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A COLLABORATIVE PROJECT

COMMUNITY INVOLVEMENT IN PREVENTION OF MOTHER-TO-CHILD TRANSMISSION (PMTCT) INITIATIVES

Women, Communities and the Prevention of Mother-to-Child Transmission of HIV: Issues and Findings from Community Research in Botswana and Zambia

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The International Center for Research on Women

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ICRW

POSITIVE ACTION

Glaxo Wellcome in Global Partnership with HIV/AIDS Communities

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Ginny Bond and Phillimon Ndubani, in association with Laura Nyblade. *Formative research on mother-to-child Transmission of HIV/AIDS in Zambia: A report of focus group discussions held in Keemba, Monze, November 1999.* June 2000.

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Glossary of Acronyms

AIDS	Acquired Immunodeficiency Syndrome
ANC	Antenatal clinic
AZT	Azidothymidine (zidovudine)
FGD	Focus group discussions
HIV	Human Immunodeficiency Virus
MCH	Maternal child health
MTCT	Mother-to-child transmission
PLWHA	Persons living with HIV/AIDS
VCT	Voluntary counseling and testing

Executive Summary

Across the globe, more than one million children are currently infected with the HIV virus and at great risk of dying from AIDS (UNAIDS 1999b). The major cause of HIV/AIDS among children under 15 years of age is the transmission of HIV from mother to child during pregnancy, delivery, and breastfeeding. This problem is particularly prevalent in urban centers in southern Africa, where rates of HIV among pregnant women tested anonymously at antenatal clinics can be as high as 20-30 percent (UNAIDS 1999a).

Clinical trials in several countries have shown that mother-to-child transmission (MTCT) of HIV can be dramatically reduced through the administration of a short course of Zidovudine (commonly known as AZT) to pregnant women. The United Nations Children's Fund (UNICEF), in collaboration with the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO), has initiated pilot projects in 11 African countries to provide mothers with both a short course of AZT and information on alternatives to breastfeeding. However, these projects—in large part due to time constraints—have been conducted with little consultation with or feedback from residents of the targeted communities.

For this reason, in 1999, GlaxoWellcome and UNAIDS jointly funded two formative research studies in Botswana and Zambia on the perspectives, needs, and preferences of women and communities regarding the MTCT of HIV. Carried out by the International Center for Research on Women (ICRW) in collaboration with in-country partners, the main objective of the studies was *to obtain information and data that could be used to improve the effectiveness and acceptability of messages and services for MTCT prevention on the community level.* To do so, focus group discussions were held with diverse residents of one community in each country. In-depth interviews were also conducted with women in Botswana, where an MTCT program was launched in two cities in 1999. Preparations for establishing an MTCT program are currently underway in Zambia.

Research findings reveal that levels of knowledge about HIV transmission and HIV and MTCT prevention range widely among residents of Bontleng, Botswana. In contrast, residents of Keemba, Zambia were well informed about both the transmission and prevention of HIV, but knew little about MTCT due to a lack of a prevention program. In both countries, the main source of information about health issues in general, and HIV/AIDS in particular, was talks given at antenatal and well-child clinics. Since men and community elders do not usually frequent clinics, they know less than women do about both HIV/AIDS and MTCT.

In addition, members of both study communities emphasized that people living with HIV/AIDS (PLWHA) suffer from stigma, discrimination, and isolation. This pattern in turn deters many residents from being tested for HIV. With regard to MTCT specifically, strong cultural norms support breastfeeding and inhibit HIV-positive women from considering other infant feeding choices.

By actively listening to the voices of individuals, it is possible to gain insight into how to design and deliver interventions that can be widely utilized and effective in saving the lives of adults, children, and infants across the globe. This study underscored how local communities can benefit from the research process by gaining knowledge about HIV/AIDS and MTCT and confronting difficult issues. The primary conclusion of the study is that *MTCT prevention programs have an urgent need for the information and perspectives that emerge from community dialogue about HIV/AIDS and MTCT prevention.*

The studies yielded several recommendations. In the area of community education, it became clear that efforts should emphasize participant feedback and quality control mechanisms in order to ensure that communities understand the information they receive on HIV, MTCT and related issues. Effort should be made to ensure that service providers understand the relative (rather than absolute) effectiveness of AZT in preventing HIV transmission, the links between MTCT and breastfeeding, and the potential risks of other infant feeding methods.

In addition, counseling services should be extended beyond antenatal clinics so that a broad community audience can be reached. Men and elders should be particularly targeted with information on and opportunities to discuss both HIV and MTCT. Support services should also be increased for the families of PLWHA in order to reduce the burden of care and encourage community residents to seek testing and counseling.

Background

To date, AIDS has caused the deaths of more than three million children worldwide, while more than one million more are currently infected with the HIV virus that causes the disease (UNAIDS 2000). Among children under 15 years of age, the major cause of HIV/AIDS is the transmission of the HIV virus from mother to child during pregnancy, delivery, and breastfeeding. In the absence of preventive measures, the risk that an infant of an HIV-positive mother will be infected with the virus ranges from 25-35 percent in developing countries (UNAIDS, 1999a).

Although Africa accounts for only 10 percent of the world's population, 90 percent of all HIV infected people live in the region (UNAIDS 2000). In urban areas in southern Africa, rates of HIV infection among women attending antenatal clinics (ANC) can be as high as 20-30 percent (UNAIDS 1999b). Until recently, strategies to prevent infants from becoming infected with HIV have consisted primarily of recommendations on the primary prevention of infection of the mother prior to and during pregnancy, as well as information about breastfeeding. Other strategies have included family planning to prevent pregnancy itself, or pregnancy termination where this option is legal and available. In addition, specific guidelines exist on practices to reduce the likelihood of transmission during labor and delivery.

In an increasing number of countries, however, additional options for MTCT prevention are now available. Recent trials in Thailand (Shaffer 1999), Burkina Faso, and Côte D'Ivoire (Dabis 1999) have shown that giving a short course of Zidovudine (commonly known as AZT) to pregnant women reduces the risk that HIV will be transmitted from a mother to her child to below 10 percent – representing a 50 percent reduction below normal rates – as long as the mother does not breastfeed. More recently, a study in Uganda revealed a similar effect when Nevirapine was given to the mother at the onset of labor and to the baby 72 hours after birth (Guay 1999).

The Need for Qualitative Research

As more pregnant women throughout Africa become infected with HIV prior to and during pregnancy, prevention of transmission of the virus to infants has become an increasingly important component of many national AIDS programs. Following a 1998 meeting, the United Nations Children's Fund (UNICEF), in collaboration with the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO), began the process of initiating pilot projects in 11 African countries to provide mothers with both a short course of AZT and information on alternatives to breastfeeding. It was soon observed, however, that these projects—in the context of a raging epidemic and time constraints—were being conducted with little consultation of or feedback from residents of the targeted communities.

It is critical that communities have a voice in solving health problems that affect them. This is especially true for programs – such as MTCT prevention – that can have an enormous impact on the lives of women, their partners, and their extended families. The benefits of many technologies (prescription drugs and a required blood test in the case of MTCT) are often overshadowed by conflicting community norms, values, and beliefs. The issues surrounding MTCT are particularly challenging because of the complexity of the HIV transmission process and the stigma associated with HIV/AIDS. Because of the sensitivity of MTCT and the nuances of diverse cultures and communities, talking to women and other members of a community is a vital step in the process of preventing HIV transmission to infants.

Research Objectives

The study described in the following pages gathered information on the perspectives, needs, and preferences of women and communities regarding MTCT of HIV. Funded by GlaxoWellcome and UNAIDS, research was conducted between October 1999 – May 2000 in two African countries, Botswana and Zambia.

The central goal of the study was *'to obtain information and data that could be used to improve the effectiveness and acceptability of messages and services for MTCT prevention at the community level.* To achieve this goal, the research process documented the beliefs, views, wishes, and needs of women and their communities regarding the MTCT of HIV, counseling and testing, treatment and infant feeding options.

Specifically, the study sought to gain insights about what women and communities know about MTCT and whether they define it as a problem. An answer to why women often decline to participate in voluntary counseling and testing (VCT) – a critical first step in MTCT prevention programs – was also sought. The research was designed to provide insight into the community context in which MTCT prevention programs exist, and to thereby contribute to the design of successful strategies.

Study Partners

ICRW worked with the Society for Women and AIDS in Botswana (SWAABO), an NGO established in that country in 1995 to provide HIV/AIDS education, support, and prevention programs to women throughout the country. SWAABO has experienced an increased demand for information about MTCT. In turn, the organization has needed data about community beliefs, perceptions, and requirements related to MTCT in order to improve the design and focus of its education efforts.

In Zambia, ICRW worked with the MTCT Research Team of the National MTCT of HIV Working Group. Appointed by the Minister of Health in August 1998 to offer technical assistance and advice to the Government's Central Board of Health, the working group conducts research and develops country-specific interventions and strategies related to the MTCTof HIV.[1]

[1] The membership of the working group is diverse in order to reflect the various populations that are involved in issues related to HIV. Members of the group represent people living with HIV, HIV counsellors, doctors, nutritionists, biologists and other scientists, policymakers, and bilateral and multilateral agencies.

The Study Sites

Although in the same region of Africa, Botswana and Zambia differ in important ways. Botswana's Gross Domestic Product, literacy rate, and health infrastructure are all significantly better in comparison to Zambia. At the beginning of the research study, the government of Botswana was already providing MTCT prevention services to pregnant women through a program established in April 1999, whereas Zambia was in the preparatory stages of doing so.[2] In this context, Botswana provided an opportunity to learn from and explore the experiences of women participating in an MTCT program. In contrast, the study in Zambia allowed researchers to gather data that could contribute to the design of a new program.

In Botswana, nearly 36 percent of adults are now infected with HIV, representing more than a tripling of the adult prevalence since 1992 (UNAIDS 2000). In Botswana in 1998, the median rate of HIV infection among women attending antenatal clinics (ANC) was 43 percent in urban and 30 percent in non-urban areas (UNAIDS 2000). The research study focused on Bontleng, a low-income urban community within the city of Gaborone in Southeast Botswana, where residents have access to the government MTCT prevention program through a clinic with excellent infrastructure.

As in most of the sub-Saharan region of Africa, HIV/AIDS is a rapidly growing problem in Zambia. More than one in four adults living in cities is infected with the HIV virus, as well as one in seven adults in rural areas (UNAIDS 2000). Heterosexual contact and MTCT account for most new HIV infections in the country. In Zambia in 1998, median rates of HIV infection among women tested at ANC were 27 percent in urban and 14 percent in non-urban areas (UNAIDS 2000).[3]

Before the current study was launched, the Zambian MTCT working group had selected three sites for implementation of the UNICEF pilot program, and had already conducted formative research at one site. The group requested that ICRW, in collaboration with the MTCT research team of the working group, conduct research in Keemba in the South-Central Monze district, with the intention of feeding data directly into the development of a broad communication strategy for an MTCT prevention program. Keemba is a rural community where residents have access to basic clinic services. At the onset of the study, several meetings with community elders had been held to discuss the establishment of an MTCT prevention program.

Methodology

Focus group discussion (FGD) was the principal method of data collection in both countries. In addition, several in-depth interviews were conducted with women in Botswana to explore their experiences with the existing MTCT prevention program.

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[2] In 1999, Botswana launched pilot MTCT prevention projects in all government health clinics in the cities of Francistown and Gaborone. This was accomplished by training health workers in counseling and obstetric practices; strengthening systems at laboratories; providing supplies to conduct HIV tests; and purchasing and distributing AZT and breast milk substitutes. These activities were implemented collaboratively by the Botswanan government, UNICEF, and the Harvard AIDS Institute. Zambia recently launched an MTCT program in the community in Lusaka, and is in the process of expanding to other pilot sites this year, including Keemba.

[3] In comparison to Botswana and Zambia, several African countries have much lower rates of HIV. For example, in Ghana in 1998, the median prevalence among women tested at antenatal clinics was under 4 percent in both urban and non-urban areas (UNAIDS 2000).

All moderators and interviewers were trained to use FGD and in-depth interview guides developed collaboratively by ICRW and the in-country research partners. The guides were pre-tested and text analysis was used to analyze data from both communities. Methodological aspects specific to the work in Botswana and Zambia are described below.

It should be noted that the study was conducted in only one location in each country. Contrasting findings between the countries may therefore be attributable to urban-rural differences to at least the same degree as national or cultural variations. In addition, the study methodology would have ideally been complemented by other methods in order to achieve the benefits of triangulating data. However, the studies were designed to increase understanding of the issues surrounding MTCT prevention in relation to women and their communities, and the results certainly reflect the views of many local residents. Although the same views are likely to be found in other communities, a study conducted on a national scale would certainly yield important variations.

Botswana

Moderators conducted a total of 11 FGDs with 8-12 participants in each. Participants included people who are most closely affected by MTCT programs and who play a significant role in shaping community norms and supporting individuals in making decisions related to MTCT prevention. Because of the complexity and sensitivity of the issues involved, discussions were sometimes extended to two sessions. In several cases, it proved difficult to bring together the same group of people twice, prompting moderators to involve different participants for the second round of discussions.

The Botswanan sample included several different groups:

- breastfeeding women between the ages of 18-30;
- breastfeeding women 30 years of age or older;
- pregnant women between the ages of 18-30;
- men between the ages of 18-30;
- men 30 years of age or older; and
- male and female community elders.

Different methods were used to select focus group participants. The research study was announced and described to women attending ANC and well-child sessions at Bontleng Clinic and a request was issued for volunteers to attend discussions in the evenings at the Bontleng Community Center. Men were selected through male contacts in the community, who announced the study in neighborhoods and asked fathers to volunteer. Community elders were brought together by both the local councilor (politician) and the chairperson of the Village Development Committee. Focus group discussions were held at a time and place that were convenient for the participants, usually in the evenings or on the weekends at local gathering places.

The research team worked with local clinic nurses to identify women who had participated in MTCT prevention programs and were willing to be interviewed. Ten in-depth interviews were then conducted to learn why they had or had not chosen to participate and how they were responding to programs. As expected, finding women who were willing to be interviewed was extremely difficult because of the mobility of the population between urban and rural areas and within Gaborone, busy work and home schedules, and the sensitive nature of MTCT and HIV/AIDS. Because many women did not want to be interviewed, the composition and number of interviews in the final sample differed

from what was originally planned.[4] None of the women agreed to have their interviews taped and one terminated the interview before it was completed.

In addition, interviews were conducted with providers, specifically one semi-structured group interview with family welfare educators based at clinics and working in the community and two semi-structured individual interviews with nurse-midwives who provide counseling for the MTCT prevention program.[5]

In-depth interviews conducted in Botswana

Level of MTCT program participation	**Number of women**
Refused HIV testing	2
Wanted to consult partner first; never returned	1
Accepted HIV test; never returned for results	2
Was tested; got results (HIV-negative)	1
Was tested; took AZT; chose to breastfeed	1
Was tested; took AZT; chose to formula feed	3

Zambia

Moderators conducted 15 FGDs with 8-12 participants in each. In order to address complex and sensitive issues and to allow the maximum time for discussion, the FGD guide was divided into two sections to be addressed in separate sessions. Thirteen of the focus group discussions were held in Keemba near the health center. Two were conducted at Chuungu village at an outreach health post where clinic staff conduct ANC, well-child, and outpatient clinics once a month. Due to time constraints, the groups in Chuungu and the community elders were interviewed using a condensed version of the FGD guides.

The Zambian sample included several different groups:

- breastfeeding women in Keemba;
- breastfeeding women in Chuungu;
- pregnant women in Keemba;
- pregnant women in Chuungu;
- men in Keemba; and
- male community elders in Keemba (i.e., ministers, church elders, community health workers, and village health committee members).

The female focus group participants were selected by clinic staff from the pool of women who attended an ANC or maternal and child health (MCH) program at the health center on the days that focus group discussions were scheduled. Women were asked to volunteer and information about their age and residence was collected. The study team then randomly selected participants based on their

[4] See Botswana country report for details.

[5] The study remained focused on the perspectives of women and their communities. An evaluation of the pilot MTCT programs that was recently (June 2000) conducted by the Ministry of Health/Family Health Division provides a much fuller account of provider perspectives on the program.

place of residence to ensure that the women selected came from different parts of the Keemba clinic catchment area. Participants in the Chuungu focus groups were recruited by a community health worker, who was given a random list of women registered for ANC and well-child clinics at the health post. Men were selected through announcements about the study made at local churches asking those interested in participating to report to Keemba health center.[6]

Findings and Discussion

This section synthesizes, compares, and contrasts key findings from the two communities studied.[7] Results are divided into two areas of concern. First, findings on the context in which women make decisions about MTCT prevention are reported. The data in this section are related to the perceived extent of HIV/AIDS; knowledge and beliefs about HIV/AIDS; sources of information about HIV/AIDS; care and support for PLWHA; and knowledge and beliefs about MTCT and its prevention.

Second, community residents' perceptions of and participation in the central components of current and planned MTCT prevention programs are presented, including counseling and testing, drug treatment during pregnancy and infant feeding. This section discusses the knowledge, perceptions, issues, and desires of study participants in relation to these issues.

Summary of Key Findings

- Study participants in Botswana revealed a wide range of knowledge and understanding about HIV transmission and HIV and MTCT prevention. Those who knew about the MTCT prevention program recognized that it can save the lives of babies, but questioned why little was being done to help mothers.
- In contrast, the groups in Zambia were well informed about HIV/AIDS, but had yet to be exposed to the concept of and issues surrounding MTCT.
- In both countries, health education talks at antenatal and well-child clinics were the primary source of information about health issues in general, and HIV/AIDS in particular.
- Men and community elders rarely utilize clinic services, a factor that contributed to women being better informed than men about all aspects of HIV/AIDS and MTCT.
- In both communities, stigma, discrimination, and isolation are faced by PLWHA, and are deterrents to residents taking advantage of HIV testing. services.
- The majority of study participants had little experience with counseling and testing services and thought disclosure of testing, particularly if the test was positive, would be very difficult.
- Participants expressed fear that if HIV was determined to be the cause of an illness, family and community members would be less willing to provide care and support.
- A key barrier to VCT that has direct implications for MTCT prevention programs is the belief that the first person to be tested in a couple will be blamed for bringing HIV into the relationship.
- Breastfeeding was found to be a near-universal practice. The strength of cultural norms and pressure to breastfeed was reflected in derogatory references to women who do not breastfeed.
- Although legitimate reasons to not breastfeed are recognized in both countries, women are pressured to explain their choice to family and community members. This process is made more difficult by the tendency (particularly in Botswana) to suspect that women who do not breastfeed are HIV positive.

[6] While this method of selection is potentially biased toward church members, staff at the health center confirmed that a very high percentage of male residents of the community do attend church.

[7] More detailed information is available in the study reports from each country. See Sheila Tlou, Laura Nyblade, Ross Kidd, Mary Lyn Field, Koketso Rantona and Samson Sentumo. *Report on formative research on community responses to initiatives to prevent mother-to-child transmission in Bontleng, Gaborone, Botswana* (June 2000) and Ginny Bond and Phillimon Ndubani, in association with Laura Nyblade. *Formative research on mother-to-child transmission of HIV/AIDS in Zambia: A report of focus group discussions held in Keemba, Monze, November 1999* (June 2000).

The Community Context

Participation in MTCT prevention programs forces pregnant women to think about and make decisions on three complex, sensitive issues: HIV testing and counseling, drug treatment during pregnancy, and alternative infant feeding practices. Pregnant women do not face the issues that arise through MTCT prevention programs in a vacuum. Partners, family, and community members influence the decisions that a pregnant woman makes about each of these issues.

The choices made have potentially far-reaching implications for a woman's emotional and physical health, the well being of her child, the relationship to the father of her child, broader familial relationships, and how she is viewed and treated within the community. The design and implementation of effective programs that allow for voluntary participation should therefore be based on an understanding of the lives of women and what they and the significant people in their lives have to say about these decisions and the basis on which they are made.

Similarly, the overall context of HIV/AIDS in the community is an important determinant of the need for and potential success of an MTCT prevention program. In order to determine what should be included in programs, it is crucial to understand what communities know about HIV/AIDS and MTCT; where they obtain relevant information; how they view, treat, and care for PLWHA; and what they think about VCT, using drugs during pregnancy, and infant feeding. Findings related to these aspects are discussed below.

Perceptions of HIV/AIDS prevalence

All of the focus groups defined HIV/AIDS as widely prevalent in their communities, although differences existed between urban Botswana and rural Zambia with regard to recognition of the personal and community-wide impact of the disease.

In Botswana, estimates of HIV/AIDS prevalence by participants in the FGDs ranged from 30-90 percent of community residents. However, the majority also claimed that they had little personal knowledge of people living with HIV/AIDS and the groups did not discuss HIV/AIDS as an overriding problem in their community. As one woman who was breastfeeding stated:

> *"Personally, I don't know what people are talking about when they mention this disease AIDS. I have always heard about it, but I can't actually say that I have seen someone like that. What I have seen is someone that loses a lot of weight and later on has a continuous, running stomach."*

Thus, while AIDS or the relation of a given illness to AIDS was not commonly acknowledged, a progression of symptoms that may be indicative of AIDS was. In the words of a Botswanan man:

> *"When it starts they never get healed of flu. They always have diarrhoea. They also complain about aches in their legs, then it is TB. They take a lot of tablets but they continue losing weight. They change colour, they look like a pot, they become so black that even body lotion doesn't seem to help. They are always vomiting..."*

Not "knowing" anyone with HIV/AIDS in Botswana was also discussed in conjunction with the perceived secrecy surrounding PLWHA, as evidenced in this statement by a male elder:

> *"When people have HIV, it is always a secret. It will just remain a rumor that so and so has HIV, but it will never be verified whether it is true or not. They only mention AIDS when someone is already dead."*

In addition, because many of the symptoms associated with HIV/AIDS also characterize other illnesses, participants in the groups said things to the effect that, in the words of a Botswanan man *"We can't identify such people [PLWHA] because mostly we all look the same."*

In sharp contrast, the groups in Zambia viewed HIV/AIDS as an overwhelming problem. For example, male participants in Keemba pointed out that such large numbers of community members are dying of HIV/AIDS that, in the words of one, *"There isn't a Sabbath day which can pass without witnessing two or three deaths"* and that equal numbers of people are severely ill and *"just waiting for the day."* The need to care for an increasing number of orphans was also associated with HIV/AIDS, as well as the fact that even healthy looking people may be infected.

While the residents of the community in Zambia recognized HIV/AIDS as a major issue, they were overwhelmed by it to the point of feeling as if there is nothing they can do about the problem. The focus group discussions often elucidated a sense of hopelessness, as represented by a remark by a Zambian man that *"It is beyond our control, so we have given up and stopped fearing."*

This evidence points to the need for messages that inspire hope to be included in MTCT prevention programs in Zambia. In Botswana, on the other hand, messages may need to focus primarily on convincing a community that both MTCT and HIV/AIDS are in fact real, growing concerns that must be addressed.

Knowledge and beliefs about HIV/AIDS

In both study communities, women were generally better informed than men about HIV/AIDS, in particular with regard to factual details on modes of transmission and methods of prevention. An unexpected finding was that residents of rural Zambia had greater knowledge about HIV/AIDS than their counterparts in urban Botswana. In Zambia, knowledge was uniformly high among all the sample groups, while in Botswana it varied widely and many participants knew some, but not all, of the correct information about transmission and prevention.[8]

As mentioned, the level of community knowledge about HIV/AIDS influences the context within which women make decisions about MTCT prevention, and in turn the design and implementation of appropriate messages. The lack of a clear understanding of transmission and prevention feeds directly into the widespread fear of contracting HIV from casual contact with or care of an infected person, which in turn fuels the stigma and social isolation felt by those people presumed to be ill with AIDS. Pregnant women trying to decide whether or not to be tested for HIV are influenced by the negative community attitudes towards individuals suspected of having AIDS. In addition, if a community tends to blame women for the spread of HIV, then women will be even more reluctant to take an HIV test.

[8] It is not clear why this strong difference between Zambia and Botswana exists, making such variations a critical area for future investigation.

All groups in both communities defined multiple partnerships outside marriage or sanctioned relationships as the major cause of HIV transmission. Those who have the virus may therefore be assumed to have engaged in this type of behavior, in turn fueling prejudice and stigma. With regard to attitudes, a subtle difference between the two communities became clear that has possible implications for MTCT prevention.

While focus group participants in Botswana recognized that both men and women are "promiscuous," the men talked more about how, in the words of one, *"Girls change partners like they are changing dresses"* and *"women get [HIV] because they don't respect their husbands."* Not surprisingly, women discussed male "promiscuity " more, and in stronger language, than did the men or elders. One breastfeeing participant stated emphatically that *"There is no man who doesn't cheat."*

In contrast, the Zambia groups described both men and women as engaging in unsanctioned sex, although each gender group was attributed with having different reasons for such behavior. Both the male and female groups described women more sympathetically, saying that they engage in unsanctioned sex because their economic circumstances offer them little choice. As explained by a pregnant woman in Keemba in reference to local migrant workers, *"In the presence of money from these contractors, it is difficult to refuse sex from them."* On the other hand, men were viewed as having an innate need for multiple sex partners and as lacking sexual control. In the words of another pregnant participant, *"Men go for variety. There is a Tonga phrase that says you do not eat one type of food everyday, such as pumpkin leaves with groundnuts or okra all the time."*

Thus, in Botswana participants tended to focus on and blame women's behavior, while in Zambia, men were also held responsible. The fact that men in Zambia recognized their contribution to the spread of HIV suggests their potential readiness to support MTCT prevention efforts, a trend that could be harnessed to improve programs in the future.

Information about HIV/AIDS

In both communities, study participants cited several sources of HIV/AIDS information. Women indicated that they received most information from health workers at the local clinic, specifically in the form of health talks during ANC and well-child sessions. While other sources were mentioned in both communities, it became clear that clinics are the main places where information is available.

Discussions also underscored that residents of both communities perceive a gender differential in the ability to gain information, since women of child-bearing age access health facilities far more often than do men and elders, who consequently are less informed and feel excluded. As a breastfeeding participant from Zambia explained, *"Our husbands are not taught as we are about HIV/AIDS."*

Nonetheless, men and elders play a significant role in women's lives and influence decisions on issues such as HIV testing and infant feeding. Women, men and elders in both study communities expressed a wish to bridge the gender-related information gap, indicating the possibility of developing and implementing creative strategies to communicate vital information on HIV/AIDS and MTCT to husbands, partners, and other community residents.

Care and support of PLWHA

In both Botswana and Zambia, focus group participants voiced the expectation that the immediate family will always care for PLWHA, possibly with assistance from extended family members. In Zambia, this expectation was explained by a man in Keemba as *"You keep them in the house because they are part of the family,"* while a pregnant woman in Chuungu said that *"families must depend on themselves."* In Botswana, a breastfeeding woman felt that *"The person is my family so I cannot desert him."*[9]

However, discussions in Botswana generated debate and elucidated strongly differing opinions about the extent of care and support that PLWHA would receive from the extended family. Some felt that families would always care for PLWHA, while others thought that if relatives knew that the cause of the person's illness was HIV, they would no longer provide care. One breastfeeding woman believed that *"They [relatives] may be helping in the beginning, but when they hear that the person is suffering from AIDS, they disappear."*

In addition to the stigma attached to HIV/AIDS, the perceived breakdown of the extended family today (in comparison to the past) and the urban setting of the study may have contributed to this view. As a young man explained, *"These days, relatives don't help each other like they used to. If you get HIV, no one in the family seems to care about you and they want to distance themselves from you."*

Other possible reasons that were cited for the perceived reluctance of relatives to care for a PLWHA fell into three main categories, as illustrated by the following quotes from participants in Botswana.

Blame: *"I don't think they [family members] are interested [in care and support] because sometimes the disease attacks a young person after the parents or elders have tried to talk to him/her [about sexual behavior], but to no avail."* (breastfeeding woman).

Fear of contagion: *"Even when a person knows that the person is family, they don't help care for him. All they are thinking about is that if they help that person they are also going to get infected."* (breastfeeding woman).

Burden of care: The female groups discussed the emotional stress of caring for a patient when death is the only possible outcome and feelings of hopelessness and emotional exhaustion prevail.[10] In the words of one breastfeeding woman, *"In the long run even family members lose hope and feel helpless towards the patient."* It is also physically difficult to care for someone who is very ill, as a young pregnant woman indicated: *"The relatives never used to come to help...when this sister of mine was sick and had diarrhea, I used to go to the clinic to get gloves. It is very difficult when someone has diarrhea and is always vomiting."*

Although the burden of care and need to support PLWHA was discussed in Zambia, few people questioned that families would be responsible. However, some participants described parents as being angry about having to look after chronically ill, adult children at a time when economic resources are increasingly limited. Although there was little expectation expressed in Botswana that neighbors or

[9] It should be noted that, while formal support structures exist in many areas to help PLWHA and their families (in particular home-based care groups), these are not well-developed in either of the study communites. Consequently, participants in both communities were not obviously familiar with such support options and only a few mentioned them after direct probing from the moderators.

[10] The fact that only women, and one male participant, mentioned the strenuous aspects of care most likely reflects the fact that women are almost always the exclusive caregivers for the ill.

the larger community would provide help, in Zambia the community was described as assisting families caring for PLWHA with such tasks as cooking food and drawing water.

Information about the care of PLWHA enhances understanding of the issues that pregnant women face in making decisions about MTCT prevention. For example, knowing that potential sources of support exist can positively influence an individual to get an HIV test. While not clearly articulated, the discussions in both communities contained an undercurrent of fear that if HIV was the confirmed (as opposed to merely suspected) cause of illness, care and support might be given less readily, or even withdrawn, by family and community members. This fear is probably based on the perception that PLWHA are blamed for their own illness, as well as the harsh reality of deciding whether to allocate limited resources to care for a patient who has little hope of getting better.

Knowledge and perceptions of MTCT

Discussion groups in both communities perceived HIV infection among infants as quite prevalent. In Botswana, participants expressed the sense that the problem is largely "invisible." Reasons for why MTCT is not a more obvious problem in Botswana include the lack of clearly identifiable symptoms and the short life span of HIV-infected babies. As summarized by a breastfeeding participant:

> "*They look fresh [fat] and they die fresh. So we don't know whether it was HIV or just another disease. The babies don't usually struggle like adults. They just cough a little and then pass on, so it is very difficult to know whether it was HIV or not.*"

In both study communities, participants expressed a general understanding that HIV can be transmitted from mother to child, but knowledge about the points during pregnancy, delivery, and breastfeeding when MTCT can occur was limited. Participants in Botswana knew more than their counterparts in Zambia about the details of transmission, though only one or two out of the three possible avenues were mentioned in most groups. In Zambia, only two groups mentioned transmission through breast milk and three groups were aware of the possibility of transmission through razor blades, which are used by traditional birth attendants to cut a baby's umbilical cord.

Only one respondent (male) in Botswana stated that it was possible for an HIV-infected mother to have an HIV-negative baby. The overall consensus in the groups in both communities was that if the mother was HIV-positive, the baby would inevitably be, too, as indicated by two pregnant participants:

> "*The baby feeds on the birth supply from the mother during pregnancy - if the mother's blood has the HIV virus, it means that the baby will get it.*" (Botswana)

> "*The blood that has made the child has the infection and the child will be born with it.*" (Zambia)

MTCT prevention

At the start of this study, the government MTCT prevention program had been operational at the local health center in Bontleng, Botswana, for seven months, while MTCT prevention program services were not yet available at the research site in Zambia. Consequently, most Botswanan participants (particularly women) were aware of the possibility of preventing MTCT through a program at the clinic. Many were also familiar with the HIV testing and drug components of the MTCT prevention program, although they mentioned alternative infant feeding and the provision of infant formula less frequently. According to a young breastfeeding woman:

> *"At the clinic they ask you whether you have an interest in checking for the HIV virus so that if you have the virus in your blood they can give you AZT to prevent transmission from mother to child."*

The availability and the specific components of the MTCT prevention program were largely unfamiliar to men and community elders, who play an influential role in women's lives. These participants often expressed skepticism about the effectiveness of the program, indicating that they are not being reached by current education efforts or receiving information about the transmission process. As stated by a male elder:

> *"The womb is attached to the mother and this womb is blood, which comes from the mother to feed the baby. That is why we don't believe that this so-called treatment [AZT] would be able to separate the baby from the mother's womb. How will this treatment avoid contact with the infected mother to keep the baby free from infection?"*

As mentioned, several preliminary meetings had been held with local leaders in Zambia to discuss proposals for future MTCT prevention programs. Through comments made in the focus group discussions about pregnancy and HIV, as well as counseling and testing during pregnancy, it became clear that some information from these meetings had been communicated to the wider population. For example, one man explained that women would be happy to be tested if they were offered a medication to prolong life. Several women in both Keemba and Chuungu made similar comments, including the following:

> *"Maybe agree [to testing] because [they] will help you if you have a disease [HIV]."*

> *"Tablets protect a bit so live longer."*

> *"All of us could tell our husbands if we all had blood taken and there were drugs to protect the baby."*

Such statements indicate that information can spread quickly through a community and generate a demand for more information. This important finding is tempered by the need for an element of caution in presenting information. Some study participants hinted at the expectation or understanding that drugs also help mothers, underscoring the need for very clear messages and ongoing monitoring of how a community understands the information and ideas that a program provides.

When the groups in Botswana were asked how they felt about the MTCT prevention program, support was expressed because of the benefits to the child and the potential for saving a child's life. While there was general agreement that doing this was very important, some groups were concerend about what would happen to a child whose life was saved, since the mother was going to die. As one

breastfeeding participant explained, *"It is a good program for the baby. But in the process a pregnant woman will be thinking – you know, I am going to die anyway, my baby might live, but if I die what is the point because there will be no mother to raise my baby."*

Similarly, a group of men expressed concern that the government was focusing on curing babies but not mothers, and some asked questions such as *"Why don't we get medication that will cure both the baby and the mother?"* This concern is exacerbated by the belief that pregnancy hastens the onset of AIDS and death. In the words of one male respondent, *"If one has the virus and gets pregnant, the virus will increase in her body. The person may end up dying before her time."*

MTCT Prevention Program Components

Voluntary counseling and testing

Offering VCT in the context of ANC services is a relatively new phenomenon in Botswana and currently not an option in Zambia. In addition, locally available, freestanding VCT services (i.e., those not connected to a medical facility) are not available in Keemba. Until recently, such services were available only in Gaborone, Botswana, in non-hospital settings, specifically through a VCT center run by the Red Cross.

In Zambia, the focus groups knew that it was possible to get tested for HIV at the Monze Mission Hospital as part of a diagnostic process to determine the cause of an existing illness, but thought that health personnel would not share positive results with a patient. In the words of a breastfeeding woman, *"We are tested at the hospital but not told that we have HIV. Instead we are told that we have TB. They do not tell us that it is HIV because they are worried that we would commit suicide. They tell us that it is TB of the bones."*

Because no "culture" of VCT existed in either Bontleng or Keemba, the concept of voluntarily choosing to know one's HIV status while still healthy was unfamiliar to residents. In both communities, participants thought that few people would seek VCT on their own and that those who did would certainly not voluntarily disclose an HIV-positive test result. As stated by a breastfeeding woman in Botswana, *"If I do test positive I will keep my status a secret. This way we do not know that so and so has AIDS."* And in the opinion of a man in Zambia, *"It is not a disease that people would announce like malaria...It is not treated like any other disease."*

Given this lack of familiarity with VCT, group discussions focused largely on the hypothetical situation of "if testing were available," rather than on testing as part of ANC services. The questions asked about testing in the context of ANC, in particular regarding decision-making by women, did not generate much discussion because the groups did not differentiate much between pregnant women and others with regard to VCT. Although VCT offered within an ANC setting differs somewhat from that provided at freestanding centers, understanding what women and communities think about VCT in general provides a sense of how women might respond to the offer of testing during an ANC visit. This is especially helpful information in settings where women, their partners, and the community are largely unaware that HIV testing is in fact available through an ANC, and can be used as the basis for developing messages about VCT in general and within the ANC system in particular.

The reason mentioned most frequently in both communities for seeking VCT was to determine whether a chronic illness was indeed caused by HIV. A young Botswanan man stated that *"Many people go for a test when they are sick. But when they are fit, like me, it is rare for a person to check."* Because a person who falls ill is often suspected of being HIV-positive, the negative social consequences of others finding out that that person has used VCT – and has therefore potentially received positive test results – may be somewhat mitigated.

Although groups in both communities gave a few reasons for getting a test, discussion about the potential benefits of VCT was sparse in comparison to discussion about the drawbacks. In both communities, the most positive aspect of VCT mentioned was that it could help people change their lifestyles, which could in turn increase life expectancy in cases of a positive test, and help avoid infection if results were negative.

Diverse participants expressed this view. For example, a breastfeeding woman in Botswana said that VCT "*...is important because if my attitude was bad and I find that I have the HIV virus, I would have to change so that I live longer.*" In the words of a male community leader in Zambia, "*[One] can live for ten years if HIV-positive and look after yourself, or if HIV-negative maintain yourself and abandon [risky] behavior.*"

All the groups in both communities had something to say about the potential disadvantages of VCT. The reasons given for not wanting to be tested included fear of one's own reaction and not being able to cope if results were positive, as well as fear of the reactions of partners, family members, and the community as a whole. The reality that little help is available also weighed heavily on many participants, including two men from Keemba who summed up the reality of the situation as "*There is no life apart from death,*" and "*because it [HIV/AIDS] has no cure you know that death is around the corner.*"

Personal reaction

A range of individual reactions were envisioned, from depression to suicide. Participants in both communities expressed concern that knowing that they were HIV-positive would accelerate the process of severe illness and death. One young Botswanan man said that "*It may affect that person so much that she will have problems and then the manifestation of the illness will develop much faster,*" while a man in Zambia simply stated that "*If you knew your HIV status, it would shorten your life.*"

Suicide as a potential response to a positive test result was mentioned across groups and communities. Some explanation was given as to why HIV-positive individuals would commit suicide, such as a statement by a young man in Botswana that "*Some people will say that since they are dying, there is no point in prolonging it and so they commit suicide.*" A male elder thought that people might commit suicide because they "*...fear discrimination... They prefer to die before people despise them.*" And in Zambia, a breastfeeding participant told the following story:

> "*It happened here in Keemba that the relative to my father was told that he had HIV... When his parents went for church services on the sabbath day, he removed all the things in the house, drank poison and set the house on fire. He died inside the house. He thought it was better to die than to suffer especially after seeing people with AIDS and the way they suffer without dying early... Those people await nothing but death.*"

In addition to these adverse reactions, groups in both communities worried that knowledge of an HIV-positive status would cause people – in particular men – to purposely try to infect others. A breastfeeding woman in Botswana expressed the concern that "*He would make it worse by infecting everyone, because he does not want to die alone.*" According to a breastfeeding participant in Zambia, "*If men know they have HIV they will give it to others so that others follow him...[he will be] bragging 62 [women] behind me are coming.*'"

A partner's reaction

Men and women in both communities feared that their partner would blame or even leave them if they found out that they had participated in VCT, especially if it had resulted in a positive test. In Botswana, participants mentioned concern about physical violence toward women and emphasized the risk that men would be more likely to abandon women than the other way around. During a discussion there about a partner's negative reaction, men and women focused almost exclusively on the reaction of a man when a woman disclosed her HIV-positive status or reported that had been tested without consulting her partner. In the words of one breastfeeding woman, *"She would keep quiet because the man might leave when he finds out I am HIV-positive. So I would keep quiet so that he helps me with the baby."*

In contrast, while male and female participants in Botswana thought that a woman might get angry with her partner if he was infected, it was generally believed that she was likely to accept him. As one breastfeeding participant explained, *"Women would scold the man a few times and then give in because we women are very soft."*

An undercurrent in all the discussions about VCT (particularly regarding disclosure of results and women being tested during ANC) was that the first person to be tested would be blamed for bringing HIV into the relationship. One young, pregnant woman in Botswana summed up the opinions of many of her peers by saying that *"He will think you brought the disease."* In Zambia, a man stated simply that *"The spouse that goes for an HIV test first is guilty."*

Male participants in Botswana underscored this view by talking about how men would accuse women who get tested, or are HIV-positive, of either being unfaithful or of questioning his sexual behavior. One young man explained that *"He will be thinking that how can his wife betray him like that and to tell him that she has got HIV. Some men ask in an accusing manner with the questions such as: if you are testing, does that mean I have HIV or do the other men you sleep with have it?"*

Upon the analysis of study results, it became clear that the fear of a negative reaction by a partner was of greater concern in Botswana than in Zambia. This may reflect differences in the stability of partnerships between the two sites. The rate of formally sanctioned marriages is higher in Zambia than in Botswana, where unions tend to be more fluid and shorter lived. Women in these types of relationships may justifiably fear a partner's negative reaction more because of the relative ease of terminating them.

Reactions by family and community

A common concern expressed in all groups in both countries was how an HIV-positive person would be treated by the extended family and community. The fear of stigma and discrimination was clearly a major deterrent to seeking VCT, as well as disclosing one's intent to have an HIV test or positive test results. As explained by a man in Botswana, *"People are afraid to tell others because of the looks they fear that they will get. People are not open about such things."* In Zambia, the groups also discussed how the family would be disappointed, embarrassed, and shamed publicly if a relative was HIV-positive, and that the person would lose respect, access to loans, and votes (if he/she held an elected office).

Discussing community attittudes and behaviors towards PLWHA provided a lens through which to understand attitudes about VCT. The groups in both communities focused extensively on how people either suspected or known to have HIV/AIDS are talked about and treated. This information was

revealed in response to a direct question by moderators about how the community views PLWHA, as well as during the discussions on both VCT and care and support for PLWHA. Groups in both communities portrayed quite negative situations, which helps explain the widespread reluctance to be tested. Participants also reported reactions such as gossip, naming, and blaming, as well as overt acts of isolation. As a breastfeeding woman in Zambia put it, *"The majority will denounce you, and point fingers at you. At weddings [they] leave you alone, give you your own plate and make up a song about you."*

Examples given in Zambia of teasing and stigmatizing included:

"Diarrhea has just walked past."
"This one be careful! It's fire! It's fire!"
"He will make people finish."
"She is the killer of the world."
"He knows he is not okay, but he is still busy going into other peoples' wives."
"Enda-enda [going, going, gone]."

Physical acts of isolating a PLWHA apparently follow gossip and derogatory references. In Botswana, a male participant explained that *"They say this person is not supposed to stay with people or share things like the toilet with them..."* In Zambia, a pregnant woman summed up descriptions by several members of her discussion group: *"Relatives fear you and segregate you when it comes to eating and do not want to stay with you."* In Botswana, many participants talked about how stigma and isolation extend to the children of PLWHA, as described by one man: *"The child is teased and rejected by other children who will stop playing with it."*

In addition, because communities commonly equate HIV infection with "promiscuous behavior," it is often assumed that a PLWHA has engaged in unsanctioned sexual behavior and to some degree has brought the illness on him/herself. As a breastfeeding participant in Botswana stated: *"People will be saying that is what you get for bitching around."* The idea that many women are unable to protect themselves from infection because of a partner's promiscuous behavior was recognized by female groups in both countries and summed up by a breastfeeding woman in Zambia: *"Nothing we can do [to stop getting HIV] because it can be brought by unfaithful husbands."*

A young, pregnant woman in Botswana aptly described the added injustice of facing community stigma based on the assumption of one's "immoral" behavior, when HIV infection in fact was due to the actions of a partner: *"When you get AIDS you are ridiculed by society, they laugh at you, they don't regard it as just an illness. You are ill-treated, you are no longer related to like before. People think you have been careless, promiscuous. They don't know that AIDS can just come to you at home."*

Despite the overwhelming evidence from this study that PLWHA are often treated poorly, it is important to emphasize that many families and individuals in both countries treat PLWHA compassionately and with dignity. In Botswana, many discussion group participants were able to cite the radio slogans of the National AIDS Control Program (NACP), including *"A friend with AIDS is still a friend"* and that PLWHA *"should be treated the same way as any other person, sharing everything with them."*

Disclosure of test results

At the present time, fear of how one might be treated if one is HIV-positive remains strong, as reflected in the discussions about the difficulty of disclosing test results. In Botswana, only mothers were cited on a consistent basis as the person to turn to with the news of a positive HIV status. While some participants in Botswana said they would tell their partners, other participants (particularly women) said that there was no one they could turn to. As one male respondent explained, *"If a person comes from testing and it is positive, they will probably find it difficult to tell anyone."* In Zambia, participants generally seemed to think that individuals would disclose test results to at least one person.

The findings in Zambia revealed a gender differential with regard to both the ability to get tested and disclosure. Participants believed that it is not only easier for men to get tested and find out their status, but that they can more easily disclose their status to their wives. On the other hand, it was thought to be difficult for women to disclose positive results to their husbands and that they would instead turn to their mothers, a female relative or friend, or a health worker.

In addition to disclosure of test results, the groups were asked about making the decision to get an HIV test. In both countries, this discussion focused on women, with a general consensus that they should consult their partners first and that not doing so could have negative ramifications. Only two participants, a man and a woman in Botswana, thought that a woman could make the decision to be tested on her own. This finding once again underscores the need to fully involve men in MTCT prevention because of the influence they have over women's lives.

VCT service delivery

The groups also suggested ways to make VCT "easier to use" with regard to the setting, quality, and public perceptions of services. In Zambia, only one of the groups of women indicated a willingness to go to the Keemba health center for VCT, while all others emphasized the difficulty of confidentiality within the health center service delivery setting. Similarly, a male participant stated that *"Health workers at the health center are [community] residents and will tell others and force you into isolation and to withdraw from the community."* Other issues that were raised in Keemba included the need for privacy, individual contact, and ongoing support. Suggestions for how this might be achieved included not designating a particular day, time, or room for testing in order to increase confidentiality, "normalize" the process, and persuade more people to take an HIV test.

The groups in Botswana also discussed the need to make VCT a more frequent, accepted experience, since, in the words of one participant, *"Seeing someone else going for the HIV test is very encouraging."* One strategy to acomplish this that was suggested was that HIV-positive role models be brought in to talk to groups about how VCT has improved their lives. Other suggestions were described as *"Door-to-door education through educators and counselors"* and actions by medical staff because *"Doctors should encourage people to go for the test."* The importance of good counseling was raised in both communities. A female participant in Botswana explained that how one copes with a positive result *"...really depends on what type of counseling you received before the test,"* while men in Zambia emphasized the importance of *"being told nicely"* and receiving *"support like a pillar"* from a counselor.

Drug treatment

AZT has been available in Bontleng since the MTCT prevention program was established in Gaborone in April 1999, while AZT and/or Nevirapine is projected to be available in Keemba later this year. Hence, with regard to taking drugs, the study included specific questions about AZT in Botswana and more general questions in both communities. One question focused on the prenatal supplements given at ANC clinics.

In Zambia, the groups had mixed views about taking supplements during pregnancy. Several of the groups of women thought that taking the tablets was beneficial and not at all problematic, as did men and community elders. In-laws were also thought to be supportive, as long as they could be sure that the tablets were not intended for family planning purposes. However, several of the female participants expressed concern about taking the supplements because of a belief that they would result in babies that would be too big at birth and make delivery difficult. Additional concerns included the possibility of forgetting doses or getting sick from the drugs. In the words of one pregnant woman from Zambia:

> *"Some people discourage from taking drugs saying that the drugs will make the baby too big and can lead to difficult delivery and operation [a Caesarean]. As a result, women do not take their drugs, they just store them at home."*

In Botswana, most men and elders were aware that there was something available at the clinic to help prevent MTCT, but fewer were certain that it involved a drug. One male elder stated that *"Now, I have heard on the radio that there is a medicine or rather the doctors do something to pregnant women so that the virus cannot be transmitted from mother to child."* However, most of the women in the Botswana study not only knew that AZT existed, but could name it. Knowledge about the drug, how it is administered, and how it works was, however, tenuous. Most women knew that it is given as a tablet, though several thought it was administered through an injection. Only two mentioned that treatment begins at eight months of pregnancy.

When asked specifically how AZT works, responses were quite general, making it difficult to assess how well women understand the effects of AZT and whether they know that it is not 100 percent effective in preventing MTCT. One breastfeeding woman said emphatically that AZT *"...prevents the virus from passing from mother to her unborn baby."* However, some women did use the terms "reduce" and "decrease," rather than "prevent," perhaps suggesting that they understood that the probability of transmission would simply be diminished. Still others put the two types of terms together, causing some confusion with regard to what they knew. For example, one breastfeeding woman stated that AZT *"...reduces the virus. The child will be born without the virus."*

In addition, some confusion existed about the effects of AZT on a woman. On the one hand, there seemed to be a clear understanding that the treatment was not going to benefit the mother directly. In the words of one breastfeeding participant from Botswana, *"When we are given talks at the clinic we are taught that it does not mean when a person is HIV-positive they will be cured, but they say they have found some medicine that will protect babies in the mother's womb."* Other women questioned and expressed anger about this fact, as illustrated by the statement by another breastfeeding participant that *"When you are eight months pregnant you are injected to protect the baby, not you."*

However, a few participants indicated a different perception – or perhaps a hope – that a mother would in some way benefit directly from AZT. Regarding how men view the drug program, one breastfeeding woman from Botswana said that *"The men who seem to know about the program say, 'Yeah, it is okay. My wife, if they give you the injection for prevention of transmission from mother to child it means that even you yourself will be cured'."*

In addition, two groups of women believed that once a woman stopped taking AZT she would become ill, and perhaps even die because, according to one breastfeeding participant, *"She starts to lose weight and now shows clearly that she has the virus. She becomes actively ill, or even dies."* This belief seems to stem from the knowledge that AZT works by "decreasing" the virus in the body. In addition, in the words of a pregnant woman, *"it also makes you strong"* and if AZT treatment is ended, *"... the HIV will get worse, because when you stop the AZT it means what will be making it less [is now gone]."*

Female participants also discussed factors that influence compliance with an AZT regimen. Concerns expressed in two of the three groups in Botswana were related to possible side effects and whether the drugs could be taken confidentially. Perceived side effects ranged from *"It make them overeat."* to *"Some put them aside because they make them vomit."* One breastfeeding woman said that *"Some may just take the tablets home and decide not to take them, thinking the tablets have a virus."* Only one woman thought that she might forget to take the tablets.

The ease with which women can take AZT without others in the household noticing was debated, with a slight majority of women thinking that it would be problematic. Only one woman thought that her peers would not even want to take the drugs home for fear that people would notice. Others believed that husbands and partners would notice, but that others would not. Men were more apt to notice because of their proximity, as illustrated by the statement that *"Your man would notice [taking AZT] because you stay with him in the house."* (breastfeeding participant)

A pregnant Botswanan woman explained that *"Even the supplement tablets that pregnant women bring home, the men usually ask us what they are for,"* while another pregnant participant said that *"I bring the tablets home he will ask what they do, one by one saying those brown ones, what do they do."* However, some women didn't agree that this was an issue, as indicated in one statement by a breastfeeding participant that *"I don't think even the man will notice because men don't take too much notice of anything. He would just assume that you have to take them because you are pregnant."*

Learning what community members know and believe about taking supplements or drugs during pregnancy is directly relevant to the development and implementation of MTCT prevention programs. Some women apparently have trouble taking prenatal supplements (such as folic acid) because of side effects, the tendency to forget, and fears of having very large babies and difficult deliveries. MTCT programs need to consider how these issues affect the willingness to undergo and compliance with an AZT regimen, and in turn what is the best way to frame messages about AZT in order to overcome potential barriers.

In addition, the fact that women find it difficult to take drugs without others (particularly partners) noticing again points to the need to gain the support of men and communities for MTCT programs because of the influence they have on women's lives and decisions. On the other hand, if AZT can be provided in such a way that it appears to be just another routine prenatal drug, then women might not face any questions about taking it. Finally, ongoing monitoring of what the community knows and

understands about AZT is necessary to formulate effective education and communication messages and to respond to incorrect assumptions about what the drug is and how it works.

Infant feeding

Groups in both Botswana and Zambia reported that breastfeeding is very clearly the norm with regard to infant feeding. In fact, women who do not breastfeed are closely scrutinized by family members and community residents and often pressured to justify their decision. Participants in both communities mentioned the impracticality of not breastfeeding, noting that it is difficult to find tinned milk and usually too expensive and inconvenient to purchase and use baby formula. The groups noted the dangers and difficulties of bottle-feeding (e.g., the need for plentiful, clean water and sterile conditions for preparation), as well as the additional cost that this feeding method entails, which could at times result in parents running out of formula.

Participants in both communities conveyed the symbolic significance of breastfeeding, which is widely associated with being a good mother. One young breastfeeding participant in Botswana summed up this view by saying that *"Breastfeeding means she is a real woman."* In addition, all groups reaffirmed that breastfeeding is the norm not only because of tradition, but also for health-related, practical, and economic reasons. A Botswanan man cited the health benefits for a baby by stating that *"We have all been breastfed. We are told breast milk has nutrients and it is very clean. The bottles are not properly washed and a baby who is breastfed is stronger than the one who is bottle-fed. Breastfeeding is very necessary."* Women in Zambia expressed the same opinion, with one pregnant participant stating that *"The first yellowish milk is very important for the growth of a baby. They better not miss it because it has good nutrients."*

The strength of the breastfeeding norm, as well as the extent of the pressure on women to adhere to it, is reflected in comments made by all of the groups about how women who don't breastfeed are perceived. They are suspected to be bad mothers who don't love their children and are more concerned about their own needs (e.g., their appearance) than the health of their baby. However, the most frequent and strongest perception of non-breastfeeding women, as expressed by a breastfeeding participant in Botswana is that *"She does not breastfeed so that she can fool around [have sex]."* This conclusion was apparently based on taboos that exist in both communities against a woman being sexually active while breastfeeding. A traditional belief in Botswana is that an infant will be harmed if a woman has sex with a man who is not the father of her baby while she is breastfeeding. As expressed by one man, *"In our culture breastfeeding means to prevent the mother from sleeping around...if they sleep around during breastfeeding they will affect the baby."*

Nonetheless, groups in both study areas noted that a community often recognizes legitimate reasons for women not to breastfeed. This was mentioned more frequently in Botswana, possibly because infant formula is widely available and more affordable there in comparison to Zambia. Acceptable reasons included breast diseases (e.g., cancer or lumps), problems with breasts, insufficient milk, refusal by a baby to breastfeed, the need to return to work, pregnancy, and HIV infection.[11] At the same time, despite recognition of these issues, pressure to breastfeed remains strong and women who choose not to are expected to openly explain themselves.

In Botswana in particular, participants emphasized that women should consult several people before opting for bottle-feeding. In addition, the people who should be consulted were ranked in order of importance. The first person is the child's father, since he is often the one who *"buys the formula."*

[11] In Botswana, pregnancy was cited because of the belief that breast milk from a pregnant mother is harmful to the child and would stunt its growth and development.

The next in importance is the woman's mother, who takes care of her daughter during her 2-3 months of confinement (known as *botsetsi*). In the words of a breastfeeding participant, *"She is the one who is going to look after the baby when she [the mother] is not in."* Last on the list are in-laws.

The need to justify the decision not to breastfeed, together with the suspicion that HIV infection might be the reason, puts HIV-positive mothers in a difficult position. As HIV/AIDS increases, it is becoming more common for the community to assume that non-breastfeeding mothers are indeed HIV-positive. Women who receive formula through participation in an MTCT prevention program are therefore essentially making a public declaration of their positive HIV status. As a male elder in the study community in Botswana said *"They also think that if she is not breastfeeding she must be in the government MTCT program. Therefore, she must be HIV-positive. That is what people are afraid of so people just say let me breastfeed him so that people may not think I am infected."* Another man in Botswana stated simply that *"Breastfeeding is a common practice. It is therefore difficult on a woman who is HIV infected."*

Conclusions and Recommendations

The information gleaned from the focus group discussions and interviews in Botswana and Zambia is rich with perspectives and ideas. By actively listening to the voices of individuals, it is possible to gain insight into how to design and deliver interventions that are widely utilized and effective in saving the lives of adults, children, and infants across the globe. This study underscored how local communities can benefit from the research process by gaining knowledge about HIV/AIDS and MTCT and confronting difficult issues (such as stigma and discrimination against and the care of PLWHA), as well as the widespread need to access and utilize VCT.

Findings from this study highlight the complex challenges and opportunities posed by MTCT prevention programs. The primary conclusion is that **MTCT prevention programs have an urgent need for the information and perspectives that emerge from community dialogue about HIV/AIDS and MTCT prevention.** While community participation is important for all types of health programs, it is especially critical in the case of MTCT prevention because program components (i.e., VCT, treatment, and infant feeding) require women to make difficult decisions that are sensitive in nature. The data generated by the studies reported here are evidence that community members have opinions, beliefs, and values that directly affect their decisions about participation in HIV/AIDS and MTCT prevention programs. **The effectiveness of MTCT programs can be improved by using community perspectives in both designing and implementing programs.**

It is clear from the study findings that **women trying to decide whether to participate in an MTCT prevention program are profoundly influenced by the opinions of their spouses and partners, as well as family and community members.** The focus group discussions in both Botswana and Zambia illustrated the fact that spouses and partners impact decisions about HIV testing, as well as treatment and infant feeding decisions. Parents, in-laws and other relatives may have a somewhat less direct influence on testing and treatment decisions, but are clearly involved in infant feeding. The study findings underscore that **in order to succeed, MTCT prevention programs must reach these significant others in women's lives with information, education, services, and support.**

Several study findings illustrated that the **MTCT program is strongly affected by how the community deals with the HIV/AIDS epidemic.** Specific influential factors range from the level of community knowledge about HIV/AIDS to attitudes towards those who are infected. Participants cited stigma against HIV-positive people, the poor treatment of PLWHA, and fears about the

availability of care and support as barriers to seeking VCT. In addition, the HIV/AIDS situation in a community in part determines infant feeding choices, and to a lesser degree drug treatment during pregnancy, both of which are public actions that can signal to others that a woman is HIV-positive.

The data revealed that **men are less informed than women about HIV/AIDS in general, and MTCT in particular.** This finding is significant because of the influential role that men play in women's lives and decisions. Participants recognized this disparity in knowledge and said that the problem lay in the venue and manner in which information is shared, namely health care provider talks during ANC and well-child clinics, where men and elders – who expressed a desire to improve their knowledge – are unlikely to go.

The discussions that emerged from this research illustrated that **a powerful and potentially negative relationship exists between the misinformation and lack of community dialogue about HIV/AIDS and MTCT, stigmatization of PLWHA, and the difficulties faced by HIV/AIDS prevention efforts, e.g., the reluctance of women to participate in MTCT prevention programs.** For example, misinformation about how HIV is transmitted leads to the fear and stigmatization of PLWHA, who are in turn less likely to share their HIV-positive status with others. This results in a social climate of secrecy and fear, again leading to an escalation of the stigma surrounding the disease and those who are infected. Methods such as focus groups with an informed moderator can break this cycle, a critical first step toward engaging communities in the prevention of MTCT of HIV. It is only when communities can interact compassionately with those who are HIV infected that they will be willing to be tested for HIV, thereby meeting the prerequisite for participating in an MTCT prevention program.

The various aspects of this cycle illustrate that **designing an MTCT prevention program without sufficient information about community perspectives could quickly lead to failure.** In other words, the investigation and utilization of community perspectives can be the key to the success of a program. As the AIDS epidemic grows, it is critical that programs not be launched without an understanding of what communities think, believe, and desire regarding HIV and MTCT. Doing so will increase the likelihood of failure and the waste of limited, valuable resources at a time when the means of many countries to address HIV/AIDS and MTCT are already stretched.

MTCT prevention programs have the potential to both save the lives of many children and bring HIV/AIDS to the forefront of public discourse, often in new ways. But they also have the potential to fail if they do not ensure that women are full participants and result in the stigmatization and rejection of women who participate. In most communities, women lack independence and decision-making power and are integral parts of nuclear and extended family systems that have defined roles and expectations for them. Many women are economically dependent on partners, who can therefore sway decisions related to pregnancy, breastfeeding, and HIV testing. Successful programs are designed to take these factors into account. It is abundantly clear that **the overarching goal of saving young lives while supporting mothers can only be fully realized if communities understand and support women seeking to prevent the transmission of HIV to their infants.**

The research studies in Botswana and Zambia yield a range of perspectives and lessons pertaining to education, counseling and testing, and community acceptance and support. It is recommended that MTCT programs implement the following recommendations for these areas:

MTCT Prevention Education

- *Education strategies should be participatory and create opportunities for open discussion and participant feedback about HIV/AIDS and MTCT. Focus group discussions should be considered an essential tool for both research and education.*

The focus group discussions conducted through this study highlighted the lack of community dialogue on many issues that are critical to effective HIV and MTCT prevention programs. This type of forum provides a unique opportunity for participants to gain information and reflect on the complex issues they face as a result of the AIDS epidemic. The fact that most participants in this study were discussing these issues for the first time underscores the fact that communities have long been passive recipients of prevention efforts, rather than active participants in debating and solving the problems that plague their own lives. It also makes clear how MTCT prevention efforts have often lacked the critical component of dialogue.

- *Educate community residents on basic anatomy and physiology in relation to pregnancy in order to enhance understanding of the MTCT process.*

An abundance of misconceptions about pregnancy and HIV transmission currently exist, including the notion that it is not possible for an HIV-negative baby to be born to an HIV-positive mother. Ending such misconceptions can help communities to understand what an MTCT prevention program does, and thereby enhance participation.

- *Create messages that have a hopeful tone and use positive role models to promote the benefits of VCT.*

Communities with a high prevalence of HIV/AIDS are often characterized by the sense that trying to address the problem is pointless. In the face of much hopelessness, messages should highlight the advantages of being tested, rather than the consequences of HIV infection in infants. This approach is more likely to motivate participation in counseling and testing programs.

- *Use strategies that reach men and elders in the community with information and opportunities for discussions about HIV and MTCT.*

Men and elders are key decision-makers in communities regarding issues such as counseling and testing and infant feeding. It is critical to help men and elders learn about MTCT in order to engage them as partners in prevention. Reaching them requires that educational sessions, materials, and messages are available beyond the walls of antenatal clinics. Possible alternative sites are primary or outpatient clinic waiting rooms, where talks on health-related subjects should include information about MTCT of HIV. Community outreach is an another useful strategy to reach men.

- *Prepare health providers to understand the link between HIV and breastfeeding, as well as the risks associated with other feeding practices, to ensure that they can competently and compassionately counsel women about infant feeding options. In addition, it is important to convey to the community that MTCT programs assist women in making infant feeding choices and do not dictate one method over another.*

Recent studies and recommendations regarding breastfeeding by HIV-positive mothers are complex and confusing. Because the knowledge and attitudes of health providers about infant feeding affect

their ability to assist mothers in making informed choices, it is important to ensure that they have good information and the opportunity to resolve questions. Above all, providers must provide emotional support to HIV-positive mothers regardless of the decision they make. Where relevant, programs should encourage those providers who promote breastfeeding to instead counsel HIV-positive mothers about their options. In addition, if a community understands that MTCT programs do not attempt to coerce women into making a specific choice, the tendency to assume that women who choose not to breastfeed are HIV-positive may be reduced.

Counseling and testing services

- *Whenever possible, counseling and testing services should be offered outside of antenatal clinics.*

Although MTCT prevention programs encourage couples to be tested together, the location of testing in ANC clinics makes it more difficult for men to retain anonymity, since they don't generally attend clinics. In both Botswana and Zambia, study participants expressed the fear that the first partner to be tested will be blamed for bringing the infection into a relationship. Thus, if VCT is available only at ANC clinics, men will be less likely to seek services, while women who test HIV-positive will be more likely to be blamed for the infection.

- *Ensure that community members are not limited to receiving counseling and testing from health workers who are personally familiar to them.*

Many health providers play conflicting roles when they serve their own community. This is particularly evident when they are required to give bad news (e.g., an HIV-positive test result) or maintain confidentiality. Study participants frequently mentioned the difficulty faced by providers in sharing diagnoses with patients and violations of confidentiality as barriers to participation in VCT. MTCT programs must either find a way to successfully motivate and train providers to give sensitive, competent counseling, education, and support to members of their community, or use providers who are not closely connected the community that they serve.

- *Train and encourage health providers to discuss the possibility of HIV infection and the benefits of VCT openly with their clients and to encourage participation in MTCT programs.*

Study participants expressed resentment when they were given inadequate information or false explanations for HIV-related symptoms. Knowledgeable, nonjudgmental, confident communication between providers and patients is essential to decreasing the stigma of being HIV-positive.

Community Acceptance and Support

- *Address and reduce stigma and discrimination against PLWHA, making it psychologically safer for women to participate in VCT.*

Women faced with a decision about VCT will be influenced by perceptions of how their family and community will treat them if it becomes known that they participated in the program, in particular if they prove to be HIV-positive. MTCT prevention programs need to recognize the influence that general community attitudes towards PLWHA have on women's participation, and work towards improving community support and acceptance of both VCT and PLWHA.

- *Increase the level of knowledge about HIV transmission and safe ways to care for AIDS patients in order to reduce the fear and isolation of PLWHA.*

Misconceptions abound about how one can become infected with HIV (including casual contact with or caring for an infected person), contributing to the physical and social isolation of PLWHA and, in turn, reluctance to be tested. Education about HIV/AIDS and how to safely care for AIDS patients is critical to ending this cycle of ignorance and fear.

- *Provide support and services to families to increase their willingness to provide adequate care and support to relatives with AIDS.*

A sense of hopelessness that stems from the inevitability of death, as well as the heavy burden of care, influence the attitudes of family members toward caring for PLWHA. Because of the stigma attached to HIV, there is a perception that families who know that the virus is the cause of a relative's illness seem to decrease their investment in the provision of care. This attitude undermines confidence by PLWHA that they will be adequately cared for when they become ill, in turn increasing resistance to finding out whether one is HIV-positive and sharing this news with others. HIV/AIDS programs should include services, such as home-based care, in order to help alleviate the burden of care on families of PLWHA.

- *Create mechanisms to receive ongoing feedback from community members to monitor their understanding of messages and their perceptions of MTCT prevention programs in order to ensure that misconceptions and problems are addressed quickly.*

Community input is not only valuable for the design of programs, but to periodically engage both participants and others in discussions once an MTCT program has been established. Reactions to the way that VCT services are organized, for example, might result in improvements in the counseling approach used or reinforce the success of what is already in place.

References

Dabis, F., N. Msellati, N. Meda, et al. for the DITRAME Study Group. 1999.
"Six-month efficacy, tolerance, and acceptability of a short regimen of oral zidovudine to reduce vertical transmission of HIV in breastfed children in Côte d'Ivoire and Burkina Faso: a double-blind placebo-controlled multicenter trial." *Lancet* 353:786-92.

Guay, L., P. Musoke, T. Fleming, et al. 1999.
"Intrapartum and neonatal single-dose nevirapine compared with zidovudine for prevention of mother-to-child transmission of HIV-1 in Kampala, Uganda: HIVNET 012 randomised trial." *Lancet* 354:795-802.

Shaffer, N., R. Chuachoowong, P.A. Mock, et al. 1999.
"Short-course zidovudine for perinatal HIV-1 transmission in Bangkok, Thailand: A randomised controlled trial." *Lancet* 353:773-780.

UNAIDS. 1999.
UNAIDS Questions and Answers: Mother-to-Child Transmission (MTCT) of HIV: Background Briefs. Geneva.

UNAIDS. 2000.
Report on the Global HIV/AIDS Epidemic. Geneva.

UNAIDS and WHO. 1999a.
AIDS Epidemic Update: December 1999. Geneva: Joint United Nations Programme on HIV/AIDS and World Health Organization.

UNAIDS and WHO. 1999b.
HIV in Pregnancy: A Review. Geneva: Joint United Nations Programme on HIV/AIDS and World Health Organization.

ICRW Report-in-Brief

0-ICRW

Women, Communities, and the Prevention of Mother-to-Child Transmission of HIV: Issues and Findings from Community Research in Botswana and Zambia

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The International Center for Research on Women

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"The babies don't usually struggle like adults. They just cough a little and then pass on, so it is very difficult to know whether it was HIV or not."
-- Breastfeeding woman, Botswana

Background

To date, AIDS has caused the deaths of more than three million children worldwide, while more than one million are currently infected with the HIV virus that causes the disease (UNAIDS 2000). Among children under 15 years of age, the major cause of HIV/AIDS is the transmission of the HIV virus from mother to child during pregnancy, delivery, and breastfeeding. In the absence of preventive measures, the risk that an infant of an HIV-positive mother will be infected with the virus ranges from 25-35 percent in developing countries (UNAIDS/WHO 1999a).

Until recently, strategies to prevent infants from becoming infected with HIV consisted primarily of the prevention of infection of the mother prior to and during pregnancy, labor, and delivery, as well as information about breastfeeding. Other strategies have included family planning to prevent pregnancy itself, or pregnancy termination where this option is legal and available. Fortunately, additional options for the prevention of mother-to-child transmission (MTCT) of HIV are increasingly available, in particular the administration of a short course of Zidovudine (commonly known as AZT) during pregnancy or a dose of Nevirapine at the onset of labor.[1]

The Need for Qualitative Research

Although Africa accounts for only 10 percent of the world's population, 90 percent of all HIV-infected people live in the region (UNAIDS 2000). In urban areas in southern Africa, rates of HIV infection among women attending antenatal clinics (ANC) can be as high as 20-30 percent (UNAIDS/WHO 1999b). Following a meeting in 1998, the United Nations Children's Fund (UNICEF), in collaboration with the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO), initiated pilot projects in 11 African countries to provide mothers with both a short course of AZT and information on alternatives to breastfeeding. However, these projects—in large part due to time constraints—have been conducted using little consultation with or feedback from residents of the targeted communities.

It is critical that communities have a voice in solving problems that affect them. Pregnant women do not face the issues that surround MTCT (i.e., HIV testing and counseling, drug treatment during pregnancy, and alternative infant feeding practices) in a social and economic vacuum. Partners, family, and community members influence, and are influenced

[1] See Dabis, F., N. Msellati, N. Meda, et al. for the DITRAME Study Group. 1999. "Six-month efficacy, tolerance, and acceptability of a short regimen of oral zidovudine to reduce vertical transmission of HIV in breastfed children in Côte d'Ivoire and Burkina Faso: a double-blind placebo-controlled multicenter trial." *Lancet* 353:786-92; Guay, L., P. Musoke, T. Fleming, et al. 1999. "Intrapartum and neonatal single-dose nevirapine compared with zidovudine for prevention of mother-to-child transmission of HIV-1 in Kampala, Uganda: HIVNET 012 randomised trial." *Lancet* 354:795-802; and Shaffer, N., R. Chuachoowong, P.A. Mock, et al. 1999. "Short-course zidovudine for perinatal HIV-1 transmission in Bangkok, Thailand: A randomised controlled trial." *Lancet* 353:773-780.

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by, the decisions that a woman makes about each of these issues. Because the benefits of many technologies (prescription drugs and a required blood test in the case of MTCT) are often overshadowed by conflicting community norms, values, and beliefs, talking to women and other members of a community is a vital part of the process of preventing HIV transmission to infants.

The Study[2]

Between October 1999-May 2000, GlaxoWellcome and UNAIDS jointly funded two formative research studies in Botswana and Zambia on the perspectives, needs, and preferences of women and communities regarding the MTCT of HIV. In Botswana, nearly 36 percent of adults are now infected with HIV, representing more than a tripling of adult prevalence since 1992 (UNAIDS 2000). In 1998, the median rate of HIV infection among Botswanan women attending ANC was 43 percent in urban and 30 percent in non-urban areas (UNAIDS 2000). In Zambia, more than one in four adults living in cities are infected with the HIV virus, as well as one in seven adults in rural areas (UNAIDS 2000). In 1998, median rates of HIV infection among Zambian women tested at ANC were 27 percent in urban and 14 percent in non-urban areas (UNAIDS 2000).[3]

The main objective of the studies, carried out by the International Center for Research on Women (ICRW) in collaboration with in-country partners, was *to obtain information and data that could be used to improve the effectiveness and acceptability of messages and services for MTCT prevention on the community level.*[4] Specifically, the studies sought insights about what women and communities know about MTCT and whether they define it as a problem, as well as the factors that determine their participation in voluntary counseling and testing (VCT), a critical first step in MTCT prevention.

To this end, focus group discussions (FGDs) were held with residents of one community in each country.[5] Each FGD was made up of 8-12 participants from distinct populations, including breastfeeding and pregnant women, men, and male and female community elders. Moderators and interviewers used guides developed by ICRW and the research partners, while local contacts and clinic personnel helped to identify and recruit study participants.

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[2] A comprehensive synthesis paper of the study (with the same title as this brief and available through ICRW) is based on two separate reports: Sheila Tlou, Laura Nyblade, Ross Kidd, Mary Lyn Field, Koketso Rantona, and Samson Sentumo. *Report on formative research on community responses to initiatives to prevent mother-to-child transmission in Bontleng, Gaborone, Botswana.* June 2000; and Ginny Bond and Phillimon Ndubani, in association with Laura Nyblade. *Formative research on mother-to-child transmission of HIV/AIDS in Zambia: A report of focus group discussions held in Keemba, Monze, November 1999.* June 2000.

[3] In comparison to Botswana and Zambia, several African countries have much lower rates of HIV. For example, in Ghana in 1998, the median prevalence among women tested at antenatal clinics was under 4 percent in both urban and non-urban areas (UNAIDS 2000).

[4] ICRW worked with the Society for Women and AIDS in Botswana (SWAABO), an NGO established in 1995 to provide HIV/AIDS education, support, and prevention programs to women throughout the country. The collaborating partner in Zambia was the MTCT Research Team of the National MTCT of HIV Working Group, appointed by the Minister of Health in August 1998 to develop interventions and offer technical assistance and advice to the Government's Central Board of Health.

[5] Because the studies were conducted in only one location in each country, contrasting findings between the countries may be attributable to urban-rural differences to at least the same degree as national or cultural variations. In addition, although the same views are likely to be found in other communities, a study conducted on a national scale would certainly yield important variations.

In Bontleng, a low-income urban community within the city of Gaborone in Southeast Botswana, residents have access to a government MTCT prevention program through a clinic with excellent infrastructure. Moderators conducted a total of 11 FGDs, as well as ten in-depth interviews with women participating in the MTCT program, one group interview with family welfare educators, and two individual interviews with nurse-midwives.[6] In Keemba, Zambia, a rural community in the South-Central Monze district, residents have access to basic clinic services. Moderators conducted 15 FGDs, 13 near the Keemba health center and two at an outreach health post in Chuungu village.

"When you get AIDS you are ridiculed by society, they laugh at you, they don't regard it as just an illness. You are ill-treated, you are no longer related to like before. People think you have been careless, promiscuous. They don't know that AIDS can just come to you at home."
-- Pregnant woman, Botswana

Findings

The studies focused on two overarching areas of concern: the context in which women make decisions about MTCT prevention, and community residents' perceptions of and participation in current and planned MTCT prevention programs. Key findings in these areas included the following:

- In Botswana, participants perceived HIV/AIDS to be a highly prevalent problem. However, many also defined it as largely "invisible," stating that they lacked personal experience with the epidemic. In Zambia, HIV/AIDS was perceived as a large and overwhelming problem.
- Study participants in Botswana revealed a wide range of knowledge and understanding about HIV transmission and HIV and MTCT prevention. Those who knew about the MTCT prevention program recognized that it can save the lives of babies, but questioned why little was being done to also help mothers.
- In contrast, the groups in Zambia were well informed about HIV/AIDS, but had yet to be exposed to the concept of and issues surrounding MTCT.
- In both countries, talks at antenatal and well-child clinics were the primary source of information about health issues in general and HIV/AIDS in particular.
- Men and community elders rarely utilize clinic services, a factor that contributed to women being better informed than men about all aspects of HIV/AIDS and MTCT.
- In both communities, stigma, discrimination, and isolation are faced by persons living with HIV/AIDS (PLWHA). These trends in turn deter residents from seeking HIV testing and counseling.
- The majority of study participants had little experience with counseling and testing services and thought disclosure of testing (particularly if the test was positive), would be very difficult, primarily due to the stigma of being HIV-positive.
- Participants expressed fear that if HIV was determined to be the cause of an illness, family and community members would be less willing to provide care and support.
- A key barrier to VCT is the belief that the first person in a couple to be tested will be blamed for bringing HIV into the relationship.

[6] An MTCT program was launched in two Botswanan cities in 1999. Preparations for establishing an MTCT program are currently underway in Zambia.

- The strength of cultural norms and pressure to breastfeed was reflected in derogatory references to women who do not breastfeed. Although legitimate reasons to not breastfeed are recognized, women must explain their choice to family and community members, a difficult process because of the tendency (particularly in Botswana) to suspect that women who do not breastfeed are HIV-positive.

Conclusions

Overall, an MTCT program is strongly affected by the perceptions and beliefs that exist about HIV/AIDS and how a community deals with the epidemic. The primary conclusion from the study is therefore that *MTCT prevention programs have an urgent need for the information and perspectives that emerge from community dialogue about HIV/AIDS and MTCT prevention.*

Data revealed that *a powerful and potentially negative relationship exists between the misinformation and lack of community dialogue about HIV/AIDS and MTCT, stigmatization of PLWHA, and the difficulties faced by HIV/AIDS prevention efforts.* Because women trying to decide whether to participate in an MTCT prevention program are profoundly influenced by the opinions of their spouses/partners, family, and community, *MTCT prevention programs must reach these significant others in women's lives with information, education, services, and support.*

MTCT prevention programs have the potential to both save the lives of many children and bring HIV/AIDS to the forefront of public discourse, often in new ways. But they also have the potential to fail if they do not ensure that women are full participants and if they contribute to the stigmatization and rejection of women who participate. *Success is only possible if communities understand and support women seeking to prevent the transmission of HIV to their infants.*

"The goodness of being tested for HIV is not yet known in the villages."
-- Male participant, Zambia

Recommendations

Focus group discussions provide a unique opportunity for participants to gain information and reflect on the complex issues they face as a result of the AIDS epidemic. This *strategy of participation, open discussion, and feedback should be the basis for research and education programs on HIV/AIDS and MTCT.*

In order to enhance understanding of the HIV/AIDS and MTCT processes, *community residents should have access to education on basic anatomy and physiology in relation to pregnancy.* To ensure that misconceptions and problems are addressed quickly, *mechanisms should be created to receive ongoing feedback from community members to monitor their understanding of communications messages and their perceptions of MTCT prevention programs.* Because of the overwhelming nature of the epidemic and the growing prevalence of MTCT, *education programs and VCT should be supported by messages that have a hopeful tone and use positive role models.*

In order to reach groups other than pregnant women and mothers, *whenever possible, counseling and testing services should be offered outside of antenatal clinics.* In particular, because they are key decision-makers in communities, *men and elders in the community should be the target of program strategies that offer information and opportunities for discussions about HIV/AIDS and MTCT.*

Similarly, because they assist mothers in making informed choices, *health providers should be prepared to understand the link between HIV and breastfeeding, as well as the risks associated with other feeding practices.* This will ensure that they can competently and compassionately counsel women about infant feeding options and convey to the community that MTCT programs do not dictate one method over another. In addition, because of the potential social stigma and "conflicts of interest," *community residents should not be limited to receiving counseling and testing from health workers who are personally familiar to them.*

MTCT prevention programs need to recognize the influence that general community attitudes towards PLWHA have on women's participation, and should therefore *work to reduce stigma and discrimination against PLWHA, making it psychologically safer for women to participate in VCT.* In order to reduce the fear and isolation of PLWHA, programs will have to *increase the level of community understanding about HIV transmission and safe ways to care for AIDS patients.* It is also crucial to *provide support and services to families in giving adequate care and support to relatives with AIDS so that those infected with HIV can be confident that they will be cared for if needed.*

Glossary of Acronyms

AIDS	Acquired Immunodeficiency Syndrome
ANC	Antenatal clinic
AZT	Azidothymidine (zidovudine)
FGD	Focus group discussions
HIV	Human Immunodeficiency Virus
MCH	Maternal child health
MTCT	Mother-to-child transmission
PLWHA	Persons living with HIV/AIDS
VCT	Voluntary counseling and testing

References

UNAIDS
- 1999. Questions and Answers: Mother-to-Child Transmission (MTCT) of HIV: Background Briefs. Geneva.
- 2000. *Report on the Global HIV/AIDS Epidemic.* Geneva.

UNAIDS/WHO
- 1999a. *AIDS Epidemic Update: December 1999.* Geneva.
- 1999b. *HIV in Pregnancy: A Review.* Geneva.

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ICRW Information Bulletin

Draft 9 March 2000

Summary
AIDS in Africa: Related Legislation of the 106th Congress

I. Health Legislation with an AIDS Component

Global Health Act of 2000
HR 3826, Crowley, Leahy
Saving Women's Lives through International Family Planning Act of 2000
HR 3634, Maloney

II. AIDS Specific Legislation

A. House/Senate Bills

World Bank AIDS Prevention Trust Fund
HR 3519, S 2033 Leach, Kerry
Lifesaving Vaccine Technology Act of 1999
HR 1274, S 1718 Pelosi, Kerry

B. House Bills

AIDS Marshall Plan Fund for Africa Act
HR 2765 Lee
To Suspend Temporarily the Duty on HIV/AIDS Drugs
HR 1952 Becerra

C. Senate Bills

Global AIDS Prevention Act of 2000
S 2026 Boxer
Mother-to-Child HIV Prevention Act of 2000
S 2032 Moynihan
AIDS Orphan Relief Act of 2000
S 2030 Durbin
Vaccines for the New Millennium Act of 2000
S 2132 Kerry

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I. Health Legislation with an AIDS Component

Title: **The Global Health Act of 2000**

Bill Number: Not yet assigned; legislation expected to be introduced in early March

Sponsors: Crowley (D, NY), Leahy (D, VT)

Highlights: Authorizes a $1 billion increase over FY 2000 funding for **existing global health programs,** including those addressing HIV/AIDS, family planning, infectious diseases (other than HIV/AIDS), and maternal health programs. Includes funding for strengthening health care delivery systems to ensure the delivery of vaccines, drugs and medical devices for people in developing countries.

	Proposed Funding Increases over FY 2000 Levels	**Proposed FY 2001 Total**
Child survival	$225 million	$525 million
Maternal health	$100 million	$150 million
Family planning and reproductive health	$200million	$610 million
HIV/AIDS	**$275 million**	**$500 million**
Infectious diseases (non-HIV/AIDS)	$200 million	$314 million

Comment: Comprehensive, requests large amount of increases, builds on existing structures rather than establishing new mechanisms. Limited to health sector.

Status: Expected to be introduced in March. Endorsed by 116 organizations.

Title: **Saving Women's Lives through International Family Planning Act of 2000**

Bill Number: HR 3634

Sponsor: Maloney (D, NY)

Highlights: Authorizes $541.6 million for USAID population assistance programs for FY 2001; authorizes $35 million U.S. contribution to the UN Population Fund. Population assistance programs address reproductive health needs, including HIV/AIDS and others sexually transmitted diseases.

Status: 2/10/2000: Referred to the House Committee on International Relations.

II. AIDS-Specific Legislation

A. House/Senate Bills

Title:	**World Bank AIDS Prevention Trust Fund**
Bill Number:	HR 3519, S 2033
Co-Sponsors:	Leach (R, IA) and Kerry (D, MA)
Highlights:	Establishes a fund at the World Bank that could accept contributions from governments, private sector, nongovernmental entities to address the AIDS epidemic in developing countries who are eligible to borrow from the International Development Association (IDA). Authorizes appropriations to the Treasury Secretary for payment to the trust fund. Reporting by Secretary to congressional committees on the goals, programs, projects, and activities (including any vaccination approaches) supported by the trust fund and their effectiveness in reducing the worldwide spread of AIDS. Stated Purpose includes "advancing research to understand the causes associated with HIV/AIDS and to assist in the development of an AIDS vaccine." Authorizes appropriations of $100 million for each of fiscal years 2001 through 2005 for payment to the trust fund.
Status:	Referred to House Committee on Banking and Financial Services. Referred to Subcommittee on domestic and international monetary policy.
Comment:	Question of increased indebtedness if funds are available as loans rather than grants. Government, NGO balance of activity and competitive advantages and access to funds not addressed. Some countries that do not qualify under IDA have significant AIDS problem and would not be able to access assistance under this mechanism. Technical oversight unclear. No specified connection with current World Bank program for Africa. Good opportunity to leverage private funds. Puts AIDS in context of overall development.

Title:	**Lifesaving Vaccine Technology Act of 1999**
Bill Number:	HR 1274, S 1718
Sponsors:	Pelosi (D, CA), Kerry (D, MA)
Highlights:	Amends the Internal Revenue Code of 1986 by providing a tax credit for medical research related to the development of vaccines against widespread diseases—specifically malaria, TB and HIV. Vaccine research is defined as including vaccines and microbicides for malaria, tuberculosis and HIV or any infectious disease of a single cause which, according to WHO, causes over one million deaths annually. Research credit is determined for the taxable year as an amount equal to 30 percent of the qualified vaccine research expenses for the taxable year; not including incurred expenses paid by government or private research grants. No credit for testing other than human clinical testing outside of US; details shareholder equity investment credit in lieu of research credit, and other general business credit issues. Corporations receiving credit must, within one year after a vaccine is first licensed, establish a good faith plan utilizing technology transfer, differential pricing, in-country production, or other mechanisms to maximize international access to high quality and affordable vaccines. The IOM shall conduct a study of the effectiveness of the credit in stimulating vaccine research. The Institute of Medicine (IOM) shall submit to Congress the results of such study with recommendations to improve effectiveness of such credit in stimulating vaccine research. Includes sense of Congress language calling for flexible or differential pricing for vaccines, providing lowered prices for the poorest countries, is one of several valid strategies to accelerate the introduction of vaccines in developing countries.
Status:	In House, referred to Ways and Means Committee, Commerce Committee, referred to the Commerce Subcommittee on Health and Environment. In Senate, referred to Committee on Finance.

B. House Bills

Title:	**AIDS Marshall Plan Fund for Africa Act**
Bill Number:	HR 2765
Sponsor:	Lee (D, CA)
Highlights:	Introduced in August of 1999, this bill proposes to amend the Foreign Assistance Act of 1961. The bill would establish a corporation, the AIDS Marshall Plan Fund for Africa Corporation (AMPFA Corporation) which would, in consultation with the Director of the Office of National AIDS Policy (ONAP) and the Overseas Private Investment Corporation (OPIC) and the heads of other Federal agencies involved in HIV/AIDS activities in Africa, establish and carry out a program to provide assistance for HIV/AIDS research, prevention, and treatment activities in Africa. The Corporation would have a Board of Directors, an Advisory Board of Directors, a President, an Executive Vice President and such other officers and staff as the Board of Directors may determine. The Board would be appointed by the President with the advice and consent of the Senate as would the President and Vice President of the Corporation. Activities would be carried out in consultation with representatives of community-based African health, education and other related organizations, provide grants to African governments and nongovernmental organizations for projects that provide research, prevention and treatment for individuals in Africa with HIV/AIDS and would solicit and accept contributions to the fund form private sources, foreign governments, including G-8 countries and disburse such contributions to carry out the program. Governments receiving grants would be required to establish a comprehensive plan for activities in the country and a system of accountability. Matching fund requirements would be determined. Appropriation of $200 million each of fiscal years 2001 through 2005 plus additional amount of equal to 25 percent of total amount of funds contributed to the fund. Administrative expenses could not exceed more than 8 percent for the total amount appropriate for a fiscal year.
Comment:	Does not recognize or direct coordination with existing mechanisms and establishes a new institution. Questions about OPIC's ability to assume prescribed role. Incorporates local community organizations in grant process. Uses the term "provide treatment" but does not specify drug purchase mechanism.
Status:	Referred to the House Committee on International Relations.

Title:	**To Suspend Temporarily the Duty on HIV/AIDS Drugs.**
Bill Number:	HR1951
Sponsor:	Rep. Xavier Becerra
Co-Sponsors:	None
Highlights:	Temporarily suspends duty on specific HIV/AIDS drugs
Status:	Referred to the House Committee on Ways and Means.

C. Senate Bills

Title:	**Global AIDS Prevention Act of 2000**
Bill Number:	S 2026
Sponsor:	Boxer (D, CA)
Highlights:	Amends the Foreign Assistance Act of 1961 to authorize appropriations for HIV/AIDS efforts. Adds language that specifies that the agency will be expected to make HIV/AIDS a priority in the foreign assistance program and to undertake a comprehensive, coordinated effort to combat HIV/AIDS, including the provision of primary prevention and education, voluntary testing and counseling, medications to prevent the transmission of HIV/AIDS from mother to child and care for those living with HIV/AIDS. Appropriation is $300 million for FY2001, $350 million for FY2002; $400 million for FY2003; $450 million for FY2004 and $500 million for FY2005. Not less than 50 percent of funds made available each fiscal year will be used for AIDS in sub-Saharan Africa. Funds will remain available until expended.
Comment:	Uses existing structure to conduct programming and oversight. Requests significant increase in funding. Does not indicate role of government and NGOs in implementation. Specifies strategies that are limited to traditional public health interventions. Mentions no other sectors, e.g., finance, labor, agriculture.
Status:	2/2/2000: Read twice and referred to the Committee on Foreign Relations.

Title:	**Mother-to-Child HIV Prevention Act of 2000**
Bill number:	S2032
Sponsors:	Moynihan (D, MA), Feingold (D, WI)
Highlights:	Amends the Foreign Assistance Act of 1961 to address the issue of mother-to-child transmission of HIV in Africa, Asia, and Latin America. Directs agency responsible for administering strategy to prevent mother to child transmission to coordinate with UNAIDS, UNICEF, WHO, local governments and other organizations to

develop and implement effective strategies to prevent vertical transmission of HIV and to coordinate with those organizations to increase in scale intervention programs and introduce voluntary counseling and testing, antiretroviral drugs, replacement feeding and other strategies more widely in due course.
Authorizes appropriation of $25 million in addition to amounts otherwise available for years 2001 through 2005. Funds are authorized to remain available until expended.

Comment: Not limited to or specified as to concentration of efforts in Africa. Specifically for prevention of mother to child transmission which is not major source of transmission. Mentions implications of work in this area for overall HIV prevention. Includes recognition of the issue of stigma, but does not indicate means by which stigma can be overcome. Encourages counseling and testing. Mentions Nevirapine but not AZT. Assumes infrastructure improvement.

Status: Referred to Senate Foreign Relations Committee

Title: **AIDS Orphans Relief Act of 2000**
Bill Number: S 2030
Sponsor: Durbin (D, IL)
Highlights: Amends the Foreign Assistance Act of 1961 to authorize microfinance and food assistance for communities affected by AIDS and for other purposes.
Sets forth program requirements. For the purpose of making microfinance programs an important component of US policy in fighting effects of AIDS pandemic and encourage targeted use of food and food-related assistance for humanitarian purposes and for sustainable development in communities affected by AIDS.
Authorizes appropriation of $50 million to assist microcredit programs that serve the very poor, especially women, in communities heavily affected by AIDS.
Maximum amount to one individual not over $600 and average loan size for program receiving resources may not exceed $300.
Amounts are to be provided for programs that provide HIV prevention or AIDS care and support whether directly or through linkages with other programs; employ best practices for assisting very poor and operate in a sustainable manner.

Amends Title IV of the Agricultural Trade and Development Assistance Act of 1954 by adding a section that provides food assistance under the Act to developing countries in order to assist them in mitigating the effects of AIDS on communities in such countries, including assistance to address nutritional needs of individuals in such communities, assistance for households

	affected by AIDS and assistance as part of other aid or assistance designed to create or restore sustainable livelihood strategies in communities affected by AIDS. Appropriates each fiscal year, $50 million for purposes of providing assistance under this section.
Comment:	Only bill that focuses primarily on mitigation and acknowledges economic determinants of AIDS prevention and mitigation. Little focus on prevention. Background focuses on sub-Saharan Africa but bill does not specify use as limited to this region.
Status:	Read twice and referred to Committee on Foreign Relations
Title:	**Vaccines for the New Millennium Act of 2000**
Bill Number:	S 2132
Sponsor:	John Kerry (D, MA)
Highlights:	A bill to create incentives for private sector research related to developing vaccines against widespread diseases and ensure that such vaccines are affordable and widely distributed. This bill addresses a number of vaccines, including those related to HIV. Sections of the bill include: universal early childhood immunizations, voluntary contributions to global alliance for vaccines and immunizations and international AIDS vaccine initiative, credit for medical research related to developing vaccines against widespread disease, credit for certain sales of lifesaving vaccines, lifesaving vaccine purchase fund, multilateral lifesaving vaccine purchase fund, appropriated to the President for fiscal year 2001 an amount not in excess of $50,000,000 and for fiscal year 2002 an amount not in excess of $100,000,000 to be available only for United States contributions to the Global Alliance for Vaccines and Immunizations. The bill has sections that are intended to 1) create incentives for private sector research into vaccines for HIV, malaria, tuberculosis, and other major infectious diseases; and to (2) ensure that vaccines for major infectious diseases are affordable and widely distributed. It establishes in the Treasury of the United States a trust fund to be known as the `Lifesaving Vaccine Purchase Fund.' The Secretary of Treasury is authorized to expend amounts in the Fund for purchases of eligible vaccines. Such vaccines shall be distributed to developing countries.
Status:	3/1/2000: Read twice and referred to the Committee on Foreign Relations.

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ICRW
International Center for Research on Women

Bridging the Gap

Addressing Gender and Sexuality in HIV Prevention

Ellen Weiss
Geeta Rao Gupta

Findings from the Women and AIDS Research Program

WHAT DOES AIDS HAVE TO DO WITH ECONOMICS?

Number of people newly infected with HIV in one year: Six Million
Annual cost of treating one person with the latest drugs: $8,000–$25, 000
Annual per capita health expenditure in low income countries: $2–$6
Cost of preventing a new HIV infection: $0–$400, depending on the intervention

THE INTERNATIONAL AIDS-ECONOMICS NETWORK

Data, tools, and analysis on the economics of HIV/AIDS prevention and treatment, for compassionate, cost-effective responses to a global epidemic

ONLINE RESOURCES OF THE AIDS-ECONOMICS NETWORK

http://www.iaen.org

- Full Text of *Confronting AIDS: Public Priorities in a Global Epidemic*
- *Considering HIV/AIDS in Development: A Toolkit*
- Methods and Models: Cost-Effectiveness Analysis for HIV Prevention
- The Economics of Anti-Retroviral Treatment in Developing Countries
- Bibliographic Database
- Free monthly e-mail newsletter

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AIDS epidemic update:

December 1999

Joint United Nations Programme on HIV/AIDS

UNAIDS

UNICEF • UNDP • UNFPA • UNDCP
UNESCO • WHO • WORLD BANK

World Health Organization

Joint United Nations Programme on HIV/AIDS
UNAIDS
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US Media Office (212) 584-5024

Facts and Figures

- Over 33 million people are HIV-positive, that is 1 out of every 100 people worldwide between 15 and 44 years old.

- AIDS has already become as big a killer in Africa as malaria. Economic losses due to AIDS may soon outweigh foreign aid in some countries.

- A study in Kenya in 1995 came to the conclusion that over the period of the next 20 years the gross domestic product (GDP) will be 14.5% smaller than it otherwise would have been had AIDS never occurred. Per capita income will decrease by 10%, and the country's macro economy will decline as more money is spent on health care.

- In households in Thailand and Côte d'Ivoire where a family member is HIV-infected, household income declines by 40–60%. The Thai epidemic is projected to cost Japan 1.2% of its gross national product (GNP) by the year 2000 as a result of losses in trade and potential markets.

- Uganda Railways has lost about 5600 employees to AIDS and has a labour turnover rate of 15% annually. The medical and funeral expenses of another Ugandan company doubled in one year.

- By the year 2000, one-third of the deaths among the work population in Thailand will be from AIDS.

- In Asia, the business response to the AIDS epidemic has until now been weak. The 885.8 million people working in Asia have received only sparse HIV prevention support.

- In Madras, India, a study of large industries found that absenteeism is expected to double in the next two years, largely as a result of STDs and HIV-related illness. This study also found that 75% of employees were unaware that condoms could prevent STDs and AIDS and only 5% of employees used condoms properly.

- The death rate among young adults in formal employment in South Africa is projected to increase threefold by the year 2000 due to AIDS. A study in South Africa projects that the total costs of employee benefits will rise from 7% to 19% between 1995 and 2005 because of AIDS.

- ILO projects there will be 3 billion men and women in the productive sector by the year 2000, and 80% of them will be in the less developed countries of the world. 2.1 billion will be in the 15–44 age group, the segment of the population most affected by HIV. Where national AIDS programmes have created opportunities for business leaders to contribute strategically, as for instance in Thailand, there are relatively successful responses. Their workplaces are the platforms and opportunities to reach them in large numbers and with high impact.

- An average of 15 years of working life will be lost per employee due to AIDS, according to ILO estimates.

- Nearly 10,000 men and women in sub-Saharan Africa are becoming infected every day. While they may work productively for a decade or more, most will die before they reach retirement age.

UNAIDS BEST PRACTICE COLLECTION

A review of household and community responses to the HIV/AIDS epidemic in the rural areas of sub-Saharan Africa

UNAIDS
Geneva, Switzerland
1999

Acknowledgement

This review was compiled by **Gladys Mutangadura, Duduzile Mukurazita** *and* **Helen Jackson**

UNAIDS/99.39E (English original) June 1999

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Foreword

In 1997 the Cosponsors of UNAIDS proposed planning a project on the impact and consequences of the HIV/AIDS epidemic to be carried out in 1998–99. Sectors to be surveyed include agriculture, children and families. The present report was initiated by UNAIDS with the cooperation of UNDP and FAO following a regional conference in Harare in June 1998 that focused on the impact of HIV/AIDS on smallholder rural households. This initiative in form of a background paper is part of the Coordinated Appeal among the Cosponsors of UNAIDS and focuses on rural areas. It takes the form of a literature survey of the information gathered so far on rural household and community responses to alleviating the HIV/AIDS epidemic with the focus on sub-Saharan Africa. Such knowledge is imperative for improving the planning of the future response in rural areas. It is crucial that we know what works and what the costs are to make it work.

The report is based on the work of Gladys Mutangadura, Duduzile Mukurazita and Helen Jackson who compiled and analysed the review on rural household and community responses to the HIV/AIDS epidemic.

In many countries and areas with a high prevalence, HIV/AIDS represents not only a health threat to the individual, and a social and economic threat to families and communities, but also destroys developmental gains acquired with difficulty over the past decades. The overall effect on society is often measured in loss of growth of GNP or lost development (points) in the Human Development Index used by UNDP. Such values/points are often abstract figures to decision makers, but such loss directly affects people when disaggregated at the household level. The effect of HIV/AIDS on households is devastating: from household surveys in Africa and Asia (Côte d'Ivoire, Tanzania and Thailand) we know that families living with HIV/AIDS have a substantial income reduction of 40–60%. This loss is compensated through spending of savings, borrowing, and reduction of consumption. These are the economic aspects; the social response strategies involve the dissolution, or part dissolution, of families: children are sent away to live with relatives; a spouse or a child migrates to earn an income; and sometimes, on the death of a spouse, the widow has to move to a brother's house.

In order to improve conditions for rural families living with HIV/AIDS and to help sustain their income base, we, the international and national decision makers and NGOs working in this field, need to broaden our knowledge of the coping strategies already being exercised by the families and communities themselves. In the process of doing this, we need to cast light on what strategies work in a sustainable way and what costs are involved in ensuring the success of such initiatives.

Hopefully, the present report will serve as inspiration for communities, NGOs and donors working in rural areas, mainly in Africa where the epidemic is not only a problem in cities or specific sub-populations, but where the disease is also taking a heavy toll on villages

and communities. The report provides examples of what strategies have worked and failed. However, it does not answer the question of the costs and effectiveness of the response initiatives as originally intended. Very few initiatives undertaken regarding the response of rural households and communities to the HIV/AIDS epidemic have been evaluated for their effectiveness and virtually none for their costs to society. It is an important finding in itself, and serves as a reminder to implementers, that few can adopt methods used by others when only the process itself is described. Process evaluation is important but not sufficient to serve as a basis for a decision of implementation. We need to know what works and why if we are to assist policy in this field.

Systematic evaluations in this field, including cost-effectiveness analyses, should be incorporated to ensure that choices are made taking into account efficiency, affordability, sustainability and equity issues when planning for the responses. It is clear from the survey that standards of impact and effectiveness are seldom defined. To ensure appropriate planning, measures of impact and outcome (in the short and long term), as well as the costs of the initiatives are needed. Such evaluations could include indicators of success such as the number of families covered by the scheme, school attendance, food security and cash availability depending on the objectives of the programme. Hopefully, this background paper will feed discussions on what can be done in rural areas to mitigate the impact of HIV/AIDS at both the household and the community level. We also hope that it will encourage policy makers and communities to monitor and document the effectiveness and the costs involved in such initiatives and so create a collective memory in this field.

Acronyms

ABEKA	*Abemahamo ba Karagwe, CBO in Tanzania*
AIDS	*Acquired Immune Deficiency Syndrome*
ASO	*AIDS support organization*
AZT	*Azidothymidine/zidovudine*
CBO	*Community-based organization*
CIDA	*Canadian International Development Agency*
DANIDA	*Danish International for Development Agency*
DFID	*(UK) Department for International Development*
HIV	*Human immunodeficiency virus*
ELCT	*Evangelical Lutheran Church of Tanzania, Huyawa*
FACT	*Family AIDS Caring Trust*
FOCUS	*Families, Orphans and Children Under Stress Programme*
GASCO	*Gomba AIDS Care Organization*
GTZ	*Deutsche Gesellschaft für Technische Zusammenarbeit (German Technical Cooperation)*
HIVOS	*Humanistic Institute for Cooperation with Developing Countries (Netherlands)*
IDS	*Institute of Development Studies, University of Zimbabwe*
IGP	*Income-generating project*
KAKAU	*Kanisa Katoloki na UKIMWI, CBO in Tanzania*
KARADEA	*Karagwe Development Association*
KISA	*Kisa Farm Women's Group*
KOCC	*Kemondo Orphan Care Center*
KOTF	*Kagera Orphans Trust Fund*
MACOP	*Missenyi AIDS Control Orphans Project*
MoHCW	*Ministry of Health and Child Welfare, Zimbabwe*
NACWOLA	*National Community of Women Living with HIV/AIDS*
NGO	*Nongovernmental organization*
NORAD	*Norwegian Agency for Development Co-operation*
PLWHA	*People living with HIV/AIDS*
PSG	*Project Support Group, University of Zimbabwe*
ROSCA	*Rotating Savings and Credit Association*

SAfAIDS	*Southern Africa AIDS Information Dissemination Service*
SAFO	*Society for AIDS Families and Orphans, South Africa*
SARDC	*Southern Africa Regional Documentation Centre*
SHG	*Self-help group*
SIDA	*Swedish Agency for International Co-operation*
STD	*Sexually transmitted disease*
STOGA	*St Theresa's Old Girls Association*
TARSC	*Training and Research Support Organization*
TASO	*The AIDS Support Organization, Uganda*
UNDP	*United Nations Development Programme*
UNICEF	*United Nations Children's Fund*
USA	*United States of America*
USAID	*United States Agency for International Development*
US$	*United States dollar*
VCT	*Voluntary counselling and testing*
WAMATA	*Walio Katika Mapambano na Ukimwi, Rubya Branch (Those at War with AIDS in Tanzania)*
WB	*World Bank*
WHO	*World Health Organization*
ZAN	*Zimbabwe AIDS Network*

Executive summary

Introduction

The purpose of this study is to review the literature on household and community coping responses to HIV/AIDS and make policy recommendations. This paper serves as a background paper for a much shorter and more advocacy-oriented tool to stimulate discussion among the UN theme groups and the major stakeholders on what can be done in sub-Saharan Africa. This study was a desk review and analysis of relevant literature. The literature review has some limitations: because it focuses on sub-Saharan Africa, the findings may not be applicable elsewhere; and as it was a desk review, it was difficult to obtain "grey" material, which has inevitably led to gaps in coverage.

Findings

The literature review on household coping responses revealed that a variety of responses are used which can be categorized as:

1. Strategies aimed at improving food security;
2. Strategies aimed at raising and supplementing income so as to maintain household expenditure patterns; and
3. Strategies aimed at alleviating the loss of labour.

Coping strategies not requiring any cash were the ones most frequently adopted. Examples of these strategies include intra-household labour re-allocation, taking children out of school, diversifying household crop production and decreasing the area cultivated. While some of the coping responses can be reversed, some, such as withdrawal of children from school, are often irreversible. These could be viewed as short-term strategies with long-term consequences for survival.

Costs and effectiveness of indigenous household coping strategies have not been documented in research. This is clearly a knowledge gap that needs to be investigated in the future.

Policy options that can be adopted to strengthen the coping capacity of households with the impact of HIV/AIDS include:

- improving the access of households to limited resources such as labour, land, capital, draught power, and management skills;
- promotion of optimal use of available resources through improved technologies; economic support to improve incomes of affected households through income-generating activities;

- provision of self-support (empowerment) to affected groups such as child-headed households, widows, grandparents, youths, orphans, sex workers, etc., with the aim of reducing further vulnerability and strengthening their coping capacity.

Different community initiatives have sprung up to support and mitigate the impact of HIV/AIDS, driven by NGOs, religious groups, traditional healers, people living with HIV/AIDS, women, youth and others. These include:

- community-based child care;
- cooperative day care and nutrition centres to assist women cope with their work load;
- orphan support in the form of nutritional and educational assistance;
- repair of deteriorating houses;
- home care and visits to orphans and HIV/AIDS patients;
- preparation and distribution of school uniforms;
- apprenticeships and training in marketable skills to orphaned adolescents;
- agricultural projects at various levels to increase output;
- labour sharing; income-generating projects to produce food and cash;
- savings clubs and credit schemes for funeral benefits.

Community coping responses take the form of traditional grassroots or indigenous organizations such as social support groups, savings clubs and informal self-help groups, and formal community-based organizations which rely to some extent on external support from NGOs or other agencies.

Traditional indigenous groups are a major source of support in communities that are experiencing the impact of the AIDS epidemic. Literature in Tanzania, Zambia and Zimbabwe indicates that many communities have traditional indigenous groups such as savings clubs, burial societies, grain-saving schemes and labour-sharing schemes which play a major role in helping households cope with the HIV/AIDS epidemic.

In the hardest hit regions of Kagera in Tanzania, a household demographic study found that new emergency associations had specifically been formed to cope with the income and labour demands of the AIDS epidemic. The major activities done by these emergency associations include assisting with burial ceremonies, communal farming, supporting sick patients, re-building dwellings and rehabilitating farms, supporting survivors and income-generating activities. As well as providing material support, these informal groups are a major source of psychosocial support. But as the number of AIDS-related deaths increase, these existing local strategies are increasingly under pressure and there is need to design policies and programmes that are capable of providing support when existing strategies become inadequate.

Formal community initiatives include community-based organizations and AIDS support organizations which rely to some extent on external support from NGOs, governments or other development institutions. Their mitigation activities vary from country to country, but include agriculture and off-farm income-generating activities such as

handicrafts, bee-keeping, carpentry, tailoring, sewing, pig-farming, poultry-farming, banana and vegetable cultivation and building construction.

The literature also revealed that changes in community cultural norms and values have been experienced as communities try to cope with HIV/AIDS. Many communities today do not have the human and material resources to continue the culturally prescribed rituals, and rapid adjustments have had to be made. Several studies indicate that periods of mourning have been reduced substantially. Some studies also indicated changes in some traditional cultural practices which increase the spread of HIV transmission. For example, in a study undertaken in Zambia, ritual cleansing which involves sex was found to be on the decrease, particularly if the cause of death is suspected to be AIDS.

The community-based programmes which depend on external support have been responsive to the needs of those affected by AIDS, providing a much wider and more holistic package to affected and infected members. However such programmes have limitations which include: poor organizational management skills; lack of adequate funding and technical support to sustain the project when the donor pulls out; poor targeting of support; founders' problems; and, where the programme is church-funded, discrimination against non-members. Policy options aimed at tackling these problems can help strengthen the capacity of communities to cope with HIV/AIDS.

Recommendations

The main recommendations arising from the literature review include the following needs:

- to strengthen the capacity of rural households to cope with HIV/AIDS by improving their access to limited resources; labour, land, capital, draught power, and management skills. This can be achieved by extension services promoting technologies that make optimal use of available resources, research systems developing technologies that can improve productivity given the labour and capital constraints, improving the incomes of affected households through income-generating activities, and better targeting of support to households that are highly vulnerable.

- for social assistance programmes to target a wider group of households based on both poverty and AIDS indicators. This can be achieved best by working through communities themselves in identifying the most needy.

- for policy makers and development agencies to help mitigate the impact of HIV/AIDS by working through existing indigenous traditional community mechanisms instead of displacing them. Programmes and policy should aim at strengthening indigenous responses such as savings clubs and labour and draught power clubs. In addition, there is need to closely monitor the situation in communities so that policies and

programmes can be designed that are responsive to the new challenges that arise as the epidemic progresses.

- to promote the effectiveness of community-based organizations and NGOs. Community-based coping strategies can be strengthened through the reinforcement of the management skills of CBOs and training on project design, planning, management, monitoring and evaluation.

- for meaningful partnership between the communities, governments, donor agencies, international NGOs, local NGOs, private sector and others in mitigating the impacts of HIV/AIDS.

- to intensify mitigation programmes. Multinational donors need to be more flexible in support of local initiatives with their funding, preferably by making many small grants rather than one large project grant. The present emphasis on large-scale grants and projects undermines local initiatives that may be far more effective and appropriate, as well as sustainable. Donors are, however, reluctant to have to manage numerous small projects. A mechanism is needed to resolve this problem, with perhaps an intermediate body to manage small-scale funds and report to the donors.

- for long-term government strategies to address the underlying problems which make rural households vulnerable to the impact of HIV/AIDS. Strategies should be aimed at eliminating poverty through rehabilitation and expansion of essential services such as primary education, preventive health care, clean water, sanitation, and improved access to land, credit, markets and protection against droughts through introduction of irrigation, and at creating more wage employment for the poor and landless.

- to develop a more encompassing approach to the evaluation of mitigation programmes and to ensure appropriate planning, measures of impact and outcome (in the short and long term), as well as the costs of the initiatives are needed.

- for community-based organizations and NGOs not to duplicate work that is already existent in communities but should strive for integration by supplementing or complementing community responses. External support should build on existing community structures such as churches, women's groups, schools and foster families.

- for governments to be prepared to play a more active leadership role and review their commitment to rural development. They need to undertake this with a clear analysis of the impact of AIDS on development, and of the impact of development on the AIDS epidemic itself.

1. Introduction

In the past 20 years HIV/AIDS has become an increasing global phenomenon. In countries hard hit by the pandemic, morbidity and mortality have risen and are expected to continue to rise. The implications of rising morbidity and mortality are not only that HIV/AIDS is changing the demographic structure of the household but also that it is taking a heavy toll on the socio-economic well-being of households and communities. It has become apparent from research studies done mostly in the 1990s that HIV/AIDS is having an adverse impact on smallholder agriculture and therefore on the livelihoods of rural households. This alone demands attention at policy level. These socio-economic effects are largely borne by individuals, households, and communities with little, if any, support from the technology change community and policy makers. According to the 1998 report of the Joint UN Programme on HIV/AIDS (UNAIDS), more than 33 million people are living with HIV/AIDS throughout the world. Some 60% of those infected live in sub-Saharan Africa, where poverty, gender inequality and vulnerability to natural disasters create an environment that exacerbates the impacts of HIV/AIDS.

The major route of HIV infection in sub-Saharan Africa is heterosexual intercourse, estimated to account for 93% of all adult cases, followed by vertical transmission and blood transfusions. Research in developing countries on the socio-economic impacts of HIV/AIDS on households has shown the main impacts to be social, psychological and economic (see Table 1, p. 15, for a detailed listing of impacts). Rural subsistence households are often more acutely affected than urban families. They suffer loss of productive labour, loss of income, loss of food reserves, savings and assets which are diverted to meet health care and funeral costs. Additionally, educational opportunities are reduced as children are withdrawn from school to care for the sick or to do odd jobs for extra income. Reduced levels of nutrition have been found in poor households (Loewenson et al. 1997).

At the community level, as the HIV/AIDS epidemic deepens, the socio-economic impacts widen to affect the whole community, resulting in an adverse long-term effect on community structure and function. The loss of human resources affects all institutions (NGOs, CBOs) and community structures, and these losses need to be planned for. Community problems that arise include the need to support an increasing number of orphans, reduced participation of the community in neighbourhood and community structures, increased homelessness and increased crime. In other words, social cohesion is threatened, a situation that in turn increases the risk of HIV transmission.

Households and communities have already taken some initiatives to cope with the impacts of HIV/AIDS as they have done with other calamities such as drought. If they did not, they would simply cease to exist. The worst affected households are the poor

households where the impact of AIDS is to compound the problems, deepen the poverty and extend the length of the time to recover. The traditional community safety net has been weakened by the growing economic decline in sub-Saharan Africa and the increase in households in need (Tibaijuka, 1997).

Very little research has been done in identifying and analysing the cost-effectiveness of the household and community coping mechanisms. The aim of this study is to document rural household and community responses to HIV/AIDS and their impact and sustainability. It will also suggest areas for potential improvement and consideration by policy makers and form the basis from which an advocacy tool may be developed. This literature review will focus on some of the following questions:

- What are the existing household and community responses to the impacts of HIV in rural areas?
- How frequent is the response adopted by different households in different localities?
- What are the costs associated with each particular type of response?
- What are the impacts (social and economic) associated with each type of response?
- How sustainable is each type of response?
- What are the emerging policy implications for future policy formulation?

Answers to these questions are crucial to policy makers and development organizations concerned with developing short-term and long-term strategies to overcome the impacts of HIV/AIDS. Without information on the responses by households and communities most affected by morbidity and mortality, few specific conclusions can be reached about the impact of alternative policies and projects.

This report is divided into six sections. Section 2 outlines the study objectives, methods and definitions of the major terms used in the study; section 3 describes current household responses to alleviate the impact of HIV/AIDS in rural areas and discusses the identified household coping strategies; section 4 identifies policy implications on strengthening the household's coping capacity; section 5 details existing community responses to alleviate the impact of HIV/AIDS in rural areas and discusses the identified community coping strategies; section 6 presents options for strengthening such strategies; and section 7 presents conclusions.

Table 1: **Potential impacts of AIDS on household**

Potential impacts of AIDS on families	Impact of AIDS on children	Community stresses
- Loss of members, grief - Impoverishment - Change in family composition and in adult and child roles - Loss of labour - Forced migration - Dissolution - Stress - Inability to parent and care for children - Loss of income for medical care and education - Demoralization - Long-term pathologies (increased depressive behaviour in children) - Number of multi-generational households lacking middle generation will increase	- Loss of family and identity - Depression - Reduced well being - Increased malnutrition, starvation - Failure to immunize or provide health care - Loss of health status - Increased demands on labour - Loss of schooling/educational opportunities - Loss of inheritance - Forced migration - Homelessness, vagrancy, crime - Increased street living - Exposure to HIV infection	- Reduced labour - Increased poverty - Inability to maintain infrastructure - Loss of skilled labour, including health workers and teachers - Loss of agricultural inputs and labour - Reduced access to health care - Elevated morbidity and mortality - Psychological stress and breakdown - Inability to marshal resources for community-wide funding schemes or insurance

Source: Hunter and Williamson (1997).

2. Objectives, methods and definition of terms

2.1 Objectives

The general objective of this study is to improve understanding of mainly rural household and community responses to HIV/AIDS and the cost-effectiveness of these responses. More specific objectives include:

- identifying the household and community responses, and
- assessing the responses on impact and sustainability.

2.2 Methodology, scope and limitations of the study

This study is a desk review and analysis of relevant literature. It involved reviewing material in the SAfAIDS Resource Centre and in external data centres. Visits were made to the University of Zimbabwe, Institute of Development Studies, Project Support Group, UNICEF, SADC Food Security Unit, SARDC, the local UNDP and World Bank offices. The review is geographically confined to sub-Saharan Africa. Electronic data searches were done through AIDSline and Africa Health Anthology. A complete list of references reviewed for this study may be found at the end of the paper.

The study focused on literature in English obtained from sub-Saharan Africa. The diversity of different agro-ecological situations creates differences in the coping mechanisms that are adopted. No research could be located that documents costs for households or community responses. Most of the literature documenting costs pertain to preventive and care responses. Obtaining reliable data on the household economy is difficult (World Bank, 1997). Although the literature review was supposed to focus only on rural areas and the section on household coping responses reflects literature from rural areas only, the section on community coping responses reflects literature from both urban and rural areas. This is because there is a rural-urban continuum: people move frequently between rural and urban areas and community responses tend to be similar, and in some cases some types of community responses start in urban areas such as those supported by NGOs. A major limitation of a desk review is that "grey" material might not be available in resource centres.

2.3 Definition of terms

Community—a specific group of people usually living in a common geographical area who share a common culture, are arranged in a social structure and exhibit some awareness of their identity as a group (Allman et al. 1997).

Household—A group of persons who live in the same dwelling and eat meals together.

Cost-effectiveness—Cost-effectiveness is a measure of efficiency. It compares the costs of a programme with its effectiveness. A measure of effectiveness of alleviating the HIV/AIDS epidemic could be coverage of food security and of school attendance. Efforts have been made in this study to capture the documented costs and effectiveness of the different household and community strategies. However, such information has proved difficult to obtain for each of the strategies because no cost-effectiveness studies have been done on the initiatives, particularly those initiated traditionally or indigenously and because the documentation of costs of the initiatives has not been consistently presented.

3. Household responses to HIV/AIDS in rural areas

Households adopt a wide variety of strategies to mitigate the effects of HIV/AIDS. This section presents the types of coping strategies adopted by households, the sequencing of the strategies and their costs and effectiveness.

3.1 Types of household coping strategies

There are many ways in which coping strategies can be categorized. In Table 2, we have divided them into three basic categories:

- strategies aimed at improving food security
- strategies aimed at raising and supplementing income so as to maintain household expenditure patterns, and
- strategies aimed at alleviating the loss of labour.

Table 2: Household coping strategies

Strategies aimed at improving food security	Strategies aimed at raising and supplementing income so as to maintain household expenditure patterns	Strategies aimed at alleviating the loss of labour
· Substitute cheaper commodities (e.g. porridge instead of bread) · Reduce consumption of the item · Send children away to live with relatives · Replace food item with indigenous/wild vegetables · Beg	· Income diversification · Migrate in search of new jobs · Loans · Sale of assets · Use of savings or investments	· Intra-household labour reallocation and withdrawing of children from school · Put in extra hours · Hire labour and draught power · Decreasing area cultivated · Relatives come to help · Diversify source of income

The literature on the impact of adult illness and death and the way households cope suggests that individuals and households go through processes of experimentation and adaptation as they attempt to cope with immediate and long-term demographic changes. The HIV/AIDS impact in Zambia in particular and Africa in general is described as a long-wave disaster (Barnett and Blaikie, 1992; Drinkwater, 1994; Bond, 1993). Over a five-year period one episode of illness may be followed by others which gradually deplete the resources and labour supply of one or more interdependent households. The Kagera (Tanzania) study showed movements of household or family members into and

out of the household within six months prior to and soon after death and these were identified to have an important role in household coping strategies (Over, 1995). From these studies (Sauerborn et al. 1996; Donahue, 1998; Hunter et al. 1997) it was discovered that household coping mechanisms are adopted sequentially or in stages (see Table 3).

Table 3: The three stages of loss management

Stages	Loss management strategies
I. Reversible mechanisms and disposal of self-insuring assets	· Seeking wage labour or migrating temporarily to find paid work · Switching to producing low-maintenance subsistence food crops (which are usually less nutritious) · Liquidating savings accounts or stores of value such as jewellery or livestock (excluding draught animals) · Tapping obligations from extended family or community members · Soliciting family or marriage remittances · Borrowing from formal or informal sources of credit · Reducing consumption · Decreasing spending on education, non-urgent health care, or other human capital investments
II. Disposal of productive assets	· Selling land, equipment, or tools · Borrowing at exorbitant interest rates · Further reducing consumption, education, or health expenditures · Reducing amount of land farmed and types of crops produced
III. Destitution	· Depending on charity · Breaking up household · Distress migration

Source: Donahue (1998).

After their study on strategies of coping (Sauerborn et al. 1996) with illness-related costs in rural Burkina Faso, a coping strategy sequence was developed which fits well with the stages identified by Donahue. The generated sequence was as follows:

1. Use of savings
2. Sale of assets (livestock, equipment, etc)
3. Borrowing
4. Wage labour
5. Community assistance
6. Doing nothing (on the verge of calamity).

What is important to note from the studies is the factors determining a household's ability to cope, which include: access to resources, household size and composition, access to resources of extended families, and the ability of the community to provide support.

Households that have higher incomes or better alternative resources are better able to cope with the impact of HIV/AIDS. Households with the cushion of support are more likely to recover during steps 1 or 2. Poor, small households that have no margin to absorb the extra costs of HIV illness are the most vulnerable to the epidemic. They do not have the assets, particularly livestock assets, which influence the choice of subsequent coping strategies such as borrowing or hiring labour. These households were identified to be at risk (at the verge of calamity) and require special assistance to help strengthen their coping capacity.

3.1.1 Household coping strategies aimed at improving food security

Reduced consumption of food, substitution with cheaper alternatives and reliance on wild food

When a breadwinner dies, households are faced with limited food to meet consumption requirements. Rugalema (1998) in Tanzania, Sauerborn et al. (1996) in Burkina Faso, and Barnett et al. (1995) in rural Uganda, found that some households cut back the number of meals when faced with food shortages. This was also reported to be a common strategy used by households to cope with a shortfall of income from one sector or individual following an unexpected crisis in Ethiopia (Webb et al. 1992). SAfAIDS research in Zambia in 1998 found that households were buying less expensive foods as an alternative or were substituting purchased relish (a side dish served with the staple carbohydrates e.g. maize or cassava) with indigenous or wild vegetables.

Begging

SAfAIDS research in Zambia (SAfAIDS, in press) identified begging as a survival strategy in times of need. Sauerborn et al. (1996) indicates that this survival strategy is practised when the households that are at risk have been pushed into calamity.

3.1.2 Household coping strategies aimed to raise income

Income diversification

Sauerborn et al. (1996) in rural Burkina Faso, SAfAIDS (in press) in rural Zambia, and Barnett et al. (1995) in Uganda, found that rural households that cannot meet their food requirements, or obtain cash, through agricultural production, undertake a range of income-generating activities such as selling firewood, brewing millet beer, selling livestock, building fences, handicrafts, tailoring, and petty trade to supplement their income. In Malawi, Munthali (1998) reports that households cope by doing ganyu (casual labour). In rural Zambia, some members of rural households were reported to have migrated to urban areas in search of employment so that they can remit some income to their rural area, while some work in neighbours' fields as casual labour so as to earn some income (SAfAIDS, in press). There are documented cases of children as young as 10 going out to work in an effort to cope with the illness of a parent (UNDP, 1997). Households that do not have the ability to diversify the source of income are particularly vulnerable to the epidemic. Prevailing poverty drives women into sex work as a source of income. In Malawi, 12-year-old girls were driven to have sex to fulfil short-term income needs (Little, 1996).

Sale of agricultural produce and use of savings

In a study in Zimbabwe by Kwaramba (1997) sale of agricultural produce was reported to be a dominant coping strategy to raise income to meet additional health costs. Barnett et al. (1995) in rural Uganda, Drinkwater (1993) in Mpongwe rural area, Zambia, Rugalema (1998) in Bukoba district, Tanzania, and Sauerborn et al. (1996) in Burkina Faso, report similar findings and indicate this widely used coping strategy to be among the first strategies used. Tibaijuka (1997) in Kagera Tanzania reports that households sold bananas (their staple food) in desperation to raise money to meet medical costs. The same studies also indicate that households use up savings to raise money to meet health and funeral costs.

Loans

Sauerborn et al. (1996) indicates that the informal financial sector is an important source of income used during times of need. Aryeetey and Hyuha (1990) report that households in Tanzania, Zimbabwe, Ghana, Kenya, Malawi and Uganda resort to borrowing from the informal sector for other disasters such as drought. Sauerborn et al. (1996) in rural Burkina Faso, SAfAIDS (forthcoming) in rural Zambia, and Rugalema (1998) in Bukoba district, Tanzania, Tibaijuka (1997) in Kagera Tanzania identify the informal financial sector to include:

1. relatives, friends and neighbours
2. rural cooperatives
3. rotating and savings club associations
4. rural traders and
5. rural money lenders.

Loans are given without much bureaucracy and with minimal paperwork. Interest rates are non-existent or very low for sources (1), (2) and (3), but can be substantial for sources (4) and (5) (levels higher than 100% have been reported). When interest rates are high, not all households borrow, as indicated by the following reports from a socio-economic impact study conducted in Zambia (SAfAIDS, 1997).

"When we are stranded and have no food we borrow money from Kaloba [a 100% interest rate credit facility run by individuals]" (SAfAIDS, in press, in Zambia).

Sale of assets

Tibaijuka (1997) in Kagera, Tanzania and Rugalema (1998) in Bukoba district, Tanzania, report that households that did not have enough income to buy food or to pay for health care, funeral expenses or education costs sold assets in response to the crises. The amount and type of assets so disposed vary across households. Evidence shows that a wide variety of assets, except land, were disposed of to generate cash for use in seeking treatment. In a study by Rugalema in Tanzania and by SAfAIDS in Zambia, the range of assets most commonly sold included cattle, bicycles, chickens, furniture, carpentry tools, radios and wheelbarrows. Some households report pledging future crops to meet immediate cash needs (Rugalema, 1998, SAfAIDS, in press).

"After mother died we were left with no means of survival. She was the one who looked after us. My brother had just completed school and could not go to college because there was no money to pay for his fees. I cannot get a job myself—jobs are difficult to find these days. We decided to sell blocks that

were meant for extending our house. There were 500 and we sold them for K150,000.00 and used the money to set up a business. We started selling charcoal by the roadside near our house. At least we are able to have a meal a day."
"Since I am the eldest, I started doing small jobs for people to earn something (he took on a task of becoming the head of the household). But people do not pay me in time, life is just difficult. My aunt, who used to take care of my mother, is now paying school fees for our youngest brother. I spend more time looking for money to make ends meet." (SAfAIDS, in press).

The role of the extended family

Throughout history the family, or in economic parlance the household, has formed the crucial social and economic unit on which most human societies have been based. The extended family as safety net is still by far the most effective community response to the AIDS crisis (Mukoyogo and Williams, 1991). Literature reveals that affected households in need of food send their children to live with relatives: Sauerborn et al. 1996 in rural Burkina Faso, SAfAIDS (1998) in rural Zambia, Barnett et al. (1995) in Uganda, Lwihula (1998) in Kagera region, Tanzania, Rugalema (1998), Drinkwater (1993) in Zambia, Kwaramba (1997) in Zimbabwe and SAfAIDS (in press) in Zambia. Relatives will then be responsible for meeting the children's food requirements. However, these studies did not probe into the types of relatives, or the length of time the children stayed with those relatives. Relatives and friends may provide both moral and material support to the sick on the assumption of future reciprocation. Preparation of food, work on land or overseeing livestock will be done by another family member or neighbour in addition to their own tasks. Over time the ability of families and social networks to absorb these demands will decrease as more adults die young of HIV/AIDS.

3.1.3 Household coping strategies aimed at alleviating the loss of labour

Intra-household labour reallocation and taking children out of school

Sauerborn et al. (1996) in Burkina Faso reported that reallocation of tasks among household members was the most frequently used strategy to cope with expected production losses resulting from adult morbidity and mortality. Children may be taken out of school to fill labour and income gaps created when productive adults become ill or are caring for terminally ill patients or are deceased. In Tanzania (Rugalema, 1998) intensive use of child labour was a major strategy typically used by the afflicted household during care provision.

Although children are not directly involved in care provision they are involved indirectly, by fulfilling mothers' and fathers' roles in some domestic and agricultural activities (such as collecting water and firewood and harvesting crops). They also prepare food for the rest of the household, gather food, tend livestock and run errands.

Removal of children from school is a common coping strategy and was mentioned by teachers at the local primary school as one of the major factors of low school attendance among orphans and children whose parent(s) were sick (Rugalema, 1998; SAfAIDS, in press). Girls are more likely to be taken out of school than boys.

Postponement of registration at school of children of school-going age due to parental illness was also common. Whether children withdrawn from school are able to go back to school in the future is not known and this warrants research.

In some hard-hit households, young orphans might inherit considerable resources but cannot manage them. In a study in Kagera region in Tanzania, Tibaijuka (1997) found that some young orphans inherited large farms which were rapidly degenerating into bush because of lack of care. Traditionally such farms would have been maintained by the clan, but such institutions were breaking down because of shortage of labour.

Hiring labour and draught power

In Zambia, Burkina Faso, Tanzania, Malawi and Zimbabwe, affected households reported hiring labour and draught power to meet their production requirements (SAfAIDS, in press; Sauerborn et al. 1996; Rugalema, 1998; Kwaramba, 1997). Labour was hired to meet the needs of the most labour-constraining activities, namely land preparation, weeding and harvesting. However, hiring labour depends on the availability of income to pay the workers. Only households with a stable income or source of remittance were able to hire labour and draught power. Some households had to pay the labour in kind, e.g. using maize or other commodities. Poor households relied on free labour from relatives and supportive and sympathetic community members.

Changing household crop production and substitution of crops

Research in East Africa reports that households involved in any agricultural production may cultivate a mixture of subsistence and cash crops (Barnett et al. 1994; FAO, 1995). The demand for labour varies as some crops are more sensitive to timing services than others. For example, a delay in planting maize, beans or groundnuts greatly reduces yields and impacts on food security. Bananas, yams and cassava, on the other hand, do not require activity at such specific periods and can be left unattended for some time without affecting the harvest.

Extended interruption of the labour supply may also affect important activities such as land preparation or maintenance of irrigation systems which in turn affects future production. FAO studies in East Africa (FAO, 1995) have shown that affected families substituted cash crops for crops which required less labour and expensive inputs such as fertilizer and pesticides. As a result, crops like coffee were abandoned by affected households in Gwanda and Nakyerira regions of Uganda and households depended on food crops such as cassava and bananas. Tropouzis (1994) in a different study in Uganda found that widows stopped growing tomatoes, a major cash crop, owing to lack of fungicides and rice and millet, which are labour intensive, in favour of maize and cassava which require less labour. In Zimbabwe, Kwaramba (1997) found that affected households were substituting cash crops like cotton and groundnuts with maize.

Decreasing area cultivated

A socio-economic impact study (Black, 1997) in Burkina Faso and Côte d'Ivoire found that cultivated areas declined in response to labour shortages caused by illness and death in both countries. Topouzis (1994) found similar results in rural Uganda.

Depending on the price balance, households chose between food and cash crops to economise on labour. In some countries, however, innovative coping strategies have been adopted, such as sharecropping, illustrated by the following case.

"Jane is a widow aged 45 living with her two children, a son aged 22 and a daughter of 11. She had eight children. Four died of AIDS and the others left home and married. Jane owns a coffee plot, but it has largely returned to bush because there is no labour available to maintain it. The main labour input is her own and that of the 11-year-old daughter. But she also hires some labour on a sharecropping basis and this allows some coffee to be cultivated. Having adequate land has enabled this woman to enter into sharecropping agreements with landless or land-short people. This is an effective method of coping with agricultural production in cases where there is land surplus. However, she has changed her cropping pattern, and largely abandoned coffee production in favour of food crops. She has also taken her daughter out of school to contribute more labour on the farm and to the home." (Barnett and Blaikie, 1992).

Lengthening of the working day

Topouzis (1994), in Uganda and SAfAIDS (in press) in Zambia, found that many affected households put in extra hours to make up for the labour shortages and loss of income. For example, a son with a sick mother in Zambia reported that he spends more time looking for money to make ends meet by working in the field and doing casual jobs and in addition he has to contribute an average of three hours a day towards caring for his mother and stay up part of the night attending to her needs. "The overall time allocated to tasks has increased with very little time for me to sleep" he says (SAfAIDS, in press).

3.2 Most common coping strategies

Coping strategies not requiring any cash were most frequently adopted (Sauerborn et al. 1996). Examples of these strategies include intra-household labour re-allocation, taking children out of school, diversifying household crop production and decreasing the area cultivated. In other studies (Rugalema, 1998; SAfAIDS, in press; Webb, 1992; Barnett and Blaikie, 1992) the dominant coping strategies were, in order of importance, income diversification, reduced food consumption, use of savings and sale of assets particularly livestock and household goods such as bicycles and radios.

No major variations in coping responses were documented by type of community in the literature reviewed. The literature however acknowledged that religious-based support tended to be discriminatory, supporting households that were of the same religious affiliation. Climatic conditions were a major source of variation in coping responses. Kezaala (1998) asserts that East Africa, because of its agro-ecological potential, has communities that are more resilient and can absorb a bigger orphan burden than southern Africa which is drought-prone and might have more households requiring external support because of food insecurity.

4. Policy implications on strengthening the household's coping capacity

Several policy options arise out of the literature review that can be taken up to strengthen the capacity of rural households to cope with HIV/AIDS. Policy and programmes should seek to support households to overcome negative coping responses (such as withdrawing children from school) and reinforce households' positive responses. The overall aim of the policies and programmes should be to improve the short- and long-term well-being of the household in ways which do not create dependency, and to minimize the risk of household members being infected with HIV. This section presents a range of possible policy and programme options that can be adopted. There is need for country- and local-specific policies and programmes and the ones presented below merely give a broad indication of possible strategies that can be promoted to mitigate the impact of AIDS.

4.1 Improving agricultural production

Since most rural households are dependent on agricultural production for their livelihood (as a source of income and food), strengthening the household's agricultural production capability is one way in which the impacts of AIDS can be mitigated. Agricultural production ability of the household can be reinforced by improving their access to labour, land, capital, draught power, and management skills, promoting use of existing labour- and capital-saving technologies, and by developing technologies that can make optimal use of the available limited resources.

4.1.1 Promotion of existing labour- and capital-saving technologies

Technology is already available that makes optimal use of available resources and can be adopted by these resource-poor agricultural systems. This technology can be promoted by extension officers for use by AIDS-affected households. This technology includes:

- inter-cropping to reduce weeding time
- promoting use of high-yielding crop varieties which are not labour-intensive
- zero or minimum tillage to reduce the need for expensive ploughs and oxen
- promoting natural pest management, thus reducing the need for expensive chemical inputs, e.g. pesticides.

4.1.2 Technology development for resource-deprived households in the smallholder farming sector

Agricultural research institutions need to consider the emerging technological needs of smallholder farmers resulting from the AIDS epidemic. In planning the technology that

will lessen the impact of HIV/AIDS, it is important that the technology proposed should be based on an appropriate analysis of the local situation. The following techniques should assist households to maintain and improve production:

- selection of the appropriate variety of crop (e.g. early maturing, disease-resistant, easily threshed or pounded)
- improvement of existing inter-crops
- concentration on high-value food crops which are drought-resistant
- the introduction of farm equipment that can be used by the weak or by donkeys (e.g. lighter ploughs and planters and a modified hoe)
- improved indigenous technologies in mulching, inter-cropping, and seed selection
- improved technologies of animal husbandry, such as cattle dipping at individual levels.

4.1.3 Strengthening draught power and labour-sharing clubs

Draught power, labour-sharing and money-lending clubs help alleviate the major constraints of AIDS-affected households, which are labour, capital and draught power. Policy and programmes that support such activities will help affected households cope with the impacts of AIDS.

4.1.4 Implications of human resource losses

To reflect the change in the rural environment, all formal and non-formal rural development institutions need to review their human resource programmes and policies. It is important that institutions respond to the AIDS epidemic by planning for the impact on labour. The central responses to the AIDS epidemic must involve HIV prevention, prolonging life and reducing morbidity from HIV: this includes creating awareness and introducing prevention policies. There is a need to plan for skills, managerial and professional losses, and to introduce multi-skilling at all levels so that rural agricultural production does not suffer unduly.

4.2 Income-generation and diversification of source of income

Programmes which help improve and diversify the source of income of affected households help mitigate the impacts of AIDS. Such programmes help maintain household expenditure patterns and thus help the household avoid further losses in welfare.

4.2.1 Improve households' income-generating capacities

The first line of response should be to mitigate the impact of AIDS on households by improving their income-earning capacities (Donahue, 1998). The aim is to maintain household expenditure patterns and promote savings. This can be achieved through micro-credit projects which are typically small, short-term and rapid turn-over in nature

(such as handicraft production). Another response could be to increase the asset buffer of households by expanding their opportunities to own livestock and by protecting existing herds through good veterinary care (Sauerborn et al. 1996). For example in Uganda, Addo (1998) reported that under a project, trickle-up micro-grants of US$ 100 were given to 30 families or a group of PLWHAs to finance non-capital-intensive income-generating activities such as knitting, weaving, gardening and fishmongering.

Economic empowerment can boost the morale of PLWHAs who have lost hope. Schemes to empower communities must specifically be targeted to women and youths who perform most of the caring work. There is need to encourage self-sustenance of such schemes through training the participants and recycling funds. Social assistance funds need to be part of a comprehensive national social policy, with well defined priorities and institutional co-ordination to ensure production of better designed projects that are sustainable. Short-term strategies do not address the most crucial problems, so there is need therefore for a combination of relief-oriented and investment-oriented strategies to ensure that, when the funds are finished, the projects can continue.

Some households depend on casual labouring as a main source of income for the family. This in turn is dependent on the creation of employment opportunities in the area. For the poorest and the landless, having access to wage employment is crucial.

4.2.2 Promotion of income diversification

Promoting income diversification can strengthen households' coping capacities. Provision of wage employment may be a strategy to provide households with additional sources of income (Sauerborn et al. 1996). In risky agricultural climates, households with more diversified off-farm income are less vulnerable to food insecurity. Another strategy is to encourage crop diversification and promote a reduction in external input requirements. Non-farm sources of income, particularly home-based income-generating and petty trading activities (after a sound analysis) are other options. Given the low success rate of IGPs in many countries, these activities should be promoted with considerable care, planning and realism.

4.2.3 Schemes to finance health services

The introduction of prepayment schemes in which payments are collected after the harvest season to cover medical costs throughout the year (Sauerborn et al. 1996) could be recommended.

4.3 Reducing demands on women's labour

There is need to explore ways of reducing women's work burden, through the development of labour-saving methods of food preparation and improving access to water and fuel supply. Development and promotion of efficient stoves can reduce the

time women spend collecting firewood; the time saved can be used to undertake productive activities such as harvesting, transport, storage, processing (particularly hulling and milling) and marketing of produce. In some areas the use of donkeys for transporting has helped women undertake other essential activities. Making more water points available reduces the distance walked to fetch water and can benefit women in a similar way. Some programmes aimed at providing substitute caregivers or child minders can free women to undertake other productive activities.

4.4 Improving the welfare of children in need

The effectiveness of most social programmes could be improved by targeting specific needy populations. It is only through targeted relief that desperate households can be reached. This means decentralisation and reformed screening techniques. Assistance in the form of education, health and nutrition can facilitate long-term human development. One important aspect of social assistance is the fact that poor households which are not facing AIDS need the same type of assistance as their children are also malnourished and drop out of school. Equity can be achieved if the government targets social assistance to the most needy regardless of the immediate cause of their poverty. Thus, as suggested in reviewed literature (Over, 1998; Donahue, 1998), targeting of assistance should be based on both direct poverty indicators, not just the presence of AIDS in the household.

4.5 Long-term strategies

Long-term government strategies should address the underlying problems that make rural households vulnerable to the impact of HIV/AIDS. Strategies should aim to address the following:

- health problems, e.g. through incorporating improved water and health services
- agricultural constraints, including poor access to land, credit and markets; mitigation of droughts, e.g. through introduction of irrigation
- poverty.

4.6 Areas of further research

Important gaps in knowledge have been noted on the cost and effectiveness of household responses, information that could assist programmes to mitigate the household impact of AIDS. One way of obtaining reliable household data on the impact is to include specific questions on the impact of mortality and morbidity on household income, expenditure and other welfare indicators in the current household surveys (poverty surveys, demographic health surveys or censuses). The current census or poverty survey questions do not probe the interrelationships between disease prevalence and the socio-economic status of the household.

4.7 Who is responsible for the policy and programme options?

The foregoing section has outlined a set of policy-oriented and programme-oriented recommendations but did not say whose responsibility it is to undertake a particular recommendation. The state organizations (ministries of agriculture, rural development, health, social welfare, research and extension services etc) cannot do it alone: they need to collaborate with other development agencies (such as CBOs, NGOs, ASOs) and communities if efforts to mitigate the impact of HIV/AIDS are to be successful.

5. Community responses to HIV/AIDS

Most communities have developed a wide range of complex and innovative strategies to survive the adverse impacts of HIV/AIDS. The literature revealed that in many areas, communities have spontaneously joined together to support and assist families and children affected by HIV/AIDS. The paradox is that community-based responses may be the most cost-effective interventions while being the least visible (Hunter and William, 1997). Even before the advent of HIV/AIDS, food security in sub-Saharan Africa was under threat (see Kadonya, 1998). Droughts and floods are some of the disasters with which rural communities have had to cope. African families have shown resilience in coping with disease and illnesses (Barnett & Blaikie 1992, Sauerborn et al. 1996).

Some community coping mechanisms are initiated from within the communities—one might refer to them as being indigenous or grassroots responses—and some are introduced into the communities and are financially supported by outside agencies such as NGOs, international development agencies, the government or churches. Depending on how communities are mobilized and how receptive they are to the initiatives, such projects can be successful and be sustainable when the donors withdraw. Figure 1 categorizes community responses into three broad groups that are not mutually exclusive. The responses under each group are also not mutually exclusive. For example, a community-based organization might be involved in several support and mitigation activities that include orphan support, labour-sharing, income-generating projects, and treatment and care.

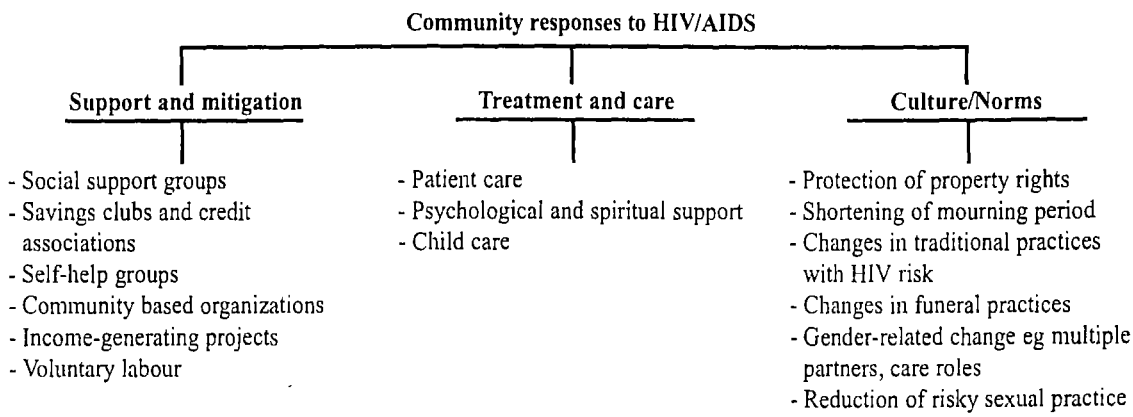
According to the literature reviewed, e.g. Hunter and Williamson, (1997); Barnett & Blaikie (1992); Sauerborn et al. (1996); Donahue (1998), different community initiatives have sprung up to support and mitigate the impact of HIV/AIDS. Reviewed studies show that people affected by HIV/AIDS access help principally from family, neighbours, community institutions and local informal organizations. The World Bank Kagera study in Tanzania found that families who lost breadwinners through AIDS reported that 90% of

their material and other assistance came from family and community groups such as savings clubs and burial societies. Only 10% of assistance was supplied by NGOs and other agencies.

The major forms of community support and mitigation activities include the following:

- community-based child care: co-operative day care and nutrition centres to free women to work in or outside the home
- orphan support in the form of nutritional and educational support
- repair of deteriorating houses
- home care and visiting orphans and HIV/AIDS patients
- preparation and distribution of school uniforms
- apprenticeship and training in marketable skills for orphaned adolescents
- agricultural projects at various levels to increase output
- labour sharing
- income-generating projects to produce food and cash
- credit schemes for funeral benefits.

Figure 1. Community responses towards HIV/AIDS



Community coping responses take the form of different organizational groupings, i.e. social support groups, informal associations, self-help groups, community-based organizations supported by external development agencies, and AIDS service organizations (ASOs). While the differences between the different groupings is not necessarily clear, the first three groups tend to be grassroots or indigenous responses to AIDS by the community, where membership is by choice rather than ascriptive and the groups attempt to solve social problems through local participation, social action, resource mobilisation and building a sense of community (Altman, 1994). The other two tend to be formal grassroots organizations which rely to some extent on external support from NGOs or other agencies who act as intermediaries in the development process in which some decisions may be made externally.

ASOs is a term developed by WHO's Global Programme on AIDS to describe all those organizations other than government which provide services related to HIV/AIDS

(Altman, 1994). The following section will first present the role of the grassroots/indigenous groups which do not depend on external sources of finance, and then that of the more formal groups which depend on external financial sources.

5.1 Informal grassroots community organizations

Different forms of informal and traditional grassroots social security systems have been in existence in many societies in developing countries for a long time. Examples of such organizations include social support groups such as burial societies, grain saving schemes and labour-sharing clubs, and savings associations such as rotating savings and credit associations. Operation of such organizations is not governed by any legislation. They operate in accordance with rules agreed by the membership.

5.1.1 Social support groups

Lwihula (1998) in Kagera, Tanzania, indicates that most communities have social support groups organized by men or women or both. Members of such groups support one another in routine ways, for example, by helping cultivate one another's fields, and by contributing labour, food and money to one another in times of special need (such as sickness and funerals), or on special occasions (such as marriage ceremonies). The amount of assistance such groups can provide is very small and, in the case of a death, is limited to the period of mourning. Some social support groups are formed for specific activities, for example, burial societies, grain-saving schemes and labour-sharing schemes.

Madembo (1997) in Zimbabwe, and Rugalema (1998) in Tanzania, found that burial societies are established indigenous social support organizations that provide mutual assistance to members in rural areas in the event of death and illness. They offer a measure of financial security in the event of bereavement and also cater for some of the other social needs of their members. As part of the package, burial society members also devote part of their time to assisting the bereaved by cultivating their fields.

Grain-saving schemes have a very long history in Africa's rural areas, and for many years have been used to cater for the requirements of people in the community. In Zimbabwe, Madembo (1997) and Ncube (1998) report that grain-saving schemes have been revitalized as an adapted form of the traditional system of zunderamambo (literally, the king's field) in which people in a community would contribute labour in the field of the chief or headman, and store the produce for when it was needed. In Zimbabwe, these grain-saving schemes have formed an important source of community support to affected households.

Rugalema (1998) in Tanzania, SAfAIDS (forthcoming) in Zambia; and Ncube (1998), in Zimbabwe, found free community labour-sharing to be a common community coping response adopted by communities to help support affected households. In Zimbabwe,

these labour-sharing schemes (nhimbe) have been in existence a long time and formed a major source of social security for households in times of disaster.

5.1.2 Indigenous savings associations

Lwihula (1998) in the Kagera area, Tanzania, Ncube (1998) in Zimbabwe, and SAfAIDS (in press) in Zambia, found that many communities have indigenous savings clubs which play a major role in helping households cope with the HIV/AIDS epidemic. The major forms of indigenous community savings association are the rotating savings and credit associations (ROSCAs), and conventional savings clubs.

Madembo (1997) indicates that ROSCAs have been in existence for a long time in many African countries. A ROSCA is a group of people who agree to make contributions to a fund which is given in whole or in part to each contributor in turn; each member makes the same contribution. After everyone has had their turn in receiving the contributions, the group may disband or start another cycle. Among rural people, the contributions are either in cash or in kind (e.g. food, agricultural inputs, kitchen utensils, etc). Madembo emphasizes that ROSCAs are popular because they impose few transaction costs on members, they build mutual trust, they provide insurance and reciprocity that can be called upon in times of emergency, and they give members access to a relatively large amount of money that would otherwise be difficult to accumulate. In Cameroon, the ROSCAs have a social fund which provides life and health insurance to members (Kaseke, 1997). This is done by placing part of the contributions in a fund to be accessed as grants or loans in the event of death or sickness of members or their dependants.

In addition to ROSCAs, savings clubs are an important informal source of finance for rural households during emergencies. The funds are usually used for buying agricultural inputs such as seeds and fertilizer, for paying school fees, for buying clothing or are reserved for eventualities such as medical treatment, births and deaths. The funds can also be used as working capital in small enterprises and for starting up income-generating projects. The use of savings as security against low and uncertain incomes is the prime motive for participating in savings clubs. Most rural farmers receive their income only once a year: the savings club pool offers finance after the marketing of agricultural produce and so acts as a buffer during difficult periods.

In Zimbabwe, savings clubs have been very successful in rural areas. According to Madembo (1997) members hold a pre-savings meeting to decide what they want to save for during a twelve-month period; they then decide on their requirements for seed, fertilizer and insecticides, which are ordered in bulk to benefit from quantity discounts. Zimbabwe experienced severe droughts in the 1991/92 and 1994/95 seasons; Madembo (1997) observed that many savings club members were able to keep their children in school and also start their new investments more quickly after the rains had come, because of their prudence and the self-help orientation of their clubs. Savings clubs thus play a vital role, both directly and indirectly, in meeting the social security requirements of communal farmers.

5.1.3 Indigenous emergency assistance associations

The World Bank-sponsored Kagera household demographic study in Tanzania found that, in addition to the pre-existing traditional saving and mutual assistance associations, the inhabitants of many villages, particularly in the hardest hit areas (Bukoba rural, urban and Muleba districts), had launched new organizations specifically in order to cope with the costs of the AIDS epidemic (Lwihula, 1998). Lwihula's major findings (see Table 4), based on focus group discussions, reveal that:

- Traditional savings and mutual assistance associations already existed but specific organizations had sprung up in villages hard hit by the AIDS epidemic, especially among the Haya and Nyambo.
- Even households that had not yet had a member die are participating in these organizations to insure themselves because of anticipated deaths in future.
- The associations are mostly run and organized by women.
- These associations have a wide range of specific objectives and agendas (e.g. coping with crisis and burial ceremonies, and communal farming activities).
- Assistance associations among the Haya and Nyambo have regularised assistance practices (e.g. monthly meetings and contributions as insurance for imminent deaths).

Table 4: Indigenous associations in Kagera Region, Tanzania

Activities	Monthly contribution	Size of association	Beneficiaries
Mourning and burial	money, food, fuel, labour	10-40	bereaved families
Supporting sick patients	money, food, visits	10-40	families with sick patients
Re-building dwellings and rehabilitation of farms	labour, money, building materials	10-40	families in a crisis
Communal farming	labour, seedlings	10-40	participating families
Supporting survivors	money, visits	10-20	orphans, widows
Income-generating activities	money	10-40	women's groups

Source: Lwihula, 1998.

Barnett and Blaikie (1992) found that informal women's counselling groups and impromptu meetings had sprung up, where women assist each other in the plantations, caring for the sick and relieving the care giver (see an example presented in Box 1). Neighbourhood women will appear unannounced to weed and trim the banana gardens of a woman who is ill. They have persuaded the local Resistance Councils to solicit outside help for the orphans and some have assumed the responsibility of caring for them in their homes. Informal counselling sessions enable women to share their experiences and concerns and "keep them sane" (Barnett and Blaikie, 1992). There is need for public space for women since it is felt that most of the public spaces available belong to men.

Box 1: Mothers' Unions in Zimbabwe

Many religious denominations in Zimbabwe have women's sections known as the Mothers' Union. They are guided by the principle of providing spiritual, economic and social support to those facing economic hardships. The members contribute a certain amount of money each month and the benefits range from financial assistance during funerals and weddings to visiting the sick, praying and counselling. These women's groups have been very active in taking care of children whose parents are dying of HIV/AIDS-related illnesses.

(From Gumbo, 1998).

5.1.4 Self-help groups of people with HIV/AIDS

In a number of African countries, AIDS organizations formed by infected and affected people play an increasing role in the response to the epidemic although the number of PLWHA involved is still tiny compared with the full scale of infection. In reality an estimated 90% of the population do not even know they are infected and of those who do know, the majority try to keep their HIV status private and do not join open PLWHA groups. In Côte d'Ivoire, the country with the highest prevalence of AIDS in western Africa, two self-help groups (SHGs) of people with AIDS were created in 1994. In other parts of Africa, some of the motivations to belong to a SHG of PLWHA are: the search for psychological, social and material support and the need to avoid stigma. Self-help groups play an important social role which includes:

- provision of services to other PLWHA;
- acting as an intermediary between PLWHA and relatives;
- HIV prevention and mobilisation among non-infected and non-affected people;
- division of labour with health care professionals;
- lobbying and advocacy (interactions with local authorities, international organizations and donors).

SHGs of PLWHA in Côte d'Ivoire and elsewhere are a collective response to an individual crisis, providing psychosocial support to people who very often are, or feel, socially rejected. Self-help groups in general have to cope with cultural and organizational problems and economic problems, as they may have little funding. A further source of that tension is that most members are poor and SHGs are regarded as a source of income. Indeed the motivation to join is often primarily an economic one, rather than a collective response to human rights violations.

It is noticeable how few middle class, affluent or professional people are active in HIV/AIDS support groups in most countries. An exception is South Africa, where NAPWA, the National Association of People with HIV/AIDS was initiated by relatively affluent gay white males, although its membership is changing. In 1998, an organization for women with HIV/AIDS was initiated by Mercy Makhalamele called Women Alive National Network (WANN). This network seeks to respond to the cultural, socioeconomic and psychosocial needs of disempowered and often impoverished women and their dependants.

At the wider level, African Chapter of GNP+, the Global Network of People Living with HIV/AIDS, is based in Nairobi. Called NAP+, the Network of African People Living with HIV/AIDS, this body tries to support the role of national networks in advocacy for human rights of people with HIV.

In Zimbabwe, The Centre was established in 1994 by PLWHA to promote counselling and health services and assist the emergent Zimbabwe National Network of People Living with HIV/AIDS (ZNNP+). Now ZNNP+ has hundreds of members in support groups across the country and, as in South Africa, an independent network for women is being formed to address their needs.

The informal groups do not generally have documented records of costs or effectiveness, but they tend to have lower transaction costs because they are more informal, based on mutual understanding and involve less paperwork and organizational costs. These groups can be a major source of support in communities experiencing the impact of the AIDS epidemic by providing important inputs to agricultural production, such as labour and capital and food needs. Besides material support, these informal groups are a major source of psychosocial support.

As the number of AIDS-related deaths increase, these existing local strategies are increasingly under pressure and there is need to design policies and programmes that are capable of providing support when existing strategies become inadequate. The literature reviewed did not provide extensive empirical information on what proportion of PLWHA are members of SGHs or to what extent they can cope before they collapse. Some authors (Webb 1995; Sabatier 1997) indicate that some communities are failing to cope, particularly as far as absorbing AIDS orphans. This is particularly true in communities where the number of orphans has rapidly increased to levels which tend to overburden the community's capacity. Drought and economic decline are factors that weaken communities' coping capacity. However, the exact threshold level when a community starts to feel strained is not known, neither is the type of coping capacity that gives in first. This is an information gap which warrants investigation.

5.2 Formal community-based organizations

Many of the community-based programmes assisting those affected by HIV/AIDS are developed and run by community-based organizations (CBOs). These organizations generally aim at being democratic, to represent the interests of their members, and to be accountable to them. They are formed as a response to shared experiences. In some areas where inter-household cooperation has not been the norm, NGOs have assisted the development of self-help groups which are a form of CBOs. They are usually local but can spread and grow into networks of grassroots organizations. In 1993 the United Nations Development Programme (UNDP) estimated that there were at least 100 000 CBOs worldwide (Hunter and Williamson, 1997).

Agencies working with CBOs and ASOs in some countries include ActionAid, InterAid, PLAN, SIDA, HIVOS, GTZ, DANIDA, OXFAM, European Union, Catholic Relief Services, CIDA, NORAD, UNICEF, USAID, Red Cross and World Vision. CBOs and ASOs' activities vary from country to country, ranging from home-based care through psychological support to material assistance. In the rural areas of southern Uganda, World Vision has encouraged the formation of small self-help groups engaged in agriculture and off-farm income-generating activities such as handicrafts, bee-keeping, carpentry, tailoring, and building construction.

In Kagera, Tanzania, WAMATA (a voluntary non-profit grassroots survivor assistance organization) is open to anyone who either has HIV/AIDS, or has helped to care for a relative or friend with the disease. Members contribute small amounts of money and food for some of the most needy AIDS-affected families, carry out house repairs and bring medical supplies from the local dispensary to the bedridden. However such programmes have limited local resources for sustainable services, and need external assistance in the form of food supplements, school fees, uniforms, clothing and bedding and revolving funds to enable AIDS-affected families to start schemes such as vegetable production, raising poultry and cattle, carpentry and tailoring.

In South Africa, the Society for AIDS Families and Orphans (SAFO) was formed in Soweto in 1992 to provide care and support to affected families (Gilks et al. 1998). Many CBOs depend on a number of volunteers and a few paid staff. Annex 1 shows selected self-help community groups supported by ActionAid Uganda. Annexes 2, 3 and 4 present some of the main activities of CBOs in Kagera region, Tanzania, and rural areas of Zimbabwe and Kenya, respectively.

Some CBOs have grown to become NGOs, for example The AIDS Support Organization (TASO) in Uganda. TASO started off as a small community-based organization in 1987 in Kampala, today it has expanded to six sites covering the south-eastern part of Uganda and servicing both rural and urban areas with a staff of 150 and 2 000 volunteers. TASO provides a range of services which include counselling, day-care centres for children, treatment and care, home-based care, social support such as school fees for needy children and income-generating activities such as sewing, pig-farming, and banana and vegetable cultivation. In the evaluation of TASO in 1994, treatment and care (including counselling and nursing care) were cited as the most helpful TASO services by 86% of the 619 interviewed clients, 10% indicated social support and 4% indicated other services (TASO, 1994). Its main sponsors include ActionAid, DANIDA, USAID, DFID and Australian International Development Agency Bureau.

Although it should be easier to obtain the costs and the cost-effectiveness of community-based organizations that are supported by external development agencies since they are more formal, this proved to be a difficult task. The 1994 evaluation of TASO provided no information on costs or cost-effectiveness of TASO activities. The 1998 evaluation of ActionAid's Strategies for Action community-based programmes in Uganda and Malawi also provided no information on costs or cost-effectiveness of the community-based support activities.

5.2.1 Child and orphan support

Two main forms of support to orphaned children in especially difficult circumstances are institutional support such as orphanages and traditional fostering and adoption by relatives and the community. The following section first discusses programmes that are aimed at strengthening traditional fostering and care by the extended family and the community, followed by those that support institutional support programmes.

Traditionally it is assumed that the extended family and the community at large assist the household socially, economically, psychologically and emotionally. This is a common practice in most parts of eastern and southern Africa. As more households are affected by the AIDS epidemic, the literature indicates that some communities are failing to absorb all orphans from AIDS because of lack of resources, urbanisation and migration (Webb, 1997). This failure is seen, for instance, in the existence of unsupported child-headed households or, in the World Bank Kagera study, of the disappearance of some households. Nevertheless many community-based orphan support organizations have been initiated as the number of orphans increases.

The development of orphan and child care support in the community is illustrated by case studies from Zimbabwe, Malawi and Tanzania in Box 2. Where orphans do not have any extended family safety net, residential institutions or orphanages are a last resort to meet their requirements. Orphanages may be run by community churches, particularly for the under-threes, or by NGOs, government, or private individuals. As the number of children orphaned by AIDS increases, the demand for orphanages may well increase.

The review revealed that orphanages are unlikely to be sustainable on financial grounds because of the heavy, long-term burden which they place on the Department of Social Welfare or other organizations responsible for running them. According to Ainsworth and Over (1997), the cost of supporting a child in an orphanage was about eight times the cost of support in a foster home. The demanding nature of caring for infants necessitates lower child: care giver ratios in infants' homes (Powell et al. 1994). This Zimbabwe national survey of formal children's homes found that infants in homes are at a great risk of recurring infections. Powell report states that a survey of two homes with a total of 100 infants revealed that 42 infants had been admitted into hospital once and 26 had two or more admissions. It is also clear that such orphanages are rarely in the best interests of the children, either on economic or social grounds.

Box 2: Case studies on orphan support

In Zimbabwe, *the Families, Orphans and Children Under Stress (FOCUS) community-based programme was established in 1993 in a rural area by a local church with technical support from the Family AIDS Caring Trust (FACT) in Mutare. The main activities of the project include the recruitment of volunteers from the community to identify, register and visit orphans within a two-kilometre radius of their homes. Volunteers are provided with basic training and they visit orphan households twice per month, but those orphans in greatest need, such as those in child-headed households are visited weekly. Orphans are supported materially with agricultural inputs (such as maize seed and fertilizer), primary school fees, food and blankets.*

Other activities undertaken by FOCUS include: assistance in ploughing orphans' fields, repairing of houses, health care, child care, income supplementation and income-generating activities. The later includes the provision of material inputs to community-based projects such as poultry and vegetable gardens. Income from income-generating projects is used to support destitute families. Psycho-social support is provided through sporting and cultural activities held frequently. The FOCUS programme does not differentiate "AIDS" orphans from other orphans, and tries to target those in greatest need. They include support to non-orphaned children in exceptionally needy circumstances.

By 1998, the FOCUS programme had 137 volunteers in five rural sites and one high-density urban residential area in Mutare. The total catchment of the programme is 50 000 households with 1200 orphan households assisted. The total cost of the FOCUS programme is US$ 1150 per month of which 44% is FACT administrative costs and 56% direct expenditure on the programme (78% was spent on material assistance to orphans, 13% on volunteer allowances and uniforms, 9% on training and meeting costs) (Foster and Makufa, 1998). Volunteers receive minimal financial incentives: uniforms, annual Christmas gifts of US$ 10 and training. The FOCUS programme has been replicated in some other provinces in the country and other programmes have been established in Zambia, Kenya and Malawi following visits to FOCUS sites as part of FACT's regional training programme.

In Malawi, *the COPE programme of the Save the Children Federation USA, also stands as an example of projects designed to strengthen community capacity. The purpose of the COPE intervention is to mobilize community action to mitigate the impact of HIV/AIDS on families and children. The first phase involved setting up the programmatic strategy, which involved formation of community care coalitions that united government, religious leaders, business, community elders and other stakeholders to respond to needy families' health, psychological and economic requirements. The second phase of the programme involved strengthening the capacity of the coalitions to identify and mobilize internal resources, access external resources and organize the CBOs that would drive the initiative forward.*

Community AIDS committees were able to identify, monitor and assist orphans and other vulnerable children by helping some return to school and providing material assistance in the form of school uniforms, clothing, maize, rice, soap and educational materials. The same community organizations were able to raise funds from community gardens, working in farmers' plots for cash, and undertaking charity walks. Orphans' guardians were assisted with agricultural inputs and technical

advice through the village AIDS committees. Other achievements of the village AIDS committees include the formation of youth clubs involved in promoting HIV prevention and care work, community-based child care and structured recreation activities for children. The outstanding features of this programme are the creation of partnerships between the public and private sector, and the fact that COPE acted as a facilitator in the project. At the end of the project cycle, COPE field workers were removed from villages and communities that are now said to be self-sustaining (Krift and Phiri, 1998).

In Malawi some CBOs have started to offer non-formal education to orphans. For example, Chifundo Orphan Home in Manase district was established by women who joined hands to help orphans continue with some form of education. The home works through the chief to identify orphans who are not attending school.

***In Kagera region, Tanzania,** 12 community-based and international NGOs assist about 47% of all orphans. External aid seems to create some degree of dependency: people or communities are likely to wait for external NGOs to come to their aid. The UKIMWI Orphan Assistance project provides limited assistance to communities to help them solve their own orphan problems. Family and community resources are mobilized, primarily to increase food production, this includes cultivation of plots and keeping two cows, and bananas/coffee cash crop farming. Other activities include organising community support to carry out housing repairs for orphans, providing school fees for a number of orphans, medical assistance for orphans, and income-generating activities for women's groups or female orphans (tailoring, needle-work, basketwork and so forth). (Ng'weshemi et al. 1997)*

Mukoyogo and Williams (1991) noted that in Tanzania, by leaving their village, these children forfeit their right to inherit their parents' land and will lose their sense of belonging. They also experience poor socialization and a loss of cultural roots which proves to be very costly in the long term, as it results in maladjusted adults and perpetuation of the epidemic. Children in orphanages are not fully integrated into the community because the institutions operate in isolated communities, with integration taking place only in school (Powell et al. 1994). Targeting support directly to the community is more effective, though it is difficult for the government to determine which orphan families are most in need. CBOs have a critical role to play as discussed earlier.

5.2.2 Income-generating projects (IGPs)

Local and internationally funded NGOs strive to improve the income of community members through supporting income-generating projects which will mitigate the effects of HIV/AIDS. NGOs can work through CBOs and offer assistance to either group IGPs or individual IGPs. In Uganda, CBOs with group IGPs supported by ActionAid tend to comprise members with distinct characteristics (e.g. widows, PWAs and women). On the other hand, individual IGPs are operated by individuals in the CBO. Asingwire et al. (1998) evaluated five CBOs directly supported by ActionAid Uganda which included NACWOLA, GASCO, TASO Kumi, STOGA and KISA. The IGP activities that each CBO is undertaking are presented in Table 5.

Table 5: Income-generating project activities undertaken by CBOs in Uganda

Group income-generating project	Individual income-generating project
NACWOLA	TASO-Kumi
Rabbit rearing - Tailoring	Goat rearing
TASO Kumi	STOGA
Agriculture, sales of agricultural produce, restaurant, goat rearing	Revolving fund
GASCO	KISA
Piggery	Revolving fund

Evaluation findings by Asingwire et al. indicate that the rabbit rearing IGP does not seem to be a worthwhile venture for PLWHAs. NACOWLA is a national NGO formed in 1991 by women living with AIDS. At the time of the evaluation by Asingwire et al. the IGP had been in existence for about 10 months, and no member had yet benefited in terms of income although they had expended time, money and labour on rearing the rabbits. Despite this limitation, there were some advantages in that the group offered strong psychosocial support to people living with HIV/AIDS.

The goat-rearing scheme operated by TASO-Kumi was found not to benefit PLWHAs either, because of the nature of the project. It takes two years before a PLWHA can profit from the sale of the goats, and as beneficiaries received very young goats this placed a heavy burden on the PLWHA raising the goats. Many PLWHAs might be ill or dead before realizing a profit.

The KISA revolving fund scheme was a failure because the loans were too thinly spread among many members. However, the fund in STOGA was a success story which provided important lessons for other CBOs. Members of STOGA agreed not to spread the loan too thin by adopting a formula of just a few initial grants. These few members, all women, were able to return the loan installments in time for the other members to get their turn. In addition, the group has a drama outreach programme which earns some money, which is shared. If a member completely fails to pay, she gets less during the shareout as the rest is retained to recover the defaulted amount.

In their findings Asingwire et al. found that group projects tend to have problems as no one was specifically responsible for projects. Group projects should nevertheless be encouraged among PLWHAs because of the satisfaction they derive from the projects and the benefit they receive from meeting together and sharing their experiences. Asingwire et al. recommend that individual IGPs should be encouraged among people who are not PLWHAs. Individuals are in a position to monitor themselves and are more likely to offer total commitment to their "own" projects rather than that of a group. Experiences of IGPs in Malawi are similar, as shown in Box 3.

In Uganda, one scheme, the "Zero Grazing Heifer Project", provided families with an expectant cow, so that they could benefit from the milk production. The family fully own

the cow after it has given birth to a female calf which is taken away to continue the cycle. While the project was a success under loan circumstances, an indivisible item such as a cow may actually increase the vulnerability if the recipients are forced to make a distress sale when faced with calamity (Kezaala and Bataringaya, 1998).

Box 3: ActionAid's experience with income-generating projects in Malawi

In 1996 ActionAid Malawi established a pilot project targeted at orphans, the chronically ill and people living with AIDS. With funding from UNICEF, ActionAid provided capacity-building to CBOs to facilitate the formation of functional revolving savings and credit schemes. The grant funds and the small loans could be used for IGPs involved in:

- *small-scale manufacturing and production like tailoring, baking, weaving, leather craft and food processing*
- *agricultural activities e.g. poultry, egg and broiler production, vegetable growing, etc*
- *service business, e.g. shoe repairing, bicycle repair, running of tea rooms*
- *petty trading–vending, hawkers, small retail outlets, and the selling of various food commodities e.g. beans, and maize*
- *fishing*

Members of a functional group can get loans as a group or as individuals and are expected to repay their loans promptly to keep the fund revolving. The initial amount loaned out was Malawian Kwacha (MK) 400 but later members could receive up to MK1500.00 per person. The support group decides the maximum amount that can be borrowed on the basis of the beneficiaries' capacity to pay back the money. Money is lent out without any form of collateral required. Interest is charged at rates ranging from 10% to 20% per annum. Repayment periods vary from group to group. The recovery rate of loans has been good. A Zomba woman doing stone crushing repaid her loan IGP within a month and got a bigger loan which has enabled her business to grow. A number of CBOs like NASO in Nkhotakota have recovered 85% of all loans that were given to individuals and are in a position to give out second loans.

Achievements of the project objectives included reaching 3000 orphans in 756 households, benefiting 62 people living with HIV/AIDS who have received funds to run IGPs, and management and IGP training for the volunteers managing the support groups. The major problems experienced included complaints that the loans were too small for the type of business that some of the beneficiaries wanted to venture into, and some of the beneficiaries did not have enough skills to run IGPs but have now gained some knowledge and skills.

The major lessons learnt include:

- *Individual IGPs are better managed than group IGPs as there is greater control when a single person is responsible for managing the IGP.*
- *Income-generating activities that are locally administered by the community using their own regulations are more beneficial and less costly. It is important for communities to own their own credit schemes as this ensures sustainability.*
- *A savings and credit programme that relies upon community participation and a spirit of voluntarism has greater chances of sustainability than one that relies on a public servant for daily operations.*
- *A programme that targets the family unit will be more responsive to the needs of the ultimate beneficiaries.*

Adapted from: Khonyongwa (ActionAid Malawi) (1998).

In rural areas of Zambia, coping strategies are related to farming activities and brewing beer. Because of poor markets there is less buying and selling of commodities. Community small-scale agricultural schemes are managed with the profits going to those most in need, as identified by the project committee (Webb, 1995).

In their Mpongwe field study in Zambia, FAO found that livestock loans are an important intervention that strengthen household and community coping responses, especially for women. Microcredit is deliberately packaged to attract female clients, because they have shown better repayment rates worldwide (Hunter and Williamson, 1998). Experience has also shown that women are more likely to use their income to help meet children's immediate needs.

There were no documented costs and effectiveness of income-generating projects in the literature reviewed. Evaluation of income-generating projects by Asingwire et al. in Uganda in 1998 did not document any costs and effectiveness of the IGPs. According to Sabatier (1997), AIDS NGOs have poor economies of scale and administrative and overhead costs take up the biggest part of their budgets, sometimes resulting in less than 20% of the budget actually reaching the intended beneficiaries. This has been found to be true for highly personalized support such as home care (considered in the next section), counselling and crisis support. Having the programmes more community focused makes the projects much cheaper and more effective. A similar lack of data has been found in the literature with NGOs involved in mitigation work. Some particularly group-oriented types of income-generation projects have been reported to offer more psychological benefits than material ones. IGP schemes were shown to improve self-esteem as members were too busy to indulge in self-pity (Julian et al. 1996).

Some studies emphasise the need to evaluate carefully the relevance of any income-generating projects before they are introduced to the community to see whether they are relevant to community skills and resources. Evaluation of a vanilla agricultural project in Mukono district, Uganda, revealed that the project was not viable owing to the lack of a market (Kezaala et al. 1998). Lack of relevant skills and knowledge was identified in several studies to be the major reason for failure. "Good intentions, a small injection of capital and a few quick lessons cannot turn out successful tailors, poultry farmers and bakers" (Jackson et al. 1993). Interventions that are well evaluated, are low-cost and are built on community resources, skills and needs have higher chances of success, but Jackson et al. warn of the difficulties inherent in establishing successful IGPs based on cost-effectiveness and income generating criteria alone. If cost-effectiveness is not the goal, then this should be clear to all participants to avoid mistaken assumptions and false hope.

5.3 Treatment and home-based care programmes

Home-based care programmes for people with HIV/AIDS or integrated with other health needs are rapidly expanding in sub-Saharan Africa as a response to HIV/AIDS. This is because of the inability of hospitals and other formal health institutions to cope with the increased demand at the same time as their real budgets are in decline because of

economic structural adjustment measures. At its worst, home care equates to home neglect, but at its best, it helps patients live through their illness and die in some dignity and comfort in familiar surroundings with their family around them. Osborne et al. describe various models of home care (from hospital outreach to NGO-led schemes to CBO and PLWHA-led ones) and discuss their relative merits. They and others (e.g. Woelk et al. 1997) note that the key difficulties facing home care concern costs and long-term sustainability, quality of services, and coverage. Foster et al. (1993) estimate that in the best schemes, under 10% coverage is likely to be achieved, and it is often less. The first home-care programmes in Uganda, Zambia and Zimbabwe were developed by hospitals but it was found that 75% of the hospital staff time was spent travelling to patient's homes in the rural areas which was very costly for the hospitals.

The WHO-sponsored study of 1993 (WHO, 1994) in Zambia found out that the average cost of a home visit by a three-person team was US$ 26, and concluded that home care was a costly, capital-intensive service but that it could become more efficient if communities were allowed to play a major role. In a different study Gilks et al. (1998) also concluded that hospital-run home-based care units were not cost-effective since they were expensive and could not cover all the those in need. In the early 1990s, hospital-based home-care programmes began to work more closely with community-based volunteers from churches and other social groups. The community home-based programmes, which involve local volunteers in home visits, are more cost-effective and the community-based teams are able to spend more time with patients than hospital-based teams.

The home-based care study in Zimbabwe by Woelk et al. (1997), albeit based on a small and not necessarily representative sample, found the cost of community home-based care to be substantially higher in rural areas than urban areas, mainly because of increased transport costs (US$ 42 per visit in rural areas compared to US$ 16 per visit in urban areas). Salaries and transport costs accounted for the greatest part of the costs (ranging from 78% to 90%). The authors concluded that it is essential to increase the involvement of communities and to develop the sense of community ownership of programmes so as to minimize costs.

Many community home-based care programmes take the form of medical and nursing care, material assistance, as well as emotional, spiritual and social support. However, there is a basic assumption that resources will be available to meet the drugs and material requirements. This might not be the case in resource-poor rural areas and might be a major obstacle for the functioning of the community home-based care programmes. Another major obstacle is when the number of people requiring home-based care rises to levels that outstrip the capacity of the community home-based care service.

Gilks et al. (1998) indicate that costs for the Chikankata home-based care programme in the rural area of Zambia were about US$ 1000 per client served. The largest costs were transport costs. Chikankata hospital is a Salvation Army-supported hospital, serving a rural population of about 100 000 people. In comparison, the costs of the Catholic Diocese Copperbelt home-based care programmes in Zambia are modest in relation to

the number of beneficiaries. An analysis of programme costs (excluding orphan support) in the township of Ipusukilo over a 24-month period in 1996–98 found that the average expenditure per month was US$ 2216 for 400 patients, or 3600 people including household members. The largest single item was welfare support (food, clothing, blankets, bed sheets) for families which accounted for 39% of money spent, followed by drugs and equipment which accounted for 21% (Blinkhoff et al. 1999). Evaluation of home-based care programmes in Zambia is shown in Box 4, and the conclusion of the study described is that community-rooted home-based care can make the programme much cheaper, reducing substantially the staffing and transport costs and allowing the greater proportion of the funds to go as direct service benefit to patients and families.

5.4 Changes in cultural norms and values

In the African context, as more and more people die of AIDS, communities have to forgo traditional mourning practices. Many communities today do not have the human and material resources to continue culturally prescribed rituals and rapid adjustments have had to be made. African funeral rituals usually involve bringing the body into the home for at least one night, washing it, a public viewing, a graveside service, a big meal for the mourners and a week-long period of mourning in which friends and relatives sleep in and around the house of the deceased (McNeil, 1999). Several studies indicate that periods of mourning have been reduced from seven to two or three days for an adult and from three to two days for a child (Lwihula, 1998; SAfAIDS, in press; Kilonzo et al. 1996). In Uganda, the custom of showing respect when a neighbour dies by not working in one's garden for four days has been dropped. "You cannot afford to do that now or else you will have no food"-Dr D Kabatesi, head of the Theta AIDS-education Project (McNeil, 1999).

Some studies also indicated changes in some traditional cultural practices that used to increase the spread of HIV transmission. For example, in a study undertaken in Zambia by SAfAIDS (in press), ritual cleansing involving sexual intercourse after a woman is widowed is now on the decrease, more so if her late husband's cause of death is suspected to be AIDS. Instead ritual cleansing now involves putting a beaded ring around the waist of the widow, and smearing her with mealie meal. The widow should not get married or have sex, lest she dies or goes mad, until the ring drops off on its own.

Some communities have made efforts to protect the property and inheritance of widows and children from being appropriated by the family of the deceased spouse by working together with community leaders.

Box 4: Cost and effectiveness of home-based care in Zambia

In Zambia, AIDS is already the most common cause of death for adults admitted to hospital. Total HIV infection projections for 1998 are as high as 1.8 million, or nearly 28% of the total population. The vast majority of those infected will seek health care at some point in their illness, causing demand for hospital beds to increase by as much as 20% annually in the next decade. PLWHAs are expected to occupy 90% of the country's 25,000 hospital beds by 2010.

Forty-seven home-based care programmes have been set up since 1987 to provide services for PLWHAs in their communities. Further, the Zambian government has responded by formally endorsing home-based care as a part of its health strategy, urging district health boards to support home-based care and encouraging home-based care programmes to improve efficiency through increased integration with other community health care systems.

A study has been carried out to examine some home-based care programmes initiated by hospitals and communities. Broad comparisons were made between these two major types of infrastructure to explore their relative efficiency and success in integrating into existing health care services. Unit cost per home visit varied significantly, ranging from US$ 10 to US$ 40 for the hospital-initiated programmes (due to the difference in structures, services and productivity of these programmes) to US$ 2 for a community-based programme. Major costs include transport, supplies, salaries and training. Hospital costs varied between US$ 3 and US$ 8 per day, although neither costs incurred by visiting family members nor loss of opportunity costs could be calculated.

The key conclusion of the study is that, although external financing is required, support for the home-based care movement in Zambia should be continued and increased. Home-based care programmes in Zambia have been exemplary and an inspiration to the rest of the world. They have clearly brought immeasurable comfort and service to thousands of PLWHAs, their families and communities. Nevertheless, there is an urgent need to improve the efficiency and lower the cost associated with current home care services as carried out in some countries.

Increased use of home care could alleviate some of the pressure on tertiary care centres. Costs can be lowered by avoiding vertical programmes based on outreach activities which require vehicles, have low coverage and demand a great deal of senior staff time. The demand for hospital care could be diverted to community care, if the existing primary care facilities located closer to households were to be better utilized and supported, including the availability of comprehensive care. Communities would be able to organize and offer a broader spectrum of clinical as well as emotional and spiritual support. To accomplish this, however, the capacity of communities and families to care for PLWHAs will need to be increased and made more sustainable. Often, as shown in the case studies, capacities are available but underutilized and not linked together, such as church groups, local health workers, traditional healers, caring by family members.

Source: Ng'weshemi et al. 1997.

6. Policy implications on community coping responses

Rural communities that are coping with increasing losses due to HIV/AIDS draw on the existing family and community for support. They are sharing their experiences of how to cope with HIV/AIDS losses with other communities. Service organizations and NGO support help bring in resources that are required particularly for treatment and home-based programmes. The literature has shown how people are mobilizing themselves using traditional and modern systems of care in order to provide support to the sick and the disadvantaged in their communities. People living with HIV are playing an increasing role in the community.

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. The main limitation of these grassroots initiatives is that they do not generate enough resources to buy drugs and other treatment and care requirements, so their support in this aspect is rather limited. In addition they may place a heavy work load on women who already work long hours.

The literature has shown that, as the numbers of AIDS-related deaths increase, the existing community strategies are increasingly under pressure. This observation underscores the importance of closely monitoring the coping capacity of communities so that policies and programmes can be designed that provide support in strategic ways to maximize the effectiveness of local initiatives and help them to continue. External support by health planners, policy makers, donors and NGOs should support community-rooted initiatives and not replace them. The need for sustainable approaches that can reach the growing number requiring support and ensure a basic quality of service makes it essential that effective community mobilization and development form the cornerstone of strategies for care. HIV prevention efforts should be an integral element of these strategies if the emphasis is on openness and community recognition and ownership of the problem. This also requires the creation of a non-discriminatory legal and human rights framework in which people with HIV/AIDS feel secure in disclosing their situation.

The community-based programmes that are dependent on external support have been very responsive to the needs of those affected by AIDS. The responses supported by such programmes were much wider and more holistic than others and included support to orphans, improved life skills such as training youths, home-based care (nursing care and drugs), income-generating projects and counselling. However, such programmes also have limitations which include poor organizational management skills; lack of adequate funding and technical support to sustain the project when the donor pulls out; poor targeting of support; founder's problems; and, sometimes when the programme is church-funded, discrimination against non-members.

Some policy options arise out of the literature review that can be taken up to strengthen the capacity of communities to cope with HIV/AIDS. This section presents a range of possible policy options that can be adopted.

6.1 Enhancing and mobilizing community capacities

As indicated in an earlier section, families depend on the extended family, neighbours and informal community groups for much of their support. It is important that programmes and policy aim to enhance and mobilize capacities that exist within communities. The pandemic is placing enormous strain on the traditional coping mechanisms of the extended family, steadily eroding the extended family's capacity to care for those suffering from or bereaved by HIV/AIDS. According to a 1997 study by McKerrow in Zimbabwe on the willingness of communities to absorb orphaned children, families are more willing to care for orphans if some form of support is offered, for example free education, free health care and food supplements (Michael, 1998). It is therefore important that programmes and policy are aimed at enhancing and strengthening the traditional coping responses of extended families and their communities.

NGOs and CBOs can greatly increase the effects of their resources by facilitating and strengthening the autonomous AIDS responses of communities, rather than attempting direct provision of services. This can be achieved by supporting activities that are owned by communities such as child care, non-formal education and labour sharing, providing programme ideas and seed funding to community groups, by supporting informal societies so that they can expand to bring in new members and by building community capacity to undertake these responses through the provision of training and technical assistance to community volunteers. Churches and women's groups are willing to help but lack the resources and skills to make orphan visiting programmes work (Foster and Makufa, 1998). However, before making any intervention an external change agent (whether it be government or NGO), should conduct a thorough situation assessment to determine community needs and survey the existing responses. The change agent should build on existing responses to the crisis, seeking to strengthen and not to replace or eliminate initiatives already underway.

6.2 Strengthening community responses

Community responses to AIDS can be strengthened in a number of ways. These include:

- the democratization and localization of resource allocation;
- reinforcement of the management skills of CBOs;
- training on project design, planning, management, monitoring and evaluation;
- the establishment of a forum for NGOs and CBOs to exchange their views and experiences;
- building links between donors, NGOs, CBOs, and the government.

Again, sound community mobilization and development strategies including participatory rural appraisal (PRA) are essential.

6.3 Mitigation support

In a survey of 75 NGOs in six selected countries in sub-Saharan Africa (Cameroon, Côte d'Ivoire, Kenya, Tanzania, Zambia and Zimbabwe), the United States National Research Council found that, while on average 65% of the selected NGOs indicated AIDS prevention as one of their goals or objectives, only 32% mentioned mitigation of the impact of AIDS as their goal. Of the NGOs who did, the breakdown of the mitigation interventions provided for all countries was: counselling 50%, community awareness 11%, economic assistance and self-help projects 34%, and training 5%. These results suggest that mitigation is not receiving the support and attention that it deserves. Particularly in some hard-hit countries, increasing numbers of households require mitigation support.

The literature review revealed that there is a need to have a combination of relief and mitigation activities. Even in a community with very low HIV/AIDS prevalence, there is a need to set up mechanisms to respond to locally identified determinants that may increase vulnerability to HIV/AIDS and to work towards strengthening community responses to reduce that vulnerability. Of major importance is the issue of timing of support to strengthen household and community responses. Affected households which are failing to cope because of the youth of the head of household or the lack of land or other basic assets need relief support to help them from entering permanent destitution. Once signs of recovery appear, relief support can be gradually replaced with mitigation support for longer-term needs. The emphasis should be on helping families avoid jeopardizing long-term survival to meet short-term needs, the most obvious examples being withdrawal of children from school and sale of remunerative assets.

Communities are best placed to identify needy families, vulnerable children and orphans. There is need, therefore, to involve communities in developing systems to enumerate and assess the needs of families and children, to determine the extent of problems, to raise awareness, and to promote informed decision-making (Donahue, 1998). Communities are also best placed to monitor and maintain contact with children, supervise their activities, and prevent child labour abuses. Support is more effective when channelled to the poorest families and orphans to prevent them from falling into permanent destitution. Given the large and growing numbers of orphaned children where the epidemic is mature and severe—and the poverty prevailing in many countries—it is important that countries develop an orphan policy that seeks to integrate orphans in national development. Orphan policy will help collaborating organizations identify and target resources to affected children, monitor their progress and protect their rights.

6.4 Income-generating activities

It is still questionable how income-generating projects can be feasible and sustainable in severely constrained economic environments where markets are scarce. But specific income-generating activities can be very effective when participants already have the

necessary skills and access to resources and markets. Efforts by outsiders to introduce unfamiliar income-generating projects incur significant costs and fare poorly.

In developing interventions to improve income-generating capacities, it is important to recognise that the composition and vulnerabilities of households differ and change over time, as do their capacities. Their potential to participate in and benefit from economic and other interventions depends to a large extent on how children and adults use their time and whether they can make time for additional activities. Activities that help reduce demands on household members' labour so as to free them to undertake other productive activities are the most valuable. However, women risk being doubly affected by engaging in some income-generating activities since they are also expected to provide community care. It is, therefore, important to evaluate carefully the impact of particular policies and programmes to ensure that they do not overburden women. Projects that supplement or complement existing coping mechanisms can become sustainable. Interventions that are low-cost and community-centred have a higher chance of success.

An important objective needs to be the development of employment. For the poorest and the landless, having access to wage employment is crucial, in both rural and urban settings.

6.5 Working in partnership

Policy makers and programme planners should recognize that HIV/AIDS is not only a health problem but a development crisis, with an impact not only on community members' health but on nearly all aspects of community development. Policy and programmes that seek to benefit HIV/AIDS-affected families should be multi-sectoral, linking the government, religious groups, NGOs, the private sector and the community in endeavours aimed at improving cooperation in supporting and strengthening community-based responses. If government is committed then there should be evidence of support both at national policy level and involvement at local levels. The government is expected to play the leading role in creating an environment conducive to the promotion of sustainable development in the rural areas. All formal government organizations (Ministries of Agriculture, Education, Health and others) could play a bigger role if they reform their policies and programmes to respond to the needs of the HIV/AIDS-affected households. These government departments can achieve this by reviewing the existing policies and programmes and replacing them with ones more responsive to the epidemic, and showing political and economic commitment for AIDS intervention. They need to contribute and show commitment for promoting, among others, adequate services to affected households through human resource capacity assessment and capacity building of agricultural and rural development institutions while reviewing their policies on a continual basis so that emerging challenges posed by HIV/AIDS are taken into account.

Donors can help NGOs and CBOs to engage in longer-term planning and capacity building. Multinational donors need to be more flexible with their funding in support of

local initiatives, preferably by making many small grants rather than one large project grant. The present emphasis on large-scale grants and projects undermines local initiatives that may be far more effective and appropriate, as well as sustainable. Donors are, however, reluctant to manage numerous small projects. A mechanism is needed to resolve this problem, with perhaps an intermediate body to manage small-scale funds and report to the donors. It is strongly recommended that avenues be explored to achieve this.

6.6 Measuring effectiveness of community responses

Meaningful cost and benefit analysis should be undertaken so that the actual costs of community and household responses are estimated. This could help in selecting and strengthening cost-effective responses that will yield the greatest benefits to communities. Given the current economic crisis experienced by developing countries, resources for HIV/AIDS mitigation are on the decrease and funds from many donors are on the decline. It is essential that mitigation responses by communities are closely monitored and evaluated so that the greatest impact is achieved with the limited resources available.

7. Conclusions

In the past 15 years, the HIV/AIDS epidemic has placed severe stress on households and communities. The increase in morbidity and mortality is taking a heavy toll on the well being of individuals, households and communities. The epidemic has greatly affected access to education and health services, fulfilment of basic needs such as food and housing and the right to privacy and human dignity. Yet people throughout the world have mobilized themselves to confront its challenges (Williams et al. 1995).

A variety of coping responses have been deployed by households to mitigate the impact of the pandemic. In general terms, some of the coping responses adopted by households have been found to render households insecure and vulnerable. Sale of assets, withdrawal of children from school, reduced food consumption and use of savings and investment, all have negative impacts on the future well-being of the family. On the other hand, some household coping responses have positive impacts on the long term well-being of the household, such as income diversification, share-cropping, adoption of labour saving technology such as inter-cropping and diversification of crop production. It is therefore important that policy and programmes are designed in such a way that the positive household responses are reinforced while at the same time households are discouraged from adopting coping responses that can compromise their future well-

being. For example, agricultural research policies can be geared towards development of appropriate technology suited to low-resource conditions, and the planning of rural development projects that can support orphans, create employment, and promote household food security.

The community responses documented in this literature review demonstrate how communities have developed traditional and modern responses to help meet the urgent needs of people with HIV/AIDS. The responses have included: labour sharing, orphan support, community-based child care, repair of deteriorating houses, home care and visits to orphans and HIV/AIDS patients, preparation and distribution of school uniforms, apprenticeship and training for orphaned adolescents to give them marketable skills, income-generating projects to produce food and cash, and credit schemes for funeral benefits. Traditional community coping mechanisms are limited to activities that do not demand substantial amounts of financial resources such as buying drugs and other treatment and care requirements, and the literature revealed that if the whole community is impoverished due to AIDS, community coping responses can be overburdened. But if measures can be taken to prevent the spread of the infection or to intervene before community resources are stretched to breaking point, they can be much more effective in the long run.

Community-based organizations that receive financial support from external agencies have been very beneficial to many affected households, although they do have some limitations that need addressing. If these community strategies are adapted to local needs and take into account locally available resources, they can be applied to other developing countries. Community-based organizations and NGOs should try not to duplicate work that is already existent in communities but should strive for integration by supplementing or complementing community responses. External support should build on existing community structures such as churches, women's groups, schools and foster families.

If programmes are to be effective it is also important to target households that are most in need. However, targeting AIDS-affected households only is unethical, since it may leave out households that are equally in need for other reasons. It is, therefore, important that programmes target a wider group of households based on both poverty and AIDS indicators. This can be achieved best by working through communities identifying the most needy themselves.

Without investment in human development, there is no long-term progress in national development, stability and the skills base to overcome development obstacles. Government alone cannot achieve the basic well-being of the entire national population. This calls for meaningful partnership between the communities, governments, donor agencies, international NGOs, local NGOs, private sector and others in order to address the problems of HIV/AIDS successfully. But governments should be prepared to play a more active leadership role and review their commitment to rural development. They need to undertake this with a clear analysis of the impact of AIDS on development, and of the impact of development on the AIDS epidemic itself.

References and literature sources

Addo SK (1998) "Trickle-up micro-grants and positive living with HIV/AIDS", 12th World AIDS Conference: Bridging the Gap, Geneva (June 28–July 3).

Allman D, Myers T, Cockerill R (1997) *Concepts, definitions and models for community-based HIV prevention research in Canada, and a planning guide for the development of community-based HIV prevention research,* Faculty of Medicine, University of Toronto, Toronto.

Altman D (1994) *Power and Community Organizational and Cultural Responses to AIDS,* Taylor and Francis, London.

Aryeetey E, Hyuha M (1990) *The informal financial sector and markets in Africa: an empirical study,* IBRD Africa Economic Conference, Washington D.C.

Asingwire N, Muhangi D (1998) *Strategies for Action (SFA) Phase III: Supported CBOs/NGOs,* Evaluation Report, Makerere University, ActionAid Uganda.

Baguma P (1996) "The cost-benefit analysis of AIDS traditional healing in Uganda", 11th International Conference on AIDS: One World, One Hope, Vancouver (July 7–12).

Barnett T, Blaikie P (1990) *Community coping mechanisms in the face of exceptional demographic change.* Final Report to the Overseas Development Administration, London, ODA (July).

Barnett T, Blaikie P (1992) *AIDS in Africa: Its Present And Future Impact,* John Wiley & Sons Ltd, Chichester, UK.

Barnett T (1994) *The effects of HIV/AIDS on farming systems and rural livelihoods in Uganda, Tanzania and Zambia,* FAO, Rome.

Barnett T, Blas E, Whiteside A (1996) *AIDS Briefs:* "Integrating HIV/AIDS into sectoral planning", WHO, Geneva.

Barnett T, Tumushabe J, Bantebya G, Sebuliba RS, Ngasongwa J, Kapinga D, Ndelike M, Drinkwater M, Mitti G, Haslwimmer M (1995) The social and economic impact of HIV/AIDS on farming systems and livelihoods in rural Africa: Some experience and lessons from Uganda, Tanzania and Zambia. *Journal of International Development* 7:1.

Black M (1997) *Impact du VIH/SIDA sur les systèmes d'exploitation agricoles en Afrique de l'Ouest,* FAO, Rome.

Blinkhoff P, Bukanga E, Symalevwe B, Williams G (1999) *Under The Mupundu Tree; Volunteers in home care for people with HIV/AIDS and TB in Zambia's Copperbelt,* Strategies for Hope 14, ActionAid, London.

Boerma T, Ngalula J, Isingo R, Urassa M, Senkoro KP, Gabone R, Mkumbo EN (1997) Levels and causes of adult mortality in rural Tanzania with special reference to HIV/AIDS. *Health Transition Review,* 7 (Supplement 2): 63–74.

Bond VA, Wallman S (1993) *Community capacity to prevent, manage and survive HIV/AIDS,* Report on the 1991 Survey of Households in Chiawa, Working Paper no. 5, Karolinska Institutet, University of Hull; Sociology and Social Anthropology, and University of Zambia; Institute of African Studies.

Christen RP, Rhyne E (1995) *Maximising the outreach of microenterprise finance: an analysis of successful microfinance programs,* USAID Programme and Assessment Report No.10 Washington, DC: USAID Center for Development Information and Evaluation (July).

Corbett J (1988) Famine and household coping strategies. *World Development,* **16**(9):1099–1112.

Cornu C (1998) "Self-help groups of people with AIDS in Côte d'Ivoire: People with AIDS as social reformers in Western Africa?" 12th World AIDS Conference: Bridging the Gap, Geneva (June 28–July 3).

Develay A, Sauerborn R, Diesfeld JH (1996) Utilisation of health care in an African urban area: results from a household survey in Ouagadougou, Burkina Faso. *Social Science and Medicine,* 43(11):1611–1619.

Donahue J (1998) *Community-based economic support for households affected by HIV/AIDS,* Health Technical Services Project Report of TvT Associates, The Pragma Corporation, USAID HIV/AIDS Division.

Drinkwater M (1993) *The effects of HIV/AIDS on agricultural production systems in Zambia; an analysis and field reports of case studies carried out in Mpongwe, Ndola Rural District, and Teta Seranje District,* FAO, Rome.

Dube N, Kathuria R, Sabatier R, Chirenda P, Wilson D (1998) "A peer education project evaluation schema: Inputs, outputs, unit costs, coverage, behavioural impact and biomedical impact", 12th World AIDS Conference: Bridging the Gap (June 28–July 3, 1998), Geneva.

Dunn E, Kalaitzandonakes N, Valdivia C (1996) *Risk and the impacts of microenterprise services: assessing the impact of microenterprise services (AIMS) project,* USAID Washington, DC.

FAO (1993) *The effects of HIV/AIDS on agricultural production systems in Zambia: An analysis and field reports of case studies carried out in Mpongwe, Ndola Rural District and Serenje District,* Adaptive Research Planning Team Report, Ministry of Agriculture, FAO, Rome.

FAO (1995) *The Effects of HIV/AIDS on Farming Systems in Eastern Africa,* FAO, Rome.

Farm Orphan Support Trust (FOST) (1998) *Farm orphans: Who is coping? A study of commercial farm workers and their responses to orphanhood and foster care in Mashonaland Central Province of Zimbabwe,* FOST, Harare.

Foster G, Makufa C (1998) "The Families, Orphans and Children Under Stress, (FOCUS) Programme", Paper presented at the UNAIDS Community Mobilisation in Eastern and Southern Africa Meeting held in Pretoria, South Africa, (November 9–11).

Foster S (1993) *The cost and burden of AIDS on the Zambian health care system: policies to mitigate the impact of health services,* Report commissioned by the Government of Zambia and USAID.

Gilks C, Floyd K, Haran D, Kemp J, Squire B, Wilkinson D (1998) *Sexual Health and Health Care: Care and Support for People With HIV/AIDS in Resource-Poor Settings,* UK Department for International Development, Health and Population Occasional Paper.

Gumbo P (1998) *The gender dimension in social security: a historical perspective,* Friedrich Ebert Stiftung, Harare.

Hampton J (1990) *Living positively with AIDS, The AIDS Support Organization (TASO), Uganda,* Strategies for Hope 2, ActionAid; AMREF (African Medical Research Foundation), World in Need, Marianum Press, Kisula, Uganda.

Haslwimmer M (1994) *What has AIDS to do with agriculture?* FAO, Rome.

Hansen K, Woelk G, Jackson H et al. (1998) The cost of home-based care for HIV/AIDS patients in Zimbabwe. *AIDS Care,* **10**(6):751–759.

Hemrich G, Schneider B (1997) *HIV/AIDS as a cross-sectoral issue for technical co-operation; focus on agriculture and rural development,* GTZ HIV/AIDS Prevention and Control in Developing Countries, Series No. 1.

Hunter S, Williamson J (1994) *Children on the brink: strategies to support children isolated by HIV/AIDS,* Health Technical Services Project of TvT Associates, The Pragma Corporation, USAID HIV/AIDS Division, Arlington, Virginia.

Hunter S, Williamson J (1997) *Developing strategies and policies in support of HIV/AIDS infected and affected children,* Health Technical Services Project of TvT Associates, The Pragma Corporation, USAID HIV/AIDS Division, Arlington, Virginia.

Hunter S, Williamson J (1997) *HIV/AIDS orphans and NGOs in Zambia: strategy development for programming,* The TvT Associates for USAID and Zambia Mission for Family and Community Care of Children Affected by HIV/AIDS, Washington, DC (June).

Hunter S, Williamson J (1998a) *Children on the brink: strategies to support children isolated by HIV/AIDS,* Arlington, VA: Health Technical Services (HTS) Project for USAID (January).

Hunter S, Williamson J (1998) *Responding to the needs of children orphaned by HIV/AIDS,* A report produced by the Health Technical Services Project of TvT Associates and The Pragma Corporation for the HIV/AIDS Division of the USAID, Discussion paper 7.

IFPRI (1996) *Rural Financial Markets and Household Food Security: Impact of Access to Credit on the Socio-Economic Situations of Rural Households in Malawi,* International Food Policy Research Institute (September).

Jackson H, Civic D (1994) Family coping and AIDS in Zimbabwe. *Journal of Social Development in Africa,* School of Social Work, Harare.

Jackson H, Udwin M, Chandra-Mouli V, (1994) AIDS support and income-generation. *Global AIDS Network* **10**(4):10–11.

Julian V, Atayan S, Pinoy P (1996) "Capability building for people living with HIV/AIDS", 11th International Conference on AIDS, Vancouver (July 7–12).

Kadonya C (1998) "The Impact of HIV/AIDS on Smallholder Agriculture in Tanzania: Rethinking of other intervention Strategies", Regional Conference for Eastern and Southern Africa on Responding to HIV/AIDS: Technology development needs of African Small-holder Agriculture, Harare (June 8–10).

Kaseke E (1997) *Social Security in Systems in Rural Zimbabwe,* Friedrich Ebert Stiftung, Harare.

Kelly M (1998) The Children in Distress Conference. *AIDS Analysis Africa* (Southern Africa Edition), **9**(3).

Kenya AIDS NGO Consortium (1998) *AIDS in Kenya; A Directory of HIV/AIDS Service Organizations working in Kenya,* USAID, FHI.

Kezaala R, Bataringaya J (1998) "The practicalities of orphan support in East and Southern Africa: planning, and implementation of multi-sectoral social services for children and child carers", Paper presented at the Conference on Raising The Orphan Generation, Pietermaritzburg, (June 9–12).

Khonyongwa L (1998) "Children and families affected by HIV/AIDS: A community-based income-generation project with a focus on needy children", (ActionAid Malawi) Paper presented at a Conference on Raising the Orphan Generation, Pietermaritzburg (June 9–12).

Kilonzo GP, Hogan NM (1996) "African communities forgo traditional mourning practices in the face of multiple untimely losses through AIDS: Implications for Mental health in Tanzania", Poster presentation at the 11th World AIDS Conference, Vancouver.

Krift T, Phiri S, (1998) "Developing a strategy to strengthen community capacity to assist HIV/AIDS-affected children and families: The COPE Programme of Save the Children Federation in Malawi", Paper Presented at Children in Distress (CINDI) Preparing for Life after AIDS Conference on Raising the Orphan Generation, Held in Pietermaritzburg, South Africa, (June 9–12).

Kwaramba P (1997) *The Socio-Economic Impact of HIV/AIDS on Communal Agricultural Systems in Zimbabwe,* Zimbabwe Farmers Union, Friedrich Ebert Stiftung Economic Advisory Project, Working Paper 19, Harare.

Ledward A (1997) *Age, Gender and Sexual Coercion: Their role in creating pathways of vulnerability to HIV infection,* Master's Thesis submitted to University College of London.

Leshabari M (1995) "Household and Community Responses in Kyela district, Tanzania", Report from a consultation on the socio-economic impact of HIV/AIDS on households, UNAIDS, World Health Organization, (September 24–25).

Little ML (1996) *Adolescents and AIDS in Malawi: Issues of Hopelessness and Fatalism in Effective AIDS Education,* Independent Contribution to Bachelor's Degree, Dartmouth College.

Loewenson R, Kerkhoven R (1996) *The Socio-Economic Impact of AIDS: Issues and Options in Zimbabwe,* SAfAIDS and TARSC, Harare.

Loewenson R, Whiteside A (1997) *Social and Economic Issues of HIV/AIDS in Southern Africa: A Review of Current Research,* A consultancy report prepared for SAfAIDS.

Lwihula G (1998) "Coping with AIDS Pandemic: The experience of peasant communities of Kagera Region, Tanzania", Paper Presented at the East and Southern Africa Regional Conference on: Responding to HIV/AIDS: Development Needs of African Smallholder Agriculture, Harare, (June 8–10).

Madembo RC (1997) "The Role of Savings and Credit Schemes in Meeting the Social Security Needs of Communal Farmers", in *Social Security Systems in Rural Zimbabwe,* Kaseke E (Ed.), Friedrich Ebert Stiftung, Harare.

McNeil (1999) *Africa's Culture of Mourning Altered by AIDS epidemic,* The Zambia Electronic Mailing list on Health Issues: health-l@zamnet.zm.

Moses S, Plummer FA, Ngugi EN, Nagelkerkes NJD, Anzala AO, Ndinya-Achola JO (1991) Controlling HIV in Africa: Effectiveness and cost of an intervention in a high-frequency STD transmitter core group. *AIDS,* **5**:407–411.

Mukoyogo C, Williams G (1991) *AIDS Orphans: A Community Perspective from Tanzania,* Strategies for Hope, 5: ActionAid, AMREF, World in Need.

Munthali SM (1998) "Socio-economic Impact of HIV/AIDS in Malawi: Focus Group Discussions on Community Impacts and Coping Strategies", Report Submitted to NACP Malawi, OATUU Health Safety and Environment Programme.

Mwanza A (1997) The Poverty Phenomenon in Zambia. *Southern Africa Political and Economic Monthly,* **11** (1):28–30.

Ncube G (1998) "The Impact of HIV/AIDS on Smallholder Agriculture Production in the Districts of Gweru/ Shurugwi in Zimbabwe and the Current Recommended Sustainable Coping Strategies and Areas of Research", Paper Presented at the East and Southern Africa Regional Conference on Responding to HIV/AIDS: Development Needs of African Smallholder Agriculture, Harare, (June 8–10).

Ng'weshemi J, Boerma T, Bennett J, Schapink D (1997) *HIV prevention and AIDS care in Africa: A district level approach,* Royal Tropical Institute, KIT Press, Amsterdam.

Over M (1995) *Kagera Health and Development Project,* Report from a consultation on the socio-economic impact of HIV/AIDS on households, UNAIDS, World Health Organization.

Over M, Bertozzi S, Chin J, N'galy B, Nyamuryekung'e K (1988) The direct and indirect cost of HIV infections in developing countries: The cases of Zaire and Tanzania, in the *Global Impact of AIDS* edited by Fleming AF, FitzSimons DW, Mann J, Carballo M, Bailey MR; New York: Alan R Liss, 123–135.

Over M (1998) Coping with the impact of AIDS. *AIDS Analysis Africa* (Southern Africa Edition), 9(3).

Poulter K (1996) *A Psychological and Physical Needs Profile of Families Living with HIV/AIDS in Lusaka,* Lusaka.

Powell GM, Morreira S, Rudd C, Ngonyama RP (1994) *Child welfare policy and practice in Zimbabwe,* A Summary Report based on a Study by the Department of Paediatrics and Child Health, University of Zimbabwe in collaboration with the Department of Social Welfare, Ministry of Public Service, Labour and Social Welfare, Harare.

Reardon T, Vosti SA (1994) Links between rural poverty and the environment in developing countries: asset categories and investment poverty. *World Development* **23**(9):1495–1506.

Romano EM, Aplasca MR, Monzon OT (1996) "Coping Mechanisms of Families/Households of HIV-infected AIDS Patients in the Philippines", 11th International Conference on AIDS, Vancouver.

Rugalema G (1998) *It is not only the loss of labour: HIV/AIDS, loss of household assets and household livelihood in Bukoba district, Tanzania,* Paper Presented at the East and Southern Africa Regional Conference on Responding to HIV/AIDS: Development Needs of African Smallholder Agriculture, Harare (June 8–10).

Sabatier R (1997) NGO Responses to HIV/AIDS: A need to shift gears. *AIDS Bulletin,* **6** (1&2).

SAfAIDS, Commercial Farmers Union (1996) *Orphans on Farms: Who cares? An Exploratory Study into Foster Care for Orphaned Children on Commercial Farms in Zimbabwe,* Harare.

SAfAIDS (in press) *Socio-economic Impact of Adult Mortality and Morbidity on Households in Kafue District, Zambia,* Harare.

SAfAIDS, ZAN (1995) *Zimbabwe AIDS Directory – 1995; NGOs, ASOs, Support Groups, Funders, Resources,* Harare.

Sauerborn R, Adams A, Hien M (1996) Household Strategies to Cope with the Economic Costs of Illness. Social *Science and Medicine,* 43(11):291–301.

Save the Children UK (1996) *Living on the Edge: A Study of the Rural Food Economy in the Mchinji and Salima Districts of Malawi,* London, Save The Children UK (March).

Save the Children UK (1998) *Drought in Zimbabwe: Effects and Responses at Household Level,* Report of a PRA study on the 1992 drought in Zimbabwe, Harare.

Shreedhar J, Colaco A (1996) *Broadening The Front; NGO responses to HIV and AIDS in India,* Strategies for Hope 11, ActionAid, London, The British Council, New Delhi, UNDP, New Delhi.

TASO, WHO (1995) *The inside story, Participatory Evaluation of HIV/AIDS, Counseling, Medical and Social Services 1993–94,* TASO Uganda, WHO Geneva.

Tibaijuka AK (1997) AIDS and Economic Welfare in Peasant Agriculture, Case Studies from Kagabiro Village, Kagera Region, Tanzania. *World Development,* **25**(6):963–975.

Topouzis D (1998) *The Implications of HIV/AIDS For Rural Development Policy and Programming: Focus on sub-Saharan Africa,* Paper prepared for HIV and Development Programme, UNDP, Sustainable Development Department, Rural Development Division, FAO.

Topouzis D (1994) *Uganda: The Socio-economic Impact of HIV-AIDS on Rural Families with Particular Emphasis on Rural Youth,* Paper prepared for the UN Food and Agricultural Organization, Rome.

UK NGO AIDS Consortium (1996) *Effective HIV/AIDS Activities: NGO Work in Developing Countries,* Report of A Collaborative Study, London.

UNAIDS (1998) *UN Co-ordinated Response to the National HIV/AIDS Programme in Zambia 1998–2000,* UNAIDS, Lusaka.

United States Bureau of Census (1998) *HIV/AIDS Surveillance Data Base,* June 1998.

United States National Research Council Panel on Data and Research Priorities in Sub Saharan Africa, (1996) *Preventing and Mitigating AIDS in Sub Saharan Africa: Research and Data Priorities for the Social and Behavioural Sciences,* Edited by Cohen B and Trussell J, National Academy Press, Washington D.C.

Wallman S (1996) *Kampala Women Getting By: Wellbeing in the Time of AIDS,* Eastern African Studies, James Currey Ltd, London.

WCC (1997) *Facing AIDS: The Challenge, The Churches' Response,* WCC publications, Geneva.

Webb P, Reardon T (1992) Drought Impact and Household Response in East and West Africa. *Quarterly Journal of International Agriculture,* **31**(3):230–246.

Webb D (1995) Orphans in Zambia: Nature and extent of demographic change. *AIDS Analysis Africa,* **6**(2):5–6.

Williams G, Blibolo AD, Kerouedan D (1995) *Filling the Gaps; Care and Support for people with HIV/AIDS in Côte d'Ivoire.* Strategies for Hope 10, ActionAid, Hamlyn House, London; Comité National de Lutte Contre le SIDA, Abidjan, Côte d'Ivoire.

Woelk G, Jackson H, Kerkhoven R, Hansen K, Manjonjori NN, Maramba P, Mutambirwa J, Ndimande E & Vera E (1997) *The Cost and Quality of Community Home Based Care in Zimbabwe, University of Zimbabwe,* SAfAIDS and Ministry of Health and Child Welfare, Harare.

WHO, Zambian Ministry of Health (1994) *Cost and Impact of Home-based Care for People Living with HIV/AIDS in Zambia, Lusaka.*

World Bank, University of Dar es Salaam (1993) Report of a Workshop on: "The Economic Impact of Fatal Adult Illness in sub-Saharan Africa", Held in Bukoba, Kagera Region, Tanzania, 16–20 September, 1992.

World Bank (1997) *Confronting AIDS: Public Priorities in a Global Epidemic,* A World Bank Policy Research Report, Oxford University Press, New York.

Zambia Government (1994) *Report of the Workshop on the Effects of HIV/AIDS on Agricultural Production Systems,* National AIDS/STD/TB, Leprosy Programme, Ministry of Health, FAO, Rome.

Zambia Government (1996) *Zambia's Children in 1995; Key results of a Survey to monitor progress towards goals of children,* Lusaka.

Literature Sources

- *AIDSLink*
- Vancouver Conference Abstracts 1996
- Geneva Conference Abstracts 1998
- Southern African Network of AIDS Service Organizations (SANASO) Abstracts 1997
- African Health Anthology
- World Wide Web Internet searches and databases

Resource Centres

- SAfAIDS
- World Bank
- UNDP
- SADC Food Security Unit
- SARDC
- University of Zimbabwe Department of Economics
- UNICEF
- ActionAid
- Save the Children UK
- Ministry of Health and Child Welfare
- Health Economics and HIV/AIDS Research Division, University of Natal, Durban

Annex 1: Selected self-help groups in Uganda

Name	*Location*	*Activity*	*Type of group*	*Year when support started*
Kisiizi	Rukungiri SW	Home-care, counselling and sensitization	Hospital and community-based	1994
Kuluva	Arua North	Home-care, sensitization, testing	Hospital and community-based	1995
BWC	Rukunguri SW	Sensitization, counselling	Women's group	1995
STOGA	Nebbi North	Drama, IGA	Women's group	1995
AEGY	Kamuli, East	Youth, sensitization, IGA	Youth group	1994
YAAC	North, Apac	Youth, drama, sensitization	Youth group	1995
SED	Central	Counselling and family life education	Catholic church	1994
Kisa	North, Nebbi	Sensitization for youth in school	Teachers' group	1995
TASO Kumi	East	IGA, Home care, counselling	NGO	1994
EUDO	Central	Sensitization for youth in school	NGO	1993
GASCO	Central	Counselling and sensitization	Community placed	1995
THECA	Central	Sensitization and training of traditional healers	NGO	1997
NACOWLA	Central	Women's group, PLWHA group with a national remit and doing IGAs	National PLWHA women's group	1997

Source: Asingwire et al. 1998.

Annex 2: Survivor assistance organizations in Kagera, Tanzania

Organization	*Date started*	*Target group(s)*	*Programme interventions*
ABEKA	1987	Orphans	Food, education, health, home-based care
Huyawa (ELCT)	1991	Orphans, families	Food, education
KAKAU	1990	Orphans, widows, elderly	Prevention, education, health, food, home-based care
KARADEA	1987	Orphans, AIDS patients, elderly	Income-generation
KOCC	1991	Orphans	Food, education
KOTF	1988	Orphans, caretakers	Food, education, health, home-based care
MACOP	1991	Orphans	Food, health, home-based care

Source: World Bank, University of Dar es Salaam (1993)

Annex 3: Examples of CBOs in rural areas of Zimbabwe

Organization	*Date Started*	*Source of Funding*	*Target Population*	*Activities*
Chabwira Sewing Club	1993	Donations	Affected families	Income generating through trading of clothes, emotional support, training on counselling, sewing
Chorovakamwe PLWHA Support Group	1993	FACT and FASO	Affected families, people living with HIV/AIDS	Sewing, vegetable production, home care services
Kumutsirana Suppport Group	1994		People living with HIV/AIDS and affected families	Sewing, knitting, poultry raising, emotional support, information sharing
Regina Coeli Mission Hospital Support Group	1994	Regina Coeli Mission	People living with HIV/AIDS and affected families	Income-generation, sewing and knitting, emotional support and information sharing
St Peter's Mission Hospital Support Group	1994	St Peter's Mission Hospital	People living with HIV/AIDS and affected families	Sewing and knitting, emotional support, home care and information sharing
Tshelanyemba AIDS Care and Prevention		SAT	Affected families	Soap making, jam making, emotional support, information sharing and practical assistance
Usizo Kuzulu Support Group	1994		People living with HIV/AIDS and affected families	Income and emotional support, information sharing and home-care service

Source: SAfAIDS, ZAN (1995) Harare.

Annex 4: Examples of CBOs in rural areas of Kenya

Organization	*Target population*	*Activities*
AKADO HIV/AIDS Interventions	People living with HIV/AIDS; women; the aged; rural communities	Advocating for HIV/AIDS issues, clothing distribution, general HIV/AIDS education, HIV/AIDS counselling and testing, home-based care, information services, support services
Anti-drugs movement for better living	People living with HIV/AIDS; children; rural communities	General HIV/AIDS education; IEC materials distribution; training on specific issues.
Busia Young Men Christian Association (YMCA)	People living with HIV/AIDS; children; orphans; youth; people with disabilities; trainers; rural communities; community development workers	Advocating for HIV/AIDS issues, condom distribution; day care for children; general HIV/AIDS education; IEC material distribution; training of trainers; HIV/AIDS education through theatre.
Catholic Diocese of Homa Bay	People living with HIV/AIDS; youth; women; men; widowed; rural communities; urban communities; community development workers; health workers	General HIV/AIDS education; IEC material distribution; training non-health professionals
CDC/KEMRI	Rural communities	General HIV/AIDS education; HIV/AIDS counselling and testing; HIV/AIDS education through theatre
Community Initiatives Support Services	Rural communities	Capacity building; bereavement support services; general HIV/AIDS education
Msamaria Community Health Youth Group	Orphans; youth; women; hospital patients; rural communities; community development workers	General HIV/AIDS education; HIV/AIDS counselling; day care for children; home-based care for PLWHA; training of health and non-health professionals

Source: Kenya AIDS NGOs Consortium (1998).

The Joint United Nations Programme on HIV/AIDS (UNAIDS) is the leading advocate for global action on HIV/AIDS. It brings together seven UN agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations International Drug Control Programme (UNDCP), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO) and the World Bank.

UNAIDS both mobilizes the responses to the epidemic of its seven cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV on all fronts: medical, public health, social, economic, cultural, political and human rights. UNAIDS works with a broad range of partners – governmental and NGO, business, scientific and lay – to share knowledge, skills and best practice across boundaries.

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March 14, 2000

Dear Sandy,

Thank you for taking part in our first policy roundtable. Your comments set the tone for a constructive dialogue. We look forward to working with you in these next few critical months. With best wishes,

Geeta