The scene, San Francisco. The time, 1989. The STOP AIDS Project has just closed its doors because massive behavior changes in the gay community have led to a marked decline in HIV infections. But Bob Hays, CAPS researcher, begins to notice anecdotal reports that young gay men are still engaging in risky behaviors.

Bob approaches Susan Kegeles, another CAPS researcher, and they call the National Institute of Mental Health to see if they would fund a study. Together they write up a behavioral survey and hand it out in three small towns, Santa Cruz and Santa Barbara, CA, and Eugene, OR. People mail back their responses and they find a shocking 43% of young gay men are engaging in unprotected anal intercourse.

When the findings were published in the journal AIDS in 1990, it was the first mention in a scientific publication that younger gay men were at risk for HIV. Bob and Susan then set out to develop and test an intervention for young gay men. Thus was born the MPowerment Project, a community-level intervention to reduce HIV risk among young gay men.

“We knew that community-level interventions were the best way to try to reach young men, and we wanted to try something innovative,” said Bob. The MPowerment Project works by promoting a norm of safer sex among young gay and bisexual men through a variety of social, outreach and small group activities designed and run by young men themselves. The program has four components: formal peer outreach at events and with an outreach team; peer-led small groups called M-groups; informal peer outreach where young gay men encourage other men to engage in safer sex; and a publicity campaign (see sidebar on page 6 for an outline of the program).

The MPowerment Project is based on the following four guiding principles: 1) For many young gay and bisexual men, HIV prevention may not be the most important thing in their lives; finding friendships, partners and community may be more pressing. 2) Peers can have a great deal of power to influence their contemporaries. 3) Interventions that facilitate empowerment – that engage participants in identifying, finding and implementing solutions to their problems – bring more lasting change. 4) Social change occurs when innovative practices are adopted by a critical mass.

Growth of the Program
Since 1990, Bob and Susan have set up interventions in six cities in California, Oregon, Texas and New Mexico. They started in the three cities in which they had conducted the surveys. They chose smaller communities because these communities often had no resources or programs in place for gay men. They also chose college towns, to make sure there’d be lots of young gay men around. In Santa Cruz, they began developing the program and changed a lot of their ideas in the process. The first official version of MPowerment was implemented in Eugene, OR, in 1992. Santa Barbara followed in 1993.

“We learned a lot in those first programs,” said Susan. “Not just about prevention and safer sex, but about community dynamics, political issues and forming Community Advisory Boards (CABs).” As a result, the program expanded to include a publicity campaign to raise awareness among young gay men. The program continues to evolve, with new strategies and tactics being developed to reach different populations.

Albuquerque MPower Staff: John Hamiga, Susan Kegeles, Steven Romero, Bob Hays and Chris Norton
Welcome to CAPS Exchange, a publication of the Technology and Information Exchange (TIE) Core at the Center for AIDS Prevention Studies (CAPS), as one of the HIV/AIDS programs at UCSF. The TIE Core is the part of CAPS that integrates the research and community responses to the HIV epidemic. We bring community concerns to bear on CAPS research and get research findings to the community where they can inform programs and services. We do this through our CAPS web site (www.caps.ucsf.edu), HIV Prevention Fact Sheets, monographs, conferences and Town Hall meetings. The TIE Core provides consultation, technical assistance and referrals for community-based agencies and health departments through individual contacts (call 415/597-9396). The TIE Core also funded community-initiated collaborative research with 22 community based agency partners over the last 5 years along with our co-funders, Northern California Grantmakers, AIDS Task Force and the California State Office of AIDS.

Welcome to the first issue of CAPS Exchange. We look forward to exchanging ideas with you about how research and community can best work together to end the HIV epidemic. Please fill out the enclosed reply card to let us know what you think of CAPS Exchange and what you would like to see on these pages.

First Person

Recruitment: Day One

by Mary Truskier

This column features personal essays by researchers and service providers that give an intimate look into the day-to-day process of those of us working in the HIV/AIDS field. Submissions are welcomed.

During their monthly visits to the hospital, Sally and Mimi have discovered they have a lot in common. They take ballet lessons, carry Winnie the Pooh lunchboxes, and love Frosted Flakes. They think their adoptive mothers are the greatest. When they're older, they'll learn of another connection: their birth mothers were HIV-positive, and so are they.

I chat with the girls' mothers who listen patiently to my pitch to enroll their daughters in the School Entry Project, a CAPS study. In previous work, our research team has shown that starting kindergarten is stressful enough to boost stress hormones, dampen immunity and change behavior in many healthy children. What about children living with HIV? How are they coping with the many challenges in their lives?

As study coordinator, I explain how we will collect data over six months, measuring the girls' stress hormones.
RESEARCH TIPS

In-depth Interviewing

If there's one thing a research center should do, it's help people conduct research, right? This column will feature research tips on varying subjects, provided both by CAPS scientists and service providers.

In-depth interviewing

In-depth interviewing is a qualitative data collection method. In general, qualitative methods are used when we want to understand more about the context in which a behavior occurs and to understand the process people go through when making decisions about their behaviors. Using qualitative methods thus answers the questions “how?” and “why?” as opposed to “how many?”

The questions

You want rich, in-depth information, so it is important that the questions encourage this. For this reason, in-depth interview questions are usually open-ended, while qualitative survey interview questions are typically closed-ended.

- **Open-ended:** “What did you find most helpful about the facilitator? What was least helpful?”
- **Closed-ended:** “How helpful did you find the facilitator? 4=Very helpful; 3=Somewhat helpful; 2=Somewhat unhelpful; 1=Very unhelpful”

The process

- **Use follow up questions** (also referred to as “probing”), to get more information, or to clarify statements already made by the participants (e.g., “Please tell me more about that;” or “How did that make you feel?”). Stay away from questions that can be answered “yes/no.”
- **Use appropriate body language.** Show that you’re interested by maintaining eye contact and making sounds indicating you’re listening, such as “um hum, I see, yes.” Don’t cross your arms, doodle on your form or check the time repeatedly.
- **Don’t break silence.** Some interviewers feel uncomfortable when participants don’t say anything. However, the participants may simply be composing their answers. If you interrupt them, you may miss a thoughtful response.
- **Don’t insist on an answer** if the participant seems uncomfortable. Forcing a response may simply make him or her even more reluctant to answer future questions. It may also make the responses less valid.
- **Keep the participant focused** on the subject. A little drifting may be acceptable, but try to gently bring them back in a positive way (e.g., “I understand that you think teachers need to be paid more, and that’s an important issue. But right now let’s focus on the role of sex education in classrooms, OK?”)
- **Take notes.** It can be very helpful to ask the interviewer to rate the participant and the responses. This may include putting a star in the margin next to questions about which the participant seems to feel particularly strongly, or developing some kind of rating system to be completed at the end of the interview. Items may include issues such as whether the participant appeared comfortable or anxious, truthful or lying, sober or under the influence of drugs. This will help you make decisions later during the analysis phase about the validity of a given interview.

Common challenges/problems

- **Interviewer has anxiety.** It is important that you get plenty of practice so that you are comfortable with the questions. Practice with a co-worker or friend at least 2-3 times before meeting with a participant. If you are still anxious, you could do your first interview together with a co-worker who is more experienced.
- **Interviewer doesn’t like the participant.** It is all right not to like everyone you are interviewing. However, you also need to remember that you are not interviewing the person to establish a personal relationship, but because you are interested in his or her thoughts and feelings about your program. It may be useful for you to take a moment and think about what pushes your buttons. If you really feel it is impossible to work with a particular kind of participant, it may be possible to reassign that person to another interviewer.
- **Interviewer has emotional reactions to the responses.** An in-depth interview is different from a counseling or education session. Interviewers may find themselves shocked or alarmed at what they hear, but it is important that they keep the goals of the interview in mind. If you are really concerned with the welfare of a participant, wait until the interview is over and then provide him or her with referral information to an agency where the participant can receive help.
- **Interviewer talks too much/tries to influence participant.** This can happen almost unconsciously. Therefore you may need to carefully pay attention to your own speech. It can be difficult to keep your own opinion to yourself, especially if you are interviewing someone about a topic you really care about. However, again, please remember that the focus here is to solicit information, rather than having a discussion or a debate about the topic.
Project Access: Research that

by Pamela DeCarlo

“We’re not academics,” said Karen Vernon, Project Director for Project Access. “OK, we’re working at a university and we have advanced degrees, but all of us come from a history of working at community organizations. So some of the structural issues of academia—the barriers to working with the community—aren’t there for us.”

From the start, Project Access has been involved with the agencies they’re studying, offering ongoing technical assistance and sharing their findings to help improve services as the project progresses. This is not a research project whose findings will only be published in academic journals two years after the project is completed.

Project Access is a qualitative study that examines some of the barriers and facilitators to providing HIV counseling and testing (C&T) to drug-using clients. The project began in July 1996 with funding from the California State Office of AIDS to interview HIV C&T service providers in three Bay Area counties. The Office of AIDS was interested in better collaboration with providers. Project Access staff interviewed providers, riding with them in vans, going wherever outreach workers went to get an understanding of how C&T worked in the field.

“It was so good to start with interviewing providers,” said Karen. “It really helped us to understand the data on C&T utilization. Providers’ expertise is often skipped over when conducting research, so it’s a good thing to formalize. It also made me feel like I was participating in research in a real way.”

A year later, the Centers for Disease Control and Prevention (CDC) awarded Project Access a grant to expand their research by interviewing drug users themselves to understand barriers and facilitators to C&T (see sidebar for some of the findings). Again the Project Access team took to the road, this time interviewing drug users at needle exchange programs, shooting galleries, parking lots and drug treatment centers. “We tried to do all the interviews in community settings,” said Karen. “That way, if someone expressed a need, we could link them directly to services after the interview.”

The CDC was also interested in drug users’ personal prevention strategies. Project Access found that a lot of people they interviewed use testing as their main prevention tool. They also found that incentives for testing, such as money, food coupons or phone cards, are helpful for attracting clients. “Now that we understand these things a little better, the next step is helping translate that into prevention services,” said Moher Downing, Key Investigator.

Susan Black, Director of HIV Counseling & Testing for Alameda County

by Beth Freedman

When Susan Black first started in her position as the Director of HIV Counseling and Testing (C&T) for Alameda County, Moher Downing paid her a visit. Moher wanted to let her know that Project Access was in Alameda County and to get ideas about who to talk to for interviews. “In the past, I hadn’t found research to be especially useful,” Susan said. “Research is often intrusive and unhelpful to people because the researchers simply conduct the study and leave. They don’t share the findings with the participants.” In contrast, Project Access quickly wrote up and disseminated the results of the study to the providers who were involved.

“The study results didn’t just sit in Susan’s file. She turned to the data and the results frequently: to help her with quality assurance of HIV C&T, to learn about why people get tested and why they don’t, and to find out what participants liked and didn’t like about the test sites. In fact, she used the study findings to completely change how Alameda County delivers HIV C&T when they shifted from a clinic-based program to a street-based program to better meet the needs of the clients.

Project Access also connected Susan with HIV C&T directors in eight other Bay Area counties through quarterly meetings. Directors came together to share information such as testing data between counties, and to strategize and advocate for change. As a group, the coordinators lobbied the state for increasing the rate at which counseling and testing was reimbursed to the county. Susan then saw an increase in HIV testing in Alameda County, which she partially attributes to the increased reimbursement rate. “When one county calls the state and points out what doesn’t work, it doesn’t matter. But when nine counties call the state, it really makes a difference.”

Susan is now also the Hepatitis C Coordinator for Alameda County. She plans to use the data that Project Access gathered to encourage Alameda County to develop a similar Hepatitis C initiative, addressing issues of screening, testing and treatment.
Research Informing Service
From the very beginning of the process, Project Access has used their research to help improve services. For example, after a few weeks of conducting provider interviews, Project Access noticed some confusion and overlap among outreach workers at two East Bay agencies working with some of the same client populations. They immediately facilitated a meeting between the two agencies where they could air concerns and problem solve. The meeting was successful, and now the two programs share outreach staff.

Project Access has also shared their research findings with providers along the way. They wrote an article outlining provider, county and state concerns around C&T for drug users. The paper was distributed to all the providers they interviewed, and has been used to help make the case with county officials for changes in testing procedures. The paper is also currently under review to be published in an academic journal.

Getting Providers Together
In addition to working with local providers on an as-needed basis, Project Access facilitates technical assistance and information sharing between providers. This process began after Karen presented preliminary findings at the statewide HIV C&T coordinators meeting in Sacramento. An agency from Fresno, CA heard her presentation and invited her to speak at a training for their prevention staff. Karen spoke about field-based HIV testing using mobile vans, sharing what Project Access had learned from talking to drug users and providers. The positive response Karen received gave Project Access the idea to give a similar presentation to all of the counties they were studying.

Next, Project Access hosted a roundtable in Oakland to present their findings to C&T outreach workers and program coordinators from Alameda, Contra Costa and San Mateo counties. “There are a lot of differences in drug users’ experiences across counties—structural factors like police enforcement, public transportation. But here they could also see what was the same,” said Moher. “The roundtable also included time for discussion and feedback.

Two or three more roundtables with providers followed. Again, the response was overwhelmingly positive, and the roundtables turned into quarterly C&T Coordinators meetings. Although Project Access initially hosted them, these meetings soon took on a life of their own as the C&T coordinators took over leadership and the group grew to incorporate other Bay Area counties. Now, HIV C&T coordinators from all nine Bay Area counties meet to complain and commiserate, problem solve and share solutions.

The collaborative roundtable model is now being disseminated as a way for providers to cooperate more effectively. A representative from the C&T coordinators was asked to present at the statewide Community Planning Group for California. They’ve been designated to serve as a “model group” for other counties on how to collaborate with HIV C&T services.

Improving Communication with State and County
Project Access also facilitated a roundtable between local providers and county and state folks. “We had heard a lot about what the tensions were between the county and CBOs and the county and state,” said Moher. “At the meeting, CBO folks could see that the county was restrained by regulations at the state level, that they weren’t just trying to make their lives miserable. And the state could see how their regulations were affecting services at the street level.”

Project Access found that simply providing people a space, a structured time and structured facilitation to discuss these issues was incredibly liberating. As a result, they feel that the relationship between CBOs, county and state has improved.

“I think most CBOs are happy with their relationship with the state,” said Moher. “From talking about issues over and over at the quarterly C&T coordinators meetings, they know where the specific problems are. So when they meet with state and county folks, they don’t just have a long list of grievances. They can state the problems and work on solutions for solving them or lessening their impact on service delivery.”

Future Plans
As they complete their currently funded projects, the Project Access team is looking for new directions. One possibility is to use their research data to develop training materials for field-based outreach programs. Offering HIV C&T in a park or in a van is a very specific act with related barriers and facilitators, and they’ve learned a lot about what works best in these kinds of settings. Such field manuals are urgently needed by community service providers to share effective methods and set standards of practice.

“It’s very exciting doing the work we’re doing—actually helping programs implement changes to improve their services. It’s been great to be able to translate our findings so quickly,” said Moher.
Operating Structure of the MPowerment Project

Core Group
The project is run by a “core group” of 12 to 20 young gay men in the community who coordinate and conduct, with other volunteers, all project activities. The Core Group meets weekly to make key project decisions. The program employs several Project Coordinators who are responsible for organizing and leading the program, but the bulk of the project activities are carried out by volunteers.

Community Advisory Board
The Core Group is assisted by a Community Advisory Board, comprised of men and women from the AIDS, gay and lesbian, public health, and university communities, who meet monthly with the core group to give advice about project activities.

Community Center
Ideally, the project has its own physical space which serves as the headquarters for the project and as a community center for young gay men. The center provides information and referrals to other organizations and services as well as safer sex materials and equipment.

Program Components
Each of the four components of the MPowerment Project is essential – together they work synergistically to make an effective program.

Formal Outreach
Formal outreach includes two types of activities: an outreach team and outreach events. The outreach team involves teams of young men who go to settings frequented by young gay and bisexual men to promote safer sex. Since most communities typically have very few settings where young gay and bisexual men socialize, a major aspect of the MPowerment Project’s formal outreach is the creation of new events (outreach events) that will attract young gay and bisexual men, at which safer sex can be promoted.

M-groups
The second major component of the project are small group
Research on Gay Youth

by Beth Freedman

Got a question? We may have an answer for you. The Technology and Information (TIE) Core of CAPS provides limited technical assistance (TA) to service providers, Health Departments and other scientists outside of CAPS via telephone and e-mail (call 415/597-9396 or e-mail CAPSWeb@psg.ucsf.edu). This column will feature one or two questions we have received and our responses.

Q: I’m looking for information about the health risks for gay youth in California. I’m writing a grant for a nonprofit that works with gay youth and I need supporting documentation about their health risks.

A: The following CAPS HIV Prevention Fact Sheets are available online at http://www.caps.ucsf.edu/FSindex.html or by calling the National Prevention Information Center at 1-800-458-5231.

• What are young gay men’s HIV prevention needs?
• What are women who have sex with women’s HIV prevention needs?
• What are adolescent’s HIV prevention needs?

HIV InSite features statistics and HIV risk information about young gay men at http://HIVInSite.ucsf.edu/topics/gay_men/2098.3c18.html.

Recently, the California State Office of AIDS conducted a study about young gay men and HIV, entitled, “HIV Risk Factors Among Adolescent Males Who Have Sex with Males in California.” Call David Webb at 916/327-6773 for a copy.

I also suggest that you contact The Bridges Project of the National Youth Advocacy Coalition. The Bridges Project provides resources, information and referrals regarding lesbian, gay, bisexual and transgender youth and can be reached at 800/541-NYAC or www.nyacyouth.org.

Sexuality Information and Education Council of the United States (SIECUS) is an organization which promotes comprehensive education about sexuality. A recent issue of SHOPALK featured a study about the increased risk of pregnancy and STDs among young women who identify as lesbian, bisexual or transgender. (Volume 4, Issue 11; August 12, 1999.) SHOPALK is available at www.siecus.org or 212/819-9770.
physiologic reactions to laboratory tasks, and their stress hormone levels and immune function before and after the first day of school. I tell them about the questionnaires, the physical exams and the puppets who will "interview" the kids next spring.

Suddenly the two girls glide by, heads together, gossiping. Both are connected by clear plastic tubing to boxy IV pumps clamped on tall rolling poles. Graceful and unself-conscious, the girls push the pumps like sporting gear: necessary equipment, but hardly the main event. They compare notes on teachers, hair bands and what’s for lunch in the Day Hospital. They rush to the playroom while IV solution drips into their tiny veins.

“It’s just not that big a deal for Sally, getting her blood drawn,” says her mom. “Mimi used to be the same way,” her mom tells me, “but now her hand veins are shot, and it’s so much harder starting the IV further up her arm. I don’t know if it hurts more or if it’s because it’s new and scary.”

The next minute Mimi swings around the corner to her mother’s arms. The IV has infiltrated, and a painful bump is growing at the needle site. Sally’s mom calls for the nurse and slips a ballet video into the VCR. Sally looks on quietly. Mimi’s composure returns after a minute in her mother’s embrace, and soon the girls are staring at the TV: “Watch, watch, watch!” they shout. “Here comes the good part!” The nurse arrives, and the new IV insertion is underway.

My twenty years as a nurse practitioner don’t provide the compass I want in this world of children and HIV, with its peculiar amalgam of ordinary childhood, phantom threats and medical intervention. My ordinary arsenal— a round of antibiotics, a vaccine, some well-timed advice— seems a weak reply to this aggressor. So does the research I’m here to begin. Neither will stop the virus or the sadness that haunts these families.

But charting the ebb and flow of cell types and calculating the right antiretrovirals are puzzle pieces that fit with others. They can link with knowledge of stress reactivity and the complexities of child development. The borders of the puzzle pieces become less distinct when the pieces start to join. The whole child starts to appear, and our odds start improving.

Mary Truskier, RN, MS, is a pediatric nurse practitioner and project coordinator for the School Entry Project at CAPS.