THE RYAN WHITE CARE ACT:
SPECIAL PROJECTS OF NATIONAL SIGNIFICANCE
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This inspection was performed 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 the project were:

Barbara Butz (Project Leader)
Jean DuFresne

For a copy of this report, please call (312) 353-4124.
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PURPOSE

To describe grantee expenditures under the Ryan White Act's Special Projects of National Significance.

BACKGROUND

On August 18, 1990, Congress passed Public Law 101-381 entitled The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 (the Act). The purpose of the Act was to provide "emergency assistance to localities disproportionately affected by the Human Immunodeficiency Virus (HIV) epidemic and to make financial assistance available to States and other public or private nonprofit entities to provide for the development, organization, coordination and operation of more effective and cost efficient systems for the delivery of essential services to individuals and families with HIV disease." Congress funded the Ryan White Act at about $221 million for Fiscal Year (FY) 1991, $276 million for FY 1992, and $348 million for FY 1993. The FY 1994 appropriation is $579.4 million.

The Act, which is administered by the Health Resources Services Administration (HRSA) within the Public Health Service (PHS), 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. Title I provides emergency relief grants to cities, or eligible metropolitan areas, disproportionately affected by the HIV epidemic. Title II provides formula 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. Title III(a), intended to provide formula grants to States for early intervention services on an outpatient basis, has not been funded to date. Title III(b) supports early intervention services on an out-patient basis, including counseling, testing, referrals, clinical and diagnostic services, and other therapeutic services. Title IV was to provide demonstration grants for research and services for pediatric patients, and requires studies on partner notification and HIV disease in rural areas. Congress appropriated $22 million for FY 1994 for existing HRSA pediatric and adolescent AIDS demonstration projects to be folded into Title IV.

Special Projects of National Significance

Up to 10 percent of funds appropriated for Title II may be set aside for Special Projects of National Significance (SPNS) grants. The SPNS grants are competitive grants to public and private nonprofit entities for special projects that advance knowledge and skills in the delivery of health and support services to persons with HIV or AIDS. Projects are also chosen for their potential for national replication and must include provisions for internal evaluation and dissemination of findings. Grants are provided on a 3-year cycle.
In FY 1991, Title II was funded at $88 million, and out of this, about $4.4 million went to 22 SPNS grantees with actual spending occurring in FY 1992.1 In FY 1992, $5.7 million was appropriated for 26 SPNS projects to spend in FY 1993. The next year, the projects were funded at $6.3 million. For FY 1994, nearly $11 million was appropriated for SPNS grantees to spend in FY 1995. See Appendix A for a description of the 22 SPNS projects funded in FY 1991 (1992).

Projects must target one of the following goals:

- Improve access to health and support services through the reduction of sociocultural, financial and/or logistical barriers as especially experienced by rural residents, women, children, adolescents, incarcerated persons, recently released inmates, American Indians and Alaska Natives.

- Provide advocacy services to ensure adequate, appropriate and timely receipt of health and support services.

- Reduce social isolation of people with HIV to improve their quality of life.

- Integrate mental health services with primary care services to develop a comprehensive treatment regimen.

Grantees submit annual reports which contain a description of the project’s progress in reaching the goal(s) and objectives stated in their management plan. The management plan is required as part of the grant application, and must describe measurable project objectives that specifically relate to the selected service goal (such as access), the project’s methodology, and the population to be served by the proposed project. The annual progress report must also include descriptions of any problems encountered, steps taken to remedy the problems, and any significant findings to date. Continuation funding decisions are based upon these reports.

SCOPE AND METHODOLOGY

The Ryan White Act will come up for reauthorization in FY 1996. This study is one in a series of studies on the implementation of the Ryan White Act which will provide information useful for the debate surrounding reauthorization. The other reports are:

The Ryan White CARE Act: Funding Formulas
OEI-05-93-00330

The Ryan White CARE Act: FY 1992 Title I and Title II Expenditures By Service
OEI-05-93-00331

1The fiscal year for regular Title II grantees begins in April following the beginning of the fiscal year. However, due to the competitive nature of the grants, SPNS grantees do not receive their awards until the following October, creating a year delay in spending. This created some initial confusion in our requests for information from both HRSA and the grantees. However, appropriated FY 1991 funds were spent and reported on by the grantees as FY 1992 funds, and are so regarded in this report.
To obtain information regarding SPNS service category expenditures we used information in the "HRSA AIDS Activities" manual issued in December 1992, as well as grantee award and expenditure information given to us by HRSA. We also contacted some of the grantees for this information.

This inspection was conducted in accordance with the *Standards for Inspections* issued by the President’s Council on Integrity and Efficiency.
FINDINGS

SPNS GRANTEE ACTIVITIES

The SPNS grant awards for FY 1992 ranged from about $112,000 to $275,000. The scope of the projects varied widely. For example, with a grant of approximately $142,000, one project recruited older women from the African-American communities in their city to volunteer as emotional support persons and network conveners for African-American women with HIV disease. For about the same grant amount, another grantee conducted anti-discrimination activities by operating a hotline, developing multi-lingual brochures, developing a directory of resources and coordinating the activities of public and private agencies capable of addressing HIV discrimination. Several of the grantees focused on coordinating mental health services with primary care services, and one of the grantees tested a model for training members of minority populations as community health advisors in rural counties.

Below are the SPNS service goals and target populations as served by the SPNS grantees:2

<table>
<thead>
<tr>
<th>Service Goals</th>
<th>Target Populations</th>
</tr>
</thead>
<tbody>
<tr>
<td>access - 13 grantees;</td>
<td>rural - 3 grantees;</td>
</tr>
<tr>
<td>advocacy services - 6</td>
<td>women - 3 grantees;</td>
</tr>
<tr>
<td>grantees; social</td>
<td>children - 3 grantees;</td>
</tr>
<tr>
<td>isolation - 5 grantees;</td>
<td>adolescents - 1 grantees;</td>
</tr>
<tr>
<td>mental health - 6</td>
<td>prison inmates - 2 grantees;</td>
</tr>
<tr>
<td>grantees.</td>
<td>recently released inmates - 3 grantees;</td>
</tr>
<tr>
<td></td>
<td>Native Americans - 1 grantees;</td>
</tr>
<tr>
<td></td>
<td>open population - 3 grantees.</td>
</tr>
</tbody>
</table>

Grantees include community based service organizations (10), State and local health departments (6), public or private hospitals (3), institutions of higher education (2), and national service provider organizations (1). In terms of geographic distribution, 11 of the projects are located in the east, four each are located in the midwest and the south, and two are located in the west. One project is located in Puerto Rico.

SPNS EXPENDITURES

From the FY 1991 appropriation, HRSA granted $4.4 million to 22 SPNS grantees to spend in FY 1992. We found that the grantees actually spent $3.3 million, or 75 percent

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2The numbers of grantees add up to more than 22 because some projects address more than one service or population.
of the awarded money, leaving over $1 million to carry over into the next year. We divide expenditures into four broad categories: medical services, support services, pharmaceuticals, and administration/planning and evaluation. The medical services and support services categories are comprised of a number of services which are broken out in Table 1. Below, Figure 1 shows that 22 percent of the funds were spent on medical services, 65 percent went to support services, less than 1 percent went to pharmaceuticals, and at least 12 percent were expended on administration and planning and evaluation.

It is important to keep in mind that due to the innovative natures of the SPNS grantees, actual services provided by the grantees may change from year to year.

### FY 1992 SPNS Expenditures

**Figure 1**

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Services</td>
<td>22%</td>
</tr>
<tr>
<td>Support Services</td>
<td>65%</td>
</tr>
<tr>
<td>Pharmaceuticals</td>
<td>1%</td>
</tr>
<tr>
<td>Admin/Planning</td>
<td>12%</td>
</tr>
</tbody>
</table>

Table 1 breaks out SPNS grantee expenditures by actual service (as opposed to category or goal) provided. We obtained this information in two ways. First, if the SPNS project was specific in the service it provided, such as mental health counseling, we used information provided to us by HRSA.

Second, if their activities involved more than one service, we contacted the grantees directly. The grantees we contacted were able to provide us with specific information to varying degrees. Some grantees could only describe general areas of expenditure while others provided specific amounts and services. For example, one grantee explained that costs for mental health counseling, outreach, and education/risk reduction, were all included under the heading "case management." Also, in one case, the amount spent reported by the grantee did not match the amount given to us by HRSA. In this case we used the amount reported by the grantee as it was specifically broken down by service.
<table>
<thead>
<tr>
<th>SERVICES</th>
<th>FY 1992 EXPEND.</th>
<th>TOTAL %</th>
<th>GRANTEES</th>
</tr>
</thead>
<tbody>
<tr>
<td>TOTAL</td>
<td>$3,326,956</td>
<td>100%</td>
<td>22</td>
</tr>
<tr>
<td>Pharmaceutical</td>
<td>$8,385</td>
<td>*</td>
<td>2</td>
</tr>
<tr>
<td><strong>Medical Services</strong></td>
<td>$730,218</td>
<td>22%</td>
<td></td>
</tr>
<tr>
<td>Mental Health Treatment/Therapy/Counseling</td>
<td>$712,123</td>
<td>21%</td>
<td>6</td>
</tr>
<tr>
<td>Dental Care</td>
<td>$15,575</td>
<td>*</td>
<td>2</td>
</tr>
<tr>
<td>Medical Care</td>
<td>$2,520</td>
<td>*</td>
<td>1</td>
</tr>
<tr>
<td><strong>Support Services</strong></td>
<td>$2,172,370</td>
<td>65%</td>
<td></td>
</tr>
<tr>
<td>Case Management</td>
<td>$1,028,730</td>
<td>31%</td>
<td>9</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td>$787,293</td>
<td>24%</td>
<td>7</td>
</tr>
<tr>
<td>Outreach</td>
<td>$239,095</td>
<td>7%</td>
<td>3</td>
</tr>
<tr>
<td>Housing Assistance</td>
<td>$37,925</td>
<td>1%</td>
<td>1</td>
</tr>
<tr>
<td>Education/Risk Reduction</td>
<td>$22,588</td>
<td>*</td>
<td>1</td>
</tr>
<tr>
<td>Other Counseling/Not Mental Health</td>
<td>$19,121</td>
<td>*</td>
<td>1</td>
</tr>
<tr>
<td>Transportation</td>
<td>$17,004</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>Client Advocacy</td>
<td>$9,561</td>
<td>*</td>
<td>1</td>
</tr>
<tr>
<td>Food Bank/Home Delivered Meals</td>
<td>$5,935</td>
<td>*</td>
<td>3</td>
</tr>
<tr>
<td>Emergency Financial Assistance</td>
<td>$5,118</td>
<td>*</td>
<td>1</td>
</tr>
<tr>
<td><strong>Admin/Planning</strong></td>
<td>$415,983</td>
<td>13%</td>
<td></td>
</tr>
<tr>
<td>Administration</td>
<td>$321,936</td>
<td>10%</td>
<td>22</td>
</tr>
<tr>
<td>Planning &amp; Evaluation</td>
<td>$94,047</td>
<td>3%</td>
<td>3</td>
</tr>
</tbody>
</table>

*Indicates less than 1 percent.

Table 1

3 This category presents dollars related to direct medical services. For this reason, we place case management in "support services" rather than "medical services."

4 These activities include anti-discrimination activities, the development of support networks, and the training of cultural advisors.

5 For grantees that we did not directly contact, we assumed 5 percent of funds were spent for administration because the grantees we did contact often allocated significantly more than 5 percent to administration. According to HRSA, because of the innovative nature of their work, SPNS grantees are not held to the same 5 percent cap as other grantees under Title II. Therefore, we believe 5 percent is a conservative estimate. We did not make the same 5 percent assumption for planning and evaluation, as these expenditures must be built into the project design.
THE SPNS GRANTEES:

Arecibo Municipal Government
Arecibo, Puerto Rico

This project identifies women and children with HIV disease in five low-income housing projects, and attempts to improve their access to medical and psychosocial services through coordination with private and public agencies.

Association for the Care of Children’s Health
Bethesda, Maryland

This project assists communities to develop local family-to-family support networks in order to reduce isolation and increase social and emotional support for families affected by HIV disease.

Chase-Breton Clinic, Inc.
Baltimore, Maryland

The Chase-Breton Clinic provides a basic mental health assessment for its HIV-infected clients and offers case management services to clients following the assessment.

The Damien Center, Inc.
Indianapolis, Indiana

The Indiana HIV Advocacy Program attempts to increase access to care for HIV-infected people by eliminating the barrier of discrimination. To this end, the Advocacy Program educates legislators and others about civil rights protection for HIV-infected persons, strengthens linkages between advocacy resources and creates new resources in targeted areas, uses the Indiana HIV Services Coalition to advocate for protection for HIV-infected persons, and maintains a data base of collected discrimination cases against HIV-infected persons.

Family Planning Council of Southeastern Pennsylvania
Philadelphia, Pennsylvania

The Inmates and AIDS Intervention Program assists HIV-infected inmates and their dependents receive care in the community after their release or parole.
The Fortune Society, Inc.  
New York, New York

Through its ETHICS II program, The Fortune Society addresses the needs of recently released inmates with HIV disease. The goals are to train new staff to provide services including counseling, education, career development, court advocacy, and outpatient drug treatment.

Henry Street Settlement  
New York, New York

The Henry Street Settlement's Community Consultation Center (CCC) has developed the first school-based AIDS Bereavement Group for young children. Among other mental health services, the CCC helps children whose parent has died from AIDS resolve emotional feelings and adjust after the parent's death.

Indiana State Board of Health, Acquired Disease Division  
Indianapolis, Indiana

The Indiana Integration of Care Project integrates mental health services with primary health care of HIV-infected clients on a State-wide basis. Referrals to a State-wide system of comprehensive health care and human services are enhanced by a voucher system.

Massachusetts AIDS Discrimination Initiative, Inc.  
Newton, Massachusetts

The Massachusetts AIDS Discrimination Initiative provides information through an AIDS discrimination hotline, multi-lingual brochures, and a directory of public and private resources to persons who experience HIV discrimination. The Initiative also documents the nature and scope of HIV discrimination, and coordinates activities of public and private agencies available to address HIV discrimination.

Michigan Protection and Advocacy Services  
Lansing, Michigan

The HIV/AIDS Advocacy Project provides legal education and advocacy services for persons with HIV disease to allow them to gain access to support services and medical care.

Missouri Department of Health, Bureau of AIDS Prevention  
Jefferson City, Missouri

This project creates Rural Resource Centers (RRCs) to work with the established network of local community action agencies to provide a wide range of services for rural HIV/AIDS clients. The RRCs will provide information about support services available,
including emergency financial assistance and programs to finance dental and medical care.

Montefiore Medical Center, Department of Family Medicine
Bronx, New York

In three Montefiore Ambulatory Care Network sites, and through a Drug Abuse Treatment Program, this project integrates an AIDS-related mental health service into its primary care network. The mental health service provides culturally sensitive psychosocial care to improve patients’ participation in medical and psychosocial regimens.

National Native American AIDS Prevention Center
Oakland, California

The National Native American AIDS Prevention Center operates community-based programs in Tucson, Arizona and Oklahoma City, Oklahoma. The programs provide case management and client advocacy services to increase access to care for Native Americans with HIV disease.

New York University College of Dentistry
New York, New York

The New York University Dental Center provides clinical outreach programs to adult women, adolescents, and children from social groups at high risk for HIV-infection. Dental screening and detection of various oral pathologies related to HIV-infection are provided as are routine and emergency dental care, and referral to other medical and social care. In addition to making care accessible to an often neglected segment of the HIV-infected population, the project educates dental students and increases their knowledge of and confidence about working with HIV-infected patients.

North Carolina Department of Environment, Health, and Natural Resources
Raleigh, North Carolina

Project REACH (Rural Education, Advocacy and Care for HIV) trains members of minority populations as community health advisors in five rural counties. The advisors help community residents access local or regional services and overcome the barriers of transportation, confidentiality, geographic or social isolation, and stigmatization of people living with HIV.

Outreach, Inc.
Atlanta, Georgia

Mothers Offering Mothers Support (MOMS) recruits older women to serve as support network conveners and emotional support persons for African American women with HIV disease. The program also gathers information from females with HIV disease, regarding access to care and support services.
Protection and Advocacy System
Albuquerque, New Mexico

The project is a State-wide effort to address discrimination issues in a largely rural State with significant minority populations. The project provides advocacy services to people with HIV/AIDS, and training to health care providers on advocacy and legal issues.

Rhode Island State Department of Health, AIDS/STD Division
Providence, Rhode Island

This project, in collaboration with the Rhode Island Department of Corrections, helps HIV-infected inmates access services in the community upon their release. The program provides pre-release counseling, discharge planning, and follow-up monitoring, to ensure the continuity of medical services and psychosocial care.

St. Joseph's Hospital and Medical Center
Paterson, New Jersey

The program provides mental health services to HIV patients receiving care the hospital's primary care clinics. Each HIV patient receives a thorough mental health assessment and is assigned to the most appropriate treatment, including support services for the patient’s family and linkages to drug rehabilitation programs if necessary.

Trustees of Health and Hospitals
Boston, Massachusetts

No One Alone with HIV (NOAH) is a hospital-based program designed to increase the sensitivity of primary care providers to the potential or actual mental health problems of HIV/AIDS patients. The program aims to increase the use of available mental health services and psychosocial support for HIV-infected patients and their families.

University of Miami School of Medicine, Department of Obstetrics/Gynecology
Miami, Florida

Through home visits, the Transitional Advocacy for HIV-infected Women and their Children project provides information, support, and guidance to women newly informed that they have HIV-disease. Other assistance includes meal vouchers, transportation, pre-enrollment in the social service network, and other advocacy.

Ware County Board of Health
Waycross, Georgia

This project tests a model of establishing HIV wellness centers in five counties to provide early medical and social services for rural people with HIV/AIDS. Case management is used to overcome barriers to care such as isolation, poverty, transportation, and limited health resources.