

An Integrated Service Delivery System for Rural People Living with HIV/AIDS

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This article highlights some of the lessons learned from the North Carolina SPNS Integration Project (NC SIP). It is based on a four-year intervention.

Introduction

Current systems for providing health and social services are fragmented for individuals with HIV living in rural areas. No adequate model of care has yet been developed for these rural areas where the spread of AIDS is occurring at the fastest rate. NC SIP is forming an integrated delivery system (IDS) across 54 counties of eastern North Carolina to improve the coordination of comprehensive medical and social services for underserved rural persons with HIV/AIDS.

The Integrated Delivery System

Model of care

The combination of components that compose the Integrated Delivery System are what truly make NC SIP unique in its intervention. These components include: formal and informal communication among HIV providers (e.g. meetings, trainings, telephone calls, newsletters, web site); agency coordinators continuously facilitating the working relationships and communication of HIV providers; a computer network to assist HIV providers in tracking all health and social services; and clinical and ambulatory care mapping. More about the specifics of each component will be discussed later in this document.

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Services

The intervention does not provide direct client services. Medical and social services are funded through other sources. Through multiple strategies, such as a computer network and agency coordinators (these will be outlined later) NC SIP focuses on developing an integrated delivery system to enhance provider communication and coordination for the care of HIV-positive people.

Partner Agencies

Three Infectious Diseases (ID) Clinics of Duke University Medical Center, University of North Carolina-Chapel Hill and East Carolina University School of Medicine, HIV case management agencies, Ryan White CARE consortia, the AIDS Care Unit within the NC Department of Health and Human Services, NC prison systems and other community-based AIDS service organizations form the Integrated Delivery Systems in 54 counties through-out eastern North Carolina.

Lessons Learned

The success of NC SIP is attributed to a mélange of linkage strategies. We briefly describe these strategies, then proceed to illuminate important lessons learned in developing these linkages. In implementing the intervention, the project had to modify these linkages to make them more suitable to participating agencies' needs. Each linking strategy chosen offers a way to bring together agencies and organizations that are not close geographically or personally. These linking strategies form the necessary infrastructure/foundation for communication across different providers to ensure quality care.

Lesson #1: Agency coordinators are the glue that holds it all together.

Agency coordinators are a critical link in NC SIP efforts to create an integrated system of care. Three agency coordinators are involved in rolling-out and stabilizing Provide, the computer network software, via including group and individual trainings and monitoring. Coordinators conduct HIV-related training workshops (i.e., substance abuse, grief/dying); organize regular regional provider meetings; serve as liaisons for case managers, consortia directors and ID clinicians; help address client concerns and needs in providing appropriate care (i.e., creating Provide billing functions, prepare HIV informational fact sheets); and ensure that all who provide HIV-related care are educated about other HIV-related providers in their area. In short, agency coordinators provide local technical assistance in all matters ranging from Provide to issue-specific training workshops. In these ways, HIV providers are the agency coordinators' "clients."

The agency coordinators have worked hard to build and maintain the providers' trust in the project's purpose and work. NC SIP has been fortunate in hiring agency coordinators whose past ties in the HIV community crossed over into their work with NC SIP. They built upon this trust and helped agencies see the utility of Provide and of coordinating efforts with other providers to benefit clients. Providers have learned they can contact the agency coordinators easily via telephone, fax or email, which further enhances trust. The agency coordinators also often travel to meet with providers individually and for group meetings/trainings. They have coordinated two case

managers' conferences, which addressed training in an open and supportive environment. The frequent contact with and attention from the agency coordinators allow providers a sense of support from a working environment in which they often do not feel support.

Lesson #2: The computer makes distances managable.

To develop an IDS that spans this large rural area is a challenge in itself. To overcome difficulties in communicating over a large rural area, the project chose to establish a computer network as the main feature of the IDS because of its ability to allow efficient and confidential information sharing and communication over great distances. Additionally, the computer network, based on the software Provide, serves multiple other purposes. It contains resource pages that provide information on such topics as Medicaid and ADAP eligibility. A billing template was created for agencies to bill the consortia directly for services; this form was designed in direct response to requests from case managers who wanted to utilize the computer system more efficiently. Another important advantage of the computer network is its ability to accommodate varying schedules and personalities of the groups involved (physicians seeing clients and case managers in the field). Providers are able to receive and respond to questions and information in a timely manner. The system also has a discussion page used primarily by the case managers to pose and respond to questions regarding client care. This information exchange functions as a support network for individuals doing similar work who otherwise would be isolated.

Why a computer network-based system?

- Efficient communication over large geographic area**
- Confidential information sharing**
- Specialized software provides a variety of resources**
- Allows direct billing**
- Instant access 24/7/365**
- Provides support to remote locations**
- High cost of implementation and maintenance**
- Must develop and maintain a secure system**
- Staff hours required for user training**
- Technical assistance must be made available to users**
- Must motivate people to actually use the system**

Computer net users
must trust the
confidentiality of the
system
or they will not use it.

There are also disadvantages to the computer network which include the cost to create and maintain a secure network, and necessary training, and technical assistance to get users onto the system. This assumes agency staff will want to use the system. That is not always the case. Users must trust the confidentiality of the system and feel it meets their needs.

Lesson #3: Caremaps get everyone on the same page.

Another strategy that NC SIP utilizes in developing the Integrated Delivery System is caremaps, which are standards of care for providers of people living with HIV/AIDS. The purposes of the caremaps are to: 1) standardize care between different sites; 2) facilitate communication concerning goals and means to achieve the goals of the different components of the health care and social services system; and 3) provide educational material for the physicians-in-training and rural physicians who have less exposure to HIV/AIDS. Caremaps outline recommendations for the care of persons with HIV/AIDS: their use should be tempered with good clinical judgement that takes into account individual needs of the patient.

While the caremaps were not originally proposed to address issues of integration, they have in fact become a means by which providers come together as well as communicate with each other. Each caremap has been distributed to more than 600 providers in North Carolina and nationwide during conferences. The opportunity has enabled providers to learn about concerns faced by counterparts in different areas of the state, which facilitates cooperation. Distribution of the caremaps has enhanced integration efforts by educating providers across eastern North Carolina about: 1) standards of care and; 2) the work of NC SIP. The caremaps help providers understand the overall goal of NC SIP from a perspective different than the computer system or trainings.

Lesson #4: NC SIP Philosophy 101—all parties must buy-in.

NC SIP needed to invest much effort in convincing different groups (ID clinics, case managers, AIDS Care Unit, consortia) to join the collaborative initiative. While a variety of providers and administrators at all levels of HIV care were involved in the preparation of the proposal, when grant funding was awarded, different providers were in place and others who had not been directly involved were threatened by the potential of the grant. Persuasion involved developing trust. Trust building efforts consisted of face-to-face meetings in which an open process was emphasized and the goals, opinions and missions of participating agencies were respected. NC SIP worked to create an open process by which all providers, regardless of title and position, had equal opportunity to participate in the discussion to develop an integrated model of care. It was this process that best facilitated the development of the IDS.

Initial efforts were critical due to NC SIP's position in the state. NC SIP is its own entity and does not provide direct client services nor does it have any financial obligation to providers or clients. Therefore, NC SIP's success is based on the willingness of providers to volunteer their time and resources to create the

infrastructure needed for integrated care. This structure encourages flexibility and allows for greater responsiveness than is seen in other organizations. As an example, the original proposed intervention did not include a computer network as the primary focus of the IDS. The idea for the network was born out of meetings of case managers and ID clinicians. It was through these open meetings that NC SIP staff realized potential difficulties and problems with the original proposed intervention. It became essential to make changes to the intervention to address conflicts.

NC SIP had originally proposed to create a system by which case managers would be linked to the ID clinics via a “super case manager” who would work out of the ID clinics and act as a link between the ID clinics and the case managers. After the proposal was funded and presented to consortia administrators, the state-level AIDS Care Unit and case managers, providers were outraged that 1) they were not all included in the preparation of the proposal (the AIDS Care Unit had been involved, but not other providers) 2) that the proposed model was hierarchical in nature with the ID clinics holding the top rank and required case managers to report to yet another entity. NC SIP brought together the ID clinicians, case managers and consortia directors to discuss an alternative. The group developed the idea for a computer network to facilitate the transfer of information regarding clients.

By addressing their needs and incorporating a computer network into the overall structure of IDS, providers saw NC SIP as an entity that listened to their needs and make their ideas a reality. In this way, the NC SIP team was seen as a liaison for and supporter of community and medical providers, thereby aiding the implementation and regular use of the computer system. Since NC SIP could not enforce agencies’ computer usage, one may think it difficult to build an IDS based on a computer network. However, since participation was voluntary, IDS devoted much time to listening, involving, persuading, and bringing on board staff at the difference agencies. As a result, the agencies that agreed to use the system were excited about it and were convinced of its advantages.

This relationship building also was crucial in dispelling preconceived distrustful or negative stereotypes that might have resulted in complications with the implementation of the computer network. The groups of agencies that NC SIP is trying to integrate are represented by many different professions with varying perspectives and opinions. For example, case managers had previously reported negative experiences with the ID clinics of the academic medical centers. ID clinicians would not respond to questions regarding client visits and would not provide essential information such as HIV diagnosis necessary to meet Medicaid eligibility. Case managers said physicians would

**Building trust
requires
face-to-face
meetings
in which the
goals of
network partners
are openly
discussed.**

not respond to their telephone calls and were sometimes rude when they did respond. ID physicians and social workers reported case managers also would not return telephone calls and often did not provide adequate case management services they believed to be integral to client care. In addition, consortia administrators and case managers were distrustful of an academic medical center leading the integration of care. They were convinced the academic medical centers would want to buy the case management agencies or create capitated payment rates that would benefit the centers. They felt that academic medical centers were out of touch with the realities of working with HIV positive clients on a day-to-day basis, and were not capable of putting together a network that would benefit client care.

By involving all participating parties in the development of the intervention through open meetings, the different groups who were thought to differ drastically in professional views and their standards of care were able to work past their distrust of and negative experience with each other by focusing on the common goal of providing the best and most comprehensive and continuous care for these rural clients. Additionally, they were able to make modifications to the intervention to take into account their needs. It is the belief of NC SIP that a computer network would not have succeeded had case managers and ID clinic staff not given critical input in the final design of the Integrated Delivery System computer network.

Lesson #5: NC SIP Philosophy 201—flexibility is required

From the very beginning, the need for the NC SIP team to be flexible in its efforts and vision has been integral to the success of the project. As exemplified in the creation of the clinical database within Provide, NC SIP had to constantly address the multiplicity of providers and their interests. The initial Provide package contained the care management database, which enabled case managers to electronically maintain records and communicate with the ID clinics, but the ID clinicians did not see Provide as useful on a daily basis. Therefore, in order for the ID clinics to utilize the software regularly, it was necessary to create a database that they too could use to maintain records electronically. With the creation of the clinical database, ID clinics are using Provide on a regular basis and communicating with case managers to coordinate care by sharing client information as needed.

Lesson #6: The sky's the limit.

All the initial efforts spent on convincing partners of advantages of using the computer network as well as making them feel that they were full and active participants of the system paid off in terms of NC SIPS's success. Many of the ID clinics are convinced that the computer network is an effective way to provide the most coordinated care. This had led ID clinics to fund, on their own, the renewal of the software for the computer network. Part of this success was contingent on the efforts made in the beginning to make participants feel they were active in the decision-making process. Providers who were able to experience the advantages of the computer network are most likely to discuss the advantages of the network with colleagues, which will facilitate growth of the network. Additionally, institutional norms have been altered which allow for the possibility of the network to be continued with or without funding after the project.

NC SIP Project Chronology

April 1996

- Academic medical centers begin to speak with each other through the investigators.
- The North Carolina AIDS Care Branch assists in the editing of the proposal.

August 1996

- HRSA expresses interest in proposal but the budget must be cut in half. A new survey firm is found and resources for the entire project are cut.

October 1996

- Negotiations with direct care providers.

January 1997

- Collaborating agencies meet and commit to the project.
- Creation of caremaps.

April 1997

- NC SIP commits to finding computer system and funding.

June 1997

- Four research assistants work full-time on the research arm of the project. Clients from Infectious Diseases clinics consent to participate in research.

August 1997

- Agency coordinators and demonstration team hired.

October 1997

- HRSA provides additional funding to assist with computer network proposal.
- NC SIP raises \$55,000 from pharmaceutical companies to purchase laptop computers.
- Computer administrator hired.

January 1998

- 37 agencies linked via computer and 62 individuals become users.
- Computer network training begins.

February 1998

- Agency participants meet to review and update software fields.

June 1998

- Case managers surveyed regarding substantive training needs.
- Team members meet with NC home health and hospice to assess the possibility of creating joint caremaps.
- Project staff and survey firm begins the work of refining the survey data.

Further Information and Technical Assistance

Should you wish to obtain additional information about the service delivery model developed by NC SIP, you are welcome to contact the project director and request technical assistance:

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