

Young People and HIV/AIDS: The Need for a Continuum of Care: Findings and Policy Recommendations from Nine Adolescent Focused Projects

Elizabeth R. Woods, Cathryn L. Samples, Barney Singer, Nadine P. Peters, Lee A. Trevithick, Arlene Schneir, Steven Tierney, Rudy Feudo, Gilbert Pickett, Eric R. Wright, Gary Remafedi, Brian L. Greenberg, Lisa A. Melchior, and G.J. Huba

ABSTRACT

To generate research about the provision of care and services for young people affected by HIV/AIDS, the Special Projects of National Significance (SPNS) Program of the HIV/AIDS Bureau in the Health Re-

sources and Services Administration (HRSA) funded a group of adolescent-focused projects in 1993. At the end of 1998, nine projects completed five years of health services research and collaboratively developed specific policy recommendations regarding the care of adolescents who are HIV

Elizabeth R. Woods, MD, MPH, is _____ in the Division of Adolescent/Young Adult Medicine, Harvard Medical School in Boston.

Cathryn L. Samples, MD, MPH, is _____ in the Division of Adolescent/Young Adult Medicine, Children's Hospital, Harvard Medical School.

Barney Singer, JD, is _____ at the Academy for Educational Development in Washington, D.C., and was formerly Director, of Special Projects of National Significance.

Nadine P. Peters, AB, is _____ in the Division of Adolescent/Young Adult Medicine, Harvard Medical School.

Lee A. Trevithick, MA, is _____ at YouthCare in Seattle, Washington.

Arlene Schneir, MPH, is _____ at Childrens Hospital in Los Angeles.

Steven Tierney, EdD, is _____ at the Department of Health, San Francisco, and formerly was with Health Initiatives for Youth,

San Francisco.

Rudy Feudo, PhD, is _____ at the Bridgeport Teen Outreach and Primary Services (TOPS) Project, Division of HIV Programs and Services in Bridgeport, Connecticut.

Gilbert Pickett, _____, is _____ at Bay Area Young Positives, San Francisco.

Eric R. Wright, PhD, is _____ in the Department of Sociology at Indiana University-Purdue University Indianapolis, Indianapolis.

Gary Remafedi, MD, MPH, is _____ in the Department of Pediatrics at the University of Minnesota, Minneapolis.

Brian L. Greenberg, PhD, is _____ at Walden House, Inc., in San Francisco.

Lisa A. Melchior, PhD, is _____ at the Measurement Group in Culver City, California.

G.J. Huba, PhD, is _____ at the Measurement Group in Culver City.

positive or a risk. These are delineated in this article. A detailed description of each project and its implementing organization, as well as a consensus model for adolescent targeted HIV/AIDS services, have been published elsewhere.

INTRODUCTION

At a time when the youth in the United States is becoming increasingly diverse and increasingly impacted by the HIV/AIDS pandemic,¹ adolescents in America are confronted with a healthcare delivery system that is both in the throes of dramatic change, and in need of retrofitting to meet the specific needs of vulnerable populations.² Several epidemiologic observations highlight the urgency of this need.

- Many HIV-positive young adults became infected during their adolescent years.³
- HIV is now the ninth leading cause of death among adolescent and young adults 15 to 24 years old.⁴
- A 1996 report released by the White House Office of National AIDS Policy stated that 25 percent of all new cases of HIV infections occur in young people who are between the ages of 13 and 20 years.⁵
- Sexual exposure accounts for the vast majority of adolescent AIDS cases.⁶
- Young women, young men who have sex with men, and youth of color are disproportionately affected by HIV.⁷
- As treatment improves, a generation of children born with HIV is increasingly surviving to and through adolescence.⁸
- Sexually transmitted diseases (STDs) enhance the transmission of HIV, and one-third of the two million reported STD cases annually are in youth less than 25 years old.⁹

Because of the behaviors, development, and psychological changes necessary to reach adulthood, children and adolescents are constantly at risk and in need of effective prevention interventions and services. Adolescent populations can be particularly difficult to engage in care,¹⁰ and despite programs to expand access to care (such as SCHIP), adolescents and young adults remain one of the most underserved populations in the United States.¹¹ Adolescence is a time when there are developmentally normal struggles for independence and experimentation, which can put young people at risk for HIV.¹² Especially vulnerable are youth in high-risk situations, including those who are out of school, homeless, involved in social service and juvenile justice systems, gay/lesbian/bisexual/transgender/questioning, as well as those engaging in sexual activity, drug and alcohol use, and sex with injection-drug users (IDUs): such youth are particularly difficult to reach by traditional medical care systems.¹³ Many such young people, as well as youth of color, feel disenfranchised and are wary of adult providers and of healthcare establishments.¹⁴ The use of alcohol and other drugs contributes to potential HIV exposure,¹⁵ by increasing a young person's likelihood of participating in sexually risky behaviors and reducing the likelihood of condom use.¹⁶ Although injection-drug use is relatively rare among adolescents, rate of occurrence increases with age, and drug and alcohol use and abuse have been associated with prostitution and sex with high-risk partners.¹⁷

All of these considerations create significant obstacles for healthcare providers and policy makers who attempt to address the needs of adolescents who live with, and at high risk for, HIV. To generate research about the provision of care and services for young people affected by HIV/AIDS, the Special Projects of National Significance (SPNS) Program of the HIV/AIDS Bureau

in the Health Resources and Services Administration (HRSA) funded a group of adolescent-focused projects in 1993. At the end of 1998, nine projects completed five years of health services research and collaboratively developed specific policy recommendations regarding the care of adolescents who are HIV positive or a risk. These will be delineated here. A detailed description of each project and its implementing organization, as well as a consensus model for adolescent targeted HIV/AIDS services, were published in a special supplement to the *Journal of Adolescent Health*.¹⁸ A brief description of the nine projects, the implementing organizations, and the national cross-site evaluators is contained in table 1.

FINDINGS AND POLICY RECOMMENDATIONS

Through individual and cross-project evaluations, these SPNS-supported projects identified seven practical care and systemic principles related to the continuum of services that will be needed to engage, retain, and care for hard-to-reach youth.

1. *A variety of outreach approaches is needed to engage hard-to-reach youth by utilizing both youth and adult staff.* All nine of the projects provided services to young people who traditionally have been difficult to engage in care. Based on the combined experiences of the projects, the use of a variety of outreach approaches, shaped to suit the target populations, is critical for success. Street outreach workers who provide HIV-prevention information are especially effective in reaching homeless or street-involved youth, who are at particularly high risk for HIV infection.¹⁹ To promote the initiation of care, it is essential for programs to include culturally competent street and community outreach to gay/lesbian/bisexual/transgender youth and youth who are questioning their orientation, youth

of color, and youth who are trading sex for money or to survive.²⁰

Linking outreach services with community-based drop-in centers that provide high-priority services such as food, warmth, showers, clothing and safety, and support services can also be an effective way to initiate trust and engage young people into HIV Counseling and Testing Services (CTS) and healthcare.²¹ Outreach providers who reflect and understand the target population can be particularly effective at connecting with hard-to-reach youth to increase their use of services. Youth will often trust and respect peer outreach workers and counselors more than they will adults. Peer counselors can direct more of the highest-risk youth to case finding and care,²² but these counselors require training, supervision, and support.²³

Outreach at community locations can reach youth who may not have previously considered using HIV CTS or primary care services. These locations include youth-serving community-based organizations (for homeless youth, incarcerated youth, youth with serious emotional problems, and youth in protective services systems), residential programs, and schools.²⁴ Health fairs and targeted HIV prevention/education, risk-reduction and case finding activities present a window of opportunity to engage HIV-positive youth who may need services.²⁵

In states where name-linked HIV reporting is required, connections between the Department of Public Health and healthcare and youth-serving agencies can be a particularly effective way to link HIV-positive young people with healthcare services.²⁶ For example, the Minnesota SPNS project supported a disease intervention specialist at the Minnesota Department of Public Health, who linked HIV-positive clients (with their consent) to case managers at the University of Minnesota Youth and AIDS Project.²⁷

Youth who are marginally involved in episodic healthcare or reproductive healthcare (especially for STDs, pregnancy test-

Table 1
A Brief Description of the Nine SPNS Models of Adolescent Care and the National Evaluator

| Name of Organization | Brief Description |
|---|---|
| SPNS Projects | |
| Bay Area Young Positives, San Francisco | A youth-based approach to HIV/AIDS services which was founded and run by youth living with HIV who are under 26 years of age. ¹ |
| Boston HAPPENS (HIV Adolescent Provider and Peer Education Network for Services) Program, Children's Hospital, Boston | A collaborative network of care for at-risk, homeless, and HIV-positive youth (12-24 years) providing a continuum of care involving 3 community health centers, 3 hospitals, and 2 multi-service outreach agencies. ² |
| Bridgeport's Teen Outreach and Primary Services (TOPS) Project, Greater Bridgeport Adolescent Pregnancy Program, Inc., Bridgeport, Connecticut Childrens Hospital Los Angeles | A teen-focused community outreach project by peers and adults to ensure outreach and connections to health support services primarily to under-served youth of color (15-24 years) who are at-risk for, or living with, HIV/AIDS. ³ |
| Health Initiatives for Youth, San Francisco | An integrated care model for youth (12-24 years) with and at high risk for HIV infection including community outreach, HIV counseling and testing, and health services within a general adolescent clinic. ⁴ |
| Indiana Youth Access Project (IYAP), The Indiana Youth Group, Inc., and Department of Sociology, Indiana University Purdue University Indianapolis Seattle's YouthCare Project | A youth/adult partnership approach to HIV/AIDS services for and by young people (25 years and under) to bring about individual and systemic changes in care. ⁵ |
| University of Minnesota, Department of Pediatrics, Minneapolis | A peer-based project to help under-served gay/lesbian/bisexual HIV-positive or at-risk youth to access support and care services, assist in building peer support networks, and provide case management and related services. ⁶ |
| Walden House, Inc., Young Adult HIV (YAH) Project, San Francisco | A project serving runaway, homeless, sexual minority, and other youth "on the margins" (14-22 years). Its creative service approaches involve youth and reach other youth where they live providing outreach, HIV counseling and testing, and case management. ⁷ |
| Evaluator | An adolescent early intervention program to connect youth (13-22 years) to case management and healthcare services through linkage with Minnesota Department of Health HIV reporting system. ⁸ |
| The Measurement Group (TMG), Culver City, California. | A residential drug treatment program providing case management and serving HIV-positive and at-risk young people (13-25 years) with multiple diagnoses. ⁹ |
| | The national cross-cutting evaluators for the Adolescent SPNS projects and local evaluator for several individual projects, The Measurement Group worked with the SPNS projects to develop a collaborative evaluation design and measurement tools, developed and maintained the cross-cutting databases, conducted analysis of the cross-cutting evaluation data, and disseminated cross-cutting evaluation results and resources. ¹⁰ |

NOTES

1. T. Bettencourt et al., "Bay Area Young Positives: A Model of a Youth-Based Approach to HIV/AIDS Services," *Journal of Adolescent Health* 2, no. 23 supplement (1998): 28-36.
2. E.R. Woods, "Overview of the Special Projects of National Significance Program's 10 Models of Adolescent HIV Care," *Journal of Adolescent Health* 2, no. 23 supplement (1998): 5-10.
3. R. Feudo et al., "Bridgeport's Teen Outreach and Primary Services (TOPS) Project: A Model for Raising Community Awareness about Adolescent HIV Risk," *Journal of Adolescent Health* 2, no. 23 supplement (1998): 49-58.
4. A. Schneir et al., "Childrens Hospital Los Angeles: A Model of Integrated Care for HIV-Positive and Very High-Risk Youth," *Journal of Adolescent Health* 2, no. 23 supplement (1998): 59-70.
5. B. Bourdon et al., "Health Initiatives for Youth: A Model of Youth/Adult Partnership Approach to HIV/AIDS Services," *Journal of Adolescent Health* 2, no. 23 supplement (1998): 71-82.
6. E.R. Wright et al., "Indiana Youth Access Project: A Model for Responding to the HIV Risk Behaviors of Gay, Lesbian, and Bisexual Youth in the Heartland," *Journal of Adolescent Health* 2, no. 23 supplement (1998): 83-95.
7. A.D. Tenner et al., "Seattle YouthCare's Prevention, Intervention, and Education Program: A Model of Care for HIV-Positive, Homeless and At-Risk Youth," *Journal of Adolescent Health* 2, no. 23 supplement (1998): 96-106.
8. G. Remafedi, "The University of Minnesota Youth and AIDS Projects' Adolescent Early Intervention Program: A Model to Link HIV-Seropositive Youth with Care," *Journal of Adolescent Health* 2, no. 23 supplement (1998): 115-21.
9. M.S. Hymel and B.L. Greenberg, "The Walden House Young Adult HIV Project: Meeting the Needs of Multi-Diagnosed Youth," *Journal of Adolescent Health* 2, no. 23 supplement (1998): 122-31.
10. Huba and Melchior, "A Model for Adolescent," see note 2 above; Huba, Melchior, Panter, and the HRSA/HAB SPNS Adolescent Initiative Project Directors (1999), *The Measurement Group Knowledge Base on HIV/AIDS Care* < www.TheMeasurementGroup.com > .

ing, pregnancy care, family planning, or treatment for cervical dysplasia) can be encouraged to access HIV CTS through ready access to HIV counseling and testing in adolescent clinics and at reproductive health treatment sites. Young people need to be able to access these services without parental involvement or financial barriers. Youth who only utilize emergency rooms for services may be able to be linked to adolescent-specific HIV CTS follow up if the systems are designed to be youth-friendly and accessible. The best ways to engage this vulnerable populations need to be studied further.

2. *Collaborative networks of care are needed to link the resources that are available locally.* Collaborative networks can provide a greater array of services than any one single agency or institution.²⁸ Linked resources can build a continuum of care that crosses institutional and agency barriers.²⁹ Coordinating care across agencies requires case managers, service coordinators, and realistic and fluid collaborative agreements.³⁰

Within the networks, trained youth serving as peer providers may be particularly effective at reaching young people and providing support.³¹ Youth may benefit from assisted referrals to collaborating sites, and adult or peer advocates who escort them to services, provide public education and support, or help them to access services at more than one site.³²

When providers work at more than one location, their familiar faces can help engage and retain youth in care.³³ Young people comprise many diverse populations and often prefer to access services through a variety of modalities, including community-based organizations, community health centers, adolescent practices at hospitals, school-based health centers, drop-in multi-service centers, and free storefront clinics.³⁴ Many young people have strong feelings about why one location is preferable to another, and no one program or site has proven to be seen as universally accessible.³⁵

Providers and agencies at the local level may already provide services to overlapping groups of youth. Programs can work collaboratively with these local providers and agencies. Regular network meetings,³⁶ progressive tours with food,³⁷ network afternoon teas, breakfasts,³⁸ and other social and educational events can foster communication and collaboration. The coordination of care can be enhanced by sharing personnel who provide services at more than one collaborative site.³⁹ Referrals of identified adolescents and young adults to HIV services can enhance the efficiency and effectiveness of programs.⁴⁰ Young people with psychiatric illness, cognitive and behavioral limitations, histories of victimization, or who abuse substances are at particularly high risk for HIV, and comprehensive services are needed to assist multi-diagnosed youth.⁴¹ Since young people may often perceive referral as rejection, when networks offer comprehensive services, integrated care can meet each client's stage of readiness for behavior change without referral out of the network.⁴² The integration of substance abuse and mental health services into HIV prevention/education, case finding, and care may be a way to reach at-risk youth and should be studied further.

Little information is available about the nature and evolution of integrated networks of care. Comprehensive healthcare networks

have shown increased effectiveness in providing necessary medical and social services.⁴³ Yates and colleagues found that they were able to meet more of the needs of street youth when they subcontracted services with outreach and social services agencies in Los Angeles.⁴⁴ Such collaborations were strengthened by scheduling frequent local network functions that related to care in Los Angeles⁴⁵ and in Boston.⁴⁶ The Larkin Street Youth Center in San Francisco⁴⁷ and the Boston Street Youth Outreach Program⁴⁸ found that linking medical care to a drop-in center that provided basic needs improved connects between street-involved youth and the provision of care. The Adolescent AIDS Program at Montefiore Medical Center in the Bronx has demonstrated the importance of outreach in connecting youth with the provision of services at potential referring agencies.⁴⁹

Wright and Shuff studied the process of integrating mental health and primary healthcare services for person with HIV/AIDS in Indiana.⁵⁰ In their study of the relationships of mental health services with the AIDS care sector, they found that an inter-organizational network environment and communication in collaborative AIDS care were very important.⁵¹ In a structural evaluation of the gaps in care in the Boston network, the consensus of regional providers indicated a lack of sufficient HIV-related substance-abuse services, inpatient mental health services, hospice and home care services for youth.⁵² This evaluation provided important information for regional and network planning. Barriers to expanding care for adolescents included lack of funding for services, a lack of transportation, and a lack of awareness among youth about available services.⁵³ The authors addressed the relationships among the core agencies.⁵⁴ These interagency relationships seemed to be both dependent on geographic relations, the populations served, and the philosophical approach used.⁵⁵ The development and evo-

lution of collaborative networks of care should be studied further so that they can be fostered in new areas. Incentives to maintain collaborative networks need to be developed and evaluated over time.

3. Case management is critical to coordinate care across institutional barriers. Because funding is often provided according to particular categories of services, there are often a limited number of providers and services for adolescents that are available, and, often, collaborative networks are essential to provide a full range of services. These services can cover a continuum of care and case management--from street outreach, to basic needs services, to medical, mental health, and supportive services. Adolescent care providers from various kinds of agencies and institutions must collaborate to optimally serve youth--even when their institutions may compete in other arenas. Managed care has provided additional challenges for youth who are mobile, or who may not want to access care at the same sites as their parents, or who may make impulsive care-seeking decisions. These young people may need services at more than one location, but may have an insurance card that requires a particular locus and mode of access to care. Case managers need to coordinate care across sites to make the system seem as seamless as possible. Such coordination is time-consuming, but improves the continuity of care.

Active case management to stabilize the young persons' living situations can improve young persons' health-enhancing behaviors, improve their access to supportive housing (in some cases), increase the accessibility of regular meals, and help maintain a medication schedule, which is necessary for current treatment regimens to be effective. Case management and support services can be critically important in maintaining youths in care. Outreach and case management need to be intensive in support of young peoples' needs and growth, and fo-

cused on actively engaging and retaining youth in care with an individualized, client-centered approach. Case managers may come from a range of backgrounds and may have different roles, depending on the specific agency goals of their projects.⁵⁶ However, client-centered case management is needed and is the keystone of adolescent HIV care. Case loads for adolescent case managers need to be smaller, since the amount of time devoted to 10 to 20 active adolescent cases is considerably greater than for adult or pediatric cases.⁵⁷ This is in part due to developmental issues, the level of cognitive skills attained, lack of formal education, mistrust of the system, and lack of parental support for young people living with HIV. Instructions need to be concrete and repetitive, and many more interactions per client are required to retain youth in care. In a residential substance-abuse treatment program, in-patient case loads are seven youth per mental health professional, and outpatient substance-abuse caseloads are 10 to 12 clients per counselor (half of an adult caseload). More study is needed to identify the core resources that are necessary to engage and retain young people in care.

Services that complement healthcare and enhance general well-being are often called "wrap-around" services. Wrap-around services are rarely reimbursed by traditional health insurance, and are critically important in engaging and retaining youth in care. Some of these services may be currently supported by Ryan White Title I funds, but often programs for young people have insufficient client numbers to seek these funds to support core staff and services. Programs offered to adults may be seen as undesirable by youth. It is critically important to find routine ways to support such services as part of basic care for HIV-positive young people. The tremendous need for integrated outreach, case management, mental health and substance services

for young people requires additional thought and planning. Without the ability to motivate young people to be tested and to engage and maintain them in care that is relatively seamless and barrier-free, it is impossible to access appropriate health maintenance services and effective, feasible treatment regimens.

4. *HIV counseling and testing services, as well as early case identification and linkages to care, are important tools in assessing risk and reducing harms.* Young people are often wary of both adult and pediatric services and of health services in general, and they may not be aware of the availability of these services if they do not have parental consent or involvement. Peer leaders and youth providers help these to youth who are suspicious of traditional medical or mental health systems, including CTS.⁵⁸ Adolescents may need more extensive HIV counseling than adults on the meaning of the test results, personal safety and support systems, risk assessment, and harm reduction.⁵⁹ HIV CTS for adolescents and young adults may require longer and more frequent counseling sessions that are sensitive to adolescents' developmental issues before the actual testing. HIV CTS should be adjusted to both the developmental level and the needs of the young person.⁶⁰ Youth-sensitive providers, in accessible locations and trained in gay/lesbian/bisexual/transgender youth issues, should use gender-neutral terms to help all young people to be comfortable with the process. Many cultural and educational issues may complicate a decision to complete HIV testing; therefore, a variety of culturally and linguistically competent providers are essential to match the diversity of the local populations.⁶¹ The unique cultures of ethnically diverse groups of homeless and runaway, gay/lesbian/bisexual and transgender, substance-abusing youth, and new comers are among those who may require, particular attention.⁶² Many at risk youth have had negative ex-

periences in hospitals and are wary of medical settings and of needles. With privacy protections in place, oral mucosal testing can be performed at health fairs, outreach and residential sites, and in clinical settings without the need for phlebotomy, to engage larger numbers of at-risk youth in HIV CTS.

There may be many cultural concerns about testing and feeling safe in a society with many prejudices. More effort is required to "normalize" testing and knowing one's HIV status within youth culture. Providers, community leaders, parents, and teens need to be part of a larger effort to alter the cultural norms on HIV testing, and ensure that harassment and discrimination are actively contested. Successful providers and programs should be identified and their approaches used. Since effective treatments and preventive care are available for HIV, ideally more young people should be encouraged to seek HIV counseling and to have HIV testing as part of their care. However, state laws are inconsistent concerning confidentiality and parental and partner notification. Providers must realize that a youth's future livelihood, health access, relationships, and housing may be adversely affected impacted by disclosure of their HIV status, sexual identity, or risk behaviors. Further study is needed to identify the personal, cultural, and policy issues that affect young persons' decision be tested. Expanded educational efforts are needed to assure individual rights are protected and expanded.

Since "normalizing" HIV testing is so important, no young person should be turned away from these services because they are perceived to be at low risk. The principles of HIV CTS for youth were outlined by the AIDS Policy Center in 1996.⁶³ Although they are expensive to produce, media campaigns that incorporate HIV testing into the standards care for youth can make the topic more familiar, and can promote counseling and testing. Such cam-

paigns have been implemented in several cities, and can be replicated.⁶⁴ Providers must work with community and grassroots organizations to develop testing environments that are comfortable and safe for youth. Individual counseling by youth-friendly providers is essential to making HIV CTS an effective prevention intervention. Special outreach to street and substance-involved youth and to young people who are exploring their sexual identity can increase their comfort with testing and care. A variety of rapid and standard blood, urine, oral transudate, and saliva HIV antibody and protein tests are available, in a range of sensitivities and specificities, that have gained some acceptance by adolescents.⁶⁵ New approaches that are rapid and do not require blood drawing can be used in street-based, non-medical environments and may help connect more youth with CTS. Those using emergency departments and care sites for homeless people particularly benefit from rapid, same-day test results. All positive results from these rapid tests must then be confirmed by blood testing.

Now that HIV status is a reportable disease in some states, it is unclear what the impact will be on HIV CTS for adolescents. Name-linked reporting and partner notification could greatly affect infected adolescents,⁶⁶ and it may discourage testing and entry into care, because confidentiality and safety issues tend to affect youth more than adults. However, in Minnesota, where name-linked reporting has existed for some time, a system that utilizes a disease intervention specialist within the Minnesota State Department of Health has been helpful in connecting youth who were tested with the necessary HIV care.⁶⁷ Unfortunately, the number of youth who go out of state to be tested or to avoiding being tested completely is not easily measured, although youth do appear to be less aware of surveillance systems than adults. This is also less of an issue now that all states are develop-

ing HIV-reporting systems. Alternatively, a few states plan to use unique identifiers for reporting HIV results until the impact on adolescents and young adults can be further evaluated.

HIV CTS is an important gateway to initiating the delivery of general medical care to adolescents and young adults, as well as an initial step in identifying youth who need to receive HIV care. However, several SPNS projects expressed concern--and relief--about the relatively low rate of positive HIV tests in their counseling and testing programs. It is difficult too determine who is positive based on an evaluation of risk behaviors, so that providing testing to anyone interested is important. Nevertheless, reaching the youth who are at greatest risk should be a high priority. Unfortunately, few adolescents know when their partner is infected. Ideally, HIV testing and risk-reduction counseling and information about the availability of HIV care and treatment should be made a routine part of care for sexually experienced adolescents and young adults. Low seroprevalence is expected in teens, but this should not deter testing, as it can promote behavior change and early identification of HIV, and care. Although many youth will test negative, HIV counseling and testing is a perfect "window of opportunity" to address any risk related behaviors with the client and offer harm reduction approaches and impact the incidence in young adults. Frequently at-risk youth enter care through HIV counseling and testing and are connected to needed services and primary care.

Prochaska and DiClemente have developed a Trans-theoretical Model of stages of behavior change, which is a useful framework for HIV risk reduction and the counseling and testing process.⁶⁸ HIV counseling is an intervention itself, and an assessment of the client's readiness for change,⁶⁹ harm reduction, and skills building can be integrated into sessions. Young people need

to acquire skills, including the appropriate use of condoms and how to prevent breakage. CTS can assist youth realize their degree of risk, and help motivate them in the progression to changing their risky behaviors. Harm-reduction counseling grew out of substance-abuse counselling as a non-judgmental, individualized approach to reduce HIV and co-morbidity in individuals who are unwilling or unready to reduce their substance use or risky sexual activity. For example, a person who is involved in injection-drug use may reduce his/her risk by cleaning needles with bleach or by exchanging needles even when he/she is not willing to stop injecting drugs. Similarly, an adolescent who has chosen to be sexually active can decrease his/her risk by using or negotiating the use of condoms, by decreasing alcohol or drug use in social situations, and reducing his/her number of partners. Identifying risks, offering alternatives that reduce risk, and practicing these alternatives through role playing can help young people make better choices.⁷⁰ More research is needed to measure and improve the affects of HIV CTS and repeated testing on the behaviors of young people and their partners.

Early detection of HIV in adolescents is critically important in the delivery of optimal care and treatment.⁷¹ However, organizational support and funding for HIV CTS is not clearly within the purview of HIV prevention or HIV care, and it frequently falls short. Funding sources should recognize the importance of facilitating case finding and individualized risk reduction for young people, and encourage the support of youth-oriented, confidential testing sites. Even if cultural norms change and testing is perceived as more normal than it is now, most youth will still test negative and related services should still be available for those who test negative but continue to be at-risk. New approaches are needed to connect the highest risk populations to HIV CTS.

5. Individualized, client-centered approaches are essential to engage and retain young people in care. Adolescent care should be sensitive to individual's needs, should facilitate case entry and retention by maximizing the accessibility of services and youth's comfort with services, and minimize any existing barriers to using services. Complex treatment regimes should be adjusted to the lifestyle and daily schedule of young persons, or should be deferred until the client's life circumstances can begin to be made more stable.⁷² Access to developmentally appropriate research and treatment regimens are critical to the delivery of optimal care.⁷³ A youth's readiness for treatment and any barriers to adherence to treatment should be assessed prior to recommending or initiating antiretroviral therapy. Young people are often more willing to access HIV care in a general adolescent setting rather than at a specialized HIV clinic.⁷⁴ Active case management is needed to work on the problems of daily living, such as housing, food, clothing, and transportation, which may interfere with the delivery of consistent care. Case-management services are essential to initiate and retain young people in medical care. The impact of case management specifically on the retention of young people in care should be studied further.

Young people who have perinatally acquired HIV now live through adolescence and beyond.⁷⁵ Adolescents who have recently acquired HIV may need to transition to adult care. Transitions from pediatric care services to adolescent care services, and from adolescent to adult services require planning in advance. Visits to careproviders may need to overlap for a number of months until a young person becomes familiar with new careproviders. Case managers may need to overlap sites and create bridges between sites during this transition period. Careproviders may need to share the provision of services until a transition to a new site is fully complete.

Access to care is a major issue for adolescents and young adults. Even with the new initiatives for health insurance for children, young people 18 to 25 years old are frequently uninsured, especially if they are out of school and not working, or are working at part-time or entry level jobs. Youth who are runaways, "throwaways," homeless, or foreign-born newcomers have even less access to care. Multi-service agencies that are near locations where homeless and street youth congregate can act as "stepping stones" to the delivery of care by providing the basic needs of living and a safe place where counseling is available.⁷⁶ These multi-service agencies can provide some episodic healthcare services or screening clinics, as well as counseling and job and housing placement. Storefront clinics located in areas where youth congregate can offer primary care, mental health/substance-abuse services, and can link clients with other services. Links with youth-friendly community health centers and hospitals can increase the mental health and medical services that are available. Many young adults who live on their own may qualify for some form of uncompensated health care services pool or publicly funded care. Formal agreements can facilitate the provision of care across the continuum of services that are needed. The linking of complimentary care sites can help provide care to youth who are at risk.

HIV care systems and entitlements can be confusing to even the most knowledgeable adults, and can be especially problematic for adolescents. Intensive support and education are needed to help young people negotiate these systems. A caseload of 10 to 20 active adolescent/young adult clients may keep a case manager extremely busy.⁷⁷ Outreach providers frequently need to locate young people who do not follow-through with care and who do not have stable living situations. Providers may need to escort patients or provide transportation

to service sites to ensure that young people are comfortable and access care at new locations. Ongoing outreach to keep young people in care is important, even when they are not yet ready to follow a specific treatment regimen.

6. *Providers should become partners with young people about treatment decisions.* Adherence to complex treatment regimens is particularly challenging for young people who often do not have consistent schedules, sleep times, or meal times, and who may live with people who are unaware of the young person's HIV status. Young adolescents have a difficult time thinking abstractly about problems that may occur in the future. When they feel healthy, young persons may feel immune to complications that may develop down the road. In addition, adolescents who have chronic illness frequently rebel against treatment regimens as they separate from their parents and aspire to be more like their healthy peers. This is particularly problematic when regimens require extremely consistent adherence schedules, and can cause significant side-effects in an asymptomatic person. Homeless youth who are trying to live independently may place basic needs such as food, clothing, and shelter before medications.⁷⁸

Even when a young person is prepared to initiate a highly active antiretroviral treatment (HAART) regimen,⁷⁹ intensive follow-up and case management services are needed to increase the likelihood of adherence. Research indicates that for younger persons, poor adherence with HAART regimens is associated with a lack of insurance, a lack of access to therapies, low levels of education, female gender, or membership in a minority group. Careproviders report some success in increasing youths' adherence to therapeutic regimens and self care by using reminders, home care, school care, weekly pill containers, beepers, and alarms.⁸⁰ Also helpful are behavioral programs to work with young persons to de-

velop strategies for taking medications and pills. The transtheoretical model of change may be useful in staging a young person's readiness to begin or adhere to treatment.⁸¹ A modular approach, developed by AMHARN, Project Treat, is currently being evaluated as a clinical tool.⁸²

Since resistance to antiretroviral medications can develop rapidly unless therapeutic regimens are carefully followed, treating a youth too soon or with a complex regimen may not only be ineffective, it may change or eliminate future treatment options.⁸³ It is essential to balance personal issues, lifestyles, quality of life, and medications. Having stable, trusting relationships with careproviders is also critically important. Recent preliminary studies describe successes with simplified protease-inhibitor sparing regimens that are equal or superior to complex protease-inhibitor regimens.⁸⁴ Successful treatment plans will attempt to keep HIV-positive young people engaged in care over time, use the simplest feasible therapeutic regimens and help young people reduce the incidence of opportunistic infection, and other risks. Further research with the adolescent and young adult population should include trials and assessment of short-term and long-term sequela of new approaches, such as simplified protease-inhibitor sparing regimens, once-a-day dosing, directly observed therapy, and pulsed therapy. The assessment of balance of these approaches with the individual's lifestyle and quality of life is critically important. Young people should actively work with their careproviders to identify an optimal treatment plan, given their current life choices.

7. Youth involvement is needed in the planning, implementation, staffing, and evaluation of projects. A consistent theme throughout the SPNS projects was the need for youth involvement in the development, implementation, staffing, and evaluation of projects.⁸⁵ The level of youth involvement

varied throughout the projects, but all were strengthened by young people's active participation. Bay Area Young Positives was completely run by young adult staff and directors.⁸⁶ Health Initiatives for Youth fostered an atmosphere of youth-adult partnership, and had many visible youth staff.⁸⁷ Other projects incorporated youth advisory boards, with feedback through their evaluation process, and peer leaders or outreach staff.⁸⁸ Youth involvement is essential in all aspects of HIV programs for this population, but young people prove to be especially valuable as members of the project staff.⁸⁹ As peer educators, counselors, or advocates, youth serve as a source of support for other youth, and are likely to effect change in the behavior of their peers.⁹⁰ Youth from the groups at highest risk might best help improve service delivery and reduce high-risk behavior among the targeted population, but young staff require significant program commitment to ongoing training, supervision, and support. Youth-oriented projects must include feedback and contributions from youth to plan new initiatives, develop outreach and educational materials, and assess outcomes.⁹¹ Peer leaders can be effective at encouraging young people to choose CTS and to use services.⁹²

Projects that serve young people must involve them in making decisions. Programs should elect, recruit, pay, and support young people as members of their regional planning councils, advisory boards, and planning committees. Young people should be allowed to advocate and provide a voice for youth in their communities. Major efforts by several projects helped to make young peoples' voices heard at regional planning meetings and consortia.⁹³ Locally, meetings should be held at times that youth can attend, even if they are in school or working, and in settings they will feel comfortable. Stipends, transportation, and child care are needed to encourage the participation of young people.

RECOMMENDATIONS FOR FUTURE PLANNING AND POLICY

There are a number of important recommendations for those planning to develop or improve projects for at-risk and HIV-positive adolescents and young adults (see table 2 for a summary of the core recommendations for future planners, policy makers, and

program funders). Active outreach to young people is necessary to engage and retain them in care. A network of agencies that combines their resources to maximize the availability of youth-specific services in a particular geographic area is best. HIV CTS is an important entry into services, and should be utilized as an intervention, in itself, to help young people make better

Table 2
Recommendations for future planning and policy

Program and Regional Planning

- Youth oriented outreach is necessary to raise awareness and to connect hard to reach youth to care.
- Collaborative networks should link resources to provide a spectrum of services needed for at-risk and HIV positive youth should be provided.
- A continuum of care should include basic needs services, and primary and referral health care across multiple sites.
- Case management is essential to coordinate services across institutions and agencies.
- HIV counseling and testing services (CTS) should be accessible without parental involvement or fee, developmentally and culturally appropriate, and available at youth-friendly sites.
- HIV CTS should be recognized as an intervention through risk assessment and harm reduction efforts as well as a critical step in early case identification and linkage to care.
- Providers trained in culturally and developmentally competent care are more effective.
- Young people should be partners in their own treatment decision making, which needs to be adjusted to their individual lifestyles, and to optimize their quality of life and treatment efficacy.
- Youth involvement and feedback at all levels of program development and evolution are critical for the success of youth-friendly services.
- Law enforcement agencies should become allies in identifying youth who may be helped by these programs.
- Involve community organizations and communities of faith in the planning process.
- Systems of care need to be developed in response to the needs of the population served.

Policy Makers and Funders Should Do the Following

- Ensure access to youth oriented services at multiple well-utilized sites.
- Support comprehensive continua of care for youth.
- Support youth-sensitive and -accessible HIV CTS.
- Train healthcare providers to work with adolescents concerning HIV/AIDS.
- Identify new sources of support for core services (outreach and case management) to engage and retain youth in care.
- Fund youth oriented case management at appropriate case loads.
- Ensure within HIV reporting mechanisms that issues of confidentiality, disclosure, safety, and access to care, housing, and employment are taken into account.
- Support new research in youth specific issues (see table 3).
- Involve youth and youth-serving providers in policy development
- Ensure that lack of health insurance and fears of disclosure do not create barriers to case finding, care or support.
- Avoid categorical approaches and fund programs with holistic approaches to risk reduction for adolescents and young adults.

choices. Providing services to young people requires special training and flexibility to implement a non-judgmental, nurturing approach that responds to their needs and enhances their understanding, self-efficacy, and hope. More training for healthcare providers is needed to prepare them to work with adolescents. Policy makers must not allow a lack of health insurance or fear of disclosure to present barriers to HIV case finding and early intervention. Policy makers must avoid categorical funding, as many behaviors should be addressed in a holistic way that reduces risk. The voices of youth must be heeded throughout the evolution of projects and local planning efforts.

THE NEED FOR RESEARCH AND EVALUATION

From the findings and policy recommendations described in table 2, there are specific areas needing further research (summarized in table 3). To improve local plan-

ning, the gaps in services in specific regional networks must be identified. Those aspects in the development and evolution of successful networks should be studied, and successful approaches continued, enhanced, and replicated. The unique role of outreach and case management in the engagement and retention of youth in care should be studied.

Cultural, behavioral, and developmental barriers to HIV testing must be identified and effective interventions evaluated. The affect of name-linked reporting on adolescents and young adults regarding HIV testing and access to care requires further study,⁹⁴ as should new behavioral approaches to improve young people's adherence to complex treatment regimens. New treatment regimens that are flexible, effective, respect an individual's lifestyle preferences, and improve quality of life must be found. It is necessary to find new ways to involve youth in decision-making processes and project development. As young

Table 3
Areas for Future Research

1. Identify methods to optimize outreach to difficult to engage vulnerable populations.
2. Identify ways to integrate HIV prevention/education, substance abuse, and mental health services.
3. Recognize the gaps in services in specific collaborative networks to improve regional planning and policies.
4. Study the factors involved in the development and evolution of successful integrated networks of care and ways to enhance communications between institutions and agencies.
5. Evaluate the care resources needed to engage and retain youth in care.
6. Identify the cultural, behavioral and developmental barriers to HIV counseling and testing (CTS) and test methods to overcome these barriers.
7. Evaluate new approaches to connect youth at greatest risk for HIV to CTS.
8. Evaluate the impact of name-linked reporting on adolescent/young adult HIV CTS and access to care.
9. Study ways to increase and evaluate the use of HIV CTS as a behavioral intervention for young people.
10. Examine the impact of needle exchange programs on the transmission of HIV and connection of youth to services.
11. Test behavioral interventions to access treatment readiness, and to improve adherence to complex treatment regimens.
12. Identify new approaches to improve the balance of treatment regimens with life style and quality of life issues.
13. Evaluate new ways to involve youth in policy and programmatic decision making.
14. Evaluate the service needs of vertically infected youth reaching and surviving adolescence.

people infected at birth increasingly survive to and through adolescence, programs need to assess and respond to their needs.

More research is needed to identify the spectrum of services needed to engage and retain youth in care. Intensive case management was identified by all of the projects as a critical service to help coordinate care within and across agencies. Young people may not know what their case manager does, but they are very clear about what is helpful to them.⁹⁵ Trained providers can work with young people to balance their personal needs and effective treatment regimens. New approaches are critically needed to simplify treatment regimens, and to balance problems with adherence with personal lifestyles and quality of life for adolescents and young adults.⁹⁶

Local and regional collaborative networks can provide a continuum of care for at-risk youth--with careful planning. Agencies often provide complementary services that need to be recognized by and accessible to youth. The study of the evolution of HIV/AIDS networks of care and ways to enhance communications between sites has had little published research to date. More needs to be known about the glue that holds networks of care together and helps them to evolve in a coordinated manner. Adolescent-specific projects must be identified and funded in an ongoing manner to provide access and high quality care to young people with HIV/AIDS.

CONCLUSIONS

The Adolescent HIV Care projects found that with extensive outreach and youth-oriented CTS, young people with HIV can be identified and engaged in care. A tremendous amount of effort and flexibility is needed to identify these youth and connect them with needed services. Services from a range of agencies and models are necessary to meet the needs of a diverse popula-

tion of young people in a specific region. Providers must work together to bridge institutional barriers. Case management services are critically important to coordinate services. Despite young people's mistrust of traditional systems and lack of knowledge of available services, youth-sensitive outreach and individualized services can engage hard to reach youth. HIV prevention education, peer education, and CTS are critical gateways to connect youth with care.

These nine models of adolescent HIV care supported by the SPNS Program demonstrate innovative methods of linking youth with care. Several projects have developed linked service networks that bridge institutional barriers. All projects demonstrate the importance of intensive youth-oriented case management services to negotiate complex care systems and maintain youth in care. Two projects are youth-managed, and several offer peer support to disenfranchised youth. The involvement of young people in the development, implementation, and evaluation of programs is critical to their success. Most projects link adolescents and young adults to comprehensive services, including HIV care. Using ideas from youth in the development of projects can improve their accessibility and appeal to young people who are outside traditional healthcare systems. More research is needed to identify the core services needed to engage and retain youth in care, involve young people as partners in their care, develop youth-oriented treatment regimens, and define the most important aspects of effective models of care.

Because there are a limited number of sites that offer youth-oriented services in any given region, agencies and institutions must form collaborative networks that work closely together and meet regularly. Many types of care sites need to be available that are culturally and developmentally appropriate for young people. Particular efforts are required to engage at-risk populations,

including homeless youth, street youth, gay/lesbian/bisexual/transgender and questioning youth, incarcerated youth, linguistic minorities, and youth of color. In addition, perinatally infected youth survive longer, and transition in care to adolescent and young adult sites should carefully planned. Multiple routes to care are needed, including prevention/education activities, CTS, basic services, and comprehensive care. Case management services and coordination of care across sites is essential. Ranges of services including multi-disciplinary care, mental health, and substance services and support groups are needed.

Retaining youth in care requires individualized care and treatment plans. Intensive case management services are necessary to address the problems of daily living and to juggle complex treatment regimens. Access to health insurance and care are also a challenge. Active case management services and coordination of care are required across sites and must include active follow up and frequent contact with clients. It may be more appropriate for youth-oriented case managers to have fewer active cases (20). Treatment regimens and clinical trials for young people must be simple, straightforward, and easy to incorporate into daily schedules. Providers must balance what may be medically ideal with what a young person is willing and able to follow. Care teams need to work with each individual to adjust complex treatment regimens to the individual's lifestyle, personal needs, and daily schedule.

HIV/AIDS planning and policy makers must specifically include adolescents in their programs and plans. Because many adolescents with HIV are not identified, services do not always account for their needs, and adolescents are often left out of traditional adult and pediatric services. A broad continuum of care should be developed to connect young people with care, provide case finding, and allow for early

initiation of care. Many areas of evaluation and research are desperately needed to offer the best possible care and services for young people. Innovative approaches to youth-oriented collaborative networks, HIV CTS, and treatment are critically needed. Federal, state, and local planning efforts are needed to reach, engage, and retain young people in care.

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