

# An Inventory and Evaluation of HIV/AIDS Support Networks in Rural Pennsylvania

By

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## Executive Summary

HIV/AIDS continues to be a health concern across the United States and Pennsylvania since its limited beginnings in the early 1980s. Advances in the treatment of HIV in the mid 1990s, primarily in the form of a combination of antiretroviral drug therapy, have led to a major shift in the progression of the disease, with fewer cases of AIDS, and lowered death rates, even as estimates suggest that rates of HIV infection appear to be on the increase.

This 2004-2006 study investigated services and local support networks available to rural Pennsylvanians living with HIV/AIDS. It analyzed the extent of data available; reviewed current trends and made short term predictions of rural infection rates; described current services available and the role of the state in funding and supporting these services; compared Pennsylvania to other states identified as leaders in the provision of services and data collection; and identified policy considerations for the Pennsylvania General Assembly.

Research data was gathered from interviews with key informants, library holdings, and the electronic media including the Internet, government databases, and scholarly databases to identify all data on HIV/AIDS that are relevant to Pennsylvania. Regional planners<sup>1</sup> and providers assisted in determining the kind of data desired and in describing differences between desired data and what is available.

## Goals and Methodology

The purpose of the project was to provide an inventory and evaluation of HIV/AIDS support networks in rural Pennsylvania. This goal was achieved through the completion of the following five objectives.

- Identify sources of data available for planning and analysis of the trends of HIV/AIDS infection rates in rural Pennsylvania.
- Inventory and analyze programs and services that comprise local support networks for rural people living with HIV/AIDS (PLWH/A).
- Evaluate how other states are addressing the needs of rural PLWH/A.
- Assess the role and effectiveness of state government in providing services to rural PLWH/A.
- Identify policy considerations that will improve the quality and effectiveness of HIV/AIDS programs and services in Pennsylvania.

Qualitative and quantitative methods were used to describe the various aspects of the HIV/AIDS service delivery system in Pennsylvania, as well as to describe and categorize the perceptions of HIV/AIDS service providers, regional planners, and administrators.

## Data availability and trend analysis

In Pennsylvania, seven regional planning coalitions help coordinate and/or provide services to state residents affected by HIV/AIDS (See the map on Page 2). The coalitions receive funding from the Pennsylvania Department of Health, Bureau of HIV/AIDS, with some funding typically originating from the federal Health Services Resources Administration (HRSA). Two of the coalitions primarily serve large urban populations and the remaining five serve primarily rural counties, some of which include smaller cities and urban centers. Pennsylvania's rural regional planners and service

<sup>1</sup> The term "regional planners" refers to the administrative staff of the seven HIV/AIDS Title II Planning Regions in the commonwealth.

providers are faced with the challenge of providing education, prevention, and treatment services in areas with lower rates of HIV/AIDS and in areas where the local culture is often ignorant of the existence and/or impact of HIV/AIDS on people in their region.

The researchers used several methods to identify the data that are used by regional planners and HIV/AIDS service providers in Pennsylvania. The researchers reviewed each planning region's biannual strategic plan, known as the *Coalition Regional Services and Strategic Plan*, which outlines HIV/AIDS trends in each region and provides short- and long-term service goals. Planning regions were sent short questionnaires, as was a random sample of service providers in each region. These questionnaires sought to identify gaps in the data available to providers versus additional data that was desired.

To broaden the context and understanding of the data typically used by other states similar to Pennsylvania, the researchers surveyed AIDS service providers in 20 states to determine what data they were most likely to use, and the data's accessibility and quality.

HIV/AIDS infection rates in the commonwealth, with a specific emphasis on rural Pennsylvania, were analyzed through mapping of AIDS prevalence and the number of consumers receiving case management services; statistical estimation of HIV in rural communities; and statistical estimation of the future incidence of HIV/AIDS in rural counties.

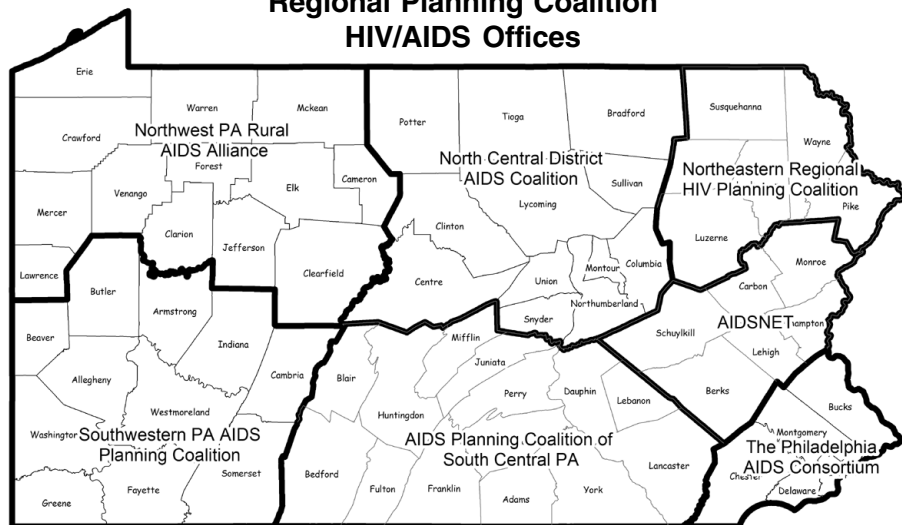
### Local support networks inventory and analysis

The researchers described the HIV/AIDS service delivery system by collecting information from the seven HIV/AIDS planning regions and the state Department of Health's HIV/AIDS Bureau. The researchers examined each region's structure, subcontractors, and epidemiology in detail, and developed several templates and questionnaires to elicit information about planning data and funding streams that the various agencies use. Participants self-selected whether they served rural clients, urban clients, or both.

### Data Results

Specific data about each planning region and county is in the full research report, which is available by contacting the Center for Rural Pennsylvania.

## Regional Planning Coalition HIV/AIDS Offices



### Evaluation of service delivery to rural PLWH/A in other states

The Rapid HIV/AIDS Service Delivery Assessment (RHASDA) was developed specifically for this study to determine which states were exemplary in HIV/AIDS service delivery and to provide a list of innovative HIV/AIDS programs. Twenty states were selected based on their similarity to Pennsylvania in its urban/rural mix and AIDS prevalence<sup>2</sup> and through referrals of exemplary programs from national experts. Participants self-selected how rural they were in terms of clients served.

### Role and effectiveness of state government in providing services to rural PLWH/A

The researchers conducted in-depth interviews with state officials from the HIV/AIDS Bureau and Pennsylvania Department of Health to aid in describing HIV services and the role state government plays in providing the services. State officials were identified with the help of regional partners. The researchers completed a guided interview with each official identified to understand the most relevant issues of state government officials.

### Findings and Policy Considerations

Based on their findings, the researchers offered several policy suggestions to address the needs of rural Pennsylvanians living with HIV/AIDS. A single, overriding issue included in most of the suggestions is the opportunity for improved communication and cooperation between the Pennsylvania Department of Health and the seven regional planning coalitions. While a clear division of roles may be important, it is apparent from the

<sup>2</sup> The researchers were unable to factor in HIV prevalence, because all states did not report HIV as of 2003 (CDC, 2003).

research that opportunities exist for the state to take a proactive role in helping the regional planning coalitions do more for the people they serve. Several of the considerations that follow outline how such a new partnership could be constructive.

### **Transportation services**

Along with the need for specialized medical care, the need for transportation services for rural PLWH/A was mentioned repeatedly throughout the research and is corroborated by the current literature. Rural clients and case managers alike must travel long distances for services; specialty care and ancillary services are often not just lacking in rural areas, but are too far away to allow for cost effective travel to them. Policies that encourage specialty providers and clinics to reach out to rural areas would help address this issue. Another strategy that has proven to be effective is to have the planning coalition become directly involved in setting up care pathways, including visiting clinics in rural areas.

### **Specialized medical care**

Rural HIV/AIDS service providers have an especially high need for access to specialized medical care in rural Pennsylvania. While this problem is difficult to address, innovative solutions from other states have included a centralized medical center with telemedicine support for satellite clinics in rural regions.

### **Mental health services**

There is great need for improved access to properly trained mental health experts for rural Pennsylvanians living with HIV/AIDS. Mental health networks should be established in rural areas so that service providers with the proper education and training may assist PLWH/A. Professional agencies, such as the American Psychological Association and the Pennsylvania Psychological Association, could serve to facilitate the professional development of mental health workers to assist PLWH/A. The Pennsylvania Department of Health, and possibly HRSA and the AIDS Education and Training Centers, could reach out to such professional groups with more training programs, HIV/AIDS mental health certifications, and cooperative HIV/AIDS service agreements between mental health professionals and AIDS service providers in rural areas.

### **Adoption of a continuum of care model that is sensitive to the needs of rural Pennsylvania**

There is a risk that core services identified in the Ryan White CARE Act<sup>3</sup>, will not best meet the needs of rural Pennsylvanians. The researchers recommend that the seven regional planning coalitions work with the

Pennsylvania Department of Health to outline the best possible strategy for creating a continuum of care in the state and in rural areas. This strategy could then be presented in a unified and coherent way to HRSA.

### **Improved access to relevant data**

HIV/AIDS service providers in the commonwealth report general satisfaction with access to broad epidemiological and demographic information regarding the epidemic in Pennsylvania and across the U.S. However, those same providers and planners report dissatisfaction with the amount of time it takes the Pennsylvania Department of Health to release data. In addition, they seek more detailed data reports on specific issues that affect the services they are trying to provide.

The researchers recommend a policy of regular annual meetings between the planning coalitions and the Department of Health to specifically address the data needs of the service planners. This meeting should take place at a time shortly after the Department of Health acquires regular annual HIV/AIDS related data. This meeting will allow the Department of Health to become more familiar with the data-driven programming needs of the coalitions and how the department can produce reports that are of maximum benefit to those serving PLWH/A in Pennsylvania. The meeting will also allow the regional coalitions to be more aware of what data the state can and cannot disseminate in a timely manner, thereby reducing the coalitions' feelings of frustration and concern that their requests are not being heard.

### **Further analysis of dissimilarities in the structure of the seven planning coalitions**

As evidenced in the RHASDA data, dissimilarity in the structure of HIV/AIDS service provision is the norm across states and across AIDS service organizations within states. The same is certainly true in Pennsylvania. What is not clear are the strengths and weaknesses of such a patchwork approach.

Identifying the relative strengths of each existing model within the commonwealth could lead to coalitions adopting more comparable structures and achieving greater efficiency. This is another area where a closer partnership with the Pennsylvania Department of Health may be beneficial. To be effective, any structural changes would have to come primarily from the coalitions.

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<sup>3</sup> The Federal Ryan White Program was enacted in 1990 and reauthorized in 2000 and 2006 to improve the quality and availability of care for low-income, uninsured, and underinsured individuals and families affected by HIV disease—those hit hardest by the epidemic. (<http://hab.hrsa.gov/history.htm>)

tions themselves, but the state could sponsor and facilitate the review process.

### **More effective identification of non-governmental/competitive sources of support**

The analysis shows that the overwhelming sources of funding are programs administered by state and federal governments. The high cost of care and planning for HIV/AIDS services necessitates such sponsorship. However, non-governmental and/or competitive sources of financial support would have a disproportionately large impact on programs for the local regions. Such sources of income would give the local regional coalitions flexibility to plan more innovative programs and achieve a greater sense of independence to meet the unique needs of their regions. The problem is that tracking down and successfully competing for such funding takes time and effort away from the HIV/AIDS service planners.

The researchers recommend that the Pennsylvania Department of Health assist in identifying private and/or competitive funding opportunities for which the coalitions (collectively and/or individually) would be eligible to compete. The coalitions would then assume responsibility for the further pursuit of such funding opportunities. As this partnership bears fruit, the researchers expect that such cooperation could extend to greater cooperation and competitiveness for more demanding federally sponsored grants.

### **Need to integrate services**

One way to overcome barriers to services would be the integration of HIV/AIDS services with other sexually transmitted infection (STI) services. The research shows a high correlation between HIV infection and other STIs. The researchers contend that the coordination of services relevant to all STIs, not just HIV/AIDS, would positively affect outreach efforts and increase service efficiency.

### **Need for employment services**

Consistent with the theme of needing a greater emphasis on increased self-determination and self-sufficiency is the need for employment services for PLWH/A. The need for employment services was explicitly raised during the focus group session with the regional providers. Ryan White funds do not include money for the provision of employment services, so this need is widely neglected in AIDS service organizations. The research literature provides examples of effective employment services for PLWH/A. Another way to address the need for employment services would be to develop some explicit partnerships between AIDS

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