000

Other program costs (\$2,500)

Included is local travel associated with the large rural service region and provisions for two (2) persons attending the annual Ryan White Title III grantee conference,

- Local travel 1,500
- Title III conference 1,000

E. Supplies**\$21,115***Primary Care Services* (\$16,962)

Supplies for collection / postage for HIV testing, VDRL, and GenProbe *Chlamydia / gonococcal* smear includes collection supplies and shipping (postage) to the state operated laboratory. Supplies for primary care are based on consultation with a private practice specializing in HIV care and our reference model program at the Comprehensive Care Center in Nashville, TN. We estimate cost of \$4,437 for initial supply stocking and then to average approximately \$1,000 per month. This estimate is based on a client census of 100-150 clients.

Other Program Costs (\$3,000)

Materials for prevention outreach including HIV C&T services are estimated at \$250 per month. This includes literature and condom purchases to supplement the materials and services we can obtain without cost from our state health departments.

Administrative (\$1,153)

This cost reflects basic office supply expenses.

This category will be supplemented with program income funding.

F. Contractual**\$265,000**

All contractual services are provision and/or support of primary care activities required by Ryan White Title III. In general, description of these categories is found in the statute and elsewhere in this text, particularly in the referenced attachments.

Physician (0.4 FTE) (\$100,000)

This figure represents the earnings we guarantee our physician medical director. This figure will be offset by 50% of the net program revenue (after 5% commission collected by MARS). Primary care revenues in excess 200% of the guarantee will be paid to the physician at *pro rata* 50%, as well. Operational and occupancy costs *pro rata* will be deducted from this amount for non-HIV infected clients seen in the clinic on a private basis by the medical director.

The physician is a board-certified internist and will be board-certified in infectious disease medicine following sitting for board exams in November.

Dental Care (\$30,000)

Dental care is perhaps the largest single cost category of required primary care services to be out-sourced on a fee-for-service basis. We estimate the frequency of dental care for clients with more advanced disease (25%) to be once every 3 months. Those without advanced disease and oral health complications (25%) will need dental care every 6 months. The majority (50%) will need dental care every 4 months. In this scenario, we estimate the average frequency of dental exam/cleaning visits to be 3 visits annually. The cost of basic dental care is based on interviews and pricing quoted by three local dentists in Paducah. This model includes the cost of visit and exam, one Panorex x-ray, cleaning and fine scaling, and two amalgam / composite fillings or extractions per year. From these findings and assumptions, we have constructed a model of annual oral health care for each client. For purposes of inclusion in Primary Care above, we have divided the overall cost by three to reflect an average of three units of service per client per program year.

Specialty Care (\$30,000)

Based on 300 visits / year at \$100 per visit.

Laboratory (\$50,000)

Heartland CARES has negotiated a contractual outsource agreement with LabCorp, which provides a 60% off-book pricing and with greater discounts of some routine lab services.

Diagnostics (X-ray) (\$7,500)

Our standard of care does not include routine chest X-ray (CXR) exam. However, we expect some 30% of clients to require CXR at least once per year for differential diagnosis of pulmonary disorders. The cost of the X-ray (PA & lateral views) with interpretation by radiologist is negotiated at **\$75.00** per CXR exam.

Outpatient Mental Health and Substance Abuse Treatment Services (\$37,500)

This category is out-sourced to ensure access to care while maintaining capitation of cost for Heartland CARES and assuring guaranteed cost reimbursement to the contracting provider. In this agreement, Heartland CARES will support the salary of a licensed mental health / substance abuse counselor employed by the West Kentucky Mental Health and Mental Retardation Board, Inc. The contract amount for this agreement is **\$50,000 per year per FTE.** One FTE counselor will be provided initially at the Paducah clinic. At the mid-point of the first year, this position will be supported equally by the Ryan White Title III program and SHP.

Nutritional Services (\$10,000)

Nutritional services will be provided by the outpatient service of the dietary / nutritional department of Lourdes Hospital in Paducah upon referral order by a clinician of Heartland Clinic. In addition, nutritional information will be presented and reviewed in our client educational program, "HIV 101". The negotiated cost per visit for **nutritional services is \$25.00 per visit** to be provided through Lourdes Hospital outpatient education department. This allows 400 visits per year.

G. Other Costs**\$67,300****Primary Care Services** (\$58,300)**Medications** (\$36,000)

Kentucky and Illinois ADAP programs have differing guidelines and formularies. Kentucky ADAP currently has no cap on benefits but limits its formulary to 18 medications, which does not include any protease inhibitors. Kentucky ADAP provides protease inhibitors on a pilot program managed by Community Health Trust, a community-based program in Louisville, Kentucky. This program provides one protease inhibitor for a total of fifty (50) persons statewide. CHT determines which applicants are enrolled in the program. There is currently a waiting list for enrollment.

Eligibility requirements for Kentucky ADAP include Kentucky residency, a CD4+ count of less than 550, and income less than 300% of the federal poverty level. The Illinois ADAP program covers 23 medications but has imposed a cap of \$1,000 per month per client. This figure is presumed to provide two (2) nucleoside analogs and one protease inhibitor per client at any given time. Illinois ADAP does not allow off-label prescribing. For example, fluconazole (Diflucan) is not covered for prophylactic use. Two courses of therapy of two weeks each per year is allowed each client.

Clients enrolled in Medicaid in each state are provided their medications in accordance with the federal requirements that Medicaid formularies must include all FDA-approved drugs within 30 days of approval. Our aim is to provide assistance to the client in payment of deductibles and co-payment for medication, and particularly with respect to "*spend-down*" costs between the level of supplemental security income (SSI) and the Medicaid spend-down threshold. Of the difference, we plan to cover up to 50% of the spend-down gap.

Calculation method of determining pharmaceutical assistance allowances:

SSI Monthly payment	\$470.00
[Less Spend-Down threshold]	[238.00]
Difference	232.00
[Less HCI Pharmaceutical supplement (50%)]	[116.00]
Client liability to pharmacy (<u>Maximum</u> monthly)	<u>\$116.00</u>

This provides medication coverage for at least 25 clients per month:

$$\frac{\$36,000}{12 \text{ months/yr} \times \$116/\text{client}} = 25.8 \text{ clients/month}$$

Malpractice Insurance (\$12,000)

We have estimated professional liability (malpractice) insurance at roughly \$1,000 per month. Heartland CARES will provide full coverage insurance for its clinicians (including 0.4 for the physician). The total coverage package will include liability for research activities to be carried by the lead institution and the research sponsor. This area is too complex and dependent of interagency collaboration to define precisely at this time.

Continuing Education Fees (\$1,000)

This allows payment of continuing education registration fees of up to \$250.00 for four (4) individuals.

Title III Conference Fees (\$300)

This allows payment for registration fees for two (2) individuals

Occupancy Expense (\$9,000)

Occupancy is based on negotiated lease at \$1,500 monthly (\$18,000 annually). This budget reflects 50% of the monthly expense. Included in this cost are utilities, maintenance and interior/exterior janitorial services.

*Administrative*Occupancy Expense (\$9,000)

This budget item reflects the balance of the occupancy expense described above. Occupancy expense allocable to non-HIV infected clients will be recovered *pro-rata* through deduction from the contractual payment to the medical director.

Property Liability and Damage, and Theft Insurance

This budget item provides \$1 Million coverage for property-related liability and coverage for damage / destruction / theft of the furnishings, equipment, and contents of the clinic.

Operational Revenue

Operational revenue received by Heartland CARES will be largely limited to Medicaid and Medicare payments for office visits. Coverage for referrals, laboratory, and diagnostics will be billed directly by the providers.

We estimate roughly 80% our clients will have no insurance coverage at the time of enrollment. Of these, we expect a total of 40% to remain uninsured. We therefore expect some 60% of our clientele to be uninsured at any given time.

100 clients X 40% covered = 40 covered clients

Estimated visits / yr X6

Est. covered visits 240

Estimated payment** \$ 28

\$6,720

[Less 5% (MARS fee)] [336]

Estimated Revenue **\$6,384**

This estimate for first year revenue anticipates a large enrollment of persons without coverage for an average of nine months awaiting a Social Security disability determination, which is required for a single person without children to qualify for Medicaid in Kentucky, and a similar provision in Illinois. Revenue should improve appreciably as case management coordination enrolls clients in coverage and Title II expands its program of health insurance continuation, which will place some clients on commercial coverage.

Kentucky has begun implementing its program of Medicaid Managed Care authorized by its 1115 waiver issued by HCFA. Thusfar, implementation has been limited to the Louisville and Lexington areas. The areas which include the Heartland CARES service area have not yet begun the planning process, but Heartland CARES will be an original participant in the process when it begins.

Sliding Scale Discounted Fee Schedule

Clients of the Heartland Clinic will have the out-of-pocket expenses for services provided through the Ryan White Title III program limited to the following amounts of direct charge to the client:

<u>Income</u>	<u>Limit of Direct Client Charge</u>
<100% of Federal Poverty Level	NO Charges
101% - 200% F.P.L.	5% of gross annual income
201% - 300% F.P.L.	7% of gross annual income
>300% F.P.L.	10% of gross annual income

Policy of Pay and Chase - FAST! Heartland CARES will ensure all clients receive needed and appropriate services to provide the comprehensive continuum of care for HIV. While we are working in an environment of tremendous uncertainty in terms of client census, revenue potential from a Medicaid system currently under substantial revision, and uncertainty about future costs of developing therapies, we are dedicated to delivery of state-of-the art standard of care for all clients.

We clearly understand the single component of the financial picture over which we can exert control is through aggressive price negotiation to hold down costs, contracting with providers who will bill third parties directly and offset our costs with revenue they receive, and working to extend these savings to the Title II agencies in our service region so all Ryan White resources are conserved.

Heartland CARES' receivables will be managed by Medical Account Receivables System (MARS) at a contingent commission rate of 5%. This will reduce staff time in handling third party billing activities and taps into the economy of scale with an agency whose income is based solely on performance in collections. MARS will provide financial management services and grant management, reporting, and auditing services *pro bono*. Any direct costs to MARS in this respect will be reimbursed at their actual cost.

Financial Contribution from Other Funding Sources Heartland CARES, Inc. has been approved for funding through other related programs sponsored by the U.S. Department of Housing and Urban Development and has additional applications pending, as well as more applications currently in development. Specifically, Heartland CARES will be funded at \$563,950 for three years through the Supportive Housing Program through HUD's Continuum of Care initiative. A portion of this funding is dedicated to increasing the primary care provider staff of the Heartland Clinic, as well as enhancing the operational budget with respect to costs of supplies and administration. When implemented, the capacity of the Heartland Clinic will be increased with respect to the HIV-infected client as well as others with HUD-defined disabilities. In general, provider capacity will be expanded through support of salaries (i.e., nurse practitioners and/or physician assistants) by multiple grant funding programs. The condition of HIV-seropositive status qualifies the client for services through both Title III and Supportive Housing Program's supportive services component. Similarly, Heartland CARES serves as regional project sponsor for the formula allocation Housing Opportunities for Persons With AIDS (HOPWA) program. HOPWA funds case management and assorted other supportive services with the *exception* of medical care except when no other resources are available for this purpose.

We have constructed a multi-program base to support our program by identifying, accessing, and coordinating these several similar and complementary programs. On July 10, 1998, Heartland CARES submitted application for additional funding through HOPWA's competitive Special Projects of National Significance (SPNS) program to record, demonstrate replication, and disseminate our experiences and findings from such coordination of programs in building a rural comprehensive continuum of care.