

**OAAID
(NEED LOGO)**

WIDENING THE CIRCLE OF CARE

A REPORT ON THE ALAMEDA/CONTRA COSTA COUNTY OUT OF CARE SUMMIT

AUGUST 2002

**PREPARED BY
THE ALAMEDA/CONTRA COSTA COUNTY
OUT OF CARE SUMMIT PLANNING GROUP**

WRITTEN BY ROBERT WHIRRY, PROGRAM DEVELOPMENT CONSULTANT





ACKNOWLEDGMENTS

The Alameda/Contra Costa County Out of Care Summit came about through the dedicated work of a diverse group of committed activists and planners in the East San Francisco Bay HIV service community. We would like to thank the members of the Out of Care Summit Planning Group, who planned and guided the Summit to fruition:

DAN BARBA/FAMILY CARE NETWORK
LEROY BLEA/CITY OF BERKELEY PUBLIC HEALTH DEPARTMENT
DR. KATHLEEN CLANON/ALAMEDA COUNTY MEDICAL CENTER
TOM FOSTER/CENTER FOR APPLIED LOCAL RESEARCH
CARLA GOAD/CONTRA COSTA COUNTY DEPARTMENT OF PUBLIC HEALTH
NANCY HALLORAN/ALAMEDA COUNTY MEDICAL CENTER
LARRY HILL/OAKLAND EMA HIV SERVICES PLANNING COUNCIL
LOIS LINDSAY/HIV ACCESS
GING LOUIE/EAST BAY AIDS ADVOCACY FOUNDATION
GWEN ROWE-LEE/EAST BAY AIDS FOUNDATION
MADELYN STONE/EAST BAY COMMUNITY RECOVERY PROJECT
STEVEN TYSON/ALAMEDA COUNTY OFFICE OF AIDS
ROBERT WHIRRY/PROGRAM DEVELOPMENT CONSULTANT
LORI WILLIAMS/ALAMEDA COUNTY OFFICE OF AIDS

THE OUT OF CARE SUMMIT WAS FUNDED THROUGH THE GENEROUS SUPPORT OF THE FOLLOWING CORPORATIONS:

AGOURON PHARMACEUTICALS, INC.
BRISTOL-MYERS SQUIBB COMPANY
GILEAD SCIENCES, INC.

The fiscal agent for the Oakland Out of Care Summit was the **East Bay Advocacy Foundation**, a coalition of HIV service providers dedicated to enhancing the quality of HIV care in the East Bay through collaboration and service integration. For information on the organization's mission and programs, please visit their website at www.ebaaf.org.

RDL Enterprises, a Sacramento-based firm, carried out logistical planning and coordination for the Out of Care Summit. For additional information on their services, please see their Web site at www.rdlent.com. The Out of Care Summit was facilitated by **Monika Hudson**, a specialist in multi-disciplinary and multi-cultural group process. Additional information on Monika's services may be obtained by calling (650) 343-1059. Robert Whirry helped conceive the Out of Care Summit, assisted in planning, and prepared this report on Summit outcomes. Robert can be reached at (415) 863-0325.

Generous underwriting for the production of this report was provided by the Alameda County Office of AIDS, Division of HIV Prevention Services. We are grateful to the Division's Director, **Maria Aguilar**, for making production of this report possible.

Finally, we would like to thank **Dr. Kathleen Clanon**, HIV Medical Director for the Alameda County Medical Center, who gave generously of her time and energy to generate the funding needed to organize the Out of Care Summit. Without her support and dedication, neither the Summit nor this report would have been possible.

TABLE OF CONTENTS

Acknowledgments/2

Key Findings and Recommendations/5

Ten Overarching Barriers That Keep People Out of Care/5

Ten Overarching Strategies to Help Bring People Into Care/6

Summary of Findings of Out of Care Discussion Groups/7

Background to the Out of Care Summit/16

Living with HIV and Out of Care: A Growing Problem/16

Defining What it Means to be Out of Care/17

Laying the Groundwork: A Summary of the CAL Research Out of Care Study/18

How the Alameda/Contra Costa County Out of Care Summit Was Structured/20

Findings of Out of Care Summit Discussion Groups/23

Active Substance Users, including Injection Drug Users/

African American Barriers and Issues/

African American Men Who Have Sex with Men/

Beliefs, Attitudes, and Stigma Regarding HIV and Homophobia/

Immigrant and Undocumented Populations/

Incarcerated Populations/

Latino Barriers and Issues/

Men Who Have Sex with Men/

Mental Health Barriers and Issues/

Poverty, Economic Issues, and Homelessness/

Sexually Active Young People/

Transgender People/

Women/

Young Men Who Have Sex with Men/

Other Populations and Issues/

Conclusions and Next Steps/50

KEY FINDINGS AND RECOMMENDATIONS

On April 26, 2002, in Oakland, California, a group of HIV service providers and planners presented the **Alameda/Contra Costa County Out of Care Summit** - a full-day gathering designed to gain new insights into the reasons why many people with HIV are not in care, and what can be done to bring them into care. The Summit was attended by over **75** health and social service providers, HIV planners, and people living with HIV. The Summit discussed out of care issues as they related to **15** distinct HIV-related issues and populations. The following are some of the Summit's key findings.

TEN OVERARCHING BARRIERS THAT KEEP PEOPLE OUT OF CARE

- **Continued negative attitudes and stigma regarding HIV and HIV risk behaviors, which lead to a reluctance on the part of people with HIV to disclose their HIV status to family members, friends, and care providers, or to seek care**
- **Lack of tailored services to meet the needs of specific underserved populations and groups in a safe and sensitive way**
- **Lack of trained, culturally competent health providers capable of providing respectful, empathetic services to disenfranchised populations**
- **Shortage of staff who reflect the communities served by HIV agencies, including a shortage of people living with HIV in professional positions, and a shortage of staff who speak languages other than English**
- **Fear and suspicion on the part of people living with HIV of traditional medicine and the health care system in general**
- **Denial by people with HIV of personal risk for illness or death as a result of HIV**
- **Difficulties faced by people in poverty in prioritizing personal health care over more basic needs such as food, shelter, and caring for one's family**
- **Lack of immediate linkage to services at the time an individual learns of his or her HIV-positive status**
- **Lack of services located directly within communities in which disenfranchised people live**
- **Negative, fearful, and often uninformed attitudes of organized religion toward HIV and the behaviors that transmit HIV**

TEN OVERARCHING STRATEGIES TO HELP BRING PEOPLE INTO CARE

- **Provide tailored, personalized approaches to care for populations with special issues, such as homeless people, people in poverty, communities of color, women, transgender populations, men who have sex with men, formerly incarcerated populations, substance users, and people with mental illness**
- **Expand provider trainings - particularly training of medical, front-line, and client contact staff - in order to increase their capacity to sensitively serve members of underserved and disenfranchised populations**
- **Mandate greater staff representation by members of populations served by HIV organizations, including greater representation by people living with HIV**
- **Provide safe, welcoming service settings that are easily accessible and that are not identifiable as HIV service sites**
- **Provide immediate linkage to HIV services at the time that individuals receive a positive test result, preferably through peer advocates**
- **Plan and conduct specialized retreats and events for members of specific underserved HIV-diagnosed populations**
- **Create more high-tolerance settings to serve people with HIV who are active substance users**
- **Create and expand family-centered services that help friends and loved ones deal with an HIV diagnosis**
- **Create community-based media and social marketing campaigns to change negative attitudes toward HIV, people living with HIV, and the behaviors that transmit HIV**
- **Sponsor focused, caring campaigns to begin to change the attitudes of organized religion toward HIV, and to generate expanded faith-based HIV care responses**

ACTIVE SUBSTANCE USERS, INCLUDING INJECTION DRUG USERS



SIGNIFICANT BARRIERS TO CARE

- Too many different service sites - clients must continually shuttle between HIV, substance abuse and mental health facilities in order to access care
- Lack of cultural and linguistic competence within some drug treatment organizations
- Lack of respect for and understanding of substance users within some traditional HIV service agencies
- Requirement that heroin addicts must complete detoxification prior to admission to substance abuse treatment programs
- Lack of alternative approaches to traditional substance abuse treatment

POTENTIAL EFFECTIVE STRATEGIES

- Create one-stop centers for active substance users that incorporate HIV, substance abuse, and mental services in one accessible location
- Broaden drug treatment admission policies to accept more people who are currently detoxifying, while creating more accessible, affordable detoxification programs overall
- Implement more high-tolerance models to serve substance users in HIV service settings
- Expand availability of alternative and holistic substance treatment models, such as yoga, acupuncture, relaxation therapies, and spiritual and faith-based approaches
- Expand availability of drug treatment services on demand

AFRICAN AMERICAN BARRIERS AND ISSUES

SIGNIFICANT BARRIERS TO CARE

- Institutionalized racism, and the resulting mistrust of traditional health and medical systems by African Americans
- Organized religion's negative attitudes toward HIV
- Broken community structure and the disintegration of a sense of connectedness in African American communities
- Internalized racism, and the resulting low self-esteem and pessimism in regard to the future
- Continuing stigma and shame around HIV
- Continuing epidemic of crack use in the African American community

POTENTIAL EFFECTIVE STRATEGIES

- Design and implement more African American-centered HIV programs
- Create 24-hour sober community centers for African Americans with HIV
- Require clinicians to participate in activities to increase cultural sensitivity
- Provide non-denominational, across-the-board training of African American religious leaders on HIV, including in the context of pastor training
- Use loving people in the church to create HIV-focused care teams and prayer groups
- Teach African American young people in the school system about HIV and self-esteem from the elementary level on



AFRICAN AMERICAN MEN WHO HAVE SEX WITH MEN

SIGNIFICANT BARRIERS TO CARE

- Widespread stigma against HIV in the African American community, leading to a reluctance to seek services for fear of having HIV status revealed
- Prevalence of homophobia in the African American community and churches, leading to fear of same-sex behaviors being revealed
- Institutionalized racism, resulting in a lack of adequate services and an internalization that leads to low self-esteem and a lack of self-protection
- Lack of services specifically designed for young African American men who have sex with men



POTENTIAL EFFECTIVE STRATEGIES

- Work within religious communities to overcome anti-HIV and anti-gay stigma
- Sponsor community-wide retreats for African American men who have sex with men to build mutual support and plan effective programs
- Develop workshops to help young African American men 'unlearn' homophobia and build pride and self-esteem
- Create club-based African American young men's safe sex nights to initiate support groups and service participation
- Develop positive images of effective and compassionate HIV service programs in the African American community
- Foster greater collaboration and integration among organizations that serve gay and bisexual African American men

BELIEFS, ATTITUDES, AND STIGMA REGARDING HIV AND HOMOPHOBIA

SIGNIFICANT BARRIERS TO CARE

- Fear of losing the love and support of family and friends by having HIV status and/or same-sex behavior revealed
- Continuing stigmatization of HIV as a 'gay' disease
- Prevalence of anti-gay and anti-HIV attitudes within organized religion
- Continuing taboos against talking openly about sex or sexuality in American society
- Lack of services accessible to active substance users

POTENTIAL EFFECTIVE STRATEGIES

- Create social marketing campaigns to overcome stigma against both HIV and same-sex behaviors, including campaigns that show the faces of real people with HIV, and that spotlight compassionate caregivers
- Provide people with immediate access to peer-based support and service linkage when they learn of their HIV status
- Create family-based programs that help loved ones overcome negative attitudes toward HIV and gay/bisexual behaviors
- Do not require clients to be taking HIV medications in order to access HIV-specific health and social services
- Create dialogues between doctors, health care providers and people living with HIV to increase provider sensitivity to disenfranchised communities



IMMIGRANT AND UNDOCUMENTED POPULATIONS

SIGNIFICANT BARRIERS TO CARE

- Fear of deportation and of having one's residency status revealed
- Stigmatization of HIV and the behaviors that cause HIV, leading to a reluctance to seek services for fear of having these revealed
- Lack of health care services for day laborer and migrant farmworker populations
- Lack of cultural and linguistic competence within many HIV service organizations, including lack of translation and interpretation services
- Attitudes of organized religion toward HIV and HIV-related behaviors, particularly attitudes that treat HIV as God's punishment, and that lead to a sense of guilt among people with HIV



POTENTIAL EFFECTIVE STRATEGIES

- Overcome fear of deportation by posting information on rights related to immigration in community sites, and through PSAs, Hispanic radio and television, and other public information channels
- Develop effective translation and interpretation services and staffing that includes medically competent translation
- Work to change the idea that if one is living in the U.S., one should speak English
- Identify clergy leaders and work to provide education on HIV and HIV behaviors, and to develop effective church-based initiatives
- Develop community outreach projects to reach people in the fields, on street corners, and in community gathering sites

INCARCERATED POPULATIONS

SIGNIFICANT BARRIERS TO CARE

- Lack of effective linkage to HIV health and social services upon release from incarceration settings
- Lack of affordable housing for recently-released inmates
- Fear of being discovered in a parole violation by seeking HIV services
- No recognition of sexual diversity in prison or parole systems
- Sense of hopelessness among many incarcerated and formerly incarcerated individuals
- Lack of acknowledgment by the corrections system of harm reduction as a prevention or care strategy

POTENTIAL EFFECTIVE STRATEGIES

- Create structured transitional case management/client advocacy programs that follow people with HIV from the prison or jail setting into the community
- Create a system of voice mailboxes for recently released clients so that service providers may contact them expeditiously
- Expand education of HIV service providers on the needs of formerly incarcerated populations
- Expand education for parole officers on services for people living with HIV, including education to reduce HIV stigma
- Create coalitions of community agencies to expand housing opportunities for recently released prisoners with HIV



LATINO BARRIERS AND ISSUES

SIGNIFICANT BARRIERS TO CARE

- Lack of cultural awareness on the part of many providers, including a shortage of Latino physicians and other professionals
- Lack of front-line Spanish-speaking staff in many agencies that serve Spanish-speaking clients
- Fear of rejection by family and friends as a result of HIV stigma, homophobia, and stigma regarding substance use
- Lack of public information on how and where to confidentially access HIV services
- Fear of deportation and being reported to immigration authorities



POTENTIAL EFFECTIVE STRATEGIES

- Establish policies to require **all** front-line staff in agencies that serve a majority of Spanish-speaking clients to be Spanish-speaking
- Fund Latino organizations to conduct community forums on rights to healthcare for potential clients
- Conduct trainings for healthcare providers on rights to healthcare
- Fund Latino organizations to develop radio and tv programs and PSAs on HIV and HIV service access
- Link dissemination of HIV service information to activities such as voter registration campaigns, health fairs, and church events
- Train non-HIV Latino groups on HIV stigma and services, particularly within legal and religious communities

MEN WHO HAVE SEX WITH MEN

SIGNIFICANT BARRIERS TO CARE

- Internalized and societal homophobia, which in turn causes people not to seek care for fear of having same-sex behavior revealed, especially in the case of closeted men who have sex with men
- Disrespectful and/or judgmental treatment by the health care system, which leads men – especially flamboyant or effeminate men - to not return for treatment
- Lack of self-esteem related in part to internalized homophobia, leading men to not prioritize personal health and well-being in the context of their lives
- High prevalence of substance abuse in this community, resulting in men not seeking care for fear of having substance use revealed, or not taking medications for fear of drug interactions

POTENTIAL EFFECTIVE STRATEGIES

- Increase availability of off-site or satellite locations separate from traditional medical facilities to overcome fear of judgment or disclosure of behaviors for those seeking services
- Create accountability within medical and HIV agencies for insensitive or homophobic behaviors, such as through reporting or complaint systems
- Create broad anti-homophobia social marketing campaigns, as well as focused campaigns directed toward organized religion and the health care system
- Expand mental health and counseling services for men who have sex with men to increase self-protective, self-loving attitudes



MENTAL HEALTH BARRIERS AND ISSUES

SIGNIFICANT BARRIERS TO CARE

- Lack of adequate mental health services for people with HIV, leading to an inability to access services or to adhere to medications because of mental health problems
- Lack of provider knowledge regarding mental health issues and symptoms, and a frequent lack of information on where to refer patients for services
- Shortage of accessible mental health services for those who do not have a “severe and persistent mental illness” diagnosis
- Prevalence of shame and stigma around mental illness, leading to a reluctance to seek care



POTENTIAL EFFECTIVE STRATEGIES

- Expand general availability of mental health services for people with HIV, especially long-term individual counseling services
- Expand provider training on mental health issues, including training on how to assess mental health issues in the care and service setting, and how to make qualified referrals
- Incorporate mental health assessments and referrals into all HIV-related health and social service assessments
- Expand availability of peers with HIV to provide support and advocacy services for individuals with mental health issues
- Create comprehensive strategies for preventing depression in people with HIV, particularly in the period immediately following diagnosis, by providing immediate referrals to services; by ensuring rapid linkage to peer support; and through frequent follow-up in the weeks following diagnosis

POVERTY, ECONOMIC ISSUES, AND HOMELESSNESS

SIGNIFICANT BARRIERS TO CARE

- The struggles that people living in **poverty** face in addressing basic life needs – such as food and housing – often result in a de-prioritization of HIV health care and psychosocial services
- Rigid attitudes and beliefs among HIV providers regarding how care and services must be accessed – such as the belief that everyone with HIV must be case managed, or that homeless people cannot comply with medication regimens - can create barriers to **homeless** people accessing care
- A lack of adequate housing resources to help poor people with HIV achieve stabilization can be a significant barrier to their maintaining health and wellness

POTENTIAL EFFECTIVE STRATEGIES

- Provide HIV health care services directly within areas where homeless people congregate
- Relax clean and sober housing requirements for people with HIV and other life-threatening illnesses
- Recruit poor and formerly homeless men and women to serve as case managers for poor and homeless people
- Provide better support for staff of HIV agencies who work with impoverished and homeless populations, such as expanded time off and sabbaticals, and enhanced continuing education opportunities
- Provide buddy support services to help homeless and impoverished populations deal with feelings of anger regarding both HIV and their own life circumstances



SEXUALLY ACTIVE YOUNG PEOPLE

SIGNIFICANT BARRIERS TO CARE

- Frequent stigma and discrimination by health care providers in regard to HIV risk behaviors among youth, leading to a reluctance to disclose HIV status or HIV risk behaviors
- Judgment and the enforcement of cultural norms by family members in regard to HIV risk behaviors – and the fear of losing family ties – creating a lack of willingness to disclose HIV status or risk behaviors
- Intrinsic belief in immortality, and the lack of personalization of the concepts of illness and death
- Lack of youth-tailored health programs and youth-specific health education and outreach programs
- Difficulty of incorporating HIV self-care into the already challenging issues of adolescence



POTENTIAL EFFECTIVE STRATEGIES

- Conduct outreach where young people congregate, including homes, schools, and youth gathering places
- Expand HIV outreach and services conducted directly by young people
- Work through families and the church to create a more accepting environment to allow young people to disclose and discuss HIV status
- Distribute youth-appropriate educational materials and information wherever possible, including through mass media sources
- Create HIV outreach materials and programs that are not directed exclusively to gay-identified young people

TRANSGENDER PEOPLE

SIGNIFICANT BARRIERS TO CARE

- Widespread lack of culturally effective care, including a shortage of providers who understand, respect, and communicate competently with transgender people
- Lack of sensitive and safe environments in which transgender people can access services
- Stigmatization and lack of community understanding of transgender people, their lives, and their needs
- Frequent lack of self-esteem among transgender people, including insecurity around personal appearance, and fear of being mistreated or ridiculed in service environments

POTENTIAL EFFECTIVE STRATEGIES

- Expand training on transgender issues for physicians and service staff, especially those who are not members of the HIV care community
- Hire more transgender staff in HIV agencies that serve transgender people
- Ask all HIV clients about their personal gender identification early in the client relationship
- Expand availability of resource referral information for HIV-positive transgender people in HIV service settings
- Develop aggressive prevention case management programs for transgender people
- Develop media campaigns to expand visibility and understanding of transgender people in the community at large
- Provide training on transgender issues within corrections settings



WOMEN

SIGNIFICANT BARRIERS TO CARE

- Fear of disclosing HIV status to male partners because of fear of domestic violence, or fear of having HIV risk behaviors revealed
- Prevalence of mental health issues that prevent women from consistently accessing health care, including depression, bipolar disorder, and schizophrenia
- Cultural and socioeconomic barriers that restrict many poor women from seeking care, including poverty, struggles in caring for children and families, mistrust of traditional medicine and the health-care system, and shame or guilt regarding HIV risk behaviors
- Prevalence of substance use issues that prevent women from seeking services, in part from fear of having drug behaviors revealed



POTENTIAL EFFECTIVE STRATEGIES

- Expand partnerships between HIV service agencies and domestic violence organizations to develop collaborative approaches to care
- Provide family-focused care that help spouses and children deal with women's HIV diagnoses
- Eliminate use of the term "substance abuse" and deal with the problem of alcoholism and alcohol use on an equal footing with drug use
- Expand provider training in HIV-specific women's health and medical issues, including recognizing women-specific health issues and asking questions related to family and life issues
- Expand staffing opportunities for HIV-positive women in HIV care settings wherever possible

YOUNG MEN WHO HAVE SEX WITH MEN

SIGNIFICANT BARRIERS TO CARE

- Shame around being young and HIV-positive - e.g., “You should have known better”.
- Denial of health risks among young people with HIV, including personal feelings of immortality and invulnerability, a sense of fatality around HIV infection and death, and a growing belief among young people that HIV has become a manageable, chronic medical condition
- The fact that the medical system as it is currently organized often does not sensitively address lesbian, gay, bisexual, transgender, and questioning youth and their experiences
- Lack of public information on how and where young men who have sex with men can access HIV services, especially for young men who hide their same-sex behavior (young men “on the down low”)

POTENTIAL EFFECTIVE STRATEGIES

- Design non-judgmental outreach and educational materials for young men that do not single out gay young men specifically, but are instead inclusive of males from all ranges of sexual behavior and exploration
- Create a retreat camp for recently diagnosed HIV-positive young people to allow them to assess their lives, prioritize their needs and goals, and receive education and empowerment and leadership training, including support from mentors
- Expand provider training to increase competence in appropriately serving youth
- Increase hiring of HIV-positive young men who have sex with men in organizations that serve a high percentage of these populations



OTHER POPULATIONS AND ISSUES

SIGNIFICANT BARRIERS TO CARE

- **Asians/Pacific Islanders:** Linguistic and cultural barriers to seeking care; cultural taboos against HIV risk behaviors; and the need to preserve family ties by not revealing HIV status
- **Native Americans:** Suspicion/distrust of western medicine; isolation within urban environments; and lack of HIV services by and for Native American populations
- **Seniors:** Belief they are not at risk, coupled with stigma regarding HIV risk behaviors among older men and women; also a lack of senior-appropriate services at HIV care agencies
- **Infants:** Lack of access to or knowledge of prenatal care services, and lack of coordination of adult and pediatric health care services
- **Developmentally Disabled Persons:** Lack of HIV knowledge among developmentally disabled people and their caregivers, and denial of HIV risk among these populations by health and psychosocial providers
- **People Co-Infected with Hepatitis C:** Lack of coordination among health providers, and burden of accessing services for impoverished and underserved individuals



OVERARCHING STRATEGIES

- Expand education for providers in all issues related to underserved or poorly served communities
- Expand availability of culturally competent and population-sensitive services in both HIV medical and social service provision
- Mandate HIV testing for pregnant women in all health care settings

BACKGROUND TO THE OUT OF CARE SUMMIT

LIVING WITH HIV AND NOT IN CARE:

A GROWING PROBLEM

As the number of people living with HIV in Alameda and Contra Costa Counties has grown over the past two decades, so has the number of people living with HIV who are not receiving adequate medical or supportive services to deal with their illness. While the care system has done an excellent job of reaching and serving **most** people living with HIV, there are still **many** individuals with HIV who know they are infected, but are **not** receiving appropriate health or psychosocial services. Accessing HIV care is vital because it can help people with HIV better cope with their illness, access needed support and resources, and live longer and healthier lives.

The importance of receiving care has achieved urgency with the emergence of combination drug therapies to treat HIV. For many people with HIV, these therapies can dramatically reduce symptoms of HIV disease, and have so far greatly increased the average life expectancy of people with HIV and AIDS. The importance of combination therapies has been recognized by the U.S. Health Resources and Services Administration, the federal agency that distributes HIV treatment and service funds through the Ryan White Emergency CARE Act. The agency has stressed the importance of bringing **all** people with HIV into care so that they can monitor their health status and make informed decisions about whether or not to use combination therapies.

At the same time, it is important for people with HIV to access **other supportive services in addition to medical care**. These services are critical because they can help people with HIV increase the quality of their lives, reduce overall health risks, and prepare to manage complex drug regimens. Many people with HIV in Alameda and Contra Costa Counties live on very low incomes, and do not have access to traditional health or social services. If they are not in care, these individuals may not be able to access many of the HIV programs that can improve their health status - programs such as food assistance that allows them to receive adequate nutrition, or housing programs that help them achieve the stability needed to adhere to medication regimens. Many people with HIV also are struggling with substance use, or have untreated mental illness. In many cases, these individuals cannot fully address their medical needs until they are given help to confront and manage their substance use and mental health issues.

The problem of out of care populations is increasingly urgent because the number of people who are living with HIV in Alameda and Contra Costa Counties is increasing on a daily basis. Over the 18-month period between December 31, 2000 and June 30, 2002 alone, the number of people living with HIV increased by an estimated **14%** in the two counties, meaning that at least **1,000** new HIV infections occurred in the two counties over that period. Most of these individuals are low-income individuals and families who do not have experience in accessing preventive and long-term medical care and supportive services. As these populations increase over the coming months and years, so will the number of people with HIV who know their status but are not receiving adequate care.

In Alameda and Contra Costa Counties, it is believed that as many as 3,500 people who know their HIV status may not be receiving HIV-specific medical care or supportive services. ¹ These individuals are either not receiving appropriate medical care and treatment to manage their HIV infection, and/or are not receiving appropriate social and supportive services to meet their life and health needs. Why are so many people not receiving HIV-specific care, despite the fact that they know they have HIV? What are the barriers that keep them from accessing care, or that prevent them from knowing that care is available? And how can the HIV service system do a better job of bringing these people into care, and of keeping them in care on a long-term basis once they are identified?

The Alameda/Contra Costa Out of Care Summit was devised as a way to begin to answer some of these questions. The Planning Group that developed and presented the Summit represented a range of diverse agencies in the two counties, including representatives of County government, public and private health care providers, and agencies offering non-HIV-specific social and supportive services. The group also included members of the Oakland Eligible Metropolitan Area (EMA) HIV Services Planning Council, which in 2002 is developing a new three-year Comprehensive Plan for HIV services in Alameda and Contra Costa Counties - a Plan that will include priorities for bringing people with HIV into care. The East Bay AIDS Advocacy Foundation - a non-profit organization dedicated to expanding and integrating HIV services in Alameda and Contra Costa Counties - served as fiscal agent for the Summit, and provided extensive administrative support.

DEFINING WHAT IT MEANS TO BE OUT OF CARE

There are many possible definitions of what it means to be 'out of care'. For example, people with HIV who do not yet know they **have** the virus are almost always not receiving appropriate medical care or HIV support services. These individuals may account for **25% or more** of all people living with HIV. For people who **do** know they have HIV, it is often suggested that being 'in care' means receiving regular and ongoing HIV medical care only. But many people with HIV make informed decisions to use so-called 'complementary therapies' instead of traditional medications, while others who are receiving non-medical HIV services are simply not ready to begin taking combination therapies, perhaps because of substance use, homelessness, or mental illness.

For purposes of this gathering, the planners of the Alameda/Contra Costa County Out of Care Summit made the decision to define 'out of care' as referring to individuals who: a) Already know they have HIV; and b) Are not currently utilizing HIV-specific medical or social services on a regular basis. People with HIV who do **not** know they have the virus were not included in our Summit definition because approaches to these groups are centered on the need to bring these individuals into **HIV testing**, rather than care - a task that is often the primary responsibility of HIV prevention agencies. At the same time, the Planning Group did not limit those who are 'out of care' only to those who are not receiving **medical** services, since many people we regard as being 'in care' choose not to access HIV medications or medical monitoring.

Our definition of out of care left us with a large population about which very little is known. Very little research has been conducted to identify who out of care

populations are; how many individuals make up these populations; or what can be done to involve them in the care system. Both Alameda County and Contra Costa County - the two jurisdictions that comprise the Oakland Eligible Metropolitan Area (EMA) - began to recognize this information gap two years ago, when our two regions began to develop a series of projects to help identify who the out of care populations in our area were.

One of these efforts involved commissioning an initial assessment of the nature of out of care populations by the Richmond-based Center for Applied Local Research (CAL Research) in 2001. The results of this study - which consisted of a series of focus groups attended by both in care and out of care populations - are described in the following section. Also, as part of its Title I application process in 2001, the Oakland HIV Services Planning Council developed a taxonomy of out of care populations that sought to define the overall universe of individuals with HIV who could be considered as being 'out of care' in the widest possible sense. This taxonomy appears on the following page. Both documents provided useful beginnings for describing the nature and needs of out of care populations in the Oakland EMA - strategies that were later augmented by the 2002 Out of Care Summit.

LAYING THE GROUNDWORK:

A SUMMARY OF THE CAL RESEARCH OUT OF CARE STUDY

In 2001, in order to help allocate Ryan White CARE Act funding, and as an early phase of the 2002 Comprehensive HIV Services Plan, the Oakland EMA HIV Services Planning Council commissioned a report on the needs and status of out of care services populations in Alameda and Contra Costa Counties. Prepared by the Center for Applied Local Research, this report - entitled ***Service Needs of Out of Care People with HIV/AIDS*** - was based on the findings of 11 focus groups held with out of care populations throughout the Oakland EMA, as well as on a series of key informant interviews. The report was an important step in documenting the service needs of people not currently in care, and provided critical information on the nature of out of care populations in our region.

Among the most significant findings of the report was the identification of a series of **barriers to care** that exist for people out of care in the Oakland EMA. The study identified these barriers both in terms of **personal barriers** people living with HIV/AIDS experience themselves, and barriers that are created by the **healthcare system**. Among the barriers identified by the study that **people with HIV bring themselves** are the following:

1. **Difficulty in Relating to the Healthcare System:** Many people living with HIV - especially if they are low-income - have learned ways of relating to the system that are not consistent with active participation in primary HIV medical care. Many do not seek care because they have too many competing priorities in their lives, or feel they are too busy trying to survive. Others view the healthcare system with mistrust, or believe the system will not really help them. Particularly important is the view that the healthcare system is a place to go only in a **medical emergency**, and not a place to go for regular care.

2. **Psychological and Emotional Barriers:** While healthcare workers frequently cite mental illness as a factor in keeping people from participating in primary medical care, focus group members discussed factors such as **fear, shame, depression, and denial** as barriers to seeking medical care and to taking prescribed medications. Participants say they often sense a connection between seeing a doctor and becoming sicker, or say they fear the side effects of HIV-related drugs. **Shame** is also a common barrier, closely related to **embarrassment** and **guilt**, all of which are tied to a desire not to seek care for fear of HIV status being disclosed to family, friends, and co-workers. **Depression** can have an impact by increasing feelings of loneliness, and by diminishing the drive for self-protection. **Denial** is perhaps the most commonly cited barrier, with many participants stating in regard to seeing their doctor, “I don’t feel sick anymore, so I just don’t go.”
3. **Lack of Knowledge:** Ignorance regarding the HIV virus is still cited as a barrier by many, with some focus group participants saying they do not have enough knowledge about the virus to understand the importance of being in primary care.
4. **Unstable Living Conditions:** Many participants cite homelessness, lack of housing availability, not having enough money to pay rent or utilities, and constantly moving from one place to another as problems that impact their ability to seek and use primary care services. These conditions are also severe barriers to taking HIV medications regularly, such as by making it impossible to have a place to keep medications refrigerated, or not having enough regularity in day-to-day life to maintain drug-taking regimens.
5. **Substance Use:** Providers frequently note that many clients who are active substance users believe they cannot get medical help because of their active substance use, while the problem of trying to live from fix to fix precludes primary medical care from being a priority.

Among the systemic barriers to accessing HIV/AIDS primary care services identified by the CAL Research report are the following:

6. **Difficulty in Understanding the Health Care System:** Many participants emphasized that they simply did not have enough **information** regarding how to use the health care system. They said they were sometimes not sure where to go to get their needs met, and/or were confused about health benefits, eligibility requirements, and reimbursement issues. This issue is closely related to **confusion regarding HIV medications**, including the effects certain medications may have on them, or the possible negative consequences of mixing over-the-counter drugs with prescribed medications.
7. **Difficulty in Entering the System:** Many participants report that the process of seeking and gaining access to primary medical care often feels over-

whelming and discouraging. In addition to common barriers such as eligibility requirements and daunting paperwork, participants spoke of their belief that the standards for entering the health care system are **too high**, often involving residency and income requirements they do not believe they can fill.

8. **Difficulty in Accessing Providers:** Transportation is a significant barrier cited by many focus group participants, most of whom lack their own source of transportation and must rely on buses or taxis to get to appointments. For those out of care, taxi vouchers are clearly not accessible, yet are the sole means of transport for many.
9. **System Seen as Inhospitable and Unwelcoming:** Some focus group participants spoke of barriers related to organizational cultures that “keep them at arms-length,” or that make health care centers cold and unfriendly places to visit.
10. **Race and Language Barriers:** Many participants noted that they rarely see health care professionals who “look like them” in terms of either ethnic affiliation or socioeconomic status, and that this serves as a further barrier to accessing care.

HOW THE ALAMEDA/CONTRA COSTA COUNTY OUT OF CARE SUMMIT WAS STRUCTURED

One reason it is so difficult to learn about out of care populations is that, in most cases, the HIV service system simply **does not know who these individuals are**. By their very definition, people who are out of care are **not** receiving HIV medical or social services, and so have not been identified by care agencies. Even people who have received HIV services in the past and who have ‘dropped out’ of the system are often difficult or impossible to locate. Many of these individuals have moved to another addresses or region, while others have invalid phone numbers. When CAL Research attempted to organize focus groups made up of out of care individuals in 2001, it faced almost insurmountable problems in trying to locate sufficient numbers of individuals to participate. Even offering incentives to people with HIV in return for anonymously inviting friends and acquaintances proved difficult, since most people who are out of care are apparently not connected to support systems that link them to other people living with HIV.

However, there are two key groups of people who do have regular contact with out of care populations, and who know a great deal both about why people are out of care, and what may be needed to bring them into care. The first of these groups is people living with HIV who are in care. Many of these individuals have been out of care on one or more occasions, or have friends with HIV who are not seeking care. As people who know what it means to live with HIV, these individuals have critical insights into the personal struggles that are involved both in living with an HIV diagnosis and in seeking care. People with HIV who are in care also have a close understanding of the HIV service system, and how it can be improved or modified to incorporate underserved populations.

The **second** group of knowledgeable individuals consists of **staff and volunteers of social service agencies who have direct contact with HIV-affected populations**. These street-level and direct client providers include community outreach workers, intake workers, case managers, client advocates, drug treatment counselors, mental health professionals, and others who interact with members of disadvantaged and underserved populations on a daily basis. These individuals may work directly with people who are living with HIV, or who are at high risk for HIV as a result of behaviors or environmental circumstances. These professionals - whether they work with HIV-specific or non-HIV-specific agencies - understand the problems out of care populations face both in seeking care and in remaining in care for long periods of time.

The Alameda/Contra Costa County Out of Care Summit was organized as a way to obtain the direct input of members of both of these groups. The Summit provided an opportunity to ask these individuals why people were not in care, and what could be done to bring them into care. It also provided a unique chance to bring street and client-level staff together with HIV planners and administrations and people living with HIV to discuss critical issues affecting care in our two counties.

Because the reasons people are out of care differ for different populations, the Summit sought information in terms of specific HIV-related groups and issues. Over the course of the Summit, following introductory sessions, a total of **three** separate breakout sessions were held, with **five** distinct populations and issue areas discussed in each session. During each breakout, participants spent two hours identifying key reasons why members of these populations were not in care, and how specific issue areas limited access to and utilization of HIV services. Each group then brainstormed strategies for overcoming these barriers to bring in and retain people in care. The findings of these Summit discussion groups - the heart of the Out of Care Summit - are summarized in detail the following section, and in a condensed version in the preceding Findings Summary.





FINDINGS OF OUT OF CARE SUMMIT DISCUSSION GROUPS

The Out of Care Summit was organized both in terms of **specific populations** that have been hard-hit by HIV in Alameda and Contra Costa Counties, and in terms of **specific issue areas** that can create barriers to entering or remaining in the system of care. The Summit organizing group designed these 15 topic areas around the specific demographics of the HIV epidemic in the two counties, as well as on needs assessment information regarding populations who are chronically underserved by the local care system. The 15 populations and issues discussed at the Out of Care Summit were as follows:

- ACTIVE SUBSTANCE USERS, INCLUDING INJECTION DRUG USERS**
- AFRICAN AMERICAN BARRIERS AND ISSUES**
- AFRICAN AMERICAN MEN WHO HAVE SEX WITH MEN**
- BELIEFS, ATTITUDES, AND STIGMA REGARDING HIV AND HOMOPHOBIA**
- IMMIGRANT AND UNDOCUMENTED POPULATIONS**
- INCARCERATED POPULATIONS**
- LATINO BARRIERS AND ISSUES**
- MEN WHO HAVE SEX WITH MEN**
- MENTAL HEALTH BARRIERS AND ISSUES**
- POVERTY, ECONOMIC ISSUES, AND HOMELESSNESS**
- SEXUALLY ACTIVE YOUNG PEOPLE**
- TRANSGENDER PEOPLE**
- WOMEN**
- YOUNG MEN WHO HAVE SEX WITH MEN**
- OTHER POPULATIONS AND ISSUES**

The results of Summit discussions around each of these issues and populations are described in the sections that follow. These findings summarize both the reasons that specific populations are not in care, and the specific strategies that can be employed to bring them into care.

ACTIVE SUBSTANCE USERS, INCLUDING INJECTION DRUG USERS

Because of the intense needs of substance using populations, the discussion group - rather than list the full range of barriers these individuals face - focused exclusively on strategies for addressing the needs of these populations. The group's **strategies** were divided into several categories, including: **1)** The problem of **multiple service providers**; **2)** The complex issues facing **heroin users**; **3)** The need for **alternative** substance abuse treatment approaches; **4)** The need for **cultural and linguistic accessibility** within HIV and drug treatment settings; and **5)** The need for expanded **drug treatment opportunities** overall.



The problem of **multiple service providers** creates barriers for people with substance use issues. When individuals whose lives are already made difficult because of addiction and HIV must travel to several different locations each week by bus or on foot, access often becomes so taxing that the individual simply gives up trying. Many group members felt that the availability of **one-stop service centers** where people with HIV could access basic health and psychosocial services as well as substance treatment and sobriety maintenance programs in one location would be extremely effective in helping people remain in care. Barring this, even locating services in more central and accessible locations, or expanding video-conferencing opportunities between providers, would also help people with substance issues remain in care. Other suggested strategies for service accessibility and coordination include conducting case conferencing in conjunction with clients at accessible locations, and creating a mobile clinic for providing substance treatment together with other HIV and health services.

People addicted to heroin face a tragically challenging addiction, and need special support in order to help them save their own lives and live with HIV. The need for 21-day detoxification services are critical for these populations, as are approaches to make these services more accessible, and to help clients obtain such services without insurance - such as by creating a fund to purchase detox services for them. In general, drug treatment programs could also show greater flexibility in accepting people who are in the **process** of detoxing, rather than serving only clients who have fully completed detoxification.

While most referrals for substance treatment programs tend to focus on conventional programs, **alternative approaches** to drug treatment are becoming increasingly important, and have shown notable success, particularly for individuals who have not responded to traditional approaches in the past. The group noted that some clients could benefit from expanded referrals to alternative approaches such as **yoga, acupuncture, relaxation therapies**, and even **faith-based** programs. Expanding such access would involve creating new standards for assessing such services in order to determine which are suitable for client referrals, and exploring new reimbursement strategies, such as recruiting pro bono providers of these services. In general, alternative approaches to substance treatment can be effective in keeping people in care when they are tied to an overall

holistic approach to drug treatment, in which treatment is integrated with a well-ness-based approach incorporating HIV care.

Ensuring the **cultural and linguistic accessibility of services** is vital for bringing people into drug treatment and HIV care. This includes not only 'culture' in the sense of ethnicity and national origin, but the culture of drug use, of inner city populations, and of people living in poverty who must struggle to survive. In the former sense, for example, undocumented individuals may unnecessarily fear an HIV diagnosis because of the new non-names reporting system, or may fear that getting an HIV test will jeopardize residency status or lead to deportation. It is also important to ensure that HIV and drug treatment services are available in languages other than English, and that advocates are available who speak the client's language to help him or her maneuver through other parts of the system. Expanding cultural competency training for providers - particularly medical providers - would also be an important step, as would expanding the availability of staff who reflect the ethnicity and primary languages of their service populations.

In terms of the culture of drug use, it is critical that HIV providers treat **all** clients - including active substance users - with **respect** and **empathy**, and that substance users not feel judged when they seek care. By the same token, clients who do not feel they are being adequately listened to or respected by a service provider or staff member should have the option of changing service sites or providers as needed. It is critical that persons confronting substance use be able to develop trusting, long-term relationships with providers, which means that HIV agencies should take increased steps to help support staff members to be able to serve on a multi-year basis.

Finally, the ongoing problem of lack of adequate substance treatment services remains a barrier to HIV care for people who are using drugs and are ready to stop. Drug treatment on demand remains a distant dream, and there are unclear policies and procedures for obtaining benefits to access services that already exist. Services for persons recently released from corrections settings are also limited. HIV providers often do not understand that relapse following treatment is a normal and expected part of recovery, and that people who use drugs have not 'failed' and should not be abandoned if their initial drug treatment program is not successful in the long run.

AFRICAN AMERICAN BARRIERS AND ISSUES

Barriers to care within the African American community are substantial, and begin with the twin problems of **institutionalized racism** and **internalized racism**. The former presents a wide range of barriers to care, including exclusion of individuals from service access; lack of funding for minority health services overall; a lack of quality services; a lack of trained providers - particularly when it comes to cultural competence and relevance; and fears regarding institutionalized medicine and other authority systems. The latter includes significant self-esteem issues; the belief that one is not going to be helped by seeking care; resistance to



and lack of basic knowledge concerning HIV; lack of HIV-positive role models; a lack of political representation; and significantly, a lack of a community voice in health-care decision making.

The African American community also faces a host of additional significant barriers disproportionately affecting the community. These include substance abuse - particularly the ongoing epidemic of crack cocaine use; fragmentation of community structure in the African American community; poverty; homelessness; incarceration; lack of health insurance; unemployment; and negative attitudes toward HIV and HIV risk behaviors within organized religion and throughout the heterosexual African American community. Other related barriers include shame regarding AIDS and homosexuality; a belief that HIV is a problem of white gay men; and the idea that someone who is sharing information about HIV must have the disease themselves. African American women face special barriers, such as the belief that if HIV is revealed, their children may be removed from the home. Other barriers confronting African American women including a lack of self-esteem and a lack of HIV knowledge, especially among older African American women.

Strategies identified by the group for addressing barriers to care within the African American community centered around **six** key areas, including those targeting **1)** Institutionalized racism; **2)** Internalized racism; **3)** Organized religion's attitudes towards HIV; **4)** Broken community structure; **5)** Shame and the need to keep HIV and AIDS a secret; and **6)** Substance abuse. Suggested strategies to combat **racism** in the care system include designing and implementing African American-relevant HIV programs and services; conducting summits in hospitals and care systems on ethnic and cultural service issues; requiring clinicians and providers to participate in activities to increase cultural competence and sensitivity; working in the school system to provide education regarding HIV issues from an early age; and increasing policy and advocacy in decision-making at top levels. The group placed special emphasis on the need to think creatively about how to address out of care issues, and to devise **multiple strategies** for engaging clients in care. Publicity of services is a significant strategy, as is consumer empowerment and creating models of service-oriented care, including effective grievance systems that keep people in care and do not alienate those seeking it.

The importance of **religion** in the African American community – while sometimes acting as a negative influence on attitudes toward HIV and those it affects – is also a powerful tool that can be harnessed positively, and that can have a tremendous impact on the response to HIV within African American neighborhoods. According to the group. Pastors and congregations should be educated and involved inter-denominationally in HIV care, and strategies should be designed to elicit help within the religious community and to remove the stigma of HIV and AIDS as emblems of “sin” through the vehicles of love and prayer. Programs also need to be designed that emphasize prevention and not simply abstinence. In particular, strategies that work directly with pastors need to be developed with the intent of encouraging churches to see help as a “plus,” and to persuade the religious community to listen to the issue of AIDS and to suspend moral judgment.

Strategies addressing the role of **broken community structure** include increasing the sense of building community from within through programs to build

empowerment; working in schools beginning at the elementary level to equip young people with an understanding of AIDS issues; requiring that social and medical service providers, prior to obtaining a degree, do field work to increase their understanding of and sensitivity to the community; and publicizing service availability within the community. Publicity can also serve as a strategy to address issues of **shame** surrounding AIDS in the community.

A wide array of strategies was suggested for addressing the very significant role of **substance use** as a barrier to care in the African American community. Strategies include emphasizing **harm reduction** so that active users can gain access to care without stigma; providing basic services to clients as a way of gradually engaging them in care; offering treatment on demand; creating an atmosphere of tolerance for relapse, and providing care services outside of the usual Monday-Friday, 9-5 period, with accessible alternative treatment, such as 12-step programs, available 24 hours a day. Long term treatment was seen as necessary to address care issues of substance abusers, including comprehensive follow-up care with relocation upon release from residential care. Grassroots efforts and greater coordination among community providers were seen as critical strategies. These include using religious centers as “safe havens”; developing greater collaboration between substance use providers and the entire service system; conducting publicity campaigns to create more acknowledgement of the problem within the community; and, on a macro level, considering legalization of drug use to eliminate the possibility of pushing.

AFRICAN AMERICAN MEN WHO HAVE SEX WITH MEN

The discussion group identified a wide range of barriers to care faced by members of this population. The group emphasized the ‘triple’ stigma and discrimination experienced by members of this group as African Americans; as men who have sex with men; and as people living with HIV. The multiple problems of AIDS stigma, homophobia, and racism can make it extremely difficult for members of this group to disclose their HIV status for fear of having HIV status and/or personal sexual behaviors revealed. Also, because of the way they have been battered by discrimination and rejection, members of this group often do not have stable lives that allow them to access health care regularly, and frequently lack the self-esteem and sense of future-directedness that would motivate them to access services. Because of the lack of information directed toward African American men who have sex with men, there is also a lack of knowledge about how to access services, and misperceptions about HIV and the threat of HIV illness, often coupled with a mistrust of traditional medical care and pharmaceuticals.

For African American men who are closeted in their same-sex behavior, the problems of fear of disclosure are multiplied. Such men may fear that by seeking care, their sexual behavior will be revealed to wives or girlfriends, and they may not practice safe sex with partners, in order to avoid the suggestion that they could have HIV. For these men, accessing HIV care in community settings can



be difficult because of the fear of being seen entering or leaving a facility, or the fear of being called at home, or of having one's HIV status included in permanent medical records.

In order to overcome the stigma around HIV within the African American community, group members suggested a series of **community-wide campaigns** directed at church leaders, families, and the community at large to increase the level of understanding around HIV, and to negate the perception of HIV as a shameful or embarrassing condition. Drawing attention to positive service models in the local African American community – such as the HIV care programs of Allen Temple Baptist Church in Oakland – would also be of tremendous value. Such campaigns could center on reinforcing values of community and commonality, rather than difference.

In regard to homophobia, the group proposed the concept of a series of **African American men's retreats** where men could gain support and care from one another to build self-esteem and to create a strong sense of community. The group also proposed a series of workshops on “unlearning homophobia”, to begin to counter a lifetime of negative images and mistreatment. Support groups for African American men who have sex with men are badly needed, as are late-night, club-style sober events with safe sex themes. The group mentioned that early education against homophobia is essential, including in-school programs that help young children counteract negative social messages. More funding for substance abuse treatment programs is also needed.

Finally, in regard to countering racism, the group agreed that focusing on provider training would be a good first step in helping to create more welcoming services within the HIV service community. The group also suggested that community-based organizations work together to create more welcoming environments, perhaps through designated evening office hours specifically for African American men who have sex with men. African American men themselves must also be more empowered to take responsibility for their own service needs, in partnership with peers who share common culture and experiences.

BELIEFS, ATTITUDES, AND STIGMA REGARDING HIV AND HOMOPHOBIA

Beliefs and stigma associated with homosexuality, intravenous drug use, and their connection to HIV pose significant barriers to care. For the most part, barriers to accessing care were seen by the group as resulting from people not wanting to be associated with HIV because of stigma around the illness. Many persons are afraid of family and friends discovering their HIV status, or their sexual orientation or drug use. Others fear talking about sexuality. AIDS/HIV is still often seen in many communities as a white gay male disease. Denial in many forms is another significant barrier. Among many beliefs keeping people from accessing care are those particular to **ethnic traditions** and/or to **organized religion**. These include the beliefs: that HIV can be contracted through casual contact; that people on medication cannot transmit the



virus; that older people cannot contract HIV; that medication may do more harm than good; that medical treatment or testing for HIV is a conspiracy to harm; that one cannot afford HIV treatment; that children will be taken away if parents are HIV positive; and that HIV is a death sentence or is automatically debilitating. Other barriers stem from service providers' attitudes and beliefs. Providers may be insensitive to HIV issues, gay issues, or active drug users; may fear inquiring or advocating around HIV issues; or may assume that intravenous drug users don't take their health seriously unless they are attempting sobriety.

Strategies for combating beliefs and stigma around these issues vary widely. The need to keep persons at risk for HIV connected to family, friends, and community is seen as paramount. So too is getting the message out that HIV does not discriminate; that it is just a disease; and that sex, HIV, and health need to be talked about. The group felt that people living with HIV need to be empowered to be more visible; need to show their diverse faces; need to advocate; and need to be active in their communities. Mentors, peers, and other support groups representative of clients need to be easily accessible, and - along with counselors and health workers - need to address stigma. Services should also be extended to families with one or more members living with HIV. Such services would ideally emphasize caregivers' compassion and forgiveness; remove negative reputations and judgments; and provide good quality follow-up, not just after diagnosis. The medical community also needs to be involved, with roundtable discussions and open dialogue between doctors and people with HIV; education of medical personnel; and involvement of pharmacists and nutritionists - the latter of whom can serve as gatekeepers between doctors and alternative medicine. The group emphasized that clients should **not** be required to take medications in order to access care.

IMMIGRANT AND UNDOCUMENTED POPULATIONS

Bringing members of immigrant and undocumented populations into care involves overcoming a range of significant barriers. The discussion group identified the primary barriers to care facing this population as: **1)** Fear of deportation and of governmental agencies in general; and **2)** Lack of adequate translation and interpretation services. Primary among the former is the perception that providers may reveal information that will jeopardize individuals' immigrant or undocumented status, or their standing among family and community. Individuals fear not only who might see them and potentially jeopardize their status, but may also fear the stigma associated with seeking HIV treatment or information that may come from friends and family members. Immigrants and undocumented individuals may also avoid seeking care due to fear of being required to provide documentation, such as a Social Security number or permanent address. Another significant barrier appears to be the lack of translation and interpretation services, including the lack of assurance that care information is being adequately delivered where translation and interpretation is inadequate or absent. Even when providers offer such services, they are often available only in a single other language, or may



be inappropriate for illiterate populations.

High levels of poverty and/or an itinerant lifestyle also present barriers. For instance, many persons in these populations face difficulty in meeting basic needs such as food and shelter, and prioritize these needs over the need to obtain basic medical care. Many in these populations also lack health coverage or are reluctant to seek out care if they are unaware of available free resources. Others lack access to transportation needed to access care, or cannot afford potentially long waits for services, or may have childcare responsibilities that do not allow time to access care. Frequent movement back and forth between countries by migrant workers or other immigrant groups may imperil continuity of care and access to medications. Cultural barriers may also be present, with immigrant populations relying on alternative or traditional medicine, or holding cultural beliefs that are contrary to or mistrustful of Western medicine. Others may have difficulty in accessing confidential care due to lack of privacy resulting from close family or co-worker living conditions.

Strategies for addressing the care needs of immigrant/undocumented populations can be roughly divided into those dealing with **1) Fear of deportation and immigration problems; 2) Addressing gaps in translation and interpretation services; and 3) Addressing the role of organized religion in limiting access to HIV care.** Education regarding immigrant and undocumented persons' rights - as well as their HIV care options - is seen as a key strategy, with possible approaches including promotional campaigns, particularly on immigrant groups' radio and television programs; outreach to areas where immigrant or migrant groups are concentrated; use of "gatekeepers" to access immigrant communities; and programs that counter fear of deportation and immigrant rights with accurate information on the lack of risk in accessing HIV care. These and related strategies must be particularly tailored to the needs of **migrant workers**, including education on accessing health care as populations move back and forth across borders; education on how to transition and link to healthcare in home countries; and outreach to migrant camps to provide information and education regarding healthcare and available services. Service providers may also need to post and/or provide lists of client rights specific to immigration in their service environments, in the language of the communities they serve.

Strategies dealing with the problems of language and interpretation include expanding the availability of translation and interpretation services related to healthcare issues for immigrant populations, including training provider staff; hiring multilingual staff; providing instructions for care and medications in community languages; working with healthcare and social service providers in home countries; identifying and paying gatekeepers to assist in interpretation; and in general providing a level of language access that allows clients to receive clear, uncomplicated information in a comfortable setting.

Given that many immigrant groups and newly arrived immigrants have strong ties to organized religion, strategies to link with religious leaders in immigrant communities are essential to enlist religious groups in efforts to bring and maintain people with HIV in care. Efforts should be made to identify and educate religious leaders on HIV and immigration rights issues, and to use the strength of churches to get people into care and to educate congregations. Ac-

ording to the group, this strategy should include enlisting leaders from non-traditional faiths. Overall, strategies for addressing care needs of immigrant and undocumented populations must be tailored to specific groups, and should stress outreach to populations that may be reluctant to seek care for fear of deportation or other immigration problems, language difficulties, or the belief that they are not entitled to care.

INCARCERATED POPULATIONS

Incarcerated populations face critical barriers to care both **within** and **outside** the incarcerated setting. Within incarcerated settings, the respective prison or jail system is responsible for providing essential care and treatment needed to ensure the health of the individual. Barriers within such settings include the lack of methods to prevent transmission of the virus to others, and a lack of adequate support for gay and bisexual men. However, group members noted that there is also a shortage of liaisons within corrections settings who can help prisoners plan for their release; secure necessities such as housing and employment; and facilitate rapid linkage to needed medical and social services upon their release. Immediate linkage to housing and employment can help ensure that people with HIV stabilize their lives, maximize their health, and avoid illegal activities. Immediate linkage to care and social services means that recently-released people can continue their medications without interruption, and obtain support for the process of transitioning to the community as a whole.



Once incarcerated people are on the outside, they face a range of barriers that can keep them out of care. In terms of life stability, group members believed that **lack of housing** is the most critical problem faced by recently released individuals, with difficulties finding **employment** a close second. In terms of HIV care specifically, the most important barriers were the **lack of linkage to community services upon release**, and the related risk this creates for former prisoners upon returning to old neighborhoods and old habits. Many formerly incarcerated persons also face a sense of hopelessness regarding their ability to permanently change their lives, which can lead to a sense that seeking HIV health care is futile or a waste of time. For prisoners who have violated their parole, there is a fear of accessing services for fear of having parole violations exposed. The group also noted that many HIV service providers are unfamiliar with the issues and problems facing formerly incarcerated people.

In terms of strategies to address a lack of linkage to services upon release, the group suggested **in-prison liaisons and case management programs** to establish relationships in the corrections setting that can be continued upon release - a system that has already been implemented with success in many settings. Parole officers could also be trained to provide or distribute HIV service information to parolees during their first interview. One group member suggested creating individual voice mailboxes for recently-released clients so that service providers could contact them easily before they had a permanent address or phone number.

The group also stressed the need for greater networking and communication among service providers in order to develop new strategies to serve formerly incarcerated people, and working together more extensively with county jails to bring integrated services to local communities.

To address housing, the group stressed the need to de-link the provision of housing to drug treatment requirements, in order to ensure housing access to those clients who are not prepared or able to stop drug use at a specific time. Greater advocacy is also needed to expand affordable housing availability, and to build coalitions for affordable housing funding that includes advocacy for housing for ex-offenders. This could include outreach to local neighborhood associations in order to change attitudes toward accepting and incorporating ex-prisoners into the community.

In terms of overcoming fears of accessing community services among parolees, the group suggested increasing the number of community providers working on linking prisoners to community services, and educating parole and corrections personnel regarding HIV, harm reduction, and the barriers faced by parolees in accessing services in the community. All members of the social service system need to understand that the goal of helping avoid a return to jail or prison is linked to ensuring life stability and access to health and wellness services for recently released individuals. Citizen advisory boards could be helpful in informing and influencing corrections policies, and in creating integrated approaches to parolee health and well being.

LATINO BARRIERS AND ISSUES

Key barriers to care among Latino populations identified by the discussion group include a lack of information and individuals with whom to speak about healthcare; a fear of being reported to immigration authorities; a lack of publicity or information about rights to healthcare; a lack of providers who have cultural awareness or speak the language; and fear of family rejection, particularly for men who have sex with men and/or drug users. A particular barrier for these populations is a lack of provider staff who speak Spanish or who are culturally competent in agencies that serve Latino clients. Other barriers include a lack of information about HIV and AIDS; long waits at places of care because of linguistic barriers; communication difficulties with providers due to fear; lack of insurance and stable housing; and a distrust of Western medicine and/or institutions.



The discussion group suggested that in order to address the lack of bilingual and bi-cultural services in Latino-serving organizations, policies should be put in place requiring **all** front line and client staff to be bilingual in the language of the majority of the clients. The group also suggested recruiting more Latinos as provider staff and on decision-making bodies; requiring agencies that provide services in Spanish to publicize this ability in Spanish; and educating the Latino community on job and volunteer opportunities that exist within HIV agencies.

Strategies to address the lack of information on rights to healthcare and on HIV/AIDS include funding Latino organizations to conduct community forums on rights to healthcare; implementing training for providers on rights to healthcare; creating and implementing radio, television, and newspaper PSAs, particularly during evening novellas; and providing laminated health care rights cards in Spanish to clients. Efforts should also be made to “hook up” dissemination of information with events attended by the community such as voter registration campaigns, or at locations where Latinos congregate, such as churches, BART stations, supermarkets, and health fairs. Informational materials and campaigns must reflect Latinos of **all** colors, and they must be planned in conjunction with non-traditional medical and religious practitioners in order to get information out to these communities. Strategies to address the fear of being deported include funding Latino organizations to develop a list of “safe” places to go; conducting community forums on rights to healthcare; implementing trainings for providers on rights of healthcare; and creating and implementing radio, television, and newspaper PSAs. Also, Latino providers need to be trained on HIV stigma and acceptance, and must work with legal services and churches to disseminate information.

MEN WHO HAVE SEX WITH MEN

While identifying a wide range of barriers that keep men who have sex with men out of care, the discussion group focused in large part on the continuing problem of **homophobia** in American society, and its negative effects on accessing care. The group made a distinction between **internalized** homophobia – in which society’s negative attitudes toward same-sex behavior are absorbed and turned inward upon the individual – and homophobia **within the HIV care system**, which can limit an individual’s willingness or ability to seek care. As a result of internalized homophobia, individuals may not practice self-protective behaviors, or may take a pessimistic or fatalistic attitude toward their own health, feeling on some level that they don’t deserve care. Closeted men who do not wish to have same-sex behaviors revealed may avoid services so that others do not see them entering a clinic or service setting, or they may hide their HIV status so that friends, family members, and partners do not discover their behaviors. They may also be afraid that partner notification policies will require them to report their sex partners to service providers. These problems can be magnified for members of communities of color.

Homophobia within the care system can play itself out in terms of disrespectful or judgmental treatment, particularly toward flamboyant or effeminate men, which can cause these individuals not to return for treatment. Additionally, the care service system can discriminate in less obvious ways, such as through a lack of sensitivity to gay lifestyles by providers; the use of distancing and clinical language; a lack of respect; inappropriate referrals; and a lack of sensitive or targeted services for transgender or non-English-speaking clients. Other barriers to care for men who have sex with men include negative attitudes of organized



religion; the difficulty of adhering to medication regimens – including side effects, perceived interference with “having a life,” and the difficulty of staying on regimen - and the denial of HIV until a time of health crisis. An additional major barrier for men who have sex with men is substance abuse, which interferes with medications and creates instability. Other barriers include lack of insurance to cover medications and services, and the need for mental health services to address issues that may be keeping men who have sex with men out of care.

Strategies to address the barriers to care faced by men who have sex with men were divided by the group into **three** primary categories, including measures to deal with: **1)** The homophobia of the health care system; **2)** Internalized homophobia; and **3)** Medication overwhelm. In the first category, a primary strategy involves providing sensitivity training for all clinicians and service providers, and expanded hiring of gay staff members. Also identified was the need for off-site services free from the context of the traditional medical establishment, in order to provide a comfortable and non-threatening environment. A further strategy may be to institute a system of accountability for providers -- in addition to existing grievance procedures – in order to guarantee sensitivity of services. To address internalized homophobia, a number of strategies were suggested. These include training provider staff to be sensitive to all religions to avoid strict interpretations of religious dogma; reclaiming spirituality in the context of personal health care; involving the religious community in addressing issues of HIV, sexuality, and shame; providing mental health and social support approaches to help gay men feel better about themselves; and using counseling and support groups – particularly professional models of such approaches as opposed to short-term or peer-based approaches.

Development of methods to lessen the stigma associated with seeking out mental health and other supportive services was also seen as crucial. For isolated individuals, contact with other gay men like themselves could be effective and valuable, including peer counseling and mentoring from older to younger gay men. In general, strategies that validate gay culture and celebrate community were seen as essential to keep people in care. Strategies to deal with medication overwhelm among gay and bisexual men in care included the following: offering more medication alternatives, including training medical professionals to give competent referrals for alternative therapies; increasing patient education prior to prescription, including one-on-one counseling and advice; and incorporating nutrition advice into an overall health plan. Clients could also be taken through a distinct process when going on medications. Better training of providers and treatment educators on medication effects and nutrition is also important. In addition, better strategies for helping clients stay with their medication regimen on a long term basis are needed. Offering incentives for some populations for whom quality of life itself is not an incentive may be an effective strategy.

MENTAL HEALTH BARRIERS AND ISSUES

Mental health-related barriers to HIV care encompass a wide variety of illnesses and conditions, including depression, anxiety, anti-social behaviors, substance abuse, Schizophrenia, AIDS dementia, and many other conditions. At the same time, the lack of availability of basic mental health support for clients **not**

suffering from serious mental illness – such as basic counseling, support groups, and short-term therapy – can serve as an important limitation that keep individuals from entering and remaining in care. While barriers such as homelessness, lack of family or community support, and distrust of mental health treatment certainly are factors in keeping people out of care, the discussion group agreed that primary barriers in this category appear to be **1) Knowledge barriers**, including a lack of information on how to access mental health and HIV services, and a lack of understanding of HIV issues among mental health providers; **2) Barriers associated with shame and stigma** regarding mental illness and HIV; and **3) Barriers to care within the HIV delivery system.**



Included in the **first** category related to **knowledge** are such specific barriers as lack of knowledge about HIV among mentally ill populations; a lack of knowledge regarding where to go for HIV treatment; lack of skills to access treatment; and reluctance to take HIV medications, particularly based on fears of interactions with drugs to treat mental illness. Mental health providers may also often lack knowledge concerning HIV; do not know how to identify or deal with problems associated with HIV/AIDS; and do not know how or where to refer patients for HIV services. In the **second** category, **shame and stigma** pose significant barriers for mentally ill populations. Many men and women living with mental illness may suffer from low self-esteem, or fear that HIV or health care providers will reject or belittle them based on their conditions. Others have confidentiality concerns, or are in denial about their level of illness. Still others may have a host of phobias associated with institutions, doctors, interaction with others, and HIV specifically. In the **third** category, the **HIV service system** itself also presents significant barriers to care for mentally ill populations. These may include too much paperwork or bureaucracy for patients to access care comfortably; unwieldy intake processes; a lack of coordination of services; a lack of funding and services for multiple-diagnosed patients; and denial of access to health services for Medi-Cal patients. Other barriers to care may include lack of transportation; masking of mental health problems with substance abuse; and a lack of stable address or contact information for mobile and poor populations.

In order to address knowledge-related barriers, the group believed it would be useful to provide comprehensive mental health service information directly at the time an individual receives his or her HIV diagnosis, along with distribution of usable resource guides for accessing mental health services in a range of languages. This could also include the use of videos to educate patients in potential mental health issues, and to give advice on recognizing warning signs of mental illness and accessing services early. Extensive training of mental health providers is also needed to increase their ability to more effectively care for people with HIV. Meanwhile, expanded training of HIV service providers – particularly in identifying mental health issues and making qualified referrals - would greatly increase the overall quality of HIV care. In general, the group agreed that HIV agencies should incorporate regular, ongoing mental health assessments for **all** their case-managed clients, with a special focus on preventing depression and hopelessness by providing services and support at the time of HIV diagnosis.

These efforts should include consistent follow-up over a period of time to check patient condition and to ensure that clients are keeping their initial service appointments. HIV agencies could also expand their efforts to educate people with mental health conditions on the availability of local services and programs, while providing buddy and peer advocacy support, especially to ensure medication adherence for these populations.

Strategies proposed to address mental health-related shame and stigma barriers included expanding peer advocacy services by people living with HIV who are coping or have coped with mental health issues themselves. The group suggested that such services might be particularly effective if provided by and for young people. The group also noted that expanded public information campaigns to decrease negative images around mental illness are badly needed in general, as are approaches that use terms that are less stigmatized than “mental health.” Strategies to address system barriers include instructional videos for newly diagnosed people living with HIV, and the availability of mental health-specific “Warmlines” to help clients navigate mental health services. The group also proposed formulating and implementing standards of care for presenting diagnosis information, and recommended expanded collaboration between primary care practitioners and mental health clinicians as a way to improve integrated care for patients living with HIV and mental illness.

POVERTY, ECONOMIC ISSUES, AND HOMELESSNESS

The discussion group stressed the fact that poverty and homelessness can frequently create insurmountable barriers to care that are neither rapid nor simple to overcome. People living in **poverty** face great difficulty in meeting basic life needs such as food and housing, and often do not have time or energy to put their own health and medical needs first. This is particularly true for single parents caring for children, or for those who are responsible for the day-to-day operation of their households. Even those who are focused on their own health care may find it difficult to access medical and psychosocial services because of a lack of transportation, childcare, or phone service, or because clinical sites are only open during hours in which the person is working. Others in poverty may believe they are not eligible for health care, or may prioritize medical care over psychosocial services such as mental health care or substance abuse treatment – conditions that if left untreated can in time undermine the ability to remain on combination therapies. Care providers may also not treat impoverished populations with sufficient respect or understanding for these individuals to return for a second or third appointment.



People in **homelessness** face an even more daunting range of barriers to care, beginning with their own lack of knowledge regarding HIV health issues or of where to access health services, and continuing through the difficulty homeless people often have in utilizing conventional HIV health and psychosocial service programs. In many cases, the group noted, HIV providers may have rigid beliefs

and ideas about whether homeless people with HIV can access care, or whether they can remain on combination therapies effectively. Other agencies may have problems working with homeless people because of requirements that clients have an identifiable mailing address. Many homeless individuals live with a sense of hopelessness and pessimism in regard to the future that can keep them from monitoring their HIV status. Many homeless people are dealing with substance use and mental health issues that can impact their ability to access care until these are treated.

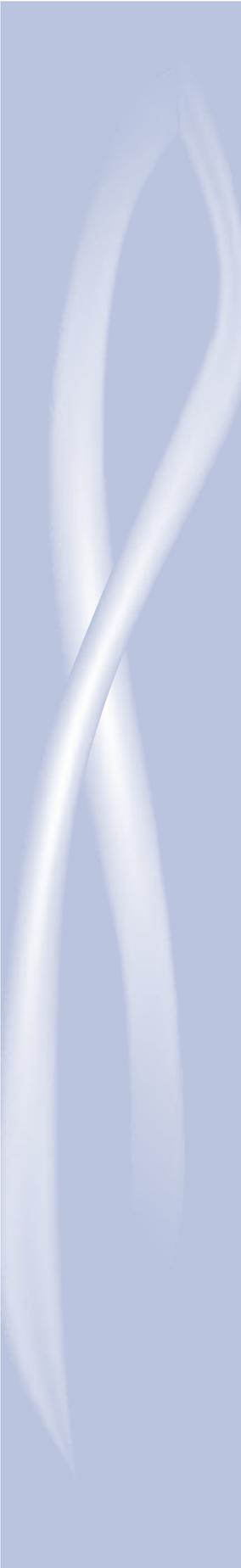
The discussion group identified several strategies for improving access to care for impoverished and homeless populations. Foremost was a need to address **basic needs** such as shelter and food. Perhaps the most important need among members of this population is for **stable housing** and for the linking of healthcare to housing and to places where homeless persons congregate. Providing transitional services such as health care, education, self-esteem building, and harm reduction programs within low-income housing facilities was seen as an effective strategy for facilitating access to care. Changes in the way in which service providers work with these populations were also suggested, including a need for greater rapport between case managers and clients; better cultural competency and sensitivity training in medical schools; an increase in community service work by doctors and nurses; and a variety of measures for decreasing staff burnout in this difficult service area. Measures for decreasing staff burnout in order to help staff building long-term relationships with clients might include expanded time off and sabbaticals; expanded support for continuing education; the use of non-paid interns; and having a regulatory body to examine reasons for high staff turnover.

A number of strategies were also proposed for dealing with the “no hope” attitude prevalent among many homeless persons. According to the group, providers need to offer services in new ways and provide consistency in service delivery. Connections to others need to be fostered, such as through a buddy system to deal with anger management. Job fairs targeting the homeless, field trips, “quiet” rooms and other changes in environment, and demonstration of barrier breakdowns were also seen as potentially effective strategies.

SEXUALLY ACTIVE YOUNG PEOPLE

The normal stresses of adolescence present a range of challenges to young people. However, adding a diagnosis of HIV or AIDS to this time of life can be devastating. Sexually active young people are at a time of their lives in which they are exploring a wide range of sexual and life options, and they may already have invincible attitudes that keep them from personalizing the health risks of having HIV, especially in that they are often focused on the ‘now’, rather than the future. The group noted that these issues can be complicated further for young people who have a history of sexual abuse; who face peer pressure regarding sex; are dealing with poverty and/or homelessness; are confronting substance use or mental health issues; are dealing with





pregnancy in the face of HIV; or are involved in abusive or neglectful family relationships or home environments. Many young people with HIV are homeless or runaway young people, or have been kicked out of the home by their parents, often for the same behaviors that caused them to contract HIV. Homeless young people are often engaged in survival sex for housing, food, or drugs, and face enormous self-esteem and self-destruction issues.

Young people living with HIV also face systemic barriers to care that include the stigmatization by providers of the personal sexual or substance use behaviors and choices that young people make. Negative attitudes such as these can cause many young people to discontinue care, or to become alienated from care before they have even begun a course of medical monitoring. Young people also lack their own personal resources, and often may not know how to access care without their own insurance, or without their HIV status being revealed through their parents' health plan. Young people who fear that specific sexual, drug use, or other behaviors will be revealed by seeking care may also choose to avoid treating HIV until they are diagnosed with a serious opportunistic infection. Young people also face many of the same barriers that confront adult populations, including the shortage of culturally and linguistically sensitive HIV service programs; organized religion and its relationship to stigma and shame; lack of peer support; immigration reporting fears; and fear of public institutions and medicine. Young people may also balk at the number of pills that have to be taken; the side effects of medications; and the fact that there is sometimes some degree of parental control over their healthcare. The group also noted that more and more members of this population consist of young people who have had an HIV diagnosis since birth, and who are accustomed to dealing with and monitoring HIV as an ongoing fact of their lives.

Strategies to deal with stigma and a lack of family support among sexually active young people may include having providers, churches and educators first create an environment for youth to share openly regarding sex and HIV. This type of environment needs to be created at work sites, at schools, and at places where adults and parents go. Small group workshops and counseling with adults and parents may help build skills that assist parents in a gentle way to face issues of sexuality and other behaviors, particularly with workshops that are run by health facilitators who keep these discussions broadly focused on health and wellness. Such forums may give information specifically to parents and adults to involve them in youth care; to encourage open and inclusive talk on support of youth activities; to encourage open discussion regarding sexuality, and to increase awareness of stigmas associated with HIV. Such programs may also recognize the difficulty parents have when youth begin to explore these issues outside the family; and should help parents understand when to be hands-on and hands-off on issues that youth face.

Public relations campaigns to raise awareness of HIV care issues among youth are another key strategy noted by the group, including advertising in mainstream publications and on television and radio, and expanding the availability of trained community and peer educators available to young people. The face of HIV in the media overall also needs to be changed, with an emphasis on HIV being **everyone's** issue. Strategies to deal with cultural issues include teaching people

that HIV is **not** a culture specific issue, and sponsoring **cultural summits** to reshape how families in particular cultural groups talk about HIV and sexuality.

TRANSGENDER PEOPLE

Transgendered persons face significant barriers to care, stemming in part from the lack of transgender-specific care and education within the society at large, and in part from the widespread discrimination and stigma members of these populations face. The culture of transgender people is a distinct and complex one, and the group believed that a lack of culturally effective and culturally sensitive care is one of the primary reasons people in this group are not in care. The group identified a wide range of additional discriminatory forces faced by transgender persons in the community. These include low self-esteem; social dysfunction; substance abuse and mental health problems; a lack of support from family and friends in areas such as coming out and/or transitioning between genders; and housing and employment discrimination, which can affect access to medications, meals, and general care. As with people in poverty, these and other issues may loom large enough in a transgendered person's life that basic needs like shelter, employment, and social support may force HIV into the background as a priority.



In regard to provision of care, the group more specifically identified an absence of transgender-identified programs and services; lack of general community education regarding transgender issues; lack of transgender staff in HIV agencies; bureaucracy forcing "identification" into male/female categories; lack of sensitivity in environments where services are received; lack of client transportation to access services; lack of access to internet resources, which are in themselves inadequate; inadequate understanding of legal issues relating to transgendered persons; and in general a minimal acknowledgement of the transgender community among providers.

The discussion group examined three areas of strategies in regard to these populations: **1) The need for more culturally effective and sensitive care; 2) Strategies to address self-esteem issues; and 3) Community education.** In the first category, the group stressed the usefulness of mandated trainings in transgender issues for medical, correctional, mental health, and shelter staff; preferably with at least part of the trainings provided by transgender trainers living with HIV. The group also suggested hiring more transgender staff in HIV and medical service agencies; asking gender questions as a standard procedure early in the client relationship; and encouraging a broader view of gender identity as part of the larger array of overall diversity issues. Strategies to address self-esteem issues include networking among providers; education regarding appropriate referrals; developing support systems beyond the gay/lesbian/bisexual/transgender communities; and educating health care allies on transgender issues. The group also placed an emphasis on proactive, positive messages and media campaigns; on creating welcoming and safe service facilities; on doing the research necessary to create a supportive environment for transgender clients; and on working

with transgender clients to ensure that their needs are being met. Also included among self-esteem strategies was providing prevention case management **before** a positive diagnosis to help overcome barriers, and widening the availability of support groups, counseling, and other incentives to invite participation in such programs. Finally, in regard to community education strategies, the group emphasized programs to promote understanding of transgender issues and transgender people within the community at large and the HIV and medical service communities in particular. These could include, for example, creating programs to allow transgender people to describe their lives and realities through creative approaches such as writing and arts workshops; and making presentations in the community at large about transgender issues through transgender speakers and presenters. The group also suggested increasing linkages between the HIV service and transgender communities as a way to promote understanding and access to services, including by targeting clubs and social groups affiliated with the transgender community, and by using a variety of interactions, including humor, to engage community members. Linkages to other non-HIV organizations serving transgender people was also stressed, as was the need for follow-up to ensure that referrals occur and are appropriate.

WOMEN

The discussion group identified a range of barriers to care for women, including the overarching issues of domestic violence, substance use, mental health



issues, and cultural and socioeconomic issues. **Domestic violence** presents a nearly insurmountable barrier to care if a woman fears a partner's retribution if her HIV status or the behaviors that led to her HIV infection are disclosed. **Substance use** may stop women from seeking services if they are unable to access care while they are using, or if they are not focused on self-care as a result of their addiction. Substance use can also lead to additional barriers to care such as poverty and homelessness. **Mental illness** conditions frequently affecting women include depression, schizophrenia, and bi-polar disorders.

Cultural or socioeconomic barriers to care include poverty; stigma regarding mental health care - particularly among Latina and African American populations; the necessity of staying at home and taking care of family; stigma against doctors and Western medicine; and a lack of trust in institutions in general.

Other barriers include lack of medical secrecy when attending clinics as opposed to a private doctor; a fear of lack of confidentiality; lack of insurance and medical coverage; lack of knowledge of available services; and a lack of women providers, particularly women of color. Women who are caring for children or a family - particularly low-income women - frequently lack access to transportation and child care services to allow them to attend medical and psychosocial appointments, while a loss of economic opportunities, including unemployment, can create depression, incapacity, and a need to focus on the primary necessities of life as opposed to HIV. In general, a lack of women-specific services and pro-

grams within the HIV service system was also cited by the group as a significant barrier to care.

Strategies for bringing women into care covered a similarly wide range of issue areas. Strategies to deal with **domestic violence** include broadening the availability of family focused care; building trusting relationships between clients and providers over time; developing programs to build women’s self-esteem; forging partnerships with domestic violence agencies; educating providers on domestic violence issues and signs, building a network of providers; and building “Hen” parties or women’s support groups. Strategies to deal with **substance use** among women include programs to address both prescription and non-prescription “street drugs”; using straightforward language in a respectful manner that women can understand; creating awareness of the stigma of “substance abuser”; broadening harm reduction approaches to HIV care; and building greater awareness for the prevalence of alcoholism as a distinct substance use issue. The group also suggested that more programs be developed that combine mental health and substance abuse information/education to make up for time constraints and to provide a “one stop shopping” environment for services. Strategies to deal with **cultural barriers** include training of medical and service providers in women-specific medical and psychosocial services, particularly from a culturally competent perspective, and providing greater linkages between medical and service providers via triage and case conferences. The group also suggested developing assessments for providers in the area of cultural sensitivity, and the integration of **cultural competence** into standards of care. Practical strategies for increasing provider effectiveness in regard to women’s services include training in fundraising; overcoming political hindrances between agencies and staff; providing multi-cultural staff who speak different languages; and increasing quality assurance and program evaluation in order to keep track of outcomes.

YOUNG MEN WHO HAVE SEX WITH MEN

The discussion group defined the population of young men who have sex with men as being between the ages of 12 and 24 years of age, and falling into **two** basic categories: **1)** Young men who self-identify as or are on a path toward being gay-identified, and **2)** Young men who have sex with other men largely in secret, or “on the down low,” whether these young men are closeted, bisexual, or experimenting. In regard to young men who are growing into a gay or bisexual identity, barriers to care for this population tend to center around the exclusion by the medical system of lesbian, gay, bisexual, transgender, and questioning (LGBTQ) young people and their experiences. Young people in this group may also feel a sense of shame resulting from being young and seroconverting (e.g., “You should have known better”), or may fear that health care providers will judge their status negatively (e.g., “How can you be HIV positive with all the prevention information that’s available?”). The group also felt that an increasing number of young men believe that HIV is no longer a life-threatening medical condition, or that it can not affect them personally – a fact that may keep young



people both from getting tested and from seeking care if they are HIV positive. Some young people may feel that they can put off medical care because HIV will not affect them for many years due to their youth – a factor that builds on an already-present sense of invulnerability and immortality in many young people. The fact that youth have no direct memory of a time when HIV took more lives more rapidly increases the difficulty in breaking through this barrier.

In regard to young men with HIV intent on hiding their same-sex behavior, the group noted that young men in this group may have great apprehension about other people finding out about their HIV status or their sexual behavior if they visit a center or provider – a fact that may keep them out of treatment for months or years. Young people also may be at widely differing levels of personal development both in terms of their sexuality and their identity. These issues can affect young people's willingness and ability to seek care, regardless of age. Other barriers identified by the group include homophobia within the medical system; a lack of youth-specific services; substance abuse issues among youth; cultural norms and family circumstances; lack of transportation; and survival issues among poor and/or homeless youth that causes HIV to be pushed into the background as a priority.

The group believed it was important to develop strategies of care that were both more welcoming to young gay and bisexual men, and safer and more inclusive for young men on the down-low. In the case of young men coming into a gay or bisexual identity, the group felt it was critical that service providers be well-versed in the issues facing young men who are coming to terms with their sexuality, and that providers be competent both in the cultural issues facing their clients, and in issues related to youth in general. Providers working with young gay male populations need to continually stress both the normality of being gay or bisexual, and the fact that HIV exists and needs ongoing medical attention. The group felt that achieving this goal will require training providers in youth development issues, and hiring more young gay men as peer advocates to work with other newly-diagnosed young men who are coming to terms with HIV. For young men on the down-low, the group believed it was important to develop non-judgmental outreach and educational materials for young men that do not single out gay young men specifically, but that are instead inclusive of males from **all** ranges of sexual behavior and exploration. Such messages, for example, could focus on young men's health and sexuality **in general** – an approach to male youth wellness that is rarely employed presently. It is also critical to provide these populations with places to access care that are confidential and anonymous, and that are fully accessible to young people who may lack transportation of their own – particularly in the case of low-income young people and youth under age 16.

For **all** populations of young men who have sex with men, the group noted the importance of working directly with young people to develop messages and materials to reach members of their own community. The group also proposed a series of **retreat camps** for recently diagnosed HIV-positive young people to allow them to assess their lives, prioritize their needs and goals, and receive HIV education and empowerment and leadership training, including through support from **mentors**. Building the **self-esteem** of young men who have sex with men is critical, whether or not these young people eventually identify as gay or bisexual. Youth speakers bureaus and HIV-positive youth buddy programs can be extreme-



ly effective both in overcoming denial around HIV diagnosis and in overcoming internalized homophobia that limits a sense of self-protectiveness.

OTHER POPULATIONS AND ISSUES

The intent of the “Other Populations and Issues” discussion group was to identify populations and barriers that were **not** included in the other focus groups developed for the Out of Care Summit. To respond to this change, the group first identified some of the key HIV-affected groups who face barriers to HIV care that were not the subjects of the Summit’s out of care discussion groups. The primary populations identified through this process were the following:

- Asians/Pacific Islanders
- Native Americans
- Seniors (Men and Women 50 Years of Age and Over)
- Infants
- Developmentally Disabled Populations
- People Co-Infected with Hepatitis C and Other Conditions

Because of the large number of populations identified, the group focused on identifying key **barriers** for each of these populations, rather than developing an extended list of suggested strategies. However, an overarching strategy that presented itself for each of the populations below involved **increased training of providers** to offer more competent, effective care to members of the groups below.

Asians and Pacific Islanders encounter a range of barriers due to language and culture. In Alameda and Contra Costa Counties, multiple Asian languages and cultures exist – including Laotian, Filipino, Burmese, Chinese – and language and cultural barriers are significant for each population. In addition, many persons from these cultures are refugees, asylum-seekers, or recent immigrants. It is devastating to immigrate and discover that one is HIV-positive. Many fear being “outed” in small communities, a fear closely related to the fear of lack of privacy and confidentiality within service settings. Within these communities, there may also be a lack of knowledge about risk, greater fear of transmission, and high levels of denial, such as the belief that “we don’t have gay people.” Additionally, cultural beliefs or practices may pose barriers, such as a sense that HIV is karma, punishment, or that Western medicine is not to be trusted. In many of these communities, there is also often shame associated with sexuality (especially homosexuality), and talk of sexuality may be taboo. The difficulty in disclosure may be exacerbated by the fact that there is sometimes little privacy in living conditions. Family is of paramount importance within Asian/Pacific Islander communities, and family concerns, including fear of being outed, may take precedence over HIV care. As with other immigrant populations, access to HIV care and knowledge of HIV services may be reduced due to lack of culturally accessible information.



Native Americans face other types of barriers. Generally, Native American populations live in small pockets within rural areas, and may be isolated as individuals and families, often living peripherally to society. There is little cultural competency among service providers regarding traditional Native American health care, and almost no strategies for integrating western health approaches with Native American beliefs. For this reason, Native American distrust of Western medicine may serve as a long-term barrier to seeking HIV services.

Many group members believed that **seniors** with HIV might not know their HIV status because of a belief that they are not at risk for becoming infected. While sexual activity is more common among seniors than the social taboo against such activity may allow us to admit, there may often be a sense of shame regarding such activities among seniors, or a sense that they should know how to avoid HIV infection. Fear of disclosure in these cases may lead to an unwillingness to seek care. By the same token, seniors must deal with a range of additional health issues that may push down HIV on one's overall scale of health priorities. For seniors on low or fixed incomes, there may be a reluctance to seek care for fear of high costs or a fear of lack of coverage to cover HIV medications. As elderly men and women with HIV live longer lives, there may be increasing needs for in-home care and support, particularly to help with medications, and to provide transportation and ensure mobility.

Because **infants** with HIV cannot serve as their own advocates, they must rely on their parents and on the HIV service system as a whole to ensure that they receive adequate medical attention to prevent or delay the onset of HIV-related conditions. Because of the importance of early intervention during pregnancy, many group members noted that a lack of access to or non-utilization of prenatal care serves as a significant barrier to infants receiving the early attention they need to avoid HIV infection or HIV-related illness. For poor or substance using mothers, however, there may be reluctance to seek prenatal services because of the fear of losing one's infant to a public agency. Group members also noted the general segmentation of health services between adult and pediatric medicine, which sometimes results in a lack of integration of parent and child care, particularly where both the parent and child are infected with HIV. Group members felt that greater **coordination** of HIV services on a family-wide basis could improve care for both infants and their parents.

Developmentally disabled populations face a range of barriers to care, many related to their dependence on others for basic health and self-care information. Group members felt that there was a general lack of information on HIV services provided to developmentally disabled groups, and a lack of knowledge of how to serve these populations within caregiver communities. Other disabled populations - including physically disabled and hearing impaired populations - face a similar lack of ability on the part of many HIV groups to effectively serve them.

People infected with hepatitis C face a complex range of challenges as they attempt to deal with the effects of HIV and hepatitis C. The already-difficult problem of accessing services is increased for many of these individuals, since hepatitis C services are still generally not integrated into non-medical HIV services. A general lack of integration between HIV and hepatitis C providers results in fragmented services that inadequately address the need for integration of services for these groups. Other health conditions apart from hepatitis C, such as heart

conditions, cancer, and other ailments, present similar needs for service integration and coordination among both health and social service providers.

CONCLUSIONS AND NEXT STEPS

The Alameda/Contra Costa County Out of Care Summit produced significant new information regarding the reasons people are out of care, and important new potential strategies that might be employed to involve or re-involve them in the HIV care system. The following steps are designed to apply these findings in order to move the Alameda and Contra Costa County care systems forward in involving increasingly larger percentages of HIV-infected people in the region's comprehensive system of care.

- Step # 1:** Beginning in October 2002, the Oakland EMA HIV Services Planning Council – under the auspices of its Services Planning Committee - will undertake a three-month process to assess the strategies proposed in the Summit Report in order to identify those that can be effectively and appropriately implemented or adopted by the Planning Council. The recommendations that flow from this process will be brought forward to the Planning Council for review and preliminary adoption.
- Step # 2:** In early 2003, the HIV Services Planning Council, the East Bay AIDS Advocacy Foundation, and the Alameda and Contra Costa County AIDS Offices will co-convene a **Mini-Summit** of HIV care groups, agencies, and consumers within the two counties to consider the recommended strategies brought forward through the Out of Care Summit. The Services Planning Committee will report on those strategies that might be coordinated in whole or part by the Planning Council. Other participating agencies will then have the opportunity to take leadership on implementing other strategies as appropriate to their mission, expertise, and resources.
- Step # 3:** At the Mini-Summit, participating agencies will form an **Ad Hoc Committee on Out of Care Issues** that will prepare a report on the Mini-Summit, and oversee implementation of out of care strategies over an **18-month** period. This committee will act as an independent, collaborative body acting under the auspices of an independent agency such as the East Bay AIDS Advocacy Foundation, or another organization in Alameda or Contra Costa County.
- Step # 4:** On or before March 31, 2003, the Ad Hoc Committee on Out of Care Issues will summarize the results of the Mini-Summit in an **18-Month Comprehensive Out of Care Action Plan** for Alameda and Contra Costa Counties. The Plan will describe the activities to be undertaken to involve more people with HIV in care over the following year and a half, specifying in each case the agency or agencies that will be responsible for carrying out each activity, along with a proposed timeframe for enacting each action step. The Plan will include strategies for tracking the success of the Plan in bringing or re-involving people with HIV in care, such as through increases in caseloads at local HIV service agencies, or through the outcome of specific activi-

ties and programs organized as a result of the Out of Care Action Plan.

- Step # 5:** On or before April 30, 2003, the organizations that attended the original Mini-Summit will meet again to revise and approve the Comprehensive Out of Care Action Plan, and to set a calendar of future meeting times throughout the subsequent 18-month period.
- Step # 6:** Between May 1, 2003 and October 31, 2004, the Ad Hoc Committee will hold regular meetings to track progress toward Action Plan objectives, and to propose revisions in the Plan as needed. These revisions will include amending timeframes and organizational responsibilities to respond to problems that arise, and/or enhancing responses by building effective collaborations to address specific out of care issues. The All Ad Hoc Committee will distribute minutes of all meetings to Mini-Summit participants and other interested parties - including the HIV Services Planning Council - and will delegate responsibility for follow-through to specific Committee members
- Step # 7:** On or before July 31, 2004, the Ad Hoc Committee on Out of Care Issues will make a presentation to the Oakland EMA HIV Services Planning Council reporting progress on out of care issues, and recommending additional actions that could be incorporated by the Planning Council into its Fiscal Year 2005 Ryan White CARE Act Title I prioritization and allocation process. These findings may also be incorporated into needs assessment activities of the Council prior to this date.
- Step # 8:** On or before October 31, 2004, the Ad Hoc Committee will prepare a **Final Report** on the first 18-Month Comprehensive Out of Care Action Plan for Alameda and Contra Costa Counties, and will reconvene Mini-Summit participants to present the report, and determine whether or not to continue the Ad Hoc Committee. If the Committee is continued, Mini-Summit participants will begin to develop a **second** 18-Month Out of Care Plan, which builds on the lessons and successes of the first plan in order to continually expand the number of HIV-infected populations who are accessing consistent, quality HIV health and social services throughout Alameda and Contra Costa Counties. If the Committee is not continued, other regional planning and coordination activities may be initiated to move progress on out of care issues forward. Whatever form these actions take, they will be fully reported and incorporated into activities of the HIV Services Planning Council on an ongoing basis.

ENDNOTE

1 This figure is based on the total number of people estimated to be living with HIV in Alameda and Contra Costa Counties, as well as estimates from the U.S. Centers for Disease Control and Prevention (CDC) on the percentage of people living with HIV in the U.S. who know their HIV status and are not receiving care. As of December 31, 2001, a total of **3,382** individuals were living with diagnosed AIDS in Alameda and Contra Costa Counties. At the same time, an estimated **9,900** additional persons were living with HIV (not AIDS) as of that date, based on estimates by the Alameda and Contra Costa County epidemiology programs. This results in an approximate total of **13,282** people in the two counties living with HIV and AIDS. The CDC estimated in February 2002 that approximately **75%** of all people living with HIV know their HIV status, and that as many as **one-third** of these individuals may not be receiving care (Fleming, P., et. al., "HIV Prevalence in the United States 2000," Abstract Presentation at the 9th Conference on Retroviruses and Opportunistic Infections, Seattle, WA, Feb. 25, 2002, www.retroconference.org/2002/Abstract/13998.htm). If these percentages are successively applied to the 13,282 individuals estimated to be living with HIV and AIDS in the two counties as of December 31, 2001, we obtain a total of **3,422** individuals who know their HIV status but are not receiving care. At the same time, the disproportionately high impact of the HIV epidemic in Alameda and Contra Costa Counties on poor and disenfranchised communities means that a slightly higher percentage of individuals can be expected not to be receiving adequate or appropriate care, resulting in the **3,500**-person high-end estimate in this report.



