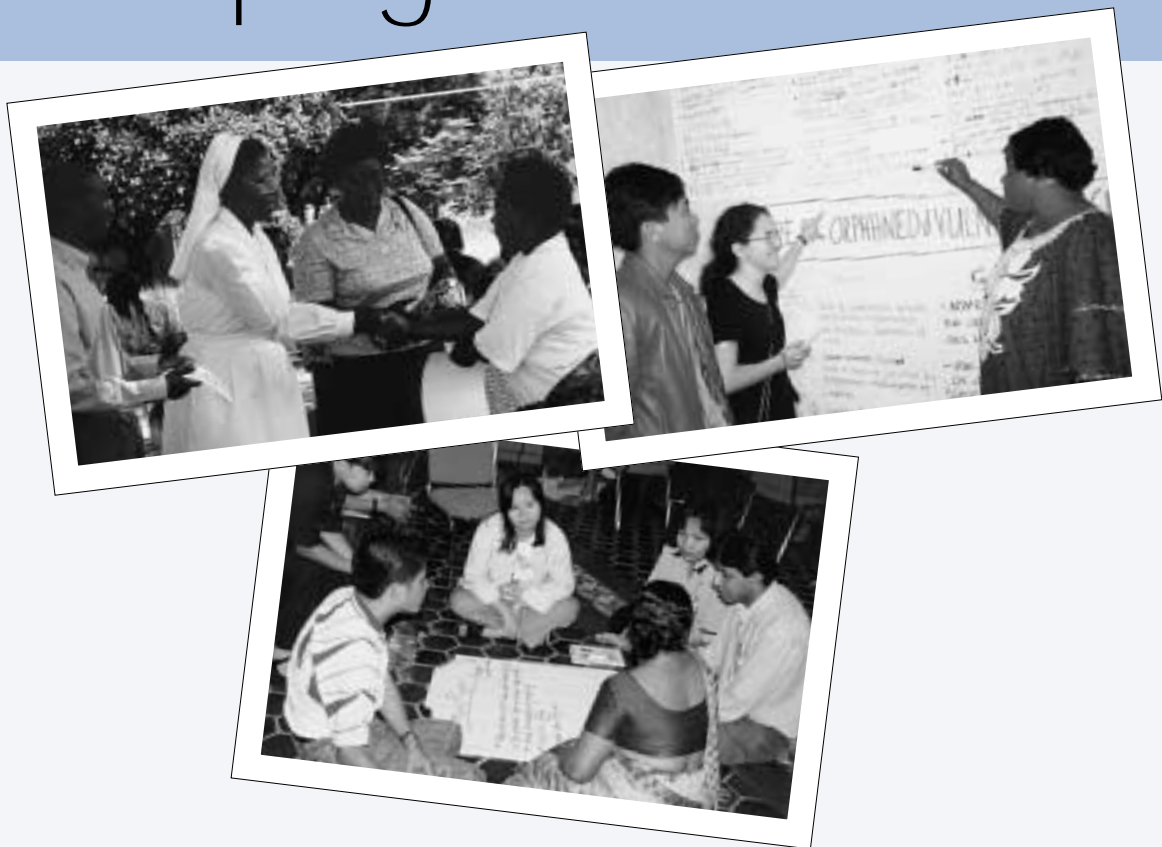


# Care, Involvement and Action: Mobilising and supporting community responses to HIV/AIDS care and support in developing countries



## Front cover

(Top right) Representatives of Alliance Linking Organisations from Ecuador and Cambodia sharing lessons with a local NGO at the "Community Lessons, Global Learning" workshop in Zambia.

(Bottom) Small group discussion during the Alliance's Asia Regional Care and Support workshop, Phuket, Thailand.

(Top left) Group activity during the Needs Assessment, for the Access to Treatment Toolkit, Zambia

## Abbreviations

**CBO** community based organisation  
**DOTS** directly observed treatment  
**NGO** non-governmental organisation  
**PLHA** person living with HIV/AIDS  
**STD** sexually transmitted disease

## Alliance linking organisations and partners

### Bangladesh

HIV/AIDS/STD Alliance – Bangladesh (HASAB)

### Brazil

Grupo Pela Vidada/RJ  
Grupo de Incentivo a Vida (GIV)

### Burkina Faso

Initiative Privée at Communautaire contre le Sida au Burkina Faso (IPC/BF)

### Cambodia

Khmer HIV/AIDS NGO Alliance (KHANA)

### Ecuador

Programa de Iniciativas Frente al VIH/SIDA de COMUNIDEC (now operating as Corporación Kimirina)

### India

YRG Care  
Indian Network of People Living with HIV/AIDS (INP+)  
Naz Foundation (India) Trust  
India HIV/AIDS Alliance

### Mexico

Colectivo Sol

### Morocco

Association Marocaine de Solidarité et de Développement (AMSED)

### Philippines

Philippines HIV/AIDS NGO Support Program (PHANSuP)

### Senegal

Alliance Nationale Contre le SIDA (ANCS)

### Zambia

Zambia Integrated Health Programme Component 2 (ZIHP-SERV)

The second 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.

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# 1

## Introduction

### **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 and support 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 implement prevention and care initiatives more effectively.

### **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, and enhanced care and support for people living with or affected by HIV/AIDS.

“Often you can see that things are not working, but you don’t know why. With this systematic way of looking at our work – our strengths, weaknesses and lessons learned – we’ll be able to move forwards.”  
Henry Zulu, Nchelenge District AIDS Task Force, Zambia.

This report shares the highlights and lessons learned from the second year of “Community Lessons, Global Learning” – a collaboration between the International HIV/AIDS Alliance and Positive Action, Glaxo Wellcome.

The Alliance is an international non-governmental organisation (NGO) that supports community action on HIV/AIDS in developing countries. To date, the Alliance has supported over 1,100 community based prevention and care initiatives in more than 13 countries in Africa, Asia and Latin America. Positive Action is Glaxo Wellcome’s long-term international programme of HIV education, care and community support.

“Community Lessons, Global Learning” was launched in October 1997. The aims of the three year project are:

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

The theme of the first year of “Community Lessons, Global Learning” was moving beyond awareness raising in HIV prevention. The lessons and recommendations from the project were published in “Beyond Awareness Raising: Community lessons about improving responses to HIV/AIDS” – a report disseminated worldwide to over 2,000 NGOs, policy-makers, people living with HIV/AIDS (PLHA) and donors.

Based on the lessons learned in the first year of the project, the theme of the second year was community care and support. Experience in the first year clearly demonstrated how “moving beyond awareness raising” could be practically achieved through:

- linking prevention and care, and
- enhancing community based care and support.

As in the previous year, the project was carried out through a series of intensive workshops – which focused specifically on sharing lessons and experiences to strengthen the capacity of community based organisations. In total, there were three national workshops (Ecuador, Senegal & Zambia) and one regional workshop (Asia – with organisations from Bangladesh, Cambodia, India, Nepal, Philippines, Sri Lanka and Thailand).

Summary of results: Years 1 and 2 of  
"Community Lessons, Global Learning"

- ✓ **KEY LESSONS LEARNED AND MODELS OF GOOD PRACTICE ON TWO MAJOR THEMES - BEYOND AWARENESS RAISING IN HIV PREVENTION AND COMMUNITY CARE AND SUPPORT - IDENTIFIED AND SHARED IN AND BETWEEN AFRICA, ASIA AND LATIN AMERICA.**
- ✓ **8 COUNTRY WORKSHOPS (IN BANGLADESH, BURKINA FASO, CAMBODIA, ECUADOR X 2, SENEGAL, SRI LANKA, ZAMBIA) AND 1 REGIONAL WORKSHOP (IN ASIA) CARRIED OUT AND DOCUMENTED.**
- ✓ **OVER 300 REPRESENTATIVES OF NGOS, PLHA, GOVERNMENT, PRIVATE SECTOR AND DONORS PARTICIPATED FROM 15 COUNTRIES.**
- ✓ **OVER 2,000 COPIES OF THE REPORT "BEYOND AWARENESS RAISING" - SYNTHESISING THE LESSONS FROM THE FIRST YEAR - DISSEMINATED INTERNATIONALLY.**
- ✓ **RESULTS AND LESSONS OF THE PROJECT SHARED THROUGH THE MEDIA AND AT 1 WORLD AIDS CONFERENCE (GENEVA 1998) AND 5 REGIONAL AIDS CONFERENCES (MANILA 1997, ABIDJAN 1997, LIMA 1997, LUSAKA 1999 AND KUALA LUMPUR 1999).**



Article in The Lancet featuring the "Community Lessons, Global Learning" project.

The workshops enabled NGOs, community based organisations (CBOs) and PLHA to exchange their practical experiences, successes and problems around work in community care and support. To increase opportunities for learning, they also included participants from organisations outside the Alliance, such as government and national and international NGOs. For example, the workshop in Ecuador involved representatives from the government (such as the Ministry of Education), donors (such as USAID), national NGOs (such as the Family Planning Association), United Nations (such as UNAIDS) and the corporate sector (such as Glaxo Wellcome; Merck, Sharp & Dohme). The workshops also incorporated technical exchanges between different countries. For example, four representatives of the Alliance partner programme (or linking organisation) and local NGOs from Burkina Faso participated in the workshop in Senegal and staff from the linking organisations in Ecuador and Cambodia participated in the workshop in Zambia. In total, the second year of the project involved over 182 participants in four workshops from 15 countries.

This document is based upon the reports of the "Community Lessons, Global Learning" country and regional workshops held during the second year of the project. It also incorporates other documentation about the Alliance's work in

community care and support. As well as bringing together the relevant information, it aims to identify lessons learned and "good practice," and to promote policy recommendations for future action. Therefore – while designed to be of interest to a variety of stakeholders in the global response to HIV/AIDS – it is particularly aimed at policy makers, donors and NGO support programmes.

"I'm impressed. One of the things I noticed here is that everyone has been very open – which is what makes the difference. If we are prepared to be open, we have the potential to learn and to improve what we're doing."  
Cathie Mukwakwa, Zambia Integrated Health Programme.

"I've been delighted to hear the type of soul searching and self analysis that has happened in this workshop. It's good to hear that there are many things that we do well, but it's also important to know that there are many things that we could do better."  
Karen Shelley, United States Agency for International Development Mission, Zambia.

# 2

## The Alliance and community care and support

### A definition of the continuum of care, India

At an Alliance workshop, YRG Care in India concluded that:

*“The continuum of care and support for PLHA begins with their first inquiry and carries on to meet as many of their needs as possible, finishing up with care and support to their family after death. The continuum is defined not only by the range of services it encompasses – counselling and information, clinical care and treatment, home care and family counselling – but also by the common quality that links together and strengthens service delivery. This quality comes from the attitudes and values of the carers and from the dignity and trust of the patients. The individual needs of patients and their families shape service delivery. As a result, the energy of caring is equally shared among care-givers, people with HIV, and their families and communities. Patients, family members, doctors, counsellors, nurses, nutritionists, educators, laboratory technicians, administrators and support staff can all contribute to care and support. Through contributing they are changed and the care and support they give to others is made more effective. The effects of HIV infection are different for each patient and each family, the continuum provides a supportive framework, in which these different needs can be recognised and addressed as they arise.”*

(Reference: “Scaling up a Continuum of Care and Support Services: Workshop Agenda,” India, April 1999).

From its inception in December 1993, the Alliance has been committed to supporting action in three broad areas of the response to HIV/AIDS: prevention, care and support and alleviation of the impact of HIV. However, in the early years of the Alliance’s development, while its framework emphasised all three, programme work focused almost exclusively on the area of prevention. In the initial stages the involvement in community care and support was modest. Over the past three years, this has grown to become an integral part of the Alliance’s work, alongside continuing involvement in prevention activities.

The commitment to increase the Alliance’s involvement in care and support was developed as the scale of the HIV/AIDS pandemic grew and a clear gap emerged in the responses of many countries where the Alliance worked. Neither governments nor NGOs were able to meet the growing needs of those who were ill, those living with HIV and those affected. This was felt most strongly at community level, particularly in countries where a combination of low visibility of HIV/AIDS and little political commitment meant an acute lack of services for people in need. Alliance linking organisations, which were already supporting NGO efforts in prevention, recognised that it was critical to respond to existing and emerging needs for care and support. The linking organisations also

recognised that they would have to plan for the future by building local capacity within individuals, organisations and sectors to respond to these needs. For the Alliance, this community-level reality reinforced a broader realisation of the importance of care and support within its mission.

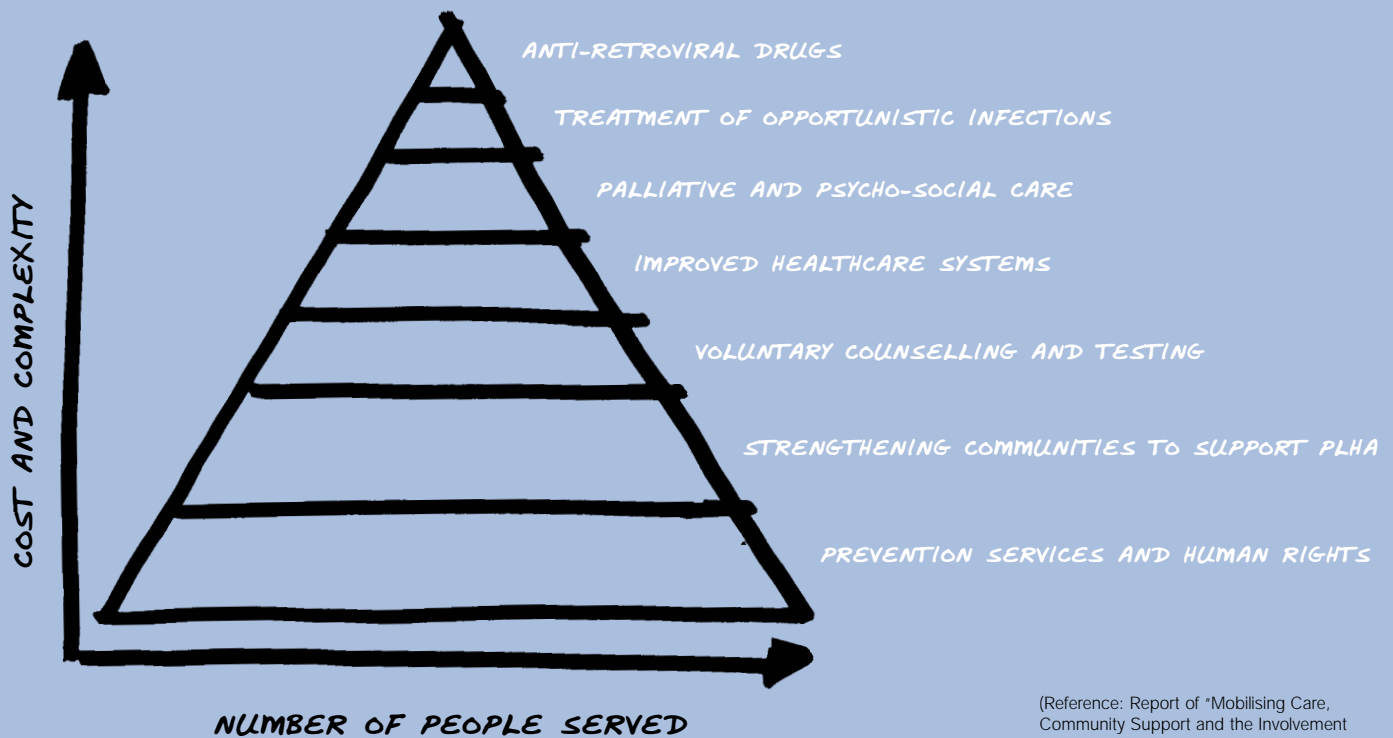
In order to develop and define its mandate on community care and support, the Alliance undertook an examination of the following:

**Definition of care and support:** Using the existing care and support frameworks of the World Health Organisation (WHO) and the United Kingdom’s Department for International Development (DFID), a practical model of a comprehensive approach to care and support within a “continuum of care” was developed. This model included curative and palliative care, psychological support and material help for PLHA and for those affected. It also involved the support of people in the public, private and community sectors, family, friends, and professionals.

**Rationale for supporting care and support:** The Alliance’s existing organisational mission, vision and values emphasise attention to areas such as human rights and support to vulnerable populations. This, combined with the experiences of the Alliance and other

## 'Cost benefit' pyramid of HIV/AIDS care and support

At the "Community Lessons, Global Learning" Asia regional workshop in Thailand, participants used this tool to compare the cost and complexity of aspects of care and support against the number of people they could reach:



(Reference: Report of "Mobilising Care, Community Support and the Involvement of People with HIV/AIDS in Asia", Thailand, October 1998).

organisations who participated in the workshops, such as the Salvation Army (Chikankata Hospital) in Zambia and the Red Cross in Thailand, compelled urgent attention to the area of care and support. Such experiences also demonstrated that something could be done – in terms of appropriate and high quality efforts having multiple, tangible benefits for individuals, families, communities and countries. As a result, the Alliance's community care and support initiatives focus on **getting basic care and support services to the poorest people in communities, with the aim of developing cost effective, sustainable approaches to improve quality of life and increase life expectancy.**

Increasingly the Alliance has been putting its policy commitment to community care and support into practice. On one level, this is reflected in the number of care and support initiatives supported by the Alliance which increased by 91% between 1995 and 1999. However the real story lies within the experiences and achievements in the Alliance's key areas of work – mobilising action, enhancing quality, building capacity and sharing lessons learned.

### The purpose of care and support

At a plenary session at the "Community Lessons, Global Learning" workshop in Zambia, participants defined the purpose of care and support as:

**"To improve the quality of life of persons living with and affected by HIV/AIDS."**

(Reference: Report of "Workshop on Sharing Lessons in Community Care and Support for People Living with and Affected by HIV/AIDS in Zambia". Zambia, July 1999).

# 3

## Linking prevention and care

Participants at the workshop on 'Sharing Lessons on Community Care and Support for People Living with and Affected by HIV/AIDS in Zambia', Zambia, July 1999.



"In terms of care, orphans and vulnerable children tend to need treatment for common diseases – such as diarrhoea – rather than being HIV-positive and needing treatment for that. However, prevention strategies are missing from this work. The reality is that these young people are growing and facing new opportunities – such as sexual activity – which mean new needs to be addressed."

John M Munsanje, Project Manager, Children in Distress Project, Family Health Trust (FHT), Zambia.

**Linking prevention and care enhances the impact, sustainability and credibility of the response to HIV/AIDS. It contributes to maximising the use of resources and increases the potential to reach more people, including those who are most vulnerable to the impact of HIV.**

HIV/AIDS prevention and care are intrinsically linked in many ways. Care and support activities improve the ability of prevention programmes to reach infected and vulnerable populations, increase the credibility of prevention programmes and, by strengthening communities, create a sense of ownership of the problem and its solution. More specifically, including care and support programmes in strong prevention programmes, or vice-versa, is a practical strategy in countries with low visibility of HIV/AIDS and a lack of services for PLHA.

The Alliance's prevention and care programmes are based on this fundamental concept. In the first two years of the "Community Lessons, Global Learning" programme, the Alliance has been drawing on the experiences of the community based organisations it has supported to "move beyond awareness raising". This term – which was the theme of the first year's activities – means doing more than

delivering information, education and communication (IEC). It implies action to reduce people's vulnerability to HIV, and promote behaviour change while addressing contextual issues – such as establishing referral links to local STD services.

There are a number of practical strategies that effectively link care and support and prevention. Including PLHA in the delivery of care and support creates opportunities for direct interpersonal links with the community and can have a dramatic effect on behaviour change. Providing voluntary testing and counselling reinforces both prevention and care and support efforts. When people know their HIV status, referral to appropriate services can support behaviour change, and in the case of those who test positive, encourage early management of opportunistic infections and facilitate planning for the future. In the case of pregnant women, voluntary testing and counselling can lead to reducing mother to child transmission and identifying appropriate care and support for mother and child.

Linking care and prevention has been shown to increase the effectiveness of organisations implementing both kinds of programmes, whichever their primary focus may be. For example, in Burkina Faso, during the home visits carried out by La Bergerie – an NGO

## Why are prevention & care linked?

“Programmes would not be complete without the combination of prevention and care. It’s not meaningful if you do prevention without care, or care without prevention. The elements are inter-related and can’t be separated. They’re both integral to an effective programme.”

*Clement Mufuzi, Network of Zambian People Living with HIV/AIDS*

affiliated to a Protestant church in Ouagadougou which focuses predominantly on care and support – volunteers combine discussion of nutrition and hygiene with information about high-risk behaviour. In Cambodia, during the evaluation of a joint Ministry of Health and NGO home care initiative, community leaders said, *“Until the home care teams started visiting, people didn’t believe that there was AIDS in the village.”* In the same evaluation, 87% of community leaders specifically said that the home care teams were helping to increase understanding of preventive measures. This clearly demonstrates that home care teams providing care and support were also contributing significantly to prevention efforts.

The Asociación de Mujeres del Milagro – a community group of commercial sex workers in Ecuador – became involved in care and support through a short-term HIV/AIDS awareness project by a family planning association. During this, issues about support to sex workers living with HIV/AIDS and discrimination by the public health system were raised alongside concerns about STDs and HIV/AIDS. With support from COMUNIDEC, the Alliance linking organisation in Ecuador, the Asociación took the step of combining its prevention work with developing a small health post – which is fully managed by the sex workers – to provide them with basic care and support services. They also advocated to the health sector for better care and treatment for PLHA within state institutions.

The Zambia workshop addressed links between prevention and care and identified the following strengths of linking prevention and care:

- ✓ **CREATING AN ENABLING ENVIRONMENT - TO HELP ACCEPTANCE OF PLHA AND REDUCE STIGMA AND DISCRIMINATION.**
- ✓ **MAXIMISING RESOURCES - BY INTEGRATING PREVENTION WORK IN COMMUNITY HOME-BASED CARE VISITS.**
- ✓ **UTILISING REFERRALS - EVEN IF AN NGO IS FOCUSED ON CARE AND SUPPORT WORK, THEY CAN AT LEAST REFER SOMEONE TO A PREVENTION INITIATIVE.**
- ✓ **DEVELOPING HOLISTIC PROGRAMMES THAT CATER TO A RANGE OF NEEDS.**

(Reference: “Workshop on Sharing Lessons in Community Care and Support for People Living with and Affected by HIV/AIDS”, Zambia, July, 1999)

# 4

## Getting the facts



Participants carrying out small group work on care and support issues at the "Community Lessons, Global Learning" workshop in Thailand.

(Reference: Report of "Mobilising Care, Community Support and the Involvement of People with HIV and AIDS in Asia," Thailand, October 1998).

**Approaches and concepts that have proved effective in one region are not always understood or accepted as being relevant in another region. Concepts around care and support and NGO development often need to be examined in the local context for their relevance to be clear.**

### The continuum of care

The Alliance promotes a comprehensive approach to care and support within a continuum (as outlined in Section 2) – in order to meet the varied material, psycho-social and medical needs of PLHA and those affected, and encourage the involvement of relevant stakeholders.

The concept of a continuum of care has been developed from experience in a number of regions over a period of time, and refined by the World Health Organisation. In its move from awareness raising to involvement in care and support, the Alliance explored the concept of this continuum with its partner organisations.

As a starting point, the Alliance supported its partners to develop a clear understanding of the meaning of "comprehensive" and "continuum" in order to adapt these concepts to their own specific needs and resources. In practice, this

has been carried out through a variety of means. For example, there has been an ongoing technical exchange process between the AIDS Programme in Ecuador and partner organisations in Brazil, which has enabled NGOs from Ecuador to observe the range of services provided by government and NGOs and how these can link together. The workshops addressed this by looking at the specific needs of the PLHA with whom participants were working, to see how these needs fitted into a continuum of care. The chart on page 9 is an example of this from Thailand.

### Access to Treatment

Access to treatment has emerged as perhaps the most significant issue affecting PLHA. The issues around access to treatment are complex, with different interpretations from different organisations about what "access to treatment" actually means. At community level, especially in countries where the visibility of HIV is low and service provision is poor, treatment may be limited to the most basic drugs – and even these may not be accessible to the poorest people. Making these drugs, and other more complex drug regimens, both available and accessible at community level is part of improving access to treatment. But treatment is broader than just drugs, and cannot be provided without psychological support and practical assistance.

## Planning a continuum of care, Asia

At the "Community Lessons, Global Learning" Asia workshop, a small group developed a simple grid to brainstorm the "ideal" continuum of care for specific groups of PLHA:

### EXAMPLE: POTENTIAL ROLES WITHIN A CONTINUUM OF CARE FOR PREGNANT PLHA

GOVERNMENT	HOSPITALS	NGOS	CBOS	PLHA
✓ POLICY FOR TESTING WITH CONSENT OF WOMEN	✓ LABORATORY SUPPORT ✓ COUNSELLING	✓ COUNSELLING ✓ INFANT FEEDING ✓ HOME VISITS	✓ COUNSELLING ✓ HOME BASED CARE ✓ STRENGTHEN FAMILIES OF PLHA ✓ TRANSPORT TO HOSPITALS ✓ HOME VISITS	✓ BASIC INFORMATION PROVISION ✓ COUNSELLING ✓ LEGAL RIGHTS AWARENESS
✓ SUBSIDISED OR FREE AZT ACCORDING TO INCOME LEVEL	✓ DELIVERY OF SERVICES WITHOUT DISCRIMINATION	✓ TRADITIONAL ATTENDANT SERVICES		

In particular, concepts of access to treatment do not always take into account barriers to accessing treatment and drugs, however cheap and simple. NGOs at local or national level often have limited experience and/or knowledge of what is involved in providing or improving access to treatment. Discussion and analysis enable NGOs to understand the complex issues around supply, storage, ethical issues and a range of other challenges in improving access to treatment. The Alliance has been developing these ideas in order to provide tools for organisations working at community level who want to facilitate access to treatment for people with HIV.

While promoting a model of care and support that is never just about drug treatment, the Alliance recognises the vital role of drug therapies within a comprehensive approach. As one PLHA from Ecuador says, "This country is very poor. The majority of PLHA have died because of their economic situation and because of a lack of medicines. If we don't... find help and medicines, we do not stand a chance. It's not a question of taking one pill a month – we need proper, long-term medication."

Making drugs available and accessible is not simple. Challenges include the technical issues, such as supplies and storage. For example, as

a representative of the joint Ministry of Health and NGO project on home based care in Cambodia, says, "An ongoing problem has been finding and storing drugs... Although more of a problem for patients in hospital than at home, adequate analgesia is also difficult to find, with no opium-derivatives permitted in the country. In addition, keeping home care supplies stored properly and safe from theft has been troublesome."

Sharing lessons and experiences has shown that there a number of different models to achieve improved access. In Senegal, the multi-sectoral "cellules" – or "solidarity networks" – supported by the Alliance linking organisation, ANCS, (Alliance Nationale Contre le SIDA) have each found local ways to improve access to treatment for PLHA. While some facilitate access to subsidised drugs from hospitals, others have developed "comités de santé" – a type of local insurance scheme. These are managed by a committee of community members and health personnel who buy generic drugs that are on the government's essential drugs list and re-sell them at a reduced, subsidised cost.

In Burkina Faso and Cambodia, groups have been encouraged to ensure ongoing and monitored provision of essential drugs, within the context of home care, rather than short

# Getting the facts

Contents of a home care kit, Cambodia:

<i>PARACETEMOL 500MG TABLETS</i>	<i>GENTIAN VIOLET 15ML VIALS</i>
<i>POTASSIUM PERMANGANATE 10MG SACHETS</i>	<i>BICARBONATE OF SODA 500MG TABLETS</i>
<i>10% IODINE SOLUTIONS 30ML VIALS</i>	<i>HYDROGEN PEROXIDE 30ML VIALS</i>
<i>CALAMINE LOTION 500ML</i>	<i>ORAL REHYDRATION SALTS</i>
<i>BENZYL BENZOATE 30ML</i>	<i>NYSTATIN SUSPENSION 25ML</i>
<i>GLOVES</i>	<i>BANDAGES</i>
<i>SOAP POWDER</i>	<i>HOUSEHOLD BLEACH</i>
<i>CLOTHS</i>	<i>CONDOMS</i>
<i>MATCHES</i>	<i>PLASTIC BAGS</i>
<i>TWEEZERS</i>	<i>SCISSORS</i>
<i>PLASTERS</i>	<i>COTTON WOOL</i>
<i>MICROPORE TAPE</i>	<i>ELASTIC BANDS</i>
<i>SAFETY PINS</i>	<i>MENTHOL BALM</i>
<i>TALCUM POWDER</i>	<i>COCOONUT OIL</i>
<i>PROMETHAZINE 100ML</i>	<i>LOPERAMIDE</i>
<i>MULTIVITAMINS</i>	<i>PRIMPERAN</i>

Source: February 1999, Project Review, Cambodia.

term or ad hoc provision of complex treatments. For example, in Cambodia, the home care teams use a medical kit that contains a range of basic treatments to improve the clinical status and personal comfort of the PLHA (see above). In Burkina Faso, AMMIE, an NGO based in Ouahigouya, tries to provide free drugs when the family cannot afford treatment. They estimate that the cost of a basic care package is about US \$20 per person to start the treatment and up to US \$5 per person per month during the following months. In contrast, it is estimated that hospital care costs US \$18 per day. Data from Alliance partners in Cambodia and from IPC in Burkina Faso also indicate that home based care is better value than hospital care both for the patient and to the provider.

YRG Care in India has developed a system where consultations are free, but there is a charge for testing and medication if the patient is able to pay. Medical care is linked to counselling and social support. YRG Care advises on treatment regimes and symptom control, but also on accessing social welfare systems. The cost of medical care is very high in human and financial resources, and strategies for sustainability are vital. The organisation currently depends on donations – in cash or in kind, and from businesses, patients and friends – to meet some of their costs.

At a national level, linking organisations in both Cambodia and Burkina Faso have contributed to national policy. For example, IPC, the linking organisation in Burkina Faso, has developed a list of the cheapest, most effective essential and generic drugs for the management of the most common HIV-related conditions, based on the experiences of NGOs and the government's essential drugs list. This resource has been distributed to other NGOs.

Home based care is part of a continuum of care and support. At the "Community Lessons, Global Learning" seminar in Senegal, IPC shared their experiences of supporting NGOs to carry out home based care in Burkina Faso. They explained how the system of identifying potential patients varies according to the circumstances of the NGO. La Bergerie is one of IPC's partners whose members include many health professionals so, for example, identification of patients may occur at the National Yalgado Hospital and the TB Prevention Centre. As one PLHA recalls: "I was hospitalised and I got to know one of the nurses. After being discharged, he came to see me at home."

NGOs in Burkina Faso carry out visits several times a week or a month, depending on the individual's need. They follow a basic procedure (see page 11), and always include psychological and, if requested, pastoral support. As one



Members of AMMIE with their home care kit containing basic supplies, Burkina Faso.

Home care programmes can reduce the cost of care to PLHA and their families by giving them information about effective treatments.

The report of the Home Care Evaluation from Cambodia illustrates this:

“When asked specifically if households visited by the home care teams saved money on health care, 98% of respondents stated that they saved money, with a range of savings from US\$ 0.80 to US\$ 1.30 per week.”

(Reference: Home Care Evaluation Report, Cambodia, June 2000).

PLHA volunteer says, “I try to raise their morale and I pray with them”. People do not identify themselves as ‘AIDS volunteers’, but as volunteers working with the chronically ill, and volunteers involve the family and talk openly about the disease only when a PLHA agrees. However, the reality is that many have not been tested and very few mention HIV/AIDS.

In Burkina Faso, India and Cambodia, the volunteers and health professionals delivering home based care are provided with a home care kit (see page 10). Basic clinical care is offered within a continuum of care that focuses on the overall well-being of the PLHA. Time is spent talking through how people are coping – both physically and psychologically – and helping with domestic chores, such as washing and cooking. Time is also allocated to the family members, supporting them both to care for their relative and to ensure protection against HIV. By including an informal assessment of the child members of the family, home care teams can also identify “soon to be orphans” and set in motion the process of planning support.

In Zambia, a major barrier to appropriate treatment was the lack of adequate food, making treatment much more difficult and less effective. While this did not apply in Côte d’Ivoire (see page 12) the issues there are equally complex.

#### Basic procedure for home based care visits, Burkina Faso

Home visits by La Bergerie in Ouagadougou include:

- ✓ Customary greeting.
- ✓ Review of how the illness has developed since the last visit.
- ✓ Physical examination of the patient.
- ✓ Questioning of the patient to find out their complaints, care and supplies of medicines.
- ✓ Provision of hygiene advice to the PLHA and their family.
- ✓ Spiritual support (if needed or requested).
- ✓ Date given for next visit.

The following is a summary of two of the key questions and findings arising from the Alliance needs assessment on access to HIV-related treatment in Côte d'Ivoire:

### 1. What is a basic care package?

- ✓ Prescribers pointed out that their provision of treatment was essentially dictated by the availability of resources rather than a strategy to address the care and support needs of PLHA.
- ✓ There is currently no consensus or guidelines for what a basic care package should offer.
- ✓ Treatment algorithms were considered un-adapted to the local availability of resources.
- ✓ Generic drugs were not widely used or available, so prescribers were not familiar with their optimal use in the treatment of HIV infection and its complications.
- ✓ Pharmacists said that using drugs requires knowledge and skills both in procurement and in counselling and follow-up. These are not widely available, even in pharmacy training.
- ✓ Counsellors felt easily overwhelmed by the economic and emotional needs of their clients, and are vulnerable to burn-out. Questions of the boundaries of support were often raised.
- ✓ All felt that they would have benefited from more knowledge of different models of care delivery – to allow them to select and blend elements most appropriate to their patients.

### 2. What must be in place to assure this basic care package?

All care-givers stated that they were very much "learning on the job" and had never anticipated a number of issues that were essential to ensuring good care delivery. These included:

- ✓ Good medical records, including: knowing how to identify records while protecting confidentiality; filing systems; and managing information such as test results.
- ✓ Systems for ensuring patient follow-up, including how to give out appointments and know whether patients are returning or not; and monitoring drug efficacy "in the field".
- ✓ A mechanism to recover at least some of the costs incurred, such as fixed prescription costs or monthly registration fees.
- ✓ Having several independent drug suppliers – to get the cheapest, most effective drugs and protect against supply disruption.
- ✓ A drug inventory system to monitor drug stocks and re-order efficiently.
- ✓ A system for supporting the work of volunteer counsellors to build solidarity, avoid burn-out, and ensure quality support to clients.

(Reference: Adapted from "Summary of Key Points: Needs Assessment on Access to HIV-Related Treatment," Côte d'Ivoire, January 2000.)

# 5

## Enhancing the quality of community care and support

### Mobilising care and support

#### **NGOs can play a critical role in mobilising other NGOs that may be reluctant to become involved in care and support.**

Burkina Faso is experiencing the second highest HIV prevalence in West Africa, with around 10% of adults living with HIV/AIDS. At the “Community Lessons, Global Learning” workshop in Senegal a representative from IPC, the Alliance linking organisation in Burkina Faso, shared experiences in moving from prevention efforts to care and support activities. In 1996, they recognised the need to mobilise action on care and support and, as a first step, developed their own policy on what kind of initiatives to encourage. They emphasised comprehensive, community based models driven by a volunteer ethic and linking prevention with care and support. IPC then mobilised four pilot initiatives – by offering a combination of funding and intensive, tailor-made technical support. Three of the NGOs were urban and one rural, and all had established relationships with their communities through development work. In the case of La Bergerie, IPC built on both their organisational experiences in prevention and their personal experiences as health workers already in contact with PLHA.

In Cambodia, one mobilisation strategy by KHANA has been to hold a care and support workshop for 15 NGOs implementing prevention projects. The workshop was highly experiential, using participatory tools and visits to local services to help participants to “internalise” the issues. Feedback included the following comments: “I learned in the hospice that PLHA want honour like everyone else” and “I saw that the needs of PLHA are good care and good motivation in the community.” The workshop helped NGOs to reflect on the growing care and support needs in their communities, and to take the first steps in both building on their existing work and identifying new strategies. For example, Phok Bun Roeun of the Cambodian Children Against Starvation and Violence Association (CCASVA) – an NGO focusing on work with young people – remarked, “We have a plan to provide home care in Prey Veng. We are just starting to learn about this through this KHANA workshop and to make contact with the local hospital. CCASVA is starting to research about home care because there are no other organisations working in HIV/AIDS. There are people in Prey Veng who are dying of AIDS so CCASVA is trying hard to design a programme that will meet their needs”.

“IPC’s involvement in mobilising groups to do care and support work has shown that properly supported local NGOs can be the ideal conduits for effective and low cost community care.”  
Marie Rose Sawadogo, Initiative Privée et Communautaire, Burkina Faso.

“In Burkina Faso, IPC has become an essential partner in the promotion of community care and support, and the involvement of people living with HIV/AIDS. Important and unique lessons have been learned which are crucial for the development of comprehensive care programmes in other countries in the region.”  
Dr Eric van Praag, World Health Organisation.

# Enhancing the quality of community care and support

## The reality of stigma and discrimination, India

“Ravi\* – a 30 year old fisherman from a small village, and living with HIV/AIDS – says “Doctors are there [at the hospital], but, if you’re HIV positive, they don’t treat you well and don’t even touch you.”

“Sima\* is a 35 year old woman who has two daughters. She lost her husband just one week back. Once her husband died, the in-laws threw them out and blamed Sima for their son’s HIV status. Her husband owned some property but her in-laws refused to give [it to her]. Now, she and her two daughters are living with her younger brother. Though Sima’s brother is good to them, his wife doesn’t want to keep them in her house. Sima tried hard to get her daughter married to someone as soon as possible since she thinks her future is at stake. But her daughter is just 14 years old and wants to continue her studies. But Sima is helpless because she and her daughter live at her brother’s mercy.”

(Reference: Extracts from a report of Needs Assessments for Scaling up the Continuum of Care, Kakkinada, Andhra Pradesh, India, 1999).

(\* Names have been changed).

“Prevention and care and support fit together. Prevention activities are needed to help overcome discrimination. Our organisation is known and trusted in the communities where it works as a result of the attitudes and behaviour of the staff. We are therefore in a position to address sensitive subjects such as discrimination against PLHA.”  
NGO representative, Asia workshop.

## Minimising stigma and discrimination

**Stigma and discrimination are key barriers to accessing care and support. NGOs can be powerful agents of change in reducing stigma and discrimination through the provision of community care and support, ensuring the inclusion of PLHA and promoting a non-discriminatory environment.**

How to address stigma and discrimination was a key area of concern during all the “Community Lessons, Global Learning” workshops. It was recognised that within a discriminatory environment, people living with HIV are unlikely to thrive and their families face almost insurmountable obstacles in trying to support them. An example of how giving care and support can in itself reduce stigma and discrimination was offered by health visitors of Sangram – an NGO working with sex workers in rural India. As one villager said, “We didn’t want to help the people with AIDS because we were afraid, but when we saw strangers doing what we should have done ourselves we were ashamed. Now we help each other.”

The reality of stigma and discrimination can be intensely debilitating for individuals, their families, organisations and the community alike. One NGO member shared an experience from his organisation’s work in providing care and support, “People are afraid that if they have HIV/AIDS their families will discriminate against them. They are afraid that if they die and it is known that they died from AIDS, people will not attend the funeral. They are afraid that their family honour will be lost. The reasons for discrimination are the idea that HIV/AIDS is the result of the behaviour – or ‘bad history’ – of the person infected, and a lack of clear knowledge of how HIV/AIDS is transmitted. For example ... five children were orphaned when their parents died from AIDS and went to live with their grandmother. People would not buy the produce from her or allow their children to play with the orphaned children for fear of infection.”

Participants in the workshops recognised that the primary aim of reducing stigma and discrimination would be to improve the psychological and physical well-being of PLHA. But they also saw the practical and political benefits for their own work in facilitating a supportive environment.

<b>STRENGTHS</b>	<b>WEAKNESSES</b>	<b>GAPS</b>
✓ <b>COLLECTIVE RESPONSIBILITY, CREATIVITY, INVOLVEMENT AND SOLIDARITY.</b>	✗ <b>INADEQUATE BUSINESS MANAGEMENT SKILLS, INCLUDING MARKET RESEARCH.</b>	? <b>NATIONAL RESEARCH, DOCUMENTATION AND EXCHANGE ABOUT VIABLE INCOME GENERATION.</b>
✓ <b>FINANCIAL EMPOWERMENT – BY CUSHIONING THE IMPACT OF POVERTY, DEVELOPING A COPING MECHANISM AND REDUCING DONOR DEPENDENCY.</b>	✗ <b>INSUFFICIENT CAPITAL, PARTICULARLY FOR THE START-UP PHASE – CONTRIBUTING TO DONOR DEPENDENCY.</b>	? <b>TECHNICAL CAPACITY, FOR EXAMPLE IN BUSINESS MANAGEMENT.</b>
✓ <b>INCREASED PRACTICAL SKILLS, MOTIVATION AND SELF CONFIDENCE AMONG CARERS.</b>	✗ <b>LACK OF INNOVATION AND ENTREPRENEURSHIP IN APPROACHES.</b>	? <b>LOCAL CAPITAL BASE, COMBINED WITH FORESIGHT IN PLANNING THE SUSTAINABILITY OF INCOME GENERATION ACTIVITIES.</b>
✓ <b>PROMOTION OF PROGRAMME SUSTAINABILITY AND VIABILITY.</b>	✗ <b>POSSESSIVENESS ABOUT PROGRAMMES AND COMPETITION FOR PROFITS.</b>	
	✗ <b>INADEQUATE NEEDS ASSESSMENTS TO IDENTIFY COMMUNITY PRIORITIES AND WHAT IS FEASIBLE.</b>	
	✗ <b>DUPLICATION OF INCOME GENERATION ACTIVITIES IN THE SAME COMMUNITIES.</b>	

(Reference: "Workshop on Sharing Lessons in Community Care and Support for People Living with and Affected by HIV/AIDS in Zambia," July 1999, Zambia)

## Impact on household income

Income generating activities help to provide economic support for PLHA and form an essential component of the comprehensive care and support continuum. In order to undertake income generating activities successfully, NGOs require support in planning, management and technical expertise.

HIV/AIDS is acknowledged to have a disproportionate impact on the poorest and most vulnerable members of society. However, even for people with incomes and high social status, a diagnosis of HIV/AIDS can lead to serious consequences – such as loss of employment of the family "breadwinner", or high levels of expenditure on treatment. Adequate income is essential for people with HIV to be able to maintain their health, self-esteem and overall quality of life. The Alliance recognises the need to consider economic and material support as a key component of a package of comprehensive care and support. In practice, this has usually been at a very basic level. In Burkina Faso and Cambodia, home based care teams try at least to provide free "staple" materials such as food, soap and blankets to the most needy PLHA and their families.

In other instances, technical support has focused on economic support, often in the form of income generation activities. One way of doing this in a sustainable manner is to link such income generating schemes to local NGOs with established micro-credit programmes. When this works, the effects include the encouragement of acceptance of people with HIV through reducing stigma and discrimination and providing an entry point for behaviour change. To maximise these effects, technical support for such schemes needs to include training in interpersonal as well as business skills.

At the "Community Lessons, Global Learning" workshop in Zambia, participants brainstormed the strengths, weaknesses and gaps of their income generating activities for PLHA (see above). Lessons have been learned from other sources too, in particular about the benefits of well-planned, appropriate income generation. For example, ANCS has supported SIDA Service – a Catholic NGO based in Dakar – to set up a series of income generating activities with PLHA, including setting up kiosks, market stalls and kitchen gardening. As Baba Goumbala of ANCS described, "Through an income generation programme, SIDA Service has enabled a man living with HIV to open a school in the suburbs of Dakar ... for poor children who are not able to attend normal

"In many projects for PLHA, there are income generation activities, but the reality is that they're not making enough profit for people to survive." Representative of the Network of Zambian People Living with HIV/AIDS.

# Enhancing the quality of community care and support

## Facilitating joint NGO planning, Senegal

At the end of the “Community Lessons, Global Learning” workshop in Senegal, NGOs from each region committed to future collaborations. For example, the six Northern groups planned:

- ✓ **HOLDING A DAY OF REFLECTION FOR NGOS IN THE NORTHERN REGION TO RE-FOCUS ACTIVITIES.**
- ✓ **STRENGTHENING A SOLIDARITY NETWORK IN SAINT LOUIS, BASED ON THE “CELLULE” MODEL IN LOUGA.**
- ✓ **HOLDING TRAINING ON IEC AND COUNSELLING IN LOUGA AND SAINT LOUIS.**
- ✓ **DEVELOPING AND MONITORING MICRO-ENTERPRISE PROJECTS (USING THE EXPERTISE OF OTHER NGOS).**
- ✓ **CARRYING OUT AWARENESS RAISING FOR STAKEHOLDERS IN THE NORTH DISTRICT.**
- ✓ **HOLDING COORDINATION MEETINGS EVERY THREE MONTHS.**
- ✓ **SHARING RESOURCES AMONG LOCAL ORGANISATIONS.**

schools. They pay a small amount each term, and he is paid a monthly salary. This man dropped out of college when he knew that he was HIV positive. This man feels very useful and he has gained acceptance in the community”. As a report by SIDA Service notes, “The mere fact of being responsible for a given activity has helped raise the self-esteem of some PLHA... Some of them were able to ‘come out’ as seropositive to their family and rediscovered how caring their loved ones could be: something that they had missed so much”.

Building on their successes and their experiences of unsustainable projects, ANCS have now developed a policy of only funding income generation activities that are managed by organisations with proven track records, such as development NGOs with experience in micro-credit. They also emphasise that income generation must be complementary to, rather than instead of, other forms of support. For example, Sida Service insists that PLHA involved in income generation still have access to psycho-social support and treatment. These dual policies have led to stronger projects, with clear benefits not only for individuals, but also services. Baba Goumbala continues, “PLHA who are involved in income generation activities are very busy, they earn money and feel useful. We have noticed that they attend the hospital less often. It seems that their health is really improving”.

## Networks and referrals

**Networking and developing referral strategies are practical approaches for addressing the growing demand for care and support. NGOs can develop specific, practical partnerships and referral plans to ensure a continuum of care and support for PLHA.**

Collaboration through networks and partnerships increases the impact of NGO action, and a combined voice is stronger than many individual ones. As the demand for care and support grows, referral networks become increasingly important. NGOs need to make effective links with other organisations and sectors in order to build partnerships to provide a continuum of care; an example of this is in the provision of voluntary counselling and testing. It is often inappropriate for NGOs to provide this service, but it is a key component of a continuum of care and support. NGOs and community based organisations can both advocate for the provision of voluntary counselling and testing services where these do not exist, and establish effective referral systems where these services are provided by another organisation.

### “Cellules” model of collaboration, Senegal

The Cellule of Louga started in 1997, based on a model from St Louis that was shared at an ANCS National Forum on Care and Support. It is based in the Social Services Department, and focuses on mobilising and coordinating services through existing agencies. The volunteers include social workers, health professionals and PLHA. They are trained in counselling and hold regular meetings to discuss difficult cases and plan activities. The Cellule works closely with a network of health professionals and community groups, including the Louga Hospital and community pharmacy, to ensure services for PLHA such as home and hospital visits, referrals, and confidential counselling. They also provide small grants to PLHA to establish income generating activities, and carry out awareness raising among people with the potential to provide support to PLHA (such as local cooperatives and youth groups).

Their challenges have included convincing doctors to refer PLHA. As one member says, “We had to talk frankly with the doctors and explain our strategies in order to convince them of the mutual interest they and we had in collaborating.” Their achievements include supporting PLHA, developing a medication bank for treating opportunistic infections and referring PLHAs to free health services. The Cellule is now a leader in care and support in the region.

(Reference: “National Workshop on Sharing Lessons about the Development of Community Organisations and Programmes for Care and Support for People Living with HIV,” Senegal, May 1999).

In Mexico, group discussions led to a heightened awareness of the importance of NGOs working more closely with different sectors and with each other. As one participant said, “During the analysis of previous conflicts, we were able to put ourselves in the place of our adversary. We saw how we were relating to others. NGOs have common objectives, and so we are necessarily linked in a complementary fashion”. A comment from an NGO representative from Ecuador also underlined the importance of networking among NGOs, “We need to know exactly what each other is doing and to work together so we can respond as a whole. We need NGOs to put their problems on the table, work them out and see how we can work together”.

### Multi-sectoral collaborations

**Sharing resources between sectors improves the quality and efficiency of services available to PLHA. Multi-sectoral collaboration should focus on finding ways for different groups and sectors to work together to maximise the use of limited resources.**

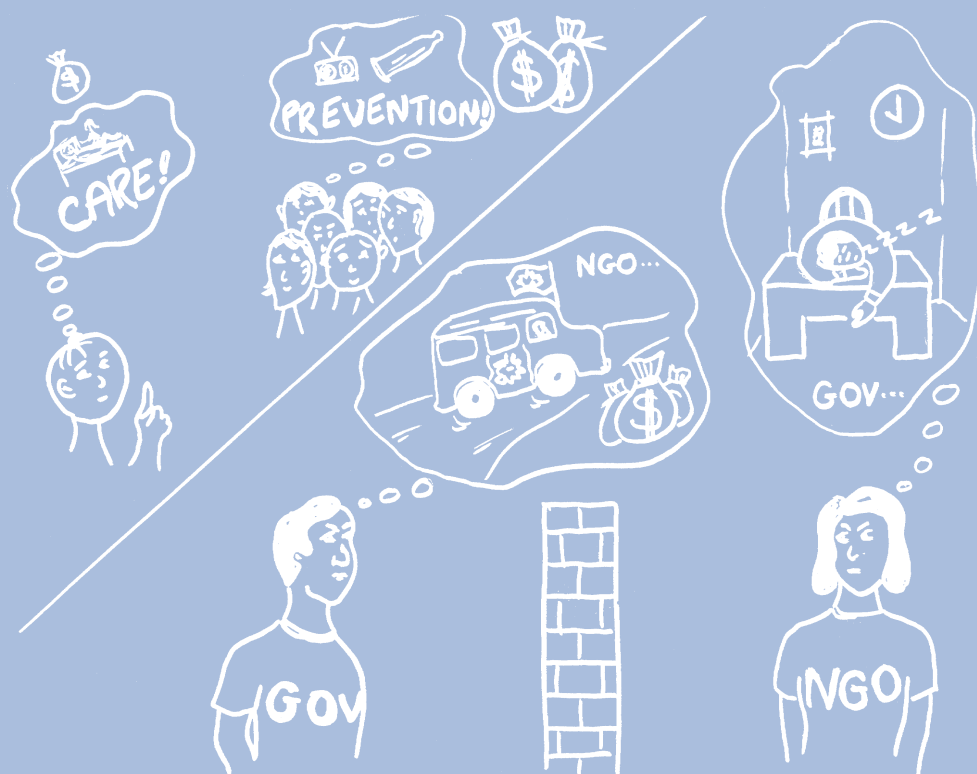
The nature of HIV is such that no single organisation can hope to address all aspects of its impact, particularly in the area of community

care and support. It is essential to mobilise a coordinated, multi-sectoral response to meet the care and support needs of the community. In practice, the models developed by the Alliance have varied from broad collaborations with multiple stakeholders to specific partnerships with individual institutions. At the “Community Lessons, Global Learning” workshop in Senegal, ANCS shared a model of local collaboration in the form of four “cellules” or “solidarity networks”. In Ecuador, Fundación Vivir, a local NGO in Quito, collaborated with one specific local sector, the military. By offering prevention services to military personnel they were able to arrange for the Military Hospital to provide for clinical back-up for PLHA in the community. With the support of COMUNIDEC, they achieved this through a variety of strategies – including holding a participatory assessment among military personnel, incorporating STD referrals into prevention activities, and carrying out advocacy with high-ranking officials and hospital personnel.

At the Asia regional workshop for “Community Lessons, Global Learning”, Alliance linking organisations also shared their strategies for forming partnerships at a national level to complement NGO efforts. For example, in Cambodia – the country with the fastest growing epidemic in South East Asia and where approximately 4% of adults are living with

# Enhancing the quality of community care and support

Establishing a collaborative care response, Cambodia



"In getting the project off the ground we faced two major challenges. At such an early stage in the epidemic, care was not yet on the agenda, and it was difficult to find both the motivation and the funding for anything other than prevention. A second obstacle was the conceptual wall between government and NGOs. The popular perception of NGOs by government is of four-wheel drives and expensive programmes that do not conform to government policy. The reciprocal view of government is one of corrupt and poorly motivated staff. Nevertheless when the teams got out there and realised how well they collectively met the community's needs for appropriate care, the 'wall' began to come down and the partnership has gone from strength to strength."

Henrietta Wells, Joint Ministry of Health/NGO Home-Care Pilot Project Co-ordinator

HIV/AIDS – the government and NGOs have collaborated on a model of home based care. The project started in Phnom Penh in 1998, as a one year pilot by the World Health Organisation (WHO) and the UK Government's Department for International Development (DFID). In February 1999, coordination was handed over to the Ministry of Health, with funding coming through NGOs, six of which are supported by KHANA. The project arose from NGOs' desire to respond to growing PLHA needs in a non-competitive, sustainable way. Its aims were to provide appropriate home based care and support services for people with HIV and other chronic conditions, and to try out a model of combined government and NGO health care. It involves teams of health centre nurses and NGO staff and volunteers, with two objectives – to provide care and support and to educate communities about HIV/AIDS. Based at the health centres, they spend the majority of their time in the local districts, visiting people in their homes. They share referral systems and co-ordinate through a monthly meeting of project partners.

Although the Cambodia project faced initial challenges, it has demonstrated how mixing government staff with medical backgrounds and NGOs with HIV/AIDS prevention backgrounds can both share skills and provide a comprehensive service. Also, the sharing of

other resources and equipment has reduced costs and enabled effective coverage in the catchment areas. For example, between February and December 1999, the six KHANA-supported teams made over 8,000 home visits, with 28,000 family contacts. Over 2,000 community leaders and 6,000 other community members were reached indirectly, including through education sessions. Despite increasing caseloads, the mortality rate has stayed stable at around 7%. The programme has also made a considerable contribution to increasing recognition of the effectiveness of home based care. For example, the Ministry of Health's National AIDS Programme has included home based care as one of its seven priority areas in their strategic plan for 2000-2003, and is currently developing plans for adapting and scaling up the model to rural areas.

## Finding partners

**Partnership building is a key strategy for NGOs in the delivery of comprehensive care and support to PLHA. Partnerships with different types of organisations need to be fostered, and may require a broader view of potential partners.**

Building partnerships is an important strategy



Opportunities and challenges for building partnerships, Latin America  
The partnerships programme in Latin America has supported care and support NGOs to develop practical collaborations with other sectors – through the use of tools such as “partnerships maps”.

for providing comprehensive care and support for PLHA. A key element of this is to identify a varied range of potential partners in order to provide better services to PLHA. This may mean building relationships with a new range of organisations. For example, NGOs with a secular approach may not have identified religious groups as a partner in prevention work, especially if views on condom use differ. However, their experience in community care and support means that religious organisations may be a crucial partner in responding to the needs of PLHA.

At the “Community Lessons, Global Learning” workshop in Ecuador, participants from Mexico shared their experiences of an Alliance Collaborative Programme. This was based on methodologies developed in countries such as the Philippines, Ecuador and Zimbabwe and promoted in an Alliance toolkit, “Pathways to

Partnerships”. The programme in Mexico aimed to build local capacity in planning and implementing practical strategic partnerships with other sectors. It involved developing a team of trainers which included staff and volunteers from eight national NGOs involved in prevention and care as a “resource pool” to mobilise and train other local NGOs. A formal evaluation of the programme in August 1999 showed impressive results (see below). For example, when the programme began, only six out of the 64 NGOs had identified key partners. By the end of the first phase, this had increased to 63. The qualitative feedback was positive, with participants reporting a series of benefits – from enhanced individual empowerment, to increased organisational access to equipment, to a united national vision among NGOs. Based on this success, a similar capacity building programme has now been adapted for NGOs in Brazil.

#### Building partnerships capacity, Mexico

Goal for capacity building programme	% of participating NGOs achieving goal	
	... before training	... after training
Written mission statement	31	97
Key partners	9	98
Partnership building strategy	11	84

(Reference: Evaluation Report, Phase 1, Mexico, August 1999).

Opportunities and challenges for building partnerships, Latin America  
Using a "universe map".



# 6

## Making a difference

### Examples of tools for appraisal of children affected by HIV/AIDS, Cambodia

Tool	Activity
Vulnerability drawing and story telling	Participants draw a picture of a “vulnerable” and “non-vulnerable” child of different ages and make up a story about each. Discussion is held about the comparisons – to draw out the factors of vulnerability and resilience. Then participants add HIV/AIDS to both stories. Discussion then focuses on the impact of HIV/AIDS on the vulnerability factors. Participants make a summary by defining issues for children affected by HIV/AIDS, including what helps minimise the impact of HIV/AIDS for children and what hinders this.
Network diagram of AIDS-related life events	Participants make a network diagram showing the links between AIDS-related life events (such as parents falling sick and dying) and their impact on the family. When the diagram is finished, participants indicate the action necessary to minimise negative impact on affected children at each of the network diagram nodes. Discussion draws out who could carry out the action and what would be the most effective strategy to use in each case.

(Reference: “Children Affected by AIDS: Appraisal of Needs and Resources in Cambodia”, Draft Appraisal Design, KHANA, Cambodia, February 2000).

### Assessing needs

**Care initiatives should be based on participatory assessments of the needs and capacities of PLHA and communities. Such assessments should include all stakeholders, with PLHA as central participants.**

Care and support initiatives need to be built on an assessment of the real needs of PLHA, their families and their communities. While such assessments should look at the comprehensive care and support needs of PLHA, they should avoid the danger of creating false expectations of what NGOs can offer. The Alliance’s experience of participatory community assessments in developing prevention activities serves as a basis for evolving methodologies for assessment of care and support needs.

At the “Community Lessons, Global Learning” workshop in Ecuador, the participants identified needs assessment as one of the most important tools in responding at community level – “Participatory action begins with a needs assessment which can have various forms (such as evaluative studies, interviews, site visits, and focus groups) but which is an essential element of developing and running a project. It allows one to know the target

audience better and helps to develop trust and build confidence (and often a level of ownership) of the project.”

The Alliance developed experience in this through its support for over 180 participatory community assessments for prevention initiatives in Africa, Asia and Latin America. In Cambodia, KHANA has supported over 35 prevention orientated assessments and is now helping NGOs to appraise needs and resources for care and support of children affected by AIDS. The appraisal of children’s needs formed the basis of two KHANA workshops about how to develop strategies for integrating services for children affected by HIV/AIDS into ongoing HIV prevention and care and support projects.

### Involvement of a wide range of stakeholders

**Effective responses to HIV require the involvement of a wide range of stakeholders at many levels. NGOs can often facilitate a neutral environment for a variety of stakeholders to meet and talk.**

Stakeholders at national level may come from a variety of backgrounds. Where NGOs can facilitate discussion at this level, joint strategic

# Making a difference



Participants of a small working group during the "Community Lessons, Global Learning" workshop in Senegal

planning taking into account stakeholders' different priorities becomes a possibility.

One of the most significant achievements shared by participants at the "Community Lessons, Global Learning" workshops was the mobilisation of action on care and support at a national level. In countries such as Uganda and Thailand, the importance and concrete impact of coordinated national responses to HIV/AIDS have been well documented. However, when many Alliance linking organisations began their care and support work, they found that their efforts were occurring in a near vacuum, with minimum support in terms of policy environment and infrastructure. Despite innovative efforts, it was clear that NGOs could only ever have limited efficacy and impact without the collaboration and scale-up that could be offered by national stakeholders.

In Ecuador, COMUNIDEC, the Alliance linking organisation, decided to mobilise national action both for programmatic reasons (to strengthen existing responses and mobilise sectors) and for political reasons (to foster solidarity and mobilise resources). In practice, this process combined a variety of strategies including national workshops, meetings with government officials, and funding projects. Meanwhile, in Senegal, ANCS became increasingly concerned about the lack of attention being given to strategies

and policies for care and support by both NGOs and the government, compared to the attention being paid to prevention activities. They saw that, although prevalence in Senegal was relatively low, the needs of PLHA were increasing. Nevertheless, care initiatives remained limited and poorly organised. As a response, ANCS coordinated Senegal's first ever National Forum on Care and Support. This brought together senior representatives of NGOs, PLHA, government, donors and health professionals. Four major themes were covered – including the place of care and support in national HIV/AIDS policies – and a number of recommendations were made, with all participants held accountable for their implementation.

Since then, ANCS and the Government of Senegal have gone on to coordinate two further National Fora, including one in 1999 as part of the "Community Lessons, Global Learning" programme. These have focused on different issues, including the involvement of PLHA, the re-integration of PLHA into community life and an overall analysis of the strengths and weaknesses of the national response (see page 23). One of the most tangible results has been the creation of local "cellules" – or "solidarity networks" (see Section 4) – which have decentralised action to beyond the capital.

Strengths of existing national response, Senegal

During the “Community Lessons, Global Learning” workshop in Senegal, participants analysed the strengths and weaknesses of the current national response to care:

Strengths	Weaknesses
<p><b>1. Community mobilisation:</b></p> <ul style="list-style-type: none"> <li>• Quality and quantity of volunteers.</li> <li>• Involvement of PLHA.</li> <li>• Partnerships with the medical sector.</li> <li>• Development of resources.</li> </ul>	<p><b>1. Management:</b></p> <ul style="list-style-type: none"> <li>• Low capacity in administration.</li> <li>• Difficulties in managing clients.</li> <li>• Dissemination of information within organisations.</li> <li>• Lack of expertise in certain sectors, and need for training.</li> </ul>
<p><b>2. Comprehensive care and support:</b></p> <ul style="list-style-type: none"> <li>• Psycho-social support as well as medical.</li> <li>• Projects for the socio-economic re-integration of PLHA.</li> <li>• Care for those affected.</li> </ul>	<p><b>2. Material and financial constraints:</b></p> <ul style="list-style-type: none"> <li>• Lack of tools.</li> <li>• Lack of transport systems.</li> <li>• Access to treatment.</li> <li>• Funding for projects.</li> </ul>
<p><b>3. Creative responses:</b></p> <ul style="list-style-type: none"> <li>• Advocacy.</li> <li>• Awareness raising and training programmes.</li> <li>• Income generating activities.</li> </ul>	<p><b>3. Inability to know the limits:</b></p> <ul style="list-style-type: none"> <li>• Financial limits.</li> <li>• Human limits.</li> <li>• Physical limits.</li> </ul>

At the local and organisational level, stakeholders include individuals with a particular interest in an organisation or a particular skill to offer. Individuals keep the motivation and momentum of organisations going and individuals within the community are a key part of starting and maintaining a response. They can be people who are themselves infected or affected, community leaders or health workers. Once support services are established, the quality of staff and their relationship with the people they are caring for is essential to sustainability and success.

Local leaders are an essential part of making home based care and support acceptable and reducing stigma and discrimination. Local leaders should be asked for their support early in the development of any programme, and community volunteers need to have a continuing role in communication as the project is developed. When families and communities have accurate and trusted information about HIV they are often willing to provide a supportive environment for community members who have HIV.

### Involving volunteers

**Training and support of volunteers is essential, particularly when volunteers are themselves living with HIV and**

### **may need to balance self-help with supporting others.**

Many organisations depend on the involvement of volunteers. NGOs in turn need to provide training, support and information to their volunteers to ensure effective participation. A session on volunteers at the Senegal workshop concluded, “You need to really get to know volunteers from the very beginning of their involvement and to help them find a place within the organisation that suits their interests, skills and availability”.

At the workshop in Senegal, NGOs from both the host country and Burkina Faso exchanged their experiences of working with volunteers at a community level. SIDA Service, based in Dakar, Senegal, shared their experiences of mobilising and training over 100 active volunteers (see page 24). REVS+, one of the Burkinabé groups, described their work with PLHA volunteers whom they actively recruit to become involved in self-help, medical, psychological and social support services. The volunteers are required to have basic knowledge about HIV/AIDS, and do not receive any payment. The NGO has found that their formal organisational structure – 40% of members are living with HIV, and the executive office is composed of 50% PLHA – has significantly helped with the recruitment of PLHA volunteers and led to their active

# Making a difference

## Mobilising and training volunteers, Senegal

SIDA Service has over 100 active volunteers, including teachers, nuns, lawyers, social workers and young people. This multi-disciplinary expertise allows much of their initial and ongoing training – in areas such as group dynamics – to be carried out “in house” by the volunteers themselves. Their activities include hospital and home visits, counselling, spiritual support and practical support – such as food, clothing and income generating activities. A few of them are considered permanent and full time, and receive small honoraria. But the majority work for free. The NGO provides back up through access to a documentation centre and “tailor made” resources, such as a SIDA Service counselling guide.

Volunteers have enabled SIDA Service to respond to the needs of PLHA on a scale way beyond that possible with just staff members. However, they have also encountered a number of challenges, including: reconciling PLHAs’ wishes for confidentiality with mobilising community volunteers; managing volunteer rotas and coping with their lack of availability at the times when they are most needed; and supporting people to cope with the challenges of their work. As one volunteer says, “Home care visits are often much more difficult than they seem. We don’t have a car when we need to travel far, the family is often not aware of the situation, and, when they are, they don’t want the neighbours to know.”

involvement in both decision making and the implementation of activities. Their slogan is: “*Se soutenir pour etre soutenu*” (“support and be supported”).

## Involving PLHA

**The empowerment of PLHA, getting HIV/AIDS on to the agenda of policy makers and the general public, reducing stigma and discrimination and providing psycho-social support can all be benefits of involving PLHA in the provision of care and support. But it is essential to ensure that such involvement does not expose people to further stigma and discrimination and that appropriate and continuing support is available to them.**

Bringing PLHA together helps to build self-esteem, mobilise communities and enhance advocacy. Self-help groups have a significant role to play in developing care and support responses and particularly in fighting social isolation and providing psychological support. Stigma and discrimination are a reality everywhere and while people living with HIV have a key role to play in reducing this, they are also vulnerable to its effects. Confidentiality is

central, and people need to be sufficiently supported if they are considering becoming involved in activities around care and support. PLHA should not be pressured to give public testimonies or to compromise their privacy.

Self-help groups can encourage PLHA to play a fuller role in the community. As a means of strengthening community responses to both care and prevention, the Alliance has provided technical support to promote the involvement of PLHA. In practice, this has involved supporting partners to develop concrete strategies and learn for themselves about the benefits and challenges of PLHA involvement.

In many countries, involving PLHA has been a catalyst in encouraging Alliance linking organisations to get involved in care and support efforts. COMUNIDEC, the Alliance linking organisation in Ecuador, shared some of the key results of involving PLHA at the “Community Lessons, Global Learning” workshop in Zambia. “Upgrading COMUNIDEC’s skills, in order to be able to provide adequate technical support to NGOs and CBOs in care and support of PLHA, started by providing direct contact and exposure to the human dilemmas surrounding HIV/AIDS. The conviction that PLHA play an essential role in providing a real life dimension to the epidemic strengthened COMUNIDEC’s capacity to

#### Lessons learned about involvement of PLHA work:

- ✓ Involvement of PLHA facilitates psychological support to clients, and builds self-esteem among PLHA.
- ✓ Visibility of PLHA magnifies the impact of prevention interventions and reduces stigma in the community.
- ✓ Technical know-how and a sensitive approach to involvement are vital.
- ✓ Succession planning (such as in self-help groups) helps to ensure ongoing involvement of PLHA and avoid crises.
- ✓ Involvement in income generating activities can facilitate acceptance of PLHA – as they provide opportunities for them to be self-sufficient.
- ✓ Involvement in peer counselling can increase the numbers seeking services – by helping people to feel less fearful.

(Reference: "Workshop on Sharing Lessons in Community Care and Support for People Living with HIV/AIDS in Zambia", July 1999).

advocate for the creation of opportunities to ensure the participation of PLHA and their integration in the planning and delivery of services with its partner organisations."

For ANCS in Senegal, the involvement of PLHA was a "corporate" priority from the very beginning. ANCS considers PLHA in its hiring policy, and three out of 11 places on their board are allocated to PLHA.

With some NGOs, the involvement of individual PLHA can occur gradually within the context of ongoing programme work. This can be seen with WOMEN (Women's Organisation for Modern Economy and Nursing) – a community development and human rights NGO involved in home based care in Cambodia. One of their volunteers – a woman living with HIV – became involved following a request from her counsellor at the hospital. She believes that she now plays an important role "giving a face to AIDS" and showing people that the disease is a reality in her country.

#### The next steps

The "Community Lessons, Global Learning" programme for 1999 brought together and shared many valuable experiences in developing appropriate responses to the needs of communities and the NGOs working with them. The lessons learned this year on care and support will be integrated into the Alliance's work on care and support, and shared amongst a broad range of stakeholders.

The next challenge is to respond to the rapidly growing demand for care and support and prevention. Support and services must reach as many people in as many places as possible. Scaling up NGO work in these areas – i.e. increasing coverage, maintaining impact and ensuring sustainability – will be the focus of the third and final year of the "Community Lessons, Global Learning" programme.

These issues will be explored during the workshops planned for the next year, building on the shared experiences and lessons learned about the development of effective prevention, care and support at community level which have been identified in the first two years of the project.

"The experience of PLHA is very inspiring. Before, we said that we were counselling PLHA, but others did not believe us. Then a counsellor living with HIV came and worked with us. He provided an example, and things began to change. People began to come forward and seek support. Now, our counselling sessions are full." Participant in the "Workshop on Sharing Lessons in Community Care and Support for People Living with and Affected by HIV/AIDS in Zambia", Zambia, July 1999.

# 7

## Recommendations

Based upon the lessons shared within “Community Lessons, Global Learning” and its other experiences to date, the Alliance promotes the following broad recommendations in relation to community care and support work:

### Recommendations for donors and policy makers

The Alliance recommends that donors and policy makers should:

- Recognise that, while important, drug treatments are only one component of HIV/AIDS care and support in developing countries. High quality, low cost care and support reaches the greatest number of people, increases quality of life and prolongs the lives of people with HIV. Improving access to complex, expensive treatments must not jeopardise more readily achievable goals such as the immediate provision of low cost care and support.
- Play a lead role in fostering national dialogue and partnerships on care and support. For example, by bringing different sectors together to share experiences, and by facilitating access to key decision makers for NGOs.
- Actively and formally promote the involvement of PLHA – not just in words, but through official structures and measures. For example, by assigning seats on National AIDS Committees to PLHA or introducing anti-discrimination legislation.
- Responsibly and responsively collaborate with NGOs around sustainability of community care and support. For example, modest funding that is secured for multiple years is often more useful to local groups than a high level of funding on a “one off” basis.
- Continue to support operations research initiatives on key areas that have a demonstrable, practical benefit for community care and support initiatives. Future priorities should include:
  - Addressing stigma and discrimination.
  - Scaling up community based care and support.

Participants carrying out group work at "Sharing Lessons on Community Care and Support for People Living with and Affected by HIV/AIDS" workshop in Zambia, July 1999.



# Recommendations

## Why care, involvement and action matters

**“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. If we don’t get together in groups and find help and medicines, we don’t stand a chance.”**

Member of PLHA self-help group, Ecuador

**“Our staff find out about people living with HIV/AIDS from their families or from people like the Village Chief. These people want staff to go and visit the person with HIV/AIDS because the person feels hopeless. The organisation is trusted by the community. The people can see the heart of the organisation in the behaviour and attitudes of the staff.”**

NGO representative, Cambodia

**“Before, I felt that it would be better for me to die than to be alive. But with the support and advice of the organisation, I’ve regained the courage to live.”**

PLHA mother of two, ALAVI, Burkina Faso

## Recommendations for NGO support programmes

The Alliance recommends that NGO support programmes should:

- Help NGOs to develop realistic strategies about what they can and cannot do. This should involve encouraging NGOs to prioritise basic, low cost, psycho-social support above providing more complex responses, such as drug therapies. The latter should only be carried out after very careful planning, and should only be a complement to – and never instead of – basic care and support services.
- Complement the above by promoting a continuum of care and support – with NGOs actively complementing the efforts of other sectors, and working together to respond to the full range of needs of PLHA.
- Insist that partner NGOs access appropriate expertise for their care and support initiatives. For example, if supporting income generating activities, they should be coupled with an organisation with experience in micro-credit. If providing treatment, they should work with qualified medical professionals.
- Ensure workshops and other forms of intensive technical support are complemented by follow-up support. This is particularly the case for NGOs new to care and support which may initially find the work challenging and overwhelming.
- Play a lead role in identifying and nurturing care and support projects that have the potential to be scaled-up. Even if they are not able to implement scale-up themselves, NGO support programmes have a vital role to play in documenting and sharing models – so that scale-up can be carried out by others.
- Monitoring should be a priority area of technical support for NGOs in care and support. For example, NGO support programmes can help NGOs to collect baseline data and to work with PLHA and community members to develop appropriate indicators and gather relevant data.
- NGO support programmes need to measure their own success – in terms of building the capacity of NGOs in care and support. For example, in addition to recording the number of people involved in efforts such as workshops, they need to assess areas such as how their cumulative work has enhanced the national response to care and support.

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HIV/AIDS

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