FORUM FOR COLLABORATIVE HIV RESEARCH

LINKING HIV TESTING, PREVENTION AND CARE

Background Paper

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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.ⁱ 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.ⁱⁱ

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).^{III}

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 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.^{iv} 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 negative 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.

Effects of HIV C/T on Sexual Risk Behavior: A Meta-Analytic Review of Published Research, 1985-1997

The guestion 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 metaanalysis 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.^v 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.^{vi} 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.^{vii} In one study, long-term non-presenters were uninsured, male, or injecting drug users.^{viii}

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.^{ix} 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 ageappropriate. 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 HIVnegative 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 HIVnegative 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.^{xi} 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 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%).^{xii} 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.^{xiii} 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^{xiv} 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.^{XV} 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)."

ⁱ Anderson JE, Carey, JW, and Taveras S. HIV testing among the general US population and persons at increased risk: Information from national surveys, 1987-1996. *American Journal of Public Health 90*(7):1089-1095. July 2000.

ⁱⁱ Centers for Disease Control and Prevention. *HIV Counseling and Testing in Publicly Funded Sites Annual Report, 1997 and 1998.* Atlanta GA: Centers for Disease Control and Prevention. 2001.

^{III} California Department of Health Services. *California HIV Counseling and Testing Annual Report: January-December 1998.* Sacramento CA: California Department of Health Services. June 2001.

^{iv} Silvestre AJ, Gehl MB, Encandela J, and Schelzel G. A participant observation study using actors at 30 publicly funded HIV counseling and testing sites in Pennsylvania. *American Journal of Public Health 90*(7):1096-1099. July 2000.

^v Weinhardt LS, Carey MP, Johnson BT, Bickham NL. Effects of HIV counseling and testing on sexual risk behavior: A meta-analytic review of published research, 1985-1997. *American Journal of Public Health 89*(9):1397-1405. September 1999.

^{vi} Samet JH, Freedberg KA, Stein MD, Lewis R, Savetsky J, Sullivan L, Levenson SM, Hingson R. Trillion virion delay: time from testing positive for HIV to presentation for primary care. *Arch Intern Med 158*(7):734-40. Apr 13 1998.

^{vii} Bindman AB, Osmond D, Hecht FM et al. Multistate evaluation of anonymous HIV testing and access to medical care. *JAMA 280*(16):1416-1420. Oct 28, 1998.

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^{ix} Centers for Disease Control and Prevention. *Revised Guidelines for HIV Counseling, Testing and Referral: DRAFT*. Atlanta GA: Centers for Disease Control and Prevention. October 17, 2000.

^x ORC Macro. Referrals and Linkages in HIV Counseling, Testing, and Referral and Partner Counseling and Referral Services: Annotated Literature Review. Unpublished document. April 2001.

^{xi} Holloway J, O'Neill J, Powell A, Gomez, M. Early Intervention Demonstration Projects in the U.S.: Linking HIV Care and Prevention Services at the Local Level.

^{xii} Truax, Steve. Analysis of Referrals from HIV Counseling and Testing Programs. California Department of Health Services Office of AIDS. September 2001.

^{xiii} NASTAD. Targeted Testing and Referral Efforts for Minority Communities: A Report from the NASTAD STATUS Project. Washington DC: NASTAD. April 2001.

^{xiv} NASTAD. *Monograph: Linking HIV/AIDS Services with Substance Abuse and Mental Health Programs.* Washington DC: NASTAD. January 2000.

^{xv} HRSA/HAB and HUD/HOPWA. *Lessons Learned: Innovations in the Delivery of HIV/AIDS Services*. March 2001. Accessed at <u>www.hab.hrsa.gov</u>.