ORIGINAL ARTICLE

Overview of the Special Projects of National Significance Program's 10 Models of Adolescent HIV Care

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Ten models of adolescent human immunodeficiency virus (HIV) care were funded in 1993 by the Special Projects of National Significance (SPNS) Program, HIV/Acquired Immunodeficiency Virus (AIDS) Bureau, Health Resources and Services Administration, through the Ryan White CARE Act. These models were supported to advance knowledge about the engagement of HIV-positive and at-risk adolescents and young adults in care. This article provides an overview of the SPNS Program's adolescent initiative, which developed and evaluated innovative models of HIV care, and provides background information on and summarizes the 10 models of care. The models are organized into four groups emphasizing different concepts: (a) youth involvement; (b) outreach to bring youth into services; (c) case management and linkage to services; and (d) a comprehensive continuum of care for youth. © *Society for Adolescent Medicine, 1998*

KEY WORDS:
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In 1993, 10 models of adolescent human immunodeficiency virus (HIV) care were funded by the Special Projects of National Significance (SPNS) Program of the Health Resources and Services Administration (see Preface to this issue). Because many HIV-positive adults were infected during adolescence and because young people are particularly hard to engage in care, these 10 innovative models were funded to advance the understanding of the issues around connecting adolescents and young adults (ages 12–24 years) to HIV care. This article summarizes the background information leading to the development of the adolescent models, and introduces the articles contained in this issue which describe in detail the 10 models of care.

National HIV/Acquired Immunodeficiency Virus (AIDS) Statistics

National HIV/AIDS statistics indicate that adolescents and young adults represent important risk groups. The Centers for Disease Control and Prevention (CDC) report that as of June 30, 1997, there were 612,078 reported cases of AIDS in the United States, with 2953 in the 13–19-year-old age group, and 22,070 cases in the 20–24-year-old age group (1). Owing to the long delay in developing symptoms associated with HIV infection, many of the young adults were probably infected during adolescence. The male/female ratio for AIDS cases is 1.6:1 for adolescents and 2.8:1 for young adults (20–24 years old), reflecting the increased number of young women with HIV in these age groups compared to adults (1). Estimates indicate that there are as many as two to three HIV-positive youth for every known case of AIDS (2). A 1996 report released by the White House Office of National AIDS Policy stated that

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25% of all new cases of HIV infection occur in young people between 13 and 20 years of age (3). Sexual exposures continue to account for the majority of adolescent AIDS cases (1). The majority of sexual risk for young men is through same-sex contact, and for young women, is heterosexual contact (1). HIV disease occurs disproportionately in black and Hispanic adolescents and young adults (1).

Special Issues for Adolescents

Adolescent subpopulations are particularly difficult to engage in the care needed for the diagnosis and treatment of HIV (4). Adolescents also are one of the most medically underserved populations in the United States (5). Even when physician–adolescent encounters occur, communication about HIV risk behaviors is frequently limited (6,7). In one study, fewer than half of the adolescents with histories of "survival sex," injection drug use (IDU), same-gender sexual behavior, or a sexually transmitted disease (STD) associated with genital ulcers or sores had sought or received help for these HIV-related issues (8). STDs are synergistic with HIV in terms of transmission and offer a marker of increased health risk behaviors (9,10). Taking risks and testing limits are necessary for normal adolescent psychosocial development. For most adolescents, however, these developmental tasks are accomplished without risk to health. When risk taking and limit testing include sexual risk behaviors, the chances of STDs and HIV increase. Developmentally appropriate and culturally competent HIV counseling and testing is particularly important for youth, since a significant number of young people state that they would commit suicide if they test HIV positive (11). Gay and bisexual adolescents have high rates of depression and a threefold increased risk in suicide intent and sevenfold increase in suicide attempts (12). Use of alcohol and other recreational drugs contributes substantially to potential HIV exposure (13,14), since both increase the likelihood of teens' participating in sexual risk behaviors and reduce the likelihood of condom use (15,16).

Homeless and Street Youth

Currently, there are between half a million and two million homeless and runaway teenagers in the United States (4). Many homeless youth have run away from family violence and sexual abuse or are "throw-away" youth because of issues such as sexual orientation and pregnancy (4,17). Many of these adolescents exchange sex for food, shelter, or drugs to survive ("survival sex") (17–19). Homeless youth have particularly high seroprevalence rates (20) and require sensitive youth-oriented programs to connect them to care (21–23). Specialized training is required for health care providers to reach these populations (6,7,21,24–28).

Previous Efforts

The knowledge and experience of earlier programs for HIV-positive and homeless youth were helpful in the development of the SPNS Program's adolescent models of care. The Larkin Street Youth Center in San Francisco established a central drop-in center and medical clinic that demonstrated the importance of basic needs (such as food, clothing, and shelter) as a stepping stone to health care (28). The Adolescent AIDS Program at Montefiore Medical Center in the Bronx showed the importance of outreach to referring agencies to connect youth to care (29,30). The Los Angeles system of care for homeless youth discovered the importance of collaborating with agencies in a defined geographic area solidified by frequent network functions to care for homeless and street youth (31–34). CDC-funded programs found that HIV interventions in specific communities needed to be "based on local needs" using an empirically tested theoretical framework to develop prevention activities (35). Guidelines from the Title I programs for evaluation of local HIV service delivery programs emphasize the need for both qualitative and quantitative methods to evaluate service provision, consumer opinion, and HIV-related outcome measures (36). These prior efforts demonstrated important components and evaluation mechanisms for the SPNS Program's Adolescent Initiative.

Theoretical Background

Adolescents engage in clusters of HIV risk behaviors, often in association with other health-risk and problem behaviors, such as drug and alcohol use (13,14,31,32,37,38). Many of the effective health education programs aimed at preventing or changing adolescents' health-impairing behaviors have been based on social cognitive theory (39). According to social cognitive theory, interventions aimed at motivating self-directed behavior changes, thereby reducing the risk that adolescents will engage in HIV risk behaviors, should include four components: (a) in-

formation designed to increase awareness and knowledge of the consequences of behavior; (b) social and self-regulative skills development aimed at translating knowledge into preventive action; (c) opportunities for guided practice and corrective feedback in applying the skills in high-risk situations, resulting in skills enhancement and resilient self-efficacy; and (d) changes in social norms and social supports for desired behavior change (39). Many programs emphasize all four of these components through youth involvement in program design, management, outreach, and skills building risk-reduction efforts (40–42). Peer educators can help shift normative behaviors and integrate skills into the individual's values (33,43–45). Interactive skills-based education has greater impact on behavior than knowledge-based education (46,47).

The Need for Outreach

Homeless adolescents are particularly difficult to treat because of their behaviors and vulnerabilities (4), the inability of providers to work with adolescents, and the legal status of adolescents in some states (48). Outreach has been shown to be effective for connecting homeless youth to services (20,22,31,49). Outreach programs are more effective when they are linked to integrated services including food, clothing, shelter, risk-reduction education, and health services (50). The CDC and others have reported that peers within the community should be recruited to deliver intervention messages and to reach less accessible populations (35,51–53), and help link hard-to-reach youth to services (54).

Issues of HIV Care

Once adolescents and young adults are connected to services, a balanced approach to HIV management is essential to maintain youth in care (29,55–57). The emphasis should be on continuing to engage youth in care rather than on obtaining particular laboratory results. Working with the adolescents to evaluate how tight a control of their infection they desire and enlisting their involvement in maintaining this control are essential (55,56). As in other chronic diseases, youth adherence to complex care plans is difficult and often not a high priority to the young person (55,56). Since resistance to antiretroviral medications develops so rapidly unless regimens are carefully followed, one should be careful not to eliminate medications which might later be useful (55,58,59). Providers should work with the young person to balance personal issues and develop a care plan. These SPNS Program models of care provide a variety of culturally sensitive projects for at-risk populations which provide youth-oriented services, linked services networks, case management, and/or comprehensive HIV health care. Integration of culturally sensitive mental health and substance use care into all health care visits is important to serve vulnerable populations (60).

Models of Adolescent Care

Ten models of adolescent HIV care have been supported by the SPNS Program to demonstrate innovative concepts in youth-oriented HIV care. Those 10 models are described in the articles that follow. Several programs have developed linked services networks which cross institutional barriers. Many have demonstrated the importance of intensive case management to coordinate and maintain youth in care. Two programs are managed by young people and offer support to historically disenfranchised youth. Most of the programs contain youth advisors, providers, and educators. Outreach, HIV counseling and testing, and interagency referrals are important gateways to case identification and early intervention. Many programs link adolescents and young adults to comprehensive services, which include HIV care. Comprehensive care is more appealing to young people than specialized clinics or locations (54). Integrating ideas from youth themselves into program development improves the accessibility and appeal to young people who frequently would not obtain care.

Based on the literature reviewed above and the findings of the 10 grantees described below, it is very important to emphasize the word "adolescent" in "adolescent models of care." These perspectives converge on the idea that programs for youth must have significant youth input in their design and continuing operations to be attractive to the clients they wish to serve. Because of their ages, young people may not have had technical training in many areas which are needed to build and sustain a program. Hence, it is essential that trusting partnerships be formed between youth and traditional professional service providers.

Description of 10 Models: The Consensus Model

In the next article (pages 11–27), Huba and Melchior described a consensus model for the SPNS Program's

adolescent projects that summarize some major themes explored later in this issue. Tables are included which show the ways in which the five major consensus elements were expressed in the different projects and ways that future projects might implement these concepts. While there are several consistent themes among the programs, each model addresses the issues somewhat differently and offers unique solutions to the question of how to develop youth-friendly services that will attract large numbers of clients, keep them engaged in care, and produce useful medical and other outcomes. This synopsis is provided so that the reader can choose to read about models that are of particular interest or can compare the models as they are reviewed. In terms of their overall functional similarities, the projects can be clustered into four major groups. Those groupings are as follows:

I. Models stressing youth involvement

- Bay Area Young Positives (pp. 28–36)
- Health Initiatives for Youth (pp. 71–82)

II. Models stressing outreach to bring youth into services

- Bridgeport's Team Outreach and Primary Services (TOPS) Project (pp. 49–58)
- The University of Alabama Teenage Access Project (pp. 107–114)

III. Models stressing case management and linkage to services

- The Indiana Youth Access Project (pp. 83–95)
- Seattle YouthCare's Prevention, Intervention, and Education Program (pp. 96–106)
- The University of Minnesota Youth and AIDS Projects' Adolescent Early Intervention Program (pp. 115–121)

IV. Models stressing a comprehensive continuum of care for youth

- Boston HAPPENS Program (pp. 37–48)
- Childrens Hospital Los Angeles (pp. 59–70)
- Walden House (pp. 122–131)

National Evaluation

A special feature of the grant initiative was HRSA's decision to fund a national cross-cutting evaluation center. The Measurement Group has staffed this center throughout the history of the grants and helped develop, collect, and analyze standardized information across sites. Some of these data are presented in the articles throughout this issue for the individual sites; the cross-cutting national results are available elsewhere (61–63). Fax-in forms and questionnaires can be obtained directly from the Measurement Group (5811A Uplander Way, Culver City, CA 90230) or on its Web site (http://www.tmg-web.com) (64–69). The evaluation modules are also published in the SPNS Program's reports (61–63). In addition, the three SPNS reports summarize the national data from their study of the infrastructure for adolescent services in their communities and cross-cutting analyses (61–63) and can be obtained from the Measurement Group.

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