

Children Affected by HIV/AIDS: Rights and responses in the developing world

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Douglas Webb
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Acronyms

AIDS – Acquired Immune Deficiency Syndrome
CAC – community AIDS committee
CAFOD – Catholic [Fund for Overseas Development](#)
CBO – community-based organisation
CCA – community counselling aides
CCDT – committed communities development trust
CHH – child-headed households
COPE – community-based options for protection and empowerment
DACC – district AIDS co-ordinating committee
FAO – Food and Agriculture Organisation
HIV – Human Immuno-deficiency Virus
IGA – income generating activity
M&E – monitoring and evaluation
MIS – management information system
NACP – national AIDS control programme
NACWOLA – national community of women living with HIV/AIDS
NGO – non-governmental organisation
OVC – orphans and vulnerable children
PAR – participatory action research
PLA – participatory learning and action
PLWHA – people living with HIV/AIDS
PM&E – participatory monitoring and evaluation
PRA – participatory rural appraisal
RRA – rapid rural appraisal
SC UK – Save the Children UK
STI – sexually transmitted infection
UN – United Nations
UNAIDS – Joint United Nations Programme on AIDS
UNCRC – UN Convention on the Rights of the Child
UNICEF – United Nations Children’s Fund
VAC – village AIDS committee
VDC – village development committee
WHO – World Health Organization

Chapter 1: Introduction

AIDS is now the greatest threat to child development in many parts of the world. In responding to HIV/AIDS, however, the children affected by the epidemic, especially those *indirectly* affected, are too often the forgotten ones. There is already a significant body of literature on the care and support of children living with HIV/AIDS, but most of this focuses on children in developed countries. The needs of children who are affected through the sickness and death of parents, guardians, siblings and others in the community, however, have not been seen as a priority – even though the number of such children dwarfs the number actually infected and will continue to do so.¹

This growing cohort of vulnerable children will have an all-pervasive effect on society.² The majority of those infected with HIV are young people in their reproductive years and most of them are parents. By the end of 2000, an estimated 13.2 million children under the age of 15 – the majority of them in Africa – will have lost one or both parents to AIDS (UNICEF and UNAIDS 1999). The growing pressure HIV/AIDS exerts on both household and community is shown by the increase in elderly carers and child-headed households in severely affected African and Asian countries.

Generations of children are growing up in Africa whose right to education and health, to protection and care, is being challenged by HIV/AIDS, thus curtailing their capacity to develop as adults. The decline in standards of living for young children – as illustrated by the reversal of recent improvements in child mortality rates across Africa – is clear evidence of this.

Particularly where children are concerned, HIV/AIDS must be treated as a broad developmental issue rather than as a narrow public health issue. Most children affected by HIV/AIDS live in poor countries and have limited access to health, education and welfare services. Accessible public health services are just one part of the broad developmental approach needed to support such children: their need for psychosocial support and for acceptance in a non-discriminatory environment is just as important as their material needs for food, shelter and education.

This paper will examine the situation of children affected by HIV/AIDS who live in poor countries, and will analyse the responses of households, communities, programming organisations, governments and donors. We

¹ Barnett and Blaikie make the distinction between 'afflicted' households, which have one or more members suffering from HIV/AIDS or who have already lost someone, and 'affected' households, which have received orphans (Barnett and Blaikie 1992, p. 58). For the purposes of this book, children living in these households are all 'affected' – and we would add that children can be affected through living in communities where large numbers of people are dying, even if their own households are not directly affected.

² Save the Children UK was one of the first organisations to attempt to quantify the problem, through research in Uganda (see Dunn et al. 1992).

explore a range of different programming responses, with the aim of drawing out useful lessons for Save the Children UK (SC UK) and other organisations. We shall also look at how the theme of children's rights can be integrated into HIV/AIDS programming.

One of our original objectives was to identify 'best practice' in responding to the needs of children affected by HIV/AIDS. However, we discovered that not only is there is no widely accepted model for such responses, but also that the systematic monitoring and evaluation needed to identify good practice are missing from existing programmes (Webb and Elliott 2000). We therefore concluded that this particular objective was premature. The process of identifying and sharing good practices will depend upon greater collaboration between agencies and more systematic monitoring and evaluation by programmes. We hope to contribute to the process with this paper.

Chapter 2 examines how HIV/AIDS affects children's access to education and training, their physical and emotional health, their welfare and protection. The effect of the epidemic on household economies is closely linked to its effects on children: those living in the poorest households are among the most vulnerable. The impacts of HIV/AIDS on children are largely determined by the context in which children live. How children cope is shaped by the poverty in their homes and communities, their spiritual and cultural heritage, access to basic services, the existence and enforcement of relevant laws and policies, and the level of awareness of HIV/AIDS in the community.

Chapter 3 discusses the use of a conceptual framework of child rights, based on the UN Convention on the Rights of the Child (UNCRC). Here we consider traditional responses to the epidemic, such as targeting resources at 'AIDS orphans': this essentially top-down approach can discriminate against other, less 'visible' but equally vulnerable children, and can be at odds with the community's own definitions of vulnerability. Our response must be to include orphans in broader programmes that address the needs of all vulnerable children. Using the UNCRC as a conceptual framework for HIV/AIDS programming can lead to a broader policy through a commitment to participation, equity, sustainability, non-discrimination, anti-poverty, multi-sectoral working, advocacy and capacity-building (SC UK 1999). As yet, however, there are few tried and tested methods for organisations adopting a rights-based approach to community-based interventions.

Chapter 4 examines a range of programming responses for children living in households and communities affected by HIV/AIDS. We focus particularly on how external agencies can support spontaneous, community-based responses. The 'dual strategy' of combining community mobilisation with access to micro-finance services is discussed, as are orphan identification, monitoring and support projects. There follows an analysis of the different components of a multi-sectoral response, including programmes providing education and training opportunities for children, health and nutrition, emotional support and protection.

Chapter 5 discusses the need to break down the traditional boundaries between programme activities, which may focus on HIV prevention, care and support for people living with HIV/AIDS (PLWHA), or impact mitigation. This specialisation tends to reflect the availability of resources and the skills of implementing organisations rather than the reality for children and their families affected by HIV/AIDS. Mobilising communities and supporting interventions that are 'owned' by the community will lead to a more integrated response, as this more accurately reflects the needs of people living in affected communities. The synergy that can be realised by combining activities in prevention, care and impact mitigation is explored.

Chapter 6 looks at the role of national governments in addressing the needs of children affected by HIV/AIDS and calls for greater collaboration between a range of stakeholders including governments, donors, non-governmental organisations (NGOs), community-based organisations (CBOs), the private sector and others. There is a need for a comprehensive national policy framework, which provides direction to the different agencies and organisations working to support children affected by HIV/AIDS.

Chapter 7 examines monitoring and evaluation and specifically the methods most appropriate for programmes supporting affected communities. Programmes that have been evaluated and/or reviewed are discussed, and the lessons for future monitoring and evaluation are set out.

Chapter 8 synthesises the lessons learnt from a decade of programme support for children affected by HIV/AIDS and identifies pointers for the future. Evidence has been drawn from a wide range of research and reviews, programme documentation and correspondence with experts. Country case study material has been drawn from Uganda, Malawi, Zimbabwe, Thailand and India.

Chapter 2: The impacts of HIV/AIDS on children

The HIV/AIDS epidemic began earlier and has progressed further in Africa than in any other developing region. Although only a tenth of the world's population lives in Africa, 95 per cent of all children under 15 who have lost one or both parents to HIV/AIDS live on this continent. Most research and programme interventions relating to the impact of HIV/AIDS on children have therefore taken place in sub-Saharan Africa. The literature on the subject singles out orphans as one of the most visible and distressing effects of the epidemic.³ Very high rates of adult sickness and death from AIDS, and consequent high rates of orphaning, are typical of the mature, generalised epidemics many African countries are experiencing.⁴

The epidemics in Asia and Latin America are more recent and the impacts of adult HIV/AIDS on children in these regions are as yet less visible. However, new infections are increasing rapidly throughout Asia: for example, if current trends continue India will soon have more people living with HIV than any other country. Approximately one third of all HIV-positive mothers, in the absence of effective interventions, will pass the virus on to their unborn babies, and most of these mothers will eventually die, leaving behind their orphaned children.

While there are major differences between the African, Asian and Latin American contexts, there are generic impacts of HIV/AIDS on children, which are likely to be broadly the same across all regions. These impacts are many and interrelated. They can only be understood through a close examination of the children's environment and their often complex relationship with surrounding adults. The situations children find themselves in profoundly affect the way they react to HIV/AIDS, and hence the support that they need.

2.1 Key determinants of need

The ways in which HIV/AIDS affects children are rooted firmly in the local, and to a lesser extent national, context. The impacts of HIV/AIDS are also perceived differently by different communities (see Chapter 4).

Every society shapes its own AIDS epidemic. (Barnett and Blaikie 1992)

Definitions of impact used by programmers must be based on an understanding of the local environment – including children's own perceptions of the epidemic – as well as the experience of researchers, programmers and policy makers.

³ All statistics in Chapter 2 (except where specifically referenced) are taken from *AIDS epidemic update: December 1998* and the *Report on the global HIV/AIDS epidemic: June 1998*, both available at the UNAIDS publications website.

⁴ A generalised epidemic is defined by UNAIDS as more than 5 per cent of the adult population infected with HIV. The many countries in Africa suffering from such epidemics include Uganda, Zambia and Zimbabwe.

The principal factors that determine how HIV/AIDS affects children include:

- economic status
- social and cultural context
- attitudes to, and knowledge of, HIV/AIDS
- access to basic services
- the legal and policy environment.

Economic status

The current economic situation influences the coping mechanisms that the household and the community use; indeed, it has been suggested that an adult death in the household may have a lesser impact than the existing socio-economic status of the family. For already poor households, the advent of AIDS can lead to a transition from poverty to extreme poverty, or even destitution (Williamson 1995). The existence of economic safety nets in the community is crucial where poor households are unable to manage during crises.

Social and cultural context

Social, cultural and religious practices strongly influence children's needs. A child from a culture in which the extended family is the principal care-giving unit for children will have different needs from a child from a community where nuclear families are the norm or where there is a high proportion of female-headed households or elderly care-givers. The organisation of households and families, the roles assigned to men, women and children within the family, and the cultural practices associated with sickness, death and property inheritance are just some of the factors which determine the needs of children.

Attitudes to, and knowledge of, HIV/AIDS

People's knowledge of HIV/AIDS, and their attitudes towards it, will influence how children deal with the epidemic. For example, ignorance of reproductive health issues will put children at risk of infection from HIV and other sexually transmitted infections (STIs). Local attitudes to HIV/AIDS will be influenced by how government, employers and charitable and religious organisations respond at national level. There may also be specifically local explanations for the cause of illness, which may lead to the stigmatisation of those affected. Stigmatisation of affected children (and adults) will increase their need for psychological and material support.

Access to basic services

Access to child welfare and to health services, the availability of home-based care, and the cost and cultural appropriateness of services will all affect the health of children and the support they receive in their roles as carers for sick parents. Children who care for sick adults as well as their siblings in the household will have the greatest need of help. Access to reproductive and sexual health services is vital to reduce the vulnerability of affected children to HIV infection. Access to social welfare services will also influence the ability of children to manage.

The legal and policy environment

The following laws and policies will influence the ability of children to cope:

- those relating to the protection of children in the absence of parental care, for example, whether the emphasis is on community-based care or institutional care
- those relating to property and inheritance, which will determine whether children can remain in their homes after the death of a parent and survive economically
- those relating to children's rights, such as the right to an education or to protection from abuse or discrimination.⁵

Also crucial is the willingness of governments to enact policy on HIV/AIDS prevention and care, and to create the necessary structures to put these policies into effect. There is a further set of factors specific to children who have lost one or both parents to AIDS. These are outlined in Box 2.1 below.

Box 2.1 Determinants of the impact of HIV/AIDS on orphans

Age and sex

The age of children when they are orphaned, as well as their gender, will affect, for example, the survival prospects of very young children and the education opportunities of older orphans, especially girls.

Type of orphan

Children who have lost their mothers will have different needs from those who have lost their fathers or both parents.

Kinship systems

Recent evidence suggests that whether kinship is matrilineal or patrilineal may influence the vulnerability of children orphaned by HIV/AIDS to physical and emotional abuse and to property grabbing by relatives.

Age of guardian and relationship to orphan

More and more orphaned children are living with elderly carers, and there has also been a rise in the number of child-headed households in some countries. The age and gender of the principal carer, and her or his relationship to the child (relative, foster carer, neighbour, or sibling) will all influence a child's vulnerability.

Location

⁵ The right to education is set out in Articles 17 and 29 of the UNCRC. The right to protection from physical or mental violence is set out in Article 19. The right to protection from discrimination is set out in Article 2.

Vulnerability may also vary according to whether the orphan household is urban or rural. Children in rural, female-headed households may be particularly vulnerable.

(McKerrow 1996; Foster et al. 1996 and 1997; UNICEF/CEDC 1998a and b; Barnett and Blaikie 1992; Nampanya-Serpell 1998; Elliott 1999; de Guerny 1998).

2.2 The direct impacts

In terms of its demographic impacts, HIV/AIDS affects children in the following ways:

- higher infant and child morbidity and mortality rates
- lower life expectancy
- higher rates of orphaning.

Higher infant and child morbidity and mortality rates

By December 2000, UNAIDS estimated that some 5.7 million children aged under 15 had become infected with HIV, 4.3 million of whom had died of AIDS.⁶ Over 90 per cent of young children with HIV acquire the infection from their mothers before or during birth or through breast-feeding. In addition, an unknown number of children and adolescents acquire HIV through contaminated blood and blood products, unsterile injections, the sharing of needles in illicit drug use, and through sex, including sexual abuse and commercial sex (Tarantola and Gruskin 1998). Half of all people with HIV become infected before they are 25, and they typically die of AIDS while their children are still too young to fend for themselves.⁷

Sadly, HIV/AIDS will have the greatest impact in countries that have achieved the most impressive reductions in under five child mortality (Hunter and Williamson 1998a): by 2005-2010, for example, 61 out of every 1,000 infants born in South Africa are expected to die before they reach twelve months old. Were it not for AIDS, it is thought that infant mortality would have been as low as 38 deaths per 1,000 children by this time.⁸ One study has estimated that, where the prevalence of adult HIV is 3 per cent, child mortality will increase by 3 to 6 per cent, and where the adult HIV prevalence is 10 per cent, mortality will increase by 9 to 26 per cent (Nicoll et al. 1994).

Most young children born HIV-positive begin to show symptoms of HIV infection in their first year of life. A study in Uganda found that roughly a third of HIV-positive children died in their first year, half had died by 21 months and three quarters after five years (Marum et al. 1996). Similarly in Malawi,

⁶ UNAIDS website: www.unaids.org.

⁷ From *AIDS epidemic update: December 1998*, UNAIDS website.

⁸ From 'The children left behind: UNICEF and UNAIDS issue new report on AIDS orphans', press release 1999, UNAIDS.

where an estimated 90 per cent of HIV-infected children do not survive beyond their third birthday.⁹

Lower life expectancy

The trend in most developing countries is towards older people outnumbering younger people, but the decrease in life expectancy caused by the AIDS epidemic means that the reverse will remain true in sub-Saharan Africa. By 2020, nearly 90 per cent of the world's children aged under 15 will be living in developing countries. As a consequence, the impact of the HIV/AIDS epidemic on children and families will be much more severe in these countries. In sub-Saharan Africa, there will be twelve times as many children under 15 as adults over 64. This is likely to lead to increased dependency ratios within households¹⁰ (Hunter and Williamson 1998a).

Rates of orphaning

By the end of 2000, 13 million children – 10.4 million of them aged under 15 – will have lost their mother or both parents to AIDS (UNICEF and UNAIDS 1999).¹¹ In some societies, there could be one orphan for every two healthy, economically active women (Gregson et al. 1994).

With orphans eventually comprising up to a third of the population under age 15 in some countries, this outgrowth of the HIV/AIDS pandemic may create a lost generation: a large cohort of disadvantaged, undereducated, and less-than-healthy youths. (Hunter and Williamson 1998a)

Definitions

How programmers and policy makers interpret the word 'orphan' will influence the nature and extent of support that children affected by HIV/AIDS receive. Western definitions of orphanhood may overlook equally vulnerable children who are not technically 'orphans' or who are too old to fit the specified category. For instance, researchers sometimes assume that orphanhood ends at age fifteen, or eighteen, whereas communities may use more practical definitions such as marriage or a demonstration of self-sufficiency.

Furthermore, research often ignores children who have lost their fathers. In polygynous societies, the death of the father can create many more orphans than can the death of the mother. The death of the father can also affect opportunities for school-age children, who often depend on the availability of money for their schooling.

⁹ 'Malawi: most untreated African HIV Children will die by age 3' Reuters news release, 26-12-00. Original paper in *Paediatrics*, December 2000.

¹⁰ Defined as the sum of children under 15 and persons 60 years or older divided by the number of persons aged 15 to 59 years. There is as yet little evidence of an increase in this ratio as a result of HIV/AIDS, as households have adjusted to cope with the growing number of orphans. See Section 2.3 for a discussion of the impacts of HIV/AIDS on dependency ratios.

¹¹ Estimates of orphan numbers vary widely. The World Health Organisation (WHO) estimates that more than ten million children will have lost one or both parents to HIV/AIDS by the end of the year 2000, and the US Census Bureau estimates that as many as 35 million children will have lost either or both parents, with AIDS being the major cause (Hunter and Williamson 1998a).

UNAIDS defines an orphan as a child under 15 years of age who has lost her or his mother (maternal orphan) or both parents (double orphan) to AIDS. UNAIDS global estimates are based on this definition. The estimate for end-1999 is 11 million AIDS orphans worldwide, and the figure is projected to rise to 24.3 million in 2010 and to reach 40 million by 2020.

However, these figures significantly underestimate the extent of the problem since they exclude the following categories of orphans and other children affected by AIDS:

- paternal orphans
- orphans aged 15 to 17
- non-AIDS orphans – i.e. children orphaned as a result of other causes.

Recent research into the orphan situation in one district in Uganda¹² found that the children in these three categories are often as severely affected as orphans that fitted the UNAIDS definition. Indeed, paternal orphans were often more severely affected than maternal orphans. Moreover, the experience of orphanhood often increases the age at which adolescents become independent, due to factors such as disrupted school attendance. Hence 18 years is argued to be a more appropriate upper age limit, as well as being consistent with the UNCRC. The research also showed that children sometimes called 'co-residents', who are not themselves orphans but who shared households with fostered orphans, suffered from increased poverty as a result.

A broad definition of AIDS-affected children including all the categories described above, i.e., maternal, paternal and double orphans from all causes under the age of 18, plus co-residents, when applied to the study district in Uganda yielded a total that was *nine times higher* than the one based on the UNAIDS definition of AIDS orphans. If other research yielded similar findings this would give rise to even more alarming estimates and projections than those produced by UNAIDS, i.e., 99 million at the end of 1999, 218.7 million by 2010 and 360 million by 2020.

Frequently, the community's own definition of vulnerability also includes children who are not technically orphans in the western sense, such as disabled or destitute children. This mismatch between notions of vulnerability and the imposition of external definitions tend to result in a top-down approach that is unlikely to encourage community 'ownership' of programme activities.

Finally, by treating orphans, and indeed children in general, as a homogeneous group from birth through to adolescence, programmers ignore the many important developments that occur in children's lives and consequently their differing needs at different ages (de Guerny 1998;

¹² Neil Monk for the Association Francois-Xavier Bagnoud, *A Study of Orphaned Children and their Households in Luweero District, Uganda*, February 2000, presented at the XIII International AIDS Conference.

Foster et al. 1998; Gregson et al. 1993 and 1994; Tarantola and Gruskin 1998; UNICEF/CEDC 1998a and b; authors). Current estimates of orphan numbers are included in the appendices.

2.3 The impacts on children's welfare and development

The morbidity and mortality experienced by *adults* leads to significant changes at the level of both the household and the community. These changes in a child's principal support units can have a significant negative impact on the child's development and chances of survival. In communities severely affected by HIV/AIDS, the growing incidence of adult deaths has a significant impact on the ability, and even willingness, of the community to act as a safety net. The effect of these changes on children's survival and welfare have not been sufficiently researched and documented (Chapter eight). The following section provides a summary of the evidence to date of the impacts of HIV/AIDS on children, drawn from formal and informal research, and from anecdotal reports, programme reports and other documentation.

Although the problems experienced by children living in HIV-affected households are often the same problems that poor children face everywhere, HIV/AIDS exacerbates them. Stigmatisation, discrimination, the psychological impacts of long-term care for sick parents and relatives and the escalating number of AIDS deaths in the family and wider community are problems that are largely unique to children affected by HIV/AIDS. Never before have we seen deaths on this scale over such a wide area, and it is this huge scale of the pandemic which has created a development crisis which is *qualitatively* unique (Hunter and Williamson 2000).

Assessments of the needs of children in AIDS-affected families indicate that education, health and food security are the major material problems, while social welfare, protection and emotional health are the major non-material problems (see Box 2.2 below).

Box 2.2 Common problems for children affected by HIV/AIDS

Education

- Children withdrawn from school to care for siblings, for the sick, or for economic reasons, particularly girls
- Reduced parental or adult responsibility
- Increased truancy
- Fewer vocational opportunities
- Traditional knowledge and practices not passed down

Health

- Lower nutritional status of orphans
- Less attention to sick orphans
- Less likely to be immunised
- Increased vulnerability to disease
- Less access to health services
- Increased vulnerability to HIV/AIDS
- Higher child mortality
- Higher exposure to opportunistic infections, especially tuberculosis and pneumonia

Livelihoods, social welfare and protection

- Increased poverty
- Loss of property and inheritance
- Stigma and social isolation of orphans
- Discrimination based on HIV status

- Loss of food security, particularly in rural areas
- Loss of shelter and material needs
- Increased labour demands in the home and in the fields
- Harsh treatment of orphans
- Forced early marriage for girls and sexual debut
- Abandonment
- Institutionalisation
- Increased sexual abuse of unprotected children

(UNICEF/CEDC 1998a and b; Hunter and Williamson 1998b; authors)

2.3.1 The impacts on household economies

The most important impact of HIV/AIDS, and one that is inextricably linked to all other effects, is poverty. This link is not uni-directional and certainly not simple. How does HIV/AIDS impact on the economic livelihoods of families, how does increasing poverty affect coping strategies at the household and community level, and how do coping strategies affect children in the household?

It is often hard to differentiate between the effects of HIV/AIDS and those of chronic poverty. A review of the UK NGO CAFOD's HIV/AIDS projects found that in most participating communities, HIV/AIDS was not identified as being among the main problems facing them. Their focus was on more immediate welfare or development needs:

This, in situations where almost everyone has been touched by HIV/AIDS in some way, is indicative of the overwhelming poverty of the communities in which the programmes are operating. (Welbourn 1998)

Although the problems identified by communities may be symptomatic of HIV/AIDS – such as widespread tuberculosis and diarrhoea – communities are often either unable (through insufficient knowledge) or unwilling (through fear of stigma) to identify AIDS as a major problem. Pre-existing economic stress, both at the household and community level, gives rise to a *disabling* environment for AIDS impact mitigation, particularly for children (see Table 2.1 below).

For children, poverty not only forms the single most powerful and multifaceted negative influence on physical and psychological development; it increases the demands on both households and communities whilst simultaneously undermining their resources and coping mechanisms. (McKerrow 1998)

Although poor households can often be surprisingly resilient in coping with the economic impact of death (World Bank 1997), the cumulative effect of multiple deaths in the family, as caused by HIV/AIDS, can overwhelm them:

It is only when the gross scale of deaths gradually becomes apparent that coping at the margin is seen to be inadequate. (Barnett and Blaikie 1992)

The high cost of health care for people with AIDS-related symptoms, and the loss of the income they formerly brought in, may cause a drastic short-term decline in household income. Different households will experience these economic pressures in different ways and this is borne out in the research. While some research has shown that household expenditure falls following an adult death to a low point around six months later, and then partially recovers (from the Cote d'Ivoire, World Bank 1997), other studies have found the economic impacts of HIV/AIDS to be longer-term. In addition, there are large differences in income between affected and non-affected households (Mutangadura and Webb 1999; Godwin 1997). Research conducted in Philippines, India and Thailand showed that coping with HIV/AIDS crippled household income-earning capacity and that it took several years to recover after a death (Godwin 1997). The economic impact of HIV/AIDS seems to be particularly acute on rural households, largely owing to the loss of adult male labour. Female-headed rural households are particularly disadvantaged since women generally have less access to other people's labour than men (Barnett and Blaikie 1992).

In the face of disaster and loss – including that caused by HIV/AIDS – households use a predictable range of techniques to mitigate the effects on their livelihoods (Barnett and Blaikie 1992; Donahue 1998; Williamson and Donahue 1996). Donahue (1998) has adapted a matrix that sets out the different stages of household coping mechanisms in the face of declining household income. This analysis, in Table 2.1 below, can be used to illustrate the potentially catastrophic effects of HIV/AIDS on poorer families.

Table 2.1 Three stages of loss management

Stages	Loss-Management Strategies
1. Loss management strategies are reversible and have little or no impact on the household's future income-earning or productive capacity	<ul style="list-style-type: none"> - Seeking wage labour - Temporary migration to find work - Switching to producing low maintenance subsistence crops (often less nutritious) - Liquidating savings accounts - Selling items of property - Short term exchange of labour for food - Tapping obligations from extended family members and community - Borrowing: formal or informal sources - Reducing consumption - Decreasing spending on education, non-urgent health care or other human capital investment
2. Disposal of productive assets – undermines ability of households to produce food or generate income	<ul style="list-style-type: none"> - Selling land, equipment or tools - Borrowing at exorbitant interest rates - Further reducing consumption, education or health expenditures - Reducing amount of land farmed and types of crops produced
3. Destitution – few, if any,	<ul style="list-style-type: none"> - Dependent on charity

coping strategies available	- Break up of household - Distress migration
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Source: Donahue 1998 (slightly adapted)

Household coping strategies, in both rural and urban areas, tend to be short term, even when such measures compromise the long-term survival of the household (Baylies 1996; Donahue 1998; Nampanya-Serpell 1998; Waller 1997). Those used in Stage I, such as reducing consumption and expenditure, are usually reversible and have little impact on the future income-earning potential of the household.

Whether the household avoids Stages II and III depends on its ability to reduce risk. Poorer families, being more sensitive to risk, typically resort to activities that are perceived to be low risk and, thus, offer only a low return. Such a family, therefore, finds it harder to insure against the losses associated with HIV/AIDS, such as loss of adult labour and associated income, and the high costs of medicines and funerals. Poorer families may thus be forced into Stage II strategies, where they dispose of productive assets and reduce consumption and expenditure to dangerous levels. This undermines the ability of the household to produce food or to generate income in the future. Finally, the household may slide into Stage III, destitution.¹³ At this stage the household may disintegrate entirely, with members dispersing. The household is then 'lost' to surveys and other information tracking systems.

Economic problems are a significant cause of mental stress within households and as a result children may be more exposed to harsh treatment and abuse (Mutangadura and Webb 1999). In many societies, when households are no longer able to respond to economic disaster unaided, they traditionally call on family, friends and neighbours for short-term assistance, and in this way the community provides a safety net (Donahue 1998). However, due to the long period of illness and the escalating number of adult deaths, the HIV/AIDS epidemic can be seen as an unprecedented 'long wave' disaster¹⁴ (Barnett and Blaikie 1992), meaning that communities have little previous experience on which to base their responses.¹⁵

Although many households will manage with the economic impacts of HIV/AIDS, others will not. We need to know what set of circumstances can render a household unable to cope, and how children are affected by this failure. This can only be discovered through intra-household research that

¹³ Information for this paragraph is taken from Donahue, J., *Community-based Economic Support for Households Affected by HIV/AIDS, 1998*.

¹⁴ The length of the disaster wave is explained as the period between the onset of the HIV/AIDS epidemic (people become infected with HIV) and the mobilisation of coping responses based on the visible consequences of the epidemic (the symptoms of AIDS). This period is typically five years for an adult, but less in children (Barnett and Blaikie 1992, p. 57).

¹⁵ See Section 4.1 for a discussion of community-based responses to HIV/AIDS and Chapter 8 for a summary of further research needs.

directly addresses the situation of children, as well as inter-household research, which commonly relies on information provided by the household head.

2.3.2 Education and the impacts of HIV/AIDS

Adult illness and death has a major effect on access to education and training for children in affected households. This section examines some of the evidence that children affected by HIV/AIDS have reduced educational opportunities. The evidence to date suggests that school enrolment, school (especially secondary) drop-out rates and performance are all affected (see Box 2.3).

Box 2.3 How does HIV/AIDS affect educational opportunities for children?

- in schools, discrimination against affected children by pupils and teachers
- reduced ability of families to pay for school fees, shoes, uniforms, books, etc.
- increased demand for children's labour at home or in the workplace
- need for children, particularly older ones, to care for sick relatives
- lower expected return on the investment in children's schooling¹⁶
- rising mortality among teachers and trainers.

(World Bank 1997; Ali 1998 (on Malawi); Baggaley et al. 1999 (on Zambia); McKerrow 1996 (on Zambia); Sengendo and Nambi 1997 (on Uganda); Muller et al. 1999 (on Uganda); Urassa et al. 1997 (on Tanzania).

Other factors may include sibling dispersal after the death of a parent and poor treatment by guardians at home, such as regular beatings and inadequate meals (Baggaley et al. 1999).

At national level, differences of up to 20 per cent in enrolment rates between orphaned and non-orphaned children have been recorded in countries severely affected by HIV/AIDS (World Bank 1997). However, in countries where enrolment rates are high for all children (such as Zimbabwe), little difference has been found in enrolment rates between orphans and non-orphaned children. Where enrolment rates are low for both orphans and non-orphans, such as in Tanzania and Zambia, where roughly half of school age children do not attend school, AIDS may have a more visible effect on drop-out rates and secondary school enrolment rates, rather than primary school enrolment rates (Urassa et al. 1997). Because of the need to care for sick parents, the schooling of older children may be more likely to be disrupted (Sengendo and Nambi 1997). There are some dramatic examples of AIDS impacting on education access – a study in Kenya found that 52 per cent of

¹⁶ Education becomes relatively more 'expensive' as the value of the child's labour increases at home.

orphans in four sample communities were not attending school compared with 2 per cent of non-orphans (Elmore-Meegan, Conroy and Tomkins 1999).

Some of the key factors affecting a child's access to education are explored below.

Economic situation of household

Once again, a key factor is poverty. The research shows that children's education is at considerable risk where HIV/AIDS impacts on already poor households. A study in Kenya found that 67 per cent of a sample of orphans had stopped schooling due to lack of money. According to teachers in the survey areas, most of the pupils drop out of school two or three years after their parents die, and this may be linked to the need to acquire new uniforms. Despite this, their caretakers still considered education to be very important regarding the long-term needs of the orphans and would go to great lengths to avoid withdrawing children from school (Saoke and Mutemi 1994). A study in Kampala, Uganda, in 1997 found that nearly 70 per cent of a sample of households caring for orphans did not have enough money for school fees, compared with 26 per cent of households without orphans (Muller et al. 1999). Children in AIDS-affected households in Zambia reported that the biggest problem they faced as a result of having sick parents or becoming orphaned was being 'chased' from school because they did not have the money for school fees or uniforms (Poulter 1997).

Gender

Another key factor is gender. When household income declines, the education of girls is generally considered more dispensable than that of boys (Nampanya-Serpell 1998). In Kenya a study of orphans discovered that 56 per cent of girls compared with 46 per cent of boys dropped out of school within the 12 months following a parent's death (Elmore-Meegan, Conroy and Tomkins 1999). Although there is much anecdotal evidence that the education of girls is affected to a greater extent than that of boys due to the gendered role of caring for the sick, there is little formal evidence of this. This is an area that needs further research.

Evidence suggests that the sex of the head of household is an important factor. Research in Uganda found some difference in schooling between orphans and non-orphans living within the same household. This difference was found to be greatest in male-headed, rural households, suggesting that an orphan's educational access is more assured when the household is headed by a woman (Aspaas 1997). This difference was most noticeable in rural areas.

Location of household

Orphans in rural areas may be especially discriminated against. A study in Zambia found that in urban areas 32 per cent of orphans did not attend

school compared with 25 per cent of non-orphans, but that in rural areas a staggering 68 per cent of orphans did not attend compared with 48 per cent of non-orphans (UNICEF and UNAIDS 1999). This may be due to the burden on rural children of supporting production and subsistence farming in the absence of healthy adults (McKerrow 1996). In Kenya, adult care-givers rely on the work of children at weekends, and in the early mornings and evenings on school days (Ayieko 1999).

Age differences

The age of both affected children and their carers would also seem to influence the way in which HIV/AIDS impacts on school attendance. In Uganda, there is relatively more disruption of schooling amongst older children, linked to the need to care for ill parents. A study in Rakai district showed that 16 per cent of children aged between 15 and 19 combined school with caring for a sick relative. On the death of the parent, 16 per cent of children in the same age group lost school time and 29 per cent left school altogether. Children fostered by grandparents before or after the death of parents had the least chance of an undisrupted education (Sengendo and Nambi 1997).

It is likely that orphan status affects not only the attendance but also the *performance* of children at school. In Zimbabwe, it was reported that teachers could identify orphans by their appearance, behaviour and lack of school fees (Foster et al. 1998). Research with primary school teachers in Lusaka, Zambia, discovered that orphans had problems with concentration and many of the teachers cited hunger and beatings at home as principal causes (Baggaley et al. 1999). In Kenya school performance has suffered due to low class attendance, lack of school materials, poor diet and appalling living conditions at home (Ayieko 1999).

Grief and depression associated with sickness and death in the family, as well as discrimination and stigmatisation that AIDS orphans routinely experience at school, are also likely to influence both attendance and performance. A study in India (in Tamil Nadu and Maharashtra) found that discontinuation of education is one of the first impacts of HIV/AIDS on affected children, particularly children from nuclear families. Children whose parents are infected face stigmatisation and discrimination in schools and some schools were asking these children to leave (Rajkumar 2000).

Decline in the number of teachers and quality of education

HIV/AIDS impacts not only on the 'demand' for education, but also on the supply. A World Bank study in Tanzania projected that 14,460 teachers would die from AIDS by 2010, costing US\$21 million in training for replacements (World Bank 1996). Furthermore, policies intended to support children affected by HIV/AIDS, such as Uganda's introduction of free primary education for all children, have overstretched the education system and dramatically reduced the quality of education available to all children. In addition, anecdotal reports suggest that parents may be claiming that

children are orphans when they are not, to qualify them for free education, subtly discriminating against genuine orphans.¹⁷ Long-term consequences of policies to support children need to be thought through before changes are implemented.

Increased vulnerability to HIV/AIDS infection

Children who drop out of school may be more vulnerable to HIV infection. A study in Uganda found evidence of earlier sexual activity and a larger number of partners among young people who had dropped out of school (Baragukayo-Bagarukayo et al. 1993). In Delhi and Rajasthan in India both girls and boys who dropped out of school initiated sexual activity and alcohol use earlier than those children still at school (Rajkumar 2000).

Even when HIV/AIDS-affected households are poor, adults will still make significant sacrifices to keep children in school (Williamson 1995). A survey in Zambia found that over half of households had reduced their food intake and nearly a third had begged from friends, but only four per cent had removed children from school (Hunter and Donahue 1997). The strong desire to keep children in school is also shown by the spontaneous setting up of community schools (Donahue 1998; UNICEF and UNAIDS 1999).

Non-formal and vocational education

HIV/AIDS also impacts on areas of non-formal education, but these impacts are not as well understood. Knowledge, practices and skills passed down to children by family, as well as by elders and other members of their communities, form a valuable part of a child's education, particularly production methods and survival techniques. When children are sent away or forced to leave home on the death of a parent, this can cut them off from their traditional forms of learning and isolate them from their customs and traditions. The learning of practical and marketable skills may be especially important for children affected by HIV/AIDS as they are likely to have to survive on their own early in life (Barnett and Blaikie 1992). Out-of-school education, such as that conducted in youth groups or through clubs and associations for young people, may also be affected by HIV/AIDS for many of the same reasons that impact on formal educational opportunities. A study of over 1,000 orphans in two rural districts of Kenya found that a number of orphans terminated their membership of youth clubs soon after the death of parents due to lack of guidance and the cost of membership (Ayieko 1999⁷). These organisations provide opportunities not only for education but also, importantly, for socialising and emotional support among peers.

In conclusion, access to formal and non-formal education and training for children living in AIDS-affected households and communities is compromised by HIV/AIDS for a number of reasons, including stigmatisation and

¹⁷ Personal communication, SC UK Uganda office. No formal research has validated this, but most commentators agree that quality has declined since the introduction of Universal Primary Education. Reports of over 200 children in one class are common. The current policy states that all orphans and the first four children in a household have free access to primary education.

discrimination, and the economic impact of HIV on the household. It is possible that the capacity of affected children to benefit from their education is also at risk due to the material (mainly abuse and hunger) and psychological impacts of HIV/AIDS that impair school attendance and performance. This is an area that needs further investigation. Orphans may not always be at a specific disadvantage compared to non-orphans and the ways in which HIV/AIDS impacts on children's education depends to a large extent on the social, cultural and economic context in which they live. For example, in Uganda anecdotal evidence suggests that guardians of orphans often want the child to be tested for HIV before they will pay school costs. HIV/AIDS accentuates problems commonly associated with poverty and affected children living in poorer households face significant difficulties in accessing education and training. Research is urgently needed that shows to what extent, and why, girls are more disadvantaged than boys in terms of both starting and continuing with their education. Possible programme responses to mitigate the impacts of HIV/AIDS on the educational opportunities for children are considered in Section 4.2.1.

2.3.3 The impacts on health and nutrition

The HIV epidemic affects both the supply of health care and the demand for services. In Zimbabwe, government projections are that HIV/AIDS will consume 60 per cent of the health budget by 2005 (UNICEF 1999b). The epidemic is also seriously reducing the number of available, qualified health professionals (World Bank 1996).

The greatest impact will be on those who cannot afford to pay for, or cannot access, private health care, such as poor families. Children in poor HIV-affected families are less likely to be fully immunised or able to visit health clinics (Mulenga et al. 1993). The reasons are familiar: if the adults in a household are sick and household income is declining, the available funds will be diverted towards medical treatment for the adults – children will often be neglected. In Tanzania, household medical expenses were found to be much higher for AIDS than for other causes of death (World Bank 1997).

Where adults are sick, or where children or elderly relatives are the primary carers, children who need medical treatment may not be taken to health centres for a variety of reasons including reduced adult attention and lack of transport. The guardians of children whose parents have died of AIDS may not take the children to health centres because symptoms of normal childhood illnesses are mistaken for the onset of AIDS and it is therefore assumed that the child is bound to die anyway (UNICEF 1999b; Brown and Sittitrai 1995).

Children in AIDS-affected households, particularly younger ones in rural areas, also face increased health risks. They may be more exposed to infections commonly associated with HIV such as tuberculosis, pneumonia, diarrhoeal diseases and respiratory infections (Nampanya-Serpell 1998).

Children who are HIV-positive or are associated with an HIV-positive adult may be discriminated against both in private clinics and public hospitals (Brown and Sittitrai 1995). This discrimination has been recorded in Thailand. In India, discrimination against people living with AIDS – including denial of treatment – is common, despite being illegal.¹⁸

The indirect consequences of adult illness and death can often increase children's vulnerability to HIV infection, for example:

- starting sexual activity early
- child abuse (especially orphans and street or working children)
- sexual abuse of young girls (because they are thought less likely to be infected).

This is compounded by a lack of 'youth-friendly' reproductive and sexual health services and information.

HIV/AIDS restricts the supply of both public and private health care for the following reasons:

- the high cost to governments of providing care for the increasing numbers of people living with AIDS
- the growing numbers of health professionals living with HIV who will eventually develop AIDS
- practices that discriminate against HIV-affected children and adults.

The high cost of medical care for HIV-positive adults, the reduction in adult attention to children living in HIV-affected households, and the inability of previously productive adults to earn income all mean that children living in HIV-affected households may not receive the medical care or the food they need.

HIV/AIDS and malnutrition

Childhood malnutrition is potentially one of the most severe and lasting consequences of a prime-age adult death. (World Bank 1997)

Children in AIDS-affected households are often inadequately nourished, for the following reasons:

- a decline in household income and hence expenditure on food, particularly protein
- changing patterns of food production, particularly in rural areas
- reduction in adult ability to nurture a child.

Box 2.4 summarises some of the evidence linking HIV/AIDS to malnutrition.

¹⁸ Mandeep Dhaliwal, Sea-AIDS network, *PRE-JCAAP 7: Health Care Discrimination in India*, July 1999.

Box 2.4 Malnutrition in HIV/AIDS-affected households with children

- malnutrition is widespread among orphans, but also among non-orphans in AIDS-affected households
- age is important: younger orphans suffer more from malnutrition, and very young orphans suffer the most
- socio-economic status does not appear to affect the level of malnutrition in orphans
- patterns of malnutrition and other indicators of health status are different among children in rural and urban areas, with younger children in rural areas suffering the most frequent ill health
- in households of young orphans, the age and gender of the oldest child is important. While boys are more prone to begging and malnutrition, girls as young as 12 often take responsibility for meals and even limited cultivation.

(Barnett and Blaikie 1992; World Bank 1997 (Kagera, Tanzania); Poulter 1997; Nampanya-Serpell 1998; Webb and Nkamba 1997 (Zambia).

Children affected by HIV/AIDS seem to suffer more from malnutrition than unaffected children, even in households with a relatively high socio-economic status. A study in Kenya found that nearly 30 per cent of orphans were below the recommended weight for height ratio, compared with only 12 per cent of children in the control group (Conroy et al. 2000). It has been suggested that the death of the parent or primary care-giver may cause grief and depression in the surviving adults, impairing their ability to work, obtain food and provide adequate meals (Nampanya-Serpell 1998). A study in Zambia also discovered that children not living with their biological parents were often punished disproportionately for misdemeanours: for example, they were deprived of food or sleep, or given extra work (Haworth and Mayeya 1999).

In rural communities, the loss of labour caused by sickness, death and the need to care for others can have serious effects on agriculture (Baylies 1996). These may include a concentration on staple foods such as maize, selling livestock, reducing the size of fields, growing crops for consumption rather than for sale, and letting the land lie fallow (de Guerny 1998). In Uganda affected households formerly reliant on subsistence agriculture switched to income generation, mainly through brewing (Monk 2000). The consequences for children may include an overall reduction in food, less dietary protein, and less variety in their diet at a time when they are doing more physical labour and, therefore, need a higher calorie intake.

There is a lack of data showing how food is allocated among the members of HIV/AIDS-affected households. Is age a significant factor in food distribution? Do girls receive less food than their male siblings, and if so, why? Evidence of how effectively project food aid is targeted is also lacking due to inadequate monitoring or consistency in targeting approaches (ODI 2000; Webb and Paquette 2000).

2.3.4 Impacts on children's emotional health

Caring for sick parents and siblings places a heavy emotional burden on children. They not only witness the illness and death of close relatives, but also suffer the stigmatisation and social isolation that often accompany the disease. Children display a wide range of psychological reactions to these pressures, and it is therefore necessary to consider each child's individual situation when determining an appropriate response.

A review of the available information on these impacts (much of it anecdotal) is summarised in Box 2.5 below.

Box 2.5 The impacts of HIV/AIDS on the emotional health of children

Summary of the key points of research evidence:

- this is a subject that is inadequately understood, particularly where children living in poor communities are concerned
- although prolonged sickness of parents is associated with higher than usual levels of stress and unhappiness in children, orphanhood is associated with even higher levels
- HIV/AIDS attracts stigmatisation and discrimination in almost all societies
- the emotional needs of children vary according to the age of the child, and also to the age of the orphan when the parent(s) died
- children who have lost their mothers have been found to be more depressed than children who have lost their fathers
- the psychosocial impacts of HIV/AIDS are closely linked with other factors such as declining household income, hunger and poor health status
- psychosocial impacts of parental AIDS death on children are remarkably similar across different contexts.

(Ali 1998; Ledward 1997; Nampanya-Serpell 1998; Poulter 1997; Sengendo and Nambi 1997; UNICEF/CEDC 1998b; Devine and Graham, 1999; authors).

The emotional needs of affected children are less well understood than their material needs. Adult care-givers often fail to identify psychological difficulties as the cause of more visible problems such as truancy or anti-social behaviour. In community-based orphan support programmes, volunteers often assess children's needs in terms of material goods, neglecting their psychosocial needs (Lee 2000). When emotional problems are identified few people in positions of responsibility for children, such as teachers and guardians, are equipped to handle them.

Discrimination and stigma

One can be 'contaminated' just by being near somebody with HIV or AIDS: the stigma is transmitted by casual contact, even if the disease isn't. Thus, children whose parents have HIV or AIDS are 'contaminated' by association. (Brown and Sittitrai 1995)

In most cultures, children who are either HIV-positive themselves, or are associated with an adult who is HIV-positive or who died of AIDS, routinely face discrimination from their peers, their guardians and teachers, and from the community in general. They may be barred from school, harassed by peers and even prevented from joining in village activities (Brown and Sittitrai 1995).

Children involved in a community-based orphan support project in Zimbabwe made the following comments¹⁹ (Lee 2000).

At school, those with parents play on their own – they know we don't have parents because the teacher asks us in class.

Even if we do good, no one notices because we don't have parents.

With the exception of emotional problems arising directly from the stigma and social discrimination of HIV/AIDS, it is difficult to differentiate between the emotional needs of children that are a direct consequence of the AIDS epidemic and emotional needs arising out of everyday problems associated with poverty. There are, however, a number of important differences. A major difference is that of the *scale* of the crises experienced by children; the unprecedented number of adult deaths, together with social events associated with sickness and dying, that is likely to give rise to acute emotional problems in children.

Rituals connected with death, such as funerals and prescribed periods of mourning, can help children to come to terms with their loss (Doka 1994); in Africa, they are also the moment when relatives discuss the orphaned children's future care. But in communities severely affected by the epidemic, funerals and periods of mourning are being reduced or abandoned due to the sheer scale of adult deaths in affected communities (Ankrah 1993; Barnett and Blaikie 1992; Mutangadura and Webb 1999).

It has been suggested that some children who have witnessed cumulative suffering and deaths from AIDS among family members may develop a post-traumatic syndrome more usually associated with young survivors of war or natural disasters (Martin 1998). However, the usefulness of the concept of 'trauma' in addressing the needs of children has been questioned since it raises the issue of the difference between normal distress following adverse circumstances and mental illness. Although much of the literature concerns children who have survived conflict, the conclusions are equally applicable to children living in communities severely affected by HIV/AIDS:

¹⁹ See case study in Box 4.7.

Most children [in conflict zones] are showing a normal response to extreme circumstances, and require support rather than psychological treatment.
(Pereira and Richman 1996)

In many parts of Africa, when parents die, children are not encouraged to talk about them after the prescribed period of mourning, despite the fact that the full impact of a parent's death is rarely felt immediately. Suppression of emotions can lead to anxiety and depression in children. In many cultures where it is customary not to tell younger children of their parent's death in the belief that this protects them, the discovery of this fact years later, often through teasing from peers, has devastating effects (Ali 1998).

The slow, progressive and usually unpredictable nature of illnesses associated with HIV is another source of stress in children (Bor and du Plessis 1998). A study in Zambia found that children of HIV patients were significantly more likely to be unhappy, solitary and fearful of new situations than the children in a control group (Poulter 1997).

If children associate HIV infection with immoral behaviour, they may find it distressing to discover their parents are HIV-positive. However, skilled counselling and carefully planned disclosure can minimise their distress.

As already mentioned, children experience the trauma associated with HIV/AIDS in different ways; for example, there is some suggestion that, in patrilineal groups, social isolation is more common on the death of the father. In such cases, children often suffer the additional trauma of being forcibly separated from their mothers, who are sent away by the father's family. In matrilineal societies, in contrast, adults and children often make special efforts to include orphaned children (Chancellor College, reported in UNICEF/CECD 1998b).

Studies of orphans show that, while younger children are more likely to be withdrawn and shy, older children sometimes experience behavioural problems, such as truancy. Guardians have reported problems with disciplining children who are not their biological children (Ali 1998). Sibling dispersal has also been found to have a negative effect on the emotional health of orphans, particularly in urban areas (Nampanya-Serpell 1998).

Within the household, discrimination against affected children may cause further emotional problems. A study in Uganda found that children often leave home at a young age because they are continually disadvantaged in the distribution of material resources and psychological support (Dunn et al. 1992). As domestic labour requirements increase for children, girls tend to take on more additional tasks in the household than boys (Ledward 1997); this is likely to cause resentment and to affect educational opportunities for girls.

Research in Zimbabwe has shown that orphans tend to stay away from school in order to gain economic independence through employment, and are said to feel fewer family obligations (Ledward 1997). This indifference to

traditional obligations may be related to poor communication between extended family adults, step-parents and orphans, which in turn may lead to withdrawal and unhappiness in orphans.

In conclusion, the epidemic impacts on children's emotional health in the following ways:

- the stigmatisation and discrimination they experience
- the high incidence of illness and death in the child's family and community
- the long periods spent caring for ill parents and relatives
- the subsequent bereavement.

Approaches to addressing the psychosocial impacts of HIV/AIDS on children are discussed in Section 4.2.5.

2.3.5 The impacts on child welfare and protection

The family, extended or nuclear, is a child's principal support unit, responsible for his or her welfare and development until they are judged to be old enough to cope alone. A major part of this role is to protect the child from danger, abuse, destitution, etc., and to represent his or her interests to others. The death of the parent(s) and other adults in the family often removes this protection, or transfers it to another, possibly less capable adult.

The most devastating impact of HIV/AIDS on children is when their immediate family environment and support system is challenged by the sickness, disability, and premature death from AIDS of one or both parents (Tarantola and Gruskin 1998).

In sub-Saharan Africa, the high rates of adult mortality associated with HIV/AIDS, and the resulting increase in numbers of orphans, have put unprecedented pressure on the extended family. This has led to new household coping strategies and changes in household structures, as summarised in Box 2.6.

Box 2.6 Changing family structures in response to HIV/AIDS

- the emergence of child-headed or adolescent-headed households
- an increase in grandparent carers and elderly carers
- changing cultural patterns of child care
- household restructuring and mortality-related migration
- a high rate of sibling dispersal
- possible changes in household dependency ratios
- higher rate of complete family breakdown
- higher rate of child abandonment
- higher rate of remarriage

- more young couples taking on child dependants, affecting their willingness to have children of their own.

It has been suggested that the capacity of the extended family to cope with the growing numbers of orphans may be nearing exhaustion in some severely affected communities. However, there will always be families that cope and families that do not cope. Indeed, the traditional practice in many parts of Africa of fostering children within the extended family may mean that the impact of orphanhood will be less than predicted in the region.

A study in Zambia found that some people even expressed optimism about being able to cope with orphans, suggesting that they might provide an extra pair of hands (Baylies 1996). Willingness to foster children often depends on whether they are viewed as consumers or producers within the household. For example, older boys are more likely to be fostered, as they are perceived to add to the productive capacity of the household (Caldwell 1997).

The following box summarises evidence from available research, largely in sub-Saharan Africa.

Box 2.7 Who looks after the orphans?

- guardians are more likely to be women
- while the mother is alive, she is most likely to be the care-giver
- on the death of the mother, other female relatives are more likely to look after the children, even where the father is still alive
- grandparent carers and elderly carers are increasingly common, particularly in rural areas, and in some studies account for up to 80 per cent of care-givers
- children are increasingly looking after their younger siblings
- orphanages may look after children who have no supporting relatives but this is increasingly seen as a solution of last resort
- in a small, but growing, number of cases, children are simply abandoned: for example, put on buses to find (sometimes imaginary) relatives in the city.

UNICEF and UNAIDS 1999; Foster et al. 1996 and 1997; Foster 1997a)

Some of the principal changes in household composition due to HIV/AIDS are explored briefly below.

Child-headed and adolescent-headed households

The emergence since the late 1980s of child-headed households (CHHs) in certain sub-Saharan African countries has been linked to the HIV/AIDS epidemic (Foster et al. 1997; Foster 1997a). CHHs are more likely to be the result of a maternal rather than a paternal death, since in AIDS-affected communities, the father is likely either to have predeceased his wife or to have abandoned the household on the death of his wife.

The death of a child's parents from AIDS considerably reduces his or her chances of finding shelter with people who are not family members. A South African study found that, although 74 per cent of close relatives are prepared to look after a child orphaned through AIDS, only 42 per cent were willing to do so if the child was a stranger (McKerrow and Verbeek 1995).

A summary of research on possible reasons for the emergence of child-headed households follows in Box 2.8.

Box 2.8 Possible reasons for the emergence of child-headed households

- there are no relatives to look after the children
- relatives are refusing to look after the orphans because:
 - stigma is attached to those whose parents have died of AIDS
 - it is breaking up marriages
 - resources are already insufficient
 - because they were on bad terms with the deceased
- it is the preferred option of the children themselves
- it makes it easier to maintain property and other assets in the family
- siblings will be able to remain together
- orphans were mistreated in the guardian's household and thus moved out to live alone.

(Ali 1998 (Malawi); Foster 1997a; Foster et al. 1997 (Zimbabwe); Barnett and Blaikie 1992 (Uganda); Nampanya-Serpell 1998; Webb and Nkamba 1997 (Zambia))

Although the children themselves may prefer to live in a child-headed household, members of such households typically suffer from a lack of supervision and care, poor nutrition, declining health status, educational failure, exploitation and abuse by adults, early or delayed marriage, discrimination, and disruption of childhood and adolescence (Foster et al. 1997).

Elderly carers

A study in Zimbabwe found that nearly half the care-givers of paternal or maternal orphans were grandparents, their average age being 62 (Foster 1997b), and in Tanzania and Zambia an estimated 80 per cent of foster parents are grandmothers (Caldwell 1997).

The specific demography of a country may influence the nature of the response. In Cambodia, the most seriously affected country in south-east Asia, the genocide of one-third of the population by the Khmer Rouge has meant that, proportionally speaking, there are fewer than half as many grandparents (especially grandfathers) as in neighbouring countries. Hence there are potentially fewer carers for orphans, implying an increased burden on other extended family members such as uncles and aunts. The result is

likely to be more child-headed or adolescent-headed households and abandoned children.

Research in Uganda found that behavioural problems were common in grandparent-headed households. Children being cared for by grandparents in their fifties and sixties were vulnerable to malnutrition and infectious diseases because food production was low and medical care could not be afforded. Where there is a single female grandparent carer, particularly in the rural areas, the situation is even worse, as women generally have lower incomes and depend heavily on friendship-based goodwill (Barnett and Blaikie 1992).

Children are likely to experience further trauma when their elderly carers eventually die. In an extended family, grandparents expect to be looked after by the younger members, and the inversion of this tradition puts severe strain on the household economy as well as on family relationships (Brown and Sittitrai 1995). Elderly guardians are forced to be economically active for longer, which affects their health and hence their ability to care for young children.

Changes in traditional kinship practices

The AIDS epidemic is also disrupting traditional patterns of child support. Research in Zimbabwe and Malawi found that, even in patrilineal societies, the maternal side of the family is now more likely to be looking after orphaned children (Foster et al. 1998; Chancellor College 1998 quoted in UNICEF/CEDC 1998b). In Zimbabwe, members of the paternal side of the family are increasingly refusing to take in orphaned children, and a growing number of fathers are abandoning their children after the death of the mother.

It should, however, be noted that, even in supposedly 'traditional' societies, custom does not invariably prevail over individual, household and familial choice (Barnett and Blaikie 1992). Abnormal circumstances, such as the HIV/AIDS epidemic, for which there is no collective experience on which to base a response, will make people even less likely to adhere to custom.

Intra-household migration

Households affected by high adult mortality may change their composition in order to replace lost labour and maintain a relatively stable dependency ratio. A study in Tanzania found that, over six-month periods, adults left or joined about 20 per cent of unaffected households, but about 40 per cent of affected households (World Bank 1997). These households tend to gain older adults and lose younger adults, adolescents and children.

Sibling dispersal

There is as yet no clear evidence of sibling dispersal as a consequence of adult mortality. Studies in Tanzania and Zambia have found little difference in mobility between orphans and non-orphans (Urassa et al. 1997; Poulter 1997). Recent studies have suggested that sibling dispersal after the death of a parent only occurs after considerable family debate, with the decision

based on a combination of traditional obligations and perceptions of relative economic status (Mutangadura and Webb ~~2000~~-1999). However, a study in Zambia found that although families often wish to keep siblings together after the death of a parent, practical considerations often force them to be separated (McKerrow 1996).

Orphan siblings who are separated will experience more emotional problems than those who are kept together in the original household (Nampanya-Serpell 1998). These problems may arise from discrimination in the new household, difficult relationships with step-parents or guardians or the loss of emotional ties with siblings. The death of a parent followed by loss of contact with siblings can be traumatic for a child, especially when the reasons are not explained.

Household dependency ratios

It is often assumed that the AIDS epidemic leads to more dependent children or elderly people in households, and fewer economically active adults to support them. This is likely to have an adverse effect on children, particularly in poorer households.

However, the evidence is mixed. Studies in severely affected districts of Tanzania and Uganda found only small increases in household dependency ratios (Urassa et al. 1997; World Bank 1997). There is some evidence that terminally ill adults and widows return to their rural villages, and that the latter often take their very young children with them (Webb 1996a). Research in Tanzania discovered that households with orphans tended to be larger than other households (7.9 and 6.3 people respectively) and have more children (4.4 and 3.5 respectively), although both had an average of 1.2 children under five (World Bank 1997). This suggests that households are able to adjust their size and dependency ratio, even in the face of high adult mortality.

Protection of inheritance

In the absence of clear legal protection for inheritance rights, reinforced through local structures, children whose parents have died of AIDS are at risk of losing their homes and being separated from their possessions. In many cultures in Africa and Asia, women and children have no legal entitlement to property on the death of the father. Property traditionally passes to – or may be seized by – the husband's relatives on his death, even where the law of the country states that the wife and/or children should inherit.

Such uncertainties can be exploited to the disadvantage of women and children in particular – those who are least able to protect themselves through the courts. (Barnett and Blaikie 1992)

A study in Zimbabwe found that, although a dying man's wishes were generally respected for fear of upsetting his spirit, relatives rarely made plans for distributing his property after his death, as they might be accused of showing too great an interest in the property. More generally, discussion

of death is taboo, as it can lead to accusations of malevolence and 'wishing' death upon someone (Foster et al. 1998).

There is to date, however, little evidence of women and children actually being evicted from their homes on the death of the husband (Barnett and Blaikie 1992). Research in Zimbabwe found that 76 per cent of orphans had inherited their parents' property, although only [seven.7](#) per cent had made any form of will (Drew, Foster and Chitima 1996).

Child abandonment, street and working children

The AIDS epidemic is thought to be responsible for an increase in family breakdown and a consequent rise in the number of street and working children. These children routinely suffer from exhaustion, deprivation, hunger, social isolation and a lack of emotional support (Elliott 1999, Marcus and Harper 1997). They are particularly vulnerable to HIV infection through sexual abuse and drug use. Girls are particularly vulnerable since sexual abuse is often followed by commercial sex work. There is an almost total lack of youth-friendly sexual and reproductive health services, which might provide some support and protection for these children.

Crime

The potential link between the impacts of HIV/AIDS on children – particularly the removal of protection – and rising crime rates have not yet been fully explored, but there are warning signs. For example, the expected boom in the orphan population of South Africa will coincide with a situation in which one in four South Africans is between 15 and 24 – the peak age for committing crime.

Large numbers of juveniles in the general population, and a high proportion of children brought up without adequate parental supervision, are beyond the control of the state . . . No amount of state spending on the criminal justice system will be able to counter this harsh reality.²⁰

The rising numbers of street children may also resort to crime in order to survive. In addition, the high incidence of abuse in prisons and secure units for children places them at great risk from HIV infection.

2.3.6 Gender²¹ and the impacts of HIV on children

The HIV/AIDS epidemic tends to exacerbate existing gender inequalities, and this in turn affects the welfare of children. Box 2.9 summarises some of the consequences that arise from the interaction between HIV/AIDS and the existing gender norms and relations.

²⁰ Martin Schonteich, reported in the *Village Voice* at www.villagevoice.com, November 1999

²¹ The term 'gender' is used to describe socially constructed behaviours for males and females that begin in early childhood when families, cultures and societal norms define what is considered to be appropriate masculine and feminine behaviour. It is not an alternative term for 'sex', which relates to the biological characteristics of men and women, girls and boys.

Box 2.9 Impacts of HIV on gender relations and norms

- increased burden on women and young girls of caring for the sick and the growing numbers of orphans
- increased burden of care on women and young people as a result of existing programmes that emphasise home-based care
- increase in female-headed households, which tend to be poorer than male-headed households
- where household income is declining, the education of girls is regarded as less important than that of boys
- earlier marriage for girls and early sexual relations among affected children
- sexual and other physical abuse associated with HIV, particularly of younger girls
- men tend to abandon an HIV-positive partner, whereas women experience anger, then ultimately accept an HIV-positive partner.

(Barnett and Blaikie 1992; Baylies 1996; Mutangadura and Webb 1999, Nampanya-Serpell 1998; Tarantola and Gruskin 1998; Waller 1997; authors).

In general, women shoulder the greater burden of caring for children and the sick – and HIV/AIDS has intensified this imbalance by increasing women's burden of care. A study in Zambia found that: over 60 per cent of the carers were female and only 18 per cent male; half the carers were widowed, and of these 90 per cent were women; and a lone carer was most likely to be the mother (41.3 per cent) or the grandmother (27.4 per cent) (Webb and Nkamba 1997).

The high proportion of widows and lone female carers indicates not only that men tend to die before their wives in HIV-affected communities, but also that men are much more likely than women to remarry if their spouse dies. A Tanzanian study found that women headed nearly 40 per cent of orphan households, compared with 15 per cent of non-orphan households (Urassa et al. 1997). Thus, HIV/AIDS is contributing to a rise in female-headed households, which are generally more impoverished than male-headed households, especially in rural areas. The economic impact of the illness and death of the head of the household from AIDS, however, is greater on male-headed households than on female-headed households (Mutangadura and Webb 1999).

Ironically, home-based care programmes for people living with AIDS may be increasing the burden on women, since it is they who mostly shoulder such care. When women themselves fall ill, they typically receive less care than their husbands and male relatives (Waller 1997).

This extra burden of caring for sick people and orphans is in addition to women's other roles. When the husband dies, women often have to take responsibility for agricultural production. This is particularly onerous for them, as women generally have less entitlement to other people's labour than men (Barnett and Blaikie 1992). A study in Zambia found that women's responsibilities were increasing due to the extra caring burden, but that they received limited help from men (Waller 1997).

What effect will these increased burdens on women and the growing number of impoverished female-headed households have on children's welfare? Children in female-headed households typically have less access to education and healthcare, and are more likely to be malnourished, than children living with their fathers (UNICEF 1998b). Girl children will be expected to take on a greater proportion of the household tasks than their brothers, often at the expense of their education. In rural areas, women may experience problems with food security because of the difficulties of cultivating land as well as looking after children.

The AIDS epidemic also exacerbates gender imbalances in access to education. In most developing countries, school enrolment, attendance rates and literacy are already lower for girls than for boys (UNICEF 1999c). When children are taken out of school to contribute to labour in the home or the fields, or to care for siblings on the death of a parent, girls are usually withdrawn first (Williamson 1995).

In a crisis, therefore, the education of girls seems to be less valued than that of boys. In a Zambian study more girl orphans were found to have dropped out of school following a parental death than boy orphans in both urban and rural areas²² (Nampanya-Serpell 1998). Not only will the girls themselves suffer through being denied an education, but their future children will also suffer, since better female education is linked with reduced infant and child mortality (World Bank 1993, UNICEF 1999c).

Research in Uganda found a tendency for women, especially young and educated ones, to be blamed for the spread of HIV (Barnett and Blaikie 1992). The fact that these women are educated, and therefore present a challenge to the tradition of female subordination, was held to be 'dangerous' for the rest of the population. Similar tendencies to blame women for infecting men are found in many countries (Sabatier 1988; Panos 2000).

There is some evidence for a link between the AIDS epidemic and a rise in early marriage, early sexual activity and sexual abuse of young girls (UNAIDS/WHO 1999; UNICEF 1999a and b; UNICEF/CEDC 1998a and b; Elliott 1998). This may be connected with the belief in many parts of Africa that young girls are less likely to be infected with HIV and are therefore safer to have sex with. In some areas, traditional healers have perpetuated the myth that sexual intercourse with a young virgin will cure a man infected with HIV (UNICEF 1999b). Research in Uganda found that some men believe

²² This effect was stronger in urban areas, with 24 per cent of girls dropping out compared with 19 per cent of boys. In rural areas, the proportions were 9 per cent and 7 per cent respectively.

that by paying women for sex they will appease one of the lesser gods who will otherwise cause the man to become infected (Barnett and Blaikie 1992). Similar beliefs condoning paid sex, especially with young girls, are also widespread across south and south east Asia (Brown 2000).

Organisations can unwittingly exacerbate gender inequalities by focusing exclusively on women and girls in the name of a 'gender-sensitive' approach. This can alienate men from programme activities and lead to accusations of bias. For example, although women shoulder the burden of care for HIV/AIDS almost exclusively, CAFOD's projects have been perceived by the community as focusing on women and youth to the exclusion of men; and men regarded women who participated in programme activities as rebelling against cultural norms (Welbourn 1998). Clearly, organisations need to undertake gender-sensitive activities (involving men and women, girls and boys) that are also culturally sensitive, and which work to change existing norms that subjugate women.

The implications of gender differentials for the prevention, care and mitigation of HIV/AIDS have not yet been fully researched. However, we know that the epidemic is:

- placing girl children and young women increasingly at risk from HIV infection
- making already poor child health and nutrition even worse by increasing household poverty
- reinforcing a situation where the health and education of boys are given priority over those of girls
- directing already scarce resources away from children through greatly increasing the burdens on women.

The picture regarding the various impacts of HIV/AIDS on children is changing all the time but what is becoming apparent is the need to develop theoretical and programming frameworks to help organise and inform responses. One such approach is the rights based approach, and there is a consensus developing amongst both policy makers and practitioners that the rights based approach to child development is the framework to inform interventions towards children and communities affected by HIV/AIDS. This approach and its implications for programmes are the subjects of the next chapter.

Chapter 3: A rights-based approach to mitigating the impacts of HIV/AIDS on children

When choosing a theoretical framework for designing and evaluating activities to mitigate the impacts of HIV/AIDS on children, we need to take two key points into consideration:

- the impacts of HIV/AIDS on children are diverse, interrelated and complex
- HIV/AIDS intensifies the burden on the poorest households and communities, but it is almost impossible to separate its effects from those of other factors, such as impoverishment or structural adjustment.

Although there are certain broad areas of impact that are particularly relevant to children – such as physical and mental health, development, education and protection – the specific nature of the problems children experience depends upon the situation in which they find themselves.

This does not mean that every situation requires a different solution, but that solutions must be based on participatory needs assessments at local level. The community-based approaches that have evolved in response to the expressed needs of communities show marked similarities, even in different continents. These similarities point the way towards a common strategic approach, based on mobilising and supporting communities and households to cope with the impacts of HIV/AIDS (see Section 4.1).

Problems of defining the impacts of HIV/AIDS have hindered debate about an appropriate framework for programme activities. Up to now, much of the assistance given to mitigate the impacts of HIV/AIDS has been targeted largely at children orphaned by the epidemic. This 'relief-type' approach largely arises from the need to direct scarce resources to those in most need, and to some extent reflects external ideas of what is an appropriate activity.

Any generic approach to HIV/AIDS mitigation runs the risk of being inappropriate in a given local context. This is in contrast to HIV prevention activities where, despite local differences, certain overarching objectives are shared at all project sites.²³ However, some generic approaches might be less prescriptive and more flexible to local needs, for example, an approach based on human rights, and more specifically the UNCRC. This would involve looking at how the impacts of HIV/AIDS on children directly challenge their rights as set out in the UNCRC.

In this chapter we now look at the comparative advantages and disadvantages of the traditional relief-based approach and the rights-based approach.

3.1 The relief approach

²³ See Webb, D. *Principles of good practice in HIV prevention programmes*, unpublished report, SC UK, 1999.

The relief approach involves the targeting of support at specific consequences of HIV/AIDS, such as the increase in numbers of orphans and widows or the lack of access to education. It assumes a vulnerability to such impacts that might be true at provincial, national or even global level, but which is not necessarily true for a local target group or community. When these targets are defined too narrowly – for example, 'AIDS orphans' – other vulnerable people, such as other children affected by HIV/AIDS who are not technically orphans, will be excluded from support (see Section 3.1.1).

Indeed, many programmes assume that, in communities affected by HIV/AIDS, orphans are the most vulnerable group in terms of health, access to health care and education, and the likelihood of being exploited and abused. As one of the most visible consequences of the AIDS epidemic in Africa, orphans are also 'media-friendly' and 'donor-friendly'; organisations have found it relatively easy to fundraise for orphanages, as these are familiar concepts in the west. But as we shall see, orphans are not invariably the most disadvantaged of the children affected by the epidemic (see Section 3.1.1).

In communities where the incidence of AIDS (and therefore orphans) is low but the incidence of HIV is high, people rarely see HIV/AIDS as a priority. Does this therefore remove the justification for targeting specific consequences of the AIDS epidemic? Programme planners face the problem of how to mobilise communities to act before crises begin to materialise, when there is little or no collective experience on which to base their actions. This is particularly true of poor communities, where survival takes precedence over all other problems, including HIV/AIDS.

As we have discussed in Chapter 2, it is difficult, and sometimes impossible, for community members to distinguish the effects of AIDS from those of chronic poverty. But project planners often assume that the community can perceive the impacts of HIV/AIDS clearly, and this can lead to conflict. In South Africa, for instance, one project tried to address the question of AIDS orphans in communities which did not perceive them as a problem; it proved difficult for the needs of children to be given priority over needs considered more immediate, such as housing, roads and water (Harber 1998).

Within the relief approach, a wide range of different emphases is possible. At one extreme, an intervention might be based on external assumptions that have not been tested in the local situation and designed regardless of how the problem is perceived by the target group: for example, a school in the UK might raise funds to build an orphanage in Africa, despite the local belief that caring for orphaned children in the community is the best option. At the other extreme, the validity of the project's assumptions could be rigorously tested at local level before any intervention took place: this would be time-consuming, expensive and probably not provided for in project budgets. The logical conclusion would be that the organisation should be prepared to pull out if its assumptions were shown to be invalid, i.e., who makes the decisions – within and without?

Most projects fall somewhere between these two extremes. Projects that target vulnerable groups can improve the likelihood of achieving their desired outcomes by the use of participatory research to ensure that they are responding to needs articulated by beneficiaries as well as by donors.

However, even if we accept the problems arising from inequitable targeting of funds, we still need strategies that direct available resources more efficiently at the most severely affected communities, and, within them, at the most vulnerable groups, particularly children.

When an epidemic has reached a mature stage²⁴ and the short and medium-term social and economic impacts are apparent, targeting contributes to mitigating the impact of the epidemic and resolving equity/efficiency problems. (Barnett and Whiteside 1999)

One way of identifying target communities *before* the social and economic impacts become apparent is to use the Jaipur Paradigm developed by Barnett and Whiteside.²⁵ This is based on the hypothesis that the shape of the epidemic curve (that is, how many people are infected and how rapidly the infection spreads) is determined by two key variables:

1. the degree of social cohesion in society
2. the overall level of wealth in the community.

Social cohesion refers to the strength of 'civil society': groups outside the household and workplace such as NGOs, community and voluntary organisations, church organisations and parent-teacher associations. A degree of social cohesion may be achieved through an authoritarian political system or through national ideologies. Initially, the epidemic curve is expected to rise quickly in areas with poor social cohesion and slowly in areas with good social cohesion. In areas of poor social cohesion and high wealth, the curve is expected to decline sharply after the initial peak as people begin to cope with the impacts of HIV/AIDS. In areas of poor social cohesion and low wealth, however, the level of infection is expected to remain high.

Areas with poor social cohesion and low wealth could therefore be targeted by strengthening civil society – e.g., through community mobilisation – and maintaining economic stability – e.g., through micro-credit services (see Chapter 4). It has been suggested that the social cohesion created by the efforts of affected communities to cope with the epidemic – as distinct from the nature of the interventions themselves – is one of the main reasons why Uganda has succeeded in slowing the rate of new HIV infections (Barnett and Whiteside 1999).

²⁴ UNAIDS generally defines a 'mature' epidemic as one in which 5 per cent or more of the general population is HIV-positive.

²⁵ All information on the Jaipur Paradigm has been obtained from Barnett, T. and Whiteside, A. (1999) *The Jaipur Paradigm, HIV/AIDS, Society and Economy: Case Studies and a Conceptual Framework* (see bibliography).

3.1.1 Is the specific targeting of orphans justifiable?

Although some targeting is necessary to make efficient use of scarce resources, the targeting of assistance to 'AIDS orphans' presents problems. As we have noted, it may mean that resources are not allocated to those most in need, discriminating against other vulnerable children who are affected by the epidemic but are not officially classified as orphans. Any form of discrimination is in direct contravention of the UNCRC.

The external targeting of orphans may also undermine the ability and willingness of the community to define its problems and seek local and sustainable solutions;

Sometimes a donor can come with their own agenda. You cannot say no to the donor, when they have got money for focusing on one particular thing, e.g., easy money for orphans. (project worker quoted in Welbourn 1998)

The targeting of orphans can also generate expectations within the community about outside assistance:

The problem is that, whatever we try to do, when people think of orphans they think of handouts. (project worker cited in Harber 1998)

It can also lead to the further stigmatisation of children, which hinders their reintegration into the community. A report on research from Uganda stated:

When families know that orphans are receiving assistance, they are likely to continue to label a child in their care as an orphan. The prolonged use of the word will serve constantly to remind children of their bereavement, but more importantly may prevent them from becoming a full member of the new family. (Dunn et al. 1992)

UNICEF defines children affected by HIV/AIDS as:

Children infected with the virus directly; children whose parents, particularly the mother and/or primary breadwinner, are HIV/AIDS affected; children living in affected families and/or those families that have taken in children orphaned or displaced by HIV/AIDS.

But even this broad definition involves some targeting: every child in a community severely affected by HIV/AIDS could be said to be 'affected'. This underlines the need to use definitions of vulnerability generated by the community. These definitions vary widely according to context, as this list (prepared by the Orphans and Vulnerable Children programme of Project Concern International in Zambia) of the factors used by the community to determine vulnerability shows:

- age and sex of orphan
- economic activity of parent lost

- economic activity of surviving parent
- total number of household members
- relationship of orphan to breadwinner
- economic activities of other household members
- relationship of other household members to the breadwinner
- separation from parents' possessions
- separation from other siblings
- frequency of moving.

If it is left to the community to define who the vulnerable children are, their definitions will often include those who are not orphans, such as children caring for sick parents and relatives, children in destitute households and disabled children.

A project in South Africa wished to avoid targeting assistance solely to orphans, and particularly AIDS orphans, because this might stigmatise them. It therefore decided to target other needy children as well, but this in itself created problems:

Fieldworkers found that, while it was possible to generate concern within the communities for the plight of orphans, interest floundered because many of the children identified as 'most needy' were not orphans, but were children of another stigmatised group, single teenage mothers. (Harber 1998)

It is often assumed that what is true at national level will also be true at local level, but this is not always so: initial participatory needs assessments are required to test the validity of such assumptions.²⁶ There is a large body of research showing that orphaned children, particularly younger ones, are very vulnerable (see Chapter 2), but there is also research showing little difference between the access to food, education and health care of vulnerable orphaned and non-orphaned children (Foster et al. 1998; McKerrow 1996; Urassa et al. 1997; Poulter 1997).

The growing number of orphans places families and communities under pressure, leading to situations where food security, health and education become increasingly precarious for every child in the household. The more destitute the community, the less justification there is for targeting orphans for assistance. Although malnutrition and stunting are more severe among orphans, the problem is also very serious among other children, and so the policy response must be to include orphaned children within a broader nutritional programme (World Bank 1997). Similarly, though the psychosocial needs of orphans seem to be more acute than those of non-orphans, and may warrant specific interventions, this should occur within a broader programme of support for all vulnerable children.

3.2 Integrating a rights-based approach

²⁶ This programming version of the 'ecological fallacy' is surprisingly common in planning. National or provincial data are unquestioningly used as a basis for categorising vulnerability at local level, whereas in reality totally different categories may be called for.

The UNCRC may represent a useful theoretical framework for programme design, evaluation and mitigating the impact of HIV/AIDS on children, and avoiding some of the pitfalls of traditional relief-type approaches set out above (Barrett 1998; Tarantola and Gruskin 1998). It is based on individual human rights (UNHCHR and UNAIDS 1998) and implies that human development is the realisation of a set of universally applicable, inalienable rights. It involves setting standards for the quality of life in any given context, and focuses on generic services and equity of access. Governments, through the ratification of the UNCRC, are obliged to respect, protect and fulfil these rights. The four guiding principles of the UNCRC are:

1. non-discrimination
2. best interests of the child
3. survival and development
4. participation.

These four principles can be used to examine specific rights, such as the right to education, the right to benefit from an adequate standard of living, the right to protection in the absence of their families, and the right to the highest standard of health possible, including access to health services.

Children's rights are denied by any kind of bias – and bias is often a by-product of projects that specifically target AIDS orphans for education or health care. This approach is discriminatory, as it excludes children outside the category from the services offered. 'In the best interests of the child' means putting children at the heart of programme design, on an equal footing with the interests of adults, communities and governments. This is linked to the right of children to be heard, which means involving children directly in the design and evaluation of programmes.²⁷

'Survival and development' is the basis for all other rights set out in the Convention. This refers not only to children's right to avoid infection with HIV, but also to economic and social policies that will enable them to survive their childhood and develop into happy and productive adults. The UNCRC reaffirms the position of the family as the provider of guidance for children, and sees the state's responsibility as supporting the family in this role, rather than taking it over (Barrett 1998). This underlines the need to support spontaneous community responses to the epidemic where the household is the first line of support, and the community safety net supports the most destitute households.

3.2.1 The validity of the UNCRC as a planning and evaluation framework

We shall now look at the benefits, as well as the practical difficulties, of adopting a rights-based approach. Such an approach provides a long-term goal towards which all developmental activities are directed (SC UK 1999). Clearly stated goals have traditionally been lacking in projects to mitigate the

²⁷ For an analysis of how children can be involved in evaluation design, see 'Participation of children' in Chapter 7.

impacts of HIV on children (beyond the loosely defined aim of improving their situation). The holistic and multi-sectoral approach implicit in the UNCRC would overcome some of the problems with vertical programming, such as the segmentation of programming into prevention, care and support for PLWHA and orphan care (see Chapter 5). It would also avoid the discriminatory practice of singling out AIDS orphans for support (see Section 3.1.1 above).

One interpretation of the rights-based approach is a series of five questions for planners when assessing a situation (UNICEF/USAID 2000):

1. Rights orientation – build consensus on rights ('what should be?');
2. Assessment – identify rights violated or at risk ('what is?');
3. Define rights gaps – between 'what should be' and 'what is';
4. Analysis – duty bearers and roles ('whose responsibility is it?');
5. Action – agree on strategies ('what will we do?').

These questions are addressed in a particular way, emphasising specific principles of process. The SC UK Guidelines on Children's Rights Programming state that programming based on individual human rights "...is seen as incorporating what is widely regarded as 'good development practice', viz. a focus on participation, equity, sustainability, non-discrimination, anti-poverty, multi-sectoral working, advocacy and capacity-building" (SC UK 1999). These guidelines are as essential to HIV/AIDS programming as in other fields.

It has been suggested that the success of various HIV/AIDS interventions is directly proportional to the degree to which they promote and protect human rights (UNAIDS 1997). However, this perspective comes from monitoring and evaluating existing activities and not from planning the incorporation of rights into project design.

So how, in practical terms, do we use the UNCRC as a framework so that children's rights are promoted and protected?

The protection and fulfilment of children's rights can be seen as a long-term and somewhat Utopian vision rather than an obvious means of addressing children's short and medium-term needs. Despite the growing debate about rights and a trend towards rights-based programming among certain donor countries and international welfare organisations (SC UK 1998; 1999), the methodology for a rights-based approach has not yet been developed or tested. While national governments are increasingly using a human rights framework to shape laws and policies concerning children, particularly orphans (see Chapter 6), there has been criticism of rights-based approaches from programming organisations.

The holistic nature of a rights-based approach may be incompatible with budgetary and logistical restrictions at project level, which often dictate the targeting of predetermined categories of children. There may also be occasions when the protection of children's rights is seen to be opposed to

the needs of the community. For example, rural farming households can be seen as complex systems geared towards survival and production. When one component of the system is affected by HIV/AIDS, there will be knock-on effects on other components, of which the child is only one. In such circumstances, the survival of the system normally overrides the interests of the individuals within that system (de Guerny 1998).

In times of crisis – such as the illness and death from AIDS of adults in a household – the decision-makers in the household may perceive the rights of the child to be at odds with the survival of the household. In the face of adult sickness and death in the household, it may be more important that the child learns farming methods than attends school, since the child may find him or herself in charge of the farm at an early stage in life. A study in Zambia found that children are very important in areas where labour-intensive farming techniques are used; they start to help their parents at the age of six or seven and are working productively in the fields at eight or nine years. One effect of HIV/AIDS has been to increase the value of children as an economic resource (Barrett and Browne 1998).

A project may target young children living in low-technology farming areas for support with schooling and other needs, but its approach would have to take account of time spent working in the fields. In order to target assistance more effectively, a balance must be struck between the fulfilment of children's rights and the survival of the children and the households they live in, particularly in the case of orphans.

Child labour will become a reality in ten years' time. Children will find means to survive if they are not provided for, and the issue of rights cannot be clarified by a simple invocation of the Convention on the Rights of the Child. (Michael 1998)

Furthermore, the concept of individual human rights is alien to many cultures. Advocacy campaigns for children's rights have met resistance from the community in many countries: for example, a study in Malawi found that communities viewed children's rights as a tool used by children to get their own way (Ali 1998). Guardians have also said that their ignorance of children's rights has made their job difficult – perhaps because government advocacy for the rights of the child has targeted children rather than raise awareness among parents and guardians. So in the absence of widespread understanding of children's rights, is it appropriate to adopt a rights-based approach?

A purely rights-based approach would involve investigating matters such as discrimination or child development with the community without specific reference to the HIV/AIDS epidemic, and designing interventions to address these matters. Such interventions may or may not include activities to alleviate the impact of AIDS. This would remove the logical justification for HIV/AIDS programming, even though the impacts of HIV/AIDS on children have been shown to be significant and to warrant intervention. It would also

remove the justification for allocating resources to HIV/AIDS programming, without providing guidance on where else to direct existing funds.

So despite general agreement that a rights-based approach should be used when developing laws and policies that affect children, there is a long way to go before the UNCRC can be adopted as a practical tool for planning and implementing activities.

3.2.2 The search for the middle ground

Given that sectoral programming is currently the reality for donors and governments, and that this is unlikely to change in the near future, the rights-based approach should therefore be modified to fit in better with this reality. This would involve using the rights-based approach, and specifically the UNCRC, as a framework within which to approach HIV/AIDS programming for children at the community level. We need answers to these questions:

1. How far can we predict how HIV/AIDS will impact on the rights of children?
2. What are the best ways to address these impacts within a rights framework at different stages of the epidemic and in different contexts?
3. Are there specific contexts (such as extreme poverty) where a rights-based approach would be inappropriate?

As shown in Chapter 2, the first of these questions is being answered through new research and programme evaluations.

As regards question two, using the UNCRC as a framework would not invalidate current debate about the need for a multi-sectoral response to AIDS, since the UNCRC addresses children's rights in all aspects of their lives, including physical and mental health, education, development and protection. Neither would it necessarily conflict with the dual strategy of mobilising communities and providing access to credit (see Chapter 4), since the ways in which children's rights are being challenged could form the basis for community mobilisation activities. Furthermore, use of the UNCRC may solve the problem of using HIV/AIDS as the basis for participatory assessments in areas where the community members do not accord HIV/AIDS a high priority.

For example, governments have a duty to respect, protect and fulfil a child's right to education. This involves ensuring universal access to primary education – a right that would be unfulfilled if certain children were denied access to education because of their association with HIV/AIDS. An agency might therefore investigate school enrolment and attendance rates with different groups in communities affected by HIV/AIDS. The community may not identify HIV/AIDS as a specific obstacle, even where this is clearly the case. If, however, the community identifies education as a problem, the next step would be to identify the reasons for non-attendance, using the four guiding principles of the UNCRC. They might include truancy and bullying due to stigmatisation, lack of economic means, lack of a nearby school

and/or the need to look after siblings at home, all of which may be directly related to HIV/AIDS.

Although in this way the rights of the child can be examined, care should be taken when using the vocabulary of child rights, so as to avoid the mistrust with which the concept is sometimes viewed by adults in the community (Ali 1998). The most appropriate way of using the UNCRC in community mobilisation and participatory needs assessment exercises, including the use of language, could usefully form the subject of further research.

The external agency's role would be to investigate areas where the HIV/AIDS epidemic has led directly or indirectly to the denial of children's rights. An appropriate intervention would address issues specifically raised by the community in ways that the community finds acceptable and which reflect their needs and priorities. The community might, however, raise other issues than children's rights,²⁸ such as malaria or sanitation. In such cases, HIV/AIDS programming agencies must be prepared to put that community in touch with other agencies that can provide the support needed, or attempt to be more comprehensive themselves.

3.3 Conclusions

Although orphans are among the most needy groups in all communities affected by HIV/AIDS, there is little justification for the specific targeting of AIDS orphans. Programming organisations should mobilise communities to develop their own definitions of vulnerability, and we need to address the impacts of HIV/AIDS on children within a broader approach that targets all vulnerable children in the community. In broadening the target group, however, organisations may find it difficult to mobilise community concern around the new issues that arise, such as the situation of single teenage mothers.

Which is the most appropriate approach to use? There is no simple answer to this question. Using HIV/AIDS as the starting point for investigating areas where children's rights are being challenged may combine the best of the rights-based and the relief approach – though this may not be the most effective approach for communities where HIV/AIDS is not perceived as a problem. In such cases the answer may be to target communities known to be most affected by HIV/AIDS, and then to explore possible activities with community members using a framework of child rights. Alternatively, an organisation could more usefully begin with community mobilisation around HIV/AIDS issues to sensitise community members to the impacts of the epidemic on children and their families.

There is particular need to mobilise communities where HIV infection rates are high but where AIDS-related mortality and numbers of orphans remain relatively low. The Jaipur Paradigm may be used to target these

²⁸ It is usual for many other topics to come up in participatory exercises such as focus group discussions, and it is important the community should not feel that the facilitating agency has its own strict agenda: for example, HIV/AIDS.

communities, if tools can be developed that NGOs and other programming organisations can use at the sub-national and local levels.

Adopting a participatory, rights-based approach would mean that the objectives of a programme, and therefore the indicators used for evaluating it, are more likely to be relevant to the beneficiaries, who are the primary stakeholders (and also the primary information gatherers). These objectives are more likely to reflect the wide range of needs experienced by children and their families, and participatory learning and action (PLA) is probably the most appropriate methodology in this respect. This difficult area of indicators and impact assessment is addressed in Chapter 7.

A rights-based approach may result in interventions that appear similar to those based on the relief approach, but that have the advantage of local validation by the community. Approaches that are owned by the community will be more sustainable.

Chapter 4: Programme approaches to caring for children affected by HIV/AIDS

This chapter examines a wide range of approaches that have been used to mitigate the impacts of HIV/AIDS on children. Most approaches to date have involved targeting specific groups of children, such as orphans, and providing support in a specific sector, such as education or health, but broader, community-based approaches are increasingly being championed.

We begin by looking at the significance of spontaneous, community-based responses to the epidemic, the dual strategy of community mobilisation and access to credit, the identification and support of vulnerable children, and the role of external agencies in community-based activities.

Community-based approaches often involve supporting adults in households and communities affected by HIV/AIDS, rather than specifically child-centred activities. These approaches recognise the fact that children are rarely independent of adults, and that efforts to respond to the needs of children affected by AIDS must reflect the complex relationship of children both to adult care and decision-making and to their wider communities.

We next examine a multi-sectoral response to the epidemic, looking in turn at approaches to education, vocational training, health, psychosocial well-being, welfare and protection. The need for a gender-sensitive approach is emphasised throughout the chapter as is the need for further research and programming.

It is as yet too early to judge the success of approaches that target support to households and communities in benefiting children. This, together with a lack of systematic evaluation of traditional approaches, makes it difficult to identify the principles of good practice.

4.1 Community-based approaches

The extended family remains the principal support unit for children in sub-Saharan Africa. If we are to make best use of local strengths, the household, extended family and the community should arguably be the main recipient of support for children affected by HIV/AIDS. The challenges are how best to support these families and communities as they care for the growing number of vulnerable children, and how to ensure that children will directly benefit from programme intervention.

4.1.1 Spontaneous community-based initiatives

Many communities affected by the epidemic have devised their own methods of helping vulnerable children and their families. These include communal lands for crop production, orphan registration and visiting programmes, home-based care for people living with HIV/AIDS, labour sharing to relieve carers and enable children to attend school, communal labour to repair houses and schools, and a range of income generating

activities (IGAs). Communities have also given direct financial help with, for example, food, clothing, and school fees. These spontaneous initiatives are sometimes organised by community-based organisations, but more often by groups of concerned individuals.

Although such initiatives often provide a short-term solution, their long-term viability is often limited by lack of external funding and technical assistance. People may give their time voluntarily, and may often generate some income, but it is much harder to provide continuing material support, such as food or school fees. The challenge for external organisations is to strengthen these initiatives so that they can become more sustainable.

Many development workers involved in HIV/AIDS projects believe that strengthening spontaneous community-based initiatives is as urgent as preventing the further spread of HIV. (Donahue 1998)

Spontaneous initiatives at the household level are more directly related to survival. In urban areas, AIDS-affected households typically employ a range of activities, usually revolving around petty trade such as selling home-made food, vegetables or second-hand clothing, or subletting rooms in the house (Webb 1996a). In rural areas, households often grow and sell food, brew beer or provide labour on other people's land. [\(Kezaala and Bataringaya 1998\).](#)

Spontaneous community responses are most common in countries where AIDS-related mortality, and hence the number of orphans, is high: for example, Uganda, Malawi, Zimbabwe, Zambia and Tanzania. In countries where the incidence of HIV is high but AIDS-related mortality and number of orphans are still relatively low – such as Botswana, Namibia, Mozambique and some Asian and Latin American countries – other issues are perceived to be more pressing than AIDS and spontaneous initiatives are less common.

There remain two key challenges for NGOs:

1. to stimulate community action before the epidemic progresses
2. to encourage governments and others to generate community awareness of the impacts of HIV/AIDS.

4.1.2 The role of external organisations

If community-based interventions are the best way of supporting children affected by HIV/AIDS, external agencies need to define more explicitly their role in planning and implementing these interventions. If the roles of all the key stakeholders are not discussed and agreed, the presence of an external organisation may compromise the long-term sustainability of community-based activity. The problems listed below are not unique to HIV/AIDS projects, but are perhaps more common in such projects because the perceived need to act quickly may lead to inadequate planning and consultation.

Box 4.1 Common problems with involving external agencies

- existing social support and coping mechanisms may be undermined by an external agency that imposes a new agenda
- untargeted material support from outside may persuade community members that they are relieved of their responsibilities for the duration of the programme
- when material help is eventually withdrawn, the community may be worse off because it has lost the habit of spontaneous activity
- programme activities may divert the community's resources away from areas that the community sees as more urgent, and thus cause resentment
- targeting by external agencies may lead to bias in programming and leave important groups without support.

It should be remembered that a focus on community-based approaches does not reduce the role of government, which must create an enabling environment for community activity. One of the most useful ways for NGOs to support community-level activity is through advocacy: gathering information, disseminating good practice and securing additional funding. International NGOs can place issues that are important to communities on the national agenda and thus influence policy development.

Box 4.2 How international NGOs can support community-based activities

- raising awareness of HIV/AIDS, particularly the impacts on children
- training and capacity building
- strengthening institutions and developing systems
- supporting the gathering and analysing of information for HIV-affected communities
- disseminating examples of good practice
- providing technical assistance on HIV/AIDS
- linking communities with other appropriate sources of support
- monitoring and evaluation
- advocacy on behalf of affected groups.

(Donahue 1999c and 1999d; Foster 1997b; authors)

We cannot assume that all affected communities will spontaneously develop strategies to help their most vulnerable members. At the same time, programmes that involve paid staff providing material and financial support directly to people in need are too expensive to sustain over time or to be able to help more than a small proportion of the children at risk (Williamson 1999b).

A consensus is growing²⁹ that external agencies should promote the dual strategy of community mobilisation and better access to income earning opportunities, particularly through micro-credit or micro-finance services. Although neither approach is designed specifically as a response to HIV/AIDS, together they seem to offer a more sustainable way of mitigating the impacts of the epidemic (Williamson 1999a and b, Donahue 1999a, c, d, 2000).

Community mobilisation and IGAs are considered in more detail in Sections 4.1.3 and 4.1.4. However, we should point out that, to be successful, both activities must be carried out with state-of-the-art methods and it may well be necessary to use two different organisations:

Attempting to design and manage a community mobilisation initiative and deliver micro-finance services according to state-of-the-art principles is probably beyond the capacities of most organizations. (Donahue 1999d)

However, even if operationally separate, the activities must be linked as they are both designed to achieve the same objectives. In particular, there should be joint planning to define target groups and programme objectives, and use of participatory monitoring and evaluation.

What does this mean for agencies such as SC UK? As we have seen, the traditional approach is for an agency to intervene in known areas of need, such as education for 'AIDS orphans', or in its area of expertise, such as providing health care to vulnerable children. But community mobilisation necessarily supports activities chosen by the community (see Section 4.1.3). This dual strategy is based on the belief that poor households in communities affected by HIV/AIDS know what they need in order to avert further crises, and that their capacity to cope with these crises should be strengthened.

This dual strategy would mean that, over time, support for communities in AIDS-affected areas will largely come from:

1. Agencies skilled in community-based HIV/AIDS interventions and participatory methodologies.
2. Specialist micro-finance institutions with experience of community-based activities, such as village banking schemes.

This may require further training for the staff of existing agencies working in the HIV/AIDS field, and/or wider involvement of freelance specialists or specialist agencies. There will still be a need for organisations skilled in community-based health interventions or education, but these must work together in a multi-sectoral framework and should recognise that their particular area of expertise may not be a priority for the community.

²⁹ This principally involves Jill Donahue and John Williamson, who are at the forefront in developing the dual strategy. Sections 4.1.3 and 4.1.4 are partially based on their work. See the references to their work in the bibliography.

It is not clear whether this dual strategy is the most appropriate way of supporting vulnerable children affected by HIV/AIDS since few evaluations have taken place. As yet, few programmes have used the strategy, although community mobilisation and micro-finance are often part of wider projects. Income generating projects are often added to other mitigation activities in response to pressure from the community; but these often fail owing to the implementing organisation's lack of expertise.

4.1.3 Community mobilisation

Community mobilisation sets out to achieve community 'ownership' of activities through awareness raising, resource identification and by encouraging as wide a participation of community members as possible. It is usually based on participatory techniques such as PLA, which aim to include groups who traditionally may not have had a voice, particularly women and children.³⁰ The chosen focus for community mobilisation is often the growing number of vulnerable children in communities severely affected by HIV/AIDS, and community members often rally around activities designed to provide care for these children and support for their guardian households (Donahue 1999d). These include:

- starting community schools
 - providing school uniforms and other equipment
 - visiting HIV-affected households containing vulnerable children
 - labour substitution to enable women to participate in income-generating activities and/or children to attend school
 - fundraising for essential items such as food.
- (Donahue 1998 and 1999d; Williamson 1999b)

The external agency's role is to use participatory methods to enable mobilisation. Successive stages in the process might be:

1. raising awareness of the effects of HIV/AIDS, particularly on children
 2. recognition by community members that they are already dealing with the consequences of HIV/AIDS and that collective action can be more effective
 3. the sense of ownership that comes with this recognition is the starting point for identifying what further responses are possible
 4. mapping existing resources in the community: knowledge, skills and physical assets such as land
 5. identification of priority needs within the community
 6. community members plan and manage activities using internal resources
 7. the growing ability of community members to sustain their chosen activities and to obtain external resources: for instance, through micro-credit or linkages with other organisations
 8. monitoring activity to ensure that it continues to reflect the community's priorities and that the community is aware of the progress being made.
- (Donahue 1999c and 1999d; Williamson 1999b)

³⁰ See the discussion on the participation of children in monitoring and evaluation in Chapter 7.

The number of steps in this process, and their order, may vary. The challenge for the facilitating agency is to know when community members are ready for specific kinds of training and support (Donahue 1999d). The community's existing resources, identified through participatory appraisal, should be built on. External NGOs should work through existing community-based groups, which may already maximise trust and solidarity within the community. Community mobilisation may also be used as an entry point for other HIV/AIDS prevention, care and mitigation activities in the community (Chapter 5).

However, community mobilisation is a developmental approach that has largely been used to address the needs of adults. We do not know as yet if this is the most effective way to mitigate the impacts of HIV/AIDS on children. For resource-poor communities faced with other crises, such as a breakdown in agricultural production, the needs of children beyond their basic survival may not be considered to be a priority.³¹ Some experimentation will be needed to adapt this approach to the needs of vulnerable children living in households affected by HIV/AIDS.

Possible problems include:

- an insufficiently strict application of participatory methodology, particularly a failure to involve vulnerable children themselves in needs analysis
- a tendency for the external organisation to impose its own solutions on community-defined problems
- the external funding of community-based projects, and its timing, may inhibit community ownership and threaten sustainability
- a concentration on areas that fit the external agency's particular skills rather than those of the community.

(Donahue 1999d, the authors)

4.1.4 Economic and financial support

This section looks at ways of providing sustainable economic and financial support to households affected by HIV/AIDS, and more specifically to women and young people. It then looks at the advantages and disadvantages of IGAs.

It has been suggested that the ability of families to cope with the consequences of HIV/AIDS depends largely upon their capacity to stabilise or increase their incomes (Donahue 1999a). The level and stability of household and community resources depend on two factors: existing economic resources (in the form of savings, livestock, land for growing crops and other assets) and the ability to generate income. IGAs aim to increase the capacity of households and the wider community to earn income and acquire income-earning assets in a sustainable way.

³¹ See also Section 3.2.1 'The validity of the UNCRC as a planning and evaluation framework', where the difficulties are discussed of emphasising children's rights where these are not the community's own priorities.

The term 'income generating activity' is often used indiscriminately for a wide range of activities (Donahue 1999a and 1999b), and this can cause confusion. Different types of IGA include credit to both individuals and groups, material assistance (such as equipment, animals or agricultural inputs), technical know-how and training, and support in setting up small-scale enterprises, but in general they fall into three broad categories:

1. activities that strengthen household resources in anticipation of crises
2. activities that provide relief assistance to households already in distress
3. activities that assist community associations to create a source of funds for their activities.

Each type of IGA requires different skills and inputs, and is designed to produce different outcomes. We must therefore specify clearly what kind of IGA is being considered and why. For instance, micro-credit or micro-finance (see below) is a key method of strengthening the resources of individual households, by enabling them to avoid future actions that might push them further into poverty.

Providing financial or material assistance to destitute households by concerned community members and helping community associations build funds for social development activities are only usually sustainable if community safety nets can be strengthened. Community mobilisation (see 4.1.3) is one of the most effective ways of doing this. Some form of IGA may result from community mobilisation, but it is the community itself that must analyse its problems and choose the most appropriate solutions.

Micro-credit

Micro-credit programmes offer small amounts of credit, often to groups of women, to support existing activities (often known as micro-finance). They do not always include a savings element, but where they do, the savings are generally used as collateral for defaulting loans (Donahue 1998). Credit is typically targeted at short-term, high turnover activities such as petty trading. The main function of this support is to mitigate poverty and avert financial crisis for individual households, rather than to create wealth and employment or build businesses (Donahue 1998). Micro-credit has not proved successful in funding group activities. By directing support to poor households before they experience the worst effects of HIV/AIDS, micro-credit can help prevent them from sliding into destitution (Williamson and Donahue 1998). Even so, many believe that micro-credit programmes rarely reach the poorest households (Barnes, Morris and Gaile 1997³², Research International 1999³³, Wright et al. 1999; Williamson and Donahue 1996).

The exclusion of the poorest is largely due to their lack of viable businesses and their inability to access the social networks required to join institutions based on group solidarity mechanisms (Wright et al. 1999).

³² Reference quoted in Wright et al. 1999.

³³ Reference quoted in Wright et al. 1999.

Opportunities for the poorest households (such as female-headed rural households or those headed by elderly or child carers) to make productive use of loans are often limited (Wright et al. 1999). Such households typically lack the time, labour or skills to participate effectively. The availability of income generating services to the poorest households may also be restricted: for instance, many community-based credit and savings programmes will not lend to young people with little regular income, and people living with life-threatening diseases, such as HIV/AIDS, may be perceived as a poor risk and therefore excluded.

But although micro-credit programmes may not reach the very poorest people, they can improve the food security of poor households and protect their existing economic status (Donahue 1998 and 1999). Although few poor households have enough income to reinvest or to increase their contributions to community or group activities, the income they do receive can safeguard them against a slide into destitution. It may also enable the household to engage in higher-risk activities (and thus receive higher returns).

It is often assumed that additional income for a household will automatically benefit children, and a recent study in Uganda did indeed find that improvements in health and education were among the most valued consequences of access to micro-finance (Wright et al. 1999). However, further research is needed into exactly how children benefit and whether all children in a household benefit equally from micro-finance activities.

Are poor people in AIDS-affected communities an 'acceptable risk' for credit programmes? Evidence would indicate that they are. Programmes in severely AIDS-affected areas of Malawi and Uganda record repayment rates as high as 99 per cent, despite the large proportion of families caring for orphans (Williamson and Donahue 1998). The importance of micro-finance as a key tool to alleviate the socio-economic impacts of the epidemic on vulnerable households becomes clear once it is understood (and accepted) that the principal objective of micro-finance in HIV/AIDS-affected communities is to maintain existing economic resources as opposed to generating financial gain.

Box 4.3 Potential benefits of savings and credit schemes for poor households

- small but steady income flows that make essential purchases possible
- opportunities to acquire savings that are secure, easy to liquidate quickly and retain their value over time
- reduced vulnerability to loss through improvements in coping mechanisms
- affected households are able to avoid coping strategies that inhibit future income earning capacity.

(Webb and Mutangadura and Webb 1999; Donahue 1999a and c; White and Robinson 1999)

To ensure the success of micro-finance programmes:

- they must use state-of-the-art methodologies, which means employing specialist micro-finance institutions in programme design
- they must adhere strictly to standards regarding repayment rates
- subsidies are not helpful for the long-term sustainability of programmes as they make implementation expensive.

(Donahue 1998)

The advantages of targeting women

Micro-credit programmes targeted at women have two major benefits:

1. they increase the status of women within the family
2. they promote solidarity among women.

Women who take part in credit programmes strengthen their position within the family, not only because they have access to credit, thus increasing their contribution to household finances, but also because they can help their husband's business and act as the family banker. The delivery of credit through solidarity groups is widely recommended (Donahue 1998, Wright et al. 1999). A study in Uganda found that the participation of women in group-based activities was seen by participants as a major benefit of credit programmes (Wright et al. 1999).

In this way, women can be empowered by increasing their human assets – self-esteem, bargaining power, control over decisions and, to a limited extent, skills and knowledge – as well as their social assets – social networks, membership of groups, relationships of trust, and access to wider institutions of society (Wright et al. 1999).

There may also be benefits to children living in female-headed households – who, as previously discussed, are often particularly vulnerable:

- women devote a larger proportion of household resources to children's needs and maintaining food security (Donahue 1998, Williamson and Donahue 1996 and 1998)
- women are more likely than men to ensure equal access to education for both their biological children and foster children (Aspaas 1997)
- women have better repayment records and make more reliable clients (Wright et al. 1999).

Therefore, when planning micro-credit and savings programmes, organisations should look closely at women's participation in community-based activities and make a point of encouraging solidarity among women. A good understanding of both gender issues and social capital, and how they function in the project area, is essential on the part of the implementing organisation.

Activities that involve young people: Vocational training and apprenticeships

Providing children or adolescents with opportunities for direct income generation often requires them to be provided with vocational skills training.

This can be extremely valuable if it helps the young people to acquire marketable skills, but the training must be based on a careful assessment of the demand for those particular skills. Those who complete the training will also have to be equipped with the tools, and possibly capital, they need for the job. Non-formal vocational training courses, often with an income generating component, may be targeted at orphans and other vulnerable children to help them prepare to support themselves. However, when a group of girls in Uganda wanted to set up a co-operative to make school uniforms, they found that credit institutions would not lend them money because of their youth (see case study in Section 4.2.1). Adults are sometimes willing to underwrite the loan on behalf of minors, but it may be more effective to lend directly to young people who can prove themselves creditworthy.

A second possibility is apprenticeships. These have several advantages:

- special training facilities are not needed (though tools may need to be provided)
- employers often regard the prospect of additional labour as an incentive
- participants will gain experience of the workplace as well as useful skills.

The problem remains that few artisans are willing, or able, to take on apprentices, particularly in areas severely affected by HIV/AIDS. Ways need to be found to encourage and support people to take on apprentices.

If IGAs are to benefit vulnerable children, they must either be targeted directly at households containing such children, particularly those headed by women, or carried out alongside activities to sensitise the community to the needs of vulnerable children. A stronger link needs to be established between IGAs and improvements in the welfare of children before such activities can become the principal means of support for vulnerable children affected by HIV/AIDS; this link could most convincingly be demonstrated through programme-based research.

Factors contributing to success or failure of IGAs

In general, the more new elements – skills, technology and equipment – that have to be introduced for an economic initiative to succeed, the greater the likelihood of its failing.

The most effective interventions are those that target support to income-generating activities for which people already have most of the necessary skills and ongoing access to markets and resources. (Hunter and Williamson 1998a7)

Implementing organisations must also be clear about which type of IGA will generate which type of benefit. They must make a distinction between support to households and larger, more complex group-based activities that aim to raise funds for the social development of the whole community. If this distinction is not clearly understood, individuals may harbour expectations of personal income from group-based activities, which in practice rarely occurs.

Group-based IGAs, such as small community businesses, are particularly risky. The Committed Communities Development Trust (CCDT) in India found that group-based activities were unsuccessful for the following reasons:

- people living in scattered communities may have to travel a long way to participate in the activities
- conditions within the home are often unsuitable for the production of saleable or standardised items
- women are not interested in the activities
- women are busy caring for sick relatives and children and so cannot participate in the activities – or they themselves fall sick.

(communication with Kamini Kapadia, Director, CCDT)

Box 4.4 What can cause IGAs to fail?

- they do not capitalise on existing resources in the community
- the managing agency lacks the requisite know-how
- the community, particularly female and elderly household heads and members of more destitute households, do not have the time or physical resources to contribute
- poor rural households, which have the greatest need for such activities, are the least accessible
- insufficient market research
- instability of prices for commodities and/or services
- the most socially and economically vulnerable households may have difficulty in managing credit
- group-based activities that raise expectations which are in practice difficult to meet and leave the community worse off
- disagreements over group benefits versus individual benefits, particularly when individual households are in crisis.

(Bajanja [et al](#) 1995 (on Uganda); Senkusu 1995 (on Uganda); Donahue 1998 and 1999a; Williamson and Donahue 1996 and 1998; Harber 1998; Williamson 1995; authors)

An additional factor specific to AIDS-affected communities is the health status of clients. Micro-credit organisations may not consider people living with HIV/AIDS, or their dependants and other relatives, as a viable risk. What if a client dies before she or he can repay the loan? These fears can be partially overcome by explaining to the organisations the patterns of ill health associated with HIV/AIDS. Groups of people can also jointly accept liability for a loan, thus spreading the risk of default. These difficulties underline the need for state-of-the-art micro-finance techniques to be used.

An example of failed IGAs comes from an AIDS orphans project in South Africa where programme implementers felt pressurised into developing IGAs but failed to seek specialist help with programme design and implementation. When the project failed, the following causes were suggested:

- the lack of market research before setting up the IGAs meant that there was no market for their products
- many of the women caring for children that the community identified as the 'most needy' were unable to join the project as they were elderly, lived in remote areas and were already burdened with caring responsibilities
- the way the activities were organised did not make best use of available skills and resources.

(Harber 1998)

In the past, the preoccupation of agencies with financial sustainability has usually meant that emergency loans not linked to specific business activities were rarely available. However, it seems that the poorer clients of micro-credit programmes seek loans principally for crisis management and 'solving problems', rather than to 'accumulate for future investments' (Wright et al. 1999). This mismatch between the priorities of the agency and the community must be resolved at the outset, perhaps through community mobilisation activities.

Also, although IGAs may be regarded as having failed because they did not produce a steady stream of income for participants, they may have brought equally valuable benefits, such as new skills and increased solidarity, particularly for women (Wright et al. 1999).

4.1.5 Identification, monitoring and support of vulnerable children

To date, national orphan registration programmes in Africa have largely been unsuccessful, owing to the problems listed in Box 4.5.

Box 4.5 Problems with orphan registration programmes

- the high cost of implementation
- difficulties with maintaining systems for gathering and updating information
- programmes tend to raise expectations of help, and when this is not forthcoming, people withdraw their co-operation
- unreliable and inconsistent data
- inconsistency often within the same survey about who to include.

(UNICEF/CEDC 1998a; 1998b)

It has been suggested that the accuracy of national orphan estimates is largely an academic question, since the problems of children affected by HIV/AIDS are already far greater than the capacity of any country to respond (Williamson 1999a). However, national estimates of the number of orphans (or indeed 'children living in HIV-affected households') do provide some basis on which policy makers, practitioners and others can plan the allocation of resources. Statistics are also useful for attracting media coverage.

The National Task Force on Orphans in Malawi, after the failure of the national registration programme, recommended that registration be carried out in small areas as a prelude to assistance programmes (UNICEF/CEDC 1998b). This could form part of community mobilisation, with a view to the participatory planning of programme activities. If programmers can find ways of aggregating these local estimates, they could then be compared with figures based on national surveys and censuses to produce national (or at least regional) estimates of the number of vulnerable children.

Orphan identification and visiting programmes based in the community have overcome many of the problems associated with large national programmes. In participatory assessments, communities often cite the identification and support of orphans and vulnerable children as a major priority. External support for community-based programmes of this type may therefore serve as a good entry point for exploring the impacts of HIV/AIDS on children and for raising HIV/AIDS awareness generally.

There are, however, some concerns about orphan registration programmes:

- they tend to focus on the material needs of orphans, since these are easier to address, and overlook their psychosocial needs
- sensitive issues, such as the sexual abuse of affected children, are often difficult to address, particularly if the volunteers are from church-based organisations or where the community prefers not to discuss the matter. Greater participation of affected children in programme activities could make discussion of such issues easier (Lee 2000)
- direct material assistance such as donations of food and clothing to affected households may not be sustainable, particularly as the number of sick adults in a community increases.

Children should be enabled to participate directly in orphan registration and support programmes, in order to build greater trust between them and the volunteers. This should be combined with support for care-givers and guardians, which is sometimes overlooked. Methods of support may include:

- raising awareness of the impacts of HIV/AIDS on children
- supporting carers in addressing the emotional needs of children who have lost one or both parents
- providing space to facilitate the care of extra children
- building skills in childcare, hygiene and basic health
- IGAs
- occasional relief from care-giving responsibilities
- providing emotional support and counselling to adults where necessary
- facilitating access to material support, physical and financial aid.

(McKerrow 1996; authors)

Recommendations for NGOs: Community-based approaches

Spontaneous approaches

- NGOs should build on spontaneous community-based initiatives, where these exist, to strengthen the community's capacity to provide support (Section 4.1.1)
- community mobilisation will generate data on existing activities, the principal areas of need in the community and the availability of internal resources (Section 4.1.3)
- where a community does not give HIV/AIDS priority, despite evidence of its impact on children, NGOs must try to build awareness. This may form a first step in community mobilisation (Section 4.1.3)
- concern among the community for vulnerable children may serve as an entry point for exploring the impacts of HIV/AIDS on children and their families.

The dual strategy

- a dual strategy combining community mobilisation with access to micro-finance will strengthen the capacity of communities to cope with the impacts of HIV/AIDS on children. NGOs must, however, employ state-of-the-art methodologies for both parts of the strategy
- NGOs providing support to adults in the community should try to focus on especially vulnerable children. This can be done by raising awareness of the impacts of HIV/AIDS on children and by targeting services, particularly to women heading orphan households
- where possible, NGOs should build local capacity to undertake research into how this dual strategy benefits vulnerable children
- NGOs might consider lending small amounts of credit to previously excluded groups, such as young people, who are starting small businesses
- NGOs should facilitate a gender and social analysis within the project area and encourage the community to take the results into account when planning activities.

Identification and support of vulnerable children

- NGOs should try to standardise their approach to monitoring the number and situation of especially vulnerable children in target communities. This requires greater inter-agency collaboration
- NGOs should avoid targeting orphans, particularly AIDS orphans, as this can lead to further stigmatisation (see Chapter 3). Definitions of vulnerability should be developed by and agreed within the community
- NGOs should build on the community's existing support for vulnerable children, and should work through existing groups in the community in order to capitalise on their good will and solidarity
- NGOs should encourage the direct participation of children, while taking into account cultural norms concerning a child's right to be heard (see Chapter 7)
- NGOs should ensure that children's psychosocial needs are addressed alongside their material needs, and that sensitive issues, such as vulnerability to sexual abuse, are also considered
- where programmes rely on volunteers from the community, ways must be found of sustaining their motivation, such as small incentives or allowances, training and positive feedback.

Programme management

- NGOs must negotiate their roles with other key stakeholders in the community. Building capacity and providing technical support, rather than direct material assistance, will ensure greater sustainability. Advocacy is another important role. NGOs should be aware of the potential problems listed in Section 4.1.2 and Boxes 4.1 and 4.2
- NGOs pursuing a dual strategy of community mobilisation plus IGAs will need to assess their own capacity; they may need to retrain staff in participatory methodologies, collaborate with other organisations (such as experienced micro-finance institutions) or buy in technical assistance
- NGOs should also build capacity to undertake operations research
- NGOs should advocate for funds to undertake large-scale needs assessments of vulnerable children
- more collaboration between NGOs working in the same region and nationally, and between NGOs, government and donors, is essential for developing a standardised methodology for identifying and supporting vulnerable children (see Chapter 6).

4.2 Multi-sectoral and sectoral responses

Although the multi-sectoral approach to HIV/AIDS has been hailed as the natural response to the wide range of needs experienced by affected children and their families, it is far from clear what this actually means in practice.

In the past, programmes typically addressed only a small area of need, such as health or education. This approach tended to reflect the skills and resources of the programming organisations rather than the real needs of the target population. Furthermore, programmes have traditionally been based on two assumptions:

1. children's needs start with the death of a parent
2. their primary need is for material assistance.

Although there has recently been a growth in research into the psychosocial needs of children affected by HIV/AIDS, multi-sectoral approaches that cater for the whole range of children's welfare and development needs – needs that arise long before the death of a parent – remain rare.

Their needs are psychological, emotional, ethical, legal and spiritual; they are for acceptance, nurturing, support, counselling and care; they include financial, material, educational, health and social development needs. (Reid 1997)

Children not only need such support – they have, as set out in the UNCRC, a fundamental human right to it. Using the UNCRC as a framework for programme planning would lead to a more holistic approach to children's needs as set out in Chapter 3.

Another way of pursuing the multi-sectoral approach is for organisations to support initiatives that are 'owned' by the community and to target assistance at areas of need identified by community members. Involving children and their families at all stages of the project cycle means that activities will be more likely to meet the community's needs, which usually span a range of different sectors. The twin strategy of community mobilisation and providing micro-finance (see Section 4.1.3) is an example of this approach since it supports the identification of the community's needs and provides some means by which to address them.

Organisations supporting a multi-sectoral approach must advocate at a national level for the involvement of different line ministries and promote the message that HIV/AIDS is more than just a health problem. The location of national AIDS programmes in ministries of health in most African countries continues to block the development of a national multi-sectoral response. Furthermore, the drive to decentralise the administrative structure in many developing countries means that organisations have had most success in bringing together representatives of different ministries at the district level and below. A well-known example of a multi-sectoral approach to mitigating the impacts of HIV/AIDS is the Community-based Options for Protection and Empowerment (COPE) project of the Save the Children Federation in Malawi.

Box 4.6 Multi-sectoral approaches: Community-based Options for Protection and Empowerment (COPE)

The COPE programme of SC US was set up in 1995 in Mangochi District in Malawi. The main focus of activity was in Namwera. It revitalised a structure set up by the National AIDS Control Programme in 1992 with support from UNICEF, comprising District AIDS Co-ordinating Committees (DACCs), Community AIDS Committees (CACs), and Village AIDS Committees (VACs). COPE I was reviewed in 1996 and a second phase of the programme initiated (COPE II) which was evaluated in 1998.³⁴ COPE II included a geographical expansion to Dedza and Nkhotakota and there are currently also plans to move into Lilongwe.

The original objective was to develop an intervention strategy that could be used by external agencies to mobilise sustainable, effective community action to mitigate the impacts of HIV/AIDS on children and families. The approach incorporates two stages: the first aims to catalyse the formation of a broad-based coalition of parties in a community concerned about the impacts of HIV/AIDS; and the second stage provides training to build capacity within the community to undertake initiatives of benefit to HIV/AIDS-affected children and families, as well as to mobilise internal and external resources.

While the overall objectives have remained the same, the primary area of intervention has shifted from the community in COPE I to the district level

³⁴ See Williamson and Donahue 1996 and 1998 in bibliography.

in COPE II. Using a cascade model, COPE supports the DACC, which is then responsible for supporting the CACs. At the village level, training and support are provided by the CACs but it is the village members who decide which problems will be addressed and how. Village chiefs, Muslim religious leaders, clan heads and families caring for orphans have been the most active VAC members.

A key aspect in the drive for sustainability has been, and remains, the high degree of community ownership and motivation among community and village committee members. This has proved to be successful and, since COPE withdrew from Namwera, the Namwera CAC has continued to mobilise VACs on its own. A recent review found levels of motivation to be high particularly concerning orphan support, care for the sick and youth-based activities.

Activities carried out by community members have included identification, monitoring, and support for orphans, community fundraising, home-based care programmes, youth club and anti-AIDS club formation, structured recreational activities and childcare, and training of teachers on the psychosocial needs of vulnerable children. The extent and range of activities varies in each village.

The current pyramidal structure reflects an attempt to promote a multi-sectoral approach at the district level. Although at national level the National AIDS Programme is situated in the Ministry of Health, the DACC comprises representatives from different government ministries, including agricultural extension workers, and representatives from the ministries responsible for community services, gender, education and health. Inputs for the project, such as seeds for community gardens, are procured through the relevant line ministry. Some ministries have been more active than others.

In order to maintain the economic stability of poor households in the target areas, the second evaluation recommended that COPE link up with specialist micro-finance services. The VACs rely solely on voluntary support and community-generated resources. As more families fall into acute poverty, the long-term viability of this type of support is threatened. The economic stability of the guardian household is vital for the adequacy and quality of care for children affected by HIV/AIDS.

After COPE has provided assistance for a 2- to 3-year period, the aim is that DACCs are funded by local government through the District Executive Committee (to be replaced by District Assemblies). DACCs are also able to fundraise on their own behalf. The degree of activity at district, community and village levels will need to be monitored once the structure becomes locally funded.

For a brief discussion on the COPE monitoring and evaluation system, see Chapter 7.

Sources: Williamson and Donahue 1998, and 1996; case study provided by

Different sectoral approaches

Although the multi-sectoral approach is most likely to be effective in meeting the complex and interrelated needs of children affected by HIV/AIDS and their families, it can be useful for programme planning purposes to examine approaches within specific sectors such as education, physical and emotional health, welfare and protection; this is the theme of this section.

4.2.1 Ensuring access to education

Chapter 2 has described how the consequences of HIV/AIDS can reduce opportunities for both formal and non-formal education, at a time when parental illness and death makes it imperative for them to have access to education and training that will enable them to support themselves economically and survive on their own.

By decreasing and re-directing family incomes, HIV/AIDS pushes children into poverty and helps keep them there by cutting them off from school, formal training and the transfer of skills from parents (Williamson 1995).

Children drop out of formal schooling for a variety of reasons, hence there is no single way to prevent them from doing so: interventions must address the specific problems faced by a community, or even a single household. Here are some possible approaches to the situation.

Direct assistance

This involves direct payment for uniforms, books, fees and other necessary expenses; it is a common element of community-based orphan identification and support projects. Direct assistance may also include direct grants or other help to schools that address the needs of children affected by HIV/AIDS.

Direct assistance can provide short-term relief, but its cost, together with the growing numbers of children affected by the epidemic, makes it difficult to sustain in the long term. It also involves the targeting of specific groups at the expense of other vulnerable children in the community. Even so, short-term financial assistance is sometimes the only option for households in distress.

Provision of early childhood care and education

Early childhood care and development centres – sometimes known as kindergartens or crèches – provide a place for young children to spend the day while their parents or carers are occupied. Centres vary widely in the services they offer; some provide teaching, others simply provide shelter; most provide food.

These centres enable the carers of small children to join the workforce, to study, to participate in income generation and other community-based

activities, or if they are elderly carers, simply to rest. They also facilitate the monitoring of children's nutrition.

It has been claimed that early childhood education will help to prevent children failing in their later school career. This type of education is, however, based on western notions of child development, which stress the individual, self-esteem and choice; any approach to early childhood education must take into account the local contexts in which children learn.

Community-based schools

Community-based spontaneous responses to HIV/AIDS have included setting up community-based schools, finding volunteer substitutes to enable children to attend school, and providing uniforms, books and school fees (Donahue 1998). External agencies can support these existing activities and talk to the community about introducing new ones.

Community-based schools have been shown to be less expensive per pupil than government schools. To operate, such schools often need considerable community inputs such as trained volunteer teachers, donated, locally constructed or rented buildings, and some teaching materials (Nampanya-Serpell 1999). As the epidemic depletes local resources, both human and material, the sustainability of community schools may be threatened. One possible solution is to introduce micro-finance services to improve the economic stability of households (see Section 4.1.4).

Support to schools in dealing with psychosocial problems in children

This involves training teachers to address the psychological problems of children so that they can remain in school. Tackling teachers' own fears about HIV infection is a first step towards making them good 'guardians' of the children in their care, and helps them to recognise signs of distress and depression and learn ways to deal with them (Baggaley et al. 1999).

Passing on knowledge and skills within the family

This involves helping parents who are sick either to pass on, or to arrange for their children to acquire, traditional skills and knowledge that will help them to become economically and socially more independent. Rural children traditionally learn farming skills through working with their parents, but if this learning process is halted because of the illness and death of the parent, there may be no other way of enabling children to continue cultivating the parental land (de Guerny 1998).

Vocation training and apprenticeships

Older children who have missed out on their education may not wish to return to school, and the pressures of supporting the family may mean that they are simply unable to. In Zambia, Kwasha Mukwenu ('Help your friend') has carried out a pilot project to provide adolescents with income-earning skills (tailoring and carpentry) and equipment. Box 4.7 below details its findings (see also Section 4.1.4).

Box 4.7 Kwasha Mukwenu

A local consultant was contracted to manage the project. She trained a group of out-of-school, adolescent orphans in survey techniques to carry out a household survey gathering basic information on household status and demand for skills and training in Kwasha Mukwenu's project area in Matero, Lusaka. Based on the survey results, tailoring and carpentry were selected as the most useful and marketable skills. Ten girls joined a tailoring workshop and six boys were taught carpentry skills (both courses were open to girls and boys but no boys signed up for the tailoring and no girls wanted to learn carpentry). The tailoring training started earlier due to the availability of trainers. During the training, the girls received information on other issues such as starting a co-operative, operating small businesses, and how to present oneself to future employers. The training was highly successful with all the girls finishing the training in less than the planned time. They decided to stay together and to set up a co-operative. The first tranche of income received went to service the sewing machines hence contributing to project sustainability, and to purchase fabric to make school uniforms.

Problems encountered include finding the wages for the carpentry teacher (the other teacher volunteered), and obtaining assistance for the girls to start a co-operative since credit programmes will not lend to young people. These obstacles can be partially overcome with external support. Lessons learned include the fact that the young people are keen to participate and, with a only a basic education, can learn new skills fast. Young people can be trained to carry out household surveys for planning, monitoring and evaluating purposes. This was a small-scale, urban project, which may prove to be a sustainable and replicable approach for community-based organisations in urban areas, with limited external finance.

Source: UNICEF and UNAIDS 1999

Schooling for working and street children

This entails providing informal education to enable children working or living on the streets to gain numeracy and literacy skills and some vocational training. One such programme in Kenya has provided education for children alongside income-earning activities, such as waste collection and recycling (Williamson 1995).

Provision of income-earning opportunities

This can release household resources that can be used for education (Donahue 1998; Wright et al. 1999). The loans provided by the Uganda Women's Finance Trust meant that each household's own capital was freed up and could be used for school fees and health care (Wright et al. 1999).

Revision of education and other policies by governments

In response to the impact of HIV/AIDS, Uganda and Malawi introduced free primary education for all children. The policy is subsidised by the government (UNICEF 1999a) and by external donors, raising concerns about its long-term sustainability. Both countries also have policies guaranteeing orphans free access to education and prohibiting discrimination against children on any grounds (including illness, cause of parents' death and poverty) (UNICEF 1999a).

NGOs can advocate for changes to education policies. But waiving the fees for government schools does not guarantee access for poor children, since many schools levy their own fees. Also, the necessary infrastructure must be in place before policies are changed: Uganda has had problems coping with the steep rise in primary-school pupils and the quality of education has considerably declined.

To be effective, the approaches just described require continued monitoring of the attendance rates, performance, and mental and physical well-being of the children participating. One method of monitoring performance of these activities would be to measure the 'social rate of return' for the different approaches by comparing the subsequent earning power of participants with the cost of the programme to communities and governments (Nampanya-Serpell 1999).

Recommendations for NGOs: ensuring access to education

- there is a wide range of possible methods for ensuring access to education and training for children affected by HIV/AIDS. The response chosen must address the specific and often changing problems of children and their families. This requires good participatory needs assessment and continuing monitoring and evaluation
- 'education' must be taken to include formal schooling, non-formal education, vocational training and apprenticeships and the transfer of traditional skills and knowledge within kinship systems. Too often organisations focus on formal schooling to the exclusion of other types of education
- providing early childhood care and community schools can be valuable for rural communities severely affected by HIV/AIDS, particularly when linked with income generating activities
- in urban areas, vocational training and education for street and working children are useful approaches
- raising awareness among teachers and trainers of the psychosocial impacts of HIV/AIDS in children is an effective way of addressing stigmatisation and providing emotional support
- direct assistance with school fees, uniforms and equipment may provide short-term relief to households affected by HIV/AIDS, but is not sustainable. It should be used in the short term as part of efforts to stabilise the economies of severely affected households (see Sections 4.1.3 and 4.1.4)

- although free primary education for all is a desirable goal, it should not be introduced without first ensuring that the infrastructure can accommodate it.

4.2.2 Ensuring access to healthcare

Children living in HIV-affected households face a wide range of various health-related problems as explained in Chapter 2 (see Section 2.3.3):

- their health needs may seem less urgent than the more pressing needs of the sick adults: for example, they are less likely to be immunised than other children
- they are at risk from opportunistic infections such as tuberculosis, pneumonia and diarrhoeal diseases
- they are often isolated in the community, with little access to general, reproductive or sexual health services.

In addition, the capacity of the health care system may be severely stretched by the epidemic. How can we improve the health status of affected children?

Care within the community

Problems arising from lack of capacity in the formal health services, and from the stigma and poverty that prevent children affected by HIV/AIDS from using those services, can be avoided by providing basic healthcare within the community. External organisations can assess the availability and accessibility of health care within the community and help to strengthen this.

Home-based care teams are particularly well placed to monitor the health of children at risk. Outreach services linked to day-care centres, youth clubs and community schools also provide opportunities to monitor children's health. Teachers, guardians and other adults can be trained to identify and refer children whose health is at risk on to higher level clinical support as necessary. Pooled resources at community level (from individual donation or profits from IGAs) can help pay for such treatment. The capacity of traditional healers to support affected children should also be strengthened.

Protecting children from opportunistic infection

Children who care for sick relatives in households affected by HIV/AIDS are at risk of contracting opportunistic infections, such as tuberculosis and diarrhoeal disease. Experience in rural Zambia shows that simple techniques can minimise the likelihood of children or other family members being infected (Williams 1992).

4.2.3 Access to adequate nutrition

Younger children and orphans are particularly at risk from malnutrition (see Section 2.3.3). One solution might be to target nutritional assistance at younger children who have lost a parent to HIV/AIDS and risk becoming malnourished. The long period of illness that typically precedes an AIDS

death should make it possible to identify children before they become malnourished and enrol them in a community-based feeding programme.

This approach is likely to be more sustainable than providing help to all children in an AIDS-affected community, as the number of children under five living in AIDS-affected households is likely to be relatively small. Also, providing assistance directly to children rather than to families avoids the problem of families who take in children with the expectation of assistance (World Bank 1997).

However, including all children affected by HIV/AIDS in a broader feeding programme is more equitable than targeting AIDS orphans. Such programmes give children the nutritional support they need and are easy for the community to manage. Short term costs of start-up, training and transport may be met by external agencies (McKerrow 1996).

Community or village feeding posts and day-care centres

Day-care centres and early childhood education and development centres (see Section 4.2.1) can be used to provide a combination of food, education, development activities and recreation for young children. Day care centres with child feeding programmes are particularly valuable for enabling women to engage in income generating activities (see Section 4.1.4).

School-based feeding programmes

In communities severely affected by HIV/AIDS, school-based and other group feeding programmes are a further way of ensuring that children have a nutritious meal at least once a day (UNICEF 1999b).

Recommendations for NGOs: Access to healthcare and nutrition

- the only sustainable way of providing basic health care and adequate nutrition for children affected by HIV/AIDS is through the strengthening of community-based services. Children under five are particularly at risk, and should be targeted
- home-based care teams, as well as day-care centres and crèches, are well placed to monitor the health and nutrition of children living in affected households
- community-based services need to develop referral systems so that children in need of more sophisticated health care can be referred on, and some means of accessing further care needs to be provided such as financial help or transport
- the provision of food directly to children may be more effective than distributing to households. Places where children gather, such as schools, day-care centres and crèches, offer an opportunity to provide meals for children
- providing food for all young children in the community, particularly in communities severely affected by HIV/AIDS where malnutrition is widespread, is more equitable than targeting AIDS orphans
- 'youth-friendly' reproductive and sexual health services must be provided for young people living in severely affected communities.

4.2.4 Addressing children's emotional needs

It has been suggested that a combination of psychosocial and technical support for children and their families with, for instance, income generation or agricultural inputs may enable African families to cope with the growing number of additional children (UNICEF/CEDC 1998a and 1998b). Organisations that support children affected by HIV/AIDS may be aware of their psychosocial needs, but often feel they lack the skills to address them appropriately.

Psychosocial support by trained specialists and therapists, as provided by welfare systems in western countries, is rarely available to children in developing countries. Nor is it necessarily appropriate: the role of the community and the extended family is sometimes overlooked by the 'medicalised' approaches used in the west, i.e., traditional family therapy based on western concepts of the family (Richman 1996).

Each culture constructs its own particular model for explaining calamities, expressing distress, and arranging support for those who suffer. (Shweder and Bourne 1984, quoted in Richman 1996)

Communicating with children and gaining their trust is the skill that should be encouraged in communities affected by HIV/AIDS. Church organisations, NGOs, informal community-based groups, donor projects and other organisations can provide this vital support, often under the general heading of 'counselling'.

Box 4.8 Counselling: What does this really mean?

The word counselling is often used indiscriminately to describe different forms of psychosocial support, for individuals and groups, for adults and children affected or infected by HIV/AIDS. The word is rarely defined in programme documentation, and the meaning of 'counselling' for different groups is far from certain. For instance, the most appropriate form of psychosocial support for adults caring for HIV-affected children will be quite different from that required by children who are themselves HIV-positive. Children and adults of different ages and in different socio-economic circumstances will have different psychosocial needs.

Programme participants often request counselling, but it is not clear whether this is a term borrowed from western practitioners, or whether it is a generic term referring to the general provision of advice and emotional support, that must be understood according to local constructs.

'Help will be unacceptable if local culture is ignored, but frequently western models are put forward without considering their applicability, and therapies are introduced by enthusiastic experts with little thought as to their practicality' (Richman 1996).

Counselling covers a very wide range of activities, but perhaps the most useful of the many definitions is: 'a series of activities in which helpers and clients engage. These activities, however, have value only to the degree that they lead to valued outcomes in clients' lives.' Research is needed that examines to what extent different forms of 'counselling' (individual, group, peer, etc.) provided by projects is leading to 'valued outcomes' for clients, particularly children. Programmes need to explore with the community the type and extent of counselling support they need.

Sources: *The Skilled Helper: a problem-management approach to helping*, by Gerard Egan, 5th Edition, 1994 and *Principles of help for children involved in organised violence*, by Naomi Richman, SC UK 1996.

Research is needed into how far the different forms of counselling and support, for example, individual, group, or peer, provided by projects lead to 'valued outcomes' for clients, particularly children. Agencies should discuss with the community the type and quantity of counselling they need and monitor performance on a regular basis.

Too often, meeting children's material needs has taken precedence over meeting their emotional needs when programme resources are allocated. This means that there is little experience on which to base recommendations for future programming. However, two broad areas of support have been shown to be important:

1. direct support to children
2. support for parents, guardians, teachers and others with responsibility for children.

Identifying children in need of support

Support can either be targeted directly at children, or these children can be involved in a broader programme of support open to all children in the community.

Targeting involves identifying the children who are suffering emotional problems. Home-based care teams who regularly visit households containing people sick with HIV/AIDS are well placed to do this. Adults who regularly come into contact with children living in affected households – such as guardians, teachers, youth leaders, etc. – can also be trained to identify children in need of support.

The following symptoms might indicate that a child needs extra attention:³⁵

³⁵ The list is provided for children who have been involved in organised violence. It is, however, equally applicable to children suffering other types of crisis, such as living in communities severely affected by HIV/AIDS.

- no friends, withdrawn, isolated
- apathetic, does not play or study
- very sad, clinging to adults
- worries, fears and panics, nightmares
- over-eating or under-eating
- aggressive, disobedient
- restless, poor concentration
- many symptoms, such as headache, that cannot be explained on a physical basis
- marked change in behaviour or capacity to learn.

(Richman 1996)

Opportunities to express anxieties and fears

Enabling children whose parents are ill to express their anxieties about the future, and helping them to accept their parents' impending death are two important tasks. Children should be allowed to express themselves not solely through talking, but through play, drama, song and other activities that form part of their culture. Schools, youth clubs and anti-AIDS clubs can provide opportunities for children to express their feelings, particularly in the presence of trained facilitators.

Play, exploring and learning are important means of rehabilitation for younger children (Reid 1997; Donahue and De Lay 1999). Day care centres, village feeding centres and crèches may provide appropriate settings for these activities.

Group support

Enabling children affected by HIV/AIDS to build relationships of trust with their peers as well as with trained facilitators can help to address psychosocial problems (Kamya 1997; Richman 1996).

Groupwork can be helpful in addressing the complexity of issues associated with HIV/AIDS especially around issues of safety, information, the expression of emotion and greater insight regarding themselves and their relationships with their sick family members. (Kamya 1997)

Groups can be used to explore issues that might be difficult to discuss one-to-one: for example, revenge, anger, conflict, unacceptable behaviour and lack of trust in adults (Richman 1996). Useful methods include drama, pictures, storytelling, films, painting and poetry.

Group work of a different type is being explored in Zimbabwe by the Salvation Army, which runs camps for children from AIDS-affected households. The camps focus on life skills development and experiential learning. The camp builds confidence in the children and young people and aims also to strengthen support links within the communities involved.³⁶

Strengthening community cohesion

³⁶ Stefan Germann, personal communication.

This approach is based on the premise that providing support for all the children and families in a community will increase the capacity of the whole community to cope. The aim is not to target specific children for specialist care but to strengthen overall health-promoting activities (Richman 1996).

One obstacle to this approach is the fact that certain cultures do not regard children's emotional needs as important. Children may not be encouraged to speak about their parents' deaths, particularly when the prescribed period of mourning is over, and young children are often not even told about their parents' death in order to protect them. Furthermore, the fear and stigma attached to HIV/AIDS may mean that people will not discuss it.

The strengthening of social cohesion alone may therefore be insufficient to overcome the cultural obstacles to addressing the emotional and psychosocial needs of children. However, when linked with raising the community's awareness of HIV/AIDS, particularly the emotional needs of affected children, it may prove to be an effective method. Further research is needed that identifies the most appropriate methods of strengthening cohesion within communities. Community mobilisation would be one such methodology (see Section 4.1.3).

Maintaining continuity of care

Continuity of care is particularly important for vulnerable children (Kamya 1997), and parents should therefore be encouraged to plan for their children's future. If possible, the children should be introduced to their appointed guardian while their parents are still alive (Williamson 1997).

Before they die, sick parents often ask that all their children be kept together in the community (McKerrow 1996). For children in a rapidly changing environment, staying with one's siblings offers much-needed continuity. Children often prefer to remain in child- or adolescent-headed households rather than to live with other relatives if this means being separated from siblings.

Encouraging and helping children to compile 'memory books' with pictures and poems recording personal and family history will provide some continuity in their lives and may help them cope with loss. The aim is to create for the children a permanent reminder of their family long after the parents have died.

Support to parents, guardians and other adults

Providing emotional support to parents, guardians, teachers and others responsible for children will help them to work more effectively. This may involve:

- psychosocial support to help HIV-positive guardians in dealing with their children
- helping teachers and others to deal with the emotional impacts of HIV/AIDS on children
- recognition of adults' efforts in supporting affected children.

Adults responsible for children can be trained to recognise the signs of emotional distress. Traditional healers and local religious leaders also play an important, though sometimes forgotten, role in providing emotional support to children.

Disclosure of HIV status to children

Being open and honest with children may enable them to deal more effectively with the situation and to provide greater help in the household. A study in India found that children whose parents had told them of their HIV-positive status were better able to accept the situation than children whose parents did not feel able to speak about their illness. Children who were aware of their parents' HIV status were also more ready to take on additional responsibilities at home, including caring for sick parents.³⁷ Such disclosure can assist with the arrangements of foster care for the children after the adult's death, and can bring children into the discussion. The National Community of Women Living with HIV/AIDS (NACWOLA) in Kampala, Uganda, has pioneered much of this work (Box. 4.9).

Box 4.9 Succession Planning: The national community of women living with AIDS (NACWOLA), Uganda

NACWOLA is a Kampala-based NGO, with a national membership of 40,000 women, and branches in 18 districts. In 1996, a partnership was forged with SC UK to establish the Memory project. The overall goal is to empower mothers living with HIV/AIDS to face the reality of AIDS in their families, to talk to their children, to start to plan for their future, and to start to safeguard family history using memory books.

There are four key objectives of the Memory Project:

1. to encourage open dialogue, about their illness, between HIV-infected mothers and their children, and the likely psycho-social impact on the children
2. to pass on (in time) vital family history and information to AIDS-affected children
3. to initiate and facilitate child counselling by accessing and providing vital family information to AIDS-affected children, their counsellors, foster parents and caretakers
4. to initiate a uniting factor between AIDS-affected children/orphans in case of separation after the death of their parents.

Phase two of the Memory Project aims to respond further to the needs of children affected by HIV/AIDS by:

- training mothers in communication-with-children skills
- counselling of children
- writing memory books
- home visits and follow-up of children and mothers in the homes

³⁷ This study was not published at the time of going to press, but the results were e-mailed by the director of CCDT.

- children's drama and music
- publication of children's quarterly newsletter
- children's legal project to address children's legal needs
- mothers' legal project
- a monthly children's forum.

Sources: NACWOLA, personal communication and Douglas Webb

Regular monitoring

Regular monitoring of children affected by HIV/AIDS will enable them to be given more consistent support, as well as providing useful information for programmers and policy-makers. Methods of assessing a child's emotional state can include conversation, observation and activities such as drama, story-telling and song.

We have seen that the impacts of HIV/AIDS on children are interlinked and that approaches to address children's material needs, such as protecting women's, and children's inheritance rights, and removing children from abusive situations, also affect children's emotional health. Awareness raising, mobilising of community and religious leaders, and involving the media are three further strategies that will lessen discrimination and stigmatisation of affected children and adults and thereby support their ability to cope with the psychosocial impacts of HIV/AIDS.

Raising awareness of HIV/AIDS

In Thailand and Uganda, government-backed national campaigns that have brought together ministries, NGOs, grassroots organisations and the private sector to raise awareness of HIV/AIDS have led to a decline in stigmatisation and in HIV infection rates (FAO 1999; UNICEF and UNAIDS 1999).

NGOs can raise awareness at all levels, particularly in communities where they are known and trusted. They can help develop information systems, both formal and informal, to provide information and advice to affected communities and thus reduce stigmatisation and discrimination of affected children.

Involvement of religious and community leaders

The involvement in HIV-related activities of village or community elders, religious leaders and other influential men or women in the community can act to decrease stigmatisation of those affected by HIV/AIDS, including children. A project in Thailand (see Box 4.10) is involving Buddhist monks and nuns and village elders and chiefs in providing information to the community about HIV/AIDS and services such as meditation and counselling (SMP 1998, 1999).

Box 4.10 The Sangha Metta Project, Thailand

The Sangha Metta Project provides Life Skills Training for monks and nuns who return to their villages and, using participatory methodologies, help community leaders, members of local committees, village headmen, and others, to develop their understanding of HIV/AIDS and its impact on their communities. Community members are then encouraged and supported in working together to manage the problem at the local level.

From an initial focus on education and awareness raising, the project has expanded to include a range of other prevention and care activities, including vocational skills training for women and youth, home visits for PLWHA, support for children of PLWHA including pre-school centres, and advice on herbal and traditional treatments. Traditional Buddhist activities such as meditation and contemplation are also used for their therapeutic effect.

The project has been so successful in involving religious and lay community members in its awareness raising, prevention and care work that it has expanded geographically to Central and Southern regions of Thailand, as well as to neighbouring countries including Myanmar, Laos and Cambodia. Links have also been established between the Sangha Metta Project and monks in China and Bhutan. The network of Buddhist monks, novices and nuns engaged in HIV/AIDS prevention and care work now exceeds 800 and reaches throughout Southeast Asia (with the exception of Vietnam). The first annual evaluation found that the project had made significant progress towards decreasing stigmatisation of, and discrimination against, children and adults affected by HIV in the communities where it is active.

Sources: Sangha Metta Project documentation (see references SMP 1998, 1999)

Involvement of the media

The media can help to dispel myths associated with HIV/AIDS by reporting the facts and describing how families and communities are coping by means of mutual support.

Recommendations for NGOs when addressing children's emotional problems

- addressing children's emotional needs does not normally require trained specialists but can often be achieved by strengthening existing capacity within the community
- adults with responsibility for children can be trained to identify those who need emotional support and to address the problem themselves or refer the children on
- emotional support for parents, guardians and teachers is also important – as is supporting parents in disclosing their HIV status to their children

- traditional healers and spiritual advisers have an important role to play in addressing children's emotional problems
- counselling for children must accord with local cultural traditions, and must be monitored to ensure that it leads to 'valued outcomes'
- group support can be particularly effective in addressing children's emotional problems, particularly when managed by a trained facilitator
- continuity of care is vital for vulnerable children: for example, they can be introduced to their future guardians while their parents are still alive
- siblings should be kept together
- raising public awareness about HIV/AIDS and involving religious and lay community members in programme activities will reduce stigmatisation.

4.2.5 Ensuring children's protection

The UNCRC places a duty on governments to protect and respect children's rights (see Chapter 5), and this is reflected in a growing number of national laws and policies that address children, and particularly orphans.³⁸

A child's right to protection is embodied in many of the UNCRC's articles (see Chapter 3), for example, the right to protection from physical and mental abuse and from discrimination (Articles 2 and 19). The impacts of HIV/AIDS deprive children of their rights: for example, by removing them from parental care, separating them from their possessions and their families, and alienating them from their communities. The following are among the many possible actions that may protect children affected by HIV/AIDS:

- protecting the inheritance rights of women and children
- protecting children from physical and sexual abuse
- finding appropriate alternative care for orphans when they cannot be cared for by members of their extended families.

Protection of inheritance rights

Women need to know and understand laws that can protect their and their children's inheritance rights. Although children are traditionally the responsibility of the father's family, when a man dies in a patrilineal society it is becoming increasingly common for his family to seize his possessions but to leave his children either with their mother or with their maternal relatives (UNICEF/CEDC 1998b). Where the mother is absent, children separated from their homes in this way may be forced into living on the streets unless alternative care can be arranged.

Helping terminally ill parents or guardians to draw up future plans for the care of the children and the distribution of property is sometimes called 'succession planning'. Where no plans are made, relatives and community members may be reluctant to interfere for fear of upsetting the spirit of the deceased.

³⁸ The African Charter on the Rights and Welfare of the Child is based on the UNCRC.

Depending upon traditional customs or national laws, parents or guardians may need to take specific steps – including the payment of fees – to safeguard their children’s inheritance rights. External organisations can support this process by helping people to write their wills, discussing the property rights of widows and orphans with local leaders and others in the community, and providing funds for legal action where necessary.

Advocacy, media campaigns and strengthening the law courts can help to ensure that laws and regulations on inheritance are observed (Mutangadura and Webb 1999).

This type of support is usually most successful if it forms part of a multi-sectoral approach. The community needs to be convinced that the proposed inheritance plan is the best option for all concerned, and that the extended family will carry out the dying person’s wishes, particularly where support to women and children in inheritance matters contradicts societal norms and traditions.

Protection from physical and sexual abuse

The beating, starvation and sexual and general abuse of orphans and other vulnerable children in communities affected by HIV/AIDS has been well documented (Baggaley et al. 1999; Dunn et al. 1992; Lee 2000; Tarantola and Gruskin 1998; Haworth and Mayeya 1999). Children need to be better informed about HIV/AIDS and abuse, and how they can protect themselves.

Orphan identification and support programmes and home-based care programmes are both well placed to support children who are vulnerable to abuse (see Section 4.1.5). Volunteers, care team members, teachers and others should be trained to identify cases of abuse and to deal with them sensitively.

Care for children outside the extended family

Family-based help is not always available for children affected by HIV/AIDS, and therefore a range of other types of care need to be available, for example, institutions, foster care, adoption and residential projects.

Few governments, donors or international NGOs now believe that institutions are the answer to the growing number of children orphaned by AIDS in developing countries. However, in some communities the increasing pressure on extended family networks is leading people to assert that these children are the responsibility of the state and not the community (Ayieko 1999; Webb 1997).

A study in Kenya found that, even in communities where the concept of institutionalising children is alien, villagers are urgently demanding orphanages to be built. This has resulted in institutions that provide sub-standard care (Ayieko 1999).

For these reasons, programme activities planned on the assumption that vulnerable children will be accommodated within the community may be at odds with the community's own priorities. Community mobilisation (see Section 4.1) may be a good methodology for discussing the pros and cons of why children should remain in their communities. There is an urgent need to develop new forms of institutional childcare within communities (see 'surrogate care' below) and to choose initiatives that are both acceptable to the community and that provide appropriate care.

Orphanages

Some form of institutional care may be the only viable option when:

- a child is abandoned at or soon after birth (perhaps because of the death of the mother)
- the child has no extended family, or the family refuse to take in the child
- the capacity of the community to take in more orphans is exhausted
- providing shelter for street children
- providing temporary care for young children who later return to their communities.

(Brown and Sittitrai 1995; McKerrow 1996; CCDT personal communication; Williamson 1995).

There are, however, typical problems associated with institutionalisation of children, including those set out in Box 4.11 below.

Box 4.11 Common problems with institutions for children

- financial sustainability: orphanages are expensive to build and they need to be staffed and maintained
- children's emotional needs may be neglected
- continuity of care is difficult to achieve
- children's needs for play and recreation may be neglected
- children may be separated from their communities, culture and traditions
- children often suffer stigma and mistreatment because of their association with HIV/AIDS
- children may experience difficulties reintegrating into the community as adults
- the availability of institutional care can undermine a community's sense of responsibility for children whose parents have died.

(Sources: Drew, Makufa and Foster 1998; Dunn et al. 1992; McKerrow 1996; Rajkumar 2000; Williamson 1995 and 1997; UNICEF and UNAIDS 1999).

In many countries, orphanages are viewed with suspicion and children are thought to be better off in their communities (McKerrow 1996). Indeed, childcare institutions are widely associated with financial corruption, child abuse and poor standards of care (Dunn et al. 1992).

Although the vast majority of children are cared for in their communities, childcare institutions exist practically everywhere. Most of the orphanages in Africa are run by NGOs and other private and voluntary organisations (McKerrow 1996). They rely for much of their income on contributions from the local community; this obviously limits the quality of care that they can provide, particularly in communities severely affected by HIV/AIDS.

Children affected by HIV/AIDS are often barred from childcare institutions and are routinely discriminated against. In Thailand, children from HIV-affected households are often refused entry to childcare institutions (Brown and Sittitrai 1995). In India, separate homes have been set up for infected and affected children, and in most children's homes children whose parents are HIV-positive are tested for the virus and the results made known (Rajkumar 2000).

Some projects that previously focused on providing institutional care according to the welfare model have begun to adopt an increasingly community-oriented focus. The AIDS Orphan Project in KwaZulu Natal run by the Thandanani Association in South Africa is an example of one such project. The project originally aimed to move abandoned children out of hospitals where they were largely cared for and into more appropriate forms of institutional care. However, on the publication of research by McKerrow and Verbeek (1995), which assessed community responses to the growing problem of orphans, the Association set up a new project to investigate community-based alternatives for orphaned children (Harber 1998).

Formal child fostering and adoption

There are alternatives to institutional care – such as foster homes, collective foster care, surrogate parenting and adoption – that are less likely to 'institutionalise' children and can provide more personalised care in a family-type environment. Although financial sustainability remains a problem, family-based care in a child's own community generally offers the best opportunities for positive psychosocial development (Reid 1997).

In Uganda, the church runs houses where orphans live with a full-time housemother responsible for their total care (McKerrow 1996). In South Africa, volunteer women or couples are recruited as 'surrogate parents', trained in basic childcare, provided with state funding and given responsibility for small groups of children. Community workers support these homes by linking them with other projects in the community (McKerrow 1996).

'Collective foster care' involves placing children in the care of an organisation whose members undertake to act collectively as surrogate carers for the children (McKerrow 1996). This is unlikely to be helpful for younger children, however, who develop best when they have a long-term caring relationship with one or two adults (Reid 1997).

Although informal adoption is very common within extended families, formal adoption is rare in Africa. Certain cultural beliefs – in Zimbabwe, for

example, taking unrelated children into the house is thought to invite avenging spirits – may also inhibit formal adoption (SAfAIDS 1996).

Informal fostering of unrelated children is more acceptable, but is still rare (Parry 1998).

The following observations can be made, based on a review of approaches to date:

- children in care should remain within or close to their own communities
- people providing care should be trained in basic childcare, including health and psychosocial support
- institutional care should aim to provide temporary care only and support the long-term rehabilitation of children into their communities
- children should maintain contact with their own families where possible
- siblings should remain together
- children need an adult whom they can trust and who can provide continuity of care
- the community should be encouraged to participate in the care of orphaned children
- the physical, social and psychological condition of children in care should be monitored regularly.

Recommendations for NGOs: Ensuring children's protection

- external organisations should champion women's and children's inheritance rights by advocating changes to national laws and sensitising the community and its leaders to existing and new legislation
- terminally ill people should be helped to plan for the future care of their children and the distribution of their assets
- external organisations can only bring about changes in traditional inheritance practices if they are trusted by the community. Training community members to fulfil this role is a more sustainable approach
- orphaned and vulnerable children, particularly girls, need protection against physical and sexual abuse. They should be told how to recognise potentially abusive situations, how to protect themselves and where to seek help
- people who come into regular contact with children, such as teachers, youth leaders and volunteers, should be trained to recognise cases of abuse. The community's awareness of child abuse should also be raised
- if children cannot be cared for by their families, alternative solutions must be found. Orphanages remove children from their families, communities and traditions and often provide inadequate care (see Box 4.11). Formal fostering and adoption are unlikely to provide adequate solutions for children whose parents have died of AIDS
- new forms of childcare need to be developed within the community, using both internal and external resources, including government funds where possible
- people living in communities severely affected by HIV/AIDS often insist that orphans are the responsibility of the state. External organisations can

help by encouraging the community to devise its own response to the orphan crisis.

Chapter 5: Integrating prevention, care and impact mitigation activities

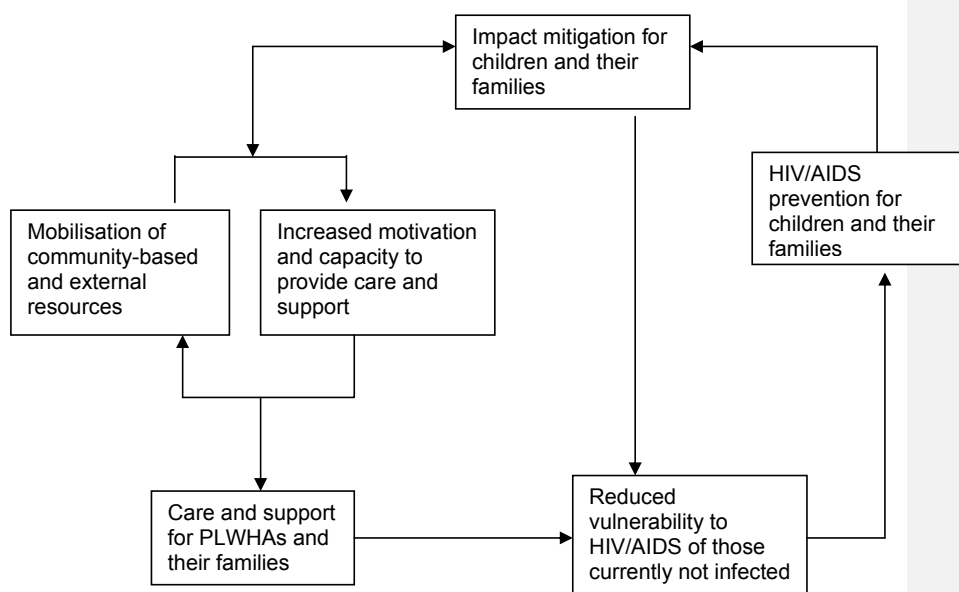
Programme responses to HIV/AIDS are traditionally of three kinds: HIV prevention; care and support for people living with HIV/AIDS; and orphan care. However, this categorisation of programme types largely reflects the priorities of the implementing organisation, rather than the needs of people affected by HIV/AIDS, which tend to be broader. Furthermore, 'orphan care' is too narrow a category; the real need is to support *all* vulnerable children affected by the epidemic.³⁹

Until recently, programme planners seldom considered the benefits of combining strategies for prevention, care and impact mitigation.

Discussions about integrating HIV/AIDS prevention, care and support should acknowledge the fact that care and support enhance prevention, while prevention enhances care and support – a two-way effect that sustains a cycle of benefits. (Girma and Schietinger 1998)

How prevention, care and support and impact mitigation interact is illustrated in the diagram below:

The Prevention-Care-Mitigation Continuum



(Adapted from Girma and Schietinger 1998, p. 15)

An example that illustrates the potential synergy of integration follows:

³⁹ See Chapter 3 for a discussion of definitions of vulnerability and targeting of resources.

Home-based care for people living with HIV/AIDS and their families can alleviate suffering for the sick, help children and the other adults in the family to adjust psychologically to the situation and reinforce the determination of the PLWHA to remain economically and socially productive (Sanei 1998). Supporting adults in revealing their HIV status to their children or in planning for the future (particularly concerning childcare and future ownership of family assets) will benefit the vulnerable children in the household. People working in home-based care are well placed to identify children at risk and to suggest how the family might be given support: for example, by linking it with child feeding centres, day-care centres or education programmes. Happier, healthier and better-educated children are less likely to be at risk of HIV infection.

The sustainable response to HIV/AIDS described in Section 4.1 is based on the premise that communities define their own priorities for action. The needs that people affected by HIV/AIDS have for prevention, care and support, as well as for impact mitigation, will vary, so programmes should grow organically, taking their lead from households and communities.

CCDT in India researched the impacts of HIV/AIDS with adolescent children and identified the following range of areas of intervention:

- providing information on HIV/AIDS
- vocational training and advice
- developing the capacities of children as carers
- working with the family unit to encourage the development of family bonds and to enhance support systems
- preparing children for their parents' deteriorating health and eventual death
- encouraging mothers to tell their children about their illness and help them assume new roles.

CCDT's programme has evolved through two main processes:

1. regular interactions with people affected by HIV/AIDS at individual, family and group level
2. regular monitoring of objectives and studying of client responses.

A far greater proportion of external resources continues to be used for prevention and patient care than for impact mitigation, yet the results so far have been disappointing. The challenge for programmers is to recognise the important links between prevention, care and impact mitigation and to achieve a balance between these activities.

Structures for prevention and care often already exist within the community. For instance, home-based care networks or school-based HIV prevention programmes offer a way of identifying, monitoring and supporting vulnerable children. Providing children with accessible information about HIV/AIDS can not only help prevention but also reduce discrimination in the community (see Section 4.2.5).

Using a framework of child rights, focusing on the 'best interests of the child', will enable organisations to adopt a broader approach (see Chapter 3). HIV/AIDS challenges many of the rights of children: to accessible information and services, to education, to good health status and to protection from violence and discrimination. A rights-based framework makes clearer the need for approaches that combine prevention, care and mitigation.⁴⁰

What does this mean for organisations working in the field? There should be better co-ordination and more sharing of information between agencies working in prevention, care and impact mitigation, including government, NGOs and the private sector (Chapter 6). This will avoid duplication of effort, promote good practice and make more efficient use of scarce resources. People working with communities affected by HIV/AIDS should be made aware of the need for a more holistic approach to the care of vulnerable children.

It may also be necessary to cross-train staff from different programmes; for instance, teachers and children involved in school-based prevention programmes can be trained to identify and support children from affected households. Community meetings and group activities provide an ideal opportunity for discussing different approaches and delivering advice on HIV/AIDS prevention.

Recommendations for NGOs: Integrating prevention, care and impact mitigation

- organisations working in impact mitigation must capitalise on the networks and structures the community has already set up to provide HIV/AIDS prevention and care for PLWHA. The community's resources can be identified as part of community mobilisation (see Section 4.1.3) and/or participatory needs assessment (see Chapter 7)
- organisations working in the same target areas must collaborate with each other, linking the different programme components and developing a shared, community-based approach
- programmes that grow organically, taking their lead from the community, are more likely to initiate a broad range of activities. Supporting community mobilisation can be the first step (see Section 4.1)
- organisations need to assess their capacity to deliver more holistic programmes for children affected by HIV/AIDS
- the emphasis in all programmes should be on building the capacity of communities to plan, implement and monitor their own activities.

⁴⁰ See Section 3.2 on 'Integrating a rights-based approach'.

Chapter 6: The role of government

Governments have a vital role to play in mitigating the impacts of HIV/AIDS on children. They can provide the policy and strategy direction for responses to the epidemic; they also have a legal mandate to respect, protect and fulfil the rights of children.

But the governments of developing countries are severely under-resourced, which means that they must concentrate on mobilising all the actors involved – particularly the affected communities themselves – together in a national response.

What distinguishes all successful and sustainable efforts to combat the HIV/AIDS crisis, including providing care for orphans, is political will.
(UNICEF and UNAIDS 1999)

Ideally, a national policy should inform responses to the needs of vulnerable children at all levels from the local to the national. But the reality is that, even where the political will exists, policies are often either non-existent or too narrowly defined: for example, restricted to orphans. Resource-poor governments rely heavily on funding and other help from donors and NGOs to provide essential services to children, including health, education and social welfare. Without a clear policy framework, and without close collaboration between national and local government, NGOs and the private sector, programme activities will tend to reflect the policies of the funding organisations rather than those of national governments. This may mean that programmes reach only a small proportion of the children at risk.

Some national governments, such as those of Uganda and Zimbabwe, have set out clear policy guidelines for the care and support of orphans, based on children's rights as set out in the UNCRC and the African Charter (UNICEF/CEDC 1998a, b; UNICEF and UNAIDS 1999). But even in these countries, there remain many obstacles at local level to implementing policies and laws to protect women and children – usually because the necessary infrastructure is absent. Organisations can do much to interpret laws and policy, particularly on discrimination and property inheritance, to the communities in which they work.

As we have seen in Chapter 3, a narrow focus on 'orphans' is inappropriate in view of the growing numbers of vulnerable children who are not technically orphans, but who are severely affected by the epidemic. In many African countries, two ministries are responsible for mitigating the impacts of HIV/AIDS on children: the ministry for social welfare and child protection, and the ministry of health. Governments must ensure that these two ministries collaborate.

In Uganda, the Children's Statute of 1997 has consolidated the body of law relating to children and has made its implementation a local responsibility. This has provided a strong framework within which children's rights can be

protected at all levels (Glenfrey De Mel, SC UK, quoted in UNICEF/CEDC 1998a).

The positioning of national AIDS agencies within ministries of health tends to imply that HIV/AIDS is purely a public health issue, and this can lead to resources and technical expertise being concentrated on health-related services. This obscures the fact that HIV/AIDS also challenges the social, economic, developmental and legal rights of children.

Collaboration is vital, not just between different government ministries, but between government and donors, NGOs, CBOs and the private sector. The national government needs to play a co-ordinating and facilitating role.

A planned and co-ordinated set of policy, social mobilisation and programmatic interventions by public sector and civil society actors is needed. This requires government leadership for a strategic response – leadership which, with few exceptions, has been absent. (Williamson 1999a)

In practice, there is probably more informal collaboration between organisations and local government in community-based programmes than there is formal collaboration at national level. This is because the local groups involved in these programmes, such as community AIDS committees, often include local government representatives. However, whether their presence helps or hinders community-based activities is a subject that requires further investigation (Brown et al. 1999).⁴¹

District level is perhaps where external NGOs and donor agencies should concentrate their efforts to collaborate with government. Closer collaboration between district authorities and community-based organisations can significantly help such organisations to meet the needs of vulnerable children in the longer term. In Malawi, for example, community-based organisations working closely with district social welfare officers have set up childcare centres that have been important in providing care for the country's orphans (UNICEF and UNAIDS 1999).

Some governments are simply too poor to pay for the welfare services needed to cater for the growing number of orphans resulting from the epidemic. They therefore need to think of more imaginative ways of tackling the problem. In South Africa, it has been suggested that the government trains a new cadre of workers ('surrogate parents') to care for AIDS orphans; this would not only go some way to solving the orphan problem but also create new jobs (Whiteside 1999). However, this approach implies a significant level of government financing, which is not always forthcoming.

As a way of scaling up their response to children affected by HIV/AIDS, governments could consider the contracting-out of services to NGOs. In Botswana, for instance, district authorities in Bobirwa have contracted out

⁴¹ See Chapter 7 for a brief review of the COPE evaluation system.

the delivery of essential government services for orphans to the Bobirwa Orphan Trust (UNICEF and UNAIDS 1999), and this has made limited resources go much further.

Practitioners now recognise that governments need support and guidance in the development of appropriate policy frameworks. One such process was initiated in 2000, bringing together policy makers, practitioners and researchers to agree on a set of 'programming principles' to support orphans and vulnerable children. The process has been led by UNAIDS, UNICEF and USAID and involves many different NGOs in east and southern Africa. Once finalised and approved, the document will provide a programming framework, which sets out minimum standards of interventions, based on the UNCRC (see Appendix 2).⁴²

In most developing countries, the private sector remains a largely untapped resource in addressing the impacts of HIV/AIDS on children. NGOs could explore the potential for local companies to become involved in support for orphans and vulnerable children: for example, through schools programmes, vocational training and apprenticeships, crèches and other forms of childcare, the provision of technical assistance to community-based groups, and many other activities. Private sector activity must, however, be regulated and promoted by government

NGOs and other organisations working with children affected by HIV/AIDS have a responsibility to advocate on their behalf for the development of effective laws and policies that will enable them to develop and prosper.

Box 6.1 What governments can do to create an appropriate policy framework to support children affected by HIV/AIDS

- enact policies to respect and protect children's rights, particularly the right to health, education and protection from violence or abuse
- enable and encourage women to own land and hold jobs, and protect women's and children's right to inherit family assets
- encourage men to take responsibility for the support of their families
- promote a multi-sectoral response and involve relevant line ministries
- redirect national investment to develop new and imaginative ways of caring for children affected by HIV/AIDS
- create the necessary infrastructure at district level to enable national policy to be reinforced through local structures and translated into local actions
- prohibit discrimination and stigmatisation of affected children
- provide accessible information, services and training on HIV-related issues for people with responsibility for children
- support and co-ordinate increased NGO activity
- co-ordinate and regulate activities by donors, NGOs, civil society and the private sector.

⁴² Connolly, M. 'Principles to guide programming for orphans and other vulnerable children', UNICEF/UNAIDS/USAID, draft October 2000.

- encourage private sector participation in efforts to mitigate the impacts of HIV on children and their families.

(Hunter and Williamson 1998a; Reid 1997; Williamson 1999a; authors)

Chapter 7: Monitoring and evaluation⁴³

There have been too few systematic evaluations of programmes for mitigating the impacts of HIV/AIDS on children to enable different approaches to be compared. This is partly because impact mitigation covers such a broad range of interventions across different sectors. Programmes have typically addressed a specific issue, such as poor school attendance by orphans, rather than being planned in a more holistic way with the community to address their longer-term needs. Hence few programmes have developed measurable objectives on which to base monitoring and evaluation structures. Also, activities that support children are often undertaken as part of wider programmes addressing many aspects of HIV/AIDS, and the evaluation of these programmes has not necessarily measured the child-centred activities.

Box 7.1 Problems in evaluating HIV/AIDS mitigation activities

- the impacts of HIV/AIDS on children are themselves poorly understood
- the overall goal of project activities is hard to define, and is often different for each programme. Project objectives are, therefore, difficult to articulate
- the local context is crucial in determining the vulnerability of children; a generic evaluation procedure or set of indicators may be inappropriate
- because the welfare status of children changes rapidly, baseline data may become irrelevant to the project and the community
- in resource-poor settings with a high prevalence of HIV, it is difficult (and possibly unethical) to differentiate between the impacts of HIV/AIDS and those of poverty
- severely affected communities are most likely to be poor and may not consider HIV/AIDS, or project evaluation, to be a priority.

The evaluations carried out to date have tended to monitor activities and processes, for example, the number of children given nutritional supplements or of teachers trained in counselling. Information on project outcomes has mostly taken the form of descriptions and anecdotal accounts. Such evaluations have their uses, particularly where it is believed that certain activities or processes can lead to specific outcomes. However, this belief is easier to sustain where HIV prevention is concerned. An example that illustrates the potential synergy of integration follows – for example, if a man uses a condom during sexual intercourse his partner is less likely to contract the disease – than with impact mitigation. Returning children from affected households to school may or may not enable them to benefit from an education, depending on why they did not attend school in the first place. It all depends on the specific circumstances.

⁴³ For a detailed, theoretical discussion of the debates surrounding the evaluation of HIV/AIDS prevention and mitigation activities, see Webb, D. *The Search for Best Practice in HIV/AIDS Programme Development*, unpublished report, SC UK.

Developing monitoring and evaluation systems will, therefore, involve a degree of experimentation. We need to measure and document the evaluation process itself, as well as the data it produced. The challenge then is to promote the systematic application of methods developed.

7.1 What is monitoring and evaluation?

Monitoring is the process of regularly collecting, analysing and using information to guide project implementation. Its main elements are project inputs, performance and progress.

Evaluation is the careful examination of a continuing or completed project. It usually involves examination of the project design (objectives and plan), implementation (inputs and outputs) and results (effects and impacts). (Barton 1997)

Monitoring tends to consist of frequent, mainly descriptive, recording of inputs, outputs and activities, whereas evaluation is periodic, more analytical and more concerned with processes and their outcomes (Roche 1999). How far impact is measured through evaluation depends on the individual programme. An evaluation usually takes place at stages during the project (such as mid-term) and at the end, while impact assessment endeavours to measure the longer-term impacts:

the systematic analysis of the lasting or significant changes – positive or negative, intended or not – in people's lives brought about by a given action or series of actions. (Roche 1999)

Monitoring and evaluation has conventionally involved outside experts coming in to measure performance against pre-set objectives, using standard procedures and indicators. However, few HIV/AIDS mitigation programmes have developed standard indicators, and the huge variety of projects working in this area means that standardised procedures may not necessarily capture key outcomes.

In response to the limitations of this conventional approach, participatory monitoring and evaluation (PM&E) emerged in the 1980s (IDS 1998). It fits better with the philosophy of many development NGOs to improve poor people's lives in ways they define themselves. Communities must be active in monitoring and evaluation (M&E), and see their benefits. Otherwise, M&E systems simply enforce a 'top-down' approach and cannot be sustained in the long term, since the community will see little benefit for itself in using these systems.

Four broad principles underpin PM&E:

1. *Participation*: Including all stakeholders in the design process and analysing the data together

2. *Negotiation*: Agreeing what will be monitored and evaluated, how data will be collected, what the data actually means, how findings will be shared, and what action will be taken
 3. *Learning*: Using the intervention as the basis for subsequent action, both in organisations and in the participating communities
 4. *Flexibility*: Essential for keeping pace with changes in the number, role and skills of stakeholders, and the context in which they operate.
- (IDS 1998)

Beneficiaries should be the subjects rather than the objects of evaluation (Guba and Lincoln 1989). Evaluation should take account of the views of a far wider range of stakeholders, particularly those who are not normally heard, such as vulnerable children in AIDS-affected communities.

The principal methods of PM&E include rapid rural appraisal (RRA), participatory action research (PAR), and participatory rural appraisal (PRA, now often called PLA or participatory learning and action) (Chambers 1997). In addition, there is a host of other techniques for collecting qualitative data, such as drama, focus groups, workshops, participant observation and even 'hanging around'.⁴⁴

7.1.1 Participation of children

Stakeholder participation is particularly important for children. The UNCRC states that children have a right to be heard and that all actions concerning children should be in their best interests (see Chapter 3). We know that the situations in which children find themselves profoundly influence how HIV/AIDS impacts on their lives. We also know that children experience things differently from adults. Therefore, it seems illogical that decisions about their future should be based solely on adult interpretations of their needs:

Only children and young people themselves can tell us what it means for them to live in a world with AIDS. (Colling 1998)

It is for the community to decide which children are vulnerable, based on their own classifications,⁴⁵ for example:

- children living with HIV
- children living in affected households (one or more adults with HIV/AIDS)
- maternal and/or paternal orphans
- abandoned and destitute children
- disabled children
- children living in child- or adolescent-headed households

⁴⁴ For an excellent résumé of participatory methods for collecting data, see Roche, C. *Impact Assessment for Development Agencies Learning to Value Change*, Oxfam/Novib, 1999, pp. 97–163.

⁴⁵ See Section 3.1.1 'Is specific targeting of orphans justifiable?', which gives information on community-generated criteria for assessing vulnerability.

- children living with elderly carers.

How children are involved in participatory monitoring will depend upon their age and the local circumstances. Hart's ladder of children's participation is one conceptual model.⁴⁶ It recognises eight levels, ranging from manipulation, decoration and tokenism at the bottom (the three categories of non-participation) to child-initiated shared decisions with adults at the top. Levels 4 to 8 indicate increasing degrees of initiation of children, but it is not suggested that all projects should aim to operate at the top level, since some children are better collaborators than initiators (Johnson et al. 1998).

Increasingly, programmes are experimenting with PLA to involve children in different stages of the project cycle, for example, a project in Eastern Zambia found that a combination of mapping, child-to-child interviews and small discussion groups was an effective way of involving children in research (Barrett and Browne 1998).

In some cultures, children are neither expected nor encouraged to participate in decisions about their well-being, and community members may not wish to see children consulted by outsiders. In the COPE project in Malawi, children were reluctant to talk for fear of being 'chased away from the house by guardians' and being considered 'rude'.⁴⁷ This underlines the need for a culturally sensitive approach and for skilled facilitators who are known and trusted by the community.

A useful set of questions about child participation in evaluation appears in a booklet from UNAIDS, reproduced in Box 7.2 below.

Box 7.2 Questions to ask when evaluating children's and young people's activities

- Have children and young people and their families been involved in deciding the measure for the evaluation?
- Can children and young people benefit from the evaluation, and how?
- What have been the risks and costs for children of their involvement?
- Have confidentiality and privacy been respected at all times?
- Do the children involved know that they are free to refuse or to withdraw at any stage, and that this will not be held against them?
- If certain children have been excluded from participating, can their exclusion be justified?
- Have the children concerned and/or their carers helped to plan, implement, analyse and evaluate the activity?

⁴⁶ Information on Hart's ladder of children's participation can be found in *Children's Participation: From tokenism to citizenship*, UNICEF, 1992.

⁴⁷ Report of Malawi visit by Douglas Webb, SC UK, February 2000.

Are the children concerned aware of the purpose and nature of their participation, methods, timings, benefits, consequences and outcomes?
What have project workers learnt from the participation of children and young people?
Will the children and young people and their families be informed of the main findings?
Aside from the effects of the activity on the participants, how might the conclusions affect other children and young people?
(Colling, J. *Children living in a world with AIDS: Guidelines for children's participation in HIV/AIDS programmes*, UNAIDS, 1998)

7.2 Why evaluate and who is the information for?

The justification for spending money and effort on monitoring and evaluation will vary from organisation to organisation. For example, an organisation such as SC UK may do so:

- to demonstrate impact at local level and thereby encourage communities to take action to mitigate the impacts of HIV
- to target resources more effectively at activities that achieve successful outcomes as defined by the community
- as a response to growing competition for resources and increasing pressure to demonstrate accountability and transparency
- to enable the organisation to learn lessons
- to disseminate examples of good practice among organisations working on HIV/AIDS and children.

Beneficiaries may perceive M&E to be time-consuming and to use up scarce local resources at the expense of other activities they regard as more important. Monitoring and evaluation may also arouse expectations of future assistance. For these reasons, all stakeholders must agree at the outset on the purpose and focus of the evaluation and must discuss the question of future assistance (Roche 1999).

A wide range of potential stakeholders need information about programme activities, and it is doubtful if any one system can satisfy them all. Management must therefore decide what information will be gathered and who it will be given to. This will always involve striking a balance between the constraints of finance, time and available skills and the pressure to produce yet more information. The emphasis should be on simple, practical information that can be fed back into programme activities at a local level to improve the likelihood of successful outcomes. The principal beneficiaries of any evaluation system must be the target communities, and, in this case, children affected by HIV/AIDS.

Table 7.1 Benefits of monitoring and evaluation

Stakeholder	Potential Benefit
Target group/ community	<ul style="list-style-type: none"> • ownership through participation • empowerment for change (removal of fatalism through demonstration of project effectiveness) • sense of belonging for children involved in programme monitoring • Possibility of attracting additional support through systematic reporting of scale of problems
CBO/NGO/government counterpart	<ul style="list-style-type: none"> • information for planning and strategic choices • development of intervention good practice • improved reporting to funding agency • improved information for fundraising • improved information for advocacy • capacity building in M&E techniques
SC UK Project Officer	<ul style="list-style-type: none"> • development of intervention good practice • assessment of project impact/cost effectiveness • capacity building in M&E techniques • improved reporting to programme officer • assessment of indicator validity
SC UK Country Director	<ul style="list-style-type: none"> • information for programme strategic choices • development of intervention good practice • recognition of project impact/cost effectiveness • improved accountability to government/donors • improved information for fundraising • information for advocating policy change
SC UK Globally	<ul style="list-style-type: none"> • development of examples of good practice • improved financial accountability to donors • improved chance of achieving intended outcomes • demonstration of project effectiveness to other stakeholders - advocacy
Donors/NGOs/other key actors	<ul style="list-style-type: none"> • sharing of experiences regarding the monitoring of project implementation effectiveness • recognition and implementation of good practice • reporting to governments/parliaments/funders

(Webb, D. and Elliott, L. *Learning to Live: Monitoring and evaluating HIV/AIDS programmes for young people, SC UK, 2000*).

7.3 The use of indicators for monitoring and evaluation

Using indicators to monitor the qualitative changes brought about by an intervention is particularly difficult for projects aiming to mitigate the impact of HIV/AIDS on children. Whereas matters such as the registration of children who have lost one or both parents lend themselves relatively easily to quantitative monitoring, the measurement of behaviour, such as

discrimination or abuse, is more difficult since different stakeholders may have different, and perhaps conflicting, opinions. Furthermore, opinions change over time (CARE 1997b).

It is also difficult for indicators to capture accurately improvements in children's quality of life, which are an important goal of mitigation activities.

7.3.1 Locally derived indicators

Participatory monitoring and evaluation involves the use of locally derived indicators: those developed and monitored by the community themselves. There are, however, disadvantages in using such indicators:

- they make comparisons between different project areas difficult, even within the same programme
- national and district-level monitoring systems may have difficulty in collecting the information they require from community-level activities
- there is a danger of subjectivity when the qualitative information gathered is analysed
- the sheer range and variety of indicators proposed by the community may make programme monitoring impossible.

As a result, there can be a tendency to avoid using experiential and participatory approaches because they raise difficult issues (Welbourn 1998). External agencies can have an important role here in facilitating negotiation between the different stakeholders so that a consensus is reached.

But locally derived indicators also have advantages:

- they are more sensitive to the changes that the community considers important
- the information gathered is relevant to those who gather it, and this can be both motivating and empowering
- developing the evaluation system helps to mobilise the community and maintain community ownership, which is crucial for sustainability.

7.3.2 Generic or core indicators

Generic indicators are generally used in conventional, standardised evaluations and are developed by the implementing agency or other external bodies. Community members will not be greatly committed to gathering this kind of information unless they can be convinced of its value. The principal advantage of generic indicators is that they generate information directly comparable across programmes and countries. Their main disadvantage is that they may not take account of contextual factors, but as we have seen, these are critical to assessing the vulnerability of children.

What mixture of indicators is most appropriate for activities to mitigate the impact of HIV/AIDS on children? We have already stressed the need for a participatory approach to the planning, design, monitoring and evaluation of

programmes. Within this approach, how valid is the use of indicators? The alternative would be to generate narrative reports that take into account the changing perceptions of stakeholders. However, given the growing pressure for accountability and transparency among donors and programming agencies, and the benefits that accrue to stakeholders through demonstrating progress (see Table 7.1 above), this method is unlikely to be appropriate for programmes that receive external funding.

An over-emphasis on indicators can, however, lead to a situation where data collection, rather than the achievement of objectives, becomes the main focus of the programme. A mixture of locally derived indicators with a few simple generic indicators is probably the most appropriate recipe; the precise ingredients should be negotiated between the key stakeholders in the programme (see Table 7.1 above). Data gathered through the monitoring of indicators should always be crosschecked using qualitative evaluation methods, such as in-depth interviews, focus group discussions, ranking and other PLA tools.

7.4 Needs assessments and the collection of baseline information

7.4.1 Needs assessments

Although country-level situation analyses are desirable, many organisations do not have the resources to undertake them. UN agencies and international NGOs should therefore take responsibility for conducting and disseminating such analyses.

Prior to project planning, programming organisations must undertake locally based needs assessments. These should empower everyone who participates – particularly those (such as children) whose voices are rarely heard – and build consensus among the different stakeholders. They should produce information about the availability of local resources, and enable decisions to be made about the effective targeting of those resources and the prioritisation of different approaches. The project should be visibly 'owned' by the participating communities, as this will help to ensure its sustainability. The techniques of PRA – such as diagrams, impact-flow charts, time-lines, historical profiles and ranking – are the most suitable for locally based needs assessments. However, other techniques, such as storytelling, drama and drawing, are more appropriate for children's participation.

Before conducting a needs assessment, agencies should gather information from as many sources as possible, including other community-based programmes in the area, national or district-level data, local government officials and research findings. Some of the communities participating in a new HIV/AIDS initiative may previously have taken part in other such initiatives, and the needs assessment must investigate their impact.

Standardising those parts of a needs assessment that collect information about vulnerable children – where they are, the circumstances of their lives,

the nature of their needs – can contribute much to national-level situation analyses.

In areas where the number of affected children is currently low but is expected to grow, there is a strong argument for developing community-based surveillance and tracking systems. Through local structures such as village development committees (VDCs) a simple tracking system can be set up that:

- monitors adult illness and death
- identifies vulnerable children in households affected by illness and death
- monitors rights violations, i.e., regarding property, inheritance, or exploitation
- identifies cases of informal child fostering
- identifies household coping responses to the anticipated 'shocks'.

Such tracking could feed into government programme development at both provincial and national level, providing valuable evidence for other agencies looking to support vulnerable children.

7.4.2 Collecting baseline information

There are two main problems with baselines:

- it is difficult to predict the future information needs of a project, as these will change as the situation of communities affected by HIV/AIDS changes
- there may be difficulties in collecting, analysing, storing and recovering information once time has elapsed.

But in the absence of baseline information, projects must rely on retrospective techniques that may provide a completely different picture (Roche 1999). To overcome these problems, organisations use a 'rolling baseline' which allows changes in people's lives and priorities to be recorded regularly by tracking 'panel groups' or 'cohorts' (groups of individuals or households) over the lifetime of the project (Roche 1999).

This inability to predict exactly the future information requirements of a project means that indicators must be regarded as flexible instruments that may need to be modified during the life of the project. By definition, indicators can only capture those changes that are expected to take place as a result of the intervention. Also, indicators are usually designed to capture positive changes only, such as percentage increases or reductions in negative behaviour, which means that unexpected outcomes or negative changes may not be captured by an M&E system that uses only indicators to assess change (Roche 1999). This underlines the need to cross-check information from different sources, both for the baseline and for the subsequent monitoring of indicators.

7.5 What can we learn from existing evaluation activities

To give examples of good practice is difficult at present, owing to the absence of a conceptual framework for programmes and the small number of systematic evaluations so far carried out. Some of the projects listed in Box 7.3 below are currently developing evaluation methods, including the generation of indicators to measure activities, outcome and impact, and a number of others have undertaken more qualitative reviews.

Box 7.3 Programmes that have been reviewed and/or evaluated

Community-based Options for Protection and Empowerment, the COPE Project in Malawi (Save the Children Federation, US).
Orphans and Vulnerable Children (OVC) Project, the OVC Project in Zambia (Project Concern International).
Community Counselling Aides Project, National AIDS Control Programme of Uganda (Action-research supported by the Population Council).
FOCUS in Zimbabwe (Family AIDS Caring Trust).

What do these programmes tell us about evaluating activities to mitigate the impact of HIV/AIDS on children?

1. Participatory monitoring and evaluation should be the key methodology

Context is vital for understanding the needs of children affected by HIV/AIDS, and therefore participatory monitoring and evaluation is the best way of assessing the changes brought about by interventions. Monitoring and evaluation will take place against a constantly shifting baseline, as the demography and socio-economic situation of participating communities change, and therefore the development of tracking systems, participatory formative needs assessments or situation analyses must be the first step in project design.

This does not mean that generic indicators have no place in monitoring and evaluating mitigation activities, but that they must be locally validated by the community. A skilled facilitator will be able to suggest generic indicators that can be debated by community members.

2. The process of setting up and implementing M&E systems can itself improve project performance and enhance sustainability

The Community Counselling Aides (CCA) Project of the National AIDS Control Programme in Uganda (NACP) participated in a Population Council action research project to test the hypothesis that:

...with a monitoring and evaluation system and defined indicators of success in place, the output of project activities in AIDS prevention and care at the community level are significantly improved⁴⁸ UNICEF and UNAIDS 1999).

The project devised simple monitoring tools – a reporting format for the CCAs, a summary format for monthly reporting and a supervisor's checklist – and trained the CCAs and their supervisors to use them. A baseline survey was carried out using interviews with local households and the CCAs, a review of programme and other documentation, observation and questionnaires. This was then repeated at the end of the trial period. The lessons learned included:

- materials as simple as a school exercise book and a few sheets of paper can be used to monitor the performance of HIV/AIDS interventions
- with appropriate training and support, community volunteers with basic literacy skills can benefit from systematic monitoring of their activities
- local organisations are better able to support the volunteers when provided with the data collected through the monitoring system
- the information collected can help to attract additional support for a community programme from local government, health authorities and the community
- the information can also provide important feedback to a national organisation, such as the NACP, on the effect of its programmes in the field.

(Children Orphaned by AIDS: Front-line responses from Eastern and Southern Africa, UNICEF and UNAIDS, 1999)

3. Effective training and support for those collecting the data is vital for the success of M&E systems

The COPE II project of SCF/US in Malawi (Brown et al. 1999) used a 'cascade' method to train officers at district level to use the management information system (MIS); these officers then delivered training at community and village levels. The project review found that VACs were enthusiastic about project activities and perceived information gathering to be important. However, despite their enthusiasm, most participants at community and village levels had had insufficient training to participate effectively; they did not really understand why they collected the data and did not believe it to be useful to them.

4. The involvement of government employees can significantly improve data collection

The COPE review also found that data collection was more systematic when government employees (extension workers) sat on the community and

⁴⁸ Although the project was mainly concerned with HIV prevention and care for PLWHA, community-based counselling is equally applicable to many of the impacts of HIV/AIDS on children, particularly psychosocial impacts.

village committees, as the gathering of data was part of their job. Agencies should collaborate with local government in designing management information systems, since some kind of data collection system, however rudimentary, is usually in place already.

7.6 Conclusions

When setting up monitoring and evaluation systems, an organisation such as SC UK should, therefore:

- consult a wide range of stakeholders – including local government, local NGOs and other community-based groups, donors, programming organisations and the private sector – in order to identify a local partner or partners
- conduct a local needs assessment using participatory techniques. This should be facilitated by someone skilled in PM&E. (If these skills do not exist within the organisation, they can be learned or an external facilitator can be brought in.) Explore the use of generic and locally derived indicators, as well as other qualitative methods for collecting data. Acquire a thorough understanding of how people are currently coping with the HIV/AIDS epidemic, including its impacts on gender relations
- encourage the active participation of children. At least one facilitator must be known and trusted in the community and be skilled at communicating with children
- conduct a baseline study using a combination of data collection methods, including the measurement of indicators that will be monitored throughout the project. Where feasible, try out all methods in advance in communities that are not participating in the project. Disaggregate data by age and gender and also by affiliation to different socio-economic groups, such as orphans
- use the situation analysis and baseline studies as opportunities to mobilise the community, map available resources and negotiate a consensus among stakeholders.⁴⁹ Explore potentially difficult questions, such as possible negative outcomes from project activities
- co-ordinate with other donors and programming organisations working in the target areas so as to avoid duplication of information gathering
- keep the system as practical and simple as possible. Think about the ease of data collection, the availability of resources (such as stationery and transport), the skills of those who will gather the data and its relevance to their lives
- make sure that children are involved in all stages of the project, including information gathering and analysis; let the community decide who should be included
- monitor the context of your activities, as represented by the baseline information, throughout the life of the project. A rolling baseline may be a good method, but make sure you use the same measurements at each stage

⁴⁹ See Chapter 3 for a list of steps to undertaking community mobilisation.

- review the M&E system regularly and be prepared to make changes if necessary. A flexible system that can accommodate new indicators and adapt existing ones is needed to keep pace with the changes in people's lives
- devise ways of feeding back to the community the information you have collected and analysed
- disseminate the information as widely as possible among other organisations, donors and policy-makers.

SC UK has compiled a handbook for programming organisations working to mitigate the impact of HIV/AIDS on children to help them develop monitoring and evaluation systems.

Chapter 8: Lessons learned and conclusions

This chapter attempts to synthesise the key points from the previous chapters.

8.1 The conceptual framework

Targeting

- A situation analysis should be the first stage in the identification and subsequent targeting of vulnerable children, households and communities.
- Resources will always be insufficient, so it will always be necessary to target them efficiently.
- AIDS orphans are among the most vulnerable groups in any community, but to target interventions solely at them risks stigmatising them further, and also constitutes discrimination against other vulnerable children affected by HIV/AIDS.
- Definitions of vulnerability must be agreed with the community; this will need skilled facilitation.
- Simple and practical methods should be developed for targeting resources at the most vulnerable groups within the most severely affected communities. Existing methods, such as the Household Economy Approach developed by SC UK (Seaman et al. 2000), can be adapted for this purpose.

A rights-based framework

- Using a framework based on child rights involves taking a broader approach to HIV/AIDS programming for children than has traditionally been used. This would place the emphasis on multisectoral working, advocacy, participation, non-discrimination and equity.
- Programming organisations should develop field methods that will enable them to broaden their approach in line with the UNCRC. In particular, they need to tackle discrimination, stigmatisation and the psychosocial needs of children affected by HIV/AIDS, and encourage the active participation of children at all stages of the project cycle.
- Methods should be flexible enough to cope with potential conflicts between a rights-based approach and the priorities of the community.

8.2 The programme approach

- A more generic approach is needed to mitigate the impacts of HIV/AIDS on children – one that is flexible enough to address the range of different contexts in which children live.
- This can be achieved by strengthening the capacity of communities to deal with the impacts of HIV/AIDS on children and their families, and by building on spontaneous community-based approaches (Section 4.1).

The dual approach

- There is growing support for a dual strategy of community mobilisation, to mobilise enthusiasm and internal resources, and access to micro-finance, to improve the economic stability of affected households and communities.
- Organisations using the dual strategy should, however, be aware of its potential pitfalls; for example, severely affected communities may not prioritise the needs of children over more pressing survival needs, and children's psychosocial needs may be overlooked in programmes that are planned and implemented by the community.
- Community mobilisation and awareness raising may be used to address these matters.
- In some communities there are so many destitute families that they will be unable to participate effectively in this dual strategy. In the absence of a community safety net, these families may need to be given short-term material support.
- There are strong arguments for targeting women, particularly where IGAs are concerned.
- The focus on children affected by HIV/AIDS must be maintained by supporting the community in identifying, monitoring and addressing the needs of especially vulnerable children, and by involving children in the assessment of their needs and in all subsequent stages of the intervention.

Building community resources

- Approaches must capitalise on, and further strengthen, existing resources and structures within the community, including:
 - community-based groups;
 - church-based and other religious groups;
 - co-operatives and small enterprises;
 - structures for the delivery of health care and education;
 - informal groups based on solidarity, such as mothers' groups or guardians of orphaned children.
- Organisations must work with the existing structures for HIV/AIDS prevention and care for PLWHA within the target communities.
- Where the community does not consider HIV/AIDS to be a priority, a different approach may be necessary. Entry points for HIV/AIDS activities may be provided by helping with child identification and support, and by building on other spontaneous community-based interventions.
- Awareness raising exercises on HIV/AIDS must be culturally sensitive and serve to mobilise the community around the impacts of the epidemic on children. This will require expert facilitation by someone skilled in participatory methodologies.

Broadening the approach

- Public health interventions are only one small element of the developmental approach needed to support children affected by HIV/AIDS.
- Programming organisations must work together to deliver a multisectoral response to children affected by HIV/AIDS, including impact mitigation, HIV prevention and support for PLWHA.
- Interventions that grow organically, taking their lead from the community, tend to initiate a broader range of activities.
- Interventions that tackle specific areas of need, such as education or child protection, are also important, but are more effective when undertaken as part of a multisectoral response.

8.3 Programme management

- Both community mobilisation and micro-finance services require state-of-the-art technical assistance. Therefore, two organisations may need to work together to support the same target groups.
- Programming organisations must assess their capacity to mobilise community-based action, and if necessary should provide staff with training, particularly in participatory methodologies, gender analysis and facilitation skills.
- It may be necessary to buy in expert technical assistance, for example, in micro-finance or PM&E.
- Programmes should enable staff to visit programmes in other countries/regions to assess different approaches and learn about new methods.
- Organisations should use operations research to test the appropriateness of different approaches.

8.4 The role of NGOs in bringing about change

Advocacy

- NGOs working to mitigate the impacts of HIV/AIDS on children need to unite and advocate for the development of child-focused policy and strong, government-backed campaigns to address the HIV/AIDS epidemic.
- NGOs can use their contacts and other resources to mobilise the media to advocate for a responsible attitude and appropriate actions by national governments.
- NGOs can use their contacts and lobbying skills to place issues important to the communities with which they work on to the agendas of national governments.
- NGOs should advocate for increased funds for operations research.
- Advocacy is also important in securing funding for large-scale needs assessments and the development of standardised methodologies to identify and support children affected by HIV/AIDS.

Monitoring and evaluation

- M&E are crucial to a programme, as they enable progress to be measured and lessons to be learned.
- Systematic M&E can improve the likelihood of a successful outcome to a project.
- M&E must be participatory and must produce clear and simple results, as this will improve the impact of a programme and empower the individuals and communities participating in it.
- Generic indicators should be incorporated into M&E systems, to establish an objective measure of programme impact, to enable programmes to be compared, and to facilitate national data collection.
- Children should be enabled to participate effectively in M&E.
- Indicators should be disaggregated by gender and age of the child.
- M&E systems must be flexible enough to take account of changes in the circumstances of children affected by HIV/AIDS.
- There should be regular opportunities for feeding back information and analysis to communities.

Collaboration

- Greater collaboration is needed between agencies working to support children affected by HIV/AIDS. There is currently no focal point for orphan issues in the UN to provide leadership and a focus for collaborative effort.
- Since many developing countries plan to decentralise, NGOs should develop good working relationships with local government; this can ensure greater sustainability of activities.
- There is an urgent need for improvement in the sharing of information, both nationally and regionally, among the key actors in HIV/AIDS programming, including governments, international programming and funding organisations, NGOs, communities affected by HIV/AIDS and the private sector.

Research

- NGOs should collect data on programming at local level and disseminate to a wide audience examples of innovative, simple and pragmatic approaches that have succeeded in mitigating the impacts of HIV/AIDS on children (see M&E above).
- To achieve this, there must be operations research to test the effectiveness of different approaches.
- Longitudinal research is needed into the impacts of HIV/AIDS on different groups of children over time and also the longer-term impacts of different programme approaches.
- Quick and efficient dissemination of results is important. Although the internet is useful in this respect, communities affected by HIV/AIDS must also be given access to this information.

- Intra-household studies are needed that examine how children of different ages and gender benefit from different approaches.
- There is a need to assess the benefits to children affected by HIV/AIDS of approaches that aim to strengthen the coping capacity of households and communities (such as the dual strategy discussed in Sections 4.1.3 and 4.1.4).

8.5 Conclusion

HIV/AIDS is causing unprecedented demographic change, but only in the past decade have communities, organisations and governments started to experience the long-term impacts of AIDS on children. The resulting process of analysis, of which this document forms a part, highlights not only areas where experience is being gathered but also those where there is no experience at all. The general picture is one of pockets of local knowledge and experience, but a continued collective ignorance of what the real impacts of AIDS are on children and families, and what the appropriate response should be in any given context. The importance of context in determining our response leaves us in the position of having to look for 'best' or 'good' practices while hampered by an immature information network, and short of good evaluations, hard evidence and demonstrated efficacy across the range of possible contexts.

We also face the dilemma of trying to be proactive while at the same time recognising the need to build upon existing community support structures. These structures emerged in the pre-AIDS era and may not be suited for the long-term crisis that AIDS represents. In addition, the priority given to AIDS by external agencies may clash with the community's own view of its needs – should organisations step in or wait until the impacts are visible enough to galvanise the community?

Evidence of effective responses can shake governments, NGOs and communities themselves out of their apathy and into a co-ordinated and committed response. But experience shows that this can be a long and difficult process, and by the time there is official recognition and resources are committed to intervention, the problems may have grown enormously.

When so many children are affected, the practice of targeting is called into question. Singling out small numbers of children for support eventually begins to seem unethical and based on false assumptions of vulnerability. Making the conceptual framework of the UNCRC into a practical and usable resource is crucial in this regard, as this will allow responses to the epidemic to be built on solid, locally relevant premises.

As time goes on, general principles will surely emerge. There are many examples of effective responses, but these have not yet been tested across the whole range of possible contexts. The definition of success will vary, as the impacts of AIDS are not consistent and the objectives of projects will, therefore, differ. The rights-based framework allows the epidemic and its impacts to be analysed from one consistent viewpoint and should, therefore,

be encouraged. Mitigating the impacts of AIDS is a development issue, and development is increasingly seen as a human rights issue: children have the *right* to be protected from the impacts of AIDS.

As experience accumulates, it becomes vital that it be shared. Recent developments in information technology go some way towards achieving this. But the magnitude of the problem means that responsibility lies with the practitioners to learn from their own experiences and communicate these lessons to others. Policy makers need this information and practitioners are best placed to supply it. The monitoring and evaluation of interventions is currently weak, but will no doubt be improved – although it is not clear who will build the capacity of organisations to provide the information policy makers need. Even when the information is available, policy makers sometimes ignore it, and the imperative for action is dissolved in the rhetoric of multi-sectoral programming. In other words, those with the power to act do not act because they think someone else should. However, we cannot stand around waiting for governments to respond, but must continue to provide information and learn from our actions.

In the end, the leadership may come from the affected communities themselves. The beginnings of an effective response are already stirring within them. The resilience and strength of these communities is beyond dispute, but chronic poverty remains the biggest obstacle to helping children affected by AIDS. Poverty exacerbates the spread of HIV and is itself a consequence of AIDS. This must mean that, over time, mitigating the impacts of AIDS will become a developmental response, fully integrated into the wider processes of social and community development. The psychological and emotional impacts of high death rates will no doubt require specific responses, but again these should be integrated over time into continuing community support. In the meantime, the work and the learning must go on, and we must not shirk the huge challenges that face us all.

Appendix 1: Estimates of the global orphan situation

Definitions of orphans as shown in the tables

Since the UNAIDS definition is limited, the following tables of orphan estimates give estimates for other definitions as well as those provided by UNAIDS. The definitions used are as follows:

1.a UNAIDS estimated number of orphans (under 15): Estimated number of children who have lost their mother (maternal orphans) or both parents (double orphans) to AIDS and were alive and under 15 at the end of 1999.⁵⁰

2.a USAID estimated number of orphans (under 15): Estimated number of children who have lost their mother (maternal orphans), their father (paternal orphans), or both parents (double orphans) due to all causes (i.e., not only due to AIDS), alive and under 15 in 2000.⁵¹

3. Estimated number of orphans under 18 – all causes: Estimated number of children who have lost their mother (maternal orphans), their father (paternal orphans), or both parents (double orphans) due to all causes, alive and under 18 at the end of 1999.⁵²

These estimates were derived using the ratio between the total yielded by the UNAIDS definition of orphans in the study area in Uganda (Monk 2000), and the total after three additional categories were added – i.e., paternal orphans, children between 15 and 17, and children whose parents were recorded as having died of causes other than AIDS. The figures for the Uganda study derived from adding the three additional categories were 4.7 times higher than the UNAIDS definition. The UNAIDS estimates for the different countries were then multiplied by 4.7 to arrive at the new estimates incorporating the additional categories. These estimates are shown to give an idea of the potential scale of the current orphan situation, although it is acknowledged that similar research would be needed in other countries to verify their accuracy.

⁵⁰ UNAIDS website: www.unaids.org

⁵¹ Susan Hunter and John Williamson for USAID, *Children on the Brink 2000* (figures where available)

⁵² Neil Monk (ibid.)

Orphan estimates for selected SC UK programme countries

Africa

	1.a UNAIDS estimated number of orphans (under 15)	1.b UNAIDS estimated orphans as a percentage of population under 15 ⁵³	2.a USAID estimated number of orphans (under 15)	2.b USAID estimated orphans as a percentage of population under 15 ⁵⁴	3. Estimated number of orphans under 18 (all causes)	4. Population of children under 15
East and Central Africa						
Kenya	546,965	4.2	1,216,711	9.4	2,570,736	12,985,458
Burundi	150,086	5.3	515,971	18.1	705,404	2,854,493
Rwanda	172,398	5.5	936,691	30.1	810,271	3,106,905
Ethiopia	903,372	3.0	5,149,467	17.1	4,245,848	30,144,741
Uganda	997,426	8.4	2,354,064	19.7	4,687,902	11,923,399
Tanzania	666,697	4.2	1,533,084	9.7	3,133,476	15,853,895
DRC	464,322	1.9	2,245,571	9.0	2,182,313	25,087,723
Note: No figures are given for Eritrea, Somalia or Sudan.						
Southern Africa						
Swaziland	7,200	1.5	74,991	15.2	33,840	493,451
Zimbabwe	623,883	13.9	1,066,702	23.7	2,932,250	4,496,405
Lesotho	29,469	3.5	75,811	8.9	138,504	848,119
South Africa	370,952	2.6	1,283,211	9.1	1,743,474	14,093,765
Malawi	275,539	5.9	947,602	20.3	1,295,033	4,659,452
Mozambique	248,177	3.0	1,511,718	18.4	1,166,432	8,201,818
Angola	62,519		n/a			n/a
West Africa						
Côte D'Ivoire	287,269	3.8	1,246,669	16.6	1,350,164	7,500,047
Burkina Faso	211,503	3.7	724,933	12.7	994,064	5,689,351
Ghana	119,410	1.5	601,013	7.3	561,227	8,184,200
Sierra Leone	36,456		n/a		171,343	n/a
Liberia	20,337		n/a		95,584	n/a

⁵³ Column 1.b figures were calculated by taking column 1.a as a percentage of column 4 figures, derived from Hunter and Williamson (2000).

⁵⁴ Column 2.b was calculated using figures from Hunter and Williamson (2000).

Asia and the Pacific

	1.a UNAIDS estimated number of orphans (under 15)	1.b UNAIDS estimated orphans as a percentage of population under 15	2.a USAID estimated number of orphans (under 15)	2.b USAID estimated orphans as a percentage of population under 15	3. Estimated number of orphans under 18 (all causes)	4. Population of children under 15
South East Asia and the Pacific						
Cambodia	11,649	0.2	373,082	7.3	54,750	5,115,941
Myanmar	35,458	0.3	1,195,422	9.6	166,653	12,428,196
Thailand	n/a	n/a	494,924	3.4		14,493,241
Vietnam	2,772		n/a		13,028	n/a
China	3,901		n/a		18,335	n/a
Philippines	1,313		n/a		6,171	n/a
Indonesia	1,735		n/a		8,155	n/a
Laos	236		n/a		1,109	n/a
South and Central Asia						
India	557,570		n/a		2,620,579	n/a
Nepal	2,157		n/a		10,138	n/a
Sri Lanka	462		n/a		2,171	n/a
Bangladesh	500		n/a		2,350	n/a
Note: No figures are given for Pakistan, Afghanistan, Kyrgyzstan, Tajikistan or Uzbekistan.						

Latin America and the Caribbean

	1.a UNAIDS estimated number of orphans (under 15)	1.b UNAIDS estimated orphans as a percentage of population under 15	2.a USAID estimated number of orphans (under 15)	2.b USAID estimated orphans as a percentage of population under 15	3. Estimated number of orphans under 18 (all causes)	4. Population of children under 15
Latin America						
Honduras	13,599	0.5	65,553	2.5	63,915	2,664,300
Guatemala	4,654		n/a		21,874	n/a
El Salvador	1,885		n/a		8,860	n/a
Brazil	30,828		n/a		144,892	n/a
Peru	6,261		n/a		29,427	n/a
Colombia	2,301		n/a		10,815	n/a
Nicaragua	427		n/a		2,007	n/a
Caribbean						
Haiti	49,134	1.7	350,924	12.4	230,930	2,823,683
Jamaica	896		n/a		4,211	n/a
Cuba	125		n/a		588	n/a

Appendix 2: Proposed principles and approaches to guide OVC programming

Strengthen the caring and coping capacities of families and communities:

1. Increase and strengthen community care rather than institutional care.
2. Enhance the capacity of families, communities and local groups to respond to the psychosocial needs of vulnerable children and adolescents.
3. Reduce stigma and discrimination.
4. Foster linkages between HIV/AIDS prevention activities and efforts to support vulnerable children and adolescents.
5. Foster linkage between home-based care and support to children/adolescents.
6. Target communities where HIV/AIDS makes children vulnerable, not 'AIDS orphans'.
7. Give particular attention to women and girls.
8. Involve children and adolescents as 'part of the solution'.
9. Accelerate learning and information exchange.
10. Strengthen partnerships at all levels and build coalitions among key stakeholders.
11. Develop multi-sectoral, mutually reinforcing programming strategies.
12. Ensure that external support does not undermine community initiative and motivation.
13. Scale up and scale out.

Reproduced from the Eastern and Southern Africa Regional Workshop on Orphans and Vulnerable Children, UNICEF/USAID Zambia, November 2000.

Appendix 3: Bibliography

Ali, S. (1998) *Community Perceptions of Orphan Care in Malawi*. Paper presented at the conference Raising the Orphan Generation, Pietermaritzburg, South Africa, June.

[Ankrah \(1998\) \[find full reference\] PAGE 27](#)

Aspaas, H.R. (1997) *AIDS and Orphans in Uganda: A Geographical and Gender Interpretation of Household Resources*, Utah State University, paper presented at the conference The Socio-Demographic Impact of AIDS in Africa, Durban, South Africa, February.

Authors refer to Grainger, c., Webb, D. and Elliott, L. 2001.

[Ayieko, M.A. \(1997\) \[find full reference\] PAGE 22, IS THIS ALSO 1999??](#)

Ayieko, M.A. (1999) 'From single parents to child-headed households: the case of children orphaned by AIDS in Kisumu and Siaya districts. Kenya.' UNDP *Sustainable Human Development*. Issues paper No.32, September.

Bagarukayo, H., Shuey, D., Babishangire, B. and Johnson, K. (1993) *An Operational Study Relating to Sexuality and AIDS Prevention among Primary School Students in Kabale District of Uganda*. Amref, Entebbe, Uganda.

[\(TEXT IS BARAGUKAYO PAGE 22 – WHICH IS CORRECT??\)](#)

Baggaley, R., Sulwe, J., Chilala, M. and Mashambe, C. (1999) 'HIV stress in primary school teachers in Zambia.' In *Bulletin of the World Health Organization*. Vol. 77 (3), WHO.

[Bajenja, E. \(1995\) \[find full reference\] PAGE 59 Facing the Challenge: The role of Women's Community-based Organisations in the Support of AIDS Widows and Orphans. Paper presented at The IXth International Conference on STDs and AIDS in Africa, Kampala, Uganda.](#)

Barnett, T. and Blaikie, P. (1992) *AIDS in Africa: Its Present and Future Impact*. London, Belhaven Press.

Barnett, T. and Whiteside, A. (1999) 'The Jaipur paradigm, HIV/AIDS, society and economy: case studies and a conceptual framework.' In *The European Journal of Development Research*, December.

Barrett, H. and Browne, A. (1998) *Environmental and Social Change in Zambia: the Value of Children to Rural Household*. ESRC Global Environmental Change Programme, Briefings, No. 22, July.

Barrett, K. (1998) *The Rights of Children: Raising the Orphan Generation*. Paper presented at the CINDI conference Raising the Orphan Generation, Pietermaritzburg, South Africa, June.

[Barton, T. \(1997\) \[find full reference\] PAGE 93 Care Uganda – Guidelines to monitoring and evaluation: how are we doing? Care Uganda, Kampala.](#)

Baylies (1996) [\[find full reference\] PAGES 18, 52, 03, 35 Fertility Choices in the Context of AIDS Induced Burdens on Households and Environment.](#) Unpublished report, University of Leeds,

Bor, R. and du Plessis, P. (1998) 'The impact of HIV/AIDS on families: new perspectives on recent research.' *In Families, Systems and Health.*

Brown, L. (2000) [\[find full reference\] PAGE 36 Sex Slaves: The Trafficking of Women in Asia.](#) London, Virago.

Brown, L., Mungoche, S., Duncan, J., Sosler, S., Williams, E. and Phiri, S. (1999) *Monitoring and Evaluating Community-based Care and Support Activities.* Oral presentation, XIth International Conference on AIDS and STDs in Africa, Lusaka, September.

Brown, T. and Sittitrai, W. (1995) *The Impact of HIV on Children in Thailand.* Program on AIDS, Thai Red Cross Society and SC UK, June.

Caldwell, J. (1997) '[PAGES 30-34 The impact of the African AIDS epidemic.](#)' In [Health Transition Review, Supplement 2 to Vol. 7,](#) pp. 169-188.

CARE (1997b) *Lessons Learned. Program Indicators for Comprehensive Care.* The Integrated Community Based Care for Persons with HIV/AIDS and their Families Project, CARE International Thailand, May.

Chambers, R. (1997) *Whose Reality Counts? Putting the First Last.* IT Publications, London.

Chancellor College (1998) Chancellor College's Center for Social Research and Department of Psychology in Zomba, in collaboration with Victoria University in British Columbia, Canada, the MOWYSC, UNICEF, SCF/US, and World Vision, and funded by ISRC, research presented at the Best Practices Conference, in Mangochi, Malawi, February. Reported in UNICEF/CEDC 1998b (cited below).

Colling, J. (1998) *Children Living in a World with AIDS: Guidelines for Children's Participation in HIV/AIDS Programmes.* CAINN/UNAIDS.

Connolly, M. (2001) [Principles to Guide Programming for Orphans and other Vulnerable Children.](#) [\[find full reference\] Page 90](#) Draft version, New York, UNICEF.

Conroy, R., Tomkins, A., Landsdown, R. and Elmore-Meegan, M. (2000) 'Identifying emerging needs among AIDS orphans in Kenya.' *Annual Scientific Review.* University of Nairobi, January.

de Guerny, J. (1998) *Rural Children Living in Farm Systems Affected by HIV/AIDS: Some issues for the rights of the child on the basis of FAO*

HIV/AIDS studies in Africa. Presented at the UNHCHR Committee of the Rights of the Child: day of discussion on 'Children living in a world with AIDS', Geneva, October 1998.

Devine, S. and Graham, D. (1999) *Parental HIV Positive Status as a Variable Associated with Orphans in Chiang Mai, Thailand*. Unpublished report.

Doka, K.J. (1994) 'Suffer the little children: the child and spirituality in the AIDS crisis.' In *AIDS and The New Orphans: Coping with Death*. Edited by B.O. Dane and C. Levine, Location, Auburn House.

Donahue, J. (1998) *Community-based Economic Support for Households Affected by HIV/AIDS*. Discussion Papers on HIV/AIDS Care and Support No. 6, Health Technical Services (HTS) Project, for USAID, June.

- (1999a) *Children Affected by HIV/AIDS in Kenya: An Overview of Issues and Action to Strengthen Community Care and Support*. Unpublished, May.

- (1999b) *Community-based Responses to the Economic Impact of AIDS on Children and Families*. Presentation to the Orphan's Project Conference, November. (OR orphans'?)

- (1999c) 'Community mobilisation and microfinance services as HIV/AIDS mitigation tools.' Supplementary report to the report *Children Affected by HIV/AIDS in Kenya: An Overview of Issues and Action to Strengthen Community Care and Support* (see Donahue 1999a), May.

- (1999d) *HIV/AIDS Care and Support Initiatives via Community Mobilisation*. For the Displaced Children and Orphans Fund, [date?<fill>Washington DC](#).

- (2000) *Microfinance and HIV/AIDS...it's Time to Talk*. Unpublished paper, Displaced Children and Orphans Fund, Washington DC.

Donahue, J. and De Lay, B. (1999) *HIV/AIDS Alliance and IPC Proposal Assessment: Assisting Orphans and Vulnerable Children in Burkina Faso*. Report on behalf of the Displaced Children and Orphans Fund and War Victims Fund Contract, under the auspices of USAID, July. ~~Donahue and Williamson (1996) and (1998) PAGES 55, 56, 59, 61 then become Williamson and Donahue in later text and are in Bibliography as such — which is correct??~~

Drew, R. S., Foster, G. and Chitima, J. (1996) 'Cultural practices of orphaned families in the north Nyanga district of Zimbabwe.' In *Journal of Social Development in Africa*. Vol. 11 pp. 79-86.

Drew, R. S., Makufa, C. and Foster, G. (1998) 'Strategies for providing care and support to children orphaned by AIDS.' Family AIDS Caring Trust, Mutare, Zimbabwe. In *AIDS Care*, Vol. 10, Supplement 1: S9-15.

Dunn, A., Hunter, S., Nabongo, C. and Ssekiwanuka, J. (1992) 'The social consequences of HIV/AIDS in Uganda.' Background paper, based on the report *Enumeration and Needs Assessment of Orphans in Uganda – Survey Report*, London, SC UK.

Egan, G. (1994) *The Skilled Helper: A Problem-management Approach to Helping*. [[find full reference](#)] PAGE 73 [<have asked Liz for it>](#)

Elliott, L. (1999) *HIV/AIDS Prevention for Children and Young People: Making the case*. Draft report, London, SC UK.

Elliott, L. (1998) *The Barriers to Putting Children and Young People on the Agenda for the Global Prevention and Care of HIV/AIDS*. Paper contributed to General Discussion on Children Living in a World with AIDS, CRC Theme Day, Geneva, London, SC UK, October.

Elmore-Meegan, M., Conroy, R. and Tomkins, A. (1999) Kenya Orphan comparison study, presentation at the Collaborative Symposium on AIDS Research, January. [<place?>](#) [<don't know -found it on e-group network>](#)

FAO (1999) Food and Agriculture Organisation, News and Highlights, December 1999, from their website: www.fao.org/NEWS.

Foster, G. (1997a) *Children Rearing Children: A Study of Child-Headed households*. Presented at the conference The Socio-Demographic Impact of AIDS in Africa, Durban, South Africa, February.

Foster, G. (1997b) *AIDS and Child Health*. Presented at the Amsterdam Homecare Conference, May.

[Foster, G. \(1998\) \[\[find full reference\]\(#\)\] PAGE 32](#)

Foster, G., Makufa, C., Drew, R., Kambeu, S. and Saurombe, K. (1996) 'Supporting children in need through a community-based orphan visiting programme.' In *AIDS CARE*, Vol.8, No. 4, pp. 289-403.

Foster, G., Makufa, C., Drew, R. and Kralovec, E. (1997) 'Factors leading to the establishment of child-headed households: the case of Zimbabwe.' In *Health Transition Review*. Supplement 2 to Vol. 7, pp. 155-168.

Foster, G., Shakespeare, R., Chinemana, F., Jackson, H., Gregson, S., Marange, C. and Mashumba, S. (1998) 'Orphan prevalence and extended family care in a peri-urban community in Zimbabwe.' In R. Bor and J. Elford *The Family and HIV Today: Recent Research and Practice*. Cassell, London.

Girma, M. and Schietinger, H. (1998) *Integrating HIV/AIDS Prevention, Care, and Support: A Rationale*. Discussion Papers on HIV/AIDS Care and Support, Health Technical Services Project of USAID, June.

Godwin, P. (1997) *Socio-Economic Implications of the Epidemic*, UNPD Regional Project on HIV and Development, New Delhi.

Gregson, S., Garnett, G. P., Shakespeare, R., Foster, G. and Anderson, R. M. (1993) *Mathematical Model Simulations and Empirical Estimates of the Impact of HIV-1 on Orphanhood in Sub-Saharan Africa*. Paper presented at

the conference AIDS Prevention in Developing Countries: The Role of Demography and Social Science, Annecy, France, December.

Gregson, S., Garnett, G. P., Shakespeare, R., Foster, G. and Anderson, R. M. (1994) Determinants of the demographic impact of HIV-1 in sub-Saharan Africa: the effect of a shorter mean adult incubation period on trends in orphanhood.' In *Health Transition Review*. Vol. 4, pp. 65-92.

[Guba and Lincoln \(1989\) \[find full reference\] PAGE 94](#) Harber, M. (1998) *Developing a Community-based AIDS Orphan Project: A South African case study*. Paper presented at the conference Raising the Orphan Generation, Pietermaritzburg, June.

Havens, J.F., Mellins, C.A. and Ryan, S. (1997) 'Mental health treatment of children and families affected by HIV/AIDS.' In L.A. Wicks, ? Taylor and ? Francis (eds) *Psychotherapy and AIDS*. PLACE AND PUBLISHER.

Haworth, A. and Mayeya, P. (1999) *A Report on a Project to Study Child Abuse in Three Cities in Zambia*. UNICEF Zambia, June. [Hunter, S. and Williamson, J. \(1997\) \[find full reference\] PAGE 58](#)

Hunter, S. and Donahue, J. (1997) *HIV/AIDS Orphans and NGOs in Zambia: Strategy development for programming by the USAID/Zambia mission for family and community care of children affected by HIV/AIDS*. Displaced Children and Orphan Fund and War Victims Fund Project, June.

Hunter, S. and Williamson, J. (1998a) *Children on the Brink: Strategies to support children isolated by HIV/AIDS*. Health and Technical Services Project, for USAID, January.

Hunter, S. and Williamson, J. (1998b) 'Responding to the needs of children orphaned by HIV/AIDS.' Discussion Paper on HIV/AIDS Care and Support No. 7, Health and Technical Services (HTS) Project, for USAID, June 1998.

Hunter, S. and Williamson, J. (2000) *Children on the Brink*. USAID, [Washington DC](#).

IDS (1998) 'Participatory monitoring and evaluation: learning from change.' *IDS Policy Briefing* Issue 12, November.

Johnson, V., Ivan-Smith, E., Gordon, G., Pridmore, P. and Scott, P. (eds.) (1998) *Stepping Forward: Children and Young People's Participation in the Development Process*. ITP UK.

Kalemba, E. (1998) *The Development of an Orphans Policy and Programming in Malawi: A Case Study*. UNICEF Malawi, presented at the CINDI Conference Raising the Orphan Generation, Pietermaritzburg, June.

Kamya, H. (1997) 'Groupwork with children from HIV/AIDS-affected families.' In *Journal of HIV/AIDS Prevention and Education for Adolescents and Children*. Vol. 1(2).

[Kezaala and Bataringaya \(1998\) \[find full reference\] PAGE 50](#)

Ledward, A. (1997) 'Age, gender and sexual coercion: their role in creating pathways of vulnerability to HIV infection.' Masters Thesis submitted to UCL, quoted in *SAfAIDS*. Vol. 6, No. 4, December.

Lee, T. (2000) *Evaluating Community-based Orphan Care in Zimbabwe: Monitoring and Evaluation of the Quality of Services and Programmes*. SAfAIDS website, 14.02.2000.

Marcus, R. and Harper, C. (1997) *Small Hands: Children in the Working World*. SC UK Working Paper No. 16, London, SC UK.

Martin, T. (1998) 'AIDS hospices and orphanages.' In *Annals of Tropical Paediatrics*. Vol. 18, S21-S25.

Marum, E., Bagenda, D., Guay, L., *et al.* [NEEDS COMPLETE AUTHOR LIST](#) (1996) *Three Year Mortality in a Cohort of HIV-1 Infected and Uninfected Ugandan Children*. Paper presented at the International Conference on AIDS, Vancouver.

McKerrow, N. (1996) 'Implementation strategies for the development of models of care for orphaned children.' Based on the report *Responses to Orphaned Children in the Copperbelt and Southern Provinces of Zambia*. UNICEF, October.

- (1998) *The Vulnerability of the Southern African Family*. Paper presented at the CINDI Conference Raising the Orphan Generation, Pietermaritzburg, June.

McKerrow, N. and Verbeek, A. (1995) *Models of Care for Children in Distress: The Current Status of Children in the KwaZulu-Natal Midlands and the Nature of the Community Response*. CINDI.

Michael, K. (1998) [\[find full reference\] page 45](#). 'The children in distress conference.' *AIDS Analysis Africa* Vol. 9(3), October/November.

Monk, N. (2000) *Orphans of the HIV/AIDS Pandemic: A Study of Orphaned Children and their Households in Luweero District, Uganda*. Association Francois-Xavier Bagnoud.

Mulenga, C., Kamwanga, J., and Ngwisha, J. ~~et al.~~, (1993) [Orphans, Widows and Widowers in Zambia: A Situational Analysis and Options for HIV/AIDS Survival Assistance](#). Lusaka, Zambia, [Institute of African Studies](#). [find full reference](#) PAGE 23

Muller, O., Sen, G. and Nsubaga, A. et al (1999) [\[find full reference\]](#) PAGES 49-20 'HIV/AIDS, orphans, and access to school education in a community of Kampala, Uganda.' In *AIDS*, Vol. 13, No.1.

Mutangadura, G. and Webb, D. (1999) 'The socio-economic impact of adult morbidity and mortality on households in Kafue District, Zambia.' In *SAfAIDS, Harare*, Zimbabwe.

Nampanya-Serpell, N. (1998) *Children Orphaned by HIV/AIDS in Zambia: Risk Factors from Premature Parental Death and its Implications*. PhD thesis, University of Maryland, Baltimore.

Nampanya-Serpell, N. (1999) *Cost Effectiveness Analysis of Programs of Assistance to HIV/AIDS Orphaned/Affected Children in Selected African Countries*. Draft, incomplete report.

~~NOTE UP TO PAGE 67 THIS IS REFEED IN TEXT AS 1998, THEN 1999 FROM PAGE 62 ONWARDS—WHICH DATE IS CORRECT OR ARE THERE TWO PUBLICATIONS???~~

Nicoll, A., Timaeus, I., and Kigadye, R. ~~et al~~ [NEEDS COMPLETE AUTHOR LIST](#) (1994) 'The impact of HIV-1 infection on mortality in children under five years of age in sub-Saharan Africa: a demographic and epidemiological analysis.' In *AIDS*, Vol. 8.

ODI (2000) *Reforming Food Aid: Time to Grasp the Nettle?* ODI Briefing Paper, 1 January.

Panos (2000) [\[find full reference\]](#) PAGE 36 ~~<will get>~~

Parry, S. (1998) *Community Care of Orphans in Zimbabwe – The Farm Orphans Support Trust (FOST)*. Paper presented at the conference 'Raising the Orphan Generation', Pietermaritzburg, June.

Poulter, C. (1997) [\[find full reference\]](#) PAGES 20, 25, 26, 28, 32, 42 [A Psychological and Physical Needs Profile of Families Living with HIV/AIDS in Lusaka, Zambia](#). Family Health Trust, Lusaka, Zambia.

Rajkumar, V. (2000) *HIV and AIDS and Children: Vulnerability and Impact*. India, SC UK.

Reid, E. (1997) *Children in Families Affected by the HIV Epidemic: A Strategic Approach*. *HIV and Development Programme*, Issues Paper No. 13, part of a series issued by UNDP and UNICEF in collaboration with UNAIDS.

Richman, N. (1996) [Principles of Help for Children Involved in Organised Violence](#). London, SC UK.

Roche, C. (1999) *Impact Assessment for Development Agencies Learning to Value Change*. Published by Oxfam with Novib. **Where? Oxford?**

Sabatier, R. (1988) *Blaming Others: Prejudice, Race and World-wide AIDS*. London, Panos Institute.

| SAfAIDS News, Vol. 6, No. 1 and 4, 1996.???????

SAfAIDS News, Vol. 6, No. 4, December 1998. (SEE Ledbury)

Sanei, L. (1998) 'Palliative care for HIV/AIDS in less developed countries.' Discussion Paper on HIV/AIDS Care and Support No. 3, Health Technical Services Project, for USAID, June.

SMP (1998) *The Sangha Metta Project, Final Evaluation Report*. October.

SMP (1999) *The Sangha Metta Project, Annual Report, Executive Summary*. October.

Saake, P. and Mutemi, R. (1994) *Needs Assessment of Children Orphaned by AIDS, Final Report*. Funded by UNICEF Kenya Office.

SC UK (1998) Save the Children UK *Position Paper on Children's Rights*. London, SC UK.

SC UK (1999) Save the Children UK *Draft Guidelines on Children's Rights Programming*. London, SC UK.

Seaman, J., Clarke, P., Boudreau, T. and Holt, J. (2000) *The Household Economy Approach: A Resource Manual for Practitioners*. London, SC UK.

Sengendo, J. and Nambi, J. (1997) 'The psychological effect of orphanhood: a study of orphans in Rakia district.' In *Health Transition Review*, Supplement to Vol. 7, pp. 105-124.

Senkusu, S. (1995) *Constraints in Community-based Approaches for Orphans*. Paper presented at The XIIIth International Conference on AIDS in Africa, Kampala, Uganda.

Tarantola, D. and Gruskin, S. (1998) 'Children confronting HIV/AIDS: charting the confluence of rights and health.' In *Health and Human Rights*, Vol. 3, No.1.

UNAIDS (1997) *The UNAIDS Guide to the United Nations Human Rights Machinery for Service Organisations, People Living with HIV/AIDS, and Others Working in the Area of HIV/AIDS and Human Rights*. UNAIDS.

UNAIDS and WHO (1999) *AIDS Epidemic Update: December*. From the UNAIDS website.

UNHCHR and UNAIDS (1998) *HIV/AIDS and Human Rights: International Guidelines*. From the Second International Consultation on HIV/AIDS and Human Rights, Geneva 23-25 September.

UNICEF (1998) 'Breast milk and transmission of HIV.' In *The State of the World's Children 1998*. pp. 30-31, New York. UNICEF.

~~THERE IS NO UNICEF (1998b) AS IN PAGE 36 DOES THIS REF REFER TO THE ABOVE ORIGINAL~~

UNICEF (1999a) *Children and HIV/AIDS: Government and Community Responses in a Multicultural Context, Report of an Assessment of the Situation of the HIV/AIDS Epidemic and its Consequences for Families and Children, Focusing on Orphans*. Swaziland, February.

UNICEF (1999b) 'The AIDS emergency: the toll on women and children.' In *The Progress of Nations 1999*. New York, UNICEF.

UNICEF (1999c) 'The education revolution.' In *The State of the World's Children 1999*. New York, UNICEF.

UNICEF/CEDC (1998a) *Integrated District Planning for Vulnerable Children in Uganda: Is It Enough?* Draft report of a Uganda site visit by a CEDC Team from UNICEF/New York, March.

UNICEF/CEDC (1998b) *Community-based Orphan Assistance in Malawi: Demographic Crisis As Development Opportunity*. Draft report of a Malawi site visit by the CEDC Team from UNICEF/New York, March.

UNICEF and UNAIDS (1999) *Children Orphaned by AIDS: Front-line Responses from Eastern and Southern Africa*. UNAIDS publications website, December.

UNICEF/USAID (2000) *Eastern and Southern Africa Regional Workshop on Orphans and Vulnerable Children*. Workshop report, UNICEF/USAID, Zambia.

Urassa, M., Ngweshemi, J., Isingo, R., Kumogola, Y. and Boerma, J. (1997) 'Orphanhood, child fostering and the AIDS epidemic in rural Tanzania.' In *The Socio-demographic Impact of AIDS in Africa conference*. South Africa, February.

Waller, K. (1997) *Prospects for Agriculture in Southern Province: The Impact of HIV/AIDS on Farming Households in the Monze District of Zambia*. Centre for Development Studies, University of Bath.

Webb, D. (1996a) 'Children in especially difficult circumstances (CEDC) in Zambia: a situation analysis.' In *SAfAIDS News*, Vol. 4, No. 1, March.

- (1996b) 'The socio-economic impact of HIV/AIDS in Zambia.' In *SAfAIDS News*, Vol. 4, No. 4, December.

- (1997) *HIV and AIDS in Africa*. London, Pluto Press.

- (1999) *The Search for Best Practice in HIV/AIDS Programme Development*. Unpublished report, London, SC UK.

Webb, D. and Elliott, L. (2000) *Learning to Live: Monitoring and Evaluating HIV/AIDS Programmes for Young People*. London, SC UK.

Webb, D. and Nkamba, G. (1997) [\[find full reference\] Profile of AIDS-affected Households in Lusaka](#). Zambia, UNICEF.

Webb, D and Paquette, ?? (2000) 'The potential role of food aid in mitigating the impacts of HIV/AIDS: the case of Zambia.' In *Development in Practice*, Vol. 10, No. 5, pp. 694-700. ~~Webb and Mutagadura (1999):~~

~~MUTANGADURA AND WEBB (1999) PAGES 17, 18, 27, 32, 35, 40, 80 then become Webb and Mutangadura later text PAGES 56, 80, and are in Bibliography~~ Welbourn, A. (1998) [Safely through the Night](#). Vol 1, CAFOD, London.

White, J. and Robinson, E. (1999) *HIV/AIDS and Rural Livelihoods in sub-Saharan Africa*. Policy Series No. 6, Social Sciences Department, Natural Resources Institute, University of Greenwich.

Whiteside, A. (1999) 'The Real Challenge: The orphan generation and employment creation.' Article printed in the *Sunday Independent* (South Africa) on 28th November and reprinted on AF-AIDS website as Message 623 (www.hivnet.ch:8000/africa/af-aids/viewR?623).

Williams, G. (1992) *From Fear to Hope, AIDS Care and Prevention at Chikankata Hospital, Zambia*. Part of the Strategies for Hope series, No. 1, revised edition, January.

Williamson, J. (1995) *Children and Families Affected by HIV/AIDS: Guidelines for Action*. New York, UNICEF.

- (1997) 'Children and Families Affected by HIV/AIDS.' Draft chapter, September.
- (1999a) 'Finding a way forward: principles and strategies for intervention.' In C. Levine and G. Foster (eds.) *The Orphan Generation – The Global Legacy of the AIDS Epidemic*, forthcoming.
- (1999b) *Community Mobilization for Orphans in Zambia: An Assessment of the Orphans and Vulnerable Children Program of Project Concern International*, January.

Williamson, J. and Donahue, J. (1996) *Developing Interventions to Benefit Children and Families Affected by HIV/AIDS: A Review of the COPE Program in Malawi for the Displaced Children and Orphans Fund*, October 6-18.

- (1998) *Community Mobilization to Address the Impacts of AIDS: A Review of the COPE II Program in Malawi*, January 17-30.

~~(OR DONAHUE AND WILLIAMSON – SEE EARLIER)~~

World Bank (1993) *World Development Report 1993: Investing in Health*. Oxford, Oxford University Press.

World Bank (1996) *AIDS Prevention and Mitigation in Sub-Saharan Africa: An Updated World Bank Strategy*. April 20.

World Bank (1997) *Confronting AIDS: Public Priorities in a Global Epidemic*. Washington DC, World Bank.

Wright, G., Kasente, D., Ssemogerere, G. and Mutesasira, L. (1999) 'Vulnerability, risks, assets and empowerment – the impact of microfinance on poverty alleviation.' Contribution to World Development Report 2001, MicroSave-Africa and Uganda Women's Finance Trust, March.

Appendix 4: Useful websites

www.sas.upenn.edu/African_Studies/Listserv/netlist_112398.html A discussion forum where members share experiences of working on HIV/AIDS in Africa. There is also news of forthcoming events, conferences and workshops.

www.aidsmap.com/home.htm Provides information on treatment, services, publications and news.

www.bmaids.demon.co.uk The site of the BMA Foundation for AIDS, focussing on: health policy re AIDS; medical education, including ethical advice health professionals; HIV prevention, sexual health promotion and sex education; responses of UK organisations to HIV/AIDS in developing countries; broader social policy in the UK.

www.iaen.org/ The site of the International AIDS Economic Network, provides data, tools and analysis on the economics of prevention and treatment in developing countries. It holds on line conferences and includes listings of conferences, and materials produced by World Bank, UNAIDS, European Commission and USAID.

www.aidsonline.com The site of the official journal of the International AIDS Society. This gives limited access only to users who are not subscribers to the journal. The journal comprises academic medical research articles.

www.safaids.org The site of SAFAIDS a not-for-profit voluntary organisation based in Harare, Zimbabwe, which conducts research, advises on policy, and provides general information on HIV/AIDS in Southern Africa. They also have a comprehensive Resource Centre in Harare.

www.unaids.org The site of the UNAIDS (The joint United Nations Programme on HIV/AIDS) providing wide ranging global, regional, and country level statistical information on the progress of the epidemic. The site also provides case studies on best practice.

www.fhi.org The site of Family Health International (FHI) is an international NGO working on reproductive health. FHI carries out applied research on medical, behavioural and programmatic issues using a wide range of methodologies. Articles based on the research studies are posted on the web-site.

www.unicef.org The site of UNICEF providing articles and press releases on HIV/AIDS in relation to children and young people, as well as country by country general statistical information on children and young people.

www.iied.org IIED is an independent not for profit organisation with a mission to promote sustainable patterns of world development through collaborative research, policy studies, consensus building and public information. They produce regular papers on research studies using Participatory Learning in Action (PLA) – the PLA Collection. These are accessible through a word-search database on the web site.

www.orphans.fxb.org Association-Francois Xavier is involved in initiatives on children's rights, health and human rights and paediatric HIV/AIDS in 13 countries. Their orphans Webster contains their Orphans Alert report for the International AIDS Conference in Durban (July 2000) giving a global, regional and national overviews and studies of the orphan situation in particular countries.

www.hivinsite.ucsf.edu This is a joint project of the University of California, San Francisco AIDS Programme at San Francisco General Hospital and the UCSF Centre for AIDS Prevention Studies. The site provides general information on HIV/AIDS, covering medical issues, treatment, education and prevention and social policy. The site also has a topics section on children.

www.hivnet.ch The site is run by The Foundation of Now who work with people and organisations in developing countries on HIV/AIDS related topics.

www.worldbank.org/html/extdr/thematic/htm The site of the World Bank containing statistics on children orphaned by AIDS and information on the economics of AIDS.

www.seahorse.oxi.net.nu The site is Europe's first interactive on-line HIV resource. This is a gateway to all the major resources available on the web.

CABA@info.usaid.gov Discussion forum on HIV/AIDS and children

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Appendix 5: Related Save the Children UK publications

Gender, HIV/AIDS and Emergencies

Refugees and displaced people need access to gender sensitive education on HIV/AIDS, the means to prevent it and access to services for the treatment of sexually transmitted diseases (STDs) and HIV/AIDS. This article makes recommendations on how this can be achieved by agencies working in disaster and emergency situation.

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Gender and HIV/AIDS - Guidelines for Integrating a Gender Focus into NGO work on HIV/AIDS

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Drawing together information from a variety of sources, this text aims to provide a practical resource to carry out research and to plan HIV/AIDS interventions more effectively. These guidelines aim to help identify some of the issues which relate to the vulnerability of different groups to HIV/AIDS by enhancing understanding of gender relationships and roles, and the spread of HIV/AIDS.

| **📄 *Learning from Experience - Young People and HIV/AIDS***

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This newsletter, aimed at staff and other practitioners, contains articles about HIV/AIDS initiatives in SC UK programmes across the world.

| **📄 *Children Living with HIV/AIDS in South Africa - A Rapid Appraisal***

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Report on children affected by AIDS in South Africa which shares the lessons learnt from the experiences of selected models of care and support. The information accrued provides the data for a series of recommendations that will hopefully provide a framework for action for both government and civil society.

| **📄 *Overview of Vulnerable Children in Zimbabwe***

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This paper is a background document on the vulnerability of young people in Zimbabwe to HIV/AIDS and sexually transmitted diseases. The paper is designed to raise awareness on the issue of HIV/AIDS, reproductive health, sexual abuse and exploitation concerned with the vulnerability of young people to HIV transmission. The paper makes a number of recommendations about the future needs of young people with respect to HIV/AIDS prevention and reproductive health care. Recommendations are also made on ways of coping with the impact of HIV/AIDS on young people in affected communities.

| **📄 *The Impact of HIV on Children in Thailand***

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Research was carried out to examine the situation in Thailand of children at risk from HIV infection and children already affected by HIV. This report explores a range of recommendations for action. Also included are sections on lessons learned from experience in Africa, the future of the Thai epidemic, economic impacts and the impact on the Thai education system.

| **📄 *HIV/AIDS and Children - A South Asian Perspective***

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This study in South Asia aims to raise key research and policy questions with regards to HIV/AIDS and children by analysing different existing projects through case studies and identifying gaps and difficulties in implementing work.

| **📄 *HIV/AIDS Prevention Strategies for School Age Children - Examples and Possibilities***

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This report presents points of views and discussions around HIV prevention education in Thailand, China, Nepal, Pakistan and India. It aims to gain an understanding of programmatic interventions in reducing the incidence of

HIV/AIDS in children in South East Asia at a micro level and to assess its relevance and significance in South Asia programming.

▣ **Participatory Rural Appraisal - Handbook to Promote HIV/AIDS Prevention**

Handbook using Participatory Rural Appraisal to establish programmes raising awareness of HIV and AIDS in rural communities, produced by Save the Children and Chiangmai University, Thailand.

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▣ **Learning to Live - Monitoring and Evaluation for HIV/AIDS Programmes with Young People**

The specific aims of this handbook for practitioners are:

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- ✦ to provide an introduction to the concepts which underlie project monitoring and evaluation
- ✦ to demonstrate how these principles are practically applied in projects addressing HIV/AIDS
- ✦ to provide an overview of existing good practice in key sectoral areas, and how these practices have been identified
- ✦ to provide examples of methods and procedures which can be used in monitoring and evaluating HIV/AIDS projects
 - to encourage the use and adaptation of these methods by project staff, in order to provide learning which can be used:
 - (a) to improve programming and
 - (b) to advocate for the expansion and adoption of effective projects by others.

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