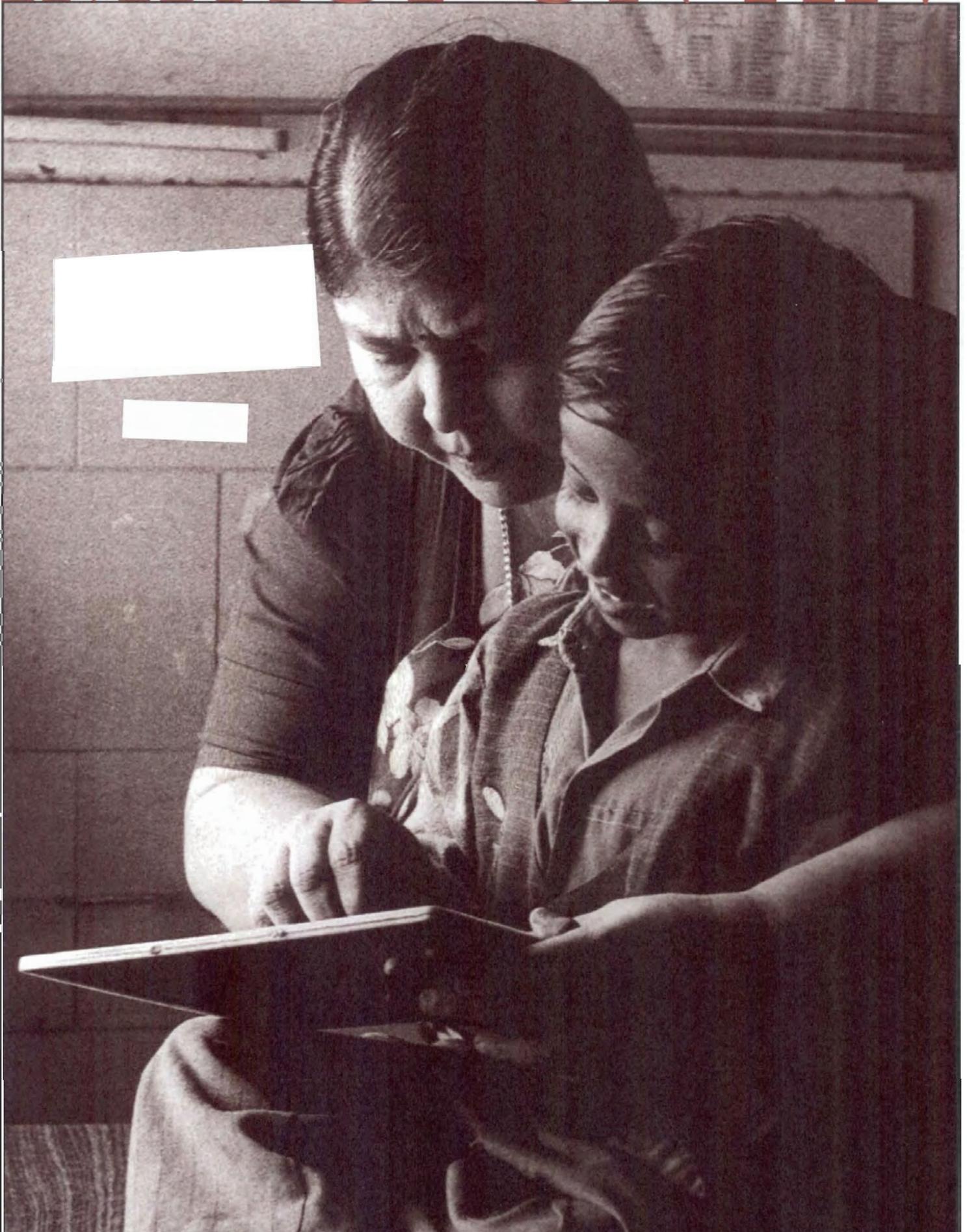


IMPACT ON HIV



Jonathan Mann: The Visionary Leader Who Linked Health and Human Rights

This first issue of *Impact on HIV* is dedicated to Dr. Jonathan Mann, who made a global impact in the field of HIV/AIDS prevention and care and on the lives of thousands of individuals around the world. Dr. Mann died in a plane crash off the coast of Nova Scotia on September 2, 1998, along with his wife, Dr. Mary Lou Clements-Mann, a prominent HIV/AIDS vaccine researcher and professor at Johns Hopkins University. Both were 51.

Dr. Mann was a visionary in the fields of international HIV/AIDS research, prevention, care, advocacy and human rights. He was the first to define HIV/AIDS as a global pandemic made up of multiple HIV epidemics spreading at different speeds through various countries and populations.

Realizing early on that HIV/AIDS was one of the most profound health challenges of our time, Dr. Mann leaped at the opportunity in 1984 to found and guide a new HIV/AIDS research program in Zaire. Under his leadership, *Projet SIDA* became known as the best HIV/AIDS research program in Africa. It was dissolved by President Mobutu Sese Seko in 1991.

Working tirelessly as the founding director of the World Health Organization's Global Programme on AIDS from 1986 to 1990, Dr. Mann mobilized international recognition of HIV/AIDS as both a public health issue and a human rights issue. He courageously challenged the world to consider HIV/AIDS as a manifestation of individual as well as societal vulnerability, inextricably linking human health with human dignity.

Dr. Mann left the World Health Organization in 1990 to become a professor of epidemiol-

ogy and international health at the Harvard School of Public Health. Two years later he was named the school's first François-Xavier Bagnoud Professor of Health and Human Rights, as well as the founding director of Harvard's FXB Center for Health and Human Rights.

Drawn by the opportunity to guide a new institution as well as to be closer to his new wife, who was based in Baltimore, Dr. Mann left Harvard to become the dean of the new School of Public Health at Allegheny University of the Health Sciences in Philadelphia, Pennsylvania, in January 1998.

A charismatic and compassionate leader, Dr. Mann often championed issues that were highly controversial. In April 1998, after receiving international criticism for a speech in which he challenged the U.S. government to speed up HIV/AIDS vaccine development, he said privately, "I think lightning rods perform a useful function, but it is not pleasant being a lightning rod!"

Dr. Mann was the senior editor of *AIDS in the World* and *AIDS in the World II*, considered to be landmark texts in the field of HIV/AIDS. A gifted writer and speaker, he held a bachelor's degree in history from Harvard College, a medical degree from Washington University in St. Louis and a master's degree in public health from the Harvard School of Public Health.

Dr. Mann and Dr. Clements-Mann were killed while en route to Geneva, Switzerland, for meetings on HIV/AIDS at the World Health Organization. He is survived by his first wife, Marie-Paule Bondat, and their three children, who work in the fields of law, health and international development.

IMPACT in 25 Countries
U.S. Agency for International Development (USAID) missions in 25 countries and two of the agency's regional offices have requested assistance from the IMPACT (Implementing AIDS Care and Prevention) Project during its first year.

The project is working in Benin, Ethiopia, Egypt, Ghana, Madagascar, Malawi, Nigeria, Rwanda, Senegal, Tanzania and Zambia in Africa; in Bangladesh, Cambodia, India, Indonesia and the Philippines in Asia; in Brazil, the Dominican Republic, El Salvador, Honduras, Jamaica, Mexico and Nicaragua in Latin America and the Caribbean; and in the Russian Federation and the Ukraine in Eastern Europe. In addition, IMPACT is assisting USAID regional programs in Asia and the Near East and in western and central Africa.

IMPACT was established under a cooperative agreement between USAID and Family Health International (FHI) to help the agency's missions and bureaus slow the spread of HIV/AIDS and ease its social and economic impact on families, communities and nations. The project is designed to apply the lessons learned from more than a decade of HIV/AIDS prevention programs, including the USAID's flagship AIDS Control and Prevention (AIDS-CAP) Project, which FHI implemented in 45 countries from 1991 to 1997.

Like AIDSCAP, IMPACT focuses on strengthening the capacity of local private and public organizations to respond to the HIV/AIDS pandemic. However, recognizing that sustained individual behavior change is unlikely without wider social support, IMPACT emphasizes achieving prevention and care results by influencing social norms, health service delivery and public policy, as well as the beliefs and practices that put people at risk of HIV infection.

IMPACT works with dozens of nongovernmental organizations and government agencies. Technical assistance is provided in behavior change interventions, management of sexually transmitted infections, communication, counseling and testing, HIV/AIDS care and support, policy development, behavioral research, financial planning and management, private-sector leveraging, and program design, planning, monitoring and evaluation.

HIV and Women

Scientists have discovered that women who are infected with HIV tend to have less of the virus circulating in their blood than men at the same stage of infection (as measured by CD 4 cell counts). The findings, which were presented in July at the 12th World AIDS Conference in Geneva, Switzerland, have significant implications for the treatment of HIV-positive women.

Researchers from Johns Hopkins University studied a group of 650 injection drug users over six years. They concluded that an HIV-positive woman will develop AIDS as quickly as a man with twice the amount of virus in his blood. The reasons for this gender difference are unclear, but higher levels of the hormone estrogen in women may account for the disparity.

Where possible, HIV-positive women should be prescribed antiretroviral drugs at an earlier stage of infection than men. Clinical guidelines for antiretroviral combination therapy were initially developed based on studies of white homosexual men. These guidelines received additional support from a recent study of a group of predominantly male African-American injection drug users. The Johns Hopkins study, which will be published in *The Lancet*, is the first to demonstrate the importance of gender to HIV treatment.

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IMPACT ON HIV

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MUTHIAH MUTHURAMAN

Cover photo: Barred from attending school because of his HIV status, Ravi learns the ABCs of life at a home for AIDS orphans in Chennai, India.

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Dr. Manorama Pinagapany with Helen, one of three AIDS orphans she has adopted.

HIV Care and Prevention: An Indian NGO's Seamless Approach

BY JAYA SHREEDHAR

An Indian AIDS service organization shows that a meaningful coalescence of care and prevention can be a cutting-edge strategy for curtailing further spread of HIV.

A nondescript building looms over a sleepy lane in Kodambakkam, the throbbing heart of Chennai (formerly Madras), the capital city of India's southern state of Tamil Nadu. Inside, muted light from a curtained window spills over a group of children, aged 2 to 9 years, sleeping peacefully together on straw mats spread on the floor. In a room nearby, an HIV/AIDS education session is in progress, with people speaking in hushed tones so as not to awaken the children. Downstairs, a nurse gently feeds an HIV-positive woman who is too weak to feed herself. And so begins another day at the hospital that houses the Community Health Education Society (CHES), a nongovernmental AIDS service organization.

The brainchild of Dr. Manorama Pinagapany, a pediatric gastroenterologist, CHES came into being five years ago at a time when the HIV/AIDS epidemic was largely invisible in Tamil Nadu.

"I was working at the Institute of Child Health when two children from a local orphanage were brought to us with severe jaundice," relates Dr. Pinagapany. Krishnaveni, the girl, was 5 years old and Ravi, the little boy, was barely 3. The children had been tested for HIV by the orphanage and found antibody positive. "Over a period of time they became the darlings of the ward. Unfortunately, the orphanage did not want them back after they recovered. They had no place to go, and I, who had come to grow very fond of them, simply decided to take them home."

The entry of the two AIDS orphans into Dr. Pinagapany's life led to CHES's initial project, the *Ashram* (hermitage), a full-fledged shelter for people living with HIV/AIDS. CHES's primary aim was to provide care for AIDS orphans, regardless of their HIV status. To learn how to do this better, Dr. Pinagapany received informal training at the state-run Government General Hospital in Chennai.

Over time, the doctors at the General Hospital began referring destitute children and HIV-positive women to CHES. Many of the women had been abused, and some had been sold into the sex trade.

"The women required more than food and shelter," Dr. Pinagapany said. "They needed an emotional outlet of some

kind. As the orphan children at CHES needed love and physical attention, it seemed only natural to connect these two groups to fulfill each other's needs."

The *Ashram* also serves as a temporary shelter for women and their children who have become destitute because of their HIV-positive status. It has had 69 admissions to date, from Mumbai (formerly Bombay), Calcutta and other parts of Tamil Nadu as well as Chennai. The care *Ashram* residents receive includes spiritual counseling and educational support. Older members who are illiterate are taught to read and write.

Up every morning at 7, the *Ashram* children meet the day with an energetic two-lap jog around the hospital compound, enthusiastically jostling each other in a bid to finish first. Twice a week Valavan, a student volunteer, patiently teaches the children yoga, which they have come to love. Following a simple breakfast of *idlies* (steamed cakes of rice flour), they settle down to learn to read and write the English, Tamil and Hindi alphabets till lunchtime. Vijaya, a CHES worker, also teaches them simple mathematics, craft work and singing.

"They are very endearing and this never fails to evoke a response from us workers or visitors," says Geetha, a sex worker who left the sex trade to work with CHES full time. "Early in the project, a friend of mine who had looked after the children for a long time suddenly decided she would leave us, and the effect on the children was devastating. They had grown to love her so, and it took them days to recover their sense of security.

"What I earn here is not comparable to what I could earn in the sex trade," Geetha added. "But I feel wanted and respected and feel I am part of a family. I cannot buy that with money, can I?"

Funding Dilemma By September 1995 CHES had eight women and four orphaned children under its wing, most of whom were HIV-positive. The space to house the inmates was provided free of charge by Raasi Hospital, a private hospital owned and run by

Dr. Pinagapany. Institutional and outpatient care and counseling services were also wholly funded by the hospital, while relatives and well wishers donated food and clothing.

Gradually, the NGO realized that it could no longer sustain its work through gifts and donations. However, obtaining the requisite funding to run a shelter for AIDS orphans and HIV-positive women proved next to impossible. "Funding shelters, hospices or institutional care for people living with HIV hardly figured on the list of the donors' priorities," Dr. Pinagapany said. "We were advised to submit proposals for HIV prevention projects instead."

In September 1995, CHES received a one-year grant from the Tamil Nadu State AIDS Control Society for an intervention with female sex workers. Weeks of painstaking work with a few friendly brokers and sex workers helped the CHES staff understand the structure of the sex circuits in the coastal areas of South Chennai that were chosen for the project, named *Thozhi* (companion).

Interestingly, *Thozhi* did not start with HIV education. Again, care was offered first. Brokers and women in the sex circuits began to invite their contacts to the hospital for free medical help. There was no mention of venereal disease or AIDS. Once the women underwent a checkup and relaxed to a point where they could share their health concerns, the subject of HIV and other sexually transmitted infections (STIs) automatically came up.

Companions As the women began attending the hospital regularly to obtain treatment for various problems, mostly STIs, they learned how to use condoms. Those who were interested were trained as peer educators and condom suppliers.

But they learned their most valuable lessons while nursing some of the *Ashram's* residents who were dying of HIV-related illnesses. AIDS was no longer an abstract intangible, but a friend, a colleague or a relative.

Siva, a sex broker who began by bringing his employees and their friends to the hospital for free medical care, is now a full-time CHES worker. "I did not think I would stay on, but I have," he said.

His change of heart came when Siva was entrusted with the task of nursing 27-year-old Veni, a sex worker from the neighboring state of Andhra Pradesh. Veni was bedridden due to weight loss, had herpes zoster (shingles) and could not speak. "I used to talk to her every day and she would seem to understand," Siva said. "She would refuse food and eat only if I fed her.



Dr. Pinagapany examines Krishnaveni's eyes. Medical care is just part of CHES's holistic approach to helping people live with HIV/AIDS.

"Her death affected me greatly," he continued. "I have risked getting HIV-infected hundreds of times in the course of my job but have been spared. But what about the innumerable girls I procured for the profession?"

Condom use in the project area increased to 63 percent in October 1997 from a baseline of 7 percent two years earlier. During 1997 alone, *Thozhi* reached some 700 new entrants to sex work, 150 brokers and 2,400 clients, and peer educators distributed 288,150 free condoms. The project also improved its STI care facility with financial support from the U.S. Agency for International Development's (USAID's) AIDS Prevention and Control (APAC) Project through the NGO Voluntary Health Services.

Reaching Men Dusk had already fallen over the narrow paths dissecting the slums into myriad patches of tiny houses when CHES field workers Raju and Muthupandian swung into action. Watched by a straggly group of adolescent boys, Raju spread a large blanket on the mud path to demarcate the dance floor. As the lyrics about AIDS set to hit film tunes pulsed out from a tape recorder, a crowd of mostly teenage boys and men collected. Male dancers from CHES's student volunteer corps, each made up to impersonate a popular film star, began dancing, accompanied by much cheering and clapping from the audience.

Between the dances, Muthupandian seized the mike to talk to the audience about STIs and HIV/AIDS, and a boisterous interaction followed. "What are the ways you can protect yourself from AIDS?" he yelled, and was answered correctly by a chorus of voices. The show usually ends with a quiz on AIDS. Prizes are handed out to the winners, and they are invited to come to CHES for further information.

Those who accept this invitation—and many do—receive counseling on safer sex and condom use and are trained as peer educators for Project *Velicham* (light). CHES developed this project for men with funding from the Tamil Nadu

State AIDS Society following complaints from the sex workers that they were often forced to agree to unprotected sex because clients refused to use condoms. *Velicham* staff have staged over 300 such programs in the slums and reached an estimated 40,000 people along the coastal areas of South Chennai.

Reuniting Families After reading newspaper reports that CHES was taking in people living with HIV/AIDS, a family of four from

*AIDS was no longer
an abstract intangible, but a friend,
a colleague or a relative.*

a remote district in Tamil Nadu arrived at the NGO's doorstep in early 1995. They had fled their village, following a relative's attempt to poison them.

Raghu, his wife Mala and their elder son, barely aged 3, were HIV-positive. Their 2-year-old son was uninfected. "Mala, who was found to have genital warts during a routine antenatal checkup, was tested for HIV first," says

Dr. Venkateshwar K. Rammohan Rao, CHES medical officer. "We counseled them and gave Raghu the job of office assistant. Mala was extremely depressed, and we got help from psychotherapists from the Institute of Mental Health to help her handle her feelings better."

The couple's relatives visited regularly and were counseled by CHES. After a year, their families wanted the couple and their children back home.

"They saw us eating and working with them every day and realized that their fears of contagion on casual contact were baseless," says Dr. Pinagapany. "For them, seeing was believing."

The family subsequently visited CHES twice for checkups. Raghu got a job selling cloth in Wyzag, a coastal town. Mala

began to neglect her health and eventually succumbed to tuberculosis. In a letter to the CHES staff, she wrote that she would not forget CHES until her last breath.

When they received news of Mala's death, two CHES workers, Siva and Vetri, went to her village to attend the funeral. Although relatives were at the funeral in large numbers, nobody wanted to be a pallbearer. It was only when Siva and Vetri started performing the last rites without hesitation that other family members followed suit.

A few months later, Mala and Raghu's elder child was readmitted to CHES's *Ashram* with HIV-related symptoms and died. Raghu's elder brother, also HIV-positive, died

recently. This brother's HIV-positive wife lives with her two children, who are uninfected. Raghu's widowed sister also lives alone, looking after his second son. Only Raghu's younger brother is uninfected, and CHES is trying to help arrange his marriage to a female relative so that this couple can look after all the imminent orphans in their family.

"When you care for the emotionally or physically abused, it is

"When you care for the emotionally or physically abused, it is difficult to remain a dispassionate service provider."



Dr. Manorama Pinagapany holds one-year-old Helen as the children of the CHES Ashram try to amuse her. An HIV antibody test when Helen is 18 months old is expected to confirm that she is infected with the virus.

difficult to remain a dispassionate service provider," Dr. Pinagapany said. "We foster strong emotional ties between everyone here because it can make a qualitative difference to the depth to which a carer can recognize and fulfill another's needs."

Bringing Hope A home-based care project developed by CHES in September 1997, currently funded by the Tamil Nadu State AIDS Control Society, reaches about 120 people living with HIV/AIDS. The number of those who are too ill to come to the hospital is slowly increasing.

Staff and volunteers from all the CHES projects provide psychosocial support, medical advice and care in the homes of HIV-positive people. This helps prevent the onset of HIV-related symptoms and reduces the number of inpatient visits. Another 120 who live outside Chennai are visited periodically. Named *Vidiyal* (dawn), the project also conducts classes on yoga and meditation with help from the Chennai-based Bihar School of Yoga.

Vidiyal runs a "Hope Club," where HIV-positive people meet monthly to exchange experiences and learn about healthy living. At each meeting, the Hope Club provides a talk and a screening by a medical specialist, such as a neurologist or chest specialist.

Among CHES's more notable efforts has been a beauty contest for transsexuals, organized with guidance from the APAC Project. This unusual event, which drew widespread media attention, succeeded in promoting community acceptance of transsexuals as well as raising their own awareness and getting them involved in HIV/AIDS prevention.

"We wanted people to realize that *alis* (transsexuals) are as much a part of society as anyone else," Dr. Pinagapany explained.

CHES helped develop a self-help group for transsexuals, which will be registered as a society to enable them to improve their welfare and fight for their rights. As a positive step in this direction, CHES played a major role in convincing the collectorate of Villupuram, the traditional seat of the transsexuals' religious festivals, to allot plots of land to members of this community. Houses will be constructed on 46 plots with financial help from the Rotary clubs in the area. CHES also plans to help establish income-generating activities such as poultry farming to reduce the likelihood that transsexuals will resort to sex work.

Working with people who have been rejected by society, such as transsexuals and women and men in the sex industry, can be controversial. But unlike most Indian NGOs that help sex workers, CHES has been able to avoid the problem of police harassment. Speaking to police inspectors in the project areas before interventions began and offering education programs for police helped enlist their full cooperation.



CHES does not try to convince women or their brokers to leave the sex industry, but it has been able to offer a few alternatives. Some of the women take turns using a donated sewing machine that is kept in the CHES office. "I can make about 700 to 800 rupees a month by sewing blouses," one woman explained. "That way

I can cut five or six clients and reduce my HIV risk."

The NGO itself employs 25 sex workers and five sex brokers as full or part-time peer educators. HIV-positive people are trained in counseling to help them find jobs as counselors with other non-governmental organizations.

"We feel like a family because each of us understands what it feels like to be rejected, hunted or hurt by society."

Care and Prevention In order to deal with the diverse needs of its extended family, CHES has woven a web of symbiotic relationships with organizations that have skills different from its own. For example, CHES links its drug users to the T.T. Krishnamachari Hospital, a clinic specializing in detoxification programs. In turn, T.T.K Hospital obtains HIV counseling services from CHES. For HIV



Krishnaveni cradles Helen as Ravi sleeps beside her.

testing, CHES uses the testing facilities provided on payment by YRG Care, an AIDS service organization. Destitute HIV-positive women are referred to CHES by an NGO, The Banyan, that cares for destitute women, and positive women who do not need institutional medical care at CHES are referred to The Banyan. For spiritual counseling, CHES turns to a variety of Christian, Muslim and Hindu religious organizations.

The imaginary line between prevention and care is blurred at every level in each of CHES's projects, whether it be the shelter for people living with HIV, the sex worker and client interventions, or the home-based care project. Each is an organic response to the growing needs of the other. Women from *Thozhi* look after the children in the *Ashram*. Brokers and clients from *Velicham* provide home-based care, including prevention counseling, for HIV-positive people. And *Vidiyal's* HIV-positive members serve as counselors in all the projects.

"The fact that some of us have HIV and some do not, does not preoccupy us," Siva said. "We feel like a family despite such minor differences because each of us understands what it feels like to be rejected, hunted or hurt by society."

Finding funding for CHES's work remains a challenge. The NGO has no funding for its *Ashram*, and condom supplies cannot

keep pace with the demand created by CHES projects. Local schools will not admit the children of the *Ashram*, and CHES does not yet have the resources to run its own school.

Despite these obstacles, Dr. Pinagapany refuses to change her approach. "Fragmenting one's work along the clichéd lines of an AIDS proposal in order to connect to a funder's mindset may prove detrimental to the spontaneity and effectiveness of one's work," she said.

In many ways, CHES has transcended the thinking that sees care as being distinct from prevention and places it at the final stage of the spectrum in the response to HIV/AIDS. Instead of first increasing awareness of HIV—in other words, telling people that they have a problem—CHES goes to them with a solution: free medical care. CHES puts people ahead of project goals, say staff and clients, and the result is greater self-esteem, trust and openness to HIV prevention messages among those who need them most. ▢

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Nigerian NGOs Foster a Caring Community

BY EKONG EMAH

Community outreach workers and volunteers bring practical support and compassionate care to the homes of people living with HIV/AIDS in three Nigerian towns.

Six years ago, a Catholic missionary from Argentina started seeing AIDS patients at the hospital where she worked in Onitsha, a town in the eastern part of Nigeria. Initially, the cases were few—one or two in a fortnight. But as Dr. Susi Coddazi became known and identified with the disease, the case profile rose.

Dr. Coddazi soon realized that the minimal hospital-based care she was able to provide was grossly inadequate. Most HIV-positive patients did not come to the hospital until they were critically ill, and many came when it was too late. When they were well enough to return home, their families did not know how to take care of them. Troubled by the suffering of her patients, she dreamed of offering them care and support in their communities.

While Dr. Coddazi was nursing this hope in Onitsha, the United States Agency for International Development (USAID) mission in Lagos and the U.S.-based nongovernmental organization (NGO) Family Health International (FHI) were also recognizing the need to help fill the gaps in care for those living with HIV/AIDS. They hoped that attention to care would also stimulate a stronger community response to the epidemic, reinforcing their efforts to promote HIV prevention through the AIDS Control and Prevention (AIDSCAP) Project.

Although most AIDSCAP funds were already committed to prevention projects, FHI had set aside money to support short-term activities and small, innovative pilot projects. In 1996 the AIDSCAP program in Nigeria used its "Rapid-Response Fund" to give Dr. Coddazi's group, the Focolare Movement, a grant for community-based HIV/AIDS care in Onitsha.

Under this pilot project, Dr. Coddazi trained outreach workers to provide care and support to people living with HIV/AIDS and their families in their homes. In just three months, the Focolare outreach workers were able to reach 20 families.

This experience was an eye-opener for all concerned, drawing attention to the needs of families affected by HIV/AIDS and to the potential for strengthening prevention efforts through a more inte-

grated approach. When USAID signed a cooperative agreement with FHI to continue HIV/AIDS activities in Nigeria after the AIDSCAP Project ended, it included an expanded commitment to community-based care. And at the conclusion of that "bridging" agreement in July 1998, the mission planned to continue and support such care projects.

Community Care Givers Two new community-based care projects were established with support from FHI in December 1997. The Kano state branch of the Society for Women and AIDS in Nigeria (SWAAN) began a pilot project in the northern town of Kano, while the Family Health and Population Action Committee (FAH-PAC) started one in Ibadan in the west. The Focolare Movement continued its project in Onitsha, in Anambra state.

The three NGOs work in different parts of the country, but follow the same basic model. Each project is linked to a number of hospitals, where it helps train staff members in medical and nursing care and counseling for people living with HIV/AIDS. When patients are discharged from these hospitals, they are turned over to a support team of community caregivers.

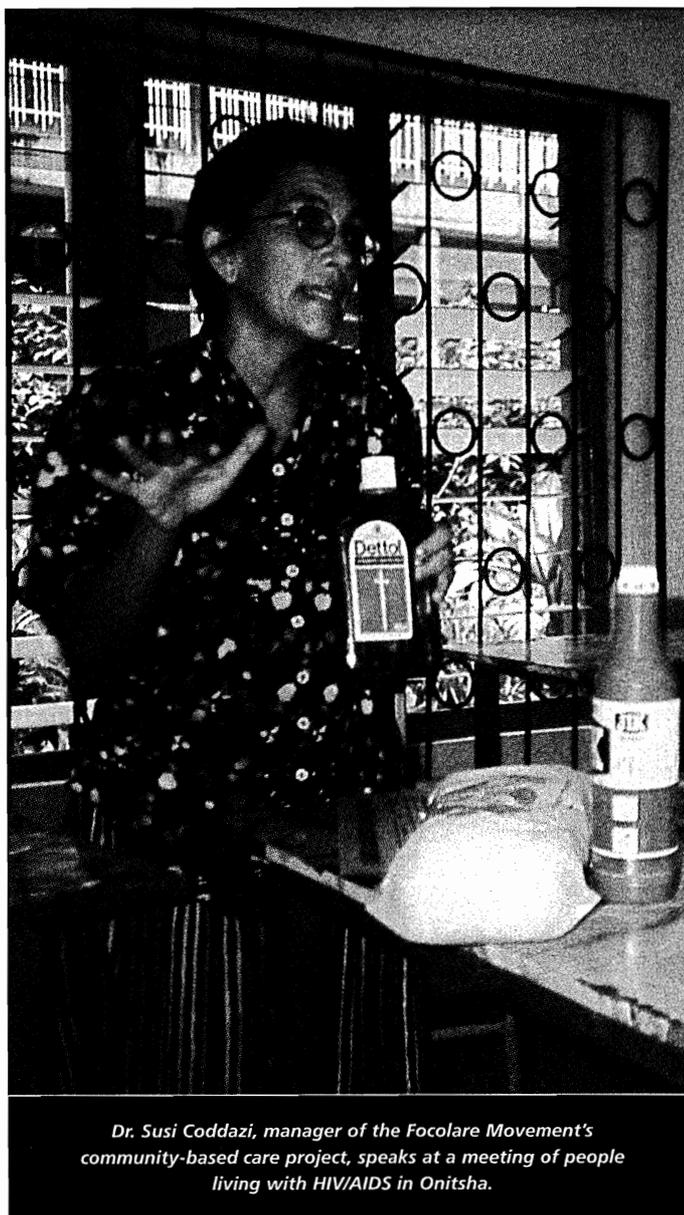
These motivated volunteers have been trained in HIV/AIDS and sexually transmitted infection (STI) education, basic hygiene, counseling, referral and nutrition. They visit people living with HIV/AIDS and their families at home and also provide counseling and nutrition education at the project offices. Support group members see an average of four families a week.

When support team members encounter difficulties, they are quick to refer clients to the more experienced counselors and health workers in the project. Health workers and volunteers also help families provide palliative care to the terminally ill, making it possible for them to spend their last days at home rather than in a hospital bed.

Dr. Lola Mabogunje, manager of the SWAAN project in Kano, reports that most of her patients with HIV/AIDS have died as a

result of tuberculosis (TB). Few families can afford drugs to treat TB, and the health care system is also unable to adequately fill this gap. FHI helped the Focolare Movement approach the German Leprosy Relief Association (GLRA), which now provides anti-TB drugs for the project, and hopes to find a similar source of the drugs for the projects in Ibadan and Kano.

If medications to treat tuberculosis and other opportunistic infections are hard to come by, most Nigerians living with HIV/AIDS can only fantasize about the antiretroviral "cocktail." Two pharmaceutical companies—Roche Nigeria Ltd. and Glaxo Wellcome—market antiretroviral drugs in Nigeria, but only the affluent can afford them. A month's supply of Hivid and Invirase from Roche, for example, costs N56,000 (U.S.\$651).



Dr. Susi Coddazi, manager of the Focolare Movement's community-based care project, speaks at a meeting of people living with HIV/AIDS in Onitsha.

SINA BALANA/FHI

Getting Started Starting a community-based project is a challenge under any circumstances, but it is doubly difficult in an environment of denial, stigmatization and government apathy. Such was and is still the environment in Nigeria, yet the three FHI-supported projects are thriving. After just eight months, they have reached 1,347 families.

One reason for this success is the role of the private sector NGOs and the commitment of dozens of community volunteers. Project managers say that what they look for in outreach workers and volunteers are compassion, a willingness to help without being judgmental, and a sound knowledge of the disease.

These qualities are essential because the initial phase of the work might be discouraging. "You may be alone, as the community is full of suspicion and fear for your real intentions," Dr. Coddazi said.

The first practical step involves reaching out to traditional and local authorities. The three project managers agree that it is important to make them the entry point into communities.

doctors at a hospital in Ibadan even refused to perform surgery on at least one HIV-positive man after learning of his serostatus.

It took time to convince health care providers at this hospital to refer their patients to FAHPAC for follow-up, but now they recognize that the project's services are useful and even comple-

mentary to their own work. In all three projects, these referral linkages have been strengthened by the training the projects have provided to virtually all hospital staff who counsel patients about HIV/AIDS.

New Allies Referrals also come from traditional healers, who once looked upon the community caregivers with suspicion.

But project staff allayed their fears by offering to help the healers protect themselves from HIV infection.

Many traditional healers are at risk because they use unsterilized equipment and do not know how to take basic precautions against exposure to HIV while treating patients. This danger was brought home to Dr. Coddazi when an HIV-positive patient

Now many of the traditional healers are among the converted, using universal precautions and helping to pass on accurate information about HIV/AIDS.

sought treatment from a traditional healer, who opened an abcess. "I realized that this traditional healer would soon be infected, and I saw the need to get in contact with him through the patient," she said.

By working with this traditional healer, Dr. Coddazi was able to bring many of the healers in the area together for a seminar on HIV/AIDS. For many of them, it was a turning point.

Before the seminar, traditional healers considered AIDS just another disease and thought its impact had been overdramatized. But Coddazi's commitment impressed them. "If someone paid her way to come and tell us about this AIDS, then it must be true," one seminar participant reasoned. Now many of the traditional healers are among the converted, using the universal precautions Dr. Coddazi taught them and helping to pass on accurate information about HIV/AIDS and its prevention to their patients.

Since traditional healers are the first source of health care for many people throughout Nigeria, project staff in Kano and Ibadan also realized that it would be unrealistic to leave them out. Now it is not unusual for healers to seek out project staff and volunteers for information about HIV/AIDS.

Lessons Learned The need to involve traditional healers was only one of the many lessons the NGOs learned about community-based care during the eight-month pilot projects. Another was the importance of having a physician to provide medical care in the community.

Finding that people living with HIV who identified with the project wanted to receive medical attention in the same environment of love and compassion, the projects took measures to respond to this need. Doctors who volunteer their time help FAH-PAC and SWAAN operate clinics, while a physician coordinates the Focolare Movement.

All the projects recognized the importance of involving community members from the beginning. But SWAAN found that in Kano, it also needed to recruit semiliterate men and women to visit families. Having semiliterate women on the support team was particularly important in order to reach other women.

In Moslem northern Nigeria, most men marry more than one wife and their wives are secluded in purdah, explained Dije Abdullahi, the assistant project coordinator for SWAAN/Kano. Even when educated women are available to do the work, they are regarded as being "too civilized and empowered" and in a position to corrupt other women. The semiliterate women, though empowered, are seen as harmless.

Other important lessons include the value of networking with pro-

fessional groups such as psychologists to help clients with AIDS dementia, suicidal tendencies and other difficult problems and the need for access to a reliable screening center where an antibody test can be done. With the benefit of field experience, the NGOs are using these lessons learned to strengthen their projects' linkages with community members, traditional healers and other health care professionals.

Stigma and Denial Overcoming the stigma associated with HIV and AIDS is one of the community-based care projects' most difficult challenges. Nigerians living with HIV/AIDS often experience discrimination, abandonment and neglect.

Stigmatization appears to vary by class in Nigeria. Upper-class families, fearing loss of social standing, tend to hide or deny the fact that a family member is HIV-positive. They may even reject a family member

and withdraw financial support to avoid society's censure. Those in the lower socioeconomic classes are more likely to stand by the infected. They also shield their serostatus, but for them the fear is of losing jobs or suffering other reprisals by the privileged.

Support team members in Kano tell of a young man living with HIV/AIDS who has been abandoned by his wealthy family. They often wonder aloud why his father, who can afford antiretroviral drugs without any financial stress, chooses to consider social status at the expense of his son's well-being. But for the support team and the new family of fellow HIV-positive people he has found through SWAAN, he would have nowhere to turn.

Some wealthy men will pay for antiretroviral drugs for themselves but not for their wives. Yet in the polygamous setting in Nigeria, one infected man may have up to four wives who are exposed to the risk of infection.

Because of their social and economic dependence on men, women often have no access to information about HIV/AIDS or any means of protecting themselves from the virus. One example is a woman in Kano whose husband refused to tell her that he had tested HIV-positive. After some counseling, he consented to allow the support team to educate his wife about HIV/AIDS prevention. The woman wondered why she needed such information, but her husband kept assuring her that they meant no harm.

Trouble came when the family's eldest daughter requested information and a support team member gave her literature about HIV/AIDS. When her father found it, he rushed to Dr. Mabogunje in a fury and forbade the support team members to visit his home again. The woman still does not know her husband's serostatus, and he will not allow her to take the HIV antibody test herself.

Women often have no access to information about HIV/AIDS or any means of protecting themselves from the virus.

AIDS Orphans As more and more women become infected with HIV, the number of AIDS orphans is also increasing. The community-based projects are still struggling to find ways to meet orphans' needs for food, clothing, schooling and adult care.

Awelu Ibrahim is 22. His parents died of AIDS, leaving behind nine children. Soon after their mother's death, the youngest child also died.

Their mother's last wish was that the children not be separated. As the eldest, Awelu decided that he would do his utmost to fulfill that wish.

Awelu collects old iron beds, breaks them and resells them to earn enough to feed his brothers and sisters. He leaves home before 6 a.m. to trade and rushes home with whatever money he has made by 10 or 11 in the morning to give the younger ones breakfast. If he does not earn enough to buy food, the family goes hungry that day.

The burden of this responsibility is visibly aging the young man. Sometimes SWAAN/Kano comes to Awelu's aid by providing some food. But the project is not able to help buy medicine for his 5-year-old brother, who is infected with HIV. Awelu wonders how long he can continue before death comes calling.

SWAAN was able to help another 5-year-old AIDS orphan. His aunt came to project staff after his parents died, explaining that her husband refused to let the boy live with them. Members of the support team persuaded the man to take in his nephew by assuring him that the boy could not infect his own children.

Turning the Tide The extreme poverty of families living with HIV/AIDS is the greatest obstacle to effective community-based care. People look to the caregivers, who are largely volunteers and often have minimal income themselves, to provide virtually everything.

Poverty and a perilously weak economy have also made it difficult to involve communities in HIV/AIDS care and prevention. With many people investing considerable time in wondering how to survive each day, the epidemic is often dismissed as an unnecessary distraction. A popular saying is "Na AIDS I go chop?"—meaning the thought of AIDS will not put food on my table.

But in the areas where the community-based care projects are being implemented, the larger communities are now more concerned and prevention education has intensified. Other communities are also starting to take note. "Communities refer people to us and we get invitations from some local governments outside our project sites to address their people," said Dije Abdullahi of SWAAN/Kano.

One such invitation came from the district head of Dawakin Kudu local government in Kano state, where two women and one man with symptoms associated with AIDS had been driven from the community. A team from SWAAN educated the community leaders, who realized that they should not have expelled people just because they were HIV-positive. Others in the community are learning about ways of preventing HIV transmission.

The projects have also mobilized those living with HIV to change their behavior. Anecdotal evidence gleaned from the monthly meetings of HIV-positive people shows a resolve not to infect others.

In Onitsha, HIV-positive people have formed a support group called "Save the World." Through this group, they hope to create a support network throughout Nigeria.

Members of the group also take personal responsibility for preventing further spread of HIV. Dr. Coddazi says they believe they can make one important contribution to the future of humanity: to "keep the virus to ourselves."

Sustaining Care The networks of people living with HIV/AIDS associated with the projects offer some hope that a base for continuous community-based support is being developed. For many of them, this work is a lifetime commitment. Other members of the support teams, who have become role models in their communities, are also fired with a zeal to continue.

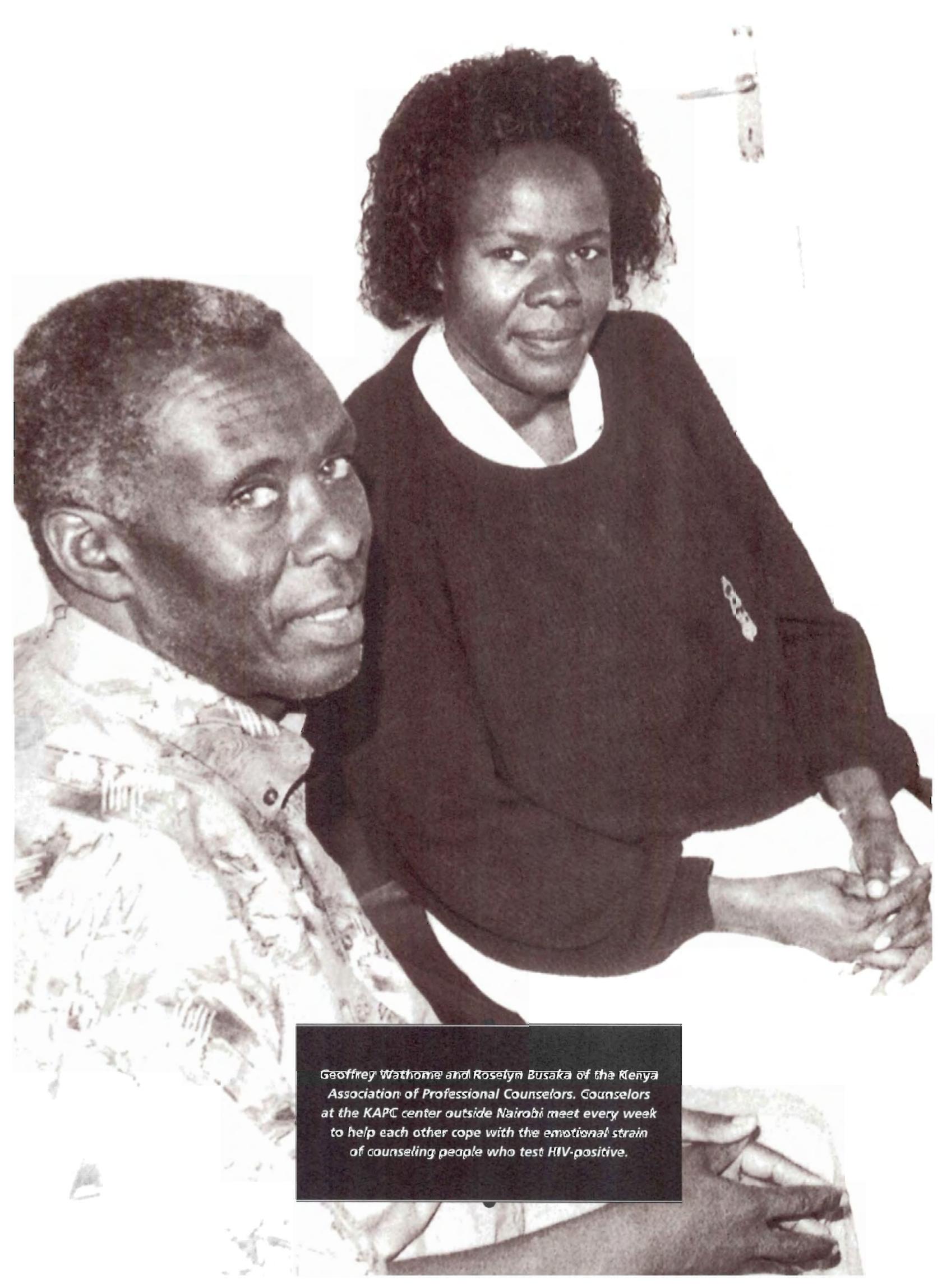
More community members, including church leaders and local officials, are beginning to wake up to the reality and challenge of HIV/AIDS. "With the important leaders in the church, the barriers are collapsing, and they are realizing that they have to help," Dr. Coddazi said.

Such community support is desperately needed throughout Nigeria, where an estimated 2.3 million people were living with HIV/AIDS by the end of 1997. Although the three FHI-supported projects collectively represent the largest single community-based care effort in the country, they are available in only three towns—a mere drop in a mighty ocean.

Even at this early stage, the three projects are looking for ways to expand and sustain their efforts. Project staff plan to ask religious groups and other prominent organizations for support now to help continue community-based care once donor support ends. "We still have to find a way of doing something because the people will keep coming," Dr. Mabogunje said. "They are our people, and we cannot tell them that we can't help them." □

EKONG EMAH IS SENIOR PROGRAM OFFICER IN FHI'S OFFICE IN NIGERIA.

Although the three FHI-supported projects collectively represent the largest single community-based care effort in the country, they are available in only three towns—a mere drop in a mighty ocean.



Geoffrey Wathome and Roselyn Busaka of the Kenya Association of Professional Counselors. Counselors at the KAPC center outside Nairobi meet every week to help each other cope with the emotional strain of counseling people who test HIV-positive.

Study Shows Voluntary Counseling and Testing Promotes HIV Prevention

BY KATHLEEN HENRY

The first randomized controlled trial of the prevention impact of voluntary HIV counseling and testing in non-industrialized countries reveals that providing such services can reduce HIV risk behavior.

Simon's* first thought after learning the results of his HIV test was of ending his own life. "After I was told that I was positive, I was frightened," he said.

But gradually, with the help of counselor Geoffrey Wathome of the Kenya Association of Professional Counselors (KAPC), Simon started looking to the future. He received treatment for a sexually transmitted infection (STI). He convinced his wife to go to counseling with him and started using condoms. "Now I do not infect anybody or reinfect myself," he said.

Making HIV counseling and testing available to men like Simon is a cost-effective way of preventing further spread of the virus, according to a three-country study sponsored by the AIDS Control and Prevention (AIDSCAP) Project of Family Health International (FHI), the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization. This randomized, controlled trial conducted at counseling centers in Kenya, Tanzania and Trinidad found that voluntary testing, combined with professional pre- and post-test counseling, encourages people to change their behavior in order to prevent HIV transmission.

"What we have for the first time is unequivocal data using the strongest possible design that counseling and testing is wanted by people, attracts high-risk people, and results in risk reduction," said Dr. Thomas Coates, director of the Center for AIDS Prevention Studies (CAPS) at the University of California at San Francisco, which was the coordinating center for the study.

Client-centered Counseling A neighbor told Simon about the counseling center at Kariobangi, a low-income neighborhood outside of Nairobi, where he could get a free HIV test. During his first visit, he learned about the study and agreed to participate.

Assigned through random assignment procedures to the counseling and testing arm of the study, Simon met with Wathome for a pretest counseling session and received 25 condoms, then

*His name has been changed to preserve confidentiality.

had blood drawn for an HIV test. He would return for the results in two weeks.

Others who were assigned at random to the health information arm of the study were offered the option of receiving counseling and being tested for HIV six months after their enrollment. In the meantime, each member of this group attended a health information session that included a video about HIV/AIDS prevention and a group discussion led by a health educator. At the end of these sessions, the health educator gave each person 25 condoms and invited everyone to come back for more at any time.

Dr. Claudes Kamenga, FHI's technical monitor for the study, explained that the comparison group was given health information for ethical reasons. "These people were concerned about HIV, so we had to make sure we were not denying them crucial information," he said.

A separate video was produced for each site, using local languages, actors and settings. These videos were shown during the health information sessions in an effort to standardize the content and to ensure that the two groups received distinctly different services.

The line between health information and counseling can be a fine one, explained Dr. Kamenga, a technical officer in FHI's HIV/AIDS Prevention and Care Department. "If it's given one-on-one, health information can become counseling, depending on the background of the person giving the health information."

In fact, many health information sessions were conducted with one individual or couple because study participants often came to the counseling centers at different times.

What distinguished the counseling sessions from these one-on-one discussions, however, was the counselors' use of a culturally appropriate, client-centered counseling model. Counselors worked with each client to assess his or her own risk of acquiring or transmitting HIV and to develop a personal risk reduction plan based on the client's level of knowledge, relationships with partners, practice of HIV-risk behaviors and readiness to change.

In developing risk reduction plans, clients chose the method of prevention they believed would be most effective for them.

"A client may say, 'I have more than five sexual partners,'" Wathome explained. "After counseling, and exploring how high risk he is with more than five sexual partners, he may decide himself, 'I'm going to reduce my five sexual partners to one.' Another client may decide, 'With my five sexual partners, I will no longer have sex without condoms.' It is the client himself who makes that decision."

Clients also decided how many counseling visits they needed. Most returned for only one post-test counseling session, but others visited the counselors more often. Those returning for more than one visit usually had tested positive.

Clients at Risk Simon was one of 4,293 people who agreed to participate in the study at the three sites. Roughly equal numbers of men and women participated, and 27 percent enrolled as couples.

All of the sites reported some difficulty in recruiting people to participate in the study as couples. In Trinidad, only 107 couples were recruited. Many people who enrolled in the study as individuals, however, later brought partners to the center for counseling and testing.

"I think that people were testing the waters for the quality of the service," explained Dr. Colin Furlonge, principal investigator of the study in Trinidad. "If one partner felt it was good, and felt safe and comfortable, then we had many who would bring their partners along."

Overall demand for counseling and testing proved high even after the study was over. "The study sites had to continue providing counseling and testing, given that clients continued to show up at the sites beyond the recruitment period," Dr. Kamenga said.

The counseling centers used various methods to recruit participants, from television in Trinidad to word of mouth in Kenya, but all attracted people at high risk of HIV infection. HIV prevalence rates among those randomly assigned to the counseling and testing group, ranging from 21 percent in Kenya and Tanzania to 4 percent in Trinidad, were higher than those among the general population in each of the three communities.

Confidentiality and Trust Most participants said they had enrolled in the study because

they wanted to know their HIV status, and 82 percent of those tested returned for their results. The same percentage of all the participants returned at six months.

Although free HIV testing and STI treatment attracted participants to the study, they were not necessarily what motivated clients to return, according to Francis Kihuhoo, counseling director at the KAPC site. "People came for the testing at first, but they really valued the counseling," he said.

Researchers believe the intervention succeeded in changing behavior because of the quality of the counseling. Quality assurance measures included ensuring sufficient space to guarantee privacy to counselors and clients, careful selection and training of counselors, rigorous monitoring and evaluation of the service, supportive supervision of staff

and early identification of appropriate referral systems.

"Unfortunately, in most other places, due to limited resources, all of these important aspects of HIV voluntary counseling and testing are not addressed," Dr. Kamenga said. "The results are poor quality of service, low retention of trained counselors, burnout among retained counselors, and lack of confidence in the service by the clients and the community."

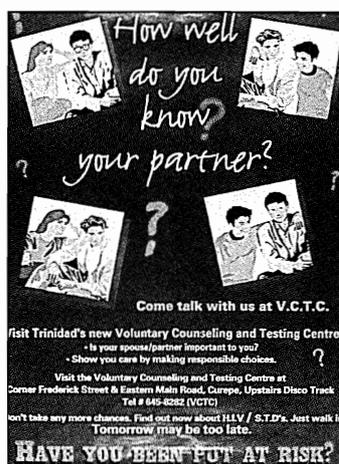
Confidentiality was critical in building that confidence among study participants, according to the findings of a qualitative interview study conducted in Kenya and Tanzania as part of the counseling and testing trial. It was also what set the counseling

apart from the kind of counseling participants were used to receiving from elders or health care workers.

"At every stage, staff members took time to show clients how they ensured confidentiality," Kihuhoo noted. Each participant was assigned a unique number, which was used to identify all samples, test requests and interview forms. The files linking names and identification numbers were always kept in locked file cabinets, and staff members were trained in confidentiality procedures.

Counselors were able to overcome clients' initial reluctance to trust the promise of confidentiality. "Because their personal information was not released into the community, clients gained confidence in the counselor and in the counseling center," said Dr. Olga Grinstead of CAPS. "This facilitated disclosure of risk behavior, which in turn

"Because their personal information was not released into the community, clients gained confidence in the counselor and in the counseling center."



A poster advertising the Voluntary Counseling and Testing Centre in a suburb of Port of Spain. Television proved the best medium for attracting clients to the center in Trinidad.

facilitated the effectiveness of counseling for risk reduction.”

Changing Behavior Simon did not change his behavior overnight. After learning that he was HIV-positive, he decided to be monogamous and to use condoms. But at first his wife refused to use condoms because they had only one child and she wanted to have more children. It was months before Simon could muster the courage to ask his wife to go to the counseling center with him.

After Simon's wife also tested HIV-positive, they talked with counselor Wathome about how they could reduce their risk of reinfection. “Now I always use condoms with my wife,” Simon said.

Like Simon, members of both the counseling and testing and the health information groups reported changing their behavior to reduce HIV risk. Counseling and testing, however, produced more than a 50 percent greater reduction in risk behavior.

Counseling and testing and health information led to similar declines in unprotected sex with a spouse or other “primary” partner. But those who received counseling and testing were significantly more likely to report decreases in unprotected sex with any non-primary partner and with partners in commercial sex.

Counselors cite less scientific but still powerful anecdotal evidence of behavior change.

Counselor Rose Kairuthi of the KAPC in Kariobangi, Nairobi, remembers one client at high risk of infection when he enrolled in the study, a young man who said he had had 20 sex partners.

“When he came negative, he cried,” she said. “When he came back after six months, he had reduced the number of sexual partners and was still negative. At twelve months—still negative. He went around recruiting other young men to put in the study.”

Behavior change was assessed by comparing the behaviors reported by participants during interviews at enrollment and at six months. STI tests on urine samples collected at baseline and at six months confirmed the validity of this self-reported behavior. Those who reported unprotected sex with a non-primary partner were twice as likely to have a new case of STI as those who did not.



KAPC counselor Rose Kairuthi recalls the transformation of one study participant, a young man who had had 20 sex partners before testing negative for HIV.

Researchers are analyzing the data collected at twelve months. Since all study participants were offered counseling and testing at six months and most chose to be tested, Dr. Kamenga noted, “the information 12 months can provide is more in terms of sustainability of the behavior change accomplished by counseling and testing.”

Counseling Couples Many of the couples enrolled in the study made some changes in their sex lives. Couples from both the counseling and testing and the health information

groups reported less unprotected intercourse with each other and more abstinence from sex.

Among couples, as among individuals, greater change was seen in the counseling and testing group. The difference between the two groups of couples, however, was not statistically significant.

FHI's Dr. Kamenga believes that this finding may not be as contradictory as it seems. “If you come as a couple to a health information session, that may be a starting point for you as a couple to take some action,” he explained. “Whereas if you are a single person watching a video and learning how to use condoms, it's still a challenge to initiate a discussion with a partner. So this may be one of the possible explanations why, among couples, we didn't notice a significant difference between the two study arms.”

Dr. Grinstead also points out that the couples had a lower baseline rate of risk behavior than the people enrolled as individuals. “They had less change to make,” she said.

Counselors, researchers and many study participants believe that counseling couples is even more effective than counseling individuals. Couples' counseling

was particularly effective in reducing unprotected sex when one or both partners had tested positive for HIV.

“A discordant couple may be more likely to use condoms than a couple that is concordantly HIV-negative or HIV-positive, so it's important to provide couples with that information,” Dr. Kamenga said. “And it's even more crucial for couples because there are so many decisions to be made about children and whether to have children.”

Both groups reported changing their behavior to reduce HIV risk. Counseling and testing, however, produced more than a 50 percent reduction in risk behavior.

Positive and Negative Experiences After Simon learned that he was HIV-positive, he told his boss—a Catholic priest—in confidence. But the priest revealed his secret to all Simon's coworkers, who shunned and ridiculed him. When he could bear it no longer, Simon quit his job.

The study results suggest that Simon's experience was not typical of most participants. When asked at six months, few said they had been estranged by peers, discriminated against by employers or neglected by family members.

On the other hand, many participants reported improvements in their lives, such as strengthening of sexual relationships and increased emotional support from family, peers, employers and health professionals. Participants enrolled as couples were more likely to say that their relationships had grown stronger.

"In general, the bad experiences tend to make the news," Dr. Furlonge noted. "But one thing the study does show is that there are far more positive experiences than negative experiences."

In all three sites, participants randomly assigned to the counseling and testing group were no more likely to report negative experiences than those who had been assigned to the health information group. "Counseling and testing didn't seem to be associated with negative effects," Dr. Kamenga said.

Dr. Gloria Sangiwa, principal investigator at the Muhimbili center in Tanzania, attributes the low frequency of adverse effects among those in the counseling and testing group to the quality of the counseling and the strict confidentiality the study maintained. "Confidentiality enabled clients to control negative life events," she said.

Other researchers agree that lack of disclosure of HIV status may have helped reduce the risk of negative experiences. They are analyzing study data to determine the impact of disclosure on participants' lives.

Negative experiences were more common among those who tested positive for HIV. Of those in the counseling and testing group, HIV-positive people were more likely to

report estrangement from peers, discrimination by employers and neglect by families.

HIV-positive women enrolled as couples were five times more likely than those in the counseling and testing group as a whole to say that their marriages had broken up and more than three times more likely to have experienced physical abuse. HIV-positive women with HIV-negative spouses were at greatest risk of adverse

effects, with 23 percent reporting physical abuse and 18 percent reporting marital breakup.

Dr. Sangiwa has vivid memories of the first women who told counselors they were experiencing these problems. She and her staff quickly identified an organization, the Tanzania Media Women's Association, where they could refer the two women and others in need of

more specialized counseling and legal assistance.

In addition to providing such support for clients, either directly or through referrals, Dr. Sangiwa recommends alerting counseling staff to the potential for abuse and abandonment among women who may be too ashamed to broach these subjects. "It's important that counselors are aware so they can look for this and talk to people about it," she said.

A Valued Service As participants in the Voluntary HIV Counseling and Testing Study, Simon and his wife received free HIV tests, counseling and STI treatment. But the time they spent receiving these services was still costly for a family with a small income.

Clients in Kenya and Tanzania reported that their participation in the study cost them an average of \$U.S.2.57 to \$7.75. Lost wages were the main expense in both countries, with clients at both sites giving up a day's wages to travel to and from the site, receive services and participating in the interviews.

Despite these costs, clients said they would be willing to pay an average of \$1.64 in Kenya and \$5.11 in Tanzania for counseling and testing.

Clients overestimated how much people would actually pay, according to Dr. Michael Sweat, assistant professor of international health at the Johns

Was the public health benefit of counseling and testing worth the cost in countries with such limited resources? Results of the cost-effectiveness analysis suggest that the answer is yes.



Peter and Anne Kanjiri at the KAPC center in Nairobi. She convinced her fiancé to go for counseling and testing before they married, and exulted when both tested negative.

Hopkins School of Public Health, who analyzed the cost-effectiveness of the services in Kenya and Tanzania. "It seems that many people are inclined to overestimate their willingness to pay as a sign of how much they appreciate the services they received," he said.

The number of clients at the Muhimbili center in Tanzania plummeted when a fee of \$3 was instituted at the end of the study. The fee was reduced to \$1.50, and the client load rebounded. In Kenya, where clients were charged \$0.35 for counseling and testing, the fee had little effect on client access.

Cost-effective Prevention

Counseling and testing helped Simon and thousands of other people enrolled in the study, but was its public health benefit worth the cost in countries with such limited

resources? Results of the cost-effectiveness analysis suggest that the answer to this central research question is yes.

The cost of providing counseling and testing to each client—U.S.\$27 in Kenya and \$29 in Tanzania—was relatively high for countries where per capita health expenditures do not exceed \$10. Using a probability-based model of the likely number of HIV infections that did not occur as a result of the behavior change reported by participants, however, researchers estimated that the cost of averting each new case of HIV was only \$241 in Kenya and \$303 in Tanzania.

These costs are comparable to the estimated \$217 per infection averted through enhanced treatment of sexually transmitted infections in the first randomized controlled trial of that HIV prevention intervention, which was conducted in the Mwanza region of Tanzania.

Voluntary counseling and testing is much less cost-effective in areas with low HIV prevalence. In the United States, for example, one study estimated that the cost per infection averted in a setting with at least 1 percent prevalence was \$60,000.

In the study sites, voluntary counseling and testing proved most cost-effective for those who were infected with HIV. It was also more cost-effective for couples than for individuals and for women than for men. These findings reflect differences in initial risk of

HIV infection among members of these groups and in the numbers of high-risk partners they had, as well as the reductions in risk behavior that occurred after counseling and testing.

Dr. Sweat recommends that counseling and testing services target populations with high HIV prevalence by working with groups that serve those populations, such as STI clinics and camps for transport workers. This was one of the key recommendations in his recent report to the U.S. Agency for International Development (USAID) on the sustainability of the Kenyan counseling center.

"We have enough data to indicate that voluntary counseling and testing is an essential part of the national response to AIDS."

Building a Bridge Now that the study has ended, clients continue to receive voluntary HIV counseling and testing at the three centers. The USAID missions in Kenya and Tanzania are supporting the services in

Nairobi and Dar es Salaam, and UNAIDS funds them at the Voluntary Counseling and Testing Centre, which was established for the study in Port of Spain, Trinidad.

The study results seem to have sparked greater interest in HIV counseling and testing. A new pilot project in Zimbabwe, sponsored by the USAID mission in Harare and implemented by Population Services International and FHI, will assess a social marketing approach to counseling and testing.

Dr. Sangiwa noted that the Tanzanian national AIDS control program included recommendations for district-level counseling and testing in its latest medium-term plan for HIV/AIDS control. "Implementation will be something else, but in terms of policy, we have had an impact," she said.

Despite growing recognition of the value of counseling and testing, future support for continuing and expanding such services remains uncertain. UNAIDS Director Peter Piot believes that policymakers and program managers have a responsibility to act on the study findings.

"We have enough data to indicate that voluntary counseling and testing is an essential part of the national response to AIDS," Dr. Piot said. "As the bridge between prevention and care, the investment in counseling and testing services will go a long way in making needed care available to the invisible majority which today does not even know its HIV status." □

FHI-UNAIDS Voluntary HIV Counseling and Testing Study

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Coordinating Center

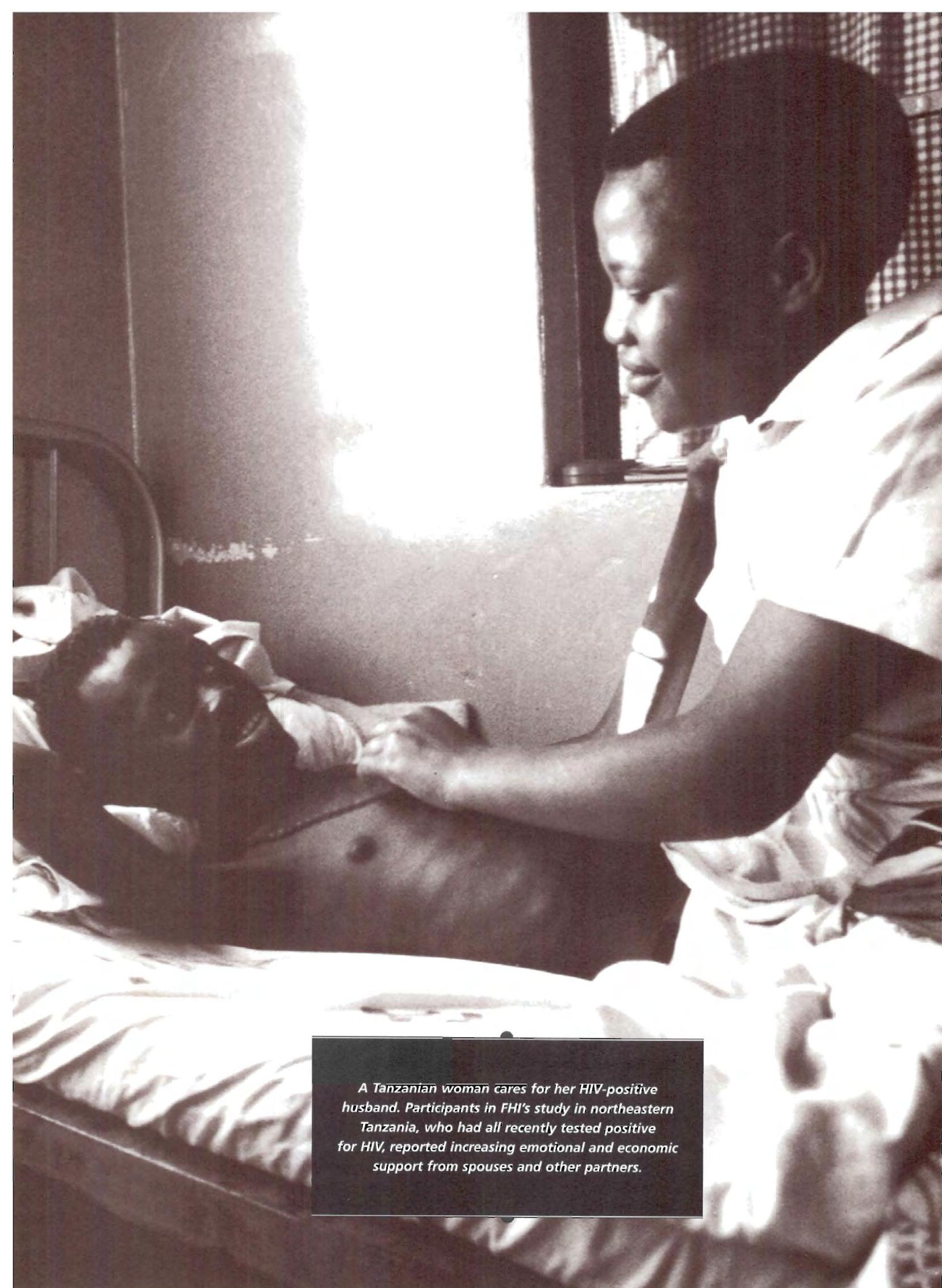
The Center for AIDS Prevention Studies,
University of California, San Francisco

Study Centers

Kenya Association of Professional Counselors
Nairobi, Kenya

Muhimbili University College of the Health Sciences
Dar es Salaam, Tanzania

Queens Park Counseling Centre
Port of Spain, Trinidad



A Tanzanian woman cares for her HIV-positive husband. Participants in FHI's study in northeastern Tanzania, who had all recently tested positive for HIV, reported increasing emotional and economic support from spouses and other partners.

Study on Prevention-Care Link Yields Unexpected Results

BY KATHLEEN HENRY

Research on AIDS care and support in northeastern Tanzania finds that voluntary counseling and testing is an important HIV prevention measure.

When they analyzed the results of a study conducted in Tanzania to assess how care and support for HIV-positive people can contribute to prevention efforts, Tanzanian and U.S. researchers were surprised.

“Our results reinforce the importance of voluntary HIV counseling and testing, at least in the short term, and that’s not necessarily what we expected to find,” said Dr. Joan MacNeil of Family Health International (FHI), which initiated the study in 1996 through the AIDS Control and Prevention (AIDSCAP) Project.

The randomized controlled study was designed to detect any differences in behavior change reported by HIV-positive people who received continuing support from counselors and by those who received only post-test counseling and regular medical services. But researchers found minimal differences between the two groups.

Instead, the study revealed significant levels of behavior change among all study participants. Reports of two important HIV prevention measures—condom use and having fewer sex partners—increased in both the experimental and control groups during the six-month study.

Like the more extensive trial of counseling and testing sponsored by FHI and the United Nations Programme on HIV/AIDS in Kenya, Tanzania and Trinidad (see page 13), the study in Tanzania’s Tanga district showed that learning one is HIV-positive and receiving professional post-test counseling can be a powerful motivator. However, the results also indicate that this effect on behavior may be short-lived.

“Even though condoms continued to be readily available throughout the district, condom use started to decline among members of the control group between three and six months after their enrollment in the study,” said Dr. MacNeil, the associate director for care and research in FHI’s HIV/AIDS Prevention and Care Department. “This relapse into unsafe behavior suggests that additional counseling and care and support at this later point may be critical in sustaining behavior change.”

The Tanga Study The Tanga AIDS Working Group (TAWG), one of dozens of local groups that implement the Tanzania AIDS Project with support from FHI, offers HIV counseling and testing at centers in the towns of Tanga, Muheza and Pangani. Positive results are not uncommon in the Tanga district, where an estimated 7 percent of the adult population is infected with HIV.

Even with such high infection rates, it was not easy to find enough people who met the study criteria of being HIV-positive, sexually active, 18 to 54 years old, and not seriously ill. Counselors report that most people are reluctant to get tested for HIV and many do not want to know their serostatus. As a result, most HIV tests are performed in the hospital after people have become ill.

By early 1997, however, 154 HIV-positive people had been recruited to participate—16 more than the 138 needed to allow researchers to make statistically meaningful conclusions.

All of the study participants had received post-test counseling no more than four weeks before their enrollment. They were randomly assigned to one of two groups: a control group with access to regular health services or an experimental group that received enhanced care and support.

For this study the researchers defined enhanced care and support as the services of a trained counselor at least once a month. The counselors, all public health workers from TAWG, provided counseling, condoms and—when necessary—referral for treatment. They also visited some participants’ homes to counsel and educate family members.

Researchers and members of the TAWG agreed on this definition of care and support based on the needs of the community as well as budgetary considerations, Dr. MacNeil explained. TAWG staff members, who were spending most of their time managing AIDS-related illnesses and providing palliative care to the terminally ill, saw a need for a different kind of support for people in early stages of HIV infection.

"Since study participants were relatively healthy, we felt that counseling and education would be an appropriate level of support," Dr. MacNeil said.

All study participants were interviewed in Kiswahili at enrollment, after three months, and after six months to gather information for the study. A final round of interviews had been planned at 12 months, but the study ended after the six-month follow-up because of time and funding constraints.

Trained interviewers used a 57-item questionnaire that covered a wide range of issues, including discussing HIV with partners, HIV risk behavior and use of health services. Participants also talked about how they felt about their HIV status, its impact on their decisions about having more children, and the reactions of their families and communities.

Women at Risk In many African countries, women are becoming infected with HIV at faster rates than men. This high risk of HIV is partly a result of women's greater biological vulnerability to the virus, but it is compounded by social and economic pressures that make it difficult for women to refuse unwanted sex or insist on condom use.

Such pressures are evident in the Tanga district. Women enrolled in the study were more likely than men to be widowed, divorced or separated. They also were more likely to be unemployed or to work in unskilled manual labor or small businesses. Incomes were low for all study participants, but the women earned significantly less: an average monthly income of U.S.\$35, compared to \$57 a month for men.

Earlier research conducted in Tanga to provide information for HIV/AIDS prevention planning found that women working in small businesses, such as street vending or market stalls, often supplement their income by having sex with customers.

Study data suggest a high risk of HIV infection among women in monogamous relationships. At the beginning of the study, only 16 percent of the women reported having more than one sex partner in the previous three months. Forty-five percent of the women—all of whom were HIV-positive—were married or widowed. Many of them said they had sought an HIV test after learning

that a husband, partner or child was infected with the virus.

"In Tanzania, as in other parts of the world with a high prevalence of HIV, being in a marriage or a stable relationship is actually high risk for many women," Dr. MacNeil said.

Improving Health Proponents of voluntary counseling and testing say that early detection of HIV infection can prompt people to take better care of their health. This seems to be true in Tanga, where reports of illnesses by all participants decreased and researchers found significant increases in reported use of home care, folk healers, and medical, counseling and religious services.

"The significant decline in reported illness suggests that knowing one's serostatus can encourage those who are positive to seek care earlier for illnesses and symptoms that may be easily treated, such as diarrhea, rashes and headaches," Dr. MacNeil said.

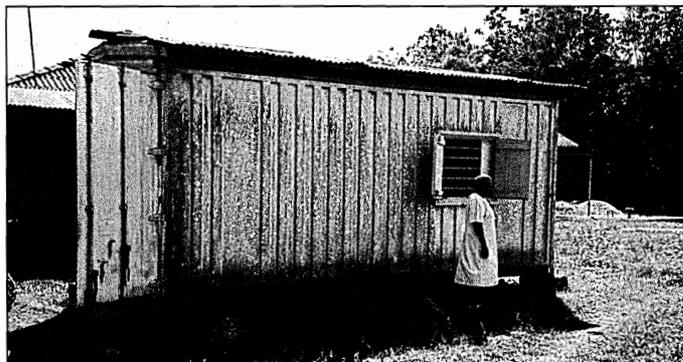
The most striking decline was in reports of pain, burning or discharge on urination—common symptoms of sexually transmitted infection (STI). Although 35 percent of participants reported such symptoms at baseline, only 13 percent were experiencing them after six months.

The number of people seeking STI treatment after six months was also reduced, suggesting that symptoms declined because of effective treatment and preventive measures. This decline has important implications for HIV prevention because people are more likely to transmit HIV when they have an STI.

Knowledge of HIV serostatus had an impact on reproductive choice as well as reproductive health. Those reporting that they used any family planning method rose from one-fifth of all participants at the beginning of the study to almost one-half at the end as a result of increases in condom use. A substantial number of participants did not use any family planning method, however, because they wanted larger families.

Changing Behavior Reports of condom use for family planning and disease prevention rose dramatically in both the experimental and control groups, with most of the increase occurring during the first three months. Fidelity to one partner also increased, as

"In Tanzania, as in other parts of the world with a high prevalence of HIV, being in a marriage or a stable relationship is actually high risk for many women."



An old shipping container has been refurbished to serve as a satellite office and counseling center for the Tanga AIDS Working Group in Muheza.

JOAN MACNEIL/PHI

the number of people reporting more than one sex partner dropped throughout the six-month study.

Since these preventive measures were adopted by people in both groups at similar rates, the additional care and support given to one group did not appear to have played a role in reducing HIV risk behavior.

"Enhanced care and support in this early phase did not have a significant impact on behavior change, yet the study as a whole decreased risk behavior," Dr. MacNeil said.

The researchers attribute this behavior change to the quality of the post-test counseling all participants received and the easy access to condoms and information about condoms provided by an energetic social marketing project.

Condom use did begin to decline among the control group after three months, suggesting that care and support may be more important after the initial shock of a positive test result subsides.

"Although this decline was not statistically significant, there was really a drop-off," Dr. MacNeil said. "I would speculate that if we could have followed them at 12 and 18 months, it would have been significant."

Also troubling was the number of people in both groups who continued to put their partners at risk of HIV and themselves at risk of reinfection. After six months, 28 of these HIV-positive individuals reported having more than one sexual partner, and many others said they had not used condoms.

Such findings are not unusual and probably reflect the difficulty most people have in accepting a positive test result, Dr. MacNeil noted. "It just takes time," she said. "And this shows that even after the first six months, there is still a lot of work to be done."

Opening Up Another important preventive measure—revealing serostatus—proved difficult for all participants. At the beginning of the study, four weeks after learning of a positive test result, only 29 of the 154 people had told anyone about it.

"Most of them wanted to get on with their lives and not even talk about HIV," Dr. MacNeil said.

The main reason cited for telling others about a positive result was the need for support. Only a handful of people—three during the first round of interviews and two during the third round—mentioned protecting partners as a reason for revealing their status.

"Counselors emphasize the preventive aspects of knowing



Dr. Mberesero (center) and Dr. MacNeil (right) with some of the nurse-counselors who provided support to study participants.

one's serostatus, but sometimes we feel that our clients were infected when they had no knowledge of AIDS and HIV," said Dr. Firmina Mberesero, TAWG chairperson. "It takes them some time to realize their role in preventing the spread of HIV."

The number of people who had disclosed their serostatus

increased by almost 64 percent during the study, with no significant difference between the experimental and control groups. After six months, however, 24 participants had not told anyone that they were HIV-positive, and 80 hadn't told their spouses or other sexual partners.

"Even after six months there were a lot of problems with revealing status," Dr. MacNeil said. "People were worried about abuse, discrimination and being abandoned."

In fact, most responses to the news of a positive HIV test were surprisingly supportive in a community where HIV/AIDS is considered a "self-inflicted" disease and people dying of AIDS are often abandoned by all but their mothers or grandparents.

Participants in both groups also reported increasing emotional and economic support from spouses and partners. And when asked about their interactions with family members, such as eating or sleeping together and being included in discussions or cared for when ill, 91 percent of participants reported active inclusion in family life.

Although the enhanced care and support had no impact on sexual behavior, they appear to have had a positive impact on the response to HIV/AIDS in families and communities.

After the study, TAWG staff noted greater interest in HIV counseling and testing and greater support from other health care workers. "The majority of medical personnel thought that counseling was useless, but they are now in the forefront of sending clients to us," Dr. Mberesero said.

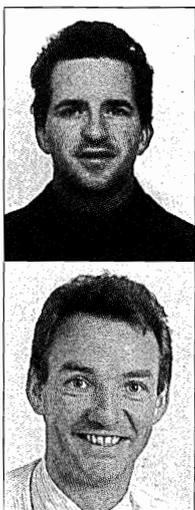
Another important sign of change is the support group formed by some of the study participants—the first of its kind in the Tanga district. Members meet to talk about their experiences and problems, visit each other, and help counsel other TAWG clients who have trouble accepting that they are HIV-positive.

Counselors believe that the study helped make community members more willing to discuss HIV/AIDS and more accepting of people living with the virus. "Ongoing care and support seem to bring people together and also bring issues out in the open," Dr. MacNeil said. ▣

Reports of condom use for family planning and disease prevention rose dramatically.

Policymaking and Antiretroviral Therapy: *A Framework for Rational Policymaking*

by Steven Forsythe and Charles Gilks



Pressured from within by a growing demand for therapies that are reducing AIDS death rates in industrialized countries and from without by offers of donor funding, policymakers in low- and middle-income countries are being forced to make decisions about providing access to antiretroviral (ARV) treatment for HIV. In some cases, they are making investments that will not be affordable, cost-effective, sustainable or equitable over the long term, which may eventually lead to the withdrawal of subsidized access in the future. Conversely, some policymakers in countries that could realistically afford to subsidize open access to ARVs incorrectly assume that these medications cannot be affordably purchased.

In either case, vital decisions are being made based on severely limited information. Little is known about the extent of the demand for the drugs, the ability of governments and individuals

inhibitors), 2) providing AZT to pregnant women to prevent vertical transmission, 3) offering partial government subsidies, or 4) negotiating discounted, but unsubsidized, purchase of ARVs.

In order to evaluate the costs and benefits of each of these options and to identify creative ways of affordably subsidizing access to ARVs, policymakers need information on the demand for ARVs, the ability of those who need the drugs to pay some portion of the cost, the economic impact of the health benefits of ARVs, and the cost-effectiveness of ARVs compared to that of other drugs. They also need to evaluate their countries' overall capacity to deliver ARV therapy and effectively monitor clinical progress.¹ Finally, they need to assess the political and financial commitment of their own governments to sustain support for ARV therapy and the potential impact of government subsidies on health care for the impoverished.

Once this critical information has been collected, it should be assessed in the context of an objective and dynamic framework that enables policymakers to weigh issues of affordability, cost-effectiveness, sustainability and equity. Such a framework should not only allow countries to decide what is affordable now, but also to monitor how changes in drug prices and physical capacity should affect policymaking in the future.

It has been estimated that full public subsidization of HAART would consume 84 percent of Malawi's gross national product.

to pay for them, or the economic impact of various levels of public subsidy for ARVs. In such a vacuum of information, short-term political considerations, rather than a realistic assessment of what can be offered, are likely to predominate.

In deciding whether and how to provide access to ARVs, policymakers in non-industrialized countries have a number of options, ranging from full public subsidy of the three- or four-drug combination known as highly active antiretroviral therapy (HAART) to no public involvement in providing access. So far, most policymakers have opted to support more limited access by: 1) funding some ARVs (but not the more expensive protease

Affordability

Although ARVs have been shown to reduce mortality and improve the quality of life of people living with HIV/AIDS in many high-income countries and some middle-income countries, the economic realities of providing access to these drugs can be overwhelming. In countries where annual public health expenditures are U.S.\$3 to \$30 per person, public provision of HAART, which can cost from \$7,000 to more than \$20,000 per person per year, is likely to be unrealistic.

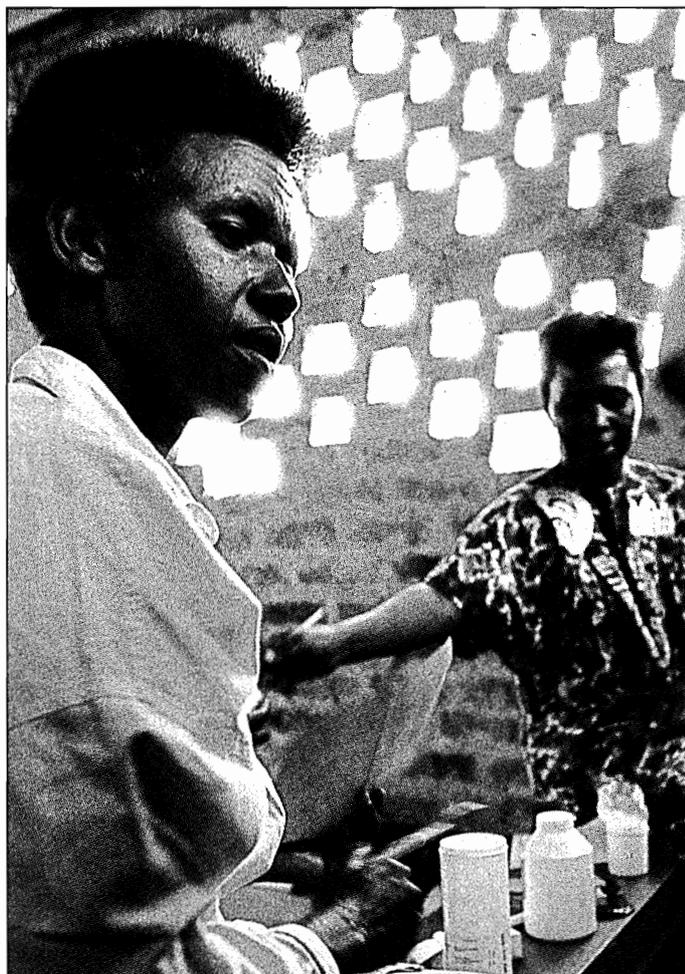
In Malawi, for example, per capita income is \$180 and public health spending is only \$3 per

capita. More than 700,000 people—15 percent of the adult population—are currently living with HIV or AIDS. It has been estimated that full public subsidization of HAART would consume 84 percent of the country's gross national product.² Thus, for Malawi, access to HAART for all who need it is completely unaffordable.

In Costa Rica, where the per capita income is \$2,640, the annual purchase of \$7,000 worth of ARVs is also out of reach for most people living with HIV or AIDS. However, unlike Malawi, Costa Rica is at an early stage in the epidemic, with only about 360 people who are aware of their HIV status (out of an estimated 3,200 people living with HIV). The small number of people who require access to therapy, combined with a relatively well-financed and well-equipped health system, means that the recently enacted public policy of fully subsidizing HAART consumes only about 2 percent of the social security budget. The actual cost incurred by the Social Security Institute might be even less if one includes the economic benefits of introducing HAART, such as reductions in inpatient visits, decreased demand for drugs to treat opportunistic infections and increased labor productivity.

The countries most likely to be able to afford ARVs are those with the smallest demand (lowest HIV prevalence) and the highest level of available resources (highest per capita income). Brazil, Mexico and Costa Rica, which have initiated some public subsidization of ARV therapy, are relatively high-income, low-prevalence countries. Countries such as Zimbabwe and Malawi, which have a relatively low gross domestic product and a high HIV prevalence, have so far not pursued access to ARVs. Others, such as South Africa, are taking a middle ground by offering AZT to pregnant women. Côte d'Ivoire, Chile, Uganda and Vietnam are making ARVs available to selected centers with appropriate clinical capacity through a Joint United Nations Programme on HIV/AIDS (UNAIDS) initiative that provides discounted, but unsubsidized, access to ARVs.

In some cases ARVs may be affordable to some through partial subsidies. While partial subsidies might not be equitable, they are likely to expand the number of people who can afford ARVs. For example, it might be feasible for a government to



CRISPIN HUGHES/PANOS PICTURES

subsidize 60 percent of the cost of ARVs and for individuals to pay the remaining 40 percent. Before pursuing this option, government officials must have an idea of the number of people who would take advantage of such a subsidy (their "willingness to pay" for the unsubsidized portion of the costs) and how this in turn might affect budgetary requirements. The amount that consumers are willing to pay at various prices (the elasticity of demand) will determine the total public and private resources needed when offering a subsidy for ARVs.

Cost-effectiveness

It is also necessary for policymakers to determine whether an investment in ARVs would be cost-effective. In other words, given other pressing health care needs, is it wise to invest in ARVs? While a country might find ARV therapy affordable, its policymakers might not necessarily conclude that it is a cost-effective use of limited resources.

There is growing evidence that ARVs can provide significant medical and economic benefits to a country's health care system. Data from the United States, for example, illustrate that HAART reduced AIDS-related mortality by 75

A pharmacy in Kampala, Uganda, dispenses drugs to women, many of whom are HIV-positive.

percent and AIDS-related morbidity by 73 percent over three years.³ In the Brazilian state of São Paulo, AIDS-related mortality has declined 32 percent since protease inhibitors became available in 1996.⁴

Data from industrialized countries suggest that despite the high cost, the benefits achieved by averting opportunistic infections and inpatient visits may make HAART

a cost-effective option and may even produce savings. It is noted, for example, that one inpatient episode in the United States costs an average of \$7,000. Therefore, the cost of a year's supply of protease inhibitor (a type of drug that must be taken in combination with other ARVs) at an annual cost of \$6,000-\$7,000 could be completely offset if even one inpatient episode were averted.⁵

The cost of HAART has been

shown to be at least partially offset by reductions in inpatient hospital care and shifts toward outpatient care in the United States, Ireland and France. The CAESAR trial in Canada, Australia, Europe and South Africa showed that patients receiving lamivudine, compared to those in the placebo group, had significantly fewer hospital admissions (11 versus 6 percent), unscheduled outpatient visits (15 versus 10 percent) and prescriptions for an HIV-related illness (43 versus 30 percent).⁶

Despite the medical and economic benefits of ARVs in predominantly industrialized countries, many low- and middle-income countries are likely to find it more advisable to invest in less complex and costly drugs. For example, in the poorest countries, where access even to essential drugs is not assured, it is likely to be more cost-effective initially to invest in drugs to treat chronic symptoms of HIV/AIDS, such as imodium for diarrhea or non-essential antibiotics such as ceftriaxone or ciprofloxacin for septicemia, rather than in more expensive ARVs.⁷

While it is unlikely that countries will have the complete information necessary for performing a rigorous cost-effectiveness or cost-benefit analysis before making a decision about the public purchase of ARVs, it is imperative that they pursue a preliminary assessment of the resources necessary

to invest in such expensive drugs. Furthermore, countries should establish the mechanisms necessary to monitor the costs and benefits of such drugs once they are purchased, so that future decisions regarding longer-term commitment of resources can be more fully informed.

Sustainability and Capacity

Policymakers who do conclude that ARVs are both affordable and cost-effective must next determine whether such care is sustainable. Sustainability depends on the amount of time during which treatment will be necessary. Unfortunately, the duration of treatment required for patients using ARVs remains unclear. Most data indicate that patients with a few years of treatment with HAART quickly relapse if they discontinue therapy. Current estimates suggest that treatment will have to be continued for 5 to 20 years, or possibly even longer.

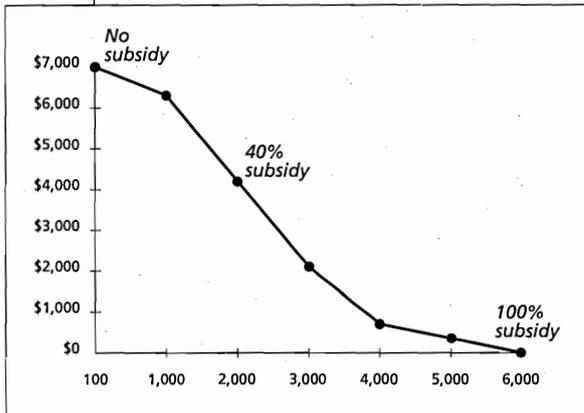
The impact of discontinuing ARV treatment can be devastating from both a clinical and a political perspective. A lack of politically and financially sustainable commitment to subsidizing ARVs and to the infrastructure needed to deliver

In the poorest countries, where access even to essential drugs is not assured, it is likely to be more cost-effective initially to invest in drugs to treat chronic symptoms of HIV/AIDS.

them can lead to an interruption of therapy, which can cause drug resistance that could make future treatment ineffective.

Politically, offering an effective combination of drugs and then withdrawing them is probably worse than never introducing the drugs in the first place. Therefore, if governments do introduce ARVs, they must be committed to providing these drugs for the indefinite future.

In addition to the length of treatment, policymakers need to carefully review the national capacity (human and technical resources and infrastructure) necessary to administer and monitor complex and potentially toxic drug regimens.



Cost of ARVs to consumers and number of consumers who will buy them at different levels of subsidy: a hypothetical example of the elasticity of demand

Any decision to provide access to ARVs must include a realistic assessment of the ability to sustain the staff training and improvements in infrastructure required for treatment, safe drug delivery and storage, laboratory testing, patient follow-up, and treatment of drug side effects.

Equity

The fourth consideration in selecting a policy on ARV therapy requires evaluating the equity of ARV provision. On the one hand, global equity would demand that ARVs be made available to all, regardless of whether they live in a low-income or a high-income country.

Proponents of global ARV access to all argue that people should have equal access to life-saving drugs. Despite this appeal, few donors or pharmaceutical companies have been convinced that it is their responsibility to provide access to ARVs to all those cannot afford them. Donors have noted that the cost of providing these drugs at a global level is likely to be close to \$36 billion per year.²

Conversely, others maintain that a concern for equity should discourage countries from spending scarce public resources to subsidize access to expensive drugs. The argument is made that ultimately the impoverished will pay the price of subsidizing ARV access for a few (probably the most wealthy or influential) when health care resources get diverted. Such arguments against AIDS exceptionalism have also been aired within the United States.⁸

Policymakers must assess who the winners and losers are in any effort to subsidize access to care. They must ensure that, at the very least, the most vulnerable members of society are not made worse off by the diversion of scarce resources for ARVs, and that there are ways of encouraging equal access for those who are most in need. ▣

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Providing Access to ARVs: What Policymakers Need to Know

Affordability

What kind of treatment will be offered (e.g., dual nucleoside therapy alone or full HAART)? What are the indications for starting treatment? What monitoring will be appropriate, and where will clinical centers be established? What pricing mechanisms are likely to be adopted (e.g., negotiated discounts, public subsidy, donor aid)?

What is the likely demand for ARV treatment? How many HIV-seropositive people are likely to fulfill treatment requirements, and how many will be able to access treatment centers? What would be the cost of meeting that demand?

Cost-effectiveness

What other therapeutic options or interventions could be implemented prior to ARV therapy that could also prolong quality of life (e.g., effective tuberculosis services, antifungal agents and other drugs for specific opportunistic infections, drugs for symptomatic care and pain relief, better inpatient facilities)?

Sustainability

What kind of capacity strengthening is required to introduce and sustain effective ARV therapy (staff training and new recruits, improvements in capacity for safe drug delivery and storage, infrastructure, technical and laboratory equipment)? What would these measures cost?

Equity

What are the equity issues that are likely to arise? What needs to be done to address them adequately? (For example, adopting indications for treatment that do not discriminate against at-risk groups such as sex workers or drug users or offering therapy in rural as well as urban areas.)

What are community health-care priorities? How does interest in HIV/AIDS care and prevention compare with concerns about other pressing health care needs, such as malaria control, safe motherhood and childhood vaccination?

Improving Access to Antiretroviral Therapy in Latin America

BY MARGARET J. DADIAN

Spurred by the advocacy of people living with HIV/AIDS and their allies, a number of Latin American governments are starting new programs to finance and deliver antiretroviral medications to HIV-positive citizens.

In many developing regions of the world, the high cost of the new antiretroviral (ARV) drugs has been a near-unbreachable barrier to governments struggling to care for their HIV-infected citizens. In the poverty-stricken nations of sub-Saharan Africa, for example, public health programs are so underfunded that health agencies cannot afford inexpensive medications for opportunistic infections, much less the thousands of dollars it can cost to treat a single patient with ARVs.

Increasingly, though, countries with stronger economies are devising strategies to provide ARVs to those who need them. While a comprehensive combination therapy program is still beyond its means, Thailand now dispenses AZT to pregnant women with HIV to curtail perinatal transmission. Even more impressive are the efforts of several Latin American countries—including Brazil, Argentina, Colombia, Costa Rica and Mexico—that are working both individually and collectively to make ARVs a standard treatment option for their citizens. Many of the ARV programs that have emerged in the region were born of tireless advocacy by grassroots organizations seeking to convince health officials that these medications could be made affordable and accessible through government intervention.

Improving Access, Improving Infrastructure Brazil, burdened with a severe HIV epidemic, has created one of the most extensive ARV programs on the continent, providing double and triple combination therapy free of charge to some 58,000 people with high viral loads or full-blown AIDS. National legislation guarantees access to these medications for all affected Brazilians who are covered by the social security system (a parastatal organization that provides health care to private and public sector employees and their families) and to all HIV-positive pregnant women and their newborns. With funding from its own treasury and a World

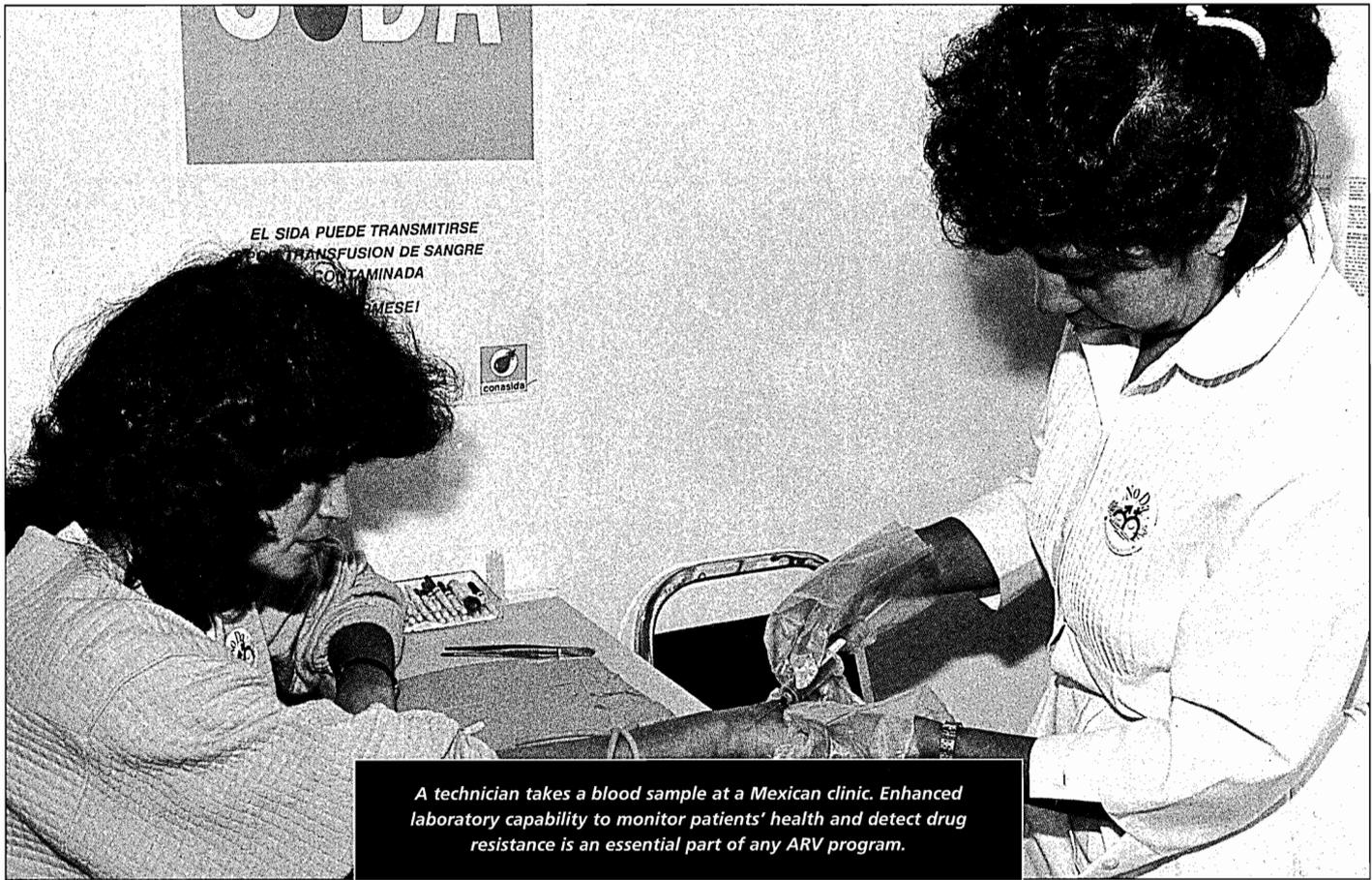
Bank loan, Brazil's projected 1998 budget for ARVs and monitoring will top \$545 million. Many credit the two-year-old program for the dramatic 32 percent decrease in AIDS-related mortality in São Paulo state—one of Brazil's highest HIV prevalence areas—between 1996 and 1997.

"Brazil has worked hard to put together the kind of comprehensive system required to make a large-scale antiretroviral program successful," said Dr. Carlos del Rio, associate professor of medicine at Emory University School of Medicine and former director of Mexico's AIDS control and prevention program. "It has created national networks for drug supplies and lab facilities and put a lot of time and effort into making it all work."

As in Brazil, Argentina's ARV program owes its existence to the passage of a federal law that provides the most advanced drugs available to HIV-infected citizens through the national social security system. But the Argentinian program goes a significant step further in its creation of a special fund to pay for ARVs for those not covered by social security—street vendors, small businesspeople, the unemployed—and for low-income pregnant women. Some 11,000 HIV-positive Argentinians receive ARV therapy through these two sources and through private insurance plans.

But the process of setting up this program in Argentina was not simple. When the program first began, its managers discovered that they could not rely on the existing national drug delivery system to handle the complex job of distributing multiple therapies and to guarantee their consistent availability.

"With several expensive drugs being dispensed simultaneously, we needed a new system," said Dr. Laura Astarloa, director of Argentina's National AIDS Control Program. "We needed new computers, new computer programs, and new staff dedicated exclusively to tracking and distributing the medications, or else the program would not have succeeded."



A technician takes a blood sample at a Mexican clinic. Enhanced laboratory capability to monitor patients' health and detect drug resistance is an essential part of any ARV program.

J. HERNANDEZ CLAIRE/PAHO/WHO

High Costs—and Cost-saving In fact, infrastructure improvement can be a major expense for nations that embark on ARV programs—and it often entails much more than a more efficient distribution system. Enhanced laboratory capability is essential to follow the progress of patients who receive the medications and to determine whether virus strains have developed resistance to certain drugs. Clinic and hospital staff must receive extensive training in order to prepare patients to follow difficult drug regimens and to monitor their progress. In some countries, conditions are so poor that a complete overhaul of the infrastructure would be necessary before ARV therapy could be successfully introduced.

“Examining these issues is all part of determining the benefits of instituting an ARV program in each country,” said Dr. Rafael Mazin, regional advisor for HIV/AIDS and STDs at the Pan American Health Organization (PAHO). “How much must be invested to bring capabilities to necessary levels?”

Although they must shoulder these expenses, large countries such as Brazil and Argentina have also found ways to control some of the costs of their programs. Negotiating bulk prices with the pharmaceutical firms that manufacture ARVs helps make these drugs much more affordable. For example, Argentina now pays 33 cents for AZT pills that once cost \$2 each.

The Horizontal Technical Cooperation Group (HTCG), made up of national AIDS program directors from several Latin American countries, wants to see that kind of price break made available not only to countries that can buy in quantity but also

to smaller nations that are currently paying premium prices for their ARVs. Even though the members of the group are for the most part unable to buy these drugs together—national regulations make such joint purchases difficult unless the countries involved already collaborate in a trade agreement—the HTCG hopes to convince drug companies to offer lower prices as standard throughout the region.

“Uruguay is paying six to seven times what Argentina pays for the same medications because they have only 100 patients,” said Dr. Astarloa. “This kind of inequality should not exist between countries.”

Another proposal would create a revolving fund, administered through PAHO, that could loan money for ARV programs to Latin American countries that cannot afford the medications without financial help. But securing sufficient

seed money to get the fund started has been difficult.

“Our estimates of the amount needed to undertake this are so high that identifying potential sources for funding is a real challenge,” said Dr. Mazin.

Involving the Private Sector While Mexico cannot afford to consistently offer triple combination therapy to all HIV-positive citizens, Mexicans with HIV/AIDS who participate in the nation’s social security system are eligible for monotherapy or dual therapy. Pregnant women receive AZT to prevent transmission of the virus to their fetuses and newborns and, after they deliver, are eligible to receive triple therapy, as are all children under 18.

Managers discovered that they could not rely on the existing national drug delivery system to handle the complex job of distributing multiple therapies.

For the 50 percent of Mexicans not covered by social security, publicly funded access to ARVs has been nonexistent—but not for much longer. This year, Mexico's National AIDS Control Program worked with university researchers to develop a new funding model to cover the medication needs of HIV-positive members of this huge segment of the population. With seed money from the government, FONSIDA will operate as a nongovernmental organization, soliciting donations from a wide diversity of sources—notably, the private sector.

"We expect to involve industry, banks, community organizations and international donors in our fund-raising drive," said Dr. Griselda Hernandez, deputy director of CONASIDA, Mexico's national AIDS prevention and control program. "Perhaps we can serve as an example to other countries with limited resources that are seeking ways to expand treatment to all."

The Mexican program has made a significant investment in improving lab capacity in four states and in training medical personnel. It continues negotiations with pharmaceutical companies for lower bulk prices on drug purchases. Upgrading the national drug distribution system is also on the agenda.

"Although the program in Mexico has a way to go to reach 100 percent access, it's actually quite remarkable how much has been achieved in such a short time," said Dr. del Rio.

The Power of Advocacy In most of these countries, the initiative behind ARV programs grew out of the activities of advocacy organizations and support groups for people living with HIV. Although these groups are generally smaller than their counterparts in North America and Europe, they have had an enormous impact on national treatment policies in Latin America.

In Costa Rica, the national health care system did not offer combination ARV therapy when the drugs first became available. After months of negotiation between the Costa Rican social security system and a committee of nongovernmental organizations and groups representing people with HIV, activists helped an HIV-positive college student file a petition with the



An HIV-positive patient receives a hug at a clinic in Santos, Brazil. All people living with HIV/AIDS who are covered by the country's social security system are entitled to free ARV therapy.

ARMANDO WAKAFHOTO/WHO

Supreme Court asking for triple combination therapy that he could not afford but that could save his life. The justices ruled in his favor, and although he died less than a month after their decision, his courage prompted more than a dozen others to present their own petitions. Within a few weeks, the Court ordered the national social security system to develop a plan for delivery of these medications to Costa Ricans with AIDS. Activists in Panama, inspired by the victory in Costa Rica, plan to file similar petitions with the Panamanian Supreme Court.

"Advocacy is alive and well in Latin America, and it's a very

powerful force in this process," said Dr. del Rio. "Whether in Brazil or in smaller countries, the new laws and policies that guarantee access to antiretrovirals are due to the activities of these groups."

Elsewhere in Central America, resource-poor countries such as Honduras—which has more than half the reported cases of AIDS in the region—offer no ARVs to their citizens. People with HIV in Honduras who take combination therapies either pay for them themselves or are enrolled in drug trials conducted by pharmaceutical companies. Activists in Honduras continue to lobby for improve-

ments in national treatment policies and for government funding of ARV therapy.

In Nicaragua, activists have become directly involved in the treatment process itself. The country's only ARV program is operated not by the financially constrained government, but by a nongovernmental organi-

zation, the Fundación Nimehuatzin, and a team of health professionals based at a public hospital, Hospital Manolo Morales, in Managua. With support from the private sector, foundations and international donors, NGO and hospital staff have managed to provide 30 patients with ARVs. They closely track both the medical progress of the patients and all expenses to enable them to build an argument for the cost-effectiveness of ARV therapy.

"Our aim is to be able to prove to the government how important it is to provide this kind of medication and how it can cut costs in the long run," said Rita Arauz, president of Fundación Nimehuatzin. □

"Advocacy is alive and well in Latin America, and it's a very powerful force in this process."

U.S. Doctors and Patients Find HAART Poses Challenges

BY MARY O'GRADY

Debilitating side effects, demanding drug regimens and high costs are some of the barriers that limit the benefits of highly active antiretroviral therapy in the United States.

The benefits of highly active antiretroviral therapy (HAART), the three- and four-drug combinations against HIV, have been widely publicized. In many industrialized countries, these potent drug regimens have reduced deaths from AIDS and prolonged the lives of thousands of people.

Less well-known are the formidable challenges HAART presents, including its side effects and the potential for rapid spread of drug resistance. Antiretroviral drug combinations have been available in the United States for less than three years, yet there is a rapidly growing body of knowledge about their disadvantages as well as their benefits. This knowledge may be instructive for other countries searching for ways to make antiretroviral therapy available to their HIV-positive citizens.

Limited Options In the countries where it is available, HAART generally includes three or four drugs in two distinct categories: nucleoside analogs and protease inhibitors. They are commonly prescribed as part of the same regimen in the United States because one or two protease inhibitors strengthen the effect of one or two nucleoside analogs. Unfortunately, protease inhibitors do not work as well with a third category of HIV drugs, non-nucleoside analogs, and they should not be taken alone.

By the end of August 1998, the U.S. Food and Drug Administration had approved four protease inhibitors—indinavir, nelfinavir, ritonavir and saquinavir—and five nucleoside analogs—didanosine (ddI), lamivudine (3TC), stavudine (D4T), zalcitabine (ddC) and zidovudine (AZT). Only two non-nucleoside analogs—nevirapine and felavirdine—had been approved for prescription use.

If one of the drugs involved in the triple or quadruple therapy is not well tolerated or if a patient's HIV infection becomes resistant to it, a whole new set of drugs must be prescribed for the regimen to be effective. Thus, with a limited number of HAART medications available on the U.S. market so far, only a few different drug

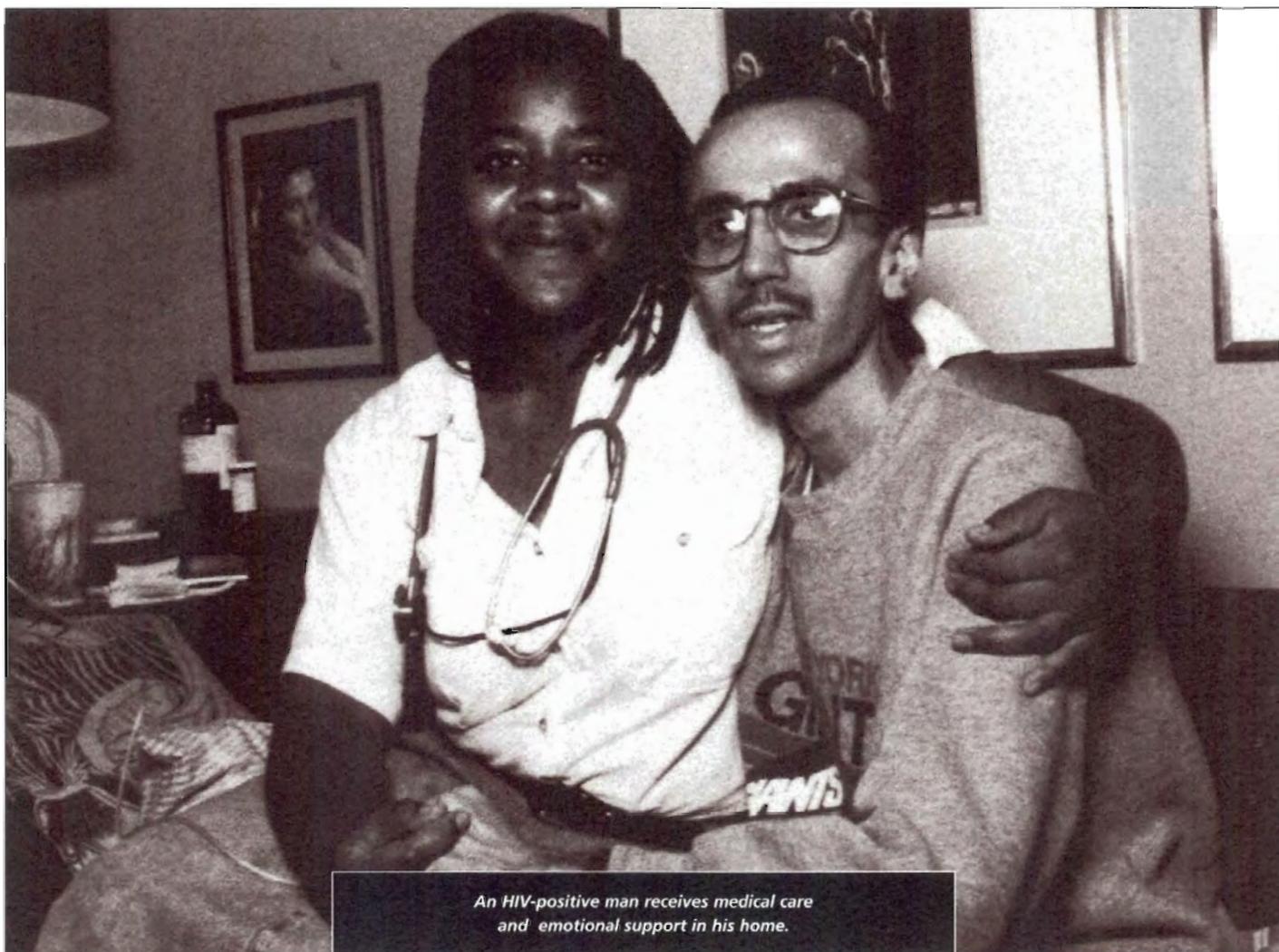
combinations are possible. HAART regimens can also fail because of lack of viral load response or poor treatment adherence.

Resistance and Adherence Because of its "highly active" nature, HAART can provide a symphonic response to HIV infection. If doses are missed or taken improperly, however, the crescendo falls flat. Not only does the treatment lose its potency, but also the patient's HIV infection can rapidly become resistant to the drugs involved, meaning that their HIV infection changes its chemical or genetic form to resist the effects of these drugs. Even more ominously, sexual transmission of HIV strains resistant to HAART medications has been documented and may be a growing problem.

Missing a single dose of HAART medication even twice a week can cause the development of drug-resistant HIV—a real danger because adherence to the drug regimens is difficult. Once HAART is initiated, a patient must be willing and able to take as many as 40 pills (12 is the minimum daily dosage in any currently recommended HAART regimen) and drink as many as eight glasses of water a day. The pills must be taken at several times during the day, some with food and others on an empty stomach.

A patient's ability to adhere to these complicated regimens is one of several important considerations for clinicians in determining when to begin HAART, according to Dr. Frederick Hecht, a clinician at San Francisco General Hospital Medical Center who has been treating HIV-positive patients since 1986. He noted that U.S. physicians generally prescribe HAART based on the current recommendations provided in the *Journal of the American Medical Association* by the International AIDS Society,¹ but they may follow these recommendations to different degrees.

"I'm slightly more conservative than the guidelines because of the long-term side effects," said Dr. Hecht, an assistant clinical professor of medicine at the University of California, San Francisco, Medical School. "I want to be clear that someone will not be at risk of developing resistance because of non-adherence."



An HIV-positive man receives medical care and emotional support in his home.

DE. HALAMANDARIS/PHOTO/WHO

Side Effects The side effects experienced by many people on HAART can readily provoke a patient to miss a dose or take a “drug holiday” from the regimented existence the treatment necessitates. Sometimes side effects are so severe that a physician must prescribe a different drug combination, involving a totally new regimen.

Most of the information available about HAART side effects is self-reported by patients because of the lack of placebo-controlled clinical research trials, according to Dr. Hecht. One study he is involved in, the Options Project, is looking at the most appropriate time for HIV-infected individuals to begin HAART, taking into account the potential side effects of this treatment. The side effects from individual drugs as well as the deleterious drug interactions reported so far are many, and vary from one individual to the next. The most common ones, however, are becoming

better documented and recognized by health care professionals.

According to Dr. Hecht, who currently treats about 100 HIV-positive patients, long-term side effects include lipodystrophy, which is a nearly complete lack of fat below the skin (or some-

times a redistribution of it to the pelvic area), and, less commonly, diabetes. After two years of HAART availability in the United States, coronary heart disease also emerged as a side effect in some patients who had lived long enough to develop it. “This makes me concerned,” he said, “especially

for those who would be on treatment five to ten years.”

Common short-term side effects that Dr. Hecht has seen in his patients include medication-related nausea, fatigue, kidney stones (from indinavir) and diarrhea (from nefinavir). Patients taking ritonavir have experienced mouth numbness, loss of taste, nausea and, occasionally, vomiting.

This powerful therapy demands commitment from patients, physicians and health care systems.

More than Drugs HAART is not always readily available to or feasible for everyone infected with HIV, no matter where they live. This powerful therapy demands commitment from patients, physicians and health care systems.

Since HAART became available in the United States in early 1996, it has become increasingly clear that it must be prescribed and monitored by highly trained physicians and nurses who maintain the most current knowledge of all the potential side effects, drug interactions and resistance variables. Counselors who can provide emotional and psychosocial support and case managers who can identify financial assistance options are also a critical part of the HAART team wherever this form of care is attempted. In addition, such highly complex pharmaceutical treatment demands a sophisticated

health care infrastructure and delivery system to support the necessary laboratory tests, drug supplies and outpatient clinic visits.

For industrialized nations, another lesson of the experience with HAART to date might be the realization that HIV care involves much more than a technological fix. With viral strains already developing drug resistance, prevention may indeed be the best medicine against HIV. In the end, however, care is not only a basic human right, but a crucial part of the HIV prevention cycle, and it involves much more than simply dispensing medications. ▣

¹CCJ Carpenter, MA Fischl, SM Hammer, et al. Antiretroviral Therapy for HIV infection in 1998: recommendations of the IAS-USA Panel. *Journal of the American Medical Association*. 1998;280:78-86.

Study Reveals Gaps in HIV Care in the United States

Preliminary results from the first nationally representative sample of adults living with HIV/AIDS in the United States show that less than half of them—43 percent—receive regular health care, defined as one visit to a health care provider every six months.

These results, presented at the 12th World AIDS Conference in Geneva, Switzerland, in June 1998, also indicate that slightly more than half of HIV-positive Americans have tried highly active antiretroviral therapy (HAART).

Access to the newer HIV/AIDS therapies mirrored the overall deficiencies in health care for HIV-positive adults revealed by this national HIV Cost and Services Utilization Study (HCSUS).

Nevertheless, the proportion of HIV-infected adults who had tried HAART rose from 16 percent to 55 percent during 1996.

Conducted from January 1996 through July 1997, the HCSUS used two rounds of client interviews to learn about five types of care accessed during the previous six months: doctor or clinic visits, emergency room visits, hospitalizations, use of antiretroviral medications and use of prophylactic therapies.

Nearly 3,000 HIV/AIDS patients were sampled at 148 urban and 51 rural sites, chosen based on caseloads, in the 48 states in of the continental United States. Fifty-four percent of the study group consisted of individuals aged 35 to 50, with 34 percent younger than 35.

More than three out of four participants were male and almost half were men who have sex with men. Twenty-four percent were drug users, and 18 percent were heterosexuals. Nearly half the study participants were white, one-third African-American, and 15 percent Hispanic. Most were unemployed.

Study participants reflected the following categories of disease stages defined by the Centers for Disease Control and Prevention: 38 percent had clinical AIDS, 52 percent had symptomatic HIV infection and 10 percent had asymptomatic HIV infection.

Study results released in Geneva by the HCSUS Consortium,

representing the National Opinion Research Center at the University of Chicago, Harvard University, Project Hope, the University of California at San Diego, and seven other research organizations, show that the cost of HIV/AIDS treatment in the United States is \$6.7 billion a year. Forty-six percent of the total is spent on hospital costs, and 39 percent covers pharmaceuticals. The remaining 14 percent (some \$938 million) funds outpatient treatment, emergency room visits, lab costs, and other care services.

The average annual per patient cost is \$20,000, double the average annual income of nearly half of those infected with HIV in the United States.

The researchers estimate that HIV is responsible for 8 percent of the total potential years of life lost in the mainland United States. Expenditures for care of those living with HIV, however, account for less than 1 percent of total personal health costs.

The study also found that one out of five people living with HIV in the United States has no insurance to cover the cost of health care. Only thirty-two percent have private health insurance, while 48 percent are covered by the government programs Medicare or Medicaid.

HIV-positive women, African-Americans, Hispanics, drug users, and others with low socioeconomic status, no health insurance or only Medicaid have lower levels of health care.

The researchers concluded that until new strategies are identified and utilized and additional funding is allocated to provide adequate and equitable health care for all HIV-positive adults in the country, the United States will not be able to optimize health outcomes for this disease.

The HCSUS was funded by the U.S. Agency for Health Care Policy and Research, the Health Resources and Services Administration, the National Institute of Mental Health and the National Institute on Drug Abuse, among others.

Positive with a Positive Attitude

BY GEORGE KERR III

An HIV-positive survivor shares his often harrowing but rewarding experience with highly active antiretroviral therapy.

October 31, 1995. I was sitting across from my counselor. She did not have to say a word. I already knew the results: I was HIV-positive. I was filled with shock, rage, hatred and fear.

Almost three years later, in July 1998, I received a call from my doctor. He told me that my viral load had dropped from over 750,000 to 650 in four months. Again I was filled with emotion—this time, excitement and relief.

The years between my first post-test counseling session and my doctor's call were difficult ones. It took all the support I could get to go through the anger, the denial, the sadness. I had to let my family and friends go through this process too. And I had to understand when some of them were not ready to accept the news.

The only experience I can offer is that of living day to day as a survivor. And the most valuable lesson I've learned is how powerful the mind and spirit are.

My experience with antiretroviral drugs shows just how important the mind and spirit can be. It also shows that these new drug combinations that some people have called an AIDS "cure" are not easy to take and don't always work.

I've been on seven different drug combinations. Some didn't affect the amount of HIV in my system, and others caused severe side effects. I'm actually running out of possibilities. I had to get FDA approval to take one of the drugs I'm on now, Sustiva, because it wasn't on the market yet. It was an experimental drug.

Even when the drugs do work, the side effects are very difficult. With some of the pills I used to take, I'd have blackout periods. I'd be walking and all of a sudden I'd be unconscious for a few seconds. Once I had to be wheeled out of my office in a chair and taken home because I couldn't even walk.

I have what's called neuropathy in my left hand. I feel tingling and numbness, and sometimes the pain is so bad I can't use it. There are times when I have a problem simply picking up a book with it. Sometimes I can do it, but other times the pain that goes through my hand is so bad that all I can do is cry. And I am not one to cry.

Neuropathy is a very common side effect. Other common side effects that I have experienced are headaches, upset stomach, diarrhea and loss of balance.

I take 38 pills a day. That's eight different medicines a day, including two allergy medicines and a multivitamin. When I have a side effect, I take more.

All but one of the medicines have to be taken with food. One of the side effects of these medicines is nausea. But even when I don't have the appetite to eat, I have to force myself to eat in order to take the pills. They are all pills, so I need fresh water to take them too.

One of the medicines must be taken on an empty stomach. I take four tablets dissolved in water first thing in the morning. Then I take ten pills at 10 a.m. and another nine at 4 p.m. Before I go to bed I take 15 more pills.

It took me a couple of years to learn to take these medicines the way I am supposed to. I was saying, yes, I'm taking my pills, but in all honesty, I wasn't always. I was not brought up to take pills—I rarely took even an aspirin. So taking all these pills was a difficult new process I had to learn.

I started with AZT. I think the biggest reason AZT didn't work for me is that I went in with a negative attitude. I thought, I'm going to get all these side effects. And I did. I experience some side effects with the pills I'm taking now, including the neuropathy in my hand. But I'm learning that with a positive attitude, I'm able to overcome the side effects, or at least live with them.

For example, whenever I start feeling ill, I remember a walk I took with my parents in the spring when the cherry blossom trees were starting to bloom. I try to remember that feeling—how gorgeous it was, and how at peace I was with myself. And that helps tremendously—not just mentally, but physically.

I remember one time in particular, when I was walking and I tripped and scraped my hand. It really hurt. But I made myself think of the cherry blossoms, and then my hand didn't hurt any more. If I had sat down and looked at my hand, it probably would

have hurt for a couple of days. But I didn't let the pain affect my mind. I took it away from the pain.

Of course this is not going to work every time. I still have pain in my hand, no matter how much I think about cherry blossoms. But there are times when you can overcome pain. Most of the time you can. You just have to keep trying until it works.

I realize that I am very fortunate to have access to antiretrovirals and even experimental drugs for HIV. But in my opinion, the most important factor in improving my health has been a positive attitude.

Adopting a positive attitude has made a direct difference in my life. Now HIV is making me take care of not only my body, but also my mind and spirit.

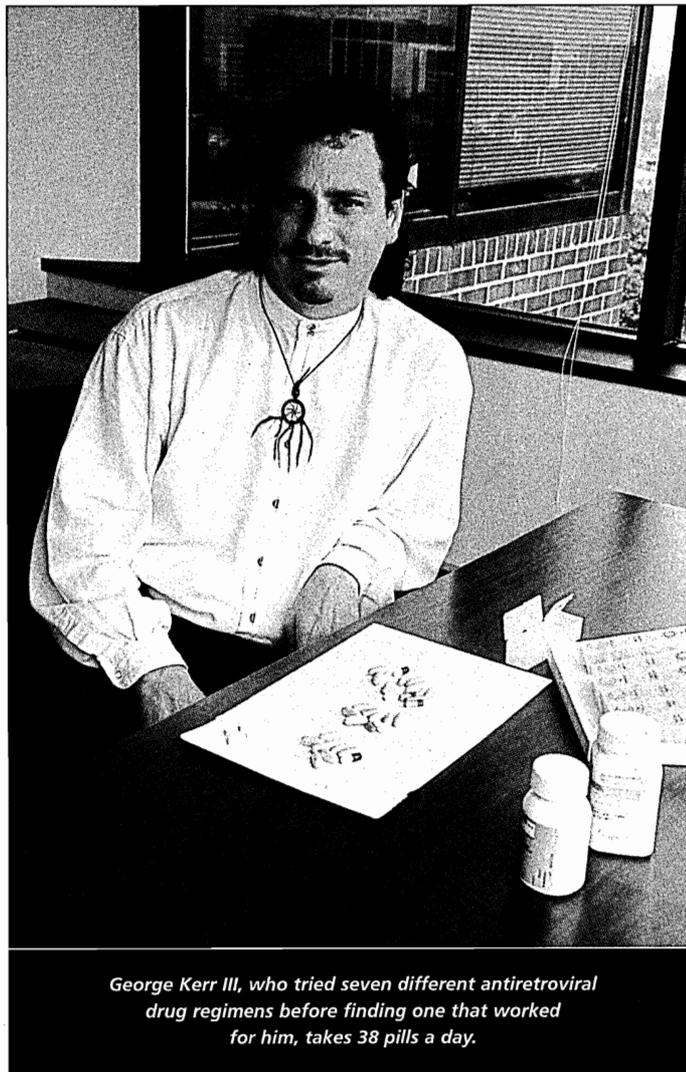
It took me three years to learn just how powerful the mind and spirit are. I think the turning point was when I had a lymph node removed from my neck. They removed a mass the size of a tennis ball. Fortunately, it wasn't cancerous. But that was a real eye-opener for me. And I think that was when I stepped over the line and started to take an active role in making my HIV status a positive rather than a negative.

What helps me most is meditation, the support of family and friends, and reading—a lot of reading. Through reading, I've learned how to use meditation to conquer pain and I've been inspired by the success stories of other HIV-positive people.

The biggest success of my life so far has been riding my bike 350 miles from Raleigh, North Carolina, to Washington, D.C., last year in an "AIDS Ride" to raise money for HIV/AIDS care and support programs. I wore a jersey that said "Positive Pedaler" on the back, and I got so much support from the people in all the towns we went through. And seeing other people out there—all age groups, all genders, all races—for a cause that affected me directly was so uplifting.

When I started to train for the ride, I hadn't ridden a bike since I was a child. I couldn't even change a tire. So I never thought I could do the whole thing. But getting out there and proving to myself that I could do it was a wonderful feeling. When I grow old, that's one thing I will always remember.

Of course everyone doesn't need to go out and bike 350 miles. But regular exercise and good nutrition can help keep you healthy. Just getting out and walking every day can make a big difference.



George Kerr III, who tried seven different antiretroviral drug regimens before finding one that worked for him, takes 38 pills a day.

MARY O'GRADY/FHI

And you can use that time to meditate and relax, to concentrate on the positive things in your life.

Being at peace with myself helps me maintain a positive attitude as well. Many of us are told that we are being punished by a higher power. Once we realize that that isn't true, we can let spirituality back into our lives.

My daily inspiration is a quote that I have posted above my desk at work: "By being open about my status, I found it served more people than just myself. And that attitude has kept me alive."

I count myself extremely lucky because I can be very open about my HIV status with my friends and coworkers. And I enjoy talking about it because I like educating people. That edu-

cation is three-fold: teaching people who are positive how this can be a good experience, talking to caretakers about how to care for those who are positive, and helping people who are negative understand how important it is to stay negative.

To all of them I say: "How we protect and care for ourselves matters now. Our positive attitudes and behavior matter now." ▣

GEORGE KERR III IS AN ADMINISTRATIVE SERVICES ASSISTANT IN FHI'S HIV/AIDS PREVENTION AND CARE DEPARTMENT IN ARLINGTON, VIRGINIA.

George Kerr's Medication List

March 26, 1998

(excluding allergy medications)

Meds	7am	10am	4pm	Bed
Fortovase (200mg) With food		6 Tabs	6 Tabs	6 Tabs
DDI in H ₂ O W/O food	4 Tabs			
Hydroxyurea (500mg) With food		1 Tab		1 Tab
Sustiva (200mg) With food				3 Tabs
Bactrim,DS (800/160) With food			1 Tab	
Lamictal (100mg) With food				1 Tab

Practical Nutritional Advice Helps People Live Longer with HIV

BY KATHLEEN HENRY

An NGO run by people living with HIV/AIDS in Zimbabwe teaches others who are HIV-positive how to improve their health by eating nutritious traditional foods.

If your granny didn't eat or drink it, you shouldn't either.

This simple rule of thumb and other practical advice on nutrition from The Centre in Zimbabwe has helped hundreds of HIV-positive people live longer, healthier lives.

What it means, explains Centre director Lynde Francis, is reverting to the foods used before colonization and avoiding low-fiber Western diets that are high in fat, sugar and stimulants, which have harmful effects on the immune system.

"Where there is a traditional cuisine, that is the one people should adopt," she said. "The only exception is where the staple is a potato or cassava or yams—what we call ground produce. Then they need to supplement it with unrefined grains."

In Zimbabwe, for example, a traditional staple is *sadza*, a stiff porridge made from ground maize, millet or sorghum.

Centre staff show clients that a nutritious diet is effective and affordable. "When you tell people that they can stay healthier by eating well, their faces fall because they think that's expensive," Francis said. "But in most developing countries, to eat healthy is almost always cheaper."

In fact, when Centre staff compare the cost of buying food for a nutritious traditional diet to a client's regular shopping bill, the savings are substantial. They recommend that clients use these savings to buy vitamins to strengthen their bodies' natural resistance to infection.

Francis noted that scientific papers on nutrition tend to focus on parenteral feeding, supplementation with micronutrients, and other high-tech interventions that are irrelevant to most people in low- and middle-income countries, rather than food.

Centre staff show people that they "don't need Western packets of protein powder," Francis said. They do so by translating nutritional theory into useful information, suggesting foods that are available and affordable to people with limited incomes and explaining the health benefits of a nutritious diet in clear, understandable terms.

This advice is provided through individual counseling, group education sessions and training workshops. Until last year, when

a grant from the Canadian Public Health Association's Southern African AIDS Training Service enabled The Centre to open an office, these services were offered from Francis' home in Harare, the country's largest city.

The Centre's materials include sample menus and meal plans, lists of foods to eat and foods to avoid, and guidance on the best foods and vitamins to take during various illnesses, such as diarrhea, herpes or shingles attacks, and thrush. Its "Golden Rules of Eating for Health" emphasize the importance of unrefined, unprocessed indigenous foods, clean water, and small, frequent meals.

This is good advice for anyone, but for people living with HIV/AIDS, it is a survival strategy.

Francis and the other six staff members at The Centre know this first-hand. All HIV-positive, they do not take antiretroviral drugs. Instead, they practice what they preach and share what they have learned about diet and natural remedies with others.

"I thought the best thing I could do was helping other people not to have the kind of experience I had when I was diagnosed with HIV in 1986 and there was nothing—no support or information and absolutely no hope," Francis said.

Since it was founded in 1991, The Centre has worked directly with more than 700 clients, in addition to reaching hundreds more through training workshops and educational awareness sessions at workplaces. Of those 700-plus clients, only 68 have died.

This relatively low mortality rate has been achieved without antiretroviral treatment or—in many cases—other drugs. Like most people in countries with limited resources, many Centre clients have little or no access to any medical intervention.

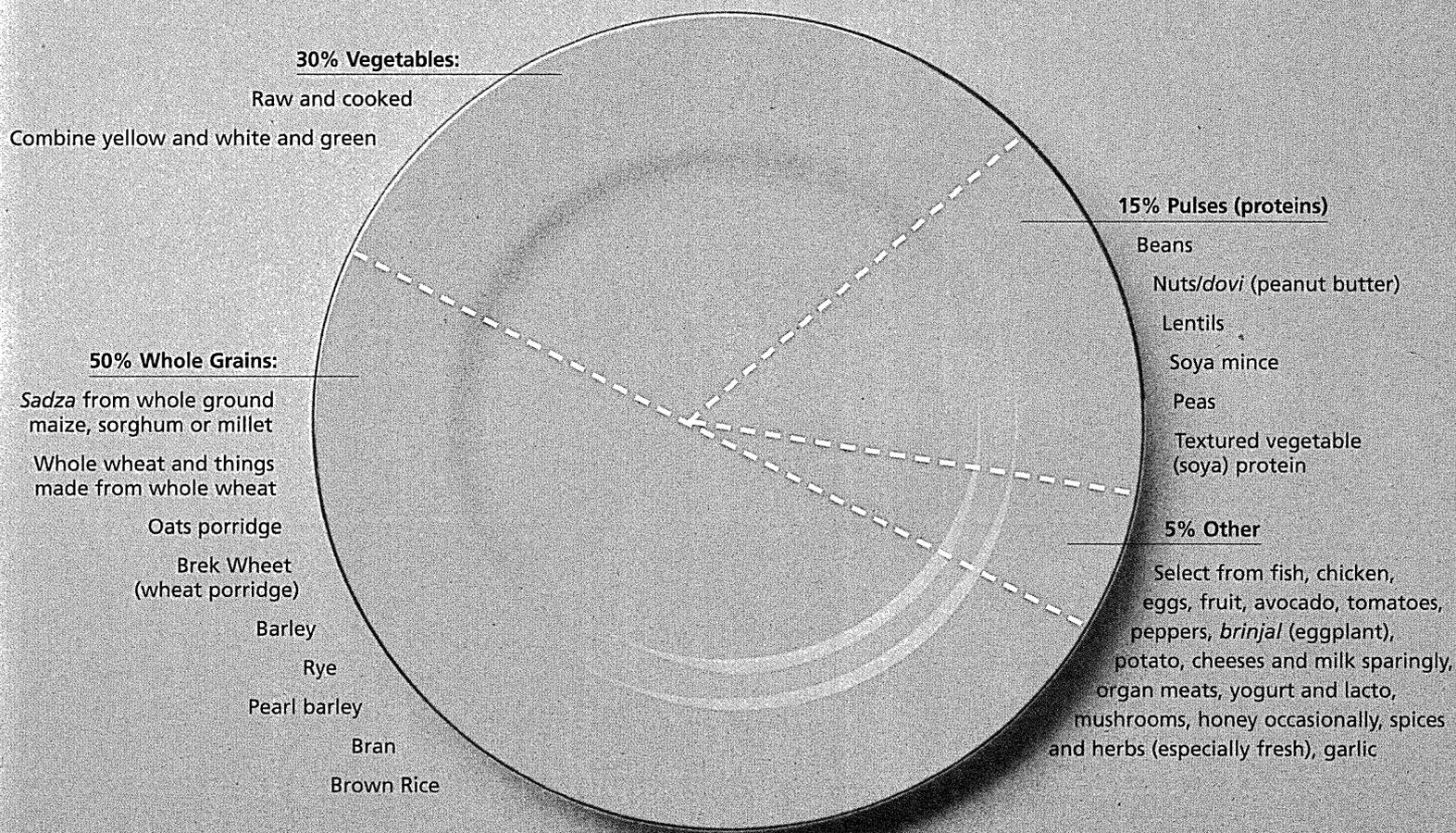
"For many people, good nutrition is the only therapy available," Francis said. "The good news is, it's available, affordable, effective and—importantly—enjoyable, with no adverse side effects like drugs." ▀

FOR MORE INFORMATION, CONTACT THE CENTRE, 21A VAN PRAAGH AVENUE, MILTON PARK, HARARE, ZIMBABWE.

Golden Rules of Eating for Health

- Eat whole (unrefined) foods
- Eat natural (unprocessed) foods
- Eat indigenous (not imported) and in-season foods
- Drink clean water (if not bore-hole, boil for 10 minutes or filter)
- Eat little and often: five times daily (every three hours)

Healthy Combinations: Putting Together a Well-Balanced Meal



Foods to Avoid

Sugar and all food containing sugar: this includes cool drinks, cakes, sweets and cookies

Cooking oil (except olive oil or cold pressed oils). Heating oil to cook with it destroys any goodness—use for salads only.

Red meat and pork (liver and kidney are best if you crave *nyama* [meat])

Strong tea and coffee (rooibos tea, herb, fruit and bush tea, and decaffeinated coffee are substitutes)

Alcohol and tobacco (do not go into smoky places)

Fats should be used sparingly and not at all with diarrhea.

Tinned, processed and refined foods

Sample Menu

7 am
Good breakfast (porridge with lacto and fruit)

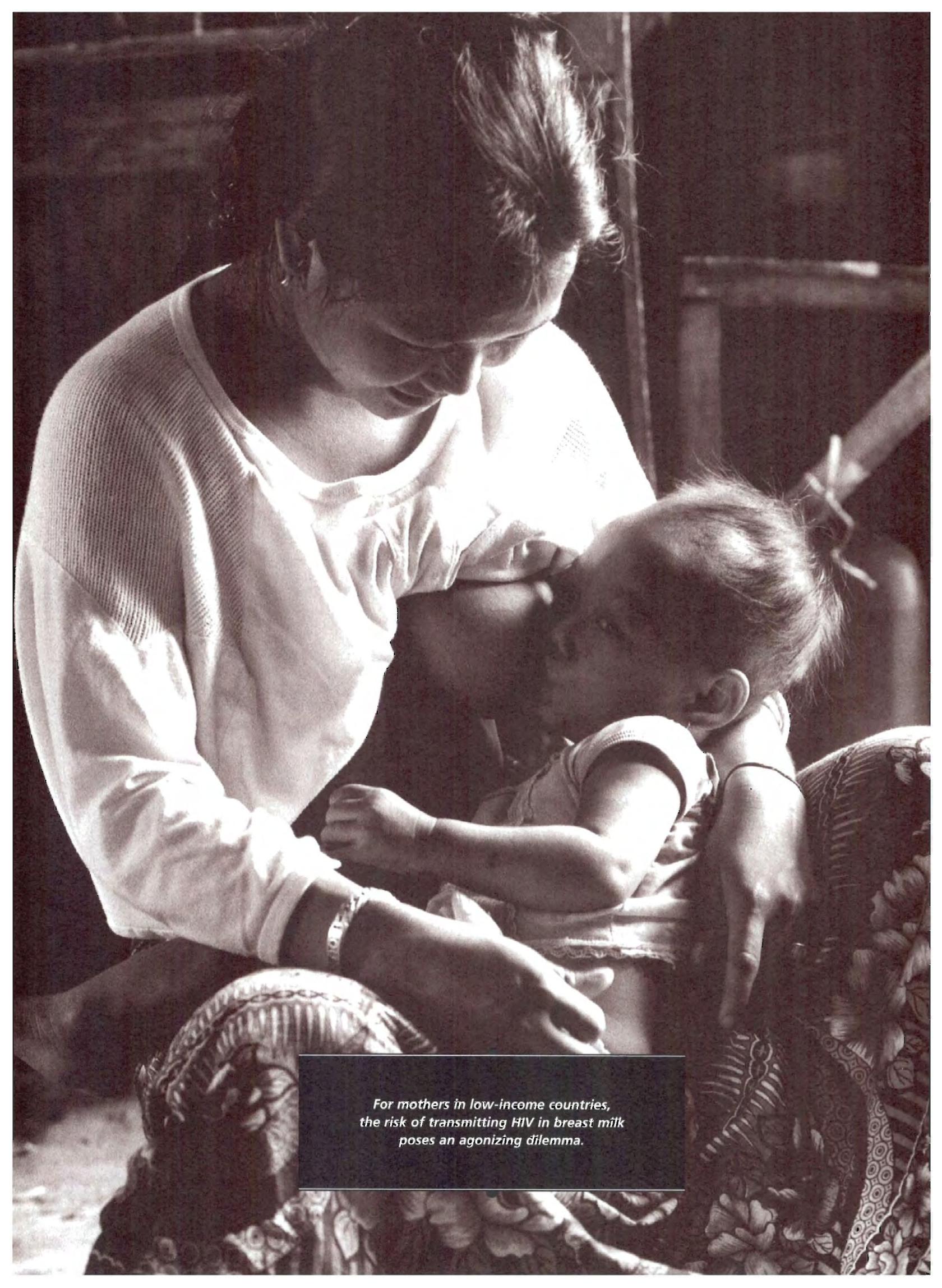
10 am
Snack (biscuits and banana)

1 pm
Lunch (whole wheat sandwich with egg and salad)

4 pm
Snack (small yogurt or some nuts and fruits)

7 pm
Supper (*sadza*, beans and vegetables)

Always combine pulses and grains at the same meal.



*For mothers in low-income countries,
the risk of transmitting HIV in breast milk
poses an agonizing dilemma.*

Preventing Mother-to-Child Transmission of HIV

BY JOAN MACNEIL

Antiretroviral therapy and alternatives to breast milk can reduce mother-to-child transmission of HIV, but they are not realistic options for most mothers living with the virus.

Since the beginning of the HIV pandemic, almost 3 million children have died of AIDS. Another million children were estimated to be living with the disease at the end of 1997, half of them infected last year alone.

Most HIV-positive children acquire the virus from their mothers in the uterus, during labor and delivery, or through breast milk. Their numbers will continue to rise as the number of HIV-positive women of childbearing age increases. In a growing number of countries, HIV has already become the single greatest cause of child death, undermining decades of progress in child survival.

The majority of children infected with HIV live in low- and middle-income countries. This gap in mother-to-child HIV transmission between industrialized and non-industrialized countries continues to widen. For example, in France and the United States fewer than 5 percent of children born to HIV-positive women in 1997 were infected with the virus. In non-industrialized countries, the average was between 25 percent and 35 percent.¹ There are two major reasons for this difference—access to drugs for reducing mother-to-child transmission and breast-feeding practices.

AZT and Access Four years ago research in the United States and Europe showed that giving an antiretroviral drug, Zidovudine (AZT), to pregnant women during pregnancy and delivery and to their infants after birth could cut HIV transmission from mother to child by as much as two-thirds.² This quickly became common practice in industrialized countries.

That particular regimen of AZT has not been available to women in resource-constrained settings, however, because of its complexity and cost. It is difficult to administer, involving regular drug taking over several months and intravenous administration during delivery. It is also prohibitively expensive, at approximately U.S.\$800 per pregnancy.

Recognizing that most women in non-industrialized countries would not even have the opportunity to consider a drug regimen

that must be taken throughout the last trimester because they have limited or no access to antenatal care, researchers set out to evaluate a more feasible course of therapy. They chose a shorter course of oral AZT administered throughout the last days of pregnancy and during labor and delivery—the time when most mother-to-child transmission appears to occur.

Trials of this short course of AZT, sponsored by the ministries of public health in Thailand and Côte d'Ivoire and the U.S. Centers for Disease Control and Prevention, began in 1996. This year, the results from Thailand showed that the shorter regimen reduced mother-to-child transmission by half.³

Both the reduced course of AZT and the HIV testing and counseling that must precede it are beyond the grasp of many HIV-infected pregnant women. But these results have triggered interest among governments and international donors in making this method of preventing maternal-child HIV transmission more widely available. The manufacturer of zidovudine, Glaxo Wellcome, recently agreed to reduce the price for women in low- and middle-income countries, and the Joint United Nations Programme on HIV/AIDS (UNAIDS) is working with governments to provide access to short-course AZT in 11 African, Asian and Latin American nations.

The cost of this therapy still poses a barrier for governments trying to expand access and for individuals who may try to buy it through private health care providers. The discounted price of U.S.\$50 is many times the per capita health expenditure of most non-industrialized countries, and it does not include the additional cost of antenatal HIV counseling and testing and baseline laboratory tests. These costs raise questions of long-term sustainability after subsidies are reduced or eliminated.

Another critical question rarely mentioned in the debate or the research on AZT and maternal-child transmission is how to maintain the health and well-being of HIV-positive mothers. One of the many contradictions of preventing mother-to-child HIV transmis-

sion is that while short-course AZT decreases child mortality, it has no known impact on the health of the mother.

After short-course AZT treatment, HIV-positive mothers are still faced with the burden of their own infection and the likelihood that they will die from AIDS before their infants grow up. Preserving the health of HIV-positive mothers after they give birth should also become a priority, for their own sake and to ensure the continued survival of their infants.

Breast-feeding Dilemma Providing short-course AZT therapy to breast-feeding mothers may not be effective because the infants who escaped HIV infection during pregnancy and delivery may become infected through breast milk. Up to one-third of all mother-to-child HIV transmission is due to breast-feeding.

For mothers in resource-constrained countries, this risk poses an agonizing dilemma. By choosing artificial feeding, a woman may avoid passing on HIV to her child. But where the water supply is unsafe, she may also expose her child to other deadly diseases. Research results suggest that in populations with high levels of infant mortality (usually due to infectious diseases), the risk of child death is actually lower if mothers with HIV breast-feed their infants.

Even when an HIV-positive woman knows she can bottle-feed her child safely, there are other disadvantages to artificial feeding. The most formidable obstacle is cost. For example, a year's supply of artificial milk for an infant will cost a Vietnamese family more than the country's per capita annual income. In addition, since prolonged breast-feeding has a naturally contraceptive effect, a woman who does not breast-feed may become pregnant again, repeating the dilemma. And if bottle-feeding becomes a badge of HIV status, a woman who decides not to breast-feed may risk loss of confidentiality and social rejection.

In the absence of clear guidance, mothers who know or suspect that they are HIV-positive must weigh the odds of infecting their babies with HIV, with its certain mortality, against risking infection and possibly infant death by feeding their babies formula mixed with water that may be contaminated.

Given the importance of breast-feeding for child health

and the increasing prevalence of HIV infection around the world, health policymakers and service providers have struggled to develop appropriate and feasible guidelines on breast-feeding for HIV-positive mothers. This has proved to be extraordinarily difficult for a number of reasons.

First and foremost, most mothers do not know their HIV status. In non-industrialized countries, nine out of ten HIV-positive women are unaware that they are infected. Therefore, broader promotion of bottle-feeding could do more harm than good because it might encourage women who are HIV-negative to needlessly seek alternatives to breast-feeding.

On the other hand, more specific guidance is difficult because it is still not possible to compare the risk of HIV acquisition from

breast-feeding with the risk of infant and child morbidity and mortality from unsafe artificial feeding in various settings. Researchers' attempts to determine these risks using mathematical models have been constrained by the limited information available, including a lack of consensus on the mechanisms and timing of HIV transmission through breast-feeding.

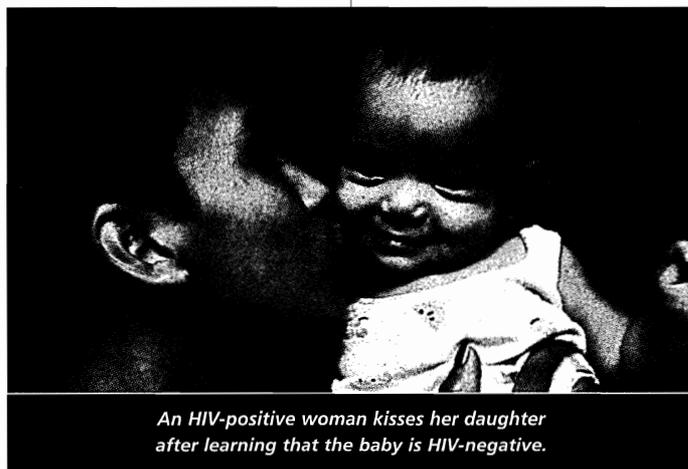
Early policy guidance to HIV-infected mothers in industrialized countries (where safe and affordable alternatives to breast milk usually exist and HIV counseling and testing are widely available) advised them to avoid breast-feeding. Consequently, very few HIV-positive mothers in these countries chose to breast-feed their children, and few children were infected from breast-feeding. At the same time, mothers in non-industrialized countries were being advised to continue breast-feeding.⁴

Recently, however, UNAIDS changed its guidelines from wholesale support of breastfeeding for HIV-positive mothers to supporting breast-feeding as the best method of feeding only for infants

whose mothers are HIV-negative or whose mothers do not know their HIV status.⁵

The new guidelines emphasize the importance of supporting HIV-positive mothers in their right to choose an infant feeding method appropriate to their needs. They say that mothers who decide not to breast-feed must be ensured access to safe and sufficient quantities of nutritionally adequate breast milk substitutes—a costly and problematic recom-

After short-course AZT treatment, HIV-positive mothers are still faced with the burden of their own infection and the likelihood that they will die from AIDS before their infants grow up.



An HIV-positive woman kisses her daughter after learning that the baby is HIV-negative.

ANNIE BUNGEROTH/PANOS PICTURES

mentation in many settings. They also call for improved access to antenatal services and voluntary, confidential HIV counseling and testing for pregnant women.

Without such services, women will not be able to make an informed choice about whether or not to breast-feed their children. Through counseling, both women and men of reproductive age can be informed of the implications of their HIV status for the health and welfare of their children. Women who are aware of their HIV-positive status need the best available information on the risk of HIV transmission through breast-feeding and on the risks and possible advantages of other methods of infant feeding. And women who are HIV-negative need to know that if they become infected after they begin breast-feeding, they are at heightened risk of passing on the virus in their breast milk because of the high concentrations of HIV in a person's blood early in infection.

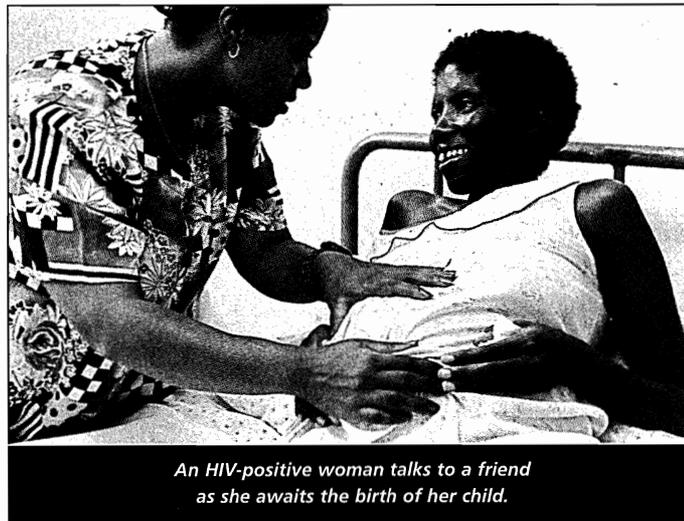
Unanswered Questions In the search for more effective and feasible ways of preventing mother-to-child transmission of HIV, many questions remain. Little is known about the interaction between short-course AZT treatment and breast-feeding, the potential of more affordable alternatives to AZT and bottle-feeding, or the impact of the fear of maternal-child transmission.

As efforts to expand access to short-course therapy begin, there is some concern that this drug regimen may actually increase the amount of HIV in a person's system during breast-feeding, reducing its efficacy in breast-feeding populations. This concern is based on observations of a rebound effect on viral load in some adults after they stop taking AZT and on the fact that short-course therapy ends just before breast-feeding begins.

Continuing AZT treatment during the breast-feeding period might reduce the risk of HIV transmission through breast milk, but no research has examined this question. If AZT was found to have a protective effect during breast-feeding, it would increase the rationale for countries to expand access to the drug for HIV-positive pregnant women. Otherwise, HIV transmission through breast-feeding will weaken the effect of AZT on child mortality.

Research is also needed to assess more affordable and feasible ways of preventing mother-to-child HIV transmission. For example, little is known about promising options for reducing the risk of HIV transmission through breast milk, such as adding Vitamin A to the diets of HIV-positive mothers and treating other maternal infections.

Even less is known about the psychological, sociological and possibly even immunological impact of the choices HIV-positive mothers must make. We do not know how the fear of infecting a young infant through breast-feeding—a practice with deep cultural, emotional and psychological roots that is universal in many countries—



An HIV-positive woman talks to a friend as she awaits the birth of her child.

GISELE WULFSOHN/PANOS PICTURES

affects women, families and society. We also do not know what toll the fear of infecting an unborn child takes on women and their families, particularly in cultures where children are highly valued and a woman's identity is closely associated with child-

bearing. These fears may play a role not only in decisions about treatment or infant feeding, but also in HIV transmission itself.

Protecting Women and Children Two interventions have been shown to reduce the risk of mother-to-child transmission: antiretroviral therapy for HIV-positive pregnant women and alternatives to breast-feeding. Another important—and often overlooked—option is primary prevention, or prevention of HIV in women of childbearing age.

The role of primary prevention in preventing HIV in children adds urgency to the need for policies and programs to reduce women's vulnerability to HIV. Practical measures to prevent HIV infection in women and men should include providing information about HIV/AIDS and its prevention, promoting safer sex and ensuring access to reproductive health services that include family planning and treatment for sexually transmitted infections.

It is encouraging that effective methods to limit mother-child transmission have been identified, but discouraging that, for the most part, they are too complicated and costly for universal use in the countries where they are most needed. Further research to answer the many unanswered questions and to develop simpler approaches is critical. Meanwhile, the most effective mechanism we have to prevent mother-to-child transmission remains prevention of the initial HIV infection in women. □

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AIDSCAP PROJECT PUBLICATIONS

The following publications, published at the end of the AIDS Control and Prevention (AIDSCAP) Project (1991-1997), are available from FHI's HIV/AIDS Prevention and Care Department:

AIDS Control and Prevention Project Final Report This two-volume report highlights the accomplishments and results of the world's largest international HIV/AIDS prevention effort. Volume I contains detailed information about AIDSCAP regional programs and the technical and program strategies used to support them. Volume 2 contains summaries of individual country programs and activities.

HIV Risk Behavioral Surveillance Surveys (BSS): Methodology and Issues in Monitoring HIV Risk Behaviors This report summarizes the recommendations from an international workshop, "HIV Risk Behavioral Surveillance: Country Lessons, Lessons Learned, and Recommendations for the Future," held in Bangkok, Thailand, August 11-14, 1997.

The Female Condom: From Research to the Marketplace This report presents consensus recommendations from a two-day conference held May 1-2, 1997, in Arlington, Virginia, to develop strategies for making female condoms available to women worldwide.

SPECIAL REPORTS

Making Prevention Work: Global Lessons Learned from the AIDS Control and Prevention (AIDSCAP) Project, 1991-1997 This report presents AIDSCAP lessons learned in the areas of behavior change communication, sexually transmitted disease prevention and treatment, condom social marketing, policy development, behavioral research, program evaluation and capacity building. It also describes the project's experience in building gender-sensitive initiatives, integrating care and support into HIV/AIDS programs, and targeting mobile populations for HIV/AIDS prevention.

Meeting the Challenge of the HIV/AIDS Epidemic in the Dominican Republic. The AIDSCAP Response, 1992-1997 This special report shares the accomplishments and lessons learned of the AIDSCAP program in the Dominican Republic, which reached and influenced thousands of people in the workplace, adolescents, young adults, women, and men who have sex with men.

The Tanzania AIDS Project: Building Capacity, Saving Lives. The AIDSCAP Response, 1993-1997 This special report describes the accomplishments and lessons learned of the Tanzania AIDS Project and presents its unique "cluster" strategy as a global model for HIV prevention programming in resource-poor settings.

BCC HANDBOOKS

HIV/AIDS Care and Support Projects: Using Behavior Change Communication Techniques to Design and Implement Care and Support Projects This handbook outlines how to design care and support interventions, select target audiences and use effective communication approaches. It also addresses confidentiality and supporting people living with HIV/AIDS.

Policy and Advocacy in HIV/AIDS Prevention: Strategies for Enhancing Prevention Interventions Written for program managers and policy advocates of HIV prevention, this handbook offers suggestions for making policy an effective component of HIV/AIDS programming.

Partnership with the Media: Working with the Media for HIV/AIDS Prevention This handbook provides readers with a strategy and practical suggestions for forming a long-lasting partnership with the media to inform people about HIV/AIDS and its prevention. Available in English and French.

SYNOPSIS SERIES

Regional Accomplishments and Lessons Learned This booklet discusses the accomplishments and lessons learned of AIDSCAP's HIV/AIDS prevention programs in Latin America and the Caribbean.

Capacity Building This booklet provides a theoretical framework and practical strategies for enhancing the ability of individ-

uals, organizations and institutions to design, manage, evaluate and sustain HIV/AIDS prevention programs.

Civil-Military Collaboration

This booklet introduces key issues in civil-military collaboration for HIV/AIDS prevention and provides suggestions for integrated prevention planning.

Religious-Based Initiatives

A collaborative production of AIDSCAP's Latin America and Caribbean Regional Office and MAP International, this booklet outlines strategies for collaboration between religious and health organizations on HIV/AIDS prevention and describes model interventions in Latin America, where religious-based initiatives are filling a strategic niche in HIV/AIDS programming.

Other booklets in the Synopsis Series include **Gender-Sensitive Initiatives, The HIV/AIDS Multidimensional Model, Behavioral Research and STD Syndromic Management.**

Ordering Information

All publications are in English unless otherwise specified. Single copies are available free of charge. Organizations from industrialized countries are asked to pay shipping charges (please include a DHL or Federal Express account number with your request). To order these publications, contact Information Programs, Family Health International, 2101 Wilson Boulevard, Suite 700, Arlington, Virginia 22201, USA. Phone: (703) 516-9779; Fax: (703) 516-9781.

OTHER RESOURCES

Positive Development

Healthlink Worldwide (formerly AHRTAG). This 144-page manual was developed by and for people living with HIV/AIDS to increase the confidence and skills of those wishing to establish self-help groups to advocate change. It contains step-by-step instructions, training exercises and case studies addressing important topics such as project development, fundraising, working with the media and campaigning. The manual also lists additional resources and organizations that can offer more information. Single copies are free to indigenous organizations in developing countries with no access to Sterling or U.S. dollar currencies. For others the cost is 15 pounds or U.S.\$30, which includes postage. Contact Healthlink Worldwide at Farringdon Point, 29-35 Farringdon Road, London EC1M 3JB, United Kingdom. Fax: (44 171) 242-0041; e-mail: publications@healthlink.org.uk.

AVERT: A Tool for Estimating Intervention Effects on the Reduction of HIV

Transmission Family Health International. AVERT is a computer program designed to estimate the impact of prevention interventions on HIV transmission. The estimates of HIV infections averted that it produces can also be used to carry out cost-effectiveness analyses of intervention programs that were tailored for specific target populations in defined epidemiological settings. The program is easy to use: with only a brief intro-

duction, a computer-literate user with some background in epidemiology can learn to operate AVERT within about an hour. The manual accompanying the AVERT software includes complete instructions for operation and a tutorial with practical examples of applications. Computer requirements: IBM-compatible PC with DOS 3.1 or higher (or equivalent OS) and 1.6MB disk space. To receive a free copy of the AVERT program and manual, contact Dr. Thomas Rehle at Family Health International, HIV/AIDS Prevention and Care Department, 2101 Wilson Boulevard, Suite 700, Arlington, VA 22201, USA. Fax: (703) 516-9781; e-mail: trehle@fhi.org.

Care and Support for People with HIV/AIDS in Resource-Poor Settings

Department for International Development (DFID). This 192-page publication, part of DFID's series on sexual health and health care, helps planners and policymakers identify strategies for HIV/AIDS care and support activities that maximize limited financial and human resources. The monograph is also useful for individuals who need basic information about HIV/AIDS care and support issues, including cost-effectiveness analysis, gender, and health sector reform. To request a copy, contact International Family Health, Parchment House, 13 Northburgh Street, London EC1V OAH, United Kingdom. Tel: (44 171) 336-6677; Fax: (44 171) 336-6688; e-mail: infor@ifh.org.uk.

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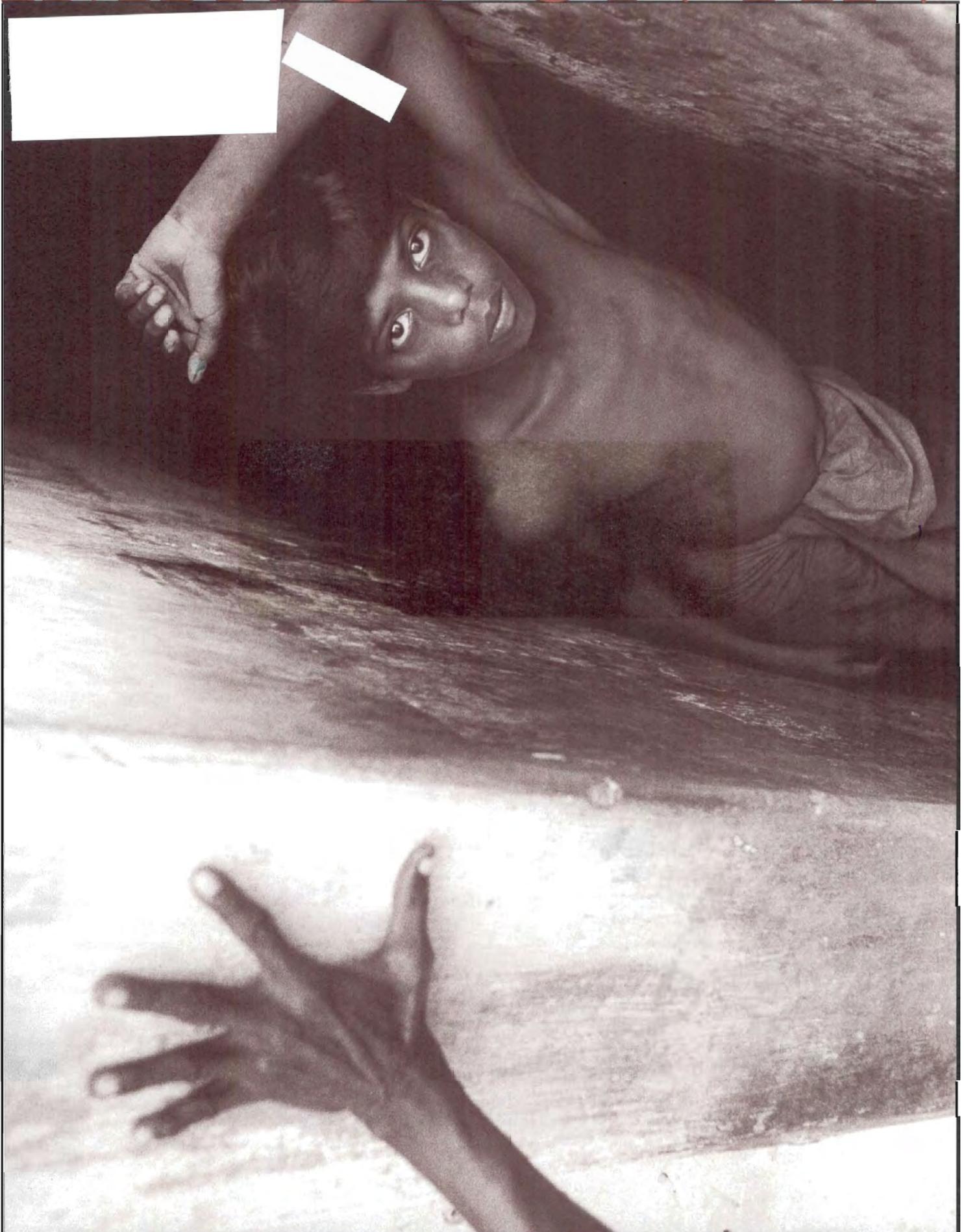
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Cooperative Agreement HRM-A-00-97-00017-00



Breast-Feeding and HIV

Recently published studies from sub-Saharan Africa suggest that early weaning could reduce some, but not all, mother-to-child transmission of HIV through breast-feeding and that combining breast-feeding with formula-feeding may carry a higher risk of such "vertical" transmission than exclusive breast-feeding.

The findings of the first study, conducted in Malawi among 672 infants born to HIV-positive mothers, contradict the hypothesis that most HIV transmission through breast-feeding occurs during the first few months of an infant's life. "The HIV transmission risk due to breast-feeding was highest in the early months of life, but remained substantial for as long as an infant continued to breast-feed," the researchers wrote in the August 24, 1999, issue of the *Journal of the American Medical Association (JAMA)*.

They found that an HIV-negative infant, breast-fed by an HIV-positive mother for 23 months, had at least a 10 percent risk of becoming infected with HIV. From one month to the end of the fifth month, the infection rate was 3.5 percent. After that, the cumulative infection rate was 7 percent at 11 months, 8.9 percent at 17 months, and 10.3 at the end of 23 months.

Another study, conducted among 549 infants born to HIV-positive mothers in Durban, South Africa, examined the impact of different feeding practices on vertical transmission. At three months of age, 18.8 percent of the infants who had never been breast-fed were infected with HIV, compared to 21.3 percent of the breast-fed babies. Of

those breast-fed children, however, 24.1 percent who received both breast milk and formula became infected, while only 14.6 percent who were exclusively breast-fed acquired HIV from their mothers.

"Our results do not accord with the conventional wisdom because they suggest that the vertical transmission of HIV-1 through breast milk is dependent of the pattern of breast-feeding and not simply on all breast-feeding," the authors write in the August 7, 1999, issue of *The Lancet*. "Exclusive breast-feeding carries a significantly lower risk (almost half the risk) of mother-to-child transmission of HIV-1 than mixed feeding."

In an editorial accompanying the *JAMA* article, Dr. Mary Glenn Fowler of the U.S. Centers for Disease Control and Prevention and colleagues note that additional research is underway examining transmission of HIV to infants via breast milk and evaluating the use of breast milk substitutes. "Until these results are available, any HIV-infected women in resource-poor settings will be faced with the difficult dilemma of making choices regarding breast-feeding with only very limited information," they write.

The authors of the Malawi study emphasized that breast-feeding recommendations for HIV-positive mothers must balance the risk of HIV transmission against the many health benefits of breast-feeding. "Recommendations may be most usefully made at the level of the individual mother, because communities in developing countries include women from various socioeconomic strata who have different access to safe breast milk alternatives," they conclude in *JAMA*.

HIV/AIDS Funding

New Funds Proposed

Spurred by the recommendations from a fact-finding mission to sub-Saharan Africa, the Clinton Administration is asking the U.S. Congress to almost double funding for international HIV/AIDS prevention and care next year. This record increase of US\$100 million would bring the U.S. international HIV/AIDS budget to \$225 million for fiscal year 2000.

The additional investment is recommended in a report on the HIV/AIDS crisis in Africa by the Office of National AIDS Policy released July 19, 1999. The result of a presidential mission to Zambia, Uganda and South Africa led by National AIDS Policy Office Director Sandra Thurman from March 27 to April 5, 1999, the report also describes the extent of HIV/AIDS in Africa, examines the social and economic impact of the pandemic, and identifies effective approaches to HIV/AIDS prevention and care.

If approved by Congress, the funding would be used for several initiatives to reduce the spread of HIV and mitigate its impact worldwide. The Clinton Administration proposes spending \$48 million of the money on prevention and stigma-reduction strategies; \$23 million on community-based care and support for people living with HIV/AIDS; \$10 million to assist families and communities in caring for children affected by HIV/AIDS; and \$19 million to strengthen local capacity to plan and implement effective prevention and care interventions.

Global Response Lags

The U.S. proposal comes shortly after publication of a report showing that global spending on HIV/AIDS efforts

is vastly outpaced by the pandemic, with wealthy nations allocating less than 1 percent of their annual official development assistance budgets to HIV/AIDS programs in non-industrialized nations.

This report outlines the findings of a study, prepared by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the François-Xavier Bagnoud Center for Health and Human Rights at the Harvard School of Public Health, of spending on HIV/AIDS prevention and care in the countries most affected by the pandemic. It includes an analysis of donor funding and governments' own contributions to national AIDS programs in 64 resource-constrained countries in 1996 and 1997.

The study found that while the number of people living with HIV/AIDS more than tripled from 1990 to 1997—soaring from about 9.8 million to 30.3 million—funding for HIV/AIDS prevention and care rose by only \$108 million, to \$273 million.

"Twenty years into the epidemic, it's alarming that AIDS is expanding three times faster than the funding to control it," said Dr. Peter Piot, UNAIDS executive director.

Among industrialized countries, the United States is the largest supporter of international HIV/AIDS programs, contributing \$135.2 million in 1997. When donor funding for HIV/AIDS is broken down as a proportion of gross national product, Norway and the Netherlands rank first and second.

The 64 countries surveyed reported spending a total of \$548.5 million on HIV/AIDS. However, nearly \$280 million of that total was reported by Brazil and Thailand.

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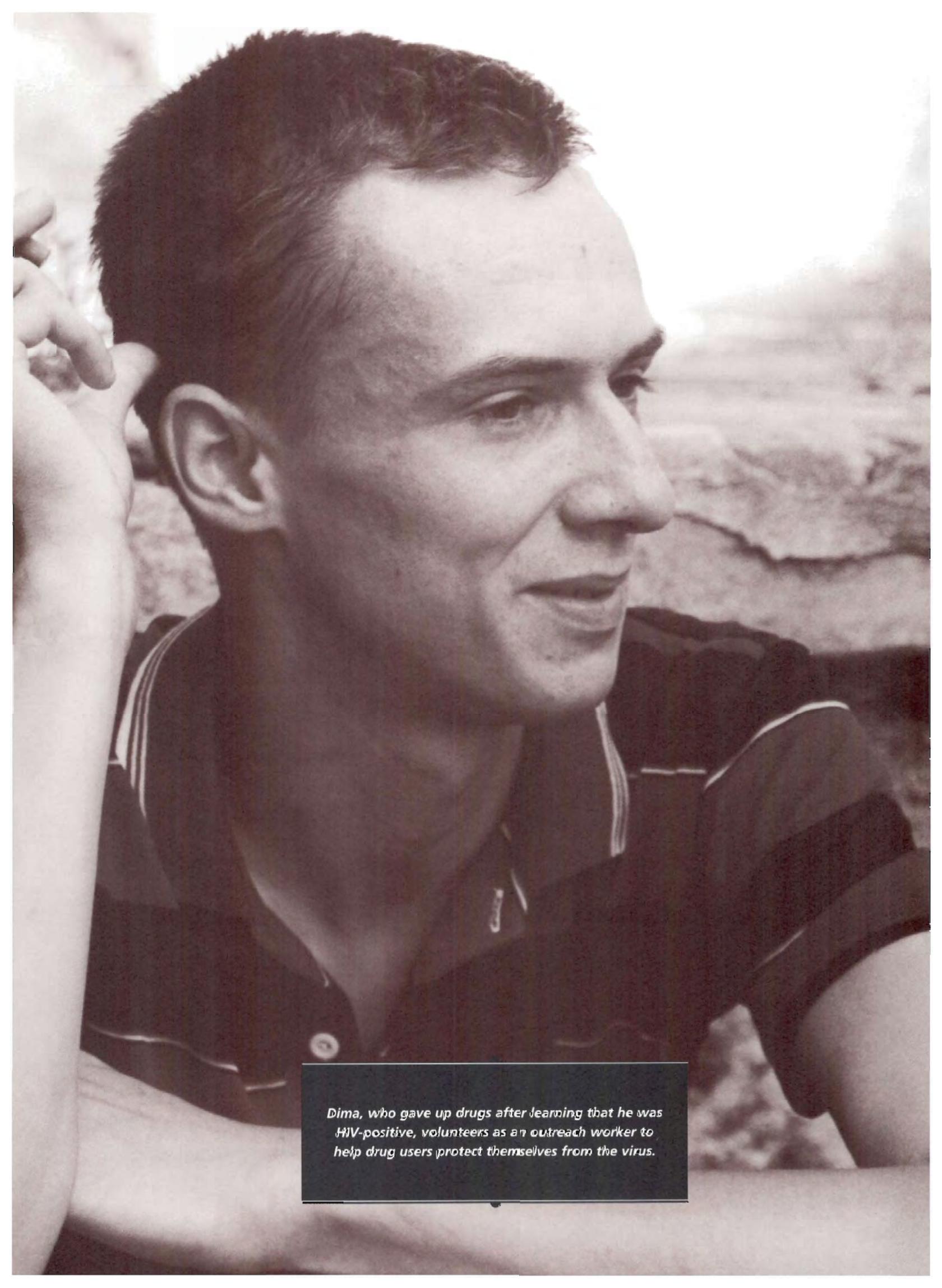
STEPHEN GILL/PANOS PICTURES

Cover photo: Raja, a Sri Lankan boy trapped in the employ of a sex broker.

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Dima, who gave up drugs after learning that he was HIV-positive, volunteers as an outreach worker to help drug users protect themselves from the virus.

HIV and Drug Users in Ukraine: Building Confidence to Reduce HIV Risk

BY LILY HYDE

After gaining the trust of many of society's "marginal people," an NGO refines its methods to promote changes in the drug injecting practices and sexual behaviors that fuel an explosive HIV/AIDS epidemic in Mykolaiv, Ukraine.

Mykolaiv's nighttime streets are pitch-black beneath a thick canopy of trees—the town council cannot afford street lighting. Neon-lit bars for the newly rich “new Ukrainians” make islands of light between which cars cruise slowly, sometimes stopping to pick up one of the 150-odd girls and women who work Lenin Prospekt in the city's center.

Some of the sex workers are students earning money for their tuition, but the majority are unemployed. Many are single mothers, and virtually all are addicted to poppy straw, a cheap heroin substitute that Ukrainian drug users make at home and inject.

“Only about ten girls here don't shoot up,” says Lilya, a thin, febrile woman in her thirties. “We use drugs just so we can stand here.”

Lilya says she has been an injecting drug user since the mid-1980s, when the town, otherwise famous for its shipyards, began to get a name in the Soviet Union for drugs.

“In Mykolaiv 15 years ago, it was fashionable,” she explains. “Nearly everyone injected. Now lots of them have died. Of drugs, of illness, collapsed veins.” Her husband is one of those who died, leaving her with an 11-year-old son to support.

“AIDS only appeared here two or three years ago—earlier we never heard anything about it,” she continues. “It was in the West that you had it already for a long time. Here, everything was quiet. Of course I'm afraid of it, I'm afraid of everything. But fear doesn't bring me anything. All the same, I have to make money.”

Drug-addled, running a temperature and sporting a black eye from a recent run-in with some drunks, Lilya seems beyond help. But in fact, she and others like her are the focus of outreach efforts by a nongovernmental organization based in Mykolaiv. This NGO, Blagodiynist (Charity Foundation), has been working with drug users and sex workers for more than a year to encourage safer behavior and thus slow the rapid spread of HIV.

An Explosive Epidemic Mykolaiv's first official case of HIV was

registered in 1994. A year later, more than 700 infections had been reported. By April 1999, that number had jumped to 1,683 HIV-positive people—77 of them ill with AIDS.

Thousands more HIV infections go unrecorded. HIV—spread through shared needles and the widespread practice of preparing poppy straw by boiling it, sometimes with blood added as a cleaning agent, in a common pot—is thought to have infected an estimated 80 percent of the town's injecting drug users. Nationwide, 70 percent of the more than 40,000 HIV cases in Ukraine are attributed to injecting drug use—a fairly typical proportion in the former Soviet republics of eastern Europe.

HIV has already started to spread outside the drug-taking community in Ukraine. According to Dr. Irina Petrovskaya, a physician from Mykolaiv's AIDS center, 99 percent of Mykolaiv's HIV and AIDS cases in 1998 were in drug users who had become infected through shared needles. That proportion has now dropped to 80 percent, with the rest infected through sexual contact or mother-to-child transmission.

Although Ukraine has the fastest-growing rates of HIV and AIDS in Europe, the country has no national AIDS program. The government even dissolved the National Committee for AIDS Prevention at the beginning of 1999. The response to the epidemic has been left to dedicated individuals like the group of Mykolaiv physicians and psychologists who founded Blagodiynist.

Reducing Harm Drug taking has lost much of the trendiness that distinguished it in Mykolaiv in the 1980s, when drug users had their own style of dress called *strogaya moda*—strict fashion. These days drug users are more impoverished and less tolerated, yet their numbers are higher than ever, and they are starting younger. Officially this town of 500,000 has 4,000 drug users. Unofficially, add a zero to get the real number. Natives, with a kind of dreary pride, call it the city of drug addicts.

"Mykolaiv has always had a special atmosphere," explained Alina, a drug user who turned to sex work to support her habit and her little daughter. "If you go away from Mykolaiv to another town, you can have a normal way of life. But as soon as you come back to Mykolaiv, anyone who has tried drugs will immediately take up their old life again."

Blagodiynist, in association with the municipal and regional social services for youth, organizes drugs prevention events for the town's young people, such as discos and concerts. Groups of volunteer student psychologists and teachers give regular lectures in schools. But the NGO members recognize that drug prevention programs are much slower and less successful than the spread of the AIDS virus. In a desperate race against a relentless epidemic, they have turned to an approach commonly known as harm reduction. This approach focuses on reducing HIV transmission by encouraging drug users to use safer injecting techniques and condoms while working gradually to reduce or eliminate injecting drug use.

"Whatever we do, there will always be new drug users," said Dr. Petrovskaya. "What's important is that the older drug users don't pass on HIV to the younger ones. New drug users always turn to the older ones, who will pass on their experience, where to buy, how to inject. We'd like the older ones to teach correct usage."

Blagodiynist offers a number of services to drug users, sex workers and their partners. The NGO's members have built good relationships with the city health and social services and can refer people to a surgeon, a sexually transmitted disease (STD) clinic, or the infectious diseases hospital for free health care. Many of its outreach workers, both volunteer and paid, are psychologists who offer free counseling. And in 1999, Blagodiynist began working with Family Health International's Implementing AIDS Prevention and Care (IMPACT) Project, with funding from the U.S. Agency for International Development, to refine its communication strategies and improve its outreach and support services.

The purpose of this collaboration, explained Dr. Joan MacNeil of FHI, is to help the NGO's members learn more about theories of how behavior change occurs and to work with them to translate those theories into effective interventions.

"While enhanced knowledge and awareness of risk are important precursors of behavior change, knowledge in and of itself has never proven to be the chief motivator for change," she said. "Exposure to communication and outreach activities based on theory has been shown to help personalize HIV risk and to develop individuals' confidence in their own ability to change behavior."

A second Blagodiynist project, supported by the New York-based Lindesmith Center and funded by the Open Society Institute, has one stationary point at the infectious diseases hospital and seven mobile units where people can exchange used needles for clean ones and obtain information, advice and condoms. The names of participants are not recorded, but each person who uses these services is given a card with a number so NGO staff can keep track of who comes and how often. Since the project began in 1998, 2,000 cards have been distributed. Up to 75 percent of clients use the exchange regularly.

True stories about people confronting the risk and reality of HIV, told in their own words, can help bring home the threat the virus poses to others in similar circumstances.

Understanding Risk Behavior

The needle-exchange project has played an important role in gaining access to the target group of drug users, winning their confidence and persuading them to read educational materials prepared by the

NGO. Now, says Blagodiynist director Tatyana Vanenkova, drug users come to exchange points especially to collect something to read.

"The main problem is that they have such poor memories," said Vanenkova. "Each time we give out information in a different form so they'll read it and remember."

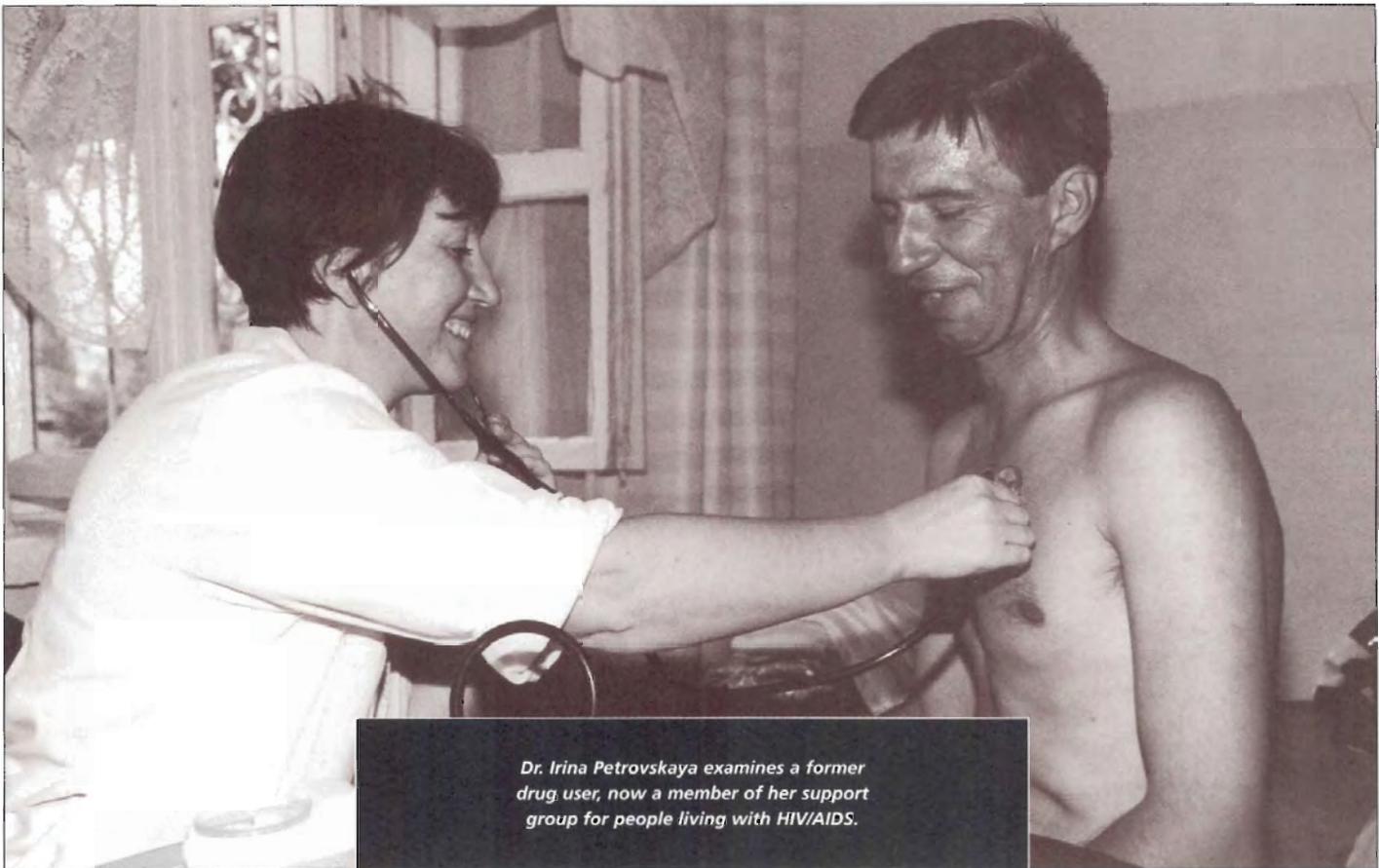
Initially the NGO distributed prevention information on printed sheets of paper, but people simply used the paper to wrap their clean needles, said Vanenkova. Drawing on the experience of harm reduction programs in Ukraine and abroad, Blagodiynist members have started developing both the format and the content of their materials. The NGO now distributes booklets illustrated with photos and pictures instead of plain text and has tried to make the text more compelling to the target groups.

Dr. Nancy Corby, an FHI/IMPACT consultant who has been working with Blagodiynist and the NGO Faith, Hope and Love in Odessa, offered valuable advice on how to use the experience of drug users and sex workers to positively influence their peers.

"People change their behavior gradually over time," said Dr. Corby, who is associate director of the Center for Behavioral Research and Services at California State University. "We need to focus on what they believe about the behavior we are trying to get them to adopt."

Dr. Corby recommended that Blagodiynist try using role-model stories, an approach that has proved effective with drug users, sex workers and their partners in Long Beach, California, and other U.S. cities. True stories about people confronting the risk and reality of HIV, told in their own words, can help bring home the threat the virus poses to others in similar circumstances.

Such stories also offer practical, relevant examples of how to adopt and maintain safer behavior. "Role-model stories show



Dr. Irina Petrovskaya examines a former drug user, now a member of her support group for people living with HIV/AIDS.

people strengthening positive or weakening negative beliefs,” Dr. Corby explained.

Alyona, a 22-year-old sex worker and drug user, agreed that real-life experience was far more valuable than mere preaching. “I knew about the risk of AIDS, but I didn’t think of it happening to me,” she said. “It’s impossible not to know about it, but you don’t need someone to tell you. You need to realize for yourself.”

Alyona was one of the subjects of in-depth interviews NGO staff conducted after participating in an IMPACT-led workshop on qualitative research techniques for a dozen Ukrainian NGOs. The purpose of Blagodiynist’s research was to gain a better understanding of the HIV risk behavior of its target audiences and to explore what approaches might work best with them.

As part of the same research process, Dr. Petrovskaya gathered together eight women ages 18 to 35—all HIV-positive drug users—into a focus group to discuss HIV prevention and to generate real-life role-model stories.

“We talked about all the methods [of HIV transmission], and of course they knew most of them, and they’d say yes, we use condoms. But it turned out they didn’t always use them, maybe with a particular lover or a sponsor,” said Dr. Petrovskaya. “When we got into the nuances of HIV transmission, they began to think more deeply, and they got more active. They started to speak more to who they met, that it’s better to use condoms, better to disinfect needles. It turned out that they very often used the same needles as an HIV-positive person.”

“I knew about the risk of AIDS, but I didn’t think of it happening to me.”

Role Models The stories collected by Blagodiynist are convincingly real. They clearly show a target group where rules for safe sexual behavior and drug-use are half-known, and often not followed.

One sex worker, despite knowing the importance of condom use, nevertheless agreed to have sex without one with a client who paid her only an extra 5 Hryvnas for the privilege—about \$1. She details her terror and anger at herself as she awaits the results of an AIDS test.

Another drug user explains how he and his friend thought they used drugs safely by collecting poppy straw from a pot with sterilized needles and then sterilizing the dose itself by boiling it in a spoon. Nevertheless, the man’s friend was diagnosed with HIV. After boiling the dose to disinfect it, the two men had injected it with the same needle they had originally used to collect the drug from the common pot.

“So it turned out all our disinfecting was for nothing, because all the same [my friend] Zhenka got HIV,” said the man, whose own test came back negative. “Now I do everything right and definitely disinfect needles. And I say to all my friends, that if they don’t prepare the dose themselves but buy it, they have to do everything carefully because you just don’t know who has put their needles into the pot.”

Blagodiynist uses the role-model examples to encourage and support continued behavior change. This support, along with individuals’ own experience with safer behaviors, is designed to generate the self-confidence people need to refuse sex without a condom or to spend that little bit less on drugs so they can buy clean needles.

“Now I always think, ‘That I’m a street walker means nothing, all the same I should take care of myself,’ ” said the woman who agreed to have sex without a condom. Her assertion of self-worth is a natural result of adopting safer behavior, Dr. Corby believes.

“Self-esteem is something that comes as a result of behavior change: ‘I have power over myself,’ ” she said.

Building Trust Dima, 26, who was diagnosed with HIV in 1996, is an example of that metamorphosis. He is a member of Dr. Petrovskaya’s support group for HIV-positive people who have, at least temporarily, given up drugs. He also works for Blagodiynist as a volunteer.

When Dr. Petrovskaya initially invited him to volunteer, Dima was worried that working with drug users would be an inducement to return to drug taking, which he gave up in 1996 after finding out he was HIV positive.

“At first I felt like it was provocation—I was scared to get into that circle of people,” he said. “But now it’s all right. It doesn’t provoke me now.”

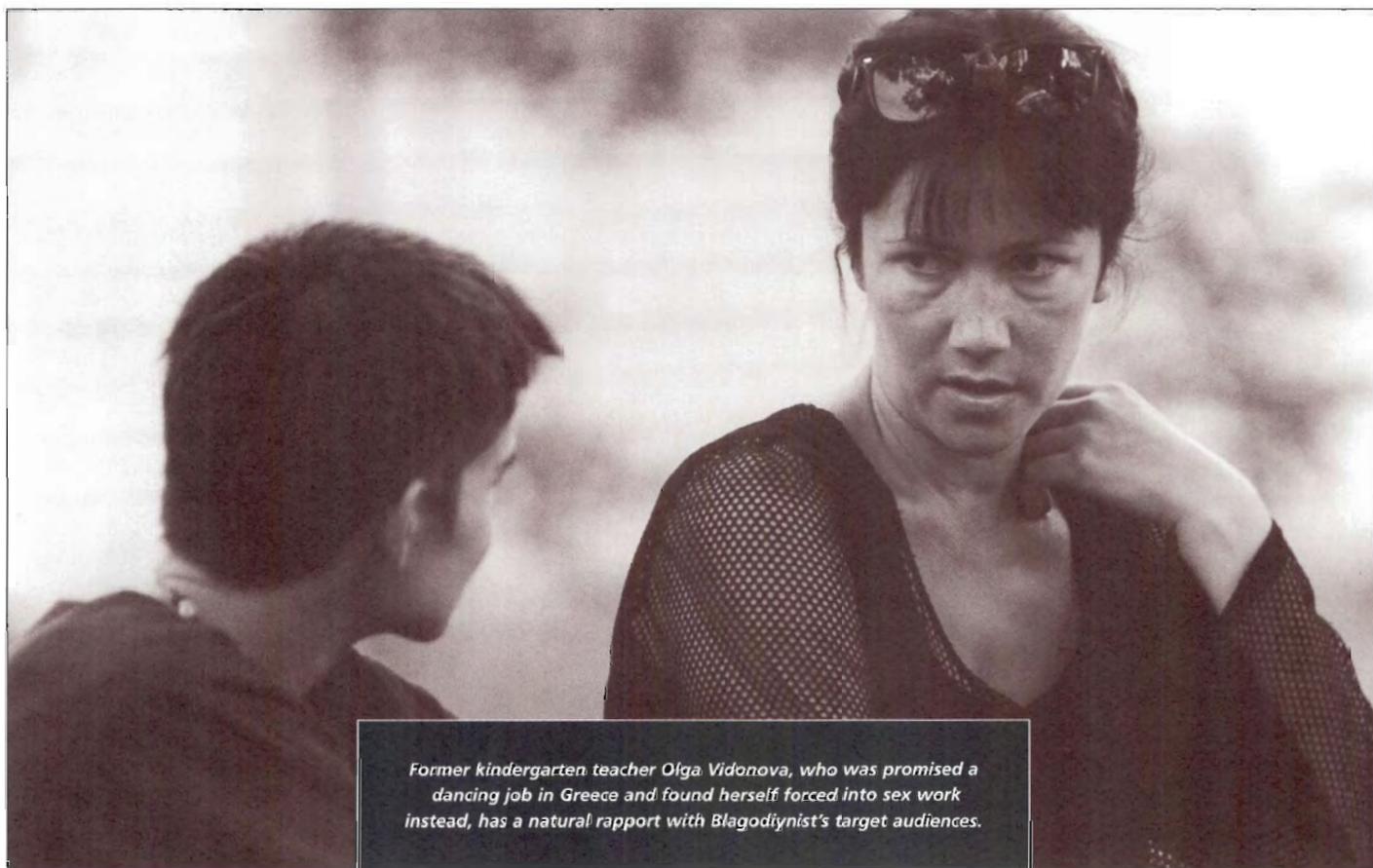
Blagodiynist has been hugely successful in building up trust between project members and target groups. Sex workers and drug users greet the volunteers with familiarity and even affection.

“We’re not afraid of [the organization], on the contrary, it’s pleasant to talk with them,” said Diana, a 24-year-old drug user and sex worker on the highway just outside Mykolaiiv. “They are the only ones who understand drug addicts and prostitutes. They don’t regard us as the dregs of society.”

Although the drug user and sex worker groups largely overlap, reaching the sex workers posed more of a challenge because police harassment made them wary of strangers. When the NGO was making initial contact, women complained that one of their number who had been seen talking to an outreach worker was later arrested.

The NGO made real inroads only after it started working with Olga Vidonova, a former kindergarten teacher who underwent a traumatic experience in Greece when the dancing job she had been promised turned out to be forced sex work. She has been able to turn her experience to some good with Mykolaiiv’s sex workers.

“Self-esteem is something that comes as a result of behavior change: ‘I have power over myself.’ ”



Former kindergarten teacher Olga Vidonova, who was promised a dancing job in Greece and found herself forced into sex work instead, has a natural rapport with Blagodiynist’s target audiences.

"They know that I'm like them and they talk freely," she said simply. "I ask them if they've got work, are there clients. We talk about ourselves, then I tell them, you know, there is this project. We get to know each other and they are not so scared, not so wary."

Vidonova's work takes her regularly onto the dark streets at night. She doesn't just offer advice and dole out condoms. When she sees a sex worker surrounded by three men, she immediately goes to her rescue. The sex worker loses her (empty) purse to the three would-be Mafia men who take protection money without giving protection. But if Vidonova had not interfered, she says, the girl would have been beaten up.

It's an attitude like this that has won the women over. But while most of them will now willingly talk and read the information, most are far from forming the safe habits that Blagodiynist wants to instill. Even if they know they should always use condoms, turning down clients who do not want to use one is something many do not yet have the confidence to do.

"It often happens that clients don't want to use condoms," said Diana. "I practically won't do the sexual act without a condom—but sometimes they say no, without. Girls agree, of course. They're afraid. What can they do if the clients don't want to?"

Reaching the clients to overcome a common dislike of condoms is something that can only be done via the sex workers, Vanenkova said. Prostitution is tolerated but illegal, and the moral stigma it carries is strong, so identifying clients as a group is a delicate job. And although the NGO's education and prevention work has attracted the attention of some clients, members said that 99 percent of the population, outside the risk groups of sex workers and drug users, simply walk away when they hear the word AIDS.

"Practically, it starts with the girls," said Vanenkova. "Now when we talk to the girls, they say in principle the clients are already more informed. They bring condoms themselves and use them. Of course there are cases where the client doesn't want to use one and agrees to pay not to use one."

Despite these obstacles, Vanenkova adds, the sex workers are motivated to avoid HIV. "The girls are themselves afraid. If one of the guys knows he was infected by a girl, it will be really hard for her. So the girls have a strong interest in protecting themselves."

Challenges Ahead However successful is Blagodiynist's outreach to its target groups, the NGO still faces the frustration of how to



Surgeon Igor Gavrilishin treats Sveta at the infectious diseases hospital. Sveta started using drugs only about a year ago to help ease the pain from a blood clot in her leg.

reach wider groups: sex workers' clients and their other sex partners, drug users' partners, and beyond that to the police, medical staff and government officials, all of whom are instrumental in checking the spread of HIV. While members of the target groups have already begun to take to

heart the risk of HIV infection, the rest of the population still think the epidemic is not their problem.

Things have improved since Dima tested HIV-positive in 1996, when, despite the supposed anonymity of AIDS testing, medical staff leaked the news to his relatives and his workplace. He lost his job and was told to go work as a security guard so he would not have contact with others. At home, his parents gave him a separate place to sit and his own cup and plate.

Now, thanks to the work of Blagodiynist, the AIDS center and the social services for youth, Dima's parents and others are more informed. But as the epidemic spreads, facilities for monitoring the disease are failing drastically. Although by law AIDS testing is free and anonymous, in practice there is such a shortage of test kits that Mykolaiv's AIDS center is forced to charge. With the concomitant drop in the number of people being tested, 1999 figures in Mykolaiv probably do not accurately reflect the real number of new HIV cases.

Even when people know that they are HIV-positive, expensive antiretroviral therapy is almost unheard of in Ukraine. In Mykolaiv, most drug users living with HIV do not live long. Since 1994, there have been about 40

deaths of diagnosed AIDS. But according to Dr. Petrovskaya, many more deaths from tuberculosis, hepatitis and STDs were probably hastened by AIDS.

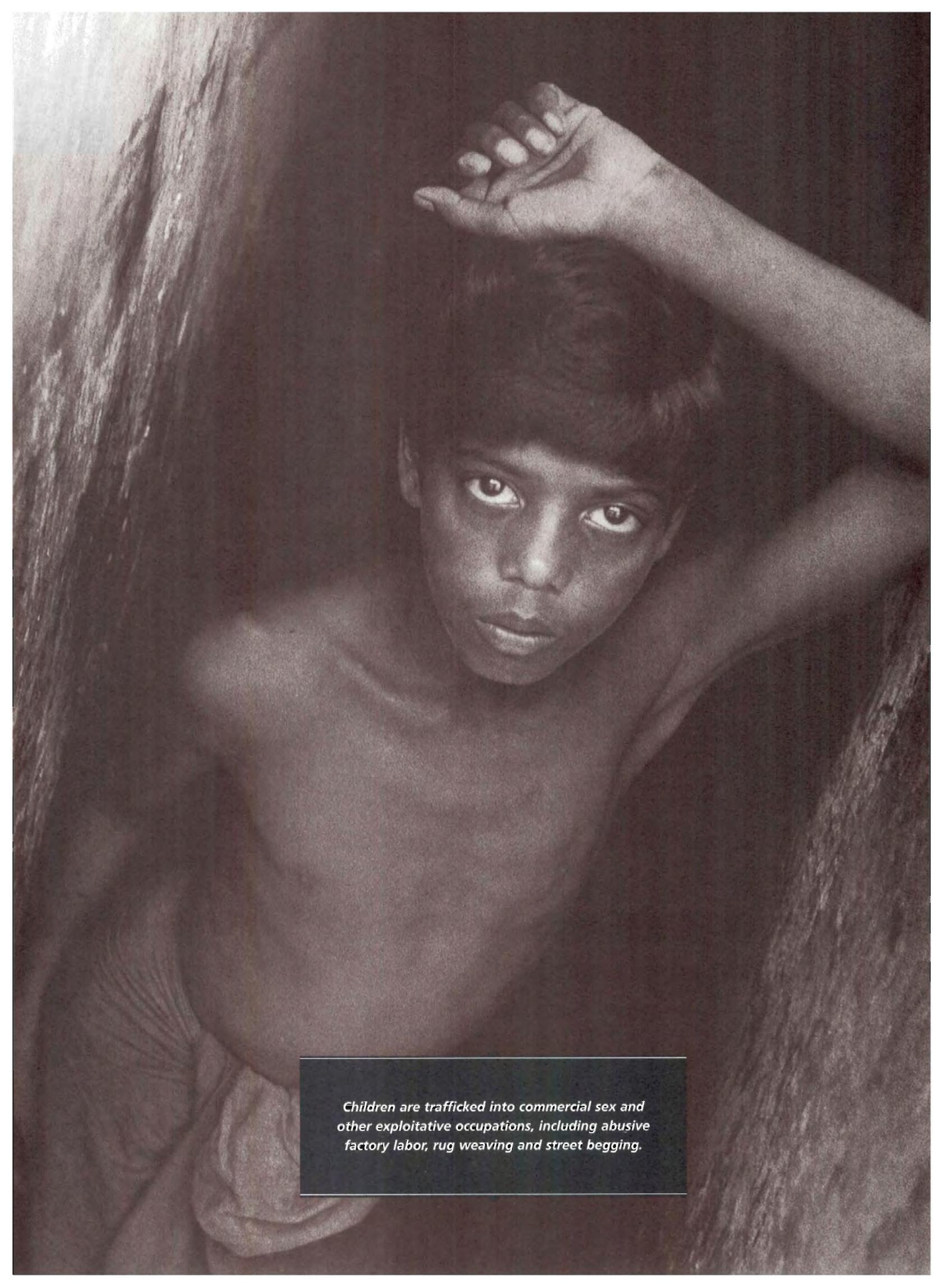
"Active drug users started to die more and more from the second half of 1997," she said. "Now we're expecting a flood of AIDS deaths."

That makes Petrovskaya's job all the harder, considering her oft-repeated litany that "you have to love these people." She clearly does. Every day, she and her fellow members of Blagodiynist show people living at society's margins that someone cares about them.

"Lots of girls ask what [the project] is, where it's from, who's paying, who needs it," said Vidonova. "They can't understand. They say, 'Who needs us? We're drug addicts, we're finished people.' And they come to us again, just to talk on a normal, human level." ▀

LILY HYDE IS A FREELANCE JOURNALIST BASED IN KIEV, UKRAINE.

"They don't regard us as the dregs of society."



Children are trafficked into commercial sex and other exploitative occupations, including abusive factory labor, rug weaving and street begging.

Preventing Trafficking in Women and Children in Asia: Issues and Options

BY TONY BENNETT

Increasing concern about violence against women and the role of commercial sex in HIV epidemics has led to high-profile efforts to understand the forces that drive trafficking and identify the best options for preventing such exploitation of women and children.

An age-old problem that has plagued almost every society in recorded history, trafficking in women and children is a grim reality of modern life in many countries. Every day, young people striving for a better life for themselves and their families are routinely deceived and exploited to satisfy a demand for cheap goods and services.

In the past, efforts to prevent trafficking have been few and relatively small-scale. Collusion between families and agents, corruption of law enforcement and border officials, and difficulty in knowing when and where transactions take place have all thwarted prevention efforts. Recently, however, growing concern about violence against women worldwide has put trafficking on the international agenda, and its connection with the sex industry that is such a driving force of HIV epidemics has added urgency to global anti-trafficking efforts, particularly in Asia.

With the leadership of Hillary Rodham Clinton and the President's Initiative on Violence Against Women, human trafficking is also receiving greater attention in Washington. The departments of Justice, Labor, State, and Health and Human Services, the U.S. Information Agency (USIA) and the U.S. Agency for International Development (USAID) are joining forces against what is seen as a worsening problem with ramifications for the United States as well as nonindustrialized countries. Recent exposés of Thai and Latino workers in southern California sweatshops and of trafficked labor in the Northern Mariana Islands, a U.S. commonwealth,¹ are testimony to the fact that trafficking is not just a problem of nonindustrialized countries.

During November 1998 through February 1999, an eight-person, multisectoral team analyzed the problem of trafficking in women and children in Asia through a six-country assessment in Nepal, India, Bangladesh, Philippines, Cambodia and Thailand. Specialists from the U.S. State Department, Department of Justice and USAID combined forces with technical experts in the

areas of gender and development economics, public health and HIV/AIDS to design a strategy for intervention in Asia. Asia is seen as the most vulnerable region for trafficking because of its huge population pyramid, growing urbanization, and renewed poverty in the wake of currency devaluations and recession.

Defining Trafficking Estimates of the number of people trafficked each year vary from tens of thousands to millions. This wide range is hardly surprising given the inherent difficulty of tracking a criminal, clandestine activity, but it is also a result of different definitions of trafficking.

The word trafficking is most often used to describe kidnapping and enslavement of workers—usually women and girls in the commercial sex industry. But some governments and international agencies have adopted a much broader definition of the term. The President's Interagency Council on Women, for example, defines trafficking as:

“All acts involved in the recruitment, transport, harboring or sale of persons within national or across international borders through deception or fraud, coercion or force, or debt bondage for purposes of placing persons in situations of forced labor or services, such as forced prostitution or sexual services, domestic servitude, or other forms of slavery-like practices.”

The definition is deliberately broad, addressing working conditions as well as how a person is recruited. This is because not everyone is abducted or enticed away with false promises of good jobs. Others go willingly, seeing the trafficker's offer as the best option for themselves or their families, but later regret the decision when they find themselves trapped by debt and fear in abusive conditions.

In fact, the number of people who are actually kidnapped and enslaved is believed to represent a small percentage of those who are trafficked. A person who is trafficked may have been pushed



Teenage girls from a Thai hill tribe, liberated from brothels, work on sewing at the New Life Center in Chiang Mai.

HELDUR NETOCNY/PANOS PICTURES

or pulled or—more likely—some combination of the two. These forces are legitimately viewed from both sides of a continuum, with dire poverty and lack of opportunity creating fertile ground for traffickers, while rising aspirations and increasing exposure to mass media lure young people to cities.

Whether someone is “pushed” or “pulled” does not change the fact that she or he has been trafficked. However, an understanding of these factors does influence one’s opinion of where prevention resources should be invested. For example, one popular prevention strategy is to educate families about “evil agents” and procurers who snare vulnerable girls for brothel service. Yet other observers of the relationships between trafficker and traveler paint a more complex picture of such trafficking as often being an important service to poor villagers who need a temporary source of ready cash.²

The Response Anti-trafficking options fall under the three lines of action recommended by the President’s Interagency Council on Women: (1) preventing women and children from being trafficked; (2) protecting and assisting victims of trafficking; and (3) prosecuting traffickers and enforcing laws against trafficking.

A number of programs in Asia have already begun addressing the trafficking problem. Governments are slowly becoming active, but most programs are carried out by nongovernmental organizations (NGOs) in communities. Other NGOs have regional or even global mandates to combat trafficking. Examples of anti-trafficking programs at the community,

national and global levels illustrate the range of responses to the problem and some of the concerns they raise.

Community action In Nepal, a woman’s *maiti* is her parent’s home—the place where she starts out before going to her true home with her husband. The award-winning Maiti Nepal program helps women who have been trafficked to India return to their home country, with re-entry centers at the border where they can prepare to reintegrate into life in their former villages or elsewhere. The program also provides viable occupational alternatives to vulnerable young women before they are trafficked and conducts awareness campaigns in the villages throughout Nepal’s central plains (Terai) region to counter the information provided by

traffickers, agents and other brothel or factory recruiters.

The Maiti Nepal program is based on the overriding assumption that if families and communities knew the true consequences of what happens to girls when they leave home, then trafficking would die out rapidly. Others have questioned whether or not families are indeed aware and are making a calculated risk-benefit choice. Nevertheless, the Maiti program is impressive for the sheer numbers of participants—hundreds each year—and their testimonials of life in the brothels of Mumbai (formerly Bombay), India, which probably have the highest levels of sex worker HIV infection of any large brothel community in Asia.³

National efforts Thailand is more open than many countries about the extent and nature of its role in human trafficking. It is generally recognized that Thailand is both a sending and receiving country of women and children who are trafficked.

Trafficking is not just a problem of nonindustrialized countries.

Chakali's Story: A Nepali Community Learns a Lesson in Tolerance

When Chakali Bal announced that she was going to be married, there were few well-wishers. Even her closest friends expressed more concern than joy.

An outreach worker for General Welfare Pratisthan (GWP), a Nepali nongovernmental organization (NGO) that carries out HIV/AIDS prevention and other social service activities, Chakali was well known in the village of Barsamadhi. People admired her courage in living openly and positively with HIV and her dedication to helping others avoid HIV infection.

But all that changed when she accepted a proposal of marriage from Sukra Badhur Lama, a truck driver's assistant she had met in her work. He loved Chakali, and her HIV-positive status did not deter him—though many in the community thought it should have.

Community outrage exploded during a village meeting shortly after Chakali and Sukra left to be married in another village. With the couple out of sight, the villagers blamed GWP members, who had counseled the couple about consistent condom use after finding that they were determined to marry.

GWP staff responded by doing what they do best—educating community members. The NGO has been working with Family Health International since 1994 to encourage safer sexual behavior among the men who travel Nepal's major highways and their partners in towns and villages along the way.

Mahesh Dev Bhattarai, who founded GWP in 1991 with profits from his family's paper products business, went to visit the village chief. The chief was furious that an HIV-positive woman from his village had dared to marry, but he listened as Mahesh told him how Chakali had become infected with HIV.

She was nine or ten years old when her uncle came to her family's house with an Indian friend. The two men offered her parents 25,000 rupees, or about US\$365—a fortune to a Nepali family living in desperate poverty—and said they would find Chakali a job in India where she could earn enough to send money home.

Her parents did not understand what was happening. Perhaps they did not want to ask too many questions. They needed the money and could not resist the men's offer.

Chakali was taken to a brothel in Bombay (now Mumbai), where the madam lost no time in initiating her to her new life. On her first day, she was pushed into a room where a client was waiting. When she struggled and protested, he raped her. Soon she was seeing four to 15 clients a day.

At first Chakali and the other girls in the brothel knew little about HIV/AIDS. But after one of their friends was turned out of the brothel for being HIV-positive, the girls tried to persuade clients to use condoms. Some agreed, but others refused and complained to the brothel owner.

After six years of virtual imprisonment in a series of brothels,

Chakali and her friends Batuli Majhi and Anita Titung managed to escape by convincing the brothel owner to let them go to the temple on their own. It was during their arduous, month-long journey to Nepal that the girls learned they were HIV-positive through blood tests they were required to take at a government-owned shelter for trafficked girls in India.

"Yes, Chakali is HIV-positive, but who is to be blamed?" Mahesh concluded. "And why should we cause Chakali more disappointment and trouble rather than giving her support?"

Mahesh urged the chief to consider the societal issue of trafficking and HIV rather than the personal one of Chakali's right to marry, pointing out that many Nepali girls are returning from Indian brothels with HIV. He also made the pragmatic argument that marriage makes it easier for an HIV-positive person to practice safer sex with one partner, thus reducing the risk of transmitting the virus to others in the community.

But what seemed to sway the chief was Chakali's own story. Mahesh later learned that one of the chief's own beloved relatives had died after returning from India in the late stages of HIV disease.

With the chief's support, GWP staff members were able to persuade many community members to change their attitudes. Gradually, they accepted the marriage and began to treat Chakali and her husband with respect.

The couple was interviewed for a Young ASIA Television program. Mahesh, who also spoke to the TV reporter, expects his comments to anger many people.

The GWP founder now views such reactions as an opportunity rather than a problem. "While they are angry and vocally active against us, we get real time to interact with them and a chance to clarify many issues related to HIV," he explained.

Chakali told the TV reporter she often wondered why she had ended up in the brothels. "I used to think that maybe I had committed some sin in my previous life, and that was why I was having such a meaningless and sorrowful life this time," she said.

Today, with a loving husband and a job that allows her to help save lives, Chakali finds her life very meaningful.

Mahesh believes this is why Chakali and her friends Batuli and Anita remain healthy, while most HIV-positive Nepalis do not live long. "I believe they are surviving because they are working and they are proud of their work," he said.

—BY KATHLEEN HENRY

GWP IS A PARTNER IN FHI'S HIV/AIDS PREVENTION AND CONTROL PROJECT IN NEPAL, WHICH IS FUNDED BY THE U.S. AGENCY FOR INTERNATIONAL DEVELOPMENT. IN 1998 GWP'S PARENT COMPANY, GET PAPER INDUSTRY, WAS ONE OF FIVE COMPANIES WORLDWIDE TO RECEIVE THE GLOBAL BUSINESS COUNCIL ON HIV/AIDS FIRST INTERNATIONAL AWARDS RECOGNIZING EXEMPLARY BUSINESS RESPONSES TO THE PANDEMIC.

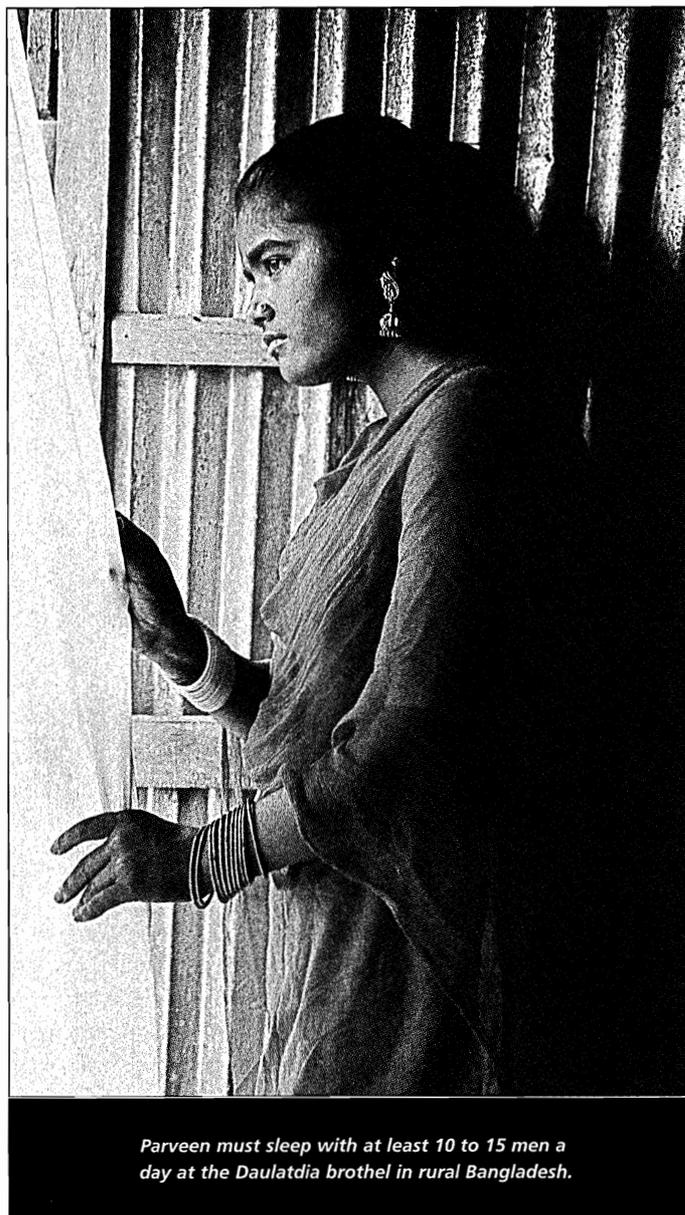
What makes Thailand's response unique is its focus on the source of demand for trafficked services, such as the clients of underage sex workers. Through the lobbying of the National Commission on Women's Affairs (NCWA), Thailand became the first country in the region to pass laws that impose greater penalties on customers than on sellers for involvement in commercial sex with underage partners. Application of the law has been lax so far, but it is a basis for future action. The NCWA is also trying to change male sexual norms through a national poster campaign with messages showing a child saying (with hope) "my father does not visit prostitutes."

These types of demand-reduction initiatives target the exploitation of young women and children and are not intended to eliminate commercial sex altogether. However, some anti-trafficking groups are concerned that demand reduction will have a harmful impact on women who have voluntarily entered prostitution and who depend on their commercial sex income.

Global alliance As indicated by its name, the Global Alliance Against Trafficking in Women (GAATW) takes a global view of the problem of trafficking, with roots in feminist activism. It produces tools and provides training to assist individuals and programs to "empower women rather than treat them as victims." Among its materials include a *Practical Guide to Assisting Trafficked Women* and *Minimum Standard Rules for the Treatment of Trafficked Persons*.

GAATW is careful to point out that its advocacy efforts are not intended to reduce migration or occupational options for women. In their recent comments on the Draft Protocol to Combat International Trafficking of Women and Children, GAATW members and others observed that international anti-trafficking efforts should give equal weight to preventing trafficking, punishing traffickers and protecting the human rights of those who are trafficked.⁴ Some in the anti-trafficking field, however, believe that prostitution in any form is trafficking and should be eliminated.⁵

Supply and Demand Trafficking is driven by both supply and demand. Poverty and gender inequality make it easier for agents



Parveen must sleep with at least 10 to 15 men a day at the Daulatdia brothel in rural Bangladesh.

SHEHZAD NOORANI/WOODFIN CAMP

to procure young women and children, yet it is the buying power of consumers for submissive women and children that makes trafficking lucrative. Where, then, should the emphasis of prevention be placed: intercepting agents, reducing poverty, penalizing consumers, equalizing gender relationships, or other pressure points? The President's Interagency Council plan implicitly addresses these intervention opportunities but does not offer guidance on where the majority of resources should go.

After hearing the stories of young girls sold into virtual slavery in brothels, the natural response is to focus on protecting them. But many believe that local efforts to reduce the vulnerability of women and children, such as poverty alleviation and job training, will have a limited

effect at best on the number of trafficked individuals. As long as demand remains strong, agents and procurers will merely find vulnerable populations from other locations. On the other hand, if vulnerability could be reduced region wide, then traffickers would have fewer opportunities to recruit, and the exploitative labor practices would decrease.

Others advocate aggressively enforcing anti-trafficking laws and prosecuting traffickers. Cracking down on trafficking has proved difficult, in part because of the involvement of organized crime in many countries and the informal systems of bribes to law enforcement and immigration officials in others.

Moreover, approaches that focus on prosecuting traffickers can be harmful to the people they are designed to help. In their comments on the draft anti-trafficking protocol, GAATW and its partners emphasized the need to "ensure that states, in their zeal to punish traffickers, do not inadvertently violate the principle of 'do no harm' to trafficked persons." As an example they cited enforcement efforts that increase the risk of exposure to abuse and further marginalize groups such as migrants and people working in the sex industry.⁴

Some would argue that since trafficking is demand-driven, efforts to reduce demand such as those advocated by the NCWA in Thailand are the most effective approach to the problem.

This approach, however, does nothing to help vulnerable populations directly or to address the conditions that made them susceptible to traffickers.

Trafficking and HIV The trafficking of young women into prostitution has a formidable impact on HIV transmission. Studies have shown that brothel sex workers are most likely to become infected during the first six months of work, when they probably have the least bargaining power and therefore have more customers and fewer customers who use condoms.⁶

With the increased prevalence of HIV/AIDS in Asia, some agencies say there is a greater demand for virginal sex workers, who are perceived to be a low risk. Ironically, though, it is the newly trafficked woman or child who is at greatest risk of rapidly becoming infected with HIV and then being more highly infectious during the first few months of work.

Conceivably, trafficking into other occupations such as street begging and factory work could increase vulnerability to HIV by heightening the risk of coercive sex and drug use. The direct link between these occupations and HIV, however, has not been well documented.

What is clear is that the anti-trafficking and HIV prevention programs could combine resources in an active partnership to reduce the number of young women and men entering brothel prostitution and to help those already trafficked stay as healthy as possible until they can be safely removed and reintegrated into their communities of choice.

Next Steps Trafficking is a microcosm of many of the complex social issues facing global society today, including gender disparities, economic inequality, migrants' rights and cultural imperialism. This makes thoughtful discussion of the issues and the needed response difficult.

The discussion of trafficking in Asia is dominated by issues of commercial sex. Yet the anti-trafficking agencies recognize that women and children are coerced, tricked or bonded into occupations and situations other than prostitution. Of notable concern include trafficking into abusive factory labor, rug weaving, street-begging cartels, domestic work and arranged marriage.

This variety presents another dilemma to anti-trafficking programs: given limited resources, how does one prioritize interventions? The International Labor Organization has developed a system whereby work sites can be quantitatively evaluated, scored and classified into more extreme and less extreme labor. Similarly, within the group of occupations that are supplied by trafficked labor, some hierarchy of violence against women and children is

needed to help decision makers allocate prevention resources.

One obvious criterion of need is the potential for the work to result in permanent damage to the health or psyche of the trafficked worker. Another criterion clearly should be the age of the individual. Indeed, some make the case that anyone under 16 who is working in prostitution is trafficked. Period.

A combination of short-, medium- and long-term strategies will constitute the most effective response to the problem in Asia. Examples of short-term action (months) include targeting

and prosecution of procurers and raising awareness in the communities from which women and children are drawn. In the medium term (years), mass media campaigns to change social norms and reduce consumer demand for trafficked individuals and

products are appropriate. Typical long-term solutions (decades) include poverty alleviation and gender equalization. Action on all three levels must begin now, however, because by the time you finish reading this magazine, 30 more Asian girls and boys will have been sold into exploitative labor markets. ▣

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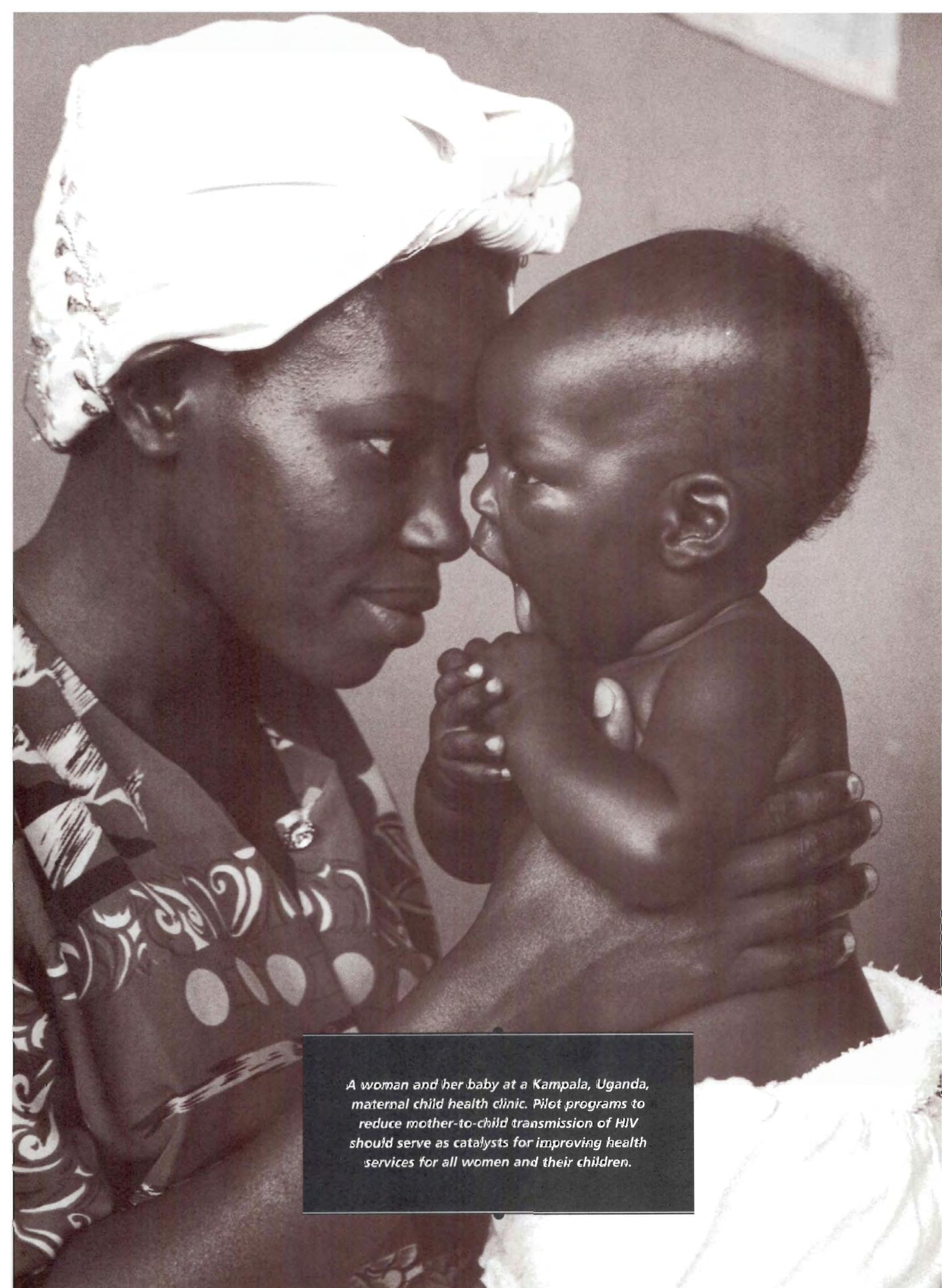
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*Not everyone is abducted or enticed
away with false promises of good jobs.*



A woman and her baby at a Kampala, Uganda, maternal child health clinic. Pilot programs to reduce mother-to-child transmission of HIV should serve as catalysts for improving health services for all women and their children.

Affordable Drug Offers Hope for Preventing Mother-to-Child Transmission of HIV

BY KATHLEEN HENRY

Evidence that an inexpensive antiretroviral regimen can significantly reduce HIV transmission from mothers to their infants has raised hopes of saving millions of lives worldwide and prompted scientists and health officials to reconsider the international recommendations on such preventive therapy.

Preliminary results of a study conducted in Uganda by members of the HIV Prevention Trials Network (HIVNET) showed that a potent and long-lasting drug, nevirapine, was 47 percent more effective in reducing mother-to-child transmission of HIV than a short but much more expensive course of zidovudine (AZT). At about US\$4, the cost of the two doses of nevirapine used in the study (one for the mother and one for the newborn) is a fraction of the cost of other antiretroviral regimens.

Ugandan officials announced the findings of the HIVNET study, which was conducted by researchers from Makerere and Johns Hopkins universities and sponsored by the U.S. National Institute of Allergy and Infectious Diseases (NIAID), in Kampala, Uganda, July 14. "This research provides real hope that we may be able to protect many of Africa's next generation from the ravages of AIDS," said Dr. Crispus Kiyonga, Uganda's Minister of Health.

Other health officials and policymakers also hailed the findings as a major breakthrough. According to Dr. Philippa Musoke, a lecturer and pediatrician at Makerere Medical School and co-investigator on the HIVNET study, this is because the two-dose course of nevirapine is the first antiretroviral regimen that is truly affordable in the resource-constrained countries where 95 percent of HIV transmission occurs.

At the same time, Dr. Musoke and others cautioned against expecting too much too soon. They pointed to the expense and logistical difficulties of getting antiretroviral treatments such as nevirapine to HIV-positive pregnant women in countries with inadequate health care systems and limited access to voluntary HIV counseling and testing.

"Even if they are cheap and affordable for everyone, it doesn't mean that people will access them tomorrow," observed Dr. Joseph Saba, clinical research specialist at the Joint United Nations Programme on HIV/AIDS (UNAIDS).

Dr. Saba is chairman of UNAIDS' International Working

Group on Mother-to-Child Transmission, which met August 31 to develop technical recommendations on the use of nevirapine and other new antiretroviral regimens. "These results are certainly very encouraging, but we need to look more carefully at the real cost of implementing them," he said.

Searching for a Solution Because of the life-saving potential of its results, the HIVNET study (known as HIVNET 012) has been compared to the "ACTG 076" trial that in 1994 provided the first real breakthrough in prevention of mother-to-child HIV transmission. The drug regimen used in that study, which was shown to reduce perinatal HIV transmission by two-thirds (from 24 percent to 8 percent) in the United States, quickly became the standard preventive treatment in industrialized countries. Largely as a result of its widespread use among HIV-positive pregnant women, the number of U.S. infants who contract HIV from their mothers has dropped by two-thirds, from a peak of 907 in 1992 to 297 in 1997.

But the ACTG 076 regimen, which begins as early as the 14th week of pregnancy and includes intravenous administration of zidovudine (AZT) during labor and six weeks of treatment for newborns, costs \$800 to \$1,000. Even if the price were not prohibitive, the requirement that a woman receive antenatal care early in her second trimester would still make this regimen impractical in most resource-constrained countries.

These countries are also home to virtually all of the infants born with HIV infection worldwide—somewhere between 600,000 to 800,000 a year. In the hardest-hit areas of sub-Saharan Africa, one-third to one-half of pregnant women are HIV-positive, and 25 to 35 percent of them pass the virus on to their infants in the uterus, during labor and delivery, or through breast milk.

Since 1994 a number of studies have sought to identify more affordable and practical antiretroviral regimens for the resource-

constrained countries where they are most needed. This research included a trial of short-course AZT therapy supported by the U.S. Centers for Disease Control and Prevention (CDC) in Thailand, a study of a similar AZT course in breast-feeding women in Côte d'Ivoire, and a UNAIDS-sponsored trial of three different regimens of AZT and lamivudine (3TC) in South Africa, Tanzania and Uganda, known as the PETRA study.

The Thai trial, in which women were randomly assigned to receive either AZT from the 36th week of pregnancy to labor and delivery or a placebo drug, found a 50 percent reduction in HIV transmission among those taking AZT after six months of follow-up. Since the release of these results in February 1998, the four-week course of AZT, which costs about \$268, has been the recommended therapy for preventing mother-to-child transmission of HIV in nonindustrialized countries, though it has been implemented in only a few limited settings.

Surprising Results The Thai findings affected ongoing HIV research protocols as well as treatment recommendations. At Mulago Hospital in Kampala, where the HIVNET 012 trial of even shorter regimens of AZT and nevirapine had been underway for a few months, the placebo arm of the study was eliminated. Enrollment of women in the placebo arms of the PETRA trials also ended.

With evidence of the efficacy of a less expensive, shorter course of AZT that could be feasible for resource-constrained countries, trials using placebo controls were no longer considered ethical. The HIVNET 012 protocol team received approval from its ethical review boards to continue enrolling women in the other two arms of the study to determine the best regimen to use in a redesigned efficacy trial.

More than 600 HIV-positive pregnant women and their infants participated in HIVNET 012. Half were randomly assigned to take a very short course of AZT—two pills (600 milligrams) at the beginning of labor, then one pill (300 mg) every three hours until delivery, plus twice-daily doses of AZT (200 mg) syrup for their infants for one week. The other half took a single nevirapine pill (200 mg) at the beginning of labor, and their newborns were given one liquid dose (2 mg per kilogram) within 72 hours of birth. The health of each mother and infant was monitored carefully, and the infants were tested for HIV at



A patient receives a checkup at a Kampala antenatal clinic. Preventing mother-to-child transmission of HIV with new antiretroviral regimens will require improvements in maternal health care and expanded access to voluntary counseling and testing.

ERIC MILLER/IMPACT VISUALS

six to eight weeks of age and again at 14 to 16 weeks.

At six to eight weeks of age, 12 percent of the infants who had received nevirapine had become infected with HIV, compared to 21 percent of those whose mothers had taken AZT. At 14 to 16 weeks, 13 percent of the infants in the nevirapine arm and 25 percent of the infants in the AZT arm were infected. Compared to the very short course of AZT, the nevirapine regimen had reduced the risk of HIV infection through 14 to 16 weeks of age by almost half.

The findings surprised even the members of the HIV Trials Network, who had hoped that nevirapine would perform as well or better than AZT because it is cheaper and easier to administer.

“Based on the pharmacokinetic data from our Phase I trial, we thought nevirapine would provide some protection,” said Melissa Allen, a clinical research specialist at Family Health International, which has managed HIVNET’s vaccine preparation studies and trials of other prevention methods in 12 international sites since 1993. “But we had no idea how dramatic the results would be.”

The HIVNET results are not directly comparable with those of the CDC-sponsored trial in Thailand, which tested a longer AZT regimen among women who were not breast-feeding. Nevertheless, the HIVNET team believes that its data are strong enough to serve as the basis for several recommendations.

“The short-course regimen of nevirapine may be appropriate for women in both developed and developing countries who are first diagnosed with HIV very near to delivery and have received no other antiretroviral therapy,” said Allen, a member of the HIVNET 012 protocol team. “In the context of future studies of other preventive interventions in settings where the longer-course antiretroviral regimens are not the standard of care, the nevirapine regimen could be offered to all participating women.”

New Agenda Because safe alternatives to breast-feeding are not widely available, affordable or culturally acceptable in many countries, one of the top priorities is to identify an intervention that will provide protection to infants during breast-feeding. The HIVNET is likely to undertake a trial to determine whether giving nevirapine to infants for the first few months of life reduces HIV transmission through breast-feeding.

Researchers will continue to follow the infants in HIVNET 012

for 18 months after delivery to monitor safety and also to determine the relative impact of the nevirapine and AZT regimens on long-term survival and on HIV transmission through breast-feeding after 14 to 16 weeks. Researchers say that a prolonged effect on transmission through breast-feeding is unlikely without additional doses of the drug.

Once the research protocol for an efficacy trial of nevirapine therapy during breast-feeding has been developed and approved by various technical and ethical review boards, Allen estimates that the actual research will take at least three years—18 months for enrollment and 18 months for follow-up. The length of the study will depend, she explained, on the number of mother-infant pairs needed to detect statistically significant differences between groups, the study design and the time it takes to recruit participants.

In the meantime, nevirapine is likely to be combined with efforts to offer HIV-positive women safe alternatives to breast-feeding. For example, as part of a pilot program sponsored by UNAIDS and UNICEF in Uganda, UNICEF will offer counseling and free formula to women who take antiretroviral drugs to prevent transmission of the HIV to their infants.

UNAIDS, UNICEF and the World Health Organization will support pilot programs in 11 countries. They hope to include a total of 30,000 women a year in programs that provide early access to antenatal care, voluntary and confidential HIV counseling and testing, antiretroviral treatment for preventing perinatal transmission, counseling on infant feeding options, and support for women who decide not to breast-feed.

In Uganda the pilot program will soon begin in three sites, with plans to expand to an additional five sites, each serving 1,000 women a year. "The UNAIDS initiative is a good starting point to see whether what we're planning to do can actually be done in a non-study setting," Dr. Musoke said.

Catalyst for Change For now, the Ugandan pilot program will use supplies of AZT donated by Glaxo Wellcome, the company that makes the drug. Once recommendations on the use of new antiretroviral regimens are in place, UNAIDS will begin negotiating with the manufacturer of nevirapine, Boehringer Ingelheim Pharmaceuticals, and other companies on ways to expand access to the drugs.

When they met in August, members of UNAIDS' International Working Group on Mother-to-Child Transmission and other experts on perinatal transmission examined the results of

the Thai and Côte d'Ivoire studies, HIVNET 012 and the PETRA trials. The PETRA study found that 3TC added to the standard four-weeks of antenatal AZT treatment for mothers cut perinatal HIV transmission by half, while giving the two drugs to both mothers and newborns for a week reduced transmission by more than one-third.

Given the margins of statistical error for each study, however, it was impossible to say that one regimen was more effective than another. The group concluded that all five were effective in preventing mother-to-child transmission, and that decisions about which regimen to use or to make available in a country will depend on the setting, the circumstances and the resources at hand.

The group recommended that policymakers and health care providers consider all five regimens for different settings or patients, but recognized that short-course nevirapine may be the most feasible option in many countries. "We did say that nevirapine appears to be by far the least costly and most practical regimen, and that we need to make it available," Dr. Saba said.

For areas with high HIV prevalence and no access to voluntary HIV counseling and testing, some have even suggested that nevirapine could be offered to all pregnant women.

"This is something that theoretically could be feasible if we have enough safety data," Dr. Saba said. "But the benefits of voluntary counseling and testing go far beyond the prevention of mother-child transmission. If we are to really make a difference in this epidemic, we need to let people know whether they are infected."

Dr. Musoke agrees, saying that to offer nevirapine without voluntary counseling and testing would be to avoid "the real issue, which is to find those women who are HIV-positive and support them and find those women who are not infected and help them stay negative."

Presumptive nevirapine treatment might be cost-effective, she adds—particularly in areas where every other client at antenatal clinics is HIV-positive—"but I think it's a short-term investment."

Instead, both Dr. Musoke and Dr. Saba believe that nevirapine could serve as a catalyst for making desperately needed improvements in health infrastructure and services in sub-Saharan Africa and other areas.

"The fact that the drug is cheap makes it something we can strive for, but we should also be striving to improve infrastructure," Dr. Musoke said. "We should use this opportunity to improve the overall health care of all pregnant women." □

"This research provides real hope that we may be able to protect many of Africa's next generation from the ravages of AIDS."

After Rakai: What Next?

By Gina Dallabetta



In August 1995, the results of a landmark study demonstrated that community-based treatment of symptomatic sexually transmitted infections (STIs) could dramatically reduce HIV incidence.¹ Strong biological and epidemiological evidence had long pointed to a critical role for STI control in HIV prevention.² But the magnitude of the impact shown in this randomized controlled trial in the Mwanza region of Tanzania—a 40 percent reduction in new HIV cases—was striking.

Less than three years later, the findings from a second community-based randomized trial of the impact of STI treatment on HIV incidence delivered yet another surprise. This study, which offered treatment for common curable STIs to all adults in ten communities in Uganda's Rakai district, found that the intervention had reduced some STIs, but had had no impact on the rate of new HIV infections.³

These apparently contradictory results have understandably left many people confused about the role of STI control in HIV prevention. Many assumed that one of the studies must be wrong. Others argued that discrepancies in the findings are a result of distinct differences between the epidemics in the two study sites. The debate continues, as scientists, health care providers, HIV program managers and international donors seek to understand the implications of the Mwanza and Rakai studies.

Understanding Rakai

The eagerly awaited results of the Rakai trial came as a shock to many who had expected them to clarify the additional HIV prevention benefit of treating all STIs in a community, rather than just those in people who sought treatment for symptoms. In order to ensure coverage of asymptomatic STIs in these communities with high STI prevalence, the study had offered directly observed home-based antibiotic treatment to everyone 15 to 59 years of age, regardless of symptoms, clinical signs or STI treatment-seeking behavior.

Conducted by a team of U.S. and Ugandan researchers, the Rakai study involved more than 12,000 participants in ten clusters of four to seven villages. Every ten months participants in half the communities received single doses of three antibiotics, while those in the other half received a treatment for intestinal worms, an iron-folate tablet and a low-dose multivitamin. Pregnant women in both groups who tested positive for syphilis were treated. All had agreed to participate with the understanding that their communities had an equal chance of being assigned to the intervention or the control group.

Originally designed to provide five rounds of mass STI treatment, the trial was halted after three rounds when an analysis of the data showed conclusively that the intervention was having no effect on HIV incidence (the rate of new infections occurring during the study period). Although the levels of some STIs were significantly lower in the intervention group than in the control group, the incidence of HIV-1 was 1.5 per 100 person years in both groups.

Several explanations have been proposed for the discrepancy between these findings and the substantial reductions in new HIV cases that occurred in Mwanza as a result of improved STI treatment. One is that the Rakai intervention decreased the prevalence of some but not all the STIs that facilitate HIV transmission. After three rounds of mass treatment, only syphilis and trichomoniasis levels were significantly lower in the intervention group than in the control group. However, the authors of the Rakai study note that significant reductions in the prevalence of gonorrhea, chlamydial infection, trichomoniasis and bacterial vaginosis (BV) were achieved among pregnant women enrolled in the study, with no effect on their acquisition of HIV.

Another possible confounding factor in Rakai was the high prevalence of two STIs—bacterial vaginosis (BV) and herpes—for which there is no highly effective, affordable treatment. At baseline

half of the women in the study had BV, which is difficult to cure and has been linked with increased risk of HIV. Moreover, 42 percent of genital ulcers in the Rakai study population were positive for herpes simplex virus-2 (HSV-2), which can be treated but not cured with expensive antiviral therapy that was not given in this study. Only 7 percent of the genital ulcers were caused by syphilis or chancroid. No studies have explicitly examined the role of herpes in HIV transmission, and the Rakai results certainly point to the need for such research.

The limited effect of the mass treatment on gonorrhea and chlamydial infection, the high prevalence of BV and herpes, and other factors may have contributed to the striking difference between the findings in Mwanza and Rakai. Perhaps the most important factor, however, is the one proposed by Penelope Hitchcock and Lieve Fransen.⁴ In their commentary on the Rakai results, published in the same issue of *The Lancet*, Hitchcock and Fransen note that the seemingly contradictory results from the two studies are actually consistent with a widely accepted model of the forces necessary to establish an HIV epidemic.

In this model, STIs have their greatest impact on HIV transmission during the early stages of an epidemic, when HIV spreads primarily among groups with high rates of sexual

STIs have their greatest impact on HIV transmission during the early stages of an epidemic.

partner change and STIs. Since people who have many sex partners tend to engage in fewer acts of intercourse with each of those partners, their risk of transmitting an HIV infection is actually quite low. This is because HIV is not transmitted efficiently during its long latency period—unless one or both partners have an STI. But those with multiple partners are more likely to have an STI, which increases the efficiency of HIV transmission and the likelihood that the virus will be acquired during a few sexual encounters with an HIV-positive partner.



RONALD GRAY

In a more mature epidemic, STIs are less important in driving the epidemic. This is because HIV is spreading throughout the general population, among people who have fewer sex partners but engage in many more acts of intercourse per partner. If one partner has HIV, eventually, after many acts of unprotected sex, transmission will occur.

When the Mwanza study began in 1992, the HIV epidemic there was in an early phase, with an HIV prevalence rate of 4 percent among the general population. The Mwanza results, therefore, reflect the impact of STI prevention and treatment in an immature epidemic where STIs were still a driving force in the spread of HIV. In Rakai, on the other hand, HIV prevalence had already reached 16 percent by the time the trial began in 1994. In such a mature epidemic, STIs are still an important risk factor for individuals, but their contribution to the spread of HIV among the population may be negligible.

A Rakai study participant and her child. Follow-up data on women who had participated in the trial during pregnancy and their babies confirmed the important maternal and infant health benefits of STI treatment.

Lessons from Rakai and Mwanza

A closer analysis of the differences between Rakai and Mwanza, then, points to the urgency of improving STI treatment and prevention for populations with low HIV prevalence but high rates of other STIs. Providing effective STI services to these groups could save millions of lives—if we act now, before HIV becomes well established and that window of opportunity is closed forever.

Many countries worldwide, from India to Madagascar to Jamaica, can benefit from this lesson. But even in countries with high HIV prevalence, the epidemic is not uniform. In most countries with mature epidemics, for example, adolescents have high rates of STIs and low rates of HIV and should be targeted with accessible, user-friendly STI services.

It's important to remember that the Rakai study confirmed that STI treatment is an extremely effective way of improving the health of mothers and children. Unpublished data from Rakai also show that STIs do increase an individual's risk

Effective, affordable STI services are needed everywhere.

of acquiring or transmitting HIV. Although the Rakai results suggest that STI control is most effective as an HIV prevention strategy in an immature epidemic, they certainly should not be used to justify continued neglect of STI services in resource-constrained areas with high rates of HIV. Effective, affordable STI services are needed everywhere—not only to help contain HIV, but also to reduce the tremendous burden of morbidity and mortality caused by STIs themselves.

Next Steps

What constitutes effective STI services? Rakai is less helpful on that question. What is often forgotten in the debate over the Mwanza and Rakai studies is that both interventions had limited success in controlling STIs. Mwanza seems to have reduced HIV incidence primarily by reducing the duration of STIs, while showing a reduction in symptomatic urethritis and

syphilis incidence. The mass treatment in Rakai, on the other hand, did not produce significant reductions in most STIs, except among pregnant women, whose sexual behavior is unlikely to be representative of the general population.

The failure of these interventions to achieve STI control is hardly surprising. Mwanza demonstrated both the value and the limitations of the syndromic approach to STI management. Because this approach uses clinical algorithms based on the constellation of patient symptoms and clinical signs, it is only effective when people have, recognize and seek appropriate treatment for symptoms. STIs are asymptomatic in most women and many men, and many of those who do have symptoms seek care in the informal sector.

In Rakai, on the other hand, the lack of effective, routine STI treatment between mass treatment rounds appears to have allowed reintroduction of STIs into the study communities, either by travelers who acquired these infections elsewhere or by community members who did not participate in the study. Although the study achieved impressive levels of participation—80 percent of eligible residents who were present in the community during each round received mass treatment—this still meant that 30 percent of all those eligible throughout the study were not covered because they were not present.

Mass treatment is by definition an emergency measure, and is most cost-effective when applied to groups with high STI prevalence and rates of partner change high enough to maintain epidemic growth of STIs—what are known as “core groups.” In an FHI study in South Africa, for example, presumptive treatment and peer education targeting women in communities where miners live away from home in single-sex hostels resulted in significant reductions in STIs among the women and the miners.⁵

Clearly such presumptive treatment cannot stand alone as an STI control intervention, even in core groups. Implicit in the logic of this strategy for reducing STI prevalence is the need for maintenance strategies. To sustain lower rates, more long-term control measures, such as primary prevention and improved case management, must be in place.⁶

Improving STI services for women is particularly challenging because asymptomatic infections are so common in women and because of the social and cultural barriers they face in seek-

ing treatment for symptomatic STIs. Syndromic management is of limited value, even for women who experience symptoms, because current algorithms for vaginal discharge do not work very well. There is a critical need for inexpensive, easy-to-use diagnostic tests for gonococcal and chlamydial infections to improve case management and identify asymptomatic infections. In the meantime, the best strategies for controlling STIs in women are syphilis screening and treatment of all pregnant women who test positive for syphilis, stronger efforts to refer the partners of male STI patients for treatment, and concerted efforts to make existing services more comfortable and convenient for women.

Because of the rapport they have built with sexually active women over the years, family planning clinics are often hailed as the solution to many of these challenges. The experience to date, however, has been disappointing. In most settings STI programs should not be implemented through reproductive health clinics alone because of the weakness of the tools available for managing STIs in women and because these programs lack experience in reaching men and core groups.

Family planning and reproductive health programs certainly have an important role to play in counseling clients about STIs, promoting condom use and referring clients for diagnosis and treatment of STIs, as outlined in the U.S. Agency for International Development's technical guidance on integrated services.⁷ And in some selected settings, integration of syndromic management may be appropriate. Whatever the setting, it is important to remember that there is no uniform approach to STI management and prevention for women or men. The best approach in a given setting will depend on the resources available—including staff skills and time—and the populations affected.

We are beginning to better understand what is appropriate in different settings, and there is much we can do now with the imperfect tools at our disposal to improve STI prevention and treatment. First and foremost, we need a stronger commitment to improving services at the places where people first seek treatment of STIs, whether that be a pharmacy, a physician's office or a public health clinic. At the same time, research is urgently needed to identify better tools—from more affordable, appropriate diagnostic tests to innovative

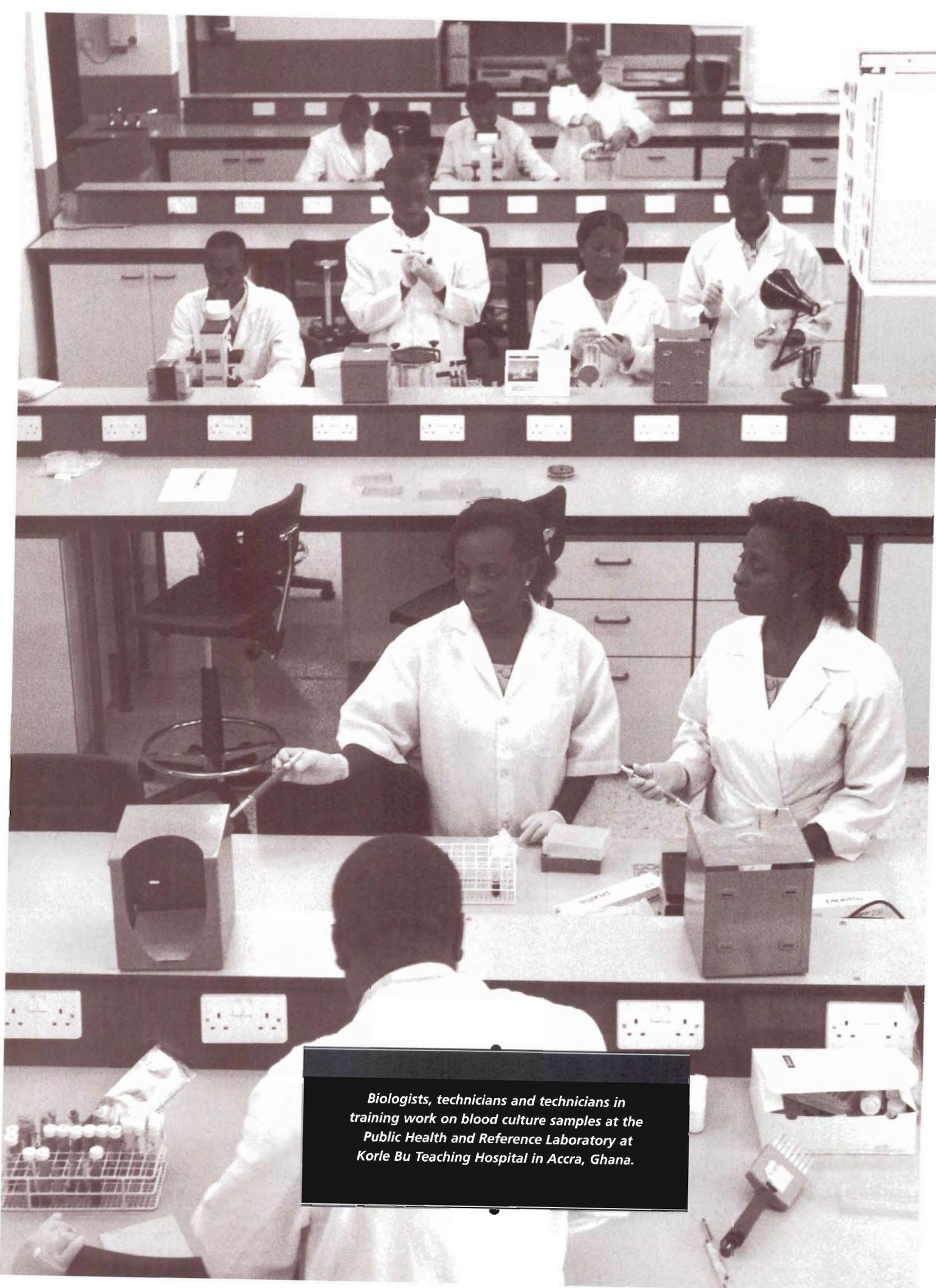
strategies for treating asymptomatic infections.

The Rakai results have highlighted some important unanswered questions for further research—questions about the role of asymptomatic, difficult-to-treat and incurable STIs in HIV transmission and about the most effective mix of interventions for controlling the spread of STIs, including HIV, in different populations. Nevertheless, what is clear is that management and prevention of STIs remains critical as a public health measure in its own right and as one of the most effective ways to reduce HIV transmission among many of the populations most at risk.

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Biologists, technicians and technicians in training work on blood culture samples at the Public Health and Reference Laboratory at Korle Bu Teaching Hospital in Accra, Ghana.

Making Lab Tests More Accurate: Ghanaian Effort Offers Model Process

BY PAULA STAUFFER

With an ambitious effort to standardize testing procedures, the national public health laboratory makes an important contribution to Ghana's response to HIV/AIDS and other infectious diseases that can serve as a model for countries in sub-Saharan Africa and beyond.

Providing the prompt, accurate diagnostic services so critical to effective health services is a challenge in countries with limited resources. Even in Ghana—a country with a well-established public laboratory system and well-trained staff—the accuracy of laboratory test results is not always a given.

Findings from a series of proficiency tests conducted by Ghana's National Public Health and Reference Laboratory (NPHRL) sounded the alarm about the quality of laboratory diagnostic services. "We would send the same sample to two different labs and get two different results," said Veronica Bekoe, NPHRL chief biologist.

These findings suggested that many cases of HIV, sexually transmitted infections (STIs), malaria, meningitis, hepatitis and other diseases were being misdiagnosed.

NPHRL officials suspected that a lack of standardization among the laboratories was at the root of the problem. During supervisory visits, NPHRL representatives had noted that specialists and technicians at all levels of the laboratory system, from the health centers to the district and regional labs, were using different methods and reagents to test for the same disease, with widely differing results.

"We knew that it could be human error that contributed to the high level of inaccuracy, but that it could also be the result of non-standardized testing procedures," said Veronica Bekoe, NPHRL head technologist.

The NPHRL moved quickly to address the problem. From December 1998 to March 1999, with technical assistance from Family Health International's IMPACT Project, its staff developed standardized operating procedures (SOPs) for the most commonly used tests performed in all the country's clinical and public health laboratories. "We decided to address the problem by first developing the SOPs, and then providing training and follow-up," explained Bekoe.

These SOPs will help lab specialists and technicians conduct more accurate tests, contributing to more effective treatment, dis-

ease control and surveillance. As a means to achieving more accurate diagnosis of HIV and other STIs and obtaining better information about the spread of these infections, the procedures are an important part of a wider FHI/IMPACT effort to strengthen the National AIDS Control Programme's response to HIV/AIDS through technical assistance to the public health system in laboratory services and STI training, service delivery and evaluation.

The Challenge Like many other countries around the world, Ghana faces daunting challenges in controlling infectious diseases. HIV prevalence—though relatively low for sub-Saharan Africa at 4 percent of the adult population—has reached the critical level at which experts believe HIV/AIDS epidemics can still be contained, but only if they are addressed promptly and effectively. Diseases once thought to be largely under control, such as malaria and tuberculosis (TB), are resurging, and the development of drug-resistant strains of these and other common infectious diseases makes treatment difficult and even more expensive.

Improving the ability of laboratories to provide prompt, accurate information to health care providers and decision makers is one of the cornerstones of the U.S. Agency for International Development's infectious disease control strategy and a critical step in strengthening national responses to HIV/AIDS.

"Laboratory testing is essential to the diagnosis, monitoring, and surveillance of disease, particularly emerging diseases," said Sheila Mitchell, a specialist in laboratory sciences and consultant for FHI/IMPACT. "Clinicians and public health officials rely on accurate laboratory test results for diagnosis and treatment and also for monitoring disease trends and drug resistance."

Other challenges pose a threat to the accuracy of laboratory diagnostics in Ghana, including shortages of supplies and equipment. But standardizing testing procedures is an important first step in improving laboratory services because even slight varia-

tions in methodology can affect the accuracy of a test, Mitchell explained.

Such variations include differences in timing and in the dilution of reagents used in certain tests. For example, when using staining methods to detect acid-fast TB bacilli, one lab technician might leave the stain on for five minutes and another for ten. One might mix a 50 percent solution of a required reagent, while another mixed a 75 percent solution.

"It's really like cooking," Mitchell said. "Some people follow the recipe exactly, and some people put in a pinch of this and a pinch of that. But unfortunately, with laboratory diagnosis the consequences of getting it wrong are much more serious."

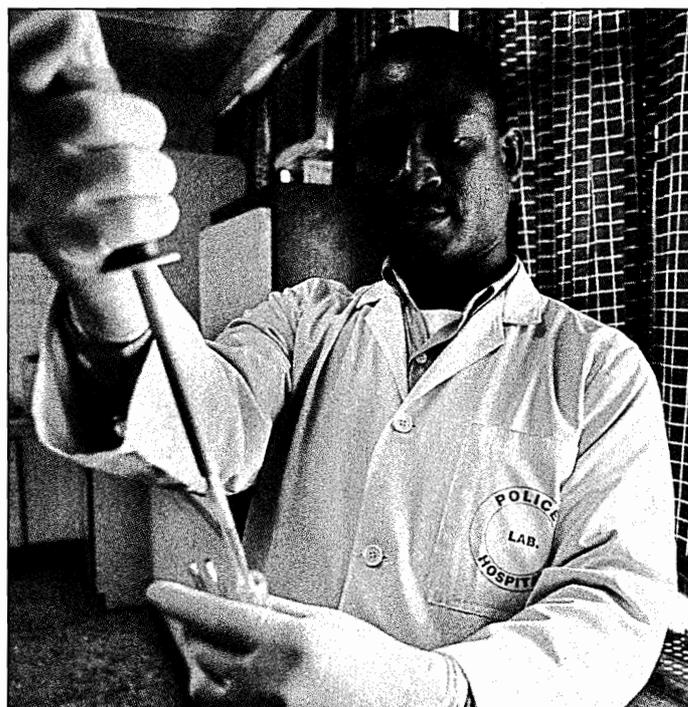
For TB diagnosis, for example, precise timing and use of the correct reagents are critical to the sensitivity of the test. "Any modification can lead to inaccurate results," Mitchell said.

The Response A lack of national standards for laboratory procedures is hardly an unusual problem. What is noteworthy is the response of the national laboratory system in Ghana, which has grown over the past 90 years from its humble beginnings as a small laboratory in a classroom to a network of more than 800 laboratories operating in health centers and district, regional, and teaching hospitals.

The NPRHL used a participatory approach to develop the SOPs. In October 1998, Bekoe organized a technical group with representatives from all laboratory disciplines who compiled lists of the tests used at the different levels of laboratories. Then, with technical assistance from FHI/IMPACT, technical group members developed a format for the SOPs and began drafting the procedures.

In December 1998, FHI/IMPACT supported a one-week workshop for 48 lab specialists and technicians from all ten regions in Ghana and the two teaching hospitals to further develop and refine the SOPs. At the end of the workshop, more than 100 SOPs had been drafted and were ready for editing and review.

"This many SOPs could not have been agreed upon and produced in this short time period using any other process," said Mitchell, who worked with the NPHRL to manage the process and



Sergeant Aboso Mensah, a lab technician at the hospital of the Ghana Police Service, which is working with FHI to strengthen the HIV/AIDS and STI prevention services it offers its members.

edit the manuals. "The participation of lab specialists from all levels of laboratories, different geographic regions and different lab disciplines also will ensure that the SOPs are practical, easy to follow, and will be used in the laboratories."

Each SOP includes a brief explanation of the principle behind the testing method, lists of the reagents and equipment to be used, a step-by-step description of the procedure, and instructions on any special requirements or precautions.

For example, the SOP for a rapid HIV test (performed only

at regional hospitals in Ghana), explains the principle behind the HIV Spot Method, a test that uses what is known as a "capture reagent" absorbed on a porous membrane to trap antibodies to HIV-1 and HIV-2. It lists eight detailed steps to follow, beginning with writing the sample number on the testing device, and nine special precautions for performing the test safely and accurately.

The SOPs have been compiled into manuals for each level of laboratory. In addition, 15,000 laminated sheets of the ten most common procedures have been produced for use by technicians on the bench. "While the manual is an important reference tool, we hope that the laminated sheets will help technicians on a daily basis in their testing of common diseases," said Mitchell.

Mitchell, who was a microbiologist at the U.S. Centers for Disease Control and Prevention for ten years, noted that it is an ambitious objective for laboratories in any country to systematically standardize and document SOPs and to keep them updated.

"Unless they are regulated by law to do so, few laboratories willingly take the initiative to develop and maintain SOPs because of their heavy workloads and competing priorities," said Mitchell. "But the public health laboratory system in Ghana recognizes the importance of high-quality laboratory testing. It has established a model process and product which can, and should, be shared with other resource-poor countries." □

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Many cases of HIV, sexually transmitted infections, malaria, meningitis and other diseases were being misdiagnosed.

Testing Positive in El Salvador: HIV Stigma Continues, But Counseling Improves

INTERVIEW BY SUSAN CALDERÓN

The painful experience of one Salvadoran man who tested positive for HIV illustrates the urgent need to ensure the quality and confidentiality of HIV counseling and testing in El Salvador—a need that is starting to be met with training in state-of-the-art counseling techniques and principles.

In 1991, when Jorge (a pseudonym) found out that he was HIV-positive, HIV/AIDS was almost unheard of in El Salvador. A total of 132 AIDS cases were reported to health officials that year, while hundreds more AIDS cases and HIV infections went undetected.

Eight years later, the stigma and discrimination associated with HIV/AIDS remain—so much so that Jorge is afraid to give his real name—even though more than 6,900 Salvadorans have contracted AIDS since the beginning of the epidemic and at least 6,300 of them have died. What has begun to change, though, is the availability and quality of HIV counseling.

Change has come slowly. Members of some nongovernmental organizations who refer clients for HIV testing received training in counseling in recent years, and they are passing on their new skills to their NGO colleagues. But until 1998, little or no HIV counseling was available in most public hospitals, where the majority of HIV tests are performed.

Salvadorans are usually tested for HIV only after they become so sick with an AIDS-related illness that they are admitted to a hospital. In the past, whether patients received any kind of counseling before or after an HIV test depended on the knowledge and inclination of individual hospital staff members, explained Family Health International (FHI) consultant Mariana Iurcovich.

Most hospital staff members did not know how to counsel patients about HIV, and many did not even recognize the need for pre- and post-test counseling. “There was no official training, so in fact they didn’t have counseling,” Iurcovich said.

Recognizing the problem, Ministry of Health (MOH) officials requested assistance from FHI’s Implementing AIDS Care and Prevention (IMPACT) Project. In August 1998, Iurcovich trained 50 health care professionals to enable them to facilitate training in voluntary counseling and testing for public health staff in El Salvador’s 14 departments. She also worked with the MOH’s

national AIDS program to develop a training manual on HIV counseling and testing.

The training and the manual emphasize the need to respect patients’ rights and offer compassionate, nonjudgmental support. Trainees also learned to follow strict procedures for ensuring the confidentiality of results.

The manuals will be distributed in September 1999, when Iurcovich returns to El Salvador to train 50 more health educators and other public health staff from every department to provide training in voluntary counseling and testing.

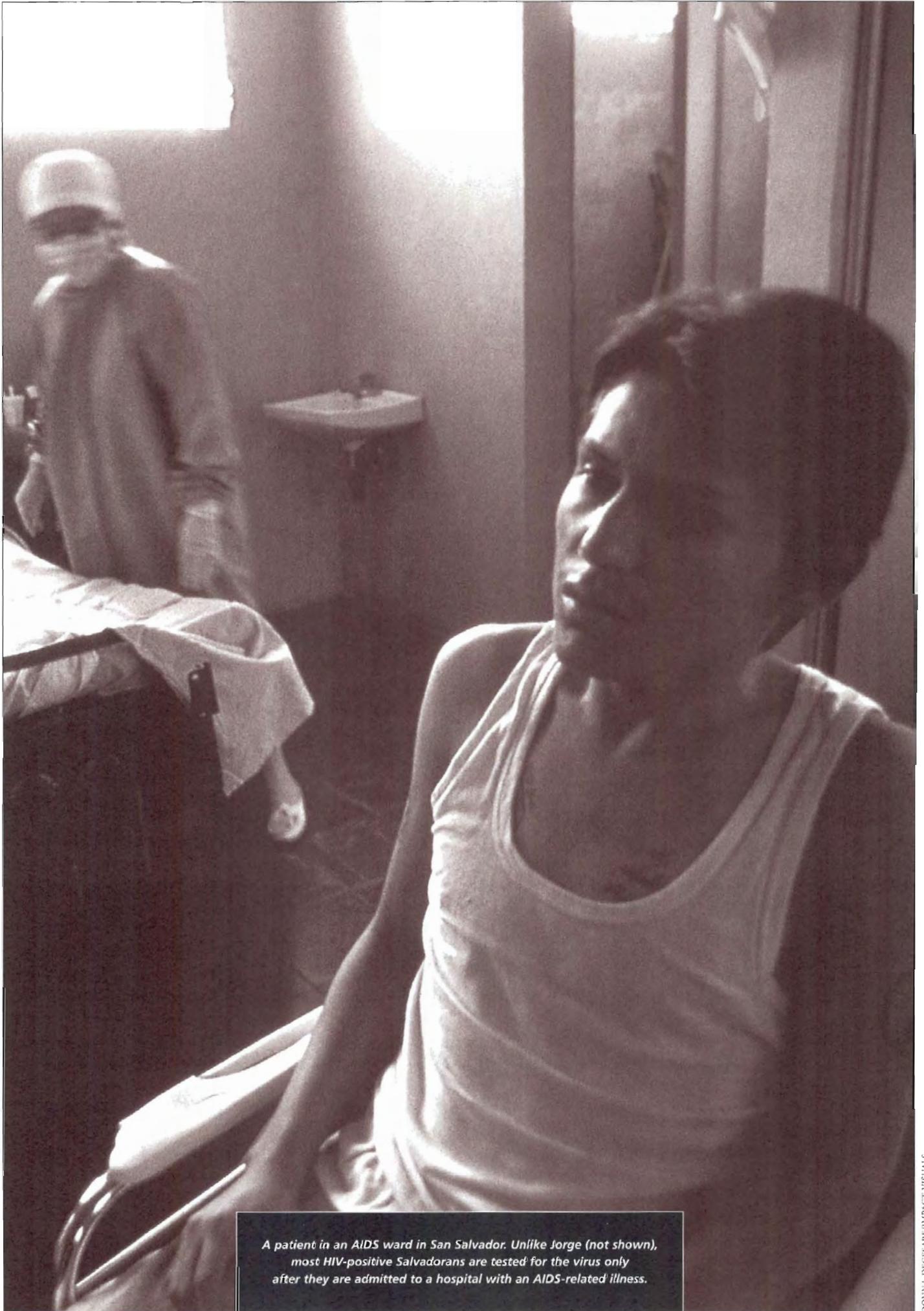
Iurcovich will use the curriculum from last year’s workshop, incorporating suggestions from the first group of trainees on how to improve the training. The week before the second workshop begins, she will visit those facilitators to talk to them about their experiences as trainers and counselors. She also plans to talk to some of the health care professionals the facilitators have trained and observe these new trainees as they provide HIV counseling.

Iurcovich is eager to visit public hospitals and health units to assess the impact of the first workshop on the quality and availability of voluntary counseling and testing. “I want to see if it’s something that is really happening all over the country.”

During her last visit to El Salvador, when Iurcovich observed and provided technical support to facilitators during training workshops in five districts, she already saw encouraging evidence of a new commitment to providing quality counseling services.

“Before it wasn’t so clear to them why it was so important for the client to have someone to support him or her and to explain the meaning of the HIV test,” Iurcovich said. “They didn’t realize how important it was to keep this kind of information confidential. And they have really changed their way of thinking about this.”

Such a shift in thinking is essential to ensuring that no other Salvadorans have an experience like that of Jorge’s, whose nightmare began eight years ago when he volunteered to donate blood.



A patient in an AIDS ward in San Salvador. Unlike Jorge (not shown), most HIV-positive Salvadorans are tested for the virus only after they are admitted to a hospital with an AIDS-related illness.

DONNA DECESARE/IMPACT VISUALS

No Way Out: One Man's Experience With HIV Testing

My principal motivation was to donate blood, not to have the HIV test. I was not ready in any way to be tested for HIV. In my mind there was no reason to think that the result could ever be positive because, I thought, "I belong to the health personnel union, and my profession makes me invulnerable to getting such diseases." This idea is one of the worst mistakes you can make.

Since I never thought that the result could be positive—and besides I never had such an active sexual life, or many partners—I did not practice any prevention. I think that if I had received information on time—and I don't mean academic information from the university, I mean the kind of information that makes us conscious of the risks we can have in life—then my story would be different.

The way I learned of the result was through a letter in an unsealed envelope sent to me at my job. The terse letter said that I should be present at a specific hour, Monday to Friday, and ask for a person (since then I've been told that she was the director of the blood bank).

This letter hit me like a ton of bricks. I lost all peace of mind, and I kept wondering what they needed to tell me, or what had happened to my blood. I confess that I once thought that maybe the result of one of the three tests—syphilis, hepatitis or HIV (then we used to say AIDS)—could be positive, but I immediately put it out of my mind and changed my thoughts to "maybe they need me to donate more."

The result was communicated very calmly. But whenever you receive a positive result, you do not listen to what the counselor is telling you. Your life is like a movie—in a few seconds, you see everything, very fast.

I remember how I cried, like a child. Then I asked the doctor to allow my friend to come and stay with me. I hugged my friend and asked him to hold me, while at the same time I told him about my health situation. It was one of the worst moments in my life, and its impact still exists in my mind today.

I felt like the only person in the universe with this problem. One of the most serious problems that came to mind was how could I tell my family, and suddenly I saw myself traveling down a road with no way out. How could it be possible that a professional like me could have this disease? Could I ever work with patients with their health problems? Suddenly I felt that six years at the university were going directly into the garbage and also a whole promising future.

But the worse had not yet started. People I had known for so long turned their backs on me in every way. It was disappointing to see how human beings can treat each other.

There was no information about how to avoid infecting others. For more than a year I became absolutely asexual. There were no stimuli that could change my position. I was scared, and I thought that I was never going to use my sexuality again. I did not even know how to use a condom and when it should be used. After some years, I realized that I could have sexual partners again, always using condoms. I also learned to have one stable partner for a long time.

What I do remember is that I was required to inform my job as soon as possible, and I remember they even gave me a deadline. If I did not do it, they were going to inform my chiefs about my health status. And they really did, without my approval. They did not even tell me they were going to

do it. I realized that everyone at the university knew my health status. Even my chief confessed that he knew it one week before I was told about it.

I wish it could have been different—not just for me, but for everyone. It is the lack of confidentiality and professional discretion... There are

many professionals with no ethics or morals, and they do not know the damage they can do with their comments.

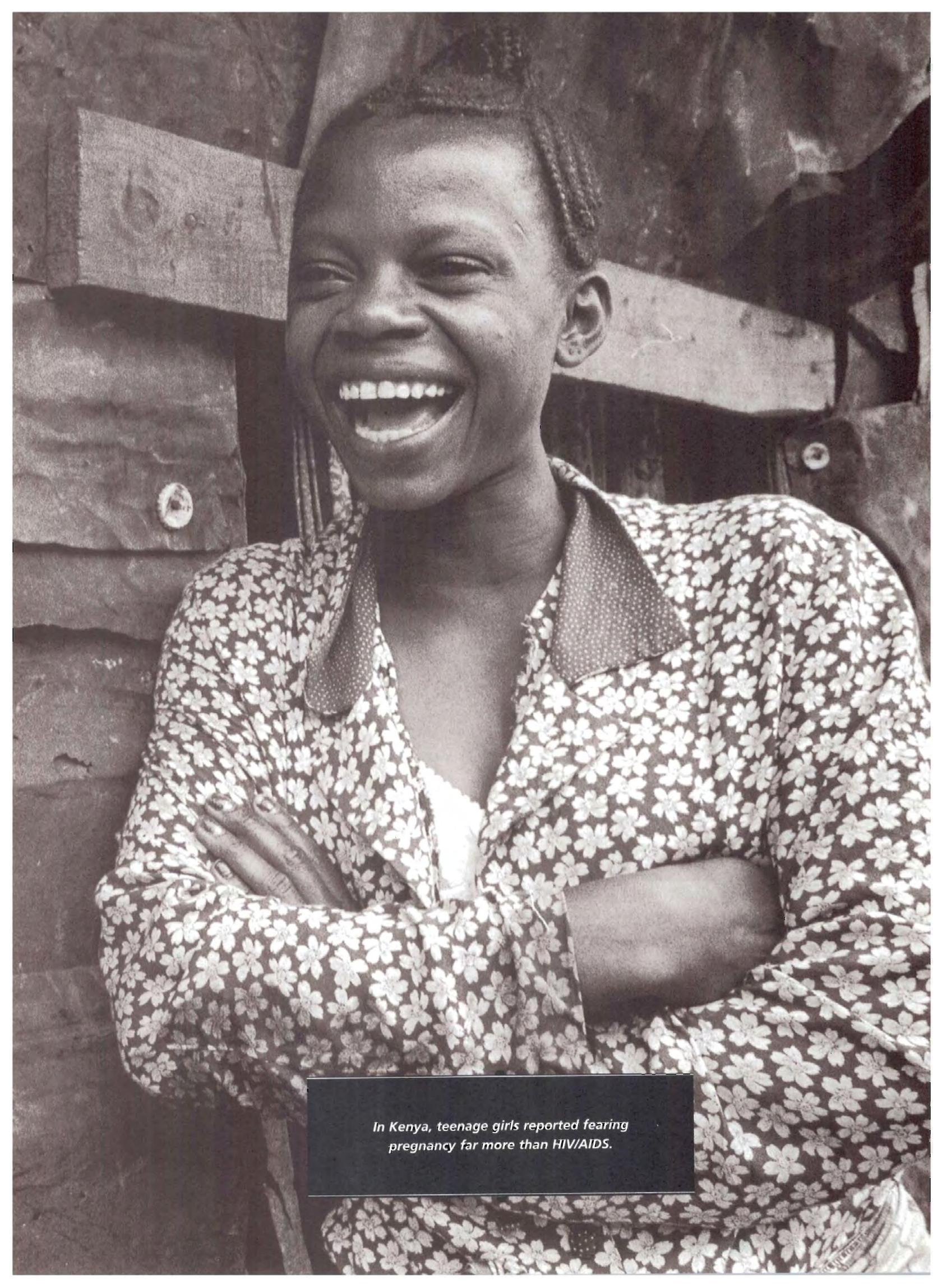
I communicated the result of my test to two people directly, and I told my family ten days after I learned it. After that, how the news was spread in my union is something I'll never know.

I received support from close friends, but the news started spreading. Then people started with prejudices and with really discriminatory and wounding comments.

Discrimination is a mild word for the whole Calvary I passed through. If I could put it into words, I'd say: cornered, persecuted, humiliated, accused, judged and I do not know what else. But what hurts most is that people you've known for such a long time are the ones who can do this to you. It does not hurt that much when it comes from people you do not know, but it does when it comes from people you call friends.

Thank God I always have my family's and God's support, and that's the important thing today. And even with all the terrible things that it has meant, learning that I was HIV-positive was a jolt that helped me in many ways, such as maturity, ways of confronting problems, and my life's vision and my self-esteem. ▣

"Even with all the terrible things that it has meant, learning that I was HIV-positive was a jolt that helped me in many ways."



In Kenya, teenage girls reported fearing pregnancy far more than HIV/AIDS.

Systematic Behavioral Surveys Recommended for Next Generation of HIV Surveillance

BY KATHLEEN HENRY

FHI's behavioral surveillance surveys (BSS) have been recognized as a flexible tool for evaluating HIV/AIDS prevention interventions and an integral part of UNAIDS' surveillance guidelines for national AIDS programs.

Thirty percent of Kenyan teenagers in schools in the city of Mombasa report that they have had sex with one or more partners, becoming sexually active at an average age of 15 for boys and 16 for girls. In Cambodia's five provincial capitals, three out of four members of the military and police forces admit using the services of a sex worker in the past 12 months. And 36 percent of truck drivers interviewed along Côte d'Ivoire's main highway say they have had sex with someone other than their wives or steady girlfriends during the previous year.

Getting people to talk directly and accurately about their own sexual behavior can be difficult. But in countries throughout the world, well-trained survey interviewers are doing just that in an effort to better understand the behaviors driving HIV epidemics and to assess whether interventions to reduce risky behavior are working. And people from all walks of life are opening up to these interviewers, revealing details about the most private aspects of their lives, in hopes of helping to curb the spread of the deadly virus that causes AIDS.

The data from these repeated behavioral surveys among cross sections of selected populations, which have been conducted in more than 10 countries, have proved so useful that the Joint United Nations Programme on HIV/AIDS (UNAIDS) included such surveys in its recommendations for "second-generation" surveillance of HIV/AIDS and sexually transmitted infections (STIs).

The first generation of recommendations had focused on measuring levels of HIV infection in "sentinel" groups, such as clients of STI or antenatal clinics. But experience with these epidemiological surveillance systems showed that HIV prevalence data alone cannot explain trends in the spread of the virus.

"Behavioral data are as essential as biological data for program design, monitoring and evaluation," said Dr. Michel Caraël, UNAIDS prevention team leader.

Standardized guidelines for behavioral data collection, devel-

oped jointly by UNAIDS and Family Health International (FHI),¹ will help national AIDS programs gain a better understanding of the HIV/AIDS epidemics in their countries, says Dr. Thomas Rehle, FHI's associate director for evaluation, surveillance and epidemiological research. "Behavioral data complement the findings from HIV sentinel surveillance and allow a contextual analysis of the observed trends in HIV prevalence," he explained.

These guidelines recommend that systematic, cross-sectional behavioral surveys be carried out annually or biannually among groups that engage in high-risk behavior in countries at all stages of the HIV/AIDS epidemic.

The most extensive data from this type of survey has come from FHI's application of its behavioral surveillance surveys (BSS) methodology. Since conducting the first BSS in the city of Bangkok in 1993, FHI has assisted governments and local research organizations to adapt and apply the methodology in more than 20 countries.

Stephen Mills, associate director for technical support in FHI's Asia Regional Office in Bangkok, believes that interest in BSS is growing because the surveys fill two important gaps in HIV/AIDS evaluation. "The BSS help us understand whether the combined interventions of different groups are working together to change risk behaviors," he explained. "In the absence of HIV or in low-prevalence settings, they can also give us an early warning of where HIV may appear in the future."

Evaluating Programs The BSS grew out of FHI's experience in evaluating hundreds of HIV/AIDS prevention projects in more than 60 countries during the past 12 years. Under the USAID-funded AIDS Control and Prevention (AIDSCAP) Project alone, FHI supported more than 165 knowledge, attitudes, beliefs and practices (KABP) surveys among the groups targeted by specific projects.

Although these surveys generated a great deal of interesting information, FHI evaluation specialists concluded that they were not the most efficient or effective way to evaluate the impact of prevention efforts on HIV risk behavior.

Instead of measuring indicators of behavior change for many individual projects with overlapping target groups, FHI now consolidates its resources to assess the collective effort against HIV/AIDS in a city or region using a more methodologically rigorous approach than the typical KABP study.

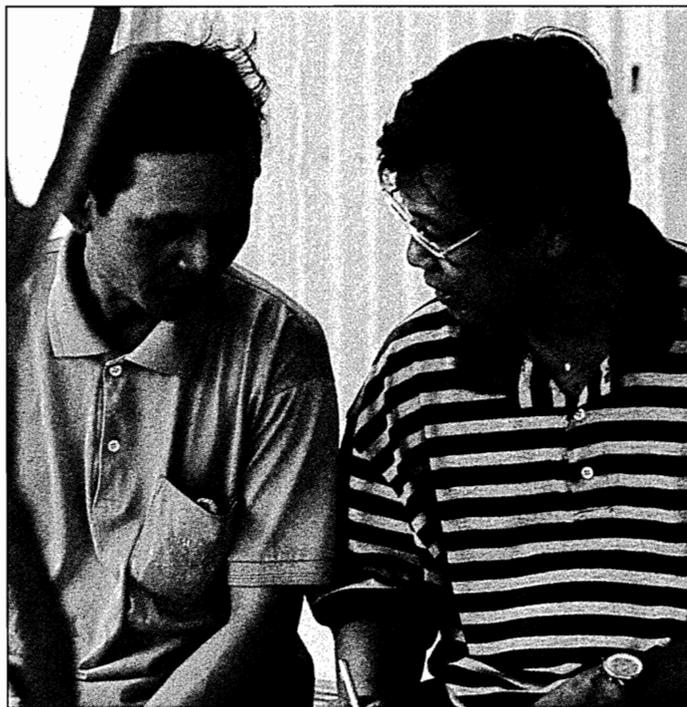
As a result, says FHI evaluation officer Christine Kolars Sow, "the data are more useful to more people."

While many welcome this approach, others lament the lack of data directly related to their own projects or activities. BSS data cannot show that any one intervention is responsible for trends in HIV risk behavior—a limitation, Mills points out, that the methodology shares with KABP surveys. "The only way to show causality is through large and expensive quasi-experimental or experimental designs," he said. "These would rob scarce funds from prevention interventions."

This inability to attribute findings to specific projects is not necessarily a disadvantage, adds Mills, because no HIV/AIDS project works in isolation. "An appropriate strategy is multiple overlapping interventions that hit people from different sides," he said.

To assess a project's contribution, Mills suggests, evaluators can look at its role in a country's response to HIV/AIDS and at temporal relationships between specific interventions and behavioral trends. In Tamil Nadu, India, for example, the size of the USAID-funded AIDS Prevention and Control (APAC) Project and the fact that men in the target groups began changing their sexual behavior during its implementation suggest that the project has played a significant role in reducing HIV risk behavior.

Organizations can also assess whether interventions of any size are making a contribution to the collective effort against HIV/AIDS by monitoring whether their projects are being carried out as planned. FHI recommends collecting and tracking process indicators, such as number of people educated or trained



Motorcycle taxi drivers are included in Cambodia's BSS because they are one of the groups that serves as a "bridge" between the groups at highest risk of HIV infection and the rest of the population.

FRANCESCA STUER/FHI

and number of condoms sold or distributed. Actual coverage of target populations could be evaluated through rapid surveys to determine, for example, recall of a program's prevention messages.

The key to ensuring that interventions have an impact, says Dr. Tobi Saidel, technical officer for evaluation and surveillance in FHI's Asia Regional Office, is sound project design and careful project monitoring. "We already know from research that if state-of-the-art interventions are implemented according to recom-

mended standards, they do result in behavior change," she said.

Ownership and Sustainability In each country, many local partners are involved in designing the BSS and disseminating their results. But usually one organization—often a private research firm, university or research institute—is chosen to collect and analyze the data with technical assistance from FHI.

In Cambodia, where contracting with a private company or nongovernmental organization (NGO) was not an option because of the lack of a private sector, the national AIDS pro-

gram's Planning, Monitoring, Evaluation and Research (PMER) Unit conducts the BSS. Some have urged the PMER to contract out various parts of the surveys, but many observers say the system works well.

Dr. Saidel believes that the PMER's assuming responsibility for BSS in Cambodia makes

it likely that the surveys will be sustained. When she began to assist the PMER to coordinate BSS with its HIV surveillance system in 1998, she said, "What I saw was a group of people with a tremendous ownership over the data."

Government HIV/AIDS programs in two other Asian countries—China, where Mills has served as a World Bank consultant to help design BSS for four provinces, and Vietnam—are interested in collecting their own data. But others warn that Cambodia's experience is unusual. "It's really unique there because this is a new government, and they don't have a history of mistrust between government and the target groups," said Dr. Pamina Gorbach, an FHI consultant who has worked with the PMER since 1996 (see page 34).

"The BSS help us understand whether the combined interventions of different groups are working together to change risk behaviors."

“Often governments don’t have very good rapport with disenfranchised groups,” agreed Mills, noting that having government employees survey people about sensitive and sometimes illegal behaviors such as commercial sex and drug use could pose problems in many countries. In others, government agencies simply may not have the time or capacity to collect the data.

When surveys are conducted by NGOs, whether they be private companies or nonprofit institutions, the biggest challenge is ensuring that BSS becomes an integral part of the country’s surveillance system. Different models are emerging for various countries, but the common thread is the need to involve national AIDS program officials in designing, reviewing and disseminating results from the beginning.

Ensuring Quality BSS is designed to gather information from groups rarely captured by traditional household surveys. This makes it much more difficult—but not impossible—to achieve a representative sample of the target group.

“With a little bit of extra effort in terms of mapping and finding out about the population in those sites, we can move from non-probability to probability sampling,” Dr. Saidel said.

Mapping enables researchers to identify where target groups congregate and to estimate the size of the group in each site. Local organizations working with the target groups may already

have lists of sites or maps showing the places where target groups can be found, but even then BSS researchers often need to do further research.

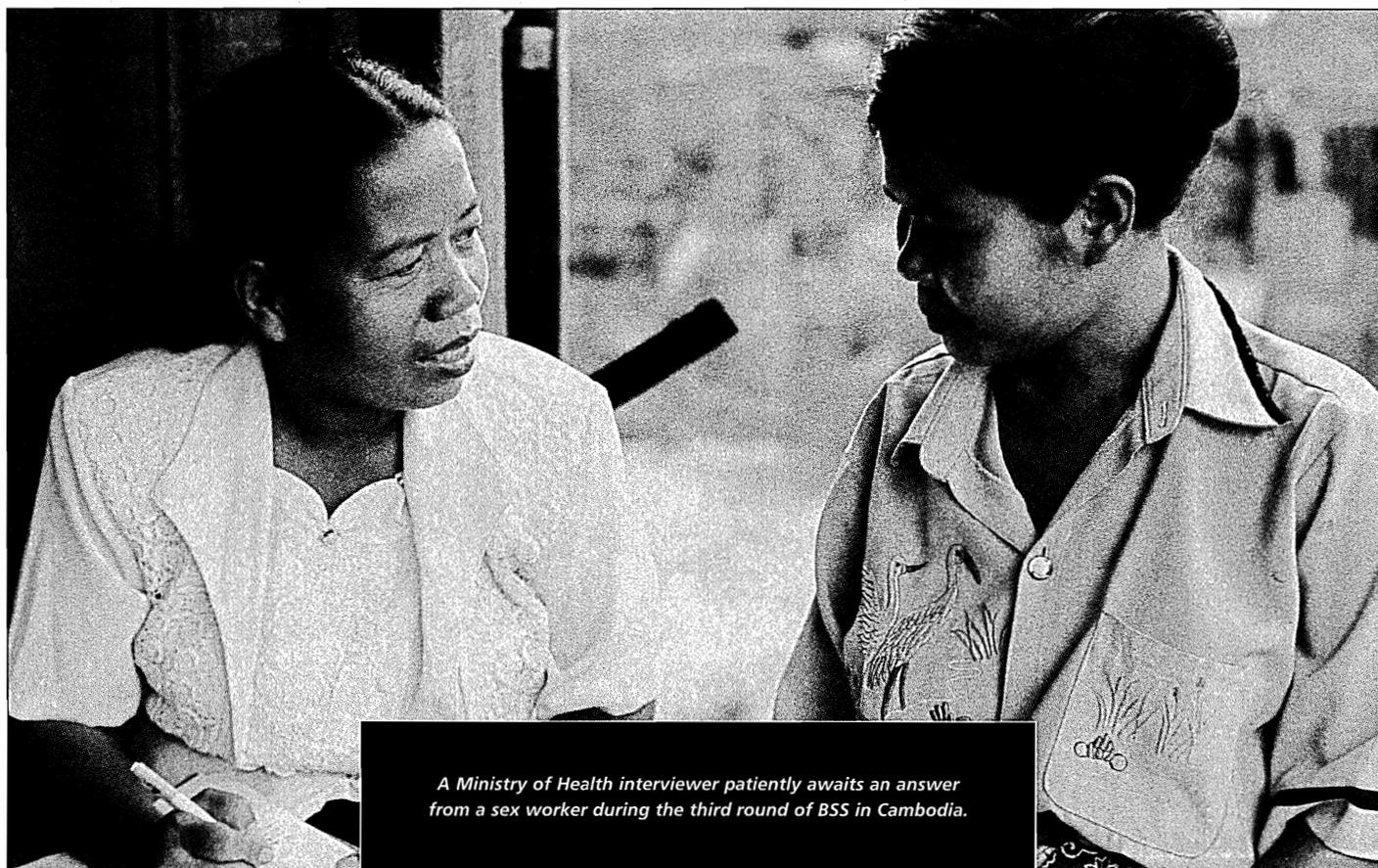
For the Kenyan BSS in the city of Mombasa, for example, lists were available of two kinds of sites where commercial sex workers meet their clients. Using one of the lists, BSS supervisors went to each of the bars and discos frequented by the more expensive sex workers and talked to bouncers and waiters to estimate the number of women working at each site.

“Initially, we did try getting the supervisors to take a physical count, but this was too subjective,” said Carol N’Katha Kageenu of Steadman Research Services, the firm FHI hired to conduct the first round of BSS in Kenya.

Visiting the almost 300 establishments where less expensive sex workers work would have been prohibitively expensive and time-consuming, so most of these estimates were obtained by phone. To learn about the size of this group, Steadman had to rely on the district health officer and his contacts.

“We tried to do this exercise with our own supervisors, but the bar owners were extremely hostile,” Kageenu explained. “The bottom line is that you need to work closely with local leaders to obtain useful information.”

Once this information on the target groups has been collected, FHI and its partners use creative approaches to probability sam-



A Ministry of Health interviewer patiently awaits an answer from a sex worker during the third round of BSS in Cambodia.

FRANCESCA STUER/FHI

pling. A decision tree developed by FHI helps researchers design an appropriate sampling strategy.

Mapping, developing a sampling strategy, testing and adapting questionnaires, and other preparations for the first round of a BSS in a country take about three months. "By taking that extra time, you can get better data," Dr. Saidel said.

No matter how well designed a study may be, self-reported data on sex is often considered suspect. Yet experience with research on sexual behavior and comparisons of behavioral survey data with findings from other types of studies suggest that survey participants tend to tell the truth most of the time.

Ultimately, says Dr. Saidel, "getting people to tell the truth relates to the skill of the interviewers and management of the whole survey process."

BSS supervisors and interviewers must build trust among the target groups, create an environment where people feel confident that their privacy and anonymity will be maintained, and convince target group members that accurate research results will benefit them and their communities.

"You need to take the time to carefully train interviewers and prepare target groups," Dr. Saidel said. "All of this contributes to the validity of the data."

Learning From Results During the past six years, FHI and its partners have disseminated BSS results and recommendations to various audiences in eight countries through publications, media interviews, and presentations at meetings, workshops and conferences. By tailoring the way the data were presented to meet the needs of specific audiences, they have encouraged policy-makers and program planners to act on the recommendations drawn from BSS data.

The results have been encouraging. In most cases, the data are used extensively for program design and evaluation. And in some countries, BSS findings have also been used to develop policies that support HIV prevention and to advocate for policy reform.

Promising trends in risk behavior from Cambodia, Nepal and Tamil Nadu, India, suggest that prevention efforts are on the right track. In Tamil Nadu, for example, annual surveys conducted from 1996 to 1998 found that significantly fewer men reported having sex with anyone besides their wives, girlfriends or other regular partners. Among male factory workers who did have sex with other partners, the proportion using condoms during the last such encounter rose from 17 percent to 50 percent, and condom use with sex workers soared from 28 to 67 percent.

In Indonesia, on the other hand, the results of three rounds of BSS showed little or no behavior change. According to Mills, these trends are not unexpected. "Low prevalence and socioeconomic disruption make behavior change very hard," he said. "In such settings, people do not have HIV on their agenda, and thus it may take longer to produce behavioral change."

Nevertheless, the survey results and findings from qualitative research are being used to revise strategies for containing the HIV/AIDS epidemic in Indonesia. To Dr. Saidel, this experience is a perfect example of the BSS's value as a diagnostic tool.

BSS results are also being used to reorient interventions in Senegal, where the first-round results in 1997 showed that knowledge of HIV was much higher than knowledge of other STIs—even though the latter are much more prevalent. "The BSS enabled

us to verify that sexually transmitted diseases were not well-recognized, and a specific intervention has been carried out among students," said Idrissa Diop, director of Hygea, the research firm that carried out BSS in Senegal.

Data from the second round of the Senegal BSS revealed that only 9 percent of male workers and 5 percent of truck drivers had visited a sex worker during the previous year. No trend data are available for these two groups, which were not surveyed in the first round. But if subsequent rounds of BSS show that this unusually low level of commercial sex patronage is a trend, it may offer a partial explanation for Senegal's relatively low HIV prevalence of less than 2 percent.

The explanatory power of combining HIV behavioral and epidemiological information was perhaps best illustrated in Thailand. An analysis of five rounds of BSS data from Bangkok helped confirm that declines in HIV incidence and prevalence were the result of behavior change.

Combining quantitative and qualitative information can also make behavioral data even more useful for program design and evaluation. In Kenya, focus group discussions and in-depth interviews carried out to explore some of the questions raised by the first-round BSS results yielded a wealth of information about how and why risk behaviors persist. Youth spoke candidly about how a desire to preserve virginity can lead to experiments with unprotected anal sex and made it clear that their fear of pregnancy far overrides fear of HIV infection. Sex workers talked about the pressures of competition from girls as young as 14 selling sex on the street at cut-rate prices. This qualitative information will be used with BSS data to help strengthen behavior change interventions to address the real obstacles to HIV risk perception and reduction.

Promising trends in risk behavior from Cambodia, Nepal and Tamil Nadu, India, suggest prevention efforts are on the right track.

Meeting Evolving Needs As interest in BSS has increased worldwide, FHI's evaluation specialists have been challenged to adapt the methodology to meet the needs of many different HIV/AIDS programs, donors and target groups. The flexibility of the methodology has enabled them to design BSS for a variety of situations and audiences, from assessing the contribution of a voluntary counseling and testing intervention in Zimbabwe to monitoring trends in risk behavior among mobile populations served by a cross-border prevention project in Indochina.

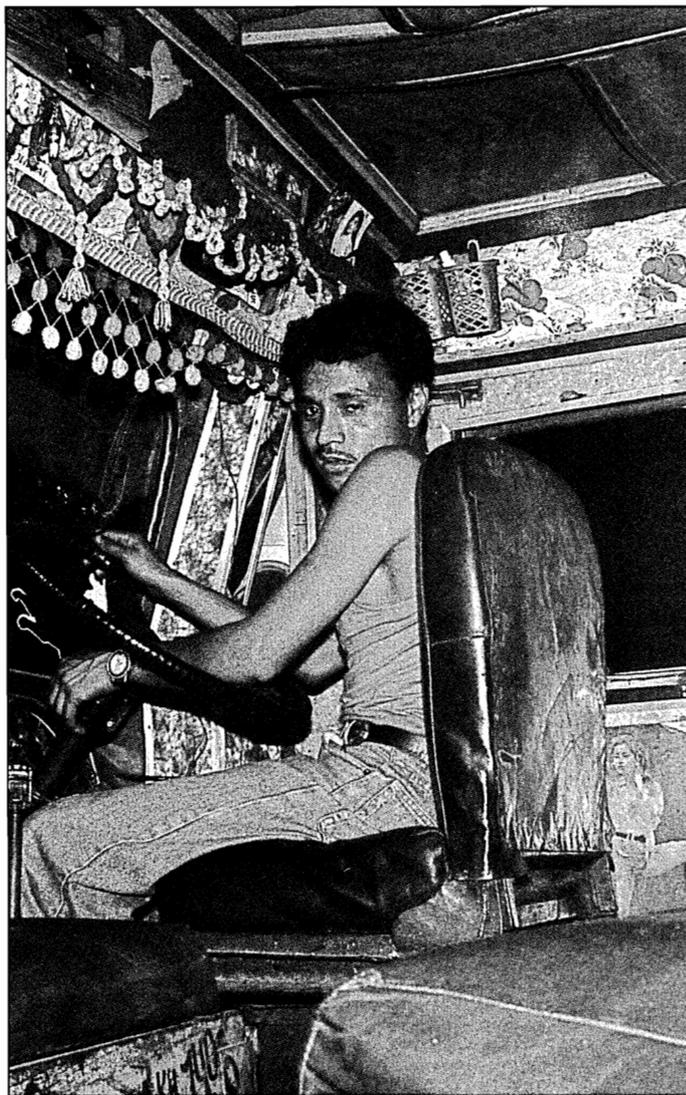
Adapting the BSS to gather information from women in marriages or other stable relationships is one challenge FHI faces in a number of countries. Since the BSS are designed to track risk behavior, the recommended indicators and sample questionnaires FHI has developed are not relevant for the many women at risk of HIV because of the behavior of their partners.

For such groups, "it's necessary to adapt the approach," Dr. Sow said. "We're doing this now in Zimbabwe and Nigeria, looking at issues of sexual negotiation and empowerment."

Other target groups that are relatively new to BSS—drug users and men who have sex with men (MSM)—pose different challenges. According to Dr. Saidel, little is known about the HIV risk behavior of these two groups in Asia. "The people who work with them will tell you it's a huge problem, and people aren't paying attention," she said.

In many parts of the world, research is needed to document levels of risk behavior among MSM and drug users and to assess the impact of this behavior on local HIV/AIDS epidemics. FHI has begun this work in collaboration with partners in Cambodia and India.

Working with MSM and drug-using communities and the organizations that serve them is the only way to carry out effective behavioral research among these groups, according to Dr. Saidel. Her research on indicators for drug users' risk behavior led her to the slums of Delhi, where she observed a large needle-exchange program run by an NGO called Sharan. From Sharan's members—some former drug users themselves—she learned about the



A Nepali truck driver stops at a town along the highway between India and Kathmandu. Drivers and other clients of sex workers along the route reported increasing condom use in three rounds of behavioral surveys.

MARY O'GRADY/FHI

wide range of potential risk behaviors, from actually passing a needle around to dipping needles into a shared vial or pot to mixing a drug with blood that may be contaminated.

Indicators of sexual behavior among drug users are also important to provide data for program implementation and advocacy.

"Condom use is a big area that gets ignored with drug users," Dr. Saidel said. "And the next thing you want to know is who are their partners. That might be a wake-up call to people who might be at risk."

Designing appropriate indicators is only one of the challenges of surveillance among disenfranchised groups, as FHI and its partners discovered during a first round of BSS in West Bengal, India, that includes MSM as a target group.

The West Bengal survey, funded by the United

Kingdom's Department for International Development (DFID) as part of a comprehensive assessment of sexual health interventions in five Indian states, is one of the first to track sexual behavior among MSM. "This will move them beyond anecdotal information to knowledge of risk levels," Mills said.

But such information is particularly sensitive in cultures where homosexuality and bisexuality are not recognized, and Mills acknowledges that it may surprise many people. "We don't want a backlash against the MSM community in West Bengal, so we have to present the data very carefully," he said.

DFID's West Bengal Sexual Health Project worked with local NGOs and their clients in the MSM community to build consensus on the interpretation of this data and on the accompanying recommendations to policymakers.

Such collaboration is essential in disseminating the results of any BSS, Mills notes. "You have to make sure that good information leads to more informed choices." ▣

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BSS Experience Builds Capacity in Cambodia

In 1996, when Cambodia was just beginning to confront an explosive HIV/AIDS epidemic, the country's national AIDS program fit in one room.

"The national AIDS program was tiny," recalls Dr. Pamina Gorbach, who came to Cambodia that year with a team from the University of Washington to work with the program's staff on a study of the prevalence of sexually transmitted infections (STIs), including HIV, and the associated risk behaviors.

Today, the National Center for HIV/AIDS, Dermatology and Sexually Transmitted Disease (NCHADS) has its own building and a staff of 61 men and women. But most of those who worked on the 1996 study remain, including a core group of researchers in the Planning, Monitoring, Evaluation and Research (PMER) Unit. From that first behavioral study, their research has grown into a full-fledged series of annual behavioral surveillance surveys (BSS) that provide invaluable information about the behaviors that drive one of Asia's most severe HIV/AIDS epidemics.

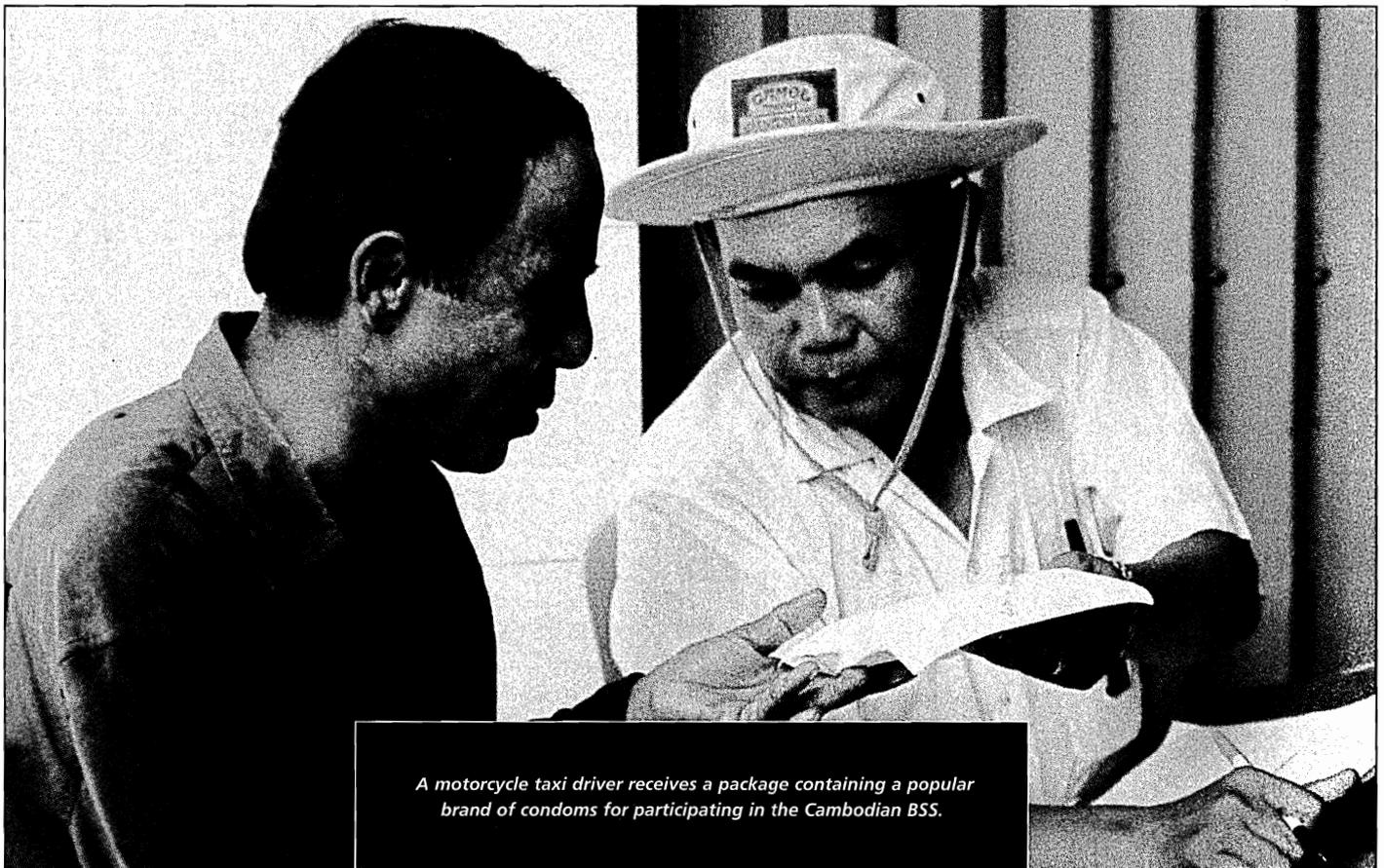
First Steps The 1996 research began as an STI prevalence study, conducted with assistance from Family Health International (FHI) and one of its partners in the AIDS Control and Prevention (AIDS-

CAP) Project, the University of Washington. Recognizing that little was known about STIs or STI risk behavior in Cambodia, the University of Washington added a behavioral component to the research.

The country was ruled by two prime ministers in an uneasy power-sharing arrangement that would lead to a coup a year later. Yet in spite of this political instability, Dr. Gorbach remembers, the timing was good. "It was a country in the process of being reborn, so we were there at the right time to get this started," she said.

The national AIDS program team was relatively young—as was the leadership of most sectors of Cambodian society after the loss of a generation to genocidal civil war. But its members more than made up for their inexperience with intelligence, energy and commitment. Team members worked with Dr. Gorbach on every aspect of the study, learning skills that they would teach to others in subsequent years.

Three of the Cambodian researchers spent two months in the field with Dr. Gorbach, conducting 781 interviews in three sites. The next year, they drew on that experience to train and supervise 30 interviewers for Cambodia's first BSS.



A motorcycle taxi driver receives a package containing a popular brand of condoms for participating in the Cambodian BSS.

FRANCESCA STUER/FHI

A Head Start Through the 1996 study, the researchers had already learned a great deal about which groups in Cambodia were at risk of HIV and other STIs and why. But additional research was required to gather the information needed to obtain a representative sample of each group. Much of his research was done on the streets and in public parks.

One of the interviewers—a Ministry of Health (MOH) physician—was particularly gifted. “She could talk to anyone,” Dr. Gorbach said. Nevertheless, a pilot survey of female vocational students found no one who would admit to having sex, so that group was dropped from the BSS.

Like many other BSS, the Cambodian surveys used “cluster sampling” to obtain representative samples of the target groups. Team members made lists of the areas where members of each target group assembled, such as brothels, police departments, beer companies, workplaces and vocational schools, and numbers of individuals in each of these “clusters.” Then they randomly selected clusters from each list and all members of those clusters were interviewed until the target sample size for each group was reached.

The researchers had a fairly good idea of what questions they would like to ask. They started with the questionnaire they had used for the 1996 survey and pared it down by about half for the BSS. The supervisors then did sample interviews with members of the target groups to pretest the questionnaire.

The questionnaire was also pretested during the field-based interviewer training. “The final pretest was really done by the people who were going to use the instrument,” Dr. Gorbach said. “This gave them a lot of experience with the instrument, and it engaged them in the process of developing it.”

Each of the interviewers belonged to one of five provincial teams. All were employees of the provincial health departments of the MOH, but not the NCHADS. To avoid having provincial AIDS office staff members interview their own clients, the AIDS program borrows staff from other provincial health programs, such as malaria or tuberculosis control, for a few weeks.

Supervisors from the NCHADS’s central office monitored the data collection in each province during the first two rounds of the BSS. This job includes ensuring the safety of the interviewers, checking all the forms, observing the interviewers to ensure that they are interacting appropriately with survey participants, and intervening when necessary to maintain privacy and confidentiality.

“For the first two years, four supervisors were there every day, watching the interviews, so we have really good quality data,” Dr. Gorbach said.

Continuity and Change Interviews for the 1999 BSS, funded through a World Bank loan for HIV/AIDS programs, began in

mid-June. Most of the same interviewers and supervisors have returned to work on the second and third rounds of the survey, and all three rounds were supervised by field coordinator Dr. Heng Sopheab, giving it a remarkable continuity. And as the NCHADS researchers have gained more experience with the methodology, they have assumed increasingly greater responsibility for different aspects of the survey.

The 1999 BSS marks the third round of the surveys in Cambodia and the first year of decentralization to the provincial level. Provincial AIDS office staff will serve as field supervisors, and the former supervisors who trained them will observe the interviews.

Decentralization will help free central level staff to manage an expanding portfolio of research and interventions. But according to Dr. Hor Bun Leng, NCHADS deputy director and head of PMER, their first-hand knowledge of the behavioral surveillance process has proved invaluable.

“It has helped the NCHADS a great deal in terms of capacity building to have experience in developing the BSS, conducting the interviews and doing the supervision,” he said.

Using the Results An analysis of two years of BSS results and a comparison with the 1996 behavioral study findings revealed encouraging progress in HIV/AIDS prevention. Consistent condom use during commercial sex had increased significantly among high-risk groups since 1996. For example, the proportion of sex workers reporting that they always used condoms with clients rose from 16 percent in 1996 to 53 percent in 1998.

This means, however, that only about half of the sex workers—a group with an HIV prevalence of more than 40 percent—use condoms consistently. Condom use with regular, usually non-commercial sex partners called *sangsa* (sweethearts) was low among all the groups surveyed, ranging from 5 percent among working men to 24 percent among sex workers. And a regression analysis showed that sex workers who have a regular partner or fewer clients are least likely to use condoms.

Findings such as these have been used to make adjustments in the NCHADS outreach program to sex workers and to develop guidelines for a national 100 percent condom policy based on a similar and very successful intervention in Thailand. Dr. Leng reports that the BSS results have also been used for strategic planning and advocacy.

“The most important and useful aspect of the BSS is the information on sexual behavior, which is surprising to the general public and to some conservative policymakers,” he said. “With these results, we can easily gain support from policymakers in different ministries and institutions to create their own programs in response to the HIV/AIDS epidemic.”

IMPACT PROJECT PUBLICATIONS

Meeting the Behavioural Data Collection Needs of National HIV/AIDS and STD Programmes This joint report released by Family Health International's IMPACT (Implementing AIDS Prevention and Care) Project and the Joint United Nations Programme on HIV/AIDS (UNAIDS) in January 1999 offers guidance on how to collect information about HIV risk behavior that will meet the needs of national programs. The result of a series of international meetings, the report recommends basic combinations of data collection methods for countries at different stages of the epidemic. It also describes how to link behavioral data with trends in HIV prevalence to gain a better understanding of the dynamics of transmission and the impact of prevention efforts.

An Expanded Response to the HIV/AIDS Pandemic This document describes the key technical strategies of IMPACT, a five-year international HIV/AIDS prevention and care project funded by the United States Agency for International Development and implemented by Family Health International (FHI). These strategies drive an expanded response to the pandemic designed to involve all sectors of society in giving people the knowledge, skills and support they need to prevent HIV transmission and to help those who are already infected or affected by the virus.

Through these strategies, IMPACT addresses sexual and non-sexual transmission of HIV, including unsafe handling of blood, injecting drug use and mother-to-child transmission.

BCC HANDBOOKS

Partenariat avec les Média: Collaboration avec les Média pour la Prévention du VIH/SIDA Part of FHI's Behavior Change Communication Series, this handbook provides readers with a strategy and practical suggestions for forming a long-lasting partnership with the media to inform people about HIV/AIDS and its prevention. Available in French and English.

Projets d'Accompagnement et de Soins VIH/SIDA: Utilisation de Techniques de Communication pour le Changement des Comportements dans la Conception et la Mise en Oeuvre des Projets d'Accompagnement et de Soins. Designed to help organizations use behavior change communication techniques to implement HIV/AIDS care and support projects, this handbook describes how to: decide whether your organization can effectively incorporate such interventions into its current activities; plan and design care and support interventions; meet the training and educational needs of staff, volunteers and target audiences; and develop systems for supervising, supporting and monitoring activities. Available in French and English.

Utilisation de Méthodes de Communication Capables de Changer les Comportements dans le Cadre des Activités de Prévention et de Traitement des MST: Approches Communicationnelles Communautaires et Cliniques des Programmes MST This BCC handbook provides readers with suggestions and examples for designing behavior change communication components for sexually transmitted infection (STI) control and prevention projects. Topics addressed include assessing client's and community members' beliefs about STIs and perceptions of STI services; training health workers in communication for STI prevention and management; and involving the community in the BCC program. Available in French and English.

Ordering Information All publications are in English unless otherwise specified. Single copies are available free of charge. Organizations from industrialized countries are asked to pay shipping charges for multiple copies (please include a DHL or Federal Express account number with your request). To order these publications, contact Information Programs, Family Health International, HIV/AIDS Prevention and Care Department at 2101 Wilson Boulevard, Suite 700, Arlington, Virginia 22201, USA. Phone: (703) 516-9779 Fax: (703) 516-9781

OTHER RESOURCES

Sexually Transmitted Diseases

Family Health International. This slide and lecture module is designed to help family planning programs address sexually transmitted diseases. Covering policy issues, prevention priorities, and approaches to diagnosis and treatment, the module is part of FHI's Reproductive Health Series for physicians, nurses, medical students, program managers and policymakers. It includes 35mm slides, lecture narrative, audience handouts, and reprints of key scientific studies. The module is available in English, French and Spanish. Single copies are free to developing country providers and trainers upon written explanation of need and may be purchased by others. For pricing details or to obtain a copy, please contact Ms. Carol Smith, Reproductive Health Series Project Coordinator, Family Health International, P.O. Box 13950, Research Triangle Park, NC 27709, USA. Tel: (919) 544-7040, ext. 589 Fax: (919) 544-7261

Under the Mapundu Tree: Volunteers in Home Care for People with HIV/AIDS and TB in Zambia's Copperbelt Teaching AIDS at Low Cost (TALC). This 68-page book and 35-minute video from ActionAid's Strategies for Hope Series showcases an innovative program that has successfully integrated tuberculosis (TB) control into home care for people living with HIV/AIDS and their families. Free copies of the book and video are available to organizations in sub-

Saharan Africa that are unable to purchase them. To receive a copy, contact TALC UK, P.O. Box 49, St. Albans, Herts AL1 5TX, United Kingdom, or visit TALC's Web site at www.strats-hope.org. Tel: (44 1727) 853869 Fax: (44 1727) 846852 Email: talculuk@btinternet.com

Clinical Tuberculosis, 2nd Ed. TALC. Written for non-specialist doctors and health workers in countries with a high prevalence of TB, this revised and updated edition of *Clinical Tuberculosis* includes an expanded chapter on HIV and TB. The cost is £3.50 plus £2.75 postage and handling (£3.75 airmail). To order a copy, contact TALC UK, P.O. Box 49, St. Albans, Herts AL1 5TX, United Kingdom, or visit TALC's Web site at www.strats-hope.org. Tel: (44 1727) 853869 Fax: (44 1727) 846852 Email: talculuk@btinternet.com

Joint United Nations Programme on HIV/AIDS Summary Booklet of Best Practices Joint United Nations Programme on HIV/AIDS (UNAIDS). In this 221-page booklet from its Best Practice Collection, UNAIDS identifies and examines 61 practices around the world that have successfully responded to the HIV/AIDS epidemic. The practices are arranged by their main topic areas, which range from antiretroviral therapy to community mobilization to workplace initiatives. To order copies of this booklet, contact UNAIDS, 20 Avenue Appia, 1221 Geneva 27, Switzerland.

Tel: (41 22) 791-46-51
Fax: (41 22) 791-41-87
Email: firleya@unaids.org

Trends in HIV Incidence and Prevalence: Natural Course of the Epidemic or Results of Behavioural Change?

UNAIDS. This 32-page report presents the results of a workshop organized by UNAIDS and the Wellcome Trust Centre for the Epidemiology of Infectious Disease. It provides an overview of the transmission dynamics of HIV-1 and reviews the impact of interventions by looking at three main areas: monitoring HIV infection, monitoring risk behavior, and evaluating interventions and national policy. To order copies of this report, contact UNAIDS, 20 Avenue Appia, 1221 Geneva 27, Switzerland, or download the report from the UNAIDS Web site at www.unaids.org. Tel: (41 22) 791-46-51 Fax: (41 22) 791-41-87 Email: firleya@unaids.org

Sexual Behavioural Change for HIV: Where Have Theories Taken Us? UNAIDS. This 55-page report from the UNAIDS Best Practice Collection showcases successful behavioral change interventions around the world and reviews the different theories and models on which the interventions are based. To order copies of the report, contact UNAIDS, 20 Avenue Appia, 1221 Geneva 27, Switzerland, or download the report from the UNAIDS Web site at www.unaids.org. Tel: (41 22) 791-46-51 Fax: (41 22) 791-41-87 Email: firleya@unaids.org

IMPACT ON HIV

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IMPACT ON HIV



Mother-to-Child Transmission Recommendations

Experts have advised the World Health Organization (WHO) that the safety and effectiveness of antiretroviral (ARV) regimens that prevent transmission of HIV from mother to child warrant their use beyond pilot projects and research settings.

This was the conclusion of a WHO technical consultation, held in Geneva Oct 11-13, 2000, on behalf of a United Nations interagency task force on the prevention of mother-to-child transmission of HIV. The meeting brought together scientists, managers of national HIV/AIDS programs, HIV-positive mothers, and representatives of UN agencies and nongovernmental organizations from Africa, Asia, Europe, the Caribbean and the Americas.

Meeting participants also recommended that prevention of mother-to-child transmission of HIV be considered part of the minimum standard of care for HIV-positive women and their children.

The safety of preventive treatments, including zidovudine (AZT) alone, zidovudine and amivudine, and nevirapine, has been studied in both breastfeeding and non-breastfeeding populations worldwide. Information currently available does not suggest any adverse effects on the health of mothers, the growth and development of infants, or the health and mortality of infants who become infected despite preventive therapy.

The most complex regimen includes zidovudine for the mother during pregnancy,

labor and delivery and postnatal doses for the infant. The simplest regimen requires a single dose of nevirapine at the onset of labor and a single dose for the newborn.

Recommendations from March 2000 had stated that because of possible concerns about the rapid development of nevirapine-resistant virus in women using this intervention, nevirapine should be used only within the context of pilot and research projects.

Resistant virus may develop quickly to ARV drug regimens that do not fully suppress viral replication, such as those including lamivudine and nevirapine, but evidence indicates that virus containing drug-resistant mutations decreases once the antiretroviral drugs are discontinued.

Mutant virus might remain present in an individual at very low levels, and this could reduce the effectiveness of future ARV treatments for the mother. However, the meeting concluded that the benefit of decreasing mother-to-child HIV transmission with these ARV drug regimens greatly outweighs any theoretical concerns.

Preventing mother-to-child transmission, however, involves more than simple provision of antiretroviral drugs. It also requires appropriate voluntary HIV counseling and testing services, as well as support for mothers and infants, including counseling on infant feeding options.

HIV Prevention Trials Network

The U.S. National Institutes of Health (NIH) has selected 25 research institutions in 13 countries to join the cooperative HIV Prevention Trials Network (HPTN), a five-year global effort to evaluate promising interventions to prevent the spread of HIV.

Funded by several institutes within NIH, HPTN will conduct research on means of reducing HIV transmission. This research will focus on six areas: preventing mother-to-child transmission of HIV; microbicides; controlling other sexually transmitted infections; changing behaviors that expose people to HIV; reducing substance abuse; and using antiretroviral drugs to prevent transmission of HIV.

In 1999, NIH chose Family Health International to lead and manage the HPTN, FHI

is joined by Johns Hopkins University, which provides the central reference laboratory for the network, and the Fred Hutchinson Cancer Research Center, which serves as the network's statistical and data coordinating center.

The HPTN continues work begun in 1993 through the HIV Network for Prevention Trials (HIVNET) sponsored by the National Institute for Allergy and Infectious Diseases (NIAID). Under this earlier effort, FHI oversaw vaccine and non-vaccine HIV prevention studies in 11 non-industrialized countries.

NIAID is HPTN's lead sponsor. Other NIH cosponsors of the network include the National Institute of Child Health and Human Development, the National Institute of Mental Health and the National Institute on Drug

Abuse. Funding for the first year of the project totals slightly over \$US 30 million.

Scientists worldwide competed for inclusion in the HPTN through a peer-reviewed evaluation process. Seventeen investigators have been chosen to lead the research at nine sites in the United States and 16 sites in non-industrialized countries.

The research sites outside the United States are in the following countries: Malawi, South Africa, Tanzania, Uganda, Zambia and Zimbabwe in Africa; China, India and Thailand in Asia; the Russian Federation in Eastern Europe; and Brazil and Peru in Latin America.

NIH will also sponsor clinical trials of HIV vaccines through a similar cooperative effort known as the HIV Vaccine Trials Network.

CORRECTION

Due to editorial error, the people pictured on pages 10, 15 and 17 were misidentified in the captions for the article entitled "INP+: India's HIV-Positive People Unite Against Discrimination and Repression" in some issues of the June 2000 IMPACT on HIV before the errors were discovered. IMPACT on HIV regrets these misidentifications and apologizes for any inconvenience they may have caused the individuals concerned.

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IMPACT ON HIV

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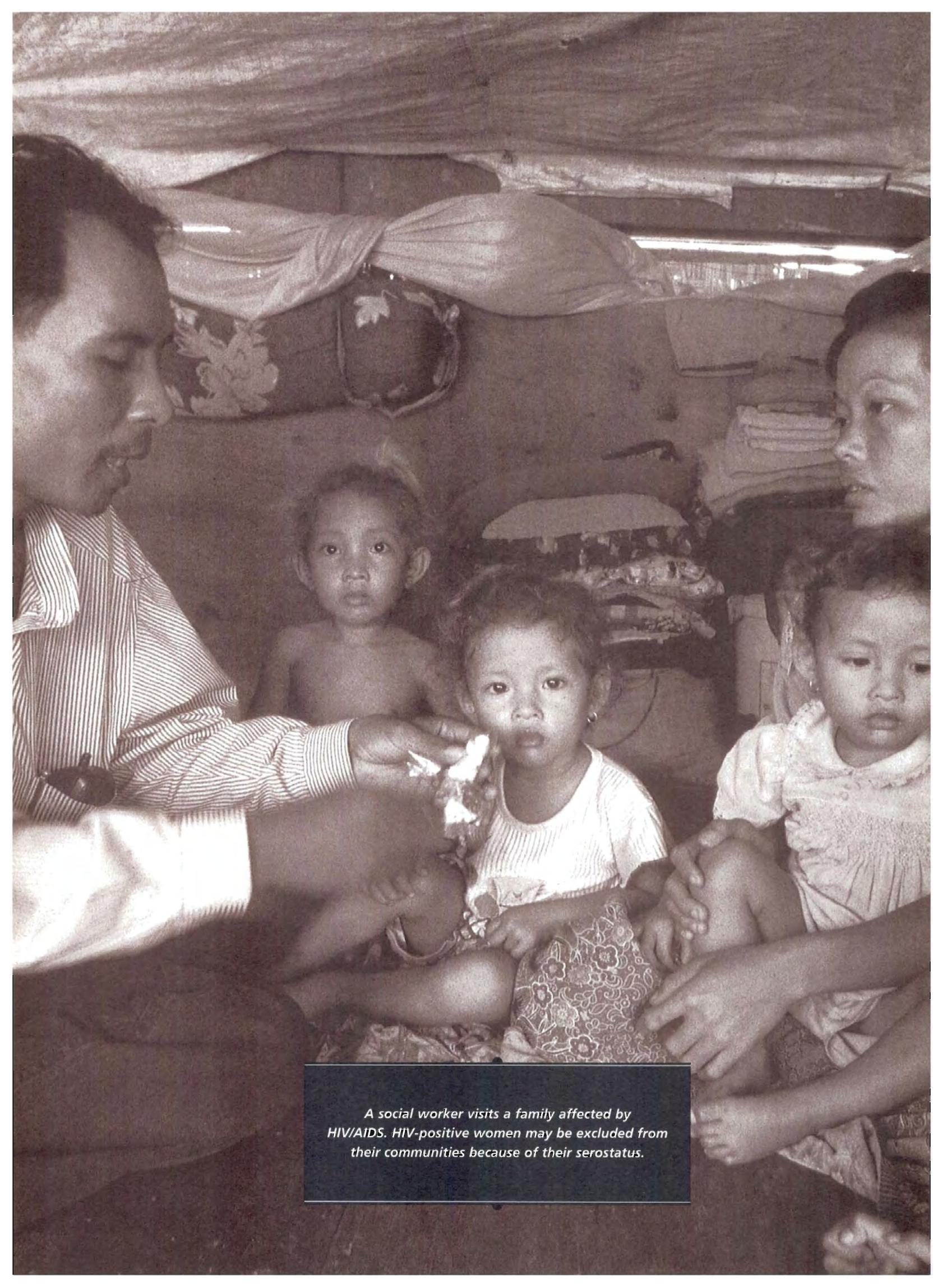


Cover photo: Thai schoolboys plot projections of growth in HIV/AIDS cases.

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A social worker visits a family affected by HIV/AIDS. HIV-positive women may be excluded from their communities because of their serostatus.

Making an Impact on HIV/AIDS in Cambodia

BY GILL FLETCHER

In Cambodia, where desperate poverty drives Asia's worst HIV/AIDS epidemic, comprehensive prevention programs are beginning to have an impact on the spread of the virus.

Now at peace after a recent history of genocide and 20 years of civil war, Cambodia faces another deadly threat. Nearly 8,000 people in the country are expected to die of AIDS in 2000—an average of 20 people a day.

Cambodia has the most severe HIV/AIDS epidemic in Asia, with an estimated 170,000 adults living with HIV/AIDS in 1999. That's out of a population of around 11.5 million people, more than 42 percent of whom are younger than 15 due to high birth rates, gradually improving health and, in some part, to lives lost during the years of conflict.

This epidemic is one of many challenges facing a country where Khmer Rouge genocide, famine and civil war killed at least 1.7 million people and destroyed whole infrastructures in education, health and transport. Today

Cambodians work to rebuild their country amid enormous social inequalities, low levels of food production, and high levels of homelessness and poverty. But despite this daunting post-war legacy, the country's leaders are working with local and international nongovernmental organizations (NGOs) to mount an impressive multisectoral response to HIV/AIDS.

"Luckily for Cambodia, its government recognized the scale of the country's HIV/AIDS problem early on and took measures to respond," said Francesca Stuer, country director of Family Health International's programs in Cambodia.

Cambodia's National AIDS Program, established in 1991, has developed into the National Center for HIV/AIDS, Dermatology and Sexually Transmitted Diseases (NCHADS), which manages HIV/AIDS prevention and care efforts nationwide. The National AIDS Authority (NAA), chaired by the Minister of Health with

the Prime Minister as honorary chairperson, is responsible for coordinating the Cambodian government's response to the epidemic by working to ensure that all Cambodian ministries and provinces integrate HIV/AIDS initiatives into their policies.

But NCHADS and the NAA know they cannot succeed alone. Their resources are limited, and the problem is great. Hence, there is national acknowledgment of the need for partnerships between the public, social, NGO and business sectors. Prime Minister Hun Sen emphasized this point in his closing address at Cambodia's first

international conference on AIDS in March 1999. "This is not just an issue for the government," he said. "Everybody should be involved."

"Luckily for Cambodia, its government recognized the scale of the country's HIV/AIDS problem early on and took measures to respond."

Encouraging Trends FHI established the Implementing AIDS Prevention and Care (IMPACT) program in Cambodia, which is funded

by the United States Agency for International Development (USAID), in 1998. Through IMPACT and other projects, FHI works with the government at the national level to conduct studies and inform policy development and with NGOs at the community level to support and strengthen HIV/AIDS prevention and care.

An important collaboration between FHI/Cambodia and the NCHADS is the technical assistance FHI provides on the national surveillance system. Based on the principles of "second-generation surveillance" outlined by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO), this system uses several different sources of data to decipher trends in the prevalence of HIV and other sexually transmitted infections (STIs) and in the behaviors that put people at risk of infection.

Every year, the NCHADS staff conducts a national HIV Surveillance Survey (HSS) in which people in selected groups are tested anonymously for HIV. Levels of risk behaviors for many of the same groups are assessed by analyzing interview data from annual behavioral surveillance surveys.

The groups included in the surveys are chosen according to the current stage of the epidemic in Cambodia. As a result, Cambodia's surveillance system monitors HIV, STIs and HIV risk behavior in those at highest risk of infection—primarily female sex workers and their partners, as well as those who might provide a “bridge” for HIV from these sexual networks to the rest of the population. It also includes pregnant women attending antenatal clinics, who are considered a reasonable proxy for the general population.

Though the surveys have found high levels of HIV infection and HIV risk behavior in Cambodia, there is some good news. Results from the 1999 HSS show that the epidemic might be declining among several groups at high risk of HIV infection. There is also no evidence of rapid increase in the national prevalence of HIV among women visiting antenatal clinics during the past few years, indicating that rates of transmission in the general population are fairly stable.

Data from three rounds of BSS suggest that these trends may result from behavior change. For example, the percentage of sex workers who work in brothels reporting that they always use condoms with their clients has risen steadily, increasing from 42 percent in 1997 to 78 percent in 1999.

These are encouraging signs, but they must be interpreted cautiously. “Improvements in the quality of data available each year may mean that previous estimates were too high, rather than indicating a true drop in prevalence,” said Dr. Hor Bun Leng, deputy director of the NCHADS. “It is too early to conclude that Cambodia is an HIV prevention ‘success story.’”

Data for Decision Making Dr. Tobi Saidel of FHI's Asia Regional Office in Bangkok, Thailand, is a member of the team of consultants who provide technical support in data management and analysis for the HSS. She notes that the 1999 surveillance data offer hope and a warning at the same time.

“Prior to 1996, it was more difficult to predict which way the trends would go,” she said. “The figures in the last few years are more comforting, since we now see indications of a leveling off of trends among high-risk groups and the general population.”

However, Dr. Saidel points to other worrisome trends, including evidence of an expansion of HIV transmission dynamics beyond sex workers and their clients. “The gap between the per-

centages of infected males and females is closing, indicating that transmission is increasingly occurring between men and their regular sexual partners,” she explained. “In addition, there are rising concerns about shifts from brothel-based commercial sex to more indirect venues, such as bars, karaoke lounges and massage houses, which could make conditions right for a new wave of infections.”

Given these trends, Dr. Saidel concludes, “Cambodian officials are wise to retain a highly vigilant stance with regard to the epidemic.”

Like current HIV prevention efforts, the response to these new trends in the epidemic will be driven by data. The talented and dedicated staff of NCHADS and the support they receive from donors such as USAID, the French Cooperation for Development, UNAIDS, WHO, the United Nations Children's Fund (UNICEF) and the Cambodian World Bank project have enabled Cambodia to maintain a continually improving surveillance system that provides data to inform program implementation.

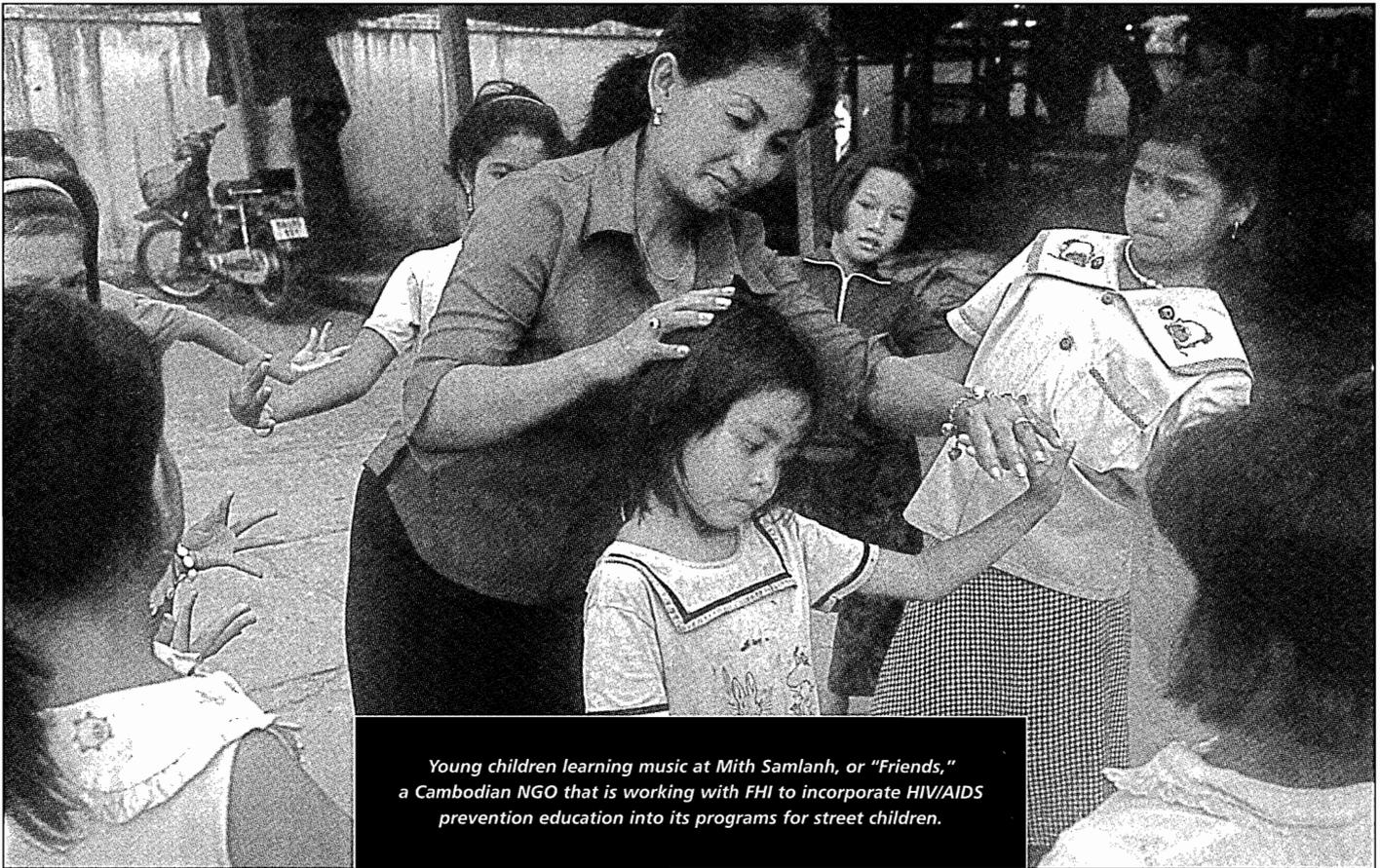
FHI/Cambodia uses HSS and BSS results, along with STI prevalence data, to identify the groups most at risk of HIV infection and the behaviors that put them at risk. More in-depth behavioral studies reveal constraints to individual behavior change and opportunities to support such change, and this information

is used to guide program design. With this information, the project—working through an HIV/AIDS prevention and care network of local NGOs and government agencies—has been able to reach out to members of the uniformed services, sex workers and their clients, street children, and mothers and children affected by AIDS.

Findings on the expansion of the HIV epidemic beyond high-risk sexual networks have prompted responses from FHI/Cambodia. For example, FHI is supporting the Nyemo Counseling Center for Women and Children Living with HIV/AIDS, which provides a safety net for families headed by women who are infected with HIV in Phnom Penh. Often separated from their extended families, these women either have been, or are at risk of being, excluded from the communities in which they live because of their HIV status.

The Nyemo Center will strengthen and expand the existing woman-to-woman support networks in Cambodian society, which already sees women taking responsibility for and caring for children from both within the extended family and from outside. Birth families often hand over their children if they feel that another family could look after them better. This practice seems to be based in an existing sense of communal responsibility for chil-

Though the surveys have found high levels of HIV infection and HIV risk behavior in Cambodia, there is some good news.



Young children learning music at Mith Samlanh, or "Friends," a Cambodian NGO that is working with FHI to incorporate HIV/AIDS prevention education into its programs for street children.

SHEHZAD NOORANI/WOODFIN CAMP

dren's well-being; however, the ties are loosened when women are physically or emotionally distanced from their extended families.

There is also a danger that, because of the possible stigma around HIV/AIDS and the increasing numbers of children being orphaned by AIDS, this natural coping mechanism may break down. Thus, the Nyemo Counseling Center will support communities and individuals in strengthening existing coping mechanisms and encouraging a sense of communal responsibility for the welfare of HIV-positive women and their children.

"Broken Women" Phan Vuthy, research team leader with Action, the NGO that develops information, education and communication materials for the IMPACT/Cambodia program, is not surprised by the finding that HIV seems to be moving into the general population.

"Every week one, two or three people living near to my mother's village die from AIDS," he said. "Every week. We all know about it."

Most of those who die, Phan Vuthy reports, are men with families —"moto taxi drivers, farmers, ordinary men." He adds that these men probably "went to play" with sex workers.

As a rule, in Cambodian society sex within marriage is for procreation, while sex with sex workers is for recreation. Men of all levels of education and social status make use of the brothels, bars and other sex work sites that can be found in larger villages and towns across Cambodia. It is particularly common for unmarried men in their late teens and early twenties to patronize sex workers: an active libido is considered a sign of strength, and most

young men have no alternative to commercial sex but abstinence. A Cambodian marriage is permitted only if the man can prove he can support a family, and many men must save for years before they can marry and have access to sex within marriage.

In Cambodia, as in many cultures around the world, sex workers are treated more judgmentally than those who use their services. In Khmer, the common phrase for sex worker is *srey khoch*, or "broken woman." All it takes for a woman to be "broken" is for her to lose her virginity outside of marriage—even if she loses her virginity through rape. Once broken, goes the Cambodian belief, she can never be repaired. The loss of virginity outside of marriage is a non-negotiable loss of "acceptability."

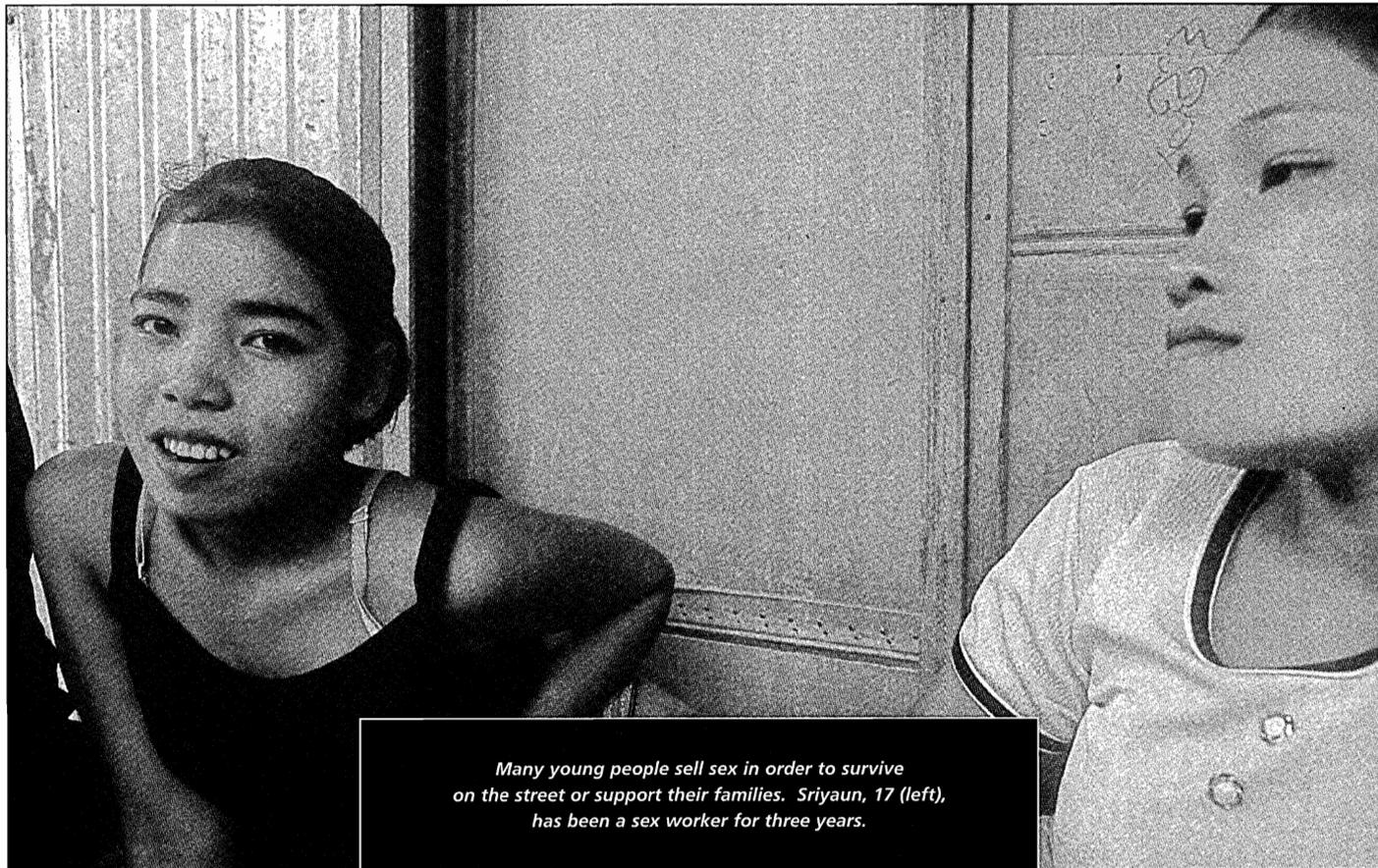
The stories of four young women who work in a well-known Phnom Penh site for commercial sex are illustrative of the difficulties many women face in Cambodia. Each has a mother or father and siblings who depend on her meager earnings, yet not one of the women would tell her family

what she did. They all pretended to do other work. "If my mother or father knew what I do, they would not accept the money," said Sophal, 20. "They would be angry."

"I feel difficult in myself, doing this," added Sophy, 31. "Each time I earn 20,000 riel [about \$US 5—the amount Sophy hopes to earn for one sex act], I feel like crying. It is bad work. But I feel forced to do it because I have no money."

The women provide emotional and practical support to each other and use condoms when they can, but it's not easy. Srey—who is 31 years old but tells prospective clients she is 26 so they

"Every week one, two or three people living near to my mother's village die from AIDS."



Many young people sell sex in order to survive on the street or support their families. Sriyaun, 17 (left), has been a sex worker for three years.

SHEHZAD NOORANI/WOODFIN CAMP

won't think she is too old for them—explains that sometimes men want only “the very pretty girls.”

“Sometimes I have met three, four, five men, and they haven't wanted me,” she said. “I have no choice. If I don't have any money, then I will accept someone who only wants to pay 5,000 riel or 10,000 riel [just over one U.S. dollar or \$2.50]. And sometimes it is very difficult to say they must use a condom. By that time, there are just the two of us in the room, and I have to do what the man wants. I cannot force him to do anything.”

Empowering Women Srey, Sophy and other Cambodian sex workers are slowly finding strength from each other and from a number of local organizations. Staff members from one of FHI/Cambodia's partners in the IMPACT program, Cambodian Women for Peace and Development (CWPD), have spent months gradually building relationships with women working in brothels and in shared, rented spaces, winning a little of the trust the women understandably find so hard to give. Now “team leaders” have been elected from among the sex workers, and CWPD is working with the women to develop skills for negotiating safer sex and to build their sense of self-worth. It's hard for the women to value their health if they are constantly told that their only worth is to service men's desires.

The women are encouraged to try to save money. Refusing sex without a condom becomes a lot more difficult if you are desperate and have no money at all. CWPD also lobbies on

behalf of the women and helps them get regular STI and general health checkups.

Phnom Srey Association for Development (PSAD) works in a similar way with different groups of women. The association is supported by FHI/Cambodia's IMPACT program to reach out to more than 200 young women who work in karaoke bars and brothels in Kompong Cham, the most heavily populated province in the country.

Large numbers of soldiers regularly pass through the town of Kompong Cham, which is the headquarters for Military Region 2. It also has a major port and houses the largest market in the region, which draw many more men in and out of the town,

making it a prime site for commercial sex. Scores of karaoke bars are home to hundreds of women who work in the bars but are often asked for sex by clients. Some are threatened with the loss of a job and home if they refuse a man. Sex is sold either in karaoke bar back rooms or in nearby guesthouses. There are

some brothels, but the police regularly crack down on them, taking money from sex workers and brothel owners alike or simply closing businesses down.

Back in Phnom Penh, the Urban Sector Group (USG) also emphasizes empowerment in its work with another group of women involved in commercial sex. Known colloquially as “orange sellers,” these women charge just 5,000 riel (under \$1.50) for sex. Their unusual name comes from times past when single women in the parks did indeed sell only oranges.

“Sometimes it is very difficult to say they must use a condom. By that time, there are just the two of us in the room, and I have to do what the man wants.”

Peer Educators Arm Military, Police Against HIV

Yim Akhara is chief of the Health Office for the Cambodian Navy. It's an important job, yet he unhesitatingly finds time to take on an extra workload, supporting an innovative HIV/AIDS project for members of Cambodia's uniformed services.

Why? "In my unit in 1994, we had to do some medical screening for staff who were going abroad," he explained. "We found that five men out of 75 were HIV-positive. They are all now dead. They all had families.

"It was very difficult because we didn't know how to help those men," he added. "That was before we began to work with FHI. Now I hope that I can help my colleagues to protect themselves from HIV."

The latest statistics show that his colleagues in the military, police force and the Cambodian Mine Action Center are in need of protection from infection. Seven out of every 100 men in these services are infected with HIV. That's second only to HIV rates among sex workers.

To reduce HIV among this group at high risk of infection, FHI/Cambodia's IMPACT program is assisting the Ministry of National Defense and the Ministry of the Interior in establishing and running peer education programs for the uniformed services. Currently operating in Kandal Province, Phnom Penh and Kampong Cham, the project is the largest single HIV/AIDS intervention with Cambodia's police, members of the military and the "deminers" who find and disarm the many explosive mines and unexploded bombs left scattered about the country after years of conflict.

Dr. Akhara is one of a team of "core trainers" at the top of a training pyramid designed to ensure that every unit involved in the program will have its own peer educators. The huge numbers involved make it impossible for FHI/Cambodia to train all the peer educators needed, so FHI trains core trainers, who then train peer educator

trainers, who in turn train peer educators. Each stage also has "quality control" built in, to ensure that the training meets the standards set for the initial work with the core trainers.

Colleagues can easily identify the peer educators within their units by the T-shirts and baseball caps they wear, which proclaim in Khmer: "AIDS. Come and talk to me." And, gradually, more and more members of the military are going to the peer educators for information and advice on protecting themselves and their loved ones.

These men are the public face of a program that, although currently implemented only in a small part of Cambodia, already reaches out to 30,000 members of the

uniformed services. The peer education program thus seeks to benefit Cambodian society as well by helping the men protect their wives, unborn children and other sex partners, including sex workers.

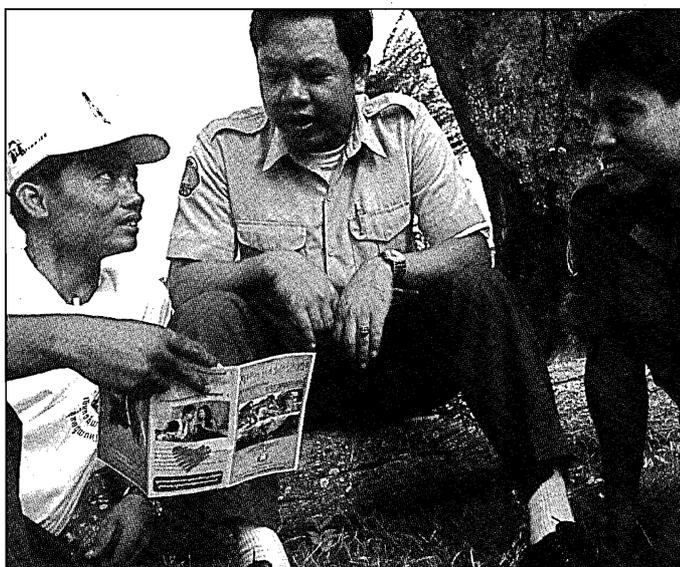
The most recent round of behavioral surveillance surveys in Cambodia revealed that slightly more than 55 percent of men in the military had visited a sex worker within a month of being interviewed. Unsafe sexual behavior is often influenced by peer pressure; alcohol, lust and condom use can be uneasy bedfel-

lows. Peer education helps the members of the uniformed forces to reconcile such conflicts—and to think about their own responsibilities when it comes to HIV prevention.

Recent data suggest that HIV prevalence may be stabilizing among police, an encouraging sign that prevention efforts are beginning to have an impact.

"If there was no peer education program, then the HIV epidemic would spread very fast among the military," said Dr. Akhara. "I am glad to be a core trainer. I think about my friends, about the people I work with, and about their families."

More and more members of the military are going to the peer educators for information and advice on protecting themselves and their loved ones.



Sitting by the bank of the Mekong River, a peer educator discusses myths and facts about HIV/AIDS with fellow members of the Cambodian Royal Navy.

SHEHZAD NOORANI/WOODFIN CAMP



The kind of poverty that residents of Phnom Penh's Bassac area know so well drives many women into sex work.

GILL FLETCHER/FHI/CAMBODIA

Then they began to sell “squeezed oranges,” or breast fondles, and now they usually sell oranges and commercial sex. Many of Phnom Penh’s orange sellers live in Bassac, one of the city’s most impoverished areas, where ramshackle shacks made out of banana leaves perch precariously on stilts over the mudflats of the river, Tonle Bassac.

With one-third of the country’s female sex workers infected with HIV and an epidemic believed to be fueled by male-female sex, the NCHADS has paid much attention to the need for condom use in sex work. Sex workers are encouraged to have regular tests for STIs and HIV, condoms are made easily available through social marketing schemes, and a 100 percent condom use policy is being implemented with support from a range of organizations, including FHI. The policy aims to ensure that condoms are used in every sexual transaction in every brothel in selected communities. This “blanket” use of condoms in very high-risk-transmission situations has been shown, from the experience in Thailand where the first such policy was developed, to play a significant role in reducing the incidence of STIs and HIV.

In Cambodia, if a client refuses to use a condom, sex workers are urged to withhold services and refund the client’s money. All sex establishments are required to be involved in the project to limit clients’ ability to purchase sex in other places without using condoms.

Common Threads It’s no coincidence that sex work and poverty go hand in hand in Cambodia. In a society that puts such a high premium on virginity and faithfulness to a husband, sex work is the refuge of desperate women: women with little or no education and often with a cultural imperative to help support their families.

“Poverty affects nearly all of the groups with which we work,” said FHI/Cambodia Country Director Stuer. “People who don’t know where the next meal is coming from are far more likely to display high-risk behavior, to have little or no concept of the need to plan or protect themselves for the future, and to have little or no power when it comes to negotiating safer sex because of their often overwhelming financial needs.”

It should come as no surprise, therefore, that many street children sell sex. Both boys and girls know that if they sell themselves, they can earn money to eat. Often they go to the streets because their families are too poor to support them.

In fact, many young boys and girls work to support their families.

Mith-Samlanh, or “Friends,” works to educate and support Phnom Penh’s street children. Among its many activities, Friends provides HIV/AIDS interventions with technical and financial support from FHI/Cambodia. The aim is to equip the street children with the tools they need to help protect themselves from risk and to work with them on the much more nebulous areas of self-esteem and a sense of the future.

In a society that puts such a high premium on virginity and faithfulness to a husband, sex work is the refuge of desperate women.

Street children usually report having higher numbers of sex partners than other young people their age, sniffing glue and generally taking greater risks with their health. They live from day to day, and find money where they can.

Such survival is, in itself, testimony to the strength of the children, and Friends works hard to build up the children's faith in their own capacities and in the possibility of a better future. It does so by offering education, health care, and emotional and practical support and through projects that aim to raise the children's self-esteem by giving them responsibility, the power to make decisions, and the assurance that their views are valued. One way Friends does this is by involving street children in its decision making and project planning.

Such a holistic approach is one of the common threads that bind the FHI/Cambodia program together. Partners in the program's HIV/AIDS prevention and care network share similar goals, approaches and challenges.

To strengthen the linkages among these partner organizations, FHI holds regular meetings and training workshops and, where possible, provides opportunities for partners to work together on intervention projects.

"The different agencies working in HIV/AIDS in Cambodia are all keen to support and learn from each other," said Stuer. "And we are all working to build greater links between Cambodian mainstream society and members of the high-risk groups, who are often seen as being outside of society."

Ultimately, all FHI projects and activities are designed to build the country's own capacity to deal with the HIV/AIDS epidemic. "Any interventions carried out by FHI/Cambodia's partner agencies are based within the communities which they serve," Stuer said, "and both successes and issues encountered along the way are fed into the development of national strategies."

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THE NAMES OF ALL THE SEX WORKERS QUOTED IN THIS ARTICLE HAVE BEEN CHANGED AT THEIR REQUEST.

Sopeap's Story

Sopeap, 16, is the eldest of six sisters. Their father—who was violent toward their mother—earned money riding a cyclo (similar to a rickshaw), and the family struggled to earn enough to eat. So after just three years of school, Sopeap was sent to help her mother sell vegetables at the market. At age 13, she was kidnapped and sold to a brothel miles away from her family.

The resultant rape changed what Sopeap now accepts as her position in life. "When a girl is not a virgin anymore, everybody can see it," she said.

Having lost her "honor," Sopeap spent six months in the brothel. Then she managed to steal some money from a client, took a taxi back to Phnom Penh, borrowed clothes from girls she met, and "began to work and sell sex myself."

Sopeap has renewed contact with her mother, who is sick and can no longer work. She gives her mother money when she can and worries about what will happen to her young sisters, who must work instead of going to school. They beg, sell small snacks on the street and collect waste, which they sell to adults who in turn sell it to recycling organizations. Once her sisters pass

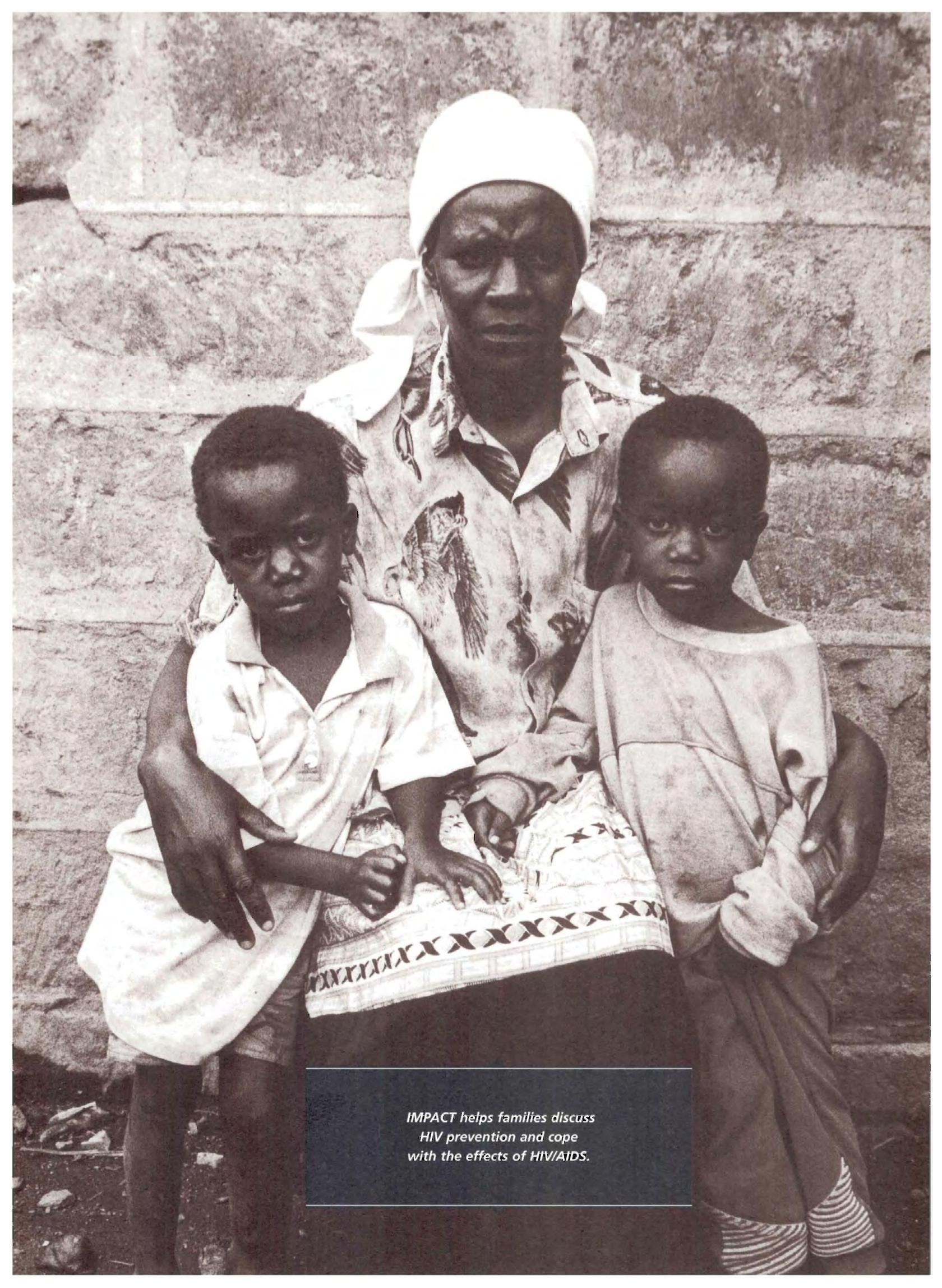
puberty, sex work will be another, slightly more economically viable, option—albeit an extremely limited one.

The sale of virginity brings with it a relatively high price (perhaps as much as \$US 400, split between the family and the brothel or go-between to the sale). But the income from sex work goes downhill from then on, in stark contrast to the social, personal and health costs of sex work.

Sopeap says she does not earn much. "When I cannot find a customer, I just don't have anything to eat," she added. Such desperation means Sopeap will always accept a customer—whether or not the customer wants to use a condom.

An HIV/AIDS program can't give Sopeap the money she needs to live. It can't restore her "honor." But such programs can offer more than just information about preventing HIV and other sexually transmitted infections. They can give Sopeap and others like her education and training to help them find more lucrative work and help them save the little money they have. Perhaps most important, they can help these young women develop self-esteem and negotiating skills so that they can protect their health.

*"When a girl is not a virgin anymore,
everybody can see it."*



*IMPACT helps families discuss
HIV prevention and cope
with the effects of HIV/AIDS.*

Realizing the HIV Prevention-to-Care Continuum in Kenya

BY GEORGE OBANYI AND LEE PYNE-MERCIER

A program that combines intensive behavior change interventions with community-based care and support for individuals and families affected by HIV/AIDS aims to make the prevention-to-care continuum a reality in Kenyan communities.

When Mary tested HIV-positive at the hospital where she had sought care for frequent illnesses during her pregnancy, she was sure there had been a mistake. A second test confirmed the result. "It was difficult to absorb the shock," she said. "I was worried about my baby."

Local health workers could not provide much assistance. They referred the 27-year-old expectant mother to Kenyatta National Hospital in Nairobi, almost 400 kilometers from her home in Kenya's Western Province.

What followed was intensive counseling on positive living with HIV. The information and encouragement she received from counselors at Kenyatta helped Mary accept her HIV status and face the challenges ahead, including the death of her husband a few months later and raising her children alone.

This kind of support will soon be available closer to home at a new HIV voluntary counseling and testing center at St. Mary's Hospital in the Western Province town of Mumias. Family Health International's Implementing AIDS Prevention and Care (IMPACT) program in Kenya is providing technical assistance to establish this center, with funding from the United States Agency for International Development (USAID).

Through the Mumias center and 11 other voluntary HIV counseling and testing centers, FHI/IMPACT will link interventions to reduce the risk of HIV/AIDS among vulnerable populations with community-based care and support for those already infected or affected by the virus. Outreach workers and volunteer peer educators will refer people to the centers and help them change the behaviors that put them at risk of infection. Those who test positive for HIV and their families will be referred to community-based teams of caregivers and other nearby sources of support.

Such linkages are one of the hallmarks of a new generation of programs responding to the challenges of HIV/AIDS prevention

and care in areas with high HIV prevalence, according to John McWilliam, the FHI country director in Kenya.

"Many programs are working on prevention in one part of the country and care and support in another part of the country—hence the target community does not see the connection," McWilliam said. "IMPACT is addressing the needs of the uninfected through prevention and clinical service interventions, the infected through care and palliation, and the affected through psychosocial support interventions in a given target community."

Priority Communities Almost everyone in Kenya knows about AIDS and how deadly it is. A recent IMPACT study carried out by the Program for Appropriate Technology in Health (PATH), however, found that there is widespread misunderstanding of the relationship between HIV and AIDS. The National AIDS and Sexually Transmitted Disease Control Programme (NASCO) estimates that 2.2 million Kenyans will be living with HIV by the end of the year 2000 and 3 million, or 15 percent of the total population, will be infected by 2005.

Reversing this trend calls for strategies that incorporate lessons from past interventions and intensify proven approaches. FHI's experience with its USAID-funded AIDS Control and Prevention (AIDSCAP) program in Kenya from 1992 to 1997 showed that targeting groups whose activities and settings expose them to a higher risk of HIV/AIDS can contribute significantly to halting the spread of the epidemic.

FHI and the 22 nongovernmental organizations (NGOs) and other local and international groups that are its partners in IMPACT/Kenya have used such lessons to design a targeted intervention strategy for the program. The design combines intensive prevention and care activities in selected regions with activities at the national level to help create an environment that supports sustained behavior change.

To have the greatest possible impact on HIV with the resources available, the IMPACT design focuses on eleven “priority communities” in three provinces—Western, Rift Valley and Mombasa—which were selected based on HIV prevalence, the presence of high-risk situations and settings, and programmatic needs and gaps. The high population densities in the chosen communities further justify the investment.

The largely rural Western Province has a population density six times the national average and high rates of HIV infection among those tested in prevalence studies. In the town of Busia on the Kenya-Uganda border, for example, prevalence among women at antenatal clinics has approached or exceeded 30 percent. Before FHI/IMPACT started activities in this province, the region had few HIV prevention programs.

More than one out of four adults are estimated to be infected with HIV in Nakuru, Kenya’s third largest city and capital of Rift Valley Province. Nakuru is surrounded by small towns dominated by agricultural industries, military bases and truck stops, where the practice of high-risk behaviors has fuelled the epidemic.

In the coastal town of Mombasa, a major port, numerous industries and tourism have attracted Kenya’s highest immigrant worker population after that of the capital city of Nairobi. Some 2,000

women serve commercial sex clients in Mombasa’s port, rail, trucking and tourism businesses, and half of all the sex workers tested in prevalence surveys have tested HIV-positive.

Five priority communities in these three provinces were originally targeted for IMPACT program interventions. Additional funding from the U.S. government’s Leadership and Investment in Fighting an Epidemic (LIFE) Initiative enabled IMPACT/Kenya to expand from five to 11 communities. It also gave the program, whose original mandate had primarily been HIV prevention, an opportunity to help people cope with the impact of HIV/AIDS on their families and communities.

Collaboration and Participation To facilitate collaboration among the IMPACT partners, FHI established field offices in Mombasa and Nakuru. FHI also holds monthly meetings that bring together an “implementation team” of representatives of all the IMPACT partners in each province to review progress, plan future activities, and discuss opportunities and constraints. These kinds of regular interaction have helped the program achieve a unique degree of collaboration, according to Dr. Elizabeth Ngugi, co-director of the University of Nairobi’s Strengthening Sexually Transmitted Disease (STD)/AIDS Control in Kenya Project. Under IMPACT, University of Nairobi staff members help train clinicians at clinics

managed by the Family Planning Association of Kenya and collaborate with Arnet Waves Communications on community outreach.

“Each one of the implementing partners is contributing an aspect in the prevention-to-care continuum, and we all feel as members of a family,” Dr. Ngugi said.

Community Involvement In all the priority communities, FHI/IMPACT promotes behavior change and a more supportive social environment for reducing HIV risk. The program also strengthens or helps establish the services necessary to support behavior change, such as accessible, effective diagnosis and treatment of sexually transmitted infections (STIs).

Interpersonal approaches are at the core of IMPACT’s intervention strategy. Peer education in the priority communities targets sex workers, men at workplaces, adult women in low-income neighborhoods, and students. Outreach through performances by youth drama groups is primarily aimed at youth, but also speaks to parents and other community members.

“These interventions make it possible to bring HIV and AIDS into daily living room discussions among families in the priority communities,” says Peter Mwarogo, field operations manager for FHI/Kenya. “The man gets the same message from his peers at the workplace, so does his wife from neighbor-

hood peer educators, and the children from the school and the youth theater outreaches. Issues brought out through these various sources can trigger discussions at dinner time, thus making HIV/AIDS an everyday agenda in the home.”

Peer educators across the priority communities initially receive one week of training, which is updated at regular meetings with IMPACT field coordinators. During the meetings, participants discuss the questions they’ve received and how to respond to them. They also develop and practice the use of participatory approaches to peer education.

The standard curriculum for peer educators emphasizes interpersonal communication skills and participatory techniques. For example, “picture codes,” or illustrations depicting various risk situations, are used to provoke spirited discussion and individual and group reflection. Participatory games capture audiences’ attention and make learning fun.

“One does not feel like you are put in a corner to receive education,” observed Stephen Mukare, who has participated in peer education sessions at the Kenya Ports Authority. “We contribute as much as we receive the information.”

Ask Me FHI and its partners knew that IMPACT needed an innovative communication strategy to help move Kenyans beyond aware-

“These interventions make it possible to bring HIV and AIDS into daily living room discussions among families.”

ness of HIV/AIDS to action. "It is well known that the usual messages about HIV and AIDS have perhaps outlived their shelf life and lost their edge and power to trigger reflection and behavior change," said C.Y. Gopinath, creative director for PATH/Kenya.

The theme of the IMPACT strategy, executed by PATH and the rest of the partners in all sites, is "question your relations and take charge of your life."

"AIDS is a consequence of fractured relations, just like violence and other social problems," Gopinath explained. "This strategy encourages inquiry into the quality of relationships that dominate within communities—between husband and wife, young man and woman, CSW [commercial sex worker] and her client, infected and uninfected."

Such inquiry, captured in the Kiswahili slogan "*Niulize*" ("Ask me"), is intended to create a more positive view of what these relationships could be, and thus lay the foundation for optimism and change. Peer educators and outreach workers provide information in response to questions from community members, and the issues raised become more complex as people's ability to reflect on their own situations deepens.

The concerns and themes that arise within the communities will be amplified to a wider public, mainly through a 30-minute interactive radio show that will be broadcast nationwide. The program will include a soap opera called *Pendo's Story*, a panel discussion, news, interviews and song.

Reaching Youth Discussions about sexual relationships and the Kenyan HIV/AIDS epidemic often turn to the relations between girls or young women and older men. "In Kenya, like in many other African countries, older men are targeting younger girls who they believe are 'clean,'" said Theophil Orangi, a teacher and Girl Guide leader. "It is attitudes such as these that have led to an increase in HIV among girls."

Studies in Kenya have identified youth, and particularly girls, to be at high risk of HIV infection. National statistics indicate that the highest HIV prevalence rates are found among women ages 20 to 24 and men ages 30 to 39. Studies from Nyanza Province show that 22 percent of young women in the 15- to 19-year age group are already infected with HIV, compared with just 4 percent of their male counterparts.¹

One IMPACT project uses the national network of the Girl Guides to bring HIV/AIDS prevention education to girls. This



As caregivers, widows and people affected by the virus, women often shoulder much of the burden of HIV/AIDS.

WENDY STONE/ELIASON AGENCY, INC.

peer education initiative, carried out by the Kenya Girl Guides Association with technical assistance from IMPACT, includes contests and a merit badge that Girl Guides can earn through work and study.

"Our youth usually influence each other to do negative things," said Margaret Ochieng of the Kenya Girl Guides Association in Mumias. "In this case, we are empowering the youth to influence each other in a positive way."

Young people also influence their peers through the popular theater program run by Artnet Waves Communications. Artnet

trains members of local youth groups in basic theater production skills, and other IMPACT partners educate them about HIV/AIDS so they can stage short performances with HIV/AIDS messages.

Schools are also part of the effort to reach youth with potentially lifesaving information and support. FHI/IMPACT is working with the Centre for British Teachers (CfBT), which has enlisted teams of parents and teachers from 100 schools in Nakuru to determine how to integrate HIV/AIDS messages into subjects such as home science, music, languages, arts and crafts, and drama.

Empowering Women In its work with sex workers, FHI/IMPACT has adopted the model developed by the STD Project of the University of Nairobi in Nairobi and Nakuru. By mobilizing sex workers to use condoms, seek prompt treatment for STDs and form support groups through which they were empowered with negotiating skills, the project helped the women take measures to protect themselves from HIV. As a result, the annual incidence of HIV among 4,000 sex workers in the project sites dropped from nearly 50 percent in 1987 to approximately 10 percent in 1997.

The project paid dividends for other community members: a 15 percent decline in the number of pregnant women testing positive for HIV. This result illustrates how interventions targeting groups at high risk—a common strategy in areas with low HIV prevalence—can also have a dramatic impact in high-prevalence settings.

"By reducing STD in sex workers, we are reducing STD in men and, by extension, we are reducing STD in the men's spouses," said Dr. Ngugi.

FHI/IMPACT is expanding the work of the STD Project to all of its priority community sites, involving other organizations in the effort, and incorporating more participatory methods. Laura Wangari, a project coordinator attached to the International Centre for Reproductive Health, which is an affiliate of the

University of Ghent in Belgium and an IMPACT partner in Mombasa, says the approach is proving effective.

"Many of the women did not believe in condoms and some were initially hostile when approached," she said. "But once the peer educators were trained and starting using condoms, the demand for condoms shot up."

Rose Wambua, a sex worker in Mombasa, appreciates the negotiating skills she has learned and the caring attitudes of program staff. "In a community with a lot of negative attitudes towards female sex workers, the program has made us feel someone values us as human beings and is interested in our health and welfare," she said.

Still, Wambua notes, it takes time and patience to convince men to use condoms. Sometimes solidarity with other women helps. "In some groups, the women have blacklisted clients who still insist on not using condoms," Wangari reported.

Involving Workers and Employers Members of another important audience—men—are reached on the job. In Mombasa, for example, IMPACT supports four large workplace HIV/AIDS projects. As part of one of these projects, 200 peer educators hold weekly meetings and informal talks with their coworkers at the Kenya Ports Authority (KPA), which has about 7,000 mostly male employees.

Qualitative evaluation suggests that such workplace programs are beginning to affect norms of social behavior and that they have stimulated demand for HIV prevention services such as STI treatment and condom social marketing. Most programs, however, have been donor-driven, and only a few businesses are directly funding HIV/AIDS prevention activities.

In Western Province, the Mumias Sugar Company is emerging as a model of what companies can do. During a recent launch of the IMPACT program in Mumias, the company's chief executive officer, Errol Johnstone, announced that the organization would set aside funds for a comprehensive HIV/AIDS program and request technical assistance from FHI.

To encourage other companies to respond as Mumias Sugar Company has, FHI is collaborating with the Regional AIDS Training Network at the University of Nairobi to develop a package of HIV prevention services that employers can purchase. FHI/IMPACT is also working at the national level to heighten management and employee awareness of the need for workplace-based interventions. The aim is to institutionalize sustainable, high-quality workplace HIV/AIDS programs funded primarily by employers.

"We know many companies are trying to find ways to address the problem," said McWilliam. "We'd like to help them find ways to assist their workers in prevention, care and support for HIV and AIDS."

Linking Prevention and Care Voluntary HIV counseling and testing (VCT) is seen as the linchpin in the prevention-to-care continuum that local organizations and communities are building with the help of FHI/IMPACT. Through a referral network of peer educators, field coordinators, counselors, healthcare staff and community caregivers, HIV VCT services will help link prevention efforts with the newer care and support interventions made possible by the LIFE Initiative.

HIV VCT can be an effective behavior change intervention in its own right, as the findings of a multicenter randomized study conducted in Kenya, Tanzania and Trinidad confirmed.² Mary, the young HIV-positive widow from Western Kenya Province, knows this link between VCT and prevention all too well. An active volunteer in the Society of Women Against AIDS in Kenya (SWAK), one of IMPACT's partners, she has taken her role in HIV prevention very seriously since learning of her status.

"Men sometimes try to seduce me, but I resist their advances," Mary said. "If I was careless, I would have spread the disease to many people."

Mary also knows how important the psychological support she received from Kenyatta Hospital counselors was in giving her the will to survive. She believes that better access to such services is essential for reducing the stigma associated with HIV/AIDS.

"Counseling, especially in rural areas, should be increased,"

she said. "This will help people come out in the open and speak about AIDS."

Assessments of HIV VCT services in Kenya have shown that few services are available, and most sites offering counseling and testing provide poor service. Confidentiality may not be guaranteed, the quality

of counseling is variable, and linkages between HIV VCT and HIV/AIDS care and support services are often non-existent. One study conducted by FHI and the Population Council found only one site in Nairobi offering walk-in counseling and testing services in 1999.³

FHI/IMPACT's vision is to bring quality HIV VCT services to the community. The program is working with a variety of partners to establish voluntary counseling and testing centers in each of the priority communities, usually by adapting and equipping existing health centers to provide such services. Lab technicians are trained in HIV testing and quality assurance, and counselors receive training in pre- and post-test counseling.

LIFE Opportunities VCT center staff will refer HIV-positive clients to sources of AIDS care, psychological and social support, and diagnosis and treatment of tuberculosis and other opportunistic infections. LIFE Initiative funding will enable FHI/IMPACT

"It is well known that the usual messages about HIV and AIDS have perhaps outlived their shelf life."

to complete the continuum from prevention through care by working with Kenyan health services, NGOs and communities to improve such services.

For example, FHI/IMPACT is collaborating with the public health system to strengthen the capacity of medical facilities to offer diagnosis and treatment of TB, which has reached epidemic proportions in communities with high rates of HIV. Even in countries with successful TB control programs like Kenya's, AIDS-related TB is overwhelming existing resources. As a result of rising HIV infections, Kenya has experienced a 600 percent increase in its TB caseload over the past 11 years.

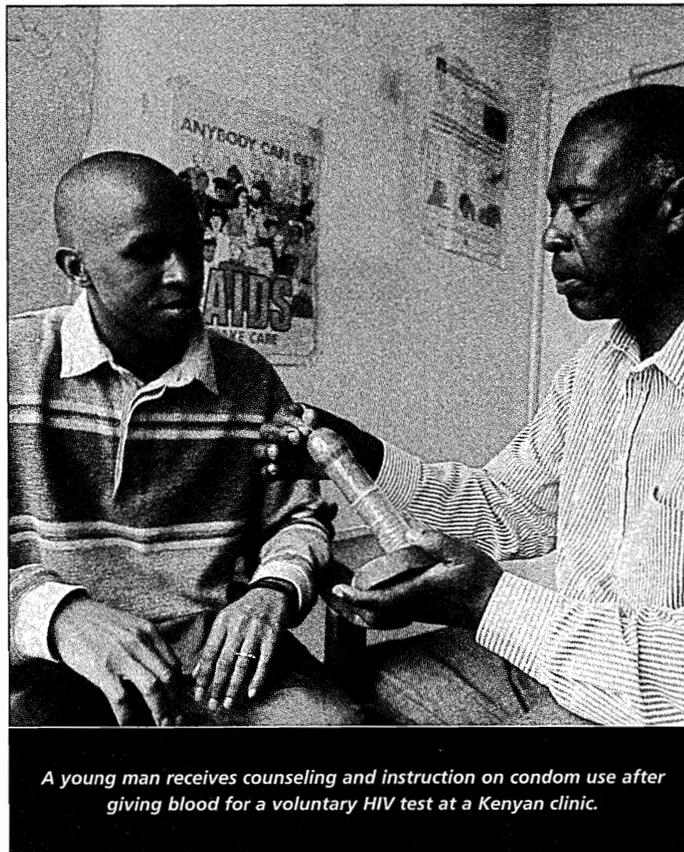
FHI/IMPACT will also help forge an often missing link in the continuum of care by preparing a number of health centers to serve as HIV clinical care centers. These centers will offer much needed medical support to the family members and volunteers who provide home-based care to a growing number of people living with HIV/AIDS.

FHI is working with ICROSS (International Community for Relief of Starvation and Suffering), a local NGO, and Kenya's district AIDS committees to improve home-based care. Collaboration with district AIDS committees enhances sustainability because staff salaries are paid by the Kenyan government.

The district AIDS committees will form home care teams of government health personnel and community volunteers to provide individualized care and support services to HIV/AIDS-affected households. The services offered may include counseling, nutrition, infection prevention and palliative care, depending on the needs identified by families affected by HIV/AIDS in participatory assessments.

Once the ICROSS home care program is underway, a similar participatory process will help mobilize communities to support orphans and other vulnerable children. Peer educators, support group members, home care teams and other community members will be involved in identifying children in need of support and the community resources available to support them.

A Beginning Before they began implementing IMPACT projects, the partner NGOs mapped out their communities together, highlighting areas where HIV risk behavior was prevalent, as well as existing prevention and care services in their communities. Mapping the communities and dividing them into zones assigned to different field coordinators and peer educators helped the



A young man receives counseling and instruction on condom use after giving blood for a voluntary HIV test at a Kenyan clinic.

GIACOMO PIROZZIPANOS PICTURES

IMPACT partners ensure that their communities were covered and that high-risk areas were adequately targeted by interventions.

"With this intensity, we are covering *everyone* in each of our priority communities," explained Stella Kilalo, a field coordinator for the Mkomani Clinic Society, an IMPACT partner in Mombasa.

The experience of Mariam Abdalla, a resident of the IMPACT priority site of Kisauni, illustrates how such intensive community-based prevention and care activities can have a pervasive influence.

The wife of a driver at Bamburi Portland cement factory, one of the IMPACT workplace sites, Abdalla says these days she discusses AIDS issues with her family and is impressed that her daughter, son and husband are equally well informed. Her neighbor, Rukia Mohamed, has been trained as a community caregiver by another USAID partner, Pathfinder International, and Abdalla has referred people to her.

Of late, Abdalla says, the health workers at the Kisauni clinic are very friendly. Every time she visits the clinic, the providers talk to her about HIV/AIDS and STIs. Abdalla has not yet decided to go for HIV testing but thinks she will as soon as the services are introduced at the Kisauni health center. Only time will tell.

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Breaking the Silence in Nigeria: An Appeal to Presidents

SPEECH BY JOHN IBEKWE

A courageous speech by a Nigerian man living with HIV/AIDS—and the response from Nigeria's President and the visiting President of the United States—made a profound impression on a nation mired in denial of an epidemic that has already spread to 5 percent of its adult population.

John Ibekwe of Onitsha, Nigeria, never thought he'd meet a president. But on August 27, 2000, in the Nigerian capital of Abuja, he had the opportunity to tell his story to the leaders of the Federal Republic of Nigeria and the United States. A program officer with the Humane Health Organization, which is a partner in the Family Health International (FHI) Implementing AIDS Prevention and Care (IMPACT) program in Nigeria, Ibekwe was one of four speakers at an event organized for U.S. President Bill Clinton's visit to Nigeria. Ibekwe also introduced President Clinton. Tayo Akinmuwagun, a volunteer peer health educator with the Environmental Development and Family Health Organization, a youth-focused NGO that is also a partner in the FHI/IMPACT program, introduced Nigerian President Olusegun Obasanjo.

As President Obasanjo, President Clinton and an audience of about 1,200 health workers and community members listened, Ibekwe told of the discrimination he faces as a person living with HIV. He urged both presidents to serve as powerful advocates against the pervasive stigma and denial associated with the virus.

Almost two weeks later, at a reception for African leaders assembled in New York City for the United Nations Millennium Summit, President Clinton spoke with emotion about Ibekwe's presentation, calling it "one of the most moving experiences I have had as a president."

"I have been through a lot of interesting and profoundly emotional experiences the last eight years," he added. "But one of the most moving things that's happened to me happened when

we were just in Nigeria and President Obasanjo and I went to this event in an auditorium with a lot of people to talk about what they were doing in Nigeria to try to prevent AIDS."

President Clinton recounted Ibekwe's story and told his audience that at the end of the presentation, President Obasanjo had embraced Ibekwe's wife, Angela, who is also HIV-positive, in front of hundreds of people. "It was all over the press in Nigeria the next day," President Clinton added. "It changed the whole thinking of a nation about how to approach this disease—to treat the disease as the enemy, but not the people who are gripped with it. It was an amazing encounter."

—Kathleen Henry



President Bill Clinton congratulates 15-year-old FHI peer educator Tayo Akinmuwagun on her speech.

REUTERS

“Mr. Presidents, I am an adult living with AIDS. I used to think there was no hope for those of us living with HIV/AIDS in this country. But my perception of the future has changed. For the first time in this country, we have a president who has openly acknowledged that AIDS is a problem and has decided to lead the fight against it.

I wish to applaud the dedication of President Obasanjo in the fight against AIDS in Nigeria. But the size of the problem in Nigeria is huge and looks suffocating.

Distinguished guests, this is my story. My wife and I lived together from January of 1995 after our traditional marriage and got a date in April of that same year for our church wedding. But part of the conditions to be met before marriage in the Catholic Church in Onitsha, where we stay, was an HIV antibody test. Without pre-test counseling, my wife and I took the HIV antibody test, and the result was positive for my wife and negative for me.

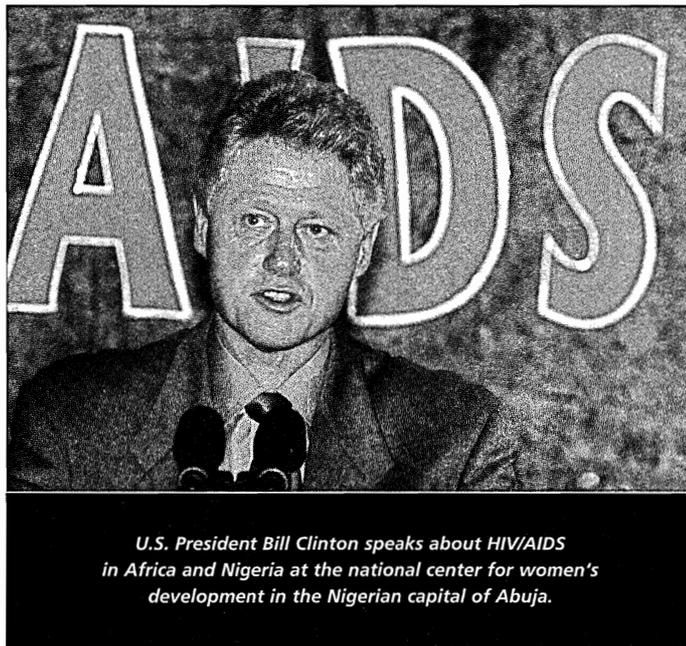
First, the church announced the revocation of the wedding. When we insisted, our parents were invited. The priest asked our parents if they knew our serostatus. They said yes. The church took time to explain the implications to our parents, but they still supported the marriage. The church thereafter agreed to wed us.

After the wedding, we became close to the archbishop and all the reverend fathers involved. The archbishop referred us to an Argentine doctor, Suzi Coddazi, who was then implementing Family Health International's community home-based care project in Onitsha, funded by the United States Agency for International Development. Our situation improved with the counseling and home visits by outreach workers from the project. I am today a program officer of the care and support project.

In August 1995, my wife was one of those offered an American visa through the lottery. We were then referred to

St. Nicholas Hospital in Lagos by the American Embassy for medical tests that included the HIV antibody test. My wife tested positive again. Here, I tested positive for the first time. We presented our documents at the American Embassy and were informed that we could not be given the visa on the basis of our serostatus.

Soon after this, a national meeting of people living with HIV/AIDS was convened in Ibadan. It was at this meeting that I was elected national president. I granted press interviews, which



U.S. President Bill Clinton speaks about HIV/AIDS in Africa and Nigeria at the national center for women's development in the Nigerian capital of Abuja.

TIM SLOAN/AGENCE FRANCE-PRESSE

were widely published in Nigerian dailies. My employers got the information and terminated my appointment, giving me two months' salary in lieu of notice.

During this period, my wife became pregnant. Then came the Twelfth World AIDS Conference in Geneva in 1998. USAID, through FHI, supported me to attend the conference. It was an eye opener. It was at this conference that

I learnt more about the possibility of preventing mother-to-child transmission of HIV.

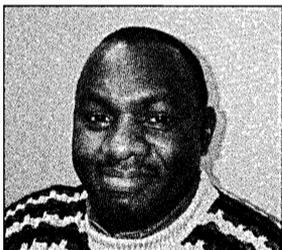
I saved enough money from my food allowance for the conference to buy antiretrovirals for my wife and the baby. In Onitsha, we had a long, drawn-out battle with the hospital staff to provide my wife care. They abandoned her because of her HIV status. It was discouraging, but we persisted. My wife had a caesarian section to further protect the baby. The baby was delivered October 8, 1998. My wife is here with me today, and our baby, at 18 months plus, is still seronegative.

Mr. Presidents, the problems of people living with HIV/AIDS are indeed basic and fundamental. While a lot can be achieved with effective community-based care for people living with HIV/AIDS, this level of care is not readily available. Protecting people living with HIV/AIDS from retrenchment and dismissal from work when diagnosed will go a long way to keep hope alive.

Mr. Presidents, I do not wish to bore you with many requests but only to say that we request your support for advocacy to break the silence and denial at different levels of decision making. We request your support in the area of advocacy to discourage stigma and halt discrimination. And drugs that will prevent children from being infected in pregnancy should be made available, affordable and easily accessible.

“I used to think there was no hope for those of us living with HIV/AIDS in this country.”

Mr. President of the United States, you can do something today that will change the entire course of the AIDS pandemic in our world. With you as an advocate on our side, governments in Africa will do more than they are currently doing. Just as you have touched many homes and hearts in Africa with your good works in the area of health, I call on you today to touch the hearts of all ailing persons living with HIV/AIDS with your soothing hands. The war against AIDS can be won if we all come together.”



Targeting Tuberculosis in Countries with High HIV Infection Rates

By Mukadi Ya Diul

Tuberculosis (TB) is one of the leading causes of death and illness among people living with AIDS in developing countries. More than one-third of people living with HIV/AIDS worldwide are also infected with *Mycobacterium tuberculosis* (the TB bacillus), and 40 percent to 60 percent of them will develop tuberculosis.¹

The two infections have been closely linked since the beginning of the HIV/AIDS pandemic in the early 1980s, when AIDS patients living in TB endemic areas began to present with disseminated tuberculosis, along with other opportunistic infections. Today we know that this relationship is mutually advantageous. HIV contributes to the reactivation of latent TB infection and makes individuals with recent TB infections more susceptible to rapid progression to active disease. Active TB, in turn, may accelerate the course of HIV infection.

Targeting TB in areas with high HIV infection rates is critical because tuberculosis is one of the few infectious diseases fueled by the HIV epidemic that does not remain confined to people infected with HIV. It is also one of the first opportunistic infections to appear in those who are infected with HIV, providing a warning sign that offers opportunities for early intervention. Yet while HIV and TB work together in deadly partnership, most countries continue to address the two epidemics through separate—and therefore less effective—programs.

A Fragmented Approach

The priority of TB control programs remains implementing the strategy called DOTS (directly observed treatment, short course), which has been promoted since the World Health Organization (WHO) declared tuberculosis infection a global emergency in 1993. The goal of DOTS is to detect 70 percent of all sputum-smear-positive TB cases and to cure 80 percent of them through passive detection and directly observed treatment. This means using sputum smear microscopy to

identify infectious TB cases among patients seeking treatment, providing a standardized treatment regimen of six to eight months, and ensuring that someone observes the patient taking the drug, at least during the initial two months. Successful implementation of DOTS requires an efficient system for monitoring and evaluation, regular and uninterrupted supply of all essential anti-TB drugs, and a strong government commitment to sustained TB control activities.

Many TB program managers have assumed that DOTS alone would control TB, regardless of the HIV epidemic. This has not proved to be the case. In fact, since their HIV epidemics began, many countries that had successfully implemented DOTS have been struggling to control TB. In one such country—Tanzania—a DOTS program that is considered a model reported a 160 percent increase in the number of TB cases between 1984 and 1993, despite reported cure rates of 80 percent. During that period, an estimated 24 percent of all new smear-positive TB cases were attributable to HIV.²

Botswana is another example. After introducing the DOTS strategy in 1986, the country's TB control program recorded a decrease in the incidence of TB cases throughout the 1980s. However, this trend was reversed in the early 1990s. Today Botswana has one of the highest TB incidence rates in the world.³ Similar trends in the number of TB cases have been reported in other countries in sub-Saharan Africa and in selected areas in Southeast Asia, such as the province of Chiang Rai in northern Thailand.⁴

In addition to increasing the number of TB cases, HIV epidemics have also had an impact on the performance of TB control programs. Countries with high HIV rates, where more than half of TB patients are infected with HIV, are reporting increasing mortality among TB patients. Malawi, for example, reported that in 1996, 21 percent of smear-positive TB patients died during the course of their treatment. With

such high case fatality rates, these countries cannot reach the DOTS goal of curing 80 percent of TB cases. High mortality rates among tuberculosis patients also threaten the reputations of TB programs, the morale of TB healthcare workers and the popular perception that TB is a curable disease.

While TB programs focus on implementing DOTS, the priority of HIV/AIDS programs is to prevent HIV transmission and mitigate the health, social and economic impact of the HIV epidemic. Most HIV/AIDS programs have left TB control to their countries' TB programs.

Many people living with HIV, however, do not have access to TB services. This may be because they do not want to reveal their HIV status outside the settings where they usually receive care and support services or because they do not have financial means to gain access to TB services.

The poor management of TB by HIV/AIDS services and increasing transmission of TB reflect the consequences of this fragmented approach to the dual epidemic. In countries with high HIV prevalence, HIV/AIDS and TB programs should be working together to support and strengthen the DOTS strategy and to address the needs of people living with HIV.

Strengthening DOTS

Five years after the introduction of DOTS, 119 of the 189 countries reporting to WHO were implementing this strategy. In 1998, only 17 percent of all estimated cases and 21 percent of estimated smear-positive TB cases were detected under the DOTS strategy. According to WHO's 2000 global TB report, TB treatment success with DOTS varies from 62 percent to 93 percent.⁵ In countries with an HIV prevalence of at least 10 percent in the general population, however, TB treatment success ranges from 58 percent to 73 percent and, on average, 19 percent of the patients die before completing treatment or are lost to follow-up.

In countries with low HIV prevalence, the DOTS strategy, when applied properly, has helped achieve high cure rates and limit the emergence of TB strains resistant to multiple drugs. In countries with high HIV prevalence, this strategy should be reinforced with innovative approaches to detecting TB cases and improving compliance with treatment.



SEAN SPRAGUE/IMPACT VISUALS

TB is a leading cause of death and illness among people with HIV/AIDS.

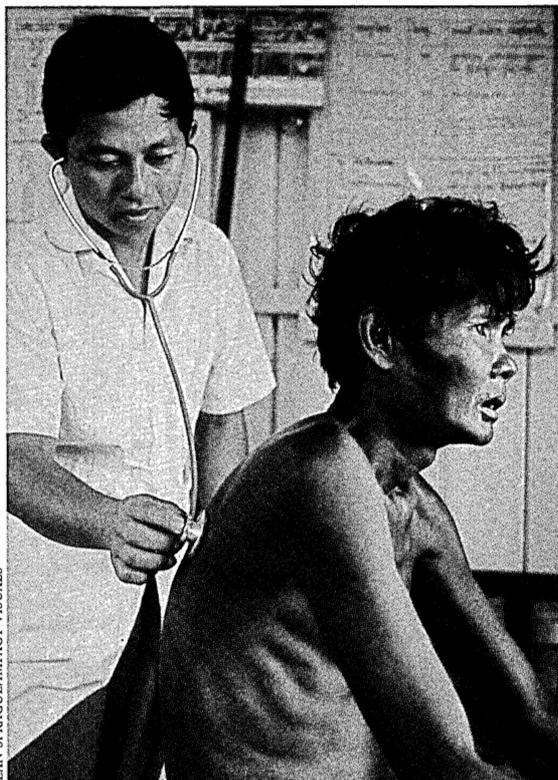
Improving case detection

Detecting infectious TB cases is critical in TB control. Early detection of infectious TB cases reduces the pool of infectious individuals in the community and therefore limits the transmission.

Under DOTS, TB programs rely on patients to present themselves to TB clinics for evaluation of their symptoms. This approach assumes that patients are knowledgeable of TB symptoms and that structural and cultural barriers to TB services do not exist. Unfortunately, that is not always the situation. WHO's 2000 global TB report clearly shows that 60 percent of the estimated 3.57 million cases of infectious TB in 1998 were not detected.⁵

The current strategy of TB control programs is to concentrate on increasing case detection only after a program has raised its cure or treatment success rate to around 80 percent. When programs do try to improve case detection, their impact is generally limited at best. This is because these efforts usually overlook the impact of cultural beliefs on healthcare-seeking behavior and do not always target (in their language or approaches) hard-to-reach populations.

Many studies are revealing the impact of cultural beliefs on healthcare-seeking behaviors. In Cambodia, for example, FHI's investigation of perceptions of cough found that people categorize coughs as different types and have a differ-



SEAN SPRAGUE/IMPACT VISUALS

A doctor examines a man with TB at a floating clinic in Cambodia.

ent approach to seeking a diagnosis for each type.⁶ A recently published study shows that in Thailand, many people with TB symptoms were reluctant to seek medical care because they feared being identified as AIDS patients.⁷

Efforts to improve TB case detection offer an opportunity to draw on experience in changing behavior for HIV prevention. TB control programs can work with HIV/AIDS programs to develop interventions and communication strategies to change healthcare-seeking behavior and ensure prompt and effective treatment of new cases.

TB case detection can also be improved by introducing active case-finding interventions. Such interventions can initially target selected groups, such as family members of HIV-positive TB patients, confined populations and people living in overcrowded settlements.

Encouraging treatment compliance

TB treatment is a key element in tuberculosis control. Adequate treatment not only cures the patient, but also reduces transmission, and thereby the number of new infections. But treatment of TB requires at least three different drugs, which should be taken for at least six months. Patients may, for many reasons and particularly when their TB symptoms disappear, opt to interrupt their treatment. Poor compliance with TB treatment is even more dangerous than no treatment because it may increase the risk of developing multi-drug-resistant TB.

TB programs must develop strategies and interventions to ensure that patients who start treatment will complete it. Programs can use formative research among healthcare workers, community members, patients who default on treatment and those who comply with treatment to identify reasons for poor compliance. Then, based on data from this research, they can develop interventions, such as staff training and patient education and support, to encourage patients to complete treatment. This is another area where TB control program might seek assistance from HIV/AIDS programs, which have been studying and applying principles of behavior change for many years.

Another strategy for addressing compliance is to involve others in monitoring TB treatment. The involvement of communities in TB care has contributed to increased treatment success rates in Peru, Haiti and Bangladesh. WHO has just completed eight pilot studies in six sub-Saharan African countries (Botswana, Kenya, Malawi, South Africa, Uganda and Zambia) in which community members were trained to supervise treatment and support TB patients throughout their treatment. Data from these projects indicate that involving community members in TB care is cost-effective and helps achieve higher cure rates.

Beyond DOTS

Most TB control programs in high HIV-prevalence countries do not address HIV, even though many of their patients may be infected with the virus. Services such as HIV/AIDS education and counseling and testing are not always available at TB service points.

In many countries, HIV information and education is provided in TB clinics as part of the general health education given to TB patients. But TB and HIV are usually presented separately, and the interaction between them is often ignored. In some areas, HIV is not mentioned at all because healthcare workers believe that providing HIV education at TB clinics would scare away patients. Sometimes healthcare workers are so poorly informed about HIV that they are uncomfortable talking about it with their patients. Such attitudes obviously contribute to fears about AIDS and to the existing stigma associated with HIV.

Providing HIV education to healthcare workers in TB clinics can build their confidence in their ability to discuss HIV with their patients. Regular HIV education can also empower patients and provide them with the skills they need to reduce the risk of acquiring or transmitting HIV. And, by filling gaps in HIV knowledge and dispelling misunderstandings about the disease, HIV education can help reduce the related stigma and discrimination. TB control programs can seek the assistance of HIV/AIDS programs in training TB clinics' healthcare staff and developing educational materials addressing TB and HIV.

Access to counseling and testing

Given the strong relationship between TB and HIV, TB patients should be given the opportunity to know their HIV status. Most of them are aware of the strong correlation between TB and HIV, and once the diagnosis of TB is made, many live with the anxiety of believing that they might be infected with HIV.

Knowledge of serostatus will alleviate anxiety for those who test negative for HIV and motivate them to adopt lifesaving skills. But even for a person who is infected with HIV, knowledge of his or her status is valuable. Such knowledge makes it possible to plan for the future and change one's behavior to protect others. It also makes HIV more visible in communities, contributing to the reduction of stigma. And even though antiretroviral therapy is not widely available in most countries, people living with HIV can benefit from basic healthcare services and early preventive treatment or diagnosis and treatment of opportunistic infections.

TB patients' access to voluntary HIV counseling and testing can be improved by introducing such services into TB clinics or by building strong referral mechanisms between TB clinics and existing HIV voluntary counseling and testing services. In both cases, TB clinics need to train healthcare workers in educating TB patients about HIV, inform TB patients about the availability of the service, and establish linkages between medical services and support groups within the community. If voluntary HIV counseling and testing services are being introduced into a TB clinic, clinic managers need to arrange for the training of counselors, nursing staff and laboratory technicians. They also need to develop

mechanisms for a regular supply of HIV testing kits and the referral of blood specimens and results between a laboratory and the clinic.

Managing HIV-related diseases

Health care workers in TB clinics generally know how to manage common, uncomplicated HIV-related illnesses. However, most non-industrialized countries do not have guidelines that would facilitate the management of HIV-infected TB patients and help healthcare workers decide when and where to refer patients. TB programs' proven experience in developing and disseminating TB control guidelines can be exploited by both TB and HIV/AIDS programs to establish guidelines on managing common, uncomplicated HIV-related illnesses. National tuberculosis control programs could build on existing TB training mechanisms to provide regular refresher training that keeps healthcare workers informed about new developments in the management of HIV-related disease.

Providing appropriate care to HIV-infected

HIV/AIDS programs can only benefit from collaborative efforts to treat and prevent the leading killer of people living with HIV.

patients will boost the credibility of healthcare workers in TB programs. Moreover, involving TB healthcare workers in the management of HIV-related disease offers another advantage: if highly active antiretroviral therapy (HAART) for HIV infection becomes more widely available, TB clinics could be used to offer directly observed HAART to TB patients who are also infected with HIV as well as others living with HIV/AIDS.

TB in HIV/AIDS Programs

In countries with high rates of HIV infection where TB is prevalent, HIV/AIDS programs can contribute to TB control programs in various ways. For example, most of the community-based organizations that provide care and support to people living with HIV/AIDS must care for people who are also infected with TB. However, an evalu-

ation by the WHO of the management of TB in HIV/AIDS community care schemes revealed that the quality of such care was generally poor.⁸

The WHO review clearly recognized that HIV/AIDS community care schemes could help improve TB care. HIV/AIDS community-based organizations can educate people living with HIV about TB, prompt early TB case detection, and facilitate access to appropriate TB diagnosis and treatment. The staff and volunteers of these organizations can be trained to conduct active case finding of TB, particularly among partners of TB patients infected with HIV. They can also assist in providing and monitoring TB treatment.

The only potential pitfall in enlisting HIV/AIDS community-based organizations as partners in TB control is the stigma associated with HIV. In areas where such stigma is particularly strong, for example, TB patients may decline to be supervised by a member of an HIV/AIDS organization.

Preventing TB

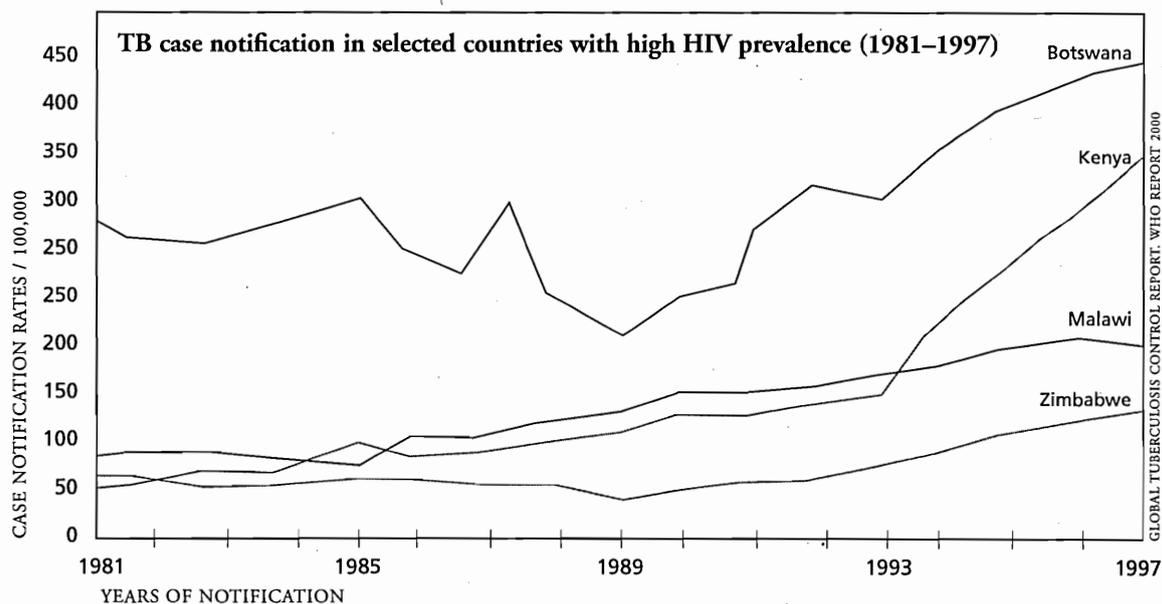
TB preventive therapy—which is the use of a simple regimen (usually isoniazid for at least six months) to prevent the development of active TB disease in a person known or likely to be infected with TB bacilli—is an effective means of preventing TB in people living with HIV/AIDS and therefore may reduce the TB burden in a community. The WHO and the Joint United Nations Programme on HIV/AIDS (UNAIDS) recommend that TB preventive therapy be given as part of a

package of care for people living with HIV/AIDS.⁹ However, care must be taken not to drain limited resources from TB control program activities, where diagnosis, treatment and cure of smear-positive cases must remain the priority. In addition, this TB preventive strategy requires identification of people who are infected with HIV. For both reasons, HIV voluntary counseling and testing centers may be an ideal site for such programs.

Implementation of a TB prevention intervention requires strong commitment from and collaboration between both the TB and HIV programs. Before implementation, TB programs should provide training in TB symptom recognition, diagnosis and treatment, exclusion of active TB, drug supply, treatment monitoring and diagnosis of active TB. Each HIV voluntary counseling and testing center participating in the program should have a clear plan for excluding active TB (systematic symptom evaluation for all HIV-infected patients or a clear referral mechanism to TB diagnostic services), and TB and HIV/AIDS programs should design a plan for monitoring and evaluating treatment. Such interventions could be coupled with other preventive therapies, such as cotrimoxazole (Bactrim) to prevent opportunistic infections.

Conclusion

TB program managers need to understand that there are more benefits than disadvantages to introducing HIV/AIDS services in TB clinics and responding to the needs of TB patients who are living with HIV. In fact, TB programs in countries



with high HIV prevalence will not succeed without addressing HIV/AIDS. HIV/AIDS programs, in turn, can only benefit from collaborative efforts to treat and prevent the leading killer of people living with HIV. In countries with high rates of HIV infection, HIV and TB control programs need each other, and they must work together to reduce transmission of both infections and to improve care and support for all their clients.

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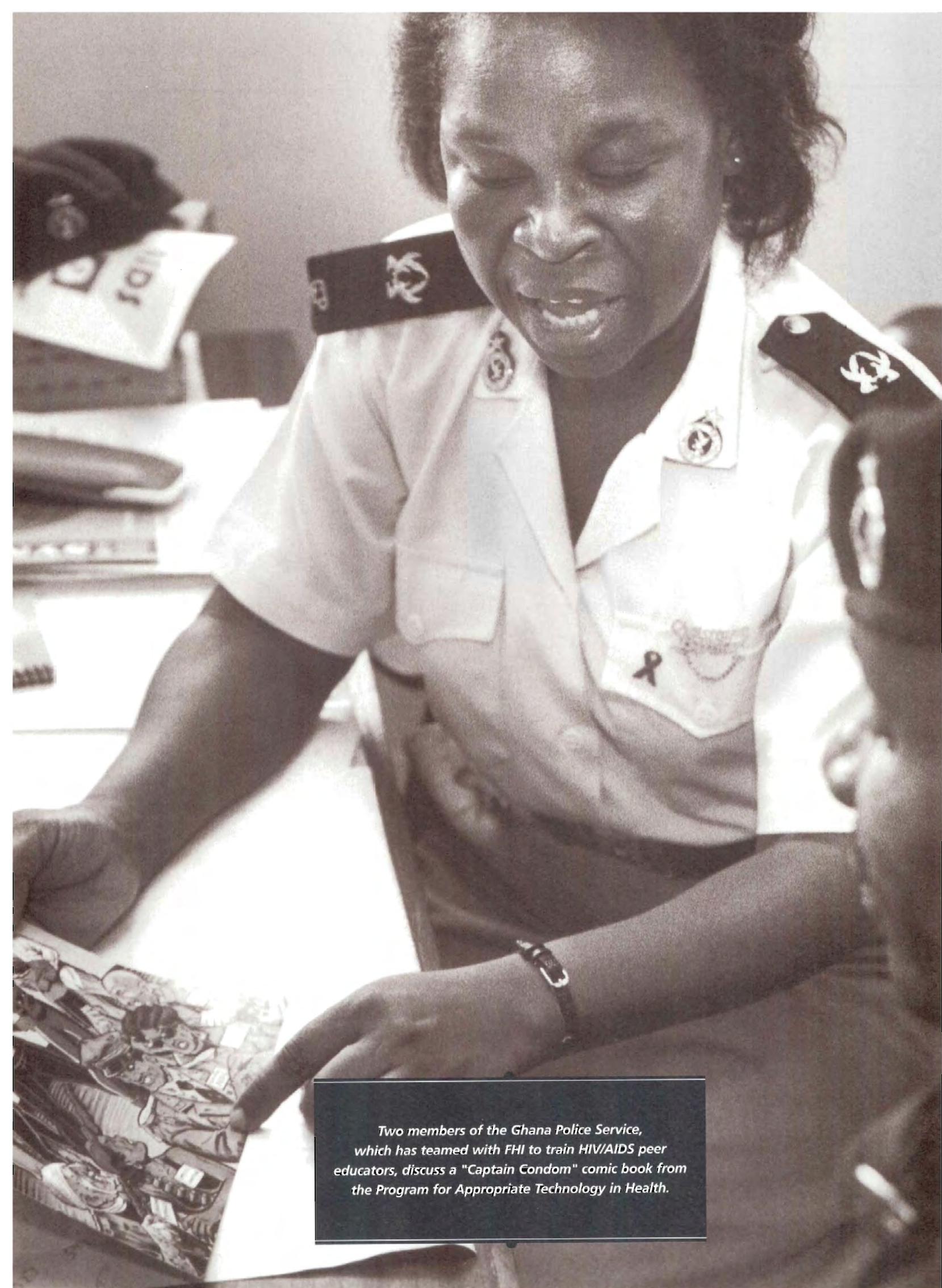
Integrating TB and HIV/AIDS Services: FHI Examples from the Field

In Kenya and Rwanda, FHI is working closely with the national TB and HIV/AIDS programs to implement integrated TB and HIV interventions. These interventions consist of:

- Increasing TB patients' access to HIV prevention education and voluntary counseling and testing.
- Active case finding of TB cases among partners of HIV-infected TB patients.
- Integrating TB services, including TB preventive therapy for those who test positive for HIV, into voluntary HIV counseling and testing services.
- Introducing services to prevent opportunistic infections using cotrimoxazole (Bactrim).

In Cambodia, FHI, in collaboration with the Gorgas Memorial Institute/University of Alabama, is developing a TB pilot project in Phnom Penh serving squatters, prisoners, people living with HIV/AIDS and their families, and other hard-to-reach populations in this urban setting. The project includes:

- A study of the prevalence of active TB among the target groups and of mycobacterial resistance to TB drugs.
- Behavior change interventions and collaboration with community groups in order to increase case detection of TB and compliance with treatment.



Two members of the Ghana Police Service, which has teamed with FHI to train HIV/AIDS peer educators, discuss a "Captain Condom" comic book from the Program for Appropriate Technology in Health.

Helping Men Make A Difference in HIV Prevention

BY JOHN-MANUEL ANDRIOTE

Efforts to involve both men and women in HIV prevention have shown that containing the spread of the virus will require fundamental changes in societies' expectations of men and women.

What makes a man?

As simple as the question may be, its varied, complex answers are the keys to effective HIV prevention throughout the world.

Worldwide, women bear the greatest burdens of AIDS. They are physiologically more vulnerable to HIV. There are more HIV-infected women than men. And women typically provide the most care to others who are sick with AIDS-related illnesses.

But it is men who drive the HIV/AIDS epidemic. Whether they are infected via sex or drug use—the most common ways men are infected—men are the vehicles through which HIV is transmitted to both men and women.

Even the best prevention campaigns targeting women are rendered ineffective when male partners refuse to change their risk behaviors or use condoms. More often than not, men's behaviors and refusal to change are rooted in their own beliefs and society's expectations about what it means to be a man.

In Asia, for example, there is "the basic double standard between men and women," said Pratin Dhamarak, regional program manager of the Family Health International (FHI) Asia Regional Office in Bangkok, Thailand. "Men are supposed to be experienced and know what to do in regard to sex," she explained, "while women are supposed to be innocent and submissive."

In other cultures, too, there are long-held ideas about what being a man means that contribute to the spread of HIV by, for example, viewing condoms as "unmanly." Women are often unable to protect themselves against HIV because their culture tells them they must comply with a man's wishes.

And HIV continues to spread. The Joint United Nations Programme on AIDS (UNAIDS) estimates that 4.7 million adults throughout the world became infected with HIV in 1999, with new infections almost equally divided between men (2.4 million) and women (2.3 million). Of the 33 million adults believed to be living with HIV or AIDS, 17.3 million are men.

Men Make a Difference In recognition of the role men play in virtually every case of sexual transmission of HIV, FHI supports many prevention projects around the world that specifically target men.

The work of these projects will be in the spotlight on December 1—World AIDS Day 2000—because this year's theme is "Men Make a Difference." It is also the theme of a two-year campaign, launched by UNAIDS in March 2000, focusing on the role of men in the HIV/AIDS epidemic. The campaign's objectives include motivating

men and women to talk openly about sex, drug use and HIV/AIDS and encouraging men to take care of themselves, their partners and their families.

Programs aimed at men seek to build connections with men in places where they come together for work or to socialize with one another. Often men who travel or are separated from their families or communities for extended periods gather in border or port cities where there are ample opportunities to contract or spread HIV—and to carry it home. For this reason, a number of FHI-supported prevention projects focus on these "mobile men," such as truck drivers, policemen, fishermen, taxi drivers and migrant workers.

Even the best prevention campaigns targeting women are rendered ineffective when male partners refuse to change their risk behaviors or use condoms.

A “Condom Tunnel” in Vietnam A full day’s travel by air and car from Hanoi is Can Tho. Traffic—mainly motorbikes—moves slowly along a stretch of highway lined by small brothels. In an initiative dubbed “the condom tunnel” by FHI’s Implementing AIDS Prevention and Care (IMPACT) program in Vietnam, a series of billboards and banners with condom use messages will be placed strategically along both sides of the two kilometers of highway at this “hot spot.”

“Once the client hops off the motorbike and parks it, he will be faced with more posters or possibly a leaflet from the parking attendant,” explained Donna Flanagan, FHI’s resident advisor in Vietnam. “Inside the bar-restaurant-brothels, the men find similar messages on the beer mats, wall posters and over the sound system.” Besides the condom messages, teams of dramatists will offer comedy skits about subjects such as the challenges of men, women, sex and condoms.

The condom tunnel and street dramas are only two components of an overall men’s campaign under the IMPACT program in Vietnam, which is funded by the United States Agency for International Development

(USAID). Peer education in factories is another component. Then there are the six contests for such titles as “Mr. Great Farmer,” “Mr. Great University Student” and “Mr. Great Civil Servant.”

The idea is a bit like a beauty pageant, explains Flanagan, “in which the guys will be judged on a number of

things—one of which is their knowledge of and concern about their own health and that of their family.” There will be “a lot of TV exposure for the winners,” she added.

The men’s campaign was designed to complement an IMPACT project that includes a new women’s health club for sex workers in Can Tho. “No matter how we strive to help women develop self-esteem and sexual negotiation skills, they are nevertheless the weaker, non-paying partners in commercial sex,” Flanagan said. “Putting the entire burden of condom negotiation on them is just adding one more chore to their already difficult lives.”

Cambodian Seafarers in Thailand In Rayong, a port city on the east coast of Thailand, some 40,000 Cambodian seafarers work in the fishing industry—despite the government’s official quota of 3,500 foreign workers for the industry. More than 90 percent of the Cambodians working in the port are illegal immigrants who pay up to \$US 90 to agents who recruit them from their villages.

Men with limited education and without documents such as passports and visas can often find jobs as fishermen. The adventure attracts young men, but the work is hard and full of physical risks. For these reasons, Dhamarak says, “when fishermen get paid, they

want to have a good time, spending money on drinks and sex.”

Of course alcohol and condom use are often incompatible. But also undermining efforts to prevent these fishermen from contracting or spreading HIV is a low sense of self-worth. “Some men say their life is full of risk anyway,” Dhamarak explained. “They don’t know when they are going to die or get thrown overboard—so why be afraid of AIDS?”

Preliminary focus group discussions with Cambodian seafarers revealed the men’s limited knowledge of HIV/AIDS. About 60 percent of the participants reported engaging in commercial sex. Although most of them said they did not use condoms, they did not perceive themselves to be at risk for sexually transmitted infections (STIs), including HIV.

Limited access to condoms is also a problem. Language barriers make it difficult to buy condoms, and the “freelance” sex workers these men frequent (as opposed to those who work out of brothels) often do not carry condoms.

Prey Veng Province, with nearly 1 million residents and among

Cambodia’s most impoverished regions, is one of the “source communities” from which migrant Cambodian seafarers working in Thailand originate. A 1998 survey of sex workers in Prey Veng found an HIV prevalence rate of 34 percent—the second highest in the country—among “indirect” sex workers (who work in entertainment establishments or as

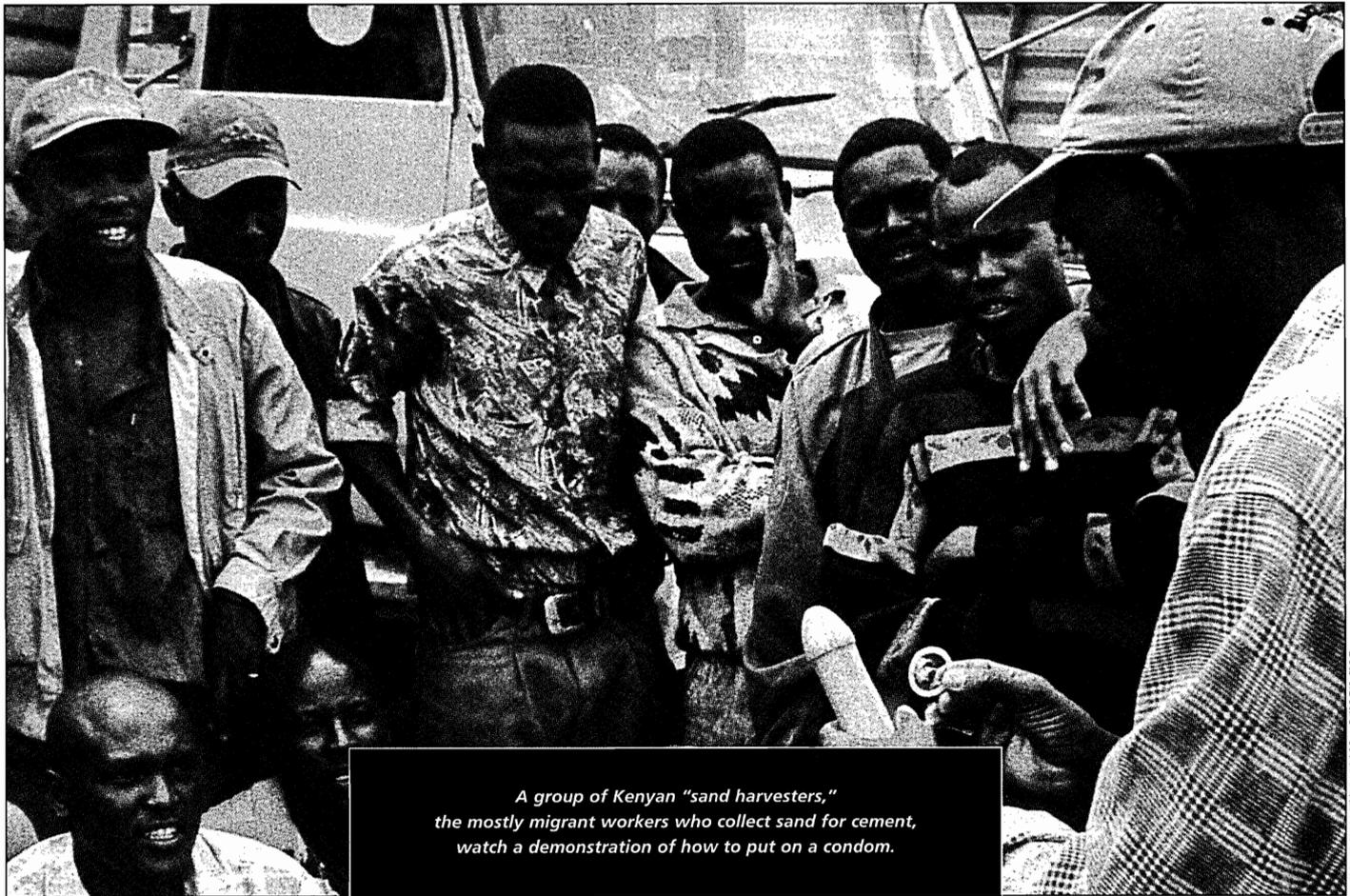
beer promoters) and 29 percent among “direct,” usually brothel-based, sex workers.

A new FHI project funded by USAID’s Asia Near East Bureau is providing simultaneous cross-border HIV/AIDS interventions for Cambodian seafarers in Rayong and their families in Prey Veng. In Cambodia, a team operating under the Provincial AIDS Committee of Prey Veng will identify specific villages and families of seafarers working in Rayong. They will offer reproductive health education and HIV/AIDS counseling to families of migrants in the source communities. For those already ill with AIDS, home care services will be organized to strengthen existing health resources in the community.

In Rayong, mixed Thai-Cambodian teams will conduct outreach education, working within social networks and with government and private STI and health clinics to offer or expand their services to the target population. They will also make sure condoms are available around the areas where sexual contacts often take place.

The project will test innovative interventions that address the whole context and lifestyle of migrant seafarers. For example, because many fishermen cannot send money home and have no

“No matter how we strive to help women develop self-esteem and sexual negotiation skills, they are nevertheless the weaker, non-paying partners in commercial sex.”



A group of Kenyan "sand harvesters," the mostly migrant workers who collect sand for cement, watch a demonstration of how to put on a condom.

WENDY STONE/LIAISON AGENCY, INC.

safe place to keep it, they are more likely to spend their earnings on alcohol and sex. "We try to help them maximize the benefits of their earnings and increase the communication and contact with families," Dhamarak said.

FHI also plans to provide "predeparture" information to fishermen, who often have unrealistic expectations about the working conditions they will face and the money they can make as undocumented migrant workers.

Ghana Police Service Time away from home and a stressful job also put members of the uniformed services at high risk of HIV. The USAID-funded IMPACT Project is working with the military in Cambodia, Ghana and Nigeria and with the Ghana Police Service to support prevention efforts among these men.

Two years ago, with technical and financial assistance from IMPACT's program in Ghana, the country's national police force began a program aimed at preventing HIV among the police. Lectures on STIs, including HIV, are incorporated into the training curriculum used with police recruits. According to Dr. Godfried Asiamah, a chief superintendent and manager of the Ghana Police Service AIDS Control Programme, "these lectures emphasize safer sexual behavior in order to prevent sexually transmitted diseases, HIV and AIDS, and promote healthy living."

One obstacle the police training program has encountered is police wives questioning the usefulness of condom promotion. "They will ask, 'Are you not promoting promiscuity among our husbands by promoting and providing them with condoms when they go on operations outside their homes?'" Dr. Asiamah reported.

"Police are aware that the duties away from home, night patrols, a high rate of casual sex, unprotected sex, multiple sexual partnership and high alcohol intake common with the police are

risky behaviors," Dr. Asiamah said. Nevertheless, he adds, police service members' perception of their own risk of HIV is low.

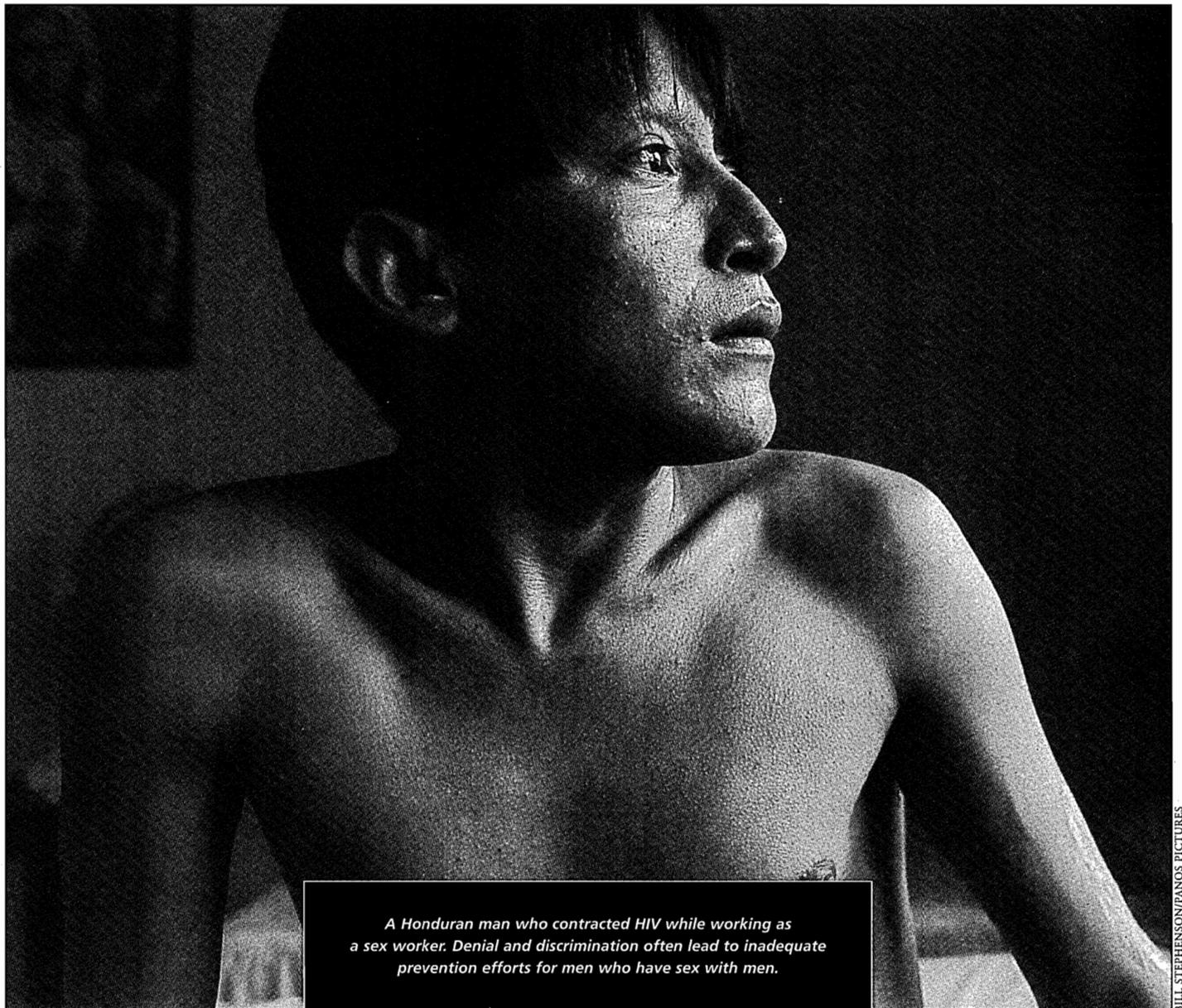
The Ghana Police Service's AIDS Control Programme is targeting about 20,000 policemen, as well as 80,000 of their dependents, including wives, for HIV prevention education and services. To date, 65 peer educators have been trained in three out of Ghana's ten police regions. The program plans to provide every police station and barracks in Ghana with at least one peer educator within the next five years.

Dr. Asiamah believes that peer education works "because peer educators are in continuous dialogue with their colleagues." Such dialogue is necessary, he adds, even though a 1999 survey showed that knowledge of STIs and HIV/AIDS was almost universal among the police. "This knowledge is not committed, as condom use was found to be low and other unsafe sexual practices were common among the police," Dr. Asiamah explained.

Besides education, peer educators offer condoms for sale to the policemen. Experience has shown that condoms distributed freely may not be used. "Policemen attach more importance to condoms if they are acquired with their own money," Dr. Asiamah observed.

The Risks of Secrecy Whether for pleasure, economic reasons, compulsion or a lack of available women, many men have sex with one another despite often-harsh taboos against homosexual behavior in their societies. Surveys suggest that as many as eight in ten men who have sex with men practice anal sex. Unprotected anal intercourse—whether between men or men and women—has the highest level of risk for HIV transmission.

In countries where homosexuality is not accepted, men often hide their sexual orientation by having clandestine encounters or



A Honduran man who contracted HIV while working as a sex worker. Denial and discrimination often lead to inadequate prevention efforts for men who have sex with men.

even ongoing relationships with other men. In these sometimes hurried circumstances, condoms are not likely to be used. Some men, married to women because of social or family expectations, have sex with other men “on the side.”

All-male settings such as the military and prisons tend to increase sexual contact between men. Outside these settings, however, most of the men are likely to have sex with women—increasing the risk of spreading HIV and other STIs to female partners outside the institutions.

Men who have sex with men—whether exclusively or only occasionally—are at heightened risk of contracting HIV and transmitting the virus. Both for the men’s protection and to protect female partners—and, by extension, offspring—HIV prevention targeting men who have sex with other men is essential.

Hostility toward homosexuality has resulted in inadequate HIV prevention efforts in many countries. Some governments have refused to acknowledge that sex between men takes place. Others criminalize anal sex. Many governments refuse to support prevention efforts for men who have sex with men.

As a result, little is known in most non-industrialized countries about the extent of HIV/AIDS among men who have sex with men, the behaviors that put them at risk, or the kinds of HIV prevention services they need. Recent studies sponsored by FHI in

Bangladesh, Cambodia, India and Nepal yielded some answers to these questions that are being used to design HIV/AIDS interventions for men who have sex with men in those countries.

Community Building in Bangladesh The same-sex scene among men in Bangladesh is “distinctive,” says Dr. Carol Jenkins, who was recently an FHI advisor there. In the fundamentalist Islamic area of Sylhet, for example, traditions tacitly permit older men to have sex with younger men because it contributes to the maintenance of female purity.

However, as Dr. Jenkins puts it, “the acceptability is in private—publicly it is deplored.” She noted that a random sample of rickshaw pullers this year in Chittagong, another conservative city in Bangladesh, revealed that 60 percent of the men had engaged in sex with other men in the last year.

Faced with this double standard of private tolerance and public condemnation, FHI is supporting the Bandhu Welfare Society, a local organization that has developed an effective, discreet strategy for reaching men who have sex with men in Bangladesh. “As being a man who has sex with men is a serious source of shame to men if their families find out,” Dr. Jenkins said, “bringing these men together and giving them a safe space in which to discuss their sexual health issues has been extremely valuable and successful.”

Youth Are Most Vulnerable Expectations for how a man “should” behave can take on exaggerated importance for younger men concerned about “measuring up.”

Young men in developing countries typically have more sexual partners than older men. They are more likely to inject drugs. But they do not usually see themselves as being at risk for HIV.

The disconnect between young men’s behavior and perception of their own risk is apparent in Zambia, for example. There, 64 percent of young men ages 15 to 24 thought they had no risk at all of HIV infection—even though having unprotected sex with multiple partners is relatively common among this age group.

The cultural power differentials between men and women frequently play out between young men and their female partners. These relationships can be exploitative or may involve money or gifts in exchange for sex. They can even be violent. In Southern Africa—South Africa in particular—young men frequently subject their partners to rape and other violence.

Boys and young men in some areas are less likely to know about HIV/AIDS than older men, despite their greater risk. One study of adolescents in Pakistan, for example, found that 25 percent did not know how HIV is spread. Surveys of young men in southern Africa also find them less likely to access medical treatment for STIs.

On the positive side, young men are open to influence, as Martin Foreman notes in a

Panos Institute media briefing on men and HIV/AIDS.¹ “Catching these boys and young men while they are still learning about their bodies and responsibilities to others makes more sense than trying to counter habitual attitudes and patterns of behavior in older adults,” Foreman writes.

Opening the Dialogue Jamaican boys are “under a lot of pressure to prove they’re a man,” says Hally Mahler, an FHI health communication and training officer. “I have some young Jamaican friends who tell me that in high school, boys race their friends to see how many girls they can sleep with. In a year they’ll sleep with 40 to 50 girls. It’s a manhood ritual.”

To educate boys in Jamaica about sexuality and disease prevention requires addressing issues of power and even violence between men and women, Mahler explains. “Girls have little power in Jamaica in negotiating sex, like everywhere else,” she said. “Boys are pressured to go out and sow their seed, prove they’re not a sissy.”

In Rwanda, Mahler has been assisting a youth group associated with the Catholic Church, Jeunesse Ouvrières Chrétienne,

through an IMPACT project that focuses on behavior change. As elsewhere, bringing about changes in behavior requires first changing deeply held attitudes and beliefs.

In Rwanda, a girl is not allowed to consent to sexual relationships. “Even if she wants to have sex,” Mahler explained, “she has to say no—and to resist physically.”

This means that even sex that might otherwise be consensual plays out as rape. “The sexual power is so skewed,” Mahler said. “It’s not that boys want to rape girls, but that’s the sexual dialogue, and boys feel they have no way around it.”

Mahler used a metaphor to help members of the Rwandan youth group challenge some of these assumptions. She asked for a gift, then repeatedly refused it as a colleague continued to press it on her. Finally, as he grew more insistent, she reluctantly accepted the small, gift-wrapped box. This led, somewhat haltingly at first, to a discussion about sending mixed messages with one’s body and one’s words.

In Jamaica, the same message is addressed more directly. In an exercise that has proved particularly effective, boys and girls exchange gender roles for a day, then talk about the experience.

“In Jamaica we’ve been doing this gender exchange for some time, and you really see it makes a difference—kids start to respect each other more,” Mahler said. “They find that boys and girls really want the same things in terms of respect and communication.”

Such realizations are a small step toward an essential shift in the balance of power between men and women. Without strong expectations within their cultures that they will respect themselves and their sex partners (both female and male), men are unlikely to heed messages about condom use and safer sex.

As Mahler points out, “Until you can create an opening in the sexual dialogue, there’s no place to start talking about prevention effectively.”

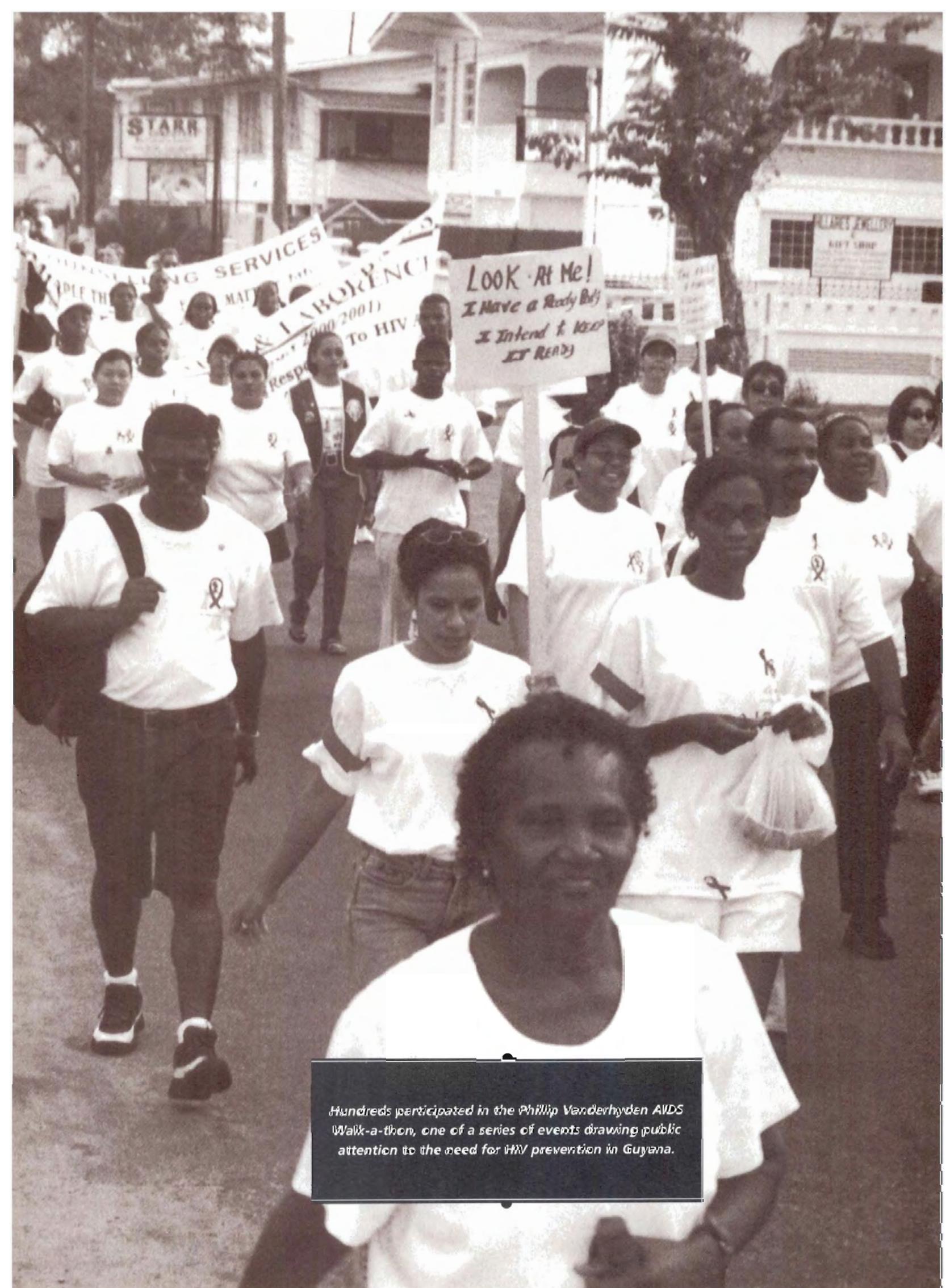
Put another way, until men and women alike accept that part of being a man means protecting oneself and one’s sexual partners against a deadly virus, HIV will continue to spread.

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JOHN-MANUEL ANDRIOTE IS A FREELANCE WRITER BASED IN WASHINGTON, DC, AND AUTHOR OF *VICTORY DEFERRED: HOW AIDS CHANGED GAY LIFE IN AMERICA*.

Expectations for how a man “should” behave can take on exaggerated importance for younger men concerned about “measuring up.”



Hundreds participated in the Phillip Vanderhyden AIDS Walk-a-thon, one of a series of events drawing public attention to the need for HIV prevention in Guyana.

Guyanese NGOs Join Forces to Ready Youth for Healthy Living

BY CHERYL SPRINGER

A project that unites NGOs in the small South American country of Guyana uses music, drama and popular culture to appeal to youth at risk of HIV infection.

The short advertisements first appeared on Guyanese television stations a few weeks before the event. "Teasers," they're called. In these brief TV spots, an attractive girl and a handsome boy pass each other on the street. They eye each other appreciatively. "Mmmm," thinks the girl, "he has a 'ready body.'"

She looks over her shoulder to admire the boy further and finds that he is looking back at her. Both smile. The girl frowns. "But is it really ready?" she wonders to herself. Then words come up on the screen: Do you have questions? Visit the Main Street Fair on August 28, 2000.

Next posters advertising an "Operation Ready Body" event appeared around Georgetown, the capital of the South American nation of Guyana. What was it? No one knew for sure. Because the ads and posters used the popular slang phrase for a good-looking, sexy or well-dressed person, some thought Operation Ready Body might be a beauty pageant, or even a wet T-shirt contest.

Their curiosity—and the driving dance music blaring from enormous speakers—drew hundreds of young people to Georgetown's Main Street August 28. What they found there was a street fair, with booths lining a central block in the capital's main thoroughfare and "Operation Ready Body" banners fluttering overhead.

Far from being disappointed, the young people stayed to enjoy the music spun by disc jockeys and the performances by theater and youth groups. Many stopped at the booths to pick up information about how to take care of their bodies and, in particular, how to protect themselves from sexually transmitted infections (STIs), including HIV. Some pocketed the free condoms that were available at the booths.

As they watched a performance on the stage, one group of young people pronounced the fair, which marked the official launching of the Guyana HIV/AIDS/STI Youth Project, a "brilliant initiative."

The Threat of HIV When Dr. Carol Becker became director of the United States Agency for International Development

(USAID) mission in Guyana in 1998, the agency did not support any health projects in the country. But Dr. Becker, who had served in USAID missions in Asia and Africa, soon recognized that HIV/AIDS was a serious threat to health and development in Guyana.

The proportion of people testing HIV-positive at a given time in surveys among various groups suggests that Guyana's HIV/AIDS epidemic has already moved from those at greatest risk to the rest of the population. For example, 7 percent of women tested for the virus in a 1995 survey at antenatal clinics in Georgetown were HIV-positive.

One prevalence survey found that 45 percent of the sex workers tested in Georgetown—where one out of four Guyanese live—were HIV-positive.

Three to five percent of Guyana's population of 800,000 are believed to be infected with HIV. Among urban, sexually active adults and young people, the level of infection could be much higher.

Most reported AIDS cases are in adults ages 19 to 35, with the greatest concentration among those 25 to 35 years old. Although more cases have been reported among men, the trend in the 1990s was toward an equal number of male and female AIDS cases.

Armed with these alarming statistics and a report documenting limited efforts against HIV and other STIs, Dr. Becker requested additional funds from USAID/Washington to support a "special objective" for HIV/AIDS prevention in Guyana. The amount approved was up to US \$1.1 million over five years, of which \$200,000 was granted for a pilot project in the first year.

Pooling Talents Dr. Becker asked Family Health International's Implementing AIDS Prevention and Care (IMPACT) Project, which is funded by USAID, for assistance in designing the project and providing technical support. Following further consultation with Guyana's Ministry of Health (MOH), USAID decided to support HIV prevention activities by six nongovernmental organi-

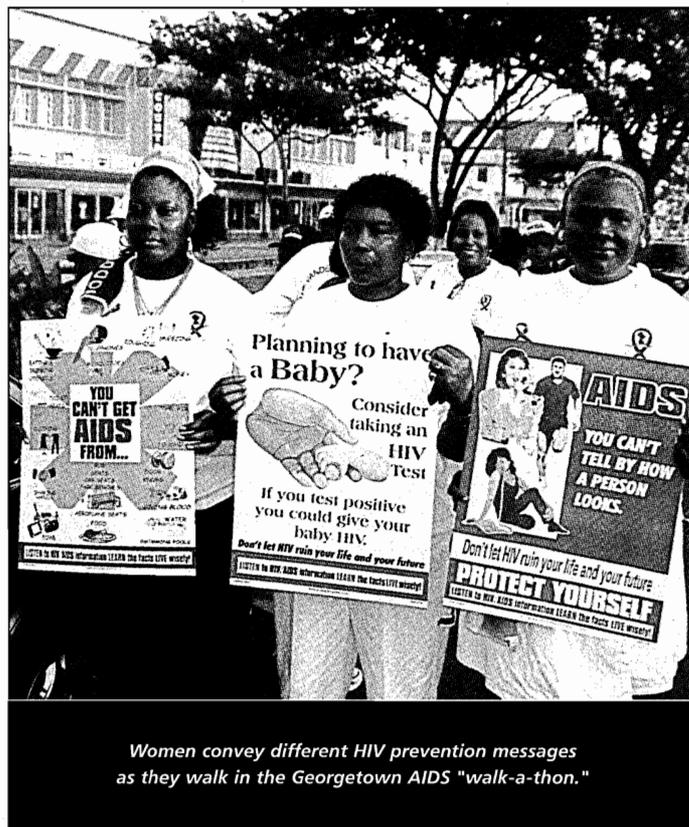
zations (NGOs) from three urban areas. A governmental organization, the Regional AIDS Committee 10 (RAC 10), also expressed interest in collaborating with the NGOs. These groups would work in alliance with the National AIDS Programme Secretariat (NAPS) and the local representatives of the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the United States Peace Corps.

"With limited funds, it was thought that developing a design that allowed all of the NGOs to work together seemed the most practical approach," explained Carol Larivee, a senior technical officer for the IMPACT Project.

Each of the six NGOs had experience working with youth or in HIV/AIDS prevention, and each brought special skills to the project. Artists in Direct Support educates people about HIV/AIDS through drama and dance. Comforting Hearts provides care and support to people living with HIV/AIDS. The Guyana Responsible Parenthood Association (GRPA) is the country's main source of family planning and sexual and reproductive health services. Lifeline Counselling Services was established to provide pre- and post-HIV-test and support counseling, but it also runs HIV/AIDS education and training programs. Another group that has broadened its mandate to include HIV prevention education, the Volunteer Youth Corps, was originally formed to offer emotional support to all patients in the Georgetown Public Hospital. Youth Challenge Guyana is the local chapter of Youth Challenge International, which sponsors young volunteers to undertake development work in countries around the world.

Dr. Becker recognized the efforts of each of these NGOs to respond to the epidemic. "But while they were all working towards the same goal, each was operating in isolation," she said. "There was the need to pool their talents, and we hoped that the HIV/AIDS/STI project would act as a catalyst."

Catching the Young The five-year project began with a design workshop in May 2000 that brought together people from all the organizations involved in the Guyana HIV/AIDS/STI Youth Project. It was organized by the Steering Committee, with representatives from the NGOs, RAC-10, USAID, FHI, UNAIDS, NAPS and the Genito-Urinary Medicine (GUM) Clinic, that helps direct project strategies and activities. Along with these groups, other participants represented organizations that collaborate with the project.



Women convey different HIV prevention messages as they walk in the Georgetown AIDS "walk-a-thon."

KENMORE/STARBUCK NEWS

The project plan calls for design workshops at the beginning of each of the three phases of the one-year pilot project to ensure that what is learned during one phase is used to improve interventions and strategies for the next.

During the first phase of the project, the NGOs and RAC-10 would assess young people's need for HIV/AIDS and STI prevention education and services and begin to stimulate a dialogue among youth on HIV/STI risk and risk behaviors. The project aims to reach

young people who are not yet sexually active as well as those who are. Lifeline Counselling Services Chairman Dereck Springer explains that defining youth as those 8 to 25 years old "will ensure that we catch the young."

Within that broad age range, the target audiences of young people identified for the project fall into three different groups: "limers," as Guyanese youth who hang out on the street are called, minibus drivers and conductors, and young people in organized groups.

Participants in the first design workshop met in three different groups to develop more complete profiles of the target audiences. Limers, they agreed, like to "hang out" at creek and pool parties, on the sea wall, and at fast food joints and minibus stops. Sex is seen as entertainment. Some limers use drugs and alcohol, have many sex partners, and will have sex in exchange for favors or material items.

Limers and other youth look up to the young men responsible for Guyana's foremost form of public transportation. These drivers and conductors of 12- to 15-seat minibuses are perceived as being macho and "super cool," with lots of spare cash. Workshop participants said that when a minibus driver or conductor becomes infected with an STI for the first time, his friends call it "getting your first stripe." HIV is known as "the Major General," or "the Big Truck."

Workshop participants noted that young people in organizations are a different group from the other two. They are more disciplined and have goals related to their group activities, whether they be athletics or community service. However, they also "lime," or hang out, on occasion, and some are sexually active. They may be misinformed about HIV and STIs and think that they are safe if they have sex only with people in their own groups.

Being "Ready" Workshop participants also divided into groups to begin developing strategies for communicating with members of the three target audiences. It was during this exercise that the theme and slogan "Ready Body—Is It Really Ready?" was born.

The group working on a communication strategy for limers turned to a phrase Guyanese youth have adopted from the dub, rap and reggae music they love: "ready body." Members of the project's Communications Working Group seized on the idea, pretested it with youth from the target audiences, and refined it.

"Ready body is something youth use in Guyana to say it's looking good," explained Desiree Edghill-Adams, a member of the project's Steering Committee and a co-founder of Artistes in Direct Support. "A ready body is cool, dresses well, looks sexy. The main idea was to grab their attention, which we did."

But the project also takes this theme to another level by asking, "Is it really ready?" This question encourages young people to challenge false assumptions about their invulnerability to disease and to assess their risk of STIs and other health threats. Project outreach workers and peer educators will help guide young people through this process and provide the information and referrals to "youth-friendly" services that youth need to become or stay healthy.

Originally the plan was to use the ready body theme only for the first phase of the project. "We were supposed to change the theme, but we haven't because 'ready body' is in the air," said Edghill-Adams. "It has been so popular, we don't want to move away from it just yet."

Youth at Risk The plan developed at the May workshop called for efforts to get young people's attention, culminating in three street fairs in Georgetown, New Amsterdam and Linden at the end of the summer, as well as an assessment of HIV/AIDS and STI prevention needs among the targeted youth.

The Steering Committee hired CESRA Technical Support, a local firm, to develop survey questionnaires and other assessment tools, train NGO members in data collection, and analyze the data. The NGOs worked together to conduct a rapid assessment that included a survey, interviews with health workers and community leaders, and focus group discussions and more informal discussions ("rap sessions") with members of the target audiences.

The thick assessment report paints a grim picture of the risks facing these youth. More than 60 percent are sexually active, and the majority do not use condoms consistently.

Almost half of the youth surveyed said they worried about contracting an STI, indicating that they are probably having unprotected sex with one or more partners.

Perceptions of personal risk of contracting HIV varied among the different groups. Thirty-percent of the minibus drivers and conductors felt that they were greatly at risk of HIV infection, compared to 19 percent of limers and 9 percent of youth in organized groups.

The survey revealed widespread misconceptions about the transmission and prevention of HIV, which were echoed by participants in focus group discussions. Some young people, for example, thought that God would protect them from becoming infected with HIV, regardless of their sexual behavior. Others believed that HIV and other STIs could be contracted from toilet seats, perspiration, sneezing and fingernails.

Prevailing myths about condom use also surfaced during the focus group discussions. Many participants said they don't like to use condoms because they rob sex of its pleasure. Others said using a condom is a waste of time because they don't work.

Some young women had agreed to sex without a condom because they thought they would be raped if they refused. Violence was seen as a threat by an alarming proportion of the young people surveyed. Almost 27 percent said they worried about being sexually abused, and half of them worried about physical abuse.

"What the survey has done is to make us aware of how much at risk our young people are of contracting STIs and the factors which put them at risk," LCS Chairman Dereck Springer said.

The Power of Music The Steering Committee and other project partners started using the assessment results right away at the design workshop for the second phase of the pilot project in September. After reviewing the results and the project's progress, they developed a plan that includes producing communication materials for the project, completing a peer education manual and other training materials, and identifying and training peer educators.

Assessment findings on the judgmental attitudes of many healthcare providers toward young people led to plans for a more detailed study of the available HIV/AIDS and STI services. Youth-friendly services identified through this assessment will be promoted and strengthened during the third phase of the project, when peer educators will begin to spread the word about HIV/STI prevention to their friends and acquaintances.

The assessment also looked at where young people get their information about sexual health and other health issues and their preferred sources of such information. Based on these findings, the assessment report recommends mounting a sustained and aggressive campaign to dispel myths and promote safer behaviors through music, street theater, disc jockeys (DJs) and popular artists.

The NGOs and others working in HIV/STI prevention in Guyana recognize the power of DJs and popular music. The NAPS, for example, had conducted a workshop with DJs to encourage them to educate young people about how to avoid STIs. The GRPA plans to produce rap messages developed by the DJs and disseminate them on cassettes to minibus drivers and conductors.

Most young people use minibuses. Some refuse to ride minibuses that are not equipped with the large portable radio and cassette players known as "boom boxes," which are illegal but pervasive.

After the Main Street Fair, taped advertisements were distributed to minibus drivers to advertise the street fairs in the two other project areas, New Amsterdam and Linden. As in Georgetown, DJ music drew young people to these fairs and kept them there. However, it also attracted criticism from some adults who thought the music was too loud and went on too long—especially in Linden, where the street fair became a street festival, with people dancing into the night.

Young people's reaction to such criticisms may be some indication of the project's success in reaching its audience. At a forum

organized by Comforting Hearts head Muriel Sandy, the young people asserted that they would not have attended the New Amsterdam fair if there were no music. Nevertheless, they insisted that the fair provided an opportunity for them to learn about protecting themselves from STIs.

"But this has served as a further learning for all of us," said Kenroy Roach, head of Volunteer Youth Corps, of some of the negative reactions to the street fairs. One lesson, for example, is to start events earlier so that they do not become all-night parties.

Building a Foundation Julia Rehwinkel, Peace Corps volunteer and Jack-of-all-trades, is the project coordinator. She acts as the liaison between USAID, FHI/IMPACT and the Steering Committee, coordinates project efforts with regional and international groups, and monitors project activities.

From this vantage point, Rehwinkel has seen a rapid evolution of the relationships among the NGOs and the ways they work together. "At the beginning of the project, each NGO would ask me to arrange any assistance that was required, even if it could be provided by another NGO on the project," she said. "All that has now changed. The group has jelled, and they are now more likely to work directly with each other."

Rehwinkel sees the unity engendered by the work of the Steering Committee as one of the pilot project's most important accomplishments, noting that the groundwork has been laid for the NGOs to continue their collaboration after the five-year project ends.

"I think the consolidation of the framework is a measure of success," agreed Larivee. "This framework, as it is strengthened, should allow for more organizations and donors to participate."

The project recently received its first contribution from a donor other than USAID—\$US 44,000 from Japanese Grant Assistance for Grassroots Projects. The grant will be used to purchase much-needed equipment for the NGO centers.

Moving Ahead In October, the project moved into its second phase. NGO members have begun identifying young people who will be trained as peer educators. The project's Communications Working Group is working with a local consultant to produce a peer education manual and other training materials.

Meanwhile, the NGOs are keeping the Ready Body message in the spotlight. Steering Committee members and project consultants appear frequently on the interview and call-in shows aired by Guyana's 20 TV stations. The combination of many content-hungry TV stations and dynamic, media-savvy promoters has resulted in a great deal of free media coverage for project messages.

The main events of the second phase are the annual Phillip

Vanderhyden AIDS walk-a-thons to raise money for HIV/AIDS care and support. Hundreds of Guyanese joined Minister of Health Dr. Henry Jeffrey at the first walk in Georgetown October 29. DJs wrote safer sex (Ready Body) messages that were chanted along the five-kilometer route.

The NGOs were also gearing up for World AIDS Day, held every year on December 1. Comforting Hearts, for example, was organizing a rally in New Amsterdam for secondary school students. Members of Artistes in Direct Support were working on their annual "The Flame and the Ribbon" program, which drew inspiration from this year's World AIDS Day theme, "Men Make a Difference." Edghill-Adams, who wrote a play for the program, says it opens with a disco scene and the song, "Let's Hear it for the Boys."

Carrying On "The Guyana Youth HIV/AIDS/STI Project is off to an excellent start, but it faces some tough challenges," Dr. Becker noted. These include a dearth of accessible condom outlets, lack of confidentiality in HIV counseling and testing, and little involvement of the Indo-Guyanese population in HIV/STI prevention efforts.

HIV/AIDS is perceived as a problem of the Afro-Guyanese, explains Edghill-Adams. "They think it's a black thing."

This may be because the majority of those who rely on the public health system in urban areas are Afro-Guyanese. Urban-based Indo-Guyanese tend to use the private hospitals and clinics, which do not report on HIV statistics.

Nationwide, the Indo-Guyanese account for 51 percent of population, so it is particularly important for the project to engage them and their religious leaders. The Communications Working Group makes a point of using people of all ethnic backgrounds in its materials. In the Georgetown fair teaser, for example, the girl was Indo-Guyanese and the boy was Afro-Guyanese.

Another major challenge is identifying STI, HIV and other health services that the project can recommend to youth. Without additional funding from other sources, the project will be able to offer only limited training in STI diagnosis and treatment to selected health personnel. Yet the need for high-quality, accessible reproductive health services for youth is great.

The assessment found that more than half of the young people surveyed had sought medical care at public clinics. For STIs, however, two out of three said they would go to a private doctor. Few services, public or private, make youth feel welcome.

Only 18 percent of survey respondents had been tested for HIV. All said that such services should be confidential—a major problem in Guyana, where the stigma associated with HIV is strong.

*Violence was seen as a threat by
an alarming proportion
of the young people surveyed.*

People who test HIV-positive have few places to turn in Guyana. A handful of church groups provide community-based care. Doctors and nurses are often reluctant or unsure of how to treat people living with HIV/AIDS.

Edghill-Adams learned this firsthand when Keith André Sobryan, chairman of the National AIDS Committee and dramatist extraordinaire, fell ill. His doctor was out of town, and she could not find another physician who would come to Sobryan's house. Sobryan died in a private hospital, where his friends took over his daily care because the nurses were afraid to tend to him.

All those involved in the response to HIV/AIDS in Guyana will miss Sobryan, whose candor, talent and insights contributed so much to the fledgling project during its first five months.

While many involved in the project are grieving this loss, they are also inspired to continue the work Sobryan did with such passion and flair. As Edghill-Adams explained, "I am more determined than ever to carry on the legacy he has started."

CHERYL SPRINGER, A GUYANESE JOURNALIST, IS CHIEF SUB-EDITOR OF THE *STABROEK NEWS* IN GEORGETOWN, GUYANA.

Guyana Says Good-bye to "Miss Lottie"

Everyone wore red to André Sobryan's funeral.

It was the way he wanted it, explained Desiree Edghill-Adams, his friend and a co-founder of *Artistes in Direct Support*, a group of performing artists who use their talents to educate the public about HIV/AIDS. "He said, 'When I die, I don't want people to know it's a funeral. I want people to think my funeral is a wedding.'"

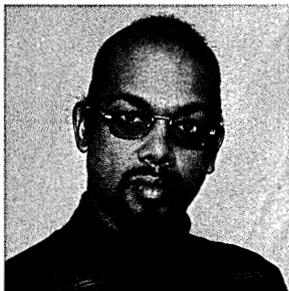
So his friends organized a funeral that was a celebration of the life of Keith André Sobryan, with music, song and laughter. Almost two weeks after his death, virtually every musician, actor and dancer in Guyana performed at a memorial for Sobryan—a fitting tribute to one of Guyana's most gifted artists.

A student of modern and ethnic dance and an accomplished actor and director, Sobryan performed, directed and produced plays, taught acting and dance, and wrote for the *Guyana Review* news magazine. Intensely nationalistic, he represented his country at the annual Caribbean Festival of Creative Arts and introduced North Americans to the Guyanese arts through his performances in the United States and Canada.

In Guyana, Sobryan was a celebrity, known for his larger-than-life personality, his enormous talent, his flamboyant costumes, and his big heart. To some he was best known as "Miss Lottie," the character he created for a Guyana Theatre Guild production called "Ban the Brink, Damn the Brink" in 1979. With her big feet and loud voice, Miss Lottie became a household name, appearing in stage shows, TV programs and advertisements for everything from paint to voter registration.

After Sobryan learned that he was HIV-positive in December 1989, he began lending his talents to the cause of HIV prevention and to fighting the pervasive stigma associated with the virus. In 1993, he helped found *Artistes in Direct Support* to use the arts to convey HIV prevention messages creatively and memorably.

Sobryan pioneered public education about HIV/AIDS in Guyana.



André Sobryan

He was also a founding member of the Network of Guyanese Living with HIV/AIDS and the Caribbean Network of People Living with HIV/AIDS.

As director of the National AIDS Committee, which represents NGOs and advises the national AIDS program, and a member of the new Guyana HIV/AIDS/STI Youth Project Steering Committee, Sobryan was a part of almost every HIV/AIDS initiative in Guyana. "All the NGOs in the project

called him for advice," said Edghill-Adams. "He used to be involved in everybody's projects."

Sobryan had returned from the XIIIth International AIDS Conference in Durban, South Africa, where he gave a presentation, and was planning *Artistes in Direct Support's* World AIDS Day show when he became ill in August 2000.

It was his first bout with AIDS-related illness. Sobryan had lived a remarkably healthy 10 years with HIV, even though he never took antiretroviral drugs. He was reluctant to try the potent drug "cocktails" because of their prohibitive cost and because he did not want to "live on tablets."

Sobryan was also troubled by the inequities in access to antiretrovirals. "He said, 'Why should I benefit from the cocktail when there are so many young people who are beginning their lives who could benefit from it?'" Edghill-Adams remembered.

Nevertheless, as he lay dying in a hospital in Georgetown, Sobryan's friends searched for an affordable source of the medicine that might save his life. They found a group in New York City that was willing to donate the drugs, but it was too late.

André Sobryan died September 11, 2000, with his closest friends at his side. They take comfort in all he was able to accomplish and experience in a life that ended too soon.

"He lived more in 41 years than most men live in a lifetime," Edghill-Adams said.

—Kathleen Henry

FHI PUBLICATIONS

The Family Health International/UNAIDS Best Practices in HIV/AIDS Prevention Collection Family Health International (FHI) and the Joint United Nations Programme on HIV/AIDS (UNAIDS). This book contains 20 case studies chosen by a joint team at FHI and UNAIDS to document and share some of the accomplishments and key lessons from the AIDS Control and Prevention (AIDSCAP) Project. Funded by the United States Agency for International Development, AIDSCAP was implemented by FHI in 50 countries from 1991 to 1997. From decreasing sexual violence against women in Rwandan refugee camps in Tanzania, to increasing access to condoms during political turmoil in Haiti, to salvaging the reproductive health of sex workers through accurate diagnosis and treatment of sexually transmitted infections by chemists in rural Nepal, these case studies report key program innovations launched by AIDSCAP on three continents in the 1990s. They also provide insights into the lessons learned from these experiences that can be applied in other resource-constrained settings to achieve greater impact on HIV epidemics. The book will be published in January 2001.

Behavioral Surveillance Surveys: Guidelines for Repeated Behavioral Surveys in Populations at Risk for HIV These guidelines provide practical information on how to conduct behavioral surveillance surveys (BSS), which are a moni-

toring and evaluation tool designed to track trends in HIV/AIDS-related knowledge, attitudes and behaviors in subpopulations at particular risk of HIV infection. BSS consist of repeated cross-sectional surveys conducted systematically to monitor changes in behaviors that put people at risk of HIV and other sexually transmitted infections. The guidelines cover important topics such as identifying priority subpopulations, developing sampling frameworks and approaches, analyzing data and disseminating results. Sample questionnaires for surveys among youth, adults, female sex workers and injecting drug users are included. An electronic version of the guidelines can be found at <http://www.fhi.org/en/aids/wvdo/wvd12a.html#anchor545312>.

Behavioral Surveillance Surveys Executive Summaries These reports summarize major findings on trends in HIV risk behavior from behavioral surveillance surveys (BSS) in selected countries. Reports are available on BSS results in Bangkok, Thailand (1993-96), Cambodia (1997-99), Côte d'Ivoire (1998), Indonesia (1996-98), Senegal (1997-98) and Tamil Nadu, India (1996-98). Electronic versions can be found online at <http://www.fhi.org/en/aids/wvdo/wvd12a.html#anchor1074959>.

FHI Focus on...Fact Sheet Series Each fact sheet in this series provides an overview of a key topic in HIV/AIDS prevention and care, a description of Family Health International's approach to

interventions in that area, and examples of FHI activities. Fact sheets available in this continuing series cover topics such as FHI's AVERT model for estimating the impact of prevention interventions, behavior change communication, behavioral surveillance surveys, blood safety, evaluation, gender-based interventions, HIV/AIDS care and support, information dissemination initiatives, intervention-linked research, participatory program design, management and prevention of sexually transmitted infections, support for orphans and vulnerable children, TB and HIV, voluntary HIV counseling and testing, and workplace HIV/AIDS programs. Some fact sheets focus on HIV/AIDS interventions for specific populations, such as injecting drug users, men who have sex with men, mobile populations, sex workers and youth.

Ordering Information Single copies of the fact sheets, BSS publications and the best practice case studies are available free of charge. Organizations from industrialized countries are asked to pay shipping charges (please include a DHL, Federal Express or Air Express account number with your request). To order publications, contact Information Programs, Family Health International, HIV/AIDS Prevention and Care Department, 2101 Wilson Boulevard, Suite 700, Arlington, Virginia 22201, USA. Phone: (703) 516-9779 Fax: (703) 516-9781

Meeting the Needs of Young Clients: A Guide to Providing Reproductive Health Services to Adolescents This handbook for reproductive health service providers, program managers, educators and others who work with adolescents focuses on prevention of unplanned pregnancies and sexually transmitted infections, including HIV. The 100-page handbook contains role-play exercises that providers can use to help young people negotiate condom use and say "no" to sex. Free copies are available to those working in non-industrialized countries.

Reproductive Health of Young Adults: Contraception, Pregnancy and Sexually Transmitted Diseases Part of Family Health International's Contraceptive Technology Update Series, this slide lecture module on adolescent reproductive health is designed for healthcare providers, program managers and policymakers. It is available in English, French and Spanish. Single copies of the module are free to trainers and educators in non-industrialized countries upon written explanation of need and may be purchased by others. The module is also available online at www.fhi.org/en/ctu/adoltpm/.

Ordering Information To obtain a copy of the slide lecture module or the adolescent reproductive health manual, contact Family Health International, PO Box 13590, Research Triangle Park, NC 27709, USA. Telephone: (919) 544-7040 Fax: (919) 544-7261 E-mail: publications@fhi.org

OTHER RESOURCES

Open Secret: People Facing Up to HIV and AIDS in Uganda ActionAid. The authors of this new book in the Strategies for Hope series argue that the reason for Uganda's apparent success in HIV prevention is the openness that has characterized the national response to the epidemic. Their book captures the courage and honesty with which Ugandans in many different walks of life have faced the reality of HIV and overcome stigma and denial. The book, which is number 15 in the Strategies for Hope Series published by ActionAid and distributed by Teaching AIDS at Low Cost (TALC), costs £ 4.50, including postage. Organizations in sub-Saharan Africa that are unable to pay in foreign currency may request up to three copies each, free of charge, of books 8 to 15. Requests for larger quantities will also be considered, on receipt of an explanatory letter. These requests will be considered as long as stocks are available. To order books in the series, write to TALC, PO Box 49, St. Albans, Herts AL1 5TX, United Kingdom, or visit the Strategies for Hope Web site at www.stratshope.org. Tel: (44 1727) 853869 FAX: (44 1727) 846852

Health-Net News-AIDS SATELLIFE. This electronic HIV/AIDS newsletter for health professionals in non-industrialized countries is published twice a month as a supplement to SATELLIFE's weekly *HealthNet News*. It offers summaries of articles, abstracts, full text articles, clinical guidelines and other useful informa-

tion about HIV/AIDS prevention, diagnosis, epidemiology, therapeutics, education and best practices in the response to the epidemic. Research conducted in Africa and published in international medical journals is a key feature of the newsletter. In accordance with SATELLIFE's agreements with medical publishers, subscriptions to *HealthNet News* and *HealthNet News-AIDS* are restricted to health professionals working and living in non-industrialized countries. To subscribe, e-mail autoinfo@usa.healthnet.org.

Facilitating Sustainable Behaviour Change United Nations Regional Project for Asia and the Pacific on HIV & Development for Asia and the Pacific, the Macfarlane Burnet Centre for Medical Research and the Sydney Myer Fund. This guide suggests issues to consider when designing programs to facilitate behavior change and provides an overview of approaches that have proven to be effective. It draws together theories from various disciplines and life experiences and offers a framework that makes these theories accessible and easily applicable in program design. The guidebook also provides an outline for a workshop, based on the framework, to assist participants in understanding how behavior change may take place in their own settings, designing programs that are relevant in those settings, and conducting participatory evaluations. To request a copy, e-mail Benjamin Brown at benjamin.brown@undp.org or Angeline Ackermans at angeline.ackermans@undp.org.

IMPACT ON HIV

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