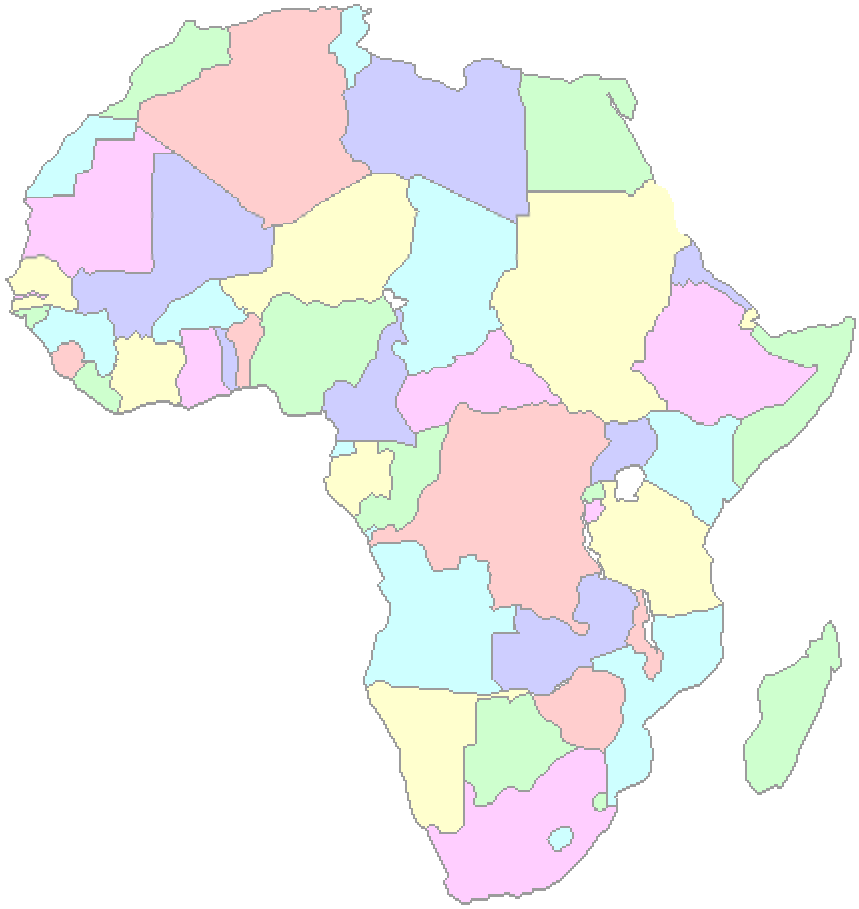
Community Realities & Responses to HIV/AIDS in Sub-Saharan Africa



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La situation et l'action des communautés face au VIH/sida en Afrique subsaharienne

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EXECUTIVE SUMMARY

HIV/AIDS continues to spread throughout sub-Saharan Africa. Its devastating impact has underscored the urgent need to halt the pandemic. At the 21st Special Session of the United Nations General Assembly in July 1999, Member States adopted the first specific global target against HIV/AIDS. In the following year, January 2000, the UN Security Council made history when for the first time it debated a health issue, and subsequently adopted a Resolution (1308) recognizing and highlighting the potential threat HIV/AIDS poses for international security, particularly in conflict and peacekeeping settings. The same year, the UN Millenium Summit adopted the Millennium Development Goals, which largely depend on international resolve to support the fight against HIV/AIDS and other infectious diseases. During 2000 and 2001, UN system agencies engaged in the development of a UN System Strategic Plan for HIV/AIDS for 2001-2005 (UNSSP), aimed at guiding the UN system response over the five-year period. In June 2001, the United Nations General Assembly Special Session on HIV/AIDS adopted the Global Strategy Framework on HIV/AIDS. This concern and call for action has been echoed by the Heads of African States in the NEPAD (Paragraphs 126-189).

In line with these global goals, this report examines HIV/AIDS at the community level in sub-Saharan Africa. 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 since 1996, this report examines the local impact of and response to HIV/AIDS in sub-Saharan Africa. Produced by the newly created United Nations Office of the Special Advisor on Africa (UN-OSAA), which is in charge of the implementation of the NEPAD at global level, it is expected that this report will be useful for policy and program initiatives that can potentially strengthen the capacity of communities to confront HIV/AIDS. As the Executive Director of UNAIDS, Peter Piot, expressed in the Preface to *The Global Framework on HIV/AIDS* (UNAIDS 2001b: iv):

> *The only way the epidemic can be reversed is through a total social mobilization. Leadership from above needs to meet the creativity, energy, and leadership from below, joining together in a coordinated program of sustained social action.*

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 important to keep in mind that, "A uniform global approach might not be suited to the extreme geographic and epidemiological heterogeneity of the pandemic" (Cock et al. 2002: 57).

Acknowledge & Demystify HIV/AIDS

At all levels, it is imperative to demystify HIV/AIDS and acknowledge its current and potential devastating impact in sub-Saharan Africa. The effect of the epidemic at the local level is profound, but often neglected in research and policy decision making. Society at large must accept the responsibility for the epidemic, which requires that people understand its urgency and the consequences of inaction. **Better understanding of HIV/AIDS will engender receptivity to HIV testing and screening, so that people will not wait until they are ill to confront and deal with the epidemic. And while addressing the sexual transmission of HIV is critical, people must also understand the other avenues for the spread of HIV through bodily fluids, such as un-sterilized circumcision or the transmission of HIV to care givers without rubber gloves.** Aid awareness education and consciousness-raising demystifies the virus and breaks down associated stigmatization, discrimination, and other cultural barriers to effective action. This fosters an atmosphere in which community members feel more able to speak out and mobilize towards issues regarding HIV/AIDS. "In AID-competent communities, it is predicted that quality of life will start to improve from the point in time that the community acknowledges the problem collectively and begins to take action" (Lamboray & Skevinton 2001: 617).

Maintain a Multi-Sectoral Perspective

The AIDS epidemic in sub-Saharan Africa has clearly demonstrated that it is a systematic problem, closely connected with poverty. HIV/AIDS exacerbates existing development problems, but we should not forget that problems due to the epidemic are not specific to

AIDS alone. As Haddad and Gillespie aptly advise: "Development practitioners should not be blind to the threat of HIV/AIDS, but neither should they be blinded by it" (Haddad & Gillespie 2001: 497). Top-down planning and programs, "typically focused far more on prevention and care than on the livelihood security of affected households and their need for assistance toward poverty" (Baylies 2002: 620). **Food insecurity, for example, is a key factor in the vicious poverty cycle that exacerbates the sub-Saharan Africa's AIDS epidemic. As we have seen, low nutritional status is critically linked to susceptibility to the HIV virus and opportunist infections that are associated with AIDS.** Research on AIDS prevention in sub-Saharan Africa suggests that mitigation is not receiving the support and attention it deserves (USNAIDS 199a: 47). The AIDS epidemic is not simply about public health, and if communities are to be truly supported, the range of interventions must be broadened from treatment and care to prevention and mitigation. HIV/AIDS issues must be included in core areas of development policy, such as food security and public education, and involve the multiple ministries representing these sectors. Likewise, if the epidemic is to be contained at the community level, assistance must not be based solely on the presence of HIV/AIDS, but also on poverty indicators that reflect future vulnerability to the epidemic.

Identify & Utilize Preexisting Knowledge, Skills, and Practices

Preexisting resources in a community – skills, knowledge, and practices – are valuable tools in the fight against AIDS. Community initiatives that build upon traditional systems are more efficient as they typically require less training and input from external sources, more relevant as they are readily understood and accepted by community members, and more sustainable as people are quicker to identify with, adopt, and take ownership of such initiatives. **As we have seen, the incorporation of traditional healers in AIDS awareness initiatives is culturally compatible and thus effective. Likewise, identifying and utilizing nutritious vegetables and herbs indigenous to local areas can play a key role in mitigating food insecurity and subsequent vulnerability to AIDS opportunist infection, rather than importing more expensive foodstuffs.** Lessons learned from other societal crises should be brought to bear in designing community mitigation strategies, and outside intervention should be aimed at enhancing and mobilizing capacities inherent to communities, such as the traditional coping responses of extended families and their communities. External assistance must refrain from imposing their cultural paradigm on localities, which could "alienate the local populations whose cooperation is crucial if we are to prevent the further spread of AIDS" (Gausset 2001: 517). Instead, efforts must be made to understand the local beliefs and practices, and to adapt outside knowledge so that it can be understood and appreciated in local terms. **Special efforts ought to be made to portray positive moral traditions and practices that support the fight against AIDS, so that people not only see what is forbidden, but what good can come from their cultural heritage.**

Research & Relevance

Effective, external assistance to organized community efforts largely depends on an understanding of existing social and organizational patterns, and their strengths and

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 likely to instill ownership and relevance for the project design. Furthermore, the outcome will be more relevant. For example, income-generating activities for community women may seem like a worthwhile activity to introduce, but their input will be needed to determine whether it will actually empower them, or double-burden them with additional work.

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 relationship to the State, it also presents new possibilities for negotiation and collaboration. A mutually supportive partnership in development could benefit both CSOs and governments. In addition to financial support, governments can provide technical assistance and research in the fight against AIDS that is typically beyond the reach of communities and their respective CSOs due to their limited budgets and lack of access to scientific and technical information. **For example, while rubber is a raw material in sub-Saharan Africa and products such as rubber sandals and tires are already produced in certain countries, the State can direct such industrial technology towards the production of much needed condoms and rubber gloves.** The State can also help uphold a fair and regulatory environment, judicial system, and advantageous tax incentives for community CSOs. CSOs, in turn, can help address development priorities that are on the national agenda, reducing the burden of the state. Co-operation with the government may also

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).

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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 du Sommet du Millénaire, les Nations Unies ont adopté les objectifs du Millénaire pour le développement, dont la réalisation dépend dans une large mesure de la détermination de la communauté internationale à soutenir la lutte contre le VIH/sida et les autres maladies infectieuses. En 2000 et 2001, les organismes des Nations Unies ont entrepris l'élaboration d'un plan d'action stratégique sur le VIH/sida pour 2001-2005, dont le but est d'orienter la riposte des organismes des Nations Unies pendant ces cinq années. En juin 2001, l'Assemblée générale des Nations Unies, lors de sa session extraordinaire consacrée au VIH/sida, a adopté le Cadre stratégique mondial sur le VIH/sida. Cette préoccupation et cet appel à l'action ont trouvé un écho chez les chefs d'État africains qui participent au NEPAD (par. 126 à 189).

Dans la perspective de ces objectifs mondiaux, le présent rapport aborde la question du VIH/sida au niveau des communautés d'Afrique subsaharienne. S'inspirant des publications de plus en plus nombreuses qui traitent du VIH/sida en Afrique subsaharienne, ainsi que des travaux de recherche sur la société civile réalisés depuis 1996 par le Bureau du Coordonnateur spécial pour l'Afrique et les pays les moins avancés, le présent rapport analyse l'impact du VIH/sida et les interventions auxquelles il a donné lieu sur le plan local en Afrique subsaharienne. Établi par le Bureau du Conseiller spécial pour l'Afrique qui vient d'être créé à l'ONU et qui a pour mission de veiller à la mise en oeuvre du NEPAD au niveau mondial, le présent rapport devrait en principe se révéler utile pour mener à bien des initiatives concernant des politiques ou des programmes qui sont de nature à renforcer les moyens d'action des communautés pour faire face au VIH/sida. Pour reprendre les termes utilisés par le Directeur exécutif de l'ONUSIDA, Peter Piot, dans la préface du *Cadre stratégique mondial sur le VIH/sida :*

Une mobilisation sociale totale sera le seul moyen d'inverser le cours de l'épidémie. Le leadership des dirigeants doit s'associer à la créativité, à l'énergie et au leadership de la base, réunis en un programme coordonné d'action sociale soutenue.

Principales conclusions et recommandations du rapport

Comme on l'a vu, l'épidémie de sida en Afrique subsaharienne est un phénomène multiforme, et les démarches empruntées et obstacles rencontrés pour la combattre sont aussi diversifiés que les communautés africaines elles-mêmes. C'est pourquoi le rapport offre de multiples recommandations à chaque niveau d'intervention, du local à l'international, recommandations qui sont étroitement liées et qui ont une incidence sur les communautés. Qu'il s'agisse des politiques et des moyens institutionnels à l'échelon national ou du poids de la dette et des brevets protégeant l'industrie pharmaceutique au niveau international, les diverses recommandations peuvent influer sur la manière dont les communautés se trouvent confrontées au VIH/sida et sont en mesure de le combattre. Les conclusions et recommandations qui suivent sont loin d'être concluantes car le présent rapport n'aborde pas tous les aspects du vécu des communautés ni du combat qu'elles mènent contre le VIH/sida. Elles s'appuient plutôt sur le débat en cours, ainsi que sur les publications et monographies de plus en plus nombreuses consacrées à l'action des communautés ou des organisations de la société civile face au VIH/sida. Considérant la diversité des acteurs responsables du développement qui influent sur la riposte des communautés face à l'épidémie, les conclusions et recommandations qui suivent valent non seulement pour les communautés africaines et leur organisations de la société civile respectives, mais aussi pour des acteurs qui interviennent dans un contexte de développement plus large qui est de nature à favoriser un environnement propice à la société civile africaine. Toutefois, leur pertinence n'est pas universelle et variera selon le cas. Il importe de se rappeler qu'« une démarche uniforme à l'échelle planétaire n'est pas nécessairement adaptée à l'extrême hétérogénéité géographique et épidémiologique de la pandémie » (Cock et al. 2002 : 57). Admettre l'existence du VIH/sida et le démystifier À tous les niveaux, il est absolument nécessaire de démystifier le VIH/sida et d'admettre l'existence de ses effets dévastateurs actuels ou potentiels en Afrique subsaharienne. L'épidémie a un profond retentissement au niveau local, mais celui-ci est rarement pris en compte dans les travaux de recherche et le choix des politiques. L'ensemble de la société doit accepter qu'elle a une part de responsabilité dans l'épidémie, ce qui suppose que chacun comprend la nécessité urgente d'agir et les conséquences de son inaction. Une meilleure compréhension du VIH/sida suscitera une attitude favorable au dépistage du VIH, de sorte que les populations n'attendront pas d'être malades pour affronter l'épidémie et la combattre. Certes, la transmission du VIH par la voie sexuelle est préoccupante, mais il faut également comprendre qu'il existe d'autres modes de transmission du virus à travers les fluides corporels, due par exemple à une circoncision au moyen d'instruments non stérilisés ou à l'absence de port de gants en caoutchouc par le personnel soignant. Une prise de conscience et une meilleure connaissance du sida permettent de démystifier le virus et font disparaître le discrédit et la discrimination

qui lui sont associés ainsi que d'autres obstacles culturels à une action efficace. Il peut ainsi se créer un climat dans lequel les membres de la communauté se sentent plus capables de prendre la parole et de se mobiliser pour des problèmes en rapport avec le VIH/sida. « Dans les communautés qui ont acquis une compétence en matière de lutte contre le sida, la qualité de vie devrait commencer à s'améliorer à partir du moment où la communauté accepte collectivement l'existence du problème et commence à agir » (Lamboray et Skevinton, 2001 : 617).

Maintenir une perspective multisectorielle

L'épidémie de sida en Afrique subsaharienne a clairement démontré qu'il s'agit d'un problème systémique, étroitement lié à la pauvreté. Le VIH/sida exacerbe les problèmes de développement qui existent déjà, mais il ne faut pas oublier que les problèmes dus à l'épidémie ne tiennent pas uniquement au sida. Comme le conseillent judicieusement Haddad et Gillespie : « Les praticiens du développement ne doivent pas se désintéresser de la menace du VIH/sida, mais ne doivent pas non plus se laisser aveugler par cette menace » (Haddad et Gillespie, 2001 : 497). Les plans et programmes décidés en haut lieu « sont généralement axés beaucoup plus sur la prévention et les soins que sur la sécurité des moyens d'existence des ménages touchés et sur l'aide dont ils ont besoin pour ne pas verser dans la pauvreté » (Baylies, 2002 : 620). **La précarité alimentaire, par exemple, est un élément clef, dans le cercle vicieux de la pauvreté, qui exacerbe l'épidémie de sida en Afrique subsaharienne. Comme nous l'avons vu, un état nutritionnel médiocre est un facteur déterminant de vulnérabilité au virus et aux infections opportunistes qui lui sont associées.** Les travaux de recherche sur la prévention du sida en Afrique subsaharienne donnent à penser que les actions d'atténuation ne reçoivent pas le soutien et l'attention qu'elles méritent (USNAIDS 199a : 47). L'épidémie de sida n'est pas simplement une question de santé publique, et si l'on veut réellement apporter un soutien aux communautés, il faut élargir la gamme des interventions aux mesures de prévention et d'atténuation et ne pas la limiter aux traitements et aux soins. Il faut faire figurer les questions relatives au VIH/sida dans les volets fondamentaux des politiques de développement, la sécurité alimentaire et l'éducation du public par exemple, et associer les multiples ministères qui ont la charge de ces volets. De même, si l'on veut contenir l'épidémie au niveau communautaire, il faut dispenser une assistance qui tienne compte non seulement de la présence du VIH/sida mais aussi des indicateurs de la pauvreté annonciateurs de la vulnérabilité future face à l'épidémie.

Déceler et utiliser les connaissances, compétences et pratiques préexistantes

Les ressources dont dispose déjà une communauté – qu'il s'agisse des compétences, des connaissances ou des pratiques – sont de précieux atouts dans la lutte contre le sida. Les initiatives communautaires qui s'appuient sur des systèmes traditionnels donnent de meilleurs résultats car elles nécessitent généralement une

formation moins poussée et de moindres apports de l'extérieur, et elles s'accordent mieux à la situation car elles sont plus aisément comprises et acceptées par les membres de la communauté et peuvent davantage s'inscrire dans la durée étant donné que la population a besoin de moins de temps pour se trouver en empathie avec ces initiatives, les adopter et en devenir partie prenante. **Comme nous l'avons vu, la contribution des guérisseurs aux initiatives de sensibilisation au sida est culturellement acceptable et donc efficace. De même, le choix et l'utilisation d'herbes et de légumes nutritifs qui poussent sur place peuvent jouer un rôle déterminant dans la réduction de la précarité alimentaire et de la vulnérabilité qui s'ensuit aux infections opportunistes dues au sida, et il est ainsi inutile d'importer des aliments plus coûteux.** Il faudrait s'inspirer des enseignements tirés d'autres crises sociétales pour concevoir des stratégies d'atténuation au niveau communautaire, et les interventions extérieures devraient avoir pour but de renforcer et mobiliser les capacités intrinsèques des communautés, par exemple les comportements adoptés traditionnellement par les familles élargies et leurs communautés face à l'adversité. L'assistance apportée de l'extérieur ne doit pas s'assortir de paradigmes culturels qui seraient imposés aux collectivités, ce qui pourrait « aliéner les populations locales dont la coopération est primordiale si l'on veut empêcher toute nouvelle propagation du sida » (Gausset, 2001 : 517). Au contraire, il faut s'efforcer de comprendre les croyances et pratiques locales et d'adapter les connaissances importées de l'extérieur afin qu'elles soient comprises et appréciées par la population locale. **Il faut s'efforcer tout particulièrement d'exposer les traditions et pratiques éthiques positives qui sont de nature à appuyer la lutte contre le sida, afin que la population se rende compte non seulement de ce qui est interdit, mais aussi de tout ce qu'elle peut tirer de bon de son héritage culturel.**

Recherche et utilité pratique

Pour que l'aide apportée de l'extérieur aux efforts organisés à l'échelon communautaire soit efficace, il faut surtout comprendre les comportements sociaux et caractéristiques structurelles ainsi que leurs points forts et leurs points faibles. Il est absolument indispensable de procéder à une recherche sur le contexte socioculturel et à une évaluation des besoins pour mettre en évidence les normes culturelles, les valeurs et la vision du sida ainsi que pour comprendre les besoins et priorités, l'économie, les ressources naturelles, la structure du pouvoir, le rôle respectif des hommes et des femmes, les groupes et sous-populations, etc. sur le plan local. Les initiatives de lutte contre le sida doivent correspondre à la réalité de ces caractéristiques locales pour pouvoir s'inscrire dans la durée. Il faut tout particulièrement observer les dispositions déjà prises pour faire face à l'épidémie et les renforcer plutôt que les éliminer ou les remplacer. **Cela revêt une importance particulière lorsque l'on propose des arrangements sociaux différents pour atténuer les multiples effets de l'épidémie sur la famille traditionnelle et les structures communautaires. Comme le montre l'exemple d'Ukimwi Orphans Assistance, cette compréhension de la culture peut être un formidable atout**

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 effectivement plus autonomes ou s'il représentera une surcharge de travail.

Coopération entre les gouvernements et les organisations de la société civile

Par leur nature même, les efforts de la communauté sont très localisés et ne bénéficient pas de moyens de pression politico-économique, alors que l'État est en dernier ressort celui qui procède à des arbitrages et détermine l'environnement politico-économique plus vaste dans lequel s'inscrivent les communautés et leurs organisations de la société civile respectives (Edwards et Hulme, 1992; Farrington et Bebbington, 1993; Chaplowe & Madden, 1996). C'est pourquoi, malgré les différences qui existent entre les communautés et les organisations de la société civile et malgré leurs relations potentiellement antagonistes, le succès des actions qu'elles mènent contre le sida dépend dans une large mesure du soutien et de la coopération des pouvoirs publics (Bebbington et Riddell, 1995; Johnson, 2001; Nel, 2001; UN/OSCAL, 2002). Certes, la démocratisation et la décentralisation en cours en Afrique présentent certaines remises en question politiques pour les organisations de la société civile dans leur relation avec l'État, mais elles offrent également de nouvelles possibilités de négociation et de collaboration. L'établissement d'un partenariat pour le développement dans lequel les organisations de la société civile et les pouvoirs publics seraient complémentaires pourrait être bénéfique pour les unes comme pour les autres. Les pouvoirs publics peuvent non seulement apporter un soutien financier mais également fournir, pour lutter contre le sida, une assistance technique et des moyens de recherche hors de la portée des communautés et de leurs organisations de la société civile respectives parce que leurs ressources financières sont limitées et qu'elles n'ont pas accès aux informations scientifiques et techniques. **Par exemple, si le caoutchouc est une matière première en Afrique subsaharienne et que certains pays produisent déjà des articles tels que les sandales et les pneus en caoutchouc, l'État peut**

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 également renforcer leur influence sur la politique gouvernementale et contribuer à l'établissement d'un plus grand nombre de liens fonctionnels pour aiguiller les ressources vers les populations défavorisées.

Mise en réseau et collaboration

Trop souvent, de bonnes initiatives prises sur le plan local pour combattre le VIH/sida – en d'autres termes, de meilleures pratiques – sont demeurées localisées et de faible envergure. Les nombreux enseignements qui ont pu être tirés n'ont pas été repris dans des projets à plus grande échelle ou de plus grande envergure (UNAIDS 2001 : 2).

L'établissement de réseaux et d'une collaboration avec les organisations de la société civile ou entre ces organisations non seulement réduit le risque de concurrence mais, de surcroît, améliore les résultats obtenus. Comme la lutte contre le VIH/sida nécessite une démarche multisectorielle, la communication entre les diverses organisations et communautés est d'autant plus indispensable afin qu'elles coordonnent leurs efforts. Une collaboration entre les organisations de la société civile et les organisations qui leur apportent un concours permet aux communautés de mieux se partager et conserver leurs ressources limitées et d'éviter les doubles emplois (Chaplowe & Madden, 1996). Par exemple, à une certaine époque, plus de 405 projets financés par des donateurs étaient en cours de réalisation au Ministère mozambicain de la santé; il aurait fallu établir en priorité une stratégie destinée à harmoniser les efforts (Banque mondiale, 2001b : 193). Un échange de vues entre les organisations de la société civile et les gouvernements africains peut atténuer les tensions, réduire bon nombre des obstacles politiques rencontrés par les organisations de la société civile et mettre les décideurs nationaux au courant des structures sociales existantes afin de concevoir des politiques mieux adaptées aux réalités locales. À cet effet, il faudrait créer, de préférence à l'échelon national, des mécanismes propices à cet échange de vues; il pourrait s'agir, par exemple, de consultations au sujet des politiques à mener, de conférences, d'évaluations réalisées en commun et de forums. **Ainsi, l'un de ces mécanismes destinés à faciliter la communication et la collaboration entre les organisations de la société civile africaine et avec ces organisations est le *Réseau d'interconnexion : Annuaire des ONG africaines*, établi par l'OSCAL/ONU.**

Un échange de vues entre tous les acteurs améliore la mise en commun des connaissances, qui favorise une diffusion plus large des stratégies ayant donné de

bons résultats et des enseignements tirés des problèmes rencontrés, d'où l'apparition d'un effet multiplicateur qui accroît la sensibilisation et l'impact au niveau communautaire. Grâce à cet échange de vues, les partenaires de développement sont également en mesure de dégager des intérêts communs, ce qui favorise l'établissement d'un programme de travail unifié et l'instauration d'un sentiment de solidarité. Une coopération entre et avec les communautés et les organisations de la société civile est également favorable à la participation, à l'entretien d'un bon moral, à l'attachement à une cause et à l'apparition d'un sentiment identitaire, et elle renforce les efforts collectifs en faveur d'action de sensibilisation. De surcroît, la communication ouvre la voie à des retours d'informations positives : « Pour parvenir à créer une société en mesure de lutter avec compétence contre le sida, il est donc absolument indispensable de faire savoir systématiquement et en permanence que les actions entreprises par la communauté améliorent indubitablement l'état de la santé physique et mentale de ses membres ainsi que leur qualité de vie » (Lamboray et Skevington, 2001 : 520).

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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; UN/OSCAL, 1998, 1999, 2000, 2002), this report examines the local impact of and response to HIV/AIDS in sub-Saharan Africa. It first provides an overview of the serious consequences of the epidemic at the household and community level, and how it is perpetuated in a downward poverty spiral that is reinforced at the national level. It then examines the traditional and innovative responses that communities and civil society organizations (CSOs) have employed in fighting AIDS. This is followed by a discussion of the limitations such civil society initiatives face. The concluding lessons and recommendations frames how

communities and supportive CSOs can better address HIV/AIDS, and how other development actors can better support such efforts.

LOCAL IMPACT - AIDS' DEBILITATING CYCLE

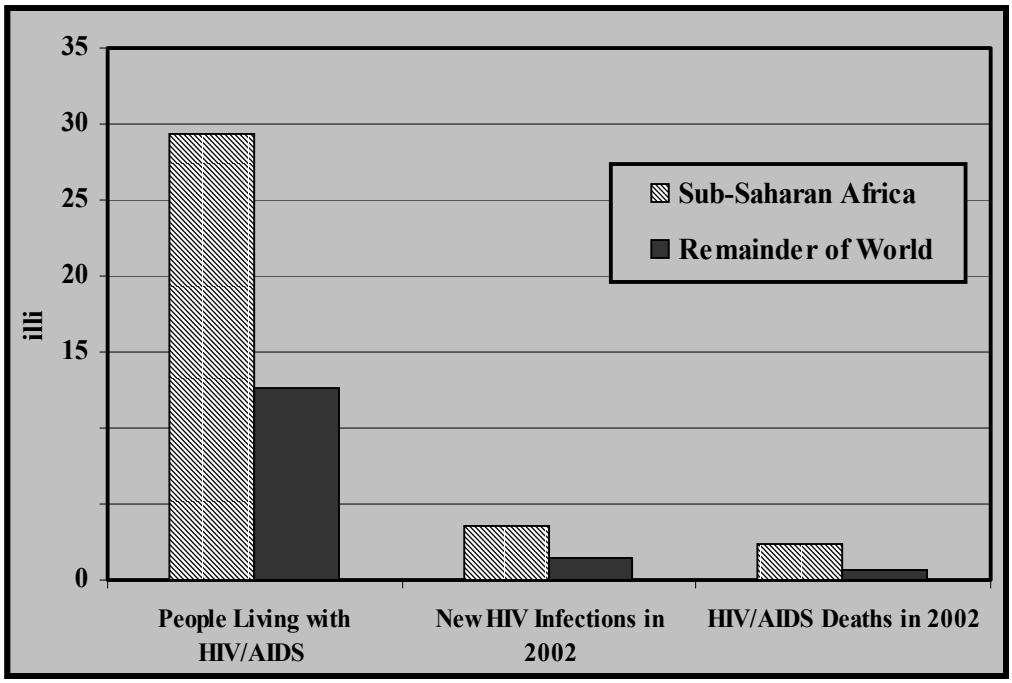
> *Twenty years after the world first became aware of AIDS, it is clear that humanity is facing one of the most devastating epidemics in human history - one that threatens development in major regions of the world.* (UNAIDS 2002a: 44)

By any measure, sub-Saharan Africa has experienced the most devastating consequences of the global AIDS epidemic, (DIAGRAM 1). While HIV/AIDS is the world's fourth biggest killer, it is number one in sub-Saharan Africa (UNAIDS 2002). In 2002, sub-Saharan Africa contained only about 7.5% of the world's population but accounted for approximately 70% of people living with HIV/AIDS, 70% of incident HIV infections, and 77% of the AIDS deaths (UNAIDS/WHO 2002). Approximately 29.4 million sub-Saharan Africans between ages 15 and 49 are living with HIV/AIDS – almost 9% of the adult population (UNAIDS/WHO 2002: 6). Whereas life expectancy in the sub-continent increased from 44 years in the 1950s to 59 years in early 1990s, it has now dropped to 49 and is projected to drop further (UNDP 2002a). According to the World Health Organization (WHO: 2002: xv), life expectancy in the region would be 62 years without the epidemic.

Certainly, these statistics do not uniformly represent all of sub-Saharan Africa; the epidemic varies geographically, culturally, and temporally. In the *AIDS Belt* – the global epicenter of the epidemic, (Botswana, Namibia, South Africa, Swaziland, Zambia and Zimbabwe) – the statistics are even "beyond what was thought imaginable," with more than a third of the population infected in Botswana, Swaziland and Zimbabwe (World Bank 2003: 1). In Botswana, the most AIDS-afflicted country in the world, a child born there today can expect to live only 36 years – about half as long as it would have if the disease did not exist (UNDP 2002a: 27).

It is also worth noting that the AIDS epidemic is made of many epidemics. For instance, sexually transmitted diseases (STDs) magnify and complicate HIV transmission as much as tenfold, as these infections create additional entry points for the HIV virus and/or facilitate virus reproduction. [Four of the most common STDs – syphilis, gonorrhea, Chlamydia, and trichomoniasis – are still prevalent in sub-Saharan Africa, although they could be easily treated with antibiotics – if they were more accessible]. Other diseases, like malaria and tuberculosis, also conspire to worsen the epidemic; countries with the highest HIV rates also have the highest tuberculosis rates, posing additional risk to struggling communities.

DIAGRAM 1: 2002 HIV/AIDS Global Estimates



Source: (UNAIDS/WHO 2002)

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 following discussion, which will take a closer look at how this pervasive pandemic is experienced by individuals, families, and communities. Working upwards from the household and community levels, the discussion will then briefly examine the epidemic's impact at the national level as it bears upon the local reality. It will conclude by situating the epidemic as part of the larger poverty cycle in which it thrives, entangled with a myriad of humanitarian and development challenges.

Household Burden

> *Where state welfare provision is minimal and the capacity of the government limited, the role of the household in dealing with illness and death becomes critical by default.* (Baylies 2002a: 618)

The tragedy of the HIV/AIDS epidemic is foremost that of the individual and the immediate family, the building blocks of the community and society as a whole. The epidemic exerts enormous social, psychological, and economic stress on the family unit (Barnett and Blaikie 1992, Baylies 2002a, Garnett et al. 2001, Ngwira et al. 2001, Nnko et al. 2000, Poku 2001, Rugalema 2000, Sauerborn & Hiem 1996; UNAIDS 1999a, Whiteside 2002). The costs are substantial, yet partially hidden insofar as borne by households (Rugalema 2000), and not always addressed in the literature (Baylies 2002a). The impact upon households varies across communities and among families according to a variety of factors, including the stage of family formation, size, composition, dependency ratios, and, especially, resource endowment. Likewise, the resilience of the household varies according to the number of illnesses/deaths, access to health care and education, and community attitudes towards assisting infected households.

Acknowledging such variation, five important commonalties are worth noting. First, the nuclear family in sub-Saharan Africa merges with the extended family, including uncles, aunts, grandparents, and nephews, whether living together under the same roof or not. Second, the HIV virus tends to cluster in households and communities, often infecting more than one

family member. Third, AIDS-related deaths are concentrated in the working adults of a household, rather than the very old or very young. Fourth, the disease distinguishes it from other disasters by its long-term or "long-wave" impact, resulting in a lengthy and costly illness (Barnett and Blaikie 1992; Whiteside 2002). Fifth, poverty amplifies the transmission and devastation of the epidemic among households and communities. In sub-Saharan Africa, the latter four insidious features dovetail to weaken the extended family to the extent that the household risks collapsing under the pressure in a devastating downward spiral.

Household Care Costs

The AIDS cycle begins when someone in the household, particularly an adult, falls ill. Oftentimes, people living with HIV/AIDS (PLWHA) do not know they are infected until the HIV virus progresses to AIDS. For the PLWHA and the family, emotions range from confusion and despair to anger and frustration, and can result in long-term pathologies (UNAIDS 1999a, USAID & FHI 2001). This is typically compounded by the social stigma associated with the disease, and sometimes abuse, abandonment and neglect (Temmerman et al 1995). In addition to these emotional consequences, there is the actual pain and discomfort of the PLWHA.

As antiretroviral (ARV) treatment of AIDS is priced well beyond the budgets of all but the wealthiest Africans, treatment costs are for palliative care for the disease and opportunist infections. In sub-Saharan Africa, the annual cost of such care has been estimated at US $30 per capita, while overall public health spending is less than US$10 in most African countries (Loewenson & Whitestone 2001: 8). Whether care is administered at home or in a hospital, costs are prolonged by the slow process by which a PLWHA dies – about one year in sub-Saharan Africa (Nnko et al. 2000). Care costs are exacerbated in poverty contexts, where households lack income, access to medical resources (i.e. common drugs) and knowledge of proper care and pain management for bedridden patients. Furthermore, household food costs increase because the nutritional requirements of PLWHA increase up to 50% for protein and 15% for energy (Piwoz & Preble 2000). AIDS reduces the efficacy of nutrient absorption and utilization of nutrients, requiring more nutritious food than normal diets (Semba & Tang 1999; Stillwaggon 2002). Such material costs are considerable for a region already struggling with the highest material poverty in the world.

Household Labor Loss

Human capital is the most important asset of poor households lacking material resources, heightening the consequences of labor loss due to AIDS (Cohen 2002, Loewenson & Whiteside 2001, UNAIDS 1999a). Care for PLWHA diverts household members from primary income generating activities. In Tanzania, it was estimated that if a household contained an AIDS patient, it absorbed 29% of the household labor supply (Tibaijuka 1997). Labor loss due to AIDS is especially pronounced as the bulk of infections fall upon the most productive members of the household (ages 15-45), compounding costs for PLWHA care with decreased productivity. In Zambia, AIDS led to a rapid transition from relative wealth to relative poverty; in two-thirds of the families where the father had died, monthly disposable income fell by more than 80% (Loewenson & Whiteside 2001: 10). In Botswana, it is estimated that the number of households living below the poverty line will rise by 8% over the next ten years due to AIDS, while household per capita income

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 epidemic has had grave consequences for rural food production and security (FAO 2001; Haddad & Gillespie 2001; Liere 2002; Ngwira et al. 2001). The aforementioned labor loss is a major contributor to food insecurity. According to the FAO (2001: 6), between 1985 and 2000, 16 million agricultural workers died due to AIDS in the 27 most affected African countries, and in the ten most affected African countries agricultural labor forces losses are projected to increase from 10% to 26% by 2020. In Ethiopia, AIDS-afflicted households spent 50-60% less time on agriculture than households that were not afflicted (FAO 2001: 7), and in Kenya, there was a 68% reduction in the net value of farming output due to the death of a household head (UNAIDS/WHO 2002: 28).

Agricultural labor loss is especially significant among women in sub-Saharan Africa. While they make up the majority of those living with HIV/AIDS, they are responsible for 50%-80% of food production – including the most labor intensive work, (planting, fertilizing, irrigating, weeding, harvesting, and marketing) (UNAIDS/WHO 2002: 28). The epidemic's impact on agricultural production extends to the loss of knowledge and institutional support with the loss of veteran farmers and the organizations, networks, and infrastructure that they sustain (Haddad & Gillespie 2001; UNAIDS 1999a). In response to labor loss, farmers cultivate smaller areas, weeding is neglected, and fast maturing crops of poorer nutritional value often replace labor-intensive crops, i.e. substituting starchy root crops deficient in key micro-nutrients for nutritional leafy crops and fruits.

HIV/AIDS not only reduces food production, but also the household's capacity to generate income to purchase food (FAO 2001; Loewenson & Whiteside 2001). In the formal and informal economy, non-agricultural employment is for many households the primary source of income for food procurement. In South Africa, for instance, while about 60% of the mining workforce was between age 30 and 44 in the late 1990s, in 15 years it is predicted to drop to 10% due to AIDS mortality and morbidity (Simon et al. 2002: 232). Such job loss will impact household income and food security.

This enormous impact on food security feeds into and accelerates the AIDS cyclical trap. Food insecurity and the resultant

malnutrition in Africa is a formidable development problem. Between 1997 and 1999, 34% of the total sub-Saharan population was undernourished (UNDP 2002a: 173), and at end of 2002 an estimated 14.4 million people were at risk of starvation in Lesotho, Malawi, Mozambique, Swaziland, Zambia, and Zimbabwe (UNAIDS/WHO 2002: 26). The outcome for households struggling with AIDS is often a vicious cycle where failure to maintain nutritional status further weakens the immunity of PLWHA, thus increasing vulnerability to opportunist infections, which in turn further undermine overall nutritional status and immunity (FAO 2001; Ngwira et al. 2001; Stillwaggon 2002). It also degrades mood, motivation, and self-esteem necessary to take care of oneself, and sometimes to take proper precautions to prevent the spread of the virus to others. Meanwhile, non-infected household members also suffer the consequences of insufficient foodstuff and ensuing malnutrition. Their poor nutritional status diminishes their capacity to care for PLWHA and the young in the household and compromises their job performance in the household and workplace. As we shall discuss below, bereft of food, people often adopt extreme survival strategies that further endanger their lives.

Household "Coping" Mechanisms

Sub-Saharan households have employed a variety of coping mechanisms to mediate the consequences of AIDS. While some of these responses have positive impacts on the long term well-being of the household, oftentimes stressed households respond in ways that render the household more insecure and vulnerable to poverty and AIDS. For example, income diversification, the adoption of labor saving technology such as inter-cropping, and diversification of crop production can be beneficial in the long run. However, the sale of key assets, withdrawal of children from school, and risky income generating activities such as prostitution are coping mechanisms that inadvertently expose the household to higher risk. Therefore, some are careful to point out that the term "coping" can be a misnomer, and does not necessarily mean that "things are fine" or that the household is successfully negotiating the crisis in the long run (Rugalema 2000; Whiteside 2002).

Drawing upon Donahue (1998) and Sauerborn (1996), as well as reviews of household response sequencing (Baylies 2002a; Liere 2002; UNAIDS 1999a), three stages in household coping strategies are identified: TABLE 1. Although these stages do not represent an inevitable progression, households typically progress to each stage as their AIDS burden increases, and the respective coping mechanisms progressively jeopardize long-term recovery. In **Stage 1**, Reversible Coping Mechanisms, the household employs coping responses that have short-term consequences and are more-or-less reversible. These are the initial responses to the AIDS burden while household resources are still relatively intact. For example, during this stage the family will often reduce its household expenditures, rely upon household savings, and seek the support of family and friends.

During **Stage 2**, Consequential Coping Mechanisms, the household's coping responses threaten long-term security and recovery. Households turn to these responses when those in the first stage are either unavailable or depleted. By this stage the AIDS burden exerts extreme pressure on the household; health costs rise, nutritional status deteriorates, children receive less attention, general household health deteriorates, and the family often falls into debt, mortgaging their belongings to meet

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).

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

TABLE 1: Household Coping Mechanisms by Stage

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

Source: Compiled from Donahue 1998, Sauerborn 1996, Baylies 2002a, Liere 2002, UNAIDS 1999a

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

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

limited decision-making power and access to resources, as well as less knowledge, experience, and physical
strength to maintain a household. Relatives may be unable to care for orphaned children, and the household dissolves.

Women & Children – The Most Vulnerable

> *As women, we recognize HIV/AIDS as a disease of inequality and marginalization. Our vulnerability arises out of a combination of poverty, unequal access to basic needs and resources, oppressive cultures and traditions, the denial of sexual and reproductive choices and the absence of adequate health-care and information.* "Statement of Concern on Women and HIV/AIDS" (Gender AIDS Forum 2000)

Women

As the above statement conveys, gender inequalities place the burden of HIV/AIDS disproportionately on women (Baylies 2002b; Jackson 1998; Mill & Anarfi 2002; WHO 1994; WHO 2002a). At the household level, women typically provide the daily care for the sick and dying, in addition to maintaining the heavy workloads relating to household upkeep, provisioning, and raising the children (Nnko et al. 2000). After the death of a husband, many women lack marriage certificates or wills to protect their properties, and dominant inheritance customs often transfer assets to the husband's family, amplifying their destitution and resultant dependency.

The household burden has become especially heavy for older women, who "have now taken on the roles of primary and sole care providers, but without the expertise and resources to render effective care to their dying sons and daughters" (WHO 2002a: 27). In addition to caring for the sick, the elderly have also been expected to take on the role of caring for AIDS orphans, often without even the most basic resources. Such a task at their stage in life has a serious physical and emotional toll, as expressed by a 72-year-old woman in Harare, Zimbabwe (WHO 2002a: 18):

> *We are old and we need to look after us and yet we are expected to take care of these orphans.*

Gender inequalities also place women at greater risk of HIV infection; over 58% of those living with HIV/AIDS in Africa are women (World Bank 2003: 1). Gender inequalities deprive women of the ability to refuse risky sexual practices, can result in coerced sex and sexual violence, keeps women uniformed about safe sex practices as well as the safe care of PLWHA, and places women last in line for medical attention and treatment. Gender inequalities undermine marriage as a protective institution against HIV transmission as it constrains women's ability to exert control over their choice of sexual partners and enforce safe-sex practices. This is compounded in that women are more biologically prone to HIV infection, (their cervix being susceptible to lesions). As the World Health Organization suggests, women's powerlessness is one of, "the most intractable barriers to the control of AIDS" (WHO 1994: 56).

Poverty, which women also disproportionately experience (UNDP 1997; World Bank 2001b), accelerates their AIDS-risk (Booysen & Summerton 2002; Loewenson Whiteside 2001; Poku 2001). Lacking education and other productive economic assets, poor and under-employed women often resort to multiple partners, "sexual networking", as an economic

survival strategy to sustain their families in the face of increased economic uncertainty and the absence of viable alternatives (Baylies 2002a; Booysen & Summerton 2002; Mill and Anarfi 2002). Beliefs among older men that younger women are less likely to be HIV-infected (Jackson 1998; Mill and Anarfi 2002), or that sexual intercourse with uninfected women has healing powers (Haddad & Gillespie 2001) exacerbates the problem. Amidst the extreme poverty that accompanies HIV-intense regions, a "sugar daddy" phenomenon, whereby young girls exchange sexual favors for food, shelter, employment, school fees, etc., has instead proven itself as a strategy for premature death rather than survival (Browne & Barrett 2001). In 2001 in sub-Saharan Africa, it was estimated that about twice as many young women as men (aged 15-24) were HIV infected (UNAIDS/WHO 2002: 18). Clearly, women do not uniformly experience the epidemic; while younger women are more vulnerable to HIV infection, older women bear a greater burden for caring for the survivors (Baylies 2000, 2002ab).

Children & Orphans

Like women, the children of sub-Saharan Africa are extremely vulnerable to the consequences of HIV/AIDS (Hunter & Williamson 2000; UNICEF 2002; USAID & FHI 2003). As a household tumbles into an AIDS-poverty cycle, the child is beset by a lack of material and emotional attention. As already noted, food insecurity is a major concern, resulting in higher child malnutrition, especially among girls; there is a 10% incidence rate of child malnutrition throughout sub-Saharan Africa (excluding South Africa), and as much as a 40% incident rate in six countries (UNDP 2002a: 21).

Child malnutrition has serious long-term consequences; under-nourished children fall repeatedly ill due to their weakened immune systems and the absence of micronutrients. Also, under-nourishment often results in perennial underachievement, which is modeled and internalized by children of underachievers – with implications for future generations of afflicted and affected households and communities. Chronic malnutrition often results in stunting; in central Malawi, for instance, 56% of the children under five are stunted and will never reach their full physical or mental potential (Piot & Pinstrup-Andersen 2002). With malnourished pregnant women, the brain, body, and development of the baby is affected, causing irreversible repercussions. Sadly, many infants are born to HIV-infected mothers: in 2001, the HIV prevalence among pregnant women in urban centers was 44.9% in Botswana, 35% in Zimbabwe, 29.6% in Namibia, and 32.3% in Swaziland. (UNAIDS 2002. 23).

As the AIDS parents fall ill and die, the family burdens shift to the children, (as well as the elderly). Younger children are pulled out of school to provide care, upkeep of household, and replace lost labor (Kelly 2000a). Upon the loss of a parent, the child may not understand what is happening, and without proper support mechanisms children experience profound confusion, grief, fear, and anxiety. Like malnutrition, the long-term consequences can have a serious impact on the child's future. The traumatic experience, compounded with the other hardships of living in an AIDS household, can cause "psychosomatic disorders, chronic depression, low self-esteem, low levels of life skills, learning disabilities, and disturbed social behavior" (USAID & FHI 2001: 5).

One of the more disturbing measures of the epidemic's impact on the lives of children is

the tragedy of AIDS orphans. In 2001, an estimated 11 million of the world's 14 million AIDS orphans were in Africa, and this number is projected to almost double by 2010 (UNAIDS et al. 2002: 6). By 2010, 5.8% of all children in sub-Saharan Africa are estimated to be orphaned by AIDS (UNAIDS et. al. 2002: 6). In 2001, 10 countries in SSA had orphan rates higher than 15%; in Zimbabwe, for instance, the orphan rate was 17.6%, with three-quarters due to AIDS.

> *I am so afraid of what the future has in store for these orphans. If I were to die and leave them, there would be no one to look after them*. (62-year-old woman, Zimbabwe. WHO 2002a: 9)

As the above quote reflects, the orphan crisis is dire for many, and the burden is overwhelming and straining the traditional kinship networks and communities. Outcomes vary from grandparent-headed households to the fostering of other people's children. In communities such as Lusaka, Zambia, 85% of families living in low-income outskirts of Lusaka care for orphans (UNAIDS/WHO 2002: 29). Often, the eldest child takes on responsibility as the head of the household. Sometimes, children have no recourse but to live on the streets, where they are exposed to even greater medical, social, and psychological difficulties. However it unravels, it generally entails increased risk of loosing opportunities for school, health care, growth, development, nutrition, and shelter.

Societal Consequences

> *It is reasonable to hypothesize that the epidemic may pose one of the greatest current challenges to sustained economic development and human and social relationships.* (Dixon et al. 2001a: 412)

The consequences of HIV/AIDS extend wide into African society, exacerbating each other, with major consequences for individuals, households, and communities. As we have seen, it begins by undermining the very cornerstone of society, the household. It then extends into the socio-economic infrastructure of the nation-state, ultimately unraveling the very fabric of society as a whole. This, in turn, feeds back into the viscous cycle, amplifying the burden at the local level.

Frayed Kinship & Community Safety Nets

When the resources of individual households become exhausted, whether from natural or manmade disaster, African families traditionally turn towards extended family, friends, and neighbors for support and assistance. Such kinship and community safety nets arise from humanitarian concern, as well as reciprocity – members endorse communal mechanisms that ensure that they receive support should they be affected by similar adversity. However, the reliability of these safety nets to absorb the impact of the AIDS epidemic has been stretched throughout sub-Saharan Africa (Baylies 2001; Donahue 1998; UNAIDS 1999a; Whiteside 2002). The prolonged burden of HIV/AIDS places enormous strain on the capacity of these informal mechanisms, steadily eroding resources and resolve to care for those suffering or bereaved. As one care provider in Tanzania commented (Nnko et al. 2000: 553):

> *If it is not your relative you can't do it…It needs courage…A mere neighbor will not agree to care.*

When one episode of illness is successively followed by others, they gradually deplete resources and labor supplies of

interdependent households. Communal safety nets, which can usually endure normal traumas, begin to fray: "In the case of AIDS, the limits of communal safety nets are a function of the way the epidemic feeds on and deepens existing levels of deprivation" (Baylies 2002a: 623). Weakened by AIDS, communal coping strategies also become too frail to cope with further threats such as armed conflict, crop failures or natural disasters.

Strained Cultural &Civic Norms

The breakdown of social institutions is accompanied by the **loss or modification of related customs, traditions, and values** (Browne & Barrett 2001; Gausset 2001; Haddad & Gillespie 2001; UNAIDS 1999a). Adult mortality not only impairs the transfer of labor knowledge and skills, but also the transfer of cultural traditions, beliefs, folklore, and values between generations, undermining organizational life. Social reproduction of role modeling of norms of trust and citizenship is impaired as the immediacy of the epidemic removes community leaders and distracts community members. Faith in traditional institutions is often eroded, such as the efficacy of traditional healers (as well as modern medicine) after the death of the first AIDS patient (Nnko et al., 2000).

The very nature of HIV transmission also challenges cultural morals and norms. It **confronts society's sexual behavior**, creating tension between moralistic and pragmatic forces (Browne & Barrett 2001). This has been particularly contentious with regards to child and teenage sexuality, as well as gender inequalities regarding control over multiple sexual partners and safe sex preventative measures (discussed above). For many Africans, (as well as Europeans and Americans), condoms are associated with mistrust, infidelity, and prostitution, challenging communication and relations between partners (Gausset 2001; Mill & Anarfi 2002). Individuals and communities have been forced to wrestle with the rapid reconstruction of moral boundaries during a time of overall social and moral anxiety.

The epidemic has also strained **civic norms and values relating to reciprocity, collective action, and exclusion** (Haddad & Gillespie 2001). In addition to the loss of community leaders and adults that embody these norms, the epidemic erodes overall confidence and morale in the community, harming productivity and willingness to save and invest in the future not only of the household, but the community as a whole (Beresford 2001: 22). For instance, research shows that burial rituals have been modified, reducing the periods of mourning and assistance from kin and neighbors (Barnett and Blaikie 1992; Baylies 2002a; UNAIDS 1999a). With regards to agriculture and food security, "Social capital and property rights are tested to the limit as HIV/AIDS may rip into the social fabric, reducing the ability and incentives for collective action and threatening property rights due to a breakdown in traditional structures" (Haddad & Gillespie 2001: 507). The social incentive for coordinated group behavior often diminishes as expectations and trust of members are lowered due to AIDS-stress. This has especially negative consequences for collective responsibility towards community resource management practices, property rights, such as watershed development, or integrated pest management. As more people do not envisage a long term for themselves, they despair and loose hope as well as their incentives for civic norms and duty.

> *People who used to be friendly to me have severed their ties. Now I feel very lonely and dirty.*

The above quote, from a 76-year-old woman caring for three orphans in Zimbabwe (WHO 2002a: 15), underscores the formidable barriers AIDS-related **stigmatization, scapegoating, and discrimination** pose to social cohesion. Fueled by ignorance, fear, and denial, the HIV virus has acquired a severe social stigma, (Cock et al. 2002; Gilmore & Somerville 1994; ICRW 2002). Resultant discrimination and scapegoating increases exclusiveness within the community and among network groups. Targeted households, people, and groups not only struggle with the absence of social support, but also hatred and fear; HIV-positive diagnosis has often resulted in questioning people's ability to work and perform responsibilities, domestic violence, abandonment, or even murder (Temmerman 1995). These harmful practices are not only counterproductive for much needed social cohesion, but also to combating the spread of HIV itself. Fear of identification with HIV prevents people from participating in voluntary counseling and testing (VCT) and programs to prevent mother-to child transmission (Mill & Anarfi 2002; Painter 2002). This, in turn, prevents people from learning their sero-status, changing unsafe behaviors, and caring for PLWHA.

National Incapacity

> *Countries ravaged by the HIV/AIDS epidemic are facing a double jeopardy. On the one hand, their capacity for planning and implementing development strategies is greatly compromised by the loss of human capital and diversion of scarce resources due to HIV/AIDS. On the other hand, strong national capacity is becoming even more crucial as countries face the formidable challenge posed by the epidemic.* (Loewenson & Whiteside 2001:14)

National resources, institutional capacity, and infrastructure play a critical role in how the AIDS epidemic is experienced at the local level. However, as traditional family and community systems break down, rather than providing assistance, national support systems themselves are deteriorating. In the cyclical manner that characterizes HIV/AIDS, the epidemic accelerates the very national conditions in which it thrives. Absenteeism, high turnover, and loss of institutional memory cause delays, disruptions, and inefficiency in the public and business sectors. AIDS deaths are proportionately higher among skilled, professional and managerial labor, (due to their disposable income to engage in risky sex - although better educated populations are quicker to change their behaviors and mitigate infection, Cohen 2002; Dixon et al. 2001). Public investment in trained labor is also lost among university students; an estimated two-thirds of the students at South African University will be HIV-positive by the time they graduate (Beresford 2001: 20).

The outcome has had serious consequences for national economies, and thus resources to assist AIDS-stricken communities (Barnett & Whiteside 2000; Beresford 2001; Dixon et al. 2001b & 2002). It is estimated that AIDS reduces economic growth in sub-Saharan Africa by 2% and 4% annually (Dixon et al. 2002: 232). In South Africa, which represents 40% of sub-Saharan economic output, it is estimated that AIDS will reduce gross domestic product by 17% (UNAIDS 2002A: 57). Economic hardship has been exacerbated by increasing economic marginalization of sub-Saharan Africa resulting from the post-Cold War trend towards globalization and privatization of global markets (Deacon 2000; Killick

2001; UNDP 1999). Per capita incomes in sub-Saharan Africa are now lower than they were in 1970, leaving it the economically poorest region in the world (UNDP 2002a: 17). Such economic insecurity severely handicaps a nation's institutional capacity to address a long-wave disaster of the magnitude of HIV/AIDS.

Economic stagnation has fueled, and is exacerbated by, state ineptitude in a cycle all too familiar to sub-Saharan Africa – bureaucratic and political corruption, political violence, incentive systems that encouraged opportunism, and incompetent state leadership (Englebert 2000; Gray 2001; Mbaku 1999). In turn, national resolve and capacity to implement effective national health plans to deal with HIV/AIDS has been insufficient (Kumaranayake & Watts 2001; Waal 2003). In 2001, funding gaps in national AIDS programs were reported by health directors and ministers in fourteen sub-Saharan countries (UNAIDS 2002: 165). As Baylies (2000a: 488) points out, "there has often been a stance of denial or, alternatively, official acknowledgement of the need for an AIDS policy coupled with a persistent failure to accept the depth of the crisis or the urgency of the situation, much less to follow through on construction of a comprehensive policy."

It is important to note there are exceptions to State lethargy and incapacity, such as Uganda (discussed later), and the New Partnership for Africa's Development (NEPAD)[1] reflects greater resolve among the continent's leaders to address development challenges such as HIV/AIDS. It is also important to remember that national incapacity is not solely due to poor domestic leadership. There are also formidable international considerations impacting national capacity to address AIDS (i.e. structural adjustment programs, debt burden, decreased in ODA, pharmaceutical trade practices - discussed later). Nevertheless, throughout much of sub-Saharan Africa, economic instability, accompanied by political instability and civil strife, severely handicap a nation's institutional capacity to address a long-wave disaster of the magnitude of HIV/AIDS (World Bank 2003: 13).

Deteriorating Public Service

> *Today, a generation of young Africans is growing up watching their peers fall sick and die, while the governing institutions do little or nothing.* (Waal 2003: 20).

Compromised public services sadly illustrate the impact AIDS has had on social institutions and the people they serve. As many Sub-Saharan households and communities live in poverty, there are few options whereby the burden of health care and education can be shifted from the public to households and communities (Cohen 2002; Loewenson & Whiteside 2001; World Bank 2002b). However, public services in countries are facing a widespread attrition of trained staff and are unable to replace them due to the drained employment pool and severe constraints in the public budget. The loss of the trained and educated personnel erodes the very foundation of national infrastructure, from ministries and departments downward to community extension services, schools, health clinics and hospitals. As the State's ability to provide public services deteriorates, the socio-economic effects are largely borne by individuals, households, and communities (Baylies 2002a; Nnko et al. 2000; UNAIDS 1999a).

[1] Approved by the Organization of African Unity (OAU) Heads of State in 2001, and later adopted by the African Union (AU), NEPAD presents a strategic framework for African development, stressing the commitment of African governments to work with their people and the international community.

> *In care and support, communities bear the lion's share of the responsibility, especially for home-based care for those living with HIV/AIDS and support for orphans.* (World Bank 2003: 13)

In the health sector, government and NGO health facilities have been overwhelmed by AIDS patients, crowding out non-AIDS patients and doubling bed occupancy rates (Loewenson & Whiteside 2001). Meanwhile, the epidemic jeopardizes the lives of the very health workers meant to mitigate it; in countries like Malawi and Zimbabwe, health facilities are experiencing five- to six-fold increases in staff illness and death rates (UNAIDS 2002: 51). The result is increased stress, work, and fear for personal safety in the remaining staff, making health care even scarcer and more expensive for poor communities. As the Government of Botswana reports (Cohen 2002: 18):

> *HIV/AIDS will not only create a massive new need to be met by the health system but it will also reduce the capacity of the health system to respond to this need.*

The education system in sub-Saharan Africa faces a similar plight – at a time when it is also urgently needed to help counter the epidemic and accompanying poverty (Cohen 1999 & 2002; Gregson et al. 2001; World Bank 2002b). The human capital loss within the educational system has been especially acute, draining the teacher and administrator pool, eroding the quality of education, and increasing the sector's costs to re-train and replace lost staff. In Botswana, death rates among primary teachers rose from 0.7% in 1994 to 7.1% in 1999 (Loewenson & Whitestone 2001: 9), and in 1999 an estimated 860,000 children in the entire sub-Saharan region lost teachers to AIDS (Kelly 2000b). According to calculations from its funeral planning, the South African Democratic Teachers Union estimates that nationwide AIDS-related deaths among teachers rose over 40% in 2000-2001 (UNAIDS, 2002a: 53).

Such losses cripple education in a region where universal primary education goals are unmet in fourteen of the 21 countries providing data (UNDP 2002a: 22). Even when schooling is available, many of the poor households affected by AIDS can't afford to send children to school under the increased burden of the epidemic, or worse, many children do not survive to school age. In the Central African Republic and Swaziland, for instance, school enrollment is reported to have fallen by 20-36% due to AIDS and orphan-hood, with girls most affected (UNAIDS 2002: 52). Numerous studies show the benefits of education in reducing HIV transmission (World Bank 2002b). As Loewenson & Whitestone (2001: 9) express, "Given the crucial role education plays in informing and promoting positive responses to HIV/AIDS in young people, these losses generate a vicious cycle of increased risk of HIV." Clearly, sex education can make a huge difference in reducing the spread of HIV in countries like Kenya, where one study revealed that 54% of the young people do not believe that condoms protect against HIV infection (UNAIDS 2002: 87).

Public bodies charged with maintaining law and order have also been greatly compromised. The police, army, and uniformed forces are especially vulnerable to the epidemic due to increased mobility and sexual activity with multiple partners (Fleshman 2001; Schneider & Morrison 2002; UNAIDS/WHO 2002). In Kenya, for example, an estimated three-quarters of all police force deaths are due to AIDS (UNAIDS 2002: 58). As these societal

institutions deteriorate, society as a whole becomes more susceptible to civil disorder, crime, and conflict – leading some to rightfully perceive AIDS as a direct security threat (Ostergard 2002; Schneider & Moodie 2002). For instance, AIDS orphans destitute in the streets, existing without role models or a strong police presence, resort to crime or are recruited into crime or military activities with promises of food, alcohol, and drugs (Schoneteich 1999 in Loewenson & Whiteside 2001). In extreme civil strife, such as civil war, the impact of AIDS can be exponential. Such conflicts fuel HIV/AIDS by creating many of the conditions and human rights abuses in which the epidemic flourishes. In Rwanda, for example, genocide and war spread the epidemic from the city to the countryside, where the HIV rate increased from 1% prior to the 1994 genocide to 11% in 1997 after massive migration and rape (UNAIDS/WHO 2002: 30).

The Poverty Connection

> *Across the continent, poverty structures not only the contours of the pandemic but also the outcome once an individual is infected with HIV…..The cruel irony, of course, is that Africa is the least equipped region in the world to deal with the multiplicity of challenges posed by this deadly virus*. (Poku 2002a: 545, 2001: 191).

As the foregoing discussion illustrates, Africa's AIDS epidemic is not simply a health crisis, but a development crisis with a multitude of inter-linked factors operating at various scales. At the household, community, and regional levels it exacerbates preexisting poverty: "The epidemic is deepening poverty, reversing human development achievements, worsening gender inequalities, eroding the ability of governments to maintain essential services, reducing labor productivity and supply, and putting a brake on economic growth" (Loewenson & Whiteside 2001). As the AIDS epidemic swelled in sub-Saharan Africa during the 1990s, the number of people living in extreme poverty likewise increased from 242 million to 300 million, and 23 African countries are now poorer than in 1975 (UNDP 2002a). A study in Burkina Faso, Rwanda, and Uganda concluded that AIDS will not only reverse poverty reduction efforts, but increase the percentage of people living in extreme poverty from 45% in 2000 to 51% in 2015 (UNAIDS 2002: 47).

Certainly, correlation and estimates do not prove causation, but the synergistic relationship between AIDS and poverty is undeniable, especially with regards to malnutrition – a key feature of poverty. Biomedical evidence shows that malnutrition weakens the immune system, which increases the risk of contracting HIV with each contact, regardless of the number of sexual encounters, and hastens the progression from HIV to AIDS (Stillwaggon 2002). Where poverty and accessibility of food is lowest, HIV prevalence is greatest. Thus, it is no coincidence that AIDS has spread throughout sub-Saharan Africa, where 34% of total population was malnourished between 1997 and 1999 (UNDP 2002a: 173). In the six worst famine-affected countries – Lesotho, Malawi, Mozambique, Swaziland, Zambia, and Zimbabwe – an estimated 14.4 million people were at risk of starvation at end of 2002 (UNAIDS/WHO 2002: 26).

The link between AIDS and poverty can sometimes be deceptive. South Africa, for example, the wealthiest African country, has one of the highest HIV/AIDS rates. This is because macro measures of wealth, such as

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, and its progression from HIV infection to AIDS. Poverty resulting from AIDS then interacts with other dimensions of poverty, producing an especially "fertile terrain" for diffusion of the virus, which, in turn, further complicates an already volatile situation (Stillwagon 2002).

The AIDS epidemic in sub-Saharan Africa must be examined and understood in the socioeconomic context in which it unfolds – especially for a local perspective. From the household level upward, we have seen how the context is largely one of poverty. AIDS amplifies preexisting poverty and is fueled by the byproduct – increased poverty – accelerating a vicious, debilitating cycle. The poverty cycle is not new to Africa, (or other regions in the world), but the exponential rate at which it is occurring is unprecedented. While the variety of factors in the AIDS-poverty connection prevent definitive, causal conclusions, the link between the two is widely acknowledged (Baylies 2000, 2002; FAO 2001; Lier 2002; Loewenson & Whiteside 2001; Poku 2001; Stillwaggon 2002; UNAIDS/WHO 2002; Whiteside 2002; WHO 2002). The challenge is to mainstream this knowledge into development practice so that it informs policy and programs targeting HIV/AIDS, as well as other multi-sectoral development challenges.

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 cohesion as communities organize initiatives to address this urgent crisis. Vulnerability, such as HIV/AIDS, can foster a collective response among community members, which, in turn, fosters personal empowerment and social change (Baylies 2002b; Haddad & Gillespie 2001; Lamboray and Skevinton 2001; Man & Tarantola 1996). If properly harnessed, "Collective action might be stimulated in the face of a community-wide threat before that threat begins to undermine the ability and incentive to act collectively" (Haddad & Gillespie 2001: 490). In sub-Saharan Africa, "Communities are mobilizing themselves, showing great resilience and solidarity, despite their vulnerability to external shocks such as premature death of their most productive members" (Loewenson & Whiteside 2001: 3). Effective community-centered action can initiate an *empowerment cycle*, a counterweight to the poverty cycle, in which a community's success engenders more positive feelings, solidarity, and momentum for another successful cycle. As Lamboray and Skevinton (2001: 516) remind us:

> *It is a group phenomenon that has the potential to generate a coherent system of activities that are more than the sum of the parts.*

The following section presents a brief overview of informal and formal community responses to HIV/AIDS. It then examines some of the key attributes of successful community initiatives and the strategies employed. It concludes qualifying these "potentials" with some of the principal limitations community initiatives and civil society organizations (CSOs) confront. Although community and their respective CSOs hold much promise, they are not a panacea for Africa's AIDS crisis.

Informal & Formal Community Initiatives

UNAIDS (1997: 3) defines a community as, "a group of people who have something in common and will act together in their common interest." It is worth noting that shared commonal**i**ties, such as geographic proximity, gender or ethnic background, or occupations and behaviors, are not enough in this otherwise broad definition. The critical element in the definition is not just a common sense of mutual belonging, but also purpose. This is what identifies a "resilient community" – a community that has a shared vision of its future and "takes intentional action" to ensure the personal and collective capacity of its citizens and institutions towards their common goal (Hsu et al. 2002: 3). For example, following a civil conflict, inhabitants of a refugee village may share the same immediate locality and similar refugee experiences, but they may be from different parts and lack common bonds, leading people to compete rather than cooperate when stressed by limited

resources. Of course, the ability of communities to sustain resilience is not temporally static, but will vary according to location and stresses placed on the community (i.e. after a plentiful harvest versus during a drought). The goal is to build and reinforce community resilience to better confront future challenges.

Informal Grassroots Responses

> *Even the poorest and most vulnerable people have set up resilient and ingenious coping mechanisms such as voluntary association, self-help groups, burial associations and rotating credit and loan clubs.* (Foster 2001: 4).

Although AIDS has placed enormous strain on kinship and community safety nets, informal and traditional grassroots responses nevertheless play an essential role in mitigating the epidemic (Barnett & Blaikie 1992; Baylies 2002a; Nnko et al. 2000; Sauerborn & Hiem 1996; UNAIDS 1997, 1999a, 2000). A World Bank study in the Kagera Region of Tanzania reported that 90% of the assistance to families that lost breadwinners through AIDS came from family and community groups (UNAIDS 1999: 29). Informal grassroots initiatives are as varied as the cultures of the Sub-Saharan continent. It may be neighbors assisting families with PLWHA by providing money, fruits, vegetables, milk, soap; labor to fetch water and firewood, cooking, and cleaning clothes (Nnko et al., 2000). Or it may be a traditional practice, as in Zambia, where women have "kitchen parties" for which friends of a bride's mother gather on the eve of the wedding to offer advice to the betrothed, or at the wedding itself, when advice is traditionally given to the couple (Baylies 2002b).

UNAIDS (1999a) identifies four different forms of informal grassroots organizations:

1. **Social support groups** provide mutual support to members ranging from burial societies to grain-saving and labor-sharing clubs.
2. **Indigenous saving associations**, such as rotating savings and credit associations (ROSCAs) and savings clubs, are a traditional and important source of finance during emergencies.
3. **Indigenous emergency assistance associations** are specific initiatives providing assistance to individuals and households in particular need, such as informal counseling groups and impromptu meetings in response to the AIDS epidemic (Barnett & Blaikie 1992).
4. **Self-help groups of PLWHA**, as we shall see, play an important role through material and psychological support, especially to offset stigma.

It is worth noting that many informal responses are deeply embedded in the culture, unstructured, and difficult to measure. For instance, informal information and advice networks among care givers, primarily women and elderly people, are receiving increasing recognition as a valuable community response (Baylies 2002a; Nnko et al. 2000; WHO 2002a). In Zimbabwe, knowledge gained from caring for the first patient by elder caregivers – handling diarrhea, provision of psychological support and food preparation. – was shared with others in the community (WHO 2002a). Furthermore, these caregivers were more apt to identify AIDS in subsequent patients. In Zambia, women who were thrust into the health care role acquired experience, knowledge and wisdom so that they were, "better positioned than younger women to speak out on behalf of themselves, their children, other women and their communities" (Baylies 2002b: 371). In Tanzania, experienced care

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;

DIAGRAM 2: Stages of Community Response

Acknowledge ⇨ Change Behavior ⇨ Mobilize ⇨ Evaluate

Loewenson & Whiteside 2001; UNAIDS 1999a):

1. **Prevention** focuses on reducing the number of new infections and containing the epidemic through advocacy, information and education campaigns, behavior change communication, condom distribution, programs targeting specifically vulnerable groups, etc.
2. **Treatment and care** targets those individual and families directly effected by the epidemic, providing medical supplies and training, foodstuff, counseling, and other supportive resources.
3. **Mitigation** provides poverty reduction that not only alleviates the hardships of those directly impacted by AIDS, but reinforces the community's resilience to better resist and respond to the epidemic.

These focus areas are not exclusive of each other; for example, the NGO, COFAL-SP (discussed below) pursues preventative, care and mitigation activities.

The expression, effectiveness, and sustainability of community initiatives will vary according to a host of factors: i.e. traditional culture and its adaptation or resistance to outside intervention, local power structures, environmental conditions (i.e. drought), regional economy and infrastructure, educational level, and physical proximity and political access to resources. Yet, certain key commonalities identify these "AIDS-competent" (Lamboray & Skevington 2001) or "mobilized communities" (UNAIDS 1997): TABLE 2.

The evolution of a community initiative also varies according to context, but a common sequence can be observed: DIAGRAM 2. Some of the more successful initiatives may scale-up, expanding services beyond initial boundaries or target population to serve more people. Scaling-up may also occur through replication, which is when people from other communities observe and copy successful initiatives, or through facilitation by external organizations (Foster 2001).

The remainder of this section will highlight some examples of more successful community approaches to AIDS in sub-Saharan Africa. Far from conclusive, the following list is only a sampling of exemplary initiatives and the key attributes that are making a difference in sub-Saharan Africa's anti-AIDS efforts.

Culturally Appropriate Drama Groups

In Zambia, drama groups illustrate the success of initiatives that are well adapted to local cultures to disseminate information about HIV, sexual behavior, and condom use. St. Francis' Hospital in Katete District uses a drama group to perform skits in villages, schools and work places (Browne & Barrett 2001). The effectiveness of the performances **is due in part to the fact that, "the drama group adapts** it message and style to suit its audience" (Browne & Barrett 2001: 31). The entertainment value attracts people, and rather than being preached at, the audience is treated to skits reflecting their own lifestyle so they can relate better to the message. In a separate study in a Tonga village in Zambia, research comparing the effectiveness of the educational programs of Community Health Workers AIDS in villages with that of drama groups found that better knowledge

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 Assistance (UOA), has successfully assisted AIDS-impacted villages largely because its initiatives are built upon the preexisting kinship system. In Tanzania, Uganda, and Kenya, UOA works in villages to ensure that AIDS-orphans grow up in homes of their kinsfolk, with lives resembling that with their own parents, by providing short- and long-term assistance to households with orphans. Critical in this strategy is the utilization of the *kibanja* – a traditional family small farm. The *kibanja* is an economically valuable asset and a symbol of social prestige. Developing the *kibanja* of the orphans and the foster families socially and economically empowers these families and their capacity to provide care for the children. UOA-assisted villages create about 70% of the resources needed to raise AIDS-orphans, an important source of food security (Rutayuga 2003).

Raising HIV Awareness through Community Mapping

As Lamboray & Skevington (2001: 617) underscore, "In AIDS-competent communities, it is predicted that quality of life will start to improve from the point in time that the community acknowledges the problem and begins to take action." In Mwanza, Tanzania, "risk mapping" has been employed as a successful participatory strategy to raise AIDS awareness (Lamboray & Skevington 2001). With the assistance of the NGO, TANESA, community members draw the geographical boundaries of the village and its immediate environs, and then community discussion is used to identify the areas where people are most at risk of HIV infection. An important aspect of the exercise is that community maps and activities are plotted and discussed separately for the sexes and then debated in village meetings before the information is disseminated. Such activities raise awareness by involving the local people in identifying the problem in a format where they feel free to openly address taboo subjects such as condom use, rape, incest, and child abuse. The activities also have a supportive and destigmatizing effect for those already HIV infected.

PLWHA and Peer-Based Education

The use of peers as outreach workers is a successful participatory strategy to, "ensure that messages are appropriately communicated and the needs of the target group are better understood" (UNAIDS 1999a: 61). The success of the strategy rests on the principle of an equal relationship between peers, which lends the peer educator more credibility and people are generally more receptive to information. In Uganda, the Philly Lutaaya project is an initiative of young men and women volunteers living with HIV (UNAIDS 1998). These volunteers are trained in communication skills and visit communities to offer testimony of their experiences in efforts to change risky sexual behavior and people's attitudes toward PLWHA. As they travel between villages, they carry a banner and utilize music, drama, and face-to-face discussion. This approach has been especially effective in a country where a large percentage of rural people cannot read or write. In addition to educating the target communities, such initiatives provide valuable psychological, social and material support for the PLWHA. Such empowerment and

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 diseases. (4) Support for AIDS orphans is provided through the collection of clothes, school supplies, and other donations, and COFAL-SP works with various trade associations and other sponsors to provide training and educational opportunities for orphans. (5) COFAL-SP members sponsor HIV-afflicted households, particularly widows, grandparents, and orphans, to receive micro-loans following counseling on micro-enterprise development. (6) As noted below, COFAL-SP also provides legal support to AIDS households.

Advocacy for Inheritance Law Reforms

Some of the AIDS-related challenges communities face have legal roots, such as laws and customs that deal with inheritance. NGOs based in the urban areas, where civil law is conducted, are especially valuable in working with communities to lobby for legal reform. In Malawi, for instance, NGOs like Women and the Law in Southern Africa Trust (WILSA), Malawi Care, and Women's Voice have targeted laws that condone property grabbing (Ngwira 2001). These NGOs have worked with communities to demand changes in the Wills and Inheritance Act, which does not reflect the changed realities due to AIDS deaths and the ascendancy of nuclear families. Similarly, in Burkina Faso, COFAL-SP provides legal counseling to widows or orphans to help them keep their family inheritance (UN/OSCAL 2002: 20). Some of the members attend legal assistant training, and a judge provides free consultations with PLWHA or families, especially women affected by AIDS. Such initiatives help to reduce the already heavy burden that survivors of AIDS afflicted households confront.

Targeting Marginalized Groups

Marginalized groups, such as sex workers or street children, are extremely vulnerable to the impact of HIV/AIDS. Challenges stemming from social stigma, lack or education and resources, food insecurity, and lifestyles place them at high risk of HIV-infection. In Malawi, the CBO, Youth Net and Counseling (YONECO), initially provided counseling and skills training to for AIDS-afflicted youth (Ngwira et al. 2001). However, it soon extended its services to address the growing need of street children, providing shelter and food, as well as activities such as sports. Then, after tracing the backgrounds of these street children to commercial sex workers, it developed a parallel program, providing counseling, safe

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). In 1995, under the leadership of the well-known retired nurse, "Mama" Khoza, a group of retired and concerned nurses visited over 2,000 households to identify the need for home-based AIDS care. After consulting with the Department of Health, a home-care policy and training materials were developed and the group began providing home-based care services that same year. Following Tateni's initial success, it was approached the following year by the Department of Health to join a team developing a model for home-based care for the whole province modeled on Tateni's work. Pilot projects based on the model were then set up in other locations in partnership with the provincial government. As one Tateni nurse summarized: "When Tateni began, we weren't really anything formal. Not even a registered NGO, just a group of retired nurses and volunteers brought together by Mama Khoza. She's a retired nurse herself, and a very important figure locally" (UNAIDS 1999b: 57).

Mitigating AIDS with Microfinancing

Although income generating projects have inherent risks of economies of scale and overhead costs (UNAIDS 1999a: 41), "the ability of microfinance institutions to respond to the changing needs of their clients will be crucial to HIV/AIDS mitigation efforts" (Haddad & Gillespie 2001: 490). The Nigerian NGO, Country Women's Association of Nigeria (COWAN), has successfully used microfinancing to empower communities in addressing AIDS (UN/OSCAL 2002). Building upon traditional savings and credit systems, COWAN developed the African Traditional Banking (ATRB) scheme to provide credit to poor people, especially rural women, who lacked the credit and financial resources for modern commercial banks. Central to ATRB is that each member must save to participate: "No savings, no membership", and its success has allowed COWAN to scale-up its efforts into health care. COWAN asserts that, "Health is Wealth", and utilizes several strategies towards these ends. For instance, members save profits from micro-enterprise schemes not just to repay loans, but for compulsory payments into a ATRB Health Development Fund, which ensures essential health care services in case of an emergency. COWAN also pools together resources among members to arrange for a nurse and/or doctor to visit communities on a monthly basis, providing talks on health concerns and practices. Similarly, members pool together funds to buy medicine in bulk for affordable re-sale in the community, and to purchase more medicines with the profits.

Collaboration with Traditional Healers

It is widely accepted that about 89% of the people in Africa rely on traditional medicine for many of their health care needs (UNAIDS 2000: 7), including the treatment of sexually transmitted disease, as well as social and psychological counsel during misfortune (Gausset 2001, Green 1994, UNAIDS 2000). Traditional healers, and the respect that they hold in their

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 influencing behavior change" (UNAIDS 2000: 21).

Effective Government Support

Clearly, recognition, prioritization, and pro-active leadership among government officials can play an essential role in supporting community AIDS initiatives – which Uganda aptly illustrates. Soon after President Museveni came to power in 1986, he established an open policy of cooperation with community and AIDS service organizations, demonstrating, "a unique partnership which has been the foundation of the current strides made in the national HIV/AIDS response" (UNAIDS 1998: 50). Uganda has become the first African country to have "subdued a major HIV/AIDS epidemic," with HIV prevalence among pregnant women in Kampala dropping from 29.5% in 1992 to 11.25% in 2000 (UNAIDS 2002: 24). One of the more notable examples of community-government partnership has been The AIDS Support Organization (TASO), which started out as a small CBO in 1987, one year after President Museveni began the county's AIDS campaign. TASO initially advocated for care and support for AIDS patients, as well as people and families living with HIV, and with government cooperation, it rapidly grew, culminating in 1992 when one of its founders was appointed to the national AIDS Control committee. Today, TASO is one of the largest AIDS service organizations in Africa, providing HIV prevention education, counseling and support activities, basic medical care for opportunistic infections and sexually transmitted infections, and skills training for income generating activities. As of 2001, more than 65,000 clients (66% women) had received care and support through TASO and more than 4000 children had been assisted by its "orphan support" activities (US Department of State 2002).

Limitations to Community Responses

As with the successful examples above, the constraints communities and supporting CSOs face in their fight against HIV/AIDS also offer lessons. Like other development actors, communities and respective CSOs face formidable external and internal challenges. The following barriers are not uniform, and vary both temporally and geographically according to local environmental and cultural conditions, community cohesion and resilience, national support, etc. Some of these limitations stem from the AIDS epidemic itself, some from the very nature of communities and CSOs, some from relationships with external

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's initial AIDS awareness efforts included a moralistic short story published in the *Malawi News* entitled, "AIDS is a punishment from God" (Browne & Barret 2001: 27). Clearly, such perceptions impact community efforts to address the epidemic.

The sexual nature of HIV transmission, (principally through heterosexual intercourse in Africa), also has cultural bearing on community receptiveness to AIDS awareness and prevention initiatives (Gausset, Hunt 1996). Sex is deeply

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 the responsibility of the households (Baylies 2000).

Internal Vulnerability to AIDS

As with society as a whole, CSOs themselves are directly impacted by the epidemic (Manning 2002). Community CSOs are especially *susceptible* to the HIV infection, and vulnerable to its consequences. *Susceptibility* refers to the likelihood that CSO staff will contract HIV due to the very nature of their work, thus jeopardizing the organization as a whole. *Vulnerability* refers to the negative effects that the loss of staff will have on the organization's performance – which tends to be high for CSOs, due to their small size and limited resources. HIV infection and loss of staff and volunteers to AIDS not only affects CSO personnel, but it also imposes substantial financial and organizational costs on the CSO, decreasing productivity and effectiveness, while undermining staff morale. Turnover of staff and volunteers affects the CSO's institutional memory and overall ability to achieve its mission. As Manning (2002: 25) points out, "Community development work is particularly vulnerable, because it requires at least a year of "start-up" before a given community is ready to accept and work with a given individual; hence, the loss of any community facilitators would be highly disruptive and it would take extended time to replace these individuals." AIDS-affliction within a CSO can also affect public perceptions of the organization and, possibly, the availability of funding.

Resource-Restricted

"Communities are not closed, self-sustaining systems. The ability of communities – no matter how well organized and motivated – to meet all of their needs is limited" (UNAIDS 1997: 6). While community initiatives are ideally built upon local resources and knowledge, outside resources are necessary. This is especially true for HIV/AIDS; unlike traditional disasters, i.e. drought, for which there is a knowledge base, HIV/AIDS requires non-native medicines and training in treatment. Yet with the added burden of the epidemic on human and material capital, compounded by a poor national infrastructure and economy, the capacity for communities to attain these resources is often constrained. For instance, in sub-Saharan Africa, the "condom gap" is estimated at 2 billion per year (UNAIDS 2002: 87). If an AIDS awareness initiative disseminates information about the use of condoms or voluntary HIV testing, it will loose credibility if such resources are limited or absent. There is often a fixation on generating human resources for an initiative with a latent assumption that material resources will be available: this is not always the case, especially in resource-poor rural areas (UNAIDS 1999a: 42).

Operational & Planning Inefficiencies

Community initiatives from CSOs, especially those external to the community, often have poor economies of scale. Administrative and overhead costs sometimes use up the better part of their budget – in some instances, less than 20% of the budget actually reached the intended beneficiaries (Sabatier 1997). This is particularly true of larger AIDS NGOs. For

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 been characterized as "sporadic and patchy," rather than comprehensive and sustained: "Boutique" projects that provide services for one or two communities, while large areas of the countryside are neglected (UNAIDS 2001: 2). Furthermore, despite their immediate proximity to the people, and capability to reach a wider cross-section of the population than government or bilateral/multilateral agencies, CSOs can nevertheless exclude certain segments. In some instances they have neglected the landless and other marginalized peoples, thereby failing to reach the poorest of the poor (Carroll, 1992; Farrington and Bebbington, 1993). Even among CSOs that successfully promote participatory practices, qualitative aspects of development such as participation are not enough if projects fail to meet the urgent needs of the people. External CSOs and organizations often providing "patchwork" HIV/AIDS services that favor communities that are well-equipped with local CSOs while neglecting other deserving areas. Oftentimes, such shortcomings stem from a perpetual scarcity of funds and other resources. Consequently HIV/AIDS efforts often follow established channels of assistance where networks already exist, in efforts to minimize costs and focus their resources where they are most likely to bring about tangible and immediate improvements; (such efforts are subject to urban and language biases).

Risks of Scaling Up

With the heightened urgency of the AIDS epidemic, there is a tendency of many community initiatives to scale-up prematurely. Scaling-up includes expanding the population and/or area served (outreach), and/or acquiring new tasks and responsibilities (services). CSOs may attempt to scale-up to improve outreach and impact, and/or due to expectations and pressure from donors (discussed below). While diversification and increase of services is an important strategy, it is important that communities and CSOs do not 'trip up' when they scale-up, attempting too much and sacrificing quality for quantity (Edwards & Hulme, 1992). For example, the Get Ahead Foundation (GAF), a microfinance CSO in South Africa, spread itself too thin trying to impress USAID, resulting in a portfolio risk of 60%,, followed by major institutional (UN/OSCAL 2000). However, in some instances the benefits from economies of scale and increased outreach can mean greater overall improvement in serving the poor (Krishna et. al. 1997). When pursued, scaling-up requires restraint not to expand scope and pace too rapidly (Uphoff et. Al. 1998).

Coping with Initial Success

Oftentimes, the initial success of a community AIDS initiative is due to one person who spearheads an awareness-raising phase (as with the Tateni Home Care

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 exclusionary trends, especially for sex workers, AIDS orphans, and families of AIDS victims. Governance inside communities and CSOs should not automatically be assumed fair and democratic, as there are important questions as to who participates in decision-making, and how power is distributed (Baylies 2001; Edwards & Hulme 1996; Nyamugasira 1998; Rakodi 1999; UN/OSCAL 2002). Community safety nets, for instance, typically reflect entitlements embedded in the prevailing power hierarchy within a community and may overlook those most in need (Baylies 2001).

Even when participatory methods are employed in community health initiatives, they do not guarantee "pro-poor" results, and CSOs advocating participatory or democratic principles are not always "practicing what they preach" (Cornwall et al. 2000; Loewenson 2000; Rakodi 1999). This is particularly true in the health sector, where, "the paternalistic attitude of health workers and mystified nature of health information may discourage community inputs" (Loewenson 20001: 14). Research from the Overseas Development Institute (ODI) concludes that participatory development among NGOs is not easy (Bebbington and Theile 1993; Farrington and Bebbington, 1993; Wellard and Copestake 1993). Community CSOs commonly lack systems for internal monitoring and self-evaluation to ensure that they uphold principles of transparency and democracy for effective participation. "Despite this, and the common inclusion of 'participation' as both means and end in health policy, participation as a factor in itself is often poorly operationalized and evaluated, both in planning and implementing health systems" (Loewenson 2000: 14). In health care, participation models imported from external agencies, such as international NGOs, are often constrained in the "absence of democratic fora, limited access to information, lack or denial of rights" (Cornwall et al. 2000: 7). Furthermore, health workers may be poorly trained in organizing and supporting participation, due to the hierarchical nature of their profession and training, which typically takes place in urban centers distant from recipient communities.

Inter-CSO Competition

Civil society is not some amorphous, harmonious family, but is susceptible to the same political-economic challenges that characterize development itself: i.e. there are

real conflicts between groups in civil society (Gibbon 2001; Orvis 2001; Pearce 2000). With aid becoming more scarce in Africa, and increasing inequalities during globalization, competition and opportunism between CSOs is becoming more commonplace (Edwards, 1999; Wallace, 2002). This trend has been compounded by the enormous costs and heightened urgency of the AIDS epidemic. One specific outcome worth noting among CSOs is that of opportunism – when the mission of some *self-proclaimed* development CSOs is not actually *development*, although they do participate in the process. Such "opportunist" CSOs accept donor or state money and projects without any of the deep concern for socio-political change that characterizes more progressive CSOs (Bebbington and Thiele 1993; Edwards and Hulme, 1996a). These 'mercenary' CSOs (Malena, 2000) are market-driven and design products and services for the development purposes of donors or governments rather than citizens, and their proliferation in the development industry is a response to the increased availability of development funding for CSOs. In many cases, African CSOs that were formed under the pretext of assisting grassroots groups serve as survival strategies for a professional middle class, in ways that are more akin to a private business than a CSO (Hudock, 1999).

Donor Dependency

While external funding and support is essential in the fight against AIDS, dependency on donor funding entails substantial risk to the identity, autonomy, and thus mission of community organizations (Edwards & Hulme 1996ab; Hudock 1999 2000; Sabatini 2002). The aid industry is fraught with donor self-interests and political/economic priorities that often supersede the missions of CSOs (Abubakar 1989; Hankock 1989; Hudock 1999; Sabatini 2002). As the World Bank (2001a: 190) expresses, "Historically, aid flows have been determined more by political and strategic interests than by poverty reduction goals." Primary donors in the fight against AIDS include governments and bilateral/multilateral agencies, as well as other NGOs, especially those from the non-African countries. When the donor–CSO relationship is "too close for comfort" the latter risks losing the innovative, local attributes that make it an attractive alternative to mainstream development (Edwards & Hulme, 1996a).

The erosion of autonomy can commence with the adaptation of donor criteria for program implementation and monitoring, and include influencing appointments and the internal organizational structures of CSOs, as well as the introduction of western languages and logical framework (Hulme and Edwards 1997). In this process, CSOs become more attuned and accountable to the donors' needs rather than the people they are meant to represent and serve. As a result, PLWHA and AIDS-afflicted communities become *customers* rather than members; participation can be seen as instrumental rather than fundamental, and village groups can become branches rather than autonomous people's organizations. This can undermine the very community-based sensitivity associated with CSOs and erode their reputation for downward accountability as they are viewed as outsiders rather than "one of us".

At worst, the role of a CSOs can be relegated to *service provider*, filling the space created by the retrenching state, with very little participatory input and community empowerment for durable change (Manji 2000). For example, increasing CSO involvement in World Bank

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 more involved in large-scale service delivery they risk expending limited time and money coping with these bureaucratic layers. As Loewenson (2001: 14) warns, "Bureaucratization of health care can distance services from people and communities." When CSOs become standardized and "sectoralized" along official lines, they loose their comparative advantages over larger organizations (Fowler 2000). In her discussion of NGO involvement with World Bank projects, Malena (2000) identifies how the relationship can cause NGOs to over-extend their capacity, burdened with procurement of goods and services and accounting and reporting requirements that are geared towards large-scale interventions and private sector firms. As the World Bank (2003: 14) observes, "Conflict between donor desire for comprehensive monitoring and service delivery data and 'top down' planning and budgeting systems can result in burdensome monitoring/data collection efforts among field staff (NGO as well as governmental) with little payoff in terms of local decisions."

Pre-Determined Schedules

As communities scale-up their operations and interact with external CSOs, government agencies, and international organizations, they often encounter rigid guidelines that include pre-planned project deadlines that can build inflexibility into a project. These pre-determined schedules can impose an unrealistic and culturally incompatible pace for the local reality (UNAIDS 1997). For example, a series of tightly planned village training workshops based upon the busy schedules of outside facilitators driving in from an urban village can easily be disrupted by village funerals, marriages, or an unexpected rainfall. While the schedule may be rigid, the project cycle itself may be unrealistically short. Too often donors are unwilling to provide the long-term support and careful nurturing needed to attain the local capacity enhancement and gradual qualitative results that

characterize successful institutional development. Instead, development activities are often packaged in compressed project cycles that stress immediate or short-term quantitative targets and leave little time for innovation or lessons from experiences.

Competing Cultural Perceptions

The fight against AIDS in Africa is fraught with cultural prejudices and pursuant theories as to the cause and thus best solution of the epidemic (Gausset 2001). Prevalent external and indigenous explanations often contradict and compete with each other, undermining community involvement. For example, Western theories are often racially deterministic, based on prejudices about sexuality in Africa, placing the blame for the exponential spread of the epidemic on excessive promiscuity among African peoples (Hunt 1996, Gausset 2001). Consequently, remedies often fixate on behavioral change while overlooking other critical factors, such as poverty. On the other hand, Gausset (2001) shows that in rural Zambia people perceive the spread of AIDS due to excessive Western customs and urban life. AIDS is brought back to the village from towns and cities where people visit with prostitutes and do not follow the traditions and the old moral code. Both discourses have in common that they blame 'the other' for the spread of AIDS. The result is counterproductive: "It may transform the fight against AIDS into a fight between cultures, one culture trying to impose its own conditions on the others" (Gausett 2001: 512).

Uncooperative State

In addition to shaping the national infrastructure and public services, the State is the primary determinant of the political and economic climate in which communities and CSOs operate (Farrington & Bebbington, 1993; Loewenson & Whiteside 2001; UN/OSCAL 2002). However, examples like Uganda are the exception, and genuine partnerships between African states and CSOs can be quite challenging (Wellard & Copestake, 1993). Structural adjustment pressures towards democratization and decentralization has fragmented special interests and often leads to polarization, violence, and political paralysis. In this context, CSOs confront vested and competing interests from government bureaucrats and politicians who may oppose attempts to transfer power and resources to the local causes that CSOs support. As multilateral and bilateral donors bypass governments, the latter have made attempts to control CSOs and their resources. Government officials are often suspicious of social elements beyond their patronage and control, such as CSOs that receive external sources of funding. They can refuse to recognize these CSOs, excluding them from policy debates (Bratton 1989). In some cases, African governments actively attempt to restrain NGOs and nullify their impact on political reform (Fowler 1991; Cherrett et al 1995; Obi 1997).

International Political-Economic Constraints

Communities and CSOs do not operate in a political-economic vacuum, and the outcome of their anti-AIDS efforts are largely shaped by the policy context in which they unfold. International policy decisions have significant impacts on African State policy and resources affecting HIV/AIDS and, consequently, communities. It is well beyond the scope of this report to examine this contentious topic in-depth, yet four policy issues merit mention:

- **SAPs.** Critics assert that the structural adjustment programs (SAPs) of the World Bank and IMF prioritize fiscal goals, such as debt reduction, over human welfare priorities, such as Africa's AIDS epidemic (Cheru 2002;

Poku 2001). SAP emphasis on fiscal discipline and restrictions on government health expenditures, contribute to high prevalence of HIV infections by reducing funding for the treatment of STD and blood screening, proper hygiene practices in clinics, health education programs, and other health related expenditures. In many countries, such as Tanzania, cutbacks in government health budgets resulted in the imposition of "user fees" for primary health care (Nnko et al. 2000).

- **Foreign Debt.** Closely related to SAPs, is the huge debt owed by African countries to bilateral donors and multilateral institutions (Baylies 2000; Poku 2002; Cheru 2000, 2002). Their relationship to SAPs is that in order to receive help in servicing their debts, countries must implement the structural adjustment reforms. Although the heavily indebted poor countries (HIPC) debt initiative of the World Bank and IMF attempts to relax debt constraints, debt servicing continues to consume a disproportionate amount of resources that could otherwise be directed towards the AIDS epidemic. As USAID (2002: 168) points out, "*These debt burdens mean that annual debt-servicing obligations can undermine countries' social spending, including that required for their HIV/AIDS and orphans responses. In 15 African countries in 2001, governments were still spending more on servicing debts than on the health of their citizens*."
- **Official Development Assistance (ODA).** As the AIDS epidemic escalated during the 1990s, ODA to sub-Saharan Africa steadily declined, reaching its lowest point in two decades in 1999 (Loewenson & Whiteside 2001; O'Connell & Solundo 2001; Whiteside 2002). ODA flow to countries worst affected by AIDS fell by a third between 1992 and 2000, from US$36 per person to just US$20 (UNAIDS 2002: 171). The importance of this source of funding is reflected in the fact that international donors accounted for approximately two-thirds of the budget for HIV/AIDS spending in 2002 in low- and middle-income countries (UNAIDS 2002: 165). While it is true that many governments and multilateral donors are placing an increasing proportion of their shrinking ODA into AIDS, the overall magnitude of the cuts in ODA nevertheless impacts multisectoral development initiatives to mitigate the AIDS epidemic.
- **Globalization and Pharmaceutical Patents.** The impact of globalization and international trade policy on Africa is poignantly illustrated by the availability of antiretroviral drugs (ARV), raising serious issues of credibility for global health governance and the global market system (Heywood 2002; Poku 2002; Ostergard 2002; Thomas 2002). Since the discovery of antiretroviral drugs (ARV) in the early 1990s, World Trade Organizations patent rules (codified as the agreement on Trade Related Intellectual Property Rights – TRIPS) have allowed pharmaceutical companies to patent these life-sustaining drugs and price them beyond the means of all African health systems. Of the 28.5 million people living with AIDS in Africa, fewer than 30,000 people benefited from ARVs in 2001 (UNAIDS 2002: 22). As Poku (2002: 2920) observes, "This has produced a perverse position where these drugs are more expensive in the developing world – where they are most needed."

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 context. It is important to keep in mind that, "A uniform global approach might not be suited to the extreme geographic and epidemiological heterogeneity of the pandemic" (Cock et al. 2002: 57).

Acknowledge & Demystify HIV/AIDS

At all levels, it is imperative to demystify HIV/AIDS and acknowledge its current and potential devastating impact in sub-Saharan Africa. The effect of the epidemic at the local level is profound, but often neglected in research and policy decision making. Society at large must accept the responsibility for the epidemic, which requires that people understand its urgency and the consequences of inaction. **Better understanding of HIV/AIDS will engender receptivity to HIV testing and screening, so that people will not wait until they are ill to confront and deal with the epidemic. And while addressing the sexual transmission of HIV is critical, people must also understand the other avenues for the spread of HIV through bodily fluids, such as un-sterilized circumcision or the transmission of HIV to care givers without rubber gloves.** Aid awareness education and consciousness-raising demystifies the virus and breaks down associated stigmatization, discrimination, and other cultural barriers to effective action. This fosters an atmosphere in which community members feel more able to speak out and mobilize towards issues regarding HIV/AIDS. "In AID-competent communities, it is predicted that quality of life will start to improve from the point in time that the community acknowledges the problem collectively and begins to take action" (Lamboray & Skevinton 2001: 617).

Maintain a Multi-Sectoral Perspective

The AIDS epidemic in sub-Saharan Africa has clearly demonstrated that it is a systematic problem, closely connected with poverty. HIV/AIDS exacerbates existing development problems, but we should not forget that problems due to the epidemic are not specific to AIDS alone. As Haddad and Gillespie aptly advise: "Development practitioners should not be blind to the threat of HIV/AIDS, but neither should they be blinded by it" (Haddad & Gillespie 2001: 497). Top-down planning and programs, "typically focused far more on prevention and care than on the livelihood security of affected households and their need for

assistance toward poverty" (Baylies 2002: 620). **Food insecurity, for example, is a key factor in the vicious poverty cycle that exacerbates the sub-Saharan Africa's AIDS epidemic. As we have seen, low nutritional status is critically linked to susceptibility to the HIV virus and opportunist infections that are associated with AIDS.** Research on AIDS prevention in sub-Saharan Africa suggests that mitigation is not receiving the support and attention it deserves (USNAIDS 199a: 47). The AIDS epidemic is not simply about public health, and if communities are to be truly supported, the range of interventions must be broadened from treatment and care to prevention and mitigation. HIV/AIDS issues must be included in core areas of development policy, such as food security and public education, and involve the multiple ministries representing these sectors. Likewise, if the epidemic is to be contained at the community level, assistance must not be based solely on the presence of HIV/AIDS, but also on poverty indicators that reflect future vulnerability to the epidemic.

Exercise Foresight

Both the urgency and the long-term character of sub-Saharan Africa's AIDS epidemic must be considered in planning and supporting community responses. Clearly, the magnitude of the AIDS crisis warrants a timely response. In its progress report, the World Bank (2003: 10) asserts, "Funding 'good' programs quickly is more important than delaying action to identify an optimum cluster of 'best practices', which is likely to prove futile in the majority of cases and runs the risk of excluding important activities which are not yet fully understood." Yet at the same time, it can be counterproductive to compress community assistance into rigid, pre-determined project cycles that are culturally inappropriate. Community interventions need to be designed and assessed not only in terms of their ability to address the immediate impacts of the epidemic, but also their ability to reduce future vulnerability to HIV/AIDS and its consequences (Haddad & Gillespie 2001). Community initiatives must anticipate the prolonged impact of the epidemic and plan strategies to maintain momentum and avoid resource and psychological exhaustion – "burn-out" (UNAIDS 1997). Foresight also includes planning in communities where HIV/AIDS prevalence is still low, because there is nevertheless a need to establish preventative mechanisms, such as AIDS awareness campaigns, to reduce vulnerability to the epidemic, and to mitigate its potential impact. Living so close to the "riverbank of AIDS", less-affected communities should not wait until they are drowning in the floodwaters to take preparative action.

Identify & Utilize Preexisting Knowledge, Skills, and Practices.

Preexisting resources in a community – skills, knowledge, and practices – are valuable tools in the fight against AIDS. Community initiatives that build upon traditional systems are more efficient as they typically require less training and input from external sources, more relevant as they are readily understood and accepted by community members, and more sustainable as people are quicker to identify with, adopt, and take ownership of such initiatives. **As we have seen, the incorporation of traditional healers in AIDS awareness initiatives is culturally compatible and thus effective. Likewise, identifying and utilizing nutritious vegetables and herbs indigenous to local areas can play a key role in mitigating food insecurity and subsequent vulnerability to AIDS opportunist infection, rather than importing more expensive foodstuffs.**

Lessons learned from other societal crises should be brought to bear in designing community mitigation strategies, and outside intervention should be aimed at enhancing and mobilizing capacities inherent to communities, such as the traditional coping responses of extended families and their communities. External assistance must refrain from imposing their cultural paradigm on localities, which could "alienate the local populations whose cooperation is crucial if we are to prevent the further spread of AIDS" (Gausset 2001: 517). Instead, efforts must be made to understand the local beliefs and practices, and to adapt outside knowledge so that it can be understood and appreciated in local terms. **Special efforts ought to be made to portray positive moral traditions and practices that support the fight against AIDS, so that people not only see what is forbidden, but what good can come from their cultural heritage.**

Engage Community Members

When people are able to participate in identifying their own problems, setting their own priorities, and designing locally appropriate solutions, ownership and personal investment is enhanced, and cultural compatibility and thus sustainability of the initiative as a whole is greater. The participation of well known, respected, and/or connected community members further increases community motivation for and the success of an initiative. For instance, PLWHA participation in AIDS awareness campaigns helps to ensure that education is relevant – people can relate to a message coming from someone in their own community – and it also serves as a positive coping mechanism for PLWHA, empowering them with a purpose and meaning. Community involvement can lead to an *empowerment cycle*, in which successful community participation creates a multiplier effect: "If problem-solving and innovative capacities are well instilled, there will be greater local responsiveness to *new problems* that might arise after the aid program has moved on" (Pettit 2000: 57). Committees are best placed to identify local needs and priorities, such as needy families, vulnerable children and orphans. There is need, therefore, to involve communities in developing assessment systems to determine the extent of the problems, raise awareness, and promote informed decision-making. Such involvement also informs people in a meaningful way that demystifies AIDS. Process-oriented approaches in which priority setting, timelines and outcomes, and monitoring and evaluation unfold in consultation with the community also helps to counterbalance the often-alienating character of external health interventions, which tend to be top-down and hierarchical.

Empower, Rather Than Overburden, Communities

The recognition and promotion of community initiatives in the fight against HIV/AIDS should not distract policies and expenditures from examining the underlying systemic economic, social, and political causes of the poverty in which the epidemic flourishes (Baylies 2000). Focusing too heavily on the local tends "to underplay inequalities and power relations as well as national and transnational economic and political forces" (Mohan & Stokke 2000: 247). Political questions of resource allocation are fundamental in a global context where 80% of the resources targeted for HIV/AIDS-related expenditure are in regions accounting for less than 5% of the pandemic (WHO 2001: 1). Communities are increasingly forced to take on a larger share of the burden of AIDS through under-resourced and under-supported programs, as is often the case with home and community-based health care programs (Rugalema

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 romanticize or over-estimate Africa's civil society, but to recognize the distinctly political and economic realities that shape African civil society and adopt development strategies accordingly" (UN/OSCAL 2002: 13). 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 especially paramount in the context of HIV/AIDS, where social stigmatisation, discrimination, and competition for increasingly scarce resources strains social and organisational cohesiveness. CSOs are not automatically democratic and participatory, but must actively strive to include all people in program planning and implementation, regardless of gender, race, nationality, religion, age, or income.

Strengthen Capacity & Resource Base

While the autonomy of a community CSO is essential, so is the need for external assistance to confront AIDS. Sub-Saharan African communities are limited in their capacity and resources, largely due to material poverty and the magnitude and duration of the AIDS epidemic. The pandemic is placing an enormous strain on the traditional coping mechanisms of the extended family and community, steadily eroding capacity not only to care for AIDS victims, but the very survival of households and communities. As Haddad and Gillespie (2001: 508) warn, "Capacity as a constraint to effective interventions is often overlooked with disastrous consequences, and the fact the HIV/AIDS directly undermines this capacity makes it even more important to assess what remains." Research shows that community-based initiatives relying on external support have been very responsive to the needs of those affected by AIDS (UNAIDS 1999a: 45). Local CSOs should be assisted in strengthening both their own capacity and in undertaking activities to strengthen the capacities of other collaborating organizations. As the epidemic systematically destroys human capital and undermines organizational structures, there is a need not merely for a strengthening of capacity but also for its maintenance. In this process, recognizing the CSOs "lifecycle" in its organizational maturity can ensure that CSOs are not pressured to scale up too quickly, which can lead to the pre-mature withdrawal of support (Hudock 1999; Uphoff et. al. 1998).

Research & Relevance

Effective, external assistance to organized community efforts largely depends on an understanding of existing social and organizational patterns, and their strengths and weaknesses. Background research and needs assessment are crucial to identifying cultural norms, values, and perceptions

TABLE 3: CSO Planning for & Reponding to HIV/AIDS

Step One	⇨ Build HIV/AIDS awareness and knowledge.
Step Two	⇨ Evaluate potential impact on organization.
Step Three	⇨ Evaluate and revise policies.
Step Four	⇨ Plan for and mitigate human resource implications.
Step Five	⇨ Plan for and mitigate the financial implications.

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 likely to instill ownership and relevance for the project design. Furthermore, the outcome will be more relevant. For example, income-generating activities for community women may seem like a worthwhile activity to introduce, but their input will be needed to determine whether it will actually empower them, or double-burden them with additional work.

Keep it Simple

While a multi-sectoral perspective is essential in community initiatives, this should not imply that a community initiative or organizations should "bite off more than it can chew." Community CSOs need to be weary that they don't "trip-up" while attempting to scale-up before they have developed sufficient institutional capacity. Short-term, small-scale, and achievable objectives are a good initial strategy for long-term participation. If strategies are well designed and involve as many people as possible, timely and visible achievements will help to sustain people's interest and confidence in initiatives, encourage more participation, and show people that collective action can actually succeed. On their part, outside donors need to be more flexible with their funding in support of local initiatives, providing smaller grants rather than one large grant. The present emphasis on large-scale grants and projects undermines small, local efforts. Also, external donors need to understand the CSOs 'lifecycle' in its organizational maturity so that they do not unintentionally pressure CSOs to scale up too quickly, or prematurely withdraw support (Hudock 1999; Uphoff et. al. 1998).

CSO Self-Maintenance

Community CSOs themselves are not invulnerable to the impact of HIV/AIDS, and thus must take precautions to effectively sustain their mission. Therefore, "organizations must recognize, plan for, and take steps to minimize the impact of HIV/AIDS on themselves and their work" (Manning 2002: 5). CSOs are advised to build organizational resilience to HIV/AIDS, which includes AIDS awareness, impact, and policy planning: TABLE 3. Planning includes AIDS prevention programs for employees and volunteers to build awareness and knowledge, and nutrition and treatment provisions for HIV-positive workers to minimize decreased productivity and effectiveness (Manning 2002).

CSO Monitoring & Evaluation

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 relationship to the State, it also presents new possibilities for negotiation and collaboration: BOX 1. A mutually supportive partnership in development could benefit both CSOs and governments. In addition to financial support, governments can provide technical assistance and research in the fight against AIDS that is typically beyond the reach of communities and their respective CSOs due to their limited budgets and lack of access to scientific and technical information. **For example, while rubber is a raw material in sub-Saharan Africa and products such as rubber sandals and tires are already produced in certain countries, the State can direct such industrial technology towards the production of much needed**

condoms and rubber gloves. The State can also help uphold a fair and regulatory environment, judicial system, and advantageous tax incentives for community CSOs. CSOs, in turn, can help address development priorities that are on the national agenda, reducing the burden of the state. Co-operation with the government may also allow community CSOs to magnify their impact on government policy, promoting more functional links to direct resources for the poor.

Prioritize Local Autonomy & Accountability

Given the tendency for many community initiatives and organizations to be eclipsed or co-opted by the agenda of external donors, CSOs, and governments, special emphasis must be placed on maintaining autonomy and accountability. Community CSOs have a potential far greater than mere "service providers", and their activity "should not be confined to filling the space of the retreating state, or to the agendas of more powerful development actors which CSOs depend upon for funding" (UN/OSCAL 2002: 13). Many of the very attributes that distinguish community CSOs from larger development organizations – flexibility, speed of response, and ability to innovate – shouldn't be sacrificed in their relationships with external organizations. Donors, governments, and external CSOs should not impose their organizational norms, values, and management systems, but acknowledge and utilize pre-existing practices whenever possible. Likewise, they should avoid "blueprint" models for project planning and management that straightjacket a community CSO's ability to experiment, modify, and better adapt to and serve specific localities. Cumbersome bureaucratic procedures, predetermined and time-bound project cycles, and quantitative short-term targets, rather than qualitative long-term investments, sacrifice the very comparative advantages CSOs offer the development community. Due to the dynamic and prolonged nature of the Aids epidemic, it is especially important that community CSOs remain flexible, "continually in a learning mode, identifying problems and weaknesses, experimenting, evaluating, and modifying" (Uphoff et al. 1998: 208).

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).

Enabling, Not Disabling, Partnerships

Partnerships between communities and governments, NGOs, and international organizations can play an essential role in channeling resources, funds, training, and technical assistance to communities and their respective organizations: BOX 1. Yet caution must be exercised with the use and practice of *partnership*. Like most development jargon, this term has acquired its own mythic proportions that are too often far from the truth (Fowler 2000a,b,c; Hudock 2000; Malena 2000). Partnership is an idealized notion that must be qualified with the understanding that conflict of interest is inevitable: the challenge is how to resolve this conflict constructively in order to enhance mutual understanding, trust, and benefit. As already noted, external partnerships can threaten community autonomy and accountability. Civil society partners must not lose sight of the question, "Is this [partnership] really strengthening civil society, or merely an attempt to shape civil society in ways that external actors believe is desirable?" (Hulme & Edwards 1997: 277).

When abused, partnerships can be used as a facade to disguise underlying political-economic agendas of more powerful *partners*. However, as well noted, there are clear limits to what communities can do on their own in the fight against AIDS – underscored by the multi-sectoral nature of the epidemic, its debilitating magnitude and duration, and strained community resources. Thus, communities and their respective CSOs must cultivate skills to negotiate externally with other communities, various levels of government, private companies, banks, donor agencies, and other relevant institutions (Cornwall et al. 2000: 7). Partnerships are a *necessary risk* that communities and their respective CSOs must carefully negotiate to accomplish their mission. Likewise, external partners must pursue enabling rather than disabling relationships with community civil society. Some guiding questions to ask when establishing and maintaining community/CSO partnerships include:

- **What is the primary reason for community/CSO partnership?** Don't lose sight of basic objectives, which does not necessarily equate with the CSO, but the CSO's stated mission, i.e. the target population or cause.
- **What is the domestic/local context in which the community/CSO operates?** Don't loose sight of *the big picture*, i.e.

program relevance, political-economic constraints, pre-existing knowledge/skills.

- **What is the community/CSO capacity?** This allows partners to better shape expectations and working relationships with the CSO, and to avoid pressuring a community organization from scaling up before it is ready.
- **How can the partnership better serve the community/CSO in its evolution?** Better understanding of the CSO can inform appropriate organizational planning, as well as assistance, including training, technical assistance, media and publicity, diplomatic intervention, and meaningful inclusion in program design, implementation, and monitoring.

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