POZ In Asia (Introduction)

July 1, 2000 By Marina Mahathir

What DO westerners need to know about Asia and the Pacific? It is an incredibly diverse continent, with a mind-boggling number of ethnic groups, languages, cultures, traditions and religions in countries with vastly different political systems and economic levels—from the very poor in Papua new guinea to the very rich in Japan. The AIDS epidemics here are equally diverse, and elicit widely differing local responses. Thailand has been cited as the most responsive and successful, having reduced infection rates among pregnant women and army recruits.

Countries such as Indonesia and the Philippines still report very low figures, due to several factors—denial of the gravity of the situation not the least of them. The military dictatorship in Myanmar (Burma) officially claims that the country has no epidemic, despite estimates of 440,000 infections, all the while quietly asking for help as transmission soars among drug users and women. Cambodia has the worst prevalence rate in Asia, with 40 percent of sex workers and 2 to 3 percent of adults infected, but is stymied by poverty and a rudimentary health care system. India has an estimated 4 million HIVers in a population of 1 billion cursed with myriad health crises; although focusing exclusively on AIDS isn't an option, the government has made it a priority. China has generally had a realistic approach to HIV, promoting condoms and sex education in schools, but there are enormous challenges in enlightening such a vast population, especially one undergoing economic transition. So that is the Asia epidemic from the sky. But what is it like here on the ground?

Not long ago, the death of a man named Arif—one of 33,000 Malaysians with HIV—sparked a debate among those of us who do AIDS work here in my country, Malaysia. In the year before he died, Arif—of course, that is not his real name—became very special to the organization that I head, the Malaysian AIDS Council. He had been a soldier in the Royal Malaysian Army and served in peacekeeping missions in Bosnia. Although his first wife had died of AIDS, he tested negative and remarried, only to find that both he and his second wife, Ida, had become infected. Arif was never sorry for himself, always polite and cheerful, quick with a hello and willing to help out. At a meeting on Islam and AIDS, his simple yet eloquent recounting of his life left many in tears and gave the religious leaders a human face to the epidemic for the very first time.

Arif had come out to small, closed groups, and he knew what good came of this. Last fall, at the opening of the fifth International Congress on AIDS in Asia and the Pacific, a video told the contrasting stories of Jack, who had a supportive family, and Arif and Ida, who did not. Jack was able to appear both in the video and onstage. But after agreeing to be filmed, fear got the better of Arif and Ida—to be exposed in a video in front of 3,000 people as well as the press was too

much—so actors had to substitute.

Sadly, Arif and Ida were too ill to attend the opening. Since neither of their families could take them both in, Arif returned to his hometown to pass away separated from his wife and daughter. But Ida managed to make it to the closing of the conference, where she met HIV positive women from other countries. I know that she took heart from knowing she wasn't alone; she also did her best to give courage to them. I believe that she is now more motivated to want to stay alive.

Time and again, we have witnessed how nothing has more power to overcome people's fear and hatred of this disease and those who have it than the testimony of a PWA such as Arif. That is why, right now in Asia, ensuring greater involvement of people with AIDS in our advocacy is the urgent priority. As HIV negative activists, we can make intelligent guesses as to what people with HIV need, but we cannot know.

I am always surprised by the takes that PWAs have on certain issues; often they bring up an angle that I would never have thought of. For instance, in Malaysia there was recently a rash of claims in the media of so-called cures for AIDS, usually by homeopathic or traditional medicine practitioners. Very few have been tested enough to know if they are even safe. Though our instinct is to pooh-pooh them, we get many phone calls from PWAs asking if they work and how to get them. Antiretrovirals are as expensive here as anywhere else, and most Malaysians cannot afford them. Desperation makes any cheaper alternative attractive. Yet, as one PWA pointed out, to come down hard on alternative medicines—no matter how dubious their claims—strengthens the pharmaceutical industry's hand in pricing drugs. In trying to protect PWAs from these snake-oil salesmen, we inadvertently not only keep HAART inaccessible but leave people with AIDS no one else to turn to but the quacks.

Our activism never gets enough of this kind of PWA input. But there are simply too few people with HIV willing to come forward and do this work. Not that they are to be blamed. In Asia, the fierce discrimination against PWAs is a huge deterrent to any coming out. Of course, one way to dispel these stereotypes is for PWAs to come out, but few are like Arif, able to look at the big picture, to realize they have a role to play to shatter society's stereotypes about people with HIV.

Many people with AIDS in Asia come from marginalized communities—sex workers, IV-drug users, immigrants—where life even before HIV was pretty much a hand-to-mouth proposition. AIDS only made things worse. For those who want to be more involved in advocacy, dealing with the day-to-day issues takes up too much time. Their absence causes a narrowing of PWA involvement that does not reflect the diversity of the actual community. While there are many middle-class Malaysians who are HIV positive, we rarely see them, either. More important, they rarely see one another. They feel they have so much more to lose from exposure. Apart from some support groups, they generally stay away. Yet it is from their ranks that the most effective AIDS advocates will come—they have greater access to information, influence, money, everything.

I have been awed by many PWAs around the world who can speak out in a passionate and

articulate fashion and who are fully involved in AIDS policymaking in their countries—and not all hail from the developed world. But in my country, as in most of Asia, this has yet to happen. Our challenge—and the world's, too—is to draw them out.

But that creates its own set of problems: If they do come out, what can we offer them? Treatment? Absolutely not. In Malaysia we are fortunate to have a drug-assistance scheme for some poor people with HIV, but white-collar PWAs do not qualify. If they come out, can we protect them and their families from stigma? No. It's a cruel catch-22: Their coming out will do much to reduce the stigma, but they risk the effects of the stigma—ultimately, they risk their lives—if they come out. Should we turn them into circus animals, to have their lives probed and pried into by the media?

For Asians with HIV, there is a deep suspicion about the motives of HIV negative advocates, even of those of us who have been at this for a long time. This lack of trust leads, in turn, to a weariness among HIV negative advocates. It is not enough for us to be well-intentioned when only a handful of HIV positive people will take up the challenge. These are hard questions. Yet there is no avoiding them. The days of the HIV negative leading Asian AIDS efforts must end.

I don't think that Arif would be displeased that we are grappling with these issues. But I think he'd frown on us for allowing them to paralyze us and becoming enmeshed in a vicious cycle. He never wanted to die as just another statistic.

So what can Western advocates do to help? It's fine for you to lend moral support and to keep us informed, especially about treatment advances. But leave us to work out what to do ourselves. I often hear Westerners say that they have to come and teach Asians because we don't know what activism is. And just as often I see Asians attacked for daring to question this patronizing attitude. So when East meets West at our occasional global conferences, most of us Asians keep politely quiet, and this only increases the impression that we are passive. To pressure us to impose a Western strategy on our AIDS movement is not useful because of how diverse our communities are. And critics in our own countries often use as an excuse that we are "furthering Western agendas" to attack our activism. The best Western advocates are those who ask us first if we need help and in what form. The worst are those who "help" without asking—and so put us and our work at risk. As we all work to create a global AIDS movement, we must be as aware of our differences.

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