



Economic Commission for Africa



The Impacts of HIV/AIDS on Families and Communities in Africa



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Commission on HIV/AIDS and Governance in Africa

The Impacts of HIV/AIDS on Families and Communities in Africa

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About CHGA

Under the Chairmanship of the Executive Secretary of the Economic Commission for Africa (ECA), K. Y. Amoako, the Commission on HIV/AIDS and Governance in Africa represents the first occasion on which the continent most affected by HIV/AIDS will lead an effort to examine the epidemic in all its aspects and likely future implications. The challenge for CHGA is to provide the data, clarify the nature of the choices facing African governments today, and help consolidate the design and implementation of policies and programmes that can help contain the pandemic in order to support development and foster good governance.

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Abstract

This paper outlines the major impacts of HIV/AIDS on the social and economic structures of households and communities in sub-Saharan Africa. It continues with a discussion of some of the most significant responses, some organized by communities themselves, others facilitated by outside agencies. The evidence used in the paper reflects the current state of research and analysis. In some instances, the evidence might be called “best practices.” In other instances, the evidence is still emerging, and clear directions remain to be further explored. Following a brief introduction, section II summarizes the relevant and current information on the social impacts of HIV/AIDS. It includes discussion of changes in family structure and the multiple impacts on women, girls and boys. Section III deals with the income costs of the epidemic on households and communities. Section IV identifies some key responses at all levels that seek to mitigate the impacts of HIV/AIDS.

I. Introduction

By the late 1990s, many governments and major international donors reacted to the growing evidence of the impact of HIV/AIDS on households by suggesting that “traditional” coping mechanisms would minimize the impact and allow households and communities to absorb the loss of members and of their income and assets and social contributions. This belief had an important political dimension. By acknowledging this element of African societies’ traditional strengths, governments and international agencies were not obligated to respond to the multiple crises they faced as a critical emergency. As the impact of the epidemic has deepened and broadened, however, new evidence has been gathered that suggests these broad generalizations about the impact of HIV/AIDS must be supported with credible evidence and qualified in particular circumstances. The slow evolution of the impact of HIV/AIDS does disguise the immediate general affects, but the cumulative affects registered over several years or one or two decades is already producing, and will continue to produce significant changes across society.

The need for a degree of caution in assessing the impact of HIV/AIDS on households and communities is because other factors are at work at the same time. Dramatic economic changes in sub-Saharan Africa over the past several decades, for example, have left some households more exposed to the impact of HIV/AIDS than others. Households and communities already suffering conditions of poverty are, usually, most harmed by the loss of adult members to illnesses, including HIV/AIDS. Female and elderly-headed households are likewise least able to cope with the economic, labour and social losses arising from HIV/AIDS. Thus, if we want to know whether households are coping with the impact of HIV/AIDS, we need to include the wider socioeconomic context in the analysis and identify who is affected, and within that group, who is most affected. Differentiation of data by gender, age, and socioeconomic status is critical.

Another parallel change to the prevailing poverty in many societies, more directly associated with structural adjustment-induced reforms, is the greater cost and difficulty in accessing basic social services, including education and health care by many families. Again, these costs have been most deeply felt by lower income groups. The additional costs arising from medical care for people with HIV/AIDS and related illnesses can readily deplete household savings and assets. Eco-

nomically stressed families may withdraw girls and boys from school to reduce expenses, assist in the care of ill relatives and free up an adult (usually a woman) to seek work. Households with more assets, more adults able to contribute their labour for productive activities or care, and greater wealth are usually better able to absorb the expenses of treating HIV/AIDS and related illnesses and the loss of one or more family members.

Three broad statements do seem reasonable at this stage in the pandemic:

1. The presence of HIV/AIDS in a household quickly results in a depletion of household income earning capacity and of household savings and assets. Many households quickly move into conditions characterized by poverty: very little income or wealth, debt, reduced access to services, and fewer than ever options for attaining socioeconomic security. Women and girls, in particular, are likely to be most affected.
2. HIV/AIDS exacerbates and is exacerbated by prevailing economic conditions. HIV/AIDS is not a stand-alone condition, but exists within a wider socioeconomic context that deepens the vulnerability of households, communities and nations.
3. The economic costs of HIV/AIDS, the stigma surrounding the disease that leads to discrimination and withdrawal, and the ability to access social services combine to expand socioeconomic inequalities in society. HIV/AIDS is not only killing people, it is further dividing national societies.

II. The Social Impact of HIV/AIDS

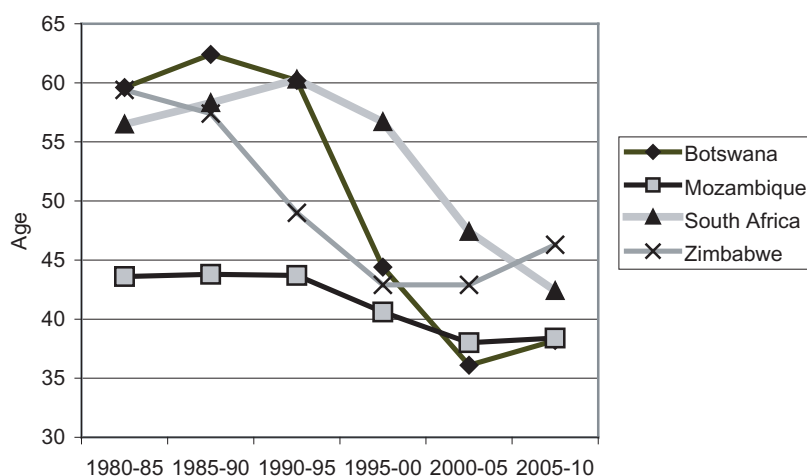
1. Demographic Changes and Households

Morbidity and mortality due to HIV/AIDS and related illnesses is concentrated among adults between the ages of 25 and 50. People in this age group are often described as at the prime of their productive years, working and raising families. Illness and death of adult members of a household reduces the ability of households to provide for themselves. Dependency ratios increase, as fewer adults care for children and the elderly. Increasingly, older members of extended families assume a greater role in caring for and supporting remaining family members. As important as an adult death is whether that person was a woman or a man. The loss of a male adult can leave the remaining women and children with fewer economic opportunities and less control over productive assets, including equipment and land. The loss of a female may result in increased malnutrition and generally less care for the children.

Especially in high prevalence countries, the impact of HIV/AIDS on mortality, life expectancy, and household structures is increasingly evident. Changes that are occurring include:

- *Increases in mortality* are particularly noticeable among young children and people 20 to 50 years of age. In South Africa, HIV/AIDS accounted for 40 per cent of all adult deaths in 2000-2001, an increase from ten per cent in 1995-1996. In eastern and southern Africa, female mortality due to HIV/AIDS tends to occur five to ten years earlier than for men because women are generally infected at earlier ages.
- *Declines in life expectancy* follow as adults die at younger ages than would have been the case without HIV/AIDS. Figure 1 illustrates changes (and projected changes) in life expectancy for four countries in southern Africa over a three-decade period.

Figure 1: Changes in Life Expectancy due to HIV/AIDS: Select Southern Africa Countries



Source: UN Population Division, World Population Prospects: 2001 Revision

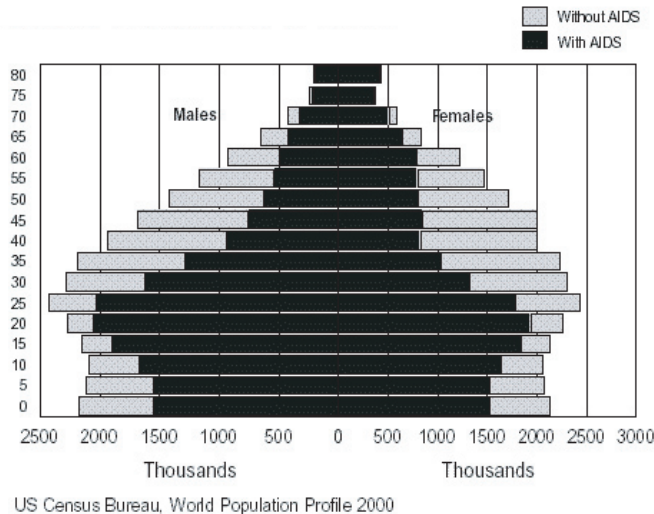
Declines in life expectancy are not confined to the most severely affected countries. In Burkina Faso, where HIV prevalence was expected to reach “only” about ten per cent of adults in 2000, projections indicate that life expectancy will fall by ten to eleven years by 2010.

- **Re-distribution of population:** Because AIDS deaths are most heavily concentrated among women and men 20 to 50 years of age, the classic population pyramid is projected to morph into the pyramid illustrated in Figure 2. Infant and child mortality will increase, as will mortality in the age brackets of people 20 to 50 years old. In South Africa and elsewhere, young women will die at a younger age than young men, reflecting the earlier age at which women are infected. This may increase social tensions and gender violence as fewer younger women are available for partnering with young men. At the same time, it may give young women greater control over relationships as they may have greater flexibility in the choices of men they wish to be with.
- **HIV/AIDS does not affect males and females at the same rate.** A 2000 survey in Bobo-Dioulasso, Burkina Faso, showed that infection rates among young girls aged 13 to 24 were 5-8 times higher than those among boys of the same age. In lower prevalence situations, young men usually have higher infection rates than young women; as the pandemic progresses, an increasing number of women are infected. Females have

higher infection rates at an earlier age than males for a combination of socioeconomic (e.g., gender discrimination in schooling, jobs access and wage rates, greater difficulty in accessing preventative and curative health care) and biological reasons (e.g., susceptibility to vaginal infections and abrasions, particularly at young ages).

- Population growth will slow as HIV/AIDS mortality increases. In Côte d'Ivoire, it is estimated that the population growth rate will decrease by about 0.5 per cent per year as a result of HIV/AIDS. According to one assessment, the slowing down of the growth of the population means that by the end of 2007, Côte d'Ivoire will have around one and a half million fewer people than it otherwise would have had. This will be as a result of two factors: first, increased mortality as a result of AIDS, and second, decreased fertility (fewer people of reproductive age etc).
- Household structures will change. As indicated above, households will change, with more female, child and elderly-headed households. Some households, however, will dissolve completely, either because of economic destitution or the death of parents and dispersal of children. Projections done in Botswana suggest that nearly 7 per cent of all households—particularly small households—will disappear by 2008.

Figure 2: Population of South Africa with and without AIDS: 2020



2. The Burden of Care

Women and girls tend to provide most of the care for sick individuals, but men do play an important (albeit less full) role, especially in the care of other men. Also, the differences in the time spent on care between women and men may not be as great as sometimes assumed, although the evidence is incomplete. A survey of households affected by HIV/AIDS in several provinces of South Africa found that in more than two thirds of households women or girls were the primary caregivers. Almost a quarter of caregivers (23 per cent) were over the age of 60 and just under three quarters of these were women. Similar findings were seen in Zimbabwe. There, most people caring for children orphaned by HIV/AIDS were over 50 years of age. Of those, over 70 per cent were 60 years or older. The stress of caregiving was clear. Caregivers report regular concerns about adequate food and clothing, the high cost of medical fees, and inability to pay school fees for orphans. Indeed, the health of the older caregivers had deteriorated as a result of the physical and emotional stress of assisting the children.

The burden of care on households is significant. A study of urban and rural households in the South African Free State Province found that caregivers devoted four hours a day to caring for sick relatives, including additional time to accompany a sick relative to a health facility. Interestingly, for most caregivers, the assistance they provided came on top of regular work. When a person became terminally ill, the time devoted to care nearly doubled, to 7.5 hours per day. A household survey in Côte d'Ivoire found no respondents with AIDS hospitalized over the four months of the last survey round, indicating that care was provided at home. Further, urban-based relatives often return to a rural home when they become too sick to work or care for themselves, thereby shifting primary caregiving to family members. On the other hand, some rural-based civil servants apply for transfers to urban posts when they become ill, so as to be closer to medical facilities.

Caregiving involves opportunity costs. In South Africa, 40 per cent of caregivers took time off from work or income generating activities. Children took time off from school or studying to provide care. Food production and household chores all suffered in lieu of caregiving in 60 per cent of affected households.

3. Orphaned Children

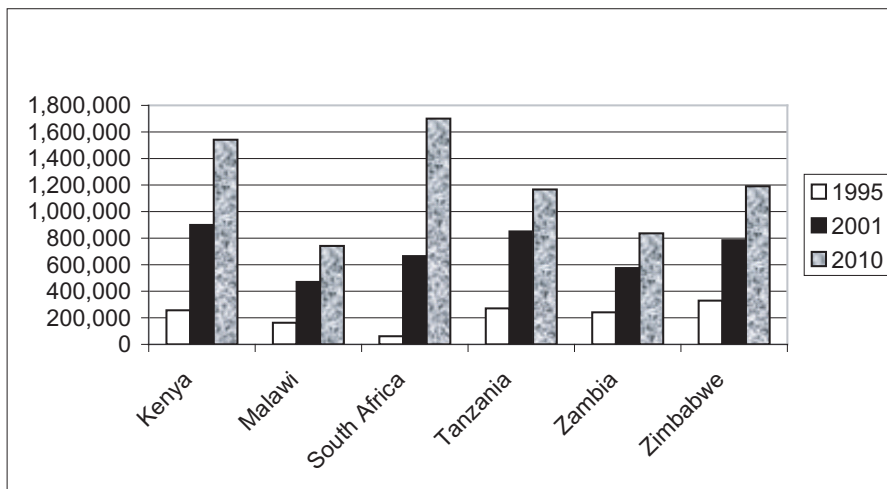
As young and middle-aged adults die of HIV/AIDS, hundreds of thousands of children are orphaned. The growing number of orphaned children is most evident in southern and eastern Africa (see Figure 3), but such girls and boys can be found wherever HIV/AIDS is present. In sub-Saharan Africa, an estimated eleven mil-

lion children had lost their mothers or both parents as of 2001; the number is expected to climb to 20 million by 2010. Although children are orphaned for a number of reasons, by 2010 in Zambia, Swaziland, and Namibia, 75 per cent of all orphans will be due to AIDS. Though the absolute numbers are important, perhaps more important is the speed at which the numbers are increasing, indicating the mushrooming pressures on households, communities, government services, and civil society to address the needs of orphaned children. Local community leaders regularly report that their groups are overwhelmed by the number of orphaned children they find and who need various forms of assistance.

In addition to the daily care of people ill with HIV/AIDS or related illnesses, the care of children while a parent is dying and after the death is a major burden for immediate and extended families. Increasingly, one hears that the extended family system is overwhelmed by the magnitude of the burden of caring for so many orphaned children. The changes in living arrangements, well-being and opportunities for a secure future for children is one of the most significant long-term outcomes of the HIV/AIDS pandemic.

Although HIV/AIDS is but one cause of orphanhood, it plays an ever increasing role in removing parents from their children. A sizeable portion of children in southern and eastern Africa are orphans. For example, one study found that almost a quarter (22 per cent) of all children under the age of fifteen in the South Africa sample were maternal orphans in that they had lost either their mother or both parents. The greater number of these orphans are girls.

Figure 3: Trends in Number of Orphaned Children, 1995-2010, Select Countries



Source: Children on the Brink 2002

Children experience the stresses of parental illness. They may be withdrawn from school to reduce expenses as medical costs rise or to assist in the care of the sick relative. The emotional upheaval of seeing a dying parent may leave children feeling abandoned and increase their susceptibility to sexual abuse. A study in South Africa found that illness or death had resulted in twelve per cent of households sending children away to live elsewhere.

Some children are encouraged by parents or foster parents to work to supplement household incomes. Others work out of economic necessity. An already bad situation is then exacerbated by the fact that many of these children wind up in the worst forms of child labour. Most working orphans surveyed in a study in Tanzania complained of a whole complex of problems, among them going without food, forced initiation to commercial sex work, and failure to receive wages.

Recent ILO-sponsored surveys in Tanzania, South Africa, Zambia and Zimbabwe confirmed the linkage between HIV/AIDS orphanhood and a likelihood that a child would work, frequently outside of the household and in conditions that are sexually and economically exploitative and prone to harassment or violence. Orphaned children in Zambia have been found to be twice as likely to be working as non-orphaned children. At home, once a household member became ill the children's participation in domestic and farm work increased, often interfering with schooling, and is detrimental to health. AIDS orphans were also found to shoulder a big portion of the household and farm chores in foster homes.

Although most children are cared for within some family arrangement, there are a significant and growing number who have lost both parents and live in child-headed households without an adult presence. It is estimated that nearly seven per cent of Zambia's nearly two million households are without any adult member, and are headed by a boy or a girl aged fourteen or younger. Surveys found between two and four per cent of children in Gweru, Zimbabwe, lived in child-headed households. A similar survey in Tanzania found that over nine per cent of children lived on their own, essentially heading a household—at least where a house and living arrangements actually existed.

While they represent only a small proportion of all households, child-headed households and children living on the street without any adult supervision present an especially important challenge for policy-makers, programme planners, and service agencies alike. The existence of children living on their own is a new phenomenon in Africa and is a manifestation of social disruption and social inequalities associated with HIV/AIDS. Child-headed households exist because no relatives are left to care for the children, or else the surviving relatives are already too burdened to adequately care for the children they have inherited.

Many children who become household heads have little option but to seek work to support themselves and their siblings. Stories exist of older children earning the cash to keep younger siblings in school; however, continued schooling for any of the children in these households is problematic.

Orphaned children, including children in households with a parent ill with HIV/AIDS or related illness, may find their education cut short and future economic opportunities compromised. Children from families where one or more adults are HIV-infected are more likely than children in non-affected households to be withdrawn from school because families can not afford the school costs, need the children to help supplement household income, or need them to help care for sick relatives. These trends are especially evident in countries with high HIV/AIDS rates and where school fees and costs are relatively high for low income groups. In Zambia, rural orphaned children have a 20 per cent higher rate of non-school attendance than non-orphaned children. In western Kenya, 20 per cent of households with orphaned children report having no children in school, primarily because of lack of money. Girls, more often than boys, are withdrawn from school or have entry postponed.

4. Changes in Extended Family Systems

One of the major issues arising from the impact of HIV/AIDS on households is the ability and willingness of extended family members to assist in the care of remaining family members, especially children who have been orphaned. As noted earlier, a prevailing assumption in many national HIV/AIDS policies is that “traditional” family structures could and will cope with the pressures caused by the epidemic. A growing number of field studies bring that assumption into doubt. Particularly in light of major social and economic changes of the past several decades (and stretching back well into the colonial era), what is often referred to as the “extended family” takes numerous forms across Africa and offers numerous variations on coping with the impact of HIV/AIDS. At the most simplistic, family members who have settled for two or three decades (or more) in urban centers may have weak links with their wider family. Social networks may actually have become stronger than family membership for some people. Families which have little contact with their extended family have greater likelihood of orphans being abandoned should the current caregiver die. While it is not an either/or situation (i.e., extended families are coping or they are not), it does appear that HIV/AIDS is inducing new pressures on many families that increasingly find it difficult to cope.

A good portion of the burden of support for affected families and family members falls to older adults. A study in rural Zimbabwe found that grandmothers were the primary caregiver for orphaned children or children left behind when one or both parents went to look for work (or land) elsewhere. Another study in Zimbabwe found that half of all foster parents for orphaned children were grandparents and that over 60 per cent of fostering households were headed by women. A study in KwaZulu-Natal Province of South Africa found that 57 per cent of households caring for orphaned children were headed by women who, on average, were 59 years old—i.e. likely to be grandmothers. Yet a fourth study, from rural southern Zambia, found that nearly 70 per cent of all households caring for orphaned children were headed either by a woman or an elderly person.

In other cases, relatives with jobs are expected to play a larger role in direct support for extended family members (such as fostering a child) or indirect support (providing money for medical expenses or school fees). It is not unusual in eastern and southern Africa to find salaried workers supporting two, three or more extended family members with their earnings.

5. The Dissolution of Households

Under the impact of HIV/AIDS it appears that a significant number of households cease to exist, especially if the deceased is a woman. A widowed woman may return to her home community and some of the children are dispersed to other relatives. If both parents die, the children are likely to live with other relatives, or, as noted, care for themselves. In a study covering both rural and urban areas of Zimbabwe, 65 per cent of the households where the deceased adult female used to live before her death were reported to be no longer in existence. Other studies have found that deceased wives are more likely to be replaced – the widowed man remarries. However, the children from the previous marriage may still be sent away, and so remarriage does not necessarily mean that the members of the original household stay together.

Either migration or dissolution seems to follow the death of a HIV-infected responsible adult in a family, according to a study in rural KwaZulu-Natal Province, South Africa. There, households where an adult member has died of HIV/AIDS or related causes were nearly three times more likely to have dissolved by the end of the year than other households.

Another aspect of household change is that where a married woman may leave her husband to care for a parent or for siblings who have been orphaned.

6. The Impact of HIV/AIDS on Women and Girls

Women and girls face an inordinate burden in the era of HIV/AIDS. Not only are girls and young women at greater risk of HIV/AIDS than their male counterparts, the impact of household illnesses and deaths causes greater sacrifices by females. This is not to minimize the impact of HIV/AIDS on boys and men, but economic, social and cultural patterns places males in more favourable positions to cope with the impact. Existing gender inequalities intensify along with the pandemic. Gender inequalities are likely to be intensified by the presence of HIV/AIDS. Women may have to give up jobs and income earning to care for a sick spouse or relative. The burden of caregiving falls primarily on women, and that burden carries over into dealing with the possible loss of assets to relatives upon the death of a husband. Girls tend to be withdrawn from school earlier than or rather than boys, to assist with caregiving, household chores and family income support. There are widespread anecdotal reports of men seeking ever younger girls for sexual purposes, including under twelve years of age, on the assumption that the girls are not HIV-infected or that the man will be cured of his infection.

Girls in households affected by HIV/AIDS are twice as likely as boys to have dropped out of school, because families could not pay the school fees or needed the children for household help. In addition, girls and women are subject to sexual exploitation and abuse. A study in Kenya found that the most important reason for high infection rates among girls is the frequency of sexual intercourse with older men. “Sugar daddies”, as they are known around the world, seduce naïve and impressionable girls with offers of cash, consumer goods, and supposed status. In the war-like conditions of Burundi, the threat of forced sex is a weapon used by men against women and girls. In turn, women and girls may agree to sexual relationships in exchange for some level of physical and material security. Household violence toward women and girls is increasingly being documented and linked to HIV/AIDS transmission. Girls who have been orphaned by HIV/AIDS and who lack strong family support and peer networks may become vulnerable to further sexual harassment and exploitation. Lack of appropriate legal mechanisms to address such abuse creates conditions where this can continue. A report from Botswana argues that amongst children aged five to fifteen, sexual abuse by older males may well account for the majority of, if not all new HIV/AIDS infections.

This is partly a reason for the major disparities in HIV/AIDS infection rates between adolescent girls and boys. For example, in major urban areas of eastern and southern Africa, epidemiological studies have shown that seventeen to 22

per cent of girls aged fifteen to nineteen are already HIV infected compared with three to seven per cent of boys of similar age.

In addition to possibly becoming the head of a household, women face other burdens. A study in the early 1990s in areas of Uganda highly affected by HIV/AIDS noted the following potential situations faced by widows. The scenarios can be applied to many societies. Women may experience:

- the loss of land and perhaps the right to use the land;
- the loss of their property to the husband's family, unless the husband has left a will. Women often do not inherit property when their husbands die;
- being brought into a relationship with the late husband's brother or other male relative otherwise they may be forced to return to their maternal home;
- assuming sole responsibility for the children, with limited outside support;
- a significant loss of cash income;
- the loss of access to support services that traditional go to men, such as agricultural services and the loss of farm production knowledge for work done by men; and
- an increased workload as they struggle to meet basic needs.

The report further notes that HIV/AIDS contributes to a dramatic rise of female-headed households and that many of these women are younger, with young children, than previously has been the case of female-headed households. Most female-headed households tend to be among the poorest in communities across Africa. Again, HIV/AIDS is intensifying, if not deepening, the gender inequities of society.

In western Kenya, a study found that some households cope with the loss of an adult member by encouraging the marriage of a teenage daughter in order to gain the financial assets (i.e., cattle or other livestock) of a dowry. The same study noted that in households in which a female spouse had died, children were likely to be sent to live with relatives or in other households. In contrast, the death of a non-spouse female adult is associated with an increase in the number of boys in the household. This is most likely to help out with household activities formerly handled by the now-deceased female adult. This indicates, as might be expected, that the effects of adult death do not depend only on the age and gender of the deceased, but also the position of the individual in the household.

III. The Economic Impact and Consequences of HIV/AIDS on Households and Communities

HIV/AIDS is costly to most households and communities. During periods of illness, medical costs rise, work and incomes are disrupted, family members are drawn away from work to provide care and in some instances children have to work to supplement household incomes. After death, funerals can be costly, sometimes more than the amount previously spent on medical care. The loss of an adult undermines a family's income generating abilities, adding to the work burden of surviving family members, including children. AIDS-affected families may experience rapid transition from relative wealth to relative poverty. For poorer and rural households, the ability to cope with external shocks, such as drought or increases in the prices of staple products, will be reduced further.

What stands out from numerous studies over the past decade is how HIV/AIDS induces impoverishment of many (but not all, and how many in a particular community or region is unclear) affected households. Income is lost and assets are sold or rented in order to get cash. Widespread disinvestment of assets appears to be occurring as households spend their savings and wealth to cope with HIV/AIDS. This section sets out some of the economic conditions that follow HIV/AIDS.

1. Loss of Income

The economic impact of HIV/AIDS is significant and often dramatic in terms of changes in income, asset wealth and longer term prospects for economic security. A study in KwaZulu-Natal, South Africa, found that households that had experienced a death in the previous 12 months (not only from HIV/AIDS, it needs to be pointed out), had a mean monthly income equal to only 64 per cent of households that had not experienced a death. Another South African study in the Free State Province found that HIV/AIDS affected households tended to have monthly incomes one-third less than non-affected households. In the Côte d'Ivoire, the income of affected families was half that of total average household income.

The burden of caregiving can deepen the poverty of households, moving some households into destitution. A household study in southern Zambia found households with very high dependency ratios of three to five times national averages, primarily, but not exclusively, due to the caring burdens created by HIV/AIDS. In these households, labour that might contribute to household necessities or income simply did not exist. Children in these households are likely to have to work in order to survive.

Efforts are made to draw on resources from wherever possible, utilizing existing family and social networks. A study based on household data in Rakai, Uganda, one of the earliest centres of the HIV/AIDS epidemic, showed that extended family members, community members, and NGOs provided from 40 to nearly 70 per cent of the medical and burial costs experienced by affected families.

2. Shifts in spending

The burden of medical and related expenses induces changes in family spending patterns.

In Côte d'Ivoire in the mid-1990s, households affected by HIV/AIDS spent nearly twice the proportion of their budgets on medical care as did households not affected by HIV/AIDS. In Rwanda, a household survey found expenses on health care to be over twenty times higher in HIV/AIDS affected, as compared to non-affected, households. Further, health care expenses for men were 2.6 times greater than for women, illustrating deep biases in accessing and using health care. Expenditures at this level became a major burden on family budgets. Among households affected by HIV/AIDS in the Kagera region of Tanzania, almost all cash income was used to pay medical bills relating to HIV/AIDS.

As medical expenses climb, spending on other items tends to decline. In South Africa, households with an AIDS-sick member were found to reduce spending on necessities. The most likely expenses to be cut were clothing (21 per cent), electricity (sixteen per cent) and other services (nine per cent). Some six per cent of affected families reduced spending on food. While not as high a percentage as might be expected, most families reported that they already had insufficient food at various times. Spending on food and education may be reduced significantly, as in Côte d'Ivoire where spending on basic consumption items (food and accommodation) fell by 40 per cent after the death of a family member of AIDS. These cuts in basic necessities further contribute to overall household poverty as malnutrition, health of children and women, and future work opportunities are compromised.

The “savings” incurred through these cuts in spending on necessities were used for medical care and drugs for the person living with HIV/AIDS. The spending on health care was far higher in rural than urban locations, and in both cases was six to twelve times greater than the national average. Withdrawing children from school or delaying their entry is another way that some families adjust spending patterns.

3. Paying for the Costs of HIV/AIDS

Households meet the costs of HIV/AIDS in a variety of ways, in addition to changing spending patterns. New members may be added to the household to compensate for a lost adult member. Loans may be acquired from relatives or neighbours. Assets may be sold or rented. In cattle-owning communities, the sale of animals to meet costs frequently occurs. For example, in pastoral communities in Uganda, over thirteen per cent of the households that had cattle, had sold off animals to meet family needs resulting from HIV/AIDS. In other cases, the animals had died due to poor management, or they were stolen after the death of able-bodied household members. In mixed farming households, nearly one-third (32 per cent) reportedly had sold animals to pay for medical care and other household expenses. In Namibia livestock and grain sales are commonly used to get money to meet illness-related expenses or to replace lost income. Therefore, the productive assets that livestock represent are taken out of the farming system.

A study in western Kenya confirmed the trends in disinvestments of assets by households experiencing a prime-age adult death. Sales of small livestock would occur before that of cattle. As noted earlier, some households with a prime-age adult death could even gain cattle through dowry, as daughters were married off.

Studies in both Tanzania and Zimbabwe have found that AIDS-afflicted households sold assets to cope with the death. Similar findings come from the Rakai region of Uganda. The latter study found that only those households that experienced a death due to HIV/AIDS (as opposed to a death due to other causes) had a depletion in resources. Health care and funeral expenses related to HIV/AIDS, coupled with loss of income, therefore leads to rapid depletion of household resources.

In one study in Zimbabwe, 24 per cent of surveyed households sold an asset to cope with the death of the adult female. There was a greater chance that assets would be sold among rural as opposed to urban households. Cattle and smaller

livestock, clothing and household furniture were the items more commonly sold. Disinvestment can continue after a death of male adult in the household. In the Oshana region of Namibia, it was found that in households where the husband died of HIV/AIDS livestock, sometimes all animals, are taken by relatives from the surviving family members.

Funeral expenses can add significantly to the economic burden of households and communities experiencing HIV/AIDS. One South African survey found that, on average, funeral costs were equivalent to one-third of annual household income. In another study, this in KwaZulu-Natal, South Africa, funeral costs represented the equivalent of two months mean household income).

In the months and years after a death, the ability to earn income is reduced and surviving households may sell additional assets, borrow, or search for new sources of income. In a household study in Free State Province, South Africa, affected families (already poorer than non-affected families) tended to borrow first and then sell assets. In that study, affected households largely spent the borrowed money on medical expenses and funerals, while unaffected households generally used the money for education, durables and clothing. The same study also found that HIV/AIDS impacts savings disproportionately. Affected households on average utilized 21 months' worth of savings, while nonaffected households only utilized five months' worth of current savings.

4. Differentiation in Coping with the Costs of HIV/AIDS

The ability to deal with the economic pressures arising from HIV/AIDS varies by the wealth, size, and social position of households. As might be expected, poorer households respond differently than better-off households. Analysis of data generated in the Kagera region of Tanzania found that among the poorer half of households, both food expenditure and food consumption fall dramatically in the six months following a death of an adult member of a household, in contrast to increases in non-poor households suffering a death. The differences are, not simply a reflection of relative wealth, but of decisions about how to cope with an adult death. One method used more by wealthier than poorer people is acquiring informal forms of credit and transfers; however, these forms of "informal insurance" are available only to a limited extent to the poorest households. However, the latter may get some assistance from formal structures, such as the government.

Findings from a rural area of eastern Zimbabwe indicated that the capacity of HIV/AIDS-affected households to cope with shock is severely compromised by

not having additional labour of their own to rely on, as opposed to non-affected households. Thus, the size of a household, the person who is ill/dies, the level of household assets, and the ability (with cash, kind or social arrangement) to call in additional labour play a pivotal role in managing an AIDS-related death and the time it takes to adjust to the loss.

The death of an adult male is especially costly in terms of lost income and assets. By contrast, when the wife dies, livestock assets and grain production are less affected, in part because fewer resources are invested in the medical care of women. Grain production levels are usually maintained, although tasks normally done by women, such as weeding, may decline in intensity. However, high value or cash crop production does change when a male head dies, as the available household labour is devoted to food crops.

In Uganda, one study showed that 44 per cent of respondents reported reduced variety of crops in the last ten years, in response to reductions in labour supply due to AIDS. Reduction was more common in female-headed households (77.3 per cent), especially those where the woman was widowed. In Zimbabwe, food consumption in households where a woman had died declined and variety narrowed. It should be noted, however, that it is difficult to distinguish between changes in food consumption arising from the death of a woman or resulting from the economic hardships of a contracting economy.

Of course, where households are already poor or very poor, there is little to sell. Outside assistance by religious and community groups and family and friends played a large role in helping HIV/AIDS affected households in Rwanda to meet the financial burdens arising from HIV/AIDS. In that country, two-thirds of surveyed households were found to receive some kind of assistance. Eighteen per cent had to borrow money to pay for care, and five per cent had to sell assets.

In Zimbabwe, following an adult female death, a study found that female-headed households relied more heavily on remittance from family members, informal activities and agriculture and subletting. Male-headed households, on the other hand depended more on the use of savings, followed by borrowing from informal sources and remittances from family members.

5. The Widening and Deepening of Poverty

For affected households and communities, HIV/AIDS is rapidly inducing and deepening conditions of poverty. In South Africa, a study found that incomes of affected urban and rural families were, on average, just 60 per cent of unaffected

families. Another South African study concluded that HIV/AIDS has its greatest impact on poor people and deepens “poverty among the already poor”.

The pattern of coping, outlined for poor and very poor urban households in Burundi, illustrates how the circumstances arising from the impact of HIV/AIDS intensifies poverty:

- children are expected to work, and working children are seen at increasingly young ages;
- decreased/interrupted payments for basic services (school);
- interrupted debt reimbursements;
- increased demands to the community for gifts in cash or kind;
- sale of sex, for cash or in-kind payments;
- begging;
- sale of household goods; and
- shared housing, with 3-4 women plus children sharing one room.

Clearly, the ability of poor households to deal with the multiple losses arising from HIV/AIDS is pushing members into increasingly desperate and risky situations. For these households, the basic goal is to survive and on a daily basis find ways to manage with minimal resources. Existing poverty is exacerbated by HIV/AIDS and is contributing to destitution.

Larger and better endowed households are less likely than smaller households to become poor as a result of HIV/AIDS. They are better able to distribute the impacts of medical care and funeral expenses, as well as loss of labour and income across family members and through social networks. Simulation modeling in Botswana indicates a fall of eighteen per cent by 2010 in the average income of households in the lowest quartile. This is nearly double the income loss in the population as a whole. Similarly, modeling of the pandemic in Burkina Faso predicted that with a stabilized HIV prevalence rate of ten per cent in 2005, the incidence of poverty would increase from 45 to 52 per cent in nine years (from 1997 through 2005) and from 45 to 53 per cent after fourteen years (from 1997 through 2010).

The intuitive implication of these findings is that HIV/AIDS intensifies prevailing income inequalities in society. However, the Botswana simulation does not predict any change in the level of income inequality. This is explained by an overall downward shift in per capita incomes. In other words, societies as a whole are becoming poorer as a result of HIV/AIDS. Three observations, however, arise from the findings of the Botswana simulation:

1. Inequalities are already significant in Botswana. HIV/AIDS sustains those patterns during the overall downward shift in poverty levels across society.
2. The models do not adequately take into account the most impoverished, the households that become destitute or dissolve altogether.
3. Access to services, a factor of poverty and inequality, is not included in the equations.

For Botswana, and other countries with advanced epidemics, the pandemic narrows the range of opportunities for reducing economic and social inequalities while deepening national poverty. As noted earlier, access to education is already compromised for many children affected by HIV/AIDS. In the health sector, access to affordable treatment and adequate health services has become one of the most important differentiating factors between HIV-related survival in rich and poor countries and communities.

In summary, the economic impact of HIV/AIDS on households and communities is far-reaching and is likely to worsen over the coming decade. In the absence of significant subsidies for medical and drug care, households will be spending a significant portion of their incomes on health care. To pay for health care, assets will be sold, further impoverishing many households. Extended family and community members will find increasing demands on their resources to assist affected households. Some households will be better able to cope with these changes and will recover economic stability after several months or years. Others, however, will become economically worse off. Poverty will intensify. What proportion of all affected households will be most adversely impacted remains speculative, but given the prevalence of poverty in many African countries, it is reasonable to suggest that at least half of HIV/AIDS affected households will experience long-term economic distress.

With national services and community and household resources already strained, it is difficult to foresee quick fixes that will alleviate the economic and social impacts of HIV/AIDS. Rather, a development-based orientation is needed. Elements of a development response will include large-scale job creation and youth job training, infrastructure re-building, and substantial subsidies for local development initiatives. Whether it is through targeted initiatives or broad, national-scale programmes, development efforts must be designed and implemented that minimize the impoverishment and inequalities that are occurring in the wake of the HIV/AIDS epidemic.

IV: Responses to the Impact of HIV/AIDS

Given the broad socioeconomic impacts of HIV/AIDS on households and the communities in which they live and work, it is useful to focus a discussion of responses on those that address the nature of that broader impact. These are what can be called development-oriented responses, in contrast to responses that remain narrowly focused on immediate symptoms of the wider impact. The focus in this section is primarily on community responses rather than household coping mechanisms, which are discussed in the previous sections. However, it is obvious that neither individuals nor families can be separated from the communities in which they live.

Development-oriented responses to HIV/AIDS are occurring on a small and very local scale. They are seen in some community and NGO activities. However, the models of effectiveness and sustainability and local resource mobilization that those activities provide have yet to find their way into national or international HIV/AIDS or national development policies and strategies.

1. Community mitigation efforts and initiatives

The ability of households to manage the ill-health and death of one or more adult members depends on numerous factors: socioeconomic status prior to the presence of HIV/AIDS, ability to minimize loss of assets and minimize debt, the support of extended family and of community and formal and informal support agencies. In addition, in many local communities, such as those in Zimbabwe, families affected by HIV/AIDS become subject to stigmatization and discrimination, leading to secrecy around HIV/AIDS.

These factors may be described in terms of stages in the sequence of impact and their reversibility. The first stage impacts include the reallocation of economic resources and labour. This impact may be temporary, and is reversible. The second stage is when family and household assets are sold to meet changed household needs. Children are deprived of education and care. This stage is difficult,

if not impossible, to reverse. The household may then proceed to enter a stage of dependency on charity and aid, and/or eventually breaking up. This is the third and final stage of impacts. This model is likely to be too simplistic for programming purposes, but it does outline an initial method for a more thorough investigation of the patterns of impact. What has been done in areas of programming helps fill in some of the outstanding questions about responding to the social and economic needs of HIV/AIDS affected families and communities.

Turning to the secrecy resulting from stigma and discrimination, a South African survey reported, based on focus group discussions with people living with HIV/AIDS (PLWHA), that the negative orientation to people with HIV/AIDS, even when only exhibited by a minority of community members, and the fear of negative reactions from community members and other persons, is sufficiently strong to provide reason for PLWHA not to be open about their status in their own communities. PLWHA described how they had found it much easier to talk about their HIV positive status in other communities and only later within their own community. Interestingly, support networks did not seem to have evolved, and the individuals living with HIV feel very alone in their struggle to lead positive lives. Social support networks are important for well-being, and a consequence of this finding is that to build a strong support base for PLWHA would be important.

The same survey found that, as of 2001, little community mobilization in South Africa had occurred around HIV/AIDS issues, other than information campaigns run from outside communities. This seems in line with findings in Zimbabwe, where affected households report often turning to extended family and/or community members for help. A study found that about half of affected households studied in urban and rural areas of Zimbabwe had asked for some help with food or money from relatives, friends and neighbors within the previous twelve months. One of the greatest needs was money for school fees. However, those same families reported that the help they needed, however, often was not forthcoming.

While the above examples illustrate that the responses of communities can be negative, one feature in these examples is the absence of positive images and directions that can alter the negative images and response. In the examples that follow, in many instances an outside organization or firm local leadership provide an alternative framework to the fear and stigma that may exist.

Thus, any discussion about community mobilization should understand and include the need to thoroughly describe the context, given the marked differentiation in forms, intensity, duration and levels of community mobilization to

address various issues arising from HIV/AIDS. While a number of effective initiatives can be cited (see below), in other instances, relatively little is being done by and with communities. For example, in the Eastern Cape of South Africa, only 27 per cent of adults report ever having been to a meeting of people where AIDS has been discussed. This supports the impression that there is very little community level mobilization around HIV/AIDS issues. Additionally, there is little evidence that structures for prevention, care or support are emerging. There is a need for access to advice, information and support at village level, including remote villages with little access to services.

Although institutional support seems a critical factor in assisting households, some communities do provide support for affected households without external interventions. UNAIDS outlines four forms of community-based responses to HIV/AIDS:

- Social support groups, including labour sharing, grain savings, and food donations;
- Savings associations;
- Emergency assistance associations, including interventions by faith-based groups;
- Self-help groups of people with HIV/AIDS.

All of these are little understood in the context of addressing the impact of HIV/AIDS. Whether these local, informal and sometimes spontaneous responses can be strengthened from outside is unclear. Imposing external views and expectations may undermine local initiatives and ownership. Poorly designed and externally imposed programmes could jeopardize fledgling community initiatives.

In addition, while the strengths and capacity of local communities is often credited as a substantive means to cope with the multiple impacts of HIV/AIDS, there are limits imposed by wider economic conditions. The difficult economic conditions facing most people prevented communities from offering any or much assistance in a study of both urban and rural locales in Zimbabwe. While a grain savings scheme was highlighted for its effectiveness in providing for some of the needs of rural people, churches, savings clubs and other informal support networks offered only limited assistance to affected households. This, too, is likely due to the constraints imposed by the general economy. Evidence from Kenya, Tanzania and Uganda indicates active concern by such networks, but the demand far exceeds any one organization's ability to fully respond. The ability and willingness of communities to assist household affected by HIV/AIDS varies greatly within and across countries. In many cases, communities would be willing to do more, but lack the resources.

Thus, outside assistance is likely to be essential, or at least be an option for communities to access. There are some well-studied programmes that offer credible and effective models for working with communities. In cases where sensitive programmes, often led by NGOs with long-lasting community presence, have implemented flexible responses, the results reflect support that serves people's needs. Several of those NGO-supported programmes are outlined below.

- Families, Orphans and Children Under Stress (FOCUS) is a programme of FACT, a Zimbabwean AIDS service organization established in 1987. It is centered in eastern Zimbabwe and uses churches as a basis for its outreach to affected families and communities. Its purpose is to provide care and support to orphaned children. The programme relies on community volunteers, usually women. The programme emphasizes identification and monitoring of vulnerable children through visiting households regularly, providing community ownership, keeping children in school, establishing income-generating activities, and training and motivating volunteers. Volunteers identify unmet basic household needs and provide essential material support, including maize seed, fertilizer, food, clothing, blankets, and school fees. The visiting volunteers also offer emotional and spiritual support to the children and their caregivers. In 2000, over 2,700 orphaned children were registered and supported by nearly 180 active volunteers. Total programme cost was US\$20,000-30,000 per year, a very modest sum.
- The COPE Program in Malawi, operated by Save the Children (US), mobilized communities at area and village levels to address the needs of orphaned and other vulnerable children. In addition to community participants, government, religious and business groups were involved. With the facilitation by the COPE programme staff, area villagers came together to assess their concerns. The number of COPE staff was eventually reduced substantially as village and area AIDS Committees assumed greater control and ownership over the functioning of activities. The local committees were linked to government and religious services, creating a stronger network of support in the process. By 2000, over 200 village AIDS committees existed. Over 12,000 orphaned children and nearly 12,000 families had received food and other material assistance. The average annual cost was US\$ 317,000.
- Chikankata is a mission-run health facility in southern Zambia. Over a period of ten years an HIV/AIDS programme has evolved that is built on basic community development principles: strong local ownership and direction, building on the skills and knowledge of a wide range of people

and groups, supplementing local resources with external aid. Initially, the medical staff of Chikankata sought to provide treatment for people living with HIV/AIDS through mobile clinics. This proved to be too costly and insufficient to meet people's daily needs. Over time, the programme moved into family training for home-based care and then into mobilizing communities to be involved in care of people with HIV/AIDS. As community members confronted the needs of affected families, they designed initiatives that drew upon the resources all local government departments and organizations. The approach that has evolved at Chikankata has, like the FOCUS and COPE programs, become models for other eastern and southern African groups.

- A programme in Luweero District, Uganda, illustrates the power of simple organization and local ownership. The programme is run by the African Medical & Research Foundation (AMREF) and is designed to address the range of needs of affected individuals and families. It encompasses a variety of support functions, from assisting with school fees for orphaned and other vulnerable children, to developing water supplies, to microfinance loans for business activities. A three-tier structure has been created to respond to problems, including the large number of orphaned children in the area. Organizationally, guardians of orphaned children are linked to Village Orphan Committees and select their representatives on those committees. Guardians may be grandparents, older siblings, aunts or uncles, or non-relatives. The Village Orphan Committees maintain a register of vulnerable children and help generate local resources to support the children and the guardians. In turn, the Village Orphan Committees select representatives to Parish Orphan Committees and these are linked to local government authorities. A sense of local ownership is strong at all these levels and the committees have begun tackling other development problems. Notable changes in the well-being of children and affected families are seen by community members.

These and other examples of NGO-supported local programs illustrate some of the key components of effective responses to the impact of HIV/AIDS:

- strong local ownership and control over decision making;
- the evolution of programmes over time, allowing for experiences to inform decisions;
- facilitation, not control, from outside, especially with volunteers, and recognition of established or new leadership; and
- functional links to all levels of community resources, including government social services.

These examples reflect an integrated community response to HIV/AIDS. They are integrated in being able to draw upon the resources and skills of all community groups and agencies, not simply a health clinic or school. They are also considered integrated in that they address the underlying causes of issues, including the reasons for poverty and political disenfranchisement. There are variations on the models, some with a formal center from which the activities are coordinated and others more loosely organized. Some programmes use only a portion of the integrated community models. For example, many home based care programmes in southern Africa are designed to offer a continuum of care, especially palliative care, for PLWHA. Often support for family members is included. A programme may be structured around a care centre or similar, located within the community, possibly attached to a church or school, where home-based care services are coordinated from. Volunteers, supported by medical and community development staff, play a major role in the functioning of this model.

Some NGO programmes offer only specific services. For example, they may provide assistance to individuals and families in preparing for death and its consequences. This preparation may involve the making of individual memory books by ill parents that will be passed along to children, or the drafting of wills to formalize and legalize asset transfers. Such services may also be a part of a wider programme for PLWHA and affected families.

One area that is receiving growing attention for both infected and affected individuals and groups is income generating activities, sometimes involving small grants, other times small loans (microcredits). A good deal of emphasis has been on increasing the economic well-being of affected households and of HIV-infected individuals. This has taken several forms: education grants for school children, food relief, and small loans/grants for what are generically called income generating activities (IGA). Many of these programmes arise from experiences over the past two decades with micro-finance to stimulate small business formation and economic security for groups of women and men. Although there is much enthusiasm for IGA among NGOs dealing with HIV/AIDS in communities, implementation and sustainability remain to be fully assessed. To date, experiences with IGA loans and grants have very mixed records, with the trend toward initiatives that are non-sustainable in the absence of fairly substantial (by local standards) outside organizational support, or of such small scale as to offer little economic value to all but a handful of individuals.

More effective are initiatives that have addressed the poverty underlying HIV/AIDS through established micro-finance agencies. The experience of working with micro-finance programs and recipients, as opposed to simply setting up

income generating activities with small grants, provides improved design and structures, greater sophistication in offering finance for a range of needs and uses, and usually involve facilitation for expanding community mobilization. Several programmes in Uganda and Zambia have been identified as exhibiting “best practices”. In Uganda, these include a programme supported by The Foundation for International Community Assistance (FINCA) that offers loans for family health and funeral insurance and community mitigation efforts and another supported by AMREF/Lutheran World Relief to provide loans for business support and a strong community mobilization component. In Zambia, the SCOPE project has been identified for the effectiveness of its loans to communities to develop mitigation activities. There remains, however, a need for more descriptive experiences with and critical analyses of micro-financing activities for HIV/AIDS prevention and mitigation, especially initiatives that engage communities.

2. Faith-based Initiatives

Many faith-based groups are playing a significant role around HIV/AIDS issues. Congregations are involved in care and support for PLWHA, affected families and orphaned children. Home visits and spiritual support by congregation members are common. Arising from the policies and traditions of various faith-based groups, different activities are stressed. The Catholic Church in many areas provides support for affected households and for orphaned children. Churches, such as the Evangelical Lutheran Church in Tanzania, run health facilities and provide medical attention. Two of the examples cited above of community mobilization are associated with faith-based support and involvement (FOCUS in Zimbabwe and Chikankata in Zambia).

Many faith-based responses go unreported. In part, because secular NGOs and international agencies have been cautious, if not skeptical, about the commitment of faith groups to address HIV/AIDS prevention. Controversies surrounding the promotion and use of condoms, symbols of sexual activity, are associated with some faith groups. Also, faith groups have not done a good job of illuminating their positive contributions. The lack of good documentation on the roles and contributions of faith groups remains a major gap in organizing and promoting society-wide responses to HIV/AIDS.

What is clear is that many local faith communities are highly concerned and actively involved in HIV/AIDS issues. Church and mosque members provide spiritual, emotional and material support to affected households, contribute to the support of orphaned children, and take a lead in organizing other commu-

nity members to mitigate the impact of HIV/AIDS. Denominations as a whole, however, have been slow to speak out on HIV/AIDS issues, invest substantial resources, or offer sustained leadership. This has made the work of local faith groups more difficult and isolated.

3. Government Responses

It appears that only a small percentage of affected households benefit from state social welfare and support programs to mitigate the impact of HIV/AIDS or to reach very poor families. In Zimbabwe, it was reported that no more than two per cent of people in need receive such support. A South African state grant programme for older adults does provide some minimal financial assistance, but usually not enough for grandparents to adequately care for fostered children. The state also offers grants for children, but not all parents/guardians are able to produce the required birth certificate to register for the grant. As of early 2000, less than five per cent of eligible children were benefiting from the monthly grants to guardians. In Zambia, the Ministry of Labour and Social Security offers grants to implementing NGOs for street children projects. Education reforms that have recently occurred in many countries are designed to offer free or reduced-fee education at primary school levels. These changes do offer some mitigation support to families, although many observers note that other costs for school attendance remain.

It is clear that across Africa, governments are not prepared and are budgetarily constrained in terms of offering financial support to individuals, families and communities affected by HIV/AIDS. In fact, most governments with HIV/AIDS policies and programmes stress that care and support will fall primarily on families; little mention is made of mitigation as a role of government. There is a growing willingness on the part of state governments to absorb some of the cost of providing antiretroviral drugs for pregnant women and newborn infants. Also, some governments are paying for (or preparing to pay for) the cost of antiretroviral drugs for a select group of people living with HIV/AIDS. To date, only Botswana has implemented its programme to cover the costs of providing antiretroviral drugs to their citizens. As of mid-2003, some 9,000 people, in four priority groups, are receiving antiretroviral drugs in Botswana.

Broad social welfare, social transfer and job creation schemes exist on paper in numerous countries, but have been undermined by prevailing economic conditions and practices over the past two decades. In one district in southern Zambia, half of one per cent of potentially eligible people receive state welfare assistance, for example. In most African countries, pensions and other old age funds exist

primarily for permanent public service employees. Likewise, many governments pay funeral and some medical costs for civil servants, thus reducing some financial pressures on affected households. Civil servant beneficiaries are likely, also, to receive a death benefit or have access to pension benefits. However, civil servants represent only a small portion of all adults in most countries.

National policies offer frameworks for developing interventions and guidance for other sectors in setting priorities and designing actions. Most countries in Africa now have HIV/AIDS policies and structures designed to coordinate policy development and programme implementation. There are, however, wide differences between countries (and also within some countries) in the effectiveness of multi-sectoral coordination. Malawi, for example, has on paper a structure that includes village AIDS committees that will facilitate local mobilization and activities. However, the local committees have not, for the most part, been activated or supported by either communities or outside agencies.

The national policies of most countries include statements about community responsibilities. These tend to stress the importance of home-based care for HIV-infected individuals and care for orphaned children by the extended family and communities. In 1994, Malawi became the first country in the region to develop a policy statement and guidelines on the care of orphans. The guidelines emphasize community-based responses, but the ability of communities to cope with the demands of the growing number of orphaned children prevents full and effective implementation of those community initiatives.

Several countries have policies, or drafts of policies, on child welfare. Most countries have signed ILO conventions that define a minimum age for work by children and prohibit children from working in especially harsh and risky occupations. All African countries have signed the Convention on the Rights of the Child, and many have signed up to regional conventions such as the African Charter on the Rights and Welfare of the Child. The ability of government authorities to fully enforce these and related international conventions is incomplete, however, especially given the stresses of poverty and the social and economic impact of HIV/AIDS on households.

In most countries, obtaining the commitment of senior national political leaders to actual programme implementation is difficult. Also, existing programmes and organizations addressing the needs of orphans and vulnerable children are too small to organize lobbying at the required level.

The broad generalizations often drawn from the available evidence about the impact of HIV/AIDS, including the generalizations made in this paper, require

further testing and specification. Even the most commonly accepted assumptions about the impact of HIV/AIDS, such as the inability or unwillingness of extended families and communities to cope, need to be tested. It is not that the generalizations and assumptions are wrong. In many instances they are most likely correct, especially where evidence exists to confirm the statements. Rather, conditions of affected families and communities differ by a number of factors: socioeconomic well-being prior to HIV/AIDS; size and demographic factors of households; prevailing social networks; local leadership; links to outside facilitating organizations and services. The interlinkages between and the implications of these factors merit further investigation.

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