HIV/AIDS PREVENTION, CARE AND SUPPORT: STORIES FROM THE COMMUNITY
Preface

In a little over two decades, HIV/AIDS has invaded communities, crossed borders and continents, and gained a firm foothold in many parts of Asia and the Pacific. By the end of 2002, there were over 8 million people living with HIV/AIDS in the Asian and Pacific region, of whom 2.6 million were young people aged 15 to 24. Millions more have been affected by HIV/AIDS – as orphans, parents, wives, husbands, partners, caregivers, relatives, friends and neighbours of people living with HIV/AIDS.

Asia and the Pacific could become the region with the most HIV infections. With 62 per cent of the world’s population, there is cause for serious concern. Inaction would lead to a predictable scenario – more infections, more deaths, more devastation and a tragic reversal of the social and economic gains made in the past half century in Asia and the Pacific.

Several broad development issues feature significantly in the spread of HIV in Asia and the Pacific. These dynamics include poverty, gender inequality, low levels of education, population mobility, and a lack of access to basic services and opportunities. There is also a lack of information about HIV/AIDS, especially among young people and other vulnerable groups such as sex workers and their clients, injecting drug users, men who have sex with men, and mobile populations. Immediate action to address the issues faced by vulnerable groups can change the pathway towards death and destruction.

HIV/AIDS Prevention, Care and Support: Stories from the Community touches upon these dynamics; it shares positive ideas and creative solutions for action to stop the spread of HIV/AIDS. This is a collection of stories of community partners working together: individuals, civil society organizations, governments and donors. The collection includes inspiring local responses to the challenges of HIV/AIDS. It covers HIV prevention. It also includes stories on care and support for people living with, or affected by, HIV/AIDS.

All the stories in this publication were chosen for their innovativeness, effectiveness and responsiveness. Some of the achievements described have been replicated in other communities, and in other parts of the world. The stories also bring to light the difficulties that people living with HIV/AIDS and civil society groups and organizations confront – financial hardship, widespread stigma and discrimination, and ignorance. These are challenges that hamper direct action on HIV/AIDS.

An inter-linking theme, which weaves all the stories together, is the critical importance of breaking barriers – social, cultural and religious – to overturn unfounded assumptions and dispel myths about HIV/AIDS and those that it affects. The stories in this publication underscore partnership with civil society, including non-governmental organizations, faith-based organizations and the private sector, as central to action and results. The stories also highlight the importance of involving people living with HIV/AIDS as key actors in developing policies and programmes that have an impact on their lives and the lives of their communities.
The programmes described in this publication work with vulnerable groups as well as with the wider society. They are comprehensive HIV/AIDS programmes, which address prevention as well as access to care, treatment and support, and thus serve as effective mechanisms in halting the spread of the HIV/AIDS epidemic. An understanding and supportive environment that improves the quality of life of people living with HIV/AIDS is a hallmark of these comprehensive programmes.

At its fifty-eighth session, the United Nations Economic and Social Commission for Asia and the Pacific (ESCAP) adopted as the theme topic for the fifty-ninth session, in April 2003, “Integrating economic and social concerns, especially HIV/AIDS, to meet the needs of the region.” This publication is one in a series of three complementary publications that have been prepared for the fifty-ninth annual Commission session.

The Health and Development Section, Emerging Social Issues Division, ESCAP prepared this publication, with the valuable contributions of the organizations and individuals cited in these stories.

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Part I

COMMUNITY RESPONSES TO PREVENTION
HIV/AIDS in the spotlight:
Vanuatu uses drama to break barriers
(Wan Smolbag Theatre, Vanuatu)

Approximately 200,000 people live on the 83 islands of Vanuatu. Inter-island travel is difficult, with poorly developed inter-island transport infrastructure. Vanuatu’s adult literacy rate is approximately 35 per cent – one of the lowest in the world. Adherence to traditional values is strong. Under these circumstances, raising awareness of HIV/AIDS and other sexually transmitted infections (STIs) presents enormous challenges.

Wan Smolbag Theatre has pioneered innovative ways to use theatre to impart messages on sensitive issues, such as STIs, including HIV, as well as other sexual and reproductive health issues. Wan Smolbag has responded to the urgent need for fresh, innovative and powerful educational tools by using plays, songs, dance, workshop techniques and storytelling as well as video and radio productions to increase awareness, promote dialogue, and help empower communities in the areas of health, good governance, human rights, and sustainable environmental practices.

The state of HIV/AIDS in the Pacific subregion

Extensive spread of HIV/AIDS has yet to appear in most Pacific island countries and territories. By November 2000 the cumulative reported cases for the Pacific island countries and territories had reached 3,568 and 1,304 respectively for people with HIV and AIDS; Papua New Guinea alone accounted for 80 per cent of the HIV cases and 79 per cent of the AIDS cases.1

Compared with other parts of the world, these figures might look insignificant. But, measured against the small populations of the Pacific island countries and territories, the numbers represent a considerable and growing problem.

In Vanuatu, only one reported HIV infection has so far been confirmed by the country’s Ministry of Health. However, any data from the Pacific should be interpreted with caution as under-reporting is suggested to provide an incomplete picture and sample sizes of the few HIV seroprevalence studies are small. Although data is limited, health trends indicate that the Pacific island countries and territories are extremely vulnerable to HIV/AIDS, given the low levels of condom use and high incidences of sexually transmitted infections (STIs) which can increase the risk of transmission (see box, page 43). In 2000, studies of women attending antenatal care in Vanuatu and Samoa showed that one in three women had an STI. The highest rates of infection (up to 50 per cent) were found in women below 25 years of age, suggesting that approaches to HIV prevention must emphasize youth to be successful.2
prior to marriage, are not in monogamous relationships, and/or do not use condoms regularly, or at all. Experimentation with alcohol and drugs is also often associated with youth curiosity and adventurism. These characteristics accentuate the need for prevention programmes that raise awareness and offer health services that diminish the threat posed by HIV. Wan Smolbag Theatre has responded to this urgent need with innovative and powerful drama tools that teach communities about good health and other social issues.

How the epidemic in the Pacific island countries and territories will evolve largely depends on whether young people are provided with the knowledge and skills to protect themselves against HIV/AIDS and its devastating consequences. As in many other Pacific island countries and territories, more than half of Vanuatu’s population is younger than 20 years. Many of them are vulnerable to HIV because of high-risk sexual behaviour, substance use, or because they lack access to youth-friendly HIV/AIDS information and prevention services. They are also vulnerable because of a host of social and economic reasons.

Why provide sexual and reproductive health education to young people?

Young people cannot protect themselves if they do not know the facts about HIV/AIDS. Educating young people about HIV/AIDS, and teaching them skills in negotiation, conflict resolution, critical thinking, decision-making and communication, improves their self-confidence and ability to make informed choices, such as postponing sex until they are mature enough to protect themselves from HIV, other STIs and unwanted pregnancies.

Research shows that:

- Sexual and reproductive health education is best started before the onset of sexual activity.
- Good quality programmes help delay the age of first intercourse, and protect sexually active youth from STIs, including HIV/AIDS, and from pregnancy.
- Education on sexual and reproductive health and/or HIV/AIDS does not encourage increased sexual activity.

Theatre in a suitcase

“Wan Smolbag” is a Bislama (local language) expression that means: ‘one small suitcase’, or as it sounds in English, “one small bag”.

HIV/AIDS in the spotlight: Vanuatu uses drama to break barriers

“In too many countries an official conspiracy of silence about AIDS has denied people information that could have saved their lives. We must empower young people to protect themselves through information and a supportive social environment that reduces their vulnerability to infection.”

Kofi Annan, Secretary-General of the United Nations

While it is difficult for many adults to openly acknowledge, large numbers of young people in the Pacific begin sexual activity at a relatively early age. They are sexually active
Peter Walker, Director of Wan Smolbag Theatre, explains: "The idea is simply to show that we can make theatre out of what we carry in one small suitcase."

Founded in 1989, Wan Smolbag Theatre began with 15 voluntary part-time actors. Over the years, international donor funding from organizations such as the Australian Agency for International Development (AusAid), the European Community, New Zealand Aid (NZAID), Joint United Nations Programme on HIV/AIDS (UNAIDS), United Nations Population Fund (UNFPA), the United Kingdom’s Department for International Development (DFID), and the David and Lucile Packard Foundation have enabled the group to more than double its size as well as support and train other troupes throughout the Pacific islands, who create and perform community theatre. Wan Smolbag Theatre has become so well known that their videos have been broadcast on television in nearly every country in the Pacific.

The core group comprises 11 actors, a director, a scriptwriter, two research officers, a finance manager and several project managers who rehearse and perform in a warehouse converted into a studio/theatre. There are five other theatre groups attached to the organization that employ over 40 people full time.

While youth are not the exclusive focus of Wan Smolbag’s activities, they are a major target audience. Many of the subjects addressed in their plays, workshops, videos and radio work are of particular interest to youth and provide vital information related to their sexual and reproductive health.

**Drama breaks barriers about HIV/AIDS**

A core component of Wan Smolbag’s work is performing short theatre skits to audiences on the outer islands of Vanuatu and neighbouring island countries. The live theatre presentations are between 20 and 50 minutes. The plays, largely written by Wan Smolbag’s scriptwriter, Jo Dorras, after discussions with the actors, include stories about women’s and men’s health, contraception and sexually transmitted infections, including HIV/AIDS.

Drama is increasingly recognized as an effective medium for advocacy and information transmission. In a unique way, it breaks barriers and taboos associated with discussions on sexual and reproductive health matters. Watching a play about a character who has an unwanted pregnancy for lack of contraception, or a person who becomes infected with HIV/AIDS, evokes a connection to “real life”, making people more willing to accept information on how to protect themselves from the dangers and potential outcomes of unprotected sex, such as unwanted pregnancy and/or STIs, including HIV. When Wan Smolbag
A Wan Smolbag Theatre skit

One Night

“One Night” is about two couples. Both the men have had sexual relations with other women and their wives have found out. The wives are angry and hurt and the men do not really see what they have done wrong. The men expect their wives to forgive them, but the women are very upset.

There are no pauses between the lines; each person speaks right after the other until the line “Darling…” then there is a pause before the actors turn to the audience.

The two women stand back to back in the middle and the two men face them on the outside. The audience sees the two couples in profile.

Man 1: I’m sorry!
Woman 1: Why did you do it?
Man 2: I didn’t mean to...
Man 1: I know I did wrong.
Woman 1: I can’t believe it!
Woman 2: Why did you do it?!
Man 2: All men do it!
Man 1: Don’t get cross...
Woman 1: Did you use a condom?
Man 1: Please, stop going on.
Woman 2: Did you use a condom?
Man 2: Look, um...
Woman 1&2: Tell me!
Man 1&2: No.
Woman 1: Didn’t you think about me?
Man 1: Look um...
Woman 2: You could kill me!
Man 2: You’re crazy!
Man 1: It was only one night!
Man 1 &2: Darling...

The actors freeze and turn to the audience

Woman 1: One night can destroy your life
Man 1&2: One night
Woman 2: Long enough to catch
Woman 1: Gonorrhoea
Man 1: Herpes
Man 2: AIDS
ALL: ONE NIGHT.

Discussion:

Can wives trust their husbands?
Is it better or worse if men use condoms when they sleep with another woman?
Is AIDS really a danger if you have a “one-night stand”?

HIV/AIDS in the spotlight: Vanuatu uses drama to break barriers
performs these plays in schools or villages, the audiences are often completely captivated. With only a few props, costumes, songs and dances, complex health issues can be transformed into community concerns.

“One Night” is a small workshop exercise showcased in Wan Smolbag’s educational materials. Handed out to small groups for discussion, it draws attention to the dangers of engaging in risk behaviours.

Wan Smolbag Theatre uses humour, improvisation, and interactive communication in its skits. A popular skit uses props with actors playing STIs and HIV/AIDS characters in combat with their super-enemy, the ‘CONDOM’. In the midst of the play, members of the audience may be asked if they comprehend the subject matter. If not, or if they raise good questions, the actors might spontaneously adjust the story line to incorporate responses to their questions. At the end of each play, the ‘CONDOM’ victoriously wins the fight against the STI and HIV.

Wan Smolbag also uses video to bring its stories to a wider audience – especially given the difficulties of travelling throughout the multi-island nation, video has enabled them to reach a larger number of people. The latest video production entitled “Positive” looks at AIDS from a political perspective. Rather than serving as a “How to get it and how to prevent it” type of video, the film carries a call for action to leaders at all levels – government, community, village and school – and challenges them to commit to economic and policy changes in both the public and private spheres. “Positive” conveys the idea that a widespread HIV epidemic would further compound and deepen many of the economic and development problems the Pacific island countries and territories are facing. The video and the accompanying user’s guide are utilized in workshops with educators or health professionals, as well as in public showings throughout Vanuatu.

2 for 1 combo: Drama and health services

Perhaps one of the most notable and innovative results of Wan Smolbag’s work is the development of a health clinic for young people at a community centre/theatre. In 1997, a six-month community theatre production in Blacksands, a poor urban settlement on the outskirts of Vanuatu’s capital Port Vila, led Smolbag’s actors to address first-hand young community residents’ problems and critical needs for sexual and reproductive health information and services. Wan Smolbag created the Kam Pussem Hed Youth Drop-in Centre in Port Vila.

“We recognized that teaching young people about safer sex through our theatrical campaigns risks being lost if the young people do not have access to further information, and reproductive health services and treatment,” says Wan Smolbag Director, Peter Walker.

The centre combines a health clinic with a community centre where youth can go for information, counselling or recreation. The non-judgmental atmosphere of the Theatre has been replicated at the clinic in its approach and mandate.

Achievements and challenges

Wan Smolbag’s performances have been widely received and are in high demand. Outreach activities have been extended to other Pacific island countries, in addition to training other drama groups, ministries of health and selected non-governmental organizations (NGOs) in the use of theatre for sexual and reproductive health education. The plays are so popular that the actors have become...
well known across the Pacific and many have become household names in Vanuatu.

Feedback from young people who have watched the plays has been overwhelmingly encouraging. They have reported improved self-respect and a higher level of awareness about their health and well-being. Some participants have stayed involved with Wan Smolbag by taking part in films and short-term campaigns after seeing the play(s).

Community research has shown that knowledge about sexual and reproductive health, including STIs and HIV/AIDS, among youth has significantly increased due to Wan Smolbag’s interventions. For instance, in areas where the group has been performing, the demand for birth-control pills has noticeably risen in the local clinic. Finally, Kam Pusem Hed Youth Drop-in Centre has seen its clients’ base grow enormously over its first four years. Today, the clinic receives up to 300 clients a month who come either for STI treatment or other reproductive health needs.

Recognizing the need and demand to get information out to vulnerable groups, Wan Smolbag is currently exploring funding options to also work with groups such as seafarers and sex workers. Nevertheless, major challenges persist: Although Wan Smolbag advocates sexual and reproductive health, these efforts are at times hampered by traditional views and are still resisted by local communities. For instance, many youth are unable to access condoms from most local clinics because the health worker either refuses to distribute them to unmarried people or is prohibited from doing so by a village chief.

Despite these challenges, Wan Smolbag Theatre is gaining access to rural communities and has performed its latest sketches in communities which had previously barred them – indicating that, perhaps, humour and drama serve as irreplaceable tools in breaking barriers.

Empowering young people: A conversation with a Tongan youth (Tonga National Youth Congress, Tonga)

Tonga is a small island country in the Pacific, comprising 169 islands, of which 36 are inhabited. It has a population of over 100,000, 65 per cent of which is below the age of 25. To date, the reported number of people living with HIV/AIDS in Tonga is still quite small (12 reported cases of HIV and AIDS, by the end of 2001). However, this figure should not delay action by communities since about half of all new infections are occurring among young people between the ages of 15 and 24 worldwide.

Conditions that increase Tongan youth vulnerability to HIV include: high levels of school drop-out, high unemployment, high mobility, risky sexual behaviour, experimentation in alcohol and drug use, and limited access to youth-friendly information and health services. Recognizing the fertile ground for the spread of HIV/AIDS and the potential crisis at hand, the Tonga National Youth Congress (TNYC) is working with young people on HIV/AIDS prevention efforts.

Founded in 1991, TNYC encourages young people to become involved with their communities through volunteer service and educational outreach programmes. Its activities aim to nurture the future leaders of Tonga by providing youth with a safe and fun environment in which they can express themselves, build self-esteem, and develop their decision-making and coping skills. TNYC works with youth to develop information, education and communication (IEC) programmes that motivate their peers to make choices for a healthy and fulfilling life, including their reproductive and sexual health.

Moana Fakava Kioa is a young TNYC advocate and health educator. She first got involved at the age of 19, as a member of her village youth group. Using her experiences as a youth volunteer, Moana joined the small staff of TNYC in 1998 and started the HIV/AIDS peer education programme. Since 2001, she has been the HIV/AIDS Education Coordinator, and is currently working on the development of the Pacific Star Life Skills course, a programme designed to address the health and emotional needs of adolescents in the Pacific (see box, page 13).

Moana shares her story and describes some of the challenges Tongan youth are facing in today's society.
Can you tell us about the Tonga National Youth Congress, and how it became involved in HIV/AIDS prevention?

The Tonga National Youth Congress (TNYC) was established in 1991 with the approval of His Majesty King Taufa‘ahau Tupou IV of Tonga. TNYC involves the young people of Tonga in participatory and entertaining activities that aim to empower youth to lead healthy, confident and active lives, so that they may become responsible citizens who can lead the future development of Tongan society and culture. Our activities focus on developing youth life skills, such as communication and negotiation skills, which help young people make smart decisions for a healthy and fulfilling life.

Who does TNYC reach with its programmes?

The school enrolment rate for youth aged 10 to 14 years is over 95 per cent, but this falls to less than 70 per cent for young people between the ages of 15 and 19. In order to reach as many youth as possible, our programmes make use of both school-based and out-of-school channels. All together, TNYC has to date reached approximately 70 per cent of the youth population in Tonga, or over 40,000 young people.

Tonga has an unemployment rate of 13.3 per cent, which is a most pressing problem for youth since we constitute more than half of Tonga’s population. TNYC recognizes that this means there is a wider range of people in need of information and services. So, our definition of youth is broader to include people in the age range between 14 and 35 years.

How do you reach out-of-school youth?

Village youth groups are registered with the Congress, so we can access youth, whether they are still in school or have dropped out. For example, out-of-school youth as young as 14 years of age come in weekly to talk with each other, play sports, take part in our educational programmes, and generally occupy their time in a safe and healthy environment. Out-of-school youth are often bored, so they come to the centres to hang out. Sports activities are also popular, and sometimes we give young people incentives, such as food, to come. Some youth have

Young people should be at the forefront in the fight against HIV/AIDS.
Moana Fakava Kioa, youth advocate, age 25.

Empowering young people: A conversation with a Tongan youth
commented that they find the activity topics interesting. With our magazine and radio, many youth send in materials. They are excited to see their names in print or mentioned on the air. We think the centre’s activities can help prevent them from turning to crime and other anti-social activities.

**Why is it important to target youth?**

In Tonga, the incidence of sexually transmitted infections (STIs) and teenage pregnancy is on the rise. On the main island of Tongatapu, 75 per cent of confirmed gonorrhoea cases in 2000 were found among youth aged 15 to 24 years. We’ve encountered cases where children as young as 11 years old have STIs! That tells us that young people are engaging in sexual activities, whether it is coercive or consensual, but parents are in denial.

Reproductive health is taught in biology, but it is not compulsory, so every student does not take it. This is the gap that TNYC aims to fill. We provide information to youth about reproductive and sexual health. We use creative, fun and interesting activities, such as a radio programme, a magazine and theatre skits that are written for a youth audience, by youth members and TNYC staff (who themselves are still youth). Through these activities, we provide education and life-saving information, such as how to prevent STIs and how to negotiate safer sex for self-protection.

**Could you describe some of your HIV/AIDS programmes for youth?**

**Peer education**

One of our major programmes is peer education training. Every year since 1998, we’ve held a one-week training session on the main island of Tongatapu, with participants from all of the outer islands of Tonga. These participants are trained to lead their peers to think and talk about HIV/AIDS issues through interactive and fun activities. When the peer educators return to their islands, they hold workshops, lectures, and drama events with the local youth groups and schools. There are now approximately 20 to 25 peer educators based in Tonga’s six main islands.

**Outreach**

We also have outreach education programmes, targeting both out-of-school and in-school youth. The out-of-school youth are frequently reached through church youth groups and village youth groups. We begin the two-hour sessions with a talk about HIV/AIDS prevention, care and support: stories from the community.
AIDS, presenting global, regional and local statistics and trends. Then, we ask the youth participants to identify body parts and sexual activities, and rank each one for its level of risk for contracting HIV. We can demonstrate how to use a condom, if participants wish. There is also an opportunity for the young people to ask questions.

The need and request for these sessions has been strong. We aim for no more than 30 or 40 participants per session, although we’ve had audiences of up to 70 people. When we conduct these sessions in schools, the teachers often wish to sit in, but this tends to make the students feel less comfortable. More than once, a student has confessed, “I can’t ask my question because my teacher is here.” When that happens, we usually politely request the teacher to leave the room. Increasingly, we are trying to respect the students’ wishes and discourage teachers from observing the sessions, in order to encourage open discussions.

Men’s and women’s groups have also shown interest in our programmes. For example, when I was holding an outreach session for youth in one of the villages, the mothers of the youth also expressed an interest in learning about HIV/AIDS. Although there is an NGO that is responsible for women’s affairs in Tonga, I held a session with the women’s group, since I was already there and it didn’t require any additional funds. We try to remain flexible and meet needs where they arise, and don’t limit ourselves strictly to working with youth.

Life skills

TNYC’s newest programme is the Pacific Star Life Skills programme, which is a regional programme funded by the United Nations Children’s Fund (UNICEF) that targets young people between the ages of 12 and 18 from Tonga and four other Pacific countries. The term “life skills” refers to those abilities that help promote well-being and competence in young people as they face challenging situations in life. The training programme aims to help youth gain inner resilience, so that they are better equipped to deal with life’s ups and downs. Life skills are highly relevant to HIV prevention, as they empower youth to avoid risk behaviour. For example, a young person can make a decision based on available information that he or she should avoid drug use and abstain from sexual intercourse, or use appropriate protection if having sex, in order to prevent unwanted pregnancy or STIs, including HIV. The person would also have the communication and negotiation skills to put that decision into practice.

Empowering young people: A conversation with a Tongan youth

What are life skills?

“Life skills” are a group of emotional, social and inter-personal skills, which can help people make informed decisions, communicate effectively, and develop coping and self-management skills, so that they might lead a healthy and productive life.

- Communication and interpersonal skills include the ability to express one’s feelings, give and receive feedback, assert one’s decisions, listen and understand one another’s needs and circumstances, and influence others.
- Decision-making and critical thinking skills include the ability to gather information, evaluate future consequences of present actions for self and others, find alternative solutions to problems, and analyze attitudes, values, social norms and beliefs.
- Coping and self-management skills include the ability to build self-esteem/confidence, evaluate oneself, manage anger, manage time, think positively, and cope with loss, abuse and trauma.
The training programme was developed based on a 1999 youth needs assessment, and we began implementation of the training course in 2002. A group of youth “master trainers” undergo a two-month course, during which they improve their skills of communication and negotiation. Master trainers are also trained to conduct a two-week version of the life skills programme. Upon completion of the course, the master trainers return to their islands and begin training the youth in their communities in developing life skills through various activities, including the two-week life skills course, both in and out of school.

We now have 25 master trainers in Tonga, who are conducting activities in their communities. Through the master trainers, we have achieved our initial goal for 2002, to reach 20 per cent of the young people in Tonga. We are optimistic that we will be able to reach another 15 to 20 per cent in 2003. This is an important number, given that, as previously mentioned, more than half of our population is young people.

Magazine

TNYC publishes a free monthly magazine called “Voice of the Future.” One section is always dedicated to health, and we provide information on HIV/AIDS primarily in the Tongan language, with a few items written in English. The magazine is widely distributed. It's sent out to the remotest islands, and distributed to local youth through TNYC youth centres/offices and youth groups. We print about 500 to 800 copies each month. When we conducted a reader survey, many commented that they would like more copies to be made available, as one copy is currently shared among many readers. The survey also revealed that the readers found the content useful, and that some youth would like it to be made into a weekly publication.

We keep the magazine entertaining by focusing on health and sports. It's a good way to disseminate information about HIV/AIDS, as it's easy for anyone to pick up a copy, and it's a good supplement to our other interactive programmes.

Radio

The Congress has a weekly 30-minute radio show during prime-time hours, hosted by young people. In that show, 15 to 20 minutes are always spent talking about HIV/AIDS. It can be challenging because we can’t talk openly about sex due to conservative norms that consider it taboo. We have to use very respectful language. For example, we can't say “condom.” Instead, we must say “plastic that is used for protection.” Unfortunately, this means that some of the younger people might not understand the message, and won’t know how to protect themselves, so we have to be creative.

The weekly radio programme reaches all outer islands of Tonga, including the remotest ones. On the main island, we realize it might not reach everyone because there are many other radio stations to listen to, but I'm confident that it does reach a wide audience.

✔ What are some challenges to your work, and how are you overcoming them?

Young people have the information, but we have to measure our effectiveness by the changes in behaviour of the target group. There are still many barriers. For example, people still don't want to talk about sex. When we contact schools to visit them, they ask us, “What are you going to talk about?” We have to assure them that we won’t use the word “sex.” Instead, we use drama, for example, to convey issues related to teenage pregnancy and STIs and HIV/AIDS, and focus on imparting life skills.

HIV/AIDS Prevention, Care and Support: Stories from the Community
Some parents say, “We don’t allow our young people to learn about such things because it would encourage them to have sex.” Some of the kids have told us: “You know, my parents said that they think I must be promiscuous if I am coming to get this information. They think I’ve engaged in promiscuous behaviour.”

We know that we won’t be effective if we just work with young people. We have to get parents, chiefs, and religious leaders involved. That’s always a challenge for us. But we’ve been able to reach some of them. And when we come to our limits, we turn to the TNYC president for help. As an older figure with more experience and authority, he is sometimes better able to convince teachers and community leaders to work with TNYC in conducting the programmes.

Language is another issue. Although both Tongan and English are official languages and the Tongan literacy rate is over 99 per cent,10 when we contact people or run programmes, there’s always a high demand to use the local language, especially in rural areas. We try to satisfy that need by doing all the activities and preparing the materials mostly in the local language.

Where do you obtain funding for your programmes?

Currently, we’re getting funding from the United Nations Development Programme (UNDP) and UNICEF for our HIV/AIDS programmes. Some embassies, such as the New Zealand High Commission and Australian High Commission, help us, as well as organizations such as the United States Peace Corps.

One of the granddaughters of His Majesty the King is our royal patron, and members of the royal family have been involved in several HIV/AIDS campaigns. We hope that this valuable royal family support will encourage the Government and private sector to increase funding for youth HIV/AIDS prevention programmes.

Can you tell us what you hope to achieve in the future?

I’d like to see more information and more activities in the rural and outer islands and to see a lot of young people involved in the programmes. Another future goal is to address the issue of stigma and discrimination among young people against people living with HIV/AIDS. Above all, we would like to see young people stand up for themselves and get involved in activities, from planning to monitoring and evaluation. Since young people under the age of 25 make up 65 per cent of Tonga’s population, we need to be at the forefront in the fight against HIV/AIDS. Without us there will be no future.

Youth involvement in combating HIV/AIDS – is this an attainable goal in the foreseeable future?

If we have full support from parents and communities, and financial support from the Government, yes, I believe this is attainable. The young people in the Congress are dedicated – most of them work as volunteers – so if we have political support and community support, I’m sure we will be successful.

We’re making good progress. We’ve conducted a lot of education and awareness-raising programmes. Young people, including sex workers and other high-risk groups, are coming to us for information or materials, or for help.

Other indicators, like STI rates among young people, tell us that we need to reach young people now to prevent a disastrous spread of HIV/AIDS. Young people who try to access social and medical services for their problems often get scolded instead. So they run away

Empowering young people: A conversation with a Tongan youth
and bottle up their problems, close their doors and don’t get the help they need. But if we can provide them with an “enabling environment” in which they have access to information and services, I am sure we can change things.


A deadly battle: Cambodia fights HIV/AIDS among its uniformed services (Family Health International/IMPACT, Cambodia)

Cambodia has experienced one of the fastest growing HIV/AIDS epidemics in the world, with the highest national adult prevalence of HIV in the Asia-Pacific region. In a country of 13.5 million people, UNAIDS estimated in 2001 that 170,000 Cambodian adults and children were living with HIV/AIDS, 12,000 adults and children had died from AIDS, and there were an estimated 55,000 HIV/AIDS orphans. By the year 2010, the Government expects the death toll to reach 230,000.

Despite such grim statistics, Cambodia has made significant progress towards reducing HIV infection and recent data indicates that the epidemic appears to be stabilizing. In 1998, the HIV prevalence rate peaked to a high of 3.2 per cent. The past five years has seen a decline to an estimated rate of 2.6 per cent in 2002. According to the National Centre for HIV/AIDS, Dermatology and STD (NCHADS), the decrease is attributed to reductions in risk behaviours and AIDS deaths.

The military and police forces in Cambodia have some of the highest HIV prevalence rates in the country. In 1998, in response to this crisis, the Ministry of National Defence and the Ministry of Interior, in collaboration with Family Health International (FHI)/Implementing AIDS Prevention and Care (IMPACT) began an innovative large scale intervention programme to decrease the prevalence rates of HIV/AIDS among uniformed services, their families, and the general community.

Taking steps to decrease HIV/AIDS in Cambodia

Much credit is given to the Government and civil society for working together in Cambodia to establish sustained and multifaceted prevention initiatives aimed at vulnerable groups and the Cambodian population. Programmes that have been implemented in various areas include a 100 per cent condom policy that requires condom use as a condition for commercial sex; antiretroviral treatments for pregnant woman so that HIV is not passed on to their newborns; and an assertive HIV/AIDS awareness campaign among the uniformed services. These examples indicate impressive prevalence decreases among these populations, such as sex workers (from 42 per cent in 1998 to 29 per cent in 2002), pregnant women (from 3.2 per cent in 1996 to 2.8 per cent in 2002), and police (from 6 per cent in 1998 to 3.1 per cent in 2001).

In Cambodia, heterosexual sex is the major transmitter of HIV, although in the future, injecting drug use could become a major mode of transmission. Men are considered to serve as the “bridge” or link between subpopulations – passing HIV infections between sex workers, and their wives or girlfriends and families.
Focusing on the military and police

The military and police in Cambodia are the largest male group “bridging” HIV infection to the Cambodian population. The military and police have the highest risk behaviours: a higher number of partners than the national male average, and more sex with sex workers than any other occupational group. Data from the Behavioural Sentinel Surveys (BSS I-III) in Cambodia found that the mean number of lifetime sex partners (LSPs) for military personnel and police were 43 and 31 respectively. For urban and rural Cambodian (i.e., non-military and police) men surveyed, the number of LSPs were 9 and 4 respectively. This trend thus contributes to elevated HIV/AIDS prevalence rates among the military and police, and a higher probability of transmitting sexually transmitted infections (STIs), including HIV, to and/or from sex workers as well as to wives and songsaa (sweethearts).

The high percentage rate of STIs (including HIV) among the uniformed services is attributed to a series of social and behavioural factors. For instance, military and police work environments make personnel extremely susceptible to peer pressure. This peer pressure tends to encourage participation in risk-taking activities such as high alcohol consumption and visits to sex workers. In addition, servicemen are a mobile population group who often spend lengthy periods away from home and regular sex partners. Brothels or other venues that offer sex services are often located close to military or police quarters. The above conditions combine to encourage high-risk behaviours, including sex with more than one partner and/or unprotected sex.

Fighting back

The severity of HIV/AIDS among uniformed personnel has been compared to a war that is killing and infiltrating the country’s servicemen – only this time the “ammunition” penetrates deeper, causing economic, social and physical devastation and death to servicemen, their families and community members. In 1998, given the above-mentioned crisis, the Ministry of National Defence and the Ministry of Interior in collaboration with Family Health International (FHI)/IMPACT Cambodia recognized the critical need to fight back. Unlike conventional wars, however, this strategy would use a different form of ammunition – condoms and education programmes – to mitigate the impact of HIV/AIDS on uniformed services personnel, their families and the community at large.

Noting that the military and police institutions have strong traditions of organization and discipline, the Government and FHI recognized that peer or “friend-to-friend” programmes are a practical means to move decisively against HIV/AIDS to avert an even worse crisis.
The peer education programme has been designed for long-term sustainability with a current five-year strategic plan on HIV/AIDS prevention and care. HIV/AIDS education has been incorporated into every unit of the military training programme. Personnel, from the central ministry to the grassroot level, are involved in the programme’s management, which emphasizes strong capability development and collaboration. The programme is introduced by core trainers, who are one or two people assigned per province by FHI. They visit project sites and meet with the commanders of each unit to gain their support. In subsequent visits, the core trainers work collaboratively with military and police personnel to plan peer education activities, obtain feedback about the strengths and weaknesses of the programme, discuss areas in need of improvement, and plan future activities.

Commanders are the first persons invited to learn about the peer education programme. The initial meeting is usually set up with little resistance, as most commanders in the units take the problem of HIV/AIDS seriously, having witnessed the reality of the epidemic as it has infiltrated their units. At the initial meeting, commanders are updated by core trainers about the current HIV/AIDS situation in Cambodia, its impact on the military and police, and the socio-economic impact of HIV/AIDS on society.

Following this meeting, commanders then select peer educator trainers (PETs) in their units who will be trained and who then identify and train other peer educators from their units. For cost-effectiveness, monitoring, and easier facilitation, PETs are the vital link working with both the core trainers and peer educators. As a result, many PETs are deputy commanders.

Supervision and monitoring are other key components. Throughout the year, peer educators and peer/core trainers gather together for refresher courses, support sessions and participation in special events such as World AIDS Day, the Candle Light Memorial and the Water Festival, which all include HIV/AIDS education campaigns. These activities help to reinforce motivation and provide a valuable support system.

In 2002, the HIV/AIDS programme was expanded to include military personnel in theatrical performances that highlight real-life stories, information, attitudes and practices about STIs, including HIV, and the importance of love and compassion for people living with HIV/AIDS. Launched with the assistance of the Royal University of Fine Arts in Phnom Penh, 12 teams have performed for their colleagues, military families and surrounding communities, reaching more than 9,600 people.

**Key components to the HIV/AIDS awareness programme include:**

- Senior level military and police personnel endorse and support the HIV and STI prevention programme.
- Education of military and police personnel by their own peers, encouraging them to adopt safer sex practices including abstinence, condom use and a reduction in the number of sex partners.
- Provision of care and support services to HIV-positive military and police personnel.
- Joint management of the HIV/AIDS and STI prevention programme by the HIV/AIDS Section of the Ministry of National Defence and the Ministry of Interior.

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HIV/AIDS Prevention, Care and Support: Stories from the Community
military or police personnel already living with HIV/AIDS. In light of the forthcoming needs for enhanced care, treatment and support, FHI is expanding activities that will improve uniformed health services and provide supportive counseling to deal with AIDS and AIDS-related illnesses.

As the programme progresses, assessments of health services and training activities have been made with health care providers that cater to uniformed personnel, to improve STI treatment, and education to reduce HIV transmission. The Ministry of National Defence, the Ministry of Interior and FHI, with supplementary support from the United States Agency for International Development (USAID), will continue the prevention programme, as well as plan new programmes in care, treatment and support for military and police personnel living with HIV/AIDS and their affected families in forthcoming years.

**Achievements and challenges**

The programmes aimed at uniformed personnel have transformed awareness and behaviour. To date, the initiative has reached over 71,000 military and police personnel.

**HIV/AIDS Peer Education Training (PET) in the Cambodian military**

PET programmes operate under a “friend educates a friend” model and distribute free condoms. Peer educators teach their colleagues about a wide range of topics including:

- HIV/AIDS and STI awareness;
- Condom use;
- The socio-economic impact of HIV/AIDS on individuals, families and communities;
- HIV testing;
- Risk assessment and options for reducing risk;
- Negotiation skills in the face of peer pressure;
- Decision-making skills;
- Anti-discrimination; and
- Care and compassion.

The current decline in HIV prevalence rates unfortunately does not reduce the number of military or police personnel. In 1999 & 2000 always use condom specified “in last 3 months”

**Always use condoms with female sex workers: Military (1997-2001)**

Source: BSS 2001, NCHADS.

A deadly battle: Cambodia fights HIV/AIDS among its uniformed services
almost nationwide. Qualitative research in 2000 conducted by the Ministry of National Defense, the Ministry of Interior and FHI indicates high HIV awareness levels, fewer visits to sex workers and nearly 100 per cent condom use with sex workers.

In the years 1997 and 1998, 6 per cent of police were HIV positive; only 42.9 per cent and 65.4 per cent of military and police, respectively, always used condoms with female sex workers. In the years 2000 and 2002, 3.1 per cent of police surveyed tested HIV positive, and near universal condom use was reported by both groups (86.7 per cent of military and 85.1 per cent of police reported always using condoms with female sex workers). The marked improvements in condom use and the lower HIV/AIDS prevalence rate can be attributed, in large part, to the success of the peer education intervention programme.

FHI programme evaluations suggest that HIV/AIDS awareness education alone is not enough to help protect uniformed men from HIV infection. Rather, the inclusion of effective counselling and support systems, which provide military and police personnel with tools on how to address peer pressure, is central to its success. Other key elements include the collaboration and support of all personnel, as well as close monitoring and supervision. By concentrating efforts on a high-risk group, and involving the target group directly in programme activities this initiative has been able to bring about real behavioural change.

7 Beginning in 1998 the HIV Sentinel Survey (HSS) omits the military as a separate sentinel group, as over time, its prevalence appeared to be similar to that of the police. A decision was made to survey only one group, the police.
In the Philippines, UNAIDS has estimated that 9,400 people are living with HIV/AIDS. While the actual number may be much higher, the Philippines is currently a low prevalence country. This is possibly due to several factors, including its geographical position as an island state and/or prevailing social and religious traditions. The latter, while presumably containing the spread of the epidemic, may in turn also contribute to a low level of HIV/AIDS awareness among Filipinos, endanger their susceptibility to infection, as well as expose Filipinos living with HIV/AIDS to stigma and discrimination.

The Positive Action Foundation Philippines, Incorporated (PAFPI) is a community-based organization. It was founded in 1998 as one of two Filipino organizations run by HIV-positive people themselves, providing care and support services for people living with HIV/AIDS (PLWHA). Recognizing the need for the greater involvement of people living with HIV/AIDS (GIPA), and the important role HIV-positive people can play in prevention, PAFPI also implements prevention education programmes. One such programme is aimed at migrant workers – people who are particularly vulnerable to HIV due to their working and living conditions. PAFPI provides migrant workers with information and skills that raise their awareness and knowledge levels, and encourage responsible sexual behaviour.

Recognizing that as people move, so too does HIV, non-governmental organizations, such as the Positive Action Foundation Philippines, Incorporated, and government agencies, such as the Overseas Workers Welfare Administration (OWWA), are targeting HIV/AIDS prevention education campaigns to migrant workers who are highly vulnerable to HIV infection. According to the nation’s Department of Health, 30 per cent of all reported HIV/AIDS cases in the Philippines are migrant workers, although this figure may appear high due to the fact that many receiving countries require migrants to undergo an HIV test.

The Philippines: Low levels of HIV, but high signs of risk

Although the prevalence of HIV infection is currently lower than 0.1 per cent in the Philippines, several factors place the country in jeopardy of increasing rates, including: extensive overseas migration; high levels of sexually transmitted infections (STIs); and behavioural data showing low levels of condom use. This combination may provide fertile ground for the spread of HIV that could reach wider populations.
HIV/AIDS Prevention, Care and Support: Stories from the Community

Prevention for migrant workers

The Philippines is one of the leading exporters of labour in the world. More than 7 million Filipinos are working abroad, representing 8 per cent of the total population. Filipinos leave for prosperous destinations, including Hong Kong, China; the Arab States; Taiwan, Province of China; and Japan. They directly support more than 30 million family members who are highly dependent on the income earned by their relatives abroad.

The linkage between HIV/AIDS and migration mainly accrues from the arduous living and working conditions of migrants. Most migrant workers live abroad as singles. Lacking their traditional social networks and cultural values, migrants try to cope, create new social networks, and develop new relationships. Undoubtedly many of them have sexual contacts in the host country, often without any condom use. Migrant workers are thus highly vulnerable to HIV/AIDS, and so too are their partners upon their return from distant locations.

While a small proportion of male overseas workers are factory-based or work on construction sites, the majority of male migrant workers are seafarers who are known for their “girl-in-every-port” practice, meaning that – voluntarily or due to social group pressure – they frequent commercial sex establishments in ports.

Most migrant workers are in fact women who leave home to become income earners for their families. They work as domestics, or as “entertainers” and often work in societies where women’s human rights are not respected or where women enjoy very little social status. Most of the jobs the women obtain are at the bottom of the occupational hierarchy, placing them in individualized work situations involving isolation, risk and the absence of social support networks. They often take jobs where they are underpaid, exploited and where they have very little bargaining power, making migrant women particularly vulnerable to both violence and HIV/AIDS. Filipina women are also vulnerable to human trafficking. They are sold as mail-order brides or they work as “entertainers”, a euphemism for women in the sex industry.

Gender inequality inhibits many of these women’s ability to discuss safer sex and fidelity, insist on condom use, or to break free of abusive and violent relationships.

Most overseas workers also have limited access to health care or are prevented from seeking medical care for a variety of reasons: the high cost of going to a doctor, the fear of being sent home if found sick or pregnant, the pressure of sending money home instead of spending it on oneself, and the lack of health consciousness. A lack of knowledge about STIs, including HIV, may also delay them from being tested.

Prevention works: Reaching people before they depart

HIV prevention works best in the early stages. People need to have the knowledge to protect themselves before they are exposed to behaviour that puts them at risk of infection. Recognizing that migrant workers are a vulnerable group who could also become a “bridge group” – a population that passes HIV infections from one group to another – the Philippine Government has incorporated compulsory
HIV/AIDS education in its pre-departure orientation seminars for migrant workers. The Positive Action Foundation Philippines, Incorporated, is one of several agencies that are assisting the Government with this task.

The daily seminars discuss issues like remittances, law and culture in the country of destination or how to deal with problems at the future workplace, but also include an intensive two- to three-hour workshop about preventing HIV and other sexually transmitted infections. The HIV/AIDS seminar is facilitated by a PAFPI educator, and begins with an informal evaluation of the participants’ knowledge and awareness. The participants are then provided with accurate information about the nature, transmission modes and prevention methods of both STIs and HIV/AIDS. Discussion of gender relations and communication activities, such as role-play, that introduce different ways to negotiate safer sex, are included to strengthen the individual’s capacity to better protect himself/herself. Participants’ knowledge is again tested after the session to check their understanding and to determine the effectiveness of the session.

Life testimonies: Where GiPA and prevention meet

The Positive Action Foundation recognizes the valuable position it is in to help others learn about HIV/AIDS and prevent its transmission. Personal testimonies by HIV-positive staff members are a major component of the education and prevention sessions. These counselors give first-hand accounts of living with HIV/AIDS and its consequences on their lives and that of their friends and family members.

“Experience around the world suggests that the greater involvement of people living with HIV/AIDS – an HIV-positive person’s account of his/her personal experience is one level of involvement – not only adds a powerful voice to prevention messages, but also empowers PLWHA by ending their isolation and curbing the effects of stigma and discrimination (see box, page 73).”

In the first five months of the project (July-November 2002) more than 6,800 overseas contract workers were provided with HIV/AIDS information in over 100 sessions. A large majority (80 per cent) were women. PAFPI aims to target a total number of 15,000 overseas contract workers by the end of June 2003.

Achievements and challenges

Positive Action Foundation Philippines, Incorporated, is a distinctive organization that is making a dent in the way HIV/AIDS is viewed in the Philippines today. With its promotion of the greater involvement of people living with HIV/AIDS, as well as its education programmes for some of the Philippines’ most vulnerable groups, PAFPI is helping to break barriers, reduce stigma and discrimination against PLWHA, and teach Filipinos how to protect themselves from HIV/AIDS. This is done by raising awareness, knowledge, reducing risk-taking behaviours and encouraging
responsible sexual behaviour. It is anticipated that these focused interventions will help reduce the number of STI and HIV infections among migrant workers and other high-risk groups.

As the programme is in its nascent stage, it is too early to measure total impact. Surveys from earlier HIV/AIDS prevention education activities do, however, show that knowledge levels about HIV are relatively higher among Filipino overseas workers, compared to people from other countries. A recent study indicated that Filipina maids working in Malaysia were aware of the risk of HIV/AIDS and knew about prevention methods and the dangers of high-risk behaviour. This suggests that HIV/AIDS programmes, which are tailored to the specific realities and needs of the people for whom they are intended, along with access to care and treatment, can help keep infection rates low and reduce the risk of an extensive spread of HIV into the Filipino population.

Story of Melanie,* an HIV-positive Filipina

“I worked as a domestic worker overseas in Singapore. Like most other people, I looked at overseas work as the only way I could give my family a better future. I worked there for five years without ever going home. I only thought about work and about my plans and dreams of going to other countries like Hong Kong, China, or Canada. Being far away from my family, I also felt homesick. So on my days off, I mingled with people of other nationalities. I made some friends and even had a boyfriend. At that time, I had heard a few things about HIV/AIDS, but I basically knew nothing about it.

I was diagnosed with HIV in late 1998 during a routine medical check-up. The doctor told me that as a migrant worker, I bring bad luck to his country. I felt so depressed. It was difficult to talk to anybody about it because I was afraid that they would discriminate against me, people can be very cruel when they know someone has HIV/AIDS.

After the diagnosis, I was sent home to the Philippines immediately. I wondered how I would explain my sudden arrival to my family. When I got back to Manila, I decided not to tell them at all because I was not sure if they would accept me. I only told my four closest friends about my status. It was really hard for me. I didn't know who to turn to until I met a group of people living with HIV/AIDS in Manila's San Lazaro Hospital. They gave me comfort, hope and courage to face reality.

I have been HIV positive for four years now. I don't want to be dependent on social services. I want to contribute and be a productive and active person in society. If people living with HIV/AIDS can show society that they can still live meaningful and productive lives, then perhaps, it is more likely that we will be accepted.”

* not her real name

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5 UNAIDS (2002).
6 Provided by Action for Health Initiatives (ACHIEVE).
MEN WHO HAVE SEX WITH MEN (MSM)

Photo: Chi Heng Foundation
The boy next door:
Preventing HIV/AIDS among Japanese MSM
(OCCUR, Japan)

In Japan, there are no laws against men who have sex with men (MSM) (both gay identified and other). Yet, Japanese society as a whole tends to treat MSM with disrespect and does not openly acknowledge the existence of the MSM community. Without positive role models of successful, openly gay men, many MSM, fearful of discrimination or ridicule, become socially isolated and hide their sexual identities. In search of anonymity, as well as greater acceptance, many young MSM migrate to the larger cities.

Founded in March 1986, OCCUR (Japan Association for the Lesbian and Gay Movement) is a non-profit organization that aims to help lesbians and gay men find self-acceptance, to address their fears and concerns, and to bring about change in the social institutions that perpetuate stigma and discrimination against them. From the outset, a main component of OCCUR’s work has included outreach and educational activities. They have developed two innovative HIV/AIDS awareness programmes that aim to provide vital information and modify risky behaviours, in an effort to reduce HIV/AIDS in the MSM community.

HIV/AIDS in Japan

Today, the face of HIV/AIDS is changing in Japan. UNAIDS estimates that approximately 12,000 people were living with HIV/AIDS in Japan in 2001. Initially, the vast majority of people living with HIV were haemophiliacs, who had contracted HIV through transfusions using contaminated blood products in the 1980s. Over the past five years, HIV infection rates have increased significantly among Japanese men (see Figure 1). Within this group, transmission through unsafe sex between men now accounts for more than twice as many infections as through heterosexual sex. The cumulative number of HIV-positive MSM now exceeds the number of people infected through contaminated blood products.

Meeting the needs of the MSM community

At the onset of the so-called “HIV/AIDS crisis” in the 1980s, media sensationalism and confusing information led the public to mistakenly believe that HIV/AIDS was a “gay disease”. This misrepresentation increased discrimination against MSM, but it also triggered an increasing number of men to openly challenge stigma and discrimination and led to a “coming out” movement that made Japanese MSM society more visible. OCCUR emerged as part of this movement, with the aim of facilitating self-acceptance among MSM, promoting their rights, and meeting the critical needs of the MSM community (both gay identified and other) for correct HIV/AIDS information and related support.
OCCUR has around 350 registered members throughout Japan, and 2,500 registered supporters. It maintains a staff of 50 volunteers, based in Tokyo, who conduct a wide range of programmes, including:

- Telephone counselling services (regarding HIV/AIDS, other sexually transmitted infections, general concerns, and legal advice);
- Educational outreach in bars;
- Social service programmes, such as HIV/AIDS prevention awareness events;
- Other activities in human rights protection, research, policy, and international cooperation.

Presented below are two of its HIV/AIDS prevention activities that are particularly unique.

- “HIV Next Door”: Innovative information education and communication (IEC) materials

As a marginalized group, MSM in Japan have inadequate information related to sexual health. Sex education in schools is limited and young MSM are left without knowledge that addresses their sexuality or safer sex practices. To fill this gap, OCCUR has been developing IEC materials that are tailored to provide key information to young MSM.

A popular item is the booklet, “Bokura no tonari no HIV” (“HIV Next Door”), which provides information to MSM regarding safer sex practices. The booklet was developed in collaboration with a number of partner non-governmental organizations. It fits into a personal organizer, and contains:

- HIV/AIDS information;
- A How-to-Have-Safer-Sex guide with information about MSM, the myths and risks of contracting HIV, and safer sex practices such as using condoms;
- Resource guides for more information;
- Testing centres and hours open;
- Support services.

OCCUR has also developed an information web site where users can obtain information about sexually transmitted infections (STIs), including HIV, as well as learn about safer sex

The boy next door: Preventing HIV/AIDS among Japanese MSM
practices. A question-and-answer section addresses common concerns, such as how to communicate with one’s sexual partner about practising safer sex. The web site is accessed over 300 times a day.

Another IEC material, “Brush Up! Safer Sex”, is also written in an informal tone, sometimes uses slang, and makes active use of popular *manga* (cartoons) by Inukai Reiji, a well-known artist. Each *manga* engages readers to think and reflect about how they would protect themselves in particular sexual situations. Four ways that an individual might negotiate safer sex are then suggested. By presenting these options, OCCUR hopes to demonstrate to the reader that alternatives are always available, and that it is not as difficult to negotiate for safer sex as they might think. Many of these ideas were conceptualized by MSM who participated in OCCUR’s research studies, focus group interviews and workshops (see box on this page).

Custom-tailored brochures, which meet the informational needs of readers, have a great impact and are an innovative component of OCCUR activities. The HIV/AIDS information pamphlets are distributed in bars and MSM entertainment centres and have been produced in three versions: one each for the Tokyo area, Sapporo City, and Matsuyama City. The content for each city brochure was based on a needs and risk assessment survey conducted in 2001 with partner NGOs.

- *Life Guard workshops: Working together*

OCCUR’s flagship programme is “Life Guard,” a workshop for MSM which aims to promote safer sex. It is designed to provide a safe environment for MSM to meet other MSM. It seeks to empower them with key information that can enhance their communication and negotiation skills to practise safer sex. HIV-positive people help moderate the three-hour sessions.

The workshops are offered free of charge in bars and non-bar settings – to reach as many people as possible – in the Tokyo area, Sapporo City, and Matsuyama City. Between September 2002 and February 2003, 260 people participated in the workshops. To encourage an open exchange of ideas and opinions, attendance is restricted to MSM. Humour, skits and games are actively used to create a fun and positive atmosphere. Discussions are not restricted to HIV/AIDS, but also cater to the broader social and emotional needs of the participants.

**The Life Guard programme**

The programme starts off with an ice-breaker followed by a short interactive lecture on HIV/AIDS and risk recognition. During this segment, participants are asked to identify infectious bodily fluids, body parts related to transmission, and risks related to common sexual practices. The lecturer provides the correct information, and responds to the participants’ answers. The participants also complete a quick self-assessment on the risk level of their own sexual behaviour.

During the break, participants intermingle and are encouraged to look at and feel different condoms that are on display, and to vote for their favourite kind. Staff members explain how condoms should be worn properly, and audio and visual IEC materials are presented.

In the second half of the workshop, a game-show format is used to involve participants in devising new ideas on how to negotiate safer sex in various hypothetical sexual situations. The responses involve how to avoid risky situations, and improve negotiation skills. The activity aims to make safer sex more appealing to the participants, and highlight safer sex options such as kissing or hugging.
Educational materials developed for Life Guard are used to facilitate discussions on sensitive topics. They are part of OCCUR’s adaptation of imported participatory workshop techniques. For example, Japanese are generally not comfortable with role-play, which is used extensively in other societies. Instead, illustrated panels are used to set up a hypothetical situation of physical intimacy, and participants are asked to brainstorm on possible ways the character(s) may negotiate for safer sex in that scenario. The ideas are then posted on the panel to stimulate further discussion.

Participation in Life Guard has been boosted since the launch of an informational website that can be viewed through mobile devices. This increases the accessibility of the information, especially for younger MSM who are more likely to own mobile phones with web-browsing capability than a computer.

The development of the Life Guard workshop provides an effective, safe, fun and participatory forum to reach members of the MSM community with HIV/AIDS knowledge and practical prevention methods. Preliminary results from OCCUR’s programme evaluation show a significant increase – from before the workshop to immediately afterwards – in the participants’ knowledge and attitudes towards HIV/AIDS and safer sex practices. The increase in awareness was sustained in follow-up evaluations one month later, which suggests that the workshop is on the right track towards affecting change in awareness levels and reducing risk behaviours.

Within Japan, holding workshop activities in three different city-sizes – a mega-city, a large city, and a medium-sized city – in partnership with local NGOs is an important step in reaching a wider range of MSM in Japan. The fact that the workshop was well received in Matsuyama signals the potential to reach a larger and more representative population of MSM, the majority of whom reside in numerous medium-sized cities like Matsuyama.

The Government of Japan is also increasingly receptive to collaborative activities with NGOs on HIV/AIDS prevention programmes. OCCUR believes that NGOs have an important role to play in providing expertise and services to complement the Government’s HIV/AIDS interventions. OCCUR also is convinced that local administrative bodies could incorporate NGO programmes and services for a more comprehensive response to HIV/AIDS. It is an encouraging sign that OCCUR is being approached by some local governments, such as Kawasaki City, to hold Life Guard workshops.
Achievements and challenges

OCCUR is breaking new ground and has filled a critical gap with its HIV/AIDS prevention programmes. Its workshops and educational materials are teaching MSM how to improve their decision-making and negotiation skills as well as reduce the risks for HIV infection.

Due to limited interest from the corporate sector and foundations, membership fees and donations from supporters from all communities sustain OCCUR activities. OCCUR’s 15 years of activity is a testament to its success in mobilizing the lesbian and gay community and in meeting its needs. Their achievements have in turn fuelled higher levels of interest and member motivation.

At the same time, however, reaching MSM who do not participate in its workshops remains a challenge. Compounded with this issue is the fact that participating in workshops and support groups is still an unfamiliar concept for many Japanese who are traditionally unaccustomed to openly discussing personal matters. Currently, the workshops are being advertised in the major gay magazines, and free Life Guard brochures are distributed in gay bars and clubs. However, OCCUR hopes that news about the workshops will spread via word of mouth to encourage more participation.

In the future, OCCUR plans to continue holding Life Guard workshops, and to work with other NGOs to expand workshop coverage to other cities. It also hopes to offer the workshop model to organizations working in HIV/AIDS prevention, so that they may adapt the format to reach their respective target groups.

5 UNAIDS (2002a).
6 An ice-breaker is a short, simple activity that helps participants “warm up” by getting to know each other and preparing them for more sensitive discussions such as sex and HIV/AIDS. In a “chatting roulette” session, the participants pair off and are given 30 seconds to introduce themselves to each other. After 30 seconds, they must find another partner to do the same self-introduction talk for 30 seconds, and then another, so that participants have the chance to meet as many others as possible.
Reaching out: Connecting to Chinese MSM  
(Chi Heng Foundation, China)

China’s HIV epidemic is largely concentrated among injecting drug users and spread, in some areas, by unsanitary blood collection practices. While heterosexual transmission is now on the rise, sex between men is another mostly “hidden” source of the spread of HIV in China.

Whereas stigmatization and discrimination of men who have sex with men (MSM) are widespread, particularly in the countryside, homosexuality is more openly expressed and tolerated in big cities, where people can lead relatively independent and anonymous lives. To some degree, this has triggered a higher risk for MSM to become infected with HIV/AIDS because the rapid growth of gay communities and MSM establishments has made casual sex more accessible – with limited or no access to safer sex methods.

The Chi Heng Foundation reaches out to those commonly known as tonghzi – a standard Chinese term meaning "comrade" that now also refers to lesbians, gays, bisexuals and transsexuals. Established in 1998, this community-based organization promotes the rights of sexual minorities and devotes much of its efforts to HIV/AIDS awareness and protection of the rights of people living with HIV/AIDS (PLWHA). Its outreach activities include peer-led HIV/AIDS awareness and prevention education efforts and free condom distribution programmes in Beijing and Shenzhen.

HIV/AIDS and MSM in China

Heterosexual transmission is on the rise in China, already accounting for 6.9 per cent of HIV infections.¹ This increase is in part attributed to a change in social mores and sexual practices, such as increased premarital sex and non-monogamous sexual relationships.² One factor that increases the risk of HIV transmission is a large workforce of approximately 3 million sex workers in China, many of whom report never using condoms. Other factors are population mobility and low levels of knowledge about HIV/AIDS prevention measures among a large population.³

In China, as in many other Asian societies, cultural factors inhibit discussion of sexual behaviours that are central to the spread of HIV/AIDS. In the case of men who have sex with men, the social unwillingness to acknowledge its existence, together with stigma and discrimination, feed the secrecy around male-to-male sex, increasing risk-taking behaviours and making it difficult to reach men with HIV/AIDS prevention and care services.

Many homosexual men struggle with tremendous social pressure to hide the fact that they engage in male-to-male sex. They may lead double lives, getting married and leading ‘straight’ lives at work and at home, but occasionally returning to the MSM world.
Infection rates in the MSM community are anticipated to increase. The fact that most Chinese MSM are as likely to be having sex with women as with men, magnifies and bridges the risk of HIV transmission to a large proportion of the population.

**Up close and personal with Chi Heng Foundation’s Chung To**

Mr. Chung To, a former investment banker, is a tireless and outspoken advocate of sexual minorities, working to educate tonghzi on how to prevent HIV/AIDS. The 36-year-old co-founder of the Chi Heng Foundation, with the help of volunteer outreach workers – many of whom are tonghzi themselves – distributes condoms and information and education materials in discos, saunas and traditional bathhouses (establishments which are not necessarily gay, but which have a large tonghzi clientele) as well as to male sex workers in brothels and parks, to help reduce their risks of HIV/AIDS infection.

In the remainder of the text below, Chung To shares his reflections about some of the experiences and challenges Chinese MSM face in a time of increasing risk of HIV/AIDS.4

- **Over the past three years we have seen the institutionalization of male sex work.**

  Commercial sex in China has become brothel-based. Previously, many male sex workers worked independently in parks. From an outreach perspective, this made it very difficult to reach them, because it demanded intensive one-on-one communication. You would see the sex worker one day and the next day he would be gone. However, in the past three years, male sex work has largely become institutionalized, with 10 or 20 men now working for a manager or a pimp. This trend can, in some respects, be attributed to the social and economic changes in China. For instance, perspectives about homosexuality have changed. Being gay is no longer considered a crime or a psychiatric illness, so it has become easier to establish MSM venues, to find men who are willing to work there and clients who frequent the establishments. At the same time, economic growth has generated considerable demand for brothel-based male sex work, especially in prosperous cities, such as Shenzhen, where many male clients come from Hong Kong, China. Having said that, the legal environment has remained the same: sex work is illegal in China, so MSM establishments are very discrete. They are not as obvious and “open” as their female counterparts. The brothels are mostly located in private apartments. A three- or four-bedroom apartment might house about 10 male sex workers.

- **We deliver the condoms to the pimps and they distribute them.**

  What we have to do is convince the brothel managers that our work is worthwhile and important. Condom distribution is a key component of our prevention work. We deliver
the condoms to the pimps and they pass them out to the boys. We no longer have to keep track of all the sex workers. As long as we keep in contact with the pimps, our work is successful because we can pass out condoms and do outreach work through this channel. It is very effective.

The Chi Heng Foundation has worked long and hard to forge good relationships with the proprietors of popular MSM establishments in Beijing and Shenzhen. I was lucky because, initially, I was introduced to most of the managers by friends who were their customers. So, I quickly gained their trust. I also established more significant contact with the proprietors by bringing them information resources and gifts, from Hong Kong, China, especially merchandise that could not be obtained in mainland China.

I said, 'It's a win-win-situation. You have nothing to lose.'

When I became a friend to the brothel managers, I would ask them: “Why don't you care about your boys' health? It is in your interest, because if they get sick you get a bad reputation.” They agreed but wanted to know how they could keep the men clean from infections. And I said, “Well, safer sex,” and then there would be a pause and then I said, “Look, I'll provide you with free condoms, free lubricants and safer sex educational materials. It's a win-win-situation. You have nothing to lose.”

Several brothels in Beijing and in Shenzhen accepted. In total, there may be about 8 to 10 MSM brothels in each of these two cities. So the Chi Heng Foundation covers a large part of the male commercial sex scene, at least in terms of institutionalized male sex work.

Apart from providing condoms and information, education and communication materials, the proprietors have permitted us to conduct safer sex workshops in the brothels. This usually takes place in the early afternoon before the clients come in. The safer sex education is short and simple, but it is important to offer it regularly because the brothels get new boys all the time. Many of them come from the countryside and often do not know anything about HIV/AIDS, so they might therefore be involved in high-risk behaviour.

We keep trying to convince those managers who do not yet permit us to do outreach in their establishments about the importance of our work for their boys, their clients and their businesses. Slowly, as we build trust and raise awareness, I think we will have success with them, like we have had with other brothels. However, security remains one of their main concerns. Sex work is illegal in China. So, they do not want to get into trouble with the media or the police. But on the other hand, tensions have eased. For instance, condoms can no longer be used as evidence for sex work. That is an important step for our outreach work in general since we can now tell sex workers not to be afraid to carry condoms around.

China is too big to provide everyone with free condoms forever.

After three years of condom distribution and outreach we see some encouraging changes. One manager of a brothel in Beijing recently told me: “Chung, look, you no longer need to bring me the condoms because I will buy them myself.” Later I found out that the pimp purchases the condoms, but actually charges the clients for providing them. It is a good thing. I don’t care who pays for the condoms as long as they get used. The proprietor also introduced a very strict practice in his establishment. All boys have to use condoms with customers. If a customer refuses, then they can refuse him. I was very moved by this, because it seems that we are having an impact. China is too big to provide everyone with free condoms forever. We are
striving to modify risk behaviours. And, once the practice is changed people will buy condoms on their own.

Unfortunately, those sex workers who freelance in public cruising areas and bars are much more difficult to reach and this is one of our greatest challenges. We pass out condoms to them when they are working in parks, but it is very labour intensive. But, without a doubt, there is also a strong need for this. Establishment-based sex workers tend to be more content and less desperate than their counterparts because they have a place to stay, food to eat and probably some savings as well. So, they aren't as willing to take lots of risks. But, sex workers in public cruising places might be runaway kids without any money. They might be more desperate and more willing to take risks. It is a very big problem and sadly, we do not have the staff or funding to do all of the outreach work required.

We hope that one day the Chinese Government will provide funding in order to help us carry out MSM prevention activities on a greater scope. But presently, we are happy that officials do not restrict our programmes, which are financed in large part by private donations, generally from Hong Kong-based sponsors. Hopefully, we will get increased donor funding soon and be able to expand our activities to up to seven other cities, such as Shanghai, Dalian, or Chongqing. Fortunately, the Chi Heng Foundation was recently granted the status of a charitable organization. This has helped facilitate funding and support from collaborative partners.

- Due to the tongzhi websites people have become more organized.

The Internet is of rising significance in the Chinese tongzhi community and helps facilitate capacity building and information sharing about HIV/AIDS. We have just compiled an online resource centre for webmasters who operate “gay-oriented” web sites. The webmasters are able to select the most current MSM specific information on HIV/AIDS and other sexually transmitted infections to post on their web sites. In addition, the resource centre will include an online question-and-answer section. Because webmasters might not have the expertise to answer users’ questions, we developed a team of four or five doctors and experts to be on duty. However, it is not a “real time” chat, meaning that the user gets an answer to his question one or two days after he has posed it.

This form of community outreach will help educate many tongzhi people who need information about HIV/AIDS and actively engage members of the web community to help get prevention messages out to the public. As of the beginning of 2003, there were approximately 300 tongzhi web sites and between 5 and 7 million tongzhi Internet users (out of the total number of 50 million Internet users) in China. At the same time, we estimate that around 3 million gay or lesbian users have obtained HIV/AIDS-related information from the Internet. While many tongzhi websites contain some messages about HIV/AIDS, the information may not be accurate, may be of poor quality or is sometimes limited to slogans like “Protect yourself!” or “Please stay clean!” The reason for this is that the webmaster’s resources and time are restricted. They might work at an IT company or study computer science and are doing this in their free time. Feedback from webmasters told us: “We want to post more HIV/AIDS-related content on our web site but we do not have the time to research all the updated materials or to translate them into Chinese.” So, we are providing some vital information out there that the webmasters can just download to their sites.

As a supplemental HIV/AIDS awareness activity, the Chi Heng Foundation will host in 2003 an HIV/AIDS Conference for Tongzhi
Web Sites, an event that took place for the first time in Beijing in 2001 and established the first national network of tongzhi web sites. For the upcoming 2003 conference, people who fund and maintain tongzhi web sites will be invited to discuss the importance and the challenges in promoting HIV/AIDS awareness and prevention via the Internet. The Foundation also bestows the biannual Chi Heng Tongzhi Web Site Award in three categories: community service, news/information and health promotion. The 5,000 yuan (US$ 600) prizes are aimed to encourage more web-based information that can safeguard the tongzhi community’s health.

I think this activity has been very successful and a great example of virtual community mobilization. Although you can only reach a certain part of the population, the Internet will become increasingly important, especially among younger MSM.

- **Our strategy is non-confrontational.**

Activism in general, regardless of the cause, carries tremendous risks and can be counterproductive in China. The Government may not dislike what we do, but if our activities become too well known we might get into trouble. Not because the things we do are bad. They are positive and help the community. But stigma and discrimination are still serious problems that the MSM community faces everyday. That’s why we are very low profile, meaning we do not deal with the media a lot and we work very quietly for the community. Only health officials know about us. We are not here to criticize and to make trouble. HIV/AIDS is a big problem in China and it is getting worse every day. We are here to assist the Government to do a better job. Some officials are intrigued by the fact that we are working with MSM and male sex workers. We try to think from their perspective and argue that when we work with sex workers we are working for mainstream society. We are protecting the general public from getting HIV/AIDS.

I think the key to our success is that our programmes speak directly to the needs of the individuals. We are empowering MSM with knowledge and the means to protect themselves. Our HIV/AIDS services are reaching MSM because we utilize outreach and peer network approaches and we bring our services to the places where MSM work, live and socialize.

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Far from society – close to HIV:
Working with Uzbekistan’s sex workers
(Sabo Tashkent City Women and Children Centre, Uzbekistan)

Central Asia is credited with the dubious distinction of having the world’s fastest-growing HIV/AIDS epidemic. In 2001 the number of documented HIV cases in Kazakhstan and Uzbekistan increased three-fold in comparison with the year 2000, and according to unofficial estimates, the number of people living with HIV/AIDS in the five Central Asian countries – Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan, and Uzbekistan – was about 35,000 in 2002.1 A severe lack of government resources has prevented countries in this subregion from implementing prevention measures for HIV/AIDS, especially for high-risk groups. In addition, a cultural reluctance to openly address issues such as drug abuse and changes in sexual norms, perpetuates and compounds the HIV/AIDS problem.

Uzbekistan is the most populous of the five Central Asian Republics. Reports indicate that in 2002 between 1,000 and 2,000 people were HIV-positive.2 A sudden surge is paving the way for an imminent epidemic, unless urgent action is taken immediately.

Founded in 1998, Sabo Tashkent City Women and Children Centre focuses on HIV/AIDS prevention programmes and social and health services for youth and high-risk women, particularly for sex workers. With the help of peer educator volunteers, Sabo provides information, education and counselling programmes, legal aid, and contraceptives.

A burgeoning epidemic: The state of HIV/AIDS in Central Asia

Central Asia is perfectly situated for a massive HIV/AIDS epidemic. The explosive growth of HIV experienced by many of the Central Asian Republics is unfolding against a complicated backdrop of political upheaval, economic crisis, rapid social change, increasing unemployment and poverty, and changes in sexual norms. The surge of injecting drug use and a growing sex industry are major drivers of the epidemic across the subregion. Young people are particularly hard-hit by the epidemic with the majority of drug users and sex workers in the subregion aged under 30.3 At the same time, the proportion of sexually transmitted infections (STIs) such as syphilis and gonorrhoea, have increased 100-fold since 1991 – presenting increased risks for HIV infection.4

Uzbekistan: Nascent spread of HIV

The spread of HIV in Uzbekistan is at an early stage. As in many neighbouring Central Asian countries, HIV prevalence among the adult population in Uzbekistan has not yet
exceeded the rate of 0.1 per cent. Yet, evidence is mounting that the country is ripe for a full-blown epidemic: In the first six months of 2002, 620 new infections were registered – almost as many as the total number for the previous decade. The highest number of cases has been identified in Uzbekistan’s capital, Tashkent, the country’s largest city.\(^5\)

Injecting drug use accounts for 71 per cent of new HIV infections in Uzbekistan.\(^6\) Partaking in drugs and unsafe sex seems to be an integral part of the subculture among young people between 15 and 29 years of age, who comprise more than one-fourth of the population.\(^7\) At the same time, ignorance about how to contract HIV and other STIs is relatively high, particularly among youth. According to a 2001 survey, one-third of young women aged 15 to 24 had never heard of AIDS.\(^8\)

**Condoms are important!**

Condom use is uncommon in Uzbekistan, including among sex workers. Consequently, a high proportion of sex workers contract sexually transmitted infections. Up to 30 per cent of sex workers also inject drugs. For sex workers and their clients, the biggest risk of contracting HIV is through unprotected sex. Some sex workers report every third client refusing to use a condom.\(^9\) With the number of sex workers estimated to be between 10,000 and 15,000 in Tashkent alone, the cause for concern is great.\(^10\)

**Oksana\(^*\) can’t afford safer sex\(^{11}\)**

Young, bright-eyed and hopeful, Oksana came to the western city of Nukus, a rapidly growing city of the autonomous republic of Karakalpakstan, three years ago to study at the university. However, her application was rejected. In the desperate economic climate, she was unable to find employment. She has been working as a sex worker ever since.

“I came here from a remote village, and I have only recently learned what AIDS is and how it is transmitted,” she said. “I don’t know if I have this disease, but I’m too scared to go for an HIV test. Not one of my clients has ever practised safe sex.”

Oksana is not alone. Doctors at the Nukus branch of the Centre for Reproductive Health have concluded that the majority of sex workers are at extremely high risk, as their clients are not using condoms. Many of them know nothing about the symptoms of sexually transmitted infections or ways to prevent the infections.

Sex workers in Nukus fear that potential clients will pay much less if they insist on condom use. As the going rate for one session can be as little as US$ 3, the sex workers are not inclined to further lower their prices.

* not her real name

**A ray of light and an open door**

Today, Sabo is a busy community centre with 20 staff members and 20 volunteers. Sabo began as a small-scale project. The founders, among them doctors and teachers experienced in social and education work, had almost no funding.

“But we had extensive life experience and the desire to change society for the better,” recalls Tadjikhon Saidikramova, chairperson of Sabo’s coordination council. At first the group provided sexual and reproductive health education and HIV/AIDS-related knowledge to students, housewives or people entering marriage. Soon Sabo staff identified the need to focus on HIV/AIDS prevention efforts, particularly for sex workers because they are among those most at risk and most marginalized in Uzbek society. The centre now serves over 400 sex workers per month with medical service, counselling or outreach work.
“We have won the trust of sex workers”, says a Sabo volunteer, acknowledging that this serves as a precondition to effective counselling and subsequent referral to medical care.

Sabo also offers sex workers important and valuable social services. They can consult, confidentially and for free, a gynecologist, psychologist, immunologist or a lawyer. Sabo offers workshops about methods of protection from pregnancy and STIs, including HIV, and about their legal rights. The centre also runs a counselling hotline and distributes informational materials, syringes and condoms.

“Uzbek laws are undefined regarding sex work and liability for engaging in sex work is not clearly established. But public opinion is clearly established, condemning women for frivolity with men and blaming them for prostitution.”

Tadjikhon Saidikramova, Sabo

The stigmatization that sex workers frequently face often forces them into secrecy, making them difficult to reach and mistrustful of people who try to help them. Given this climate, mutual trust between Sabo and sex workers grew slowly. But once a sex worker visited the centre and benefited from medical, psychological or legal aid, she helped to bring more of her peers to the centre.

“They know that Sabo accepts them for who they are. We don’t judge them. Our goal is solely to lower behaviour risks,” explains Tadjikhon Saidikramova.

A six-month needs assessment project extended Sabo’s ideas about the needs of women working the streets and revealed a clear overlap between sex workers and drug users. Some drug users turn to sex work out of financial necessity to support their drug habits. Sex workers use drugs to seek an escape from their harsh lives. One may also lead to the other. The desperate exchange of sex for drugs or “drug money” was identified as a high-risk encounter that reduces appropriate judgment around safer sex behaviours. The sharing of unclean needles and syringes is a well-documented mode of HIV transmission. Consequently, Sabo has included harm reduction information about injecting drug use in its programmes and has introduced a needle and syringe programme for the distribution of sterilized needles and syringes to prevent HIV/AIDS and other infections (see box, page 65).

“In ancient Uzbek, 'sabo' means 'morning freshness' and calls to mind a brighter future. In contemporary language it's a female's name. We decided to name our organization after one of those whom we wanted to support in her hard times.”

Sabo, Uzbekistan

At present, the extent of the project's success on HIV prevention has not yet been determined. However, Sabo is working hard to assist the number of women who come to its centre for STI treatment. A recent report indicates that 10 per cent of sex workers examined by Sabo health workers were diagnosed as having syphilis and half of the women had gonorrhea or trichomoniasis. A contributing factor to the STI problem is lack of access to medical care for sex workers. Many of the women who were diagnosed by Sabo had previously been diagnosed with STIs but had been denied treatment in private clinics because they did not have the money to buy the medication to treat their infections.”

HIV/AIDS Prevention, Care and Support: Stories from the Community
Achievements and challenges

Sabo programmes have helped to educate and empower sex workers, and contribute to their health and well-being. Many of these women have constantly had doors closed on them. At Sabo, the light has remained on and the doors kept open for them. Sabo is giving many of these women an opportunity to try to live safer and healthier lives. The programme has been so inspiring that some sex workers have joined as volunteer counsellors.

The high number of users has also served as an effective measure to continue the programme with the possibility of expanding the HIV/STI preventive education outreach. However, financial sustainability is one of the most difficult challenges. Currently, the Netherlands Organisation for International Development Cooperation (NOVIB) as well as the Open Society Institute Uzbekistan/Soros Foundation serve as the community organization’s main sources of funding while Sabo continues to explore new avenues for financial support.

Sabo has accepted yet another challenge: meeting the needs of a growing population of HIV-positive people who have begun to frequent the centre. Sabo is now exploring additional ways to formally meet their care, treatment and support needs.

Sabo is also stepping up its advocacy work. The centre is planning to work with the media to address the urgent necessity for public information about HIV prevention, and care and support for people living with HIV/AIDS. So far, the state media has not been forthcoming on this issue, and has often taken a harsh stance on HIV/AIDS — sometimes even blaming sex workers, men who have sex with men, and drug users for “bringing it upon themselves”. These attitudes, frequently shared by the general public, further the importance of collaborating with the media to address the stigma and discrimination that fuel the spread of HIV/AIDS.

Sabo has taken action to combat the lack of knowledge about STIs, including HIV/AIDS, in Uzbek society. But Uzbekistan, and Central Asia as a whole, require more HIV prevention programmes — both governmental- and civil society-based — that address the needs of vulnerable groups. The time frame for action is short. Collective national, subregional and regional efforts that emphasize prevention and harm reduction programmes related to drug use are most urgently needed. The development of such programmes can help open the window of opportunity for Central Asian countries to avert a full-scale epidemic.

Treating STIs aggressively reduces HIV infection risk

The presence of sexually transmitted infections magnifies the risk of HIV transmission during unprotected sex since the infection creates additional entry points for the virus or facilitates viral replication.

Many STIs — including the four most common ones: syphilis, gonorrhea, chlamydia, and trichomoniasis — can be cured relatively easily with antibiotic treatment. But lack of services, poor availability of drugs, limited access to diagnosis, and disparaging attitudes by service providers are barriers to more effective detection and treatment of STIs, as part of HIV/AIDS prevention.

These problems are surmountable, even in resource-poor settings. Research in low- and middle-income countries has confirmed the effectiveness of syndromic management. This involves recognizing clinical signs and patient symptoms (or syndromes) and prescribing treatment for the major causes of that syndrome. Syndromic management enables health workers who lack specialized skills and access to sophisticated laboratory tests to effectively treat most symptomatic infections during a patient's first visit.

Far from society – close to HIV: Working with Uzbekistan’s sex workers


4 USAID (2002).


6 USAID (2002).


13 UNAIDS (2002).
Social mobilization in the era of HIV: India’s sex workers fight against HIV/ AIDS (Durbar Mahila Samawaya Committee and the All-India Institute of Hygiene and Public Health, India)

India has around 3.97 million people living with HIV/AIDS, making it the most seriously affected nation in the Asia-Pacific region, and the second most impacted in the world following South Africa. India’s socio-economic status, social mores, cultural myths on sex and sexuality and a vast population of marginalized people, make its population highly vulnerable to HIV/AIDS, resulting in one of the most serious development problems the country has ever faced.

Throughout the country, the epidemic continues to shift towards women and young people, with about 25 per cent of all new HIV infections occurring in women. Adverse gender discrimination such as poor access to education, and low economic and social status, undermine women’s ability to negotiate for equality in sexual relations. In addition, women’s biological vulnerability increases their risk of contracting HIV.

Heterosexual sex has been identified as the chief mode of HIV transmission in India, accounting for roughly 80 per cent of reported HIV/AIDS cases. This makes sex workers and their clients a significant reservoir for spreading sexually transmitted infections (STIs), including HIV.

The Sonagachi District in Kolkata, known as having the oldest, largest and most-storied “red-light” district in the city, has been the breaking ground for a multilateral cooperative partnership between the Durbar Mahila Samawaya Committee (DMSC), Asia’s first organization of sex workers, and the Indian Government’s All-India Institute of Hygiene and Public Health. Their HIV/AIDS project, which was launched by the Indian Government and 18 non-governmental organizations in 1992, remains one of the largest community-run intervention projects in the world. The Government continues to support the programme. And the results are promising – compared to a 30 per cent HIV infection rate among sex workers in Sonagachi less than a decade ago, today, 9 per cent of the roughly 6,000 sex workers tested HIV positive. This can be compared to a 60 per cent HIV-infection rate in similar communities in Mumbai.

In partnership, these groups have worked together to develop the STI/HIV Intervention Programme (SHIP) in Kolkata and West Bengal. This pioneering initiative is empowering sex workers and providing them with an innovative HIV/AIDS prevention programme that offers a safer environment in which to live and work.
Behind the red lights: Sex workers in Sonagachi

Sonagachi is a red-light district that has been around for nearly a century. The area consists of three- and four-story crumbling houses overlooking a chaotic din, where sex workers, hawkers, revellers, bicycles, scooters, and rickshaws jostle for space in narrow congested lanes. An estimated 6,000 sex workers reside here in nearly 370 houses. Another 1,500 “floating” sex workers can be found in the vicinity. The community is financially dependent on the 20,000 or so men who visit Sonagachi monthly. Sonagachi consists of five areas, namely Sonagachi, Rabindra Sarani, Jorabagan, Rambagan and Sethbagan. Each tenement building houses several brothels in which the numbers of rooms vary from five to twenty-five. Accommodation is diverse, ranging from a cramped, badly lit cubbyhole to a spacious air-conditioned room. Not surprisingly, sanitation and civic amenities are in deplorable conditions in many locations. Instances of four to six sex workers sharing a room partitioned by curtains are common.

Sonagachi boasts of a long tradition in the sex trade industry, with a regular influx of young girls from remote places. A large number of sex workers from different parts of India, Bangladesh, and Nepal have congregated here. Their ages range from 13 to 45, and income varies from US$ 4 to US$ 47 per night. Most of the sex workers are illiterate and joined the sex industry due to poverty and deprivation.

The sex workers may operate independently or under the control of madams. Pimps act as middlemen and collect one-fourth of the earnings, while madams take 50 per cent (known as the adhia system). In addition, the sex workers are also expected to pay their rent daily or monthly for the small floor space that they occupy.

Most of the sex workers average three to four customers a day. When the project began in 1992 a survey of 450 sex workers indicated that 45 per cent took precautions against pregnancy, with only 27 per cent taking precautions regularly. In addition, while 69 per cent of the sex workers knew about STIs, only 31 per cent had heard about HIV/AIDS.

Probable source of infection of reported HIV/AIDS cases in India (n = 20304) May 1986 – March 2001

- 82.6% Sexual
- 7.5% Perinatal
- 4.2% Blood & Blood Products
- 4.0% IDU
- 1.8% History not available

Empowerment brings change!

The above indicators, combined with the rising STI and HIV prevalence rates, motivated the All-India Institute of Hygiene and Public Health, along with 18 NGOs, to initiate the STI/HIV Intervention Programme (SHIP). The objective of this programme was to provide sex workers with prevention education and services. Right from the beginning, the programme involved female sex workers as peer educators and programme coordinators. By 1997, the sex workers of Sonagachi were sufficiently empowered to establish their own organization, the Durbar Mahila Samawaya Committee (DMSC), which now facilitates the local HIV/AIDS project in Sonagachi.7

Initially, a group of 12 peer educators were selected, trained, and sent to the field for direct association with the sex worker community. Today, the number of peer educators has increased to 430.8 Since the sex workers themselves act as peer educators, the response has been quite positive. The peer educators, who are trained for a period of six weeks, visit the tenements and distribute condoms free of charge. The female sex workers report that they find it easy to relate to their fellow sisters. They attend lectures on HIV prevention and get free treatment for STIs and examinations in project-run centres. Even male clients are involved – they are educated about the importance of condom use during evening education sessions. The peer educators informally try to verify the extent of condom use by different methods. They inquire about the total number of clients, the number of clients who refuse to use condoms, and the number of clients who have been motivated to use them.

The demand for condoms by sex workers has been increasing steadily. During the first month of the project’s inception in 1992, 3,592 condoms were distributed; in December 1994, 79,420 condoms were distributed. In 2000, over 100,000 condoms were distributed monthly.9

- Raising awareness is just the beginning

In addition to its awareness raising components, SHIP has given sex workers (both male and female) information and access to health services, education, and policy activities. The creation of DMSC has given the sex workers their own organization, managed by a board comprised of some of the older sex workers. They have managed a literacy programme and an immunization programme for their children. They have created the Usha Multipurpose Cooperative Society, which provides loans to sex workers, keeping loan sharks at bay. And they have established a commercial market. Formerly the sex workers had to depend more on their pimps and madams, as they were discouraged from going out to shop, and therefore paid higher prices for goods. Now, with the help of their organization, these women can shop freely at their local cooperative and avoid being overcharged.

Although originally funded by the Norwegian Agency for Development Cooperation (NORAD), World Health Organization (WHO) and the National AIDS Control Organisation

Social mobilization in the era of HIV: India’s sex workers fight against HIV/ AIDS
(NACO), DMSC is now funded not only through continuing assistance from these organizations, but also through local charitable donations, on-going contributions from the All India Institute of Hygiene and Public Health, the United Kingdom’s Department for International Development (DFID), UNDP and several other major aid agencies. Activities are also funded through members’ dues and profits from their cooperative.

Furthermore, once the community was convinced that SHIP was not going to upset their self-interests, or the sex industry, they extended a willing hand. Such an interaction has given the programme a more supportive environment in which to continue.

Achievements and challenges

The SHIP programme has made striking progress in Sonagachi. Sex workers are more conscious of their health needs and requirements. A 1998 survey of sex workers in Sonagachi found that more than 94 per cent knew how HIV/AIDS spread, and how to prevent it from spreading. In 1992, only 1.6 per cent of sex workers said they were using condoms regularly; by 1998, more than 80 per cent were using condoms often (see figure, this page).10

Despite the high condom use and the training of over 430 peer educators in the community, infection rates hover around 9 per cent (although this is much lower than similar areas in the rest of the country). According to sex workers, this is because most clients still do not want to use condoms. Many sex workers continue to face high-risk situations, because of their client’s willingness to pay more for sex without condoms. With some willing to pay double or triple the amount, sex workers, who need the money desperately, unhappily agree to forgo the use of the condom.

However, more Sonagachi women have begun refusing clients who are reluctant to use condoms, despite the higher amount paid. Some pimps and madams intervene when clients refuse to use condoms. Many brothel owners realize that it is easier to keep a sex worker healthy than to keep looking for new workers. More importantly, infected workers keep clients away. The realization of this economic advantage to keeping sex workers healthy has made many madams/brothel owners advocate condom use and safer sex practices. Although this is still not a conventional practice among all brothels and sex workers, it is becoming more common.11

“When a customer comes, I take the money first and then let him in my room. Then I ask whether he’ll use a condom. If he says no, I keep the money and show him out”

Priya Begum, 23, Sonagachi sex worker12
Programme participants and peer educators have noted the change in their lives since working with SHIP. Many feel they have gained self-respect, dignity, and a new social identity. They have an increased sense of self-esteem and authority. Initially, the sex workers could not muster the courage to speak to anyone. Now they can communicate with other sex workers as well as negotiate more effectively for safer sex with their clients.

The sex workers of Sonagachi have established their own financial cooperatives. They are becoming literate with the implementation of a literacy campaign that has, as a secondary effect, helped raise awareness among sex workers about STIs, including HIV, and increased their knowledge about their rights. They have advocated for the prevention of child abuse, sexual exploitation and police harassment. As a result of their literacy and advocacy programmes, many sex workers aspire for a better work and living environment.

Today, Sonagachi’s success has been projected as a role model for other areas. DMSC has attended national conferences and is working towards official recognition as a labour union under the Government’s labour law. They have also extended their outreach to other states of India and neighbouring countries, such as Bangladesh and Nepal. Sonagachi’s latest project is an awareness campaign and treatment of tuberculosis among members, particularly among the most poverty stricken who live in cramped rooms.

The principles of the Sonagachi project have been replicated in a very short time in Bangladesh, demonstrating that the lessons learned from the project are replicable and adaptable to other organizations and areas.

The organization of sex workers is now actively involved in preventing girls under the age of 18 from entering the sex work profession. Initial results of this activity are encouraging, indicating an increase in age of entry into sex work. This has tremendous significance for the sex workers’ lives and HIV prevention efforts, as police and other state powers have often kept control of the brothels, and dis-empowered sex workers, through raids carried out in the name of rescuing underage girls from sex work.13

DMSC is a model of what grassroots social mobilization can achieve when coupled with empowerment and human dignity initiatives. It is also an example of multi-sectoral partnerships and how early government actions such as the above programme, in partnership with NGOs and community-based organizations, can develop long-term and sustainable programmes that can shift the outcomes of HIV/AIDS infection in India, Asia and the rest of the world.

For the women of Sonagachi, it is no longer enough just to survive and live on the periphery of society. It is now the right to self-determination and having a say in the way they work and live that has become the main agenda. With these changes in Sonagachi, the lives of women such as Priya, are set to keep on improving.

2 NACO (2002).
5 NACO (2002).
13 Personal communication with Dr. S. Jana, former project coordinator, Sonagachi project. March 2003.
Getting in tow about HIV/AIDS:
Education for Bangladeshi rickshaw pullers
(Nari Unnayan Shakti, Bangladesh)

Bangladesh is a South Asian country recognized for its low HIV/AIDS prevalence rate. UNAIDS estimated in 2001 that some 13,000 people in Bangladesh were living with HIV/AIDS. Despite the low prevalence rate, many high-risk behaviours in place suggest that HIV/AIDS is likely to spread rapidly in the near future.

One report noted that 60 per cent of long-distance truck drivers in the country have sexual relations with sex workers about twice a month, without any basic knowledge of how to prevent HIV/AIDS. Studies of the sex industry have also identified over 100,000 sex workers, whose customers represent all socio-economic segments of society. Female sex workers have an average of two to five clients a day, most of whom do not use condoms. At risk are the sex workers, their clients, which total about half a million men a day, and the clients’ partners and families.

In recognition of a potentially looming HIV/AIDS crisis, Nari Unnayan Shakti (NUS) is working in poverty-stricken districts in Dhaka, implementing HIV/AIDS education and advocacy programmes that have currently reached approximately 10,000 people. Based in Dhaka, NUS’s main projects address capacity building, poverty reduction, sustainable livelihood, HIV/AIDS and sexually transmitted infection (STI) prevention, general health care promotion, advocacy for gender equality, and the protection of women and children from trafficking, sexual exploitation and other forms of abuse.

This is a story about one of their most innovative HIV/AIDS prevention programmes, which worked with 3,000 rickshaw pullers and their families in the Dhaka slums of Khilgaon and Shabujbag Thanas.

Life as a rickshawala

The streets of Dhaka come alive every morning as hundreds of thousands of human-powered rickshaws fill the streets in their colourful finery. They battle traffic with cars and vans, vying for a piece of the road to get passengers to their destinations.

The rickshaw is to Bangladesh, what the tuk-tuk is to Thailand: an inexpensive form of transportation that is available any time of day or night. However, the rickshawala, who peddles his three-wheeled cycle throughout the city, earns much less than his Thai counterpart, with daily earnings amounting to less than US$ 1.
Rickshaw pullers are one of the largest groups that patronize sex workers. Their participation in high-risk behaviours such as unprotected sex and injecting drug use serves as a significant bridge between populations, and threatens the spread of HIV between sex workers, and the clients’ wives and families. A 2002 NUS survey, prior to the start of their HIV/AIDS programme, found that out of 1,000 rickshaw pullers and their families, more than 80 per cent of men admitted to not knowing what high-risk sexual behaviour caused HIV/AIDS to spread and what preventive measures could be taken to avoid becoming infected.

The NUS survey showed that more than 84 per cent of the wives and daughters of these rickshaw pullers were aware of HIV/AIDS and what preventive measures should be taken. This group of women, however, differed considerably from general surveys in Bangladesh, which indicated that men were better informed about HIV/AIDS than women.

This meant that despite the high level of knowledge among wives, husbands still continued to infect the family because of their high-risk sexual behaviour, and because of gender inequalities which compromised women’s and girls’ ability to negotiate condom use and to adopt safer and healthier practices. Further compounding women and girls’ vulnerability are prevalent social norms that limit their access to economic opportunities.

As a result of the survey findings, NUS embarked on a major initiative to educate and promote behaviour change among rickshawalas, which encouraged safer sex practices. Launched in November 2001, and financed by UNDP, the project aimed to create an enabling environment for HIV/AIDS prevention work, increase rickshaw pullers’ knowledge of sexually transmitted infections including HIV, and increase safer sex behavioural practices.

**Potential spread of HIV from high risk groups to the Bangladesh population, Central Bangladesh**

<table>
<thead>
<tr>
<th>High Risk Group</th>
<th>Married</th>
<th>Visit FSW</th>
<th>Visit MSM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rickshaw pullers</td>
<td>76%</td>
<td>69%</td>
<td>34%</td>
</tr>
<tr>
<td>IDU (40%)</td>
<td>33%</td>
<td>2%</td>
<td>1%</td>
</tr>
<tr>
<td>MSM (46%)</td>
<td>9%</td>
<td>9%</td>
<td>34%</td>
</tr>
<tr>
<td>FSW (9%)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Going to the garages**

Extremely long days and nights on the streets of Dhaka leave the rickshawalas exhausted with little free time to attend classes or workshops on subjects that would improve their well-being. Besides, attending a class would take away time that could be spent earning another fare. To address this constraint, NUS developed an innovative one-on-one outreach programme. Eight staff members from NUS were sent out to speak to the rickshaw pullers individually, or in small groups, when they were resting in the garages – a time when they were more open to instruction and advice. Close to 8,000
mini-meetings were held that addressed sexual health needs and priorities, relationship problems and the consequences of not getting treatment for STIs. The outcomes resulted in greater awareness of STIs, including HIV, and a greater number of rickshaw pullers seeking medical treatment.

In order to expand its outreach, NUS incorporated peer education training into its programme. In 2002, NUS trained 64 new peer educators. Peer educators were identified as those who were in positions of influence and were willing to learn and spread key messages about HIV/AIDS. The programme incorporated the following strategy: For three days participants were given information about HIV/AIDS transmission and prevention methods, as well as issues that impact HIV/AIDS, such as gender inequalities, and how to improve communication skills. In addition, 104 peer educators who were trained under a separate health education project in 2001 were invited, and given refresher courses on HIV/AIDS issues.

At the end of the training course, evaluations indicated that the participants could explain at least three methods by which HIV/AIDS could be spread (e.g., sexual relations, injecting drug use, contaminated blood) and three ways to help prevent transmission (e.g., abstinence, monogamy, condom use). In addition, many peer educators felt more empowered to help raise awareness about STIs, including HIV, and the importance of safer sexual behaviour, including condom use. They also valued their roles in the community as peer advisors who could provide reliable information to their colleagues.

- **Expanding alliances**

NUS recognized that even more allies and partners were needed within the community to help strengthen HIV/AIDS prevention efforts. Accordingly, they targeted the owners of the garages where the rickshaw pullers work. The garages serve as homes for most rickshawalas – it is here that they eat, sleep and bathe. It is also where many of their sexual encounters take place, in close proximity to other rickshaw pullers. The dormitory-style accommodation means that there are no partitions between people; sexual intercourse is not necessarily a private affair. Thus, rickshaw pullers put on condoms and have sex in the presence of other rickshaw pullers, with many commenting on each other’s prowess or weakness.

“Even if I am now tired, I try to get a condom and use it ... I know it will help to save my life and my family and I can continue to send more money to my wife.”

*Mohammad Abdul Habib, rickshaw puller*

*Photo: Hoque, Muhammad Towhidul (2002). Amori Bangladesh*
To increase stakeholder participation, NUS staff and peer educators strategically educated and recruited the owners of the rickshaw garages and mobilized them into action. As a result, condoms supplied by NUS were made more easily available for distribution among rickshaw workers. The alliance of the garage owners helped break barriers, stigma and misconceptions about condoms being “unmanly”\textsuperscript{12} and helped address some of the rickshaw pullers’ complaints that they lacked privacy in putting on condoms or in carrying them.

In order to reach a wider range of people, NUS also organized 31 video shows for rickshaw pullers and slum dwellers in 2002. Before and after the show, health educators interacted with the audience to respond to any concerns or questions. Each video discussed HIV/AIDS, with key messages reiterated by the staff educators at the end of the show. This medium was highly effective. Not only did it provide entertainment to the rickshaw pullers and increase community participation, it also made many of the rickshaw pullers seek more information on how to prevent HIV/AIDS.\textsuperscript{13}

In addition, NUS organized five meetings with community leaders in the slum districts. These meetings addressed issues such as HIV/AIDS, family and social violence, as well as communication strategies to improve people’s decision-making and negotiation skills in matters related to their sexual and reproductive health. These workshops and policy discussions have gone a long way in getting the community leaders to accept that education and community-driven initiatives were needed in preventing HIV/AIDS.

The other link: Increasing access to health care

NUS recognized that prevention education without health care and support would be highly ineffective. Once rickshaw pullers were educated about sexually transmitted infections, many would wish to seek medical assistance. Consequently, in order to address the health concerns of rickshaw pullers and provide them and their families with access to primary health care, counselling and information and education materials, NUS established a medi-

In addition, NUS organized five meetings with community leaders in the slum districts. These meetings addressed issues such as HIV/AIDS, family and social violence, as well as communication strategies to improve people’s decision-making and negotiation skills in matters related to their sexual and reproductive health. These workshops and policy discussions have gone a long way in getting the community leaders to accept that education and community-driven initiatives were needed in preventing HIV/AIDS.

Achievements and challenges

The NUS programme with rickshaw pullers highlights the importance and value of highly targeted and focused advocacy and education
efforts and partnerships. The *rickshawala* programme has trained 168 peer educators and set up a medical facility to treat patients with STIs and other health problems. Rickshaw pullers and their families, slum dwellers and garage owners have all been educated about the importance of safer sex practices and modifying sexual behaviour.

When the programme began, more than 50 per cent of rickshaw pullers were not using condoms among the NUS target group. In response, NUS organized regular visits to the garages and conducted education courses for garage owners in order to mobilize the power structure into full action and support. From September 2001 to the end of the programme in September 2002, a survey at the medical facility indicated that more than one out of every three rickshaw pullers used a condom during his last sexual encounter, compared to none at the start of the programme.

At the end of the programme, NUS had reached over 10,000 rickshaw pullers and their families, who are now aware of HIV/AIDS and how to prevent its spread. In addition, their communities were mobilized to create a greater enabling environment for STI and HIV/AIDS prevention efforts.

Despite the programme’s success, it has not been renewed by the Ministry of Health and Public Welfare, which distributes the UNDP funding for it. The Ministry is presently utilizing the UNDP funds for other projects. NUS is thus presently seeking funds to continue with its *rickshawala* project.

It is still a long road ahead in getting all rickshaw pullers in Bangladesh to change their sexual behavioural patterns, but increasingly, projects like the one run by NUS are helping to make a big difference in the life of the common *rickshawala*. Where there was once only suffering, stigmatization and a lonely road to death, there is now hope for a longer and happier life, peddling on the streets of Dhaka.

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6 Bloem, Maurice (1999).
9 NUS (2002).
11 Bloem, Maurice (1999).
13 NUS (2002).
14 Anti-AIDS initiatives in the doldrums (2002, November 22). The Independent Bangladesh

15 NUS (2002).

16 NUS (2002).

17 Anti-AIDS initiatives in the doldrums (2002, November 22).
INJECTING DRUG USERS
Taking it to the streets: A harm reduction programme for Pakistani drug users
(Nai Zindagi, Pakistan)

The spread of HIV by injecting drug use is one of the most serious, “hidden” problems in Asia. New patterns of drug use, in particular the shift from opiate smoking to drug injection, are contributing factors to rapid increases in HIV infection levels among injecting drug users (IDUs). Many countries in the region have high HIV prevalence rates among IDUs, including Myanmar (63 per cent), Thailand (50 per cent), and Nepal (50 per cent) in urban areas. In Viet Nam, injecting drug use represents the predominant mode of HIV transmission, accounting for 65 per cent of the cumulative total of reported HIV cases. Similarly, in the Islamic Republic of Iran and China, 75 per cent and 70 per cent of HIV infections, respectively, are also traced to injecting drugs.

Currently, HIV/AIDS prevalence is low in Pakistan. The WHO and UNAIDS estimate that 0.1 per cent of the adult population, or about 76,000 adults, were living with HIV/AIDS in 2001. Overall, Pakistan is estimated to have between 4 and 4.8 million drug users, with the number of injecting drug users estimated at 180,000. This figure however, is likely to increase, given the recent trends in accelerated drug use. Reliable data about HIV prevalence among IDUs in Pakistan does not exist. However, several studies revealed that an alarming 70 to 90 per cent of street drug users were infected with Hepatitis C, another life threatening illness spread through contaminated needles and often seen as a forerunner to HIV.

Nai Zindagi (New Life) is filling a critical gap in Pakistan by addressing both injecting drug use and HIV/AIDS. Founded in 1990, the organization provides a range of harm reduction and drug treatment services to more than 6,500 street drug users in the cities of Lahore, Quetta and Rawalpindi. Nai Zindagi aims to help drug users improve their health, reduce drug-related harm and risks, prevent the transmission of HIV/AIDS, and provide opportunities for socio-economic rehabilitation.

Injecting drug use and HIV/AIDS in Pakistan

The linkages between drug use and HIV/AIDS are widely neglected. Few countries in Asia have implemented appropriate harm reduction strategies (see box, page 65). Limited health resources and increased pressures on health care delivery systems make harm reduction programmes a low priority. Instead, drug policies have usually concentrated on law enforcement and penalization rather than rehabilitation. This trend prevails despite evidence that prevention and rehabilitation programmes are most effective and reduce HIV prevalence.
rates when law enforcement agencies are supportive of harm reduction practices and do not harass health service providers reaching out to drug users.

In Pakistan, injecting pharmaceutical drugs is becoming the preferred method of drug use. In the past, many drug users smoked heroin or heated it on pieces of tinfoil to inhale the fumes. Since the end of the 1990s, however, an increasing number of chronic heroin users have shifted from smoking or inhaling heroin to injecting a combination of legal and illegal drugs. This shift may be attributed to the fact that opiate painkillers, antihistamines and tranquillizers, that are used in combination, cost half the price of heroin, and are legal and widely available. Furthermore, injecting the drugs delivers a faster “high”. Injecting also spreads HIV and other blood-borne infections more rapidly since drug users often inject in groups, share unclean needles and syringes and other drug-use equipment that might be contaminated.  

The potential for an HIV epidemic in Pakistan, or anywhere else, despite currently low numbers of infections, should not be underestimated. Epidemics among IDUs, with prevalence rates reaching 50 to 90 per cent, have been documented within a few months of the first reported case. For example, in Manipur, India, HIV prevalence among IDUs jumped from below 10 per cent to more than 70 per cent in 24 months.  

In Pakistan, a pattern has developed among street drug users. An increasing number of injecting drug users are sharing unclean needles and syringes and there is an increase in the prevalence of Hepatitis C, a leading precedent to HIV. Additionally, drug use is on the rise among younger age groups who are becoming a large part of the street drug sub-culture.

Injecting drug users are usually stigmatized, criminalized and marginalized. Many lack awareness and education about communicable diseases, including HIV.

**Nai Zindagi’s street-based HIV prevention and harm reduction services**

Nai Zindagi co-founder, Mr. Tariq Zafar, reports that Nai Zindagi is a non governmental organization working with, and for, drug users. Its overall objective is to improve the health (especially prevent the transmission of HIV and other blood-borne infections), and the livelihood and rehabilitation of street drug users in major cities throughout Pakistan. Major activities include:

- The collection of information and data to monitor changing trends and needs of drug users in Pakistan;
- Harm reduction outreach services;
- Residential drug treatment and rehabilitation services;
- Follow-up and family services.
On the street with Nai Zindagi

“Drug use cannot be looked at in isolation ... and, above all, drug use can no longer be disassociated from HIV/AIDS”, says Tariq Zafar. To prevent high-risk behaviours, such as the sharing of syringes and needles and engaging in unprotected sex, and to improve the overall health and socio-economic conditions of injecting drug users, Nai Zindagi opened its first harm reduction programme in Lahore in the year 2000. Subsequently, the success of that first programme led to its replication in Quetta and Rawalpindi, as well as by other national drug programmes.

At a Nai Zindagi shelter, drug users are registered in order to monitor their care and well-being. Next, they are provided with primary care for health problems such as abscesses and stomach cramps. A health worker may show clients how to avoid injecting drugs into the arteries, which causes health complications, and familiarize them with the value of always using clean needles. The health worker also tells them about HIV/AIDS, a disease relatively few Pakistani drug users have ever heard of.

Clients can also be tested and treated for sexually transmitted infections (STIs). Additionally, the centre provides counselling and peer education for drug users and vulnerable groups that stress the importance of not sharing needles, of proper condom use, and of maintaining personal hygiene. On the streets and in the centres, information and education materials are disseminated at group sessions, lectures, and one-on-one meetings that inform the reader of the dangers involved in high-risk behaviours, such as needle sharing and unsafe sex. In other situations, clients are also referred for advanced medical care and legal care. At their own volition, they also have access to Nai Zindagi’s rehabilitation services and residential care drug treatment. Another step in Nai Zindagi’s programme includes initiating contact with family members to improve a drug user’s chances of reintegration into society.

Gaining community support

Since its establishment in 1990, Nai Zindagi has developed a close relationship with communities. Affected and unaffected people are involved in its mission to help reduce groups such as the injecting drug users’ sex partners, sex workers who service injecting drug users, street children and family members.
harm in drug use. For instance, cooperation with the local police has improved as the police increasingly recognize that drug treatment is often more effective than penalization. A registration card is issued to drug users who are currently utilizing Nai Zindagi’s services. In situations of minor offences, police sometimes return the drug offenders to one of Nai Zindagi’s centres rather than arrest them.

Peer-led education and counselling is another form of community support. Once drug free, many former drug users are employed by Nai Zindagi or partner organizations as counselors and treatment staff members. Their involvement with the communities and other drug users has helped link the communities and reduced stigma and discrimination associated with drug users. To date, more than 200 former drug users are working in Nai Zindagi’s vocational businesses, harm reduction and drug treatment programmes.

Achievements and challenges

The Nai Zindagi model of continuum of care – from street-based services to socio-economic rehabilitation and reintegration – is unique in Pakistan and is receiving national and international recognition. Nai Zindagi’s harm reduction and treatment model has attracted the attention of several Caribbean countries that are replicating various components of the programme.

Nai Zindagi is also a unique NGO because it is largely self-sustaining. “We started out with donor money from the European Union, the United States and other donors. But like drugs, it created a dependency too. When funding stopped, so did the project, so we realized this was an addiction we also had to break”, reflected Tariq Zafar. “So now, many of our activities are self-sustainable. Our drug rehabilitation clients are given vocational training to make crafts, furniture and other items that we sell in the shop to sustain our programmes.”

Nai Zindagi also works in partnership with governmental organizations, community-based organizations, NGOs and UN agencies. Many of the innovative and landmark activities that Nai Zindagi has developed, such as community intervention programmes, training,
as well as studies on prevalence rates of HIV/AIDS, Hepatitis C, and other research have been undertaken in collaboration with these groups to scale-up interventions and activities that maximize coverage, as well as ensure effectiveness of service delivery.

Nai Zindagi also plans to respond to the needs of newly emerging target groups, such as homeless children who use drugs, refugees and sex workers who are in critical need of HIV/AIDS awareness and service programmes.

Nai Zindagi activities show that the development of harm reduction programmes, combined with HIV prevention among injecting drug users, can make a significant impact on reducing harm and HIV among the IDU community and other vulnerable groups.

The organization’s non-judgemental approach to drug users and support for the participation of former drug users, especially as peer educators and outreach workers, are important factors in its success. Also important is its wide involvement of family members, as well as diverse community groups and government agencies, including the police, in supporting its programmes.

Given that Asia is estimated to have the largest number of injecting drug-related HIV-positive persons, Nai Zindagi’s work deserves close attention for wide-scale adaptation and replication.


4 Reid, Gary and Genevieve Costigan (2002).

5 Email communication with Nai Zindagi, 19 December 2002; and UNDCP/UNAIDS (1999).


7 UNDCP/UNAIDS (1999).
Progressive political support

A growing number of governments and programmes in Asia recognize that drug use should be considered a health and development issue, and not just a legal issue. Policy makers have already recorded some remarkable achievements in terms of designing effective interventions, reducing the spread of HIV through injection, and involving local communities and governments in the development of practical solutions to the complex problems associated with injecting drug use.

While drug use is illegal in Australia, the Government’s policymakers recognized very early on that drug use does occur and efforts should be made to reduce harm associated with it, including Hepatitis C and HIV infection. Needle and syringe programmes were introduced in the 1980s, based on the following rationale:

- Despite drug education and treatment programmes, many people will continue to inject licit and illicit drugs for varying periods of time;
- People must be provided with the knowledge and skills they need to make informed decisions about high-risk behaviours.

In response to the risk of HIV being spread through injecting drug use, the first Australian needle and syringe programme began in...
HIV/AIDS Prevention, Care and Support: Stories from the Community

Sydney in 1986 as a trial project. Soon after, all Australian States and Territories introduced the programme. Given what some may consider the unconventional nature of the programme, the Government has had it carefully evaluated. The results provide overwhelming evidence that needle and syringe programmes are an essential and successful public health measure. Most importantly, there is no evidence that the programmes increase injecting drug use. Rather, NSPs can actually decrease drug use among IDUs, as they provide a referral point for drug rehabilitation and education. Joint activities in which local organizations and local citizens work with injecting drug users have led to the creation of over 3,000 NSPs in Australia. They have also averted thousands of new infections of HIV and Hepatitis C (see box, this page).

The Australian NSPs provide a range of services that include education and information on prevention of blood-borne viruses, reduction of drug use, referral to drug treatment, medical provision and care, and legal and social services. Equipment provided includes needles and syringes, swabs, vials of sterile water and “sharp bins” for the safe disposal of injecting equipment. The aim is to prevent the shared use of injecting equipment, which can lead to the transmission of blood-borne viral infections. Programme staff members also provide sex education and distribute free condoms to help prevent sexually transmitted infections (STIs), including HIV.

Needle and syringe programmes tend to be located in relatively public places because they need to be accessible. There are three different types of programmes operating in Australia. Primary outlets are stand-alone agencies that are concentrated in areas of high drug use. These programmes are specifically established to provide sanitary injecting equipment, usually along with primary medical care. Programme staff members are trained to provide non-judgmental treatment and are encouraged to develop rapport with individuals who are otherwise hard to reach. In this context, the collaboration of people with a history of injecting drugs has helped to facilitate trust among the clients.

Typical secondary outlets include hospital accident and emergency departments and

25,000 HIV cases averted in 10 years

According to a recent Return on Investment Report, Australia’s needle and syringe programmes (NSPs) have prevented 25,000 new HIV infections and 21,000 Hepatitis C infections over the past 10 years. By 2010, it is projected that needle exchange will have prevented 4,500 AIDS-related deaths throughout Australia.

The research, commissioned by the Government, analyzed data from more than 100 cities worldwide, comparing HIV and Hepatitis C infection among injecting drug users in countries with and without NSPs. The data was then used to calculate the return on investment from these programmes in Australia from 1991 to 2000, providing potent, measurable evidence of the benefits of one of Australia’s most controversial public health policies.

Whereas, in Australia the 10-year-old NSP cost Federal and State Governments US$ 71.8 million, the report estimates public health savings of US$ 1.3 billion in long-term HIV and Hepatitis C treatment costs alone, from this 10-year investment.

More importantly, cities with NSPs had an average annual 18.6 per cent decrease in HIV prevalence compared with an average annual 8.1 per cent increase in cities without those programmes.
community health centres. Health workers such as nurses, receptionists, social workers or youth workers are responsible for the distribution of sterile injecting equipment and the provision of health information and education.

Mobile services are the third outlet for distribution and exchange programmes. NSP vehicles travel throughout the community to extend their reach. There are also vending machines that dispense “Fitpacks” containing several one-millilitre syringes for a nominal fee. These machines are monitored and restocked by needle and syringe programme staff members. Fitpacks are hard plastic containers in which used syringes can be “locked-in” for disposal so that they cannot be removed for re-use or cause injury. In addition, over 500 pharmacies throughout Australia provide one-millilitre syringes, which can either be purchased, or, as in the State of New South Wales, be exchanged free in return for a pack of used syringes.

Working hand-in-hand with drug users

Peer education is an important component of the successful public health response in Australia. A part of the programmes’ innovative and unique features is that injecting drug users are themselves involved in the harm reduction programmes and services. IDUs are brought into the process as advisors who use their own experiences to suggest ways to help other IDUs access much-needed services. As a result, there are policies in place which do not require a drug user to reveal individual identity in order to access provisions, confidentiality is guaranteed, more than one needle per person can be distributed, and participants in the NSPs are encouraged to take printed health information, which they can distribute to their peers.

Harm reduction principles

Harm reduction is a set of practical strategies aimed at reducing the individual and social harms associated with drug use, especially the risk of HIV infection. It seeks to lessen the problems associated with drug use through methodologies that safeguard the dignity, humanity and human rights of people who use drugs.

This approach is based on the pragmatic acknowledgement that, despite years of trying, there are no known effective interventions for eliminating drug use or drug-related problems in any community, city, or country. In most cultures, adopting a harm reduction approach requires a shift in thinking that moves away from deeply rooted, long-term idealistic goals of eliminating drug use altogether.

Harm reduction does not deny the value of helping people become drug free, or the desirability of abstinence as an eventual goal. It simply recognizes that, for many drug users, these are distant goals. Services to reduce the risk in the interim are therefore essential if personal and public health disasters are to be avoided. Recognizing the reality of drug use, harm reduction programmes measure success in terms of individual and community quality of life and health, and not in relation to levels of drug use.

Harm reduction entails a prioritization of goals. Given the high individual and social costs associated with HIV/AIDS, measures to prevent the spread of HIV are at the forefront of harm reduction priorities.

Harm reduction uses a range of services to achieve its goals. Needle exchange is one of the most effective interventions to reduce drug-related harm. It is often complemented by other supportive services for drug users such as replacement therapy treatment, health and drug education, HIV and sexually transmitted infection (STI) screening, psychological counselling, and medical provision and services.

Minimizing HIV/AIDS infection rates among IDUs: An Australian response
While the programmes have been funded by the Government, the involvement of civil society should not be underestimated. Drug user groups have been involved in the promotion of these programmes. In the face of political or community opposition to their implementation, the drug user groups have played an important advocacy role in ensuring the continuity of the NSPs. Their public education activities have also contributed to combating stigma and discrimination against drug users as well as increasing the success of harm reduction programmes that reduce HIV infection among drug users.

**Achievements and challenges**

The major goal of the Australian Federation of AIDS Organisations (AFAO), the leading non-governmental body representing the community-based response to HIV/AIDS in the country, is to continue and expand the harm

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**Annie’s story**

“As an Australian drug user who has been injecting drugs for 20 years, I am well positioned to see the differences between when I began and now. In the seventies when I first started injecting drugs, one learnt everything from friends: this included information about how to inject and where to get equipment. Where did we get needles? Anywhere we could… we re-used old equipment, sharpened needles on matchboxes and sometimes, if we had money, bought needles and barrels from chemists. We usually had to tell a story about needing them for tattooing or artwork and ended up with huge “horse” needles, which destroyed our veins. We had no knowledge of the dangers of sharing needles or equipment, even though we used common sense about being as clean as possible.

When the needle and syringe programme started in Australia in the late 1980s, things started changing. We were able to take our used equipment back to a pharmacy in exchange for new equipment and we didn’t feel that we had to lie about what they were for. Needle exchange programmes started up and we could get clean equipment and also obtain information about safer ways of injecting. Although some users were a little wary at first, most were slowly won over when they realized that the needle exchange workers were in most cases non-judgmental and could also usually answer their queries about injecting and other aspects of drug use.

The needle and syringe programme has now become a regular part of my life and the lives of most of my drug using friends. I visit my local needle and syringe programme most days and the workers know what I need without me even having to ask. They are very well informed about safer using issues and are very helpful when I do want information.

I have no doubt that without needle and syringe programmes I would probably still be sharing equipment, and that the only reason I have avoided Hepatitis C and HIV is because of this programme.”

Annie Reed
reduction programmes where there is a need. Don Baxter, AFAO’s Executive Director considers this an increasingly complex task since the environment for NSP outlets and drug user organizations to operate effectively has become more difficult. Over recent years both the national government and some provincial governments have placed added policy emphasis on ‘drug prevention’, including additional funding, he notes.

“While commitment to harm reduction principles continues to be official government policy, some local law enforcement authorities have used this different emphasis to close or threaten to close NSPs, or to threaten closure of other agencies that participate in harm reduction practices, such as disposal bins in brothels”, Baxter reports.

From a public health perspective, however, this environment undermines government policy and needs to be constantly monitored – and challenged where appropriate. According to UNAIDS, evidence from high- and low-income countries shows that effective HIV/AIDS prevention and care programmes for IDUs tend to be most successful when laws and police practices facilitate outreach work and service provision to injecting drug users.8 Many workers in the Australian NSP sector agree that the key to providing effective harm reduction services for injecting drug users is the capacity to deal with drug use compassionately and work with users non-judgementally. Understanding the philosophy of harm reduction, the rationale for NSP, and drug use are thus key components in NSP training curricula.9

A highly innovative and cost-efficient component of NSPs is their integration into existing public health structures. Most NSP outlets operate without additional sources of funding since the needs of clients fall under existing service programmes. The Government therefore only needs to provide funds for the additional health education materials and medical provisions. Australia’s response to HIV has benefited from an extensive, multi-faceted and highly innovative series of needle and syringe programmes. Analyses such as the one cited earlier (see box, page 64) prove their economic effectiveness and their role in health promotion. Furthermore, studies have disproved the myth that needle-exchange leads to higher rates of illegal drug use or injecting.


7 Story provided by New South Wales Users and AIDS Association (NUAA), Sydney, Australia.


Part II
COMMUNITY RESPONSES TO CARE AND SUPPORT
Out of the dark: PLWHA unite in China
(Mangrove Support Group, China)

With 1.2 billion people, China is the most populous country in the world. With such a significant population base, even a limited HIV epidemic in China would translate into millions of infections. The first AIDS case in China was reported in 1985. Since 1994, the national figures for HIV infection have been rising rapidly, due in large part to increased levels of high-risk behaviours, such as injecting drug use and sex work, as well as through unsafe blood collection methods. Government of China figures for end-2002 estimated that there were over 1 million people living with HIV/AIDS in China. Furthermore, over 100,000 people each year are expected to become symptomatic over the next few years. These numbers illustrate how a low national HIV prevalence rate, such as China's 0.1 per cent, can hide the grave magnitude of HIV/AIDS in a country. By the year 2010, it is estimated that more than 10 million people could become HIV-positive, if drastic actions are not taken in the immediate future.

Mangrove Support Group is a unique organization of HIV-positive individuals working to facilitate the formation of mutual support groups of people living with HIV/AIDS (PLWHA) and people affected by HIV/AIDS. Mangrove is dedicated to improving the well-being and quality of life of PLWHA through fighting discrimination and ignorance surrounding HIV/AIDS, establishing and strengthening networks to promote communication and exchanges among PLWHA, and acting as a resource for related groups. Mangrove aims to empower PLWHA with the means to support themselves and to promote PLWHA’s rights, especially within their local communities.

The twin barriers: Stigma and discrimination

People living with, or affected by, HIV/AIDS face stigma and discrimination on a daily basis. Stigma and discrimination *hamper prevention and care efforts by perpetuating silence and denial about HIV/AIDS, as well as reinforcing the marginalization of PLWHA and those who are particularly vulnerable to HIV infection.* Through prejudice and stigma, many PLWHA are marginalized and excluded from society. People with, or suspected of having HIV, may be turned away from health care services, denied housing, or dismissed from their jobs. They are often rejected by people they love, their family and their communities. Stigma can also be internalized by PLWHA, which has a powerful psychological impact on how HIV-positive individuals view themselves. In many cases, this leads to depression, lack of self-worth and despair.

Living with HIV/AIDS in China

Fear, discrimination and locally restrictive practices and punitive regulations could fuel the
HIV/AIDS problem by creating an environment in which people cannot talk openly about HIV and are reluctant to obtain voluntary counseling and testing (VCT) if and when it might be available in their communities.7

In recent years, the Government of China has taken significant steps to raise levels of awareness, including among young people. The Government has also acted to review and update its relevant national policies, laws and regulations to face the challenge of HIV/AIDS. Despite such efforts, the actual severity of HIV/AIDS in China has not yet been realized. Changes are slow to be acted on at the provincial and local levels. In the meantime, an increasing number of PLWHA have limited access to urgently needed information and services, ranging from non-discriminatory psychological and social support to effective medical treatment and home-based care.9

In 1999, the Ministry of Health of the Government of China issued a policy regarding PLWHA, which called for the “maintenance of confidentiality and the guarantee of individual legal rights,”10 and stressed the right of PLWHA to work, attend school, and obtain medical treatment. However, putting these principles into practice at the provincial and local levels remains a challenge. In fact, “several provincial and local laws and regulations are contradictory to the national guidelines,”11 incorporating such elements as mandatory testing and reporting, and prohibition of marriage for HIV-positive individuals.

**Overcoming stigma and discrimination through the greater involvement of people living with, or affected by, HIV/AIDS (GIPA)**

Stigma is created based on existing social inequalities and prejudices. It can cause discrimination, leading people or institutions to “take, or omit to take, action that results in unfair and unjust treatment based on a person’s presumed or actual HIV/AIDS status.”12 Stigma and discrimination “increase people’s vulnerability and, by isolating people and depriving them of care and support, worsen the impact of infection. Indeed, they impede every step to an effective response.”13

Individuals who engage in activities that are illegal or considered immoral are especially susceptible to discrimination. These can include men who have sex with men, sex workers, and injecting drug users.14

An effective HIV/AIDS strategy is one that is based on principles of non-discrimination, equality, and participation. The most relevant human rights principles for protecting the dignity of people living with, and affected by, HIV/AIDS include: non-discrimination, the right to health; the right to equality between men and women; the rights of children; the right to privacy; the right to education and information; the right to work; the right to marry and found a family; the right to social security, assistance and welfare; the right to liberty; and the right to freedom of movement.15

One important way to combat stigma and discrimination is the active involvement of PLWHA in the responses to the epidemic. The involvement of people living with, or affected by, HIV/AIDS at all levels of programming, from the decision-making process to the provision of home-based care, is in itself empowering for the individuals. It also recognizes the important contribution they can make to ensure a holistic response that meets their needs effectively. Furthermore, GIPA is a powerful way of reducing discrimination and fear within society, by giving a human face and voice to the epidemic in the minds of people not directly touched by it.16

Out of the dark: PLWHA unite in China
Taking action: HIV-positive people step up to meet the needs of PLWHA

“Only when you live under the shadow of death, do you fully understand the value of life.”
Xiao Zhou, Mangrove Support Group

Given the challenging circumstances facing PLWHA in China, the Mangrove Support Group is a distinctive organization of HIV-positive individuals that is pioneering the promotion of the rights and well-being of PLWHA. Led by Mr. Adam Li, one of the few outspoken HIV-positive individuals in China, Mangrove not only helps PLWHA access more services, but it also practises the principle of the greater involvement of people living with, or affected by, HIV/AIDS (GIPA), by recognizing that PLWHA are key players in the development and implementation of programmes that directly affect them. In fact, Mangrove provided key input to the drafting of China’s first GIPA Strategic Workplan for 2003-2004.

Mangrove was established in March 2002, with the support of the Ford Foundation. It has since forged partnerships with such organizations as Marie Stopes China, UNAIDS, a private consulting company APCO, and the Ministry of Health, Government of China. It has received United Nations recognition, and was commended by Dr. Peter Piot, Executive Director of UNAIDS, and Mr. Kofi Annan, United Nations Secretary-General, on their visit to Mangrove. Mr. Li and three other young HIV-positive staff members work out of Mangrove’s Beijing office, which is located on the premises of a hospital with an AIDS treatment centre. While Mangrove has yet to be formally registered as an NGO, it has the support of the Government and aims to complement the Government’s work to combat HIV/AIDS in China.

The quilt is made up of mangrove trees bearing dozens of hearts crafted by nearly 30 HIV-positive individuals from all around China, attending a Mangrove workshop in June 2002. The hearts represent the participants’ hopes and dreams.

The mangrove plant is full of vitality with the natural ability to both survive and flourish under harsh conditions. This spirit of determination and strength that distinguishes the plant is also shared by the Mangrove Support Group.
The power of many: Formation of support groups

Mangrove’s pioneering activity is to encourage PLWHA to form self-support groups, which are still at a nascent stage in China. To encourage individuals to start such groups, Mangrove hosted three capacity-building workshops for PLWHA in 2002. HIV-positive individuals from diverse regions of China were brought together to discuss GIPA principles and brainstorm ways in which they could begin activities together with other PLWHA in their respective communities. These workshops resulted in the development of four projects, in Guangdong, Sichuan, Henan and Xinjiang provinces. These four provincial projects address two areas of immediate concern for PLWHA – the need for psychosocial support, and the need for education on healthy living with HIV/AIDS.

The projects are being implemented and managed by four HIV-positive individuals. Each individual has expressed a strong interest in conducting local support activities and has the potential to do so with the limited technical and financial support that Mangrove can provide. Collaboration with Mangrove has given these individuals the confidence and the tools to bring together PLWHA in their communities. At the same time, the leaders of Mangrove and its affiliate groups are highly sensitive to the importance of providing a “safe space” for PLWHA. Individuals taking part in support groups may choose to remain anonymous and the confidentiality of those involved is strictly maintained.

Mangrove and other government and non-governmental partners provide technical support for the projects, such as how to conduct needs assessments among PLWHA. While the project managers are paid small stipends, Mangrove and affiliate groups mostly rely on unpaid volunteers.

Responding to PLWHA needs

The Mangrove-affiliated groups respond to the immediate needs of PLWHA community members, as determined through needs assessments conducted in the target communities.

One of the main needs that all four projects address is the gap in essential information about living with HIV. In Xinjiang, for example, 85 per cent of the reported 4,436 HIV diagnoses in this remote autonomous region of China, are among the Uighur ethnic group. In the latest figures available as of September 2000, some estimate that actual numbers of people living with HIV in this region could be as high as 15,000 to 25,000. However, there are as of yet no materials available in the Uighur language. Information materials are thus being translated into Uighur and distributed through this project. In Henan, it is estimated that as many as 80 per cent of some villages include people living with HIV. Since access to materials on HIV/AIDS is severely limited, health education booklets are being developed on home-based care and will be disseminated to villagers through home care visits.

Psychological support is another major need for people living with HIV who face social rejection and discrimination, which often lead to feelings of despair and worthlessness. In Sichuan, the project manager makes home visits to approximately 20 HIV/AIDS-affected households. The project manager also arranges informal support gatherings for the households during which they can share experiences and information, thus easing the psychological burden associated with HIV/AIDS. In Guangdong, eight HIV-positive former drug users have established a halfway home where they provide each other with care and support. They also conduct outreach work to other PLWHA in the local community. Mangrove itself visits in-patients.

Out of the dark: PLWHA unite in China
Empowering PLWHA

Capacity building is a central aim of Mangrove. At these early stages of both Mangrove and its affiliates, much of the capacity building takes place through learning by doing, with a significant amount of technical support provided by Marie Stopes China and other partners. Some of the affiliates have already replicated activities, based on the capacity of its members. For example, the residents of the halfway home in Guangdong are starting new groups upon return to their hometowns.

Making HIV/AIDS visible

The other leg of Mangrove’s activities is its advocacy work, which aims to combat prejudice and stigma against PLWHA by improving public knowledge about HIV and by giving HIV/AIDS a human face. Targeting all Chinese people, the Mangrove Support Group is currently preparing to publish a book entitled “My Story”, featuring, in a positive manner, 10 to 15 individuals living with HIV/AIDS. There will also be a documentary film version of the book and an exhibition.

Mangrove is also involved in the content development and distribution of the quarterly magazine, “Hand in Hand”, which is produced by the United Kingdom Department for International Development (DFID) in China. The Chinese-language magazine provides information on HIV/AIDS and how to live a healthy life with HIV. It has a personal section for HIV-positive individuals to facilitate networking for support and information exchange. Several thousand copies are distributed through a network that includes the Centre for Disease Control, hospitals, and Mangrove.

Achievements and challenges

Mangrove recognizes that there are many important activities that need to be implemented to assist PLWHA in China. As Mangrove continues to grow, sustained support to its affiliate members will become essential, especially at the local level, to enable them to implement their projects effectively and independently. Mangrove itself is still very much an evolving entity. Both Mangrove and its affiliates are working to develop its financial and technical capacity, such as through training in project planning, management and implementation. Already, some of the new groups have begun to stand on their own. The halfway home in Guangdong has secured some funding from UNDP, as well as from public donations collected through their web site.

Staff recruitment is also a challenge, as many capable individuals are discouraged from participating in PLWHA activities out of the very real fear of losing their jobs and of
being ostracized by neighbours and families. By advocating for greater public understanding and openness towards PLWHA and by the development of a support group network, Mangrove hopes to foster an environment in which more PLWHA feel empowered to participate in the response to HIV/AIDS.

Mangrove also looks forward to working in greater collaboration with the Government, given the Government's key role in leading the response to HIV/AIDS. In particular, the cooperation and understanding of local-level officials is crucial, and this remains a central challenge for Mangrove's work.

The road to GIPA is long and the challenges facing PLWHA groups, such as Mangrove and its affiliates, vast. Given the sheer size of the country, PLWHA needs inevitably differ from location to location and group to group. Community-based PLWHA groups could be an effective way to begin to address those wide-ranging needs. Mangrove cannot help all of the PLWHA in China. Nonetheless, it has taken a major step in mobilizing PLWHA as central partners in the response to HIV/AIDS, by providing motivated individuals living with HIV the technical, financial and psychological support for action. In so doing, Mangrove facilitates PLWHA in taking some of the first steps that meet their emotional and physical health needs, and makes a positive impact on the lives of PLWHA.

9 Home-based care refers to medical and social services provided in the client's home. Such services may include medical treatment, physical therapy, and assistance in housekeeping, shopping and food preparation.
13 UNAIDS (2002).
14 UNAIDS (2002).
15 UNAIDS (2002).
17 Report of Strategic Planning Meeting for Taking forward the Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA) in China (2002, November 7-8). Beijing: Marie Stopes China.
18 The drafting of the GIPA Strategic Workplan for 2003-2004 was supported by Marie Stopes China, China AIDS Association, Australian Red Cross, UNAIDS, Save the Children, the United...
Kingdom Department of International Development (DFID), the Australian Agency for International Development (AusAID), Médecins Sans Frontières, and Asia-Pacific Network of People Living with HIV/AIDS.


*Report of Strategic Planning Meeting for Taking forward the Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA) in China* (2002, 7-8 November).
HIV/AIDS status and trends in Malaysia

In Malaysia, in 2001, there were an estimated 42,000 adults and children living with HIV/AIDS. Most of the people living with AIDS (65.9 per cent) and HIV-positive persons (81.5 per cent) were males. The epidemic in Malaysia is still concentrated among injecting drug users (IDUs). In 2000, injecting drug users accounted for the majority of reported people living with AIDS (63.9 per cent) and HIV-positive persons (74.7 per cent). Indeed, HIV prevalence among injecting drug users has, over the past decade or so, risen dramatically – the average percentage of IDUs who tested HIV-positive at screening sites was 0.1 per cent in 1988, 17.6 per cent in 1997 and 24.9 per cent in 2000. Evidence also shows that the HIV prevalence rate among female sex workers in Kuala Lumpur is increasing. In some urban areas of the country, this rate has begun to exceed 5 per cent.

Worldwide, it has been found that HIV spreads from the IDU population to a wider population through unprotected sexual contact. Injecting drug use and sex work are linked – injecting drug users visit sex work-
ers, and sex workers may also inject drugs. Once HIV infection becomes well established within an injecting drug user community, IDUs act as a “bridge” through which the virus crosses over into the wider population. \(^{10}\) Hints that the virus is beginning to spread to a wider population can be discerned in the rising HIV prevalence rates among people with sexually transmitted infections which, in some areas, have risen above 5 per cent. \(^{11}\)

**Under one umbrella: Birth of the Malaysian AIDS Council**

Grasping early on the need for a coordinated effort to avert an epidemic, in 1992, the Ministry of Health brought all HIV/AIDS-related NGOs under one umbrella. Its purpose was to use limited resources more effectively and to maximize the impact of NGO efforts to combat HIV/AIDS. Thus, the Malaysian AIDS Council was born.

Starting with only two employees, MAC has since expanded to over 20 staff members. A ten-person Executive Committee administers the Council, composed of elected representatives from affiliated organizations. \(^{12}\) In 1992, there were 18 NGOs affiliated with MAC. Today, there are 37.

**Reaching all walks of life**

MAC’s goal is to create an environment in which all Malaysians can live free from the negative impact of HIV/AIDS. It aims to accomplish this through, and with, its affiliates, by mobilizing, strengthening and representing them.

People living with HIV/AIDS (PLWHA) and people affected by HIV/AIDS play a key role in MAC. MAC actively promotes PLWHA involvement in all sectors – social and cultural, economic and political. Many MAC affiliates are PLWHA networks or are staffed by PLWHA. HIV-positive individuals participate in the decision-making processes of their respective organizations, with MAC often taking the lead in planning and implementing programmes, and in mobilization and advocacy.

MAC affiliates undertake activities in many areas, including prevention education, peer outreach, public awareness, training workshops, hotlines, support and care services, and hospices. They work in diverse communities, targeting, among others, women, young people, PLWHA, injecting drug users, sex workers, mobile populations, men who have sex with men, medical personnel, religious communities, and the media. Recognizing that coordinated efforts make for more effective interventions, MAC aims to streamline the work of its 37 affiliates by ensuring that there is no overlap in their scope of work.
and that their target groups cut across all boards of society. The Programme Unit of MAC, with the Programme Manager as a liaison officer between the affiliates and MAC, is primarily responsible for managing, as well as monitoring, the various programmes undertaken by the affiliates.

MAC also provides affiliates with training materials, as well as financial and human resource support. In this way, MAC helps guarantee that programmes do not duplicate efforts. It also ensures wiser use of resources.

Influencing policy

A prerequisite for HIV/AIDS prevention, care and support is high-level political commitment. Such commitment, translated into action, is essential for the development and implementation of effective national responses to the epidemic.13

One of MAC’s main accomplishments is its role as a key player in the policy arena. Indeed, MAC is a main contributor to Government policy on HIV/AIDS. Through quarterly council meetings with its affiliates, MAC coordinates and channels the organizations’ opinions, develops common positions and advocates these stands during regular meetings and dialogue sessions held with the various relevant ministries and Government bodies. MAC has a seat in the National Coordinating Committee on AIDS and holds an annual dialogue with the Ministry of Health and the Ministry of National Unity and Social Development.

MAC’s Subcommittee on Law, Ethics and Human Rights reviews laws in Malaysia, to assess their potential impact on managing the HIV/AIDS epidemic. Through these efforts, the ground-breaking Malaysian AIDS Charter was issued in 1995, underscoring the rights and responsibilities of multisectoral segments of Malaysian society in relation to HIV/AIDS.15 The Charter, which has private sector support, focuses on the rights and responsibilities of individuals, including PLWHA, and health-care workers, as well as rights and responsibilities in relation to employment, education, prisons and detention centres. The Charter also provided the backdrop for the Department of Occupational Safety and Health to develop the Code of Practice for the prevention and management of HIV/AIDS in the workplace.

Listening to hidden voices

Stigma and discrimination keep many PLWHA from participating in society. HIV-positive individuals may internalize society's negative perceptions of PLWHA and isolate themselves from society. In an unenlightened milieu, the psychological suffering that PLWHA experience can be as painful as the physical effects of HIV/AIDS. In addition to its unique role in placing HIV/AIDS on the policy agenda in Malaysia, MAC advocates for greater support and understanding of

“Growing political engagement in the response to HIV/AIDS is grounded in two decades of AIDS activism, led by individuals and communities…”

UNAIDS14

“Try to imagine how you would feel if you suddenly found out you have HIV. Treat others with HIV just as you would like to be treated. Anyone with HIV or AIDS needs love, compassion, help, care, support, treatment and preventive services just like any other person who is sick or likely to become sick. No one deserves to get HIV and no one deserves to be treated poorly just because he or she has it.”16

Turning promises into policy and action:
Malaysia’s diverse communities come together to combat HIV/AIDS
PLWHA. It provides an avenue for self-advocacy and self-articulation by PLWHA so their voices may be heard, thereby working towards a more participatory and more effective response to HIV/AIDS.

In its brochure, “We care, do you?”, MAC provides information on the causes of stigma and discrimination, an overview of such practices in Malaysia, and how to help HIV-positive people.

Recognizing the importance of listening to the voices of PLWHA, MAC published in 1999 Hidden Voices, a collection of stories by HIV-positive Malaysians. The publication aimed to provide space for PLWHA, as well as people affected by HIV/AIDS, to “speak out” directly to other Malaysians, without having to give up their anonymity. As MAC President, Marina Mahathir, stated:

“We are in a chicken-and-egg dilemma: to prevent an increase in HIV/AIDS cases, we have to deepen our awareness of HIV/AIDS to include the realities of the lives of PLWHA. But, at the same time, we have to bridge the chasm of silence between PLWHA and the rest of society when so many PLWHA are wary of disclosing their status.”

Jane’s story (excerpted from Hidden Voices)

My name is Jane and I am 41 years old. I became infected with HIV through my husband who had sex with a prostitute. We were married for 20 years, and have two children – a 14-year-old daughter and a son, 11 years old. Our happiness suddenly changed when my husband was diagnosed as HIV-positive. Our private doctor didn't want to treat him and was so stern with me. I became very depressed and had to sacrifice my work and stay at home with my husband for 12 days. During the last two days, he developed a high fever and experienced difficulty in breathing. I had him admitted into the hospital. My children and I could not control our tears and hugged him until his last breath. There was a lot of stigma and discrimination at the hospital from the doctors and nurses, and I felt ashamed at being followed by the health official to the cremation.

I was then instructed by the doctor to have a blood test. On being confirmed HIV-positive, I felt so depressed and scared that I resigned from my job as a nursery teacher. I isolated myself. I dared not go out. I separated my things from my children’s, and for two years of my life I felt like a failure. My supportive family had to bear the pain, including my children. I was in a state of mental breakdown and my mother insisted I see a psychiatrist. After that, I was on anti-depression pills and tranquilizers. For two years, life was terrible and I thought of suicide.

Luckily, one day I decided to move from my home to Rumah Penyayang, a halfway home for women and children. I stayed there for three months and became involved in charity work. We observed Islam as a concept in our approach to counselling, discipline, vocational training and other activities. I am indeed grateful and thankful to Hawa, the Director of Rumah Soleha, another halfway home, for all her love, concern and support in helping me regain my confidence in life. She encouraged me to expose myself to the outside world and be a good role model as a mother. I learnt a lot from her counselling and moved back home. My family was so happy to see some change in me.

The programme has benefited me. I now feel that I have to go on living and accept HIV. I hope to recapture those two lost years of my life. Till today, the memory of my husband still lives with me and will remain forever in my heart. To those who have been faithful wives like me, take a lesson from my journey of pain – HIV stalks around every corner.
Hidden Voices brings out the distinct multicoloured strands that make up the impact of HIV/AIDS on the lives of real people. As MAC itself represents a diverse community of affiliate organizations, so too does Hidden Voices reflect a wide range of voices – truly representing Malaysia’s rich ethnic, cultural and religious diversity.

Achievements and challenges

MAC takes a holistic approach to addressing HIV/AIDS in Malaysia. It looks at HIV/AIDS from all perspectives. In discharging its coordinating role, it ensures the use of available resources for maximum impact. MAC’s diverse affiliates work with a wide spectrum of groups in Malaysia, touching the lives of people from all walks of life, at all social and economic levels of society.

MAC’s work is built on a solid foundation of partnership with its affiliate NGOs, PLWHA networks, and Government. MAC uses a custom-made approach with each group, to engage them. Fostering partnership with such heterogeneous entities is an essential modality for effective prevention and a distinct MAC accomplishment.

Most notably, MAC has institutionalized its relationship with the Government to provide a channel for NGOs and PLWHA networks to help shape HIV/AIDS-related Government policies. This is an important link through which MAC can ensure that its advocacy efforts are translated into concrete Government policy and programme documents, including the landmark Malaysian AIDS Charter.

Empowerment and involvement of PLWHA is important. Having a face to associate with the concept of HIV/AIDS can help overcome fear and prejudice among people who conjure up phantom images of a deadly virus or a terrible disease, whenever HIV/AIDS is mentioned.

The heightened visibility of PLWHA serves not only to decrease stigmatization, but also to help foster an environment in which HIV-positive individuals are able to contribute to solutions in the search for a more effective response to HIV/AIDS. Thus, they would be able to provide care and support, as well as to seek help when they need it, without having to fear, or deal with, the negative fall out of disclosing their sero-status.

By giving a human face to the epidemic, courageous voices, such as those of Jane and many others, help chip away at the wall of stigma and discrimination. MAC is a pioneer in bringing into the public domain the hidden voices of PLWHA in Malaysia. MAC is unique in its capability to make heard, at the policy level of Government, PLWHA perspectives, for a more effective response to HIV/AIDS.

At all levels of society, from the individual to the community, and the national levels, MAC is working towards the creation of an Asian society that is free of stigma and discrimination towards people living with HIV/AIDS.

3 UNAIDS (2002a).


8 UNAIDS (2002c).


11 UNAIDS (2002c).


14 UNAIDS (2002b), p. 11.

15 Malaysian AIDS Council / Malaysian AIDS Foundation (n.d.).

16 Excerpted from the Malaysian AIDS Council brochure titled “We care, do you?”


VILLAGE RESPONSES

Photo: Raks Thai Foundation
There’s no place like home: Providing home support visits to Cambodian PLWHA
(Khmer HIV/AIDS NGO Alliance and Khmer Buddhist Association, Cambodia)

Cambodia currently has the highest HIV prevalence rate in Asia. Cambodia has an estimated 200,000 HIV positive people.1 It also has 60,000 children who are affected by HIV/AIDS – the highest number in all of Asia.2 The main mode of transmission is heterosexual sex. Poverty, labour migration, and the low status of women are all factors that contribute to the spread of HIV.

Cambodia also has one of the lowest rates of health utilization in the world. Emerging from three decades of conflict, the amount of care and medicine that can be provided by the health system is severely limited. Many people remain without access to basic health services. For many Cambodians, living with HIV/AIDS leads to their destitution as they struggle to survive and pay for medical and funeral costs. They also suffer from stigma, discrimination and the loss of livelihood.

The Khmer HIV/AIDS NGO Alliance (KHANA), is a local Cambodian non-governmental organization (NGO) whose mission is to contribute to a reduction in vulnerability to HIV and other sexually transmitted infections (STIs), and to mitigate the impact of AIDS by strengthening the capacity of NGOs and community-based organizations (CBOs) to develop appropriate, effective and sustainable responses to HIV/AIDS and STIs. It currently provides leadership, and financial and technical support to over 40 NGOs in 15 Cambodian provinces and two municipalities working on HIV/AIDS care and prevention activities. It is also the linking organization of the International HIV/AIDS Alliance, which supports communities in developing countries to play a full and effective role in the global response to HIV/AIDS.

The Khmer Buddhist Association (KBA) is one of KHANA’s community-based partners working to integrate care and support activities into HIV/AIDS prevention projects. The following story shares how home support visits are having a positive impact on the lives of people living with HIV/AIDS (PLWHA), their families and their communities.
Bringing care and support back home

The impact of HIV/AIDS is pervasive – affecting not only people living with HIV/AIDS but their families, caretakers, and the community.

The majority of Cambodians live in rural areas, where their main source of sustenance is farming. A lack of awareness, as well as stigma and discrimination, destroy opportunities for people living with HIV/AIDS to sustain themselves and their families. People often refuse to give them work or purchase goods from them or their family members. In some cases, families are reported to have sold everything – their livestock, land, and homes, leaving surviving family members destitute.

Home support visits developed by KHANA and some of its partner community-based organizations were designed to address the pressing needs of HIV-positive people. The basis of the programme is to provide home-based care and support for PLWHA, care and support for children affected by HIV/AIDS to sustain themselves and their families. The activities are funded by the International AIDS Alliance and the World Bank with future support from The Global Fund to Fight AIDS, Tuberculosis and Malaria.

Home support visits include some or all of the following:

- **Direct services** for PLWHA, including provision of basic information about nutrition, assistance in basic care such as washing, and small material support for items such as food or soap;
- **Services for families**, such as provision of basic information about caring for PLWHA, including basic hygiene;
- **Community advocacy**, including mobilizing community members such as village leaders and volunteers to be involved with visits to PLWHA, and encouraging all community members to get involved in the care and support of PLWHA in some way;
- **Community education**, including provision of information and education materials about HIV/AIDS, such as transmission modes and prevention. This includes community education for neighbours and family members of PLWHA;
- **Emotional support services** for PLWHA, families, and caretakers. Components include providing advice, counselling, encouragement and ideas;
- **Facilitating medical services**, including access to medical services and HIV testing. Some CBOs may also assist with access to medicine by collecting prescriptions on behalf of the patient.

Home support visits are established in a variety of ways. For instance, local NGOs may seek out clients and/or are informed about potential clients by people in the community. Village leaders, community assistants, participants in discussion groups, health workers, clients, or other people involved in the project may suggest a referral. KHANA stresses that home support visits are for chronically ill people, who include not only people living with HIV/AIDS, but also others such as older persons in poor health. This approach is considered key in avoiding stigma, and facilitates the client’s ability to disclose as much or as little information about their illness as each wishes. When an NGO becomes aware of an HIV-positive person in the villages where it works, the staff visit the person. The following excerpt highlights the commitment of community organizations in the provision of care and support to PLWHA.

**There's no place like home: Providing home support visits to Cambodian PLWHA**
Trust is the key

Gaining the trust of clients is key to the programme’s success. It often takes time to establish a relationship and determine whether or not other support visits are accepted and needed. In a 2001 report that discussed home support visits, KHANA shared the story of one of its local NGO partners who wished to help a man who was believed to be HIV positive. Local people and the community-based organizations were initially cautious because he was a military commander. A staff member from the NGO established a relationship with the commander’s wife – by asking to buy mangoes from their garden. After several visits, a relationship was established and the wife was able to discuss her husband’s illness. Eventually, the NGO staff members also spoke with the commander. The relationship positively moved forward and the couple was most appreciative of the support that the CBO provided.6

What is care and support?

Care and support mean offering medical help, psychosocial support, practical advice and general kindness to people in need. It means listening to their feelings and responding to their needs as much as possible. With HIV/AIDS, this includes family members, particularly children, as well as caretakers such as elderly parents.

The most appropriate place for care and support is in the home, but other places such as the pagoda, health centre, school and other community organizations are also important.

The aim of care and support is to improve the quality of life of PLWHA, their families and the communities. It cannot be separated from prevention.5

A main motivating factor for home support visits is the positive impact that it is having on the lives of PLWHA. Organizations like the community-based organization, Khmer Buddhist Association (KBA) report that PLWHA and their families are appreciative of the visits they make, and look forward to them. The visits counter negative attitudes many PLWHA experience by other people in their communities, including family members. The visits also remove their isolation. Just knowing that someone cares about them has provided positive encouragement and reduced feelings of hopelessness and depression, which are linked to a hastened death.8

In addition, reducing the isolation of PLWHA through home support visits has, by example, made local people more aware of the

Stigma, discrimination and HIV/AIDS

Stigma is based on a person’s perception and attitude. With HIV/AIDS this is often based on fear and inaccurate information.

Discrimination is what happens when someone acts unfairly towards another, based upon stigma.

Self-stigma is common among people living with HIV/AIDS, preventing PLWHA from seeking care and support.

Both stigma and discrimination are barriers to providing care and support. Conversely, care and support can reduce stigma and discrimination.7
needs of PLWHA and has made them feel and be more valued by others. KHANA's NGO partners mentioned in their project reviews that their organizations have seen the number of visits from other community members increase and they have seen a decrease in myths, stigma and discrimination towards PLWHA. For example, since home support visits provide education about how HIV is not transmitted, community members are learning that they cannot get HIV/AIDS by touching someone who is HIV positive.

The story of Heoung and her family

Along the Thai/Cambodian border in the northern part of Cambodia is Thmar Puok in the Banteay Meanchey Province.

KBA began prevention programme activities in 1997 working with sex workers, brothel owners, uniformed personnel and out-of-school youth. But, prevention could not help those already infected, and as the numbers of people living with HIV/AIDS kept increasing, so too did the need to do something. In 1999, KBA expanded its activities to include care and support for PLWHA and orphans and children affected by HIV/AIDS. At present, KBA provides care and support to 35 people living with HIV/AIDS and 133 children affected by HIV/AIDS in Thmar Puok.

KBA is helping people living with HIV/AIDS, like Hoeung, a 45-year-old widow. Hoeung’s husband died of AIDS four years ago, leaving her to take care of their four children, whose ages range from 3 to 14 years. Although she is very ill, Hoeung must support her family. Until recently, Hoeung would go out everyday with her eldest son to harvest vegetables. While they were out in the field, her 9-year-old son would care for his two younger siblings, feeding them and bathing them. School was not possible. Someone else in the village was hired to sell the vegetables in the market for fear that if the villagers knew she was HIV-positive, they would not want to buy her produce.

At times, Hoeung would cross the border into Thailand for work her children in tow – since there was no one else to take care of them. The family would sleep in the forest at night and wake up early in the morning so that Hoeung and her two eldest children could work. As illegal workers, they lived in fear of being caught. When they were caught, the Thai authorities returned them to Cambodia.

Hoeung earned 15 to 30 baht a day (US 35 to US 71 cents) from selling vegetables and 30 to 60 baht (US 71 cents to US$ 1.42) when working in Thailand. The money never lasted long and would need to go towards medicines for herself and for her children. Some days there was not enough money. Not even to buy rice.
KBA began to work with Hoeung and her family in 2002. This assistance has made a huge difference in their lives. The home support visits helped identify her most critical need – to provide for her family. KBA helped Hoeung to buy a small plot of land and to build a small house for which KBA contributed 300 baht (US$ 7.14) and Hoeung paid 400 baht (US$ 9.52). Providing support has helped release the younger children from some of the burden of care, and the two eldest children have been able to return to school with the provision of school supplies, one set of clothes and a monthly allowance of rice. Hoeung is also able to get treatment for her opportunistic infections and was given advice on how to improve her health and well-being with good nutrition and hygiene.

Hoeung no longer needs to go to Thailand to try and find work. She has more time to take care of herself and her children, and to help her youngest child, who is also HIV-positive, receive treatment at the local health centre. KBA has also helped Hoeung plan ahead for the future. In the time that KBA has been helping Hoeung, her condition has deteriorated and the issue of long-term care for her children has been a concern. Now, with KBA’s assistance, Hoeung’s 18-year-old daughter has returned home to help care for the family.

As a result of KBA’s work, the local community is also learning more about HIV/AIDS and is more supportive to Hoeung and her family, giving them food and visiting them more frequently.

### Achievements and challenges

Perhaps one of the most vital accomplishments of the programme is that home support visits have been instrumental in reducing discrimination against PLWHA in their communities. Anecdotal information shows that home visits have increased understanding of HIV/AIDS by helping to forge links between care and prevention, and reducing stigma and discrimination against PLWHA in the community. Community leaders report that the home-care programmes have had an impact on community attitudes towards PLWHA, have reduced discrimination, anger and fear, and have increased support, understanding and sympathy towards PLWHA. By providing social and economic support, KHANA is also helping to empower some of the poorest and most vulnerable individuals and families in the community. KHANA NGO partners have provided direct care and support services to 2,676 PLWHA during 2002 and supported 2,004 orphans and vulnerable children. Many of these children were supported to return to school and continue their education.

Thirty-four of KHANA’s partner NGOs have initiated home support visits. This includes 17 who are providing specific home-based care and 17 who are integrating prevention and care and support activities into their work. All programmes are in response to the needs of people living with and/or affected by HIV/AIDS. KHANA expects to continue to develop these strategies in partnership with the communities where they work. In addition, KHANA is working jointly with the National Center for HIV/AIDS, Dermatology and STD (NCHADS) to increase community home care programmes, especially in rural areas. Khana’s partner NGOs are also working with other organizations such as the National Tuberculosis Centre to ensure stronger part-
nerships, since tuberculosis is an opportunistic infection that greatly affects persons living with HIV/AIDS.

Further, KHANA is advocating for antiretroviral drugs (ARVs) to be made more widely available since only a few HIV-positive Cambodians have access to medication and treatment. Recently, the organization conducted an appraisal to advance a multisectoral response that would increase the availability of ARVs to a larger number of Cambodians.

Factors such as the deepening of poverty and the sale of assets such as land or animals to meet the costs of medical care are major challenges that PLWHA and their families face. These problems are further exacerbated when children are orphaned. KHANA and its local NGO partners are working to develop an increased range of strategies aimed at addressing the poverty spiral and supporting the economic development of families affected by HIV/AIDS and the broader community. They are also working to further involve PLWHA into the organization of KHANA programmes.

Despite the above-mentioned challenges, the home support visit programme in Cambodia demonstrates that it is having a significant impact on the lives of PLWHA. The programme is reducing the suffering and improving the quality of life for people living with HIV/AIDS. It is also improving the lives of their families and caregivers.

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5 KHANA (2002, July 22-26).
6 KHANA (2001).
7 KHANA (2002, July 22-26).
8 KHANA (2001).
Broken dreams, troubled lives: 
Supporting older people coping with HIV/AIDS in Thailand and Viet Nam
(HelpAge International, Thailand; and Viet Nam Women’s Union, Viet Nam)

The HIV/AIDS epidemic is sweeping across Asia with devastating effects, including a ravaging but under-reported impact on the lives of older people and on those who depend on them. Some older people are themselves HIV-positive, or vulnerable to infection (see box, page 93), but a far greater number are affected by HIV. This category includes those who must take care of their sick adult children, surviving grandchildren and other elderly partners and/or family members.

HIV/AIDS imposes care responsibilities on older people never before experienced by earlier generations. Instead of retirement and having their adult children look after them, older people are now economically, physically, and emotionally devastated, as HIV/AIDS rips apart their families and they find themselves with little or no external financial assistance, care or support to help them cope.1

HelpAge International is a global network of not-for-profit organizations with a mission to work with, and for, disadvantaged older people worldwide to achieve improvement in the quality of their lives. Like other development organizations, it increasingly mainstreams HIV/AIDS issues into its activities, such as educating older people on HIV prevention and providing them with much-needed information about caring for HIV-positive family members.

Older people are involved in the struggle against HIV/AIDS in two ways: through being at-risk themselves, or through their role as caregivers. Here we review how older people’s lives have been transformed through their role as carers.

The impact of HIV/AIDS on older persons

Traditionally, in many Asian communities, adult children support their parents in old age. HIV/AIDS, however, has denied many older persons the comforts of this privilege and practice. As HIV/AIDS penetrates communities, increasing numbers of older people are not only losing the support that they might otherwise expect to receive from their adult children, but they must also sustain an income, nurse the sick, and care for grandchildren – all at a high cost to their own livelihoods, health and well-being. Often, their children’s illnesses deplete the family’s money for medicines, treatments and funeral costs, leaving little or nothing to support themselves and their grandchildren.
With one of the highest infection rates in Asia, Thailand is home to many older people caring for sick relatives and their dependants. In 2001, 55,000 people died from HIV/AIDS-related illnesses in Thailand. In 2002, there were an estimated 670,000 people living with HIV/AIDS. Most HIV-positive people in Thailand are poor farmers and wage labourers. In Thailand, about 70 per cent of people living with HIV/AIDS (PLWHA) are cared for by parents or relatives. The vast majority of caregivers are 50 years or older. Many are in their sixties and seventies. Some of them are in need of care themselves. According to UNAIDS, 290,000 children under the age of 15 have been orphaned by HIV/AIDS in Thailand. A region particularly hit by the epidemic is the northern Thai province of Chiang Mai, where the Thai Red Cross estimates that over 4,000 grandparents are taking care of their orphaned grandchildren.

Parenting in old age

Grandma Di and Grandpa Oiy never thought it would be necessary to work in their old age. They fully expected their daughter and son-in-law to support them so that they could lead a quiet retired life, enjoying their time with their grandson.

When their daughter, Toy, and her husband Jeerakorn succumbed to AIDS in 1997, their lives changed forever. In his mid-sixties, Grandpa Oiy once again became the family’s sole breadwinner. He and Grandma Di took on the responsibility of caring for their young orphaned grandson. They had already spent the past several years taking care of their sick daughter and son-in-law. Now, it was time to raise their young grandson left behind in their care.

Older people’s vulnerability to HIV/AIDS: The forgotten population

Existing HIV/AIDS prevention and control programmes often sidestep older people, despite the risks they face in dealing with HIV/AIDS.

The dominant risk factor for older people is the same as for other age groups, i.e., unprotected heterosexual sex, which disputes general perceptions that older people are not sexually active. HIV infection rates among those over 50 are on the rise. In Thailand, about 5 per cent of HIV cases are among people over 50 years old. The disease is harder to diagnose and contain among older people, partly because early symptoms of HIV infection – fatigue, poor memory, shortness of breath, sleeplessness, weight loss – may be mistaken for signs of ageing. Health care workers often fall into the trap of age stereotypes, and are less likely to ask older people about their sexual behaviour. They do not provide the prevention information they would routinely offer younger people. Nor do prevention education programmes target older people.
“When Toy was sick I cared for her,” Grandma Di remembers, “I fed her and gave her medicine and tucked her into bed. My husband and I looked after her. There was no one else to help out at home. Now, I am my grandson’s mother.”

For grandparents Di and Oiy and thousands of other grandparents affected by HIV/AIDS, life must continue—with or without financial assistance. Whenever possible, youngsters are encouraged to remain in their homes and communities, but most of these children come from very poor homes with little or no outside assistance and support.

Grandma Di and Grandpa Oiy decided to use the loan to buy pigs, which can be sold for their meat. Grandpa Oiy explained, “The earnings we make from selling the pigs help us take care of our grandchild and support his education.”

Once their small pig-raising undertaking becomes self-sustaining, the grandparents will pay off the loan. However, the funds will remain in the community and be redistributed to other needy older people by a committee. The committee manages the revolving loans at the local level, and comprises community leaders as well as HIV/AIDS-affected older people.

“HelpAge International decided to be involved in this project because we could see how grandparents had been impacted by the HIV/AIDS pandemic,” explains Mr. Christopher Elderidge, HelpAge International’s Representative in Asia. “Most of these grandparents are very poor, and have neither the financial resources nor the physical strength to support their sick children and surviving grandchildren. We needed to provide them with a source of funding so that they can take care of their sick and strengthen their income-generation ability.”

HIV/AIDS programmes have been very effective in targeting middle-aged generations and youth, as well as people living with HIV/AIDS. But the elderly have been noticeably omitted from most HIV/AIDS programmes in Thailand,” comments Mr. Ben Svasti, Programme Coordinator of the Mother Child Concern Foundation. This local non-governmental organization recognizes the needs and responsibilities of Grandpa Oiy and Grandma Di, and other HIV/AIDS-affected older people in Sanpatong District in Chiang Mai Province, by providing them with loans at low interest rates. The programme, initiated in 1998, is a collaborative effort between HelpAge International and the Mother Child Concern Foundation.

A much-needed income

Grandma Di and Grandpa Oiy are an example of grandparents who are making a difference in the lives of their grandchildren. Their story is a testament to the resilience and determination of grandparents who are facing the challenges of HIV/AIDS.

By hitting the middle generation, HIV/AIDS strikes at the heart of how families and communities provide for old and young.

HelpAge International
While other income-generation programmes are often short-term and are rarely self-sustaining, this project has the long-term objective to remain as a revolving fund project. “The loans should circulate from one affected family to another, supporting older caretakers as long as they need to” says Mr. Elderidge.

The project in Thailand is a great source of financial assistance to the local community. It is helping older people to better manage the tremendous impact of HIV/AIDS on their lives as well as preserve the strong bond between grandparents and their grandchildren. The programme helps grandparents earn an income so that their grandchildren can finish school, find work and then switch roles again, with the grandchildren taking care of their grandparents. Projects like these are scarce and are serving only a fraction of grandparents in Thailand who have been affected by the HIV/AIDS epidemic and are in need of assistance.

Similar voices from Viet Nam

Viet Nam’s older people, like Thailand’s, must shoulder the responsibility of caring for HIV-positive children and orphaned grandchildren. The Viet Nam Women’s Union (VWU), a mass organization founded in 1930, has a membership of 11 million people. It is organized from the local level, through the district and provincial levels, up to the central level. Its aim is to work for women’s advancement, equality and well-being through capacity building and skills training.

VWU began its partnership with HelpAge International in 1997. This collaboration has helped VWU to build its capacity to provide practical support and assistance to older women. Since 2000, VWU has set up 14 clubs for older women living with, or affected by, HIV/AIDS. Below, one woman recounts her story.

Letter from a member of the “Women of Sympathy” Club, Viet Nam

My name is Luong Thi Lan. I am 58 years old and live with my family in Halong City, Quang Ninh Province. Our neighbourhood is a hub for drug trading in Halong City. Many families here, including mine, have children who are engaged in drug abuse and have acquired HIV.

My family’s tragedy started seven years ago when my youngest daughter Oanh, who was 22 at the time, returned from Hong Kong, China. While in the refugee camp in Hong Kong, China, she was lured into drugs. Returning home, jobless and disappointed, she turned to drugs again. For days and nights, I tried to convince her to quit. With help from the Viet Nam Women’s Union, I brought her to the rehabilitation centre, where she gained weight and looked healthy. She even became an advocate on drug control in the local Women’s Union. This made my husband and me very happy.

This happiness did not last long. Many hard lumps and inflamed sores appeared on her body and she rapidly began to lose weight. I took her to the hospital for blood testing and we found out what I most feared: she was HIV-positive. I was scared, worried and ashamed. In despair, Oanh relapsed into drug use. She tried committing suicide twice by taking sleeping pills. She felt isolated and discriminated against, because people did not know very much about HIV/AIDS. The more depressed Oanh became, the more she turned to drugs. Finally, she engaged in drug trading to obtain money, and was arrested. Now, she is in prison.

Three years later, my only son became addicted to drugs. My son-in-law is also a drug user and HIV-positive, and both have been arrested for drug trading.

(continued)
Achievements and challenges

In Thailand, the innovative programme is helping grandparents to generate an income. Many have started home-based agricultural projects, including chicken-, pig- and fish-breeding farms — activities the grandparents are experienced in and can manage on their own.

So far, over 200 families affected by HIV/AIDS in the Sanpatong District have benefited from the fund. Grandpa Oiy explains, “The business has given us enough income to send our grandson to school but we still need to earn more money to make ends meet.”

What has given a further boost to the project is the high rates of return on the loans,
explains HelpAge International’s Mr. Eldridge: “The success rates with regard to paying back the loan have been very high – around 95 per cent.” Hence, HelpAge International is planning to initiate similar income-generation projects in other parts of Thailand as well as abroad. In Viet Nam, for instance, HelpAge International and its key partner, the Viet Nam Women’s Union, are planning to provide revolving loans to HIV-affected older people in the near future.

For those like Grandpa Oiy, Grandma Di and Luong Thi Lan, the ability to stand on their own feet and support their grandchildren has not only given them strength and a sense of purpose, but also helped forge a closer relationship with their grandchildren.

In many ways, older persons are the forgotten victims of HIV/AIDS. Grandma Di’s, Grandpa Oiy’s and Luong Thi Lan’s contribution to coping with the effects of HIV/AIDS have yet to be valued or recognized by most policymakers and organizations working in the area of HIV/AIDS. The international community has often perceived older persons more as a burden than as part of the solution to help fill gaps in prevention, care, treatment and support in a world of HIV/AIDS. As caregivers, they are an indispensable resource – the linchpin keeping households together and helping to ensure the well-being of their dying loved ones and of the orphans.

For their contributions to society to be as effective as possible, older people need new programmes and resources that can meet their needs and the needs of their families. As policies develop, it will be essential to foster more explicitly a synergy between health and development strategies aimed at, and for, older people, which give them and their loved ones a better chance of life beyond HIV/AIDS.

6 Story adapted from Young Hopes in Elderly Arms. Video produced by HelpAge International Asia-Pacific Regional Development Centre, Chiang Mai, and written by Teena Amrit Gill.
8 Provided by the Viet Nam Women’s Union.
Giving shelter, giving hope:
Care and support for Korean PLWHA
(Korean Alliance to Defeat AIDS, Republic of Korea)

Some Asian countries such as Japan, Mongolia, the Philippines, and the Republic of Korea currently have low HIV prevalence rates compared with some other countries in the region. According to UNAIDS, HIV prevalence rates in the above four countries were below 1 per cent at the end of 2001.1

With specific reference to the Republic of Korea, the Government is often commended for its 0.1 per cent prevalence rate which has, in part, been attributed to its HIV/AIDS prevention and control programmes. The comparatively low number of infections, however, has little significance for people already living with HIV/AIDS. Furthermore, despite advances in prevention, the numbers are increasing. Today, there are an estimated 4,000 people living with HIV/AIDS (PLWHA) in the Republic of Korea.2

Many Korean PLWHA are beleaguered by stigma and discrimination. They have limited resources to pay for medical treatment. They face enormous challenges in finding shelter and obtaining care, treatment and support services. To meet their needs, the Korean Alliance to Defeat AIDS (KADA) has established short-term shelters. The KADA shelter system has effectively supported more than 6,000 visits from PLWHA. KADA provides outpatient and shelter services, medical assistance, professional counselling, vocational training and hospice service from its four shelters in Seoul (2), Pusan (1), and Inchon (1).

Status and trends of HIV/AIDS in the Republic of Korea

In the Republic of Korea, the first HIV positive case was reported in December 1985, and the first AIDS case in February 1987. The great majority (97.4 per cent) of HIV infections are sexually transmitted. Based on survey research, the Korean National Institute of Health (KNIH) indicates that heterosexual sex is the leading mode of transmission, followed by sex between men.3

Prevention efforts

A wide range of community organizations are working to tackle the rising prevalence of HIV/AIDS. For example, the Korean Anti-AIDS Federation (KAAF) and the Korean Alliance to Defeat AIDS (KADA) are non-governmental organizations that are active in HIV/AIDS prevention education and in providing care and support services. The Korean Health Promotion Association (KHPA) is actively involved in providing counselling services for AIDS prevention through its
hotline. It is also largely responsible for disseminating accurate and easy-to-understand information about prevention of HIV/AIDS to the public. The Planned Parenthood Federation of Korea (PPFK) is a key facilitator and partner in HIV/AIDS awareness and education for young people. Lastly, the Korean Nurses Association (KNA) provides innovative education sessions on HIV/AIDS for its members who are trained as HIV/AIDS counselors at the primary health care level.

Providing shelter, care and support

For many Korean PLWHA, the various forms of stigma and discrimination that they face are multiple and complex. As a consequence of their HIV/AIDS status, some are denied housing and employment, shunned by family, friends and/or colleagues, and suffer emotional and physical pain from their illnesses. Individuals tend to be stigmatized and discriminated against, not only because of their HIV status, but also because of the sexual behaviour it is associated with (such as multiple-partner sex or sex between men).

PLWHA are widely perceived to have become infected through their own “unethical conduct” by partaking in risk behaviours. This perception is internalized by many PLWHA who may view themselves as wearing the “scarlet letter”. In these cases, this perception delays them testing for HIV, seeking treatment, or from acknowledging their HIV status for fear of community rejection.

Agencies that work with PLWHA have also indicated that stigma and discrimination have made it difficult to expand care, treatment and support programmes. “KADA is challenged in its ability to provide services to PLWHA,” says its Director, Chang-Woo Lee. “Our shelters are not publicly advertised. People come to know us by word of mouth, or by referrals of some infectious disease clinics and public health centres. We have no signs outside that say that this is a shelter for people with HIV/AIDS. If we did, there is the possibility that our neighbours would protest and shut the facilities down. Many Korean people do not understand HIV/AIDS. There is still much prejudice against PLWHA so our services remain discreet.”

Giving shelter, giving hope: Care and support for Korean PLWHA
In a country of 47 million people, low prevalence rates as well as negative public sentiment have contributed to a gap in meeting the care and support needs of PLWHA.

According to a needs assessment survey by the Korean Anti-AIDS Federation, PLWHA in the Seoul area are most in need of shelter where they can meet other PLWHA, receive counselling, education, and medical services.6

In 1997, the Catholic Social Welfare Commission (CSWC) in Seoul was approached by a man in the terminal stages of AIDS. Gravely ill, destitute and in need of shelter, the man requested housing and care for himself and another person living with AIDS. This triggered the birth of the first shelter for persons living with HIV/AIDS. Recognizing that many other PLWHA were without basic resources and in desperate need of social assistance, CSWC provided a building facility. KADA agreed to extend financial and programme management, and the first formal shelter was established in Seoul in April 1999.

Not unexpectedly, the need, demand and success of the first shelter led to the expansion of three more shelter facilities in Pusan, Inchon and Seoul (for women). The programmes are working with financial and political support from the Government, implementation by NGOs, as well as in-kind contributions from religious organizations.

The target populations of these shelters are HIV-positive people and people living with AIDS who come to the shelters for outpatient care or temporary housing, which is limited to a maximum duration of one month in principle. In 2002, more than 6,000 visits were serviced by KADA’s four shelters – a six-fold increase from 1999.

### Causes for stigma and discrimination

- Fear
- Lack of knowledge and understanding
- Myths
- Prejudice
- Irresponsible media reporting
- Beliefs regarding sexuality
- Attitudes towards illicit drug use
- Irrationality towards death and dying

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HIV/AIDS Prevention, Care and Support: Stories from the Community
KADA shelter: A ray of light for PLWHA

KADA shelters offer housing, medical assistance, professional counselling, vocational training, and hospice service.

Common trends exist among clients who turn to KADA for help. An especially common scenario is abandonment. Families who are ashamed that their family member has HIV, or fear negative responses from their neighbours and communities, kick them out. Many clients come to KADA shelters when they have nowhere else to go.

Almost 40 per cent of the shelter's clients have medical complications largely because they did not access medical services earlier – often because fear and discrimination stood in the way. The shelter offers them basic medical care. However, its strength is its links with a medical service network. The shelter provides referral services to its clients for entry to several leading hospitals in the Republic of Korea.

KADA also provides its clients with psychological care. One of its most innovative programmes is a peer education initiative that is managed by other PLWHA who are specially trained to provide health and psychological counselling. The peer education programme has been assessed as highly effective by the clients, since the counsellors are able to relate to many of the psychological and social situations their peers endure and can offer sound advice and referrals.

The peer education is also useful for clients’ families. Outreach is extended to relatives (including those who have previously been non-supportive) who are invited to learn more about HIV/AIDS with other families in similar situations. The family-family sessions help teach clients’ families how to provide better support for their kin living with HIV/AIDS and also offers them a network to face HIV/AIDS and its challenges.

The shelter operates a work-placement programme that helps PLWHA maintain their self-respect and dignity by providing them with full-time or part-time jobs through job skills training and job information networking. In addition, the shelter assists the PLWHA in applying for social welfare benefits, including the Government's minimum income supplementary programme. With these functions, the shelter is not merely a shelter for the clients, but a pipeline to peers family and society.
The shelters also have network linkages with several hospice-care centres for AIDS patients in the terminal stages of their illness. This essential service helps the clients to complete their life in dignity and peace.

Achievements and challenges

The growing number of PLWHA in Korea is having an impact on KADA’s ability to provide services to everyone who has a need. The KADA shelter system currently has a limited capacity to shelter only 40 clients at any one time. The demand for services far exceeds the number of beds that are available. Unfortunately, KADA cannot help as many people as they would like due to spatial and financial constraints. The clients are therefore selected according to specific criteria. PLWHA who cannot be cared for by family members, those who are unable to live independently, and/or people with limited economic resources have priority in obtaining services.

KADA recognizes that more care, treatment and support services are necessary to meet the current and upcoming needs of PLWHA. This is, in large part, a consequence of the progression of first generation HIV-positive people’s illnesses, which are moving from the early stages of HIV to the advanced stages of AIDS. Mr. Chang-Woo Lee, KADA Director, indicated that his organization is working to expand its activities. First, another facility will open shortly in Kwangju, the fifth largest city in the Republic of Korea. Plans also include the expansion of services in existing shelters to meet the needs of more clients. Another goal is to establish long-term care facilities so that HIV/AIDS patients can stay longer than one month at a time. The ultimate challenge to achieving these goals will be to overcome public stigma and discrimination, expand the involvement of people living with HIV/AIDS and to obtain increased Government funding to support these programmes.

Discrimination against Korean PLWHA has had an impact on their ability to access care, treatment and support. In many circumstances, their health has been compromised by a delay in detection and in obtaining health and social services, for fear of abandonment, denial of treatment, and other forms of stigma and discrimination. In light
of these circumstances, the KADA shelters have successfully provided essential services to many PLWHA in the Republic of Korea. Their peer-led approaches, outreach work, and care and support have been a bright beacon for PLWHA.

Hand in hand:
Thai children join together against HIV/AIDS
(Raks Thai Foundation, Thailand)

Thailand has among the highest HIV prevalence rates in the Asia-Pacific, at 1.8 per cent as of end-2001. In 1991, the Thai Government launched a highly successful nationwide HIV/AIDS campaign that has, in the past 10 years, prevented an estimated 200,000 new HIV infections. Even with concentrated efforts, 984,000 people have been infected with HIV since the start of the epidemic, including 33,000 children. In 2001, 55,000 people in Thailand died from AIDS. With the peak age range for developing AIDS being between 25 and 34 years, a large number of young children are left orphaned. According to the Ministry of Health, Thailand, over 232,000 children under the age of 15 years are expected to lose their mothers to the disease by 2005. Many of these children will also be HIV-positive.

Raks Thai ("Care for Thai People") Foundation (originally known as CARE Thailand until the development of the Raks Thai Foundation in 1997) first began work in Thailand in 1979. The Raks Thai Foundation (RTF) works with individuals and families in the poorest communities to strengthen their capability to help themselves, increase economic opportunities, and address discrimination. Its HIV/AIDS programmes target rural children and youth, migrant workers, seafarers, and families and communities living with, and affected by, HIV/AIDS. The programmes aim to create a supportive environment for people living with HIV/AIDS (PLWHA) and to prevent more people from acquiring the infection.

Orphans and children vulnerable to HIV/AIDS

Children who lose a parent to HIV/AIDS face numerous difficulties, even before the actual death of their parent. The emotional pain of witnessing the progression of a parent’s illness is compounded by drastic changes in family structure, which place a heavy burden on some children who must assume the role of caretakers and breadwinners for themselves and their siblings. When the parent eventually dies, the children must adjust to new life circumstances while undergoing the anguish of their tremendous loss, often with little or no support. The majority of Thais living with HIV are poor, and orphans are often left destitute. Although in Thailand, extended families, most notably grandparents and aunts and uncles, often step in to take care of the child, orphans are nonetheless less likely to stay in school and more likely to become child labourers. Orphaned children are also at an increased risk of exploitation and abuse. HIV-positive orphans are particularly vulnerable, with increased susceptibility to death. Estimates indicate that child mortality could be 30 per cent higher by the year 2010 as a result of AIDS.
Not only must children bear the psychological pain and economic hardship associated with losing their parents to HIV/AIDS, but they are also forced to face the stigma of being an “AIDS orphan”. While awareness of HIV/AIDS is fairly high in Thailand, it does not necessarily translate into sympathy or compassion, and AIDS orphans often find themselves ostracized by the community. Ignorance and misunderstanding have led to circumstances in which parents forbid their children from playing with AIDS orphans, or communities have banded together to place pressure on schools to keep out a child who may be HIV-positive or whom the community perceives is HIV-positive.

Communities play a pivotal role in determining the impact of HIV/AIDS on vulnerable children. While at times communities can band together to reinforce stigma and discrimination against HIV/AIDS, they also can be important partners in providing access to a continuum of care for children living with, or affected by, HIV/AIDS, including psychosocial and economic support. Providing such support in an environment that is as “familiar, stable and nurturing as possible” can help orphans cope better with the enormous challenges that they face.

A village responds: Integrating children affected by, or infected with, HIV/AIDS

Raks Thai Foundation assists orphans and children vulnerable to HIV/AIDS in Banmai area, Muang District, Phayao Province, Northern Thailand. AIDS has been particularly devastating in this part of Thailand, where five northern provinces (of 76 provinces nationwide) accounted for 40 per cent of reported AIDS deaths between 1984 and 1997. In the year 2000, in 17 northern provinces of Thailand, 10,270 children aged 0 to 18 lost one or both parents to AIDS or had one or both parents living with HIV/AIDS. Raks Thai Foundation estimates that approximately 10 per cent of children attending primary school in Banmai have lost one or both of their parents to AIDS. Villagers from Banmai associate the high incidence of HIV with out-migration, which is common in rural regions where villagers cannot support themselves on income from farming alone.

Almost everyone in Banmai has a relative or knows someone who has HIV or AIDS. The high prevalence of HIV/AIDS initially led to heightened fear, stigma and discrimination against people living with HIV/AIDS. Education interventions by many organizations, such as the Raks Thai Foundation, have however, in recent years, paid off in greater levels of understanding and acceptance of PLWHA among community members.

- A girl named “O”

The Raks Thai Foundation works with the community to establish and run a local
HIV-positive children also have the opportunity to enjoy activities such as drawing, craft making and games when RTF staff members and Waew make home visits.

Inclusion of all vulnerable children is an important theme for Baan-O. Originally, the project targeted only AIDS orphans to help them cope with some of their everyday difficulties. Soon after, the project's scope evolved to include all children in the community, since HIV prevalence in Banmai is so high there is not a child in the village who is not affected by HIV/AIDS. RTF recognized that singling out children orphaned by AIDS would only serve to increase stigma and discrimination, and that more effective interventions are those that “address the needs of all vulnerable children in a community affected by the epidemic.”

Through daily interactions with HIV-positive children, as well as through sexual health education at school, many of the older children have learned how HIV can be transmitted, and how to ensure the safety of younger children at Baan-O in situations such as if someone gets a cut and starts to bleed.

Who is O?

“O” is a character that the children created. O lives in the village with her mother and father. She is a very curious and active girl, and asks many questions.

When I was a child, I never attended these kinds of activities. I have no skills except embroidering. I am not good at speaking in front of people. I had no experience teaching children. But now, I strongly feel that I want to help improve children's skills and let each of them lead a meaningful and enjoyable life.”

Waew, 19, volunteer manager of Baan-O

Many of the children at Baan-O are older siblings of HIV-positive children. Children living with HIV tend to be either too young or too weak to attend the centre, or often die before they are old enough, and for these reasons, there are currently no HIV-positive children at Baan-O. Many other children at the centre have lost a parent, friend, relative or neighbour to HIV/AIDS. The centre provides a safe haven for these children to engage in fun and educational activities, and to find support among their peers.
Raks Thai Foundation provides psychosocial support to HIV/AIDS-affected children and helps keep them integrated within their community. Children who have lost someone to HIV/AIDS and are coping with their grief have outlets such as art therapy, counselling with trusted adults, and peer interaction. In addition, economic support in the form of scholarships is provided to children who have lost their parents to HIV/AIDS. The scholarship provides for items the child needs to continue school, such as uniforms, shoes, school supplies, lunch and transportation costs. As of February 2003, 69 orphans, including 30 in Banmai, are being supported by the Foundation.

Baan-O also aims to empower vulnerable children to meet their own needs. The Banmai community recognizes that capability development is the best way to tackle HIV/AIDS in the long term, to protect their children from future infection. Baan-O plays a key role in building rural poor children’s self-esteem and their ability to express their thoughts and feelings. Skills such as problem solving and communication, often referred to as “life skills” (see box, page 13), are taught, to enable children to avoid, and safely navigate through, risk situations in life, as well as provide them with coping mechanisms, should someone in their families fall ill.

Baan-O’s approach, focusing on the long-term development of children, is complemented by other active community programmes that specifically address HIV/AIDS prevention and support. For example, youth aged 15 years and older take the lead in awareness-raising theatre productions targeting peers and villagers. The fact that correct HIV/AIDS information is widely available in the community gives Baan-O an advantage in implementing broader development activities more successfully.

Activities at Baan-O

The activities at Baan-O were introduced by the Raks Thai Foundation, but the children at Baan-O have adopted and adapted them according to their interests. The activities foster children’s understanding of, and love for, their communities, their culture and values, and encourage the children to actively engage in community development. Some activities include:

- Drawing, crafts and storytelling – which are useful tools to encourage children’s creativity, as well as their ability to express themselves and their feelings. If any child loses a parent, sibling, friend or relative to AIDS, art therapy is used to help them cope with grief.

- Community-mapping exercises – are projects that engage the children in local culture. The children begin by choosing a topic to research. They then visit relevant sites in their village and interview farmers, monks and older people to gather information about local history, local wisdom, folktales, the environment, and resources. The children then create a large map that reflects their findings which is exhibited at various community events. The exercise encourages children to take initiative, and builds their analytical thinking and communication skills, as well as their knowledge and pride in their community.

- Volunteer work – includes making home visits to older persons and people living with AIDS in the community, to help them with chores and to keep them company. The children are currently planning to extend their visits to nearby villages and the provincial hospital.

- Income-generating skills – are taught, such as vegetable cultivation, embroidery, and fish- and frog-raising. These can help poor children supplement their families’ small incomes.

Hand in hand: Thai children join together against HIV/AIDS
Of their own volition, the children of Baan-O have enthusiastically embarked on fund-raising activities for their centre, such as selling their crafts at temple festivals and other community gatherings. While the proceeds from these activities do not yet suffice to make Baan-O completely self-sustaining, the children are highly encouraged by their excursions and are thinking of additional ways to improve their fund-raising. The Raks Thai Foundation provides basic funding for Baan-O, particularly to pay for supplies and to pay a small stipend to the volunteer director.

Local schoolteachers have allocated regular class time for the community-building and skills training activities in the classroom. The possibility of incorporating the activities into a regular course is being explored.

**Achievements and challenges**

Baan-O is a children’s centre that provides a holistic and safe environment for rural children to flourish, and helps keep HIV-positive children, or those affected by HIV/AIDS, integrated with other children in their community.
The centre gives all children a chance to build their self-esteem and to find support among their peers. Positive messages instilled at the centre can also be conveyed to adults through the children, thus helping to decrease discrimination against children living with, or affected by, HIV/AIDS. A caring and supportive environment in which all vulnerable children can thrive and become confident, articulate adults, complemented by correct HIV/AIDS information widely available in the community, are important components in the long-term fight against HIV/AIDS, and for sustainable development in general.

The project still faces challenges in garnering greater community support and participation. In a poverty-stricken area, general interest in child development is still low, and communities treat children’s participation in community development with scepticism. Community members may not recognize the value of child participation or may place greater value on children’s economic activities than just “play time”. The children of Baan-O are working to elicit greater community understanding towards child-centred, participatory activities by presenting their community maps and other items at local events in temples, schools and health centres. By doing so, the children hope that more adult community members will endorse Baan-O activities.

There is no one best way to help the children orphaned or vulnerable to HIV/AIDS face the difficult realities of their everyday lives. Their many needs call for a wide range of responses, including appropriate medical care and treatment, as well as psychosocial and economic support. Although Baan-O’s activities are by no means comprehensive, they build upon the children’s abilities to meet their own needs while providing psychosocial and economic support within the community. The children’s centre serves as a positive example of how community support and participation make a difference in the everyday lives of children affected by, and vulnerable to, HIV/AIDS.

7 Im-em, Wassana and Gary Suwannarat (2002).
8 Rhucharoenpornpanich, Orratai and Aphichat Chamratrithirong (2001).
10 UNAIDS (2002).
11 Quoted in Im-em, Wassana and Gary Suwannarat (2002).
13 Im-em, Wassana and Gary Suwannarat (2002).
14 UNAIDS (2002).
For goodness sake!: Asia-Pacific faith-based organizations battle HIV/AIDS
(Wat Norea Peaceful Children’s Home, Cambodia; Yayasan Dana Islamic Centre, Indonesia Mosque Association Mushallah Muttahidah, Indonesia; and Anglicare-StopAIDS PNG, Papua New Guinea)

Religion has always played a significant role in the vibrant tapestries of life in Asia and the Pacific. The region has been tolerant and accepting of a wide variety of religions. It is the birthplace of Hinduism and Buddhism. It also includes the largest Islamic countries in the world – Indonesia, Bangladesh and Pakistan. And, Christianity has flourished in countries such as the Philippines and the Republic of Korea, and throughout the Pacific island countries and territories.

HIV/AIDS poses new challenges to religions. It raises sensitivities around religious teachings and beliefs about sexuality and illicit drugs. Yet, at the same time, faith-based organizations are effective tools in responding to HIV/AIDS, as they constitute perhaps the largest institutions in the world with the greatest built-in infrastructures of leadership and fellowship. Religion can build upon its moral and value-based leadership, trust garnered over generations, and channels of communication and organization, in order to have a tremendous influence over cultural norms that guide individual and community behaviour and that affect how information about HIV/AIDS is, and can be, interpreted.

Religious institutions were among the first to become active in fighting the spread of HIV/AIDS, and are often caregivers of the sick, the dying and the orphans. Around the world, individual places of worship within communities – including churches, mosques, synagogues, temples and hospitals with religious affiliations – have taken the initiative to address HIV/AIDS and its impact at the local level.

In Asia and the Pacific, responses have varied. In Indonesia, for example, the Islamic community is including HIV/AIDS awareness messages in everyday sermons. In Papua New Guinea, an Anglican community-based organization is putting HIV/AIDS on the agenda in schools, at the workplace and among street children. In Cambodia, Buddhist monks are now at the frontline of providing care and support for people who are living with HIV/AIDS.
Faith-based organizations respond

“For many Asians and Pacific islanders, religions are not just a matter of paying homage to the supernatural. They provide important ethical guidelines for living, for interpreting natural events, including disasters and misfortune, and for coping with life’s milestones, from birth through illness to death.”

Religion is often cited as both a facilitating factor as well as an “obstacle” in the fight against HIV/AIDS. Traditional religious views often regard HIV/AIDS as a form of divine punishment for sexual transgression, from premarital sex and extramarital sex to homosexuality. Such views perpetuate the stigma and discrimination associated with HIV/AIDS. These views also discourage open discussion of issues – particularly those that relate to sex. Without open and frank discussion, it is difficult to prevent the spread of the disease and combat the stigma and discrimination that makes HIV/AIDS a “hidden” epidemic – all the harder to control.

Increasingly, however, faith-based organizations are working to address HIV/AIDS. Indeed, they are seen around the world as essential partners in HIV/AIDS prevention and care and support. Faith-based organizations are combining their beliefs with actions. For example, some faith-based organizations promote HIV/AIDS awareness and prevention with teachings of monogamy and abstinence as preventive measures. Such teachings are effective in helping change behaviour in positive ways, if people adhere to it in their daily lives.

HIV/AIDS, Indonesia and an Islamic response

With over 200 million inhabitants, Indonesia is the world’s fourth-most populous country. It is the largest Islamic country in the world, with almost 90 per cent of its population adhering to Islam. According to UNAIDS, 0.1 per cent of the adult population, or 120,000 people, are living with HIV/AIDS. However, an exponential rise in HIV infection among blood donors (identified during routine testing of donated blood) indicates that HIV is spreading out from high-risk groups. The situation in Indonesia underlines the fact that, where high-risk behaviour exists, the epidemic can spread from vulnerable groups to the wider population, even if it takes some years to become apparent.

Recognizing the strong tie between religion and everyday life in Indonesia, Muslim leaders are addressing and responding to HIV/AIDS

“We will strive to eliminate the following vices related to HIV/AIDS, at all levels in our community: ignorance, apathy, stigmatization, irresponsibility, disorganization, and poverty.”

Excerpt from the Resolution of the First International Muslim Leaders Consultation on HIV/AIDS, November 2001

- An illness, not a curse

Yayasan Dana Islamic Centre (YASDIC), popularly known as IMMIM (Indonesia Mosque Association Mushallah Muttahidah), is an Islamic preachers’ coordinating agency based in Makassar, provincial capital of South Sulawesi. IMMIM illustrates how an Islamic organization can take a frontline role in addressing HIV/AIDS. Funded by the Australian Agency for International Development (AusAID) in 1999, within a three-month
period, IMMIM trained more than 300 Islamic preachers known as *Muballights*, throughout the South Sulawesi province, to promote HIV/AIDS awareness and prevention messages.

The training programme provided male as well as female preachers (known as *Muballighats*) with general health information and facts about sexually transmitted infections (STIs), including HIV, and counselling skills to provide care and support to their local community members. Special emphasis is placed on discussing ways to diminish discrimination towards people living with HIV/AIDS. The training uses group discussion and role-play to make the sessions more interactive and dynamic.

"The three-day training course helped the participants to become more accepting towards people living with HIV/AIDS," recalls IMMIM Director, Mr. Ridwan Abdullah. Pre- and post-session evaluations indicated that the training seminars dismantled many of the myths and preconceived stereotypes about people living with HIV/AIDS.

Since the training programme, Muslim religious leaders have addressed HIV/AIDS in their sermons, in mosques, schools and community halls. From the provincial capital to the villages, the education initiative aims to reach up to 6 million believers in South Sulawesi with basic information about HIV/AIDS and its transmission modes. The preachers also advise on prevention methods, such as abstinence and fidelity, that focus on the avoidance of high-risk behaviours.

Teachings convey the message that, while illicit sexual relations (*zina*) "is a religious sin, particularly for those already married... *zina* without protection (i.e., without the use of condoms) [is] an even greater sin because it allows a deadly virus to be transmitted". Somewhat less controversial is the issue of condom use within a marital relationship. Protection of the family is a top concern for Islam. If either the husband or wife knows that he/she is HIV-positive, then condoms should be used to protect the family.

While an increase in knowledge about HIV/AIDS or concrete behaviour change has not yet been internally assessed, an independent evaluation by the University of Indonesia, Depok, showed that about 90 per cent of the community members had heard the Islamic preachers talk about HIV/AIDS during their sermons. Undoubtedly, the endeavour demonstrates that with effective training, Islam, as well as other religions, can find a middle ground in the interest of community welfare. Indeed, Islamic *Muballights* can be active key partners in preventing HIV/AIDS in Indonesia.

**HIV/AIDS, Papua New Guinea and an Anglican response**

Since the mid-1990s, Papua New Guinea has had the highest HIV infection rate in the Pacific. An estimated 0.7 per cent of the population (16,000 adults aged from 15 to 49 years) lives with HIV/AIDS, out of a total population of approximately 5 million people (as of end 2001).8

The majority of people living with HIV/AIDS appear to be concentrated in the capital city of Port Moresby. Generally low levels of condom use, a rise in extra-marital and pre-marital sex, and low levels of awareness and knowledge about HIV/AIDS contribute to the country’s potential crisis.9 Trends in HIV/AIDS prevalence rates indicate a considerably high level of HIV infection among sex workers (17 per cent in Port Moresby in 1998). The trends also show a 1 per cent HIV prevalence rate among women attending antenatal clinics and high STI prevalence among both high-risk and low-risk groups that increases the risk of HIV infection.10 These indicators normally signal the onset of a widespread epidemic.
Among the roughly 5 million inhabitants of Papua New Guinea, two-thirds are Christians, primarily Roman Catholic and Lutheran, with 5 per cent Anglican. The Anglican Church shares the widely-held religious position that sexual intercourse should only be within the confines of marriage; however, it also acknowledges the efficacy of condom use and sanctions its use as a form of protection against contracting STIs, including HIV/AIDS.

The Anglican Church of Papua New Guinea emphasizes compassion, not condemnation, in its teachings. Its affiliate organization, Anglicare StopAIDS PNG, sees itself in a unique position to address the needs of people living with HIV/AIDS (PLWHA). It provides care and support to PLWHA with a holistic approach that promotes the physical, spiritual, and emotional well-being of the individual and the affected community.

- **Teaching prevention, care and support**

Anglicare, a ministerial arm of the Anglican Church of Papua New Guinea, initially ran literacy courses for Anglican communities in Port Moresby. In 2001, it changed its mission to address HIV/AIDS issues and adopted the name StopAIDS PNG. Today, it is one of the leading HIV/AIDS prevention and care programmes in Papua New Guinea that aims to improve the health and well-being of all people, regardless of their religious affiliation.

StopAIDS PNG recently launched the Red Ribbon Club, a venue that offers counselling, care and support, and vocational training for 10 HIV-positive mothers. StopAIDS also undertakes outreach work for disadvantaged street youth, working to strengthen their life skills and self-esteem by enrolling them in income-generation projects, in which they set up and manage chicken farms, local bakeries or condom-selling projects. Moreover, StopAIDS conducts HIV/AIDS and life skills education programmes in senior schools, targets employees of private companies or government departments with HIV/AIDS awareness sessions, and regularly trains peer educators.

Although a quantitative evaluation of the projects has not yet been undertaken, given its nascent stage, StopAIDS' success is evident: anecdotal reports indicate that its life skills programme in schools has influenced some teachers to incorporate STI, HIV/AIDS, and drug and alcohol abuse prevention education in the classes that they teach. In addition, about 1,300 street youth are already committed to one of StopAIDS' income-generation projects. Condom distribution is also on the rise in the approximately 100 companies where StopAIDS has already undertaken HIV/AIDS education sessions and established a distribution system.

Despite StopAIDS' successes, significant barriers still exist. For instance, traditional attitudes discourage open discussions about sexual matters. In addition, some local Anglican churches have rejected StopAIDS' condom and safer sex promotion initiatives, although the Anglican Church authorities have approved these practices for prevention purposes.

Much of StopAIDS funding comes from international donors, especially the Australian Agency for International Development (AusAID), and the British High Commission in Papua New Guinea. The Anglican Church's international body, the Anglican Communion, also contributes up to 20 per cent of the budget. In addition, StopAIDS closely cooperates with other faith-based community organisations.
organizations working in the area of HIV/AIDS, such as HOPE Worldwide PNG, a charitable NGO affiliated with the International Churches of Christ. StopAIDS is also seeking ways to involve the Government in its HIV/AIDS programmes.

Among the future goals of the organization is the extension of programmes to other provinces, a greater involvement of people living with HIV/AIDS, the increase of condom availability in remote areas, and intensified training and education for caregivers of PLWHA. Since the organization’s prevention and care programmes do not solely target Anglican communities, StopAIDS continues to seek new approaches to the many ways it can contribute positively towards reducing the spread of HIV/AIDS in Papua New Guinea.

“We raise our voices to call for an end to silence about this disease – the silence of stigma, the silence of denial, the silence of fear. We confess that the Church itself has been complicit in this silence. When we have raised our voices in the past, it has been too often a voice of condemnation. We now wish to make it clear that HIV/AIDS is not a punishment from God. Our Christian faith compels us to accept that all persons, including those who are living with HIV/AIDS, are made in the image of God and are children of God.”

Statement of the Primates of the Anglican Communion on HIV/AIDS, April 2002

HIV/AIDS, Cambodia and a Buddhist perspective

Cambodia faces an AIDS epidemic that could potentially reverse development gains made over the last decade. In 2001, 2.7 per cent of the adult population was HIV-positive. Tens of thousands have already died from AIDS, leaving behind at least 55,000 orphaned children under 15 years of age. The crisis is predicted to worsen, with possibly 200,000 people, including children, developing AIDS within the next 10 years. It is also estimated that, by the year 2005, there will be another 140,000 AIDS orphans.

The epidemic does, however, appear to be stabilizing thanks to large-scale prevention programmes that have considerably raised HIV/AIDS awareness throughout the Cambodian population and included a determined campaign for safer commercial sex. But the majority of prevention and care and support programmes target cities such as Phnom Penh and Sihanouk Ville, as well as the provinces bordering Thailand. Given that 84 per cent of Cambodia’s population is rural, it is crucial to scale up prevention and care interventions in village settings.

Asia is the cradle of Buddhism. In countries such as Cambodia, Lao People’s Democratic Republic, Myanmar and Thailand, most people subscribe to the Buddhist principles of kindness, compassion, joy in altruism, and equanimity – principles that offer important guidelines for HIV/AIDS prevention, care and support, and can help people living with HIV/AIDS cope with the disease and find the strength to continue with life.

A growing number of Buddhist monks, nuns and lay teachers in the region carry out low-cost, sustainable prevention and care activities in their local communities. These activities include prevention targeted at young people, as well as provision of spiritual counselling, food and other essentials to people living with HIV/AIDS.

Among Cambodian people, who are 90 per cent Buddhist, there is a high level of respect for monks, and their religious teachings are
highly influential. In 2000, Cambodia became the first Buddhist country in the world to develop a detailed national Buddhist response to HIV/AIDS, a policy that aims to upgrade the participation of Buddhist monks in HIV/AIDS prevention and care efforts. 18

- **A spiritual response**

Wat Norea Peaceful Children’s Home (NPC) is a project in Norea Pagoda, near Battambang, Cambodia's second largest city. It was launched by the Venerable Muny Vansaveth, a former boxer turned monk, who started an orphanage for children whose parents had died as a result of earlier civil conflict. By 1997, Venerable Muny Vansaveth realized that there was a new source of conflict killing people and leaving thousands of children as orphans – this new opponent was HIV/AIDS.

In 1998, while continuing to provide shelter for orphans and street children, NPC launched an HIV/AIDS prevention, care and support programme. Venerable Muny Vansaveth began to visit villages. He supported people living with HIV/AIDS and provided information to family members, mostly wives, on taking care of people living with AIDS.

Venerable Muny Vansaveth believes that Buddhist temples should and can play an important role in the fight against HIV/AIDS. He advocates these ideas widely and has set up a peer educator project for “monks teaching monks”. As far as the meagre funds allow, monks from Norea Pagoda visit other temples to educate other monks about HIV/AIDS prevention, care and support. By the end of 2003, it is planned that all of the estimated 3,000 monks in the Battambang area will have received the training, including basic information about HIV/AIDS, its transmission and prevention. Once trained, the monks will disseminate messages about HIV/AIDS prevention and provide care and support in the communities.

“When villagers see monks go to the houses of HIV-positive people, it makes them realize ‘Yes, AIDS is suffering. But, if we look at the teachings of the Buddha, we will see that there is a cause for suffering. As the Buddha has taught, ignorance is the cause of suffering. What causes the suffering of AIDS? It is also ignorance. Ignorance is the root cause for the suffering of AIDS.”

Lawrence Maund, The Four Noble Truths of HIV/AIDS 19

Achievements and challenges

Religious institutions have not always responded appropriately to the challenges posed by HIV/AIDS. Sometimes they have contributed to stigma, fear and misinformation. Faith-based organizations, however, are practical settings for HIV/AIDS education:
Throughout the region, the various faith-based organizations may be approaching HIV/AIDS differently, but they are all tapping into formidable religious infrastructures that recognize the importance of action at the international, national, and community levels. The involvement of monks, nuns and religious teachers is invaluable. Their acts of kindness and compassion, the messages they convey to their followers, and the working partnerships they build with the lay community can revolutionize people’s attitudes and behaviours towards HIV/AIDS and help rebuild lives damaged by HIV/AIDS.

The religious responses highlighted in this case study advocate for change in community attitudes and responses to HIV/AIDS. They are teaching their followers preventive measures. They are speaking out against prejudice. And, they are raising money and organizing home-based care for people living with HIV/AIDS.

Theavy* gains new courage to live

When her husband died from HIV/AIDS a year ago, 24-year-old Theavy knew that she too was likely to have the virus. Indeed, she tested positive for HIV, as did her son, who is now 4 years old.

When the Venerable Muny Vansaveth first met Theavy she was unable to cope with her devastating loss. She suffered from depression and had suicidal thoughts. Stigma and discrimination pushed her further into isolation from the community, whose members wished to have nothing to do with her.

Venerable Muny Vansaveth provided spiritual guidance, moral and material support. He also talked to community members to help them overcome their prejudice and misconceptions. He told them about HIV/AIDS, how the virus is spread and, more importantly, how it is not transmitted.

Slowly, the young woman regained her self-esteem. She has hope for the future and a willingness to live and care for her son. Theavy has since opened a shop in the community and, according to the monk, four men in the village want to marry her.

* not her real name

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4 UNAIDS (2002).
8 UNAIDS (2002).
14 Church of the Province of Southern Africa (2002, April 16).

For goodness sake!: Asia-Pacific faith-based organizations battle HIV/AIDS
## Appendix A:
### Contact Information

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<tr>
<th>Country</th>
<th>Organization</th>
<th>Address</th>
<th>Contact Information</th>
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<tbody>
<tr>
<td>Australia</td>
<td>Australian Federation of AIDS Organisations (AFAO)</td>
<td>PO Box 51, Newtown, NSW 2042, Australia</td>
<td>Tel: (61) 2 9557 9399, Fax: (61) 2 9557 9867, Email: <a href="mailto:aquan@afao.org.au">aquan@afao.org.au</a>, Web site: <a href="http://www.afao.org.au">www.afao.org.au</a></td>
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<tr>
<td>Bangladesh</td>
<td>Nari Unnayan Shakti (NUS)</td>
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<tr>
<td>Cambodia</td>
<td>Family Health International/Impact Cambodia</td>
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<td>Tel: (855) 23 211 914, 212 516, Fax: (855) 23 211 913, Web site: <a href="http://www.fhi.org.kh">www.fhi.org.kh</a>, <a href="http://www.fhi.org">www.fhi.org</a></td>
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<td>Khmer Buddhist Association</td>
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<td></td>
<td>c/o Khmer HIV/AIDS NGO Alliance, (KHANA)</td>
<td>#25 Street 71, Sangkat Boeung Keng Kang, Khan Chancar Mon, Cambodia</td>
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<td></td>
<td>Khmer HIV/AIDS NGO Alliance (KHANA)</td>
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Appendix B: Glossary

A

- **Abstinence**: The voluntary decision not to engage in sexual relations of any kind, or only not to engage in penetrative sex. Reasons for abstinence include the following: prevention of pregnancy, religious reasons, or because of concerns about sexually transmitted infections (STIs)/human immunodeficiency virus (HIV) infection. See also ‘STI’ and ‘HIV’.

- **Acquired Immune-Deficiency Syndrome (AIDS)**: The most severe manifestation of human immunodeficiency virus (HIV) infection in which HIV has severely damaged the immune system, leaving the affected person susceptible to infections and malignancies. See also ‘opportunistic infection’.

- **AIDS orphans**: Children under the age of 15 who have lost one or both parents to AIDS.

- **Antiretroviral drugs (ARV)**: Substances used to kill or inhibit the multiplication of retroviruses such as HIV.

- **Community-based care**: All activities that are based outside conventional and institutional health services and which are integrated within a community environment. Community-based care supplements health care services provided by medical institutions, and can address any aspect of the ‘continuum of care and support’ by making available curative and palliative care, psychological support and material help for persons living with or affected by HIV/AIDS.

- **Concentrated epidemic**: An epidemic is considered concentrated when less than 1 per cent of the wider population, but more than 5 per cent of any group, displaying high-risk behaviour, has acquired the virus.

- **Continuum of care**: A wide range of treatment, care and support options, provided by the health care system, as well as by community-based and home-based care, which addresses the evolving needs of a person living with HIV/AIDS, as her/his condition develops and progresses through the different stages of HIV infection. See also ‘care and support’.

C

- **Care and support**: Personal and/or professional concern resulting in attentive assistance or treatment. This concern is focused on the physical and mental well-being of the person who is ill and entails maintaining that person’s well-being through the provision of psychological and/or socio-economic assistance. See also ‘continuum of care’.

D

- **Detoxification**: The process by which an individual who is physically dependent on a synthetic or chemical substance is withdrawn from it, often by gradually administering, in a supervised environment, decreasing doses of the drug of dependence or of a cross-tolerant drug. The primary objective of detoxification is to relieve physical and
psychological withdrawal symptoms while the patient adjusts to a drug-free state.

- **Direct sex workers**: Full-time sex workers, including brothel-based and street-based sex workers. They are also formerly known as ‘prostitutes’. Direct sex workers frequently maintain working relationships with pimps or madams/brothel owners.

- **Drop-in centre**: A safe and supportive environment in which counselling and support services are available to people with alcohol, drug abuse, personal or social problems or other special needs.

**E**

- **Empowerment**: Enabling a target population to take more decisive control over their daily lives. The term is often used in association with vulnerable groups, such as women, men who have sex with men, and sex workers.

**G**

- **Generalized epidemic**: An epidemic is considered generalized when more than 1 per cent of the total population has acquired the virus.

- **Greater involvement of people living with or affected by HIV/AIDS (GIPA)**: Recognizing that individuals living with HIV/AIDS, as well as those who are not necessarily HIV-positive but who have friends or family members living with HIV/AIDS, can make important contributions to ensure a holistic response that meets their needs effectively. GIPA empowers individuals, and helps reduce discrimination and fear within society.

**H**

- **Harm reduction**: A set of practical strategies that reduce the negative effects of high-risk behaviour. Most commonly used in relation to drug use, it incorporates a spectrum of strategies from safer use, to managed use, to abstinence.

- **Hepatitis C**: A viral infection mainly transmitted through exposure to infected blood. HIV infection causes a more rapid progression of chronic hepatitis C to cirrhosis and liver failure in persons with HIV/AIDS. Shares the same route of transmission as HIV. See also ‘HIV’.

- **Heterosexual**: A person who is sexually attracted to persons of the opposite sex.

- **High-risk behaviour**: Activities that put an individual at greater risk of contracting a particular infection. With regard to HIV/AIDS, high-risk activities include unprotected sex and the sharing of needles and syringes.

- **HIV prevalence rate**: Percentage of people tested in a particular group (e.g., pregnant women, sex workers, injecting drug users) who were found to be infected with HIV.

- **Home-based care**: Medical and social services provided in the client’s home. Such services might include medical treatment, physical therapy, and/or assistance in housekeeping, shopping and food preparation.

- **Homosexual**: A person who is sexually attracted only to people of the same sex. Gay men and lesbians are homosexual.
Human immunodeficiency virus (HIV): The retrovirus isolated and generally recognized as the cause of AIDS. When a person is HIV positive, his/her immune system cannot create effective antibodies to stop the infection before it can cause illness. HIV then is able to destroy the immune system, despite the presence of antibodies.

Indirect sex worker: Individuals who engage in sex work on an ad-hoc basis or as secondary employment. Indirect sex workers are not associated with brothels, and can work out of venues such as karaoke bars, massage parlours, and hotels.

Information, education, and communication (IEC) materials: A package of planned interventions that combine information, education and motivation processes. IEC materials aim to achieve measurable behaviour and attitude changes or reinforcement in specific audience groups based on their needs and perceptions.

Injecting drug user (IDU): A term used to refer to a person who injects drugs directly into her/his bloodstream by using a needle and syringe. Sharing unclean needles is one of the most efficient means of transmitting HIV.

Life skills: Refers to a group of psychosocial and interpersonal skills that enables people to make informed decisions, communicate effectively, and develop coping and self-management skills. Having various life skills can help people live healthy and productive lives.

Men who have sex with men (MSM): Men who report having sexual contact with other men, and may or may not identify themselves as gay or bisexual. As MSM often remain hidden in society, it could be difficult to reach them with HIV/AIDS programmes.

Mother-to-child transmission (MTCT): The transmission of infection, typically HIV, from the mother to the child during pregnancy, labour, delivery or through breastfeeding.

Needle and syringe programme (NSP): Activities aimed at avoiding transmission of HIV by people who inject drugs, through promoting safer injection practices, providing sterile injecting equipment and safer injection sites, and collecting used syringes and needles.

Older people affected by HIV/AIDS: Individuals, many over the age of 60, who are not only vulnerable to HIV/AIDS but often faced with the challenge of providing care and support for adult children, or children living with HIV/AIDS, and/or children whose parents have died of AIDS.

Opportunistic infections: Illnesses caused by organisms that usually do not cause disease in a person with a normal immune system. Opportunistic infections take advantage of a weakened immune system to cause illness. Those common in persons diagnosed with AIDS include pneumonia, chronic diarrhoea and eye infection.

Appendix B: Glossary
• **Outreach**: Education and other service interventions that are generally conducted by peer or paraprofessional educators. This involves face-to-face contact with individuals engaged in high-risk behaviour, in their neighbourhoods or other areas where these individuals usually gather in their recreation time. HIV/AIDS interventions typically include the distribution of condoms and education materials.

• **People living with HIV/AIDS (PLWHA)**: HIV-positive individuals. PLWHA face numerous challenges, including stigma and discrimination and exclusion from social services. They are an important part of any response to HIV/AIDS. See also ‘Greater involvement of people living with or affected by HIV/AIDS (GIPA)’.

• **Peer education**: Dissemination of information and discussion about specific topics, such as safer sex practices, drugs or family planning, by members of a person’s own age group, occupation, or social and economic status group.

• **Preventive education**: Education, including HIV awareness and sexual health information, targeted at reducing behaviour that can be considered harmful to oneself or one’s surroundings.

• **Rehabilitation**: Process of returning a person to productive daily activity at whatever level is appropriate for that individual. The aim is to either improve or else maintain the quality of life and functional capacity, decreasing hospitalization and increasing self-care.

• **Reproductive health**: Concerns well-being in all matters relating to reproduction. It implies that people have the capability to reproduce and the freedom to decide if, when and how often to do so. It recognizes men’s and women’s right to information and access to safe, effective, affordable and acceptable methods of family planning. Reproductive health care includes the prevention and treatment of sexually transmitted infections.

• **Risk factors**: Anything that increases the chances of HIV infection, including: unprotected sexual intercourse; sharing needles that have not been sterilized; being born to an HIV-positive mother; and receiving a transfusion of HIV-infected blood.

• **Safer sex**: Sexual activities in which no potentially harmful bodily fluids (i.e., blood, semen, pre-ejaculate, vaginal fluids, and breast milk) are exchanged. Also known as ‘safe sex’.

• **Self-care**: The manner in which an HIV/AIDS patient without a professional medical background cares for himself or herself. Care encompasses such facets of health care as nutrition, precautions (e.g., against risk factors), health promotion and maintenance. The patient practising self-care can be guided by a medical professional and supported by family and friends.

• **Sex worker**: A person who has sex with others to acquire money, goods or favours, in order to make a full-time or part-time living for himself or herself. The term ‘commercial sex worker’ is also used.
- **Sexual health:** Women’s and men’s ability to enjoy and express their sexuality free from the risk of STIs, unintended pregnancy, coercion, violence and discrimination. The ability to have an informed, enjoyable and safer sex life.

- **Sexuality:** The interplay of gender, gender role, gender identity, sexual orientation, sexual preference, and social norms as they affect physical, emotional and spiritual life.

- **Sexually transmitted infection (STI):** Any infection whose primary route of transmission is via sexual intercourse. Previously known as ‘sexually transmitted disease (STD)’.

- **Surveillance:** The on-going and systematic collection, analysis, and interpretation of data on a disease or health condition, also referred to as ‘epidemiological surveillance.’

- **Target group:** A group of individuals defined by specific characteristics, such as demographic or geographic characteristics, to which a programme or campaign is directed.

- **Transfusion:** The process of giving blood or parts of blood, such as serum, plasma, or red blood cells, from one person to another.

- **Youth:** Defined by the United Nations as the age group of 15 to 24, although the definition varies by country. The term is often used interchangeably with ‘adolescence,’ which is the stage of life during which individuals reach sexual maturity, or the transition period from puberty to maturity.

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**Sources**


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The Health and Development Section, Emerging Social Issues Division, UNESCAP prepared this publication. Ms Laura Skolnik coordinated the preparation and editing of the publication. The main authors were Mr Stephan Grosse Rüschkamp, Ms Ema Naito, Ms Marilyn Piels and Ms Laura Skolnik, with case study contributions by Mr Romen Bose and Mr Kim Ganglip. Ms San Yuenwah undertook final overall editing of the manuscript for publication. Mr Cengiz Ertuna undertook final review of the manuscript. The team would like to thank UNAIDS SEAPICT, especially Dr Swarup Sarkar, Ms Adriana Gomez-Saguez, Mr David Bridger and Mr Paul Toh for their contributions in reviewing technical aspects of the manuscript.

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