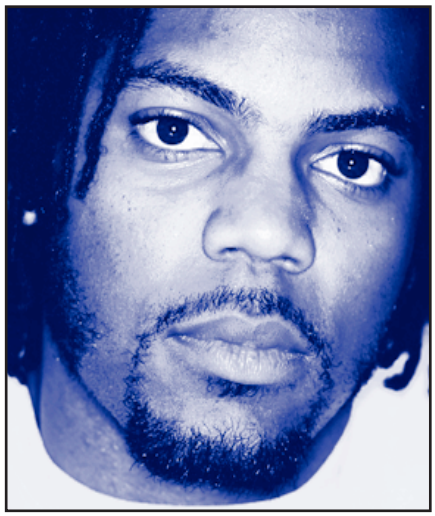
FINDING HIV-POSITIVE YOUTH
AND BRINGING THEM INTO CARE



AIDS Alliance for Children, Youth & Families

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FINDING HIV-POSITIVE YOUTH AND BRINGING THEM INTO CARE

by Positive Outcomes, Inc.

Cooperative Agreement, grant no. 5U69HA00037-03
AIDS Alliance for Children, Youth & Families

INTRODUCTION

The AIDS epidemic is a global and national public health crisis. This is especially true for young people between the ages of 13 and 24 and for the communities in which they live. HIV infection among youth is a significant portion of the epidemic and appears to be growing in the United States. Centers for Disease Control and Prevention (CDC) economists estimate that $3 billion in lifetime HIV medical costs will be generated by HIV-positive youth in the United States.

For a variety of reasons, the exact nature of the epidemic among youth is difficult to describe. The vast majority of HIV-positive youth remain unaware of their infection (Murphy, Durako, Moscicki, Vermund, Ma, Schwartz, & Muenz, 2001). Most young Americans do not believe they are at particular risk for HIV infection, so they are not learning about their serostatus (Office of National AIDS Policy, 2001). Even so, a considerable number, perhaps as many as one-third of all young people who are infected, have been tested for HIV within the last year.

Finding HIV-Positive Youth and Bringing Them Into Care is a resource for programs interested in developing or expanding outreach services to identify HIV-positive youth and engage and retain them in care. It provides practical suggestions for organizing youth-centered outreach programs and delivering services and offers checklists for key areas. The guide was developed for AIDS Alliance for Children, Youth & Families by Positive Outcomes, Inc. It incorporates findings from a Positive Outcomes study of over 30 youth-centered HIV programs funded through the Ryan White CARE Act to reach HIV-positive youth and engage them in care.

With support from the HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA), Positive Outcomes contacted Title I, II, and IV grantees to identify programs with innovative youth-centered activities and summarized peer-reviewed literature and HAB-funded reports published since the early 1990s related to engaging and retaining HIV-positive youth in care. AIDS Alliance also interviewed HRSA staff and surveyed programs across the country funded by Title IV.

HIV and Youth in the United States

In the United States, adolescents and young adults comprise a growing number of the HIV and AIDS cases reported in recent years. CDC estimates that at least 15,000 youth 13 to 24 years of age are HIV-positive, although inadequacies in the HIV reporting system mean that this estimate is likely low.

HIV and AIDS among youth occur disproportionately among young people of color, particularly African American youth, who make up only 15 percent of American teenagers but accounted for 65 percent of new AIDS cases among teens in 2002 (Kaiser Family Foundation (KFF), 2005a). Latino youth are also overrepresented in the epidemic among youth. In 2002, they comprised 16 percent of American teens, but accounted for 20 percent of new AIDS cases that year (KFF, 2005b).

Particularly at risk are young men who have sex with men, African American teen girls – who made up half of the HIV cases reported among teens in 2002 — runaway and homeless youth, and youth who inject drugs.

Surveillance data from 25 states with integrated HIV and AIDS reporting systems also indicate that young people 13 to 24 years of age accounted for a much greater proportion of HIV cases (13 percent) than AIDS cases (4 percent) between January 1996 and June 1999. These data also show that even though AIDS incidence is declining, there has not been a comparable decline in the number of newly diagnosed HIV cases among youth and young adults. CDC epidemiologists believe that cases of HIV infection diagnosed among youth 13 to 24 are indicative of overall trends in HIV incidence because this age group has more recently initiated high-risk behaviors.

The increasing impact of HIV in young people is occurring at a time when great advances have been made in HIV therapies. These advances have made it possible for HIV-positive children, adolescents, and adults to survive many years beyond the time of diagnosis and to lead productive, albeit challenging, lives. The impact of HIV therapies is particularly noteworthy among HIV-positive youth who were infected perinatally or through blood products. Significant numbers of youth now treated in adolescent HIV clinics around the nation have “graduated” into these programs from pediatric HIV clinics. Such longevity was unthinkable a decade ago, when most HIV-positive children died before their tenth birthday. Further, people diagnosed during adolescence now survive well into their twenties, with many maturing into their thirties.

The success of HIV care and psychosocial support among HIV-positive children and adolescents has led to the development of specialized youth-centered HIV clinical, psychosocial, and outreach services. Staff in youth-centered HIV programs view their work as part of a lifelong continuum of care that transitions clients from pediatric to youth and from youth to adult services in a seamless care continuum.

Federally and locally funded youth-centered HIV initiatives have yielded substantial knowledge about how to effectively design and implement outreach services. When comparing CDC surveillance data with reports from projects funded by the federal HIV/AIDS Bureau, however, the number of HIV-positive youth enrolled in care is generally far less than the number of youth estimated to be HIV-positive. Some experts believe that as many as 60 percent of young people living with HIV are not in routine HIV care. Youth-centered HIV programs report that one of the most challenging aspects of working with HIV-positive youth is engaging them initially and retaining them in care once they are enrolled. Despite the best efforts of outreach staff, lost-to-follow-up rates remain undesirably high.

HIV-positive youth, particularly those disenfranchised from economic and social systems, are often underserved by pediatric and adult HIV and broader care systems (Tenner, Feudo, & Woods, 1998). Significant barriers to care include:

- lack of a trusting caregiver;
- cultural incompetence and linguistic incompatibility;
- age inappropriateness;
- lack of information about youth-centered services;
- laws and institutional policies governing adolescents' rights to confidentiality and consent;
- insufficient income or health insurance;
- inability to independently qualify for entitlement programs;
- complexity of gaining access to health care institutions;
- perceptions of invulnerability that often delay seeking medical care;
- lack of stable housing;
- economic and employment instability;
- lack of family support;
- communication issues with authority figures;
- high rates of unmet mental health needs;

- slow referral processes; and
- limited transportation resources.
  (Rosenfeld, Keenan, Fox, Chase, Melchiono, & Woods, 2000)

Engaging HIV-Positive Youth in Care: An Overview

HIV infection among youth is also likely to be under-reported because youth commonly lack access to medical care for HIV diagnosis and treatment (Lynch, Krantz, Russell, Hornberger, & Van Ness, 2000). An unknown, but probably substantial number, of HIV-positive adults between 25 and 35 years of age were likely infected when they were adolescents or young adults. Commonly, it is only when they become symptomatic for HIV infection that they seek HIV care.

HIV-positive young people are a diverse group, differing in age, gender, sexual orientation, race and ethnicity, educational attainment, economic circumstances, and cognitive abilities. HIV-positive youth also experience differing rates of mental illness, chemical dependency, social isolation, and lack of economic opportunity. HIV-positive youth are more likely to be female, men who have sex with men, from racial/ethnic minority populations, and from economically deprived groups than their uninfected counterparts. HIV-positive youth tend to be infected through sexual activity at higher rates than older HIV-positive individuals. High-risk sexual behavior is the dominant mode of HIV transmission among youth. HIV-positive young men are much more likely to acquire the virus through same-sex contact including unprotected anal intercourse. HIV-positive young women are more likely to be infected through heterosexual activity, such as unprotected vaginal and anal intercourse. HIV-positive youth tend to be infected at lower rates through injection drug use than older HIV-positive individuals.

High-risk sexual behavior is common among youth, primarily associated with a culturally prevalent expectation of sexual interaction among this age group. Almost one-half (46 percent) of U.S. high school students and almost 80 percent of college students between 18 and 24 years of age have engaged in sexual intercourse (Robinson, Telljohann, & Price, 1999). Almost 7 percent of students report initiating sexual intercourse before the age of 13 (Lammers, Ireland, Resnick, & Blum, 2000). Almost one-half (47 percent) of teens who have engaged in sexual activities report feeling pressured to do something they were not necessarily ready to do.

Features of Adolescence and Young Adulthood That Affect HIV-Related Behavior

In developing youth-centered HIV identification, engagement, and retention activities, it is critical to understand the developmental stages and changes of adolescence and reflect that understanding in outreach and care strategies. Relevant

changes among younger teens include physiological growth and maturation, intense sexual feelings, movement away from dependence on parents to peers, and growth of abstract thought, such as logical skills and understanding of cause and effect. As they age and mature, youth increase their ability to take responsibility for planning and evaluating their own actions. Adolescent development features periods of self-consciousness and self-criticism, bouts of low self-esteem, mood swings that can be caused by hormonal changes and depressed thinking, an increased desire for independence, and vacillation between what could be described as rational versus irrational decision-making (Centers for Substance Abuse Prevention, 1993).

Older teens who may have overcome some of the challenges of early adolescence may still be concerned with body image. They are likely to have a strong desire for social status. They may want to belong to a group but also want to be unique individuals. They may have reached high levels of abstract thinking and problem solving, with increased self-knowledge and development of a personal philosophy. Emotional changes are associated with older adolescence, with feelings of inferiority and inadequacy competing with a desire for independence and development of an individual identity.

These developmental features of adolescence and young adulthood are important considerations in designing youth-centered HIV identification, engagement, and retention activities. Recognizing and addressing these features increase the likelihood that youth-centered HIV services will be successful.

A Checklist for Understanding HIV-Positive Youth

- ☑ Identify training programs in your community that focus on behavioral aspects of adolescence and young adulthood. Ensure that your outreach staff receive formal training in these topics.
- ☑ Collaborate with experts in your community who are trained and experienced in behavioral aspects of adolescence and young adulthood to design or enhance your youth-centered HIV outreach program.
- ☑ Identify ways to include HIV-positive youth in designing services, choosing venues in which outreach can be undertaken, and determining ways to best identify youth and engage and retain them in care.

DEFINING YOUR PROGRAM'S YOUTH OUTREACH SERVICES

Targeted Outreach

Targeted outreach requires deploying outreach staff to places, neighborhoods, and communities where youth live, work, socialize, and learn. Outreach encompasses interacting with young people in these environments, establishing ongoing relationships, building trust, educating, introducing behavior change, and inviting use of HIV services, both medical and psychosocial support services. HAB has identified key points of entry into care for youth (see Table 1) that should be considered for outreach activities to HIV-positive youth or youth at risk who have not been tested.

Targeted "in-reach" involves identifying and working with programs within your own agency that serve HIV-positive or at-risk youth and creating relationships to ensure their transition into care. For example, if your HIV program is located within a hospital system, in-reach might focus on emergency departments or urgent care centers where HIV-positive youth seek episodic care for HIV-related conditions, adolescent or sexually transmitted infection (STI) clinics, and obstetric-gynecology clinics where HIV-positive pregnant youth receive prenatal care.

Outreach is commonly provided by peer or "near-peer" workers who share many, but not all, characteristics of the target youth population. These outreach workers are closely linked with adult professional supervisors who train, guide, and support them. In the words of one HIV-positive youth program staff member, "outreach staff must be close to the target population and related to them and their issues."

Outreach Models

Several approaches can be taken to identify HIV-positive youth and engage and retain in care. Direct community outreach recruits HIV-positive youth into services through individual outreach in community-based settings.

***HAB defines outreach services** as "programs which have as their principal purpose identifying people with HIV disease so that they may become aware of and may be enrolled in care and treatment services (i.e., case finding), not HIV counseling and testing nor HIV prevention education. Outreach programs must be planned and delivered in coordination with local HIV prevention outreach programs to avoid duplication of effort; be targeted to populations known through local epidemiologic data to be at disproportionate risk for HIV infection; be conducted at times and in places where there is a high probability that HIV-infected individuals will be reached; and be designed with quantified program reporting that will accommodate local effectiveness evaluation." HAB (2003), Attachment A.*

DEFINING YOUR PROGRAM'S YOUTH OUTREACH SERVICES
CONTINUED

Table 1
Points of Entry of HIV-positive Youth Into the Care Continuum

- HIV counseling, testing, and referral (CTR) sites
- Emergency rooms and urgent care centers
- Substance abuse treatment programs
- Detoxification programs
- Adult and juvenile detention facilities
- Sexually transmitted infection (STI) clinics
- Federally qualified health centers
- HIV disease counseling and testing sites
- Mental health programs
- Homeless shelters
- Public health departments
- Current Title I, II, III, and IV providers
- Hemophilia diagnostic and treatment centers
- Migrant health centers
- Community health and family planning centers
- Nonprofit private agencies providing comprehensive primary care to youth at risk of HIV

Peer outreach workers with a supervised, limited scope of work can serve an important role in encouraging newly identified HIV-positive youth to engage rapidly in care. Outreach workers can be incorporated into counseling, testing, and referral (CTR) sites to provide information and referral to newly identified HIV-positive youth about the availability of prevention case management, HIV clinics, case management agencies, and psychosocial support services.

Once HIV-positive youth are identified and invited into youth-centered HIV primary medical care, outreach workers serve an important role in ensuring that youth are engaged and retained in routine care. Outreach workers can work with clients to keep their medical and other appointments, follow up on referrals for laboratory and medical specialist visits, and maintain routine contact with their case managers. Outreach workers also are essential in locating clients who have missed appointments or dropped out of routine medical or case management. Outreach workers can conduct home visits or visit venues clients are known to frequent to contact them, discuss reasons why they have dropped out of care, identify barriers to care, and invite them to return to care. Such case finding activities should be closely coordinated with case managers to identify and remove barriers to retention in care.

Outreach workers' scope of activities is designed to enhance the care team's ability to work with HIV-positive youth, eliminate duplicative activities, and enhance youth-centered services. Since outreach workers may have limited professional training, they are closely supervised by experienced professionals to ensure that they are effective in their defined role.

There are generally two levels of outreach:

- **Low Intensity Outreach** involves outreach workers who contact potential clients at key points of entry into care. This type of outreach is characterized by provision of brief information about available HIV care and support services. Its main goals are to disseminate HIV information within the target audience, influence social norms to encourage HIV secondary prevention and use of HIV services, and make HIV care and support services accessible and acceptable to HIV-positive youth.
- **High Intensity Outreach** involves in-depth intervention in which individualized screening takes place with specific needs identified and service referrals made. Such outreach includes activities such as meeting with HIV-positive youth to discuss available services, attending case conferences with service providers at key points of entry, visiting repeatedly to establish relationships with youth at-risk for HIV infection, and meeting with the sex or drug-using partners of HIV-positive youth in care. The goal of this outreach is to identify specific HIV-positive youth and recruit them into services that will benefit their health and well-being. In addition to HIV CTR, service links often include addiction treatment or emergency food and shelter.

Several models are commonly adopted to organize outreach to HIV-positive youth. Youth-focused agencies tend to develop HIV outreach programs in collaboration with youth-centered HIV clinics, case management programs, or other HIV service providers. Youth-focused agencies tend to serve the needs of youth in their service areas, with multiple service programs available for youth such as education, vocational training, substance abuse and mental health services, and recreation. Youth-centered HIV clinics may include outreach services as part of their continuum of HIV services. In clinics, outreach workers may work closely with other members of a multidisciplinary team to provide youth-centered care. HIV case management agencies may also provide youth-centered outreach in close collaboration with youth-centered HIV clinics.

DEFINING YOUR PROGRAM'S YOUTH OUTREACH SERVICES
CONTINUED

A Checklist for Defining Outreach Services for HIV-Positive Youth

- ☑ Establish preliminary written goals and objectives for your youth-centered HIV outreach activities.
- ☑ Identify the outreach models that work best in your organizational environment and that optimize the staffing and other resources available.
- ☑ Identify the types of outreach that best meet the needs of the population of HIV-positive youth that your program wants to serve.
- ☑ Determine the staffing model that works best within your organizational culture and that meets the human resources requirements of your agency.
- ☑ Define the workscope of outreach workers, their roles and responsibilities, and the role of supervisors in monitoring outreach workers' activities.
- ☑ Identify organizations experienced in youth-centered services that your program can collaborate with to conduct outreach services.
- ☑ Identify key points of entry into HIV care that your program can collaborate with in conducting outreach.
- ☑ Identify programs within your organization within which to conduct in-reach activities.

IDENTIFYING YOUR PROGRAM'S TARGET POPULATION

Successful engagement and retention of HIV-positive youth are based on a careful, well-informed identification of the target population, assessment of their needs, and identification of agencies with which to partner. Your program can undertake several activities to help guide development or refinement of youth-centered HIV outreach:

- epidemiologic profiles;
- comprehensive needs assessment;
- resource inventory; and
- gap analysis.

***Epidemiologic profiles** describe characteristics of the general population of youth and specific youth who are living with, or at high risk for, HIV infection who may be the target for outreach services; the HIV epidemic among youth; neighborhoods or cities with relatively high rates of HIV infection among youth from which your program's service area can be defined; and the demographic, clinical, and epidemiologic characteristics of sub-populations of youth.*

Several federal resources are available to help your program design and undertake planning activities:

- *Integrated Guidelines for Developing Epidemiologic Profiles: HIV Prevention and Ryan White CARE Act Community Planning,* US DHHS, CDC, (2003). Available online at: http://www.cdc.gov/hiv/epi_guidelines.htm.
- *Needs Assessment Guide, 2003 Version,* US DHHS, HRSA, HAB, (2003). Available online at: http://hab.hrsa.gov/tools/needs/.

Epidemiologic Profiles

Commonly available epidemiologic data can help your program estimate the number and characteristics of HIV-positive youth, including demographics, geographic origin, HIV exposure categories, and AIDS-related clinical conditions. Data gathered over time provide useful trend analyses for understanding whether HIV infection rates are growing, declining, or remaining stable. Comparing trends among HIV-positive youth also helps to identify geographic or demographic targets for outreach. Epidemiologic reports and administrative data generated by counseling, testing, and referral sites and CARE Act-funded programs are useful in

identifying key points of entry into care, sources of HIV care and psychosocial support services, and barriers to engagement and retention in care.

Sources of commonly available epidemiologic data include:

- ***HIV/AIDS Surveillance Reports*** are published by CDC and by state and local HIV surveillance programs. These reports provide data on new and cumulative reported AIDS cases, with breakdowns by state and metropolitan area, gender, age group, HIV exposure category, race/ethnicity, and other categories. They also present case fatality rates and the estimated incidence of AIDS-defining opportunistic illnesses. In many states, similar data are available through the HIV surveillance system.
- ***HIV Seroprevalence Reports*** measure the rates of HIV infection among selected populations targeted for surveys. CDC periodically publishes a National HIV Serosurveillance Summary that provides information on the percentage of people in high-risk groups testing HIV positive. Sometimes data are aggregated by state or eligible metropolitan area (EMA) or by gender, race/ethnicity, and HIV exposure categories to document geographic and epidemiologic patterns of HIV infection. By reviewing data from different periods, you can analyze trends in HIV seroprevalence rates among youth.
- ***HIV Prevalence Estimates*** are published by CDC and estimate the number of people living with HIV by gender, race/ethnicity, HIV exposure category, and stage of disease. These estimates are based on sentinel studies, such as the National HIV Survey of Childbearing Women, and other HIV surveillance data. When these prevalence data are inconsistent with locally available estimates, CDC works with the local prevention planning agency to reach a mutually acceptable set of estimates. HRSA periodically provides these estimates to HIV planning councils and consortia.
- ***HIV Prevention and Care Planning Documents, Needs Assessment, and Special Studies Focusing on HIV-Positive or At-Risk Youth*** may have been conducted in your community. CDC-funded HIV prevention planning groups fund planning documents that summarize HIV epidemiologic trends among the general population, as well as among specific populations such as youth. The National Alliance of State and Territorial AIDS Directors (NASTAD) maintains a website that lists state HIV prevention program contacts. (See www.nastad.org). Epidemiologic studies of HIV-positive or at-risk

youth may also have been conducted by other agencies and organizations. The National Institutes of Health (NIH) maintains an Internet-based search engine, Pub-Med, that can help identify studies of HIV-positive or at-risk youth in your community: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi.

Comprehensive Needs Assessment

Comprehensive needs assessments help identify the needs of HIV-positive youth who have not entered care, as well as youth in care who are lost to follow-up by their HIV clinician. Needs assessments help identify the need for and nature of outreach services for specific sub-populations of HIV-positive youth, as well as venues in which outreach can take place. Needs assessment also can help program staff understand the barriers that HIV-positive youth encounter in entering and staying in HIV care.

Data for needs assessments can be obtained directly by your program from youth or their caregivers (i.e., primary data directly collected through surveys, interviews, focus groups, etc.) or indirectly through existing data sources (i.e., secondary data gathered for other purposes and analyzed to meet your program's needs).

Approaches to Data Collection for Needs Assessments

- ***Quantitative data*** are gathered using objective data collection processes such as HIV/AIDS surveillance reports and CTR site interviews. Quantitative data are number-based and collected using scientifically based methods for which statistical tests have been applied. Quantitative data provide information about who, what, how many, and how much.
- ***Qualitative data*** are descriptive and may be gathered from focus groups, key informant interviews, and observational studies. These data provide meaning, contextualization, and insight to supplement quantitative data. Qualitative research methods attempt to answer how and why.
- ***Mixed methods*** integrate quantitative and qualitative data to measure phenomenon and contextualize its meaning. In designing and refining youth-centered HIV outreach programs, a mixed methods approach is useful for assessing the needs of HIV-positive youth not in care and designing activities to engage and retain them in care.

Common data collection techniques include interviews with youth and other key informants, written surveys, focus groups, community forums, public hearings, and observational data gathered from visits to venues in which HIV-positive youth gather. Secondary data can be obtained from reports published by public health programs, HIV prevention and care planning groups, university researchers, and HIV clinics and other care providers. Useful data also can be gathered from articles published in professional journals. Using primary and secondary data, a needs assessment can provide substantive information that can be used to determine your program's target population, plan for outreach activities, identify service venues, and establish service priorities.

Specific sources of data for needs assessments include:

- ***Titles I, II, and IV Needs Assessments and Special Studies*** are conducted regularly as part of program planning. Many Ryan White CARE Act grantees conduct assessments and studies that focus on HIV-positive sub-populations, including youth. A contact person for the Titles I, II, and IV grantees in your area can be located at: http://hab.hrsa.gov/programs.htm.
- ***Ryan White CARE Act Title I, II, and IV CARE Act Data Reports (CADR)*** summarize information regarding an agency's characteristics, client characteristics, services provided, and other information. These data are submitted annually to HAB where they are summarized in national reports. Some limited information regarding the number of youth served can be obtained from these CADRs. Title I and II grantees may be able to provide you with a frequency of youth served by their subgrantees. These data identify other agencies serving HIV-positive youth. CADR data also can be obtained from Title IV youth grantees and Title I, II, or IV subgrantees engaged in youth-centered services.
- ***Ryan White CARE Act Title I, II, and IV Youth-Focused Needs Assessments, Program Evaluations, and Special Studies*** may have been conducted specific to HIV-positive youth. Information of interest may include epidemiologic trend data, documentation of unmet need, results of focus groups and other studies that identify barriers that your program can address, and no-show and lost-to-follow-up rates that document the need for case finding and other outreach activities.
- ***Statewide Coordinated Statements of Need (SCSN)*** synthesize the findings from HIV seroprevalence and other epidemiologic studies, needs assessments, gap analyses, and special studies to identify needs for maintaining, changing, or developing new HIV services. The most recent SCSN can be obtained from the state Title II program, which is responsible for its development. A contact person for your state's Title II program can be located at: http://hab.hrsa.gov/programs/t2roster.htm.
- ***Focus Groups and Community Forums*** provide important contextual qualitative information to identify external factors that impede and facilitate entrance into and retention in care. Trained facilitators experienced in interviewing and conducting focus groups are important in obtaining useful information. Experienced facilitators ensure that all focus group members

actively participate and that the questions to be addressed are fully explored. Targeted recruitment for focus groups and community forums should be undertaken in venues in which HIV-positive youth are likely to congregate such as Internet chat rooms, and through youth-focused media. Focus groups and community forums can be a collaborative effort with planning councils and HIV prevention community planning groups and consortia, as well as Title IV grantees.

- ***General Information About Youth*** can round out information gathered from HIV data sources, as it is important to know the social and economic factors that may influence the HIV infection rate among youth. Non-HIV specific data that may be relevant include youth- and geographic-specific unemployment, injection drug use, poverty level income rates, and high school dropout rates. Trends in STIs, teen pregnancy, and substance abuse also can be used as indirect measures of risk for HIV infection. Demographic data can be obtained online from the U.S. Census Bureau (see http://factfinder.census.gov). Data on non-HIV-related health disparities experienced by youth also can be gathered from local and state health departments.

Service Inventory

The service inventory provides a comprehensive picture of the continuum of services for HIV-positive youth in a service area, regardless of the funding source. Service inventories identify existing youth-centered HIV clinical, case management, psychosocial support, and outreach programs that operate in the venues identified by your needs assessment. The inventory also identifies key points of entry for HIV-positive youth not in care.

The inventory should include a description of the types of services provided, number of clients served, and funding levels and sources. Information to be gathered includes: agency contact information, nature and extent of services, funding sources, service area, target sub-populations, estimated number of clients served per year, and number of units of service provided annually. To determine the need for new or additional youth-focused outreach, informal interviews can be conducted with key program staff, such as program directors or supervisors of outreach services. Information gathered should include a provider capacity and capability profile that describes the extent to which services identified are available, accessible, and acceptable to youth. Other data sources for the inventory include HIV provider directories developed by local HIV service planning groups, such as Title I planning councils or Title II consortia. Title IV grantees may also have conducted youth-focused inventories that can be used to identify clinical and psychosocial support programs already providing youth-centered outreach.

Gap Analysis

Gap analysis determines unmet needs and service gaps by bringing together information gathered in earlier steps in the planning process and examining service needs of HIV-positive youth in and out of care, resource requirements, and barriers to enrollment and retention of youth in care. These data help to set priorities and inform program design. Service gaps can occur because no services are currently available, because available services either are not appropriate for or not accessible to the target population, or because insufficient funds and other resources are available to deliver services. The gap analysis should be informed by data gathered from HIV-positive youth and HIV youth care experts, such as through focus groups.

A Checklist for Identifying and Targeting Youth

- ☑ Contact your local/state HIV/AIDS surveillance program for epidemiologic data on the local HIV epidemic among young people. These programs should be able to provide AIDS and HIV data by age group, gender, race/ethnicity, risk behavior, income level, residential ZIP code, and CTR sites serving HIV-positive youth.
- ☑ Check with your local/state HIV prevention program for data regarding HIV-positive youth in your area. You may also want to review recent HIV prevention planning documents that summarize local HIV surveillance data for youth. They may also have qualitative data from focus groups and key informant interviews.
- ☑ Check with your local/state HIV/AIDS program, which should be able to help you locate data that can provide insight into local adolescent health behaviors and patterns. These include STIs, substance abuse and addiction, unplanned pregnancies, mental illness, and interpersonal violence.
- ☑ Check with state government officials who maintain U.S. census data on the demographic and socio-economic characteristics of youth and young adult populations. You can locate the agency in your state by browsing the state websites.
- ☑ Check with your local health department and school systems, which may have local data from the Youth Risk Behavior Survey, a national survey administered every other year to high school students on a variety of health issues.
- ☑ Consider convening two or three focus groups and conducting key informant interviews with local young people and providers of youth services. Be sure your group meetings or interviews cover a diverse group of young people and providers. You may want to collaborate with your local/state HIV prevention planning staff to prepare and convene the groups. Local universities may also have faculty experienced in convening focus groups who can help you.

Once all the data is gathered, can you answer these questions?

- ☑ What are the characteristics of young people who are becoming HIV positive?
- ☑ In which neighborhoods or cities do HIV-positive youth live?
- ☑ What behaviors or activities are they engaging in that lead to HIV infection?
- ☑ What factors do youth cite as barriers or facilitators to engagement in care?
- ☑ What assets do HIV-positive young people bring to help them engage in care?
- ☑ What services do HIV-positive or at-risk youth identify as being important? Are they being offered?

ORGANIZING YOUR PROGRAM

Overarching Program Practices

Ideally, youth-centered HIV outreach is initiated at the point that at-risk youth are identified. Outreach workers may accompany youth to HIV testing sites and help them transition into HIV care after they receive a positive test result. Outreach workers can link HIV-negative youth with a prevention case manager to address high-risk behavior. With the adoption of new rapid, non-invasive HIV testing technologies, youth-centered HIV programs are adopting merged outreach and counseling, testing, and referral. In this model, outreach workers identify youth in need of CTR and link them to mobile or community-based CTR units serving neighborhoods in which high-risk behavior is identified through HIV prevalence and other epidemiologic studies.

Programs wishing to identify, engage, and retain HIV-positive youth offer or arrange for high-quality medical care, case management, psychosocial support, and secondary prevention counseling. Most youth-centered HIV programs provide these services via multidisciplinary teams that actively incorporate outreach workers. In settings that include integrated clinical and case management services, multidisciplinary care teams develop individualized care plans that address a wide spectrum of short- and long-term needs. In decentralized HIV care systems, separate but complementary clinical and case management care plans are developed. In either system, successful youth-centered HIV programs include youth, their family members, and other significant individuals in the development of care plans. Care plans are commonly developed within 30 days of entry into care, contingent upon initial clinical diagnostic assessment, and are updated about every three months or when significant changes in health or psychosocial status occur.

Youth-centered HIV outreach workers can play an important role in developing, maintaining, and refining care plans. Successful outreach informs youth about HIV self-care and clinical services and invites their involvement in care. Once youth are in care, ongoing outreach focuses on keeping them in care. Based on an initial assessment and history, the team may identify youth who could benefit from early and ongoing outreach. Such youth may be difficult to reach, have a history of

non-adherence to medical treatment, actively use drugs, experience mental illness, be involved in the criminal justice system, be homeless, or be unstably housed. Outreach workers ideally are assigned to such youth from their earliest entrance into counseling, testing, and referral or care, providing them periodic outreach and case finding.

Many youth-centered HIV programs have tailored outreach for transgender youth, young men who have sex with men, youth of color, young heterosexual women, runaway youth, and "street" youth. Examples of targeted youth-centered HIV programs include:

- A youth-centered HIV program holds a weekly seven-hour meeting in a community venue for young men of color who have sex with men. It begins with a potluck dinner at 7 p.m. and lasts through 2 a.m. the next morning. Each weekly event features a mix of culturally specific education and socialization activities, with strong participant planning and leadership.
- Another program deploys mental health counselors to residences and social gathering places to meet with and re-engage clients who have been lost to follow-up.
- An inner-city program convenes support groups for difficult-to-reach youth in mobile vans that travel to social gathering places in the community.
- An urban program targets social networks of known HIV-positive clients, in the belief that it is likely that there have been high-risk interactions and that other social network members are also infected. The confidentiality of clients and social network members is protected throughout.

Youth-centered HIV programs also commonly target youth who are difficult to reach. These youth are described as having histories of incarceration or juvenile detention, being homeless, spending most of their waking hours on the street, and having high rates of mental illness and substance abuse. Programs for these youth tend to undertake high intensity outreach that includes teams of outreach workers and volunteer peers. They focus on places where these youth congregate such as shelters, detention centers, shopping districts, and entertainment venues.

Strong working relationships with agencies and programs that provide broader youth-focused support services help youth-centered HIV programs engage and retain youth in care. They may support staff at these programs to help them identify and serve HIV-positive youth and resolve other health and psychosocial issues. Given the fluid nature of adolescent life, these networks commonly find that they must function 24 hours a day, seven days a week to address clinical and psychosocial crises. Finally, because many HIV-positive youth who enter care lack basic knowledge

about HIV, youth-centered programs create and distribute accurate, timely, and youth-oriented HIV educational materials. Since relatively low rates of literacy are common among HIV-positive youth, graphics and text are geared to a low reading level (Positive Outcomes, 2005). Several youth-centered HIV programs have designed educational materials in a comic book format. Your program can adopt many of these as you identify materials needed by your target population. The National Youth Advocacy Coalition (NYAC) is a source of such materials. They can be found online at: http://www.nyacyouth.org/nyac/resources.html.

Developing an Outreach Strategy and Care Plans

A youth-centered outreach strategy is critical to successfully identifying HIV-positive youth, especially asymptomatic positive youth, and engaging and retaining them in care. Without a formal strategy, it is difficult to determine which neighborhoods and service areas need outreach and what services should be offered.

A focused outreach strategy includes goals and objectives for target service areas and populations that are clearly defined, youth-focused, and relevant. The outreach strategy should include steps to achieve the goals and objectives and to determine the level of intensity of the outreach efforts. Similarly, individualized client outreach plans should set goals and objectives that are youth centered and defined by client needs, barriers to care, and clinical and psychosocial support requirements.

Youth-focused outreach requires identifying and addressing barriers to entrance and retention in care. The multidisciplinary team should identify those barriers and the steps to eliminate them. If outreach workers are engaged in an HIV care system in which clinical and case management services are conducted separately, it is the responsibility of the outreach worker to inform key providers working with the client about those barriers.

The outreach worker's job description should clearly identify roles and responsibilities in carrying out the care plan and relationships to other HIV care providers and agencies. This will depend, in part, on the formal education, on-the-job training, and supervision mechanisms within your program.

Individualized outreach plans should be designed, to the extent possible, in collaboration with the client, his or her family, and other significant stakeholders, with the youth identifying the individuals to be included in developing the plan. The roles and responsibilities of HIV-positive youth in developing their care plans should be articulated at a pace that is appropriate to the circumstances of the individual. The first contact with an HIV-positive youth is extremely important in establishing the relationship between the outreach worker and the client. The youth needs to feel comfortable, secure, and accepted. All youth must be treated with respect, and outreach workers should view the client's experiences or lifestyle choices neutrally.

Social and Community Outreach Activities

Social and community outreach activities inform youth about HIV issues and available clinical, case management, and psychosocial support services. These activities also establish an inviting environment. Many youth-centered HIV programs convene large groups of 20 or more youth. These meetings emphasize prevention and engagement in HIV counseling, testing, referral, and care and tend to be entertainment oriented, such as movie nights, plays, and poetry slams. Clients and peer outreach workers often determine the specific entertainment. Food and other incentives are offered to encourage youth attendance. Many youth-oriented HIV programs also offer support activities for clients through professional counseling, small groups, and peer buddies. Programs use peer buddies and social networks to promote engagement and retention in care. Social networks are used to track individuals who are lost to follow-up, to let them know they are missed and to invite them to return to care. Confidentiality is ensured throughout interactions with social networks.

Support services that youth-centered HIV programs identify as particularly helpful include mental health services, drug treatment, nutrition, family and partner counseling, housing, and treatment adherence. Creative approaches help integrate support services in youth-centered programs. For example, one program uses art therapy to engage youth in addressing their mental health issues.

Several other ancillary services are commonly offered to HIV-positive youth. Transportation helps ensure that youth keep their appointments for medical visits and other services and is often provided through bus or subway tokens and taxicab vouchers. Onsite child care is helpful for clients with young children. Youth-centered HIV programs also increasingly offer or arrange for education and vocational programs — reflecting the need to address problems with literacy and to help youth complete their high school education.

Privacy, Confidentiality, Informed Consent, and Other Legal Issues

Youth-centered HIV programs must establish strong protections for their clients' privacy, confidentiality, and informed consent. Adolescents are keenly aware of their vulnerability to discrimination and harassment because of HIV status or sexual orientation. It is important to keep these concerns in mind in developing outreach policies and procedures and training outreach workers. These policies are particularly important when a program employs peer or near-peer workers or when outreach workers live in targeted service areas.

Confidentiality and trust are particularly important in working with youth. Assurances of confidentiality have been shown to increase youths' willingness to disclose sensitive information about sexuality, substance abuse, and mental health. Moreover, privacy and confidentiality become greater issues for HIV-positive or gay and lesbian youth because of the risk of inadvertent disclosure that may lead to stigma, discrimination, and violence (Standford, Monte, Briggs, Flynn, Tanney, Ellenberg, Clingan, & Rogers, 2003).

Several activities should be undertaken to ensure privacy, confidentiality, and informed consent for HIV-positive youth receiving outreach:

- Have written policies and procedures reviewed by legal counsel familiar with federal and state statutes regarding privacy, confidentiality of client written records, and informed consent.
- Develop informed consent and information release forms in collaboration with legal counsel to ensure that they are consistent with federal and state statutes, as well as your agency's policies. Pay special attention to keeping such forms in simple, straightforward, and accessible language.
- Establish the format of your client records early in program development, with careful consideration of the nature and extent of outreach notes to be recorded in the record.
- Design automated client records using highly secure software. Establish procedures for read and write access to client files to determine who has access to the files and under what circumstances. Establish firewalls and secure password policies and procedures.

- Post policies and procedures in prominent areas in which youth and staff congregate, such as interview rooms, mobile vans, and out-stationing sites.
- Contact clients only at telephone numbers provided for that purpose, and leave messages in a discreet manner. Do not send written materials to clients' homes without their written permission. Use stationary that does not disclose the nature of your program.
- Consider distributing pagers to clients who have confidentiality concerns or who do not have permanent homes.
- Train outreach workers carefully on policies and procedures for privacy, confidentiality, and informed consent. Upon initial hiring, counsel outreach workers on the need for these policies and procedures and on the penalties if they are violated, including termination of employment and civil and criminal sanctions. Require that employees sign a written acknowledgement of receipt of those materials.
- Retrain outreach workers periodically to review your program policies and procedures.
- Investigate and document violations of your program's policies and procedures quickly. Impose sanctions as required.
- Comply with state laws and regulations regarding protection of youth from potential abuse. Background checks and fingerprinting of all staff help ensure that employees do not have a criminal history related to potential abuse of minors. Seek legal counsel to ensure that your program is in compliance with state and federal laws.
- Have a clear understanding and written policies regarding disclosure to parents or guardians. Many states have laws that require release of certain information under specific circumstances to a parent or guardian. Establish written policies and procedures and train staff about how to implement them. Such policies and procedures should outline the nature and extent of services to support families, including addressing steps toward family reconciliation — when safely possible — in situations where family members are estranged from one another or if the client is a runaway. Inform youth of disclosure requirements at the earliest opportunity.
- Counsel outreach clients regarding ways to minimize unnecessary disclosure of HIV serostatus.

Staff Characteristics

A high quality staff is critical to program success. Youth-centered programs agree that it takes a unique kind of individual to work in youth-oriented HIV services. Pay careful attention to recruiting, orienting, and supporting staff. Key characteristics to consider in recruiting staff include:

- knowledge of youth health and development;
- enjoyment in working with youth;
- flexibility and patience with youth;
- rapport and comfort with youth;
- willingness to advocate for youth;
- cultural competence and compassion with various sub-populations of youth;
- ability to work as a team to serve and support youth;
- shared cultural characteristics with the youth being served; and
- recognition and acceptance of interpersonal boundaries to reduce transference and co-dependence.

Youth-centered HIV outreach programs commonly employ trained peers and near-peers. Peer-based youth outreach is a significant aspect of the consensus model that has evolved in youth HIV projects. Youth-centered HIV outreach programs tend to use the consensus model to identify youth and engage and retain them in care. This model includes major themes or elements that fit the accumulated data and experiences of successful projects (Huba & Melchior, 1998). The consensus model consists of targeted outreach linked to CTR services, engaging individuals in care, and retaining them in care. The model recognizes and builds upon developmental changes that occur during adolescence and uses culturally specific and meaningful images.

Youth-centered HIV outreach programs commonly train and involve youth in their programs as outreach workers. Benefits derived from this approach include the ability to achieve comfort and trust among outreach clients, as well as ease in identifying the target populations and identifying outreach venues and strategies to reach youth. Typically, professionals closely supervise these workers, although experienced peers work relatively independently in some programs.

An important factor in the success of HIV-positive youth outreach is achieving staffing that reflects the demographics of the target population, including their generational, racial, ethnic, and economic characteristics. Staffing must also address cultural competence. In serving HIV-positive youth, cultural competence encompasses a wide array of cultures and includes not only race and ethnicity but also the varied cultures of youth, street life, heterosexuality, homosexuality, bisexuality (including "down low" behavior), transgenderism, drug addiction, and homelessness. Since outreach workers tend to be relatively young and share many characteristics with their clients, it is common for them to identify closely with their clients. As a result, it is important that ongoing mental health services be routinely available to outreach workers. Support groups and other mechanisms for self-care should be established to reduce burnout and turnover.

Youth-centered HIV programs sometimes employ clients as peer outreach workers. While this employment model offers important vocational opportunities for youth, it also poses some challenges. Boundary issues must be addressed so that role confusion is minimized. Over-identification with other clients and its likely impact on the peer workers' mental health should be addressed routinely through careful supervision.

Facilities and Program Environment

The location and nature of the physical facilities of youth-centered HIV outreach and care programs greatly affect the receptivity and use of these services by youth. Successful programs report that a centrally located facility within the targeted service area is key to enrolling youth and keeping them engaged in care, as is locating services in community settings that youth can get to without depending on parents or other adults. Many youth-focused HIV outreach and care programs locate near mass transportation outlets and large health care facilities to make possible easy access and links to other services.

Most youth-centered HIV programs also stress the importance of having clean, functional, uncluttered, inviting, and youth-oriented facilities. Youth orientation includes posters with age-appropriate messages and graphics, as well as youth-created art. Youth who see themselves and their culture reflected and respected in service sites develop a more positive attitude toward them.

Centralized outreach services must be integrated with clinical services. It is equally important that at least some outreach workers in your program be highly visible in venues frequented by HIV-positive or at-risk youth. Mobile vans are used in some inner-city neighborhoods to maximize the visibility of outreach workers. These vans maintain consistent schedules so that youth are aware of their availability.

Quality Management

Planning for and conducting quality management is integral to youth-centered HIV program design. Quality assurance (QA) is a formal, systematic exercise in which problems in service delivery are identified, activities are undertaken to overcome those problems, and follow-up is conducted to ensure that no new problems have developed. The emphasis in QA is on meeting minimum standards of care. These standards may be set by funders, such as Title I grantees, or established by your program. Continuous quality improvement (CQI) is a QA approach that identifies mechanisms to improve policies and procedures that affect clients. In CQI, program staff identify a policy or procedure that should be addressed, design a change in that policy or procedure, study the impact of the change, and assess the need for future changes. More information about CQI and other aspects of QA are available at:

- HAB webpage: http://hab.hrsa.gov/special/qualitycare.htm;
- The HRSA Center for Quality: http://www.hrsa.gov/quality/; and
- The Institute for Healthcare Improvement: http://www.ihi.org/IHI/Topics/HIVAIDS/.

Operational Policies

Youth-centered HIV programs identify several organizational policies as key to engaging and retaining youth in care:

- Rapid enrollment in HIV care should follow identification of HIV-positive youth. Some newly diagnosed youth may require mental health or case management services before they are willing to engage in medical care. Supervisors, case managers, mental health professionals, and other care team members can help the outreach worker ensure that entry into care is as supportive of client needs as possible.
- Outreach workers need time to become familiar with their clients and to plan for services. Taking the time is necessary and helps ensure that a trusting relationship is established and that services are culturally competent, age appropriate, relevant to clients and their needs, accessibly located, and not duplicative of other services youth are receiving. This does not mean delaying intake once an HIV-positive youth is identified. Rather, it is an acknowledgement that many youth come to services with a distrust of institutions and authority figures, and they need to be nurtured into care, especially if they do not face immediate health threats.

- Youth should be actively engaged in developing and monitoring their individual care plans. This helps ensure commitment to and support of the strategies contained in the plan. It also enhances prospects for treatment adherence. Quarterly reviews are good opportunities for youth to assess their care plans and adjust them to address newly identified barriers to care or other important developments.
- Strong quality management and improvement policies should be incorporated in staff training and performance reviews. This approach ensures that youth receive high quality care and have mechanisms to advise your program on ways to improve services.
- Supervisors and program managers should closely monitor the performance of outreach workers, the size and nature of their caseloads, and their mental health. Programs should create a highly supportive atmosphere with clearly defined roles, responsibilities, and boundaries on staff conduct relative to clients.
- A supportive environment also ensures that outreach workers needs are addressed, including professional development, rest and recuperation, and support for family and personal issues. Such an environment is necessary if staff are to have the energy, insight, and capacity to meet the complex needs of youth. Youth-centered HIV programs accomplish this environment through flexible leave policies, supporting attendance at professional conferences, and staff support groups, among other methods.
- To be effective, outreach must reflect a culturally competent understanding of the clients served. Recruitment of outreach workers who understand and embrace varied cultures is critical to successfully recruit HIV-positive youth and engage and retain them in care.
- Minimizing bureaucracy in interactions with youth promotes recruitment and retention in care. Youth-centered HIV programs report that youth universally dislike bureaucratic structures and avoid organizations that exhibit such impediments. Most programs handle this challenge by removing as many bureaucratic barriers as possible. However, as programs transition older youth into adult HIV care, they often begin to involve them in addressing structural barriers to help them build skills they will need once adolescent-oriented care ends.
- Openness and originality in programming are key to engaging youth. Youth-centered HIV programs commonly adopt youth-oriented mass media, Internet communication, and social marketing strategies. These approaches capitalize on the interest that youth frequently show in innovative, technologically advanced communication methods. For example, one outreach program regularly conducts an Internet chat room for HIV-positive youth where questions can be asked and information disseminated in an anonymous environment.

- Meaningful involvement of HIV-positive youth in planning, implementing, and evaluating outreach ensures that services are relevant to the target population, meet their needs, and enhance a long-term commitment to being in care. Involving clients can be undertaken through a consumer advisory board or focus groups, although existing youth-centered HIV programs report that sustaining client involvement in such efforts can be difficult. Formal structures often do not lend themselves to the circumstances and lifestyles of youth. Less formal opportunities to involve youth in planning and evaluating services include listening sessions, community forums, discussions among social and support groups, and individual discussions.
- Although it can be difficult to anticipate the reporting requirements of funders or information that is useful for program management and performance assessment, planning for administrative reporting and program evaluation should take place before program implementation. This will ensure that mechanisms are in place to capture data in a consistent manner and with minimum intrusiveness on the client.
- As your youth-centered HIV outreach program evolves, periodic updating and review of local epidemiologic, geographic, client satisfaction, service utilization, and performance data will provide data to guide the evolution of your program.

Institutional and Financial Support

Institutional support must be in place to ensure a program's long-term viability. Youth-centered HIV programs tend to be funded primarily by grants and institutional in-kind contributions. HIV care programs, including outreach, are heavily dependent on their agencies to provide resources that cannot be fully covered by grant funds or health insurance, including human resources, accounting, payroll, and facilities management. Third party insurance is less commonly a major source of support, as youth tend to be disproportionately uninsured as compared to children and adults (Positive Outcomes, Inc., 2005). Even if clients are insured, Medicaid, commercial insurers, or other third party payers may not cover many necessary services for youth, including outreach, medication education, adherence counseling, multidisciplinary team meetings, case conferences, or QA processes.

Commitment from within the local community to fund quality adolescent HIV services is also critical. If community leaders lack the will to fund high quality,

age-appropriate services, the development of service networks that reach and engage youth will be significantly compromised. Many programs achieve community commitment through active engagement with community leaders. Speaker bureaus of HIV-positive youth, outreach workers, and other HIV program staff are particularly useful in humanizing the face of HIV. Co-location of services in other community agencies also helps create committed partnerships with long-standing local service providers. (Tenner, Feudo, & Woods, 1998).

Assessing Capacity

Estimates of capacity describe how much of specific kinds of services a provider can deliver. Capability assessments describe the degree to which a provider is actually accessible and has the needed expertise to provide services. In planning HIV outreach and other youth-centered services, it is critical that your program conduct a careful assessment of the capacity to increase the number of youth to be served either directly by your program or within your HIV care network. Nationally, about 60 percent of Ryan White CARE Act direct service providers report that they do not have sufficient capacity to meet the needs of their current caseload. Such inadequate capacity includes insufficient professional and support personnel, treatment and other direct service space, and other resources (Positive Outcomes, Inc., 2002). New HIV testing technology is likely to increase the number of newly diagnosed HIV-positive individuals entering care.

Your program's capacity to meet the diverse needs of HIV-positive youth also should be considered. Inner city, youth-focused HIV programs tend to focus on specific, defined youth populations living in specific service areas. Youth with needs outside the mission or geographic focus of the programs are referred to programs designed to meet their needs. In suburban and rural communities, youth-focused HIV programs tend to have a broader mission that reflects, in part, the lack of other resources in their communities.

A Checklist for Organizing Your Outreach Program

- ☑ Identify the location, mission, and services provided by other HIV outreach programs to minimize duplication.
- ☑ Brainstorm with your staff, including peer and near-peer workers, and clients about locations where HIV-positive youth can be found and outreach conducted. Use the results of your epidemiology profile and needs assessment to inform your choice of locations.
- ☑ Select a manageable number of locations to initiate outreach. Be realistic about the number you select.

A Checklist for Organizing Your Outreach Program continued

- ☑ Choose locales and strategies based upon the number of youth with high likelihood of HIV infection who can be reached safely and effectively. It may be best to start with low intensity outreach in general, coupled with high intensity outreach in a specific location.
- ☑ Review articles in the professional literature and talk to existing HIV and youth service providers to learn about outreach strategies that have been effective in reaching particular youth and locations. Check also with local law enforcement agencies about safety issues and how outreach workers and public safety officers can work together.
- ☑ Develop plans to recruit, support, and retain a culturally competent staff for the populations of young people being served.
- ☑ Place counseling, testing, and referral and follow-up services in locations that are safe and accessible to youth.
- ☑ Ensure that your facility is clean, safe, and reflective of the cultures of the young people being served.
- ☑ Establish policies for client involvement in care plans, quality assurance and improvement, staff oversight and support, youth involvement in the agency, minimizing bureaucracy, and program evaluation before offering any services. Each of these can begin with simple actions that can be expanded and elaborated upon as services are developed.
- ☑ Allow for creativity and openness in program ideas. Keep your approach to young people fresh, and take advantage of new social trends that may be emerging in adolescent culture.
- ☑ Develop and maintain institutional and community backing to ensure long-term support.
- ☑ Become knowledgeable about privacy, confidentiality, and consent to treatment issues and how they affect service provision, and develop policies and procedures that address them. Inform youth clients about these policies and procedures.
- ☑ Develop policies and procedures for screening potential staff and protecting clients. Inform clients and staff of actions that should be taken if these policies and procedures are violated and of the consequences.
- ☑ Develop an evaluation plan that describes the kind of evaluation, key evaluation questions, data that will be collected and examined to answer these questions, data sources, data management and analysis, report writing, and dissemination of findings, as well as who will be responsible for each required action.

STRATEGIES FOR INTEGRATING YOUTH OUTREACH INTO HIV CARE NETWORKS

Successful youth-centered HIV outreach programs are closely linked to existing systems that seek to ameliorate health and social challenges and foster resilience among youth. Linkages are established through informal or formal networks. The linked programs then engage and retain youth through network referrals.

"Outreach is effective when it is youth-sensitive, developmentally appropriate, culturally competent, and provides quick and easy access to services, including HIV CTR and risk reduction counseling, that youth need." Youth-centered HIV program staff member.

Counseling, Testing, and Referral

Provision of CTR to sexually active youth is not routinely practiced by clinicians in the United States. Outreach services must be integrated into CTR with the goal of helping HIV-positive youth rapidly initiate HIV clinical assessment and treatment. Outreach within CTR sites helps to promote early identification and engagement of youth in care that is culturally competent and youth oriented. CDC's Advancing HIV Prevention campaign and the advent of non-invasive specimen collection and rapid HIV testing technologies are likely to result in sharply increased counseling, testing, and referral among youth. CDC's current guidelines for CTR services can be found at: http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5019a1.htm.

Understanding the barriers is necessary to promoting HIV CTR among youth. Effective CTR helps youth address the cultural context of their lives and develop specific coping and HIV risk reduction skills. Behavioral risk factors associated with decision-making by youth regarding use of HIV CTR services include:

- history of an STI;
- five or more years of sexual activity;
- injection drug use; and
- age (Goodman & Berecochea 1994; Murphy et al., 2001).

Age is associated with the CTR sites that youth select. Community health centers are the most common CTR sites used by runaway and homeless youth. Older adolescents are less likely than younger adolescents to obtain CTR at private hospitals or doctors offices. Adolescents with a sexually transmitted infection are more likely to go to an adolescent-specific site than other CTR sites.

A primary factor associated with HIV testing among youth is concern that sexual behavior has resulted in HIV infection. Health care providers' recommendations also influence testing (Murphy et al., 2001). Among both HIV-positive and uninfected youth, males were more likely to be tested because of feeling sick than females.

The American Academy of Pediatrics (2001) recommends that all youth who are sexually active or engaged in substance use be encouraged to use HIV CTR. While more routine CTR at health facilities that serve youth may be helpful, such CTR will only reach individuals who are currently engaged in health care services. Youth who are not engaged in routine health care will not be tested. Innovative approaches need to be implemented to identify and engage adolescents who are infected but unaware of their HIV serostatus and not engaged in care.

Successful interventions that promote HIV counseling, testing, and referral either take these services to venues that youth frequent or use outreach to make CTR easily accessible. Increased use of CTR is also associated with social marketing campaigns, school-based CTR, community-based peer outreach, and adoption of non-invasive HIV testing methods.

Using Existing HIV Clinical and Psychosocial Support Networks

HIV-positive youth tend to select HIV providers who offer the following services on-site or through referral:

- adolescent-specific primary and specialty medical care;
- obstetrical/gynecological services for young women;
- state-of-the-art pharmaceutical therapies for HIV;
- adolescent-oriented mental health services;
- provision of or referral to affordable, safe, emergency and long-term housing;
- substance abuse, counseling, treatment, and referral;

- HIV and adolescent health research projects, such as youth-centered HIV clinical trials, and;
- specialty medical and mental health services.

Youth-centered HIV programs tend to enhance or reinforce existing youth services networks, rather than replicate them. They commonly develop linkages with a network of agencies providing youth-focused services. Your service inventory can help to identify youth-centered HIV programs with which to partner. These agencies might like to establish or expand youth-centered outreach activities.

Participation in existing HIV care networks helps to reduce duplication of effort, while building on established relationships and processes. For example, existing networks tend to have informed consent and release of information processes in place to coordinate the services provided by multiple agencies. Ideally, participation in existing networks also maximizes funds in an environment in which HIV funds are limited.

Outreach programs can effectively link HIV care to other services used by youth, such as schools, emergency food, clothing, housing, health care, and other community services (Woods, 1998). Other youth-focused HIV programs link to local emergency shelter programs, teen crisis pregnancy programs, and juvenile detention systems. Some programs deploy outreach workers to those venues and help link high-risk youth to youth-centered CTR services.

Building New HIV Service Networks

Successful youth-centered HIV programs form strong collaborative relationships with other HIV and youth-centered agencies to ensure that youth receive the comprehensive array of services they need. These comprehensive services help youth stay engaged in care by addressing their personal needs so that they do not become barriers to care. Assisting youth to establish relationships with other agencies also helps to move youth into stronger positions of interdependence with others and less passive reliance on HIV outreach program staff.

Youth-centered HIV outreach programs should have collaborative relationships with the following:

- community-based HIV primary prevention programs to engage youth identified by those programs;
- pediatric, adolescent, and adult HIV clinics to assist in the transition of children and adolescents as they age out of programs;

- general adolescent primary care clinics serving youth at risk for HIV infection to refer youth to once they are identified;
- clinical research programs to ensure access to state-of-the-art care;
- local public health HIV agencies for purposes of surveillance reporting, case finding, partner notification, technical support, and coordination of services;
- other health and social service providers that work with youth to coordinate care;
- local departments of social services to coordinate benefits such as Medicaid, AIDS Drug Assistance Programs (ADAP), Food Stamps, Social Security Administration, and other entitlement programs;
- HIV planning bodies such as Title I Planning Councils, and Prevention Community Planning Groups, to ensure that adolescent HIV services receive resources for care;
- local institutions that have a history of work with youth; and
- public and private technical support and research projects and programs to incorporate best practices as they are developed.

Programs serving difficult-to-reach youth pay particular attention to collaboration with other agencies and systems. Detention centers, homeless shelters, substance abuse treatment programs, and children's hospitals are common venues in which these youth are served. Collaboration with these agencies can be accomplished by locating youth-focused HIV outreach, HIV testing, and referral services at the partnering agency's site.

Working Collaboratively With Providers

Strong working relationships among agencies are highly effective in generating referrals and identifying HIV-positive youth (Dilorenzo, Abramo, Hein, Clare, Dell, & Shaffer, 1993). A strong basis for collaboration must be developed before linkage agreements can become a reality. When creating youth-centered care networks, it is important to understand the needs of individual staff members, their clients, and their agencies. Each collaborating agency has a different set of needs to address. A collaborative network can adapt to the needs of each agency, while retaining the integrity of the care system. Some agencies may want to enhance their youth services, while others may want to implement HIV prevention, CTR, or case

management services. Successful youth-focused HIV networks are made up of agencies that interact with their collaborative partners to identify their particular strengths and capacity. Ongoing re-definitions of relationships are needed as staff changes over time. A flexible approach in which network members clearly and honestly articulate their needs is essential.

The George Washington University's Center for Integrated HIV Care Networks (CIHCN) has worked with networks throughout the United States. Common aspects of integrated networks identified by CIHCN include:

- providing directly or supporting the provision of integrated health care and social support services to a defined population in a community;
- offering comprehensive services and having a centralized structure that coordinates and integrates services provided by member organizations and clinicians participating in the network;
- adopting local strategic, systemic planning that focuses on the greater good of the care delivery system rather than individual organizational self-interest;
- emphasizing purposeful development of care models that reflect local needs;
- blending funding sources to maximize revenue;
- providing one-stop shopping where feasible; and
- using provider assignment and utilization management to reduce duplication of services or unnecessary care.

The first step in building an HIV services network is educating the community at large to recognize that a public health threat exists. Then, community leaders and key stakeholders must be engaged in a long-term process that will take persistence, vision, and patience to result in the creation of a service network. Agencies that work with HIV-positive or at-risk youth can often be powerful allies in initiating network development. CIHCN has developed practical training and technical assistance for helping programs partner with other agencies to establish or formalize a youth-centered care network: http://www.gwhealthpolicy.org/cihcn.html.

STRATEGIES FOR INTEGRATING YOUTH OUTREACH INTO HIV CARE NETWORKS CONTINUED

A Checklist for Integrating HIV-Positive Youth Outreach Into HIV Care Networks

- ☑ Establish clear collaborations with other HIV and youth-serving providers with letters of agreement that spell out the specific roles and responsibilities of each party. Typically, it takes several meetings between agencies' staff to work this out.
- ☑ Illustrate the service network and working relationships among providers using a graphic device such as a "service web" to help identify service gaps and prevent duplication of services.
- ☑ Establish or enhance HIV care networks in which your HIV youth-focused outreach program is a participant by:
  - ☑ Identifying network partners;
  - ☑ Establishing network goals;
  - ☑ Selecting a network model;
  - ☑ Assessing network and managed care readiness;
  - ☑ Developing a work plan;
  - ☑ Scheduling regular network meetings and forming committees;
  - ☑ Establishing governance and legal structure;
  - ☑ Conducting training for management, board members, and line staff;
  - ☑ Identifying network service area and service population; and
  - ☑ Identifying and establishing relevant policies and procedures.
- ☑ Identify where youth will be linked after CTR. It is best to have two places: one where high-risk, HIV-negative youth can be referred for prevention and risk reduction services and another where HIV-positive youth can be referred for treatment and support. Having more than one provider for each will ensure that youth don't have to wait to get engaged in care if services get backlogged at one provider. It also increases the options for culturally competent care.
- ☑ Identify how youth will be linked to services after they complete CTR. There are three major strategies, listed here from less to more effective: a simple referral, linking by having staff from agencies to which referrals are being made present at post-test counseling, or linking by accompanying clients to the referral site for intake.
- ☑ Consider placing CTR and follow-up services in the same location. This minimizes the risk of clients being lost to care and increases the likelihood that youth will enroll in recommended services. If the full range of follow-up services cannot be co-located in this manner, try for a minimum of intake into the follow-up services at the same location.

A Checklist for Integrating HIV-Positive Youth Outreach Into HIV Care Networks

continued

- ☑ Establish working relationships with all other HIV and youth-serving programs in the community for purposes of mutual referrals, coordination of care, and cross-training.
- ☑ Plan for social and psychological support services. An advisory group of adolescent clients is an excellent resource for this task.
- ☑ Plan how high-risk individuals will be identified, screened, and either offered immediate CTR or linked to an existing CTR site. An outreach protocol is a useful tool here.
- ☑ Plan how individuals identified as being HIV-positive will be promptly linked to care and support services.

REFERENCES AND RESOURCES

American Academy of Pediatrics, Committee on Pediatric AIDS. (2001). Adolescents and Human Immunodeficiency versus infection: The role of pediatrician in prevention and intervention. *Pediatrics, 107*(1), 188-190.

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

Brady, R.E., Singer, B., & Marconi, K. (1998). Special Projects of National Significance Program: Ten models of adolescent HIV care. *Journal of Adolescent Health, 23*(2S), Preface.

CDC. (2001, November 9). Revised guidelines for HIV counseling, testing, and referral: Technical Expert Panel review of CDC HIV counseling, testing, and referral guidelines. *Morbidity and Mortality Weekly Report, 50*(RR19), 1-58.

CDC. (2001). Youth Risk Behavior Surveillance System. Available online at: http://www.cdc.gov/nccdphp/dash/yrbs/.

CDC. (2002, March 11). Young people at risk: HIV/AIDS among America's youth. Available online at: http://www.cdc.gov/hiv/pubs/facts/youth.htm.

Centers for Substance Abuse Prevention (CSAP). (1993). *The Second National Conference on Preventing and Treating Alcohol and Other Drug Abuse, HIV Infection, and AIDS in Black Communities: From advocacy to action* (CSAP Prevention Monograph 13). Rockville, MD: U.S. Department of Health and Human Services, CSAP.

Dilorenzo, T.A., Abramo, D.M., Hein, K., Clare, G.S., Dell, R., & Shaffer, N. (1993). The evaluation of targeted outreach in an adolescent HIV/AIDS program. *Journal of Adolescent Health, 14*(4), 301-306.

Feudo, R., Vining-Bethea, S., Shulman, L.C., Shedlin, M.G., & Burleson, J.A. (1998). Bridegeport's Teen Outreach and Primary Services (TOPS) Project: A model for raising community awareness about adolescent HIV risk. *Journal of Adolescent Health, 23*(2S), 49-58.

Goodman, E., & Berecochea, J.E. (1994). Predictors of HIV testing among runaway and homeless adolescents. *Journal of Adolescent Health, 5,* 566-572.

HIV/AIDS Bureau (HAB). (1999). CARE action: HIV care for sexual minority youth. Available online at: http://www.ask.hrsa.gov/detail.cfm?id=HAB00024.

HAB. (1999). *Evaluation monograph series.* Available online at: http://hab.hrsa.gov:80/tools/topics/monographs.htm.

HAB. (1999). *Outcomes evaluation technical assistance guide: Titles I and II of the Ryan White CARE Act.* Available online at: http://hab.hrsa.gov/tools/outcomes.htm.

HAB.(2003). Comprehensive planning self-assessment manual, 2003 version. Available online at: http://www.hab.hrsa.gov/tools/samCP/samCPattachments.htm.

Huba, G.J., Woods, E.R., Wright, E., Remafedi, G., Melchior, L.A., Trevithick, L., Panter, A.T., Schneir, A., Pickett, G., Sturdevant, M., Tierney, S., Wallace, M., Greenberg, B., Feudo, R., Singer, B., Brady, R., & Marconi, K. (1999). *Retention and initiation of services in 10 adolescent HIV care models services.* Los Angeles: The Measurement Group. Available online at: http://www.themeasurementgroup.com/adolspns.htm.

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

Kaiser Family Foundation (KFF). (1998). *National Survey of Teens: Teens talk about dating, intimacy, and their sexual Experiences.* Menlo Park, CA: Author.

KFF. (2005a, February). *African Americans and HIV/AIDS* (fact sheet, no. 6089-02). Menlo Park, CA: Author.

KFF. (2005b, February). *Latinos and HIV/AIDS* (fact sheet, no. 6007-02). Menlo Park, CA: Author.

Lammers, C., Ireland, M., Resnick, M., & Blum, R. (2000). Influences on adolescents' decision to postpone onset of sexual intercourse: A survival analysis of virginity among youth aged 13 to 18 years. *Journal of Adolescent Health, 26,* 41-46.

Leonard, B. (Ed.). (1997). Getting HIV-positive youth into care: Issues and opportunities: *A study of the Special Programs of National Significance Program Adolescent Care Projects.* Collingdale, PA: Diane Publishing Company.

Lynch, D., Krantz, S., Russell, J., Hornberger, L., & Van Ness, C. (2000). HIV infection: A retrospective analysis of adolescent high-risk behaviors. *Journal of Pediatric Health Care, 14*(1), 20-25.

Murphy, D.A., Durako, S.J., Moscicki, A., Vermund, S.H., Ma, Y., Schwarz, D.F., & Muenz, L.R. (2001). No change in health risk behaviors over time among HIV infected adolescents in care. *Journal of Adolescent Health, 29*(3S), 57-63.

Office of National AIDS Policy. (2001). *Youth and HIV/AIDS 2000: A new American agenda.* Washington, DC: Author. Available online at: http://www.whitehouse.gov/onap/aids.html.

Positive Outcomes, Inc. (2002). Minority providers in the Ryan White CARE Act: Their roles and challenges. *Voices from the field, Report 3.* Available online at: http://www.positive-outcomes.net/Publications/Files/rpt_ HRSA_MinProvider.pdf.

Positive Outcomes, Inc. (2005, January). *Best practices for reaching and engaging HIV-infected youth in care.* Available online at: http://www.positiveoutcomes.net/Publications/Files/rpt_HABIV_ Youth_Final_Report_Appendices.pdf.

Robinson, K.L., Telljohann, S.K., & Price, J.H. (1999). Predictors of sixth graders engaging in sexual intercourse. *Journal of School Health, 69,* 369-375.

Rosenfeld, S.L., Keenan, P.M., Fox, D.J., Chase, L.H., Melchiono, M.W., & Woods, E.R. (2000). Youth perceptions of comprehensive adolescent health service through the Boston HAPPENS program. *Journal of Pediatric Health Care, 14*(2), 60-67.

REFERENCES AND RESOURCES
CONTINUED

Stanford, P.D., Monte, D.A., Briggs, F.M., Flynn, P.M., Tanney, M., Ellenberg, J.H., Clingan, K.L., & Rogers, A.S. (2003). Recruitment and retention of adolescent participants in HIV research: Findings from the REACH (Reaching for Excellence in Adolescent Care and Health) Project. *Journal of Adolescent Health, 32*(3), 192-203.

Tenner A., Feudo, R., & Woods, E.R. (1998). Shared experiences: Three programs serving HIV-positive youth. *Child Welfare, 77*, 222-250.

Woods, E.R. (1998). Overview of the SPNS Program: Ten models of adolescent HIV care. *Journal of Adolescent Health, 23*(2S), 5-10.

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

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