United Nations
Economic Commission for Africa

African Development Forum 2000

AIDS: the Greatest Leadership Challenge

3- 7 December 2000
Addis Ababa, Ethiopia

Theme Paper

Building on lessons learnt from intensified responses to HIV/AIDS

13022

Theme paper

Scaling-up the Response to HIV/AIDS

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Introduction

As discussed under theme 2, the HIV/AIDS epidemic is a major development crisis that threatens the social and economic fabric, and political stability, of many nations on the continent of Africa. As was illustrated, Africa already possesses most of the "tools" – if not the resources – needed to change the course of the epidemic.

There are fine examples throughout Africa of political commitment to change and action, and community-based programmes have been especially effective in enhancing prevention, care, support and treatment for those infected and affected by AIDS. However, national programmes have, by and large, not been successful in scaling up their own proven and culturally adapted interventions to achieve nation-wide coverage (MAP).

There is an urgent need to build on the lessons learned about HIV/AIDS prevention and care over the past two decades. The major challenge is how to develop successfully within the resource constraints facing African countries, the scale and reach of the many programmes which are successful in their work but which only help a small percentage of the population. This must also involve mobilizing communities to own and take responsibility for their response to the epidemic, and providing them with the programmes to support their actions.

An example of 'limited reach' (Binswanger) is given from the Kagera region of Tanzania, the first region hit by HIV/AIDS 16 years ago. An estimated 200,000 of the region's 1.9 million inhabitants are AIDS orphans. As well as health posts and hospitals, there are HIV/AIDS services provided by 10 NGOs. They are staffed by dedicated volunteers, but they are dramatically under-funded. The NGO leaders have pointed out that they operate mainly in two out of five districts, leaving the other three with virtually no services. In the two districts on which they do concentrate, they reach no more than 5% of the population with any of the HIV/AIDS services (such as counselling and testing, care of opportunistic infections, home-based care and support to orphans).

Such low coverage characterizes most of sub-Saharan Africa. In Côte d'Ivoire, only two out of eight regions have any programmes in rural areas, and the services are confined to prevention. In most other countries in Africa, HIV/AIDS services are only available in the largest cities, and even there the reach is limited.

The aims of all National AIDS Strategic Planning must be to provide national coverage; to build truly national HIV/AIDS programmes; to expand prevention activities to reach all vulnerable individuals; to support and care for the vast numbers of people who are infected, and affected, by HIV/AIDS and to promote an atmosphere for reducing discrimination and stigma. Only then can there be any real possibility of changing the course of the epidemic and saving countless thousands of lives.

It should also be stressed that nowhere in the world has achieved the vitally needed level of 'AIDS competence', that is, the ability of societies to deal with AIDS by an accurate assessment of the factors that put their people and communities at risk and hamper the quality of the lives of people affected by AIDS.

How can the scale of small projects be increased?

So how can these 'boutiques' be scaled-up so that they serve the whole population, not just the 'lucky few'? It calls for changes in leadership, in policy-making, in the mobilization of resources and the transfer of funds, a strengthening of multisectoral approaches and of community involvement and empowerment. First of all, it calls for a change in the way of thinking – the 'mindset' – of policy-makers and all those who influence policy and practice.

Changing the 'mindset'

First of all, we must dare to think to scale. Even thinking of, let alone beginning to implement, such a major development requires courage from all concerned. It also requires strong leadership, at all levels. But again, it is necessary to rethink the definition of 'strong leadership'. It should not be defined as command and control. For far too long, people working in areas of health such as HIV/AIDS have taken their cues from the military. Policy-makers are the generals, health workers are the soldiers and the population is the target of their interventions. We like to think we are "in control" but for health problems such as AIDS, we are not and never can be.

Over the years, we have learned that the issues surrounding HIV/AIDS are deeply embedded in the cultural and social beliefs and practices of communities. Many of the issues are intimate, personal and private. Under these circumstances, our approach needs to be as participatory as possible at individual, community and national levels.

We have to win people's respect and confidence, only then can we hope to influence people's decisions about their personal lives and behaviour. Policy-makers need to listen and to involve, and to facilitate actions and change.

This change in ways of thinking is not easy. It will mean painful shifts in administrative culture, in governments, NGOs and UN agencies. But the rewards are considerable, leading to personal growth and facilitating the processes that are essential to scaling up local responses to HIV/AIDS to national coverage. These processes, which are not discrete but overlap, include:

- Multisectoral approaches
- Decentralization
- Community empowerment and involvement
- Mobilization of resources

Leaders – political, religious, traditional – need also to confront and deal with taboos and stigma against HIV/AIDS (their own as well as those of their societies). They must speak openly about the virus and be seen to involve people living with HIV/AIDS in planning and policy-making.

Multisectoral approaches: ' Involve all the actors'

In scaling-up any national plan, it is essential that it becomes truly inclusive. This 'drama' must be ensemble playing, not a vehicle for star names. Currently, the impact on the epidemic at all levels is compromised by fragmentation (IPAA); different actors pursue agendas in isolation from each other. Instead of working within nationally negotiated and agreed strategic agendas, actors – whether government or non-government, United Nations or private sector – have tended to address HIV/AIDS as an area for designing and implementing multiple, often small-scale projects, with their own objectives, management, monitoring and evaluation systems. Other types of fragmentation result from governments' lacking the means and the skills to ensure the coordination of all actors in all sectors – all levels of government, health, education, agriculture, community development, business and others.

All those stakeholders willing and able to help at local level must be involved; for example, staff and elected officers of local and district governments and services, private firms, persons living with HIV/AIDS, community-based organizations such as churches or mosques, local chambers of commerce and NGOs. For government and local government authorities, such work should no longer be a matter of 'willingness'; it should be made part of their duties. For example, in

Swaziland, at Regional level, the Strategic Plan is coordinated through the Regional Secretary who is head of the Regional Development Team in each region. As the Strategic Plan is based on the bottom-up approach, the structure will be organized at chiefdom level. The chief will be expected to establish multisectoral community HIV/AIDS teams to educate their communities on prevention, care and support. The Chairperson of the HIV/AIDS community team will report to the chief and also represent the chiefdom at Inkhundla (that is, district) level.

In this multisectoral approach, the actors must include NGOs, development partners such as UN agencies, and the private sector. In South Africa and Tanzania, a partnership forum has brought these sectors together in order to implement the National Strategic Plan.

The challenge in the coming months and years is building the capacity of the different sectors, maintaining that capacity, monitoring their activities and providing relevant feedback. In order to ensure effective coordination between the many different sectors, all the actors in these sectors must be provided with all the necessary training, financial resources and other inputs. All sectors have to become 'AIDS-competent'; they need the ability to assess the impact of the epidemic on their work, and their staff, to analyse their factors of vulnerability and risk, and to act on those factors.

Several governments in Africa have already started taking bold and innovative steps in this direction:

- The Government of Malawi held a training programme to build the capacity of sector ministries to 'mainstream' HIV/AIDS into their day to day activities;
- The Government of Mozambique contracted a private company, Austral, to help sector ministries and provincial governments develop their HIV/AIDS sectoral and provincial plans; and
- The Government of Swaziland in collaboration with the UN Theme Group on HIV/AIDS has contracted the Swaziland Institute of Management and Public Administration to develop and provide HIV/AIDS prevention and control training to all civil servants. This training targets 21,275 individuals in 30 departments and 16 different ministries.

Governments may be uncomfortable working with socially excluded groups such as commercial sex workers or men who have sex with men. Issues such as distributing condoms to young people may raise cultural and religious sensitivities. The experience of NGOs and people living with HIV/AIDS (PLWHA) in dealing with such issues will help overcome these cultural barriers in locally appropriate ways and ensure that no group is excluded from programmes.

If sectors work together, they can be creative in providing expertise and support to each other. For example, the private sector can advise and train NGOs in developing and running small businesses in order to raise financial resources (such as the Population and Community Development Association in Thailand).

Decentralization

An important lesson learnt over the past decade is that national HIV/AIDS responses cannot reach the necessary scale through centrally operated programmes. For example, most National AIDS Programmes are not reaching enough people in the rural areas. A decentralized, participatory approach with the involvement of all sectors (that is, the multisectoral approach) leads to wider coverage, especially of people at the "grass roots" level. Such an approach is also the only way to ensure wide-ranging behaviour change. People anywhere in the world, required to make such major and personal shifts in behaviour, have to trust and share in the thinking behind this major requirement being asked of them. We all need to make sense of what is happening to us; only then can we begin to react and change.

In the same way, policy-makers and planners need the input of local people to understand the particular socio-economic conditions affecting the epidemic locally. For example, why and how are so many young women going into commercial sex work? What are the cultural and traditional barriers to safe sex? Only through decentralization can responsiveness to day-to-day needs, arising from community activities, be coordinated.

There has to be the active participation of all the actors at community level, and the decentralized control of finances. The need for strong central coordination does not disappear, but the role shifts to policy creation, facilitation, finance and support to local efforts. Since decentralization of planning and decision-making must be accompanied by decentralization of funding, it is essential to develop standards and procedures for the disbursement of funds. Lost, late or misapplied funding can torpedo a local initiative, so financial administration must provide safeguards through consistent monitoring. Development of procedure manuals and help with office automation may be areas in which central governments can be helpful. Moreover, the accountability of service providers and contractors to local populations is easier to achieve than with distant agencies (Binswanger).

Decentralization of funding must not, however, lead to more bureaucracy nor should it disburse monies without clearly earmarking them for HIV/AIDS. Denial and fear are active forces in Africa, and local (and national) decision-makers do not allocate funding to something about which they cannot talk.

Decentralization must involve the government in facilitation and funding skills and abilities at the local project level. There must be access at local level to facilitators, trainers and a variety of service providers from the private, non-profit and public sectors. However, it is also important to start with existing capacities and build on them through

"learning by doing" - or learning on the job. This can be one of the most effective and sustainable ways of learning.

There are several African countries that contain in their National Strategic Plans comprehensive planning for decentralized action at provincial, district and community level. These include Kenya, Namibia, Zimbabwe, Swaziland and Zambia. Some are using UNAIDS Programme Acceleration Fund money to build capacity at these levels.

Decentralization requires considerable shifts in thinking (as mentioned earlier) and in doing. It also requires some humility, and the ability to listen to people at local level and understand that they have much to offer at all levels. There are enormous variations in needs and capabilities across communities and districts. Only local stakeholders will be able to know these local conditions and put the required programmes in place.

Thus, decentralization leads to, and overlaps with, another essential process in scaling-up the response to HIV/AIDS: community involvement and community empowerment.

Community involvement and empowerment

AIDS programmes have relied heavily on traditional information, education and communication (IEC) messages based on the premise that "getting the message right" (IPAA) would lead to appropriate behaviour. It is increasingly evident that true participation of families and communities in analysing their own situation, particularly that of women and girls with respect to HIV/AIDS, is a prerequisite to success in addressing every aspect of the epidemic, including stigma and discrimination. There is an increased realization that this essential strategy needs to be implemented with the same level of priority as activities to support prevention and care.

The eventual outcome of the AIDS epidemic is decided within the community. People, not institutions, ultimately decide whether to adapt their sexual, economic and social behaviour to the threat of HIV infection. They are the subjects of the response to AIDS, not merely the

objects of outside interventions. So responses to HIV are, in the first instance, local. They imply the involvement of people where they live – in their homes, their neighbourhoods and their workplaces.

Effective programmes such as home care in the community for people living with HIV/AIDS have grown out of very real needs in that community. It started in Zambia in the late 1980s, and has also developed strongly in Uganda. Developing out of the recognition of the need to care for bed-bound patients, the programme grew over time by responding to the many other needs of people living with HIV/AIDS and their families. This home care programme has allowed community ownership of the problem of HIV/AIDS and led to prevention measures being implemented as well.

Community members are also indispensable for mobilizing local commitment and resources for effective action. In particular, people living with, and affected by, HIV/AIDS must play a prominent role in the local response and bring their unique experience and insights into programmes, from the start of the planning process.

Once a single district can be covered, the approach can be scaled-up quickly to national levels. But this can only happen if governments, multilateral institutions, and bilateral donors are willing to empower communities and local and sectoral HIV/AIDS committees with financial resources. They have to enlist those people who have struggled for years in the small under-funded "boutiques" to train and guide the large numbers of locally credible volunteers needed to reach the entire population (Binswanger).

Mobilization of resources

Because of limited resources, priorities have to be clearly agreed, focusing on a core set of activities in prevention and care that have been proved effective and feasible. Working with all the sectors and at a local level will help in this process.

National policy can support effective local partnerships in many ways. National policy-makers can develop job opportunities in areas most vulnerable to HIV by adopting an AIDS-sensitive macroeconomic framework. Policy-makers can reduce widows' economic vulnerability by reviewing inheritance laws. By maintaining peace, they will make local action and sharing of experience possible.

Decentralizing the national response will of course re-route funds to regional, district and community level projects, but national funds are limited, hard hit as African countries have been by the HIV/AIDS epidemic and its impact on their economies, and by the burden of debt. There is an urgent need to increase available resources for the response, both financial and human resources. The latter will be sorted through the process described above – a multisectoral approach, decentralization and community involvement. But how can financial resources increase?

- *Donor assistance*: there is strong evidence that donors are willing and eager to help in combating the HIV/AIDS epidemic in Africa. The donor response to the International Partnership Against AIDS in Africa (IPAA) has been positive. The challenge is to ensure that this growing enthusiasm results in a steady increase in concrete support to national HIV/AIDS prevention and control programmes. There must be an emphasis on building partnerships between donors and countries. There is also a great need for more solid data on coverage in countries, for example, the numbers and location of commercial sex workers or the extent of sexually transmitted infections (STI) services. Donors want to know what is needed, what works, and what is cost-effective.

Resources are more likely to flow towards well designed, clearly costed and well implemented programmes, especially where it is clear that mechanisms are in place for moving resources to district and community level (IPAA).

- *Reallocation of countries' own budgets*: Governments need to examine spending priorities in light of the rapidly growing costs of AIDS and reallocate accordingly. The redirecting to AIDS of existing project resources already programmed for social funds, education and health projects, infrastructure and rural development is fully justified, as the AIDS epidemic is undermining the very goals of those other investments. Governments can also leverage existing programmes such as education and agricultural extension by integrating HIV/AIDS into them at modest cost. The costs may be modest but the outcome considerable. Including information on HIV/STIs and life skills in a school curriculum may bring about major benefits such as decline in STIs, unwanted pregnancies and drug use. In the same way, boosting the educational and economic opportunities of young girls in rural areas not only reduces HIV transmission by providing alternatives to commercial sex but also contributes to sustainable rural development and improvement in the status of women.

- *Debt relief:* Lack of funds for an expanded response to HIV/AIDS in Africa has been worsened by the high levels of foreign indebtedness. Across Africa, national governments pay out four times more in debt service than they spend on health and education. Relieving this burden is one of the more promising new approaches that could increase the funds flowing into programmes to combat HIV/AIDS. A major initiative to reduce debt is the Highly Indebted Poor Country initiative (HIPC), supported by all the major creditor governments from the Organization for Economic Cooperation and Development (OECD) countries and implemented by the World Bank and the International Monetary Fund (IMF). Several African countries have started to feature HIV/AIDS more prominently in their poverty reduction programmes. However, a concerted effort by a coalition of interested African government officials, civil society representatives, creditor governments, and UN and multilateral agencies will be required to ensure that debt relief is actually used to mobilize substantially increased funding for combating AIDS.

Conclusion

We have to build on the lessons learned over the past two decades and we have to develop and extend the scale and reach of African countries' national responses to HIV/AIDS. There is no alternative if we are to have any chance of changing the course of the epidemic and saving countless thousands, if not millions, of lives.

The strategies for scaling up are clear. They include:

- Strong leadership at all levels;
- Changing the 'mindset' from trying to control to facilitating, listening, involving;
- Challenging discrimination and stigma at every level;
- Involving all the actors, through a truly inclusive, multisectoral approach, to counter fragmentation;
- Decentralization;
- Community involvement and empowerment; and
- Mobilization of resources through donors, reallocation of government budgets and debt relief.

So the way is clear; we have the maps and the charts. How soon can we make the journey?

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