

States' Responses to Title II of the Ryan White CARE Act

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Synopsis

Title II of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 provides formula-based grants to States to help them improve the quality, availability, and organization of health care and support services for people with human immunodeficiency virus (HIV) infection. This article reviews State expenditures during the first year of CARE Act funding (April 1991-March 1992) within the context of Title II guidelines and

the federally funded grant programs that preceded and helped shape Title II. The authors also discuss future challenges that require development of resources, the assessment of program impact, and the evaluation of the quality and appropriateness of HIV-related services.

Ninety-one percent of the \$77.5 million awarded to States during fiscal year 1991 went for the provision of medical and support services through HIV care consortia, drug reimbursement programs, home and community-based care programs, and health insurance initiatives. The remaining monies were used for planning, evaluation, and program administration. Forty States allocated \$38.9 million for the establishment of HIV care consortia to assess service needs and to develop comprehensive continuums of health and support services in the areas most affected by HIV disease. Fifty States allocated an additional \$28.3 million for the continuation or expansion of FDA-approved drug therapies for low-income people with HIV infection. Twenty-five States allocated \$2.2 million for the provision of home- and community-based health services, and 16 States allocated \$1.3 million for programs that help low-income people with HIV infection to purchase or maintain health insurance coverage.

RECENT STUDIES OF GOVERNMENT responses to the Acquired Immunodeficiency Syndrome (AIDS) epidemic have focused almost exclusively on the metropolitan areas with the highest incidence of AIDS and have overlooked the increasing demands on State governments to support a wide range of medical and support services for people infected with the human immunodeficiency virus (HIV). A 1991 survey conducted by the AIDS Policy Center of George Washington University's Intergovernmental Health Policy Project reveals that the 50 States and the District of Columbia spent almost \$170 million in *non-Medicaid* funds on HIV-related patient care and support services during fiscal year 1991 (1). This amount represents a 38 percent increase over the State-only funds appropriated for

HIV-related medical and support services in fiscal year 1986.

The AIDS epidemic has placed even heavier demands on State Medicaid Programs. In 1992, for example, about one out of every four dollars spent on AIDS-related health care will be covered by State and Federal Medicaid Programs at a total cost of \$2.1 billion (2). If the total cost of treating people with HIV reaches \$15.2 billion by 1995 (3), the amount covered by State Medicaid Programs could be \$3.8 billion or higher.

State efforts to provide outpatient health and support services for people with HIV infection received a much-needed boost in August 1990 when the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 was signed into

law. Title II of this act directed that formula-based grants be awarded to the States to "enable them to improve the quality, availability, and organization of health care and support services for individuals and families with HIV infection" (4). Although Medicaid remains the largest payer of HIV-related medical care, Title II funds allow States to provide services to people with HIV infection who have no public or private insurance coverage. Title II funds also can be used to pay for essential health and support services that are not covered by Medicaid or whose use exceeds Medicaid limits. In States with more restrictive Medicaid Programs, these services may include case management, prescription drugs, dental care, mental health counseling, hospice programs, and personal care.

This article reviews State responses to Title II of the CARE Act during the first year of funding (April 1991–March 1992). After summarizing the federally funded grant programs that preceded and helped shape Title II, the article describes the types of services that are eligible for Title II funding, the planning and fiscal requirements that States are expected to meet, and the different ways in which the States chose to allocate their grant funds during fiscal year 1991. The article concludes with a discussion of the major challenges faced by State governments as they attempt to build the coordinated systems of care envisioned by the CARE Act.

History of HRSA HIV-Related Grants

Between fiscal years 1986 and 1990 when the CARE Act was signed into law, the Health Resources and Services Administration (HRSA) awarded \$209.5 million for HIV service delivery programs and \$14.9 million to support the construction or renovation of facilities that provide nonacute care and intermediate and long-term care for people with HIV disease. The pre-CARE Act service delivery initiatives included five demonstration programs and two formula-based grant programs that helped States to fund drug therapies and home- and community-based care for people with HIV infection (table 1).

The five HRSA demonstration programs tested a variety of service delivery models that, along with the Robert Wood Johnson Foundation AIDS Health Services Program, laid the groundwork for the CARE Act (5). The two largest programs were the adult and pediatric AIDS service demonstration projects which funded service provider coalitions in high incidence urban areas to develop and deliver coordinated continuums of case-managed health

and support services for people with HIV infection. Other HRSA initiatives included projects that assessed the cost effectiveness of providing subacute care to HIV-positive persons recovering from acute illnesses, a program to assist lower incidence States and communities in planning for HIV-related services, and the development of service delivery models for providing HIV-related risk assessment, testing and counseling, and clinical care in community and migrant health centers.

Although most of the demonstration programs targeted the metropolitan areas that were hardest hit by the HIV epidemic, State agencies sometimes had lead responsibility for planning and implementation. For example, the State departments of health in Maryland and New Jersey and the New York AIDS Institute received adult and pediatric AIDS service demonstration grants to develop outpatient health and support service alternatives to institutional care in their high incidence metropolitan areas. Ten low and moderate incidence States receive 1-year grants through the HIV Services Planning Program to conduct needs assessments, identify resource requirements, and plan for integrated service delivery systems.

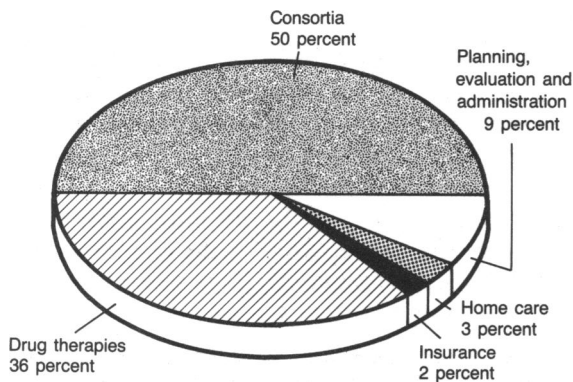
Two formula-based grant programs to assist States in providing FDA-approved medications and home- and community-based care to people with HIV infection were established in the 3-year period before the passage of the CARE Act. Later, they were subsumed under Title II of the act.

The HIV service demonstration programs and formula-based grants share several important themes that have helped to shape the CARE Act. These themes include the following:

- the establishment of local and regional consortia of service providers, community-based organizations, and people with HIV infection to assess service needs and plan for the delivery of coordinated services;
- the development of locally accessible outpatient alternatives to inpatient care;
- efforts to "mainstream" HIV outpatient care into existing service delivery systems; and
- the development of case management systems to help HIV-positive clients access timely and "culturally appropriate" services.

All of the HRSA grant programs emphasized broad community participation in planning outpatient medical and support services that were cost-effective, responsive to the needs of different populations with HIV disease, and that allowed in-

Percentage distribution of \$77.5 million in Title II funds of the Ryan White Comprehensive AIDS Resources Emergency Act by service component, fiscal year 1991



SOURCE: Fall 1991 grantee progress reports.

dividuals and families to receive care in the least restrictive settings.

Passage of the Ryan White CARE Act of 1990

The CARE Act represents the largest dollar investment by Congress, to date, specifically for the provision of HIV-related outpatient medical and support services. The act authorizes formula-based and competitive supplemental grants to the metropolitan areas with the largest numbers of reported cases of AIDS to help them meet emergency service needs (Title I); formula-based grants to States to improve the quality, availability, and organization of medical and support services (Title II); AIDS early intervention service grants to State health departments (Title III-a) and community-based primary care facilities (Title III-b); and grants for research and evaluation initiatives, including pediatric AIDS research demonstration programs (Title IV).

The legislation authorized up to \$881.5 million in fiscal year 1991 funding for the four titles. One-quarter of this amount (\$220.5 million) was appropriated for Titles I, II, and III-b. Title III-a and Title IV did not receive any funding.

Title II of the CARE Act authorizes grants to the 50 States, District of Columbia, Puerto Rico, and eligible U.S. territories to support the planning and delivery of outpatient medical and support services for people with HIV. The funds are awarded according to a formula that takes into account the State's per capita income and the number of reported AIDS cases for the 2 most recent fiscal years (6). Each State must submit a Title II Comprehensive Plan describing the service

components that will be funded and how the services will be organized and delivered. State officials are required to conduct a public hearing on the plan before submitting a grant application to HRSA and to invite and receive public comment on the proposed uses of Title II funds within 120 days of the grant award.

Title II funds may be used for any or all of the following service categories:

- HIV care consortia to plan and deliver comprehensive continuums of medical and support services in the areas most affected by HIV disease;
- home- and community-based care services;
- financial assistance programs to assure the continuity of health insurance coverage; and
- drug therapies that have been determined to prolong life or prevent serious deterioration of health.

To receive a Title II grant, each State must assure that expenditures for HIV-related activities will be maintained at the same level as the year before the State applied for Title II funds, and that at least 15 percent of the Title II grant will be used to provide health and support services to infants, children, women, and families with HIV disease. Because the CARE Act is intended to fund direct services, States cannot spend more than 5 percent of their Title II grant awards on planning and evaluation activities. Administration, accounting, reporting, and program oversight functions are capped at an additional 5 percent.

State Allocations of Title II Funds

In April 1991, HRSA's Bureau of Health Resources Development awarded 54 grants, totaling \$77.5 million, to the 50 States, District of Columbia, Commonwealth of Puerto Rico, and the two U.S. Territories of Guam and the Virgin Islands. Although funds were awarded based on the act's required formula, a State could apply for a one-time-only supplement if its Title II grant was less than the total funds the State had received in fiscal year 1990 under the AIDS Drug Reimbursement Program, Subacute Care Demonstration Program, Home- and Community-Based Care Program, and the Adult AIDS Service Demonstration Project. Even with these supplemental awards, 13 States received less money under Title II than they had received from HIV-related grant programs in the previous fiscal year.

In their fall 1991 progress reports to HRSA, the

Table 1. History of grants from the Health Resources and Services Administration for HIV-related programs, fiscal years 1986–90

HIV-related programs	Appropriation level (millions of dollars)					Total
	1986	1987	1988	1989	1990	
Adult AIDS Service Demonstration Program	\$15.3	\$10.0	\$14.4	\$14.7	\$17.2	\$ 71.6
AIDS Drug Reimbursement Formula Grants to States.....	...	30.0	NA	15.0	29.6	74.6
Pediatric AIDS Service Demonstration Program	4.8	7.8	14.8	27.4
1610(b) Facilities Renovation Demonstration Program	6.7	3.9	4.3	14.9
HIV Services Planning Demonstration Program	3.9	...	3.9
Home and Community-Based Care Formula Grants to States.....	19.7	19.7
Subacute Care Demonstration.....	1.5	1.5
Community Health Care Services for AIDS Demonstration Program.....	10.8	10.8
Total funding	\$15.3	\$40.0	\$25.9	\$45.3	\$97.9	\$224.4

NOTE: HIV = human immunodeficiency virus; NA = not applicable.

States projected the amounts that they would spend on each service category through March 31, 1992. The figure shows how the Title II funds were distributed across the consortia, drug therapies, home care, insurance, and planning, evaluation, and administration categories. Almost \$71 million (91 percent of the total Title II funds awarded) went for the provision of medical and support services through HIV care consortia, drug reimbursement programs, home- and community-based care programs, and health insurance initiatives. Because of the mandated caps on State expenditures for planning and evaluation and program administration, the \$6.8 million allocated for these functions represented only 9 percent of the total Title II funds awarded.

Table 2 displays the number of States that funded each service component and the minimum, maximum, and median percentages of State grant awards allocated. There was considerable variation among the States in the types of services funded and in the proportion of the grant award allotted to each service component. HIV care consortia and drug reimbursement programs were more apt to receive Title II funding and to claim larger shares of the grant awards than home- and community-based care and health insurance coverage.

HIV care consortia. Title II of the CARE Act defines an HIV care consortium as “an association of one or more public, and one or more nonprofit private, health care and support service providers and community-based organizations operating within areas determined by the State to be most affected by HIV disease” (7). Membership or representation on the HIV care consortium is a requirement for service providers that receive funding through the consortium. The consortium also may include service providers that do not receive Title II funding;

Table 2. Fiscal year 1991 allocations by service component under Title II of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act (ranges and median percentages)

Service components	Number of States	Minimum percent	Maximum percent	Median percent
Drug therapies	50	6	100	35
Consortia.....	40	5	95	50
Home care	25	2	67	15
Insurance.....	16	2	52	10

SOURCE: fall 1991 grantee progress reports.

representatives of the business, educational, and religious communities; and other community leaders. All consortia are expected to have people with HIV infection and representatives of affected communities as members.

The CARE Act outlines five tasks for consortia. Their legislated responsibilities are to assess the service needs of all populations with HIV disease, develop a plan for meeting identified needs through a comprehensive continuum of outpatient medical and support services, promote the coordination and integration of community resources, assure continuity of services through effective case management, and periodically evaluate the consortium’s effectiveness in responding to service needs and providing cost-effective alternatives to hospitalization.

In fiscal year 1991, 40 States allocated \$38.9 million for the establishment and operation of HIV care consortia (see figure). This sum represents about half of the total Title II funds awarded. The percentage of Title II funds allocated by individual States for consortia ranged from 5 to 95 percent, with a median value of 50 percent. Twenty States with 1 percent or more of the total number of AIDS cases (as reported to and confirmed by the Centers for Disease Control for the 2-year period

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preceding the fiscal year of the grant) were required to allocate at least 50 percent of their grant awards for HIV care consortia. The median percentage of Title II funds allocated by these States (50 percent) was somewhat less than the median percentage allocated by the 20 States that elected to fund consortia (54.5 percent).

States that allocated funds for consortia were required to balance the service needs of areas with a high or growing incidence of HIV disease with service needs in more rural areas and to give funding priority to existing consortia such as the HRSA-funded Adult AIDS Service Demonstration Projects. The States also were encouraged to consider the unmet needs of areas that had not received emergency relief grants under Title I of the CARE Act. Within these broad guidelines, the States had considerable latitude in determining how many consortia to form and where to locate them.

The 40 States that allocated funds for consortia chose to bound their service areas in different ways (table 3). Thirteen States formed one statewide consortium. Another 13 awarded contracts to regional consortia in public health districts, health planning areas, or State-defined AIDS service areas. Six States awarded contracts to consortia in the cities or counties with the highest incidence of AIDS. The remaining eight States funded combinations of regional and city-county-based consortia or statewide, regional, and county-based consortia.

Although States were given the option of establishing service priorities for consortia in their comprehensive plans, 22 of the 27 States with regional, city, or county-based consortia (81 percent) allowed service priorities to be determined at the local level. The remaining five States with regional and city- or county-based consortia required their consortia to establish HIV service priorities within broad State guidelines.

The 220 HIV care consortia that operated during fiscal year 1991 used their contract awards to

support outpatient services such as medical and dental care, mental health counseling, home health and homemaker services, hospice care, transportation services, benefits advocacy, home-delivered meals, housing referrals, and HIV support groups. The Ohio Department of Health contracted with an insurance company to serve as third-party administrator (TPA) and to pay claims for services that had been authorized by local case managers based on consortium-approved rates and service categories. Periodic reports from the TPA allowed the eight consortia to monitor the number and demographic characteristics of clients served as well as cost caps. The Oklahoma City Area AIDS Consortium established an employment program to help people with HIV infection assess their work goals and job skills and to locate employment opportunities.

Provision of treatments. Fifty States chose to allocate Title II funds to continue or expand coverage of FDA-approved drug therapies for low-income people with HIV infection. The four remaining grantees used State funds or unexpended AIDS Drug Reimbursement Program grant funds to cover AIDS-related medications. The \$28.3 million spent on this service component accounted for 36 percent of the total Title II funds awarded to States in fiscal year 1991. Individual State allocations ranged from 6 percent to 100 percent, with 35 percent being the median value.

Five States included all FDA-approved medications in their drug reimbursement programs. Among the remaining States, the most frequently funded drug therapies were zidovudine (44 States), aerosolized pentamidine (30 States), didanosine (26 States), and trimethoprim-sulfamethoxazole (22 States). The number of drugs approved by individual States ranged from 1 (zidovudine only) to 49, with a median value of 4. Even with this Federal support, the States were hard-pressed to meet the growing demand for drug therapies. One low incidence State reported, for example, that it was spending \$36,000 per month for outpatient drugs.

Home- and community-based care. Twenty-five States allocated \$2.2 million for the provision of home- and community-based health services for people with HIV infection. This sum represented only 3 percent of the total Title II funds awarded, largely due to the fact that many States requested and received no-cost extensions of their fiscal year 1990 home- and community-based care formula grants. Individual State allocations for these ser-

vices ranged from 2 percent to 67 percent, with a median value of 15 percent.

Under the home- and community-based care component, States could choose from seven service categories that included durable medical equipment, homemaker services, home health and personal care services, day treatment and partial hospitalization, home intravenous and aerosolized drug therapy, in-home diagnostic testing, and mental health, developmental, and rehabilitative services provided in the home or in community settings. Six States authorized reimbursement for all of these services. Among the remaining 19 States, the most frequently funded services were home health or personal care aides (16 States), home intravenous and aerosolized drug therapy (11 States), and homemaker services (9 States). In addition, six States supplemented their home care programs by funding case management, transportation to clinics, home hospice care, or HIV prevention education for families. The mean number of services funded under this component was four.

Continuity of health insurance coverage. Sixteen States used Title II funds to establish programs that assisted low-income people with HIV infection in purchasing or maintaining health insurance coverage. The \$1.3 million allocated for this service component accounted for just 2 percent of the total Title II funds awarded to States in fiscal year 1991. Individual State allocations ranged from 2 percent to 52 percent of their grants, with 10 percent being the median value. Funds were used to cover the costs of premiums, deductibles, and co-insurance, with each State establishing its own financial eligibility and medical expense criteria. In Rhode Island, for example, the department of health funded Rhode Island Project AIDS to make direct payments to insurers on behalf of HIV-positive individuals who had lost their health and dental insurance coverage and who were not yet eligible for Medicaid.

Challenges for the Future

Although Title II has helped States to assess and plan for the medical and support service needs of uninsured and underinsured populations with HIV, a number of implementation challenges remain. These challenges relate to funding, assessing program impact, evaluating the quality and appropriateness of services, and developing and maintaining consortia.

Table 3. Organization of HIV care consortia in fiscal year 1991 under Title II of the Ryan White Comprehensive AIDS Emergency Resources (CARE) Act

Organizational approach	Number of States	Number of consortia	
		Range	Median
Statewide.....	13	NA	NA
Regional.....	13	1-24	7
City or county-based....	6	1-29	2.5
Other ¹	8	2-17	5

¹ Combination of 2 or more of the above approaches.

NOTE: HIV = human immunodeficiency virus; NA = not applicable.

SOURCE: Reports on FY 1991 activities from FY 1992 grant applications.

Funding issues. As the AIDS epidemic moves beyond the large cities to less populated areas, there is a growing need to expand and redistribute medical and support services for people with HIV infection. Changes in the demographics of AIDS are stimulating the development of new programs that are responsive to the needs of different racial and ethnic groups, women, children, and people who use injection drugs. State and local governments are being challenged to meet these growing and diverse needs in the face of budget shortfalls and competing requests from other health and human services programs.

A few States have been able to reallocate general purpose revenues for HIV-related services; however, most are struggling to maintain existing levels of State support. Some States have decided to reallocate Title II home care and health insurance continuation funds to HIV care consortia so that the consortia can identify and fund the most critical service needs. Other States are helping consortia to develop grant-writing skills and to seek supplemental sources of funding.

A related challenge facing all States is how to better coordinate Title II, Medicaid, and other sources of third-party coverage. Baily and colleagues outline a number of areas that need to be coordinated in order to maximize the medical and support services available to people with HIV (8). These areas include eligibility requirements, the services that each payer covers, utilization controls, provider participation standards, and reimbursement rates. Title II support for State programs that help low-income people with HIV to purchase or maintain private health insurance coverage offers one example of a public-private approach to the financing of HIV care. Other creative approaches could be encouraged through Federal and private sponsorship of demonstration projects and the participation of third-party payers with HIV care

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consortia and statewide Title II as advisory councils.

Assessing program impact. To assess whether their HIV treatment and social support programs are effective and to plan for future services, States need to know whether HIV-related services are reaching priority populations, the level of use of services, their costs, and the impact of services on patient morbidity and mortality. HRSA is supporting this evaluation effort by working with States and Title I eligible metropolitan areas, service providers, people with HIV infection, and representatives of national AIDS organizations to design and field-test a Uniform Reporting System (URS). The URS will facilitate the collection and analysis of

- *provider-level* data on the unduplicated number of clients served, the volume of services provided, HIV revenues and expenditures, and staffing profiles, and
- *client-level* data on the demographic characteristics of each person served and the number and types of services received.

With the URS in place, HRSA can assist State health departments and HIV care consortia in designing more sophisticated evaluation studies that examine the cost effectiveness of different services, the extent to which these services reduce inappropriate hospitalization, and relationships between the use of outpatient services and clinical or psychosocial outcomes.

Assessing the quality and appropriateness of services. The CARE Act requires States to conduct periodic, independent peer reviews to assess the quality and appropriateness of Title II-funded medical and support services. This peer review process is supposed to include health, mental health, and social service providers; representatives of

community-based organizations; people with HIV infection; and representatives of State and local government agencies. Quality indicators have been developed for hospital-based care, but these indicators may not be applicable to the services offered by AIDS service organizations, community mental health centers, social service agencies, and other HIV service providers. Thus, in developing procedures for statewide or locally based peer review, the States will have to define "quality of care" for a very diverse array of services. Their definitions and quality assessment processes may well be transferable to medical and social support programs for other diseases and patient populations.

Preliminary State reports suggest that many will be working through HIV care consortia to assess the extent to which service objectives are being met, the level of client satisfaction with the services, and whether the services are being provided in accordance with quality standards. In North Carolina, for example, a Peer Review Quality Improvement Subcommittee that includes physician, nursing, social work, and consumer representatives is designing a program for implementation by the State's nine consortia that will assess service providers' adherence to statewide service definitions and standards. As these peer review processes are implemented, it will be important to monitor how the CARE Act's cap on State planning and evaluation expenditures (5 percent of the Title II grant award) affects the frequency and thoroughness of the evaluations.

Consortium development. The consortium component of Title II has provided States with a promising mechanism for involving medical and social service providers, community-based organizations, and people with HIV infection in identifying critical needs and planning for coordinated service delivery. However, the legislation's lack of specificity with respect to what types of service providers and community representatives should serve on a consortium, and how members should be appointed (or elected), has made it difficult for many consortia to achieve the legitimacy that they need to effect change (9). Although many consortia are still adding members, there have been charges that the current memberships of some do not adequately represent the different ethnic and minority groups affected by HIV infection. In addition, the requirement that HIV care consortia be comprised of agencies with a "record of service to populations and subpopulations with HIV" (10) has made it difficult for consortia to avoid conflict of interest

when deciding how Title II funds should be allocated.

To achieve broad community participation in the planning and evaluation of medical and support services, the HIV care consortia will need extensive guidance and technical assistance. At a December 1991 workshop sponsored by HRSA, State health department representatives discussed the issues and problems that they have encountered in organizing and working with consortia. Key issues identified at this workshop and through a HRSA-funded study of HIV care consortia (9) will be used to develop capacity-building workshops, peer consultant networks, and on-site technical assistance for consortia.

Conclusions

Title II of the CARE Act provides a participatory planning framework and an essential funding base for making medical and support services available to people with HIV infection, with a special emphasis on reaching those who are uninsured and who do not have coverage under Medicaid or other public programs. The legislation encourages States to seek extensive public input regarding HIV service needs in both urban and rural communities and to organize coordinated systems of care that are responsive to these needs. More than 200 HIV care consortia have been organized in 40 States to assess service needs and to develop mechanisms for delivering, coordinating, and evaluating patient care and support services. Title II funds have helped States to maintain AIDS drug reimbursement programs and to increase the availability of in-home services and health insurance coverage for low-income people with HIV infection.

While there has been much progress, the Title II Comprehensive Plans developed by the States reveal significant variations in the availability and accessibility of HIV-related drug therapies and services. HRSA's case studies of HIV care consortia suggest that different funding streams, with different eligibility and reporting requirements, have made it difficult to integrate HIV prevention and service programs and to adapt substance abuse, maternal and child health, and other categorical programs to meet the special needs of people with HIV (9). As the demand for HIV-related services continues to grow, a collaborative approach to the funding and evaluation of HIV care offers the most promise for directing limited Federal and State resources to the most cost-

effective services and to the populations most affected by HIV disease.

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