

Department of Health and Human Services

**OFFICE OF
INSPECTOR GENERAL**

THE RYAN WHITE CARE ACT:

LOCAL IMPLEMENTATION ISSUES



JUNE GIBBS BROWN
Inspector General

JUNE 1995
OEI-05-93-00336

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This report was prepared under the direction of William C. Moran, Regional Inspector General, and Natalie Coen, Deputy Regional Inspector General, Office of Evaluation and Inspections, Region V. Participating in this project were:

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EXECUTIVE SUMMARY

PURPOSE

To describe local implementation issues facing Ryan White grantees.

Reauthorization Studies

The Ryan White Comprehensive AIDS Resources Emergency Act of 1990 (the Act) expires in 1995 and its first reauthorization is pending before Congress. We have previously examined the Act's funding formulas, reviewed data on expenditures, and analyzed consortia activities and special projects of national significance. In addition, we studied current Centers for Disease Control and Prevention statistics and other reports describing the spread of the disease.

In this current report, we utilize data both from our previous reports and from more current field work in developing our findings and recommendations. The more recent field work occurred in seven major cities that comprise 43 percent of the 1994 Title I Ryan White funding. As a part of our visits to those cities, we reviewed funding and service plans along with progress reports; listened to issues discussed and deliberations held at planning council and committee meetings; visited and observed on-going operations at a wide variety of local providers who receive funding from a variety of sources including Ryan White; examined minutes of meetings and other material collected on site; and held discussions with a range of respondents including public health officials, grantee administrators, local providers, and persons with HIV/AIDS.

BACKGROUND

The Act was created as a comprehensive response to the HIV epidemic and its impact on individuals, families, communities, cities, and States. The Act was designed to provide health care to those who would otherwise not have access to health care. It was also meant to provide emergency relief funding to communities with the highest number of reported AIDS cases.

The Health Resources and Services Administration (HRSA) within the Public Health Service administers the Act. In fiscal year 1994, grantees received \$579.4 million in Ryan White funds from the funded provisions of the Act.

FINDINGS

Emerging HIV/AIDS populations present service delivery problems for Ryan White grantees

HIV/AIDS is increasing among minorities, women, immigrants, young people, and those who do not speak English. In all likelihood, the number of those infected in the emerging HIV/AIDS populations is greatly underestimated. In minority, immigrant, and non-English speaking communities, cultural mores often discourage those who might be infected with HIV/AIDS from being tested or seeking treatment. The emerging populations affected by HIV/AIDS are difficult to serve because of their many needs and often their overwhelming poverty further complicates their treatment. In addition to living with HIV/AIDS, they may also suffer from substance abuse or addiction, homelessness, mental illness, or other conditions requiring considerable care.

In spite of efforts by grantees, many respondents believe that Ryan White programs do not serve minorities and other emerging populations as well as they should

In each city visited, respondents spoke of the gaps in services or lack of facilities for these populations. Many also pointed to the lack of cultural, language, or gender appropriate programs. In some cities, services for emerging populations exist, but geography and/or lack of transportation make them difficult to access.

Little program outcome evaluation has been undertaken at the national or local levels

While individual success stories in problem areas can be identified in each community we visited, little program outcome evaluation has been undertaken that measures whether the Act is accomplishing its overall goals. Client satisfaction surveys are relatively widespread among providers at the local level, but these surveys are limited to an assessment of an individual provider's services rather than a comprehensive evaluation of the Ryan White program in their communities.

RECOMMENDATIONS

The HRSA should work with Ryan White grantees to identify and disseminate ways to serve the emerging populations affected by HIV/AIDS

The Public Health Service should develop practical ways to determine whether Ryan White program goals are being accomplished overall and by individual grantees

AGENCY COMMENTS

We received comments from the Assistant Secretary for Planning and Evaluation, and the Assistant Secretary for Health. Both support the recommendations and suggested pertinent clarifications. Their comments are included in Appendices A and B respectively. We made appropriate revisions to the report based on their comments.

TABLE OF CONTENTS

	PAGE
EXECUTIVE SUMMARY	
INTRODUCTION	1
FINDINGS	5
•Facing service delivery problems	5
•Difficulties serving new HIV/AIDS populations	7
•Evaluating the Ryan White program	8
RECOMMENDATIONS	11
AGENCY COMMENTS	12
APPENDIX A	A-1
APPENDIX B	B-1

INTRODUCTION

PURPOSE

To describe local implementation issues facing Ryan White grantees.

Reauthorization Studies

The Ryan White Comprehensive AIDS Resources Emergency Act of 1990 (the Act) expires in 1995 and its first reauthorization is pending before Congress. We have previously examined the Act's funding formulas, reviewed data on expenditures, and analyzed consortia activities and special projects of national significance. In addition, we studied current Centers for Disease Control and Prevention statistics and other reports describing the spread of the disease.

In this current report, we supplement previously acquired data with observations and discussions at the local level. These included our attending planning council and committee meetings; visiting local project sites and providers; holding discussions with grantee administrators, project staff, providers, and persons with HIV/AIDS¹; and reviewing funding and service plans, and progress reports.

This study is complemented by another report, *Examples of Local Coordination* (OEI-05-93-00335) that describes experiences of Ryan White grantees. The previous Ryan White CARE Act reports are: *Funding Formulas* (OEI-05-93-00330); *FY 1992 Title I and Title II Expenditures* (OEI-05-93-00331); *Consortia Activities* (OEI-05-93-00333); *FY 1992 Special Projects of National Significance - Expenditures by Service* (OEI-05-93-00332); and, *Technical Report of 1992 Expenditures* (OEI-05-93-00334). The General Accounting Office (GAO) recently released a report describing the extent to which Ryan White services are provided to minorities, women, and substance abusers. While GAO did not examine the barriers to providing Ryan White services to these emerging HIV/AIDS populations, their findings dovetail with this report regarding grantees' limitations in treating these populations.

BACKGROUND

In response to over 128,000 cases of AIDS reported to the Centers for Disease Control and Prevention (CDC), the 78,000 AIDS deaths, and the nearly one million infected with HIV, Congress passed The Ryan White Comprehensive AIDS Resources Emergency Act of 1990. The Act was created as a comprehensive response to the

¹ Since the Ryan White Act enables grantees to deliver a wide range of services to people diagnosed with either HIV or AIDS, this report uses the term "HIV/AIDS" to refer to either or both groups of Ryan White clients.

HIV epidemic and its impact on individuals, families, communities, cities, and States. The Act was designed to provide health care to persons with HIV/AIDS who would otherwise not have access to health care. It was also meant to provide emergency relief funding to communities with the highest number of reported AIDS cases.

Congress attempted to meet a number of needs with the Act. They attempted to address the needs of urban areas hit hardest by the epidemic, and to assist smaller cities and rural areas experiencing rapid rates of growth. They also intended to confront emerging problems facing local public and private organizations.

As a result, the Act is multifaceted, with four titles directing resources to various entities and allowing grantees maximum flexibility in the use of funds, particularly at the local level. The Federal role is minimized in favor of State and local control. The Health Resources and Services Administration (HRSA) within the Public Health Service administers the Act. In fiscal year (FY) 1994, grantees received \$579.4 million in Ryan White funds.

Title I - Grants to Cities

Title I provides emergency relief grants to eligible metropolitan areas (EMAs) disproportionately affected by the HIV epidemic. Congress intended these funds to relieve the overwhelming burden that HIV imposed on urban health care systems. Grants are for HIV-related outpatient and ambulatory health and support services, including case management and comprehensive treatment services. Title I funds comprise 56 percent of the FY 1994 Ryan White appropriation.

Grants are awarded to cities, specifically to the chief elected official (CEO) that administers the public agency providing outpatient and ambulatory services to the greatest number of individuals with AIDS, in most cases the public health agency.

Under Title I, the CEO is required to establish a planning council representing health and social service agencies, individuals with AIDS, State government, community leaders, AIDS organizations, and others. This planning council is responsible for: (1) establishing priorities for the allocation of funds, (2) developing a comprehensive plan for the organization and delivery of services, and (3) assessing the efficiency of the administrative mechanism in rapidly allocating the funds to areas of greatest need within the EMA.

Public or non-profit private organizations are eligible for funding to provide services on a contract basis with the EMA. These organizations include hospitals, community-based organizations, hospices, ambulatory care facilities, community, homeless and migrant health centers.

Title II- Grants to States

Title II provides grants to States and territories to improve the quality, availability and organization of health care and support services for individuals and families with HIV disease. A major intent of Title II was to develop service delivery systems to provide essential services throughout the complex course of HIV disease. Title II funds comprise 32 percent of the FY 1994 Ryan White appropriation.

States have the option of using Title II funds in one or more of the following ways. They may establish HIV care consortia in areas most directly affected by the disease. Consortia are community-based, coordinated, continuums of care to which all persons with HIV/AIDS would have access. These continuums of care are intended to close existing gaps in services, coordinate health and support services, build community infrastructure and service networks with an emphasis on integration of expanded community resources, and provide continuity of care through case management.

Other State options for Title II funds include providing home and community-based care services, including outreach services to individuals in rural areas. States may also furnish medications that prolong life or prevent serious deterioration of health. In addition, they may also provide assistance to assure the continuity of health insurance coverage.

Title III(b) - Grants to Community Health Providers

Title III(b) supports early intervention services on an out-patient basis, including counseling, testing, referrals, clinical and diagnostic services, and other therapeutic services. It provides competitive grants to private non-profit organizations and public migrant, community, and homeless health centers, hemophilia centers, and federally-qualified health centers. Title III(b) funds comprise 8 percent of the FY 1994 Ryan White appropriation.

Title IV - Grants for Pediatric AIDS

Title IV aims to improve and expand the system of comprehensive care services and increase access to research for children, youth, women and families who are infected with or affected by HIV/AIDS. Title IV grantees provide, arrange, or coordinate a wide range of services. These services include prevention and education activities, primary medical care, psychosocial services, substance abuse treatment, housing, child welfare, legal advocacy, and other support activities. Comprehensive systems of care are linked with clinical research trials and other research activities, intended to increase access for a target population of children, youth, women and families. Title IV funds comprise 4 percent of the FY 1994 Ryan White appropriation.