

Chapter 11

Poverty and HIV/AIDS: Impact, Coping and Mitigation Policy *

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Summary: This chapter looks at the relation between HIV/AIDS and poverty and tries to say something about the relation between poverty and HIV/AIDS: a difficult task as there is little in the way of conclusive or persuasive research. An important finding is that mitigation of the impact of AIDS is so far rather poorly documented – which is not say that there is not a multitude of mitigation responses, just that few of them are recorded and most remain at the communal or household level.

AIDS is a very long wave event. The true death toll cannot be estimated until the full wave form of the epidemic has been seen. It may be as long as 50 years before we can say that the world epidemic has peaked and/or begun to decline. If we take into account its social and economic impacts, in particular HIV/AIDS related impoverishment, then HIV/AIDS impact related deaths have already reached very large numbers indeed. The wave form of the socio-economic impact alters the historical trajectory of some societies. The epidemic is a development crisis, which deepens poverty and increases inequality at every level, from household to global. AIDS has reversed progress towards international development goals.

Like sustainability, the idea and language of “coping” has to be questioned in relation to AIDS and its impact. The policy implications of the chapter are that we need to better understand the long wave implications of this disease and think about more than “coping”. The HIV/AIDS epidemic has social roots and needs social as well as medical and technical responses.

JEL: D13, I12, I32, I33

*** This study presents the views of its authors and not the official UNICEF position in this field.**

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AIDS, PUBLIC POLICY AND CHILD WELL-BEING *

edited by Giovanni Andrea Cornia

Table of contents

Introduction - *Giovanni Andrea Cornia*

Part I: Overview of the HIV/AIDS Impact and Policy-Programme Responses

1. Overview of the Impact and Best Practice Responses in Favour of Children in a World Affected by HIV/AIDS - *Giovanni Andrea Cornia*

Part II. The Social and Economic Impact of HIV-AIDS on Children:
Evidence from Eight Country Case Studies

2. The Impact of HIV/AIDS on Children: Lights and Shadows in the “Successful Case” of Uganda - *Robert Basaza and Darlison Kaija*

3. The Impact of a Growing HIV/AIDS Epidemic on the Kenyan Children – *Boniface O.K’Oyugi and Jane Muita*

4. The Socio-economic Impact of HIV/AIDS on Children in a Low Prevalence Context: the Case of Senegal - *Cheikh Ibrahima Niang and Paul Quarles van Ufford*

5. HIV/AIDS, Lagging Policy Response and Impact on Children: the Case of Côte d’Ivoire - *Jacques Pégatiénan and Didier Blibolo*

6. The Current and Future Impact of the HIV/AIDS Epidemic on South Africa’s Children – *Chris Desmond and Jeff Gow*

7. Perinatal AIDS Mortality and Orphanhood in the Aftermath of the Successful Control of the HIV Epidemics: The Case of Thailand - *Wattana S. Janjaroen and Suwanee Khamman*

8. HIV/AIDS and Children in the Sangli District of Maharashtra (India) - *Ravi K. Verma, S.K. Singh, R. Prasad and R.B. Upadhyaya*

9. Limiting the Future Impact of HIV/AIDS on Children in Yunnan (China)
China HIV/AIDS Socio-Economic Impact Study Team

Part III: The Sectoral Impact of HIV-AIDS on Child Wellbeing and Policy Responses

10. The HIV/AIDS Impact on the Rural and Urban Economy - *Giovanni Andrea Cornia and Fabio Zagonari*

11. Poverty and HIV/AIDS : Impact, Coping and Mitigation Policy - *Tony Barnett and Alan Whiteside*

12. Mitigating the Impact of HIV/AIDS on Education Supply, Demand and Quality - *Carol Coombe*

13. The Impact of HIV/AIDS on the Health System and Child Health - *Giovanni Andrea Cornia, Mahesh Patel and Fabio Zagonari*

14. Increasing the Access to Antiretroviral Drugs to Moderate the Impact of AIDS: an Exploration of Alternative Options - *Pierre Chirac*

15. The Impact of HIV/AIDS on Orphans and Program and Policy Responses - *Stanley Phiri and Douglas Webb*

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1. Introduction: Situating HIV/AIDS Related Poverty

In this paper we are able to say a great deal about the relation between HIV/AIDS and poverty and something about the relation between poverty and HIV/AIDS. We will discuss attempts to mitigate the poverty inducing impact of AIDS, although so far little has been done, at least on a national basis. Families and communities have had to respond through necessity but in most cases their responses, described as “coping”, have gone undocumented.

There is a huge and – twenty years into the epidemic – disgraceful lacuna in what we know about HIV and poverty, both the ways that the epidemic exacerbates poverty and the reverse. In fact very little is known about the more general relation between infectious disease and poverty. With regard to HIV/AIDS and poverty, little is known at the analytical level, less is known, or at least “known” to academic and agency personnel, about the policy and practical implications. Even where there is information we need to recognise that we are only 20 years into what will be a long wave event whose effects will be felt for generations to come. HIV/AIDS is a very long wave event as compared to an epidemic of influenza. The true death toll cannot be estimated until the full wave form of the epidemic has been seen. It may be as long as 30 more years before we can say that the world epidemic has peaked and/or begun to decline. If we take into account the social and economic impacts of the epidemic, in particular HIV/AIDS related impoverishment which is the focus of this paper, then the epidemic and its impacts can be considered as an event which lasts as long as a century.

AIDS deepens poverty and increases inequalities at every level, household, community, regional and sectoral. The epidemic undermines efforts at poverty reduction, income and asset distribution, productivity and economic growth. AIDS has reversed progress towards international development goals because of the influence it has on all development targets (see chapter 1 of this compilation of studies).

Responses to the epidemic seem to chase rather than lead it. Apart from persistent fear, denial and stigma, there is still lack of clarity on biological, social, economic and development relationships and HIV, and what *is* known may be poorly implemented. While prevention must remain a priority, the reality is that the impact of the disease must be mitigated. AIDS has already become the number one cause of death in many parts of the world and the impacts due to illness, death and orphan-hood are in fact just beginning

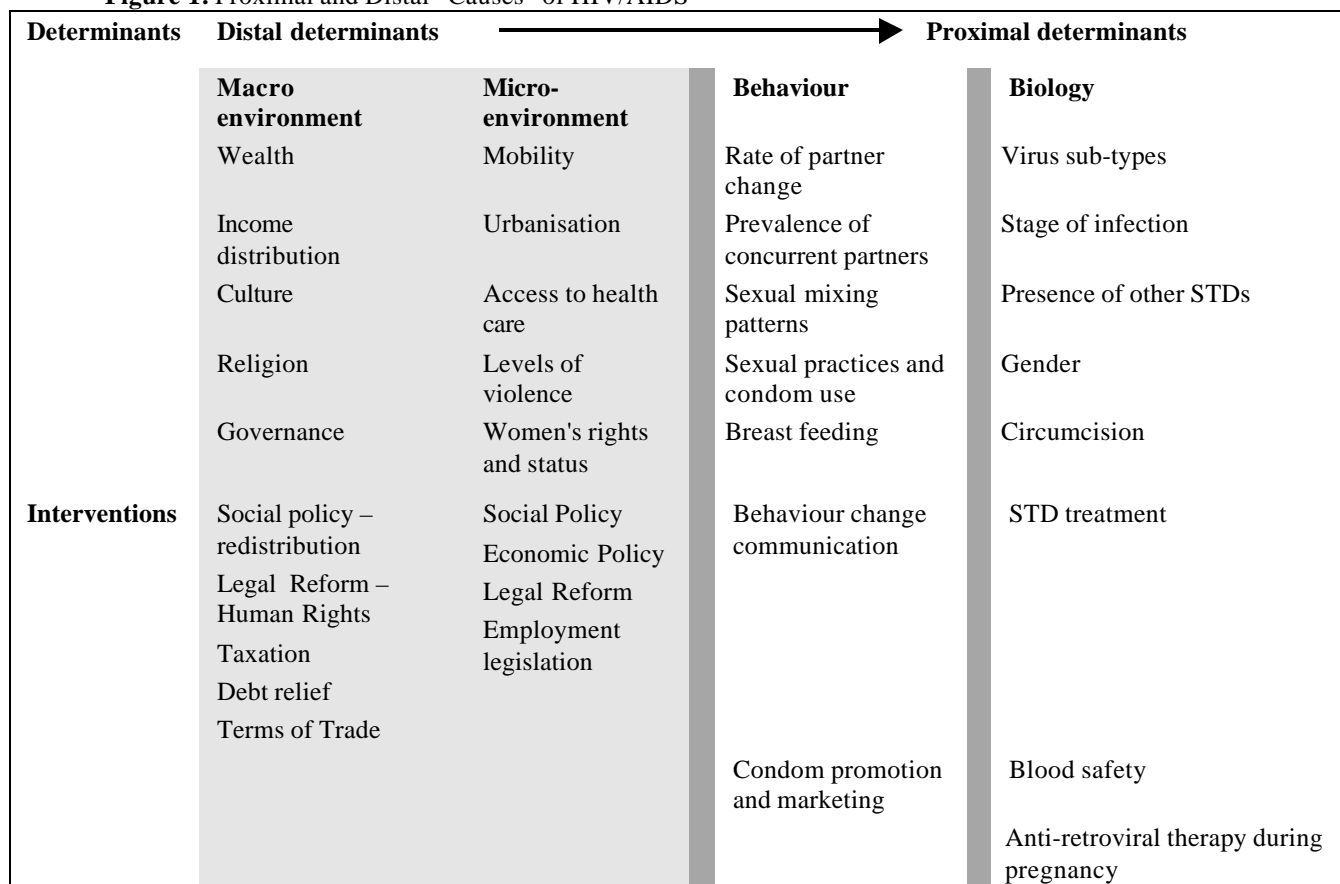
2. The Relationship between Poverty and AIDS

There is an undoubted relationship between poverty and the development of epidemics of communicable disease and at the same time epidemic disease – like any illness – has the potential to increase poverty.

Stillwagon, has recently convincingly argued “that HIV prevalence is highly correlated with falling calorie consumption, falling protein consumption, unequal distribution of income and other variables conventionally associated with susceptibility to infectious disease, however transmitted.” (Stillwagon, 2001). The causal chain runs from macro-factors that result in poverty: through the community, the household, the individual and into the resilience of the individual’s immune system. Work in cell biology has shown the mechanisms which connect malnutrition and parasite infestation, depress both specific and non-specific immune responses by weakening epithelial integrity and the effectiveness of cells in the immune system (Stillwagon, 2001). Protein-energy malnutrition, iron deficiency anaemia, vitamin-A deficiency, all of these poverty related conditions decrease resistance to disease in general and to HIV in particular.

Figure 1 shows some of the general relationships. Each column is an area where policy interventions can be hypothesised can be and tested. The shaded columns are those where poverty based interventions are appropriate.

Figure 1: Proximal and Distal “Causes” of HIV/AIDS



Source: Barnett, Whiteside, Decosas, 2000.

Poverty contributes to epidemic disease and epidemic disease contributes to poverty: causation is bi-directional and occurs through many different pathways. For example, loss of labour from a farming system may result in failure to maintain infrastructure such as terracing, leading to soil erosion, and decreasing agricultural productivity. This will impoverish households and communities, reduce their ability to sustain themselves and resulting in poorer socialisation, less formal education and ultimately cultural as well as material impoverishment. Although the problem of AIDS related

impoverishment might usefully be thought of as a livelihood problem, this framework will ultimately turn out to be limited. A livelihood approach will only provide an entry point to a problem that is much wider. This perspective has applications beyond HIV/AIDS and will be relevant to consideration of the effects of other communicable diseases.

That the HIV/AIDS epidemic impoverishes people, their households, communities and enterprises is by now widely accepted. What is not well understood is how it acts on different social and economic units, how these interact with each other, and how we can better understand these effects and processes. There has been surprisingly little work on this problem.

HIV/AIDS leads to financial, resource and income impoverishment. Households become poorer as a result of the illness and death of members, and in many cases it is the income-earning adults who are lost. However impoverishment is more than financial. Illness and death leads to an erosion of social capital and socially reproductive labour. In other words, we are bound to consider impoverishment as a characteristic of systems rather than solely of commonly identified social and economic units. The notion of social reproduction is of greatest importance. It is not the same as “social capital”. The term is used to refer to the effort that goes into the reproduction of social and economic infrastructure. To give one example, we may think of market systems. At the purely economic level, a market is a mechanism whereby goods and services are exchanged through a process of price setting. At the social level, this system consists of a wide variety of relationships including for example: physical infrastructures, beliefs about trust, rituals of bargaining and price setting, mechanisms for regulating weights and measures, means of resolving disputes, and repeated activities which ensure that all these things continue to exist. These are not solely matters of economic activity. They include the maintenance and development of institutions, the reinforcement of systems of belief and the continuation of physical infrastructure and channels of communication. The effort that maintains these is the work of social reproduction. Death and illness means that some of these activities will no longer be possible or will be done less effectively.

Poverty is also about more than income and economics. There are many types of poverty:

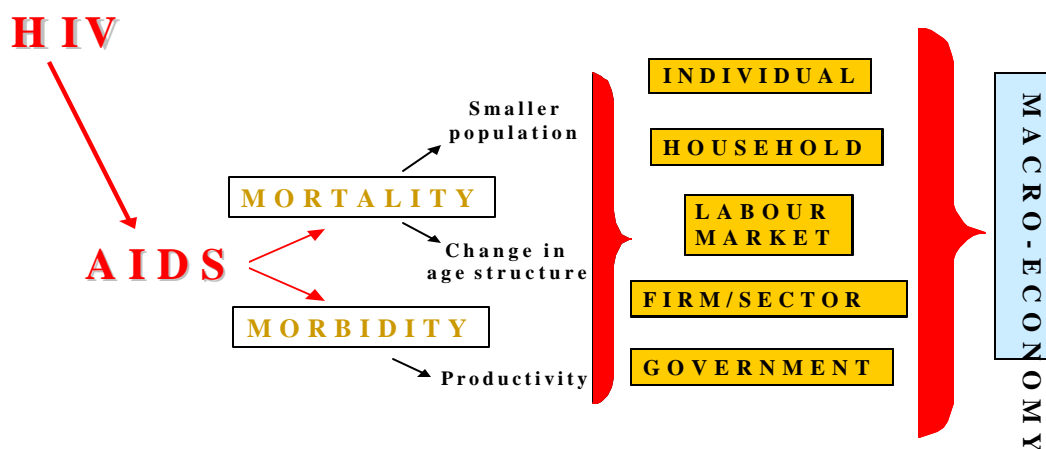
- service poverty, where people are unable to access or are not provided with services such as health and education;
- resource poverty, where though they have sufficient incomes people are unable to access resources because they may be poor in terms of their rights, representation or governance.

For reasons of space, we focus on income and social capital in this paper. This is not to say that other forms of poverty are unimportant. AIDS will affect them as well and these are areas where further research and discussion are necessary, not only in relation to AIDS but in relation to the impact of infectious diseases more generally.

3. The Impact of AIDS on Poverty

The pathways of impact are illustrated on Figure 2. The first and worst impact is at the level of individuals and households. In the longer term there may be a macro-economic impact (see chapter 10 of this compilation of studies). The precise scale and magnitude of macro-impact will depend on the number and location of the micro-level impacts. Early attempts to identify and predict macro effects were seen as a way of justifying action. If it could be shown that AIDS would cause national economic growth to slow then it would perhaps be easier to make the political case for policy intervention.

Figure 2. Pathways to Economic Impact



Source: Chris Desmond, HEARD

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4. Macro-economic Impact

In the late 1980s and early 1990s a number of studies looked at the macro-economic impact of AIDS. These suggested that national economies would grow more slowly as a result of the impact of HIV/AIDS (Over 1992, Cuddington, 1993). But these studies were based on modelled impact rather than observation. There was little additional work in this area until 2000. Why the renewed interest? The answer is:

- The scale and speed of the epidemic has been worse than expected.
- Known demographic effects are now such that recognition of economic consequences is unavoidable.
- There is evidence of impact at micro-levels, making macro impacts credible.
- The complexity of disease impact and the scope of its consequences are better understood. For example loss of key government workers means work is not done efficiently, investment is reduced, and economic growth slows.
- The development consequences of the disease are becoming apparent, in these circumstances there must be a macro-economic impact.

At third general level of analysis, World Bank economist Rene Bonnel estimates AIDS reduced Africa's economic growth by 0.8 percent in the 1990's (Bonnel, 2000). HIV/AIDS and malaria combined resulted in a 1.2 percentage point decrease in per capita growth between 1990 and 1995.¹ In two countries, South Africa and Botswana, there has been some rigorous national level analysis (Quattek, 2000, Arndt and Lewis, 2000, Bureau for Economic Research, 2001; BIDPA, 2000). The conclusions of these analyses are that AIDS will cause the economies to grow more slowly. Household income and expenditure will decrease as will government revenue and domestic savings. One of the South African studies suggests that the main reasons are the shift in government spending towards health, which increases the budget deficit and reduces total investment and slower growth in productivity. (Arndt and Lewis, 2000).

In Botswana a report on the macroeconomic impacts of HIV/AIDS (BIDPA, 2000), (one of a number of studies on HIV/AIDS impact) focused on the effect of HIV/AIDS on GDP growth and per capita incomes from 1996 to 2021. It predicted GDP growth would fall from 3.9% a year without AIDS to between 2.0% and 3.1% a year with AIDS. After 25 years the economy would be 24% to 38% smaller.

It is increasingly recognised that conventional economics misses the complexity and full significance of the epidemic. (MacPherson et al., 2000; BER, 2001). When the epidemic was in its early stages projections based on scenarios computed 'with AIDS' and 'without AIDS' were reasonable. Such comparisons are no longer valid. "The impact of the disease cannot be treated as an 'exogenous' influence that can be 'tacked on' to models derived on the presumption that the work force is HIV-free. HIV/AIDS has become an 'endogenous' influence on most African countries that has adversely affected their potential for growth and development. In some cases, such as Zambia, Zimbabwe, and the region covering the former Zaire, the spread of HIV/AIDS may have already undermined their ability to recover economically"(BER, 2001). AIDS has the potential to push economies into decline and then keep them there. "The reduction in savings and loss of efficiency associated with the spread of the disease is akin to 'running Adam Smith in reverse' (BER, 2001).

Thus we have seen the significance of AIDS impact at the macro-economic level. There are however additional consequences which have rarely been considered in the literature. These include particular the strong possibility that governments will have fewer resources to spend on poverty alleviation and social services at the very point when demand for those services is most likely to increase. In Botswana the increased demand for resources and the likely reduction in revenue have been calculated. The Government will have to spend between 7 and 18 percent more by 2010 because of AIDS, assuming current levels of service are maintained. The greatest share of spending will go to health care followed by poverty alleviation. Revenue in Botswana is predicted to fall by 9.6 percent – and this is a relatively protected economy because of the country's huge diamond deposits. South African government revenue will be 0.7 percent lower in 2000 than in the absence of AIDS. By 2011 it will be 4.1 percent lower. (Quattek, 2000).

¹ Recent work by the Liverpool School of Tropical Medicine suggests that the interactions between malaria and AIDS may be marked. The rates of malaria fever rose sharply with falling CD4 cell counts. The data suggest that with worsening immunosuppression caused by HIV/AIDS, protective immune responses to malaria in adults are progressively lost. (Gilks, personal communication 2000)

Finally the consequences for those not directly affected by AIDS will be considerable. They will have to bear the consequences of the general slowdown in economic activity, erosion of government revenue and capacity, and other associated effects of the epidemic.

5. Poverty Impact at the Household Level

Household and community level impacts are most serious when considered within the macro-economic context sketched above. The BER in South Africa warned that “the macro results may conceal more substantial negative impacts at a more disaggregated level”, (2001 p.42). Despite this type of statement, there is a paucity of information on the impact of HIV/AIDS on poverty or on policy to mitigate it. What there is sparse and uncoordinated. Indeed, it may be said that economic modelling, despite its well-known flaws, at least provides a baseline for discussing the poverty implications of the disease. In contrast, existing household studies tell us very little and there have been very few attempts to model the impact of AIDS on households (Bechu, 1998, 341-8). From the limited household studies, it can be concluded that the effect of illness and death on poverty in households depends on:

- The number of cases the household experiences - this is where clustering becomes important.
- The characteristics of deceased individuals: age, gender, income and cause of death.
- The household’s composition and asset array
- The community’s attitudes towards helping needy households and the general availability of resources - the level of life - in that community.
- Broader resources available for assistance to households - from the state or Community Based and Non-Governmental Organisations, CBOs and NGOs.

5.1. The Limits of Household Studies

Household studies have limitations. These are:

- Even in the worst affected areas adult illness and death is comparatively rare;
- Because HIV is sexually transmitted it clusters in households. The average household in a community will not be affected in any given year. This can be illustrated with a simple example. In a village of 100 households with an average of three adults per household, in a region with 10 percent HIV prevalence and a mature epidemic, we would expect to see three to five adult deaths per annum. It is likely that only one or two households will experience illness or death in any one year. However impact will ‘accumulate’ in the community.
- Most of the studies deal with Africa;
- Most are of rural households. Why this is so is unclear. It may arise from a basic paradox: foreign researchers want to work in rural areas, which, they believe, represent the “real” Africa, and prefer to avoid places which are squalid or

dangerous like poor parts of large cities. But in Africa and South Asia nearly a third of the population lives in urban areas. (UNDP, 2000, page 226).².

- As their titles indicate, in most cases they are *economic* studies.
- Most frame the problem as a *household* study and depend exclusively on survey methods, thus failing to capture the most seriously affected households, those that have disappeared before the survey.
- Policy makers, politicians and agencies often demand quantitative survey based studies because they have the ring of a form of evidential ‘truth’ which coincides with the demands of funders’ referees who are often academics. Such forms of ‘truth’ although valid are partial and do not tell of the underlying misery.
- Single or even multi-visit surveys unsupported by ethnographic methods tend to underestimate impact and tell us little about *processes* of impoverishment.
- Commonly used survey methods fail to capture the dynamics of household and intra-household allocation and relations which underlie household decision making (Chong 1999, Rugalema, 1999).
- AIDS may be seen as the major problem by the researcher – who has written and submitted a research proposal or is responding to a terms of reference or scope of work document. Communities and households may not have the same perception of its importance. This was illustrated by a Zambian study which looked at how children were valued in a situation of environmental and social change, The social change identified by the researchers in an area with 14.8 percent HIV prevalence among ANC attenders was increased morbidity and mortality due to the epidemic. They concluded “research methods used in the study villages found that there was almost no link made in people’s minds between HIV/AIDS and either the value of children or fertility. At present AIDS is not seen as a major problem by the majority of people, despite its recognition as a worrying disease.” (Barrett and Browne, 2000 p22)
- Measurement of impact of HIV/AIDS on poverty is difficult. The effect of illness ranges from not feeling very well to complete inability to function. It is difficult to unravel these subtleties with survey methods because: surveys of “households” will not collect data on complex relations between clusters of households; and the “household” may not be the appropriate unit of analysis for understanding poverty effects of AIDS related events.
- Finally the epidemic and its impact are still evolving. The HIV epidemic may have run its course only in Uganda and Thailand. In all other countries HIV prevalence continues to rise and the number of AIDS illnesses and deaths will follow suit some years hence. Thus surveys are trying to measure and quantify something that is still to happen.

5.2. Short Term Poverty Impact

Often the first sign of infection is when the youngest child (infected in vitro) fails to thrive, and dies. The mother is likely to have been infected by her partner. It is estimated that 60 to 80 per cent of African women with HIV have had only one partner but were infected because they were not in a position to negotiate safe sex or prevent their partners from having additional sexual contacts. (Colvin, 2000). The next death is often that of the father followed by the mother.

² According to the 2000 United Nations Human Development Report 32.7 percent of the populations of both sub-Saharan Africa and South Asia are urban.

The illness has two effects on household resources and income. No matter who is ill they will need care, medicines, treatment and possibly a special diet. All this costs extra money. When the person dies the funeral will be a further drain on resources. The second impact is felt if the person is an adult. Their illness and eventual death will deprive the household of labour. This may be income earning or unpaid labour on the farm or labour used in caring for the family.

5.3. Understanding the time scale of impact

The impact on households is long term. It begins with illness as additional resources are required for care and household labour is reduced. Unlike with many (if not most) illnesses the person affected will not recover but periods of illness will increase in frequency, duration and severity requiring more care and, if the person is a labour provider, it results in a greater household labour deficit. Usually there will be more than one case in the household thus the pattern of illness and impoverishment may be repeated.

If the household dissolves then dependents, usually children but sometimes the elderly, either have to fend for themselves or are taken in by other household. Where care is provided by others this means that in many instances fewer resources will be available to their own members. Examples include grandmothers in South Africa making do with a pension of less than \$100 per month and caring for one or two children. As the number of dependents increases so resources are stretched thinner. The net effect is that there is less for everyone.

5.4. Income, Consumption and Expenditure Patterns.

What effect does AIDS have on household expenditure and consumption patterns? An adult illness or death reduces household income. Less labour is available, not only because the affected individual can't work but also because time is diverted to care of the sick. Illness increases expenditure on medical care, food, washing materials etc.

There are limited studies of the effects of AIDS on households and most focus on economic impacts of death rather than illness. These paint a bleak picture. The classic survey-based study was in the Kagera region of Tanzania in the late 1980s and early 1990s by the World Bank with Tanzanian co-investigators³. With regard to adult death the Kagera study (World Bank, 1997) found households experiencing an adult death spent less during the person's illness, but that a greater percentage of their expenditure was on medical care. They spent 33 percent less on non-food items such as clothing, soap and batteries and their food purchases decreased. Income was diverted but may also have been reduced as the number of hours worked was cut (World Bank, 1997, 213).

³ The study was a four round panel survey between 1990 and 1994. The survey looked at the impact of adult mortality and a total of 913 households were interviewed at least once with 759 household completing all four waves. The study was funded by USAID, Danida and the World Bank Research Committee. The findings have unfortunately neither been fully analysed nor published although some have been presented in various fora including international conferences. The most accessible account can be found in World Bank, 1997. Some further findings were discussed in Lundberg and Over, 2000.

In South Africa the Bureau of Economic Research modelled the impact of the AIDS epidemic on final household consumption expenditure. This is shown below. These results suggest that total final household consumption expenditure is slightly higher in the AIDS scenario over the period 2002-2010. This is explained by increased consumer spending on health care products and services (non-durable goods and services spending), use of personal savings and positive employment effects associated with the government and companies' efforts to combat the epidemic. (BER, 2001, 33)

Table 1: The impact on final household consumption expenditure (FCE) (% difference in constant price levels of AIDS and non-AIDS scenarios).

	Durables Total	Semi- durables	Non- durables	Services	FCE	Savings
2002	-1.0	-0.7	0.3	1.5	0.5	-0.5
2005	-3.1	-2.4	-0.1	3	0.7	-0.8
2010	-5.7	-5.4	-1.6	6.3	0.8	-1.5
2015	-7.9	-9.8	-6.3	3.5	-2.8	-0.2

Evidence from both Kagera (World Bank, 1997) and Cote d'Ivoire (Bechu in Ainsworth et al, 1998) indicates that households are resilient and there is a partial recovery in levels of consumption as time passes after the death. In other words households "cope". However, our experience and that of others has been that anecdotal evidence often shows they do not cope, or that 'coping' may turn out to be another way of saying "desperate poverty, social exclusion and marginalisation".

There is an unresolved problem: existing quantitative studies indicate effective coping while anecdote makes us believe otherwise. And recent work from Zambia supports this view. A five-year retrospective study of 232 urban and 101 rural AIDS affected families found that "One of the striking features of the economic impact of AIDS in affected families in Zambia is the rapid transition from relative wealth to relative poverty" (Namposya-Serpell, 2000, p1)⁴. This was particularly marked where a father died (70 percent of the recorded urban deaths). Monthly disposable income of more than two-thirds of the families in this study fell by more than 80 percent.

Household surveys underestimate the degree of household dissolution and failure. Mutangadura's (2000) study of 215 households in Manicaland, Zimbabwe examined how adult deaths may cause the dissolution of households. She found that about 40 percent of the sample households had taken in orphans who had lost both parents. More strikingly she states that: "Sixty five percent of households where the deceased adult female used to live before her death were reported to be no longer in existence in both the urban and rural sites" (Mutangadura, 2000, 11). This lends weight to the supposition that often the worst impact is invisible because it is among those who are not counted.

Death is expensive. In Kagera households, medical expenditures were higher when AIDS was the cause of death. But 'strikingly for all groups except men with AIDS, medical expenses were overshadowed by funeral expenses. On average, households spent nearly 50 percent more on funerals than they did for medical care.... In Thailand ... just as in Tanzania, the households spent much more on funerals than on

⁴ AIDS-affected was defined as a family in which one or both parents and/or major breadwinner died due to AIDS in the five year period from January 1991 to December 1995.

medical care.” (World Bank, 1997, 211). It should also be remembered that while the state may make some contribution to health care and medical expenses, home care and funeral costs fall entirely on households.

One method by which households cope is by sale of assets. Table 2 summarises data on how adult death is linked to households’ disposal of assets from Kagera, Tanzania and Rakai, Uganda.

Table 2: Asset Ownership in Households with and without an adult death (% of total households) (World Bank, 1997, 217)

Asset	Rakai District, Uganda		Kagera District, Tanzania	
	Households w/o adult death	Households with adult death	Households w/o adult death	Households with adult death
Bicycle				
First visit	34	39	27	26
Last visit	41	35	29	28
Radio				
First visit	30	40	31	36
Last visit	37	36	35	35

Around the city of Chiang Mai in northern Thailand, 41 percent of households where there had been an adult death had subsequently sold land. Fifty seven percent reported some other form of what economists euphemistically describe as “dis-savings”, while 24 per cent borrowed money. (World Bank, 1997, 218). In Zimbabwe 24 percent of households said they had sold assets to cope with the death of an adult woman with “the main assets being sold being cattle, goats, furniture, clothes, televisions, poultry and wardrobes”. (Mutangadura, 2000, 15).

For rural and poor urban households to survive it is crucial that they do not dispose of productive assets which are necessary for recovery and reconstruction. The assets described in table 2 are mainly consumer goods, a household can sell a radio and survive. The question is what happens when productive assets – a plough, oxen or seed stock are sold. The implications for the future of such households must be bleak: they can no longer maintain and reproduce themselves.

Whatever the case, two points should be noted. The first is that people who are driven to sell the clothes of the dead or their own clothes can hardly be said to be coping: these are the actions of the desperately impoverished. And, following from this, we have to be aware that the very notion of “coping” is deeply ideological and may smack of the rich telling the poor how to manage their poverty (Rugalema, 2000).

5.5. Household Reproduction, Size and Structure

What effect does the epidemic have on household reproduction, the household’s ability to sustain itself from day to day and to reproduce itself over time? The demographic impacts on households affect their ability to reproduce themselves at all. Households with adult female infections experience lower birth rates and higher infant and child mortality rates. In households where a parent or both parents have AIDS, the likelihood is that fewer children will be born and a significant proportion of those who are will die very young. Inevitably this means that the personnel of the household are not reproduced and neither are the life-ways and traditions of that household.

That the structure of a household experiencing a death will change is axiomatic. It might be assumed that one unit – the deceased - would reduce its size. However evidence from a number of studies suggests that in practice the change is hard to predict. In Kagera, most households experiencing a death *added* at least one member when a previously absent member or non-member joined. The average size of these households declined by less than one - from 6 to 5.7 (World Bank, 1997, 215). In Rakai, Uganda, by contrast, mean household size fell from 6.4 to 4.7 (Menon et al, 1998). People left the household, perhaps children were sent to stay with relatives or adults moved in search of employment. In Thailand the decline was from 4.1 people per household to 3.1, the decrease being equivalent to the death of the one person (Janjaroen, 1998). The significance of this has not been evaluated but it should draw to our attention the regional and national effects of large numbers of deaths in a community.

Deaths in individual households have implications for other households because of their interdependence. Rugalema (1999) shows how coping mechanisms become increasingly weakened as more households in a community are affected and communal support networks are less and less able to cope.

It has been argued by some that an entity called “the extended family” will absorb the orphans and destitute created through AIDS related mortality. This view has been heard from people ranging through senior policy makers in international agencies to politicians in Africa and Asia and people in local communities. It is now heard less as the full effects of the epidemic become apparent. The reasons for this are: :

- the extended family is variable, it is dynamic and can become more or less extended depending on resource availability;
- ideological, it is something people want to believe because it validates their traditions;
- ideological because belief in it relieves politicians of responsibility for thinking through the implications of the epidemic;
- households do reach a point where they can no longer cope.

Affected households will try to adapt. One way in which they do this is by changing their composition. Three key points must be made:

- Societies where extended households are the rule or where clusters of households operate together to pursue a common livelihood strategy may be more robust in the face of adult death.
- Sending children to stay with relatives means the effect of the adult death will be felt beyond the sending family. Whoever takes care of the children can expect to expend resources.
- Orphans need care, either in other families or through some form of public support. Increasingly they do not receive this support.

New forms of household are developing as a response to the impact of HIV/AIDS. some of the more unique responses include elderly household heads with young children, grandparent headed households; large households with unrelated fostered or orphaned children attached; child headed households; cluster foster care – where a group of children is cared for formally or informally by neighbouring adult

households. Unfortunately where care is not available children are increasingly itinerant, displaced or homeless often in groups or gangs or found in subservient, exploited or abusive fostering relationships Hunter, 2000, 195).

5.6. The Unmeasured Impact on Poverty

Economic studies of impact have understandably tended to focus on “economic” variables. Economics studies what economics studies. But the impact of HIV/AIDS on poverty goes beyond these relatively easily measured and familiar variables. In particular it engages with what may be called relational good, public goods and issues of social reproduction (Barnett, Whiteside and Desmond, 2001). Social relations contribute to wellbeing. They may be:

- ‘relational goods’ (Gui, 2000),
- goods which have characteristics of being “public” or “common” (like, for example transport infrastructure).

It may not be possible to supply the former category through markets, depending on whether a relationship, which is the good, is provided through a market. For example a foster parent provides care and support and parent provides love as well. Can money buy love, how do you cost a cuddle? The latter is not supplied or is under-supplied by markets because individuals and corporations have little incentive to supply those goods. Relational goods can be final consumption goods (i.e. valued for themselves) and/or intermediate goods (e.g. certain social relations may facilitate co-operation and trust). Social relations can be a source of value in themselves (Sugden, 2000a, Bruni and Sugden, 2000).

The effects of loss of such goods are apparent at the household and community levels. The study of households and their interaction has long been an area of research for sociologists and anthropologists. There is information on how households cope with shocks and respond to disease. However AIDS is new and different. AIDS affected households have to cope with more than one death, because the disease clusters. They also have to deal with a long and debilitating illness that is costly in its use of resources – both financial and time, and which ends in death. In addition, the epidemic has a wider effect weakening the ability of the community to lend support.

An in-depth study of the impact of the disease in Bukoba district of Tanzania (Rugalema 1999) illustrates the stark impact on households. In the study community 32 percent of households were AIDS afflicted – they had experienced direct illness or death of one or more of their family members in the last 10 years. A further 29 percent were affected “in the sense that although they have not experience direct death or illness of a household member from AIDS, they have experienced *ripple effects* ... include (ing) fostering orphans, providing labour or cash to help care for the sick person, and providing for survivors in an afflicted household.” (Rugalema, 1999, 73).

The worst impacts will be felt in households and clusters of households. It is here that costs of the disease have to be borne. It is here that mitigation interventions have to be

located if they are to be cost effective and sustainable. It is here that social reproduction occurs at its deepest level: in the stories told by parents and grandparents to their children, in the giving and receiving of affection, in the taking and relinquishing of responsibility. It is also here that the state and large multilateral agencies have most difficulty responding. The scale is too small and the variability in circumstance too great to be covered by large programmes. The great danger is that it is here – where it is most needed and where the very long term costs are stacking up - that response to impact will be impossible because there is no way of dealing with small scale and large variability. This is a major policy challenge.

5.7. The Intergenerational Bargain

Another area where the loss of relational goods is significant is in the relations between the old and the young. The HIV/AIDS epidemic has altered and will progressively alter the demographic structure of many societies (Low-Beer et al; 1997; Stover, 1998). These demographic changes are indicative of long term impoverishment, as relations of intergenerational support become eroded or impossible.

Under normal circumstances the young are cared for by their parents, who later provide support for their own parents. Some social scientists describe this as the “inter-generational bargain” (Carmichael and Charles, 1999; Collard, 1999). In Greek tradition this has been likened to a vine, where the young adults stand straight and firm as the new shoots climb up and the old ones make their way down to the earth. If you take out the middle support the children can’t climb and the old collapse.

This is one of the core and most important bargains made and maintained between people. It is a basis on which social order is constructed: its destruction points to impoverishment far beyond the material. In most societies there is no social pension or welfare and while people may accumulate assets during their productive years these are often not, on their own, enough to provide for old age.

Care of the aged is a global issue. In all societies people are living longer, or at least they were before the advent of AIDS. In wealthy societies there is increasing concern about how to respond to ageing populations. Here, the problem is the potential burden of care and supports which the young face in caring for the increasing number of elderly. In the poorer, AIDS affected countries, life expectancy may be falling but this overall figure disguises the fact that people who reach their 50s and 60s have a much better chance of living into their 70s and 80s. AIDS impact is therefore being felt in a setting where ageing and care for the elderly were already issues of concern. It makes a bad situation worse.

The effect of AIDS on the young needs to consider all who are AIDS affected. The classic definitions of an orphan by UNAIDS is “a child under 15, who has lost either both parents (double orphan), or the mother (maternal orphan), and it is from this definition that the UNAIDS global estimation is made”. This underestimates the ‘true’ number of orphans. In addition the definition needs to be expanded to consider children who are affected – prior to the death of parents and also to children in households that take in affected children. Definitions are important and there is no final way of deciding who is or is not an orphan, it is a social role and varies from

place to place and culture to culture and impoverishment goes beyond the mere fact of being orphaned.

5.8. Long term impoverishment

The World Bank's study in Kagera showed that even in "richer" households (and we must not forget that these are all very poor communities) 29 per cent of non-orphaned children were stunted (had a very low height for their age) while 50 per cent of orphaned children were wasted. In poorer households 39 per cent of non-orphaned children were stunted while 51 per cent of orphaned children were wasted (World Bank, 1997, 224). These figures point to the effects on all children of growing up in a poor society.

Stunting has long term effects. Foundations for future life are poorly built with poor physical condition, compromised immune systems and mental functioning. This will affect the ability of children to benefit from education and to function socially and economically later in their lives. It can cripple a society for a generation or more.

Orphans are less likely to have proper schooling. The death of a prime age adult in a household reduces a child's school attendance (World Bank, 1997, 225). Households may be less able to pay for schooling.⁶ An orphaned child may have to take on household or income earning work. Sick adults may have reduced expectations of the returns to investing in children's education, as they do not expect to live long enough to recoup the investment. When a child goes to another household after its parents' deaths, the obstacles become greater as the child is not their own.

The standard of education that a child receives may be low. This is in part because of the under-resourcing of public education; it is also a result of the AIDS epidemic. AIDS increases teacher deaths and they may be difficult to replace, particularly in deprived, rural or otherwise remote communities. Teachers' illness is of particular importance. Classes remain untaught for extended periods and replacement is difficult while staff members are on sick leave.

In Kagera children from poor households had the lowest school enrolment rates whether they were orphaned or not. But orphaned children inevitably had lower rates than non-orphaned children. Differentials are striking. The enrolment rate for non-orphaned children between the ages of 7 and 10 from better-off households was 44 per cent. But for orphaned children in the same age group and from poorer households, the rate dropped to 28 per cent (World Bank, 1997, 228).

Girls carry a larger burden of domestic responsibility than do boys and are more likely to be kept out of school. As with much else about HIV/AIDS, impacts are inter-related: poor nutrition, poor care, and poor or little schooling affects orphans. Other children in the community are affected by general household impoverishment.

Caring for children has costs. Taking in orphans increases demands on household resources. In societies affected by HIV/AIDS many children live in households in which their own parents have fostered or are fostering orphans. In a study in

⁶ In many countries fees are only part of the costs of attending school. There are book fees, building fees, PTAs, uniforms and of course the opportunity costs of time and labour foregone.

Buganda, southern Uganda in 2000 (Monk, 2000), 152 households were interviewed. A total of 342 non-orphaned children resided in these units. In addition there were 383 orphans. In the majority of cases there was no distinction between levels of care given to orphans or to the guardian's own biological children. Therefore, all children in the household suffer the same economic and other deprivations resulting from spreading resources more thinly as a “coping” response to the epidemic.

AIDS disrupts social roles, rights and obligations. For the orphaned child there is often a premature entrance to burdens of adulthood, all without the rights and privileges – or the strengths - associated with adult status. Becoming an orphan of the epidemic is rarely a sudden switch in roles. It is slow and painful and the slowness and pain have to do not only with loss of a parent but also with the long term care which that parent's failing health may require. Children who care for adults may experience a world gone seriously awry. A young girl of eight or nine may be used to caring for younger siblings: she is unprepared to care for her mother, father or both of them. As well as the physical difficulties there are inevitably difficulties of culture and sensibility. Coping with a parent who is weak and requires food cooked or water brought is one thing. Coping with a parent's severe diarrhoea, declining mental function and mood changes is quite another. Children also become uncommonly familiar with death.

It is not only in relation to their own parents that children take on new and premature roles. When they become orphans, they go to their grandparents or to another relative. An aunt or uncle may also die of HIV/AIDS or a grandparent from old age. Double or even triple orphaning is not unknown. It is all too common for quite young children or early adolescents to be caring for aged and infirm grandparents.

These unmeasured consequences for the orphan generation are of great concern. We are talking about unsocialised, uneducated and in many instance unloved children struggling to adulthood. The cost to them as individuals remains unmeasured. The costs to the wider society are potentially enormous and already being felt and seen.

It has been speculated that the high levels of orphaning will lead to an increase in crime. This has been spelt out as follows for South Africa “AIDS and age will be significant contributors to an increase in the rate of crime over the next ten to twenty years. There will be a boom in South Africa's orphan population during the next decade... Growing up without parents, and badly supervised by relatives and welfare organisations, this growing pool of orphans will be at greater than average risk to engage in criminal activity.” (Schönteich, 1999, 1). At worst there may be increased political instability with orphans swelling the ranks of the child soldiers (Zack-Williams, 1999).

5.9. Poverty and Older People

Population ageing is now a global phenomenon and is set to accelerate over the coming decades (Kinsella and Tauber, 1993). The standard definitions, population aged 65 years or over, do not reflect the nature of old age in most of sub-Saharan Africa (Apt, 1996; 1997) and other poor regions of the world and in poor communities. Limited life expectancy, poverty, hard work, frequent illness and, in the case of women, childbearing, all result in relatively early onset of “old age”.

In contrast to children who are orphaned or otherwise at risk, older people are less appealing to donors. There is prejudice against older people and rapid social change and “development” often places them in positions of severe disadvantage. For example, the migration of young adults from rural to urban areas means that their adult children will not be around to look after them. The changed status from respected elder to burdensome old person is particularly likely when their children’s generation ceases to take traditional responsibilities seriously as they pursue new individualistic lifestyles. The HIV/AIDS epidemic magnifies all of these problems and older women face more difficulties than older men. Rural old women are among the populations most adversely affected. A measure of the degree to which the impact of HIV/AIDS on older people has been neglected is that we are aware of only one scientific study and indeed few other publications on this express theme⁷.

The main problem that confronts the elderly in a society affected by HIV/AIDS is poverty. An inevitable second problem is grief. Grief and poverty go together for the old because the epidemic affects them through the death of one or more of their adult children. Older people are likely to be among the poorest in poor societies. Their failing powers make it more difficult for them to work on a farm or earn a living in some other way. They become increasingly dependent physically and financially in all societies and once again “the extended family” and its strengths can turn out to be more myth than reality (Laslett, 1965; Gubrium, 1973, Foner, 1984).

Poverty and frailty are made worse in two main respects by the loss of adult children. One is the loss of financial and other support that they could have expected and might have received. The other is the unexpected burden of orphaned grandchildren who come to live with them.

In contrast, a rich older person can buy their way out of the worst effects of the death of an adult child or children. Fieldwork in rural Uganda in 1989 identified an apparently prosperous elderly couple. In depth interviews elicited the following story: the couple had worked hard and saved by investing in their children’s education. For many years they had enjoyed the fruits of their investment in remittances from their son the headmaster, their daughter the nursing sister and their other sons, both government officials. Then one by one and in quick succession the children all died. The couple found themselves hosting 15 grandchildren from under two years of age to mid-teens. Their solution was for the old man, now in his eighties, to take a young woman of 26 as his second wife. This is one way of coping but it is restricted to the relatively rich. The reality for the majority of the elderly is quite different.

5.10. Old Age: poverty exacerbated

A detailed study of older people in Buganda (Williams, 1998) illustrates graphically the conditions which the elderly endure in a rural society in Africa. They have poor housing and are often unable to build anew or to repair what they have. Poor housing means poor security and loss of food and other valuable items to insects, animals and theft. Preparing and cooking food can present challenges. Within their homes, poor old people may not have sufficient bedding to stay warm at night. One of Williams’

⁷ We arrive at this conclusion through a careful literature search which turned up fewer than 10 articles, theses or book. Only Williams (1998) presents extensive and detailed data.

respondents told him: “I sleep on a bark cloth on the ground and I cover myself with my dress. I’d sleep better if I had a blanket.” (Williams, 1998, 140). Another said: “The problem is that I don’t have the strength to carry pots from outside and I am afraid I will fall over. I used to have it (the kitchen) outside, but it was hard to get in and out of the door at night, and once I fell over. So now I have it in here, but I still fall down sometimes. When I cook near my bed I can cook lying down and that is easier.” (Williams, 1998, 138.)

Old people living alone face considerable difficulties obtaining water for washing, cooking and drinking. Failing adequate water supply, the results for the elderly may include: thirst, hunger because there is no water with which to cook, dirty clothes, lack of personal hygiene, intestinal worms associated with poor sanitary conditions (Williams, 1998, 143). Another constraint is fuel wood. This is a very labour intensive and demanding task and old people often find it hard to obtain enough. The result of this combined with falling ability to produce food from the farm or purchase it is inadequate diet.

The elderly are dependent. Dependence requires support. Support is found in social life. Social life requires energy and inputs if it is to be maintained and reproduced. The elderly lack energy to make these investments. That is why children are important and why when they die and their work, remittances and other support cease, the circumstances of an old person can decline dramatically. What then happens when the grandchildren come to live with them?

5.11. Old age and Orphans

Williams suggests that “Old people are affected by the epidemic more through the fulfilment of their parental obligations than the loss of their children’s support.” (Williams, 1998, 230). First of all they care for their children who are sick. Then they bury them. Finally they care for their grandchildren.

In Uganda⁸ as long ago as the late 1980s aged grandparents had increasingly assumed responsibilities for rearing orphans. Lack of energy to work in the fields meant the range of food available to them and their dependants became smaller and nutritional status became worse. Many grandparents with orphans said they faced problems of discipline. Young people were to be found playing truant in the nearby town and were identified by members of the community as orphans coming from grandparent homes.

But sometimes it is the sheer numbers of orphans who come to rest in the grandparent’s household which overwhelm its capacity to offer material and emotional care.

5.12. Young trees make a strong forest (Kiganda proverb⁹)

It is estimated that by 2005 just over 30 per cent of Malawi’s children will be orphans because of AIDS and other reasons: by 2010 that will have risen to 35 per cent

⁸ This section is based on fieldwork by Barnett and Blaikie in the late 1980s. It describes a situation that has not altered very much if at all and which is now more widespread in Africa and elsewhere than when these notes were first made.

⁹ Williams, 1998, 216.

(Hunter and Fall, 1998, 7). The situation in Malawi is no worse than in any other country of East, South and Central Africa, indeed it may be better.

The breakdown of inter-generational dependency and support is not unique to an HIV/AIDS epidemic. It has been commented on in many countries of Europe (Carmichael and Charles, 1999). Provision can be made through the market or the state in rich countries. Poor countries have not and cannot provide support nets for their people. There is little in the way of public provision. People cope by caring for themselves in households and in communities as best they can.

The HIV/AIDS epidemic confronts us with a new situation. Societies remain poor and will be further impoverished by the epidemic itself. The growth of dependent populations and the disappearance of mature adults erode the possibilities of “coping” at the local level and nationally. This is apparent all over Africa but also elsewhere, for example in Ukraine. Ukrainians have the oldest average age in Europe, and per capita one of the largest numbers of pensioners. Under the Soviet system a pension was provided by the state. Money did not come from investments but from current revenue. The dramatic decline in government revenues since 1991 has been reflected in a decline in the real value of pensions as well as delays in paying them. Not only are the old poor and without any substantial social safety nets, but because of the unfavourable dependency ratio they are unlikely to have either family or state provision in their final years. Our calculations suggest that as a result of the HIV/AIDS epidemic, there will be an additional 30,000 totally unsupported old people in Ukraine within ten years (Barnett and Whiteside, 1997).

The evidence from Africa and from Ukraine shows that a serious situation exists in both places. Throughout Africa the intergenerational bargain is becoming progressively harder to maintain. The outcome is awful for the people themselves; its long-term effects have to be imagined as one and possibly two generations of children grows up with inadequate care.

5.13. The Policy Response

“Our extended family system will cope with orphans” people used to say in Africa in the early 1990s. In Uganda it was realised and accepted by the mid-1990s that “the extended family” system was (a) various and variable (b) often not coping. Institutional care is unacceptable to people in Uganda and in most other parts of Africa. It is necessary to find ways to care for orphans within family and household systems that have been increasingly stretched, using institutional care as a last resort. Institutional care has a bad name in some places where “orphan farming” has developed as an income generating activity (Barnett and Blaikie, 1992).

An assessment of the cost of orphan care in South Africa looked at six different approaches. The costs are summarised in Table 3.

Table 3: The Cost of Orphan Care in South Africa. (Rand \$1 = R8.2)

Care Model	Cost (minimum standard)	Increase	Reason for increase
Community-based support structures	276	-	-
Home-based care and support	306	+30	-Process for identification -Process for placement and grant access
Informal fostering/ Non-statutory foster care	325	+19	-Higher degree of supervision -Smaller scale
Statutory adoption and foster care	410	+85	-Security of accommodation -Quality of accommodation -More administration
Unregistered residential care	956	+546	-High staff to child ratio -Provision of emergency care -Care of sick children
Statutory residential care (caring mainly for HIV positive children)	2590	+1634	-Very high staff to child ratio -Care only for sick children -Meet statutory requirements for a children's home -High over heads -On site medical care -On site pre-school education

Source: Desmond and Gow, 2000.

There is a wide range of care options, from the less costly informal to the more costly formal care models. Although community based care and home-based care and support appear to be the most cost efficient ways of caring for orphans, these models are not always appropriate or feasible. Appropriate resource allocation – a political and practical issue - is a major limitation to be addressed if the basic needs of the children are to be effectively met by informal family orientated care models. In addition, the appropriateness of the less formalised care options in caring for children who may be sick or suffered abuse needs to be considered.

It is difficult to know how to support households with AIDS orphans. Targeting them is neither practical nor desirable and is potentially stigmatising. It could also mean that other orphans and their carers – with the same needs – would be excluded from benefits. The majority of orphans are in poor countries where even the better off households are poor by the standards of rich countries. The problem is how to support all orphans and other vulnerable children more effectively in such contexts.

Botswana has the highest levels of infection of any country. It has a major orphan problem. Current discussions concern whether state intervention or institutional care are appropriate. As in Uganda 10 years ago, so in Botswana today. People say that fostering and institutional care are not part of the tradition, that the extended family will cope (Jacques, 1998, quoted in Rajaraman, 2001). But “(t)he Rapid Assessment on the Situation of Orphans in Botswana tells a different story ... of orphan suicides, destitute children eking their living out of garbage dumpsites, and a growing number of child-headed households. In a context of intense social and economic pressures, orphans are increasingly reported to be mistreated and abused by caregivers; deprived of their inheritances by opportunistic relatives and neighbours; forced to drop out of school to perform domestic labour or bring home wages; pressured into entering commercial sex work and vulnerable to sexual abuse.” (Rajaraman, 2001).

Although the government offers some additional support for orphans, carers are sometimes reluctant to accept this assistance, particularly if acceptance may identify the dead parent as having died of AIDS. Or it may suggest that the family cannot cope, another stigma. Given the possibilities of abuse, neglect and poverty, Rajaraman suggests that the Government has an obligation to intervene, in order to protect the human rights of the children involved.¹⁰ This does not imply overriding traditional systems of caring for orphans; it will, however, mean developing institutions to monitor, support and supplement them. But despite considerable rhetoric and funding, the Government of Botswana does not appear to have mobilised sufficiently to develop a structure of care for orphans. NGOs and particularly the churches are bearing the heaviest load. The Government has not yet introduced an effective system either for registering orphans or for ensuring that different ministries' activities are co-ordinated to provide effective support. This is the situation in one of Africa's wealthiest countries; it is far worse in the poorer countries of the continent.

As the epidemic's range increases, these problems will appear elsewhere. In Calcutta, India, there have been reports of numerous AIDS orphans for some years¹¹ while in Ukraine, the predicted number of AIDS orphans in the next five years may well overwhelm existing institutional provision (Barnett, Whiteside, Khodakevich, Kruglov, Steshenko, 2000, 1399). The Ukrainian case is of particular concern as the situation there is replicated in all of the former Soviet Union – implying a vast orphan population from the Polish border to Vladivostok¹². A visit to a Ukrainian orphanage in 2001 made the implications of this painfully clear. Children who have spent their childhood in an institutional regime that is simultaneously under-funded and deriving from the Soviet tradition cannot make a satisfactory transition to the world outside at age 16. This is particularly so when the Soviet support services of health care, employment and housing have disappeared. The deputy-Director of the orphanage was close to tears when describing the trauma for staff and orphans of pushing the latter out of the institution when they reach 16. In economic and social terms, in the “transitional economies” of the Former Soviet Union, the potential costs of “the orphan problem” which existed before HIV/AIDS but which will be exacerbated by it, is very large indeed. There are the immediate problems of institutional care, the costs of assisting the transition from care to adult life (a transition which will fail in many if not most cases), and finally the costs as these neglected people make their ways through their societies, in most cases to a premature death.

5.14. Current responses to AIDS related impoverishment

There have been very few explicit responses to the social and economic impact of HIV/AIDS. Most effort and money has gone into prevention. While this was a sensible response the balance between prevention and impact mitigation responses has been wrong— particularly when it has been clear for at least a decade that there would be long-term social and economic impacts. Here we review what is known about the possibilities, limitations and prospects for responses in general. We then go on to make some concluding and inevitably brief observations about poverty related responses to HIV/AIDS.

¹⁰ Botswana became a signatory to the United Nations Convention on the Rights of the Child in 1995.

¹¹ Personal communication from Veena Lakhmalani

¹²

The first thing to say is that most responses to poverty related impacts of HIV/AIDS have been at the local and community level. There are few records of poverty related responses at the regional, national and most certainly not at the international level. From the earliest days of the epidemic the tendency has been to move with the dominant neo-liberal ideology and to phrase response in terms of “coping”. This is has been inadequate because – as noted above - the concept itself has severe limitations.

5.15. Current responses and the myth of coping

Like sustainability, the idea and language of “coping” has to be questioned in relation to HIV/AIDS and its impacts. Yes, people “cope”, the alternative - not coping - means households dissolving or people dying. But it is odd and indeed offensive for the wealthy to suggest the poor should “cope” and the rich will show them how to do it. The idea of “coping” originates from the unwillingness of the rich to do anything more than apply sticking plaster to the wounds of global inequality when what has been required for a very long time is expensive surgery. This surgery requires major transplantation and reorganisation of resources.

Rugalema (2000) argues that coping is often a myth because:

1. Many households affected by HIV/AIDS do not cope. On the contrary, they break up and their members, orphans, widows and the elderly, join other households.
2. It is not households that cope – rather it is individuals within them who manage to *survive*.
3. There may be precious little in the way of “strategies” about how people manage crises. Rather the decisions made by household members may merely reflect efforts to survive in the very short term.
4. Short-term solutions to crises – sale of household assets, withdrawal of young girls from school to help with domestic and farm work - have long term effects and costs. These may include lower or no educational achievement, poor diet with associated stunting or wasting, lack of care and poor socialisation.
5. The impact of a large-scale event such as an HIV/AIDS epidemic has effects on wider social, economic and even environmental systems. For example, in a community or region that is hard hit, there are changes and costs at the levels of the farming system, social infrastructure and the maintenance of physical infrastructure. These all point to general impoverishment in many dimensions.
6. The effects of “coping” are shouldered unequally between poorer and better off households, men and women, generations, and different social groups and geographical regions.

Why use the term “coping”? It originates in literature about individuals and how they cope with stress (McCubbin, 1979; McCubbin, 1980). It has been used to discuss famines (Watts, 1983; Corbett, 1988; De Waal, 1989; Devereux, 1993). Other roots lie in ideas from social work and childcare. Here the notion of “good enough care” (Winnicott, 1965) emerged in the 1960s. It was an attempt to sensitise social workers to the idea that, while their clients’ standards of care might appear inadequate by their

own social and cultural standards, the clients' was "good enough" as long as everyone was "coping".

In relation to HIV/AIDS, the story of coping mechanisms is really a part of the wider story of structural adjustment policies – before they began to be offered "with a human face" (Mehrotra and Jolly, 1997). Rugalema hits the nail on the head when he says that the concept of coping strategies is rooted in the neo-liberal worldview of the 1970s and 80s. Non-intervention by governments and freedom or autonomy of economic agents to participate in the market were fundamental points of departure. As this worldview dominated that period, not least due to the influence of Reaganomics in the US and Thatcherism in the UK, so the concept of coping strategies gained credence (Rugalema, 2000, p 5).

It is well-known that human societies have developed and continue to develop "coping mechanisms" and risk sharing mechanisms for dealing with adversity, it is also well-known and evident that there are severe limits to those mechanisms, that they do break down. The notion of a "coping mechanism" can surely only be maintained when a society or community remains able to meet its needs at some culturally acceptable level – hence the importance of the distinction between "famine" and "famine that kills" (De Waal, 1989) among dryland people in Darfur who distinguish between "mere" famine and the other type. Coping becomes impossible. It is for these reasons that we are sceptical about and critical of the all too frequent use of the term "coping mechanism" derived as it is from disaster theory and in particular from famine theory (Rugalema, 2000). The notion has limitations when applied to famines and implies a rational response following logical processes of retreat in the face of a shock. It is a notion that fits comfortably with neo-liberal ideologies that assume and often implicitly make moral judgements about the desirability of a particular calculating stance towards the world on the part of individuals and households. "The Little House on the Prairie" comes rapidly to mind, but the point here is that for each little household that made it into literature, there were others that perished. This becomes downright cynical when very poor people are told that they are "coping" and their strategies are studied and reported to little purpose other than to provide assurances to major lenders such as the World Bank that their policies are in some sense working.

We have underlined the social roots of the HIV/AIDS epidemic and the social and cultural filters through which its impacts manifest themselves. Coping is about dealing with risk. Risk is not equally distributed. It is constructed for individuals and socio-economic groups through complex processes of economic, social and cultural relations. The constant struggles to survive that characterise the livelihoods of so many do not leave room for coping in the extraordinary circumstances in which many poor people live. That is what they do every day of every year. That is the nature of poverty. And when the big crisis hits them they do not cope. Thus, to talk of such poor people "coping" is to cross the line between technical appreciation of what is possible and barely disguised cynicism and clear acceptance that different groups of human beings can only be offered second, third or worst best options. It is to accept the unjust structures of distribution in the world. A term such as "coping" may be a way of escaping from the challenge of confronting how people's capabilities are stunted, their entitlements blocked and their abilities to function as full human beings with choices and self-definitions frustrated.

5.16. Transfer interventions

We have already noted that little is known about responses to HIV/AIDS induced poverty. This is for three reasons:

- There have been no large scale interventions
- Most interventions have been small scale, community based (often components of “coping”) initiated by CNGOs, NGOs or in a few cases (such as Action Aid) by BINGOs (Big NGOs - major international actors such as Oxfam, World Vision, Save the Children or Care).
- Above all because the interventions have not been documented.

Most interventions have been small scale. It is only in the last year or so that large-scale programmes are coming into existence. This is evident most of all in the World Bank’s Multi-Country AIDS Programme Africa (MAP) which had approved nine projects funded by the end of 2001 and a further 16 in the pipeline. Despite the efforts of the *ACT Africa* (AIDS Campaign Team for Africa) group in the World Bank who have been responsible for pushing this initiative, what is most significant about it is that so little is being done so late in the epidemic – particularly given the lavishly funded Kagera household study which was done almost a decade previously!

Current (November 2001) World Bank publication about the MAP project (World Bank, *ACT Africa*, Multi-Country HIV/AIDS Programme for Africa, November 2001, CD-ROM) provide information about nine programmes¹³ funded by the initiative. While these programmes are broad ranging and indicate that impact issues do at least figure in addition to prevention measures, none of the programmes seems to have poverty related transfers as a focus for their activities. It is not that transfers are excluded – they could be included in a large number of community based activities which might be funded. Rather it is that transfers are an option rather than a recognised component of the strategies that have been jointly developed for each country.

This is an interesting situation. The Bank is responding to pressure and opinion. Its activities in this sphere are in fact quite limited and these soft loans are not large, few are much bigger than a few tens of millions of dollars and even Nigeria’s is under \$100m over 5 years repayable over 35 years. The Bank is endeavouring to respond to local need and to make the process participatory (as between government and funder) and yet despite the best efforts of the *ACT Africa* team programmes remain not only prescriptive but prescriptive to a degree which appears to reduce the possibilities for transfer programmes. This is clearly shown in the following outline of what the overall programmes are intended to cover:

“The proposed project will support key components, including:

- **Prevention**, including information, education, and communication (IEC) for specific target groups, condom promotion, voluntary

¹³ Burkina Faso, Cameroun, Ethiopia, Eritrea, Gambia, Ghana, Kenya, Nigeria, Uganda.

- counselling and testing for vulnerable groups of the population; participatory approaches to behaviour change;
- **Care and treatment**, including the treatment of STIs and opportunistic infections such as TB; strengthening the availability of and access to essential drugs, training of health workers, clinical management of HIV/AIDS-related conditions, and support to home and community-based care and support activities; ensuring a safe blood supply through improved screening and blood transfusion;
 - **Research and surveillance**, including baseline surveys of epidemiology, knowledge and behaviour, improved HIV sentinel surveillance to monitor the epidemic, and analysis for the design and implementation of cost-effective interventions;
 - **Capacity building** for program coordination, resource management, and implementation at all levels; and
 - The establishment of sound **monitoring and evaluation systems** to enable program implementing agencies to monitor performance indicators for each component of their programs.”
- (World Bank, MAP, 2001, file MAPOperation, p. 4).

This initiative is important but it raises some very important questions about poverty related interventions. A key idea in the World Bank’s approach is “scaling up” of local level initiatives. For some time this has been pushed hard by Hans Binswanger (Binswanger, August 30 1999). The approach has some difficulties. On the one hand, large lenders like the Bank have to be seen to disburse large amounts of money; on the other, scale may not always be easily combined with the specificities of local circumstances and with requirements for national and community ownership of programmes and projects. So, the need to respond on a scale in keeping with the perceived urgency of the situation may not necessarily result in projects that really meet local needs.

Interventions have mainly been small scale and under the auspices of NGOs of one kind or another. These have not been described in any detail and have rarely been evaluated. Here we summarize a number of these in case study format.

i. The Firelight Foundation (www.firelightfoundation.org): this US based organisation operates on a very small scale and concerns itself with children affected by HIV/AIDS. It gives one year grants of \$500 to \$20,000 to grassroots, community-based projects directly supporting the fundamental needs and rights of children orphaned or affected by HIV/AIDS in sub-Saharan Africa. These projects have aimed to train children, pay school fees, and in some cases provide food and medicine. The organisation has been active in Kenya, Rwanda, South Africa, Tanzania, Zambia and Zimbabwe. Its activities up to an including the year 2001 are summarised in Table 4. Projects in which some type of transfer can be said to take place are italicised.

Table 4

COUNTRY	US \$
Kenya	
Rural Education and Economic Enhancement (REEP), Butula District	\$ 30,000
The grant will provide guardians and foster parents of orphans: training in counselling, project management, and savings programs as <i>well as offer food aid</i> . They will also train orphans in vocational skills, project management and reproductive health.	

AIDS, PUBLIC POLICY AND CHILD WELL-BEING

Teenage Mothers and Children Family Health Care (TEMAC), Eldoret The grant <i>provides food and medicine</i> for the children.	\$ 2,500
Catholic Diocese of Kitui-Orphan Support Program, Kitui The grant will assist the program to train social workers and orphans, <i>purchase drugs</i> and provide other social programs.	\$ 5,000
WiRED, Advanced Technical Assistance to Orphans, Mombasa The grant will train six AIDS orphans in a pilot program of computer learning at a conference in Mombasa.	\$ 7,350
Community Resource Mobilization Initiative Group (COREMI), Raibai Funding will offer <i>vocational training for 20 orphans</i> , and counselling and training for 45 community AIDS educators.	\$ 12,000
Kibera Community Self Help Program (KICOSHEP), Nairobi The grant provides for <i>orphan support</i> through KICOSHEP's various programs.	\$ 21,000
Child Health Program—Bactrim, Kendu Bay, Kenya http://www.globalstrategies.org	\$ 7,000
<p>This Firelight Foundation grant will be matched with \$7,000 from Global Strategies for HIV Prevention to support the Child Health Program of Kendu Bay, Kenya. The grant will provide Bactrim for 200 children and 100 adults for one year as well as covering HIV screening tests, fuel for the doctor and funds for home visits.</p>	
Rwanda	
Association de Chef de Famille: Giribanga-Bakery Project, Kigali Funding will cover: equipment, personnel costs, raw materials, and a five-day training program for 100 children in micro-projects, their rights and the law.	\$ 13,400
Benishyaka Association's Education Sponsorship Program for Orphans, Kigali Benishyaka Association focuses on the needs of widows and orphans who are victims of the 1990 war and the 1994 genocide for the betterment of their welfare. The grant will cover one year of <i>school fees and related expenses</i> for 150 children.	\$ 40,000
South Africa	
After School Program for Orphans, Alexandria Township The funds will purchase <i>supplies for an after school tutoring program</i> and bereavement art program for 40 children, several of whom are also participating in a Firelight funded pen-pal program with Anzar High School in California.	\$ 5,000
Botshabelo Babies Home, Midrand http://www.botshabelo.co.za The grant will pay for half of the yearly salary of a social worker, the cost of two caregivers and some operating costs.	\$ 8,700
South Coast Hospice's Memory Book Project, Port Shepstone The funds will provide 200 rural children about to be orphaned with a Memory Box. The box contains a letter from their mother giving her hopes and dreams for that child, along with photos and other small mementos.	\$ 48,000
Tanzania	
Activities Related to AIDS Orphans, Musoma The grant will make available services to 140 orphans and vulnerable children including: educational, counselling and support services, <i>material aid to attend school</i> and peer education programs to improve community outreach.	\$ 8,000
Education for AIDS Orphans & Peer Education and Service, Musoma Youth Alive Program, Musoma The grant covers <i>school fees and related expenses</i> for 30 orphans. The Youth Alive Program grant covers the purchase of six bicycles, the coordinator's salary and an emergency fund for people with AIDS. The Youth Alive Program trains youth outreach volunteers to visit rural people ill with HIV/AIDS.	\$ 8,500
School Fees & AIDS Out-Reach, Mwanza Funding will assist more children to attend primary school through the provision of <i>fees and food assistance</i> . In addition, the Youth Alive group will be able to continue programs, plays, and training to teach other young people about the dangers of HIV/AIDS.	\$ 3,500

Zambia**Anglican Street Children Project, Lusaka**

\$ 5,000

The grant will enable the Project to provide counselling, *school needs (books, uniforms, pens, and shoes)* and other basic necessities of the children as well as providing outreach to their parents and/or guardians.

Fountain of Hope Shelter for Street Children, Lusaka

\$ 4,000

The grant will enable 40 mothers to receive business skills training and seed money for small businesses. *Helping mothers is one of the most sustainable ways to help orphaned children. The grant will also pay for 32 children to attend one year of secondary school.*

Zimbabwe**Salvation Army Masiye Camp, Bulawayo**

\$ 4,500

<http://www.masiye.com>

With the grant, Masiye Camp is establishing *an emergency fund, which will assist over 200 of the most needy orphans.*

Child Protection Society, Harare

\$ 15,500

The grant will fund three desktop computers, one printer and supporting software as well as vehicle costs.

Girl-Child Network-Safe House & Training, various locations

\$ 10,000

The grant will enable the Girl-Child Network to establish its third safe house for girls escaping sexual abuse in the village of Rusape. It will also cover the cost of a counselling workshop dealing with sexual abuse for club coordinators.

\$ 33,000

Island Hospice-Children's Support Program, Harare

The grant will pay for training and support to institutions and communities involved in the care of terminally ill children and orphans. The training includes grief and bereavement counselling and therapy for caregivers of children and support sessions for bereaved children.

Discretionary Grants**Girl Child Network, Zimbabwe**

\$ 1,800

To support the cross training of two women from Fountain of Hope in Lusaka, Zambia to provide services for the vulnerable girl-child.

Girl Child Network, Zimbabwe

\$ 200

For *miscellaneous educational expenses.*

Children Affected by AIDS Foundation, Los Angeles, California

\$ 10,000

To further their work with children.

AIDS Outreach Program, Tanzania

\$ 214

Paid shipping costs of donated children's books for distribution in local schools.

Paediatric AIDS Foundation, Santa Monica, CA

Funding for Call to Action, a project to reduce the rate of mother-to-infant transmission through: community education, health care worker training, HIV counselling and testing, and the provision of antiretrovirals to prevent MTCT.

There is no evidence that this programme and its associated projects have been externally evaluated.

ii. CINDI – Children in Distress (www.togan.co.za/cindi/)

An informal South African consortium of more than 30 government and non-government agencies, this organisation collaborate around the issues of children affected or orphaned by AIDS. It is supported by the Department of Welfare and Population, Kwa-Zulu Natal and the Nelson Mandela Children's Fund. The

organisation does not set out to make transfers but it does provide some school scholarships for children in South Africa, as well as providing access to and dispensing some medicines. It also gives some free toiletries and disinfectants. Its activities are small scale and community oriented. There is no evidence that the programme and associated projects have been externally evaluated.

iii. Aids Orphans Education Trust (www.orphanseducation.org): This is a **Ugandan** NGO. Its aim is to provide an education either formal and/or vocational to poor children whose parents have died of AIDS. It certainly makes a variety of transfers, including support for school fees, school materials and clothes. The AOET also provides support to widows in the form of blankets, food, laundry soap as well as clothes for families of sick people or families caring for orphans. There is no evidence that the programme and associated projects have been externally evaluated.

iv. International Fund for Agricultural Development (www.ifad.org): this specialised agency of the UN provides micro-credit to rural communities especially in **Uganda**. IFAD works through a partnership with the Belgian Survival Fund and UWESO (Ugandan Women's Effort to Save Orphans). The associated UWESO Development Project has enabled 2000 young children to attend primary school and has provided vocational training for older children. There is no evidence that the programme and associated projects have been externally evaluated.

v. USAID's Community-Based Options for Protection and Empowerment project (COPE) project in Malawi: this project is interesting because its aims are not to make transfers but rather to facilitate communities' potential to develop income generating activities and to make internal transfers – for example through the creation of food banks. The project was evaluated in January 1999 (Lloyd Feinberg, Namposya Serpell, John Williamson **Review of the COPE II and OVC Programs in Malawi**, January 8-24, 1999, Displaced Children and Orphans Fund and War Victims Fund Contract (HRN-C-00-98-00037-00), for USAID). An important question arising from this type of project is whether in many cases where the epidemic and its impacts are already very well advanced, such an approach is more in keeping with the ideological needs of the ultimate funder rather than meeting the requirements of the communities and households affected by the epidemic. Once again, Rugalema's comments about "coping" must come to mind.

vi. Association François Xavier Bagnoud (AFXB) Micro-Grant and Education Program for Orphans: The AFXB programmes – among the earliest to respond to the HIV/AIDS epidemic - helps families who are caring for orphans by providing micro-grants for income-generating purposes, paying for the primary education of one orphan per household, and educating people in hygiene, basic health care, and the rights of widows and children. They operate their programme in three sub-counties around Luweero, a town 70 miles north of Kampala, Uganda, where many children have been orphaned by AIDS or civil war.

Each autumn, the 90 neediest families in each sub-county are offered a one-time \$100 grant for the income-generating activity of their choice. Because of the lush grazing land, about 80% of the families elect to rear animals, with the remainder primarily engaged in coffee or banana cultivation. Rather than providing their clients with the \$100 in cash, AFXB social workers purchase the agreed-upon goods for them. AFXB

hires a veterinarian to select the healthiest animals and, since they are buying 30 to 40 cattle at a time, AFXB can negotiate the best deal.

An Evaluation Survey in 1999 found that over 80% of the AFXB micro-grants given since 1992 have met the objective of increasing the income of the families taking care of orphans.

AFXB pays for the primary education of 3,060 orphans per year. The school fees are not paid in cash, but the PTAs determine what is most needed at the school (i.e., a new classroom, desks or books) and AFXB pays the labourers for building the classroom or provides the desks or books directly to the school. In addition, AFXB holds a competition among each year's Primary 7 (7th grade) class, and the top six students are given scholarships to secondary school. The rest are eligible for vocational training.

AFXB relies upon a committee of volunteers to run their program. Each local committee area of guardians elects one spokesperson to represent them on the 50- to 60-person steering committee. The steering committees recommend the neediest families for the micro-grants, keep an eye on the orphans, monitor how the income-generating activities are working, coordinate with the schools, and provide regular feedback to the social worker running the AFXB program in each sub-county.

This approach makes transfers, ensures that they are under community control and direction and works on a small scale. It is an approach which once more throws into sharp relief the problems of “scaling-up” as it deals in micro-level interventions and requires close attention to the role of the local steering committee.

6. Conclusion

We have emphasised that the relation between poverty and HIV/AIDS and HIV/AIDS and poverty is bi-directional. There is much conceptual confusion about the nature of the relationship, perhaps pre-eminently because so little rigorous research has been done but also because of the ideological emphasis on “coping” which informed much thinking about and response to the social and economic impact of the epidemic during the 1990s. Another factor was the general reluctance among academics and policy makers to take the issue of broad epidemic impact seriously. All too often they demanded “scientific evidence” of impact, research which was rarely funded but which has now been provided by the unavoidable results of twenty years of impact on poor communities across the world but disproportionately in Africa.

In the early 1990s a very few NGOs (Action Aid, SCF UK and FXB among them) began to do something about the impact of the epidemic on poverty. By the late 1990s, more agencies took the issue on board – but few major multilateral or bilateral donors among them. It has been the NGOs that have made the running in providing transfer based interventions. Their activities have been small scale, variable in goals and intentions and usually unevaluated.

In sum, little has been done to respond to the impact of HIV/AIDS on poverty, we know little about it and have no idea whether these responses can or ought to be “scaled up” or how to do that.

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