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SPECIAL REPORT

A Model for Involving Youth in Health Planning: HIV Prevention in Pennsylvania

By Anthony J. Silvestre, John F. Faber, Michael D. Shankle and Janice P. Kopelman

Despite major advances in the treatment of HIV and AIDS, continued transmission of HIV remains a major public health problem. Declines in AIDS incidence during the 1990s were not accompanied by comparable declines in the number of newly diagnosed cases of HIV.¹ Furthermore, the Centers for Disease Control and Prevention (CDC) estimates that at least half of all new HIV infections in the United States are among individuals younger than 25, and almost 30,000 men and women aged 13-24 have already received AIDS diagnoses.²

Data from 54 focus groups conducted in 1994³ and in 1995⁴ in Pennsylvania (excluding Philadelphia) indicate that a number of factors interfere with effective HIV prevention among young people. Two-thirds of participants—who included young people, teachers, parents, staff of juvenile detention facilities and people at high risk of HIV infection—rated the HIV education offered at their schools as inadequate and said that television was their primary source of HIV information. The young people suggested that they perceived HIV as a disease of older people but at the same time expressed regret about having missed out on the sexual liberation of an earlier generation. They cited a lack of free condoms, the use of alcohol and drugs before and during sex, and the need to choose anonymous sex (so that parents and others would not hear about their behaviors) as other reasons for not following HIV prevention recommendations.

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Anthony J. Silvestre is associate professor, John F. Faber is HIV prevention specialist and director of Youth Initiatives and the Pennsylvania Young Adult Roundtables, and Michael D. Shankle is youth HIV prevention research specialist—all with the Department of Infectious Diseases and Microbiology, Graduate School of Public Health, University of Pittsburgh. Janice P. Kopelman is director, Division of Communicable Diseases, Pennsylvania Department of Health, Harrisburg.

The focus-group data highlighted particular needs of specific populations. For example, data from youth in juvenile detention centers and staff from these centers suggest that more than half of these young people are drug-dependent and that they have had, on average, more than 15 sexual partners by the age of 20. Data from deaf young adults indicate that HIV information for deaf people is lacking and that much of the available information is not easily understood. Additionally, the close-knit nature of the deaf community discourages HIV testing and education because potential candidates for testing fear being found out by their community. Despite these barriers, the youth and parents who participated in the focus groups expressed strong support for more HIV education through all grades of school, churches and family.

It seems clear that the continuing spread of HIV will remain a problem until effective prevention interventions can reduce the barriers related to HIV risk among young people.

Knowledge alone is not sufficient to bring about effective HIV-related behavior change.⁵ People at highest risk of infection—men who have sex with men,⁶ injection-drug users⁷ and the sexual partners of these individuals,⁸ particularly those who are young, have multiple partners or are members of racial and ethnic minorities⁹—face many cultural,¹⁰ environmental, social, psychological and economic¹¹ barriers to effective behavior change.

A number of theoretical frameworks and prevention models have been proven effective by the CDC¹² and others,¹³ and have been successfully used to reduce HIV risk behavior. These include the transtheoretical model developed by Prochaska¹⁴ and the AIDS Risk Reduction Model,¹⁵ which take into account the barriers to change at each stage of change. Interventions based on these models use approaches such as consciousness-raising, self-evaluation, peer counseling and effective communication to enhance knowledge, change attitudes, and increase and maintain safer behaviors. To be successful, they must be grounded in an accurate understanding of the factors that influence or determine at-risk populations' knowledge, norms, beliefs, access to services and barriers to change. They also must be appropriate for and acceptable to the targeted population.

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Thus, to develop effective prevention interventions for young people, one needs to thoroughly understand their values and experiences, and apply this understanding at all phases of intervention development, implementation and evaluation. Involving young people in all steps of project planning and execution is one way of increasing understanding and of bringing their perspective to bear. Furthermore, since young people's characteristics, beliefs and behaviors change, a mechanism is needed by which to review and revise programs so that they remain relevant.

In this article, we describe a model for involving young people in prevention planning

in a way that supports their full participation and integrates their views into the process.

BACKGROUND

In 1993, the CDC required that all jurisdictions receiving CDC funds for HIV prevention activities¹⁶ develop an HIV prevention plan and that each planning committee include members who represent groups at highest risk of infection.¹⁶ Further, each committee must take a number of steps to analyze problems related to the spread of HIV and to create an HIV prevention plan in conjunction with its department of health. The health department is supposed to incorporate the plan in its application for federal funds, which the committee reviews. If the committee does not agree that the application has incorporated the plan, committee members can urge the department to change the application; as a last resort, they can refuse to sign off on it. In the latter case, the CDC reviews the application and the plan, and decides what steps are needed to remedy the situation; if warranted, the CDC might even cut funding.

Pennsylvania comprises two jurisdictions: Philadelphia and the rest of the state. When notified of the new requirements for HIV prevention planning, the Pennsylvania Department of Health asked faculty at the University of Pittsburgh's Graduate School of Public Health to provide technical assistance in developing a planning committee for the state, excluding Philadelphia. The department asked the school to organize the committee, to gather data about needs from those directly affected by HIV, and to negotiate and monitor subcontracts with demonstration projects.

We used a number of methods to ensure the full participation of members of high-risk groups. High-risk individuals, particularly men who have sex with men, have been successfully recruited into HIV education in projects that have used social marketing¹⁷ or community organizing¹⁸ principles, which rely on knowledge of the targeted community, effective and long-lasting communication, and interactions that are beneficial to the recruits and the recruiter. Applying these principles, faculty were quickly able to organize community leadership groups of racial and ethnic minorities and men who have sex with men.¹⁹

However, bringing young people—one of the groups at highest risk of infection—into the process was more challenging, because university organizers, health department staff and committee members had observed that in other situations, simply adding a few young people to larger groups of adults seldom resulted in significant involvement by the youth. This may be so because young people are not familiar with the processes, language and procedures used in committee meetings and, perhaps, because they find large groups of adults operating in an "official" setting intimidating.

Janice P. Kopelman, who was then director of the health department's Bureau of HIV/AIDS and cochair of Pennsylvania's community planning committee, suggested that a roundtable of youth be brought together to parallel the larger committee. The roundtable, organized along the principles of a focus group, would provide continuous input into the planning process. Since the committee defined "youth" as 13-21-year-olds, recruitment was limited to that age-group, although roundtable members subsequently decided to allow sitting members who reach age 21 to continue to participate.

To deal with problems of travel and to ensure that large enough numbers of young people from each risk group participated, the committee voted to form a number of roundtables in different parts of the state. Four groups were organized in 1995. Locales for the group were chosen to represent the various regions in the state. Roundtables met in the largest town or city in their region unless the members chose otherwise.

DESIGN

Organizing Principles

The CDC identified and described four characteristics of committee membership that could strengthen the planning process: inclusiveness, representativeness, parity and empowerment.²⁰ These characteristics provided a valuable framework around which we organized our principles and policies regarding young people's involvement, and they help shape the roundtables' structure and functions.

...the roundtables' support systems proved strong enough to provide members what they needed to get through difficult times

Inclusiveness is achieved when representatives of every constituency of young people at highest risk of acquiring HIV—young men who have sex with men, injection-drug users, and male and female sexual partners of both of these groups—are involved in the process in a meaningful manner. People who engage in risky behaviors are of all races and socioeconomic statuses; live in urban, suburban and rural areas; and may or may not be HIV-infected.

Since no three or four young people can represent this diversity, each roundtable is organized to mirror one at-risk group. For example, a group of teenage mothers was organized in one city, and a group of lesbian, bisexual, gay and transgendered young people in another. This approach provides a sense of security and safety, and is particularly helpful in increasing the comfort of participants who are still developing their identity. It also helps reduce tension among the diverse members and promotes group cohesion, peer support, openness and a respect for confidentiality. At meetings, discussion focuses on HIV as it relates to the particular group's identity, and the young people are able to see how their experiences relate to the pertinent policy issues.

Three mechanisms reduce the likelihood that homogeneity will blind the participants to the needs of other groups. First, each roundtable elects two representatives and an alternate to an executive committee, which meets three times a year; meetings are scheduled to overlap with planning committee meetings so that the youth can attend those as well. Representatives report on these meetings to their roundtables, to provide an opportunity for discussion about the needs of a wide array of youth. Second, mentors from the planning committee attend roundtable meetings, to help educate and inform young people about diversity and the need to understand all people at risk. Finally, large meetings of all or some of the roundtable participants

provide opportunities to meet, learn about and empathize with members of the other risk groups.

The planning committee maintains close ties with the roundtables. The roundtables' executive committee elects three of its members to full participation in the planning committee, and each meeting of the planning committee includes time for these young people to report on and raise issues of concern. As young people age, they are encouraged to nominate themselves for regular seats on the planning committee (although most leave the planning process altogether, and some remain on their roundtables). Further, planning committee mentors convey information between the roundtables and the committee.

Representativeness means that the young people involved in the process truly reflect their community's values, norms and behaviors. Participants are not expected or required to adhere to particular values, or to share the views and beliefs of the larger committee, university personnel or state staff.

A number of approaches have been used to achieve representativeness. Initially, young people were chosen to reflect those at high risk in Pennsylvania on the basis of a sampling frame derived from the state's AIDS epidemiological data. Using the sampling frame, the university organizer identified a local "gatekeeper," who identified recruits and assisted in convening a group of targeted young people who were representative of their communities. In each subsequent year, adults and peers have nominated for participation in the roundtables young people whom they have considered to represent at-risk youth. Also, the youth are surveyed yearly about their attitudes, values and behaviors, and their responses are compared with those from larger samples of young people at risk of infection to assure that they continue to represent their communities even as their own knowledge and attitudes change. The infusion of new members to replace those who move out of the group also helps ensure that members continue to represent the at-risk cohort.

Parity suggests that all members have equal opportunity for participation and input, and an equal voice in voting and decision-making. To achieve parity, the organizers focus on three issues: full voting rights, respecting boundaries and cultural competence.

Voting rights are ensured in two ways. Each member of a roundtable has the right to nominate and vote for representatives to the executive committee, and each representative has the right to nominate and vote for the three planning committee members. Executive committee members are given all of the resources they need to fully participate in the planning committee's decision-making. The young people (along with the rest of the planning committee members) receive a per diem and have their travel and hotel expenses paid.

Parity requires that the university organizers, planning committee mentors and committee members respect boundaries. Specifically, older participants are urged not to inquire into the personal lives of the young people and not to play the roles of parents, teachers or older siblings. In other words, the younger participants are to be treated as valued members of the process. Their input is regarded as seriously as the input of other members.

Cultural competence is relevant in matters of race, ethnicity, sexual orientation, gender and age. Committee members are expected to know about and respect the young people's life situations, and to acknowledge and accommodate issues related to school schedules; inexperience with group process, hotels and travel; financial limitations; food preferences; limited freedom because of age or restrictions imposed by parents; and peer pressure. Cultural competency issues are also the topic of discussions at various meetings and are a subject of training at planning committee meetings and conferences.

The university organizers, health department staff and committee members believe that the young people should be empowered to exhibit leadership in the planning process. This necessitates providing them with all of the information that they need and allowing them to define problems, to identify determinants of problems and to determine what actions are necessary to bring about change.²¹ The organizers spend a significant amount of time at roundtable meetings providing education about HIV disease, behavior change, cultural issues, group process and conflict resolution. When possible, longtime roundtable members help to educate newer members. Mentors are also available to assist the group and individual members, as well as serve as contacts with the planning committee and the local community.

Empowerment suggests that significant resources—staff, funds and time—have to be devoted to the process. A full-time organizer, other professional personnel and volunteer mentors staff the six meetings that each roundtable holds each year and provide support for a newsletter, executive committee meetings, report writing and other necessary tasks. Stipends for roundtable members plus costs of transportation, rent for meeting space and refreshments add up to a substantial amount of money.

Empowerment also means respecting the life circumstances of the young people and providing a flexibility that allows them to fit their roundtable activities into their very demanding life activities. Family, school, and social and romantic relationships are complex and require a great deal of time and energy. The young people need respect and acknowledgment of the many pressures that they experience. A day and time convenient to the participants' schedules are chosen for meetings. The youth choose locations that they consider safe and neutral. For example, they have ruled out a drug clinic site because some young people might find it stigmatizing; they also have chosen to leave a site because they felt that the staff there were interfering with their program. Time is needed at meetings and in out-of-meeting interactions for having fun, decompressing, sharing experiences and offering support.

[Young people's] participation has consistently been valued by other members of the committee.

Perhaps most important, every effort is made to protect the young participants from stigmatization and loss of confidentiality. Without this protection, we could not ethically recruit young people to participate.

PLANNING AND MONITORING

Through formative and process evaluation, we regularly review our program, using an evaluation model Card has developed to assess teenage pregnancy prevention programs.²² The model describes nine components of successful programs, which provide a helpful checklist for planning and monitoring: (1) The group must maintain a clear focus on risky sexual behaviors (we add drug and alcohol use). (2) All activities must be culturally relevant (in our program, the focus is on age, race, gender, socioeconomic status, locale, ethnicity and sexual orientation). (3) The work must be theory-based. (4) Enough time must be realistically allocated for completion of planned activities. (5) Participants in planning must receive the information they need to plan effectively. (6) A variety of teaching methods that involve participants and support personalized information must be employed. (7) Social pressures must be addressed. (8) Models and skills, particularly in communication and negotiation, must be provided. (9) Leadership training must be available (and leaders nurtured).

LIMITATIONS

Organizers of the planning process have to deal with a number of problems. First, there is significant but not disruptive amount of turnover, either because young people's living arrangements change (e.g., if they go away to college or are incarcerated, or if their parents move or divorce) or because the demands of everyday life create too many pressures for them. The organizers deal with attrition by using the input of new people as a way of keeping abreast of changes in values, perceptions and behaviors among young people over time.

Second, it is common for professionals who hear about the program to want to recruit the young people for their own committees and programs. This threatens to overwhelm the roundtable members with too much activity. Further, some older people tend to condescend to the young people, treating them like their own children or students. The energy that older participants feel when they are around the young people is very satisfying and can distract the older participants from their role as information providers and supporters. Careful supervision and support of older participants is needed, and clear role expectations have to be defined orally and in writing throughout their involvement. A handout and mentor orientation tool, "Mentor Responsibilities," provides a helpful way to reinforce appropriate behavior.

A third problem has to do with group conflict. In the few instances when roundtables have taken positions at odds with some or most of the planning committee or organizers, conflict has occurred. In one instance, the young people participating in the planning committee argued against the use of the phrase "risk groups" and instead suggested that only "risk behaviors" be used in the plan. In another instance, they argued for stronger actions to support HIV prevention in prisons and schools. During these discussions, it was clear that younger participants could be intimidated by older participants and that frequent characteristics of group conflict, such as raised voices, "pulling rank" and sarcasm, could be particularly demoralizing to young people who had little experience in committee "warfare." These conflicts were all successfully resolved. Whenever conflict cooled down, some participants pointed out inappropriate conduct and discussed ways to avoid it in the future. Roundtable staff also met with the young people after the meetings to discuss what had occurred. The

planning committee is introspective, and members are used to reviewing their process and taking steps to make conflict useful and not harmful. Younger members proved to be resilient, and the roundtables' support systems proved strong enough to provide members what they needed to get through difficult times.

Fourth, many of the young people expressed frustration with the slow process of changing policy and practice in government agencies, school boards, churches and other organizations. Like many adults, some youth have difficulty participating in a group whose charge is only to plan, because it seems abstract. Yet, it is important that they not dissipate their resources, energy and time in social actions that are not likely to work. The inclusion in the process of planning how to advocate for youth and how to choose effective prevention interventions for them may help relieve the young people's frustration. Opportunities to put these ideas into action occur when the committee or the state adopts their recommendations.

THE ROUNDTABLES IN ACTION

Composition

Eight roundtables operated in 2001. A total of 131 young people (5-22 from each roundtable) attended the first meeting of their roundtable, at which anonymous data forms were distributed and collected. Of these, 14% had been with the roundtables for five or more years, and 46% for one year or less. Participants ranged in age from 13 to 27 (mean and median, 19 years).

Sixty-five percent of the young people were female. Forty percent identified themselves as black, 31% as white, 15% as Hispanic and 1% as Asian; 15% classified themselves as multiracial. These proportions overrepresent racial and ethnic minority groups, who make up only about 15% of the state population.

Participants' reported behavior indicates that they were representative of youth at risk. Fifty-six percent had used drugs in the prior 12 months. More than half of these young people had used two or more drugs. The most commonly used drugs were alcohol and marijuana. Fifty-five percent of the young people identified themselves as heterosexual, 16% as gay males, 6% as lesbians, 18% as bisexual and 3% as not sure; 2% did not answer. Only 15% had had no sex partners in the previous 12 months; 69% had had more than one partner. Eighty-five percent of those who were sexually active did not use condoms all of the time. Fifty-seven percent had been tested for HIV at least once, and 46% had been tested more than once. Eighteen percent of the young people had a history of sexually transmitted infections. Seventy-eight percent believed themselves to be at no or low risk for HIV infection.

PARTICIPATION IN PLANNING

Representatives of the roundtables executive committee have maintained a consistently high level of participation in planning committee meetings: On average, they attended 76-91% of meetings each year from 1998 through 2001. (Participation by other committee members ranged from 70% to 75%.)

Not only have the young people fully participated in the state's planning process, their participation has consistently been valued by other members of the committee. For example, in the annual process evaluation for 2000, when asked the extent to which

they agree that the roundtables give youth a voice in planning, using a scale ranging from one (completely disagree) to four (completely agree), the committee members gave a mean score of 3.5.

ROUNDTABLE ACTIVITIES

All of the roundtables have engaged in various prevention activities at the local level. The number and type of activities have varied according to the decisions and needs of the local members.

- **Planning and promotion.** The roundtables have planned the state's Young Adult HIV Summit and participated in national HIV meetings, including the CDC Prevention Summit, the U.S. Conference on AIDS and the Ryan White Conference; they also have participated in state and local educational activities such as university conferences, Ryan White Coalition trainings, and a child and adolescent service system program. Closer to home, they have invited guest speakers to address the roundtables, recruited other youth into the roundtables, and created formal and informal support groups (e.g., for teenage mothers). Notably, they have strongly advocated for revising Pennsylvania schools' HIV curricula and hiring health education professionals to assist public schools in developing HIV prevention curricula. (As a result of their strong advocacy during the summer of 2001, a full-time staff person was hired to provide such assistance.)
- **Direct action.** After discovering that few young HIV peer educators existed in Pennsylvania, roundtable members created a peer education program, which is currently being piloted; they also have participated in American Red Cross HIV peer education training and negotiated with cooperating local schools to present HIV prevention programs to students. Roundtable members have participated in long- and short-term HIV prevention activities such as decorating a town's Christmas tree with condoms for World AIDS Day, displays of the AIDS quilt, prevention outreach to other youth and fundraising walks. They have reviewed HIV videos and reported their assessment to the department of health, and have taken part in Ryan White regional trainings and sat in on Ryan White Coalition committees.
- **Web page and newsletter.** The young people have identified a need to create a mechanism for easy communication among their members as well as the wider world, and for advocating their views. They have chosen the Internet and a newsletter as their means of communicating. The Web site, which is on a University of Pittsburgh server, was developed and is maintained by members of the roundtables. The site is confidential and can be accessed only with an approved user name and password. Pages include a message board, a chat line, a copy of the consensus statement developed by the young people, links and HIV information. A link is provided to the planning committee's Web site (<www.stophiv.com>), and that site contains information about more than 1,500 HIV service providers in the state, information on funding opportunities, planning documents and HIV information. The newsletter is published every six months and is put on the young people's Web site.
- **NiteStar.** With the realization that few HIV prevention programs have directly targeted young people, members of the roundtables have searched for an appropriate program to adapt to the state. On the basis of conference presentations and articles in

peer-reviewed journals, the young people have chosen NiteStar, a program developed in New York City in 1988 that uses young people to create and write HIV-relevant scenarios and perform them for targeted audiences of young people.²³ Performances are followed by facilitated discussions that encourage interaction between audience members and actors. In Pennsylvania, scripts have been targeted to sexually active young people, especially men who have sex with men, and members of racial and ethnic minority groups. At the young people's suggestion, the committee is providing three years of funding for two demonstration projects based on the NiteStar model. Each project has developed six targeted scripts that deal with developmental issues, peer pressure and HIV risk reduction.

- Young Adults Intervention Plan. Roundtable members have worked in partnership with a planning group of high-risk young people and peer educators recruited from the Pittsburgh area to develop an HIV prevention intervention that is culturally appropriate and tailored to the needs of these sexually active young people. This Young Adults Advisory Team, together with a facilitator from the university and a recorder, meet for two days each month for one year.

- Consensus statement. By far, the most important contribution to the HIV planning process in Pennsylvania has been the development and revision of the youth roundtables consensus statement (available at <www.stophiv.com>). The statement was the result of a three-day conference in the fall of 1998, in which young people, health department and university staff, and mentors from seven roundtables participated. The conference began with presentations on epidemiology, prevention needs in Pennsylvania, prevention theory and personal perspectives of two youth with HIV infection. The larger group broke into working groups to identify and prioritize obstacles to HIV prevention, groups needing to be targeted and prevention needs.

The working groups identified 33 obstacles to HIV prevention among young people. The 10 most important were lack of cultural competency; lack of resources for prevention programs; poverty; stigma; laws and policies preventing needle exchange; drug and alcohol use; lack of knowledge about how to reach high-risk young people; sexual abuse, including rape; poor self-esteem; and parental and family attitudes.

In 1999, the roundtable members moved parental and family attitudes to the top of the list and added school polices as the second greatest obstacle. The other nine obstacles from the 1998 version were listed after those.

The youth fiercely debated whether *behaviors* or *groups* should be targeted, an issue that continues to generate discussion. In the end, they targeted males between the ages of nine and 25 who have sex with males, racial minority members and white females with any risk factor for infection.

They also identified 34 HIV prevention needs. The first four were advocacy and education; cultural competency in all prevention activities; programs that promote harm reduction, such as needle exchange and peer education; and more HIV counseling and testing targeted at youth. They plan to develop a "solutions" section to add to the consensus statement that will respond to the needs they have identified.

STATE AND NATIONAL IMPACT

In 1995, the roundtables had a major impact on state HIV policy, when the state planning committee adopted its recommendation to target young people in every priority population identified in the plan. These populations now must be targeted by all state-supported HIV prevention programs in Pennsylvania. Since the formation of the roundtables, their influence has also been evident when other state programs, such as the sexually transmitted disease program, have adapted some of their principles for recruiting young participants.

In July 1997, roundtable participants spoke publicly for the first time at the CDC Division of Adolescent and School Health's conference in Cambridge, Massachusetts. As a result of that conference, the roundtables have become a national model for involving young people in HIV prevention planning. Roundtable members—sometimes with the financial support of the National Alliance of State and Territorial AIDS Directors, and in collaboration with that agency and Advocates for Youth—have presented at numerous national conferences and networked with youth attending them. During 2000, through the Mid-Atlantic AIDS Education and Training Center, roundtable members served on panels dealing with recruiting high-risk groups for HIV interventions. Through these exchanges, several jurisdictions have sought technical assistance from the university and the Pennsylvania Department of Health to adopt the roundtable model. Minnesota and Iowa, for example, have adapted the model to fit their jurisdictions' needs and capabilities.

Currently, roundtable members are developing criteria for peer-based prevention intervention programs that they plan to distribute to all AIDS service organizations in Pennsylvania.

CONCLUSION

Creating the opportunity to bring young people into HIV planning is important. Their input is as necessary as the input of people with HIV infection, members of other high-risk groups, experts and others identified by the CDC. Because of developmental issues, lack of strong advocacy groups, few resources and constraints imposed by their families or schools, youth are not likely to participate as fully as members of larger groups of adults. Venues such as the roundtables provide the environment needed to encourage young people's full participation. The level of resources devoted to the effort is a measure of commitment to the belief that input from all groups at high risk of infection is needed for sound planning; in Pennsylvania, that commitment now extends to the state's providing new resources for peer-based interventions targeting youth at risk of HIV infection.

The last words on the issue should be those of the youth. The following declaration is part of their consensus statement, developed at the 1998 summit:

"We are your sons and daughters. We are still getting infected. We are chained to your fears. We are still getting sick. We are having sex. We are the future. We are exhausted by your silence. We are tired of your excuses. We are still dying. How many more infections do we have to count before you listen to us? We are demanding that you help us. We are hoping that you will help us. Please act on what you have read."

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