

# Directions in HIV Service Delivery & Care

**A POLICY BRIEF**

**Number 3**

## Responding to the Changing Epidemic

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



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

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## **Responding to the Changing Epidemic**

**Caitlin Ryan, MSW, ACSW**  
**Editor**

**Health Resources and Services Administration  
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# 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).



## The Role and Effectiveness of Title I Planning Councils in Making HIV Service Delivery Systems Responsive to New Treatment Therapies

Michael DeMayo, M.P.H., Paul Harder, M.A., M.B.A., Marla Gold, M.D.

**PURPOSE:** To assess the effectiveness of Title I Planning Councils in responding to changing treatment and care-related needs of people living with HIV. **METHODS:** Researchers used a case study approach to explore the impact of treatment advances on six EMAs, selected for diversity and year of Title I eligibility. They also reviewed Title I applications from FY1995-98 along with other key planning documents from each EMA. **FINDINGS:** Most Planning Councils responded effectively to treatment advances, with wide variability in how they received and incorporated information on new treatment options. The local health care environment directly influenced planning activities, and EMAs consistently prioritized primary care and care management as the most essential services. **RECOMMENDATIONS:** Researchers provide recommendations for improving administrative support and facilitating planning.

## An Assessment of Title II Program Implementation, Planning, and Effectiveness

Mariella Cummings, R.N., M.S.

**PURPOSE:** To understand and describe the implementation, effectiveness, and changing needs of Title II programs in six States. **METHODS:** The author conducted an assessment of Title II program implementation in six States selected for demographic and resource diversity. Telephone consultations were conducted with Title II program administrators from each of six grantees, and with 15 consortia leaders from about one-half of the consortia in three States. Consultations were supplemented with a review of grant applications and other relevant documents from each State. **FINDINGS:** From FY 1996-99, Title II funding has shifted to more direct medical care and medications and away from end-of-life support services. Ancillary services, especially case management and transportation, have become more critical. Consortia are improving their needs assessment and prioritizing, but challenges in involving people with HIV and people of color persist. Assuring access to ADAP services is a high priority and an ongoing challenge. **RECOMMENDATIONS:** The author provides suggestions related to the structure and administration of Title II, with an emphasis on supporting HIV care consortia services and ADAPs.

## Access to HIV/AIDS Drugs for Title III and Title IV Clients

Matthew McClain, B.A., Gloria Weissman, M.A., George W. Dowdall, Ph.D., Gretchen Maenner, M.A.

**PURPOSE:** To assess the extent to which Title III and IV clients access HIV/AIDS medications, and Title III and IV programs actively work to enroll clients in ADAP programs. **METHODS:** Researchers obtained written consultation from 134 respondents, representing 63 percent of Title III grantees and 48 percent of Title IV grantees, and conducted follow-up telephone interviews with key informants from six States selected for geographic diversity and extent to which clients were known to have access to HIV-related drugs. **FINDINGS:** Title III and IV clients rely on many funding sources for drug treatment; Medicaid eligibility criteria appear to be the most significant barrier to accessing AIDS medications; many barriers confront Title III and IV clients in accessing drug treatment and care; and a range of strategies are being used at the State and grantee level to reduce these barriers. **RECOMMENDATIONS:** Researchers provide recommendations for technical assistance, follow-up research and improving data collection activities.



# The Role and Effectiveness of Title I Planning Councils in Making HIV Service Delivery Systems Responsive to New Treatment Therapies

Michael DeMayo, Paul Harder, Marla Gold

## Background

Recent advances in medical therapies for treating HIV/AIDS have significantly changed the character of the HIV epidemic. The advent of protease inhibitors has greatly improved the medical outcomes of people living with HIV disease, enhancing quality of life and increasing longevity. According to the Centers for Disease Control and Prevention (CDC), AIDS deaths dropped 25 percent from 1995 to 1996, due in large part to combination antiretroviral therapy, including protease inhibitors.<sup>1</sup> As the medical outcomes of people living with HIV/AIDS continue to improve, their service needs have also dramatically evolved which adds to the planning challenges facing local communities.

HIV Health Services Planning Councils play a critical role in shaping community response to local HIV epidemics and building a continuum of care in eligible metropolitan areas (EMAs) that receive Title I funds. Comprised of a representative from the grantee (usually the local health department), persons living with HIV (PLWH), and community providers, Planning Councils develop a comprehensive plan and set local service priorities through an ongoing series of planning activities. These include conducting an annual needs assessment, prioritizing and allocating Title I funds, and evaluating the responsiveness and effectiveness of the local service system in meeting the needs of PLWH.

In carrying out their mandates, Planning Councils must make a range of decisions that are often complicated by several factors. These include difficulty obtaining accurate and timely epidemiological information (many EMAs do not have HIV reporting requirements so planners may have to depend on estimates of affected persons); lack of detailed and valid information about consumer needs, and lack of standard assessment methods; a rapidly changing care environment that affects planning and service needs; policy changes in public assistance programs, immigration, health care financing, and the availability of substance abuse and mental health services; lack of adequate training and support for Planning Council members; and challenges in effective collaboration between Planning Council members and grantees.

## Methodology

Researchers examined the responsiveness of Title I Planning Councils to changing client and community needs, based on the introduction of combination antiretroviral drug therapies between 1995 and 1998. The study explored four primary questions:

- ◆ How have Planning Councils responded to new treatment advances, and to what degree have they implemented new Federal treatment guidelines?
- ◆ How have Planning Councils acquired information on treatment advances and how do they use it in planning?
- ◆ How is the local health care delivery environment configured and how does that affect planning for the medical needs of PLWH?
- ◆ How does the local HIV/AIDS service system change over time? To what extent has the emphasis shifted from social services to primary medical care?

### Purpose of the Study:

To assess the effectiveness of Title I Planning Councils in responding to changing treatment and care-related needs of people living with HIV.

### Sites Selected

Chicago ◆ Kansas City ◆ New Orleans  
Philadelphia ◆ Portland ◆ San Francisco



TABLE 1

<p style="text-align: center;"><b>PRIMARY ASSESSMENT AREAS</b></p> <p style="text-align: center;"><b>Site Visit Interviews</b></p>	
♦ <b>Planning Process</b>	<p>How/why service priorities and allocations change in relation to treatment advances</p> <p>Whether improvements in health outcomes affect planning</p> <p>Extent to which funding priorities are implemented</p>
♦ <b>Impact of HRSA Guidance/Requirements</b>	<p>Impact of consumer planning input, Planning Council membership, Title I funding application content, and changes in the external environment on priority setting and funding allocations</p>
♦ <b>Information on Treatment Advances</b>	<p>Sources of information available to Planning Councils and methods of integration into planning activities</p> <p>Impact of treatment advances on health status and service needs of PLWH</p>
♦ <b>Outside Influences</b>	<p>Structure of local health care environment and relationship to CARE Act-funded services</p>

Investigators used a case study approach that included consultations with a total of 89 key informants in six EMAs—Chicago, Kansas City, New Orleans, Philadelphia, Portland (OR), and San Francisco. Sites were selected based on the size of the local HIV epidemic, geographic variability, year of Title I eligibility, and the diversity of affected populations.

Interviews were conducted with grantee and Planning Council staff; Planning Council chairs; members of PLWH committees and clinical task forces; and key AIDS service providers, particularly case managers and primary care providers. Interviews focused on the planning process (including how and why treatment advances affected service priorities and funding allocations); the impact of HRSA's requirements on the planning process; the extent to which Planning Councils have access to information on treatment advances, and how that information is incorporated into planning activities; and the relationship of outside influences, such as the local health care environment, to CARE Act-funded services (table 1).

Researchers also used secondary data from a review of Title I applications for FY 1995 to FY 1998, comprehensive HIV plans, Annual Administrative Reports, needs assessments, and outcome studies and evaluation reports. They focused on summaries of grantee service allocations by fiscal year and program/service categories; priority ranking of service categories; State CARE Act program profiles; and annual tables of AIDS cases by demographic group and exposure category. Most of the findings are based on information from interviews and funding applications.

## Limitations

The following limitations were noted:

- ♦ The small sample of study sites limited the ability to observe a full range of patterns in Planning Council responses to changing care needs, so these results may not reflect the experiences of other Planning Councils or EMAs.
- ♦ The review was an assessment of various Planning Council approaches rather than a formal evaluation, so findings were based on interpretations rather than analyses of performance or other standardized measures.

## Major Findings

During the mid-1990s, several policy-related and demographic shifts occurred that, together with significant treatment advances, had a major impact on Title I planning activities and response. These shaped both the planning process and service configuration in EMAs included in this study.

### ♦ **Planning Councils made understanding treatment advances and their impact on services a priority.**

In some EMAs, Planning Councils have integrated Federal guidelines and information on new technologies directly into the planning process. In 1998, for example, the Planning Council in San Francisco made understanding rapid treatment advances and their impact on services a priority for all members. Several EMAs, including Kansas City, developed systems to enhance the use of AZT among pregnant women with HIV, which greatly reduced perinatal transmission.

### ♦ **Most Planning Councils responded effectively to treatment advances, although there was wide variability in the way they received information on new treatment options and how this information was integrated into planning activities.**

Most, though not all, of the Planning Councils studied appeared to have ready access to information on treatment advances and policy change, generally through the grantee (usually a health department) and other Planning Council members with clinical expertise. EMAs that institutionalized planning activities were able to more seamlessly link changes in clinical care with priority setting and resource allocation. Scopes of work with sub-grantees were modified to include services related to medication adherence and disseminating new treatment information directly to clients, while primary care providers responded by following HRSA guidelines or standards of care developed by the Planning Council or grantee. Planning Councils used two primary strategies to determine when new needs required a shift in funding—needs assessments (particularly client-level) and the mid-year review. These strategies provide a systematic means of responding to demographic, policy, and clinical changes within the care environment in a timely manner.

In Chicago, the EMA's largest HIV service provider responded to treatment advances by conducting in-service trainings and multi-disciplinary meetings for clinicians on medication updates and developing an information sheet for clients describing new medications. Priorities shifted to focus on increasing needs for housing, food, and other basic necessities, along with vocational and rehabilitation services to help PLWH enter or return to the workforce. Concerns with preventing development of drug-resistant viral strains through poor adherence led to greater emphasis on consumer education, support and reducing barriers to adherence.

New treatment options prompted Philadelphia's Planning Council to conduct special studies. Based on epidemiological data showing a disproportionately lower decrease in the death rate as a result of treatment advances among African Americans compared with whites, the Planning Council's African American caucus commissioned a study to explore the relationship between access and barriers to care and use of protease inhibitors. This year, a consumer survey will examine work re-entry, disability, child care needs and adherence.

In late 1995, highly active antiretroviral therapy (HAART) became available in Philadelphia and, by 1997, virtually all PLWH in care received protease inhibitors. Morbidity and mortality were quickly reduced, along with hospitalization. Providers responded to the emerging challenge of treatment adherence with several successful innovations: One program trains peer counselors to do adherence counseling and to help clients develop strategies to maintain their treatment regimens, while another provides beepers, med sheets and pill boxes to help clients keep track of daily dosages. As a result, CD4 counts have improved in both children and adults.

For all EMAs, medical care costs have either increased, or increased and then slightly decreased between 1996 and 1998. Only Chicago experienced a slight increase (from 24.2 to 30.1 percent). The proportion of funds allocated to case management in San Francisco (6.6 to 7.5 percent) was dramatically lower than in other EMAs, perhaps because well-integrated services allowed funds to be shifted to other categories, such as housing, an urgent need in San Francisco.

## RESPONDING TO TREATMENT ADVANCES

### What Planning Council Members Say

*"While the new medications do help, they are beginning to see that the effectiveness of the medication can be reduced over a period of several years. The drugs were widely disbursed when they were introduced, although many patients did not understand them or know the importance of adherence. There is now more patient education involved and more of a selective process of who receives these medications... That is, trying to treat the barriers to adherence before prescribing these new treatments. Otherwise, resistant strains of the disease are created by non-compliance."*

—Chicago Planning Council Provider

*"There should be a case management model to ensure a proper social support system is in place, and that primary care needs are met before the new medication is provided. Case management would be responsible for followup, outreach, and medication education and adherence."*

—Chicago Grantee

*"Protease inhibitors have an impact on oral health. People are living longer and having side effects such as teeth loss and decreased saliva. Key discussions about how people are living longer and changing priorities provide a backdrop to priority setting."*

—Philadelphia Planning Council Member

*"The Council has really focused on the population that has the hardest time with the meds. We've increased the number of treatment advocates (treatment education at Asian/Pacific Islander Wellness Center) and the amount of money spent training them. The goal of that was to ensure that when someone went to their case manager and talked about problems with adherence, they would know what they're talking about and what to do about it, rather than automatically directing them to their doctor."*

—San Francisco Grantee

The impact of advances in treatment and reduced mortality among people with AIDS is evident in minimal or no allocations to hospice care in most EMAs. Day and respite care and home health services have also declined. While the need for buddy services has also decreased, San Francisco and New Orleans increased funds for client advocacy.

During this period as well, some EMAs began to focus on populations with severe need. In San Francisco, this reflects increased attention to the homeless, injection drug users, and PLWH who have tuberculosis and/or mental illness. Because these groups have traditionally been outside the health delivery system, they are less likely to have access to treatment advances. Although effects of new treatment options are less evident in these underserved populations, funding shifts are also clearly visible, with an overall decrease in hospice care, home care, and discharge planning and increased allocations for mental health and housing.

- ♦ **In nearly all cases, the local health care environment directly influenced planning for medical services. In EMAs where alternate sources of funding, such as Medicaid, were more readily available to meet client needs by supporting the HIV service delivery system, Planning Councils shifted funds to targeted areas such as the State AIDS Drug Assistance Program (ADAP) budget or developed special programs, such as adherence initiatives.**

In Chicago, when HAART was introduced in 1995, a primary goal was to mainstream HIV-related care when possible, and to build the health infrastructure in communities of color and rural areas where access to basic health services was lacking and there were few or no specialized HIV-related services. By 1997, however, nearly all available resources were being used to maintain the existing health delivery system, and limited funds were available for expanding care delivery systems. Lack of infrastructure was particularly acute in communities of color and isolated rural areas.

Recent changes in the Medicaid program also place a burden on city and county-financed health services and potentially hamper client access to specialized HIV-related care. A new system, MediPlan Plus, is designed to contain costs by increasing the number of Medicaid recipients enrolled in managed care, while also directing money away from city and county HIV/AIDS clinics towards managed care providers. Despite the lack of funds for infrastructure development, unmet need for primary care services has decreased from 25 percent in 1997 to 16 percent in 1999 (as measured by client reports), while unmet need for treatment access also declined from 34 percent in 1998 to 21 percent in 1999.

- ♦ **EMAs in the study have consistently prioritized primary medical care and case management services as the most essential services for PLWH in their region. As a result, local service system characteristics have remained fairly stable since Title I funds became available.**

In the Kansas City EMA, medications became the number one priority for the first time in 1997. The Planning Council and Title II consortium responded by attempting to address primary care as a critical priority when protease inhibitors were introduced. In 1998, they began monitoring unmet needs for medication and conducted workshops for physicians, nurses, and other health care professionals on treatment advances. The Planning Council and consortium also developed a cooperative agreement linking Title I and II programs for rapid enrollment of eligible clients on protease inhibitors.

San Francisco's health delivery system has focused on provision of medical care since initially receiving Title I funds. As new medications became available, new services were added to accommodate the growing demand. In 1995, the ADAP program was expanded to allow an additional 100 clients access to medications. Eight new pharmacy sites were added and dental services were expanded. In 1996, perinatal services were improved to allow 54 dually diagnosed low-income women access to primary care services, while in 1998, the dramatic change in HIV medications led to a review of all Title I-funded services.

Although the past 5 years have introduced major changes that have significantly affected the care environment, prioritization, and delivery of services, most EMAs were able to respond effectively. Researchers found no evidence in the EMAs studied that treatment advances had any effect on Planning Council functioning or capacity to respond.

## Recommendations

Title I Planning Councils have become an integral part of effective assessment and service delivery to people living with HIV throughout the United States. Additional guidance and assistance from HRSA in several specific areas can enhance the planning process and create a more effective planning structure at the local level.

### **I. Create a more realistic timetable for needs assessment, service prioritization and resource allocations in the Title I application process.**

The current application process does not allow sufficient time for EMAs to determine the impact of recent priority setting and funding allocation procedures. Extending the application process to a 2-year cycle can give EMAs more time to assess the impact of care delivery on affected populations. The timetable for data reporting should be realistically retrospective to allow for system lags at both the local and Federal level. AIDS case data can take up to 18 months to be reported, and HRSA requires estimates every 12 months. By switching to a less frequent timetable for reporting, the data would be more accurate and would not necessarily be based on prevalence estimates.

### **II. Provide more guidance and funding to integrate data collection and reporting for monitoring services.**

Most EMAs in the study lack the resources or capacity to develop effective service tracking systems to enhance accountability and to conduct effective outcome studies. In addition, the application guidance often requires Planning Councils to modify data collection methods in ways that make it difficult to meet application deadlines. Earlier notification of the types of information required would enable planners to respond more effectively.

### **III. Provide clearer guidance and more resources to improve the collection of service outcome data.**

Planning Council members interviewed for this study reported a lack of clarity with HRSA's requirements for collecting outcome data. A standardized data collection system across EMAs would allow HRSA to compare service delivery regionally and nationally, while giving local EMAs the ability to realistically evaluate their service delivery systems.

### **IV. Improve opportunities for CARE Act programs to exchange information and share concerns with one another and with HRSA.**

Many EMAs have developed effective planning strategies that could serve as models for other EMAs with similar characteristics. Currently, however, no ongoing mechanisms are available for Planning Councils to share their work. The recent All Titles meeting should be held on an annual basis to provide a forum for Title I and other CARE Act programs to share information and ideas, rapidly and routinely.

### **V. Provide Planning Councils with training and technical assistance on obtaining and understanding epidemiological and planning data.**

Comprehensive health services planning is a complex task, requiring inclusion of diverse groups and affected populations with a need to synthesize data and technical information. More resources should be directed to educating Planning Council members on effective use of data and addressing differences between the technical abilities of providers and community members who serve on Planning Councils.

### **VI. Recognize that service needs of target populations have changed, and allow funding categories to meet these changes, such as greater flexibility in paying for housing services.**

Current service category restrictions do not give EMAs adequate flexibility to respond to the dramatic changes in health service needs that have taken place during the past few years. For example, although treatment advances have enabled many people with HIV to return to the workforce, many fear they will lose disability or Medicaid coverage if they do so. Even when Planning Councils prioritize this need, CARE Act funds do not cover return-to-work assistance.

### **VII. Provide assistance in managing the relationship between Planning Councils and grantees.**

Community planning is a complex and at times highly charged process that brings together diverse groups of health professionals and community members in an unprecedented way.

Greater support and technical assistance are needed to enhance effective communication and relationship building between community members and grantees.

### *References*

1. Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, U.S. HIV and AIDS cases reported through December 1997. Year-End Report. 1997;9(2).

# An Assessment of Title II Program Implementation, Planning, and Effectiveness

Mariella Cummings

## Background

CARE Act Title II grants fund home and community-based health and support services, health insurance continuation, medication through the AIDS Drug Assistance Program (ADAP), HIV care consortia costs, and direct medical and support services. Awarded on a formula basis to an agency designated by the governor—usually the State health department—grants are disbursed to all 50 States, the District of Columbia, Puerto Rico, Guam and the Virgin Islands. Some States provide services directly while others subcontract with Title II HIV care consortia—associations of public and nonprofit providers, including community-based organizations, that plan and deliver HIV services.

Consortia are required to submit applications to the State that document their planning and care delivery process by: 1) conducting a needs assessment; 2) developing a plan and determining priorities to meet identified needs; 3) promoting coordination and integration of community resources and addressing the needs of affected populations; 4) assuring the provision of comprehensive health and support services; and 5) evaluating their success and cost-effectiveness in responding to identified needs.

The National Alliance of State and Territorial AIDS Directors (NASTAD) estimates that in 1998 over 300,000 people received Title II services and over 100,000 individuals received ADAP services.<sup>1</sup> While funding for Title II services has continued to increase, it has not kept pace with the growing number of clients and their increasingly complex needs. Access to resources varies substantially by State. Although each State receives some Title II funding, availability of other CARE Act resources (Titles I, III and IV) varies considerably. Funding may be supplemented by a variety of sources, including other public funds from Medicaid and State HIV-related resources, private insurance and non-profit services often funded by charitable foundations.

## Methodology

The author conducted a descriptive study of Title II implementation in six States chosen for their demographic diversity and size of the affected population, access to CARE Act resources, and funding level. Selected States include Florida, Indiana, Maryland, New Mexico, South Dakota, and Washington. Collectively they account for 15 percent of the 711,344 cases of AIDS cumulatively reported in the United States through June 1999.

The study explored three primary questions in a series of telephone interviews and written consultations with State AIDS directors, Title II program staff and consortia leaders: 1) Do Title II funds support the right services for the right populations in the most effective and accountable ways? 2) To what extent does Title II funding complement other publicly-supported services for people with HIV? and 3) How can Title II services improve access to quality care for people with HIV in all jurisdictions receiving CARE Act funds? Program administrators were also asked to rank the effectiveness of various consortia activities on a scale of one to five, ranging from ineffective to very effective.

The study explored how use of Title II resources has changed from FY 1996 to FY 1999 (the period when combination drug therapy became the standard of care for people living with HIV).

### Purpose of the Study:

To explore the implementation, effectiveness, and changing needs of Title II programs in six different States.

TABLE 1

### Primary Funding for HIV-Related Care

- ♦ Titles I, II, III, IV
- ♦ Medicaid/Medicare
- ♦ State funding
- ♦ Private insurance
- ♦ Public health system
- ♦ Charity

### Sites Selected

Florida ♦ Indiana ♦ Maryland  
New Mexico ♦ South Dakota ♦ Washington



Information was also collected about the program structure and challenges experienced by each ADAP program. In three States (Florida, Maryland, and Washington) where consortia are used to plan and coordinate HIV-related services, consortia processes and priorities were examined in greater detail. The investigator also reviewed Title II grant applications for FY 1997-1999, ADAP monthly reports, summary program reports from grantees, and supplemental materials from Title II program staff.

Limitations



The investigator noted several limitations of the study:

- ◆ The assessment was limited to six States so it does not include all Title II programs and may not be representative of other Title II grantees and consortia. Four of the six States included in the study fund consortia services. Leaders from 15 of 33 consortia in Maryland, Florida, and Washington provided consultation.
- ◆ Although participants were told that data would be summarized and specific consortia would not be identified, concerns about confidentiality may have influenced their responses.
- ◆ Lack of time and resources limited the study design and prevented pre-testing of questions for telephone consultation.

Major Findings

- ◆ Title II resources are being used to enhance access to care, and use of these funds has shifted as needs have changed.

TABLE 2

Funding Shift FY 96-99	
	
End-of-life support	Medical and dental care
Home care	Medications
Hospice	Case management
Buddy services	Substance abuse + mental health services
	Transportation
	Housing and food

The strategies used in each State are designed to make the greatest use of Title II funds to improve services to low-income persons with HIV. None of the Title II systems are static. All are being modified to one degree or another in response to changing needs, and each State shows a shift in its overall Title II budget from FY 1996-99. Increasingly, Title II programs are funding medical and dental care and medications. Fewer Title II resources are being allocated for end-of-life support services, such as home and hospice care (table 2). Much of this shift was prompted by the introduction of combination antiretroviral therapy with protease inhibitors in 1996. As a result, ADAP funding for all Title II grantees has increased substantially as Title II funds became the primary source for ensuring access to drug treatment. From FY 1996 to FY 1999, ADAP funding in six States included in this study quadrupled from \$18.5 million to \$83.4 million. And in FY 1999, ADAP funds represented more than one-half of the total national Title II grant award.

In some States, significant outreach efforts are being initiated to improve access to care among underserved populations, including racial and ethnic minorities. At the same time, the need to properly track utilization and costs of Title II programs and services is also increasing. And several grantees (e.g., Florida, Indiana, and New Mexico) are upgrading their information systems to improve their ability to monitor and plan.

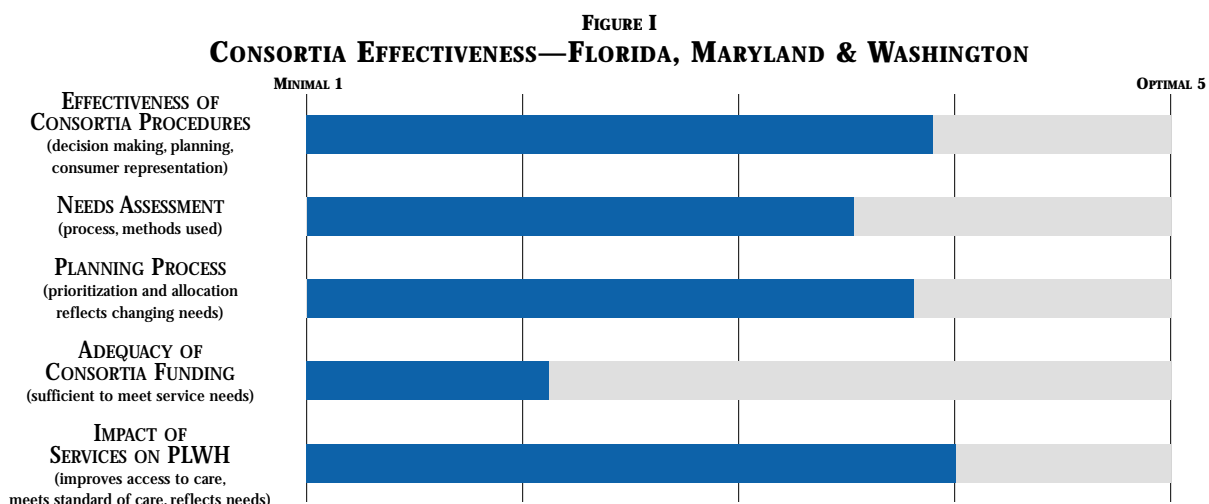
- ◆ Consortia are improving their needs assessment and prioritizing process, but challenges to involving people with HIV in these activities persist.

Traditional consortia services are funded by only four of the six States (Indiana and South Dakota do not use consortia). Consortia in States that participated in interviews (Florida, Maryland, and Washington) met Title II funding requirements (e.g., conducting a needs assessment, planning, and assuring comprehensive services). But methods and level of sophistication varied considerably among consortia within each State. Some receive less than \$30,000 per year, while others receive more than \$1 million, and the differences in staff and resources hamper efforts to establish common processes even within States. Data suggest that consortia that receive \$100,000 or less tend to have

\*New Mexico’s consortia were not included in this portion of the study since they provide a full range of medical and support services under a unique State-directed medical service plan that is different from traditional Title II consortia.

a less rigorous planning process. And consortia serving communities that receive Title I funds often defer to the more formalized planning procedures required of HIV Health Services Planning Councils.

In spite of these broad differences, consortia leaders rated the overall effectiveness of their consortia favorably (figure 1) with the highest scores for members' knowledge of HIV/AIDS (4.2 on a scale of 1-5) and lowest for consumer representation (average score of 2.9). Leaders felt that their planning process and needs assessment were acceptable given available resources, and they have consistently requested technical assistance to improve their operating and planning procedures. In assessing the impact of Title II services on the lives of people living with HIV (PLWH)—perhaps the most significant measure—consortia received high marks, ranging from an average of 3.7 for helping clients access primary care to 4.3 for enabling clients to maintain optimal health and quality of life.



Recruiting new consortia members and retaining current ones is a frequently cited challenge, especially for people living with HIV/AIDS. The challenge is even greater in rural communities where fewer potential volunteers, concerns about privacy and confidentiality, and volunteer burn-out are common problems for the limited number of persons with HIV who are asked to serve on multiple boards and committees. Representation of women and racial and ethnic minorities in Title II consortia and other planning activities is another ongoing concern, and efforts to address these issues have met with varied success.

Formal evaluation of consortia efficiency and effectiveness has not been a major focus of most consortia or grantees. Many Title II staff and consortia leaders question how consortia service/process outcome evaluations could be performed without diverting resources from service delivery. However, Florida was able to complete a 2-year peer review process of Title II programs that included a consumer survey and 32 public forums throughout the State's 14 consortia service areas.

Consortia members are also experiencing planning fatigue, driven partly by yearly grant cycle demands. In many cases, consortia are in the process of contracting out and starting new service programs in April, while simultaneously having to begin planning the grant application for the following year. Members report having no break from planning to enable them to address program evaluation, develop service capacity, or build relationships with other CARE Act Titles. While the needs of clients change over time, shifts on a year-to-year basis are not that significant. A majority of informants favor moving to a grant award cycle of 2 to 3 years, with annual abbreviated updates and a mechanism to amend budgets as needs emerge. A longer cycle would allow for more program evaluation efforts and outreach to underserved populations.

♦ **Consortia leaders remain concerned about meeting service needs with available funds.**

Leaders report that clients' basic medical needs (including outpatient medical services and medications) are being met through Title II and other resources, including Medicaid. But consortia leaders say many needs remain unmet for ancillary services, such as case management, transportation, client advocacy, housing, food, and direct emergency financial aid. They note that the nature and complexity of case management services is changing: some clients who are doing



well on medical regimens often require only intermittent traditional case management support, but a growing number of clients have more complex needs that require greater case manager expertise. The need for these services is primarily fueled by poverty, discrimination, and significant co-morbidities among emerging, newly-diagnosed populations. As a result, case management continues to be viewed as a priority service in most communities.

Consortia are trying to tackle these issues. But respondents are concerned with at least two major gaps in primary care services—dental care and a troubling lack of qualified and willing medical and support service providers, particularly in rural areas where the local health department may be the only HIV provider. In some communities, expanding provider capacity is essential before Title II priorities and funding can be redirected to address unmet needs.

**♦ Assuring access to ADAP services is a high priority for all grantees but will likely become more difficult as care becomes increasingly complex and costly.**

Managing ADAPs is a major challenge in all jurisdictions—the client base continues to grow at the same time that standards of care are becoming more complex and costly. ADAP managers have struggled to implement systems to provide prescription medications within available resources. Client enrollment in ADAPs has increased dramatically since 1996, when the standard of care shifted to combination therapy with protease inhibitors. In some cases, triple-drug therapy is being replaced with four drug regimens, particularly when the initial regimen is not effective or when viral resistance occurs. A typical highly-active antiretroviral therapy (HAART) regimen costs more than \$10,000 per year, exclusive of medical office visits and laboratory monitoring.

Funding for ADAP services appears to be sufficient to meet current demand in five of the six States (only Indiana anticipates a shortfall in the current fiscal year), but many ADAPs still struggle to meet client needs, even with additional funding from other sources. South Dakota has insufficient funds to provide protease inhibitors. In Florida, Maryland, and Washington, funding is adequate only because the States supplement ADAP resources or receive funds from other CARE Act Titles. Most ADAP administrators anticipate a continued increase in both enrollment and per client costs. But they do not anticipate any new or increased State funding for ADAPs. As State ADAP funds level off, additional Federal funds will be required to sustain these programs.

TABLE 3

<p><b>Funding Strategies to Meet Medication Needs of PLWH</b></p> <ul style="list-style-type: none"><li>♦ Supplement ADAP allocations with State or other CARE Act funds</li><li>♦ Carryover Federal funds from one fiscal year to another</li><li>♦ Fund health insurance continuation for people with HIV</li><li>♦ Piece together client-specific short-term drug financing options with multiple local resources</li></ul>	<p>Each year, most ADAP administrators must spend all allocated State funds, which cannot be carried over into the next fiscal year. Federal ADAP resources, because of the potential for “carryover,” are perceived to be more flexible. And timely approval for use of carryover funds is an essential part of the fiscal management strategy of a number of State ADAPs, helping balance resources from year to year. South Dakota, for instance, is relying on approval of Federal carryover to support increased pharmaceutical costs.</p> <p>Another important and expanding strategy utilized by ADAP administrators is helping clients access insurance to conserve ADAP resources and improve overall access to health services. Informants are requesting additional flexibility to use ADAP funds for outpatient medical services and laboratory tests for uninsured clients. The ADAP also serves as a “gap filler” for clients with inadequate private insurance. Even in State ADAP plans that have enrollment waiting lists or do not provide protease inhibitors, administrators report that case managers are piecing together other short-term mechanisms to provide combination therapy.</p>
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**Recommendations**

Important opportunities exist to improve and enhance Title II programs and services. While not reflecting the experiences of all Title II programs throughout the country, this study provides specific information on challenges and changing needs that may help improve the effectiveness of Title II programs in other jurisdictions.

**I. Retain ADAP as part of Title II, rather than restructure it as a separate Title.**

Close monitoring of ADAP resources is needed. The number of ADAP clients continues to grow. Newly approved medications and more complex medical regimens are raising treatment costs. Managing enrollment and drug formularies within available resources is especially challenging. In this environment, ADAP managers could not identify any advantages to restructuring the

ADAP as an independent CARE Act Title. Integration with Title II and existing program flexibility has been and is likely to remain an advantage in assuring continued financial solvency of these programs. Any structural changes in how the ADAP is administered could potentially decrease rather than promote service integration.

**II. Consider allowing ADAP resources to be used for outpatient medical care and laboratory diagnostic testing.**

These services are essential for medical management of HAART therapy. In jurisdictions with inadequate resources to support outpatient medical care and laboratory testing, the ADAP could serve a valuable function by supporting these “medication-related” needs.

**III. Limit any core ADAP formulary that might be developed.**

If a core national formulary is adopted, ADAP administrators recommend that it be limited and that it include sufficient Federal funds for all grantees to achieve the minimal level of service. ADAPs with sufficient funding are invested in maintaining their current formulary levels and program flexibility. Some administrators also expressed interest in working with HRSA to develop a mechanism to shift ADAP resources mid-year from grantees with anticipated ADAP budget surpluses to those with severe budget shortfalls.

**IV. Provide additional technical assistance to grantees and consortia.**

Title II grantees and consortia would benefit from technical assistance in several areas, including: 1) help with ADAP administrative systems and quality assurance; 2) help with outcome evaluation and evaluating the cost effectiveness and efficiency of services; 3) assistance with data forecasting and predicting changes in utilization patterns; and 4) sharing “best practice” experiences with other jurisdictions to improve procedures. Methods that are effective in Title I Planning Councils may not be feasible in small consortia and rural communities; specifically, rural consortia would benefit from the opportunity to identify and share successful strategies.

**V. Do not make the Title II planning process more proscribed, like the process required of Title I EMAs.**

Consortia are appreciative of existing flexibility in terms of meeting Title II planning requirements. Further requirements would add to administrative burdens, contribute to “consortia burnout,” and draw resources away from client care. These repercussions would be especially severe in rural consortia and those that have budgets of \$100,000 or less per year.

**VI. Avoid establishing firm minimum levels of client participation in consortia processes.**

Consortia are committed to expanding representation of consumers, racial and ethnic minorities, and other emerging affected populations. Successful models for consumer and minority outreach should be identified and shared broadly, rather than imposing requirements that will be difficult or impossible to meet in jurisdictions with a limited number of potential members who are willing and available to serve on consortia.

**VII. Consider moving toward a multi-year grant award.**

Changes in client needs and planning priorities are more stable now than in 1991. The quality of assessments on which consortia and Title II applications are based would improve with an extended grant cycle. Budgets should be submitted and modified as needed on an annual basis.

**VIII. Distribute guidance for grant applications by July for the following fiscal year.**

Particularly in States with local and regional planning processes, receiving the final grant application guidance in September or October occurs after local consortia have finished their grant development processes. Grant applications should be distributed no later than July and final grant awards should be announced as early as possible.

**IX. Refine the Annual Administrative Report (AAR) form and process.**

Informants found the AAR form and process too time consuming, and reported that the current system is not capable of generating unduplicated client counts. They question its value in terms of content, level of effort, and timeliness. They suggested that HRSA strive for consistency in reporting forms and data elements incorporated into the grant application guidance, from year to year, and across CARE Act Titles.

**X. Process carryover requests in a timely manner to enable grantees to provide uninterrupted services.**

Some State programs rely on carryover of Federal funds from one fiscal year to another to help manage their HIV program budgets. Timely approval of requests is especially important for program managers who often lack flexibility to carry over unexpended State funds, especially since some of them rely on carryover as a fiscal management strategy to meet ongoing service and increased pharmaceutical costs.

*References*

1. National Alliance of State and Territorial AIDS Directors. Recommendations to guide the next reauthorization of the Ryan White CARE Act, September 24, 1999.

# Access to HIV/AIDS Drugs for Title III and Title IV Clients

Matthew McClain, Gloria Weissman, George W. Dowdall, Gretchen Maenner

## Background

Many clients in CARE Act-funded programs are eligible to receive medications through State-administered AIDS Drug Assistance Programs (ADAPs). ADAPs are funded under Title II to provide pharmaceuticals to low-income people with HIV who have limited or no coverage through private insurance or Medicaid. ADAPs are changing rapidly, as updated treatment guidelines reflect new medications approved for use. Each State ADAP is responsible for determining financial and medical eligibility criteria, the number and types of medications included on its drug formulary, and the design of its drug purchasing and distribution system. Because each ADAP operates within a unique delivery and financing environment, ADAPs vary considerably from State to State.

Title III programs provide primary care and early intervention in community settings, while Title IV programs support networks of comprehensive, family-centered care and treatment for children, youth, women, and families affected by HIV. Although people with HIV served by CARE Act Title III and IV programs are eligible for ADAP-funded medication, little is known about their experiences and utilization patterns in accessing drug treatment through ADAPs. For example, many Title III programs report needing additional funds to cover pharmaceutical costs for their clients, but the reasons for this pattern of need are unclear. Similar knowledge gaps exist about access to ADAP and utilization experiences of Title IV clients. State ADAPs appear to enroll very few children or adolescents although they are eligible for services. While one might assume their drug treatment needs are covered by Medicaid, many adolescents are not eligible for Medicaid or are outside existing systems, such as school or other health programs, that might facilitate Medicaid access.

As the single most important source of financing care for people with AIDS, Medicaid covers at least 50 percent of people with AIDS and up to 90 percent of children with AIDS (as well as other people with HIV who lack an AIDS diagnosis). The CARE Act was intended to fill gaps in services for people with AIDS already on Medicaid and to provide services for those who cannot afford them and are not eligible for Medicaid. The high cost of new HIV treatments and the growing number of people seeking care—often earlier in their disease and for a longer period of time—present ongoing challenges to meeting these needs.

## Methodology

Researchers used both quantitative and qualitative approaches to obtain information on access to HIV-related medications for clients served by Title III and IV programs. In the first phase of the study, researchers developed a written consultation form which HRSA mailed to all Title III and IV grantees in August 1998. Response was voluntary, and grantees were asked to provide information on client demographics, funding source, access to antiretroviral therapy, and barriers and strategies to accessing HIV-related drugs. Grantees who did not respond received follow-up calls to encourage participation (including calls from HRSA Title III project officers). These activities generated response rates of 63 percent for Title III grantees and 48 percent for Title IV grantees, for a total of 134 returns for both programs. Each

### Purpose of the Study:

To assess the extent to which clients in Title III and IV programs access HIV/AIDS medications, and Title III and IV programs actively work to enroll clients in AIDS Drug Assistance Programs (ADAP).

TABLE 1

### PHASE I PARTICIPATION

Category		Title III	Title IV
Written Consultation Mailed		174	50
Written Consultation Returned		110	24
Response Rate		63%	48%
States/Territories Represented		35	17
Estimated HIV+ Clients Served (1998)		53,414	13,089
Gender	Male	71%	31%
	Female	28%	69%
Race	Black	52%	70%
	Hispanic	22%	18%
Age		94% ≥25 yrs	36% ages 2-12 39% ≥ 25 yrs
Increase in Clients Served 1995-98		45%	112%

variable was coded and checked, and data were entered into two separate databases (for each CARE Act program) and analyzed using SPSS. Data from Phase I provided guidance in conducting key informant interviews with Title III and IV grantees in six States—Alabama, Florida, Massachusetts, Missouri, Texas and Washington—during the second phase of the study.

Researchers selected States for follow-up interviews based on several criteria, including geographic distribution, balance of Title III and IV grantees responding to Phase I, and extent to which clients were known to have access to HIV-related drugs. Information was collected on perceived barriers and strategies for accessing drug treatment, changes needed to reduce barriers, and technical assistance needs. Thirty-one interviews were conducted, ranging from 25-60 minutes each. Participants included representatives of Title III and IV programs, one Medicaid official from each State, and the State AIDS director or ADAP manager (or both) from each State. Grantees included community-based organizations, academic medical centers and public health agencies. Interview notes were entered into Microsoft Access for analysis.

## Limitations

Researchers noted several limitations in conducting the study:

- ♦ The sample did not include all Title III and IV grantees, so a full range of patterns may not have been observed, and findings may not be applicable to all grantees.
- ♦ Assessing access to care is difficult since it requires inclusion of clients who are both receiving and not receiving care. This study focused on people with HIV who are seeking and cannot obtain care (or aspects of care), not on those who are not seeking care.

## Major Findings

Findings suggest that CARE Act programs, rather than functioning as payor of last resort, serve as gap-filling payors that are needed to varying degrees, often by the same individual, to obtain resources for quality treatment and care. Most Title III and IV grantees provide all CARE Act services, including primary care, medications, case management, and related services.

### Follow-Up Sites

Alabama ♦ Florida ♦ Massachusetts  
Missouri ♦ Texas ♦ Washington

Understanding the challenges faced by Title III and IV clients in accessing HIV-related drugs requires insight into their changing and overlapping needs. People living with HIV who access care through Title III and IV programs are primarily people of color, generally at least 25 years old, and are uniformly poor. Respondents report changing demographics, with increases in the overall number of clients, more adolescents and women without children, African Americans, and heterosexuals, and fewer gay and bisexual clients, and infants with HIV. Title III and IV providers also report increasing comorbidities among clients, such as substance abuse, mental illness, and hepatitis C.

Title III and IV grantees and sub-contractors are primarily client-centered organizations, where making health services available regardless of a client's ability to pay is as significant a part of managing HIV disease as medical care itself. Consequently, these programs have learned how to access CARE Act sources, local public programs, compassionate use programs, their own resources, and charity care to provide a range of health and social services, including HIV-related drugs—and seem to be doing this effectively. Specific findings include the following:

- ♦ **Title III and Title IV clients rely on many sources of financing for AIDS medications.**

Clearly, the ADAP is only one of several major sources of access to AIDS drugs for uninsured, under-insured, and episodically-insured persons. Drug funding sources most often accessed by Title III clients include Medicaid (about one in four grantees access it for more than one-half of their clients), ADAPs (slightly fewer than one in three grantees access it for over one-half of their clients), Title III (about one-third of grantees access it for more than one-half of their clients), and Title I (13 percent of grantees access it for more than one-half of their clients). In addition, 15 percent of Title III grantees access non-Federal public sources more than 75 percent of the time. Title IV clients rely on these same sources of financing for AIDS drugs, with even greater reliance on Medicaid than Title III clients. One-half of Title IV grantees report that more than three-quarters of their clients rely on Medicaid for AIDS medications. For people not eligible for Medicaid who are served by Title III and IV programs—such as immigrants or people who lose Medicaid coverage because of welfare reform—discretionary public and private programs, such as the CARE Act, are their primary source of drug financing.

- ♦ **While access to ADAPs facilitates access to AIDS drugs, Medicaid eligibility criteria appear to be the most significant and prominent barrier to accessing AIDS medications for Title III and Title IV clients.**

Medicaid-related issues were the most frequently mentioned barrier in both phases of the study. Generally, the most important factor in explaining ADAP variations is the relative “generosity” of State Medicaid programs (a measure of Medicaid programs’ eligibility criteria and scope of services). Because States have flexibility in setting Medicaid criteria, the extent to which a Medicaid program’s relative generosity poses a barrier is likely to vary from State to State. For instance, Massachusetts and Washington have multiple public insurance programs designed to increase the number of insured citizens, and both States offer enhanced HIV benefit programs that provide initial primary care and medication assistance. In contrast, Texas ranks first among all States in the percentage of uninsured persons, and Florida’s Medicaid criteria for their Medicaid “medically needy” program is restrictive, which increases the burden on other public health programs, including the ADAP.

Although respondents represent a range of organizations and settings, they frequently encounter the same obstacles. Chief among those mentioned were Medicaid’s application process, eligibility criteria, re-certification rules, required documentation, “aging out” of eligibility among adolescents, and loss of coverage resulting from Medicaid/welfare reform. Medicaid policy changes have recently been made or are underway in a number of States to expand access to people with HIV disease. Massachusetts has submitted an amendment to its Medicaid program, using \$10 million from tobacco settlement revenues, to expand coverage by 33 percent, enabling them to serve approximately 1,000 low-income HIV-positive individuals over a 2-year period. And Maine has recently expanded its Medicaid program to cover eligible persons with HIV.

Because Medicaid is a critical funding source for people with HIV/AIDS, the administrative challenges in receiving Medicaid coverage are of great concern. While most State ADAP applications appear to be approved within 1 or 2 weeks, a wider range of time was reported for the Medicaid application process. A national study is needed to fully evaluate this situation.

At the same time, most participants report that Medicaid services and formularies are adequately organized and financed to deliver quality HIV care. Exceptions to this generalization include States with restrictive eligibility criteria for recently-pregnant women and for adolescents who “age out” of eligibility; sanctions related to welfare reforms that cause Medicaid benefits to be suspended; States that limit the number of allowable prescriptions; and difficulties in accessing over-the-counter medications to manage side effects of HIV-related drugs.

- ♦ **Barriers to accessing drugs can best be reduced by changing Medicaid and Medicare eligibility requirements.**

Respondents from both Title III and IV programs identified broadened Medicaid/Medicare eligibility as the change most needed to reduce barriers to accessing pharmaceuticals. The second most-cited strategy was more program funding to purchase medications. Title IV respondents also named lower prices and higher discounts for medications as an important need.

- ♦ **Numerous barriers, many of them systemic, continue to confront Title III and IV clients seeking HIV-related care, in general, and HIV drugs, in particular.**

Participants identified numerous barriers to accessing primary care, medications, substance abuse treatment, housing, and mental health care (table 2, page 22). These include barriers related to geography and transportation; ADAP-related issues (including the length of time for ADAP application/renewal process, and limited ADAP drug formularies); lack of local funds for HIV and total dependence on CARE Act funds; and lack of knowledge among low-income persons with HIV about programs and eligibility.

Many other barriers to care are not systemic, but also serve as obstacles (table 2, page 22). The effects of poverty, including lack of insurance, inability to afford co-pays, and cost of medications, remain a primary barrier to care. One grantee reported a common finding, that 97.5 percent of its clients are below 300 percent of the Federal Poverty Level (FPL), while an ADAP administrator in another State indicated that 80 percent of its clients are below 200 percent of the FPL. “Co-existing problems,” such as substance abuse, homelessness, chronic mental illness and histories of trauma and violence were also frequently mentioned. Other obstacles relate to fear of disclosure and stigma associated with being HIV positive; cultural and language barriers; lack of knowledge of HIV



TABLE 2

## BARRIERS TO CARE

### System-Related Barriers

- ◆ Barriers related to geography and lack of transportation
- ◆ ADAP-related issues (e.g. length of time for ADAP application and renewal, limited ADAP drug formularies)
- ◆ Lack of providers and resources in non-urban areas
- ◆ Complexity of payment and service systems
- ◆ Lack of local funds for HIV and dependence on CARE Act funds
- ◆ Poor reputation of local public hospital
- ◆ Lack of dental care in rural areas
- ◆ Lack of coordination among services (e.g., primary care and substance abuse treatment)
- ◆ Destabilization of public health services through expansion of managed care
- ◆ Lack of HIV knowledge/insufficient provider training
- ◆ Lack of knowledge of programs and eligibility among HIV+ low-income people

### Other Barriers

- ◆ Poverty (e.g., lack of insurance, inability to afford co-payments, and cost of medications)
- ◆ Co-existing conditions (substance abuse, housing/homelessness, chronic mental illness, histories of trauma and violence)
- ◆ Fear of disclosure and stigma associated with being HIV+
- ◆ Complexity of payment and service systems
- ◆ Cultural/language barriers
- ◆ Problems related to treatment adherence and compliance with care-related appointments
- ◆ Concerns related to immigration status, including reluctance of undocumented clients to seek benefits for fear of deportation
- ◆ Lack of knowledge of HIV status
- ◆ Avoidance of care among HIV-positive individuals who are aware of their HIV status
- ◆ Distrust of health care and government
- ◆ Consumer decisions related to treatment
- ◆ Side effects of HAART

status; and distrust of health care and government. Participants also identified specific barriers to treatment access including the limited number of drugs on the ADAP formulary and challenges to adding over-the-counter drugs to an ADAP formulary; for example, thousands of separate unique codes exist for aspirin alone (table 3).

### ◆ Numerous strategies are being used, both at the State and grantee levels, to reduce these barriers to care.

Both Title III and IV grantees were well-linked to ADAPs in their States and highly evolved in their efforts to help eligible clients access AIDS drugs. Grantees were familiar with accessing other CARE Act sources, local programs, and charity care. Frequent reliance on compassionate use and other non-public sources suggests the sophistication of grantees' efforts to address access-related problems.

Given the challenges of maintaining stable funding for HIV-related medications, grantees use a variety of strategies to assemble a patchwork of payment sources to ensure client access. This includes using clinic funds to make drug co-payments or to purchase drugs directly and give them to clients, and using Title II and III funds to "bridge" eligibility gaps for clients who are waiting for ADAP approval. It also includes strategically timing highly active antiretroviral therapy (HAART) prescriptions submitted to ADAP and Medicaid to avoid exceeding monthly limits. In some States, clients on HAART who exceed the monthly prescription limit (covered by either ADAP or Medicaid) must figure out how to fill remaining prescriptions to avoid disrupting their treatment regimen. For example, Texas Medicaid has a three-prescription limit per month, so Medicaid coverage is used for the most expensive medications, including protease inhibitors, while ADAP is used for others.

Other grantees turn to compassionate use programs, and frequently use free samples from pharmaceutical companies to fill gaps in drug financing. Grantees rely on interdisciplinary team members—social workers, outreach workers, nutritionists, and psychologists—to help with benefit applications and appeals, to monitor appointment compliance and to maintain client contact. In some sites, case managers and social workers (often supported by unstable grant funding) spend all or most of their time helping clients access financing sources and services. Some grantees have made organizational changes, such as expanding walk-in clinic hours; designating a staff member to serve as ADAP liaison; locating nurse practitioners in non-urban areas; and educating staff about HAART adherence. Some States have responded by modifying ADAP programs by raising the ADAP enrollment cap; expanding the ADAP formulary to include medications to counteract side-effects of a primary drug; using State funds to pay for clients' private-sector health insurance premiums; and developing an ADAP consumer hotline. States have also trained Medicaid workers to increase their effectiveness in enrolling people with HIV disease; targeted efforts to increase Medicaid and ADAP enrollment among historically disenfranchised communities; and used specific wording in State managed-care contracts to increase the number of HIV providers.

Some strategies have been more successful than others in reducing barriers to services and medication. These include making medication available on the same day as initial appointments; helping clients access other public or private resources in clinics they use; and tapping Title III and community health center funds to cover patients' medication and laboratory costs as a "bridge" pending ADAP or Medicaid eligibility determination. Leveraging manufacturers' financial assistance programs can also improve access; for example, one grantee's efforts to obtain drugs through these programs generates \$1.4 million worth of medications per year for clients.

- ♦ **Grantees have a range of needs for additional technical assistance.**

TABLE 3

Grantees also expressed needs for technical assistance to enhance their management information systems; build staff skills to manage program and client data; inform providers on how to enhance access to Medicaid and how to best integrate HIV care into Medicaid; improve grantee and client access to the internet; simplify manufacturer assistance programs; and help establish a unique client identifier system for ADAP.

- ♦ **Specific changes at both the system and program levels can help ensure access to medications and care.**

Participants most often cited the need to expand Medicaid eligibility for adults, youth, and newborns of HIV-positive mothers (assuring access to discharge medications), and the need to eliminate State sanctions that deny Medicaid to people with HIV due to welfare reform. A second key change is increasing funds from all sources for infrastructure support and program enhancements, such as satellite sites, transportation, medications, support services, housing, outreach, mental health services, and substance abuse treatment. Other changes include making the Medicaid, ADAP, and manufacturer financial assistance program application processes easier and faster; allowing prescription refills and changes to be made by telephone; and enabling online access to Medicaid/ADAP for application and status. (All six States reported in 1998 that ADAPs coordinate eligibility with Medicaid, but only three—Missouri, Texas, and Washington—report online access to Medicaid status data.)

- ♦ **While Title III and Title IV clients and providers struggle to maintain drug access, they face other pressing and overlapping challenges not related to HIV.**

Challenges include social, financial and health-related complications, including challenges to education. The strategies to respond are numerous, and they appear to be carefully designed to accommodate an environment in which access to preventive health services and early intervention is largely a function of income. At the same time, the incentives are strong from both a medical and public health point of view to maintain financial access to medications, especially once a client has initiated HAART. These incentives have encouraged Title III and IV grantees to be creative and proactive in their solutions.

### **BARRIERS TO TREATMENT ACCESS**

- ♦ Insufficient inventory of newly-approved drugs at pharmacies
- ♦ Lack of support for adolescents at home
- ♦ Termination of Medicaid benefits eligibility for post-partum women
- ♦ Geographic distance to ADAP pharmacies and distance between ADAP and Title I pharmacies
- ♦ Inability to receive ADAP medications by mail
- ♦ Lack of experienced providers for children and adolescents
- ♦ Lack of refrigerators in clients' homes to store medications
- ♦ Medicaid prescription limitations
- ♦ Administrative challenges to adding over-the-counter drugs to an ADAP formulary

## **Recommendations**

- I. Provide technical assistance to expand use of manufacturers' financial assistance programs, HCFA waivers, quality improvement, ADAP enhancements, and adherence.**
- II. Collect and analyze program data in all CARE Act Titles on ADAP and CARE Act services utilization data through ADAP's data collection process.**
- III. Provide additional Federal and other public sector resources to improve ADAP administrative efficiency.**
- IV. Study the extent to which CARE Act providers use CARE Act funds for comprehensive treatment and support services while their clients wait for Medicaid benefits to begin or to resume.**
- V. Study the relationship between Medicaid eligibility and the continuity of HIV care for pregnant women and recently pregnant women.**
- VI. Facilitate dialogues between HCFA and States to address Medicaid barriers to accessing HIV/AIDS drugs.**
- VII. Study the accessibility and availability of HAART and its relationship between payor and client morbidity and mortality.**





