



International HIV/AIDS

# Alliance

Supporting Community Action on AIDS in Developing Countries

## “Beyond Awareness Raising: Community lessons about improving responses to HIV/AIDS”

The first report of “Community Lessons, Global Learning” – a programme to share lessons about responding to HIV/AIDS between communities, countries and continents.



“Community Lessons, Global Learning” is a partnership between the International HIV/AIDS Alliance and Glaxo Wellcome’s Positive Action programme.



Glaxo Wellcome in Global Partnership with HIV/AIDS Communities



# contents

1	Community Lessons, Global Learning	page 4
2	A challenge for NGOs: Moving beyond awareness raising	page 6
3	Responding to HIV/AIDS: Prevention, care and people living with HIV	page 8
4	Understanding vulnerability: Focusing resources and creating strategies for change	page 11
5	Gender, sexuality and sexual health: Pathways beyond awareness	page 15
6	Community mobilisation and participation: Making it happen	page 18
7	Conclusion: Key lessons, questions and recommendations	page 23



# 1

## Community Lessons, Global Learning

**This report aims to communicate the key lessons of the first year of “Community Lessons, Global Learning” – a collaboration between the International HIV/AIDS Alliance and Positive Action, Glaxo Wellcome.**

The International HIV/AIDS Alliance is an international non-governmental organisation (NGO) that supports community action on AIDS in developing countries. Positive Action is Glaxo Wellcome’s long-term international programme of HIV education, care and community support.

The central aim of the three year “Community Lessons, Global Learning” programme is to:

- help community groups to improve the quality of their HIV/AIDS work – by learning from the successes and failures of other organisations working in a similar context both within their own country and in other continents.

The programme also aims to:

- improve the quality of support to community groups by regional and international policy-makers and donors – by communicating community-level experiences and needs.

A key element of the “Community Lessons, Global Learning” initiative is the organisation of annual country seminars in six of the countries where the Alliance and partner linking organisations have established comprehensive NGO support programmes. These are Bangladesh, Burkina Faso, Cambodia, Ecuador, Senegal and Sri Lanka.



Participants at the IPC country seminar, Burkina Faso, sharing their experiences in community care and support.

The seminars enable NGOs and people living with HIV/AIDS to exchange their practical experiences and lessons learned in HIV/AIDS prevention and care. To increase opportunities for learning, the seminars include representatives from organisations outside of the Alliance as well – from the private sector, government, donors, and the United Nations, as well as other NGOs.

“Community Lessons, Global Learning” also encourages international technical exchanges among linking organisations and other NGO support programmes. For example, Lilly Marquez of COMUNIDEC, Ecuador, participated in the Partners’ Meeting of HASAB, Bangladesh, while Marie Rose Sawadogo of IPC, Burkina Faso, participated in that of ANCS, Senegal.

### Bringing stakeholders together

For example, the Partners’ Meeting of Alliance Lanka, Sri Lanka, was held during 20–21 January 1998 in Colombo. The participants included 32 representatives of partner NGOs from throughout the country, including those working with youth, free trade zone workers and slum communities. They also included staff and board members of Alliance Lanka, representatives of the Alliance, and participants from the European Union, UNAIDS, USAID, and the National AIDS Control Programme. It was also attended by Md. Enamul Kabir, Programme Director of HASAB, the Alliance linking organisation in Bangladesh.



NGO participants at the Alliance Lanka country seminar, Sri Lanka, exchanging lessons in participatory prevention work.

## International HIV/AIDS Alliance – Our mission

The mission of the International HIV/AIDS Alliance is to enable communities in developing countries to play a full and effective role in the global response to AIDS. The Alliance accomplishes this by mobilising a broad range of NGO and community groups, increasing their access to resources at a local level, and enhancing their technical and organisational skills. The Alliance also supports groups to share lessons learned, to collaborate with others, and to have a voice in national and international policy development. In this way, the Alliance encourages creative prevention and care efforts that respond to the real needs of communities, are owned by local people and have a sustainable impact.

In many countries, the Alliance works with and through one primary partner NGO in order to facilitate a broad response to the epidemic. These partner groups – known as “linking organisations” – facilitate collaborative planning and priority setting within the NGO sector responding to HIV/AIDS, and help other NGOs and community groups access technical, financial and management support in order to more effectively implement prevention and care initiatives.

## Positive Action – Our mission

Glaxo Wellcome, as a world leader in HIV therapy, is committed through the Positive Action programme, to engage in open dialogue and to collaborate closely with individuals, community groups, healthcare providers, governments, international agencies and others worldwide, in order to pursue the common goals of more effective HIV prevention, education, enhanced care and support for people living with or affected by HIV/AIDS.

“Community Lessons, Global Learning” was launched at the 4th International Congress on AIDS in Asia and the Pacific in Manila, October 1997. By June 1998, the first round of country seminars had been held – directly involving over 300 participants from NGOs and community groups, and many more from other sectors.

This report is based upon the documentation materials of those meetings as well as the 1997 Alliance Linking Organisations’ Meeting in Senegal (held in collaboration with NGOs supported by the Population Council in Eastern and Southern Africa, with the support of Positive Action). It also draws on lessons from Alliance partners in other countries – such as India, Morocco, Mexico and the Philippines.



Lilly Marquez, of COMUNIDEC, Ecuador, being interviewed for national television at the HASAB country seminar, Bangladesh.

## Perspectives on “Community Lessons, Global Learning”

*“Programmes that focus on the cultural and psycho-social issues faced by people living with HIV/AIDS, such as this, have been demonstrated to have a major impact in fighting this epidemic. We are delighted to be working with the International HIV/AIDS Alliance which has a strong track record in helping local communities develop innovative and effective strategies to fight the virus.”*

Ben Plumley, Positive Action, Glaxo Wellcome

*“This is a very positive project. It will help communities to share ideas and to benefit from the experiences of similar groups not only from other parts of their country, but other continents. The project will help to remove some of the isolation experienced by some of these communities and will help to give the communities and the individuals most vulnerable to or affected by HIV and AIDS the skills, ideas and innovation necessary to do their work as effectively as possible.”*

Jeffrey O’Malley, International HIV/AIDS Alliance

# 2

## A challenge for NGOs: Moving beyond awareness raising

There is an emerging consensus around the world about the conceptual under-pinnings of a more effective response to the HIV epidemic. Many similar ideas are reflected in the “Best Practice” collection of UNAIDS, advocacy positions of networks like the International Council of AIDS Service Organizations (ICASO) and the Global Network Of People Living With HIV/AIDS (GNP+), and evaluations from large multi-year programmes like the European Union’s AIDS Task Force and Family Health International’s AIDS Control and Prevention (AIDSCAP) project. One key message is that programmes must do more than raise people’s awareness of HIV and AIDS. In many countries around the world, high levels of reported awareness of the basic facts of HIV and AIDS co-exist with an increasing incidence of HIV transmission, a worsening epidemic and inadequate care and support for people living with HIV and AIDS.

Despite this broad consensus, large numbers of NGO programmes on HIV/AIDS continue to depend on simple information dissemination, perhaps accompanied by condom distribution.

An external evaluation conducted in 1996 of the Alliance’s first two years found that this was the case for most of the Alliance’s partner NGOs as well. It stated that: “IEC activities have been the main feature of NGO interventions to date... An increase in enabling rather than persuasive strategies is required”.

The Alliance and its partners took up this challenge, focusing energies through 1997 and into 1998 on helping NGOs to “move beyond awareness raising”. This then became the theme of the first year of country seminars for “Community Lessons, Global Learning”.

The key questions being addressed were:

- What does it mean to put “best practice” into practice?

### What does the Alliance mean by “moving beyond awareness raising”?

The Alliance uses the phrase “moving beyond awareness raising” to describe HIV/AIDS programmes that go beyond general information, education and communication (IEC), and focus on reducing vulnerability and ensuring behaviour change.

Programmes which “move beyond awareness raising” often involve initiatives to address contextual issues – such as empowering women to address cultural barriers to discussing sex with their husbands and to develop negotiation skills for condom use. They may also combine community outreach work with the provision of practical services to enable people to reduce their vulnerability – such as sexually transmitted disease (STD) treatment and counselling, and condom information and distribution.

- In the real world of complex community needs and organisational challenges, how do we actually promote effective behaviour change and care? What processes help NGOs to get there?

The “Community Lessons, Global Learning” programme – and, therefore, this report – draws lessons from the Alliance’s experience in supporting HIV/AIDS prevention and care strategies which not only build on but also move beyond the provision of information and the raising of awareness. It is based on the work of the Alliance’s linking organisations and their partner NGOs in developing countries in Africa, Asia and Latin America. For the sake of brevity, this “family” (comprising the international secretariat, linking organisations and partner NGOs) will be collectively referred to as “the Alliance”.



Participatory methodologies being used to help community members to “move beyond awareness” in Cambodia.

## Strategies for “moving beyond awareness raising”

The following are examples of the types of “moving beyond awareness raising” initiatives supported by Alliance Linking Organisations and shared at Partners’ Meetings during the first year of “Community Lessons, Global Learning”:

### ..... through providing services

In Bangladesh, HASAB has supported JTS in integrating STD advice and treatment into community outreach, health information and counselling with a marginalised “sweeper” colony in Dhaka.

### ..... through participatory prevention activities

In Morocco, PASA/SIDA has supported Association Oued Srou in the use of group discussions within socio-economic activities with poor young urban women in Khenifra.



Association Oued Srou combining sexual health and sexuality discussions with economic activities with young women in Khenifra, Morocco.

### ..... through addressing contextual issues

In Cambodia, KHANA has supported IDA in developing strategies to address gender and power relations and to involve the local police and military in their project with sex workers in Phnom Penh.

### ..... through mobilising marginalised groups

In the Philippines, PHANSuP has worked with IWAG to mobilise action and peer support within their programme with gay men in Davao City.

### ..... through harm reduction

In Bangladesh, HASAB has supported SHEASS in developing a harm reduction approach – including a needle exchange programme – with injecting drug users in Rajshahi.

### ..... through linking prevention and care

In the Philippines, PHANSuP has supported OCAFI in combining counselling and self-help services with integrating people living with HIV/AIDS into community prevention work in Olongapo City.



OCAFI linking prevention and care at a community level in Olongapo City, the Philippines.

### ..... through community based care

In Burkina Faso, IPC/BF have supported La Bergerie in Ougadougou in building on their prevention activities by combining out-patient and home-care, including the provision of basic drugs and training family members as care givers.

### ..... through self-help for people living with HIV/AIDS

In the Philippines, PHANSuP have supported Pinoy Plus, a self-help group for people living with HIV/AIDS based in Metro Manila, in carrying out peer counselling, income generation, advocacy and network building.

### ..... through the involvement of people living with HIV/AIDS

In Senegal, ANCS has involved people living with HIV/AIDS in its own priority setting and programme planning, including incorporating two members within their management committee.

### ..... through networks of people living with HIV/AIDS

In Ecuador, COMUNIDEC has supported the nascent National Network of People Living with HIV/AIDS in building their skills in organisational development and strategic planning.

To date, the Alliance has supported over 600 care and prevention initiatives with over 400 NGOs and community groups. The number of these initiatives moving beyond awareness raising has increased considerably. For example, in 1995, only 3% of projects in Burkina Faso were “moving beyond awareness.” By 1998, this figure stood at 93%.

This report describes the Alliance’s work towards the goal of HIV prevention and care. Its starting point is the recognition by Linking Organisations and their partner NGOs that this goal is not being, and cannot be, achieved by awareness raising strategies alone. The report looks at the Alliance’s search for a richer understanding of the epidemic, one which permits a greater clarity about the meanings of risk and vulnerability in relation to

the community, and about the meaning of community in response to HIV prevention.

Drawing lessons from the Alliance’s Linking Organisations and their partner NGOs, the report acknowledges that these lessons constitute a work in progress. The projects from which they are drawn are relatively young and there is a lack of impact evaluation data on which to base firm conclusions. However there is an emerging consensus within the Alliance “family” about the concepts and practices of a more effective response to the HIV epidemic, one which works with communities and with the experience of the community. The report articulates this consensus and its implications for achieving the goal of HIV prevention and care.

# 3

## Responding to HIV/AIDS: Prevention, care and people living with HIV

**As many individuals and institutions have learned during the past decade, HIV/AIDS prevention and care can, and should, inform each other. Indeed at community level, it is often hard to imagine continuing with prevention work without responding to care needs, or providing care which does not address the sexuality of people living with HIV and AIDS. Complementing this emphasis on linking prevention and care, there has been a broad political consensus since the 1994 Paris AIDS Summit that all HIV/AIDS programmes are strengthened through the greater involvement of people living with HIV/AIDS.**

The country seminars of "Community Lessons, Global Learning" provided an opportunity for many groups to share their own experiences of strengthening their prevention work by addressing care needs and/or by involving people living with HIV.

The success of FAES, and its HIV prevention project with transvestites in Quevedo, Ecuador [described in more detail in section 6], springs from its own staff's direct experience of the epidemic, and of living with HIV. For FAES, HIV is not an external threat or mystery virus; it is a lived reality, a daily challenge, an everyday emotion. The humanity of HIV and AIDS is an essential part of what FAES is and how it works.

This humanity has enabled FAES to work from within its own community, a highly marginalised and oppressed group of transvestites, to reach a point where they "felt treated like human beings," where HIV prevention meant something to them, where

they were able to care about themselves as individuals and as a community.

A trainer from COMUNIDEC, the Alliance linking organisation in Ecuador, described the FAES project when she participated in the March 1998 country seminar in Bangladesh. COMUNIDEC has come to believe that the involvement of people living with HIV and AIDS has been a crucial component of their success at helping NGOs involved in prevention to move beyond awareness raising. As they say: "The care and support projects are the ones that have shown us the face of AIDS, the ones that have sensitised the prevention projects – and even COMUNIDEC. [These projects] have become the catalysts that place us in touch with the reality of the epidemic."

However, the Alliance, like many others, is acutely aware that the experiences, expertise and example of people living with HIV and AIDS are usually absent from not only prevention, but also care programmes. Indeed, the continuing social exclusion and discrimination faced by those people living with the virus is one of the most disturbing aspects of the global epidemic, both hastening their illness and fuelling the silent spread of the epidemic.

In this context, the Alliance recognises the importance of creating safe spaces and supportive environments for people living with HIV and AIDS. In the Philippines, PHANSuP, the Alliance linking organisation, has supported Pinoy Plus, based in Metro Manila, to become the first Filipino self-help group for people living with HIV and AIDS, offering counselling, recreation facilities and income generation.



EUDES providing support for people living with HIV and AIDS in a community hospice in Quito, Ecuador.

## Case Study: Ensuring community care for people living with HIV and AIDS, L'AMMIE, Burkina Faso



Members of L'AMMIE with their medical kits containing basic supplies, Ouahigouya, Burkina Faso.

Association pour l'Appui Moral, Matériel et Intellectuel à l'Enfant (AMMIE) was founded five years ago when health workers at the regional hospital in Ouahigouya, in the northwest part of Burkina Faso, grew frustrated with the growing number of preventable illnesses and emergency health visits among the local community.

AMMIE decided to work in 10 of the 14 sectors surrounding Ouahigouya to provide primary health care including basic health promotion. Each sector contains approximately 5,000 people, and each was invited to elect a male and female "community agent" (CA) to be trained, supported, and paid a small monthly honorarium to act as health visitors in villages. In 1994, the Alliance (through the linking organisation IPC) supported AMMIE to train their CAs to begin providing HIV/AIDS education as part of their visits.

At the December 1997 Burkina Faso country seminar, AMMIE described how it had received support from IPC to move beyond their initial HIV education activities into care, and the impact of this on their work. It was decided that the CAs should be trained to provide basic home care, conduct home visits, facilitate referral and transport to the doctor and/or local hospital when necessary, and otherwise provide immediate basic care. They now carry medical kits containing basic supplies including soap, alcohol, cotton, and gloves, as well as some essential drugs, like immodium for diarrhoea. The main problems they described were the high cost of basic drugs, transport for the CAs within the sectors, and poor HIV testing practices in the region.

*"The volunteers at AMMIE were very eager to get involved with HIV care, because they encountered many people living with AIDS, and felt inadequate when all they could do was to provide information about how the virus is and isn't spread", explained Guiadoma Moré, IPC Programme Officer. "Adding HIV care both helped to respond to an immediate need, and increased the status and legitimacy of the health visitors."*

Discussion at the IPC country seminar and afterwards drew attention to the fact that while AMMIE had successfully shifted into a care role, it had not maximised all opportunities for prevention. For example, while CAs were including some syndromic STD diagnosis and treatment among their services, they were not carrying and promoting condoms nor offering family planning advice. These are now priorities for improvement.

An important focus of this work is secondary prevention – enabling the Pinoy Plus members to avoid behaviours which would risk transmitting the virus. This not only protects the health of others, but also reduces members' own exposure to other infections, including possible re-infection with HIV.

From this supportive foundation, Pinoy Plus members have become involved in HIV prevention activities in the wider community, advocacy with policy makers on the rights of people living with HIV and AIDS, networking with AIDS service organisations and welfare services, as well as reaching out to other people living with HIV and AIDS, including those in other parts of the country.

The importance of relieving isolation, building supportive networks and initiating collective action has also been recognised in Ecuador, where COMUNIDEC has supported the nascent Red Nacional de Personas Viviendo con el VIH/SIDA (National Network of People Living with HIV/AIDS) to build their skills in organisational development and strategic planning.

The country seminar in Senegal drew attention to another approach to working with people living with HIV/AIDS – involvement in the institutional processes of prevention planning and policy-making.



Baba Goumbala of ANCS, Senegal, sharing his experiences in community care and support with colleagues from Burkina Faso, Ecuador and Morocco at the 1997 Linking Organisations' Meeting in Dakar.

ANCS, the linking organisation, has, from its inception, included people living with HIV and AIDS in its decision and policy-making structures – with three out of 11 seats on its Board reserved for them. ANCS has also stimulated a wider dialogue between those infected and directly affected by HIV/AIDS and others – by organising national fora and meetings to discuss policy and strategy.

The National Forum on Care in November 1996 brought together for the first time people living with HIV/AIDS from all ten regions



*“With this disease, the people who suffer most are the poorest. The majority of people with HIV have died because of their economic situation. NGOs are the ones based in the community. They know about HIV because many have learned through the experience of living with HIV. We mustn’t lose this experience. This country is very poor. If we don’t get together in groups and find help and medicines, we don’t stand a chance.”*

Eduardo, a person living with HIV and a member of EUDES, an NGO supported by COMUNIDEC, Ecuador

of Senegal with care-givers, community groups, public sector policy makers and health personnel, as well as national and international stakeholders. As Baba Gumbala, of ANCS, says: “ANCS has enabled people with HIV/AIDS ... to sit for the very

first time on action committees alongside members of the government and leading NGOs .... facilitating a transfer of knowledge and encouraging collaboration.”

However, such dialogues, whether at local or national level, remain relatively rare. People living with HIV and AIDS continue to face stigma, discrimination and exclusion from the community, their sero-status often only compounding their existing marginalisation as a varying result of their poverty, sexuality or behaviour.

In many, if not most, of the countries in which the Alliance works, people infected with HIV lack the protection of basic human rights. Some groups, like the Centre for Policy Alternatives (supported by Alliance Lanka in Sri Lanka) are responding to this by sensitising opinion formers and policy makers to the ethical and human rights dimensions of the epidemic.

## Lessons learned and challenges for the future

Integrating HIV prevention programmes with strategies which address the exclusion experienced by people living with HIV and AIDS, and attend to their care and support needs, is a continuing challenge for the Alliance. Placing people at the centre of discussion of the epidemic makes it real, human, and close.

Some of the most important insights to emerge from “Community Lessons, Global Learning” include:

- **Encouraging those with direct experience of the epidemic to speak out – especially people living with HIV – is both possible and valuable.** Effective strategies include the creation of structures and processes which actively promote the involvement of people living with HIV and AIDS, as in the case of ANCS’ National Forum, and working with people living with HIV and AIDS to create safe spaces from which they can speak out, as in the Philippines and Ecuador.
- **Difficulties can emerge from the involvement of people living with HIV and AIDS in terms of mixed or unclear objectives.** Solidarity, support, a desire to protect others from HIV, and a need for income or access to care may all be important to people living with HIV and AIDS when getting involved in AIDS organising. NGOs, NGO support programmes and donors may be seeking to improve the quality of care or prevention services, influence policy and public perceptions, or respond to political pressure. Open discussion of objectives and clear definitions of beneficiaries are essential.
- **We are not yet successfully measuring the contribution of people living with HIV and AIDS to improved services.** We need to refine our abilities in this area if we are to justify their involvement, as well as to learn which methods of involvement make the most sense in particular circumstances.
- **In addition to creating safe spaces, we must continue efforts to counter the stigma and discrimination faced by people living with HIV and AIDS, and their carers.** Promotion and defence of basic human rights must not only address the issue of HIV status, as in Sri Lanka, but must also attend to the correlated marginalisation and oppression experienced by many people living with HIV and AIDS, whether as a result of sexuality, gender, ethnicity, religious faith and/or socio-economic class.
- **Implied within this human rights work is a recognition of the commonality and diversity of issues faced by people living with HIV and AIDS, their unity and their heterogeneity.** Acknowledging that there are many faces of HIV means working with people living with HIV and AIDS as people and not as embodiments of a hidden virus; people whose unique experience, and not simply their HIV status, will inform their work in HIV prevention. We also must learn much more about people living with HIV and AIDS who do not get involved, or who do not access services. How do we respect people’s choices while ensuring that they have access to what they need?
- **Expanding voluntary HIV testing and counselling services is not just a prevention intervention for the individuals involved. It may help to engender a dialogue within communities about how they can live with the epidemic.** The emergence of “People living with HIV and AIDS” groups and the involvement of people living with HIV/AIDS in other NGOs is consistently linked to the availability of testing. However, this also creates many demands for increased NGO capacity, especially in relation to counselling and the personal ability of staff to cope with the multiple issues faced by many people living with HIV and AIDS.

# 4

## Understanding vulnerability: Focusing resources and creating strategies for change

The experiences of Alliance-supported NGOs trying to move beyond awareness raising are consistent with the belief that vulnerability to HIV is associated with socio-economic marginalisation. Participatory community assessments have emerged as a key methodology to help NGOs develop concrete programming strategies to address these contextual issues. However, much more still needs to be learned.

In recent years, increasing numbers of academics, evaluators and people directly involved in HIV prevention have pointed out the inadequacy of prevention efforts which work on the basis of individualistic and/or cognitive models and fail to address other influences on behaviour. UNDP's "HIV and Development Programme" is well known for drawing attention to poverty and under-development as key factors making people vulnerable to HIV infection and inadequate care. The World Bank concurs, but also notes that economic growth may facilitate the spread of HIV. Researchers at the Harvard School of Public Health have emphasised the centrality of human rights abuses. Others point to economic and social disparities and difference more than deprivation per se. The emerging consensus is that programmes must understand and address the context in which people live in order to succeed.

As shared within "Community Lessons, Global Learning", NGOs working with poor and socially marginalised people within communities often instinctively understand the wisdom of addressing these "contextual issues" as part of their response to HIV, but many struggle to identify how relatively small programmes can make a difference.

### Focusing resources on the most vulnerable

There are continuing controversies in the world of HIV programming regarding the "targeting" of programmes and the risks that some HIV prevention campaigns are counter-productive: increasing discrimination against particular groups like sex workers, and creating a false sense of security amongst people who do not see themselves as at risk. On the other hand, programmes aimed at the "general public" rarely change behaviour, and are unlikely to be cost-effective even in high prevalence countries. For example, the AIDSCAP project demonstrated that even in high-prevalence Kenya and Tanzania, voluntary testing and counselling was much more cost-effective as a prevention intervention when aimed at women and specific groups of men. Given these challenges, an important theme of the "Community Lessons, Global Learning" seminars was how to focus resources effectively while avoiding stigmatisation.

The work of ACD with young Bangladeshi women [see case study] illustrates some of the complexities of the concept of vulnerability to HIV. A range of factors interact in their lives to produce their vulnerability, including class background, poverty, gender-related norms, and a lack of access to sexual health information and services. These factors combine to severely

### Case study: Addressing vulnerability among young migrant women, ACD, Bangladesh



Members of ACD receiving technical support from the Alliance linking organisation HASAB, Bangladesh.

At the country seminar in Bangladesh, the Association for Community Development (ACD) shared their experiences in working with young women being trafficked or migrating across the Bangladeshi/India border. Staff members described the nature of the women's vulnerabilities to HIV infection:

*"People here are very, very poor and their economic situation forces them to find ways to survive. For example, there are officials on both sides of the border [who] demand bribes from people crossing the border. However, the young women from the community don't have any money to pay the bribes, so they sell sex to the men. The women are very poor and have no work, so they have to sell sex to survive. However, because of their community's social pressures and values, they can't do it here, so they go to India."*

Md. Towhidul Alam, Community Educator, ACD

*"The young women have no information about their personal health and hygiene. They know nothing about sex, except for the act of intercourse, so when they sell sex they have full intercourse with the men. If they become pregnant, they receive no support and go to the quack to try to resolve the situation. Social pressures mean that they don't like to visit the doctor or talk about their problems - so they have to just keep it within themselves. As a result, some of them become suicidal."*

Monirul Islam, Co-ordinator, ACD

constrain the choices that they are able to make about protecting themselves from HIV infection. By contrast, the border guards who buy sex from the young women appear to have choices – such as the power to demand the bribe by virtue of their position, and the power to determine the nature of the sexual encounter by virtue of their gender. However, they too are shaped by economic, social and cultural pressures, which

create norms of masculinity. These norms – which are often heightened in uniformed services – celebrate men’s power over women and sanction the satisfaction of male sexual desire when, where and how they choose it. The men, too, may lack accurate information on their sexual health and lack the social support, from their peers and others, to question the role that expectations of masculinity play in exposing them to greater risk of HIV infection.

Thus, NGOs are learning that an understanding of vulnerability helps them to focus their resources and efforts more effectively. Developing an analysis of vulnerability within particular societies also demonstrates the inadequacy of an over-simplified notion of choice, which often underpins HIV awareness programmes (i.e. that people can simply choose whether or not to risk infection).

Ly Chan Sophal of the KHANA programme in Cambodia illustrated this point starkly at the launching of “Community Lessons, Global Learning” at the 4th International Congress on AIDS in Asia and the Pacific: “There’s no point spending all your time giving AIDS education to poor prostitutes when the police – who are their clients and bosses – live in barracks across the road. You have to work with the policemen too”.

But what can we do with the policemen? An understanding of vulnerability helps the NGOs decide who to work with, but it does not help them develop programmatic responses to complex relationships between risk and responsibility, personal agency, social background and setting.

More often than not, the NGO success stories shared through “Community Lessons, Global Learning” addressed these questions by starting their programme development processes with participatory community assessment methods and techniques adapted from proven success in rural development work.

## Participatory community assessments

In all of the countries where linking organisations have been developed, the Alliance has placed increasing emphasis on participatory community assessments as the foundations of appropriate and effective programmes. This strategy – which focuses upon various forms of “action research” to both mobilise community action and identify key information – was piloted by HASAB in Bangladesh in 1995. Since then it has been shared with other countries – where, in each case, the approach and methodologies have been adapted to meet the specific contexts and needs of the linking organisation and partner NGOs.

The participatory nature of the work carried out during the community assessment phase helps many NGOs to better understand community vulnerability. Participatory assessments strengthen relationships between NGOs and communities, by requiring NGOs to listen to and ask questions of communities rather than making assumptions. This is especially important in HIV prevention work, where, in the Alliance’s experience, the assumption is often made that the problem is a lack of AIDS information. The process of assessment has helped to open the eyes of NGOs to the complexity of problems they must consider when planning their projects. By actively involving the community in the assessment, a participatory process can also engender a community commitment to and ownership of the problems identified and responses planned. In this way, the assessment process helps to mobilise community concern about and action on HIV prevention.

Participatory community assessments also engage NGOs with their communities in ways that challenge traditional ideas about expertise. Such assessments emphasise local people’s ability to

*“At first we wondered why we should do an assessment, but the more we learned, the more we realised it was crucial. The findings were astonishing. They revealed things which were completely new to us even though we’ve been working in our community for twenty years.”*

Ahmed Ilias, Al-Falah, a partner NGO of HASAB, Bangladesh, working with Bihari refugees



A. B. C. D. E. F Approaches to participatory community assessments being shared and developed in linking organisation workshops, technical support visits and community projects in Morocco, Cambodia, Ecuador, Sri Lanka, Burkina Faso and Bangladesh.

analyse and articulate their own real-life experiences, the problems that they face and the solutions that they seek. Rather than extracting information, participatory assessments draw on the expertise of the community in a process of discussion and analysis. In this regard, the community focus of the assessment is significant, too.

By emphasising exploration of community-wide issues and needs, the assessment process orients NGOs towards appreciation of the community structures, norms and values which differentially shape people's vulnerability. Importantly, as the Alliance's partners have used and improved the process of participatory community assessment, the scope of assessment has broadened beyond a narrow focus on needs to consider community aspirations and existing resources. In this way, the assessment process has developed a richer picture of the contexts within which people live and a better analysis of HIV, and its prevention, in relation to these contexts.

As shared at the country seminars, the Alliance continues to adapt and refine a number of assessment methods which promote the participation of communities. Many are drawn from the work of other NGOs and institutions involved in community development work, and are often grouped under the rubrics Participatory Rural Appraisal (PRA) and Participatory Learning Action (PLA). Their emphases on drawing and diagramming as a stimulus to and focus of analysis, and on acknowledging and sharing community expertise, have greatly enhanced community participation. Significantly, too, PRA methods provide structured and accessible ways in which to assess the contexts of HIV transmission with a specific community. These include locational risks and resources, trends over time, temporal patterns, causal relationships, differentiations by age, gender and wealth, and priorities of problems and responses.

*"The programme in Morocco has learned from the [HASAB] experiences in Bangladesh – in terms of focusing on the needs of communities. We first ask people about their general concerns, and then begin to talk about more personal factors that influence their vulnerability."*

Issam Moussaoui of PASA/SIDA, Morocco

Participatory community assessments, and the understanding of how to respond to vulnerability that they help to develop, are an important step towards more effective HIV programming. In 1997, the Alliance supported many NGOs to carry out these assessments, and in both Bangladesh and Cambodia, all projects initiated by partner NGOs were based on such assessments. The benefits of careful participatory work at the assessment stage are evident in projects that are better designed to address factors of vulnerability.

As shared at the Bangladesh country seminar, in the case of ACD in Bangladesh, Md. Towhidul Alam comments: "The needs assessment showed that there are no entertainment facilities – so we have started to initiate games here...for community members and students at the local college. Before they had nothing to do and would often watch blue films on TV. Now, there's something else for them to do some of the time – which builds our relationship with them." In the Philippines, IWAG Dabaw's assessment with the gay community in Davao City identified a range of issues, beyond the need for HIV/AIDS information and condoms, which related to their vulnerability. These

*"NGOs in the Philippines are used to thinking that we are already sufficiently participatory, but after learning about - and using - PRA together with our partners, we have realised how much the work can further be strengthened with these tools."*

Jun Cristobal, PHANSuP Programme Manager, Philippines

included discrimination, self-esteem, acceptance in the family, sexuality and gay rights. As a result, a Center for Gay Men's Concerns was planned and designed in consultation with the gay community to offer a meeting place and counselling service.

## Creating strategies for change

At almost every country seminar over the first year of the "Community Lessons, Global Learning" initiative, NGO participants shared how they had successfully used techniques and approaches from community development work to strengthen their responses to HIV/AIDS. Such work encourages an analysis of structures as well as behaviours, and of communities as well as individuals. In turn, this analysis suggests that responses to the epidemic must address not only community problems, but also problems "of community" – including the norms and values that shape relations between people which, in turn, create exposure and vulnerability to HIV.



Members of IWAG using participatory methodologies to build self-confidence among gay men in Davao City, the Philippines

In Burkina Faso, IPC supported ADESCO to conduct a participatory community assessment among travelling women traders and associated men in the Orodara region. It found that low literacy and poverty were urgent problems which influenced vulnerability to HIV. In response, they developed a strategy focusing on literacy training, micro-credit for women, and discussion groups on sexual health. More generally, IPC emphasised at its country seminar that the most successful partner NGOs : "Respond not only to AIDS-related needs but also to those other priorities, through a series of development activities undertaken alongside prevention activities."

Baba Goumbala of ANCS, the Alliance linking organisation in Senegal, describes a similar approach with one of their partner NGOs: "For three years we have supported Association des Jeunes du Peryssae pour le Development (AJPED) in Ziguinchor, in the south of Senegal. The group supports women to carry out literacy projects in the local language, and also economic activities – such as drying fruit to sell in the markets. Now, they are mobilising the community on HIV/AIDS – by including this new subject in their existing work. For example, AIDS is used as the subject of reading classes, and discussion groups on sexuality are held while fruit is being processed. Now,

the community is keen to be involved and participate in HIV/AIDS work – because their most urgent needs are being met at the same time.”

The extent to which the Alliance can address the relationship between development and HIV is clearly constrained, both by the Alliance’s own capacities and by the entrenched and complex nature of poverty and distributions of power and wealth in the societies in which it works. At the Sri Lanka country seminar, for

## Fragile communities in Sri Lanka

Sewalanka, a partner NGO of Alliance Lanka, based in Anuradhapura in northern Sri Lanka, works with communities affected by the Tamil insurgency:

*“Morale amongst the communities is low because of the displacement and disruption of culture. Death has been commonplace, people are intolerant and there are high levels of violence...[T]here may be a high level of STDs in the community, there is no easy access to health services.”*

example, an important discussion concerned how to work with communities which have been dislocated and traumatised by the continuing conflict in the north of the country. An escalating rate of HIV transmission in these communities is one of the effects of this conflict. The technical support provided by Alliance Lanka focuses on the current strengths of these NGOs’ work (such as rebuilding community identity and structure, and meeting basic needs), and identifies the connections between reconstructing shattered communities and reconstructing the psychological and material conditions in which HIV prevention becomes a feasible and desirable goal for people in those communities. Thus, Alliance Lanka encourages NGOs working in these areas to persist with their present strategies, including the provision of basic health and medical services, rather than investing their scarce resources in HIV-specific information campaigns.

A report on Rajarata Participatory Development Foundation, working with communities affected by the Tamil insurgency, notes that the NGO’s focus on income generating activities “addresses both the mental trauma – by creating grounds for hope and positive action – and sexual health – by offering alternative employment to women involved in selling sex.”

## Lessons learned and challenges for the future

The need to integrate HIV prevention into development work emerges clearly from the Alliance’s work on participatory community assessments. A particularly effective route for doing this is through links to gender, sexuality and sexual health work, as explored further in the next section. Other clear recommendations to emerge from NGOs participating in “Community Lessons, Global Learning” include:

- **Helping health and development NGOs to understand that vulnerability to HIV both motivates and focuses responses.** Otherwise NGOs are prone to work with the “general public”.
- **Participatory community assessments can make significant contributions to good programme design, even when NGOs have been working with communities for many years.** The community focus of the process has oriented NGOs towards appreciation of the community structures, norms and values that shape people’s vulnerability. Assessments also allow an exploration of the relationship between risk and responsibility, personal agency and social context.
- **The quality of the assessment and its value in project planning is linked to the focus of the assessment – particularly what questions and what issues the NGO chooses to explore.** Too much emphasis on general concerns and “felt” needs produces a long list of immediate and intractable problems. It is more useful to address a mixture of explicit sexual health problems (such as STDs and teenage pregnancy) and the issues of gender and sexuality implicit within them. It is also essential to balance such an assessment with a clarification of community expectations and NGO capacities.

- **The quality of assessments is also linked to the degree to which NGO staff and volunteers understand key concepts of gender, sexuality and sexual health, and can use this in the context of the assessment.** For many NGOs this has implications for training, which must focus both on participatory assessment skills and on building an understanding of key concepts and their application to the process.
- **NGOs are developing innovative responses to contextual issues, but impact is not yet being measured.** For example, the Alliance’s HIV prevention work in Sri Lanka and Cambodia includes a focus on rebuilding community identity and structure in situations of historical and continuing conflict, and African programmes have used income generation and micro-credit schemes as a development response to the epidemic. The benefits of these initiatives may be more psychologically than materially significant.
- **Working on development issues as a route to HIV prevention will require collaboration with partners, in government and the NGO sector, who are resourced and mandated to carry out such work.** For example, when famine struck Burkina Faso last year, IPC and its partners sought to collaborate with development agencies in the distribution of emergency food aid.



Association de Jeune de Liberté 4 integrating HIV/AIDS and the social marketing of condoms into their environmental work with young people in Dakar, Senegal.

# 5

## Gender, sexuality and sexual health: Pathways beyond awareness

Gender, sexuality and sexual health are known to be significant determinants of vulnerability to HIV. Equally, attention to these issues is a key pathway beyond awareness raising

Despertando is a women's community group working in El Guasmo, a poor urban community on the outskirts of Guayaquil, Ecuador, with the support of the linking organisation COMUNIDEC. It began its workshops for community members with basic sexual health, gender and sexuality education, as well as attention to specific issues identified as priorities by the community – such as violence against women and sex education for young people. As one community member said of the workshops: "They used our language rather than technical words, and helped us to communicate. It was very important for me because I learned things I didn't know about my own body and my own health. I've learned how to teach my children about issues such as sexual health and AIDS."

NGOs at the country seminars of "Community Lessons, Global Learning" shared that their participatory community assessments highlighted for them the key role that gender plays in determining access to and quality of sexual health service provision. Ms Anjuman Ava, a community educator with ACD in Bangladesh reports that: "Women don't like to talk to male doctors, so they don't share their concerns, and go without treatment or advice."

In Sri Lanka, Sewalanka found that their needs assessment revealed "Gender imbalance as a key area. Women's needs are neither recognised or considered." Meanwhile, for other NGOs the act of conducting participatory community assessments raised awareness of gender. As one reported: "Once the men had left, the women's discussion was very wide ranging. It revealed concerns about sexual health which had been denied in the mixed meeting."

The importance of a gender-sensitive assessment practice was stressed during all the country seminars, with groups sharing their success at encouraging single sex discussion groups and same sex facilitators. Some NGOs reported how increasing gender awareness led to changes in staffing. For example, ACD hired two female staff members to work with the young women being trafficked across the Bangladeshi-Indian border. Despertando,



Despertando raising issues of power relations between men and women during family workshops in El Guasmo, Guayaquil, Ecuador.

### Case study: Focusing on gender and sexuality among poor, urban women, Despertando, Ecuador

*"Sometimes the men would act like they were the ones in authority which was difficult for the women facilitating. There were some men who didn't want to know the information and who wouldn't let others talk, but we tried to cope with the situation. We raised issues about communication between men and women, and children and parents."*

A member of Despertando describing their family workshops

too, was sensitive to gender dynamics when planning its sexual health workshops with the community in Guayaquil, Ecuador, beginning with all-female workshops before broadening out to include male partners and young people. The difficulty of working in mixed groups on these issues became evident, highlighting the importance of basic communication between women and men.

Problems of male-female communication were also a focus of discussion in Cambodia. In response, KHANA has developed an experiential exercise for use with community groups to explore how gendered messages and practices during childhood create both barriers to communication between women and men and the gender hierarchy of power on which so much of women's vulnerability is based. But these problems of communication are related more generally to the problems of discussing sex and sexuality in the cultures in which the Alliance works.

This sexual silence not only applies between men and women but also across the generations. Samadeepa Samaja Kendraya, a Sri Lankan NGO, notes that "there is a culture of reticence about talking of sex which prevents parents from giving information to their children."

Nor has it been easy for some of the Alliance's partners to end the silence and openly discuss sex and sexuality. "In the beginning it was very hard for me, particularly as a woman, to talk about these type of sensitive issues," says Ms. Anjuman Ava, community educator with ACD in Bangladesh. Her male colleague, Md. Towhidul Alam, adds: "When I first started this work in sex and sexuality issues, I was very concerned about my status and what people would think." With the technical support of HASAB, the staff of ACD have been able to reflect on and change their practice: "We learned a lot from Kabita [the HASAB Programme Co-ordinator] about how to talk openly about sensitive issues such as masturbation."

The Alliance is also adapting and refining experiential and participatory groupwork exercises which explore related issues. These include identifying and ranking problems of sex, discussing the gender-related expectations and exercise of power in sexual situations, and developing skills in assertiveness and sexual negotiation. The transformative power of this group discussion approach is apparent in the work of Despertando in Ecuador.



With Saviya, Sri Lanka, beach boys learn not only how to fit condoms, but also how to negotiate their use.

*“We don’t just need to learn the facts about AIDS, but also how we can protect ourselves. We don’t want to stop having sex, but we do want to learn how to do it safely. We need to be able to discuss these things – because in our culture we don’t talk about sex. Here, we can talk openly about what’s on our mind, get condoms and learn about ways to take care of ourselves.”*

Chaminda, 26 year old “beach boy” at Unawatuna, involved in a project by Saviya, an NGO supported by Alliance Lanka

It has been clear from “Community Lessons, Global Learning” seminars that there is an ongoing need to strengthen the skills and concepts required to address sexuality during participatory community assessments. “We now know that homosexuality is a reality,” said one staff member of Samadeepa Samaja Kendraya after an Alliance Lanka workshop. The value of sexuality-sensitive assessments is also apparent in their descriptions of the diversity and specificity of male-to-male sexual experiences, from established gay cultures to situational male-to-male sexual encounters in all-male environments (such as military camps and prisons). The importance of documenting and discussing sexual diversity is evident in the work of FAES, a community group run by transvestites for transvestites in Quevedo, Ecuador. As Dr. Lilly Marquez, a COMUNIDEC consultant providing ongoing technical support, notes: “The community has accepted what they are doing – partly because they have learned that many of the local men – even when married – have sexual relations with transvestites.”

These issues take on special significance in low HIV prevalence countries, where issues relating to STDs, reproduction and sexual violence are of more immediate concern to communities than HIV/AIDS. It has also helped to draw attention to the ways in which communities themselves locate the HIV and AIDS information they receive within their own belief systems about sickness associated with sexual and reproductive organs.

## Transformative groupwork in Ecuador

*“Before I was a shy person and didn’t like to talk in case I said anything wrong. Working with Despertando I learned about my own sexuality and sexual health. I learned about my body and about being a woman, as well as about issues such as HIV/AIDS. I learned that I have rights as a woman and as a member of my community...I had my own ideas and thoughts, but I never said them out loud. Now I’ve learned what it is to be a woman as well as a wife and a mother...Now I have the confidence to know what I want and to speak out.”*

Elsa Almandaris describing the benefits of Despertando’s groupwork strategy

In Cambodia, for example, the Khmer term for AIDS is the same as that for syphilis, which is linked to the exchange of “bad blood”, transmission of which has a moral and spiritual, and not merely biological, quality. Thus KHANA has encouraged its partner NGOs to work with the Kruu Khmer (traditional healers) – not only as key informants in project planning, but also as partners in sexual health information provision in order to help to make sense of information about HIV and AIDS within traditional Khmer disease models.

Many of the Alliance’s partner NGOs have described how they locate HIV work within their broader mandate for sexual and reproductive health. A number of NGOs in Bangladesh, for example, combine clinic-based and outreach STD services.

In Sri Lanka, NGOs report that family planning concerns frequently provide an entry point into HIV prevention work, for both men and women. As Sabe Mithuro, a Sri Lankan NGO targeting male trainee police officers, reports: “The issues which arose were needs for information about family planning, condom use and sexual health in general.”

The quality and accessibility of appropriate services has been a central concern within the Alliance’s sexual health, gender and sexuality framework for HIV prevention. Improving access by taking services to where potential service users are, has been a common approach. As Mr Tariqul Islam of CEDAR, an NGO working with truck drivers at Aricha Ghat, Bangladesh, notes: “By combining outreach work with services, we’re aiming to provide a full ‘package’ of support for our community – of STD treatment and medicine, but also of health education, condoms, and advice.” While, in Senegal, ANCS has supported Amicales de Jeunes de Liberté 4 to promote social marketing of condoms as part of community outreach with young people in Dakar.

## The realities of male power

*“The police school was selected because of concerns about the misuse of power by male officers and the impact of this on sexual health of the officers, their families and communities where they work. An additional concern is the alleged involvement of the police in taking money from brothels and sex workers. This gives them some de facto control over the sex industry... Allied to this is a general need for gender awareness to counteract the subjugation of women by police officers.”*

## Lessons learned and future challenges

For all of the difficulties inherent in addressing gender, sexuality and sexual health, these are the areas where NGOs are clearly making the most progress in responding effectively to HIV/AIDS. The lessons learned include:

- **NGOs benefit enormously from technical support which helps them to integrate a conceptual understanding of sexual health, gender and sexuality into all aspects of organisational policy and programmatic practice.** These include recruitment and personnel policies, selection and training of technical support providers, and all stages of project design, implementation and evaluation.
- **Participatory community assessments have identified the widespread need for gender-sensitive service provision and the reality of sexual diversity in many communities.** Women's needs are frequently neglected in the design and delivery of sexual health services; recruiting more female staff has improved the ability of partner NGOs to conduct assessments and provide services which address women's needs. In addition, HIV prevention in the context of sexual diversity must address heterosexist and homophobic attitudes and practices, both external and internal.
- **Effective strategies both respect and challenge cultural restrictions on discussion of sex and sexuality, and acknowledge realities which are frequently denied in mainstream culture** – such as sexually active young people and male-to-male sex.
- **Participatory and experiential groupwork is a promising response to the basic lack of communication about sex, sexuality and sexual health in the societies in which the Alliance works.** These approaches merit careful evaluation as to their impact and potential for scaling up. This is especially the case given their dependence on sophisticated facilitation skills and the consequent need to strengthen skill development in this area.
- **There is a need to develop new strategies to work with young people on sexuality and, in particular, to adopt a harm reduction approach which works with the reality of young people's sexual experience (and desire for it) to promote its safety.** This is related to an overall dearth of appropriate operational research on sexuality, and to a lesser extent, gender.
- **The Alliance must seek to increase its work in partnership with broader movements for gender and sexual justice** – in order to challenge laws and policies which preserve or ignore the social inequalities at the heart of the HIV epidemic. Coerced sex and histories of sexual abuse are other realities which impinge on sexual health. There is a need for the Alliance and other agencies to strengthen their ability to identify and respond to these realities as a part of HIV work.



A small group discussion on experiences in gender and sexuality at the HASAB country seminar, Bangladesh.



# 6

## Community mobilisation and participation: Making it happen

The HIV epidemic is bound up with community structures, norms and values, transformation of which depends on those who live within them. Communities are not single entities but collectives of differing people, interests and ideas. However, it is important to recognise that communities themselves possess expertise, interest in and capacity to bring about many necessary changes in structures, norms and values, which outsiders do not necessarily share.

### From involvement to mobilisation

*“Everyone seems to agree that community participation is a good thing, but everyone seems to have their own definition of what this means. For some NGOs, participation is using a focus group to test education messages; for others, it is a strategy to gain local co-operation to work on sensitive issues. Those inclined to economics may be attracted to participation as a way of finding inexpensive community volunteers or ensuring financial sustainability beyond funding periods. All these things are important, but I believe what we are learning is that facilitating effective participation is one and the same as facilitating effective community mobilisation. And community mobilisation in response to AIDS may be in and of itself a crucial intervention to catalyse and sustain safe behaviour.”*

Jeffrey O'Malley, International HIV/AIDS Alliance

We know empirically that developing countries like Thailand and Uganda, with remarkable successes to date at slowing or reversing the spread of HIV, have combined top-level political leadership, engagement of civil servants throughout the Ministry of Health and beyond, and widespread community mobilisation.

UNAIDS says: “A community becomes mobilised when a particular group of people becomes aware of a shared concern or common need, and decides together to take action in order to create shared benefits. This action may be helped by the participation of an external facilitator – either a person or another organisation. However, momentum for continued mobilisation must come from within the concerned group or it will not be sustained over time”.

As experiences shared in “Community Lessons, Global Learning” have highlighted, there is solid evidence of several factors which might explain why community mobilisation is so important in effective responses to AIDS. For example:

- People are more likely to respond to safer-sex and safer-drug taking messages from their peers.
- Community norms can positively or negatively affect both risk behaviour and risk factors.
- Most people living with HIV or AIDS depend on their family and their community for most of their care.
- Some community groups can be more effective than govern-

ment services or the private sector at reaching particular vulnerable populations, especially the poorest and the most socially marginalised.

- Most community organisations can respond relatively quickly to changing needs and circumstances, while some have strong track records of innovation.

As shared at country seminars, partner NGOs of the Alliance often make additional assumptions about why community mobilisation is so important, although there is not necessarily solid data to back up their claims. These include:

- A diversity of strong and supportive community responses to HIV/AIDS are probably important safeguards to protect and promote HIV-related human rights, which in turn may be central to an effective and sustained response to the epidemic.
- Repeated health promotion messages through multiple channels are likely to help to sustain behaviour change.
- More people may respond to prevention and care work if it is linked to other concerns in their lives which NGOs and community groups address, from getting work to spacing children.
- Effective and sustained prevention and care probably require community action on contextual factors such as other sexual and reproductive health and rights issues, gender relations, poverty and discrimination.

### Community involvement

For some NGOs at the “Community Lessons, Global Learning” seminars, participation was essentially about consultation with audiences and recruitment of peers. On an international level, the Alliance has sought to strengthen community involvement by prioritising technical and financial support to nongovernmental and community groups which are closest to their local communities, both geographically and in terms of accountability. The value of reducing the gap between organisations and the communities they serve is appreciated. As Md. Shah Newaz Selim, Community Educator with ACD in Bangladesh, points out: “One important thing is that we are all ourselves from the community...not outsiders from somewhere else. Our families and peers know what we are doing.”

For all its strengths, it has become clear that there are also challenges inherent in this approach. In Burkina Faso, for example, it has meant working with many different language groups in often remote settings of extreme poverty with small organisations, whose capacity to absorb technical and financial support is constrained, and whose geographical remoteness makes them difficult for IPC, the linking organisation, to work with. While in Cambodia, KHANA is in its second year of programme development and has decided to work with a mix of smaller community groups and larger NGOs – in order to balance capacity to provide intensive technical support with the need to initiate a number of HIV prevention projects in a country of high HIV prevalence. At the Cambodia country seminar, KHANA explained how this

## Case study: Mobilising and empowering transvestites, FAES, Ecuador



FAES meeting on the riverbank - one of the few places where the transvestite members can avoid stigmatisation in Quevedo, Ecuador.

Fundación Ayuda y Educación en SIDA (FAES) was established six years ago in Quevedo – a small town where “everyone knows everyone”. They started as a response to three members finding out that they were HIV positive. The members are transvestites – mostly from poor, rural backgrounds with little education. Many are involved in sex work, alcohol and drug use, and have been the victims of violence. Many have run away from home and live in small groups that work together in cabarets or street corners. Their living conditions are appalling. FAES wanted to respond to specific situations experienced by transvestites, including:

- Constant mistreatment by the police, clients, and the people of Quevedo.
- High prevalence of STDs in young transvestites, and a lack of sex education.
- Guilt, anxiety, fears, and low self-esteem.
- Lack of opportunities for other types of productive activity.

COMUNIDEC, the Alliance linking organisation, supported FAES in a participatory assessment with transvestites aged 13–40, including those engaged in commercial sex and young people recently out as transvestites. The findings included:

- Group members were used to suffering from STDs and not treating them.
- They were aware that there is no cure for AIDS, but, if asked by a client, did not use condoms. If they used condoms with clients, they did not use them with their regular partners.
- Many had experienced sexual abuse, and were ignorant about sexuality.
- It was recognised that their orientation marginalises them from family and society. As one said: “We live in a world apart, we dress up, face humiliations, suffer.”

Based on the assessment, FAES have developed a programme focusing on the factors that contribute to the group’s vulnerability. The aim of the project is to achieve better prevention of STDs and HIV/AIDS among the transvestites, with emphasis on training in relevant areas, access to health services, and access to and use of condoms. The general

objective of the project is to educate, inform and train 32 transvestites, aged 15–30 years, in order to achieve better prevention of STDs and HIV/AIDS. The expected results are:

- To set up a group of trained transvestites who can act as “multipliers” for their group and other sectors of the population.
- To achieve a rise in the percentage of adequate condom use.
- To provide greater access to STD services and adequate treatment.

### Achievements and lessons learned

- FAES feels useful in its work on HIV/AIDS – which has improved their self-esteem. However, it is not easy to achieve self-esteem, due to the situation of everyday violence, fear and anger in the lives of group members.
- Increased interest in and use of condoms. As one says: “When we use condoms we feel safer and not so prone to catching certain diseases.” However, without regular access to condoms and services the prevention work will not be effective.
- They have begun to reject abuse and discrimination.
- There has been an awakening of interest in aspects of human sexuality.
- There is now an awareness of access to services.
- The Foundation needs organisational strengthening. Leaders need to be trained in facilitation skills.
- There is increasing access to and demand from the community – both from transvestites and from women who trust the group – to talk about sexuality.
- It is the only project in Ecuador, working with transvestites with HIV/AIDS, which is a project of equals where the target population implements the activities.

## Working with communities in Burkina Faso

*“IPC-supported associations must be based in the communities served by their activities, whether relating to AIDS prevention or to care for people with HIV/AIDS. IPC believes that the closer the proximity between members of the associations and the community targeted by their actions, the more developed their capacity to identify needs and the more adequate their response to those needs.”*

Report of IPC's 1997 Country Seminar, Burkina Faso.

*“In Burkina Faso, NGOs have worked alongside small, informal community groups to mobilise local people to respond to HIV/AIDS. For example, CEPROFET, an agriculture and development NGO, has worked with groups in 13 villages in the Gonse region. With the support of IPC, the Alliance linking organisation, they have raised interest and action through community meetings and discussion groups about gender, self-confidence, sexuality and STDs.”*

Extract from “Alliance News”, June 1998

strategy had already resulted in a doubling of the local NGO response to AIDS, despite the intensive technical support needs of most of the groups involved.

Another strategy for community involvement is recruitment from priority populations. Young Power in Social Action (YPSA), a partner NGO of HASAB working with a low caste gardener community in Chittagong, Bangladesh, established their office physically within the community and staffed its team with employees and volunteers from the local area. They have found that this mixture of local personnel is helping to stabilise and sustain both their programme and their organisation. Meanwhile, in Morocco, PASA/SIDA, the Alliance linking organisation, has learned that projects that rely solely on staff or solely on volunteers – even if they are all from the community – are not as successful as those that have a mix of both.

Many partner NGOs have used peer education strategies, in which community members are trained to serve as HIV/AIDS educators for their community. PHANSuP, in the Philippines, has supported a number of NGOs using volunteers and peers from target communities, including Baguio Centre for Young Adults



By working with community groups in Cambodia, KHANA has doubled the local NGO response to HIV/AIDS.

(BCYA) working with youth, and Olongapo City AIDS Foundation, Inc. (OCAFI) working with entertainment workers and people living with HIV/AIDS.

The participation of community members potentially enhances both the effectiveness and accountability of NGOs' work with communities. As an immediate and continuing channel of communication between NGO and community, “peer” staff can strengthen a sense of community ownership and provide a means of dialogue between NGOs and communities. Evaluations of peer education projects shared at “Community Lessons, Global Learning” seminars suggest that the use of peers improves the credibility and thus impact of HIV prevention messages. Improvements in effectiveness, accountability and reach of projects through the participation of peers in project activities, however, seems to require heavy investments in recruitment, training and staff support. High attrition rates are common and the issue of incentives and payments remains problematic, especially in demonstrably poor communities where the payment of peers may separate them from other community members and reduce a sense of peer identification.

## Building relationships with communities

Many of the Alliance's partners confirm the importance of creating relationships of respect with their communities, and a willingness to acknowledge community expertise. The trust that develops between NGO and community also depends on clarifying the “fit” between community needs and desires, project aims and resources, and also on discussing unrealistic expectations. This is an important aspect of community assessments and project planning. For example, rural community development NGOs in Cambodia starting HIV prevention projects with the support of the Alliance's linking organisation, KHANA, found that villagers expected the HIV/AIDS educators to be medical assistants, bringing much needed medicines into the village. When they did not, the villagers became frustrated with the HIV/AIDS projects. This disaffection could have been avoided if more care had been taken in designing the project with villagers and agreeing what the project could, and could not, offer them.

Another issue highlighted during country seminars is that, in building close and constructive relationships with their communities, partner NGOs have also been careful to differentiate with whom it is important to develop what kinds of relationships. While it is necessary to work with formal community leaders (often older, richer men), Alliance partner NGOs make use of the concept of stakeholders in building relationships with differing groups which have a key influence on project effectiveness. This includes informal opinion leaders, gatekeepers (such as brothel owners and commanding officers in military establishments) and, most importantly, the intended beneficiaries themselves, however marginalised or hard-to-reach they may be.

## Participation, mobilisation and social change

Many of the “success stories” cited by NGOs in the “Community Lessons, Global Learning” seminar series stemmed from the use of participatory methods in community assessments and project design. Techniques shared included community mapping, body mapping, Venn diagrams, ranking



School peer educators leading discussions about sexual health and self esteem with the support of SOWEL, Sri Lanka.

and scoring, seasonality charts and personal lifelines. As noted earlier, these approaches helped NGOs respond to real needs of community members, and develop strategies to address important contextual issues. Having benefited from these methodologies, a number of NGOs used the opportunity of the country seminars to explain how they are trying to respond to an increasing understanding of vulnerability and context – and to emphasise how they have successfully reassessed their own behaviour and attitudes as facilitators of social change.

Some of these NGOs noted that, in order to be able to facilitate participatory development, or to use PRA techniques, they had to “unlearn” many of the attitudes and behaviours that they had acquired in other work. As Jerker Edstrom, Alliance Programme Co-ordinator for Asia explained: “NGOs’ staff and volunteers are learning to step down from the position of “expert,” and learn from the communities they work with. Changing attitudes and behaviours is often the most important – and difficult – component of this work.”

### Introducing HIV messages over time

*“In the beginning, after the needs assessment, we spent three months building a close relationship with the community. We started by discussing general health and social issues – such as diarrhoea, family planning and personal hygiene. We then gradually began to talk about our project and to generally introduce the issue of HIV/AIDS. We found that this approach meant that people were interested in our work and gradually wanted to know more and more about the issues.*

*As the relationship grew stronger, we began to talk about issues more explicitly and in more detail. Having first created a supportive environment, we found that we could talk openly about issues such as STDs and sexual behaviour. It wasn’t something that happened in one day, it was a gradual process of slowly building and strengthening our relationship.”*

Monirul Islam, Co-ordinator of ACD, working with young Bangladeshi women being trafficked across the Indian border

### Community participation in community change in Ecuador

*“We began to realise that the women of Guasmo Norte could work together for the benefit and health of the whole community. The women and youth in our area now know the reality of sexual health. The team of women is my family. We’ve worked together and grown together.”*

Angelita Ullauri, member of Despertando

*“This project has been very successful for us in a personal way and in terms of showing what women in El Guasmo can do....The most important thing of being part of the group has been to show that community women have a role in improving their own lives and those of the people around them....We’ve shown that we can make a contribution to improving the quality of life of the community.”*

Malena Lara, Co-ordinator, Despertando

Many linking organisations are now encouraging NGOs to establish more participatory processes beyond assessment and design and into implementation and evaluation. An interesting minority of NGOs have already made progress in this area, thanks to staff or volunteers with the skills, attitudes and dispositions to view their HIV work as a process of establishing broader participatory processes within communities – in the hope that these continue, not just through project implementation, but beyond.

The consensus emerging from “Community Lessons, Global Learning” is that the most successful cases of participation leading to real mobilisation for social change involve NGOs which combine:

- Simple and flexible methods.
- Equalising behaviours and attitudes of their own staff.
- Empowering processes and frameworks.

Community participation can have a transforming effect on the individuals involved. IWAG Dabaw, a Filipino NGO working

with gay men, found that its peer educators developed into community organisers and counsellors. The voices of the women of Despertando in Ecuador are a powerful testimony to the transformative potential of participation. What sets aside these projects from so many others is the realisation of what UNAIDS has described as the basic principle of community mobilisation: that the people involved can now say “We did it ourselves”.

## Participation to policy

At the institutional level, locally-governed linking organisations serve as a channel through which the voices and interests of communities may be heard in national policy and programme dialogues. In 1997, for example, KHANA organised a national strategic planning workshop and the country seminar for the NGO sector. Both of these brought together an unprecedented number of small NGOs and community groups to discuss the government’s National Strategic Plan for HIV/STDs and to decide on the NGO sector’s priority roles within a co-ordinated national response. The words of Pawana Wienrawee, UNAIDS Country Programme Officer, in her closing speech to the country seminar serve as a fitting tribute to the importance and nature of community participation in HIV prevention: “Where is the hope for Cambodia? People like you in the community who are the staff of the local NGOs. I believe that

local NGOs hold the key to an effective response to AIDS in Cambodia.”

## A view of participation



*“A participatory approach means going beyond conventional IEC [information, education and communication] and into actually involving the community. In that way, our work can have a meaning – in terms of social, cultural, political and economic impact on sustainable human development. If we want to have a relevant response, we need to understand and integrate community members on an ongoing basis.”*

Baba Goumbala of ANCS, Senegal

## Lessons learned and challenges for the future

As the experiences shared in “Community Lessons, Global Learning” demonstrate, greater community participation is a key to more relevant, accountable and sustainable HIV prevention projects. The key lessons and challenges include:

- **Consultation with community members, involvement of peers in certain aspects of service delivery and paying attention to relationship building are minimum requirements of effective programmes.** This is easier when NGOs are themselves close to the community in question, but a wide variety of models now exist to help all NGOs do this work effectively.
- **A more intensive view of community involvement, but potentially far more effective, goes beyond consultation into participation and mobilisation.** The investment needed for this approach needs to be compared to its impact, not just over the life of a project, but beyond.
- **Participation does not depend on techniques alone.** Effective technical support focuses on the attitudes of respect and relationships of trust that NGOs must develop to promote community participation.
- **Participatory approaches change the relationship between NGOs and communities.** They require that NGOs listen to communities, respect community expertise and mobilise communities as partners in HIV/AIDS prevention and care.
- **Strong national NGO responses to HIV/AIDS usually combine both grass-roots or constituency groups and professional non-profit organisations.** There are particular challenges in providing both technical and financial support to community-based, grass-roots organisations which may have limited capacity to absorb it, but the investment seems worthwhile especially when links are fostered between these community groups and larger NGOs. These links can also enhance the participation of highly marginalised communities in national policy dialogues pertaining to HIV/AIDS.

# 7

## Conclusion: Key Lessons, Questions and Recommendations

The first year of the “Community Lessons, Global Learning” collaboration between the Alliance and Positive Action has enabled a rich sharing of practical experiences among communities, countries and continents. In addition to improving the quality of individual efforts in HIV/AIDS prevention and care, the initiative has highlighted vital lessons, questions and recommendations of relevance to key stakeholders involved in the global response to HIV/AIDS.



A brainstorming session on care and support as part of the IPC country seminar, Burkina Faso.

### Lessons and questions

As highlighted at the end of each chapter of this report, “Community Lessons, Global Learning” has identified many essential lessons in community responses to HIV/AIDS. The following presents a synthesis of these lessons, and also suggests key questions which will require future attention by the Alliance, Positive Action and others.

#### Lesson 1: NGOs can move beyond awareness raising into more effective responses to HIV

Key questions for the future include:

- How can the experiences of NGOs which have successfully moved beyond awareness raising most effectively be multiplied and replicated in other settings?
- Which lessons from NGO successes in moving beyond awareness raising are applicable in the public sector, and how can they be transferred?

#### Lesson 2: It is possible – and valuable – to “put into practice” the principle of involving people living with HIV and AIDS

Key questions for the future include:

- How can the Alliance and others locate its work to counter the social exclusion of people living with HIV and AIDS within a broader human rights agenda and movements for social justice?
- The meaningful involvement of people living with HIV and AIDS, and a recognition of their expertise, may challenge existing notions of expertise and power dynamics between providers and users of services. How can the Alliance and others address these shifts in relation to programme design and delivery?

#### Lesson 3: To focus their programmes, NGOs often require support in developing a more complex understanding of the concept of vulnerability and a richer picture of the vulnerabilities of specific communities

Key questions for the future include:

- Can the structural concept of vulnerability produce useful insights into ways of working with those who are advantaged by their gender, class, age and sexuality and who may be held responsible for the vulnerability of others?
- How can HIV prevention strategies reflect both the micro-level understanding of vulnerability generated by a participatory community assessment and an appreciation of macro-level factors?
- How can community assessments be used to inform national and international advocacy and policy-making?
- How can assessment tools and techniques be best adapted for use in participatory community evaluations – in order to stimulate continued and improved HIV prevention strategies?



Comité por Derechos Humanos discussing strategies to address the needs and vulnerability of sex workers in Santo Domingo de los Colorados, Ecuador.

**Lesson 4: Development work which addresses problems of socio-economic marginalisation appears to be an important strategy toward the goal of HIV prevention and care**

Key questions for the future include:

- In what ways can operations research generate a better understanding of how specific types of development work in specific situations contribute to HIV prevention?
- To what extent does a “development” focus of prevention work call for the Alliance and others to develop more political advocacy around development decisions and resource allocation, at both national and international levels?
- What is the role of organisations focused on health or HIV/AIDS, as opposed to large-scale development institutions, in responding to these challenges?

**Lesson 5: Gender, sexuality and sexual health are all significant determinants of vulnerability to HIV, and pathways for “moving beyond awareness raising”**

Key questions for the future include:

- What strategies can be developed to address the links between social constructions of masculinity and safety within male sexuality?

- In what ways can clearer conceptual and operational connections be made between movements and strategies for women’s empowerment and HIV prevention?
- To what extent does the resource-intensity of groupwork strategies to address gender and sexuality limit their wider application?
- How can the Alliance use its understanding of gender, sexuality and sexual health as part of a wider advocacy for expansion and enhancement of relevant service provision?

**Lesson 6: Greater community involvement in HIV/AIDS programming is a key to more relevant, accountable and sustainable prevention and care responses**

Key questions for the future include:

- What kinds of community involvement produce what kinds of benefits to HIV prevention and care work?
- More particularly, do participatory approaches that facilitate community leadership and social action actually have an impact on sexual, drug taking and care-giving behaviour?
- What approaches to participation last over time, and foster sustainable community responses to HIV/AIDS?

## Recommendations

The lessons and questions highlighted by the first year of "Community Lessons, Global Learning" lead to the following key recommendations:

For Donors:

- We already know a great deal about how to respond to HIV/AIDS, but there is still a need to promote and fund appropriately focused research – to generate a more strategic understanding of, and dialogue about, the links between HIV prevention and development, gender, sexuality and community participation.
- There is a need for a wider dialogue within the development "community" about HIV prevention and its implications for development policy and the roles of donors, governments and civil society.
- Linked to this dialogue is the need to consciously locate HIV prevention within a wider vision of social justice and donors' broad mission and mandates.

For the Alliance:

- To build on the lessons being learned about moving beyond awareness raising, the technical support provided by the Alliance should focus not only on participatory techniques and related skills, but also on improving an understanding of the key concepts (such as development, gender and participation), as well as promoting a reflection on attitudes and values as they relate to these issues.
- The Alliance should prioritise the strengthening of institutional capacity to continue to learn and share lessons, both nationally and internationally. This will require an increased emphasis on participatory processes and outcome evalua-

tions, as well as strategic operational research initiatives and the nurturing of information exchange and peer technical support.

- The Alliance secretariat should use its international presence and voice to articulate, and advocate for, the needs and aspirations of the marginalised communities with whom it works.

For NGOs and NGO support programmes:

- Consideration should be given to the potential that exists for NGO support programmes to expand their national advocacy role vis-a-vis HIV/AIDS prevention and care and related issues of vulnerability, in particular acting as a channel by which the findings of participatory community assessments can serve to influence policy.
- Given the lessons being learned about structural vulnerability and the links between marginalisation, inequalities and the epidemic, NGO support programmes and NGOs should collaborate with strategic partners who are addressing key issues, such as human rights, gender and development, sexuality and sexual violence.
- Priority should be given to developing practical strategies that counter the social exclusion of people living with HIV/AIDS. These must include strategies that promote their active and meaningful involvement in programme planning, delivery and evaluation.
- It is vital to continue to nurture local capacity to provide technical support and to emphasise the role that external support plays in transferring skills and in building institutional capacity. Given this role, strategic planning should explicitly focus on the timing and pace of the decrease of external support in parallel with its replacement by local expertise.



Participation and involvement have been central to helping rickshaw pullers and their wives to "move beyond awareness" with the support of CRSD, in Dhaka, Bangladesh.



International  
HIV/AIDS

# Alliance

Supporting Community Action on AIDS in Developing Countries

Barratt House, 341 Oxford Street, London W1R 1HB



*Glaxo Wellcome in Global Partnership  
with HIV/AIDS Communities*

Positive Action, Glaxo Wellcome House  
Berkeley Avenue, Greenford, Middlesex UB6 ONN, UK

Printed on Recycled paper