

# Directions in HIV Service Delivery & Care

**A POLICY BRIEF**

**Number 2**

## **Delivering and Financing Care**

**Office of Policy and Program Development  
Health Resources and Services Administration  
HIV/AIDS Bureau  
[www.hrsa.gov/hab](http://www.hrsa.gov/hab)**



Directions  
in HIV Service  
Delivery & Care

**A P O L I C Y B R I E F**

**Number 2**

# **Delivering and Financing Care**

**Caitlin Ryan, MSW, ACSW  
Editor**

**Office of Policy and Program Development  
HIV/AIDS Bureau  
Health Resources and Services Administration**

# Introduction

When the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was initially authorized in 1990, lack of public infrastructure and capacity to provide services for affected persons, particularly low-income and uninsured/underinsured people with HIV/AIDS, posed profound challenges to communities throughout the country. Since that time, the CARE Act has established a critically needed planning process and infrastructure to develop and sustain essential health and social services for persons living with HIV/AIDS. These services have improved the lives of thousands of poor, uninsured/underinsured men, women, children, youth and families throughout the United States. And their effectiveness has been borne out by the reduction in HIV morbidity and mortality among the most impoverished communities.

Although substantial gains have been made, challenges remain in meeting the care and support needs of historically underserved populations, including minorities, women, families, substance users and people with mental illness. And these continuing disparities represent new challenges for the CARE Act in its second decade.

## Guiding Principles

As the CARE Act entered a second reauthorization cycle last year, HRSA's HIV/AIDS Bureau (HAB) conducted a comprehensive assessment of disparities in access to services and care. This assessment was based on the policy framework established by HAB Associate Administrator, Dr. Joseph O'Neill, who identified four principles to guide the Bureau's mission. These include: 1) changes in demographics; 2) access to emerging therapies; 3) changes in health care financing; and 4) program accountability.

During a year-long review of the role and structure of CARE Act services, HAB explored various changes, issues and needs affecting HIV service delivery, using these principles as a lens by which to identify and assess current and future challenges in caring for uninsured and underinsured people with HIV/AIDS. HAB examined these issues in light of the following questions:

- ◆ How can HRSA strengthen CARE Act-funded programs to ensure that all persons with HIV/AIDS, regardless of race, co-morbidity, geographic location or income, have access to needed health and support services?
- ◆ How can HRSA ensure that CARE Act services meet current standards of quality HIV care?
- ◆ How can HRSA and CARE Act grantees help providers maintain fiscal and administrative viability within rapidly evolving health delivery and social welfare systems, while creating opportunities for new providers to care for affected and underserved populations?
- ◆ How can HRSA improve its ability and that of CARE Act grantees to monitor and evaluate services, becoming more accountable to Congress, State agencies and, most importantly, people with HIV/AIDS who depend on these services for their survival?

## Program Review Activities and Policy Studies

Under the guidance of Dr. John Palenicek, Director of the Bureau's Office of Policy and Program Development (OPPD), staff engaged in extensive consultation with constituents, community members and people living with HIV/AIDS. This includes collaborating with HRSA's AIDS Advisory Committee to sponsor a series of public hearings to solicit broad feedback in preparation for reauthorization. During the past year, OPPD staff undertook a comprehensive evaluation of current program activities to understand the dynamic of HIV care within an evolving system of health care finance and delivery. And they initiated a series of targeted policy studies to more fully understand the factors that affect access to care and ability to remain in care for poor, low-income and traditionally underserved populations.

Topics selected for these studies include the following:

- ◆ The experience of vulnerable populations (e.g., minority women, children, and substance users) in accessing needed services and care;
- ◆ The changing nature of health care delivery and finance systems for HIV services and their relationship with CARE Act-funded programs; and
- ◆ The role and structure of Title I, II, III and IV programs within communities.

The goal of these studies is to expand on current knowledge and to generate findings that can inform future policy directions or suggest administrative or legislative changes for the reauthorized CARE Act. Results of these studies will be presented in a series of policy briefs—*Directions in HIV Service Delivery & Care*—to help grantees and CARE Act providers render more effective services to people with HIV/AIDS. Findings and recommendations will also help inform HRSA's administrative procedures, technical assistance and training activities, improve service delivery, and enhance inter-governmental relationships between Federal agencies and among Federal, State and local jurisdictions.

These studies are especially relevant for CARE Act providers because they focus on populations and issues that—although difficult to address—offer the greatest potential for significantly improving outcomes for the Nation's most underserved populations. HRSA grantees are encouraged to read these reports and to incorporate findings and recommendations into their ongoing planning and program activities. HRSA welcomes feedback from readers on the usefulness of these monographs for their work. Send comments to: [jgrantling@hrsa.gov](mailto:jgrantling@hrsa.gov).



## Participation of Racial and Ethnic Minority Providers in Clinical and Social Support Services Funded by the Ryan White CARE Act

Julia Hidalgo, Sc.D., Rani Lewis, M.D., M. Keith Rawlings, M.D.

**PURPOSE:** To improve understanding of services provided by minority providers, to identify and reduce funding barriers, and to find the most effective ways to include minority providers in CARE Act planning and funding. **METHODS:** Researchers used multiple data sources to assess minority providers' role and level of inclusion, including: 1) an extensive document review; 2) focus groups of minority providers and HRSA staff members; 3) written consultation from selected providers; and 4) written consultation from 2,691 CARE Act grantees and contracting agencies throughout the country. **FINDINGS:** More than one-third (38 percent) of agencies receiving CARE Act funds are minority providers. Minority providers were: 1) more likely to report that CARE Act funds are hard to obtain; and 2) significantly more likely to provide social support services than non-minority providers. HIV planning bodies heavily influence HIV care delivery and financing, but more than one-half of minority and non-minority providers report barriers to planning participation. **RECOMMENDATIONS:** Researchers provide recommendations for improving minority providers' participation in planning and funding.

## The Impact of State Variability in Entitlement Programs on the Ryan White CARE Act and Access to Services for Underserved Populations

Jeffrey Levi, Ph.D., Julia Hidalgo, Sc.D., Susan Wyatt, M.P.H.

**PURPOSE:** To identify how differences in State Medicaid programs affect Ryan White CARE Act programs and the ability of people with HIV to access health services. **METHODS:** Researchers analyzed available data for all 50 States and the District of Columbia, and conducted case studies in four States to examine the range of CARE Act programs, their impact on access to care, and the relationship between Medicaid and CARE Act funding. **FINDINGS:** Medicaid is at the core of primary care access for poor people with HIV, and CARE Act funding is critical to their treatment. "Wrap-around" services like case management and housing assistance are critical components of care but are not always available; developing a core set of benefits would help ensure comparability of services nationwide. Providers can build infrastructure and ensure comprehensive, efficient services when CARE Act funds are distributed as grants, rather than on a fee-for-service basis. Barriers discourage providers from viewing Medicaid as the payer of first resort. **RECOMMENDATIONS:** The authors provide recommendations for improving coordination of Medicaid and CARE Act programs.



# Participation of Racial and Ethnic Minority Providers in Clinical and Social Support Services Funded by the Ryan White CARE Act

Julia Hidalgo, Rani Lewis, M. Keith Rawlings

## Background

Racial and ethnic minority providers play a unique role in the delivery of HIV-related services funded by the Ryan White CARE Act. Minority providers often have substantial experience in meeting the needs of underserved populations, are often geographically accessible to these populations, and are likely to employ staff who live in the communities they serve. They are also uniquely suited to reduce cultural barriers that inhibit provision of quality care for ethnic and racial minority persons with HIV/AIDS.

Rapid changes in publicly-funded health care, including the development of Medicaid managed care programs, have negatively impacted minority providers, who are likely to serve a higher rate of uninsured, underinsured and chronically ill patients. They may be under-capitalized and are likely to experience loss of local revenue, inadequate philanthropic support, inadequate capitation and fee-for-service reimbursement rates and barriers to participation in managed care networks. Many are also likely to experience caregiver “burn-out” as one of a small number of minority service organizations in local communities. As a result, minority providers are likely to need support from discretionary funding sources, such as the CARE Act.

Because their role in the HIV delivery system is so critical, minority providers must have unimpeded access to CARE Act funds to ensure their ongoing ability to provide care. They must participate fully in CARE Act decision making, in needs assessments, planning, and funding allocation. It is unclear to what extent minority providers actually do so, since a review of the literature found no publications on their role in CARE Act service delivery, and little information exists on the barriers they encounter when seeking CARE Act funds.

Information about effective ways to fund minority providers, such as targeted procurement policies, is critical to ensuring that funds are awarded equitably and that the needs of clients served by minority providers are adequately addressed.

## Methodology

In assessing the role and level of inclusion of minority providers in the CARE Act delivery system, researchers: 1) conducted an extensive document review, including administrative and procurement data and Planning Council bylaws; 2) convened separate focus groups of minority providers and HRSA staff members; 3) obtained written consultation from minority providers and other care providers in a HRSA-sponsored clinical training program; and 4) solicited written consultation from CARE Act grantees and contracting agencies throughout the country (see table 1).

Researchers defined “minority providers” as non-profit or public agencies where 51 percent or more of board members belong to racial or ethnic minority groups; where racial/ethnic minority persons comprise 51 percent or more of direct service staff; or where individual providers (e.g., office-based clinicians) are members of racial or ethnic minority groups.

Researchers examined methods used to promote participation of minority providers in planning and resource allocation activities (including funding) by reviewing grant applications for Titles I-IV for

### Purpose of the Study:

To improve understanding of services provided by minority providers, to identify and reduce funding barriers, and to find effective ways to include minority providers in CARE Act funding, planning and decision making.

### Practice Settings for Minority Providers that Receive CARE Act Funds

51%	community-based organizations
14%	miscellaneous other settings
14%	publicly-funded community health centers
10%	hospitals or hospital-based clinics
5%	health departments
3%	publicly-funded community mental health centers
3%	publicly-funded drug treatment centers

**TABLE 1**

### Minority Provider Participation in CARE Act Services: Data Sources

SOURCE	METHOD	INFORMATION SOUGHT
Document Review	I, II, III, IV grant application review FY 1999–2000/FY2000–2001	Policies to enhance minority provider participation in planning, resource allocation and service delivery
	I, II RFAs + procurement announcement review	Inclusion of minority providers (including enhanced scoring mechanisms)
	Planning Council bylaw review	Policies related to minority provider membership
	Title I + II application review FY 1999–2000	Discussion of minority provider participation in EMA/State planning, allocation or care network
	Title I application review FY 1999–2000	Rate of racial/ethnic minority Planning Council membership and relationship to rate of minorities with HIV/AIDS
HIV/AIDS Bureau (HAB) Staff	Focus group	Instructions to grantees on minority provider participation, policies on minority provider funding, technical assistance and capacity-building activities
Minority Providers	Focus group + written consultation	Experiences in CARE Act planning activities + service delivery
Sentinel Site Provider Consultation	Telephone consultation with key providers in Memphis, Miami, Oakland, and Washington DC	Experiences in CARE Act planning activities + service delivery
Grantee and Agency Consultation	Written consultation with 2,691 CARE Act-funded direct service agencies	Minority status, agency characteristics and experiences in CARE Act planning + service delivery

FY 1999–2000 and FY 2000–2001, and soliciting copies of Title I and II grantees’ most recent request for applications (RFA) or procurement announcements. Copies of RFAs were returned by 78 percent of Title I grantees and 66 percent of Title II grantees. Researchers also requested copies of Planning Council bylaws to identify specific policies related to minority provider Planning Council membership, and 87 percent of grantees submitted them. In addition, researchers reviewed Title I and II grant applications for FY 1999–2000 to identify discussion of minority provider participation in eligible metropolitan area (EMA) or State planning, resource allocation, and care network activities.

Researchers also reviewed data from Title I grant applications for FY 1999–2000 to assess the relationship between the rate of minority providers on Planning Councils and the rates of HIV/AIDS among minority populations within the EMA. Documents were electronically scanned into word processing software and key words associated with minority provider participation were searched and data analyzed to obtain findings. SPSS was used to determine the relationship between Planning Council membership and racial/ethnic demographics of clients served.

Researchers also engaged in several activities to solicit information about the experiences of minority providers and to pretest a provider consultation form. Two focus groups were conducted with: 1) key HAB policy and program staff to elicit information on instructions to grantees regarding minority provider participation; and 2) minority providers during a Title III clinical meeting in Tucson, Arizona. During the clinical meeting, attendees were invited to provide voluntary written consultation on their individual and agency role in HIV planning activities and barriers to meeting the clinical and social needs of persons with HIV/AIDS. One hundred-twenty-one attendees (61 percent) responded.

**TABLE 2**

### Minority Provider Consultation

- ◆ Type of agency/facility
- ◆ HIV services provided
- ◆ Funding sources for HIV-related care
- ◆ Minority provider status
- ◆ Types of HIV planning activities (past 12 months)
- ◆ Reasons for not participating in HIV service planning activities
- ◆ Activities/factors that increase the likelihood of CARE Act funds
- ◆ Activities/factors that serve as barriers to receipt of CARE Act funds

Minority providers in four cities were also invited to participate in voluntary, confidential telephone interviews to provide information on planning, access to CARE Act funds, perceived levels of equity in distribution of Title I and Title II funds, and recommendations for enhancing participation of minority providers. A total of 13 key informants were interviewed in Memphis, Miami, Oakland, and Washington, D.C.

Finally, researchers compiled a database of direct care agencies receiving CARE Act funds and invited them to participate in the study by providing voluntary and confidential written consultation on their agencies’ minority status, services, funding sources, planning participation and factors that facilitate or hinder access to funds (table 2). This task required the researchers to identify and enumerate an unduplicated list of providers receiving CARE Act funds, a lengthy process that had not previously been done for all four CARE Act Titles. Since the unit of analysis was at the *agency* level, agencies with field offices, satellite

clinics or other HIV programs operating within their organizational structure were only listed once. Agencies that provide non-care-related services (e.g., fiscal management, data management, Planning Council staff support) were not included in the final list. Collectively, these agencies provide more than 100 distinct HIV-related clinical and social services.

The resulting database included 2,691 agencies. Of these, 2,598 (96.5 percent) who were reachable by fax, received a two-page consultation form to return with the requested information. To date, 1,330 agencies (or 51 percent) have returned a completed form. Further analysis is being done which will provide additional findings and may alter some of these figures. Data were analyzed using SPSS. Because this sample represents a significant proportion of all CARE Act grantees, the results are generalizable to other grantees at the national, State and EMA level.

## Limitations

Researchers noted several limitations in conducting the study:

- ◆ Differences in interpretation of “minority provider” may not reflect the full complement of care provided by and for ethnic and racial minority persons. For example, a number of agencies that have traditionally served minority populations and have less than 51 percent minority staff or board members, are not represented in the definition used for this study. (To address this limitation, respondents could identify as traditional service providers to racial and ethnic minority populations; these responses were compared with those from minority providers.)
- ◆ Concerns that anonymity might not be ensured may affect providers’ willingness to speak candidly about their experiences related to funding and planning. Although researchers assured participants that their names would not be disclosed, some may have been concerned about negative repercussions from grantees or consortia that might affect potential funding.
- ◆ Lack of consistency may affect responses to some questions. For example, some providers may not be aware of all sources of funding available to their agency from various CARE Act Titles, Medicare, Medicaid and other payers.

## Findings: Minority Providers—Characteristics and Experiences

- ◆ **More than one-third (38 percent) of agencies receiving CARE Act funds meet the minority provider criteria used in the study.**

Nearly one-half (47 percent) of minority agencies that receive CARE Act funds have minority staff, but non-minority boards. More than one-third (36 percent) have both minority boards and staff, while only three percent operate in clinical practices that include a majority of racial and ethnic minority clinicians. An additional 2 percent of agencies had a combination of minority board membership or staffing, and practiced in solo or group clinical practices.

- ◆ **Strong geographic differences were found between minority and non-minority providers.**

Minority providers were more likely to be located in the Northeast, Mid-Atlantic, South Central, and Pacific regions than non-minority providers, who were more likely found in Southern and New England regions. Minority providers were significantly more likely to be located in Title I EMAs than non-minority providers (79 percent versus 53 percent). In contrast, non-minority providers were more than twice as likely as minority providers to be located outside of EMAs (21 percent versus 47 percent, respectively).

- ◆ **Minority providers were significantly more likely to provide social support services than were non-minority agencies.**

Although non-minority providers were more likely to provide substance abuse treatment and case management services than their counterparts, there was no significant association between minority provider status in delivery of specialty clinical services, mental health services, clinical support services\* or HIV counseling and testing.

- ◆ **Among clinical providers, being a minority provider was associated with Title I funds, while being a non-minority provider was associated with receipt of Title II funds.**

These differences reflect the regional location of providers. There was no association between minority provider status and receipt of Title III or IV funds, nor between minority provider status and receipt of other funds, such as commercial fee-for-service, managed care, Medicare, Medicaid or public grants.

---

\* Clinical support services include: dental, home health, medical case management, pharmacy case management, disease management, hospice, laboratory, nutritional education, nutritional supplements, retail pharmacy, early intervention programs, and clinical trials.

- ◆ **Minority providers were significantly less likely than non-minority providers to participate in Title II consortia (39 percent versus 48 percent, respectively).**

There was no significant difference in the proportion of minority and non-minority providers participating in Title I EMAs (40 percent versus 44 percent, respectively).

- ◆ **HIV planning bodies heavily influence the nature and scope of HIV care delivery and financing.**

Planning Councils, consortia and Statewide Coordinated Statement of Need advisory groups either directly set service priorities and funding allocations or heavily influence government policy makers. When minority providers are “at the table,” they can ensure that their clients, agencies, and communities have a voice.

## **Mechanisms and Support for Inclusion and Funding**

- ◆ **Title I bylaws are generally silent regarding the appointment of minority providers to Planning Councils.**

Investigators could find no EMA that set aside Planning Council seats for minority providers, although some may set aside seats for HIV programs whose representatives might happen to be minority members.

- ◆ **Several Planning Councils and States have established standing committees to address issues related to minority providers.**

For example, the EMA in Orange County, CA has established a Minority Access Committee to address issues of capacity building and outreach among minority providers. In Florida, a minority community-based organization network has been established to support community planning and minority issues.

- ◆ **HAB is currently limited in their ability to monitor minority provider participation in the CARE Act planning and resource allocation process.**

Routine communications between HAB and Title I and II grantees such as the application guidance do not require grantees to report on activities related to minority providers. While the Annual Administrative Report (AAR) does gather information regarding the minority status of contractors submitting service data, these data do not address the representation of minority providers in planning and resource allocation efforts.

- ◆ **Grantees’ ability to support minority providers with CARE Act funds is complicated by State and local government procurement procedures.**

Several EMAs and States have sought greater flexibility in procurement policies by forming separate corporate entities to award and monitor funds. Some jurisdictions established these mechanisms before the CARE Act was passed, while others did so to distribute CARE Act funds more rapidly. These separate procurement structures allow targeted funding to minority providers and other types of organizations.

- ◆ **Several EMAs and States have minority vendor set-aside requirements for most procurement activities, and several EMAs have RFA scoring mechanisms that might indirectly benefit minority provider applicants, but only one EMA systematically ensures access for minority providers to Title I funds.**

Several States, such as Michigan, routinely require information about minority provider status of Title II contractors and subcontractors. Jurisdictions with minority vendor set-asides (e.g., District of Columbia, Kansas City, Maryland) stipulate that services using CARE Act funds meet these requirements unless exemptions are sought. Some EMAs, such as Boston, Austin, Palm Beach and

Miami, credit additional points for demonstrating cultural and linguistic competency and organizational ability to serve clients of different languages or ethnicities. In Philadelphia—the only EMA where researchers identified a systematic effort to ensure that minority providers receive Title I funds—contractors are required to demonstrate cultural competence and a history of service to communities of color in their funding applications. When minority providers want to serve racial and ethnic minorities but lack capacity, technical assistance is provided.

- ◆ **Some Title I and II programs are prohibited from awarding public funds that are specifically based on the race or ethnicity of board members or staff of agencies that apply for funds.**

In some jurisdictions (in several California cities, for example) grantees are unable to implement minority provider set-asides due to local or State laws that prohibit such practices.

- ◆ **Although HAB policymakers recognize the importance of establishing and supporting minority care provider capacity, insufficient funds have been allocated to monitor the use of CBC funds.**

Funds earmarked by the Congressional Black Caucus (CBC)—Department of Health and Human Services (DHHS) Initiative to Address HIV/AIDS in Racial and Ethnic Minority Communities—have allowed HAB to address capacity development through the Title III program and training needs through the AIDS Education and Training Centers (AETCs). While agencies receiving CBC funds will likely need significant technical assistance over the course of their grants, funds have not been allocated for technical support.

## Barriers to Participation and Funding

- ◆ **Over one-half (57 percent) of respondents (both minority and non-minority) identified barriers to participating in planning activities.**

Respondents were asked about their participation in a full range of activities, including: HIV/AIDS service and prevention planning groups or subcommittees, AIDS Drug Assistance (ADAP) advisory groups, Title I Planning Councils and committees, Title II consortia, public hearings, or other organized AIDS service planning activities. Regardless of minority status, respondents frequently described the planning process as inaccessible due to the commitment of time and meeting locations. Many respondents expressed concern that participation interfered with their ability to deliver care. Other concerns include the financial burden that participation puts on their agencies, and dissatisfaction with the stressful and political nature of planning groups and conflict of interest. For small, underfunded organizations that are reimbursed on a fee-for-service or unit cost basis, not being able to claim planning time as a unit of service (despite mandatory attendance) is particularly burdensome and takes away from time with clients and provision of care. Lack of representation among a wide spectrum of groups was also considered a barrier to furthering the goals of HIV care planning.

- ◆ **Respondents strongly agreed on the factors that can help or hinder participation in HIV planning and resource allocation.**

Motivators include: commitment to advocate on behalf of people with HIV/AIDS, particularly for disenfranchised populations; and collaboration, coordination, information gathering, and networking. Key factors that make participation easier include meeting logistics (time, date and location) and a perception that planning activities will help improve delivery of HIV care.

## Minority Providers' Concerns

*"There has not been enough representation of African American and Latino populations on the service planning committees, therefore the needs of these populations are not being met."*

—Minority community-based organization, California

*"We feel we have to fight to keep our program funded year after year."*

—AIDS service organization, New York

*"We feel particular concern for small groups who may not have the staff to prepare proposals."*

—Large Northeastern hospital system

*"We are a small agency and this is a small contract. We expect to be at meetings when our input is needed and we need to answer questions. However, the present policies [regarding Planning Council agendas] make it difficult for small providers such as ourselves to be available. We simply cannot afford the extras involved in delivering services."*

—Small community-based organization, Midwest

*"Funding is consistently provided on a level basis from year to year. While we are growing our services and client population, CARE Act funds hamper our ability to expand services quickly and force us to spend more time administratively on a search for other funding and sources of income."*

—Minority community-based organization, Pennsylvania

- ◆ **Minority providers were more likely to report that CARE Act funds were very difficult or somewhat difficult to obtain than were non-minority providers.**

Minority providers were significantly more likely than non-minority providers to report specific barriers to obtaining CARE Act funding (46 percent versus 41 percent, respectively). The single most important factor in obtaining funds was having an experienced grant writer on staff or having funds to pay for a grant writer. Other factors that both minority and non-minority providers identified as giving applicants a distinct funding advantage include: serving a particular high-risk population, such as women or substance users; participating in planning activities; establishing a strong relationship with grantee staff; collaborating well with other providers; and having a high-quality, well-organized and experienced program.

- ◆ **One of the most frequently-cited barriers to receiving CARE Act funds was the increasing demand for services in the face of flat or diminished funding.**

Respondents expressed concern over the trade-offs between maintaining a social support infrastructure and gearing up to meet increasing demands for clinical care. As one California-based minority provider pointed out, “Everyone is being asked to do more with less.” Significant tension also exists between sustaining funds for existing programs and distributing funding more broadly, across a greater numbers of agencies. Other problems were systemic: the procurement, grants management, and reporting requirements were described as burdensome, unnecessary and unreasonable. Grantmaking and reimbursement mechanisms were also problematic. Of particular concern are limits (administrative caps) imposed on the amount of funds that can be spent to meet administrative demands.

## **Recommendations**

- I. Clearly articulate CARE Act program activities and policies related to racial and ethnic minority providers.**
- II. Carefully review grant and contract systems at State and local levels to identify ways to streamline requirements, and conduct a similar review of planning and resource allocation activities.**
- III. Ensure that criteria used to award funds to minority providers are flexible enough to recognize the different ways these agencies may be organized.**
- IV. Allocate funds for additional staff to monitor use of Congressional Black Caucus funds, provide technical assistance, organize training, and evaluate the impact of those funds on the health of impacted communities and the stability of minority providers.**
- V. Require grantees to submit a complete updated list of contractors receiving CARE Act funds annually, and to disclose their policies and procedures related to minority provider participation in planning, resource allocation, and care funding.**
- VI. Provide technical assistance to CARE Act-funded agencies at start-up and during infrastructure development to help ensure viability.**
- VII. Improve coordination between: 1) HAB program, policy and technical assistance staff and training focusing on racial and ethnic minority providers; and 2) national organizations, HAB, NIH, and the pharmaceutical industry in planning and operating clinical and other training programs.**
- VIII. Ensure that trainers in HAB-sponsored clinical training programs have HIV experience in serving diverse populations in a variety of settings, and address the multi-cultural nature of HIV care in designing clinical training programs.**
- IX. Facilitate the inclusion of CARE Act-funded treatment sites in HIV clinical trial programs, and collaborate with NIH and AHRQ (Agency for Healthcare Research and Quality) to identify opportunities to include clinical and non-clinical investigators in HIV-sponsored research.**





# The Impact of State Variability in Entitlement Programs on the Ryan White CARE Act and Access to Services for Underserved Populations

Jeffrey Levi, Julia Hidalgo, Susan Wyatt

## Background

The Ryan White CARE Act was designed to supplement, not substitute for, other sources of health care funding for people with HIV/AIDS. The CARE Act was intended to fill gaps in services for persons already on Medicaid and to provide services for those who cannot afford them but are also ineligible for Medicaid.

### Purpose of the Study:

To identify how differences in State Medicaid programs affect Ryan White CARE Act programs and the ability of people with HIV to access health services.

Medicaid is the single most important source of financing care for people with AIDS. Estimated Federal/State spending on Medicaid for people with AIDS in FY 1999 was \$3.8 billion, compared to \$1.4 billion for the CARE Act. The Health Care Financing Administration (HCFA) estimates that over one-half of people living with an AIDS diagnosis and over 90 percent of children with AIDS in the United States receive Medicaid-financed care.<sup>1</sup> The Centers for Disease Control and Prevention (CDC) estimates that over one-half of all people living with HIV depend on the public sector for their care, either through Medicaid or publicly-funded clinics.<sup>2</sup>

While Medicaid is a Federal program, it is jointly financed and administered by the States. The Federal government sets basic eligibility and benefit standards, giving the States significant discretion to move beyond the minimum benefit and eligibility standards; many do, which creates tremendous variation among State programs. As a result, people with AIDS living in three different States may encounter three very different Medicaid programs: one might receive a very generous benefits package, one a very basic package, while another might be declared ineligible for any benefits at all.

One element of a State's Medicaid program that is particularly important for people with AIDS is the presence of a "medically needy" program. These programs permit disabled persons with high medical expenses to deduct those expenses from their incomes and "spend down" to Medicaid income eligibility levels. Medically needy programs are not required by the Federal government, and only two-thirds of the States have them. In addition to focusing on how variations in State Medicaid programs affect CARE Act services, this study was designed to assess the impact of State variability on the AIDS Drug Assistance Program (ADAP), the fastest growing part of the CARE Act.<sup>3</sup>

## Methodology

In approaching the study, investigators evaluated access to care in terms of purchasing power: how care for individuals with HIV/AIDS is financed. Specifically, they assessed whether: 1) differences in Medicaid benefits and eligibility criteria affect the range of services and eligibility criteria for CARE Act programs; and 2) States with more restrictive Medicaid eligibility criteria are more likely to have ADAPs with budget shortfalls and/or stricter eligibility and coverage criteria.

These two primary assumptions (or hypotheses) link generosity of State Medicaid programs with greater access to AIDS-related care. Based on these premises, States with relatively more generous Medicaid programs would be more likely to use CARE Act funds to provide important ancillary or "wrap-around" services\* that Medicaid generally does not cover, or use CARE Act funds to provide primary care to those ineligible for Medicaid. Conversely, States with less generous Medicaid programs are likely to serve fewer people with HIV than States

### Measures Used to Assess the Relationship Between Medicaid and CARE Act Funding

- ◆ Aspects of State Medicaid payments:
  - per capita pharmaceutical payments
  - per capita Medicaid payments for disabled adults (SSI)
  - per capita payments for all Medicaid recipients
- ◆ Per capita ADAP payments
- ◆ Scale to assess the generosity of Title II programs, including health care, case management, social support, ADAP, community-based care and insurance premium continuation

with more generous programs (even using both Medicaid and CARE Act funds), since CARE Act funds would be used to cover basic medical and support services in these States. In addition, States with more generous Medicaid eligibility criteria (e.g., higher income thresholds or medically needy programs) are less likely to use ADAPs to fill gaps in prescription drug coverage that will reduce demand for ADAP services and/or permit more generous ADAP eligibility criteria.

To explore the relationship between Medicaid and CARE Act funding, researchers analyzed available data for all 50 States and the District of Columbia\*\* and conducted case studies in four select States. This study did not include the territorial jurisdictions. From summary Medicaid administrative data, researchers focused on three aspects of State Medicaid payments: per-capita pharmaceutical payments; per-capita payments for disabled adults (a barometer of generosity of coverage for adults receiving SSI, the assistance category in which most adults with HIV are enrolled); and per-capita payments for all Medicaid recipients, including dependent children, indigent women with children, disabled adults, and the elderly. The most recent available payment data were for the year ending June 30, 1998.

Similar per-capita expense data were not available across or within CARE Act Titles. As an alternative, per-capita ADAP payment data were used from ADAP allocations for FY 1999.<sup>4</sup> Per-capita ADAP payments help gauge the generosity of overall State expenditures of CARE Act funds. To assess the generosity of a State's Title II program, researchers created a scale that considered the array of services that might be funded under Title II, including health care, case management, social support, ADAP, home and community-based care, and insurance premium continuation.

Case studies conducted in Massachusetts, North Carolina, Wisconsin, and Georgia provide important in-depth information from key stakeholders on Medicaid funding and access to AIDS-related care.

### Sites Selected

Georgia ♦ Massachusetts  
North Carolina ♦ Wisconsin

Researchers selected these States based on variations in the relative generosity of State Medicaid programs and access to CARE Act funds, including the availability of additional funding through a Title I EMA. At one end of the spectrum, for instance, Massachusetts ranks first among all States in spending per Medicaid beneficiary and eighth in spending for disabled adults on Medicaid; at the other end, Georgia ranks 47th in per-person Medicaid spending and 45th in spending for disabled adults on

Medicaid. Researchers interviewed Medicaid officials, State and local health department policy makers (Title I and II administrators), and providers serving Medicaid and/or CARE Act beneficiaries, and representatives of community-based AIDS service organizations. Researchers concentrated on Title I and Title II programs, but examined the full range of CARE Act funding streams and their impact on access to care.

## Limitations

Investigators noted several limitations in conducting the study:

- ♦ Assessing the full range of mechanisms that support care for people with HIV/AIDS requires more resources than were available for the current study;
- ♦ HIV-specific Medicaid data are generally unavailable at both national and State levels; what exists are essentially national actuarial estimates of overall Medicaid spending.<sup>\*\*\*</sup> Similarly, the analyses of CARE Act allocations are based on reviews of Title I and Title II applications, which do not reflect actual spending.
- ♦ Focusing on Medicaid generally limits the analysis to people with advanced HIV disease, since most people with HIV become eligible for Medicaid as a result of becoming disabled.
- ♦ The impact of Medicaid differences on CARE Act programs beyond ADAPs could not be assessed, because uniform data on income eligibility criteria were not available.

\* For the purposes of this study, these "wrap-around" services are defined as non-medical services that State Medicaid programs tend not to cover, such as comprehensive case management, social services, housing assistance, outreach and other support services.

\*\* For the rest of this paper, collective references to the States will include the District of Columbia. For Medicaid and CARE Act funds, DC functions as a State, running its own Medicaid program and receiving Title II funds. The District is also the grantee of Title I funds for the metropolitan Washington EMA.

\*\*\* HCFA estimated that the Federal government would spend \$2.1 billion on AIDS-related Medicaid costs in FY 1999. The State match for these funds is approximately \$1.743 billion, for a total of \$3.843 billion.

- ◆ The generosity scale greatly simplifies the funding decisions made by State Title II programs.
- ◆ The selection of States, while based on criteria related to their CARE Act status and Medicaid programs, is not necessarily a representative sample of Title I or Title II States.

## Major Findings

### ◆ Access to Medicaid services is at the core of access to primary care for poor people living with HIV/AIDS.

Throughout the country, people with HIV/AIDS rely deeply on Medicaid funding to ensure access to HIV-related care. CARE Act planning bodies should acknowledge the pivotal role of Medicaid in conducting needs assessments and setting priorities; however, this understanding is not adequately reflected in planning activities, regardless of the relative generosity of a State’s Medicaid program. Although the availability of “medically needy” programs with feasible eligibility thresholds can make a critical difference for people with HIV/AIDS, only two-thirds of the States currently have them.

### ◆ Significant differences exist in Medicaid eligibility criteria and in the way eligibility criteria are implemented.

While most States use 75 percent of the Federal Poverty Level (\$6,180) as the income eligibility threshold for disabled individuals applying for Medicaid, eight States have set lower levels; North Carolina has the lowest rate at 41 percent of the Federal Poverty Level (\$3,378). Even greater differences exist among the 34 States with medically needy programs: Here, income eligibility criteria ranges from \$1,895 per year in Tennessee (after deducting medical costs) to \$7,086 in California. And, although disability determination is the first step to Medicaid eligibility for many people with AIDS, there is tremendous variation in acceptance rates of SSI disability applications by State agencies.<sup>5</sup> Faced with constant denials for individuals who clearly meet the Federal SSI disability definition, one provider reported having to “shop” among local disability determination offices to find one willing to make the appropriate finding.

Regional variability is a concern for HIV service providers and people with HIV living in southeastern States. Although HIV appears to be increasing fastest in the Southeast, States in this region have the least generous Medicaid programs, ranking near the bottom of per capita spending for all Medicaid recipients and for disabled adults (table 2). They either lack medically needy programs (three of six) or have very restrictive ones (the remaining three States set eligibility at a very small proportion of the standard rate for those who are eligible). As a result, even if people with HIV are found to be eligible for Medicaid, the amount of funds available for provider reimbursement is likely to be inadequate to cover HIV-related care. Access to primary care will be more difficult for people living in the Southeast, and CARE Act and other public health programs are likely to shoulder a greater burden of care in these States.

**Generosity of Medicaid Programs  
Southeastern States**

TABLE 2

STATE	SSI-ELIGIBLE INCOME LEVEL*	MEDICALLY NEEDY INCOME LEVEL*	GENEROSITY RANK AMONG ALL STATES (SPENDING PER MEDICAID ELIGIBLE PERSON)	GENEROSITY RANK AMONG ALL STATES (SPENDING PER DISABLED ADULT)
Alabama	75%	no program	49	43
Florida	75%	28%	42	32
Georgia	75%	35%	45	47
Mississippi	75%	no program	50	50
North Carolina	41%	34%	36	33
South Carolina	75%	no program	39	35

\* Percent of Federal Poverty Level

### ◆ CARE Act funding is crucial to providing appropriate care for people living with HIV/AIDS.

Clearly, CARE Act funds help fill gaps in Medicaid coverage in all States, regardless of the generosity of Medicaid programs. CARE Act funds were seen as the glue that connects the continuum of care for people with HIV/AIDS. This perception was expressed most strongly by Title III and Title IV grantees.

### ◆ Spending CARE Act funds on “wrap-around” services makes a critically important contribution to people living with HIV/AIDS.

Wrap-around services—such as outreach, case management, and housing assistance—are often the essential first step in obtaining primary care services. Without these services, many people

with HIV are unwilling or unable to access primary care. Wrap-around services also play a critical role in promoting treatment adherence because primary care providers are unable to provide these services (and often would not be reimbursed by third party payers, including Medicaid, for providing them). Thus, patient adherence (including prevention of drug-resistant virus) depends on links to CARE Act-funded programs.

◆ **Developing a core set of benefits would help ensure comparability of services for people living with HIV/AIDS, nationwide.**

In developing a minimum core set of benefits, however, care should be taken to ensure inclusion of wrap-around services and the full continuum of care that HRSA and other Federal agencies have historically encouraged. This is especially important since wrap-around services contribute significantly to quality care, and promote effective and efficient use of primary care funds, including Medicaid-funded care.

◆ **States that impose non-income-related restrictions on ADAP access are most likely to have restrictive Medicaid eligibility criteria and/or a low generosity ranking.**

According to the National Alliance of State and Territorial AIDS Directors (NASTAD),<sup>6</sup> ADAP programs restrict access beyond income eligibility criteria by creating waiting lists, restricting protease inhibitor access in some way, or setting eligibility based on CD4 counts (mostly restricting access to those with counts below 500). These restrictions are generally due to budgetary constraints. In March 1999, nine States maintained active waiting lists for new enrollees; all of them either have no medically needy programs or very low income eligibility criteria. Seven of the nine States are in the bottom one-half of States ranked by Medicaid generosity, based on disability expenditures. Similarly, in the eight States that restrict access to protease inhibitors, there was either no medically needy program or one with extremely low income eligibility standards; six of the eight are in the bottom one-fifth of the Medicaid generosity scale.

◆ **Providers are able to build infrastructure (ensuring comprehensive and efficient services) when CARE Act funds are distributed on a grant basis rather than on a fee-for-service basis.**

This funding mechanism improves providers' ability to serve all clients, including Medicaid enrollees. When Title II funds were distributed on a fee-for-service basis, some informants felt that this reduced the CARE Act's role to a reimbursement mechanism, undermining its larger purpose of helping expand capacity to serve people with HIV/AIDS.

◆ **Significant barriers remain to treating Medicaid as the payer of first resort.**

While all informants acknowledged HRSA's policy that Medicaid serve as the payer of first resort, many cited barriers in attempting to comply. These include a clear financial disincentive since some Medicaid rates are lower than CARE Act reimbursements, and impose an administrative burden in filing Medicaid claims for relatively small amounts of money that could be covered by CARE Act funds.

◆ **Prioritizing Title II funds appears to be less formalized than the process undertaken by the Title I grantees.**

None of the Title II consortia grantees studied undergo an annual needs assessment or prioritization process mandated by Title I. One State had not changed its list of covered services under Title II since the CARE Act's inception, a source of concern to providers in that State.

◆ **Systematic interaction between Medicaid agencies and Title II program administrators is rare.**

Informants in most States surveyed felt that consultation was adequate, although some had stronger relationships than others. In only one State was outright suspicion reported between the two agencies. However, researchers found no ongoing programmatic relationships between Title II administrators in State health departments and Medicaid agencies.

◆ **The challenge of dealing with multiple funding streams for AIDS care is perceived as a benefit rather than a problem.**

Currently, program administrators are able to piece together a comprehensive set of services based on perceived needs—if one funder prohibits use of funds for a particular service, the program can generally find another funding source to cover it. Although being able to access funds through one funder rather than through multiple funding sources might simplify the process for providers, many were concerned that streamlining HIV financing might reduce this kind of flexibility in designing programs.

## Recommendations

Researchers were able to confirm their hypotheses, at least in part, demonstrating that: 1) variability in Medicaid programs affects the decisions of States and localities about allocating CARE Act resources, which affects the range of services provided by CARE Act funds; and 2) States with less generous Medicaid programs experienced ADAP shortfalls. Medically needy programs were also found to be a key variable in determining the relative generosity of a State's Medicaid program for people with HIV/AIDS. Because the Medicaid program is so central to building a continuum of care for people with AIDS—and because it is the starting point for determining how CARE Act funds are spent in a jurisdiction—it is critical to develop as generous a Medicaid program as possible in every State.

**I. Define a core set of benefits for people living with HIV/AIDS that includes care and support services that are considered essential to delivering a quality continuum of care.**

Developing a federally-defined core set of benefits for all CARE Act beneficiaries could improve the delivery process and assure a more consistent set of expectations around the nation. But this should only be done if the definition is sufficiently expansive and reflects the full continuum of care that HRSA has encouraged in the past, including comprehensive case management and adherence services, which are often essential to facilitating entry into care. These services are critical to achieving public health goals and to the cost-effective use of primary care resources.<sup>7</sup>

**II. Monitor trends in State and local management of Title I and II funds so that CARE Act dollars do not become part of a fee-for-service reimbursement system.**

The hallmark of the CARE Act has been its support for capacity-building by safety net and other community-based providers. The principal message from State program consultants is the need for a structure that promotes capacity-building. If CARE Act subcontractors are reimbursed on a fee-for-service basis, they will lose the flexibility to ensure the availability of dedicated, experienced providers for people with HIV/AIDS. This will reduce the quality of care and, ultimately, the efficiency and cost-effectiveness of care provided through both CARE Act and Medicaid dollars.

**III. Monitor more closely the requirement to treat Medicaid as the payer of first resort and evaluate ways to remove obstacles to seeking Medicaid reimbursement.**

HRSA and HCFA should work with the States to determine if the administrative burden of seeking reimbursement can be reduced. Given the specialized nature of the care rendered by CARE Act providers, HRSA might also consider permitting States to use CARE Act funds to supplement Medicaid reimbursements to experienced HIV providers. This can probably be achieved under current rules; however, States need more clarification of HRSA policies and technical assistance in implementing them.

**IV. Work with the Social Security Administration to address the apparent differences in eligibility determination rates experienced in States.**

Since Medicaid enrollment should be the core of an eligible person's HIV-related care, HRSA should work with the SSA to determine why variation exists and what steps can be taken to improve eligibility determination procedures. This could help stem the flow of CARE Act dollars being diverted to provide services for people who have been inappropriately denied Medicaid eligibility. HRSA should also consider creating a special demonstration program through the Special Projects of National Significance (SPNS) Program to assess how CARE Act grantees might help clients gain Medicaid eligibility.

**V. Require a more defined and regular process to ensure that Title I and II priority setting reflects the underlying Medicaid program.**

HRSA should require systematic inclusion of Medicaid officials in CARE Act planning and demonstration of ongoing efforts to coordinate policies and programs. It may also be appropriate for HRSA to ask HCFA to provide occasional guidance to States on the standard of care for HIV.

**VI. Offer States incentives to expand the generosity of their Medicaid programs.**

Although it may not be possible for HRSA or HCFA to provide incentives to States to make their overall Medicaid program more generous, it may be possible to provide incentives to fund care for Medicaid beneficiaries with HIV/AIDS. As part of the CARE Act reauthorization, legislative authority could be sought to permit States to use CARE Act savings to budget for Medicaid eligibility or programmatic expansions.

**VII. Work with HCFA, CDC, and State AIDS directors to address particular weaknesses in Medicaid programs throughout the country.**

While people with HIV/AIDS are affected in many States that have less generous Medicaid programs, southeastern States should receive special focus, given the high rate of new HIV infections in this region. These increasing rates of HIV infection are occurring in States that have relatively less generous Medicaid programs, relatively small Title II grants, and residents that on average are poorer than the rest of the country (with the exception of Florida). The current Title II formula does not take into account new HIV epidemics, only decades-old epidemics in first wave communities. HRSA might consider: 1) adjusting the funding formula to take into account spikes in incidence; 2) creating special capacity-building grants for States experiencing increased incidence; and 3) targeting Title III dollars to create primary care capacity in these jurisdictions.

**VIII. Consider a demonstration program to permit States and localities to integrate entitlement and discretionary dollars to support a comprehensive continuum of care.**

Integrating entitlement and discretionary funding streams may help overcome the problems associated with varying levels of eligibility, coverage, and reimbursement within a State (and possibly among the States). This would result in eligibility criteria that reflect the needs of people with HIV, rather than attempting to fit the needs of people with HIV into a larger, bureaucratic system. However, care must be taken to address issues of control in designing and implementing the demonstration program; in particular, maintaining the sense of inclusion felt by CARE Act grantees in decision making, in strong contrast to their feelings of exclusion from Medicaid decision making.

*References*

1. Office of the Actuary, Health Care Financing Administration, 1998.
2. Unpublished data from the Centers for Disease Control and Prevention's Supplement to HIV/AIDS (SHAS) Project; personal communication from A. Allyn, M.D., April 1998.
3. Another reason to focus on ADAP is that this is one program for which there are strong data regarding eligibility criteria as opposed to other parts of the CARE Act.
4. ADAP At-A-Glance: Summary Information for FY 1999. Division of Service Systems (DSS), Health Resources and Services Administration; personal communication, December 1999.
5. Letter from Ken Apfel, Commissioner of Social Security, to Rep. Henry A. Waxman, May 5, 1998.
6. NASTAD. National ADAP Monitoring Project: Annual Report. Washington, D.C.: National Alliance of State and Territorial AIDS Directors, March, 1999.
7. This continuum of core services has already been defined in the Sample Purchasing Specifications for HIV Infection, AIDS, and HIV-Related Conditions published by the Center for Health Services Research and Policy and developed in collaboration with HRSA and CDC (see [www.gwu.edu/~chsrp](http://www.gwu.edu/~chsrp)).

