

F C
H R

Forum for Collaborative HIV Research

Linkage and Integration of HIV Testing, Prevention, and Care Services

A Project Sponsored by the Forum for Collaborative HIV Research, the Centers for Disease Control and Prevention (CDC), and the Health Resources Services Administration (HRSA) of the U.S. Department of Health and Human Services, Washington, D.C.

***Alexandria, VA
October 1-2, 2001***

Linkage and Integration of HIV Testing, Prevention, and Care Services

October 1 & 2, 2001
Washington, D.C.

David Barr, Facilitator
John Palen, Ph.D. – Report Editor
Veronica Miller, PhD
Director, Forum for Collaborative HIV Research

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.

Table of Contents

Executive Summary	5
Background Materials	9
Summary of Review “Linking Testing, Prevention, and Care” by Helen Schietenger for the Forum	9
List of other Materials Distributed	9
The Challenges of Linking Services –Summary Presentations	11
HIV Testing and Care: Identifying the Gaps – Patricia Fleming, PhD – CDC	11
Integrating HIV Prevention into the Care Setting – Laura Cheever, MD – HRSA	21
A Consumer Perspective on Integrating Prevention and Care Services – Steve Wakefield	27
Challenges to Effective Linkages and Program Models	29
<i>Panel 1: Organizational and Systems Issues</i>	
Linking Prevention Providers with Care Providers: Brenda Starks-Ross	29
Establishing Prevention Services in Public and Private Care Settings: Holly Buckendahl, and Mark Loveless, MD	31
Linking Centers of Excellence with Prevention Providers Robert A Larsen, MD	36
Planning and Establishing Integrated Prevention and Care Services: Jean Flatley McGuire, PhD, and Patricia Bass	39
Summary of Panel Presentation	46
<i>Panel 2: Social Needs and Co-occurring Health Issues</i>	
Homelessness, Substance Abuse, and Mental Health Issues: Louise Treherne	48
Women: Jean Keller, PA-C, and Rosemary Ramroop	50
Incarcerated Persons: Sam Rivera, and Pamela Goodrich	52
Summary of Panel Presentation	53
<i>Panel 3: Cultural and Regional Issues</i>	
Immigrant and other Non-English Speaking Communities: Ernesto Parra, MD, MPH	55
Gay Youth of Color: Jaime Martinez, MD	57
Rural Communities: Sally Lou Patterson	60
Summary of Panel Presentation	62
<i>Panel 4: Evaluating of Links and Referrals</i>	
The New York State Experience: Jeff Rothman, MD	63
The Experience of the Center for Integrated HIV Networks: Julia Hidalgo, PhD	67
Workshop Discussions and Recommendations	71
Identifying Links and Points of Entry into Care, and Barriers to Linking HIV CTRS, Prevention, and Care Services	72
Recommendations to Reduce Barriers	74
Federal Recommendations	74
State Program Administrator Recommendations	76
Community Based Service Provider Recommendations	79
Evaluation Recommendations	81
Summary of Recommendations	82

Appendices.....84

- A. “Linking of Testing, Prevention, and Care” by H. Schietenger84
- B. “Referrals and Linkages in HIV Counseling, Testing, and Referral and Partner Counseling and Referral Services: An Annotated Literature Review” by ORC Macro93
- C. Executive Summary, Report Of The NASTAD Status Project113
- D. Meeting Agenda115
- E. Tables from Breakout Session I: Identifying Links and Points of Entry into Care, and Barriers to Linking HIV CTRS, Prevention, and Care Services118
- F. Detailed Notes from Breakout Session II: Recommendations for Action at the Federal, State, and Local/Provider Levels, and for Evaluation121
- G. Background Information on Programs Discussed by Speakers128
- H. Members of Meeting Planning Group134
- I. Other CDC Background Materials137

Executive Summary

The idea for this workshop emerged when representatives from the Forum for Collaborative HIV Research, HRSA and CDC began to discuss during early 2001, how to better engage people in HIV prevention, and HIV counseling, testing, and referral services (CTRS), and how these services could more strongly link to HIV care and treatment services. An additional issue that discussants identified was how to best evaluate the quality of links and the effectiveness of strategies for integrating prevention services into medical care and social service programs. Agency representatives started the dialogue with a broad view. Eventually, participants decided that these questions, integration strategies, and methods for evaluating them would be best explored in an event that called together key agency representatives at the federal level, leaders from grantee organizations (such as state health agencies and Title I Planning Councils), and key informants from public and private organizations involved in HIV service delivery.

A main concern of planners was to increase access of people living with HIV to an array of services, so that all of the HIV prevention, care, and treatment needs are adequately met. Planners do not want such persons to “get lost” to the system, but rather begin receiving services as soon as possible. Planners knew that this could be accomplished by a variety of means: locating all services in one place, referring to other services, and creating networks (or “linkages”) among service providers. In this endeavor, CTRS play a key role, primarily as a means to further prevention, care, and/or treatment services.

The workshop opened with remarks by leaders of sponsoring organizations, presentations on how prevention can be integrated into clinical settings, how service networks can be created, and overviews of current data on HIV CTRS and linking such with HIV prevention and care. Speakers stressed that in order to develop effective strategies to link prevention and care services, it is important to understand the nature the HIV epidemic in the U.S., HIV testing patterns, who is getting tested and receiving care services, the benefits and challenges to counseling, testing, and care. Knowing the perspective of clients is also critical. Speakers highlighted the following:

- HIV prevalence is steadily increasing across all groups, and a large portion of those at risk for HIV infection appear to have availed themselves of CTRS;
- A significant proportion of HIV-infected persons are not in care, and, therefore, not benefiting from services to either prolong the quantity and quality of life, or reduce transmission to others;
- Trends in HIV diagnoses by stage of disease indicate that a remarkably stable proportion of cases are diagnosed at the time AIDS is diagnosed;
- A new and complementary approach for HIV prevention is needed, focusing on the HIV-infected individual already in care;
- Delivering prevention messages must become an integral part of delivering care;
- Motivating individuals to use CTRS and reduce risk activities requires client trust and community and/or family support;
- Outreach programs targeting high risk persons can be very effective at raising participation in CTRS, prevention and/or care services;

Several panel discussions then followed, offering examples of links and integration, barriers, and methods that have been used at the government, community, and health care provider levels to address barriers. Presenters highlighted some ongoing innovative programs and recommended some solutions based upon their experience. Successful strategies have included: co-locating services in a single site, joint marketing of services, cross training of service staff, including brief prevention counseling in each primary care visit, using multidisciplinary teams to provide prevention and care services, using peers to conduct outreach and provide peer counseling, embedding messages in the language and culture of the target audience, offering services during times other than the usual workday, and using communications media familiar to the target audience. Speakers described how competing social needs and co-occurring health problems may have a significant impact on an individual's ability and interest in using services. Culture, language, and geographic location may also create barriers. Panel members also offered suggestions as to how various barriers could be overcome, including linking of local public and private providers by the state each time a specific HIV case is reported, development of model policies and protocols for use by providers, targeting specific geographic areas for "saturation" education and outreach campaigns, linking ambulatory care and CTRS programs to outreach initiatives, establishing links to programs that can help clients with average daily needs such as food or shelter, and coordination of HIV-related services with other services already reaching the target population (e.g. prenatal care with CTRS).

To capitalize on the collective knowledge and experience of workshop participants, two breakout sessions were convened during the workshop, one toward the end of the first day, the other toward the end of the overall workshop. These sessions generated ideas and recommendations for the sponsoring entities to consider with regard to future programs and services. The focus of the first breakout session was: identifying points of entry into medical care, social services, and educational services that result from or lead to HIV diagnosis; theorizing how primary and secondary prevention can be linked; identifying opportunities to create linkages, referrals, and integration of services from and to these points of entry; and identifying barriers that hinder the delivery of comprehensive services. All participants in this session seemed to agree on two key points. First, multiple points of entry into care are needed. Participants felt that such overlapping points of entry are necessary to reinforce messages and also because of the various reasons for which persons seek HIV CTRS. Secondly, effective linking of primary and secondary prevention services is very difficult.

During the second breakout session, three groups formulated recommendations for actions that can be taken by (1) the federal government, (2) state program administrators, and (3) community direct-service providers to better integrate care and prevention services. A fourth group focused on how linkage quality and effectiveness could be evaluated. Major categories of recommendations are summarized below.

Based on Session II break out groups, recommendations were proposed and further delineated based on priority (below). These were specific to types of efforts to reduce existing barriers and improve the linking of HIV-infected persons to care for government officials, State health administrators, community based service providers, and evaluators. Complete notes from this session are included in **Appendix F**.

Recommendations of Workshop Participants:

Federal Government

1. Federal agencies involved in HIV issues need to integrate the funding and disbursement process for HIV counseling and testing, care and treatment, and prevention programs.
2. Federal agencies need to simplify and coordinate administrative activities and procedures to encourage and support cross-agency formation of linkages at the state and local level.
3. Federal agencies need to develop standard data and evaluation systems that can be used across services at all levels.

State Program Administrator

1. States must increase state funding for HIV prevention services, complementing resources available from federal sources, especially through establishing reimbursement mechanisms in Medicaid programs.
2. States must simplify and coordinate the administration of HIV prevention and care programs.
3. States should enhance planning activities aimed at linking CTRS with care and prevention services.
4. States should establish one or more networks of providers that provide a continuum of health and social services, and facilitate the formation of linkages at local levels.
5. States need to improve the quality of data and program evaluation, and establish standards of care that guide provider evaluation activities.

Community Based Service Providers

1. Each agency should define its unique role and mission in the community, based on the needs of the community, so as to complement and improve existing services and enhance formation of networks with other providers.
2. Agencies need to devote resources to establishing relationships with other providers.
3. Agencies need to examine and build staff and clinic skills in linking persons to needed services, especially from CTRS to prevention and/or care services.
4. Individually and collectively within networks, agencies need to enhance client tracking procedures to ensure that individuals are linked to relevant prevention and care services.

Evaluators of Linkage Programs

1. To the extent possible, evaluators should use existing data sources and avoid creation of a separate evaluation system exclusively for links and referrals.
2. Evaluation activities should focus on client outcomes, and not just provider outputs.
3. Federal agencies need to provide leadership and technical assistance with regard to use of existing data sources for evaluation, and fund research into evaluation methods and projects that demonstrate results of links and referrals.
4. States can play a leadership role in forming cross-site continuous quality improvement activities and correlating data on counseling/testing, care, surveillance, and service utilization.
5. Providers should adopt a continuous quality improvement approach to evaluation, and adapt or create linkage and referral models that can be monitored in their service areas.

This workshop's collaborators intend that the outcomes of this workshop help HRSA, CDC, and other organizations involved in HIV services to develop and improve new and existing programs, and identify and reduce barriers to effectively linking HIVCTRS, prevention, and care services as highlighted by workshop participants. The ultimate outcomes are to reduce the numbers of HIV-infected individuals who know their status but are not receiving necessary care and prevention services, and reduce the number of newly infected individuals. Portions of the workshop presentations and several taped interviews were used in a videoconference that followed the workshop.

Background Materials

In preparation for the two-day workshop, participants were provided with a comprehensive review of published and unpublished literature in the area of linking HIV-infected persons to care. One paper, titled “Linking of Testing, Prevention, and Care” by Helen Schietenger, presented recent data on HIV CTRS and linking such to prevention and care services. The following is a summary of the main points in the document as related to the specific topic areas discussed at the workshop. The complete document is included in **Appendix A**.

- Approximately one-third of adults in the U.S. have been tested for HIV antibodies.
- Rates of receiving CTRS among high-risk populations (such as drug users, men who have sex with other men, etc.) are often considerably higher.
- The majority of persons who are tested for HIV (even in publicly funded clinics) report that a health professional did not discuss HIV-related issues with them.
- HIV CTRS programs, STD clinics, prisons, and drug treatment programs report the highest percentages of HIV positive tests among various testing venues.
- While slightly more than one-half of all HIV tests involve women, more than two-thirds of HIV positive tests involve men.
- While 20-29 year olds are the age group with the highest proportion of tests, the 30-39 age grouping has the highest proportion of HIV positive tests.
- The proportion of testing events with post-test counseling has ranged from 50-55%; in publicly funded CTRS sites the proportion has ranged from 62-68%.
- In practice, counseling services offered in conjunction with testing are often not adequate, with great variation across sites that claim to follow the same or similar protocols.
- CTRS appears to have a limited impact in reducing risk behavior. One meta-analysis has shown that HIV infected persons and serodiscordant couples are the only ones showing a significant degree of risk reduction as a result of CTRS.
- Delay in treatment is a common reality for many who test HIV positive. A 1988 study showed that almost 40% of persons diagnosed with HIV infection do not engage in treatment for at least one year; 18% do not do so for five years.
- Those agencies that do the best job of referrals and linking regularly educate and support their staff in meeting client needs, maintain accurate information regarding referral resources, and develop and sustain strong working relationships with other providers.
- Some states (California, Pennsylvania, and New York were cited) and cities have unique experience with trying to enhance referrals and linkages. These are described in the document.

Other materials distributed at meeting included the following:

- Centers for Disease Control and Prevention, “Best Practices in Prevention Services for Persons Living with HIV,” Remarks by R. Janssen, M.D., M.P.H.. See **Appendix I** for full text.

- Centers for Disease Control and Prevention, “Evaluation Plan for the Referrals and Linkages in HIV Counseling and Testing, and Referral and Partner Counseling and Referral Service Project” presented .See **Appendix I** for full text.
- HIV/AIDS Bureau, *Lessons Learned: Innovations in the Delivery of HIV/AIDS Services* (Washington, D.C.: HRSA, 2001). Available at: www.hab.hrsa.gov.
- Executive Summary, Report of the NASTAD Status Project (Washington, D.C: National Alliance of State and Territorial AIDS Directors, 2001). See **Appendix C** for full text.
- Program Evaluation and Research Branch, Division for HIV Prevention, “Referrals and Linkages in HIV Counseling, Testing, and Referral and Partner Counseling and Referral Services: An Annotated Literature Review” (Atlanta, GA: Centers for Disease Control and Prevention, 2001). See **Appendix B** for full text.

The Challenges of Linking Services –Summary Presentations

In order to develop effective strategies to link HIV counseling and testing sites and care settings, it is important to understand the nature the HIV epidemic in the U.S., HIV testing patterns, who is getting tested and receiving care services, the benefits and challenges of providing direct and immediate access to counseling, testing, and care, and the perspective of clients. Expert presenters were selected to provide a summary of these issues to workshop participants at the beginning of the workshop. Their presentations follow.

HIV Testing and Care: Identifying the Gaps

Remarks of Patricia Fleming, PhD, Chief of HIV/AIDS Surveillance Branch, Division of HIV/AIDS Prevention, Surveillance, and Epidemiology, Center for HIV, STD, and TB Prevention, CDC, Atlanta, GA

CDC has considerable data on how many people are living with HIV, and on receipt of testing in high risk populations, which can inform us on the issues of met and unmet needs for services. CDC has data on the prevalence of testing in high risk populations, reasons people test or do not test, where people are tested and diagnosed, when in the course of disease people are first diagnosed, and, finally, met and unmet needs for prevention and care.

Some of the data sources available include the Behavioral Risk Factor Surveillance System (BRFSS), HIV Testing Survey (HITS), Arrestee Drug Abuse Monitoring survey (ADAM), HIV/AIDS Reporting System (HARS), HIV counseling and testing system (CTS), Supplement to HIV/AIDS Surveillance (SHAS), Recent Infection Project, and the Adult/Adolescent Spectrum of Disease (ASD) project. Data also come from unpublished sources provided by CDC colleagues.

Epidemic Overview – HIV Prevalence is Increasing

Here are some of the current trends that are relevant to our discussion.

- CDC estimates the cumulative number of HIV infections to be between 1.2 and 1.3 million.
- CDC estimates that about three-fourths of infected know their HIV serostatus. Approximately 670,000 individuals are diagnosed with HIV or AIDS and alive.
- As of 1998, HIV prevalence was estimated to be between 800,000 to 900,000 persons. The prevalence of AIDS has been steadily increasing across all risk groups. At the end of 2000, approximately 340,000 people were living with AIDS in the United States. From the States with HIV reporting we know the number of diagnosed cases living with HIV(non AIDS) to be about 131,000. CDC uses those data to model the number of persons diagnosed with HIV. CDC estimates that in States that do not have HIV case reporting, about 200,000 people are likely to have been diagnosed with HIV infection, but not AIDS.

- New infection numbers have remained fairly stable at around 40,000 per year since the early 1990's.
- Cumulatively, there have been about 775,000 AIDS cases reported to CDC and about 450,000 deaths.

Who Gets Tested?

Answer: CDC data demonstrate that a large proportion of individuals at-risk for HIV infection have been counseled and tested and, among HIV-infected persons, certain individual characteristics (e.g., race, age, and risk group) increase the likelihood of getting tested.

The CDC has supported numerous studies over the past four years to examine testing patterns among high-risk populations. The HIV Testing Survey (HITS) of at-risk populations, done by CDC in collaboration with state and local health departments, has been conducted in over 20 States one or more times. Respondents were found via outreach to MSM and injection drug users. High-risk heterosexuals were identified at STD clinics. In the first two surveys (HITS I and HITS II) conducted between 1996-8 (Table 1), the percentage of at-risk individuals self-reporting HIV testing was high (77% to 80%).

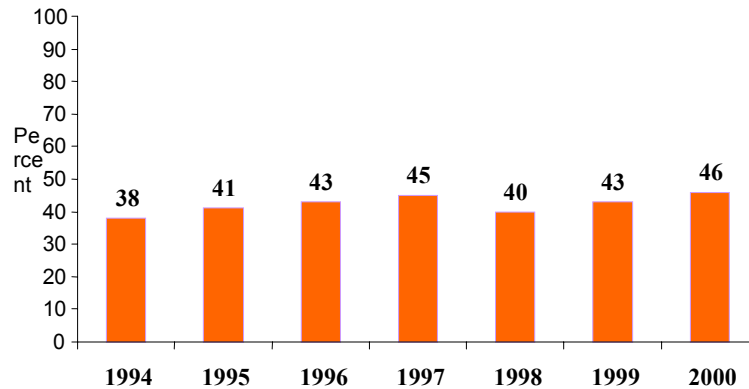
Table 1. Percentage of At-Risk Individuals Tested for HIV, by Self-Report
Source: HIV Testing Survey I and II

	HITS I (11/95 to 12/96)	HITS II (8/98 to 2/99)
N	2394	2077
Overall percentage reporting having been tested	77%	80%
Percentage reporting having been tested, by gender	M (77%); F (80%)	M (80%); F (81%)
Percentage reporting having been tested, by risk group	MSM (82%) IDU (79%) STD (69%)	MSM (84%) IDU (90%) STD (68%)

Surveys of high-risk people and population-based surveillance in infected populations indicate that the proportion of HIV-positive individuals who know their status is approximately 70% to 80%. Because of targeted CTRS promotion among pregnant women, a recent survey in seven states of HIV-positive pregnant women has shown that more than 90% know their status.

Figure 1. Percent of respondents, aged 18-64 years, ever tested for HIV, by year

Source: Behavioral Risk Factor Surveillance System, 1994-2000



The BRFSS, a general population survey, documents the percentage of people who have ever tested for HIV. In 2000, 46% of respondents indicated that they had been tested (Figure 1.). In the 1999 BRFSS, more than 50% of pregnant women reported being tested, whereas 26% of non-pregnant women reported being tested (data not shown).

In the HIV-infected population, factors that increase the likelihood of late testing include: being a member of a racial or ethnic minority group, a reported heterosexual risk factor, and increasing age (see Table 2 with regard to men, below).

Table 2. Factors Associated with Late Testing, Multivariate Analysis: SHAS data.

<u>Men</u>	<u>AOR</u>	<u>99% CI</u>
Race		
White (referent)	1.0	---
Black	1.6	1.4-1.8
Hispanic	1.8	1.6-2.0
Risk		
MSM (referent)	1.0	---
Hetero.	1.9	1.6-2.2
MSM/IDU	0.6	0.5-0.7
Age at AIDS diagnosis		
18-29 (referent)	1.0	---
30-44	2.7	2.4-3.0
45	4.7	4.1-5.6

Why Are People Tested?

Answer: Most people get tested because of personal interest, or during a routine or acute health-related visit.

The 1998 BRFSS included the question, “What was the main reason you had your last test for HIV?” to uncover the reasons behind HIV testing. Twenty-one percent of men responded “just to find out,” and 20% were tested during routine checkups. Most women (29%) cited pregnancy as the reason behind testing, followed by routine checkups (19%).

Finally, the preliminary data from a behavioral survey in populations at risk for HIV conducted in States during 2000, HITS 2000, give further insights into HIV-negative person’s motivation for testing (Table 3).

Table 3. Reasons for Seeking Testing among Persons Who Tested HIV Negative (n = 2137)
Source: HITS 2000 preliminary data

Reason	% Gave as a Reason	% Gave as Main Reason
To know where they stood	91	50
Thought exposed through sex	55	10
Thought exposed through drug use	28	7
Part of STD or routine checkup	42	7
Concerned about transmitting HIV	38	5
Wanted to have child	11	4
Partner was HIV-positive	7	3
Wanted medical care if HIV-positive	56	3

Reasons for avoiding testing among people not tested in the past year include the following (Table 4).

Table 4. Reasons for Avoiding Testing among People Not Tested for HIV in the Past 12 Months (N=1137). Source: HITS 2000 preliminary data

Reason	% Gave as a Reason	% Gave as Main Reason
Unlikely to have been exposed	53	30
Thought HIV-negative	64	24
Afraid to find out	26	10
Some other reason	15	10
Did not want to think about being HIV-positive	33	7
Didn't have time	19	7
Unsure where to go	8	2
Worried name would be reported to government	8	2
Worried about who would find out results	11	1
Could do little if HIV-positive	8	1

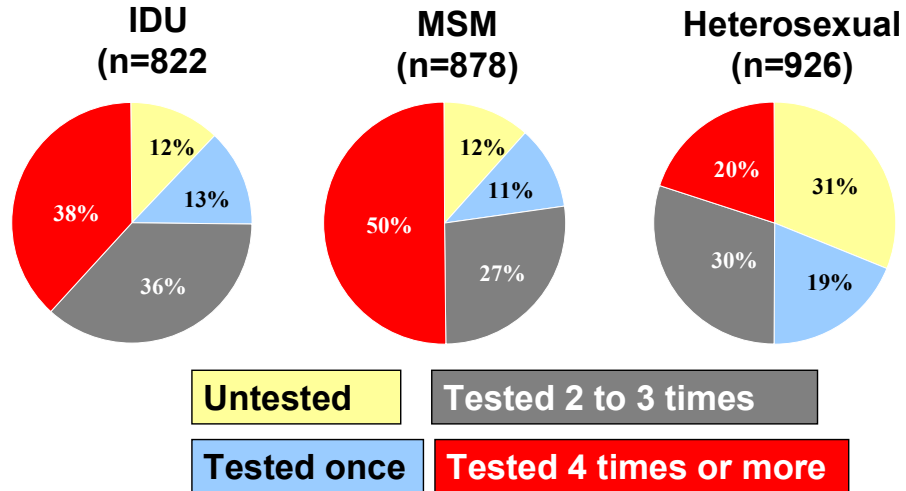
In the Recent HIV Infection Study (1997-1998) conducted in three states, the leading reasons cited by men for getting tested were that a doctor or friends told them to be tested (28%) or that they were worried that they were infected (22%). Among females, pregnancy care was cited as the reason by 33%, and 18% reported that a doctor or friends had recommended testing.

How Often People Are Tested?

Answer: It depends on the risk group. For example, IDU are more likely to repeat testing than MSMs.

Figure 2 (below) represents some preliminary data from HITS 2000 regarding rates of repeat testing among IDUs, MSM, and heterosexuals. Of individuals surveyed in 1999 at CTRS sites and heterosexuals in STD clinics, about a third specified no previous test, and 45% specified a prior positive, negative or inconclusive result.

Figure 2. Frequency of HIV Testing Among IDU, MSM and Heterosexuals, HITS-2000 Preliminary Data*



Where Are People Tested?

Answer: For at-risk populations, most were tested in a community health center. This was followed by a doctor's or health maintenance organization (HMO) office (Table 5).

Table 5: Testing sites utilized, by risk group.
Source: HITS 2000

	n=776	n=725	n=636	n=2137
HITS 2000: Site Tested	MSM(%)	IDU(%)	Hetero.(%)	Overall(%)
Community Health Center	18	14	23	18
Private MD Office/HMO	31	8	11	16
STD Clinic	5	3	28	11
AIDS prevention project	10	18	2	10
Medial clinic in hospital	7	9	8	8
HIV C/T	12	8	1	7
Correctional Facility	<1	12	5	6
Drug treatment program	<1	13	3	6
Hospital	2	4	3	3
Other	7	6	4	10

Among positive persons reported with HIV or AIDS in 12 States that interview PWH/ A reported as cases to the health department, 22.8% were tested as inpatients. (SHAS, 6/97-12/00, N=7,286). Other locations include: HIV C/T (18.3%), Private MD/HMO (16.0%), Clinic (including HIV) (12.3%), STD clinic (9.8%), jail/prison (5.8%), blood bank (2.7%), drug treatment center (2.4%), and other (9.9%).

For the subset of HIV-infected persons simultaneously diagnosed with AIDS, most were diagnosed as inpatients (59.4%). Others were diagnosed in private doctors or HMO offices (19.1%), with small numbers diagnosed in CTRS sites or in correctional institutions (HARS, 1/94-12/99).

There are some common threads among these data. If people are not seeking testing, but are waiting until they become symptomatic, most are diagnosed in clinical care settings. However, if individuals seek testing without regard to symptoms, approximately 25% receive testing at CTRS sites or STD clinics.

When Are People Tested?

Answer: Trends in HIV diagnoses by stage of disease indicate that a remarkably stable proportion of cases (approximately 25%) are first diagnosed as HIV infected when they have AIDS (Figure 3).

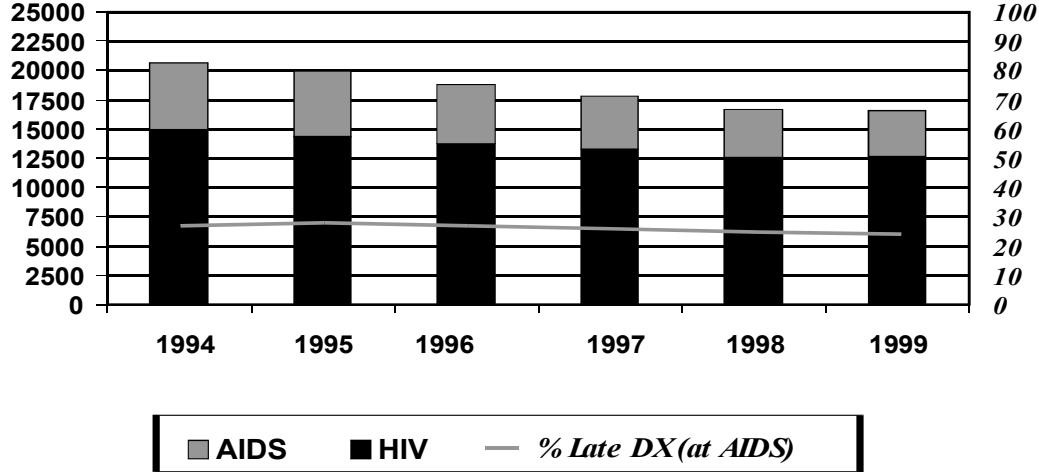
The AIDS patient survey carried out in seven states between 1995 and 1996 compared the time from HIV diagnosis to diagnosis with AIDS for anonymous versus confidential testing. For anonymous testing, the mean time from HIV diagnosis to AIDS was 918 days. With confidential testing, the mean number of such days was 531. This comparison demonstrates that anonymous test seekers tend to be diagnosed earlier in the course of the disease than those who may first seek or be offered a confidential test when they are ill with symptoms of HIV/AIDS.

Figure 3, based on data from 25 HIV-reporting states shows a figure of approximately 25% of HIV infection diagnoses are being made at the time of AIDS diagnoses. HARS data, however, show that many are entering care late in the disease, as shown by the short time (less than 1 month) from HIV infection diagnosis to diagnosis with AIDS.

Based upon data from 25 states that conduct HIV reporting (Table 6), late diagnosis appears to vary according to gender and risk group characteristics.

Figure 3. Trends in HIV diagnoses by stage of disease at earliest HIV diagnosis, 1994-1999*

Source: Centers for Disease Control and Prevention



*25 HIV reporting states; data adjusted for reporting delays

Table 6. Late diagnosis, 25 states (N = 108,260)

Sex/Risk	% of Total	% HIV→AIDS in 0–11 months	@ HIV→AIDS in less than 1 month
Men	75	44	29
Women	25	32	19
MSM	43	45	29
IDU	24	42	27
MSM-IDU	5	40	25
Heterosexual Contact	27	33	20

Source: HARS, 1994–1999

Are HIV-infected Persons Receiving Care and Treatment?

Answer: Not all persons aware of their HIV infection are receiving care and treatment. Stage of illness, symptoms, and other related factors may affect a person's use of health services.

Table 7 shows how CD4+ cell count tests used as proxy data to determine when people come into treatment for HIV, demonstrate that a certain proportion of persons may not be receiving care services. Persons in early stages of HIV disease appear less likely to use care services.

Table 7. Time from Diagnosis to Earliest Reported CD4+ Test, by Stage of Disease in 24 HIV-reporting states

Source: P Fleming, Centers for Disease Control and Prevention, 2000

Stage	HIV	HIV→AIDS later	HIV diagnosis at AIDS	Total
N	9389	2672	3772	15833
% with no CD4+ count	59%	5%	8%	38%
CD4+ <3 mos	33%	72%	90%	53%
CD4+ 3–5 mos	4%	15%	1%	5%
CD4+ > 5 mos	3%	7%	1%	3%

Furthermore, a recent HIV study conducted in three States assessed reasons for not receiving care. Among 178 respondents who had evidence of recent (within 1-3 years) of HIV infection, 15 per cent were not receiving medical care services. Two main reasons were given for not receiving medical care include: 48 per cent of such respondents felt well and did not think important to seek medical care right away, and 44 per cent of such respondents did not want to think about being HIV-infected.

Concluding Group Discussion

One participant noted that these data from CDC indicate that 75% of people now know their diagnoses, leaving 25% who do not know their diagnosis. Does this represent a change? Most recent published estimates are that about a third of people are unaware of their diagnosis. Dr. Fleming responded that the one-third figure was based upon 1998 data; the 25% figure was recently reported at a national meeting on HIV treatment and services.

Integrating HIV Prevention Services into the Clinical Setting **Remarks of Laura Cheever, MD, HIV/AIDS Bureau, HRSA, Rockville, MD**

Based on previous published research, one-third of people who are infected with HIV do not know their status. Another third of the infected know their status but are not in care. The remaining third—those who are in care—consistently do not receive prevention messages. Clearly, we need a different approach to integrate testing, prevention, and care into a broad array of services and community-based organizations (CBOs) accessed by high-risk patients.

Even when patients are referred for care, delays can be considerable. Of 189 HIV-infected people seeking primary care, 39% had been diagnosed more than 1 year earlier, 32% were diagnosed 2 years earlier, and 17% were diagnosed 3 years earlier. Those delaying care are more likely to be marginalized by poverty, addiction, or lack of insurance (Samet, Arch Intern Med, 1998).

A New Approach for HIV Prevention

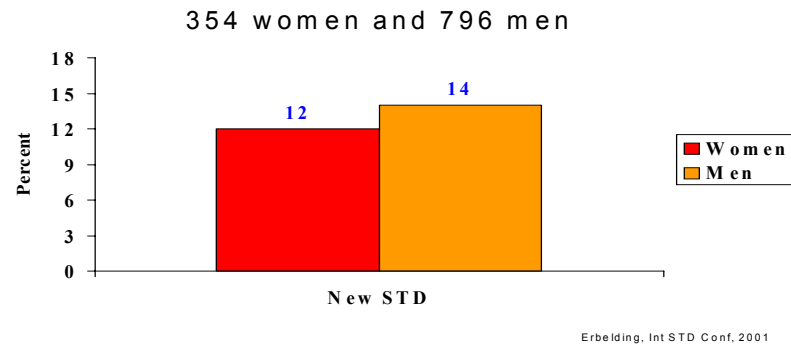
The traditional focus in HIV prevention has been to identify those at risk, for example, men having sex with men (MSM), injection drug users (IDUs), and those with sexually transmitted diseases (STDs), and then work on changing their risk behaviors to prevent them from acquiring HIV.

An alternative, complementary approach is to identify those with existing HIV infection (the reservoir of HIV in the community) and work to change their behaviors to prevent transmission to others and to reduce their HIV infectiousness with highly active antiretroviral therapy (HAART). In the clinical setting, we have a cohort of HIV-infected individuals in a trusting relationship built during the course of repeated visits. This is an opportunity to introduce long-term, potentially complex interventions to change behavior.

Risk behaviors and STDs, epidemiologic markers of unsafe sex, are increasing in the era of HAART. For example, studies have shown increases in unprotected anal intercourse among MSM in San Francisco, with largest increases in these behaviors occurring among men less than 25 years old. Rectal gonorrhea rates are also on the rise in this population (MMWR 48:45, 1999).

These trends are mirrored in other areas including Seattle where a resurgence of syphilis occurred in 1997–1998 (Williams et al. Am J Public Health, 89:1093, 1999). At one STD clinic in Baltimore, among patients who had been diagnosed with HIV, 12% of women and 14% of men were diagnosed with new STDs on follow-up over a 5-year period (Figure 4).

Figure 4. New STD after HIV diagnosis
Baltimore, 1993-1998



Other investigators have found that embarking on treatment for HIV *increases* risk behaviors. Scheer et al. showed that people on HAART are more likely to develop an STD, an epidemiologic marker of unsafe sex (Lancet, 2001 Feb 10; 357(9254): 432-5). Another study conducted in Amsterdam found an association between achieving undetectable viral load on HAART and three-fold higher risk of unprotected sex with casual partners (Dukers, AIDS, 2001). Clearly, one unintended consequence of HAART has been an increase in high-risk behavior. HIV prevention messages must be integrated into the clinical setting.

Other risk behaviors continue among HIV-infected individuals. For example, one survey of 12 state and city health departments conducted between 1990 and 1995 found that of 1,527 HIV-infected IDUs, 51% had injected over the past year, and 50% of those reported sharing syringes in the past year.

Delivering Prevention Messages

The reality is that HIV-infected people are having sex and using drugs. The traditional approach to prevention needs to be supplemented. We, as providers of health care, are not talking enough about sex and drugs. Too many opportunities to deliver prevention messages to HIV-infected people have been lost. HIV prevention messages must become an integral part of delivering medical and social services to those who are HIV-positive.

Risk assessment and prevention education are not a routine part of clinical care in the United States. Of 63 providers of HIV clinical care surveyed in Los Angeles, Baltimore, Atlanta, and Miami last year, only 56% discuss prevention at every or almost every visit (abstract in preparation, Natl Prev Conf). Data from Seattle are even more discouraging. Only 47% of providers ask about current drug use, 32% about sexual behaviors, and 18% inquired about STD history (Natter, unpublished data).

One survey offers another perspective of this problem: the client's. Forty-nine clients were interviewed in two clinics funded through the Ryan White CARE Act (Morin et al. personal communication). Sixty-one percent reported being sexually active, and 23%

reported being concerned about possibly transmitting HIV during the previous year. Although 57% had received counseling about HIV transmission in the past year, only 4% reported receiving counseling at their current visit.

Reducing Transmission

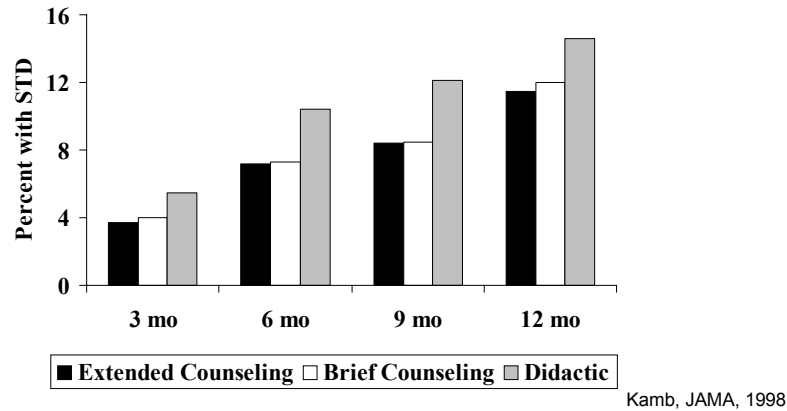
Given that people receiving HAART maintain high-risk behaviors, what can be done to reduce transmission by those in care? Clinicians can try to reduce the infectiousness of HIV-infected population by initiating HAART, which is known to reduce plasma viral loads. But, it appears that HAART may lead to increased risk behaviors, perhaps nullifying any benefit conferred by decreased viral loads. Another means of reducing transmission is to treat STDs, because inflammatory secretions associated with STDs can increase HIV shedding.

Several studies show that integration of prevention counseling into primary HIV medical care works. Golden et al. (STD, 23: 370, 1996) showed that HIV-positive men at a Baltimore STD clinic, where they had already been tested and counseled about their HIV status, experienced lower rates of gonorrhea and syphilis after entering an early HIV care program that was integrated into the STD treatment clinic. Similarly, a study of HIV seroconverters in Los Angeles revealed high rates of unsafe sexual behaviors at the time of diagnosis. Yet, a year later, follow-up interviews showed the rates of unsafe behaviors in this group had dropped significantly, perhaps the result of receiving posttest counseling and/or entering HIV care (Sey, CROI, abstract 216, 2001).

Kamb (JAMA, 1998) compared the effectiveness of extended client-centered counseling, brief client-centered counseling, and didactic sessions with patients. Both brief and extended client-centered counseling decreased the incidence of STDs in these groups (Figure 5, below), and the effect persisted for up to 12 months after the intervention. Although these two interventions seemed to help people modify their risk behaviors, STDs were not completely eliminated by any means, indicating that something more is going to be needed.

Another approach for reducing transmission is risk screening. Patients are often not honest with their primary medical care providers about socially undesirable behaviors. Therefore, medical providers may not always be the best persons to conduct risk screening. Computer-assisted self-interview (CASI) technology may be part of the answer to this problem. In research studies, CASI subjects—especially women and youth—have tended to answer “yes” more often to questions about socially undesirable behaviors than they did in face-to-face interviews (Kissinger, Am J Epidemiol, 1999). Furthermore, there was no effect on risk reporting based on whether or not patients were told that a clinician would be given CASI results (Gerbert, Med Care, 1999). Therefore, CASI could be used in medical settings with the results given to the provider for follow-up intervention(s).

Figure 5. Interventions to Prevent STDs
Baltimore, Denver, Long Beach, Newark, San Francisco, 1993-1996



Another important issue is getting clinicians to ask about sex and drug use. Even those who do ask may believe they lack the skills to counsel effectively. One study demonstrated that training using simulated patients had a positive effect on HIV-risk screening practice among 65% of participating providers (Epstein, *J Gen Intern Med*, 2001). Another study showed that physicians who were trained using simulated patients increased STD risk-reduction counseling from 42% (control) to 73% (Rabin, *Ann Intern Med*, 1994).

Barriers

It is clear that clinician training in screening and risk-reduction counseling will not be sufficient. During a typical HIV primary care visit (perhaps 30 minutes), the physician must

- establish rapport with the patient
- review new and resolving physical symptoms,
- review medication adherence and lab results
- review medication side effects
- conduct a physical examination (if indicated)
- discuss laboratory testing
- negotiate a care plan for the next few months
- review health maintenance measures
- fill out forms (disability, Medicaid, FMLA, ADAP)
- dictate notes.

No wonder, then, that risk-reduction counseling often comes down to: “You’re practicing safe sex, aren’t you?” Time is a significant constraint for clinicians in what they can do in the

way of prevention. Clinicians also need training in risk screening, behavioral change, and brief interventions that is efficient.

A further barrier is the complexity of issues around high-risk behavior and HIV prevention. Co-morbid conditions, including substance abuse, antisocial personality disorder, and dysthymia, are all associated with high-risk sexual behavior. A clinician working alone with a brief intervention will not be able to solve these problems. Integration of the prevention interventions throughout the clinical experience, including use of nursing, social work, and peer staff, appropriate referrals for ongoing interventions, and better systems for partner notification must be part of the solution.

Prevention Guidelines

HIV-positive men and women will use the primary care setting as a touchstone during HIV care, enabling the provider to deliver ongoing, integrated prevention messages. HRSA has been working with the CDC for some time on HIV prevention guidelines for primary care providers. The guidelines emphasize opportunities for integrating and reinforcing prevention in the care setting. Behavioral change interventions are an important part of the guidelines. These include:

- trying to understand underlying reasons for risk behavior (context)
- delivering targeted prevention messages
- being prepared for referrals, based on underlying barriers to prevention (e.g., violence, mental illness)
- reinforcing messages elsewhere in the clinic among various clinic staff (structural interventions).

HIV prevention in the clinical setting must include regular, documented risk screening, behavioral intervention with referrals, a mechanism for partner notification, STD screening and treatment, and counseling about risk behaviors concomitant with antiretroviral treatment. To accomplish these goals, clinical staff will need training in screening for risk behaviors as well as risk-reduction counseling.

Concluding Group Discussion

Subsequent discussion touched on several subjects. Participants expressed concern about the costs of implementing the new guidelines with no mechanism to pay for them. How do are providers to be compensated for clinical time?

Questions also arose about the proposed guidelines and whether they will incorporate such concepts as language and cultural competency. The response was that the guidelines would address these issues.

Another participant noted that other staff are part of the care system besides the primary care providers. Some successful models use other kinds of staff, including peer educators. The medical model is not the only one. We must be mindful of that.

Others expressed concern that partner notification is often perceived as the “long arm of the government.” Such mechanisms may be barriers to care. Dr. Cheever responded that partner notification is a complex issue, but in the pilot programs, people have been open to bringing partners into care.

A Consumer Perspective on Integrating Prevention and Care Services Remarks of Steve Wakefield, Director of Community Education, HIV Vaccine Trials Network

All this is a heavy amount of information for the expert, and it is too much information for the consumer. Somehow consumers intersect with the health care system, possibly through a confidential testing program, a public health center, or even in prison. But, before we get into policy decisions, we need to find out what motivates individuals to consider testing for HIV and then actually get tested? What brings them back to get their results?

Motivating Individuals to Use CTRS

Let me share my own experience. I was not motivated to get tested because “Jesse Jackson told me what to do” or because I saw his friends get sick and die or because “It’s the right thing to do.” It was my fear of not knowing my HIV status that drove me to a setting where I might get tested.

As a consumer representative on Chicago’s Board of Health, every 6 months I went to a different testing and counseling site run by the city. Anonymity was precarious at times. The voluntary testing and counseling system relies upon anonymity; it must not be compromised.

Waiting for test results is an anxious, fearful time. In Uganda there is an HIV test club where people can do role-play exercises while awaiting results. They can act on scenarios: “What if the test is positive?” “What if the test is negative?” They can talk about their fears, as well. Perhaps this could be a model for the United States to emulate.

During the session when the patient first hears that the HIV test result—be it positive or negative — he or she won’t likely hear anything for some time after that moment. When we deliver the test results we should not start talking about treatment or referrals right away, because we will not have the patient’s attention. And, it is the person who delivers the test results who should initiate the next steps for treatment, counseling, and so forth.

Developing Patient Trust and Action

Whether it is the private medical system or a health maintenance organization, or the government, many people do not trust health care messages if they don’t come from a trusted friend or family member. As we deliver messages about referrals to counseling, testing, prevention, treatments, and social services, remember that we may not have the attention or trust of the patient.

When we deliver the news that someone has tested positive, that is bad news. Even telling a person that lifelong chemotherapy is available is not going to be seen as good news. If someone tests negative, he or she is thinking, “I’ve dodged a bullet.” But, that is a time for teaching about safe sex and ways to keep test results negative in the future.

How can we discover which resources are the right ones? How do we develop the listening skills we need for working with an HIV-positive person? How can we follow up with the newly diagnosed?

The background materials contain valuable data. But, we need more data from long-term trials. We do not know that zero viral load actually reduces transmission. We have evidence that points in that direction, but we have not done the large trials we need. We do not know what reduces risk behaviors. Demonstration projects are nice, but having limited data over a short term is not good enough to get people to change their behaviors over the long term. We will need resources, staff, and information on human issues.

Concluding Group Discussion

One participant emphasized the point made by Mr. Wakefield that we are working on an assumption about what we think might work in terms of prevention but we have no data on long-term efficacy on any of the interventions we are talking about. Data collected over 6 or 12 months is interesting but meaningless in the context of an epidemic that has lasted 20 years. We are asking people—HIV-positive and HIV-negative — to make lifelong changes in the way they live. We need long-term studies that will show us what works and what does not so that we do not have to have another meeting like this in 20 years.

Challenges to Effective Linkage and Program Models

Based on Planning Committee discussions, several key barriers to the development and implementation of effective linkages between HIV counseling and testing and care were identified. These were used as “Issue” areas for panel presentations. They include: (1) organizational and systems; (2) social needs and co-occurring health problems; (3) cultural and regional issues; and (4) evaluation and research. Panelists were selected based upon their understanding challenges (such as barriers) and their affiliated organization’s ability to effectively address the needs of their communities. **Appendix G** contains background information shared by presenters for Panels #1, 2, and 3 on the organizations they represented.

Panel Session #1: Organizational & Systems Issues

The intent of this session was to show some of the organizational challenges faced when trying to form services links, and how they can be resolved at the level of the service provider, local government, state government, and the federal government. The presenters highlighted some ongoing innovative programs and recommended some solutions to overcome the barriers identified in the breakout session. Speakers were grouped under four subtopics: Linking Prevention Providers with Care Providers, Establishing Prevention Services in Public and Private Care Settings, Linking Centers of Excellence with Prevention Providers, and Planning and Establishing Integrated Prevention and Care Services.

The panel session began by the moderator noting that the epidemic is very different now, in terms of who is affected and what the needs are, than when it first emerged. Now there are many different kinds of people being infected, and many more treatment options. This poses the challenge of how we change infrastructure and approaches, some of which were developed many years ago.

The moderator further noted that the community is often way ahead of us, that leaders must try to respond and model programs after what the community has already begun. But, those who are disenfranchised (substance abusers, mentally ill) remain disenfranchised. The moderator finally noted that we are faced with a situation where the pendulum may be swinging backwards after a few years of pushing the epidemic back. HIV/AIDS is first and foremost, a social disease. We need to keep the community base in place.

Subtopic: Linking Prevention Providers with Care Providers

Remarks by Brenda Starks-Ross, Deputy Executive Director, AIDS Service Center of Lower Manhattan

Ms. Starks-Ross spoke about links between community-based organizations (CBOs) and providers from the perspective of the AIDS Service Center of Lower Manhattan.

The Center offers dynamic programs that are responsive to ethnically and culturally diverse communities. But, even with all that is available at the Center, there still exists a need for referrals, integration, and collaboration. No single entity can be everything to everyone, and clients need to be able to draw upon all the resources available to them.

Outreach activities rely on an extensive network of links involving the New York City housing authority, Parent-Teacher Associations, workshops, single room occupancy hotels, a methadone maintenance clinic, and designated AIDS centers, to name a few. A link exists with the New York Department of Health to distribute condoms.

The Challenge of Collaborations

Challenges are often encountered in the context of collaborative linkages. Sometimes organizations sign linkage agreements but the integration is not totally functional, causing problems. Some organizations and people become territorial over their clients. Competition for funds can also threaten collaboration and referral linkages. It is important to verify that no conflicts of interest exist among collaborating organizations.

Collaboration is hard, but it is a good tool to get people into CTRS and treatment. Successful collaborations can be built starting at the top and ending at the bottom. Collaborations must involve top-line people and the front-line people, too. Remember that no single entity can be everything to everyone. Clients need to be able to draw upon *all* the resources available to them. Making appropriate referrals is the key to giving clients access to the services they need.

The AIDS Center has collaborated with the NY Public Housing Authority to sponsor house parties. The hostess receives a stipend to invite friends in and teach condom use. The Center is also collaborating with three drug treatment communities, but Center staff had to be very mindful of the rules in those settings. The Center also engages in outposting staff to other organizations, an arrangement that requires an immense amount of trust.

Recommendations

Some challenges require further investigation and response.

- Funders must extend prevention grants from the present 3 years to 5 years. That way, client trust can be established, allowing for delivery of prevention messages and reinforcement of behavioral changes that can reduce HIV transmission in the community.
- Funders must earmark additional funds for evaluation, and stress the importance of evaluation to encourage buy-in by staff.
- Providers must institute more peer programs, which seem to be very effective. At the Center, peers go through 7-week training and then do an internship within the agency for which they receive stipends.
- More networking meetings are needed among providers to teach about collaborations.
- Critics seeking better collaborations need to stop beating up on doctors. They continually have to do more with less money and with less time.
- The prevention message needs to be on primetime television. Such messages should be as prominent as advertising is.
- Additional funding is needed by providers and by clients for mental health treatment. By helping people with such problems, we can reduce barriers to care and encourage behavioral changes that can help reduce transmission of HIV.

- Funders need to stabilize HIV prevention funding. HIV/AIDS is not going away and we need to be committed for a long haul. Providers should use focus groups to evaluate effectiveness of programs. Consumers are often ones who have answers.

Subtopic: Establishing Prevention Services in Public and Private Care Settings

Remarks of Holly Buckendahl, Director of Community Services, Kansas City Free Health Clinic

At the Kansas City Free Health Clinic there are challenges related to integrating HIV services themselves, not to mention integrating with other services, even with the in-house general medicine side. The benefits of a whole clinic approach are as follows.

- Clients receive HIV prevention information from many diverse angles.
- Seamless service delivery is offered to clients.
- Risk reduction is normalized. All staff have become well versed in talking about risk reduction. Risk reduction tools are readily available. Clients can ask any staff member openly about condoms, lubricants, posters, and so forth.
- Because the clients are already comfortable in the setting of the Kansas City Free Health Clinic, a “one-stop shopping” approach can facilitate the client’s access to other services, legal aid, for example.
- Patient follow-up is promoted. A client who comes in from the street is linked immediately to services on site. In addition, the clinic can do baseline laboratory studies on the initial visit.

These successes of the Clinic in achieving integration have not always come easily. Some adjustments have been made along the way. For example, when new leadership comes on board bringing a new philosophy, the staff must adjust to that philosophy shift. Some of the change is due to growth, but some is due to a shift in the way that the clinic integrates services. The clinic strives to market services in an integrated manner. A single brochure was developed with a uniform look. Staff training and development is a continual challenge, and some revamping of front office staff/receptionist procedures necessary to make sure services look integrated on the front end. Keeping the corps of 400 volunteers up-to-date with training and continuing education is managed using email systems and internal methods. Another challenge is office space coordination for service integration. Beyond these adjustments lie some other challenges for the clinic:

- maintaining boundaries, roles, and responsibilities among professionals
- keeping everyone informed about procedural and referral changes
- finding time for interdepartmental meetings to support integration—a necessity to keep abreast of challenges faced by all
- juggling priorities among program staff who (understandably) tend to emphasize their own program’s priorities rather than those of other programs
- establishing better integration with the general medicine side of the clinic.

To reduce integration barriers, the Kansas City Free Health Clinic is undertaking certain targeted activities. An internal program team is being developed, and HIV service staff meet quarterly. Staff have access to a client scheduling software system, and a master calendar is maintained.

In addition, staff cross training helps reduce integration barriers. The training provided is still not enough, but it is a good start. All staff receive training on HIV case management, primary care, outreach, and prevention case management. Counseling and testing staff and volunteers receive specialized training in eliciting partner information, eliminating the need for the health department to come in and do such. (The clinic staff, however, do not do partner notification.) They also receive training on client-centered prevention counseling, needle exchange, oral specimen collection, and clinic-based HIV testing procedures.

The clinic has also offers special initiatives to get more people in for CTRS and to pick up test results. Among the incentives are, free movie tickets. Case managers give these incentives to their clients so that they will bring someone in for CTRS. They also give the incentives to the primary medical care staff. To encourage the medical staff to ask about clients about HIV testing, they were given badges that say, "Have you asked me about HIV testing today?" This approach encourages the people who come into the medical side to ask about and seek testing from the HIV side.

Ms. Buckendahl closed with some recommendations to be implemented at the state and federal levels to help providers deal with the challenges they face.

- Integrate care and prevention funding.
- Increase provider training.
- Build additional capacity.
- Create an example of integrated leadership at the federal level

**“Linking HIV-Positive Clients to Prevention and Care Services: A Role for HIV Reporting”
Remarks of Mark Loveless, MD, Medical Director, HIV Program, Oregon Health Services**

Dr. Loveless spoke of how the epidemic looks from the state’s viewpoint in the context of the HIV program for which he serves as the medical director and epidemiologist. The goal of the program, which exists within Oregon Health Services, is to maintain a system of comprehensive, unfragmented HIV care and prevention. As part of the continuum of care, the program weaves together pre-diagnosis services for at-risk individuals, other services for those who have a positive diagnosis but are asymptomatic, treatment for complications and advanced illness, and care for those in end-stage illness. Program managers must constantly survey HIV/AIDS networks and identify gaps so they can be closed.

The Oregon model of HIV health care consists of two sides, one consists primarily of private providers and the other mainly of public providers (Figure 9, below). The health care/medical services side resides primarily (85%) in the private sector. It includes primary care physicians, HIV specialists, alcohol and substance abuse treatment providers, mental health care and dental providers, hospitals, urgent care centers, insurance companies, pharmaceutical companies, and pharmacy services. In addition, some care is integrated with managed care organizations that are to some extent private, including Medicare/Medicaid providers. One challenge that exists in Oregon is integrating the public sector with the private sector and establishing effective conduits for communication between these two sectors.

On the public side of the Oregon model are state AIDS programs and the state AIDS director. The state administers AIDS drug assistance programs and Ryan White Title II programs, supports prevention planning, and coordinates with Medicare and Medicaid programs. The state also maintains and supports through technical assistance the critical role of HIV case managers who connect directly with primary care providers and their clients. State ADAP and insurance programs are combined under a program called CareAssist, which leverages the state's purchasing power and Ryan White Title II funds to buy medical insurance for clients. The state also engages in surveillance and reporting activities, conducts prevention planning, coordinates resources and referrals, institutes best practices guidelines and provider education, and develops policy. Oregon is expanding the state's role in quality management, technical assistance, and evaluation. Direct services are provided at the state level only as a last resort and at the specific request of local health departments.

In the Oregon system, the county health departments are the main public service providers. The state coordinates with the county health departments, which, in turn, coordinate with CBOs. In fact, county health departments hire case managers locally who provide support services to clients and their families. The health departments implement and deliver prevention programs, offer education for the general public, and promote risk reduction/harm reduction for people at high risk for HIV. Clinical services are also offered at the county level, primarily through STD clinics. Disease intervention specialists (DIS) are available and are hired at the county and state levels. The only publicly funded HIV clinic in Oregon is sited in Multnomah County and is funded through Ryan White Title III.

A recent development is a four-county pilot program dedicated to prevention for positives to reduce transmission events from those who are HIV-positive through a prevention case-management approach. The program is in its second year and will soon be evaluated. It is hoped that the program will be extended to other counties.

The Oregon Health Plan

The "big gorilla", however, in Oregon is the "Oregon Health Plan". The Plan provides more than \$18 million dollars for HIV health care through its Medicaid waiver, granted in 1994. The Plan's goal is to provide limited care to a large number of people rather than comprehensive care to a few individuals. The Plan is funded through a combination of state general funds and federal Medicaid funds. More than 40% of HIV care statewide emanates

from the Oregon Health Plan, and is based on a unique, explicit list of prioritized diagnosis/treatment pairs.

The Plan is instituted primarily through managed care organizations. The largest of these organizations is CareOregon. Because it is sited in the Portland metropolitan area, CareOregon provides more than half of Medicaid-level HIV health care in the state. It pays physicians on a modified fee-for-service basis rather than operating under a capitated system.

Using Reporting to Overcome Challenges

A recent out-of-care analysis revealed that Oregon's single biggest barrier to care is getting people connected and into health care. The problem stems from a lack of knowledge about what services are available at the level of the local county health department (LCHD).

To address this barrier, Oregon put into place an HIV reporting system on October 1, 2001 (Figure 6). The effort has been undertaken by the data and analysis section of Oregon Health Services, which is responsible for care reporting and analysis. This is not a passive reporting system; the state will take a proactive role by contacting local providers and LCHDs after receiving a positive report. In developing its reporting system, Oregon built in evaluation mechanisms to track how well the system is working.

In this new system, the private provider orders the HIV test, and the laboratory reports positive results to the state. The state then contacts the provider about resources available in the community for the newly diagnosed individual. The state, by acting as the "conscience" of the HIV care system, ensures that the provider has the necessary information about resources that the client can obtain, that the information is delivered to the client, and that treatment guidelines are followed. The LCHD will work with private providers to make sure that the client is linked to a clinician.

The State's perspective encompasses "the big picture." A reporting system can be an asset by ensuring that newly diagnosed individuals know about the resources available to them and showing them how to access those resources. Oregon has taken a proactive approach in working with county health departments and clinicians to ensure that knowledge of the system is present.

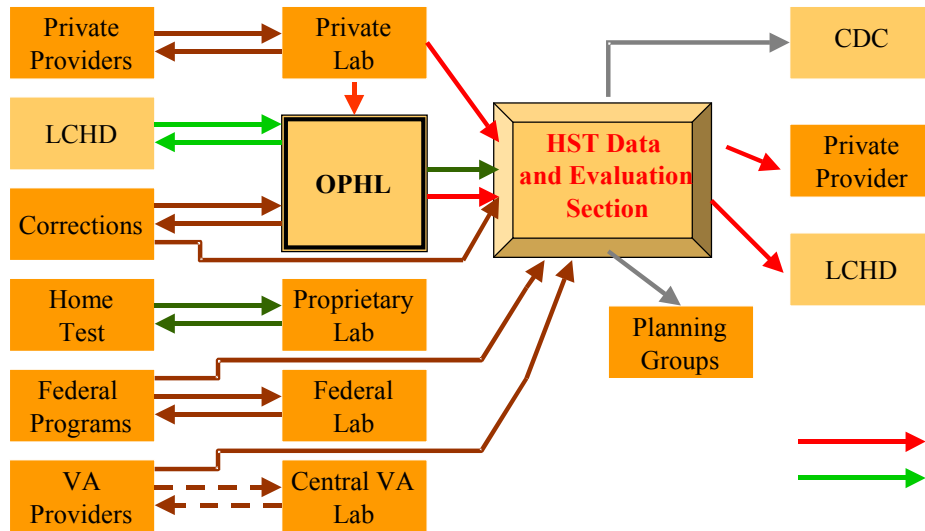
Recommendations

Prevention services and access to CTRS are made available for individuals before diagnosis. Post-diagnosis services for HIV-positive individuals include medical and dental care, substance abuse treatment, mental health services, case management, and prevention programs. To provide a high-quality, multidisciplinary continuum of care, programs should:

- be client-centered and tied to identified needs;
- involve care coordination/case management, including private provider groups;
- be culturally conscious and capable;
- involve a minimum of bureaucratic requirements;
- maximize communication among agencies;

- engage in outreach to specific populations;
- enhance skills of providers through specialty education, consultation, and technical assistance.

Figure 6. HIV reporting in Oregon: October 1, 2001.



Subtopic: Linking Centers of Excellence with Prevention Providers**Remarks of Robert A Larsen, MD, Associate Professor of Medicine, University of Southern California Medical Center**

The Paul Schrader AIDS clinic offers comprehensive HIV/AIDS care for the approximately 2 million people living in the northeast cluster of Los Angeles. While a number of Clinic services are integrated, significant challenges are still faced. Medical services provided at the clinic span internal medicine (e.g., infectious diseases, hepatology), psychiatry (30% receive psychiatric services), general surgery, obstetrics/gynecology, pediatrics (including three pediatric AIDS specialists), dermatology, neurology, and ophthalmology. Also offered on site are: social services (e.g., legal aid, housing, social workers), on-site medical records (independent of the hospital medical records system), financial services (to help clients with insurance forms), and an on-site pharmacy.

The clinic has an NIH-sponsored AIDS clinical trials unit for adults and children and is participating in the Women's Interagency HIV Study. Three ongoing studies sponsored by the Centers for Disease Control and Prevention (CDC) are ongoing, including a 10-year program project grant from the CDC for tuberculosis research. Funding is also provided by the state of California through the California Collaborative Treatment Group.

Prevention services are somewhat limited because the clinic's focus is on HIV/AIDS care rather than prevention. Confidential CTRS is available through the public health clinic, and a community liaison for counseling and testing provides confidential and anonymous oral specimen testing. A Ryan White funded prevention program is designed to contact newly diagnosed individuals and get them into care. Clinic programs include client follow-up for missed appointments and outreach for counseling and testing of partners of HIV-positive individuals.

There are opportunities for expanding prevention services at the Rand Schrader clinic, but certain barriers exist. One is its visibility. The public health clinic is literally "underground", as it was designed for tuberculosis care. Another is financing. From time to time, the AIDS Clinic staff use that clinic's codes to bill for HIV prevention services, to avoid patients being billed for directly for prevention services, which are often not reimbursable. Personnel for CTRS, an extremely labor-intensive process, are not provided by the public health department or the CBO. This means that whatever CTRS the clinic provides must be paid for from other sources. The Ryan White supported program is still not operational. For most AIDS providers, the Rand Schrader AIDS Clinic among them, the priority is to provide care, not prevention. No program exists for longitudinal prevention services in HIV-positive or HIV-negative populations.

The Role of Prevention Services in HIV/AIDS Care Centers

To refresh, the 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 in care.
- Prevention messages are most influential when provided by the primary care provider.

A research initiative at the Clinic may serve as a model for how HIV comprehensive health centers could be carrying out prevention programs. It was designed to deliver brief safe-sex counseling in AIDS clinics. The goal was to integrate 3–5 minutes of safe-sex messages into every AIDS clinic visit with the primary provider. The study involved randomly assigning clinic clients to receive either consequence-framed or advantage-framed safer-sex messages. The control group received only treatment adherence counseling and no safer-sex message. An example of a consequence-framed message would be “If you do not use a condom during anal intercourse, your partner may become HIV-positive.” Conversely, an advantage-framed message would be “If you use a condom during anal intercourse, you will feel better about yourself because you are keeping your partner safe.”

Regardless of the type of message given, during the clinic visit several specific behaviors were targeted by the 3–5 minute prevention discussion:

- disclosure of HIV status to sexual partners
- abstinence as acceptable form of sexual expression
- condom use
- limiting number of sexual partners
- alternatives to high risk sexual acts
- avoiding alcohol and drug use prior to sex.

The research was carried out at six clinics in California where nearly 10,000 HIV-positive people receive care. Baseline information was collected on 885 sexually active people. Follow-up information was obtained from nearly 600 of these same 885 people, but the results of intervention are not yet available.

The baseline data, however, revealed some significant findings. Seventy percent of HIV-positive individuals were sexually active. Thirty-eight percent of HIV-positive men having sex with men (MSM) reported unprotected anal and/or vaginal (UAV) sex, 24% of HIV-positive men having sex with women report UAV sex, and 29% of HIV-positive women reported UAV sex with men. Table 8 shows rates of UAV sex among sero-positive men and women who had one sexual partner, whether a main partner or a casual partner, during the 3-month period prior to the interview. Table 9 shows rates of UAV sex among sero-positive MSM who had more than two partners in the prior 3-month period. Baseline data can be summarized this way:

- UAV intercourse is reported by 34% of HIV-positive individuals overall and 20% even when the contact is a main partner who is HIV-negative.
- Rates of UAV sex are higher when the partner is of unknown or positive sero-status.
- Rates of UAV sex increase when there are both sero-positive partners and partners who are sero-negative or of unknown sero-status.

Linking Prevention Services to HIV/AIDS Care

In conclusion, prevention messages must target the HIV-positive individual and his or her partners. Episodic counseling and testing are not enough to alter sexual behavior; prevention services must be a routine part of comprehensive HIV/AIDS care. Providers of prevention services must be prevention specialists. Finally, funding for longitudinal prevention activities is essential to reduce transmission rates in a significant way over the long term.

Table 8. Percentage having unprotected anal/vaginal intercourse in the last 3 months when subject has one partner ($N = 541$). Source: RA Larsen, University of Southern California, 2001.

Sero-status of Partner	MSM (n=326)	MSW (n=122)	WSM (n=93)
Main sero+	40% (n=98)	37% (n=27)	46% (n=24)
Main sero-	20% (n=92)	20% (n=46)	16% (n=44)
Main Unkn.	32% (n=32)	33% (n=9)	40% (n=15)
Casual +	27% (n=22)	14% (n=7)	100% (n=1)
Casual -	14% (n=21)	8% (n=13)	25% (n=4)
Casual ?	14% (n=59)	25% (n=20)	20% (n=5)

Table 9. Percentage of HIV-positive individuals reporting UAV sex in last 3 months when MSM has ≥ 2 partners (N = 284). Source: Larsen RA, University of Southern California, 2001.

Casual known sero-	17% (n=6)
Casual Unknown	42% (n=69)
Casual known sero+	56% (n=32)
Casual sero+ &/or Unkn. ?	53% (n=55)
Both main & casual sero-	50% (n=6)
Both main & casual Unkn.	21% (n=14)
Both main & casual sero+	64% (n=14)
Both main & casual with sero+ &/or Unknown	67% (n=72)

Subtopic: Planning and Establishing Integrated Prevention and Care Services

Remarks of Jean Flatley McGuire, PhD, HIV/AIDS Bureau Director, Massachusetts Department of Public Health

Dr. McGuire also spoke about the experiences and challenges of links at the state level. Taking a different look than Dr. Loveless did in his presentation on the Oregon HIV care model, Dr. McGuire focused on data-related issues, program initiatives, and policy interventions.

Dr. McGuire began by noting a need to improve our understanding of critical linkage and integration issues through insights that can be gleaned from relevant data analyses (quantitative and qualitative). We must develop data analysis protocols and models for application in settings with varied resources and surveillance capacities.

Previously presented data show that an estimated 25% of people have come into care late. To find out what is behind that number, the states need help from CDC and HRSA to determine what other questions can be answered using the state's surveillance database and the service utilization database.

To improve preventive care delivery, we need to develop preventive care protocols for use in clinical and non-clinical settings. She acknowledged CDC's efforts to replicate programs that work in other settings. Other actions include developing staffing profiles and skill-set descriptions for effective risk assessment and risk reduction interventions, maintaining important front-line people, increasing the skills of clinically skilled professionals, and building capacity by bring more good people on board. We also need to

determine incentives for client participation and establish reimbursement models for behavioral health services that are not dependent on a mental illness diagnosis.

Defining the Problems

This workshop is devoted to integration and linkages, but how did we decide that these are the answers? Yet, we must be clear about what questions we are asking. Who does not have access to care? Who does not know their status? Who comes into care late? Who is episodically in care? Who is in care and has differential outcomes? Who continues to pose a risk of transmitting HIV?

HRSA and CDC are working on these questions through analyses of unmet needs, late-into-care figures, and statistics on missed opportunities. Yet, we still lack understanding of patient and provider needs for prevention services. We do not know what motivates patients and providers in regard to participation in prevention activities. We falter when it comes to providing training, support, and reimbursement for prevention services. To get answers to these questions, the state of Massachusetts is asking those who know: community members, providers, and consumers.

Who Lacks Access to Care?

In 2000, Massachusetts collected data on CTRS use. Although African Americans constitute 32% of sero-positives, they account for only 13% of service use in Massachusetts. Hispanics constitute 28% of sero-positives, but account for 38% of service use. Whites account for 49% of service use but only 13% of sero-positives. Although service use is still heavily weighted toward whites, these data actually represent an improvement over previous years. Dr. McGuire inferred, however, that significant barriers to access must still exist for African Americans, and that major action must be taken if this imbalance is to be improved.

What will Massachusetts do with these data? First, the plan is to tighten service population requirements for CTRS funding, and step up outreach programs and media campaigns targeted toward African Americans.

People Are Coming into Care Late

Various state studies are showing that, generally speaking, people are coming into care late. One state study of HIV/AIDS co-diagnosis based on surveillance and chart reviews supports the estimate given by Dr. Fleming of 25% of HIV diagnoses being made late. Furthermore, the study revealed that five Massachusetts hospitals account for 70% of late (AIDS) diagnoses. The state's Hospital Inpatient Routine Testing Study (1999–2000) conducted in the largest hospital in Boston revealed a 7% seropositivity rate among all admissions with no population targeting or selection of patients. Finally, the Hospital Urgent Care Acute Seroconversion Study was carried out at the same (largest) hospital in an attempt to identify presenting symptomatology. This study differed in that it involved enrollment in a study by the participants. The study uncovered 2% new positives (1% acute). Had the burden of study enrollment been removed, the numbers would probably have been higher.

Because of these studies, Massachusetts is launching routine urgent-care CTRS programs at four hospitals. The state also plans to develop local profiles of individuals who come late into care, thereby helping the state's efforts in prevention service planning and improvement of clinical service access in the areas served by those hospitals.

Who Has Differential Outcomes?

The Massachusetts Department of Public Health has looked at gender as a possible basis for differential outcomes. The data sources included HIV/AIDS surveillance data, clinical chart reviews, and family planning survey data (not specific to HIV-positive women).

HIV/AIDS surveillance data revealed that in Massachusetts, the number of reported AIDS cases for men has come down significantly but the rates for women have remained quite steady since 1993, albeit at a lower level. Women are not dying faster, but they are experiencing greater morbidity. In some cities, women represent more than 50% of cases now. Two-thirds are women of color. Injection drug use is the most frequently reported risk factor among women in Massachusetts, exceeding the national average significantly. Eighty-six percent of female cases are of reproductive age. Thirty-two percent are born outside of the United States. This group was twice as likely to be late into care and twice as likely to learn their HIV status while pregnant.

Chart review data gleaned from regionally funded Centers of Excellence showed that 45% of HIV-positive women were injection drug users and that 6% of them had been incarcerated during the previous year. Chart reviews also yielded comparative demographic data for women. Compared to HIV-positive men, the HIV-positive women tend to be younger and more nonwhite, and have higher CD4+ counts at entry. Women are more likely than men to have interrupted therapy, have been hospitalized in last year, and have active mental illness. Women are equally likely to have been incarcerated, use injected drugs, and be born outside the United States. Women also experience a process of care similar to that of men.

Massachusetts then turned to some data outside the HIV arena that might be useful for prevention discussions with women. The Family Planning Survey revealed that 27% of women reported anal intercourse (ever), 28% coerced sex (ever), 27% reported multiple partners (last 12 months); and 58% believed male partner to have HIV risks. Fifty-seven percent reported inconsistent condom use.

These data make clear that to address women's prevention concerns, we must be concerned about why women are more likely to have interrupted therapy and experience ancillary problems, such as mental illness.

What States Can Do

Massachusetts is embarking on four major initiatives for people who are not in care, not diagnosed, out of care, and episodically not in care. These include:

- policy and protocol development, including updated clinical advisories for perinatal HIV transmission and non-occupational PEP;
- program requirement changes, including clinical site preventive protocols, site-based service integration plans, client-centered programming, and active referral documentation;
- provider incentives, including retention of cost reimbursement contracts, and a state-supported quality assurance/continuous quality improvement process;
- reimbursement planning, to include the Medicaid agenda and collaboration with health maintenance organizations.

States need to first develop data profiles to answer critical questions by selecting around the range of available data elements that are informative despite some shortcomings. Secondly, states need to obtain help from CDC and HRSA to help us map the process, not necessarily in the context of unmet needs data or cross-titles data or surveillance data. Capacity issues are serious in terms of data collection and analysis, but the components are already in place for good decision-making. Third, states can leverage collaboration in public and private medical sectors. Fourth, states can develop innovative payment and programmatic initiatives. Finally, states must promote consumer understanding and involvement if we are to make any headway.

In closing, we must not assume that integration and linkages are the complete answers. There is much that we do not know about personal motivation and sustainability. Ensure that the necessary data, training, support, and reimbursement are in place. Finally, the effect of stigma on getting people into care and keeping them in care cannot be ignored, and must be addressed aside from whatever can be via linkages and integration.

Remarks of Patricia Bass, R.N., M.A, Co-Director, City of Philadelphia Health Department

Philadelphia has stopped, looked, and is changing. The city's Department of Health is responding to the changing face of the epidemic, and dealing with uncertain economic times, by instituting rapid assessment response evaluation (RARE).

Currently, the HIV epidemic in Philadelphia resembles that in other large cities. About 28% of the population is uninsured, mostly because of periods of ineligibility for benefits. Consequently, people must be re-certified from time to time and brought back into care. In the flux associated with these changes, new challenges have arisen:

- new public health issues associated with HIV;
- political and social implications of providing services to people living with HIV;
- an increasing of stakeholders with varying interests;

- new understandings of the HIV disease process;
- co-morbidities;
- an increasing diversity of CBOs, with varying infrastructure strengths;
- cultural differences; and
- an increased emphasis on monitoring and planning for improvement.

In these challenges, the focus for the Philadelphia Department of Health has remained on increasing access and retention into care, enhancing self-management of the medical and social service systems, adherence and treatment advocacy, and ensuring cost effectiveness. The continuum of care offered through the Department of Health truly does embrace primary, secondary, and tertiary prevention (Table 10).

Table 10. System of care at the Philadelphia Department of Health

Source: P Bass, Philadelphia Department of Health, 2001.

Health Promotion	Targeted Health Promotion	Early Diagnosis and Prompt Treatment	Access to Care	Health Maintenance
<ul style="list-style-type: none"> • Health education/sex education • Attention to social and economic issues • Risk assessment and risk reduction counseling 	<ul style="list-style-type: none"> • Periodic testing if at risk • Targeted outreach • Prevent transmission • Harm Reduction • Avoidance of virus 	<ul style="list-style-type: none"> • Prevent progressive disease process • Prevent complications • Shorten period of disability 	<ul style="list-style-type: none"> • Promote treatment • Provide quality primary care • Provide supportive services • Encourage treatment adherence 	<ul style="list-style-type: none"> • Reduce opportunistic infections • Continuing access to full continuum of care • Increase quality of life • Access to treatment advances

----PRIMARY PREVENTION----

----SECONDARY PREVENTION----

--TERTIARY PREVENTION--

The Risk Dynamics Approach

In trying to address HIV prevention in Philadelphia, the City Health Department decided to look into risk dynamics: characteristics and unique features of HIV risk factors (i.e., target populations, locations and times of risk activities, major landmarks, and environmental conditions). The Health Department worked closely with the local planning council to identify target populations. The Department then looked at target areas-intersections, small

concentrated areas, census tracts, zip codes, or larger areas within the city-rather than looking at the city as a whole.

Data was collected through visits to target areas. Hours of observation provided complete coverage of activity. Discussions with people who have knowledge of the target areas (residents, sex workers, drug dealers, community leaders, clergy, law enforcement), and with service providers (especially small CBOs) have also yielded valuable information about risk dynamics in the target areas.

By applying this approach, the Department was able to identify risk pockets-small geographic areas where there are high concentrations of individuals engaged in high-risk behaviors. One such target area is Hunting Park in Philadelphia, an area of about 1 square mile with about 18,000 residents, most of who are African American or Latinos. The median household income is \$16,430, and 36% have incomes below the federal poverty level. There are many abandoned buildings in the area, which are strewn with drug paraphernalia. The unemployment rate is about 16%. Despite the bleak picture painted by these statistics, Hunting Park is a community where people live.

What has been done since the risk dynamics assessment? The first step was the initiation of a street-level HIV risk educational campaign, developed in conjunction with a marketing firm. Next, the area was saturated with primary, secondary, and tertiary prevention interventions (see Table 10, above). They worked to link people to existing services rather than bringing in new providers. They would link to whichever organization is achieving results in the target area. They incorporated qualitative methods into planning process to facilitate evaluation. Finally, the health department trained and certified case managers and care outreach workers, so they all would have an adequate knowledge base in HIV/AIDS.

Continuum of Care

Two things the Department has learned is that not everyone is ready for care, and people come into care in several different ways (Figure 7, below). Some people need to go to case management or to get help with their activities of daily living (ADL) before they can become engaged in primary care. One new program is a personal care initiative that puts people into homes where they can receive wrap-around services.

One interesting challenge has been how to address care outreach. Care outreach in Philadelphia can no longer be a stand-alone process. Organizations engaged in care outreach must have in place contractual agreements with ambulatory care and CTRS sites. The ambulatory care and CTRS providers may arrive at their own definitions of “lost to care” and use care outreach organizations to find those who fit the definition. Care outreach organizations are the best at finding people; they know aliases, and hangouts in the target areas. This system is working.

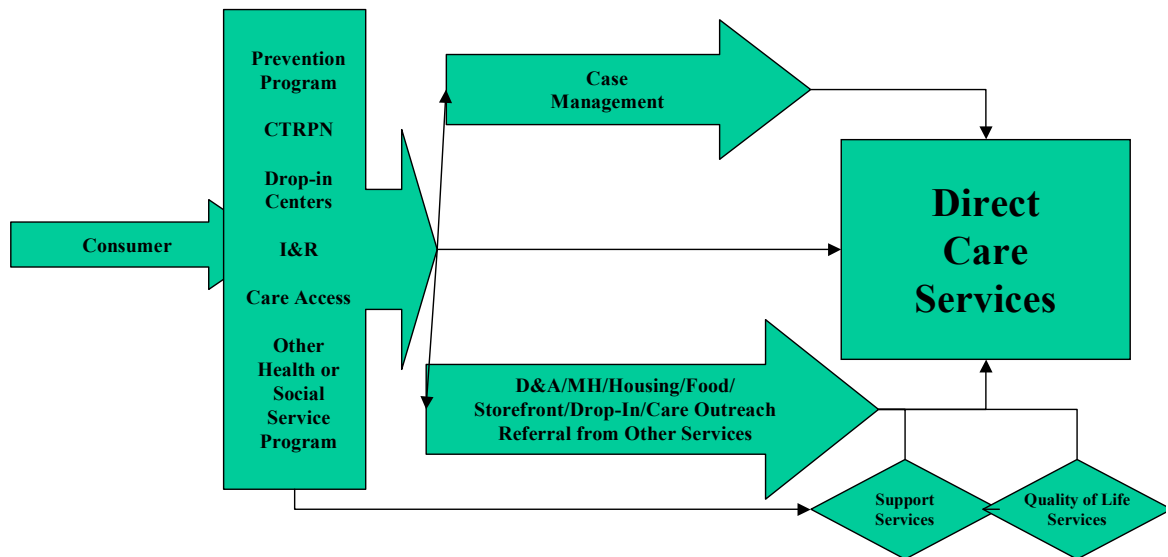
Another accomplishment has been the establishment of an interagency task force composed of appropriate representatives from agencies that have as their charge improving services to the target populations. Task force members generally represent

- the housing authority

- the school district
- Coordinating Office for Drug and Alcohol Programs (CODAAP)
- human services
- the health department (including STD and TB clinics)
- the criminal justice system.

Figure 7. Getting people into care: Different forms of access.

Source: P Bass, Philadelphia Department of Health, 2001.



The Task Force has established storefront initiatives throughout the Philadelphia metro area in high-risk areas that lacked the resources to bring people into care. These drop-in centers are not HIV centers; they are social service centers that provide basic needs and link to services through case management, primary health care, nursing triage, substance abuse counseling, housing, life skill classes, and so forth. The storefronts have hired folks from the communities they serve. (Some of the hires were identified through the RARE program, previously noted.) The storefronts reflect the ethnic and racial communities in which they are located.

What's Next?

Philadelphia, like many other communities, is struggling with identifying points of entry and removing weaknesses where they exist in systems of linkages and referrals. Two identified weak points have been hospital emergency rooms and substance abuse programs. In these situations, it may take 10, 20, or 30 contacts to make a link occur. We have learned that “one-stop shopping” is not just a goal for providers, it should also be a goal of the health department.

Summary – Panel #1 Presentations

The panelists addressed organizational challenges from multiple perspectives, particularly community-based provider, academic health center, and State and city health planner/administrator. Although these perspectives identified unique challenges and solutions, several common organizational issues and solutions were identified. They are as follows.

1. Funding – Integration, Stabilization, Reimbursement Levels, and Targeting
 - a. Agencies at the federal level need to integrate care and prevention funds and grant activities.
 - b. Agencies at the federal level need to stabilize HIV prevention funding and extend grant periods.
 - c. Federal and State entitlement and categorical programs need to sufficiently reimburse CTRS and HIV prevention personnel and services.
 - d. Agencies at all levels need to increase funding of substance abuse and mental health services.
 - e. Federal and State level need to tighten and target service population requirements for CTRS funding.
2. Policy and Program Development – Comprehensiveness, Network Development, Protocols, and Competencies.
 - a. Agencies at all levels need to develop service models for comprehensive, seamless CTRS, prevention, and care systems, by increasing existing provider capacity and establishing networks based on community health and social service needs.
 - b. Network development to include both private and public providers and public and private payers (e.g., Ryan White, Medicaid, substance abuse block grants, private insurance/managed care providers, etc)
 - c. Providers of care need to integrate prevention protocols in clinical and non-clinical settings, and establish provider training, technical assistance, and quality management procedures for such protocols.
 - d. Providers need to integrate at the local level personnel and programs that address ethnic and cultural differences in the community.
3. Research, Evaluation, and Community Profiling – Access and Differential Outcomes
 - a. Federal and local levels need to develop HIV prevention care standards and protocols for purposes of integration into primary care and quality/performance assessment.
 - b. Federal level agencies need to develop integrated service models for local use.

- c. State and local level agencies need to develop good reporting systems (e.g., HIV surveillance data and “Risk Dynamic Approach”) to identify risk pockets or subpopulations in small geographic areas.
 - d. Federal, State, and local level agencies need to develop evaluation methods and systems that create a profile of who is coming in late and the differential treatment outcomes of certain communities and subpopulations.
 - e. Local service providers need to apply evaluation and community profiles to target CTRS activities, public awareness campaigns, and locate networks providers
4. Commitment of Senior Administrators and Leaders – Collaboration and Administration
- a. Senior Administrators and Leaders need to show commitment and leadership in working across multiple agencies to integrate services.
 - b. Senior Administrators and Leaders need to reduce administrative burdens at Federal, State, and local levels.
 - c. Local administrators and leaders need to reach out to other agencies or service groups such as PTAs, human service providers, STD/Tb clinics, family planning clinics, emergency rooms and acute care settings, substance abuse service providers, and housing providers.
 - d. Agency staff and senior directors at the federal level need to develop stronger collaborative working relations with each other.
5. Outreach – Staff and Awareness
- a. Local providers need to develop outreach staff and relationships with family, support providers, and other service providers (e.g., schools, human services, jails and prisons) to identify and bring individuals into care.
 - b. Local providers need to use targeted public awareness campaigns.
 - c. Local providers need to use peer outreach workers in the clinical and non-clinical settings.

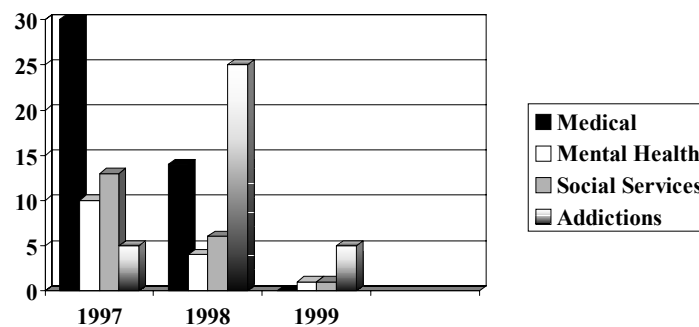
Panel Session #2: Social Issues and Co-occurring Health Issues

Competing social needs and co-occurring health problems may have a significant impact on an individual's ability and interest in getting HIV tested and engaging in medical care. Panelists presented on a number of issues, including homelessness, substance use, incarceration, that need to be assessed and directly addressed in order to assure client access to care services

Remarks by Louise Treherne, Clinical Operations Officer, Health Care for the Homeless, Baltimore, MD, on Homeless, Substance Abuse, and Mental Health Issues

With regard to the homeless: "Housing equals health care." The following data illustrate a sharp decrease in use of medical and social services after a client finds housing. (Figure 8).

Figure 8. Service utilization of a homeless client* with AIDS, schizophrenia, and alcoholism
(courtesy of L Treherne, Health Care for the Homeless, Inc. 2001)



***Client housed in supportive living
and transitioned in late Fall 1998**

To further understand how HIV services can be integrated for the homeless, it is important to understand what homelessness is. Homelessness is a continuum that encompasses anyone who lacks a fixed, regular, and adequate nighttime residence. It is often a state that individuals and families move in and out of over time.

Homelessness is a health hazard. It causes problems and exacerbates existing problems. It complicates treatment because homeless individuals lack the wherewithal to keep appointments, store medication, take medication, or even eat properly. It complicates continuity of care because it disrupts entitlements and state assignments to managed care organizations, and introduces loss of control over location, eating schedules, and a general chaotic state of living.

HIV is a particular problem among the homeless population. Studies indicate that HIV prevalence rates among the homeless are between 3% and 20% compared to 0.3% in the

general population. In the population served by HCH, approximately 14% are HIV positive. By conducting outreach, HCH has been able to target homeless individuals at risk for HIV infection. For example, 1,008 clients were seen on outreach over a 3-year period, and 491 presented on site for care. Of these, 346 agreed to HIV counseling and testing. One-third of those tested were HIV-positive, more than twice the rate seen in the general HCH population.

Co-morbidity coupled with HIV is common among the homeless. Seventy percent of HCH clients also struggle with substance abuse, 35% have mental health diagnoses, and 60% have HIV and another medical condition. HIV-positive, homeless individuals face significant barriers to prevention and care. Among these barriers are access to HIV testing, access to test results, lack of medical insurance, competing life priorities, social stigma, provider bias, unstable living situations, and inaccessible service systems.

Homelessness stymies treatment regimens, often resulting in non-adherence to treatment. People on the street have nowhere to store or even carry their medications, their medications may be stolen or sold, and they may not be able to take their medications on schedule because of chaotic living or the lack of a timepiece. Co-morbidities complicate daily living and compromise the ability of homeless people to adhere to treatment. For the homeless, appointment-driven systems do not work. The lack of an alarm clock or transportation can present insurmountable obstacles. Many lack insurance and financial resources, or even a basic support network.

Fewer homeless individuals receive HAART than people who have a place to call home. Only 4% to 18% of treatment-eligible homeless individuals actually receive HAART, largely because providers doubt their ability to adhere to treatment regimens and, so do not prescribe HAART. A national survey (HRSA, 1999) found that 17% of homeless persons were getting HAART compared to 51% of housed persons.

How can we improve adherence to treatment? First, providers must be accessible, trustworthy, responsive, culturally competent, flexible, and willing to establish relationships with homeless clients. Providers must consider the limitations imposed by homelessness when prescribing treatment, for example, by relying on regimens with less frequent dosing, fewer pills, and medications that do not require refrigeration.

The following are barriers to providing integrated prevention and treatment services for the homeless:

- clinical framework issues;
- competition among providers for clients in order to meet organizational goals and requirements;
- technical assistance needs;

- managed care and insurance issues;
- disconnected funders and funding;
- disconnected science or best practices and policy (for example, the prohibition against using federal dollars for needle exchange despite proven efficacy);
- reporting conflicts, burdens, and costs.

How can these barriers be minimized or overcome? HCH's experience is that outreach is a critical first step to getting people into care and linked with the services they need. Yet, "Drive-by" outreach is not enough. Providers must become part of the community in order to understand and meet clients' basic needs.

Walk-in services are a must for those who cannot keep appointments. Clients should be rewarded when they make incremental positive changes in their lives. At the level of funding agencies, integrated funding sources are needed to support integrated prevention, treatment, and advocacy efforts. Also needed are harm-reduction interventions.

In order to provide integrated services, HCH has constructed a network of collaborations for medical care, mental health services, substance abuse treatment, social services, and so forth. Programming is interdisciplinary, allowing for relationship "lending." Outreach services are provided by peer leaders. All services have daily walk-in service available. The addiction treatment program employs a philosophical continuum that combines a harm-reduction approach with the traditional, abstinence-based approach.

Each provider is expected to assess for health risk factors, including HIV-specific factors, at *every* encounter. In addition, each provider is required to complete training in HIV counseling and testing. Competencies for these interventions are assessed during yearly evaluations for every provider.

Finally, providers know the needs of homeless clients, and homeless clients themselves, need to speak to legislators and policy makers. Otherwise, our efforts to stem the tide of this epidemic will be for naught. To provide excellent treatment care and prevention programs, we must build collaborations among agencies. Providers must institute cross training, write joint proposals, share resources, and build capacity together to meet the needs of the community. We need to teach each other about our clients and their needs.

Remarks of Jean Keller, PA-C, and Rosemary Ramroop, Peer Outreach Worker, Women's HIV Health Program, the Johns Hopkins University Hospital, Baltimore, MD, on Women

In Maryland, some 7,000 women are living with HIV, accounting for about a third of HIV cases statewide. Eight-six percent are African American, 12% are white, and 2% are of other races and ethnic origins (mostly Hispanic). Twenty percent are uninsured, 60% are covered by Medicaid or Medicare, and 20% have coverage through an HMO or private insurance.

In terms of risk factors for women, injected drug use (IDU) accounts for 53% of cases, closely followed by heterosexual transmission (46%), and only 1% of cases are attributable to other causes. Rates of heterosexual transmission are increasing rapidly, and will likely exceed IDU as a risk factor in the near future. This fact must be considered when planning outreach activities, especially for younger women who are at greater risk of becoming infected by heterosexual transmission.

Challenges to Integration of Services

Academic centers in Maryland do a good job of identifying HIV-positive pregnant women, but it appears that challenges exist in the community and at HMOs. One of the challenges is to educate providers about the importance of counseling and testing all pregnant women. Immigrant populations encounter barriers when accessing health services. Getting immigrants from CTRS into care is a challenge because of the fear of deportation and concerns about the stigma of HIV identification within their communities. The Johns Hopkins program has a Hispanic outreach worker on staff to help overcome some of these barriers in the local Hispanic community.

Adolescents also encounter barriers to testing and accessing health services. They have concerns about confidentiality and being seen in the HIV clinic. They fear social isolation and may be in denial. A common reaction is: "If you don't know you don't have to worry about it."

Barriers to integration may also be encountered in hospital emergency rooms where patients may feel like victims of the stigma associated with HIV and active illicit drug use. While the staff is diverse, high turnover rates make it difficult to engage in education in an effective way. For many clients, the emergency room is the main place where they encounter health care professionals. An unfortunate encounter there may color the client's perception of health care in a negative way, setting up more barriers to care.

Substance abuse is another barrier. Someone who is actively using often does not keep appointments and may not adhere to treatment. To reduce challenge and barriers, providers must use peer outreach with an interactive team approach. This includes targeting high incidence areas, using multiple outreach services, and maintaining strong linkages to HIV primary care and community support services. Treatment for substance abuse should come before HIV treatment to maximize the benefits of treatment and reduce viral resistance. If someone is not ready for substance abuse treatment, harm reduction services are provided. In this approach, counselors advise clients about needle exchanges, how to clean their tools, and not to share their works. Condoms are also distributed.

Living with HIV

The Johns Hopkins Women's HIV Health Clinic uses a stage-based model of behavior, consisting of five elements: (1) pre-contemplation, (2) contemplation, (3) preparation, (4) action, and (5) maintenance. This model is used because it moves people to take action and get to maintenance. The procedure is the same whether it is for quitting drugs, quitting smoking, or deciding to take an HIV test.

Every woman is counseled about testing. It is emphasized that testing is voluntary, giving the client the power of making the choice. If a client declines testing, two testing outcome scenarios are used. In one, the counselor describes how a woman comes into the clinic and declines HIV testing. In the other, the counselor describes what it is like when a baby is admitted to the hospital with pneumocystis pneumonia and how sad it is for the mother who has this sick baby. The counselor then asks, "Which woman do you want to be?" These scenarios often motivate test acceptance.

Risk Assessment for Women

When conducting risk assessments with clients, counselors urge them not only to think about their own risk behaviors, but the risks of their sex partners and the risk of those partners' sex partners. By explaining these connections, it helps the clients see how they are at risk for HIV.

Counselors use extra care with teenagers. Language terms like "main squeeze" or "main girl" are used to help clients talk about other sexual partners. Rather than asking about the number of sexual partners, the counselor may ask, "Did you ever "creep" on your man?" Such questions open them up to thinking that if they are "creeping," their partners might be, too, so perhaps they need to use condoms with their main partner, too.

The Role of Peer Counselors

Presently Johns Hopkins has peer counselors involved in many aspects of health care, and the clinic is seeking to hire one more. Peers who take medications can help others take their medications. To change a client's behavior, the peer counselor must build a working relationship.

Counselors must learn about the area and know the people. They can talk to the clients about what is important to them during pretest counseling. Counseling and education is often time well spent. By educating one, you are educating many as people spread the word to those who need it.

Remarks of Sam Rivera, Director of Client Training Programs, and Pamela Goodrich, Trainer and Case Manager, the Fortune Society, New York, NY, on Incarcerated Persons

The Fortune Society is a nonprofit self-help organization that runs one of the country's most successful and intensive array of programs serving people at risk for incarceration, prisoners, and former prisoners. Using peers in an HIV testing program boosted testing rates at the Taconic Prison in New York State. Peers—prisoners—were certified to conduct HIV CTRS. As a result, testing rates jumped from nil to 50%. If peers are involved in the process the odds of success increase greatly.

The Society believes that it is best to hire peers as full-time employees; it is not enough to provide stipends or honoraria. Peers are not 100% of the answer, but programs need to rely on people who have had the experience of the target population.

Not everybody can walk into a prison and have the trust of the prisoners. Peers—those with similar background and in the same age group—can garner the trust necessary to get prisoners into CTRS and treatment. Peer education is essential.

The Fortune Society operates two training programs: one for adolescents and one for adults. Twenty-five adolescents have graduated from the PEPSA (adolescents preventing the spread of AIDS), which “trains kids to talk to kids.”

Peer educators must sign an agreement that by the end of training they will be drug-free. After training, they visit methadone clinics, churches, jails, prisons, and high schools where they speak. After a time, they are paid, usually \$100 per week, from which they must cover their own carfare. The peer educators go anywhere and everywhere. Peer education is about changing minds and saving lives.

Discussions so far have focused on different categories of people living with HIV. Remember that HIV is a human disease; people are the ones affected. Furthermore, testing is important for everyone, not just “those people.” The disease knows no boundaries. Few can say that they have never engaged in any type of risky behavior. Can anyone say honestly that they used complete protection the first time they had sex and every time thereafter? Everyone would like to believe that his or her mate is loyal and truthful, but no one really knows what is going on. Everyone needs to be tested.

Peer educators at the Fortune Society provide life skills and coping skills. The Fortune Society helps people live life on life’s terms. We, as a team, must fight and stop this disease the best way we can. And, don’t forget the babies; they are our future.

Summary – Panel #2 Presentations

Presenters dealt with a wide range of issues affecting the access and use of service among HIV-infected individuals with other co-occurring health and social conditions. Particular attention was given to persons with substance abuse problems, minority women, homeless persons, and the incarcerated. While each presenter identified an array of challenges in linking individuals from these groups to care and treatment, many of the challenges were similar across groups. The following is a summary of the common challenges identified among presenters. These include:

1. Multiple challenges exist in identifying at risk individuals in the community. Persons with active substance abuse, mental health, and/or housing problems may not have access to, or prioritize the importance of, HIV counseling and testing in relation to other personal needs. Without treatment of the individual’s problems, the individual may perceive unwillingness on the part of the medical community to provide care services.

2. The identification of the individual needs to occur in the community. It is unlikely that most of these hard to reach individuals will come into the primary care setting for HIV testing alone. Thus, links need to be made with non-AIDS community providers and services that may be providing some type of service to at-risk clients, such as detoxification and methadone maintenance sites, emergency rooms, family planning clinics, STD/Tb clinics, and homeless shelters. Training of community providers and outreach activities in these settings is essential.
3. It is important to gain the initial and ongoing trust of at-risk individuals and HIV-infected persons in the care system. Peer outreach workers and peer counselors are an essential component of the care team that do this work. They are often the only ones who can go into a community to interact with high-risk clients, establish relations, and provide clients with ongoing peer support.
4. HIV health care providers must be integrated or linked with other essential service providers through meaningful business relations. This is particularly important in the delivery of HIV care, substance abuse services, mental health services, and housing and social services. Clients present with a multitude of health and social problems, along with HIV disease, that must be addressed in order for the client to remain effectively engaged in his/her HIV care. Thus, providers need to create (within their clinics or through networks with other providers) a wide continuum of physical and behavioral services that can address acute, short term, and long-term treatment needs.
5. It is essential that providers assess risk activities at every client visit. Because of the discontinuous or intermittent nature of many of these problems, individual clients may need varying levels of risk reduction, substance abuse treatment, housing and other services throughout their course of treatment for HIV disease. Providers must be able to assess these needs and provide referrals or access to appropriate services within the established provider network. These referrals must be done within the context of established relations with HIV providers, not simply to give the person a phone number or contact at an HIV facility.
6. Many management challenges exist. These include:
 - a. Integration of funding streams in order to develop comprehensive service programs and linkages between CTR and clinical care services to meet client needs;
 - b. Establishment of reasonable reimbursement levels and staff salaries for personnel delivering HIV prevention services;
 - c. Establishment of an interdisciplinary team of physical and behavioral health providers that can communicate and share in patient care decisions;
 - d. Creating flexibility in the provision of care (e.g., walk-in services, late night office hours, co-location of services and staff, transportation or child care services, or others) to assure that when the client is available he or she is provided care services;
 - e. Understanding the impact of insurance and managed care programs and the limitations set by them related to the amount, duration, or scope of services, plans/strategies of these programs to identify at-risk persons and to link them to care services, and working with policy-makers to change these limitations.
 - f. High administrative requirements for reporting information and operating costs.

Panel Session #3: Cultural and Regional Issues

A wide range of potential cultural, linguistic, and regional barriers were identified by Planning Committee members in advance of this meeting. Among them, several common themes emerged. First, providers need to understand and address a client's HIV status within the context of his or her community. For example, stigmatization, isolation, lack of power and authority, sexual orientation, and age are strong forces that may drive clients away from the care system. Second, a client's ability to meaningfully engage in care may be significantly influenced by cultural and linguistic considerations. For example, non-English speaking clients or persons from migrant communities have unique needs in understanding HIV disease, treatment options, and the use of care services. Third, geographic location and residence may pose specific barriers for getting person into care after HIV testing and counseling. The following panelists presented on several of these issues: including immigrant and non-English speaking communities, gay youth of color, and rural communities.

Remarks by Ernesto Parra, MD, MPH, Clinical Associate Professor and Staff Physician, University of Texas Health Science Center at San Antonio, on Immigrant and other Non-English Speaking Communities

Barriers to care for immigrant and non-English speaking persons fall into several categories. The first is language. Many immigrants lack English proficiency. It is very difficult for the clients when they go to a clinic where they cannot understand and be understood. The South Texas Family AIDS Network (STFAN) program has overcome this barrier with a bilingual staff. Similarly, there is a dearth of educational materials available in Spanish. Many materials are also incompatible with the literacy level of the clients, or they are presented in an unsuitable format. STFAN has created materials appropriate for the target population. These include videotapes and novellas.

Another barrier is lack of formal education and lack an understanding of HIV transmission and safe sex. Clients often hold misconceptions about HIV infection and AIDS, thinking that if someone does not appear ill that he or she cannot be sick.

Cultural influences can also be a barrier, preventing health-seeking behavior. One such influence is stigma associated with HIV, sexual promiscuity, prostitution, IDU, homosexuality, and so forth. In one survey conducted at four local prenatal clinics, women were queried about why they declined HIV testing. The most common response by a wide margin was that if the test results were positive that they would be considered promiscuous. Cultural barriers related to stigma include embarrassment brought to the family; fear of loss of lover, family, employment. Men imagine that they will be unable to protect or care for their family. Women, who normally see themselves as caretakers for children and elderly, feel that they will not be able to fulfill that role. Finally, a sense of fatalism and belief in spirituality can be cultural barriers.

Household economics often create a number of barriers. Many migrants have a strong work ethic and so fear the loss of work that may come with illness. For them, missed work equals missed family income. They worry that they may lose their jobs due to ill health or days of lost work. Low incomes and erratic earnings are themselves barriers to care. Most workers have no insurance, and undocumented workers cannot qualify for benefits. Seasonal earnings may disqualify some workers for benefits for several months until they spend down their earnings. Possession of a vehicle, which may be necessary to hold a job, may disqualify some for benefit eligibility. Migrant work, a common form of employment, is associated with social isolation. Men often leave their families behind when they go to work for several months at a time. They may return infected from IDU or unprotected sex. Social and familial isolation also often lead to substance abuse.

Immigration status is another barrier. Fear of the Immigration and Naturalization Service may lead to concerns about being picked up when coming into clinics for treatment, or that they will be deported because of an HIV diagnosis. Most immigrants lack the wherewithal for seeking legal recourse.

Lack of transportation and childcare are further barriers to care. The family vehicle is oftentimes dedicated to work. Childcare services are often needed to attend to personal health needs and appointments. These are often hard to come by and may be prohibitively costly.

Many health care centers are inaccessible for a variety of reasons. Farm-site “clinics” are often cost prohibitive. Most clinics are open only during business hours when the workers are off at their jobs or are located too far away. Rural or migrant clinics may not offer HIV services. Clinic staff may not have language or cultural competency. Medical records may have to be sent over from another clinic. Additionally, in many states Medicaid (the means for obtaining services at some clinics) covers only AIDS and not HIV infection, and most states do not have Medicaid reciprocity.

Finally, Clinic clients may fear a loss of confidentiality, of being identified while receiving CTRS or health care. Many clients are concerned about being ostracized at work or in the community.

Strategies to Reduce Cultural and Legal Barriers

Staff from STFAN recommended the following actions to reduce the above-described barriers:

- Recruit bilingual staff to assist in outreach, education, case management, and health care services.
- Target education materials at the appropriate educational and literacy levels.
- Deliver educational information in culturally and socially attractive media. People must want to read material and be stimulated to find out more.

- Boost safe-sex education, CTRS, and prevention messages at targeted seasonally high-density migrant camp locations. Place outreach workers and case managers at sites that are heavily infiltrated at different times of the year.
- Recruit spiritual and community leaders to assist in reducing the misconceptions, stigma, cultural barriers, and fear of obtaining services (especially CTRS) associated with HIV.
- Reformulate eligibility rules to allow benefits for food, utilities, housing, health care, and medication.
- Legislate Medicaid eligibility for HIV infection, and not just AIDS.
- Facilitate Medicaid eligibility between states.
- Provide HIV screening and related health care at existing migrant camp facilities or in mobile units.
- Increase the number of community health centers and expand their services to include HIV-associated care.

Remarks by Jaime Martinez, MD, Principal Investigator, Cook County Children's Hospital on Gay Youth of Color

Unfortunately, when trying to understand HIV among adolescents data for youths are too often lumped in with adults. Yet, the demographics of the disease in adolescents are very different from those for adults. Data for adolescents must be, therefore, be teased out from the aggregated data.

A recent message from CDC is that we need to be particularly targeting young men of color who are acquiring their infections through sexual contact with other men. During 2000, one-fourth of new cases of HIV in the United States are occurring in youths under 21 years old. At that time, African Americans constituted 64% of AIDS cases occurring among 13-19 year olds. Fifty-four percent of new cases among 13-19 year olds involved young women (many of whom were African-American). Recent data also show that the higher prevalence of HIV occurring in young men within communities of color is often because those engaging in same-sex (MSM) activity are not being effectively reached by present prevention programs.

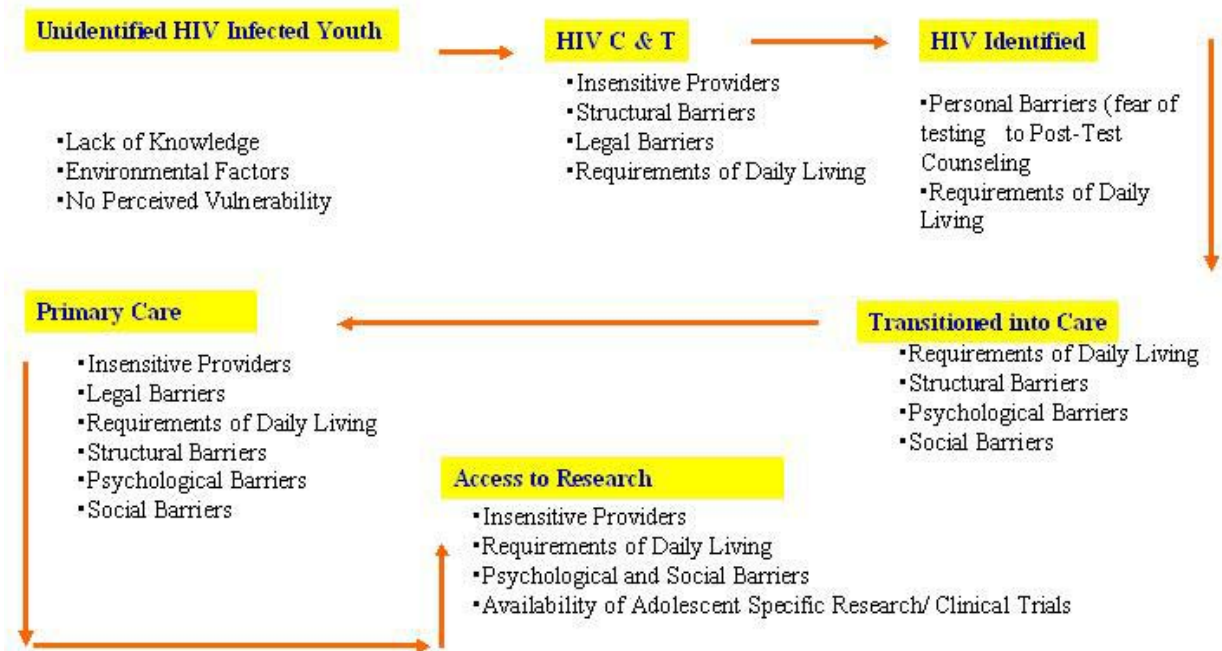
Another problem is the stigma of acknowledging homosexual and bisexual activity. Forty five percent of our CORE program clients between the ages of 13 to 19 years list no known risk factors for HIV. Young men engaged in MSM activity are often reluctant to acknowledge that activity, at least in the first few visits until some trust is established. Generally, they still identify themselves as heterosexuals. These young men may be more likely to identify with their racial/ethnic minority community than reveal any affiliation with a local MSM community. Further, some clients at the CORE clinic are reporting a new subculture of young men-“the down-lows”. These are men who perceive themselves as heterosexual but engage in homosexual activity. These young men would be unlikely to seek services from organizations that primarily serve the MSM community.

In general, CTRS takes a low priority in young people's lives. Only about half of clients show up at the clinic if they are just given an appointment time. To ensure that they will appear, it is often necessary to escort them to clinic appointments.

Adolescents Using Services

To better understand these issues, the CORE staff conducted focus groups with young people to identify barriers to primary health care (Figure 9, below). As a way of looking at services available to youths, some young people even visited clinics in Cook County. Many of the youth were dressed in the fashion of youth from various cultures, with blue hair, green hair, torn jeans, body piercing, or cross-dressing to evaluate how they were treated in the clinics. At more traditional, adult-focused clinics, they reported that staff seemed to focus in on their differences. The youths also reported other barriers, such as limited hours, the necessity of crossing gang territories, and, for homeless youth, needs to obtain food, shelter, warmth, and clothing. Finally, some sites required parental consent.

Figure 9. Barriers to primary health care identified by focus groups at the CORE Center.
 Source: J. Martinez, Division of Adolescent Medicine, Cook County Hospital, Core Center, 2001.



To overcome these barriers, CORE created a case-finding program and trained young people and adults to serve as case finders and peer health educators. These case finders and health educators deliver developmentally appropriate information in the form of HIV education. They engage youths according to what their needs are on any given day. The case finders also do on-site CTRS and traditional case management. Members of the primary care team meet monthly with youths; those on medication have weekly contacts with their case managers. Contacts are escorted to appointments. Peer youth advocates (also called Buddies) are able to relate as peers with young people to allay their fears. To engage young MSM and young women in care, the case finders go out to detention centers, social service

agencies for gay youth, gay dance clubs, homeless shelters, alternative schools, and other sites.

The CORE Center has also developed a videotape to promote use of services by adolescents. On it, youths explain what HIV is and some of the services available at CORE. Also depicted are oral specimen counseling and testing procedures, and the roles of case finders, case managers, nurse practitioners, and physicians who work together to provide primary care services. A physician reviews what a first visit to CORE will include: taking a detailed history and an assessment of risk factors. The physician emphasizes that it is important to know that young people with this infection can have long, productive, happy lives. Mental health workers cover disclosure issues and issues that may arise while facing a “scary” experience. The message they deliver is: “You don’t have to go through this by yourself.” The videotape concludes with a discussion of research participation.

Recommendations

Core staff recommended the following actions to enhance use of services by youth.

- Have effective service models and an environmental context. Dominant models that are suitable for adults and children are not effectively transportable to youth. Effective service models must reflect competence in the culture of adolescents, i.e., consideration of gender, race and ethnicity, developmental stage, psychological issues (e.g., health-related beliefs, attitudes, and motivational factors), family composition and relationships, social aspects (e.g., economic resources, peer reference groups) and behaviors (e.g., substance use), sexuality, and sexual behavior.
- Build Trust: Youth are very distrustful of adult health care services and settings. So, developing trust or a therapeutic alliance with youth is critical to engaging youth in a case finding service and retaining youth in care.
- Use Youth peers: Programs should make sure to involve youth in as many aspects of program development and delivery as possible.
- Focus on engagement and stabilization: These processes should recur from transition case management in the field to reassessing care plans at regular intervals, and must include an assessment of the adequacy and stability of the youth’s requirements for daily living.
- Give attention to transition and linkage to care: The transition of an HIV-infected youth into treatment should be personally managed by a case manager or case aide who develops an individual relationship with the infected youth. More often, the outreach worker, case finder or post-test counselor becomes that transition case manager, having already developed a trusting relationship through the C/T process.
- Also consider access to care: All aspects of accessibility should be considered—location, hours, language, culture, and so forth. Consumer engagement in treatment is enhanced by collocation of services and staff, evening and weekend clinic hours, integrated service delivery through multidisciplinary teams, and a consistently flexible approach by all staff.

HIV prevention programs for youth should be driven by knowledge of and experience in working with the targeted subculture. Prevention programs must be especially shaped to target from within communities of color adolescent women and adolescent men engaging in MSM and who may not identify themselves as homosexual or bisexual. Racial and ethnic

minority community leaders should promote dialogue about issues of sexual orientation to overcome social barriers to HIV prevention for racial and ethnic minority MSM, especially among young men.

Remarks by Sally Lou Patterson, Director of HIV/STD Program, Maine Bureau of Health, on Rural Communities

The challenges in Maine can be summed up as follows:

- lack of public health infrastructure
- limited resources for public health programs
- categorical funding of programs
- limited state funds
- lack of culturally sensitive health care
- separate state agencies oversee HIV prevention and care
- the state is a geographically large area, with low population density
- clients and services are geographic inaccessible to one another
- prevention messages are often competing and conflicting
- the public's fear of change.

In addressing these issues, Maine has learned that listening to clients and providers is helpful. When talking about integration of services, we need to connect people to services they need and want. One of the most vexing challenges is that many programs deliver competing prevention messages, essentially trying to "outshout" each other. Even within the Bureau, prevention messages are overwhelming and sometimes inconsistent. One common situation is a pregnant woman who leaves a primary care provider's office with a shopping bag full of information about nutrition, breast feeding, infant care, folic acid supplementation, and so on, with any messages about HIV prevention getting lost in the shuffle. What is needed is better coordination and consolidation of messages.

People's fear of change is the most difficult to surmount. Attitude adjustment is a slow and painful process.

Accomplishments in Maine

The state's community planning group is very engaged in the idea of integrating services for HIV/AIDS. About a year ago a panel was convened, consisting of a HRSA representative, the Ryan White grant manager, a Ryan White case manager, people living with HIV/AIDS, the manager of a large specialty clinic, and the state's HIV/AIDS program manager. The panel addressed some of the challenges in the state and larger issues, such as mental health services and care within the department of corrections. Planning committees for Title III applications stimulated the creation of new connections among diverse entities, and those connections have lasted. This is also true for the long awaited but not yet implemented Medicaid waiver. The people who came together to form the planning committees represented a variety of disciplines and organizational levels.

A conference has been planned on HIV prevention with HIV-positive people. The CDC is involved in the conference, as well.

The Program for HIV/AIDS developed a short course (5 hours) to equip people with the tools they need for providing CTRS. Previously the certification course had involved 2 or 3 days of conventional training. The short course is offered at various locations around the state and has been very popular.

Providers have opportunities for contact with a disease intervention specialist, which are facilitated through integrated services. When the state receives a positive HIV report, the Bureau contacts the provider and offers an interview with the specialist.

The Bureau conducted a special project that brought together groups of prevention staff, case managers, consultants to come up with ideas for screening and education.

The Bureau continues to support a multi-disciplinary hepatitis C prevention working group, which has been in place for several years. Counseling and testing services and disease follow-up closely parallel the service model for HIV and STD.

Another emphasis has been a low-barrier CTRS system, including oral specimen testing and outreach services. They are trying to integrate those programs much more so than in the past.

The HIV Program provides a complete list of resources statewide. It is extremely complete, updated frequently, and distributed widely. It is sent out to many organizations, including shelters, corrections institutions, and social service agencies,

Persisting Challenges

Despite these accomplishments, the following challenges remain.

- Better integration of program oversight is needed on local, state, and federal levels. It is embarrassing and confusing to tell providers to do something when the public health agencies are not doing it.
- More involvement of people living with HIV/AIDS is needed in planning, developing, and implementing programs.
- More provider training is needed for prevention educators, clinicians, case managers, and others who are involved in eligibility determination, and so forth.
- Engagement of priority populations is lacking. Maine, for example, is the whitest state in the nation, which makes it very hard to operate programs targeted to racial and ethnic minorities that are being disproportionately affected by HIV.
- We need to be better listeners, more flexible, and more open-minded.

Summary – Panel #3 Presentations

Many of the issues raised in Panel #2 were restated in Panel #3. These included cultural and linguistic competency of programs and staffs, flexibility of clinic services, use of peer outreach workers and counselors, management challenges, and an integrated “one-stop” shopping service environment as important factors for increasing linkages between HIV counseling and testing, care and prevention services. Additional challenges, included:

1. The multiple challenges that exist in identifying at risk individuals in the community. Persons may not perceive their vulnerability or be unaware of the potential exposure from a sexual or needle sharing partner. Also, persons may not want to learn their status for fear of isolation or stigma. Immigration status may also play a significant role in persons not getting tested or, once tested and found to be HIV-infected, linked to medical services. In rural communities, the lack of health facilities (i.e., capacity) and adequate attention paid to HIV prevention services (including HIV CTRS) among providers also play important roles.
2. Migratory patterns of seasonal workers (especially across state lines), the isolation of rural residences, and the common daily activities of adolescent lifestyles create serious problems in accessing and utilizing HIV care services. Lack of sensitive and knowledgeable HIV providers, lack of inter-State Medicaid eligibility, lack of public health infrastructure, legal barriers to acquiring services, lack of program models to deal with issues of psychological and sexual development in adolescents, and the lack of trust of health care systems are challenges that must be addressed in these populations.
3. Health care providers and policy makers must engage in creative solutions to address the needs of these clients. In doing so, it is important that Federal and State agencies support the financing and organizational planning of multi-disciplinary medical and social services centers and models. This flexibility includes integrating funding streams, reducing administrative and reporting requirements, reformulating Federal benefits programs (e.g., Medicaid) to cover persons earlier in their HIV disease, and providing persons with equal access to services regardless of State residence or immigration status.

Panel Session # 4: Evaluating Links and Referrals

Significant resources and planning efforts may be expended in establishing linkages between HIV counseling and testing and care services. However, without effective program evaluations the effectiveness of providing adequate or appropriate types of service linkages will remain a mystery. In addition, services may be missing their intended target populations or having an unintended effect. To date, little has been done in the area of assessing the effectiveness of linkage efforts. Few programs have been evaluated and fewer standard models of evaluation have been proposed. This panel will present a current evaluation effort underway in the state of New York and challenges to effectively evaluating this program. Additionally, panelists will provide suggestions for improving existing evaluation efforts and recommendations for establishing evaluation efforts and models within federally funded programs.

Remarks by Jeff Rothman, MS, MBA, Assistant Director, Bureau of HIV Ambulatory Care, New York State Department of Health

New York State probably has the largest network of drug treatment programs in the country, with some 46,000 in methadone treatment at any given time and well over 100,000 treatment slots overall. Mr. Rothman spoke today about referral systems and tracking strategies in their substance abuse initiative model, developed in 1990. The initiative provides for co-location of comprehensive HIV prevention and primary care services within substance abuse treatment settings throughout NY State. It is funded with allocations and grants from NY State, HRSA (Ryan White), CDC and SAMHSA and now encompasses 32 providers who serve a combined census of approximately 50,000. The initiative also supports CBOs that engage in outreach to active users and sex workers, and helps build capacity at small drug treatment programs..

Integrated Services at Co-Location Sites

In the initiative, HIV services have been integrated within drug treatment. All clients receive an orientation to HIV when they come in for drug treatment. All are offered CTRS, and a risk assessment, and are referred for risk reduction and support services, which are provided as needed. If the results of an HIV test are positive, the client is referred to HIV case management and primary medical care. If HIV test results are negative, the client is referred for behavioral change counseling. Everyone is assigned a substance abuse counselor, a key individual who is the primary counselor and case manager in the drug treatment program.

Outreach

Several programs provide outreach from well-equipped mobile units. Oral specimen CTRS is made available. If possible, clients are referred back to the outreach provider's facility for health care services; otherwise, they are referred to alternative providers according to the clients' preference. The agency then attempts to follow up to see if the client has obtained care.

Referral Linkages

A variety of reciprocal referral relationships exist between the HIV/substance abuse clinics and other entities, including designated AIDS centers (hospitals where HIV expertise resides), other drug treatment programs, legal services, HIV-specific CBOs, mental health providers, county and government health departments (which can provide health care and case management, community health centers, and other hospitals (not designated AIDS centers)). But, complications may arise within these referral relationships due to:

- lack of trust by clients
- poor communication among providers
- competition among providers for ambulatory care clients (important in the era of managed care)
- lack of understanding about how the drug treatment and health care systems work
- concern over confidentiality.

Referral linkages are evaluated in several ways. None of the methods by themselves gives a complete picture of how well the system is working. Yet, each contributes to the evaluation in some way. Monthly aggregate data reports from prevention and primary care providers are required of providers as well as monthly data reports on referral activities and success. These components can indicate if a referral linkage was made and whether the client was actually able to access the service.

Client satisfaction surveys are required of each provider. The surveys were developed by the Department of Health. Some questions relate specifically to access to care (e.g., “How long did it take you to get an appointment? What kind of experience did you have accessing care?”)

The Department of Health also conducts annual on-site chart reviews to track clients from the point of a positive test result to ensure that they accessed care and that feedback has been provided either from on-site or off-site care.

Follow-up is conducted using a continuous quality improvement (CQI) approach. The medical director’s office also provides technical assistance. Programs are encouraged to incorporate referrals and linkages into their own CQI systems.

Medicaid data have many strengths and weaknesses. It is possible to collect information on Medicaid recipients testing positive for HIV and then review subsequent Medicaid billing for medical services. This approach is objective and yields an enormous amount of data for evaluation and research. Recent research that relied on Medicaid data showed that the closer the referral linkages were to the drug treatment provider, the lower the number of hospitalizations (JAMA, May 7, 2001).

Medicaid data, however, are subject to some serious limitations:

- Managed care eliminates HIV test counseling billing data.
- Medicaid benefits may be terminated.
- Some providers are not eligible to bill Medicaid.
- Current Medicaid information systems are not designed so that this information can be obtained and analyzed easily.

Therefore, the New York Department of Health is considering client-level tracking of referrals, which yields better data for more rigorous quality evaluation. However, it imposes an administrative burden on providers and lacks in-depth descriptive capacity. In conjunction with HRSA, the department has developed a uniform reporting system (URS) that contains a referral tracking system. The system has the capacity to report data on the outcome of appointments, the providers that receive referrals and a library of agencies that may be accessed for referrals.

Total referral activity is tracked. In general, medical referrals are up, and entitlement referrals have remained fairly constant. Some data on medical referral activity for calendar year 2000 was presented. The data show whether people actually made it to referral appointments (Table 11, below). The low point (18.4%) was referrals made to a specific hospital outpatient clinic (actions have been taken to correct this situation).

According to Medicaid data for 1999, in drug treatment programs funded by the Department of Health with CDC grants, 780 HIV-positive people received post-test counseling, and 618 received follow-up medical services that were billed to Medicaid. The overall success rate based on this 1999 Medicaid billing data for follow-up care was 79.2%.

The percentages of those testing positive by race, ethnicity, and gender have been compared with percentages of those entering HIV primary care for the initiative. This analysis has been done to ensure equitable access to health care. One should note that the population testing positive is not the exact same cohort as those entering care, because we do not yet have client level data for persons entering care. Using calendar 2000 figures, African Americans comprised 43.7% of those testing positive, and 38.6% of those entering care. Hispanics were 43.8% of those testing positive, and 43.7% of those entering care. Whites were 10.3% of those testing positive and 16.5% of those entering care. Native Americans were 0.4% of those testing positive and 0.5% of those entering care. Asian/Pacific Islanders were 0.2% of those testing positive and 0.3% of those entering care.

Table 11. Substance Abuse Section Medical Referral Activity for Calendar Year 2000

Source: J Rothman, New York State Department of Health AIDS Institute, 2001

Medical Referrals By Type	Number of Referrals	Outcome Known*	Appointments Kept	
			Number	Percentage
Physician within Drug Treatment	1774	1747	1600	91.6%
Community Health Center	154	149	131	87.9%
Designated AIDS Care Center	108	96	88	91.7%
Hospital Outpatient Clinic	322	316	58	18.4%
County Health Department	53	51	40	78.4%
STD Clinic	4	3	2	66.7%
TB Clinic	152	152	126	82.9%
Total Medical Referrals	2567	2514	2045	81.3%

* Outcome known is the number of referrals where it is known if the appointment was or was not kept.

Based on Substance Abuse Section monthly reports data.

Challenges to Integration

Obstacles to success in the Initiative have included the following.

- Communications break down between agencies that do not understand each other's language or needs.
- A great deal of effort is required to document referral outcomes.
- Collecting client-level data for tracking people from test result to service acquisition imposes a large administrative burden on providers.
- Many hospitals in New York have opened ambulatory care sites and now compete with community programs and drug treatment programs for clients.
- Clients sometimes fail to follow through on referrals because of competing needs.
- Outreach is necessary to maintain access to clients.

Recommended Future Directions

The following are some opportunities that will be explored in New York during the coming year. Other states may want to consider similar actions in their contexts.

- New York will be creating a new service model designed to move active injection drug users into drug treatment and medical care through intensive case management and aggressive networking.
- We will be expanding clinical education as a natural way to develop linkages and relationships.

- Place greater emphasis on hepatitis C virus screening and treatment in substance abuse treatment programs. (While most drug treatment providers are willing to do screening, some are not comfortable with providing treatment). Drug Treatment providers must work with hospitals and other providers who will do treatment..
- We will be helping providers make the transition to a client-level Uniform Reporting System.
- We will be developing special HIV managed-care plans (The Department of Health is working with seven plans to become certified, one of which is a partnership of methadone maintenance providers.).

Remarks of Julia Hidalgo, PhD, The Forum for Collaborative HIV Research, George Washington University, Washington, D.C.

Data from a national consultation of Ryan White CARE Act providers show the following:

- Forty-seven percent of CARE Act providers are engaged in primary and secondary prevention activities; of these CARE agencies providing prevention services, only 37% receive CDC funding.
- Ethnic minority providers are more likely to offer prevention services than providers based in the majority culture.
- Only 37% of agencies providing prevention services in the CARE Act sphere participate in community-level prevention planning activities.

In terms of linkages to address this situation, therefore, it is not enough to send clients to sister and brother organizations. We must think more systematically to link and integrate services to plan for prevention, CTRS, and clinical and other services. Such an approach will help patients move through those systems in a way to allow them to stay in care.

Previous Evaluation Approaches

Programs have used prevention and care data to carry out evaluation activities. CDC and HRSA require the collection of much programmatic information for various purposes, some of which are recycled into evaluation activities. Such data are flawed in several ways, although they have served as the basis for many significant studies. The flaws include the following.

- Cross-sectional data collected at the point of service are often not accurately linkable to create person-based records.
- Outgoing referrals may not be linked to completed referrals.
- Repeat testing inflates counseling and testing site data.
- Use of multiple agencies inflates service population data
- Use of actors to assess content of pre- and posttest counseling and other services, including referral rates, show that some agencies' reports of referrals are overstated.
- Agency staff tend to focus on collecting the data required.

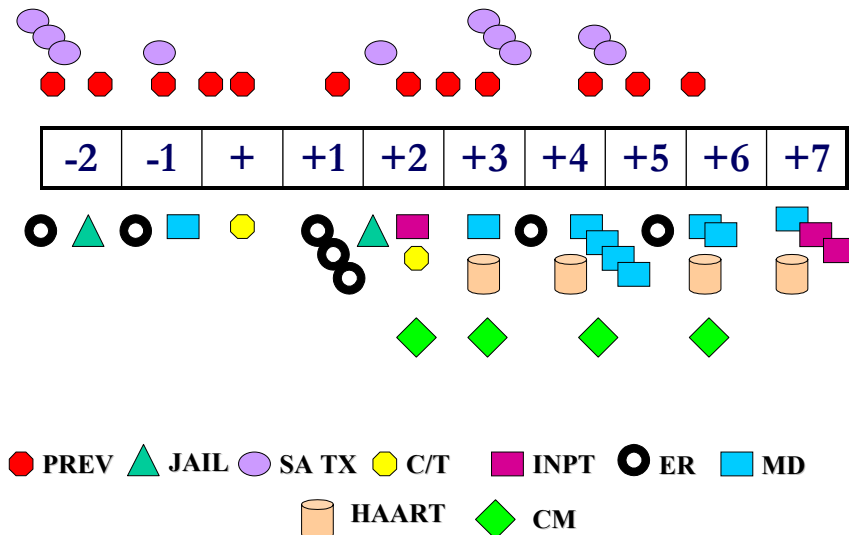
- The HIV/AIDS surveillance system is overwhelmed and underfunded, yielding a national snapshot of the epidemic that may be based on inadequate data.
- Some states do not participate in HIV reporting.
- Insurance claims records are very complex and inaccessible to many researchers. Also, in the era of managed care, these data may be flawed because no reimbursement is made on the basis of records. Enrollment changes over time, causing gaps in enrollment records.
- Prepaid, managed-care systems use encounter-based data so there is little incentive for providers to fully apply coding system to record diagnostic and procedural data.
- Institutional barriers and use of different coding systems have thwarted efforts to link publicly funded data systems.
- Geographic comparisons are increasingly difficult as state programs apply different eligibility and coverage policies.

Figure 10, below, depicts one fictitious person’s odyssey through the HIV service system from a point 2 years prior to infection to another point 7 years after infection. This person received a spate of prevention messages from a variety of sectors during this period. He has been in episodic substance abuse treatment throughout these years, perhaps representing some missed opportunities for prevention messages. Little contact with any meaningful HIV care system occurred around the time of diagnosis. It appears that the most significant engagement with HIV care occurred only after his first hospitalization. As he moved in and out of correctional institutions, he may have received HIV care.

What this scenario reveals is that HIV service systems are increasingly complex because of the diverse needs of consumers. People frequently enter the HIV service system outside of the system funded by CDC or HRSA (e.g., through office-based physicians, managed care plans, correctional system), and they may continue to receive much of their services outside such system.

Figure 10. Transition from HIV prevention to care: One person’s odyssey

Source: J Hidalgo, George Washington University, 2001



It may be difficult to define local systems and the relationships of member agencies and other providers. Agencies exhibit variable commitment to HIV prevention and care. Many organizations touch people's lives. Among them are local and state governments, CBOs, safety net programs, and hospitals. Furthermore, different communities emphasize different aspects of care. Some communities still feel that psychosocial services are more important. Others emphasize medical care. Still others sprinkle dollars throughout the system.

When we are trying to track thousands of people whose lives intersect the health care service system in so many different ways, any type of analysis of referrals and linkages becomes exceedingly complex. It is even more difficult to show that these referrals and linkages may any meaningful difference in people's lives.

Challenges Encountered in Evaluating Links

The following are some challenges that facing linkage evaluation.

- Launching new evaluation strategies may burden an already overwhelmed system of HIV prevention, CTRS, and care.
- Half of CARE Act providers report insufficient direct service staff and physical space to meet *current* demands for care.
- Two-thirds of CARE Act providers report that they need more funds to meet *current* demand.
- One-fourth of CARE Act grantees and their contractors report that they need technical assistance in evaluation.
- Consumers' self-reports regarding risk behaviors, referrals, and adherence to treatment may be inaccurate because of recall problems, insobriety, and so forth.
- Moving from descriptive studies to outcomes studies is desirable but difficult to accomplish because it may be hard to achieve sufficiently large sample sizes, follow cohorts over time, measure the cumulative effect of different interventions, account for the effect of other factors, and interpret the results.
- The state of the art of HIV treatment is changing.
- Self-determination by consumers may affect the order and frequency of services.
- The most meaningful initial HIV early intervention services may be drug treatment and mental health services to help people get ready for treatment.

Recommendations for Evaluation Design

To address these challenges, interested parties should consider the following:

- Use a multidisciplinary approach in which epidemiologists, behaviorists, health services researchers, and operational researchers join forces;
- Focus on a balance of process and outcomes measures applied in cross-sectional and longitudinal studies;
- Link epidemiologic, administrative, insurance, program performance, and clinical data;

- Apply realistic approaches that do not lead to further unfunded mandates for grantees and service providers; and
- Establish meaningful partnerships among prevention, CTRS, care providers, and consumers, to design studies.

Many suggestions for evaluation studies are listed in Table 12, below. Furthermore, evaluation should be launched to obtain baseline data before re-engineering health care systems. Demonstration projects may be used to develop conceptual frameworks and instrumentation. We must be careful to heap more responsibility on agencies until it is shown that the evaluation activities are not unduly burdensome at the local level and that they generate useful, descriptive data.

Table 12. Multipronged evaluation strategy

Source: J Hidalgo, George Washington University, 2001.

Consumer Behavioral Studies	Individual Provider Behavioral and Performance Studies	Agency Studies	Delivery System Studies	Planning Systems Studies
<ul style="list-style-type: none"> • HIV risk behaviors • Test <i>and</i> result seeking • Initial and longitudinal care seeking, • Adherence to harm reduction practices and treatment • Referral follow-up • Appointment initiation and keeping 	<ul style="list-style-type: none"> • Prevention workers • HIV counselors • Clinicians • Case managers • SA and mental health program staff • Mental health workers and social support providers 	<ul style="list-style-type: none"> • Program design • Service models • Outreach and case finding strategies • Referral relationships • Accessibility assessments • Performance measures • Quality measures • Consumer satisfaction 	<ul style="list-style-type: none"> • Planning mechanisms • Defining roles and responsibilities • Referral mechanisms and relationships • Extent of integration • Role of substance abuse and mental health providers • Co-location of services 	<ul style="list-style-type: none"> • Effectiveness of planning councils, consortia, and community prevention planning groups in (1) identifying and filling service gaps, (2) integrating high quality services, and (3) allocating funds to this end

Workshop Discussions and Recommendations

Because the primary purpose of the meeting was to capitalize on the collective knowledge and experience of workshop participants, two breakout sessions were convened during the workshop, one the first day (prior to panel presentations) and the other toward the end of the overall workshop. These sessions generated ideas and recommendations for the sponsoring entities to consider with regard to future programs and services – based on their personal experiences as well as those described by the various panelists.

The focus of the first breakout session was: identifying points of entry into medical care, social services, and educational services that result from or lead to HIV diagnosis; theorizing how primary and secondary prevention can be linked; identifying opportunities to create linkages, referrals, and integration of services from and to these points of entry; and identifying barriers that hinder the delivery of comprehensive services. A common list (and a conceptual framework) of the types of linkage and referral services needed by at-risk individuals and persons with HIV disease was proposed. All participants in this session seemed to agree on two key points. First, multiple points of entry into care are needed. Participants felt that such overlapping points of entry are necessary to reinforce messages and also because of the various reasons for which persons seek HIV CTRS. Secondly, effective linking of primary and secondary prevention services is very difficult and requires practical and reliable network relations and management systems.

Proceeding the first breakout session, workshop participants heard from various panelists on challenges of linking at-risk or HIV-infected persons from HIV counseling and testing to care and prevention services. These challenges (as described earlier in the report) were presented based on four levels: including; organizational and system issues, social needs and co-occurring health issues; cultural and regional issues; and evaluating linkages and referrals.

After the panel presentations, workshop participants reconvened into a second breakout session to discuss issues identified in the first breakout group meeting and the presentations of the various panelists. Based on this discussion, workshop participants were asked to collectively formulate and prioritize a set of recommendations for actions that can be taken by (1) the Federal government, (2) State program administrators, and (3) community direct-service providers to better integrate care and prevention services. Participants were asked to address issues of financing, organizational structures and planning, programmatic elements such as staffing, relations with other provider groups, definition of mission and organizational goals, and other issues as deemed important to participants. One group focused on how linkage quality and effectiveness could be evaluated. Major categories of recommendations are summarized below.

Breakout Session I - Identifying Links and Points of Entry into Care, and Barriers to Linking HIV CTRS, Prevention, and Care Services

Breakout Session I focused on three topics:

1. Points of entry into medical care, social services, and educational services that result from or lead to HIV diagnosis.
2. Opportunities to create linkages, referrals, and integration of services from and to these points of entry.
3. Barriers that hinder the delivery of comprehensive services.

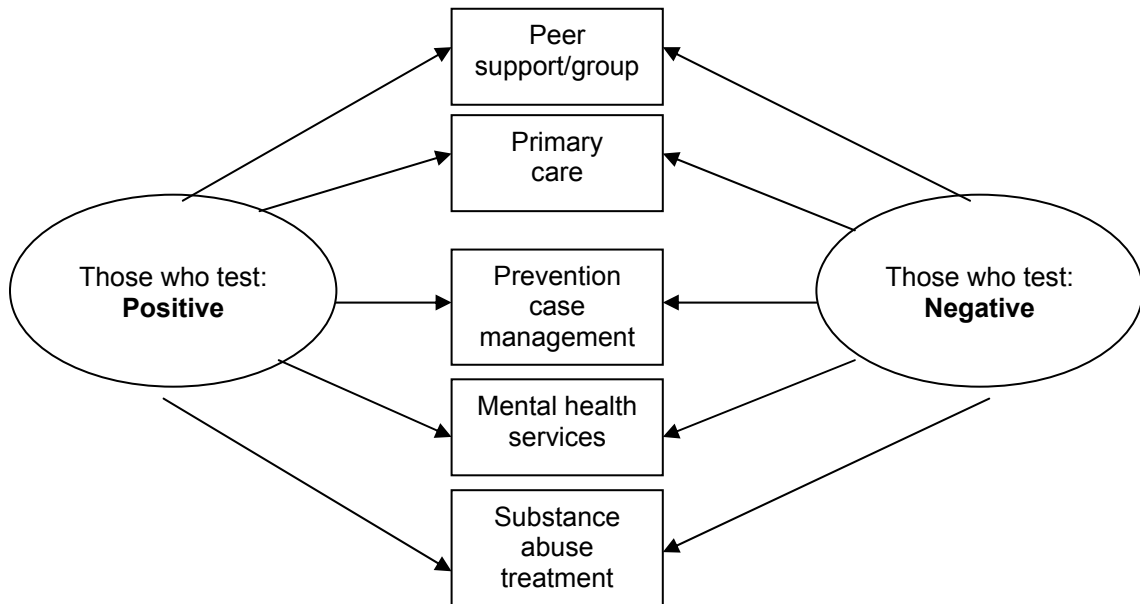
All the breakout participants agreed on one key point: multiple points of entry into care are needed. Table 1 in **Appendix E** is a comprehensive list generated by the breakout groups of possible points of entry.

Participants generally felt that overlapping points of entry are necessary to reinforce messages, delivering them at various places at repeated intervals over a long period of time. This is consistent with existing health education and promotion theory. Another reason for multiple types of entry points relates to the four main categories into which HIV CTRS-seekers fall: (1) those who are self-motivated; (2) those who take advantage of opportunities offered at blood banks and STD clinics; (3) those who miss potential opportunities for testing or CTRS as a result of their own or provider inaction; and (4) those not wanting to be tested, for various reasons. Each type of test seeker has different needs and may be more likely to seek CTRS at different sites. It is the last group that requires the greatest effort, with repeated messages to get CTRS and, if warranted, get into care.

The following were identified as strategies for creating links, referrals, and integration of services:

- Offer either “one-stop shopping” at the service site or have in place strong referral mechanisms.
- Strengthen the intersections between public and private systems, currently a weak point in linking of services.
- Agency/local-level and federal collaboration is critical.
- Keep articulating to funders and service providers the benefits of linkages and collaboration for consumer, provider, agency, and government.
- Fund and reimburse for linking and referral services.
- Locate prevention case management and substance abuse workers at community health centers and other health care facilities.
- Use the provider/client relationship to relay additional information about referrals.
- Institute public information campaigns that include wide distribution of referral lists.

One group diagrammed a network of linkages that would involve those who test HIV-negative as well as those who positive:



Participants described barriers as falling into several categories: systemic, provider-level, and client-level. In addition, one group specifically addressed barriers faced by incarcerated populations. These are all identified in Tables 2 and 3 in **Appendix E**. Additionally, two general concerns were discussed. Care providers need to be given financial resources if they are to be expected to provide prevention services along with care. Without such, the goal of comprehensive patient care will only move farther away. Secondly, the health care system in the United States needs to change its orientation from an illness system to a health care system. Without such a change, results from attempts to create links and integration will be limited.

Breakout Session II - Recommendations to Reduce Barriers

After considerable discussion regarding the challenges of linking HIV counseling and testing services to care and prevention services (e.g., operational, competing social or health needs, cultural and regional), work group participants compiled a list of recommendations for reducing barriers and establishing and maintaining linkages. Recommendations were made with regard to Federal agencies, State program administrators, community based service providers, and program evaluators. The list was further prioritized in order to identify the most important or essential areas for reducing barriers. Below, recommendations considered to be of highest priority are discussed. Detailed notes on the entire recommendations discussion may be found in **Appendix F**.

Federal Agency Recommendations

Work group participants focused on several key areas as the primary barriers in linking HIV counseling and testing with care services at the Federal level. These include: the funding nature of categorical programs (discretionary and entitlement); administrative procedures and cross training of Federal staff; and data and evaluation activities. Other issues of less priority (e.g., reducing stigma of HIV, the clarification of certain program expectations, and others) are not discussed but included in notes from the session contained in **Appendix F**.

1. Federal agencies involved in HIV issues need to integrate the funding and disbursement process for CTRS, care and treatment, and prevention programs.

Overall, the single most important issue expressed by work group participants was the challenge of acquiring, managing, and coordinating prevention and care program funds within the existing categorical funding structure. Because of the differences in application guidance and policies, management and reporting requirements, and the various authorities overseeing program administration and service reimbursement policies, there was an expressed interest in exploring (and developing) various options for integrating funding streams and the disbursement process. Specific recommendations included:

- Conduct a study of statutory, regulatory, and administrative policies that affect the integration and funding of HIV prevention and care systems and funding at a Federal level. Care services should include HIV prevention services and behavioral services (e.g., substance abuse and mental health services), as well as Medicaid and Medicare;
- Institute a Federal process to explore and develop collaborative and innovative funding across agencies, including HRSA, CDC, CMS, Housing and Urban Development, SAMHSA, and the Veterans Administration;
- Align disbursement cycles for prevention and care programs and institute a multiyear funding cycle; and
- Encourage more cooperative grants between agencies.

Within the context of the existing funding structure, work group participants expressed a concern related to the level of reimbursement of HIV prevention services and the planning and allocation of funds for both prevention (including HIV counseling and testing) and care services to certain communities and/or geographic areas. Participants recommended that:

- Reimburse HIV prevention services in Federal programs, including discretionary and entitlement programs. Reimbursement levels should reflect the true cost of the service; especially, the reimbursement and payment level for outreach workers (peer counselors/educators);
- Resources should be targeted to identified needs within communities and commensurate with epidemic trends;
- Grantees, or jurisdictions, should be expected to identify needs and base the budget on those needs with an eye to creating a needs-based budget;
- Strong support was given for the increase of Federal funding for prevention and care services and, thus, avoiding reductions to funding of some programs so that others can be expanded; and
- Seek accountability for SAMHSA block grant funds.

2. *Federal agencies involved in HIV funding need to simplify and coordinate administrative procedures to encourage and support linkages at the state and local level.*

The theme of integration (i.e., unification) and simplification was predominant in the recommendations. Participants focused attention on issues of cross training of Federal staff and increased collaborative relations between agencies. These recommendations included:

- Institute training of Federal staff (HRSA, CDC, SAMHSA, HUD, and CMS) on the benefits and procedures for linking program activities;
- Better align behavioral health services with HIV prevention and care services (SAMHSA and CDC),
- Design models for integrating and streamlining administrative procedures (e.g., surveillance, application process, funding, and data) across all relevant agencies;
- Assess and develop Medicaid's role in linking HIV positive persons to care and providing prevention services to beneficiaries;
- Develop HRSA guidance to ensure that medical providers are providing and referring patients for prevention services (e.g., compliance with the CDC's HIV Counseling, Testing and Referral Guidelines);
- Relocate Ryan White Title II grants from field offices to central office in order to link the management with the administration;

3. *Federal agencies need to develop standard data and evaluation systems that can be used across services at all levels.*

While there was a separate discussion on data and evaluation issues, work group participants raised several issues related to Federal requirements for data and evaluation activities. Participants recognized the benefits of data and evaluation activities but were generally unfamiliar with the types of data or evaluation methodologies necessary to assess the effectiveness of linking HIV counseling and testing to care. Given the need for more direction from Federal agencies, participants recommended the following:

- Establish a standard list (and definitions) of performance measures and procedures across agencies; preferably a mix of process and outcome measures;
- Increase technical assistance and resources necessary to improve data collection and analysis, including the development of templates and blended databases;
- Establish Special Project of National Significance (SPNS) initiative on developing an evaluation system to (1) link persons from HIV counseling and testing to care and (2) provide HIV prevention to persons with HIV disease;
- Increase data sharing activities between agencies in order to reduce duplicative efforts at the grantee level; and
- Improve reporting of demographic data of infected persons by age, ethnicity, and gender (including transgender) and the measure of “unmet needs” in communities.

State Program Administrator Recommendations

Work group participants identified a substantial list of issues impacting the linkage between HIV counseling and testing and care at a State/local level. Based on the list, and discussions during the panel presentations, the following recommendations were drafted. As mentioned earlier, this list includes the highest priorities as identified by the participants. Recommendations of lower priority are included in **Appendix F**.

As recommended for Federal agencies, work group participants focused their recommendations in areas of funding, administrative procedures, and data and information needs. In addition, participants included recommendations in areas of health services planning, network development, and the development and implementation of quality standards.

1. States must increase funding for HIV prevention services, complementing resources available from federal sources, especially through establishing reimbursement mechanisms in Medicaid programs.

State-originated funding for HIV prevention services was generally viewed as inadequate in types of HIV prevention services, levels of reimbursement (discretionary and entitlement programs), and the support of substance abuse and mental health treatment services. Recommendations included:

- Increase State-originated funding for HIV prevention services in discretionary and entitlement programs;
- Enhance substance abuse and mental health program resources;
- Fund technical assistance activities for implementing linkages of services and referrals, and fund the evaluation of these linkages;
- Reimburse providers adequately (including referral activities) and ensure funding for outreach workers (peer educators/workers); and
- Standardize fiscal years and simplify the request-for-application process.

2 *States must simplify and coordinate the administration of HIV prevention and care programs.*

Recommendations for reducing barriers related to the administration of HIV prevention and care programs at a State level focused on increased knowledge and collaboration between agencies. Highlighted in these recommendations were issues related to the structure of health departments, the management of prevention and care programs, and increasing the knowledge and collaboration of State HIV program staff across agencies. In addition, it was recognized that State agencies played an important role in working with Federal agencies in order to develop and implement an integrated system (financing, data and surveillance, applications, etc) for funding and administering HIV prevention and care programs. Recommendations include:

- Foster efforts to centralized the administration of HIV prevention, care, and surveillance, and build direct linkages between the three programs in the field;
- Promote the collaboration (including referrals) and cross training across relevant State agencies that deal with HIV/AIDS, STDs, tuberculosis, viral hepatitis, substance abuse, mental health, prisoners, and Medicaid.
- Establish referral relations with other State human services agencies, especially, prisons, housing, and job training programs;
- Develop, distribute, and update a directory of all HIV care and supportive services in area for all public and private health care providers; and
- Provide direct technical assistance and capacity development to community based organizations in areas of administration and linkages.

3. *States should enhance planning activities aimed at linking CTRS with care and prevention services.*

With the range of Federal and State funds supporting State prevention and care services, participants encouraged States to enhance the planning process in order to establish or strengthen the linkage between services. Recommendations include:

- Require annual HIV linkage in-service training for every State agency that receives HIV-related funding;
- Combine State HIV prevention and care planning groups;
- Convene periodically providers (public and private) to examine linking HIV testing and counseling to care;
- Increase collaborations across agencies – including data sharing – for purposes of targeting services to trends in the epidemic.
- Assure that Statewide needs document is a living document.

4. *States should establish one or more networks of providers that create a continuum of health and social services, and facilitate the formation of linkages at local levels.*

Participants described the network of providers as key to implementing an effective strategy to link persons from HIV counseling and testing to care. The network should

encompass a broad range of prevention and care providers, both public and private, and should be supported by formal agreements (e.g., contractual arrangements) between agencies where possible. The network should encourage providers to focus on program areas in which they can excel and develop capacity (within local agencies) to address areas of unmet needs. The use of a “collaboration manager” may enhance the management and overall effectiveness of the linkages between a wide range of agencies. Other recommendations include:

- Examine and understand the regional public and private health care system in order to determine the most effective ways of establishing network relations (especially services used by HIV infected persons);
- Establish a formal, documented infrastructure within the regional area to provide comprehensive prevention and care services, and publicize the network to all providers;
- Include (and work with) private sector providers, due to the significant proportion of HIV
- Include substance abuse and mental health providers (providing a broad continuum of sa/mh services), correctional facilities (jails and prisons), and other human services programs;
- Provide for opportunities of cross-training of providers across agencies; and
- Examine the possibilities of co-location of services, conducting joint planning of service delivery, and the establishment of “collaboration managers”.

5. *States need to improve the quality of data and program evaluation, and establish standards of care that guide provider evaluation activities.*

The lack of appropriate or insufficient data and evaluation information was identified as a potential barrier to developing and implementing effective linkages between HIV counseling and testing to care services. Understanding unmet needs and targeting gaps in services requires up-to-date information on communities and the effectiveness of existing programs. The lack of up-to-date information may result in ineffective planning and little or no quality improvement. In addition, public and private providers should be provided statewide standards on integrating HIV counseling and testing into the practice environment (e.g., CDC’s HIV Counseling and Testing and Referral Guidelines). Recommendations include:

- Annual up-to-date needs assessments
- Standardize performance measures and evaluation procedures for agencies;
- Establish across-site CQI systems;
- Develop Statewide standards for HIV counseling, testing and referrals;
- Increase collaborations across agencies (within State and network) – including data sharing – for purposes of targeting services to trends in the epidemic;
- Create, publicize, and continuously update a resource manual of prevention and care; and
- Encourage medical schools to incorporate HIV/AIDS curriculum.

Community Based Service Provider Recommendations

During the two-day workshop numerous agencies presented models of linking HIV-infected or at risk persons to care and prevention services. A wide range of service types (e.g., prevention CBO, ambulatory HIV primary care clinic, substance abuse CBO, HIV women's clinic, and others) were presented and each offered new and innovative approaches to reducing the challenges in moving people from testing to care. While all of these service programs mentioned funding and administration issues as barriers, they were more likely to highlight issues such as staff/professional needs and agency mission and role in the larger service community. Similarly, the work group discussion preceding the presentations focused on the role of the agency, staffing issues, and administrative/funding challenges. Many of the work group recommendations may apply to State/local agencies

1. *Each agency should define its unique role and mission in the community, based on the needs of the community, so as to complement and improve existing services and enhance the formation of networks with other providers.*

Given the diversity of agencies in the work shop (academic, community-based, prevention, care, others), one of the most important issues discussed was an agency's ability to concentrate on building capacity in areas of strength, and to partner with other agencies to provide services beyond the provider's scope. In accomplishing this task, it was recommended that agencies examine their mission through an agency-wide needs assessment, with a focus on areas of expertise that meet the identified needs of the community, and seek funds that align with the stated mission. Further, any expansions of service must include a commitment to appropriate service delivery and to a clear work plan. Other recommendations include:

- Maintain accountability for services by conducting meaningful evaluations of process and outcomes;
- Put into place administrative systems to operationalize programming;
- Learn to operationalize and implement multiple categorical funding streams and pursue funding sources aligned with mission; and
- Set priorities to make the best use of limited resources.

2. *Agencies need to devote resources to establishing relationships with other providers.*

Participants recommended that providers become a part of a formal, documented infrastructure within a regional area, offering a comprehensive set of prevention and care services. In doing so, agencies will need to establish formal, relationship-based linkages (e.g., contractual referral linkages) to ensure meaningful relations and appropriate referrals. These relationships should fill the gaps as identified in a communities needs assessment; including, care, prevention, substance abuse, mental health, incarcerated service agencies, and others. Where possible, agencies should integrate prevention, care, and counseling and testing into one program. Also consider integration and referral linkages by co-locating services and conducting joint planning of service delivery. Other recommendations include:

- Support large and small CBOs in meeting the all needs of the community while supporting referrals and linkages;
- Learn to integrate referral mechanisms into agency operations (and across agencies);
- Refer clients when appropriate; and
- Support referral and linkages by setting up a “collaboration manager”.

3. *Agencies need to examine and build staff and clinic skills in linking persons to needed services, especially from CTRS to prevention and/or care services.*

Participants identified “staff” as a key factor in successfully linking persons from HIV counseling and testing to care and for sustaining, supporting, and educating clients in the health care system. Given the importance of this interaction, work shop participants recommended that staff training and the use of non-physicians become a standard in HIV counseling and testing and referral programs, and in the delivery of prevention and care services. Recommendations include:

- Enhance provider comfort, training, and strategies for addressing sexual and social client issues;
- Enhance or expand staff cultural and language competencies;
- Make more and better use of professionals and non-professional staff other than physicians to provide care and referrals/linkages to care services (e.g., peer counselors/educators and peer outreach workers) and compensate them adequately;
- Provide cross-training opportunities for staff;
- Provide better training and teaching materials to staff related to prevention, cultural competency, harm reduction; and
- Accommodate clients’ needs by offering flexible locations and operating hours, family-centered care, childcare, transportation, and other social services.

4. *Individually and collectively within networks, agencies need to enhance client tracking procedures to ensure that individuals are linked to relevant prevention and care services.*

Workshop participants recommended the development of cross agency assessment and monitoring tools based on a modification of the existing data systems. Specifically, participants recommended the development of systems to document and track linkages to care and prevention from HIV testing sites for HIV-positive and negative individuals, and the use of common/shared intake forms and release of information forms.

Evaluation Recommendations (As with the above recommendations, please see **Appendix F** for detailed notes from the evaluation breakout session.)

All participants agreed that evaluation activities should be comprehensive across federal, state, and local/provider levels, with each level playing unique and complementary roles.

1. *To the extent possible, evaluators should use existing data sources and avoid creation of a separate evaluation system exclusively for links and referrals.*

No one needs to create another national- or state-level evaluation system exclusively for links and referrals. The system already has data sources, but lacks capacity and knowledge of how to use them well. Service providers and funders need to think creatively and apply models that have worked elsewhere.

2. *Evaluation activities should focus on client outcomes, and not just provider outputs.*

The clients are the ones for whom we are undertaking all these activities. Ultimately our goal is to provide services that improve the quality of life of people who are living with or at high risk for HIV infection. Provider outputs of referrals made and links completed are not meaningful in and of themselves. The underlying needs that are supposed to be met by facilitating linkages and referrals are what matters. Evaluation questions that should be pursued include: What is the effect of different interventions on entering and remaining in care? Where are the gaps in service and how can referrals and links work to close those gaps? How effective are we at moving people from knowledge of their HIV status (or lack thereof) into primary medical care or other services? Who is coming late into care, and why? How do we help those not in care reduce their risk, increase their access to care, and improve their quality of life?

3. *Federal agencies need to provide leadership with regard to indicators and fund research into evaluation methods and projects that demonstrate results of links and referrals.*

HRSA and CDC need to develop common definitions of terms relating to referrals and linkages, and review how these terms are being used by grantees to ensure common understandings and uses. Federal agencies can establish key indicators for measuring effectiveness of links and referrals, using data already being collected. This would include teaching, training, and disseminating models for using existing data sources for assessment, evaluation, and continuous quality improvement. Finally, CDC must integrate databases for

surveillance, prevention, and care, and overcome the bureaucratic boundaries that now separate these so that the federal leadership can occur.

4. *States can play a leadership role in across-site continuous quality improvement and correlating data on counseling/testing, care, surveillance, and service utilization.*

States should establish (if lacking) links among surveillance, prevention, and care services and correlate databases related to these. Such linking should take into account the constraints imposed by insurance, and consider the use of unique identifiers to protect confidentiality and affordable access to insurance. Secondly, states must fund and provide technical assistance on evaluation for agencies that are integrating and creating links between services.

5. *Providers should adopt a continuous quality improvement approach to evaluation and adapt or create linkage and referral models that can be monitored in their service areas.*

Providers need to collect client satisfaction data to help define need and acceptability of services. Providers can also establish qualitative interview teams consisting of administrators, direct providers, and clients, and seek funding to fully support extra data collection efforts, staffing, information systems capacity, and hardware. Finally, providers can establish partnerships with each other and with local funding agencies for data analysis and quarterly feedback, in order to do more with available dollars.

Summary of Discussion and Recommendations

As presented above, the collective knowledge and experience of workshop participants (as well as the information presented by panelists) served to address the difficulties and challenges as framed by the speakers during the opening remarks to the meeting. Specifically, how do we develop appropriate linkages between HIV CTR services and HIV care and prevention providers with particular attention paid to fostering the effective engagement of individuals (and communities) who are knowledgeable of their status but not in care. With this challenge in mind, participant set out to propose a framework for linking/integrating services necessary for addressing the needs of persons not in care, the identification of barriers to the effective development and implementation of planning, financing, and program activities, and a comprehensive set of recommendations (Federal, State, and community-based) to reducing the identified barriers.

The final recommendations are a reflection of the collective knowledge of the participants and the insight and strategies as highlighted by the numerous panelists. Recommendations cover a broad range of administrative, policy and legislative territory. They include strategies at a Federal level to integrate entitlement and categorical funding streams, cross train Federal program staff, provide training and technical assistance to grantees, develop new models for assessment and evaluation, and others. State recommendations included some similar financing recommendations but weighed more heavily in establishing a leading role in fostering comprehensive network development, capacity development, strategic planning and allocation of funds, and establishing effective contracting relations. Finally, community providers were recognized for their valorous efforts in working with individuals and communities. These

providers were encouraged to build upon its central mission, work collaborative with other public and private providers to establish comprehensive network services, integrate peer counselors, educators, and outreach workers into the central core of the clinic staff, and establish culturally and linguistically responsive care providers and services.

At the end of the meeting, participants acknowledged the enormous effort needed in developing and implementing an integrated and linked system of services. Nonetheless, participants were confident of a successful outcome given a commitment from Federal, State, and community-based providers for continued and collaborative discussions and actions to address these serious challenges.

Appendix A

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

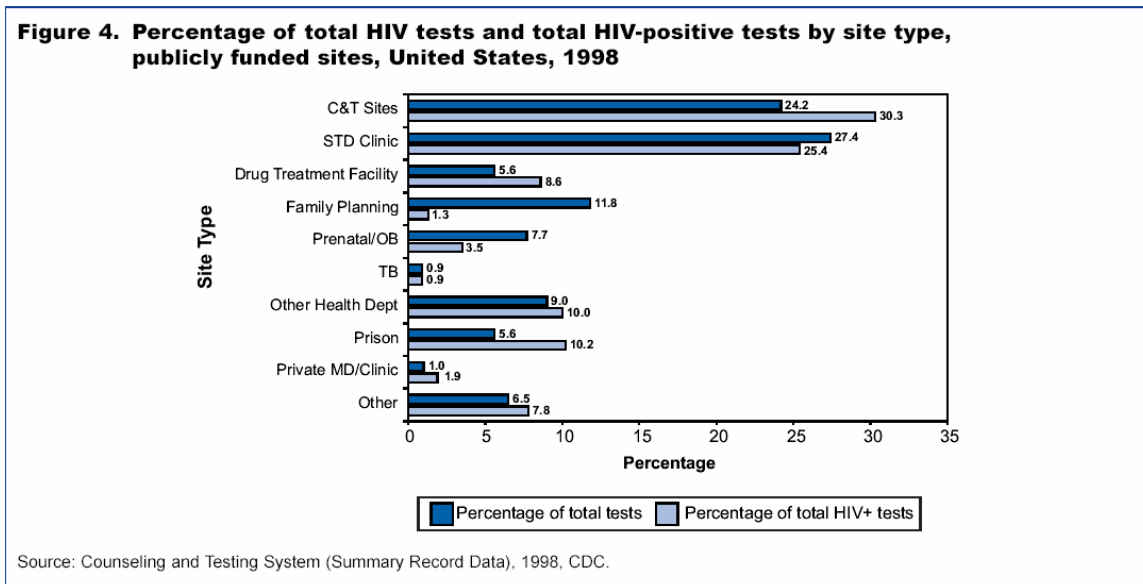
By the mid-1990's, over one-third of adults in the U.S. had been tested for HIV, including through blood donation, the proportion having increased from 16% in 1987 to 40% in 1995. ¹ In the three national surveys of household-based probability samples on which these figures are based, rates of testing 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.²

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).



¹ 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.

² 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.

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

³ California Department of Health Services. *California HIV Counseling and Testing Annual Report: January-December 1998*. Sacramento CA: California Department of Health Services. June 2001.

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.

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

4 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.

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.⁵ 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.⁶ 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.⁷ In one study, long-term non-presenters were uninsured, male, or injecting drug users.⁸

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.⁹ 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:

5 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.

6 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.

7 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; Raveis VH, Siegel K. Factors associated with HIV-infected women's delay in seeking medical care. *AIDS Care* 10(5):549-79. 1998.

8 Samet JH, Freedberg AK. Understanding delay to medical care for HIV infection: the long-term non-presenter. *AIDS* 15(1):77-85.

9 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.

- 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.¹⁰ 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)

¹⁰ ORC Macro. Referrals and Linkages in HIV Counseling, Testing, and Referral and Partner Counseling and Referral Services: Annotated Literature Review. Unpublished document. April 2001.

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

¹¹ 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.

¹² Truax, Steve. Analysis of Referrals from HIV Counseling and Testing Programs. California Department of Health Services Office of AIDS. September 2001.

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.¹³ 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 programs¹⁴ 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

¹³ NASTAD. Targeted Testing and Referral Efforts for Minority Communities: A Report from the NASTAD STATUS Project. Washington DC: NASTAD. April 2001.

¹⁴ NASTAD. *Monograph: Linking HIV/AIDS Services with Substance Abuse and Mental Health Programs*. Washington DC: NASTAD. January 2000.

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).”

¹⁵ HRSA/HAB and HUD/HOPWA. *Lessons Learned: Innovations in the Delivery of HIV/AIDS Services*. March 2001. Accessed at www.hab.hrsa.gov.

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.

HIV COUNSELING, TESTING, REFERRAL, AND PARTNER NOTIFICATION BIBLIOGRAPHY

INTRODUCTION

Centers for Disease Control and Prevention. (1998). HIV counseling and testing in publicly funded sites: 1996 annual report. Atlanta: U.S. Department of Health and Human Services.

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.

Centers for Disease Control and Prevention. (1999). Guidelines for national human immunodeficiency virus case surveillance, including monitoring for human immunodeficiency virus infection and acquired immunodeficiency syndrome. Atlanta: U.S. Department of Health and Human Services.

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

Berger, S. G., Hong, B. A., Eldridge, S., Connor, D., & Vedder, K. N. (1999). Return rates and partner notification in HIV-positive men seeking anonymous versus confidential antibody testing. AIDS Patient Care, 13(6), 363-368.

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.

Bindman A. B., Osmond D., Hecht F. M., Lehman J. S., Vranizan K., Keane D., Reingold A., & the Multistate Evaluation of Surveillance of HIV (MESH) Study Group. (1998). Multistate evaluation of anonymous testing and access to medical care. Journal of the American Medical Association, 280(16), 1416-1420.

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.

Kamb, M. L., Dillon, B. A., Fishbein, M., Willis, K. L., & Project RESPECT Study Group (1996). Quality Assurance of HIV prevention counseling in a multi-center randomized controlled trial. Public Health Reports, 111(Supplement 1), 99-107.

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.

Kamb, M. L., Fishbein, M., Douglas, J. M., Jr., Rhodes, F., Rogers, J., Bolan, G., Zenilman, J., Hoxworth, T., Malotte, K., Iatesta, M., Kent, C., Graziano, S., Byers, R. H., & Peterman, T. A. (1998). Efficacy of risk-reduction counseling to prevent human immunodeficiency virus and sexually transmitted diseases: A randomized controlled trial. Journal of the American Medical Association, 280(13), 1161-1167.

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 fourth 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.

Molitor, F., Bell, R.A., Truax, S.R., Ruiz, J.D., & Sun, R.K. (1999). Predictors of failure to return for HIV test result and counseling by test site type. AIDS Education and Prevention, 11(1), 1-13.

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.

Nakashima, A. K., Horsley, R., Frey, R. L., Sweeney, P. A., Weber, J. T., & Fleming, P. L. (1998). Effects of HIV reporting by name on use of HIV testing in publicly funded counseling and testing programs. Journal of the American Medical Association, 280(16), 1421-1426.

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.

Sikkema, K. J., & Bissett, R. T. (1997). Concepts, goals and techniques of counseling: Review and implications for HIV counseling and testing. AIDS Education and Prevention, 9(Supplement B), 14-26.

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.

Tao, G., Branson, B. M., Kassler, W. J., & Cohen, R. A. (1999). Rates of receiving HIV test results: data from the US National Health Interview Survey for 1994 and 1995. Journal of Acquired Immune Deficiency Syndromes, 22(4), 395-400.

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.

Weber, J. T., Frey, R. L., Jr., Horsley, R., & Gwinn, M. L. (1997). Publicly funded HIV counseling and testing in the United States, 1992-1995. AIDS Education and Prevention, 9(Supplement B), 79-91.

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.

Wolitski, R. J., MacGowan, R. J., Higgins, D. L., & Jorgensen, C. M. (1997). The effects of HIV counseling and testing on risk related practices and help-seeking behavior. AIDS Education and Prevention, 9(Supplement B), 52-67.

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

Bettencourt, T., Hodgins, A., Huba, G. J., & Pickett, G. (1998). Bay Area Young Positives: A model of a youth-based approach to HIV/AIDS services. Journal of Adolescent Health, 23(2 supplemental), 28-36.

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.

Booth, R. E., Kwiatkowski, C. F., & Weissman, G. (1999). Health-related service utilization and HIV risk behaviors among HIV infected injection drug users and crack smokers. Drug and Alcohol Dependence, 55, 69-78.

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.

Brooner, R., Kidorf, M., King, V., Beilenson, P., Svikis, D., & Vlahov, D. (1998). Drug abuse treatment success among needle exchange participants. Public Health Reports, 113(Supplement 1), 129-138.

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.

Dodds, S., Blaney, N. T., Nuehring, E. M., Blakley, T., Lizzotte, J., Potter, J. E., & O'Sullivan, M.J. (2000). Integrating mental health services into primary care for HIV-infected pregnant and non-pregnant women: Whole Life - A theoretically derived model for clinical care and outcomes assessment. General Hospital Psychiatry, 22, 251-260.

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.

Friedmann, P. D., D'Aunno, T. A., Jin, L., & Alexander, J. A. (2000). Medical and psychosocial services in drug abuse treatment: Do stronger linkages promote client utilization? Health Services Research, 35(2), 443-465.

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.

Greenberg, J. B., MacGowen, R., Neumann, M. Long, A., Cheney, R., Fernando, D., Sterk, C., & Wiebel, W. (1998). Linking injection drug users to medical services: Role of street outreach referrals. Health and Social Work, 23(4), 298-309.

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 those 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.

Huba, G. J., & Melchior, L. A. (1998). A model for adolescent-targeted HIV/AIDS services: Conclusions from 10 adolescent-targeted projects funded by the Special Projects of National Significance Program of Health Resources and Services Administration. Journal of Adolescent Health, 23(2S), 11-27.

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.

Kilmarx, P. H., Hamers, F. F., & Peterman, T. A. (1998). Living with HIV: Experiences and perspectives of HIV-infected sexually transmitted disease clinic patients after posttest counseling. Sexually Transmitted Diseases, 25(1), 28-37.

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 who 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.

Koenig, L. J., & Moore, J. (2000). Women, violence, and HIV: A critical evaluation with implications for HIV services. Maternal and Child Health Journal, 4(2), 103-109.

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.

Lin, Y. G., Melchiono, M. W., Huba, G. J., & Woods, E. R. (1998). Evaluation of a linked service model of care for HIV-positive, homeless and at-risk youths. AIDS Patient Care and STDs, 12(10), 787-796.

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.

Marx, R., Hirozawa, A. M., Chu, P. L., Bolan, G. A., & Katz, M. H. (1999). Linking clients from HIV antibody counseling and testing to prevention services. Journal of Community Health, 24(3), 201-214.

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.

Russell, J. M., & Smith, K. (1998). HIV infected women and women's services. Health Care for Women International, 19, 131-139.

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 day 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.

Silvestre, A. J., Gehl, M.B., Encandela, J., & Schelzel, G. (2000). 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.

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 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.

Solomon, L., Stein, M., Flynn, C., Schuman, P., Schoenbaum, E., Moore, J., Holmberg, S., & Graham, N. M. H. (1998). Health services use by urban women with or at risk for HIV-1 infection: The HIV Epidemiology Research Study (HERS). Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology, 17(3), 253-261.

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 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.

Stein, M. D., Urdaneta, M. E., Clarke, J., Maksad, J., Sobota, M., Hanna, L., & Markson, L.E. (2000). Use of antiretroviral therapies by HIV-infected persons receiving methadone maintenance. Journal of Addictive Diseases, 19(1), 85-94.

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 of 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.

Sullivan, G., Koegel, P., Kanouse, D. E., Cournos, F., McKinnon, K., Young, A. S., & Bean, D. (1999). HIV and people with serious mental illness: The public sector's role in reducing HIV risk and improving care. Psychiatric Services, 50(5), 648-652.

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.

Weissman, G., Melchior, L., Huba, G., Smereck, G., Needle, R., McCarthy, S., Jones, A., Genser, S., Cottler, L., Booth, R., & Altice, F. (1995). Women living with drug abuse and HIV disease: Drug abuse treatment access and secondary prevention issues. Journal of Psychoactive Drugs, 27(4), 401-411.

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.

Woods, E. R., Samples, C. L., Melchiono, M. W., Keenan, P., Fox, D. J., Chase, L. H., Tierney, S., Price, V. A., Paradise, J. E., O'Brien, R. F., Mansfield, C. J., Brooke, R. A., Allen, D. A., & Goodman, E. (1998). Boston HAPPENS Program: A model of health care for HIV-positive, homeless, and at-risk youth. Journal of Adolescent Health, 23(2 Supplemental), 37-48.

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 HIV 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

Campbell, C. H., Jr., Marum, M. E., Alwano-Edyegu, M., Dillon, B. A., Moore, M., & Gumisiriza, E. (1997). The role of HIV counseling and testing in the developing world. AIDS Education and Prevention, 9(Supplement B), 92-104.

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.

Dye, T. D., Knox, K. L., & Novick, L. F. (1999). Tracking sexual contacts of HIV patients: A study of physician practices. Journal of Public Health Management Practice, 5(5), 19-22.

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.

Fenton, K. A., & Peterman, T. A. (1997). HIV partner notification: Taking a new look. AIDS, 11(13), 1535-1546.

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.

Hoffman, R. E., Spencer, N. E., & Miller, L. A. (1995). Comparison of partner notification at anonymous and confidential test sites in Colorado. Journal of Acquired Immune Deficiency Syndromes and Human Virology, 8(4), 406-410.

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.

Holtgrave, D. R., Valdiserri, R. O., Gerber, A. R., & Hinman, A. R. (1993). Human immunodeficiency virus counseling, testing, referral, and partner notification services: A cost-benefit analysis. Archives of Internal Medicine, 153, 1225-1230.

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.

Holtgrave, D. R., Reiser, W. J., & Di Francisco, W. (1997). The evaluation of HIV counseling-and-testing services: Making the most of limited resources. AIDS Education and Prevention, 9 (Supplement B), 105-118.

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.

Landis, S. E., Schoenbach, V. J., Weber, D. J., Mittal, M., Krishan, B., Lewis, K., & Koch, G. G. (1992). Results of a randomized trial of partner notification in cases of HIV infection in North Carolina. The New England Journal of Medicine, 326(2), 101-106.

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.

Macke, B. A., & Maher, J. E. (1999). Partner notification in the United States: An evidence-based review. American Journal of Preventive Medicine, 17(3), 230-242.

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.

Macke, B. A., Hennessey, M. H., & McFarlane, M. (2000). Predictors of time spent on partner notification in four US cities. Sexually Transmitted Infections, 76, 371-374.

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 consideration of other factors was suggested to gain a better understanding of the resources required for efficient, yet effective partner notification.

Misir, P. (1999). Partner notification as a prevention strategy: A social system perspective. AIDS Patient Care and STDs, 13(6), 327-334.

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.

National Alliance of State and Territorial AIDS Directors. (2000). State HIV prevention evaluation systems. NASTAD Issue Brief, November, 1-15.

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.

Rothenberg, K. H., Paskey, S. J., Reuland, M. M., Zimmerman, S. I., & North, R. L. (1995). Domestic violence and partner notification: Implications for treatment and counseling of women with HIV. Journal of American Medical Women's Association, 50(3 & 4), 87-93.

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.

West, G. R. & Stark, K. A. (1997). Partner notification for HIV prevention: A critical reexamination. AIDS Education and Prevention, 9(Supplement B), 68-78.

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

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

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 holistic 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)

Federal Level	State/Local Level	Provider/Agency Level
<ul style="list-style-type: none"> • Create standardized performance and evaluation procedures • Increase funding, but avoid defunding some programs in order to fund others • Provide resources to address needs identified by providers commensurate with the epidemic trends • Emphasize realistic outcome measures as opposed to process measures • Clarify terminology and define “buzz words” such as “highly recommended” • Work toward universal health care and funding of permanent, stable housing • Encourage jurisdictions to address identified needs and base budget on those needs • HRSA and CDC should provide the Secretary with a “State of the State” assessment of needs • Improve reporting of demographic data on infected persons by age, ethnicity, and gender (including transgender) • Encourage more cooperative grants among agencies • Reimburse for prevention activities at a level equal to that for “procedures” • Develop HRSA guidance to ensure that medical providers and providing and referring patients for prevention services • Integrate at the federal level to foster integration at lower levels through a top-down effect. “Integrate by example.” • Institute cross-training at the federal level, 	<ul style="list-style-type: none"> • Convene period meetings of all providers to look at integrating prevention and care services • Ensure that statewide needs document is a living document • Increase state-originated funding and resources for HIV/AIDS services • Take a leadership role in harm reduction, prison issues, and so forth • Provide directory of all HIV and supportive services for all HIV providers (private and public) • 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 • Develop process by which private sector providers adhere to HIV standards of care for referrals and linkages • Ensure that funding levels reflect the value of peer educators as staff • Support training for development of standards of care • Encourage access to prisoners and inmates • Encourage providers to focus on areas in which they excel or demonstrate expertise • Require providers to continue education across the entire organization • Reimburse providers for referral and linkages • Fund and provide technical assistance for 	<ul style="list-style-type: none"> • Enhance provider comfort, training, and strategies for addressing sexual/social client issues • Make more and better use of professionals other than physicians to provide client-centered care • Increase cultural competency and eliminate language barriers • Bridge the gulf between medical care and support services • Develop referral tracking systems • Ensure continuity among medical and social service providers • Set priorities to make best use of limited resources • Learn to integrate linkage and referral mechanisms and operationalize them • Implement and operationalize categorical funding streams • Be willing to refer clients when necessary • Become part of a formal, documented infrastructure within regional area, offering comprehensive services • Support large and small CBOs in meeting all needs of the community while supporting referrals and linkages • Put in place administrative systems to operationalize programming • Be accountable for the services provided by evaluating processes and outcomes of activities • Involve the community in meaningful ways in the design, implementation, and

Federal Level	State/Local Level	Provider/Agency Level
<p>including project officers</p> <ul style="list-style-type: none"> • Make innovative grants similar to SPNS but ongoing in nature • Dedicate resources for data collection and analysis, including development of templates and blended databases • Develop policies to address issues around the stigma of HIV infection • Seek accountability for SAMHSA block grant funds • Integrate Ryan White CARE Act Title II administration/management. Reroute from field to care of HIV • Institute multiyear funding cycles • Issue mandate for Food and Drug Administration approval of rapid HIV screening tests • Determine Medicaid barriers to linking HIV-positive individuals to care • Align prevention and care funding cycles • 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 • Allow more flexibility in use of funding streams at local level across discretionary and entitlement programs • Better integrate behavioral health (e.g., SAMHSA) with HIV prevention and client services • Design model for integrating and streamlining the federal administrative process (surveillance, application process, 	<p>implementing integration and linkages</p> <ul style="list-style-type: none"> • Fund evaluation for technical assistance and outcomes • Foster coordinated technical assistance and capacity-building for organizations in the areas of administration and linkages • Standardize performance and evaluation procedures • Have common administration of HIV prevention, care, and surveillance at the state level • Increase collaboration—including data sharing—across relevant state agencies: HIV/AIDS, STD, TB, viral hepatitis, Medicaid, SA, mental health • Encourage interstate discussion across Medicaid programs regarding portability of benefits and eligibility • Require annual HIV linkage in-service for every state agency that receives state funding • Encourage medical schools to incorporate HIV/AIDS curricula • Encourage public health departments to work with private sector providers to make them aware of public HIV services • Enhance SA and mental health program resources by increasing number of treatment slots • Build collaborations between HIV prevention and care programs and correctional facilities, job training programs, and human services • Create, publicize, and continuously update 	<p>evaluation of program development</p> <ul style="list-style-type: none"> • Reexamine organizational missions with a focus on areas of expertise • Establish linkages with other agencies that can fill gaps identified during needs assessment • Integrate prevention, care, and counseling/testing services into one program where relevant and possible • Create meaningful, relationship-based, contractual referral linkages • Seek funds that align with the stated mission; “avoid chasing dollars for dollars’ sake” • Ensure that with expansion comes commitment to appropriate service delivery in that area • Remain committed to work plan • Include quality improvement in program development • Develop capacity to meet identified needs • Involve peer health educators to the maximum extent possible by hiring more of them and providing initial training continuing education programs • Stimulate integration and referral linkages by co-locating services, conducting joint planning of service delivery, setting up collaboration management • Establish more formal linkages across care, prevention, SA, mental health, incarcerated service agencies, and so forth • Increase cross-training opportunities, off-

Federal Level	State/Local Level	Provider/Agency Level
<p>funding, data) across all relevant agencies</p> <ul style="list-style-type: none"> • Increase data sharing across agencies • Encourage jurisdictions to identify needs and base the budget on those needs with an eye toward creating a needs-based budget. • Institute collaborative and innovative funding across agencies, including HRSA, CDC, Housing and Urban Development, SAMSHA, and the Veterans Administration 	<p>a resource manual of prevention and care services available statewide</p> <ul style="list-style-type: none"> • Link state prevention and planning groups • Develop statewide standards for HIV testing and counseling, treatment, and financing • Establish across-site continuous quality improvement system • Build linkages among surveillance functions, prevention services, and care providers • Take a leadership role in issues that the federal government cannot (e.g., harm reduction, prison issues) 	<p>siting of staff, and so forth</p> <ul style="list-style-type: none"> • Simplify sharing of client data across agencies through use of common/shared intake forms and release of information forms • 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 • Integrate prevention messages more fully in ongoing medical care services • Increase communication and collaboration among HIV care/prevention providers, regardless of funding source, with care and prevention planning groups • Accommodate client needs by offering flexible locations and operating hours, family-centered care, child care, transportation, and so forth. • Add flex-time options for staff at agencies offering flexible hours for clients • Provide better training and teaching materials related to prevention, cultural competency, harm reduction, and available services • Seek capacity-building training on key elements of successful collaborations • Better integrate prevention messages into ongoing medical care services.

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

Meeting Planning Committee

Chris Aldrige
 NASTAD
 444 North Capitol St. NW Suite 339
 Washington DC 2001
 E-mail: caldridge@nastad.org
 Work: 202-434-8090
 Fax: 202-434-8092

June Bray, Ph.D
 Forum For Collaborative HIV Research
 2021 K St NW, 800
 Washington, DC 20006
 E-mail: ihojdb@gwumc.edu
 Work: 202-530-2315
 Fax: 202-530-2336

Charles Collins, PH.D
 CDC
 1600 Clifton Road, Mailstop E40
 Atlanta, GA 30333
 E-mail: cwc4@cdc.gov
 Work: 404-639-0966
 Fax: 404-639-0944

Elaine Daniels, M.D., Ph.D.
 DuPont Pharmaceuticals
 974 Centre Rd HR 2003
 Wilmington, DE 19805
 E-mail: elaine.m.daniels@dupontpharma.com
 Work: 302-892-9504
 Fax: 302-892-7713

Hilda Douglas
 HRSA-HIV/AIDS Bureau
 5600 Fishers Lane
 Rockville, MD 20857
 E-mail: hdouglas@hrsa.gov
 Work: 301-443-3613
 Fax: 301-443-8143

David Barr
 Center for Health Services Research and Policy
 2021 K St NW, STE 800
 Washington, DC 20006
 E-mail: ihodxb@gwumc.edu
 Work: 202-530-2370
 Fax: 202-530-2336

Rose Brownridge, M.D.
 Texas Department of Health
 1100 West 49th Street
 Austin Texas 78756
 E-mail: kathie.walden@tdh.state.tx.us (secretary)
 Work: 512-490-2505
 Fax: 512-490-2544

Roxanne Cox-Iyamu, MD
 Whitman-Walker Clinic
 1407 S Street, NW
 Washington, DC 20009
 E-mail: r.cox-iyamu@wwc.org
 Work: 202-745-6148
 Fax: 202-745-0238

Sam Dooley, MD, MPH
 Center for Disease Control and Prevention
 1600 Clifton Rd NE Mailstop D-21
 Atlanta, GA 30333
 E-mail: swd1@cdc.gov
 Work: 404-639-5229
 Fax: 404-639-0910

Arnie Doyle
 NASTAD
 444 North Capitol St, NW Suite 339
 Washington, DC 20001
 E-mail: adoyle@nastad.org
 Work: 202-434-8090
 Fax: 202-434-8092

Henry Francis, M.D.
National Institute on Drug Abuse, NIH
6001 Executive Blvd. Room 5190 MSC 9593
Bethesda, MD 20892-9593
E-mail: Hfrancis@niada.nih.gov
Work: 301-443-1801
Fax: 301-594-6566

Thurma Goldman, M.D., M.P.H.
HIV/AIDS Bureau-HRSA
5600 Fishers Ln, Rm 7A-30
Rockville, MD 20857
E-mail: tgoldman@hrsa.gov
Work: 3014430493 / Fax: 3014431839

Nina Grier
5 Moor Dr, F1143
RTP, NC 27709
E-mail: nrg28286@gsk.com
Work: 9194833749
Fax: 9193153421

Miguelina Leon
National Minority AIDS Council
1931 13th ST, NW
Washington, DC 20009
E-mail: mleon@nmac.org
Work: 202-483-6622 ext 324
Fax: 202-483-1135

Gloria Maki
New York State Dept of Health-IADS Institute
Corning Tower, ESP, Rm 412, AIDS Institute
Albany, NY 122370658
E-mail: gjc01@health.state.ny.us
Work: 5184746399
Fax: 5184861315

Jerry Flanzer, M.D.
National Institute On Drug Abuse, NIH
6001 Executive Blvd
Bethesda, MD 20892
E-mail: jflanzer@nida.nih.gov
Work:
Fax:

Chris Gordon, Ph.D
NIMH
6100 Executive Blvd, Rm 6199
Bethesda, MD 20892
E-mail: cgordon1@mail.nih.gov
Work: 301-443-1613
Fax: 301-443-9719

Scott Kellerman, MD
CDC/ Division of HIV/AIDS
1600 Clifoton Rd, Mail Stop E-47
Atlanta, GA 30333
E-mail: sec0@cdc.gov
Work: 404-639-4593
Fax: 419-844-9383

Jeff Levi, Ph.D
Center for Health Services Research and Policy
2021 K St NW, STE 800
Washington, DC 20006
E-mail: ihojxl@gwumc.edu
Work: 202-530-2363
Fax: 202-296-0025

Walton Senterfitt, PhD
CDC/DHAP
1600 Clifotn Rd, NE MSD-21
Atlanta, GA 30319
E-mail: wds6@cdc.gov
Work: 4046394165
Fax: 4046390910

Matthew Tye
Gay Men's Health Crisis
119 West 24th Street
New York, NY 10011
E-mail: Matthewt@gmhc.org
Work: 212-367-1056
Fax: 212-367-1370

Steve Wakefield
HIV Vaccine Trials Network
Fred Hutchinson Cancer Research Center
1100 Olive Way, MW 832
Seattle, WA 98101
E-mail: wakefield@hvtn.org
Work: 206-667-6705 / Fax: 206-667-6366

Diana Williamson, MD, MSc
African American AIDS Policy & Training
Institute
246 West end Ave, #1G
New York, NY 10023
E-mail: dlwmdmsc@aol.com
Work: 2128778128 / Fax: 212-877-1624

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.

**b. Centers for Disease Control and Prevention,
“Evaluation Plan for the Referrals and Linkages in HIV Counseling and Testing, and
Referral and Partner Counseling and Referral Service Project”**

For additional information, please contact:

Marlene Glassman, PhD,
Program Evaluation
Research Branch, Division of HIV/AIDS Prevention,
CDC and Prevention
Atlanta, GA
404-639-1998

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	
		Data Abstraction	Interviews
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.		
	How is a referral defined?	<ul style="list-style-type: none"> - MIS - Policies - Procedures - Guidelines - Protocols 	<ul style="list-style-type: none"> - CT counselors - CT admin - other CT staff - - clients
	What types of referrals are made for: <ul style="list-style-type: none"> - HIV-positive clients? - high-risk HIV-negative clients? - partners identified through PCRS? 	<ul style="list-style-type: none"> - MIS - Policies - Procedures - Guidelines - Protocols 	<ul style="list-style-type: none"> - 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?	<ul style="list-style-type: none"> - MIS - Policies - Procedures - Guidelines - Protocols 	<ul style="list-style-type: none"> - CT counselors - CT admin - other CT staff - provider staff - clients
	How are referral needs determined (e.g., medical, prevention, other supportive services)?	<ul style="list-style-type: none"> - MIS - Policies - Procedures - Guidelines - Protocols 	<ul style="list-style-type: none"> - CT counselors - CT admin - other CT staff - - clients
	What issues are considered in determining a client's referral needs?	<ul style="list-style-type: none"> - MIS - Policies - Procedures - Guidelines - Protocols 	<ul style="list-style-type: none"> - CT counselors - CT admin - other CT staff - - clients
	How is follow-up for referrals managed by the facility providing CTR?	<ul style="list-style-type: none"> - MIS - Policies - Procedures - Guidelines - Protocols 	<ul style="list-style-type: none"> - 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.		
	What steps are taken to ensure that confidentiality of client information is maintained?	<ul style="list-style-type: none"> - MIS - Policies - Procedures - Guidelines - Protocols 	<ul style="list-style-type: none"> - CT counselors - CT admin - other CT staff - - clients
	What steps are taken to determine the client's willingness and ability to accept and complete a referral (e.g., staff training, protocols, guidelines)?	<ul style="list-style-type: none"> - MIS - Policies - Procedures - Guidelines - Protocols 	<ul style="list-style-type: none"> - CT counselors - CT admin - other CT staff - - clients
	What procedures are employed when a client's referral needs are especially complex?	<ul style="list-style-type: none"> - MIS - Policies - Procedures - Guidelines - Protocols 	<ul style="list-style-type: none"> - CT counselors - CT admin - other CT staff - - clients
	How are referrals tailored to individual clients' characteristics (e.g., HIV serostatus, culture, language, gender, age, level of risk, etc.)?	<ul style="list-style-type: none"> - MIS - Policies - Procedures - Guidelines - Protocols 	<ul style="list-style-type: none"> - CT counselors - CT admin - other CT staff - - clients
	What is the quantity and quality of the social interaction between counselors and clients, and how does this impact the referral process?	<ul style="list-style-type: none"> - MIS - Policies - Procedures - Guidelines - Protocols 	<ul style="list-style-type: none"> - CT counselors - CT admin - other CT staff - - clients
	What education and support do staff receive to ensure appropriate implementation and management of referrals (e.g., counselor training, TA, QA)?	<ul style="list-style-type: none"> - MIS - Policies - Procedures - Guidelines - Protocols 	<ul style="list-style-type: none"> - CT counselors - CT admin - other CT staff - provider staff - clients
	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)?	<ul style="list-style-type: none"> - MIS - Policies - Procedures - Guidelines - Protocols 	<ul style="list-style-type: none"> - CT counselors - CT admin - other CT staff - provider 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.			
	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?	- MIS - Policies - Procedures - Guidelines - Protocols	- CT counselors - CT admin - other CT staff - provider staff -
	What are barriers and facilitators to developing relationships among CTR facilities and provider agencies within these systems?	- MIS - Policies - Procedures - Guidelines - Protocols	- CT counselors - CT admin - other CT staff - provider staff -
	To what extent is the network of referral service provision integrated and collaborative? Or is service provision fragmented?	- MIS - Policies - Procedures - Guidelines - Protocols	- CT counselors - CT admin - other CT staff - provider staff - clients
	What client populations are served by the referral service provider agencies?	- MIS - Policies - Procedures - Guidelines - Protocols	- CT counselors - CT admin - other CT staff - provider staff - clients
	How do the providers of referral services assess the needs of referred clients?	- MIS - Policies - Procedures - Guidelines - Protocols	- CT counselors - CT admin - other CT staff - provider staff - clients
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 is (are) the site's target population(s)? How does the referral process vary as a function of the client's referral needs?	- MIS - Policies - Procedures - Guidelines - Protocols	- CT counselors - CT admin - other CT staff - provider staff - clients
	How does the referral process vary as a function of an individual client's characteristics (e.g., HIV serostatus, culture, language, gender, age, etc.)?	- MIS - Policies - Procedures - Guidelines - Protocols	- CT counselors - CT admin - other CT staff - provider staff - clients
	What particular site characteristics (e.g., geographical, demographic, structural or procedural) influence the referral and linkage	- MIS - Policies - Procedures	- CT counselors - CT admin - other CT staff

	process?	- Guidelines - Protocols	- provider staff -
	What influence do these characteristics have on the process?	- MIS - Policies - Procedures - Guidelines - Protocols	- CT counselors - CT admin - other CT staff - provider staff -
	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?	- MIS - Policies - Procedures - Guidelines - Protocols	- CT counselors - CT admin - other CT staff - provider staff - clients
	What is the counseling and testing facility's capacity (e.g., resources, adequate staffing and training, etc.) for making appropriate referrals?	- MIS - Policies - Procedures - Guidelines - Protocols	- CT counselors - CT admin - other CT staff - provider staff - clients
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 - Procedures - Guidelines - Protocols	- CT counselors - CT admin - 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 - Procedures - Guidelines - Protocols	- CT counselors - CT admin - other CT staff - provider staff -
	What are barriers and facilitators to developing relationships among CTR facilities and provider agencies within these systems?	- MIS - Policies - Procedures - Guidelines - Protocols	- CT counselors - CT admin - other CT staff - provider staff -
	To what extent is the network of referral service provision integrated and collaborative? Or is service provision fragmented?	- MIS - Policies - Procedures - Guidelines - Protocols	- CT counselors - CT admin - other CT staff - provider staff - clients
III.	Describe and understand the grantees' current tracking and management information systems (MIS) for referrals and follow-ups.		

	Is there any documentation of the referrals made? How?	- MIS - charts - progress notes	- CT counselors - CT admin - other CT staff - provider staff - clients
	Is the status/outcome of referrals documented? How?	- MIS - charts - progress notes	- CT counselors - CT admin - other CT staff - provider staff - clients
	Is client satisfaction with referrals documented? How?	- MIS - charts - progress notes	- CT counselors - CT admin - other CT staff - provider staff - clients
	Is there a formal MIS? What format (electronic, paper)? - at the counseling and testing facility? - at the service provider agencies?	- MIS -charts - progress notes	- CT counselors - CT admin - other CT staff - provider staff -
	How much MIS integration is there (e.g., is information regarding referrals shared between agencies)? If so, how is confidentiality maintained?	- MIS - charts - progress notes	- CT counselors - CT admin - other CT staff - provider staff -
	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)?	- MIS - charts - progress notes	- CT counselors - CT admin - other CT staff - provider staff - client

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?	<ul style="list-style-type: none"> - MIS - charts - progress notes 	<ul style="list-style-type: none"> - 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.