

The international newsletter on HIV/AIDS prevention and care

AIDS action

ASIA-PACIFIC EDITION

MAKING PROGRESS

All of us involved in HIV prevention and sexual health promotion, or in caring for people with AIDS, want to know how useful our work is. This issue of *AIDS Action* looks at simple ways



to collect information about our work and its effect on people, help plan future activities and adapt to changing situations.

It is also important for projects to be planned and monitored well so that senior managers or funders understand how the aims of the project are being achieved. This makes it easier for staff to participate in external evaluations and develop proposals for funding.

Monitoring and Evaluation

The words planning, monitoring and evaluation can sound technical and off-putting. Often projects are evaluated by outsiders in order to justify continued funding or political support and this can make an evaluation very threatening.

However, monitoring and evaluating do not need to be difficult. If monitoring is built into daily activities, and if evaluation is carried out regularly with the involvement of the target audience, projects become more rewarding and effective.

Both monitoring and evaluation are necessary for project management and planning.

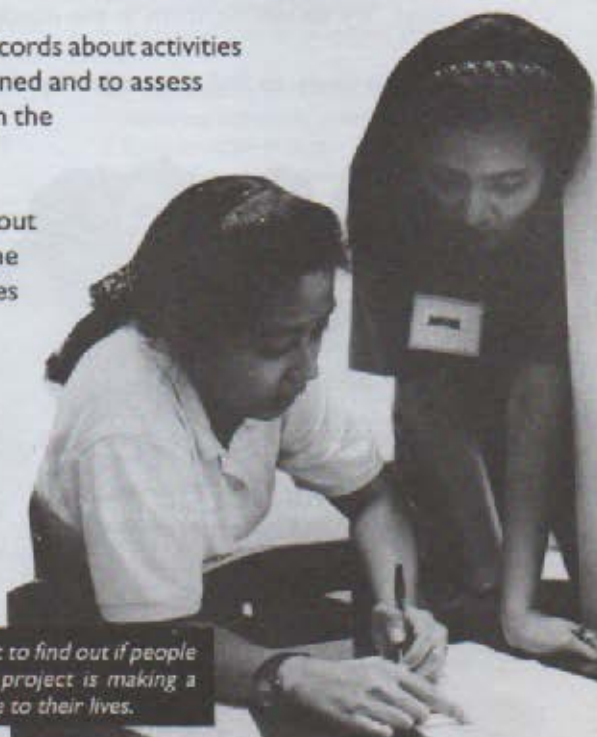
Monitoring means collecting information and keeping records about activities to check whether the work is being carried out as planned and to assess reactions of people receiving the services or involved in the project.

Evaluation means asking "Did we achieve what we set out to do?" and comparing the present situation with the past in order to find out to what extent original purposes have been achieved.

People working in community-based organisations often have a very good idea of what they are doing and how well it is being done. But it is very important for them to review their work regularly in order to answer two key questions:

- are project activities achieving what they had set out to do?
- Is the project making a real and positive difference to people's lives?

It is important to find out if people feel that the project is making a real difference to their lives.



Issue 32
July - September
1996

IN THIS ISSUE

Involving people

Steps in project planning

Rethinking Wildfire

Vancouver conference highlights

Published by



Health Action Information Network PHILIPPINES

AHRTAG

Appropriate Health Resources & Technologies Action Group

Project Plans

The diagram below shows the different stages in a project's life, using an imaginary example of where staff at a health center decide to develop a new HIV/STD project with the local community.

Planning steps

1. What do you want to achieve?

This is the overall purpose or aim of the project.

2. Find out what the situation is. Using baseline surveys, needs assessment and priority setting exercises. Issues to survey in any project include: HIV/STDs, factors increasing risk such as male or female migration and poverty; condom availability; and sexual activity and risk.

3. How are you going to achieve the aim? These are sometimes called **objectives** and refer to broad strategies that can be measured over time.

4. What specific activities will achieve these objectives? Each activity needs to have a time frame, a budget (including volunteer costs) and staff time allocated.

5. What results do you want to see from these activities? These are sometimes referred to as **outcomes** and must aim to fulfill your objectives. They can be numerical targets (e.g. number of people to be trained in six months).

6. How will you measure or monitor how far activities are achieving objectives? You need to choose markers or **indicators** which will show any changes that occur. These suggest, but do not prove, how far an objective has been achieved.

7. What tools will you use to collect this information? Staff and community volunteers need to develop simple methods to collect information about activities and chosen indicators (see pages 4 and 5).

8. How will you use this information for planning? Regular review of information will help you see whether activities are going as planned and within budget. You may decide to stop the activity, change it, or start again. **Occasional in-depth evaluations** are also needed, followed by review of aims, objectives and activities. The planning process then starts again.

Project Staff

1a. The new project aims to:

- improve sexual health among potentially vulnerable groups
- strengthen their coping strategies for reducing the spread of STD/HIV

2a. Staff prepare a baseline survey looking at:

- clinic STD figures
- STDs treated by traditional healers, private doctors and pharmacists
- deaths from HIV/AIDS, where known
- clinic attenders' assessment of service
- condom availability

3a. Staff decide that the project can achieve its aims by:

- improving STD care for women
- providing sexual and reproductive health education in clinic
- promoting and providing condoms

4a. The clinic staff plan to:

- train staff on HIV/AIDS/STDs
- provide STD education and treatment for women and men
- improve links with hospital e.g. training, drug supply and laboratory tests

5a. In the clinic, activities will result in:

- better STD diagnosis and treatment
- increased client knowledge about HIV/STDs and satisfaction with services
- increased contact tracing

6a. Clinic indicators could include:

- numbers of women seeking STD treatment
- numbers of women with STDs at ante-natal clinic
- numbers of condoms distributed
- reported client satisfaction and reduced stigma

7a. Tools include:

- clinic records
- medical supervisor checklist of counselling and diagnostic skills
- focus group discussions with clinic attenders every six months

8a. At regular project meetings, staff look at records, discuss any difficulties and review progress and possible improvements.

An evaluation includes surveys, interviews and record analysis for comparison with the baseline survey. The results are discussed internally and, with advisory group, written up for funders and national managers.

Community Links

2b. Staff set up meetings with groups including clinic attenders, women, religious leaders, teachers, traditional midwives, healers and young people, to discuss current situation and prioritise key concerns. An advisory group of representatives is selected to meet regularly with project staff at every stage, and co-ordinate community activities.

3b. With staff support, the advisory group decide on additional objectives, e.g.

- improve economic situation, especially of women
- encourage better communication, especially between young men and women



4b. The advisory group plan to:

- select and train community educators
- improve condom access via shops, pharmacies and community educators
- have community discussions about STDs and sexual relationships
- set-up income generation schemes

5b. In the community, results include:

- improved communication between men and women about sexual matters
- increased use of condoms
- increased actions to reduce poverty

6b. Community indicators could include:

- reported domestic violence/arguments
- condom sales in bars
- establishments of women's credit schemes
- more reports of sexual responsibility and willingness to use condoms

7b. Tools include:

- community questionnaire to ask about condom use, STDs, etc.
- observation of condoms displayed in pharmacies, shops and bars
- focus group discussions and community meetings

8b. Advisory group attends project meetings and discuss any issues with community.

Results are fed back to community meetings where the activities are assessed and the exercise of setting priorities is repeated.

Collecting Information

AIDS Action looks at some simple methods that community projects can use to monitor their work.

Most organisations are already collecting information about their activities – and often collecting more information than can be used! The important points to remember are:

- collect information systematically - record sheets are not useful if they are not filled in regularly
- be selective – only collect information that refers specifically

Finding out about feelings

Monitoring and evaluation can be especially difficult for projects working on sensitive issues such as sexuality and relationships, or challenging views about how men and women behave. It is hard to explore changes in people's sexual behavior, values, or attitudes. People may not want to share personal and sensitive information or may not feel able to say what they really think or do.

However, changes in public behaviour may be influenced by the same factors that affect private behaviour, and these are easier to observe. For example, activities aiming to increase young women's confidence in negotiating sexual relationships can be monitored by recording whether young women speak out more in meetings, and by asking them what they feel about their confidence levels.

- to the ways you have decided to measure whether the activity is going as planned
- make sure that the recording system is easy to use and that the person using it understands and is committed to the process
- make sure that the information is collected by the person most involved in the activity. For example, supervisors who visit village health clinics are in the best position to do regular checks on drug supplies. Young peer educators are often the best people to fill in questionnaires with participants in a peer education session.

What to Collect

Information that can be measured in numbers is often called quantitative. This means asking questions about when, who, which, how much or how often. Information about people's feelings or attitudes that cannot be measured in numbers is often called qualitative. Both of these methods are needed to be able to explore reasons for both expected and unexpected results and to examine some of the possible causes.

There are a variety of simple tools for collecting information:

- **records**, for example, of purchase and distribution of supplies, number of peer educators trained or community meetings held
- **questionnaires or surveys**, used to gather a broad range of answers

- to specific questions
- **diaries**, kept by participants in the activity
- **group discussions** of case studies or events, such as clinic staff analysing why a child was not referred to hospital in time
- **observing the community**, looking at events or people's behaviour and recording these observations



Simple and accurate record-keeping can be part of everyday work.

- **focus group discussions** where people with specialist knowledge or common interests discuss a specific topic in depth
- **interviews** with groups or individuals to collect views on a particular issue, such as whether people with HIV feel that their quality of care is improved following a training programme for their carers.

After collecting information it is important to check your conclusions with the people involved, before planning further activities.

A monitoring system can cost money and must be included in the budget. For example, training and supervising, printing forms and staff time all cost money. Community and volunteers also have their own costs in time and energy.

Focus group discussions

A focus group discussion (FGD) involves talking about a particular topic in detail with a small group of people who share a common experience or area of interest, and are often of the same sex and similar age. Holding a series of FGDs on the same topic or activity at different stages of a project can show how thoughts, feelings and reported practices are changing.

Once a topic for discussion has been decided and the objectives for the group set, a question guide should be drawn up by project staff. The questions need to be general and open-ended to let people talk about their views and concerns.

For example, a question guide for an FGD which aims to find out the needs of women carers might include:

One or two introductory questions to help people feel at ease and start a general discussion on the topic, such as: *When someone is sick in your family, who usually takes care of them? What are the advantages? What are the difficulties?*

Two to four general questions to encourage people to talk about the main issues in their own words. For example, asking what they did yesterday to help the sick person in the family and checking details, such as what tasks they did at different times of the day.

More detailed questions to find out responses to particular ideas or suggestions, such as: *How do you feel about taking care of someone who is sick at home? What is the most difficult thing about taking care of someone with AIDS? Where can you go for help when it is hard to care for someone alone?* These questions should pick up key issues raised earlier. It is sometimes



useful to have prepared a picture or a written list of questions to hand out.

Finally it is important to ask a general question such as: *Are there any other comments that you would like to make about taking care of someone who is sick at home?*

A facilitator leads the FGD, encourages people to talk freely and ensures that the conversation does not stray too far from the question guide. Another person records the key points of the conversation.

Ideally, a group should be between 6 and 12 people to allow everyone to participate. A discussion should not normally last more than an hour and a half. It is important to check that everyone agrees with what is being recorded and hears or sees the final report.

Questionnaires

A questionnaire or survey can be useful for collecting information from a larger number of people. Everyone is asked the same questions so that the results can be analysed and compared.

Designing the questionnaire

Decide what you want to find out and from whom, and think about what questions are needed to obtain this information. Closed questions are those that only need a "yes" or "no" answer or a number, for example: *Have you received any AIDS education at school?* Try not to use questions which lead to a particular answer, such as *Do you agree that the home care programme should visit you every month?* Open-ended questions require the respondent to give a longer answer in their own words. For

example: *What have you learned at school about HIV and AIDS?* It is useful to include some open-ended questions to gather opinions that you may not have expected.

Keep questions brief and use simple language. A question is easiest to understand when it addresses only one idea. Use exact words which cannot be misunderstood to obtain precise answers, such as: *How many times in the last week?* It is useful to collect only information which can be remembered accurately. For example, instead of *How many times did you feel sick last year?* ask *How many times have you been to the clinic in the past four weeks?*

Use words which are non-judgemental, such as *person with HIV* rather than *AIDS victim*, or *more than*

one sexual partner rather than *promiscuous*.

Most importantly, keep the questionnaire short by avoiding unnecessary questions. If doing the questionnaire takes longer than 15 minutes, then people may become restless.

Preparation

The questionnaire should be checked (or pre-tested) with a small group of people who are similar to those who will be interviewed. This ensures that the questions are easy to understand, that people are willing to answer them and that the interviewers know how to fill it in correctly. The pre-test will also show whether the information collected is relevant and can be easily analysed.

Designing Appropriate Evaluations for HIV Prevention Interventions: A Case for Behavioral Surveillance

"Did it work?" is the most common and critical question asked by organisations engaging in or funding HIV prevention interventions. It may seem simple enough, but embedded within the question is usually a host of other questions: *Did it work compared to nothing at all? Did it work compared to another intervention using another approach? Did it work to change behaviour? Did it work to reduce HIV prevalence? Did it work to sustain the organisation over time?*

These multiple meanings of "what works?" are what frequently lead to misunderstandings about the effectiveness or success of a particular project since two individuals evaluating a project

as noted above, but rather devote funds and effort to serving as many people as possible to reduce disease prevalence. This does not mean that such a service-oriented project should not be evaluated, but rather that the evaluation should focus on different aspects of project implementation.

The table (at right) highlights the differences between pilots and service-oriented projects.

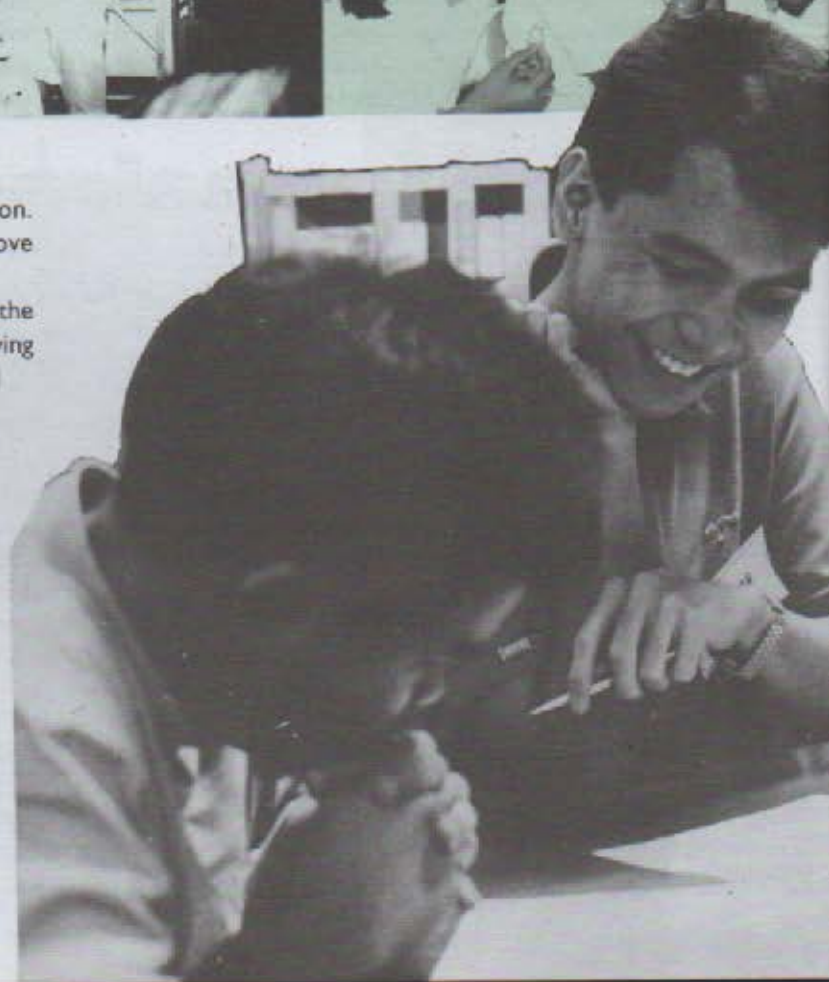
The AIDS prevention and Control Project (AIDSCAP) of Family Health International, a worldwide AIDS prevention project for developing countries which is funded by the US Agency for International Development, has been working on evaluation



intervention may have differing conceptions of the question. Furthermore, the methodologies used to answer the above questions are radically different.

A useful differentiation to help guide the evaluation of the project is to first determine whether the intervention is trying something new and innovative or whether it is using tested strategies. If the project is experimenting with a new intervention, then it should be considered a "pilot" or "demonstration" project with a considerable portion of the budget (sometimes as high as 60%) and effort devoted to evaluation. Such a project should emulate field trials of vaccines which are tested on small numbers of people and their results then analyzed before distributing the vaccine to the greater population. An untested HIV prevention intervention should likewise work with small numbers of individuals and utilize an experimental design with an intervention and comparison group or site. The results of such a design will demonstrate the effectiveness of the intervention.

Once an intervention is tested, however, it should not require such substantial evaluation designs or budgets



Project Type

	PILOT/DEMONSTRATION	SERVICE
GOAL	<i>Test the Strategy</i>	<i>Implement a Tested Strategy</i>
SETTING	<i>One Controlled Intervention</i>	<i>Overlapping Interventions</i>
PEOPLE REACHED	<i>Few</i>	<i>Many</i>
BUDGETS	<i>High Evaluation Budgets</i>	<i>Low Evaluation Budgets</i>
MANAGEMENT	<i>Low management burdens</i>	<i>High management burdens</i>
FOCUS	<i>Concentration on measurement rigor</i>	<i>Concentration on service</i>
TIMING	<i>Depends on Study</i>	<i>Fast as possible to reduce disease</i>



strategies for HIV prevention projects for the past five years. Specifically, AIDSCAP has been focusing on some alternatives to traditional knowledge, attitude and behavior (KAB) surveys which have been conducted by agencies for decades – from family planning to HIV – to determine the effects of their projects.

Evidence and experience from decades of KAB surveys suggests that they have perhaps not been useful as originally conceived. The reasons for this are varied. First, well-executed KAB surveys require social scientific expertise which many implementing agencies do not possess. Furthermore, it is often unrealistic to attempt to build this expertise into an agency whose mission is essentially intervention-based, not research. Several reviews of KAB surveys have pointed out that the sampling designs, questionnaires and analysis of a fair amount of KAB surveys have been lacking in methodologic rigor.

Finally, it is not uncommon for several agencies to be working in the same geographic area with the same populations but providing different complimentary services. If each agency is required by their funding agency to conduct a KAB survey (which is often the case), this can lead to a plethora of

low-quality data with little utility to anyone.

AIDSCAP has been increasingly implementing large-scale behavioral surveillance survey (BSS) projects to take the place of burdensome, unmanageable KAB surveys. Similar to KAB surveys, behavioral surveillance surveys are quantitative surveys based on a structured questionnaire. Unlike a KAB survey, however, the BSS is meant to serve as the evaluation instrument which provides indicators for a group of agencies who are working together in a specific geographic area with several target populations.

An organisation which implements a BSS project is usually a university or research firm with expertise in quantitative data collection. This organisation works closely with intervention agencies both in the data collection phase as well as in the analysis phase.

Examples of BSS include Bangkok, Thailand where AIDSCAP

Did it work compared to nothing at all?

Did it work compared to another intervention using another approach?

Did it work to change behaviour?

Did it work to reduce HIV prevention?

Did it work to sustain the organisation over time?

implemented a three-year, five-wave behavioral surveillance project with OPTA, a research firm, to provide information on sexual risk behaviors for over 10 agencies working with the Bangkok Metropolitan Administration in the Bangkok Fights AIDS Project. In the State of Tamil Nadu, India, AIDSCAP is assisting the AIDS Prevention and Control Project (APAC) of Voluntary Health Services in implementing a behavioral surveillance project of eight population groups across the state. The BSS there will provide yearly behavioral indicators for the project over five years. Similar BSS projects are in development with AIDSCAP assistance in Indonesia, Cambodia, and Senegal.

Behavioral surveillance can reduce much of the management burden of conducting evaluations of projects by consolidating the evaluation of multiple agencies and strategies within the high-quality project. It can likewise serve as an effective policy tool to inform government leaders and policy-makers on high-risk behaviors of key population groups.

EVALUATING

Wildfire

Wildfire – a group activity which explores the emotional issues related to HIV/AIDS – was featured in the April-June 1995 issue of *AIDS ACTION* in the article "Understanding HIV" (page 7).

In the Philippines, Wildfire has been used by both non-government organizations and the Department of Health as a component in workshops on HIV/AIDS. Wildfire is not used on its own, but rather, it is part of a workshop package and complements the other activities conducted during the workshop.

To evaluate the effectiveness of Wildfire, a focus group

discussion was conducted among Wildfire facilitators, who by now had gained a wealth of experience in using this learning activity. The facilitators were asked to share their experiences and give recommendations on how Wildfire could be improved.

Another FGD was conducted among nursing students who had just gone through a session of Wildfire in one of Health Action Information Network's workshops. The FGD among participants was intended to elicit feedback, and at the same time validate the inputs of the Wildfire facilitators.

Facilitators share their insights

The FGD among facilitators of Wildfire focused on questions regarding the effectiveness of Wildfire, factors which affect effectiveness, and recommendations on how the activity can be improved.

The FGD yielded valuable information which could be used by other facilitators to improve the conduct of the group activity. Highlights of the FGD are discussed below.

Factors that affect effectiveness

- **Capability of the facilitator.** The credibility as well as the skill of the facilitator is very important. Flexibility on the part of the facilitator would also contribute to an effective Wildfire session.

- **Composition of the workshop group.** Facilitators noted that a homogeneous group – one where the participants have similar characteristics – was often more effective than a heterogeneous group.

- **What comes before Wildfire.** Wildfire is part of a training package, and its placement within the workshop is crucial. Workshop participants would usually go through a discussion of basic HIV/AIDS before undergoing Wildfire. This way, they have a better understanding of the exercise. Wildfire also allows the workshop facilitators to check if the participants understood what had been discussed in the basic HIV/AIDS course.

- **What comes after.** Discussions or exercises in risk reduction measures are usually very effective after participants have

undergone Wildfire. Having realized their potential vulnerability to HIV infection, they are usually more receptive to ideas and suggestions on how to reduce risk of infection.

The success of Wildfire as a learning activity rests heavily on the facilitator. The following are recommendations to improve the skill of the facilitator:

- **Experience Wildfire as a participant first.** Before a person facilitates a Wildfire session, experiencing Wildfire first as a participant would be of help. This way, the facilitator will be able to empathize better with participants of Wildfire sessions he or she will facilitate in the future.

- **Be familiar with the guide questions.** While beginners may need a checklist to make sure that the discussion flows through the correct process, it is better if the facilitators do not need to refer to the training manual while handling Wildfire. A short checklist of key words may be used instead.

- **Practice is essential for improvement.** The facilitators noted that it usually takes three sessions of facilitating Wildfire before the facilitator becomes fully comfortable and confident about what he or she is doing.

Basic Components of Wildfire

While the facilitators acknowledged that there is room for flexibility in the conduct of Wildfire, there are essential components which should not be left out, otherwise the activity's effectiveness may be lessened. These components (in chronological order) are:

- Introduction/instructions
- "Sexual transmission" (shaking of hands among participants)
- Prevention
- Realization of exposure
- Counseling/testing
- Living with HIV
- De-briefing

Feedback from Workshop Participants

The focus group discussion among nursing students who had just participated in Wildfire centered on how they felt during the Wildfire session, the messages conveyed by the group exercise, and their perceptions regarding the effectiveness of Wildfire.

For the workshop participants, there were many messages conveyed by Wildfire, among them the importance of prevention – otherwise the disease can indeed spread like wildfire.

The workshop participants were almost unanimous in saying that Wildfire is effective. Wildfire gives an opportunity to explore the psychosocial and emotional aspects of HIV/AIDS at a personal level. They felt that the workshop's vicarious experience of HIV at a personal level made it easier to understand the complexities of living with HIV and AIDS.

Others cited the interaction among workshop participants as a very strong point of Wildfire. Listening to the different perspectives raised by fellow workshop participants was in itself a major learning experience.

Some participants felt carried away by the strong emotions aroused by Wildfire. It is in instances such as these that the skill of the facilitator becomes even more crucial. Also, de-briefing is a step which should not be missed.

With regard to ways to improve the conduct of Wildfire, some participants felt that there should have been a deeper "mental conditioning" or a more detailed briefing.

Some participants, however, perceived Wildfire as an "unnatural" situation, others felt that they were bound by the rules of the exercise to behave in a certain way. Understandably, some participants experienced negative feelings during the group exercise, particularly those who had been "exposed" to the virus. For example, one participant would not have had multiple partners in real life, thus risk of exposure would be lessened. The

participant felt bad because she became "exposed" to the virus in the course of the group exercise, which she felt was unfair because she would have behaved differently in real life.

It is during situations such as these that the skill of the facilitator in handling emotional issues becomes very crucial. By processing negative feelings such as these, the facilitator can help the participants turn negative emotions into more affirmative learning experiences.



AIDS Action
would like to acknowledge the participation of the

following Wildfire facilitators: Dyeri Andamo, Gladys Cortez, Joel de Mesa, Ted Nierras and Bernard Tomas.

The FGD among Wildfire participants had representatives from the following academic institutions: Aquinas University, Bicol University, Ago Medical and Educational Center and Immaculate Conception College, all located in Albay, Philippines.

One World, **One Hope:** *The Vancouver Conference*

MICHAEL L. TAN

The 11th International Conference on AIDS was held in Vancouver, Canada from July 7 to 11, 1996, with about 15,000 participants from 125 countries. The conference was preceded by media reports about breakthroughs in drug therapy, particularly around a new group of anti-HIV drugs called protease inhibitors. The last international AIDS conference was held in 1994 in Yokohama, Japan, and was marked with more pessimism following disappointing results with a large clinical trial involving the use of zidovudine (AZT). How realistic then was Vancouver's theme of "One World, One Hope," especially for Asia and the Pacific? What was, and was not, featured in the global news agencies' releases, and why? The following summary of the conference highlights should help you to decide.

Epidemiology

At the conference, a report released by UNAIDS (Joint UN Programme on HIV/AIDS), Family Health International and the Harvard Medical School evaluated the status and trends of the HIV epidemic. Globally, it is now estimated that there are some 22 million people living with HIV and AIDS, including some 21 million adults and 800,000 children. About 94 percent of people living with HIV are in developing countries. The pandemic is estimated to grow at the rate of about 7,000 new infections per day, or about five new infections per minute. Since the beginning of the epidemic, almost 6 million people have died from HIV and AIDS.

The report did have some good news: infection rates seem to have "stabilized" or are decreasing in some developed countries, including the United States, Australia and New Zealand. There is also evidence that in countries like Uganda and Thailand, HIV prevention efforts may be slowing down the epidemic at least with some population groups. At the same time, infection rates are rising rapidly in many developing countries. In Asia, there is great concern over the increasing rates in countries like India, Cambodia and Myanmar. Despite comparatively low prevalence rates, India now has the world's largest number of people with HIV/AIDS simply because of its large population. Again showing how HIV is a disease of development, infection rates continue to rise among certain populations



The Conference logo (at right), and one of the NGO booths at the conference exhibit.

in developed countries. In the United States, these include "communities of color," i.e., minority groups such as Blacks and Hispanics, who continue to be unreached by effective HIV prevention programs.

Basic Research about HIV: Viral Loads, HIV Subtypes, and Chemokines

Two areas of basic research dominated many of the discussions at the conference: (a) viral loads and (b) chemokines.

Since 1995, medical researchers in the United States have pushed for the use

of viral loads as a way of monitoring HIV disease. "Viral loads" is a lay term which is not quite accurate. What it actually refers to is plasma viremia, or the levels of virus in the plasma. Using polymerase chain reaction (PCR) tests, it is possible to detect HIV RNA fragments

(genetic material) in the blood. By looking at this viral load, it is possible now to come up with a prognosis, i.e., evaluate the patient's stage of HIV disease. For example, in men with HIV-1 RNA levels less than 4500 copies/ml of blood, about 93% would be expected to survive for the next five years while the median time for AIDS to develop would be about 7.8 years. If the RNA levels are between 4501 and 13,000, the five-year survival rate falls to 89% and the median time to AIDS would be 6.6 years. The use of viral load is a better predictor than CD4 cell (T4 lymphocyte) counts. Testing for viral load also allows for monitoring of the effects of drug treatment — a drug's efficacy would be monitored by the decrease in HIV viral load. The problem with viral load testing comes mainly with its high cost.

There were several papers on the distribution of HIV-1 subtypes. There are now ten subtypes of HIV-1 that have been identified: A to I and O. These have specific geographic distribution. For example, subtype B dominates in Europe and North America. In Thailand and parts of Southeast Asia, subtype E is identified most frequently. Papers at the Vancouver conference did show that there seems to be a trend toward mixing of these subtypes. Thus, one study showed that up to a third of the identified subtypes from patients in Germany are now non-B, i.e., subtypes from Asia and Africa are now more frequent. Dual infections with subtypes B and E are also now being reported.

There is concern that this international mixing could mean changes in the epidemic's transmission patterns. Subtypes from Asia and Africa, for example, seem to be transmitted more efficiently through heterosexual contact. The mixing of subtypes also means that vaccine research would have to be

reoriented. At present, vaccine products are based on subtype B and therefore may not be effective to protect against other subtypes that occur around the world.

Clearly, HIV-1 is marked by great genetic variation, not just across countries but also in individuals. Researchers reiterated earlier findings showing rapid mutation in the virus, including resistance to drugs.

The other focus of basic science papers was on chemokines (also known as cytokines). Until recently, HIV's destructive action was attributed to its being able to bind itself to CD4 receptors in T-cells in the blood, which are important in the body's immune system. Recent research shows that HIV also binds itself

to receptor sites on chemokines, which are chemicals in the body that attract immune cells to sites of infection. HIV's target would therefore be cells that have both CD4 and chemokine (more specifically, CC-CKR-5) receptors. These findings are important for the development of future drugs since it means that there are now two co-receptor sites that should be blocked as part of an anti-HIV treatment. Other researchers warned that more research is needed on other possible suppressors of HIV replication. Jay Levy of the University of California said CD8+ cells from long-term nonprogressors (people infected with HIV but who have not developed AIDS) have a substance that seems to inhibit HIV replication, at least in the laboratory. Levy called this substance CD8 antiviral factor (CAF).

Drugs

The use of protease inhibitors in the treatment of HIV drew the most media attention. Over the years, a number of drugs called reverse transcriptase inhibitors (e.g., zidovudine, didanosine) have been developed against HIV. These drugs work by interrupting the process of copying or transcribing HIV's genetic material. The protease inhibitors work on another phase of HIV's reproduction: the assembly of the new virus after the genetic material has been copied. Logically, combining reverse transcriptase inhibitors and protease inhibitors may offer better chances of working against HIV because it affects different phases of HIV reproduction. Since December 1995, three protease inhibitors have been approved (see box).

A small study conducted at the Aaron Diamond AIDS Research Center showed that the use of three anti-HIV drugs — zidovudine, 3TC and ritonavir — resulted in aviremia, i.e., there was no evidence of viral reproduction in the blood. However, the study involved only 12 patients, of whom only nine remained with the trial.

Shortly before the conference started, a panel of experts released a consensus statement of antiretroviral therapy for HIV infection.

Antiretroviral Drugs

Nucleoside Analog Reverse Transcriptase Inhibitors

Zidovudine (ZDV, AZT, Retrovir)
didanosine (ddl, dideoxynosine, Videx)
zalcitabine (ddC, dideoxycytidine, Hivid)
stavudine (d4T, Zerit)
lamivudine (3TC, Epivir)

Non-Nucleoside Reverse Transcriptase Inhibitors

nevirapine (Viramune)

Protease Inhibitors

saquinavir (Invirase)
ritonavir (Norvir)
indinavir (Crixivan)

continued on page 12

published in a special issue of the Journal of the American Medical Association, stating that "as many as 85 percent of patients treated with drug combinations that include the new protease inhibitors could achieve undetectable levels of plasma HIV." The optimistic mood of the statement seemed to be shared by other medical researchers, who are now using terms such as "suppression" and even "eradication" when referring to the action of the drugs on the virus. There were even suggestions that HIV disease might soon become another chronic disease, where medicines could be used to postpone, indefinitely, the development of AIDS.



"sanctuaries" where HIV may remain, for example in the central nervous system. If such sites exist, treatment would be more difficult since existing anti-HIV drugs are not able to penetrate the blood-brain barrier.

Clearly, "viral eradication" will not be easy. The drugs are all capable of causing serious side effects, which means that long-term therapy will be very difficult. Viral resistance to the drugs also develops rapidly, even when different drugs are combined. Finally, there is the high cost of the drugs. Each of the new protease inhibitors would cost from US\$6000 to \$8000 per year, an amount which is considered high even by people living in developed countries. Anger and frustration over the lack of access to these medicines were expressed both by North American AIDS activists as well as by delegates from developing countries.

While tuberculosis is now recognized as the most common opportunistic infection in AIDS, there were few papers presented on the disease. The papers that were presented focused on drugs, mainly the growing problem of resistance to anti-tuberculosis drugs.

Other medical researchers are more cautious. Dr. David Ho of the Aaron Diamond AIDS Research Center suggests that anti-HIV therapy may need to focus on different "compartments" of HIV infection: free virion (virus particles); infected cells; T-cells that carry latent infection and macrophages that harbor HIV. Treating the macrophages, which are long-lived, may be the most difficult, requiring up to 3 years of treatment. He also said that it is not clear if there are other

Prevention Technologies and Programs

With so much focus on antiretroviral drugs, it was not surprising that less attention was given to work on the development of technologies to prevent the disease.

Dr. Christopher Elias of the Population Council gave a plenary presentation on female-controlled methods to prevent sexual transmission of HIV. Elias noted that AIDS is now the third leading cause of death in the United

States for women aged 25 to 44 (and the leading cause of death among African-American women). Elias said that "...nonconsensual sex, the fear of domestic violence or economic abandonment, and difficulties in initiating or sustaining discussion concerning condom use greatly limited many women's prevention options."

Elias noted that female condoms have been available since 1992 and that these seem to be

effective against HIV. Elias described current research on microbicides, substances that could inhibit or kill HIV and other microorganisms causing sexually-transmitted diseases. These include older spermicides such as nonoxynol, octoxynol and menfegol. The problem with these spermicides is that they are detergents and can be irritating in the genital tract. Despite widespread promotion of nonoxynol as a method to prevent HIV, Elias noted that there is still no consensus about the chemical's role in preventing HIV. Research is now ongoing to develop new chemicals or reformulate the older ones. The development here is quite slow since there is still little interest from private companies, who do not see these microbicides



as being commercially viable. Such products may therefore not be available in the next few years. Elias emphasized that any female-controlled method should be seen as a complement to male responsibility.

There was renewed interest in the use of zidovudine, this time for reducing the risk of perinatal infection. Dr. Yvonne Bryson, who delivered a plenary paper on perinatal infection, noted that studies show zidovudine can reduce, by as much as 67 percent, the

perinatal infection rate. However, women with HIV would have to start taking the drugs when they are 16 weeks pregnant. The costs are, again, substantial.

Several papers in the conference focused on the need to integrate different services, and technologies, for preventing HIV. These related mainly to the integration of reproductive health services, particularly family planning and the prevention of sexually transmitted diseases (STDs). One paper showed that in Malawi, HIV levels in the semen were

much higher in patients with urethritis (caused usually by gonorrhea and trichomonas). Two weeks after treatment, the semen viral loads in these men decreased. This could reduce the infection rates.

One last non-biomedical form of technology received increasing recognition for its potential in HIV prevention: information technologies. Several skills-building workshops demonstrated how information can be accessed rapidly through the Internet and related services.

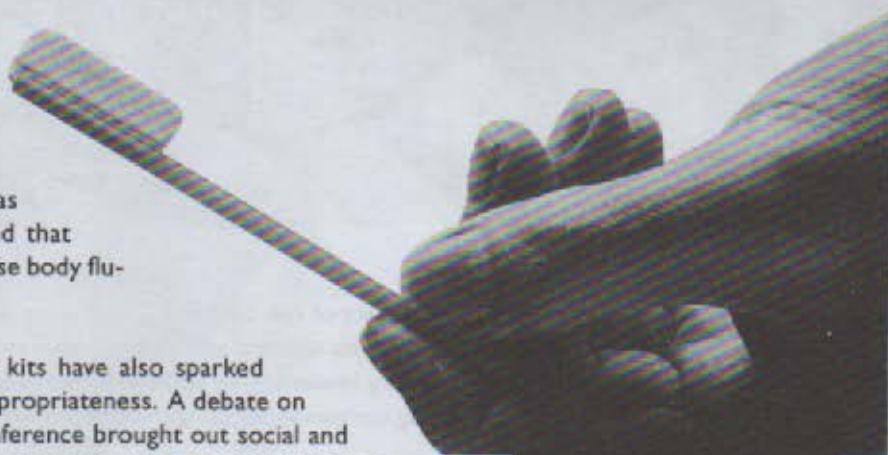
New Tests

The conference became an occasion to publicize new HIV antibody tests, including those that can be used for home testing. (The home testing kits allow for collection of samples at home but the sample still has to be sent to a laboratory for testing.) Most testing today uses blood but the new kits are able to detect HIV antibodies in saliva as well. (Shortly after the conference, a urine test was also approved by the US Food and Drug Administration.) The tests using saliva and urine are promoted as being easier to use and that they are safer since these body fluids are not infectious.

The home testing kits have also sparked off debates on their appropriateness. A debate on the first day of the conference brought out social and ethical issues relating to home testing. Proponents argue that the availability of testing in the privacy of the home could encourage more people to take the tests. Others argue that these tests may not be as accurate. All the tests rely on a detection of HIV antibodies rather than on the virus itself. These antibodies may not appear until several weeks after infection (the so-called window period). Thus, false negatives are possible. There are fears, too, that home testing might not be appropriate because of the lack of appropriate pre- and post-test counselling. Would such tests open the way to abuse by police, border guards, employers or even sexual partners who might use such tests indiscriminately?

None of the debates tackled the implications of saliva and urine tests for HIV education. Given that the tests are used to

detect HIV infection, lay people might easily become confused and think that saliva and urine can transmit HIV. Great caution is therefore needed to explain that levels of HIV in blood and urine are not infectious.



New HIV tests are less invasive such as the one which uses oral swabs.

The availability of new, less expensive tests, coupled with the introduction of new antiretroviral drugs is sure to spark more debates about testing. Increasingly, AIDS groups in developed countries are recommending testing on the premise that early detection will mean early treatment. Such arguments may not always apply to developing countries, where treatment and other support services are still inaccessible. There are also

concerns about such tests in developing countries where there are less guarantees of anonymity and informed consent. Michael Merson, who used to head the World Health Organization's Global Program on AIDS, recommended that policies on testing should be based on "sound and scientific data and in consultation with consumers." He also recommended that home HIV testing should focus on screening rather than on diagnosis.

continued on page 14

Mobilizing Communities

UNAIDS' Purnima Mane, who delivered a summary of the sessions and papers on social and behavioral sciences at the closing ceremony, noted that "Everything that needs to be said has been said. Since no one listened the first time it was said, it needs to be said again."

Earlier in the conference, Richard Parker delivered a plenary speech that in many ways set the tone for discussions on policies. Parker talked about the shifts in models, away from information-driven programs seeking individual change and toward multi-dimensional models of collective empowerment and community mobilization.

Parker noted that early in the epidemic, prevention programs had to say that everyone was vulnerable to HIV. This was a

tackled global political and economic issues. Meurig Horton of the United Kingdom said that activities of transnational corporations, assisted by policies of the International Monetary Fund and the World Bank, have imposed reductions on government budgets for social services and that these impact on the HIV epidemic. Horton noted that "People are considered worthy of health care only if they are considered economically productive contributing to the global economy." He observed that the World Bank is now more influential in defining global health policies than the World Health Organization and that priorities for AIDS programs depend on whether they represent priority growth markets for western consumer markets.

The heated discussions about politics and inequality were matched by the very active participation of AIDS activist groups.



"necessary fiction" to move away from the idea of "high-risk groups." At the same time, this tended to obscure the fact that some people are more vulnerable to HIV because of oppression, exploitation, and violence.

Parker argued that it is possible to aim both for individual behavioral change and social change, and that one must recognize how science, politics and ethics are all mutually implicated in all we do.

There were in fact several sessions marked by debate around political and ethical issues. Several presentations showed how a needle exchange program – giving clean syringes and needles to injecting drug users – could decrease infection rates. Yet in many countries, including the United States, this option has not been implemented because of opposition from conservatives who argue that the program would only encourage drug use.

One panel discussion on "AIDS, Politics and Inequality"

Members of the militant ACT-UP were active in demonstrations during the opening and closing ceremonies as well as in several plenary sessions. They also conducted daily demonstrations against drug companies, accusing them of profiteering from the epidemic.

The conference was marked by greater visibility of NGOs, particularly organizations of people living with HIV/AIDS (PLHA). Both at the opening and closing ceremonies, there were several speakers from such organizations. At the opening ceremonies, Doreen Millman, a silver-haired Canadian, courageously addressed thousands of delegates, declaring she had HIV and asking, "You're wondering how someone like me, a 63 year-old grandmother, got infected." After a brief pause, she continued: "The answer is very simple... It just doesn't matter."

At the closing ceremonies, an Indonesian PWA, Susana Murni, stunned the audience when she started her speech by rejecting the call of a previous speaker to "fast-track" medicines in developing countries. Murni said the call was "offensive and

insulting" and that Third World people were not to be guinea pigs for drug experiments. It was an eloquent contribution to the conference with a message that rejected condescending pity.

The NGOs continued a tradition of holding a community forum before the conference. The Vancouver forum resulted in the formation of a global working group of NGOs concerned with the protection of human rights of persons living with HIV/AIDS. Another working group called for global standards in treatment and care. A third group recommended the integration of research into community programs while a last group recommended that national AIDS programs should allocate at least 15 percent of their funds to NGOs and community-based groups.

As the conference came to a close, the distinction between

*"Everything that needs
to be said has been said.*

*Since no one listened
the first time it was said,
it needs to be said again."*



"biomedical" and "political" issues became artificial. At the closing ceremonies, Dr. Michael O'Shaughnessy presented a summary of Track B (Clinical Medicine) papers. He noted one paper showing that Africans with AIDS, in London had better survival rates than other population groups. Thus, the poor outcome of African patients in Africa was clearly related to a lack of access to services. O'Shaughnessy said the problem cannot be fixed by drugs alone. He concluded his presentation: "We speak of one world, but in reality we are worlds apart."

The joint report from UNAIDS, Family Health International and Harvard Medical School notes that "... the HIV/AIDS pandemic is now composed of distinct epidemics each with their own features and force, and disproportionately impacting on the developing world." The conclusion, drawn from cold epidemiological statistics, should force governments and NGOs to seriously look into the reasons why such distinctions have emerged.

Effective HIV/AIDS activities: NGO work in developing countries. Report of the Collaborative Study. UK NGO AIDS Consortium. 1996. This report summarizes highlights from evaluation studies of 19 field organisations in developing countries and 13 agencies based in the United Kingdom. The report shows how different methodologies can be used to evaluate various types of HIV/AIDS activities in the areas of prevention and care. The methodologies used include focus groups; individual and family interviews; costing analysis and process documentation of projects in various stages of implementation. One important lesson from the collaborative study was the need to analyze HIV/AIDS activities in relation to organisational structure and effectiveness. Among the participating organisations were six organisations from India, Thailand and the Philippines. Other countries represented were Ghana, Uganda, Zambia, Zimbabwe and Brazil. Copies of the report are available from the UK NGO AIDS Consortium, 37-39 Great Guildford Street, London SE1 0ES, United Kingdom.

Broadening the front: NGO responses to HIV and AIDS in India by J Shreedhar with A Colaco. 1996. Describes the pioneering work of seven India NGOs in response to the HIV epidemic in India. Limited copies are free for developing countries, £2.75/copy elsewhere. Available from TALC, P.O. Box 49, St. Albans, Herts, AL1 5TX, UK.

Evaluating HIV/AIDS health promotion. P Aggleton, D Moody, A Young. 1992. A resource for HIV/AIDS health promotion workers in health authorities, local authorities and voluntary organisations. Available from Health Education Authority c/o Marston Book Services Ltd, P.O. Box 87 Oxford OX2 0DT, UK. £10.95.

HIV/AIDS project planning manual for NGOs. J Huddart. 1993. Manual for non-governmental organisations working in AIDS with information that can assist in improving planning and project development skills. Available free from UNDP, Regional Projects on HIV/AIDS, 55 Lodi Estate, New Delhi 110 003, India.

Tools for project evaluation: a guide for evaluating AIDS prevention interventions. 1992. Reviews evaluation methodologies with suggestions for evaluating HIV/AIDS projects in developing countries. Includes guidelines and a bibliography for further reading. Available for free from AIDSTECH/Family Health International, P.O. Box 13950, Research Triangle Park, Durham, NC 27709, USA.

Toolkits is a guide for the assessment, monitoring, review and evaluation of the impact of a development programmed on people's lives. A practical aid for development workers offering tools for participatory rural assessment (PRA) and logical frameworks analysis (LFA) which can be used at different stages of the process, and adapted to different situations. Available in English from Save the Children, Publication Sales, 17 Grove Lane, London SE5 8RD, UK. £6.95 plus 15% for postage and packing.

Community HIV prevention handbook covers the key steps for action planning with communities. For more details contact UNAIDS, 1211 Geneva 27, Switzerland.

Manual of group interview techniques to assess the needs of people with AIDS gives guidelines on running group interviews to plan HIV care programmes. Available free from WHO Documentation Centre, 1211 Geneva 27, Switzerland.

Partners in evaluation is a practical handbook for community-based programmes on monitoring and evaluation with local communities. Available for £3.20 from TALC, P.O. Box 49, St. Albans, AL1 4AX UK.

Self-evaluation is a simple guide for rural community development programmes. Available for US\$5.00 plus postage from World Neighbours, 4127 NW 122 Street, Oklahoma City, OK 73112, USA.

New Resources

Stepping stones is a training package on HIV/AIDS, gender, relationships and communication skills for running workshops with community members. Available for £85.00 (4 manuals + video), £47.50 (1 manual + video) or £12.50 (manual only) from TALC. Contact TALC for details of Swahili, Luganda and French language editions. Limited copies free to organisations in Sub-Saharan Africa on written request to TALC.

Facing the challenges of HIV/AIDS/STDs: a gender-based response contains an outline of the issues that affect women and men, and practical training exercises. Available free from KIT, Mauritskade 63, Amsterdam 1092 AD, The Netherlands.

For more information on HIV/AIDS, gender issues, and sexual and reproductive health, you may contact:
HIV/AIDS Inquiry Services
AIDS Action Asia-Pacific
 9 Cabanatuan Road
 Philam Homes 1104, Quezon City
 Philippines
 Telephones: (632) 927-67-60 or 929-88-05
 Fax: (632) 927-67-60
 Email: hain@mnl.sequel.net
 Web site: http://www.hain.org

AIDS action

AIDS Action is published quarterly in seven regional editions in English, French, Portuguese and Spanish. It has a worldwide circulation of 179,000.

The original edition of *AIDS Action* is produced and distributed by AHRTAG in London.

• **AIDS Action Asia-Pacific edition staff**
Editor M L Tan
Managing editor Mercedes B. Apilado
Layout Dennis C. Corteza
Circulation A Llacuna
Board of Advisers
 Dr Roy Chan (Singapore)
 Mr Jagjit Singh (Malaysia)
 Dr Mohammad Tufail (Pakistan)
 Ms Galuh Wandita (Indonesia)

• **International edition**
Executive editor Nel Druce
Assistant editor Sian Long
Design and Production Celia Tili

Publishing partners
 ABIA (Brazil)
 Colectivo Sol (Mexico)
 ENDA (Senegal)
 HAIN (The Philippines)
 SANASO Secretariat (Zimbabwe)
 Consultants based at University Eduardo Mondlane (Mozambique)

The Asia-Pacific edition of *AIDS Action* is supported by The Ford Foundation, CAFOD, Christian Aid and Levi Strauss Foundation.

SUBSCRIPTION DETAILS
 If you would like to be put on the mailing list to receive *AIDS Action*, please write to:
HAIN
 No. 9 Cabanatuan Road, Philam Homes
 Tel: (632) 9298805 / 9276760
 Fax: (632) 9276760
 E-mail: hain@phil.gn.apc.org
 http://www.hain.org
Annual subscription charges
 Free Readers in developing countries
 US \$20 Individuals elsewhere
 US \$40 Institutions elsewhere

REPRODUCING ARTICLES
 AHRTAG and HAIN encourage the reproduction or translation of articles in this newsletter for non-profit-making and educational uses. Please clearly credit AIDS Action / AHRTAG / HAIN as the source and, if possible, send us a copy of the reprinted articles.

AHRTAG (Appropriate Health Resources & Technologies Action Group) is a UK-based international development agency which supports the goal of health for all by promoting primary health care. Registered charity (UK) no. 274260

HAIN (Health Action Information Network) is a Philippine NGO involved in research and information on health and development issues. Registered with Securities and Exchange Commission 127593

Opinions expressed in this newsletter do not necessarily represent those of HAIN or AHRTAG. The mention of specific companies or of certain manufacturers' products does not imply preference to others of a similar nature. A person's HIV status or sexual orientation should not be assumed based on her or his article or photograph.