The Forum for Collaborative HIV Research was founded in 1997 at the request of then Vice President Gore, as a public-private partnership project of the Center for Health Services Research and Policy at the George Washington University. The Forum’s mission is to address emerging issues in HIV research and the transfer of research results into care. Through our work, we identify gaps and impediments in the efforts to optimize management of all aspects of HIV disease, develop recommendations to fill those gaps and serve to catalyze constituents to implement of those recommendations.

The Forum is a coalition of representatives from five constituency groups—government, industry, patient advocates, health care providers, and researchers. The Forum is governed by an Executive Committee made up of members from each of those groups. The Executive Committee determines which projects the Forum will undertake and the scope of those projects. Most projects involve the development of a Planning Committee of experts who identify the issues for discussion and the appropriate structure for the project. We usually start by collecting and distributing background materials on the particular subject. Then, we bring together a group of experts from each of our constituency groups in a workshop to discuss the current state of knowledge, identify gaps in that knowledge, and develop recommendations to further efforts in research and quality care provision. Forum staff then work with constituents to help implement those recommendations.

For more information about the Forum or to download reports from this meeting or prior ones, visit the Website at

www.hivforum.org
Preface

The Centers for Disease Control and Prevention (CDC) estimates that between 850,000 and 950,000 Americans are infected with HIV and that approximately one-fourth are unaware of their HIV infection. Among those who are aware, CDC estimates that one-third are not receiving ongoing HIV clinical care. For persons in HIV care, a recent study showed that 40% learned their status and entered into care late in disease progression. These findings highlight serious challenges for the public health system in identifying those at risk or infected with HIV, providing timely access to HIV care services, and establishing strategies that link prevention services with the care system. In order to better understand and address these challenges, Federal agencies have started to invest time and resources in areas of research and evaluation, health planning and resource allocation, technical assistance, and community participation and training.

Funding for HIV research, care, and prevention services are included in programs within several federal agencies in the U.S. Department of Health and Human Services. The Health Resources and Services Administration (HRSA) provides funds to cities, States, and community-based organizations to support HIV health-related and social support services to low-income, under and uninsured persons with HIV disease. These funds are primarily distributed via the Ryan White CARE Act program. HIV surveillance and prevention services are primarily funded from CDC to state, territorial, and some large city health departments, and community-based organizations. The Substance Abuse and Mental Health Administration (SAMHSA) also provides funds for substance abuse treatment and prevention services. Federal support for clinical, therapeutic and prevention research projects are included in HRSA, CDC, and the National Institute of Health (NIH) programs. The majority of Federal funding for housing and housing referral services for persons with HIV disease is provided through the Housing and Urban Development (HUD), Housing Opportunities for Persons with AIDS (HOPWA) program.

On October 1 & 2, 2001, HRSA and CDC, in collaboration with the Forum convened a group of experts (government officials, health planners and researchers, program administrators, and service consumers) to provide insight and direction on how to improve linkages among providers of HIV counseling and testing, HIV care and treatment, and HIV prevention services especially programs funded through these Federal agencies. This report summarizes the activities of the meeting, comments by presenters, and findings.

The Forum would like to thank the Federal agencies for their support (and foresight) in convening a workshop on this important public health matter. In addition, we are grateful for the contributions of Federal staff in facilitating and reporting during the workshop. We acknowledge the assistance of the Planning Committee members (listed in Appendix H) who established the primary objectives of the meeting, set the agenda, and assisted in identifying presenters and programs. Special thanks go to Helen Schietenger, who prepared the document, “Linking of Testing, Prevention and Care” which provided the background for this meeting. We also gratefully acknowledge the contributions of Karen Eddleman and John Hannay in the preparation of this report and Paul Oh and Houtan Movafagh for their expert skill in editing. We thank the participants and presenters for their time, insight, and overall support in making this work shop a success. Finally, we recognize the extraordinary efforts made by all participants who were willing to travel to this meeting after the tragic events of September 11, 2001.
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FORUM FOR COLLABORATIVE HIV RESEARCH

LINKING HIV TESTING, PREVENTION AND CARE

Background Paper

Helen Schietinger
September 21, 2001
HIV TESTING AND COUNSELING

National Trends in Testing

By the mid-1990’s, over one-third of adults in the U.S. had been tested for HIV, including through blood donation, the proportion having increased from 16% in 1987 to 40% in 1995. In the three national surveys of household-based probability samples on which these figures are based, rates of testing were much higher for persons at increased risk for HIV. Twice as many people received HIV tests in private locations (MD offices, hospitals and emergency rooms, employee clinics, nursing home visits, and home testing kits) as in public locations (health departments, community clinics, HIV C/T sites, family planning clinics, military and immigration sites, STD clinics). Of those at increased risk for HIV, 70% had been tested for HIV.

While rates of HIV testing were high, more than half of the persons tested in public programs did not report that a health professional talked to them about HIV-related issues when they were tested, indicating that many persons are not receiving counseling or are not recognizing their interaction with staff as counseling. The rate of counseling is even lower in private settings.

Testing at public sites funded by the CDC

While HIV testing can be obtained in medical care settings, publicly funded counseling and HIV testing services have been available since March 1985 to provide an alternative to blood donation as a means for high-risk persons to determine their HIV status. Both anonymous and confidential voluntary HIV counseling, testing, and referral services are available through 65 local and state health departments, with emphasis placed on a client-centered risk-reduction counseling model.

With the Counseling and Testing Data System, data are available to describe trends in testing among the population who receive CDC-funded HIV counseling, testing, and referral services. In 1998, the most recent year of analyzed data, the highest proportion of total tests was recorded at STD clinics, while the highest proportion of HIV-positive test results was recorded at counseling and testing sites (including health department sites and free-standing community-based anonymous test sites).


Sites with high proportions of HIV-positive tests but a lower percentage of all HIV tests include prisons, drug treatment facilities, other health departments, test sites in private doctors’ offices or clinics, and TB clinics. On the other hand, family planning and prenatal/obstetric clinics reported a larger proportion of all HIV tests but a relatively small proportion of all HIV-positive tests.

Although slightly more than half of all HIV tests were requested by women, slightly over two-thirds of all HIV-positive test results were for men. The largest proportion of all HIV tests was provided for persons 20 to 29 years of age, but the largest proportion of HIV-positive tests was reported for persons 30 to 39 years of age. African Americans and Hispanics obtained approximately half of all HIV tests in 1998 (34.8% and 15.5% respectively) but received almost three quarters of the HIV-positive test results for that year (52.1% and 20.5% respectively).

In terms of male risk exposure groups, heterosexual men with no other risk obtained the highest percentage of total HIV tests (28.3%), while men having sex with men received the highest percentage of HIV-positive test results (38.0%). For women, the risk exposure group with the highest percentage of all HIV tests in 1998 was also heterosexuals with no other risk (42.8%), while the group with the highest percentage of HIV-positive test results was among women whose sex partners were at risk (32%).

The proportion of test events with a posttest counseling session reported was 54.9% in 1997 and 52% in 1998. A higher percentage of posttest counseling sessions was reported for freestanding HIV counseling and testing sites. The proportion of HIV-positive tests that included a posttest counseling session was higher, 67.4% in 1997 and 62.5% in 1998. Where the site type was known, HIV-positive tests in prenatal/obstetric clinics and HIV C/T sites reported the highest proportions of completed posttest counseling sessions; while HIV-positive tests in community or public health clinics and STD clinics reported the lowest proportions. The proportion of tests with posttest counseling differed greatly by project area.

**Testing at public sites funded by California Office of AIDS**

While nationally the number of HIV tests conducted at CDC-funded HIV C/T sites decreased slightly between 1997 and 1998, the number in California increased slightly (by almost 5,000 tests from testing volume reported in the previous year).3.

Half of the HIV tests obtained at publicly funded sites in California in 1998 were obtained at anonymous alternative test sites. The HIV C/T sites in California reported testing data show some interesting trends in regard to HIV testing. Many clients repeatedly test for HIV, with men who have sex with men (MSM), MSM injection drug users (MSM/IDU), and heterosexual IDU reporting the largest percentage of repeat testing. MSM and MSM/IDU had the highest rate of prior testing with the majority indicating five or more previous HIV tests. This information suggests that these three high-risk groups are aware of their increased risk for HIV and engage in a pattern of repeat HIV testing. After testing for the first time, all other risk groups show a sharp decline in repeat testing.

Regardless of race or gender, the overall positivity rate in 1998 for California Office of AIDS funded clients was 1.26%. First time testers represented over one quarter (27%) of the 1998 HIV positive results and 34% of all OA funded clients. Nineteen percent of all clients with positive test results reported a previous HIV positive test result indicating that clients often return to validate their initial test results. The average interval between tests was 21 months, suggesting some HIV infected clients may go through a period of psychological adjustment prior to accepting their status.

There was a slight increase in the number of publicly funded HIV tests administered in 1998. Compared to past years, an increased number of high-risk individuals sought HIV C/T. This may be in part attributed to increased outreach efforts to high-risk communities. Positivity rates continued to rise and remain extremely high among African Americans, MSM, IDU and transgender testers.

Rates of failing to return for test results differ among clinic types. Alternative Test Sites have the lowest no-show rate with 14% of test results not being disclosed. Mobile van testing (36%), STD clinics (32%), primary care clinics

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and ‘Other’ clinics (31%) have the highest no-show rates. There is a variety of reasons why clients may fail to return for their test results. Mobile vans reach more clients who are at risk for multiple reasons, such as homelessness and disenfranchisement from the community; in this setting it might be difficult to reunite with clients. Clients seeking services from STD or primary care clinics may have sought services other than HIV testing and therefore are less likely to return for results unless motivated by HIV counselors. Among client risk groups failing to return for test results, those clients with an unknown risk history, where risk assessments were not performed during the counseling session, were the most likely to fail to return for test results (65%). Clients who offered sex for drugs or money (31%) and heterosexual injection drug users (27%) were the next most likely to fail to return. Of all risk categories, MSM clients were most likely to return (9% failed).

To provide additional incentive to test sites to follow up with these clients, the California Office of AIDS provides reimbursement for making follow up attempts with high-risk clients who fail to return for their test results. For high-risk HIV negative clients, the reimbursement is $10, for HIV positive and inconclusive clients, the reimbursement is $25. Fifty percent of clients who received a follow up contact returned for their test result. However, in 1998 there were 9,562 confidential HIV tests with high-risk clients for which no follow up contact was reported.

**HIV testing at C/T sites does not always include counseling**

An innovative study documents in another state that HIV testing does not necessarily result in adequate counseling, even at publicly-funded C/T sites. A participant observation study was conducted at 30 publicly funded HIV C/T sites in Pennsylvania in 1994.4 Actors were trained as research assistants and sent to 30 randomly chosen sites to be tested and counseled for HIV disease. Instruments based on 1994 CDC C/T standards were designed and used to evaluate the test sites. Data were generated that identified the range of compliance with CDC guidelines and state policy. It is important to note that the study was conducted prior to the recent revision of C/T guidelines that places additional emphasis on referral.

Among the findings were that 10 of 30 sites required signed consents despite a state policy allowing anonymous testing. Only 17% of providers developed a written risk reduction plan, even though 69% of all sites surveyed by mail asserted that such plans were developed. Only 2 of 5 HIV-positive actors were offered partner notification services, even though 100% of sites visited by an interviewer claimed to offer such services.

In the prevention counseling session (pre-test counseling), the actual time the actors spent with the counselors ranged from 10 to 80 minutes, with an average of just over 30 minutes. Eighty-seven percent of the counselors (n=26) helped in identifying risk behaviors that could place the client at risk for HIV and 73% discussed the client’s understanding of risks associated with HIV infection. In the post-test counseling session, the time spent with both the HIV-positive and HIV-negative actors varied from not more than 5 minutes to an hour. Sessions to discuss negative test results averaged 14 minutes, while sessions to discuss positive results averaged 41 minutes. In the sessions to discuss negative results, 64% of the counselors (16 of 25) provided opportunities for the actors to discuss risk reduction behaviors. Forty-four percent reinforced the actors’ positive steps toward risk reduction, but only 12% (n=3) discussed the need for the actor to appropriately disclose his or her HIV status to others. Two counselors (8%) used educational materials, and 4(16%) gave the actors materials to take home with them.

In sessions to discuss positive results, all 5 counselors asked if the actors had friends and family to rely on for emotional support. Four counselors (80%) assessed the actors’ immediate need for medical, psychosocial, and other support services and discussed the need for early medical care. Three counselors (60%) discussed the availability of free CD4 testing. Two counselors (40%) wanted to retest the actor to verify that the test result was correct, and only 2 (40%) reassessed the actor’s risk for transmitting HIV infection to others and reviewed preventing transmission. All 5 counselors discussed referrals, gave the clients their names and telephone numbers, and encouraged them to call if questions or concerns arose.


The question of the efficacy of HIV C/T in reducing risk for HIV is difficult to answer. In California OA’s 1998 C/T data, forty-six percent of clients with HIV positive results reported a prior negative result indicating that HIV C/T alone often does not result in behavior change that will prevent HIV infection. A meta-analysis reported in 1999 examined 27 published studies that provided sexual behavior outcome data, assessed behavior before and after C/T, and provided details sufficient for the calculation of effect sizes. The studies involved 19,597 participants. The analysis found that after C/T, HIV-positive participants and HIV-serodiscordant couples reduced unprotected intercourse and increased condom use more than HIV-negative and untested participants. HIV-negative participants did not modify their behavior more than untested participants. Participants’ age, volition for testing, and IDU treatment status, as well as the sample seroprevalence and length of the follow-up, explained the variance in results. The authors concluded that HIV C/T appears to provide an effective means of secondary prevention for HIV-positive individuals but, as conducted in the reviewed studies, is not an effective primary prevention strategy for uninfected participants.

REFERRAL AND LINKAGES

Characteristics of people who are HIV-positive and who delay entry into treatment

A 1998 study suggests that delay in treatment is a reality for a high proportion of those who test positive. Of 189 individuals presenting for the first time for primary HIV care, 39% had delayed treatment for more than a year, 32% for more than 2 years, and 18% for more than 5 years after an initial positive HIV test. A number of characteristics were found to be associated with delayed presentation: history of injection drug use; not having a living mother; not having a spouse or partner; not being aware of HIV risk before testing; and being notified of HIV status by mail or telephone. An interaction effect between sex and screening for alcohol abuse was significant and suggested longer delays for men with positive screening test results compared with men without positive screening test results or women. This study mirrors findings of other studies that for many people there is an inappropriate time lapse between a first positive HIV test result and medical care, and that the people who fail to enter care in a timely manner tend to be those who are marginalized and have other socioeconomic risks such as poverty and addiction. In one study, long-term non-presenters were uninsured, male, or injecting drug users.

Enhancing referral from publicly-funded C/T sites

Referral of high-risk people who have been tested for HIV to care and prevention services in a timely manner is the subject of great concern in terms both of the health of the individual and of the prevention of further spread of HIV. The recent revision of the CDC Guidelines for HIV Counseling, Testing and Referral include much more specific and detailed guidance for implementation and evaluation of the process of linking clients who are tested and counseled to appropriate services. In the new Guidelines, the goal of HIV referral is to ensure that both HIV-infected persons and individuals at increased risk for HIV infection have access to appropriate medical, prevention, and psychosocial support services. Referral encompasses a series of activities including assessment and prioritization of the client’s needs for care and supportive services; assistance with accessing services; follow-up efforts to facilitate initial contact with care and support service providers; and documentation of the referral. The Guidelines explicitly state that clients should be referred to services that are responsible to their priority needs and that are culturally, linguistically, gender- and age-appropriate. Referral needs include:

• Medical evaluation, care and treatment;
• Partner counseling and referral services;
• Reproductive health services;
• Drug or alcohol prevention and treatment;
• Prevention case management;
• Mental health services;
• STD screening and care;
• Screening and treatment for viral hepatitis
• Other support services such as assistance with housing, food, employment, transportation, child care, domestic violence, and legal services.

Providing referral is recognized in the Guidelines to require certain agency capacities, including:

• Education and support of staff: Staff providing referral services must possess appropriate knowledge of client needs, the skills and resources to address them, and authority to assist the client in procuring services. Providers should develop protocols to ensure that staff receive adequate training and continuing education.
• Provider coordination and collaboration: Providers should develop and maintain strong working relationships with other providers and agencies that may be able to provide needed services. Coordination and collaboration should be formally documented.
• Referral resources: Providers of HIV prevention counseling and testing services should maintain accurate and current information regarding referral services.

**ORC Macro Literature Review**

A literature search conducted by ORC Macro for the Program Evaluation Research Branch of the CDC identified three primary foci of concern regarding referrals and linkages to services: 1) referrals of HIV-positive individuals to medical and ancillary (e.g. mental health) services, 2) referrals of high-risk HIV-negative individuals to needed services, and 3) referrals of HIV-positive IDUs to drug treatment services. According to the literature review, the literature documents the complexity of service provision to individuals with multiple needs from a variety of service providers functioning within a fragmented service delivery system.

Articles regarding referral of people who are HIV-positive identified a number of barriers to receiving care, including denial of need, lack of interest, not receiving referrals from the testing provider, and logistic problems such as restricted clinic hours and lack of transportation. While many test sites reported having protocols and policies in place regarding referrals, many counselors did not follow them and little was done by sites to ensure that the protocols and policies were followed. An important point of several articles was the need to integrate care and communication among providers to build a collaborative network of culturally and developmentally appropriate care. Women and families were noted to be especially affected by fragmentation of service delivery systems.

Fewer articles focused on the referral and linkage process for high-risk HIV-negative individuals. Low rates of prevention referrals were provided for seronegative individuals, and HIV-negative women, especially those who were African American, were noted to be less likely to have a consistent source of health care.

The literature on linking HIV-positive IDUs to needed services stressed the need for comprehensive service delivery systems. Several studies suggested that coordination of services for HIV-infected IDUs can have a synergistic effect on reduction of HIV risk. The articles about integrating services for HIV-infected individuals with mental health needs focused on the increased likelihood of high-risk sexual behaviors and IDU among mentally ill individuals, the barriers to the mentally ill receiving HIV testing, and the need for mental health services to be integrated into primary HIV care. “Nowhere is the complexity of service needs more evident, highlighting the need to integrate and coordinate HIV-related service delivery. Multiple lifestyle and psychosocial factors compound the burden of HIV infection for individuals with mental illness complicating the delivery of effective and comprehensive health care.” (p. 5)

Seven Cities Projects

Federal agencies have been concerned about linkages between HIV testing and HIV services for quite some time. In 1991, the CDC and HRSA collaborated on the Seven Cities HIV Early Intervention Demonstration Projects, involving establishment of HIV Early Intervention Demonstration Projects within the jurisdictions of seven local health departments, with Columbia University School of Public Health documenting and assessing the activities of the projects in the first year.11 The aims of the projects were 1) to enable grantees to gain experience in managing incorporation of early intervention services into publicly funded HIV programs and 2) to identify effective organizational strategies for linking emerging early intervention services into existing C/T programs.

The key lesson learned from the projects is that putting together a service delivery network is a complex task. Local health departments face three organizational challenges in developing early intervention networks:

- Maintaining effective network oversight;
- Forging interagency linkages; and,
- Gaining agency support so that they share early intervention goals.

In developing linked early intervention and primary care services programs, design should address:

- Developing trust between patients and providers and between network providers;
- Tracking HIV infected persons from counseling sites to primary care providers;
- Strong linkages to drug treatment programs, mental health services and specialty care.

Referral at public sites funded by California Office of AIDS

California tracks whether referrals were made at the time of the pre-test counseling (assessment) session and at the post-test counseling (disclosure) session. In 1998, 27% of high-risk risk assessments had ‘NONE’ indicated in the risk assessment referral column. Similarly, 24% of high-risk disclosure sessions had ‘NONE’ recorded in the referral column. This is despite the fact that the protocol designates that all high-risk and HIV positive clients should receive a referral at the disclosure session, and that there is an additional $5 reimbursement for high-risk negative clients and $15 reimbursement for HIV positive and inconclusive clients.

At the risk assessment, the most common referral is the HIV Education Service and does not differ appreciably for negative or positive clients (42% to 48%).12 This is reasonable given that only a few clients already know their HIV status. Follow-up counseling is also a significant referral (21%) which also does not vary by type of client. What is also striking is that even though a risk assessment has been completed high-risk client referrals do not differ from low risk client referrals. This is a very clear sign that while counselors are conforming to the requirement to refer, they are not discriminating what referrals are appropriate based on that assessment.

At disclosure, the referrals remain high in these two categories for high-risk negative clients, with a slight increase in the proportion referred to Prevention Skill Development (14%). Differentiation of referrals for those who are found to be HIV infected occurs at this session. Thirty percent are referred to Early Intervention Programs (EIP). However, even when Medical Services is added (13%), less than half were given a medical service provider as their primary referral even though they have been diagnosed with a life threatening illness.

In the past, many areas did not have appropriate services for these clients. However, more recently these services have been expanded and it should only be in the rare case of an HIV infection in a very rural setting that there is nothing more appropriate than HIV Education Service.

Tracking New York State HIV Testing and Referral

New York State actually tracks whether referrals are completed. The proportion of individuals who follow through with a referral and keep a scheduled appointment is tracked through monthly reports submitted to the Health

Department by AIDS Institute-funded primary care and substance abuse treatment providers. Data from these reports suggest that between 80 and 90 percent of individuals with an HIV post-test positive counseling visit who are referred for follow-up care do in fact keep their appointment. The Anonymous Counseling and Testing program reports that 86 percent of persons who returned for positive test results received referrals and 57 percent of those persons are documented as having reached their referrals. Results from the Newborn HIV Screening Program suggest that 99 percent of HIV-exposed newborns receive follow-up medical care. Preliminary analysis of Medicaid claims data suggest that approximately 87 percent of persons who have a post-test positive counseling visit go on to access Medicaid covered health or health-related services.

**Health department capacity to implement and monitor referrals and linkages to services**

The capacity for health departments to address these factors continues to be limited. In 2001, the National Alliance of State and Territorial AIDS Directors (NASTAD) conducted a survey of state AIDS Directors about the capacity of state and local health departments to provide referral services to racial/ethnic minorities. The survey examined current referral services practices, readiness to respond to the revised CDC C/T/R Guidelines, and barriers and facilitators to responsiveness to the Guidelines. NASTAD found that health departments recognize the importance of referral activities in HIV prevention efforts, but that quality and completion of referrals are influenced by provider skill in assessing and managing referrals, availability and accessibility of appropriate referral resources, and provider capacity to provide active assistance with referrals. According to NASTAD:

Survey findings strongly suggest that HDs have limited capacities to monitor referrals. While a majority of HDs appear to collect data from local providers on referral services, these data appear to be very general in nature and have limited utility in terms of assessing the quality, appropriateness and completion of referrals. Of particular concern is the finding that very few HDs currently monitor the completion of referrals. The forthcoming CDC Guidelines recommend that completion of referrals be verified. A number of respondents reported using case management, partner counseling and referral services, surveillance and other databases for clinical services to assess the proportion of referrals completed. This suggests a critical need to ensure comparability and consistency in definitions of variables and data collection methods across these databases, some of which are created by federal agencies. This also suggests a need to develop methods appropriate to monitoring referral services for individuals who are HIV-negative, but for whom referral resources may serve a key role in assisting them in remaining uninfected (p. 27).

The NASTAD case study of the Connecticut HIV CTR services identifies a number of interventions designed to enhance the completion of referrals for prevention and care. First, the counselors receive six days of intensive initial training and ongoing supervision and feedback (including a role play demonstration before a Review Committee). Second, there is quality assurance of counseling skills that includes regular direct observation of counselor sessions, twice annual skills inventories by on-site supervisors, and periodic site reviews in which counseling sessions may be observed. Third, the Early Referral and Linkage Initiative (ERLI) creates strong links between prevention and care systems. One component of ERLI is cross-training of HIV case managers and HIV prevention counselors, with the goals to: assure that they have a thorough understanding of each others’ services; facilitate networking among providers; and, provide an orientation to the data collection and monitoring protocol. Another component is strong quality assurance, including random chart reviews regarding compliance with the ERLI protocol for assessment and needed referral. Data are collected by HIV counselors and case managers and put into a database by CTDPH. Because of the unique client identifiers, services can be monitored for completion of referrals.

NASTAD also conducted a study to examine linkages between substance abuse, mental health, and HIV services programs in which they identified strategies that enhance program coordination. These strategies mirror factors identified to promote successful referrals from C/T to services: intensive and ongoing staff training; shared data and communication activities; and direct attention to the resolution of structural differences between and among programs.

**Model Programs to Link Vulnerable Populations to Services**

The Special Projects of National Significance, in the HIV/AIDS Bureau of HRSA, implemented an initiative to develop integrated service delivery systems that enable the most marginal and isolated populations affected by HIV to access services to meet their needs. Eight projects providing Networking Services have been described in Lessons Learned, recently published by HRSA.15 One of the lessons common to all the projects was that, “given the complexity of AIDS as well as the multiple needs of the client populations served by these projects, it is essential that providers offer comprehensive services or refer clients to other providers. While it would be most convenient in some cases to offer all services under one roof, this is not possible for most organizations and a system of care will have to be developed in collaboration with other providers. In addition to this specific service system, agencies and projects also operate in relation to the broad community and service environment (both HIV/AIDS specific and non-HIV/AIDS specific).”

Appendix B

“Referrals and Linkages in HIV Counseling, Testing, and Referral and Partner Counseling and Referral Services: An Annotated Literature Review” by ORC Macro

ANNOTATED LITERATURE REVIEW

Prepared for the Program Evaluation Research Branch
Centers for Disease Control and Prevention

by

ORC Macro

Prepared under contract to CDC as part
Of the “Evaluation Plan for the Referrals and Linkages in HIV Counseling and Testing, and Referral and Partner Counseling and Referral Service Project”

APRIL 23 - 24, 2001

Introduction

Given the rapid and significant changes that have occurred in our understanding of HIV disease, the importance of HIV counseling, testing, referral, and partner notification in disease prevention and delayed onset of AIDS has become more apparent than ever. According to the Centers for Disease Control and Prevention (CDC), between 1992 and 1996, publicly funded HIV test sites conducted 12,727,715 HIV tests; and 224,147 of these tests were positive for HIV (CDC, 1998). The CDC estimates that approximately 650,000 to 900,000 persons in the United States are infected with HIV, but more than 200,000 of these persons do not know their serostatus (CDC, 1999). Many of those persons could benefit from an early diagnosis of their infection through early initiation of antiretroviral treatment and participation in primary and secondary prevention programs. In addition to primary care, services such as substance abuse and mental health treatment, housing, and case management are often needed to support effective health care. Of the 2,623,873 HIV tests conducted in 1996 in publicly funded test sites, 1,115,395 negative test results (roughly 43%) were accounted for by persons reporting multiple risks (CDC, 1998). High-risk negative persons could benefit from participation in health education and risk reduction programs. Sex and needle-sharing partners of seropositive persons also need to know their HIV status and receive appropriate counseling, testing, and risk reduction services.

The CDC has contracted with ORC Macro to conduct a study that examines how six CDC grantees bring individuals at high risk of HIV infection into HIV counseling and testing programs and identify how they implement referrals to various services. Special attention will be paid to referrals to treatment, care, and prevention programs for HIV-positive persons, referrals to prevention services for high-risk HIV negative persons, and referrals during partner notification programs. Additionally, the study should assess how these grantees collect, manage, and use data and explore how the collection of client-level data affects clients’ willingness to access additional services.

Because of the national priority to increase the numbers of persons who know their serostatus and to provide treatment and prevention intervention for HIV-positive individuals (as well as counseling and testing for their partners), this project is especially timely and crucial. The CDC must know how its grantees are carrying out posttest referrals and linkages, as well as partner notification referrals and linkages, in order to develop strategies to
improve counseling and testing programs and communication and coordination with the Health Resources and Services Administration (HRSA), especially regarding early treatment and care under the Ryan White CARE Act.

As a first step in this process, ORC Macro was asked to produce an annotated literature and governmental document review. In order to thoroughly review the relevant issues, the literature review includes sections on counseling and testing, posttest referrals and linkages to services, and partner notification.

The Counseling and Testing Literature

There were three primary foci in the literature reviewed on counseling and testing: 1) the effects of risk-reduction counseling in the HIV counseling and testing environment; 2) rates of, and factors affecting, the return for HIV test results; and 3) the effects of offering confidential versus anonymous testing.

The literature on HIV risk reduction counseling focused on the efficacy of different models of prevention counseling among high-risk individuals. One article (Sikkema & Bissett, 1997) reviewed the psychological literature on counseling and behavior change and linked it to HIV counseling and testing (CT). Of the various counseling approaches they reviewed, only behavioral and cognitive-behavioral approaches addressed all the key tasks of HIV counseling. In another review of studies examining the effectiveness of HIV CT in motivating behavior change, Wolitski, MacGowan, Higgins, and Jorgenson (1997) found that results were inconclusive. The most consistent evidence that HIV CT had beneficial effects was found in studies of heterosexual, HIV-serodiscordant couples and in studies examining the relationship between serostatus and risk behaviors, but findings varied as a function of study population and study design. Kamb et al. (1998) conducted a study at multiple sites using a randomized controlled trial design to test three different counseling models: a pretest and posttest didactic HIV message; brief interactive risk reduction sessions; and extended, interactive, theory-based sessions. No significant differences were found between the two interactive sessions, indicating that interventions of a brief interactive nature can be effective. Another study reviewed STD clinic data and found the effectiveness of CT on risk behaviors to be both minimal and short-lived (Kamb, Dillon, Fishbein, & Willis, 1996). The review did find, however, that when the counseling involved multiple, client-centered sessions, clients were more likely to reduce their risk behaviors than those receiving the standard two-session counseling.

In separate articles, failure to return for test results was assessed based on types of test sites, race, age, and risk categories, as well as on whether the test was self-initiated versus recommended or compulsory and whether or not the testing process included pretest counseling (Berger, Hong, Eldridge, Connor, & Vedder, 1999; Molitor, Bell, Truax, Ruiz, & Sun, 1999; Tao, Branson, Kassler, & Cohen, 1999). Individuals whose testing was self-initiated and who had not received pretest counseling were significantly less likely to receive their test results (Tao et al., 1999). Individuals testing at STD clinics and those testing at mobile units were four times less likely to return for their results than those testing in other locations. Injection drug users were 2.5 times less likely than others to return for their results, and individuals less than twenty years old were twice as likely to fail to return for their results. Authors offer two suggestions: 1) counselors should be aware of the characteristics of those most likely to fail to return for test results in order to concentrate special efforts to encourage their return, and 2) the use of rapid testing should be promoted to eliminate the possibility for failure to return for test results (Molitor et al., 1999).

Studies examining the effects of offering confidential versus anonymous testing reported discrepant findings. One study on the changes in the number of persons tested at six publicly-funded HIV CT sites one year before and one year after the implementation of name reporting for HIV/AIDS found that confidential name reporting had no effect on the use of publicly-funded HIV CT services (Nakashima et al., 1998). However, another study examining data collected by publicly funded CT sites between 1992 and 1995 (Weber, Frey, Horsley, & Gwinn, 1997) found that by 1995 posttest counseling was more common at anonymous than at confidential testing sites. Further, a separate study, utilizing an AIDS patient survey conducted in eight states, all of which offered publicly-funded anonymous and confidential testing, reported that anonymous testing was associated with seeking testing earlier, as well as earlier access to, and a longer duration of, medical care (Bindman et al., 1998). Even after adjustment for age, race/ethnicity, education, income, insurance status, and HIV exposure group, anonymous testing remained significantly associated with a longer period of HIV-related medical care. However, in another study of the characteristics of men seeking anonymous vs. confidential testing, authors reported that acceptance of coordination of care was significantly higher among seropositive men at confidential test sites than anonymous test sites (Berger et al., 1999).
The Referral and Linkages Literature

The literature on referrals and linkages to services had three primary foci: 1) referrals of HIV-positive individuals to medical and ancillary (e.g., mental health) services, 2) referrals of high-risk HIV-negative individuals to needed services, and 3) referrals of HIV-positive injection drug users to drug treatment services. The literature documents the complexity of service provision to individuals with multiple needs from a variety of service providers functioning within a fragmented service delivery system.

Several articles focused on the need to link HIV-positive individuals to HIV-related medical care and the barriers to these linkages (Bettencourt, Hodgins, Huba, & Pickett, 1998; Huba & Melchoir, 1998; Kilmarx, Hamers, & Peterman, 1998; Russell & Smith, 1998; Solomon et al., 1998; Weissman et al., 1995; Woods et al., 1998). Many HIV-positive individuals reported not receiving needed medical care because of a denial of need or a lack of interest, while others reported not being referred for care (Kilmarx et al., 1998; Silvestre, Gehl, Encandela, & Schelzel, 2000). While many test sites reported having protocols and policies in place regarding referrals, many counselors did not follow them, and little was done by sites to ensure that the protocols and policies were followed (Silvestre et al., 2000). If referrals were made, issues of transportation or restricted clinic hours were cited as barriers to receiving needed ancillary services like mental health or dental care (Kilmarx et al., 1998). Another study that examined service provision to HIV-positive, homeless, and at-risk youth found that services tended to be clustered near large hospitals and community health centers hindering access (Lin, Melchino, Huba, & Woods, 1998). In this study, more than half of the ten service categories examined were offered by fewer than 25% of the agencies surveyed. Other authors have pointed to the need to integrate care and communication among providers to build a collaborative network of culturally and developmentally appropriate care (Woods et al., 1998). HIV-positive women with children are especially affected by fragmentation of service delivery systems emphasizing the need for facilities that offer comprehensive care in order to decrease barriers to receiving services (Russell & Smith, 1998).

Fewer articles focused on the referral and linkage process for high-risk HIV-negative individuals. One article discussed the low rates of prevention referrals given to seronegative individuals, and suggested that the referral aspects of counseling should be improved to encourage reduction of high-risk behaviors among HIV-negative individuals (Marx, Hirozawa, Chu, Bolan & Katz, 1999). Another article focused on the contrasting needs of HIV-positive and HIV-negative women citing that HIV-negative women were less likely to have a consistent source of health care (Solomon et al., 1998). African-American women especially were less likely to have a regular source of care including HIV treatment regimens. This lack of regular care was compounded by behavioral characteristics like injection drug use.

More of the literature focused on linking HIV-positive injection drug users to needed services (Booth, Kwaitkowski, & Weissman, 1999; Brooner et al., 1998; Friedmann, D’Aunno, Jin, & Alexander, 2000; Greenberg et al., 1998; Stein et al., 2000). The need for comprehensive service delivery systems again emerges as a theme for these individuals. In one study, on-site delivery of services and transportation assistance were found to be significantly associated with higher levels of utilization of ancillary services among clients needing substance abuse treatment (Friedmann et al., 2000). However, another study of access to referred antiretroviral therapies for HIV-positive injection drug users attending methadone maintenance programs found that these individuals were well-connected to primary HIV care, even though the services were provided at a different location (Stein et al., 2000).

There is some indication that coordination of services for HIV-infected injection drug users can have a synergistic effect on reduction of HIV risk. One study found that utilization of health-related services was associated with lower frequency of HIV risk behaviors; however, mental health and drug treatment services were not used with the same frequency as medical services (Booth et al., 1999). Other authors suggest that, while the primary goal of needle exchange programs is reduction of HIV transmission, the potential exists for referrals of participants to drug treatment programs to reduce or eliminate drug use (Brooner et al., 1998). Additionally, street outreach workers can include referral of injection drug users to medical services as part of their role in HIV prevention. Results of one study indicated that multiple contacts between street outreach workers and injection drug users increased the probability of the individual acting on the referral (Greenberg et al., 1998). Agency coordination of outreach efforts was cited as one way of strengthening the linkage process.
A few articles focused on integration of services for HIV-infected individuals with mental health needs (Dodds et al., 2000; Sullivan et al., 1999). While individuals with serious mental illness have an increased likelihood of high-risk sexual behaviors and injection drug use, many mentally ill individuals are not tested for HIV until they enter the public mental health system for treatment (Sullivan et al., 1999). HIV screening policies in the mental health system (e.g., avoidance of screening due to concerns about maintaining confidentiality and client competency) have been cited as potential barriers to diagnosis of HIV infection, further underscoring the need for integration of service delivery. Mental health services should be integrated into primary HIV health care in order to reduce transmission of HIV infection and improve the quality of life (Dodds et al., 2000).

Transition from diagnosis of HIV infection in the mental health system to care and treatment in the medical system is often impeded by a lack of case managers. Collaboration and coordination of service delivery again emerges as a theme for improving treatment and prevention of HIV infection for the mentally ill. Nowhere is the complexity of service needs more evident, highlighting the need to integrate and coordinate HIV-related service delivery. Multiple lifestyle and psychosocial factors compound the burden of HIV infection for individuals with mental illness complicating the delivery of effective and comprehensive health care, but some models of clinical care have been developed that address these needs (Dodds et al., 2000).

The Partner Notification Literature

The partner notification literature relevant to an examination of the referral and linkage process focused primarily on two topics. The first related to those factors associated with the notification process that promote or inhibit the successful referral of an index client’s sex and/or needle-sharing partners to appropriate testing, treatment and prevention services (Fenton & Peterman, 1997; Hoffman, Spencer, & Miller, 1995; Holtgrave, Valdiserri, Gerber, & Hinman, 1993; Koenig & Moore, 2000; Landis et al., 1992; Macke, Hennessey & McFarlane, 2000; Macke & Maher, 1999; West & Stark, 1997). These factors included identification of the person notifying the partner, demographic and other characteristics of the person receiving notification, anonymity of the testing situation, potential for partner violence, nature of the public health infrastructure, and subsequent access to care. The second addressed the ethical implications of notification policy decisions and public health law, including 1) voluntary versus mandated disclosure and 2) individual confidentiality versus the common good of the public (Campbell et al., 1997; Dye, Knox, & Novick, 1999; Misir, 1999; Rothenberg, Paskey, Reuland, Zimmerman, & North, 1995). The ethical considerations often pitted against each other include the duty to warn, the right to know, the responsibility to protect the public health, the right to privacy, and the right to freedom from discrimination.

Much of this literature compared the effectiveness of provider referral and partner referral (sometimes termed contact or patient referral) in terms of number of partners contacted, the number tested, and the number found to be HIV-positive (Fenton & Peterman, 1997; Holtgrave et al., 1993; Landis et al., 1992; Macke & Maher, 1999; West & Stark, 1997). Provider referral is typically found to be more effective than partner referral in terms of number of partners tested and the number of infected partners identified, but it is also more costly and time-consuming than partner referral (Fenton & Peterman, 1997). One study addressed the issue of domestic partner notification, finding that, of the 136 health care providers surveyed, most were opposed to partner notification by a professional if there was a strong likelihood of physical violence (Rothenberg et al., 1995).

While there is substantial evidence that provider referral is effective in getting partners to access HIV CT, several authors stated the importance of additional research to further elucidate the effectiveness of partner notification on prevention of HIV transmission, increased utilization of necessary services, and especially reduction of HIV risk behaviors (Hoffman et al., 1995; Landis et al., 1992; Macke et al., 2000; Macke & Maher, 1999). Evidence is limited, but available data suggest that partner notification can lead to a reduction in risk behaviors (Holtgrave et al., 1993; Macke & Maher, 1999). These effects could potentially be enhanced through referral to appropriate counseling, behavioral interventions and other prevention activities. Several key questions remain unanswered: Do partners reduce their risk following notification? Do they access the needed services they are referred to beyond testing? What unintended negative effects result from notification?

Current management information systems (MIS) in federally funded public health jurisdictions vary in the amounts and types of data they collect relevant to addressing these questions (National Alliance of State and Territorial AIDS Directors, 2000). Some jurisdictions are working toward development of integrated data systems that will link prevention, counseling and testing, and partner notification and referral databases. These MIS can play a key role in evaluating the effectiveness of counseling, testing, referral and partner notification (CTRPN) services. A truly comprehensive evaluation of CTRPN would involve several components, including preproduction formative
evaluation, development of goals and objectives, postproduction formative evaluation, process evaluation, outcome evaluation, impact evaluation and economic evaluation (Holtgrave, Reiser, & DiFranceisco, 1997). While the resources to conduct a truly comprehensive evaluation are rarely available for most programs, evaluation methods have been proposed (within a case study design) that optimally leverage limited resources when comprehensive evaluation is not possible.

Summary

The preceding review provides several implications for the planning and implementation of the current case study:

- Sites selected should include both name-based and anonymous testing protocols.
- The dearth of literature on referral processes and linkages points out the timeliness of this study and the importance of focusing on linkages and how clients come to HIV CT.
- Interviews and document reviews will need to focus on how the referral process works once an individual receives his or her results and recommendations for treatment and/or other services are made.
- Interviews and document reviews will need to explore:
  - the influence of an individual’s health insurance status on the referral and linkage process,
  - the relationship between HIV risk and referral, and
  - the role of provider versus partner referral in the successful linkage of referrals.
INTRODUCTION


This report summarized HIV counseling and testing results in publicly funded state and local health department HIV prevention programs. The report was based on data sent to CDC through June 30, 1997. The report represents the most recent published information available from the HIV counseling and testing data system.


This guideline articulates the CDC recommendation that all jurisdictions conduct case surveillance for HIV infection as an extension of the current requirements around AIDS surveillance activities. The impact of advances in antiretroviral therapies, the implementation of new HIV treatment guidelines, and the need for information regarding persons at all stages of HIV infection are cited as reasons for the changes in policy recommendations.

COUNSELING AND TESTING


Testing for HIV antibodies has become a necessary strategy to reduce the transmission of AIDS. This study explored differences among men seeking anonymous versus confidential HIV antibody CT in terms of demographic characteristics, risk behaviors, rates of returning for test results, and willingness to participate in partner notification. Statistically significant differences were found by race and insurance status, as well as by risk behaviors. Caucasian men were more likely to seek anonymous (86%) versus confidential testing (55%), as were those with employer health insurance (41% versus 24%). Those tested anonymously also reported more bisexual/homosexual activity (96% versus 79%), whereas injection drug use and sex exchanged for drugs or money were seen more among those who received confidential testing (5% anonymous versus 14% confidential, and 3% versus 11% respectively). The proportion of individuals who reported having sex with a man who had sex with other men was also significantly higher at anonymous test sites (79% versus 56%). Nearly one-fourth of those confidentially tested were previously tested compared to 8% of those anonymously tested. HIV-positive persons who chose anonymous testing were less likely to have tested positive previously than those who chose confidential testing raising the question of whether these individuals use confidential testing as a means of confirming a positive result and establishing access to needed treatment services. No significant differences were found in regard to returning for results or agreeing to either partner or physician notification, however a significant difference was seen for acceptance of care coordination among those confidentially tested (78% versus 53%). Since other studies have reported varying results, additional prospective studies were deemed necessary to verify these results for further evaluation of confidential versus anonymous testing.


The objective of this study was to assess whether anonymous HIV testing was associated with earlier HIV testing and HIV-related medical care than confidential testing. An AIDS patient survey was conducted in 8 states, all of which provided publicly funded confidential and anonymous HIV testing. In each of the states, the researchers sought to interview either all persons who were described as having newly diagnosed AIDS or a probability sample...
of new AIDS cases. Of the 3321 cases sampled, 2801 met eligibility criteria, and of those 1913 were interviewed. Of those interviewed, another 1078 were eliminated from the analysis for reasons such as giving a false name on a confidential test or being tested in a state that did not have anonymous testing at the time of their test. Anonymous testing was significantly associated with earlier testing, earlier access to medical care, and a longer duration of HIV-related medical care. After adjustment for age, race/ethnicity, education, income, insurance status, HIV exposure group, HIV symptom status, and state residence, anonymous testing remained significantly associated with earlier access of medical care.


Project RESPECT was designed to determine the efficacy of different models of HIV prevention counseling among high-risk individuals in order to increase condom use and prevention of new HIV and STD cases. Heterosexual, HIV-negative persons at STD clinics (who consented to participate) were randomized to receive one of three HIV prevention intervention strategies: 1) pre-and posttest HIV education, 2) interactive, HIV pre- and posttest prevention counseling, or 3) an enhanced, theory-based HIV prevention counseling offered over three, one-hour sessions. Each design was evaluated on positive changes in attitude, self-efficacy, and perceived norms. This article describes the quality assurance measures of standardized tools and training, frequent observation and feedback to project staff, and process evaluation measures taken to ensure valid and reliable results.


Project RESPECT was a multi-center randomized controlled trial specifically designed to assess the efficacy of HIV prevention counseling in reducing high-risk sexual behaviors and preventing new sexually transmitted infections among HIV negative persons being tested for STDs. This was completed by comparing various types of one-on-one HIV/STD prevention models. One cohort (C1) received four interactive, theory-based sessions (totaling 200 minutes), and another (C2) received two brief interactive, risk-reduction sessions (totaling 40 minutes), and the third (C3) and forth groups (C4) each received two brief didactic messages. The first three groups were actively followed for up to twelve months. Self-reported condom use and laboratory diagnoses of new STDs were used to measure the effectiveness of the interventions. At the three-month follow-up, both groups receiving the interactive sessions self-reported higher levels of 100% condom use (46% for C1, 44% for C2, and 38% for C3). After six months, the differences were not as pronounced (39% versus 39% versus 34%). The levels of 100% condom use within, and differences between, cohorts decreased over the 12-month period, even though consistent condom use was reported more often than at baseline. During the twelve-month study, 12.7% of participants were diagnosed with a new STD. At the six-month follow-up, participants in the didactic group (C3) had a higher incidence of new STD cases (10.4%) than the two interactive groups (7.2% for C1 and 7.3% for C2). After twelve months, the incidence of newly diagnosed cases of STDs was 14.6% for C3, 11.5% for C1 and 12.0% for C2. No significant differences were found between the two interactive models, showing that interventions of brief, interactive counseling sessions can increase condom use and prevent the spread of STDs.


The authors presented results of a study assessing predictors of rates of failure to return for results of HIV antibody testing for various types of test sites throughout California. The set of potential predictors was selected from information collected during the pretest risk assessment session. These included risk category (MSM, IDU, both MSM and IDU, sex with partners at risk, sex for money or drugs, blood transfusion, multiple sex partners, no reported risk); demographics; drug use during sex; use of condoms or other barrier methods; number of previous HIV tests; and previous failure to return. The sample comprised 366,280 clients who received an HIV test over an 18-month period at publicly funded testing sites in California. The failure to return rate was 16.4% for the entire sample. Site type, race, age and risk categories were all associated with a greater likelihood of failure to return. Individuals
tested at STD clinics and those tested at mobile test sites were approximately 4 times more likely to fail to return than others were. Failure to return was over 2.5 times more likely for IDUs and over 2 times more likely for individuals less than 20 years old. African-Americans were about twice as likely as other racial/ethnic groups to fail to return for their results. Predictors of failure to return within a particular site type varied. An implication derived was that counselors should know the characteristics of those most likely to fail to return for test results in order to concentrate special efforts to encourage their return. The authors proposed two additional policy implications. First, some form of screening for testing based on level of risk should be implemented. Second, the use of rapid testing should be promoted to eliminate the possibility of failure to return for test results, but more research would be needed to determine the likelihood that a person with a positive result on a rapid test would return for results of confirmatory testing.


There have been concerns that policies requiring confidential HIV name reporting to state health departments may deter some individuals from getting tested and seeking care. Changes in the number of persons tested at six publicly funded HIV CT sites were examined from one year prior through one year following the implementation of name reporting. Four states showed an increase (ranging from 16% to 63%) in the overall number of persons tested after the implementation of HIV name reporting. No statistically significant differences were found in magnitude of decrease for the states that reported a decrease in the number of individuals tested (Louisiana decreased by 11% and Michigan by 2%), as there had been a declining trend prior to enactment of this policy. Increases in testing for at-risk heterosexuals were seen in all states. Louisiana and Tennessee had a decrease in testing among men who have sex with men (4.3% and 4.1%, respectively). Decreases in testing among injection drug users and racial and ethnic minority populations were also seen in Louisiana (15%), Michigan (34%), and New Jersey (<1%). Comparisons also showed that the percent change in number of person tested at anonymous sites decreased by 24% in Louisiana. Nebraska saw a tremendous increase in anonymous testing (34%), but only a slight increase (3%) in confidential testing. Confidential tests among white MSMs and IDUs decreased (17% and 2% respectively). Events at that time, such as the announcement of Magic Johnson's HIV status and subsequent media coverage, increased outreach efforts. The introduction of anonymous testing sites may have also influenced attitudes toward testing in some areas. Based on the results of this study, confidential HIV reporting by name did not negatively affect the use of HIV testing.


This article reviewed approaches to counseling and behavioral change and discussed linkages to theory developed to support HIV CT in an attempt to examine, understand and improve the usefulness and effectiveness of HIV CT. The authors described various counseling approaches and placed HIV CT in the context of these approaches. Counseling approaches were compared in terms of how well they address the five tasks of HIV counseling: relationship building, risk assessment, dissemination of information, behavior change, and emotional and coping support. No single approach appeared to fulfill the requirements of all five functions. The authors considered behavioral and cognitive-behavioral approaches to be the only two that address all of the key tasks involved in HIV CT. Client-centered and crisis counseling methods were viewed as appropriate for the relationship building and emotional/coping support for HIV counseling, but they do not adequately address the behavior changes necessary to reduce HIV risk. Programmatic and research implications and suggestions for future research into the effectiveness of HIV counseling were also discussed.


This article reported on an analysis of responses from the US National Health Interview Survey in 1994 and 1995 to determine factors associated with a decreased likelihood of returning to receive HIV test results. Of the estimated 17.5 million people tested, 2.3 million did not return for testing. Self-initiated testing was found to be indicative of a significantly reduced likelihood of returning for test results versus compulsory or recommended testing (6% in 1994
and 4% in 1995 for self-initiated tests, 17% and 21% for compulsory tests and 8% and 13% for recommended tests). Those who did not receive pretest counseling were also less likely to return for their results (18% in 1994 and 16% in 1995). Only a few demographic factors, such as being young or non-white, were associated with significant reductions in the likelihood of returning for test results. The authors recommended evaluating and implementing alternative measures, such as enhanced counseling, telephone notification, and rapid HIV-screening tests, to increase the proportion of individuals who receive their test results and to promote earlier access to prevention, care and treatment services.


The Centers for Disease Control and Prevention require that certain data on HIV CT be collected and reported by sites receiving public funds. Summary and client-level testing data from 1992 through 1995 were examined and compared by age group, sex, and race/ethnicity for risk behaviors, previous history of testing, anonymous versus confidential testing, and type of testing facility (e.g., STD clinic, health department, drug treatment facility, prison, etc.). The overall proportion of those that tested positive decreased from 2.0% in 1992 to 1.6% in 1995. According to the client-level data, the proportion of tests of high-risk males and females remained fairly stable (47% in 1992 to 48% in 1995 for males and 31% to 33% for females). The proportion of those who had previously been tested increased from 38% in 1992 to 53% in 1995. By 1995, posttest counseling was more common at anonymous testing sites (86%) than at confidential test sites (70%). Because the summary records usually available at confidential testing sites are collected for each testing episode, and not for each individual, comparability of data across project areas is limited. Consideration of collecting client-level data at all sites was recommended to observe trends in HIV CT and to improve the development of HIV prevention interventions.


This article reviewed 35 domestic and international studies, published or presented between 1990 and 1996, for evidence that HIV CT motivates changes in HIV risk-related practices and promotes help-seeking behaviors among individuals who come in for testing. Based on the identified target population, the studies were grouped into four categories: men who have sex with men (7), injection drug users (9), women and heterosexual couples (12), and mixed samples recruited from sexually transmitted disease (STD) clinics and other sites (7). Like previous reviews, the results across all groups were inconclusive. Studies of heterosexual, HIV-serodiscordant couples and those examining the relationship between serostatus and risk behaviors provided the most consistent evidence for the beneficial effects of HIV CT. However, results varied based upon study population and design. Most studies were not designed to evaluate the impact of HIV CT; rather conclusions were based on secondary analysis of data collected as part of a larger research effort that was not focused on assessing the impact of HIV CT on motivating behavior change. Conducting appropriately designed research studies to evaluate the impact and effectiveness of HIV CT on risk behaviors and subsequent transmission of HIV was recommended.

REFERRAL AND LINKAGES


Bay Area Young (BAY) Positives was a peer-run, peer-based organization to help young people (up to 26 years of age) living with HIV gain entry into services and empower them to improve their quality of life. Funded by the Special Projects of National Significance (SPNS) Programs, this project targeted youths who may otherwise "slip through the cracks" of the service system. A total of 139 youths were involved with BAY Positives from June 1994 to September 1997, including young women, gay or bisexual young men and minority youth. Among BAY Positive members, 61% of males and 47% of females self-reported having engaged in sex with a partner they knew to be HIV positive. At initial contact, individuals were more likely to have reported ever having used substances or injected drugs than having sex with an injection drug user. Members of this peer-run, peer-based organization were also
actively involved in community and health fairs and conferences; they also provided in-service training sessions at other agencies and were involved with community outreach. A total of 53 presentations were made during the given time period. Limitations of the project included keeping apprised of changes in the needs of members and the availability of existing services, and transitioning youths from one group to another as they "age out" of a particular peer group. The success of the program was also dependent on the ability to provide continued support and development for staff, as many of them were HIV-infected youths.


A three-year, cross-sectional study was conducted to assess utilization of health-related services, such as medical, drug treatment, mental health care, housing and case management services, by 777 HIV-infected drug users and crack smokers one year prior to, and two years following, the availability of Ryan White Title I funding in five U.S. cities. Participants were also surveyed about their HIV risk behaviors during the same time frame. The study was based upon the health belief model, which states that a consequence of health action (i.e., service utilization) is a reduction in risk behavior. With the exception of drug treatment and mental health services, the use of services increased. However, the increase was not linear over the 3-year period. The use of health-related services was found to be associated with a lowering of HIV risk behaviors, with the exception of housing services, which was associated with an increase in risk behaviors. When composite risk scores were calculated, only slight differences were noted between those respondents receiving at least one service in the year prior to Title I funding and those not receiving any services. In the second year of funding, those having received at least one service reported a lower frequency of sex and drug-related behaviors. The receipt of services was found to be a significant factor in the reduction of risk behaviors; the interaction of year of funding and services received was also significant. Among those who utilized services, the average number of risk behaviors per respondent reported for the 30 days prior to interview decreased from 1.7 to 1.15 during the 3-year period. For respondents who did not receive any services, the composite risk score increased from 1.52 to 2.09. These findings suggested that strategies are needed to increase the attractiveness of services to substance abusers, especially of mental health and drug treatment services, in order to reduce HIV risk behaviors.


While the primary goal of needle exchange programs (NEPs) has been to reduce the transmission of HIV among injections drug users (IDUs), there also exists the potential to reduce or eliminate drug use through referrals into drug treatment programs. A comparison of new NEP referred patients versus standard referral patients (SRPs) to drug treatment programs was conducted over a 3-year period. No demographic differences were seen between the proportion of NEP patients who actually sought out treatment and those who did not. Compared to SRPs, those referred through NEPs were more likely to be African American, male, unemployed and significantly older. In the 30 days prior to the interview, NEP patients were found to have a higher baseline severity of drug use (mean of 28.8 days of heroin use and 15.4 days of cocaine use versus 17.2 and 5.2 days, respectively), to have spent more days involved in illegal activities, and to have been engaged in more risk behaviors. A significantly higher proportion of NEP patients had cocaine dependence (74% versus 41%); and a slightly, but significantly, higher percentage of SRPs (88%) finished the first 13 weeks of treatment (versus 76% for NEP-referred patients). Significant reductions in opioid and cocaine use, the number of days engaged in illegal activity, and injection drug use were seen in both groups. The extent of improvement in the needle exchange groups was, with few exceptions, comparable to that of standard referral patients. While needle exchange programs have offered a venue for admission into drug treatment programs, conducting additional studies to look at how NEPs impact successful completion of such treatment programs was recommended.

Low-income, minority women have been disproportionately infected and affected by HIV/AIDS. Psychosocial factors, such as poverty, substance abuse, and violence have complicated the effective delivery of comprehensive health care for these women. Whole Life was a theoretically-based clinical service model designed to integrate mental health services into the primary care setting for HIV-infected pregnant and non-pregnant women. Standardized instruments adapted for cultural or language differences were used to gather information during the women's first two visits. Existing case managers and clinical social workers/psychologists were trained to gather the information typically recorded in clinical notes. Upon the first visit, a case manager captured demographic and physical health information, including HIV status. A clinical social worker or psychologist would follow-up by collecting information regarding risk behaviors, disclosure or nondisclosure status, perceived stress, history of abuse, and psychological distress. During the subsequent visit, a lengthier needs assessment and service plan was conducted by the case manager, followed by an assessment of psychiatric disorders by the clinical social worker or psychologist. The implementation of Whole Life enabled the integration of mental health and psychosocial needs of women to be assessed and addressed in the primary clinical care setting. The database has also allowed for a better understanding of features and types of interventions to use to enhance outcomes for minority women.


A national survey of administrative directors and clinical supervisors was conducted to examine the extent to which linkages, such as on-site delivery, external arrangements, case management, and transportation assistance, were associated with an increase in utilization of medical and psychosocial services in outpatient substance abuse treatment units. Case management services provided on-site were correlated with utilization of routine medical care services, financial counseling, and housing assistance; off-site case management, referral and formal external arrangements were not associated with service utilization. On-site delivery and transportation assistance were significantly associated with higher levels of utilization of ancillary services among clients needing substance abuse treatment, and showed stronger relationships than case management. These findings differ from previous studies conducted in substance abuse treatment units with funded initiatives and research protocols possibly because the survey was administered in naturalistic settings where case management may lack standardization and rigor. Future initiatives and policy changes should emphasize the linkage mechanisms of on-site delivery, transportation assistance, and in some situations, on-site case management to increase clients' utilization of services. Future research should focus on the effect of linkage mechanisms on utilization of services, and their associated costs.


The role of street outreach workers in HIV prevention has extended past delivering risk-reduction messages and distributing "works," condoms, or both to include referring injection drug users to medical services. The frequency with which drug users act on these referrals has not been well studied. The CDC-funded AIDS Evaluation of Street Outreach Project (AESOP) examined levels of exposure to street outreach workers reported by injection drug users, the proportion of referrals from such contacts resulting in IDUs seeking medical services, and the predictors of acting on these referrals. AESOP provided enhancements to existing outreach services, including a mobile case management, improved training, and a tracking system. Cross-sectional interviews were conducted, before and three to nine months following the implementation of the enhancements, with over 3000 IDUs in the intervention and comparison areas of five identified cities. Receiving and acting on medical referrals varied across cities. Between 36% and 66% of IDUs reported having been referred for substance abuse treatment; of these, 14% to 55% reported actually going for treatment. More than one-third reported having previously been in treatment for substance abuse. Referrals to STD treatment were received by 27% to 40% of IDUs. The proportion of those acting on these referrals varied from 4% in New York to 39% in Philadelphia. General medical care referrals were reportedly received by 16% to 36% of IDUs. Accessing general medical services was highest in Philadelphia (57%) and lowest in New York (17%). A referral tracking system in Los Angeles showed 52% of those referred to at least four services actually went to receive those services. Of those referred to HIV counseling and treatment (40%), the majority actually went (95%), whereas only 34% of the 45% referred to substance abuse treatment acted upon their referrals.
While these results indicate that multiple contacts between street outreach workers and IDUs enhanced the probability of the IDU acting upon the referral, outreach workers reported great difficulty in reaching the majority of IDUs at least once a month. Strengthening the link between outreach and relevant social services, via agency coordination, client advocacy, or methods for tracking referrals, was recommended to maximize IDUs acceptance of referrals and access to services.


The Special Projects of National Significance (SPNS) Program of Health Resources and Services Administration awarded ten, three-year grants to projects utilizing various methods to link youth with HIV into care through new or existing networks of services. A cross-cutting evaluation of those projects yielded five key elements necessary for the successful provision of health care and support services to HIV-positive and at-risk youth. These elements include: peer-youth information and dissemination; peer-youth advisory groups; peer-youth outreach and support; professional, tightly linked medical and social support networks; and active case management and advocacy for individual clients and programs. Equality in the input from, and involvement of, both professionals and youth was also identified as crucial to the success of the program.


This study examined the services needed and received by individuals testing HIV-positive, as well as the social consequences of testing HIV-positive. A total of 154 patients of sexually transmitted disease clinics in Baltimore, Miami, and Newark who tested HIV positive in the previous 6 to 24 months were interviewed. More than half of the population (55%) identified by the clinics were unable to be located, despite the recent visit. Based on clinical records, those interviewed were similar to those not interviewed. One-fourth of interviewees reported not having received HIV-related medical care. Among those not receiving care, most reported they never received a referral (42%), were in denial (19%), or were not interested in receiving medical care (19%). The most frequently reported barriers to medical care included lack of transportation and lack of money. While the majority of individuals (89%) had disclosed their HIV status, negative social consequences of disclosing one's HIV status were fairly infrequent. The most frequently reported negative consequences were being asked to move out or having someone else move out, loss of employment, and (in two cases) assault. The majority of individuals stated that they were selective in disclosing their situation to people they thought would be understanding; despite their efforts, some patients did experience a negative response from their sexual partners, family members, or friends and would not recommend disclosure to others. However, despite some negative consequences, most would recommend HIV testing to others. Clinical staff should consider routine follow-up after posttest counseling to identify and address issues related to access and utilization of services.


The prevalence of women infected with HIV has increased each year; the prevalence of violence for many of those women has also been increasing. Little research has been conducted on the possible causal relationship of HIV to violence and if different HIV prevention practices affect the risk for violence. Literature pertaining to violence and HIV serostatus, including issues associated with disclosure and violence resulting from condom requests made to sex partners, were reviewed in this article. The literature suggested that women with or at risk for HIV, such as those with a low annual income (under $10,000) and living in a poor neighborhood with high rates of unemployment, alcohol and drug abuse, are the same populations of women at high risk for violence. Statistically significant increases in violence against HIV infected women, compared to uninfected women with similar demographic and behavioral characteristics, were not found. However, data suggest that violence related to disclosure of status affects a small, but critically important, proportion of women. The authors suggest that integrating violence screening and referral into HIV care and prevention services may be crucial in helping many seropositive women access the assistance they need while minimizing their risk for violence.

The Special Projects of National Significance (SPNS) Program of Health Resources and Services Administration awarded ten, 3-year grants to fund projects utilizing various methods to link youth with HIV into care through new or existing networks of services. The agency's type and availability of services for HIV positive and at-risk adolescents and opinions related to health care referral patterns were evaluated and assessed. Two instruments were used to rate interagency knowledge, referral patterns and general satisfaction with services. Representatives of 22 agencies from ten healthcare service categories in the Boston area participated. More than half of the services listed on the instrument were offered by less than 25% of the agencies. The majority were related to drug treatment and HIV-specific inpatient medical services, as well as dental care and clinical trial services for youths. Furthermore, services were found to be clustered near large hospitals or community health centers. Lack of funding and transportation were cited as barriers to care. A perceived lack of awareness about services among youth was also mentioned. This evaluation found that youth-oriented HIV services need to be increased and made accessible to at-risk adolescents.


This article reported results of an in-depth evaluation of referrals from the San Francisco municipal STD clinic. Reviews of HIV antibody counseling, testing, referral, and partner notification (CTRPN) have shown the effectiveness of counseling and testing in reducing risk behaviors of seronegative individuals to be minimal. Most do not change their risk behaviors, while others actually exhibit increases in risk behaviors. Any observed decreases in risk behaviors that can be attributed to CTRPN have usually been short-lived. However, the literature suggests that multiple counseling sessions are more effective in reducing risk behaviors than fewer sessions among high-risk seronegative individuals. A lack of published quantitative evaluations of CTRPN referrals for seronegative individuals prompted the study described. In 1995 and 1996, a review of HIV testing and referral data at the San Francisco Department of Public Health (DPh) (N=5,595) and an in-depth evaluation of referral data at a San Francisco STD clinic (N=747) was conducted to gather information on the prevalence of referrals and the association between risk behaviors and prevention referrals among seronegatives. The data showed that less than one-fifth of the sample received any type of prevention or non-prevention referral (19.1% of patients at DPh, 10.6% at the STD clinic). Prevention referrals were given more often (15.4% at the DPh, 5.9% at the STD clinic) than non-prevention referrals (8.7% - DPh, 5.6% - STD clinic). IDUs were the most likely to receive prevention referrals at both the DPh and the STD clinic (48.5% and 36.4%), followed by high-risk females (20.3% and 10.0%), and MSMs (19.2% and 12.7%). Individuals at the San Francisco DPh who had been previously tested were more likely to have received prevention referrals (18.1%) compared to those not previously tested (11.1%). No associations were found between reports of unsafe sex practices or needle sharing and an increased likelihood of receiving a prevention referral. Recommendations for improvements in counseling were made, especially for the referral aspects of CTRPN needed to encourage and maintain the reduction of high-risk behaviors among those testing negative for HIV.


This study surveyed existing health and social services for women living with HIV in a mid-sized city regarding the professional health, support, and educational services they offered. The authors describe a woman infected with HIV as typically being young, poor, a minority, and of childbearing age. They state there has been little research on services provided to HIV positive women, and then describe their study designed to address this gap in the literature. Seventeen facilities agreed to participate in a telephone survey, but only the 15 providing services on-site were included in the analysis. The facilities ranged from free-standing clinics (7), hospital-based providers (4), and private providers (4). Geographic locations included 12 inner-city sites, two suburban sites, and one rural site. Agencies were asked to report if they provided any of ten professional medical services, 18 support services, and 16 educational or other services identified on the survey. Only two of the 15 facilities offered all ten medical services, however these services were not all offered at the same location. Combinations of medical and support services were offered at each facility. One-third of sites offered some form of substance abuse care; but only one site offered substance abuse counseling without treatment. Less than one-fifth of facilities offered adoption assistance (3),
childcare (2), or housing (1). None of them provided home delivered meals. In this study, none of the facilities surveyed offered comprehensive care, rather many of the services needed by women were fragmented. This is problematic, especially for women with children, since the woman must go to multiple locations to receive comprehensive care. Furthermore, certain needed services were available at only a few facilities, while some were not even offered. Slightly more than half (53%) offered services during week end daytime hours only. Almost half offered some evening hours, but only one-fourth provided services during the weekend. Further, only two sites offered child care, and only one of those offered it for free, posing additional difficulties for women that work and/or have children. The authors recommend that, while additional research in this area is needed, efforts should be made to make services at facilities more comprehensive, focusing on the needs of the women served.


This article presented results from a participant observation study of 30 publicly funded HIV CT centers in Pennsylvania selected randomly from 257 CT sites recommended for evaluation in a 1994 Pennsylvania Bureau of HIV/AIDS planning document. The study was designed to explore the staff-client interaction during HIV CT sessions. The findings augmented information collected from the same randomly selected sites through a mail survey, sites visits and face-to-face interviews with center staff. Actors, who reflected the HIV epidemiological profile of the region studied, were recruited and trained for the study. Training included information on the goals of the project, HIV/AIDS knowledge, characteristics of a typical CT session, and the actors’ particular character profiles. Both HIV-positive and HIV-negative actors were recruited. Following training, the actors posed as clients at the selected sites presenting with various and typical HIV-risk activities. The actors used structured data collection forms to record the initial telephone conversation when scheduling the visit, as well as the pretest and posttest sessions. HIV-positive actors used an additional form to record information specific to HIV-positive clients, including referrals to health care services and psychological support. The forms were based on the 1994 CDC HIV CT guidelines. Results indicated that while sites have protocols and policies in place, little was done to ensure that these protocols and policies were actually followed during the client-counselor interaction. Further, while a majority of clinics surveyed reported having protocols and policies in place and that they implemented these, the majority of these protocols and policies were actually followed during the client-counselor interaction. The findings augmented information collected from the same randomly selected sites through a mail survey, sites visits and face-to-face interviews with center staff. Actors, who reflected the HIV epidemiological profile of the region studied, were recruited and trained for the study. Training included information on the goals of the project, HIV/AIDS knowledge, characteristics of a typical CT session, and the actors’ particular character profiles. Both HIV-positive and HIV-negative actors were recruited. Following training, the actors posed as clients at the selected sites presenting with various and typical HIV-risk activities. The actors used structured data collection forms to record the initial telephone conversation when scheduling the visit, as well as the pretest and posttest sessions. HIV-positive actors used an additional form to record information specific to HIV-positive clients, including referrals to health care services and psychological support. The forms were based on the 1994 CDC HIV CT guidelines. Results indicated that while sites have protocols and policies in place, little was done to ensure that these protocols and policies were actually followed during the client-counselor interaction. Further, while a majority of clinics surveyed reported having protocols and policies in place and that they implemented these, the majority of counselors assessed through the participant observation did not follow these protocols. Finally, findings suggested that the lack of adherence is not due to carelessness or indifference, but rather a lack of understanding, training or resources to implement the standards.


Over a three-year period, this study examined the use of HIV treatment regimens and assessed differences in the use of health services by a population of HIV-seropositive and HIV-seronegative women of similar sociodemographic characteristics, with the exception of racial/ethnic backgrounds. Fifty-seven percent of the participants were African-American, 23% were white, and 16% were Hispanic. Seropositive women were more likely to have a consistent source of health care (90% versus 74%). Their reported use of HIV-related services, however, seemed inadequate: 80% reported ever using antiretrovirals, whereas only 49% were currently (in the 30 days prior to being interviewed) taking antiretroviral medications. African-American women were significantly less likely to go to the same doctor or clinic for health care, including HIV-related treatments and services (86% versus 94% for whites and 97% for Hispanics). African-American women were less likely to have ever taken antiretrovirals (67%) or PCP prophylaxis (78%) compared to white (74% and 91%, respectively) or Hispanic women (75% and 81%). The observed differences were not only a associated with race, but with behavioral characteristics as well, particularly injection drug use (IDU). Current IDUs were less likely to have a consistent source of health care (81%), have ever been on an antiretroviral therapy (56%) or have taken PCP prophylaxis (73%) compared to non-current IDUs (90%, 76%, and 84%, respectively). Current use of antiretrovirals and PCP prophylaxis was also less common among African-American women and IDUs. Multivariate analysis, controlling for race and study site, found significantly less consistency in health care providers, fewer outpatient visits, and less use of prophylaxis for PCP and other opportunistic infections among current IDUs relative to non-IDUs. Intervention strategies are called for to reach HIV-positive women, IDUs and African-American women needing medical services. Although race and IDU status
were independently associated with use of medical services in this study, additional studies were suggested to better understand the association between these factors.


Methadone maintenance programs often have the capacity to integrate medical and substance abuse treatment, enabling them to provide on-site HIV care for injection drug users (IDUs). In this study, three methadone treatment facilities in Rhode Island, none of which provided primary HIV care, were evaluated regarding accessibility to antiretroviral therapies (ARVs) for HIV positive IDUs based upon provider referrals. Seventy-two HIV infected IDUs were interviewed about their beliefs regarding the benefits of HIV therapies and their sources of information for ARVs. Nearly three-fourths of the sample (73%) reported ever having taken antiretrovirals. Physician recommendations (81% among those having taken ARVs and 32% among those that had not), viral load level (85% and 26%), CD4 cell count (83% and 21%), and the out-of-pocket cost (85% and 26%) were considered most important in deciding whether or not to start new antiretroviral medications. The majority of participants believed antiretrovirals to be "somewhat" or "very" helpful, regardless or whether or not they had taken ARVs. The majority also believed antiretrovirals could prolong survival (96% among those having taken ARVs and 95% among those that had not), increase CD4 cell counts (92% and 89%), decrease viral load (84% and 95%), and decrease HIV-related symptoms (85% and 78%). A small proportion believed that ARVs could prevent transmission (26% and 39%) or cure HIV (17% and 22%). This study found that IDUs infected with HIV and enrolled in a methadone program for at least six months were well connected to primary HIV care despite having to go to a different location. Although there was no comparison to IDUs who were not in methadone maintenance programs, the authors conclude that simply being in drug treatment could potentially be associated with individuals being more likely to receive HIV care, including antiretrovirals.


In this article, the authors reviewed papers pertaining to HIV infection among persons with serious mental illness, published between 1980 and 1988. Issues relating to the reduction of HIV risk and effective treatment, along with barriers to adequate care, were discussed for this population. For a variety of reasons, individuals with severe mental illness have an increased likelihood of high-risk sexual behaviors and injection drug use, and are thus at greater risk for HIV infection. The authors note that cognitive-behavioral approaches to risk reduction have demonstrated some success, but only when "booster" interventions were employed to maintain positive behavioral changes. Such interventions have been rarely utilized because of high financial and labor costs. Many severely mentally ill individuals usually do not get tested for HIV until they enter the public mental health system for treatment. A wide range of policies related to HIV screening in this system (e.g., discouragement of staff documenting patient HIV status) contributes to delayed or missed diagnoses of HIV infection. A lack of case managers has further impeded the transition from diagnosis in the mental health system to treatment and care services. The authors recommended that additional efforts are needed for early detection of HIV among persons with serious mental illness, emphasizing that coordination and cooperation between the public mental health and physical health care systems as essential to treating this population.


Interviews with women infected with HIV and service providers were conducted in five eligible metropolitan areas to assess issues related to service use and need, especially access to drug treatment services. The majority of the 116 women interviewed were African-American and experiencing HIV-related symptoms. Less than 8% reported no history of crack or injection drug use; whereas more than half (53%) reported injection drug or crack use in the past 30 days. In the 30 days prior to their interview, approximately one-fourth of the women reported having had unprotected sex, having sex with an injection drug user (13.8%), and/or exchanging sex for money (5.8%). Less than
half of the women reported having been in a residential substance abuse treatment facility (47%) or an outpatient treatment program (44%). Gaps in the percentage of women needing detoxification, residential, or outpatient drug treatment services and the percentage of those having received them were statistically significant, especially for residential treatment: 35% reported needing it compared to 11% who had received it. For drug detoxification, 35% reported need vs. 11% reporting receipt. For outpatient drug-free treatment: 36% reported need vs. 21% reporting receipt. For outpatient drug maintenance: 21% reported need vs. 15% reporting receipt.

In addition to surveying women living with HIV, 115 providers were interviewed regarding the services offered to women. Most of the providers surveyed (95%) reported offering services for women. Approximately one-third described their agency as a substance abuse treatment/recovery program, with half of those offering detoxification services and/or long-term residential treatment. The majority of other types of agencies also offered some kind of substance abuse treatment. Many agencies also reported providing medical, dental and other support services. Providers cited lack of funding as the most common barrier to expanding substance abuse treatment services. The lack of ancillary services and lack of transportation services were also cited. Staff and client resistance were not seen as significant barriers. Findings from this study indicated that, in addition to increasing agencies’ capacities to provide substance abuse treatment services, increasing the availability of a comprehensive array of services is essential to the care of women living with drug abuse and HIV.


The Boston HAPPENS (HIV Adolescent Provider and Peer Education Network for Services), supported by the Special Projects of National Significance (SPNS) Program, HIV/AIDS Bureau, HRSA, was a collaborative project of eight area agencies to provide a network of culturally and developmentally appropriate care for homeless, at-risk and HIV-positive youth. Program components included outreach and risk-reduction, HIV CT, mental health services, comprehensive and multidisciplinary care (health status screening and services needs assessment) and support, and follow-ups. The project also aimed to integrate care and communication among providers in the metropolitan Boston area. An appointment-tracking system was developed to assist in evaluating patient adherence and referrals. More than 1000 youths, ages 12-24, were tracked. Of those served, 62% received an HV risk assessment, 53% received pretest counseling, 48% were actually tested, and 29% received posttest counseling. At the time, 65% of youths were receiving medical care and 16% were receiving mental health care. An evaluation of access to mental health and substance abuse services found that at-risk youths, especially those with more visits throughout the Boston HAPPENS program, were more likely to be referred to, and receive, these services. Youths who accessed care at an outreach site were ten times more likely to be linked into medical care. Since the inception of the program, the number of HIV-positive youths accessing coordinated services through the program increased from 18 to 46. Interviews with 22 agencies were also conducted to evaluate the structure of the network of care. The evaluation found that various outpatient services for HIV-positive youth were available, but long-term substance abuse treatment options were scarce. Structural evaluations and ongoing community and youth input into the design and implementation of the services have strengthened, and continue to strengthen, the network to reach and provide services to the target population.

PARTNER NOTIFICATION


Worldwide, HIV prevalence rates have been the highest in developing nations. Voluntary HIV CT services are considered an integral part of HIV/AIDS programs in the industrialized world and have been strongly advocated for in developing countries. However, there has been a broad range of ethical, social, policy, technical and economic issues that need to be examined in determining the feasibility for developing countries to effectively implement HIV CT. Despite the barriers, some countries, such as Uganda and Zaire, have implemented these programs, with varying degrees of success. Some obvious advantages to incorporating voluntary HIV CT into these countries' comprehensive HIV prevention strategies have included empowerment and risk reduction for individuals and serodiscordant couples.
The need for additional analysis was recommended for tailoring HIV CT programs to the needs of each individual country.


There have been many debates on the notification of sexual partners of HIV-infected individuals. Issues of confidentiality versus the common good and ethical concerns continue to challenge state and local health departments. This study surveyed physicians in Syracuse, NY by telephone to collect information regarding their experiences and opinions about HIV partner notification and the role of public health agencies in that notification process. All eleven physicians surveyed felt that counseling their patients about prevention of HIV transmission was necessary, but that its effectiveness in actually preventing transmission was dependent upon the patient (73%), and in some cases, negligible (18%). While more than half of the physicians (64%) indicated familiarity with the New York Partner Notification Assistance Program (PNAP), only 45% had actually referred a patient to PNAP. However, most were supportive of enhanced efforts regarding partner notification. The majority (82%) stated they had asked their HIV-infected patients about their sexual partners, but only one actually collected the names of those partners. All of them relied upon the HIV-infected individuals to notify their partners regarding HIV risk. While all of the physicians in this study supported partner notification, they were not always actively partaking in the process. The implementation of standard procedures and establishing linkages with public health agencies may facilitate this process.


This editorial review provided an overview of HIV partner notification (PN), the rationale behind it including related ethical issues, and a summary of the evidence regarding its effectiveness. Previous studies have shown partner notification to be an effective means for reaching individuals at risk for HIV and as a recommended method of intervention for preventing future transmission. The article also suggested that PN offers important surveillance information regarding high-risk clusters or networks. With advances in antiretroviral therapies, PN has provided potentially infected individuals an opportunity for early detection and treatment, especially in industrialized nations. Provider referrals, while costly and labor intensive, have been shown to be more effective in identifying, contacting, and testing partners of index cases compared to patient referrals. In developing countries, limited financial resources, poor public health infrastructures, the additional burden on healthcare workers’ limited time, and the stigma associated with HIV have made the implementation of partner notification programs difficult, though not impossible. The authors recommend that other issues need to be addressed, such as the potential for violence related to partner notification. Adequate training for healthcare workers, clinical guidelines, and monitoring of performance indicators in the partner notification process were suggested to better understand the effect of partner notification on HIV transmission and risk reduction.


A comparison of health department-initiated (i.e., provider referral) partner notification at an anonymous test site (ATS) and various confidential test sites (CTS) in Colorado was made to determine whether the mean number of partners identified, notified and counseled, and rates of HIV testing and seropositivity among partners varied between the two types of testing facilities. Methods of interviewing index cases and notifying partners did not differ between ATS and CTS. The mean number of named, notified and counseled partners was found to be 30%-50% greater among CTS index cases, and the seropositivity rate in newly tested partners of CTS index cases was more than double the rate in partners of ATS index cases. The authors hypothesized that individuals tested at anonymous sites were less likely to volunteer the names of their sex and needle-sharing partners than persons at confidential sites were. Additionally, the ability for follow-up by disease intervention specialists was not available for cases of ATS. While the results of this comparison may appear to favor confidential over anonymous testing, it is important to bear in mind that the availability of ATS has led certain individuals to get tested who may have otherwise avoided
confidential sites. Further evaluation into the partner notification process at both anonymous and confidential testing sites is recommended.


HIV counseling, testing, referral, and partner notification (CTRPN) services have been an integral part of HIV prevention programs nationwide. However, CTRPN services have often been costly and labor intensive. This study examined the economic costs and benefits of publicly funded HIV CTRPN services in 1990. The cost-benefit and sensitivity analyses strongly suggested that even when conservative assumptions were made, the hundreds of millions of public dollars given to states for HIV CTRPN have resulted in a favorable economic gain.


Truly comprehensive evaluations of HIV counseling, testing, referral and partner notification (CTRPN) services include a wide range of activities: preproduction formative evaluation; development of goals and objectives; postproduction formative evaluation; process evaluation; outcome evaluation; impact evaluation; and economic evaluation. Instances in which projects or programs have the necessary fiscal and temporal resources to conduct a truly comprehensive evaluation are rare. The authors briefly discussed the various components of a comprehensive evaluation. This was followed by an exemplary case study of a systems-level evaluation of HIV CT services in the state of Wisconsin that was conducted with such limited resources. The authors discuss how the state health department utilized the information. The case study was used to emphasize methods that optimally leverage limited resources when comprehensive evaluation is not a possibility.


Patient versus provider referrals were compared in terms of their success in notifying sex or needle-sharing partners of persons infected with HIV. Patients that agreed to participate were randomized into 2 groups; 39 participants were assigned to the provider referral group and the remaining thirty-five to the patient referral group. Public health counselors were able to notify 50% of the partners reported. Less than 10% of those in the patient referral group were notified by their partner. Counselors were able to locate and notify a proportion of the partners who were supposed to have been referred by the index patient, bringing the number of partners notified to about 50% as well. Approximately half of all referred partners from both groups were tested. Of those partners notified and tested from both groups, 23% were HIV positive. While provider referrals for counseling and testing were more efficacious than patient referrals, they were also more costly and labor intensive. Barriers to effective provider referral include unwillingness to provide correct partner information, anonymous or transient sex partners, or concerns about discrimination.


The authors of this article reviewed 13 papers, published between 1980 and August 1997, pertaining to the effectiveness of partner notification strategies for syphilis, gonorrhea, chlamydia, and HIV in the United States. For comparison purposes, the studies were categorized as either cohort or comparative. The articles were also assessed for their quality of study methods, analysis, and generalizability; six of the 13 were considered to be high quality. Overall, the number of infected partners found per infected person was low, however, provider referrals were found to be associated with a higher number of partners notified and evaluated rather than self-referrals. The number of infections detected per infected person was greater among provider referrals than self-referrals (0.24 per index case versus 0.03). Additionally, up to 11% of unsafe-sex or needle-sharing partners elicited by providers were found to be infected. None of the studies explored the effects of partner notification on behavioral changes, relationships with partners, or the number of infections or health consequences averted. While there is evidence that partner notification
has helped detect potential carriers of STDs, more research was recommended to better understand the
 dynamics of partner referral and its impact on health outcomes, risk behaviors and interpersonal personal
 relationships.


The article presents findings of a study examining predictors of time spent on partner notification. Disease
intervention specialists (DIS), in three urban sites and one rural site, recorded the activities involved in tracking and
notifying partners of patients infected with a sexually transmitted disease (STD) over fourteen working days. Time
spent on notification of each identified partner was computed, and random effects regression was utilized to examine
the data with regard to client type, STD diagnosis, outcome, demographic characteristics, mileage, and study site.
Identified partners who took more time than the reference case included clients who were both an original case and a
contact; those who were diagnosed with HIV/AIDS and/or primary or secondary syphilis; those infected with, and
treated for, an STD; and those for whom travel by the DIS was necessary. No significant associations were found
between time spent on partner notification and demographic characteristics, including race/ethnicity or gender
matches between the DIS and the client. Significantly less time was spent on partner notification in the northeast
urban site. This may have been due to the computerized database system utilized. While technology may have played
a role in increasing the efficiency of partner notification in some areas, examination and considered of other factors
was suggested to gain a better understanding of the resources required for efficient, yet effective partner notification.

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Provider and contact referrals have been established as means for notifying an individual's partners of possible
exposure to a contagious, yet treatable disease, such as tuberculosis and syphilis. Partner notification in cases of
HIV/AIDS, however, has been highly controversial due to the stigma and fatality associated with being HIV positive.
In this commentary, the author reviewed issues of ethics, such as voluntary versus mandated disclosure, as well as
possible reasons for violating the principles of confidentiality for the common good, and how they pertain to the HIV
partner notification amendments to public health law, enacted in 1998 in the state of New York. A comparison of
U.S. and Swedish strategies for partner notification was conducted. Areas for general improvement, such as a
guarantee of good medical and psychological care and greater confidence in anonymity, were identified through this
comparison. The author discussed how cultural differences might affect the feasibility of interchanging these
schemes. A social system perspective based on the social functions of: adaptation, including situational necessities;
attaining linkages of the infected individual to the public health system; integration of personal goals and societal
values; and maintenance of socialization patterns was also introduced to address the barriers inherent in HIV/AIDS
notification programs and for enhancing counseling programs. The objective of this review was to reinforce the
notion that knowledge and understanding of a client's culture and social context can give providers additional tools
with which to stop the transmission of HIV/AIDS and bring people to treatment earlier.


The article presents profiles of the evaluation systems in place in 11 health department jurisdictions. The profiles
were not intended as a representative sample of evaluation systems nor of jurisdiction size nor as being
geographically diverse, but rather as a technical assistance resource to provide examples of how other systems have
developed. The jurisdictions profiled include Alaska, Colorado, Indiana, Maryland, Michigan, Minnesota, New
Jersey, New York, Pennsylvania, Texas, and Virginia. Each jurisdiction was profiled regarding the data content of
the system, software, data transmission capability, capacity for collecting unduplicated client data, status of training
for providers who use the system, copyright status, and contact person. The systems varied in their level of
complexity and technical sophistication. Three of the systems were still being developed. Most used commercially
available software packages to manage the data. A few jurisdictions used custom software developed internally or
under contract by an outside source. One site utilized a Web-based system that was developed by an application
service provider firm. Most of systems in the jurisdictions profiled did not record unduplicated client data or care-
related data in their evaluation systems. However, at least two sites collected HIV-related service data including referrals made and whether the referral was completed. In summary, the systems profiled showed a wide range of capabilities and variability in the variety and comprehensiveness of the data collected.


This article presented results from a study designed to examine the knowledge, attitudes, perceptions and practices of providers as they related to domestic violence and partner notification for HIV positive women. One hundred thirty-six providers, who care for HIV infected female patients, responded to the survey. While public health policy encouraged partner notification, many providers believed that fear of emotional and/or physical abuse and abandonment were reasons why HIV positive women resist partner notification. The majority of providers encouraged about two-thirds of their female clients to inform their partners. About a third of providers assisted patients with partner notification, however when faced with a risk of domestic violence to the client, providers strongly opposed partner notification. The authors recommended incorporating the identification and addressing of domestic violence issues into partner notification strategies, emphasizing the importance of ensuring a woman's safety. Areas for additional research related to these issues were also suggested.


This article presents a discussion of the history, current status, associated controversies, and potential enhancements of the role of partner notification in HIV prevention. Concurrently, the role and function of partner notification within HIV prevention programs were re-examined. The authors reported five general findings from a review of the literature: 1) in most cases, providers find that HIV-infected clients will voluntarily cooperate in confidentially reporting or identifying at least some of their sex partners; 2) if located, the identified partners are usually receptive to notification by a provider and will seek testing services; 3) provider referrals are typically more effective than patient referrals; 4) sex partners often are unaware of, misunderstand, or deny their risk of HIV; and 5) the rate of HIV infection among sex and needle-sharing partners of HIV-positive persons is frequently high, ranging from 5 to 56%. The authors reviewed means for increasing prevention efforts, especially among recently diagnosed individuals, and discuss issues relevant to evaluating the effectiveness of partner notification for HIV prevention. They proposed that enhancing partner notification by coupling it with social and behavioral interventions will lead to the emergence of important process and outcome evaluation questions. The authors suggested a need for additional research into the effectiveness of partner notification in risk reduction, the influence of social networks in effective partner notification, and the utility of partner notification in promoting earlier access to necessary treatment and support services for HIV-positive individuals. In addition, the unintended effects of partner notification should be explored.
Appendix C

EXECUTIVE SUMMARY,
TARGETED TESTING AND REFERRAL EFFORTS:
A REPORT OF THE NASTAD STATUS PROJECT
April 2001

HIV counseling, testing and referral (CTR) services are a cornerstone of the nation’s public health response to HIV/AIDS. State, territorial and local health departments play a central role in the provision of such services. Health departments possess the authority, interest and expertise to provide CTR services to communities most impacted by the HIV/AIDS epidemic, especially communities of color. However, there are variations across the nation in health departments’ capacities to support CTR services responsive to the needs and priorities of at-risk communities.

Though a cooperative agreement with the Centers for Disease Control and Prevention (CDC), the National Alliance of State and Territorial AIDS Directors (NASTAD) implemented the Supplemental Technical Assistance, Testing and Unified Services (STATUS) Project. The STATUS Project examines three key areas of health department-supported prevention programming targeting racial/ethnic minorities:

1. capacity building and technical assistance to community-based organizations (CBOs)
2. targeted HIV testing; and
3. referral services offered in the context of HIV counseling and testing.

This report relates only to targeted HIV testing and referral services. Findings will be used to identify strengths of and challenges to health department provision of support and technical assistance to communities of color in these areas.

KEY FINDINGS

Targeted Testing

A variety of factors influence the outcome of targeted testing efforts including the availability, accessibility and quality of counseling, testing and referral services and the quality and availability of medical and support services.

< Health departments require additional resources to enhance current targeted testing efforts. Staff expansions are needed at the health department and provider levels and alternative testing technologies must be adopted. Training in cultural competence and use of new testing technologies is also required.

< Health departments currently engage CBOs in the provision of counseling, testing and referral services. The provision of CTR services by CBOs varies by jurisdiction. This includes CBOs that are predominantly operated by and/or serve members of racial/ethnic minorities.
Public health departments are divided on the topic of “know your status” (KYS) campaigns. Identified benefits of these campaigns include increasing awareness of prevention resources and personal risk and encouraging use of CTR services. Identified liabilities include overtaxing CTR resources and medical and support services. KYS campaigns should be locally developed, but nationally developed protocols and technical support can facilitate implementation.

All public health departments conduct quality assurance for CTR services. Most health departments use site visits and provider reports as their primary methods of quality assurance. The methods and mechanisms used, as well as the relative sophistication of these methods, vary by jurisdiction.

Referral Services

Provider skill in assessing and managing referrals and the availability and accessibility of referral services are among the most important factors influencing the quality and effectiveness of referral services.

Training offered by health departments that is specific to the management of referrals is rare. Many health departments incorporate referral issues into HIV test counselor training. Few address the topic in-depth or provide specialized training or skills-enhancement.

Quality assurance for referral services is also limited. Many health departments report that they address referral services as part of their ongoing quality assurance and program monitoring efforts. However, referral services do not appear to receive specific evaluation in most jurisdictions.

Health departments currently have relatively low capacity to monitor referrals. Both protocol for “tracking” referrals and appropriate information systems are lacking. Health departments expressed great interest in receiving technical assistance related to referrals. Topics of interest include: sample guidelines and protocol for referrals; guidelines for quality assurance; skills-enhancement training for providers; and assistance in developing information systems to monitor referral services.
Appendix D

Meeting Agenda

Linking HIV Testing, Prevention, and Care

October 1 – 2, 2001
Alexandria, VA

Day One

9:00 – 9:15  Welcome/Overview:
• CDC – Sam Dooley, M.D.
• HRSA – Deborah Parham, RN, Ph.D.
• FCHR – Veronica Miller, Ph.D.

9:15 – 9:45  Presentation: Integrating HIV Prevention Services into the Clinical Setting:
HRSA – Laura Cheever, M.D.

9:45 – 10:00  Presentation: Consumer Perspective of Integrating Prevention and Care Services: HIV Vaccine Trials Network – Steve Wakefield

10:00 – 10:30  Presentation: Present Knowledge about HIV Testing and Diagnosis: CDC – Patricia Fleming, Ph.D.

10:30 – 10:45  Charge to Break Out Groups

11:00 – 1:00  Break-Out Group Session One: Identifying Challenges of integrating/linking HIV preventive and care services.

1:00 – 2:00  Report Back From Break-Out Groups

2:00 – 5:00  Panel I – Organizational and System Issues

Linking Prevention Providers (CBOs) with Care Providers
AIDS Service Center of Lower Manhattan – Brenda Starks-Ross, Deputy Executive Director
Establishing Prevention Services in Public and Private Care Settings
Kansas City Free Health Clinic – Holly Buckendahl, Director of Community Services
Oregon Department of Human Services – Mark Loveless, M.D., Medical Director and Epidemiologist

Linking Centers of Excellence with Prevention Providers
LAC + USC Medical Center – Robert Larsen, M.D., Associate Professor of Medicine

Planning and Establishing Integrated Prevention and Care Services
Massachusetts Department of Public Health – Jean McGuire, Ph.D., HIV/AIDS Bureau Director

Philadelphia, Department of Health – Patricia Bass

Day Two
8:00 – 9:15 Panel II – Social and Other Health-Related Issues

Homelessness, Mental Health, and Substance Abuse
Health Care for the Homeless, Inc – Louise Treherne, Clinical Operations Officer

Incarcerated Populations
Fortune Society – Sam Rivera, Director of Client Training Programs, and Pamela Goodrich, Trainer/Case Manager

Women and Families
The Johns Hopkins Hospital Women's HIV Outpatient Clinic -- Ms. Jean Keller, PA-C, Clinical Staff, and Rose Ramroop, Outreach Staff

9:15 – 10:15 Panel III – Cultural and Regional Issues

Immigrant and/or Non-English Speaking Communities
El Centro Del Barrio, San Antonio - Ernesto Parra, M.D., M.P.H., Clinical Associate Professor/Staff Physician

Gay Youth/Adolescents of Color
Cook County Children Hospital – Jamie Martinez, M.D., Principal Investigator

Rural Communities
Maine Department of Human Services – Sally Lou Patterson, Director, HIV/STD Program
10:30 – 11:30  Panel IV – Evaluation of Linkages and Referrals

NY AIDS Institute – Jeff Rothman, M.D., Asst. Dir, Bureau of HIV Ambulatory Care

George Washington University – Julia Hildago, Sc.D., M.S.W. M.P.H, Senior Research Staff Scientist

11:30-2:00  Break Out Group Session Two: Developing consensus on operational and policy principles that support effective integration and linking of programs, and providing recommendations to reduce barriers to government agencies, program administrators, and professional staff.

2:30 – 3:00:  Report back from Break Out groups

3:00  Adjournment
Appendix E

Tables from Breakout Session I: Identifying Links and Points of Entry into Care, and Barriers to Linking HIV CTS, Prevention, and Care Services

Table 1. Points of entry into comprehensive services

<table>
<thead>
<tr>
<th>Points of entry into comprehensive services</th>
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<tbody>
<tr>
<td>12-step programs</td>
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<tr>
<td>alternative medicine sites</td>
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<tr>
<td>bars and entertainment centers</td>
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<tr>
<td>bathhouses</td>
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<tr>
<td>blood drives</td>
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<tr>
<td>CT sites (anonymous, and confidential)</td>
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<tr>
<td>case management service sites (HIV and others)</td>
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<tr>
<td>college health centers</td>
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<tr>
<td>community and school research projects</td>
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<tr>
<td>community-based organizations (CBOs)</td>
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<tr>
<td>community pride events</td>
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<tr>
<td>courts</td>
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<tr>
<td>dental services</td>
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<tr>
<td>drop-in centers for recently released prisoners</td>
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<tr>
<td>drug treatment sites</td>
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<tr>
<td>emergency rooms</td>
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<tr>
<td>family planning centers and clinics</td>
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<tr>
<td>health fairs</td>
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<tr>
<td>homeless shelters</td>
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<tr>
<td>hospital inpatient treatment</td>
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<tr>
<td>hospital outpatient services</td>
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<tr>
<td>houses of worship</td>
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<tr>
<td>housing services</td>
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<tr>
<td>insurance testing</td>
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<tr>
<td>job training programs</td>
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<tr>
<td>mental health centers</td>
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<tr>
<td>military induction centers</td>
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<tr>
<td>needle exchange programs</td>
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<tr>
<td>partner counseling services</td>
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<tr>
<td>peer support groups</td>
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<tr>
<td>prisons, jails, detention centers</td>
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<tr>
<td>public assistance sites</td>
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<tr>
<td>rape trauma services</td>
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<tr>
<td>refugee services</td>
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<tr>
<td>runaway youth services</td>
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<tr>
<td>school health centers</td>
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<tr>
<td>social service centers</td>
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<tr>
<td>STD clinics</td>
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<tr>
<td>street outreach programs</td>
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<tr>
<td>substance abuse treatment</td>
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<tr>
<td>youth centers</td>
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</tbody>
</table>

Table 2. Systemic barriers

- separate funding streams for various HIV services
- lack of agency collaboration
- lack of resources in some areas
- lack of clarity on use of resources
- institutional racism and discrimination
- struggle over limited resources
- not making referrals to local resources
- lack of knowledge about what is available in the community
- case management not funded sufficiently
- lack of technical knowledge about what works and what doesn’t
- failure to make information available in a way accessible by all (technology transfer)
- required navigation by clients to move among the systems of care
- lack of innovative funding: CDC, HRSA, and NIH need to consider a more wholistic approach so that funding streams can encompass CTRS, prevention, and care in seamless, integrated fashion rather than a patchwork of services and funding
- lack of provider training
- provider practices of often overstating the number of those who will be served; funders should take a more relative approach to discourage this practice
- lack of ongoing quality assessment because of insufficient funds
- need for innovative ways of funding, CTRS and disseminating successful models of comprehensive service delivery.
- Difficulty in ascertaining what works and translating new approaches to other areas.
• societal opposition to harm reduction approaches
• lack of collaboration across federal agencies
• Insufficient reimbursement rates
• lack of clarity about which services can be funded under which program, Title, etc.

• lack of public awareness and understanding about and access to services and systems
• inconsistency in education

### Table 3. Provider-level barriers

- competing priorities among service providers
- responding effectively to heterogeneous needs of target populations
- peer educators/counselors don’t feel rewarded
- providers lack referral resources (no beds, wait-lists)
- time constraints for service provision
- resistance among community providers to work together in new ways
- lack of client-centered orientation
- data system limitations
- trusting other providers in establishment of working relationships
- funding application processes take away time for working with clients
- insufficient and/or delayed reimbursements
- lack of managed care readiness, especially with regard to Medicaid
- challenges in caring for multiple-diagnosis clients
- language and cultural competency requirements
- having to compete for clients
- working with clients who choose not to come back to for test results and entry into care
- lack of incentives to provide both prevention and care services
- lack of performance measures that would support the need for combined services
- lack of confidence and training in addressing sexual and social issues
- under use of non-medical professionals
- separation between medical and social services
- lack of referral tracking systems
- having to struggle for limited resources
- lack of provider continuity -- influences the client’s ability to maintain contact
- being properly matched to needed tasks

### Table 4. Client-level barriers

- variations in treatment readiness
- variations in client motivation
- multiple diagnoses and illness
- lack of strong relational supports
- lack of peer support
- economic poverty
- services location is remote, transportation is not available
- homelessness
- active drug/alcohol addiction
- services may cost the client
- variations in client needs by gender
- HIV infection is only one of several life issues needing to be handled
- Community stigma, shame, guilt, denial related to illness, life style, etc.
- language, culture, and literacy
- concerns about confidentiality
- lack of care appropriate to age and developmental level
• lack of knowledge and aptitude to understand what their health status means
• lack of trust in and negative perception of the health care system
• mental illness
• perception that issues beyond HIV issues are not being addressed
• perception that needs of one’s family will not be addressed
• immigration laws and requirements (for undocumented clients)
• requirement for parental approval (for adolescents)

Table 5. Barriers with Regard to the Penal System

• Links and referrals within the system are virtually nonexistent.
• Medical records often do not follow inmates to new assigned locations.
• Prerelease programs have limited capacity, if they exist at all.
• Little or no links exist with community providers
• Confidentiality is often limited and compromised
• Uncertainty surrounding time of release to allow for planning and coordination of services
Appendix F

Detailed Notes from Breakout Session II: Recommendations for Action at the Federal, State, and Local/Provider Levels, and for Evaluation

Four breakout groups were given the following charge: Develop recommendations for actions that can be taken by (1) the federal government, (2) state program administrators, and (3) community direct-service providers/agencies to better integrate care, HIV testing, and prevention services.

First, the groups were to make a comprehensive list of the recommended actions, reflecting the diverse viewpoints of the workshop participants, and then come to a consensus about which three actions should receive high-priority attention at each of the three levels listed above. Table 2 is a comprehensive listing of all recommendations generated by the breakout groups.
Table 1. Comprehensive list of breakout group recommendations (Breakout Session II)

<table>
<thead>
<tr>
<th>Federal Level</th>
<th>State/Local Level</th>
<th>Provider/Agency Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Create standardized performance and evaluation procedures</td>
<td>• Convene period meetings of all providers to look at integrating prevention and care services</td>
<td>• Enhance provider comfort, training, and strategies for addressing sexual/social client issues</td>
</tr>
<tr>
<td>• Increase funding, but avoid defunding some programs in order to fund others</td>
<td>• Ensure that statewide needs document is a living document</td>
<td>• Make more and better use of professionals other than physicians to provide client-centered care</td>
</tr>
<tr>
<td>• Provide resources to address needs identified by providers commensurate with the epidemic trends</td>
<td>• Increase state-originated funding and resources for HIV/AIDS services</td>
<td>• Increase cultural competency and eliminate language barriers</td>
</tr>
<tr>
<td>• Emphasize realistic outcome measures as opposed to process measures</td>
<td>• Take a leadership role in harm reduction, prison issues, and so forth</td>
<td>• Bridge the gulf between medical care and support services</td>
</tr>
<tr>
<td>• Clarify terminology and define &quot;buzz words&quot; such as &quot;highly recommended&quot;</td>
<td>• Provide directory of all HIV and supportive services for all HIV providers (private and public)</td>
<td>• Develop referral tracking systems</td>
</tr>
<tr>
<td>• Work toward universal health care and funding of permanent, stable housing</td>
<td>• Coordinate with federal and local governments to develop processes that streamline administrative contractual requirements to allow providers to do what they do best—provide services to clients</td>
<td>• Ensure continuity among medical and social service providers</td>
</tr>
<tr>
<td>• Encourage jurisdictions to address identified needs and base budget on those needs</td>
<td>• Develop process by which private sector providers adhere to HIV standards of care for referrals and linkages</td>
<td>• Set priorities to make best use of limited resources</td>
</tr>
<tr>
<td>• HRSA and CDC should provide the Secretary with a &quot;State of the State&quot; assessment of needs</td>
<td>• Ensure that funding levels reflect the value of peer educators as staff</td>
<td>• Learn to integrate linkage and referral mechanisms and operationalize them</td>
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<tr>
<td>• Improve reporting of demographic data on infected persons by age, ethnicity, and gender (including transgender)</td>
<td>• Support training for development of standards of care</td>
<td>• Implement and operationalize categorical funding streams</td>
</tr>
<tr>
<td>• Encourage more cooperative grants among agencies</td>
<td>• Encourage access to prisoners and inmates</td>
<td>• Be willing to refer clients when necessary</td>
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<tr>
<td>• Reimburse for prevention activities at a level equal to that for &quot;procedures&quot;</td>
<td>• Encourage providers to focus on areas in which they excel or demonstrate expertise</td>
<td>• Become part of a formal, documented infrastructure within regional area, offering comprehensive services</td>
</tr>
<tr>
<td>• Develop HRSA guidance to ensure that medical providers and providing and referring patients for prevention services</td>
<td>• Require providers to continue education across the entire organization</td>
<td>• Support large and small CBOs in meeting all needs of the community while supporting referrals and linkages</td>
</tr>
<tr>
<td>• Integrate at the federal level to foster integration at lower levels through a top-down effect. &quot;Integrate by example.&quot;</td>
<td>• Reimburse providers for referral and linkages</td>
<td>• Put in place administrative systems to operationalize programming</td>
</tr>
<tr>
<td>• Institute cross-training at the federal level,</td>
<td>• Fund and provide technical assistance for</td>
<td>• Be accountable for the services provided by evaluating processes and outcomes of activities</td>
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<td>• Involve the community in meaningful ways in the design, implementation, and</td>
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<td><strong>Federal Level</strong></td>
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<td><strong>Provider/Agency Level</strong></td>
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<tr>
<td>including project officers</td>
<td>implementing integration and linkages</td>
<td>evaluation of program development</td>
</tr>
<tr>
<td>Make innovative grants similar to SPNS but ongoing in nature</td>
<td>Fund evaluation for technical assistance and outcomes</td>
<td>Reexamine organizational missions with a focus on areas of expertise</td>
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<tr>
<td>Dedicate resources for data collection and analysis, including development of templates and blended databases</td>
<td>Foster coordinated technical assistance and capacity-building for organizations in the areas of administration and linkages</td>
<td>Establish linkages with other agencies that can fill gaps identified during needs assessment</td>
</tr>
<tr>
<td>Develop policies to address issues around the stigma of HIV infection</td>
<td>Standardize performance and evaluation procedures</td>
<td>Integrate prevention, care, and counseling/testing services into one program where relevant and possible</td>
</tr>
<tr>
<td>Seek accountability for SAMHSA block grant funds</td>
<td>Have common administration of HIV prevention, care, and surveillance at the state level</td>
<td>Create meaningful, relationship-based, contractual referral linkages</td>
</tr>
<tr>
<td>Integrate Ryan White CARE Act Title II administration/management. Reroute from field to care of HIV</td>
<td>Increase collaboration—including data sharing—across relevant state agencies: HIV/AIDS, STD, TB, viral hepatitis, Medicaid, SA, mental health</td>
<td>Seek funds that align with the stated mission; “avoid chasing dollars for dollars’ sake”</td>
</tr>
<tr>
<td>Institute multiyear funding cycles</td>
<td>Encourage interstate discussion across Medicaid programs regarding portability of benefits and eligibility</td>
<td>Ensure that with expansion comes commitment to appropriate service delivery in that area</td>
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<tr>
<td>Issue mandate for Food and Drug Administration approval of rapid HIV screening tests</td>
<td>Require annual HIV linkage in-service for every state agency that receives state funding</td>
<td>Remain committed to work plan</td>
</tr>
<tr>
<td>Determine Medicaid barriers to linking HIV-positive individuals to care</td>
<td>Encourage medical schools to incorporate HIV/AIDS curricula</td>
<td>Include quality improvement in program development</td>
</tr>
<tr>
<td>Align prevention and care funding cycles</td>
<td>Encourage public health departments to work with private sector providers to make them aware of pubic HIV services</td>
<td>Develop capacity to meet identified needs</td>
</tr>
<tr>
<td>Conduct a study of the statutory, regulatory, and administration issues that affect integration and blending of HIV prevention and care systems and funding at the federal level</td>
<td>Enhance SA and mental health program resources by increasing number of treatment slots</td>
<td>Involve peer health educators to the maximum extent possible by hiring more of them and providing initial training continuing education programs</td>
</tr>
<tr>
<td>Allow more flexibility in use of funding streams at local level across discretionary and entitlement programs</td>
<td>Build collaborations between HIV prevention and care programs and correctional facilities, job training programs, and human services</td>
<td>Stimulate integration and referral linkages by co-locating services, conducting joint planning of service delivery, setting up collaboration management</td>
</tr>
<tr>
<td>Better integrate behavioral health (e.g., SAMHSA) with HIV prevention and client services</td>
<td>Create, publicize, and continuously update</td>
<td>Establish more formal linkages across care, prevention, SA, mental health, incarcerated service agencies, and so forth</td>
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<tr>
<td>Design model for integrating and streamlining the federal administrative process (surveillance, application process,</td>
<td></td>
<td>Increase cross-training opportunities, off-</td>
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<tr>
<td>Federal Level</td>
<td>State/Local Level</td>
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<tr>
<td>funding, data) across all relevant agencies</td>
<td>a resource manual of prevention and care services available statewide</td>
<td>siting of staff, and so forth</td>
</tr>
<tr>
<td>• Increase data sharing across agencies</td>
<td>• Link state prevention and planning groups</td>
<td>• Simplify sharing of client data across agencies through use of common/shared intake forms and release of information forms</td>
</tr>
<tr>
<td>• Encourage jurisdictions to identify needs and base the budget on those needs with an eye toward creating a needs-based budget.</td>
<td>• Develop statewide standards for HIV testing and counseling, treatment, and financing</td>
<td>• Develop systems to document and ensure linkages to care and prevention for HIV-positive individuals and for prevention and other appropriate services for HIV-negative individuals</td>
</tr>
<tr>
<td>• Institute collaborative and innovative funding across agencies, including HRSA, CDC, Housing and Urban Development, SAMSHA, and the Veterans Administration</td>
<td>• Establish across-site continuous quality improvement system</td>
<td>• Integrate prevention messages more fully in ongoing medical care services</td>
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<td></td>
<td>• Build linkages among surveillance functions, prevention services, and care providers</td>
<td>• Increase communication and collaboration among HIV care/prevention providers, regardless of funding source, with care and prevention planning groups</td>
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<td>• Take a leadership role in issues that the federal government cannot (e.g., harm reduction, prison issues)</td>
<td>• Accommodate client needs by offering flexible locations and operating hours, family-centered care, child care, transportation, and so forth.</td>
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<td>• Add flex-time options for staff at agencies offering flexible hours for clients</td>
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<td>• Provide better training and teaching materials related to prevention, cultural competency, harm reduction, and available services</td>
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<td></td>
<td></td>
<td>• Seek capacity-building training on key elements of successful collaborations</td>
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<tr>
<td></td>
<td></td>
<td>• Better integrate prevention messages into ongoing medical care services.</td>
</tr>
</tbody>
</table>
When the groups assigned priority rankings to the recommendations generated during the “brainstorming,” significant overlap and areas of emphasis became apparent. These items, which clearly rank high in the minds of the participants, can be summarized thus:

**Recommendations at the federal level:**

- Demonstrate “integration by example” among all federal agencies within and without the department (HHS). In the short term, work toward increasing consistency in guidance, definitions, and application processes. Create more demonstration programs and evaluate their effectiveness. Build infrastructure for counseling, testing, and care, and promote partnerships with NGOs. Conduct cross-training across agencies. Increase sharing of data across all agencies. In the long term, integrate funding streams.
- HRSA and CDC should dedicate resources for data and analysis. An example would be working together to create data templates and blended databases that can help avoid barriers at local level.
- Simplify and unify federal administrative procedures—surveillance, application processes, funding, data collection, administration, and reporting—across all relevant agencies.
- Linkages should be highly recommended and adequately funded by the federal government, especially payment for outreach workers. Funding levels should reflect the true cost of the services being provided.
- Jurisdictions should be encouraged to identify needs and base funding requests on those needs. If the federal government asks agencies to document needs in their communities, those needs should be acknowledged and reflected in the funds provided.

**Recommendations at the state level:**

- Simplify and unify. Coordinate within and across state agencies for such functions as reporting, funding, cross-training. Standardize fiscal years, and simplify the request-for-application process.
- Ensure continuity of care across state lines, specifically related to entitlement programs. Put ADAP dollars to better and more consistent use across state agencies. Address issues related to portability of benefits across state borders.
- Promote collaboration and cross-training across relevant state agencies that deal with HIV/AIDS, sexually transmitted diseases, tuberculosis, viral hepatitis, substance abuse, mental health, bureau of prisons, and Medicaid.
- Enhance substance abuse and mental health programs and resources. Make more slots available for care and not more administrative staff positions.
- Reimburse providers adequately and provide technical assistance for implementing and integrating linkages of services and referrals.
- Coordinate prison programs, job training, and human resources to build referrals across these state agencies.
- Take a leadership role in areas that the federal government cannot (e.g., harm reduction, prison issues).
Recommendations at the provider/agency level:

- Do agency-wide assessments and work on capacity-building and training for identified assets and deficits. Concentrate on building capacity in areas of strength, including key elements of successful collaborations and infrastructure development to provide services.
- Partner—through meaningful linkages and referrals—with other agencies that provide services that are beyond one provider’s scope.
- Include the community and consumers in the planning, implementation, and evaluation of programs. Make sure that the provider’s activities meet identified needs.
- Learn to implement multiple categorical funding streams.
- Define a mission and seek funding that supports it.
- Expand the role of peer educators and compensate them adequately.
- Set up “collaboration managers” to handle such issues as co-location, joint planning, linkage of programs, and quality assurance across programs.
- Maintain accountability for services by conducting meaningful evaluations of process and outcomes.

Evaluation

A separate breakout group dealt with two questions centering on evaluation issues: (1) How do we successfully evaluate the effectiveness of referrals? (2) How do we evaluate the effectiveness of successful linkages and integration?

The breakout group recommended that evaluation measures should encompass federal, state, agency/provider, and client outcomes. A successful evaluation would pinpoint gaps in service and determine if referrals and linkages are working to close those gaps. Among the questions to be answered are: How effective are we at moving people from knowledge of their HIV status into primary medical care? Who is coming late into care, and why? Is there a lack of support for risk reduction in clinical settings? How do we help those not in care reduce their risk, increase their access to care, and improve their quality of life?

At the federal level, there is a need to fund research into methods, demonstration projects, and results of linkages and referrals. What is the effect of different interventions on accessing and remaining in care? Also needed is research to identify key indicators for measuring effectiveness of linkages and referrals.

At the state level, an across-site continuous quality improvement system should be implemented. In addition, states should establish (if lacking) linkages among surveillance, prevention, and care services. Another possibility is correlating databases on counseling/testing, care, surveillance, and service utilization, perhaps using unique identifiers across services areas and databases. States should seek technical assistance stratified by levels of data available. The constraints imposed by underinsurance need to be understood and taken into account. Finally states must fund and provide technical assistance for agencies that are integrating and creating linkages of services.
For the provider/agency level, the group suggested collecting client satisfaction survey data to help define need and acceptability of services. Providers can establish qualitative interview teams consisting of administrators, direct providers, and clients. The group further recommended that providers seek funding to fully support extra data collection efforts, staffing, information systems capacity, and hardware. Another recommendation was to establish partnerships for data analysis and quarterly feedback in order to do more with fewer extra dollars. Finally, providers should adopt a continuous quality improvement approach using their own indicators, and adapt and apply models that work to lower-resource areas.

The group also offered several caveats and guidance:

- Remember that linkages and referrals are not meaningful in themselves. We must define the underlying needs that are supposed to be met by facilitating linkages and referrals. Ultimately, such linkages and referrals should improve the quality of life for people living with HIV.
- Clarify HRSA and CDC definitions of terms relating to referrals and linkages, and review how these terms are being used by grantees (e.g., cultural competency). We must remediate these diverging definitions now while we still can.

In terms of recommendations for federal agencies, the group recommended that:

- The CDC should integrate databases for surveillance, prevention, and care, and overcome the artificial boundaries that now separate these functions.
- Choose and publish intrinsically meaningful indicators by state every year with guidance on how to use them. For example, one indicator could be the number of individuals who learn their diagnosis only at the time of an AIDS diagnosis. That figure is a key indicator; the data are already being collected, and we can track the progress we make toward decreasing this number.
- Federal agencies need to teach, train, and disseminate models of how to use existing data sources for assessment, evaluation, and continuous quality improvement. We do not need to create another national- or state-level evaluation system exclusively for linkages and referrals. We already have data sources, but we lack capacity and knowledge of how to use them well. We need to think creatively and apply models that have worked elsewhere.
- Do not expect or demand that agencies at the local provider level to collect and analyze data for which they do not have the necessary money or capacity.
- Fund prevention research projects to develop simple best indicator(s) of linkages and to test intervention models. Choose two or three indicators at the provider level that correlate with real improvements in quality of life for people living with HIV. Collect a great deal of data on a few people to validate these indicators and test intervention models. Replicate successful models elsewhere.

Client survey data is essential. Remember for whom we are undertaking all these activities. The clients are the ones who can tell us if their needs are being met and if they are being met in the best way possible. Ultimately our goal is to provide services to people who are living with HIV. We want to end the epidemic by shrinking transmission asymptotically to zero. And, we want to enable people living with HIV to live the best lives they can.
Appendix G
Background Information on Programs Discussed by Speakers
(listed alphabetically)

The AIDS Services Center of Lower Manhattan (Brenda Starks-Ross)

The AIDS Services Center is a multilingual service organization founded in 1990 “to help many one by one.” The organization’s goal is to help people maintain a high quality of life even in the face of AIDS. A “non-bureaucratic” environment of the AIDS Service Center is designed to make clients feel at home. In this setting, the Center offers dynamic programs that are responsive to ethnically and culturally diverse communities. As a “one-stop shop,” the Center offers low- and high-intensive case management, support services, substance abuse (SA) counseling, and treatment adherence counseling. The Center does not provide CTRS, nor is there a doctor on site. A quasi-day center features entertainment, handicrafts, and a creative writing workshop. In fact, after the 8-week writing workshop, clients collaborate to produce a magazine of poems. Support groups serve as a venue for clients and peers to meet, help each other, and discuss treatments. The Center’s prevention unit focuses on primary prevention. The Center also helps meet clients’ basic needs through its pantry, home starter kits, and legal services. A Ryan White Treatment Educator works in the unit, and case management is offered under the umbrella of client services. The Center uses peer organizations as a means of getting people into care, keeping them in care, and delivering prevention messages.

CORE Program, Cook County Children’s Hospital (Jaime Martinez, M.D.)

The Core Program targets adolescents who are at risk or already-infected with HIV. As of June 2001, 223 clients had been seen in the clinic. Before organizing this program for young people, only 1% of youth were undergoing CTRS. Now 65% of youth reached via outreach are undergoing CTRS. More than 50% of their male clients between the ages of 13 and 24 years are MSM. Seventy-four percent of their clients are African American, 18% are Latino, and 8% are white and of other races. Just over half of CORE clients are female.

A recent focus has been on MSM activity in young men, because it is most common mode of infection for males between the ages of 13 and 24. Furthermore, case-finding activities have been initiated to bring youths into care.

The Fortune Society (Sam Rivera and Pamela Goodrich)

The Fortune Society has a dual mission: to educate the public and decision-makers on criminal justice issues, and to provide former prisoners the skills and services needed to break out of the cycle of crime and incarceration and to build productive lives in the community. Since its founding in 1967, Fortune has helped tens of thousands of former prisoners and at-risk youth rebuild their lives. Fortune serves over 2,000 clients on site yearly, and over 8,000 prisoners and former prisoners receive HIV-related outreach and education each year. Eighty percent of the staff have been incarcerated or have abused drugs at some point in their lives.
The demographic makeup of the client base largely reflects that of the prison population: approximately 49% are African American, 45% Latino, 88% male, 15% homeless. Roughly 70% have a history of drug abuse and an estimated 20% are HIV-positive.

The Fortune Society believes in building minds and changing lives. To that end, the Society offers walk-in crisis intervention, individual and group counseling, case management and support services, job-search training, job retention and placement services, HIV education in jails/prisons and in the community, independent living skills training for recently homeless, and peer training for adults and youth. In addition, licensed outpatient substance abuse treatment services are available to clients referred by the NYC Department of Probation, Community Supervision. The menu of services includes specialized programs for substance abusers; Spanish-speaking defendants and women; individual tutoring; and classes in literacy through GED preparation, mathematics, English as a Second Language, and computer skills. The Fortune Society will begin to provide housing early 2002.

Health Care for the Homeless, Baltimore (Louise Treherne)

Health Care for the Homeless, Inc. (HCH) in Baltimore has a developed threefold mission: direct client health delivery, education, and advocacy. The organization, with its staff of 70, serves up to 5,000 clients annually. Some 75 to 150 people come through HCH’s doors every day seeking services, leading to more than 35,000 encounters per year.

Kansas City Free Health Clinic (Holly Buckendahl)

The mission of the Kansas City Free Health Clinic is “to promote health and wellness by providing quality services, at no charge, to people without access to basic care.” The clinic does not engage in Medicare or Medicaid billing. For more than three decades, the clinic has operated as “the net below the safety net,” offering medical, dental, and HIV care to those in need. The clinic’s two facilities are staffed with a corps of 40 staff and 400 volunteer doctors, nurses, dentist, social workers, laboratory technicians, phlebotomists, counselors, and lay people who assist the clinic in offering quality services free of charge.

The target population for the clinic consists of melting pots of disenfranchised communities in the Kansas City metropolitan area and beyond. It includes at-risk individuals, youth, medically indigent, those who are under- or uninsured, and those who cannot access other health care resources. The clinic has a general medicine side and an HIV service side. The general medicine side conducts some 12,000 visits per year for:

- well-child care and immunizations,
- women’s health and family planning,
- pregnancy testing,
- family medicine,
- dental services,
- health education,
- tuberculosis testing,
- mental health, and
- social services.

In terms of HIV services, the clinic offers:

- primary medical care
- case management
- prevention case management
- street and community outreach
- peer counseling (e.g., for treatment adherence)
- counseling and testing
- needle exchange
- access to research and clinical trials.

**Maine Bureau of Health** (Sally Lou Patterson)

Maine is a large, rural state, the most sparsely populated state east of the Mississippi. The state’s population is about 1.2 million people, of whom approximately 1,200 are living with HIV. New HIV infections are occurring at a steady rate in recent years. New AIDS cases have declined slightly, and deaths have declined significantly. Most cases are in the Portland area, but there are cases in every county.

Maine has a weak statewide public health infrastructure. Three municipal health departments are in place, and a central health department at the state level. HIV/AIDS services are available through an integrated HIV/STD program. The program contracts for all services with CBOs.

The state program staff works closely with an HIV prevention planning group. This group has prioritized populations by behaviors, not categories. The prioritized behaviors are:

- unsafe sexual contact with both partners male,
- people who share needles, and
- unsafe sexual contact with members of the opposite sex.

**Oregon Health Program** (Mark Loveless, M.D.)

The population of Oregon is about 3.4 million, about a quarter of the New York City metropolitan area. Approximately 10% of the state’s population is uninsured at any given time; about 3% are persistently uninsured. The main group at risk for HIV—young adults between 18 and 30 years of age—has a higher rate of uninsurance (about 22%). Most of the state has a very low population density. Eighty percent of people with HIV reside within 50 miles of downtown Portland.
The number of HIV infected people who know their status is estimated to be 4,500, with some 3,800 in care. Of these, 1,500 are covered by the Oregon Health Plan. Approximately 7% are uninsured as they cycle through periods of eligibility for the Oregon Health Plan because of fluctuating income levels. An estimated 2% (about 120 individuals) are persistently uninsured but are fully covered under the Ryan White CARE Act. There appear to be three different types of HIV care networks in the state, which have been termed alpha, beta, and delta. By understanding these types of networks, the state has been able to understand the needs of the communities, provide relevant technical assistance to counties as they develop their local plans for care and prevention services.

Alpha networks are characterized by an integrated, one-stop shopping approach to HIV care. Seven such networks engage 2,650 clients throughout the state and offer comprehensive, integrated care and strong linkages with public health entities. The primary care clinician may well be an HIV specialist, the case manager may be on site, and research is available. Six of these alpha networks are sited in the Portland area, clustered in health systems. One is in Eugene. Examples of alpha networks are those established by HIV Services Center of Multnomah County and the Kaiser Permanente health cluster.

Outside Portland and Eugene, beta networks offer support services that are less well-unified and are not integrated into a one-stop shopping concept. The primary care clinician, although not an HIV specialist, provides skilled HIV care for approximately 25 individuals and maintains good connections with HIV specialists. Five beta networks care for about 450 clients. In Linn County, for example, one clinician stepped up to provide care for HIV-positive individuals in the area. He maintains strong connections to a case manager from the Linn County Health Department, a pastoral counseling center, and an alcohol and drug treatment program. An HIV specialist comes in annually to conduct a specialty clinic and provide specialized training.

A different type of beta network has developed in Deschutes County (Bend, OR). In this area, many private physicians and a case manager are available, but few private providers offer alcohol or substance abuse treatment, although some county-based systems are available.

Delta networks consist of a primary care clinician who sees one to five patients in the context of a large primary care clinic in rural Oregon. The challenge arises here because little is available in terms of support services. Statewide, some 200 patients are covered by delta networks. Examples are migrant health centers and federally qualified health centers.

Rand Schrader AIDS Clinic, University of Southern California Medical Center (Robert Larsen, M.D.)

The Rand Schrader Clinic is the largest HIV/AIDS care program in Los Angeles, caring for 3,500 HIV-positive people, 87% of whom have AIDS. The clinic logs about 45,000 visits
per year and sees 40 to 50 newly diagnosed people each month. It is staffed by USC faculty under a professional services agreement with the Department of Health Services. The target population served is of mixed payer status, but more than 50% have no insurance. Sixty percent of the population served is Hispanic; of these, 60% are monolingual Spanish. Twenty percent are African American, and the remainder is of various races and ethnic backgrounds. About 10% of clients are in active clinical research programs. The Clinic’s rationale behind prevention programs is fourfold:

- HIV positive persons are the source of new infections.
- Prevention programs must target the behaviors of the population that put their partners at risk.
- The majority of HIV-positive persons are known and are in care.
- Prevention messages are most influential when provided by the primary care provider.

**South Texas Family AIDS Network** (Ernesto Parra, M.D., M.P.H.)

The South Texas Family AIDS Network (STFAN) program provides comprehensive family-centered health care and support services for women, youth, children, and families infected and/or affected by HIV in South Texas. Four clinics serve the target area comprising 47 counties in south Texas. Funding is through Ryan White Title IV.

Sixty-one percent of the program’s clients are Hispanic, 19% are African American, 12% are white, and 8% are of other races and ethnic backgrounds. Sixty-three percent are female. Sixty-five percent are the clients are over 23 years old, 30% are less than 13 years old, and 5% are between the ages of 13 and 22. The program’s focus is on first- and second-generation Hispanics, migrant seasonal farm workers, documented and undocumented immigrants.

The program offers HIV CTRS, medical care, case management, as well as training in STD education, health care, and prevention. The achievements of the program stem from this formula:

- one-stop, family-oriented health care and case management
- culturally sensitive, bilingual staff
- creative solutions to needs
- networking with CBOs for housing, medication, transportation
- 24-hour nurse availability
- locating HIV services at multidisciplinary health centers so clients can avoid being identified as HIV-positive.

**Women’s HIV Health Program**, Johns Hopkins University Hospital (Jean Keller, PA-C, and Rosemary Ramroop)

The mission of the Women’s HIV Health Program is to provide:
• access to comprehensive reproductive health care services
• HIV CTRS services with an emphasis on women of reproductive age
• early HIV intervention and access to health care
• assistance with psychosocial, support issues, and counseling needs of women living with HIV
• education about HIV, treatment options, and reproductive health to the community
• services in locations that are familiar and convenient to patients.

The Johns Hopkins Adult HIV Clinic offers primary care, sub-specialty gynecologic services, as well as peer counseling and education. Peer counselors offer partner counseling and testing, HIV education, adherence counseling, and safer-sex counseling. One unique aspect of the Johns Hopkins program is that peer counselors have been trained to serve as assistants and are present during the examination. That way, they can provide counseling services as issues arise. To encourage honesty, counselors frame their questions in such a way as to allow clients to say “not always” when asked about safer sex practices. Clients need to feel secure enough that they can admit, for example, that they do not always use a condom.

All women who present to the obstetric clinic are offered CTRS by peer counselors; between 95% and 98% of all pregnant women accept CTRS services. Outreach workers then provide links to care of identified HIV infected clients and their partners. Another important facet of care is preconception counseling to reduce vertical transmission.

The continuum of care extends into an obstetric clinic, which is staffed by physicians with a specialty in maternal-child health, a nurse, and peer counselors. This program provides comprehensive obstetric care for HIV-positive women, client advocacy, peer education, access to clinical trials, and a liaison with adult and pediatric infectious disease specialists.
Appendix H

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Appendix I

Other Background Materials

a. **Centers for Disease Control and Prevention, “Best Practices in Prevention Services for Persons Living with HIV,”** Remarks by R. Janssen

The goal of the *Best Practices in Prevention Services for Persons Living with HIV* project, which is being implemented for CDC by the Academy for Educational Development, is to provide general guidance based on the available research, programmatic experience, and expert consultation. To that purpose, we have conducted a series of consultations and associated literature reviews focused on improving case finding, prevention interventions, and legal and ethical issues. Consultation participants included affected populations, front-line prevention and care service providers, program managers, researchers, and agency representatives (HRSA, NIMH, CDC).

We are also planning a series of key informant interviews in each of these areas. We will include findings from the interviews, the literature reviews, and input from the consultations in a document for distribution to HIV prevention service providers, including health departments, health care professionals, community organizations, and other agencies that have an interest in providing HIV prevention services to persons living with HIV and AIDS. The anticipated publication date is Spring 2002. The document will describe those HIV prevention interventions and services regarded as best practices by consumers, front-line providers, program administrators, researchers, and other key experts. The document will also describe the primary research, program, and policy issues associated with prevention for persons living with HIV and AIDS.

Although the first drafts of reports from the consultations are just now coming out, we can point to a number of themes that ran through each of the consultations. For example:

1. Effective and ethically sound prevention interventions for HIV-infected people should be developed in the context of addressing multiple and often competing medical, social, and personal needs of HIV-infected populations
2. Prevention interventions that address locally specific needs at both individual and community (structural or contextual) levels should be evaluated and supported, rather than relying on more typical intervention approaches
3. This implies the need for stronger, more effective collaborations, including but not limited to collaborations among funding agencies such as CDC and HRSA, and funding initiatives that overcome the operational separation required by categorical funding
4. The links between case-finding, medical and other care, and prevention are critical to this effort
5. Programs focusing on HIV-infected persons need to be developed carefully in order to “do no harm” to affected populations, given the social and political contexts within
specific communities; we need to look for ways to acknowledge and address the risks that we are asking vulnerable communities to take in this strategy.

(6) Need to make informed and ethical decisions about how to target our counseling and testing strategies and prevention interventions; for example, do we put resources into targeting the relatively small number of individuals who may be driving the epidemic? What are the practical implications of such a policy, and do we have the resources to do otherwise (i.e., more wide scale counseling and testing, outreach, and prevention approaches)?

(7) Need to encourage and support new models of case-finding and linking to prevention and care services, including community organizing efforts that would be more successful in contacting and working with “hard to reach” populations (e.g., drug users, heterosexually identified MSM). Such efforts may also serve to impact social norms, influence policy, and diminish stigma.

The final drafts of the consultation reports will be available for review during the fall.
For additional information, please contact:
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Goal

The overarching goal of this project is to describe and understand the referral and linkage processes in HIV counseling, testing and referral (CTR) programs and data collection and management systems of those programs in a variety of illustrative jurisdictions in order to improve the quality of these programs, to assist people in learning their HIV status, to provide better services to clients, and to inform the development of indicators for subsequent evaluation of the referral services in light of the CDC Revised Guidelines for Counseling, Testing and Referral.

Objectives

As part of the evaluation, the following objectives will be addressed:

Describe and understand how grantees implement referrals and follow-ups for HIV-positive persons, for HIV-negative persons, and for sex and needle-sharing partners identified through partner counseling and referral services (PCRS) programs with a specific focus on referrals to treatment, physical and mental health care, social services, and prevention programs.

Describe and understand the influences of geographical, demographic, structural and procedural differences among counseling and testing facilities on the referral and linkage process, and how these might vary as a function of the strategies that grantees use in bringing individuals at high risk of HIV infection into HIV CTR.

Describe and understand the grantees’ current tracking and management information systems for referrals and follow-ups. For purposes of the current study, an MIS is defined as any system used to collect, track and manage client and program data regarding referrals in HIV CTR/PCRS.

The following table and narrative will specify the proposed research questions and case study evaluation methodology, and will discuss criteria for selection of the jurisdictions and facilities
to participate in the evaluation. It will also address data sources, data collection procedures, proposed data collection instruments, and plans for data analysis.
**Research Questions**

Based on the objectives described above, a series of research questions has been generated. The research questions appear in the following table linked to the objectives they address.

| Objectives                                                                                                                                                                                                 | Methods                                                                licht to the objectives they address.  
<table>
<thead>
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<td>Describe and understand how grantees implement referrals and follow-ups for HIV-positive persons, for HIV-negative persons, and for sex and needle-sharing partners identified through PCRS programs with a specific focus on referrals to treatment, physical and mental health care, social services, and prevention programs.</td>
<td>Data Abstraction</td>
</tr>
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| How is a referral defined?                                                                                                                                                                               | - MIS  
- Policies  
- Procedures  
- Guidelines  
- Protocols | - CT counselors  
- CT admin  
- other CT staff  
- clients |
| What types of referrals are made for:  
- HIV-positive clients?  
- high-risk HIV-negative clients?  
- partners identified through PCRS? | - MIS  
- Policies  
- Procedures  
- Guidelines  
- Protocols | - CT counselors  
- CT admin  
- other CT staff  
- clients |
| To what agencies/services are referrals made? Are referral recommendations made to specific services? Are referral recommendations made to specific agencies? Why? | - MIS  
- Policies  
- Procedures  
- Guidelines  
- Protocols | - CT counselors  
- CT admin  
- other CT staff  
- provider staff  
- clients |
| How are referral needs determined (e.g., medical, prevention, other supportive services)?                                                                                                             | - MIS  
- Policies  
- Procedures  
- Guidelines  
- Protocols | - CT counselors  
- CT admin  
- other CT staff  
- clients |
| What issues are considered in determining a client’s referral needs?                                                                                                                                    | - MIS  
- Policies  
- Procedures  
- Guidelines  
- Protocols | - CT counselors  
- CT admin  
- other CT staff  
- clients |
| How is follow-up for referrals managed by the facility providing CTR?                                                                                                                                     | - MIS  
- Policies  
- Procedures  
- Guidelines  
- Protocols | - CT counselors  
- CT admin  
- other CT staff  
- clients |
I. Describe and understand how grantees implement referrals and follow-ups for HIV-positive persons, for HIV-negative persons, and for sex and needle-sharing partners identified through PCRS programs with a specific focus on referrals to treatment, physical and mental health care, social services, and prevention programs.

<table>
<thead>
<tr>
<th>Question</th>
<th>Responsible Parties</th>
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<tbody>
<tr>
<td>What steps are taken to ensure that confidentiality of client information is maintained?</td>
<td>- MIS - Policies - Procedures - Guidelines - Protocols</td>
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<tr>
<td>What steps are taken to determine the client’s willingness and ability to accept and complete a referral (e.g., staff training, protocols, guidelines)?</td>
<td>- MIS - Policies - Procedures - Guidelines - Protocols</td>
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<td>What procedures are employed when a client’s referral needs are especially complex?</td>
<td>- MIS - Policies - Procedures - Guidelines - Protocols</td>
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<td>How are referrals tailored to individual clients’ characteristics (e.g., HIV serostatus, culture, language, gender, age, level of risk, etc.)?</td>
<td>- MIS - Policies - Procedures - Guidelines - Protocols</td>
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<tr>
<td>What is the quantity and quality of the social interaction between counselors and clients, and how does this impact the referral process?</td>
<td>- MIS - Policies - Procedures - Guidelines - Protocols</td>
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<tr>
<td>What education and support do staff receive to ensure appropriate implementation and management of referrals (e.g., counselor training, TA, QA)?</td>
<td>- MIS - Policies - Procedures - Guidelines - Protocols</td>
</tr>
<tr>
<td>What information is available regarding providers of referral services in the community? How current? How is this information provided to clients (e.g., format, presentation)?</td>
<td>- MIS - Policies - Procedures - Guidelines - Protocols</td>
</tr>
</tbody>
</table>
and mental health care, social services, and prevention programs.

<table>
<thead>
<tr>
<th>Question</th>
<th>MIS</th>
<th>Policies</th>
<th>Procedures</th>
<th>Guidelines</th>
<th>Protocols</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are there agreements between the CTR facility and the referral service provider? Are these formal (e.g., MOA) or informal (e.g., personal relationships among specific people)? What is the nature of these agreements?</td>
<td>- CT counselors</td>
<td>- CT admin</td>
<td>- other CT staff</td>
<td>- provider staff</td>
<td>- clients</td>
</tr>
<tr>
<td>What are barriers and facilitators to developing relationships among CTR facilities and provider agencies within these systems?</td>
<td>- CT counselors</td>
<td>- CT admin</td>
<td>- other CT staff</td>
<td>- provider staff</td>
<td>- clients</td>
</tr>
<tr>
<td>To what extent is the network of referral service provision integrated and collaborative? Or is service provision fragmented?</td>
<td>- CT counselors</td>
<td>- CT admin</td>
<td>- other CT staff</td>
<td>- provider staff</td>
<td>- clients</td>
</tr>
<tr>
<td>What client populations are served by the referral service provider agencies?</td>
<td>- CT counselors</td>
<td>- CT admin</td>
<td>- other CT staff</td>
<td>- provider staff</td>
<td>- clients</td>
</tr>
<tr>
<td>How do the providers of referral services assess the needs of referred clients?</td>
<td>- CT counselors</td>
<td>- CT admin</td>
<td>- other CT staff</td>
<td>- provider staff</td>
<td>- clients</td>
</tr>
</tbody>
</table>

II. **Describe and understand the influences of geographical, demographic, structural and procedural differences among counseling and testing facilities on the referral and linkage process, and how these might vary as a function of the strategies that grantees use in bringing individuals at high risk of HIV infection into HIV CTR.**

<table>
<thead>
<tr>
<th>Question</th>
<th>MIS</th>
<th>Policies</th>
<th>Procedures</th>
<th>Guidelines</th>
<th>Protocols</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is (are) the site’s target population(s)? How does the referral process vary as a function of the client’s referral needs?</td>
<td>- CT counselors</td>
<td>- CT admin</td>
<td>- other CT staff</td>
<td>- provider staff</td>
<td>- clients</td>
</tr>
<tr>
<td>How does the referral process vary as a function of an individual client’s characteristics (e.g., HIV serostatus, culture, language, gender, age, etc.)?</td>
<td>- CT counselors</td>
<td>- CT admin</td>
<td>- other CT staff</td>
<td>- provider staff</td>
<td>- clients</td>
</tr>
<tr>
<td>What particular site characteristics (e.g., geographical, demographic, structural or procedural) influence the referral and linkage</td>
<td>- CT counselors</td>
<td>- CT admin</td>
<td>- other CT staff</td>
<td>- provider staff</td>
<td>- clients</td>
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<tr>
<td>Process?</td>
<td>Guidelines</td>
<td>Protocols</td>
<td>Provider staff</td>
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<tr>
<td>What influence do these characteristics have on the process?</td>
<td>MIS</td>
<td>Policies</td>
<td>CT counselors</td>
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<td></td>
<td>Procedures</td>
<td>Guidelines</td>
<td>CT admin</td>
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<td></td>
<td>Protocols</td>
<td></td>
<td>other CT staff</td>
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<td></td>
<td></td>
<td></td>
<td>provider staff</td>
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<tr>
<td>5. How does the referral process differ for the identified sex and/or needle-sharing partners of HIV-positive individuals (e.g., collaboration with other health jurisdictions)? And how is confidentiality maintained?</td>
<td>MIS</td>
<td>Policies</td>
<td>CT counselors</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Procedures</td>
<td>Guidelines</td>
<td>CT admin</td>
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<td></td>
<td>Protocols</td>
<td></td>
<td>other CT staff</td>
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<td></td>
<td></td>
<td>provider staff</td>
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<td></td>
<td></td>
<td></td>
<td>clients</td>
<td></td>
<td></td>
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<tr>
<td>What is the counseling and testing facility’s capacity (e.g., resources, adequate staffing and training, etc.) for making appropriate referrals?</td>
<td>MIS</td>
<td>Policies</td>
<td>CT counselors</td>
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<tr>
<td></td>
<td>Procedures</td>
<td>Guidelines</td>
<td>CT admin</td>
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<td></td>
<td>Protocols</td>
<td></td>
<td>other CT staff</td>
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<td>provider staff</td>
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<td></td>
<td></td>
<td></td>
<td>clients</td>
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</tbody>
</table>

II. Describe and understand the influences of geographical, demographic, structural and procedural differences among counseling and testing facilities on the referral and linkage process, and how these might vary as a function of the strategies that grantees use in bringing individuals at high risk of HIV infection into HIV CTR.

| What barriers to access exist (within CTR facility and at provider agency) and how does the site address them? | MIS | Policies | CT counselors |
| | Procedures | Guidelines | CT admin |
| | Protocols | | other CT staff |
| | | | provider staff |
| | | | clients |
| What is the nature of linkages between the CTR facility and referral service providers? Are there agreements? Are these formal (e.g., MOA) or informal (e.g., personal relationships among specific people)? What is the nature of these agreements? | MIS | Policies | CT counselors |
| | Procedures | Guidelines | CT admin |
| | Protocols | | other CT staff |
| | | | provider staff |
| | | | clients |
| What are barriers and facilitators to developing relationships among CTR facilities and provider agencies within these systems? | MIS | Policies | CT counselors |
| | Procedures | Guidelines | CT admin |
| | Protocols | | other CT staff |
| | | | provider staff |
| | | | clients |
| To what extent is the network of referral service provision integrated and collaborative? Or is service provision fragmented? | MIS | Policies | CT counselors |
| | Procedures | Guidelines | CT admin |
| | Protocols | | other CT staff |
| | | | provider staff |
| | | | clients |

III. Describe and understand the grantees’ current tracking and management information systems (MIS) for referrals and follow-ups.
<table>
<thead>
<tr>
<th>Question</th>
<th>MIS</th>
<th>CT counselors</th>
<th>CT admin</th>
<th>other CT staff</th>
<th>provider staff</th>
<th>clients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is there any documentation of the referrals made?</td>
<td>- MIS - charts - progress notes</td>
<td>- CT counselors</td>
<td>- CT admin</td>
<td>- other CT staff</td>
<td>- provider staff</td>
<td>- clients</td>
</tr>
<tr>
<td>How?</td>
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<tr>
<td>Is the status/outcome of referrals documented?</td>
<td>- MIS - charts - progress notes</td>
<td>- CT counselors</td>
<td>- CT admin</td>
<td>- other CT staff</td>
<td>- provider staff</td>
<td>- clients</td>
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<tr>
<td>How?</td>
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<tr>
<td>Is client satisfaction with referrals documented?</td>
<td>- MIS - charts - progress notes</td>
<td>- CT counselors</td>
<td>- CT admin</td>
<td>- other CT staff</td>
<td>- provider staff</td>
<td>- clients</td>
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<tr>
<td>How?</td>
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<tr>
<td>Is there a formal MIS? What format (electronic, paper)?</td>
<td>- MIS - charts - progress notes</td>
<td>- CT counselors</td>
<td>- CT admin</td>
<td>- other CT staff</td>
<td>- provider staff</td>
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<td>- at the counseling and testing facility?</td>
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<tr>
<td>- at the service provider agencies?</td>
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<tr>
<td>How much MIS integration is there (e.g., is information regarding referrals shared between agencies)? If so, how is confidentiality maintained?</td>
<td>- MIS - charts - progress notes</td>
<td>- CT counselors</td>
<td>- CT admin</td>
<td>- other CT staff</td>
<td>- provider staff</td>
<td>-</td>
</tr>
<tr>
<td>What, if anything, is done to determine successful completion of referral? What is being documented (e.g., medical, specific referral, etc.)? Why is this information being collected (e.g., state requirement or local need)?</td>
<td>- MIS - charts - progress notes</td>
<td>- CT counselors</td>
<td>- CT admin</td>
<td>- other CT staff</td>
<td>- provider staff</td>
<td>- client</td>
</tr>
</tbody>
</table>
III. Describe and understand the grantees’ current tracking and management information systems (MIS) for referrals and follow-ups.

| What barriers and/or facilitators exist to the development and implementation of MIS? | - MIS - charts - progress notes | - CT counselors - CT admin - other CT staff - provider staff - clients |

**Evaluation Methodology**

The evaluation will involve site visits to a variety of counseling and testing facilities in four selected CDC-funded public health jurisdictions (plus two pilot jurisdictions) to conduct a series of case studies of CTR/PCRS programs.

**Site selection criteria.** The specific criteria for selection of jurisdictions have been defined based on input from the CDC and the recommendations of members of an expert panel. Potential jurisdictions will be selected based on:

1. variation in referral practices
2. urban vs. rural settings
3. variations in use of CTR report forms
4. anonymous vs. confidential testing
5. target population(s)
6. the Health Department’s cooperation and willingness to participate

The case study protocol will likely require visiting a number of CTR facilities and other agencies within a jurisdiction. These may include designated CTR facilities, STD clinics, prenatal/OB clinics, other family planning clinics, and drug treatment facilities among others. Within each jurisdiction, a variety of types of facilities will be selected based on the number of tests performed by the facility, funding levels, prevalence of HIV+ and/or HIV- tests, and recommendations from the jurisdictions’ AIDS Directors.

**Case study methodology.** The case study approach provides a potentially strong method for learning more about service delivery within a community context from the perspective of clients and their providers because of the quantity of information available and the opportunities for validation from multiple data sources. Data will be collected through reviews of existing data, reports, documentation, and other information; observations at the sites; and in-depth, semi-structured interviews.

The selected sites will likely vary in the availability and quality of their existing data, reports, and documentation. Therefore, an initial component of the evaluation protocol will be an assessment of the selected sites to determine the components that comprise their referral system; the relationships among CT agencies and service provider agencies; the types of data these agencies can provide regarding their HIV CTR and PCRS programs, and the extent to which these data can address the research questions. These data sources may include administrative regulations,
brochures, manuals, annual reports, minutes, grant proposals, program records of service provision, and other MIS data. The goal of this initial document review is to minimize the burden that data collection will place on the grantees.

Each of the case study sites will be contacted to inform them of the project and request information on existing data, reports, documentation, and other information. A letter introducing the project, its purpose and the proposed data collection will be sent to the primary contact at each site. This letter will include a request for participation. Upon acceptance, a follow-up letter will be sent that will include suggested data sources, desired data elements for the data collection, and any other specific requests. Follow-up telephone conversations will clarify any questions sites have and further develop a plan for the data collection, including negotiation of a date for the data collection to take place. Suggested data elements will be determined based on input from CDC and a panel of subject matter experts. The information collected through data abstraction will be used to provide background and context for the subsequent semi-structured interviews.

The semi-structured interviews will be conducted with key informants in each jurisdiction to clarify and further explore topics that were identified and insufficiently addressed through data abstraction relevant to understanding the elements of the program, the structure of the service delivery system, and the nature of the referral process. Key informants will likely include:

- counselors at the CTR facilities
- CTR facility administrators
- other CTR facility staff knowledgeable of the referral process
- service provider agency staff
- clients with referral experiences.

Pilot testing of data collection instruments and the case study protocol will be conducted at two of the six sites. All the data collection instrumentation and methods will be pilot tested during an approximately 3-4 day site visit to each selected site.

**Data analysis plan.** The individual semi-structured interviews will be analyzed for content relevant to an understanding of the various perspectives on the service delivery and referral linkage structure. The next step in the analysis will be to triangulate individual perspectives of key informants on how services are meeting the needs of clients with data from record reviews and other documentation to establish the degree of consensus regarding program objectives and elements and service delivery system structure. In addition, the information obtained will be reviewed to generate recommendations to inform the development of indicators for subsequent evaluation of the referral services in light of the CDC Revised Guidelines for Counseling, Testing and Referral.