

Center for Applied Public Health  
722 West 168<sup>th</sup> Street, Suite 1119  
New York, NY 10032

# Delayed Entry to HIV Care

**Summary: Year 1 Report**

**A Study of Factors Associated with Delayed Care Seeking among HIV-Infected  
Individuals in New York City**

Angela A. Aidala, Ph.D., Principal Investigator

Jo L. Sotheran, Ph.D., Co-Investigator

Elizabeth Needham Waddell, Ph.D., Project Director

September 2003

This research was made possible by a grant from the U.S. Health Resources and Services Administration (HRSA) under Title I of the Ryan White Comprehensive AIDS Resources Emergency Act of 1990, with the support of the HIV Health and Human Services Planning Council, through the NYC Department of Health and Mental Hygiene and the Medical and Health Research Association of New York City, Inc. Its contents are solely the responsibility of the researchers and do not necessarily represent the views of the funders. We particularly acknowledge the NYC Department of Health and Mental Hygiene/Office of AIDS Policy Coordination, for facilitating the passage of this study through the contracting process, and Dr. Jay Cross for invaluable data programming assistance.

## STUDY BACKGROUND

Even in the era of effective antiretroviral medications and increased life expectancy, some persons living with HIV and AIDS (PLWHAs) do not take advantage of evaluation and treatment available at the time of their HIV diagnosis. The Delayed Entry to HIV Care Project aims to isolate factors leading to delayed entry into treatment among these individuals. We examine two stages between HIV infection and entry into HIV primary care: 1) the time between infection and initial positive HIV test result; and 2) the time between awareness of serostatus and presentation to HIV care.

This report documents our activities in Year 1 of this 2-year study<sup>1</sup>. We define “entry to treatment” as presentation for evaluation and initial diagnostic work-up subsequent to HIV infection, regardless of what decisions are made about medication.

## KEY FINDINGS

- New York City DOHMH HIV surveillance data indicate that over 25% of all new HIV diagnoses are persons with a fairly advanced stage of infection indicating considerable delay between infection and diagnosis. This rate is comparable to what CHAIN study participants report with regard to learning about their HIV diagnosis because they were very ill or in the hospital with an HIV-related illness.
- Among those who did not delay getting tested for HIV, CHAIN data indicate that an additional 20% delay entry into medical care for 4 months or more after becoming aware of their infection. Taken all together, approximately half of HIV infected persons in New York City do not enter medical care in a timely fashion, as a result of delayed testing, delayed entry into care after diagnosis, or both.
- Most of the same individual and contextual factors underlie both delayed HIV testing and delayed entry into HIV care.
- Many PLWHAs delay testing and/or delay entry into care because they perceive the costs of HIV care-seeking are greater than likely benefits.
- Perceived costs include concerns about stigma and rejection, and fears of social and legal consequences of revealing risk behavior.

### A “DELAYER” IS DEFINED AS SOMEONE WHO:

Waits more than 3 months after the diagnostic HIV test to present for treatment evaluation

**OR**

Is diagnosed with HIV at the time of presentation for care with:

- Fewer than 200 CD4 cells (indicating an advanced state of disease course, even if no AIDS-defining illness has occurred)

**OR**

- One or more AIDS-defining illnesses (per CDC definition)

---

<sup>1</sup> Delayers is funded as a contract to the Center for Applied Public Health, Mailman School of Public Health, Columbia University (#PE06Y11). It is closely coordinated with the ongoing CHAIN (Community Health Advisory & Information Network) study, which is also carried out by the Center.

- Misunderstandings about HIV disease processes, the accessibility of treatment, and the role of medications for disease management are widespread. Misunderstandings and fear about HIV medications are major barriers to both testing and early treatment for infection.
- Among persons more recently diagnosed (post 1996), fewer are likely to delay entry into care than at earlier stages of the epidemic. However, at the present time, more than 1 in 7 individuals who receive a diagnosis of HIV still delay entry into medical care for many months after diagnosis. Among those who delay, the average time between testing and treatment is 12 to 18 months.
- Contextual factors at the time of diagnosis seem to constrain timely entry into HIV treatment. Persons with a history of heavy drug use, individuals outside of or only marginally connected to general systems of medical care, and those who were homeless or unstably housed were more likely than others to delay entry into medical care.
- Delayed entry into care varies by testing site. Persons tested in correctional settings are more likely than persons tested in hospital or community based medical settings to delay entry into HIV primary care.
- Among persons who delay entry into HIV medical care, the most common reason for eventually seeking medical care is general decline in health or contracting an opportunistic infection. Some persons, however, are motivated to enter the health care system because they need the practical benefits that may accompany an HIV or AIDS diagnosis (e.g. supportive housing).

Our preliminary recommendations include:

1. Disseminate realistic information about HIV treatment -- its potential effects and benefits as well as liabilities – in advance of testing or the need for treatment.
2. Improve the ease, speed, and convenience of HIV testing by expanding testing sites and encouraging wider use of the newer rapid testing technologies.
3. Expand services available at testing sites beyond providing referrals to include actively attempting to facilitate entry of HIV positive persons into appropriate care.
4. Bring HIV testing and health care to stigmatized populations in settings where they are already comfortable.
5. Make it easier for cultural sub-populations, and/or highly stigmatized groups to use existing mainstream services by providing “advocates” or “adherence specialists” who can help clients navigate treatment systems.
6. Expand outreach efforts that target marginalized populations such as substance users and the homeless for whom there is continued need to actively engage persons infected with HIV into HIV testing and systems of care.

## METHODS

Our methods include newly collected qualitative data and analysis of existing CHAIN data. All protocols were reviewed and approved by the Columbia Health Sciences' Institutional Review Board, as part of the larger program of research included in the CHAIN study.

### ***Analysis of CHAIN data***

We make use of existing CHAIN survey data collected from approximately 1000 PLWHAs who were interviewed between 1994 and 2001. In addition, preliminary findings from current interviews (2002-2003) with an additional 400 new CHAIN study participants are included here. The CHAIN study provides longitudinal information on study participants' needs for health and human services, their use of health care and social service organizations, their satisfaction with services, and the impact of these services on physical, mental and social well being. This information is specifically prepared for the NYC HIV Health and Human Services Planning Council to assess the full spectrum of services for HIV infected persons in NYC. The sample was drawn from organizations providing medical or social services for the HIV infected, and is broadly representative of the HIV-infected population in services in New York City.

### ***Modified Community Assessment Process (MCAP)***

A 6-month community assessment was conducted which included several basic reconnaissance methods that have been used successfully in other studies to learn about "hidden" or less-known populations:

**a. Key informant interviews.** We conducted more than two dozen open-ended interviews with service providers, researchers, and others knowledgeable about HIV testing and care within particular populations or risk groups. These "key informant interviews" provide a range of perspectives on the testing-and-care process among different population segments. The interview protocol included general questions related to the nature of their client populations, the provider's experience and position within an agency or program, the kinds of testing and treatment-referral patterns they observed, and their perceptions of barriers to timely testing and treatment.

Key informant interviews	
1. MSM	5. Homeless people
• Gay ID'd	• Youth
• MSM of color	• Drug users
• Sex workers	6. Criminal justice
2. High-risk women	7. African-Americans
3. Prenatal care	8. Latinos
4. Drug-users	9. Immigrants
• Active	• Arab
• Treatment	• Asian
• Methadone	• W. African
• Residential	• Caribbean

**b. Focus groups.** We conducted 5 focus groups, drawn from different populations where the "delay" problem is thought to be significant. In all groups, several of the participants were HIV-positive and had previously disclosed their status to the group. Our respondents were all drawn from ongoing support groups at agencies that serve the following populations: MSM of color; transgender-experienced of color; active drug users, criminal justice involved; and women at risk. We plan to conduct additional focus groups with homeless individuals and youth at high risk of HIV infection.

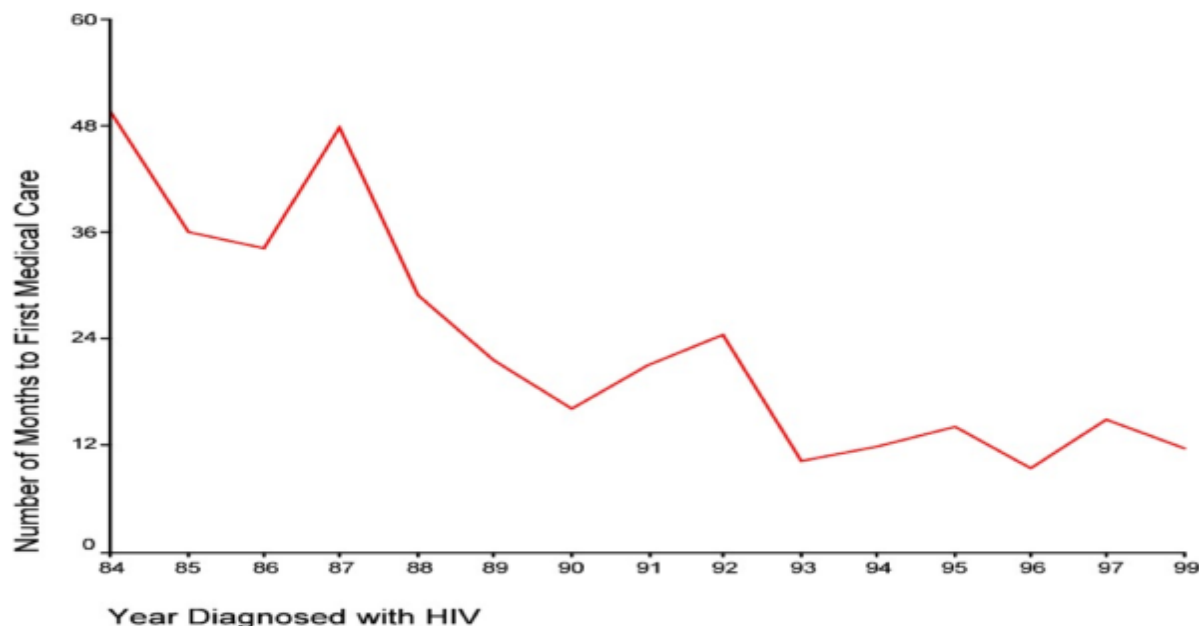
**c. Community Advisory Board.** We recruited and convened a Community Advisory Board of members from agencies that serve or study HIV-infected or affected populations. Board members have expertise in medicine, research, service administration, and social-service provision. The

CAB will review findings and help formulate recommendations to the Planning Council. We first convened in late February to present our preliminary findings and the study design. The Board will meet at least once during the second year of this study.

### WHO ARE THE DELAYERS? PERSPECTIVES FROM THE CHAIN STUDY

Over time, the rate of delayed HIV care seeking has fallen, especially among persons diagnosed post- 1996 when antiretroviral treatments began to become widely available. For example, in the original CHAIN cohort, 37% of persons who were diagnosed with HIV prior to 1992 delayed entry into care. For persons diagnosed between 1992-1995, the rate was 18%. At the present time, for persons diagnosed since 1996, it is still the case that 15% or approximately 1 in 7 persons who receives a diagnosis of HIV will delay entry into medical care. In addition, as displayed in Figure 1 below, the length of time "delayers" remained outside of care has declined in recent years. Nonetheless, among those who delay entry into care, the average lag between testing and treatment remains more than one year, currently averaging 12 to 18 months.

**FIGURE 1: MEAN TIME TO HIV MEDICAL CARE AMONG PERSONS WHO DELAY ENTRY INTO CARE BY YEAR OF HIV DIAGNOSIS**



In the original CHAIN cohort, diagnosed primarily in the 1980s and early 1990s, individual socio-demographic characteristics including gender, race/ethnicity, education, insurance and source of income did not have a significant independent influence on delayed entry into care. Factors associated with being a Delayer in the original CHAIN sample were primarily experiences and situations at the time of diagnosis:

1. current serious drug use
2. current homelessness
3. mental health difficulties
4. little or no social support (as reflected in number of relatives and friends)
5. no regular source of medical care

Findings from a preliminary analysis of the first 400 respondents in the new CHAIN cohort currently being recruited are generally consistent with the original findings, with a few important differences. Among persons more recently diagnosed with HIV/AIDS, men, persons under the age of 35, and new immigrants are more likely than others to delay entry into medical care. Persons who were heavy drug users at the time of HIV diagnosis, especially those also diagnosed with mental illness, and those who were homeless or unstably housed, continue to be those most likely to delay entry into HIV medical care.

Drug use, homelessness, new immigrant status are all conditions that suggest lack of personal resources with which to face the transition to life as an HIV-infected person, and/or to seek out treatment. As in earlier years, being a “Delayer” is affected more by situational context and resources available at the time of diagnosis than by demographic and personal characteristics. The implication is that, as the significant factors are not fixed personal characteristics, it is possible to intervene in the process of transition to care to improve outcomes.

## **WHY DELAY? PERSPECTIVES FROM THE AFFECTED POPULATIONS**

Four major themes that ran through the focus groups, all of which affect timely use of testing, timely presentation to care after testing, or both.

1. **STIGMA AND DISCRIMINATION.** In several of the focus groups, undergoing HIV testing *at all* was described as stigmatizing. What behavior had resulted in the *need* to be tested? The groups all described conditions in which they felt they had been mistreated by the medical system simply because of who they were or were perceived to be. In its most benign form, stigma took the form of routinized or depersonalized treatment. In others, treatment was described as humiliating and deeply upsetting.
2. **PERCEPTIONS OF THE MEDICAL SYSTEM.** Focus group participants complained of long waits for scheduling appointments and seeing providers. They often attributed poor treatment to not having money, or having Medicaid rather than private insurance. Respondents described two “tiers” in the medical system, one of HIV-specific clinics and providers with their many ancillary services and generally more caring staffs, and the “general” one of everyday medicine. Prior to HIV diagnosis, many had avoided the “general” medical

system, through which potentially they could have been funneled into HIV testing and/or treatment.

3. **ANTICIPATING TREATMENT.** Before seeking HIV medical care themselves, participants frequently assumed that they would immediately be given medication, as has been the case during some phases of the epidemic. Also, as in the case for other chronic diseases with asymptomatic stages, many did not recognize any value in being evaluated or followed solely for monitoring. Other anticipations included fear of rejection or poor treatment by significant others or society at large since to enter into treatment would be a form of disclosure of HIV status.
4. **LACK OF REALISTIC INFORMATION ABOUT TREATMENT.** Particularly among women at risk for infection where knowledge about HIV care is not widely diffused, HIV-positive focus group participants commented on how little they knew about what to expect from treatment. They emphasized the need for more information in the schools, as the affected population is quite young. Participants also stressed that that they had been completely unaware of benefits and programs (medical, financial and social-service) that are available to PLWHAs, and suggested that if more people knew about these opportunities, they would be more willing to come forward for testing and care.

## STAGES OF ENTRY INTO TREATMENT

To simplify presentation, we have used a model of seven stages of entry into treatment. In the ideal testing-and-treatment scenario, each stage serves as a “filter” into the next. The stages offer a framework for identifying points where individuals can get stuck or fall out of care and show that the determinants of action may differ by stage.

1. **UNDERSTANDING BASIC HEALTH CONCEPTS AND USING MEDICAL CARE.** Most of the populations at risk for delayed care have had a history of discrimination and poor treatment in the health care system, which has left a legacy of distrust. Respondents described barriers of time, effort, and inconvenience of accessing medical care, especially for preventive care or non-emergency problems. These points are particularly salient among the newer immigrant populations (such as West Africans and Chinese) who are rarely insured and speak languages in which translation services are scarce. Providers also described several cultural barriers to care, namely gendered appropriateness of care (health care seen as a “women’s” domain; women requiring husband's permission to seek health care, etc.), reversal of generational roles (where children must serve as guides and translators for parents) and fear of disapproval based on cultural belief broadly shared within their communities.
2. **KNOWING ABOUT HIV.** Basic knowledge about HIV is a prerequisite to seeking out early HIV testing, the ideal portal into the HIV care system. Populations vary considerably in their knowledge of HIV, based on the history and prevalence of the epidemic in their communities. Knowledge of HIV is widespread and often sophisticated within MSM and drug-using populations, but far lower among heterosexual women at risk, and almost non-existent in many newer immigrant populations. The problem is complicated by the low levels of general education about basic health concepts needed to understand HIV (such

as “virus” or simple anatomy). Finally, limited knowledge about HIV sometimes coincides with conspiracy theories that discourage use of health care.

3. **PERSONALIZING HIV.** Providers told us many stories about PLWHAs who had assumed they had been “careful” or “it couldn’t happen to them”. In some populations these misconceptions stem from a lack of knowledge about basic transmission processes. In others, such as MSMs, processes such as “phobic denial” (being unwilling to come to terms with one’s sexual identity, so also unable to recognize the risks) were said to be important. Those who were unable to recognize their risk before they were tested are more likely than others to delayed entry into testing as well as entry into care for HIV.
4. **CONSIDERING HIV TESTING.** A very common barrier to testing derives from HIV/AIDS stigma, and its possible impacts on relationships with family and significant others. Especially in populations where seroprevalence is relatively low, taking an HIV test may be regarded as a visible “mark” of some type of stigmatized behavior (drug use, same sex experiences). Another barrier is anticipating the impact on oneself. Focus group participants and Providers both described people who “knew” or “knew inside” that they were positive, but put off actually being tested until there was some practical benefit to an HIV diagnosis, or they felt psychologically ready to deal with the knowledge that the test would probably deliver. A final – and probably the most significant – barrier to testing is fear of social (sexual partnerships and family relationships, drug use with others), legal (child custody, immigration, criminal justice sanctions), or financial (public assistance) consequences.
5. **FINDING AND USING HIV TESTING.** Several members of the highest-risk populations argued for the importance of decreasingly available anonymous test sites, because of the ability to keep the results completely private. The group with the best-developed word-of-mouth knowledge of both testing and care facilities was the MSMs. On the other hand, there are at least two populations who are tested routinely, not because they knew how to find and use testing resources but because of situations they enter where testing is mandatory or strongly encouraged. In neither case, however does this routine testing always translate into timely presentation for treatment.
  - **PREGNANT WOMEN.** Recent legislation has made testing of newborns mandatory. However, testing before delivery, as a part of prenatal care, is at best inconsistent, either because physicians hesitate to raise the issue or because women at greatest risk of HIV (chiefly drug-using women or women with multiple sex partners) are the least likely to receive timely prenatal care. Providers told us of women who find out about their own HIV status immediately following delivery, then abandon the baby and take months or even years to come to terms with their own infection.
  - **INMATES IN THE CORRECTIONAL SYSTEM.** Testing is routine at Rikers Island, the City’s jail facility, which maintains a separate medical unit for HIV-positive prisoners. However, under the best of circumstances, there are many opportunities for “slipping through the cracks” given that multiple providers and institutions may be involved in inmate care, and follow-through after release is inconsistent. As the

CHAIN data show, persons tested in correctional settings have the highest rates of delayed engagement with HIV primary care.

6. **ANTICIPATING TREATMENT.** There is an increasing amount of "folk knowledge" about HIV treatment. It is common for HIV-infected people to assume that HIV medications are toxic or have serious side effects. Varying degrees of information circulate among PLWHAs about treatments that are possible or desirable given other ailments or medications. The major co-infection and treatment regimen complicating HIV treatment decisions is Hepatitis C, found among 70-90% of injection drug users and methadone maintenance patients (who are largely former injectors). There are potential interactions with methadone and gender-changing hormones, as well as illicit drugs. Beliefs about interactions as well as doubts about the ability to maintain more than one drug regimen and/or the ability to give up illicit drugs, lead some PLWHA to avoid HIV medication.
7. **LOCATING AND ACCESSING TREATMENT.** Both providers and focus group participants favored a "one-stop-shopping" model, where one could get tested and treated all in the same environment, with minimal burden of paperwork, appointment coordination, and stress of new facilities. All focus groups described their ideal in terms of promptness, cleanliness, professionalism, empathy, respect, and confidentiality.

TWO ADDITIONAL DESIRABLE CRITERIA, SPECIFIC TO PARTICULAR GROUPS, INCLUDED:

- **POPULATION-SENSITIVE SERVICES.** MSM and Transgender focus group participants especially emphasized the importance of a facility where people like themselves were common (as patients, clinicians, or both), and they would not be the object of curiosity or derision. This was more important to them than geographical location.
- **GEOGRAPHICAL LOCATION.** Some patients prefer not to be cared for in a location in their community because of the potential risk of being seen. Many focus group participants preferred a Manhattan location because of the concentration of services there, others because the density and anonymity of Manhattan offered easier concealment of their use of HIV medical care and other HIV services.

TWO GROUPS FACE SPECIAL CHALLENGES IN FINDING SERVICES APPROPRIATE TO THEM

- **CURRENTLY ACTIVE (USUALLY LONG-TERM AND/OR HIGH-FREQUENCY) DRUG USERS.** These are often also burdened with homelessness, criminal justice involvement, other medical problems, or mental health conditions. Even in settings targeted to IDUs, staff report that clients who know their status may not disclose and seek help until a trusting relationship has developed around work on other health problems.
- **NEWER IMMIGRANT POPULATIONS.** Some newer immigrant populations will avoid any health care if at all possible, for fear of drawing attention of the INS or compromising their citizenship eligibility. In some groups, systems for raising consciousness and increasing screening for HIV is still in nascent stages, and the stigma remains

enormous. Immigrant PLWHAs are among the most treatment resistant Delayers, entering treatment only when their health has vastly deteriorated. Another consideration is that some newer immigrant groups do not speak any language for which translation services are available in service settings.

The complexity of transitioning some types of clients into care is illustrated by the number of CBOs dealing with high-risk populations that now provide staff under various titles, such as “systems advocate” or “adherence specialist” whose duties include accompanying clients to appointments outside the facility to ensure that clients do not fall (or get pushed) through the cracks of a complex system of care, as well as intervening with health care personnel and translating treatment regimens into terms patients can understand.

## **THE CHANGING ENVIRONMENT OF HEALTH AND SOCIAL SERVICES**

We identified three major changes underway that while not directly connected to HIV, may have important impacts on the epidemic and the climate around seeking and using diagnosis and care.

- 1. IMMIGRATION.** An increasing proportion of New Yorkers are born abroad. Many are from countries that have only recently become major sources of immigrants to New York, and arrive with little education, little or no English, and little tradition of health care use. Many are undocumented. In some immigrant populations, conditions including high male/ female sex ratios, frequent travel, and easily available commercial sex work set the stage for HIV transmission. Others are from countries where there are already pockets of infection.
- 2. WELFARE AND MEDICAID REFORM.** Post-1996 changes in eligibility for benefits and Medicaid may restrict access to affordable primary and basic health care that provides a mainstream entry to HIV information and testing. The impact of these changes may be greatest among those at highest risk, such as drug users and homeless adults. At the same time, the restriction of the more generous HASA program of benefits to those at relatively advanced stages of infection creates little practical incentive to earlier testing and diagnosis. Trends such as Medicaid managed care and HIV Special Needs Plans may change the shape of medical care available to marginalized populations in ways that discourages service use.
- 3. DRUG TREATMENT.** The shape of the drug treatment system is also changing. Many treatment programs are adding increasingly sophisticated medical treatment to their offerings. At the same time, the increasing practice of mandating treatment as an alternative to incarceration is bringing large numbers of HIV-infected clients into settings such as residential programs, where they have not been as common. While these are both increasing the ability of HIV treatment to reach high-risk populations, it is not clear that the experience of medical care associated with treatment facilitates engagement with care outside of the treatment setting. In addition, it must be remembered that large numbers of HIV-infected drug users remain outside treatment, and have a distinct set of problems that exacerbate their tendency to become “Delayers.” Such individuals require outreach, community education and other specific services organized around their needs.

## PRELIMINARY RECOMMENDATIONS

Our work has identified three major themes about delaying or not delaying entry into care:

- HIV infected individuals need to perceive some concrete, recognizable benefit to motivate them to seek testing and to seek treatment after diagnosis
- Consistent messages and realistic information about treatment options in advance of diagnosis are needed to remove barriers associated with misunderstandings and fear
- Delayed entry into medical care is affected more by situational context and resources available at the time of diagnosis than by fixed personal characteristics.

Based on the work of this preliminary report, we have, in collaboration with our Community Advisory Board, developed recommendations to encourage early testing as well as more timely presentation to treatment. These include:

- T Provide more realistic information about treatment – its potential effects, benefits, and liabilities – in advance of the need for treatment. This will decrease misunderstandings and fear of the unknown that are barriers to both testing and early treatment.
- T Improve the ease, speed, and convenience of HIV testing, to make it more available to those most likely to become Delayers by conducting targeted outreach to marginalized populations, expanding the availability of treatment sites within existing service organizations, and encouraging wider use of the newer rapid testing technologies. Given client and provider concerns about HIV stigma as a barrier to care, expanding and publicizing the availability of anonymous test sites may facilitate early entry into testing and treatment among several high risk populations (e.g. transgendered individuals, MSMs of color, active IDUs).
- T Expand the availability of culturally sensitive providers, especially for the most highly stigmatized populations of PLWHAs. This could take the form of:
  - Making it easier for highly stigmatized and marginalized populations to use existing “mainstream” care, for example through training providers or providing “advocates” or “adherence specialists” who can help clients navigate treatment systems.
  - Bringing health care to marginalized populations in settings where they are already comfortable, such as specialized community-based organizations. Examples include organizations serving specific immigrant communities, or harm-reduction services for high-risk drug users.
- T Explore regulatory or funding changes to make it easier for CBOs to provide medical care (particularly as Article 28 providers) to patients they already serve, rather than relying on partnership arrangements.

- T Provide comprehensive, accurate, and specific information on the consequences of HIV testing and treatment for involvement in other administrative, legal, and benefit systems, both to those administering as well as those receiving HIV testing and care.
  
- T Address contextual factors such as housing situation, social isolation, and pre-HIV involvement with systems of medical care, during HIV testing and counseling, and post-diagnosis service planning to facilitate more timely entry into medical care and continued engagement with care among those most at risk for delaying.