What's Going on @SPNS

AN UPDATE FROM THE RWCA SPNS PROGRAM, HRSA HIV/AIDS BUREAU AUGUST 2006

User Name: Outreach Worker

It's anonymous. It's relatively private. And it's part of a new strategy for reaching young men who have sex with men (YMSM).

It's the Internet.

Internet tools—Web sites, chat rooms, and bulletin boards (see glossary, p. 3)—can be tailored to the needs of an infinite number of audiences to provide help and support for social and medical issues from depression to child rearing to sexually transmitted infections (STIs).

The Internet's unique characteristics give it great potential for disseminating information about HIV and bringing people into care. The Internet is available 24 hours a day, has a broad cultural and geographic reach, and affords a high level of privacy. MSM, particularly young men who have grown up using the Internet, are likely to use it for everything from social support to finding information on STIs. Chat rooms help MSM quickly find like-minded souls for friendship—and more. Men (and women) who are not sure of their sexuality can use the Internet as a safe way to explore their feelings before coming out. In addition, many MSM appear to prefer the Internet to public settings, such as "cruise parks" and bars, as a means of seeking sex partners.

HIV Among Youth

HIV infection rates among youth are of great concern to epidemiologists and others trying to slow the spread of AIDS. An estimated one-fourth of all HIV infections occur in people younger than age 21—a segment of the population that is among the most medically underserved[1] (experts estimate that only 11 percent of HIV-positive youth in the United States receive adequate health care[2]). Approximately one-half of new HIV infections are in people under 25 years old. Moreover, HIV/AIDS among youth appears to be on the rise: In 2004, there were 2,114 estimated AIDS cases among people ages 15 to 24, an increase of 30.5 percent since 2000.[3] HIV diagnoses are disproportionately higher among women and non-Hispanic Blacks. Blacks ages 13 to 24 account for 56 percent of HIV diagnoses.[4] Social and economic factors facing young men of color—such as discrimination, high rates of poverty and unemployment, and lack of access to health care—are associated with HIV risk behavior.

Most HIV-infected youth are asymptomatic, do not know they are infected, and are not enrolled in treatment.[5] For example, the Centers for Disease Control and Prevention's (CDC's) Young Men's Survey[6] found that most HIV-infected YMSM participants, particularly Black participants, were unaware of their infection. The CDC survey, conducted between 1994 and 1998, interviewed men ages 15 to 22 who attended MSM-identified venues (e.g., shopping areas, dance clubs, bars, and organizations) in six large cities (Baltimore, Dallas, Los Angeles, Miami, New York, and San Francisco). Participants were interviewed with a standard questionnaire, had blood drawn for HIV testing, were given appointments to obtain test results, and were provided HIV prevention counseling and referrals for care when needed.

Of the 920 Black YMSM who participated in the survey, 150 (16 percent) tested positive for HIV; of those who were HIV positive, 139 (93 percent) were unaware of their infection. Among those who were unaware, 99 (71 percent) perceived their chances of being infected with HIV as unlikely. In addition, 58 (42 percent) believed themselves to be at low risk for ever becoming infected, and 45 (32 percent) perceived themselves as at low risk both for being and for ever becoming HIV infected.

SPNS YMSM of Color Initiative

In response to the CDC study and other research, the Health Resources and Services Administration, HIV/AIDS Bureau, Special Projects of National Significance (SPNS) program created a project to fund demonstration models of outreach, care, and prevention targeting HIV-infected YMSM of color. Eight demonstration projects are developing and implementing innovative service models to reach YMSM of color ages 13 to 24 and link them to appropriate clinical, supportive, and preventive services. Support also is provided to an evaluation center to coordinate demonstration model evaluation and provide technical assistance to grantees.

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Two grantees—the Men of Color Health Awareness Project (MOCHA) and the Horizons Project—are using peer outreach methods that include the Internet. A third organization, Bronx AIDS Services (BAS), is not using the Internet in the SPNS project but has significant experience with it as an outreach tool; BAS has provided information and assistance to the two grantees who are implementing an Internet outreach protocol.

Bronx AIDS Services

The Bronx Boogie Down Project is a collaboration of BAS and the Adolescent AIDS Program of the Children's Hospital at Montefiore Medical Center. The SPNS project is using social and geographic mapping to identify high-risk areas for YMSM of color and then develop new methods of outreach. The project incorporates a community-organizing model that involves the use of community ethnographer-organizers (CEOs), who are peers connected to YMSM social networks.

BAS was one of the first AIDS service organizations (ASOs) to use Internet outreach to bring YMSM of color into care. The organization received a grant from the CDC 5 years ago to conduct online outreach to YMSM ages 13 to 24. Although the BAS SPNS project is not using Internet outreach, the CDC project is a source of referrals for the SPNS project.

According to Mario de la Cruz, project coordinator, the outreach program under the CDC grant uses two health educators who go online three or four times per week. They go into a chat room and initiate a conversation by presenting a health fact that is relevant to the target audience (e.g., data on HIV prevalence in the area, information on risky behavior). The outreach workers have profiles that identify them as being affiliated with BAS and do not include personal information. The goal of the outreach workers' online sessions is to encourage people to get tested and to modify their risk behaviors. The project has implemented a tracking system whereby the outreach workers complete a form that summarizes each online conversation and includes the screen names of the people who receive online referrals to testing. Counselors are given copies of the forms, and the chat room participants who receive referrals are told to give their screen name when they arrive for testing.

Most conversation takes place in the chat room, but sometimes participants send an outreach worker an instant message (IM). In those cases, the outreach worker will continue the conversation by IM with that person. De la Cruz says that although some organizations discourage one-on-one IMs as a way to maintain boundaries and ensure outreach worker safety, BAS has found that the IMs facilitate communication, particularly because some chat room users know each other, so the environment is not completely anonymous. De la Cruz says that "people seem to be willing to ask questions in an anonymous/confidential format. They are also comfortable with receiving referrals and information."

For More Information . . .

For additional information on the SPNS YMSM of Color Initiative, visit http://hab.hrsa.gov/special/ocp_index.htm. The SPNS project officers for the initiative are

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Additional information is available at the evaluation center Web site: www.yescenter.org.

BAS conducted a needs assessment based on street outreach before initiating the project. Over the 4 years of the project, the protocol has been refined to address issues such as maintaining boundaries and ensuring confidentiality.

MOCHA

The MOCHA Youth Empowerment Around HIV Project (Project YEAH) has adapted the CDC's Many Men, Many Voices curriculum, a comprehensive, theory-based, and culturally appropriate prevention intervention program, for its young target audience. The goal is to identify seropositive YMSM of color and link them to counseling and testing and care. The project's outreach efforts include participation in Internet chat rooms.

Sheldon Fields, principal investigator for MOCHA, says that the first step in developing an Internet outreach protocol was to conduct a pilot study to discover what was taking place in local chat rooms. Staff asked a focus group of youth ages 18 to 24 which sites were popular and then simply observed what was going on in those chat rooms. They compiled data on the content of chats and the times of heaviest online chat room use. They also culled demographic information from the profiles of the people in the chat rooms. Data from 200 online profiles are being analyzed.

Another part of project planning consisted of MOCHA assessing its ability to do Internet outreach, a step Fields says is extremely important. "You can't do this type of intervention on a dial-up connection," he says. "You need DSL or high-speed Internet along with updated computer equipment. You have to do an internal assessment." Programs hoping to implement Internet outreach need to assess their computer hardware and software capabilities.

The pilot study has ended, and the outreach protocol is being finalized; in general, the plan is for the outreach workers to log on to chat rooms as Project YEAH outreach workers and offer a "health message" that is relevant to the target audience (e.g., "Did you know that there is a syphilis outbreak among MSM in Rochester?") to spark conversation—an approach similar to that of BAS. The outreach workers' profiles will designate them as "YEAH Gray" or "YEAH Black" or something similar and will not

include personal information. If a participant IMs the outreach worker, he is responded to in the public chat room on the assumption that more than one person likely has the same question; in addition, avoiding one-on-one IMing helps maintain boundaries and ensure outreach worker safety. The outreach workers encourage participants to get tested and to modify their risk behavior.

Many colleges and universities are near Rochester, and a large YMSM population comes to the city on weekends to socialize. College students are comfortable with using the Internet for all kinds of purposes, including online chat rooms, and anecdotally, Project YEAH is reaching many of them. Many students do not want to be tested on campus, and MOCHA helps raise awareness about community testing resources.

The population of greatest concern to the MOCHA project, says Fields, is the group that logs on between 2:00 and 4:00 a.m. after the clubs close. "They didn't 'score,' they are probably intoxicated, and their defenses are down," he says. "They are not so inhibited and are likely to engage in the riskiest activity." Trial runs indicate that Project YEAH is successfully reaching the target population.

Brothers Saving Brothers

The Brothers Saving Brothers (BSB) program of the Horizons Project at Wayne State University/Children's Hospital of (Detroit) Michigan is using a motivational interviewing (MI) strategy to encourage at-risk YMSM of color to receive counseling and testing for HIV. The approach combines traditional peer outreach and Internet outreach strategies. One component of the project is targeting 18- to 24-year-olds via online chat rooms. Forty chat room participants will be enrolled in a study: 20 participants will be randomized to traditional peer outreach, and 20 will receive motivational interviewing according to a specific protocol. Like MOCHA and BAS, the goal of BSB's Internet outreach is to provide information about HIV and encourage chat room users to come to the Horizons Project for counseling and testing.

As in Project YEAH and BAS, BSB staff focused their initial efforts on project planning. They spent the first year of the SPNS project conducting an online survey, which is nearly complete, to develop a greater understanding of the target population. The survey has found that many chat room participants in the target age range of 18 to 24 who are at high risk for HIV do not consider themselves to be at risk.

The Internet outreach protocol is still being finalized, but it involves participation in a small number of Internet chat rooms frequented by YMSM of color. Peer outreach workers participate in the chat room by presenting themselves as resources for information; their profiles say that they are "educators with Horizons." The workers answer questions from chat room participants and sometimes have more in-depth discussion with individuals via IM. They encourage the participants to get tested for HIV and give them a tracking number to give to BSB staff when they present for testing.

According to Angulique Outlaw, data director for the Horizons Project, the outreach workers are already having an impact. "We are seeing a spike in people getting tested," she says. "We usually are struggling to meet the State goal of 75 YMSM tested, and we have already reached that."

Glossary

Chat room: A section of a Web site that allows real-time online communication.

Instant messaging (IM): A way to send real-time messages to a specific Internet user; unlike a chat room, the communication is private—only the users involved in the IM can see the text. Many chat rooms and Internet service providers (e.g., AOL, Yahoo) provide IM service.

Profile: A Web page that contains information about a chat room user; the level of detail permitted depends on the rules of the chat room. Chat room users can usually click on the name of a participant or search on the name to see the person's profile.

Screen name: Also known as an alias or "handle"; the name a chat room user goes by while online (e.g., "HandsomeGuy30" or "SmileyFace").

Keys to Success

Understand the Audience

Outlaw notes that online, "people open up more, even with surveys. People confess to behavior they won't in person." She notes that people who come in for testing often have a feeling of relief; they feel comfortable because they have shared personal information and established trust with BSB staff, who are known by their screen names.

At the same time, Fields notes, "People lie all the time online. They post other people's pictures, lie about their serostatus." Therefore, one component of outreach is to encourage people to "act as though everyone is HIV positive, no matter what." Fields also notes that even though it is easy to lie online, especially about one's age, outreach workers really do have to be part of the peer group; a 34-year-old posing as a 22-year-old will be found out quickly. "Slang, language are very important. Our outreach scripts were rewritten by the [peer] outreach workers," because the older staff who originally wrote them did not have the language and flow just right.

Cultural competence, a fundamental qualification for all outreach workers, extends to Internet culture. "Slang changes from room to

room; it differs for YMSM, transsexuals, adult married men," de la Cruz says. Staff need to use appropriate language for the audience. Although their age presents unique challenges, the youth of the outreach workers is ultimately an asset because it enables them to relate to the target audience and interact in a nonjudgmental way.

In all three projects, outreach workers are seen as neutral parties who are there to help. Outreach workers' honesty about their intentions helps encourage frank communication, and the trust that builds helps the users feel confident in the sponsoring organization. The hope is that chat room users will eventually feel comfortable enough to visit the sponsoring organization and get tested.

Plan, Plan, Plan

Everyone interviewed for this article agreed that taking the time to plan is vital to success. "Don't keep it in your head. Write it down," says Outlaw. Likewise, "the key to [Internet outreach] is taking a step back; not many people spend the time assessing what is going on in the area," says Fields.

In addition, notes de la Cruz, programs must choose online venues with care. "Use observations first," he says. "Which rooms will have the target population available, people willing to engage in conversation? If people are looking just for partnering, most of the conversation will take place via IM, not in the chat room." For outreach to be effective, he notes, programs should choose sites that have a lot of chatting in the chat room.

De la Cruz emphasizes the importance of organizational readiness. In addition to assessing training needs, programs must decide whether staff will be permitted to work from home or must use the organization's equipment. Outreach workers in the Internet setting must work unusual hours, and staff who monitor their work must be willing to work some of those hours as well. As noted earlier, programs must have the right computer equipment—and factor in computer maintenance costs and Internet service provider fees.

Beyond planning, ongoing training and monitoring of outreach workers is important, too. Both BSB and Project YEAH monitor peer outreach workers online and give them feedback. Outlaw says that BSB outreach workers review chat transcripts regularly. Boundaries are crucial: "It is too easy to blur the line. They need lots of guidance because they are younger," says Outlaw. Project YEAH does not keep conversation transcripts on file (although it often has workers print them out for audit and feedback purposes), but it maintains a log of all contacts made.

Think Safety

Outreach workers in all the projects do not use their real names in their profiles, and they may not meet online contacts in person outside the counseling and testing context. Those boundaries are there not just to keep peer workers from forming inappropriate relationships with chat room users: They are for safety. All three projects use a "script" of sorts, but it is not set in stone. Outreach workers must maintain a fine balance of "having the flexibility to go 'off script' yet stay safe," says Fields. They must keep in the back of their mind, "When do I need to shut this down?" Peer outreach workers must be able to maintain boundaries and confidentiality while handling a variety of unique situations, some of which may involve people they know.

To protect the privacy of chat room users, outreach workers must maintain their anonymity. In the BAS protocol, an outreach worker who knows the person behind the screen name generally passes that person on to the other outreach worker. Revealing that the outreach worker knows a user could affect that person's willingness to approach other outreach workers. Any personal chatting must take place outside of work hours using the outreach worker's private screen name and on the worker's own computer.

Promise and Perils

Disadvantages of Internet outreach, compared with street outreach, include lack of face-to-face communication and the inability to bring people to a mobile testing van for immediate testing. Moreover, Internet outreach is not likely to reach people of low literacy or people who cannot afford a computer and Internet connection. None of the programs have conducted cost-benefit analyses at this time, although it seems likely that Internet outreach could provide some cost advantages over street outreach, simply because so many people can be reached with so few outreach workers.

In addition, Internet outreach efforts are difficult to evaluate. De la Cruz notes that it is not yet clear how effective BAS's Internet outreach efforts are, in part because the project reaches people who have many testing options: Chat rooms targeting the New York metropolitan area draw people from several States and municipalities, many of which have their own ASOs providing counseling and testing. The BAS outreach workers may motivate a person to get tested, but unless he gets tested at BAS, they will never know that they were effective.

But perhaps the greatest drawback to Internet outreach is its strength: anonymity. Most Internet sites that contain sexually explicit content require users to affirm that they are age 18 or older, but there is no process for verification. "Outreach workers who talk to underage Web site users through a connection online may provide a message that is not appropriate for that person and may unintentionally violate the project funder's policies and procedures," says Blaine Parrish, senior research scientist with the YES Center, the SPNS YMSM of color project evaluation center. Working with youth under age 18 involves special legal and other issues. Even if the public health message of HIV prevention and testing is one that a community agrees is important for young people to hear, a youth who misrepresents himself as being over age 18 and engages in an explicit conversation

with an outreach worker exposes the organization to the potential for problems ranging from negative publicity to lawsuits. Moreover, adds Parrish, there is no evidence that the Internet is the best place to reach youth ages 13 to 17. Online chat rooms that cater specifically to teens, house parties and balls, and traditional street outreach may have the most impact and may be the most cost-effective. "All it takes is one inappropriate contact," says Parrish, "for an entire project to be jeopardized. The exposure never makes sense considering that there are not hoards of underage kids on sexually explicit Web sites. If you are only going to reach a few [youth in that age bracket], why jeopardize the project? Save the resources for venues where you can make direct contact with those ages 13 to 17."

What should ASOs conducting Internet outreach do to deal with underage chat room users? Parrish has a few suggestions:

- Follow the policies of the chat room host. If it becomes clear that a chat room participant is too young to be in the room (i.e., is under 18 or otherwise violates chat room policies), the outreach worker should report that user. "If State and Federal regulatory bodies are to respect what the online community is trying to do to protect underage kids, organizations need to back [the online community] up," says Parrish.
- ASOs conducting Internet outreach need to develop explicit policies for dealing with underage youth online. Outreach workers need a clear plan for what to do when they encounter an underage youth, and they need to know that, as long as they follow the appropriate procedure, their organization will back them up should problems arise.

Nevertheless, the outreach work in chat rooms is "perfect for 18- to 24-year-olds," says Parrish. "You can be direct in a way that is educational." For youth who are under 18, says Parrish, "the better money is spent on social networks and outreach at youth-identified venues and other places youth congregate."

What the Future Holds

BSB and Project YEAH are finalizing their Internet outreach protocols and intend to roll them out late this summer. The initial results are promising. Fields is exploring the possibility of expanding outreach using online social networking sites like MySpace.com and Facebook.com. The SPNS YMSM of Color project ends in 2009.

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HIV, Minorities, and Youth

- A study on infection patterns and risk behavior among young urban MSM found that HIV infection rates were high among Blacks (14 percent, compared with 3 percent for Whites).[1] In 2004, Blacks accounted for just 12.2 percent of the U.S. population but 49.3 percent of estimated new AIDS cases.[2,3]
- Only a small proportion of estimated AIDS cases have been among people in their teens. Given the time lapse from seroconversion to progression to AIDS, it is certain that a large number of people in their 20s—and some in their 30s—became infected with HIV while in their teens.[4]
- HIV is the seventh leading cause of death in people ages 20 to 24.[5]
- Large proportions of young adults, particularly minorities ages 18 to 29, report that they know someone with HIV/AIDS or someone who has died from AIDS. In one national survey, 61 percent of African-Americans said they knew someone infected,compared with approximately 42 percent of Latinos and 34 percent of Whites.[6]

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