
Ryan White CARE Act and Eligible Metropolitan Areas

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Title I of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act provides emergency assistance to eligible metropolitan areas (EMAs) to provide a continuum of care and services to people living with HIV disease. This article presents the results of a 2000-2001 survey of the 51 Title I Planning Councils. EMAs are serving significant numbers of females, with black and Hispanic persons constituting a majority of people served in 33 EMAs. Among the difficult to serve are substance abusers, people with chronic mental illness, multi-diagnosed people, the homeless, black males who have sex with males, and Hispanic persons.

INTRODUCTION

Congress enacted the Ryan White CARE Act in 1990 to improve health care for low-income, uninsured, and under-insured people and their families affected by HIV disease (Health Resources and Services Administration, 2001a). Congress reauthorized the CARE Act in 1996 and again in 2000. The CARE Act funds primary care and support services, with CARE Act programs reaching more than 500,000 people each year (Health Resources and Services Administration, 2001a). During fiscal year (FY) 2001, the CARE Act programs received about \$1.8 billion in Federal funding for four titles and other programs (Health Resources and Services Administration,

2001b). In FY 2000 Care Act programs received the third largest amount (20.9 percent) of total Federal spending for human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) care and assistance (Kaiser Family Foundation, 2000a). The Federal share of Medicaid was the largest component (28.8 percent) of Federal spending for HIV/AIDS care and assistance, followed by Medicare spending (22.2 percent). Other Federal spending on this care and assistance was allocated to Social Security Disability Insurance (11.2 percent), Supplemental Security Income (5.0 percent), Veterans Affairs (5.5 percent), and Housing Opportunities for People with AIDS (3.0 percent).

CARE ACT PROGRAM

Title I of the CARE Act provides funds to metropolitan areas that are disproportionately affected by HIV/AIDS (Health Resources and Services Administration, 2001a; 2000a). Title II assists the States and territories with improving the quality, availability, and organization of health care and support services to people and families with HIV disease, including needed medications through the AIDS Drug Assistance Programs (ADAPs). Title III provides funding for early intervention and primary care services for people with HIV/AIDS. Title IV enhances access to comprehensive care for children, youth, females, and their families with or who are at risk for HIV, including access to research of potential clinical benefit. CARE Act funding also supports the development

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of innovative HIV/AIDS service delivery models through the Special Projects of National Significance Program, AIDS Education and Training Centers Program, and the HIV/AIDS Dental Reimbursement Program.

Funding

Total funding for the CARE Act increased from about \$221 million in its first year (FY 1991) to more than \$1.8 billion in FY 2001 (Health Resources and Services Administration, 2001b). The proportions of funding allocations to individual CARE Act programs have changed over time. In FY 1991, Titles I and II each received 39.8 percent of total CARE Act funding. By FY 1995, funding for Title I increased to 56.3 percent of total CARE Act appropriations, while funding for Title II declined to 31.3 percent. However, with initiation of the State AIDS Drug Assistance Programs (part of Title II) in FY 1996, and the spectacular success of protease inhibitors in the treatment of HIV infection, Title II received an increasingly larger share of CARE Act appropriations in each successive year. By FY 2001, Title II funding increased to 50.4 percent of CARE Act appropriations, while Title I funding fell to 33.4 percent.

Safety Net

The Ryan White CARE Act was designed to fill gaps in health coverage for people with HIV, serving those who are uninsured or under-insured (Kaiser Family Foundation, 2000b). The CARE Act programs, for example, can assist people with HIV who have limits to their private health insurance coverage (Kaiser Family Foundation, 2000b). CARE Act programs also can help people with HIV who are waiting for their Medicare coverage to begin (a 29-month

eligibility process). In addition, CARE Act programs can provide access to prescription drugs for Medicare beneficiaries who lack other coverage (Buchanan, Chakravorty, and Smith, 2001; Buchanan and Smith, 2001). Similarly, Medicaid recipients with HIV can utilize CARE Act programs to gain access to needed care and support services not covered by their State Medicaid programs (Buchanan, Chakravorty, and Smith, 2001; Buchanan and Smith, 2002). For many people with HIV disease, CARE Act programs are an invaluable safety net to public or private coverage of needed care and support services. The objective of this research is to show how eligible metropolitan areas are using Title I funds to provide a continuum of care and support services to people with HIV.

Title I of the CARE Act

EMAs

Title I of the CARE Act provides emergency assistance to EMAs that are most severely affected by HIV/AIDS (Health Resources and Services Administration, 2000b). To be eligible for Title I funding, an area must have at least 2,000 reported AIDS cases during the previous 5 years and a total population of at least 500,000. The first Title I grants were awarded to 16 EMAs in FY 1991, increasing to 51 EMAs in 21 States, Puerto Rico, and the District of Columbia by FY 2001. Title I programs received about \$604 million in CARE Act funding during FY 2001 (Health Resources and Services Administration, 2001b). During FY 2001, Title I funding ranged from \$807,157 for the Vineland-Milville-Bridgeton New Jersey EMA to \$119,256,891 for the New York City EMA (Health Resources and Services Administration, 2001c). Title I funding to EMAs includes

formula and supplemental components and Congressional Black Caucus funds targeted for services to minority populations (Health Resources and Services Administration, 2000b). Formula grants are based on the number of people living with AIDS over the most recent 10-year period. If accurate and reliable data exist, Title I formula funds will be based on AIDS cases and HIV infection not yet progressed to AIDS starting in FY 2004. Supplemental Title I grants are awarded competitively, based on demonstration of severe need and other factors.

Care and Services

Title I funds are used to provide a continuum of care and services to people living with HIV disease (Health Resources and Services Administration, 2000b). These services and care may include: outpatient and ambulatory health services, including substance and mental health treatment; early intervention that includes outreach, counseling and testing, and referral services to identify HIV positive people; outpatient and ambulatory support services including case management; and inpatient case management services to expedite discharge and prevent unnecessary hospitalization.

Planning Council

Each EMA has a Title I HIV Health Services Planning Council, which sets priorities and allocate funds for services based on the size, demographics, and needs of the HIV population in their EMA (Health Resources and Services Administration, 2000b). These Planning Councils also develop a comprehensive plan to provide services to people with HIV, including strategies to identify people living with HIV who are not in care. Membership of each Planning Council must reflect the local epi-

dem, including members with expertise such as health planning, housing for the homeless, incarcerated populations, substance abuse, and mental health treatment, or include members who represent other CARE Act and Federal programs. A new provision of the CARE Act Amendments enacted in October 2000 requires that at least 33 percent of Planning Council members must be people living with HIV who are consumers of CARE Act services (Health Resources and Services Administration, 2000b).

SURVEY METHODOLOGY

This research presents the results of a 2000-2001 survey of each Title I Planning Council, that describe how each EMA utilized Title I funding.¹ The survey questionnaire collected Title I/EMA data for 1999 and 2000, including the number of people receiving benefits in each EMA, as well as the percentage of beneficiaries who were females, black, or Hispanic persons. The questionnaire included a section on medical and financial eligibility criteria. The survey asked if the EMA implemented a waiting list, and if a list was used, the number of people on the list, the average wait until benefits were received, and how people advanced on the list. The questionnaire asked how Title I funds were allocated among various service categories and each EMA was asked to list the five services provided to clients that the Planning Council had assigned the highest priority during 2000. The questionnaire asked a series of questions about Title I funding for medications in each EMA. The questionnaire concluded by asking for a list of populations that are difficult to serve in each EMA, as well as a request to discuss any barriers to serving these populations.

¹ Contact the author for detailed tables that summarize the survey responses from each EMA.

The survey was sent to the chair of the Planning Council in each of the 51 EMAs. A current mailing list of the chair of each Planning Council was obtained from the HIV/AIDS Bureau of the Health Resources and Services Administration (2001d). The 2000-2001 survey began in late January 2000. Nine additional mailings of the questionnaire were sent to those EMAs not responding at about 6-8 week intervals. By April 2001, responses were received from 50 EMAs. The results of the survey were summarized into tables during April 2001. These summary tables were mailed to survey respondents in April 2001 for verification, corrections, and any updates. During this verification process a completed questionnaire was also received from the 51st EMA, including all EMAs in the study. This verification process was completed by July 1, 2001.

SURVEY RESULTS

Title I Beneficiaries

The number of people who received Title I-funded services during 2000 ranged from fewer than 1,000 people in some EMAs to as many as 50,000 people in the EMA serving New York City. The survey questionnaire asked how the number of Title I beneficiaries in each EMA compared with the number of beneficiaries during 1999. Almost all EMAs reported that the number of Title I beneficiaries increased in 2000 compared with 1999. The survey results also documented that a diversity of people received Title I-funded services during 2000 and this diversity varied around the United States. For example, at least 40 percent of Title I beneficiaries were females in the EMAs serving New York City, Nassau/Suffolk Counties (New York), New Haven (Connecticut), Ponce (Puerto Rico.), West Palm Beach (Florida), and the various

EMAs throughout New Jersey. In contrast, less than 20 percent of Title I beneficiaries were females in a number of EMAs that are mostly located in the western United States.

Minorities are major beneficiaries of Title I-funded services, with black and Hispanic persons constituting a majority of people served in 33 EMAs. Black persons were a majority of Title I beneficiaries in at least 17 EMAs during 2000, with almost one-half of the EMAs reporting that black persons comprised at least 40 percent of Title I beneficiaries. These EMAs serving large numbers of black persons tended to be located in the north central, southeast, and eastern regions of the United States. At least 13 EMAs reported that Hispanics were at least 30 percent of Title I beneficiaries in their service areas during 2000. These EMAs were located in Puerto Rico, the north eastern United States, Dade County (Florida), Los Angeles County (California), Orange County (California), and San Antonio (Texas). Surprisingly, Hispanic persons were less than 30 percent of Title I beneficiaries in other EMAs located in the southwestern region of the United States, notably the other EMAs in Texas, Phoenix (Arizona), and parts of California.

Eligibility Policies

Medical

The medical eligibility criteria implemented by almost all EMAs in 2000 required only that an individual be HIV positive. Some EMAs had additional medical eligibility criteria for certain services. For example, the EMA in Minneapolis (Minnesota) responded to the survey that people with HIV in its service area were also required to meet the Social Security determination of disabled to receive home health services during 2000. The EMA in

San Francisco (California) responded to the survey that medical eligibility criteria vary with the different services and that some programs require a diagnosis of disabling HIV. However, in the areas served by the San Francisco EMA there were no other criteria besides HIV positive status for access to medical care during 2000.

Financial

The survey collected financial eligibility criteria implemented during 2000 for both a one-person household and for a four-person household. At least 20 EMAs reported in the survey that they did not implement income-related financial eligibility criteria for Title I-funded services during 2000. The income-related criteria that were established by the other EMAs in 2000 tended to be generous compared with Medicaid, with most of these EMAs setting income levels at least twice the Federal poverty level. The financial eligibility criteria implemented by almost all EMAs in 2000 remained the same when compared with these policies in place during 1999.

Client Fees

The questionnaire asked if each EMA charged clients for services during 2000. At least 15 EMAs responded to the survey that clients could be charged for at least some services. For example, the Orange County Planning Council in California reported that, while there was no charge for most services in their EMA during 2000, there was a charge for medical and mental health services provided to clients who exceeded financial eligibility requirements. However, all EMAs charging clients for services in 2000 utilized a sliding scale fee schedule to charge clients for services, based on the clients' income.

Waiting Lists

The questionnaire asked if each EMA had a list of people waiting to receive services funded by Title I during 1999. At least 15 EMAs utilized waiting lists in 1999 for at least some services. The number of people waiting in these EMAs for services ranged from as low as 5-7 people in Austin (Texas) to as many as 300 people in Seattle (Washington). In some areas, the EMAs reported that these waiting lists were for specific services, such as dental care in Ft. Worth (Texas), housing in Hudson County (New Jersey), and complementary therapies in San Diego (California). The length of wait varied among the EMAs, from a 5-day wait in Austin for up to an 18-month wait for Section 8 housing in Seattle. The San Francisco EMA reported that more than 4,000 people with HIV were waiting an average of 7-10 years for housing. The Hartford (Connecticut) EMA reported up to a 6-month wait for housing and the Ft. Worth EMA reported a 6-month wait for dental services.

The questionnaire also asked how people advanced on the waiting list, giving the following options for response: seniority/length of time on the waiting list; the most critically/severely ill, people with the potential for deriving the greatest improvement in their health condition, other (explanation requested). The EMAs used either seniority/length of time to advance people on their waiting lists during 1999 or a combination of seniority and the most critically or severely ill receiving priority. The EMAs also were asked if they implemented waiting lists during 2000, with at least 15 EMAs implementing, or expecting to implement, waiting lists in 2000.

Services Provided to Clients

Allocation of Funds

The questionnaire asked how Title I funds were allocated in each EMA during 2000, providing the following categories for responses: health care services; case management; support services; administration, Planning Council support, program support; and other (explain requested). Most EMAs allocated the largest percentage of Title I funds to health care services, although many EMAs, such as those in Bergen/Passaic (New Jersey), Boston (Massachusetts), or San Francisco, allocated the largest percentage of their Title I funds to support services.

Priority Services

The questionnaire also asked which services provided to clients were designated by the Planning Council as the five highest priority services in each EMA during 2000. There was a diversity of priority services among the 51 EMAs during 2000. Among those services consistently mentioned were primary care/medical care, case management, medications/medicines, dental care, substance abuse treatments, mental health services, and support services such as housing assistance, emergency financial assistance, home-delivered meals, and food/nutrition programs.

Other Beneficial Services

In addition to those services that received high priority rankings by the Planning Council, the questionnaire asked about other services provided with Title I funding that clients considered beneficial in each EMA. The EMAs reported a wide-ranging array of health care and support services provided with Title I funds that

were beneficial to people with HIV and their families in the EMAs. Among these other beneficial services provided with Title I funds were complementary or alternative therapies, respite care, client advocacy, transportation, home-delivered meals, food banks/pantry, buddy/companion services, children's hospice care, child day care, home health care, legal services, and outreach/access programs funded by the Congressional Black Caucus.

Medications

Providing medications to clients was a high priority for the Planning Councils in many EMAs during 2000, based on the survey responses. The questionnaire included a series of questions focusing on the allocation of Title I funds to medications in each EMA during 2000. The questionnaire asked for estimates of the percentage of Title I funds allocated to medications in each EMA during 2000, separate from any allocation of Title I funds to the State ADAP. The percentage of Title I funds allocated to medications (other than to the State ADAPs) varied widely among the EMAs, ranging from 1 percent or less in at least 15 EMAs to as high as 25 percent in Caguas, 38.6 percent in San Juan, and 44 percent in Ponce (Puerto Rico). The questionnaire also asked if any Title I funds were allocated to the State ADAP during 2000, with at least 14 EMAs reporting this allocation to their State ADAP. For those EMAs allocating Title I funds to the State ADAP, the percentages ranged from less than 1 percent in Baltimore (Maryland) to 18 percent in New York City.

Difficult-to-Serve Clients

The survey asked about any populations that were difficult to serve in each EMA's service area. Among the difficult to serve

populations were substance abusers, people with chronic mental illness, multi-diagnosed people (HIV positive, substance-using, and mentally ill), the homeless, black males who have sex with males, Hispanic and Spanish-speaking people, people recently released from incarceration, the Haitian community, and migrants. A number of EMAs, including three of the EMAs in Texas, also reported that people living in rural parts of their service area were difficult to serve.

The survey also requested that respondents discuss any barriers to reaching these difficult to serve groups of people in their service areas. Among the most frequently mentioned barriers were issues relating to mental illness and substance abuse. Other factors mentioned were cultural and language barriers, the stigma of AIDS/HIV, lack of transportation to care, the need to coordinate care for recently incarcerated people, and the lack of housing.

SUMMARY

Title I of the CARE Act provides emergency assistance to EMAs to provide a continuum of care and services to people living with HIV disease. Programs funded by Title I of the Ryan White CARE Act are serving significant numbers of females in many EMAs. In addition, black and Hispanic persons constitute a majority of people served in 33 EMAs. The medical eligibility criteria in almost all EMAs required only that an individual be HIV positive, while some EMAs had additional medical eligibility criteria for certain services. Twenty EMAs reported that they did not implement income-related financial eligibility criteria for Title I-funded services during 2000 and criteria tended to be generous for

those EMAs with financial eligibility requirements, with most of these EMAs setting income levels at least twice the Federal poverty level. At least 15 EMAs utilized waiting lists in 1999 for certain services. In addition, 15 EMAs either implemented or expected to implement waiting lists during 2000. Some EMAs charged clients for services, with all these EMAs utilizing a sliding scale fee schedule based on the clients' incomes.

Most EMAs allocated the largest percentage of Title I funds to health care services, although many EMAs allocated the largest percentage of their Title I funds to support services. Among the services consistently mentioned as high priority were primary care/medical care, case management, medications/medicines, dental care, substance abuse treatments, mental health services, and support services such as housing assistance and emergency financial assistance. Among other beneficial services provided with Title I funds were complementary or alternative therapies, respite care, client advocacy, transportation, home-delivered meals, food banks/pantry, buddy/companion services, children's hospice care, child day care, and outreach/access programs funded by the Congressional Black Caucus. Most, if not all, of these other beneficial services are not covered by the State Medicaid programs or by Medicare.

Among populations that are difficult to serve in many EMAs are substance abusers, people with chronic mental illness, multi-diagnosed people (HIV positive, substance using, and mentally ill), the homeless, and black males who have sex with males. Among the most frequently mentioned barriers to serving these populations were issues relating to mental illness and substance abuse.

DISCUSSION

Currently, there are as many as 900,000 people living with HIV disease in the United States, with about 40,000 new infections in this country each year (Centers for Disease Control and Prevention, 2001a). Focusing on the risk categories of newly infected people, 42 percent are males who have sex with males, 33 percent are males and females infected through heterosexual contact, and 25 percent are injection drug users (Centers for Disease Control and Prevention, 2001a). More than one-half of new HIV infections occur among black persons (54 percent), while 19 percent of new HIV infections are Hispanic persons, and 26 percent are white persons (Centers for Disease Control and Prevention, 2001a). Almost two in three newly infected females are black (Centers for Disease Control and Prevention, 2001a). In addition, evidence suggests a resurgence of the HIV epidemic among young males who have sex with males, with one study finding that the HIV prevalence was 32 percent among young black males who have sex with males (Centers for Disease Control and Prevention, 2001b).

Better treatment has also resulted in an increasing number of people living with advanced HIV disease in the United States, with about 323,000 Americans now living with AIDS (Centers for Disease Control and Prevention, 2001a). The growing number of Americans living with AIDS, the 40,000 people newly infected with HIV each year, and the possible resurgence of HIV among young males having sex with males increase the need for HIV prevention, treatment, and care-related services for people with HIV disease in the United States. This increasing need for HIV-related treatment and care services indicates a growing demand for services funded by the Ryan White CARE Act. Already, a num-

ber of States have implemented waiting lists for medications provided by the State ADAPs and services provided by HIV Care Consortia funded by Title II of the CARE Act (Buchanan, Chakravorty, and Smith, 2001; Buchanan and Smith, 2002). This study documents that at least 15 EMAs reported the use of waiting lists for services funded by Title I of the CARE Act.

Congress appropriated over \$1.9 billion for the CARE Act programs for FY 2002, an increase of \$111 million (or 6.1 percent) over FY 2001 (The Body, 2001). For FY 2002, Congress appropriated about \$620 million for Title I (an increase of \$15.3 million or 2.5 percent), about \$338 for the Title II base (an increase of \$16.4 million or 5.1 percent), and \$639 for the Title II - ADAPs (an increase of \$50 million or 8.5 percent). However, this increased funding may not be sufficient to allow the CARE Act programs to adequately care for people with HIV disease. For example, the National Organizations Responding to AIDS argues that total CARE Act funding for FY 2002 should be almost \$2.1 billion to assure an appropriate Federal response to the HIV/AIDS epidemic (San Francisco AIDS Foundation, 2001). For FY 2002, the National Organizations Responding to AIDS advocates spending of \$634 million for Title I, \$367 million for the Title II base, and \$719 million for Title II - ADAPs.

As this study demonstrates, the EMAs funded by Title I of the Ryan White CARE Act are serving a large number of females and minority clients, with 33 EMAs serving clients who are mostly black and Hispanic persons. The CARE Act was created to assist low-income people with HIV, who have no or inadequate health coverage, receive primary care and support services. Inadequate funding for the Ryan White CARE Act will harm the most vulnerable people living with HIV in the United States.

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