



**EXAMINATION OF FISCAL MANAGEMENT
AND THE ALLOCATION OF
CARE ACT RESOURCES**



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CARE ACT RESOURCES**

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INTRODUCTION

Since its initial passage in 1990, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act has been critical in ensuring access to HIV care and treatment for hundreds of thousands of persons living with HIV/AIDS and their families. Today, the CARE Act remains a cornerstone of the Federal effort to fight HIV/AIDS and continues to provide a critical safety net for over 571,000 individuals affected by HIV/AIDS who are uninsured or underinsured each year.

With approximately 40,000 new HIV infections each year in the United States, but fewer AIDS deaths (as the result of remarkable new treatments), more people than ever are living with HIV/AIDS—more people who need the care and services funded by the CARE Act. Increasingly, these are historically underserved populations, including racial and ethnic minorities. Responding to these individuals and families, who depend on the CARE Act for essential health and support services, involves a number of challenges:

- + The ever-increasing cost of health care, particularly the cost of highly active antiretroviral therapy (HAART)
- + An increasing demand on the CARE Act as a primary source for long-term ambulatory and supportive care
- + Changes in the underlying health care financing system that surrounds CARE Act programs.

Each CARE Act reauthorization offers the U.S. Department of Health and Human Services an opportunity to assess how it can make the CARE Act even more effective at responding to changes in the epidemic and appropriately targeting resources. These policy studies attempt to improve our understanding of how the above challenges affect CARE Act programs and the people they serve.

The Health Resources and Services Administration's (HRSA) HIV/AIDS Bureau is responsible for implementing the CARE Act. It is in partial fulfillment of this responsibility that the monograph *Examination of Fiscal Management and the Allocation of CARE Act Resources* is published. The goals for the monograph are to expand on current knowledge; inform policy-related, administrative, and legislative decision making; and provide technical assistance to CARE Act grantees and providers that will enhance the quality and reach of their programs.

The monograph focuses on CARE Act spending. It identifies the services that major payers (such as Medicaid and Medicare) cover and describes who is eligible for those services. Geographic and funding factors that affect the shift in treatment patterns for HIV are also discussed. The ultimate goal is to ensure maximum return on CARE Act spending—and to ensure that CARE Act funds are used only when no other source of payment is available.

Three policy studies are included in this booklet:

1. Ryan White CARE Act Reauthorization 2005: Title I and Title II Health Services Expenditures Patterns
2. Examination of Key Fiscal Issues Related to Grantees of the Ryan White CARE Act
3. Assessing the Impact of the Ryan White CARE Act Title II Emerging Communities Formula Grant Program.

Findings and recommendations from these studies will help inform HRSA's administrative procedures, technical assistance, and training activities; improve service delivery; and enhance intergovernmental relationships between Federal agencies and among Federal, State, and local jurisdictions. 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 this monograph for their work.





STUDY 1

RYAN WHITE CARE ACT REAUTHORIZATION 2005: TITLE I
AND TITLE II HEALTH SERVICES EXPENDITURES PATTERNS

RUTH FINKELSTEIN

Purpose of the Study

To investigate whether the allocation of Ryan White Comprehensive AIDS Resources Emergency (CARE) Act funds for health care services by States and eligible metropolitan areas has changed through time and whether such allocations are responsive to differences in the HIV health care environments. The study hypothesized that Title I and Title II proportional expenditures on health care services would increase over time and that CARE Act Title I and Title II jurisdictions with better resourced HIV health care environments would spend proportionately less CARE Act money on health care services because those services would be covered by other payers. It also hypothesized that jurisdictions with poorly resourced HIV health care environments would spend more CARE Act money on health care services to make up for such deficiencies.

Background

One central tenet of the Ryan White CARE Act is that flexibility and decision making at the local level are essential to respond to variations in the needs, capacity, and resources in different jurisdictions. This local control and flexibility have been driven by the recognition that the existing services and resources available to care for people living with HIV/AIDS (PLWHA) are different in different places. Moreover, historically, much emphasis has been placed on the differing characteristics of HIV epidemics in different locations, which have been driven by different modes of transmission and effects on different populations. As medical treatments for HIV have improved, however, and as these “different” HIV epidemics have increasingly converged, it has become possible to define a continuum of care for PLWHA throughout the country. Local planning in Titles I and II (and grants through Titles III and IV) can be conceptualized to identify specific, unmet needs of PLWHA in the jurisdiction and existing resources and capacities to meet those needs and to prioritize CARE Act funds to fill identified gaps. Logically, therefore, a structured relationship should exist between the existing local HIV health care environment and the services funded through the CARE Act.

Allocation of Title I and II resources to fund health care services represents a critical opportunity to investigate the appropriateness of local planning decisions for a number of reasons. First, since the enactment of the CARE Act, and particularly since the advent of highly active antiretroviral therapy in 1996, both the effectiveness and the cost of HIV primary care have increased because consistent participation in HIV primary care enhances longevity and decreases morbidity and mortality.^{1,2,3} Local health care environments vary from State to State and even within States. For HIV care and services, this variation is driven principally by enormous variation in State Medicaid programs (including covered populations, covered services, and reimbursement structures and levels).⁴ Medicaid is estimated to cover 44 percent of people living with HIV and 55 percent of people living with AIDS (PLWA) nationwide.⁴ Second, local HIV health care environments vary by the availability of publicly funded HIV health care (based on the existence of public hospitals and community health centers) and existence and the quality of HIV care capacity as well as the access of PLWHA to private insurance. Thus, local jurisdictions differ in their capacity to provide HIV health care services and the quality, accessibility, and affordability of such services. This variation makes it possible to examine whether differences in local health care environments are related to different decisions about how to allocate Title I and Title II funds.



Despite its limitations, the study supports some general conclusions about trends in spending and how key features of the HIV health care environment relate to proportional spending of CARE Act funds on health care services.

Major Findings

Health Care Spending Trends

No significant changes were observed in the proportional spending of discretionary Title I and Title II funds on health care services from FY 2000 to FY 2002. Although the total money spent on health care increased, proportional health care expenditures did not increase as expected. This finding is consistent with and lengthens the trend line developed by Young et al. in their analysis of FY 1996 through FY 2000 expenditure data.⁵ Significant variation was found among jurisdictions in proportional health care services spending as well as, in some jurisdictions, temporal changes. When the ADAP earmark was included in the analysis, proportional health care spending did increase each year. However, this increase is driven by the earmark and Federal regulation of the CARE Act, not State and local decision making. Because the study focused on local and State discretionary spending, the ADAP earmark was excluded from subsequent analyses (except as a component of the health care environment). Although no trend emerged in health care services spending, systematic trends were found in specific service categories, particularly decreased spending on services associated with care for the acutely ill (e.g., home health care, hospice services). This finding, also consistent with those of Young et al., likely reflects the decline in prevalence of PLWHA with end-stage disease. Despite this minor trend, the big picture was revealed to be one of relative stasis in proportional spending.

Relationship Between the HIV Health Care Environment and Proportional Health Care Expenditures

The analysis sought to identify significant relationships between individual features in the health care financing environment (Medicaid, other insurance, other CARE Act titles, the adequacy of the ADAP program, and other major Federal programs providing health care to PLWHA) and health care services expenditures in FY 2002. Basic demographic variables (percentage of population living in poverty and number of PLWA) were included to roughly characterize the HIV epidemic in each jurisdiction. All of these variables were then used to create a composite typology that characterized jurisdictions as having a high, medium, or low HIV health care financing environment. The study also explored the relationship between these types and CARE Act health care service expenditures.

Analysis of the relationship between individual variables in the health care environment and CARE Act health care expenditures yielded few relationships. For Title I, no significant relationships were detected between any characteristics of the health care environment and health care expenditures. For Title II, relationships were found in the expected direction for two characteristics. States that had higher income thresholds for people to qualify for their Medicaid medically needy program and States that had no medically needy program spent more Title II money on health care services than did States with a lower threshold for eligibility for medically needy programs. In addition, States that had a higher number of special Medicaid programs for PLWHA had lower proportional Title II spending on health care services than did States with few or no special programs.

As Table 1 illustrates, when jurisdictions are classified into broad types of health care environments, a full distribution of CARE Act health care spending may be found within each type. The typologies further



Table 1. Health Care Service Environment and Proportion of Award Spent in Health Care Service Allocations

Health Care Environment Score		Title II		Title I
Low	Oregon	14.2	Portland, OR	24.4
	Nebraska	16.3	Las Vegas, NV	36.7
	Hawaii	29.0	St. Louis, MO	38.0
	Arkansas	31.3	Kansas City, MO	38.6
	Vermont	37.7	West Palm Beach, FL	39.9
	Alaska	38.7	New Orleans, LA	40.1
	Kansas	39.0	Fort Worth–Arlington, TX	42.2
	Texas	40.6	Norfolk, VA	54.4
	Colorado	42.3	Austin, TX	54.5
	South Carolina	46.5	San Antonio, TX	59.3
	Kentucky	46.7	Denver, CO	68.7
	Montana	49.7		
	Idaho	54.0		
	Alabama	54.4		
	New Mexico	71.4		
	Wyoming	78.5		
	Indiana	85.0		
	Nevada	87.5		
Medium	Maine	00.1	Minneapolis–St. Paul, MN	8.6
	Washington	19.5	Vineland–Millville–Bridgeton, NJ	24.6
	Missouri	30.1	Sacramento, CA	34.2
	Wisconsin	35.0	Seattle, WA	35.2
	Iowa	38.0	Hartford, CT	36.4
	North Carolina	39.9	Jersey City, NJ	38.1
	Rhode Island	44.2	Orange Co., CA	39.5
	Utah	47.2	Phoenix, AZ	40.3
	North Dakota	47.4	Riverside–San Bernardino, CA	48.2
	Delaware	51.9	Middlesex–Somerset–Hunterdon, NJ	51.0
	Louisiana	55.5	Jacksonville, FL	51.9
	Virginia	55.5	San Jose, CA	53.1
	Arizona	63.7	Orlando, FL	56.0
	New Hampshire	67.6	Houston, TX	57.8
	Tennessee	72.1	Cleveland–Lorain–Elvira, OH	58.7
	Oklahoma	76.9	Dallas, TX	62.7
	Mississippi	88.7	Fort Lauderdale, FL	63.3
			Tampa–St. Petersburg, FL	68.8
High	Massachusetts	16.5	Oakland, CA	23.4
	Pennsylvania	16.7	Boston, MA	24.5
	Connecticut	26.9	San Diego, CA	29.0
	District of Columbia	37.6	Detroit, MI	31.5
	Florida	50.7	Philadelphia, PA	36.0
	Illinois	51.2	Newark, NJ	41.1
	New York	52.4	New Haven, CT	42.9
	Minnesota	58.6	Baltimore, MD	44.5
	Michigan	62.3	Washington, DC	46.1
	Ohio	66.3	Santa Rosa–Petaluma, CA	47.7
	Maryland	69.3	Chicago, IL	52.3
	California	73.0	Nassau–Suffolk, NY	52.3
	New Jersey	74.2	San Francisco, CA	52.7
	Georgia	80.3	New York, NY	54.6
			Bergen–Passaic, NJ	56.7
			Dutchess County, NY	58.3
			Miami, FL	62.9
			Los Angeles, CA	67.3
		Atlanta, GA	74.4	



demonstrate the absence of a structured or predictable relationship between local health care financing environments and the proportion of Title I and Title II funds expended on health care services. The case studies did, however, reveal instances of spending that were responsive to the health care environment but were not detected by the statistical analysis. For example, several jurisdictions used carryover funds to address shortfalls in other funding, such as ADAP or coverage for a specific test disallowed by Medicaid.

Table 1 shows clearly that in each health care environment—high, medium, and low—discretionary expenditures on health care services vary dramatically, from lows of under 20 percent of the award to highs of more than 80 percent in Title II programs and from less than 25 percent to more than 65 percent in Title I programs. Table 2 confirms that no trend or pattern toward a relationship exists between proportional health care spending and the adequacy of the health care financing environment. The slight nonsignificant trend suggested goes in the wrong direction for both Title I and II—that is, the more resources in the health care environment, the greater the proportional spending on health care services from Titles I and II.

Table 2. Health Care Service Allocations by Health Care Environment Typology Score

	Title I			F	p
	Low	Medium	High		
N	11	18	19	0.082	ns
Mean	45.2	46.0	47.6		
Standard Deviation	12.6	15.2	14.1		

	Title II			F	p
	N	18	17		
Mean	47.9	49.0	53.7		
Standard Deviation	21.2	21.8	19.9		

ns=not significant.

Recommendations

Policy Implications and Options

Resource allocations for Title I and, to a lesser extent, Title II are relatively impervious to local health care financing conditions.

Possible Policy Options

- + Reduce the local planning and resource allocation functions in Title I or in Titles I and II of the CARE Act. Such action would require legislative change.
- + Continue to support local planning but establish more comprehensive guidance about how it should be accomplished.
- + Continue local planning but legislatively require a hierarchy of allocations to ensure the prioritization of health care services.





STUDY2

EXAMINATION OF KEY FISCAL ISSUES RELATED
TO GRANTEES OF THE RYAN WHITE CARE ACT

JULIA HIDALGO AND WENDY WARCOLIK-MOODY

Purpose of the Study

The HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA) contracted with Positive Outcomes, Inc. (POI) to (1) closely examine three legislatively mandated requirements of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act to provide HRSA with a clearer understanding of congressional intent to share HIV costs with grantees and the primary payers of HIV-infected persons' care, including State, municipal, and other payers; and (2) provide HAB with a better understanding of whether and how these mandated requirements are being met by grantees during times of change in health care financing and during an economic downturn. The three fiscal requirements are maintenance of effort (MOE), matching funds, and payer of last resort (PLR).

Background

State and Local Funding Crisis

In recent years, the Ryan White CARE Act has operated in a highly dynamic, constrained financing environment. At the Federal level, HAB has experienced flattening in Congressional appropriations except for funds allocated to AIDS Drug Assistance Programs (ADAPs). At the same time, State and local taxes as a percentage of gross domestic product are at their lowest levels since the late 1980s. State, county, and local governments throughout the United States report significant fiscal crises. The National Association of State Budget Officers reports that beginning in fiscal year (FY) 2001, States experienced the worst budgetary situation in 60 years.¹ From FY 2001, State revenues declined for eight consecutive quarters, with slight recent growth among some States. The decline of personal income tax and other State revenue sources contributed to the fiscal crisis. Although revenue appears to be improving among some States, other States project large budget shortfalls in FY 2005 because of decreased tax revenue. In 30 States with shortfalls, deficits range from \$39 billion to \$41 billion or about 7 percent to 8 percent of State expenditures. Current deficits were offset by one-time-only Federal Medicaid funds to help State governments cover sharply rising Medicaid expenditures. Although State tax revenue is projected to increase for some States, rising Medicaid expenditures are likely to continue to result in budget shortfalls without additional Federal funding intervention.

Although some States have raised taxes to offset their deficits, the principal solution taken by States has been to cut spending. Real per capita State spending dropped by \$56.9 billion (5 percent) between 2001 and 2004. States have taken several approaches simultaneously. Many States have reduced spending through across-the-board cuts of all State programs. Other spending cuts have come in the form of elimination or significant reduction of funding for specific programs. Public health programs, including HIV/AIDS prevention, surveillance, and treatment, have experienced significant reductions in State funding. Most States also have reduced spending through one-time-only savings: layoffs, cutting vacancies, and reducing services. One-time-only savings help initially to reduce deficits, but they do not yield long-term solutions to insufficient revenue.

Medicaid programs, the fastest growing component of State budgets, have attempted to slow growth in expenditures by reducing the number of new and ongoing beneficiaries, eliminating optional benefits, or reducing payments to providers. Many Medicaid programs have narrowed eligibility criteria, eliminated programs, reduced benefits, lowered payments to providers, capped utilization, added or increased beneficiary cost-sharing, and expanded mandatory managed care enrollment. To reduce rapid growth in pharmaceutical expenditures, Medicaid programs have eliminated drugs from their formularies, capped the number of refills



Project Goals

1. Examine three legislatively mandated requirements to provide HRSA with a clearer understanding of congressional intent to share HIV costs with grantees and primary payers of HIV-infected persons' care.
 2. Provide HAB with a better understanding of whether and how these mandated requirements are being met by grantees during times of change in health care financing and during an economic downturn.
-

Case Study Sites

New York, NY
Newark, NJ
Boston, MA
Cleveland–Loraine–Elvira, OH
Austin, TX
San Francisco–CA/San Jose, CA (Santa Clara County)

Methodology

Qualitative case study methods were used to undertake an in-depth analysis of the impact of the three fiscal requirements on HIV-infected persons, their care, and the finance and delivery systems that undertake that care. Case study methods were used to identify and assess the contextual issues related to direct care, policies, and programmatic issues. These activities were conducted in 2003 and 2004.

Several approaches were undertaken, involving six steps:

1. A structured script was used to guide focus groups of approximately 70 Title I and II grantees at grantee meetings convened in July and August 2003.
2. An electronic mail solicitation requesting comments regarding the three fiscal requirements was transmitted to all CARE Act grantees.
3. Interviews were conducted with HAB staff responsible for the management of the titles of the CARE Act and the DRP.
4. Telephone interviews were conducted with State ADAP staff regarding supplemental ADAP funding.
5. Intensive case studies were conducted in six communities.
6. Interviews were conducted with representatives of the Department of Veteran Affairs (VA) and the U.S. Department of Housing and Urban Development.

The various routes available for CARE Act grantees to participate in the study made it difficult to compute a response rate among grantees or subgrantees or clearly define the denominator. As a result POI did not estimate the percentage of grantees or subgrantees that provided specific feedback.



- + TPR data were obtained for the case study communities. A summary of the Medicaid State Plan was obtained from HRSA to identify which services are covered in the Medicaid fee-for-service program and managed care contracts. Information was also obtained from State-funded health insurance pools, hospital tax districts, county or local medical indigent pools, or other publicly funded programs.
- + An Internet search of major local newspapers published in the communities of interest was conducted to identify current or recent crises in public financing.
- + A structured interview instrument was used to conduct onsite or telephone interviews.

Limitations

Several limitations hampered this study:

- + The State and local financing environments in which the CARE Act operates were highly volatile during the study period. While the funding of public financing systems stabilized in some communities, in others the economic environment continued to worsen. The absence of a nationwide State and local public financing monitoring system made it difficult to monitor closely the impact of the State and local financing system on CARE Act-funded systems.
- + No “real time” data were available to monitor the extent to which CARE Act grantees were able to adhere to match and MOE requirements. Because grantees reported on expenditures that occurred 2 years previously, a grantee might not meet the match and MOE requirements in the most recent “reporting year” but may have subsequently met its match and MOE requirements.
- + Enforcement of the PLR policies by CARE Act grantees and subgrantees is complex. Numerous third-party payers fund services for people who are HIV infected. Their eligibility requirements and covered benefits vary significantly, and rapidly shifting program modifications took place during the study period. State Medicaid programs greatly modified their eligibility, covered benefits, and payment policies, and HAB and the VA drafted a policy regarding the coverage of veterans by CARE Act grantees and subgrantees.
- + Some grantees and subgrantees were reluctant to be interviewed because they were concerned about disclosing their inability to comply with certain HAB policies or considered the policies to be an impediment to meeting the needs of HIV-infected people in their communities. To address the concerns of grantees and subgrantees, POI agreed not to disclose the names of the States or communities in which they worked. This accommodation precluded POI from providing specific examples of policies and practices that might be of interest to readers of this report.



The CARE Act includes no provision for HAB to waive the match requirement for States unable to meet their matches. The penalty made available by Congress to enforce the match requirement is reducing the grantee's award. In focus groups conducted by POI, some Title II grantees expressed concern that if the match requirement is not enforced, it will be difficult in the future to convince policy makers that the match requirement must be met. They expressed concern that a lack of enforcement of the match requirement may be seen by State officials as an opportunity to cut additional HIV funds, as they might believe no negative impacts would result.

Policy Options

HAB might consider several policy options related to the Title II match requirements.

Retain the Title II match requirement as it currently exists in the CARE Act.

Likely impact: Some grantees likely would be unable to meet their match requirement. The only option currently available for enforcement of the match requirement is to reduce the Federal grant award. States might be given an opportunity to revisit their match submissions, recompute their matches, and resubmit their match figures. Some States considering a cut to State-funded HIV services might be more likely not to cut HIV funds if active enforcement is undertaken by HAB. Other States may be so significantly in deficit that the threat of the loss of Federal HIV funds is not sufficient to outweigh their need to balance their budgets or fund other programs perceived as being more critical. Among States that must revisit their submitted match expenditures, some delay in grant award would occur, leading to delayed initiation of contracts with subgrantees and periods in which services were unfunded or suspended.

Eliminate the Title II match requirement as it currently exists in the CARE Act. Title II grantees would no longer be required to document and submit match data to HAB.

Likely impact: State funds for HIV programs including prevention and surveillance likely would be cut in States that have avoided cuts because of the match requirement. Some grantees reported that this option would lead to significant reduction in HIV funds not only at the State level but also among local governments that contribute to the match. Moreover, once these funds were eliminated, it is unlikely that they would be restored in future periods of prosperity without significant grassroots advocacy. HIV service programs would likely be significantly destabilized, if not eliminated entirely. Clinical, medication, case management, and other essential services would be eliminated, resulting in significant increases in morbidity and mortality among HIV-infected people and, perhaps, resulting in a rise in resistant virus among those who do not receive treatment for HIV disease.

A change in Title II of the CARE Act would establish a waiver program to be administered by HAB. Grantees would submit a waiver application to HAB stating the rationale for the waiver and the plan to restore State and other funds in a proposed future grant year. Grantees would also have to demonstrate that the State or territory was not petitioning for a waiver in an effort to supplant State funds with Federal funds.

Likely impact: Most States or territories experiencing fiscal crises or wishing to reduce HIV-related spending for other reasons likely would submit a waiver. It would be difficult for a grantee to reasonably assure HAB that HIV funds would be restored, particularly if the funds cut were outside the direct control of the HIV program or department in which it is located. In addition, it might be unrealistic to expect the commitment made in the waiver to be considered binding if changes in State or territorial



Among State Title II grantees, the reported MOE amounts vary greatly (from \$50,000 to \$37 million). Three Title II grantees did not report an MOE. Many of the State Title II grantees that reported difficulty in sustaining their matches also reported having trouble sustaining their MOE. The exceptions were those States that initially reported low MOE in their first Title II grant application and did not significantly increase their MOE subsequently. Eight Title II grantees did not meet their MOE in their initial FY 2003 Title II applications, although several were able to restore their MOE in subsequent submissions to HAB.

Among Title I grantees, the MOE varies greatly (from \$1,000 to \$91 million); four grantees reported no MOE amount. Title I grantees reported using a process to determine the MOE that is similar to the mechanism used by Title II grantees in quantifying their MOE.

Many Title I grantees reported having difficulty in meeting their MOE. Many Title I grantee staff that POI interviewed reported that county and city governments were experiencing substantial deficits as a result of inadequate tax revenue, decreased Federal and State funding, and outlays for public safety related to homeland security. Many of the agencies contributing to Title I MOE, including hospital tax districts, also were reported to be experiencing deficits. Seven Title I grantees did not meet their MOE in their FY 2003 applications but did meet the requirements in their FY 2004 grant applications. Several additional Title I grantees reported that they would be unable to meet their MOE requirements in their FY 2005 Title I grant applications.

Because of growing deficits at the local government level, several grantees reported that agencies and jurisdictions contributing to the MOE effort had cost-shifted to reduce their deficits. Their MOE level appears to be sustained; however, the estimated figure includes costs for personnel that do not provide management, administrative, or direct services related to HIV programs. Such cost-shifting has been identified and discontinued in some but not all cases.

Some Title I and II grantees expressed concern that the MOE requirement is not an equal burden. In the current fiscal environment, grantees that have not contributed an MOE are unlikely to do so without a statutory requirement. Grantees with relatively high MOE levels reported that they are bound to expenditure levels that are difficult or impossible to sustain.

The CARE Act Title I and II MOE requirement was not accompanied by an enforcement mechanism. Therefore, HAB staff cannot directly penalize grantees that fail to meet their MOE requirement. HAB project officers do, however, contact grantees that fail to meet their MOE to determine the barriers to meeting the requirement. They advise them regarding possible funding streams that might be used to make up the shortfalls in reporting MOE figures.

MOE submissions are retrospective: Title I and II grantees report on expenditures that occurred 2 years previously. HAB staff reported that the retrospective nature of MOE reporting makes enforcing the requirement difficult. Moreover, the documentation provided regarding the sources of funds making up the MOE is limited and difficult to audit and evaluate. In reviewing the MOE documentation provided by Title II grantees, it appeared that some grantees have maintained their effort through supplanting of Federal funds. In turn, Title I submissions appear to document supplanting of Title I funds with State and CARE Act funds, including funds obtained through Titles II and III.



control of the HIV program or department in which it is located. In addition, it might be unrealistic to expect the commitment made in the waiver to be considered binding if changes in government leadership occurred as a result of elections or other factors. Additionally, pressure likely would be put on the grantee to request a waiver of non-Federal sources of expenditures to help other governmental units address their own fiscal shortfalls. Waived expenditures likely would result in significant losses of revenue by subgrantees, possibly compromising their ability to sustain their capacity and organizational solvency.

Require a greater level of documentation regarding the sources and nature of funds used to make up the MOE.

Likely impact: Grantees reported a high level of frustration with HAB reporting requirements and other administrative activities that they perceive as being unfunded mandates. Additional documentation, however, should require only a slight modification to the MOE documentation now required. Most grantees should have sufficiently detailed information readily available to them to meet expanded documentation requirements. In requesting additional documentation, HAB would be much more likely to identify and deter efforts to supplant State or local funds with Federal funds.

Retain the MOE requirement and expand it to include Title III, Title IV, and the DRP CARE Act policies on shifting costs to the Federal government should be consistent throughout the CARE Act. Documentation regarding MOE should be requested consistently by each HAB title or program to ensure that the sources and nature of the funds used for the MOE are documented and that supplanting of funds can be readily identified.

Likely impact: Grantees that are not currently required to report MOE data would likely be concerned about the additional reporting and other administrative activities needed to meet the new requirement. Although some additional data would be needed to meet the reporting requirement, the reporting burden would likely be minimal. Documentation would afford HAB staff the ability to identify and deter efforts to supplant State or local funds with Federal funds.

Consider changes to the match and MOE requirements simultaneously.

Likely impact: Any change to MOE must be considered in light of its impact on the Title II match requirement. Because many States use the match funds as part of their MOE, any effort to eliminate or modify the MOE requirement would also significantly influence the Title II match requirement.

Payer of Last Resort

The PLR requirement was introduced in the initial authorization of the CARE Act and is found in Parts A, B, C, and F of the act. Implementation of this requirement has been addressed primarily in grant guidance and in additional instructions disseminated in December 2002 to CARE Act grantees.⁶ No specific enforcement mechanism is outlined in the CARE Act.

The PLR requirement was outlined in the December 2002 letter to CARE Act grantees from the HAB Associate Administrator. The letter covers HAB policies regarding billing to third-party payers and other sources, cost of billing third-party payers, retrospective billing for incurred costs, case management payments, use of TPR to support subgrantee programs, crediting of subgrantee budgets for TPR by subgrantees and retention of those revenues, use of TPR by subgrantees, Medicaid provider status, Medicaid professional credentialing requirements, allowable costs associated with development of billing capacity and credentialing of staff, and application of a sliding fee scale. In focus groups, numerous interviews, and electronic mail



applied in the manner outlined by Congress in the CARE Act. A small portion of HIV programs in agencies with mandatory sliding fee scales (e.g., federally qualified health centers, hospital tax districts, county health systems) did apply sliding fee scales, but the scales applied might vary from those specified by the CARE Act. Facilities commonly request out-of-pocket payments, collect the payments, and assign a patient to collections if he or she does not make the out-of-pocket payments on a timely basis. CARE Act grantees and subgrantees reported that some agencies with mandatory sliding fee scales have aggressive collection processes that often require intervention by case managers or legal aid attorneys.

In other community-based and CARE Act–funded agencies without a culture in which sliding fee scales are applied, the CARE Act sliding fee scale requirement was reported to be impractical and not used. No single point of eligibility determination or accounting for out-of-pocket payments is available to determine when the maximum amount is reached. Clients were reported to be unable to maintain the records necessary to document their out-of-pocket payments. Reception personnel were reported to feel uncomfortable asking for out-of-pocket payments, particularly from unemployed patients without health insurance.

Some CARE Act–funded grantees and subgrantees reported that they are structurally unable to collect out-of-pocket cash payments from clients. Their agencies’ policies prohibit them from handling cash, some reception staff have criminal records or are located at unsecured desks, or they have no secure means of transporting cash to the bank. HIV programs in large institutions reported that although their agencies can accept credit card payments, their accounting systems do not specifically track out-of-pocket payments made by their clients, and the funds are not returned to their budgets as grant income. These barriers are encountered in small and large institutions.

Several HIV programs have assessed the cost of implementing the CARE Act sliding fee scale policy. They reported that the additional costs associated with ensuring the physical security of employees handling cash, safe transport of cash to the bank, staff training, and accounting charges far outweigh the income projected to be generated by applying the sliding fee scale.

The CARE Act stresses that care should not be withheld from clients who do not have the means to pay their copayments based on the sliding fee scale. Several grantees and subgrantees interviewed by POI staff reported that some clients refuse to pay their copayments because they are aware that they cannot be refused services.

The CARE Act includes no enforcement mechanism to ensure application of the sliding fee scale policy. FSRs cannot be used to accurately estimate the amount of grant income that should have been generated by out-of-pocket payments resulting from the sliding fee scale. In addition, it is difficult to differentiate grant income generated by the sliding fee scale versus the cost-sharing mechanism of third-party payers (e.g., copayments and deductibles). Grantees and subgrantees do not submit data to HAB that would allow accurate calculation of the amount of grant income that should be generated. Similarly, it is difficult for grantees to assess whether their subgrantees are collecting sufficient out-of-pocket payments from eligible clients.



Eligibility Determination, Coordination of Benefits and Participation in Third-Party Reimbursement: Background

HAB's policies regarding eligibility determination and participation in TPR systems were outlined initially in an August 10, 2000, policy letter. A subsequent letter from the HAB Associate Administrator outlined HAB's policies in a question-and-answer format. Enforcement by HAB of these requirements is primarily through response to grant guidance. Review of grant income in FSRs and CADR data collected by HAB staff may also be used to assess whether grantees and subgrantees are adhering to these requirements. These data are insufficient to estimate the extent of TPR revenue that might be expected if grantees or subgrantees adhered to these requirements. Moreover, substantial variability exists between and among health care markets in health insurance enrollment among CARE Act clients, covered benefits, and payment levels. In Titles III and IV, periodic site visits by HAB staff and consultants assess TPR and other fiscal issues. These visits, however, are commonly spaced over several years and some grantees and subgrantees may not be visited very frequently. HAB staff may therefore be unable to assess the extent to which TPR policies are implemented.

Eligibility Determination

Policy: CARE Act grantees and providers should facilitate their clients' enrollment in other TPR programs for which they may be eligible for benefits. To facilitate client enrollment, CARE Act-funded agencies should provide information about enrollment options and referral for eligibility determination.

Findings

Many CARE Act grantees and subgrantees reported that there commonly is no single point of eligibility determination information and assistance for their clients. Rather, clients and their case managers or other advocates must seek information from myriad agencies, many of which change their eligibility criteria on an annual or more frequent basis. Criteria for enrollment are highly variable and include such requirements as geographic residency; U.S. citizenship; legal residency status; age [e.g., Temporary Assistance to Needy Families (TANF); Medicare]; tribal membership (e.g., Indian Health Service); race/ethnicity (Minority AIDS Initiative); family composition (e.g., TANF); veteran status; previous financial contributions by the client [e.g., Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI)]; employment status and employer insurance purchasing arrangements (for employer-based insurance plans); preexisting medical conditions, disability, and employability (e.g., SSI); income; assets; HIV serostatus; CD4 count; annual or lifetime utilization of benefits; and criminal convictions. The application materials required for enrollment are not always readily available and often require a reading level beyond the client's capability.

Few CARE Act grantees reported establishing multiagency processes to ensure that all new clients enrolled in CARE Act services are uniformly and accurately screened for eligibility for public and commercial health insurance, income maintenance, and entitlement programs. None of the grantees interviewed has systematically identified key sources of eligibility determination and TPR in its community and communicated the contact information to its subgrantees. Rather, staff of CARE Act direct service grantees and subgrantees have established their own processes for screening, information gathering and referral, and helping clients gain eligibility. In discussing the processes used to screen and refer clients, CARE Act grantee and subgrantee staff reported that highly variable effort is made to assist clients. Some agencies act as advocates for their clients in their efforts to enroll in non-CARE Act programs. Among other agencies, program staff might suggest that a client seek enrollment in a program but provide little information about how to undertake an application.



State ADAPs eligible for supplemental funds and those with waiting lists were interviewed by POI staff. Most State ADAP staff reported that they rely heavily on community-based case managers to screen clients for eligibility for ADAP, Medicaid, and other programs. Few of the State ADAPs conduct routine training with community-based case managers regarding ADAP. ADAP staff also reported that they did not routinely communicate with community-based case managers to ensure that consistent, accurate, and timely screening, referral, and application preparation was taking place for enrollment in public or commercial health insurance or income maintenance programs.

Several case study participants observed that the number of HIV-infected, employed people seeking CARE Act services has increased because many employers no longer can purchase affordable health insurance for their employees. They also report that many employers are hiring employees who are not eligible for health insurance benefits. At the same time, some commercially insured people seek CARE Act services to avoid disclosure of their HIV serostatus to their employer-based health insurance plans.

CARE Act grantees and subgrantees throughout the United States expressed considerable confusion regarding application of PLR among veterans. As a result, some State ADAPs, CARE Act grantees, and subgrantees have denied CARE Act services to veterans. To clarify its position regarding veterans, HAB recently released a policy designed to clarify the HAB's expectation that veterans should be able to access CARE Act programs.⁷ As with the coordination of benefits with third-party payers, it is likely that case managers and other staff of CARE Act grantees and subgrantees will have insufficient knowledge of the VA system to provide well-grounded information and referral. The responsibility for HIV-infected veteran information and referral services may be viewed by CARE Act grantees as an unfunded mandate for which they have insufficient resources and expertise.

Many CARE Act grantees reported that gaining enrollment in publicly funded disability programs, including SSI, is very difficult. The Social Security Administration (SSA) delegates the evaluation and processing of disability claims to States. State-by-state SSI denials by States for HIV-infected applicants are not made available by SSA. Based on POI's case study interviews, however, the processing time and denial rates for SSI applications vary considerably. Numerous case managers, patient advocates, and legal aid staff reported that initial denial of SSI claims is common, and substantial legal intervention is required to contest claims. Several HIV care providers reported that State disability staff reported that clients may not submit a claim more often than once a year, an inaccurate interpretation of SSA policy. Denials for applications are often a result of what SSI determination personnel deem to be insufficient medical documentation of inability to sustain gainful employment due to disability and a sufficient level and duration of disability.

SSDI eligibility is triggered in part by documentation of a disability lasting in excess of 12 months, so documentation of the onset of disability in SSI applications is important. Despite the critical pathway to Medicaid and Medicare coverage and income maintenance that SSI afford, few ADAP or other CARE Act grantees reported that they have collaborated with State disability or SSA staff to increase the number of accepted SSI claims. At the Federal level, HAB staff reported that they have not collaborated with SSA to improve the award rates of SSI claims among HIV-infected people.

CARE Act grantees and subgrantees reported that many of their clients have benefited clinically from anti-retrovirals and some clients are now able to return to employment. Many of those clients are reluctant to do so, however, because they do not want to lose their Medicaid or Medicare coverage.



Policy: Once a CARE Act client has been determined to be eligible for Medicaid enrollment, the grantee or subgrantee must bill Medicaid for any services rendered as of the client's effective date of Medicaid enrollment.

Findings

CARE Act grantees without access to the Medicaid EVS reported that they sometimes are not aware of the outcomes of their clients' applications to Medicaid. Clients are reported to sometimes be confused about the differences between Medicaid and CARE Act-funded services. As a result, clients do not make their CARE Act-funded HIV providers aware of changes in their insurance status.

Third-Party Reimbursement

Policy: If a CARE Act-funded agency does not provide a service covered by its State Medicaid program, there is no expectation that the grantee or subgrantee obtain a Medicaid provider number.

Finding

Several State Medicaid programs have placed a moratorium on issuance of additional provider numbers. Moratoriums are common for mental health and substance abuse provider numbers.

Policy: CARE Act funds may be used to pay for the costs of preparing to become certified as Medicaid providers. HAB considers this use of CARE Act funds to be an allowable cost for CARE Act grantees and subgrantees. CARE Act capacity development funds may be used for this purpose.

Findings

Several grantees and subgrantees interviewed by POI staff for the case studies reported that the costs incurred to become certified as Medicaid providers can be substantial. The agency and its staff must meet State licensing standards (as well as licensing requirements in county and city jurisdictions, in some cases). Other requirements include availability of telephone coverage on a 24-hour basis; numerous regulations; billing, accounting, and reporting systems that must be established or upgraded; malpractice and other liability insurance that must be obtained; quality assurance processes that must be put in place; capacity to enroll a defined number of clients that must be ensured; and Health Insurance Portability and Accountability Act and other electronic data transmission requirements that must be met. Several mental health and substance abuse programs interviewed, for example, would have had to terminate their line staff and supervisors to meet Medicaid credentialing requirements.

With flat or reduced CARE Act funding available for most grantees, many Planning Councils and consortia are unable to commit sufficient capacity development funds to assist subgrantees in becoming Medicaid providers. Among grantees allocating funds for this purpose, the amount of funding available has been insufficient to cover the costs required.

Policy: If an agency receives CARE Act funds for services that are eligible for TPR and grant funds, the agency must have a system in place to bill and collect from third-party payers.

Findings

Some grantees and subgrantees reported being confused as to what services are eligible for TPR from Medicaid or other third parties. Medicaid, Medicare, other publicly funded payers, and commercial payers



Despite HAB's funding of TA and tool development, most of the CARE Act direct service grantees and subgrantees interviewed by POI were unaware of the actual cost of their services. Several grantees and subgrantees reported that they cannot access detailed overhead and related cost data from their institutions or that their accounting systems were not sufficiently flexible to report costs specific to their HIV program. As a result, grantees and subgrantees were unable to apply the tools developed by HAB.

Policy: CARE Act grantees and subgrantees are expected to bill third-party payers what it costs them to provide a particular service.

Findings

HAB expects that CARE Act grantees and subgrantees treat payment from third-party payers as payment in full. This policy has resulted in considerable concern among many of the HIV clinical providers interviewed by POI. Grantees and subgrantees in agencies ranging from large teaching hospitals to small, community-based organizations reported that TPR falls far short of their costs.

Most of the HIV medical providers interviewed report that they routinely perform services in medical visits for insured patients that are not compensated by third-party payers. While an insurer may pay for a 15-minute medical examination, for example, the typical medical examination may take 30 to 60 minutes. Moreover, some medical services are outside the scope of their CARE Act contracts. Such services include medication education, adherence counseling, and secondary prevention counseling. Medical providers report that TPR falls far short in covering the expense of the medical visits as well as the complexity of the services provided.

Care Act–funded medical providers in case study communities reported that a new patient visit might well exceed 60 to 80 minutes, but third-party payers may pay only for a 30-minute visit. Third-party payers tend to pay clinical grantees and subgrantees at levels that are inadequate to compensate for highly intensive medical visits.

There was a lack of awareness among many CARE Act grantees and subgrantees paid by third-party payers that if a payer caps services, they might use CARE Act funds to purchase additional units of service. Examples of these capped services include home health visits and home hospice visits.

Most of the CARE Act–funded HIV clinics that attempted to adhere to TPR payment-in-full policies reported that their costs far exceeded their TPR revenue. Until recently, these clinics had benefited from considerable institutional support to make up the difference. As more institutions have experienced multidepartmental revenue losses, however, HIV clinics reported that institutional support has been cut or eliminated.

Many CARE Act–funded agencies interviewed by POI reported that TPR failed to keep pace with sharply rising costs, such as increasing salaries and fringe benefits. Similarly, throughout U.S. urban health care markets, collective bargaining and personnel shortages resulted in significant increases in nursing and ancillary personnel salaries.

Due to the financial pressures experienced by CARE Act subgrantees, several grantees reported allowing balance-billing by making up the TPR shortfalls with grant funds. In some case study communities, subgrantees were not routinely billing TPR because the cost of generating the bill exceeded the expected payment. In those situations, the subgrantees charged grant funds for the services instead.



TPR is generated by CARE Act–funded services, those payments must be used for HIV-related services. TPR funds resulting from collection efforts by the CARE Act–funded grantee or subgrantee must be used to pay for HIV/AIDS services to eligible clients.

Findings

Some CARE Act–funded HIV programs in large institutions reported that they do not have separate accounting line items for their programs. As a result, TPR funds are returned to the general accounting system or to the department or program in which they are administratively assigned. As a result, programs are unable to determine if, when, and how much has been paid on their TPR claims. Moreover, some institutions were unwilling or unable to adjust their accounting systems to correct this problem.

Policy: CARE Act–funded grantees and subgrantees should staff their programs to ensure quality of care and maximize TPR. Existing programs should evaluate the costs and benefits of adjusting their staffing mix over time to determine whether staffing changes will, in the long term, be beneficial to the quality of care provided to clients.

Findings

As CARE Act–funded community-based HIV service organizations were established in many communities, they have tended to employ paraprofessional and nonprofessional staff to provide such services as mental health and substance abuse counseling. Although some of these services might otherwise be eligible for reimbursement by Medicaid and other payers, the absence of credentialed personnel precluded participation in provider networks.

Policy: If a CARE Act client is enrolled in Medicaid and Medicaid covers the type of case management the grantee or subgrantee provides, Medicaid should reimburse for those services. State Medicaid programs vary regarding the specific type of case management that is reimbursed, the frequency of services to be reimbursed, and the qualifications of case managers.

Findings

HAB recommends that grantees or subgrantees verify whether Medicaid reimburses for the type of case management they offer. Case management and other covered benefits may be identified by reviewing the State’s Medicaid plan on the CMS Web site.⁹ The State Medicaid Plans tend to be complex, however, and information regarding covered benefits is sometimes hard to identify.

Policy Options

Maintain the current CARE Act requirements regarding eligibility determination.

Likely impact: The current CARE Act system relies heavily on a case management system whose staff may not be trained sufficiently in the eligibility requirements of entitlement programs, third-party insurance, and disability income programs. HIV care systems throughout the United States reported that case managers’ caseloads are very high, waiting time for new case management systems is increasing, turnover in personnel is increasing significantly, and the focus is on crisis management because there is insufficient time to address clients’ underlying issues. Further reliance on case managers to ensure rapid enrollment in entitlement programs, third-party insurance, and disability income programs would be challenging.



revenue would likely be difficult. Ensuring that institutions did not offset the institutional outlays with TPR also would be difficult but important. Written guidance and TA might be provided to assist grantees and subgrantees to implement this policy.

Eliminate the current PLR policy from the CARE Act.

Likely impact: Negligible impact is likely to result if the current policy is eliminated. Agencies that currently seek TPR to maximize their CARE Act grant funds are likely to continue to seek payment from third-party payers. Agencies that are currently unable to pursue TPR probably would not be affected.

Establish mechanisms within the DHHS to address barriers to implementing the PLR policy.

Likely impact: Similar to the policy drafted by HAB and the VA, a policy would be established to identify PLR among HAB, SAMHSA, CMS, and other relevant Federal agencies. In developing the policy, any unresolved legal issues regarding the PLR policy (e.g., balanced payments) would need to be resolved.

Expand TA and training to ensure that CARE Act grantees and subgrantees can undertake TPR activities.

Likely impact: Expanding TPR among CARE Act grantees and subgrantees would require substantial expansion of existing TA and training efforts. Funds to provide ongoing training would be needed to address the intermediate and advanced needs of CARE Act grantees and subgrantees.

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- ¹ National Association of State Budget Officers. *The Fiscal Survey of State: April 2004*. Washington, DC: National Governors Association; 2004.
- ² Clark R. *Counties in Crisis: A Survey of Current Budgetary Situations Facing America's Counties*. Washington, DC: National Association of Counties; 2004.
- ³ For the purposes of this report, subgrantees include agencies receiving funds from CARE Act grantees through contracts and fee-for-service reimbursement arrangements.
- ⁴ Public Health Service Act Section 2605(a)(6) applicable to Emergency Relief for Areas with Substantial Need for Services (Title I); Section 2617(b)(6)(F) applicable to CARE Grant Program (Title II); and Section 2664(f)(1) applicable to Early Intervention Services (Title III).
- ⁵ For the purposes of this report, "State Title II grantees" refers to States and territories receiving CARE Act Title II funds.
- ⁶ Managed Care and Health Services Financing Technical Assistance Center. *Ryan White Comprehensive AIDS Resources Emergency (CARE) Act Third Party Reimbursement (TPR) Frequently Asked Questions*. Rockville, MD; 2002. Available at: <http://www.hrsa.gov/tpr/TA-HIV-AIDS-Billing-FAQs.htm>.
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STUDY3

ASSESSING THE IMPACT OF THE RYAN WHITE CARE ACT TITLE
II EMERGING COMMUNITIES FORMULA GRANT PROGRAM

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Purpose of the Study

To evaluate the administration and implementation of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act Title II Emerging Communities Formula Grant program and to analyze its effect on planning and the delivery and use of services for people living with HIV and AIDS (PLWHA).

Background

The Emerging Communities Supplemental Grant program was created by Section 2620 of the Ryan White CARE Act Amendments of 2000 to provide relief to cities experiencing significant growth in their local HIV epidemics but ineligible for direct assistance under Title I of the CARE Act. Their ineligibility was the result of a combination of factors. The CARE Act Amendments of 1996 had changed the threshold formula for Title I eligibility from total cumulative AIDS cases (which included people who had died from the disease) to total AIDS cases reported over the most recent 5-year period for which data are available. Congress made this change to provide a more accurate estimate of the actual burden of care faced by communities. The intent of the authorizing legislation was also to limit the expansion of Title I cities and to address the evolving needs of potentially new Title I cities that had already established a developed infrastructure through the use of Title II funds.

At the same time that the Title I formula change was introduced, however, new highly active antiretroviral therapy (HAART) for HIV disease also began to be used widely. HAART dramatically altered local HIV epidemics. Successful application of new therapies in communities where access to those therapies was nearly universal and where people were being brought into care early in their HIV disease both slowed disease progression and significantly reduced the number of people developing AIDS. As long as eligibility remained based only on recent reported AIDS cases, not on combined HIV and AIDS cases, communities that successfully implemented the “early intervention” principles of the CARE Act were less likely to qualify for Title I funds even though their combined HIV/AIDS epidemics continued to grow. The Emerging Communities Supplemental Grant program was created to help correct this historical inequity in the CARE Act by providing vital resources to help these communities address their burdens of care.

Description

The Emerging Communities Supplemental Grant program defines emerging communities (ECs) as metropolitan statistical areas (MSAs) that were ineligible for Title I funds, had a population of at least 500,000, and reported to the Centers for Disease Control and Prevention (CDC) a total of 500 to 1,999 AIDS cases during the most recent 5-year reporting period. Qualifying communities are divided into two tiers: those reporting 1,000 to 1,999 AIDS cases (Tier 1) and those reporting 500 to 999 AIDS cases (Tier 2).¹ The program is funded by withholding the greater of \$10 million or 50 percent of the Title II funding increase from the base Title II award allotment. A minimum of \$5 million is allocated to each tier and distributed proportionately among the qualifying communities on the basis of their percentage of total AIDS cases in that tier category. The purpose of the two tiers and the 50–50 split in program funds between them was to guarantee that a significant portion of the supplemental funding was directed toward the few communities with the largest incidence of HIV and AIDS and, thus, most likely to have been adversely affected by the change in the Title I eligibility criterion.



During both data collection phases, four types of informants at the ECs were contacted: Title II directors, EC or consortium administrators, and provider and consumer representatives who were involved in the EC planning process. The data collection techniques consisted of semistructured, in-depth discussions. Discussion domains were based on the objectives of the evaluation and covered the following topics: (1) the impact of the EC program on other Title II programs in the State, (2) Title II and EC planning structures and procedures, (3) the impact of variability in eligibility and award amount, (4) the impact of the EC program on the delivery of services, (5) the impact of the EC program on access to and use of services, (6) the need for technical assistance from HRSA, and (7) recommended policy and program changes.

Limitations

The 40 communities that have qualified for funding under the EC program over the past 4 years vary widely in terms of their eligibility, funding, planning, and service provision. Although it was not feasible to include all ECs in the evaluation, information from the 15 sites chosen was nonetheless considered indicative of the key characteristics and issues confronting the EC program. Moreover, the EC program operates within the context of other CARE Act titles and non-CARE Act health service programs. An effort was made to capture the critical interactions between the ECs and these other programs, but a thorough study of the broad program effects and interactions was beyond the scope of this assessment.

Major Findings

The study's findings are based on the experiences and perceptions of informants from the 15 communities included in the evaluation.

Many ECs experienced tremendous uncertainty and fluctuations in year-to-year eligibility. Of the 15 ECs included in the study, 1 remained in Tier 1 and 5 remained in Tier 2 throughout the first 4 years of the program. Of the remaining nine, changes in the number of reported AIDS cases caused two to fall from Tier 1 to Tier 2, two to fall from Tier 1 to Tier 2 and then to requalify for Tier 1, and four to lose program eligibility altogether.

Variation in program eligibility led to large fluctuations in annual funding amounts. ECs that became ineligible lost total funding, whereas those that regained eligibility had their funding restored, sometimes on a year-to-year basis. ECs that switched from Tier 1 to Tier 2 went from sharing a \$5 million "pie" with sometimes as few as only 1 other community to sharing a \$5 million tier allocation with upwards of 30 other communities. A commensurate increase in annual funding was realized if an EC regained Tier 1 eligibility. Even ECs that remained in the same tier throughout the 4-year period experienced major annual swings in funding as other communities moved in and out of the same peer group.

Variation in annual funding amounts created obstacles to effective planning. Unexpected declines in annual funding amounts made it difficult to engage in long-term planning, write contracts, hire providers, and implement monitoring and evaluation activities.

Variation in annual funding amounts disrupted the provision and use of services for PLWHA and engendered distrust among some providers and consumers in the community. Sharp decreases in annual funding amounts led to elimination of newly created services and damaged trust among community



EC funds were used both to expand existing medical and support services and to establish a wide range of new services to infected populations with unique health care and other social service needs.

Program money was used to fund a wide variety of services, including traditional services such as primary care, medication assistance, case management, housing, transportation assistance, emergency services, and food assistance, as well as new services to better meet the needs of communities with special needs. Innovative and special needs programs and services included permanency planning to assist children in the event of a parent's death, transitional planning for people released from correctional facilities, substance abuse counseling and treatment, outreach and education, nutritional counseling, pastoral counseling, home visits to assist in medication adherence, and translation services.

The EC program contributed to an increase in client access to and utilization of medical and support services in qualifying communities.

Program funds resulted in an increase in the number of people using services and an increase in the frequency and range of services being used by clients already in care. Waiting lists and times were reduced as a result of the availability of additional funds. The utilization of primary care services was enhanced by the availability of support services such as adherence counseling, child care, housing assistance, and transportation. Program funds were often used to target women, infants, and children; the homeless; substance abusers; migrant workers; minority populations; incarcerated persons; and other populations facing historical barriers to care.

Recommendations

Refocus Reforms on Title I

The CARE Act Amendments of 2000 included a provision establishing the EC program to help address funding disparities to non-EMA States caused in part by the Title I program. Although the program partially addresses these funding disparities, it creates the same type of funding disparities caused by Title I, but for urban and rural areas that do not qualify as eligible EC MSAs or that do not meet the EC AIDS case criteria. As such, the EC program imperfectly functions somewhere between the Title II base-funded program and the Title I program. The EC program is only a partial solution toward achieving greater parity and equity across communities. Reform efforts should instead focus on addressing the disparities and inequities caused by the Title I program. Although the Title I program played a critical role in mounting a rapid response in the major cities where the epidemic was concentrated in its early years, HIV and AIDS have now imposed a health care burden on every region of the country. Today, more appropriate mechanisms than the Title I program may need to be developed for funding HIV/AIDS services in large metropolitan areas while equitably addressing HIV/AIDS care needs in all urban and rural settings throughout the United States and its territories. It is against this backdrop that the following continuum of recommendations for the EC program is proposed.

Return EC Funds to Title II Base

Ideally, the EC program should be eliminated and the funds returned to Title II base appropriations for allocation to States as part of their general award. Given the funding inequities and disparities caused by double counting of AIDS cases among the CARE Act titles, however, HRSA should consider recommending the elimination of the EC program and the establishment of a new Emerging Community *State* Formula Grant Program using the funds that currently support the EC program. The purpose of this program would be to provide supplemental Title II funding to States with qualifying ECs under the rationale that States with communities currently defined as emerging communities may be disproportionately affected by HIV and AIDS.



The specific mechanics for replacing the existing EC program with a new Emerging Community State Formula Grant Program are as follows:

- + Eliminate the two tiers and allocate the EC funds directly to the State as grantee based on the number of reported AIDS cases across all qualifying communities in the State as a proportion of the number of reported AIDS cases in all qualifying communities nationally.
- + Phase in the funding changes resulting from the proportional allocation by limiting the increases or decreases to any given EC to 25 percent per year. Doing this will minimize disruptions to existing programs and minimize funding increases that may exceed the absorptive capacity of the local service system
- + After the tier system has been eliminated, the current EC program should be dismantled through a similar phased-out approach, whereby funding to current qualifying ECs is reduced by 25 percent so that within 4 years, the current program has been eliminated completely. During this process, the funds can be reallocated to the Emerging Community State Formula Grant Program in the same fashion.
- + During this phase-out period, the loss of funds to communities that become ineligible should also be limited to 25 percent per year to minimize disruption of services and damage to community trust. In this way, the removal of funds because of loss of eligibility would be gradual, spanning a period of 4 years. Once the current EC program has been eliminated and the new supplemental State program has been fully phased in, the temporary limits on funding decreases would end.

Reform the EC Program

Eliminating the EC program may not be feasible at this time. Short of eliminating the EC program, making the following refinements to the supplemental grant program would achieve greater stability and equity in funding. Most of the following recommendations entail changes to the authorizing legislation, which only Congress can make. Therefore, HRSA should include them in its recommendations to Congress under the FY 2005 CARE Act reauthorization.

- + Eliminate the two tiers and allocate the EC funds proportionately according to the number of cases across all communities. To minimize disruption of services caused by the elimination of the dual-tier structure, increases or decreases in funding as a result of proportional allocation should be limited to 25 percent per year. Once the full effect of the tier elimination has been realized, this temporary funding guarantee should be terminated.
- + Institute a general cap on annual funding reductions to minimize the disruption caused by unexpected withdrawal of funds when an EC loses eligibility. Under this temporary funding protection, ECs that lose eligibility because their AIDS cases fall below 500 would eventually lose all funding under the supplemental program.
- + Release the number of CDC-reported AIDS cases for all current and newly eligible ECs by the October prior to the next CARE Act fiscal year so that communities can adequately prepare for the identification of needs and the allocation of funds.
- + Make clear to States and ECs that they may carry over funds after the initial year of award. A carryover provision would facilitate needs assessment, contracting, and monitoring and evaluation procedures.
- + Encourage States and communities to write provider contracts spanning 2 or 3 years at a time. Doing so would provide for better planning and greater continuity in the provision of care and help engender greater trust and commitment on the part of providers. Longer-term contracts would need to be made conditional on continued Federal appropriations for the EC program at the same level.



- + Require that States disburse funds within a fixed period of time following award notification and that they provide contractors with adequate time to spend the funds. Delays in disbursement create major challenges in implementing provider contracts and delivering services. The notification, award, and disbursement process should be made more transparent and systematic, and States should be held accountable for disbursing funds within a time period specified by HRSA.
- + Require Title I, II, III, and IV grantees that provide services in the affected geographic area to participate in the local EC planning process. Doing so would help facilitate the coordination and efficient use of EC resources.
- + Replace the provision that guarantees the EC program one-half of any increase in Title II base appropriations with something more representative of the actual proportion of AIDS cases in qualifying MSAs. HRSA should urge Congress to reevaluate this allocation formula and tie the proportion of EC funds to the resource needs of ECs relative to non-EC communities.
- + Use both HIV and AIDS counts in the allocation formula for EC funds. Including HIV counts in the allocation formula would help ensure that program resources are targeted to communities facing the greatest demand for medical and support services. It would also help ensure that resources are focused on subpopulations with the highest incidence of newly diagnosed cases. The last of the States and municipalities have just recently implemented an HIV reporting system to the CDC. Although the reliability, comparability, and completeness of the records have not yet been established, HRSA should consider using the EC program to pilot test the use of HIV counts for allocation of funds. (The Institute of Medicine recently submitted a major report to HRSA outlining the strengths and weaknesses of using HIV cases for resource allocation.³)
- + Base allocation decisions on HIV and AIDS cases in active care. Doing so would focus funds on programs whose resources are actually being used. It would also provide an incentive for communities to reach out to infected populations that are currently not receiving care and are often disenfranchised from systems of care, and get them into treatment programs. Moreover, HRSA should base allocations on point of service to account for client relocation after testing.
- + Review the EC definition, eligibility criteria, and funding formula to ensure that they adequately capture what constitutes an emerging community and that the formula allocates funding proportionately to the needs of the community. The allocation formula should reflect the community's incidence and prevalence of HIV and AIDS, the incidence of poverty, the proportion of the population without health insurance, and the resource demands of the particular geographic area.³



References

- ¹ An MSA is defined by the U.S. Office of Management and Budget as a county or group of contiguous counties that contains at least one city of 50,000 inhabitants or more or a county or group of contiguous counties that contains an urbanized area of at least 50,000 inhabitants and a total population of at least 100,000 inhabitants (75,000 in New England) based on the most recent census data. MSA boundaries and EC definitions may change based on shifts in demographics as measured by the census data.
- ² National Alliance of State and Territorial AIDS Directors. *Southern States Manifesto: HIV/AIDS and STDs in the South: A Call to Action*. Southern State AIDS/STD Directors Work Group; 2003.
- ³ Institute of Medicine. *Measuring What Matters: Allocation, Planning and Quality Assessment for the Ryan White CARE Act*. Washington, DC: National Academies Press; 2003.



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