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
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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 those recommendations.

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

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

www.hivforum.org
Preface

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

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

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

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


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

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

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.
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.

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

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

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

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.
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

<table>
<thead>
<tr>
<th>HITS 2000: Site Tested</th>
<th>n=776</th>
<th>n=725</th>
<th>n=636</th>
<th>n=2137</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Health Center</td>
<td>18</td>
<td>14</td>
<td>23</td>
<td>18</td>
</tr>
<tr>
<td>Private MD Office/HMO</td>
<td>31</td>
<td>8</td>
<td>11</td>
<td>16</td>
</tr>
<tr>
<td>STD Clinic</td>
<td>5</td>
<td>3</td>
<td>28</td>
<td>11</td>
</tr>
<tr>
<td>AIDS prevention project</td>
<td>10</td>
<td>18</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Medial clinic in hospital</td>
<td>7</td>
<td>9</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>HIV C/T</td>
<td>12</td>
<td>8</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Correctional Facility</td>
<td>&lt;1</td>
<td>12</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Drug treatment program</td>
<td>&lt;1</td>
<td>13</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Hospital</td>
<td>2</td>
<td>4</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>6</td>
<td>4</td>
<td>10</td>
</tr>
</tbody>
</table>
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.
Table 6. Late diagnosis, 25 states (N = 108,260)

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

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

<table>
<thead>
<tr>
<th>Stage</th>
<th>HIV</th>
<th>HIV→AIDS later</th>
<th>HIV diagnosis at AIDS</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>9389</td>
<td>2672</td>
<td>3772</td>
<td>15833</td>
</tr>
<tr>
<td>% with no CD4+ count</td>
<td>59%</td>
<td>5%</td>
<td>8%</td>
<td>38%</td>
</tr>
<tr>
<td>CD4+ &lt;3 mos</td>
<td>33%</td>
<td>72%</td>
<td>90%</td>
<td>53%</td>
</tr>
<tr>
<td>CD4+ 3–5 mos</td>
<td>4%</td>
<td>15%</td>
<td>1%</td>
<td>5%</td>
</tr>
<tr>
<td>CD4+ &gt; 5 mos</td>
<td>3%</td>
<td>7%</td>
<td>1%</td>
<td>3%</td>
</tr>
</tbody>
</table>

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).
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).
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 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

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.

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


<table>
<thead>
<tr>
<th>Health Promotion</th>
<th>Targeted Health Promotion</th>
<th>Early Diagnosis and Prompt Treatment</th>
<th>Access to Care</th>
<th>Health Maintenance</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Health education/sex education</td>
<td>• Periodic testing if at risk</td>
<td>• Prevent progressive disease process</td>
<td>• Promote treatment</td>
<td>• Reduce opportunistic infections</td>
</tr>
<tr>
<td>• Attention to social and economic issues</td>
<td>• Targeted outreach</td>
<td>• Prevent complications</td>
<td>• Provide quality primary care</td>
<td>• Continuing access to full continuum of care</td>
</tr>
<tr>
<td>• Risk assessment and risk reduction counseling</td>
<td>• Prevent transmission</td>
<td>• Shorten period of disability</td>
<td>• Provide supportive services</td>
<td>• Increase quality of life</td>
</tr>
<tr>
<td>• Avoidance of virus</td>
<td>• Harm Reduction</td>
<td></td>
<td>• Encourage treatment adherence</td>
<td>• Access to treatment advances</td>
</tr>
</tbody>
</table>

----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 tracks, 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.


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.

   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.

   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)

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 no 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. STFN 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.
- Legisl ate 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.
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.
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 complete 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.

<table>
<thead>
<tr>
<th>Medical Referrals By Type</th>
<th>Number of Outcome Appointments Kept</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Referrals</td>
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<tr>
<td>Physician within Drug Treatment</td>
<td>1774</td>
</tr>
<tr>
<td>Community Health Center</td>
<td>154</td>
</tr>
<tr>
<td>Designated AIDS Care Center</td>
<td>108</td>
</tr>
<tr>
<td>Hospital Outpatient Clinic</td>
<td>322</td>
</tr>
<tr>
<td>County Health Department</td>
<td>53</td>
</tr>
<tr>
<td>STD Clinic</td>
<td>4</td>
</tr>
<tr>
<td>TB Clinic</td>
<td>152</td>
</tr>
<tr>
<td>Total Medical Referrals</td>
<td>2567</td>
</tr>
</tbody>
</table>

* 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.
• 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.
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**


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<tr>
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<tbody>
<tr>
<td>HIV risk behaviors</td>
<td>Prevention workers</td>
<td>Program design</td>
<td>Planning mechanisms</td>
<td>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</td>
</tr>
<tr>
<td>Test and result seeking</td>
<td>HIV counselors</td>
<td>Service models</td>
<td>Defining roles and responsibilities</td>
<td></td>
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<tr>
<td>Initial and longitudinal care seeking</td>
<td>Clinicians</td>
<td>Outreach and case finding strategies</td>
<td>Referral mechanisms and relationships</td>
<td></td>
</tr>
<tr>
<td>Adherence to harm reduction practices and treatment</td>
<td>Case managers</td>
<td>Referral relationships</td>
<td>Extent of integration</td>
<td></td>
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<tr>
<td>Referral follow-up</td>
<td>SA and mental health program staff</td>
<td>Accessibility assessments</td>
<td>Role of substance abuse and mental health providers</td>
<td></td>
</tr>
<tr>
<td>Appointment initiation and keeping</td>
<td>Mental health workers and social support providers</td>
<td>Performance measures</td>
<td>Co-location of services</td>
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<tr>
<td></td>
<td></td>
<td>Quality measures</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Consumer satisfaction</td>
<td></td>
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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 form 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.
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”.

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.