

Chapter 1

Introduction to the HIV Service Delivery Models and the Steering Committee

On September 30, 1994, the Special Projects of National Significance (SPNS) Program of the Health Resources and Services Administration (HRSA) funded an HIV Innovative Model of Care Initiative consisting of 27 cooperative agreements, HRSA, and an Evaluation and Dissemination Center (EDC). The EDC was funded through a subcontract within one of the cooperative agreements.

Individual projects were funded for periods ranging from two to five years. During the duration of the projects, each was to participate in the Steering Committee for the cooperative agreements as a condition of funding. As stated in the original Program Guidance, the cooperative agreement mechanism allows for substantial post-award programmatic participation of federal staff in the operation and evaluation of projects. Each service delivery project is responsible for ensuring representation on the Steering Committee which oversees cooperative agreement activities within the group of projects. As a condition of award, service delivery projects are responsible for participating in the evaluation of their projects as guided by the Steering Committee. The Evaluation and Dissemination Center provides technical expertise and assistance to the Steering Committee and individual grantees, and coordinates the implementation of evaluations. The HRSA representative to the Steering Committee is a full and active member in the development and implementation of the program, providing guidance and coordination for certain programmatic activities to a degree beyond customary responsibilities in grants administration.

The cooperative agreement funding mechanism was selected for a variety of reasons. These reasons included the following.

- The cooperative agreement mechanism would help projects identify shared goals and objectives.
- The cooperative agreement mechanism would enable projects to meet on a regular basis and share technical expertise among projects, and with outside experts, on programmatic concerns, staffing issues, and evaluation.
- The cooperative agreement mechanism would enable a cross-cutting evaluation of major clusters of projects.

A. HRSA Call for Proposals

In the Spring of 1994, the Health Resources and Services Administration issued a Notice of Availability of Funds (NOFA). The NOFA solicited proposals both for cooperative agreements and for an Evaluation and Dissemination Center which would also serve as the coordinating entity for the Steering Committee of the cooperative agreements. The NOFA suggested that projects would be funded for periods of up to five years each.

The Program Guidance, issued subsequent to the NOFA, identified a number of different possible areas for funding. These potential funding areas are listed in Table 1-1. The purpose of the solicitation was to request applications that would further address the SPNS goal to advance knowledge and skills in health and support services delivery to people with HIV infection. Potential applicants were to select one of the four special project categories described in Table 1-1 when submitting their proposals.

The 27 programmatic projects or cooperative agreements recommended for funding proposed grant periods ranging from two to five years. The Evaluation and Dissemination Center was recommended to receive five years of funding. Of the programmatic projects, two received two years of funding, eight received three years of funding, three received four years of funding, and 14 received five years of funding. Appendix I shows the recommended funding cycles for all of the projects along with a brief description of each.

Table 1-1
Overview of Categories for SPNS HIV Service Delivery Models

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1. Provide a comprehensive primary care service delivery or specialized medical care system within one distinct environment or setting relating to one of the following subcategories:
 - 1a) To develop and evaluate the effectiveness of primary care as part of a managed care plan or a comprehensive, coordinated care system;
 - 1b) To test the feasibility of providing comprehensive HIV services as part of a capitated reimbursement system;
 - 1c) To add primary care services to an intermediate level of care;
 - 1d) To develop a comprehensive continuum of care in a defined rural area;
 - 1e) To develop a service delivery model for effectively managing the medical and substance abuse treatment needs of adolescents with Stage III or IV HIV infection; or
 - 1f) To develop a service delivery model for women with HIV emphasizing coordination of related services.

 2. Provide a coordinated delivery of HIV health and support services to specific "mobile" populations in the United States. (No projects were approved in this category for funding.)

 3. Reduction of cultural, linguistic, and/or organizational barriers to care in a geographically defined area as it relates to one of the following subcategories:
 - 3a) For an underserved population by addressing their access to care issues through organizational collaboration and inclusion in policy development;
 - 3b) For an ethnic group that faces both linguistic and cultural barriers;
 - 3c) For active substance abusers; or
 - 3d) For individuals or special populations experiencing HIV-based discrimination.

 4. Provider training and education models for increasing, improving, or updating knowledge about HIV infection and its treatment in rural, correctional, or mental health settings.
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Applicants submitted proposals that frequently covered more than one of the general areas specified in the Program Guidance. In addition, for any one of the Program Guidance areas, different methodologies were used. The methodologies ranged from clinic-based or alternative services to individuals' knowledge and behavior change, to institutions and individuals using techniques of advocacy and training. Many projects combined methodologies.

B. Clusters of Projects Funded

For the purposes of managing the cooperative agreements, sharing project expertise, and permitting cross-cutting evaluations, projects initially were assigned to one of five clusters of projects. Projects were clustered based on similarities in methods, outcomes, and/or processes. During the course of the first year, projects could realign themselves. The five groups of cooperative agreements are as follows.

- **Capitated Care.** Five of the SPNS projects share, as a central theme, the study of the health care provided to individuals with HIV disease under models where the health care is capitated, or paid on a “flat fee” basis per patient per month. The Capitated Care projects differ in the ways that they provide health care, ranging from a community-based clinic (*East Boston Neighborhood Health Center*) to a large “chain” of community-based clinics (*AIDS Healthcare Foundation*) to a home-based hospice (*Visiting Nurse Association of Los Angeles*) to university-based clinics (*Johns Hopkins University School of Medicine*) to a state-wide system (*New York State Department of Health/Health Research*). Each of the projects shares the goals of determining costs for providing health care services to AIDS patients under a capitated care system and of ensuring that high quality care is provided under such a system. As a group, the models and their implementation are quite different from one another; taken collectively, the experiences should serve to define those instances in which a capitated care system for the provision of AIDS-related services is appropriate and those conditions in which it is not.
- **Community-Based Organization (CBO) Models.** Six SPNS projects share, as a central theme, the goal of providing high-quality care for individuals with HIV who belong to groups that are traditionally underserved because of linguistic, cultural, racial, and economic barriers that prevent their full integration into the traditional hospital-based service system. *Outreach, Inc.*, has implemented a program wherein substance abusers, many of whom are African-Americans living in public housing projects, are offered a number of social services to link them to the traditional care system. *PROTOTYPES* has implemented a “Settlement House model” wherein women with HIV come with their children and receive a number of social services as well as linkages to medical services. If appropriate, substance abusers with HIV are enrolled in a residential program. The *Well-Being Institute* has developed a two-tier program wherein substance abusing women with HIV are offered the opportunity to receive social and support services well before such time as they decide to stop using drugs, and are later offered the opportunity to participate in a 60-day drug treatment program combined with housing in a drug-free environment. The *Haitian Community AIDS Outreach Project/Center for Community Health, Education, and Research* provides case management and other culturally-appropriate social services to individuals with HIV in the large Haitian community of greater Boston. The *Fortune Society* targets Latinos with HIV who are in prison and offers a combination of educational, social support, and legal assistance services both while the client is in prison and after release. *Larkin Street Services* has developed a comprehensive continuum of services for homeless youth living with HIV in San Francisco which includes psychosocial support, medical care, educational and vocational services, and housing. Common to all of the CBO programs is the development of alternate models of care

specifically targeted to individuals who have traditionally been underserved. In all of these models, services are provided by a combination of professional staff and “paraprofessional” or “recovering” staff who share many of the same demographic and experiential characteristics of the target clients.

- **Comprehensive Healthcare.** Three projects are developing specialized medical care models within the context of a continuum of services in a medical clinic. The *University of Vermont & State Agricultural College* has developed community clinics throughout Vermont and is determining whether patients receive better, more appropriate, and more consistent care at the satellite clinics than they had been receiving at a single central site located at the state medical center. The *University of Nevada School of Medicine* has added a nutrition component to its comprehensive AIDS care clinic and is studying the effects of adding nutrition assessment, objective measurements, counseling, and supplements to the treatment of wasting in AIDS patients. Both the University of Vermont & State Agricultural College and the University of Nevada projects are providing services to largely rural patient populations. The *Washington University* project in St. Louis, Missouri is providing a continuum of care to women with HIV and their children within a traditional medical clinic model combined with aggressive community outreach and case management. The Washington University project serves a group of inner city women, most of whom are African-American.
- **Infrastructure-Advocacy.** Projects in the Infrastructure-Advocacy group aim to increase the capacity of local health and social support service systems to provide appropriate, quality services for individuals with HIV. The projects in this group are using methods of service systems development through training and technical assistance to change the service provider infrastructure as well as the community context in which these services are delivered. The *Center for Women Policy Studies*, through the MetroDC Collaborative for Women with HIV/AIDS (with *PROTOTYPES*), is increasing the ability of service providers in the metropolitan District of Columbia area to provide services to women with HIV through leadership development with HIV-positive women, policy change, needs assessment, and appropriately-targeted training. The *Michigan Protection and Advocacy Service* is providing training to consumers and service providers on the legal rights of individuals with HIV in a number of areas including employment, housing, benefits, and medical services. The *Indiana Community AIDS Action Network* provides legal assistance to individual clients to redress discriminatory practices by health care providers, employers and others. In addition, this project provides training in legal rights, advocacy skills building, grassroots organizing and public policy advocacy. The *Hektoen Institute for Medical Research* at the Cook County Hospital’s HIV Primary Care Center/Women and Children HIV Program is increasing the

ability of the service infrastructure to provide early identification and linkage into care of women with HIV by training maternal and child health providers on how to provide HIV education counseling and testing by consent. This project is also educating providers on the use of zidovudine to reduce perinatal transmission of HIV. The *State University of New York – Health Science Center at Brooklyn* is developing systems to support and encourage women to be tested for HIV, especially during pregnancy, and if positive, route them to appropriate medical services, including strategies to reduce perinatal transmission as well as on-going HIV primary and gynecologic care. The *University of Texas Health Science Center at San Antonio* is developing a model wherein local service agencies and consumers learn strategies for developing comprehensive models of care for women with HIV and their children. The model is a combination of infrastructure development and training. The *Missouri Department of Health* is systematically developing the capacity of its AIDS service providers to provide services for individuals with HIV with mental illness (and possibly substance abuse) as well as increasing the capacity of its mental health agencies to treat individuals with HIV. Training and agency development strategies are employed.

- **Training.** While training is integral to almost all SPNS projects, six have identified training among their most key elements. These projects include the following. The *University of Mississippi Medical Center* is developing a training program for physicians, dentists, and nurses in rural and urban settings throughout Mississippi. The training programs have been designed so that medical workers in rural settings who are not comfortable treating patients with AIDS will have increased knowledge and the ability to provide appropriate care. The *University of Colorado Health Sciences Center* has developed an eight-state program to compare different ways of providing medical information to health care providers. The *Interamerican College of Physicians and Surgeons* has developed a culturally appropriate training program for Hispanic physicians so that they can be trained in the management of patients with HIV disease. A key element of this program is a series of office visits to the physician by another Hispanic physician who has been trained in the management of AIDS. The *University of Washington* has developed a training program in neuropsychiatric illness associated with HIV disease with an emphasis on delirium, and ways of developing greater expertise among practitioners. *Emory University* has instituted a training program for health care providers who provide HIV-related medical services to inmates in the Georgia State prison system. *Health Initiatives for Youth* has developed a training center for health care, social service, and other service providers to enable them to provide services in an appropriate and sensitive way to youth and adolescents.

At the end of first year, the projects had formed into clusters as listed in Table 1-2 on the next page.

**Table 1-2
Clusters of SPNS Cooperative Agreement Projects**

SPNS Project	Cluster Group 1 "Capitated Care"	Cluster Group 2 "CBO Models"	Cluster Group 3 "Comprehensive Care"	Cluster Group 4 "Infrastructure-Advocacy"	Cluster Group 5 "Training"
AIDS Healthcare Foundation (Los Angeles, California)	<input checked="" type="checkbox"/>				
Center for Women Policy Studies (Washington, District of Columbia)				<input checked="" type="checkbox"/>	
East Boston Neighborhood Health Center (East Boston, Massachusetts)	<input checked="" type="checkbox"/>				
Emory University (Atlanta, Georgia)					<input checked="" type="checkbox"/>
Fortune Society (New York, New York)		<input checked="" type="checkbox"/>			
Haitian Community AIDS Outreach Project/Center for Community Health, Education, and Research (Dorchester, Massachusetts)		<input checked="" type="checkbox"/>			
Health Initiatives for Youth (San Francisco, California)					<input checked="" type="checkbox"/>
Hektoen Institute for Medical Research/Cook County HIV Primary Care Center (Chicago, Illinois)				<input checked="" type="checkbox"/>	
Indiana Community AIDS Action Network (Indianapolis, Indiana)				<input checked="" type="checkbox"/>	
Interamerican College of Physicians and Surgeons (New York, New York)					<input checked="" type="checkbox"/>
Johns Hopkins University School of Medicine (Baltimore, Maryland)	<input checked="" type="checkbox"/>				
Larkin Street Services (San Francisco, California)		<input checked="" type="checkbox"/>			
Michigan Protection and Advocacy Service (Lansing, Michigan)				<input checked="" type="checkbox"/>	
Missouri Department of Health (Jefferson City, Missouri)				<input checked="" type="checkbox"/>	
New York State Department of Health/Health Research (Albany, New York)	<input checked="" type="checkbox"/>				
Outreach, Inc. (Atlanta, Georgia)		<input checked="" type="checkbox"/>			
PROTOTYPES (Culver City, California)		<input checked="" type="checkbox"/>			
SUNY – Health Science Center at Brooklyn (Brooklyn, New York)				<input checked="" type="checkbox"/>	
University of Colorado Health Sciences Center (Denver, Colorado)					<input checked="" type="checkbox"/>
University of Mississippi Medical Center (Jackson, Mississippi)					<input checked="" type="checkbox"/>
University of Nevada School of Medicine (Reno, Nevada)			<input checked="" type="checkbox"/>		
University of Texas Health Science Center at San Antonio (San Antonio, Texas)				<input checked="" type="checkbox"/>	
University of Vermont & State Agricultural College (Burlington, Vermont)			<input checked="" type="checkbox"/>		
University of Washington (Seattle, Washington)					<input checked="" type="checkbox"/>
Visiting Nurse Association of Los Angeles (Los Angeles, California)	<input checked="" type="checkbox"/>				
Washington University (St. Louis, Missouri)			<input checked="" type="checkbox"/>		
Well-Being Institute (Detroit, Michigan)		<input checked="" type="checkbox"/>			

In addition to the programmatic projects, there is an Evaluation and Dissemination Center (EDC). The EDC has four major functions:

1. To provide technical assistance to SPNS grantees in designing and implementing evaluation studies and dissemination activities for their individual projects;
2. To develop and coordinate the implementation of multi-site evaluations within groups of similar projects;
3. To coordinate and facilitate the activities of the Steering Committee as a whole; and
4. To provide reports and technical assistance to HRSA.

The EDC is a consortium headed by The Measurement Group and also including PROTOTYPES. The Measurement Group provides overall management for the EDC and is responsible for evaluation, and some dissemination, activities. PROTOTYPES is responsible for logistical support of the Steering Committee meetings and dissemination activities.

C. Structure and Decision-Making Processes of the Steering Committee for the Cooperative Agreement Projects

Over the course of its first year, the Steering Committee evolved a fairly straightforward decision making process which has worked well. Each of the 27 member project representatives has one vote; the Evaluation and Dissemination Center representative has one vote; and the Health Resources and Services Administration representative has one vote.

As its first official vote, the Steering Committee decided that all subsequent votes would be decided by the simple majority of all members present and voting. A chair is elected each year for the Steering Committee and guides the meetings, calls for votes, and records Steering Committee decisions. The Steering Committee adopted *Roberts' Rules of Order* to guide its meetings.

In addition to the chair of the Steering Committee, each of the Work Groups elected a chair at its first meeting of the first year. Together with the HRSA representative and the Director of the Evaluation and Dissemination Center, the chairs of the Work Groups formed an ad hoc Executive Committee that holds telephone meetings – between scheduled, face-to-face Steering Committee meetings – usually to set the Steering Committee meeting agenda and rules.

Day-to-day operations of the Steering Committee – including logistics, communications, and consultation – are guided by an Operations Committee consisting of the Steering Committee Chair, the HRSA representative, and the EDC Director. The EDC Director takes responsibility for ensuring that the decisions of the Operations Committee, the Executive Committee, and the larger Steering Committee are implemented.

The normal working procedures of the Steering Committee are as follows. A meeting is held approximately every three months at locations and times decided by the Steering Committee. The meetings cover two and a half days. While there is some variation from meeting to meeting, the “typical” meeting has consisted of Work Group meetings during the first day followed by a report-back session, a second day combining specialized trainings and full committee meetings, and a closed-session meeting in the last half day to discuss Steering Committee business.

Between Steering Committee meetings, the Operations Committee takes responsibility for preparing an agenda which is approved by the Executive Committee. The Operations Committee may also occasionally schedule conference calls for themselves or the larger Executive Committee as appropriate. Usually 2-5 such calls occur between Steering Committee meetings. Between Steering Committee meetings, the EDC takes responsibility for informing the Operations and Executive Committee of impending decision points, handles the logistics of the forthcoming meetings, and ensures that briefing materials are prepared for and disseminated to the Steering Committee.

Figure 1-1 shows the decision making and organizational structure of the Steering Committee.

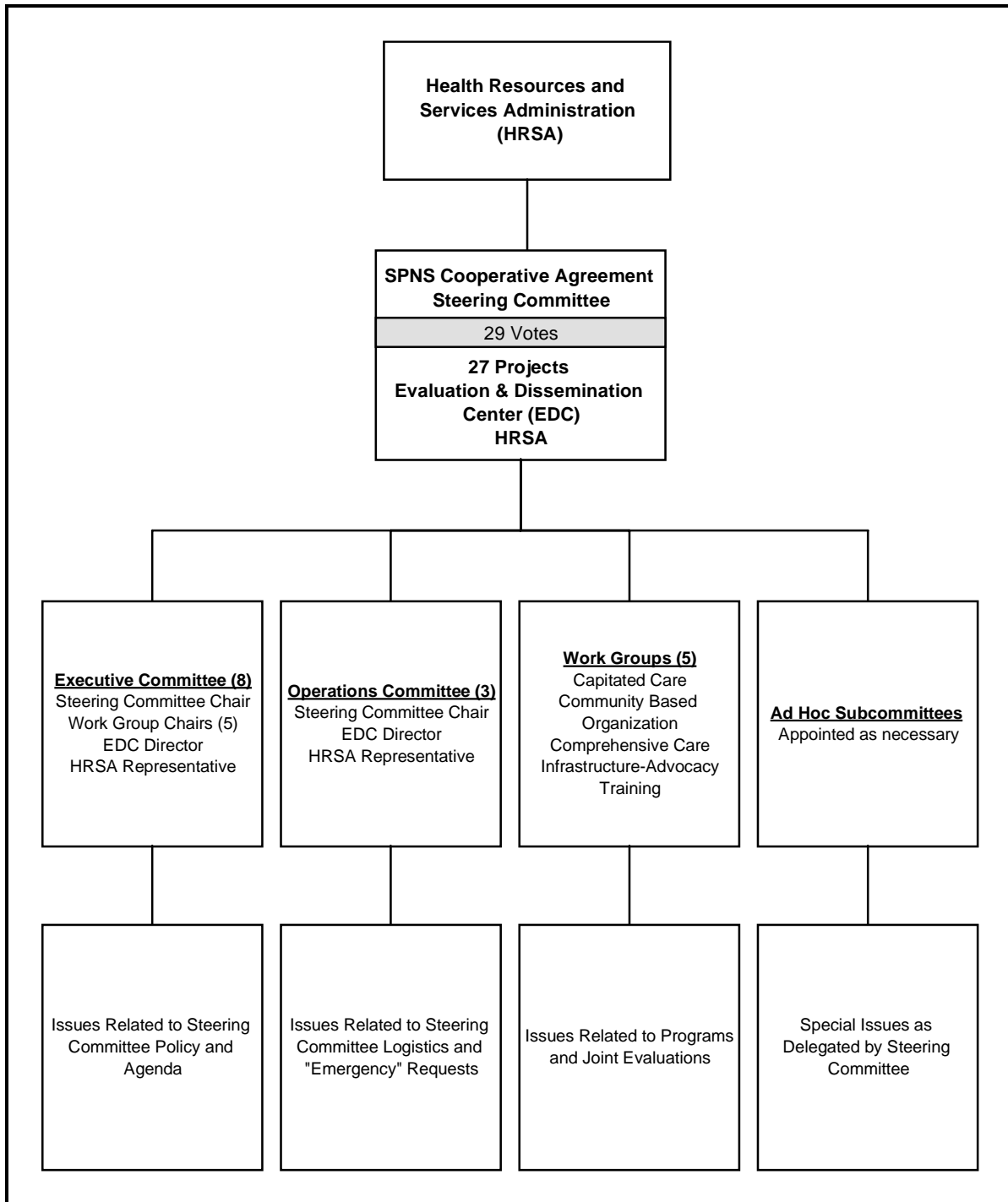


Figure 1-1. Organizational structure and responsibilities within the Steering Committee of the cooperative agreements.