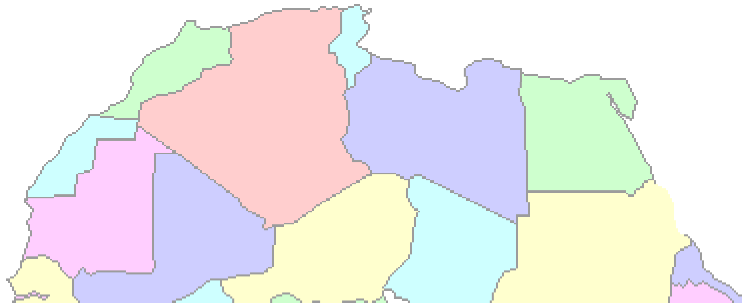
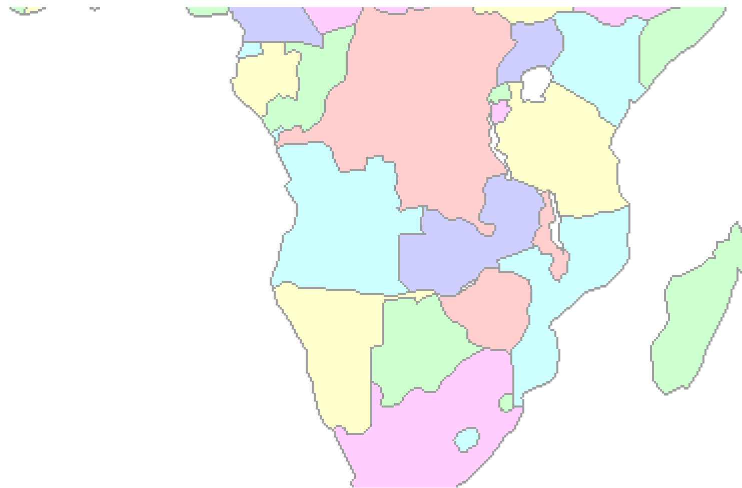
Community Realities & Responses to HIV/AIDS in Sub-Saharan Africa





Community Realities & Responses to HIV/AIDS in Sub-Saharan Africa

United Nations, New York
June 2003

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The Main Lessons And Recommendations of the Report

As we have seen, sub-Saharan Africa's AIDS epidemic is a multi-faceted phenomenon, and approaches and constraints to confronting it are as diverse as African communities themselves. Thus, there are multiple recommendations at each level of response, from the local up to the international, that are interconnected and affect communities. From national policy and institutional capacity to international debt burden and pharmaceutical patents, the respective recommendations can impact how communities both experience and are able to respond to HIV/AIDS. The following lessons and recommendations are far from conclusive, as it is beyond the scope of this report to address every aspect that affects community experience and response to HIV/AIDS. Instead, they build upon the proceeding discussion, and the growing literature and case studies on community and CSO response to HIV/AIDS. Owing to the variety of development actors affecting community response to the epidemic, the following lessons and recommendations are pertinent not only for African communities and their respective CSOs, but also actors within the larger development context that can foster a supportive, enabling environment for African civil society. However, their relevance is not universal and will vary according to context. It is im

weaknesses. Background research and needs assessment are crucial to identifying cultural norms, values, and perceptions towards AIDS, as well as the local needs and priorities, economy, natural resource base, power structure, gender roles, groups and sub-populations, etc. AIDS initiatives need to reflect the reality of these local conditions if they are to be sustainable. Particular emphasis should be upon surveying existing responses to the epidemic, which should be strengthened rather than eliminated or replaced. **This is particularly important when providing alternative social arrangements to mitigate the extensive impact of the epidemic upon traditional kinship and community structures. As the Ukimwi Orphans Assistance example illustrates, such cultural understanding can be a tremendous asset in addressing the escalating AIDS orphans crisis.** Due to the urgency of the sub-Saharan epidemic, existing community capacities should be assessed quickly, but comprehensively, employing a "Triple A" process – assessment, analysis, and action (Haddad & Gillespie 2001: 504). Fundamental in this process is "participatory action research" (UNAIDS 1998: 64). If subsequent community action is to be community driven, so must the assessment; local inputs and active involvement of the community members at this stage of an intervention is more lik

allow community CSOs to magnify their impact on government policy, promoting more functional links to direct resources for the poor.

Network & Collaborate *All too often, good local-level responses to HIV/AIDS - best practices, in other words - have remained local and small-scale. The many lessons learned have not been translated into bigger projects or wider coverage*. (UNAIDS 2001: 2).

Networking and collaborating with and among CSOs not only reduces the likelihood of competition, but also improves performance. As responding to HIV/AIDS requires a multi-sectoral approach, it is all the more essential that various organizations and communities communicate with each other to coordinate their efforts. Collaboration among CSOs and assisting organizations allows communities to better share and conserve limited resources, and to avoid duplication (Chaplowe & Madden 1996). For example, in the Mozambican Ministry of Health, where there was over 405 donor-funded projects at one point, a strategy to harmonize efforts should have been prioritized (World Bank 2001b: 193). Dialogue between CSOs and African governments can defuse tension, reduce many of the political obstacles for CSOs, and inform national policy-makers of existing social structures to better design policies for local realities. To this end, mechanisms for dialogue, such as policy consultations, conferences, mutual evaluations, and forums should be created, preferably at the country level. **For example, UN/OSCAL's (1999) directory, *Networking: Directory of African NGOs*, is one such tool that facilitates communication and collaboration among and with African CSOs.**

Dialogue between all actors improves knowledge sharing, which broadens dissemination of successful strategies, as well as lessons from problems, creating a multiplier effect that improves outreach and impact at the community level. It also allows development partners to identify common interests from which to build a unified agenda and solidarity. Cooperation among and with communities and CSOs also enhances participation, morale, commitment, and identity, and strengthens collective efforts for advocacy. Furthermore, communication opens channels for positive feedback and reflection: "Pivotal to the successful generation of an AIDS competent society therefore is the regular and sustained feedback of information that what the community is doing really makes a difference to the community's physical and mental health and their quality of life" (Lamboray & Skevington 2001: 520).

Acknowledgements

This report was prepared by the United Nations Office of the Special Adviser on Africa (OSAA). It was coordinated by Ruth Bamela Engo, and benefited from useful feedback of UNAIDS, UNICEF, WHO and the invaluable coS5A

Exécutif Résumé

Le VIH/sida poursuit son avancée à travers toute l’Afrique subsaharienne, et ses effets dévastateurs ont mis en évidence la nécessité urgente d’enrayer cette pandémie. À la vingt et unième session extraordinaire de l’Assemblée générale de l’Organisation des Nations Unies tenue en juillet 1999, les États Membres ont adopté le premier objectif mondial énoncé avec précision en vue de combattre le VIH/sida. L’année suivante, en janvier 2000, le Conseil de sécurité de l’ONU a créé un précédent lorsqu’il a pour la première fois débattu d’une question de santé, et adopté par la suite une résolution (1308) dans laquelle il a reconnu et souligné la menace que le VIH/sida pouvait représenter pour la sécurité internationale, en particulier dans des situations de conflit et de maintien de la paix. La même année, au cours

qui lui sont associés ainsi que d’autres obstacles culturels

formation moins poussée et de moindres apports de l'extérieur, et elles s'accordent mieux à la situation

pour apporter des solutions au problème de plus en plus aigu posé par les orphelins du sida. Étant donné le caractère d'urgence qui s'attache à l'épidémie au sud du Sahara, il faut évaluer rapidement les moyens d'action dont disposent actuellement les communautés tout en adoptant sur un plan général la démarche du « Triple A », (correspondant en anglais à assessment, analysis et action) c'est-à-dire en procédant à une évaluation et une analyse avant d'agir (Haddad & Gillespie, 2001 : 504). L'élément essentiel dans cette démarche est que la recherche, qui doit être orientée vers l'action, soit menée en concertation (UNAIDS 1998 : 64). Si la communauté doit être appelée par la suite à animer l'action au niveau communautaire, il doit en aller de même pour l'évaluation; les apports locaux et la participation active des membres de la communauté à cette étape d'une intervention a plus de chance d'insuffler le sentiment d'être partie prenante dans la conception du projet et de lui donner une utilité pratique. De surcroît, l'aboutissement de ce projet sera mieux adapté à la situation. Par exemple, il peut sembler intéressant de mettre en place des activités lucratives à l'intention des femmes de la communauté, mais il sera nécessaire de les associer à ce projet pour déterminer s'il les rendrait effective

aiguiller la technologie industrielle vers la production de préservatifs et de gants en caoutchouc dont on a grand besoin. Il peut également contribuer à instaurer un ensemble de réglementations équitables, un système judiciaire et des incitations fiscales avantageuses pour les organisations de la société civile des communautés. Ces organisations peuvent à leur tour contribuer à la réalisation des priorités de développement qui figurent parmi les objectifs nationaux, réduisant ainsi la charge de l'État. En coopérant avec les pouvoirs publics, les organisations de la société civile des communautés peuvent ég

bons résultats et des enseignements tirés des problèmes rencontrés, d’où l’

Community Realities & Responses to HIV/AIDS in Sub-Saharan Africa

INTRODUCTION

The staggering impact of the AIDS epidemic in sub-Saharan Africa has propelled it into the forefront of the development agenda of the 21st Century. The epidemic has evolved into a humanitarian disaster that undermines development and worsens the very conditions in which the virus thrives, simultaneously reducing the capacity of households, communities, and nations to cope with the complex social, political, and economic consequences. The degree and scope of the AIDS pandemic in sub-Saharan Africa is unprecedented, compared with the bubonic plague that ravaged Europe between 1346 and 1351 (Caldwell 2000, Ostergard 2002). Its magnitude has far-reaching implications not only for Africa, but also international development and security (Schneider & Moodie 2002); at the start of the millenium, the United Nations Security Council (2000) identified the accelerating epidemic as a threat to international peace.

This bleak picture is not meant to heedlessly fuel an *Afro-pessimism* that others correctly caution against (Gordon & Wolpe 1998, Roe 1999). While it is critical to acknowledge the extent of the epidemic, the vast majority of Africans (over 90%) have not acquired HIV (UNAIDS/WHO 2002: 18). There is hope, and people need to confront AIDS as if they can make a difference rather than as a death sentence. Africa is capable of responding to and mitigating the devastating consequences of AIDS.

The AIDS epidemic, like many development challenges, is a multi-sectoral phenomenon, with a multitude of inter-linked causes, consequences, and solutions, operating at various levels. Thus it must be addressed systematically, and at each level. This report focuses primarily on the local level. Ultimately, communities bear the brunt of the epidemic, and by default, they have likewise borne the burden of responding to and mitigating its devastating consequences. By better understanding the local impact of HIV/AIDS, how it is linked to poverty, and related factors, such as the lack of resources, it is possible to harness and empower the potential of communities and civil society organizations in the fight against HIV/AIDS.

> *It is at the community level that the outcome of the battle against AIDS will be decided. Containing and reversing the HIV/AIDS epidemic within this decade requires dramatically increased efforts in communities with increasing and/or high HIV prevalence, and in low prevalence areas where the preconditions exist for a rapid rise in HIV transmission. Local capacity for prevention, care and support efforts need to be recognized, affirmed and strengthened.* (UNAIDS. 2001: 6)

Drawing upon the growing literature on HIV/AIDS in sub-Saharan Africa, as well as research on civil society from the United Nations Office of the Special Coordinator for Africa and the Least Developed Countries (Chaplowe & Madden, 1996;

Although statistics alone can not convey the full severity of this pandemic, they do underscore its scope and why it warrants an urgent response. They also situate the follow1rgg

will fall by 10% (Loewenson & Whiteside 2001: 10).

There are also significant long-term costs to human capital as the transfer of knowledge and skills within a generation and from generation to generation becomes disrupted (Cohen 2002; Haddad & Gillespie 2001). Illness and death of adults prevents the transfer of knowledge related to the gendered nature of many tasks in agriculture, and other areas of household production including food processing, brewing, marketing, house building and maintenance. In place of the adults in the household, the epidemic leaves behind the elderly, young, or weak, and thus "renders households more vulnerable to future shock, than, say, famine" (Rugalema 2000: 543). The consequences of labor and knowledge loss, reduced income, and increased expenditure are cumulative, reducing the ability of poor households to break the poverty cycle.

Household Food Security

Sub-Saharan Africa remains one of the last regions of the world that is predominantly rural, and agricultural food production remains a primary source of household and national food security. However, the AIDS

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health costs. During such crisis, households make irreversible choices with long term consequences for their welfare. In one study in Uganda, for instance, 65% of the AIDS afflicted households were obliged to sell property to pay for the care of PLWHA (FAO 2001: 4).

TABLE 1: Household Coping Mechanisms by Stage

Stage	Mechanisms
Stage 1 **Reversible Coping Mechanisms**	Ø Sale of and/or increased labor Ø Usage of income generation and diversification schemes (i.e. selling of firewood, handicrafts, tailoring) Ø Temporary migration for employment Ø Intra-household labor reallocation, i.e. child or grandparent assumes additional household chores Ø Liquidation of savings accounts or stored values such as jewelry Ø Help or claims of reciprocity from kin and community Ø Reduced household food consumption; substitution of foodstuff with cheaper alternatives; reliance on wild food Ø Decreased spending on education, non-urgent health care, or other non-essential investments Ø Borrowing from formal or informal sources of credit Ø Labor saving agricultural changes, such as the adoption of labor-saving technologies, the substitution of labor-extensive crops, and decreased area cultivated
Stage 2 **Consequential Coping Mechanisms**	Ø Sale of productive and essential assets, such as property or livestock Ø Decreased spending on many essential items Ø Reduced food consumption leading to malnutrition, especially for the females in the household. Ø Borrowing at exorbitant interest rates Ø Removal of children from school Ø Send children to temporarily live with relatives Ø Decreased area cultivated and nutritional quality of crops Ø Labor saving natural resource management that may lead to pests and diseases.
Stage 3 **Destitution**	Ø Unsafe survival strategies, such as prostitution Ø Illegal survival strategies, such as stealing, or non-condoned use of common property resources

It is in **Stage 3**, Destitution, that the devastating toll of HIV/AIDS on the household culminates. By this point, the household has exhausted all of its resources, both material and social, and is itself exhausted, unable to employ any reasonable coping mechanisms to alleviate its predicament. In sub-Saharan Africa, where almost 50% of the population subsists on just US $1 a day (World Bank 2002a), it doesn't take much to push households beyond this threshold. Many families are already on the margins of survival, lacking savings and other assets to cushion the impact of illness and death. As already noted, caring for PLWHA is a costly and drawn-out process, compounded by the diversion of much needed labor. Sometimes the death of one family member is enough to devastate a household, especially if it is the mother; in Zambia, research revealed that 65% of households dissolve when the mother dies (UNAIDS 2002: 47). The downward cycle continues after the afflicted family member dies. In addition to burial costs, there are usually financial debts to be paid off, incurred during the costly treatment of the AIDS victim. Often, the predicament is further exacerbated, as the victim's partner becomes sick with AIDS, reducing the household to the elderly and the young. These remaining individuals usually have

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In care and support, communities

GNP, do not reflect the distribution of wealth; South Africa has some of the poorest of the poor, among whom the epidemic flourishes. As Whiteside (2001: 1) points out, "A mixture of poverty and inequality is driving the epidemic." HIV spreads along entrenched fault lines in society, taking advantage of the inequities and inequalities, and widening them in the process (Baylies 2000). Inequitable power structures, the lack of legal protection, and inadequate health standards and enforced regulations exacerbate the spread of the virus,

LOCAL RESPONSES - NO OTHER ALTERNATIVE

> *However, HIV/AIDS, in all of it tragedy, can also have a positive influence on social cohesion as people and communities join forces to face this challenge.* (Loewenson & Whiteside 2001: 12)

Despite the formidable impact AIDS has had on the sub-Saharan continent, a range of interventions have emerged in response to the crisis, foremost being those from communities (Hsu et a. 2002; Mann & Tarantola 1996; OSCAL 1998, 2002; UNAIDS 1997, 1999ab, 2001a). Local responses are, ultimately, the most immediate and direct intervention strategies, and despite **d**evastating impact, HIV/AIDS can have a positive influence on social

resources. Of course, the ability of communities to sustain resilience is not

providers had useful advice for other care providers, such as cooperating with relatives, neighbors and other community members to get support for patients and in taking patients to the hospital, rather than traditional healers, to get treatments for complaints (Nnko et al. 2000).

Formal Community Organizations

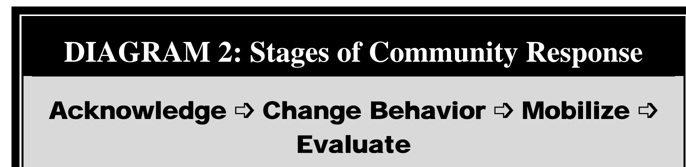
Informal community initiatives can mould themselves into more formal organizations with regular convened committees, defined responsibilities, the development of bylaws, a bank account, and training and monitoring systems. Oftentimes, this occurs with the intervention and assistance of an external organization, whether it is an international organization such as the World Bank, or an indigenous non-governmental organization, such as COWAN (discussed later). These more organized community responses are often called community-based organizations (CBOs), but can include a variety of other CSOs ranging from NGOs and faith-based organizations (FBOs) to microfinance organizations and AIDS support organizations (ASOs). NGOs are typically larger than CBOs and often play a key intermediary role, building the capacity and facilitating development of smaller CBOs and grassroots initiatives. Such assistance can include training, visits by those with facilitation skills to build community capacity, advocacy and lobbying at the state level, and networking and information sharing with other CSOs and development organizations.

The past two decades have witnessed a marked increase in the role and expectations of development CSOs, which, in turn, has influenced community AIDS programs. During the 1980s, multi- and bilateral donor agencies began to reassess the state as a vehicle for development and redirect funds from the public to the private and civil sectors. Foremost among these efforts were the structural adjustment programs (SAPs) of the World Bank and the International Monetary Fund (IMF). SAPs forced African states to reduce their level of social expenditure, (with implications HIV/AIDS later). In turn, donor governments and multilateral agencies increasingly embraced CSOs to "fill the gaps" created by retreating state services. As an alternative to the state, CSOs are perceived to have a comparative advantage over the bureaucracy and inefficiency that often characterize government ministries, as well as the technocratic paradigms and practices that typify many large, international development organizations. As we shall see in the next section, they are potentially more flexible, participatory, and responsive in community response to HIV/AIDS.

Key Attributes of Community Responses

> *The outstanding strengths of traditional grassroots community responses are that they cost less, are based on local needs and available resources and the mutual understanding of community members.* (UNAIDS 1999a: 45)

Community initiatives, both informal and formal, confront HIV/AIDS in a variety of creative, innovative ways. Organized responses pursue agendas according to their social base, constituency, and thematic orientations. The latter can be classified into three areas (Lamboray & Skevington 2001;



and condom use were associated with exposure to the latter (Gausset 2001). This study underscores that cultural relevance is especially important when external actors are involved in community initiatives. Drama group information was "better adapted culturally, or acceptable to its audience," using vernacular speech, role models, and settings the people could relate to (Gausset 2001: 516. Also, as men and women as well as older and younger people saw the same play and discussed it afterwards, consciousness raising and consensus-building on the key issues resulted.

Assisting Orphans by Reinforcing Kinship Practices.

The international NGO, Ukimwi Orphans e

purpose is a valuable counterweight to the stigma, fear, and despair that PLWHA often confront.

Multisectoral Approaches for Mitigation

Many community-focused initiatives pursue multidimensional approaches that assist communities at large to mitigate the impact of AIDS. In Burkina Faso, the Coalition of the Families in the Fight Against AIDS and Poverty (COFAL-SP) is a local association that pursues a comprehensive strategy in six areas to assist AIDS impacted communities (UN/OSCAL 2002). (1) Preventative efforts include the free distribution of condoms to targeted HIV high risk groups, HIV awareness education at community centers and during visits to households of PLWHA, and family counseling for AIDS-afflicted households, especially widows. (2) Patient follow-up services utilize home visits and organizational meetings conducted by volunteers who are trained on HIV/AIDS and community and individual counseling. These visits help families overcome fear and stigma, and learn simple but important forms of care. (3) Nutritional support is also provided to HIV-afflicted households through home visits, during which food is prepared for the household, and a nutritionist provides advice on proper diet and meal changes to combat prevalent opportunist

sex education, and instituting income-generating activities for the prostitutes. Through its efforts, sexually transmitted rates among commercial sex workers have dropped drastically, youth have learned vital skills to enable them to pursue safer lifestyles (i.e. avoid unsafe sex and drugs), and some of the street children have been re-united with their families.

Charismatic & Connected Leadership in Home Care Services

The example of the Tateni Home Care Services (THCS) in South Africa illustrates the pivotal role that inspired**,** well known and connected individuals can play in the successful start-up of an AIDS project (UNAIDS 1999b). P T1999b)5, under les "Mj12 0 0 12 124.802.13491341 5981(les a" Khoza,

communities, area valuable resources that should not be overlooked. This was not lost in the Tanzania, where in 1989 the impact of AIDS motivated collaboration between biomedical health workers and traditional healers in the northeastern Tanga region. By 1992, the collaboration spread throughout the region, forming into the Tanga AIDS Working Group (TWANG), providing training to traditional healers on the prevention of HIV/AIDS and other STDs, AIDS counseling and care, condom promotion, and community behavior change. In two districts, TWANG results reported that 120 traditional healers were trained and conducted home visits to 237 PLWHA, made 1,600 referrals for HIV testing, and organized 1,241 educational sessions conducted by traditional healers and biomedical health providers as a team, reaching over 19,200 people (UNAIDS 2000: 21). Accordingly, TWANG recommends that, "Involvement of traditional healers in identifying needs for AIDS education leads to culturally grounded messages that are relevant, culturally sensitive and have the best potential for

organizations, and others from political-economic forces. What they all share in common is that they are inter-linked, rather than separate phenomenon, and thus need to be considered in a multi-sectoral perspective of the AIDS epidemic as a whole.

Temporal Challenges

The long incubation period of AIDS, about 8-10 years, as well as the delayed effects of mortality and orphanhood, retards a community's ability to identify, respond to, and monitor the epidemic. Unlike other disasters, such as a drought or flood, HIV/AIDS is a long-wave event, making it difficult to predict and prepare for (Barnett and Blaikie 1992; Whiteside 2002). It starts slowly and gradually until it reaches a critical mass of infected people, and thereafter the infection rate accelerates (Whiteside 2002). For example, in Botswana, where the HIV prevalence rate is currently 38%, in 1986 it was only 0.1% (World Bank 2003: 4). The epidemic lacks visible urgency or tradition as motivating factors, and the poor understanding of the virus and its transmission further hinders response time: "The clustering of AIDS in households, ambivalence about its "cause" and its lack of visibility, especially in early stages, are all factors which make it less capable of calling forth a program of relief than other shocks which become politically construed as disasters" (Baylies 2002: 619). The time deception has also affected the international community, whose estimates up until the mid1990s were 1/7 to 1/5 lower than those now produced by UNAIDS (Dixon et al. 2001). The long-wave nature of the disease also strains the capacity for a sustained response (as earlier noted with community safety nets). This undermines a potential empowerment cycle, and extended epidemics can result in a "post-AIDS epidemic," when a sense of complacency emerges and people grow tired and despair, younger generations think HIV/AIDS is less relevant for them, messages have less of an impact on behavior, and efforts seem futile (UNAIDS 1998: 59).

Cultural Perceptions

As noted earlier, HIV/AIDS strains cultural beliefs and norms, which, in turn, hinders collective action and reciprocity. HIV/AIDS is a largely misunderstood phenomenon among Africans, which not only fuels fear and stigmatization, but complicates community initiatives to address the epidemic. This is particularly true with regards to identifying and treating the virus. When one person dies of chronic diarrhea, another of cough, and yet another of meningitis, people often fail to understand the link between these opportunist infections with the same conditions. As WHO (2001: 1) points out, "What is termed denial may be simply misunderstanding imposed by lack of education." The "cause" of AIDS may be perceived as external and beyond the control of those affected or trying to assist PLWHA, i.e. a burden brought on an individual or household by some virtue of their action or volition. "Social constructions of causation in turn inform notions of what should constitute appropriate responses and 'who' should take primary responsibility for mitigation" (Baylies 2002: 619). In the early 1990s, for instance, one of Malawi'sould

personal and social norms generally inhibit discussion of sexual mores and behaviors. Consequently, there is a prevalent attitude that the disease is an individual rather than **a** communal or societal responsibility. People and politicians are reluctant to address a problem embedded as it is in the realm of sexual behavior and, moreover, in what many regard as immoral activity (Ainsworth & Teokul 2000). Complicity often arises among governments and external agencies that reinforces the attitude that illness, especially AIDS, is a private misfortune, and essentially d the responsibility of a the t

instance, studies of home care programs in the 1990s conclude that those from larger NGOs were more costly and capital intensive than community home-based programs which involved local volunteers in home visits (UNAIDS 1999a). Sometimes, poor economies of scale result from inadequate planning, as is often the case with income-generating initiatives. Good intentions, the infusion of capital, and some trainings do not guarantee successful micro-enterprises. Important issues, such as the prospective market, need to be considered. For instance, in Mukono district, Uganda, the evaluation of a vanilla agricultural project revealed that it was not viable owing to lack of market (UNAIDS 1999a: 41).

Limited Outreach

Ultimately, community initiatives, by their locally specific nature, are limited in scale and outreach. HIV/AIDS programs have

Services described above). Such as person is usually endowed with charisma and enthusiasm. Once community awareness has been achieved, the initiative is ready to scale-up to prevention measures and care giving. This may entail a transition to a more formal organization with more substantial management requirements. However, many of the people who successfully lead awareness campaigns do not have good management skills (UNAIDS 1997: 5). Ideally they either learn the skills, hire qualified people, or step aside for more qualified leaders. Unfortunately, initial community leaders are not always willing to pass on responsibilities.

Incomplete Participation or Representation

Communities and supporting CSOs grapple with the same internal inequalities and power relations that occur at any level of human organization (Kasfir 1998; Mohan & Stokke 2000; Orvis 2001). Depending on the cultural context, gender, racial, or age inequalities may exclude women, minorities, and youth from resources within and outside of the CSO. Societal stigmatization, scapegoating, and discrimination associated with HIV/AIDS exacerbate these

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projects over the last decade has been accompanied by increasing criticism of the lack of collaboration between staff and NGO/communities members (Malena 2000; Nelson 1995). In its own critique of donors, the World Bank (2001a: 192) states, "Donors have often failed to coordinate their efforts, countries have not taken ownership, and there has been heavy use of conditionally both at the project level and economy wide." Clearly, a seat at the "donor's table" is meaningful to CSOs only if they are allowed to participate meaningfully (Hudock 2000).

Pre-Set & Rigid Expectations

While training and enhanced capacity for dealing with problems of the magnitude of the AIDS epidemic is critical, external relationships risk imposing foreign models on communities, retarding their own systems, structures, norms, and sanctions (Bebbinton & Theile 1993; Hulme & Edwards 1997, Loewenson 2001; UN/OSCAL 2002). This is especially true in health care, where, "Conventional public health planning tends to be a top-down process, based on expert identification of priorities and the strategies to address them" (Loewenson 20001: 14). Health facilitators hired to work on HIV/AIDS programs are often motivated by a strong sense of urgency that can impair their cultural sensitivity and thus impact: "Unless they understand the community's natural rhythms of everyday life, they are likely to be frustrated by what they perceive to be a lack of progress" (UNAIDS 1997: 4). In turn, community members may become irritated, offended, or simply confused. This is an especially harmful dynamic with HIV/AIDS, for which cooperation and trust is essential due to the culturally sensitive nature of the epidemic.

Performance constraints are of particular concern when interacting with the extensive bureaucratic procedures that characterize health programs of government organizations or larger donor agencies. As CSOs become

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Lessons And Recommendations

As we have seen, sub-Saharan Africa's AIDS epidemic is a multi-faceted phenomenon, and approaches and constraints to confronting it are as diverse as African communities themselves. Thus, there are multiple recommendations at each level of response, from the local up to the international, that are interconnected and affect communities. From national policy and institutional capacity to international debt burden and pharmaceutical patents, the respective recommendations can impact how communities both experience and are able to respond to HIV/AIDS. The following lessons and recommendations are far from conclusive, as it is beyond the scope of this report to address every aspect that affects community experience and response to HIV/AIDS. Instead, they build upon the proceeding discussion, and the growing literature and case studies on community and CSO response to HIV/AIDS. Owing to the variety of development actors affecting community response to the epidemic, the following lessons and recommendations are pertinent not only for African communities and their respective CSOs, but also actors within the larger development context that can foster a supportive, enabling environment for African civil society. However, their relevance is not universal and will vary according to cont

assistance toward povergd19,27.984u9599 Tm(assisT9c50 0se/0 1: Tw 7.98 03(assi8Ff7d povergd19,27.9

2000; UNAIDS 1999a). Only governments and intergovernmental multilateral institutions are equipped to operate on the scale that is necessary if the HIV/AIDS epidemic is to be addressed in a sustainable manner. Assigning such roles to communities and their respective CSOs is both irresponsible and counter-productive.

Don't Romanticize the "Local"

African communities are not amorphous, harmonious families, but rather complex and diverse phenomena. Community organizations and initiatives do not always practice the participatory principles that they preach, (or that we project): "It is essential not to r[illegible]ze or over-estimate Africa's civil soc[illegible] to recognize the dis[illegible] political [illegible]nomic realities that shape African civil society and adopt development strategies accordingly" (UN/OSCAL 2002: 135). The tendency to treat local organisations as harmonious can overlook gender, racial, or age inequalities that exclude women, minorities, and youth from resources within and outside of the CSO. These internal power dynamics determine, to a large degree, the CSO's capacity for civic change. Such considerations are

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Monitoring and evaluation (M&E) is critical for a community CSO, if it is to effectively sustain its mission as well as accountability to the community it serves and external partners from which it receives assistance. CSOs need to negotiate and manage internal political, organizational and financial issues, which involves priority setting, resource allocation and decision-making, ideally in a transparent manner. Effective M&E not only improves the CSO's ability to respond to these tasks, but upholds principles of transparency and democracy for effective participation. It also allows partners to better shape expectations and working relationships with CSOs, and CSOs to better understand their partners, as well as their own capabilities, and plan accordingly. Towards this end, CSOs must articulate a clear mission, and develop practical and credible mechanisms that will enable them to be accountable to their many constituents. It is important, however, that these mechanisms not be rigidly imposed by external organizations such that they impair effectiveness through excessive bureaucracy, but allow CSOs to maintain their integrity and downward accountability to their beneficiaries.

CSO-Government Cooperation

By their very nature, community efforts are highly localized and lack political-economic leverage, while the State is the final arbiter and determinant of the wider political-economic climate in which communities and respective CSOs operate (Edwards and Hulme 1992; Farrington and Bebbington 1993; Chaplowe & Madden 1996). Therefore, despite their differences and potentially antagonistic relationships, the success of communities and CSOs in addressing AIDS largely relies upon support from and co-operation with the government (Bebbington and Riddell 1995; Johnson 2001; Nel 2001; UN/OSCAL 2002). While the ongoing democratization and decentralization in Africa presents certain political challenges for CSOs in their

preferably at the country level. **For example, UN/OSCAL's (1999) directory, *Networking: Directory of African NGOs*, is one such tool that facilitates communication**

Community

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