POZ In Asia (City Profiles)

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NAME WITHHELD, 40,
professional, husband, father; developed
tuberculosis (TB) and was tested for HIV, without consent, in 1997.

So far only my wife knows I have HIV. After a period of shock, she managed to come to terms with it. She's still very afraid because of the danger, but she is an exception; she approaches the issue very scientifically and rationally. I do not know anyone else with HIV. Of course, I would like to make contact with someone, but I don't want to risk the exposure. I'm really afraid: Maybe I'll lose my job, maybe my kid will not be able to go to school—that would be a catastrophe.

Only a couple of HIV positive people have appeared in public. Otherwise, people are hidden, because there would be tremendous pressure. There was a young lady who got the problem, and when she returned to her hometown—a small village in the countryside—her family got in big trouble. Very soon, this lady died, both because of the disease and because of the terror. After her death, her family was not able to lead a normal life. People would not talk to them or contact them, out of fear. The shops refused to sell to them. Instead, overnight, the shopkeepers would leave what they wanted at their door, secretly.

In China, you have to pay your own medical bill, and the drugs cost more than $10,000 [U.S.] per year. I earn less than $2,000 [U.S.]. I pay for the drugs with my savings, plus I try to generate additional income through outside projects. It's very tough.

I'm enormously indebted to my doctor. He has played a very important role in pushing the government to allow these drugs to be imported into China—which only happened a few months ago. Before that, he personally made some informal arrangements to get the drugs; this is why I say I'm very lucky.

The government has done a lot—especially over the last several years—to focus on prevention. More and more, educated people in big cities realize how HIV is transmitted. But most still don't. You can buy condoms anywhere, and it's not expensive. But there's a debate: Some officials say you should support people to use condoms; others hold the view that by doing so you encourage people to have out-of-marriage sex.

As for the welfare of people with AIDS, the government has done little. Also, the international societies and the drug companies can do more. If the companies reduced the prices significantly, it

would not only directly save a lot of lives, but it would also reduce unfounded fears and the social prejudice toward PWAs. This disease is terrible, but people think it's some kind of evil superdisease. Please convey my view on behalf of many other people in this situation; it is a matter of life and death.

—as told to Esther Kaplan

CHINA

Total population 1.25 billion

Number of people with HIV
UNAIDS 401,400
Official gov't 17,316

Number of people with AIDS
UNAIDS: 9,000
Official gov't: 647

Number of openly positive: 6

TRANSMISSION MODE
4% Homo
17% Hetero
59% IDU
20% Blood products
In certain regions, 70% of IDUs are infected. More than two-thirds of HIVers are under 30. HIV prevention is crippled due to taboos on talk about sex. Condom ads were recently banned from TV. Seven out of 10 Chinese believe kissing spreads AIDS. TB is epidemic. 80% of rural population lacks government-funded health care. Two new AIDS vaccines in human tests by 2002.

Bangkok, Thailand
Paul Toh, 32,
Founder, APN+ (Asia Pacific Network of People Living with HIV/AIDS)

I am out in Thailand as an HIV positive gay man. I've been positive for 11 years, and I spoke as a PWA at the International Conference on AIDS in Vancouver in 1996. My family and most of my friends know about my status and have been very supportive.

I first tested because my boyfriend, a doctor, came down with the virus. I felt lost when I found out. But life goes on, and I know now that it's not how long one lives that matters, but how well. I told myself at first that if I have eight years, I will make full use of them, and if I have 10, I will be thankful to God. Well, God has been very merciful because I am in my 11th year of infection and still asymptomatic—because I am fortunate enough to get antiretrovirals from a hospital in

Bangkok and sometimes one in Sydney, Australia, unlike my positive Thai brothers and sisters.

I'm on my third cocktail—indinavir, ritonavir, nevirapine, and ddI—and I pray that the virus does not grow resistant. In Asia, available and easy access to treatment is the key to survival and what every PWA support group fights for. I have been involved in the recent push to enforce compulsory licensing in Thailand so we can have ddI at affordable prices. If we feel that AIDS is a treatable disease, but not a curable one, then why are we Asians with HIV discriminated against in terms of the basic human right to be treated? Every day, I see friends and activists falling ill and eventually dying. Every day. The developed world needs to start helping us, to ensure the continuity of our activism, to provide a better quality of life for us and simply to save our lives.

I'm an activist at heart. HIV has changed my perspective toward life. I treasure love and friendship more than other attributes like sex or money. I started the first PWA network in Asia, called APN+, in February 1994, with 40 other PWAs from eight Asian Pacific countries. Then we went through all the NGOs and medical centers in the region in search of our fellow PWAs. Now APN+ is one of the world's most progressive HIV networks, reaching thousands of PWAs—most of whom are not out to anyone else. Today I work for the UNAIDS Asia Pacific Intercountry Team, here in Bangkok. I believe in building a global PWA community. I started an e-mail discussion forum, PWA Net. You can e-mail pwha-net@hivnet.ch and register.

—as told to Angelo Ragaza

Children of A Lesser God
Iloilo City, Philippines

The young women's workday begins a few hours before the clock strikes midnight and ends before the cock crows at dawn. Wearing a flimsy piece of cloth, a skimpy bikini or nothing at all, they dance and strip in front of unsatiated male customers in pubs and massage parlors for a few hundred pesos. For a few more pesos, some will even be used in bed. They don't get benefits or insurance in this type of work—the only thing they might get, if they don't use protection, is a sexually transmitted disease (STD) or AIDS. The money that they earn will be sent to their families for food, medicine or tuition for their siblings or, young as they are, their own kids.

These young people in Iloilo City, Philippines, ranging in age from 12 to 17 years old, face a bleak future. They are the children of laborers, beggars and hand-to-mouth parents. Some earn their living washing cars or becoming "barkers" or "call boys" (children who solicit taxi passengers). But because they can make more money, some become pickpockets, snatchers or prostitutes.

Here in Iloilo, the government issues prostitutes a sort of working permit requiring a weekly vaginal smear. If they get a positive result, they can't go on duty for three days and must report for a checkup smear and take medications.

Iloilo's Kabalaka Reproductive Center is emphasizing peer education and counseling. Our educators are trained and equipped to work in establishments throughout the city, teaching about

STDs and AIDS and correct condom use. We emphasize having sex only with their customers or partners who will use condoms. Instilling this knowledge is quite difficult.

None of these kids likes the kind of job they now have, but circumstances leave them no choice. Some say they still cry their hearts out after their shows, though they have been doing them for a long time.

Through our project, we are shining a light of hope into the dark night of these youths. You who are more fortunate, what would be your response? May you extend yourselves and become a channel of blessing, and may you value the life you now have.

—Anna Mae Bambao, Jocylyn Gonzalo and Melba Sale

PHILLIPINES

Total population 77,725,862

Number of people with HIV
UNAIDS 23,620
Official gov't 1,336

Number of people with AIDS
UNAIDS 1,600
Official gov't 321

Number of openly positive 15

Transmission Mode
4% Homo
56% Hetero
34% IDU
6% Blood products

In 1998 this prosperous Catholic nation passed Asia's most progressive "AIDS law" that protects HIVers from discrimination, bans forced testing, assures confidentiality and mandates AIDS ed in schools, workplace and for all tourists. Advocates have pressured the church to allow widespread HIV prevention campaigns.

Culture Clash
Jakarta, Indonesia

Imagine a world without discrimination and you think of Utopia. Now, imagine a place where the

word discrimination—let alone activism—does not exist and you think of…Indonesia. But for people with HIV, Indonesia is no Utopia.
Despite its modernity, much of the country remains feudal. Although Sultans no longer wield power, local bureaucrats do, and few in Indonesia's less-modern countryside—home to most of the nation's 200 million people—question the authority of their village chief or district head. No surprise, then, that here the tug-of-war between the rights of the individual and those of the community pulls in the opposite direction than it does in the West. "Controlling" people living with HIV—and the personal restrictions such control entails—is not viewed as unjust or outrageous, but something done to ensure the greater good.

In Indonesia, people with AIDS are often required to report to the authorities on a regular basis and to request permission to travel; they are also held up publicly as examples of immoral behavior. And it is not only we activists who consider such measures gross discrimination; so does Indonesian law. But the "victim" accepts this treatment as reasonable, rejecting any offers from activists for defense.
Often the concept of "Asian values" is raised in activist circles when East meets West. Western-style advocacy is little understood in Indonesia, and Asians view the use of confrontational tactics as inappropriate. Sustained pressure on decision-makers has only rarely been a part of our heritage. These differences go deeper than the issue of strategy or even values; they are a matter of culture—and take patience for a Westerner to grasp. West or East, though, simply having HIV doesn't in turn make an activist, or end an era of feudalism overnight.

—Chris Green

War Buddies
Ho Chi Minh City,Vietnam

The "friends Helping Friends" meeting doesn't start at the advertised time, but then few Vietnamese get-togethers do. People—mostly men in their 30s and 40s—drift in and out over an hour and talk. One young man comes with his mother. Another guy sits down and promptly falls asleep, stoned. Two women in pajamas slip out of their sandals, curl their feet up on their plastic chairs and wait for men to bring them cold drinks. A couple of older guys play Vietnamese pop songs on guitar and keyboard.

A paid staff member clears his throat and presents a brief summary of recent activities. He states that there are small groups in eight districts of Ho Chi Minh City now but that they hope to double that number in the next year. He holds up a copy of the Asia Pacific Network of People Living with HIV/AIDS' new booklet on speaking skills, drawing a few laughs when he announces it is only published in English. He ends by explaining a new law allo-cating money for some NGOs; they might be run by people living with HIV.

Then the informal part of the meeting begins. People laugh, grumble, ask to say a few words. The food comes out, people light up, and several take the microphone in turn to talk about constraints in developing mutual support groups in other parts of the city. At first there is the predictable

whining about too little money and too many needs. Then the mood changes. Two newcomers stand up to say how much the group spirit means to them.

In this nation, the virus is spread mostly by sharing dirty needles. There is no methadone, no 12-Steps. Only a select few get antiretrovirals. Rent is paid by the Ho Chi Minh City government, and an HIV negative doctor assigned to the group is responsible for reporting on their activities. First funded two years ago, the group's members were told they would be expected to be self-sufficient by this year. As of yet they have no computer and little English. Just translating the scholarship application form for the last regional HIV conference took a week to complete.

As people start to drift away, the names of two friends who have recently died are announced, and the government benefits that they were promised but never received are bitterly recalled. One of the group leaders sums up: "Money, medicine, friends. That's what we need." Some would call this activism. Others, who don't want to use such a Western term, say they are just a group of friends helping friends.

The Hope Café, which sits on a fetid canal in a Ho Chi Minh City park, draws an unusual crowd. As morning rush-hour traffic builds, men wander into the courtyard to sit under the trees, exchange a few words and enjoy iced coffee. Most are stoned on heroin. Using narcotics can land any one of these men in a rehabilitation camp, but here, no one is arrested. The Hope Café is a "no go" zone; injectors can enjoy a few hours of peace. The coffee is strong and cheap, the bathrooms spotless, and the showers and laundry services free. Plastic syringe wrappers litter the ground under the trees from the hundreds of new works that are distributed free every day. The men who frequent the café are a mixed group, from this country's version of Vietnam vets, who have been injecting off and on since the war, to teens who have just entered the life. Some have HIV; a few are visibly sick. None will ever "just say no."

Money and staff come from the Ho Chi Minh City AIDS Committee. The peer educators say that they have tried to make a place that is thoai mai—cool, comfortable, easygoing. They spend time talking with the customers, and the sick are hooked up with doctors. But they also give the men a lot of space. The Hope Café is a cost-effective secondary prevention program. And for these men, who have learned not to hope for much in the way of help, the atmosphere of trust and care is vital.

Since he believed he was dying, Do Kim Son was surprised to receive an invitation from the National AIDS Committee of Vietnam to join a high-level delegation attending the International Conference on Aids in Vancouver four years ago. But Son, the first Vietnamese PWA to come out, came to expect the unexpected: He was surprised by the support of his family when he first got sick. And of his friends and neighbors after he appeared on national television—twice. "When they put the camera in front of me, I was scared. What would my neighbors think?" he recalls. "But after the second time, people started to speak to me, and I could see it was going to be OK."

Son asks his positive friends around the world about medications, so he has a reputation as a local AIDS expert. He can count off almost a dozen different medications—all too expensive for a

Vietnamese to afford. His face has signs of the government-funded nuke and protease inhibitor he has taken for several years now.

Son admits that being the first out PWA is hard work, and he often thinks about getting out of town for a break. “There is a place up in the hills near Dalat. The air is cleaner,” he says with a smile. “It is a place where people like us can relax for a bit.”

—Jamie Uhrig

VIETNAM

Total population 76,548,000

Number of people with HIV
UNAIDS 87,100
Official gov’t NA

Number of people with AIDS
UNAIDS 8,700
Official gov’t 1,202

Number of openly positive 1

Transmission Mode
1% Homo
18% Hetero
80% IDU
1% Blood Products

Katmandu, Nepal
Rajiv Kafle, 26,
President and Program Coordinator of Prerana,Nepal Representative to APN+, the Asia Pacific Network of People Living with HIV/AIDS

Most PWAs in Nepal will tell you it is better to die as soon as possible rather than live with HIV. Because sex workers and IV-drug users are at highest risk, discrimination is a huge problem. Doctors and nurses often refuse to touch positives. In villages, they are thrown out of their houses and even stoned and chased away. HIV positive people are not accepted by rehabilitation centers. And access to treatment does not exist. The cost of medicine is so high, and PWAs are generally so poor they can barely have two meals a day. All money for AIDS goes only to prevention, not a penny to treatment. The doctors prescribe vitamin B complex. That is all we have.

I grew up in a middle-class family and went to one of the best schools in Nepal. I finished high

school in 1990, at 16. Unfortunately, I failed my graduation exam and began spending time with others who failed. I got into injecting drugs.

One day, after I had been in rehab for seven months, I got really sick and thought that I would die, since the fever was 105 degrees. After learning my history, the doctor suggested an HIV test. After three days I collected my report: HIV positive. I went back to the rehabilitation center and cried and cried. There was one other HIV positive person in the center who helped me.

A week later, I received a letter from a school in Denmark awarding me a six-month scholarship. I went there in September 1998. I became famous in the school because of my all-around talent—though mostly among the girls. I went to bed with a couple of them, but never without a condom. I had a girlfriend propose that we marry and live in Denmark, even though she knew my status. But money and love were not as important to me as making a difference in my own country. I went home.

I joined Prerana, a support group of positives started in 1997 as a result of drug users getting infected. Four months later I became president. Since then, I have made my name synonymous with AIDS in Nepal. Leading Prerana was tough from the beginning—five HIVers, a room, a table and a chair. No one wanted to rent us space. Things changed a bit after we went to the media and some money came in.

Prerana now has more than 200 members. We are the only organization in Nepal that works in both HIV prevention and care. We run an AIDS hotline and classes in schools; observe World AIDS Day and World Candle Light Day (May 14); and use the media to tell our stories and voice our needs. We run free clinics and a skills-development program to help PWAs learn job skills and be self-dependent. We have a food program that provides nutritious meals for PWAs. Most importantly, we give moral support to each other, and try to live happy and positive. We have no regular donors—our biggest problem.

We have lost a lot of our people. But God is with us. In time, I believe we will be an example not only in Nepal, but all over the world.

This is dedicated to my dear Manisha Dijju and her little girl.

NEPAL

Total population 18,273,000

Number of people with HIV
UNAIDS 6,890
Official gov’t NA

Number of people with AIDS

UNAIDS 1,900
Official gov't 77

Number of openly positive 1

Transmission Mode
10% Homo
63% Hetero
26% IDU
1% Blood products

The government approves all news reports about sex, discouraging AIDS coverage.

Island Fever
Colombo, Sri Lanka

A reporter discovers an AIDS patient in a nearby village and runs the story in a local newspaper. Though not naming the victim, the report gives identifying details about where the PWA lives. Angry neighbors chase him and his family out of the village. In a suburban hospital, a female laboratory technician becomes agitated when she learns a patient is HIV positive. She calls people in the man's village and tells them. The victim's wife, a schoolteacher, is harassed and ridiculed so much that she flees her home in shame. This is the island nation of Sri Lanka, where 286 HIV cases have been reported and 73 deaths recorded, and where AIDS evokes anger rather than empathy.

"It's a tough life for victims of AIDS. They are a marginalized lot," says Dr. Kamalika Abeyratne, an HIV positive physician who is the first Sri Lankan to be open about her status. Abeyratne, who contracted the virus through a contaminated blood transfusion, says that it took a lot of courage to come out. "It is not easy in a conservative society like ours because most people associate AIDS with sex. But in my case, I wanted to come out into the open. I didn't want to hide."

Abeyratne, whose husband is also a doctor, concedes that she did the unthinkable by going public. She is not only Sri Lanka's first out PWA, but she also heads the AIDS Coalition for Care, Education and Support Services (ACCESS), an NGO based in the capital city of Colombo. Earlier this year, ACCESS started Sri Lanka's first AIDS hotline, offering free advice to callers seeking information on the disease. So far, Abeyratne reports, the response has been good.

ACCESS will have to fill a gaping hole in AIDS awareness. At a recent symposium for schoolchildren, participants were told that AIDS was a "four letter" word that is taboo in Sri Lankan schools, particularly those in the countryside. "Forget AIDS—discussion on sex itself is taboo, even during the bio class," says Dedunika Kumari of Diyatillake College at Hanguranketa, in the central Kandy district. "Our teachers are embarrassed to talk about it."

—Feizal Samath

SRI LANKA

Total population 18,273,000

Number of people with HIV
UNAIDS 6,890
Official gov't 286

Number of people with AIDS
UNAIDS 1,900
Official gov't 77

Number of openly positive 1

Transmission Mode
10% Homo
63% Hetero
21% IDU
6% Blood products

Melbourne, Australia
PWAs Before Profits

As AIDS has exploded in Asia recently, the paradigm of HIV-focused work has shifted from slick, quick HIV prevention campaigns to increased emphasis on underlying issues—particularly access to treatment, social justice and the rights of people with HIV. International NGOs fighting AIDS in Asia have kept step with this change with varying degrees of success. Some, such as Save the Children, the Red Cross Society, Family Health International and, above all, Doctors Without Borders, have made great strides in their commitment to involving the local community in its own programming. But others are unable to relinquish their paternalistic, almost colonial, attitudes.

One of the worst offenders is the British-based International HIV/AIDS Alliance, which betrays the best interests of HIV positive Asians by rigidly refusing to support the global campaign to lower the price of AIDS drugs. The Alliance went even further when it signed on to a consensus statement that actually argued against the effort, published in The Lancet. The Alliance's rationale? The cost of antiretrovirals is too high for a developing country's precious resources to be wasted by providing the drugs to its people with HIV. This wobbly position was developed with no regard for, or consultation with, the developing country, and without exploring how such access might be able to happen. And there was another reason—the best interests of the Alliance's corporate sponsor: Glaxo Wellcome.

Activists are well advised to be on their guard against Trojan horses like the HIV/AIDS Alliance, as they may function as the eyes, ears and even hired hands of the pharmaceutical industry. To promote the best interests of people with HIV in Asia, a code of ethical conduct for international NGOs clearly needs to be developed and implemented. Such a code will ensure that international aid organizations make their priorities those of the communities in which they work, that potential conflicts of interest are exposed, and that barriers to lifesaving HIV meds are removed.

—Joe Thomas

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