

# Creating a Service Continuum

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These lessons are drawn from the first four years of this initiative's five-year grant cycle and represent experiences during the implementation and refinement phases of the project. Information from the outcome phase of the project will be available in Fall 2001.

## Introduction

AIDS is a complex condition characterized by multiple needs. It is now generally recognized by medical and social service providers that because of the multifaceted nature of HIV illness, circumscribed medical models are seldom effective in providing standards of care to persons who are HIV positive or have AIDS. In traditional systems of care there is often little connection between medical and social services. Clinical specialties operate relatively independently of each other, and patients are expected to follow precisely defined protocols in both their approach to and compliance with care.

Persons living with HIV/AIDS often confront intrapersonal and environmental challenges that make it difficult for them to seek care within traditional systems. These challenges range from keeping medical appointments to managing the emotional stress associated with chronic and terminal conditions, to adhering to the complex protocols governing the use of advanced retrovirals and combination therapies.

The Arkansas HIV Care and Support Network project was designed to implement and evaluate two models of blended care in which enhanced case management, psychosocial services, and skills building and enrichment activities support individuals with HIV/AIDS throughout the continuum of medical and social services. The progress of clients served in these two models is compared with the progress of clients seen at a more traditional ambulatory health care delivery site.

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## Introduction

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## Location

Jefferson Comprehensive Care Systems, Inc. (JCCSI) provides services to persons with HIV/AIDS living in southeastern Arkansas. This predominantly rural area consists of eight counties that include among other areas of the state, the impoverished Arkansas Delta region. Only two of the eight counties contain urban centers. The remaining six counties have been designated as medically underserved areas (MUA) by the U.S. Health Resources and Services Administration (HRSA). The region may be generally characterized as one of severe economic and social distress, with low education levels, high rates of teen pregnancy and a large number of single parent families.

As in most regions of the U.S., Arkansas minority populations living in poverty are disproportionately infected and affected by HIV/AIDS. While African Americans comprise 16 percent of the state's population, as of 1997 they accounted for 45 percent of all HIV cases and 41 percent of all AIDS cases (Arkansas Department of Health). The remaining infections occur among the state's white, Latino, Asian American and Native American populations. In 1992 in the JCCSI service area, African Americans comprised 34 percent of the population and 67 percent of the reported HIV cases. In 1995, 70 percent of newly reported HIV cases occurred among African Americans. This epidemiological profile is reflected in the clients served by JCCSI, 71 percent of whom are African American and 29 percent white.

## Services

The Arkansas HIV Care and Support Network project operates from two sites in the agency's catchment area, the cities of Pine Bluff (Jefferson County) and Little Rock (Pulaski County). These cities are approximately 50 miles apart. This project operates three models of care across the two sites – a traditional ambulatory health care delivery model, located in Pine Bluff and two enhanced delivery models, located in Little Rock.

### *Traditional ambulatory care models*

The traditional ambulatory health care delivery site at the JCCSI's Pine Bluff offices is a clinic-based program providing a comprehensive range of primary health care services, including laboratory monitoring, case management, HIV counseling and testing, medication assistance, nutritional counseling, dental care, health education, gynecological services, family medicine and referrals to mental health and substance abuse services.

## Client profile

74%	Male
74.5%	African American
36	Average age
6%	Married, live with spouse
18%	Employed

Based on data from 71 clients at both sites collected between May 1998 and June 1999.

### *Enhanced delivery models*

The enhanced models implemented in Little Rock are blended care systems characterized by one-stop shopping and aggressive client case management. Both models include a full compliment of medical and supportive services. A series of skills building activities offered to the one group distinguishes it from the other.

Services are provided on the University of Arkansas Medical School (UAMS) campus and at the HIV Care and Support Network program's administrative office. These locations are within walking distance of each other. Clients receive medical care and some level of health education on medication adherence at UAMS. At the program offices, clients meet with an outreach case manager. When they first enroll in the program, all clients receive a psychiatric assessment.

Clients enrolled in the enhanced model group with skills building activities have access to a well-equipped gymnasium; monthly social gatherings, support group meetings and lectures on relevant topics; computer training; and quarterly field trips. These elements are offered with the intention of increasing clients' knowledge and self-esteem, and reducing the loneliness that often accompanies advancing AIDS. In addition to the initial psychiatric assessment, all clients in this group receive continuing mental health follow-up every three to six months.

### *Evaluation*

The comparison between the blended and the traditional health care delivery models is designed to assess the impact of systems level intervention on clinical and psychosocial outcomes of HIV-positive clients. The comparison between the two models at the blended model is designed to assess the impact of clinic level interventions. At the time of publication, data collection at all three sites continues. Outcomes findings from the comparisons will be available once the data collection is complete and the data are analyzed. While preliminary trends are reported below, the following lessons are drawn from experiences during the implementation and refinement phases of the project.

### **Ensuring Client Participation**

Work with the clients in the program has been characterized by a number of difficulties. These include both environmental problems, such as a lack of resources, and individual characteristics, such as a lack of motivation or persistent depression. If unchecked, these problems inevitably result in clients not adhering to treatment protocols and ultimately dropping out of care altogether. To respond effectively to these difficulties and minimize the drop-out rate, program staff have developed a number of strategies: they use intimate knowledge of their clients' lives to increase rapport; they work together to monitor and share information on client activities in the many components of the program, and they provide a range of incentives to increase participation in activities.

In order to build effective rapport and trust, program staff must meet clients in the context of their crisis.

To ensure adherence, the project had to address ancillary needs because within the last 6 months 59% reported emotional or psychological problems; of those, 90% had trouble getting help; 60% needed help with housing problems; and 73% needed assistance with

**Lesson #1: Knowing the clients helps build effective strategies.**

In order to build effective rapport and trust, program staff must meet clients in the context of their crisis. That is, staff must understand what HIV/AIDS means to the clients and how their HIV infection and illnesses relate to their lives overall. This enables staff to identify client specific needs and to assist each client access services in a way that is effective for him or her.

*Managing competing responsibilities*

Program staff have learned that a primary component of effective case management is acknowledging that clients have other responsibilities. Staff help clients manage both their HIV/AIDS related responsibilities, such as making appointments and adhering to treatment protocols, in a way that does not create conflict with other activities, like caring for children.

*Need for ancillary services*

Complementing the efforts to help clients manage their various responsibilities, is the project’s increasing awareness

of the needs clients have for services beyond the traditional HIV/AIDS clinical services. The project evaluation data shows that the majority of the clients experience mental health problems. In response to a survey of needs, 59 percent of the clients who responded reported emotional or psychological problems in the last six months, 90 percent of those experienced difficulties getting help for these problems. Other substantial problem areas are housing and transportation where 60 percent of clients surveyed needed assistance with housing problems in the last six months and 73 percent needed assistance with transportation in the same period. All three of these areas of need, mental health, housing and transportation, have a direct impact on the ability to access and maintain care.

*Clients cycle in and out of services*

Familiarity with the contexts within which clients experience their HIV infection has also increased the project staff’s acceptance of the fact that the patient population is very mobile and that clients are likely to cycle in and out of the program or to leave permanently at some point. Incarceration is a common reason for dropping out of the program for a period; more than a quarter of the clients (27 percent) have been incarcerated at some point in their lives. Because of economic, legal and family reasons, individuals in this population are also likely to relocate and to drop out of care. In order to determine the most effective intervention, it is important that staff have the skill and background knowledge to determine why a client is not active in the program.

**Lesson #2: Sharing information and working together increases adherence.**

Having thorough documentation is an essential element in delivering an effective program and demonstrating outcomes. By recording program activity, staff are able to

share client progress and difficulties with the service team. Consequently, the staff can work together to resolve difficulties,

#### *Tracking system*

JCCSI has developed a detailed tracking system that allows a case manager to interact with clients regarding all aspects of the continuum of care. The primary component of this system is a master list containing each client's contact information, information on his or her provider and a list of medications she or he is taking. The staff also obtains progress reports and clinic visit charts on each appointment to monitor the status of clients. By accessing the reports staff members can be informed of any health concerns or improvements, and possible recommendations.

#### *Communicating with clients*

The tracking system includes protocols for communicating with clients. Each client is contacted by phone once a week and monthly home visits are made when possible. The case manager and outreach counselor remind clients of clinic visits, dental appointments, therapy sessions, etc. If needed, staff members also provide transportation to and from all appointments. Providers notify the program when clients do not show for appointments. The case manager and outreach counselor immediately attempt to contact the patient, obtain information regarding the missed appointment, and reschedule for the next available appointment date.

#### *Increased adherence*

This proactive approach is the foundation to an increased partnership among program staff and between staff and clients. The morale of the program staff increased as a result and it has become easier to intervene with clients who experience difficulty adhering to treatment. In conjunction with close follow-up, home visitations and regular phone calls, the recreational activities in which some of the clients participate have improved their physical, mental and social outlook. Preliminary evaluation findings indicate that this may, in turn, increase adherence. Between baseline and follow-up data collection periods, adherence increased for clients enrolled in both of the Little Rock based enhanced service delivery models. The greatest percentage increase occurred in the clients who also participated in the skills building activities—their adherence rates rose from 67 percent at baseline to 94 percent at follow-up. Adherence in the other group rose from 56 percent at baseline to 67 percent at follow-up. Between baseline and follow-up the average CD4 count increased and the average viral load decreased for clients in both of these groups.

### **Lesson #3: Incentives increase participation in data collection.**

The evaluation of these intervention models is necessary in order to demonstrate their relative strengths and weaknesses. When enrolling in services, clients are asked to also participate in the evaluation study. It has been difficult to persuade eligible clients to participate given the mistrust of research and the length of time required to respond to the evaluation surveys.

Staff have tried a number of strategies to increase participation. The most effective has been the use of incentives. Clients are given \$5 Burger King or Wendy coupons for each segment of the data book they complete. Once a full dataset is complete, they are

given \$20 Kroger or Walmart gift cards. Working to increase client participation and involvement in program planning, especially the social and skills building activities, has also helped build trust and a deeper investment on the part of clients in their own well-being and the health of the project.

### **Implementing a Demonstration Project**

From its inception, The HIV Care and Support Network project has experienced a number of unanticipated barriers to implementing and refining the program. These difficulties have occurred at systems and administrative levels and must be distinguished from the client-level barriers detailed above, although they have affected the project's ability to work with clients. Among the areas in which the project experienced difficulties are changes in collaborative partners, the design and implementation of the evaluation design and access to clinic facilities. From these experiences lessons may be drawn concerning effective early planning, the development of collaborative partnerships and the need for systems to deal with unexpected events.

#### **Lesson #4: Allow adequate implementation time.**

*It takes six months for the basics*

It takes a great deal of time and effort to implement a new program. Anticipate a minimum of six months to put the basic elements in place and at least a year before all program components will be established. During the second year, basic problems can be resolved so that by the third year, the program will be running at the level anticipated in the proposal, although continued refinements will be required.

*Set realistic goals and objectives*

A complex intervention model will need to be built over time. By not taking the time to secure each component of the project, it is inevitable that the program will run into difficulties at some point in time. Obtaining IRB approval was one of the most difficult tasks for this program. Given that in a demonstration project services and evaluation are inextricably linked, the IRB difficulties severely curtailed the implementation of other program components. Having guidance from individuals with experience in these kinds of activities can smooth a difficult path.

*Identify key staff early and minimize turn over*

Staffing proved to be one of the most troublesome areas for this project. Hiring and recruiting key staff is time consuming. In order to reduce delays during the initial stage of implementation, identify all staff in the grant application. Some staff turnover is inevitable. One of the surest ways to minimize it is to provide a good working environment and compensation appropriate to the abilities and qualifications of staff.

#### **Lesson #5: Developing and sustaining strong collaborative relationships is essential.**

Attaining formal support for the program from the administrators of collaborating agencies and institutions is very important. The support of personnel at UAMS, the primary collaborating institution, has been critical to the survival of the project.

*Meet regularly*

Program staff laid a strong foundation for the collaborative work from the beginning of

the initiative by meeting with key directors from the Division of Infectious Diseases and hospital administrators. In these initial meetings the program was discussed in detail, transforming it from its proposed form into a plan that reflected the interests and approaches of both parties. The discussion covered program logistics, program goals, target population, evaluation designs and methods, eligibility, benefits, and anticipated outcomes. In monthly meetings, representatives from both agencies meet to address the day-to-day issues required to maintain the partnership and to ensure that the program follows appropriate procedures.

### **Lesson #6: Have a backup plan.**

Within the first 12 months of implementation, this project experienced two devastating blows. A tornado destroyed the building housing the enhanced treatment site; and the principal investigator (PI), who was also an infectious disease physician, was removed from the project. Both events delayed the project implementation, illustrating the need for contingency plans to address unexpected problems with critical program components.

Following the tornado, the program staff was faced with the task of identifying an alternate location in which to provide services. That took close to four months. Settling into this new space required additional time.

The loss of the principle investigator contributed greatly to the delay in receiving IRB approval. In addition to the time taken to identify a new PI, key components of the program were changed which required a revisions to the evaluation plan. Consequently, a new research protocol had to be reviewed by the IRB. While neither the tornado nor the change in PI could have been anticipated, having other components of the project in place ensured that progress could be made.

## **JCCSI Project Chronology**

### **October 1996**

- Jefferson Comprehensive Care System, Inc. (JCCSI) becomes the recipient of a Special Projects of National Significance (SPNS) Program grant.
- Model designed to implement an innovative blended system in partnership with the Arkansas Department of Health (ADH).

### **March 1997**

- Tornado destroys clinic where enhanced service delivery models are to be implemented. The most pressing goal is to restore access to services for existing patients.
- Identify temporary space at the ADH's Central STD Clinic in Pulaski County.

### **May 1997**

- Hire program coordinator.

### **June 1997**

- Principal investigator identifies alternative space to place staff.

- Options are either obtain space in an existing community center or use temporary module units until the clinic facility can be rebuilt.

### **July 1997**

- Decision made to obtain space at existing location, East End Community Center, with administrative office space held in an office building nearby.
- Program coordinator hires activity director and outreach counselor.

### **November 1997**

- Institutional Review Board (IRB) approves research protocol.

### **December 1997**

- Principal investigator (PI) removed from project resulting in loss of psychiatrist and program evaluator.
- Agency searches for a new PI, evaluator, psychiatrist for the project.
- Seek additional partnerships with Baptist Hospital and University of Arkansas Medical School (UAMS).

### **January 1998**

- Find administrative office space.
- Meet with key UAMS officials who verbally commit to collaborating with JCCSI.
- Due to the PI removal, JCCSI must submit a new protocol to the IRB.
- Prepare questionnaires for data collection.

### **March 1998**

- IRB notifies JCCSI to obtain single project assurances (SPA) for off site institutions.
- Contract signed by UAMS.
- Pilot test questionnaires.

### **May 1998**

- Co-investigator at UAMS writes a letter seeking permission to start study in Little Rock. IRB grants partial approval to begin the research study at the experimental site only.
- Receive single protection assurances and submit them to off site locations for signatures.

### **June 1998**

- Receive signed SPAs from off-site location and submit them to the IRB for signatures after which they are sent to the Office of Protection for Research Risk (OPRR).

### **July 1998**

- Obtain SPA approval from the OPRR with stipulations to obtain a certificate of confidentiality.

- Receive letter from IRB restricting initiation to begin study in Pine Bluff (the control site) until certificate of confidentiality is approved.
- Social worker resigns.
- Activity director resigns.
- Post vacancies and interview candidates.
- Hire activity director and case manager.

### **August 1998**

- Outreach counselor resigns.
- Post vacancy and hire outreach counselor.
- Halt enrollment for one month due to new staff orientation and program revisions.
- Revise data collection and attrition protocols.

### **September 1998**

- Restart the client enrollment process; begin home visits and skills building activities.
- IRB informs JCCSI to stop study at the experimental site until receipt of the certificate of confidentiality is granted.

### **October 1998**

- Receive certificate of confidentiality and full implementation rights to begin study.

### **November 1998**

- Re-enrollment begins in Little Rock and Pine Bluff.

## **Further Information and Technical Assistance**

If you are interested in obtaining further information about the Arkansas HIV Care and Support Network project and the service delivery model, please contact the project director:

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