

Enhancing the involvement of people living with HIV/AIDS

Last year, the Alliance started work on its first operations research project, looking at the involvement of people living with HIV/AIDS (PLHA) in the delivery of community based prevention and care services. The project aims to find out what type of involvement has the most impact on the quality and effectiveness of services, and how to make that kind of involvement possible.

Supported by USAID, the study is part of the Horizons Project, a programme of operations research being co-ordinated by the Population Council. The study was successfully piloted in Burkina Faso between September 1998 and March 1999 and is currently underway in Ecuador. It will also be implemented in Zambia and a fourth site in Asia. In each country, local community based organisations (CBOs) working in both prevention and care are actively involved in the research.

In Burkina Faso, a local team carried out the research with five CBOs, all of which are supported by the Alliance linking organisation, Initiative Privée et Communautaire de Lutte Contre le VIH/SIDA (IPC), to provide care and support services for PLHA. One of the guiding principles of the research methodology is that it should benefit the CBOs at every stage of the project. Participants reported that the

study helped them to have a clearer understanding of their organisation and to identify the strengths and weaknesses of PLHA's participation in service provision. At the end of the study, all of the CBOs felt that they had benefited from their involvement, and some of the findings are already being acted upon.

For example, one finding was that CBOs felt that they did not have the skills to advocate for the rights of PLHA at a national level. In response, IPC are organising an

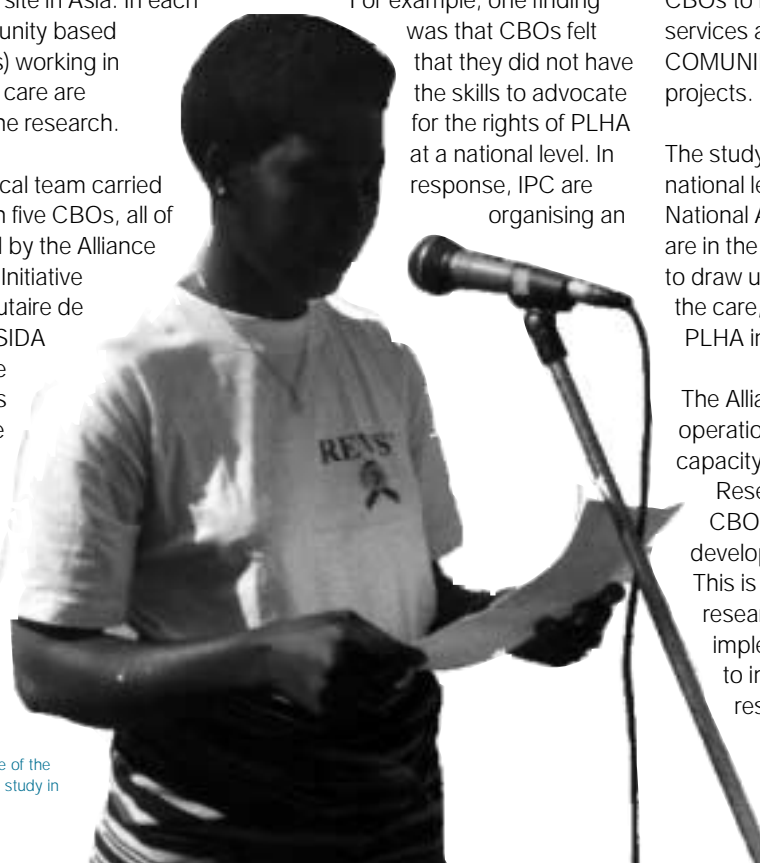
advocacy workshop for partner organisations in October 1999.

The study builds the capacity of the linking organisations (LOs), whose role is to support the CBOs to implement the results of the study. In Ecuador, the tools developed by the researchers to help CBOs to identify indicators to evaluate services are now being used by COMUNIDEC in their work with other projects.

The study has also had an impact at the national level in Burkina Faso. The National AIDS Programme and UNAIDS are in the process of using the findings to draw up a new government policy for the care, support and involvement of PLHA in the country.

The Alliance has learned that operations research can build the capacity of the CBOs and LOs.

Research of this kind can help CBOs to review their services and develop ownership of the findings. This is key to ensuring that the research findings are actually implemented at a community level to improve the quality of HIV/AIDS responses.



The Alliance works with over 500 NGOs in 14 countries, including India, Mexico and Zimbabwe.

KHANA
(Khmer HIV/AIDS NGO Alliance)
Cambodia

Tel: +855 23 214 049
Fax: +855 23 214 049
khana@bigpond.com.kh

AMSED
Morocco

Tel: +212 7 75 93 52
Fax: +212 7 75 00 98
pasasida@maghrebnet.net.ma

PHANSuP
(Philippines HIV/AIDS NGO Support Program)
The Philippines

Tel: +63 2 415 4381
Fax: +63 2 415 4381
phansup@info.com.ph

ZIHP – SERV
(Zambia Integrated Health Programme)
Zambia

Tel: +260 1 254 552
Fax: +260 1 253 839

Viewpoint

The impact of the study on local communities

Viewpoint: Issoufou Tiendrebeogo, President, Association African Solidarité, Burkina Faso

Association African Solidarité (AAS) is one of the five CBOs participating in the Horizons research project in Burkina Faso. Until last year, we focused specifically on prevention and have just recently become involved in care and support. We decided to get involved in care and support without really thinking through the role of PLHA in the organisation. The study therefore gave AAS the opportunity to consider the ways we were working with PLHA and gave me, personally, a better understanding of the day to day experiences faced by other people infected or affected by HIV/AIDS.

The study was different from others of this kind because of the way that it was conducted. We were actively involved in the process and we were able to validate the results all along. Rather than being a competition between the participating CBOs to find the best model, the study was an opportunity to share lessons and experiences with other local CBOs.

During the course of the study, AAS learned some very specific lessons:

- To improve the involvement of PLHA within AAS, we have to work with everyone in the organisation to raise awareness of the issues.

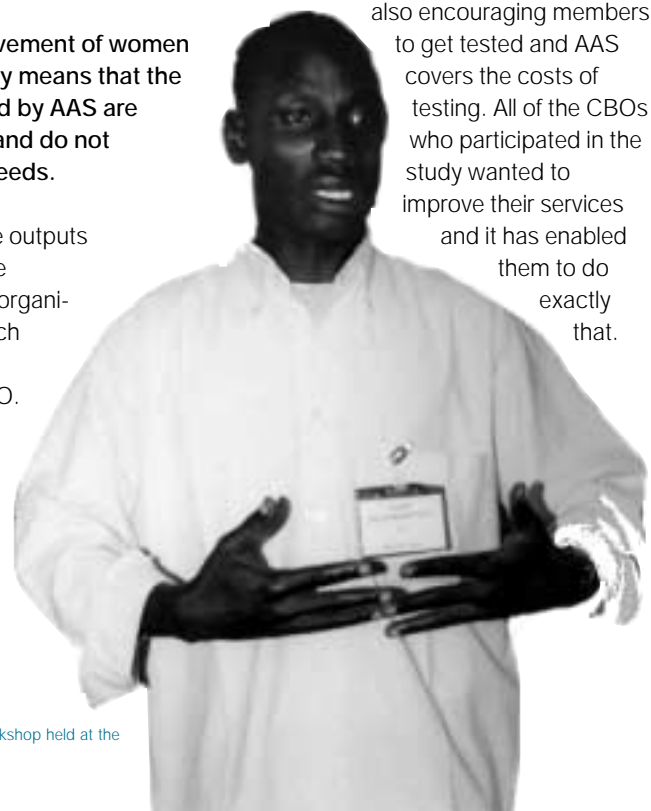
Members have to believe that PLHA have the capacity to become actively involved in the organisation, for this to happen in practice.

- Many PLHA who use our services are not given an opportunity to become involved in service delivery.
- We have to start by providing high quality care and support for PLHA within our organisation before trying to expand our services.
- The lack of involvement of women in service delivery means that the services provided by AAS are not appropriate and do not meet women's needs.

One of the concrete outputs of the study was the development of an organisational profile, which summarised the results for each CBO. We found that this was a really accurate reflection of what AAS does and are using it often as a kind of "identity card" with key partners and

donors. It has made it easier to explain our work to others and has greatly enhanced our relationships with our partners.

The most significant result for AAS is that, following the study, we have developed a plan to promote the greater involvement of PLHA within our organisation. We have also developed a plan to specifically increase the involvement of women. New positions have been created within AAS and these have been filled by PLHA. We are also encouraging members to get tested and AAS covers the costs of testing. All of the CBOs who participated in the study wanted to improve their services and it has enabled them to do exactly that.



Issoufou Tiendrebeogo, President of Association African Solidarité, at the dissemination workshop held at the end of the pilot phase of the study in Burkina Faso. (right)

Alliance Lanka
Sri Lanka.

Tel: +941 692 920
Fax: +941 692 920
alliance@sri.lanka.net

ANCS
(Alliance Nationale
Contre le SIDA)
Senegal

Tel: +221 8 24 71 34
Fax: +221 8 24 71 35
ancs@enda.sn

COMUNIDEC
Ecuador

Tel: +593 2 238 375
Fax: +593 2 553 643
comunide@ecuanex.net.ec

HASAB
(HIV/AIDS/STD
Alliance – Bangladesh)
Bangladesh

Tel: +880 2 823 021
Fax: +880 2 822 786
hasab@bdmail.net

IPC
(Initiative Privée et
Communautaire
Contre le SIDA au
Burkina Faso)
Burkina Faso

Tel: +226 36 31 01
Fax: +226 36 31 01
IPCBF@cenatrin.bf

Communities
in Action

Selected key findings from the pilot phase PLHA study in Burkina Faso

Key obstacles to PLHA involvement in CBOs working on HIV/AIDS

- X MOST PEOPLE STILL DO NOT KNOW THEIR HIV STATUS BECAUSE THEY HAVE NO ACCESS TO TESTING.*
- X MANY PLHA DO NOT JOIN CBOs WORKING ON HIV/AIDS BECAUSE THEY THINK THAT THIS WILL IDENTIFY THEM AS BEING HIV POSITIVE AND THEY ARE AFRAID OF STIGMA AND DISCRIMINATION. IN FACT, THE VAST MAJORITY OF PLHA CBO MEMBERS DO NOT REPORT DISCRIMINATORY TREATMENT AS A RESULT OF THEIR INVOLVEMENT.*
- X THE LACK OF A REFERRAL SYSTEM MEANS THAT THERE IS OFTEN LITTLE INFORMATION ABOUT THE SERVICES AVAILABLE AND THE OPPORTUNITIES FOR PLHA TO BECOME INVOLVED IN SERVICE DELIVERY.*
- X MANY PLHA EXPECT SOMETHING CONCRETE FROM THEIR INVOLVEMENT - FOR EXAMPLE, MONEY, MEDICATION OR FOOD - WHICH CBOs ARE USUALLY UNABLE TO OFFER. ORGANISATIONS NEED TO FIND WAYS TO SUPPORT VOLUNTEERS, FOR EXAMPLE BY LINKING THEM TO INCOME GENERATION PROJECTS.*
- X IN COUNTRIES WHERE ACCESS TO CARE IS LIMITED, PLHA SOMETIMES JOIN CBOs SIMPLY BECAUSE THEY SEE THIS AS A WAY TO RECEIVE BETTER CARE. THEY MAY NOT REALLY WANT, OR HAVE THE SKILLS, TO BECOME ACTIVELY INVOLVED IN THE ORGANISATION.*

Minimum conditions for PLHA involvement

AT AN INDIVIDUAL LEVEL:

- ✓ INDIVIDUALS NEED TO KNOW THEIR SEROSTATUS.*
- ✓ PLHA MUST WANT TO BECOME ACTIVELY INVOLVED, WITH THE INITIATIVE COMING FROM THE PLHA HIM/HERSELF.*
- ✓ PLHA REQUIRE TRAINING AND SKILLS DEVELOPMENT TO BE EFFECTIVELY INVOLVED IN SERVICE DELIVERY.*

AT AN ORGANISATIONAL LEVEL:

- ✓ ALL CBO MEMBERS HAVE TO BELIEVE THAT PLHA CAN BECOME ACTIVELY INVOLVED IN THE ORGANISATION.*
- ✓ CBOs MUST PROVIDE CONCRETE INFORMATION ABOUT THE ORGANISATION AND ITS SERVICES FOR PLHA.*
- ✓ PSYCHOLOGICAL SUPPORT SHOULD BE AVAILABLE TO PLHA WHO WISH TO BE INVOLVED IN CBOs.*
- ✓ CBOs SHOULD ENCOURAGE PLHA TO CARRY OUT ACTIVITIES WITHIN THE ORGANISATION, BASED UPON THEIR INDIVIDUAL SKILLS AND STRENGTHS.*
- ✓ CBOs HAVE TO BE ABLE TO OFFER APPROPRIATE TRAINING TO PLHA.*
- ✓ CBOs HAVE TO BE ABLE TO GUARANTEE CONFIDENTIALITY AND FIND WAYS FOR PLHA TO BECOME INVOLVED WITHOUT NECESSARILY REVEALING THEIR STATUS.*
- ✓ CBOs HAVE TO BE ABLE TO OFFER CONCRETE BENEFITS TO THEIR MEMBERS, FOR EXAMPLE THE OPPORTUNITY TO PARTICIPATE IN INCOME GENERATION SCHEMES.*

AT AN INSTITUTIONAL LEVEL:

- ✓ A LEGAL FRAMEWORK MUST BE IN PLACE TO PROTECT PLHA WHO DECIDE TO BECOME INVOLVED.*
- ✓ CBOs AND PLHA SHOULD BE INVOLVED IN TRAINING HEALTH PROFESSIONALS AND SOCIAL WORKERS TO RAISE AWARENESS OF ISSUES AFFECTING PLHA.*
- ✓ CBOs AND PLHA SHOULD BE INVOLVED TO ENSURE THAT APPROPRIATE TESTING AND COUNSELLING ARE WIDELY ACCESSIBLE.*

Benjie Dominguez

The former President of Pinoy Plus, Jeramie Diaz, known to many as Benjie Dominguez, died in July 1999, in Manila, Philippines. Benjie was loved and respected by those who knew him, and will be remembered for his commitment to improving the rights of PLHA. The Alliance is indebted to Benjie for his enthusiasm and support from the inception of our pilot activities in the Philippines in 1993.

Exploring new initiatives in North-East Asia

The Alliance has recently undertaken an exploratory visit to Mongolia and has been conducting desk research on HIV/AIDS in China. North-East Asia has been identified as a key site for future Alliance work because of its vulnerability to HIV and its emerging NGO/CBO sector.

Expanding access to care and support services in South India

Since 1990, YRG Care – a partner of the India HIV/AIDS Alliance – has been delivering a continuum of care and support to PLHA and their families. The Alliance is supporting YRG Care to manage its ever-increasing caseload by extending

technical support for HIV/AIDS programming and institutional strengthening to other organisations. This project will work with four organisations across South India, to replicate YRG Care's model for a continuum of care and support in their local settings. This scale-up effort will be documented through a Horizons operations research study.

First Alliance initiative in Zambia

In July, the Alliance held a workshop on sharing lessons in community care and support in Zambia. It involved 27 representatives of NGOs, CBOs and PLHA and covered issues such as the continuum of care, linking care and prevention, and income generation. The workshop was the Alliance's first initiative in Zambia – where it is a partner organisation of the Zambia Integrated Health Programme (ZIHP).

New Trustee

Dr Jens van Roey, Programme Development Officer for the Africa Middle East Desk at UNAIDS, has joined the Alliance's Board of Trustees.

Supporters:

● Alliance secretariat:

The World Health Organisation is supporting the development of a toolkit on access to treatment; the UK's DfID has provided support for care activities in Cambodia; the Howard Gilman Foundation has confirmed renewed funding; and USAID has confirmed additional funding to support monitoring and evaluation activities, as well as regional work in Africa.

● Linking organisations:

KHANA, Cambodia, has secured funding from the World Bank to support NGOs involved in prevention and care work. This is the first time that World Bank funds have been committed to an Alliance linking organisation for onward granting and technical support activities.

Resources:

● **The Alliance biennial report 1997-1998** is available in English/French from the secretariat.

● Horizons reports on the PLHA study in Burkina Faso

● Full report on the pilot phase of the study, in Burkina Faso. (In French only).

● Summary report of the key findings of the pilot phase, in Burkina Faso. (In English only).

● Profile reports on each of the 5 CBOs who participated in the study. (1 in English and French, 4 in French only).

● Zambia "Sharing lessons on community care and support" report

A report from the 'Community Lessons, Global Learning' workshop to share lessons in community care and support for people living with and affected by HIV/AIDS in Zambia is available, in English, from the secretariat.

● Asia participatory community assessment synthesis

A synthesis report on participatory community assessments carried out by Alliance LOs in Bangladesh, Cambodia and Sri Lanka is available, in English, from the secretariat.

New contact details:

The present phone and fax numbers for the International HIV/AIDS Alliance, +44 171 841 3500 and +44 171 841 3501, remain valid until 22 April 2000. All London numbers are changing to a new format, which is now running in parallel with the old. The Alliance can also now be reached on +44 20 7841 3500/ +44 20 7841 3501.

Please update all records well before 22 April 2000.