GROWING INNOVATIVE CARE

STRATEGIES FOR HIV/AIDS
PREVENTION AND CARE
ON THE U.S.-MEXICO BORDER

U.S. Department of Health and Human Services

HRSA
Health Resources and Services Administration

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Strategies for HIV/AIDS Prevention and Care
Along the U.S.–Mexico Border

CONTENTS

PREFACE

The idea for this monograph came about as grantees in Year 3 (August 2003) of the Health Resources and Services Administration, HIV/AIDS Bureau, Special Projects of National Significance (SPNS) U.S.–Mexico Border Health Initiative began to contemplate the end of the 5-year initiative. The idea of a monograph on lessons learned was first raised in a dissemination committee. In a January 2004 meeting, grantees enthusiastically agreed to contribute to the writing project.

The primary purpose of this monograph is to add information to the HIV/AIDS literature on what was learned in the course of the five SPNS projects and the work of the Evaluation Center during the 2000–2005 initiative. To facilitate consistency of content and organization, contributors were given a suggested topic outline, which will be apparent to readers in the organization of most chapters. Even so, readers will find that each chapter reflects the unique voice and perspective of its authors.

INTRODUCTION

The Ryan White HIV/AIDS Treatment Modernization Act of 2006 addresses the unmet health needs of people living with HIV/AIDS (PLWHA) by funding primary health care and support services that enhance access to and retention in care. It is the Government's largest program designed specifically for PLWHA, and it reaches more than 500,000 people each year. It is administered by the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB).

Activities funded by the Ryan White HIV/AIDS Program fill the gaps in care that would otherwise leave many PLWHA without access to life-enhancing health care services. Because the programs are the "payer of last resort," they increase access to care among underserved populations and improve the quality of life for people living with HIV disease.

The Special Projects of National Significance (SPNS) program is the research and development arm of the Ryan White HIV/AIDS Program; it assesses the effectiveness of particular models of care, supports innovative program design, and promotes replication of effective models. SPNS grants fund innovative models of HIV care and support the development of effective care delivery systems.

"The Demonstration and Evaluation of Models that Advance HIV Service Innovation Along the U.S.–Mexico Border," better known as the *SPNS U.S.–Mexico Border Health Initiative,* was designed to develop models of community-based health care networks that effectively reduce barriers to early identification of HIV disease and ensure entry to high-quality primary health care programs on the U.S. side of the U.S.–Mexico border area. The target populations included people at high risk for HIV and PLWHA who live or work on the U.S. side of the border. Five SPNS Border Health Initiative demonstration projects and an evaluation center were awarded grants under the initiative.

The sample in this study consists of 1,200 PLWHA who received primary HIV/AIDS medical services between January 1, 2001, and July 30, 2004, from any one of the five SPNS Border Health Initiative demonstration projects.

Sample

Participants were between 18 and 64 years old; 1,003 (84.0 percent) were men, and 197 (16.0 percent) were women. For the purpose of this analysis, gender was treated as missing for people who self-identified as transgender (5 male-to-female participants, 0 female-to-male participants).

Of the 859 participants (71.9 percent) who reported current ties to Mexico, most were men (84.9 percent) and of Hispanic descent (85.0 percent). For the 336 (28.0 percent) participants without current ties to Mexico, 272 (81.0 percent) were men, and more than half (73.0 percent) were of Hispanic descent. Five participants failed to provide information regarding their ties to Mexico and were excluded from further analysis.

Data

A core set of standardized data collection instruments was created collaboratively for use across all five sites. Information was obtained by SPNS staff in face-to-face interviews with participants at initial entry into the program. Interviews were conducted in Spanish or English, depending on the language preference of the participant. Each SPNS Border Health Initiative grantee provided services in a unique care environment, and their approaches reflected that diversity. Each grantee wanted to broaden the system of HIV/AIDS care throughout its region. A primary component of the strategy was to secure the active participation of the HRSA-funded Community and Migrant Health Centers in a collaborative approach to provide medical care and essential support services. Outreach was also a critical component of the grantees' activities; the objective was to reduce the time between seroconversion and entry into care. Using peers to conduct outreach was a key factor in the success of a program.

The lessons learned from the initiative, which are described in this volume, can be adopted by other programs to improve the health and quality of life of border residents and other vulnerable populations at risk for HIV/AIDS.

CHAPTER I

El Centro de Evaluación at the University of Oklahoma 2000–2005: A SPNS Evaluation Center

To respond to the growing number of Latinos living with HIV/AIDS in the United States (Centers for Disease Control and Prevention [CDC], 2001) and the substantial increase in the Hispanic population in the region of the U.S. border with Mexico (Guzmán, 2001), the Health Resources and Services Administration (HRSA) funded the Centro de Evaluación at the University of Oklahoma School of Social Work as one of four HIV/AIDS Evaluation and Technical Assistance Centers in July 2000. The Center was funded through a HRSA Special Projects of National Significance (SPNS) grant under the U.S.–Mexico SPNS Border Health Initiative, also awarded to the University of Oklahoma in 2000. The primary goal of the Centro de Evaluación (also known as the *evaluation center* or the *center*) was to facilitate coordination of evaluation and to establish a framework for systematic data reporting activities among the five SPNS Border Health Initiative demonstration projects (located along the U.S.–Mexico border from San Diego, California, to Brownsville, Texas). In 2005, the center became a division of the Center for Applied Research of the University of Oklahoma.

Overview

This chapter presents census and epidemiologic data from both before and after the start of the SPNS project in 2000. This data informed the implementation of the SPNS Border Health Initiative. The remainder of the chapter describes the role of the evaluation center staff in promoting grantee partnerships that facilitated the development and implementation of the outcome evaluation.

The evaluation is described in three stages: beginning, middle, and end. The beginning stage consisted of the work involved in actualizing process and task goals. *Process goals* are the interactional human aspects of creating sound, functional team relationships. *Task goals* are the problem-solving work associated with various tasks to achieve the objectives of the initiative. The middle stage consisted of additional tasks, such as data collection, and activities associated with continued team building to realize evaluation oversight responsibilities. The final (end) stage involved administrative and operational challenges for evaluation center staff. It also included individual and team dissemination activities undertaken over the 5-year period to report on the work of the five SPNS projects. The chapter concludes with recommendations based on the experience of the evaluation center staff in its work with the collective project sites.

The original evaluation center was given the Spanish title *Centro de Evaluación* to emphasize the focus of the initiative, which was to evaluate the service outcomes of health care centers providing outreach and care for Spanish-speaking populations living along the U.S.–Mexico border, the majority of whom are of Mexican origin.

HISPANIC OR LATINO?

Hispanics are not a homogenous group; their diversity is reflected in how people within the collective Hispanic group identify themselves by race or ethnic group and how they are referred to in the literature. Hispanic people not born in the United States, including people from Central and South American countries, tend to identify according to country of origin. U.S.-born Hispanics are more varied in their racial and ethnic identification. The terms *Hispanic* and *Latino*, which are assigned by the U.S. Department of Commerce for the purpose of collecting U.S. Census data, are not universally embraced by Hispanic subgroups. How U.S.-born Hispanics identify their ethnic or racial group may be a function of family generational history or their American education and identification with the majority White society. Among people of Mexican origin, *Mexican American* may be the preferred identification of second- or third-generation adults, but their offspring may identify as *Chicano* or *Chicana*, a term associated with youth activism of the 1970s and the civil rights movement (Curiel, 1995; Reich, 1989). Historically, Hispanic people from New Mexico have tended to identify with their Spanish heritage. Many families had land grants awarded during Spanish rule and trace their ancestors to the original Spanish settlers. They may refer to their ethnicity as Spanish rather than Mexican or Mexican American.

Given the potential for confusion over ethnic identity, the term Hispanic is used throughout this document to refer to Mexican-origin participants who were either born in the United States or have Mexican heritage. Chapters use the term Hispanic or Latino according to the preferred usage in the service area being described.

TABLE 1.1. U.S. and Selected State AIDS Cases by Hispanic Ethnicity, 2003

State	New AIDS Cases					
	N		%		Rate/100,000	
	Hispanic	Non-Hispanic	Hispanic	Non-Hispanic	Hispanic	Non-Hispanic
Arizona*	166	448	21.9	78.1	9.8	11.8
California**	2,004	3,899	31.6	68.4	12.0	12.4
New Mexico***	50	59	46.6	53.4	5.2	4.3
Texas****	924	2,455	27.3	72.7	12.1	15.2
United States	9,168	35,795	18.5	81.5	25.2	14.1

*Derived from Arizona Department of Health Services, Division of Public Health Services, Office of HIV/AIDS, 2003a, p. 7.
**Derived from California Department of Health Services, Office of AIDS, HIV/AIDS Case Registry Section, 2006.
***Derived from New Mexico HIV/AIDS Epidemiology Program, 2004.
****Derived from Texas Department of Health, HIV/STD Epidemiology Division, Surveillance Branch, 2003, pp. 1, 5.

This chapter uses the term Hispanic to refer to people of Mexican origin, the primary participants in this SPNS initiative. Care providers in U.S.–Mexico border communities have the added challenge of distinguishing between Mexican nationals, naturalized U.S. citizens, and native-born Hispanic people to determine care eligibility. Participants in this project were required to be U.S. residents.

Establishing the Need for the SPNS Border Health Initiative

In 2003, an estimated 43,171 AIDS cases were diagnosed in the United States; 43,112 of those cases were among adolescents (age 13 and above) and adults (CDC, 2004). Census 2003 population data (U.S. Census Bureau, 2004) were used to cal–culate the total rate (14. 8 per 100,000) and esti–mate the adult and adolescent rate (18.7 per 100,000) of new AIDS diagnoses in 2003.

Racial and ethnic minority populations have been disproportionately affected by the HIV epidemic. Between 1981 and 1995, non–Hispanic Whites were the predominant racial–ethnic group among people living with AIDS (47 percent); over time, the proportion of cases among racial and ethnic minorities increased. Between 2001 and 2004, an estimated 157,468 people in 35 areas reporting to CDC were diagnosed with HIV/AIDS (CDC, 2006a). During the same period, non-Hispanic Blacks accounted for 50 percent and Hispanics for 20 percent of HIV/AIDS cases.

Higher fertility rates, lower age-specific death rates, and higher immigration rates account for popula-tion growth among Hispanics. Hispanics now con-stitute the Nation's largest ethnic minority group. U.S. Census Bureau population estimates indicate that the Hispanic population grew 9.8 percent (compared with 2.5 percent for the U.S. population as a whole) between April 1, 2000, and July 1, 2002; 53 percent of the growth rate was attributa-ble to net international migration, and 47 percent to natural increase—the difference between births and deaths (U.S. Census Bureau News, 2003). Higher population growth rates among Hispanics have been shown to have detrimental effects, including higher rates of poverty and higher levels

of communicable diseases, including HIV/AIDS. Table 1.1 compares new cases of AIDS in 2003 for Hispanics and non-Hispanics.

Survival differences among racial and ethnic minorities might be attributed to late diagnosis and differential access to care. An estimated 252,000 to 312,000 people in the United States are not aware of their infection and their risk of transmitting HIV to others (CDC, 2006b).

Thus, one of the major goals of this initiative was to increase early detection of people infected with HIV to decrease new transmissions. All sites worked closely with their State health departments to coordinate HIV/AIDS prevention and treat-ment activities. Having access to epidemiologic data on sexually transmitted infections (STIs) was useful to grantees in planning outreach strategies targeting populations at risk for HIV/AIDS.

HIV/AIDS Epidemiology
Among Demonstration Sites

The following five demonstration projects were part of the U.S.–Mexico SPNS Border Health Initiative and broadly represent the border region:

* Arizona Border HIV/AIDS Care Project (Tucson, AZ)
* San Ysidro Health Center (San Ysidro, CA)
* Camino de Vida Center for HIV Services (Las Cruces, NM)
* Centro de Salud Familiar La Fe (El Paso, TX)
* Valley AIDS Council (Harlingen, TX).

Table 1.2 describes STIs reported by participating States for 2003. The data show that the potential number of people at risk for HIV/AIDS (i.e., those who reported an STI) was higher for people diag-nosed with gonorrhea and chlamydia. The data support the need for HIV/AIDS outreach in the

TABLE 1.2. Cases of Sexually Transmitted Infections, 2003, by State and Service Area

State and Service Area	Gonorrhea per 100,000	Primary and Secondary Syphilis per 100,000	Chlamydia per 100,000
United States	114.7	2.5	301.3
State of Arizona*	64.1	3.3	229.7
Arizona Project Service Area	75.8	1.8	293.2
State of California**	73.2	3.7	330.9
California Project Service Area	65.5	3.6	346.6
State of Texas***	111.2	3.0	312.9
El Paso Project Service Area	40.3	16.7	330.3
Valley AIDS Council Project Service Area	20.1	14.4	307.1
State of New Mexico****	62.4	3.8	399.0
New Mexico Project Service Area	41.9	0.0	266.6

*Derived from Arizona Department of Health Services, Division of Public Health Services, Office of Infectious Disease Services, 2003b.
**Derived from California Department of Health Services, 2003b.
*** Derived from Texas Department of Health, HIV/STD Epidemiology Division, Surveillance Branch, 2003.
**** Derived from New Mexico Department of Health, STD Epidemiology Data, 2004.

form of education and HIV testing to lower transmission of the disease. Demonstration project sites used local census and epidemiologic data to support SPNS initiative applications. In most cases, rates of infection among people younger than age 18 in counties in project service areas were higher than those of their non-Hispanic White counterparts in respective State or national total rates.

Individual sites reported that the following 2003 State data were helpful in designing their SPNS initiative strategies:

* Arizona
  * In the 1990s, the incidence rate for AIDS decreased from 14.7 per 100,000 in 1990 to 8.0 per 100,000 in 2000; it then increased to 11.0 per 100,000 in 2003 (Arizona Department of Health Services, 2003a).

* California
  * Distribution of AIDS cases among Hispanics in California (31.6 percent; see Table 1.1) parallels the percentage of Hispanics in the State population (32.4 percent; Table 1.3).
  * In San Diego, Hispanics were disproportionately represented in new AIDS cases in 2003: 37 percent of cases versus 28 percent of the population (County of San Diego Health and Human Services Agency, 2004).

* New Mexico
  * The proportion of new AIDS cases among Hispanics (46.6 percent) exceeds the State's proportion of Hispanics (42.1 percent).
  * A notable trend is the increase in people with AIDS age 40 and older, a group that constituted less than one-third of AIDS cases in the 1980s but nearly one-half of cases in the 2000–2002 period (New Mexico Department of Health, 2004).

* Texas
  * Statewide, the proportion of AIDS cases among Hispanics increased from 20 percent to 24 percent between 2002 and midyear 2003 (Texas Department of Health, 2003).
  * In 2004, AIDS cases along the 32 border counties represented 6 percent of total AIDS cases for the State. Hispanics on the border represent the majority of the State population (ranging from 76 to 95 percent) as well as of the number of new AIDS cases (190; AIDS Education and Training Centers National Resource Center, 2006).

Hispanics make up a greater proportion of the population in most of the counties in the service area than in the total population of the State in which the county is located (see Table 1.3). Given the population demographics of the region and the stigma associated with HIV/AIDS, it was anticipated that individual health care demonstration projects would encounter unique challenges that would require creative outreach and intervention strategies to overcome regional or local barriers to providing service and care.

One challenge, for example, involved providing health care in metropolitan and rural areas to indigent patients with limited English proficiency, some of whom lived and worked on both sides of the U.S.–Mexico border (i.e., *transborder patients*).

The initiative was designed to add to the body of knowledge about the size of the transborder population and to shed light on how they (and other border residents) utilize medical or alternative sources of care in Mexico and the United States. The study also explored the use of alternative care, namely, the use of informal care systems such as the indigenous health care providers referred to in the health literature as *curanderas* and *curanderos*, or folk healers (de la Torre & Estrada, 2001).

TABLE 1.3. Border Population, by State, Service Area, and Hispanic Ethnicity, 2003

State and Service Area Counties	Census Population 2003 Estimate (1)	% Pop. Change 1990–2000 (2)	% <18 Years Old 2000 (3)	% Hispanic All Races 2000 (4)	Estimated Hispanic* Population 2003 (5)	Estimated Non-Hispanic** Population 2003 (6)
United States	**290,809,777**	**3.3**	**25.7**	**12.5**	**36,351,222**	**254,458,555**
State of Arizona	**5,580,811**	**40.0**	**26.6**	**25.3**	**1,411,945**	**4,168,866**
Service Area Counties						
Cochise	122,161	20.6	26.3	30.7	37,503	84,658
Pima	892,798	26.5	24.6	29.3	261,590	631,208
Santa Cruz	40,267	29.3	33.6	80.8	32,536	7,731
Yuma	171,134	49.7	28.9	50.5	86,423	84,711
Total project service area	*1,1226,360*	*—*	*—*	*34.1*	*418,052*	*808,308*
State of California	**35,484,453**	**13.6**	**27.3**	**32.4**	**11,496,963**	**23,987,490**
Service Area Counties						
Imperial	149,232	30.2	31.4	72.2	107,746	41,486
San Diego	2,930,886	12.6	25.7	26.7	782,547	2,148,339
Total project service area	*3,080,118*	*—*	*—*	*28.9*	*890,292*	*2,189,826*
State of New Mexico	**1,874,614**	**20.1**	**28.0**	**42.1**	**789,212**	**1,085,402**
Service Area Counties						
Dona Ana	182,165	28.9	29.7	63.4	137,535	44,630
Grant	29,818	12.0	26.2	48.8	22,513	7,305
Hidalgo	5,234	-0.4	31.7	56.0	3,952	1,282
Luna	25,732	38.1	30.0	57.7	19,428	6,304
Otero	62,371	20.0	29.5	32.2	47,090	15,281
Total project service area	*305,320*	*—*	*—*	*75.5*	*230,517*	*74,803*
State of Texas	**22,118,509**	**22.8**	**28.2**	**32.0**	**7,077,923**	**15,040,586**
El Paso Service Area Counties						
El Paso	705,436˘	14.9	32.0	78.2	551,651	153,785
Total El Paso service area	*705,436*			*78.2*	*551,651*	*153,785*
Valley AIDS Council (VAC) Service Area Counties						
Cameron	363,092	28.9	33.8	84.3	306,087	57,005
Dimmit	10,341	-1.8	33.2	85.0	8,790	1,551
Edwards	2,031	-4.6	28.5	45.1	916	1,115
Hidalgo	635,540	48.5	35.3	88.3	561,182	74,358
Kinney	3,311	8.3	25.7	50.5	1,672	1,639
La Salle	5,822	11.6	29.4	77.1	4,489	1,333
Maverick	50,178	30.0	36.9	95.0	47,669	2,509
Real	3,020	26.3	23.4	22.6	683	2,337
Uvalde	26,787	11.1	31.4	65.9	17,653	9,134
Val Verde	46,569	15.8	32.1	75.5	35,160	11,409
Total VAC service area	*1,146,691*	*—*	*—*	*85.8*	*984,299*	*162,392*

*Estimated Hispanic population 2003 = (1) multiplied by (4).
**Estimated non-Hispanic population 2003 = (1) minus (5).
— = data not available.
Source: U.S. Census Bureau, 2003.

TRANSBORDER PATIENTS

Patients who travel back and forth between international borders are referred to as *transborder patients*. Transborder patients include people of Mexican origin who have U.S. citizenship or access to care on both sides of the border because of a U.S. resident visa; birth in the United States; or having one U.S. parent, which qualifies the person for U.S. resident status. Some transborder patients choose to live on the Mexico side of the border because of cultural upbringing, lower living costs, or family ties.

Beginning Stage: Process of Leadership and Instrument Development

In the initial stage of the 5-year initiative, the center leadership brought together grantees, HRSA national project officers, and center staff at one location in Norman, Oklahoma, to meet and learn how to work together as a team to fulfill the goals of the initiative. The initial process goal was to clarify roles of project members and to build trust between collective initiative players. It was important for direct service administrators to learn how to work with (and use the expertise of) evaluators at their local level and at the center. Having an evaluation component was new for most grantees.

A second process goal was to secure consensus among grantees on how to identify and evaluate unique aspects of their planned service delivery models in the context of evaluation questions based on the Ryan White Comprehensive AIDS Resources Emergency Act of 1990 (reauthorized in 2006 as the Ryan White HIV/AIDS Treatment Modernization Act of 2006). The evaluation center's initial role was to provide leadership in consensus building and relationship building among grantees to support collective evaluation outcome goals. Evaluation center staff sought to involve the grantees in identifying questions for research and development of instruments to address the research questions. It was also necessary in this first stage to secure agreement on procedures for translation and standardization of data collection instruments, along with the process for data collection, to ensure quality of data and protection of the patients and clients to be served by grantees.

In the beginning, the center leadership sought to involve the grantees in decision making related to planning the outcome evaluation goals. The initial challenge was to create a structure for identifying immediate and long-term outcomes associated with culturally appropriate service delivery models for providing HIV care to underserved populations living in U.S.–Mexico border communities. In the social science literature, the term *underserved* refers to a societal subgroup that is underrepresented in a given social system as the result of structural barriers in that society. In the context of health care systems, the underrepresentation is attributed to multiple structural barriers, particularly poverty. The demographics of the health service areas for the grantees supports the premise that grantees were serving populations with limited income and limited formal education in English. The geographic proximity to Mexico creates a dual cultural environment that presents a language challenge for residents on both sides of the U.S.–Mexico border. To engage in commerce, residents on both sides of the border find it necessary to be English–Spanish bilingual.

The center and grantees developed data collection instruments to measure the intended service delivery outcomes. The second early and urgent task goal involved multiple implementation tasks, such

as creation of data collection forms, training of data collection personnel, and creation of a mechanism for providing technical assistance. Another important task goal was creation or enhancement of grantee Web sites to link with the Centro de Evaluación and HRSA. The Web sites provided a means of disseminating service program information and progress reports to local consumers, other grantees, HRSA, and the evaluation center.

Building a Team
The original principal investigator sought staff who were competent to successfully meet the challenges of working in a bilingual and bicultural context and who could read and write both Spanish and English. Key personnel included the project director and two co-investigators, one at the University of California at Berkeley School of Social Welfare and one at the University of Oklahoma School of Social Work, who were integrated early in the project to provide cultural insights for planning initiative tasks. These key personnel were proficient in Spanish and had previous direct social service experience working with Hispanic and Latino populations in the context of health issues, particularly HIV and AIDS. A third co-investigator, a biostatistician at the University of California Berkeley School of Public Health, was added in the first year to provide expertise and consultation in applied theoretical research for instrument development and data analysis questions.

With key personnel in place, the center began its search for support staff to conduct center operations. Most initial staffing challenges were attributed to difficulty finding Spanish–English bilingual staff familiar with both Hispanic culture and HIV/AIDS. During the first year, the center added two staff research assistants: one to manage literature support activities; and the second, a webmaster, to maintain the center Web site and provide Web design support to border grantees. During the second project year, the center added an information technology analyst whose responsibility was to manage multisite data collection systems and pro-

vide electronic data technical assistance to border grantees. In the third year, the center added a data specialist to coordinate dissemination activities.

The Logic Model: Planning Goals
To facilitate the planning of initiative goals and objectives, evaluation center staff proposed a matrix logic model that was later adopted by grantees. The model required each demonstration service project to identify client-level objectives for specific intervention components. This process was helpful in developing appropriate instruments for measuring outcomes of the proposed delivery model.

The primary question guiding health service outcome assessment for the evaluation center and demonstration projects was the third HRSA Ryan White CARE Act evaluation question: "To what extent [is the Ryan White HIV/AIDS Program] providing services that remove barriers to primary care access so as to ensure that clients enter into and remain in care?" To examine this question, each project site and the center constructed a preliminary matrix model for planning, referred to as the *logic model* (Figure 1.1). The logic model gives health care planners a visual means of planning program outcomes.

The logic model uses general systems theory concepts first introduced by biologist Ludwig von Bertalanffy (1968/2006). A *system* is defined as a set of elements that are orderly and interrelated to make a functional whole. Grantees' health care systems, in the context of general systems theory, have multiple parts that collectively represent a whole system. The system's parts include the service components (i.e., physician care and nursing care) and case management staff, pharmacy experts who supply medical prescriptions, and support staff. The grantees' collaborative staff evaluation efforts, along with those of the evaluation center staff, may be thought of as another system. The grantees submit data (inputs), and the evaluation center staff process and store the data and provide feedback (outputs) to grantees in the form of accumulated data analy-

FIGURE 1.1. Matrix planning: Logic model.

Inputs	Activities	Outputs	Outcomes		
			Initial	Intermediate	Long-Term
HIV/AIDS programs and CHCs on the U.S.–Mexico border	Identify HIV-infected on the U.S.–Mexico border	500 HIV-infected clients/patients	Increased knowledge about the characteristics of those affected by HIV disease on the U.S./Mexico Border		Recognize the existence of HIV/AIDS as a social problem on the U.S.–Mexico border
Outreach workers, HIV testing and counseling staff	Outreach and testing	6,000 at-risk people	Increased number of individuals entering HIV/AIDS primary care	Earlier entry into HIV/AIDS primary care	Reduced morbidity and mortality
Case managers and case aides	Case management	500 HIV-infected clients/patients	Increased access to social support services and primary care	Increased conformity with treatment objectives	Increased sense of social or program support
Clinical staff (nurses, physicians, etc.)	HIV/AIDS primary care	500 HIV-infected clients/patients	Increased access, continuity, and use of primary care	Increased health-related quality of life	◆ Reduced client morbidity and mortality ◆ Improved health outcomes (from medication adherence and prevention of OI)
HIV/AIDS programs and CHCs on the U.S.–Mexico border	Informing and influencing service and medical providers about HIV/AIDS issues	25 agencies on U.S.–Mexico border		Increased effectiveness and efficiency of HIV/AIDS care	Reduced client morbidity and mortality
HIV/AIDS programs and CHCs on the U.S.–Mexico border	Dissemination	Evaluation findings and policy statements	Increased knowledge in general public, service providers, and policymakers about U.S.–Mexico HIV/AIDS care issues	Increased public concern and funding for HIV/AIDS care on U.S.–Mexico border	Reduced client morbidity and mortality

The system identifies (1) inputs, in the form of community health centers with expert health care providers, who engage in (2) activities related to inputs (staff identify and provide care for HIV-positive patients); and (3) outputs, which are the projected numbers of patients that health care staff at the centers hope to care for during the life of the program.
community health center (CHC); opportunistic infections (OI).

sis. Planned outcomes are identified in three stages: immediate, intermediate, and long-term.

The Structural Equation Model

Evaluation center staff developed a structural equation matrix model (Figure 1.2) to help grantees identify *care variables*, or factors believed to influence HIV/AIDS medical care. The structural equation model identified three sets of variables believed to influence HIV/AIDS care utilization:

1. The first set of variables are factors associated with demographic characteristics and risk behaviors that predispose people to need HIV/AIDS care.
2. The second set of variables are observed when predisposing factors result in medical indicators that present the need for HIV/AIDS care.

3. The third set of variables are factors in the form of equation conditions believed to influence utilization of HIV/AIDS care. Two of the three equation conditions are in the form of resource variable sets, which function as factors *enabling care* when present and, when absent, as *disabling factors to care*. The identification of disabling variable sets was particularly useful in constructing Module F, the *Barriers to HIV Care* instrument. The third condition in the structural equation model focuses on actual service availability and accessibility, which are contingent on the consumer's enabling (or disabling) factors. Thus, the structural equation model helps explain how predisposing factors lead to the need for HIV/AIDS care and how service availability and accessibility is contingent on knowing enabling and disabling factors that may be unique to the particular consumer.

FIGURE 1.2. Structural equation model: barriers to care.
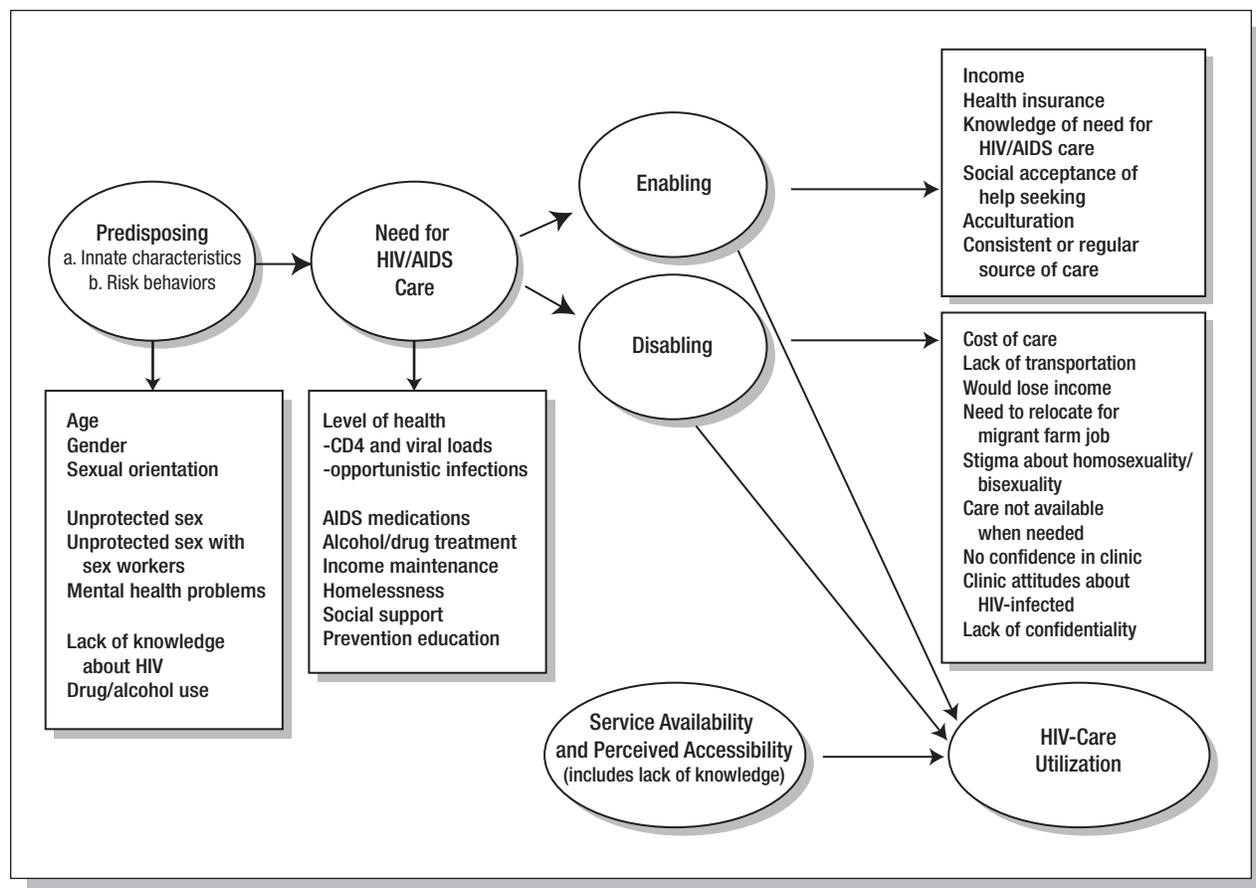
Focus of Demonstration Projects

The demonstration projects had two major foci. The first was to improve access to HIV/AIDS care through use of local, culturally relevant health care models that made use of indigenous paraprofessionals to conduct outreach activities. Those activities were designed to reduce barriers to access to HIV/AIDS care. The second focus was to develop innovative and culturally relevant case management models to support the primary medical team providing care for people who are infected with HIV. The collective goal was to identify "cross-cutting," effective care models that took into consideration cultural and language considerations of the population living with HIV/AIDS along the U.S.–Mexico border. Each service demonstration project was asked to include relevant regional or local issues, such as travel distances or personnel challenges, in planning outreach or intervention strategies. Each regional demonstration service project was required to subcontract with a local university research consultant to coordinate local and collective evaluation activities with the University of Oklahoma evaluation center.

During the first year, two grantee–evaluator meetings (including site representatives and evaluation center staff) were held for the purpose of agreeing on a multisite research plan to conduct evaluation of project outcomes. The work involved developing and agreeing on common instruments for data collection. Grantees agreed to adopt five of six instruments during the initial meetings. Barney's prior work with The Measurement Group (TMG), a leading national HIV/AIDS research organization led by consultant George Huba, is reflected in the research direction undertaken by the center (Huba, 1996–2000). TMG has a large pool of standardized instruments with translated Spanish versions for use with an Hispanic population (Huba, 1996–2000). Grantees felt the different Spanish dialects in the border service areas made it necessary to use the TMG English instrument versions and translate them to Spanish. Grantees agreed to

help with initial English-to-Spanish instrument translations. To address the variation in word meaning among different dialects, an English–Spanish questionnaire codebook was developed. Data collection began in January 2001.

The Measurement Instruments

The final multisite instruments included seven modules, labeled A through G. Module A was a demographics survey capturing sociodemographic information, and Module B was a lifestyle survey exploring ties to Mexico, ethnic identification, and level of acculturation. Module C, the "change form" (discussed later), was introduced late in the initiative cycle to track patients' status changes. Module D was designed to measure the level of behavioral risk factors associated with HIV exposure. Module E, a quality-of-life instrument developed by Huba 1996–2000, measured the level of disability in the context of activities of daily living. Module F, which assessed barriers to HIV medical care, was developed mainly from information obtained in focus groups conducted by the San Ysidro Health Center evaluation team during the initial year; it was added 6 months after the other instruments had been adopted. Finally, Module G was a client satisfaction survey used to measure satisfaction with health care services. Five of the seven instruments were adapted from previous TMG work (Huba, 1996–2000). Module instruments can be obtained from the Centro de Evaluación Web site (www.ou.edu/border).

All instruments were translated from English to Spanish. To help overcome regional colloquial language differences, the center arranged for the linguistics department at the University of Texas, El Paso, to translate five of the seven multisite instruments and an accompanying codebook. Translation of Module F (the module assessing barriers to care) was assigned to an independent consultant in Washington, DC. Evaluation center staff discovered that despite back-to-back English-to-Spanish and Spanish-to-English translations by

certified translators at the University of Texas, El Paso, debate over differences in word meanings among bilingual site staff leaders continued. The problem was resolved by listing multiple word meanings in the codebook.

Middle Stage: Data Collection and Continued Team Building

To ensure data quality, project data managers received data collection training by center staff in the use of data instruments and the codebook to use when a participant had difficulty understanding instrument language. The initial staff training provided useful feedback for center staff in refining the instrument and codebook language before the tools were used.

The successful use of seven multisite data instruments relied heavily on the willingness of grantees to participate in electronic data transfer. Center staff transformed multisite instruments to TeleForm software, which enabled grantees to have access to electronic data transmission, instrument distribution, and interactive instruments on a password-protected Web site. Grantees could access all instruments and transmit data on a continual basis to the center via the Web or by fax. The electronic transfer of data increased quality assurance and provided quick feedback of merged data files to grantees. Approximately 1,200 PLWHA participated in the study during the 5-year initiative.

The Qualitative Study
During the first 6 months, preliminary agreements were reached between grantees and the center leadership to collect qualitative data on a convenience sample of clients at each of five project locations to provide validation for information solicited in the quantitative instruments. The original study plan was for center staff to conduct two focus groups of five to seven participants per group at each site. The goal was to examine participants' pretreament associations with accessing HIV/AIDS care and perceived or experienced barriers to

medical care. The principal investigator decided to contract the focus groups to an external bilingual consultant. The focus group plan was dropped when staff from grantee sites had difficulty recruiting volunteer participants for focus groups on short notice. It is assumed that the principal investigator elected to use the external contractor and individual informant interviews because of time constraints and because he thought that study participants would feel safer sharing personal care experiences with someone not connected with the evaluation center or a particular health care site. His need to have information early and commit initiative funds before the close of the first-year funding cycle yielded a limited convenience sample of 32 informants who were recruited on short notice for the qualitative study.

Each site recruited volunteer participants, secured written consent, and arranged for the consultant to have a private office in which to conduct interviews. One interview was conducted in a participant's home. The evaluation center used HRSA funds to cover consultant costs. Interviews were conducted in either English or Spanish on location at each grantee site during April and May 2002. The recorded interviews were transcribed and translated into English before being analyzed by center staff.

The Medical Chart Review Study
In addition to collecting quantitative data on six instruments and securing participants for the qualitative study described above, the five grantees agreed to participate with the evaluation center in a study of patient medical chart outcomes to measure select medical indicators pre- and posttreatment. This medical outcomes study was an attempt to replicate TMG's previous work in south Florida (Huba & Melchior, 2001). The data were collected in the third and fifth years of the initiative.

Medical consultants traveled to all medical grantee sites to review patient medical charts. Recruitment of consultants was challenging given the short

implementation timeline, travel distance, and time required to conduct chart reviews. The consultant's initial lack of familiarity with site locations and with the complex nature of care systems having multiple service delivery sites added to the challenge. The success of the consultant's medical chart reviews depended heavily on coordination by site grantees and their working relationships with their medical records staffs.

A modified version of TMG's Broward (Florida) Study (Huba & Melchior, 2001) instrument was used to measure medical outcomes. The instrument was adapted for administration during two separate review periods to measure medical outcomes in up to 16 patient–doctor quarterly visits during the initiative period. The medical chart data collected resulted in approximately 40 pages of data per patient. Consultants received extensive orientation before conducting chart reviews and had access to center staff to answer problematic questions. Approximately 750 participants were part of the medical outcomes study.

Local Site Evaluation Projects

The center provided technical support to grantees for processing local project evaluation data. Ten local site instruments were created by site evaluators specifically to support local evaluation efforts at four of five project sites. Grantees were given the option of using the center's TeleForm system to process and merge local data with existing multisite files using the Internet.

Building on the positive collaborative data collection experience between the sites and the evaluation center staff, an attempt was made to create a form for sites to report participant status changes such as marital status, death, lost to follow-up, or service delivery changes (e.g., change in physician, service location, or patient service status). The change module was not implemented across all sites, however, in part because staff were preoccupied with other routine data collection efforts.

End Stage: Lessons Learned

Despite challenges in the fifth year of this initiative, including a new principal investigator at the evaluation center, the existing center and grantee staff were successful in continuing the work that was started in prior years.

Administrative Challenges

Administrative challenges during the initiative were of two kinds: in-house project needs within the university system and external needs of the site grantees. The initial challenges were associated with recruiting and training personnel to implement the project at all levels. One important administrative challenge was assisting grantees with in-house changes, usually personnel turnover, that could affect project performance. Those changes did not occur frequently but, in retrospect, could have been anticipated given the number of personnel working on this initiative and their diverse backgrounds. The center staff was responsible for structuring and coordinating the multisite evaluation effort with site personnel having varied education, work experience, and site resource limitations. The level and quality of communication within and between partners in this initiative was clearly a key factor in the success of the SPNS project.

The Institutional Review Board

When the center first began to assimilate itself into the formal university structure, the center's leadership quickly learned the importance of securing clear and timely institutional review board (IRB) approval. Approval was necessary before grant funds could be expended to conduct research functions. In subsequent IRB approval requests during the award period, leadership learned the importance of seeking IRB approval for reporting protocol changes and the need for shared IRB approvals across university sites when the same client populations were involved. Key research partners across projects needed IRB-approved research protocols from their own IRBs as well as from IRBs of partner institutions. Individual projects and center staff

could have saved valuable time and effort during the final award period had they known such data safeguard procedures had to be in place. The recommendations section offers suggestions for future SPNS researchers.

University personnel policies delayed and sometimes discouraged applicants for evaluation center employment. As evaluation center needs became clearer, it was evident that additional staff with research skills were needed to manage the expanding multisite database and oversight of the medical (chart review) outcomes study. Implementing and managing a Web-based data collection system (a cornerstone of the center's efforts) required off-site staff training to augment staff competencies to effectively meet technology needs of the center and its partner SPNS grantees.

Evaluation Center Staff Role Changes

As evaluation center leadership took on the management of additional grants (other than the SPNS project), roles and responsibilities had to be realigned. The shift in staff roles affected the balance of staff effort expended on SPNS partners. Staff leadership roles were reassigned and job functions were distributed across expertise of staff. The changes are mentioned here because the center experienced a change in leadership that coincided with the staff changes. It is assumed that those changes affected center staff functioning and staff interactions with counterpart grantee personnel.

Communication Among Initiative Partners

The bonding with partner grantees came about through ongoing engagement that involved frequent staff communication during regularly scheduled site visits from center staff. Those visits, along with bimonthly telephone conference calls that involved partner grantees, HRSA, and the center, were the primary means for building team relationships and addressing initiative questions. The regular telephone conference calls were invaluable sources of group support that afforded grantees a private venue for center staff consultation and validation. Sites could and did request individual telephone conferences with center or HRSA staff between staff site visits. Ongoing, open communication between center, HRSA, and grantee staff was a key element that helped achieve the successes reported here.

Partnering With Grantees

Engaging partner grantees in the development of multisite data collection modules and the dissemination efforts provided important benefits. The process helped grantees see themselves as equal partners in the initiative. Discovering regional differences in Spanish-language terminology for the questionnaires provided additional opportunities to involve grantees in efforts to find terms that would more likely be understood by the population in a particular region. This process helped reinforce the grantee partners' sense of ownership in the initiative. Many of the professional relationships that began as a result of the initiative have been sustained and have resulted in new HIV/AIDS collaborations and academic–community partnerships.

During initial data analysis, some measures were found to not completely address the intended research questions. For example, Module F was intended to measure patient perceptions of barriers to care before and after seeking care at a SPNS care site, not generally. An ad hoc committee of the initiative's dissemination committee (see below) identified a potential interpretation problem and advised the grantees. Rubin and Babbie's (1997) advice on questionnaire construction may be helpful to future SPNS researchers: "[T]ry to use unbiased wording (to minimize systemic error) and terms respondents will understand (to minimize random error)" (p. 171). Of course, the challenge for the researcher is greater when working with translated instruments in situations involving differences in regional terminology. In retrospect, the error was in rushing the process of questionnaire construction. The center and grantees could have

spent more time pilot testing the English and Spanish versions of the various instruments with groups similar to the intended study populations.

Dissemination Committee

A multisite dissemination committee was created to coordinate collective and individual dissemination efforts. The committee provided a means of sharing initiative ownership with grantees and responsibility for dissemination of SPNS findings. With seven universities, five community-based organizations, a Federal agency, and a private organization all having dissemination interests in the SPNS initiative, it was important for key contributors to understand initiative directive priorities. The diverse organizational structures, the number of colleagues with research interests, and the large pool of data made it necessary to have a centralized group to coordinate dissemination functions. Thus, the center created the dissemination committee, which was chaired by Tony Estrada, University of Arizona, the contract officer for the evaluation component of the Arizona Border HIV/AIDS Care Project. The committee was composed mainly of colleagues who had data management responsibilities. The role of the committee was to act as a clearinghouse for grantees to reduce duplication of effort and encourage collaboration. The committee was charged with review of proposals submitted by grantees to use evaluation center data. Committee approval was built in as protocol for release of collective data.

Appendix 1.A. provides a partial list of dissemination activities that resulted from the initiative. A special journal issue on HIV/AIDS in the *Journal of HIV/AIDS and Social Services* was published in fall 2006 (Curiel & Land, 2006a). The issue was published as a book: *Outreach and Care Approaches to HIV/AIDS Along the U.S.–Mexico Border* (Curiel & Land, 2006b). The list includes findings reported at conference proceedings (18 presentations from 2001 to 2006); it does not include a number of additional dissemination products, such as Web sites with links that reported ongoing activities of inter-

est to consumers, public officials, and community leaders. Several publications in CD–ROM format have been produced. One HRSA publication, *Innovations Along the U.S./Mexico Border: Models That Advance HIV Care*, features three grantee site leaders and introductory remarks by a member of the evaluation center staff. Grantee and evaluation center staff have presented research findings at numerous national and international conferences. One site, the Valley AIDS Council, is internationally known for its sponsorship of an annual HIV/AIDS international conference. The dissemination efforts have exceeded expectations.

Retrospection and Recommendations

The initiative represented in this monograph was a success because of the combined expertise of colleagues across sites and their commitment to the mutual goals of increasing access to medical care and to education to prevent HIV/AIDS along the U.S.–Mexico border. A bond was formed among staff across sites and evaluation center leadership. The bond between colleagues was nurtured by frequent staff contacts; in-person meetings with HRSA staff twice a year; and twice-monthly staff telephone conference calls among grantees, the evaluation center, and HRSA officers. Additional sources of team building came about through the creation of a network of Web sites that served to reinforce the partnership connections; periodic site visits by center staff; and, most important, the center's friendly, competent staff, who had expertise in evaluation technology and data collection resources not previously available to most service sites.

In hindsight, the center should have taken more time with instrument construction to anticipate analysis questions, particularly because of required English-to-Spanish translations. A pilot study with a sample of similar participants at each site would have prevented some of the problems encountered in determining income and education of participants. The income variable was a problem because many participants reported no income at the time

of initial project entry. The education variable did not distinguish between formal education in Mexico or in the United States.

Center staff also learned the importance of keeping IRBs informed of protocol changes. The evaluation center erred by not seeking IRB approval for leadership and format changes to a previously approved protocol for a qualitative study. An outside consultant was hired without IRB approval to conduct individual informant interviews that were not part of the original IRB-approved protocol. The lesson learned is that study protocol changes need IRB approval. IRB boards exist to protect consumers, the university, and the investigator. An investigator is vulnerable to legal action when he or she fails to follow IRB-approved study protocols.

In conclusion, outcome goals for the SPNS initiative were realized. The center and its partner grantees deserve credit for teamwork that contributed to the success of the SPNS partner initiatives. In the chapters that follow, each SPNS grantee describes the site's prior work with clients living with HIV/AIDS and its partnership development with local health care leaders during SPNS project application, implementation, and follow-up. They describe the development of their SPNS model and challenges posed at various implementation phases. Each chapter includes a case scenario to illustrate application of the model components.

Below are 12 recommendations for SPNS projects that are targeting outreach or care approaches to Hispanic communities. The recommendations are based on lessons learned by Centro de Evaluación staff over the 5-year initiative and provided in the hope that others can benefit from successful, collective SPNS work.

1. Become familiar with the five service models presented in this monograph.
2. Use local epidemiologic data for project planning and identification of at-risk groups.
3. Identify early tasks to be performed by staff at various levels and hire staff with required expertise (e.g., language skills, cultural knowledge, knowledge of HIV/AIDS, Web design, data collection systems management).
4. Use the logic and structural equation models (Figures 1.1 and 1.2) for a visual picture of anticipated staff functions, client needs, and project outcome goals.
5. Nurture staff relationships at all levels to create a team approach.
6. Have regular meetings with project staff and initiative partners, by phone or in person, to provide supportive supervision and direction.
7. Attend to language and cultural competency of staff working directly with consumers who have limited English proficiency.
8. Anticipate colloquial language differences in translation and administration of research documents.
9. Create a codebook to manage colloquial differences in language.
10. Pilot-test research instruments with a group similar to the study group.
11. Create and use Web sites to inform consumers, to educate others about the program, and to increase networks.
12. Know IRB requirements for initial approval and for protocol changes.

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APPENDIX 1.A. Border Dissemination Activities by the Evaluation Center

	Title	Year	Avenue of Dissemination
1	Fact Sheet on Border Health	2001	Available at http://casr.ou.edu/border/pdf/usmbha_factsheet.pdf and distributed at United States-Mexico Border Health Association (USMBHA) conference, Las Cruces, NM
2	HIV/AIDS issues on U.S./Mexico border	2001	Panel presentation, USMBHA conference, Las Cruces, NM
3	An annotated bibliography of research related to HIV/AIDS and Latinos, and border issues	2001	Fact sheet available at http://casr.ou.edu/border/pdf/factsheet_for_DC_grantees meeting.pdf and distributed at SPNS border project grantee meeting
4	Subpopulation characteristics predicting patient satisfaction in a U.S./Mexico border sample of HIV/AIDS primary care patients	2001	Panel presentation at American Public Health Association conference, Atlanta, GA
5	U.S./Mexico HRSA SPNS Border Health Initiative	2001	Panel presentation at American Public Health Association conference, Atlanta, GA
6	Five HIV/AIDS Care projects along the U.S./Mexico border	2002	Poster presentation at RWCA All-Titles Meeting, Washington, DC
7	Multisite HIV/AIDS issues on the U.S./Mexico border across five projects	2003	Conference presentation, All Things Are Connected conference, Las Cruces, NM
8	Cultural factors affecting HIV/AIDS service delivery on the U.S./Mexico border	2003	Social Work and HIV conference, Albuquerque, NM
9	Comprehensive health service delivery for HIV-positive people living along the U.S./Mexico border	2003	Presentation at the USMBHA conference, San Diego, CA
10	Multisite HIV/AIDS issues on the U.S./Mexico border across five projects	2003	Presentation at the Social Work and HIV conference, Albuquerque, NM
11	HIV/AIDS disparities and issues for U.S./Mexico border populations	2003	Presentation at the Making Connections conference at the University of New Mexico, Las Cruces, NM
12	Latinos and HIV/AIDS on the U.S./Mexico border: Experiences as HIV+, social services, primary care programs	2003	Presentation at the American Public Health Association conference, San Francisco, CA
13	U.S./Mexico Border Health Initiative	2004	Presentation at the Ryan White CARE Act Grantee conference, Washington, DC
14	An application of Borrayo's Cultural Health Belief Model to HIV/AIDS seropositive Hispanics living along the U.S./Mexico border	2004	*Journal of HIV/AIDS and Social Services, 3*(3), 9–34.

APPENDIX 1.A. Border Dissemination Activities by the Evaluation Center (cont'd)

	Title	Year	Avenue of Dissemination
15	A qualitative study of 32 persons living with HIV/AIDS on the U.S./Mexico border	2004	Presentation at the Ryan White CARE Act Grantee conference, Washington, DC
16	HIV/AIDS along the U.S./Mexico border: A description of demographics, lifestyles and culture, risk factors, quality of life, and barriers reported by HIV positive clients living in U.S./Mexico border region	2005	Publication on CD-ROM distributed at the 2005 American Public Health Association conference, Philadelphia, PA, and at the 2006 Ryan White CARE Act Training and Technical Assistance Grantee Meeting, Washington, DC
17	A review of the statistical aspects of quality of life measurement tools for HIV/AIDS	2005	Presentation at the American Public Health Association conference, Philadelphia, PA
18	Demographic characteristics of a population of HIV/AIDS seropositive individuals receiving care through five demonstration sites along the U.S./Mexico border	2005	Poster presentation at the American Public Health Association conference, Philadelphia, PA
19	Assessing the effects of strain on HIV/AIDS risk behavior and adherence to treatment regimes: an empirical test of general strain theory	2005	Dissertation
20	A 2000–2005 HIV/AIDS Project: A profile of 1,200 persons living with HIV/AIDS along the U.S./Mexico border	2006	Presentation at the USMBHA conference, Monterrey, Mexico
21	Demographics, Lifestyle, and Quality of Life; part of the workshop *HRSA SPNS U.S./Mexico HIV/AIDS SPNS Initiative: Selected outcomes over 5 years*	2006	Workshop presentation at 2006 Ryan White CARE Act Training and Technical Assistance Grantee Meeting, Washington, DC
22	Risk and Barriers; part of the workshop *HRSA SPNS U.S./Mexico HIV/AIDS SPNS Initiative: Selected outcomes over 5 years*	2006	Workshop presentation at 2006 Ryan White CARE Act Training and Technical Assistance Grantee Meeting, Washington, DC
23	Findings from Qualitative Data; *part of the workshop HRSA SPNS U.S./Mexico HIV/AIDS SPNS Initiative: Selected outcomes over 5 years*	2006	Workshop presentation at 2006 Ryan White CARE Act Training and Technical Assistance Grantee Meeting, Washington, DC
24	Socio-demographic characteristic of HIV/AIDS individuals living and receiving care along the U.S./Mexico border through five demonstration projects	2007	Article published in special issue of *Journal of HIV/AIDS and Social Services, 5*(4)
25	Socio-demographic characteristic of HIV/AIDS individuals living and receiving care along the U.S./Mexico border through five demonstration projects	2007	Chapter in *Outreach and Care Approaches to HIV/AIDS Along the U.S./Mexico Border* (Curiel & Land, 2006b)

APPENDIX 1.A. Border Dissemination Activities by the Evaluation Center (cont'd)

	Title	Year	Avenue of Dissemination*
26	Migrant labor, acculturation, and risk behaviors of HIV/AIDS-positive Hispanic patients receiving HIV/AIDS care along the U.S./Mexico border	2007	Poster presentation at the American Public Health Association conference, Washington, DC
27	Estimation of the prevalence of AIDS, opportunistic infections, and standard of care among HIV/AIDS patients receiving care along the U.S./Mexico border through the SPNS: a cross-sectional study	2007	Submitted for journal publication
28	HRSA Border Monograph	2007	Monograph
29	A critical review of statistical aspects of quality of life measurement tools for HIV/AIDS patients	In press, 2008	*Journal of HIV/AIDS and Social Services*

Many documents are available at http://casr.ou.edu/border/dissemconf.htm.

CHAPTER 2

The Southern California Border HIV/AIDS Project: An Innovative Approach to HIV Outreach, Primary Care, and Cross-Border Linkages at the California–Baja California Border

San Ysidro Health Center (SYHC) was founded in 1969 by a local women's organization concerned with the community's lack of access to medical, behavioral, and dental services. At that time, the northern side of the San Ysidro–Tijuana U.S.–Mexico border had no significant health infrastructure, and many local residents did without health care until medical conditions made it necessary to seek care at the nearest emergency room. Because of their low income and lack of health insurance, most local residents were unable to access primary care services.

Guided by its grassroots beginnings and longstanding commitment to community service, SYHC has pursued public and private funding opportunities to provide health care for members of its surrounding communities. In the early 1970s, SYHC received a grant from the Health Resources and Services Administration (HRSA), Bureau of Primary Health Care (BPHC), to provide primary care and limited behavioral health and dental services. Funding has been renewed over the years on the basis of SYHC's ability to demonstrate improved care delivery and a positive impact on community health.

Since 1969, SYHC has been a leader in the provision of low-cost, high-quality, comprehensive primary health care services to residents of the South Bay region of San Diego County, California. Over the past 35 years, the health center's growth has been driven by the community's need for essential health care and social services. As of 2005, SYHC has satellite community health centers (CHCs) in San Ysidro, Otay Mesa, Chula Vista, and National City, all of which were strategically located to provide comprehensive health care (medical, dental, and mental health) to the entire South Bay region.

To effectively carry out its mission, SYHC provides a continuum of health care services through fixed and mobile clinic sites, and it conducts intensive community outreach programs to bring people into care. SYHC's major stationary-site services include the following:

* Primary medical care: adult medicine, pediatrics, geriatrics, and obstetric and gynecological services
* Mental health and substance abuse services
* Dental services, including pediatric dental services
* HIV/AIDS services (Title II and Title III)
* Pharmacy prescriptions
* Laboratory services
* Radiology services
* Optometry
* Specialty medicine: podiatry, cardiology, pediatric pulmonology, and rheumatology
* Women, Infants and Children (WIC) nutrition services
* Enabling social services, such as case management, patient education, nutritional counseling, and community preventive education.

Area Demographics

SYHC is in California's 51st Congressional District. Its service area is south suburban San Diego County, California. This geographic area, referred to as the South Bay, is a subregional area of San Diego County and as of January 2006 had a population of 138,259. SYHC's service area comprises 82 census tracts. Eleven census tracts in the San Ysidro/Imperial Beach area along the California–Mexico border are designated as primary care health professional shortage areas (HPSAs), and four census tracts in SYHC's National City service area are designated as medically underserved areas (MUAs) by the BPHC.

SYHC's service area encompasses the southwestern region of San Diego County and the continental United States. Its service boundaries are the Pacific Ocean in the west; the international border between California and Baja California, Mexico, to the south; the city of San Diego in the north; and the Otay Mesa border to the east.

Target Population

SYHC's target population consists of low-income, uninsured, minority people living in the South Bay region. Historically, most of SYHC's patients have been people of Mexican ancestry with low incomes. In 2004, SYHC served 50,675 patients; 88 percent were of Latino[4] or Mexican ancestry (44,793). Significant socioeconomic disparities exist within the population in SYHC's service area, as demonstrated by the following indicators:

* *Age.* The San Diego Association of Governments (SANDAG) regional planning agency showed that the median age of the South Bay's 138,259 residents is about 30 years. Adults age 25 to 44 account for 31 percent of the population; children and adolescents from birth to age 14, 24 percent; young adults age 15 to 24, 17 percent; and adults age 45 to 64, 20 percent. Seniors—those age 65 and older—account for only about 9 percent of the service area population (SANDAG, 2006).
* *Insurance.* A major portion of SYHC's service area has the State's 14th highest rate of uninsured residents from birth to age 64 (approximately 110,000 uninsured people). Uninsured residents compose 30 percent of the district's total population; statewide, the average is 21 percent (UCLA Center for Health Policy Research, 2002).
* *Poverty.* According to SANDAG (2000), 17 percent of people living in the South Bay region live below the Federal Poverty Level (FPL). Two factors related to low income among area residents are limited English proficiency and limited educational attainment. Two service areas, National City and Imperial Beach, have the highest percentages of low-income households

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[4]In this chapter, *Latino* refers to both men and women of Hispanic heritage, unless otherwise specified.

in the South Bay region. In 2000, 25 percent of San Ysidro families (1,597 families) had incomes below the FPL, compared with San Diego's poverty rate of 8.9 percent. San Ysidro's median household income was only $25,078 (SANDAG, 2000).

∗ *Ethnicity/Culture*. According to 2000 Census data (Ramirez & de la Cruz, 2003), communities geographically closer to the California–Mexico border have significantly higher percentages of people of Mexican or Latino heritage. This pattern is especially true in SYHC's service area. Although Latinos account for only 26.7 percent of the county's total population, they comprise 89 percent of San Ysidro's population (SANDAG, 2003), 59 percent of National City's population, and 50 percent of Chula Vista's population (SANDAG, 2006).

∗ *Education*. Except in Chula Vista, educational attainment for the population age 25 and older in SYHC's service area is low. Nearly 43 percent of National City's population and 57 percent of San Ysidro's population age 25 and older did not graduate from high school (SANDAG, 2000). High dropout rates are attributed in part to language and cultural barriers.

Other Federal, State, and Local Funding

SYHC funding comes from Federal, State, local and private foundations. SYHC aggressively seeks funding opportunities to secure the community's growing need for health care services.

SYHC's experience providing culturally and linguistically appropriate HIV services to Latinos in the San Diego–Tijuana border region enabled the health center to become the lead agency for the HRSA Special Projects of National Significance (SPNS) U.S.–Mexico Border Health Initiative. Moreover, it provided the framework for the development of the SPNS service delivery model used by the partner sites to develop or enhance their HIV programs and services under the SPNS initiative.

Before receiving the SPNS grant in 2001, the funding level for HIV/AIDS services at SYHC was $450,000; funds came primarily from Part B of the Ryan White HIV/AIDS Program through a grant administered by the San Diego Department of Health Services (DHS). In 2005, SYHC's HIV/AIDS department had an annual budget of $1.8 million and administered 13 local, State, and Federal initiatives.

Development of HIV Services

SYHC is committed to providing care to HIV-positive patients, but prior to 2000, HIV services were limited. SYHC initially contracted with an HIV specialist for 4 hours of primary care services per week. In addition, SYHC provided rudimentary case management and social services at the fledgling HIV service center. Staff for this project—a case manager/project director, case worker, outreach worker, and food services coordinator—were funded through a Part B grant from the county of San Diego DHS. In 2000, a Ryan White HIV/AIDS Program Part C Early Intervention Services (EIS) grant enabled SYHC to increase primary medical care from 4 hours per week in 1999 to 40 hours per week by early 2002. Since 2000, additional funding has enabled expansion of other services, such as case management, HIV prevention education, and outreach, as well as the implementation of HIV counseling and testing services.

Service Mission and Commitment to Serving People Living With HIV/AIDS

SYHC's mission—"to protect, promote and improve the health and well-being of the community's traditionally underserved and culturally diverse people"—is woven into the fabric of all the health center's programs. This mission guides all aspects of SYHC operations, from decisions made by the health center's board of directors, to SYHC administration, to care provided by clinical staff, and to resource development to expand patient access to care. SYHC administration is committed to providing a continuum of high-quality, cultur-

ally competent services to HIV-positive patients. A full-time-equivalent HIV medical specialist provides primary care services. Other patient services include case management, nutritional counseling, dental care, and mental health and substance abuse counseling and support groups as well as linkages to more than 15 HIV social service agencies in the community. To receive HIV health care services, HIV/AIDS clinic patients must demonstrate proof of residency in the United States, have proof of diagnosis, and have valid identification.

Local HIV/AIDS Epidemiologic Data

Data from the County of San Diego (2007) show that between 1987 and 2005, a total of 13,015 people were diagnosed with AIDS in San Diego County; 23 percent, or 3,000 cases, were among Latinos. Since the mid-1990s, Latinos have been second to African Americans in the highest rate of AIDS in San Diego County among minority racial and ethnic groups. Of the total reported cases since 1987, approximately 91 percent have been among men; 90 percent of the cases among Latinos are among men as well. Of cumulative AIDS cases reported in Latinos, 58 percent of cases in men are among those who are foreign born and 64 percent of cases in women are among those who are foreign born (i.e., born outside the United States in a U.S. dependency or foreign country; County of San Diego, 2007).

Overview of the Southern California SPNS Initiative

The HRSA HIV/AIDS Bureau (HAB) established the Ryan White HIV/AIDS Program SPNS U.S.–Mexico Border Health Initiative in an effort to "diminish health disparities among individuals living with HIV disease along the U.S./Mexico border" (HRSA HAB, 2003).

HRSA was expecting a collaborative proposal. Senior staff at the San Diego County Office of AIDS Coordination (OAC) had a long history of working with other county and community agencies to develop programs; OAC agreed to

facilitate the process with the help of staff from the San Diego County Office of Border Health (OBH).

OAC and OBH organized and facilitated a series of planning meetings. Participants included representatives from grantees of Ryan White HIV/AIDS Program Parts A through D; the Pacific AIDS Education and Training Center (AETC); the County Early HIV Intervention Program; county offices of epidemiology and tuberculosis control; and staff from county and State offices of border health. The SPNS working group consisted of 33 San Diego agency representatives and 2 from Imperial County. Once the SPNS request for proposals was issued, a grant writer hired by the San Diego County Office of Public Health, the parent entity for OAC and OBH, worked with the SPNS working group on the response to the RFP. The working group named its proposed project, "Borderland HIV/AIDS Care Innovations: New Approaches to Outreach, Primary Care and Cross-Border Linkages at the California/Baja California Border."

SYHC was selected as the lead agency for the proposed project. Collaborating partners initially included five CHCs (four in San Diego County and one in Imperial County), and the University of California, San Diego (UCSD) served as the program evaluator. Family Health Centers of San Diego (FHCSD) represented the central region of San Diego County, Vista Community Clinic (VCC) represented the north region, East County Community Clinic (ECCC) represented the east region, and Clinicas de Salud del Pueblo (CSP) represented Imperial County. SYHC, the lead agency, represented the South Bay region. Comprehensive Health Centers served as technical advisors for treatment adherence services.

Early in the development of the collaboration, the ECCC was unable to participate; however, the remaining four partner sites and the evaluation team were active participants throughout the 5-year project and beyond. In June 2000, SYHC was awarded the SPNS grant. In the first year, the

FIGURE 2.1. Southern California Border HIV/AIDS Project service delivery model.
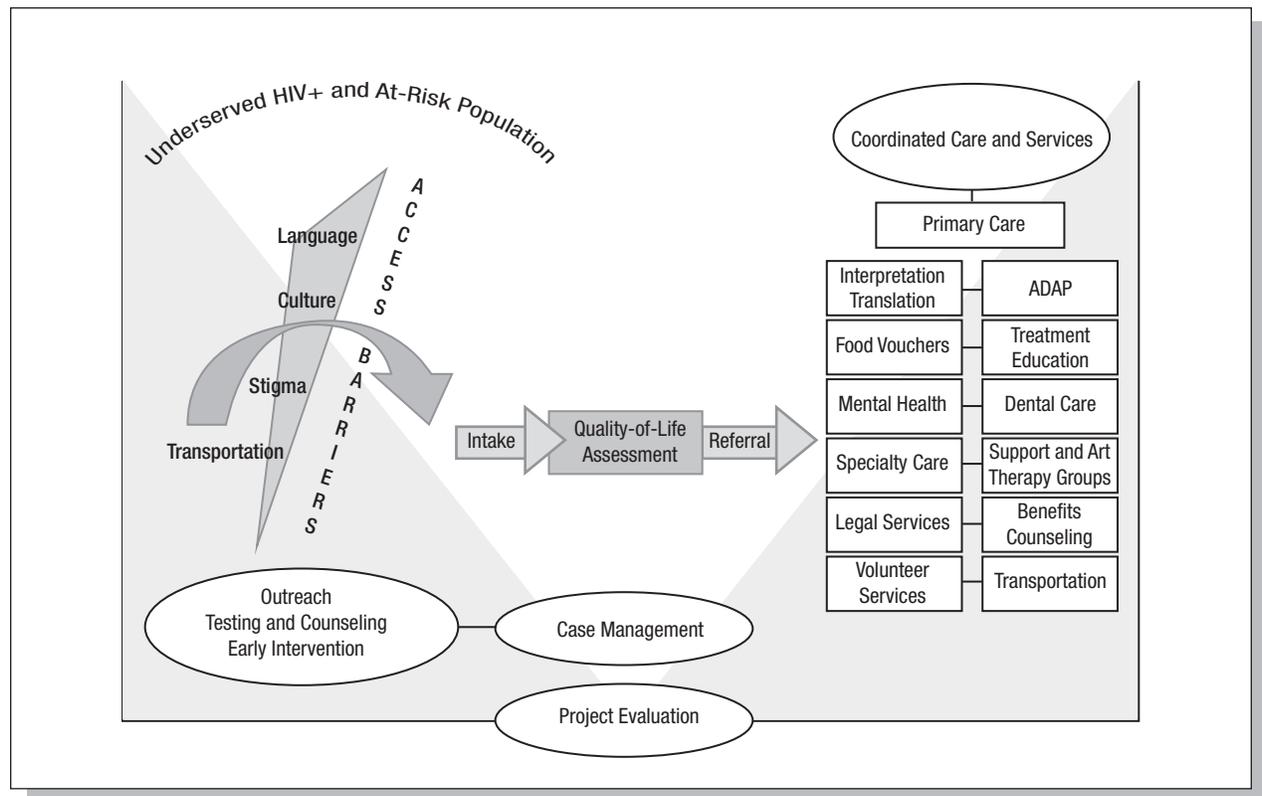
project was renamed the "Southern California Border HIV/AIDS Project."

The Southern California Border HIV/AIDS Project proposed to use innovative approaches to increase HIV/AIDS outreach, primary care services, and cross-border linkages for people who live or work in the San Diego or Imperial County border region. The project targeted underserved, hard-to-reach, minority populations, particularly Latinos. To address the diverse nature of Latino populations, each partner site was asked to designate its target population based on its organization's geographical area and unique service population. Target populations collectively included:

* Newly immigrated Latinos
* Migrant and permanent farmworkers
* Latinas
* Transborder Latinos
* Latina sex workers
* Latino men who have sex with men (MSM).

The categories were not mutually exclusive, although they represented distinct populations for each region. Initially, one target population was male Latino youth sex workers; however, because of an inability to identify that population in a consistent manner, the youth sex worker population was integrated into the Latino MSM category.

Project Goals and Model
The Southern California Border HIV/AIDS Project had three main goals:

1. To increase early detection among the under-served HIV-positive Latino population
2. To increase access to comprehensive HIV/AIDS primary care services
3. To enhance the capacity of CHCs to provide culturally sensitive care.

The service delivery model implemented at each partner site was based on the service model developed at SYHC (Figure 2.1). The SYHC

model identified five categories of primary HIV services (i.e., core services) that are necessary to reach and adequately serve Latinos:

1. HIV primary care services
2. Case management
3. AIDS Drug Assistance Program (ADAP) enrollment
4. Treatment adherence counseling
5. Culturally sensitive services in both Spanish and English, including onsite translation and interpretation services.

Three partner sites agreed to implement the SYHC HIV service delivery model, given demonstrated success observed at SYHC. The fourth site, Comprehensive Health Centers, was contracted to provide technical assistance to other partner sites for the development of culturally and linguistically appropriate treatment adherence counseling. Figure 2.2 depicts the patient flow at SYHC.

Providing HIV primary medical care was considered a basic service for meeting the needs of HIV-positive Latinos, but the case management component was essential to the success of SYHC's service delivery model. All partner sites were required to have bilingual case management services. The case manager became the primary access point for helping HIV-positive Latinos access and stay in care.

Logic Model
The initial logic model for the Southern California Border HIV/AIDS Project was found to not accurately reflect the planned intervention or realistically capture the evaluation measures proposed to assess the intervention. Minor changes in model language and target population contact estimates were made through partner consensus and approved by HRSA. The logic model is shown in Appendix 2.A.

SYHC's initial target population was transborder Latino MSM; the target population was modified to include all transborder Latinos because of the lack of MSM outreach sites in the South Bay region. As indicated earlier, a partner site, FHCSD, had to expand its initial target population of Latino youth sex workers to encompass Latino MSM as a result of similar participant recruitment problems. The proposed project plan remained essentially the same throughout the 5-year SPNS initiative. The evaluation plan for the Southern California Border HIV/AIDS Project used both process and outcome evaluation measures.

Implementation and Collaboration
Implementation of a new service delivery structure at partner sites was challenging. Most sites had established HIV services to various degrees. The longer the history of HIV services at a site, the harder it was to implement a new service delivery model and train staff in using that model.

A key to the success of the Southern California Border HIV/AIDS Project was the collaboration among the four partner sites and the local UCSD evaluation team from the outset. The successful collaboration was attributable to excellent communication established during the planning phase. Regular monthly meetings were forums to discuss project progress and problems. The monthly meetings also served as a support system for project staff and contributed to staff buy-in. Each site submitted monthly reports that provided the lead agency with regular updates on progress toward the project objectives. In addition to reports and meetings, the lead agency and evaluation team made annual site visits to provide consultation and assess progress.

Relationships With the Centro de Evaluación and the Pacific AETC
The Centro de Evaluación (see Chapter 1) provided technical support on various aspects of program evaluation. For example, it helped create TeleForm versions of two local HIV measurement instruments. TeleForm versions made it possible for local data to be entered online through the University of Oklahoma server and integrated with other multi-site data using unique record numbers (URNs).

FIGURE 2.2. Patient flow diagram for San Ysidro Health Center (SYHC) HIV testing and case management department.
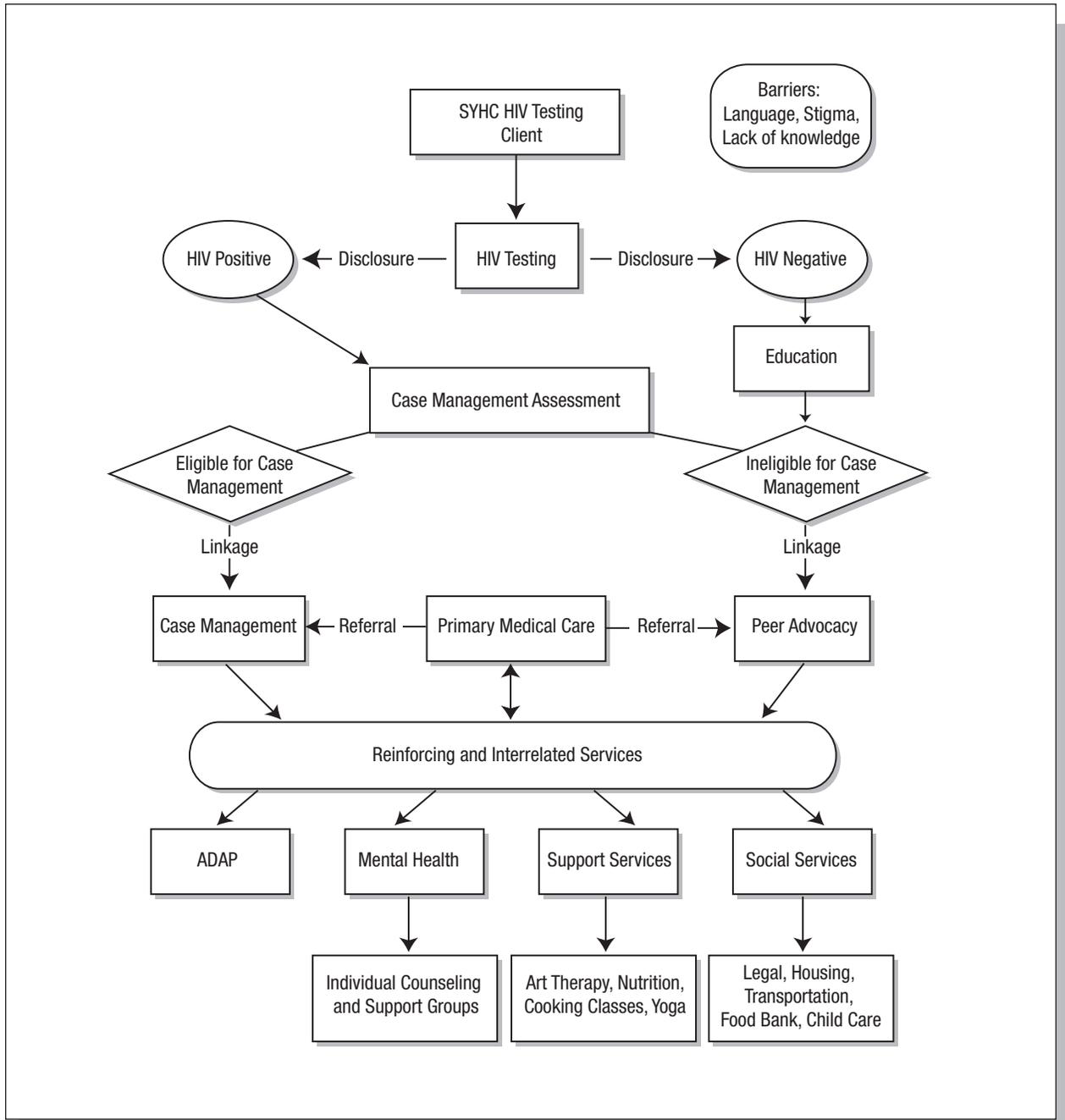
During annual site visits, the leadership of the Centro de Evaluación provided support and guid-ance when needed on evaluation-related activities. The visits proved useful for the project evaluation activities in general. The UCSD evaluation team met with the Pacific AETC director during the first project months. Her participation in monthly meetings helped identify individual site training needs and provide a source of additional funding to support staff development and education.

CASE STUDY

"José" was an at-risk, Spanish-language-dominant, Latino MSM contacted by a female outreach worker at a local trolley station. He was given a test location card with information on where to go for an HIV test. José presented for HIV testing at the clinic the following week, where he received an incentive to return for results. The incentive was a $10 gift certificate to a local grocery store. On the day of his test, he was invited to become a participant in the SPNS study. The HIV test counselor explained the purpose and conditions of the study, read the voluntary consent statement, enrolled him in the study, and administered two data collection instruments: a demographic survey and an HIV risk assessment survey. The HIV test was performed, and José was asked to return in 5 days for his HIV test results.

When José returned for his test results, he learned that he was HIV positive. He was immediately assigned a bilingual case manager. José's first appointment with the case manager took place within 48 hours of learning his HIV status. During that first meeting, the case manager asked questions to assess José's psychosocial needs and described the HIV medical care services. The data collection instruments used for program evaluation were completed during the initial assessment meeting. The surveys (i.e., the multi-site modules) became part of José's case management record. José agreed to enroll in medical care and was given information on other clinic services.

José continues to seek medical care and case management services at the clinic. He also sees the bilingual mental health counselor and participates in the weekly support group.

Role of Consumers in Determining Agency Policy

Two consumer focus groups were used to obtain feedback on barriers to accessing HIV services. From those groups, it was learned that both men and women wanted improved access to clinical trials. This information was used for a pilot study funded by the National Institutes of Health, Center on Minority Health and Health Disparities, to explore barriers to HIV clinical trials for Latinas living with HIV.

Based on data from the study, UCSD sought to continue collaborating with SYHC to expand the study to include Latinos and HIV service providers and has since been awarded a 5-year grant[5] from the National Institutes of Mental Health to improve understanding of barriers to HIV clinical trials and issues related to access to care.

Overview of SPNS Initiative Evaluation

Training and Staffing

The evaluation coordinator trained personnel at each site during first year of the project. The SYHC project coordinator met monthly with partner site representatives to discuss implementation challenges. Staff understanding of the project was critical to their buy-in, and it contributed to program stability at the sites throughout the grant period. Significant staff turnover occurred at only one partner site.

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[5]Grant No. 5K01MH072353.

Outreach to populations at risk for HIV varied by the type of population served. For example, at VCC and CSP, *promotores* (bilingual lay health workers) conducted outreach activities with farmworkers. Initially, CSP promotores were inexperienced in the field of HIV/AIDS and were hesitant to ask personal questions involving sexual practices and orientation. The evaluation team provided peer-based training for new rural promotores in which experienced urban outreach workers taught effective HIV/AIDS outreach strategies. In addition, the AETC arranged for a promotor specialist from Arizona to train the CSP promotores. Training improved their HIV/AIDS outreach activities and services.

Community outreach workers trained specifically to conduct HIV/AIDS outreach performed outreach activities at SYHC and FHCSD. The enhanced HIV/AIDS outreach training helped in the data collection process for the project.

Development of Local Data Collection Instruments

Four local evaluation measures were used in this project (Table 2.1). The HIV Test Demographic Survey developed in Year 2 used items from the multisite demographic and risk factor instruments (Modules A and D, respectively; see Chapter 1 in this volume for additional information). The Treatment Adherence Counseling Form was developed in Year 3 to study the relationship of psychosocial factors to HIV medication adherence. The instrument was developed collaboratively by the UCSD Evaluation Unit and the treatment education staff at Comprehensive Health Centers. Quality of care was measured using Module G (see Chapter 1), a multisite instrument designed to measure patient satisfaction with the care services provided. In addition, two focus groups were created in 2002 to explore patient perceptions about access to care and related issues.

Patient Participation

Patients were read an informed consent form that outlined the risks and benefits of project participation. Participants received an incentive (a $10 grocery store voucher) when they returned for HIV test results. Clinic staff administered local modules at testing, so HIV-negative participants were enrolled in the study as well.

Working With Institutional Review Boards

The UCSD Human Research Protections Program (HRPP), the university's institutional review board, oversees protection of study participants, adherence to university and Federal standards of research ethics (e.g., Health Insurance Portability and Accountability Act of 1996), and reviews all research-related projects at UCSD. Participant consent forms, protocols, and project activities were reviewed and approved by the UCSD HRPP. Each participant was read a voluntary consent form in his or her preferred language.

TABLE 2.1. Local Evaluation Instrument Overview

Description of Measure	Purpose
1. Outreach (group and individual)	Examine relationship between outreach contacts and HIV testing
2. Demographics of persons tested for HIV	Provide a profile of people reached for HIV testing
3. HIV test and return results	Compare clients who returned for HIV test results with those who did not return
4. Treatment adherence counseling	Explore psychosocial factors related to HIV medication adherence

Challenges in Collecting and Processing Data

The Southern California Border HIV/AIDS Project required extensive data collection from each participant. Data collection was carried out primarily by clinic staff. The process consumed considerable staff time, particularly that of case managers.

From the project's inception, the evaluation team worked closely with SYHC and clinic partner sites to address staff concerns and questions regarding data collection activities.

Data processing presented a set of unique challenges, such as tracking missing or incomplete data from forms, ensuring that consent forms were received for each study participant, and monitoring the ways clinic staff were documenting information. On a bimonthly basis, the data manager generated lists of missing or incomplete participant data for staff follow-up. Toward the end of the project, it became increasingly difficult to retrieve missing information from clinic sites. Close attention to missing data throughout the project, however, minimized the total amount of missing information.

One initial challenge for all grantees involved in the Southern California Border HIV/AIDS Project was achieving consensus on the wording and English–Spanish translations of data collection instruments. A professional translator translated the documents, and project leadership reviewed the materials carefully prior to approval. Some regional differences in local word meanings presented challenges, but consensus was reached by including the various meanings in a codebook for personnel administering the instruments. Local instruments also were translated by a professional translator.

Value of Partnership With the Evaluation Center

For most clinic staff, the Southern California Border HIV/AIDS Project was their first research experience. Training and technical support provided many new learning opportunities. Clinic-specific databases were developed to track patients in case management. In addition, a treatment adherence form was created on the basis of feedback from clinic sites with support from Comprehensive Health Centers' treatment adherence program. SYHC chose to adopt this form for use in its system beyond the study.

Data Collection Mechanisms

All hard copies of evaluation instruments were maintained in a locked file. Participant data were entered online through the evaluation center server, and local databases used a secure, firewall-protected server. Databases used a URN linked to the participant's name in a separate database that was password protected and available only to key staff. Individual data were identified using only the URN. Local evaluation instruments captured information described in Table 2.2.

Status of Local Evaluation Activities

Data collection for local instruments ended June 30, 2004. Multisite data collection ended September 30, 2004. Efforts to locate missing data continued until December 30, 2004. During the last months of Year 5, the evaluation team generated information for a report to HRSA, which included findings to be used for dissemination at professional meetings and for peer-reviewed publications. Project dissemination activities are listed in Appendix 2.B.

Lessons Learned

The collaboration between the lead agency and partner CHCs in the Southern California Border HIV/AIDS Project strengthened the ties between CHCs in San Diego and Imperial County. The SPNS initiative built trust among staff across partner sites and increased interest in continuing to work together, a result that should benefit the California–Baja California border region as a whole.

TABLE 2.2. Local Measurement Instruments by Select Variables and Count

Description of Measure	Select Major Variables	Total Collected at All Four Partner Sites (7/1/01–4/04)
Case management referrals	Referrals at first contact Common referrals at first contact Successful referrals by verification	229
Client service knowledge	Knowledge of core services at first contact Knowledge of core services prior to first contact	192
Treatment adherence counseling	Client support available Number of missed medication doses in past 30 days Patient education	217 (includes repeat measures)
Outreach by individual contacts	Number of persons contacted by gender Risk behavior by types	7,672
Outreach by group contacts	Estimated size of group Risk behavior by types	398
Select demographics of clients tested	Gender and socioeconomic status Number of border crossings	3,771
HIV tests and return numbers	Number of persons tested Number of persons who returned for results	3,000

At the national level, the SPNS initiative enabled lead agency staff to learn about other CHCs providing services along the U.S.–Mexico border as well as about similarities and differences across SPNS sites, particularly with regard to populations served. It became evident that differences needed to be considered in planning HIV/AIDS services to meet the needs of the diverse Latino population living along the U.S.–Mexico border.

Additional lessons from the 5-year project are as follows:

* Flexibility is needed to allow for integration of changes when new instruments are introduced or revised to meet the needs of the project.
* A realistic time period must be allocated for document translation, pilot testing, protocol development, and staff training.
* Training of promotores in HIV outreach must include issues of social stigma associated with HIV and how to build trust in order to ask sensitive risk assessment questions. Using experienced promotores or outreach workers to teach outreach strategies was found to be effective.
* Development and implementation of interagency agreements and contracts consumed a great deal of administrative time, and planning in advance is necessary.
* High staff turnover affects evaluation and requires additional staff time for training and oversight.
* Buy-in by clinic managers overseeing the project was critical. Leadership needs to be actively involved because staff enthusiasm and support for a project wanes over time. When staff have competing demands on their time for data collection, projects with less funding tend to receive less attention.
* Reaching the target population is critical to planning project outcomes. At one site, the tar-

get population was modified when sufficient numbers of youth sex workers were not found.

* Risk behaviors, not sexual orientation, must be targeted in planning prevention outreach strategies.

* The relationship between lead agency staff, the evaluation team, and clinic staff partners must be based on a foundation of mutual respect and trust. This foundation sets the stage for a productive relationship.

* Client profiles, such as risk behavior exposure, varied by site and geographic area.

* To ensure consistent quality of data, staff roles and lines of authority must be clear.

* Clinics engage in a variety of internal and external outreach activities to increase community awareness; those efforts may have effects other than increased rates of HIV testing.

* It was difficult to standardize incentive types

(all worth $10) and to determine whether incentives motivated people to return for HIV test results.

* Collaboration between lead agency administration and evaluation staff facilitated data collection monitoring.

Summary

A factor vital to the success of the Southern California Border HIV/AIDS Project was leadership participation in development of project goals at all levels. Both the project coordinator and evaluation team had strong community ties and an understanding of the cultural background of the target population. In addition, SYHC administration supported the goals of the project and the work involved in collaboration with other sites to achieve the goals of the SPNS initiative.

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APPENDIX 2.A. Logic Model: Southern California Border HIV/AIDS Project (San Diego, CA, and Imperial County, CA)

	Inputs*	Activities	Outputs**	Outcomes***		
				Initial	Intermediate	Long-Term
			Program Goal I: Increase early detection of Latino/a population infected with HIV			
1a	Clinicas de Salud del Pueblo *Imperial County* ◆ Community health center (CHC) promotora ◆ CHC case manager ◆ Comprehensive Health Center (technical assistance [TA]; treatment education and advocacy)	HIV education and testing outreach	1. Est. number of contacts per year: 2,500 farm workers (1,500 male, 1,000 female) 2. Est. number of HIV+ clients from all points of entry into system: 10 per year	Increase number of persons tested 1. Local testing form	◆ Increase HIV+ access to primary care referral ◆ Case management referral for follow-up	Early identification of clients at risk for HIV infection and enrollment into primary care systems at earlier stage of disease
1b	San Ysidro Health Center ◆ Outreach worker ◆ CHC case manager ◆ Comprehensive Health Centers (TA; treatment education and advocacy)	HIV education and testing outreach	1. Est. number of contacts per year: 180 transborder Latinos, 300 Latinas 2. Est. number of HIV+ clients from all points of entry into system: 44 per year	Increase number of persons tested 1. Local testing form	◆ Increase HIV+ access to primary care referral ◆ Case management referral for follow-up	Early identification of clients at risk for HIV infection and enrollment into primary care systems at earlier stage of disease
1c	Family Health Centers ◆ Outreach worker ◆ Data entry person ◆ CHC case manager ◆ Comprehensive Health Centers (TA; treatment education and advocacy)	HIV education and testing outreach	1. Est. number of contacts per year through outreach and testing: 250 Latino men who have sex with men (MSM) 2. Est. number of HIV+ Latino MSM clients from contacts from all points of entry into case management: 20 per year	Increase number of persons tested 1. Local testing form	◆ Increase HIV+ access to primary care referral ◆ Case management referral for follow-up	Early identification of clients at risk for HIV infection and enrollment into primary care systems at earlier stage of disease
1d	Vista Community Clinic ◆ Outreach worker ◆ Bilingual case manager ◆ Comprehensive Health Centers (TA; treatment education and advocacy)	HIV education and testing outreach	1. Est. number of contacts: 100 Latina sex workers, 500 Latino farm workers, 200 newly immigrated Latino MSM. 2. Est. number of HIV+ clients from contacts from all points of entry into system: 8 per year	Increase number of persons tested 1. Local testing form	◆ Increase HIV+ access to primary care referral ◆ Case management referral for follow-up	Early identification of clients at risk for HIV infection and enrollment into primary care systems at earlier stage of disease

APPENDIX 2.A. Logic Model: Southern California Border HIV/AIDS Project (cont'd)

	Inputs*	Activities	Outputs*	Outcomes** Initial	Outcomes** Intermediate	Outcomes** Long-Term
2	• SPNS coordinator • CHC site coordinator • CHC promotores (Imperial Co.) • CHC health workers	Implement referral program (access to testing)	Approximately 5,000 referral cards distributed (tracked in monthly report)	Number of clients who come for testing and indicate receipt of a referral card	—	Improved client access to and use of services
3	• Project coordinator • CHC site coordinator	Social marketing plan for four individual sites	Culturally appropriate marketing tools developed to reach at least 2,000 of target population	Number of clients indicating knowledge of marketing effort	—	Improved client access to and use of services
	Program Goal II: Increase access to comprehensive HIV primary care for individuals diagnosed with HIV/AIDS					
4	• SPNS coordinator • CHC site coordinator • University of California, San Diego (UCSD) evaluation field coordinator	Strengthen referral network (includes referring clients for services in Mexico as well as United States)	Develop supplement to existing resource guide	Resource guide to be distributed to four CHC sites and a minimum of 20 county agencies	—	Improve system response by increasing access to primary care
	Program Goal III: Enhance capacity of ambulatory care/primary clinics to provide culturally effective care for individuals with HIV/AIDS					
5	• SPNS coordinator • CHC site coordinator • UCSD AIDS Education and Training Center (AETC)	AETC mini-residency	Clinic providers receive AETC training as needed	Provider needs and self-perceived confidence assessed	—	Increase quality of medical care
6	• CHC site coordinator	Promote adoption of coordinated services (use South Bay Region model to promote client-centered services)	Client-centered service model implemented in Clinicas de Salud del Pueblo (CSP)	Increase number of San Ysidro Health Center model core services at CSP	—	Increase quality of medical care and social services at CSP
7	• SPNS coordinator • CHC site coordinator • UCSD evaluation unit	• Develop "Aspects of Culturally Effective Care" training curriculum • Hold in-service training on delivery of culturally effective care	• "Aspects of Culturally Effective Care" curriculum developed • Five to 10 providers or staff per site receive training (implement Year 3)	Increase in provider knowledge of delivering culturally effective care	—	Enhance quality of HIV primary care services and social services

* Year 1 activities: obtain baseline measures (e.g., number tested in target population, current number of referrals, knowledge of services) and needs assessments.

** Process evaluation will be carried out throughout the initiative. It will include clinic provider and staff feedback on the initiative and client assessment of quality of services. Qualitative measures will include community-based focus groups and context evaluation measures.

Special Projects of National Significance (SPNS) coordinator and evaluation field coordinator will be involved with sites as needed to facilitate programmatic and evaluation activities, respectively. Estimated number of contacts will include number of contacts made in individual and group settings as well as repeated contacts with the same individual in the target population.

APPENDIX 2.B. Dissemination Activities

Many dissemination activities were conducted through-out the project period. Project dissemination included the following activities:

* Presentation to Association of Community Health Outreach Workers (ACHOW), July 2002
* Presentation at U.S. Conference on AIDS, September 2002 and September 2003
* Interview, HIV/AIDS documentary, San Diego's KGTV 10, October 2002
* Presentation to National Alliance of State and Territorial AIDS Directors, October 2002
* Presentation at Binational HIV/STD Conference, November 2002
* Radio interview on *Radio Bilingüe,* December 2002
* Presentation at Binational HIV Roundtable II, December 2002
* Poster presentation at American Public Health Association, November 2003
* Presentations at U.S.–Mexico Border Health Association Meetings, April 2003, May 2004, and June 2005
* Participation in Binational AIDS Research Forum at Universidad de Baja California at Tijuana (University of Baja California), March 2004
* Poster presentation at Ryan White CARE Act Grantee Conference, Washington, DC, August 2004
* Presentation at HIV Binational Conference, San Diego, CA, October 2004
* Presentation at Coalition of Latino AIDS Service Providers (CLASP), November 2004

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CHAPTER 3

El Rio Health Center: Arizona Border HIV/AIDS Care Project

The Arizona Border HIV/AIDS Care (ABHAC) project was an effort by El Rio Health Center (Tucson, Arizona) to address HIV risk behaviors among at-risk populations along the Arizona–Mexico border. The clinic serves the population living within 62 miles of the international border between Arizona and Mexico. The region includes four counties: Cochise, Santa Cruz, Pima (where Tucson is located), and Yuma (Health Resources and Services Administration [HRSA], n.d.). The population of Pima County is 946,362 (U.S. Census Bureau, 2006) and includes the Tohono O'odham Indian Nation, which shares 75 miles of border with Mexico (Southwest Border Rural Health Research Center, 2004). Many Tohono O'odham and Yaqui Indians reside in Sonora, Mexico, which was historically a part of the Tohono O'odham homeland and was divided by the international border (Smithsonian Center for Education and Museum Studies, n.d.). The Cocopah Tribe residing south of Yuma, near Somerton, was similarly separated from tribal members who reside in Sonora, Mexico. Before the establishment of the border, these people traveled freely across tribal land, and many tribe members still have relatives living in Mexico.

Area Demographics

The counties of Cochise, Santa Cruz, and Yuma are sparsely populated rural communities and account for the bulk of Arizona's border population. The U.S. Census Bureau (2006) reported a total population of 358,392 for the three counties (Santa Cruz, 43,080; Cochise, 127,757; Yuma, 187,555). Approximately 29 percent of all Arizonans are of Hispanic origin, whereas 32 percent of Cochise County (U.S. Census Bureau, 2005), 81 percent of Santa Cruz County (U.S. Census Bureau,

2000),[6] 32 percent of Pima County (U.S. Census Bureau, 2005), and 56 percent of Yuma County residents are of Hispanic origin (U.S. Census Bureau, 2005). Hispanics represent a significant majority of the population in Arizona cities that are contiguous to the U.S.–Mexico border: 94 percent in Nogales, 95 percent in Somerton, 89 percent in San Luis and 86 percent in Douglas (U.S. Census Bureau, 2000). A majority of Hispanics in Arizona are of Mexican or Mexican American descent.

Like much of the U.S.–Mexico border region, Arizona's border region is an economically depressed area. The region continues to have higher rates of unemployment and poverty as well as a lower median household income than the State's average. For example, approximately 25 percent of individuals and 21 percent of families in Santa Cruz County live below the Federal Poverty Level, compared with 14 percent of individuals and 10 percent of families statewide (U.S. Census Bureau, 2000). Because many of the residents in the border region speak only Spanish or have limited English proficiency, access to education, employment, and health care is limited.

Local HIV/AIDS Epidemiologic Data

HIV risk behaviors among at-risk populations along the Arizona–Mexico border are as high or higher than in other areas of the United States. Intravenous drug use (IDU) has increased dramatically as the Arizona border has become a major corridor for illegal drug traffic coming from Mexico (U.S. Department of Justice, 2007). The combination of drug use, poverty, and isolation or hopelessness contributes to conditions that place people at increased risk for HIV transmission through risk behaviors such as unprotected sex.

From 1981 through June 2003, the Arizona Department of Health Services (ADHS) Office of HIV/AIDS reported 98 AIDS cases in Cochise County (in the southeast), 29 cases in Santa Cruz County (including Nogales), 1,779 cases in Pima County (including Tucson), and 108 cases in Yuma County (including the city of Yuma; ADHS Office of HIV/AIDS, 2003). Over the same period, reported HIV cases in the region totaled 1,195, including 57 in Cochise County, 11 in Santa Cruz County, 1,068 in Pima County, and 59 in Yuma County (ADHS Office of HIV/AIDS, 2003).

In 2004 the ADHS Office of HIV/AIDS revised its reporting procedures to count "emergent"[7] rather than cumulative cases, in order to identify the State's first contact with patients with a diagnosis of either HIV or AIDS. This procedure would prevent duplicate counts of patients whose disease progresses from HIV to AIDS. The State also changed from biannual to annual reporting.

Trends of emergent HIV infection among all racial ethnic groups in Arizona are reflective of broader population trends. For example, non-Hispanic Blacks constituted just 3.2 percent of Arizona's population in 2003 and accounted for 12.9 percent of emergent HIV infection cases. This disproportionate impact is not seen among other minority groups. In 2003, Hispanics of all races constituted 27.8 percent of the State population but 30.8 percent of emergent HIV infection. American Indian and Alaska Natives were 4.8 percent of the State population in 2003 and 4.8 percent of emergent HIV infection. Asian and Pacific Islanders made up 2.2 percent of the State population in 2003 and 0.7 percent of emergent HIV infections (ADHS Office of HIV/AIDS, 2004b).

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[6]2005 data are not available for Santa Cruz, Nogales, Somerton, San Luis, and Douglas counties.
[7]"In Arizona's HIV/AIDS reporting, estimates of incidence are based upon the sum of new HIV cases, and new AIDS cases which were not diagnosed as HIV infections in any prior calendar year. These cases are referred to as *emergent* cases and are used as an estimate of incidence. Cases of HIV/AIDS can only be counted as emergent in the year they were first diagnosed with HIV infection. Persons who were emergent as HIV and diagnosed as AIDS in the same calendar year are counted as emergent AIDS to avoid double counting." (ADHS, 2006, p. 1)

The proportion of AIDS cases among non-Hispanic Whites in Arizona is steadily declining. In the 1980s, when non-Hispanic Whites were about 75 percent of the State population, 83 percent of AIDS cases reported in Arizona were among this group. By 2001, the population of non-Hispanic Whites had declined to 64.3 percent, and the group's share of reported AIDS cases had dropped to 56.2 percent. Most notably among the demographic changes, non-Hispanic Blacks accounted for just 3.1 percent of Arizona's population but 12.6 percent of the State's reported AIDS cases in 2001. This disproportionate impact of HIV/AIDS was not seen among Hispanics, who constituted 25.6 percent of the State population in 2001 and accounted for 24.9 percent of the State's reported AIDS cases that year (ADHS Office of HIV/AIDS, 2004a).

In Yuma County, Hispanics made up 55 percent of new HIV cases and 50 percent of new AIDS cases (ADHS Office of HIV/AIDS, 2004c). In Cochise (Bisbee and Douglas) and Santa Cruz (Nogales) counties, Hispanics made up 53 percent of the new HIV cases and 55 percent of the new AIDS cases (ADHS Office of HIV/AIDS, 2004c). From 1981 through June 2003, the ADHS Office of HIV/AIDS (2003) reported 235 AIDS and 127 HIV cases for Cochise, Santa Cruz, and Yuma counties combined.

In Yuma County, between 1998 and 2002, heterosexual sex was the predominant mode of transmission for new HIV and AIDS cases (45 percent and 42 percent, respectively). Men who have sex with men (MSM) was the predominant mode of transmission for new HIV cases in Cochise and Santa Cruz counties (53 percent and 60 percent, respectively; ADHS Office of HIV/AIDS, 2004c).

People who were diagnosed with AIDS between 1998 and 2002 and were between ages 30 and 39 made up 45 percent of all AIDS cases. People testing positive for HIV who were between ages 20 and 29 made up 34 percent of all HIV cases,

and those who were between ages 30 and 39 made up 40 percent of all HIV cases.

The highest number of HIV/AIDS cases is reported in Pima County, but current and historical records do not report cases by residency within that designated border region. A large proportion of Tucson's HIV-positive population resides in the less affluent south and west sections of the city. For the purposes of the project's enrollment and evaluation, Pima County numbers are not included in the ABHAC project data (the goal was to focus on the border population, and most of Pima County is not on the border).

Surveys of HIV-related service providers in the border region found that the surveillance data significantly underestimate the incidence of HIV in Arizona's border corridor (ADHS Office of HIV/AIDS, 2004). The main explanation for the underreporting is that the numbers represent only people tested locally and reported to the State system. Within the rural border communities, the stigma associated with being HIV positive remains strong, especially in Mexican American neighborhoods. Given the close family ties of border communities, HIV status may not be kept confidential in communities. Consequently, many at-risk people often are not tested in their communities but prefer to be diagnosed in a larger metropolitan area, such as Tucson. The same concerns about confidentiality among those who are HIV positive hinder access to primary health care.

Access to Care

HIV care in rural border counties varies widely. In the border counties, county health departments are the primary sources of HIV counseling and testing and referral to primary health care services. After a person tests positive for HIV in either Cochise or Yuma County, the health department staff refer him or her to the community health center (CHC) for primary medical care; in Santa Cruz County, however, Mariposa

CHC provides HIV counseling and testing. There, after someone tests positive for HIV, staff register the person for primary medical care at the clinic.

Barriers in access to HIV care in Arizona's rural communities include travel distance, concerns about confidentiality and stigma, quality of medical care, and lack of health insurance (HRSA, 2003). Language and cultural differences between patient and provider, high poverty, and an international border that separates communities exacerbate the perceived barriers to care.

Overview of the Arizona Border HIV/AIDS Care Project

El Rio Neighborhood Health Center (El Rio)/ Special Immunology Associates (SIA) is a specialty clinic that provides HIV/AIDS medical care. El Rio is a nonprofit provider of comprehensive health care for uninsured and underinsured Tucson residents. It has been in operation since 1970 and has served more than 57,000 registered patients (El Rio Health Center, 2006). The Bureau of Primary Health Care recognized the clinic for its quality and scope of health care and in 2004, the clinic received the Russell E. Brady Award in recognition of its innovative HIV programs. El Rio's patient demographics are predominantly women and children of Hispanic heritage. The clinic serves equal numbers of insured (private) and uninsured patients as well as patients who qualify for Arizona Health Care Cost

Containment System (AHCCCS), Arizona's health care program for the indigent.

Within the framework of the El Rio mission (see box), services at El Rio/SIA have been designed for optimal accessibility and affordability within a comprehensive framework of culturally sensitive services delivered by providers who are highly qualified in outpatient medical care to people living with HIV/AIDS (PLWHA).

El Rio's health care services are supported through grants (e.g., HRSA Community Health Center, Migrant Health Center, Health Care for the Homeless, and Healthy Schools grants; Arizona Department of Health; and private foundations) and third-party insurance revenue. As an established clinic with an annual operating budget of more than $30 million, El Rio has the personnel and technological resources to support special projects such as those funded under the Special Projects of National Significance (SPNS) U.S.–Mexico Border Health Initiative. The center has an active and committed board of directors that seeks innovative approaches for improving health care services. El Rio has achieved recognition for numerous special creative programs, such as the Pima Community Access Program, an El Rio entity created as an insurance look-alike for the uninsured working poor; integration of behavioral or mental health with primary medical care providers; and other innovative programs to target health issues such as

THE EL RIO MISSION

To be an accessible and affordable community health center that provides comprehensive quality health care in an atmosphere of respect and dignity for patient and staff, always sensitive to the cultural differences in the community. Through direct services, advocacy, and education, the Center will strive to improve the health and well being of its patients and community.

diabetes, pediatric asthma, women's wellness, and HIV/AIDS care. In 2000, El Rio was honored by *Computerworld* magazine for its Health-e-AZ online software package, which was developed by El Rio for statewide utilization to expedite the application process of enrolling uninsured patients in AHCCCS.

El Rio/SIA has been providing outpatient medical care for HIV-positive residents of Pima County for more than 12 years. Enrollment of HIV/AIDS patients from 2000 to 2004 exceeded 1,400 and averaged more than 160 new patients each year. Staff members include four physicians and a nurse practitioner who have extensive experience in the treatment of HIV/AIDS. They provide outpatient medical care with the support of a registered nurse, three licensed practical nurses, and three medical assistants. The clinic also has on staff five continuity-of-care coordinators (i.e., medical case managers), a medical records clerk, an AIDS drug assistance medication coordinator, and two office staff. Other onsite services include mental health services with psychotropic medication prescribed by a psychiatrist and monitored by a psychiatric nurse practitioner. Nutritional counseling is provided by a certified nutritionist. Medications and lab services are available onsite, and substance abuse counseling is provided onsite through agreements with the local behavioral health agency funded under Ryan White HIV/AIDS Program Part B. Services and staffing patterns have been designed to provide an accessible, integrated, comprehensive continuum of medical and social support services.

Clinic services at El Rio/SIA are available 5 days per week; an El Rio/SIA physician is on call at all times. Services are sensitive to the special needs of HIV/AIDS patients. Patients are eligible regardless of age, gender, race, national origin, ethnicity, sexual orientation, or socioeconomic status. Through Ryan White HIV/AIDS Program funds (Parts B and C) and third-party contracts, services are provided to uninsured patients and those insured through most private or public health insurance

plans. If hospitalized, El Rio/SIA patients receive inpatient care from El Rio/SIA physicians, whose familiarity with the patient and the disease helps optimize care.

El Rio/SIA has long been an active advocate for services to PLWHA. El Rio/SIA works with and is represented in the following organizations that focus on HIV/AIDS: Pima County HIV/AIDS Care Consortium (Ryan White HIV/AIDS Program Part B), the Arizona AIDS Drug Assistance Program Advisory Committee, the Southern Arizona HIV Prevention Planning Group, the faculty of the Arizona AIDS Education and Training Center (AETC), and the statewide HIV/AIDS Coordination Council.

As indicated earlier, El Rio/SIA became a partner in the SPNS Border Health Initiative to strengthen its work with populations at risk for HIV by increasing its outreach and care capacity. An evaluation component helped the agency assess its outreach efforts and learn about patients' perceived barriers to accessing health care in Arizona border communities. The 5-year experience increased staff capacity to design evaluation protocols, collect data, and coordinate evaluation efforts with SPNS staff, other partner SPNS grantees, and staff at the Centro de Evaluación at the University of Oklahoma.

Service Delivery Model

The ABHAC project reflected the planning efforts of seven area agencies striving to address the distinctive health care needs of PLWHA who live along the Arizona–Mexico border. ABHAC proposed using the SPNS initiative to strengthen its outreach to at-risk populations by increasing opportunities for HIV testing and counseling. The goal was to increase the number of patients who accept referrals to primary health care by identifying and removing patients' perceived barriers to care. A key component of the initiative was to increase capacity of rural primary health care providers to care for PLWHA.

El Rio was well-positioned to serve as the lead agency for the ABHAC project for two reasons. First, El Rio had organizational and administrative resources for undertaking such a collaborative project. Second the unit chief at El Rio/SIA was a key resource for the clinic and a leader in the treatment of HIV/AIDS, and he was interested in developing a physician co-management model for increasing localized care for PLWHA. He had extensive experience both in providing care and serving as consultant to primary care physicians caring for PLWHA.

Potential project collaborators were surveyed to identify the needs of HIV/AIDS health care service delivery systems and potential barriers to consumers of those services. They were asked to submit ideas for innovative and extended services designed to integrate regional medical service systems, thereby ensuring proper continuity of care. The following partners agreed to collaborate in the ABHAC project:

* Arizona AETC
* Border Health Foundation
* Chiricahua CHC
* Cochise County Health Department
* El Rio CHC
* Impact Consultants, Inc.
* Mariposa CHC
* Sunset CHC
* Yuma County Health Department

The collaborating organizations agreed on the following goals for the project:

* Increase HIV testing and counseling with referrals to primary care, and target the expansion and effectiveness of outreach activities to help identify HIV-positive people
* Increase local patient access to primary care providers who are knowledgeable in treating HIV through patient co-management and training physicians

* Use the ABHAC project to ensure coordination of care and communication between HIV-related service providers in the border region.

Outreach Services

A primary focus of the ABHAC project was to increase outreach efforts to at-risk groups who live along the U.S.–Mexico border. Ryan White HIV/AIDS Program funding, including the SPNS grant funds, made it possible to increase outreach staff at CHCs, county health departments, and other health promotion programs and to provide essential training. The Arizona AETC trained outreach workers. The focus of the training was to familiarize the workers with HIV/AIDS and how the illness affects people. Training included learning about their role as a paraprofessional working with a professional medical team. Trainees were taught to recognize risky behaviors and learned strategies for helping clients overcome perceived barriers to HIV testing and accessing care. Outreach workers received ongoing supervision and participated in various staff meetings within the agency and with partner agencies to learn referral procedures, eligibility requirements, and changes in social service resources.

Primary Care System Enhancement

Training of physicians and support staff was designed to reduce interference with client and patient schedules. Training took place during lunch; the Arizona AETC facilitated training and provided food for the participants. Staff of the Arizona AETC collaborated with an El Rio/SIA physician to develop training that focused on eight core HIV educational content areas. Training sessions were offered quarterly. In Year 4 (2004), the eight core educational units were compiled into a self-paced training manual that was developed by the Arizona AETC director. The Chiricahua CHC staff translated the training manual into Spanish. The manual is now used by CHCs for their HIV training programs in southern Arizona.

Physician training used a medical co-management model developed by the El Rio/SIA physician who became the consulting HIV expert (CHE) for the project. He identified primary care physicians who were interested in strengthening their skills in treating PLWHA. In the first phase of training, the physician trainee would observe the CHE's interaction with the patient. At the end of the day, the CHE would review and discuss each patient's case with the trainee. During Phase 1 (Year 2), the CHE scheduled a monthly clinic visit at each site. In Year 3 of the training, the patient care was transferred to the health center physician, and the CHE provided consultation. The course of treatment selected by the physician was the focus of the educational consultation. In Cochise County (Chiricahua CHC) and Santa Cruz County (Mariposa CHC), the CHE provided monthly consultation to clinic staff. In Yuma County (Yuma), an infectious disease (ID) physician provided medical care to HIV-positive patients and consultation to the Sunset CHC. The CHE and Yuma County ID physician communicated quarterly to discuss ABHAC patient care.

The Medical Co-Management Model

The medical co-management model consists of a CHE, a local primary care provider (LPCP) and his or her clinic, and any ancillary local organizations that are involved in the delivery of services to PLWHA.

The Medical Co-Management of PLWHA

Physicians generally concur that PLWHA receive quality HIV care from physicians experienced in HIV care. The HIV Medicine Association (HIVMA) and the American Academy of HIV Medicine (AAHIVM) both call for all PLWHA to have access to an HIV expert. Both organizations define HIV expertise as knowledge that is based in training, experience, and HIV-specific continuing medical education (CME). The HIVMA and

AAHIVM classify as specialists physicians who see a total caseload of at least 25 HIV-positive patients over a 2-year period and pursue HIV-related CME.[8] U.S. metropolitan areas usually have had higher incidences of HIV/AIDS than rural areas. Consequently, rural areas have an insufficient number of experienced HIV providers to care for patients living there. To address this problem, the ABHAC project developed a model for the medical co-management of PLWHA. The model sought to address the needs of primary care physicians and PLWHA along the Arizona–Mexico border. The model involves in two phases: initiation and maintenance.

The Initiation Phase

The initiation phase seeks to improve the capacity of the LPCP and his or her clinic to serve HIV-infected patients with quality care. The clinic administration and staff must be informed of any plans to see PLWHA, and their concerns must be addressed. Often the administrator expresses concerns about the cost of HIV care and its potential impact on provider productivity. Clinic staff generally require education about the nature of HIV infection and possible occupational risk (e.g., needle sticks). The LPCP is provided with the reassurance that he or she will be adequately supported by the CHE. The involvement of local providers of ancillary services is important early in the process because the CHE will need to learn what services are available in the LPCP's area. Such services are generally less available than in areas of higher HIV prevalence.

In the ABHAC model, the CHE travels to the LPCP's clinic and sees HIV-infected patients with the LPCP on a regular basis, depending on patient volume and need. In the ABHAC experience, a monthly visit was necessary for the program to be successful. It also was important that the LPCP have a well-defined and sufficient period of time to

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[8] For information on specialization requirements, see www.hivma.org/HIV/HIVMA/HIVProviderDef.htm and www.aahivm.org/index.php?option=com_content&task=category&sectionid=6&id=173&Itemid=236.

devote to the patients. During the initiation phase, the CHE serves as an expert in HIV care for the LPCP and the clinic staff and provides hands-on education to the LPCP. During this phase, the CHE teaches the LPCP a culturally competent approach to bringing care to the local population of PLWHA. Finally, during this phase, the LPCP and the CHE seek to develop a mutual under-standing and trust to facilitate future collaboration and cooperation. A typical day during this phase may require devoting some time to reviewing charts and case notes to anticipate patient needs and clinical issues before seeing patients in the clinic. Asking the patients seen that day to have lunch together as a group (with the LPCP) may increase patients' awareness of new issues in HIV care and build trust in the LPCP. After lunch, patients not only have learned about HIV but also have a better idea of their physician's level of understanding of the disease. The length of this phase varies with the number of patients seen and the needs of the clinic and the LPCP. The ABHAC project found that the initiation phase requires at least 18 to 24 months.

The Maintenance Phase

The maintenance phase is intended to provide opportunities to reinforce and practice skills acquired through trainings and consultations. Throughout this phase, the objective is continued HIV patient care by the LPCP, either as a develop-ing HIV expert or within a more loosely main-tained co-management model. In some cases, the LPCP will be able to see a sufficient number of PLWHA to improve upon his or her knowledge of HIV and become an expert in this area. The CHE makes fewer personal visits to the LPCP's clinic but may continue to serve as a resource for consulta-tion, education, and quality assurance. In the ABHAC model, the CHE travels to the LPCP's clinic quarterly and meets with the LPCP to con-duct chart reviews and to discuss any specific issues of concern to the LPCP. During those quarterly visits, the CHE continues to see some patients with the LPCP to demonstrate continued commitment

to the patient community. The chart review on all active patients uses the same quality assurance and chart audit tools that are used at the CHE's clinic. The CHE then leads a didactic session over lunch with the LPCP and clinic staff as well as other local HIV caregivers.

Components of Success

The ABHAC project developed the medical co-management model at three sites along the Arizona–Mexico border. The key component for success was identification of a LPCP who was interested in participating in the program. Not all primary care physicians are interested in providing HIV care. Even though the clinic administration may be able to provide incentives, such as addition-al time or some other form of compensation to participating physicians, without genuine interest from the physician, the model will not work.

Administrative buy-in is another key to success. Adoption of a co-management model to care for PLWHA requires more provider time and more resources than caring for patients without HIV dis-ease. CHCs that do not receive funds for HIV care are less likely to participate in the delivery of HIV medical care because of the associated cost. Fortunately, CHCs like the ABHAC partners make decisions on the basis of the needs of the commu-nity they serve, not simply on fiscal considerations.

Administrative support was gained in two ways: first, by presenting epidemiological data showing that sig-nificant numbers of PLWHA live in the CHC catchment area, and second, by ABHAC staff sharing personal stories of patients who were unable to access quality care in their own communities.

The personal characteristics of the CHE also are important in ensuring success. It is critical that the LPCP feel comfortable with the CHE and that the CHE work to involve the clinic and the commu-nity in the co-management model. Often, physi-cians with expertise in HIV are so immersed in

clinical care of their patients that they overlook the anxieties that HIV still evokes in many health care providers and in the general public.

Finally, early collaboration with local community-based organizations was important in gaining their support and fostering greater understanding and acceptance of the co-management model among patients.

In summary, the medical co-management of PLWHA is a model that promotes the professional development of clinicians caring for patients living in areas of low HIV prevalence. Consequently, patients are able to access medical care from experienced providers of HIV care in their community. The application of this model has the potential to improve health outcomes and lower health care costs for PLWHA in rural areas.

Intervention Results

The goals of the ABHAC project were as follows:

* To provide HIV outreach services to 13,000 underserved people (predominantly of Mexican origin) who live or work along the Arizona–Mexico border and are at risk for becoming infected with HIV
* To enhance the capacity of regional health care agencies to provide culturally appropriate and accessible care for border-area PLWHA
* To provide for the early detection of HIV and implement treatment protocols in a culturally competent and timely manner.

By 2004, the ABHAC project had reached more than 30,000 people through in-person and group contacts. Of the people contacted through outreach, 5,336 elected to be tested for HIV; of those, 33 tested positive for HIV. Nine tests were inconclusive. By August 2004 the project had enrolled 128 patients, distributed among counties as follows: Cochise, 45 percent; Yuma, 48 percent; and Santa Cruz, 7 percent. The project also continues to serve people who test positive for HIV. The project saw a growing number of women who tested positive

for HIV but had no identifiable risk factors other than having a spouse or male partner who had tested HIV positive. The women learned of their diagnosis after their male partner was hospitalized or had died of AIDS.

Implementation

The ABHAC project experienced some obstacles during implementation. The project was helped by the established relationships among the leadership of El Rio Health Center staff and the project collaborators as well as by relationships among the collaborators. The project coordinator had a background in HIV/AIDS and behavioral health that was especially useful for the project and had collaborated with the project evaluator on other behavioral science research studies.

The departure of the Chiricahua CHC medical director proved to be beneficial to the center. The director had been ambivalent about treating HIV-positive patients because of concerns about confidentiality. After the medical director left the CHC, the CEO worked out an arrangement for the staff from the three entities (the CHC, El Rio/SIA, and ABHAC) to work together to enroll HIV-positive patients into the CHC and the ABHAC project.

Each collaborating site had turnover issues involving the staff assigned to work on the project. However, project staff were highly motivated and dedicated to the goals of the project, and site collaborators worked hard to ensure that ABHAC activities were not adversely affected by the changes. Staff working on the project were highly motivated and dedicated to the goals of the project and to education of the community about HIV disease.

The components of ABHAC were structured as follows:

* The project provided outreach to people who are HIV infected or who may be at risk for HIV infection. Outreach was also used to

educate rural border communities about HIV/AIDS and the services available in their communities. Outreach was conducted through existing health promotion programs and county health departments. Outreach workers provided information on HIV/AIDS and locations and times of HIV testing sites.

∗ HIV counseling and testing was conducted by the county health departments in Cochise and Yuma counties, respectively. In Santa Cruz County, HIV counseling and testing was conducted by the Mariposa CHC. The Mariposa CHC provided counseling and testing and enrolled patients immediately after a positive diagnosis. People testing positive for HIV in Cochise and Yuma counties were referred to their local CHC for primary medical care. The HIV counseling and testing sites recorded who was referred for testing on the Centers for Disease Control (CDC) Bubble Form for the State; as a result, it was possible for the State health department to report to the project coordinator all HIV counseling and testing by counties associated with the ABHAC project.

∗ PLWHA who received care at the CHCs were informed about the ABHAC project and invited to participate. After patients agreed to participate, they were assigned to a staff member who explained the project, asked for signed consent to collect information for the purpose of evaluation, and gave a copy to the patient. The project staff then administered the multisite data modules, a process that took approximately 45 to 60 minutes to complete. After the multisite and local evaluation forms were completed and forwarded to the project evaluators, the participant consent forms were sent to the project coordinator for recordkeeping. Data were collected for evaluation purposes on each participant at baseline, and the Quality of Life and Client Satisfaction modules (Modules E and G; see Chapter 1) were completed 30 days after the baseline. The CHE trained CHC physicians in completion and submission of

medical care data (e.g., the Karnofsky Performance Scale; Coffey et al., 2006).

∗ The Arizona AETC assessed the collaborating sites for training needs and scheduled training sessions.

∗ As the medical co-manager consultant to the CHC's physicians, the CHE kept a schedule for monthly visits and met with the participating providers on a quarterly basis. The CHE and physicians at the El Rio/SIA clinic were available for medical consultation at all times.

∗ The evaluation data (multisite modules) were collected at each enrollment site, and the completed modules were then mailed to the project evaluators or hand-delivered during the bimonthly meeting of project collaborators. The project evaluators entered, cleaned, and submitted the data to the multisite evaluation center at the University of Oklahoma. The project evaluators provided quarterly reports to the project collaborators. Data issues were discussed and resolved at the bimonthly collaborator meetings.

The project was recognized by the Arizona Department of Health Office of HIV/STD Services for its outreach work with minority communities and was awarded Ryan White HIV/AIDS Program Part B Minority AIDS Initiative funds. The funds provided outreach and education to HIV-positive minority residents of rural communities who are AIDS Drug Assistance Program (ADAP) participants.

Role of Evaluation in the Service Delivery Model

The project evaluators collected both qualitative and quantitative data and conducted quality assurance checks on all the data. The qualitative data added context to the quantitative data and provided a more meaningful analysis of the statistical findings. The project conducted a thorough evaluation of process and patient outcomes in the context of

both direct patient services and program goals and objectives.

Focus groups and in-depth interviews with PLWHA, key community stakeholders, and program staff were held to identify patient and program needs from the various stakeholders' perspectives. Information obtained through this process was used to improve outreach and case-finding strategies, service delivery protocol, and development of provider networks. The process provided the program with the means to be more responsive to the expressed needs of the targeted community groups. The qualitative evaluation also was used to identify perceived social, economic, and cultural barriers to accessing care. The strategies for reducing the barriers to access and retention to care were in part based on the input obtained from project stakeholders and collaborators.

Quantitative data collection activities entailed using standardized instruments, such as questionnaires and patient chart reviews, to provide a comprehensive account of program inputs, activities, outputs, patient outcomes, and program outcomes. Program outcome measures included the number of people contacted through outreach, the number of PLWHA enrolled in the project, and health outcomes indicators.

The project found that cultural and linguistic competencies are essential skills for working with populations who live in the U.S.–Mexico border region. Those competencies are particularly helpful in providing health care to monolingual Spanish speakers. The project contracted with local evaluators who had extensive research background in measuring cultural competency. Project providers conducted an annual assessment designed to assess staff members' cultural exposure, experience, and willingness to interact with multicultural populations and socially marginalized groups, such as IDUs and MSM. The instrument measured several domains, such as the value of human diversity, the understanding of culture and its application to particular communities, and the understanding of the

dynamics of interpersonal interactions. The Arizona AETC and CHE developed staff in-service training sessions based on findings from the annual cultural competency assessment.

The ABHAC project team worked closely with the multisite evaluation center to address local data and evaluation issues. This process ultimately resulted in improved documentation of outreach activities and improved delivery of patient services.

Importance of Evaluation Results in Service Delivery

Between February 2001 and March 2005, the ABHAC project enrolled 128 patients in the study. Sixty percent of the patients were Hispanic; 16 percent were women; and 31 percent were heterosexual. Other sociodemographic characteristics of the study population were as follows:

* Most patients (80 percent) had a high school education.
* Most patients (64 percent) were unemployed.
* Most patients (71 percent) reported annual incomes of $10,000 or less.
* More than half (56 percent) were single.
* Seven percent of enrolled patients reported being homeless.
* On the average, patients traveled 54 miles to receive health care.
* Almost 25 percent of the patients reported having no insurance coverage (this group excluded patients enrolled in AHCCCS).
* Mental health issues, alcohol abuse, and drug abuse were reported as a concern for 36 percent, 20 percent, and 25 percent of the patients, respectively. Low income (71 percent) and rural isolation (39 percent) were associated with substance abuse.

In addition, the data revealed the following HIV-related characteristics among patients:

* Most patients acquired the virus through MSM (56 percent) and heterosexual contact

(25 percent); the remaining 19 percent were infected through IDU and other categories.

* More than half of the patients (51 percent) were HIV positive but did not have AIDS and had been diagnosed since February 1995.
* A total of 34 percent of patients rated their health as fair or poor.

During each patient visit, health care providers recorded patients' CD4 counts, viral load, and number of opportunistic infections as indicators of health. The mean CD4 count for all patients enrolled was 475, and the mean viral load was 27,946. The goal is to have each patient achieve a CD4 count above 300 and a viral load in the undetectable range (below 50). Physicians completed a Karnofsky Performance Scale (Coffey et al., 2006) at each patient visit. The Karnofsky scale measures a patient's disease progression and his or her ability to care for his or her own daily needs. The scale is calibrated from 0 (death) to 100 (fully functional). The mean Karnofsky value for enrolled patients was 87. A score of 80 indicates some signs or symptoms of the disease, but the patient is able to participate in normal activities with some effort.

In January 2004, the ABHAC Annual Health Provider's Cultural Competence Assessment was administered for the third time. The assessment was given to support staff (not physicians) to assess their attitudes about providing care and culturally competent services to PLWHA. The findings indicated that most nonphysician health care providers supported the need to provide culturally competent health care. Also, each of the sites surveyed (CHCs and county health departments) endorsed the development of specialized HIV/AIDS care. This capacity would be achieved through ongoing training and education offered by the AETC and physicians who specialize in HIV medical care.

During the ABHAC project, more than 30,000 people were reached through individual and group contact encounters. A total of 88 physician-to-physician discussions involving more than 169

hours of consultation were reported through Year 4 (2004). Although ABHAC did not reach its target enrollment of 280 patients, many of the program goals, such as providing patient care in rural CHCs, were achieved. In addition, the project achieved several short-term objectives, such as improving confidentiality and increasing the willingness of physicians to care for HIV-positive patients. The project's plan to implement telemedicine was not feasible as a result of the limited availability of technology resources in rural health care settings.

The Chiricahua CHC experienced an increase in the number of HIV-positive patients, an indication that the implementation of ABHAC in the clinic was openly accepted. An issue the Chiricahua CHC and the other health centers encountered was the reluctance of PLWHA to be seen in the health center because of fear of disclosure of HIV status. With the implementation of the co-management model, the health centers' attending physician saw patients monthly and consulted with SIA's CHE. The comanagement model helped develop the physicians' comfort with seeing HIV-positive patients and changed the perception that the clinic staff had of PLWHA. In addition, the Chiricahua CHC has collaborated with the Cochise County Health Department to provide dental services to PLWHA and to coordinate case management services.

Cochise, Santa Cruz, and Yuma counties all reported an increased awareness of HIV/AIDS and acceptance of PLWHA in their communities. This change was observed by the service providers who educate the community and through events such as the community coming together to support awareness activities (e.g., World AIDS Day). In Cochise County, World AIDS Day was celebrated on the U.S.–Mexico border; the activities included a candlelight procession with participants who met at the border. In each county, the project collaborators were able to affect the perceptions and attitudes of CHC staff toward HIV/AIDS. The collaborators also were able to involve the faith-based organizations, government agencies, and social

CASE STUDY

"Juan," a 35-year-old Hispanic man, was hospitalized and referred to the SIA physician on April 14, 2003. He had difficulty walking because of neurological problems that affected his motor skills. He was diagnosed with late-stage HIV disease and enrolled in the ABHAC project on April 24, 2003. Juan's lab results revealed a CD4 count of 10, a viral load greater than 750,000, and significant neurological impairment. Juan's Karnofsky Performance Scale score was 40 (the optimum is 100), indicating significant disability and need for special care and assistance. Juan was not able to live independently and meet his daily needs.

Juan was placed on antiretroviral therapy, fluconazole for oral candidiasis, and trimethoprim/sulfamethoxazole (Bactrim) for *Pneumocystis* prophylaxis. After hospital discharge and follow-up visits to SIA to see the consulting HIV expert (CHE), Juan was transferred to the attending physician at the Chiricahua CHC in Bisbee, Arizona. There, Juan's care was managed by a physician who consulted with the CHE on the case. After 1 year of antiretroviral therapy, Juan's CD4 count was 120 and his viral load was less than 50. He was ambulatory, his mental status was clear, and he was aware of the time and the date. His Karnofsky score was 80 (indicating normal activity with some effort and some signs or symptoms of disease), an increase of 40 points. Juan seemed well groomed and was able to get around without assistance. He was referred for a mental function status evaluation to determine the presence of HIV-related dementia or other organic problem.

service providers in community outreach activities and HIV education.

Lessons Learned

From its participation in the SPNS U.S.–Mexico Border Health Initiative, El Rio/SIA learned several key lessons. First, establishing and maintaining community collaboration and structured avenues of communications are critical to achieving successful outcomes. ABHAC initiated monthly meetings among the collaborators to receive input, answer questions, and resolve issues related to project implementation. Through this process, ABHAC learned not to assume that working in a health care field in and of itself makes a person knowledgeable about the HIV transmission process or management of HIV disease.

Second, the CHC administration initially seemed reluctant to support all activities of the project. Through education and compensation for health care staff activities, health care centers became more open to project activities, including education and training.

Third, patients at the health care clinics worried that rural health care physicians did not have skills in HIV primary health care equal to those of physicians in urban centers who have experience in caring for many patients living with HIV. Consequently, educating patients about the co-management model of

HIV care became an important component of the project. Patients needed reassurance that their HIV care was of a comparable quality to what they would receive in an urban center.

Another concern among patients was the possibility of a breach in confidentiality; therefore, during the implementation of the project, patients were made aware that the CHCs were addressing their concerns. As more patients were treated by rural CHCs, their perception of receiving inferior quality care and of having their confidentiality breached was alleviated or at least diminished.

Another lesson was that assessment of the training needs of health center staff and physicians is important to the success of any project, as is having knowledgeable training staff or access to an AETC. When scheduling trainings in rural settings, it is important that staff not interfere in the daily operations of the clinic and the scheduled appointment times. The development and use of the co-management model for physician training and the self-paced HIV training manual for clinic staff proved to be effective for the project.

Finally, the process for communicating with collaborators was essential for the continued progress of ABHAC. Collaborators participated in monthly meetings that were based on a structured agenda in Years 1 and 2 (i.e., while the project was being implemented), then had bimonthly meetings in Years 3, 4, and 5; the approach successfully maintained clear communication.

Sustainability

The ABHAC project director and project coordinator began working with the collaborating partners to identify funding sources that could maintain project activities at some level. The project participants began to discuss the issue of sustainability at the start of Year 4 by adding this topic to the bimonthly meeting agenda. At each meeting, the group discussed funding opportunities for which the project might be eligible, either as an individual respondent or in collaboration with another agency. Patients who were receiving their medical care at El Rio/SIA remained at the clinic until the termination of the SPNS project; they continued to receive care beyond the SPNS project, although other Ryan White HIV/AIDS Program funds, not SPNS, paid for their care. Patients enrolled at the border CHCs that were eligible for Ryan White HIV/AIDS Program Part B funding were transferred from SPNS to that funding stream so that they could continue to receive medical care within the clinic.

The Arizona AETC continues to offer training opportunities to providers who practice along the Arizona–Mexico border. Project collaborators are aware that they may request training from the Arizona AETC at any time and that if funds are available, the AETC will try to meet their request. And finally, the CHE is seeking funds from pharmaceutical companies to support a rural medical training program that would provide HIV care updates and case presentations to rural health providers.

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CHAPTER 4

Camino de Vida Center for HIV Services: New Mexico Border Health Initiative

The New Mexico–Mexico border region is one of the fastest growing and poorest areas in the United States. Access to health care is limited by the rural nature of the area, inadequate transportation, limited resources, and low income and formal education levels. Given the lack of access to medical care, border residents infected with HIV are often diagnosed late—during an emergency room visit or inpatient hospital stay or at a sexually transmitted infection (STI) clinic. Late diagnosis translates into late entry into medical care and treatment regimens that are less effective than those started prior to the onset of AIDS.

To address those issues at the local level, Camino de Vida Center for HIV Services (CdV) applied for and received funding in 2000 under the Health Resources and Services Administration (HRSA) Special Projects of National Significance (SPNS) U.S.–Mexico Border Health Initiative. Under the SPNS initiative, CdV served as the lead agency in developing and implementing the New Mexico Border Health Initiative (NMBHI). Four other sites along the U.S.–Mexico border and a multi-site evaluation center at the University of Oklahoma were also separately funded under the SPNS initiative.

Community and HIV/AIDS-Related Needs

New Mexico is probably best known for its stunning landscapes, rich cultural heritage, and strong science and agricultural industries. Approximately 42 percent of the total population (765,000) is Latino,[4] and almost 47 percent of Latino children speak a second language (Kids Count, 2005). Despite those assets, the State is one of the poorest in the Nation. The following list captures just a few of the social and health challenges facing many New Mexicans on a daily basis:

TABLE 4.1. 2003 HIV/AIDS Cumulative Cases, Adults and Adolescents

Mode of Exposure	Region 5		Total New Mexico	
	n	%	*N*	%
MSM	199	56	2,061	64
IDU	49	14	343	11
MSM/IDU	27	7	348	11
Heterosexual	35	35	10	6
Other	8	2	58	2
No identified risk	39	11	205	6

* In 2003, New Mexico had the second highest proportion of uninsured of all the States (21 percent; U.S. Census Bureau, 2004).
* New Mexico has the highest proportion of people living in poverty (one in five; U.S. Census Bureau, 2004).
* Personal income and per capita health expenditures are fourth lowest in the United States (U.S. Census Bureau, 2002).
* New Mexico ranked 20th in the percentage of adults age 18 to 64 who had ever been tested for HIV in 2001 (Henry J. Kaiser Family Foundation, 2005).

In the border counties targeted by the NMBHI—Doña Ana, Grant, Hidalgo, Luna, Otero, and Sierra counties—the Latino population ranges from 26 percent (Sierra County) to 65 percent (Hidalgo County; U.S. Census Bureau, 2001). Together, the border counties claim 17 percent (312,200) of the State's population and face challenges that are even more staggering than those at the State level (Kids Count, 2005):

* 40 percent of children in the border counties are living in poverty, compared with 26 percent in nonborder counties.

* 19 percent of births in the border counties are to teenagers, compared with 17 percent of births in nonborder counties.

New Mexico is divided into five health regions by the New Mexico Department of Health: Northwest (Region 1), Northeast (Region 2), Bernalillo (Region 3), Southeast (Region 4), and Southwest (Region 5). Region 5 comprises the six border counties targeted by the NMBHI as well as Catron, Lincoln, Socorro, and Torrance counties. According to data from the New Mexico HIV/AIDS Epidemiology Program (2005), the rate of cumulative HIV/AIDS cases in Region 5 is 135 per 100,000, compared with 313 in Region 3 (which includes Albuquerque) and 302 in Region 2. For cumulative HIV/AIDS cases in 2003, the most common mode of exposure in Region 5 was men who have sex with men (MSM), at 56 percent (Table 4.1). Intravenous drug use (IDU) followed at 14 percent.

Sixty-three percent of the people living with HIV in Region 5 at the end of 2003 were living with AIDS, compared with 61 percent for the State as a whole. That trend is supported by national data illustrating that many people with HIV do not get

tested until late in the progression of the disease. Of those who do get tested, many never receive their test results (Centers for Disease Control and Prevention [CDC], 2003a). In one study conducted from May 2000 to February 2003 at 16 HIV testing and counseling sites across the country, late testers were more likely than early testers to have lower levels of formal education, to be exposed through heterosexual contact, and to be Hispanic or African American (CDC, 2003b).

In addition to being overrepresented among those who test late for HIV, Hispanics are overrepresented among new U.S. AIDS cases. Hispanics composed approximately 15 percent of the U.S. population in 2005 (U.S. Census Bureau, 2006) and 20 percent of the total number of new AIDS cases reported (CDC, 2005). Although race and ethnicity by themselves are not risk factors for HIV infection, social and economic elements, such as higher rates of poverty and limited access to health care, increase the risk for infection among Hispanics (CDC, 2006). Other dimensions related to race and ethnicity, language, gender, and sexuality also contribute to increased risk (Diaz, 1998).

In the six counties targeted by the NMBHI, the proportion of Hispanic HIV clients at CdV has increased, from 47 percent in 1997 to approximately 57 percent in 2004. The percentage of Hispanics living with HIV/AIDS in Region 5 in 2003 was 57 percent but 40 percent statewide.

Many Hispanics continue to enter care late in the progression of the disease. It is highly probable that the well-documented barriers to accessing health care in the region, such as the lack of medical insurance, high rates of poverty and unemployment, and a shortage of health care providers (HRSA, 1998), are contributing to the problem of late entry. Long distances between communities and, thus, medical providers, as well as confidentiality concerns in small communities, may be contributing factors.
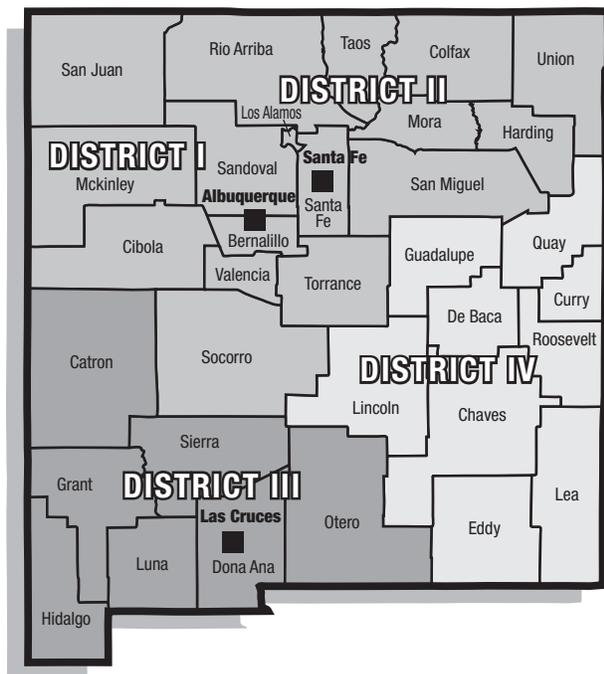
HIV Services and the CdV

Beginning in the mid-1990s, HIV/AIDS services were provided under the auspices of the Community Action Agency (CAA) of Southern New Mexico. Medical care was contracted out to a variety of providers who agreed to see people living with HIV/AIDS (PLWHA). CAA provided practical support services, such as food bank and travel reimbursement, as well as counseling services. Referrals for other services, such as case management, were made to other local agencies.

In 1996, an attempt was made to provide medical care in-house by adding a part-time physician and nurse. Because of low numbers, inadequate financial resources, and pervasive negative stigma in the community, the HIV/AIDS medical clinic was discontinued after 2 years. In 1997, the CAA's HIV program was designated as the HIV Health Maintenance Alliance (HMA) organization for District III by the New Mexico Department of Health (NMDOH) and was awarded a contract to provide a range of services for a designated number of clients (Figure 4.1). At that time, HMA District III overlapped with most of Health District III. Health District III is now Region 5 and includes additional counties.

The State contract mandated that the agency provide HIV testing and counseling; case management; medical care; prevention case management; medication regimen adherence support; and other support services, such as travel reimbursement, emergency assistance, and food bank. The NMDOH hired a consultant to develop best practice guidelines for delivering services under the new HMA model. The guidelines specified procedures to be followed by all HMAs to ensure statewide standards of quality care.

In 1998, the CAA initiated a contract with the local hospital, Memorial Medical Center's (MMC) Family Residency Program, to provide leadership and medical services. The residency program was

FIGURE 4.1. New Mexico HIV Health Maintenance Alliance.

tal insurance program for clients. The fund was initiated through a grant from the AID & Comfort Foundation in Santa Fe and is maintained through community fundraising. The fund pays deductibles and co-payments, and it enables CdV clients to purchase private insurance through the New Mexico Medical Insurance Pool when they do not qualify through other sources.

In early 2001, CdV was awarded a grant under Ryan White HIV/AIDS Program Part C. The grant provides funds for contracting medical services with target area medical providers. Those providers include the two local community health centers (CHCs)—La Clinica de Familia and Ben Archer Health Center—the MMC Family Practice Residency program, and a number of private medical care providers. Although most of the care providers are located in Doña Ana County, others are located elsewhere in HMA District III. The Roswell area is also included under Title III.

one of several satellite sites of the University of New Mexico Medical School. The residency program was designed to give medical residents family practice experience in rural communities.

In early 1999, the CAA began administering Housing and Urban Development (HUD) funds through the Housing Opportunities for People with AIDS (HOPWA) program in a partnership with the Mortgage Finance Authority in Albuquerque. The HOPWA program provides funds to assist clients with housing costs; emergency assistance, such as utility support; and supportive services, such as travel reimbursement for medical care. Also in 1999, CAA and the NMDOH created Camino de Vida Center for HIV Services, a private nonprofit with 501(c)(3) status. When the doors officially opened in September 1999, the client caseload was 85.

Another important program established at approximately the same time was a privately funded AID & Comfort account that functions as a supplemen-

The prevention program at CdV was first implemented at the CAA in the mid-1990s and included a focus on harm reduction. The prevention program today provides a variety of services for prospective and current clients. Anonymous HIV testing and counseling is offered free of charge onsite and in the field. The program also has a speaker's bureau, which facilitates community presentations by PLWHA. CdV provides individual and group-level interventions as well as prevention case management, a more intensive and longer intervention. Peer advocates, added to the program in 2004, offer partner elicitation, client transportation and assistance, and an orientation and support group for new clients.

Since its inception in 1997, the client caseload at CdV has grown from 85 to 154. In 2004, the staff of 11 included an executive director, three case managers, a Ryan White HIV/AIDS Program Part C coordinator, a prevention education coordinator, two prevention outreach workers, an MIS coordinator, a bookkeeper, and a secretary/receptionist.

The NMBHI project staff included a project coordinator, an administrative assistant/data manager, and health outreach workers. The NMBHI evaluation team included the local evaluator, an adjunct assistant professor in the sociology and anthropology department at New Mexico State University (NMSU), and a graduate assistant from the same department.

The New Mexico Border Health Initiative

In light of the numerous barriers to care that are common on the U.S.–Mexico border, CdV applied for and received funding to develop the NMBHI in August 2000. The project targeted Luna, Hidalgo, Otero, Sierra, Grant, and Doña Ana counties. Doña Ana County (DAC) is the most heavily populated. As mentioned earlier, access to health care in the region is affected by widespread lack of medical insurance, a shortage of health care providers, and low income and formal education levels. Limited English proficiency and immigration status are other potential barriers along the border. Outside the largest city, Las Cruces, the area is predominantly rural, and people must travel long distances for health care services (New Mexico Department of Health, 1997).

When the NMBHI model was being developed for the grant proposal in 1999, the original idea was to use *promotores* to reach underserved communities by providing HIV testing and counseling. In Mexican public health systems, a *promotor* is an indigenous community volunteer, usually a woman, who has the trust of her peer community. Thus, Goal 1 was to develop and maintain a promotor program to increase the identification, testing, and enrollment of MSM, IDUs, and women at risk for HIV infection.

The intent was for promotores to test and enroll into care 10 newly diagnosed Latinos every year from 2000 to 2005, resulting in a program group comprising 50 people. The plan was to compare this program group to newly diagnosed Latinos who were entering care through referrals from local hospitals or STD clinics or as walk-ins to the CdV office. Goals 2 and 3 in the original proposal—to increase access to care through comprehensive case management and to support HIV primary care through client education—were to be directed at the 50 newly diagnosed clients. Goal 4 was to enhance the quality of care for all clients through provider training and education.

To carry out and evaluate those goals, a project coordinator, case manager, data manager, administrative assistant, four promotores, and a local evaluator were hired in fall 2000. HIV testing and data collection began in March 2001, and by the end of June, close to 100 people had been tested for HIV and had participated in the NMBHI study. One participant tested positive for HIV but was lost to follow-up.

CdV MISSION STATEMENT

We are a nonprofit organization committed to connecting people affected by HIV/AIDS with prevention, community education, medical care, and support services promoting better health and wellbeing in the southern New Mexico border area.

By the middle of Year 2 and the completion of another 100 HIV tests, it became clear that finding 10 new Latino clients greatly exceeded what could be accomplished. Low HIV prevalence and incidence rates in the area were the most important reasons, but in addition, the promotores were unable to reach the highest risk populations because the targeted group differed from the traditional clientele of promotores.

Major personnel changes also occurred in the first 18 months of the program. The program coordinator, data manager, and local evaluator positions all changed, and two of the four promotores did not remain on the project. Taking into account those challenges, the new and continuing program and evaluation staff worked together to set more appropriate goals for outreach. With guidance from the multisite evaluation team at the University of Oklahoma, Goals 2 and 3 in the logic model were adjusted to include a broad focus on all CdV clients. Figure 4.2 shows the adjusted logic model adopted in Year 2.

Goal 1: Outreach

At the same time that the logic model was modified, closer examination of the outreach workers revealed that they were actually more like street outreach workers than promotores. Several important characteristics of the NMBHI outreach model set it apart from the traditional promotor model. The first and perhaps most important difference was that the NMBHI outreach workers were conducting outreach beyond their respective geographic communities. Another distinguishing factor was that the NMBHI outreach workers held full-time positions in addition to being contracted to conduct HIV outreach. To more accurately reflect the actual design, their title was changed to health outreach worker (HOW).

In addition to providing HIV testing and counseling in the field to people at risk, the HOWs were also charged with raising awareness about the importance of (1) knowing one's HIV status and (2) the benefits of early detection. For people who

tested positive, the ultimate goal of the HOWs was to support them in enrolling into care.

All the HOWs were selected on the basis of their having personal or professional experience with at least one targeted group. In Year 1 of the project, the HOWs received basic HIV/AIDS training and outreach training from the U.S.–Mexico Border Health Association. This training was tailored for promotores and included HIV testing and counseling using Orasure tests in the field. From Year 2 forward, the HOWs received HIV testing and counseling training from the NMDOH. Other mandatory training topics included data collection and safety in the field.

The NMDOH also provided early intervention nursing support from the onset of the NMBHI through July 2004.

Goal 2: Case Management

The second goal of the NMBHI was to increase access to HIV primary medical care and social services for people living with HIV in southern New Mexico. Comprehensive case management was the key in accomplishing this goal.

Unlike many other States, New Mexico made case management available to all applicants who presented proof of residence in the area, a gross income of 200 percent below the Federal Poverty Level, and verification of positive HIV status. Often, CdV clients transferred from other areas or were referred to the agency after being diagnosed through an emergency room visit or hospital stay.

To meet the needs of the increasing number of Hispanic clients at CdV, bilingual and bicultural case managers were recruited to provide case management in Spanish as well as English. A "prevention for positives" grant from the CDC allowed CdV to add a bilingual prevention case manager in Year 3 of the NMBHI. As the project evolved and barriers to care were identified, CdV moved to integrate case management with medical care by having ongoing patient care staffing conferences

FIGURE 4.2. New Mexico Border Health Initiative: Logic model.

Activities	Outputs	Outcomes		
		Initial	Intermediate	Long-Term
Goal 1: Establish and maintain a health outreach worker (HOW) program to increase the identification, testing, and enrollment of men who have sex with men, intravenous drug users, and women at risk for HIV infection into HIV services in southern New Mexico				
Train HOWs in culturally appropriate HIV testing and counseling; assess outreach efforts	Four HOWs identified, trained, and assessed	Increase HIV knowledge; improve testing skills and attitudes toward target populations	Increase outreach to people at high risk for HIV infection	Early identification of people with HIV infection and enrollment into primary care system (before diagnosis of AIDS)
Identify and recruit prospective clients (field outreach)	500 prospective clients contacted	Increase importance of being tested	HIV test and precounseling conducted	
Conduct precounseling, HIV testing, and post-counseling	150 prospective clients tested for HIV	Increase understanding of importance of know-ing HIV status	60 percent of results communicated and posttest counseling conducted	
Linkage to HIV primary care	People who are HIV positive enrolled within 60 days	Improve attitudes toward entering system of care	70 percent of people identified with HIV enrolled in care	
Goal 2: Increase access to HIV primary care and social services for clients living with HIV/AIDS in southern New Mexico through case management				
Comprehensive case management Referrals to providers	Coordination and refer-ral of services provided for 100% of clients	Reduce barriers to primary care	Increase in social support and client satisfaction	Maintain health outcomes (CD4 count, viral load, opportunistic infection) and quality of life
Goal 3: Support HIV primary care for clients living with HIV/AIDS in southern New Mexico through client education				
Client education	Disease management education provided to all clients	Increase knowledge of disease management	Improve response to primary care (appointments and drug adherence)	Same as Goal 2
Goal 4: Enhance the quality of HIV primary care for clients living with HIV/AIDS in southern New Mexico through education and training of providers				
Training and education for providers	Fifty providers trained (physicians, nurses, and staff)	Increase provider understanding of HIV care	Increase capacity of community health center providers to meet HIV standards for primary care	Same as Goals 2 and 3

Inputs were deliberately omitted.

and additional in-service trainings on other HIV/AIDS medical issues.

Goal 3: Client Education

The third goal of the NMBHI was to provide client education to increase HIV disease management knowledge and adherence to care. In Year 2 of the project, the agency attempted to specialize education and adherence support for clients by hiring a medical social worker, adherence nurse, and adherence counselor. The idea was that those positions would augment the case management services already being provided by the case managers. After several personnel changes, the agency moved away from using specialized staff for client education and instead trained case managers to respond to a greater range of client concerns.

By Year 3 of the project, it also became apparent that the client was the only constant in a system with ongoing physician and case manager turnover. The NMBHI coordinator decided to offer educational trainings directly to clients in a variety of venues throughout the area. The response was positive, and the trainings became known as the Client Educational Series (CES). Simultaneous translation was always provided at the trainings, and eventually the series was offered in Spanish with English translation. The New Mexico AIDS Education and Training Center (NMAETC) and the Southern Area Health Education Center (SoAHEC) assisted in the coordination of the trainings. Many of the client trainings were scheduled in conjunction with the provider trainings as discussed below.

Goal 4: Provider Education and Training

The fourth goal of the NMBHI focused on training physicians and other health care staff to provide HIV primary medical care for PLWHA. This proved to be a lofty goal, given the ever-changing medical community in the region. In just 4 years, from 2001 to 2005, CdV had three medical directors. Staff turnover at partner agencies, such as the CHCs and the NMAETC, was also prevalent.

Two organizations that provided support in coordinating the provider trainings were the NMAETC, located 225 miles north of Las Cruces in Albuquerque, and SoAHEC, located in Las Cruces. Though complicated at times, the collaboration between the NMAETC, SoAHEC, and CdV proved beneficial for all parties. At least six trainings were offered per year, and attendance remained stable.

Institutionalization of Program Components

Although most of the NMBHI project and evaluation staff did not remain at CdV after 2005, several key programmatic components were institutionalized in the agency. For example, in relationship to Goal 1, two peer advocates continue to do HIV outreach in southern New Mexico, although the frequency has diminished considerably. Moreover, through the efforts of the project, the outreach program now has a training manual that has been customized to meet local needs.

Bilingual and bicultural staff have become a mainstay in the agency and have had a positive impact on case management. Materials are routinely translated into Spanish, and presentations for clients are always available in English and Spanish.

In addition to those changes, CdV received a 3-year grant in late 2004 from the U.S. Department of Health and Human Services Office of Minority Health (OMH) to provide cultural competency training to CdV staff and collaborating medical providers. The emphasis on meeting the needs of clients with limited English proficiency includes training for clients and staff on the Stanford Chronic Disease Management Model (Lorig, Ritter, & González, 2003).

Related to the third goal, HIV education continues to be provided to clients by all direct service providers in the agency. Through SPNS, a second avenue of education—the CES—has now been institutionalized. Client demand and attendance at

CES trainings remains steady and collaboration with the NMAETC and SoAHEC persists.

Finally, provider education and training (Goal 4) has been institutionalized in agency programming. The coordinator for the OMH grant has taken the lead in making sure the trainings continue, and attendance has remained steady. An annual HIV/AIDS forum, first offered in 2004, was offered again in November 2005.

Coordination and Collaboration

Before the NMBHI, CdV already had an agreement with the two area CHCs and MMC's Family Residency Program to provide medical care for CdV patients; however, the NMBHI required a higher level of collaboration. New elements introduced by the NMBHI included HIV education and training for clinical providers and the need to access patient medical charts for the multisite longitudinal study. A provider follow-up study conducted in Year 4 also required greater communication.

The partnership between CdV and the NMAETC enabled CdV to provide funding for many area physicians and health care clinicians to attend various workshops on HIV/AIDS in the Las Cruces area. An intensive training in Denver at the University of Colorado Health Sciences Center also was offered through the partnership. As indicated earlier, SoAHEC at NMSU provided CdV with support in planning and coordinating the provider workshops. In 2004, SoAHEC assumed leadership for the CES, and the NMAETC took the lead in providing educational training for medical providers.

Another partnership initiated specifically because of the NMBHI was with the sociology and anthropology department at NMSU. Having a local evaluator who was an adjunct assistant professor in the department was beneficial for both CdV and the department. Institutional review board approval, as well as graduate research assistance, was secured through the department. Lisa Frehill, an associate professor in the department, provided technical assistance for the local qualitative study and other research-related issues as they surfaced.

Implementation Issues

As mentioned earlier, many personnel changes occurred during the first year of the project. When the original project coordinator resigned at the end of Year 1, the prevention coordinator was moved into the position. She had experience as a disease prevention specialist with the district public health office, so her background added a new dimension to the project.

Another personnel change involved the project assistant/data manager, who started as an administrative assistant doing primarily secretarial work. Her appointment as data manager was based on her proven ability to manage data generated by the outreach workers. Her bilingual and bicultural skills were an added asset for the agency in serving Spanish-speaking clients because she interviewed most client participants enrolled in the SPNS study.

In addition to personnel changes during the first year, several other factors made it challenging to implement the project. At the time of award in 2000, CdV was a new agency (founded in 1999) with a small staff providing limited social services and contracted medical services. With the addition of outreach and provider training and an added emphasis on client education, the NMBHI stimulated change inside as well as outside the organization. This rapid expansion resulted in growing pains related to formalizing agency policies and relationships with other organizations.

Another challenge was related to the fact that the NMBHI was treated as a separate component in the agency in the proposal period and during the first year. Despite trying to integrate the project into the agency beginning in Year 2 through increased communication and staff involvement, the project was never fully integrated. The

consequences included a lack of understanding about the project on the part of several staff members and reduced buy-in. No doubt the ongoing high turnover in personnel at CdV made it even more difficult to integrate the NMBHI. Regular case management positions changed seven times, the director position changed at the end of Year 3, and numerous changes occurred among prevention, administration, and adherence staff during the 5-year period of the NMBHI.

Evaluation

Evaluation was a key component of the NMBHI. The original contract evaluator was a faculty member based at a university satellite in El Paso, Texas. He had experience working with promotor models in HIV and was familiar with CdV. The agency decision to move away from the promotor model in the second year of the project led to a mutual decision by the agency and the local evaluator to terminate collaboration. The agency was able to secure the services of a local adjunct assistant professor at NMSU's department of sociology and anthropology to assume functions of evaluation.

Although the simultaneous change in evaluator and project coordinator was initially thought to be a major setback for the NMBHI, the change actually enabled a concerted focus on the adjusted goals. Having a local evaluator also facilitated securing graduate research assistants (GAs) from the sociology and anthropology department at NMSU. One such GA worked on the project for 2 years and then remained on the project for another year after she graduated in December 2003. Toward the end of the project, a graduate of the NMSU master's program in sociology was hired on a short-term basis to replace the data manager, who had taken a new job elsewhere.

Instrument Development and Data Collection
The NMBHI involved extensive data collection at both local and multisite levels. Unique instruments were developed at each of the five SPNS

U.S.–Mexico Border Health Initiative sites to meet local evaluation needs. Instruments that allowed data collection across all five sites were developed by the multisite evaluation center at the University of Oklahoma with input from all the sites.

The NMBHI used a total of 17 modules to collect quantitative data from four populations: the HOWs themselves, people tested for HIV in the field, CdV clients, and medical providers who attended the trainings. In the first instance, two of the modules were used to assess the HOWs annually on their knowledge of HIV, HIV testing and counseling skills, and comfort levels with the target groups.

In collecting data from the second population—people contacted through outreach—the HOWs used three modules to collect basic sociodemographic data and risk factors. A fourth module documented the impact of the contact for the outreach recipients in terms of importance of early detection and knowing their HIV status.

With CdV clients, seven multisite modules were used to document a wide variety of indicators, including basic sociodemographics, risk factors, quality of life, and client satisfaction. Two additional local modules were developed to capture social support and client understanding of disease management. In addition to the quantitative modules, two qualitative studies were conducted with a small number of clients, one under the leadership of the University of Oklahoma and one directed by the local evaluator. Medical chart reviews were also conducted by the University of Oklahoma in Years 3 and 5 of the SPNS initiative.

The fourth study population, medical providers, completed a standard NMAETC training evaluation form after every training. In collaboration with the NMAETC, the NMBHI also conducted a follow-up study of 24 providers. This study involved a 20-minute, one-on-one interview and was modeled after a previous study conducted by George Huba at The Measurement Group.

CASE EXAMPLE

The following case summarizes the experiences of several clients who participated in the local study of late entry into care. It does not focus on outreach because most new clients identified by the health outreach workers (four out of the five who received test results) were identified early in the progression of the disease.

"Javier" is a middle-aged heterosexual Hispanic man who immigrated to the United States from Mexico when he was very young. After he graduated from high school and joined the job market, he had one experience, in the late 1980s, that put him at risk for HIV. In the late 1990s, he began experiencing headaches and fatigue, which he attributed to increased stress. By 2000, he was having bouts of diarrhea, which he thought were a result of his diet. Over several months, Javier went to two different primary care physicians and a dermatologist in order to "cure" his symptoms. To save money, he first went to a physician in the United States referred by a friend. After no improvement, he went to a physician in Mexico, also referred by a friend. During this period, he was given many prescriptions and home remedies for his ailments, but they persisted. He was then referred to a dermatologist, who tried several prescriptions. Finally, when his body was literally shutting down, as evidenced by thrush, blisters, wasting, and a decrease in nervous system functioning, he was offered an HIV test by the dermatologist. The test came back positive, and Javier was diagnosed with AIDS.

When Javier was given his diagnosis, he was also given the phone number of the Camino de Vida Center for HIV Services (CdV) and urged to call immediately. When he came to CdV the next day, he met with the prevention case manager, who explained what HIV/AIDS is, how it is transmitted, and what the lab results mean. In addition, Javier was told about the services offered at CdV and invited to enroll. He was ready to enter care, so he was interviewed to determine his level of need. Because he was 100 percent below the Federal Poverty Level, he qualified for all of CdV's services, including case management, housing assistance, insurance assistance, mental health and substance abuse counseling, transportation assistance, and public benefits (food stamps and Social Security disability). He was also referred to the main medical provider caring for CdV clients and was asked if he would like to meet with a mental health specialist. After the appointments were set up, Javier was given his case manager's card in case he needed anything else before their next appointment.

Since entering care, Javier has had monthly phone contact with his case manager and has met face-to-face with her at least three times per year. When Javier and his case manager talk, they discuss everything: how he is doing physically, mentally, and emotionally; when

(Continued)

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CASE STUDY (CONT'D)

he last saw his primary care physician and had labs done; how he is doing with treatment adherence and medication side effects; prevention issues; and whether there are any substance abuse issues. The case manager also conducts an ongoing needs assessment with Javier to ensure that his needs continue to be adequately met. At the end of each conversation, Javier is encouraged to discuss any issues he might have with his case manager and physician. Finally, Javier is reminded that he can and should call his case manager whenever he needs anything, even if it is just to talk.

In summary, Javier had a slow start getting diagnosed. Indeed, he never thought he was at risk because he was heterosexual, monogamous, and was not in the "drug scene"; he believes that if he had seen one doctor instead of bouncing around to different ones, he might have been diagnosed sooner. Nonetheless, he quickly entered into care at CdV and began to receive the appropriate services. He has since greatly improved and continues to do well.

Although every HOW was responsible for collecting data from people who were tested for HIV, the data manager collected most of the quantitative data from clients. Originally, the plan was to have case managers collect the data from clients, but for reasons of continuity, consistency, and time constraints, the data manager was assigned the dual tasks of both data collection and data entry. She was also responsible for correcting data errors and coordinating the qualitative interviews.

In addition to collecting quantitative data, a local qualitative study was conducted that targeted clients who entered medical care with a CD4 of 200 or less; the study's purpose was to examine the role of relationships of any kind in entering medical care late. A local clinical psychotherapist conducted a series of three semistructured interviews with each of 10 clients in their preferred language. The findings will be used internally by CdV staff to inform their outreach and early intervention

efforts. The findings also were disseminated through an article in *AIDS Care* (Lain, Valverde, & Frehill, 2007).

Organizational Impact

The NMBHI was CdV's first experience requiring outcome evaluation at the local level. Even though introducing outcome evaluation into an existing service delivery system was challenging for both staff and the administration, the benefits of evaluation quickly emerged.

One such benefit for staff and agency administration was improved understanding of the diverse groups that make up the community that the agency serves. Before the NMBHI, agency services were planned on the basis of assumptions that lacked empirical evidence. One staff assumption, for example, was that Spanish-speaking service applicants would know that CdV had Spanish-speaking staff. CdV personnel were surprised to

learn that prior to accessing services, close to 60 percent of the NMBHI Spanish-speaking participants assumed that no Spanish-speaking staff would be available at CdV.

Another benefit for some staff members in the agency was the increased capacity in program evaluation. To different degrees, staff members at CdV gained valuable experience in collecting, entering, cleaning, analyzing, and interpreting data. Because of high staff turnover, however, and the departure of SPNS project staff in 2005, many people who gained an understanding of evaluation went on to work in other agencies. In essence, many of the lessons learned from the NMBHI relating to the value of evaluation did not have a long-term impact on the agency.

Even after CdV applied for and was selected as one of 23 national sites for the Client Level Data Demonstration Program in 2003, the agency faced the same challenges with designing, implementing, and sustaining a model that incorporates evaluation into strategic decision making, program improvement, and client care management.

Lessons Learned

Developing and implementing the NMBHI was an invaluable experience. As a relatively new agency in a State with low incidence of HIV/AIDS, CdV staff received the benefit of learning about outcome evaluation through practical application. The NMBHI also facilitated networking opportunities with other colleagues working in HIV/AIDS in the border region, the multisite evaluation team, and HRSA staff.

Along with the benefits came critical, hard-learned lessons. For others embarking on a project like the NMBHI, both staff and consumer representatives must be involved early in developing the program and evaluation plan. It would have helped if the SPNS initiative had been viewed as an integrated

program and an opportunity to define best practices within the organization from the outset. Involving an epidemiologist familiar with local statistics is also paramount, especially when projecting the number of new clients to be served.

Likewise, when designing the program, planners should pull from local resources rather than try to arrange long-distance partnerships. Entities from outside the region can provide certain kinds of technical assistance and training, but when it comes to day-to-day involvement, close proximity is key. Using formal and informal recruiting avenues can help expand the pool of candidates for various positions that need to be filled.

Once a program is up and running, it must be flexible, and the people involved must be willing to take risks. For example, it may be necessary to try several different approaches when trying to reach people most at risk for HIV/AIDS. In the case of the NMBHI, hiring HOWs who were PLWHAs proved to be the most effective way to identify new cases. Offering formal training sessions to clients as well as to the providers was another effective approach that was discovered because the coordinator was willing to take a chance. Neither option had been identified in the original plan or incorporated into the logic model.

Summary

The New Mexico–Mexico border region is primarily a rural area with its share of complex social problems, including high rates of poverty, low formal education levels, limited health resources, little to no public transportation, and confidentiality issues in small communities.

With funding from HRSA in 2000, CdV initiated the NMBHI to develop an HIV/AIDS care model under the auspices of SPNS. According to feedback from five CdV staff members and six health care partners interviewed at the end of the project, most

of those interviewed believe the effort had a positive effect in the New Mexico border region. Strengths mentioned repeatedly in the interviews were related to outreach and the addition of peer advocates, documenting the barriers to care, the building of partnerships with other agencies, and provider training and education. HIV sensitivity in the community has increased; clients are more knowledgeable about taking control of their own health, seeking appropriate care, and asking the necessary questions;

and providers feel more confident in meeting the needs of CdV's diverse clientele.

The NMBHI can serve as a replicable model that can be tailored accordingly. At the local level, the NMBHI demonstrated the importance of integrating outcome evaluation. Ideally, the next step would be to institutionalize evaluation to ensure continual monitoring and improvement of HIV/AIDS care systems in southern New Mexico.

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CHAPTER 5

A Nurse-Based Disease Management Model of HIV/AIDS Care on the U.S.–Mexico Border: Centro de Salud Familiar La Fe

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The city of El Paso, Texas, is closer to the New Mexico capital of Santa Fe and to the capital of the State of Chihuahua, Mexico, than it is to its own State capital of Austin. Located on the westernmost tip of the State, it lies in a border region where three States and two Nations come together. Its geographic location helps explain the uniqueness of the city sometimes called "The Other Texas."

The combined population of El Paso and its sister city, Ciudad Juarez, exceeds 2 million, making it one of the largest urban areas along the U.S.–Mexico border. The metropolitan area's population grew 1.5 percent between 2003 and 2004 (City of El Paso Department of Economic Development, 2007a). Approximately 82 percent of the population of El Paso County is Hispanic, and 27 percent of its residents are foreign-born (U.S. Census Bureau, 2005). The Ciudad Juarez–El Paso area is one of the largest international border crossings in the United States; a total of 43,000 private vehicles, 25,000 pedestrians, and 3,500 commercial trucks cross the border from Mexico into El Paso every day (City of El Paso Department of Economic Development, 2007b).

Texas leads the Nation in the number of citizens without health insurance and in the most uninsured residents living on the border. In fact, 41.5 percent of working-age El Pasoans are without health insurance (Ahluwalia, Bolen, Mokdad, & Garvin, 2006). The problem is further complicated because the Medicaid reimbursement rates in the State of Texas are significantly lower for services delivered in the border region than for services in any other geographic region of the State. This situation presents a major barrier to care in a city like El Paso, where Medicaid is a major payor for health care services.

Historically, the border region has been the most economically disadvantaged area in Texas. For example, the median household income is just over $32,000. Approximately 25 percent of the population falls below the Federal Poverty Level (U.S. Census Bureau, 2005), and almost 20 percent of El Pasoans age 25 and older have less than a ninth-grade education (U.S. Census Bureau, 2004). In El Paso, typical prevention strategies and service provision may prove unsuccessful if sociodemographic realities for vulnerable and hard-to-reach populations are not taken into account.

In addition, a great need exists for bilingual health care providers, whose skills are essential to any agency that provides services to residents of this community. Of the 77 percent of El Paso County residents who speak a language other than English at home, 97 percent speak Spanish (U.S. Census Bureau, 2004). Demographic data underscore that cultural competency must be part of any health care provider's expertise to deliver quality programs that are useful and relevant to this population.

HIV/AIDS Epidemiologic Data

Data from the Centers for Disease Control and Prevention (CDC; 2003) show a continued decline in the number of AIDS-related deaths nationwide and a 2 percent increase in AIDS incidence between 2001 and 2002. At the end of 2002, an estimated 384,906 people in the United States were known to be living with AIDS. The best estimates of HIV incidence continue to be an issue of grave concern (CDC, 2003).

HIV/AIDS incidence rates are consistently and disproportionately high among Hispanics, who compose 12.5 percent of the U.S. population but 19.2 percent of AIDS cases nationwide. The number of Hispanic patients using services funded by the Ryan White HIV/AIDS Program in the West Texas area mirrors local demographics. In 2002, 71.9 percent of Ryan White HIV/AIDS Program patients were Hispanic, and less than 10 percent were non-Hispanic Whites (West Texas HIV Assembly, 2002).

In Texas, 4,411 new AIDS cases were reported in 2002. Ninety new cases were reported in El Paso County, bringing the number of residents in El Paso County living with HIV/AIDS to 1,124 at the end of 2002. Men who have sex with men (MSM) continues to be the leading transmission category in the county, followed by injection drug users (Texas Department of Health, 2003).

El Paso County has seen growth in sexually transmitted infection (STI) markers that increase the likelihood of HIV transmission. In 2002, the number of reported gonorrhea cases was up by 29 percent over the previous year, cases of chlamydia increased by 4 percent, and cases of syphilis increased by 9 percent over the past year (Texas Department of Health, 2002).

While infection rates in this region have increased, AIDS-related mortality has decreased. The statistics illustrate the mounting burden on the health care system and stress the growing need for quality programs that provide life-enhancing services.

HIV Services

HIV/AIDS care in resource-poor communities on the U.S.—Mexico border has historically faced serious challenges. The weak public health infrastructure in border communities has presented a major obstacle in the delivery of HIV/AIDS services to the thousands of people who need them. Case management services for people living with HIV/AIDS (PLWHA) are fragmented and unevenly distributed within the city of El Paso and became more so when the area's only AIDS service organization closed in December 1998 after more than 10 years of operation. Few facilities have both medical and case management services onsite; as a result, patients frequently visit multiple agencies for health and support services, often completing duplicate paperwork at the various sites.

The public and nonprofit HIV service delivery system in this area is further challenged by issues

related to immigration and welfare and concerns about "public charges." Those issues have made many people afraid to seek and use the public health and human services that are available. In addition, a growing proportion of clientele are transborder dual residents (i.e., people who live or work on both sides of the border). Many patients participate in parallel, simultaneous systems of care in El Paso and Ciudad Juárez because of linguistic and cultural preferences, economic problems, and poor availability of HIV antiretroviral medications in Mexico.

The lack of qualified health care providers presents additional concerns. In the past, case management has often been confused with disease management, and unlicensed case management staff sometimes have been involved in patient triage and dispensing treatment advice.

Other barriers further impede the delivery of HIV-related services to the people who greatly need them, including transportation difficulties, lack of HIV- and AIDS-related knowledge, language issues, and comorbid illnesses. Needs assessments conducted in El Paso prior to the Special Projects of National Significance (SPNS) U.S.–Mexico Border Health Initiative revealed that several important services remained unavailable; one-third of patients surveyed stated that they were not aware that certain services existed or whether they were eligible to use them. Other concerns were lack of communication between service providers and clients, difficulty navigating the existing system, accessibility of services, and fear of discrimination.

Organization

Centro de Salud Familiar La Fe is an internationally recognized community health center (CHC) that has been providing comprehensive health care services to residents of El Paso for more than 37 years. The CHCs that are run by La Fe provide medical, dental, social, and preventive services to underserved populations in the border region. La

Fe's mission is to improve the quality of life of its clients by continually enhancing the health and human services it provides.

In October 1990, La Fe established a comprehensive HIV early intervention services program, which has served as the foundation for the concept of providing "one-stop shopping" for HIV health and support services. La Fe's CARE Center is currently the only comprehensive HIV/AIDS service center where El Pasoans at risk of or infected with HIV can receive a complete, seamless continuum of preventive and primary medical and case management services that are culturally and linguistically sensitive. Clients of the CARE Center have access to everything from initial HIV testing services and peer counseling in delivery of positive results to the medical and social services needed in the management of later stages of the illness.

In 1990, La Fe received its first grant under Part C of the Ryan White HIV/AIDS Program; in the years that followed, it has continued to develop a modern network of HIV/AIDS preventative and primary care services. This network incorporates culturally appropriate health promotion, disease prevention, and community initiatives that are necessary for delivering comprehensive wellness services to the border population.

Service Delivery Model

La Fe's service delivery model was intended to establish a single, seamless system of care for PLWHA centered on the role of a bachelor's-level registered nurse or care manager. The program involved creating multidisciplinary teams, referred to as *care teams*, consisting of three key providers: a nurse care manager, case manager, and an HIV-positive peer advocate. The model centralizes patient care by combining social and medical case management services into a collaborative team.

Patients are referred to the CARE Center from onsite testing, outreach efforts, other La Fe clinics,

the Texas Department of Health HIV counseling and testing sites, the El Paso County Detention Facility, the county hospital (R. E. Thomason), and other agencies in collaboration with La Fe for those services. For the SPNS initiative, existing patients of the CARE Center were assigned to one of three care teams alphabetically by surname. New patients were assigned to one of these teams as they became active clinic patients. Each team was responsible for a caseload of 100 to 150 patients.

The logic model in Figure 5.1 shows the various components of this innovative model of care and their intended functions and expected outcomes, including initial, intermediate, and long-term patient outcomes.

The Role of the Nurse Care Manager

The proposed model indicated an expanded role for the bachelor's-level registered nurse or nurse care manager who would function as the care team leader. The care manager would have a limited clinical role, especially in the first year of the project. A strong emphasis was placed on patient education: Nurses would conduct an individual educational consultation with each patient as he or she entered the program. The consultations would last from 1 to 2 hours, depending on the needs of the patient, and involved taking a comprehensive medical and social history. During this initial consultation, the nurse would discuss information related to the life cycle and replication of HIV; patient understanding of HIV-related health markers; and information about risk factors, risk reduction, and the importance of following through with medical appointments. The nurse also would review with the patient the various services provided by the clinic, ensuring that the patient was aware of the full scope of services and clinic hours, including after-hours on-call services. Each patient was provided with an information packet at that time.

The sessions, although somewhat structured, would be tailored to the individual needs of the patient, and more time was spent on weak areas of knowl-

edge. The one-on-one sessions provided not only important factual and concrete information to empower the patient but also an initial opportunity for patients to connect with the nurse responsible for managing their care.

Nurses also were responsible for recruiting patients into the SPNS program. During the initial visit, they were to explain the basic purpose of the study, its potential risks and benefits, and the structure of the teams. Patients expressing interest were enrolled in the program. The patients who declined participation were asked some basic questions about their reasons for declining. They received the same services as those who were officially enrolled in the program, but they did not participate in the program evaluation process. More than 99 percent of patients who were approached were enrolled in the SPNS initiative.

At the end of the initial consultation, the patient was introduced to the social worker and peer advocate who were members of the care team. The nurse emphasized to the patient that the care team would be responsible and available to him or her for all aspects of care.

Case Managers

The model specified that positions within the case management component were to be filled by trained social workers who would serve an essential function. They were responsible for assessing and addressing all aspects of patient financial and social service needs, including qualifying clients for assistance related to their diagnosis, enrolling patients in medication assistance programs, addressing housing and transportation issues, making interagency referrals, and conducting home visits to assess a patient's daily living conditions.

The role of the social worker was to ensure that the patient received all necessary social services and available benefits. Social workers served to link clients to community resources to enhance their care and decrease duplication of services. They were strong patient advocates and facilitated patient

FIGURE 5.1. Logic Model, Centro del Salud Familiar La Fe.

Inputs	Activities	Outputs	Outcomes		
			Initial	Intermediate	Long-Term
Multidisciplinary coordinated care management teams For each 150 patients: ◆ Two full-time registered nurses ◆ Two half-time positive peer advocates ◆ One full-time case manager Consulting for all patients: ◆ One dietitian ◆ One LMSW ◆ One nurse practitioner* ◆ Part-time pharmacist ◆ Part-time mental health therapist	Disease-state management	300 patients served	◆ Increased appointment attendance ◆ Increased patient satisfaction ◆ Expanded access and increased compassionate use of medications	◆ Increased adherence ◆ Increased knowledge of HIV/ AIDS ◆ Increased dietary knowledge ◆ Increased perceived social support	◆ Increased quality of life ◆ Increased physical health ◆ Increased psychosocial adjustment
Trained HIV counselors ◆ Field coordinator	HIV counseling and testing	◆ 100 completed HIV tests/month ◆ Counseling of all tested subjects	◆ Increased rate of return for test results ◆ Increased percent-age of high-risk people tested ◆ Increased number of off-site testing events	◆ Decreased latency between positive test and initiation of intervention	◆ Other variables to be determined by multisite evaluation center
AIDS Education and Training Center (AETC) personnel	HIV/AIDS training	◆ 16 hours of continuing education per year per case management team member	◆ Improved provider skills, attitudes, and comfort	◆ Annual competency rating exam passed	◆ All RNs providing patient care will receive credentials as AIDS-certified registered nurses (ACRNs)

*Paid out of another grant budget.

access to and utilization of services. Hiring licensed staff for case management was intended to address the previously described deficiencies that had existed in the delivery of those services; many of the positions had been filled by unlicensed staff with little or no training in social work.

Peer Advocates

Peer advocates who were PLWHA played an active and important role in the program. They usually had the first contact with new clients and often delivered seropositive test results and counseling to incoming patients. Peers were responsible for performing initial eligibility screening and worked closely with social workers in certain aspects of case management. They were involved in educating clients about coping with HIV and helping them develop problem-solving skills for disease prevention and health promotion. Most important, peer advocates were available to patients in situations of emotional distress and provided a safe environment in which patients could ask the questions that they might not feel comfortable asking others.

Each peer advocate was responsible for maintaining a current and complete problem list for patients on his or her team. Their duties at the CARE Center included treatment adherence advocacy, support group facilitation, "buddy" support provision, appointment reminders, missed appointment follow-up, office assistance, computer data entry, "Next Step/Positive Living" class instruction, and counseling related to HIV testing. They also were involved in outreach activities, fundraising efforts, job training and placement, and volunteer recruitment and coordination.

Care Team Meetings

The care teams met on a regular basis to discuss all issues related to patient care and to identify and resolve problems as they arose. Meetings were held on a monthly basis and were to be increased if it became evident that more frequent meetings were needed.

Case management issues commonly addressed during the meetings included concerns about housing, the need for medical equipment in the home, difficulties with transportation, and scheduling home visits for hard-to-reach patients. It was not uncommon for staff to visit homes to assess a patient's case management needs and to ensure the presence of adequate residential support systems. Similarly, all aspects related to the medical aspect of case man-

agement were open for discussion during those meetings. Problems with treatment adherence, side effects, and all concerns related to the well-being of the patient could be raised at this meeting by any team member.

Collaborations

The service delivery model required intense collaboration with various organizations, including the Texas Tech School of Medicine, International AIDS Empowerment, and the University of Texas at El Paso.

The project formed a unique, groundbreaking collaboration between La Fe and Texas Tech School of Medicine's Health Science Center, the two main public providers of primary and specialty care in El Paso. Armando Meza, a specialist in infectious diseases and medical director at the CARE Center, was contracted through Texas Tech to provide the medical oversight necessary for the implementation of the model.

Another important partnership was established with International AIDS Empowerment (IAE), a nonprofit organization staffed solely by PLWHA. IAE oversees a number of programs intended to improve the quality of life for PLWHA regionally, nationally, and internationally. The IAE's Robert Delgado Treatment Advocacy Center was involved in the El Paso SPNS project from its inception and proved to be an invaluable asset. IAE was contracted to provide the peer advocates, who were an integral part of the model. The inclusion of PLWHA in the delivery of services to other clients was one of the most successful features of the program.

Nurse Practitioner Services

Funding from Ryan White HIV/AIDS Program Parts B and C allowed the CARE Center to hire a certified family nurse practitioner (FNP-c) to provide clinical services on a full-time basis in collaboration with a part-time physician. Having a nurse practitioner onsite greatly facilitated the clinic's ability to deliver quality services to patients and

had a positive impact on the project. With an FNP-c on staff, the nurses were better able to devote time and effort to the project. The CARE Center also was able to increase its hours of operation by offering walk-in hours on two additional half-days per week.

The role of the FNP-c was to ensure totality of care. Whereas the physician provided patients with necessary medical attention and supervised clinic staff, the FNP-c functioned more as a coordinator of care and addressed any gaps in services.

Pharmacy Services

The inclusion of a part-time pharmacist was originally intended to give patients access to consultant pharmacy services as well as to establish an onsite Class D clinic pharmacy (a designation that would allow the clinic to carry a limited number of prepackaged medications that could be dispensed by medical personnel as needed).

In the first year of the project, a pharmacist was hired and began providing pharmacy-based consultant services at the CARE Center. His work involved conducting complete medication histories during individual consultations with patients and reviewing basic treatment information, such as drug interactions and side effects. His initial role was expanded over time as a number of common problems and patterns were recognized. Patient consultations were soon targeted to patients who were experiencing difficulties with treatment adherence. Medication counseling sessions focused on identifying barriers to adherence and discussing ways of overcoming those issues.

Recognizing that patient nonadherence in the management of HIV/AIDS was a paramount concern, the pharmacist and the CARE Center established a medication adherence service (MAS) to directly address the issue. The goal for MAS was to create a partnership among the clinical pharmacist, patient, nurse practitioner, physician, and other members of the health care team for the purpose of achieving responsible, effective medication use for the improvement of health outcomes.

Objectives included increasing the total number of medication doses taken to exceed 95 percent of those prescribed, improving quantitative treatment outcomes, and reducing the number and duration of physician visits. The service examined the interconnectedness of patient characteristics, medication regimen, clinical program, and health care professionals.

In MAS, patients were referred by their physician or nurse for an initial 45-minute visit with the clinical pharmacist. As part of the service, the clinical pharmacist developed an individualized management plan with individualized goals for each patient. The plan was based on information obtained from a preassessment questionnaire. Patients were then referred for assistance from other clinic staff as needed. Clinical pharmacy consults under MAS were provided to patients at least once per month until adherence goals were achieved.

Evening medication adherence classes, which taught staff to work with patients who had adherence issues, had been offered initially to clinic staff on a bimonthly basis. The classes evolved to include patients and moved from lecture-type sessions to interactive sessions that focused on various treatment issues. Topics included opportunistic infections, STIs, medication side effects and, of course, concerns about medication adherence.

The CARE Center now has a Class D clinic pharmacy in place and has taken steps to establish an expanded formulary. Having recently received AIDS Drug Assistance Program (ADAP) approval, the clinic will now be able to dispense muchneeded medications to patients free of charge.

On-Call Service

The initial project proposal included the establishment of an on-call service that patients could

access on a 24-hour basis. In January 2002, the CARE Center began providing this service, which was staffed by the nurse practitioner and clinic nurses, who rotated coverage. The availability of the service provided security to clients by offering 24-hour access to a bilingual health care provider familiar with HIV/AIDS. In part because of low utilization, the service was discontinued after funding for the program ended.

The Nutrition Component

Treatment with highly active antiretroviral therapy (HAART) often involves complicated medication–meal schedules, and common medication side effects directly affect both food intake and drug absorption. For those reasons, nutritional education and counseling at all stages of disease progression is essential to patient health.

The La Fe–SPNS logic model included the provision of consultant services from a registered dietician. In fact, the initial project proposal included a strong nutrition component in the disease management model; however, because of the scarcity of bilingual registered dieticians in the El Paso area and statewide, the clinic was forced to function without one for the first 3 years of the project. During this time, clinic nurses and the nurse practitioner filled the role of nutritionist by incorporating nutrition-based education into their consultations with patients.

In 2003, the CARE Center hired a community health education specialist, who began providing consultant services that focused on health maintenance from a nutritional perspective. Filling this position alleviated the additional burden that was being placed on clinic staff.

Mental Health Services

Preliminary findings in Year 1 of the project were instrumental in justifying the need for mental health services at the CARE Center. Thirty-four percent of patients identified mental health concerns as a reason for seeking treatment on the multisite evaluation instrument, and 30 percent reported symptoms consistent with at least moderate depression.

In 2002, the CARE Center began providing much-needed onsite diagnostic and therapeutic services through a contract with Family Services of El Paso. Services were provided by advanced clinical social work practitioners or licensed professional counselors. Consistent with initial figures, 36 percent of patients were referred for mental health services after being evaluated by a mental health professional. Although the initial logic model included the provision of part-time mental health services, initial findings confirmed the need to make those services an integral part of care.

Training

As part of the SPNS initiative, the Texas–Oklahoma AIDS Education and Training Center (AETC) provided specialized training to nurses and nurse practitioners at different sites. Nurses also attended several 2-day training sessions as part of a preceptorship program at Thomas Street Clinic in Houston. A separate preceptorship was completed by the nurse practitioner at Amelia Court Hospital in Dallas.

Through those and other onsite training sessions (many provided by the clinic's medical director), nurses on the project received more than twice the anticipated amount of continuing education and passed the examination to become AIDS-certified registered nurses (ACRN) in November 2003.

Media and Marketing

The CARE Center has cultivated important relationships with local print and broadcast media that have provided a means of raising HIV/AIDS-related awareness and of informing the public about the many services available at the clinic. In September 2003, the CARE Center established a targeted media relations system that produced a number of appearances by staff on local television stations as well as print coverage in local newspapers.

Successful media placements included coverage surrounding the National Latino AIDS Awareness Day event in October 2003. The event and issues surrounding HIV/AIDS were among the lead stories on regional newscasts for three consecutive days and were covered by the *El Paso Times*, *Diario de Juárez*, and the *Las Cruces Sun-News*.

In addition to covering other events, such as the Candlelight AIDS Vigil, National HIV Testing Day, and World AIDS Day, CARE Center staff made more than 10 appearances on local English- and Spanish-language television stations directly promoting HIV education, early testing and prevention, the OraQuick 20-Minute HIV Test, and support services for PLWHA. Staff appeared on shows including *Good Morning El Paso*, the *KTSM Morning Show*, *KINT's Despierta America*, and *Live at 5 with Felipa Solis*.

El Paso, Inc., a business, lifestyle, and news feature weekly publication, and its sister publications *What's Up!* and *Southwest Senior* all featured the CARE Center and its staff and facilities in special reports focusing on HIV/AIDS. In addition, *Gay Friendly Magazine,* a magazine directed primarily toward the gay, lesbian, bisexual, and transgender community of the border region and distributed at local businesses, featured the CARE Center's HIV Negative Card Program as a cover story and conducted a one-on-one interview with America Jones, the CARE Center's director.

Implementation Challenges

Over the course of the project, implementation of the care model faced multiple challenges. Although the general ideas behind the original model guided intervention efforts, some aspects of that model were implemented differently from how they were initially planned, either because of lessons learned or because of limitations in resources or personnel.

Staff Turnover

The most significant implementation challenge was the hiring and retention of qualified bilingual health care professionals. The issue had a considerable impact on the CARE Center's ability to implement the model as originally proposed. Although staff turnover affected all levels of service provision, it most substantially affected the nursing component of the model. Because the role of the nurse was central, turnover led to some significant alterations in the model.

The original model called for two registered nurses to serve on each of two care teams. Early growth in the caseload of the center, however, rapidly made it necessary to move to three care teams, and a shortage of bilingual nurses led to a change in team structure. The revised model made use of one nurse per team. With the new team structure, the CARE Clinic was fully staffed with three nurses by the end of the first year of implementation.

Within 8 months, however, the clinic had lost one of its nurses to a higher-paying position elsewhere. The clinic functioned with two nurses for the following 6 months, but by October 2001, only one nurse remained. For 2 months, the remaining nurse filled the role of three and provided care to patients from all three teams. Early in 2002, the clinic filled the two empty positions, and for 6 months, it again fully staffed the revised model, wherein three qualified nurses led the three teams. This period was short-lived; in September 2002, a change in CARE Center administration led to the appointment of one of the nurses as interim director. In 2003, three other nurses were hired and subsequently left, and the CARE Center had difficulty recruiting new nursing staff; the center depended more on physicians and nurse practitioners for patient care during that time. The well-publicized nationwide nursing shortage (especially acute in the U.S.–Mexico border region), challenges in maintaining salaries and benefits competitive with for-profit agencies, and aggressive recruiting practices of local hospitals and private agencies have called into question the feasibility of retaining enough qualified bilingual nurses to maintain a nurse-based care model.

Staffing challenges affected the case management component as well. During the first 2 years of the project, case management services were being provided by unlicensed staff, some of whom had virtually no training in social work. This situation posed some significant challenges to the implementation of the model because nurses were often called upon to perform social work duties. In June 2003, the CARE Center hired its first licensed social worker under the project. Several other licensed professionals were subsequently hired, and although the clinic has also seen high turnover of social workers, trained professionals had a positive impact on the project.

Growth in Client Census

Over the course of the project, the number of HIV-positive clients receiving services at the CARE Center dramatically increased. At the outset, the center served 136 patients. With regular testing and counseling services, the closing of another clinic in the community, and growth in HIV prevalence in the area, the census swelled to 500 by 2004. In many ways, resources and infrastructure that would have easily provided care for a steadily growing population had to be stretched further to cover the sudden increase in need.

Assigning Patients to Teams

The decision to assign patients to separate teams on the basis of surname had appeared reasonable on paper, but this aspect of the model led to another significant challenge. The division of patients turned out to be difficult to maintain and was unwieldy in the day-to-day provision of services. Although patients were divided among teams and informed of their team assignments and care providers, the division was never completely realized.

Although the issues with team assignments were linked to staff turnover, the process posed problems in its own right. If team members were away from the clinic for any reason, including sick leave or vacation, clients had to be assisted by whoever was available. In addition, if several patients from one team needed assistance on the same day, the care manager, social worker, and peer advocate who pertained to that team were overwhelmed with requests. Patients were required to wait to see "their" nurse or "their" social worker when members of another team might be readily available to lend assistance.

Because the lines that separated the teams were so fluid, clients often were uncertain about what team they belonged to; even when they were aware, some patients preferred to see a different provider. The situation made it difficult to preserve the separation of the teams.

Role Issues

Nurses reported that staffing shortages made it difficult for them to adhere to their defined roles. The proposed model had a strong focus on patient education and less responsibility for clinical management. Clinic demands decreased the amount of time that nurses could devote to patient education, and nurses found it difficult to separate clinical duties from other project responsibilities.

Leadership Challenges

Various changes in leadership occurred during the first 3 years of the project. After the departure of the CARE Center's chief administrator early in the project, new leadership took a different approach to the implementation of the program. In September 2002, the CARE Center again experienced a change in management when a new director was appointed. At that point, the project was again reorganized to reflect the priorities of the current administration.

Evaluation

The local evaluation team at the University of Texas at El Paso (UTEP) psychology department, was responsible for all aspects of data collection and entry. Although CARE Center staff were initially intended to be involved in data collection, issues related to staff turnover and caseload made it difficult for clinic staff to contribute to data collection

efforts. Thus, part-time, bilingual graduate and undergraduate student assistants from UTEP aided with that process.

Instrument Development

The multisite evaluation team developed all instruments to be used at the various sites. Locally, the evaluation team assembled a number of additional measures that were considered important and relevant to the patient population. The local battery of tests consisted of various self-administered questionnaires as well as some that required conducting structured interviews. A number of the instruments were previously established measures, and several were newly developed measures.

Local measures were translated into Spanish by a team of certified translators in the languages and linguistics department at UTEP. The team used the translation–back method, in which the English measure is first translated to Spanish by one person and then translated back to the original language by another person. The two versions are then compared by a committee of experts and inconsistencies are remedied. The team made every effort to ensure that the Spanish versions were accurate translations of the English that conveyed the same meaning as the originals.

Data Collection

The evaluation team was provided with numerous in–depth training sessions that covered everything from how to generate a unique record number (URN) to how to conduct a structured interview with a client. The measures were field tested to identify any problems and to rectify them as needed.

The fact that the evaluation team for the La Fe project was responsible for both data collection and data entry set it aside from other partner projects in the SPNS initiative, leading to certain strengths and challenges. Having dedicated data collection personnel permitted the clinic staff to focus on patient care responsibilities rather than evaluation activities. In addition, data collection, entry, and quality control were under unitary control, lending coordination to the process. When an inference was called for during the interview process, however, data collection personnel were at a disadvantage because they did not have a clinical history with each patient they interviewed.

Challenges

Instrument Translation

Good translation of evaluation instruments is essential to the successful outcome of a research project. Although initial measures were translated using the careful translation–back translation process described above, a measure later added to all projects in the SPNS initiative was translated using a less formal process. Some problems with unclear wording and ambiguities in the translation caused confusion among clients and left interpretation up to interviewers. This experience demonstrates the importance of strong translation services when collecting data from non-English-dominant clients.

Interviewer Drift

Over time, people involved in the process of collecting data may gradually depart from the procedures set forth in training, a process known as *interviewer drift*. Data collection efforts for the SPNS initiative demonstrated some interviewer drift, and data collected further into the project reflected more problems. For example, early in the project, interviewers were careful about following up on missing data, but incomplete data became more frequent over time. Concerns about interviewer drift were discussed during evaluation team meetings, and every effort was made at various points to address the issue and return to protocols.

Recruitment

Recruitment of patients for interviews was handled in various ways throughout the project and was generally initiated by either a nurse care manager or peer advocate who told patients about the project and referred them to the evaluation assistants who conducted the data collection interviews. This strategy was used in the hope that

patients would feel more comfortable participating in the project if approached by a staff member they had already met. Coordinating recruitment efforts was a challenge because the nurses were often kept busy with their duties in the clinic and simply were not able to devote the necessary time to patient recruitment. The demands of the clinic and providing care to an increasingly large patient caseload were understandably the first priority for nurses. Appointing an official participant recruiter for the project, perhaps someone from the evaluation team whose sole responsibility was recruitment, might have been a better strategy that could have prevented the gaps in recruitment when clinic staff members responsible for patient recruitment were on leave or unavailable.

Unique Record Numbers

The use of URNs also proved to be somewhat problematic. Although URNs did protect client confidentiality, it was very difficult to track patients longitudinally in an effective manner because of inconsistencies in generating and recording URNs. Problems arose when a patient had a change in last name, used nicknames, or had his or her name misspelled in the records. A special concern became evident in using the URN with Hispanic clients. In Mexico, people are identified by two surnames (maternal and paternal), rather than one. A system that derives unique identifiers from single last names when patients identify by two surnames is difficult to implement because there may be inconsistency in which name is used.

Organizing Data Entry

Integrating multisite and local data entry became an issue of concern because of differences in the organization of data between the multisite evaluation center and the El Paso performance site. Certain idiosyncrasies specific to the two sites made it challenging to effectively manage SPNS initiative data. Rather than entering multisite and local data separately and trying to merge multiple types of data using URNs, a better strategy may have been to enter all data at once, using a uniform

system, and transmit updates to the multisite evaluation center on a regular basis as new patients were interviewed.

Lessons Learned

The hardest lesson was simply that reality has a way of setting limits. The CARE Center made every attempt to implement the model as intended, but the model only functioned as planned for short periods of time throughout the project. Recognizing the impracticality of assigning patients to teams, the CARE Center eventually discontinued the regular assignment of patients. Instead, the clinic returned to the basic priorities of the SPNS initiative by providing quality medical and support services by advancing knowledge and reducing barriers to care. It continued to offer a multidisciplinary team approach by providing medical management, case management, and peer advocacy services from all staff to all patients at all times.

Another lesson was that staff communication is crucial in taking a multidisciplinary approach to patient care. Whether future implementation of this model offers the services of one or more teams, effective communication among members of the different disciplines is a necessity. It was evident in the present model that when communication between team members was good, it greatly facilitated the delivery of services and resulted in improved patient care. Conversely, when a given team experienced difficulty with communication among its members, the quality of service was greatly reduced. This lesson should be emphasized in future efforts to implement multidisciplinary models.

The decision to include HIV-positive peers in the care of others brings strengths and challenges. The provision of HIV services requires that the people involved be compassionate and dedicated to their profession. A strength related to involving paraprofessional patients in the provision of services comes from HIV being an integral part of their lives, rather than simply a job that they leave

CASE STUDY

The following narrative illustrates the experience of an HIV-positive person presenting for testing services at the CARE Center.

"Pedro C." was a young gay man who had just learned that he was HIV positive. His test results were delivered and explained to him by a peer advocate who sat with Pedro for more than an hour discussing what the results meant, providing comfort, and ensuring him that HIV was not a death sentence but a condition that could be managed. The shock of the results was softened by the opportunity to speak to someone who shared Pedro's experience and knew what it was like to contemplate a life with AIDS. The peer advocate gave Pedro the clinic hotline telephone number to call with any concerns or questions he might have and arranged an appointment for him to meet with a nurse care manager during his next visit.

One week later, Pedro returned for his appointment. He was met by the peer advocate and introduced to his nurse care manager. She asked about his language preference and easily transitioned to English or Spanish as required. She took an extensive medical and social history, asking Pedro numerous in-depth questions. She explained about HIV and its life cycle and discussed what "T cells" were and what the term "viral load" meant. She answered Pedro's numerous questions and cleared up some misconceptions that he had about the illness. Pedro had blood drawn for his first set of lab tests during this visit, and he was told that the tests would provide the doctor with important information about the stage of his illness. At the end of his consultation with the nurse, Pedro was introduced to the bilingual social worker and the peer advocate who belonged to his care team. He was told that they were there to assist him in any way that they could and that the team was responsible for the management of his care. His visit lasted approximately 2 hours.

Two weeks later, Pedro returned for his first appointment with the physician. By this time, he had a basic understanding of what HIV infection was and how it progressed. The doctor reviewed the lab results and recommended initiating treatment with antiretroviral medication. The physician referred Pedro to the consulting pharmacist, who discussed the side effects that were sometimes associated with the medications and stressed the importance of taking the pills as prescribed. Although Pedro understood the need for medication and agreed to begin treatment, he was hesitant about having to take so many pills and fearful of experiencing side effects at work, where his coworkers might become aware of his illness. Pedro worked at a telephone call center in a public environment, but he was very private about issues related to his sexuality and to being HIV positive. Not even his family was aware of his serostatus.

(Continued)

CASE STUDY (CONT'D)

Pedro began his treatment regimen as his doctor advised but quickly began experiencing side effects, including feeling nauseous during work hours. Because saving face at work was important to him, he stopped taking his medication as indicated by his doctor. The only person he felt he could talk to about this issue was the peer advocate on his care team. Although the physician, nurse, or pharmacist could have advised him about how to manage medication side effects, he felt only a peer could relate to his fear of being stigmatized.

The issues that Pedro was facing were brought up during a care team meeting, and the staff decided to refer him for mental health services with a licensed professional counselor. The counselor diagnosed Pedro with major depression and worked with his physician to ensure that he was started on an appropriate antidepressant medication. She also saw him in short-term psychotherapy to help him work through his fears of disclosure and stigma.

Because of the complexity of his medication regimen and his difficulty with adherence, Pedro was referred for continued medication counseling with the clinic pharmacist. He completed a questionnaire that revealed the types of difficulty he was having with his medication regimen. Specific goals were set for improving medication adherence, and follow-up visits with the pharmacist were scheduled until his goals were met.

The combined efforts of the doctor, nurse, peer advocate, social worker, and pharmacist led to the stabilization of Pedro's disease markers and to an improvement in his quality of life. His medical team helped him learn how to treat his illness, and his case management team, including the mental health therapist, helped him learn how to live with HIV. The fact that the services were centralized and available at one site made it much easier for Pedro to receive the care he needed.

behind when their shift is over. They live with HIV/AIDS every day, and this level of exposure gives them insights into the illness that other providers may lack.

Although the inclusion of peers was one of the most successful aspects of the model, the lesson was that it can be difficult to delineate the areas of care in which they should be directly involved and how much input they should have in the decision-making process. The teams sometimes struggled with finding the right balance.

Last, it was clear that the nature of project leadership was directly related to the advancement of the model. It appears to be an advantage for administrators to have some experience in direct clinical management of HIV/AIDS. An understanding of the demands of patient care from a clinical perspective can be useful for an administrator.

Despite those challenges, the consensus among everyone involved in the implementation of the model is that the concept for the model was a strong one, and that the quality of care provided to patients under the model was greatly improved. Because of the model's strengths, more patients were reached, more problems were resolved, and better services were provided than before the approach was used. Those benefits were especially pronounced when staffing was adequate and client census was manageable.

The most successful aspects of the model revolved around its multidisciplinary approach to patient care. Combining medical and social case management services with peer advocacy under a team approach proved to be an effective means of closing the existing gaps in patient care. Hundreds of PLWHA in the El Paso–Cuidad Juárez area greatly benefited from the centralized, quality care that the CARE Center provided under this project.

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CHAPTER 6

Proyecto Juntos Care Model: The Valley AIDS Council SPNS Project

The U.S. Mexican border es una herida *(is an injury) where the Third World grates against the first and bleeds. And before a scab forms it hemorrhages again, the lifeblood of two worlds merging to form a third country—a border country.*

(Anzaldua, 1999, p. 25)

This chapter presents the "Proyecto Juntos" care model that guided the project activities of the Valley AIDS Council (VAC) during the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) Special Projects of National Significance (SPNS) U.S.–Mexico Border Health Initiative from 2000 to 2005. The English translation for the Spanish title *Proyecto Juntos* is "joint project" or "together project." It is a metaphor for the primary goal of the model: to form partnerships with AIDS service organizations and health care providers in an expanded service area. VAC envisioned that community health partnerships would lead to increased health care access for people living with HIV/AIDS (PLWHA) in 12 South Texas counties. This chapter describes the population demographics of the expanded service area and provides a brief history of VAC leading to the SPNS initiative. The model components, the process of implementation, and the results are described in the context of the project's three goals.

The Texas border extends for 1,254 miles on a path from El Paso–Ciudad Juarez to Brownsville–Matamoros. Border residents fare poorly compared with non-border Texas residents. State health and income statistics indicate border residents have a significantly higher rate of poverty, HIV infection, and disease (AIDS

Education Training Centers National Resource Center [AETC/NRC], 2006). Struggles of daily survival consume people's energy, and preventative health measures are viewed as an unaffordable luxury. Eighty-six percent of the South Texas border population is of Hispanic, primarily Mexican, origin, and more than half lack health insurance (Texas Department of State Health Services, 2003). The 32 counties that make up the Texas Border County Area (BCA) are federally recognized for funding allocations and programs because of the area's impoverished population.

In individual border counties, the proportion of the population that is Hispanic ranges from 55 percent to 85 percent, compared with 28 percent in the 222 nonborder Texas counties (Texas Department of State Health Services, 2003). Health care and social service organizations face considerable challenges in meeting basic care needs for this large population. Caring for the chronic needs of PLWHA further stresses this already resource-constrained environment.

Agency History

In 1987, county health administrators from Cameron and Hidalgo counties and two leaders representing Planned Parenthood agencies in both counties met with representatives from the Texas Department of Health in response to the reported growing incidence of HIV/AIDS on both coasts of the United States. They assumed that the disease would eventually reach the Rio Grande Valley in South Texas. Those visionary community leaders sought to alert the health care community leaders to educate personnel and secure funding for an expected onslaught of HIV/AIDS patients.

That meeting led to the founding of VAC, a nonprofit organization. Early in 1988, VAC secured one HIV/AIDS community health educator position funded by the Texas Department of Health. A grant from the Texas Tech University Health Science Center the following year (1989) funded a

research position to conduct an epidemiologic study. Partly as a result of that study, in 1993 VAC was awarded one of two national grants under Part C of the Ryan White HIV/AIDS Program. By 1990, the agency had grown to a staff of six: an executive director; an education and outreach director; two education and outreach staff; an office manager; and one case manager, with a caseload of 11 clients living with HIV/AIDS.

The Federal grant enabled the agency to hire a physician to manage an HIV/AIDS specialty clinic in Harlingen, Texas (Cameron County) to care for the increasing number of PLWHA identified by the VAC outreach staff and local health care agencies. Having a full-time physician with HIV/AIDS support staff reduced the waiting period for PLWHA seeking medical care from 2 months to less than 2 weeks.

The early VAC service goal was to provide a seamless continuum of care with support services through a "one-stop" delivery system at the Harlingen clinic. In 1994, outreach education and case management services were initiated in satellite offices in Brownsville (Cameron County) and in McAllen (Hidalgo County) in 1995. From 2000 to 2005, VAC was one of five organizations awarded funds under the SPNS U.S.–Mexico Border Health Initiative. During this period, the agency's service area expanded to include nine additional South Texas counties, including four in the Del Rio area. The agency's service counties are part of the 32 federally designated border special needs counties.

The 12 service area counties were Cameron, Dimmit, Edwards, Jim Hogg, Hidalgo, Kinney, Maverick, Starr, Val Verde, Webb, Willacy, and Zapata. A once-weekly medical clinic serving PLWHA was opened at the Brownsville site in 2001. The VAC continues to be the main provider of medical care, case management, and other support services for PLWHA in the 12-county VAC service area.

VAC MISSION STATEMENT

The Valley AIDS Council by utilizing a multi-facility system will continue to provide and expand capacity of HIV services in South Texas. These services will be provided to individuals infected with or affected by HIV/AIDS and related co-morbidities. Valley AIDS Council will accomplish this by providing medical care, medical training, research, social services, education, prevention and outreach. Valley AIDS Council is committed to achieving this by employing and empowering professionally competent staff who desire success for the clients, the agency and themselves.

November 24, 2003

VAC is also a Local Performance Site (LPS) for the Texas–Oklahoma AIDS Education Training Center (TOAETC). The South Texas Rio Grande Valley, which is part of the VAC service area, has the highest concentration of Hispanics in the State (86 percent; AETC/NRC, 2006). The VAC staff reflect the Hispanic population in the border region: Most staff members are fluent Spanish–English speakers and bicultural. The agency administration is committed to having staff acquire knowledge of cultural norms that may influence prevention efforts or client acceptance of HIV/AIDS primary health care.

The Proyecto Juntos SPNS model involved creation of a health care network linking AIDS service organizations with community health centers (CHCs) in the target areas. During the SPNS project, VAC created partnerships with three CHCs and three area hospitals: a general hospital in Harlingen, a private hospital in Brownsville, and a hospital in Eagle Pass.

In March 2003, VAC responded to a request by the HRSA regional office to start an HIV/AIDS clinic in Corpus Christi (Nueces County) to serve the Coastal Bend Health Service Delivery Area. The new HIV/AIDS clinic replicates the Harlingen medical care treatment model.

Since its founding, VAC has earned a reputation as a local, national, and international leader for its successful HIV/AIDS education and medical care programs, which include an array of support services. VAC support services include pharmacy medications, oral health care, case management, transportation, a food pantry, housing, pastoral care, and substance abuse counseling and prevention education.

Target Population and HIV/AIDS

In 2003, a total of 233 cases of HIV (not AIDS) were reported for the 32 counties in the border region, an increase of 16 percent over the 187 cases reported in 2002 (Texas Department of State Health Services, 2003). The 32 border counties reported 220 AIDS cases in 2003, a rate of 11.9 cases per 100,000 population (Texas Department of State Health Services, 2003). AIDS cases in border counties located contiguous to the Mexican border were 6 percent of the total number of cases for the State in 2003 (AETC/NRC, 2006, p. 4).

The goals of Proyecto Juntos were (1) to increase access to HIV/AIDS primary health care for PLWHA along the South Texas–Mexico border; (2) to increase the capacity of primary health care systems to meet the health care needs of poor, underserved PLWHA along the border; and (3) to

create a health care network linking AIDS service organizations with CHCs in the target area. In 2001, VAC, historically the sole provider of indigent HIV/AIDS care in the target region, partnered with Brownsville CHC, Pharr/McAllen's Nuestra Clinica del Valle (Our Lady of the Valley), and the United Medical Center in Eagle Pass to provide HIV/AIDS medical care. The VAC partnership included an agreement between VAC and the medical centers that together (juntos), they would care for PLWHA during the interim period while physicians and nurses at the medical centers were learning about HIV/AIDS and developing their knowledge and skills for treating patients with HIV/AIDS.

A key component of the VAC Proyecto Juntos model included making available to institutional partners (i.e., CHCs) the expertise of a rotating HIV/AIDS primary health care team, which consisted of a nurse, a physician, and a case manager. The team made quarterly visits to health care centers to provide didactic instruction about HIV and mentored physicians, nurses, and case managers who wanted to learn about HIV/AIDS.

Sinclair & Cantu (2006) referred to the physician training component as "continuous mentored patient care" (p. 77), whereby the attending physician at the CHC is supported by a more experienced physician located at an institution hundreds of miles away. During quarterly visits, the Proyecto Junto HIV-specialist physician sees the patient jointly with the attending CHC physician. The team of physicians and nurses providing mentoring were continuously available for consultation between quarterly site visits by telephone or e-mail.

The physician-mentoring program was a collaboration among VAC, the three CHCs, and the TOAETC. In Year 3, the primary mentoring role for South Texas CHC physicians was turned over to the VAC physician with backup from the senior TOAETC physician. The VAC physician had been a trainee during the first 2 years of the mentoring program (Sinclair & Cantu, 2006, p. 77).

Patients were given a choice of receiving care at their local area CHC or at the VAC clinic. Some patients said that the VAC was known throughout the lower Rio Grande Valley as "the best place to go for HIV" (Sinclair & Cantu, 2006, p. 82). Some patients opted to be seen outside their CHC communities because of privacy concerns. Staff of each health care center coordinated health care referrals across partner agencies so that patients could access other medical personnel or VAC case managers.

Media and Marketing

In addition to direct patient care services, VAC engaged in a media campaign to educate at-risk Hispanic women of limited English proficiency, between ages 13 and 45, about HIV. The goal was to educate them about risk behaviors and signs of HIV disease to motivate them to seek HIV counseling and testing.

The campaign was conducted over 6 months using advertisements on local Spanish-language television and radio stations. The television ads aired mornings and afternoons during *telenovelas* (Mexican soap operas). Well-known local media personalities were featured in the HIV information ads. In addition to the electronic media, Spanish and English brochures and posters were produced and distributed in neighborhood churches, grocery stores, laundromats, and beauty salons.

The Spanish-language television ads generated more than 400 calls from people seeking HIV information that led to HIV testing and counseling. Testing identified 15 at-risk women, 10 of whom tested positive for HIV. Most women with a positive test had no knowledge they were at risk.

Evaluation and Dissemination

The evaluation component was conducted by a research team from the University of Texas Health Science Center at San Antonio (UTHSC) Department of Pediatrics. The Centers for Disease Control and Prevention's (CDC's) *Framework for*

Evaluating Public Health Programs (CDC, 1999) was used to guide the work of planning outcomes and evaluation. Community AIDS organization lead-ers were involved in conceptualization, planning, and implementation of the care model. During the SPNS application phase, the evaluation team used epidemiologic data to help local community leaders become knowledgeable about the preva-lence of HIV in their respective communities. Both quantitative and qualitative measures were used in the process of conducting local site stud-ies and to evaluate outcomes at the end of the project (see Figure 6.1). As a partner in the SPNS initiative, VAC staff collected both qualitative and quantitative data to evaluate collective SPNS outcomes.

VAC SPNS Border Project Logic Model

VAC's Proyecto Juntos used the United Way of America's (1996) logic model to create a graphic blueprint that identified key project elements and how they would (ideally) work under certain con-ditions to resolve problems. VAC staff found this approach useful in planning desired outcomes for the service model. As indicated in Chapter 1, the logic model was introduced in the initial collective SPNS meeting. The UTHSC evaluation team worked closely with the VAC staff to identify serv-ice components and outcome measures appropriate for evaluating planned outcomes. As shown in Figure 6.1, the outcomes were identified in three stages: immediate, intermediate, and long-term.

FIGURE 6.1. Proyecto Juntos logic model.

Inputs	Activities	Outputs	System and Client-Level Outcomes*		
			Initial	Intermediate	Long-Term
AIDS Education and Training Center (AETC), HIV system specialists	Training and educating providers	Number of providers trained (physicians and nurse care coordinators)	Increased provider understanding of HIV care	Increased primary care system capacity to provide "quality" HIV care (i.e., standard of care)	System with sufficient capacity to provide HIV primary care
Trained health care providers (physicians and nurse care coordinators)	HIV health care and patient education	HIV primary health care encounters (~48 new patients yearly)	Connection to local skilled HIV primary health care	Reduced barriers to HIV care (i.e., transportation, geography)	Maintained or improved quality of life (i.e., health and well-being of clients)
Case managers	Population education about location of new HIV primary care sites by case manager, care coordinator, and outreach staff	Number of PLWHA entering HIV primary care for the first time	Clients will under-stand the continuum of HIV health and social services available to them	Increased use of local HIV primary health care and case management services by informed PLWHA	Maintained or improved quality of life (i.e., health and well-being of clients)

*For clients to experience the outcomes of reduced barriers and improved quality of life and well-being (Row 2), they must have access to a service system in which providers are knowledgeable and willing to provide the best possible care (Row 1). Therefore, client-level out-comes are highly dependent on the service system and level of expertise of providers. Inputs are defined as different staff roles. Activities are tasks involving identification and care of PLWHA. Outputs are the projected number of PLWHA served during the program.

TABLE 6.1. SPNS Participants and Refusals, 2001–2004

	2001	2002	2003	2004	Total
Intakes	131	113	117	81	442
Refusals	19	29	24	34	106
% Refusals	14.50	25.66	20.51	41.97	23.98

Findings

Again, the Proyecto Juntos goals were to (1) increase access to HIV/AIDS primary health care for PLWHA along the South Texas–Mexico border; (2) increase the capacity of primary health care systems to meet the health care needs of poor, underserved PLWHA along the border; and (3) create a health care network linking AIDS service organizations with community primary care health centers in the target area.

Table 6.1 presents outcomes related to the outcome goal of increasing access to care, as reflected in the number of participants in Proyecto Juntos over a 4-year period. A total of 442 patients participated in the project (see Table 6.1). For various reasons, primarily time demands, 106 project candidates (24 percent, categorized as "refusals") over the 4-year period declined enrollment. The SPNS participants represent a fraction of the more than 700 patients served by the VAC and its partner clinic sites.

The increased patient caseloads over time reported by Cantu, Sinclair, and Duggan (2004) in the four service locations indicate that the goal of increasing service capacity for HIV/AIDS patients was achieved. The Harlingen site had 514 patients; Pharr/McAllen, 26; Brownsville, 66; and Eagle Pass, 20. The total exceeds 1,000 if the Coastal Bend area is included.

The second goal, to increase capacity of primary care facilities in the service area, was achieved through the training for physicians and allied health care personnel. This unique component contributed to the increased capacity of the CHCs. As indicated earlier, the training began with didactic instruction the first year and was continued in subsequent years with quarterly onsite mentoring visits and on-call consultations, which totaled 75 during Years 1 through 3 and 23 additional consultations between 2003 and 2004. A total of five physicians were trained during the 4 years.

The HIV specialty onsite physician training program was successful because it addressed time constraints of physicians with heavy patient loads and provided onsite the needed HIV/AIDS knowledge and skills to care for PLWHA. Providing ongoing HIV/AIDS education in remote areas with high health care personnel turnover remains a challenge (Cantu, Sinclair, & Duggan, 2004).

The third goal, to create a health care network linking AIDS service organizations with CHCs in the target area, was met through the agency's development of partnerships with those CHCs during the SPNS project. The social marketing campaign targeted to Spanish-speaking women produced more than 400 HIV phone inquiries. A total of 78 callers accepted an HIV test, which resulted in 15 at-risk women being referred for counseling and 10 additional women testing HIV positive.

Summary and Conclusion

In summary, the success of the VAC may be measured by its client caseload, which started with 11 PLWHA in 1989 and grew to almost 1,000 patients in 2005 (713 in the Brownsville Health Services Delivery Area [HSDA] and 225 in the Corpus Christi Coastal Bend HSDA). The VAC was able to extend care for HIV/AIDS patients by forming partnerships with regional CHCs and hospitals in the 12-county service area. The agency's international visibility came about because of its leadership as the primary organizer of an annual U.S.–Mexico Border Health Summit on HIV/AIDS held in South Padre Island, Texas. In October 2007 the agency will hold its 15th annual conference.

The VAC achieved the SPNS project goals. The agency can be said to have become a victim of its own success. The expanded service area increased expectations and resulted in a higher patient load. When clients were given a choice of seeing an internal medicine physician in a CHC instead of an HIV/AIDS specialist in a clinic known for its primary care for PLWHA, most patients opted to receive care at VAC. All SPNS patients treated at CHCs eventually became VAC patients.

The patients' preference for a specialist physician at VAC instead of a nonspecialist physician at a CHC seems clear. Other factors that might have contributed to patients' choice of the VAC clinic are the stigma associated with HIV/AIDS and the shame associated with the route of exposure. The therapeutic group outcome of being among others who share a common life experience tends to normalize participants' personal feelings about the disease and may explain the attraction of PLWHA to being among patients who are living with the same disease. Moreno (1994), describing his work with groups of patients with eating disorders, wrote, "With rare exceptions, patients express great relief at discovering that they are not alone, that others share the same dilemmas and life experiences" (p. 417). Of course, many patients are concerned about confidentiality and may have chosen VAC because of the fear of running into someone they know at their neighborhood CHC.

CHC administrators learned that HIV/AIDS patients have multiple medical needs and require more physician treatment time. The budget constraints became a disincentive for increasing the number of HIV/AIDS patients seen at CHCs. The Ryan White HIV/AIDS Treatment Modernization Act of 2006, which funds HIV/AIDS care, and the Bureau of Primary Health Care, which funds CHCs, use different formulas for patient care reimbursement; for the CHCs, billing requirements that added to administration costs became an additional disincentive to treating PLWHA.

Results from the project continue to be disseminated via local, regional, national, and international forums as well as in scholarly publications. The VAC Web site (www.valleyaids.org/spns) remains a source for further information and lists achievements by subject, date, and author. The Web site describes the VAC mission and lists current HIV/AIDS projects, services, and staff.

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