

AIDS Brief

for sectoral planners
and managers

NGO Sector



The HIV/AIDS epidemic is a global crisis, which demands urgent attention and committed, sustained action by alliances of individuals, organisations and sectors. The *AIDS Brief* series has been developed to support the conceptualisation and implementation of key sectoral responses. The NGO sector in most countries led the early responses to AIDS and today continues to play a critical role in mounting effective, sustained responses in both developed and developing nations.

BACKGROUND

Definition of the NGO Sector

Non-government organisation (NGO) is a catch-all term loosely used to describe a wide spectrum of non-profit organisations working outside government. Many NGOs are involved in providing HIV/AIDS-related services and projects. In different countries the voluntary response to HIV/AIDS ranges from a few relatively loosely co-ordinated organisations to literally hundreds of small community-based organisations and associations.

Facts about the NGO Sector

There are many different typologies and classifications of NGOs. One of the most familiar is distinguishing between specific AIDS NGOs, at times called AIDS Service Organisations (ASOs), and more general development NGOs. This Brief does not use a specific typology and urges the reader to understand three key principles.

Firstly, voluntary, community and non-governmental responses to HIV/AIDS are diverse, ranging from self-help groups that survive on a shoe-string to professional bodies of skilled personnel. They include various types of voluntary membership organisations, such as trade unions, churches and other community-based organisations, and service delivery



organisations registered as Welfare or Private Voluntary Organisations or even as not-for-profit companies. They are funded by governments, the private sector, other organisations and the general public.

Secondly, the relationship between government, business and the NGO sector shifts continuously. This results in a diversity, which can make it impractical to compare or apply models from other countries or settings. Some organisations act outside the direct control of government, but collaborate with or exist alongside governments.

Finally, the strength of civic society to organise people outside government and the space allowed for civic society by government often determine the response of NGOs within countries.

AIDS AND THE NGO SECTOR

Initially, many governments were slow to respond to the HIV/AIDS epidemic. When they did, they often responded with denial, ignorance or persecution, linking AIDS to certain forms of sexual behaviour. NGOs helped place HIV/AIDS on the national agenda and pioneered the development of services, mainly for prevention and care. HIV spread at a time when many developing countries were focusing on macro-economic and political reform. Today, countries dealing with the aftermath of the reforms of the 1980s and 1990s face deteriorating basic

services (health services and education), increasing food insecurity, and an expanding HIV epidemic. In these settings, basic information, adequate condom supply, effective treatment for sexually transmitted infections (STIs) and the protection and improvement of women's self-esteem through increased education seldom take place. Providing adequate care services in a setting of failing primary health care services quickly becomes an impossible target.

Towards the mid-1990s most governments had at least woken up to the HIV pandemic,

although their commitment has been varied and often slow, limited and poorly funded. As the governments' responses to the epidemic have changed, the involvement of NGOs in HIV/AIDS has diversified and grown. The first generation of NGO programmes provided basic services, the second generation has covered a wider range of issues and needs.

Northern-based NGOs have broken ground in directly selecting NGOs from the south to help in planning and developing a global response. In many countries, therefore, NGOs are accepted

as a partner of government in programming, planning and formulating policy. A few NGOs working in the north and the south have developed effective linkages and long-term alliances. Examples are Healthlink, the UK NGO Consortium for AIDS in the Third World and the NGO-Alliance; the long-standing co-operation in publishing between the Dutch Royal Tropical

Institute (KIT) and the Zimbabwe-based Southern Africa AIDS Information Dissemination Service (SAfAIDS); and the Canadian Public Health Programme and the Southern African AIDS Training Programme (SAT).

Southern-based NGOs also have to cope with their own susceptibility and vulnerability to HIV infection and AIDS and the consequent

loss of staff, demoralisation and increased staff turnover. Institutional memory and experience are lost just when NGOs need increased capacity to meet new threats in the external environment: reduced Government capacity, increased community care needs and loss of labour availability threatening both the informal and formal sectors and impoverishing households, communities and enterprises.

Strengths	Weaknesses	Opportunities
<ul style="list-style-type: none"> + Flexibility in policy and programme design + Innovative prevention and some care approaches + Pioneer function + Ability to attract additional funds + Mobilises volunteers + Watch dog + Closer to communities 	<ul style="list-style-type: none"> - Donor dependency - Lack of vision on HIV/AIDS and human development - Poor quality management - Limited impact assessment - Limited capacity - Scaling up can be problematic - Poor integration of HIV/AIDS with under-development and wider health issues 	<ul style="list-style-type: none"> + Governments' slow response + Massive need for innovative and effective strategies, programmes and projects + Linking up with existing structures and organisations + Development of a new conceptual framework

IMPACT CHECKLIST

Internal Risk Profile

- ✓ How many days are being lost to funerals, care and ill-health?
- ✓ How is AIDS impacting on the morale of staff through personal losses?
- ✓ What does it mean to work in an ASO while facing HIV infection oneself or in loved ones?
- ✓ How open and supportive is the organisation?
- ✓ Are personal needs and fears discussed openly?
- ✓ Do HIV-positive staff feel able to reveal their status and seek help? If not, how can such confidence be built to enable full support?
- ✓ How does AIDS impact on costs to the organisation?

- ✓ How effective are HIV awareness and prevention interventions for staff?
- ✓ What more could or should be done to help both staff and the organisation cope?
- ✓ What succession planning, understudying and multiskilling are in place should key staff become ill and die?

External Risk Profile

- ✓ Which are the groups most susceptible to HIV infection in the population served?
- ✓ Which are the groups least able to cope if infection levels rise, i.e. most vulnerable to the impact of AIDS?
- ✓ How can HIV awareness and prevention

- strategies be effectively integrated into mainstream organisational goals?
- ✓ What new needs are arising in the population because of AIDS? How can NGOs integrate new AIDS-related needs into existing programmes eg increasing numbers of orphans, household economic insecurity, short-term coping strategies at the expense of long-term such as withdrawal of girls from school and selling productive assets?
- ✓ How are programme goals impacted by increasing morbidity and mortality and loss of labour in the population?
- ✓ What is the commitment of government to HIV/AIDS prevention, care and mitigation?

SECTORAL RESPONSE

Several developing countries experiencing the brunt of the epidemic have an active NGO community that is addressing the spread and impact of HIV/AIDS. NGOs are often more able than government to attract additional funding for community-focused activities, develop action at the local level and initiate innovative approaches.

Facing a severe AIDS epidemic and declining socio-economic conditions, some developing countries have witnessed a mushrooming of programmes for HIV prevention, home care, and counselling in the non-governmental sector. Numerous individuals and families benefit from these programmes,

which focus mainly on service delivery by professionals or highly trained staff. Yet these services are under threat, as they are often costly and depend exclusively on external funding.

Frequently the frontline service providers are so close to the daily problems, and chronically over-stretched by individual demands, that they cannot stand back and review their strategies: indeed to do so may imply criticism of their dedicated and stressful work. Yet a radical change is needed in this fire-fighting approach. Communities must increasingly take the lead in responding to AIDS through HIV prevention, identifying families and children in need, and developing coping responses.

Communities already face the problem of AIDS and already bear the costs of declining income, increasing ill-health and burial costs, and the withdrawal of children from school. Communities need help in addressing the spread and impact of AIDS in the context of all their other needs. Particularly in rural areas, NGOs will have to transform themselves from service providers to community mobilisers. Such a transformation will be more difficult in fast-urbanising areas because they generally lack community cohesion. In such settings, direct service provision has a larger role, but even here promoting informal support networks for care, openness and coping remains worthwhile.

Examples of NGO Responses

- NGOs developed distribution and sales points for condoms outside clinics and dispensaries, the main outlets in the past. Social marketing of condoms has become a noteworthy achievement of NGOs in the prevention of STD/HIV/AIDS transmission.
- NGOs continue to develop innovative prevention programmes and interventions. Involving sex workers in distributing condoms to other sex workers has been one of the most appropriate ways to reach this group. Recruiting and training peers from the intended target group has become a commonly accepted method.
- Generally, orphan-care programmes are perceived as care activities. This perception is unfortunate because adequate orphan care is essential to avoid creating large groups of rootless young men and women who are insufficiently socialised, have inadequate parenting skills and low self-esteem, characteristics that make this group vulnerable and susceptible to HIV transmission. The number of NGOs working to develop sustainable orphan care is small but increasing.
- One of the most important voluntary responses to HIV/AIDS has been the formation of groups of people living with HIV/AIDS. Mixing peer support, self-help,

activism and income generation, this movement is as varied as the overall NGO movement. A well-organised PWA group can provide a 'safe haven' or supportive environment to help PWAs deal with their status and life in general. They can also provide a stepping-stone for local prevention and care initiatives and advocacy. The visibility of PWAs, although not without risk in announcing that one is HIV-positive, is essential in order to bring the epidemic close to home and to address social stigma. The powerful roles that social stigma and shame play are important rallying points for all parties involved in HIV/AIDS.

Current Problems

- Too many NGOs have assumed the 'right' to speak on behalf of the community, even though the NGOs are only external service providers. The international People With AIDS (PWA) movement has been active, and generally successful, in exposing this.
- HIV/AIDS education is important and should continue, but over time will have to move beyond basic facts and figures to include information about STIs and the risks for men and women. NGOs must not reinvent the wheel but learn from others and apply this knowledge and experience in the local context.
- Even successful NGOs involved in direct service delivery for prevention, care and mitigation of impact have difficulty meeting the challenges of routine quality control, effective coverage of services and of 'scaling up' innovative or pilot programmes.
- During the late 1980s and early 1990s, NGOs in the developing world benefited from easy HIV/AIDS-related funding. Today, funding for HIV/AIDS activities has suffered from donor fatigue, revealing the voluntary sector's over-dependence on external funding. The cut back in funding threatens

many specialised AIDS organisations because of their narrow focus and incapacity to develop new, attractive initiatives.

- Many AIDS-specific NGOs have been unable to move towards broader or 'second-generation' programmes. Five years from now, the same education and prevention programmes will not be effective. Few organisations dare to admit this and even fewer have the resources to deal with it. The 'narrow' approach or programme also limits co-ordination and co-operation among HIV/AIDS programmes and other reproductive health services.

Future Challenges

- There is growing consensus that NGO responses to HIV/AIDS should be situated in the broad context of human development. In the most affected countries, the epidemic and the linked rise in ill health and death rates will lead to unprecedented suffering amongst those who have limited or no means to cope. Although the macro-economic impact of HIV/AIDS remains an issue of academic debate, the projected drop in life expectancy, the rise in infant and child mortality and the worsening dependency ratio will hamper human development.
- For HIV/AIDS prevention and care interventions to be effective, the basic needs of food, clothing, safe drinking water and shelter have to be met. Similarly, development programmes will no longer be effective if planners, politicians and service providers continue to ignore the long-term impact of HIV/AIDS on households, families and communities.
- In the developing world, the non-government sector will have to take HIV/AIDS on board because HIV/AIDS cuts across all aspects of human life and invades our most intimate moments. Many of the people who are HIV-positive do not know, and probably never will know, their status. They will face increasing ill health and various opportunistic infections without knowing for certain why. With hindsight, the most effective care strategy in the developing world would have been to ensure primary health care services for all, thus providing basic health care and treatment for the increasing number of opportunistic infections, regardless of a person's HIV status.
- As the pandemic continues to spread and is linked to other structural issues such as gender, the environment, and access to resources, we need to adopt a long-term approach that does not single out HIV, but

links prevention, care and coping to general development. Community mobilisation and involvement are essential for development and they can be achieved by using participatory methods. Countries at the early stage of the epidemic can benefit from the documented NGO experience from other countries.

- NGOs must realise the enormity of the communities' needs for prevention and care. Responding to HIV/AIDS is not a quick fix activity: it requires long-term commitment and involvement. In all HIV/AIDS-related interventions, an honest assessment of means, skills, needs and impact will have to be made.
- Targeting continues to be important in terms of effectiveness and of cost. Delivering appropriate prevention and care messages and interventions can and should be based on actual involvement of the target group: it is by doing this that sustainability and ownership can be achieved.

In embracing these future challenges linked to human development, NGOs will have to entertain the following questions:

- How can NGOs best support sustainable community-rooted services for HIV prevention, home care, elderly and family support, child and orphan care?
- In what contexts should NGOs focus on direct service delivery for specific groups, and when concentrate on programming, planning and policy development, and on community mobilisation? How can they ensure their programmes are sustainable?
- What are the socio-economic and cultural characteristics of the groups most vulnerable to HIV (for instance girls, married women, orphans, prisoners, sex workers and migrant workers)? What issues do they perceive as most relevant to them?
- What are the priority interventions to address these groups' vulnerability to poverty, ill health, gender inequity, reproductive health needs and HIV?
- How can existing community and civic organisations best incorporate HIV/AIDS into their development and human rights agendas? Are new organisations needed or not?

- What roles can NGOs play in relation to mobilising and supporting private sector, media and government responses to HIV/AIDS?
- What risks adhere to people going public about their HIV status? How can NGOs effectively advocate the active involvement of PWAs and mobilise against human rights abuse of PWAs and discrimination?
- Through what methodologies and using which indicators should the quality, coverage and impact of HIV/AIDS services be monitored and evaluated?

ACTION CHECKLIST

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| <ul style="list-style-type: none"> ✓ Mobilise communities to identify and address problems facing them. ✓ Identify and address core service needs (through community mobilisation rather than top-down service delivery). ✓ Explore how HIV/AIDS-related needs can be integrated into wider programmes addressing other development issues. | <ul style="list-style-type: none"> ✓ Build institutional capacity and support staff development. ✓ Strengthen relationships within communities, between the community and support organisations, and between different development agencies, donors and government. | <ul style="list-style-type: none"> ✓ Move beyond traditional networks and links and explore new strategic partnerships, eg between development NGOs and ASOs, CBOs and PWA support groups. ✓ Monitor and evaluate your programmes closely and ensure flexibility of response as required. |
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SUMMARY

Developing, designing and delivering community focused interventions around HIV/AIDS by NGOs means engaging with the many complexities of the setting in which people live. NGOs must be aware of their chosen role as a change agent and the responsibility and power this gives them. Raising the issue of HIV/AIDS

means that this will have to involve a discussion around gender roles and responsibilities, sex and sexuality, culture, spirituality and basic needs. Education and development are about empowerment, self-esteem and being able to apply the knowledge gained. Too often the assumption is made that the mere provision of

information and education will lead to effective behaviour change. By adopting a learning approach through which services and clients are linked in sequential loops of two-way communication and interaction, the NGOs will be able gain entry, deliver services, and build confidence for themselves and the community.

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- UNAIDS Report and six-monthly epidemic updates SAfAIDS News No 3, (1999)

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